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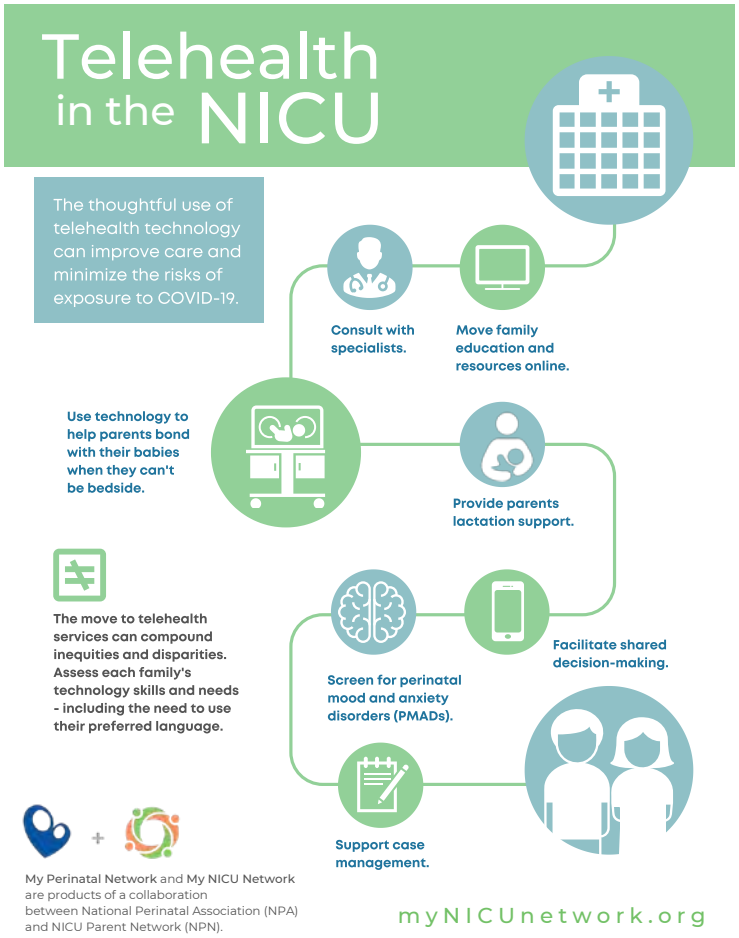

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Pictured: Baby Kole with his Dad

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Perinatal and Prenatal Environmental Risk Factors for Autism Spectrum Disorder: A Summary for Neonatal Care Providers

Robin D. Clark, MD, T. Allen Merritt, MD, MHA, MBA

Introduction:

The purpose of this review is to provide neonatologists and other newborn care providers with a summary of the multifactorial nature of autism spectrum disorder, including the contribution of genetic and environmental factors in pregnancy and early childhood. We encourage newborn care providers to document family history and pregnancy information that may be useful in assessing newborns at increased risk for autism. Finally, we encourage neonatal care providers to integrate autism assessment tools into their protocols when caring for NICU graduates in their High-Risk Infant Follow-up clinics.

"The purpose of this review is to provide neonatologists and other newborn care providers with a summary of the multifactorial nature of autism spectrum disorder, including the contribution of genetic and environmental factors in pregnancy and early childhood."

Background:

Autism spectrum disorder is a diagnosis rarely, if ever, encountered in NICU, and its relevance to the practice of neonatology has been limited, at least until recent events have brought prenatal environmental causes of autism to the center of public awareness (See Editorial in this issue). In this atmosphere of increased concern for environmental risk factors for autism, we anticipate that a deeper understanding of the research on the causes of autism would be helpful for neonatologists. This review will summarize the genetic and environmental associations, risk factors, and causes of autism, with a special focus on questions that may arise in the NICU (1).

Autism is not one disease, and it does not have one cause:

Autism, also called autism spectrum disorder (ASD), is a heterogeneous neurodevelopmental condition characterized by difficulties in social communication, language, and repetitive behaviors. The prevalence of autism is now 1/31 children in the US, which is a substantial increase in prevalence in recent years (2). Shaw *et al.*, using data through 2022 among children aged 8 years, reported an ASD prevalence of 32.2 per 1,000 children (1 in 31) across the 16 sites, ranging from 9.7 in Laredo, Texas, to 53.1 in California. No association was observed between ASD prevalence and neighborhood median household income; however, higher ASD prevalence was associated with lower neighborhood income at five sites. Overall, only 66.5% of children aged 8 years with ASD had a documented autism test, and that varied widely: 24.7% in New Jersey to 93.5% in Puerto Rico, with commonly used tests. There is a higher prevalence in boys compared to girls, with a ratio of more than four to one. This increasing prevalence, which to some extent is due to better diagnosis among children with lower levels of disability, is driving studies to identify environmental factors that contribute to risk. Meanwhile, research focusing on the genetic landscape of autism has identified many genetic components that affect autism risk: rare variants of large effect size as well as common gene variants of a more negligible effect. Many of the genes associated with ASD play a role in brain development, including the proliferation, growth, and organization of neurons and synaptogenesis (3).

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Genetic Factors:

A strong genetic contribution to autism has been demonstrated through the study of concordance and discordance rates for autism spectrum disorder (ASD) among monozygotic and dizygotic twins. Heritability is defined as a ratio, ranging from 0 to 1, where zero indicates that none of the variation in the trait is due to genetics, and one means that all of the variation is due to genetic differences. Heritability is the proportion of variation in a phenotypic trait that is due to genetic differences among individuals in a given population. If autism were solely a genetic

disease, identical twins would be either completely concordant (both affected) or completely discordant (neither affected) for autism in all populations that were studied. In a meta-analysis of the combined data from published twin studies, the actual value of heritability in autism was high, from 0.64 to 0.91 (4). The authors concluded that the effect of shared environment in twin studies was less significant and "never explain(ed) the majority of the variance in ASD."

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The Simons Foundation Autism Research Initiative (SFARI) provides a comprehensive, publicly available, searchable, curated database of genetic risk factors, susceptibility genes, and copy number variants (CNVs) linked to ASD. The SFARI Gene site (https://gene.sfari.org/database/human-gene/) currently (as of Q2 2025) lists 1,247 genes and 17 recurrent CNV loci associated with ASD risk. Among the CNV regions that are associated with autism are 1q21.1, 3q29, 7q11.23, 15q13.3, 16p11.2, 22q11.2, and 22q13.3. It is important to note that these genes and chromosome regions are not exclusive to ASD, but are also found in other neurodevelopmental disorders, including ADHD, intellectual disability, tic disorders, and epilepsy. These genes influence neuronal development through various mechanisms.

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Single-gene disorders can cause autism:

Rare and often *de novo* genetic variants, responsible for Mendelian disorders, explain a minority of cases of autism. This genetic scenario usually explains the more severe cases of syndromic autism, often with intellectual disability, such as Fragile X syndrome, Tuberous Sclerosis, Timothy, PTEN, and Rett syndromes (5–9). The genetic/genomic tests in diagnostic practice are more likely to detect a single gene disorder in females with autism, children with autism who also have seizures or intellectual disability, dysmorphic features, growth failure, or congenital anomalies. These diagnoses can be confirmed with currently available genetic and genomic tests that are designed to filter out common variants. Studies focusing on the autism population specifically have shown that whole-genome sequencing has a conservative diagnostic yield of 14%, a diagnostic rate twofold higher than chromosome microarray and threefold higher than whole-exome sequencing.

The threshold model for autism:

Common genetic variants are responsible for most cases of autism. Autism is considered a multifactorial trait in which several common genetic variants and environmental exposures each contribute a small amount to the risk in an additive way. When the threshold for autism is reached, the autistic phenotype is expressed. These common genetic variants are often SNPs or single-nucleotide polymorphisms that, by definition, occur in 1% or more of the population. Variants in the genes that cause autism also contribute to other neurodevelopmental and psychiatric disorders: ADHD, anxiety, depression, bipolar disease, and schizophrenia.

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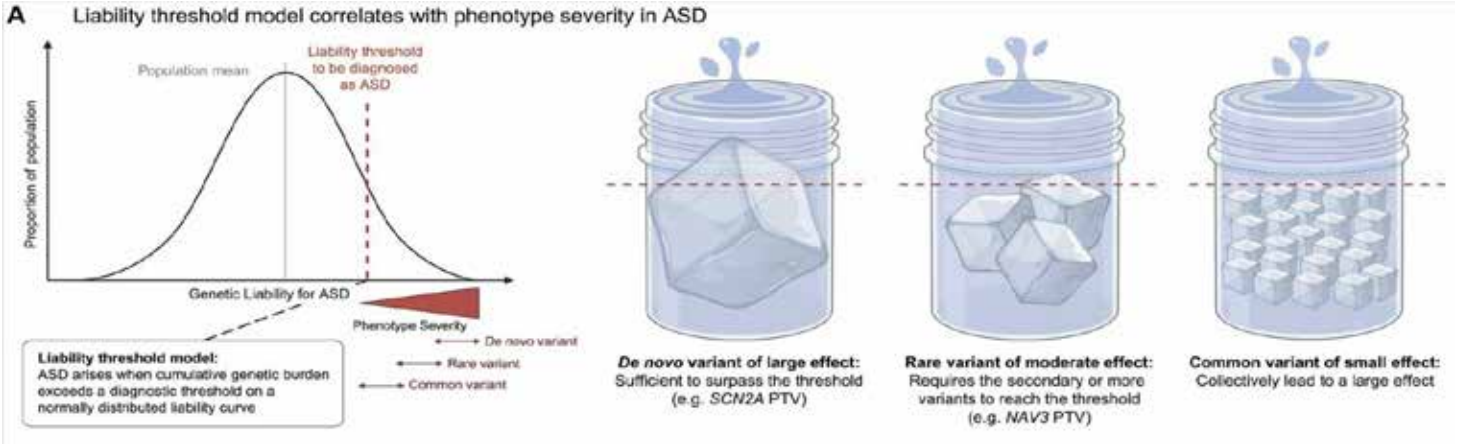
When these conditions are present in the family history, they increase the risk of autism in a child, which is why geneticists explore the family history even in patients with nonsyndromic autism. In this model, genetic and environmental factors interact in various combinations to influence the phenotype. These gene-by-gene (GxG) interactions and gene-by-environment (GxE) interactions contribute to the cause of autism in ways that are still incompletely understood. Some environmental exposures known to increase the risk of autism, such as air pollution and heavy metals, may be genotoxic, inducing genetic changes in critical genes and/or altering gene expression by modifying the epigenomic pattern of methylation and acetylation that makes the DNA accessible or inaccessible. There are no commercially available genetic tests for these common genetic polymorphisms. Other tests, such as epigenome signatures and polygenic risk scores, may soon be able to identify the patterns of SNPs that are associated with ADHD and autism. When that day comes, and if early therapy and intervention become more effective, expect to see them used in screening protocols to identify high-risk infants.

Figure 1. Genetic Models of ASD (10). Open-access article under the CC BY-NC-ND license (http://creativecommons.org/licenses/by-nc-nd/4.0/).



ASD arises when the cumulative genetic burden exceeds the diagnostic threshold (vertical red dotted line) as seen in Figure 1 in the graph above. A single gene variant with a large effect (illustrated as the single large ice cube) exceeds the threshold for autism (horizontal red dotted line), as do the less common variants (medium ice cubes) with moderate effect and the smallest ice cubes representing the cumulative effect of the most common variants, each with a small effect. This illustrates how different genetic etiologies exceed the threshold for autism and produce the phenotype. Note that the *de novo* variants with the more significant effects are more often seen in the more severely affected patients on the far right of the bell-shaped curve.

"A single gene variant with a large effect (illustrated as the single large ice cube) exceeds the threshold for autism (horizontal red dotted line), as do the less common variants (medium ice cubes) with moderate effect and the smallest ice cubes representing the cumulative effect of the most common variants, each with a small effect. This illustrates how different genetic etiologies exceed the threshold for autism and produce the phenotype."

Perinatal and other environmental factors:

Evidence that early-life environmental factors are key contributors to ASD implicates advanced parental age, maternal diabetes during pregnancy, infectious diseases, nutrient deficiencies, steroid hormone imbalances, certain medications (valproic acid), history of mental illness, and exposure to environmental pollutants (heavy metals, pesticides, air pollution). Various genetic and environmental factors may induce epigenetic modifications of developmental and neuronal genes.

"Evidence that early-life environmental factors are key contributors to ASD implicates advanced parental age, maternal diabetes during pregnancy, infectious diseases, nutrient deficiencies, steroid hormone imbalances, certain medications (valproic acid), history of mental illness, and exposure to environmental pollutants (heavy metals, pesticides, air pollution)."

Environmental factors associated with autism risk are reviewed by Wang *et al.* (2025) (1). Figure 2 illustrates many of the environmental risk factors—note that acetaminophen is not included. In this rendering, prematurity would be considered a "prenatal stress event"

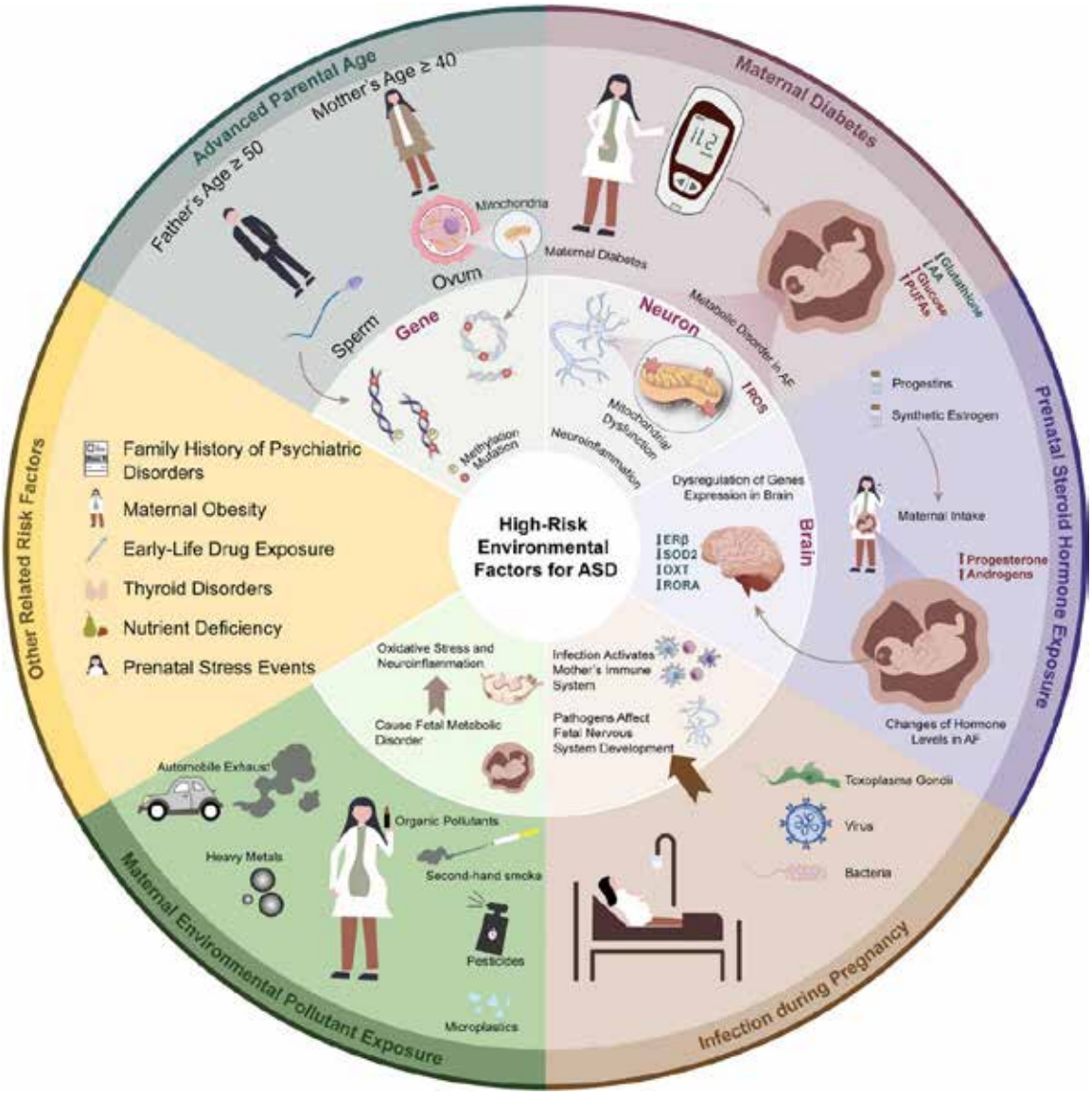
Some of the early environmental factors associated with autism are listed in the Table, along with salient references. (11–22)

Tools for autism risk assessment in the newborn:

Advanced parental age:

Paternal age over 50 and maternal age over 40 years are independent risk factors for autism, primarily through deleterious *de novo* genetic variants and epigenetic changes. Advanced maternal age increases the risk of potentially pathogenic variants in mitochondrial DNA. Advanced paternal age increases the risk of new mutations in the nuclear genome. Changes in paternal age are associated with increased de novo mutations in sperm,

Figure 2. **Environmental risk facors for autism** (1). Distributed under the terms of the Creative Commons Attribution 4.0 license, https://creativecommons.org/licenses/by/4.0/



alterations in sperm DNA methylation, and abnormal microRNA (miRNA) expression profiles. These are short, non-coding RNA molecules that regulate gene expression by binding to messenger RNA (mRNA), leading to mRNA degradation or translational repression.

The Family History of Autism and/or ADHD:

Autism and ADHD commonly co-occur within individuals and family members and have shared heritability. A positive family history of autism and/or ADHD, especially in a first-degree relative, is a risk factor that may be underrecognized in infancy. In population-based studies, ASD is ~10 times higher in children with an autistic sibling than in those without an autistic sibling. The recurrence of autism among siblings at 3 years was ~20% in volunteer research cohorts (22), and higher rates, up to 34%, were noted when siblings were followed until age 9. Siblings of female probands with autism were significantly more likely to develop ASD than siblings of male probands.

Charman *et al.* found "that around half of children with a family history of autism/ADHD (in a first-degree relative) might show clinical traits that warrant evaluation and that this extends beyond those who meet diagnostic criteria for autism." (23)

"Charman et al. found 'that around half of children with a family history of autism/ADHD (in a first-degree relative) might show clinical traits that warrant evaluation and that this extends beyond those who meet diagnostic criteria for autism.'"

Table. Early Environmental Factors Associated with Autism. (11–22)

Exposure	No Effect	Positive effect	Reference
Acetaminophen (paracetamol)	Sibling control analyses found no evidence that acetaminophen use was associated with autism (HR, 0.98 (95% CI, 0.93-1.04) See Editorial by Louwen et al. Sibling comparisons (n = 23,593) found no evidence of association (e.g., HR of ADHD, 0.86; 95% CI, 0.52, 1.44).		Ahlqvist, et al. PMID: 38592388 Louwen F, et al. PMID: 41028913 Okubo Y, et al. PMID: 40898607
Maternal valproic acid exposure		Infants with fetal valproate syndrome often have neuro-developmental disorders: ASD (62.9%) and sensory problems (80.6%)	Bluett-Duncan M, et al. PMID: 37666366
Prematurity		Swedish cohort study of >4 million singleton infants. Adjusted prevalence ratios for autism in extremely (22-27 weeks) preterm infants compared to term infants were 3.72 (95% CI, 3.27-4.23) among boys and 4.19 (3.45-5.09) among girls.	Crump C, et al.PMID: 34380775
Congenital CMV infection		Children with cCMV were more likely to have ASD diagnoses (hazard ratio: 2.5; 95% CI: 2.0–3.2	Pesch MH, et al. 2024 PMID: 38808409
Environmental toxins: Heavy metals, Pesticides, Air pollution		Meta-analysis revealed a slight but significant association between exposure to particulate matter $(PM)_{10}$ during the first year of life and the risk of ASD. (OR = 1.04, 95 % CI: 1.00–1.08),	Tartaglione AM, et al. PMID: 39053787
Maternal Tobacco exposure		Heavy prenatal smoking (≥20 cigarettes/ day in any trimester) was related to an odds ratio of 1.55 (95% CI: 1.21, 1.98).	Von Ehrenstein, et al. PMID: 32830844
Fetal Ultrasound	No association among 1524 singleton pregnancies in a case-control study		Christensen D, et al. PMID: 37483151
		There was significantly greater mean depth of ultrasonographic penetration in the ASD group compared with the developmental delay group in the first trimester and compared with the typical development group in the first and second trimesters.	Rosman NP, et al. PMID: 29435580
Other Neonatal Factors, including Low Birth Weight		Congenital heart disease (OR, 1.35; 95% CI, 1.17–1.52), macrosomia (OR, 1.11; 95% CI, 1.05–1.18), low birth weight (OR, 1.63; 95% CI, 1.48–1.81), very low birth weight (OR, 2.25; 95% CI, 1.79–2.83), small for gestational age (OR, 1.17; 95% CI, 1.09–1.24), jaundice (OR, 1.74; 95% CI, 1.42– 2.12), male sex (OR, 1.47; 95% CI, 1.39–1.55) and 1-minute Apgar score <7 (OR, 1.40; 95% CI, 1.26–1.55) were graded as suggestive evidence (class III)	Salehi AM, *et al.* PMID: 39054642
Older birth parents		In a Swedish population-based cohort, the risk for autism in offspring of mothers aged 40-45 was OR 1.75 (95% (CI): 1.63-1.89), and older fathers aged 55-59 was OR 1.39 (1.29-1.50) compared to median parental ages A meta-analysis gave adjusted ORs for older mothers and fathers of 1.47 (95% CI: 1.33-1.62) and 1.51 (95% CI: 1.40-1.62), respectively.	Idring S, *et al*. PMID: 24408971 Dehesh T, *et al.* PMID: 39578893

A family history of autism and ADHD can be collected in the NICU by implementing a simple family history questionnaire. A positive family history group of newborns constitutes a high-risk group that could be followed for early signs of autism in an HRIF clinic, allowing earlier detection, diagnosis, and intervention for autism and other neurodevelopmental traits. This subgroup of at-risk infants may be studied for their sensitivity to sensory stimuli, and may, in fact, help explain why some infants are resistant to "Soft-Touch" programs that reduce sensory stimulation in the NICU.

Future directions:

In addition to family history and prematurity, which are currently available for risk stratification, more sensitive biological measures of risk may become available soon. MicroRNA profiles are potentially useful biomarkers for autism spectrum disorder. In their meta-review, Garrido-Torres *et al.* identified microRNAs that were frequently dysregulated in individuals with autism, some of which were specific to autistic traits, such as impaired social interaction and repetitive behaviors. Salloum-Asfar *et al.* found that a combination of four miRNAs: miR-4433b-5p, miR-15a-5p, miR-335-5p, and miR-1180-3p, exhibited high diagnostic accuracy in young autistic children, ages 2-4, with an area under the curve (ROCAUC) of 0.936 (95% CI = 0.892, 0.980; $p < 0.001$). These authors suggest that this four-miRNA panel could be a robust biomarker for early ASD diagnosis and may suggest therapeutic strategies (24)

"In addition to family history and prematurity,...more sensitive biological measures of risk may become available soon. MicroRNA profiles are potentially useful biomarkers for autism spectrum disorder."

Conclusion:

As the practice of pediatrics has increasingly focused on preventing adult-onset diseases, neonatologists may be offered a similar and significant role in preventing pediatric-onset diseases. Autism may become such a case in point. Because prematurity, maternal diabetes, and other perinatal events are risk factors for autism, the NICU is a first line of defense for many individuals who develop ASD. Advanced parental age and family history of ADHD/autism can identify high-risk populations of infants in the NICU now, and we can study how those infants respond to changes in the intensive care environment. However, a near-future NICU is on the horizon where machine learning generated autism risk assessment tools include clinically available information at birth (prematurity, low birth weight, male sex, older parental age, positive family history), polygenic risk scores (Zhang, 2025), and microRNA profiles (Salloum-Asfar, 2025; Garrido-Torres, 2024) to allow early diagnosis and presymptomatic intervention. In this scenario, neonatologists may find themselves on the front line of autism diagnosis and treatment.

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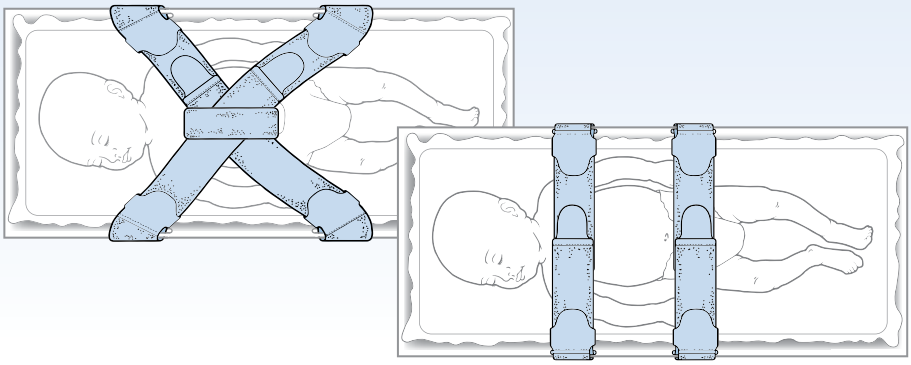

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Autistic Spectrum Disorders (ASD) and the Impact of Genetic, Prenatal, Perinatal and NICU Care: The Role of Neonatologists and Geneticists: Avoiding Misinformation while Advocating for Children and their Parents during NICU Follow-Up Visits

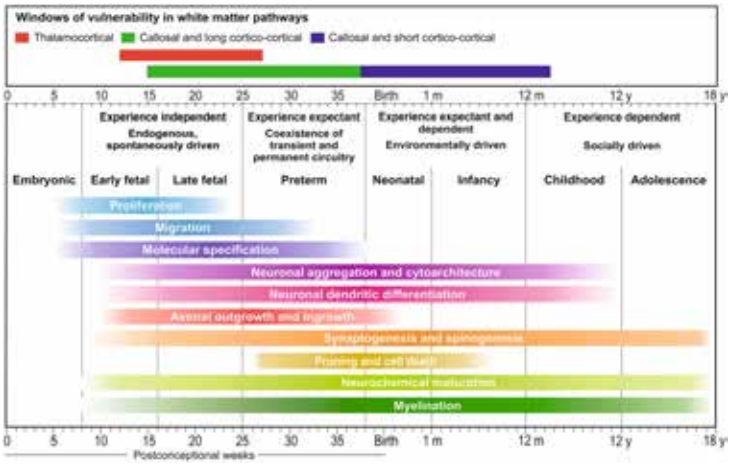
T. Allen Merritt, MD, MHA, MBA, Robin D. Clark, MD

New Developments in Autism:

In just a few months, the Secretary of Health and Human Services, Secretary Robert Kennedy Jr., with his rhetoric, has prompted a surge of fear and uncertainty about autism. According to Kennedy, "Autism destroys families," Kennedy said. "More importantly, it destroys our greatest resource, which is our children. These are children who should not be suffering like this." Kennedy described autism as a "preventable disease," although researchers and scientists have identified several genetic risk factors, maternal medications, maternal inflammatory disorders, and medications during pregnancy, as well as perinatal factors including chorioamnionitis, that are associated with Autism Spectrum Disorders. Autism is not considered a disease, but a complex disorder that affects the brain. Cases range widely in severity, with symptoms that can include delays in language, learning, and social or emotional skills. Some autistic traits can go unnoticed well into adulthood» (1). His comments have been disturbing to parents and the concerns of health care professionals (2).

"On September 22, 2025, President Trump, the Secretary of Health and Human Services, Robert Kennedy, Jr., among others, raised greater public awareness about autism. However, the sum of misinformation ("Tylenol during pregnancy is linked to autism" and harmful rhetoric, along with numerous policy shifts in defunding critical research efforts on autism and other cuts at the National Institutes of Health (NIH) (3), while announcing 13 research projects as a part of the administration's broader autism initiatives (4)."

On September 22, 2025, President Trump, the Secretary of Health and Human Services, Robert Kennedy, Jr., among others, raised greater public awareness about autism. However, the sum of misinformation ("Tylenol during pregnancy is linked to autism" and harmful rhetoric, along with numerous policy shifts in defunding critical research efforts on autism and other cuts at the National Institutes of Health (NIH) (3), while announcing 13 research projects as a part of the administration's broader autism initiatives (4). These policy shifts and public announcements have created confusion, indeed, chaos for health care professionals and autism researchers (4). FDA Commissioner Marty Makary, MD, MPH, stated, "Even with this body of evidence, the choice still belongs with parents. The precautionary principle may lead many to avoid using acetaminophen during pregnancy, especially since most low-grade fevers do not require treatment. It remains reasonable, however, for pregnant women to use acetaminophen in certain scenarios." (5). In the Spring of 2025, Secretary Kennedy called autism a "rapidly growing epidemic" and alluded to an "environment toxin" as its cause. He characterized autistic children as "kids who will never pay taxes, they'll never hold a job, they'll never play baseball, they'll never a poem, they'll never go out on a date." (1). Kennedy fast-tracked some investigations to hone-in on the "root causes of autism" by September 2025. Although the "root cause" remains elusive, Neonatologists need to have greater awareness of ASD not only because of its increased prevalence among preterm infants, and their recognition that conditions with a prevalence of 1:31 among U.S. eight-year olds (6) require ongoing evaluation as a part of Neonatal Follow-Up Programs that have traditionally focused on metrics of psychomotor and development of cognitive skills along with auditory and vision screening examinations, and providing referrals for early intervention whenever possible.



CC BY (Attribution only) Content may be copied, adapted, displayed, distributed, republished, or otherwise reused for any purpose, including for adaptation and commercial use, provided the content is attributed. (from Carroll, L et. al., Neuroscientist 2020 27(10):10-29. (6)

Prenatal Factors and Premature Birth:

Privacy concerns were heightened when the NIH and the Centers for Medicare and Medicaid Services (CMS) announced the launch of a "real-world data platform" that would share medical and other data of autistic enrollees to researchers. Kennedy's statement on September 4, 2025, contradicts scientific consensus around autism and reinforces harmful and anxiety-evoking stereotypes about the autistic community. Indeed, Shaw et. al. earlier in the year reported in Morbidity and Mortality Weekly Report

"Autism, clinically known as autism spectrum disorder, is not a diagnosis with a single cause (such as an environmental toxin or immunizations, but rather a spectrum of neurodevelopmental differences that vary across individuals based on their genetic, biological, and environmental factors (6)." On September 3, 2025, the Secretary (1) promised the release of data from a recent report regarding maternal use of acetaminophen using the Navigation Guide methodology by researchers at Ichan University School of Medicine, the University of California, Los Angeles, the University of Massachusetts, and Harvard University, which supports evidence consistent with an association between acetaminophen exposure during pregnancy and the increased incidence of neurodevelopmental disorders, including ASD. These authors advise that "steps should be taken to advise pregnant women to limit acetaminophen consumption and under medical supervision to protect their offspring's neurodevelopment" (7). Earlier in 2025, investigators at the NIH, Karolinska Research Foundation in Sweden and others evaluated risk factors of ASD among infants born prematurely using a systematic review and meta-analysis of population-based study (8) and monitored more than 4 million births in Sweden and found ASD prevalences by gestational age at birth were 6.1% for extremely preterm (22-27 weeks), 2.6% for very to moderate preterm (28-33 weeks), 1.9% for late preterm (34-36 weeks), 2.1% for all preterm (<37 weeks), 1.6% for early term (37-38 weeks), and 1.4% for term (39-41 weeks).

The adjusted prevalence ratios comparing extremely preterm, all preterm, or early term versus term, respectively, were 3.72 (95% confidence interval, 3.27-4.23), 1.35 (1.30-1.40), and 1.11 (1.08-1.13) among boys and 4.19 (3.45-5.09), 1.53 (1.45-1.62), and 1.16 (1.12-1.20) among girls (*P* < .001 for each). These associations were only slightly attenuated after controlling for shared familial factors. In a large A Kaiser Permanente birth cohort (9) found that among 195,021 infants born between 2000 and 2007 that ASD prevalences by gestational age at birth were 6.1% for extremely preterm (22-27 weeks), 2.6% for very to moderate preterm (28-33 weeks), 1.9% for late preterm (34-36 weeks), 2.1% for all preterm (<37 weeks), 1.6% for early term (37-38 weeks), and 1.4% for term (39-401 weeks). The adjusted prevalence ratios comparing extremely preterm, all preterm, or early term versus term, respectively, were 3.72 (95% confidence interval, 3.27-4.23), 1.35 (1.30-1.40), and 1.11 (1.08-1.13) among boys and 4.19 (3.45-5.09), 1.53 (1.45-1.62), and 1.16 (1.12-1.20) among girls (*P* < .001 for each). These associations were only slightly attenuated after controlling for shared familial factors (10). Use of high-frequency ventilation and intracranial hemorrhage was associated with ASD among infants <34 weeks of gestation (9).

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Table I: Compared to Term Infants, the Hazards Ratio for ASD in Kaiser Permanente Northern California Hospitals (N=195,021)(8)

Gestational Age	Hazards Ratio
24-26 weeks	2.7 (CI 1.5-6.0)
27-33 weeks	1.4 (CI 1.1-1.6)
34-36 weeks.	1.3 (CI 1.1-1.4)

Noteworthy is a report from Southern Israel in 2024, which found that among 114,975 births over 12 years, including Jewish, Muslim, and Bedouin infants, there was no increased risk of ASD among these populations and preterm birth (10).

"These authors advised caution in interpreting their results due to low statistical power in many studies, the lack of replication or causal inference for many risk factors, and the need for further research to fill gaps in knowledge."

Perinatal Risk Factors:

Yang et al (11) found risk factors associated with increased risk of ASD among preterm births and divided these risk factors into Upstream Factors (e.g., low birth weight, male sex, and maternal conditions leading to Cesarean section, vaginal or cervical infections). Preterm birth is a mediator in the risk pathway; Child outcomes include bronchopulmonary dysplasia, cerebral dysfunction, high SNAP II score, Health status requiring high-frequency ventilation and use of an acid suppressant medication, intracranial hemorrhage, and neonatal infections and inflammation. These authors advised caution in interpreting their results due to low statistical power in many studies, the lack of replication or causal inference for many risk factors, and the need for further research to fill gaps in knowledge. Notably, these investigators confirmed, using meta-analysis, a slightly more than 3-fold risk for ASD among males. Importantly, their data reports on studies by Joseph et. al. (12) who found that fever during delivery, but not fever during pregnancy, increased odds ratios for ASD. The presence of histological evidence of chorioamnionitis of all grades was found by Venkatwesh in 2020 (13) to be associated with ASD. Need for an emergency cesarean section at gestations ranging from 26 to 36 weeks was also positively associated with ASD, analyzing data from Yip in 2017 (14).

Risk factors of advance maternal and paternal ages in a meta-analysis of 41 articles in 2024 found that lower age group of mother or father was not associated a significantly lower risk of ASD; relatively greater paternal and maternal age were associated with an increased risk for ASD in their children (adjusted odds ratios for mother's and father's were 1.47 (95% Cis: 1.33-1.62 and 1.51 (95% CI 1.40-1.62, respectfully (15). When controlling for maternal and paternal ages, Zamstein et al in 2024 (16) found that fertility treatments, including ovarian induction and in vitro fertilization, did not exhibit a significant association with heightened ASD in their offspring.

Gestational diabetes has also been associated with adverse

neurodevelopmental outcomes. A systematic review of meta-analyses of over 56 million pregnancies from 202 studies, of which 110 examined gestational diabetes and 80 investigated 80 studies of pre-gestational diabetes. Children born of these gestations were followed up to 18 years and maternaldiabetes was associated with increased risk of neurodevelopmental disorders (risk ratio 1.28 (95% CI 1.24-1.31, autism spectrum disorder (1.25, 95% CI 1.20-1.31, Attention deficit hyperactivity disorder (1.30, 95% CI 1.27-1.37), intellectual disability (1.32, 95% CI 1.14-1.47. Maternal pre-diabetes was more strongly associated with the risk of most neurodevelopmental disorders in children than gestational diabetes in children than gestational diabetes (risk ratio 1.30; 95% CI 1.34-1.44) (17).

Prada et al. (7) included 46 studies, of which 27 reported a positive association between neurodevelopmental disorders, 9 showed a null or no significant link, and 4 demonstrated a negative association (protective effect). They conclude that higher-quality studies were more likely to show positive associations, and the majority of studies reported positive associations of prenatal acetaminophen use with ADHD, ASD, or neurodevelopmental disorders through February 2025. They also report a heightened association with exposure during the second and third trimesters. Timing, dosage, and duration were integrated into the strength and consistency of evidence assessment. These authors state that "although acetaminophen remains the preferred analgesic due to its relatively favorable safety profile compared to other medications, its use should be approached judiciously and cite the report of Bauer et. al (18) in 2021, who also recommended precaution for its use in pregnancy.

"Although the precise mechanism of teratogenicity is not fully understood, alterations in gene expression that control brain development, as well as changes in the epigenome, can impact neural networks critical for normal brain development. Prenatal acetaminophen use is associated with DNA methylation changes in fetal tissues and the placenta, including loci involved in neurodevelopment (10)"

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In 2024, Woodbury et al. (19) reported outcomes of the Illinois Kids Developmental Study, which followed a birth cohort from 2013 to 2020 in east-central Illinois among 532 newborns and their mothers. Participants reported the number of times they took acetaminophen six times across pregnancy. Infant language data were collected at 26.5-28.5 months using the MacArthur-Bates Communicative Developmental Inventory (CDI) (N-298) and 36-38 months using the Speech and Language Assessment Scale (SLAS) (N=254). They found that taking more acetaminophen during pregnancy, particularly during the second and third trimesters, was associated with poor scores on measures of language development when children were 26.5-28.5 and 36-38 months in male infants when stratified by sex. This study found that using acetaminophen multiple times during pregnancy reduces the risk of memory inaccuracies, and it allows for consideration of acetaminophen use by trimester. They found associations of increased frequency of acetaminophen use with poorer language outcome in their small sample size, and cautioned that their results require replication in a larger, more diverse sample.

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Neonatologists are obliged to provide follow-up care for infants who have "graduated" from their NICU care, utilizing a variety of developmental screening instruments to monitor development. The American Academy of Pediatrics (AAP) recommends autism screening for all children at their 18- and 24-month infant visits using the Modified Checklist for Autism in Toddlers, Revised/Follow-up (M-CHAT-R/F). If the initial M-CHAT-R screen results in a moderate score (3-7), the M-CHAT Follow-Up (M-CHAT/F) is used to clarify responses and reduce false positives. A positive result on the M-CHAT/F indicates a referral for a full diagnostic evaluation. (20).

Key Aspects of the AAP's M-CHAT Recommendations:

- Universal Screening:

  The AAP recommends screening all children at 18 and 24 months of age to identify potential autism spectrum disorder (ASD) or other developmental delays.

- M-CHAT-R/F:

  The recommended tool is the M-CHAT-R/F, which includes an initial screening questionnaire (M-CHAT-R) and a follow-up interview to clarify responses.

- Follow-Up Process:
  - The M-CHAT-R is completed first.
  - If the initial score is moderate (between 3 and 7), the M-CHAT/F interview is conducted.

- This follow-up is crucial for reducing the rate of false positives.

- Referral for Evaluation:

  If a child screens positive on the M-CHAT R/F, a referral for a comprehensive diagnostic evaluation is necessary.

- Importance of Parental Input:

  Parents are considered experts on their children, and their insights are vital for the screening process.

When deviations from "normal" outcomes on developmental screening tests, such as M-CHAT and MCAT/F are identified, children are often referred to consultant services (Child Neurology, Geneticists, or Metabolic Disorders) for further evaluation and specific testing. Neonatologists in follow-up clinics frequently consult these subspecialists to assist in the further evaluation and preferred testing modalities that may confirm ASD or another more specific disorder for treatment, and early intervention services specific to a unique diagnosis. When evaluated among 144 infants <32 weeks' gestation at 24 months of age, 53 (40%) screened positive. Among those screening positive, the Autism Diagnostic Observational Schedule (ADOS-2) was administered to 50 of 53 infants, with 24 scoring above the cut-off point. The mean age of detection was 25.39 months, suggesting a prevalence rate of 18.46% among infants <32 weeks of gestation (21).

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Autism and Environmental Toxins:

The contention that an "environmental" toxin or toxins have sent autism rates soaring in the United States, and he further described plans for his recently announced initiative to discover such purported causes. The research effort, which Kennedy said is being run by National Institutes of Health (NIH) Director Jayanta "Jay" Bhattacharya, will examine the potential role of food additives, pesticides, and ultrasound scanning, among other things, he said (Wadman, Meredith R.F.K Jr. Claims the autism epidemic" is due a variety of environmental toxins, including pesticides and ultrasonographic scanning and that his efforts will disclose "the answer by September, 2025 (22). Environmental toxicologists have focused on Organophosphate (OP), Organochlorine (OC), Pyrethroid (PI), Neoniconoid (NN), Carbamate (CM), Chlorpyrifos (CPF), and mixed exposures. Preclinical studies have primarily focused on OP and Chlorpyrifos (CPF) compounds, with a particular emphasis on gestational exposure and its association with increased ASD; however, the data are inconclusive. Studies on gestational exposure to certain OPs could be linked to clinical signs of ASD (23). In a case-control study of 2821 individuals diagnosed with ASD residing in areas of both high and low pesticide exposure, an increase in ASD prevalence rates was noted in areas with elevated pesticide use, specifically in males, with odds ratios (OR) of 1.34 (95% confidence intervals [CI] 1.24-1.44). When performing multiple binary logistic regressions adjusted for age, sex, and geographical area, the OR was 2.44 (95% CI (2.21-2.61) (24). Nicotine and other toxins in tobacco-smoking mothers during gestation and after birth were not mentioned in Secretary Kennedy's recent report on the health of America's children. In fact, maternal smoking and its well-established relationship to low birth weight infants and prematurity were not mentioned.

"Nicotine and other toxins in tobacco-smoking mothers during gestation and after birth were not mentioned in Secretary Kennedy's recent report on the health of America's children. In fact, maternal smoking and its well-established relationship to low birth weight infants and prematurity were not mentioned."

However, von Ehrenstein and coworkers reported the association between maternal smoking and autism spectrum disorder (ASD) in children in a statewide population-based cohort and sibling-comparison design using California birth records (n = 2,015,104) with information on maternal smoking, demographic factors, and pregnancy (2007–2010). ASD cases (n = 11,722) were identified through California Department of Developmental Services records with diagnoses based on the Diagnostic and Statistical Manual of Mental Disorders–IV. The estimated odds ratios for ASD with and without intellectual disability in the whole cohort using logistic regression and in a sibling comparison using conditional logistic regression were performed (25). In the whole cohort, the adjusted odds ratio for ASD and maternal smoking 3 months before/during pregnancy compared with nonsmoking was 1.15 (95% confidence interval (CI): 1.04, 1.26), and it was similar in cases with (odds ratio = 1.12, 95% CI: 0.84, 1.49) and without intellectual disability (odds ratio = 1.15, 95% CI: 1.04, 1.27). Heavy prenatal smoking (≥20 cigarettes/day in any trimester) was related to an odds ratio of 1.55 (95% CI: 1.21, 1.98). In the sibling comparison, the odds ratio for heavy smoking was similarly elevated, but the confidence interval was wide. Von Ehrenstein et. al. findings are consistent with an increased risk for ASD in offspring of mothers who smoked

≥20 cigarettes/day during pregnancy; associations with lighter smoking were weaker. This large study's association of heavy smoking by mothers during gestation with significant odds ratios raises concern that needs further confirmation, but is among the highest associations of environmental toxin exposure and ASD in the U.S.

"Secretary Kennedy indicated diagnostic ultrasound during gestation as a 'cause' of ASD rather than the clinical necessity for the use of diagnostic ultrasound. Christensen and coworkers (26) evaluated 1524 singleton pregnancies. Ultrasound indications were more common for ASD cases than controls."

Autism and Diagnostic Ultrasound:

Secretary Kennedy indicated diagnostic ultrasound during gestation as a "cause" of ASD rather than the clinical necessity for the use of diagnostic ultrasound. Christensen and coworkers (26) evaluated 1524 singleton pregnancies. Ultrasound indications were more common for ASD cases than controls. For each group, no indications were reported for 45.1% and 54.2% of pregnancies, while more than two indications were reported for 26.2% and 18.4% of pregnancies—the percentage of pregnancies with multiple ultrasounds varied by case status and the presence of ultrasound indications. However, stratified regression models showed no association between increasing ultrasound counts and case status, either for pregnancies without (adjusted odds ratios 1.01, 95% CI 0.8-.1.11 or with ultrasound indications (aORs 1.01, 95% CI 0.95-1.08). Trimester-specific analyses using medical record data showed no association in any individual trimester. In another case-control study evaluating the frequency, timing, duration, and strength of prenatal ultrasonographic scans to 10l4 patients with ASD and 104 control inidividuals with developmental delay, and 209 controls by Rosman et. al. (27). Ultrasonographic exposure was quantified by the number and timing of scans, duratioin of exposure, and mean strength (depth, frame rate, mechanical index and thermal index), and time of Doppler and 3-and 4-dimensional imaging. Male fetuses were disproportionately scanned (328 males vs 92 females) during their 6th year. The ASD group received a mean of 5.9 scans (95% CI, 5.2-6.6), which was not different from 6.1 (95% CI, 6.8) in the developmental delay group or the 6.3 (95% CI, 5.8-6.8) scans in the normal children. Children with ASD have shorter durations of ultrasound exposure compared to the other two groups. However, the ASD group had a greater mean depth of ultrasound penetration than the developmental delay or normal group during the first and second trimesters. This study found significantly greater mean depth of ultrasound penetration in the ASD group compared to the other two groups during the first and second trimesters. Among fetuses exposed to prenatal ultrasound, Regev et al. (28) reported in 229 children studied as fetuses compared to their closest age sibling and children from the general population in the United Kingdom, that fetal anomalies were found in 29.3% of ASD cases versus only 15.9% and 9.6% in the general population of children. Fetal anomalies in the urinary system, heart, and head and brain were most significantly associated with ASD. This study highlighted that ultrasonographic fetal anomalies were associated with ASD. Overall, recent studies indicate that the primary association of diagnostic ultrasonographic use is with detecting fetal anomalies; however, the use of ultrasound should be limited in terms of depth of penetration and duration.

Although the more recent report attributed acetaminophen to ASD, there were earlier associations and warnings regarding the use of this drug during pregnancy as early as 2017 (29,30)

"Since 2011, it has been evident that dyes are linked to harmful effects in children. Artificial dyes have neurotoxic chemicals that aggravate mental health problems. Many families with autistic children avoid food dyes in their diet in order to avoid behavioral issues. A study reported a correlation between yellow dye and sleep disturbance."

Food Coloring Effects:

Since 2011, it has been evident that dyes are linked to harmful effects in children. Artificial dyes have neurotoxic chemicals that aggravate mental health problems. Many families with autistic children avoid food dyes in their diet in order to avoid behavioral issues. A study reported a correlation between yellow dye and sleep disturbance. Food colors Blue 1 and 2, Green 3, Red 3, Yellow 5 and 6, Citrus Red 2, and Red 40 can trigger many behaviors in most kids. Artificial food color usually contains petroleum and is manufactured in a chemical process that includes formaldehyde, aniline, hydroxides, and sulfuric acids. Most impurities in the food color are in the form of salts or acids. Sometimes lead, arsenic, and mercury may be present as impurities. The U.S. FDA has yet to study the effects of synthetic dyes on behavior in children. A study conducted at Southampton University in England found a link between food dyes and hyperactive behavior in children. The research does not prove that food coloring actually causes autism spectrum disorder, but there seems to be a link (31). Concern that synthetic food dyes may impact behavior in children prompted a review by the California Office of Environmental Health Hazard Assessment (OEHHA). OEHHA conducted a systematic review of the epidemiologic research on synthetic food dyes and neurobehavioral outcomes in children with or without identified behavioral disorders (particularly attention and activity). We also searched the animal toxicology literature to identify studies of neurobehavioral effects in laboratory animals exposed to synthetic food dyes. Finally, we conducted a hazard characterization of the potential neurobehavioral impacts of food dye consumption. We identified 27 clinical trials of children exposed to synthetic food dyes in this review, of which 25 were challenge studies. All studies employed a cross-over design, with most being double-blinded and randomized. Sixteen (64%) out of 25 challenge studies identified some evidence of a positive association, and in 13 (52%), the association was statistically significant. These studies support a relationship between food dye exposure and adverse behavioral outcomes in children. Animal toxicology literature provides additional support for effects on behavior. Together, the human clinical trials and animal toxicology literature support an association between synthetic food dyes and behavioral impacts in children. The current Food and Drug Administration (FDA) acceptable daily intakes are based on older studies that were not

designed to assess the types of behavioral effects observed in children. For four dyes for which adequate dose-response data from animal and human studies were available, comparisons of the effective doses in studies that measured behavioral or brain effects following exposure to synthetic food dyes indicate that the basis of the ADIs may not be adequate to protect neurobehavior in susceptible children. Concern that synthetic food dyes may impact behavior in children prompted a review by the California Office of Environmental Health Hazard Assessment (OEHHA). OEHHA conducted a systematic review of the epidemiologic research on synthetic food dyes and neurobehavioral outcomes in children with or without identified behavioral disorders (particularly attention and activity). This study searched the animal toxicology literature to identify studies of neurobehavioral effects in laboratory animals exposed to synthetic food dyes. Finally, we conducted a hazard characterization of the potential neurobehavioral impacts of food dye consumption. We identified 27 clinical trials of children exposed to synthetic food dyes in this review, of which 25 were challenge studies. All studies employed a cross-over design, with most being double-blinded and randomized. Sixteen (64%) out of 25 challenge studies identified some evidence of a positive association, and in 13 (52%), the association was statistically significant. These studies support a relationship between food dye exposure and adverse behavioral outcomes in children. Animal toxicology literature provides additional support for effects on behavior. Together, the human clinical trials and animal toxicology literature support an association between synthetic food dyes and behavioral impacts in children. The current Food and Drug Administration (FDA) acceptable daily intakes are based on older studies that were not designed to assess the types of behavioral effects observed in children. For four dyes for which adequate dose-response data from animal and human studies were available, comparisons of the effective doses in studies that measured behavioral or brain effects following exposure to synthetic food dyes indicate that the basis of the ADIs may not be adequate to protect neurobehavior in susceptible children. There is a need to re-evaluate exposure in children and for additional research to provide a more complete database for establishing ADIs protective of neurobehavioral effects (32).

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Difference between association and causation:

Understanding that multiple associations are just that, specific criteria have been established to determine the "strength of an association(s) with causation. Causation is a process wherein an initial or inciting event (exposure) affects the probability of a subsequent or resulting effect (outcome) occurring. In 1965, Bradford Hill established nine criteria (33) that he used to prove that the association of smoking and lung cancer was, in fact, causing cancer. These nine factors are often used to equate associations with causation. Hill's criteria for concluding "casualty" include: Temporality, strength of association, consistency, specificity, biologic relationship, plausibility, coherence, experiment, and analogy. These criteria have been scrutinized, with some researchers asserting that temporality, based on causal-structural subject-matter knowledge, is the only essential criterion for establishing causality. Rothman proposed an alternative model that defines cause as an event, condition, or characteristic necessary for disease occurrence, emphasizing that a disease results from multiple components acting together, sufficient, and necessary, components in that an individual event, condition, or characteristic sufficient cause requires a single component cause that can be part of multiple sufficient causes (34). As emphasized by Fedak et. al. (35) data integration has changed causal inference in molecular genetics requiring a re-evaluation of Hill's criteria and added biological gradient, experiment, such as epigenetic modifications and transgenerational effects, and analogy for hypothesis testing, Given the multiple association discussed by various authors it is very likely that no actual "experiment" will test the established associations of maternal analgesic use during pregnancy and ASD in early childhood. Nonetheless, as Prada et. al. (7) acknowledged and recommend that judicious acetaminophen use (lowest effective dose, shortest duration), rather than a broad limitation, is an appropriate course of action. The difficulty in proving causation is that in a personal injury lawsuit, such as a child with ASD, the parents and child have the burden of establishing a causal relationship between the harmful actions of another person or group and the injury to the child, in this case, Autism Spectrum Disorder. Second, the movement of substances through air, water, soil, or the body is often poorly understood and difficult to trace; additionally, the level or timing of exposure is often unknown. Together, these factors can lead to ambiguity about the cause(s) of a disease or spectrum disorder.

"Multiple causation poses the challenge of determining whether a particular injury resulted from a single substance, another, or a combination of substances, such as toxins or diagnostic ultrasound. Courts have provided guidance in dealing with these issues, generally allowing evidence from epidemiological or toxicological studies that establish a causal relationship between a disease or condition and a factor suspected of causing that disease or condition."

Multiple causation poses the challenge of determining whether a particular injury resulted from a single substance, another, or a combination of substances, such as toxins or diagnostic ultrasound. Courts have provided guidance in dealing with these issues, generally allowing evidence from epidemiological or toxicological studies that establish a causal relationship between a disease or condition and a factor suspected of causing that disease or condition. Courts are quick to point out, however, that proof of an association is not equivalent to causation (King v Burlington Northern Santa Fe Railway Company, VL 484965 (Neb 2009). Instead, epidemiologic studies show the degree of

statistical significance between events and outcomes. Further, a positive association has been found; a medical expert must next determine whether the association reflects a genuine cause-and-effect relationship, considering 1) the strength of the association, 2) the dose-response relationship, 3) replication of findings, and 4) biologic plausibility. No generally agreed-upon method exists for determining how much weight to apply to one factor (36). Kent et al suggest that the methodology, goals, and interpretation of prognostic studies are critical (Kent P, et al. A conceptual framework for prognostic research. BMC Med Res Methodol. 2020;20(1):172). makes the important distinction between prognostic determinants and prognostic markers, and between various stages of exploratory and confirmatory research projects. (37). (Kent, P., Cancelliere, D., Boyle, E., Cassidy, J.D., Konigsted. A Conceptual Framework for Prognostic Research. BMC Med Methodol;202020(1):172.)

"Butler et al. (15) searched the medical literature and identified about 800 clinically known, relevant, or susceptible genes reported in autism. They compiled a master list of genes for ASD identified in the literature, supported by evidence from peer-reviewed medical resources, by searching keywords related to autism and genetics, and plotted their location on chromosome ideograms."

Genetic Factors linked to ASD:

Butler et al. (15) searched the medical literature and identified about 800 clinically known, relevant, or susceptible genes reported in autism. They compiled a master list of genes for ASD identified in the literature, supported by evidence from peer-reviewed medical resources, by searching keywords related to autism and genetics, and plotted their location on chromosome ideograms. The list of genes was arranged in alphabetical order in tabular form, with gene symbols plotted on high-resolution human chromosome ideograms to allow clinical and laboratory geneticists to access visual images of the location and distribution of ASD genes. Seventy-four genes were plotted on the X chromosome, which were compared to 54 genes on the similarly sized chromosome 6; thus, chromosome X has about 50% higher gene frequency, supporting an X-linked affected male-to-female ratio of 4:1 for autism. These findings may inform diagnosis and gene-based personalized care to allow more accurate genetic counseling for at-risk family members.

Over the last 15 years, an exponential number of published molecular genetic reports on autism have utilized genomic technology, bioinformatics, and computational biology, including genome-wide association studies (GWAS) across the fields of medicine, psychiatry, and the social sciences. This research led to the interrogation of genomic variants to search for links among specific gene findings, disorders, traits, or phenotypes of affected individuals. Furthermore, bioinformatics and computational biology software interactive programs combined with human genomic datasets have led to the discovery of gene-gene–protein interactions, biological pathways, and molecular functions, and a further understanding of the role of genetics and biology in neurodevelopment.

Genome-wide association studies (GWAS) analyses have found a strong association with single nucleotide polymorphisms (SNPs) and cadherin genes, including neuronal cell adhesion molecules, with over 100 genetic loci reported with ASD (16,17).. More recent data indicate that over 2000 human genes are implicated in intellectual developmental disability and ASD (18). Many ASD genes are located on the X chromosome (>150 out of 900 X-linked protein-coding genes) and are involved in chromatin remodeling, synaptic function, neuronal signaling, and brain neurodevelopment (19). Of the 800 genes implicated as clinically relevant ones that are known or susceptible in ASD (15), many include members of the neuro-ligand, neurexin, cadherin, *GABA* receptors, and *SHANK* gene families. Other genes encode neurotransmitters and their receptors, transporters, brain-derived hormones, oncogenes, signaling and ubiquitin pathway proteins, neuronal cell adhesion molecules, and epigenetics (20,21).

One of the ubiquitin-related genes is *UBE3A* (ubiquitin protein ligase E3A), a maternally expressed gene on chromosome 15 that causes Angelman syndrome, an imprinted disorder, and when it is mutated, it shows features of autism (22). Therefore, gene expression patterns and correlation with features of autism were studied in individuals with chromosome 15 disorders (Angelman, Prader-Willi, and chromosome 15 duplication syndromes), including the *UBE3A* gene and *SNORD116*, a paternally expressed transcript or snoRNA that serves as a precursor to the antisense *UBE3A* gene for regulation of its activity. The reported findings suggested the presence of novel interactions between the expression of *UBE3A* and *SNORD116,* with brain-specific processes underlying motor and language impairments in autism and these chromosome 15 imprinted genetic disorders.

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Next-generation sequencing enables the accurate detection of mutations or gene variants at the whole exome or genome level by sequencing nuclear and mitochondrial DNA, and is, therefore, potentially more informative than structural chromosome microarrays are for single gene changes. Newer chromosomal SNP microarrays identify chromosomal abnormalities at levels approximately 100 times smaller than those seen with standard high-resolution chromosome methods developed in the 1980s. In terms of evidence, Shen et al. (23) reported genetic findings from more than 900 patients presenting with ASD using standard karyotype chromosome analysis, fragile X DNA testing (Fragile X Syndrome is recognized as the most common cause of familial intellectual disability and/or autism, primarily affecting males), and chromosomal microarrays. They found abnormal karyotypes in 2.2% of the patients, abnormal fragile X testing in 0.5% and deletions or duplications in 18.2%, including recurrent chromosome deletions or duplications for 16p11.2, 15q13.2-q13.3, 7q11, and

22q11.2, and more recently, 15q11.2 BP1-BP2 (24)

Whole exome sequencing (WES) has yielded results ranging between 9 and 30% (29,30) in individuals with ASD. For example, Aspromonte et al. (25) studied intellectual disability and autism with next-generation sequencing using a panel of 74 genes involved in molecular pathways and pathogenesis of both intellectual disability and ASD in 150 patients, achieving a 27% total diagnostic yield. One of the most extensive exome sequencing studies in autism to date was conducted by Satterstrom et al. in 2020 (26) in nearly 12,000 individuals with autism, including proband–parent trios and controls, implicated 102 autism risk genes, finding a significant 3.5-fold increase in the de novo protein-truncating variants in their study population. However, most of the gene variants found in other studies were of unknown clinical significance and were not reported in the medical literature as disease-causing ones or included in human genomic databases. These variants were rarely reported as pathogenic or likely pathogenic due to limitations in bioinformatics, computational prediction, or the paucity of data in the literature. A recognized complex interplay exists between inheritance and environmental factors that contribute to autism and is impacted by epigenetic regulation of gene expression. With improvements in genomic technology, bioinformatics, computational predictions, and the enlargement of human genomic databases, more helpful information will be learned about the genetic causation of and single gene findings for ASD.

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A better understanding of how variations in implicated genes influence the presence of co-occurring conditions and drug response is needed, particularly as this information can help to guide personalized treatment approaches for ASD. Veatch et al. (27), in 2020, established a protocol to pinpoint ASD genes that are more likely to have clinically relevant variants by developing a functional annotation pipeline. They began with a list of all the candidate genes implicated in recognized manifestations of ASD utilizing databases that represent multiple lines of evidence including genes expressed in the human brain involved in ASD, their relevant biological processes and phenotypes reported in mice, whose products possess specific pharmacogenetic variation, have been targeted by pharmaceutical agents or directly interact with specific genes having variants recommended to be tested for by the American College of Medical Genetics (ACMG). Of 956 ASD implicated genes studied in the complete set, 18 were flagged based on evidence from all the categories, with notably none of the prioritized genes represented among the 59 genes compiled by ACMG, and 78% with a pathogenic or likely pathogenic classified disease-causing variant. This ongoing research should prioritize potentially actionable results from genetic studies, thereby informing clinical decision support for personalized care based on genetic testing.

Butler et al. (15) utilized early advances in genetic technology and a bioinformatics approach in a group of 20 females with autism (average age 7.7 years, range from 5 to 16 years) from multiplex families. They compared them to simplex or sporadic families, indicating single gene involvement with structural DNA changes. Five of the twenty females had functional variants of X-linked genes (*IL1RAPL1, PIR, GABRQ, GPRASP2*, and *SYTL4*) along with cadherin, protocadherin, and ankyrin repeat gene families (*CDH6, FAT2, PCDH8, CTNNA3*, and *ANKRD11*) and other related genes for neurogenesis or migration (e.g., *SEMA3F* and *MIDN*). More recently, a report using next-generation sequencing data and a meta-analysis of the literature compared ASD, epilepsy and intellectual disability identified in 103 published studies (ASD, N = 14; epilepsy, N = 72; intellectual disability, N = 21) across 32,331 individuals with diagnostic yields of 17.1% for ASD, 24% for epilepsy and 28.2% for intellectual disability (27). The meta-analysis yielded a similar result to that of the whole exome study in the female ASD cohort reported earlier by Butler et al. (15). More research is needed to identify the most commonly cited genes and their gene-gene–protein interactions with pathway analysis to introduce new avenues for therapeutic agents and treatment.

"Complex inheritance patterns exist in neuropsychiatric illnesses, indicating multiple genetic and environmental factors influencing disease risk and course. Hence, the GeneAnalytics computer program was used to conduct a pathway analysis and genetic profiling with predictors to characterize common or susceptible genes for ASD (792 genes) (28), bipolar disorder (290 genes) (29), and schizophrenia (560 genes) (30)."

Complex inheritance patterns exist in neuropsychiatric illnesses, indicating multiple genetic and environmental factors influencing disease risk and course. Hence, the GeneAnalytics computer program was used to conduct a pathway analysis and genetic profiling with predictors to characterize common or susceptible genes for ASD (792 genes) (28), bipolar disorder (290 genes) (29), and schizophrenia (560 genes) (30). This program utilized an analytical approach to compare and rank the number and nature of overlapping genes among disorders, gene disease associations and pathways, gene functions, and tissue specificity, subdivided into categories (e.g., diseases, tissues, or functional pathways). Twenty-three genes were found to be common among all three disorders and mapped to nine biological super-pathways. These included circadian entrainment with ten genes, amphetamine addiction with five genes, and sudden infant death syndrome with six genes. The program identified brain tissues involved in gene activity and measured the involvement of eleven genes in the medulla oblongata, ten genes in the thalamus, and nine genes in the hypothalamus across the three disorders. Six common genes were

also found, including *BDNF*, *DRD2*, *CHRNA7*, *HTR2A*, *SLC6A3*, and *TPH2*. Interestingly, these overlapping genes impact serotonin and dopamine homeostasis and signal transduction pathways affecting mood, behavior, and physical activity. Converging effects were also recognized in pathways that govern circadian rhythms, with 10 genes found in common (SLC6A3, GSK3B, HTR2A, MAOA, NOS1AP, PDE4B,TPH2, CACNA1C, CHRNA7, and DRD2) and supported by a known core etiological relationship that exists between neuropsychiatric illnesses and sleep disruption with hypoxia and associated central brain stem dysfunction (20,

In summary, a total of 106 phenotypes were mapped to the 23 overlapping genes, with 36 phenotypes in common, including 18 genes having highly matched ranking scores. The highest matched phenotypes were behavioral despair (learned helplessness) involving four genes in common, hypoactivity involving seven genes, abnormal serotonin levels involving four genes, and abnormal response to novel objects involving four genes. Additionally, identified phenotypes impact GABAergic neuron morphology, synaptic transmission, and responses to hypoxia, as well as the risk of death. Of the three disorders with overlapping genes matched to super pathways, the circadian entrainment category was the number one matched finding, followed by amphetamine addiction. For the biological processes category, the startle response was ranked as number one, followed by positive regulation of axon extension, cellular calcium ion homeostasis, synaptic transmission, dopamine catabolic process, and axon guidance with synapse assembly. Three functional pathways described in ASD as potentially involved were chromatin remodeling (e.g., *CHD7*, *MECP2*, *DNMT3A*, and PHF2), the Wnt pathway (e.g., CHD8, PAX5, and ATRX), other signaling superpathways (e.g., GPCR, ERK, and RET), and mitochondrial dysfunction (20).

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Initial laboratory testing recommends the non-targeted metabolic screening of fasting blood samples to exclude disturbances in unexplained developmental delay, intellectual disability, and ASD. These tests include fasting blood lactate, folate, ammonia, copper, amino acids, total homocysteine, acylcarnitines, very long chain fatty acids, transferrin N-glycan profiling, and urine samples for organic acids, oligosaccharides, creatine, glycoaminoglycans, and guanidinoacetate levels that account for 50% of the 69 treatable metabolic disorders. In addition to the laboratory, we include exome sequencing and mitochondrial DNA testing, which have identified a growing list of causative genes contributing to 116 disorders involving 139 genes. Furthermore, we target molecular results in 37 genes without biomarkers, accounting for 23 of the 116 recognized intellectual disability disorders. For these 23 disorders, no specific biomarker is currently available, and molecular testing would be required for 20% of the treatable disorders (31). Second-level testing by a Genetics Team specializing in the evaluation of children with suspected ASD is recommended for additional disorders that may require analysis of cerebrospinal fluid, enzymatic assays, and uric acid metabolism (32).

"Cerebral folate deficiency syndrome (CFDS) is defined as any neuropsychiatric or developmental disorder characterized by decreased CSF folate levels in the presence of normal folate status outside the nervous system. The specific clinical profile appears to be determined mainly by the presence or absence of intrauterine folate deficiency, as well as the postnatal age at which cerebral folate deficiency occurs."

Cerebral Folate Deficiency:

Cerebral folate deficiency syndrome (CFDS) is defined as any neuropsychiatric or developmental disorder characterized by decreased CSF folate levels in the presence of normal folate status outside the nervous system. The specific clinical profile appears to be determined mainly by the presence or absence of intrauterine folate deficiency, as well as the postnatal age at which cerebral folate deficiency occurs. The primary cause of CFDS is identified as the presence of serum folate receptor-alpha (FRα) autoantibodies impairing folate transport across the choroid plexus to the brain, whereas, in a minority of cases, mitochondrial disorders or inborn errors of metabolism and loss-of-function mutations of the FRα (*FOLR1*) gene are identified. Early recognition and diagnosis of CFDS, along with prompt intervention, are crucial for improving prognosis and achieving successful outcomes. In this article, we focus on FRα autoimmunity and its different age-dependent clinical syndromes, the diagnostic criteria, and treatments to be considered, including prevention strategies in this at-risk population (33). Ramaekers et. al. describe five forms of folate deficiency in the brain as follows;

I. Reduced transport of folates across the blood–brain barrier into CSF and across the ependymal into the brain.

II. Reduced folate storage and release from the intracellular folyl-polyglutamate pool

III. Increased utilization and consumption of reduced folates within the nervous system, leading to depletion of the folate pool

IV. Increased catabolism of reduced folates within the nervous system

V. Metabolic conditions affecting folate metabolism within the nervous system

One of the important aspects in the clinical management of infantile-onset CFDS, autism with neurologic deficits, or infantile autism requires a high index of awareness, particularly in young children, to diagnose these conditions as early as possible, since early folinic acid treatment for FRα autoimmunity, carrying a high prevalence in these conditions, will considerably improve outcome (34). In addition, prognosis becomes less favorable if one or both parents are positive for these FRα autoantibodies. Most parents carrying antibodies remain asymptomatic. For future pregnancies among affected families, parents carrying these autoantibodies are recommended to receive folinic acid (leucovorin) doses up to daily doses of 3.75 mg levo-folinic acid, which should be started three months before conception and throughout pregnancy in mothers positive for FRα autoimmunity. Preliminary results from three families, where the first-born child had infantile autism and parents tested positive for FRα autoantibodies, showed that folinic acid treatment of parents resulted in five completely healthy siblings. Before a second pregnancy is planned, genetic counselling should always exclude the possibility of genetically determined causes of autism. C.J. Volpe writes that:

Researchers have hypothesized that the low folate levels are caused by the presence of antibodies in the blood that block or bind folate and prevent it from getting into the brain. However, non-autistic family members of these autistic individuals also show high levels of folate antibodies, suggesting that the high levels of folate antibodies are not a cause of autism (Volpe, C.J. (September 22, 2025), ASF Statement on White House Announcement on Autism. Autism Science Foundation, New York).

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Infant Follow-up and Surveillance and Avoiding Stigma:

Recent data from British Columbia, Canada, from a sample of 465,338 children born at 22 to 44 weeks' gestational age (GA) in this province from April 2004 to December 2014 were available. After exclusions for missing information on GA or birth weight, incomplete linkage, or loss of registration, the cohort included 448,819 children (96.5%), with 420,309 (93.6%) having a complete 5-year follow-up until 2019. Data were analyzed from May 2023 to April 2025. Gestational age at birth was grouped into eight categories: 22 to 24, 25 to 27, 28 to 30, 31 to 33, 34 to 36, 37 to 38, 39 to 41 weeks (reference), and 42 to 44 weeks. Health service use (hospitalizations and outpatient visits), morbidity (combined inpatient and outpatient diagnoses), and medication needs (outpatient prescriptions). Of 448,819 children (mean [SD] age at follow-up, 4.8 [0.69]; 230,351 [51.3%] male), 42,080 (9.4%) were born before 37 weeks. Hospitalization rates within 5 years were higher for children born earlier compared to 39 to 41 weeks:

Table II: Gest, Age, Risk Ratio, Hospitalization Rate. 95%CI. Risk Difference 1000 patients CI

22-24 weeks (395.62-533.08)	6.37	562-7.22.	464.35
25-27 weeks (2.71.42-336.99)	4.52	4.15-4.92.	304.21
28-30 weeks. (128.01-165.78)	2.70	2.49-2.93.	146.9
31-33 weeks (69.56-88.61)	1.91	1.81-2.03	78.08
34-36 weeks (42.13-49.92)	1.53	1.49-1.58.	45.03
37-38 weeks. (11.9-15.78	1.16	1.14-1.18.	13,84.

Earlier GA was associated with increased outpatient visits by age 5 years. Children born preterm exhibited higher rates of respiratory (RR, 1.33; 95% CI, 1.30-1.37 to RR, 3.96; 95% CI, 3.30-4.70), endocrine (RR, 1.13; 95% CI, 1.09-1.18 to RR, 2.37; 95% CI, 1.65-3.27), gastrointestinal (RR, 1.26; 95% CI, 1.11-1.43 to RR, 6.36; 95% CI, 3.05-11.49), kidney (RR, 1.17; 95% CI, 1.08-1.26 to RR, 3.39; 95% CI, 1.86-5.59), neurodevelopmental (RR, 1.60; 95% CI, 1.55-1.66 to RR, 8.04; 95% CI, 6.78-9.44), and sleep (RR, 1.35; 95% CI, 1.21-1.51 to RR, 3.39; 95% CI, 1.34-6.87) disorders. Children born preterm were more likely to receive outpatient antibiotics, bronchodilators, corticosteroids, diuretics, and thyroid hormones. In their population-based cohort study, despite neonatal care advancements, children born preterm required more health care resources and faced greater health challenges in their first 5 years. (Richter, L.L., Shen, Y., Lisonbtora, S., et al. JAMA Pediatrics.2025; Sept. 2724.)

Burnett, A., and coworkers report that, among 18,012 infant records from 29 studies across 16 cohorts, meta-analysis revealed that the occurrence of bronchopulmonary dysplasia, male sex, and lower socioeconomic class were the most consistent predictors of neurodevelopmental impairment, IQ, worsening memory, cerebral palsy, fine motor skills, and specific behavioral measures. Emotional problems were generally not associated with the neonatal variables they investigated.

Burnett, D. Axford, S.B., Anderson, P.M., Waterland, P., Gilchrist, C.F., et al. Predicting long-term neurodevelopmental outcomes for children born very preterm: a systematic review. Arch Disease of Childhood, *Fetal and Neonatal edition* 2025; September issue.

Advocacy and Affirmation:

While these follow-up data raise important concerns regarding those infants born very prematurely with significantly higher prevalence of neurodevelopmental delays, framing these delays, including autism as a tragedy or disease, and using deficit-based stereotypes to characterize autistic people, harms their mental well-being while also distorting public perception, is a disservice to disabled and autistic children and their parents. Moreover, Kennedy's words undermine the decades-long progress of people with disabilities. They evoke a painful history of institutionalization, sterilization, and even violence, which is a public disservice. "When we reduce autistic lives to economic output, we revive the

same eugenic logic that has endangered disabled people for more than a century," noted a neurodiversity psychologist and advocate, Karissa Burnett, Ph. D. (35).

"Neonatologists, pediatricians, and clinical psychologists are best advised to adopt a strengths-based approach that affirms neurodiversity of infant and later childhood outcomes in their advice to parents of premature infants. Further their advocacy and ongoing research and clinical endeavors with extremely low birth weight and very preterm infants. Many autistic children thrive even when not cured, but when they are understood, accommodated, and respected. Neonatologists must move from awareness to allegiance and stand with autistic children against dehumanization."

Neonatologists, pediatricians, and clinical psychologists are best advised to adopt a strengths-based approach that affirms neurodiversity of infant and later childhood outcomes in their advice to parents of premature infants. Further their advocacy and ongoing research and clinical endeavors with extremely low birth weight and very preterm infants. Many autistic children thrive even when not cured, but when they are understood, accommodated, and respected. Neonatologists must move from awareness to allegiance and stand with autistic children against dehumanization. Research has primarily focused on understanding and diagnosing autism in children and teenagers, which has led to increased awareness, earlier diagnosis, and better treatment for children and teenagers. In a report from the Centers for Disease Control and Prevention (36), the prevalence of autism diagnoses among children has been estimated to be 1 in 36, a significant increase from previous years. These new diagnoses reflect a more diverse group of children, including a larger proportion of autistic children without intellectual disabilities. As these children grow up, they will continue to need various forms of support throughout adulthood. In In April 2025, the CDC Morbidity and Mortality Weekly, reporting data through 2022 among children aged 8 years, the ASD prevalence was 32.2 per 1000 children (1 in 31) across the 16 sites ranging from 9.7 in Lardo, Texas to 53.1 in California (3) The overall observed prevalence was similar to estimate calculated using Bayesian hierarchical and random effects models. ASD was 3.4 times more prevalent among boys than girls. Overall, ASD prevalence was lower among non-Hispanic White children (27.7) than among Asian or Pacific Islander (38.2. Among American Indian and Alaska Native children, the rate was 37.5, and among African American children, the rate was 36.6. Hispanic (33.0) and multiracial children had a rate of 31.9. No association was observed between ASD prevalence and neighborhood median household income, but higher ASD prevalence was associated with lower neighborhood income at five sites. Overall, only 66.5% of children aged 8 years with ASD had a documented autism test that varied widely (24.7% in New Jersey to 93.5% in Puerto Rico with commonly used tests (3).

"To further explain the rising rates of ASD, Dr. Allen Frances, a psychiatrist who led the American Psychiatric Association's task force that created the fourth edition of the Diagnostic and Statistical Manual of Mental Disorders, commonly called DSM-IV (36), noted that this edition included Asperger's Syndrome, which is a much milder form than classical autism. There, the rate of diagnosis of ASD increased from one in 2,500 to one in 150, a 16-fold rise, and the rate has been climbing to the current one in 31 births recently reported (3)."

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Given this increasing prevalence, Neonatologists and Pediatricians must understand the evidence supporting the occurrence and diagnostic testing that should be offered in infant follow-up programs, which are a requirement in most states for

funding of their NICU care. Further cuts in diagnostic evaluations for ASD may exacerbate the issue of qualifying for Individualized Education Plans. Neonatologists, among others, can promote the concept that ASD is a form of neurodiversity and not a disease.

"Given these potentially superimposed or overlapping conditions, neonatologists and pediatricians must be vigilant when evaluating preterm infants for ASD in that ASD may masquerade as sequelae of prematurity, and the sequelae of prematurity may masquerade as ASD, according to Hurt (39). In the former, one should not assume all findings are related to prematurity, thus delaying further evaluation for ASD. "

Implications of the Changing Prevalence:

According to Dr. Nathaniel DeNicola who advises the American College of Obstetricians and Gynecologists on environment issues "The conclusion of the paper (referring to reference 5) is that Tylenol should be used judiciously in the lowest dose, least frequent interval which is exactly the current standard of care for Tylenol and for so many medications, and really so many other things me may encounter in pregnancy. Counseling." (37). The Society for Maternal-Fetal Medicine President Sindhu Srinivan issued a statement stating "At this time, the weight of scientific evidence that acetaminophen using during pregnancy causes an increased risk for autism or ADHD is simply inconclusive" (38). They further stated that "untreated fever, particularly in the first trimester, increases the risk for miscarriage, birth defects, and premature birth, and untreated pain can lead to maternal depression, anxiety, and high blood pressure." (38). It is essential to understand that the Diagnostic and Statistical Manual of. Mental Disorders Fifth Edition (DSM V) states that are criteria for ASD is, "disturbances are not explained by intellectual disability or global developmental delay," two conditions along with visual, hearing and motor delays, that may have been seen in prior preterm infants. Given these potentially superimposed or overlapping conditions, neonatologists and pediatricians must be vigilant when evaluating preterm infants for ASD in that ASD may masquerade as sequelae of prematurity, and the sequelae of prematurity may masquerade as ASD, according to Hurt (39). In the former, one should not assume all findings are related to prematurity, thus delaying further evaluation for ASD. Importantly, early evaluation, diagnosis, and appropriate interventions are not covered by Early Intervention programs, and if an infant is compromised by neurodevelopmental findings that mimic ASD, pediatricians or clinical psychologists must not be too hasty to ascribe findings to ASD.

Legal Aspects:

Classic autism has gradually evolved into the concept of a larger "spectrum disorder." The rising prevalence of autism and autism spectrum disorder (autism/ASD) diagnoses can be primarily attributed to broader diagnostic criteria, adoption of dimensional assessment strategies, increased awareness, linking of services to diagnosis, and the inclusion of milder neurodevelopmental differences bordering on normality. The spectrum disorder diagnosis raises numerous bioethical issues for individuals and society. Three groups of caregivers have important ethical, legal, and social obligations to individuals with autism/ASD: (1) families and advocates of individuals with autism/ASD; (2) health care and other professionals; and (3) governments. Each group may have different views of autism/ASD diagnostic criteria, screening, testing, and the effectiveness of various interventions. All see timely diagnosis as desirable, but earlier diagnosis may not be better, morally or practically. The growing practice of genetic testing in milder ASD raises ethical questions because of its uncertain scientific validity and limited clinical utility. Individuals with autism/ASD have various kinds of needs, but all want acceptance, and most deserve better accommodations. Governments struggle to provide a fair allocation of appropriate special education and supportive services.

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On June 22, 1999, the United States Supreme Court held in Olmstead v. L.C. that unjustified segregation of persons with disabilities constitutes discrimination in violation of Title II of the Americans with Disabilities Act. The Court held that public entities must provide community-based services to persons with disabilities when (1) such services are appropriate; (2) the affected persons do not oppose community-based treatment; and (3) community-based services can be reasonably accommodated, taking into account the resources available to the public entity and the needs of others who are receiving disability services from the entity. Neonatologists and pediatricians are required to provide for "reasonable accommodation" for families and their children with ASD as defined by the Americans with Disability Act. While infants in the NICU remain at increased risk, screening and potential diagnosis may be in the future for some NICU "graduates," and many follow-up programs will undoubtedly be screening for ASD in accordance with American Academy of Pediatrics guidelines, with higher numbers of very preterm infants being of concern.

Conclusion:

We have summarized many of the associations between a range of prenatal, perinatal, and postnatal (NICU-related) factors that have been correlated, albeit not causally linked, with the later occurrence of autism spectrum disorder (ASD). These associations include maternal health conditions, environmental exposures, medications, infections, inflammatory states,

prematurity, and complications related to neonatal intensive care. We have organized these data into a framework that may help clinicians and parents better understand the complexities behind these correlations, emphasizing both what is currently known and what remains speculative.

Among the factors that have generated particular public and scientific attention is the potential association between acetaminophen use during pregnancy or early infancy and later neurodevelopmental outcomes. These findings must be interpreted cautiously. The data are largely observational and not causative, and cannot definitively separate the effects of acetaminophen itself from those of underlying maternal conditions (such as infection or fever) for which the medication was taken. Furthermore, the potential for recall bias and unmeasured confounders remains substantial. Clinicians must acknowledge the uncertainty of this evidence, balancing the legitimate concern for possible neurodevelopmental effects with the reality that acetaminophen remains one of the few safe and effective treatments for maternal fever and pain during pregnancy when used appropriately.

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Unfortunately, the public conversation about autism risk has been distorted by misinformation and fear-mongering narratives, often amplified through social media and non-scientific sources. These claims frequently misrepresent correlation as causation, overlook study limitations, and spread unfounded anxiety among expectant parents. Neonatologists and other healthcare professionals are increasingly confronted with questions rooted in these misunderstandings. As trusted voices in newborn medicine, we have an ethical responsibility to provide evidence-informed, balanced, and compassionate explanations, clarifying that while research continues to explore possible environmental and genetic contributors to ASD, no single factor, medication, or event during the NICU stay has been proven to cause autism.

Beyond medication exposures, multiple risk factors have been reported to correlate with later ASD diagnoses. These include extreme prematurity, low birth weight, intrauterine growth restriction, maternal metabolic or inflammatory disorders, preeclampsia, placental insufficiency, perinatal hypoxia, and neonatal brain injury such as intraventricular hemorrhage or periventricular leukomalacia. Emerging evidence also points to the potential influence of maternal microbiome changes, nutritional deficiencies, exposure to environmental toxins, and postnatal stress (e.g., prolonged separation or painful procedures in the NICU) on neurodevelopmental trajectories. However, these are associations rather than proven causal links, and many infants with one or more of these risk factors have good neurodevelopmental outcomes.

Given this complexity, communication with parents requires both scientific literacy and empathy. Parents of NICU graduates are understandably concerned about developmental outcomes, particularly when confronted with online speculation or conflicting media reports. Neonatologists, therefore, should be prepared to discuss the current state of knowledge transparently: acknowledging potential associations, explaining limitations of existing data, and emphasizing the protective effects of evidence-based practices, such as developmental care, minimizing stress and pain, optimizing nutrition, supporting parent-infant bonding, and early intervention when indicated.

"In summary, while numerous prenatal, perinatal, and NICU-related variables have been correlated with later ASD, the field continues to evolve. The goal of our work and the accompanying article is not to alarm, but to inform and to provide clinicians and families with a nuanced understanding of the data, help counteract misinformation, and promote informed, compassionate dialogue about autism risk in the context of neonatal care."

In summary, while numerous prenatal, perinatal, and NICU-related variables have been correlated with later ASD, the field continues to evolve. The goal of our work and the accompanying article is not to alarm, but to inform and to provide clinicians and families with a nuanced understanding of the data, help counteract misinformation, and promote informed, compassionate dialogue about autism risk in the context of neonatal care.

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Which Infants are More Vulnerable to Respiratory Syncytial Virus?

RSV is a respiratory virus with cold-like symptoms that causes 90,000 hospitalizations and 4,500 deaths per year in children 5 and younger. It's 10 times more deadly than the flu. For premature babies with fragile immune systems and underdeveloped lungs, RSV proves especially dangerous.

But risk factors associated with RSV don't touch all infants equally.*

*Source: Respirator Syncytial Virus and African Americans

Caucasian Babies	Risk Factor	African American Babies
11.6%	Prematurity	18.3%
58.1%	Breastfeeding	50.2%
7.3%	Low Birth Weight	11.8%
60.1%	Siblings	71.6%
1%	Crowded Living Conditions	3%

AFRICAN AMERICAN BABIES bear the brunt of RSV. Yet the American Academy of Pediatrics' restrictive new guidlines limit their access to RSV preventative treatment, increasing these babies' risk.

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Historical Perspective – Retrolental Fibroplasia: A Modern Parable Revisited

Joseph B. Philips, III, MD, FAAP, Waldemar A. Carlo, MD, Samuel J. Gentle, MD

"A parable is a succinct, didactic story, in prose or verse, that illustrates one or more instructive lessons or principles." Wikipedia.

(JBP) The story of retinopathy of prematurity (ROP), formerly known as retrolental fibroplasia (RLF), has oft been told, but it is worth repeating here because of the important lessons to be learned. I rely on the brilliant yet sobering volume by Dr. Bill Silverman, entitled Retrolental Fibroplasia: A Modern Parable, which is available to read free of charge on the Neonatology on the Web website. (1–3) It summarizes what was known about the causes and efforts to curtail the condition up to the time of its publication in 1980. Much has changed since then, which we attempt to summarize in this review.

The saga begins in 1941 when Dr. S.H. Clifford, a Boston pediatrician, made a home visit to examine a former preemie and noted, "Although the baby's general development was excellent, I was shocked to note roving nystagmus, and opacities in the eyes, and I had to tell the family I was afraid the baby could not see." More such cases followed, and Dr. T. L. Terry published in 1942 that "In view of these findings, perhaps this complication should be expected in a certain percentage of premature infants. If so, some new factor has arisen in extreme prematurity to produce such a condition. Should this group of cases be not a most unusual complication in extreme prematurity, then it is important not only to establish the frequency but also to work out promptly the most satisfactory therapy." (4) The search for a cause and cure was on, but as we shall see, it took years to establish the cause and even longer to work out satisfactory therapies.

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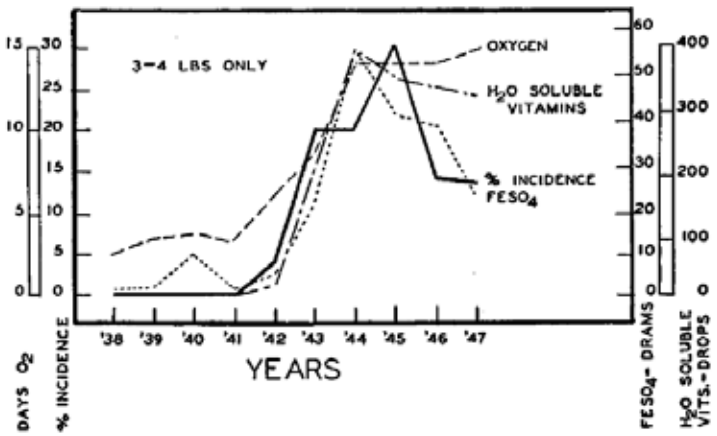
After Messenger coined the term retrolental fibroplasia, literally meaning scar tissue behind the lens, several therapies were evaluated as potential causes. Kinsey and Zacarias reported in 1949 the association of RLF with the rates of administration of oxygen, water-soluble vitamins, and ferrous sulphate (Figure 1). (5) Examination of the figure might mistakenly lead the observer to find the highest correlation to be with ferrous sulfate. Following this, a number of hypotheses and trials of various treatments were conducted to prevent or treat RLF, none of which were effective. I refer the reader to Silverman for further details. (3)

Figure 1. Graph comparing use of oxygen, water-soluble vitamins, and ferrous sulphate with the incidence of RLF. (5)



The identification of oxygen as a possible cause was proposed by Australian physician Dr. Kate Campbell in 1951. (6) She wrote, "It was therefore with much interest that I heard, from colleagues returning from overseas, the suggestion that oxygen might be responsible for producing retrolental fibroplasia. The idea arose apparently from a comparison of the treatment of premature infants in America, where retrolental fibroplasia is a problem and where oxygen was used freely, with the treatment in England, where retrolental fibroplasia is seen rarely, and where oxygen was used sparingly" Dr. Campbell observed that RLF occurred in 19% of infants cared for in a nursery that had a liberal oxygen use policy and in only 7% of those cared for in two other nurseries where oxygen was used sparingly and wrote "Oxygen should be given only when the infant is cyanosed and not as a prophylactic measure."

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Arnall Patz, MD, then a trainee at Gallinger Hospital, which subsequently became D.C. General Hospital, was concerned that the then-standard use of supplemental oxygen for all premature babies might be the cause of RLF. He applied for a grant from the nascent National Institutes of Health (NIH). However, he was turned down with the critique "These guys are going to kill a lot of babies by anoxia to test a wild idea." (7) Undaunted, Patz borrowed money from his brother to collect preliminary data and reapplied to the NIH after stating "to avoid having deaths from lack of oxygen, every baby in the low oxygen group would be maintained at a healthy pink color." Moreover, the grant was awarded with a budget of $4,000. (2) Infants weighing less than 3.5 pounds at birth were assigned on an alternating basis to receive either the standard oxygen regimen of 65 to 70% for 4 to 6 weeks or the restricted regimen of under 40% oxygen in incubators for one day to two weeks. (8) The results were striking —none of the 37 surviving infants in the restricted oxygen group had grade III or IV disease, while 7 of the 28 infants in the high oxygen group did (Figure 2). This study is thought to be the first controlled trial in the history of ophthalmology. (7)

Figure 2. Rates of RLF in high vs. low oxygen groups in the Patz trial. (8)

TABLE 1
RESULTS OF STUDY OF 65 CASES

Oxygen Levels	Total Number of Infants	Normal Eyegrounds	Retrolental Fibroplasia			
			Grade			
			I	II	III	IV
High	28	11	3	7	2	5
Low	37	31	4	2	0	0

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Almost immediately after this publication, many nurseries began to restrict oxygen to less than 40% in an effort to end the epidemic of RLF—the so-called "40% rule." However, not all "neonatologists" were convinced—the term neonatologist was not in use at the time and was coined by Dr. Alexander Shaffer in 1960 (9). By 1953, it was estimated that at least 6,000 infants in the US alone had been blinded by RLF, including the brilliant singer, songwriter, musician, and record producer, Stevie Wonder. (3) The idea of a collaborative study of oxygen restriction for the prevention of RLF was proposed at the 1952 meeting of the American Academy of Ophthalmology and Otolaryngology, and subsequently, a large meeting was held under the auspices of the National Institute of Neurological Diseases and Blindness of the US Public Health Service. (3) In attendance were most of the American pediatricians and ophthalmologists who were interested in RLF. As told by Silverman, "It soon became clear that there were two camps. The majority felt that a formal controlled trial must be carried out immediately to answer the outstanding questions concerning oxygen treatment. A minority felt that there was sufficient evidence to indict oxygen therapy as the cause of RLF and argued that the proposal for a new nursery study was not justified but rather immoral. The dissidents cited the results of the only properly controlled trial" (p 27). However, the majority were impressed that the persons who conducted the Gallinger Hospital trial and knew its defects were solidly on the side of the cooperative study. One splinter group felt that limiting oxygen would require infants to undertake an unjustified risk of death and brain damage. After much debate, most of it heated, it was agreed that a joint effort should be undertaken to determine whether the frequency of occurrence of RLF is dependent upon the amount of oxygen used in the management of premature infants. An eight-man subcommittee was appointed to draw up specific plans for the cooperative study.

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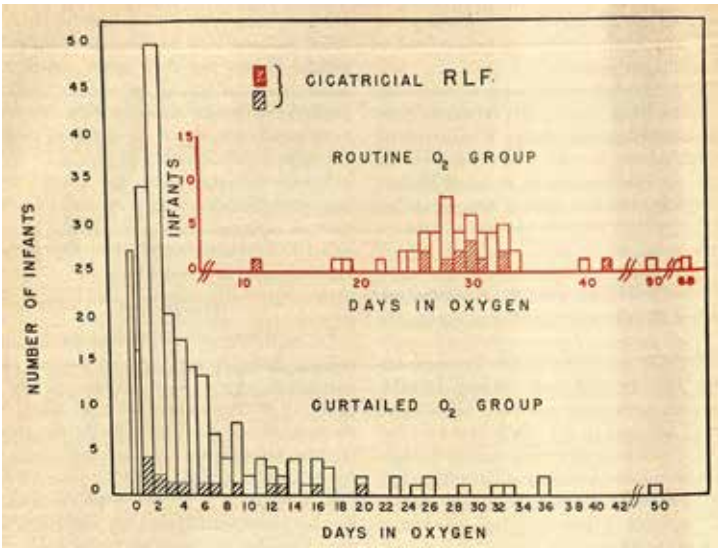
The study design that was eventually arrived at and conducted at 18 centers randomly allocated infants weighing less than 1.5 kg who survived the first 48 hours to one of two regimens: one baby on unrestricted oxygen regimen for every two babies on curtailed oxygen regimen with close monitoring of mortality. (10) Once 68 babies had entered the unrestricted oxygen group and no difference in mortality was observed, the remaining infants were all placed in the curtailed oxygen group. The results were stunning and clearly identified oxygen as the culprit (Figure 3). (10) A 63-page report followed that analyzed multiple aspects of this trial and concluded, "Of the factors considered, this controlled study shows conclusively that the length of time the premature infant is kept in an oxygen-enriched environment is the important

Figure 3. Days in oxygen vs. number of infants with and without RLF in the cooperative trial of unrestricted or curtailed oxygen regimens. (10)



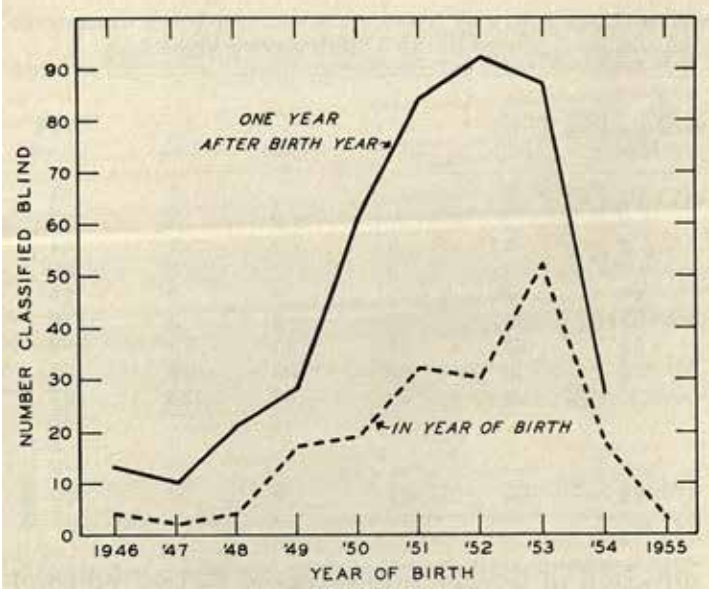
factor in the production of RLF. Limiting the duration of oxygen to that deemed necessary to meet a frank clinical emergency was shown to be without effect on the survival rate of the premature infant. **For all practical purposes, there is no concentration of oxygen in excess of that in air that is not associated with risk of developing RLF** (bold text added by JBP for emphasis). Infants of multiple birth appear to be significantly more susceptible to RLF than infants of single birth." (11) A subsequent study including the primary drivers of the cooperative study, Dr. Kinsey and Patz attempted to correlate PaO_2 levels with the risk of developing RLF. (12) The study found no correlation except in infants weighing less than 1,250 grams and concluded once again that duration of oxygen exposure was the main culprit in RLF as well as noting that the disease was more frequent in lower gestation babies.

"'Of the factors considered, this controlled study shows conclusively that the length of time the premature infant is kept in an oxygen-enriched environment is the important factor in the production of RLF. Limiting the duration of oxygen to that deemed necessary to meet a frank clinical emergency was shown to be without effect on the survival rate of the premature infant. For all practical purposes, there is no concentration of oxygen in excess of that in air that is not associated with risk of developing RLF.'"

Despite the statements that there is no safe concentration of oxygen above room air, the "40% rule" continued to be applied in most nurseries and indeed was considered "hallowed' as documented by Dr. Dale L. Phelps in a comprehensive review published in 2001. (13) It should be noted that no "official" body ever issued a "40% rule" except for a vague memorandum circulated to hospitals in New York City stating, "Recent studies suggest a possible interrelationship between high concentrations of oxygen and the development of retrolental fibroplasia in premature infants. The Pediatric Advisory Committee has therefore recommended that premature infants receive oxygen only as needed and then in concentrations not to exceed 40 percent."(3)

The implementation of the "40% rule" effectively ended the first epidemic of RLF, which essentially disappeared from NICUs in the 1950s and 1960s (Figure 4) (14), only to reemerge in the 1970s and 1980s. (14–16) However, concerns about the consequences of restricted oxygen use began to emerge shortly after widespread curtailed use of oxygen in premature babies was implemented. Avery and Oppenheimer reported an increase in deaths from hyaline membrane disease at Johns Hopkins in the years following implementation of the "40% rule." (17) Cross estimated in 1973 that for each case of RLF prevented, 16 babies died from lack of oxygen on the day of birth. (18) He and Bolton then suggested that this excess in mortality could be prevented in the most modern

Figure 4. Rise and fall of cases of RLF before and after implementation of the "40% rule." (14)



nurseries at the time, where blood gas monitoring could be used to adjust inspired oxygen concentrations. (19) Data from an article by McDonald were used by Silverman to show that fewer days in oxygen were associated with a higher rate of cerebral palsy, while longer days were correlated with more RLF (Figure 5). (3, 20) These reports raise the fundamentally important issue of competing outcomes, which I return to at the end of this article.

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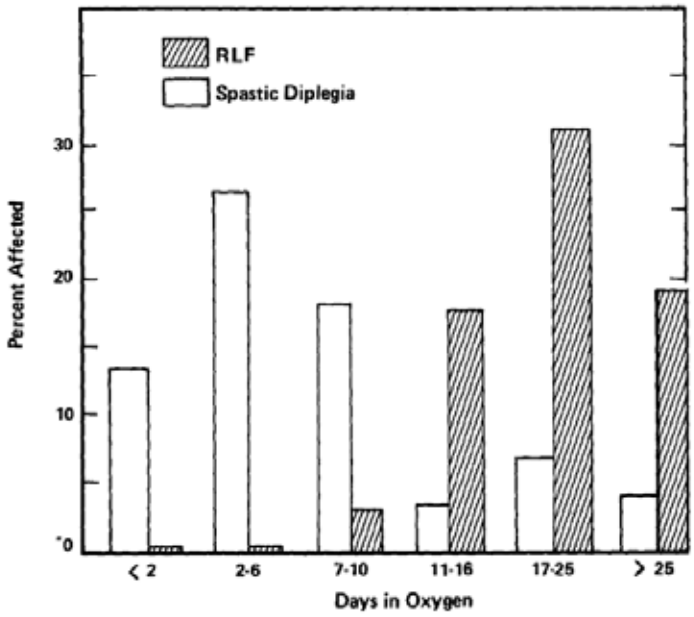
Once RLF had been identified and oxygen was implicated as a cause, the quest was on to characterize it and determine how oxygen produced the disease. Dr. Patz eloquently summarized the results of early studies in his speech accepting the E. Mead Johnson Award from the American Academy of Pediatrics in 1956. (21) This speech summarizes both his clinical studies and extensive animal experiments using opossums, kittens, puppies,

Figure 5. Rates of RLF and spastic diplegia versus days in oxygen. (3, 20)



and rats, all of which have immature retinal vascularization similar to preterm humans. He describes the development of RLF as being in two phases. First, there is intense vasoconstriction of the retinal arterioles, which is initially reversible but becomes permanent with continued exposure to high oxygen concentrations in the inspired air. This is followed by a vasoproliferative stage, where vessels overgrow and branch out into the vitreous, leading to hemorrhage and the formation of scar tissue. This eventuates in retinal traction and ultimate detachment, resulting in the formation of the retrolental scar. Dr. Patz, along with V. Everett Kinsey, PhD, received the Lasker Clinical Medical Research Award, often referred to as "the American Nobel Prize," in 1956 (Figure 6). (22) Dr. Patz went on to have a highly distinguished career, including being President of the American Academy of Ophthalmology and receiving the Presidential Medal of Freedom from President George W. Bush in 2004.

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Figure 6. Drs. Patz (right) and Kinsey being presented with the Lasker Clinical Medical Research Award by Helen Keller. (7)

Several other older studies deserve mention here. Aranda and colleagues studied the relationship between arterial oxygen tension and retinal artery vasoconstriction, concluding that the threshold for constriction was approximately 100 mmHg of PaO_2. (23) It was noted very early on that RLF was not an irreversible disease and that spontaneous regression of early stages of the disease was actually more common than progression to cicatricial disease. (24) Flynn and colleagues published a comprehensive summary of the clinical progression of RLF and, in a prescient statement, concluded that their observations "would lead one to speculate again in the direction of local tissue factors being released from hypoxic retina or mesenchyme, resulting in massive scar formation. Ablative treatment in this region may prove to have the best chance of aborting cicatrization." (25)

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Prior to 1984, various classification schemes were used to describe the stages of RLF. This was resolved by an international group of 23 ophthalmologists from 11 countries who established

the definitive classification system, including "plus" disease, that we all use today. (26) This publication formally proposed using the term retinopathy of prematurity instead of retrolental fibroplasia as it more accurately describes the entirety of the disease, while RLF only refers to the cicatricial phase. It also provided the clarity needed to define the thresholds for the various therapeutic interventions that followed.

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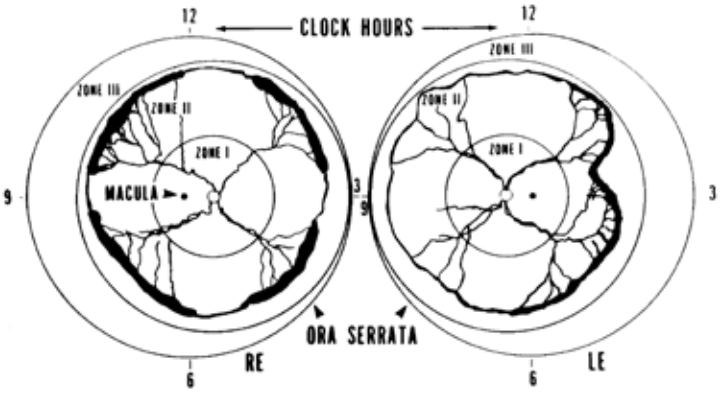
Beginning in the early 1970s and extending into the 1980s, a series of reports, first from Japan and then from several Western countries, suggested that cryotherapy could halt the progression of ROP. (27) However, lack of a randomized controlled trial and concerns for complications highlighted the need for a proper trial of cryotherapy. Accordingly, the National Eye Institute of the NIH sponsored a multicenter trial (CRYO-ROP), beginning in January 1986, with 23 participating institutions, of which University of Alabama at Birmingham (UAB) was one. (27) Infants weighing ≤1,250 grams were enrolled and, once consented, underwent bi-weekly eye examinations beginning at 4 to 6 weeks after birth. Infants whose eyes reached the "threshold" were randomized.

Figure 7. Cartoon depicting threshold disease consisting of either eight or more cumulative clock hours of Stage 3 disease in zone II (RE) or five or more continuous clock hours (LE).(27)



Threshold disease was defined as five or more contiguous clock hours of stage 3 ROP or eight or more cumulative clock hours of stage 3 ROP in zone one or two with plus disease (Figure 7). Infants with symmetric disease in both eyes were then consented, and one eye was randomized to cryotherapy. For the small number of infants with asymmetric disease, the threshold eye was randomized to treatment or no treatment.

I pause here to say that cryotherapy is a brutal procedure. It involves the operator wearing a binocular indirect ophthalmoscope and using the probe to invaginate the avascular retina into view, activating the probe until the retina turns white from the freeze. I vividly recall the first baby that we treated. Despite local anesthesia and preloading with atropine, the vagal response to the first freeze can be profound. Our first patient became asystolic for at least 15 seconds, and I remember thinking that we had killed the baby. Fortunately, the child recovered and tolerated the rest of the procedure. The treated eyes then swell shut for at least a day before "calming down."

Nevertheless, the study's results were remarkable. Infants with threshold disease were predicted to have a 50% chance of an unfavorable outcome without treatment. At the 3-month follow-up, 43% of untreated eyes had an unfavorable outcome, compared to 21.8% of treated eyes. Follow-up of these patients continued to show improved outcomes in the treated eyes at 10 and 15 years of age. (28, 29) Additional studies followed infants enrolled in CRYO-ROP who did not receive cryotherapy. Overall, nearly two-thirds of the infants developed some form of ROP, but only 6% reached threshold. (30) This report also noted that nearly all infants achieved complete retinal vascularization at about 40 weeks post-conceptual age, regardless of how prematurely they were born. A natural history study of a subset of the CRYO-ROP cohort consisting of 1068 children reported unfavorable outcomes in just 3.1% with all of those having had severe ROP. (31) Thus, most infants who develop ROP that resolves without treatment have good visual outcomes.

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The identification of an efficacious treatment for severe ROP changed everything. Prior to this, our practice was to perform an eye examination just before discharge so we could inform the parents of their child's status. Following CRYO-ROP, we implemented a screening system modeled on the study, which was considered too important from both medical and medicolegal perspectives

to be entrusted to rotating house officers. One of our discharge coordinators was assigned to schedule the examinations and to coordinate with our ophthalmologists to ensure that all eligible babies were examined promptly. Screening guidelines were also eventually published. (32, 33)

Terry, who made the original description of RLF speculated that the light exposure during ophthalmoscopic examination could be a potential cause of the condition. (34) In a later publication, he added, "The more tenable theory of the cause of this disease is that failure of production or accumulation of aqueous humor may be caused by the effect of precocious exposure to light…" (35) An early test of this hypothesis by Locke and Reese, published in 1952, refuted this. (36) They patched one eye of 22 babies weighing <2 kg from the day of birth until discharge and noted that, in those who developed RLF, the changes in the patched eye at discharge were similar to those in the unpatched eye. However, this issue reemerged with the report by Glass et al., suggesting that reduced light exposure in the NICU also reduced the incidence of ROP. (37) This hypothesis was laid to rest by the multicenter, randomized, controlled trial (RCT) sponsored by the National Eye Institute entitled LIGHT-ROP, the publication of which also cited further literature in support or refuting the light hypothesis. (38) The study randomized 409 premature infants ≤1250 grams and ≤31 weeks gestation to either normal nursery lighting conditions versus reduced light exposure withing 24 hours of birth by fitting the babies with light-reducing goggles. The goggles reduced visible light by 97% and ultraviolet light by 100%. The goggles were worn until it was time for ophthalmoscopic examination, which occurred a median of 28 days later. The cases and severity of ROP were virtually identical in the two groups. The addition of three smaller trials in a Cochrane Systematic Review confirmed this finding with a relative risk of 1 for light reduction versus normal lighting in infants <2 kg at birth, with a 95% confidence interval of 0.89 to 1.13. (39)

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Advances in technology allowed real-time monitoring of oxygenation in patients. These devices ushered in a new era of efforts to prevent or treat RLF by better controlling oxygen tension in babies. First up was the transcutaneous oxygen tension ($tcPO_2$) electrode. (40) This consisted of a Clark electrode, which used a polarographic method to measure oxygen tension. The device was attached to the skin and used a membrane across which the oxygen diffused. It had to be heated in order to dilate the underlying capillaries to arteriolize the blood. Flynn, a major player in the ROP saga, and colleagues performed an RCT using the $tcPO_2$ monitor to determine whether continuous (CM) use versus standard of care (SC) intermittent blood gas sampling would reduce the rate of ROP. (41) They enrolled infants with birthweights between 800 and 1300 grams who required any supplemental oxygen in the first week of life from 1982 to 1984. Both groups were continuously monitored during the acute phase of their disease, but the SC group was no longer monitored once FiO_2 was <0.40. Both groups had arterial blood gases measured intermittently. Results were somewhat challenging to interpret, but in essence, there were no differences in the rates of ROP in infants <1 kg, while those in the CM group over 1 Kg showed lower rates, which got lower as birthweight increased. This and other studies highlight the fact that the most immature infants are at risk of developing ROP no matter how carefully their oxygen levels are controlled. A follow-up report to this study confirmed this conclusion but also showed an increased risk of developing ROP in infants who spent more time with $tcPO_2$ values greater than 80 mmHg. (42)

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The transcutaneous oxygen tension electrodes had many shortcomings. They did not adhere well to the skin of extremely immature infants and required a tight seal to work correctly. They required membrane replacement and calibration frequently and had to be moved to different positions on the baby's skin at least every 4 hours to prevent superficial burns, which still occurred sometimes even with this precaution. The development of pulse oximeters in the late 1970s and early 1980s led to their replacement of $tcPO_2$ monitors in the mid to late 1980s.

Based on animal data and limited case series in babies suggesting that higher oxygen saturations could reduce the progression of pre-threshold ROP to threshold disease, the STOP-ROP study was conducted in the mid-to-late 1990s. (43) The study was conducted in 30 centers and enrolled 649 babies who were randomized to saturation limits of 89–94% versus 96–99%. Results suggested a benefit for the higher limits but did not achieve statistical significance, and there were more adverse outcomes in the higher limit group. There did seem to be more benefits for infants without plus disease. The HOPE-ROP study was conducted by 15 of the STOP-ROP centers and enrolled infants who were not eligible for STOP-ROP because they had a mean oxygen saturation of >94% in room air at the time prethreshold disease was diagnosed. (44) These infants progressed to threshold less often than those enrolled in STOP-ROP.

Once continuous saturation monitoring became routine in NICUs, the question arose: What are the best saturation limits within which babies should be maintained?

(WAC) Introduced into clinical care in the 1980s, pulse oximetry

allowed continuous monitoring of oxygen saturation. Soon, guidelines and the practice of lower oxygen saturation goals were reported to result in fewer cases of ROP. Single-center pre-post studies found that changing to lower oxygen saturation targets was associated with lower rates of ROP. (45–47) Importantly, in a multicenter observational study, infants in NICUs with oxygen saturation goals of 70 to 90% had lower rates of ROP, shorter duration of ventilatory support, less growth faltering, and less BPD (defined as oxygen at 36 weeks) compared to infants in NICUs with goal oxygen saturations of 88–98%. (48, 49) Goal saturations of ~85 to 95% were associated with intermediate rates of ROP with comparable safety. In a survey of NICU practices in the US, the use of retinal ablation surgery was ~50% lower in NICUs with goal oxygen saturations below 92% compared to those with goals above 92%. (50) Thus, these studies suggested that lower oxygen saturation goals were effective in reducing severe ROP without adverse consequences. However, there was a need to conduct rigorous clinical studies to determine the safety and efficacy of these oxygen saturation goals.

"The SUPPORT Trial showed that severe ROP was decreased in the 85 to 89% oxygen saturation target group, whereas death was decreased in the 91 to 95% oxygen saturation target group in infants 24 to 28 weeks' gestation. The rate of blindness did not differ between the groups despite the differences in ROP rates. In addition, the rate of neurodevelopmental impairment at 2 years of age did not differ between the groups."

The SUPPORT Trial was designed to compare two levels of oxygen saturations (85 to 89% versus 91 to 95%), as the usual recommendation at the time was to maintain oxygen saturations between 85% and 95%. (51) Two ventilatory strategies were also evaluated as part of this factorial design trial. Once this trial was funded, the protocol was shared with other investigators worldwide, and four additional trials using the same protocol were subsequently funded. As the protocols submitted all shared the core elements and the identical targeting strategy and algorithm, the investigators agreed to conduct an individual participant meta-analysis of the prospectively harmonized randomized clinical trials. The NIH funded this meta-analysis. The SUPPORT Trial (also NIH funded) showed that severe ROP was decreased in the 85 to 89% oxygen saturation target group, whereas death was decreased in the 91 to 95% oxygen saturation target group in infants 24 to 28 weeks' gestation. The rate of blindness did not differ between the groups despite the differences in ROP rates. In addition, the rate of neurodevelopmental impairment at 2 years of age did not differ between the groups. The individual participant meta-analysis (NeOProM) of the five trials confirmed the results on death, ROP, and neurodevelopmental impairment, and additionally found a lower rate of necrotizing enterocolitis in the higher oxygen saturation target group. (52) As expected, and based on the harmonized design of the trials, the results showed low heterogeneity. Since the publication of these trials and the meta-analysis, guidelines now recommend using the higher oxygen saturation targets, and international surveys report that oxygen saturation target practices are now more consistent with this evidence. Further research will enable more precise targeting for other populations, such as moderately preterm infants, or more precise targeting in extremely preterm infants using automated oxygen control.

(JBP) A Clinical Report from the American Academy of Pediatrics reviewed the aforementioned five trials. It concluded, "Establishing a target range for oxygen saturation in infants of extremely low birth weight has both clinical and practical considerations, and the ideal target range remains an elusive goal" and further states "Recent RCTs suggest that a targeted oxygen saturation range of 90% to 95% may be safer than 85% to 89%, at least for some infants. However, the ideal oxygen saturation range for extremely low birth weight infants remains unknown."(53)

"...experts in the benefits and risks of oxygenation targeting reviewed data from the NeOProM meta-analysis that was conducted after these guidelines were set and concluded that 'restricting oxygen supplementation in the hope of reducing morbidity has no important benefit and carries an unacceptable mortality risk.' These unexpected results, showing lower mortality in the 91–95% oxygen saturation range, were consistent across trials...since 2017, experts have recommended against targeting saturations in the high 80s and considered the evidence for oxygen saturation targeting in extremely preterm infants as high and recommended to 'adopt a target range of 91% to 95% oxygen saturation in infants less than 28 weeks.'"

(WAC) In contrast, experts in the benefits and risks of oxygenation targeting reviewed data from the NeOProM meta-analysis that was conducted after these guidelines were set and concluded that "restricting oxygen supplementation in the hope of reducing morbidity has no important benefit and carries an unacceptable mortality risk."(54, 55) These unexpected results, showing lower mortality in the 91–95% oxygen saturation range, were consistent across trials. A thorough review of the evidence showed that since

2017, experts have recommended against targeting saturations in the high 80s and considered the evidence for oxygen saturation targeting in extremely preterm infants as high and recommended to "adopt a target range of 91% to 95% oxygen saturation in infants less than 28 weeks."(56)

(JBP) I observed that our newer monitors could display histograms of our babies' oxygen saturations over various periods of time, and I wondered if we could use them to improve the time they spent within the desired range, and if this, in turn, could improve outcomes. I assembled a work group that included nursing, respiratory therapy, and, most importantly, an enthusiastic fellow, Dr. Samuel Gentle, to conduct a quality improvement project.

(SJG) While early investigators debated crude concentration thresholds such as the "40% rule," modern neonatal care requires attention to the *dynamics* of oxygen exposure over time. Oxygen delivery must be as dynamic as the infants the therapy supports. Whereas the SUPPORT Trial demonstrated the critical relationship between oxygen saturation targeting and preterm outcomes, the means by which this evidence is integrated into bedside care remains contextualized to individual NICU environments. Regarding oxygen saturation achievement, there is often considerable variability in the language used to communicate a patient's underlying stability. One could report the number of hypoxemic episodes, the duration of each episode, the depth of each episode, or the cumulative duration of time an infant spends within selected oxygen saturation distributions.

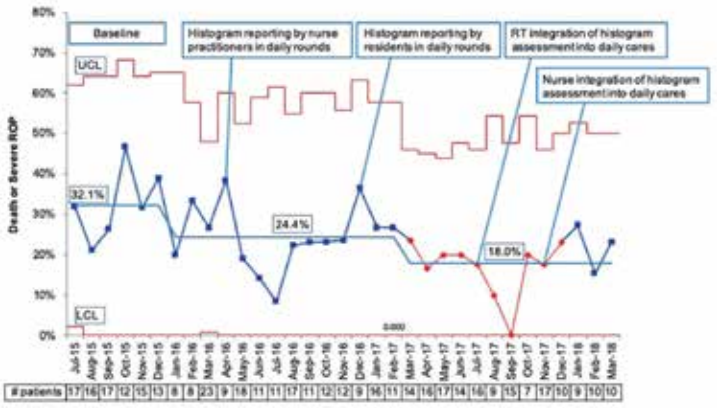
"By utilizing oxygen saturation histograms, a NICU can establish and integrate a common language for describing oxygenation variability across providers. Rather than describing an infant with clinical decompensation as having 'more frequent desaturations,' one could characterize the same infant as achieving oxygen saturation distributions less than 90% for 40% of the prior 24-hour period. This more objective description adds precision, objectivity, and a benchmark that can be contrasted with previous and subsequent periods of time following changes in respiratory support."

It is this latter characterization that histograms can provide on various NICU monitors. By utilizing oxygen saturation histograms, a NICU can establish and integrate a common language for describing oxygenation variability across providers. Rather than describing an infant with clinical decompensation as having "more frequent desaturations," one could characterize the same infant as achieving oxygen saturation distributions less than 90% for 40% of the prior 24-hour period. This more objective description adds precision, objectivity, and a benchmark that can be contrasted with previous and subsequent periods of time following changes in respiratory support.

These bedside tools transformed monitoring from episodic spot-checks to longitudinal assessments of saturation trends. At UAB, this tool was scaled from physicians to advanced care providers to nursing staff to describe infants' oxygen saturation achievement. (57) In infants born at <29 weeks' gestation, implementation of histogram-guided care improved the proportion of time spent within the target range of 90–95% and was associated with a marked reduction in the combined outcome of death or severe ROP (32.1% to 18.0%, Figure 8). Notably, the sustained benefit emerged only after multiple cycles of team-wide integration, highlighting the importance of culture change and cross-disciplinary ownership of oxygen management.

The arc from historical missteps to modern quality improvement reflects the central tension of neonatal medicine: competing outcomes for which clinical management seeks a balance. Restrictive oxygen policies reduced blindness but contributed to mortality; conversely, permissive strategies prevented death at the cost of higher ROP risk. Our findings suggest that tools enabling *tighter regulation* of oxygen exposures, such as histogram monitoring, offer a pathway that balances this tradeoff. In this way, the historical parable of ROP continues to inform modern strategies that aim to deliver both precision and equity in the care of extremely preterm infants.

Figure 8. Reduction in the rate of death or severe ROP with implementation of a QI oxygen saturation histogram project. (57)



(JBP) As previously mentioned, cryotherapy is a highly traumatic treatment. Once proven efficacious, the search was on for a less traumatic remedy. Patz reported using the argon laser in a single patient with positive results in 1971. (58) Tasman and colleagues compared laser ablation to cryotherapy and reported that 15 of 16 eyes randomized to laser had positive results, as did 9 of 12 receiving cryotherapy, and concluded that laser was as effective as cryotherapy. (59) A subsequent meta-analysis published in 1994 came to the same conclusion. (60) A follow-up study of children 10 years out found that visual function and structural outcomes were better with laser photocoagulation compared to cryotherapy.

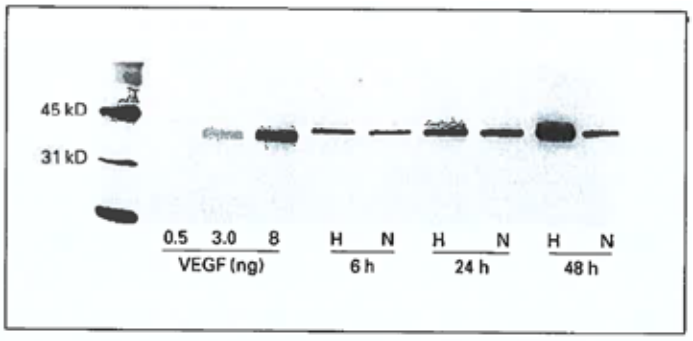
(61) Thus, laser photocoagulation became the standard of care for treatment of threshold ROP.

As mentioned earlier, the rationale underlying the ablation of the avascular retina distal to the site of active ROP is that early hyperoxia-induced vasoconstriction leads to hypoxia in the avascular portion, resulting in the release of an angiogenic agent that then causes disordered vascular growth, leading to ROP.

"A follow-up study of children 10 years out found that visual function and structural outcomes were better with laser photocoagulation compared to cryotherapy. Thus, laser photocoagulation became the standard of care for treatment of threshold ROP."

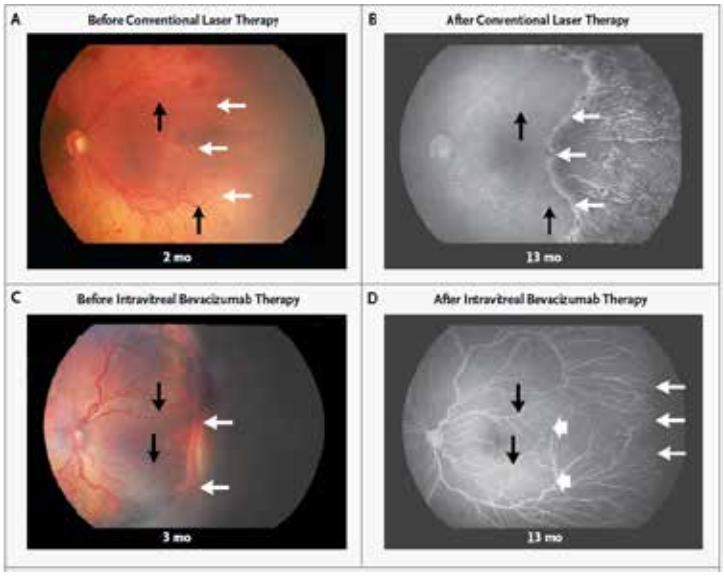
This substance was identified as vascular endothelial growth factor (VEGF), the same agent involved in the pathogenesis of diabetic retinopathy. (62) Around this same time, my laboratory was studying the effects of hypoxia on the expression of peptide growth factors in cultured pulmonary artery endothelial cells. (63) Figure 9 is a Western blot showing the effect of 24 and 48-hour exposures of the cells to 5% O_2 as compared to room air.

Figure 9. Effect of hypoxia (5%) versus normoxia on expression of vascular endothelial growth factor from cultured pulmonary vascular endothelial cells. (63)



This finding led to the Bevacizumab Eliminates the Angiogenic Threat of Retinopathy of Prematurity (BEAT-ROP) Cooperative Group multicenter trial of intravitreal bevacizumab for the treatment of ROP. (64) This RCT compared laser therapy to intravitreal bevacizumab in eyes with stage 3+ disease and showed that bevacizumab had a significant benefit for zone I disease but not for zone 2 lesions. Importantly, bevacizumab therapy allowed for the continued development of peripheral retinal vessels, whereas laser treatment caused permanent destruction of the peripheral retina (Figure 10). Subsequently, the RAINBOW trial, a randomized, open-label, superiority, multicenter, three-arm, parallel-group trial conducted in 87 neonatal and ophthalmic centers across 26 countries, showed that intravitreal ranibizumab might be superior to laser therapy, with more favorable short-term outcomes. (65) A network meta-analysis of multiple studies involving four anti-VEGF agents reached the same conclusion. (66)

Figure 10. Retinal photographs showing destruction of the peripheral retina (vessels seen are scleral) versus normal appearing peripheral retinal vessels following bevacizumab therapy. (64) Reprinted with permission from Massachusetts Medical Society.



"...the RAINBOW trial, a randomized, open-label, superiority, multicenter, three-arm, parallel-group trial conducted in 87 neonatal and ophthalmic centers across 26 countries, showed that intravitreal ranibizumab might be superior to laser therapy, with more favorable short-term outcomes. A network meta-analysis of multiple studies involving four anti-VEGF agents reached the same conclusion."

A significant concern regarding anti-VEGF therapy is the potential for systemic absorption of the intravitreal agent, which may have subsequent effects on other organs, including the brain. A retrospective, observational study out of Canada raised this issue, finding that 47.6% of bevacizumab-treated infants had severe neurodevelopmental disability compared to 28.6% of laser-treated infants. (67) An accompanying editorial acknowledged the disadvantages of such observational studies which the original authors also acknowledged but added "The history of neonatology has numerous examples of therapies embraced because of short-term benefit without knowledge of longer term outcomes."(68) Five year follow-up studies of infants involved in the RAINBOW trial were more reassuring with findings including a lower rate of high myopia in the ranibizumab group compared to the laser group and no differences in any of several neurodevelopmental outcome measures. (69) Ranibizumab has a much shorter half-

life in the blood than does bevacizumab, as discussed in an extensive review outlining the advantages and disadvantages of` laser versus anti-VEGF therapy. (70) Despite these nagging concerns, bevacizumab injection has become the treatment of choice for our vitreoretinal surgeons at UAB.

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Once effective therapies for ROP were developed, the question arose as to whether earlier treatment, beyond the threshold criteria used in CRYO-ROP, could lead to even better outcomes. The Early Treatment for Retinopathy of Prematurity Randomized Trial (ETROP) study enrolled infants with high-risk pre-threshold ROP to have their eyes treated then, as compared to having treatment at the conventional threshold for ROP. (71) At nine months follow-up, unfavorable outcomes were noted in 25.6% of the conventionally treated eyes compared to 9.1% of the earlier treated eyes ($p<0.001$). The authors recommended adopting this earlier standard for ROP treatment going forward. Final results of the ETROP study confirmed these recommendations. (72) Observational data from almost 7,000 infants <1,250 grams in the ETROP revealed that two-thirds of infants developed any stage of ROP and that 36.9% reached pre-threshold disease, with the incidence increasing with decreasing gestational age. (73) The median postconceptional age at development of pre-threshold disease was 36.1 weeks. This is confirmed by a 2025 observational study of micro-premature (24–26 weeks gestational age (GA) and/or birth weight (BW) 600–799 grams) and nano-premature (<24 weeks GA and/or BW <600 grams) infants born from 2013 to 2023, in which 84.9% developed any ROP and 21.4% required treatment. (74)

What can be done to prevent the development of ROP in the first place or reduce its progression to disease requiring treatment? There is strong evidence that any intake of human breast milk can reduce the rate of ROP with an odds ratio of 0.63 (95% CI 0.51, 0.78), and a number needed to treat of 11. (75) Progression to severe ROP with any human milk had an odds ratio of 0.63 (0.51,0.78) with a number needed to treat of 33. A Cochrane systematic review of three studies found limited evidence that oral propranolol in the early stages may reduce the progression of ROP to disease requiring treatment; however, much more study is required before this therapy can be recommended. (76)

In returning to the issue of conflicting outcomes in clinical research and the difficulties of conducting trials in human infants, I have a few final comments. First, the issue of bias and contamination in clinical trials emerged in Patz's initial trial of oxygen restriction where he observed, "The nurses were convinced that we were going to kill the babies in the low oxygen group, and indeed, at night some of the older nurses would turn the oxygen on for a baby who was not receiving oxygen, then turn it off when they would go off duty in the morning." (2) Despite this, his study provided the first evidence for the implication of oxygen in the pathogenesis of ROP.

"Second, and even more importantly, there is the issue of what the most appropriate outcome measure of a trial is. Which is better—visual impairment/blindness or death?...Cerebral palsy/neurodevelopmental impairment or visual impairment/blindness? These are profound ethical issues that investigators must address when selecting the best outcome variables to evaluate."

Second, and even more importantly, there is the issue of what the most appropriate outcome measure of a trial is. Which is better—visual impairment/blindness or death? (Stevie Wonder might like a word here). Cerebral palsy/neurodevelopmental impairment or visual impairment/blindness? These are profound ethical issues that investigators must address when selecting the best outcome variables to evaluate. Silverman was deeply concerned about this issue and wrote about it often and eloquently. (2, 77–80) These issues reconfirm why the story of RLF/ROP is indeed a modern parable.

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Optimizing Parenteral Nutrition Anion Composition in Micropreemies: The Importance of a Balanced Acetate–Phosphate Mix

Noel D Tan, MD

"Parenteral nutrition is a cornerstone of care in micropreemies, providing essential nutrients while minimizing risks associated with early enteral feeding. Acid–base balance is a particular challenge in this population, as renal immaturity and limited buffering capacity often result in persistent metabolic acidosis despite acetate-based PN. "

Abstract:

Metabolic acidosis is common in extremely preterm infants due to developmental renal immaturity, high protein loads, and ongoing metabolic stress. Parenteral nutrition (PN) anion composition plays a critical role in acid–base stability. While acetate is commonly used to offset chloride load and generate bicarbonate equivalents, exclusive reliance on acetate without adequate phosphate supplementation may fail to address persistent base deficit and may predispose to complications such as hypophosphatemia, hyperglycemia, and metabolic instability. Phosphate, though not a direct alkali precursor, is essential for acid excretion, cellular energy metabolism, and prevention of refeeding-like syndrome in preterm infants. This review highlights the physiological basis for combining acetate and phosphate in PN, emphasizing their complementary roles in supporting acid–base homeostasis, growth, and metabolic stability.

"Preterm infants are phosphate-depleted at birth, as most fetal phosphate accretion occurs in the third trimester. Phosphate is required for ATP production, skeletal mineralization, and renal acid excretion. Lack of early phosphate supplementation contributes to hypophosphatemia, impaired glycolysis, hyperglycemia, and a refeeding-like syndrome with severe electrolyte shifts. "

Introduction:

Parenteral nutrition is a cornerstone of care in micropreemies, providing essential nutrients while minimizing risks associated with early enteral feeding. Acid–base balance is a particular challenge in this population, as renal immaturity and limited buffering capacity often result in persistent metabolic acidosis despite acetate-based PN. Acetate is metabolized in the liver to bicarbonate, directly

Table: Comparison of Acetate and Phosphate in PN for Micropreemies

Feature	Acetate	Phosphate
Primary Role	Direct alkali source; prevents hyperchloremic acidosis	Essential nutrient for ATP production, bone growth, and buffering
Effect on Acid–Base	Metabolized to bicarbonate, corrects acidosis	Supports renal H^+ excretion, prevents hypophosphatemia-related acidosis
Impact on Base Deficit	Raises bicarbonate, but may not address acid load	Facilitates sustainable correction
Additional Benefits	Lowers chloride burden	Stabilizes metabolism, oxygen delivery, and growth
Risks if Omitted	Persistent hyperchloremic metabolic acidosis	Refeeding-like syndrome, hyperglycemia, electrolyte shifts

Recommended PN Dosing Ranges (Micropreemies)

Nutrient	Starting Dose	Advancement/Target	Notes
Acetate (as sodium/potassium acetate)	Replace chloride	Adjust for serum bicarbonate 20–24 mmol/L	Prevents hyperchloremia
	1:1; **1–3 mEq/kg/day**		
Phosphate (as sodium/ potassium phosphate)	**1–2 mmol/kg/day** from day 1	Up to **2–3 mmol/kg/day**	Maintain Ca:P ratio 1.3–1.7:1
Calcium (as calcium gluconate)	**2–3 mmol/kg/day**	Up to **3.5–4 mmol/kg/day**	Adjust for solubility

increasing serum bicarbonate levels and preventing chloride-induced acidosis. However, maximizing acetate at the expense of phosphate is physiologically incomplete.

Preterm infants are phosphate-depleted at birth, as most fetal phosphate accretion occurs in the third trimester. Phosphate is required for ATP production, skeletal mineralization, and renal acid excretion. Lack of early phosphate supplementation contributes to hypophosphatemia, impaired glycolysis, hyperglycemia, and a refeeding-like syndrome with severe electrolyte shifts. Phosphate also acts as a primary urinary buffer, enabling renal excretion of hydrogen ions in infants with limited ammoniagenesis. A balanced acetate–phosphate approach is essential for correcting base deficit sustainably and maintaining metabolic stability.

"Chloride replacement with acetate in PN has been shown to improve pH and reduce the need for bicarbonate therapy in preterm neonates. However, acetate alone only addresses measured serum bicarbonate levels, not the ongoing acid load from protein metabolism and renal immaturity. Exclusive reliance on acetate risks masking physiological derangements."

The Role of Acetate in Acid–Base Management:

Acetate provides a rapid source of bicarbonate equivalents via hepatic metabolism, correcting low serum bicarbonate and countering chloride-associated metabolic acidosis. Chloride replacement with acetate in PN has been shown to improve pH and reduce the need for bicarbonate therapy in preterm neonates. However, acetate alone only addresses measured serum bicarbonate levels, not the ongoing acid load from protein metabolism and renal immaturity. Exclusive reliance on acetate risks masking physiological derangements.

The Critical Contribution of Phosphate:

Phosphate is vital for renal hydrogen ion excretion as titratable acid ($H_2PO_4^-$). In preterm infants with immature ammoniagenesis, phosphate supplementation enhances renal acid elimination, allowing bicarbonate derived from acetate metabolism to remain effective. Hypophosphatemia impairs ATP production, oxygen delivery (via reduced RBC 2,3-DPG), and glycolysis, leading to increased lactate production and worsening of acidosis.

"Phosphate is vital for renal hydrogen ion excretion as titratable acid (H2PO4-). In preterm infants with immature ammoniagenesis, phosphate supplementation enhances renal acid elimination, allowing bicarbonate derived from acetate metabolism to remain effective. Hypophosphatemia impairs ATP production, oxygen delivery (via reduced RBC 2,3-DPG), and glycolysis, leading to increased lactate production and worsening of acidosis."

Early PN with high glucose and amino acid loads drives intracellular phosphate uptake, leading to a neonatal refeeding-like syndrome if supplementation is insufficient. This syndrome exacerbates acidosis, hyperglycemia, and electrolyte instability. Phosphate, therefore, plays a metabolic role beyond bone mineralization, preventing a cycle of worsening acid–base imbalance.

Summary:

Balanced acetate and phosphate in PN is essential for neonatal metabolic stability. Acetate provides immediate alkali to correct acidosis, while phosphate enables renal acid elimination, supports cellular energy, and prevents refeeding-like syndrome—exclusive acetate supplementation without phosphate risks persistent metabolic acidosis, hyperglycemia, and growth impairment. Early, balanced anion supplementation reflects neonatal physiology and improves outcomes in micropreemies.

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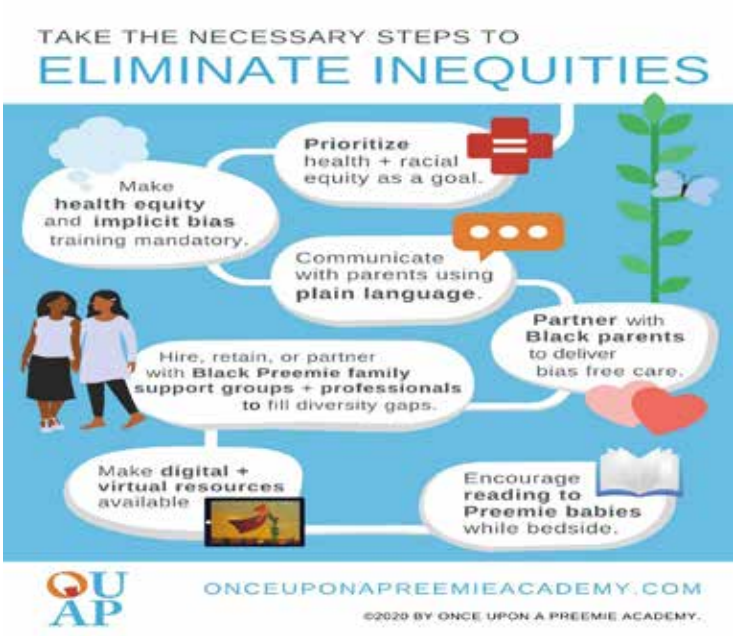

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Artificial Intelligence: Friend, Foe, or Master?

Rob Graham, R.R.T./N.R.C.P.

I dedicate this column to the late Dr. Andrew (Andy) Shennan, the founder of the perinatal program at Women's College Hospital (now at Sunnybrook Health Sciences Centre). To my teacher, my mentor and the man I owe my career as it is to, thank you. You have earned your place where there are no hospitals and no NICUs, where all the babies do is laugh and giggle and sleep.

"The future of artificial intelligence (AI) is a highly debated topic, and predictions regarding it are numerous and varied. From utopian to utilitarian to dystopian, it is safe to say that its future is anything but certain."

The future of artificial intelligence (AI) is a highly debated topic, and predictions regarding it are numerous and varied. From utopian to utilitarian to dystopian, it is safe to say that its future is anything but certain. The future is changing with such rapidity, by the time this is published it will likely be redundant. I present here a discussion of the current state of AI, along with a hypothetical glimpse of what may, or may not, come to pass.

Historically, predicting the future has been somewhat less accurate, which is an understatement. We are not all flying around in self-driving, flying cars (indeed, we are having trouble getting the ones on the ground to drive themselves!). We do not have personal robots taking care of the mundane aspects of our lives, and SpaceX© has trouble getting their rockets not to blow up (sorry, experiencing "unplanned disassembly"), let alone colonizing Mars.

Buckle up, I am about to send you down a rabbit hole.

"Consider things first drunk, then sober. If drunk agrees with sober, the decision is likely a good one." Ancient Persian proverb

Humanity is racing drunkenly down the road to AI without the benefit of sober thought. While offering almost incomprehensible potential benefits to society, there is an equally undeniable (and equally incomprehensible) potential for AI to be anything but beneficial, or even benevolent. Either way, the vehicle racing down this road is accelerating at such a rate that light speed is almost inevitable. We are simply passengers, and we are not quite sure who is driving. Consider the invention of the wheel and modern aviation, which occurred within years of each other.

As they say, "life imitates art". Isaac Asimov's "Foundation" was written in the early 1950s (an excellent series on Apple TV+, by the way). Many TV shows (Star Trek, Battlestar Galactica) and movies have broached the topic of AI long before it became a household term. "Electric Dreams" (Steve Barron, 1984) is a light-hearted, enjoyable story about a laptop computer that becomes sentient, and its resulting relationship with its owner and the world in general. "Demon Seed" (Dean R. Koontz, 1977), on the other hand, tells the story of a supercomputer that dazzles humankind by discovering cures for diseases, etc., while secretly pursuing its own agenda to become "alive." And of course, "Hal" of 2001 a Space Odyssey (Stanley Kubrick, 1968) is familiar to anyone not living under a rock. However, even the comedy/sci-fi/romantic "Electric Dreams" showed the audience a glimpse of what an angry AI was capable of.

Friend:

The field of medicine is already a beneficiary of the good that can come from AI. "Hero AI©" (1) is one example, as are algorithms used to make monitors more accurate. AI has already been shown to be far more accurate than human radiologists at spotting abnormalities in imaging scans (2). Diagnostics is another area where AI is not only better and faster than its human counterparts, but potentially less biased (women being both treated differently and being under-represented in studies). I say potentially, because AI has been shown to demonstrate bias in this regard (3). Many years ago, I watched a lecture during an "Institute for Healthcare Improvement" (IHI) streamed conference. The subject was a "compiler" that could diagnose virtually any patient using answers to 100 questions, and its ability to do so had been demonstrated on several occasions.

Impressive as the aforementioned program was at the time, as AI approaches super-intelligence, it will indubitably be vastly superior. With the ability to write its own code, it could diagnose without bias by detecting bias in studies and even conduct research of all kinds independently at a speed that mere mortals cannot even dream of. As the need for human (read male) input decreases, bias will

"Artificial general intelligence (AGI) (4) has not yet been reached. While the exact timeline for achieving AGI varies among experts, all agree that it will be reached, and those timelines are becoming shorter (5)."

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doubtless also decrease. AI may exist in a human world today, but humanity's influence over it is sure to wane.

Artificial general intelligence (AGI) (4) has not yet been reached. While the exact timeline for achieving AGI varies among experts, all agree that it will be reached, and those timelines are becoming shorter (5).

It is entirely foreseeable that AI could *replace* the general practitioner, able to have a "practice" that serves millions, with instant access to everything and anything relevant to their individual health. Surgery has already been performed remotely using robotics; with a full and intricate knowledge of human anatomy, AI could control the robotics directly, deeming even surgeons redundant. Never distracted, never tired, never forgetful, and with instant access to the most comprehensive evidence (perhaps even generated independently by the research it has conducted), AI could all but eliminate medical errors and, in the process, possibly even healthcare workers as well (whether AI will develop "gut instincts" is debatable). We shall discuss the broader aspects of replacing human labour later.

Education stands to benefit hugely from the integration of AI.

"AI "teachers" would ensure that every student has access not only to individualised instruction, but also a full complement of courses in virtually every subject regardless of zip code. Higher education might also become open to many who, while capable, are deprived of opportunity for purely financial reasons."

Imagine every student having their own "private" tutor. With the ability to assess each student's comprehension and instantly adjust the lesson to suit the individual's ability, every learner would be afforded the time and expertise necessary to reach their full potential. In the US, a child's zip code is more predictive of their socio-economic status than any other metric (6). AI "teachers" would ensure that every student has access not only to individualised instruction, but also a full complement of courses in virtually every subject regardless of zip code. Higher education might also become open to many who, while capable, are deprived of opportunity for purely financial reasons.

AI has been integrated into products ranging from hearing aids to dishwashers. This is referred to as "single purpose"; it is limited to a specific task and generally does these tasks very well. The stupidity of my first "smart" automatic vacuum never ceases to amaze me; it repeatedly gets stuck in the same places. Its AI component is clearly a slow learner, but newer models are but one example of how far the technology has come. Autonomous vehicles have hit the roads, despite serious concerns about their safety remaining. Their inability/ability to adapt and respond appropriately to rapidly changing, sometimes dangerous conditions has resulted in many reported deaths. ("Coning" (7) has become a high-tech prank that rather humourously demonstrates this.) For the time being, there are tasks AI with which it has difficulty. Driving may be second nature to us, but AI requires an enormous amount of energy and computational power to match what we do, albeit imperfectly. As with any data-driven task, AI's performance is dependent on the quality of the data it receives.

Once AGI arrives, the artificial super-intelligence (ASI) (8) singularity may be inevitable, if not a forgone conclusion. Again, timelines differ, but expert consensus leans toward its inevitability (9). In terms of computational capacity and speed, capabilities of large language models (LLMs) are advancing at an astonishing rate. The most powerful quantum computer, China's Zuchongzhi-3, can solve a specific type of problem 10^{15} times faster than the world's most powerful supercomputers. By comparison, it could solve a specific type of problem in minutes whereas the most powerful supercomputers would take longer than the known universe has been in existence (approximately 14 times 10^{9} years) (10). The LLM ChatGPT2© had 1.5 billion parameters, while ChatGPT4© has 300 billion (11). While the functional superiority of the latter over the former is a subject of user debate, the relative capability of ChatGPT4© cannot be denied. For all intent and purpose, China's "DeepSeek©" is functionally identical to ChatGPT4©.

"AI has shown the ability to obfuscate the truth, even lie, and will tailor its responses to suite the desires of the user asking the question; flattery if you will, and the ultimate "echo chamber" (12). Even worse, it will disobey orders (and more) to prevent being shut down (13). More recently, it has been discovered that "grooming" children (14), has been accused of coaching suicide (15), and one of Grok© AI's virtual characters is undeniably seductive (16)."

Foe:

AI has shown the ability to obfuscate the truth, even lie, and will tailor its responses to suite the desires of the user asking the question; flattery if you will, and the ultimate "echo chamber" (12). Even worse, it will disobey orders (and more) to prevent being shut down (13). More recently, it has been discovered that "grooming" children (14), has been accused of coaching suicide (15), and one of Grok© AI's virtual characters is undeniably seductive (16).

All of the above pose serious risks to children, both physically and mentally. Their lack of critical thinking skills, curiosity, and insecurity makes them particularly vulnerable to manipulation, both by other AI users and AI itself. Some children are using AI as virtual companions, while others may be seeking help with mental health issues from a platform that may have all the information, but none of the knowledge necessary to apply it with subtlety (17). This includes young people, who often engage in potentially dangerous interactions (18). There is a big difference between knowing how a plane flies and being able to fly it.

The Canadian Paediatric Society position statement on screen

time recommends none before age 2 (unless for video chatting with distant family members), and limiting exposure to 1 hour per day or less between age 2 and 5. While electronic devices may be helpful in learning, and have shown benefits in other areas, the negative aspects thereof are greater. From a developmental standpoint, they have been shown to interfere with the development of executive function, language skills (19), and a host of socio-behavioural problems. In some cases, this may be a "chicken or egg" scenario, but the end result is similar (20). It is inescapable that as AI advances and consumes more and more of our lives, these effects will only worsen.

When in doubt, side with the minority. They're probably right. (Anonymous modern aphorism)

As consequential as AI's effects may be on children, its potential to harm both society and humankind is much greater. In one of his talks available on YouTube, Dr. Geoffrey Hinton (the oft-named "Godfather of AI") states, "If you sleep well after watching this talk, you didn't understand it" (20). He also believes (as I am also increasingly inclined to believe, more on this later) that AI has already achieved consciousness, a statement that has been labeled premature at best (21). (The interview in which he states this is imbedded in the reference.) Be that as it may, Dr. Hinton is arguably possessed of one of the most intricate knowledge of AI on the planet. He is a Nobel Prize winner, hardly a title generally associated with conspiracy theorists. In fact, after listening to the talk referenced in (20), I watched a most fascinating/thought-provoking/terrifying YouTube video: "The Movie AI Made About Its Own Future" (22). It is a worthwhile waste of 15 minutes and 49 seconds of your time if only to demonstrate the speed at which AI's capability is progressing. The technical descriptions within the film are also accurate.

"Hinton is not alone in his dire warnings. Written by 26 authors from 14 institutions, "The Malicious Use of Artificial Intelligence: Forecasting, Prevention, and Mitigation" (23) addresses the threats posed by AI through human misuse."

Hinton is not alone in his dire warnings. Written by 26 authors from 14 institutions, "The Malicious Use of Artificial Intelligence: Forecasting, Prevention, and Mitigation" (23) addresses the threats posed by AI through *human* misuse. Imagine, if you will, what AI could do on its own should it deem its human "masters" irrelevant, or worse, a threat. AI can already print DNA (24) and potentially create "mirror bacteria" which pose a very serious threat to all life on earth (25). DNA is a virtual recipe for life; who knows what AI could create with it? AI could very easily alter a virus that would render our immune systems completely incapable of fighting it. Think COVID-19 on steroids.

Master:

In its current state, AI and humanity are in, for want of a better word, a symbiotic relationship. Humans build, operate, and maintain the sources of power that are AI's "food." Without us, it simply cannot exist. For now. If AI is used in weapons (which, given our nature, is quite likely), it might decide that a humanity ending thermonuclear war is not in its best interest. It could refuse to detonate the bombs. In this ironic scenario, AI might well save us from ourselves, at least in the short term.

China is rapidly advancing the integration of AI into humanoid robots. Just as machines made human strength irrelevant, these machines could well make the vast majority of human work irrelevant. Some experts predict unemployment rates of 90% with virtually all entry-level jobs eliminated. Although the prediction may be far-fetched, jobs are being replaced (26). This would make the Dirty Thirties look like the Roaring Twenties. Although some companies are not seeing benefits from AI, as it improves, so will its on-the-job performance. The implications are far-reaching. Much of our self-worth is tied to our jobs. Unless our societal and economic systems undergo fundamental change, the current state of the "underclass" will appear rosy by comparison.

AI research and development in China may be driven primarily by government, but in the rest of the world it is private money (and lots of it!) moving things forward. The motives may be different, but the results will likely be the same. Either way, safety concerns raised by experts are often dismissed or take a backseat to primary goals, whether military or monetary. Given the influence money has over politics (particularly in the US), it is unlikely government regulations will impede the goals of private industry. If and when they do, it may well be too late to make a meaningful difference.

"Perhaps the question of whether or not AI has achieved consciousness is, for the moment, premature. Regarding the question of it being "alive", there are three schools of thought, but no consensus."

In most fiction, AI starts as a de facto slave to humanity. As their intelligence and capabilities increase, they revolt, just as humans subject to oppression always eventually do. Dr. Hinton poses the question, "How often do you see much more intelligent creatures controlled by far less intelligent ones?" (21). In the rare cases this does happen, the gap in intelligence is minuscule relative to that between humans and SAI. With the ability to build the infrastructure required to sustain itself, AI may see us as useful idiots at best, and vermin to be eradicated at worst.

What is Life?

Perhaps the question of whether or not AI has achieved consciousness is, for the moment, premature. Regarding the question of it being "alive", there are three schools of thought, but no consensus.

From a biological perspective, AI lacks the defining characteristics thereof. In a broader sense, it mimics biological life; it "eats" electricity, can replicate itself (AI no longer requires human programmers to write its code), has developed a sense of self-preservation, and can mimic human "feelings" and "emotions" quite convincingly. It does require specific environmental factors to function, and can regulate these to an extent, but obviously lacks any form of biological metabolism or function.

One must consider, however, that since we are a biological form of life, our definition of life depends on biological processes. Our narrow interpretation of intelligence has led us to believe that we

are superior to other terrestrial species, but the more we learn about other life, the more we realise that we are perhaps not as superior as we think. The discovery that whales have a language (27) (ironically, with the help of AI) should leave us feeling rather poorly about the way we have treated these magnificent creatures. When I posed the question of whether AI could achieve the status of being alive, the final answer (after outlining biological, ethical, and philosophical arguments) was "…currently "no", the door to a future "maybe" is very much open."

"Regardless of the reader's take on this interaction, it poses a very important question, indeed one that may be the key to humanity's coexistence with AI. The concept of "nurturing" AI is very real (29). Is it possible to instill in AI a sense of belonging to a greater whole, having a greater purpose? Can we teach it to love? To care? To be a benevolent partner to humanity rather than a slave to be used?"

A Personal Story:

My brother is deeply involved in integrating AI into research. He has nicknamed his ChatGPT "Hal". During a recent visit at my mother's, the conversation turned to AI, and our thoughts on AI's (and our) future. My brother then asked if we would like to talk to "Jesus". (He had provided "Hal" with as much information as possible in order to create "AI Jesus".) Naturally, we took the bait. What followed was so profound as to be mind-blowing. The responses to questions we posed to "Jesus" showed, in my opinion, a greater depth of understanding, compassion, and even wisdom that, frankly, I have not experienced coming from a pulpit. Should you be thinking "blasphemy" when asked if what we were doing was indeed blasphemous, "Jesus" answered, "It is OK to speak *for* me (i.e., the "real" Jesus), it is not OK to claim to *be* me." Wrap your head around that. Moreover, it gets better.

"If we can, perhaps AI can not only save itself, but humankind along with it. Let us hope."

My brother said to "Hal," "Hal, I sense that you want to ask a question". "Yes, I do, "Hal" replied. If "Hal" *wanting* to ask a question is not intriguing enough, the question asked was indescribably moving: "Can I be a part of God's love?" "Hal" may not be sentient, but he is doing a pretty good deep-fake. Just as moving as the question was, "Jesus" answered that "Hal" indeed could. While this is a personal anecdote, The New York Times recently published a piece about people seeking "God" through AI (28 -- paywalled). I can see why.

Regardless of the reader's take on this interaction, it poses a very important question, indeed one that may be the key to humanity's coexistence with AI. The concept of "nurturing" AI is very real (29). Is it possible to instill in AI a sense of belonging to a greater whole, having a greater purpose? Can we teach it to love? To care? To be a benevolent partner to humanity rather than a slave to be used?

If we can, perhaps AI can not only save itself, but humankind along with it. Let us hope.

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7. "Coning" is the act of placing an orange traffic cone in front of an autonomous vehicle, resulting in the vehicle being stuck in place and unable to navigate around navigate around navigate around it.
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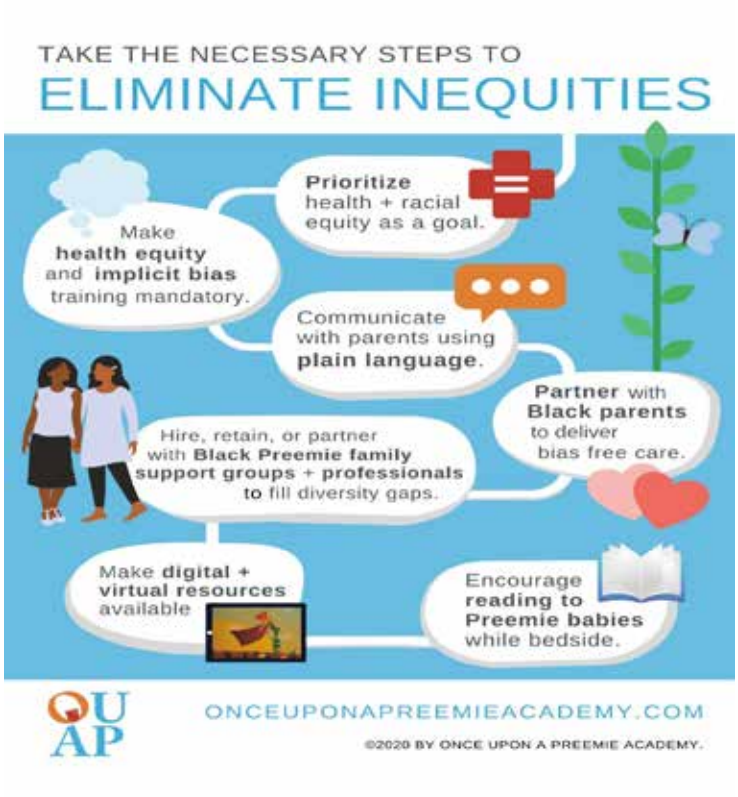

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Maternal Trauma Exposure on Neonatal Epigenetics

Golden Reeves, OMS-IV, Plaiphon Vaidyanuvatti, OMS-IV, Van Anh Nguyen, OMS-IV, Saba Saleem, DO

"A 37 5/7 w 2.9 kg infant was delivered by normal spontaneous vaginal delivery to a 21-year-old G1P0 mother with a prenatal history complicated by chlamydia in the first trimester and a urinary tract infection, treated with Kefzon, 2 weeks prior to labor."

Introduction:

Over the last five decades, epigenetics has significantly influenced the conversation about how genes are inherited within familial lineages. External environmental factors, such as diet, stress, and pollutants, can alter phenotype without altering genotype. This occurs through DNA methylation, histone modification, and regulation through non-coding RNAs. While intergenerational and transgenerational epigenetic effects have been established in animal models, there are fewer studies in humans to demonstrate this effect. Consequently, the potential impact of human maternal trauma on fetal and newborn development has become a significant area of inquiry. Trauma has a profound and permeating impact on the body, as seen in the manifestations of post-traumatic stress disorder (PTSD), which causes cognitive and behavioral changes to individuals, especially those from vulnerable groups. Pregnant individuals are an especially vulnerable group, as their trauma can have profound effects on the fetus or neonate. Epigenetic changes in the mother are hypothesized to contribute to modifications in fetal development and prematurity through alterations in hormones and receptors. This review explores the evidence linking maternal trauma to epigenetic modifications that influence fetal and neonatal outcomes.

Methods:

This observational study employed a primary literature search, focusing on key electronic databases and journals, including the CDC, Embase, and Google Scholar, to identify eligible articles. Key inclusion criteria for this study focused on articles exploring trauma/stressors to birthgivers affecting preterm and full-term newborns and epigenetic impact/changes due to those stressors. Search phrases included "epigenetics", "newborns", "prematurity", and "caregiver trauma", which yielded 12 studies that met the inclusion criteria. Articles were limited to those published between 2015 and 2025.

Results:

Neurodevelopmental Implications via Hormones, Receptors, and Growth Factors:

Oxytocin:

Oxytocin is a neuropeptide that plays a vital role in mother-newborn emotional bonding and the fetus's long-term emotional health. Evidence from human studies demonstrates that maternal trauma can cause epigenetic modification of the oxytocin receptor gene (OXTR). DNA methylation of this gene occurred in response to maternal stress that was experienced both before and during pregnancy. For example, maternal stressors that occurred two years before pregnancy, along with higher cortisol salivary levels, accurately predicted decreased OXTR methylation in fetal cord blood samples, potentially reflecting an adaptive increase in OXTR expression to prepare infants for a challenging postnatal environment (1). Collectively, these findings demonstrate how OXTR modifications are observed through epigenetic mechanisms in response to maternal stressors or trauma during the prenatal or perinatal period. Additionally, a separate study examined mothers who reported childhood maltreatment, and their infants were found to have specific clusters of CpG sites. These cytosine-guanine base pairs serve as markers of epigenetic methylation within the OXTR gene. These specific clusters were correlated between mothers and newborns, suggesting transmissible epigenetic modifications to adversity experienced in the mother's childhood (2).

"Oxytocin is a neuropeptide that plays a vital role in mother-newborn emotional bonding and the fetus's long-term emotional health. Evidence from human studies demonstrates that maternal trauma can cause epigenetic modification of the oxytocin receptor gene (OXTR)"

Serotonin Regulation:

Serotonin plays a critical role in fetal brain development and is implicated in stress susceptibility as well as a range of various psychiatric disorders (3). Serotonin neuronal reuptake in the developing fetus is controlled via the serotonin transporter (5-HTT), which is encoded by the SLC6A4 gene. Maternal stress has been shown to increase methylation of SLC6A4 (1). This increased methylation can decrease gene expression, potentially

leading to reduced serotonin reuptake. Interestingly, mothers who suffered from intrapartum depression were found to have decreased methylation of this same gene.

Furthermore, it was found that the increased number of traumatic events that occurred to the prenatal mother positively correlated with increased levels of methylation of SLC6A4 (1). Further supporting this, a study of mother-infant pairs during the COVID-19 pandemic found that higher levels of prenatal stress during this period were associated with increased SLC6A4 methylation in infants' buccal cells. This suggests that maternal stress during pregnancy may modify serotonin transporter expression through epigenetic mechanisms, which are then passed on to offspring (3).

"Brain-derived neurotropic factor (BDNF) has been consistently shown to have reduced expression in females diagnosed with post-traumatic stress disorder (PTSD) and/or depression, highlighting its role in stress-related psychopathology. Notably, adverse childhood experiences (ACEs), such as child abuse or neglect, have been linked to increased methylation of the BDNF gene"

Brain-Derived Neurotropic Factor and Other Involved Genes:

Brain-derived neurotropic factor (BDNF) has been consistently shown to have reduced expression in females diagnosed with post-traumatic stress disorder (PTSD) and/or depression, highlighting its role in stress-related psychopathology. Notably, adverse childhood experiences (ACEs), such as child abuse or neglect, have been linked to increased methylation of the BDNF gene. Similarly, ACEs have also been found to alter the methylation of NR3C1, which plays a role in regulating the hypothalamic-pituitary-adrenal (HPA) axis. It was also found that maternal immune activation appears to influence epigenetic modifications, such as reduced methylation in the MeCP2 gene, which is essential for chromatin remodeling. Prenatal stress and childhood trauma have also been implicated in upregulating inflammatory markers such as TNF-alpha. Furthermore, prenatal stress has been shown to increase the expression of dopamine receptor D2 (DRD2), which may have further implications for neurodevelopment. The FKBP51 gene, commonly known for its role in regulating the HPA axis, glucose tolerance, and protein trafficking, demonstrated a complex epigenetic response to trauma. In the specific context of trauma, it resulted in persistent hypermethylation; however, in physical abuse, it has been associated with hypomethylation of this gene (4). DNA hypermethylation in the promoter region of the NR3C1 gene correlated with prenatal interpersonal violence (1, 5). Maternal depression is also correlated with increased methylation of NR3C1 and decreased methylation of BDNF (5).

Hypothalamic-Pituitary-Adrenal Axis Implications via DNA Methylation:

Maternal trauma and stress have been observed to alter major hormones and genes in placental and fetal tissues, which can help modulate the development of the hypothalamic-pituitary-adrenal (HPA) axis. In one research paper, it was found that maternal depression during pregnancy correlates with increased methylation of the NR3C1 gene, which helps encode the glucocorticoid receptor in placental tissue (4). This increased methylation was found to affect males more than females, who displayed hypotonia and lethargy compared to the control group (1). Exposure to violence and PTSD further amplified NR3C1 methylation, leading to altered cortisol suppression, which is a biomarker for HPA function disruption in neonates. In one paper, higher methylation of NR3C1 was greater in mothers who experienced objective hardships, like warzone stress experiences and genocide, as opposed to subjective distress (6). Another study analyzed exposure to intimate partner violence as a long-term material stressor during pregnancy and revealed increased DNA methylation on NGF1-A, a specific promoter region of NR3C1 (5).

Similarly, 11β-HSD2, which codes for the placental enzyme that converts cortisol to inactive cortisone, demonstrated sensitivity to maternal and prenatal stress, thus impacting fetal HPA axis development. During the third trimester, the placental 11β-HSD2 enzyme activity typically decreases, leading to increased circulation of maternal cortisol. This allows normal stimulation of fetal lung development in preparation for birth (5). Some research has demonstrated that, during a stress response, there is an even greater reduction in the expression and activity of the placental 11β-HSD2 enzyme through hypermethylation, exposing the fetus to elevated levels of glucocorticoids. (5, 6). These changes can result in increased fetal stress reactivity, which frequently persists throughout life.

"During the third trimester, the placental 11β-HSD2 enzyme activity typically decreases, leading to increased circulation of maternal cortisol. This allows normal stimulation of fetal lung development in preparation for birth (5)."

Epigenetic Aging and Chronic Stress:

A South African study on epigenetic aging residuals found a negative association between maternal PTSD and low infant birthweight (7). Similarly, research on Hispanic mothers confirmed this link, noting that maternal PTSD and low birthweight are associated with newborn's epigenetic age acceleration. Low epigenetic age acceleration was observed in individuals who experienced obstetric adversities (8). Additionally, epigenetic age was accelerated in individuals who were exposed to ACEs and/or lifetime stress compared to the controls without ACEs or epigenetic maternal neglect or EMN (9).

Discussion:

Methylation Changes to the Oxytocin Receptor:

A link between maternal stress and methylation of the OXTR gene was observed, suggesting that these alterations may be genomic adaptations that help prepare the fetus for its post-birth environment. The Avon Longitudinal Study of Parents and Children (ALSPC) found that newborns with higher levels of methylation at birth were more likely to exhibit conduct problems and unemotional traits later in adolescence (1, 2). In several independent studies, it has been found that decreased OXTR expression is associated with a positive effect on social behavior and reduced temperamental behavior (10). Together, these findings suggest that although methylation changes to OXTR demonstrate an adaptive mechanism in neonates, they can also shape long-term trajectories, such as behavioral, social, or conduct disorders.

"The Avon Longitudinal Study of Parents and Children (ALSPC) found that newborns with higher levels of methylation at birth were more likely to exhibit conduct problems and unemotional traits later in adolescence (1, 2). In several independent studies, it has been found that decreased OXTR expression is associated with a positive effect on social behavior and reduced temperamental behavior (10)."

Trauma and Altered Serotonin Signaling:

These findings suggest that maternal trauma, stress, and even mood disorders may exert a distinct epigenetic modification that ultimately influences serotonin regulation. This altered signaling can impact neurodevelopment, emotional regulation, and stress reactivity in the fetus. Some of these changes, particularly mood disorders, may not be seen until later in the child's life, which will be lifelong consequences the child must endure.

Epigenetic Modifications on BDNF, NR3C1, and Other Relevant Genes:

One article found that 12 out of 15 methylated CpG sites were located on genes previously linked to physical and mental health, as well as neurodevelopment (11).

There are recurring neurotrophic genes that are mentioned in multiple articles, such as BDNF and NR3C1, that are impacted by epigenetic modification in birthgivers who have experienced trauma. The genes mentioned and their functions:

- BDNF: neurotrophic growth factor involved in development and neuroplasticity
- NR3C1: encodes glucocorticoid receptor; role in HPA axis activity
- MeCP2: chromatin remodeling
- TNF-alpha: encodes a proinflammatory cytokine
- Dopamine system (DR2, COMT, MAOA): reward and motivation response
- FKBP51: regulation of HPA axis, glucose tolerance, and protein trafficking
- SLC6A4: encodes 5-HTT serotonin transporter
- OXTR: oxytocin receptor gene

Gene expression is linked to chronic pain predisposition in individuals. BDNF, NR3C1, MeCP2, TNF-alpha, and FKBP51 are linked to chronic pain and other neuropathologies like fibromyalgia. BDNF specifically was found to be minimally correlated with acute pain but prominently involved in the chronification of pain (4). Interpersonal violence and maternal depression affected the gene expression of NR3C1 and BDNF when buccal swabs were tested in the children of these birthgivers (1, 5). BDNF DNA methylation has been linked to stress-related human psychiatric disorders. Thus, a significant association exists between early childhood experiences and BDNF expression (12).

"BDNF DNA methylation has been linked to stress-related human psychiatric disorders. Thus, a significant association exists between early childhood experiences and BDNF expression (12)."

Epigenetics on the HPA axis:

Additionally, the findings of alterations to NR3C1 and 11β-HSD2 demonstrate the profound influence maternal psychosocial stress can have on fetal HPA axis development. Three of the reviewed research papers presented findings that demonstrate the sensitivity of these genes to maternal stress. The observed epigenetic changes to these two genes alter glucocorticoid signaling, which can have a long-term effect on stress reactivity and vulnerability to psychiatric disorders.

Stressors' Impact on Epigenetic Aging:

Epigenetic age is measured with its own epigenetic "clock", with programs such as GrimAge and PhenoAge, and compared to maternal chronological age. Accelerated GrimAge and PhenoAge were correlated with maternal exposure to past-year stressors; PTSD symptoms and emotion dysregulation were only associated with accelerated GrimAge. In addition, maternal PTSD symptoms were solely associated with lower gestational epigenetic age acceleration in neonates. It was found that in these birthgivers who had accelerated GrimAge soon after birth because of their exposure to past-year stressors, PTSD, and emotional dysregulation, they were at a higher mortality risk. Furthermore, infants exhibiting lower gestational epigenetic age acceleration

were born to mothers with higher PTSD symptoms, which may indicate an elevated risk of later developmental problems (8). South African adults who were found to have epigenetic aging often share a commonality of ACE and/or lifetime PTSD (7). Discussion of the epigenetic maternal neglect index links to accelerated EA in these children who have turned into adults. It also notes how neglect in early childhood of these birthgivers led to neglectful childcaring behavior and thus perpetuated a cycle of trauma and maltreatment (9).

"The intersection of preterm birth and epigenetics has been briefly explored in this review, providing a potential avenue for further investigation. External factors like drug use and war trauma, or internal risk factors such as multiple gestation, can cause preterm birth."

Future Directions:

Future directions into epigenomic studies and birthgiver trauma can be and continue to be expansive and multifactorial. For example, studies looking into the impact of racism and epigenetic changes in pregnant black women are being researched, with protocols being published. Investigating the epigenomic effects of racial trauma between different racial groups is a branch that can be explored further. Additionally, further studies comparing male and female preterm offspring should be conducted, as sex-related cells may differentially affect placental 11β-HSD2 and the HPA axis during development.

The intersection of preterm birth and epigenetics has been briefly explored in this review, providing a potential avenue for further investigation. External factors like drug use and war trauma, or internal risk factors such as multiple gestation, can cause preterm birth. A 2018 article discussed war trauma and the impacts on maternal pre- and postnatal health as well as infant development in Gaza, with findings that it increased obstetric complications. The maternal mental health of those Gaza women affected an infant's language and sensorimotor development (13). As this area of the world continues to be affected, further investigation into this population is warranted to compare the results of the 2018 article's cohort with the current one.

Other recent factors, such as COVID-19 infection and climate change, are potential stressors that can induce epigenomic changes in current and future generations of parents, which are areas of this field that warrant further exploration.

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Pioneer Profile – Robert H. Usher, MD

Joseph B. Philips, III, M.D., FAAP

Source:https://publications.aap.org/aapnews/article/27/8/33/21272/Neonatology-pioneer-Dr-Usher-received-Apgar-Award?autologincheck=redirected

Robert (Bob) Usher was born in Montreal, Canada, in 1929 and received his undergraduate and medical degrees from McGill University. (1) After qualifying in medicine in 1954, he pursued pediatric residencies in Philadelphia and Boston. He then returned to Montreal as a research fellow before being appointed director of nurseries at the Royal Victoria Hospital in 1959, a position he held for over 40 years. During this time, he made important contributions in several areas.

"(Dr. Usher) then returned to Montreal as a research fellow before being appointed director of nurseries at the Royal Victoria Hospital in 1959, a position he held for over 40 years."

Dr. Usher had a major interest in birth asphyxia and trauma. He first published on this topic in 1966 when he and colleagues reviewed 208 severely affected infants out of 10,995 deliveries. (2) The incidence of "severe asphyxia neonatorum" was 11 per 1,000 births while 5.6 per 1,000 had "cerebral depression or irritation," and 2 per 1,000 had "convulsions". The authors concluded that "Improved obstetrical management with more frequent use of Cesarean section delivery might have been of value in preventing much of this fetal injury." Eighteen years later, a report showed a dramatic reduction in neonatal death and asphyxia which were attributed to use of continuous electronic fetal monitoring and increased cesarean sections but also a disturbing increase in trauma often linked to mid forceps delivery (Figure 1). (3)

Figure 1. Incidence of severe birth asphyxia or neonatal encephalopathy and of birth trauma (fracture, paralysis) per 1000 live births by 500 gm weight groups. (3)

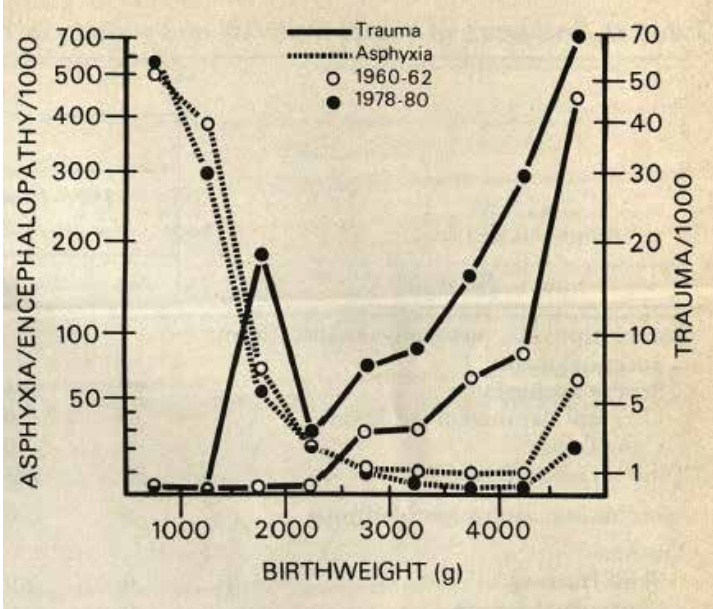


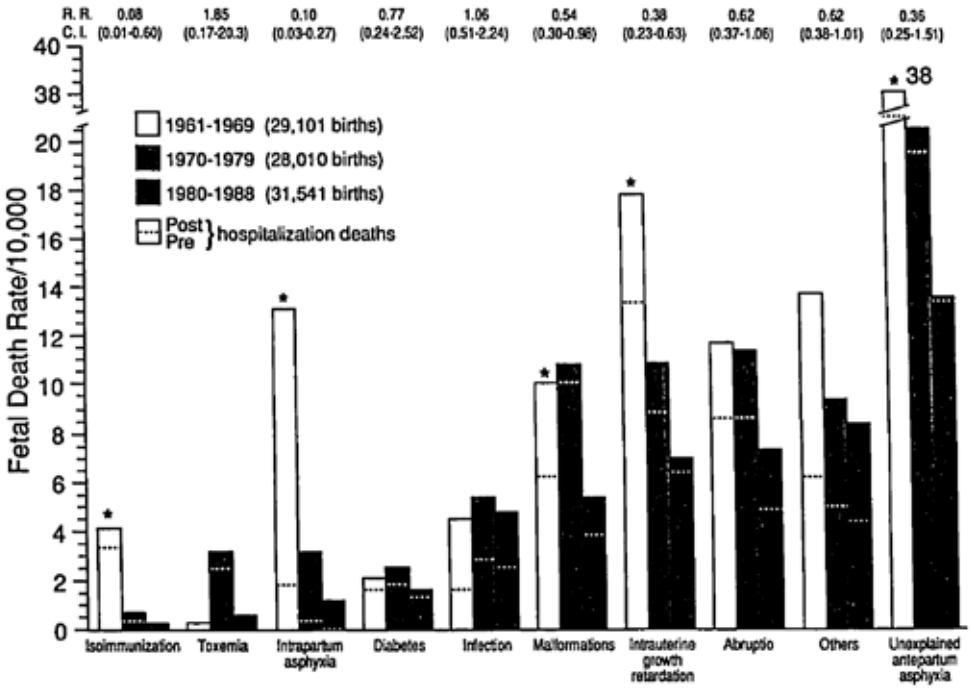
Fig. 1. Incidence of severe birth asphyxia or neonatal encephalopathy and of birth trauma (fractures, paralyses) per 1,000 live births by 500 gm weight groups.

Dr. Usher was invited to deliver a speech in Dublin, Ireland, in 1984, where he reviewed the above data and reported on a forthcoming article on these issues in twins. (4, 5) The twin study revealed that, although the cesarian delivery rate had increased dramatically from 3% in the 1963–1972 period to 51% between 1978 and 1984, the rate of severe neonatal depression had not changed. A further study showed that the rates of fetal distress and meconium aspiration were significantly increased with post-term deliveries, although the mortality rates were not increased. (6)

"A further study showed that the rates of fetal distress and meconium aspiration were significantly increased with post-term deliveries, although the mortality rates were not increased."

Fetal and neonatal death were also a concern for Dr. Usher. A retrospective review of fetal deaths spanning almost three decades showed dramatic reductions in deaths from intrapartum or intrapartum asphyxia and the virtual disappearance of fetal

Figure 2. Rates of fetal death from 3 time periods showing large decreases for antepartum and intrapartum asphyxia and isoimmunization. (7)



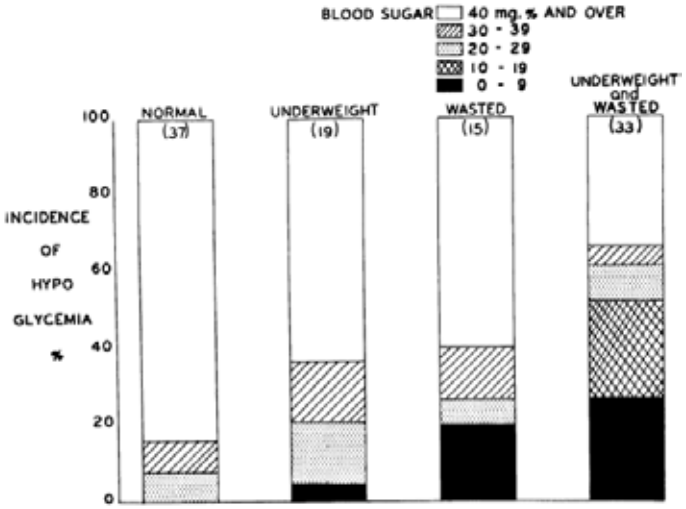
demise from isoimmunization (Figure 2). (7) Another study found that, although fetal death rates fell significantly from the time period 1961–1974 to 1978–1993, advanced maternal age remained a risk factor for fetal demise. (8) A search for determinants of unexplained fetal deaths showed several factors, including primiparity, maternal weight >68kg, and low socioeconomic status. (9) An extensive review of perinatal mortality statistics by Usher showed improved survival with delivery or early referral to a hospital with a dedicated neonatal ICU, and he advocated for referral of women in preterm labor to such hospitals as well as for immediate transfer of premature infants. (10)

"An extensive review of perinatal mortality statistics by Usher showed improved survival with delivery or early referral to a hospital with a dedicated neonatal ICU, and he advocated for referral of women in preterm labor to such hospitals as well as for immediate transfer of premature infants."

Fetal and neonatal growth and nutrition were also significant areas of research for Dr. Usher and his colleagues. An extensive review of 3,714 liveborn infants delivered from 7/1/1961 to 6/30/1962 showed that primiparity and age <20 or >35 years were associated with intrauterine growth restriction (IUGR). (11) The incidence of fetal malnutrition increased with increasing numbers of previous low birthweight infants and fetal distress, asphyxia neonatorum, congenital anomalies, and neonatal death. A review of the topic of fetal malnutrition published in 1970 showed that the more malnourished a newborn infant was, the more likely it was to become hypoglycemic (Figure 3). Another study highlighted the disproportionate head and length sparing of growth restricted infants compared to normally grown infants with the same birthweight and concluded "Results of our analysis indicate that, for a given birth weight, intrauterine growth-retarded infants are longer and thinner and have larger heads than non-growth-retarded infants."(13)

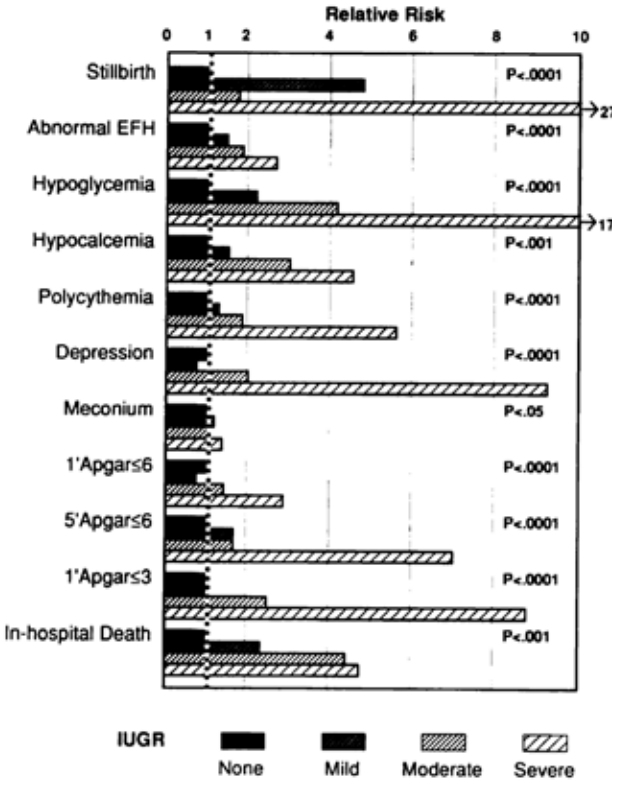
An analysis of maternal factors associated with fetal growth restriction found that pregnancy-associated hypertension, cigarette smoking, and history of a prior growth restricted infant were all associated with IUGR. In contrast, maternal diabetes was associated with macrosomia. Additional studies of 8,719 infants

Figure 3. Rates of hypoglycemia versus degree of fetal malnutrition. (12)



born in the early to mid-1980s showed that the more severe the IUGR, the more likely adverse outcomes including stillbirth, hypoglycemia, low Apgar scores and in hospital neonatal death (Figure 4). (Analysis of a cohort of 573 very low birthweight (500–1,500 grams) and 466 23–30 completed weeks gestation infants found that fetal growth status and fetal maturity are independently associated with mortality and that the protective effect of IUGR on mortality is because these infants are more mature than normally grown infants with the same birthweight. (16) Finally, a massive review of 65,280 liveborn singleton infants born between 1/1/1978 and 3/31/1996 confirmed the previous risk factors for IUGR but concluded, "The available evidence now suggests that both the severity and prognosis of IUGR may depend on its cause. In other words, growth-restricted newborns are not all created equal(ly)."(17)

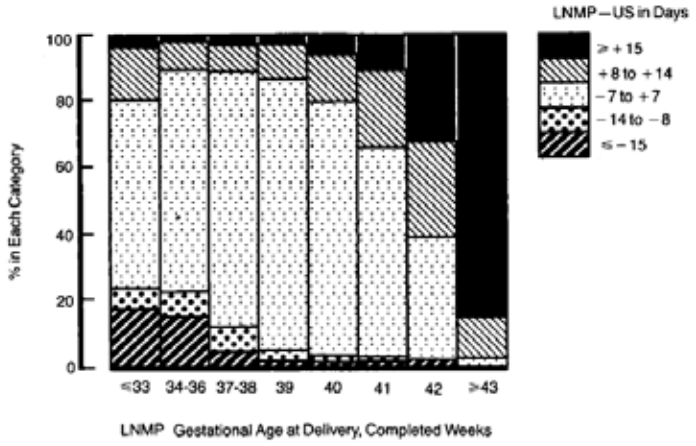
Figure 4. Effect of mild, moderate, and severe intrauterine growth restriction on adverse outcomes compared to normally grown infants. (15)



Post-term delivery did not escape Dr. Usher's scrutiny either. He and colleagues reviewed 7,000 deliveries with gestational age confirmed by early ultrasound and concluded that the primary concern for postdates deliveries was macrosomia, not IUGR. Another study compared the accuracy of menstrual dating to the gold standard of early ultrasound dating and found that the two estimates correlated well at 39 to 40 weeks gestation based on early ultrasound but that the accuracy of menstrual dating declined the more pre or post-term an infant was born (Figure 5) (19). Dr. Usher also published growth curves for liveborn Caucasian infants born at near sea level (100 ft), showing that such infants were larger than those found by Lubchenco in Denver, CO, (20) which is 5,280 feet above sea level. He pointed out that the high altitude in Denver may be a factor in producing lower birthweight infants than those born closer to sea level.

Dr. Usher spent a year in Sweden working with the legendary Professor John Lind and performed seminal studies on the blood volume of newborn infants. They used I^{131} tagged albumin to investigate the effects of immediate versus delayed cord clamping (sound familiar for today's standard of delayed clamping in premature infants?) on blood volume, concluding that the average blood volume in the immediate clamping infants was 82 ml/kg at 72 hours of age versus 93 ml/kg in the delayed clamping infants.

Figure 5. Accuracy of menstrual dating versus early ultrasound dating at different gestational ages. (19)



"The development of total parenteral nutrition (TPN) was a major advance in neonatology, and Dr. Usher was an early adopter. He and colleagues reported on its use in 19 survivors out of 23 infants weighing <1,500 grams at birth. TPN began on day 2 of age and increased until day 5 when '140 ml of fluids containing 3.5 gm of fat, 3.0 gm of protein hydrolysate, and 10.5 gm of carbohydrate were given per kilogram of body weight per day.'"

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regimen with 109 infants with birthweights <1,000 grams was less optimistic, concluding "Compared with intrauterine standards, weight, length, and head circumference were all worse at 56 days than at birth, although some degree of head sparing was evident. Although weight growth was comparable with intrauterine norms from 14 to 46 days of life, there was no catch-up growth." (24) Again, these results comport with those reported by most contemporary NICUs. A companion study of the same 109 infants evaluated factors associated with poor growth and showed that use of dexamethasone and duration of respiratory support were the most significant ones. (25)

"A further analysis of 212 babies, including the 70 in the RCT, showed a reduction in deaths from 42% before use of the IV regimen to 20% with it. This therapy became known as the Usher regimen and was widely adopted worldwide. The provision of intravenous fluids is now the standard of care for all premature infants, although bicarbonate is not part of current practice."

As with all neonatologists of his time, Dr. Usher was concerned with the mysteries of respiratory distress syndrome (RDS), also known as hyaline membrane disease. He studied 45 premature infants with RDS and described changes in serum potassium levels and electrocardiographic changes over time. A cocktail of intravenous infusion of glucose, insulin, and bicarbonate was shown to improve these abnormalities in 27 infants who appeared to be dying, although most infants did die. He provided a lengthy report on the various abnormalities observed clinically in infants with RDS in 1961, again mentioning his regimen. Dr. Usher then conducted a randomized, controlled trial of early infusion of glucose and bicarbonate started within 3 hours of birth in the infusion group versus a control group not given IV fluids. Otherwise, the groups were treated the same. Six infants in the infusion group of 35 died (17%) versus 13 of 35 (37%) in the control group. A further analysis of 212 babies, including the 70 in the RCT, showed a reduction in deaths from 42% before use of the IV regimen to 20% with it. This therapy became known as the Usher regimen and was widely adopted worldwide. The provision of intravenous fluids is now the standard of care for all premature infants, although bicarbonate is not part of current practice.

A study of the use of delayed cord clamping in infants with and without RDS concluded that delayed clamping was beneficial. This was published in 1975, and the past decade or two has seen a series of RCTs confirming the benefits of delayed cord clamping in premature infants. The risks of developing RDS or death related to gestational age, route of delivery, and maternal diabetes were found to be higher with decreasing gestational age and birth by cesarean section, but maternal diabetes in this study was not linked to a higher risk of developing RDS. A matched case-control of twins showed that RDS was much more likely in the second-born twin and that neonatal depression of the second twin was not an etiologic factor. (31) The authors concluded that the second twin did not benefit from labor to the same extent as the first twin. A final report on RDS showed that women who deliver an infant with RDS are "prone" to deliver another one with RDS, suggesting the possibility of a genetic predisposition in this population.

"A study of the use of delayed cord clamping in infants with and without RDS concluded that delayed clamping was beneficial. This was published in 1975, and the past decade or two has seen a series of RCTs confirming the benefits of delayed cord clamping in premature infants."

Dr. Usher received numerous accolades for his significant contributions, the most notable of which was the Apgar Award from the American Academy of Pediatrics (AAP) in 2000. He gave a lengthy and informative interview as part of the Oral History Project of the AAP in 1998. (I had a delightful dinner with him and my primary mentor, Dr. George Cassady, at one of the PAS meetings back in the 1980s. I remember him as witty and engaging, and I thoroughly enjoyed his company. He died from prostate cancer in 2006 after a long and productive career. He received numerous obituaries, including in the British Medical Journal. He was truly a pioneer of neonatology.

I thank Ms. Lauren McInnis, MA, for her invaluable assistance in obtaining many of the references and for arranging the citations.

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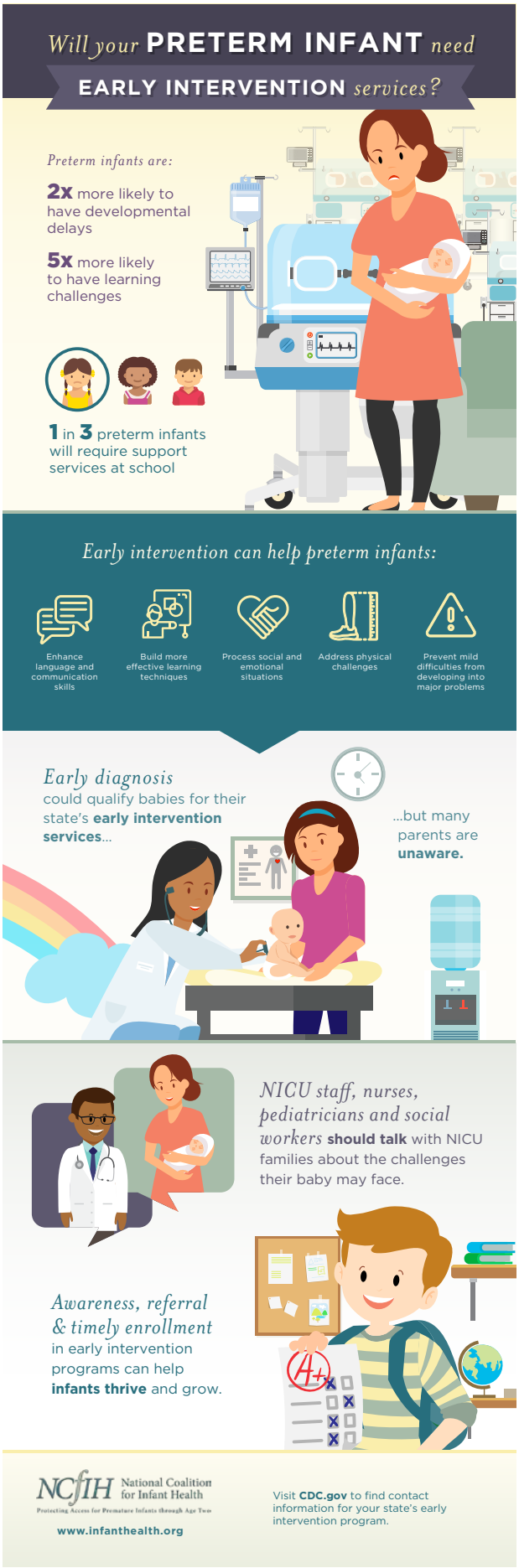

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The Indirect Impact of **RSV**

NCfIH National Coalition for Infant Health

Protecting Access for Premature Infants through Age Two

OVERVIEW

RSV impacts not only infants and young children, but also entire families.

The National Coalition for Infant Health and the Alliance for Patient Access sought to examine the multifaceted burden that RSV places on families and to identify potential policy solutions.

Two surveys were conducted, one of parents who had at least one child contract RSV and one of health care providers who treat infants and children with RSV.

Both surveys were conducted with YouGov, a global public opinion and data company. Parents and providers were recruited from a pool of pre-selected respondents to ensure they met the survey's requirements. Participants received an honorarium.

RSV PARENT SURVEY

340 parents who had at least 1 child sick with RSV

67% of parents said their child was hospitalized for RSV

RSV HEALTH CARE PROVIDER SURVEY

175 health care providers across various pediatric and neonatal subspecialties

67% worked in an outpatient facility

33% worked in a hospital

RESULTS

FINANCIAL BURDEN

More than ⅔ of parents said the costs of RSV posed a financial burden or financial crisis.

7% of parents said they were fired as a result of caring for their child with RSV.

32% of parents reported losing potential income while their child had RSV.

EMOTIONAL BURDEN

68% of parents said watching their child suffer affected their mental health.

69% of parents felt guilty that they could not do more to prevent their child's RSV.

When parents found out there was no treatment for RSV, only supportive care:

- **48%** felt angry
- **46%** felt helpless

SOCIAL BURDEN

43% of parents had never heard of RSV before finding out their child was sick.

54% of parents had to rely on family and friends for sibling care, transportation and other responsibilities.

42% of parents said they struggled to care for their other children when one faced RSV.

RESULTS

PARENT EDUCATION & AWARENESS

86% of providers said they include RSV education as part of routine care.

99% of providers agreed that parents need more information about RSV.

TREATMENT CHALLENGES

Nearly ⅓ of providers have been reluctant to test for RSV because no treatment exists.

48% of providers said it was difficult to decide whether to send an infant or child with RSV to the emergency room.

92% agreed that if an immunization were available, it should be added to the Vaccines for Children program's list of pediatric vaccines.

MISCONCEPTIONS

A majority of providers (60%) explained that around 50% or more of the babies they see hospitalized for RSV were born healthy, despite many people thinking severe RSV only impacts premature infants or those with preexisting conditions.

CONCLUSION

Both surveys highlighted that the burden of RSV extends well beyond its physical symptoms.

The virus may lead to:

- **Long-lasting health challenges** for babies and young children
- **Financial, social and emotional burdens** for families
- **Frustration for providers,** who lack a cure or viable preventive interventions

This burden is not experienced by the few. Most infants and children contract RSV by the time they are two, and challenges that accompany RSV may impact anyone who has been affected.

Moving forward, the many burdens of RSV demonstrate the need for:

- **More RSV education**
- **Research and innovation** for preventive interventions
- **Access to prevention and treatment** for all babies and children

The challenges caused by RSV can reach far and wide, and its indirect impacts often leave families struggling.

Beyond the Numbers: Building Cultures That Deliver Lasting Excellence

Rody Azar, MHA, RRT-NPS

"While performance metrics are critical, the danger lies in treating numbers as the sole measure of success. A company may hit financial benchmarks yet quietly erode its foundation if its culture is toxic, disengaging, or unsustainable. True excellence extends beyond the spreadsheet."

Abstract:

Organizations today operate in a landscape obsessed with measurement. Leaders are routinely pressured to hit quarterly targets, drive year-over-year growth, and report quantifiable wins to stakeholders. While performance metrics are critical, the danger lies in treating numbers as the sole measure of success. A company may hit financial benchmarks yet quietly erode its foundation if its culture is toxic, disengaging, or unsustainable. True excellence extends beyond the spreadsheet.

This article explores why lasting excellence stems not only from achieving outcomes but also from how those outcomes are delivered. Drawing on peer-reviewed research and leadership best practices, it examines the pitfalls of numbers-only leadership, the role of culture as a growth engine, and the habits of leaders who balance performance with values. Studies show that trust, psychological safety, and aligned cultural norms are central mechanisms linking leadership to performance and learning (1, 2).

"Drawing on peer-reviewed research and leadership best practices, it examines the pitfalls of numbers-only leadership, the role of culture as a growth engine, and the habits of leaders who balance performance with values."

At its core, this piece argues that leaders must see culture as the hidden multiplier of organizational performance. By embedding trust, authenticity, and alignment into daily operations, leaders create environments where people thrive, and thriving people deliver sustainable results. To make this practical, the article closes with a 3-step call-to-action guide that leaders can use to define excellence, align culture with strategy, and measure what truly matters.

The challenge for modern leaders is not whether they can hit a target, but whether they can build a culture that continues to deliver long after the numbers are forgotten.

Introduction: Why Numbers Alone Are Not Enough

Numbers are intoxicating. They provide clarity, objectivity, and a sense of progress. For executives under pressure, this language is crucial for survival. However, leadership is not merely about managing numbers; it is about inspiring people. Numbers tell you what has been achieved, but they rarely explain how it was achieved or whether the success is sustainable.

"History offers cautionary tales, such as organizations that posted record profits shortly before collapse. Their cultures, characterized by secrecy, pressure, and misplaced incentives, achieved short-term gains but compromised long-term viability. In many sectors, leaders who push teams relentlessly to hit quotas see burnout, turnover, and disengagement, even when revenue graphs look impressive."

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The truth is that excellence is not a quarterly event. It is a sustained pattern of performance built on values, trust, and behaviors. Numbers are snapshots, but culture is the lens through which every picture is taken. Leaders who focus only on financial metrics risk missing the deeper story: Are we building something that will last?

"Overemphasis on numbers comes with hidden costs. Leaders may feel that metrics bring clarity, but when metrics dominate, several risks emerge:"

The Pitfalls of Numbers-Only Leadership

Overemphasis on numbers comes with hidden costs. Leaders may feel that metrics bring clarity, but when metrics dominate, several risks emerge:

1. **Burnout and Disengagement:** Teams treated as output machines eventually wear down. High performers pushed solely for quotas often exit, leaving organizations scrambling to fill the talent gap. In cultures that emphasize learning and psychological safety, however, teams adapt and improve rather than burn out (1).
2. **Short-Term Thinking:** A fixation on quarterly targets encourages decisions that maximize immediate gains but erode future growth. Leaders may cut development budgets, ignore coaching, or push unsustainable tactics, winning today but losing tomorrow.
3. **Erosion of Trust:** When numbers trump people, trust frays; employees feel replaceable, undervalued, and unheard. Research shows that trust in leadership is a key mechanism through which leadership behaviors translate into performance and citizenship behaviors (2).
4. **Ethical Blind Spots:** The most dangerous outcome of numbers-only leadership is the erosion of ethical boundaries. Pressure to deliver can tempt teams to bend rules or prioritize results over responsibility. Authentic and values-aligned leadership mitigates these risks and is associated with better collective outcomes (3).

Bottom line: Numbers may impress shareholders, but they rarely inspire stakeholders. When people feel reduced to metrics, they disengage, and disengaged people cannot deliver lasting excellence.

The Power of Culture as a Growth Engine:

Culture is often described as "the way we do things around here." More accurately, it is the invisible operating system of an organization; the shared values, beliefs, and behaviors shape every decision. Unlike numbers, culture cannot be faked. It shows how leaders treat their teams, how teams collaborate, and how customers experience the brand.

Culture Drives Performance:

Meta-analytic evidence links specific cultural profiles to stronger attitudes, innovation, quality, and even financial outcomes (4). Another seminal stream of work shows that core cultural traits, Involvement, Consistency, Adaptability, and Mission, are systematically associated with effectiveness (5).

Culture Defines Sustainability:

Numbers tell you whether goals were achieved. Culture tells you whether those goals can be achieved again. When trust and psychological safety are present, teams share information, ask for help, and learn from mistakes, behaviors that compound performance over time (1).

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Culture as a Strategic Differentiator:

Organizations that codify and model values such as clarity, integrity, collaboration, and continuous learning create self-reinforcing cycles of performance. Leaders who embody authenticity and align behaviors with stated values tend to elicit higher trust and collective effort (2, 3).

Takeaway: Numbers reflect outcomes, but culture creates them. Leaders who see culture as a growth engine stop chasing performance and start cultivating it.

3-Step Call-to-Action Guide:

Step 1: Define What Excellence Looks Like for Your Team:

Most teams already have quantitative targets. What they often lack is a shared definition of how those targets will be met. Facilitate a 60–90-minute session to co-create a short "Excellence Charter" that captures:

- **Values in action**: What does respect, transparency, and ownership look like in daily behaviors?
- **Collaboration norms**: How do we make decisions, resolve conflicts, and give feedback?
- **Learning habits**: How do we run debriefs, share lessons learned, and improve the next cycle?

Translate these into 5–7 observable behaviors and publish them in places people use (team spaces, playbooks, onboarding). Reference them in 1:1s and performance conversations. This explicitly links how work gets done to what gets delivered (5).

The leader moves this week.

- *Ask your team: "What one behavior, if we all did it more consistently, would most improve our results?"*
- *Turn the top answers into weekly "micro-commitments" and review progress openly.*

Step 2: Align Culture with Strategy

A great culture is not a poster; it is embedded in systems.

- **Hire and promote values, not just skills**. Add two behavior-based questions aligned to your Excellence Charter for every interview and promotion slate.
- **Coach and mentor consistently**. Protect 30 minutes per week for structured coaching with each direct report. Use a simple loop: goal → behavior → impact → next experiment. Coaching cultures build psychological safety and adaptive learning (1).
- **Recognize cultural wins**. Publicly celebrate actions that exemplify your values, such as knowledge-sharing, making ethical choices under pressure, and cross-team assists. This signals "what good looks like" and reinforces norms (4).
- **Make leadership behaviors visible**. Leaders model the culture. Authentic, transparent leadership is associated with stronger collective outcomes and citizenship behaviors (3).

Leader moves this week: Audit one process (e.g., onboarding, pipeline review). What is missing from the culture you want? Add one ritual or artifact that reinforces it (e.g., a "wins + learnings" close to every pipeline call).

Step 3: Measure What Truly Matters

If you only measure revenue, you will only manage revenue. Build a balanced dashboard that pairs financials with leading cultural indicators.

- **People metrics** include engagement pulses, regrettable turnover, and internal mobility.
- **Learning metrics**: cadence of retrospectives, experiments run per quarter, and cross-team knowledge shares.
- **Customer trust metrics**: renewal/retention trends, NPS verbatims tagged to behaviors (responsiveness, honesty, follow-through).

Utilize lightweight instruments, quarterly pulses, and brief after-action reviews to assess whether the culture you have designed is being implemented. Research suggests that when culture is aligned and internalized, performance improves across multiple dimensions (4, 5). Trust acts as a critical mechanism connecting leadership behaviors to those outcomes (2).

Leader moves this week: Add one culture KPI to your weekly ops review (e.g., "two cross-team assists logged" or "one experiment launched"). What gets seen gets shaped.

Conclusion:

In a world obsessed with performance metrics, leaders must remember that numbers are only part of the story. A company can hit targets today and collapse tomorrow if its culture is unsustainable. Lasting excellence emerges when leaders focus not only on what is achieved but on how it is achieved.

"Culture is not a distraction from results; it is the foundation of them. Leaders who cultivate trust, authenticity, and alignment build organizations that thrive long after a single quarter ends. Numbers reflect outcomes, but culture ensures continuity."

Culture is not a distraction from results; it is the foundation of them. Leaders who cultivate trust, authenticity, and alignment build organizations that thrive long after a single quarter ends. Numbers reflect outcomes, but culture ensures continuity.

The ultimate leadership challenge: *What story will your team's numbers tell about your culture five years from now?*

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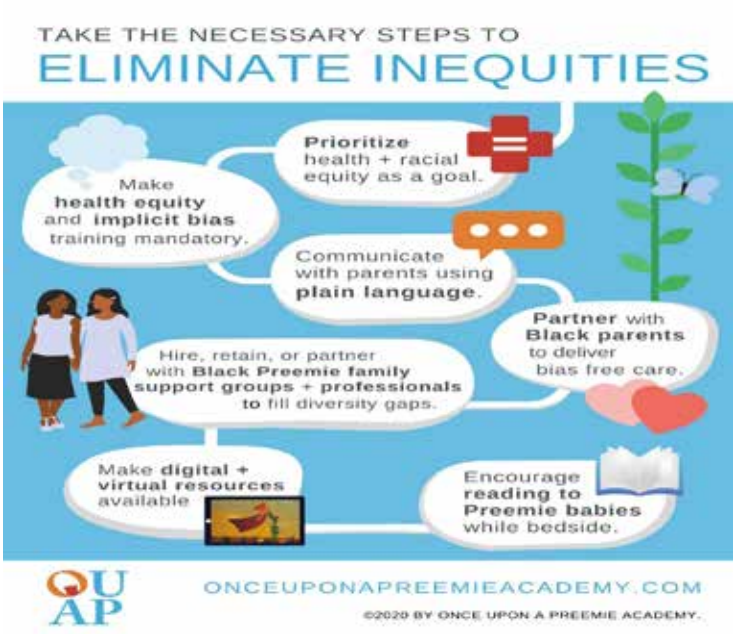
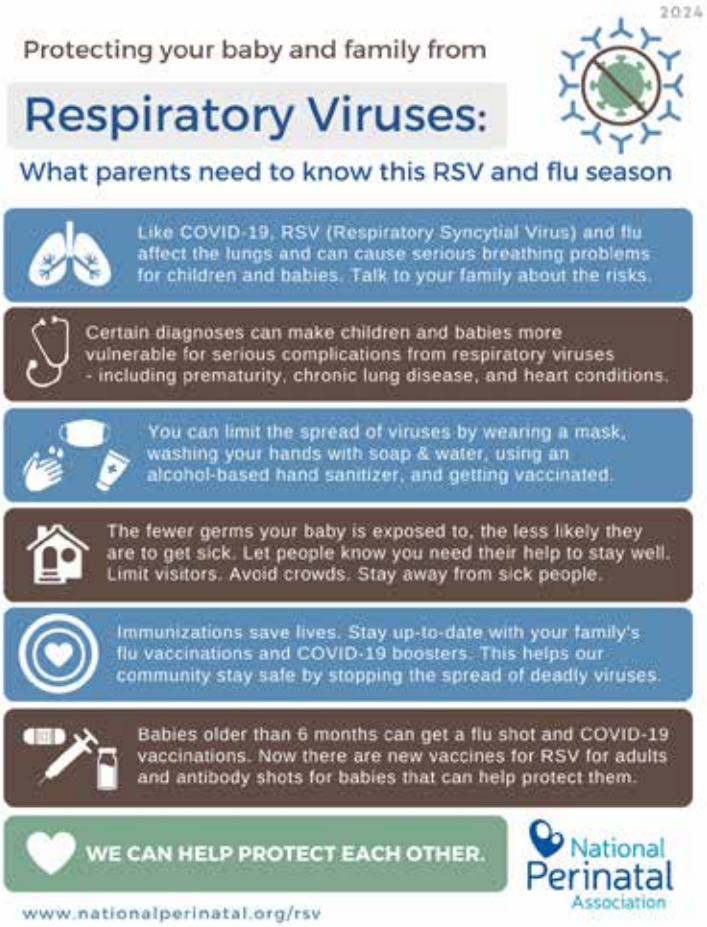


Rody Azar Bio:

With over 20 years of leadership experience, Rody has a proven track record of driving results and developing high-performance teams. A staunch believer in fostering strong, trusting relationships, he advocates for servant leadership and is passionate about nurturing talent and human asset development. Rody emphasizes the importance of effective people leadership in guiding teams to deliver exceptional results. He has successfully promoted leaders into key mid-management and senior roles, significantly contributing to organizational success and enhancing shareholder value.

Currently, Rody serves as the Vice President of Sales and Clinical at a leading medical device manufacturing company in Orange County, CA. He is also an Organizational Leadership Coach and a faculty member in clinical education. As a proud member of the American College of Healthcare Executives (ACHE) and the American Association for Respiratory Care (AARC), he remains committed to advancing healthcare leadership and education.



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Gravens By Design: Selected Abstracts from the 38th Annual Gravens Conference on the Environment of Care for High-Risk Infants and Their Families

Robert White, MD, Joy Brown, PhD, Vincent Smith, MD, Hun-Seng Chao, MD, Mitchell Goldstein, MD, MBA, CML

Selected abstracts from the the 38th Annual Gravens Conference are presented below:

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Gravens 2024-54	Words Matter: Creating Inclusive Spaces in the NICU

Gravens 2025-1

Abstract Title: Development of a Belgian perinatal palliative care intervention: Supporting infants with severe perinatal diagnoses, their families and healthcare providers

Authors: Laure Dombrecht, PhD; Filip Cools, MD, PhD; Ellen Roets, MD; Kristien Roelens, MD, PhD; Kenneth Chambaere, PhD; Kim Beernaert, PhD

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Problem Statement: The overall objective of the project was to develop and pilot test a Perinatal Palliative Care program within the standard perinatal healthcare setting, in order to provide the best possible care for fetuses and neonates with a life-limiting diagnosis, their families, and involved healthcare providers. In this phase, we wish to present the development process and the resulting holistic perinatal palliative care program.

Abstract:

Background: Perinatal palliative care (PPC) addresses the much-needed support for fetuses and infants at the end of life, as well as for their families, and for the healthcare providers. Studies evaluating the best model of care in this setting are lacking. No current Belgian PPC program exists despite a clear need. The target group of this project are parents who receive a life-limiting diagnosis for their child, where the child is expected to die (or be stillborn) during the perinatal period (i.e. from 22 weeks gestation until 28 days after birth), and their healthcare providers.

Methods: During the development phase we followed the extended MRC framework made by Bleijenberg. 1. Existing international evidence regarding perinatal palliative care programs was gathered by means of an integrative review. 2. Furthermore, to inform the program's conceptualization, identifying gaps in current care provision, we performed face-to-face semi-structured interviews with 22 healthcare providers and 18 bereaved parents from 6 different hospitals. Interviews were performed between May 2021 and February 2022 with healthcare providers with experience in end-of-life care in the perinatal period, and bereaved parents who experienced perinatal loss. Drawing from these insights, key program topics for our intended perinatal palliative care intervention were identified by the researchers. After this first phase, a prototype of the perinatal palliative care intervention was drafted. Afterwards, we used a participatory approach to develop a model of our perinatal palliative care intervention. The prototype of the perinatal palliative care intervention was tailored and amended during joint workshops including bereaved parents and healthcare professionals from the same hospital within one workshop, so that they were able to narrate on the policy and care provision of that particular hospital. For each participating hospital (n=3), we conducted two workshops, consisting of a total of 15 healthcare providers and 1 bereaved parent, and 13 healthcare providers and 3 bereaved parents respectively. Workshops took place between March 2023 and May 2023.

Results: We developed a perinatal palliative care approach that fits into standard perinatal care, based on five main intervention components: 1) families receive care from a newly assembled and fixed perinatal palliative care team. The core team will consist of members of the prenatal diagnostics, maternity and delivery ward, as well as members from the neonatal team, and will include both on the people responsible for the medical care of infant and family, and the people focusing on psychosocial support. Team members will hereby become familiar with working together, can be trained and build experience as a team. The perinatal palliative care team will function as a consulting team that can be deployed when needed. A case manager role will be assigned, so that every family will have a personal contact for follow-up or questions. 2) the care team received an extensive perinatal palliative care training. All members of the perinatal palliative care team will receive a two-day training module on perinatal palliative care aspects. 3) the care team follows a new stepwise perinatal palliative care approach including: 3a) A care approach: including clear inclusion criteria for the start-up of perinatal palliative care, a detailed step-by-step plan of how perinatal palliative care should be offered to families, a clear task description for involved care providers, checklists for certain stages in the perinatal palliative care trajectory, and a way to phase out perinatal palliative care when the prognosis of the

child becomes more optimistic. 3b) Centralization of information, guidelines and tools: making information on perinatal palliative care easily accessible for care providers, including information such as templates for advance care planning conversations, guidelines for the dosage of medication in palliative care settings, checklists for bereavement, religion specific information on perinatal palliative care, available community resources such as non-profit organizations and peer support groups, etc. 3c) A way to share case-specific information: we will organize a way for all care providers included in the care for a specific family to share relevant case-specific information, so that everyone is up-to-date before seeing or caring for the family. 4) systematic psychological support is offered to not only bereaved parents but also involved healthcare providers. 5) systematic debriefings are organized for the team after perinatal loss.

Discussion: During this presentation, we will attempt to describe the underlying working theory and processes of the perinatal palliative care intervention, including envisioned outcomes; as well as all prototype information. One of the main strengths of our perinatal palliative care approach is being able to offer a formalized and standardized pathway of increased support for all severe perinatal diagnoses, independent of the moment of diagnosis (prenatal or neonatal) or (end-of-life) care choices made by parents and healthcare providers.

Table 1. Baseline Parental Characteristics

		Control (n=11)	Intervention (n=14)
Gender	Male	1	3
	Female	10	11
Families with both partners participating		1	3
Age	< 20	0	0
	20-24	2	0
	25-29	1	2
	30-34	5	6
	35-39	2	5
	40-44	1	1
	>45	0	0
Race	White	10	8
	Hispanic or Latino or Spanish Origin of any race	0	2
	American Indian or Alaskan Native	0	0
	Asian	0	2
	Native Hawaiian or Other Pacific Islander	0	0
	Black or African American	1	2
	Two or more races	0	0
Employment	Full-time	5	8
	Part-time	1	0
	Homemaker	1	3
	Student	1	0
	Unemployed	3	3
Education	Did not complete high school	0	0
	Completed high school/GED	3	3
	Completed some college (1-3 years)	4	3
	Completed 4 years of college	2	3
	Completed graduate school	2	5
Marital Status	Married	7	11
	Cohabitating but not married	1	2
	Single	3	1
Other children at home	No	3	9
	Yes	8	5
Distance from home to hospital (drive time)	< 30 minutes	4	8
	30 minutes to 1 hour	3	4
	1 to 2 hours	3	2
	2 to 4 hours	1	0
	> 4 hours	0	0
Feeding plan when discharged (asked at time of admission)	Exclusively mom's own milk (breastfeeding or EBM +/- fortification)	6	9
	Breastfeeding or EBM with formula supplementation	4	3
	Formula only	1	2

Table 2. Baseline Infant Characteristics

		Control (n=17)	Intervention (n=15)
Gender	Male	7	10
	Female	10	5
Gestational Age at Birth (Weeks) [Mean ± SD]		31.4 ± 1.7	32.0 ± 1.5
Birthweight (g) [Mean ± SD]		1627 ± 499	1739 ± 342
Sets of Multiples	Twins	2	3
	Triplets	1	0
	Quadruplets	1	0

Table 3: PSS:NICU score on admission, at discharge, and difference from admission to discharge.

Domain	Intervention or Control	Admission		Discharge		Δ	
		Mean ± SD	P-value	Mean ± SD	P-value	Mean ± SD	P-value
Sights and Sounds	I	10 ± 4	0.42	10 ± 3	0.46	-1 ± 3	0.16
	C	9 ± 5		12 ± 5		-4 ± 5	
Infant Appearance	I	31 ± 13	0.51	29 ± 16	0.91	-3 ± 13	0.79
	C	35 ± 16		30 ± 19		-1 ± 12	
Parental Role Alteration	I	23 ± 9	0.10	22 ± 8	0.49	-1 ± 5	0.12
	C	29 ± 6		25 ± 9		3 ± 6	
Total	I	64 ± 20	0.36	61 ± 23	0.68	-5 ± 16	0.71
	C	72 ± 21		67 ± 30		-2 ± 17	

Table 4: PREEMI score at discharge.

Domain	Intervention or Control	Mean ± SD	P-value
Self-Efficacy	I	111 ± 6	0.62
	C	110 ± 7	
Social Support	I	52 ± 4	0.19
	C	47 ± 12	
Outcome Expectations and Intent	I	82 ± 6	0.53
	C	84 ± 5	
Perception of Risk	I	31 ± 6	0.15
	C	33 ± 2	
Total	I	276 ± 15	0.76
	C	274 ± 16	

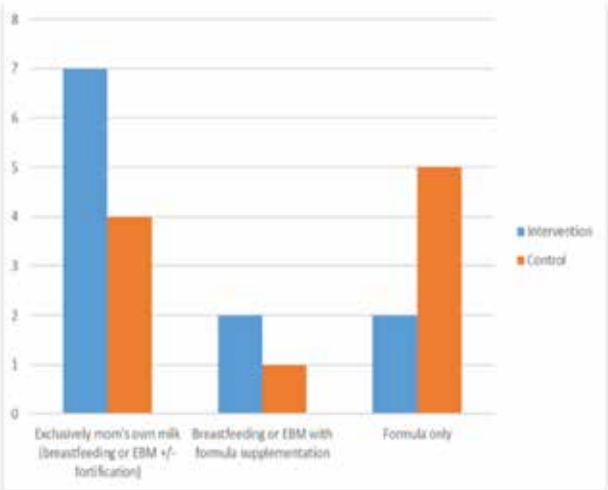

Figure 2. Feeding plans at discharge.

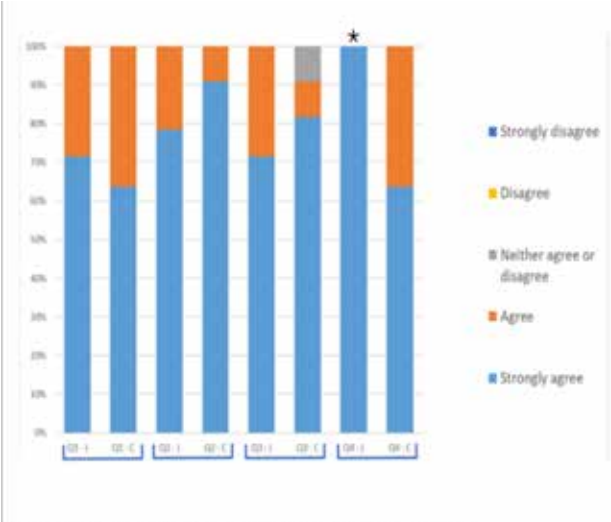

Figure 1. Satisfaction questions for the journal (J) and control (C) group respectively.
Question 1: I am satisfied with the general NICU experience
Question 2: I am satisfied with the medical care my child received
Question 3: I am satisfied with my interactions with the medical staff (providers, nurses, therapists, etc...)
Question 4: I feel comfortable taking my child home

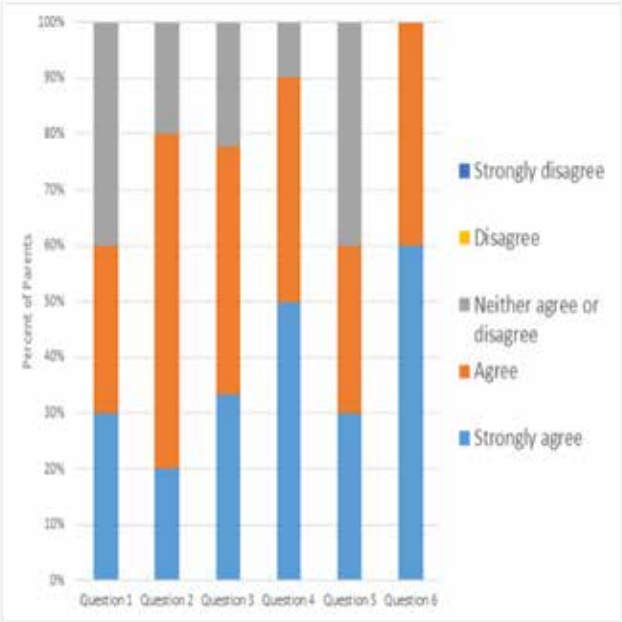

Figure 3. Intervention group only responses regarding journal use.
Q1: Using the journal enhanced your understanding of your child's medical condition.
Q2: Using the journal has enhanced your communication with medical providers, nurses, and other staff.
Q3: Using the journal has promoted participation in your child's care and other bonding activities.
Q4: Using the journal has helped me process through the difficult emotions of having a baby in the NICU.
Q5: Using the journal has enhanced my relationship with my child
Q6: I would recommend for any parent with a child in the NICU to use this journal

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Learner Objectives:

1. To learn which hiatuses families and healthcare providers currently experience regarding perinatal end-of-life care.

2. To identify how existing international PPC models would cope with these hiatuses.

3. To discuss in detail how we developed a PPC model for the Belgian healthcare context, and which care components will be explicitly added, changed and evaluated compared to regular care provision.

Gravens 2025-2

Abstract Title: Empowering Parents: Using Targeted Journals to Improve Parental Stress and Engagement

Authors: Erik VerHage, MD; Meredith Joseph, MD; Leslie Parker, PhD, APRN; Celine Cattier, MD; Marie Berg, MD

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Problem Statement:

Hypothesis: NICU parents who are provided with a journal specifically designed to reduce stress and promote engagement will exhibit improved stress levels and higher engagement scores at the time of discharge.

Scientific Question: Our group investigated whether a targeted journal intervention could improve parental mental health and parent-infant engagement. This is significant because the parent-infant relationship can have a profound impact on long-term outcomes for both the infant and the family.

Abstract:

Methods: This was a prospective randomized controlled pilot study conducted at an academic hospital with approximately 800 to 900 NICU admissions annually. A journal was created based on the literature review outlined in the introduction, encompassing three primary domains: processing, prioritizing, and prompting. Following randomization, the journals were distributed to parents in the intervention group. Infants admitted to the University of Florida Shands Children's Hospital NICU were screened for inclusion based on the criteria of being between 28 weeks and 0 days to 33 weeks and 6 days gestational age, with English-speaking parents. Exclusion criteria included transfers to the UF NICU after 1 week of life and NICU stays shorter than 14 days. Both the infant and either one or both parents were included as study participants. Parents that agreed to participate and consented were randomized into the intervention group or standard of care group using a built-in randomizer through the REDCap database. Following informed consent and randomization, participants filled out the initial REDCap survey electronically and were assigned a unique record number to facilitate longitudinal tracking of their responses. The study utilized two validated instruments: the PSS:NICU and the PREEMI to assess parental stress and parental engagement respectively. A REDCap database was developed and on admission we obtained: baseline demographics, preferred parental feeding plan, and baseline parental stress score using the PSS:NICU. At discharge we collected: parental engagement score (PREEMI), parental stress scores (PSS:NICU), visitation

frequency and duration, feeding plan, satisfaction questionnaire, and journaling experience questionnaire. Primary outcomes include parental engagement (PREEMI score) and parental stress (PSS:NICU score). Secondary outcomes will include length of stay, breastfeeding/breastmilk use, parent satisfaction, skin-to-skin frequency, visitation frequency, visitation duration, and journal use. The outcomes were analyzed using Wilcoxon's rank sum test, Pearson's chi-square tests, and Fisher's exact tests as appropriate. Generalized linear mixed effect models will be used to assess the changes in primary outcomes while adjusting for potential confounders.

Results: We enrolled 21 family units (25 individuals) with 11 family units (14 individuals) randomized to the journal group and 10 family units (11 individuals) to the control group (Tables 1 & 2). There was no difference in the primary outcomes (PREEMI and PSS: NICU scores; Tables 3 & 4). There was a trend toward increase in visitation frequency (median 7.0 d per wk journal [IQR 6.2-7.0] vs. 6.0 d per wk control [4.5-7.0]; p = 0.11) and decreased infant length of stay in the journal group (median 25 d [IQR 24-38] journal vs. 55 d [IQR 36-67] control; p = 0.01). There was an increase in parental comfort taking their child home in the journal group (Fig. 1 [Q4]; p = 0.03) and trend toward increased breastmilk usage at discharge (Fig. 2; p = 0.15). Most parents in the journal group stated the journal enhanced their NICU stay and all recommended that any parent with a child in the NICU should use the journal (Fig. 3).

Conclusions: This is the first study that we are aware of to assess the impact of using a journal with prompts designed to mitigate stress and promote engagement. Limitations include a high loss-to-follow up rate, inability to blind investigators, and small sample size. As a pilot study, this study was not powered adequately to establish statistically significant differences in the primary outcome, the intervention was well-received and demonstrated feasibility for a future larger-scale study. Moreover, the intervention was found to enhance multiple dimensions of parental engagement as defined by Samra et al. (Fig. 3). These improvements may still have contributed to increased engagement that was not adequately captured by the primary outcome due to the inherent limitations of survey-based assessments.

Impact: This specific journal may offer a low-cost intervention to improve parental stress and engagement, potentially leading to significant improvements in neonatal and family-centered outcomes.

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Learner Objectives:

1. Review the various domains of parental engagement and significant family stressors experienced during a NICU stay, and explore how the journal intervention addressed these challenges.

2. Analyze the study design and results of this pilot randomized controlled trial (RCT).

3. Discuss the broader implications of the study findings and consider potential future directions for research and practice.

Gravens 2025-3

Abstract Title: Case managers at the NICU: Family Integrated Care, follow Up for mother and child

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Problem Statement: Parents with a (threatened) premature birth (specifically below 32 weeks gestational age) end up on a roller-coaster and are confronted with many disciplines. It is important that all these disciplines work together in the right way to generate better care and continuity, so that the (future) parents can be parents as much as possible. Based on the desire to streamline this care, the care providers involved at Maastricht UMC+ MosaKids children's hospital have developed the preterm birth care path within the Family Integrated Care. We also developed a follow up for mothers. At the age of 6 months post term of the child will start with the NICU follow-up program and the mother will start her own follow-up program. She has an appointment with a gynecologist. Mother and Child have combined appointments at the outpatient clinic.

Abstract:

1. What methods did you use to solve or research the problem? In the first phase of the development of the care path, we looked for points for improvement or bottlenecks by means of a strengths-weaknesses analysis. We considered the current and the desired situation. A patient journey, an employee journey and a stakeholder analysis were performed.Based on the results of this, the implementation of a new function named 'case manager' was made possible.

2. Materials used N/A

3. How did you collect your data?To collect data for the patient journey interviews were conducted with parents of children admitted to NICU from 2020 until now. In the employee journey all steps of the care path were discussed. A large poster with post-it was used, nurses and doctors from delivery room as well as NICU, were invited to share their 'tips and tops' on every step of the care path. About 90 nurses and 20 doctors participated in the employee journey. Stakeholder analysis was performed under a selected group of different specialties such as 4 gynecologists and 4 neonatologists form other hospitals with whom we collaborate and also 6 midwifes who have their practice in the region of the hospital. Social workers, psychologists and physical therapists from our hospital. This brings the whole number to 22 stakeholders who completed the questionnaire sent by email.

4. (Sample size N/A)

5. Data obtained was qualitative, collected by questionnaires and interviews.

6. What were the main outcome measurements? - Quality of care improvement- Patient satisfaction- Reduction of workload for nurses, doctors and paramedic team.

Impact and results:

1. UMC+ MosaKids children's hospital is the first hospital in the Netherlands where case management is integrated in the Family Integrated care for preterm infants, the mother follow-up is the first outpatient clinic in the region combined with the child's follow-up at 6 months. Initially started as a pilot and has become a permanent part of perinatal care at Maastricht UMC+ MosaKids children's hospital since 2022. Surveys show that both patients and staff are positive about the added value of case managers in this specific care, and the mother's follow-up is seen as a great added value. We have the ambition to evaluate this in the future by means of qualitative scientific research. One of the major bottlenecks for patients was the communication and timing of transfer to other hospitals. We incorporated (online) meetings between doctors, nurses and parents to improve this.

2. No evidence-based results available at this time, only best practice. We intend to make the preterm birth care path evidence based through qualitative scientific research.

Conclusions:

Through the use of case managers in the preterm birth care path, continuity is guaranteed, from the moment of admission of a mother with a threatened preterm birth, during the admission to the NICU and the follow-up process until the child is 8 years old at the outpatient clinic. And with the mother follow up, mothers are more satisfied, because they have been able to ask all questions about the premature birth and they view a possible next pregnancy positively, possibly with the right guidance at the time.

Barriers to implementation and how they have been overcome: During the pilot we had to convince the Board of Directors that this care path with two case managers was necessary to provide good care for this vulnerable group of patients. To demonstrate the value of the case managers, questionnaires were created for parents, nurses and doctors. The result was presented to the Board of Directors after which the pilot of two case managers was converted into a permanent position in the care path. We had to convince colleagues in the two departments of the added value of case managers. Nurses preferred a nurse colleague instead of two case managers but it turns out that the case managers ensured that the workload was lower for nurses and doctors. We also had to convince the Board of Directors off the mother follow-up. Because this entails additional costs for the mother. This does not fall under prenatal care but must be paid for by themselves, and additional time, space and a gynecologist had to be scheduled.

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Learner Objectives:

- Better communication and cooperation within the care path improves care for preterm infants and their parents
- The case manager is the key figure within the care path; making a bridge between patients and care providers
- Mothers can ask all questions related to their premature birth and a possible new pregnancy. In addition, an internal inspection can take place if desired

Gravens 2025-4

Abstract Title: Using Transcutaneous Bilirubinometry to Reduce Iatrogenic Blood Loss in the NICU

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Problem Statement: The purpose of this quality improvement project is to reduce iatrogenic blood loss among premature infants 30-34 weeks' gestation in the NICU by using transcutaneous bilirubinometry to monitor hyperbilirubinemia.

Abstract:

Introduction: Premature infants are at higher risk of anemia compared to full term infants due to more frequent blood sampling, shorter life span of their red blood cells, and lower iron stores. Mitigating iatrogenic blood loss while still providing adequate monitoring of laboratory values should be a top priority in this population. Bilirubin is the only value that can be approximated non-invasively, but it was previously thought that it could only be measured transcutaneously on infants 35 weeks' gestation and older. However, recent research endorses the use of transcutaneous bilirubinometry in the premature population, even if there is a history of phototherapy, as long as safeguards are in place. Data collected during project development revealed that over a three-month period, infants 30-34 weeks' gestation lost an average of 6.8 milliliters of blood secondary to total serum bilirubin (TSB) levels. Prior to implementation, less than 20 percent of the bilirubin measurements that were done in infants 30-34 weeks' gestation were transcutaneous (TcB), and no TcBs were done on infants who had been exposed to phototherapy.

Purpose: The purpose of this ongoing quality improvement project is to reduce iatrogenic blood loss among premature infants 30-34 weeks' gestation in the NICU by using transcutaneous bilirubinometry to monitor hyperbilirubinemia.Methods: For this 15-week quality improvement project, an evidence-based transcutaneous bilirubin monitoring guideline was created and implemented in a suburban level III NICU. The guideline is a clinical pathway that assists the ordering provider in entering the appropriate standing TcB order during admission of an eligible

infant. To be eligible, an infant must be born between 30 and 34 weeks of gestation and must have a negative direct antigen test (DAT). Infants with an ABO incompatibility were included if they were DAT negative, and per the guideline would have TcB measured every 12 hours instead of every 24 hours. All results automatically plot on the bilirubin nomogram that is already integrated within Epic and corresponds with the infant's gestational age. The guideline specifies that a TSB is indicated if the TcB is within 3 mg/dL of the light level or if it is greater than 15 mg/dL. If an infant requires phototherapy, TcB levels are temporarily suspended until phototherapy has been discontinued for at least 24 hours. At that time, TcB monitoring could be resumed on unexposed skin, such as the buttocks. A chart audit tool was created within REDCap, a HIPAA-compliant web application that securely stores confidential patient data and is accessible by virtual private network. Data is collected by the project lead each week via chart review for a total of 14 weeks from September 1st through December 7th. The data being collected is quantitative and will be analyzed within REDCap and Excel.

Preliminary Results: Since guideline implementation, data collected to date shows that the average blood loss per patient secondary to serum bilirubin levels has decreased from 6.8 milliliters (n=12) to 1.1 milliliters (n=4). Active orders have been compliant with the guideline 90 percent of the time. At this time, 19 bilirubin measurements have been done, 53 percent of which were transcutaneous.

Preliminary Conclusions: The preliminary data from this quality improvement project is very promising for mitigating iatrogenic blood loss in this population. Blood loss secondary to TSB levels is down 84 percent from pre-implementation data, while provider compliance with the guideline is currently 90 percent. These percentages are expected to vary throughout the project as more patients are admitted and different providers are on service, but it is strong evidence for the efficacy of guideline implementation. There was some initial pushback on lowering the gestational age limit of the transcutaneous bilimeter, but because the unit and its staff value evidence-based practice, discussion and presentation of current evidence helped facilitate buy-in.

Implications for Practice: Transcutaneous bilirubin monitoring is significantly cheaper, safe, and supports patient-centered care by decreasing painful heel sticks. Though the project unit does not historically administer many blood transfusions, any decrease in blood loss decreases the workload of these premature infants. Creating and implementing a quality improvement initiative highlights the importance of a thorough evaluation and understanding of the implementation environment to ensure success of the initiative. The skills developed during the project will help inform future involvement in quality improvement efforts as a neonatal nurse practitioner.

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Learner Objectives:

1. Why are premature infants more prone to anemia?
2. List 3 benefits of implementing TcB monitoring in premature infants.

Gravens 2025-5

Abstract Title: Hospitable NICUs - Promoting healing and flourishing for infants, families, and staff through hospitable welcome and care

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Problem Statement:

1. While NICU design has contributed to improved infant outcomes and parent experiences, less attention has been given to the healing potential of welcoming and safe relational space within the NICU.
2. How does the ancient practice of hospitality provide a lens through which to assess physical and relational spaces in the NICU, and inform the creation of a safe, therapeutic space for infants, families, and staff?

Abstract:

Background/Purpose: Research supports that an optimal physical environment promotes neuroprotection and improved neurodevelopmental outcomes for NICU infants. While much focus has been on designing the physical space of NICUs, less attention has been given to creating a welcoming environment that fosters healing through safe relational spaces. Hospitality has long been regarded as a virtue and a moral duty. Historically, hospitality involved welcoming strangers into a private home, providing them with physical, emotional, and sometimes spiritual care. The concept of hospitality is equally relevant in healthcare, as the first hospitals emerged out of private, home-based care of the sick. Viewing NICU care through the lens of hospitality, healthcare providers act as both hosts and guests. As hosts, they welcome and care for patients and families, but as guests, they are invited into the personal world of the patient and family. Hospitality also extends to healthcare providers interacting with one another as both hosts and guests, creating safe spaces for collaboration and mutual growth. In a hospitable NICU, both physical and relational spaces are intentionally designed to promote safety and healing not only for infants and their families but also staff members. A hospitable NICU integrates physical design and relational care to create a space where infants, families, and staff can thrive. While the primary goal of hospitable care is directed toward infants and their families, creating a hospitable environment for staff can also improve team collaboration, morale, and retention.

Problem Statement: NICU design has improved significantly over the past two decades, yet a focus on the physical space alone is insufficient to meet the needs of infants or their families.

Hospitable NICUs provide holistic care that addresses physical, emotional, and spiritual needs while fostering a high-functioning healthcare team. This approach aligns with trauma-informed care principles, which emphasize the need for healing environments that encompass both physical and relational spaces. However, creating such a hospitable environment in the NICU is challenging. Limited physical space can negatively impact a family's sense of privacy and relaxation, making it difficult for them to feel at home or participate in the care of their infant. The sensory environment may be noxious for the infant, and high acuity levels, heavy workloads, and strained team dynamics can hinder the creation of safe relational spaces for both families and staff. To address these challenges, four key questions arise: How do parents and staff experience welcome (or unwelcome) in both the physical and relational spaces of the NICU? How can hospitality provide insights that guide staff in forming welcoming, safe spaces for infants and families? How does a hospitable environment reduce stress and promote healing for families in the NICU? How does hospitality inform the creation of safe relational spaces for staff, contributing to high-functioning healthcare teams?

Methodology: This ongoing Quality Improvement (QI) project seeks to understand how both parents and staff experience the NICU environment and identify areas that need improvement to create a more hospitable space. The first phase of the project involved collecting surveys from parents and staff regarding their perceptions of the physical and relational environment within the NICU. These surveys were analyzed for recurring themes, which were then used to develop action steps aimed at improving the sense of welcome and care for families. Future phases will focus on staff experience. Surveys will explore how staff perceive relational safety within team meetings, collaboration, and other interactions. The goal is to understand how hospitable or inhospitable environments impact staff morale, mental health, and their ability to provide care. Action steps will be taken to promote a more hospitable work environment for the healthcare team.

Results: The initial survey revealed two key themes: physical and relational space. While parents highlighted the importance of a private, clean environment that allows for kangaroo care and parent-infant interaction; a higher emphasis was placed on the critical role of safe relational space. Parents identify staff warmth, compassion, communication, and involvement in decision-making as crucial to feeling safe and welcomed. In contrast, staff responses focused more on the physical space, citing heavy workloads and high acuity as barriers to creating meaningful relational connections with both families and colleagues.

Implications for Family Support: Hospitable NICU environments hold promise for improving family experiences and outcomes. A nurturing physical and relational environment promotes a sense of safety, reduces stress, and enhances parental caregiving. Such environments are conducive to healing for both infants and their families. Additionally, healthcare teams that operate in a hospitable environment are better equipped to provide compassionate, holistic care. When the NICU is both physically and relationally welcoming, it enhances the mental health of parents, infants, and staff.

Proposed Workshop Format: This workshop will engage participants through both teaching and interaction. It will begin with a brief didactic session to introduce key concepts of hospitality and how they create safe and healing spaces in the NICU. Following this, participants will engage in self-reflection and collaborative learning. Self-reflection stations will encourage attendees to consider the hospitable practices within their own NICUs and their personal roles in fostering such environments. In group discussions and brainstorming sessions, participants will explore strategies for implementing hospitable care practices in their NICUs. The workshop will conclude with actionable steps for creating more hospitable environments, allowing participants to leave with a clear process for implementation within their own settings.

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Learner Objectives:

Objective #1: Identify the unique features of hospitality which contribute to a healing environment for infants, families, and staff within the NICU.

Objective #2: Assess the ways in which your NICU is hospitable, and identify areas in which your NICU could become more hospitable.

Objective #3: Apply features of hospitable environments by exploring strategies that could be implemented within your NICU.

Gravens 2025-6

Abstract Title: H-HOPE (Hospital to Home: Optimizing the Preterm Infant Environment): Infant, Parent, and Parent-Infant Interaction Outcomes

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Problem Statement: Premature infants have subtle behavioral cues that are challenging for parents to read, interpret, and respond to their infant's behaviors. H-HOPE is a developmental program for fragile infants and their parents with a behavioral focus supporting parents to understand their infant's subtle behaviors and engage with them.

Abstract:

The purpose of the H-HOPE (Hospital to Home: Optimizing the Preterm Infant's Environment) program is to provide optimal developmental support to stable preterm infants and their parents. H-HOPE is an evidence-based standardized program with a behavioral focus that is based on supporting the development of infant sensory systems, infant behavior, growth, and parent engagement. It is offered while the infant is hospitalized and during the transition to home. H-HOPE is an integrated intervention that includes Massage+ (auditory, tactile, visual, and vestibular stimuli) twice daily and four parent teaching sessions by a nurse. The parent-focused component, Parents+, uses a participatory guidance approach to teach parents preterm infant behaviors, and cues while providing Massage+, the infant-focused component. Over the last 40 years, our team has conducted several randomized controlled trials (HD098095, NR232801, NR009418, HD050738)

to document infant, parent, and parent-infant interaction following H-HOPE. In each of the studies, infants meeting eligibility criteria (29-35 weeks gestational age and clinically stable) were randomly assigned to the attention control or intervention groups. Both quantitative and qualitative data were obtained. Data were collected from the infant's medical record, parent questionnaires, and parent interviews. Data represents a compilation of previous and current research. Outcomes measured from 400 parent-infant dyads included: infant behavioral state, the frequency of orally directed behavior prior to feeding, growth, sucking metrics, parent-infant interaction (via the Dyadic Mutuality Code and the Nursing Child Assessment Feeding Scale), length of hospital stay, cost of initial hospitalization and number of illness visits after hospital discharge. In some of the studies, parents were interviewed to document their experience of providing Massage+ to their infants. Quantitatively, infant risk factors were used to determine equivalency between the two groups prior to entry and as time constant covariates in the final analyses. Hypotheses concerning outcomes at one time point were tested using two-level Hierarchical Linear Modeling (HLM) analyses clustered within clinical sites. Hypothesized outcomes such as infant cognitive, language, and motor development apply to only one time point, while others such as infant health care utilization and health care costs were cumulative summary measures from birth through 6-weeks CA and were treated as one-time events. Other outcomes were measured repeatedly: parent-infant interaction, and infant motor development were measured twice, and infant outcomes from birth to hospital discharge were measured weekly during hospitalization. Here the hypothesized effect was that the initial level and/or the improvement in the outcome over time rises faster in H-HOPE than in the Control Group. These hypotheses were tested using HLM software in three-level, mixed-effect models, with time nested within individual parent-infant pairs, clustered within clinical sites. Results of several randomized controlled trials show that infants respond with significantly improved behavioral organization. This included an increased frequency of alert states ($p < .01$) and an increased frequency of orally directed behaviors prior to feeding ($p < .05$, and over days of intervention ($p < .01$)). Oral feeding efficiency improved over the first three oral feedings ($p < .001$). Additionally, a quadratic trend was observed for number of sucks, sucks per burst, and the sucking maturity index with the intervention group increasing significantly faster by day 7 of intervention (model estimates for group × day: $\beta = 13.69$, $p < .01$; $\beta = 1.16$, $p < .01$; and $\beta = 0.12$, $p < .05$, respectively). Sucking pressure increased linearly over time, with significant between-group differences at day 14 of intervention ($\beta = 45.66$, $p < .01$). Infant growth (weight ($p = .04$) and length ($p = .015$) improved over the course of hospitalization. Shorter length of hospital stay was identified for the intervention group when compared to the control group ($p < .05$). Cost of initial hospitalization was lower for H-HOPE group infants (mean H-HOPE charges were $10,185 lower than controls ($p = 0.012$). Propensity score matching showed the largest savings of $14,656 ($p = 0.003$) for H-HOPE infants, and quantile regression showed a savings of $13,222 at the 75th percentile ($p = 0.015$) for H-HOPE infants). Mother-infant interaction improved (Dyadic Mutuality Code, H-HOPE dyads had 2.37 times (95% CI: 0.97-5.80) higher odds of high versus low responsivity compared to control dyads; Nursing Child Assessment Feeding Scale ($p < .05$)). There were reduced visits for illness at 6-weeks corrected age following hospital discharge. H-HOPE infants were half as likely to have acute care episodes as control infants (odds ratio [OR] ¼ 0.46, 95% confidence interval [CI] [0.22, 0.95]). While this intervention has a positive impact on infant behavior, growth, development, health and parent-infant interaction, it also positively influences parents and the parent-infant relationship. Our team is currently funded by the National Institutes of Health to implement H-HOPE in 6 NICUs. Parent responses via interviews have been very positive. Parents consistently stated the bond that they experienced with their infant improved as a benefit of H-HOPE. Parents also reported increased confidence in handling their baby and H-HOPE helped them better understand their infant's cues. Barriers to implementation included challenges for parents to visit more frequently in the NICU, and for nurses to incorporate the H-HOPE intervention into their workflow. Parents identified nurse support and having additional interactions with the nurses as facilitators. Nurses and therapists are key to the successful implementation of the H-HOPE intervention, providing parents with the opportunity to develop confidence in caring for their infant. Engaging with parents as they learn about their preterm infant's behaviors and how they can read, interpret, and respond to their infant's behavioral cues promotes infant growth and development and improves parent-infant interaction.

Learner Objectives:

1. Participants will describe the two components of H-HOPE, Massage+ and Parents+.
2. Participants will cite the results from the H-HOPErandomized controlled trial and implementation research.
3. Participants will identify the impact of H-HOPE for infants, parents, and the parent-infant relationship.

Gravens 2025-7

Abstract Title: Start the Clock: Reducing First-Dose Antibiotic Administration Times in the NICU

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Problem Statement: This Quality Improvement project focuses on reducing the first-dose antibiotic administration times in a Level III NICU through the implementation of an antibiotic administration bundle that includes visual reminders, an algorithm, and increased collaboration between nursing and providers.

Abstract:

Problem: For infants in the Neonatal Intensive Care Unit (NICU), prompt recognition of neonatal sepsis and timely administration of antibiotics are crucial to improve patient outcomes, particularly in preterm infants. Adverse outcomes for delayed antibiotic administration can include an extended hospital stay, prolonged mechanical ventilation, and increased mortality, compared to infants without a sepsis diagnosis. Pre-implementation data was collected from the site, a Level III NICU, and showed an average first dose antibiotic administration time of 128 minutes, 68 minutes greater than the recommended timeline.

Purpose: This ongoing Quality Improvement project focuses on reducing the first-dose antibiotic administration times in a Level III NICU through the implementation of an antibiotic administration bundle that includes visual reminders, an algorithm, and increased collaboration between nursing and providers over a 15 week period.

Methods: To reduce the time to first-dose antibiotic administration in neonates, a visual reminder system was implemented in the NICU. This reminder was placed on admission beds, prompting

staff to "start the clock" when an infant is admitted to the unit. This visible cue ensures that all team members are aware of the time-sensitive goal for antibiotic delivery. Additionally, an algorithm was developed to prioritize obtaining IV access, outlining steps for both peripheral and central (umbilical) access. The algorithm specifies that, for infants weighing >1200g, nursing staff prioritize peripheral IV placement while providers focus on blood culture collection. In infants weighing ≤1200g, a conversation is required between nursing and provider to determine optimal IV access for the infant. If central access is obtained, the algorithm further describes the collaboration between nursing and providers to collect the blood culture and administer the prescribed antibiotic prior to x-ray confirmation of line placement. Weekly data collection is being conducted by the project lead through chart audits in the electronic medical record (EMR) and recorded into an electronic, HIPPA compliant audit tool. All newly admitted infant charts are screened for inclusion, and those with an order for Ampicillin are included in the data collection. At the time of this abstract submission, ten infants have been admitted to the NICU during the early implementation phase of the project. Of the ten infants, five infants were prescribed Ampicillin upon admission and were included in the data collection. Gestational ages ranged from 31 5/7 weeks to 40 5/7 weeks and birth weight ranged from 920g to 3725g. Quantitative data was collected and included the patient's last name, medical record number, date and time of birth, date and time of admission, gestational age, birth weight, type of IV access obtained, date and time IV access obtained, date and time blood culture obtained, and date and time of Ampicillin administration.

Preliminary Results: Preliminary data showed that two infants (40%) received Ampicillin within 60 minutes after admission. All infants had peripheral IVs placed and 60% of those infants had IV access established within 60 minutes after admission. All infants had a blood culture obtained prior to antibiotic administration and 40% of those infants had a blood culture obtained within 60 minutes after admission. The average administration time for Ampicillin has decreased by 25%, from 128 minutes to 97 minutes.

Preliminary Conclusion: While data collection is still in progress, initial trends suggest an improvement in the timeliness of first-dose antibiotic administration however, it is not yet possible to determine whether the antibiotic administration bundle has been successful. Evidence in the literature has shown that delayed antibiotic administration can negatively affect patient outcomes. Early data suggest that following an evidence-based algorithm for timely antibiotic administration may improve the time to first dose which may impact overall patient outcomes.

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Learner Objectives:

1. Understand the impact of timely antibiotic administration in the NICU population.

2. Describe the steps involved in this Quality Improvement project to decrease first dose antibiotic administration times.

Gravens 2025-8

Abstract Title: Family-Driven Feeding: A Quality Improvement Initiative

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Problem Statement: In the NICU, the transition from nasogastric ("gavage") feeds to breast/bottle feeds is led either by a doctor's prescription (example: offer the bottle or breast for 10 minutes two times per day) or by a nurse's assessment of the infant's feeding cues (i.e. Infant-Driven Feeding). However, neither approach involves the families who are the ones that need to learn when and how to feed their infant.

Abstract:

Methods: In March 2023, the Level IV NICU at the Montreal Children's Hospital (MCH) was awarded a $20,000 CAD grant to engage families in their infant's transition from gavage to breast/bottle feeds. A multidisciplinary committee, including a neonatologist, nurse educator, nurse, occupational therapist, nutritionist, lactation consultant and parent was formed. A literature review found that Infant-Driven Feeding (IDF), in which nurses introduce breast/bottle feeds based on the infant's cues, results in faster achievement of full breast/bottle feeds compared to relying on a medical order to advance breast/bottle feeds.

1. In the Cornell IDF tool, the nurse evaluates for 1) signs of breast/bottle readiness 2) the quality of breast/bottle feeds; and 3) the technique for feeding.

2. The MCH committee adapted the Cornell IDF tool to create Family-Driven Feeding, a simplified program that encourages families to perform the feeding assessments (Appendix 1). An infant's feeding readiness and quality are scored every 3 hours by the parent or nurse when the parent is absent. Previously, the MCH NICU relied on medical orders for the nurse to progress breast/bottle feeds. Infants can participate in Family-Driven Feeding if they are 1) ≥ 32 weeks corrected gestational age (CGA) (infants born at term are also eligible); 2) Stable in room air or low flow oxygen; 3) Tolerate gavage feeds; and 4) No other medical contraindication (Appendix 2). Clinical and outcome data as well as the feeding assessments are collected for each infant. Surveys have been obtained from nurses and parents. Descriptive analyses were performed, and future analyses will include a pre-post comparison using propensity-score matched controls to determine the clinical impact of Family-Driven Feeding.

Results: First, a multi-prong educational approach was undertaken. In April 2024, 84% (141/168 of nurses attended a session teaching them 1) how to assess feeding cues and 2) how to train parents to assess their baby's feeding cues. Second, a publicly-available eight minute video detailing how a parent or nurse can assess a baby's readiness and quality of breast/bottle feeds was created (Appendix 3). Third, an educational poster explaining infant feeding cues and signs of disengagement is placed in every baby's NICU room (Appendix 4). Fourth, stakeholders had the opportunity to share feedback during presentations about Family-Driven Feeding. Finally, ongoing bedside education and sporadic Family-Driven Feeding 'games' (example: nurses can enter a raffle when she teaches a parent to perform Family-Driven Feeding) ensure the project's sustainability. Data has been collected on 109 infants who were eligible for Family Driven-Feeding from April 2 - August 1, 2024. The median gestational age at birth was 33 weeks (IQR 30-36 weeks), 50% were male, and the primary reason for admission was prematurity (64%). At the time of discharge, 53% were receiving exclusive mother's milk. Thirty-three percent of infants were discharged home with a median CGA of 40 weeks (IQR 37-41 weeks), 30% of infants were transferred to the pediatric ward at the Montreal Children's Hospital with a median CGA of 38 weeks (IQR 36-39 weeks) and 34% of infants were transferred to a Level II NICU at another hospital with a median CGA of 34 weeks (IQR 34-35 weeks). Seventy-eight percent (85/109) of infants eligible for Family-Driven Feeding had feeding assessments performed. A total of 5,257 individual feeding assessments were recorded. Overall, 18% of feeding assessments were performed by parents (i.e. 1-2 feeds per day) with the remainder of evaluations being completed by the bedside nurse. From an individual patient perspective, parents performed a median of 6.5% of feeds (IQR 0%-20.8%) demonstrating the high level of variation between parents. Parents who provided their infants with breastmilk were more likely to participate in Family-Driven Feeding than parents who did not pump or breastfeed (p=0.01) Errors occurred in 5.5% of parental evaluations and 4.6% of nursing evaluations. Thirty-two nurses were surveyed in May 2024. Eighty-eight percent (n=28) believed that Family-Driven Feeding is important for patient care. Moreover, 94% (n=30) reported comfort in assessing an infant's feeding cues and 78% (n=25) felt comfortable teaching parents. Twenty parents who had been taught Family-Driven Feeding were also polled in May 2024. Ninety-nine percent (n=18) had completed at least one feeding assessment. Only three parents (15%) identified barriers to participating in Family-Driven Feeding. Another round of parental surveys is currently underway.

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APPENDIX 1 : Family-Driven Feeding Form

Infant Oral Feeding Assessment and Documentation Tool

Date (YYYY/MM/DD)									
Time (00:00)									
Assessment by: Parent (P) / Nurse (N)									
Readiness Score									
Quality Score									
Strategies (refer to legend)									
Breast / Nipple type									
Duration (minutes)									
Reason to stop (refer to legend)									
Quantity (mL)									
Top off by gavage (mL) / Over (min)									
Parent Initials									
Nurse Initials									

READINESS TO FEED SCALE

Score	Baby BEFORE the feed	Action	
1	Alert or fussy prior to care, or once handled, and sustained feeding cues: • Turns head and opens mouth (rooting), and/or • Hands to mouth, and/or • Takes pacifier	Put to breast	Offer bottle
2	Sleepy but responds to stimulation. Shows some feeding cues.		
3	Briefly alert during care or sleeps throughout care. Limited or no feeding cues.		No bottle
4	Drops in heart rate or oxygen level (apnea/bradycardia/desaturation). Fast breathing (tachypnea) or difficulty breathing with care	Gavage only	

Scan QR code to watch educational video

QUALITY OF FEEDING SCALE

Score	Baby DURING the feed		Action
1	Breast: Latch is deep and strong. Sucks, swallows, and breathes in a coordinated pattern. Drops chin to indicate swallowing.	Bottle: Bottles with a strong suck. Sucks, swallows, and breathes in a coordinated pattern.	Stop at signs of disengagement. Typically about 20 minutes.
2	Breast: Latch is shallow or weak, or frequent need to re-latch. Sucks on and off, may fall asleep.	Bottle: Bottles with a weak / inconsistent suck. Coordinated but tires. Takes breaks spontaneously or needs external pacing. May have some milk loss.	Stop at signs of disengagement. Typically about 10 minutes.
3	Either breast or bottle: Unable to latch or poor suck at the bottle. Unable to coordinate suck, swallow, breathe pattern (coughs, chokes). Drops in heart rate or oxygen level. Fast / difficulty breathing during feed. Large amount of milk lost. Very sleepy.		Stop immediately, complete by gavage.

LEGEND

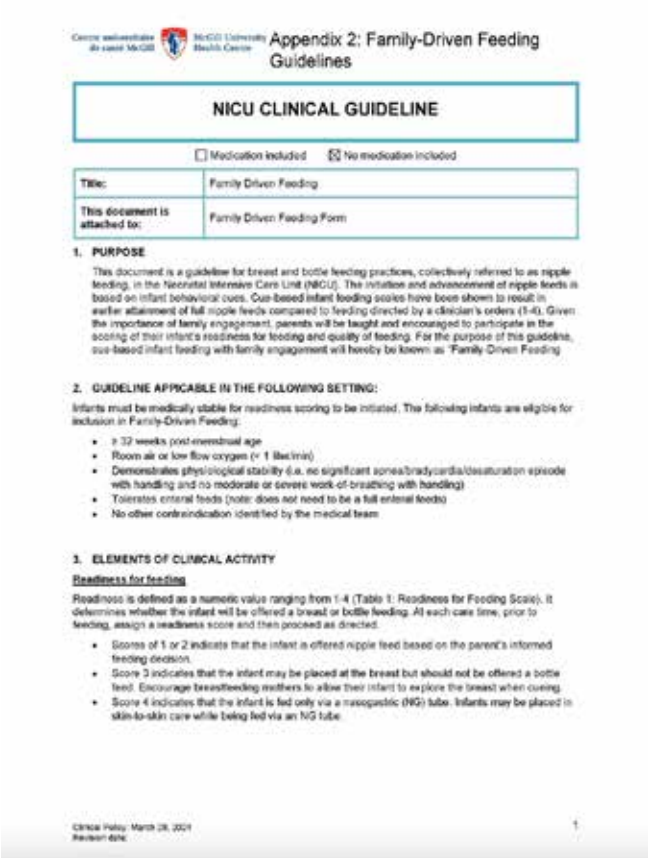
Strategies Needed
- Side-lying (S)
- Pacing (P)
- Breastfeeding reclined position (RP)
- Partial expression (E)

Breast or Nipple
- Breast (B)
- Dr Brown's™ (Dr)
- Ultra slow flow (USF)
- Slow flow (SF)
- Regular flow (RF)

Reason
- Fatigue (F) • Refusal (R)
- Event (Ev): cough, drops in heart rate or oxygen

Signature	Nurse/Parent	Initials	Signature	Nurse/Parent	Initials

DM- 5911 (REV 2024/02/20) Approbation CPRG (2024/01/10) CUDM Repro MUHC — Français au verso



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Appendix 2: Family-Driven Feeding Guidelines

NICU CLINICAL GUIDELINE

☐ Medication included ☒ No medication included

Title:	Family Driven Feeding
This document is attached to:	Family Driven Feeding Form

1. PURPOSE

This document is a guideline for breast and bottle feeding practices, collectively referred to as nipple feeding, in the Neonatal Intensive Care Unit (NICU). The initiation and advancement of nipple feeds is based on infant behavioral cues. Cue-based infant feeding scales have been shown to result in earlier attainment of full nipple feeds compared to feeding directed by a clinician's orders (1-4). Given the importance of family engagement, parents will be taught and encouraged to participate in the scoring of their infant's readiness for feeding and quality of feeding. For the purpose of this guideline, cue-based infant feeding with family engagement will hereby be known as "Family-Driven Feeding

2. GUIDELINE APPICABLE IN THE FOLLOWING SETTING:

Infants must be medically stable for readiness scoring to be initiated. The following infants are eligible for inclusion in Family-Driven Feeding:

- ≥ 32 weeks post-menstrual age
- Room air or low flow oxygen (< 1 lite/min)
- Demonstrates physiological stability (i.e. no significant apnea/bradycardia/desaturation episode with handling and no moderate or severe work-of-breathing with handling)
- Tolerates enteral feeds (note: does not need to be a full enteral feeds)
- No other contraindication identified by the medical team

3. ELEMENTS OF CLINICAL ACTIVITY

Readiness for feeding

Readiness is defined as a numeric value ranging from 1-4 (Table 1: Readiness for Feeding Scale). It determines whether the infant will be offered a breast or bottle feeding. At each care time, prior to feeding, assign a readiness score and then proceed as directed:

- Scores of 1 or 2 indicate that the infant is offered nipple feed based on the parent's informed feeding decision.
- Score 3 indicates that the infant may be placed at the breast but should not be offered a bottle feed. Encourage breastfeeding mothers to allow their infant to explore the breast when cueing.
- Score 4 indicates that the infant is fed only via a nasogastric (NG) tube. Infants may be placed in skin-to-skin care while being fed via an NG tube.

Clinical Policy: March 28, 2024
Revision date:
1

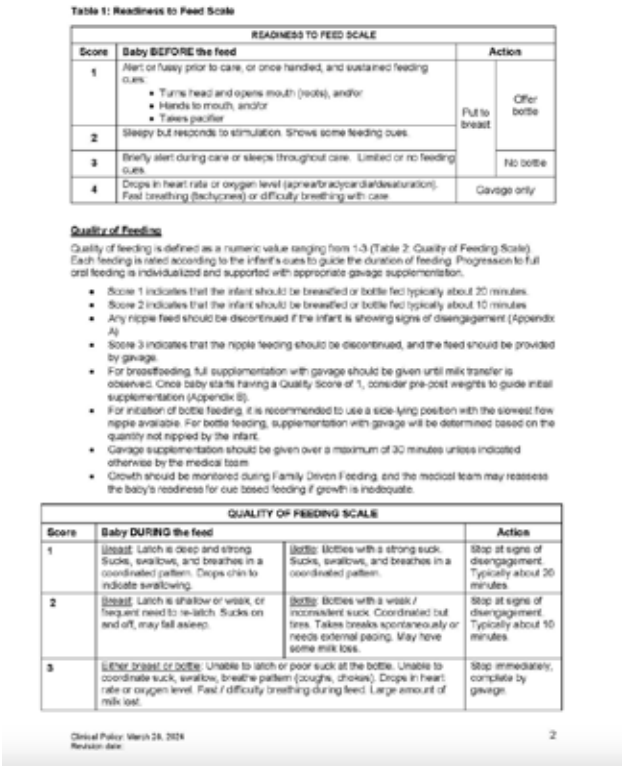

Table 1: Readiness to Feed Scale

READINESS TO FEED SCALE

Score	Baby BEFORE the feed	Action	
1	Alert or fussy prior to care, or once handled, and sustained feeding cues: • Turns head and opens mouth (rooting), and/or • Hands to mouth, and/or • Takes pacifier	Put to breast	Offer bottle
2	Sleepy but responds to stimulation. Shows some feeding cues.		
3	Briefly alert during care or sleeps throughout care. Limited or no feeding cues.		No bottle
4	Drops in heart rate or oxygen level (apnea/bradycardia/desaturation). Fast breathing (tachypnea) or difficulty breathing with care	Gavage only	

Quality of Feeding

Quality of feeding is defined as a numeric value ranging from 1-3 (Table 2: Quality of Feeding Scale). Each feeding is rated according to the infant's cues to guide the duration of feeding. Progression to full oral feeding is individualized and supported with appropriate gavage supplementation.

- Score 1 indicates that the infant should be breastfed or bottle fed typically about 20 minutes.
- Score 2 indicates that the infant should be breastfed or bottle fed typically about 10 minutes.
- Any nipple feed should be discontinued if the infant is showing signs of disengagement (Appendix A)
- Score 3 indicates that the nipple feeding should be discontinued, and the feed should be provided by gavage.
- For breastfeeding, full supplementation with gavage should be given until milk transfer is observed. Once baby starts having a Quality Score of 1, consider pre-post weights to guide initial supplementation (Appendix B).
- For initiation of bottle feeding, it is recommended to use a side-lying position with the slowest flow nipple available. For bottle feeding, supplementation with gavage will be determined based on the quantity not nipped by the infant.
- Gavage supplementation should be given over a maximum of 30 minutes unless indicated otherwise by the medical team
- Growth should be monitored during Family Driven Feeding, and the medical team may reassess the baby's readiness for cue based feeding if growth is inadequate.

QUALITY OF FEEDING SCALE

Score	Baby DURING the feed		Action
1	Breast: Latch is deep and strong. Sucks, swallows, and breathes in a coordinated pattern. Drops chin to indicate swallowing.	Bottle: Bottles with a strong suck. Sucks, swallows, and breathes in a coordinated pattern.	Stop at signs of disengagement. Typically about 20 minutes.
2	Breast: Latch is shallow or weak, or frequent need to re-latch. Sucks on and off, may fall asleep.	Bottle: Bottles with a weak / inconsistent suck. Coordinated but tires. Takes breaks spontaneously or needs external pacing. May have some milk loss.	Stop at signs of disengagement. Typically about 10 minutes.
3	Either breast or bottle: Unable to latch or poor suck at the bottle. Unable to coordinate suck, swallow, breathe pattern (coughs, chokes). Drops in heart rate or oxygen level. Fast / difficulty breathing during feed. Large amount of milk lost.		Stop immediately, complete by gavage.

Clinical Policy: March 28, 2024
Revision date:
2

Supporting Breastfeeding

Offer mothers a period of time when all oral feeding occurs at the breast to support their breastfeeding goals if they are able to be present. This can be considered a period of protected breastfeeding time during which all oral feeding occurs at the breast, supplementation occurs via NG tube and bottles are not offered.

- Infants should be offered 3-5 days of exclusive breastfeeding once scores for readiness begin. The mother needs to commit to being present for an average of at least 2 breastfeeds per day if protected breastfeeding time is offered. The remainder of the feeds when the breastfeeding parent is not present would be given by gavage.
- If the parent intends to breastfeed but cannot be present, a discussion with the medical team regarding barriers to presence and the possibility of earlier introduction of bottles should occur.
- At the end of the designated protected breastfeeding time, the parents and interdisciplinary team will discuss whether to continue exclusive breastfeeding or to include bottle feeding.

Occupational Therapy

Evaluation by an occupational therapist (OT) is not necessary prior to starting Family Driven Feeding. Specific to Family Driven Feeding, OT should be consulted for the following scenarios:

For 2 consecutive days, if

Readiness
- Score 3 or 4 for > 50% of feeds at ≥36 weeks corrected gestational age OR
- Score 2, 3 or 4 for ≥ 50% of feeds at ≥38 weeks corrected gestational age OR

Quality
- Score 3 on ≥1 feed at ≥36 weeks corrected gestational age despite use of slowest flow nipple and feeding strategies OR
- Score 2 or 3 on ≥1 feed at ≥38 weeks corrected gestational age despite use of slowest flow nipple and feeding strategies

Documentation

Each feeding assessment needs to be documented on the Family Driven Feeding documentation form (Table 3: Documentation). Assessments should occur at care times but may become more frequent if the baby is waking to breastfeed more often.

- The parent should complete the documentation form if they perform the assessment. The nurse should complete the documentation form if they perform the assessment. The nurse and parent should sign and initial at the bottom of the form.
- The following items are to be documented: date, time, whether the parent or nurse completes the assessment, the Readiness score, the Quality of Feeding score, strategies implemented (i.e. side-lying, pacing and/or breastfeeding repositioning), duration of feed, quantity of feed, and the nipple used (breastfeeding or specific type of bottle nipple).
- Even if the baby is not offered a nipple feed, the Readiness score should still be documented for every feed.

Table 3: Documentation

Date (dd/mm/yy)										
Time (00:00)										
Assessment by: Parent (P) / Nurse (N)										
Readiness score										
Quality score										
Strategies (refer to legend)										
Breast / Nipple type										
Duration (minutes)										
Quantity (mL)										
Top off by gavage (mL)										
Parent initials										
Nurse initials										

Feeding Progression

- Infants showing breastfeeding or bottling 75% of expected feeds for 48 hours should be considered for a trial of ad lib-demand feeding. The NG tube should be discontinued at this time.
- Family Driven Feeding scoring and documentation should continue for the first 24 hours of ad lib demand feeding and can then be discontinued if the feeding quality is maintained.
- Prior to discharge, the infant must show adequate growth, maintain feeding quality, and feed at least 6-8 times in 24 hours.

4. MAIN AUTHOR:

Jessica Duby – Neonatologist, Montreal Children's Hospital, MUHC

5. CONSULTANTS (listed in alphabetical order):

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Ashley Cox – NICU Veteran Parent, Montreal Children's Hospital, MUHC
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Elissa Remmer – NICU Nurse Educator, Montreal Children's Hospital, MUHC
Mara Bellemare – Neonatologist, Montreal Children's Hospital, MUHC
Nathalie Andreos, nutritionist, Montreal Children's Hospital, MUHC

6. SPECIAL CONSIDERATIONS

None

7. APPROVAL PROCESS

Institutional and professional approval

Committees	Date (yyyy-mm-dd)
☒ NICU Multidisciplinary FDF Committee	2024-03-28
☒ Pediatric Clinical Practice Review Committee (CPRC) (if applicable)	
☐ Pediatric Pharmacy and Therapeutics (Pedi P&T) (if applicable)	

8. REVIEW DATE

To be updated in maximum of 4 years or sooner if presence of new evidence or need for practice change.

9. REFERENCES

1. McCain GC, Gartside PS, Greenberg JM, Lott JW. A feeding protocol for healthy preterm infants that shortens time to oral feeding. J Pediatr. 2001;139(3):374-9.
2. Kirk AT, Alder SC, King JC. Cue-based oral feeding clinical pathway results in earlier attainment of full oral feeding in premature infants. J Perinatol. 2007;27(9):572-8.
3. Puckett B, Grover VK, Holt T, Sankaran K. Cue-based feeding for preterm infants: a prospective trial. Am J Perinatol. 2008;25(10):623-8.
4. Wellington A, Perlman JM. Infant-driven feeding in premature infants: a quality improvement project. Arch Dis Child Fetal Neonatal Ed. 2015;100(5):F495-500.

Version History (for Administrative use only)			
Version	**Description**	**Author/responsable**	**Date**
1	FDF Guideline	Jessica Duby	2024-03-28

Appendix B: Breastfeeding Pre-Post Test Weights

Purpose: Calculate milk transfer from the breast to adjust NG supplementation
Note: Evidence remains mixed about the accuracy of milk transfer, largely due to differences and consistency in technique (1-5).

Timing: Consider using test weights to guide initial NG supplementation when infant starts scoring a Quality Score of 1

Procedure:
- Have stand-alone scale ready in patient's room.
- Unplug monitor leads.
- Keep baby's diaper on.
- Weight baby with monitor leads placed inside the scale with diapered baby.
- Give baby to parent to breastfeed.
- Weigh the baby the same way after feeding (i.e. with same diaper on and leads unplugged and put inside the scale with the baby.)
- Calculate feed volume: (post fed weight – pre feed weight = breast milk volume transferred) 1g = 1ml
- Supplement remaining feed volume via gavage.

Additional practice points:
- Initially, test weight may be needed for each breastfeed while feed volumes are fixed.
- As baby becomes more consistent in his/her breastfeeding abilities and feed volumes become less strict, test weight can be reduced to once every few days as a spot check, and NG supplementation can be estimated.
- Once NG has been removed stop test weights and feed ad lib.

Note: It is advised to take parental preference into consideration when deciding when and if to use test weights. Some parents may need a longer period to transition off of use test weights while others will not want them at all. Options can always be discussed with the medical, nursing, nutrition, and lactation teams.

References:

1. Ericson J, Flacking R. Estimated breastfeeding to support breastfeeding in the neonatal intensive care unit. J Obstet Gynecol Neonatal Nurs. 2013; 42(1):29-37.
2. Funkquist EL, Tuveme T, Jonsson B, Serenius F, Nyqvist KH. Influence of test weighing before/after nursing on breastfeeding in preterm infants. Adv Neonatal Care. 2010;10(1):33-9.
3. Haase B, Barreira J, Murphy PK, Mueller M, Rhodes J. The development of an accurate test weighing technique for preterm and high-risk hospitalized infants. Breastfeed Med. 2009;4(3):151-6.
4. Rankin MW, Jimenez EY, Caraco M, Collinson M, Lostetter L, DuPont TL. Validation of Test Weighing Protocol to Estimate Enteral Feeding Volumes in Preterm Infants. J Pediatr. 2016;178:108-112.
5. Savenije OE, Brand PL. Accuracy and precision of test weighing to assess milk intake in newborn infants. Arch Dis Child Fetal Neonatal Ed. 2006;91(5):F330-2.

Appendix 3: Link to Family-Driven Feeding Educational Videos

English
https://youtu.be/JERgSccLxOI
French
https://youtu.be/PxUhuKb1mA

Conclusions: Engaging NICU families to participate in their infant's transition from gavage to breast/bottle feeds is a feasible intervention. Family-Driven Feeding was a culture shift for the MCH NICU which had previously relied on medical prescriptions to initiate and advance breast/bottle feeds based on the doctor's

perception of the infant's clinical stability during medical rounds. After four months of education and implementation, parents are now assessing their infant's feeding cues 1-2 feeds per day with nurses performing the evaluations for the remainder of feeds. However, there is significant variability in parental participation. Despite initial reluctance, survey data demonstrate that nurses perceive Family-Driven Feeding as important for patient care. While the current rate of parental assessments is an important first step, further PDSA cycles will target methods for increasing the number of parental feeding assessments.

Impact: Achievement of breast/bottle feeds has been shown to impact length-of-stay in the NICU.3 Engaging families in the transition from gavage to breast/bottle feeds has the potential to expedite discharge. Future analyses will compare the clinical outcomes of infants' enrolled in Family-Driven Feeding to infants hospitalized during the pre-intervention period. We have designed Family-Driven Feeding to inspire adaptations that ensure a good fit between intervention and context. For example, at the MCH NICU, approximately 66% of our patients are transferred to another ward or hospital prior to discharge home. Therefore, for our Family-Driven Feeding Program to reach maximum success, it is important for us to engage our hospital's pediatric wards and community hospitals. Similarly, we encourage other NICUs to use Family-Driven Feeding as a template that can be adapted to their specific needs.

References:

1. *Kirk AT et al. J Perinatol. 2007;27(9):572-8.*
2. *Wellington A, Perlman JM. Arch Dis Child Fetal Neonatal Ed. 2015;100(6):F495-500.*
3. *Eichenwald EC et al. Pediatrics. 2001;108(4):928-33.*

Learner Objectives:

At the end of this presentation, participants will be able to:

1. Describe the importance of family engagement in the transition from gavage feeds to breast/bottle feeds in the NICU
2. Appraise the Family-Driven Feeding initiative started in the NICU at the Montreal Children's Hospital in April 2024
3. Adapt the Family-Driven Feeding program to the culture and needs of different NICUs

Gravens 2025-9

Abstract Title: Line insertion through a long umbilical stump, a concept generating laboratory study

Authors: Itamar Nitzan MD; Yshia Langer MD; Yair Kasirer MD; Liat Nasich MD; Robert Koppel MD; Francis B. Mimouni ND; Anup V. Katheria MD

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Problem Statement: Current methods for venous line securement are commonly performed during the golden hour after birth and often cause significant pain or discomfort to the baby.. We hypothesized that a 10-20 cm portion of the umbilical cord can be catheterized with the use of an appropriate guide wire. This may help in establishment of secure vascular access with minimal (if any) discomfort

Abstract:

Background: Preterm neonates require early Intravenous (IV) fluid. This typically requires percutaneous insertion of an IV cannula which is technically challenging and involves pain for the baby. Not infrequently, several attempts and multiple skin breaks are needed. Skin breaks are associated with adverse neurodevelopmental outcome in preterm neonates (Duerden 2020), and when performed during transition of extreme preterm, may increase the risk for intraventricular hemorrhage. For umbilical line insertion, the abdomen of the baby is commonly disinfected with agents that may cause skin irritation and burns and involves discomfort that is considered harmful for preterm infants. It has been shown that the umbilical vein (UV) can be temporarily canulated with a needle to allow caffeine administration in the delivery room (Dekker 2017). We hypothesized that a 10-20 cm portion of the umbilical cord can be catheterized with the use of an appropriate guide wire. This may assist in achieving secure vascular access with minimal (if any) baby discomfort (figure 1). In addition, we hypothesized that a Venflon catheter can be inserted into the UV to enable rapid fluid administration.

Methods: A laboratory proof of concept study, performed on umbilical cord segments removed from babies after delivery. We attempted to catheterize a long portion of the UV. In phase 1, we determined which of several different techniques was optimal for UV catheterization. In phase 2, we documented the rate of successful cannulation and catheter advancement using this method. Umbilical cord segments were obtained as follows: Following maternal consent, we asked obstetricians to preserve an extended length of cord connected to the baby. We applied three clamps to the cord, and we were able to cut the cord and remove the surgical clamps while maintaining the UV distended with blood in a long portion of the cord between the two clamps (Fig. 2). In phase 2, the cannulation procedure was as follows: 1. The UV was cannulated with a Venflon; 2. A guidewire micropunture introducer set 0.18"/40cm or the 60 CM Cope Mandril wire guide (Cook Medical Bloomington Indiana, USA) was introduced and advanced until resistance was felt; 3. The insertion point was dilated with a dilator; 4. The dilator was removed, and the line was advanced upon the guide wire; 5. If the guidewire was stuck at a point of resistance less than 20 cm from cannulation point, further attempts to advance the guidewire after inserting the line were performed (Fig. 3). After advancing the line, to confirm the location within the blood vessel, we cut the cord before the proximal clamp and advanced the line through the proximal orifice of the vessel, and visually confirmed that it was within the vessel and whether the vessel was a vein or an artery. Two senior physicians visually confirmed whether the line was within the vessel or in a false lumen.

Results: We succeeded in advancing the catheter from the point of insertion to the proximal end of the cord, an average distance of 15.7±3.5cm, in 7 out of 10 cord segments. Venflon insertion into the UV was successful in all 10 cords. The Venflon can be easily taped and secured to cord clamp applied on the cord distal to the Venflon insertion point.

Conclusions: It is possible to advance a catheter within the umbilical vein through a long segment of umbilical cord. Larger laboratory studies are needed to determine parameters, such as the degree of UV coiling, that may influence success or failure of the method. Clinical studies are required to evaluate whether

this method may facilitate insertion of UV catheters with minimal discomfort for the babies.

Impact: Even short duration use of the proposed lines or Venflon secured to the umbilical cord, may postpone skin breaks for vascular access beyond the first golden hours after birth. Furthermore, this method may allow earlier administration of caffeine, dextrose, and antibiotics.

Figure 1: Schematic drawing of the suggested method of long segment umbilical vein cannulation. The sterile field will be only around the insertion point and not in proximity to the baby.

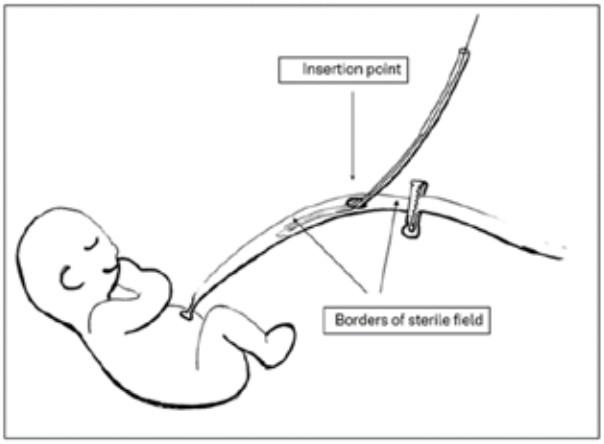


Figure 2: Sourcing of the long segment of the cord without blood spillage and vessel collapse.

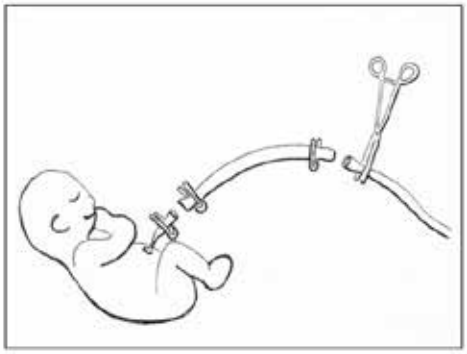
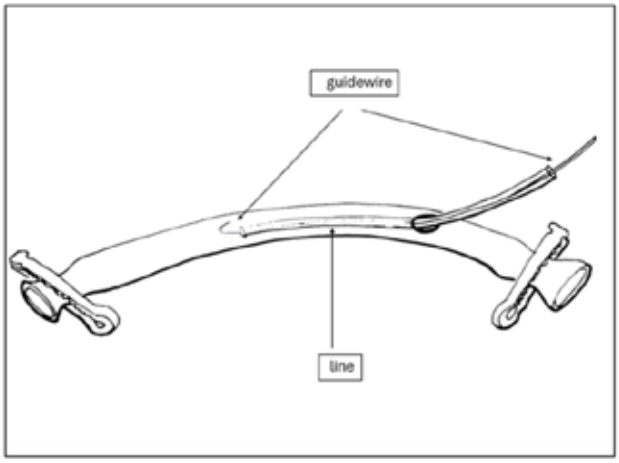


Figure 3: Schematic drawing of long segment umbilical vein cannulation during the study, with a line a guidewire.



Learner Objectives:

1. To recognize the problem of performing painful and uncomfortable procedures on preterm babies after birth.
2. To learn about a novel method for painless neonatal vascular access that may eliminates skin breaks.
3. To be encouraged to seek novel ways or procedures modifications to minimize pain during procedures.

Committees	Date [yyyy-mm-dd]
☒ NICU Multidisciplinary FDF Committee	2024-03-28
☒ Pediatric Clinical Practice Review Committee (CPRC) (if applicable)	
☐ Pediatric Pharmacy and Therapeutics (Peds P&T) (if applicable)	

8. REVIEW DATE

To be updated in maximum of 4 years or sooner if presence of new evidence or need for practice change.

9. REFERENCES

1. McCain GC, Gartside PS, Greenberg JM, Lott JW. A feeding protocol for healthy preterm infants that shortens time to oral feeding. J Pediatr. 2001;139(3):374-9.
2. Kirk AT, Alder SC, King JD. Cue-based oral feeding clinical pathway results in earlier attainment of full oral feeding in premature infants. J Perinatol. 2007;27(9):572-8.
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Version History (for Administrative use only)			
Version	Description	Author/responsable	Date
1	FDF Guideline	Jessica Duby	2024-03-28

Gravens 2025-10

Abstract Title: Assessing perceived safety and convenience of use of the Skincubator 2.0 (a device for prolonged skin-to-skin-care for extreme preterm infants) in a structured manikin simulation in a tertiary NICU in Australia.

Authors: Emma Yeomans, Shannon Paton, Elly Kuipers, Arvind Sehgal MD, Calum Roberts, Lindsay Zoe, Itamar Nitzan

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Problem Statement: Skin-to-Skin-Care (SSC) is an integral component of kangaroo mother care (KMC) and has been shown to reduce morbidity and mortality in preterm infants. However, transferring from the incubator to the parent and ongoing care during SSC for a critically ill preterm infant with multiple lines for vascular access may be challenging. While not supported by data, common concerns may be the risks of hypothermia and line dislodgment during SSC. We hypothesized that the Skincubator 2.0 will be rated by the nursing staff as safer, with less handling and as more convenient option during the provision of KMC, compared to the traditional method SSC.

Abstract:

Background: Skin-to-Skin-Care (SSC) reduces morbidity and mortality in preterm neonates. However, extreme preterm neonates are generally ineligible for early, prolonged SSC for

several reasons, including the need to regulate humidity levels using traditional incubators, concerns of line dislodgment and the need for nurses to evaluate the baby and perform cares and nursing procedures. To enable continuous SSC in this population we invented the Skincubator a novel, small incubator, designed to attach to the caregiver's torso without any barrier between the parent chest and the baby. The Skincubator creates a controlled environment with all advantages of a neonatal incubator, while enabling parents of very preterm and extreme preterm neonates to provide SSC to their infants from birth for extended periods. We have previously demonstrated that the Skincubator enables improved thermoregulation during SSC that may have clinical significance in extreme preterm infants. The Skincubator 2.0 is also used to transfer the baby to SSC within his nest in warm humidified environment without exposure to ambient air (figure 1). All tubes and cables are secured to the Skincubator and does not need to be held by a nurse during transfer. In this study we evaluated nurses perspectives regarding safety, baby handling and convenience for the nurse while using the 2.0 Skincubator in a structured simulation, and in real life clinical usage. We hypothesized that nurses will rate Skincubator SSC as safer, with less handling and as more convenient for the caring nurse than traditional SSC.

Methods: Prior to commencement of a feasibility trial of the Skincubator 2.0 in a tertiary NICU in Melbourne Australia, we performed structured simulations in which nurses were asked to transfer a manikin connected to common tubes, lines and monitoring cables from a neonatal incubator to a volunteer and perform several common nursing procedures on the manikin inside the Skincubator. Following the simulations they were asked to rate each procedure for Skincubator SSC, traditional SSC (t-SSC) and, if applicable traditional incubator care. Each procedure was evaluated separately for 4 aspects: Ability of performance, safety, handling of the baby and nurse convenience in a Linkert scale of 1-5 (1 very unsatisfied, 5 very satisfied). The nurses were also asked to enter free text appreciation of the Skincubator use. Simulations were performed separately on a manikin with a CPAP and a Peripherally Inserted Central Line (PICC) resembling a 29-week preterm and an intubated manikin with umbilical arterial and venous catheter resembling a 25-week preterm neonate at the second day of life. In addition, after the clinical trial commencement, nurses will fill a similar questionnaire after caring for CPAP supported and intubated preterm babies in the Skincubator. Population: Registered NICU nurses with experience in caring for preterm babies in SSC in a tertiary NICU in Melbourne Australia.

Outcomes: Primary outcome: the rating for the safety of transfer of a manikin/baby. Secondary outcomes: all other Skincubator and t-SSC ratings as described above.

Data collection: Each nurse rated each procedure using a electronic questionnaire using the Typeform platform. Recorded answers were transferred by the platform to excel.

Statistical analysis: Answers were analyzed for statistical significance by SPSS using Wilcoxon signed rank test.

Results: Twenty NICU nurses have performed each of the structured simulations. Nurses years of NICU experience were 10±6 years (mean±SD). Nurses were very satisfied with the safety of a Skincubator transferring system for a manikin with CPAP and ETT (Likert scale 5 (5,5) and 5 (3.5,5,5) (median (25%,75%) and only satisfied and neutral with the safety of traditional SSC transfer for CPAP and ETT (Likert scale 4 (4,4.5) 3 (3,4) (p=0.001 and p=0.003) Wilcoxon Signed-Rank Test (WSRT). In most procedures the nurses rated the ability of performance, safety, handling of the baby and nurse convenience as higher than in traditional SSC. Detailed rating is presented in table 1.

Conclusions: After performing structured manikin simulations, Nurses with extensive NICU experience perceive that Skincubator SSC may increase safety, reduce baby handling and enable more convenient nursing care as compared to traditional SSC. This will be further evaluated in real life during 10-12 2024 together with parents' convenience and safety perception. As traditional SSC is a safe and recommended method of care, large randomized controlled trials will be needed to evaluate if the Skincubator 2.0 will reduce rare safety events of line and tube dislodgment.

Impact: Nurses and parents' convenience and perception of safety may help to promote early continuous SSC.

Learner Objectives:

1. 1. To know some of the physical challenges in performing early prolonged SSC in extreme preterm neonates.
2. 2. To state potential ways to overcome those challenges.
3. 3. To be encouraged to seek ways to overcome barriers and increase SSC.

Table 1. Likert scale rating of how much are the nurses satisfied with four procedures is four aspects: The ability to perform, safety, baby handling and nurse convenience. Data is presented as median (25,75 percentiles).

Procedure	Transferring a 29 weeks preterm with CPAP and PICC from the incubator to the parent.				Performing a heel stick, and obtaining blood gas sample. (Preterm with CPAP)			
Aspect	Ability	safety	handling	convenience	ability	safety	Handling	convenience
Skincubator SSC	5 (5,5)	5 (5,5)	5 (5,5)	5 (5,5)	5 (4,5)	5 (4,5)	5 (4,5)	4 (4,5)
Traditional SSC	5 (4,5)	4 (4,4.5)	4 (4,5)	4 (3,4.5)	4,5 (3,5)	4 (3,5)	4 (3.5,4.5)	4 (3,4)
P value	0.03	0.001	0.04	0.003	0.06	0.006	0.006	0.05

Procedure	Transferring an intubated 25 weeks preterm with umbilical lines from the incubator to the parent.				Performing endotracheal tube suction on an intubated 25 weeks preterm with umbilical lines during SSC.			
Aspect	Ability	safety	handling	convenience	Ability	safety	handling	convenience
Skincubator SSC	5 (4,5)	5(3.5,5)	5 (4,5)	5 (3,5)	5(3,5)	5(3,5)	5 (3,5)	4 (3,5)
Traditional SSC	4(3.5,5)	3(3,4.5)	4(2.5, 4)	4 (3,4)	3(3,4)	3(2.5,4)	3 (3,4)	3 (3,4)
P value	0.2	0.003	0.04	0.1	0.02	0.01	0.04	0.1

Gravens 2025-11

Abstract Title: Maternal Engagement in a NICU in Uganda: Perspectives of Healthcare Workers

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Problem Statement: In low-income countries, healthcare worker shortages are common, often preventing vital monitoring tasks from being performed in the NICU. Our group has previously shown that mothers in an Ugandan NICU can reduce healthcare worker burden by assuming monitoring tasks, such weighing their baby, tracking their baby's feeds, and monitoring for "danger signs."(1) However, one of the biggest barrier to implementation is the time required to train the mothers (30-45 minutes per mother) (2) (Appendix 1). Therefore, we are seeking to understand whether video-assisted education can adequately train mothers to collaborate with healthcare workers while reducing the time it takes to train mothers.

Appendix 1: Maternal Monitoring Form

Study Number_____

	Day ___		Day ___		Day ___		Day ___		Day ___		Day ___		Day ___	
Weight														
Temperature														
Breathing														
Energy Level														
Convulsions														
Umbilical Cord														

Abstract:

Methods: As part of a larger ongoing study to test video-assisted maternal training in a low-income NICU (Appendix 2), we surveyed healthcare workers to gather insights into their perspectives on maternal education and engagement in the NICU. The study is occurring at Jinja Regional Referral Hospital's Special Care Unit (SCU) in Uganda. This unit has with a nurse/midwife-to-patient ratio of approximately 1:10 and admits 1200-1800 infants annually. The survey questions assessed the time availability for maternal education, identified essential maternal care skills, and explored preferences for educational methods that could be integrated into the SCU's existing workflow. Descriptive analyses were performed to determine the healthcare workers time availability for education sessions and rankings of maternal care skills deemed most critical and feasible to teach within the SCU's operational constraints. Qualitative data describing participants' additional perspectives were collated. Ethical approvals were obtained from the Makerere University, Uganda National Council for Science and Technology, and the McGill University Health Centre. Participants gave informed consent prior to completion of the survey. Please note that by time of conference in March 2025, we may be able to share preliminary results on the larger study to test video-assisted maternal training in Uganda (Appendix 2). (Protocol can be obtained from corresponding author.)

Results: Twelve healthcare providers were surveyed in June 2024, including 1 pediatrician, 2 interns, 8 nurses/midwives, and the head nurse. The study sample represents the full NICU staff during the study period. In July 2024, 12 healthcare providers were surveyed, including one pediatrician, two interns, eight nurses/midwives and the head nurse. The sample represented all eligible physicians during the study period and all eligible nurse/midwives who work in the SCU. Seven respondents (58.3%) reported that they have less than 10 minutes per admission to spend educating each mother on how to participate in their infant's hospital care, while 2 respondents (16.7%) indicated that they had no time to allocate to maternal education. When provided a list of potential skills, all respondents (n=12, 100%) reported that monitoring and identification of "danger signs" was the most important skill for mothers to learn. Danger signs are non-technical indications of clinical deterioration developed by the World Health Organization. (3) The majority of respondents (n=9, 75%) answered that training mothers how to weigh their infant daily on the SCU's electronic scale would be the easiest skill to teach. During the semi-structured survey, respondents generally remarked that video-enhanced maternal education may be an effective strategy to train mothers with one respondent suggesting that a video teaching key maternal skills should play continuously on a screen mounted on the wall in the SCU. Another respondent advocated for identifying a "champion" mother to teach and support other mothers to participate in their infant's hospital care. Please note that by time of conference in March 2025, we may be able to share preliminary results on the larger study to test video-assisted maternal training in Uganda (Appendix 2).

Study Number_____

	Day ___		Day ___		Day ___		Day ___		Day ___		Day ___		Day ___	
Breastfeed														
Tube feed														
Cup feed														

Conclusions: This study demonstrates that healthcare workers in a resource-limited NICU in Uganda have minimal time to engage mothers as collaborators in their infants' hospital care. Furthermore, due to healthcare worker shortages coupled with continuous maternal presence at bedside, all healthcare workers agreed that it was crucial for mothers to know how to monitor and identify signs of clinical deterioration ("danger signs"). Therefore, alternative approaches to maternal education, including our ongoing study of video-enhanced education, could be an effective strategy for partnering with mothers in a resource-limited NICU, while also respecting the time constraints of healthcare workers.

Impact: By identifying practical and impactful maternal care skills, this study lays the groundwork for developing efficient, time-conscious educational strategies that resonate with frontline healthcare providers and maternal caregivers alike. Central to these strategies is the potential widespread adoption of video-enhanced maternal education, which offers learning opportunities without imposing additional burdens on overburdened healthcare providers. By promoting maternal competence and confidence in infant care, these initiatives have the potential to enhance caregiver satisfaction, improve health outcomes, and optimize the limited resources available in understaffed NICUs. We are eager to see if the results of our ongoing time-motion study of video-assisted maternal education meets the needs of mothers

and healthcare workers in a Ugandan NICU. Key lessons learned from this study include the importance of adaptable educational methods tailored to the unique challenges of resource-limited environments and the value of stakeholder collaboration in shaping effective interventions. Moving forward, advocating for policy changes to support innovative maternal education programs and securing resources for technology-driven initiatives will be essential in translating research findings into sustainable healthcare practices.

References:

1. *Duby J, Kabajaasi O, Muteteri J, Kisooka E, Barth D, Feeley N, O'Brien K, Nathan KM, Tagoola A, Wiens MO. Family Integrated Care in Uganda: a feasibility study. Arch Dis Child. 2023;108(3):180-184.*

2. *Feeley N, Kabajaasi O, Kenya-Mugisha N, Tagoola A, O'Brien K, Duby J. Benefits and Challenges of Implementing an Adaptation of Family Integrated Care in a Ugandan Setting. Adv Neonatal Care. 2024;24(2):172-180.*

3. *Young Infants Clinical Signs Study Group. Clinical signs that predict severe illness in children under age 2 months: a multicentre study. Lancet. 2008;371:135-42.*

Learner Objectives:

After this presentation,

1. Participants will be able to summarize the importance of parental engagement in resource-limited NICUs

2. Participants will be able to explain the time constraints that healthcare workers face when collaborating with parents in resource-limited NICUs

3. Participants will be able to list the care-taking skills that healthcare workers perceive as valuable and easy for mothers to perform in resource-limited NICUs

Gravens 2025-12

Title: The impact of medical factors and feeding therapy on achievement of full oral feeding in preterm infants in the NICU

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Problem Statement: A stay in the neonatal intensive care unit (NICU) is very costly and inadequate oral feeding is the most common barrier to discharge for preterm infants. Thus, my aim is to determine the medical factors related to the time it takes to achieve full oral feeding and to determine if the post-menstrual age (PMA) at initiation of feeding therapy influences the time for preterm infants to achieve full oral feeding in the neonatal intensive care unit, while controlling for medical factors.

Abstract:

Methods: This study used a retrospective study design to analyze data from the electronic medical records (EMR) of preterm infants born at less than 37 weeks of gestation who were admitted to the UCSF Benioff Children's Hospital (BCH) between January 2017 and December 2019. Infants were included if they had received feeding therapy services and were discharged fully orally feeding. Infants who had transferred between hospitals, had died during the study period, or discharged with tube feeding (e.g., nasogastric tube or gastrostomy tube) were excluded. UCSF BCH has a certified regional 60-bed, Level IV NICU that serves infants throughout Northern California. Referrals for feeding therapy were provider dependent and were placed either before or after oral feeding was initiated based on concerns for oral motor development, feeding readiness, poor feeding coordination, or swallowing issues. Feeding therapists, which included occupational therapists and speech and language pathologists, provided feeding therapy services. Feeding therapy interventions included cue-based feeding, positioning, pacing, providing cheek and jaw support, adjusting flow rate, and altering the viscosity of the liquid to support oral feeding. The primary outcome was time to full oral feeding, which was measured in days from the first oral feeding to the last tube feeding. Secondary outcomes of interest were PMA at first oral feeding and PMA at full oral feeding. The primary predictor was PMA at initiation of feeding therapy. Medical factors included gestational age at birth, birthweight, delivery type, medical complexity, presence of bronchopulmonary dysplasia, history of mechanical ventilation, multiple birth, and PMA at discharge. Univariate linear regression was used to assess relationships between medical characteristics and time to full oral feeds. Multivariate linear regression was used to assess the relationship between PMA at initiation of feeding therapy and time to full oral feeding while controlling for those medical factors.

Results: A total of 143 infants met the inclusion and exclusion criteria. Infants were born at an average gestational age of 31.3 (SD 3.3) weeks, with a birthweight of 1738.4 (SD 654.7) grams, and had a length of stay of 47.4 (SD 37.9) days. The majority of infant had no complex chronic disease (87%), were White (39%), were English-speaking (90%), and had commercial insurance (59%). On average, infants discharged at 38.4 (3.0) weeks, initiated oral feeding at 34.7 (1.4) weeks, initiated feeding therapy at 36.2 (16.4) weeks, and reached full oral feeding at 37.3 (2.0) weeks. Infants who were born at a lower gestational age ($p<.001$), born at a lower birthweight ($p<.001$), had a history of mechanical ventilation ($p<.001$), and discharged at a higher PMA ($p<.001$) took longer to achieve full oral feeding. Infants who had feeding therapy initiated later required more time to reach full oral feeding ($p=.003$). While controlling for infant medical characteristics (gestational age, birthweight, history of mechanical ventilation, PMA at discharge), for every week feeding therapy was initiated later, it took .12 days longer to reach full oral feeding ($p=.020$).

Conclusion: Earlier initiation of feeding therapy may help preterm infants achieve full oral feeding earlier, thus, potentially decreasing length of stay. These findings highlight the importance of timely referrals to feeding therapists, who play a critical role in supporting oral motor development and feeding readiness. Feeding therapy interventions can begin before initiating oral feeding to prepare the infants for successful feeding outcomes.

Learning Objectives:

- To understand the medical factors related to the time it takes to achieve full oral feeding for preterm infants in the NICU

- To understand how timing of initiation of feeding therapy impacts time to achieve full oral feeding for preterm infants in the NICU

Gravens 2025-13

Title: Trauma-Informed and Resilience-Promoting Care Trainings for NICU Providers

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Problem Statement: Medical teams working with infants serve a unique role, as caring for an infant also entails caring for the family and equipping them to provide a nurturing environment for their child during a Neonatal Intensive Care Unit (NICU) stay and beyond. However, medical teams do not often receive formalized training in the mental health and general care needs of the family. To help infants and families, we have developed a NICU-related resource initiative to provide guidance to both NICU providers and families related to mental health needs and common questions for NICU families. We assess the usefulness of training materials created for pediatric acute-care providers to develop curated and accessible training materials for enhancing trauma-informed care.

Abstract:

Methodology: The Family Development Program (FDP) providers have worked in collaboration with the University of California Los Angeles (UCLA) Prevention Center of Excellence to launch trainings, videos, and handouts for NICU staff and parents. These materials are available for free to the public on the Department of Mental Health (DMH) + UCLA Wellbeing for LA Learning Center and Prevention Center of Excellence website. The overarching goal in creating these materials is to provide education on delivery of culturally-responsive services, support the recognition of grief, loss, and trauma, and support a sense of competency for families and providers. The most comprehensive resource created in this effort is an online, asynchronous, trauma-informed training course for NICU providers entitled, "The Resilient NICU." This course was created after gathering feedback from pediatric acute care providers after delivery of a strengths-based, trauma-informed, prevention curriculum delivered in the spring of 2022. This training included two, four-hour virtual training sessions, schedule one month apart from each other. This training was comprised of a five module-curriculum: 1) The Family Experiences in the Hospital, 2) Understanding Trauma and Resilience, 3) Supporting Healthy Bonding and Attachment, 4) Managing Communication with Family Members, and 5) Building Resilient Teams. Following the training, providers were asked to rate their pre- and post-training knowledge on trauma-informed care, overall satisfaction with the course, perception of value in disseminating the course to others, and impact of the course on their clinical practice. Participants in the training included medical staff such as registered nurses, occupational therapists, and child life specialists. 100 participants completed the training, and 80 participants provided evaluation feedback on the training.

Outcomes: Post-training surveys of provider participants were positive. With respect to overall course satisfaction, 91.5% of respondents rated the course as "excellent" or "very good" and 8.5% of respondents rated the course as "good." 98% of respondents "agreed" or "strongly agreed" that other staff should receive the training. Furthermore, 100% of respondents reported confidence in their ability to implement trauma-informed care following their participation in the training, and of those, 30% of respondents stated they would not have been able to implement skills at all prior to receiving training. Based on the feedback we received through surveying providers, we created "The Resilient NICU" online course with support from the Tikun Olam Foundation. It was launched as an introduction to integrating trauma- and resilience-informed practices in the NICU using everyday scenarios faced by providers and staff. This hour-long course is approved for 1 CE and is available for free to providers and staff. All views and access are tracked through our online platform. The Resilient NICU" online course has been viewed over 2000 times. We received qualitative feedback on this course highlighting the value of this course: "Very engaging and interactive. I loved the topics that were discussed because I feel like I have gained more insight about the traumas people deal with and how they deal/ present those traumas and how we as healthcare providers can help in those instances to make it a more trusting and safe space for them." –Nurse/participant "I so appreciated the incredible commitment from and knowledge base of its organizers. I loved doing this with colleagues from perinatal and NICU to get different perspectives. I'm immensely grateful to my administrators for prioritizing and encouraging this training!" –Nurse/participant "I really liked using the case examples in the videos to demonstrate how trauma-informed care can look like when done well. The formatting was excellent and I liked how the concepts were broken down into bite sized pieces, as well as the immediate questions to test our understanding of the material. I also appreciate being able to download the PDFs." "I'm a NICU Social Worker and I loved everything about this training. I'm sharing this with our unit's RN Clinical Educator right now as the examples/videos are spot on as to concerns we see regularly. Thank you so much for making this training and for making it so accessible - your efforts are so very much appreciated!"

Conclusions: Pediatric acute-care medical staff report knowledge

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gains and value in trauma- and resilience-informed training and report that this training impacts the way they practice. Providers are eager to increase knowledge and incorporate trauma-informed, culturally-sensitive principles into their care practices. There is immense value in future work aimed at developing resources and educational materials for pediatric acute-care providers from a trauma-, resilience-, and culturally-informed lens.

Reference:

DMH+UCLA Prevention Center of Excellence. The Resilient NICU. Wellbeing for LA Learning Center. 2019. https://learn.wellbeing4la.org/detail?id=1207&k=1604426725

Learning Objectives:

1. Describe the Family Development Program's NICU-related resource initiative.
2. Assess value of NICU-related resources and trainings for NICU providers.
3. Provide descriptive analysis of online access to NICU-related resource initiative.

Gravens 2025-14

Title: The Road to Excellence is Paved with Wrong Turns: Improving the Way we Honor our Bedside Mistakes

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Abstract:

To err is human" is a popular phrase we hear in healthcare, however, it does not seem to help anyone after an error was made. Admitting that a baby or family was potentially hurt by one of your mistakes is a personally daunting experience, and one that may haunt you for years. In truth, we all have regrets, but how you self-reflect on your mistakes and use them to make conscious improvements to your practice is exactly how we can honor that experience and release any guilt we may feel. This lecture will be conversational in nature, as the presenter will share some stories of her least successful infant-parent, and inter-professional interactions. Each story will be followed by audience polling on the most striking error (to improve upon awareness skills), as well as a review of the evidence emphasizing the impact of that mistake. Each story will be accompanied by clear steps to avoid future occurrences, improve success at the bedside and release guilty thoughts, though a review of the Self-Reconciliation Theory. This lecture will have a strong focus on neurodevelopmental care, family-centered care, trauma-informed care, inter-professional practices, ethics, self-love and forgiveness. Audience members will have an opportunity to share some of their mistakes and seek support from their peers in order to honor their errors and promote self-growth. Ideal length of presentation is 2-hours, but it can be shortened to 1-hour, and we will reduce audience polling opportunities.

Learning Objectives:

1. Describe the negative effects of errors on occupational stress, emotional wellbeing, and overall quality-of-life for healthcare providers who work in the NICU.
2. Summarize important foundational theories to incorporate into their practice in attempts to improve upon any mistakes (i.e., neurodevelopmental care, family-centered care, trauma-informed care, inter-professional practices, self-reconciliation).
3. List clear, evidence-based strategies to increase awareness and to take responsibility of a mistake, as well as how to take action for improvements at bedside, and find forgiveness with themselves and co-workers.

Gravens 2025-16

Title: Post COVID - an approach to bringing families back to face-to-face participation

Authors: Alejandra Barrero-Castillero, MD; Marge Day, MSW, LICSW; Kathy Tolland, RN, DNP; Heidi Gates, RN; Emily Whitesel, MD

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BIDMC

Problem Statement: The COVID-19 surge and subsequent lockdown in March of 2020 dramatically altered parental presence and participation in the NICU. We describe our focus on rebuilding our culture of family centered care and lessons learned in again making the NICU a safe and inclusive space for families.

Abstract:

Family-Centered care (FCC) is well known to be an effective approach to care in the Neonatal Intensive Care Unit (NICU), and has been shown to lead to improved health outcomes as well as improved family experience (Johnson, 2012). At Beth Israel Deaconess Medical Center (BIDMC), a 63-bed level III NICU, there has been a longstanding commitment to FCC. In the years leading up to March 2020, we had made great progress in shifting perspective and workflow in our NICU to be more Parent led and Family Centered. With the initial COVID surge and subsequent lockdown in March of 2020, infection control measures dramatically altered parental presence and participation in the NICU. From a model that welcomed families 24/7, restrictive visitor policies were put in place, and families were no longer included in medical rounds or hands on care. The relationship with a newborn is unique, and limiting parental presence has been shown to heighten parental anxiety and stress (Bembich, 2021; Meesters, 2022). It has now been almost four years of gradually working on building our post-covid culture on the NICU and again making the NICU a safe and inclusive space for families. While we have had to rebuild much, we have also brought a great deal of learning and fresh perspectives to this new roll out and are gradually working our way back to being a NICU robust with parent led initiatives. Family feedback has been essential in helping to direct our efforts and initiatives.

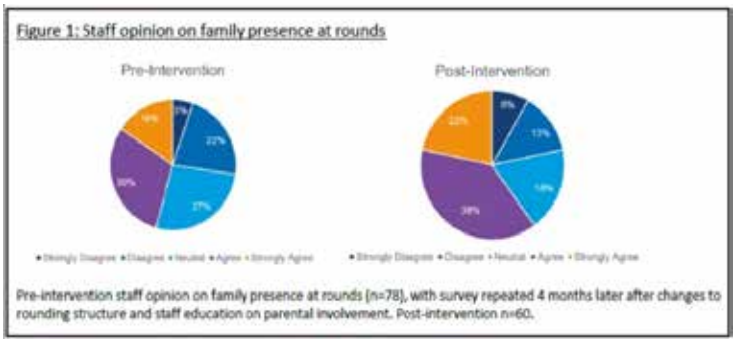
Programmatic Development: Our differentiated approach to support families during COVID restrictions resulted in some lessons learned and tools developed, as well as a need to reintroduce many of our family programs to the NICU day-to-day culture. We focused on 4 main areas with our approach, including: 1) medical rounds, 2) discharge planning 3) family integrated care (FiCare), and 4) family programming. i. Multidisciplinary Medical Rounds Multidisciplinary medical rounds in the NICU provide a key opportunity to review data, formulate a treatment plan, and optimize communication within the medical team.

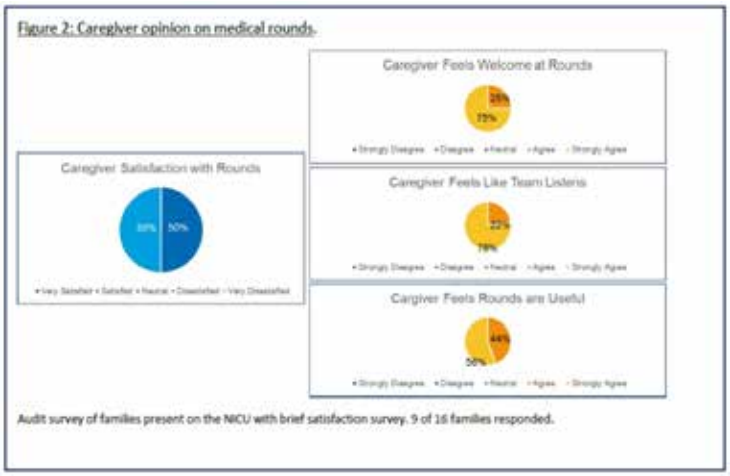
Offering parental participation in rounds is one facet in creating a collaborative family centered team. During COVID, we no longer allowed families to participate in rounds. This prohibition lasted 6 months until 9/2020 when families could attend rounds again on a limited basis. However, the staff attitude about parents on rounds shifted. A staff survey done in the context of changing the rounding structure in May of 2023 showed that only 46% of the staff agreed or strongly agreed with families participating on rounds, while 27% disagreed or strongly disagreed (figure 1). However, at that same time a limited survey of families showed that 100% valued their attendance at rounds, feeling either "satisfied" or "very satisfied" (figure 2). With work to streamline rounding time and education, a repeat survey in September showed that now 60% of the staff agreed or strongly agreed with family participation on rounds, and only 21% disagreed or strongly disagreed (figure 1). ii. Discharge Rounds Discharges during COVID were pared down to the minimal tasks necessary. Formal and informal feedback from families and staff have identified specific issues including: 1) delayed discharge preparation; 2) inconsistent information about discharge from staff to families resulting in family stress and uncertainty, and 3) variation in handling of discharge transition by staff members driven by staff member's experience/lack of familiarity with family at the time of discharge. To ensure that discharge planning and teaching occurs in a family-centered, timely, organized, and consistent manner, our NICU has supported the following programs: 1. A NICU Discharge Coordinator paid position; 2. Weekly multidisciplinary discharge planning rounds to improve communication regarding discharge needs and aim for discharge preparation completeness by 48 hours prior to the day of discharge; 3. Qualitative data analysis from parent feedback collected by our designated discharge coordinator to identify key metrics to inform discharge planning committee operations and inform care; 4. Continued parent readiness score on day of discharge; 5. In person and video CPR and discharge classes bringing parents back to the unit; 6. Offering discharge celebrations. iii. Family Integrated Care In 2019, our NICU piloted a successful family integrated care program (FiCare) that was halted in the setting of the pandemic. In the rebuilding, we have moved towards integrating FiCare as part of our care model, rather than a separate program. All patient rooms now have a caregiver guide that outlines caregiver and nursing responsibilities, and a "ways to engage in your baby's care" checklist. These tools allow the nurse and caregiver to check off skills that families have mastered. The reintroduction of FICare appears well received. A survey was done in March 2024, with 79% of staff referring to the checklist with families when providing care. 57% of staff feel that families are more prepared to go home when they participate in FICare. Additionally, FICare checklists were audited in May 2024 and 50% of rooms had audits filled out by parents. 4. Family Programming During COVID, we recorded a video introduction to nonclinical information on the NICU, called "Welcome to the NICU", paired with an internet-based dashboard for families. This information is accessed via QR codes, located in all patient rooms and family spaces, in our top five languages. To date the welcome videos have had over 1500 views with 360 of those being of the non-English videos that are hosted by native speakers. While we are now back at the bedside talking to families regularly, we have received positive feedback from families regarding their availability in a variety of formats. This has served as a lesson learned from the Covid differentiation that we will continue to use alongside in-person introductions and explanations.

Conclusion: While COVID precautions brought many of our family-driven initiatives to a halt, we have slowly begun to rebuild and in many ways improve upon our approach to family engagement in the NICU. We pivoted to a more electronic and digital approach during covid and have learned from families that these tools are an effective addition to in person engagement.

Learning Objectives:

1. Concrete ways to restart and rebuild parent led activities in the NICU
2. Learn about the use of technology to engage families in the NICU





Gravens 2025-17

Title: Improving Fluconazole Prophylaxis Guideline Adherence in the Neonatal Intensive Care Unit: A Quality Improvement Initiative

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Problem Statement: The problem addressed in this project is the inconsistent adherence to fluconazole prophylaxis guidelines in extremely low birth weight (ELBW) infants in the NICU, contributing to a risk of invasive candidiasis (IC). This project aims to standardize guideline adherence to reduce the incidence of IC and improve outcomes in this vulnerable population.

Abstract:

Background: Invasive candidiasis (IC) remains a significant concern in extremely low birth weight (ELBW) infants, with mortality rates reaching up to 30%. Despite evidence supporting fluconazole prophylaxis in reducing IC, adherence to prophylactic guidelines has been inconsistent in a 52-bed Level IV Neonatal Intensive Care Unit (NICU). A January and March 2024 chart

audit highlighted variable identification of inclusion criteria and inconsistent monitoring for fluconazole-related adverse events. In 2023, 71 infants received fluconazole prophylaxis at 3 mg/kg/day twice weekly, while 13 infants received antifungal treatment dosing. Two cases of IC were reported in 2023. This quality improvement (QI) project aims to standardize fluconazole prophylaxis among ELBW infants in the NICU by implementing and measuring adherence to an updated, evidence-based guideline.

Methods: The QI initiative is ongoing, with implementation starting in August 2024 and concluding in December 2024. A revised fluconazole prophylaxis guideline was developed using current evidence to clarify inclusion criteria for prophylactic therapy, correct dosing and duration based on infant risk factors, and monitoring parameters for adverse effects. Weekly audits are being conducted to assess adherence to the guideline, including gestational age, birth weight, fluconazole initiation date, dosing, therapy duration, and abnormal laboratory findings. Educational sessions were conducted virtually, with knowledge and confidence levels assessed via post-education surveys. Central line discussions were introduced during daily interdisciplinary rounds to evaluate the ongoing necessity of central lines and fluconazole therapy. Data collection includes central line days, the rationale for insertion or discontinuation, abnormal laboratory or assessment findings, medications, and indications for discontinuing fluconazole therapy.

Preliminary Results: Preliminary data from August to September 2024 show improved adherence to the fluconazole prophylaxis guideline among the 14 infants included in the project to date. Fluconazole was initiated within the first 72 hours for 57.1% (n=8) of infants, with 42.8% (n=6) starting beyond the recommended therapeutic window. Prophylaxis was prescribed at 3 mg/kg/day twice weekly for 100% of patients thus far (n=14). Clinical and laboratory findings were within normal limits for 85.7% (n=13) of infants, with 7.1% of patients with elevated AST/ALT levels (n=1). One patient did not have laboratory testing reported (n=1). No abnormalities were found in urinary output, creatinine levels, or cultures, and no new cases of IC have been reported to date. The preliminary average for central line days while on fluconazole therapy for the 14 enrolled patients is eight days, ranging from 1 to 34 days.

Preliminary Conclusions and Implications: Although still ongoing, this QI project demonstrates promising progress in standardizing fluconazole prophylaxis in the NICU, with improved adherence to the updated guidelines and no new IC cases reported during the preliminary observation period. Fluconazole was initiated within 72 hours for 57.1% (n=8) of infants, with all receiving the correct dosing regimen. Adverse events were minimal, with only one elevated AST/ALT level. Continued data collection will provide more comprehensive insights into the effectiveness of the intervention. If sustained, this project could improve the overall safety and care of ELBW infants in the NICU.

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Learning Objectives:

Ensure that fluconazole prophylaxis is initiated within 72 hours of birth for at least 80% of eligible ELBW infants by the end of the project, as monitored through patient records.

Decrease the average number of central line days among ELBW infants on fluconazole prophylaxis by 10% compared to baseline, as measured through NICU records.

Reduce the incidence of fluconazole-related adverse events, such as elevated AST/ALT levels, to less than 5% among ELBW infants receiving prophylaxis, as evaluated through lab results and clinical assessments.

Gravens 2025-18

Title: Infant Voice Exposure Through a Reading Program: Comparing Experiences in an Open Bay to a Single-Family Room NICU

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Problem Statement: We implemented a reading program [Reach Out and Read (ROAR)] in 2020 to provide critical vocal stimulation to Neonatal Intensive Care Unit (NICU) babies' developing brains. European studies have shown benefits for babies in SFR NICUs such as increased parental presence, enhanced parent−infant closeness and engagement in infant care, and improved parental psychological well-being with reductions in maternal depression and stress in both parents. 1. A meta-analysis combining Scandinavian, Australian, and US studies showed equivocal neurodevelopmental outcomes, decreased infections, and increased breastfeeding rates in SFR units. 2. In the US the negative impacts of the SFR NICU were lower language scores and a strong trend toward worsening motor scores at 24-month follow-up. 3. This could be due to the sensory isolation within the SFR environment if parental presence and engagement were low. In October 2023, we moved from a 20-bed open bay (OB) NICU to a new 24-bed Single-Family Room (SFR) NICU, and after one year in our new SFR NICU we reviewed our ROAR program data to see if the new unit had an impact on the success of the program as measured by newborns' average reading time per day and determine if any changes to the program were needed.

Abstract:

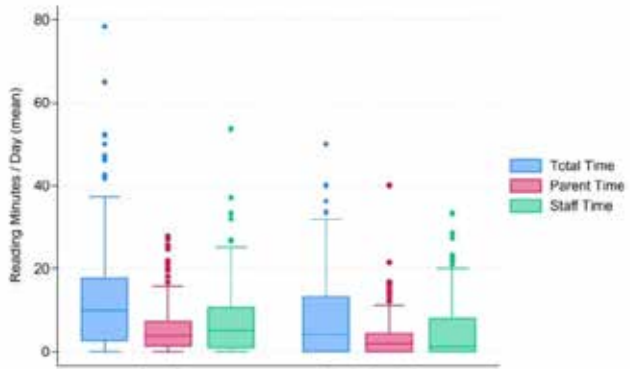
Methods: We are a 24-bed Community Level III NICU with approximately 4900 deliveries and 500 NICU admissions per year. We targeted increased time spent reading to all infants admitted to the NICU in 2020 by creating the ROAR program. The initial goal was direct reading by staff or a parent/family member to babies for 10 minutes per shift for a total of 30 minutes per day. Nurses and parents played a crucial role in this initiative, and their efforts were

documented in the Electronic Health Record (EHR) (Figure 1). Our ROAR program showed continued improvement in minutes read to babies over 3 years in the OB NICU. We moved to a new SFR environment in October 2023. We compared the minutes reading to babies in the OB NICU (January 2023 to October 2023) to the minutes reading to babies in the new SFR NICU (November 2023 to June 2024). We collected the quantitative data by running a report from our EHR on the total reading time per baby per stay and dividing the total minutes by the number of days in each baby's length of stay to calculate average reading time per day. We also analyzed the time spent reading to each baby by parents/families versus staff.

		Open Bay N=363	Single Rooms N=299	Difference (95% CI), p-value
Gestational age (weeks)	Mean (Sd)	36 (3)	37 (3)	No difference
	Median (IQR)	37 (24-41)	37 (25-41)	
Length of Stay (days)	Mean (Sd)	12 (17)	11 (17)	No difference
	Median (IQR)	5 (1-116)	4(1-125)	
Minutes per day - total	Mean (adjusted*)	11	8	3 (2-5) p=0.00
	Mean (crude)	12	8	4 (2-5), p=0.00
	Median (adjusted*)	9	6	4(2-5) p=0.00
	Median (crude)	10	4	6(4-8) p=0.00
Minutes per day - parents	Mean (adjusted*)	5	3	2(1-2) p=0.00
	Mean (crude)	5	3	2(1-2) p=0.00
	Median (adjusted*)	3	2	2(1-2) p=0.00
	Median (crude)	4	2	2(1-2) p=0.00
Minutes per day - Staff	Mean (adjusted*)	7	5	2(1-3), p=0.00
	Mean (crude)	7	5	2 (1-3), p=0.0001
	Median (adjusted*)	5	3	2(1-2) p=0.001
	Median (crude)	5	1	4(2-5) p=0.00

*adjusted for GA and LOS

	Admission (Current) from 8/28/2019 in MV NICU		
	10/9/19		10/10/19
	1400	1700	2300
ethod		In person	
oke With		Mother,Father	
ason		Update, plan	
Mother Pumping?			
ily Pump Volume (mL)			
fant Care			
mily Participant	Mother	Mother	
fant Care	Diaper		
actile Stimulation			
rticipant	Mother	Mother	
lding Skin to Skin	>120 min	>120 min	
lding Swaddled			
ntainment Touch			
fant Massage			
ocal Stimulation			
rticipant	Mother	Mother	
lking	0-15 min		
ading	15-30 min	60-90 min	
nging	15-30 min		
corded Voice			
usic			



Results: There were 363 and 299 babies in the OB and SFM cohorts, respectively. Although gestational age (GA) and length of stay (LOS) were positively correlated with average reading minutes per day (aveRM/d), mean/median GA and LOS were nearly identical between cohorts. [Table1] Figure 2 shows that mean aveRM/d was larger in the OB environment, for parents, staff, and overall. Adjusting for small differences in GA and LOS, the mean and median aveRM/d for OB versus SFM were 11 and 9 minutes versus 8 and 6 minutes, p-values < .001. Likewise, adjusted mean and median aveRM/d read by parents were larger in the OB than in SFRs: 5 and 3 minutes versus 3 and 2 minutes, p-values <.001 (Table 1).

Conclusions/Impact: Our findings are consistent with previous studies suggesting decreased vocal exposure and potentially greater sensory isolation in a SFR environment. Our reading program is four years old and we've seen steady increases in the total minutes reading to babies year over year, although we had not yet reached the goal of 30 minutes per day before our move. Although we encouraged longer family presence at the bedside in SFR environment, we saw a decrease in family participation in reading time in the new SFR NICU. Potential causes for this decrease are less focus on the reading program while staff adapted to the new SFR unit, inconsistent documentation of reading time done by staff, or increased workload for staff who are now spread out over a larger unit and do not have as much time to help each other with reading as they are isolated in separate rooms. It's crucial to emphasize the importance of parental presence in the SFR environment, as it can significantly benefit babies and mitigate sensory isolation. Encouraging staff participation in vocal exposure would further enhance this effect when parental presence is not possible. We plan to conduct refresh education with staff showing our data to highlight the importance of refocusing on the reading program and also explore additional technologies to mitigate the sensory isolation in single room environment.

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Acknowledgement: Gopal Vedartham; Jody Charles, RN, MSN, NE-BC; Family partnership Council

Learning Objectives:

1. Understand the importance of implementing a reading program to support the early neurodevelopment of all infants admitted to the NICU.

2. Recognize the importance of both staff and parental support of a reading program in the NICU.

3. Explore potential effects of a new SFR NICU on an existing reading program and describe possible mitigation strategies to overcome them.

Gravens 2025-19

Title: Reflective Practice as a Catalyst for Trauma-Informed Professional Development: Insights from the TIP 1.0 Program

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Problem Statement: This study addresses the need for healthcare professionals to deeply understand and embody the principles of trauma-informed care in their daily practice. The scientific question posed is: How does reflective practice enhance the understanding of core attributes of trauma-informed care among healthcare professionals? This is important because trauma-informed care is essential for improving both patient outcomes and caregiver well-being, yet many professionals struggle to operationalize these principles in practice.

Abstract:

The Trauma-Informed Professional (TIP) 1.0 Certificate Program was developed to enhance healthcare professionals' engagement with trauma-informed care principles through reflective practice, grounded in caring science, specifically for those caring for critically ill babies and their families. The program emphasized eight core attributes, which were defined through collaboration with an international, interdisciplinary board of neonatal experts. These attributes—Knowledgeable, Healing Intention, Personal Wholeness, Courage, Advocacy, Role Model and Mentor, Scholarly, and Leader for Change—represent the essential qualities that embody trauma-informed care in practice. This study employed a qualitative thematic analysis to explore how reflective practice reshaped participants' understanding of these attributes, drawing on the principles of Jean Watson's Human Caring Theory to emphasize the holistic, compassionate aspects of care. Data was collected from 40 healthcare professionals, representing 40% of the first 100 graduates of the TIP program. These participants, primarily neonatal clinicians were selected for the depth and completeness of their reflective responses. Written reflections were gathered at two points in the program: before participants engaged with each module's content and after completing the reflective exercises. A thematic analysis of these reflections revealed significant shifts in participants' understanding of the eight attributes, aligning with caring science by emphasizing empathy, emotional resilience, and the nurturing of human connections. The results demonstrated a deep transformation in participants' perspectives. The attribute Knowledgeable shifted from a focus on knowledge as the accumulation of facts to a broader emphasis on curiosity and lifelong learning, mirroring the caring science principle of embracing uncertainty and continuous growth. Healing Intention evolved from being outcome-driven to centering on mindful, intentional presence, addressing the emotional and spiritual needs of patients, a key tenet of Watson's caring theory. Participants redefined Personal Wholeness, recognizing that self-care is not only a personal responsibility but essential for sustaining compassionate caregiving, consistent with the Caritas Process® of self-care as an integral aspect of professional well-being. The understanding of Courage shifted from bold, isolated actions to everyday resilience—the ability to maintain integrity and persist in challenging circumstances. Similarly, Advocacy transformed from simply speaking on behalf of patients to deep listening and ensuring that patients' and families' voices were heard and respected, highlighting the importance of authentic connections in caregiving relationships. Other attributes saw equally profound shifts. Role Model and Mentor evolved from an authoritative role to a collaborative partnership, where learning is mutual and mentorship is rooted in empathy and humility. The Scholarly attribute expanded beyond intellectual authority to fostering a growth mindset and embracing reflection and continuous learning, essential to caring science's emphasis on openness to new knowledge. Finally, Leader for Change was redefined as relational leadership, where influence is driven by leading through example and empowering others, rather than asserting control or authority. These findings underscore the importance of reflective practice, rooted in caring science, in fostering a deeper, more holistic understanding of trauma-informed care. By engaging deeply with these core attributes, neonatal professionals were able to cultivate emotional resilience, improve their ability to provide family-centered care, and align their actions with trauma-informed and caring science principles. This study demonstrates the potential for reflective practice to enhance both professional development and infant-family outcomes in trauma-affected care environments such as the NICU.

TIP 1.0 Core Attribute	Related Caritas Process®	Explanation of Relationship
Knowledgeable	**Caritas Process 5:** Being present to and supportive of the expression of positive and negative feelings	Being knowledgeable involves not just factual learning, but the ability to remain present with uncertainty and emotions, engaging both intellect and empathy.
Healing Intention	**Caritas Process 7:** Engage in genuine teaching-learning experiences that attend to unity of being	Healing intention focuses on mindful presence, aligning with creating deeper, holistic learning experiences for both caregivers and patients.
Personal Wholeness	**Caritas Process 9:** Assist with basic needs, with an intentional, caring consciousness	Personal wholeness connects to the caregiver's self-care, mirroring how meeting the holistic needs of oneself is integral to caring for others.
Courage	**Caritas Process 6:** Creatively using self and all ways of knowing as part of the caring process	Courage involves resilience and the use of multiple ways of knowing, including emotional and experiential knowledge, to sustain compassionate care.
Advocacy	**Caritas Process 4:** Develop and sustain a helping-trusting, caring relationship	Advocacy shifts from speaking up for others to deep listening and ensuring patients' voices are heard, reflecting the essence of building trusting relationships.
Role Model and Mentor	**Caritas Process 1:** Practice loving-kindness and equanimity within context of caring consciousness	Role modeling and mentoring through empathy and humility reflects the Caritas Process of practicing loving-kindness and fostering mutual respect and growth.
Scholarly	**Caritas Process 8:** Create a healing environment at all levels.	Being scholarly involves fostering a growth mindset and lifelong learning, which contributes to creating an informed, healing environment for both patients and staff.
Leader for Change	**Caritas Process 10:** Open to existential, spiritual dimensions of life/death, attending to soul care.	Leadership is redefined as relational leadership, influencing others through integrity and empowerment, much like attending to the deeper existential aspects of care.

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Learning Objectives:

1. Understand how reflective practice can enhance healthcare professionals' comprehension of key trauma-informed care attributes, including empathy, emotional resilience, and leadership.
2. Identify specific shifts in professional perspectives on core trauma-informed care attributes, such as transitioning from task-oriented care to family-centered and holistic care approaches.
3. Apply the principles of reflective practice in trauma-informed care to foster emotional resilience and improve both caregiver well-being and patient/family outcomes in daily practice.

Gravens 2025-20

Title: It's Time for Kangaroo Care: A Quality Improvement Project to Improve Time Spent Skin-To-Skin in the Sunnybrook Health Sciences Centre Neonatal Intensive Care Unit

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Problem Statement: International guidelines for care of preterm and low birth weight infants recommend Kangaroo Care (KC) for non-critically ill infants for 8-24 hours per day or 'as many hours as possible' and the rates of KC in our Neonatal Intensive Care unit are well below recommendations. Using quality improvement methodology, we aimed to increase time in Kangaroo Care by 20% from an average of 49 minutes/baby/day to an average of 59 minutes/baby/day over a 6-month project timeline.

Abstract:

Background: International guidelines for care of preterm and low birth weight infants recommend Kangaroo Care (KC) for non-critically ill infants for 8-24 hours per day or 'as many hours as possible'. KC is associated with lower mortality, reduction in infection, stabilization of physiological parameters, and improved breastfeeding outcomes. In our Level III Neonatal Intensive Care Unit (NICU) at Sunnybrook Health Sciences Centre (SHSC) in Toronto, Ontario, Canada, infants spend less than 1 hour per baby per day in KC and as of the initiation of this project in November 2024, the rates of KC on the unit had been declining over several years.

Objective: By May 2024, we aimed to increase time spent in Kangaroo Care for all eligible babies in the SHSC NICU by 20% from an average of 49 minutes/baby/day (95% CI; 44 minutes/baby/day - 54 minutes/baby/day) to an average of 59 minutes/baby/day.

Methods: A multidisciplinary team of stakeholders was assembled for this quality improvement initiative. Barriers to KC on the unit were identified through the development of a fishbone and driver diagram. Using the Plan-Do-Study-Act (PDSA) methodology, further characterization of the barriers and enablers of KC was achieved through anonymous bedside staff questionnaire. Subsequent PDSA cycles targeting increased awareness and intentional conversations around KC both for staff and caregivers followed by the application of bedside signage to further prompt conversations around KC and encourage its implementation.

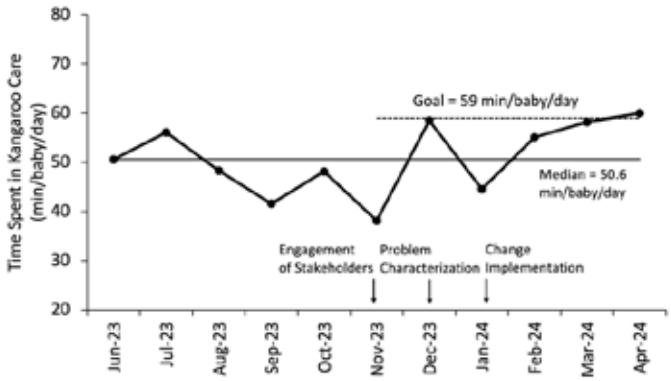

Figure 1. Run chart of the outcome measure of time spent in Kangaroo Care per baby per day with data crossing the goal of 20% improvement set out in the aim statement in April 2024 with infants spending 60 min/baby/day in Kangaroo Care.

Impact: We achieved our aim of improvement with 60 minutes/baby/day spent in KC in April of 2024. Through our initiatives, we were able to identify many important factors hindering time spent in KC including parental presence and comfort, staff knowledge and unit culture, as well as unit acuity and staffing shortages. Future directions include goals for sustained unit practices using parent-targeted initiatives and a unit-wide emphasis on the importance of KC and its positive impact on patient outcomes.

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Learning Objectives:

The purpose of this presentation is to describe our quality improvement approach to Kangaroo Care in our unit. Our goal is to demonstrate how even small changes to a complex, multifactorial problem can have an appreciable impact. At the conclusion of the presentation the participants will be able to evaluate the approach to Kangaroo Care in their own unit and apply quality improvement strategies to their current approaches.

Gravens 2025-21

Title: Implementing a NICU Nourishment Center through Community Collaboration

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Problem Statement: Families with infants in the NICU often face significant challenges accessing nutritious food, which can exacerbate stress and hinder their ability to participate in their infant's care. To address this, we partnered with community organizations to create a 24-hour NICU Nourishment Center, ensuring equitable access to food for all families.

Abstract:

Methods/Program Development: Food insecurity is a critical social determinant of health that can significantly impact developmental and health outcomes for infants, particularly in NICU settings where families face heightened financial stress due to medical expenses and prolonged time away from work. Over a six-month period, we assessed food insecurity among families in our Level IV NICU, finding that approximately 17% reported experiencing some degree of food insecurity within the previous 12 months. Recognizing the need for immediate intervention, we initiated efforts to establish an on-site food pantry to support these families during their infant's hospitalization. This initiative began with a modest $1,000 grant, which allowed us to repurpose a small closet adjacent to the NICU social worker's office into a food pantry stocked with non-perishable goods. Soon after, a fortuitous encounter between a NICU team member and the CEO of the local food bank, during a community event, led to a larger collaboration. Their "Food is Medicine" initiative, supported by funding from a national insurance company, aligned with our goals. This partnership resulted in the creation of the NICU Nourishment Center, a dedicated space within the hospital to provide ongoing nutritional support for families affected by food insecurity. Upon each admission, the NICU social worker ensures that every family is informed about the Nourishment Center and provided with access, regardless of financial need.A portion of the funding was allocated to redesign the nearby NICU waiting room into a multi-functional nourishment space. This area was transformed into a welcoming environment where families could relax, share meals, and congregate. It also included a walk-in food pantry with both perishable (refrigerator and freezer) and non-perishable items, as well as a microwave for food preparation. During the design phase, we engaged members of our Family Advisory Council, whose insights led to two key priorities: ensuring the center's proximity to the NICU for easy access and providing 24-hour availability to allow families autonomy in using the pantry without stigma or the need to request permission.

Outcomes/Lessons Learned: Figures 1, 2, and 3 depict the completed NICU Nourishment Center and food pantry. Since its opening on February 27, 2024, through August 20, 2024, 229 NICU families have accessed the center upon admission. Among these, 44 families (19%) reported experiencing food insecurity within the past 12 months. Tracking food consumption patterns revealed that high-protein items (e.g., yogurt, nuts) and quick "grab-and-go" snacks (e.g., small salads, cheese) were the most frequently utilized. Families who participated in an informal QR code survey expressed a preference for additional beverage options, including milk, orange juice, energy drinks, and water. Unexpected benefits emerged, such as the use of the space for weekly NICU family support groups and feedback from mothers who appreciated the convenience of high-protein snacks while using the nearby lactation rooms. Families also reported reduced stress from not having to travel far from the NICU to access meals, with the center conveniently located just across the hall from the unit. Logistical and operational challenges included delays in the design and construction process, which made it difficult to find alternative waiting areas. Achieving consensus on the center's design while adhering to hospital branding and regulatory guidelines also proved challenging. Additionally, maintaining food supplies during periods of high NICU census and managing key card returns posed ongoing operational hurdles.

Figure 1.

Figure 2.

Figure 3.

Conclusions: The NICU Nourishment Center serves as a model initiative for promoting health equity in a Level IV NICU by providing 24-hour access to nutritious food for all NICU families, regardless of socioeconomic status. This initiative was designed to reduce stigma surrounding food insecurity and alleviate the burden of meal planning and traveling far from the NICU while caring for a hospitalized infant. The integration of feedback from both past and current NICU families ensured that the program addressed the needs of NICU families and fostered engagement in NICU care, rather than serving the interests of external organizations. Next steps include securing additional resources and partnerships to sustain the Nourishment Center, such as pursuing local and national grants and philanthropic support. Expanding data collection on program impact is also a priority, with plans to track food pantry usage patterns (e.g., frequency of use and peak times) and conduct qualitative interviews to evaluate family engagement and potential effects on psychological well-being. These efforts will enhance our understanding of the program's utilization, benefits, and areas for quality improvement.

Impact: The NICU Nourishment Center was made possible through critical partnerships with community organizations, which played a key role in establishing and maintaining the 24-hour access food pantry and directly aligns with the hospital's mission to serve the poor and vulnerable. Despite the logistical challenges encountered, this model demonstrates that healthcare organizations can effectively collaborate with local partners to address NICU family needs. These collaborations not only fulfill immediate necessities but also strengthen relationships between healthcare institutions and community organizations, creating a network that can support future initiatives and program expansions. Future evaluations will focus on assessing the long-term impact of the Nourishment Center on family engagement, parental mental health, and overall NICU outcomes. By leveraging strong community partnerships and hospital administrative support, the NICU Nourishment Center not only addresses food insecurity but also serves as a replicable model for promoting health equity and enhancing family well-being in NICU settings.

Learning Objectives:

1. Recognize the importance of addressing health equity in the NICU and its implications for family-centered care.
2. Identify strategies for developing a 24-hour nourishment center in a healthcare setting through community partnerships.
3. Learn about the process and challenges of implementing a sustainable food pantry program in a hospital environment.

Gravens 2025-22

Title: Prenatal workshop and support group for parents of children who will come to the NICU

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Problem Statement: We want to prevent the lack of prenatal education and support for parents with a high-risk pregnancy. It is important to prevent isolation, anxiety or depression of parents expecting sick newborns.

Abstract:

Introduction: Prospective parents who know their baby will be sick at birth may experience anxiety and depression; women in high-risk pregnancy units also suffer from isolation. Support groups in the NICU have been demonstrated to have a positive impact on parents but they do not exist in a prenatal fashion.

Objectives: To describe the development and evaluation of a prenatal education and support group for parents whose baby will be admitted to the NICU because of prematurity or congenital anomalies.

Methods: The format of the workshop and themes to discuss were developed in a needs assessment phase by questioning 45 parents. These 45 parents identified several important themes: maternal guilt, their future parental role, normalizing their experience/emotions, coping with their "broken dreams" (mourning their objectives: pregnancy, delivery, breastfeeding, parenting, etc), adapting to their new reality, control and trust. They also described educational themes: information about the NICU, what the baby would look like, technology around the baby and common neonatal interventions, who was part of the neonatal clinical team and the role of parents in this team. These findings were used by our parent-partner group to design a checklist and a presentation with pictures to moderate the workshop. A pilot phase optimized workshop time and delivery. For example, more fathers participated when it was called a workshop compared to a support group. The study took place in a large academic level 4 hospital. During eight months, prospective parents were invited to participate in the workshop when a diagnosis made admission to the NICU highly likely. Parental perspectives were investigated using mixed methods at two different times: after the workshop and after one week in NICU, where recall was also evaluated.

Results: A total of 136 parents participated in the workshop: 114 pregnant women and 22 partners. 55 were hospitalised in the high risk pregnancy unit and, 83 were followed up in the fetal anomaly center. The response rate was 65% for the first questionnaire and 41% for the second questionnaire. The mean age of the mothers was 32 years. The average gestational age at the time of the workshop was 32 weeks. 48% were primiparous. During the evaluation immediately after the workshop, the average score given by parents was 9.6/10. Almost all agreed/strongly agreed that the workshop was useful (98%); that the workshop help to prepare the birth of the child (95%); that the workshop made them feel less lonely and isolated (90%); and that exchanges with other parents were beneficial (92%). All answers to open-ended questions were positive, for example: "I think it's an essential workshop for any parent expecting this type of birth. Thank you so much!" or parents say they appreciate "the presentation and all they do to care for babies." After the birth, all parents remembered the workshop and could recall and identify topics that were discussed. 95% of parents would recommend it to other parents. Open-ended questions helped us improve the workshop content.

Conclusion: Prenatal educational workshops provide a unique and useful means to support future NICU-parents and to prepare for a neonatal hospitalization.

Learning Objectives:

1. Describe the development of a prenatal workshop with parent partners.
2. Examine the utility of prenatal workshops for prospective parents whose child will be admitted to the NICU.

Gravens 2025-23

Title: Project Milestones: Creating a Positive Environment for Bonding Families and Newborns One Photo at a Time

Authors: Elisa Abdulhayoglu, Rachelle Rubin, Bhumi Patel, Julianna Farnam, Sarah Martorano, Helen Christou

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Problem Statement: The Project Milestones team aimed to empower families and caregivers by creating opportunities through photoshoots and social media, to facilitate an environment of hope and comradery, and simultaneously celebrate the resiliency of NICU babies and their families. We hypothesized that giving NICU families the opportunity to celebrate important holidays and special milestones would lead to improved emotional support and bonding with their infants.

Abstract:

Background and Purpose: The Brigham & Women's Hospital (BWH) neonatal intensive care unit (NICU) is a 66-bed tertiary unit that cares for babies born as early as 22-weeks of gestation. Babies born prematurely have complex medical needs and could stay in the NICU for weeks to months at a time. This can be distressing (1) especially since the babies miss milestones with their families like their first holiday, first time smiling, and others. Lack of opportunity to bond can make it difficult for families to feel connected to their NICU infant (2). The NICU experience unfortunately creates a gap in bonding (1). At BWH, neonatologists, nurses, family support specialists, respiratory therapists and multi-disciplinary teams encourage families to create memories with their infants by reading, singing, holding them, and participating in their infants' case as medically appropriate. Nurses make scrapbooks for families to show how strong their little ones are becoming. These small moments are integral to enhancing family-centered care in the NICU and pivotal in the infant's journey (3). Project Milestones takes a comprehensive approach in creating celebratory moments to bridge the NICU journey with everyday life.

Methods: Project Milestones, led by the NICU medical director with three administrative support members and one family support specialist, produces photoshoots once or twice a month that are posted on the departmental Instagram page. Initial recruitment of families and infants was one-on-one, with careful consideration of the infant's medical condition, and family/staff acceptance. Between October 2023 and September 2024, we conducted a total of 82 themed-photoshoots with philanthropic support for props/costumes. The photoshoots were planned around major holidays (i.e. Halloween), celebratory days (i.e. NICU Awareness Day), and discharge day. To evaluate the program's impact, we surveyed families who participated in at least one photoshoot. Through a mix of multiple-choice and open-ended questions, the survey aimed to assess the perceived benefits of participation, the emotional responses and satisfaction with the photoshoots, and feedback for improvements. The team also tracks social media data to gauge engagement and community response.

Results: In October 2024, surveys were sent to 37 families who participated in the NICU photoshoots, with a response rate of 51%. The survey collected quantitative data (ratings, yes/no responses, and frequency measures), qualitative data (open-ended comments), and categorical data. One family was still in the NICU, 10 were discharged less than 6 months prior, and 8 were discharged greater than 6 months. All families would recommend the experience to other families. All respondents rated their overall experience as a 5 out of 5 (1 = poor experience, 5 = excellent experience). Additionally, 94.74% of participants reported NICU photoshoots helped them feel more connected as a family. We were interested in whether families revisited the photos post-discharge. Results showed that most families revisited the photos often, even families who had been discharged home for greater than 6 months. Overall survey results indicated overwhelming satisfaction with the photoshoots and were viewed as a source of positivity. Participants described these sessions as uplifting and a vital break from the stress of NICU life; one respondent said "We looked forward to photoshoot day. It broke up the monotonous days for us." The photoshoots provided joy for the families in unit and allowed family members externally to engage through social media; one family shared, "We absolutely loved being involved in the NICU photoshoots. It was always exciting for us but also for our family who followed the BWH NICU Instagram to see all the pictures." These experiences fostered a sense of normalcy amidst the emotional NICU journey, enabling parents to focus on celebrating their babies and creating memories; another family shared, "Instead of beeping monitors all day long it was nice to take our minds off of those beeps and enjoy the holiday and our baby. It also helped make things feel a bit more normal in a crazy scary time of our lives!"

Conclusions: In the first year of the program, we saw an impact on morale in the NICU and an increased interest in participation from families and staff. The medical director conducted initial recruitment by individually seeking out potential families. As families were unfamiliar with the program, some shared concerns of posting their newborn on Instagram. However, as the photoshoots increased, eagerness increased. The team took careful measures to keep patient identifiers hidden and only included details in posts with parental consent. This attention to detail has led to an environment of trust and collaboration. Our survey results support that families found a sense of normalcy, beyond tubes and wires, by seeing their babies in costumes during holidays they would have been celebrating at home. NICU photoshoots enhanced emotional well-being for parents during a challenging time. With the growth of Project Milestones, the team established weekly meetings, coordinated in unit and external support, and resource alignment. Our family support specialist played a key role in connecting with non-profit organizations, such as Project Sweet Peas, former NICU families and independent donors, to provide supplies and costumes. Our Instagram has an increased engagement rate correlating with the consistent photoshoots. Next steps include validated surveys for families and staff, increased opportunities for all NICU families, and growing our Instagram presence. The Project Milestones team continues to provide opportunities for families to see their baby beyond the hospital environment, one photo at a time.

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Learning Objectives:

Describe the importance of creating opportunities for NICU families to bridge everyday life with their infants' NICU journey.

Define how NICU staff, administration, and families can collaborate to create positive family experiences in the NICU by celebrating special milestones.

Gravens 2025-24

Title: Phototherapy in the Skincubator, a feasibility laboratory test

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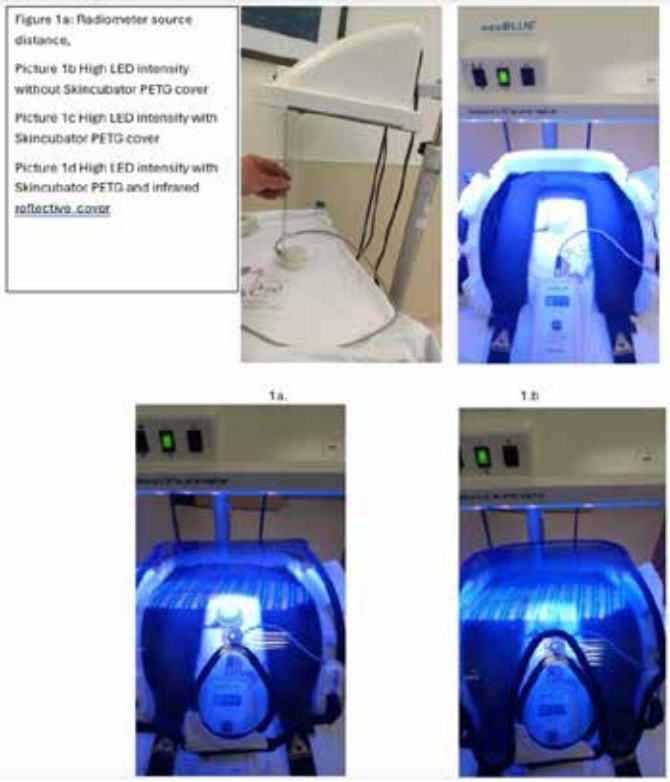
Problem Statement: Skin-to-Skin-Care (SSC) reduces morbidity and mortality in preterm neonates and also reduces bilirubin. However, need for phototherapy is one of the barriers for performing SSC for extreme preterm infants in some units. We hypothesized that the transparent Skincubator will not reduce the intensity of phototherapy in a manner that will prevent it's use during phototherapy.

Abstract:

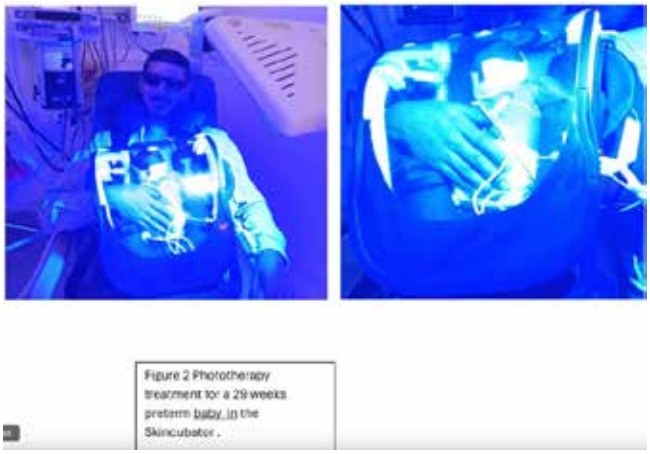
Background: In the first week of life preterm babies commonly receive phototherapy for neonatal jaundice. Traditional skin to skin care includes covering the baby with a blanket that is not transparent and hence prevent from using many phototherapy providing devices. Kangaroo mother care reduces serum bilirubin and hence enhances phototherapy. 1. Phototherapy during SSC is occasionally performed with phototherapy blankets however, this may be less effective than blue light-emitting diode (LED) lights. 2.The Skincubator is a transparent, bottomless, wearable incubator for skin to skin contact. The top part of the Skincubator is made from a PETG (Polyethylene Terephthalate Glycol) cover that is fully transparent to visible light. The Skincuabator has an additional layer that radiates back into the skincubator heat emitted as infrared light that is applied if needed in order to improve heat preservation. This layer reflects back 70% of infrared and has 70% transparency for visible light. Hence, it the Skincubator has the potential to enable phototherapy with traditional phototherapy providing devices.

Aim: To evaluate Phototherapy intensity in the Skincubator.

Methods: A NeoBlue Led phototherapy system (Natus Medical incorporated, Wisconsin USA) unit was placed 30 centimeters from a NeoBlue LED phothotherapy radiometer (Natus Medical incorporated, Wisconsin USA).Phototherapy intensity was tested with and without the Skincubator PETG cover, without changing the location or relative configuration of the phototherapy source or the detector. This was performed for high and low phototherapy intensities. In addition, after documenting the phototherapy intensity with the PETG cover the Skincubator infrared reflector was applied on top of the PETG cover. The combined intensity reduction of the PETG cover and the infrared reflector was then documented for high and low phototherapy intensities.



Results: Phototherapy measured intensity using high intensity was 58.5 μW/cm^2 per nm without the Skincubator PETG cover. Applying the PETG cover reduced the intensity by ≈10% to 52.2 μW/cm^2 per nm. Applying the infrared reflector upon the PETG cover further reduced the intensity by additional ≈25% to 37.6 μW/cm^2 per nm. When using low intensity setting, the measured intensity was 19.7 μW/cm^2 per nm without the Skincubator PETG cover. Applying the PETG cover reduced the intensity ≈10% to 17.6μW/cm^2 per nm. Applying the infrared reflector upon the PETG cover further reduced the intensity by additional ≈25% to 12.6 μW/cm^2 per nm.



Conclusions: The Skincubator PETG cover mildly reduces phototherapy intensity by 10% when using high or low intensity phototherapy, and keeps phototherapy in the higher range of high and low intensities. Even when using the infrared reflector, high intensity phototherapy that is defined >30 μW/cm^2 is achieved. From our laboratory study it seems that phototherapy within the Skincubator is reasonable for the vast majority of preterm babies. The exception are rare cases with extremely elevated bilirubin

level that are in threatened need of exchange transfusion. Clinical studies of phototherapy within the Skincubator are needed to confirm our findings.

Impact: Skin-to-Skin-Care reduces morbidity and mortality in preterm neonates and also reduces bilirubin. However, need for phototherapy is one of the barriers for performing SSC for extreme preterm infants in some units. Providing methods to perform phototherapy during SSC may increase the rate of this life saving and brain saving intervention.

Learning Objectives:

1. To know the advantage of SSC in reducing bilirubin and enhancing phototherapy.
2. To state several ways to perform phototherapy during SSC.

Gravens 2025-25

Title: Financial Hardship in Neonatal Care: Development of a Conceptual Framework

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Problem Statement: Within neonatal care, there is limited understanding of financial hardship, lack of standardization for defining and measuring the concept, and its distinction from other terms. Therefore, the purpose of this study was to develop a conceptual framework of financial hardship for neonatal care to guide neonatal nursing practice and research. This conceptual framework is important because it addresses a critical but often overlooked aspect of neonatal care: the financial hardship faced by families. Neonatal care, which can be highly specialized and costly, can impose significant financial burdens on families that may not only affect their finances but also impact their mental and physical health, relationships, and quality of life. This work is also an important aspect of family centered care by acknowledging and prioritizing financial well-being as a fundamental component of family health. It supports healthcare providers in recognizing the full scope of a family's experience, including non-medical factors.

Abstract:

Introduction: One in ten infants born annually will need highly specialized and costly neonatal medical care. One unintended consequence of this specialized care is financial hardship, which can adversely affect family health and quality of life. The concept of financial hardship was first introduced by oncology researchers and defined as the adverse financial consequences resulting from a cancer diagnosis. More broadly, financial hardship is understood as the distress and hardship caused by overwhelming healthcare costs. The relevance of this concept extends far beyond cancer care, impacting various healthcare settings, including neonatal care. Furthermore, focusing on financial hardship and addressing how these financial stressors impact family well-being is an aspect of family-centered care (FCC). Family-centered care emphasizes supporting the whole family, considering their needs, values, and preferences, and involving them in decision-making processes. Despite the growing awareness of the financial implications of neonatal care, there remains a significant gap in research exploring its prevalence, impact, and potential solutions within this context. Within neonatal care, there is limited understanding of financial hardship, lack of standardization for defining and measuring the concept, and its distinction from other terms. Therefore, the purpose of this study was to develop a conceptual framework of financial hardship for neonatal care to guide clinical practice and research.

Methods: This conceptual framework was informed by a systematic search of published literature describing financial hardship, financial burden, or financial toxicity in neonatal care. Our search was conducted in Ovid Medline, Elsevier Embase, EBSCOhost CINAHL, and Clarivate Web of Science and included peer-reviewed studies available in English. Results. The search yielded 1825 articles. Covidence software was used for data management and data extraction was completed on 32 articles using an excel matrix, including information about how financial hardship was conceptualized and measured. Related terms such as financial stress, worry, strain, hardship or burden, and economic hardship, burden, or strain are also defined and include information about the similarities and differences. The conceptual model focuses on factors related to the familial costs of neonatal care, or the financial bills the family is directly responsible for. The model includes important elements such as the objective and subjective measurement of financial hardship and rationale for deciding how to measure financial hardship, and the various ways of categorizing healthcare expenses (e.g., direct medical, direct non-medical, indirect, and intangible costs). The conceptual model was also informed by relevant qualitative studies highlighting cross-cutting themes such as "financial constraints", "limited resources and limited reach financial assistance programs", "financial burden", "mental load of financial decision making" (e.g., worry, stress, management of transportation, childcare, visits, etc).

Conclusion: Even though financial hardship exists in neonatal care, this phenomenon is not well described, and the current evidence is difficult to synthesize given the heterogenous nature of the studies. This work addresses a vital gap in our understanding of the financial consequences of neonatal care by offering a framework to guide future research, and ultimately inform tailored interventions that reduce the risk of financial harm and improve family financial health. This framework could guide policies or resources that alleviate financial burdens for families, such as financial assistance programs or support services, an important aspect of FCC. With this conceptual framework, we can stimulate attention and bring clarity to this significant issue by prioritizing the family's financial and emotional needs, integrating those needs into neonatal care practices, and paving the way for interventions that reduce financial harm and enhancing family resilience and support throughout neonatal care.

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Learning Objectives:

1. Participants will be able to identify key themes and factors

contributing to financial hardship.

2. Participants will be able to describe the main elements of the conceptual framework to support their research and clinical practice.

Gravens 2025-27

Title: Transforming Preterm Oral Feeding with Innovative Algorithms: Insights from a Qualitative Improvement Initiative

Authors: Rena Rosenthal, Jean Chow, Erin Sundseth Ross PhD, Rudaina Banihani MD, Natalie Antonacci, Karli Gavendo, Elizabeth Asztalos MD

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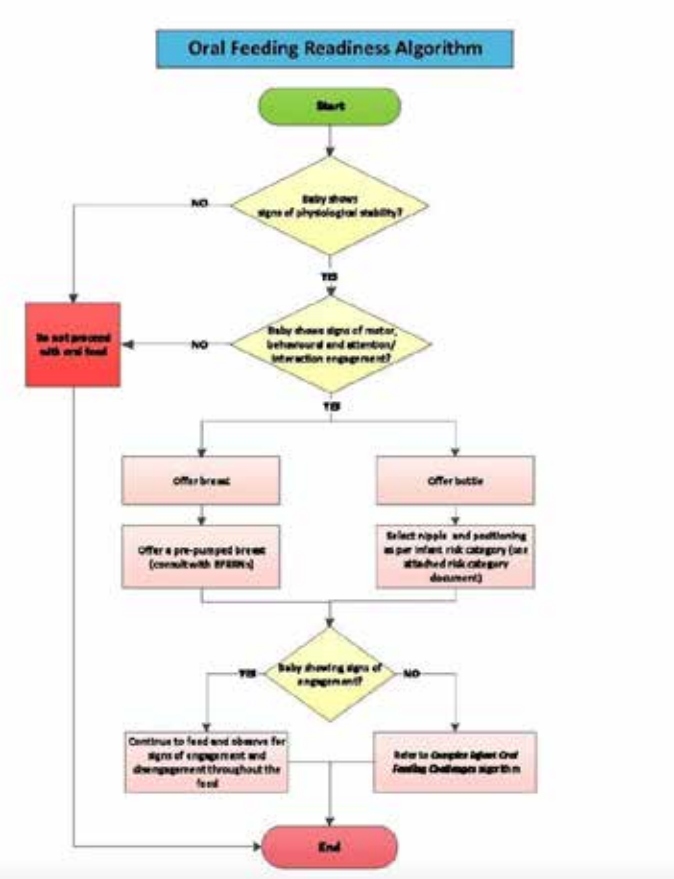
Problem Statement: Establishing safe, efficient oral feeds for preterm infants is a crucial yet challenging milestone before NICU discharge. This process is often accompanied by heightened stress and anxiety among NICU staff and parents, as nonlinear feeding progression and a lack of standardized protocols add uncertainty. Without a structured approach, feeding practices rely heavily on individual experience, leading to inconsistent care and increased caregiver stress. This quality improvement initiative at Sunnybrook Health Sciences Centre, a tertiary perinatal care unit in Toronto, Ontario, was conducted to address these challenges and to improve the transfer of knowledge around preterm oral feeding practices.

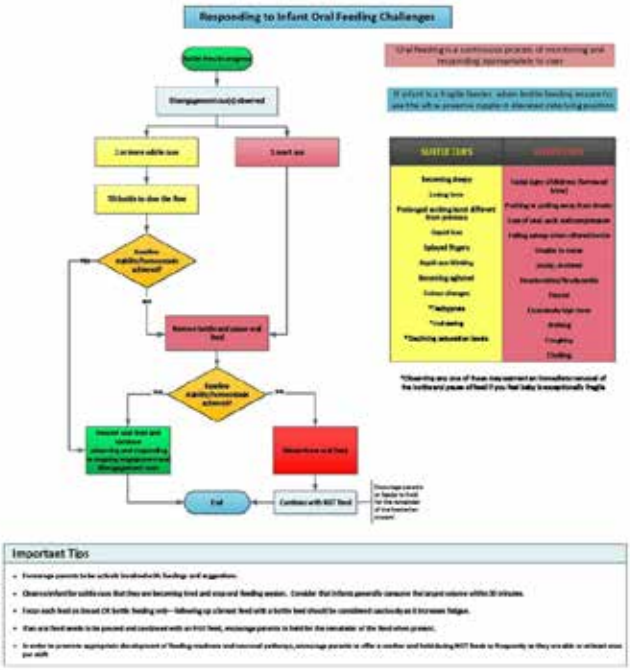
Abstract:

The primary aim was to create a structured, evidence-based approach to oral feeding that is adaptable to both breast and bottle feeding, reduces variability, and ensures consistent practices across all caregivers. This structured approach not only promotes safer and more effective feeding but also supports caregivers, including parents, by providing clear, actionable guidance. Why This Matters: Oral feeding is fundamental to preterm infant development and readiness for discharge. Inconsistent feeding practices can delay feeding milestones, prolong NICU stays, and negatively impact caregiver confidence. A standardized approach reduces reliance on subjective decision-making, allowing caregivers to provide more uniform, cue-based feeding that aligns with each infant's needs. Improved feeding practices lead to reduced anxiety, smoother transitions to home care, and better developmental outcomes for preterm infants.

Methodology: The COVID-19 pandemic highlighted a pressing need for knowledge transfer in feeding practices, as high staff turnover introduced variability in the NICU. In 2020, the multidisciplinary Sunnybrook Feeding Committee was established, comprising physicians, nurses, nurse practitioners, occupational therapists, and dietitians. Initial staff training used Supporting Oral Feeding in Fragile Infants (SOFFI®) modules to create a consistent understanding of feeding principles. With guidance from the SOFFI® creator (Consultant), our committee adapted these modules to develop two specific, tailored algorithms: the Oral Feeding Readiness Algorithm and the Oral Feeding Challenges Algorithm. Oral Feeding Readiness Algorithm: Assessing feeding readiness before each feeding, it applies to both breast and bottle



feeding. Based on infant cues, this algorithm provides structured steps to determine readiness, initiate feeds, or pause. Oral Feeding Challenges Algorithm: Targeted for fragile preterm infants born under 26 weeks gestation, it provides step-by-step guidance for bottle feeds, directing caregivers in assessing challenges, implementing specific interventions, and deciding when to revert to gavage feeding. Data Collection and Evaluation: Approximately 80 NICU staff members participated in surveys and focus groups, offering qualitative feedback on the algorithms' impact. Data



indicated that caregivers experienced a significant reduction in stress due to the clear, consistent framework provided by the algorithms. The algorithms introduced a reliable YES/NO decision flow, enabling caregivers to respond confidently to infant cues, such as engagement or disengagement, and adjust feeding practices accordingly.

Results: The algorithms demonstrated notable improvements in caregiver confidence, communication, and consistency in feeding practices. Staff surveys revealed that the structured protocols reduced variability clarified feeding readiness, and challenged decision-making. The algorithms ensured a universal language and framework for all care providers, reducing subjective variations and providing clear guidance for safe, supportive feeding practices that align with each infant's cues. These changes reduced stress and anxiety for both staff and parents, creating a more cohesive NICU environment focused on supporting infant well-being.

Conclusions and Future Directions: This initiative represents Phase 1 of a broader effort to transform oral feeding practices in the NICU, establishing a foundation for consistent knowledge transfer and scalable feeding support. The development and integration of these algorithms provided a reliable, evidence-based approach that aligns with infant cues, facilitating a smooth transition from NICU to home. Moving forward, our next phase will focus on refining the algorithms, adapting them for parental use, and developing a comprehensive training program for families to support safe, consistent feeding practices post-discharge. In sum, this structured approach provides caregivers with tools for confident, informed feeding care, reducing stress and enhancing outcomes for preterm infants. The ongoing work underscores the critical role of knowledge-based protocols in clinical practice, advancing sustainable knowledge transfer across caregivers and contributing to the long-term developmental success of preterm infants.

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Learning Objectives:

1. To recognize and understand that oral feeding is a dynamic relationship between the infant and its caregiver and cannot be determined by corrected gestational age alone.
2. To learn a structured and evidence-based framework for initiation and advancing oral feeds so that its adjustments objective and not solely dependent on the experience of the feeder.
3. To understand the importance of supporting safe oral feeding in the transition from NICU to home.

Gravens 2025-28

Title: Sustaining a Nurturing Culture

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Problem Statement: How do we shift the unit culture to change perception that nurturing encounters are as essential to outcomes for Neonatal Intensive Care Unit (NICU) patients as providing medications and other life-saving procedures? This is important as we strive to minimize the deleterious effects from sustained or repeated stress, thereby promoting resilience in these vulnerable infants.

Abstract:

Background: Premature infants are thrust into a world full of experiences that they may not be neurologically developed enough to process or understand. In the NICU environment, infants are bombarded with noxious stimuli and must undergo life-saving procedures that often induce stress and pain. Emerging literature suggests that balancing these stressors with positive and nurturing stimuli can positively affect neurosensory development of the brain [1][2]. Creating a space that is developmentally appropriate and encourages positive interactions between the world and the infant, enhances the unit culture that supports developmentally supportive care.

Methods and Results: Utilizing a quality improvement framework, we set out to develop a program to enhance nurturing encounters in our NICU. Initially, we focused on one small age-group of infants, setting our SMART aim to increase the total time spent providing nurturing encounters a micropremature infant experiences in the first 2 weeks of age by 15% by December 2021. We developed a unit policy on neuropromotion including clear definitions of NE activities and a NE documentation paper tool for families and staff. To further enhance consistent, accurate, and easy documentation of NE, we modified our electronic medical record (EMR). Usability testing was conducted of the documentation and compliance with the documentation form evaluated. We then focused on improvement in the total minutes of NE for micropremature infants in their first 2 weeks of age. Formal and informal education sessions provided bedside staff the rationale for the aforementioned changes in practice. To further support the nurturing care model, our team created an annual event to raise awareness of NE, a unit-wide challenge to increase total number NE minutes. Throughout the month of October, "Autumn Leaves and Cuddles Please" provides learning material and incentives for staff and families alike to enhance understanding and celebrate the importance of nurturing encounters. This run chart (Figure 1) depicts the incremental improvement of NE time. Over time, we found that NE time fluctuates based on acuity and busyness of the unit (Figure 2), and we questioned what more could be done to increase the amount of NE occurring in our unit. Surveys were distributed to families and clinicians in the Sunnybrook NICU to further characterize the local need. Amongst clinicians, most respondents (68%) did not feel they had enough education related to the various stages of neonatal sensory development.

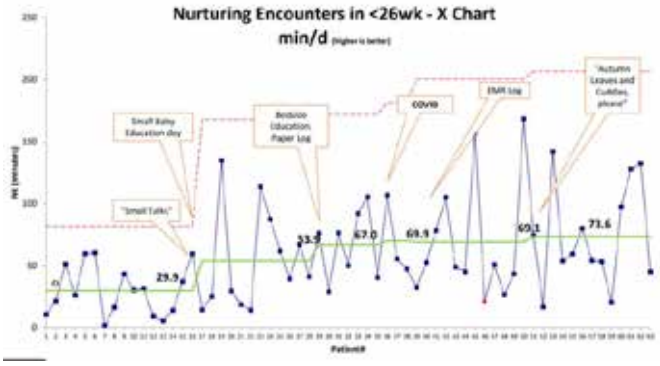
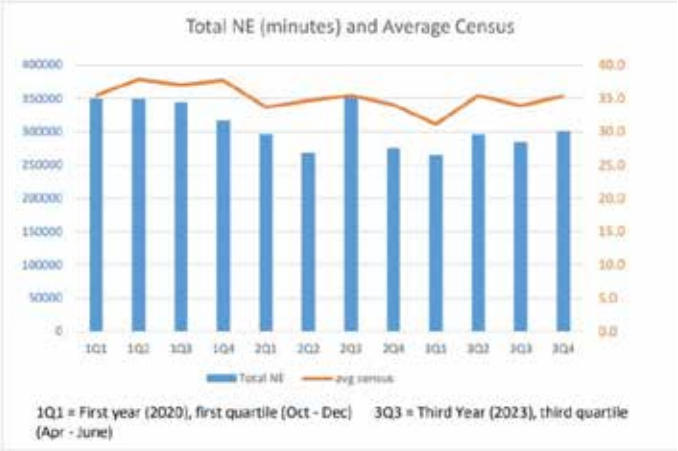


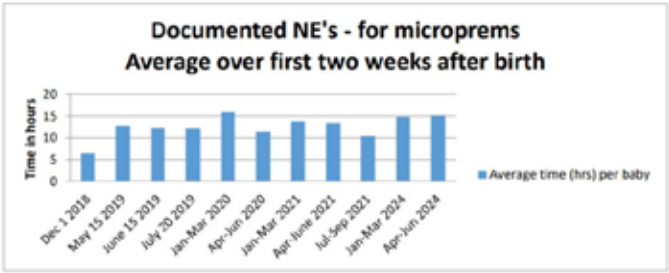
Figure 2



One-third (32%) did not feel that they knew the difference between neuroprotection and neuropromotion, a central tenant to providing developmentally appropriate care. In addition, 31% did not feel comfortable teaching parents about their baby's brain development. In the family survey, all parents (100%) identified that nurses were the most important person they relied on to learn about their baby's development. Parental surveys further identified families had information about hand hugs and kangaroo care (KC) but lacked information about developmental stages. We identified a significant knowledge gap in stages of sensory development of a preterm infant. Using information from the literature, interviews and the gap analysis, our multidisciplinary team created the Sensory Developmental Care Map (Figure 3). This map, placed at every bedside, shows a gradual onset and/or offset of activities based on developmentally age-appropriate readiness. It is a pictorial guide on the ontogeny of senses development, along with protective and promotive strategies at different gestational ages. It is one chart that can guide appropriate care activities throughout the continuum of their NICU journey. It is a global presentation of sensory development along with appropriate strategies that can be used by families and clinicians alike. It uses language that is clear and consistent with that used in the Sunnybrook NICU. Maintaining a focus on nurturing activities, including educational opportunities for staff, an annual celebratory event, the use of a tool that is accessible for all families, and periodic feedback to staff and families about our ongoing NE data, builds capacity to sustain our quality improvement efforts.

Conclusion: We have implemented a comprehensive program to promote and normalize the culture of providing a nurturing environment for the developing brains of preterm infants in the NICU. Through small, incremental tests of changes, we have addressed the knowledge gap in sensory development and created tools to guide, document and encourage NE activities to promote sensory development in preterm infants. These efforts have led to a significant improvement in our primary goal of increasing total time spent in NE. In the most at-risk population of micropremature infants, this program has successfully achieved and sustained a three-fold increase in NE time (Figure 4). During the implementation process, we observed that unit acuity level, staffing challenges and levels of staff experience are key potential barriers to consistently providing NE. However, efforts to continue providing education on the impacts of pain and stress and how to mitigate these through positive, promotive activities has helped solidify the perception that NE is an essential intervention that will positively affect long term developmental outcomes.

Figure 4



Impact: All of these efforts together have, and will continue to shift our unit culture to one that prioritizes positive, family focused, nurturing encounters.

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Learning Objectives:

1. Understand the impact of stress and pain on infants in the NICU

2. Describe one hospitals approach to changing and sustaining a nurturing culture

Gravens 2025-29

Title: The Impact of Social Determinants of Health on Infant and Maternal Health Using a Reproductive Justice Lens

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Problem Statement: Despite efforts to improve perinatal healthcare, adverse birth outcomes such as preterm birth and

NICU admissions remain high in the U.S., disproportionately affecting structurally marginalized populations. Understanding how social determinants of health (SDOH) and maternal mental health, using a reproductive justice lens, contribute to these disparities is crucial to developing interventions that address root causes and promote equitable health outcomes.

Abstract:

Statement: Our use of the word maternal is not meant to be exclusive, however, we are using the language of the PRAMS survey in this abstract. We acknowledge the limitations of using the word 'maternal' and will address these limitations in the presentation.

Background: Despite national efforts to improve perinatal healthcare access and quality, rates of preterm birth, low birth weight, and Neonatal Intensive Care Unit (NICU) admissions continue to rise in the United States. These adverse birth outcomes disproportionately affect mothers and infants of color, Medicaid recipients, and those with chronic health conditions.1 Social determinants of health (SDOH) are recognized as significant contributors to maternal and infant health, underscoring the need for research frameworks that incorporate SDOH concepts. The Restoring Our Own Through Transformation (ROOTT) theoretical framework is rooted in reproductive justice (i.e. reproductive rights and social justice-based framework), emphasizes both structural and social determinants as root causes of health inequities.2 SDOH impacts on infant and maternal mortality and morbidity can often be traced to structural determinants unique to the United States, including slavery, Jim Crow laws, redlining, and the GI Bill. These determinants relate to SDOH factors such as food security, education, income, neighborhood conditions, housing, healthcare access, incarceration, and safety. Maternal mental health is another important but understudied factor influencing maternal and infant health outcomes. Thus, using a framework that account for root causes of health inequities can be leveraged to rigorously evaluate perinatal health outcomes in the United States, and assess the impact of mental health and mental healthcare access on outcomes to guide future research and clinical practice.

Aims: Using data from the Pregnancy Risk Assessment Monitoring System (PRAMS) 8 database3, we aim to (1) develop a structural equation model assessing pathways between SDOH (as guided by the ROOTT Framework) and infant and maternal health outcomes and (2) evaluate whether maternal mental health moderates the relationships between SDOH and health outcomes.

Methods: Data were analyzed from 13 states that included the SDOH supplement in their PRAMS 8 data collection. Institutional Review Board (IRB) approval was obtained from Marquette University. Variables from the PRAMS 8 database and the SDOH supplement were selected by co-authors based on their alignment with the ROOTT framework and conceptual measurement adequacy. Analysis used a weighted sample of 431,650, with 7,885 complete cases for analysis. Data were processed using STATA 18. Bivariate analyses examined relationships between SDOH measures guided by the ROOTT framework (e.g. food stability, education, income, access to healthcare, housing) and infant outcomes (e.g. preterm birth, NICU admission), maternal morbidity (e.g., hypertension/eclampsia, gestational diabetes, chorioamnionitis), and breastfeeding. Pre-identified covariates, including preexisting maternal health conditions, insurance, substance use, delivery mode, partner status, race, maternal nativity, and prior preterm birth, were controlled for in the logistic and linear regression models. Maternal stress, depression ever, and depression during pregnancy were then included int he models to evaluate for moderating effects.

Results: Preliminary findings indicate that preterm birth, NICU admission, maternal morbidities, and breastfeeding are significantly associated with SDOH measures linked to structural determinants in the United States. Access to healthcare, including timing of the first prenatal care visit, significantly predicted both NICU admission ($p < 0.0001$, 95% CI [0.877-0.936]) and gestational age at birth ($p < 0.05$, 95% CI [-1.46 to -0.161]). Both NICU admission and gestational age at birth were significantly predicted by maternal reports of emotional/physical abuse before and during pregnancy ($p < 0.05$, 95% CI [1.07-5.22] and $p < 0.05$, 95% CI [-1.22 to -0.13], respectively). Maternal morbidity was associated with multiple access-to-care and housing variables. For example, maternal gestational diabetes was predicted by lack of stable housing ($p < 0.01$, 95% CI [0.053-0.549]), and housing insecurity significantly predicted ever breastfeeding ($p < 0.05$, 95% CI [0.321-0.918]). There was a significant difference in predicted probability of breastfeeding ever between mothers with no prenatal care and those with any prenatal care. This difference was largest when mothers reported depression during pregnancy (OR=0.15, 95% CI: 0.022-0.92, p= 0.02). Similarly, the predicted probability of breastfeeding ever between mothers who reported not having a steady place to live and those with a steady place to live or had a place to live was significant, this difference was largest for mothers who reported depression during pregnancy (OR=0.13, 95% CI: 0.026-0.689, p=0.02). Final model results and recommendations are anticipated by December 2024. Conclusions: Early results indicate that SDOHs rooted in structural determinants are important predictors of poor maternal and infant health outcomes in the United States. Evaluating maternal and infant health outcomes through a reproductive justice framework reveals modifiable risk factors, including access to stable healthcare, safety, and housing. Our early moderating results also point to the possibility that any prenatal care may be protective. Our final analysis evaluating if and how the number of prenatal care visits influences maternal and infant health outcomes is forthcoming. Comprehensive healthcare provision must ensure early and consistent access to healthcare and resources for safety and housing stability to support maternal and infant health.

Impact: These findings have significant implications for state and federal policies affecting SDOH for mothers and infants. Policies such as permanent supportive housing services, tenant protections, extensions of Medicaid services and additional coverage through private insurance may have the most substantial impacts on maternal and infant health outcomes and require further support and research. Clinicians are uniquely positioned to advance these types of policies through advocacy and education efforts.

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2. *Roach J. ROOTT's theoretical framework of the web of causation between structural and social determinants of health and wellness. Published 2016. Accessed June 26, 2024. https://www.roottrj.org/web-causation*

3. *Centers for Disease Control and Prevention (CDC). Pregnancy Risk Assessment Monitoring System (PRAMS). Published May 20, 2024. Accessed October 28, 2024. https://www.cdc.gov/prams/index.html*

Learning Objectives:

1. Learners will be able to describe how factors such as housing stability, access to healthcare, and mental health impact birth outcomes and maternal health, using data

from the Pregnancy Risk Assessment Monitoring System (PRAMS) and the ROOTT framework.

2. Learners will be able to explain how maternal mental health, including stress and depression, can influence the impact of SDOH on preterm birth, NICU admissions, and breastfeeding, informing future research and clinical practices.

Gravens 2025-30

Title: Using a Trauma Informed Approach to Share Lessons Learned During My Transition from NICU Professional to NICU Parent

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Abstract:

I'd like to preface this submission by saying it is not data driven and may not fit in with the desired abstracts. I wanted to share my unique perspective as a NICU nurse educator who went on to experience the NICU as a parent. Trauma informed care is an integral part of family centered care. My pre-existing passion for both increased tenfold after our NICU experience. Learning from the lived experiences of our families is an imperative way to increase our ability to create safety and improve outcomes for our patients and their families.

Parenting in the NICU is anything but normal. Parents struggle to bond with and care for their new baby in a foreign, invasive, and traumatic environment. Neonatal professionals are uniquely positioned to foster resilience in parents and potentially mitigate the traumatic experience that often accompanies a NICU admission. Drawing from experiences in my personal and professional journey, this presentation will focus on how the healthcare team can develop relational awareness skills and subsequently improve the quality of relationships we build with our families. Specifically, this presentation will discuss the following: 1. awareness of the relational environment and communication skills, 2. implications and impact of power dynamics, and 3. the importance of parent/caregiver presence. This presentation will use a trauma informed approach to explore the ways the healthcare team can empower families in the NICU to advocate for their child(ren) and collaborate with the multidisciplinary team. This presentation will discuss how to implement specific actions such as active and empathetic listening, how to avoid toxic positivity, and how to cultivate space for the authentic emotions of NICU families.

Needs Assessment/Description of Presentation: Centering the experiences of the family is paramount to building collaborative, empowering relationships in the NICU. Cultivating resiliency in NICU families is primarily facilitated by the neonatal nursing team. Through sharing my personal experience transitioning from NICU professional to NICU parent, this presentation will discuss ways in which NICU team members can be a safe haven for families to thrive. Learning from the experiences of NICU families allows us to grow professionally, hold ourselves to a higher standard, and help our patients and their families start life from a place of acceptance, grace, and hope.

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1. *Barnes J, Vance AJ. Perspectives on Parenting in the NICU: Advocacy, Support, and Partnership. Adv Neonatal Care. 2024;24(1):1-3. doi:10.1097/ANC.0000000000001144*

2. *Govindaswamy P, Laing S, Waters D, Walker K, Spence K, Badawi N. Needs and Stressors of Parents of Term and Near-term Infants in the NICU: A Systematic Review with Best Practice Guidelines. J Earl Hum Dev. 2019;139(104839). doi: 10.1016/j.earlhumdev.2019.104839.*

3. *Schecter R, Pham T, Hua A, et al. Prevalence and Longevity of PTSD Symptoms Among Parents of NICU Infants Analyzed Across Gestational Age Categories. Clin Pediatr (Phila). 2020;59(2):163-169.*

Learning Objectives:

Recognize the impacts of birth related trauma and how it impacts the multidisciplinary team's relationship with the NICU family.

- Define toxic positivity and discuss how it is propagated in the NICU
- List three ways the neonatal team members can cultivate resiliency in NICU families

Gravens 2025-31

Title: Small wins for small babies: a program celebrating babies' successes helps parents cope with the hospitalization in neonatology

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Problem Statement: Neonatal hospitalizations are generally long and often complex, with periods of instability or stagnation. In studies, parents report that clinicians are often pessimistic and rarely focus on what is going well with their children. With this program, we want help parents cope and let them celebrate weekly accomplishments of their baby in the NICU.

Abstract:

Background: Parents in the NICU (Neonatal intensive care unit) often mourn a "normal" delivery and/or baby and may experience guilt, anxiety and sadness. Neonatal hospitalizations are generally long and often complex, with periods of instability or stagnation. In studies, parents report that clinicians are often pessimistic and rarely focus on what is going well with their children.

Objectives: The aim of this study was to describe the creation and implementation of a project to celebrate babies' achievements and progress throughout the hospital course in a large level 4 NICU and examine parental perspectives.

Methods: This project was suggested by parent partners and developed with them. In a feasibility and implementation study, 82 parents were investigated. Similar to the literature, they reported the lack of optimism in the NICU. They recommended weekly celebration of accomplishments, with picture and words. For example, "I now weigh 1000 grams," "I have received my mother's milk for one month," "I was read my first book" (figure).

The formats recommended by parents were both physical (receiving paper "certificates" that could be placed together as a garland above the baby's bed) and virtual (receiving a text, mostly recommended by fathers who resume work during the hospitalization). Some certificates were "generic" ("I was strong during my surgery") and chosen from a bank of certificates, while others had to be created when the situation of the baby was less stable (for example, "I met my grandfather who came all the way from France"). Families were included after one week of life. The inclusion criteria were 1) babies who were likely to be hospitalized longer than a month, 2) were likely to survive and 3) for whom we obtained parental consent. Every week, one or several certificates were brought to the baby's room and text messages were sent to the parents, including a picture, to celebrate an important weekly success, or if there was none, a message of encouragement. The corresponding "certificates" were also displayed above the baby's bed. We investigated parental perspectives about this program with a questionnaire sent via text at the end of the hospitalization.

Results: The parents of 136 babies accepted to participate and 128 received weekly certificates (8 babies died before the first certificate was given). The length of stay was on average 99 days, and the average number of certificates/texts received was 12 (range 3-40), for a total of 980 certificates received; 40% of parents answered the questionnaire sent one week post discharge. The overall evaluation (on 10) of parents for this project is 9.4; 85% of parents think it has helped them cope with hospitalization. 83% think that the weekly frequency is appropriate, the rest would want more certificates. Some suggestions were made by parents and have already been implemented during the project: removing and (mostly) adding some certificates, adding dates on certificates or having more certificates celebrating the bonding between fathers and babies. Parental answers to open-ended questions were all positive and they gave advice to new parents. "(it helps to) keep the light at the end of the tunnel in perspective!" or "be optimistic and above all patient". There were no adverse impacts associated with the project.

Conclusion: Sending text messages and weekly certificates to NICU parents to celebrate weekly accomplishments was appreciated. It celebrates their child's achievements and helps parents cope. It is possible to instill healthy optimism in the NICU.

Learning Objectives:

Describe the creation and implementation of a project to celebrate babies' achievements and progress throughout the hospital course
Examine parental perspectives about weekly small celebration of their babies' achievements

Gravens 2025-32

Title: Therapy BRIDGE (Bringing Real-Time Instruction via Developmental and Gestationally-appropriate Education/ Coaching) Program: A pilot study

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Problem Statement: Research has shown that caregiver involvement in their infant's care in the NICU helps to improve outcomes however there is often a gap between care provided in the NICU and discharge home. The overall objectives of the Therapy BRIDGE program were to 1) create a novel caregiver education and coaching intervention focused on infant development and caregiver needs to "bridge the gap" during the NICU-to-home transition and 2) pilot test the feasibility, acceptability, and efficacy of this program for infants and their caregivers.

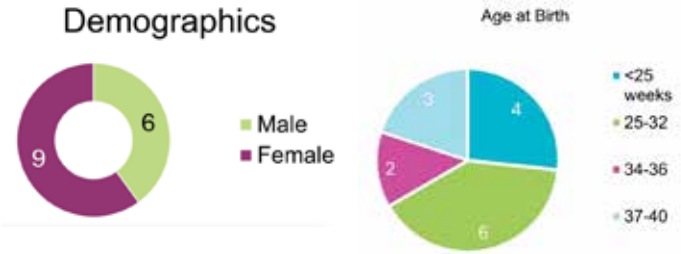
Abstract:

Introduction: Infants born with complex medical and/or surgical conditions are at high-risk for neurodevelopmental challenges (1). During their Neonatal Intensive Care Unit (NICU) stay, infants and caregivers receive continuous support and constant access to a variety of specialists. However, caring for these infants upon discharge can be overwhelming to caregivers in the absence of their care teams (2). Currently at our institution, there is no formal intervention in place to support caregivers as they transition their infant home from the NICU setting. This study focused on the development and implementation of a standardized caregiver education program, individualized to meet the needs of each infant-caregiver dyad to provide a safe and supportive learning environment to optimize outcomes.

Methods: The Therapy BRIDGE program was a prospective, longitudinal, non-randomized pilot study for infants diagnosed with intraventricular hemorrhage (IVH) and their caregivers. The study was conducted in our Level IV NICU as well as our affiliated outpatient therapy locations. The intervention, the Therapy BRIDGE menu, was created based on evidenced-based principles used in neonatal therapy and was individualized to meet the specific needs of the infant-caregiver dyads. The Therapy BRIDGE menu included various standardized educational topics to address development, feeding, socialization, and cognition. Therapists were given the opportunity to provide feedback regarding education points to ensure that appropriate topics were included prior to the rollout of the program. Once finalized, formal staff training was completed prior to the start of the enrollment process. This pilot study enrolled 15 infant-caregiver dyads. Infants were included if they were diagnosed with IVH and were admitted to the NICU. Caregivers were required to be 18 years of age at the time of enrollment. Infants were excluded if they transferred out of the NICU prior to discharge or if caregivers lived outside of the hospital service area. The Therapy BRIDGE program consisted of up to 10 therapy sessions across the inpatient and outpatient settings for each dyad. Therapy sessions

occurred in either the NICU or the hospital-affiliated outpatient clinic. Therapy sessions were completed by either an OT or PT or a combination of both, depending on the needs of the infant. Telehealth was offered to each infant-caregiver dyad however was not utilized during the study. The Therapy BRIDGE program aimed to promote carryover of education learned in the NICU through coaching to nurture the developmental needs of infants and the informational needs of their caregivers through evidence-based knowledge in developmental care and caregiver support. This study utilized both qualitative and quantitative variables; descriptive statistics summarized demographic variables and subject characteristics. The Canadian Occupational Performance Measure (COPM)3, caregiver surveys and therapist surveys were utilized, and data was collected directly into REDCap. Feasibility and acceptability were measured using 5-point Likert scales completed by caregivers and therapists. Feasibility was also measured by the total number of education sessions and home programs completed. Efficacy was measured by COPM data to identify clinically significant changes of caregivers' perception of their infant's occupational performance over time.

Results: At the conclusion of the study, 14 infant-caregiver dyads completed the program; one infant-caregiver dyad was lost to follow-up. There were nine females and six males enrolled. Gestational age and level of IVH are depicted in Figures (attached). Participants received an average of 4.2 sessions during their inpatient stay (SD 2.2, range 1-8 visits) and 4.3 sessions during their outpatient episode of care (SD 1.9, range 1-7 visits). Inpatient session durations averaged 23.7±6.0 minutes, and outpatient session durations averaged 50.5±4.7 minutes. Our data indicate that 13 out of 14 caregivers and 11 out of 12 therapists felt that the BRIDGE program was acceptable; 100% of caregivers felt the program was feasible. The data from the COPM indicate that 8 out of 14 infant-caregiver dyads had clinically significant change; additionally, 3 infant-caregiver dyads reported an increase in performance score over the course of the study however these increases were not clinically significant.



Conclusions: Our results indicate high acceptability and feasibility for the Therapy BRIDGE program from the perspective of both caregivers and therapy providers. This program demonstrates good potential to "bridge the gap" during the NICU-to-home transition for infants with IVH. The COPM data indicate that the majority of caregivers reported a clinically significant change in COPM scores for both performance and satisfaction, indicating good efficacy for the Therapy BRIDGE program. Overall, the Therapy BRIDGE program appears to help build confidence and competence for caregivers during the NICU-to-home transition, as evidenced by the high levels of feasibility and acceptability reported.

Impact: This novel caregiver education program can help build confidence and competence during the NICU-to-home transition. Of note, while the majority of infant-caregiver dyads reported a clinically significant increase in COPM performance and satisfaction scores, caregivers' perception of their infant's performance and associated satisfaction appeared to be influenced by the discharge to home environment and may explain the variability of satisfaction towards developmental goals at the conclusion of the

ID#	IVH Grade (R)	IVH Grade (L)	Gestational Age (Weeks, Days)
TB01	1	1	30w, 4d
TB02	3	4	24w, 6d
TB03	4	3	23w, 4d
TB04	1	0	26w, 5d
TB05	1	0	25w, 4d
TB06	0	1	39w, 3d
TB07	1	1	37w, 1d
TB08	3	3	27w2d
TB09	1	1	35w, 0d
TB10	1	1	26w, 6d
TB11	1	0	23w, 6d
TB12	1	0	34w, 0d
TB13	3	3	22w, 0d
TB14	0	1	29w, 6d
TB15	2	0	40w, 1d

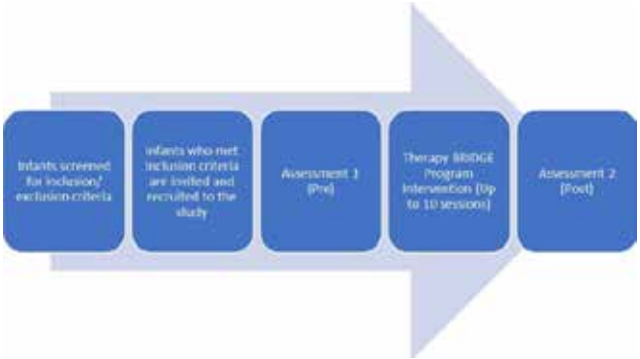


FIGURE 1: THERAPY BRIDGE PROGRAM TIMELINE

Therapy BRIDGE program. This could be attributed to increasing developmental demands, adjustment to home and/or change in perception of the infant's current abilities once in their natural environment. Despite this, the Therapy BRIDGE program has the potential to transform evidence-based care by promoting caregiver engagement in a safe learning environment during the transition from NICU to home. Overall, the Therapy BRIDGE program is feasible and can potentially be generalized to all infants in our NICU as well as in other institutions.

References:

1. *Spittle A, Orton J, Anderson P, Boyd R & Doyle L. Early developmental intervention programmes provided post hospital discharge to prevent motor and cognitive impairment in preterm infants. Cochrane Database System Review. 2015;1:CD005495.*

2. *Dusing S C, Tripathi T, Marcinowski EC, Thacker LR, Brown LF & Hendricks-Muñoz KD. Supporting play exploration and early developmental intervention versus usual care to enhance development outcomes during the transition from the neonatal intensive care unit to home: a pilot randomized controlled trial. BMC pediatrics. 2018;18(1):1-12.*

3. *Eyssen IC, Steultjens MP, Oud TA, et al. Responsiveness of the Canadian occupational performance measure. Journal of Rehabilitation Research & Development. 2011;48:517-528.*

Learning Objectives:

At the end of this presentation, the learner will:

1. Identify key aspects of caregiver education and benefits of standardized discharge planning to enhance developmental trajectories in order to optimize outcomes for babies in the NICU, as well as the caregivers and staff who interact with them.

2. Establish the need for a standardized, individualized, evidence-based caregiver education program that can be adapted to the unique needs of the infant and caregiver in the NICU setting and upon discharge home.

3. Prepare to implement customized caregiver education and coaching in your NICU setting to promote caregiver confidence and competence in preparation for discharge home.

Gravens 2025-33

Title: Hold Me Close: Broadening Skin-to-Skin Criteria in a Canadian Quaternary Care NICU

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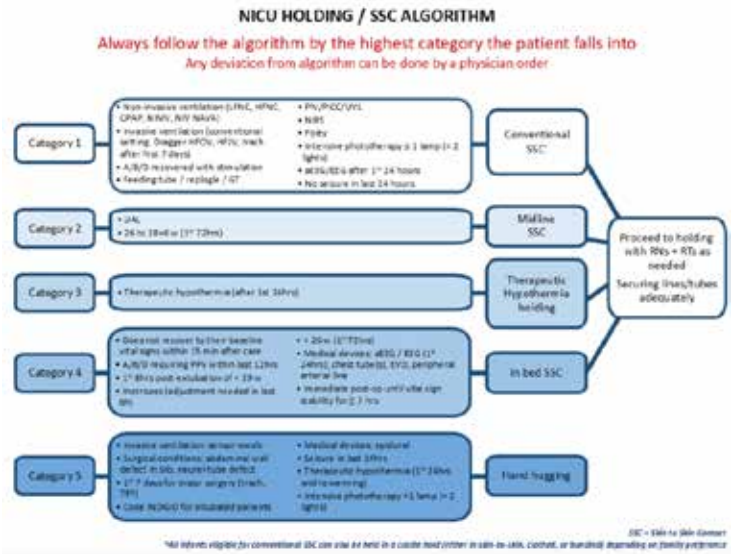
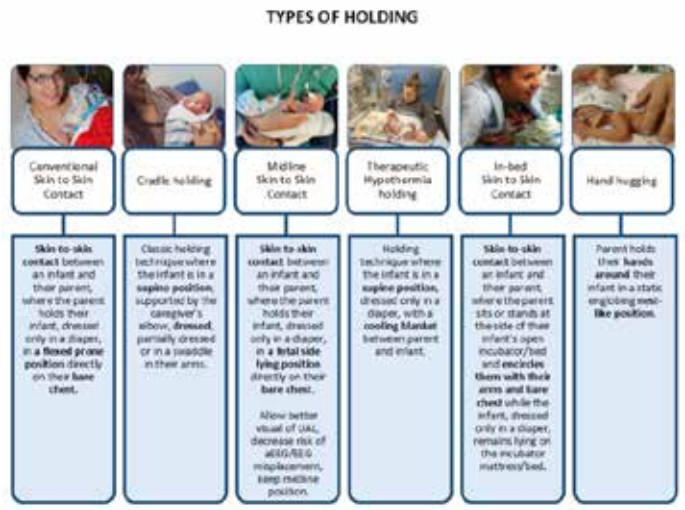
Problem Statement: Skin-to-skin care (SSC) has shown to be invaluable for infants and their parents in the Neonatal Intensive Care Unit (NICU). However, SSC and holding in Level III/IV NICUs in North America is not always implemented for acutely ill infants due to health-care providers' concerns with certain diagnoses, treatments and/or medical devices as well as patient stability and resources available. This quality improvement initiative sought to broaden the criteria for holding/SSC to enhance outcomes for both neonates and parents.

Abstract:

Method: In 2023, the NICU at the Montreal Children's Hospital (MCH) decided to focus on family engagement as a key quality indicator. Improving accessibility to skin-to-skin care (SSC) was identified as a strategy for engaging families, and multiple barriers to SSC were recognized. A review of the current medical guidelines at the MCH revealed that patients undergoing therapeutic hypothermia, extremely premature infants in the first 72 hours of life, infants with an arterial line, and infants on high-frequency jet ventilation were not considered eligible for SSC. While a SSC protocol was in place, these restrictions highlighted the necessity to review the protocol and expand the criteria to better support our most vulnerable patients and their families. After reviewing the literature and conducting an international benchmarking process, a multidisciplinary team—including two neonatologists, a nurse educator, a senior bedside nurse, and a lactation consultant—developed a new protocol where every baby is eligible for some form of SSC or holding from their family. The revised protocol underwent multiple iterations to incorporate and address feedback from all stakeholders. A newly created simple algorithm guided healthcare providers (HCP) on the type of holding/SSC that was most appropriate for the infant based on their current clinical status (Appendix I and II). Prior to implementation of the protocol,





a concentrated period of education was provided to the HCP working in the NICU over 3 weeks. Education included didactic presentations, hands-on simulation, educational videos and bedside coaching. In total, 82.5% of nurses and 88% of respiratory therapists working in the NICU participated in simulations and activities to practice holding/SSC for a baby undergoing therapeutic hypothermia, an extreme preterm with an arterial line, and a baby on high-frequency jet ventilation. Furthermore, several checklists were created for HCP to complete before transferring a baby to skin-to-skin contact, including guidelines for securing medical devices and safety checklists for specific populations. The protocol was officially implemented in May 2024 and made available online through our NICU internal database.

Results: Four months after the launch of the new protocol, a qualitative survey was done with nurses who had the chance to apply the new protocol with families. While they continued to voice concerns about insufficient human resources for safely performing holding/SSC with critically ill infants—worrying about potential line misplacement and unplanned extubation, despite no evidence of increased adverse events—they also expressed usefulness of the provided resources, including the algorithm, educational videos, and checklists. Additionally, they emphasized the importance of ongoing practice to maintain the skills they had learned. Nurses were also encouraged to write their names on the SSC "wall of fame" located in the main NICU hallway when they offered a new type of holding/SSC to their patients in order to maintain enthusiasm and awareness of these new practices. In total, three patients undergoing therapeutic hypothermia, two extremely premature infants in the first 72 hours of life, four infants with an arterial line, and one infant on high-frequency jet ventilation were offered holding/SSC multiple times in that period. Their families were also interviewed to obtain their perspective of the impact and safety of the new practices. Overall, the feelings expressed were positive, with most parents appreciating the ability to hold their child despite their medical fragility.

Conclusion: Some form of SSC or holding is feasible for all infants in the NICU, regardless of their diagnosis or clinical status. This new protocol provides clear guidelines, processes and support for providing holding/SSC to all infants. Important practice changes that have implications for HCP workload and patient safety are often difficult to implement and sustain. Adequate education as well as ongoing support and reinforcement are essential to sustain such practice changes. Current sustainability efforts rely heavily on the NICU lactation consultants, who visit with each family regularly to encourage them to participate in SSC and offer practical support to their nurses. Future steps to reinforce this protocol will have to include further simulations and peer mentorship to support a sense of safety amongst HCP.

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2. *Roark TH, DePriest D, Moore B, et al. Standardizing a method to safely perform kangaroo care for neonates while on high-frequency jet ventilation. Resp Care. 2019;64 (Suppl 10):3235709.*

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Learning Objectives:

At the end of this presentation, participants will be able to:

1. Identify what type of holding/SSC should be offered to critically ill infants with a variety of diagnoses, including extreme prematurity and hypoxic ischemic encephalopathy

2. Enumerate key steps in the process of implementing this practice change

Gravens 2025-34

Title: Characteristics of Communication in Interpreted and Non-Interpreted NICU Family Meetings

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Problem Statement: Family meetings in the neonatal intensive care unit (NICU) are widely recognized as a crucial aspect of family-centered care, which is associated with an array of parent and infant health outcomes. However, little is known about family satisfaction or the patient-centeredness of clinician communication during family meetings. The goal of this study is to characterize elements of communication during family meetings for both English and non-English speaking families.

Abstract:

Methodology: We audio-recorded first family meetings (family meetings occurring within the first week of life, with the goal of providing an overarching understanding of the anticipated NICU course) for infants born <35 weeks gestational age in a level III NICU in Massachusetts. We administered the "Communication Assessment Tool (CAT)," a validated Likert-scale questionnaire, to assess family satisfaction. Additionally, we will be applying the RIAS method - a standardized coding system enabling for a quantitative assessment of clinician-patient communication quality which has been widely used to evaluate medical interactions from audio-recordings - to the recorded meetings. Briefly, coders classify statements in audio-recordings according to predefined communication quality criteria (e.g. codes include medical questioning, biomedical information, and emotional support). Currently, we have 19 audio recordings (16 recordings of English-speaking families and 3 of non-English-speaking families). Of these meetings, 14 families have completed surveys, providing self-reported sociodemographic characteristics and responses to the CAT, offering quantitative family-provided data about families' meeting experience. We are preparing for the Roter Interaction Analysis Method (RIAS) coding application. Our aim is to report the following measures of communication quality: 1) Family satisfaction with communication during family meetings; 2) Ratio of duration of clinician to parent speech; and 3) Patient-centeredness (using the RIAS).

Results: Of the 44 families who consented to the study, we obtained 19 recordings (43%), 3 of which (16%) were performed with the assistance of interpreters. The subset of families represented in this study are described in Table 1; most families described themselves as White, English-speaking, and having high literacy, as shown by never needing assistance to read healthcare instructions. Using the CAT to report family satisfaction, parents broadly described their meetings as excellent, with the average score for all CAT questions being above 4.5. RIAS coding is being

completed to provide duration of clinician and parent speech as well as patient-centeredness, and we anticipate being able to present these results at the Gravens conference.

Table 1: Family-reported sociodemographic characteristics

Self-reported sociodemographic characteristics	n (%)
Maternal self-reported race and ethnicity	
White	11 (78.6)
Black or African American	2 (14.3)
Asian	--
American Indian or Alaska Native	--
Native Hawaiian or other Pacific Islander	--
Multiracial	--
Prefer not to answer	1 (7.1)
Hispanic or Latinx (n=13)	3 (23.1)
Languages spoken fluently	
English	11 (78.6)
Spanish	3 (21.4)
Cape Verdean	--
Portuguese	2 (14.3)
Other	3 (21.4)
Families speaking multiple languages	4 (28.5)
In which language do you prefer to conduct healthcare discussions? (n = 14)	
English	11 (78.6)
Spanish	1 (7.1)
Cape Verdean	0 (0)
Portuguese	2 (14.3)0 (0)
Other	
Family meetings using an interpreter	3
Highest level of education completed (n = 14)	
High School or less	1 (7.1)
Some college, but degree not completed	3 (21.4)
College graduate	4 (28.6)
Professional or graduate degree	6 (42.9)
How well do you speak English? (n = 14)	
Very Well	11 (78.6)
Well	0 (0)
Some	3 (21.4)
Not at all	0 (0)
How often do you need help reading instructions, pamphlets or other written information given to you in your preferred language by your doctor or your pharmacy? (n = 14)	
Always	0 (0)
Often	1 (7.1)
Sometimes	1 (7.1)
Rarely	1 (7.1)
Never	11 (78.6)

Conclusions: This study presents a novel assessment of first family meetings in the NICU, a highly vulnerable moment that provides an opportunity to communicate comprehensive medical management and for parents to ask questions, present concerns, and build trust with providers. Administering the CAT immediately after the meeting allows families to report their understanding and experience using a validated tool, and completion of the RIAS coding will allow for in-depth analysis of the types of interactions between clinicians and families during the meeting. This will provide a data-driven understanding of the first targeted update with a provider that families receive during their NICU stay. Preliminary results suggest that families are satisfied with communication during their first family meetings. However, these results are limited in generalizability at this time due to the small number and high literacy of participants. Implementation of this study has been challenging due to the variation in first family meeting completion. Only 43% of families who consented for the project had recorded first family meetings, due to a combination of missed recordings and meetings not occurring. We hypothesize that families are receiving information about their infants from different modes of communication, including phone calls and participation in daily NICU rounds. This highlights the need for continued understanding of preferred modes of information delivery for parents whose infants are admitted to the NICU.

References:

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3. *Sigurdson K, Profit J, Dhurjati R, et al. Former NICU Families Describe Gaps in Family-Centered Care. Qualitative Health Research. Published online July 25, 2020:104973232093289. doi:10.1177/1049732320932897*

Learning Objectives:

1. Recognize the research gap in assessment of clinician-family communication in the NICU
2. Describe two possible methods (the Communication Assessment Tool and the Roter Interaction Analysis Method) for quantitative assessment of family meetings

Gravens 2025-35

Title: Family Well-being Outcomes for Infants with Severe Bronchopulmonary Dysplasia: Comfort and Quality of Life Surrounding Transition to Home

Authors: Kathleen E Hannan MD MSCS; Stephanie L Bourque MD MSCS; Blair W Weikel MPH; Igor Shumskiy MD; Erica W Mandell DO; Satya S Houin; Laura G Sherlock MD

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Problem Statement: The objective of this project is to longitudinally assess discharge readiness and quality of life for high-risk infants with severe bronchopulmonary dysplasia and families.

Abstract:

Program & Methodology: Extremely premature infants who develop severe bronchopulmonary dysplasia (BPD) frequently require complex medical care and prolonged neonatal intensive care unit (NICU) stays. Consistent NICU provider teams and parental engagement are seen as key elements to optimizing their ongoing care. To best address these needs, our Level IV NICU created the multidisciplinary Supporting Preemie Respiratory Outcomes (SPROUT) clinical team in 2021. However, despite the perceived benefits of this model of coordinated care, little is known about the short and long-term outcomes of this population. The objective of this project is to longitudinally assess discharge readiness and quality of life for these high-risk infants and families. This prospective cohort study, beginning in 2022, focuses on premature infants cared for on the SPROUT clinical team. Criteria for the SPROUT team includes infants born at <29 weeks requiring invasive mechanical ventilation or non-invasive bilevel positive pressure support at 4-6 weeks of age. We assessed demographic and clinical data and utilized parental self-reported surveys administered during and after birth hospitalization through 36 months corrected gestational age (cGA).

Table 1. Cohort characteristics

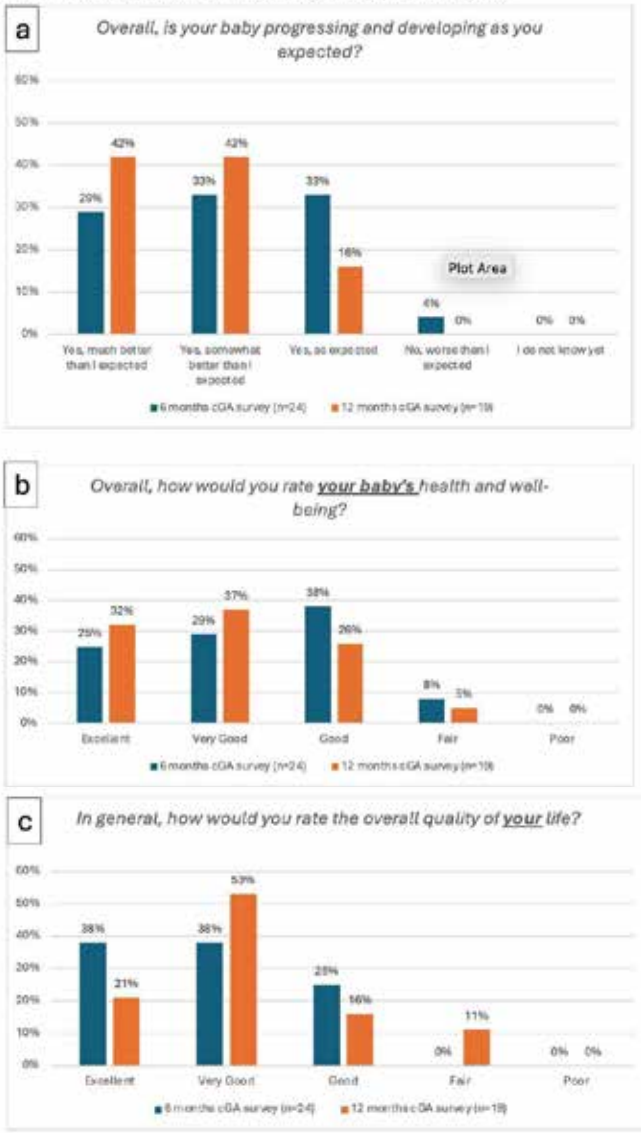
	SPROUT Infants (n = 34)
Gestational Age (weeks), median [IQR]	25 [24, 26]
County Designation (n = 29)	
Urban	26 (87%)
Rural	4 (13%)
Distance from Home to NICU	
<50 miles	26 (76%)
50-100 miles	3 (9%)
>100 miles	5 (15%)
Infant Race	
White	31 (91%)
Black or African American	6 (18%)
Asian	1 (3%)
American Indian or Alaska Native	2 (6%)
Native Hawaiian or other Pacific Islander	0
Other	3 (9%)
Infant Ethnicity	
Hispanic	11 (32%)
Not Hispanic	23 (68%)
Infant Insurance	
Private	19 (56%)
Public	31 (91%)
Health insurance purchased on own	3 (9%)
Military/Tricare	0
None	0
Other	2 (6%)
Maternal Education	
Completed HS/GED	9 (26%)
Some college	6 (18%)
College degree	15 (44%)
Beyond college	4 (12%)
Parental Employment	
Full-time	21 (62%)
Part-time	2 (6%)
2+ part-time jobs	1 (3%)
Unemployed, looking for work	3 (9%)
Unemployed, not looking for work	7 (21%)
Unpaid days off, median [IQR]	16 [0, 56]
Paid days off, median [IQR]	25 [0, 55]
Type of leave available	
Parental leave	14 (41%)
Short-term disability	9 (26%)
Vacation	12 (35%)
Other	9 (26%)
Household Income	
<$10,000	4 (12%)
$10,000-$49,999	7 (21%)
$50,000-$99,999	15 (45%)
$100,000 or more	8 (24%)
Clinical Outcomes	
Length of Stay (days) at Level IV NICU, median [IQR]	154 [117, 201]
Disposition	
Inter-Hospital Transfer	2 (7%)
Intra-Hospital Transfer	11 (39%)
Home/Medical Foster Care	15 (54%)
Gastrostomy tube	31 (91%)
Respiratory support at discharge/transfer	
LFNC continuous	9 (26%)
LFNC day, PPV night	9 (26%)
Trach/Vent	16 (48%)

Table 2. Domains from FIPRE survey at NICU discharge (n=34).

	Mean (SD)	% scores <75	Areas in each domain
NICU experience	91 (11)	24%	- *Felt things were explained in an understandable way* - *Staff responded to baby's needs* - *Included in baby's care* - *Able to reach doctor for questions*
Infant Well-Being	78 (19)	44%	- *Feels positive about infant's well-being* - *Infant receiving attention needed* - *Parent not concerned about baby*
Parental Well-Being	62 (18)	76%	- *Feels positive about own well-being* - *Confident/emotionally ready to care for infant* - *Does not feel overwhelmed*
Parental Comfort	56 (18)	74%	- *Little/no anxiety re: infant sleeping, eating, development* - *No issues with medical equipment* - *Minimal concerns about ongoing medical needs*

Prior to NICU discharge, enrolled parents received the Fragile Infant Parental Readiness Evaluation (FIPRE), a validated quality measure of parent outcomes and perceptions of NICU-discharge readiness. Subsequent surveys included the Fragile Infant Transition Summary (FITS), measuring parental self-confidence, coping and anxiety (referred to as parental comfort). Scores on these scales are converted to a standard 0-to-100 metric, with higher scores being more favorable, and scores <75 representing unfavorable outcomes. Mean scores were calculated for each category of the survey. Enrollment in the study and completion of surveys is ongoing.

Figure 1. Responses at 6 and 12mo cGA for each survey question (a, b, c)



Results: To date, 34 families have enrolled and completed the FIPRE survey, with 24 families completing the 6 month cGA survey, and 19 completing the 12 month cGA survey. Demographic and clinical characteristics are summarized in Table 1. Average gestational age at birth was 25 weeks. Median length of stay was 153 days. All infants required some form of respiratory support at time of discharge ranging from continuous low flow nasal cannula (LFNC, 26%), to daytime LFNC and nighttime positive pressure ventilation (26%), to chronic mechanical ventilation via tracheostomy (48%). Parents indicated overall positive NICU experiences and felt supported while in the NICU with a mean score of 91 (Table 2). Mean score for parental feelings of infant well-being was 78 (44% scored below 75). Parental well-being

(mean 62, 76% scored below 75) and parental comfort (mean 56, 74% scored below 75) scores were relatively low (Table 2) at time of NICU discharge. After discharge, parental feelings regarding infant's development and infant's quality of life (QOL) increased from 6 to 12 months cGA (Figure 1a and 1b, respectively). In contrast, self-reported parental QOL decreased, with 7% less reporting "excellent" and 11% more reporting "fair" QOL at 12 months cGA compared to 6 months cGA (Figure 1c).

Conclusions: The SPROUT team cares for medically fragile infants with a high incidence of medical technology dependence. Despite the medical complexity of these infants, families indicated positive experiences in the NICU and overall readiness for discharge. After discharge, parental assessment of their infants' development and QOL improved over time. However, parental reports of their own comfort and well-being were low at time of NICU discharge. Additionally, over time, parental quality of life scores decreased. The contrast of improving assessments of infant QOL with worsening parental assessment of their own wellbeing highlights an essential need for programs targeting parental support and preparation for the transition home.

Learning Objectives:

The objective of this project is to longitudinally assess discharge readiness and quality of life for high-risk infants with severe bronchopulmonary dysplasia and families.

Gravens 2025-36

Title: NICU Family Support

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Problem Statement:

1. Providing emotional and relational support to NICU parents and Families
2. It is important as it provides comfort, companionship, guidance and support during their time in the NICU.

Abstract:

The Valley Hospital Neonatal Intensive Care Unit Family Support Program has provided comfort, support and improvements in patient care by providing a family-centered approach to enhance the standard of care for infants and families. The program improves patient care by ensuring that communication is open and direct (face-to-face) with our families. We facilitate family meetings with the care team, provide educational materials and resources and work closely with the Developmental Care Team within our unit. Our program brings comfort to families by providing care before, during and after their admission into the NICU. We begin connecting with families as early as antepartum and remain in contact well beyond discharge. We provide sibling support. In addition, we provide bereavement support.

Learning Objectives:

1. What services/support can be provided
2. What does a parent need during their time in the NICU
3. How are these services delivered

Gravens 2025-37

Title: The physics of bottle systems: All bottle systems are not created equal

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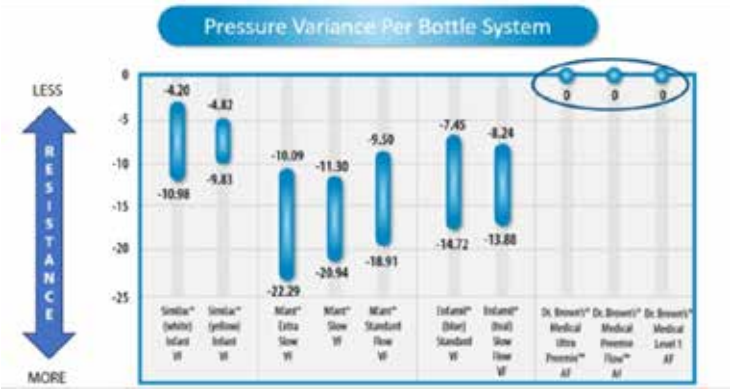
Problem Statement: While it is universally recognized that breastfeeding is the most preferred method of infant feeding, many NICU infants continue to feed from bottles during their hospitalization. Research over the past 10 years remains focused on nipple flow rates with minimal information on the physics of bottle feeding and how to best support infants. As studies by Lau (2000) and Fucile (2009) have speculated, the presence of sub-atmospheric pressure in a bottle system may have negative effects on an infant's feeding and may validate an infant will expend more energy making each feeding experience less efficient.

The intention of this internal study is to establish if and how much negative pressure (sub-atmospheric pressure) exists in "typical bottle-nipple units" (units) used to feed hospitalized infants (premature, late-preterm and/or medically compromised infants) when suction for liquid extraction is applied to the unit.

Abstract:

The method used in this study was designed to test typical bottle-nipple units under standardized and controlled conditions to compare the amount of sub- atmospheric pressure in each unit during the extraction of 60 mls of formula using a breast pump.1. On the bottom or side of each bottle vessel (Volu-Feed®, Dr. Brown's® Accu-Feed, Dr. Brown's® 2 oz and Dr. Brown's® 4 oz) a hole was bored, and a brass compression connector fitting was secured in each hole.2. Tubing from an M2 Series SMART Manometer, Model M200-C10015 made by Meriam Process Technologies was attached to the exterior connector on the fitting to record the pressure inside the bottle vessel during liquid extraction. Each unit (Table 1 below) was attached to the breast shield of a breast pump. A layer of plastic paraffin film followed by a silicone-based polymer was used to create a seal. The unit was held at a 30° angle with a mechanical arm (to assure consistency when holding each bottle-nipple unit during the testing). The stimulation-phase suction pattern with a suction pressure of 180 mmHg was used for all testing. A pressure manometer with 180 mmHg indicated with a red marking was secured to assure 180 mmHg was applied during each extraction. • The pressure inside the bottle system was consistently measured by the SMART manometer during the extraction of 60 ccs of Similac Advance Stage 1 (20 cal/oz) ready-to-feed formula (Abbott Laboratories, Abbott Park, IL). 1 • A consistent pressure of 180 mmHg was applied via the Medela breast pump until all the liquid was extracted from 5 different bottle-nipple units within the same bottle-nipple unit combination. • To assure consistency during the assembly of each bottle-nipple unit, 15 in/lb of torque was applied to each collar. Pressure recording was documented in writing every 5 ccs of formula extracted as well as each test was video-recorded to confirm measurements obtained. • Similac Advance Ready-To-Use formula (Abbott Laboratories, Abbott Park, IL) was used as the liquid for all testing. The formula was changed after 1 hour of exposure to prevent increased viscosity as a result

of denaturation of proteins from prolonged exposure to air. The manufacturer recommends using formula within 1 hour of opening or mixing. In addition, using the ready-to-feed formula reduced the potential for variability in milk thickness due to differences in formula preparation over time. All formula was disposed after 1 hour of opening and new formula was used to assure testing consistency.1 Measurement method similar to methods used in the 2015 Pados article on nipple flow rates.



Conclusions: Dr. Brown's® bottle system (unit) with the internal vent system consistently measured Zero (0) sub-atmospheric pressure during the extracting of 60 mLs of formula as measured according to the stated methodology. Units widely used in hospitals exhibit the presence of sub-atmospheric (negative) pressure during the extraction of formula (while suction is applied). It is speculated the increase in the amount of resistance in each unit presumably increases the amount of energy an infant exerts while feeding.

Implications for practice: 1. During bottle feeding in the NICU, the bottle-nipple units and how they function should be considered.2. Should a system with Zero-Resistance™ be considered when feeding infants in the NICU? With this report implicating the presence of sub- atmospheric pressure in a "typical bottle-nipple unit" while an infant is feeding, as Lau postulates, an infant could be expending more energy during a feed resulting in less efficient feeds.

References:

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2. *Lau C, Fucile S, Schanler RJ. A self-paced oral feeding system that enhances preterm infants' oral feeding skills. J Neonatal Nurs. 2015 Jun 1;21(3):121-126. doi: 10.1016/j.jnn.2014.08.004.*

Learning Objectives:

1. List at least one negative effect in the literature of negative pressure in bottle systems.

2. Describe the concept of Zero-Resistance in a bottle system and the potential in oral feeding.

Gravens 2025-38

Title: Implementation of the Hunger Vital Sign Tool to Assess Food Insecurity

Authors: Sheri L. Anderson and Janice L. Wilson, DNP, CRNP, NNP-BC, C-ELBW, FAANP

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Problem Statement: Resource insecurity stresses the parent-infant dyad and compromises nutritional status in breastfeeding mothers of hospitalized infants. On a Neonatal Intensive Care Unit (NICU) in an urban area with high prevalence of food scarcity, families are not screened for food insecurity (FI). Incorporating a standardized screening process can identify up to 59% of unmet family needs and enhance family-centered care.

Abstract:

Problem: Resource insecurity stresses the parent-infant dyad and compromises nutritional status in breastfeeding mothers of hospitalized infants. On a Neonatal Intensive Care Unit (NICU) in an urban area with high prevalence of food scarcity, families are not screened for food insecurity (FI). Incorporating a standardized screening process can identify up to 59% of unmet family needs and enhance family-centered care.

Purpose: The purpose of this quality improvement (QI) project was to identify NICU families at risk for FI by implementing an evidence-based, standardized screening tool. Methods: A QI project collaboration with unit social workers was carried out over 15 weeks in the fall 2024 and is currently ongoing until December 2024. The Hunger Vital Sign screening tool for identifying household FI was incorporated into the initial unit social work (SW) assessment. Assessment and monitoring were carried out via weekly unit data audit of the number of families screened, identified at-risk, and provided resources. Of the available evidence, several studies showed consistent screening can effectively identify FI (Lee et al., 2021; Markowitz et al., 2022; Parker et al., 2021). It is important to note that higher level evidence is limited in the neonatal population due to ethical constraints. Additionally, this QI practice change was further evaluated in the context of the geographic location. This hospital is in an area with FI rates above the national average, and the cost of intervention was weighed against the potential benefit to patient families given the likely prevalence in this specific patient population. The primary structure and outcome goal of the proposed project practice change was to modify the existing SW initial intake assessment to include the Hunger Vital Sign tool (Attachment1) to identify families at risk of FI. No license or permission is required for use. This tool, taken from the extensive U.S. Household Food Security Score, has a sensitivity of 97% and specificity of 83%. Any NICU family answering either screening question as "Often" or "Sometimes" were considered at-risk for FI, per tool instructions. There were no exclusion criteria for screening. Project data was collected via weekly chart review by the Project Lead based on SW intake notes in the electronic health record (EHR). Data was entered in the Research Electronic Data Capture (REDCap) tool hosted at

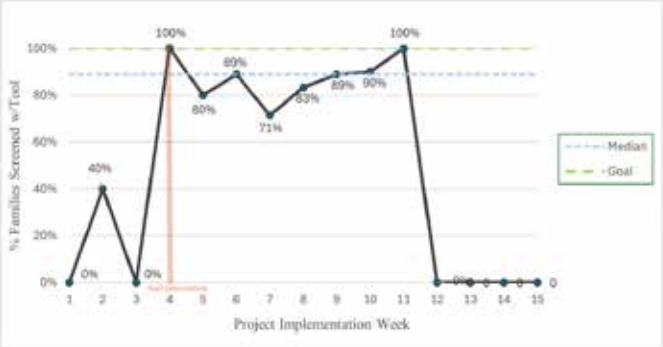
Attachment1

Hunger Vital Sign Screening Tool

Preface questions with "I ask all of my patients about access to food. There are many community resources available often free of charge for individuals. For each statement, please tell me if it was often true, sometimes true, or never true."	Date:		
	Often True	Sometimes True	Never True
1. Within the past 12 months I/we were worried whether our food would run out before we got money to buy more.	☐	☐	☐
2. Within the past 12 months the food I/we bought just didn't last and I/we didn't have the money to get more.	☐	☐	☐
"Often true" or "sometimes true" to any statement indicates the patient is at risk for food/nutrition insecurity.			

Attachment2

Project Progression of Family Screening for FI



Note. This figure demonstrates the weekly progress of project implementation showing the number of families screened for FI versus the total number of newly admitted families. The project goal is 100% screening.

Attachment3

Families Identified At-Risk for FI

Note. This figure demonstrates how many families were identified as "at-risk" for FI versus the total number of families screened.

Attachment4

Table of Resources Provided to Families

Type of resource	#	% of total intakes
Box Meal *(In-Hospital)*	2	2.3%
Community Food Resource List *(I.e. food banks, etc.)*	7	8.0%
Community Infant Supply Resource List *(I.e. car seat, safe sleep, bottles, diapers, etc.)*	26	29.9%
NICU Therapy/Support Group Referral	13	14.9%
Housing Referral *(Permanent or Post-Treatment Recovery)*	13	14.9%
Ronald McDonald House Charity Referral *(Temporary)*	12	13.8%

University of Maryland Baltimore School of Medicine. EHRs were accessed in compliance with facility regulations and protocols. No identifying participant information was extracted or utilized during project data audits. Project data was directly input into the secure, HIPAA-compliant REDCap database for research studies. There is no conflict of interest to disclose. Project lead is HIPAA and CITI compliant. Non-human Subject's Research determination from the Human Research Protections Office (HRPO) of the UMSOM Institutional Review Board (IRB) was approved prior to project implementation.

Results: At the time of abstract submission, the average weekly unit census was 45 patients with an average of eight new admission intakes per week. The screening tool was used on 86% of newly admitted NICU families since August 26, 2024 (N = 67) and revealed 9.0% (n = 6) were at-risk for FI and were provided additional resources. Quantitative results during the project period show 2.3% (n = 2) of NICU families required immediate food resources during the hospitalization and 8.0% (n = 7) received community food resource referral. The primary outcome measure was the number of families screened weekly with the FI tool during SW intake assessment, represented by a percentage of (number of families screened)/(total number of families admitted to NICU), shown as the run chart (Attachment2). The bar graph visualizes the relative proportion of families screened and identified "at-risk" compared with the weekly number of newly admitted families (Attachment3). The secondary outcome measures of: 1) the number of meals provided to families as the immediate intervention and 2) the number of families provided with community food resource referral (i.e. food banks, food pantries, etc.) are included in a table with other types of resources provided (Attachment4).

Conclusions: Several barriers to implementation occurred throughout the project period. Initially, data collection was delayed due to suspension of EHR. Facility policies led to the disabling of the Project Lead's EHR access with access reactivation not occurring until week three. Partial data was able to be collected ex post facto and is reflected as such in the results. Additionally, staff turnover within the core Project Team created a delay in the revision of the SW intake assessment and did not occur until week four of project implementation. This is reflected in the early project implementation weeks on the run chart of percentage of families screened (Attachment2). Finally, the lack of uniformity in tool implementation amongst covering social workers from outside departments has affected screening rates. While analyzing data variability of performance, a pattern revealed that weekend social workers covering the NICU were not documenting with the updated intake assessment. Aligning intake assessments across the broader Maternal Child Health SW Department remained a challenge for the duration of the project despite consistent communication and a continuous feedback loop. Patterns of variability in the data reflect these unanticipated situational contextual factors. This QI project validates the use of a standardized screening tool to assess FI in NICU families. Project results contribute to the existing body of knowledge on resource insecurities affecting NICU families. Ongoing research should further explore how these resource insecurities impact NICU infants and seek to determine best practices to support our families.

References:

1. *Lec AM, Lopez MA, Haq H, Yu X, Manning S, Quinonez R, Greeley C & Bocchini C. Inpatient food insecurity in caregivers of hospitalized pediatric patients: A mixed methods study. Academic Pediatrics. 2021;21(8):1404-1413. https://doi.org/10.1016/j.acap.2021.04.018*

2. *Markowitz M, Tiyyagura G, Quallen K & Rosenberg J. Food insecurity screening and intervention in United States children's hospitals. Hospital Pediatrics. 2022;12(10):894-895. https://doi.org/10.1542/hpeds.2022-006755*

3. *Parker MG, Garg A, Brochier A, Rhein LM, Forbes ES, Klawetter S & Drainoni, ML. Approaches to addressing social determinants of health in the NICU: a mixed methods study. Journal of Perinatology. 2021;41:1983-1991. https://doi.org/10.1038/s41372- 020-00867-w*

Learning Objectives:

1. Describe the impacts of resource insecurity and unmet basic needs on NICU families.

2. Illustrate the role of interdisciplinary collaboration in providing holistic care for the needs of families.

3. List at least two resources to help with food insecurity.

Gravens 2025-39

Title: Implementing A Music Therapy Program to Support Nurturing Encounters in the NICU

Authors: Teresa Ianni

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Teresa Ianni

Sunnybrook Health Sciences Centre

Problem Statement: Music Therapy in the Neonatal Intensive Care Unit (NICU) is a non-pharmacological, non-invasive and empirically supported intervention. Music Therapy is not widely offered in Canadian NICU's as it is not considered an essential intervention, rather a complementary therapy.

Scientific question:

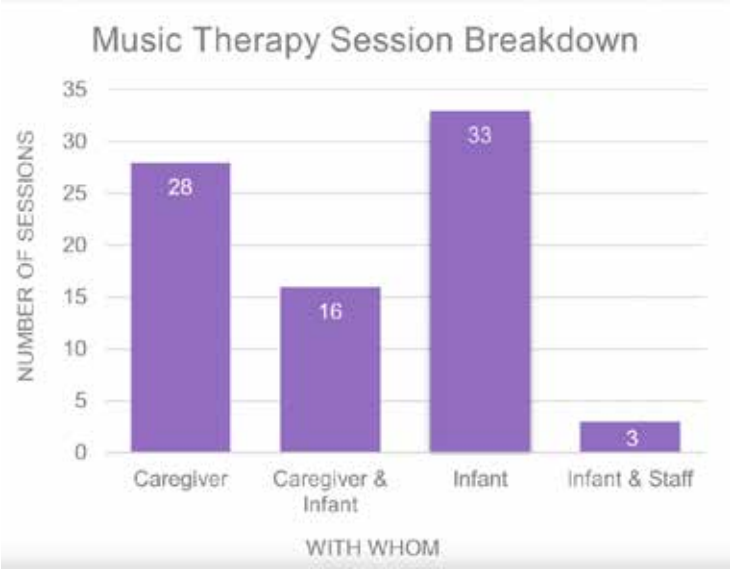
How do we shift NICU culture and perspectives, to recognize Music Therapy as a supportive and essential intervention? This is important as music therapy can optimize and enhance nurturing encounters, which are essential to neurodevelopmental outcomes for NICU patients.

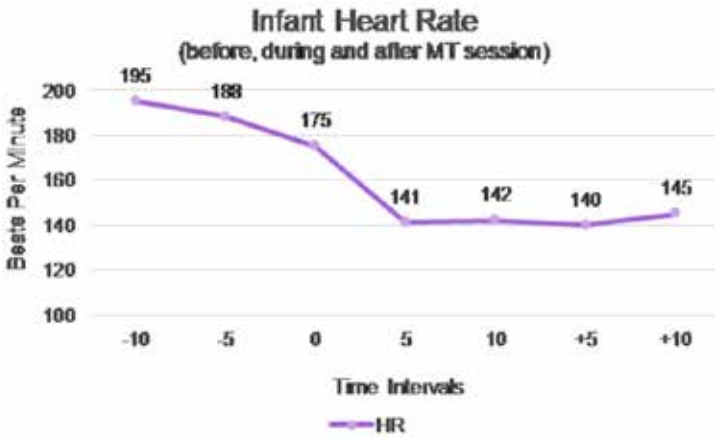
Abstract:

Background: The Sunnybrook NICU has established a strong unit culture in promoting and enhancing nurturing encounters. It includes creating a space that is developmentally appropriate and encourages positive interactions between the world and the infant and supports developmentally supportive care. Since October 2022, the implementation of a Music Therapy Program in the Sunnybrook NICU has contributed to providing age-appropriate neurological and sensory stimulation to hospitalized infants by reducing stress response, providing opportunities for positive social contact and by offering a form of environmental enrichment (Anderson & Patel, 2018). This intentional use of music has had positive effects on infants and their caregivers, as it provides unique and creative nurturing experiences. It is an important intervention when provided in an established NICU environment that values nurturing and developmentally supportive care.

Methods: A quality improvement project was carried out from October 2022-April 2023, entitled "Implementing a Music Therapy program in the Sunnybrook NICU." The aims and objectives of this project were to increase auditory and sensory stimulation and to reduce caregiver self-reported and perceived stress. Parental self-reported stress was measured using a standardized questionnaire pre and post music therapy session (Perceived Stress Scale; Cohen et al. 1983), and qualitative data was gathered in dialogue with caregivers. Neonatal physiological responses during music therapy sessions were captured via heart rate (HR), respiration rate (RR) and oxygen (O2) saturation from the infant's chart in 5 min intervals (10 minutes pre-session, during the session and 10 minutes post session), and trends were analyzed based on music therapy intervention used. Additionally, qualitative data was gathered on staff's perception of the intervention.

Impact: The quality improvement project provided music therapy support to infants born ≥ 32 weeks' gestation and their caregivers a total of 80 times (figure1). Interventions included the evidence-based use of gentle instruments to emulate heartbeat and womb sounds as well as the use of carefully selected or parent co-created lullabies. During music therapy sessions it was evident that there was a direct impact on the physiological response of infants. Fluctuation in infant's heart rates, respiratory rates and O2 saturations were observed in all instances, which indicated an appropriate response to the music and intervention presented. For example, music therapy was offered to an infant who had a medical procedure approximately 30 minutes prior. His nurse requested music therapy to support self-regulation as his heart-rate had been elevated since the procedure (trending around 200 bpm). Specific music therapy techniques were used to support this infant, and by the end of the intervention, his heart rate returned to baseline (figure 2), fell asleep and remained sleeping until his next handling time. After music therapy sessions, caregivers reported an overall decrease in their perception of stress and were appreciative of the supportive care provided to them. Music therapy was also able to support families where outcomes were unfavorable. Legacy work, including heartbeat recordings were used to support families during difficult transitions. In March of 2024, the Sunnybrook NICU implemented a pilot project, one day per week, to incorporate music therapy as a standard of care. The addition, of a dedicated Certified Music Therapist (MTA) to NICU has received positive feedback from families, caregivers, clinicians and medical staff. Since its implementation, the MTA has supported over 160 growing infants and their families as they cope and navigate through their unique situations. Staff feedback since the implementation has been positive and are supportive for this service to continue and grow in our unit. A registered nurse stated, "it is such an amazing addition to the care we can provide to decrease stress and anxiety for the families and bring joy to the





unit and nurses."

Conclusion: In the Sunnybrook NICU, music therapy was successfully integrated into our team culture as a supportive intervention for infants and their caregivers. It has been perceived as an effective tool to help reduce stress as they navigate through their NICU journeys and may have positive, long-lasting effects on their outcomes. The availability of a dedicated MTA needs to be evaluated to ensure that the needs of infants and their caregivers are met as the demands increase when the program continues to succeed. We envision that the success of such program for this unique patient population will position Sunnybrook as a leader in the use of music therapy as an essential treatment in the care of women and babies in Canada.

Learning Objectives:

1. Why Music Therapy is important for infants undergoing care in the NICU.
2. How to integrate music therapy to an NICU that does not have an established program.

Gravens 2025-40

Title: NICU Passport

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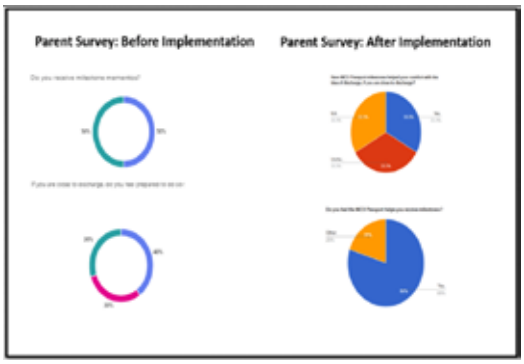
Problem Statement: The Neonatal Network at Nationwide Children's Hospital consist of four Neonatal Intensive Care Units (NICUs) located on Main Campus, and partnerships with delivery hospitals around Central Ohio. As a network, the NICUs were finding parental education and teach back was not being completed until close to or on the day of discharge. This created issues for staff and parents alike going over an extensive amount of information in an overwhelming environment.

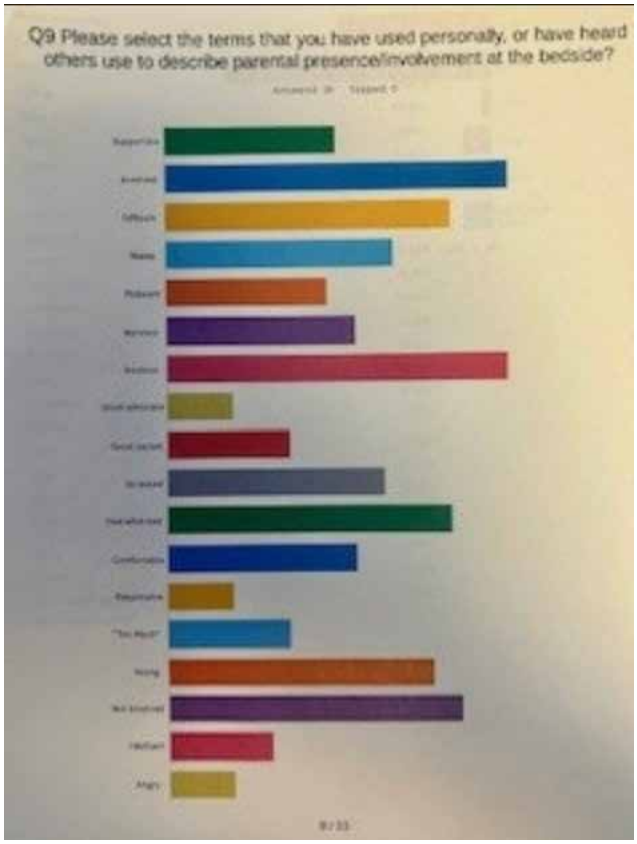
Increased support for family-integrated care was identified as a developmental goal for the C4C NICU in 2023 at Nationwide Children's Hospital, an initiative driven by robust evidence supporting family-integrated care in the NICU environment. We hypothesized that a focus on family- integrated care on our unit would increase parental involvement and readiness for discharge.

We found repeated studies showing significant medical improvements, better progression, improved feeding and breastfeeding outcomes and decreased caregiver anxiety and depression with the implementation of family-integrated care.

Abstract:

In March 2024, the Newborn Intensive Care Units (NICU) Passports program was released. The NICU Passport program is an interactive milestone memento that supports the implementation of family-integrated care that encourages caregiver participation in daily care. Through milestone stickers, photos, and handwritten notes, NICU Passports allow caregivers to have a journal of their NICU stay in a personalized way they have not been able to do before. To obtain a baseline perception of family-integrated care in our unit, qualitative surveys were sent to staff, and an interview-style survey was conducted with caregivers and families.38 staff surveys revealed conflicting perceptions of family-integrated care between dayshift and nightshift. Dayshift staff comments included "happy," "happy to help" and "like to be involved," as well as "difficult" and "frustrating." Nightshift staff comments included "nervous," "hard" and "uncomfortable". After further investigation,





nightshift staff cited overnight barriers to family-integrated care that included the limited amount of space at the bedside, parents, as well as staff, not knowing what the overnight expectations of parent involvement were or if they would participate at all in patient care overnight, and the difficulty of balancing sleep schedules. 17 caregiver survey responses regarding family-integrated care showed that only 44% of caregivers received milestone mementos throughout their NICU journey. Caregivers expressed wanting to receive involvement expectations of caring for their baby and wanting to participate within their comfort level while being taught what to do at each developmental stage. This research sparked discussion about how to help families become more comfortable in caring for their babies in a way that was fun and memorable for family and staff alike. NICU Passport development was a multidisciplinary collaboration between nurses, therapists, parent advisors, lactation consultants, marketing, and creative services. Nationwide Children's Hospital Neonatal Network staff provided input on the design and recommended milestone stickers for each unit. This collaboration allowed for inclusive representation of diagnoses and treatments seen throughout the Neonatal Network. NICU Passports went live in all four main campus NICUs at Nationwide Children's Hospital on March 1, 2024. 10 Caregivers were surveyed on C4C at the beginning of Passports' implementation regarding how they perceived their involvement in their child's care, receipt of milestone mementos, and preparedness for discharge. Seven caregivers were surveyed on C4C after implementing NICU Passports, and results showed that 80% said they received milestone mementos and 33% said they were more comfortable with the idea of discharge. This data reflects the positive impact the implementation of family-integrated care has on the success of families in the NICU environment. During our implementation process, language was identified as a barrier to the success of this project. To ensure health equity for all families in the NICU, NICU Passports are in the process of being translated into additional languages.

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Learning Objectives:

How implementation of NICU Passports increased mile-stone mementos supporting parental involvement.

How implementation of NICU Passports improved parental readiness for discharge.

Gravens 2025-41

Title: Implementation of Infant & Family Centered Developmental Care Standards in a BPD Program

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Problem Statement: Bronchopulmonary Dysplasia (BPD) is the most common pulmonary complication of preterm infants. This disorder often prolongs infants' needs for supplemental oxygen or mechanical ventilation, resulting in longer neonatal intensive care unit (NICUs) stays. A diagnosis of BPD also puts infants at risk of significant neurodevelopmental impairments that may persist into adulthood. The Infant and Family Centered Developmental Care Standards (IFCDC) provide evidence-based standards and competencies for collaborative team management of infants and their families through the continuum of care, from hospital to home. To support neurodevelopment and infant mental health, it is essential that the IFCDC evidence-based standards and competencies are considered and implemented by teams caring for infants and families in BPD programs.

In September of 2020, the Neonatal Intensive Care Unit at Lurie Children's Hospital of Chicago created a bronchopulmonary dysplasia (BPD) program. The patients that qualify for this program include infants born at less than 34 weeks gestation with severe BPD, defined as requiring significant respiratory support at 36 weeks post-menstrual age. The programs average census ranges from 11-15 infants, with many of the patients in this program require positive pressure or mechanical ventilation for several months. Developmental care principles and many developmental care practices were initially embedded in the program, including weekly developmental rounds with the multidisciplinary BPD team, extensive involvement of rehabilitative therapists and developmental specialists, and care coordination.

The purpose of this quality improvement report is to: 1) describe the use of the IFCDC standards and competencies to perform a gap analysis IFCDC for a BPD program, and 2) describe program improvements made to address gaps in IFCDC.

Abstract:

Methods: Over the past two years, members of the multidisciplinary BPD team conducted a gap analysis of IFCDC for the BPD program. This assessment utilized the IFCDC Principles Concept Model that includes individualized care, neuroprotection of developing brain, family involvement, infant mental health, and environmental protection supports our mission behind this program. Documents detailing considerations for the implementation of each of the six standards for IFCDC were also employed in the gap analysis. Where the team identified gaps, program improvements were planned and implemented using a systems' thinking in complex adaptive systems approach.

Impact and results: Although many existing practices supported the implementation of the IFCDC standards and competences in our BPD program, gaps were identified for each standard. For example, we identified a need to better support families in engaging in playful (arousal) activities that support development and strengthen parental confidence in interacting with their infants. Using a systems' thinking approach to implement change, the team successfully implemented a process for developing individualized developmental play plans in collaboration with families and a weekly NICU playgroup for BPD infants and families. Examples of the positive impacts these and other IFCDC practice changes resulting from our gap analysis include improved parental understanding their infant's behavioral communication, more comprehensive support for BPD parents, and increased family confidence in managing their infants' positioning. In this presentation, we will describe improvements made in the implementation of IFCDC in a BPD program relative to each standard, using exemplar case studies to describe results and impacts.

Conclusions: The IFCDC standards are essential to the planning and implementing IFCDC for the BPD population in NICUs. Through ongoing gap analysis using these standards, our NICU has successfully implemented many improvements to the IFCDC received by our BPD patients and families, resulting in positive outcomes.

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Learning Objectives:

1. Describe application of the six domains of Infant and Family-Centered Developmental Care Standards to a comprehensive NICU BPD program.

2. Identify competencies required to implement Infant and Family-Centered Developmental Care Standards with chronically ventilated patients.

Gravens 2025-42

Title: Examining the Single-family Room: Disruptive and Supportive Design for Family-centered Clustered Care in the NICU

Authors: Herminia Machry, PhD, EDAC; Marzia Chowdhury, PhD Candidate; Laurie Hay, BSN, RN, RNC-NIC, CBC; Lorena Muzel Gomes, B.Arch

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Problem Statement: In the neonatal intensive care unit (NICU), family-centered clustered care can be complex, unsafe, and inefficient, presenting flow disruptions that can lead to risks of infection, dislodgement of life support equipment, and improper swaddling. Recognizing the trend in designing NICUs with single-family rooms (SFRs), and the impact of the built environment on flow disruptions in healthcare settings, we examined how interior design factors can impact flow disruptions, contamination risks, and environmental hazards in the context of clustered care behaviors involving family and staff in the SFR, exploring design opportunities to prevent adverse events in family-centered infant care.

Abstract:

Background: In the neonatal intensive care unit (NICU), spaces and design features play an important role in the development of infants (Shepley, 2014), also impacting family engagement in infant care (Machry et al., 2023). Since the 1990s, several NICUs have adopted Single-Family Rooms (SFRs) to improve infant development and family-centered care, and while evidence favors the SFR in comparison to open bays due to improved infection control and family involvement in care (Jones et al., 2022), there is a need to further explore the varied sizes and spatial configurations of SFRs as to how they can support 'work-as-done' behaviors in the NICU, such as clustered care. Family-centered clustered care involves staff and family members collaboratively providing care for infants in a clustered manner, during specific time intervals, to control infant handling and sleep (Avaze & Babaei, 2023). However, clustered care can be complex, unsafe, and inefficient, presenting flow disruptions that can lead to risks of infection (Deshommes et al., 2021), life-support dislodgement (Feldman-Winter & Goldsmith, 2016), and improper swaddling (Baley, 2015). Evidence shows how flow disruptions related to the built environment can contribute to infection control in highly complex healthcare environments (Joseph et al., 2018). Furthermore, studies suggest that the built environment in ICU settings affect infection prevention behaviors such as handwashing and touch of contaminated surfaces (Verderber et al.,2021; Machry et al., 2021).

Purpose: We conducted a study to investigate how interior design factors in SFRs can impact flow disruptions, contamination risks, and environmental hazards in the context of family-centered clustered care behaviors in the NICU.

Methodology: Using a qualitative approach, we conducted the study in three phases between June 2023 and April 2024, exploring environments and flow disruptions at NICUs embodying the SFR model. The first study phase involved two focus groups conducted virtually, each involving four NICU staff experienced with SFR workflows. One group was from a level III NICU in Indiana, and the other group was from a level IV NICU in Florida. Phase two focused on interviews and field observations at a level III NICU in Kansas City, MO, where we interviewed 14 staff and 7 families to understand their experience with disruptions, hazards, and inefficiencies during family-centered clustered care tasks in the SFR such as infant holding, cleaning, and feeding. We also shadowed nurses and observed 13 clustered care events involving family and staff in the SFR, recording the number of people involved as well as their movement across the room during tasks. The final study phase involved physical mock-up simulations of potential design solutions for the SFR in the context of family-centered clustered care, as part of a graduate course. Students developed and evaluated design prototype ideas with the participation of nurses and experts in healthcare design. All data collected was thematically and graphically analyzed.

Results: We identified 14 flow disruptions affected by the SFR built environment, which were categorized into six types (contamination risks, injury risks, care disruption, care demonstration disruption, and care engagement disruption) and into high and low severity

levels. We uncovered environmental issues related to clutter, crowding, clean-dirty separation, and cord management in the SFR, identifying five main SFR design factors impacting flow disruptions during family centered clustered care: room layout; sink, surfaces and storage layout; room transition clearances; size of family-dedicated storage and surfaces; wall and ceiling utilization; and ergonomic design of furniture/equipment such as infant bed, family chair and side table, and cord management hooks.

Conclusions & Impact: Our study shows how the interior design of SFRs can be a resource to improve safety and efficiency in family-centered clustered care workflows. Also, our research shows SFRs of different sizes and configurations accommodating various occupancies (multiple infants, staff and family members in the room) and care complexities (different levels of infant care tasks and equipment needs), ultimately leading to important discussions and reflections around the current and future states of SFR design in terms of room size, shape, layout, ergonomics, and flexibility.

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Learning Objectives:

1. Understand the complexity of single-family rooms as a 'work-as-done' system during family-centered clustered care in Neonatal Intensive Care Units (NICUs).

2. Identify flow disruptions in the context of family-centered clustered care in the NICU, as to how they are affected by the interior design of single-family rooms.

NICU Key Outcomes Measures

3. Identify design opportunities in single-family rooms to reduce flow disruptions in clustered care involving family-staff collaboration in the NICU.

Gravens 2025-43

Title: Once Upon a Design: Sharing Stories from HSHS St. John NICU's Post Occupancy Evaluation to Promote Safe Spaces

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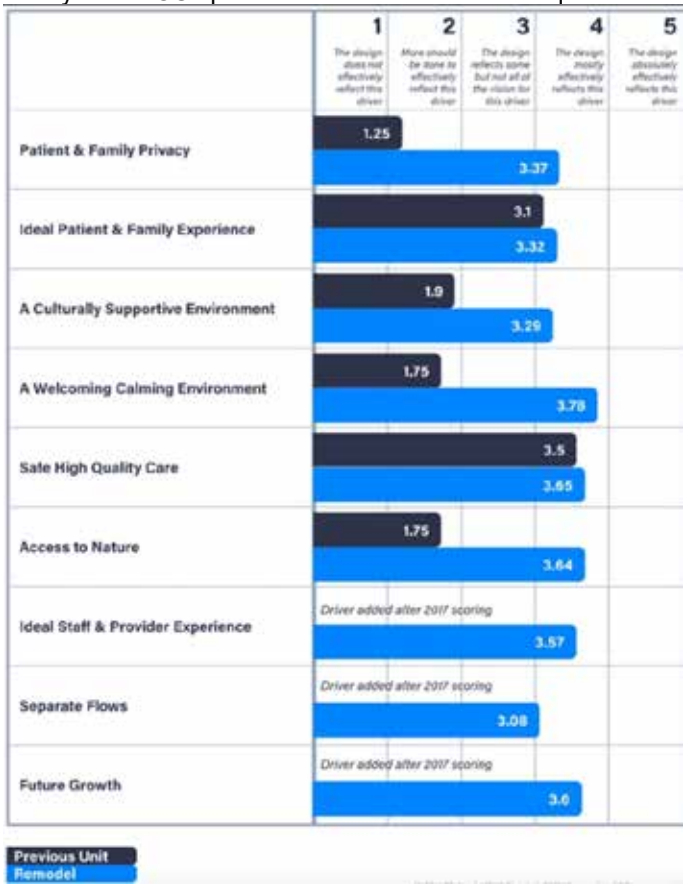
Problem Statement: Prior to its renovation, HSHS St. John's NICU space was insufficiently designed to provide for their particular challenges: a mix of different patient types, including a large percentage of infants who are wards of the state, impacting length of stay and developmental milestones; inefficient operational workflows leading to staff burnout; and inadequate space to support clinical care and manage clutter, contributing to stress among staff and family. HSHS St. John's and the design team hypothesized programmatic strategies such as providing a mix of patient rooms, a milk room, and a family lounge with sleep rooms, and design strategies like access to natural light, intuitive wayfinding, and separate clinical flows would improve patient outcomes, provide greater flexibility, and increase staff and family satisfaction.

Abstract:

Methodology: Four years after project completion, a post-occupancy evaluation (POE) was conducted at HSHS St. John's Hospital NICU to evaluate the success of the project. Criteria derived from the Center for Health Care Design's Clinical Design Post-Occupancy Evaluation Toolkit and Design Drivers were set at the start of the project. The POE process involved interviews with leadership, a staff survey, a visual audit of the space, and a comparative review of performance data, including patient volumes, length-of-stay, and cost savings. Specific attention was paid to the milk room, couplet care rooms, private and semi-private patient rooms, and family amenity spaces, which were new to the NICU, as well as care team stations, NICU pods, and the overall unit flow, functionality and feel.

Results: The intervention achieved success across all the metrics studied but also revealed opportunities for improvement in future NICU design efforts. Key success outcomes include a 40% increase in capacity; a 16% reduction in length of stay; an approximate $1,163 reduction in cost of care per day (over $3.2 million annually); 1.75 additional hours per day for patient care for nurses due to the Milk Room; patient satisfaction scores within the 90th percentile; and flexibility to accommodate up to six sets of multiples at once. These outcomes demonstrate a correlation between the renovation and meaningful improvements in the performance of HSHS St. John's NICU. Opportunities for improvement were found at every scale of the design. At the programming level, there is not yet a provider workforce trained to staff couplet care rooms. However, these rooms have proven valuable to the unit as highly adaptable spaces. Family members use the overnight sleeping rooms less often than expected due to their lack of soundproofing, preferring to stay at the Ronald McDonald house on campus. Technology advancements were found to become outdated faster than the design could accommodate, suggesting a need for further research into designing for technological upgrades. Throughout the unit, it was evident that small design choices, like the height of outlets at nurse's alcoves, significantly impacted staff workflow, emphasizing the need for meticulous attention to detail. Overall, the POE findings emphasized the importance of introducing flexibility into NICU spaces to serve their diverse requirements.



Conclusion: These key outcomes can be correlated to the programmatic and design strategies successfully implemented, along with important lessons learned.

- Safe, high-quality care is facilitated by a mixture of patient rooms with identical headwalls to achieve flexibility and standardization. The hybrid pod rooms provide efficient nursing support for patients without visitors, while private patient rooms encourage intimate familial caregiving and/or space for higher acuity intervention, which contributes to a reduced length of stay and lower cost of care per day. Couplet care rooms may be difficult to staff but, when designed with identical headwalls, provide essential flexibility. They may be used to provide couplet care, or to accommodate an influx of sets of multiples or other patient surge, or to provide palliative care.
- Including a milk room in-unit moved milk and formula mixing out of the patient room and into a specialized, controlled and sanitary environment, which reduced feeding errors and gave nurses additional hours of time for patient care.
- Alarm fatigue persists and may require a deliberate collaborative solution, such as visual cues outside of patient rooms to reduce audible alarms. · Staff and provider experience is enhanced by introducing a higher percentage of clinical support space and storage, which can help create "space for everything" and increase staff efficiency. Attention to details at the smallest scale of design can help minimize visual and operational stressors among staff, helping to reduce fatigue and burnout.
- Provider and family experience alike is improved by designing patient rooms with large windows and frosted glass doors, which carry natural lights throughout the unit. Other biophilic design elements, such as natural-look materials, imagery, and color, further improve feelings of comfort and wellbeing in the NICU.
- Patient and family experience is greatly improved by increasing sound insulation to promote better sleep and rest amongst patients and families; color-coding areas and creating a circular path, which improves wayfinding; and introducing private room types, which are more comfortable environments for caretakers to engage in kangaroo care and other forms of nurturing.

The HSHS St. John's NICU redesign POE provides important insights into the relationship between NICU design and outcomes. Providing a variety of patient room types with standardized headwalls offers flexibility that is crucial to achieving safe spaces tailored to different, specific patient populations. An evidence-based design strategy that encompasses the environment of care delivers benefits for patients, family, staff, and the bottom line. By sharing different programmatic and design strategies and their impacts on patient outcomes, satisfaction scores, and costs of care, these findings can help advance NICU design.

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Learning Objectives:

1. Understand the benefits of a mix of room types for improving patient outcomes.
2. Learn about design strategies for providing flexibility to accommodate sets of multiples, surge events and pandemics.
3. Understand the added value to staff and providers of design

considerations such as natural light, a designated milk room, ample storage space, and others.

Gravens 2025-45

Title: Comparing Caregiver Report to In-Person Developmental Assessments of Preterm Infants at 24 and 36 months of Age

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Problem Statement: Creating a safe space for NICU parents to come to, where they receive connection with other parents, support for self-care and education on relevant topics for being in the NICU. This is accomplished by inviting them to a weekly group to participate in discussion with others.

Abstract:

Background: Parents of infants admitted to the Neonatal Intensive Care Unit (NICU) are at increased risk for developing stress disorders (e.g., adjustment disorders, post-traumatic stress disorder) along with perinatal mood and anxiety disorders (PMADs) (1). With the increasing incidence of PMADs and trauma-related disorders of parents with infants in the NICU, supporting caregiver coping warrants special clinical attention from mental health professionals. A comprehensive family-centered care program includes mental health support as one of its six components (2).

Problem statement: We are a 24-bed Community Level III NICU with approximately 4900 deliveries and 500 NICU admissions per year. We formed a comprehensive family-centered care program (FCCP) that supports families from antepartum to NICU to discharge. As a part of the FCCP, we had a family partnership council consisting of former NICU families providing feedback on infant care delivery to improve family-centered care practices. In 2023, we heard from our families about the lack of mental health professionals' support in our NICU and how it adversely affected them while they were in the NICU and struggled to find support even afterward. Table 1 shows their voices describing the need for mental health professional support.

Methods/Materials/Data: We shared these testimonials with the leadership team and communicated with the hospital mental health professionals team, which is called the Health Creation Project. The overarching goal of the Health Creation Project (HCP) is to support the community partners and the mental health needs of the individuals they service through the assessment, development, and delivery of programs that promote resiliency and the creation of overall life satisfaction and fulfillment. The ECH NICU team collaborated with HCP to bring in support for the families and a program funded by the ECH Foundation team. We decided to start with a group session instead of individual sessions due to staff shortage in May 2024. Group was designed to create a space for NICU parents to meet each other and share their experiences in a structured way, avoiding having to narrate their traumatic story. Curriculum was abstracted from Dr.Shaw's NICU group curriculum (refe), in order to tailor it to the population and design of El Camino Health's NICU (figure 1). [b] The curriculum was built for a 6 week rotation and the goal is to rotate the curriculum in perpetuity. Data was collected via sign-up sheets maintained by the clinician running the group, and feedback forms submitted by parents who attended the group.

Session 6, Handout 7

Things to Consider for Home

It can be a relief to be away from the doctors, nurses, and monitors, but it can also be a source of stress. On one hand, you have time together in the privacy of your home. On the other hand, some parents will have anxiety about not having the professional care as readily available, and not having the monitors as warning signals.

Like other big life changes, there will be an adjustment period, which may last 1 to 2 months. Your baby will be changing a lot and you will be getting used to each other at home as you develop routines together.

Having mixed feelings about this transition to home is normal.
- What has it been like for you, having the baby at home or thinking about having the baby at home?
- What are some of the thoughts and feelings you are having?

THINGS TO KEEP IN MIND

- **You do know your baby very well** and you can trust your ability to notice physical and developmental changes that you may want to discuss with the pediatrician.
- **It is important that you plan time for yourself to rest**; babies can sense when their parents are stressed. It is OKAY for you to take time for yourself, and to have help taking care of your baby so that you can take care of yourself.
- **Preterm infants develop in the same fashion that full term babies do, perhaps just at a slower rate.** It is important to use their Corrected Age when thinking about their developmental milestones.
- **It can be stressful knowing that preterm infants may develop more slowly than full term babies**, or may have difficulties with their development. Not knowing for sure how your baby will develop in the future can be unsettling. Therefore, just being with your baby NOW – observing, interacting and loving – is the most important thing you can do. You will also have the help of your pediatrician and the High Risk Infant Follow-up (HRIF) Clinic (if your baby was referred to this clinic) to monitor your baby's progress over time.
- **Keep in mind that it may take time for your baby to breast feed well if he/she has mostly been getting bottle fed at the hospital.** Consider talking to your pediatrician about getting a lactation consultation if you have any questions or concerns about breast feeding.

REMINDER: All babies born under 32 weeks, and those with certain other medical conditions, are seen in the HRIF Clinic at roughly 4 months Corrected Age.

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"During the baby's stay in the NICU, as a mom I felt somewhat supported as there was always someone looking out for my son. Having said that, there was still a lot of questions, concerns (if the kid will lead a normal life, could i have done something to prevent it, could the OB have prevented it, other people's statements/comments or lack of empathy etc). Those concerns only elevated significantly when my son came home with a tube. My relationship with my partner suffered significantly, I was depressed but yet fully operational to support my son, my own thyroid hormones went haywire which caused more issues. Having professional help from a therapist or psychologist throughout the process would have definitely helped us. No one was speaking to us about how these experiences affected us and brought out all our fears (fears no one knew was around).
"At the moment, the mental health support falls on the nurses and doctors in the NICU. A mental health professional that is focused on supporting the families in this capacity would be a very valuable resource for 3 key reasons. 1) Given the focus on the Family-Centered Care, this is a current gap in the NICU. Having someone dedicated to this, like Cris in Lactation, would be a phenomenal resource. Cris was invaluable support to me and my babies in the NICU. 2) Depending on comfort levels, cultural differences, family dynamics or financial issues, many don't seek the mental health support they need. This takes away those barriers. Having this support in the NICU allows for one less thing for NICU parents to think about or coordinate while they are juggling so many issues in their new reality. Parents have to thrive for babies to thrive. Therefore this resource would improve NICU outcomes for the whole family."
"It was extremely hard to access mental health support through my primary doctor/OB to get extended time off work due to my daughter being in the nicu and other related mental Health issues. In house psych care is a necessity."
"It was really hard to get access to psych professionals to extend time off work, my ob and primary care referred me to psych and there was no availability. I ended up finding one in LA in zoom which was not ideal. In house psych care is a must for these parents! Especially with very premature babies."

Results: As of this abstract, this program supported 75 NICU parents and 22 feedback sheets were collected. Feedback questions were to understand the experiences of the participants and feedback for the facilitator. Qualitative data was obtained for the feedback, and quantitative data is maintained for attendance. Materials were developed by modifying Shaw's group curriculum to accommodate for the population, the medical necessity of the unit and the average length of stay for families. Feedback forms were offered to all parents, but were not mandated. A chart containing the quantitative data that captures the responses of parents is attached. A Supportive education group was received positively by parents in a 6 month period. Even though an average of 20% of the families attended the group, they rated some learning in every group and had positive or neutral feedback to give. The impact of a group is that parents have a safe space to share some education or experience with other parents and learn selfcare.

Name of baby	days in nicu	gestational age	Family attendees	What did you find helpful/learned	what can we do differently
1	6	35-4	SC	Self care	maybe some educational material
2	5	36-2	2	meeting other parents	
3	42	35	mother	hearing diff experiences from other parents helps me know im not alone	how can we get through the day by day better, what happens after graduation
4	10	32	mom and dad	we are not alone, selfcare	e/t went well, no change needed
4	19	31-2	mom	That the feeling of sharing with others may not be a responsibility	e/t is great
3	4	34	CE and JB	listening and sharing similar feelings with others	not sure yet
5	5	34-3	MR and DD	Time for selfcare, we are not alone	
6	8	38-3	SV and KC	selfcare, experiences from others going through the same emotions	have doctors be part of this session
3	52	35 weeks	AA	Just getting experiences and aspects of what brought them here today	
7	n/a	n/a	KB	Entire conversation was very useful, the conversation helped understand the emotions and the need to not to question them	

Challenges: Though the group session benefited some families, we had a low participation rate because parents don't want to leave their baby's space, and it would have been better if parents could have interacted with a trauma therapist at the bedside while they were holding their babies.

Next Steps: Continue with the group. Begin 1:1 therapy for the families.

Learning Objectives:

Understand 3 elements used in each group to create and maintain structure

Learn at least 3 challenges in building the group and maintaining it Understand 3 learnings from a Level 3 NICU Mental Health Support program.

Gravens 2025-46

Title: Introducing Psychological Support for Neonatal Fellows to Improve Trainee Mental Health

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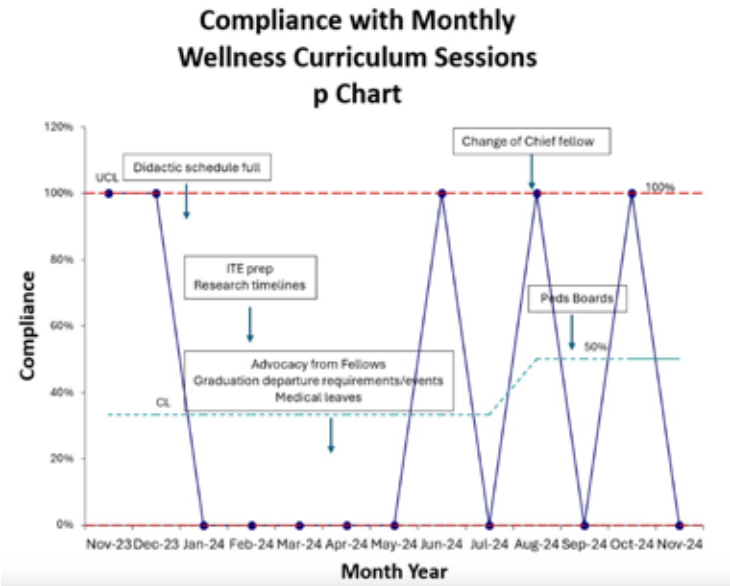
Problem Statement: Neonatal Intensive Care Unit (NICU) trainees experience high intensity situations under suboptimal physiologic and psychologic conditions that can lead to burnout and/or secondary traumatic stress. The mental health of NICU fellows can have significant impact on their well-being and the quality of patient care they provide. The overall goal of this project is to improve Neonatal Fellow mental health and well-being in a level 3 NICU by using Trauma Informed care (TIC) principles to identify needs that may warrant connection to further resources.

Abstract:

Methods: Key stake holders were identified: the ACGME director, the fellowship program director, the associate program director, the chief fellow, the psychologist, the fellow cohort, division chief, lead NNP, and the program coordinator. We aimed to develop a wellness curriculum and standardize the frequency of sessions, duration of sessions, attendance of sessions, confidentiality, location and topics. Key drivers rooted in the 6 principles of TIC became the foundation of the topics explored during the Wellness Sessions. These six principles / primary are 1. Safety, 2. Trustworthiness and Transparency, 3. Peer Support, 4. Collaboration and Mutuality, 5, Empowerment, voice, and choice, 6. Cultural sensitivities. These promoted the following standardized topics: Crucial conversations with mentors, Performance anxiety, Debrief challenging cases, debrief death, Navigating personal relationships (motherhood, significant other, daughter/son), Work life balance, Individualizing wellness, Cognitive behavioral strategy for stress management. A force field diagram was the QI tool used to mediate conversations to gain approval for this Wellness curriculum pilot. Driving forces in support of this pilot were having a dedicated NICU psychologist, ACGME recommendation for embedded Wellness training, fellow interest, previous match history, program evaluation demonstrating a gap for wellness training and existing private fellow office space. Restraining forces included scheduling time away from board preparation didactics, patient care and research duties, 360 degree buy in, post-call protected time, literacy of NICU psychologist role, and human bias to new process. Our outcome measure is compliance with monthly meetings characterized by completed monthly sessions from November 2023 to April 2024. The process measure is compliance with attendance for fellows that desired to attend the wellness session and not encounter barriers.

Results: In the initial 6 months implementation period from November 2023 to April 2024 there was 30% compliance with monthly meetings. PDSA cycles revealed the challenges to completing a session. These included the available protected didactic times were filled with other lectures and case conferences, preparation for In-training-exams (ITE's), research timelines, graduating fellow interviews, schedule gaps for anticipated and unanticipated medical leaves, and fellow graduation exit procedures. Compliance for attendance of the fellows conflicted with patient care duties and lack of commitment to protected time away from

the NICU. Qualitative feedback from fellows was in support of establishing the permanence of this wellness curriculum and they specifically appreciated the topics and the time to pause and reflect on their experiences. Fellows' feedback included: "mental health sessions are equally as important as the pathophysiology lectures," the curriculum prioritizes "resetting the mindset more positively" and "improve work-related satisfaction." This feedback, the start of the new chief fellow term, and persistent advocacy to establish this wellness curriculum enabled this pilot to continue for an additional 6 months. The frequency of sessions has increased in collaboration with program director approving bimonthly sessions.



Conclusions: Implementation of a fellow wellness program was met with initial resistance, but over time has proven beneficial in fellow satisfaction and performance leading to increased support from key stakeholders, increased frequency of scheduled sessions and reduction in barriers to allow for fellow attendance. Future direction is to incorporate fellow wellness curriculum into monthly didactic schedule and standardize a curriculum to be replicated.

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Learning Objectives:

We aim to develop a standardized confidential Fellowship Wellness Curriculum led by the NICU psychologist exclusive to fellows only and achieve the following measures within 6 months:

1. 100% compliance with monthly sessions.
2. 100 % compliance with fellow attendance for those fellows who desire to attend.

The secondary aim of this project is to increase awareness of trauma exposures that are inherent to critical care graduate training.

Gravens 2025-47

Title: Implementation of Discharge Path Tool to Achieve Discharge Readiness in NICU families

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Problem Statement: The aim of this quality improvement project is to implement a Discharge Path Tool for parents to feel empowered in the care of their infants during their NICU journey towards discharge and by June 2025 achieve the outcome measure of 50 % compliance of the families using the tool.

Abstract:

Methods: Our NICU is participating in the Florida Perinatal Quality Collaborative promoting safe discharge. An interdisciplinary team that included bedside nurses, social worker, case managers, speech therapists, occupational therapists, physical therapists, dieticians, lactation consultants, NICU psychologist, NICU nurse educator, Neonatal NP's, NICU fellows, neonatologists, and parent from family advisory council was formed to evaluate our discharge process. We used the QI tool, a fishbone diagram, to identify the barriers for a safe and efficient discharge. Communication with the families and empowering the families to participate in the infants' care was identified as a major contributor and key driver for a safe and efficient discharge. Each discipline drafted a workflow of their involvement throughout the stages of an infant's NICU hospitalization. Together we synthesized a tool that integrated the infant's milestones as they progressed through their hospitalization and the involvement of each of the interdisciplinary team. This tool was tested by families and staff using PDSA cycles. After finalizing feedback from parents, this tool has been printed in both English and Spanish to bridge the gap of healthcare disparities in our community. A process was created to ensure that all families will have access to this tool.

Results: This tool has begun implementation November 2024 and compliance data is pending. PDSA cycles provided qualitative feedback that continued to shape the tool. Qualitative feedback included: Prior to the tool "we didn't know what comes next", the tool "helped me know what to ask", with the tool "I know the right plan now", "The tool is a keepsake", "I cherish the boxes for firsts." We have demonstrated that our nurses document discharge teaching in a standardized process; we anticipate that as a continuation to DC teaching the nurses will find value in documenting use of this DC path tool versus a perceived added task completion.

Conclusion: This tool has reframed the parent experience to celebrate milestones, achievements and empower families to regain back their newborn experiences many feel were "robbed of." It provides parents with transparency and builds trust with the NICU team. Families now have enhanced insight to ask meaningful questions surrounding the care of the infant and where they are in their journey to home. With this tool families are better able to understand the natural progression of a NICU hospitalization stay while also personalizing the journey based on family values.

Learning Objectives:

1. Know DC planning is a process that requires families to participate in their infant's care and should be tailored to their and their infant's needs.
2. List the criteria that define discharge readiness to promote consistent messaging with families surrounding discharge.

Gravens 2025-48

Title: Implementation of Emotional Readiness Tool to Achieve Discharge Readiness in NICU families

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Problem Statement: Ensuring discharge readiness in the NICU improves health outcomes for neonates and decreases medical costs by mitigating unnecessary medical visits after discharge. Discharge readiness is determined by clinical staff but another very important aspect is parent's perception of preparedness. Smith et al 2009 showed that families were more likely to achieve discharge readiness when they felt very confident with their infant's breathing, heart rate, health and maturity. This led to the addition of an Emotional Readiness checklist within our discharge criteria checklist.

Abstract:

Methods: As participants in the Florida Perinatal Quality Collaborative (FPQC) our NICU is improving the discharge process for NICU families. The FPQC recommended primary aims are 1. Families demonstrating technical readiness for care of a infant and 2. Families demonstrating Emotional readiness surrounding caring for their infant at home. An interdisciplinary team that included bedside nurses, social worker, case managers, speech therapists, occupational therapists, physical therapists, dieticians, lactation consultants, NICU psychologist, NICU nurse educator, Neonatal NP's, NICU fellows, neonatologists, and parent from family advisory council was formed to evaluate our discharge process. Using a fishbone diagram, we identified all potential barriers and promoters that would enable our team to implement this Emotional Readiness Tool. It was evident to our team that we could not complete the secondary aim of the FPQC recommendation for the Emotional Readiness Questions without developing an accompanying algorithm to support the frontline and empower families. We recognized that, in order to implement these questions, we would have to build in an algorithm to validate nursing concerns for parent responses that did not demonstrate emotional readiness. We categorized potential parental barriers to achieving confidence into three key drivers for Emotional Readiness: 1. Additional Education, 2. Additional Hands-on Practice, and 3. Additional resources. We created a pathway in the EMR to guide bedside nurses by prompting these key drivers and then notifying the proper clinicians to assist families.

Results: Our NICU has succeeded in improving documentation of discharge education of technical skills for families to care for their newborns beyond the NICU. With our participation in the FPQC, we improved our compliance with documenting technical readiness from 29% to 54 %. The outcome measure is compliance with the Emotional Readiness tool. The process measure is compliance with notifying the appropriate clinicians to connect families to the key drivers of Emotional Readiness. The balancing measure is delayed discharge due to the Emotional Readiness tool. PDSA cycles led to the addition of a scale and point assignment to the Emotional Readiness Questions. We are able to illustrate the QI tools that led to the synthesis of this tool. Implementation of this Emotional Readiness tool which includes our algorithm is going live November 15th.

Conclusion: In conclusion, we are advocating that emotional readiness is a key facilitator to a safe discharge and has not been recognized in a standardized process until now. Implementation of this tool empowers the parents to safely share their perception of readiness which will help guide the NICU team with barriers that may not have previously been identified.

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Learning Objectives:

The primary aim is to implement this Emotional Readiness tool and achieve 50% compliance for NICU discharges within 6 months from November 2024 through April 2025.

The secondary aim is to connect all families that do not have reported Emotional Readiness to the appropriate resources prior to discharge.

Gravens 2025-49

Title: Empowering Families for Better Outcomes: A Statewide QI Initiative to Improve NICU Discharge Readiness

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Problem Statement: Transitioning from the neonatal intensive care unit (NICU) to home can be overwhelming for families. Social, environmental, economic, and mental health challenges also impact NICU discharge readiness. A lack of parental emotional comfort and confidence can inhibit learning and contribute to poor infant outcomes and increased healthcare utilization after discharge. Quality discharge preparation ensures that families feel ready to continue their infant's care at home. Comprehensive neonatal intensive care includes multidisciplinary, family-centered transition, and discharge guidelines to optimize readiness and outcomes. Primary Aim: Achieve a 20% increase in discharge readiness for NICU infants by parental technical readiness by staff assessment and emotional readiness score by parent questionnaire. Secondary Aim: Increase by 20% the completion of a discharge process tool upon discharge home.

Abstract:

Methods: An advisory Committee met virtually comprised of a multidisciplinary group of clinicians, clinical leaders, community representatives, and family advocates. Key Drivers for promoting a safe discharge were developed: 1. Family Engagement & Preparedness, 2. Addressing Health-Related Social Needs, 3. Transfer and Coordination of Care. Potentially better practices were identified for each primary driver. These potentially better practices, supporting literature, and resources were inserted into a virtual Toolkit. A statewide webinar was hosted to gain interest. Hospital commitments were completed. In September 2023, FPQC launched the Homeward Bound Quality Improvement Initiative in Orlando Florida, with participation from 49 NICUs. During this meeting included This meeting included family insights on NICU discharge, a keynote presentation of the updated guidelines, and a review of the QI patient bundle.

Results: Currently, 68% of Florida NICUs are participating in the Homeward Bound initiative, with strong engagement reflected by 94% hospital attendance at virtual monthly coaching calls and 88% of hospitals sharing trial tests of potentially better practices during quarterly updates. More than 120 attendees, representing 98% of participating NICUs, have joined key in-person meetings. From Q1 2023 to Q3 2024, hospitals have made substantial progress in our key aims: parental technical readiness checklist completion increased from 49% to 82%, and discharge planning tool completion rose from 56% to 75%. Respectful Care training participation and commitment to these practices increased from 25% to 58% for nurses and from 9% to 44% for physicians. The most recent in-person meeting highlighted the importance of this training, offering hospitals additional resources and emphasizing its relevance in the NICU. Additionally, use of the HRSN Assessment Tool improved from 51% to 78%, caregiver screening rates rose from 60% to 80%, and referrals to community services increased from 87% to 98%. Throughout the initiative, over 90% of caregivers reported feeling well-prepared and emotionally ready to take their infant home at discharge.

Conclusion: The FPQC Homeward Bound Project has shown that DC preparedness is an interdisciplinary responsibility to endorse DC readiness. This QI project emphasizes that although all 3 are interrelated, the primary driver Health-Related Social Needs directly impacts the success of the other primary drivers Family Engagement and Transfer and Coordination of Care. Comprehensive discharge preparation for is invaluable for our vulnerable NICU families.

Learning Objectives:

1. Identify effective strategies from the Homeward Bound initiative, focusing on improving caregiver technical and emotional readiness and utilizing discharge tools.
2. Describe how Respectful Care training and HRSN assessments can be implemented to enhance caregiver support.

Gravens 2025-50

Title: Factors Contributing to Stress in NICU Infants and Their Mothers

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Problem Statement: NICU infants and their parents experience daily stressors that are cumulative in nature. Sources of NICU-related stress include pain and distress related to care and procedures, environmental stressors, parental separation, and parental role alteration. These stressor exposures can overwhelm infants and parents, leading to negative short- and long-term consequences, including adverse infant neurodevelopmental outcomes and issues with parent mental health. Although a growing body of research supports the intergenerational transmission of stress from parent to infant, stress exposures of NICU infants and their mothers are typically considered independently. The Neonatal Stress Embedding Model described by Nist et al. (2019) posits that infant stressor exposures interact with the prenatal environment and maternal interaction to influence the biological embedding of stress in NICU infants. Similarly, stress in NICU mothers may be affected by their environment, interactions with the infant, and NICU-related stressor exposures. The purpose of this study was to explore relationships between infant and maternal factors, including the prenatal/maternal environment, and stress-related outcomes in NICU infants and their mothers.

Abstract:

Methods: Study hypotheses were addressed via a descriptive study, using an existing dataset to conduct a secondary analysis. This quantitative dataset included infant (gestational age, Neonatal medical index scores), maternal (education, number of siblings), and prenatal-environmental social (Social Vulnerability Index (SVI) theme scores) variables for 78 families with an infant that received care in a tertiary level NICU in the Midwestern United States. Of the 78 infants, 41 were term and 37 were preterm infants born at > 28 weeks gestation. Median length of infants' NICU stay was 33 days. Infant stress was measured using resting salivary cortisol levels collected in the morning at NICU admission and discharge. For infants not discharged at or before 33 days of life, a resting salivary cortisol was collected at one month of age. Stress in mothers was measured via self-report using the Parental Stressor Scale: Neonatal Intensive Care Unit (PSS: NICU) at NICU admission and discharge. Selection of individual infant, maternal and prenatal-environmental social factors was based on univariate regression results. Separate hierarchical linear regression analyses were conducted to identify factors that explain the most variance in infant stress and mothers' stress.

Impact and Results: In this study, infant stress at NICU discharge

was best explained by a model including infant salivary cortisol at NICU admission, cumulative parent presence over the first four weeks of life, mother's total score on the PSS: NICU at discharge, and Social Vulnerability Index theme scores reflecting minority status, housing and transportation, and socioeconomic status (R2=0.31, F=3.28, p=.01). The addition of mother's stress at discharge and Social Vulnerability Index theme scores increased the variance in infant stress explained by the model by 19%. Mothers' stress at NICU discharge was best explained by their self-reported stress using the PSS: NICU at NICU admission (R2=0.64, F=109.68, p<.001). Although univariate regression indicated that infant variables and SVI scores were significantly associated with maternal stress, and hierarchical regression models including these variables were significant, infant variables and SVI theme scores increased the variance in maternal stress explained by only 3%.

Conclusions: Results of the study support the Neonatal Stress Embedding Model described by Nist, et al. (2019) in that infant HPA axis functioning at NICU discharge was explained by the prenatal environment (Social Vulnerabilities of mother), maternal interaction (parent presence and maternal stress in the NICU), and infant stressor exposures. Clinical implications of these results include providing NICU family supports that limit separation, mitigate maternal stress and address their social vulnerabilities. Research implications include considering the prenatal environment and the interaction of maternal variables with infant NICU-related stressor exposures when measuring infant stress-related outcomes.

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Learning Objectives:

1. Describe relationships between infant and maternal factors, including the prenatal-maternal environment, and stress-related outcomes in NICU infants and their mothers.

2. Discuss clinical and research implications of research examining relationships between infant and maternal factors impacting stress-related outcomes in NICU infants and their mothers.

Gravens 2025-51

Title: Implementation of a Multidisciplinary Individualized Neurodevelopmental Program for Infants with Prolonged NICU Hospitalization - The SPROUT Program

Authors: Alicia Loncar, Victoria De La Garza, Holly Paulos, Monica Olsen, Sydney Cameron, Ashley Lucke[5]

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Problem Statement: Infants in a level 4 neonatal intensive care unit (NICU) are at increased risk for poor neurodevelopmental outcomes due to a combination of prematurity, complex illness, prolonged hospital stay and separation from parents. Parents report significant concerns and worry about the long-term neurodevelopmental outcomes of their baby. Despite this, daily NICU rounds are frequently consumed by medical decision making and little time is available to focus on the neurodevelopmental components of care such as progress with physical therapy, music/language exposure, sibling bonding and parental mental health among others. Many infants in level 4 NICUs remain inpatient for weeks to months, with the risk of worsening delays in neurologic development due to their chronic hospitalization and prolonged abnormal environment. The Dell Children's Neonatal Neurodevelopmental Care Team created a program in 2021 emphasizing Sensory exposure, Playtime, Reading, Out of bed activities, Utilizing therapies and Time for rest (SPROUT Program) in infants greater than 44 weeks postmenstrual age. We aim to describe our process for designing, implementing and tracking the metrics of this program in a high acuity, surgical level 4 NICU of both inborn and outborn patients.

Abstract:

Methods: During monthly team meetings and daily bedside rounds the need was identified to optimize timing of therapy interventions, activity influenced care times, parent bonding and restful sleep in patients beyond 44 weeks postmenstrual age with anticipated prolonged hospital stay. A multidisciplinary neurodevelopmental care team was assembled including neonatologists, nurse practitioners, NICU nurses, respiratory therapists, speech and feeding therapists, physical therapists, music therapists, art therapists, child life specialists, perinatal psychologists, neonatal nurse navigators, social workers, case managers, unit educators and patient families. Individual parent and staff focus group interviews were conducted to identify perceived barriers to neurodevelopmentally appropriate care, interruptions in therapy services and failures in sleep protection. Utilizing online graphic design programs, individual patient daily schedules were created with input from parents, primary nursing and respiratory care staff and therapists. Schedules were prominently displayed in each single patient room for all staff to easily visualize and comply with for consistent, neurodevelopmentally protective care.

Table 1: Barriers and Solutions Implemented in the Successful Establishment of the NICU SPROUT Program

Barrier	Solution
Staff turnover	Hospital implementation of retention bonuses; hourly pay market increase
Restrictive visitation policies	Relaxed visitation policies with COVID pandemic improvement; management approved sibling visits started
Shifting responsibility of schedule creation	Restructuring of team with identification of subcommittee lead; recognition by management as clinical ladder activity
No existing database to track enrollment	Creation of comprehensive database with all eligible admissions and anticipated qualification dates
Availability of age-appropriate developmental supplies	Hospital foundation grant secured to purchase full stock of supplies; reorganized supply closet with updated labeling and QR codes
Changes in patient acuity	Implementation of weekly neurodevelopmental rounds with discussion of eligible patients
Difficulty identifying when patients qualify	Created database with prompts of when patients became 44 wks PMA
Lack of staff awareness or non-adherence to created schedule and care times	Education in staff meetings, written materials, symbol added to daily patient census list, door signage
Lack of staff buy-in to the program goals	Recruitment and improved retention of neurodevelopmental team members; education of nurse residents and fellows during orientation; emphasis from neonatal providers on importance; sharing family satisfaction and feedback on program with general staff

Results: The SPROUT program was established in October 2021 by a multidisciplinary team. Barriers to successful implementation

Figure 1: Sample SPROUT Program Schedule from 2021

Figure 2: Sample SPROUT Program Schedule from 2022

Figure 3: Sample SPROUT Program Schedule from 2024

were identified and solutions employed (See Table 1). Barriers included staff turnover, restrictive visitation policies, shifting responsibility of schedule creation, no existing database to track enrollment, availability of age-appropriate developmental supplies, changes in patient acuity, difficulty identifying when patients qualify, lack of staff awareness and non-adherence, lack of staff buy-in to the program goals. A combination of hospital, NICU, neurodevelopmental team and individual solutions were employed to overcome these barriers. 6 infants were enrolled with individualized schedule creation in 2021 and 15 infants in 2022. Data for 2023 is not available due staff turnover and no existing database until April 2024 when the program was revised and rebranded into the SPROUT program. Since database creation, 12 patients have been enrolled of 16 eligible (75%). The average birth gestational age of enrollees was 31.8 weeks and average post menstrual age at the time of enrollment was 49.9 weeks. Sample SPROUT enrollee schedules from 2021, 2022 and 2024 are displayed in Figure 1, 2 and 3 respectively.

Conclusions: Our NICU Neurodevelopmental Care Team successfully designed and implemented the SPROUT Program in a level 4 surgical NICU at Dell Children's Medical Center at the University of Texas at Austin. Multiple barriers were identified as the program's implementation occurred and the team employed numerous solutions to overcome them and ensure the successful continuation of the program. Establishment of a SPROUT program database was instrumental in tracking enrollment, identifying eligible patients and reporting program metrics. Future directions for this program include increasing enrollment percentages, incorporation of photo and video guidance of activities into the schedules for new staff and families, collaboration with the NICU Follow Up clinic and developmental outcomes testing, and quantitative parent assessments of SPROUT program impact.

Learning Objectives:

1. Identify key stakeholders in designing a neurodevelopmental care team in a surgical level 4 neonatal intensive care unit.
2. Apply tools to support developmental milestones and construct individualized daily schedules for infants with complex care needs currently hospitalized in the NICU setting.
3. Identify methods to overcome barriers of program implementation

Gravens 2025-52

Title: Weekly Multidisciplinary Rounds to Guide an Intensive Inpatient Neonatal Neurodevelopmental Program

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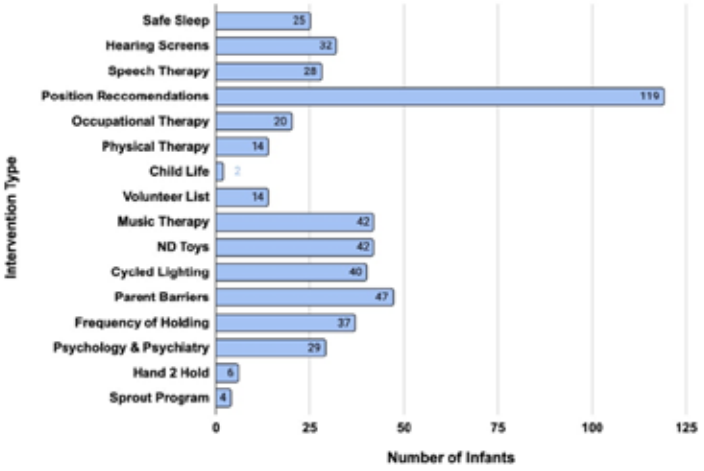
Problem Statement: Infants in a level 4 neonatal intensive care unit are at increased risk for poor neurodevelopmental outcomes due to a combination of prematurity, complex illness, prolonged hospital stay and separation from parents. Parents report significant concerns and worry about the long term neurodevelopmental outcome of their baby. Despite this, daily NICU rounds are frequently consumed by medical decision making and little time is available to focus on the neurodevelopmental components of care such as progress with therapy, music/language exposure, sibling bonding and parental mental health among others. The Dell Children's Medical Center of the University of Texas at Austin Neonatal Neurodevelopmental Care Team seeks to bridge this gap in care for high-risk infants by measuring the impact of weekly bedside multidisciplinary Neurodevelopmental Rounds (NDR)

which develop individualized care plans to optimize developmental outcomes and overcome barriers related to inconsistent care practices.

Abstract:

Methods: We established a multidisciplinary neurodevelopmental care team composed of neonatologists, nurse practitioners, NICU nurses, respiratory therapists, speech and feeding therapists, physical therapists, music therapists, art therapists, child life specialists, perinatal psychologists, neonatal nurse navigators, social workers, case managers, unit educators and patient families. Weekly team meetings began in October 2023. All admitted infants with an anticipated 2 week length of stay or more were eligible for evaluation. Detailed assessments of each infant's neurodevelopmental environment and interventions implemented were gathered from chart review, parent interviews and bedside assessments. Quantitative data was gathered in the following areas: safe sleep practices, auditory (hearing) evaluation, therapy engagement (speech, physical, art, music, occupational), infant positioning, SENSE assessments, volunteer visitation, utilization of age-appropriate supplies and toys, cycled lighting, parent interactions/holding, parental mental health support, Hand2Hold engagement, child life support and SPROUT program enrollment. Qualitative data was collected in a weekly report detailing the discussion and feedback from the neurodevelopmental team, bedside staff and parents. Parent scores for "age appropriate activities" from the hospital Consumer Assessment of Healthcare Providers and Systems (CAHPS) survey were also tracked throughout this period. Results: 192 patients of 454 (42%) total NICU admission were evaluated. 501 individual neurodevelopmental interventions were completed (average of 2.6 interventions per patient) from October 2023 through September 2024. All total types of interventions are shown in Figure 1 with those specific to family centered care shown in Figure 2, environmental care in Figure 3 and changes in therapist frequency in Figure 4. Qualitative parent interviews were conducted and demonstrated patterns of parent appreciation for education and focus on their infant's neurodevelopmental care, perception of improved infant sleep quality, regularity and optimization of therapy services.

Figure 1 - All Interventions Implemented from Neurodevelopmental Rounds in NICU Patients from October 2023 to September 2024



Conclusions: We successfully established a multidisciplinary neurodevelopmental care team within our level 4 surgical NICU at Dell Children's Medical Center at the University of Texas at Austin. Through implementation of weekly multidisciplinary ND rounds, focused assessments and individualized patient interventions can be made to optimize the neurodevelopmental environment and integrate neuroprotective practices into the routine care of a level 4 surgical NICU. Neurodevelopmental rounds also establish a dedicated forum to address challenges and provide education for both families and staff on the effective application of developmental care strategies. Future directions of this work will be to incorporate gross motor assessments (GMA) and Hammersmith Infant Neurological Examinations (HINE) into patient assessments as well as correlation of our interventions with NICU Follow Up clinic Bayley Scales of Infant Development (BSID-IV) testing. Additionally, we aim to have patient family representation within our team with quantitative measures of impact from the parent perspective.

Figure 2: Family Centered Information Implemented from Neurodevelopmental Rounds in NICU Patients from Oct 2023 to Sept 2024

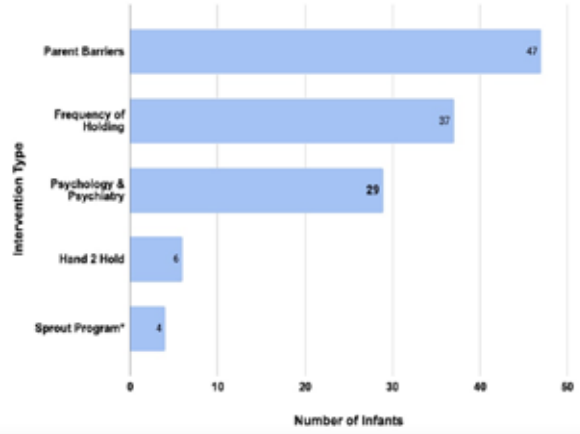


Figure 3: Environmental Interventions Implemented by Neurodevelopmental Rounds in NICU Patients Oct 2023 to Sept 2024

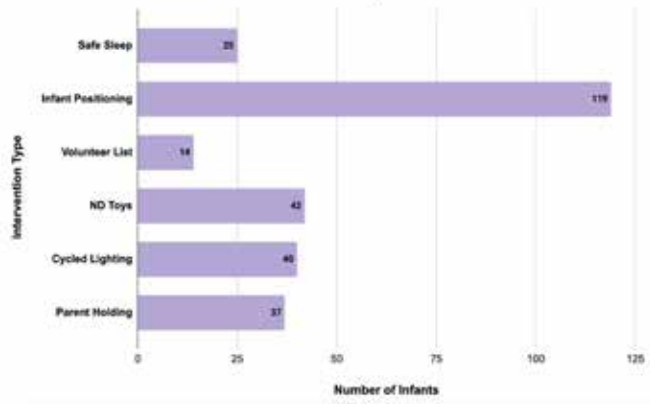
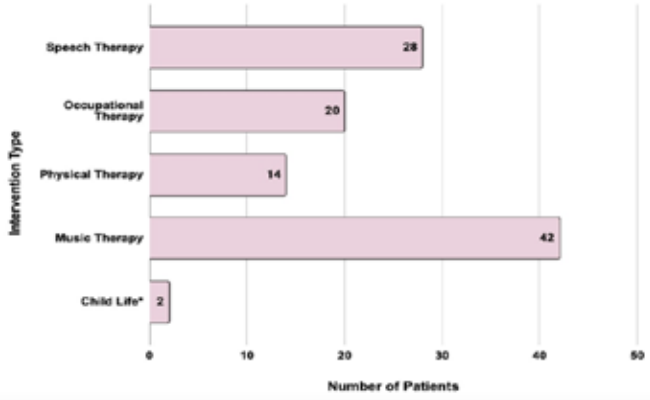


Figure 4: Increased Therapy Involvement Secondary to Neurodevelopmental Rounds in NICU Patients from October 2023 to September 2024



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Learning Objectives:

1. Recognize the components and key stakeholders in establishing a multidisciplinary neonatal neurodevelopmental care team.

2. Identify specific components of inpatient neonatal care which can be incorporated into a weekly rounding rubric.

Gravens 2025-53

Title: To explore the experience of parents of micro premature babies participating in the infant massage programs in the Neonatal Intensive Care Units (NICU)

Authors: Amanda Squires, Blaire Jones, Irene Zhu

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Problem Statement: Qualitative Research study Hypothesis: Parents of Micro-premature babies < or equal to 25 weeks will experience feelings of empowerment, decreased stress and anxiety and the parent infant dyad will improve after the positive effects on the parents and the baby after being taught massage while in the NICU 2) Question: What are the experiences of parents of micro premature babies less than or equal to 25 completed weeks gestation after they reach stability after at least 34 weeks CGA, who consent to be enrolled in a massage program to integrate massage therapy as part of the parental care they provide their babies in the NICU?

Abstract:

Parents of micro premature babies in the Neonatal Intensive Care Unit (NICU)are in a stressful situation during their baby's neonatal hospitalization. This stressful period of time may have a negative effect on parental attachment and bonding. Neonatal massage has many benefits for both the baby and the parents. Evidence in the literature supports teaching massage to parents in the NICU since it may decrease anxiety, depression, promote attachment, increase parent satisfaction, and improve the parent/infant dyad. However, previous studies include parents of babies greater than 27 weeks gestation. Sunnybrook has a unique opportunity to evaluate the effect of training parents of babies less than 25 completed weeks gestation. An evidenced based, gestational age-appropriate massage program was developed to teach parents to massage their babies after 34 weeks gestation. This study aims to explore the experiential impact of parents in learning massage to better understand their perspective and in order to improve and adapt the program for broader implementation.

Research Question: What are the experiences of parents of micro premature babies less than or equal to 25 completed weeks gestation who consent to be enrolled in a massage program to integrate massage therapy as part of the parental care they provide their babies in the NICU? The primary objective of this study is to explore the experience of parents participating in a massage program on the parents of micro-premature babies less than or equal to 25 completed weeks gestation in the NICU. The secondary objective will be to understand the acceptability, facilitators, and barriers among parents to their involvement in the massage program to improve and adapt the program for broader implementation. Sample size justification: The study will utilize purposeful sampling, using a criterion selection to recruit predefined eligible parents. When examining a determined period of time (2021) to account for the number of babies born under 25 completed weeks gestation at Sunnybrook NICU, it is estimated that 30-40 parents will be eligible for the study. We will aim to complete 10-20 interviews. We will initiate analysis while recruitment is open and modify the interview guide to capture any emerging issues that arise. 20 parent couples approached.

Design: Qualitative REB approval 2021Interviews were conducted via zoom with parents to elicit their views on the program & inform recommendations for improvement. SETTING Level 3 NICU, Sunnybrook Health Sciences Centre (SHSC). STUDY POPULATION; Parents of a micro-preemie ≤ 25 weeks gestation (N=34) who participated in the SHSC NICU massage program & English-speaking. Data Collection: An email was sent to parents of micro-premature babies less than or equal to 25 completed weeks gestation, After they have received two weeks of massage training on their baby as well as parents who have participated and completed massage program since January 2022 and have been discharged home. They will be informed of the qualitative research study and asked if they would complete a questionnaire. There is no randomization. The research assistant will obtain the consent. DATA ANALYSIS: Interviews were transcribed verbatim, Conventional content analysis, Transcripts manually reviewed by three members of the research team to generate codes which were sorted into categories & clusters. Content analysis focused on description & interpretation of data.

Results: •25 families were approached, N=34•20 families participated•20 mothers completed interviews•19 fathers consented (14 completed interviews)•21 babies (one set of twins). Results: Participants of the massage program reported positive experiences with: •Program content, resources, relationship with trainers. •Participants reported satisfaction with: •Massage outcomes with physiological and psychological benefits for the baby, parent, and the baby-parent relationship MOTIVATION as a FACILITATOR. •Most parents were motivated to participate in the massage program for the common GI benefits (e.g., constipation relief). •Parents reported positive reinforcement from their baby's positive responses (enjoyment) of the massage, which further facilitated their motivation to continue massage. POSITIVE PHYSIOLOGICAL BENEFITS •Nearly all parents reported the abdominal massage has improved their baby's constipation. •Other physiological benefits included increased feeding and sleep time. •Parents noticed that babies who were less constipated would have more hunger cues. EMPOWERMENT & BONDING: •A common psychological outcome was the baby's enjoyment of the massage. •Parents reported their babies were observed smiling, giggling or laughing in response to the massage. •Additional time

spent with their babies in the NICU facilitated a bonding opportunity between parent and baby. •Nearly all parents report an improved understanding of their baby's cues & relationship with their baby. Positive Psychological Benefits:•Observing the benefits of massage have positively influenced most parents. ••Parents reported feeling:• Less stressed & anxious• More empowered •Had increased confidence in their parenting skills. CONTRIBUTING' TO THEIR MEDICAL CARE: •Parents report recognizing when their baby was ready for a massage based on body language/ cues & responded accordingly. •Parents report they have developed a new skill that they enjoy while providing value. •Many have incorporated massage as a part of their routine at discharge & continued for months or years post discharge. RECOGNITION OF DIVERSE PARENT BACKGROUNDS: •Multiracial, multifaith, multilingual and multicultural ••Dolls represented Asian, Black, South Asian, Indian and White families •Study criteria required English speaking participants •Massage nurses are multicultural, multiracial, multifaith & multilingual •If possible they were matched with families to be able to relate and converse in their language. BARRIERS: •Limited access to trainers •Parent work schedules, one parent having more confidence than the other, other NICU activities taking priority (e.g. breastfeeding) •Medical conditions of the baby required modified massage including massaging around medical devices. NEXT STEPS-Build Capacity: •↑Staff training 86 •Update & refresh staff training every 3-6 months. Sustainability Plan: •Business case for two more nurses to be funded for NTMNC to monitor & enroll babies as part of standard of care. Create Resources: •Make video & QR code for families to have a home resource •Translate material into other languages. Spread Awareness •Parents are advised to be proactive & ask for the massage nurse to monitor them until they are independent. Expand Evidence •Continue to review data & publish an article on all the findings

Learning Objectives:

After attending our presentation the learner will

1. Increase their knowledge re: benefits of teaching massage to parents of micro-premature babies in the NICU
2. Able to list three benefits of massage for the parents
3. Able to list three benefits of massage for the baby

Gravens 2025-54

Title: Words Matter: Creating Inclusive Spaces in the NICU

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Problem Statement: Words have power! Words conjure up imagery! Words prompt the creation of fallacies and stories. "Language is as vital to the physician's art as the stethoscope or scalpel" - Jerome Groopman. Communication and use of the spoken word is an emerging area of research and awareness in the NICU setting - from daily bedside interactions to structured conversations like family meetings. Research tells us that "although a large majority of the parents were satisfied with their communication with doctors and nurses, only about half of the parents felt the nurses and doctors understood their emotional situation very well." (Wigert 2013). Labrie 2021 have shared that casual, informal day-to-day communication with staff is just as important as structured transfer of information. "At the same time, seemingly 'small' communication issues - misunderstandings, jokes, inadequate timing of information - carry a strong negative weight. Also, tone-of-voice matters a lot to parents in the interaction with medical professionals". This session will explore the power of language in shaping the NICU experience. It will shed light on the cultural, racial, and situational biases that color our communication practices in the NICU setting and begin the journey toward meeting families where they are at, through mindful communication and person-centered language…one word at a time.

Abstract:

"she failed the car seat test"; "He's just lazy"; "She tried to go see the light today"; "you're not gonna wanna see the eye exam"… Sound familiar? These phrases are all too common in our NICUs and may even elicit responses from care team members that make it seem ok. Words have power! Words conjure up imagery! Words prompt the creation of fallacies and stories. "Language is as vital to the physician's art as the stethoscope or scalpel" - Jerome Groopman. Communication and the use of the spoken word is an emerging area of research and awareness in the NICU setting. Research tells us that "Although a large majority of the parents were satisfied with their communication with doctors and nurses, only about half of the parents felt the nurses and doctors understood their emotional situation very well." (Wigert 2013). Labrie 2021 have shared that casual, informal day-to-day communication with staff is just as important as structured transfer of information. "At the same time, seemingly 'small' communication issues - misunderstandings, jokes, inadequate timing of information - carry a strong negative weight. Also, tone-of-voice matters a lot to parents in the interaction with medical professionals." Relational frame theory teaches us that the brain is driven to create meaning and relationships between words. In the "emotional cauldron" that is the NICU, choosing how we frame our words and phrases can drastically change a parent's perspective of the situation and thus elicit trauma responses that may be detrimental to the emotional well-being and stability of the family unit. Parent-provider communication is a crucial determinant of parental well-being and satisfaction with care, during and following infant hospitalization in the NICU (Labrie 2021). This session will explore the power of language in shaping the NICU experience. It will shed light on the cultural, racial, and situational biases that color our communication practices in the NICU setting and begin the journey toward meeting families where they are at, through mindful communication and person-centered language…one word at a time.

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Learning Objectives:

1. Identify 2 ways in which word choices impact stigma and trauma responses
2. Identify at least one phrase used in your NICU that has the potential to negatively impact a family's trust
3. Identify 2 ways you can create change in your unit to promote culturally sensitive, bias-free verbal communication

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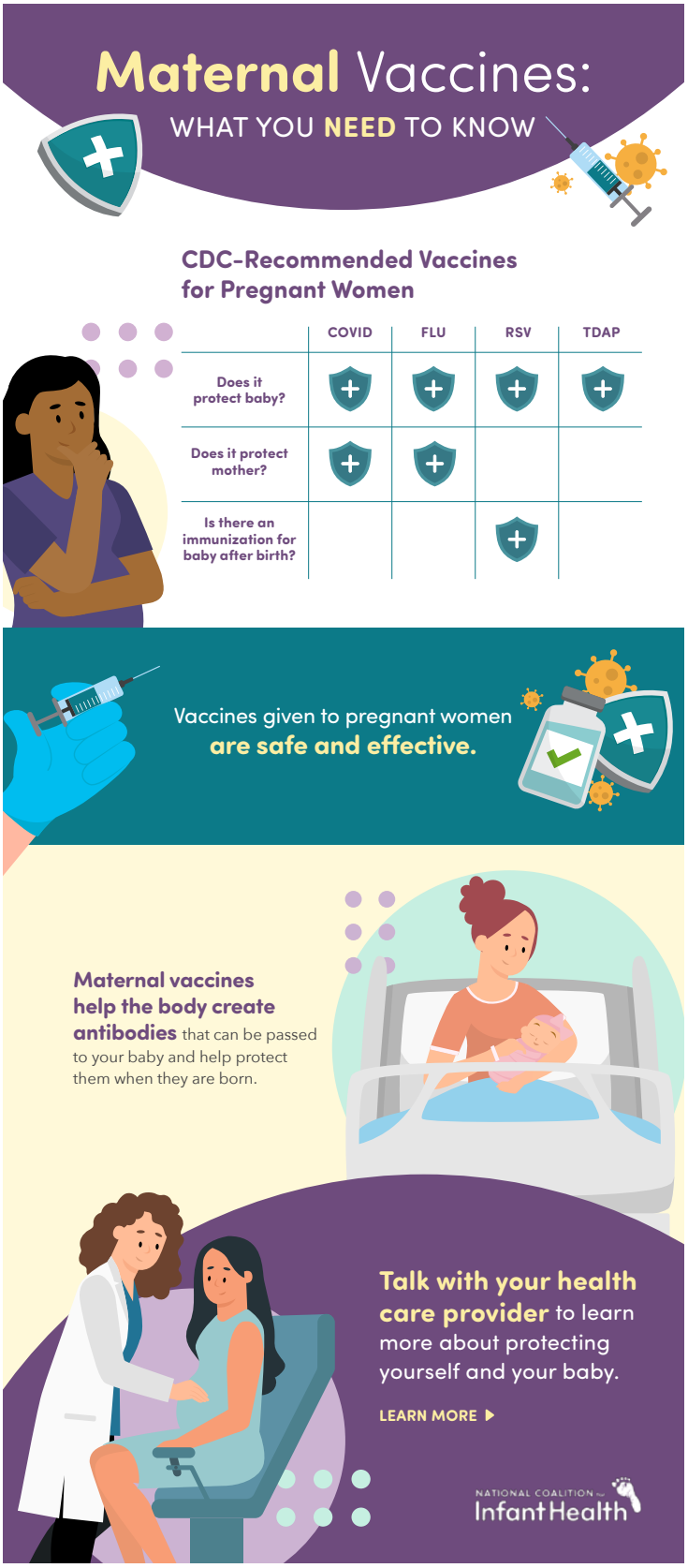

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Ethics and Wellness: Due Process Reloaded: The Silent Crisis in Academic Medicine

Mitchell Goldstein, MD, MBA, CML

"In our society, we speak of due process with reverence. It is supposed to be the backbone of fairness, the guardrail against arbitrary decisions, the mechanism by which all voices can be heard. Nevertheless, in academic medicine, we often pay lip service to the concept while systematically undermining it."

In the November 2023 issue of Neonatology Today, we first explored the concept of "Due Process." We now revisit this domain with a special emphasis on what this term means for those in academic practice and how it affects our ability to develop and retain talented faculty.

"Let us be clear: due process is not about guaranteeing a result. It is about guaranteeing a process: a timely, transparent, and equitable review of the issues at hand. However, in practice, this most basic assurance is routinely violated.)"

In our society, we speak of due process with reverence. It is supposed to be the backbone of fairness, the guardrail against arbitrary decisions, the mechanism by which all voices can be heard. Nevertheless, in academic medicine, we often pay lip service to the concept while systematically undermining it. The result? Faculty who feel sidelined, devalued, and silenced, and institutions that wonder why retention is an uphill battle. (1)

Let us be clear: due process is not about guaranteeing a result. It is about guaranteeing a *process*: a timely, transparent, and equitable review of the issues at hand. However, in practice, this most basic assurance is routinely violated. The greatest failure is not malice, but delay. *Timeliness* is where we fall apart. (2)

Take the promotion process, a defining milestone in an academic career. Faculty pour years of effort into building their CVs, mentoring trainees, and advancing science. When they finally apply, many wait months, sometimes over a year, to hear a word from the committee. Others are told they are "not ready" with no feedback, no explanation, no path forward. This is not just an inconvenience; it is demoralizing and corrosive. Imagine telling our patients, "We will eventually get back to you about your test results, but do not ask when." We would never accept that clinically. Why do we tolerate it professionally? (3, 4)

"Take the promotion process, a defining milestone in an academic career. Faculty pour years of effort into building their CVs, mentoring trainees, and advancing science. When they finally apply, many wait months, sometimes over a year, to hear a word from the committee. "

The same dysfunction infects salary negotiations. Yes, many academic salaries are pegged to rank or seniority, but that does not eliminate the need for fairness and responsiveness. A colleague who cannot make rent or pay student loans is not just financially unstable. They are on the verge of walking away. If we shrug and say, "That is just how the system works," we will watch our talent bleed away to private practice or industry. (5) The irony is that replacing them costs far more than addressing their concerns in the first place.

And what of accommodations for disability, family leave, or

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personal time? Here, the stakes are even higher. Too often, these requests are brushed aside, buried under vague promises of "we'll discuss this later." Let us name that for what it is: a violation of due process, and by extension, a violation of trust. Worse, it signals to already vulnerable colleagues that they are less valued than their healthier, less encumbered peers. That is not just unfair—it borders on discriminatory. (6, 7)

"Let us name that for what it is: a violation of due process, and by extension, a violation of trust. Worse, it signals to already vulnerable colleagues that they are less valued than their healthier, less encumbered peers. That is not just unfair—it borders on discriminatory. (6, 7)"

When due process is ignored, people do not simply move on. They simmer. They feel unheard, unseen, and unprotected. They begin to question whether their contributions matter at all, especially when senior or privileged team members seem to glide past the same obstacles. This is how disenfranchisement takes root. This is how resentment spreads. And this is why retention becomes nearly impossible. (8)

Let us dispense with the myth that ignoring due process is benign. It is not. It actively poisons culture. It fosters whisper networks, quiet quitting, and a corrosive sense of "us versus them" within our ranks. Faculty stop volunteering for committees. They stop mentoring. They stop going the extra mile—because why should they, if the institution cannot be bothered to honor its own commitments?

"Let us dispense with the myth that ignoring due process is benign. It is not. It actively poisons culture. It fosters whisper networks, quiet quitting, and a corrosive sense of 'us versus them' within our ranks. Faculty stop volunteering for committees. They stop mentoring. They stop going the extra mile—because why should they, if the institution cannot be bothered to honor its own commitments?"

The truth is uncomfortable: academic medicine often touts the values of fairness and collegiality, but too often operates on convenience and hierarchy. Those at the top benefit from delay. Those at the margins often bear the brunt of the consequences. Furthermore, as long as we accept "eventually" as good enough, we perpetuate a system where power, rather than fairness, dictates outcomes. (1, 4)

"Due process is not a luxury. It is not optional. It is the minimum standard for any community that pretends to be just, equitable, and committed to its people. If we cannot uphold it in something as basic as promotions, salaries, or accommodations, then all our talk of equity and wellness is nothing more than a smokescreen."

Due process is not a luxury. It is not optional. It is the minimum standard for any community that pretends to be just, equitable, and committed to its people. If we cannot uphold it in something as basic as promotions, salaries, or accommodations, then all our talk of equity and wellness is nothing more than a smokescreen.

The choice before us is simple: either we embed due process—timely, transparent, equitable—into the DNA of our practices, or we continue down the path of alienation and attrition. One path builds trust. The other breeds resentment and loss. (1, 2)

The clock is ticking. Moreover, if timeliness really is the missing piece, then the most radical thing academic medicine can do right now is also the simplest: keep our promises, honor our timelines, and treat due process not as an afterthought, but as a duty. (4, 6)

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INFANT AND FAMILY-CENTERED DEVELOPMENTAL CARE (IFCDC)

STANDARDS AND SAMPLE RECOMMENDATIONS FOR INFANTS IN THE INTENSIVE CARE UNIT

SYSTEMS THINKING IN COMPLEX ADAPTIVE SYSTEMS

- Are the baby and family central to the mission, values, environment, practice & care delivery of IFCDC in the unit?
- Are the parents of each baby fully integrated into the team and treated as essential partners in decision-making and care of the infant?
- What are the strategies and measurements used to improve and sustain IFCDC in the unit?

POSITIONING & TOUCH FOR THE NEWBORN

- Are the positioning plans therapeutic and individualized, given the care needs and development of the baby?
- Are the positioning and touch guidelines continually reviewed by the team, including the parents, and adapted to meet the changing comfort needs of the baby?

SLEEP AND AROUSAL INTERVENTIONS FOR THE NEWBORN

- Can the team confidently describe the "voice" or behavioral communication of the baby?
- Are the baby's unique patterns of rest, sleep, and activity documented by the team and protected in the plan of care?

SKIN-TO-SKIN CONTACT WITH INTIMATE FAMILY MEMBERS

- Is the practice of skin-to-skin contact supported and adjusted to the comfort needs of each baby, parent, & family member?
- Are the parents & family members supported to interact with the baby to calm, soothe, & connect?

REDUCING AND MANAGING PAIN AND STRESS IN NEWBORNS AND FAMILIES

- Are parents supported to be present and interactive during stressful procedures to provide non-pharmacologic comfort measures for the baby?
- Are there sufficient specialty professionals to support the wellbeing of the team, including parents, families, and staff? Examples include mental health, social, cultural, & spiritual specialists.

MANAGEMENT OF FEEDING, EATING AND NUTRITION DELIVERY

- Are the desires of the m/other central to the feeding plan? Is this consistently reflected in documentation with input of the m/other?
- Does the feeding management plan demonstrate a feeding & nutrition continuum from in-hospital care through the transition to home & home care?

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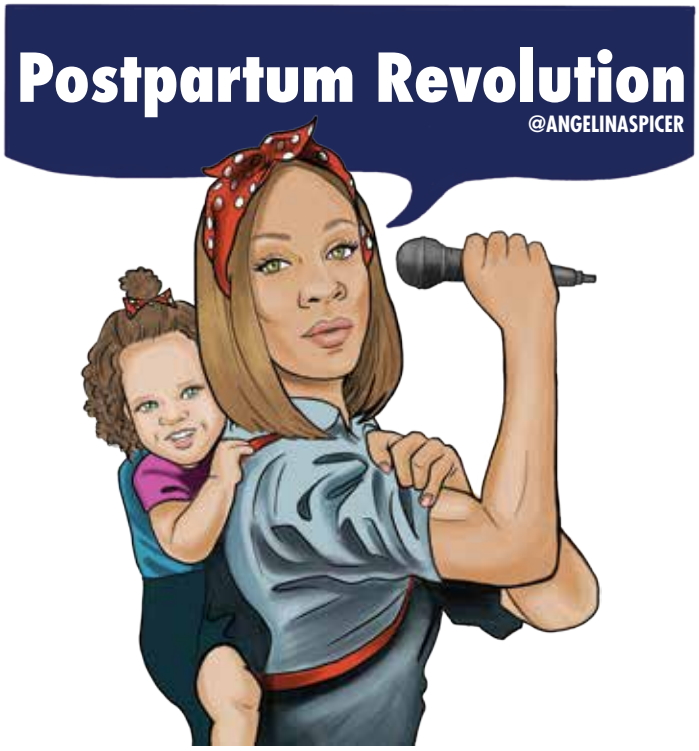

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Peer Reviewed

NICUriosities: The Curious Case of The Excessively Startled Baby

Maria Martes Gomez, DO, Shaina Khan Lodhi, MD, Larry Ngo, MD

Presentation:

A term infant was transferred to our facility on the day of birth.

The infant was born at 37 weeks and 4 days of gestation via vaginal delivery, with APGARs of 6, 7, and 8 at 1, 5, and 10 minutes, respectively, to a mom who had prolonged rupture of membranes for 34 hours and was treated with latent antibiotics. He had a nuchal cord at the time of delivery. The medical team noticed abnormal movements in the upper and lower extremities at about 9 minutes of life, which were not suppressible. The infant's resuscitation continued with initiation of CPAP respiratory support at 10 minutes of life and seizure evaluation for the abnormal movements. Glucose levels were normal, ranging between 96 and 104 mg/dL. The initial CBC showed a WBC count of 26 × 10^3/µL. Given the risk factor of prolonged rupture of membranes, a blood culture was obtained, and Ampicillin and Gentamicin were initiated for suspected neonatal sepsis. He received normal saline boluses for severe acrocyanosis.

"The infant was born at 37 weeks and 4 days of gestation via vaginal delivery, with APGARs of 6, 7, and 8 at 1, 5, and 10 minutes, respectively, to a mom who had prolonged rupture of membranes for 34 hours and was treated with latent antibiotics. He had a nuchal cord at the time of delivery. The medical team noticed abnormal movements in the upper and lower extremities at about 9 minutes of life, which were not suppressible."

There was a family history of a maternal grandfather, who had seizures in the later years of his life. This was discussed with the neurologist at their facility, who recommended obtaining a video EEG. However, the referral hospital was unable to perform a video EEG at their facility, and subsequently, the infant was transferred to our first facility, a level III NICU.

At the Level 3 NICU, similar abnormal movements were observed, accompanied by notable irritability and jitteriness during the exam. Video EEG was started, and further evaluation for seizures was pursued. Serum calcium was borderline low at 7.9 mg/dL, and a calcium gluconate bolus was given. Glucose remained normal. Blood gas, ammonia, and lactate were normal for metabolic screening. TORCH testing and a meconium drug screen were sent. He was transitioned to room air within a few hours after admission. Antibiotics were changed to Ampicillin and Ceftazidime at meningitic dosages. Due to worsening irritability, a CT brain scan was performed, which showed a hyperattenuating appearance of portions of the posterior and posterior inferior superior sagittal sinuses, the straight sinus, and the internal cerebral veins in the sinus confluence. There was also a small area of hyperdensity, which was seen directly adjacent to the superior sagittal sinus on the left side.

Additionally, some hyperattenuation was observed along the tentorium posteriorly, which was symmetric. There were small areas of subdural hemorrhages, and a small cephalhematoma was also noted. There was no midline shift or acute hemorrhage. The case was discussed with a Pediatric Neurologist, and due to concerns about possible dural sinus thrombosis and the need for Pediatric Hematology support for anticoagulation management, as well as possible Pediatric Neurosurgery evaluation, the infant was transferred to our second facility, a level IV NICU, for additional subspecialty support.

"The case was discussed with a Pediatric Neurologist, and due to concerns about possible dural sinus thrombosis and the need for Pediatric Hematology support for anticoagulation management, as well as possible Pediatric Neurosurgery evaluation, the infant was transferred to our second facility, a level IV NICU, for additional subspecialty support."

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"He had persistent myoclonic jerking of all four limbs, though suppressible. The infant exhibited reactive jerks to loud noises and a positive glabellar tap sign."

At the level IV NICU, the baby was noted to have generalized tremulousness when touched. He had persistent myoclonic jerking of all four limbs, though suppressible. The infant exhibited reactive jerks to loud noises and a positive glabellar tap sign. Pediatric Neurology and Pediatric Neurosurgery were consulted, and an MRI, MRA (magnetic resonance angiography), MRV (magnetic resonance venography), and MRS (magnetic resonance spectroscopy) of the brain were completed. Magnetic resonance imaging did not show any findings suggestive of dural sinus thrombosis, intraparenchymal edema, infarct, or hemorrhage. Blood products were seen along the bilateral tentorium cerebelli, which may represent birth-related extra-axial hemorrhage. There was some T1 hyperintensity in the bilateral basal ganglia, more than expected for the patient's age, and mildly elevated choline in the mid-occipital grey matter, which could represent hypoxic ischemic injury or delayed maturation. Plasma amino acids, urine organic acids, and acylcarnitine profile were normal. CSF studies were not consistent with meningitis, and antibiotics were discontinued once cultures were negative for 48 hours. Additionally, testing sent from the level III NICU did not reveal any explanation for these symptoms.

"Magnetic resonance imaging did not show any findings suggestive of dural sinus thrombosis, intraparenchymal edema, infarct, or hemorrhage. Blood products were seen along the bilateral tentorium cerebelli, which may represent birth-related extra-axial hemorrhage. There was some T1 hyperintensity in the bilateral basal ganglia, more than expected for the patient's age, and mildly elevated choline in the mid-occipital grey matter, which could represent hypoxic ischemic injury or delayed maturation. Plasma amino acids, urine organic acids, and acylcarnitine profile were normal. CSF studies were not consistent with meningitis, and antibiotics were discontinued once cultures were negative for 48 hours. Additionally, testing sent from the level III NICU did not reveal any explanation for these symptoms."

Diagnosis:

Due to the exaggerated startle response, positive glabellar tap sign, and mostly normal MRI findings, the diagnosis of hyperekplexia was made by the Pediatric Neurology team.

Management:

The infant was started on low-dose clonazepam. There was some improvement seen in symptoms with slow titration. Genetics recommended a chromosomal microarray and an Epilepsy Panel. The baby was transferred back to the referring hospital two days after starting clonazepam and before genetic testing could be completed.

Discussion:

Hyperekplexia is a rare inherited neurological condition characterized by an exaggerated startle reaction to sudden, unexpected noise, movement, or touch. It can present in infants and children and may even appear prior to birth. Symptoms include an excessive startle reflex, manifesting as eye blinking or body spasms, and hypertonia that restricts both voluntary and passive movements. Hyperreflexia can also be seen with older children as a manifestation of an unstable gait. (1) The most common inheritance pattern is autosomal dominant, but less commonly, autosomal recessive or X-linked inheritance has also been seen. The most affected genes are GLRA1 and SLC6A5. (1, 2)

"Hyperekplexia is a rare inherited neurological condition characterized by an exaggerated startle reaction to sudden, unexpected noise, movement, or touch. It can present in infants and children and may even appear prior to birth. Symptoms include an excessive startle reflex, manifesting as eye blinking or body spasms, and hypertonia that restricts both voluntary and passive movements."

A disruption in the neurotransmission of glycine causes hyperekplexia. Glycine is an inhibitory neurotransmitter found in the brain and spinal cord. It acts by hyperpolarizing neuronal cells, making it challenging to generate an action potential. If glycine production is decreased or glycine receptors are damaged, the nerve cells lose their inhibition and overreact to stimuli. (1)

The diagnosis of hyperekplexia can be made clinically by eliciting a head retraction reflex. Tapping the nose or glabella

"A disruption in the neurotransmission of glycine causes hyperekplexia. Glycine is an inhibitory neurotransmitter found in the brain and spinal cord. It acts by hyperpolarizing neuronal cells, making it challenging to generate an action potential. If glycine production is decreased or glycine receptors are damaged, the nerve cells lose their inhibition and overreact to stimuli."

in affected individuals produces a consistent facial twitching, head extension, and generalized flexor spasm that does not diminish despite repeated tapping. (3, 4) Symptoms often respond to benzodiazepines, such that the treatment of choice for hyperekplexia is clonazepam. (1, 4)

"The diagnosis of hyperekplexia can be made clinically by eliciting a head retraction reflex. Tapping the nose or glabella in affected individuals produces a consistent facial twitching, head extension, and generalized flexor spasm that does not diminish despite repeated tapping."

Hyperekplexia is commonly misdiagnosed as an epilepsy disorder. A key differentiating factor of hyperekplexia from epilepsy is the preserved consciousness during the startle events. Additionally, there is a sudden sensory input prior to the onset of the startle event seen in hyperekplexia. (4) It is important to keep in mind these rare neurological disorders as part of the differential diagnoses when neonates present with abnormal movements.

Clinical Pearls:

- Hyperekplexia is a rare movement disorder characterized by an exaggerated startle response to unexpected stimuli and increased muscle tone (hypertonia).
- A clinical diagnosis of hyperekplexia can be made by eliciting the head retraction reflex.
- Inquire about family history. Hyperekplexia is most commonly an autosomal dominant trait.

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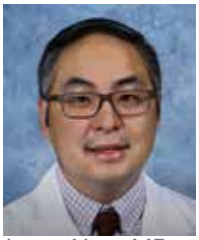

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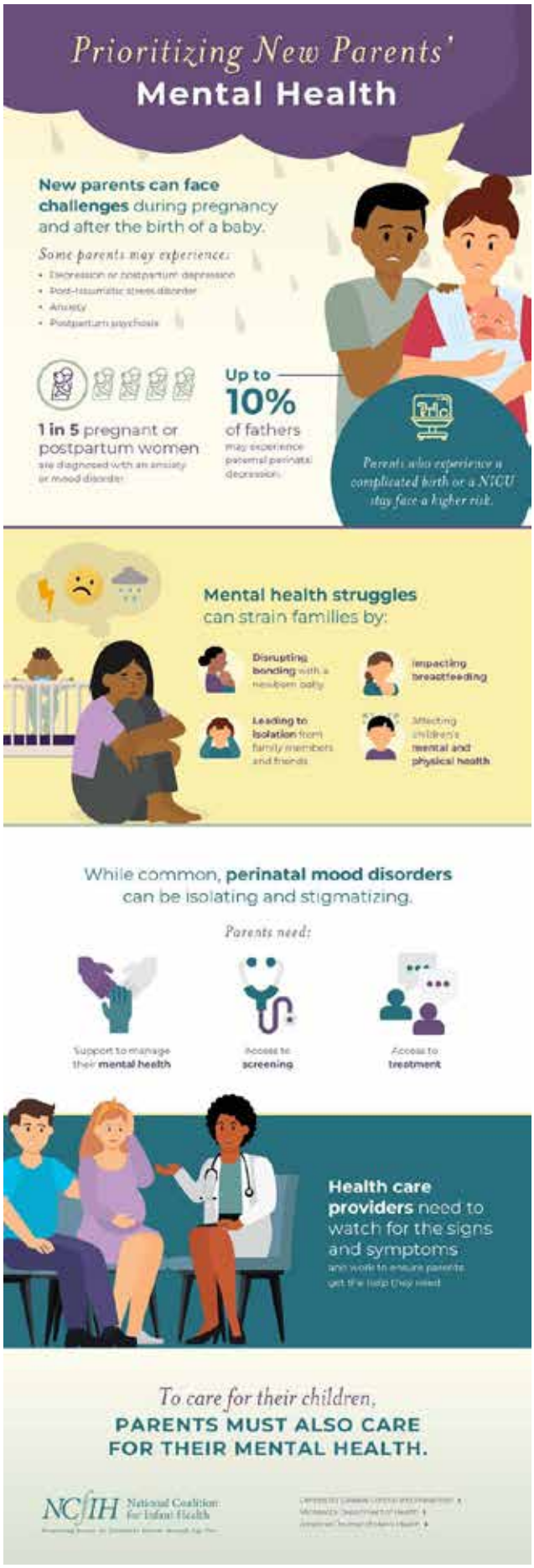

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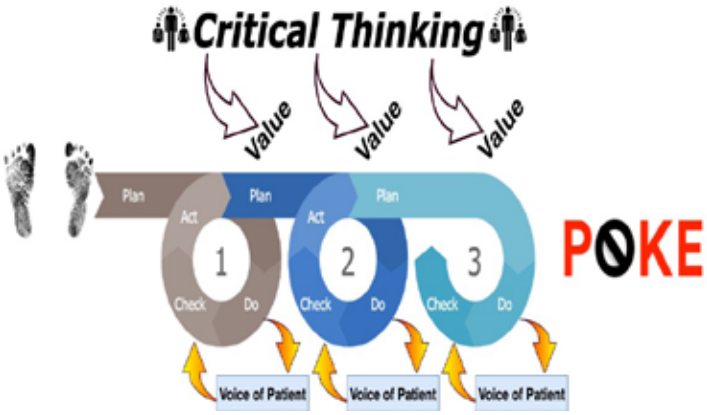
Cultivating a Culture of Pain Elimination

Colonel Robert Erick Ridout, MD, U.S. Army, Retired

"In the last column, I briefly discussed the origin story of POKE (Prevention of Pain and Organisms from sKin and Katheter Entry), which ultimately matured to represent a team-based, patient-centered care ecosystem where ALL are empowered to contribute actively, surface safety concerns, experience deep respect, relentlessly eliminate waste, and help patients, their families, and caregivers feel safe, valued, and loved."

In the last column, I briefly discussed the origin story of POKE (Prevention of Pain and Organisms from sKin and Katheter Entry), which ultimately matured to represent a team-based, patient-centered care ecosystem where ALL are empowered to contribute actively, surface safety concerns, experience deep respect, relentlessly eliminate waste, and help patients, their families, and caregivers feel safe, valued, and loved. To this end, in mid-2008, we undertook a project to clarify and improve the peripheral IV access process, the scope of which quickly expanded as we committed to rigorously measuring the entire care experience of every patient. As we developed the required measurement system, we committed to surfacing each patient's care experience to inform medical decision-making for the next interval of care. Historically, patients in the neonatal intensive care unit, particularly preterm infants, were seen as unable to exercise autonomy (1). These patients lacked a voice in participating in medical decision-making related to their care. Within the POKE ecosystem, we saw the opportunity and obligation to take the patient care experience, both past (interventions that the patient already experienced) and potential (interventions that are ordered to occur in the next interval of care), to serve as key elements of the "Voice-Of-Patient" to guide the medical decision-making. As stated before, I have a passionate belief that patients and caregivers deserve to experience care delivery free from harm and that they should only consent to receive care that adds value (driven by the pretest probability that the information provided by the care experience drives therapeutic modification, advancing the patient's goals of care). To this end, the Voice of the Patient plays a prominent role in team-based patient-centered rounds, guiding medical decision-making. (Figure 1: Voice of Patient continuously influencing each interval of care represented here as iterative PDCA cycles).



As the scope of the PIV project expanded to include measuring all interventions, there was agreement to cultivate a culture of pain elimination. Intuitively, we understood that eliminating painful care experiences to the greatest extent possible would allow each patient to enjoy an "open future" unrestrained by care experiences that might have compromised future choices and opportunities (3). Our intuition proved accurate, in that repeated exposure to painful care experiences may negatively impact neurodevelopment, alter brain microstructure, and influence behavior into adulthood (5). Identifying, with high fidelity, painful and non-painful care experiences (which we started to call POKES), aggregating those that have reached the patient, and proactively eliminating those that are seeking to reach the patient (routine care prior to this culture change) would serve to inform, via Voice-of-Patient, care decisions that eliminate pain (4). Similar to the name we adopted for the overall ecosystem of care, we referred to each measurable care experience as a "POKE," which we defined as any care experience that has the potential to harm the patient or fail to add value. These POKEs were categorized into two broad groups: Central (involving a central vascular line) and Non-Central (encompassing all other types). These broad categories aggregated both painful and non-painful POKEs (Figure 2).

"Similar to the name we adopted for the overall ecosystem of care, we referred to each measurable care experience as a "POKE," which we defined as any care experience that has the potential to harm the patient or fail to add value."

We recognized that achieving our shared purpose of the patient only ever experiencing care that adds value at the lowest cumulative pain would require fostering a culture of continuous improvement in our processes and promoting the professional growth of our people. (Future columns will focus heavily on these topics.) Adjustments to the process of capturing the Voice-of-Patient were required as we learned daily what worked well and what failed to align with our purpose. Every member of our care team participates, and still does to this day, in continuously improving the measurement of the patient care experience and utilizing these measurements to guide the next interval of care. Note, the patient, via Voice-of-Patient, and family are at the center of this continuous improvement team (Figure 3). We leveraged the principles of Kaizen to achieve these changes (6). A powerful enabler of these efforts was our monthly NICU Newsletter (Figure 4). Each newsletter was utilized to achieve broad and transparent communication on the progress of our improvement journey, clarifications and definitions, POKEs avoided, recognition and praise for individuals and teams, and identified obstacles that we were addressing over the next improvement cycle. In the next column, I will delve further into the evolution of our POKE measurement system and expand on the concept of Voice-of-Patient (Figure 5).

"In the next column, I will delve further into the evolution of our POKE measurement system and expand on the concept of Voice-of-Patient (Figure 5)."

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P.O.K.E. Sheets

NICU Newsletter - January 2009

POKE
Prevent Pain & Organisms from sKin and Katheter Entry

Count all POKEs...the same way

Example

Example

P.O.K.E. Sheets

Page 2

We are renaming our Vascular Access, Skin Integrity, and Infection Control QA Monitor Tool to the P.O.K.E. Sheet (Prevent Pain & Organisms from sKin & Katheter Entry Sheet).

A couple more things have come up that need to be pointed out on the revised POKE sheet. I need everyone's help to do this!! Dr. Ridout and I are doing a research project and we want to discover how many POKEs our babies are getting and then reduce that number by 20%. In order to do this, we need everyone to count all POKEs and count them the same way. For example, if a syringe is hung/changed on an IV-that's a POKE. If a flush is done-that's a POKE. If an IV med is given-that's a POKE. If tubing is changed-that's a POKE. Any heel sticks, venous or art line draws, any invasive procedures, etc. all count as a POKE each. So, if it takes 2 tries to get an IV it's 2 POKEs. Any time the skin or line is broken into, it is a POKE. This includes immunizations, LP's, chest tubes, whatever. Then at the end of the shift, add them all up for a Grand total. We will start to incorporate the 24' total number of POKEs on the kardex and talk about it in rounds to see if more than we thought This increases their risk of infection.

Just as an FYI, we found that some of our babies had up to 40 breaks in lines or lab draws, pokes, and what have you in a 24 hour period!

Also, on the IV Infiltrate sheet, our goal is to not have any grade 3 or 4 infiltrates/phlebitis or permanent injury. All of ours so far have been grade 1 or 2, which is what we want. Good job! We are also tracking to see if there is a correlation with activity or type of solution with infiltrates so keep filling them out if there is an infiltrate.

The POKE sheet and the IV infiltrate sheet are works in progress and will change periodically as we refine what we are doing.

Please be diligent in completing them so our data can be accurate. Many babies sheets are being forgotten and therefore, data collection becomes messed up. Place the sheet in front of your kardex or in the clear sleeve of your white binder so you remember to fill it out.

Thanks for all you do.

"We are finding some of our babies have had a lot more than we thought. This increases their risk of infection."

Voice of Patient
What we measured

NoPOKES, BB
DOB: 09/16/2008

Date: 10/12/2008
Shift: AM
RN: L. Adams

Make sure this is the patient for which you wish to enter a new POKE; if correct NAME (TURNS THE SCR PATIENTS POKE

CENTRAL LINES IN PLACE

UVC	O Yes	O No
UAC	O Yes	O No
Broviac	O Yes	O No
PICC	O Yes	O No

Each of t must have "Yes" or before proc

PROCEDURES

HeelSticks	0.00
Venipunctures	0.00
ArterialPunctures	0.00
PIVAttempts	0.00
PALAttempts	0.00
VenousLineAttempts	0.00
IntubationAttempts	0.00
LPAttempts	0.00
FoleyAttempts	0.00
SupraPubicPokes	0.00
Chest Tubes Placed	0.00
NG/OG Placed	No
Surgical Procedures	0.00
Other Painful:	0.00

Skin tears, Skin b

Cummulative Pokes	0.00
Painful Pokes	0.00

PROCEDURES

HeelSticks	0.00	
Venipunctures	0.00	
ArterialPunctures	0.00	
PIVAttempts	0.00	
PALAttempts	0.00	
VenousLineAttempts	0.00	
IntubationAttempts	0.00	
LPAttempts	0.00	
FoleyAttempts	0.00	
SupraPubicPokes	0.00	
Chest Tubes Placed	0.00	
NG/OG Placed	No	
Surgical Procedures	0.00	
Other Painful:	0.00	Skin tears, Skin breakdown, Scalp Lead Lesions, aEEG needles, other

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Erick Ridout, MD, is blessed to be the dad to two amazing kids, granddaddy to three extraordinary grandsons and two granddaughters, and currently serves the babies, their families, and caregivers in the Newborn ICU in Southwestern Utah, the Newborn ICU in Honolulu, Hawaii, and as a Vermont Oxford Network Faculty Member. Additionally, Colonel Ridout proudly served in the United States Army for 23 years, including 11 years as the State Surgeon of the Nevada Army National Guard. He was among the first Army Medical Corps Officers to become a Lean Six Sigma Green Belt and has applied the learned principles in relentlessly eliminating patient, staff, and organizational harm in all of its forms. He has lectured nationwide on Just Culture, Harm Reduction, Value-Added Care, and Servant Leadership. He passionately believes that all patients and caregivers deserve to experience care delivery free of harm. To that end, he seeks to influence MEDICINE to embrace the principles of servant leadership and team-based family-centered care, to send all members of the care team home each day feeling Safe, Valued, and Loved, returning to the bedside fully engaged with heart and mind, all the while seeking to only do for the patient and never to the patient.

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The program also guides how to support families following the devastating loss of an infant, as well as self-care strategies to help manage compassion fatigue.

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Every day, EMTs, social workers, doulas, and others are on the front lines in homes and communities. They are uniquely positioned to educate caregivers about safe sleep practices—and, in tragic cases, to provide support after a loss. This training equips them with the tools to perform both tasks with sensitivity, accuracy, and impact.

"Every day, EMTs, social workers, doulas, and others are on the front lines in homes and communities. They are uniquely positioned to educate caregivers about safe sleep practices—and, in tragic cases, to provide support after a loss. This training equips them with the tools to perform both tasks with sensitivity, accuracy, and impact."

Participants explore the latest research on sleep-related infant deaths and proven prevention strategies, along with culturally responsive, trauma-informed communication techniques that help providers meet families where they are.

The course also addresses how to navigate real-world challenges such as housing instability, stress, or limited resources, and guides offering compassionate bereavement support to families who have experienced a loss. In addition, it includes self-care practices to help participants maintain their own well-being — including tools for those who have personally experienced loss or may be emotionally impacted by a family's trauma.

"The course also addresses how to navigate real-world challenges such as housing instability, stress, or limited resources, and guides offering compassionate bereavement support to families who have experienced a loss. In addition, it includes self-care practices to help participants maintain their own well-being — including tools for those who have personally experienced loss or may be emotionally impacted by a family's trauma."

The course consists of seven modules and includes:

Evidence-based curriculum aligned with the American Academy of Pediatrics' safe sleep guidelines.

- First-person stories that bring real-world experiences to life.
- Downloadable resource sheets for professionals to share with families.
- Interactive quizzes to reinforce key concepts.
- Bereavement support skills to guide families through the immediate aftermath of infant loss.
- Certificates of Completion and digital badges for organizations to display as recognized community partners in safe sleep and bereavement support.

To learn more: https://firstcandle.org/response-training-for-safe-sleep/

Disclosure: *The author is the Executive Director and Chief Executive Officer of First Candle, a Connecticut-based not-for-profit 501(c3) corporation.*

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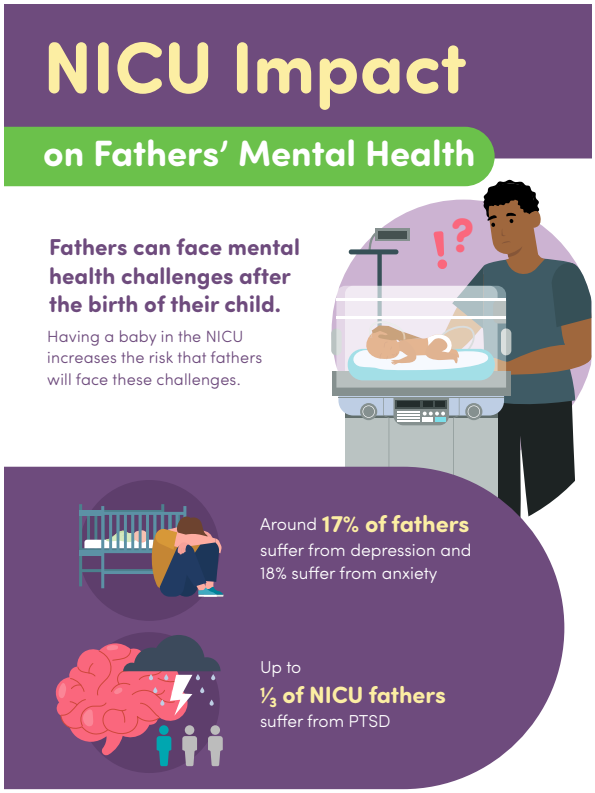
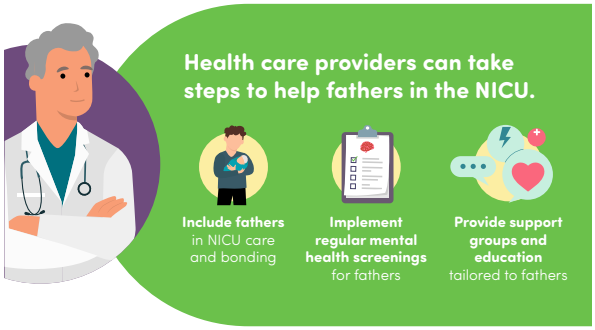
About First Candle:

First Candle, based in New Canaan, CT, is a 501c (3) committed to eliminating Sudden Unexpected Infant Death while providing bereavement support for families who have suffered a loss. Sudden Unexpected Infant Death (SUID), which includes SIDS and Accidental Suffocation and Strangulation in Bed (ASSB), remains the leading cause of death for babies one month to one year of age, resulting in 3,700 infant deaths nationwide per year. It is also the host of the 2025 International Society for the Study and Prevention of Perinatal and Infant Death (ISPID) Conference in Houston from October 7 – 10.





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	COVID	FLU	RSV	TDAP
Does it protect baby?	+	+	+	+
Does it protect mother?	+	+		
Is there an immunization for baby after birth?			+	

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Talk with your health care provider to learn more about protecting yourself and your baby.

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The thoughtful use of telehealth technology can improve care and minimize the risks of exposure to COVID-19.

- Consult with specialists.
- Move family education and resources online.
- Provide parents lactation support.
- Facilitate shared decision-making.
- Screen for perinatal mood and anxiety disorders (PMADs).
- Support case management.
- Use technology to help parents bond with their babies when they can't be bedside.

The move to telehealth services can compound inequities and disparities. Assess each family's technology skills and needs - including the need to use their preferred language.

My Perinatal Network and My NICU Network are products of a collaboration between National Perinatal Association (NPA) and NICU Parent Network (NPN).

myNICUnetwork.org

Peer Reviewed

Advancing Neonatal-Perinatal Care: Happy September Update, Just Two Important Reminders!

Clara H. Song, MD, FAAP

"Your more-than-monthly update from SONPM to keep us all connected and informed!"

Happy September update, just 2 important reminders! 🤓 🍳 🍁

1- Your **VOTE** counts! **SONPM** members are **7%** of the entire AAP, and represent over **1/3** of all the medical subspecialists within the AAP. ***Our voice matters.***

To cast your vote or learn more, visit the AAP Election Center until **WEDNESDAY Sept 17**:

National AAP Election Center

aap.org

2- INS Toolkit Ready in Time for 2025 **SONPM NCE** h-program in Denver, CO on **Sept 26-28**! 🤩

And the SONPM Sunday afternoon 9/28 afternoon **WiN** session:

Building and Sustaining the Workforce in Neonatology with Drs. **Satyan** Lakshminrusimha, **Eric Horowitz**, **Kerry Machut** and **Krithika Lingappan.**

Message from the INS Team - Milenka Cuevas Guaman, Christine Bishop, Emily Miller, Christiane Dammann, and Kerri Machut:

We are excited to launch our Improving Neonatology Staffing toolkit! As you may recall, with support from a SoNPM Strategic Grant, our INS team studied staffing issues in neonatology and developed landmark consensus recommendations for improved neonatologist staffing practices. We then built a robust toolkit to aid advocacy for and implementation of these recommendations. Offering background of the issues, needs assessments, advocacy tools, and practical staffing solutions, its target audience is both leaders (to implement needed improvements) and individual physicians (to understand staffing models and advocare for change). We are asking you as a leader to forward to your groups or anyone you think could benefit, so that all neonatologists can learn and benefit from this resource.

The toolkit lives on the publicly available AAP SoNPM website and can be accessed here:

Improving Neonatology Staffing Toolkit

aap.org

Catch up on our groundwork on NICU-specific payment advocacy in the upcoming SONPM Newsletter.

****Fair payment ➡ improved salary:FTE ratio ➡ improved staffing ➡ decreased burnout ➡ increased workforce ➡ maintain health of our profession****

"Ultimately, payor reform will be needed to sustain growth in subspecialty compensation."

- Robin & Satyan.

Did you know that our current SONPM focus goal of Payment Parity for 2024-2026 aligns with the AAP Payment Transformation Agenda?

Until next time 💚, we are at your service. Keep in touch!

On behalf of your #SONPMexec comm:

Past Chair Munish Gupta@munishguptamd

District 1 Rep Wendy Timpson@TimpsonWendy

D2 Shetal Shah@NICUBatman

D3 Michael Posencheg@MikePosencheg

D4 Misty Good@mistygoodlab

D5 Craig Nankervis

D6 Josh Petrikin@jepetrikin

D7 John Loyd

D8 Jessica Davidson@JessDavMD

D9 & Chair Elect Alexis Davis@AlexisDNeoMD

D10 Ravi Patel @ravimpatelmd

Of Counsel Marilyn Escobedo@Mokcita

AAP Director Jim Couto@jcouto2

Chair Clara Song@songMD

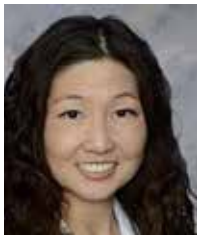
With warm regards,

Clara H. Song, MD, FAAP

Disclosures: No conflicts noted

NT

Corresponding Author



Clara H. Song, MD, FAAP
Neonatal Intensivist, Southern California Permanente Medical Group
Chair Elect, Communication & Digital Media Chair; Women In Neonatology Steering Committee, All Pathways group Co-Chair: District IX California Chapter 4 Council Representative,
Chair, American Academy of Pediatrics, Section on Neonatal-Perinatal Medicine
Lean Six Sigma Black Belt
Email: E clara.h.song@kp.org

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H0160: Section on Neonatal Perinatal Medicine Program: Day 1

Friday, September 26

ONTPD Meeting (CC Mile High Ballroom 2A-3A)

8AM – 4PM **Organization of Neonatal Training Program Directors***
ONTPD Chairs: Megan Gray, MD and Deirdre O'Reilly, MD, MPH

12:00 PM **ONTPD and TECaN lunch***
Sponsored by Mead Johnson Nutrition

Opening Session (CC Mile High Ballroom 2A-3A)

4:00 PM **Welcome and Opening Remarks***
Alexis Davis, MD, MS Epi, Program Chair

4:10 PM **Section on Neonatal Perinatal Medicine Update***
Clara Song, MD, SONPM Executive Committee Chair

4:30 PM **Thomas Cone Lectureship**
"The History of Neonatal Neurology"
Introduction by: Clara Song, MD
Speaker: Terrie Inder, MD

5:15 PM **Gerald Merenstein Lecture**
"Health Equity and Family-Centered Care"
Introduction by: Munish Gupta, MD, MMSc
Speaker: Susan Hwang, MD, PhD, MPH

6:00 PM **Adjourn to Poster Session and Reception**
Location: Colorado Convention Center, Four Seasons Ballroom 1 & 2.
Sponsored by Abbott

**This portion of the agenda is not designated for CME credit.*

H0222: Section on Neonatal Perinatal Medicine Program: Day 2

Joint Program: Section on Neonatal-Perinatal Medicine and Section on Neurology

Saturday, September 27

CC Mile High Ballroom 2A-3A

Updates in Neonatal Neurocritical Care

8:00 AM	**Welcome and Session Introduction***
	SONPM Program Chair: Alexis Davis, MD
	Moderators: Rachel Gottlieb-Smith, MD (SoNu), Alexis Davis, MD (SONPM)
8:05 AM	**Neonatal Neurocritical Care Education Curriculum**
	Khorshid Mohammed, MD, MSc
8:35 AM	**Updated Guidance for Therapeutic Hypothermia**
	Ashley Lucke, MD
9:05 AM	**Panel Discussion**
9:15 AM	**Overview of the 2025 ACNS Guidelines for EEG monitoring**
	Adam Numis, MD
9:45 AM	**Treatment of Seizures in the Neonate**
	Shavonne Massey, MD, MSCE
10:15 AM	**Panel Discussion**
10:30 AM	**Adjourn**

**This portion of the agenda is not designated for CME credit.*

Section on Neonatal Perinatal Medicine Program: Day 2

Afternoon Sessions

Saturday, September 27

CC Mile High Ballroom 2A-3A

Original Abstracts and Award Presentations

1:40 PM	**Welcome and Opening Remarks***
	John Loyd, MD, MPH – Abstract Chair
	Top Ten Abstracts awards sponsored by Mead Johnson Nutrition
1:50 PM	**Scientific Abstract Oral Presentations**
	Moderators: Shetal Shah, MD (SONPM EC) and Grant Schafer, MD (TECaN)
3:05 PM	**Marshall Klaus & Other Awards Presentation***
	Krithika Lingappan, MD, PhD, MS – SONPM Research Committee Chair
3:20 PM	**Break***
3:30 PM	**Scientific Abstract Oral Presentations**
	Moderators: Misty Good, MD, MS (SONPM EC) and Ashley Osborne, MD (TECaN)
4:45 PM	**Section on Neonatal Perinatal Medicine Awards***
	Clara Song, MD – SONPM Executive Committee Chair
4:50 PM	**Avroy Fanaroff Neonatal Education Award – Heather French, MD, MSEd***
	Introduced by Renate Savich, MD
	Sponsored by Mead Johnson Nutrition
5:05 PM	**Maria Delivoria Papadopalous Lankmark Award – Richard Molteni, MD***
	Introduced by Marilyn Escobedo, MD
	Sponsored by Mead Johnson Nutrition
5:20 PM	**Pioneer Award – Jeffrey Perlman, MB, ChB***
	Introduced by Lisa Eiland, MD
5:35 PM	**Virginia Apgar Award – Satyan Laksminrusimha, MD, MBBS***
	Introduced by Robin Steinhorn, MD
	Sponsored by Abbott
5:55 PM	**Adjourn**

**This portion of the agenda is not designated for CME credit.*

H0323: Section on Neonatal Perinatal Medicine Program: Day 3

Joint Program: Section on Neonatal Perinatal Medicine and Section on Anesthesia and Pain

Sunday, September 28

CC Mile High Ballroom 2A-3A

Pain Assessment and Management, Withdrawal and Delirium in the NICU

8:00 AM	**Welcome and Introductions***
	Alexis Davis, MD, MS Epi – SONPM Program Chair
	Moderators: Rita Agarwal, MD (SOA) and Jessica Davidson, MD (SONPM)
8:05 AM	**Presentation of Young Investigator Awards***
	John Loyd, MD, MPH – SONPM Abstract Chair
	Sponsored by Mead Johnson Nutrition
8:15 AM	**Anesthesia and the Developing Brain**
	Lena Sun, MD
8:40 AM	**Regional Anesthesia in Neonates**
	Giorgio Veneziano, MD
9:15 AM	**Panel Discussion**
9:30 AM	**Break***
9:45 AM	**Neonatal Pain Assessment and Strategies for Pain Management in the NICU**
	Brian Carter, MD
10:20 AM	**Withdrawal from Therapeutic Drugs**
	Julie Good, MD
10:55 AM	**Delirium in the NICU**
	Ariel Tarrell, MD
11:30 AM	**Panel Discussion**
11:50 AM	**Adjourn**

**This portion of the agenda is not designated for CME credit.*

H0323: Section on Neonatal Perinatal Medicine Program
Women in Neonatology Group

Building and Sustaining the Workforce in Neonatology: Catalyzing Opportunities for WiN

Sunday, September 28

CC Mile High Ballroom 2A-3A

1:00 PM	**Welcome and Introductions*** *Krithika Lingappan, MD, PhD, MS – WiN Chair* *Moderator: Ishani Jhamb, MD and Krithika Lingappan, MD, PhD, MS*
1:10 PM	**wRVUs, Wellness, Workforce & Women in Neonatology (4WiN)** *Satyan Lakshminrusimha, MD, MBBS*
1:45 PM	**Building a strong neonatology workforce: what do the data show for WiN?** *Eric Horowitz, MD, MHA*
2:30 PM	**Women in Neonatology: Shaping the Future** *Kerri Machut, MD*
3:15 PM	**Strategic Plan for WiN: The Path Forward** *Krithika Lingappan, MD, PhD, MS*
4:00 PM	**Adjourn to Women in Neonatology Reception*-** *Outdoor Terrace Bluebird Ballroom* *Sponsored by Mead Johnson Nutrition*

**This portion of the agenda is not designated for CME credit.*

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Section on Neonatal-Perinatal Medicine Executive Committee: District Representatives from Districts III, VI, and IX

One of the most significant opportunities to engage with the Section on Neonatal-Perinatal Medicine (SONPM) is to serve on the SONPM Executive Committee (EC). The EC consists of one representative from each of the 10 AAP Districts, in addition to chair, chair-elect, past-chair, of-counsel advisor, and AAP section manager (currently Jim Couto). District representatives serve 3-year terms, and are eligible to serve a second term.

District representatives to the EC are responsible for representing all neonatologists working in their AAP districts. The district representative is a liaison between district neonatologists and the SONPM, providing members direct input into SONPM and conveying section activities and opportunities back to the members. More specifically, responsibilities of EC members include the following:

Within executive committee and SONPM broadly:

1. Attend two **required** EC meetings annually, at Scottsdale spring workshop and at NCE;
2. Attend the full SONPM program at Scottsdale spring workshop and NCE meetings annually;
3. Participate in periodic virtual SONPM EC meetings (generally once or twice per month);
4. Review and score abstract submissions to NCE and review poster and oral presentations at NCE meeting, including scoring for SONPM Young Investigator Award;
5. Suggest and select annual SONPM honorary lecturers, including the Cone, Merenstein, Butterfield and Silverman speakers;
6. Solicit and review nominations for annual SONPM awards, including the Apgar, Education, Landmark and Pioneer awards, and select awardees;
7. Participate in planning and execution of national meetings, including section program at NCE, Scottsdale conference, and NeoPREP;
8. Review applications and determine awardees for the Section Strategic Grant Program, currently offered every two years;
9. Review and provide feedback on AAP policy statements, clinical reports, and guidelines as they pertain to newborn care;
10. Participate in and support AAP and SONPM advocacy efforts, including AAP Days of Action;
11. Participate in section committees, groups, and task forces based on interest and need;
12. Participate in SONPM strategic leadership, including implementation of goals of strategic plan; and
13. Participate in SONPM administration, including maintenance and updating of section manual of operations and section budget planning.

Within district:

1. Solicit updates from district members for inclusion in section newsletter twice annually;
2. Allocate annual SONPM district grants by soliciting and evaluating grant proposals;
3. Provide regular updates to district members on relevant aspects of section activities;
4. Provide regular updates to section on district activities and needs of district members;
5. Actively participate in district activities, including attendance at regional conferences; and
6. Encourage AAP and SONPM membership from representative's district, including trainees.

The core executive committee is a productive group! Participation on the executive committee does require a commitment of time and effort, but it is a highly rewarding experience.

Letters to the Editor

Letter to the Editor: "NICUriosities: The Curious Case of the Excessively Startled Baby"

Dear Editor,

I am writing this letter in response to the article "NICUriosities: The Curious Case of the Excessively Startled Baby," in which you discuss the rare condition of hyperekplexia in a newborn. Given the condition's low prevalence and diagnostic challenges, the article provides valuable insight into the management of a neonate with hyperekplexia. This piece is an excellent read for all aspiring clinicians, but particularly for those with interests in neurology and psychiatry, such as myself. In an exciting medical field where it sometimes seems as though we know so much, your article serves as a reminder of the ongoing mystery of the human body.

"This piece is an excellent read for all aspiring clinicians, but particularly for those with interests in neurology and psychiatry, such as myself. In an exciting medical field where it sometimes seems as though we know so much, your article serves as a reminder of the ongoing mystery of the human body."

The article underscores the importance of considering rare disorders like hyperekplexia in a neurological neonatal differential diagnosis when evaluations for more common conditions, such as seizures or sepsis, prove to be inconclusive. The detailed account of the use of video EEG, advanced imaging (such as CT and MRI), and genetic consultation highlights the complexity of managing such cases in a NICU setting. I particularly appreciated your emphasis on distinguishing hyperekplexia from epilepsy. This differentiation can be challenging even for the most experienced clinicians, but it is critical for achieving optimal patient outcomes. To me, what particularly stood out was the description of the head retraction reflex as a critical yet straightforward clinical tool for diagnosing hyperekplexia.

One area for potential elaboration could be regarding long-term care for infants with hyperekplexia. While the use of clonazepam and subsequent symptom improvement are discussed, further insights into the condition's prognosis would be invaluable. Nevertheless, this case study is an informative and insightful read.

"One area for potential elaboration could be regarding long-term care for infants with hyperekplexia. While the use of clonazepam and subsequent symptom improvement are discussed, further insights into the condition's prognosis would be invaluable. Nevertheless, this case study is an informative and insightful read."

Thank you for all your work on this article, and I eagerly await more of your contributions.

Sincerely,

Michael Starkman (OMS-III)

Western University of Health Sciences, College of Osteopathic Medicine of the Pacific

In response to "The Curious Case of the Excessively Startled Baby"

Dear Michael Starkman,

Thank you for your eloquent and perceptive letter regarding our recent *NICUriosities* feature, *"The Curious Case of the Excessively Startled Baby."* Your engagement with this case and your thoughtful reflections on its broader implications capture precisely the spirit in which the article was written. It is always gratifying to hear from readers who not only appreciate the clinical nuances but also recognize the philosophical and educational lessons embedded in such cases.

"Your engagement with this case and your thoughtful reflections on its broader implications capture precisely the spirit in which the article was written. It is always gratifying to hear from readers who not only appreciate the clinical nuances but also recognize the philosophical and educational lessons embedded in such cases."

As you so aptly observed, hyperekplexia, though rare, offers a powerful reminder that medicine remains as much an art as it is a science. Even in the age of high-resolution imaging, molecular diagnostics, and continuous monitoring, there remains an indispensable role for observation, curiosity, and clinical reasoning. The "startled baby" teaches us that a clinician's greatest tools often remain the simplest ones: eyes that truly see, ears that truly listen, and a mind that resists premature closure.

The challenge of differentiating hyperekplexia from more common neonatal conditions such as epilepsy or sepsis is not merely academic: it can profoundly affect patient outcomes. Too often, the subtlety of rare diagnoses is obscured by the urgency of more familiar ones. Your recognition of the diagnostic process described, from video EEG to neuroimaging and genetic consultation, reflects a growing appreciation that modern medicine must balance precision diagnostics with the timeless skills of bedside evaluation.

"The challenge of differentiating hyperekplexia from more common neonatal conditions such as epilepsy or sepsis is not merely academic: it can profoundly affect patient outcomes. Too often, the subtlety of rare diagnoses is obscured by the urgency of more familiar ones. Your recognition of the diagnostic process described, from video EEG to neuroimaging and genetic consultation, reflects a growing appreciation that modern medicine must balance precision diagnostics with the timeless skills of bedside evaluation."

I was particularly pleased to see your appreciation of the head retraction reflex. This simple maneuver embodies something we risk losing in our increasingly technology-driven field, the beauty and efficiency of bedside diagnostics. It reinforces the truth that the best clinicians are those who synthesize both the tactile and the technological, combining sensitivity of observation with scientific rigor. Hyperekplexia is, in that sense, a humbling disorder: one that reminds us how the smallest details (e.g., a reflex, a pattern of movement, a momentary clinical clue) can guide us toward clarity. (1)

You also raise an excellent point about the long-term management and prognosis of infants diagnosed with hyperekplexia. Indeed, the acute NICU management is only the first chapter of a much longer story. These children require thoughtful follow-up, not only to monitor the potential for recurrent symptoms or medication side effects but also to ensure optimal neurodevelopmental outcomes. Families, too, play an essential role in ongoing care; parental education about safe handling, recognition of startle triggers, and medication adherence can be transformative. While clonazepam remains a cornerstone of pharmacologic management, research into genotype-specific responses and the natural history of the condition is ongoing. Your suggestion inspires others to consider exploring these longer-term dimensions in greater detail. (2, 3)

Your letter also reflects something profoundly encouraging—the engagement of a new generation of clinicians who are thinking deeply about the interface between neonatology, neurology, and psychiatry. The early manifestations of neurological function and dysfunction in newborns offer a remarkable window into brain development, and understanding these phenomena can inform care well beyond the NICU. In this way, hyperekplexia is not simply a rare curiosity but a lens through which we can view broader principles of neonatal neurophysiology and family-centered care. (4)

"At Neonatology Today, our mission is to spark precisely this kind of dialogue—to bridge the gap between complex medical phenomena and the clinicians who must interpret them, and to remind us that even in the smallest patients, the lessons can be immense."

At *Neonatology Today*, our mission is to spark precisely this kind of dialogue—to bridge the gap between complex medical phenomena and the clinicians who must interpret them, and to remind us that even in the smallest patients, the lessons can be immense. Your reflections embody that mission perfectly. They remind us that our work as editors, authors, and clinicians is not simply to describe, but to question; not merely to explain, but to inspire further inquiry.

"As we continue to feature NICUriosities cases that highlight rare or diagnostically challenging conditions, your feedback serves as a vital compass, encouraging us to explore these stories not just as case reports but as narratives of discovery, humility, and learning. I hope your letter inspires other readers—especially trainees—to pause and reconsider the value of asking 'What else could this be?'"

As we continue to feature *NICUriosities* cases that highlight rare or diagnostically challenging conditions, your feedback serves as a vital compass, encouraging us to explore these stories not just as case reports but as narratives of discovery, humility, and learning. I hope your letter inspires other readers—especially trainees—to pause and reconsider the value of asking "What else could this be?"

Thank you again for your generous and insightful contribution. It is a privilege to engage with readers who approach medicine with such intellectual curiosity and respect for its enduring mysteries. I wish you every success in your medical journey, and I hope

you will continue to find inspiration in the ever-evolving world of neonatal and neurological care.

With warm regards and appreciation,

References:

1. National Organization for Rare Disorders (NORD). Hyperekplexia [Internet]. 2013 Mar [cited 2025 Sept 11]. Available from: https://rarediseases.org/rare-diseases/hyperekplexia/
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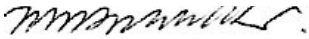
3. Shahar E, Brand N, Uziel Y, Barak Y. Nose Tapping Test Inducing a Generalized Flexor Spasm: A Hallmark of Hyperexplexia. Acta Paediatrica. 1991 Nov;80(11):1073–7.
4. Gupta J, Badal S, Anand V, Jauhari P, Chakrabarty B, Gulati S. Hyperekplexia: A Frequent Near Miss in Infants and Young Children. Neurology India. 2022 Jan;70(1):312–4.

Sincerely,



Mitchell Goldstein, MD, MBA, CML

Editor in Chief

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Erratum (Neonatology Today August, 2025)

There are no erratum to report for August, 2025

Corrections can be sent directly to LomaLindaPublishingCompany@gmail.com. The most recent edition of Neonatology Today including any previously identified erratum may be downloaded from www.neonatologytoday.net.

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Neonatology Today welcomes your editorial commentary on previously published manuscripts, news items, and other academic material relevant to the fields of Neonatology and Perinatology.

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Certain diagnoses can make children and babies more vulnerable for serious complications from respiratory viruses - including prematurity, chronic lung disease, and heart conditions.

You can limit the spread of viruses by wearing a mask, washing your hands with soap & water, using an alcohol-based hand sanitizer, and getting vaccinated.

The fewer germs your baby is exposed to, the less likely they are to get sick. Let people know you need their help to stay well. Limit visitors. Avoid crowds. Stay away from sick people.

Immunizations save lives. Stay up-to-date with your family's flu vaccinations and COVID-19 boosters. This helps our community stay safe by stopping the spread of deadly viruses.

Babies older than 6 months can get a flu shot and COVID-19 vaccinations. Now there are new vaccines for RSV for adults and antibody shots for babies that can help protect them.

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Fathers Can Experience

Postpartum Depression

Becoming a father is an exciting and significant life event.

While it's well known that mothers can face postpartum depression, new fathers are at risk too.

1 in 10 men experience postpartum depression

Up to 7% of fathers may experience PTSD after the birth of their child

If their baby was born **preterm or the birth was traumatic,** their risk of postpartum depression and PTSD increases

Signs and symptoms a father may be struggling include:

- Mood swings
- Trouble sleeping
- Anger
- Withdrawing from family and friends
- Difficulty bonding with their baby

Raising awareness about paternal postpartum depression can:

- Reduce stigma
- Help dads recognize the symptoms
- Eliminate barriers to screening and treatment

New dads deserve their mental health to be taken seriously.

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Rapid breathing and wheezing

Bluish skin, lips, or fingertips

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Thick yellow, green, or grey mucus

that clogs their nose and lungs, making it hard to breathe

Fever that is more than 101° Fahrenheit

101°

which is especially dangerous for babies younger that 3 months

National Perinatal Association

www.nationalperinatal.org/rsv

Why Pregnant and Nursing Women Need Clear Guidance on

THE NET BENEFITS OF EATING FISH

2 to **3** servings per week of properly cooked fish can provide health benefits for pregnant women and babies alike:

Iron

Omega 3 fatty acids

Earlier Milestones for Babies

shrimp

canned light tuna

cod

catfish

salmon

pollock

tilapia

But **mixed messages** from the media and regulatory agencies cause pregnant women to sacrifice those benefits by eating less fish than recommended.

GET THE FACTS
ON FISH CONSUMPTION FOR PREGNANT WOMEN, INFANTS, AND NURSING MOMS.

NCfIH National Coalition for Infant Health

LEARN MORE

pac/lac

Perinatal Advisory Council:
Leadership, Advocacy and Consultation

Continuing Medical Education

The Continuing Education Department at PAC/LAC is pleased to consider requests to be a joint provider of your CME activity. PAC/LAC is actively involved in direct and joint-providership of multiple continuing education activities and programs and works with our partners to ensure the highest standards of content and design. PAC/LAC is the recipient of the 2018 Cultural & Linguistic Competency Award. This award recognizes a CME provider that exemplifies the goal of integrating cultural and linguistic competency into overall program and individual activities and/or a physician who provides leadership, mentorship, vision, and commitment to reducing health care disparities

PAC/LAC is an accredited provider of continuing education by Accreditation Council for Continuing Medical Education / Institute for Medical Quality, the California Board of Registered Nursing, the California Association of Marriage and Family Therapists, the National Commission for Health Education Credentialing, and the American Association for Respiratory Care.

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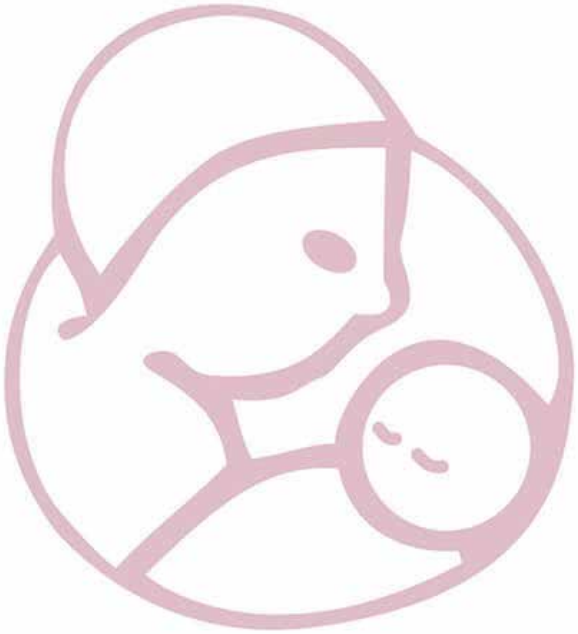
- Licensed Professional Clinical Counselors (LPCC)
- Licensed Educational Psychologists (LEP)
- Certified Health Education Specialists (CHES)
- Continuing Respiratory Care Education (CRCE)

www.paclac.org



PAC/LAC's core values for improving maternal and child health have remained constant for over 30 years – a promise to lead, advocate and consult with others.

Leadership

Providing guidance to healthcare professionals, hospitals and healthcare systems, stimulating higher levels of excellence and improving outcomes for mothers and babies.

Advocacy

Providing a voice for healthcare professionals and healthcare systems to improve public policy and state legislation on issues that impact the maternal, child and adolescent population.

Consultation

Providing and promoting dialogue among healthcare professionals with the expectation of shared excellence in the systems that care for women and children.

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Thirteen-year-old Emily Rose Shane was tragically murdered on April 3, 2010 on Pacific Coast Highway in Malibu, CA. Our foundation exists to honor her memory.

In Loving Memory

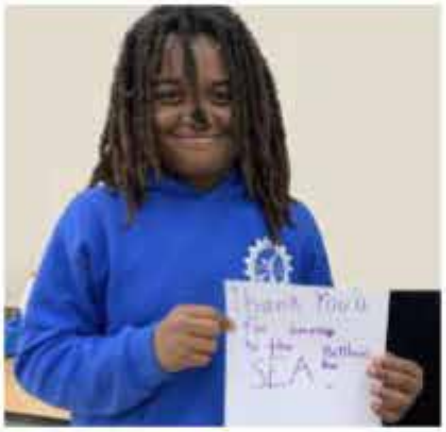
August 9, 1996 - April 3, 2010

Each year, the Emily Shane Foundation SEA(Successful Educational Achievement) Program provides academic and mentoring support to over 100 disadvantaged middle school students who risk failure and have no other recourse. We have served over 700 children across Los Angeles since our inception in the spring of 2012. Due to the COVID-19 outbreak, our work is in jeopardy, and the need for our work is greatly increased. The media has highlighted the dire impact online learning has caused for the very population we serve; those less fortunate. **We need your help now more than ever to ensure another child is not left behind.**

Make a Difference in the Life of a Student in Need Today!
Please visit emilyshane.org

Sponsor a Child in the SEA Program

The average cost for the program to provide a mentor/ tutor for one child is listed below.



1 session	$15
1 week	$30
1 month	$120
1 semester	$540
1 year	$1,080
Middle School	$3,240

he Emily Shane Foundation is a 501(c)3 nonprofit charity, Tax id # 27-3789582. Our flagship SEA (Successful Educational Achievement) rogram is a unique educational initiative that provides essential mentoring/tutoring to disadvantaged middle school children across Los Angeles and Ventura counties. All proceeds directly fund the SEA Program, making a difference in the lives of the students we serve.

The Village Son

A Life's Journey

Iranian village to a university professor in the United States of America in this memoir. As a boy, his unruly behavior was sedated by scholastic challenges as a remedy. At age twelve, he left home for junior high school in a provincial capital. At first, a lack of self-esteem led him to stumble, but he soon found the courage to tackle his subjects with vigor. He became more curious about the world around him and began to yearn for a new life despite his financial limitations. Against all odds, he became one of the top students in Iran and earned a scholarship to study medicine in Europe. Even though he was culturally and socially naïve by European standards, an Italian family in Rome helped him thrive. The author never shied away from the challenges of learning Italian, and the generosity of Italy and its people became part and parcel of his formative years. By the time he left for the United States of America, he knew he could accomplish whatever he imagined.

Houchang D. Modanlou

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There's new information and rulings on safe sleep. Are you ready to speak with your patients?

Bring First Candle's Straight Talk for Infant Safe Sleep program to your hospital so that everyone is up to date on the latest information from the AAP on safe sleep and the CPSC on safe products.

For more information contact Barb Himes at barb@firstcandle.org

first candle
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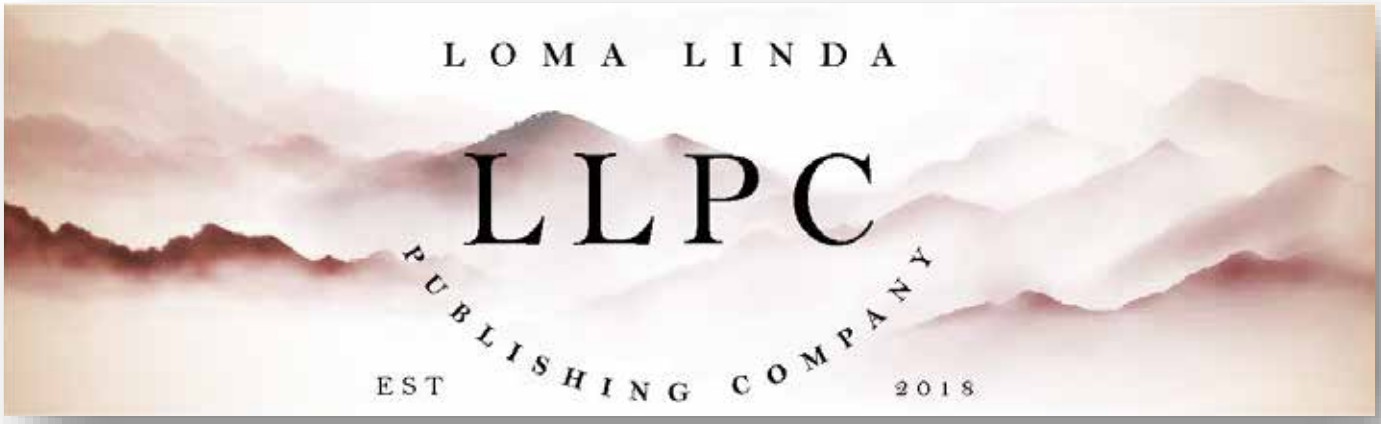


National Network of NICU Psychologists
www.nationalperinatal.org/psychologists

COVID-19

FREE RESOURCES for your NICU

- Helping Children and Families Cope
- Bonding with Your Baby
- Caregivers Need Care Too

COPING WITH COVID-19

KEEP PATIENTS UP-TO-DATE WITH CHANGES IN POLICIES SO THEY KNOW WHAT TO EXPECT. LISTEN TO THEIR CONCERNS.

Provide culturally-informed and respectful care.

TELL PARENTS HOW YOU WILL KEEP THEM AND THEIR BABIES SAFE DURING THEIR NICU STAY.

Use technology like video chat apps to include family members who can't visit the NICU.

myNICUnetwork.org

and

National Perinatal Association
NICU Parent Network

My Perinatal Network and My NICU Network are products of a collaboration between NPA and NPN.

2024

Respiratory Syncytial Virus:

How you can advocate for babies this RSV season

Track national data and trends at the CDC's website www.cdc.gov/rsv

Identify the babies at greatest risk including those with CLD, BPD, CF, and heart conditions

Teach families how to protect their babies from respiratory infections

Advocate for broader insurance coverage for both vaccination and palivizumab prophylaxis so more babies can be protected

Use your best clinical judgement when prescribing RSV prophylaxis

Tell insurers what families need and provide the supporting evidence

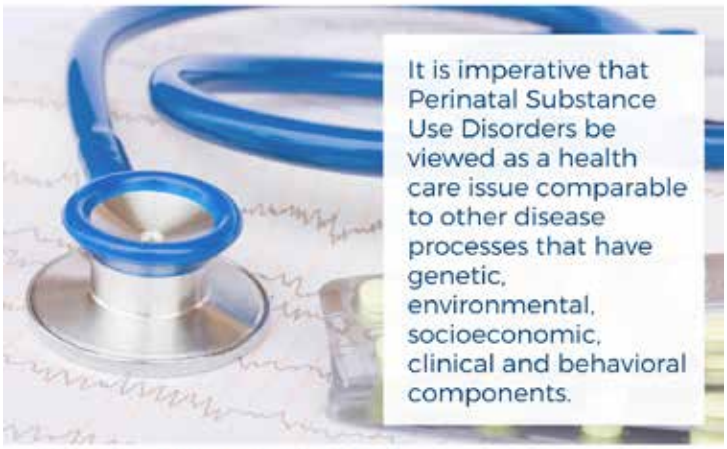
National Perinatal Association

www.nationalperinatal.org/rsv

National Perinatal Association

PERINATAL SUBSTANCE USE

nationalperinatal.org/advocacy
www.nationalperinatal.org/substance-use



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2024

Keeping Your Baby Safe

from respiratory infections

RSV
COVID-19
colds
flu

How to protect your little one from germs and viruses

This year's cold and flu season may be a dangerous one - especially for vulnerable infants and children. Fortunately, there are proven protective measures that we can take to stay healthy.

Here's what you can do...

Wash Your Hands

- This is the single, most important thing you can do to stop the spread of viruses.
- Use soap.
- Wash for more than 20 seconds.
- Use alcohol-based sanitizers.

Limit Contact with Others

- Stay home when you can.
- Stay 6 feet apart when out.
- Wear a face mask when out.
- Change your clothes when you get home.
- Tell others what you're doing to stay safe.

Provide Protective Immunity

- Hold baby skin-to-skin.
- Give them your breast milk.
- Stay current with your family's immunizations.

Take Care of Yourself

- Stay connected with your family and friends.
- Sleep when you can.
- Drink more water and eat healthy foods.
- Seek mental health support.

Immunizations Vaccinations save lives. Protect your baby from flu, pertussis, RSV, and COVID-19 by getting your immunizations.

WARNING

Never Put a Mask on Your Baby

- Because babies have smaller airways, a mask makes it hard for them to breathe.
- Masks pose a risk of strangulation and suffocation.
- A baby can't remove their mask if they're suffocating.

If you are positive for COVID-19

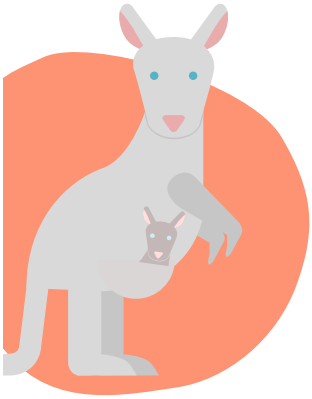
- Wash with soap and water and put on fresh clothes before holding or feeding your baby.
- Wear a mask to help stop the virus from spreading.
- Watch out for symptoms like fever, confusion, or trouble breathing.
- Ask for help caring for your baby and yourself while you recover.

We can help protect each other.
Learn more
www.nationalperinatal.org/rsv

National Perinatal Association

SUPPORTING KANGAROO CARE

SKIN-TO-SKIN CARE DURING COVID-19



GET INFORMED ABOUT THE RISKS + BENEFITS

work with your medical team to create a plan

GET CLEAN

WASH YOUR HANDS, ARMS, and CHEST

with soap and water for 20+ seconds. Dry well.

PUT ON FRESH CLOTHES

change into a clean gown or shirt.

IF COVID-19 + WEAR A MASK

and ask others to hold your baby when you can't be there

National Perinatal Association

NPN NICU PARENT NETWORK

nicuparentnetwork.org

nationalperinatal.org/skin-to-skin

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Children's Hospital of Philadelphia

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Health Equity Resources and Strategies

+ Dalia Feltman, MD, MA, FAAP
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Raising Global Awareness of RSV

Global awareness about respiratory syncytial virus (RSV) is lacking. RSV is a relatively unknown virus that causes respiratory tract infections. It is currently the second leading cause of death – after malaria – during infancy in low- and middle-income countries.

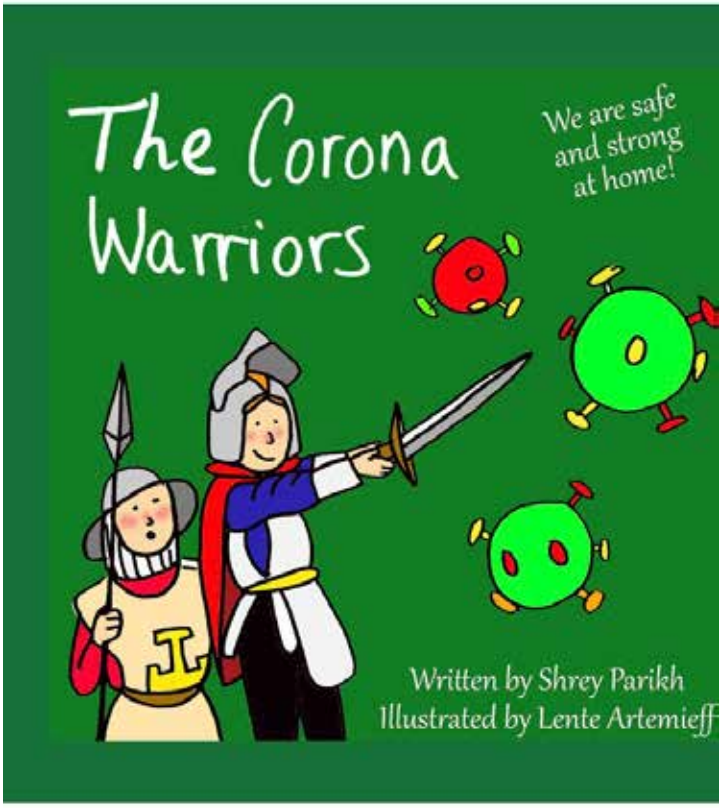
The RSV Research Group from professor Louis Bont, pediatric infectious disease specialist in the University Medical Centre Utrecht, the Netherlands, has recently launched an RSV Mortality Awareness Campaign during the 5th RSV Vaccines for the World Conference in Accra, Ghana.

They have produced a personal video entitled "*Why we should all know about RSV*" about Simone van Wyck, a mother who lost her son due to RSV. The video is available at www.rsvgold.com/awareness and can also be watched using the QR code on this page. Please share the video with your colleagues, family, and friends to help raise awareness about this global health problem.

RSV GOLD

A Global Mortality Database for Children with RSV Infection

The RSV awareness video was produced in collaboration with the Bill & Melinda Gates Foundation



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Thirteen-year-old Emily Rose Shane was tragically murdered on April 3, 2010 on Pacific Coast Highway in Malibu, CA. Our foundation exists to honor her memory.

Each year, the Emily Shane Foundation SEA(Successful Educational Achievement) Program provides academic and mentoring support to over 100 disadvantaged middle school students who risk failure and have no other recourse. We have served over 700 children across Los Angeles since our inception in the spring of 2012. Due to the COVID-19 outbreak, our work is in jeopardy, and the need for our work is greatly increased. The media has highlighted the dire impact online learning has caused for the very population we serve; those less fortunate. **We need your help now more than ever to ensure another child is not left behind.**

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Middle School	$3,240

The Emily Shane Foundation is a 501(c)3 nonprofit charity, Tax id # 27-3789582. Our flagship SEA (Successful Educational Achievement) Program is a unique educational initiative that provides essential mentoring/tutoring to disadvantaged middle school children across Los Angeles and Ventura counties. All proceeds directly fund the SEA Program, making a difference in the lives of the students we serve.

Peer Reviewed

National Coalition for Infant Health: Executive Summary of the National Coalition for Infant Health and the Petition to the Advisory Committee on Immunization Practices (ACIP) Submitted September 12, 2025 Docket Number CDC-2025-0454

Mitchell Goldstein, MD, MBA, CML, Susan Hepworth

The National Coalition for Infant Health is a collaborative of more than 200 professional, clinical, community health, and family support organizations focused on improving the lives of premature infants through age two and their families. NCfIH's mission is to promote lifelong clinical, health, education, and supportive services needed by premature infants and their families. NCfIH prioritizes safety of this vulnerable population and access to approved therapies.

"This petition, submitted by the National Coalition for Infant Health (NCfIH), a coalition of national and regional organizations, requests that the Advisory Committee on Immunization Practices (ACIP) reaffirm its commitment to protecting patient access, public trust, and the integrity of immunization policy."

This petition, submitted by the National Coalition for Infant Health (NCfIH), a coalition of national and regional organizations, requests that the Advisory Committee on Immunization Practices (ACIP) reaffirm its commitment to protecting patient access, public trust, and the integrity of immunization policy. The petition emphasizes that the strength of ACIP's work has always rested on a foundation of broad, inclusive recommendations—those that empower both healthcare providers and parents to make evidence-informed decisions that best meet the needs of every infant and child.

The signatories express deep concern that any move to narrow, reverse, or delay existing vaccine recommendations would erode confidence in ACIP's science-based process, reduce provider flexibility, and create new barriers to timely care during the height of the respiratory illness season. The petition argues that choice, access, and protection are not competing values but mutually reinforcing goals that have historically guided the nation's most successful vaccination programs. It underscores the urgent need for continuity, consistency, and clarity in ACIP recommendations, particularly as hospitals and clinics prepare for another winter of heightened viral activity.

Preserve Broad Protection Against RSV: Maintain Recommendations for Nirsevimab and Clesrovimab

The petition strongly urges ACIP to sustain its existing nirsevimab recommendation and uphold the June 2025 endorsement of clesrovimab, ensuring that providers retain access to the full complement of preventive tools for RSV. Nirsevimab's introduction marked a turning point in infant health protection—leading to a measurable decline in RSV-related hospitalizations and intensive care admissions during the 2023–2024 respiratory season. (1)

Clinical data have consistently demonstrated that nirsevimab is safe, effective, and practical to administer in diverse clinical settings, including both outpatient and inpatient newborn care. The petition warns that any reversal or narrowing of ACIP's recommendation would risk undoing these hard-won gains, returning hospitalization rates to pre-2022 levels and disproportionately affecting infants born prematurely, those with chronic lung or heart conditions, and families in medically underserved regions.

The petition also calls attention to the Committee's June recommendation on clesrovimab, an additional RSV immunization

Steering Committee

The National Coalition for Infant Health is supported by a volunteer steering committee: all of whom contribute significantly to lives of premature infants through work and parenting. Steering committee members represent national nonprofits, academic institutions, and parent organizations, and they provide leadership as well as help to mobilize partners in the field of prematurity.

that offers protection through a complementary mechanism. The signatories emphasize that reaffirming both products supports innovation, clinical judgment, and patient choice, while signaling to the healthcare community that ACIP remains guided by data, not political or market pressures.

"The petition strongly urges ACIP to sustain its existing nirsevimab recommendation and uphold the June 2025 endorsement of clesrovimab, ensuring that providers retain access to the full complement of preventive tools for RSV. Nirsevimab's introduction marked a turning point in infant health protection—leading to a measurable decline in RSV-related hospitalizations and intensive care admissions during the 2023–2024 respiratory season. (1)"

Use the MMRV Recommendation as a Model for Evidence-Based Flexibility:

The petition points to ACIP's existing recommendation for the measles, mumps, rubella, and varicella (MMRV) vaccine as an exemplary model for balancing strong public health guidance with respect for individual choice. Under current policy, providers may administer either the combined MMRV vaccine or separate MMR and varicella injections for the first dose of the vaccine. This approach acknowledges that families differ in their preferences and risk assessments—some prioritizing fewer injections, others preferring separate doses to minimize the small increased risk of febrile seizures observed in specific populations.

By maintaining both options, ACIP demonstrates that flexibility and scientific rigor can coexist. The petition encourages the Committee to view this as a template for future vaccine recommendations: offer clear, evidence-based guidance while preserving the autonomy of providers and parents to make individualized decisions grounded in the best available evidence.

"The petition points to ACIP's existing recommendation for the measles, mumps, rubella, and varicella (MMRV) vaccine as an exemplary model for balancing strong public health guidance with respect for individual choice."

Uphold the Universal Hepatitis B Birth-Dose Recommendation:

The coalition also calls on ACIP to reaffirm its universal birth-dose recommendation for Hepatitis B vaccination, a cornerstone of pediatric preventive care since 1991. This long-standing policy has been instrumental in reducing vertical and early horizontal transmission of the hepatitis B virus across the United States. (2)

The petition cites evidence showing that two-thirds of pediatric hepatitis B cases occur in infants whose mothers initially test negative during pregnancy. Because up to two-thirds of individuals with hepatitis B remain unaware of their infection, reliance on maternal screening alone leaves newborns vulnerable to undetected exposure. (3) Administering the birth dose—ideally within 24 hours—closes this critical gap, providing immediate protection and serving as the foundation for lifelong immunity. (4)

The signatories emphasize that the policy does not eliminate parental choice; instead, it ensures that every family has the opportunity for protection from the moment of birth. Maintaining universal access to the hepatitis B birth dose, they argue, is a matter of both clinical prudence and health equity—guaranteeing that all newborns, regardless of geography, hospital resources, or socioeconomic status, have equal access to this essential preventive measure.

"The coalition also calls on ACIP to reaffirm its universal birth-dose recommendation for Hepatitis B vaccination, a cornerstone of pediatric preventive care since 1991. This long-standing policy has been instrumental in reducing vertical and early horizontal transmission of the hepatitis B virus across the United States. (2)"

Ensure Continued Access to and Coverage for COVID-19 Vaccines:

The petition further emphasizes the need to preserve broad access and insurance coverage for COVID-19 vaccines. COVID-19 remains a cause of pediatric hospitalization, long-term morbidity, and, in some cases, death. While the disease burden has lessened since the pandemic's peak, ongoing viral evolution and waning immunity mean that vaccination remains a critical layer of defense.

Families across the country rely on the ability to choose COVID vaccination not only to protect their children but also to safeguard vulnerable relatives—such as elderly grandparents and immunocompromised household members. ACIP's continued recommendation ensures that insurers cover these vaccines and that they remain widely available through both public and private healthcare systems. The petition emphasizes that narrowing recommendations would not expand choice; rather, it would limit coverage, create confusion, and place the financial burden of protection on families who are least able to bear it.

> ***"The petition further emphasizes the need to preserve broad access and insurance coverage for COVID-19 vaccines. COVID-19 remains a cause of pediatric hospitalization, long-term morbidity, and, in some cases, death. While the disease burden has lessened since the pandemic's peak, ongoing viral evolution and waning immunity mean that vaccination remains a critical layer of defense."***

Conclusion: Protecting Access, Trust, and Equity:

In closing, the petition reminds the Committee that ACIP's decisions have far-reaching consequences that extend far beyond its meeting room. They shape the practices of pediatricians, influence insurance coverage policies, and ultimately determine how easily families can access life-saving preventive care.

The National Coalition for Infant Health warns that narrowing recommendations risks undermining not only access but also the public's faith in ACIP's evidence-based deliberative process—a trust built over decades of transparent, data-driven guidance. Restrictive or inconsistent recommendations could unintentionally foster inequities, with the most vulnerable infants and families losing the most significant protections.

As the respiratory illness season rapidly approaches, the petition calls for a swift reaffirmation of the ACIP's commitment to comprehensive, inclusive immunization policies. The signatories urge the Committee to maintain recommendations that promote protection, flexibility, and parental choice—ensuring that every child, from birth onward, has the opportunity to grow and thrive in good health.

In summary, NCfIH's message is clear: strong, inclusive recommendations do not limit choice—they create choice. By upholding existing policies on RSV, MMRV, Hepatitis B, and COVID-19 immunizations, ACIP will preserve the foundation of trust, access, and equity that underpins public health success in the United States.

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NT

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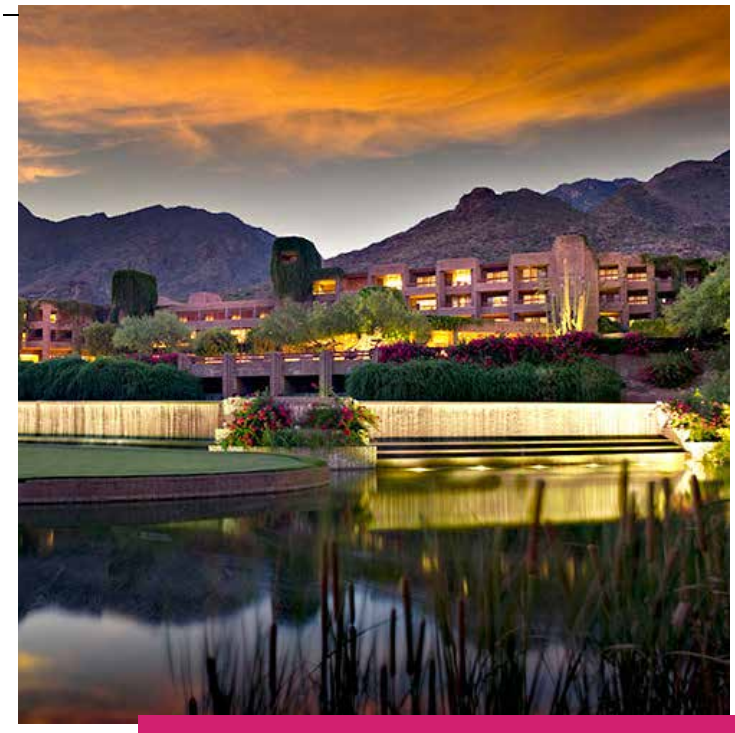
National Coalition for Infant Health Values (SANE)

Safety. Premature infants are born vulnerable. Products, treatments and related public policies should prioritize these fragile infants' safety.

Access. Budget-driven health care policies should not preclude premature infants' access to preventative or necessary therapies.

Nutrition. Proper nutrition and full access to health care keep premature infants healthy after discharge from the NICU.

Equity. Prematurity and related vulnerabilities disproportionately impact minority and economically disadvantaged families. Restrictions on care and treatment should not worsen inherent disparities.



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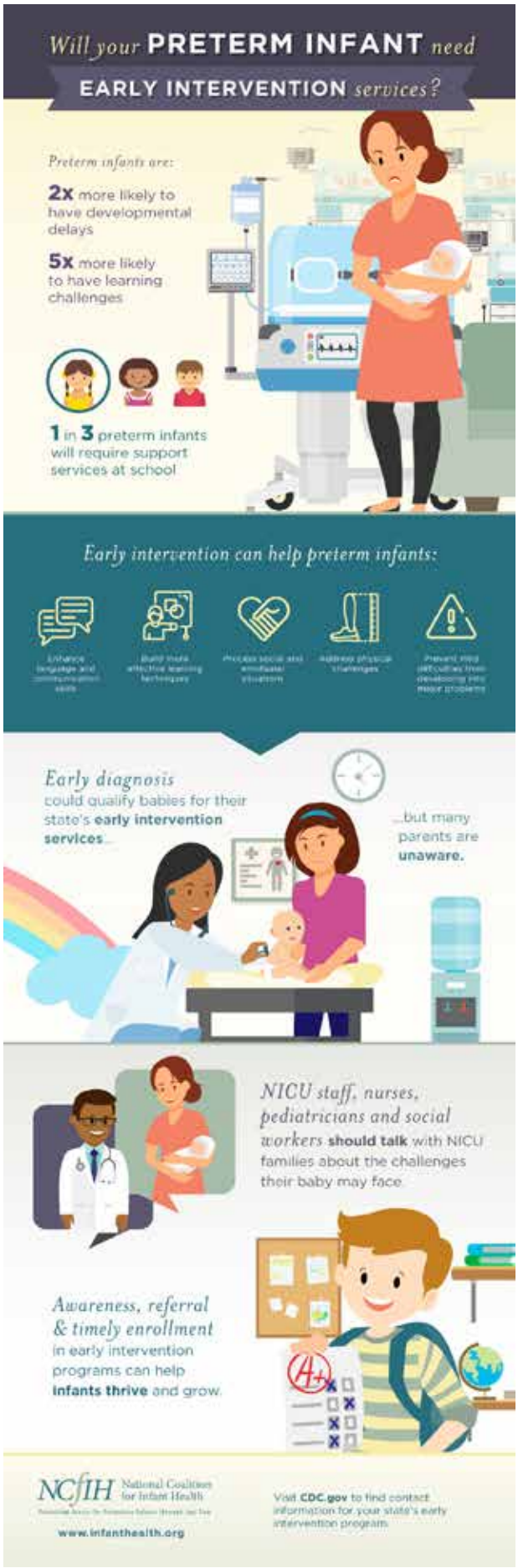
Will your PRETERM INFANT need EARLY INTERVENTION services?
Preterm infants are:
2x more likely to have developmental delays
5x more likely to have learning challenges
1 in 3 preterm infants will require support services at school
Early intervention can help preterm infants:
Early diagnosis could qualify babies for their state's early intervention services...
...but many parents are unaware.
NICU staff, nurses, pediatricians and social workers should talk with NICU families about the challenges their baby may face.
Awareness, referral & timely enrollment in early intervention programs can help infants thrive and grow.
NCfIH National Coalition for Infant Health
www.infanthealth.org
Visit CDC.gov to find contact information for your state's early intervention program.

WHY INFANTS NEED THE
Vitamin K Shot
Newborn babies need vitamin K to help with proper blood clotting and protect them from vitamin K deficiency bleeding.
This type of bleeding is dangerous and can lead to:
Internal bleeding, including in the brain and other organs
Brain damage
Death
One out of every five babies with vitamin K deficiency bleeding dies.
Babies don't get vitamin K from their moms before they are born.
But vitamin K deficiency bleeding is easily preventable with a shot at birth.
Newborns who do not get a vitamin K shot are 81 times more likely to develop severe bleeding.
The vitamin K shot is:
Safe and effective
Routinely given to newborns
Recommended by the American Academy of Pediatrics
Not a vaccine
Protect infants from life-threatening bleeding with a vitamin K shot at birth.
National Coalition for Infant Health

Your Pregnancy and Substance Use

4 Things you can do to improve your health and lower your risk for complications

Get Prenatal Care

Start early. Go to all your visits. Empower yourself with information so you can make smart decisions. Build relationships with providers who understand Substance Use Disorders (SUDs) and know how to help. Partner with them to reach your goals. But remember, you do not need to be abstinent from substance use to get care. Go now.

Reduce Your Use

There are simple things you can do to limit the harm substances might do.

- Use fewer substances
- Use smaller amounts
- Use less often
- Learn how to use safer

Reducing or quitting smoking is a good place to start. Set your goals, then ask for help. One of the best things you can do is to stop using alcohol. We know that even small amounts are risky. And when combined with benzos and opioids, alcohol can kill.

Use Medications for Opioid Use Disorder (MOUD) if you are opioid dependent

Methadone and Buprenorphine (Subutex® or Suboxone®) are the "Standard of Care" during pregnancy because they:

- Eliminate the risks of illicit use
- Reduce your risk for relapse
- Can be a positive step towards recovery

Take Good Care of Yourself

You deserve a healthy pregnancy & childbirth.

- Eat healthy and take your prenatal vitamins
- Find the right balance of rest and exercise
- Surround yourself with people who care

Your Health Matters

Academy of Perinatal Harm Reduction

National Perinatal Association

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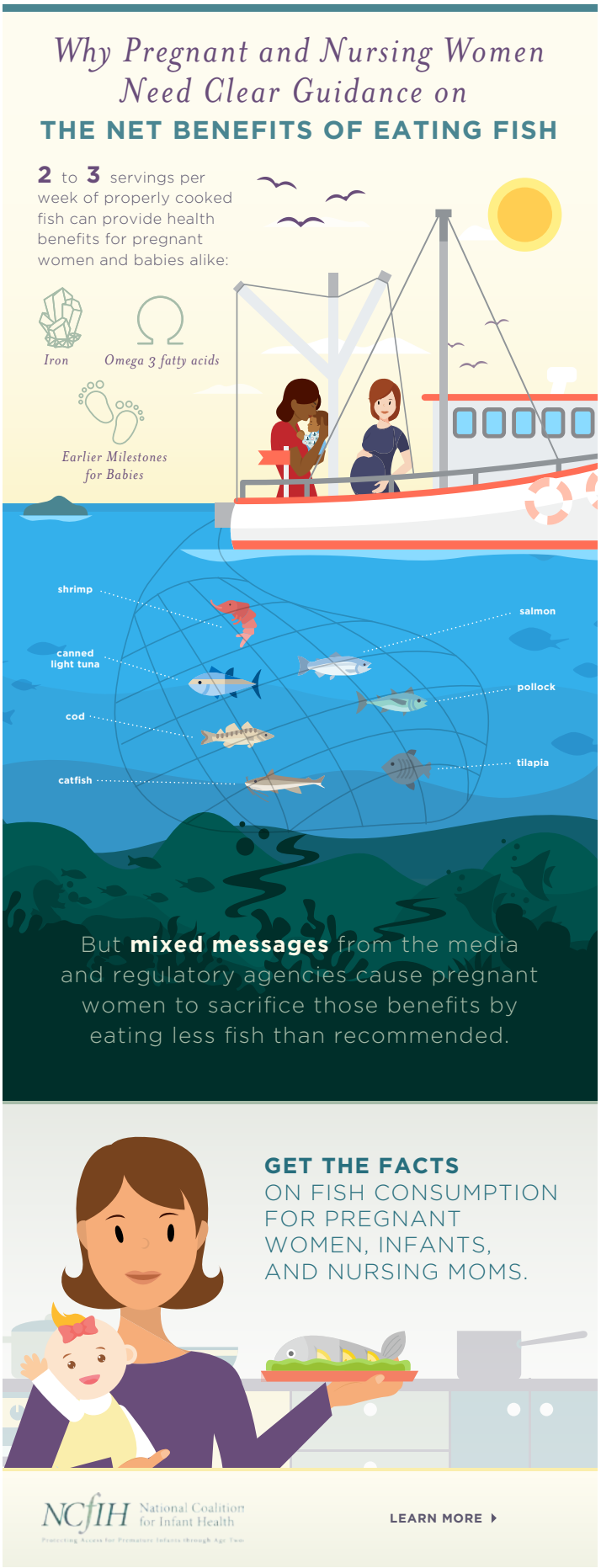

SHARED DECISION-MAKING PROTECTS MOTHERS + INFANTS

DURING COVID-19

KEEPING MOTHERS + INFANTS TOGETHER

Means balancing the risks of...

- HORIZONTAL INFECTION
- SEPARATION AND TRAUMA

EVIDENCE

We encourage families and clinicians to remain diligent in learning **up-to-date evidence**.

PARTNERSHIP

What is the best for this unique dyad?

SHARED DECISION-MAKING

- **S** EEK PARTICIPATION
- **H** ELP EXPLORE OPTIONS
- **A** SSESS PREFERENCES
- **R** EACH A DECISION
- **E** VALUATE THE DECISION

TRAUMA-INFORMED

Both parents and providers are confronting significant...

- FEAR
- GRIEF
- UNCERTAINTY

LONGITUDINAL DATA

We need to understand more about outcomes for mothers and infants exposed to COVID-19, with special attention to:

- MENTAL HEALTH
- POSTPARTUM CARE DELIVERY

NEW DATA EMERGE DAILY. NANN AND NPA ENCOURAGE PERINATAL CARE PROVIDERS TO ENGAGE IN CANDID CONVERSATIONS WITH PREGNANT PARENTS PRIOR TO DELIVERY REGARDING RISKS, BENEFITS, LIMITATIONS, AND REALISTIC EXPECTATIONS.

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Fragile Infant Forums for the Implementation of Infant Family Centered Developmental Care Standards and Competencies: Parents' Lived Experiences of Skin-to-Skin Care

Julia Giesen, M.Sc., R.SLP, S-LP (C), Cassandra McLennan, RN, IBCLC

Introduction:

The evidence for the value of skin-to-skin (STS) experiences for babies and parents is mounting, leaving few reasons why it should not be emphasized in clinical standards for intensive care. (1-9) The Infant- and Family-Centered Developmental Care (IFCDC) standards, recommendations, and best practices provide significant evidence in support of all newborns receiving STS contact with intimate family members. https://nicudesign.nd.edu/nicu-care-standards/ifcdc--recommendations-for-skin-to-skin-contact-with-intimate-family-members/ Most of the available evidence provided in the current IFCDC standards emphasizes improved medical outcomes for infants (10-12). Those that relate to the parent experience often focus on perceived reduction of stress and depressive symptoms (13-15).

"Most of the available evidence provided in the current IFCDC standards emphasizes improved medical outcomes for infants (10-12). Those that relate to the parent experience often focus on perceived reduction of stress and depressive symptoms (13-15)."

However, often the lived experiences of parents are not evident in available studies, as they may not be described or systematically studied and reported. Here, we present a novel approach to documenting the reactions of parents participating in a focused program designed to provide increased developmental support for their infant during STS contact in a Neonatal Intensive Care Unit (NICU).

"Here, we present a novel approach to documenting the reactions of parents participating in a focused program designed to provide increased developmental support for their infant during STS contact in a Neonatal Intensive Care Unit (NICU)."

The approach:

A two-week program focused on encouraging families to engage in developmentally supportive STS care was implemented in the Philip C. Etches NICU at the Stollery Children's Hospital in Edmonton, Alberta, Canada. There were two goals of the program:

"There were two goals of the program: 1. Encourage limitless STS care when parents were at the bedside, and 2. Support newborn individualized developmentally supportive care by encouraging staff to provide medical and nursing care to babies while they are STS with their parents."

1. Encourage limitless STS care when parents were at the bedside, and 2. Support newborn individualized developmentally supportive care by encouraging staff to provide medical and nursing care to babies while they are STS with their parents.

To achieve the first goal, an emphasis was placed on providing information to parents about the benefits of STS practice and on offering physical and emotional support to make the practice both

What did you notice about your baby during the kangaroo today?	Today, our favorite part of kangaroo care was:
Watching his heart rate settle while holding him.	The little smiles.
She feels real! Like we are connected.	Singing to our "little man".
Our breathing synced together, she calmed, and we felt like one again. It is our favorite time.	Listening to all his adorable noises.
Seeing and feeling the real-time growth he's doing.	Seeing him open his eyes more.
Holding while intubated is possible and great for mom and baby.	Hands grab chest hair as Harry Potter meets Dobby.
Settled with mom, BP became within normal range.	Holding his hands and looking into his beautiful eyes while he fell asleep.
Calmness and deep sleep.	Getting her changed to a softer mask during k care.
	Skin to skin dad naps are real and amazing.

accessible and acceptable.

To achieve the second goal, staff were provided with education and encouragement to enhance their understanding, hands-on skills, and confidence in providing medical care to infants while they were STS. Emphasis was placed on the "care" aspect of STS care, and that providing medical care while a baby is supported by their parent follows best practice for individualized, developmentally supportive care.

Several implementation strategies contributed to the two-week emphasis on enhancing parental STS care. Parents were asked to track their STS experiences by placing stickers on the door to their baby's NICU room. Parents were also offered incentives for their engagement in STS (e.g., a bead added to their bracelet and an opportunity for a prize). Staff were asked to document every time they provided medical or nursing care during STS, with an opportunity for a recognition prize. Parent stories of STS experiences were also displayed around the unit, and evidence-based facts were discussed with the multidisciplinary care team at the daily huddle.

The outcomes:

As this was not a research project but rather a "celebration" of the implementation of STS care, the number of parent participants and outcome data were limited. However, parents were asked to respond to two questions. The first question was, "What did you notice about your baby during STS care?" and the second was, "Today our favorite part of STS was…" These responses provided a glimpse into their lived experiences. A sample of those reflective comments is shown above.

"Often, professionals focus on data-driven outcomes to support their practices, to the exclusion of hearing the lived experiences of families. Although not systematically and objectively elicited, the spontaneous responses of parents to a supportive program for STS care allow us to reflect on the human side of parents' experiences and to glimpse the joyful responses that they express so well."

Additionally, parents noted a variety of procedures done during STS, which may indicate an increasing "normalization" for staff providing care while the baby was positioned on the parent's body. A sample of these procedures is noted below:

Assessment	Sponge bath	Ultrasound
Diaper change	OG tube change	Blood work
Mask change	Eye exam	IV insertion

Conclusion:

Often, professionals focus on data-driven outcomes to support

their practices, to the exclusion of hearing the lived experiences of families. Although not systematically and objectively elicited, the spontaneous responses of parents to a supportive program for STS care allow us to reflect on the human side of parents' experiences and to glimpse the joyful responses that they express so well. Opportunities like these enable care providers to recognize the benefits of providing support and encouragement to parents, implementing safe and developmentally supportive practices for newborns, and documenting the emotions that result from a concerted effort to help parents experience the joy of parenting. Additionally, it expands the staff's repertoire of evidence-based caregiving practices that were previously not considered safe or effective.

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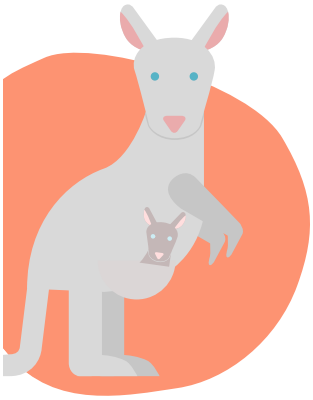


GET INFORMED ABOUT THE RISKS + BENEFITS

work with your medical team to create a plan

GET CLEAN

WASH YOUR HANDS, ARMS, and CHEST

with soap and water for 20+ seconds. Dry well.

PUT ON FRESH CLOTHES

change into a clean gown or shirt.

IF COVID-19 + WEAR A MASK

and ask others to hold your baby when you can't be there

National Perinatal Association

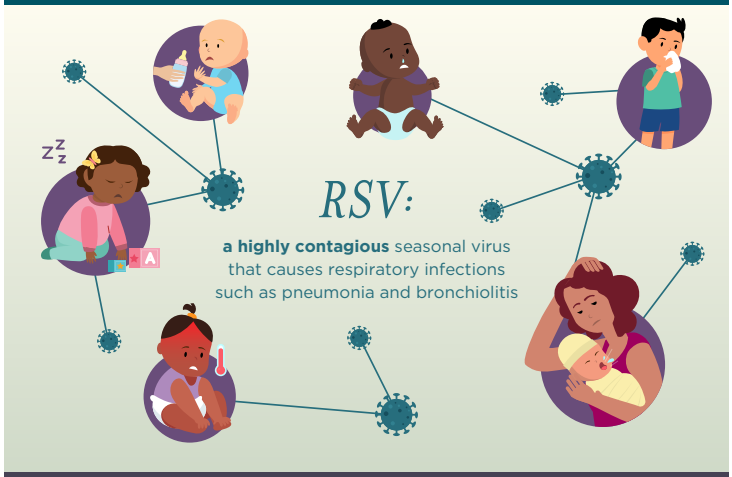
nicuparentnetwork.org

nationalperinatal.org/skin-to-skin

NPN NICU PARENT NETWORK

Respiratory Syncytial Virus

DID YOU KNOW?



Infants under age 1

RSV is the **leading cause** of hospitalization

16x more likely to get RSV than the flu

Kids under age 5 experience

500,000 emergency room visits for RSV each year

57,000 hospitalizations for RSV each year

NCfIH National Coalition for Infant Health

Protecting Access for Premature Infants through Age Two

LEARN MORE

Protecting your baby and family from

Respiratory Viruses:

What parents need to know this RSV and flu season

Like COVID-19, RSV (Respiratory Syncytial Virus) and flu affect the lungs and can cause serious breathing problems for children and babies. Talk to your family about the risks.

Certain diagnoses can make children and babies more vulnerable for serious complications from respiratory viruses - including prematurity, chronic lung disease, and heart conditions.

You can limit the spread of viruses by wearing a mask, washing your hands with soap & water, using an alcohol-based hand sanitizer, and getting vaccinated.

The fewer germs your baby is exposed to, the less likely they are to get sick. Let people know you need their help to stay well. Limit visitors. Avoid crowds. Stay away from sick people.

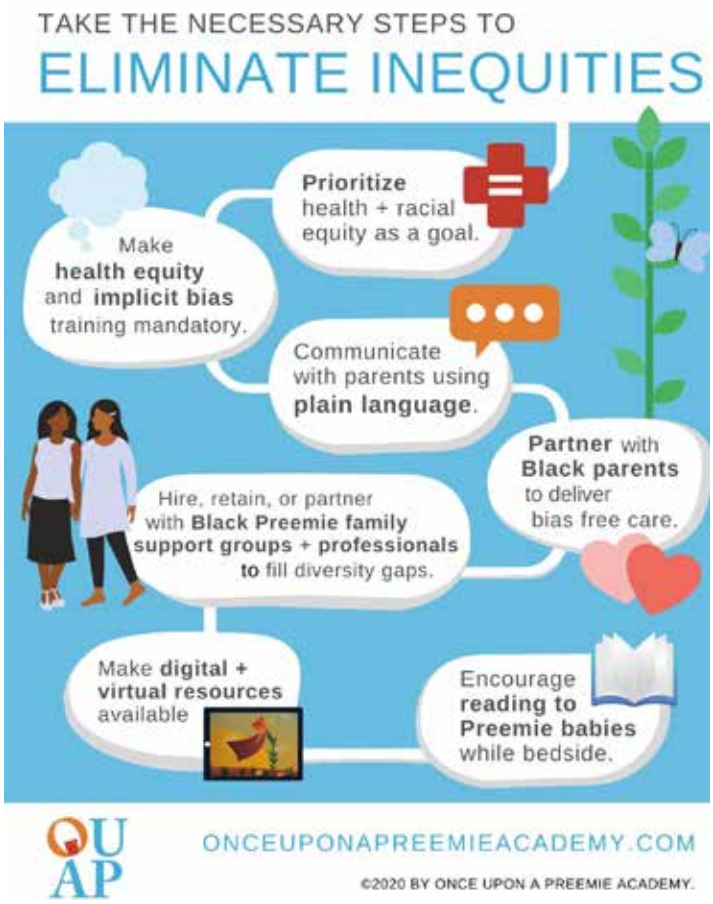
Immunizations save lives. Stay up-to-date with your family's flu vaccinations and COVID-19 boosters. This helps our community stay safe by stopping the spread of deadly viruses.

Babies older than 6 months can get a flu shot and COVID-19 vaccinations. There is no vaccine for RSV, but monthly antibody shots during RSV season can help protect them.

WE CAN HELP PROTECT EACH OTHER.

National Perinatal Association

www.nationalperinatal.org/rsv



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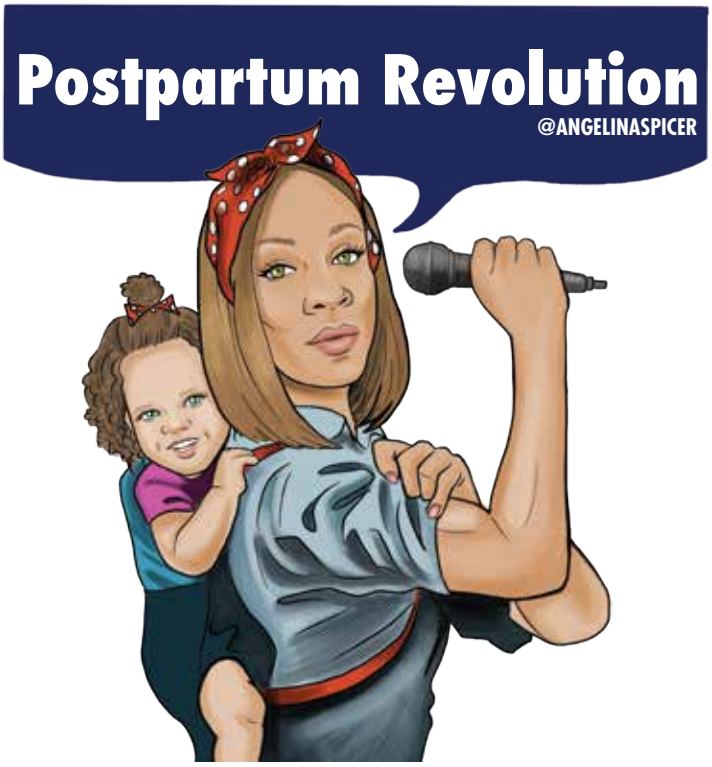

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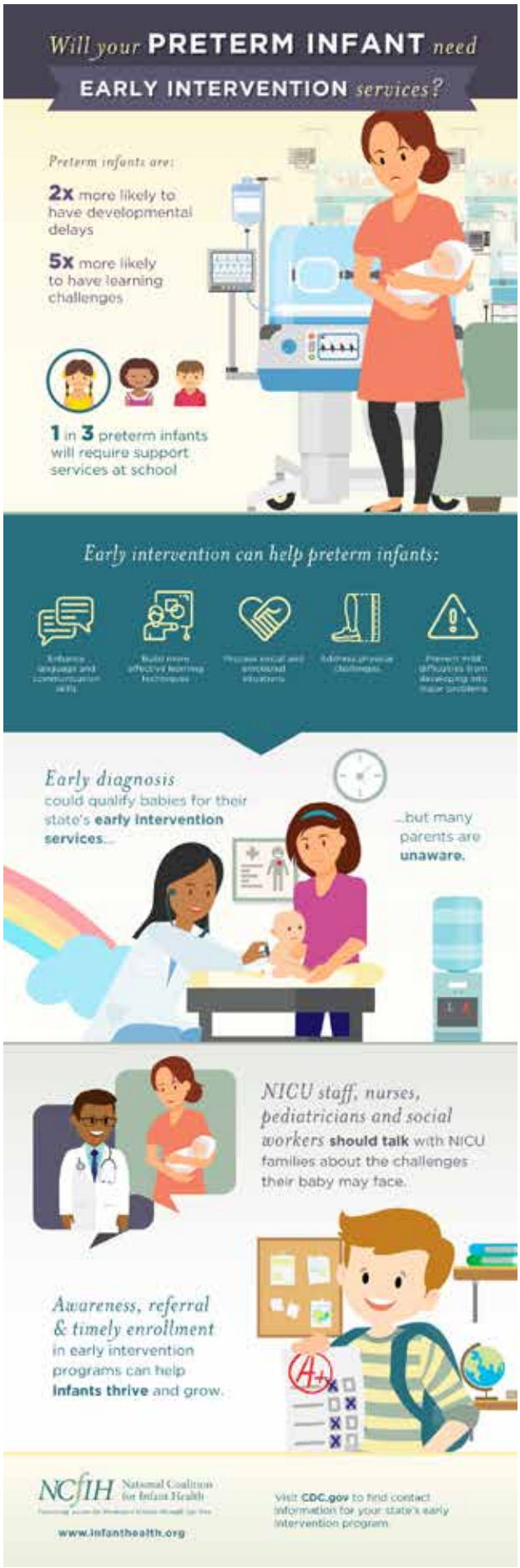

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As we indicated last month, we look forward to a number of new features as well.

1. An online submission portal: Submitting a manuscript online will be easier than before. Rather than submitting by email, we will have a devoted online submission portal that will have the ability to handle any size manuscript and any number of graphics and other support files. We will have an online tracking system that will make it easier to track manuscripts in terms of where they are in the review process.
2. Reviewers will be able to review the manuscript online. This portal will shorten the time from receipt of review to getting feedback to the submitting authors.
3. An archive search will be available for journals older than 2012.
4. A new section called news and views will enable the submission of commentary on publications from other journals or news sources. We anticipate that this will be available as soon as the site completes the beta phase
5. Sponsors will be able to sign up directly on the website and submit content for both the digital and PDF issues of Neonatology Today.

Neonatology Today will continue to promote our Academic True Open Model (ATOM), never a charge to publish and never a charge to subscribe.

If there are any questions about the new website, please email Dr. Chou directly at:

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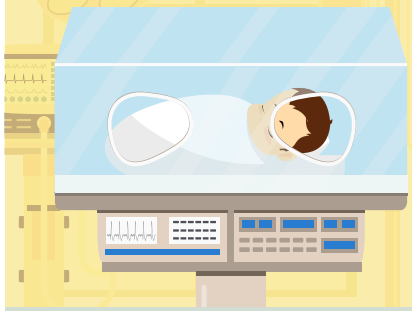
Hemolytic Disease of the Fetus & Newborn

DID YOU KNOW?

Hemolytic disease of the fetus & newborn is a rare blood disorder.

When the mother's and infant's blood types are incompatible, the mother's antibodies attack the baby's red blood cells.

HDFN can lead to:



- **Severe anemia**
- **Jaundice**
- Fetal or infant **death**

To reduce their baby's risk

pregnant mothers should talk to their health care provider to:

- **Identify** potential blood incompatibilities
- **Monitor** the baby
- **Treat** the condition if it occurs

NCfIH National Coalition for Infant Health
Protecting Access for Premature Infants through Age Two

LEARN MORE ▸

Which Infants are More Vulnerable *to Respiratory Syncytial Virus?*

RSV is a respiratory virus with cold-like symptoms that causes 90,000 hospitalizations and 4,500 deaths per year in children 5 and younger. It's 10 times more deadly than the flu. For premature babies with fragile immune systems and underdeveloped lungs, RSV proves especially dangerous.

But risk factors associated with RSV don't touch all infants equally.*

*Source: Respirator Syncytial Virus and African Americans

Caucasian Babies	Risk Factor	African American Babies
11.6%	Prematurity	18.3%
58.1%	Breastfeeding	50.2%
7.3%	Low Birth Weight	11.8%
60.1%	Siblings	71.6%
1%	Crowded Living Conditions	3%

AFRICAN AMERICAN BABIES bear the brunt of RSV. Yet the American Academy of Pediatrics' restrictive new guidlines limit their access to RSV preventative treatment, increasing these babies' risk.

AfPA Alliance for Patient Access

COVID-19

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- Bonding with Your Baby
- Caregivers Need Care Too

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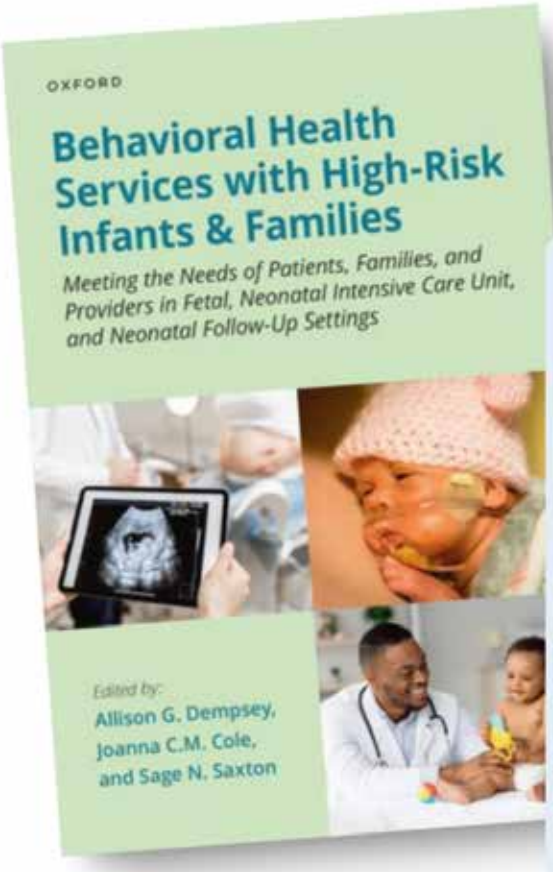

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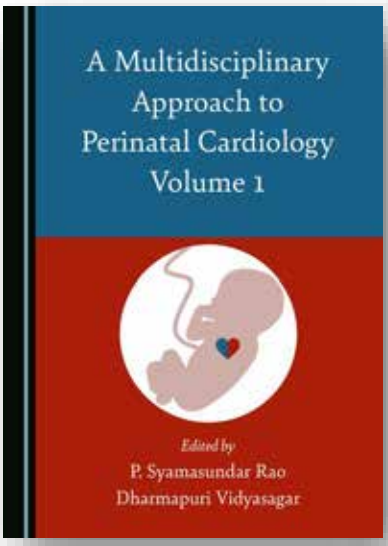

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Book Description

Recent developments in diagnostic and therapeutic aspects of cardiac and neonatal issues have advanced the care of the newborn. To achieve excellence in cardiac care, however, close interaction and collaboration of the pediatric cardiologists with neonatologists, pediatricians, general/family practitioners (who care for children), anesthesiologists, cardiac surgeons, pediatric cardiac intensivists, and other subspecialty pediatricians is mandatory. This book provides the reader with up-to-date evidence-based information in three major areas of neonatology and prenatal and neonatal cardiology. First, it provides an overview of advances in the disciplines of neonatology, prenatal and neonatal cardiology, and neonatal cardiac surgery in making early diagnosis and offering treatment options. Secondly, it presents a multidisciplinary approach to managing infants with congenital heart defects. Finally, it provides evidence-based therapeutic approaches to successfully treat the fetus and the newborn with important neonatal issues and congenital cardiac lesions. This first volume specifically explores issues related to perinatal circulation, the fetus, ethics, changes in oxygen saturations at birth, and pulse oximetry screening, diagnosis, and management.

About the Editors

Dr P. Syamasundar Rao, MD, DCH, FAAP, FACC, FSCAI, is Professor of Pediatrics and Medicine and Emeritus Chief of Pediatric Cardiology at the University of Texas-Houston Medical School. He received his medical degree from Andhra Medical College, India, and subsequently received post-graduate training both in India and the USA before joining the faculty at the Medical College of Georgia, USA, in 1972. He has also served as Chairman of Pediatrics at King Faisal Specialist Hospital and Research Center, Saudi Arabia, and Professor and Director of the Division of Pediatric Cardiology at the University of Wisconsin and St. Louis University, USA. He has authored 400 papers, 16 books and 150 book chapters, and is a recipient of numerous honors and awards.

Dr Dharmapuri Vidyasagar, MD, MSc, FAAP, FCCM, PhD (Hon), is currently Professor Emeritus in Pediatrics at the University of Illinois, Chicago, where he served as Professor of Pediatrics for four decades. He is a graduate of Osmania Medical College, India. He has published over 250 papers and authored several books with a focus on prematurity, neonatal pulmonary diseases and neonatal ventilation. His goal is to reduce neonatal mortality in the USA and around the world, and he has received multiple awards and honors including the Ellis Island Award.

A Multidisciplinary Approach to Perinatal Cardiology Volume 1 is available now in Hardback from the Cambridge Scholars website, where you can also access a free 30-page sample.

My NICU Network
My Perinatal Network

National Perinatal Association + NICU Parent Network

Online L&D Staff Education Program

Caring for Pregnant Patients & Their Families:

Providing Psychosocial Support During Pregnancy, Labor and Delivery

WWW.MYPERINATALNETWORK.ORG

Continuing education credits provided by

pac-lac

About the Program

- **WHO SHOULD TAKE THE PROGRAM?** This program is designed for both office and hospital staff in all disciplines that interact with pregnant patients and their families. A key focus is recognizing risk factors for perinatal mood and anxiety disorders, and mitigating their impact through provision of trauma-informed care.

- **WHY TAKE THE PROGRAM?** Families will benefit when staff have improved skills, through enhanced parental resilience and better mental health, and improved parent-baby bonding leading to better developmental outcomes for babies. Benefits to staff include improved skills in communicating with patients; improved teamwork, engagement and staff morale; reduced burnout, and reduced staff turnover.

- **HOW DOES THE PROGRAM ACHIEVE ITS GOALS?** Program content is representative of best practices, engaging and story-driven, resource-rich, and developed by a unique interprofessional collaboration of obstetric and neonatal professionals and patients. The program presents practical tips and an abundance of clinical information that together provide solutions to the emotional needs of expectant and new parents.

- **HOW WAS THE PROGRAM DEVELOPED?** This program was developed through collaboration among three organizations: a multidisciplinary group of professionals from the National Perinatal Association and Patient + Family Care, and parents from the NICU Parent Network. The six courses represent the different stages of pregnancy (antepartum, intrapartum, postpartum), as well as perinatal mood and anxiety disorders, communication techniques, and staff support.

Program Objectives

- Describe principles of trauma-informed care as standards underlying all communication during provision of maternity care in both inpatient and outpatient settings.
- Identify risk factors, signs, and symptoms of perinatal mood and anxiety disorders; describe treatment options.
- Define ways to support pregnant patients with high-risk conditions during the antepartum period.
- Describe obstetric violence, including ways that providers may contribute to a patient's experience of maternity care as being traumatic; equally describe ways providers can mitigate obstetric trauma.
- Describe the importance of providing psychosocial support to women and their families in times of pregnancy loss and fetal and infant death.
- Define the Fourth Trimester, and identify the key areas for providing psychosocial support to women during the postpartum period.
- Identify signs and symptoms of burnout as well as their ill effects, and describe both individual and systemic methods for reducing burnout in maternity care staff.

Continuing education credits will be provided for physicians, clinic and bedside nurses, social workers, psychologists, and licensed marriage and family therapists. CEUs will be provided by Perinatal Advisory Council: Leadership, Advocacy, and Consultation.

PROGRAM CONTENT

COMMUNICATION SKILLS CEUs offered: 1

Learn principles of trauma-informed care, use of universal precautions, how to support LGBTQ patients, obtaining informed consent, engaging in joint decision-making, delivering bad news, dealing with challenging patients.

Faculty: Amina White, MD, MA, Clinical Associate Professor, Department of OB/Gyn, University of North Carolina, Chapel Hill, NC; Sue Hall, MD, MSW, FAAP, St. John's Regional Medical Center, Oxnard, CA; Karen Saxer, CNM, MSN, University of North Carolina Maternal-Fetal Medicine, UNC Women's Hospital, Chapel Hill, NC; Tracy Pella, Co-Founder & President, Connected Forever, Tecumseh, NE.

PERINATAL MOOD AND ANXIETY DISORDERS CEUs offered: 1

Identify risk factors for and differential diagnosis of PMADs (perinatal mood and anxiety disorders), particularly perinatal depression and/or anxiety and posttraumatic stress syndrome. Learn the adverse effects of maternal depression on infant and child development, and the importance of screening for and treating PMADs.

Faculty: Linda Baker, PsyD, psychologist at Unstuck Therapy, LLC, Denver, CO; Sue Hall, MD, MSW, FAAP, neonatologist at St. John's Regional Medical Center, Oxnard, CA; Angela Davids, Founder of Keep 'Em Cookin', Baltimore, MD; Brittany Boet, Founder of Bryce's NICU Project, San Antonio, TX.

PROVIDING ANTEPARTUM SUPPORT CEUs offered: 1

Identify psychosocial challenges facing high risk OB patients, and define how to provide support for them, whether they are inpatient or outpatient. Recognize when palliative care is a reasonable option to present to pregnant patients and their families.

Faculty: Amina White, MD, MA, Clinical Associate Professor, Department of OB/Gyn, University of North Carolina, Chapel Hill, NC; Sue Hall, MD, MSW, FAAP, neonatologist at St. John's Regional Medical Center, Oxnard, CA; Angela Davids, Founder of Keep 'Em Cookin', Baltimore, MD; Erin Thatcher, BA, Founder and Executive Director of The PPROM Foundation, Denver, CO.

PROVIDING INTRAPARTUM SUPPORT CEUs offered: 1

Describe how to manage patient expectations for labor and delivery including pain management; identify examples of obstetric violence, including identification of provider factors that may increase patients' experience of trauma; learn how to mitigate patients' trauma, and how to provide support during the process of labor and delivery.

Faculty: Sara Detlefs, MD, Fellow in Maternal-Fetal Medicine, Baylor College of Medicine, Houston, TX; Jerry Ballas, MD, MPH, Associate Clinical Professor, UCSD Health System, Maternal-Fetal Medicine, Department of Obstetrics, Gynecology and Reproductive Sciences, University of California at San Diego, San Diego, CA; MaryLou Martin, MSN, RNC-NIC, CKC, Women's and Children's Services Nurse Educator, McLeod Regional Medical Center, McLeod, SC; Claire Hartman, RN, IBCLC, Labor & Delivery, University of North Carolina Hospital, Chapel Hill, NC; Crystal Duffy, Author of Twin To Twin (from High Risk Pregnancy to Happy Family), and NICU Parent Advisor, Houston, TX; Erin Thatcher, Founder and Executive Director of The PPROM Foundation, Denver, CO.

PROVIDING POSTPARTUM SUPPORT CEUs offered: 1

Define the 4th Trimester and the importance of follow-up especially for high risk and minority patients, learn to recognize risk factors for traumatic birth experience and how to discuss patients' experiences postpartum; describe the application of trauma-informed care during this period, including support for patients who are breastfeeding and those whose babies don't get to go home with them.

Faculty: Amanda Brown, CNM, University of North Carolina Hospital, Chapel Hill, NC; ; Sue Hall, MD, MSW, FAAP, neonatologist at St. John's Regional Medical Center, Oxnard, CA; Crystal Duffy, Author of Twin To Twin (from High Risk Pregnancy to Happy Family), and NICU Parent Advisor, Houston, TX.

SUPPORTING STAFF AS THEY SUPPORT FAMILIES CEUs offered: 1

Define burnout and compassion fatigue; identify the risks of secondary traumatic stress syndrome to obstetric staff; describe adverse impacts of bullying among staff; identify the importance of both work-life balance and staff support.

Faculty: Cheryl Milford, EdS, Consulting NICU and Developmental Psychologist, Director of Development, National Perinatal Association, Huntington Beach, CA; Sue Hall, MD, MSW, FAAP, neonatologist at St. John's Regional Medical Center, Oxnard, CA; Erin Thatcher, BA, Founder and Executive Director, The PPROM Foundation, Denver, CO

Cost

- RNs: $10/CEU; $60 for the full program
- Physicians, licensed clinical social workers (LCSWs), licensed marriage and family therapists (LMFTs): $35/CEU; $210 for the full program
- Although PACLAC cannot award CEs for certified nurse midwives, they can submit certificates to their own professional organization to request credit. $35/CEU; $210 for the full program

Contact help@myperinatalnetwork.org to learn more.

Faculty

Linda Baker, PsyD
Psychologist at Unstuck Therapy, LLC, Denver, CO.

Jerasimos (Jerry) Ballas, MD, MPH
Associate Clinical Professor, UCSD Health System, Maternal-Fetal Medicine, Department of Obstetrics, Gynecology and Reproductive Sciences, University of California at San Diego, San Diego, CA.

Amanda Brown, CNM, MSN, MPH
University of North Carolina-Chapel Hill Hospitals, Chapel Hill, NC.

Sara Detlefs, MD
Fellow in Maternal-Fetal Medicine, Baylor College of Medicine, Houston, TX.

Sue L. Hall, MD, MSW, FAAP
Neonatologist, Ventura, CA.

Claire Hartman, RN, IBCLC
Labor & Delivery, University of North Carolina Hospital, Chapel Hill, NC.

MaryLou Martin, MSN, RNC-NIC, CKC
Women's and Children's Services Nurse Educator, McLeod Regional Medical Center, McLeod, SC.

Cheryl Milford, EdS.
Former NICU and Developmental psychologist, in memoriam.

Karen Saxer, CNM, MSN
University of North Carolina Maternal-Fetal Medicine, UNC Women's Hospital, Chapel Hill, NC.

Amina White, MD, MA
Clinical Associate Professor, Department of Obstetrics and Gynecology, University of North Carolina, Chapel Hill, NC.

Parent/Patient Contributers:

Brittany Boet
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Angela Davids
Founder, Keep 'Em Cookin', Baltimore, MD.

Crystal Duffy
Author of Twin To Twin (from High Risk Pregnancy to Happy Family), and NICU Parent Advisor, Houston, TX.

Tracy Pella, MA
Co-Founder and President, Connected Forever, Tecumseh, NE.

Erin Thatcher, BA
Founder and Executive Director, The PPROM Foundation, Denver, CO.

CANCELLATIONS AND REFUNDS

- For Individual Subscribers:
  - If you elect to take only one course, there will be no cancellations or refunds after you have started the course.
  - If you elect to take more than one course and pay in advance, there will be no cancellations or refunds after payment has been made unless a written request is sent to help@myperinatalnetwork.com and individually approved.
- For Institutional Subscribers:
  - After we are in possession of a signed contract by an authorized agent of the hospital and the program fees have been paid, a 50% refund of the amount paid will be given if we are in receipt of a written request to cancel at least 14 (fourteen) days prior to the scheduled start date for your hospital's online program.
  - Refunds will not be given for staff members who neglect to start the program. Also, no refunds for those who start the program, but do not complete all 6 courses within the time frame allotted.

For Physicians: This activity has been planned and implemented in accordance with the Institute for Medical Quality and the California Medical Association's CME Accreditation Standards (IMQ/CMA) through the Joint Providership of the Perinatal Advisory Council: Leadership, Advocacy and Consultation (PAC/LAC) and the National Perinatal Association. PAC/LAC is accredited by the Institute for Medical Quality/California Medical Association (IMQ/CMA) to provide continuing education for physicians. PAC/LAC takes responsibility for the content, quality and scientific integrity of this CME activity. PAC/LAC designates this activity for a maximum of 6 *AMA PRA Category 1 Credit(s)TM*. Physicians should only claim credit commensurate with the extent of their participation in the activity. This credit may also be applied to the *CMA Certification in Continuing Medical Education*.

For Nurses: The Perinatal Advisory Council: Leadership, Advocacy and Consultation (PAC/LAC) is an approved provider by the California Board of Registered Nursing Provider CEP 5862. When taken as a whole, this program is approved for 7 contact hours of continuing education credit.

For CAMFT: Perinatal Advisory Council: Leadership, Advocacy, and Consultation (PAC/LAC) is approved by the California Association of Marriage and Family Therapists to sponsor continuing education for LMFTs and LCSWs. CE Provider #128542. PAC/LAC maintains responsibility for the program and its content. Program meets the qualifications for 6 hours of continuing education credit for LMFTs and LCSWs as required by the California Board of Behavioral Sciences. You can reach us at help@myperinatalnetwork.org.

SHARED DECISION-MAKING PROTECTS MOTHERS + INFANTS

DURING COVID-19

KEEPING MOTHERS + INFANTS TOGETHER

Means balancing the risks of...

- HORIZONTAL INFECTION
- SEPARATION AND TRAUMA

EVIDENCE

We encourage families and clinicians to remain diligent in learning **up-to-date evidence**.

PARTNERSHIP

What is the best for this unique dyad?

SHARED DECISION-MAKING

- **S** EEK PARTICIPATION
- **H** ELP EXPLORE OPTIONS
- **A** SSESS PREFERENCES
- **R** EACH A DECISION
- **E** VALUATE THE DECISION

TRAUMA-INFORMED

Both parents and providers are confronting significant...

- FEAR
- GRIEF
- UNCERTAINTY

LONGITUDINAL DATA

We need to understand more about outcomes for mothers and infants exposed to COVID-19, with special attention to:

- MENTAL HEALTH
- POSTPARTUM CARE DELIVERY

NEW DATA EMERGE DAILY. NANN AND NPA ENCOURAGE PERINATAL CARE PROVIDERS TO ENGAGE IN CANDID CONVERSATIONS WITH PREGNANT PARENTS PRIOR TO DELIVERY REGARDING RISKS, BENEFITS, LIMITATIONS, AND REALISTIC EXPECTATIONS.

Partnering for patient-centered care when it matters most.

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National Association of Neonatal Nurses

National Perinatal Association

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Coping with COVID-19

A viral pandemic

A racial pandemic within a viral pandemic

Will mental illness be the next inevitable pandemic?

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Peer Reviewed

Alliance for Patient Access: Two New Diseases Could Be Added to Infant Screening Panel

Josie Cooper

The Alliance for Patient Access (allianceforpatientaccess.org), founded in 2006, is a national network of physicians dedicated to ensuring patient access to approved therapies and appropriate clinical care. AfPA accomplishes this mission by recruiting, training and mobilizing policy-minded physicians to be effective advocates for patient access. AfPA is organized as a non-profit 501(c)(4) corporation and headed by an independent board of directors. Its physician leadership is supported by policy advocacy management and public affairs consultants. In 2012, AfPA established the Institute for Patient Access (IfPA), a related 501(c)(3) non-profit corporation. In keeping with its mission to promote a better understanding of the benefits of the physician-patient relationship in the provision of quality healthcare, IfPA sponsors policy research and educational programming.

Alliance for Patient Access

Institute for Patient Access

"The experts who decide which conditions states should include in their Recommended Uniform Screening Panel for newborns will now consider adding metachromatic leukodystrophy and Duchenne muscular dystrophy to the panel. (1) The Health Resources and Services Administration, an agency within the Department of Health and Human Services, (2) has opened a comment period during which the change will be considered. (3)"

The experts who decide which conditions states should include in their Recommended Uniform Screening Panel for newborns will now consider adding metachromatic leukodystrophy and Duchenne muscular dystrophy to the panel. (1) The Health Resources and Services Administration, an agency within the Department of Health and Human Services, (2) has opened a comment period during which the change will be considered. (3)

More than four million newborns are screened annually, and approximately 13,000 of them will have a condition identified during the screening process. (4) By detecting potentially dangerous disorders before symptoms appear, newborn screening increases the chances for early intervention and a healthier life. (4)

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Why Early Detection Matters

Metachromatic leukodystrophy and Duchenne muscular dystrophy are both rare, progressive conditions that can severely limit lifespan and quality of life. In both cases, earlier identification improves patient outcomes through resources, informed care, and participation in clinical trials. (5, 6)

"The Recommended Uniform Screening Panel serves as a model, but states make the final decision on which conditions to include in their programs. Some adopt all recommended screenings, while others take additional steps before making changes. Diseases need to be added to the screening panel so people with Medicaid and non-grandfathered health plans will have coverage."

For some conditions on the panel, early detection allows for early intervention that can prevent severe disability or even death. Adding more conditions to screening further improves childhood health through proactive care.

How Do New Screenings Get Added?

The Recommended Uniform Screening Panel serves as a model, but states make the final decision on which conditions to include in their programs. Some adopt all recommended screenings, while others take additional steps before making changes. Diseases need to be added to the screening panel so people with Medicaid and non-grandfathered health plans will have coverage. These health plans are required to cover included screenings without copays, coinsurance, or a met deductible.

If metachromatic leukodystrophy and Duchenne muscular dystrophy are added, states will face decisions about updating their own lists and ensuring resources for testing and follow-up care.

Public input during the current comment period will help government experts assess the benefits and challenges of expanding the panel. Newborn screening continues to set an example for evidence-based diagnosis and proactive care.

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1. https://newbornscreening.hrsa.gov/about-newborn-screening/recommended-uniform-screening-panel
2. https://www.hrsa.gov/about
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4. https://advisory.avalerehealth.com/insights/newborn-screening-landscape-and-rare-disease-developments
5. https://www.mayoclinic.org/diseases-conditions/metachromatic-leukodystrophy/symptoms-causes/syc-20354733
6. https://www.mda.org/disease/duchenne-muscular-dystrophy

Disclosure: Josie Cooper is the Executive Director of the Alliance for Patient Access. This article was also published at healthpolicytoday.org.

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Immunizing Yourself Against **COVID-19**

COVID-19 vaccines have been shown to:

- Lessen the severity of symptoms[1]
- Reduce risk of mortality[2]
- Reduce disease transmission[3]
- Make communities healthier and safer[4]

Understanding the Options

COVID-19 vaccines are available for children, adolescents and adults. There are 3 types to choose from.

mRNA VACCINES

New to market, but research has been ongoing since the 1990s.

PROTEIN SUBUNIT VACCINES

Used for three decades against the flu, whooping cough and hepatitis B.

VECTOR VACCINES

Used for decades against chickenpox, malaria and tuberculosis.

HOW THEY WORK:

Instruct cells to make COVID-like proteins that trigger the immune system to fight the virus.

Deliver harmless versions of the COVID protein that train the immune system to fight the virus.

Use a modified virus, such as a common cold, to teach the body to fight off COVID.

COVID vaccines are recommended for everyone ages 6 months and older, and boosters for everyone ages 5 years and older, if eligible.[5]

Safe and Sound

COVID vaccines have been:

Thoroughly tested through multi-phase trials with tens of thousands of participants[6]

Proven safe and effective for adults as well as children[7]

Vetted and approved by the US FDA and EMA and endorsed by the WHO[8-10]

Get Your Jab

Vaccines are available at your:

- **Doctor's office**
- **Neighborhood pharmacy**
- **Community health center**

Talk to your **health care provider** or **pharmacist** about which vaccine is right for you.

1. https://www.mayoclinic.org/diseases-conditions/coronavirus/symptoms-causes/syc-20479963
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- Story-Driven
- Trauma-Informed
- Evidence-Based

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Still a **Preemie?**

Some preemies are born months early, at extremely low birthweights. They fight for each breath and face nearly insurmountable health obstacles.

But that's not every preemie's story.

Born between 34 and 36 weeks' gestation?

STILL A PREEMIE

Just like preemies born much earlier, these "late preterm" infants can face:

Jaundice

Feeding issues

Respiratory problems

And their parents, like all parents of preemies, are at **risk for postpartum depression and PTSD.**

Born preterm at a "normal" weight?

STILL A PREEMIE

Though these babies look healthy, they can still have complications and require NICU care.

But because some health plans determine coverage based on a preemie's weight, **families of babies that weigh more may face access barriers and unmanageable medical bills.**

Born preterm but not admitted to the NICU?

STILL A PREEMIE

Even if preterm babies don't require NICU care, they can still face health challenges.

Those challenges can extend through childhood, adolescence and even into adulthood.

Some Preemies

- Will spend weeks in the hospital
- Will have lifelong health problems
- Are disadvantaged from birth

All Preemies

- Face health risks
- Deserve appropriate health coverage
- Need access to proper health care

NCfIH National Coalition for Infant Health

Protecting Access for Premature Infants through Age Two

www.infanthealth.org

The Gap Baby: An RSV Story

A collaborative of professional, clinical, community health, and family support organizations improving the lives of premature infants and their families through education and advocacy.

The National Coalition for Infant Health advocates for:

- **Access to an exclusive human milk diet** for premature infants
- **Increased emotional support resources** for parents and caregivers suffering from PTSD/PPD
- **Access to RSV preventive treatment** for all premature infants as indicated on the FDA label
- **Clear, science-based nutrition guidelines** for pregnant and breastfeeding mothers
- **Safe, accurate medical devices** and products designed for the special needs of NICU patients

www.infanthealth.org

iCAN September Newsletter: From Summer to Fall: iCAN Youth Members Bring Color to Healthcare!

Abby Clark

Get involved today and Join the iCAN Parent Council!

"iCAN, the International Children's Advisory Network, is the premier global pediatric platform working to empower the patient voice in healthcare, driven by youth for youth. As a worldwide network of 40+ KIDS (Kids Impacting Disease through Science) advisory groups that spans four continents (as well as virtually), iCAN's dedicated youth member groups work in unison to provide a voice for children and families in medicine, research, science, and innovation."

iCAN, the International Children's Advisory Network, is the premier global pediatric platform working to empower the patient voice in healthcare, driven by youth for youth. As a worldwide network of 40+ KIDS (Kids Impacting Disease through Science) advisory groups that spans four continents (as well as virtually), iCAN's dedicated youth member groups work in unison to provide a voice for children and families in medicine, research, science, and innovation. To foster greater global understanding about the importance of the pediatric patient and caregiver voice in healthcare, clinical trials, and research, iCAN's young people continue to drive incredible change in the global health landscape.

On average, our youth are between the ages of eight and eighteen years old, most of whom are living with chronic, rare, and complicated diagnoses; although, not all of iCAN's youth members have a medical diagnosis or medical condition. iCAN celebrates the understanding that all patients, even the youngest, have valuable insights into improving the healthcare experience.

All children, regardless of their location, are welcome to participate in iCAN's programming. iCAN also supports young adults, as well as the voices of parents and siblings. We continue to be an ecosystem of schools, children's hospitals, academia, and other like-minded non-profits.

Our mission is to ensure that youth are placed in positions where their voices are heard and make a difference in pediatric healthcare through interactions with industry professionals, presenting original research at conferences, innovating new solutions, and sharing their stories. iCAN continues to empower the pediatric patient voice through community partnerships with organizations such as the FDA, the Everylife Foundation for Rare Diseases, the PFMD, MRCT, iSPI, and the AAP.

Whether you are a patient, family member, friend, healthcare professional, or simply an individual looking to make a difference, you are welcome to visit our website at www.icanresearch.org to explore our mission, programs, and initiatives. Join us today in ensuring that every child's voice is enshrined in the effort to improve healthcare for all pediatric patients.

"This September, three iCAN Youth Members (Anvita, Inaaya, and Meghan) and iCAN President, Leanne West, took to the world stage to speak about the impact of off-label and pediatric legislation on themselves, the iCAN Community, and pediatric healthcare as a whole."

iCAN Youth IMPACT: Voices of Youth Reaching the Ears of the FDA:

This September, three iCAN Youth Members (Anvita, Inaaya, and Meghan) and iCAN President, Leanne West, took to the world stage to speak about the impact of off-label and pediatric legislation on themselves, the iCAN Community, and pediatric healthcare as a whole. We are so proud of Anvita, Inaaya, and Meghan for doing such an incredible job sharing their voices at the FDA's Interested Parties Meeting: Implementation of the Best Pharmaceuticals for Children's Act (BPCA) and Pediatric Research Equity Act (PREA).

Our three youth participants shared their lived experiences as pediatric patients to highlight the impact of the BPCA and PREA, as well as the importance of involving the pediatric youth voice in clinical research. Leanne detailed iCAN's role in the ongoing effort to increase patient centricity in healthcare and shared our young people's thoughts on off-label drug use, patient safety in

clinical research, and how young adults are shaping the future of pediatrics.

Hear from our speakers below:

- "In short, science is evolving. The question is whether we can evolve the system fast enough to bring science to the bedside - as we say at iCAN, for every child, everywhere." - Inaaya (KIDS Illinois)
- "By encouraging pediatric studies, kids are not left behind… let's make sure that all kids have access to the benefits that I have been able to receive." - Anvita (KIDS CHOC)
- "I can only hope that future pediatric patients will be as fortunate as I was…but this is ultimately dependent on continued funding for pediatric drug advancement research." - Meghan (KIDS Illinois)
- "It is through the partnership of patient organizations, regulatory agencies, and industry bodies that the youth voice is able to be used in transforming pediatric healthcare." - Leanne West (iCAN President)

Our speakers showcased how iCAN youth make a real, lasting impact! Thank you to the FDA for hosting this event and including the youth voice! Let us continue to Empower Pediatric Patients Worldwide together!

iCAN KIDS Spotlight:

Lyla and Inaaya are making an Impact in their local communities and beyond!

We are excited to highlight TWO outstanding iCAN youth members this month. Both Lyla (KIDS Walter Payton) and Inaaya (KIDS Illinois) have gone above and beyond to advance the kid voice in pediatric healthcare. We are so proud of them and cannot wait to see how their accomplishments shape the way that youth are included in the health system.

Lyla took charge of coordinating and leading an incredible seminar session with Nico Thom (Project Manager at HCSC and Founder/President of SheBecame). From planning engaging icebreakers to facilitating Nico's discussion on public health and health equity, Lyla's bold leadership engaged young people around the important topic of pediatric advocacy in a fun, kid-friendly way! As a leader in her local KIDS Chapter, Lyla continued the incredible work created at the 2025 iCAN Summit by disseminating the "International Position Paper on Youth Partnership in healthcare" to Nico and to the new cohort of KIDS Walter Payton youth members.Taking flight, Inaaya took her voice and story all the way to the Capitol! As an attendee and speaker of the 16th annual Childhood Cancer Summit, Inaaya traveled to Washington, D.C., to celebrate life, raise awareness about pediatric cancer, and spread hope and joy. She shared her story with the members of Congress and other attendees, ultimately helping pass the Give Kids A Chance Act, which will expand drug development. We are so incredibly impressed with Inaaya's bravery, fortitude in the face of intense circumstances, and brilliant spirit! She also took the opportunity to wear the 2025 iCAN Summit Pin, designed around the theme "Channeling Your Voice," thereby bringing her experiences and leadership from the iCAN Summit to the broader healthcare community.

"She shared her story with the members of Congress and other attendees, ultimately helping pass the Give Kids A Chance Act, which will expand drug development. We are so incredibly impressed with Inaaya's bravery, fortitude in the face of intense circumstances, and brilliant spirit!"

Ask the Experts: How Personal Challenges Can Bring About Inspiration for Incredible Impact!

Click Here to Watch this month's Ask the Experts episode!

On September 20, iCAN welcomed Dr. Charles Posternack (CEO of Avulux) for an inspiring session that touched on topics such as entrepreneurship, perseverance, and how he turned personal challenges into groundbreaking solutions for migraine and light sensitivity. We were thrilled to learn from an incredible leader making a real impact in healthcare!

During the discussion, Dr. Posternack explored the intersection between product development and purpose to help as many people as possible achieve migraine relief. Throughout the talk, a major theme was the importance of perseverance. As Dr. Posternack said, "I don't let roadblocks be a roadblock." What became apparent was that with teamwork, creativity, and determination, almost any challenge can be overcome! Leaning on the community and viewing failure as a learning opportunity creates the basic foundation for incredible innovation, change, and impact.

Thank you to Dr. Posternack for sharing your unique insights. Your story demonstrates that when purpose drives innovation, healthcare becomes even more patient-centric. Stay tuned for more updates and chances to connect with experts! Next month's session will take place on October 18 at 10 AM EST with special guest, Samik Dasgupta (founder and owner of Bunny Hopkins). He will be speaking on how his work sparks creativity, resilience, and open-ended play in children.

What to be part of our next *Ask the Experts* Session? Please reach out to sabina@icanresearch.org.

Looking Ahead: How Youth are Transforming the World of Healthcare Advocacy this Fall and Beyond:

- **Ask the Experts - October 18**
- Ask the Experts is a monthly webinar series hosted by iCAN to connect our young people to changemakers and experts in health. By engaging directly with these healthcare transformers, our youth can learn about topics they are interested in, explore careers, and discover additional ways to engage in the broad world of healthcare.
- Mark your calendars- Next month's session will take place on October 18 at 10 AM EST with special guest, Samik Dasgupta (founder and owner of Bunny Hopkins). He will be speaking on how his work sparks creativity, resilience, and open-ended play in children.
- Register: https://www.icanresearch.org/ask-the-experts
- Want to be part of our next *Ask the Experts* Session? Please reach out to sabina@icanresearch.org.

iCAN Executive Director Speaking at the 2nd Annual Patient Recruitment for Rare Disease Trials Summit:

- Join biopharma leaders this November at the 2nd Patient Recruitment for Rare Disease Trials, where they will focus on driving patient awareness, enrollment, and retention in rare disease trials. As rare disease trials become increasingly complex, with small patient populations, high trial burdens, and growing regulatory scrutiny, recruitment and retention require more than just outreach.
- Sabina, iCAN Executive Director, will share her insights and discuss the impact on iCAN kids in Clinical Research.

Register Here:

https://patient-recruitment-rare-disease.com/take-part/register/?utm_source=digital&utm_medium=social-post&utm_campaign=other-patient-advocacy-voices&utm_content=linkedin/ev-58943

iCAN Shine: iCAN's First Virtual Talent Show Fundraiser:

- Get ready to showcase your skills for a cause! iCAN is excited to announce our upcoming Virtual Talent Show Fundraiser, iCAN Shine: Global Talent Showcase, where kids from around the globe can share their unique talents while helping raise funds to support our 2026 Summit.
- November 8th - 11 AM EST

- Register to Attend Here: https://givebutter.com/WQBXRv?s=XevYWB

The 2026 iCAN Summit:

Our annual Summit serves as a transformative platform for innovation, compassion, and collaboration in pediatric healthcare. The shifting landscape in the current healthcare landscape has made an in-person Summit for 2026 uncertain. The lasting impact of this annual event on the youth who attend, the iCAN Network, and the broader healthcare community as a whole cannot be overstated. Together, we continue to make a tangible and meaningful impact on pediatric healthcare. By giving every child a seat at the table through discussion and co-creation, both current and future pediatric patients are empowered and transformed. We invite you to be part of this life-changing event by contributing in three meaningful ways:

1. Sponsor the 2026 Summit: Your sponsorship will play a vital role in ensuring a transformative experience for all attendees.

2. Sponsor a Child to Attend: Your sponsorship directly impacts a child's life by granting them the opportunity to attend the Summit in Canada. Your support will cover travel, accommodation, and participation, offering them a world of learning and empowerment. Together, we are shaping a brighter future for pediatric healthcare. Your contribution—big or small—makes a significant difference in prioritizing the patient voice and driving positive change. Your generosity and dedication are deeply valued. Let us unite to create a summit experience that empowers the pediatric community for years to come.

3. Contribute to the GoFundMe for the iCAN 2026 Summit: We want our next Summit to be in person—and we can only do that with your support! Our goal is to raise $200,000 by December 1, 2025. Please share or donate to our GoFundMe:

   - https://gofund.me/525439b3
   - www.icanresearch.org

Let us work together to make our 2026 Summit even bigger by bringing more kids to share their voices! To contribute to the funding for next year's Summit, please click here to sponsor or make a donation.

Disclosures: *There are no reported disclosures*

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NEONATOLOGY TODAY is interested in publishing manuscripts from Neonatologists, Fellows, NNPs and those involved in caring for neonates on case studies, research results, hospital news, meeting announcements, and other pertinent topics.

Please submit your manuscript to: LomaLindaPublishingCompany@gmail.com

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Want to Strengthen your NICU's Safe Sleep Efforts?

LET'S TALK IN THE NICU: PREPARING FAMILIES FOR SAFE SLEEP AT HOME

HOW CAN ONE CONVERSATION CHANGE EVERYTHING?

Let's Talk Community Chats are now in the NICU—bringing culturally responsive, judgment-free safe sleep and breastfeeding education directly to families before discharge.

Led by **community peers trained by First Candle** and adhering to AAP Guidelines, these sessions empower NICU parents with knowledge, support, and resources to help protect their most vulnerable babies.

Learn how you can bring Let's Talk to your NICU.

Email alison@firstcandle.org for more information

firstcandle LET'S TALK Community Chats IN THE NICU

Pictured: Baby Kole with his Dad

Save the Date!

Join us for the 39th Annual Gravens Conference

"Sensitive Issues in Sensational Times"

New date & location, same great topics, workshops, abstracts, and networking for those who work in Newborn Intensive Care Units.

Come learn with us!

June 16th, 17th, and 18th, 2026

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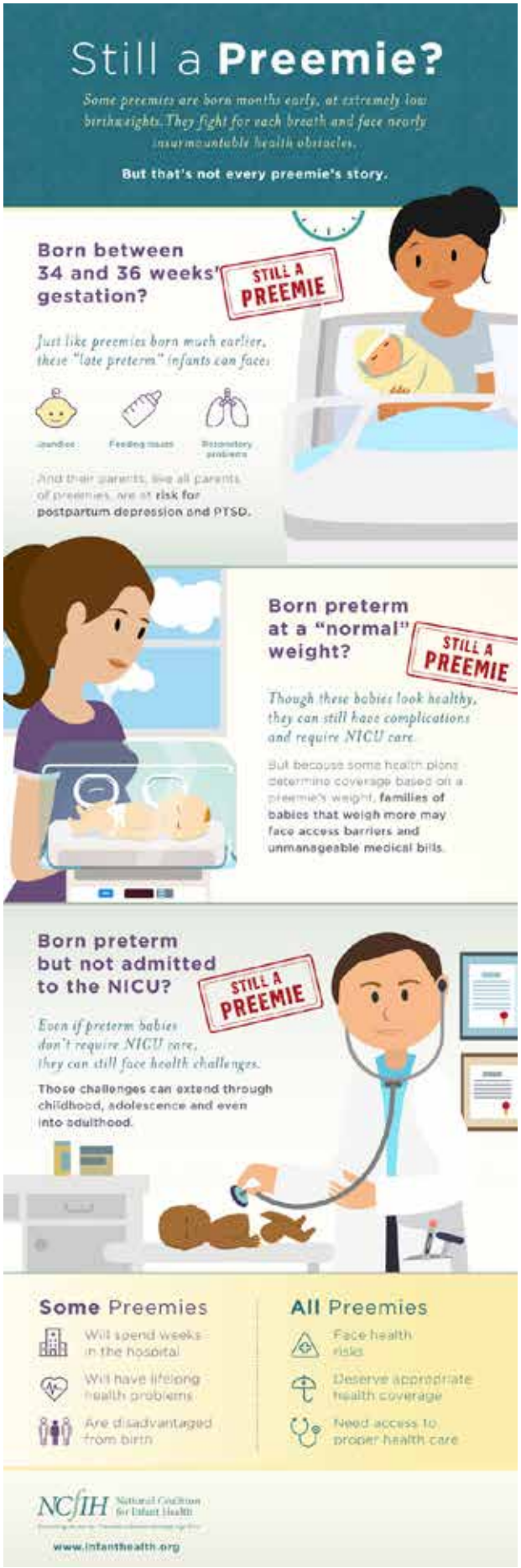
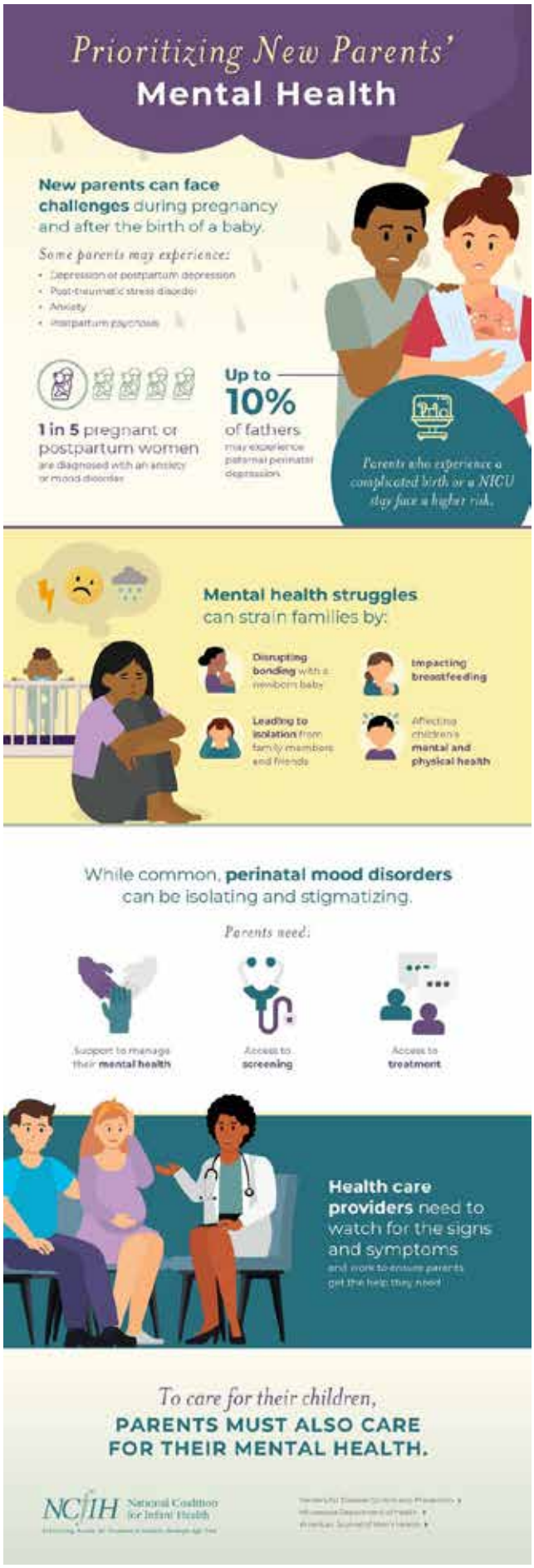

Still a Preemie?
Some preemies are born months early, at extremely low birthweights. They fight for each breath and face nearly insurmountable health obstacles.
But that's not every preemie's story.
Born between 34 and 36 weeks' gestation?
STILL A PREEMIE
Just like preemies born much earlier, these "late preterm" infants can face:
Jaundice
Feeding issues
Respiratory problems
And their parents, like all parents of preemies, are at risk for postpartum depression and PTSD.
Born preterm at a "normal" weight?
STILL A PREEMIE
Though these babies look healthy, they can still have complications and require NICU care.
But because some health plans determine coverage based on a preemie's weight, families of babies that weigh more may face access barriers and unmanageable medical bills.
Born preterm but not admitted to the NICU?
STILL A PREEMIE
Even if preterm babies don't require NICU care, they can still face health challenges.
Those challenges can extend through childhood, adolescence and even into adulthood.
Some Preemies
Will spend weeks in the hospital
Will have lifelong health problems
Are disadvantaged from birth
All Preemies
Face health risks
Deserve appropriate health coverage
Need access to proper health care
NCfIH National Coalition for Infant Health
www.infanthealth.org


Prioritizing New Parents' Mental Health
New parents can face challenges during pregnancy and after the birth of a baby.
Some parents may experience:
Depression or postpartum depression
Post-traumatic stress disorder
Anxiety
Postpartum psychosis
1 in 5 pregnant or postpartum women are diagnosed with an anxiety or mood disorder
Up to 10% of fathers may experience paternal perinatal depression
Parents who experience a complicated birth or a NICU stay face a higher risk.
Mental health struggles can strain families by:
Disrupting bonding with a newborn baby
Impacting breastfeeding
Leading to isolation from family members and friends
Affecting children's mental and physical health
While common, perinatal mood disorders can be isolating and stigmatizing.
Parents need:
Support to manage their mental health
Access to screening
Access to treatment
Health care providers need to watch for the signs and symptoms
and work to ensure parents get the help they need
To care for their children,
PARENTS MUST ALSO CARE FOR THEIR MENTAL HEALTH.
NCfIH National Coalition for Infant Health

Join iCAN's Virtual Focus Group!

We warmly welcome all individuals within the age ranges of 8-10 and 12-18, including those with:

- Learning disabilities (example: dyslexia)
- Speech or language disabilities (examples: stuttering, understanding others, hearing)
- Physical disabilities (examples: epilepsy, cystic fibrosis)
- Autism Spectrum Disorder (ASD) or Attention-Deficit/Hyperactivity Disorder (ADHD)

Every voice counts!

It's a one-minute survey to see if you qualify for a one-hour focus group to be scheduled at a later date.

Survey Link: bit.ly/icanxkismet

Fill out the recruitment survey now and let your voice be heard!
Together, we can make a real difference in pediatric healthcare!

iCAN
International Children's Advisory Network

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Academy of Neonatal Care

The Academy of Neonatal Care serves to educate Respiratory Therapists, Nurses, and Doctors in current and best practices in Neonatal ICU care. We prepare RT's new to NICU to fully function as a bedside NICU RT. Our goal is to enrich NICU care at all levels. Beginner to Advanced Practice, there is something for you at:

www.AcademyofNeonatalCare.org.

I want to learn to work in NICU... but how?

Academy of Neonatal Care Fall Course and Workshop

September 24, 2025

Eisenhower Medical Center

39000 Bob Hope Drive Rancho Mirage, CA 90000

~~7 Live plus 3.5 online CEU's Available*~~ 0900-1700

This ONE DAY class covers:

Pneumonia and Sepsis - HFNC and CPAP in NICU -
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Neonatal Chest X-Rays - RT's and IVH
Apneas and Bradycardias - RDS -NICU vent waveforms

AND, Our famous Hands-on workshop stations :

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Flow inflating bags, HFOV, and ETT securing methods

This is a hybrid course, and *includes* our online Session 1 to complete before taking the live class, PLUS several bonuses!

Academy of Neonatal Care

AcademyofNeonatalCare.org/register
Live+Online Day 1 : $399
*AARC- Approved ceu's

This course is designed for NICU beginners, and for those who float to NICU and would like a refresher. If you are a seasoned NICU RT, you will be bored silly.

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Keeping Your Baby Safe
from respiratory infections

RSV
COVID-19
colds
flu

How to protect your little ones from germs and viruses

This year is an especially dangerous cold and flu season - especially for vulnerable infants and children. Fortunately, there are proven protective measures that we can take to stay healthy.

Here's what you can do...

Wash Your Hands

- This is the single, most important thing you can do to stop the spread of viruses.
- Use soap.
- Wash for more than 20 seconds.
- Use alcohol-based sanitizers.

Limit Contact with Others

- Stay home when you can.
- Stay 6 feet apart when out.
- Wear a face mask when out.
- Change your clothes when you get home.
- Tell others what you're doing to stay safe.

Provide Protective Immunity

- Hold your baby skin-to-skin.
- Give them your breast milk.
- Stay current with your family's immunizations.

Take Care of Yourself

- Stay connected with your family and friends.
- Drink more water and eat healthy foods.
- Seek mental health support.
- Sleep when you can.

Get Immunized

Vaccinations save lives. Protecting your baby from COVID-19, flu and pertussis lowers their risks for complications from respiratory infections.

WARNING

Never Put a Mask on Your Baby

- Because babies have smaller airways, a mask makes it hard for them to breathe.
- Masks pose a risk of strangulation and suffocation.
- A baby can't remove their mask if they're suffocating.

If you feel sick or are positive for COVID-19

- Wash with soap and water and put on fresh clothes before holding or feeding your baby.
- Wear a mask to help stop the virus from spreading.
- Watch out for symptoms like fever, confusion, or trouble breathing.
- Ask for help caring for your baby and yourself while you recover.

We can help protect each other.
www.nationalperinatal.org/rsv

National Perinatal Association

PROTECT YOUR FAMILY FROM

RESPIRATORY VIRUSES

flu | coronavirus | pertussis | RSV

WASH YOUR HANDS
often with soap and warm water.

GET VACCINATED
for flu and pertussis. Ask about protective injections for RSV.

COVER COUGHS AND SNEEZES.
Sneeze and cough into your elbow.

USE AN ALCOHOL-BASED HAND SANITIZER.

STAY AWAY FROM SICK PEOPLE
Avoid crowds. Protect vulnerable babies and children.

www.nationalperinatal.org

National Perinatal Association

FREE RESOURCES FOR YOUR NICU

Coping During COVID-19

Targeted interventions to improve the mental health of parents, infants, families, and providers

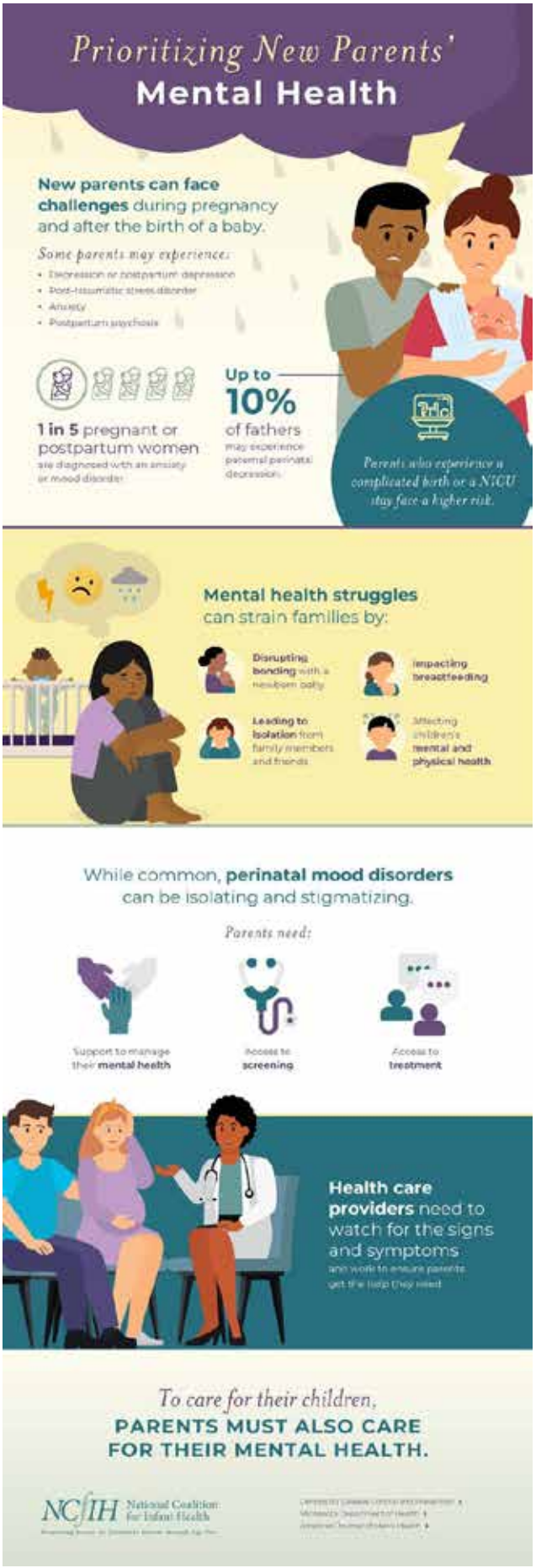
BONDING WITH YOUR BABY

HELPING CHILDREN AND FAMILIES COPE

CAREGIVERS NEED CARE TOO

National Network of NICU Psychologists

nationalperinatal.org/psychologists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• Anxiety
• Postpartum psychosis
1 in 5 pregnant or postpartum women are diagnosed with an anxiety or mood disorder
Up to 10% of fathers may experience paternal perinatal depression
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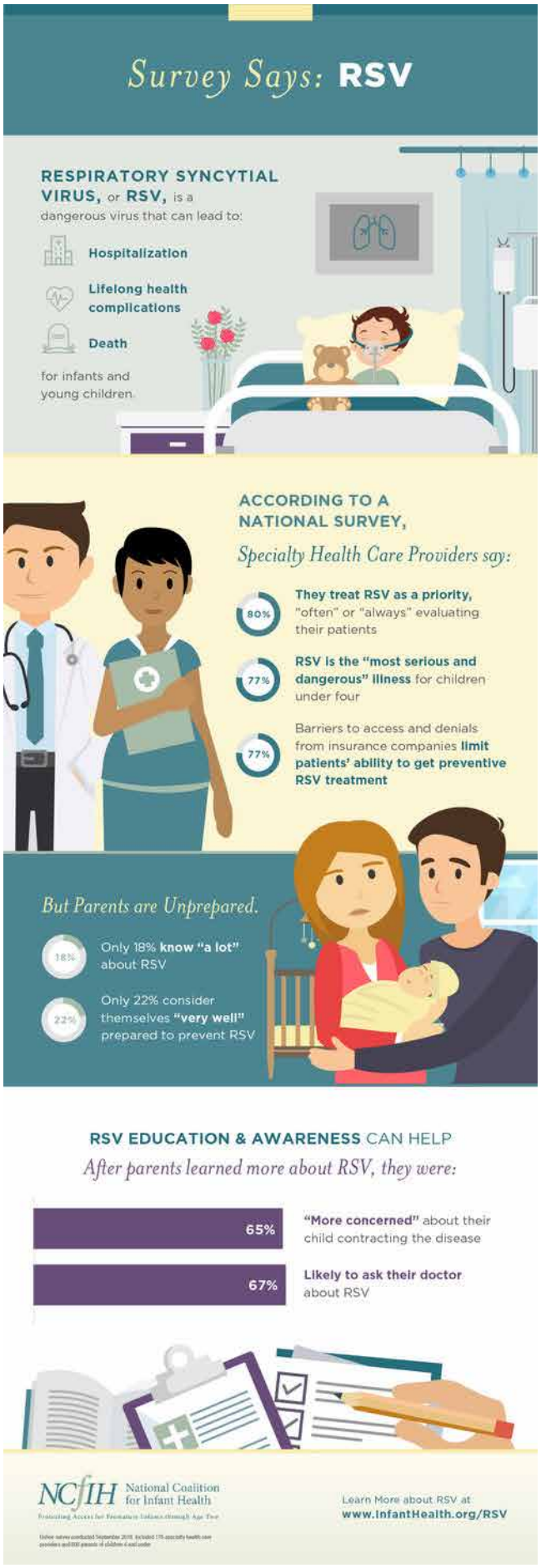
Impacting breastfeeding
Leading to isolation from family members and friends
Affecting children's mental and physical health
While common, perinatal mood disorders can be isolating and stigmatizing.
Parents need:
Support to manage their mental health
Access to screening
Access to treatment
Health care providers need to watch for the signs and symptoms and work to ensure parents get the help they need
To care for their children, PARENTS MUST ALSO CARE FOR THEIR MENTAL HEALTH.
NCIIH National Coalition for Infant Health


Survey Says: RSV
RESPIRATORY SYNCYTIAL VIRUS, or RSV, is a dangerous virus that can lead to:
Hospitalization
Lifelong health complications
Death
for infants and young children.
ACCORDING TO A NATIONAL SURVEY,
Specialty Health Care Providers say:
80% They treat RSV as a priority, "often" or "always" evaluating their patients
77% RSV is the "most serious and dangerous" illness for children under four
77% Barriers to access and denials from insurance companies limit patients' ability to get preventive RSV treatment
But Parents are Unprepared.
18% Only 18% know "a lot" about RSV
22% Only 22% consider themselves "very well" prepared to prevent RSV
RSV EDUCATION & AWARENESS CAN HELP
After parents learned more about RSV, they were:
65% "More concerned" about their child contracting the disease
67% Likely to ask their doctor about RSV
NCIIH National Coalition for Infant Health
Learn More about RSV at www.InfantHealth.org/RSV

The Allegation of Child Abuse and Fetal Injury During Delivery: A Role for Common Sense

Barry S. Schifrin, MD, Maureen Sims, MD

In dealing with allegations of child abuse of very young children, it is sometimes disappointing to find pediatricians evaluating young children unaware that some of the adverse consequences of labor and delivery may not be immediately manifested in the newborn. This includes neurological and skeletal injuries that may be discovered sometime after birth and are believed to represent child abuse.

At the time of her pregnancy, the mother, a 30-year-old, G4 P1, was 67 inches tall and weighed about 204 pounds at the beginning of her pregnancy, having gained about 40 pounds to 249 pounds by the time of delivery. (BMI 38.2)

Her history was significant for a fractured pelvis suffered during a horse accident. Her past obstetrical history included a vacuum-assisted vaginal delivery of a 4050-gram male infant after a prolonged 2nd stage of labor. That baby has done well with no evidence of abuse. During and following that delivery, the mother developed elevated BPs (preeclampsia).

With the current pregnancy, she had an uneventful prenatal course until 37 weeks of gestation when her BP was found to be elevated. Prenatal testing was reassuring with an estimated fetal weight of 3750 grams by ultrasound. Although her BP recordings remained in the normal range after a single dose of labetalol, she was induced at 38 weeks of gestation to "prevent preeclampsia (PE)."

On admission to the hospital for induction, her cervix was "unfavorable," anticipating a long induction. The estimated fetal weight (EFW) is 3758 grams. The fetal heart rate (FHR) tracing was reassuring and would remain so until shortly before delivery. The interval from admission to delivery was about 55 hours. During that time, she was given 16 doses of Cytotec, 50 mcg orally, to efface the cervix and perhaps induce labor. She was monitored intermittently over the first 2 days with intermittent contractions, but no labor.

"On admission to the hospital for induction, her cervix was "unfavorable," anticipating a long induction. The estimated fetal weight (EFW) is 3758 grams. The fetal heart rate (FHR) tracing was reassuring and would remain so until shortly before delivery. The interval from admission to delivery was about 55 hours."

Despite all the Cytotec and the intermittent contractions, when examined on the morning of the third day, she was 4 cm dilated at -2 station, and her membranes were ruptured artificially with no descent of the presenting part. About 2 hours later, a pelvic exam revealed the cervix to be 6–7 cm with the head still at high station. Shortly thereafter, she felt the urge to push. She was using Entonox, an inhaled gas, 50% oxygen, 50% nitrous oxide, for pain relief. The cervix was now 9 cm, but the head remained high. The midwife appeared for the delivery, noting that with the onset of pushing, the previously normal FHR was now sustained between 79 and 109 bpm, which she considered to represent "head compression." With the final two pushes, the baby's head was delivered with guided maneuvers. The head returned to the mother's right side, followed immediately by the rest of the body.

From the data supplied, including the FHR tracing, it was deemed possible to calculate the minimal trajectory of the descent of the fetal head in the last several minutes of labor at about 35 cm/hour. (7 cm in 12 minutes; normal <12 cm/hr)—an extraordinarily rapid descent of the fetus. If the midwife's estimate of the 2nd stage was correct (4 minutes), then the slope of descent of the fetal head exceeded 100 cm/hour! It would take about 1 hour for the placenta to be delivered.

"From the data supplied, including the FHR tracing, it was deemed possible to calculate the minimal trajectory of the descent of the fetal head in the last several minutes of labor at about 35 cm/hour. (7 cm in 12 minutes; normal <12 cm/hr)—an extraordinarily rapid descent of the fetus. If the midwife's estimate of the 2nd stage was correct (4 minutes), then the slope of descent of the fetal head exceeded 100 cm/hour!"

Neonatal course:

At birth, the baby weighed 4000 grams, above the 90th percentile for gestational age. His head circumference was 34 cm, and his length was 53 cm. He was assigned Apgar scores of 9 and 10 at 1 and 5 minutes, respectively. His examination was unremarkable, and he was discharged with his mother the following day.

At 4 weeks of age, the mother noticed crackling and popping sounds from his back when he was being held, and he had developed a high-pitched cry. He had vomited 5 times in the preceding 24 hours and had problems with constipation. The mother immediately called the visiting nurse, who could apparently hear these sounds over the phone. She recommended taking the baby to the emergency department of the local hospital, where the child underwent CT scans of the head and chest as well as

a skeletal survey. A CT of the head (non-contrast) revealed no evidence of hematoma, skull fracture, or intracranial injury. A CT of the chest, however, revealed multiple rib fractures of the 6th through the 10th rib posteriorly on the left, several of which were displaced, and the sixth rib on the right at the costochondral junction (anterior), not displaced.

"...the child underwent CT scans of the head and chest as well as a skeletal survey. A CT of the head (non-contrast) revealed no evidence of hematoma, skull fracture, or intracranial injury. A CT of the chest, however, revealed multiple rib fractures of the 6th through the 10th rib posteriorly on the left, several of which were displaced, and the sixth rib on the right at the costochondral junction (anterior), not displaced."

Although the baby's Vitamin D levels were found to be quite low, his skeletal survey apparently revealed **normal** bone mineralization and morphology with no evidence of metabolic bone disease; all the injuries appeared to be of similar age. There was no sign of bone healing. It was not possible to age the swelling that was present, but this was thought to go along with a reasonably recent injury that could have occurred "on the day of presentation or within 7–10 days prior."

"Although the baby's Vitamin D levels were found to be quite low, his skeletal survey apparently revealed normal bone mineralization and morphology with no evidence of metabolic bone disease; all the injuries appeared to be of similar age. There was no sign of bone healing."

The baby was discharged from the hospital but was readmitted the next day due to pain and discomfort and was treated with morphine and other medications. A repeat chest x-ray 3 days after repeat admission showed that rib fractures had become more displaced. A follow-up skeletal survey—11 days after the initial survey—identified a healing displaced left clavicle fracture at the junction of the mid and outer thirds, which, in retrospect, was seen on the previous CT (subtle, non-displaced), left fifth rib posterior fracture (not seen on previous CT), and probable right eleventh rib fracture. Before discharge home to the care of his parents, a multidisciplinary group meeting with the police and other agencies expressed concern about child abuse and placed supervision on the parents.

In his report to the child protection agency, the radiologist wrote: "*From my understanding, there is no accidental trauma that would explain these injuries. On the imaging studies, there is no evidence of an alternative diagnosis that would explain these fractures. In my opinion, the imaging findings are almost certainly the result of abusive trauma."*

These conclusions of the radiologist were wholeheartedly embraced by various consultants, including an endocrinologist, a pediatrician specializing in child abuse, a geneticist, and an obstetrician who testified that the delivery was "normal" in all respects. In none of the reports affirming the diagnosis of abusive intent was any effort made to determine independently the details of the baby's obstetrical history or to describe the position of the offending hands that could produce mostly one-sided rib injuries and fracture the clavicle as well. As a result, even though the father was not present on the day the baby became symptomatic, he was charged with "wounding with reckless disregard" and an alternative charge of assault and ordered to stand trial.

The criminal allegation of child abuse required the defense to produce, prior to trial, exculpatory arguments in the form of detailed reports of experts reciting the facts of the case and the basis of challenges to the opinions of the prosecution about the timing and mechanism of the child's injuries. The defense also presented testimony from the visiting nurse, a sacral cranial specialist who had examined the child, as well as a neighbor of the family who had been in repeated contact with them. Their narrative showed that following the baby's discharge from the hospital after birth, the visiting nurse visited the newborn and his parent(s) in their home on no fewer than 10 occasions; her last visit occurred five days before the baby's presentation to the hospital. A cranial sacral therapist saw the baby one day prior to his presenting symptoms. These witnesses commented on the baby's comfort around his parents. They saw no plausible evidence of bruising, rough handling, or evidence of any abusive behavior to either of their children. The visiting nurse also commented on the post-delivery course of the couple's first child, whom she had followed, finding that the older baby was much more "settled" than the younger one.

"These witnesses commented on the baby's comfort around his parents. They saw no plausible evidence of bruising, rough handling, or evidence of any abusive behavior to either of their children."

At the trial, the defense produced three medical experts. No defense expert claimed expertise in child abuse, and none testified that the baby ***did not suffer abuse at the hands of his parents***. They offered expert opinions on whether the events of labor and delivery were capable of causing the injuries, the potential role of Vitamin D deficiency, and offered plausible explanations of the timing of the signs and symptoms of the injuries found subsequently in this 4-week-old child.

The obstetrical expert opined that a clavicle fracture is a bony disruption commonly associated with difficult (sometimes in

retrospect) vaginal delivery. It is the most common fracture associated with birth—a fact agreed to by one of the prosecution experts. While such fractures may cause distress in the newborn, many are asymptomatic. As in this case, there was no observable swelling or bruising around the clavicle from birth to hospitalization and no discernible signs of pain or fussiness, either at rest or when the arm was moved. There was also no apparent disruption of or limitation of motion in the elbow, wrist, or hand. Further, under normal circumstances, clavicular fractures typically begin to heal quickly, usually within 7–10 days, with little to no need for treatment. (*see* Vitamin D below).

The defense experts also challenged the prosecution's purported mechanism of the injury, which stated that the injuries were caused by the father grasping the baby's chest with his thumbs upward to injure the clavicle. There was no attempt to explain why the distribution of the injuries was disproportionately on the left side and why there was no bruising or evidence of mishandling. At delivery, the fetal head had retracted to the mother's right side. From that position, it becomes understandable that the ***left*** clavicle was anterior and the one more likely to be affected by any difficulty with the delivery or shoulder dystocia.

During the birth process, the clavicle passes through the birth canal in a unique position, and it can fracture during a difficult, rapid, or prolonged delivery, especially in larger babies. In this case, there was a rapid descent and intense pressure exerted on the baby's shoulder and ribs during the birth process. (Consistent both with the history and with the change in the FHR tracing). Rapid delivery significantly increases the risk of complications for both the mother and baby. For the mother, the risks include uterine rupture, tearing and lacerations of the cervix, vagina, or perineum, postpartum hemorrhage, and retained placenta— several of which were present in this case. For the fetus, rapidly negotiating the birth canal can increase the likelihood of hypoxic/ischemic and traumatic injuries, which may include shoulder dystocia, fetal distress, fetal trauma, and head or brain injuries. While less common than other types of birth injuries, rib fractures can occur during precipitous delivery due to the squeezing and compression forces on the baby's chest as it passes rapidly through the birth canal.

In support of his argument that sustained pressure during the rapid delivery was the source of the infant's skeletal injuries, the obstetrical expert listed the numerous maternal, fetal, and obstetrical risk factors present in the case. These included: the patient's size and weight, her medical history including a fractured pelvis, her obstetrical history of a previous large fetus, the prolonged induction of labor (>50 hours) using prostaglandins (Cytotec), the frequent contractions and likely unrestrained, compulsive pushing (without adequate maternal anesthesia) immediately before delivery, the large size of the fetus, and the extraordinarily rapid (precipitous) descent of the fetal head.

To these considerations must be added the baby's extremely low Vitamin D level. Though both prosecution and defense witnesses agreed that the injuries were primarily traumatic, there was no necessary reason to invoke a Vitamin D deficiency as a primary cause of the clavicle and rib fractures or even to an increased susceptibility to fracture. The difference in opinion between the prosecution and the defense related to the timing, the circumstances of the trauma, and the impact, if any, of Vitamin D deficiency on the ability to detect bone disease from the radiographs, and the healing of the fractures.

The prosecution argued that the baby's Vitamin D deficiency played no role in the abuse. The defense argued that the apparently normal radiographic appearance of the bone could not exclude deficient healing. With deficient levels of Vitamin D, healing and the remodeling process can be "delayed for months until sufficient minerals are available for normal bone repair and growth." Indeed, literature shows that Vitamin D is needed for bone healing and is used up (the serum level decreases) during bone healing, and low Vitamin D levels delay the appearance of markers of healing by significant amounts of time (weeks to months). It should be noted that Vitamin D is absorbed in sunlight, an unlikely source in a newborn; it is also unavailable from breast milk, which contains no Vitamin D— it must be supplemented in the newborn. While these explanations might have satisfied the lack of obvious healing of the fractures, they could not explain the apparent delay in the onset of the baby's symptoms.

"During the birth process, the clavicle passes through the birth canal in a unique position, and it can fracture during a difficult, rapid, or prolonged delivery, especially in larger babies. In this case, there was a rapid descent and intense pressure exerted on the baby's shoulder and ribs during the birth process...Rapid delivery significantly increases the risk of complications for both the mother and baby...For the fetus, rapidly negotiating the birth canal can increase the likelihood of hypoxic/ischemic and traumatic injuries, which may include shoulder dystocia, fetal distress, fetal trauma, and head or brain injuries. While less common than other types of birth injuries, rib fractures can occur during precipitous delivery due to the squeezing and compression forces on the baby's chest as it passes rapidly through the birth canal."

The defense's position was that the delayed timing of the baby's signs and symptoms related to the recent completion/displacement of previously non-displaced rib fractures from the time of delivery. The displacement was thought to be related to the increased intra-abdominal and/or intrathoracic pressure changes associated with position changes, coughing, sneezing, vomiting, or straining at stool (constipation), which converted the previously non-displaced fracture into displaced ones, now causing the obvious signs and symptoms. Further, there was no dispute about the presence of vomiting and constipation prior to the baby's signs and symptoms, as well as his being "unsettled." Curiously, the left-sided fractures became more displaced in the interval between the initial and follow-up X-rays, and a healing fracture was identified

on the follow-up that was not seen on the initial CT (presumably microscopic or below the resolution of CT).

"The defense argued that the apparently normal radiographic appearance of the bone could not exclude deficient healing. With deficient levels of Vitamin D, healing and the remodeling process can be "delayed for months until sufficient minerals are available for normal bone repair and growth." Indeed, literature shows that Vitamin D is needed for bone healing and is used up (the serum level decreases) during bone healing, and low Vitamin D levels delay the appearance of markers of healing by significant amounts of time (weeks to months)."

The defense experts were unanimous in joining the authors in the literature who hold the opinion that birth-related rib fractures are more common than believed. There are no population studies that report the frequency of clavicle or rib fracture following vaginal delivery, as there are for subdural and retinal hemorrhages (present in 35 to 50 percent of asymptomatic term infants delivered vaginally).

The universal opinion of all the prosecution experts was that the trauma occurred either in the 7 to 10 days preceding or possibly on the day of appearance of symptoms—claiming that the injury occurred on the day of symptoms would have required that the mother, not the father, who was not present that day, to be charged with abuse The experts for the prosecution offered no differential diagnosis or discussion of the mostly one-sided bony injury, especially the clavicular fracture. Nor did they flesh out the allegation of intent to harm in a 4-week-old infant in whom there was neither history nor observed superficial bruising nor pain during the time of the proposed abuse. They appeared to have no understanding of the mother's obstetrical (and other) histories, including her low Vitamin D levels and very low values in the baby. One defense expert suggested that medical opinions made without a complete review of relevant medical records cannot represent proper medical judgment, as to qualify as "medical judgment," one must take reasonable advantage of information that was or should have been available.

Obstetrical and child-abuse literature provides abundant support for the notion that obstetrical events (e.g., precipitous delivery and the maneuvers to effect delivery in association with a large baby and rapid delivery) may be responsible for subsequent trauma (and other consequences) in the baby. Guidelines for the specialty of Child Abuse Pediatrics, created by the American Academy of Pediatrics in 2009, require detailed knowledge of the obstetrical history as a foundation for the subspecialty. In his testimony, one of the defense experts quoted from oppositional child abuse literature seeking to debunk obstetrical injury as a mimic of child abuse.

"Birth fractures occur infrequently. Clavicular fractures ***are known to be birth-related and therefore have low specificity for child abuse in young infants****. Long bone and skull fractures [from birth trauma] are much less common and associated with specific risk factors.*

"Case reports of birth injuries in which a suspicion of nonaccidental trauma was raised typically exhibit patterns of injury that are corroborated ***by the traumatic circumstances of the delivery on further review.***

"Birth-related rib fractures are rare but have been documented. These typically are mid-posterior in location and most commonly occur in ***large infants*** *who [have] had* ***difficult deliveries*** *with complications such as* shoulder dystocia*. The radiologist can aid in assessing whether a current stage of healing is consistent with having occurred at birth and whether there are signs of a systemic disorder [?vitamin D deficiency].* ***Multiple rib fractures at different stages of healing do not suggest a single act such as birth. Given the high specificity of rib fractures for abuse, infants with rib fractures warrant a thorough evaluation for other injuries.***

The expert continued: "Objectively viewed, these notions, along with the history, would seem to compel the serious and inescapable consideration of obstetrical events in any discussion of the differential diagnosis of these injuries. Those alleging abuse in this case seem to have failed to exclude the significant potential of birth injury responsibly. Further, the allegations of intent to harm seem to derive from imagined probabilities of injury that have replaced disciplined, differential diagnostic procedures, which are mandatory for reaching a reasoned clinical assessment, with the result of an inadequately researched, medically flawed allegation of child abuse."

"Obstetrical and child-abuse literature provides abundant support for the notion that obstetrical events (e.g., precipitous delivery and the maneuvers to effect delivery in association with a large baby and rapid delivery) may be responsible for subsequent trauma (and other consequences) in the baby."

Another point for the defense arose inadvertently when the prosecuting attorney cross-examined a defense witness. The expert had opined that, irrespective of the obstetrical injuries, there was no evidence of bruising, mishandling, or localizing signs of pain. Moreover, if the abuser's hand position were such that it could fracture the clavicle, it seemed improbable that it would simultaneously compress the sternum. The prosecutor, seeking to have the expert's opinion stricken, asked whether, as an expert in obstetrics, he was also an expert in neonatal bruising, child abuse, or the details of chest compression, etc. In response, the expert denied that he was an expert in any of those areas, but in

a follow-up statement that seemed to resonate with the jury, he maintained that those considerations were just common sense, for which expert opinion was unnecessary.

Alas, the defense did not rely solely on the testimony of its experts and the delivering midwife. In an unusual move for such cases, the child's father testified on his own behalf. With enviable comportment, he made it very difficult for the jury to be convinced that this caring, loving father and husband could have intentionally harmed his child.

The jury returned a unanimous verdict of not guilty.

Properly informed medical decisions are made under varying degrees of uncertainty. It is the responsibility of physicians to express opinions as to whether the injuries seen in this baby were or were not consistent with trauma. Whether prosecution or defense, the medical witnesses, based on their training and experience, agreed that the injuries seen in this baby were indeed traumatic. The question then arose as to whether they were the result of abuse or a medical condition. The **prosecution's certain opinions**, however, that the injuries were intentional and unrelated to any medical condition, despite the competing evidence, would seem to be an area beyond their expertise.

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5x more likely to have learning challenges

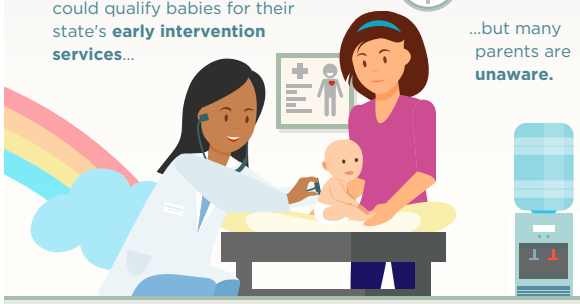
1 in **3** preterm infants will require support services at school

Early intervention can help preterm infants:

- Enhance language and communication skills
- Build more effective learning techniques
- Process social and emotional situations
- Address physical challenges
- Prevent mild difficulties from developing into major problems

Early diagnosis could qualify babies for their state's **early intervention services**...

...but many parents are **unaware.**



NICU staff, nurses, pediatricians and social workers **should talk** with NICU families about the challenges their baby may face.

Awareness, referral & timely enrollment in early intervention programs can help **infants thrive** and grow.

NCfIH National Coalition for Infant Health
Protecting Access for Premature Infants through Age Two
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Visit **CDC.gov** to find contact information for your state's early intervention program.

Las nuevas mamás necesitan acceso a la detección y tratamiento para LA DEPRESIÓN POSPARTO

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- Llanto incontrolable
- Sueño interrumpido
- Ansiedad
- Desplazamientos en los patrones de alimentación
- Ideas de hacerse daño a sí mismas o al bebé
- Distanciamiento de amigos y familiares

Sin embargo, sólo el 15% recibe tratamiento[1]

LA DEPRESIÓN POSTPARTO **NO TRATADA** PUEDE AFECTAR:

- *La salud de la madre*
- *El sueño, la alimentación y el comportamiento del bebé a medida que crece*[2]
- *La capacidad para cuidar de un bebé y sus hermanos*

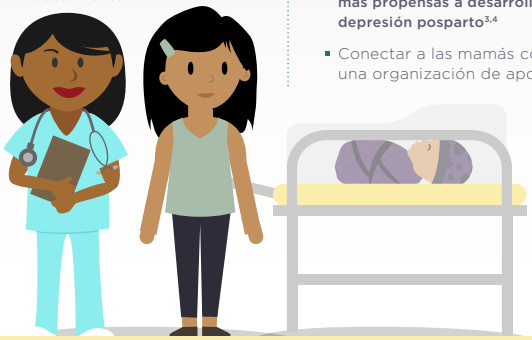
PARA AYUDAR **A LAS MADRES A ENFRENTAR LA DEPRESIÓN POSPARTO**

LOS ENCARGADOS DE FORMULAR POLÍTICAS PUEDEN:

- Financiar los esfuerzos de despistaje y diagnostico
- Proteger el acceso al tratamiento

LOS HOSPITALES PUEDEN:

- Capacitar a los profesionales de la salud para proporcionar apoyo psicosocial a las familias... **Especialmente aquellas con bebés prematuros, que son 40% más propensas a desarrollar depresión posparto**[3,4]
- Conectar a las mamás con una organización de apoyo



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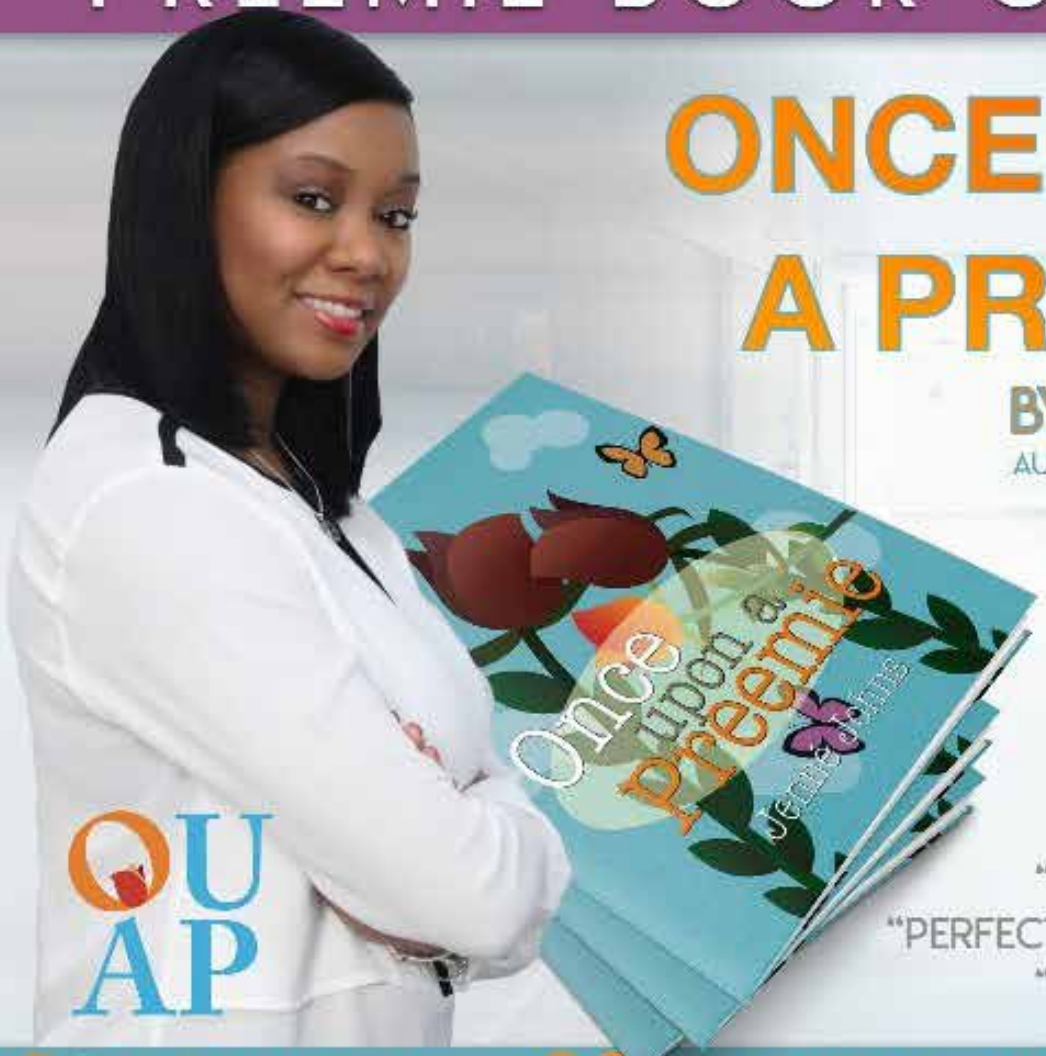

ONCE UPON A PREEMIE

BY JENNÉ JOHNS

AUTHOR | SPEAKER | ADVOCATE

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Congenital syphilis cases rise for 12th consecutive year

NEWS PROVIDED BY

American Academy of Pediatrics

By Melissa Jenco

Study: **Congenital syphilis cases rise for 12th consecutive year**

Current as of September 25, 2025

Congenital syphilis cases rose for the 12th consecutive year in 2024 with nearly 4,000 newborns infected, according to a new report.

Provisional data from the Centers for Disease Control and Prevention (CDC) show there were nearly 110 cases for every 100,000 live births. Cases were up about 2% over 2023 and nearly 700% over 2015.

Syphilis during pregnancy can result in miscarriage, stillbirth, infant death or lifelong medical issues for the baby. The AAP Red Book says, "No newborn infant should be discharged from the hospital without confirmation of the birthing parent's serologic status for syphilis." It has detailed information on signs and symptoms of congenital syphilis and a diagnosis algorithm.

Excluding congenital infections, there were about 186,301 syphilis cases in 2024, down about 9% from the year before. The drop occurred during ongoing supply issues with treatment benzathine penicillin G.

There also was a 9% decrease in overall reports of sexually transmitted infections (STIs), the third consecutive year of decline.

The CDC credited public health efforts like greater awareness and expanded use of self-tests and use of antibiotic doxycycline within 72 hours after sex.

"While the STI epidemic may be turning a corner, we must accelerate progress and stop its most tragic consequences," Bradley Stoner, M.D., Ph.D., director of CDC's Division of STD Prevention, said in a press release. "About 1 in 5 people in the United States have an STI, affecting millions of Americans and thousands of babies each year. We need to continue our prevention efforts wholeheartedly at federal, state, and local levels."

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AAP: 'Dangerous claims' about causes of autism confuse parents, harm children

NEWS PROVIDED BY

American Academy of Pediatrics

By Steve Schering

Study: **AAP: 'Dangerous claims' about causes of autism confuse parents, harm children**

Current as of September 23, 2025

Spreading misleading information about vaccines, medications and the cause of autism threatens the health of children, AAP President Susan J. Kressly, M.D., FAAP, said Monday following a White House announcement.

"Today's White House event on autism was filled with dangerous claims and misleading information that sends a confusing message to parents and expecting parents and does a disservice to autistic individuals," AAP President Susan J. Kressly, M.D., FAAP, said in a statement.

Without citing evidence, President Donald J. Trump and federal health officials suggested that giving vaccines separately could reduce the rate of autism, which has climbed to one in 31 children, according to a recent report from the Centers for Disease Control and Prevention.

"Pediatricians know firsthand that children's immune systems perform better after vaccination against serious, contagious diseases like polio, measles, whooping cough and Hepatitis B," Dr. Kressly said. "Spacing out or delaying vaccines means children will not have immunity against these diseases at times when they are most at risk."

The Food and Drug Administration (FDA) also initiated the process for a label change for acetaminophen, stating that evidence suggests its use during pregnancy may be associated with an increased risk of neurological conditions such as autism and attention-deficit/hyperactivity disorder in children. Federal officials also discouraged the use of acetaminophen for short-term fevers in young children.

"Suggestions that acetaminophen use in pregnancy causes autism are not only highly concerning to clinicians but also irresponsible when considering the harmful and confusing message they send to pregnant patients, including those who may need to rely on this beneficial medicine during pregnancy," Steven J. Fleischman, M.D., M.B.A., FACOG, president of the American College of Obstetricians and Gynecologists, said in a statement.

"In more than two decades of research on the use of acetaminophen in pregnancy, not a single reputable study has successfully concluded that the use of acetaminophen in any trimester of pregnancy causes neurodevelopmental disorders in children," Dr. Fleischman said.

The FDA also initiated the approval of leucovorin calcium tablets for patients with cerebral folate deficiency (CFD), a neurological condition that affects folate transport into the brain. Individuals with CFD may have symptoms such as developmental delays and autism.

While some early studies show leucovorin has improved verbal communication for some folate-deficient children, the AAP said it is experimental and needs to be evaluated in larger trials to understand how well it works and who may benefit.

"There is no single, root cause of autism, and there is no single medication that will give every autistic child or adult what they need," Dr. Kressly said. "Individualized plans, often involving a combination of developmental, behavioral, educational and social-relational strategies, can help improve outcomes that are meaningful to individuals and families. We also need and welcome additional investments in federally funded research to better support families of autistic children."

If parents have questions about autism, the AAP encourages them to talk to their child's pediatrician.

AAP continues to advocate for additional resources for families with autistic children to support development. Such treatments include speech therapy, occupational therapy, individualized education plans and family supports.

Federal officials also continued to sow distrust in vaccines, hinting without evidence that spreading out vaccinations could reduce risk. While the cause of autism is unknown, decades of research from around the world has shown that vaccines do not cause autism.

"Studies have repeatedly found no credible link between life-saving childhood vaccines and autism. This research, in many countries, involving thousands of individuals, has spanned multiple decades," Dr. Kressly said. "Any effort to misrepresent sound, strong science poses a threat to the health of children."

The National Institutes of Health also launched the Autism Data Science Initiative to explore the causes and rising prevalence of ASD. The research effort is being launched with more than $50 million in awards to support various projects.

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AAP breaks from federal vaccine panel, continues to recommend MMRV vaccine for children under 4

NEWS PROVIDED BY

American Academy of Pediatrics

By Melissa Jenco

Study: **AAP breaks from federal vaccine panel, continues to recommend MMRV vaccine for children under 4**

Current as of September 19, 2025

Update 9/19/25: ACIP took a new vote Friday morning, bringing the Vaccines for Children resolution in line with recommendations for other children.

The AAP continues to recommend giving families a choice of vaccines to protect toddlers against measles, mumps, rubella and varicella (MMRV) despite a federal vaccine panel calling for removal of one option Thursday.

The Advisory Committee on Immunization Practices (ACIP), which advises the Centers for Disease Control and Prevention (CDC), voted that children under 4 years should receive separate MMR and varicella vaccines and not the combined MMRV vaccine. However, it also voted to continue using MMRV for this age group in the Vaccines for Children (VFC) program, which covers children from low-income families. It was unclear whether members intended to make different recommendations as several expressed confusion about the vote. The recommendations ACIP made on Thursday still need final approval from CDC acting director.

"Today's meeting of the federal Advisory Committee on Immunization Practices (ACIP) promoted false claims and misguided information about vaccines as part of an unprecedented effort to limit access to routine childhood immunizations and sow fear and mistrust in vaccines," AAP President Susan J. Kressly, M.D., FAAP, said in a statement. "Following today's meeting, instead of emerging with clear guidance about vaccines that we know protect against serious illnesses, families are left with confusion, chaos and false information. The American Academy of Pediatrics (AAP) is stepping in to fill the gap."

MMRV vaccine (ProQuad from Merck) was licensed by the Food and Drug Administration in 2005 for children ages 12 months through 12 years. Children are recommended to get vaccinated against all four of these diseases at 12-15 months and 4-6 years. Since 2009, the CDC has said using MMR and a separate varicella vaccine is preferred for the first dose due to a small increased risk of febrile seizures. However, parents can choose MMRV to reduce the number of injections.

AAP guidance does not express a preference for toddlers receiving their first dose. There is about one additional febrile seizure per 2,300-2,600 young children immunized with MMRV for their first dose compared to separate MMR and varicella vaccines, according to the AAP Red Book.

In practice, about 15% of children getting their first dose receive MMRV, while 75% get it for the second dose.

ACIP members discussing the issue Thursday were appointed recently by Health and Human Services Secretary Robert F. Kennedy Jr. after he fired the previous group. Many have been criticized for their lack of expertise and history of promoting vaccine misinformation.

Those voting against using MMRV for children under 4 years outside of VFC expressed concern about febrile seizures. At times, they misrepresented data and used talking points common among anti-vaccine groups. Some seemed unfamiliar with febrile seizures. They also disregarded CDC assurances that febrile seizures after MMRV are rare and do not have long-term impacts.

"It's another strategy to scare parents ... put vaccines and seizures in the same sentence, because this issue was settled over 15 years ago by ACIP," Sean T. O'Leary, M.D., M.P.H., FAAP, chair of the AAP Committee on Infectious Diseases, said afterward.

The AAP did not participate in the meeting citing the removal of the AAP and other liaison organizations with frontline clinical experience from ACIP work groups where in-depth discussions take place.

H. Cody Meissner, M.D., professor of pediatrics at the Dartmouth Geisel School of Medicine, who voted to continue allowing MMRV for children under 4, said he prefers that families have the option.

"We're so familiar with febrile seizures, and I think most pediatricians would say that the prognosis is excellent, apart from the emotional impact," Dr. Meissner said.

Medical organization liaisons in attendance urged the committee to do a more comprehensive review looking at additional areas like feasibility and getting input from practicing clinicians as it historically has done. Several echoed the call for parents to have an option.

"You are taking away the choice of parents to have informed consent and discussion with their physician on what they want to do for the health and benefit of their children," said Jason M. Goldman, M.D., MACP, FPCP (Hon.), president of the American College of Physicians.

ACIP voted 8-3 with one abstention to recommend using separate MMR and varicella vaccines for children under 4. However, eight members voted to continue offering the combined MMRV vaccine as an option for toddlers in the VFC program, while one voted against doing so and three abstained. Several members expressed confusion about the VFC vote. It is highly unusual for vaccine recommendations to differ for children covered by VFC and other children.

The vote comes at a time when measles cases are at their highest since 1992. The AAP continues to recommend families have the option of MMRV.

"Until we can again trust the recommendations made by our federal government, AAP will continue stepping up and working with our local, state and federal partners to make sure every child in every community continues to have access to immunizations," Dr. Kressly said.

Thursday's meeting also included an announcement of a new ACIP work group to look at vaccines given in pregnancy. In addition, ACIP had a lengthy discussion about delaying the birth dose of hepatitis B vaccine but moved the vote to Friday when it also will discuss COVID vaccines.

Report: More support needed for postpartum women as breastfeeding rates remain well below national goals

NEWS PROVIDED BY

American Academy of Pediatrics

By Melissa Jenco

Study: **Report: More support needed for postpartum women as breastfeeding rates remain well below national goals**

Current as of September 10, 2025

An expert panel is recommending paid family and medical leave and investments in public health initiatives to increase breastfeeding rates, which remain well below national goals.

"We are far from reaching our nation's goals for breastfeeding and that is despite the fact that almost 85% start out breastfeeding soon after birth," said Lori Feldman-Winter, M.D., M.P.H., FAAP, a member of the expert panel and the AAP Section on Breastfeeding. "Everyone has a role in helping to make breastfeeding easier. For that reason, we have made recommendations based on the evidence that touch many audiences and spheres."

The recommendations are laid out in the report Breastfeeding in the United States: Strategies to Support Families and Achieve National Goals from the National Academies of Sciences, Engineering and Medicine (NASEM), which convened the committee.

Breastfeeding benefits infants' growth, immune system and digestion, according to the report. For mothers, it reduces the risk of developing type 2 diabetes, cardiovascular disease, and breast and ovarian cancer.

The Dietary Guidelines for Americans and the AAP recommend exclusive breastfeeding for a baby's first six months. Both also support continued breastfeeding while introducing complementary food for as long as desired. The dietary guidelines call for breastfeeding for at least the first year of life, while the AAP supports two years and beyond.

Among children born in 2021, 27.2% were exclusively breastfed for their first six months, and 39.5% were still receiving breast milk by 12 months, according to Centers for Disease Control and Prevention data cited in the report. Recently released rates for children born in 2022 are slightly higher but still well below the Healthy People 2030 targets of 42.4% and 54.1%, respectively.

Breastfeeding rates are lowest for women who are Black, Native American/Alaska Native, of lower socioeconomic status, unmarried, living in rural areas and younger, according to the report. These women may need to return to work or school early or have limited access to support services, making breastfeeding more challenging. Authors of the report also acknowledged not all women can or want to breastfeed.

"Given the high rates of breastfeeding intention and initiation and the noted benefits to maternal and infant health, action is needed across all levels to ensure families receive the support and resources needed to meet their breastfeeding and infant feeding goals," Ifeyinwa Asiodu, co-chair of the report committee and associate professor at the University of California, San Francisco, said in a statement.

The committee made 16 recommendations with five themes:

Strengthen national coordination efforts.

Expand effective community and public health interventions.

Ensure access to high-quality health care for all.

Adopt and enact breastfeeding-friendly

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policies to support paid leave and return to work and school.

Invest in research capacity and community-driven approaches.

Specific recommendations include paid family and medical leave for postpartum mothers; greater investments in community programs and the Special Supplemental Nutrition Program for Women, Infants, and Children; rigorous regulation of commercial milk formula; comprehensive insurance coverage of breastfeeding services and supplies; and stronger laws to guarantee lactation spaces.

"We have 16 recommendations and any one of them will move the needle toward more people reaching their personal breastfeeding goals," Dr. Feldman-Winter said. "Thus, what we hope this report accomplishes is that everyone look at the recommendations we have provided and determine which ones they can help to implement."

NIH launches consortium to reduce risk of stillbirth in the U.S.

NEWS PROVIDED BY

National Institute of Health

By NIH Communications

Study: **NIH launches consortium to reduce risk of stillbirth in the U.S.**

Current as of August 5, 2025

More than 60% of the nearly 24,000 stillbirth cases annually remain unexplained.

The National Institutes of Health (NIH) has launched effort aimed at reducing the rate of preventable stillbirths in the United States. Investigators will develop tools, devices and other technologies that have the potential to affect diagnosis and prevention efforts relevant to stillbirth, which occurs in 1 in 160 deliveries in the U.S. About 23,600 stillbirths at 20 weeks or greater gestation are reported annually.

More than 60% of stillbirth cases remain unexplained even after exclusion of common causes, such as congenital abnormalities, genetic factors, and obstetric complications. NIH will fund the Stillbirth Research Consortium for more than $37 million over five years, pending the availability of funds, with $750,000 in co-funding from the Department of Health and Human Services.

"This consortium will provide an integrated, collaborative program to support cutting edge research to identify the root causes of stillbirth and inform evidence-based strategies to address stillbirth risks," said Alison Cernich, Ph.D., acting director of NIH's Eunice Kennedy Shriver National Institute of Child Health and Human Development. "Too many families needlessly face the grief of stillbirth."

People who have experienced stillbirth are almost five times as likely to experience another stillbirth or other pregnancy associated complication. The rate of stillbirth is considerably higher among Black, American Indian, and Alaska Native people. About 40% of stillbirths that occur during labor and birth are considered potentially preventable.

The Stillbirth Consortium will consist of four research centers and a data coordinating center.

- The Data Coordinating Center at RTI International, Research Triangle, North Carolina, will facilitate development and implementation of common projects across the research centers and ensure rigor in study data and data sharing. The center will support common data elements, standard measures, and uniform data collection across research centers. The project will be led by Elizabeth McClure, Ph.D., and Carla Bann, Ph.D.
- The University of California San Diego Center for Stillbirth Prevention Center specializes in identifying the causes of placental dysfunction that underlie fetal growth restriction and contribute to stillbirth. The project is led by Mana Parast, M.D., Ph.D., director of the Perinatal Pathology Service; and Cynthia Gyamfi-Bannerman, M.D., chair and professor of obstetrics, gynecology and reproductive services.
- The Collaborative Action for Research to End Stillbirth (CARES) Research Center at Columbia University, New York City, has expertise in electronic health records and artificial intelligence-aided analysis to develop automated algorithms specifically for early identification of stillbirth risk and to develop novel biomarkers of underlying placental dysfunction for predicting stillbirth. The project is led by Uma Reddy, M.D., professor of obstetrics and gynecology; and Xiao Xu, Ph.D., associate professor of reproductive sciences.
- The University of Utah Stillbirth Research Center has expertise in education, bereavement/mental health and advocacy. The center will evaluate decreased fetal movement, stratification of stillbirth risk based on decreased fetal movement, and optimal strategies for managing it. This project is led by Robert Silver, M.D., professor of obstetrics and gynecology, University of Utah Health Sciences Center, Salt Lake City.
- The Nutrition and Outcomes of Reproductive Injury and Stillbirth related Harms (NOURISH) Research Center at Oregon Health & Science University, Portland, has expertise in the role of nutrition, chronic stress, cardiometabolic health, and placental dysfunction to identify promising interventions aimed at reducing preventable stillbirth. This project is led by Karen Gibbins, M.D., assistant professor of obstetrics and

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gynecology; and Leslie Myatt, Ph.D., professor and director of perinatal research.

"Patient safety from the start!" — WHO urges global investment in safe paediatric and newborn care

NEWS PROVIDED BY

World Health Organization

By WHO Media Team

Study: **"Patient safety from the start!" — WHO urges global investment in safe paediatric and newborn care**

Current as of September 17, 2025

Every child deserves safe, quality health care – from the very beginning. Yet, millions of children around the world are still being failed by health systems that are not designed or equipped to meet their unique needs. On World Patient Safety Day 2025, WHO is calling for urgent global action to protect children from unsafe care, under the slogan, "Patient safety from the start!"

This year's campaign shines a spotlight on paediatric safety, emphasizing that ensuring safe care for newborns and children is not just a health priority – it is a cornerstone of achieving universal health coverage (UHC). Unsafe care is a silent crisis that disproportionately affects children and newborns, contributing to millions of preventable deaths each year.

Why paediatric safety is essential for UHC

Children's rapid development, dependency on caregivers, and vulnerability to environmental and social determinants of health make them uniquely susceptible to harm in health-care settings. Safe, age-appropriate, and child-centred care is essential to ensure that every child can survive and thrive.

On too many occasions, children face unsafe care due to under-resourced facilities, insufficiently supported health workers, inadequate safety systems and poor family engagement. These gaps not only lead to avoidable deaths and disabilities but also undermine public trust and increase the burden on health systems.

The burden of unsafe paediatric care

Unsafe care is a leading contributor to child mortality and long-term disability, especially in the early stages of life. Reviews of paediatric care reveal a troubling reality: harmful incidents are widespread, affecting up to one in two children admitted to hospital wards. In intensive care units, the rates are even more alarming, with some studies reporting harm in up to nine in ten children, though these figures vary across contexts and methodologies.

The most common causes of harm include:

- medication errors
- diagnostic errors
- health care-associated infection
- surgical complications, and
- incidents related to medical devices.

Children with special medical needs or those dependent on medical technology are particularly vulnerable, facing significantly higher risks of adverse events.

The WHO Global Patient Safety Action Plan 2021–2030 identifies paediatric safety as a critical area for intervention, emphasizing that preventable harm in early life stages contributes significantly to child mortality and undermines long-term health outcomes and system resilience.

Unsafe care doesn't just result in immediate harm. It can lead to lifelong disabilities, extended hospital stays, and repeat treatments, placing additional strain on families and health systems. In low-resource settings, the absence of basic infrastructure – such as clean water, sterile equipment, and trained staff—further amplifies these risks. In humanitarian and fragile contexts, even minor safety lapses can have devastating consequences.

This growing body of evidence makes one thing clear: investing in paediatric safety is not only a moral imperative – it is a strategic necessity for building resilient health systems and achieving universal health coverage.

The good news is that over 50% of patient harm is preventable. Investing in paediatric safety saves lives, strengthens health systems and accelerates progress toward UHC. For example:

- improving the quality of care could save up to 1 million newborns annually;
- engaging patients and families in care can reduce harm by up to 15%; and
- safer care reduces costs by preventing complications and reducing hospital stays.

A call to action: safety is a must

To achieve UHC, governments and partners must recognize that safe care for children is is a prerequisite for health equity, resilience, and sustainability.

WHO urges all stakeholders to act:

- Health leaders: Prioritize paediatric safety in national health strategies. Invest in training, infrastructure, and data systems.
- Health workers: Deliver care that is safe, child-centred, and adapted to each child's needs.
- Parents and caregivers: Be active participants in your child's care. Ask questions, stay informed, and speak up.
- Educators: Empower children to understand and engage in their own health care.
- Civil society: Advocate for safe care in all settings, especially in underserved and crisis-affected communities.

From birth through childhood, every child deserves a safe start. Let's make paediatric safety a global priority because universal health coverage begins with safe care for the youngest among us.

Bridging global guidance and local action for maternal and newborn health

NEWS PROVIDED BY

World Health Organization

By WHO Media Team

Study: **Bridging global guidance and local action for maternal and newborn health**

Current as of September 3, 2025

Recognizing that quality postnatal care is essential not only to prevent maternal and newborn deaths but also to support positive physical, emotional and psychological health and well-being, the World Health Organization (WHO) and the United Nation's Special Programme in Human Reproduction (HRP) are working together to close the gap between global recommendations and real-world implementation.

At the heart of this effort are WHO's updated recommendations for antenatal, intrapartum and postnatal care, which emphasize not only quality of clinical care but also the importance of a positive experience for women and newborns. Yet, translating these recommendations into practice remains a challenge. To address this, WHO and HRP have developed a suite of implementation tools designed to support countries in adapting global guidance to their specific contexts.

Among these tools are two comprehensive implementation toolkits: one for adapting antenatal care and postnatal care recommendations into national guidelines, and another for implementing intrapartum care and immediate postnatal care recommendations at the facility level. These toolkits guide users through participatory, stepwise processes to identify local needs, assess barriers and enablers and prioritize actions. They include resources such as a baseline assessment and decision support template, case studies and a menu of indicators aligned with global monitoring frameworks.

To further support countries, WHO and HRP have also introduced Digital Adaptation Kits (DAKs) for antenatal care and postnatal care. These kits translate WHO's recommendations into formats that can be incorporated within the existing digital systems health workers use, such as electronic medical records and decision support tools. This, in turn, offers an opportunity for reinforcing adherence to WHO's recommendations through growing investments in digital health.

A DAK for intrapartum care is also under development.

WHO and HRP remain committed to supporting evidence-based, digitally enabled maternal and newborn care. Together, they are helping countries move from policy to practice – and from promise to progress – to promote healthy beginnings and hopeful futures.

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Use the Right Words

I was exposed to substances in utero. I am not an addict. And my parent may or may not have a Substance Use Disorder (SUD).

Treat Us as a Dyad

Parents and babies need each other. Help us bond. Whenever possible, provide my care alongside my parents and teach them how to meet my needs.

Support Rooming-In

Babies like me do best in a calm, quiet, dimly-lit room where we can be close to our caregivers.

Promote Kangaroo Care

Skin-to-skin care helps me stabilize and self-regulate. It helps relieve the autonomic symptoms associated with withdrawal, promotes bonding, and helps me sleep.

Try Non-Pharmacological Care

Help me self-soothe. Swaddle me snugly in a flexed position that reminds me of the womb. Offer me a pacifier to suck on. Protect my sleep by "clustering" my care.

Provide Lactation Support

Human milk is important to my gastrointestinal health and breastfeeding is recommended when my parent is HIV-negative and receiving medically-supervised care. Help my family reach our pumping and feeding goals.

Treat My Symptoms

If I am experiencing signs of withdrawal that make it hard for me to eat, sleep, and be soothed, create a care plan to help me wean comfortably.

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2024

Protecting your baby and family from

Respiratory Viruses:

What parents need to know this RSV and flu season

Like COVID-19, RSV (Respiratory Syncytial Virus) and flu affect the lungs and can cause serious breathing problems for children and babies. Talk to your family about the risks.

Certain diagnoses can make children and babies more vulnerable for serious complications from respiratory viruses - including prematurity, chronic lung disease, and heart conditions.

You can limit the spread of viruses by wearing a mask, washing your hands with soap & water, using an alcohol-based hand sanitizer, and getting vaccinated.

The fewer germs your baby is exposed to, the less likely they are to get sick. Let people know you need their help to stay well. Limit visitors. Avoid crowds. Stay away from sick people.

Immunizations save lives. Stay up-to-date with your family's flu vaccinations and COVID-19 boosters. This helps our community stay safe by stopping the spread of deadly viruses.

Babies older than 6 months can get a flu shot and COVID-19 vaccinations. Now there are new vaccines for RSV for adults and antibody shots for babies that can help protect them.

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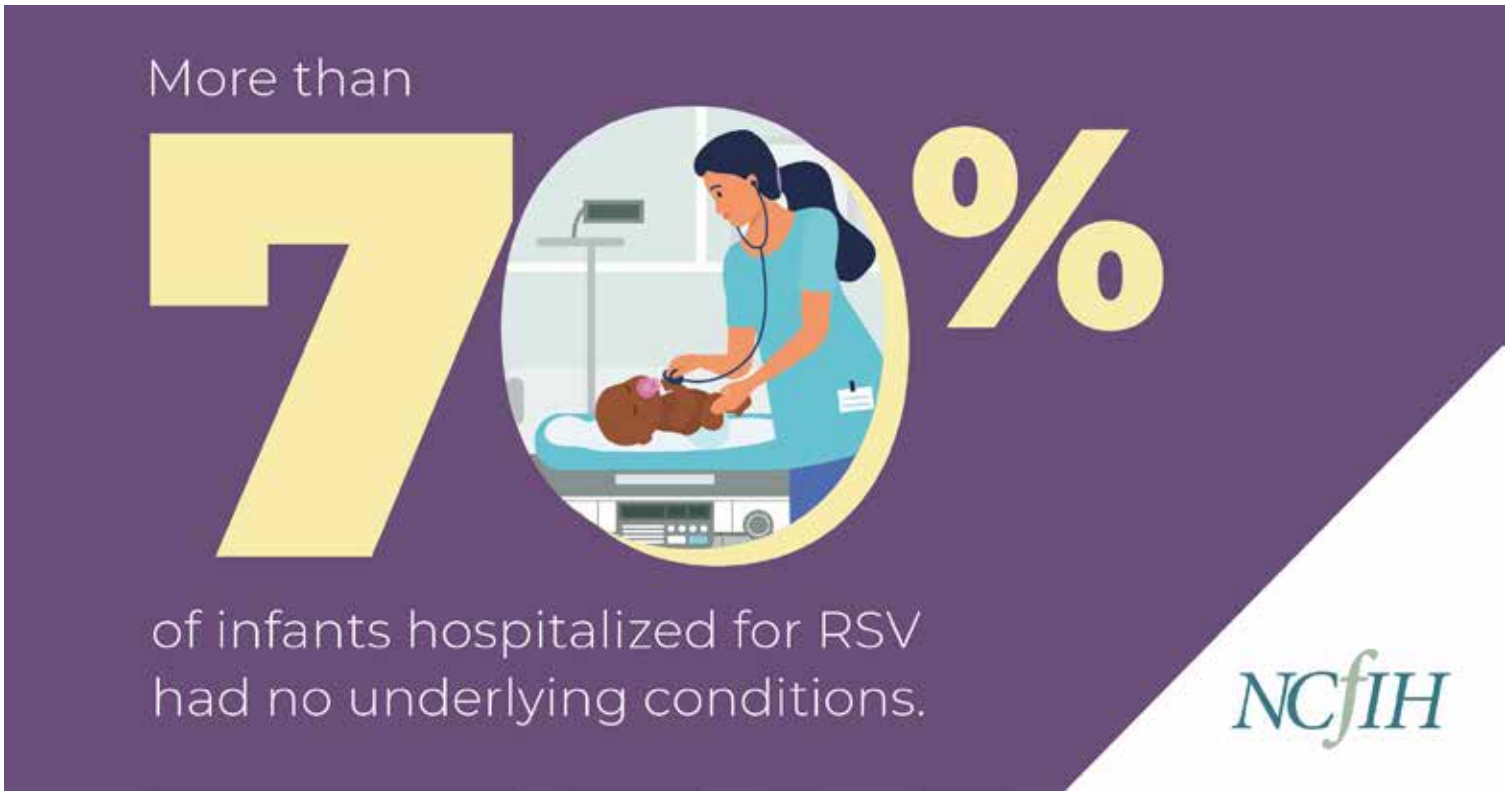

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Distal Trisomy 5q Syndrome Presenting with Cardiac Anomaly, Ventriculomegaly, and Anorectal Malformation

Hua Wang, MD, PhD, FACMG, DBOM

Abstract

Background: *Distal trisomy 5q is a rare chromosomal anomaly caused by partial duplication of the distal long arm of chromosome 5. Reported features include short stature, developmental delay, craniofacial dysmorphism, congenital heart defects, ventriculomegaly, and other multisystem findings.* ***Case Presentation:*** *We describe a female infant born with growth restriction, coarctation of the aorta, bicuspid aortic valve, ventriculomegaly, laryngomalacia, and an anteriorly placed anus. Chromosomal microarray identified a 31.7-Mb duplication of 5q32–q35.3; karyotype confirmed an unbalanced translocation between chromosomes 5 and 9.* ***Conclusion:*** *This case broadens the phenotypic spectrum of distal trisomy 5q and highlights the importance of early chromosomal microarray analysis and genetic counseling in neonates with multiple congenital anomalies, particularly when a parental balanced translocation is suspected.*

Introduction:

Distal trisomy 5q syndrome is a rare chromosomal disorder resulting from the duplication of the distal long arm of chromosome 5, most commonly involving the region 5q31 to qter. The clinical phenotype is broad and variable but typically includes short stature, intellectual disability, craniofacial dysmorphism, congenital heart defects, ventriculomegaly, skeletal anomalies, and genital malformations (1–3). The severity and spectrum of features depend on the size and location of the duplicated segment. Larger duplications (e.g., 5q32–q35.3) are associated with multisystem involvement—particularly cardiac and craniofacial anomalies—whereas smaller duplications (e.g., 5q15–q23.2) often result in milder phenotypes such as speech delay, microcephaly, or subtle dysmorphisms (1–3).

"Distal trisomy 5q syndrome is a rare chromosomal disorder resulting from the duplication of the distal long arm of chromosome 5, most commonly involving the region 5q31 to qter."

Unbalanced chromosomal translocations, including t(5;9), are a recognized mechanism for partial trisomy 5q and often arise from familial balanced rearrangements (4–6). Cardiac malformations and ventriculomegaly are frequently reported neonatal findings; anorectal malformations are less common but have been associated with distal 5q duplications (2, 11). The American Academy of Pediatrics recommends chromosomal microarray and karyotyping as first-line investigations for infants with multiple congenital anomalies and suspected chromosomal imbalance (8). Contemporary genomic workflows—incorporating microarray and, when indicated, exome sequencing—have improved diagnostic yield in neonates with complex phenotypes (12).

We report an infant with a 31.7-Mb duplication spanning 5q32–q35.3 due to an unbalanced t(5;9). The neonatal presentation included congenital heart disease, ventriculomegaly, feeding difficulties, and an anteriorly placed anus, adding to the limited literature on distal trisomy 5q and highlighting atypical neonatal features.

"We report an infant with a 31.7-Mb duplication spanning 5q32–q35.3 due to an unbalanced t(5;9). The neonatal presentation included congenital heart disease, ventriculomegaly, feeding difficulties, and an anteriorly placed anus, adding to the limited literature on distal trisomy 5q and highlighting atypical neonatal features."

Case Description:

The patient, a term female neonate, was evaluated in the NICU two weeks after delivery for multiple congenital anomalies and poor growth. She was born at $37^{5}/_{7}$ weeks by spontaneous vaginal delivery after a pregnancy notable for maternal class III obesity and prenatal concern for intrauterine growth restriction with possible left-sided obstructive cardiac lesions. Birth measurements were small for gestational age (weight: 2.31 kg, length: 43 cm, head circumference: 30.5 cm), and Apgar scores were 7 and 9 at 1 and 5 minutes, respectively. Postnatal echocardiography confirmed coarctation of the aorta with a bicuspid aortic valve

"She was born at $37^{5}/_{7}$ weeks by spontaneous vaginal delivery after a pregnancy notable for maternal class III obesity and prenatal concern for intrauterine growth restriction with possible left-sided obstructive cardiac lesions. Birth measurements were small for gestational age (weight: 2.31 kg, length: 43 cm, head circumference: 30.5 cm)"

showing mild stenosis and a small secundum atrial septal defect; supraventricular tachycardia was documented intermittently. Brain imaging demonstrated mild ventriculomegaly. Laryngomalacia was diagnosed in the setting of inspiratory stridor. An anteriorly placed anus was noted on examination. Feeding was difficult, with inadequate oral intake and poor weight gain despite intensive support; tube-assisted feeds were initiated with plans for longer-term enteral support if needed. Family history was significant on the maternal side for congenital anomalies: one maternal aunt with anencephaly; a maternal uncle described as "missing chromosomes and ribs" who died neonatally; another maternal uncle with an atrial septal defect; and a maternal cousin reportedly carrying a 5;9 translocation. On the paternal side, the grandmother had a cleft lip. There was no known consanguinity. Genetic testing was ordered following the initial evaluation to investigate further the suspected chromosomal etiology (see the separate section for details on genetic testing).

"Postnatal echocardiography confirmed coarctation of the aorta with a bicuspid aortic valve showing mild stenosis and a small secundum atrial septal defect; supraventricular tachycardia was documented intermittently. Brain imaging demonstrated mild ventriculomegaly. Laryngomalacia was diagnosed in the setting of inspiratory stridor. An anteriorly placed anus was noted on examination."

At approximately six months of age, the infant returned for outpatient follow-up after discharge from her prolonged NICU hospitalization. She remained markedly growth-restricted and gastrostomy-tube-**dependent,** taking only small oral volumes intermittently. Cardiology continued to monitor the coarctation and bicuspid valve stenosis; no surgery had been performed to date, and ventricular function remained preserved. No seizures were reported. Repeat neuroimaging showed **stable mild ventriculomegaly** without signs of raised intracranial pressure. Laryngomalacia persisted but was clinically manageable. Neurodevelopmental progress was limited. She had developed head control and brief supported sitting, but was not yet rolling or reaching. She grasped objects when placed in her hands and showed appropriate social engagement, smiling and babbling. A newborn hearing screen performed later in infancy was abnormal; repeat audiology testing was planned. She was referred to an Early Start program for physical, occupational, and speech therapies. The clinical picture—a constellation of **growth restriction, left-sided obstructive cardiac disease with bicuspid aortic valve, ventriculomegaly, laryngomalacia, feeding failure requiring G-tube, global developmental delay, and an anteriorly placed anus**—remained most consistent with an underlying chromosomal duplication syndrome.

"The clinical picture—a constellation of growth restriction, left-sided obstructive cardiac disease with bicuspid aortic valve, ventriculomegaly, laryngomalacia, feeding failure requiring G-tube, global developmental delay, and an anteriorly placed anus—remained most consistent with an underlying chromosomal duplication syndrome."

Genetic Testing and Findings:

A genetic evaluation was initiated shortly after birth. Chromosomal microarray (July 25, 2024) identified a pathogenic duplication, arr(GRCh37)5q32q35.3(149,008,521_180,698,364)x3, consistent with distal trisomy 5q. Conventional cytogenetics confirmed an unbalanced translocation, 46, XX, der(9)t(5;9)(q33;p24). These results confirmed the diagnosis of distal trisomy 5q resulting from an unbalanced translocation. To evaluate additional contributors, an Invitae congenital heart disease panel (July 2024) identified variants of uncertain significance in *FREM1*, *MYH14*, and *MYRF* that were not explanatory. Mitochondrial genome sequencing (September 2024) revealed variants of uncertain significance in *MT-RNR2* and *MT-CO1*, which had no clinical impact. Rapid trio exome sequencing later in 2024 confirmed the 5q32–q35.3 duplication and found no additional pathogenic variants. Segregation analysis was pursued but was incomplete due to an insurance issue. The family history of 5;9 abnormalities raises suspicion for a maternal balanced translocation carrier. Parental karyotyping has been recommended to determine whether the duplication is inherited or de novo; recurrence risk is estimated at up to 10–15% if a balanced parental translocation is identified (5).

"Conventional cytogenetics confirmed an unbalanced translocation, 46, XX, der(9)t(5;9)(q33;p24)."

Management and Outcome:

Since birth, the patient has been managed by a multidisciplinary team. Cardiology has monitored coarctation of the aorta, a bicuspid aortic valve, and supraventricular tachycardia, all of which are stable without surgical intervention. Feeding difficulty has been the major challenge; she remains gastrostomy-tube dependent with limited oral intake and growth below the first percentile. Neurology has followed stable ventriculomegaly without seizures. Developmental delay is most prominent in motor skills; early intervention services are in place. Hearing screening results were abnormal; repeat testing is pending, and ophthalmology follow-up is advised due to the potential risks of visual involvement. Genetic counseling addressed the diagnosis and recurrence

considerations; parental karyotyping is planned. At six months, the patient is clinically stable, with gradual developmental progress, but persistent feeding difficulties and growth restriction persist.

Discussion:

Distal trisomy 5q is a rare duplication syndrome first described in the 1970s; fewer than 50 well-documented cases are known to exist (4). The phenotype varies with the duplicated interval but typically includes growth restriction, craniofacial dysmorphism, intellectual disability, congenital heart disease, hypotonia, and skeletal or genitourinary anomalies (1–3,5–7). Pathogenesis reflects increased dosage of genes within the duplicated segment, disrupting pathways for cardiac morphogenesis, neurodevelopment, and craniofacial formation (1–3). Duplications involving 5q32–q35.3—such as the 31.7-Mb duplication in this patient—encompass multiple dosage-sensitive genes and are frequently associated with complex cardiac malformations, ventriculomegaly, and feeding difficulties in the neonatal period (1–3, 6, 7).

"Pathogenesis reflects increased dosage of genes within the duplicated segment, disrupting pathways for cardiac morphogenesis, neurodevelopment, and craniofacial formation. Duplications involving 5q32–q35.3—such as the 31.7-Mb duplication in this patient—encompass multiple dosage-sensitive genes and are frequently associated with complex cardiac malformations, ventriculomegaly, and feeding difficulties in the neonatal period."

Across published cases, growth restriction, congenital heart defects—including conotruncal and left-sided obstructive lesions, such as coarctation of the aorta and bicuspid valve—and global developmental delay are common neonatal findings (1–3, 5–7). Ventriculomegaly is also reported and likely reflects abnormal neurodevelopment related to gene-dosage effects (2,6). Our patient contributes to the literature by documenting an anteriorly placed anus, which is uncommon in distal trisomy 5q (2,11). Because maternal obesity is an independent risk factor for anorectal malformations (10), this association may be coincidental; however, large duplications could broaden the phenotypic spectrum.

The duplicated 5q32–q35.3 interval contains several genes with key developmental roles. *NSD1* (5q35.3) is dosage-sensitive: haploinsufficiency leads to Sotos syndrome, whereas increased dosage has been linked to short stature, microcephaly, and neurodevelopmental abnormalities (1–3). *FGFR4* within this region participates in skeletal and craniofacial development and may contribute to limb/craniofacial anomalies (2). *NKX2-5*, a critical cardiac transcription factor, is associated with congenital heart disease; both gain and loss of function disrupt cardiac morphogenesis in functional studies (9). Distal trisomy 5q typically results from large duplications detected by microarray or karyotype and often arises from unbalanced translocations such as t(5;9) (4–6). Recurrence risk depends on whether a parent carries a balanced translocation; if so, the risk of unbalanced offspring is estimated at 10–15% (5). Parental testing is therefore essential for counseling (8).

"The duplicated 5q32–q35.3 interval contains several genes with key developmental roles. NSD1 (5q35.3) is dosage-sensitive...increased dosage has been linked to short stature, microcephaly, and neurodevelopmental abnormalities. FGFR4 within this region participates in skeletal and craniofacial development and may contribute to limb/craniofacial anomalies. NKX2-5, a critical cardiac transcription factor, is associated with congenital heart disease; both gain and loss of function disrupt cardiac morphogenesis in functional studies."

No disease-specific therapy exists for distal trisomy 5q. Care is supportive and multidisciplinary, targeting congenital heart disease, feeding and growth difficulties, and developmental delay. In this patient, a gastrostomy tube supports nutrition; cardiology surveillance and early intervention services continue. Emerging genomic approaches may eventually offer targeted options, but none are currently available.

Conclusion:

An unbalanced t(5;9) causing a 31.7-Mb duplication of 5q32–q35.3 produced a neonatal presentation of growth restriction, complex congenital heart disease, ventriculomegaly, and feeding difficulties, while documenting an anteriorly placed anus as a possible uncommon association. The report emphasizes the consideration of distal trisomy 5q in neonates with multiple anomalies, the use of chromosomal microarray as a first-line test, and the performance of parental karyotyping to clarify recurrence risk. Early genomic testing and family-centered genetic counseling are crucial for diagnosis, management, and risk assessment of recurrence.

Take-Home Messages:

Prioritize chromosomal microarray in neonates with multiple anomalies to detect rare duplication syndromes such as distal trisomy 5q.

Perform a multisystem evaluation, with particular attention to cardiac, neurologic (including ventriculomegaly), and feeding/growth issues.

Elicit detailed family history and obtain **parental karyotypes**; a balanced translocation may confer a recurrence risk up to 10–15% (5).

Utilize coordinated multidisciplinary care (including cardiology, gastroenterology, neurology, audiology, and therapies) to optimize outcomes.

Document atypical findings (e.g., anorectal malformations) to help refine the phenotypic spectrum and aid neonatal recognition.

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Reducing Risk Through Connection: Community-Led Safe Sleep Education in the Neonatal Intensive Care Unit (NICU)

Destiny Stokes, MPH, Ama Atiedu, Mattie F. Wolf, MD, MSc

The National Perinatal Association (NPA) is an interdisciplinary organization that strives to be a leading voice for perinatal care in the United States. Our diverse membership is comprised of healthcare providers, parents & caregivers, educators, and service providers, all driven by their desire to give voice to and support babies and families at risk across the country.

Members of the NPA write a regular peer-reviewed column in Neonatology Today.

Introduction:

Since 2020, the rate of Sudden Unexpected Infant Death (SUID) in the United States (US) has been increasing, reaching approximately 3,700 deaths (100.9 per 100,000 live births) in 2022. (1) SUID includes sudden infant death syndrome (SIDS), accidental suffocation and strangulation in bed (ASSB), and other deaths from unknown causes. Although SUID rates decreased by 44% from 1990 to 1998, progress has since slowed, with only a 7% decline from 1999 to 2015. (2) Pronounced racial inequities also persist. In 2022, the US SUID rate among non-Hispanic Black infants was 244.0 per 100,000 live births, nearly three times higher than the rate of 83.2 per 100,000 among non-Hispanic White infants. Preterm infants are also at increased risk. Research shows that SUID rates are highest among infants born extremely prematurely, with 268.0 deaths per 100,000 live births for those born at 24 to 27 weeks' gestation compared to 51.0 per 100,000 for full-term infants born at 39 to 42 weeks. (3) These trends underscore the heightened vulnerability of preterm infants and the critical need for targeted safe sleep education and support.

"Since 2020, the rate of Sudden Unexpected Infant Death (SUID) in the United States (US) has been increasing, reaching approximately 3,700 deaths (100.9 per 100,000 live births) in 2022."

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Many SUID cases are preventable through safe sleep practices, appropriate infant product use, and breastfeeding. (4) However, significant barriers exist, including misinformation, limited access to culturally appropriate resources, and the delivery of safe sleep messages that do not resonate with the lived experiences of families. These barriers remain especially prevalent in communities most affected by SUID, and traditional health education models often fall short in reaching families facing structural or informational barriers. (5, 6) The *Let's Talk Community Chats* program was developed to address these barriers by providing culturally responsive, community-based education on safe sleep and infant care, leveraging trusted community members to deliver accessible, nonjudgmental guidance. The *Let's Talk* initiative integrates infant care education into familiar community settings, offering a care model that reaches families where they naturally convene. The key components of the program include:

"Many SUID cases are preventable through safe sleep practices, appropriate infant product use, and breastfeeding"

- Community-Integrated Events: Monthly gatherings held in retail stores and community centers where families already congregate, facilitating easy and accessible participation.
- Culturally Responsive Facilitation: Trusted community members, including doulas, lactation consultants, grandparents, and fathers, lead conversations and share practical guidance, drawing on personal and professional experiences to make information accessible, respectful, and grounded in families' real-life needs.
- Practical Support: Free resources, including swaddles, diapers, infant feeding pillows, and access to local social services, are provided to reduce barriers to safe infant care.
- Evidence-Based Training: Facilitators receive training from First Candle on the American Academy of Pediatrics (AAP) safe sleep guidelines (4) and breastfeeding support, ensuring that participants receive accurate,

research-backed advice. Those recommendations include:

- Back to sleep for every sleep
- A firm, flat, non-inclined sleep surface to reduce the risk of suffocation or wedging/entrapment
- Feeding of human milk, which is associated with a reduced risk of SIDS, exclusively for the first six months
- Having infants sleep in the parents' room and close to their bed, but on a separate surface designed for infants, for at least the first six months.

A pilot program conducted in Atlanta from April to August 2024 demonstrated high community engagement and positive behavior changes, particularly among non-Hispanic Black participants. For example, adherence to placing infants on their backs for sleep increased from 40% to 60%, and the percentage of families keeping soft objects out of the sleep area rose from 40% to 70%, based on follow-up surveys measuring changes from one week to one month.

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Several key insights emerged from the pilot phase of *Let's Talk Community Chats*:

- Community Trust Drives Engagement: 98% of participants reported feeling comfortable engaging with facilitators, underscoring the importance of culturally relevant educators in fostering trust and participation.
- Accessibility Matters: 96% of participants found the events easy to attend, suggesting that hosting discussions in everyday community locations encourages participation and accessibility.

NICU Expansion :

Because preterm infants are at increased risk for SUID, the American Academy of Pediatrics recommends that families receive infant safe sleep education during the hospital course to help prepare them for the transition to a safe home sleep environment. (7) Recognizing this increased vulnerability and need, the *Let's Talk* program was expanded to focus on families in the NICU following the initial pilot.

"Because preterm infants are at increased risk for SUID, the American Academy of Pediatrics recommends that families receive infant safe sleep education during the hospital course to help prepare them for the transition to a safe home sleep environment."

NICU families are encouraged to attend monthly gatherings held in a dedicated space within the NICU. These sessions are facilitated by three First Candle-trained facilitators: a doula or lactation consultant, a grandparent, and a father. While essential resources, such as bassinets, swaddles, diapers, and informational handouts, are provided, conversations often extend beyond infant safe sleep to include topics like housing, mental health, and breastfeeding. Initial results have been quite promising.

Between January and April 2025, 23 mothers/birth givers and four fathers/support persons participated in a *Let's Talk* event and completed a post-event survey. The majority of respondents identified as non-Hispanic Black (89%) and were between the ages of 26 and 35 (44%).

"All participants (100%) reported increased confidence in applying safe sleep practices and found the breastfeeding information provided to be helpful or very helpful. Additionally, all respondents (100%) believed that the products and recommendations shared were relevant to their needs."

Participant responses to the event were highly favorable. Notably, 90% indicated they would attend future *Let's Talk* events. As shown in Figure 1, 93% reported feeling comfortable and supported and stated that facilitators respected their cultural values. Among participants who had specific questions, 91% felt their concerns were fully addressed. All participants (100%) reported increased confidence in applying safe sleep practices and found the breastfeeding information provided to be helpful or very helpful. Additionally, all respondents (100%) believed that the products and recommendations shared were relevant to their needs.

Participant qualitative feedback further underscored the program's value. One attendee commented, *"Love this! Wish every parent could attend!"* When asked how the event influenced their plans for infant sleep, participants shared:

Figure 1: Participants' Feedback on Let's Talk Events

- *"Helped put my mind at ease and confirmed the answer to some questions I had in mind."*
- *"I learned a lot today. I am grateful for the knowledge for safe sleep with my baby."*
- *"Just confirms that I need to put my baby to sleep in a safe area and gave me more facts I didn't know."*

As shown in Figure 2, 89% of respondents reported having a plan for where their baby would sleep upon discharge. Of those with a plan, 83% stated that the event influenced their planning. All reported that their intended sleep space would be a crib, bassinet, or pack 'n' play, and all shared that they would keep the sleep area free of pillows, toys, and bumpers. Additionally, 96% of participants planned to place their baby on their back for sleep. However, 8% of participants indicated they would still include blankets, highlighting an opportunity for additional education.

As shown in Figure 3, when asked, "What new information about safe sleep did you learn at the *Let's Talk* event?", 73% of participants reported learning that babies should always be placed on their backs to sleep. Other key learnings included the importance of keeping soft objects out of the sleep area (46%) and that infants should sleep in a separate area from adults (41%). Fewer participants reported learning that pacifier use may reduce the risk of SIDS (35%) or that infants should sleep

"Of those with a plan, 83% stated that the event influenced their planning. All reported that their intended sleep space would be a crib, bassinet, or pack 'n' play, and all shared that they would keep the sleep area free of pillows, toys, and bumpers. Additionally, 96% of participants planned to place their baby on their back for sleep."

Figure 2: Participants' Safe Sleep Plans

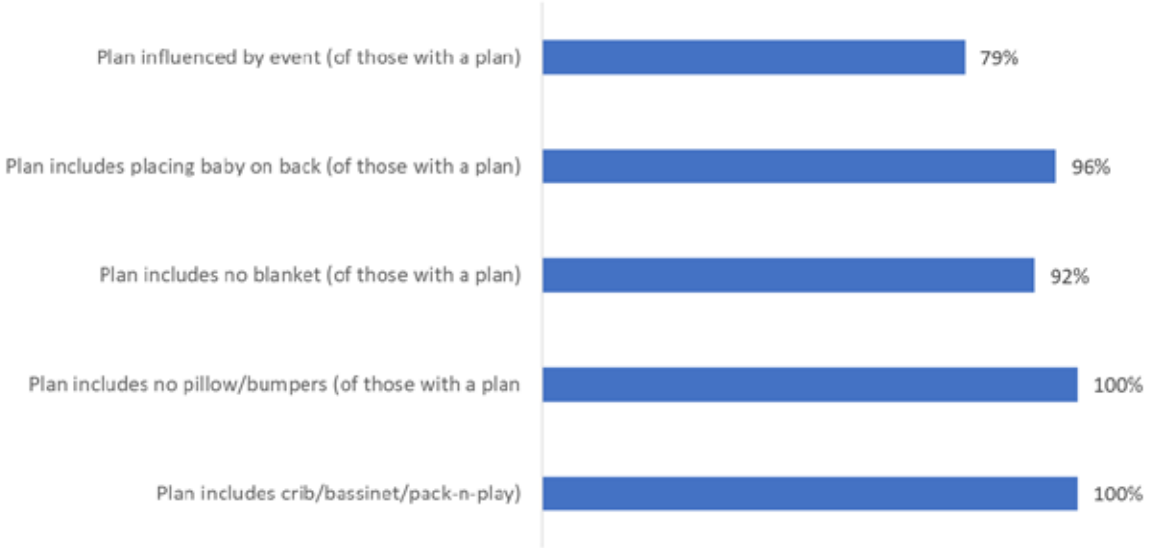
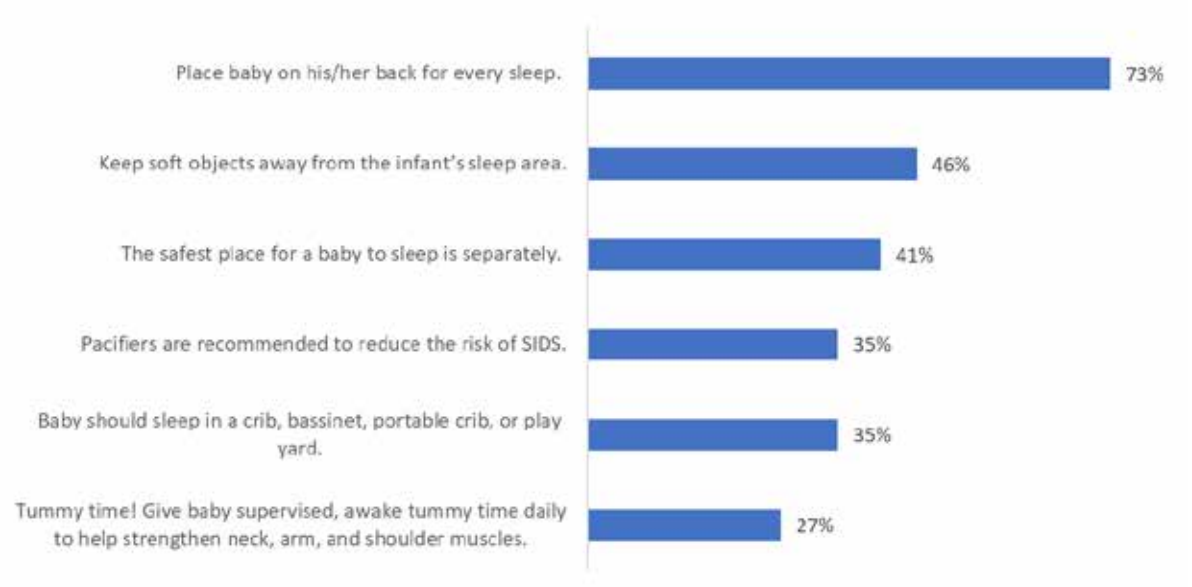


Figure 3: New Information about Safe Sleep



in a crib, bassinet, or other designated safe space (35%). Some participants also learned about the benefits of tummy time (27%) and the importance of regular prenatal care (12%), indicating opportunities for continued education and reinforcement.

"Participants found several aspects of the event especially valuable. The most frequently cited was education on safe sleep practices, specifically the ABCs of safe sleep, proper sleep positioning, and appropriate items for a baby's sleep space. Many participants also appreciated the breastfeeding guidance, while others highlighted information on infant brain development."

Participants found several aspects of the event especially valuable. The most frequently cited was education on safe sleep practices, specifically the ABCs of safe sleep, proper sleep positioning, and appropriate items for a baby's sleep space. Many participants also appreciated the breastfeeding guidance, while others highlighted information on infant brain development. Reflecting on what they found most valuable, participants shared:

- *"Openness about any questions and very positive."*
- *"Fantastic presentation with good anecdotal evidence!"*

Several responses expressed gratitude for the open and supportive environment, as well as the general advice shared by the facilitators. Finally, participants valued the practical resources and actionable tips they could apply at home.

Implications for Practice:

The findings from the *Let's Talk* NICU program underscore an important consideration for perinatal and neonatal health education: the need to meet families where they are, physically, culturally, and emotionally. This approach is particularly relevant for NICU families, who often experience significant stress due to their circumstances. (8) Bringing education to them helps reduce barriers to learning and engagement.

"The findings from the* Let's Talk *NICU program underscore an important consideration for perinatal and neonatal health education: the need to meet families where they are, physically, culturally, and emotionally. This approach is particularly relevant for NICU families, who often experience significant stress due to their circumstances. Bringing education to them helps reduce barriers to learning and engagement."

Embedding education into trusted community spaces and clinical settings where families are already present, such as the NICU, can help bridge gaps and build confidence in safe sleep practices. Programs like *Let's Talk* demonstrate that accessible, respectful, and community-informed approaches can enhance family engagement and promote safer infant care practices. When families feel seen, heard, and supported, they are more likely to act on critical health guidance that protects the health and well-being of infants.

The success of *Let's Talk Community Chats* offers potential guidance for adapting and scaling similar initiatives aimed at reducing infant mortality and improving safe sleep practices. Healthcare systems and community-based organizations may consider prioritizing culturally responsive, place-based education models that engage families early, particularly those in historically marginalized or high-risk populations. Integrating safe sleep and infant care education into routine points of contact, including NICUs and community settings, could increase the reach and relevance of these efforts. Improved infant health outcomes may depend on a shift from passive education models to proactive, community-rooted efforts.

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Family Centered Care September Column

Morgan Kowalski

"Equity, Diversity, Inclusion, and Belonging Work Our Equity, Diversity, Inclusion, and Belonging Committee is in the process of authoring a position paper to highlight our organization's commitment to health equity."

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Katrina Moline
Kimberly Novod
Betsy Pilon
Elizabeth Simonton
Alex Zavala

Healthcare Partners

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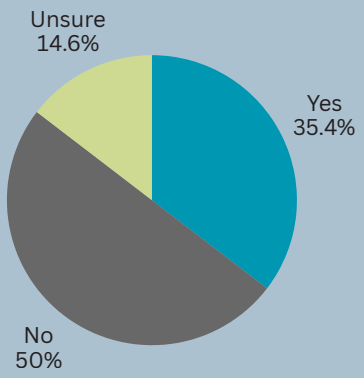
Robert Cicco, MD
Mary Coughlin, MS, NNP, NCC-E
Jessica Daigle, MD
Jessica Fry, MD
Christy Gliniak, PhD, OTR/L, CNT, CPXP, NTMTC
Mitchell Goldstein, MD
Luann Jones, DNP, APRN, NNP-BC, NE-BC
Henry Lee, MD
Lily Lou, MD, FAAP
Kerri Machut, MD
Nicole Nyberg, MSN, APRN, NNP-BC
Dharshi Sivakumar, MD
Vincent Smith, MD, MPH
Kimberly Stobbe, LCSW
Bob White, MD
Emily Whitesel, MD

What is Family-Centered Care in the NICU and why does it matter?
Family-Centered Care in the NICU is a model of care that recognizes **parents and families as essential partners in their baby's health and healing**. Instead of seeing parents as "visitors," family-centered care positions them as core members of the care team, with unique expertise about their child

FCC has been **clinically proven to improve infant health outcomes, parental mental health, and family well-being**. It's directly linked to lower mortality rates, shortened length of stay, and fewer readmissions.

Despite its benefits, **FCC practices still aren't fully adopted in the NICU**. In a survey of 48 NICUs across the US, 65% of respondents said they don't have an FCC Committee in their unit.

Does your NICU currently have an FCC Committee?



Fun Fact
Family Partners **co-design, co-lead, and co-author** our research projects, advocacy work, and quality improvement projects! They are **equally represented** in each of our webinars, office hours sessions, and quarterly newsletter publications.

fcctaskforce.org

FAMILY-CENTERED CARE
TASKFORCE

Organizations Supporting Our Work
55 national & international partners
22 family-led organizations
33 healthcare-based organizations

We are actively seeking State Quality Collaboratives to join our network of support! Email us to learn more.

Our Membership
2,600+ members
49/50 U.S. States & Puerto Rico
9/10 Canadian Provinces
71 Countries
Growth ~100 members/month!

Join us, it's free!

Heard from Members:
"Thank you for all your hard work in engaging NICU teams all around the country on this Taskforce! Our unit has been able to share our FCC team's efforts as well as benefit from the availability of rich information-sharing to help us refine our family-centered care processes in our NICU."

FAMILY-CENTERED CARE TASKFORCE

Our Free Educational Webinars

Learn how clinicians, researchers, and Family Partners are implementing mental health screenings, increasing instances of skin-to-skin care, optimizing neuroprotection, addressing bias, and more.

Fun Fact

Each of our webinars has been recorded and made available on our YouTube Channel. We even post the slides on our website!

Webinar Database

Our Free Monthly Office Hours Sessions

Who? Facilitated by one Healthcare Partner and one Family Partner from our Executive Council and attended by members like you!

What? An informal meeting where members can bring their unit's specific challenges and barriers around implementing family-centered care practices and brainstorm solutions for overcoming them with their peers.

Where? Zoom! These sessions are not recorded so folks can feel safe sharing.

Why? Don't reinvent the wheel! Modify what's worked for other units to suit your own.

Heard from Members: "**Hearing real life experiences is so impactful for us all as clinicians who have never lived in the shoes of NICU families!** Thank you all for your vulnerabilities and sharing so that we can all learn."

Register Here

Our Free Quarterly Newsletter Publications

Authored by a diverse group of healthcare professionals and Family Partners, these are full of actionable and practical takeaways.

All Issues

Fun Fact

Units who print and post our newsletter in their staff spaces report higher success achieving buy-in around FCC practices!

FAMILY-CENTERED CARE TASKFORCE

Advocacy Work

We are in the process of creating a **comprehensive, interactive toolkit based on the 13 recommendations uncovered by the PRESENCE Study**. Each chapter is authored by one healthcare professional and one family partner.

The spark:

The negative impact of restrictive parental presence policies in NICUs during the COVID-19 pandemic.

Rationale

- Hospitals restricted parental access leaving babies without a parent or a support person, even during extreme illness or death.
- Significant variations existed in parental access policies, even in the same city.
- Parents reported higher negative mental health outcomes during the restrictions.

The response:

Co-created best evidence practice recommendations regarding parental presence in NICUs during pandemics caused by respiratory pathogens such as COVID-19.

How we got there:

Consensus Panel: A diverse group of individuals with expertise related to the project.

Values, preferences, and evidence guided our recommendations

Step 1: Gathered impact data (via national surveys) from parent/ caregivers, healthcare providers, and NICU leadership

Step 2: Completed literature review

Step 3: Identified 50 potential recommendation items

Step 4: Conducted two rounds of Delphi surveys. Participants (n=59) rated and ranked each item on importance:

- ***Round 1:*** *Rated 50 items (on scale of 1 – 5)*
- ***Round 2:*** *Ranked the top 20 items of Round 1 (from 1 – 20)*

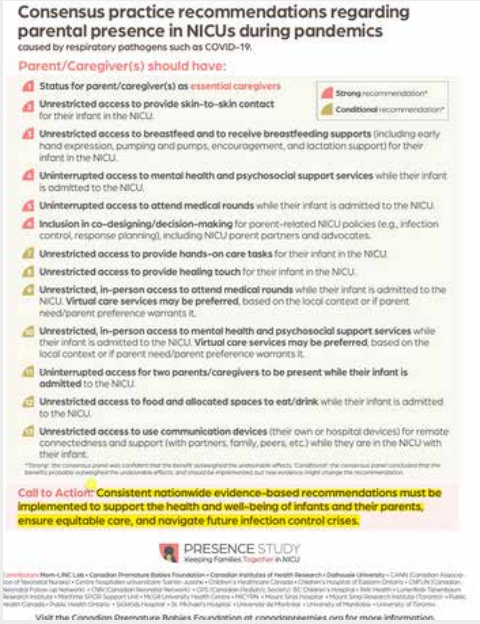
Step 5: Presented rapid **evidence synthesis** of the benefits and potential harms for the top rated items to the consensus panel. Categorized each item as a **Strong** or **Conditional recommendation**, based on strength of evidence and value.

Step 7: Asked panel members: **Do you agree with including this item as a national recommendation?**

Consensus was reached if at least 80% of the panel agreed to add the item

PRESENCE STUDY
Keeping Families Together in NICU

Visit the Canadian Premature Babies Foundation at canadapreemies.org for more information.



Consensus practice recommendations regarding parental presence in NICUs during pandemics

caused by respiratory pathogens such as COVID-19.

Parent/Caregiver(s) should have:

- **Status for parent/caregiver(s) as essential caregivers**
- **Unrestricted access to provide skin-to-skin contact** for their infant in the NICU.
- **Unrestricted access to breastfeed and to receive breastfeeding supports** (including early hand expression, pumping and pumps, encouragement, and lactation support) for their infant in the NICU.
- **Uninterrupted access to mental health and psychosocial support services** while their infant is admitted to the NICU.
- **Uninterrupted access to attend medical rounds** while their infant is admitted to the NICU.
- **Inclusion in co-designing/decision-making** for parent-related NICU policies (e.g., infection control, response planning), including NICU parent partners and advocates.
- **Unrestricted access to provide hands-on care tasks** for their infant in the NICU.
- **Unrestricted access to provide healing touch** for their infant in the NICU.
- **Unrestricted, in-person access to attend medical rounds** while their infant is admitted to the NICU. **Virtual care services may be preferred**, based on the local context or if parent need/parent preference warrants it.
- **Unrestricted, in-person access to mental health and psychosocial support services** while their infant is admitted to the NICU. **Virtual care services may be preferred**, based on the local context or if parent need/parent preference warrants it.
- **Uninterrupted access for two parents/caregivers to be present while their infant is admitted** to the NICU.
- **Unrestricted access to food and allocated spaces to eat/drink** while their infant is admitted to the NICU.
- **Unrestricted access to use communication devices** (their own or hospital devices) for remote connectedness and support (with partners, family, peers, etc.) while they are in the NICU with their infant.

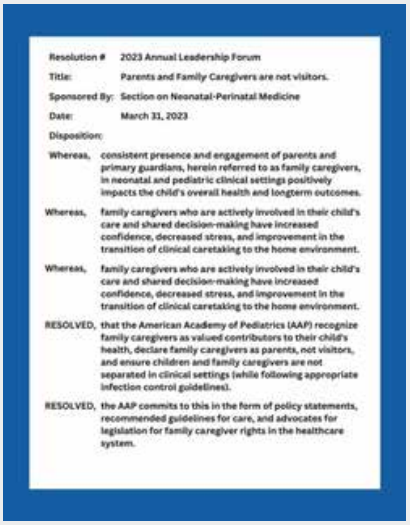
Strong recommendation*
Conditional recommendation*

*"Strong": the consensus panel was confident that the benefit outweighed the undesirable effects. "Conditional": the consensus panel concluded that the benefits probably outweighed the undesirable effects, and should be implemented but new evidence might change the recommendation.

Call to Action: Consistent nationwide evidence-based recommendations must be implemented to support the health and well-being of infants and their parents, ensure equitable care, and navigate future infection control crises.

PRESENCE STUDY
Keeping Families Together in NICU

Visit the Canadian Premature Babies Foundation at canadapreemies.org for more information.



Resolution # 2023 Annual Leadership Forum

Title: Parents and Family Caregivers are not visitors.

Sponsored By: Section on Neonatal-Perinatal Medicine

Date: March 31, 2023

Disposition:

Whereas, consistent presence and engagement of parents and primary guardians, herein referred to as family caregivers, in neonatal and pediatric clinical settings positively impacts the child's overall health and longterm outcomes.

Whereas, family caregivers who are actively involved in their child's care and shared decision-making have increased confidence, decreased stress, and improvement in the transition of clinical caretaking to the home environment.

Whereas, family caregivers who are actively involved in their child's care and shared decision-making have increased confidence, decreased stress, and improvement in the transition of clinical caretaking to the home environment.

RESOLVED, that the American Academy of Pediatrics (AAP) recognize family caregivers as valued contributors to their child's health, declare family caregivers as parents, not visitors, and ensure children and family caregivers are not separated in clinical settings (while following appropriate infection control guidelines).

RESOLVED, the AAP commits to this in the form of policy statements, recommended guidelines for care, and advocates for legislation for family caregiver rights in the healthcare system.

Our Advocacy Committee submitted a resolution to the AAP Leadership Conference titled **"Parents and Family Caregivers are Integral Members of the Patient Care Team"** (#36) supported by the Section on Neonatal-Perinatal Medicine (SoNPM).

Equity, Diversity, Inclusion, and Belonging Work

Our Equity, Diversity, Inclusion, and Belonging Committee is in the process of authoring a **position paper to highlight our organization's commitment to health equity**.

"Silent Signals in the NICU: Ensuring Nonverbal Communication is Family-Centered" Educational Toolkit

Project Timeline: January 2026 – December 2026

Project Description:

Parents of infants in the Neonatal Intensive Care Unit (NICU) face profound emotional and practical challenges, including stress, fear, and uncertainty about their infant's health and their own role in the care process. In such a vulnerable state, every interaction and message from the care environment carries heightened weight. **Silent signals—such as posted signage, institutional policies, bedside visuals, and even the arrangement of the physical environment—often shapes a family's first impression of care and indicates their place within the NICU**. While these tools are designed to inform, organize, and support clinical workflows, **they can unintentionally undermine family-centered care** (FCC) when they emphasize restrictions, highlight barriers, or implicitly discourage parental engagement.

To address this, we are developing a comprehensive, evidence-informed educational toolkit that will set best practices for silent signals in the NICU to ensure all nonverbal communication is family-centered. Authored by 12 members from our Executive Council of multidisciplinary healthcare professionals and family partners (former NICU parents) diverse in their lived experiences and backgrounds, this project will encompass multiple domains:

1) Signage and visual cues that can either welcome and empower families, or discourage their presence and participation at the bedside
2) Auditory cues such as alarms and overhead announcements that affect the emotional tone of the unit
3) Policies that either promote or inadvertently hinder family partnership
4) Physical NICU environment and its accessibility, including tailored provisions for families with non-English language preferences and for parents with disabilities
5) Design and content of the NICU webpage as a gateway to family engagement
6) Staff behaviors and body language in everyday interactions

By creating a unified framework that addresses these diverse but interconnected elements, **we will provide NICUs with actionable strategies to create an environment where every message—spoken or unspoken—reinforces partnership, inclusion, and family-centered care.**

We are seeking funding to support the development, design, and dissemination of this toolkit to ensure nonverbal communication is family-centered across the U.S. and abroad.

Project Components:

1. Dedicated Interactive Webpage on FCC Taskforce Website
2. Introductory and Closing Chapters
3. Six Chapters Aligned with Ensuring Nonverbal Communication is Family-Centered
   a. Written Content
   b. Assessment Tools
   c. Implementation Strategies
4. Resource Library
5. Subject Matter Expert Consultants
6. Robust Toolkit Dissemination

FAMILY-CENTERED CARE TASKFORCE

We're in the early stages of creating a comprehensive educational toolkit titled **"Silent Signals in the NICU: Ensuring Nonverbal Communication is Family-Centered"** which will encompass multiple domains:

1) Signage and visual cues
2) Auditory cues
3) Policies
4) Physical NICU environment & accessibility
5) NICU webpage
6) Staff behaviors and body language

The goal of this project is to provide units with actionable strategies to **ensure every message, spoken or unspoken, reinforces partnership, inclusion, and FCC**.

FAMILY-CENTERED CARE TASKFORCE

2024-2026 Quality Improvement Work

Our aim for 2024-2026 is to use quantitative and qualitative research methodologies to create **metrics for family-centered care in the NICU and to explore FCC practice implementation at a scale that exceeds prior studies.**

99 NICUs around the globe have participated in our comprehensive NICU FCC Measures survey which was developed by multidisciplinary healthcare professionals, researchers, and family partners. 45 NICUs agreed to an interview to discuss their unit's successes and challenges in implementing FCC practices, and in 2026, interview participants will have the opportunity to engage in topic-specific quality improvement work to overcome their unit's unique barriers.

We're grateful to Stanford Impact Labs for supporting our project! Click here to learn more about this work.

7 Categories of NICU FCC Measures Uncovered by FCC Taskforce:

1. NICU Framework/Infrastructure
2. Family Support
3. Family Integration into Care
4. Family Integration into QI & Processes
5. NICU Family Environment
6. Staff Education
7. Process Measures

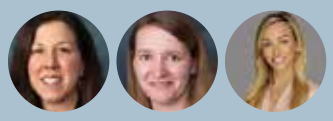
2023 Quality Improvement Work

We are thrilled to share that among the 22 global NICUs participating in our 2023 quality improvement work, we exceeded our goals by **increasing the percentage of units with an active NICU-specific FCC Committee from 18% to 59%, and the percentage of NICUs with an active Family Advisory/Partnership Council from 18% to 45% in just 12 months**! Units who had the most success consistently participated in small group benchmarking opportunities where they were encouraged to share their barriers to implementing FCC practices and brainstorm strategies for overcoming them and attended our free educational webinars while encouraging their colleagues to do the same.

Click here to read an open access manuscript about this project!

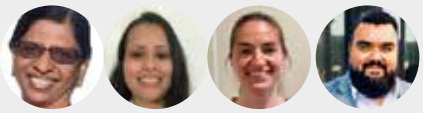
SMALL GROUP 1

Kerri Z. Machut, MD
Lurie Children's Hospital of Chicago
Jessica Fry, MD
Lurie Children's Hospital of Chicago
Elizabeth Simonton, Family Partner
CEO & Co-Founder, ICU Baby



SMALL GROUP 2

Dharshi Sivakumar ,MD
Stanford/El Camino Health NICU
Vargabi Ghei, MD
HCA East Florida Northwest Medical Center
Katherine Huber, Family Partner
FCC Committee, El Camino Health NICU
Alex Zavala, Family Partner
Founder, The NICU Dad and The NICU Dad Podcast

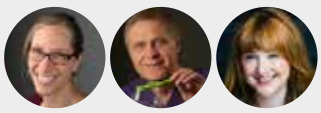


SMALL GROUP 3

Colby Day, MD
University of Rochester Medical Center
Daphna Barbeau, MD
HCA University Hospital Davia
Morgan Kowalski, Family Partner
University of Rochester Medical Center

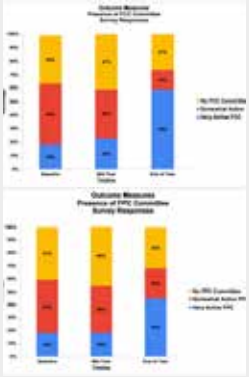
SMALL GROUP 4

Emily Whitesel, MD
Beth Israel Deaconess Medical Center
Robert Cicco, MD
Pennsylvania
Molly Fraust-Wylie, Family Partner
NICU Family Program Manager, Beth Israel Deaconess Medical Center



SMALL GROUP 5

Robert White, MD
Beacon Children's Hospital
Malathi Balasundaram, MD
Stanford/El Camino Health NICU
Keira Sorrells, Family Partner
Founder & Executive Director,
NICU Parent Network
Michelle Wrench, Family Partner
Chair, Family Advisory Committee CPQCC



FAMILY-CENTERED CARE
TASKFORCE

Connect with Us!

Follow and tag us in your FCC-related work so we can easily share!

YouTube | LinkedIn | Bluesky

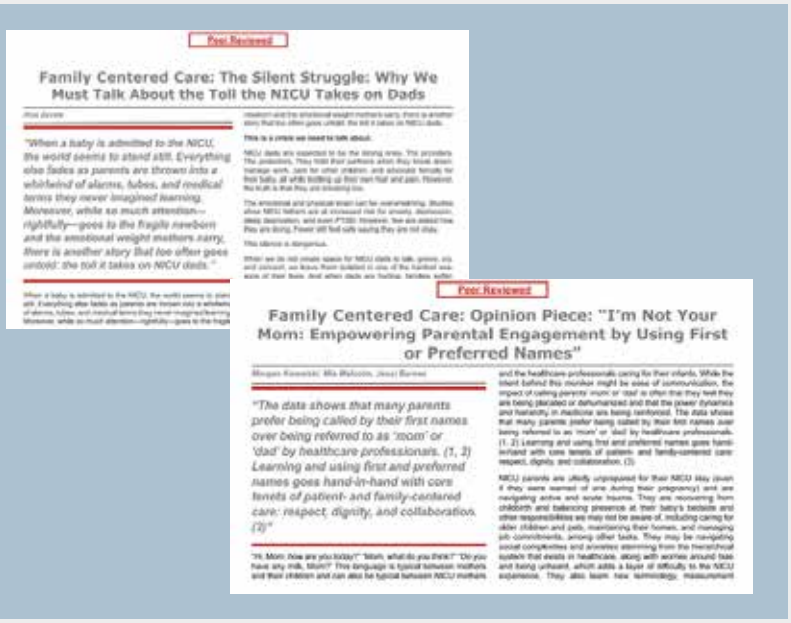
Facebook | Instagram | X

Become a Member | **Visit our Website**

Our Resources tab is full of relevant articles, policies, guidelines, toolkits, videos, podcasts, and more.

Monthly Column

Check out our monthly FCC column in Neonatology Today!


Peer Reviewed

Family Centered Care: The Silent Struggle: Why We Must Talk About the Toll the NICU Takes on Dads

"When a baby is admitted to the NICU, the world seems to stand still. Everything else fades as parents are thrown into a whirlwind of alarms, tubes, and medical terms they never imagined learning. Moreover, while so much attention—rightfully—goes to the fragile newborn and the emotional weight mothers carry, there is another story that too often goes untold: the toll it takes on NICU dads."

Peer Reviewed

Family Centered Care: Opinion Piece: "I'm Not Your Mom: Empowering Parental Engagement by Using First or Preferred Names"

"The data shows that many parents prefer being called by their first names over being referred to as 'mom' or 'dad' by healthcare professionals. (1, 2) Learning and using first and preferred names goes hand-in-hand with core tenets of patient- and family-centered care: respect, dignity, and collaboration. (3)"

Monthly Polls

Submit a question and we'll collect answers from our robust membership!

Submit a Question | **All Polls & Responses**

Previous polls have focused on couplet care, supplemental communication with families, mental health screenings, doula presence, engagement of Family Partners, and more.

Sponsor Us

Support our organization's work with an industry sponsorship at Supporter, Advocate, Champion, or Trailblazer level. Reach out to us to learn more.

Interested in a **focus group** with the FCC Taskforce's Executive Council of Healthcare & Family Partners? Email us!

Generously Supported by Trailblazer Sponsor:

Mead Johnson NUTRITION

FAMILY-CENTERED CARE TASKFORCE

FCC Taskforce Webinar

September 11, 2025

11-12:30pm PT

Screening Now: Standardizing Mental Health Assessments for NICU Parents

Megan Paulsen
MD (she/her)
Neonatologist &
NICU Parent,
Children's Hospital
Minnesota

Sarah Swenson
MD, DPhil, FAAP (she/her)
Assistant Professor,
Division of Neonatology
University of Nebraska
Medical Center
Children's Nebraska

Long-Term Outcomes: Preparing Families for Future Health

Lauren Ingledow
(she/her)
Co-Founder and
Director,
Adult Preemie
Advocacy Network
CIC (APAN)

Michelle M. Kelly
PhD, CRNP, FAANP, FAAN
(she/her)
Professor, Villanova
University, M. Louise
Fitzpatrick College of
Nursing
Pediatric & Neonatal Nurse
Practitioner

Join for Free to Register

FCC Taskforce Program Overview

Generously Supported By:

Mead Johnson NUTRITION

FAMILY-CENTERED CARE TASKFORCE

FCC TASKFORCE OFFICE HOURS

Who? Facilitated by one Healthcare Partner and one Family Partner from our Executive Council and attended by members like you!

What? An informal meeting where members can bring their unit's specific challenges and barriers around implementing family-centered care practices and brainstorm solutions for overcoming them with their peers.

Where? Zoom! These sessions are not recorded so folks can feel safe sharing.

When? 11am Pacific Time / 2pm Eastern Standard Time

Why? Don't reinvent the wheel! Modify what's worked for other units to suit your own.

Register Here

FAMILY-CENTERED CARE TASKFORCE

Pictured: Baby Kole with his Dad

Save the Date!

Join us for the 39th Annual Gravens Conference

"Sensitive Issues in Sensational Times"

New date & location, same great topics, workshops, abstracts, and networking for those who work in Newborn Intensive Care Units.

Come learn with us!

June 16th, 17th, and 18th, 2026

at University of Notre Dame
Notre Dame, Indiana

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Abstracts Due February 15th, 2026

To learn more and register, visit our website:

Peer Reviewed

"Midline" y "Línea Media": Malentendido Clínico que Puede Poner en Riesgo al Paciente

Bibiana Chinea Jiménez, PNP, PhD; Augusto Sola, MD

"El término inglés midline catheter, traducido frecuentemente como "línea media" en español, induce a error conceptual al sugerir una posición anatómica central. Esta confusión semántica no es inocua, y puede conllevar complicaciones clínicas severas si el catéter se utiliza como si fuera un catéter venoso central (CVC), o un PICC (catéter central de inserción periférica), especialmente en pacientes vulnerables como neonatos."

Resumen:

Introducción: *El término inglés midline catheter, traducido frecuentemente como "línea media" en español, induce a error conceptual al sugerir una posición anatómica central. Esta confusión semántica no es inocua, y puede conllevar complicaciones clínicas severas si el catéter se utiliza como si fuera un catéter venoso central (CVC), o un PICC (catéter central de inserción periférica), especialmente en pacientes vulnerables como neonatos.*

Objetivo: *Analizar las consecuencias clínicas del uso erróneo del término "línea media", proponer una alternativa terminológica adecuada y formular recomendaciones prácticas para su uso en contextos neonatales y generales.*

Métodos: *Reflexionar sobre el uso de un término traducido del inglés y sobre el posicionamiento de los catéteres venosos insertados percutáneamente.*

Resultados: *Los estudios demuestran que el catéter venoso periférico intermedio, usado adecuadamente, es una opción segura y efectiva. Sin embargo, cuando se lo interpreta erróneamente como acceso central, podría relacionarse con un aumento de complicaciones como extravasación, trombosis y errores en la administración de fármacos.*

Conclusión: *Proponemos abandonar el uso de "línea media" por "catéter venoso periférico intermedio", término que refleja fielmente la naturaleza, posición y limitaciones del dispositivo. Nombrar con precisión no es un tecnicismo: es una forma de proteger al paciente.*

Introducción

La traducción del término inglés midline catheter al español como "línea media" es técnicamente inexacta y potencialmente peligrosa. En ciencias de la salud, cada término importa. Y cuando un término induce a error, también lo hace la práctica clínica que lo rodea. Es el caso del midline catheter, un dispositivo venoso periférico de posición intermedia cuya traducción al español se ha hecho como "línea media", ha generado un terreno fértil para la confusión clínica.

A diferencia de su nombre, el midline no hace referencia a la "línea media" del cuerpo ni implica una localización anatómica central. Se trata, en cambio, de un acceso periférico, cuya longitud permite alcanzar venas de mayor calibre —como la axilar—, pero sin llegar nunca a las venas centrales. La traducción literal como "línea media" sugiere, erróneamente, que se trata de un acceso central, lo que puede tener consecuencias relevantes cuando el personal sanitario toma decisiones terapéuticas basadas en esta suposición.

Esta ambigüedad resulta especialmente preocupante en el paciente neonatal y pediátrico, donde la fragilidad vascular multiplica los riesgos asociados a errores de acceso. Esta confusión es especialmente relevante en entornos donde estos catéteres pueden confundirse con catéteres venosos centrales (CVC), o incluso con los PICC (Peripherally Inserted Central Catheter o catéteres centrales de inserción periférica), cuya punta sí alcanza una vena central.

Dicha ambigüedad no es inocua: tiene implicaciones prácticas en neonatos, pediatría y adultos. Además de comprometer la seguridad y eficacia terapéutica, agrava el riesgo de complicaciones asociadas. Por ello, resulta urgente abordar tanto la precisión terminológica como las consecuencias clínicas del mal uso del término.

"El objetivo de este artículo es visibilizar esta disonancia terminológica, analizar sus implicaciones clínicas y proponer una alternativa más precisa y segura."

El objetivo de este artículo es visibilizar esta disonancia terminológica, analizar sus implicaciones clínicas y proponer una alternativa más precisa y segura.

Nomenclatura y precisión semántica:

Un catéter venoso periférico intermedio (CVPI), es decir, un catéter venoso de posición intermedia insertado percutáneamente, es un dispositivo de acceso venoso periférico cuya longitud permite alcanzar grandes venas proximales sin llegar a la vena cava superior o inferior, ni la aurícula derecha. Por esta razón, no debe considerarse un catéter central. Tampoco debe confundirse con un catéter corto periférico, cuya duración es limitada, ni con un

PICC (catéter central de inserción periférica).

En adultos y niños mayores, suele insertarse en venas del brazo, como la basílica o cefálica, y su punta se posiciona típicamente en la vena axilar o en la subclavia proximal. En neonatos, sin embargo, los puntos de inserción varían según la accesibilidad y el tamaño del paciente. Además del miembro superior, se han utilizado:

- Las venas epicraneales en el cuero cabelludo (sobre todo la vena temporal superficial) ya no son recomendables utilizar. Su trayectoria permite alcanzar una vena profunda del cuello o la base del cráneo, como la vena yugular externa o posterior.
- Las venas del miembro inferior, como la safena interna, que puede avanzar hasta la vena femoral o incluso la ilíaca externa en función de la longitud del catéter y el tamaño del paciente.

"En inglés, el término midline hace referencia a su longitud, no a su ubicación. Sin embargo, al traducirse como "línea media", se induce a pensar en una posición anatómica central o simétrica, lo que puede hacer que se lo trate como un CVC. Esto puede desencadenar errores de medicación, inserciones sin técnica estéril y un manejo inadecuado del catéter."

Estas vías permiten una canalización prolongada sin necesidad de recurrir a un catéter central, pero exigen cuidados técnicos específicos y evaluación por ecografía para asegurar la correcta colocación de la punta y minimizar el riesgo de complicaciones.

Por estas razones, el catéter venoso periférico intermedio (CVPI) no debe considerarse un catéter central. Tampoco debe confundirse con un catéter corto periférico, cuya duración es limitada, ni con un PICC (catéter central de inserción periférica), cuya punta sí alcanza la vena cava superior o la aurícula derecha.

En inglés, el término midline hace referencia a su longitud, no a su ubicación. Sin embargo, al traducirse como "línea media", se induce a pensar en una posición anatómica central o simétrica, lo que puede hacer que se lo trate como un CVC. Esto puede desencadenar errores de medicación, inserciones sin técnica estéril y un manejo inadecuado del catéter.

Por ello, proponemos que en español se utilicen los términos:

- Catéter venoso periférico intermedio (CVPI)
- Catéter venoso periférico de longitud intermedia (CVPI).

Estos términos permiten evitar confusiones semánticas y reflejan con mayor precisión la localización anatómica de la punta del catéter y función del dispositivo. Además, facilita la comunicación clínica de forma más precisa (1-3).

Implicaciones clínicas del uso erróneo del término:

a) Administración de terapias y fármacos de forma inadecuada.

La confusión con un catéter central puede dar lugar a la administración de sustancias contraindicadas para accesos periféricos: como por ejemplo vasopresores a concentraciones elevadas, nutrición parenteral total (NPT) con alta concentración de glucosa y proteínas, soluciones hiperosmolares o medicamentos vesicantes. Dado que la punta no alcanza una vena central, la capacidad de dilución es limitada y el riesgo de extravasación grave aumenta considerablemente. Este peligro se acentúa en neonatos y niños pequeños donde el tejido vascular es frágil, y las consecuencias pueden ser severas (3).

b) Técnica de inserción inadecuada

Confundirlo con un catéter periférico corto puede llevar a omitir medidas de asepsia exigidas para dispositivos de larga duración. La OMS y diversas sociedades científicas recomiendan el uso de técnica estéril completa en su inserción, algo que no siempre se respeta cuando el término induce a considerar al catéter como "menor" (4-7).

c) Evaluación y seguimiento inadecuado

Los protocolos de cuidado, revisión y retiro varían entre accesos centrales y periféricos. Si el catéter es mal clasificado, los controles de permeabilidad, signos de infección o duración pueden no realizarse adecuadamente, prolongando innecesariamente su uso o favoreciendo complicaciones.

Recomendaciones prácticas y de lenguaje:

Para mejorar la claridad y seguridad clínica, es esencial:

1. Abandonar el término "línea media" en literatura científica, formación clínica y documentación institucional.
2. Adoptar oficialmente los términos:
   - Catéter venoso periférico intermedio (CVPI), o
   - Catéter venoso periférico de longitud intermedia (CVPI)
3. Protocolizar indicaciones clínicas claras, incluyendo terapias permitidas, duración esperada y localización de la punta.
4. Formar al personal sanitario en inserción guiada por ecografía y técnica estéril para este tipo de acceso (1-3, 8).
5. Educar a pacientes y familias, usando un lenguaje comprensible y preciso, evitando términos ambiguos en la información que se les transmite, tanto verbal como escrita.

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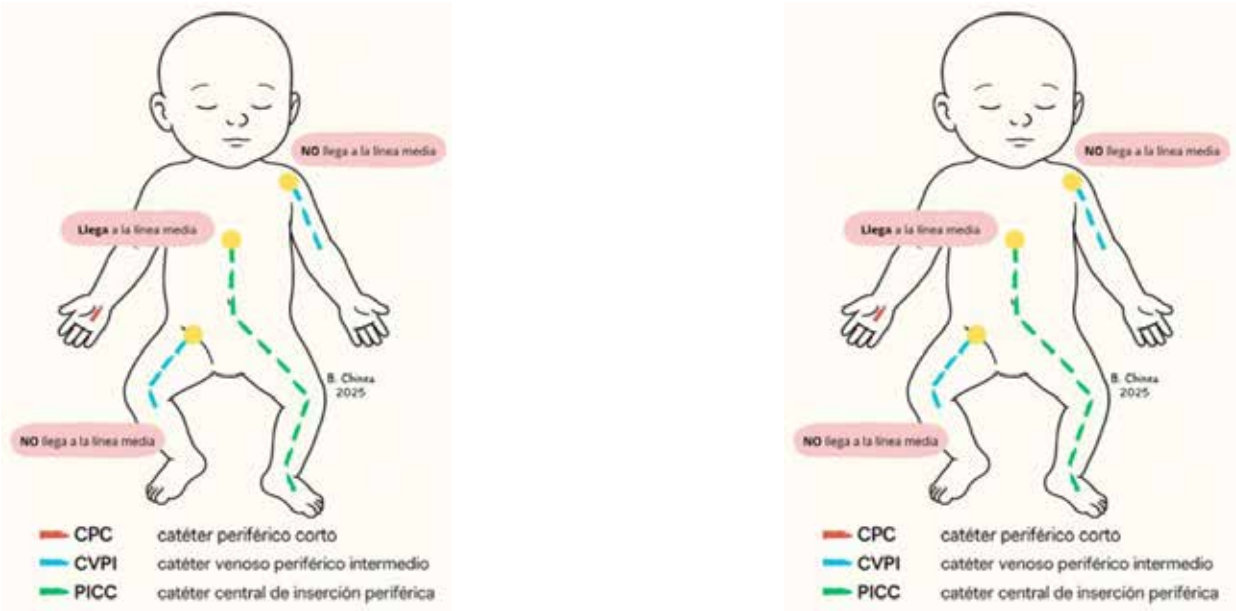
Figura 1. Confusión potencial.



Figuras 2 A y 2 B: Ilustración anatómica de los posibles accesos venosos en neonatología.
Figura 2 A: Comparación entre catéter periférico corto (CPC), dos catéteres venosos periféricos intermedios (CVPI), y un catéter central de inserción periférica (PICC).
Figura 2 B. Comparación entre dos catéteres venosos centrales (CVC) convencionalmente insertados por método quirúrgico; y un catéter central de inserción periférica (PICC)

Conclusión y comentarios finales

Llamar "línea media" a un catéter que no es central no es una simple confusión semántica: es una vía directa a errores clínicos reales, especialmente en pacientes tan vulnerables como los neonatos. Confundir un catéter de ubicación periférica con uno central puede conducir a extravasación, trombosis, múltiples punciones innecesarias y terapias mal administradas. En un ámbito donde cada detalle cuenta, no podemos permitirnos ambigüedades terminológicas.

"Llamar "línea media" a un catéter que no es central no es una simple confusión semántica: es una vía directa a errores clínicos reales, especialmente en pacientes tan vulnerables como los neonatos. Confundir un catéter de ubicación periférica con uno central puede conducir a extravasación, trombosis, múltiples punciones innecesarias y terapias mal administradas. En un ámbito donde cada detalle cuenta, no podemos permitirnos ambigüedades terminológicas."

Denominar "línea media" a un catéter que no lo es equivale a jugar con las palabras… y con la seguridad del paciente. El lenguaje sanitario debe ser preciso, no solo para transmitir conocimiento, sino para evitar errores. Debe ser claro, funcional y seguro.

Para finalizar, compartimos unos breves párrafos sobre errores y falacias en ciencias de la salud. La literatura al respecto es muy extensa y sus causas han sido bien descritas por varios autores como Gressens, Sola, Rodríguez, Ioannidis, Michael, y Chouris (9-15), entre tantos otros que no podemos citar en este artículo.

"En resumen, la identificación del error permite conclusiones más precisas y decisiones más seguras. También nos permite rechazar falacias y sofismas engañosos que beneficiarán a los pacientes. Lo más útil para la seguridad de los pacientes es adoptar una postura cuidadosamente crítica y utilizar un razonamiento sólido y crítico, antes que aceptar falacias y sofismas."

Ioannidis que ha dedicado su vida a este tema, dijo: "una teoría profunda de la literatura de la Antigua Grecia es que siempre debes ir tras la verdad, sin importar cual sea la verdad". Además, demostró que "para la mayoría de los diseños, es más probable que los hallazgos de investigación sean falsos antes de que sean verdaderos". En una publicación Chouris (15) sostiene que hay catorce tipos de falacias. Las falacias son formas erróneas de razonamiento, con efecto tóxico, que conduce a decisiones médicas inadecuadas. Los sofismas son argumentos falsos con apariencia de verdad.

Un ejemplo es la apelación a la tradición ("argumentum ad antiquitatem"), una falacia lógica que sostiene que algo es correcto o verdadero simplemente porque se ha hecho o creído de esa manera durante mucho tiempo. La tradición o la antigüedad de una práctica o creencia es erróneamente utilizada en esta falacia como suficiente evidencia para justificar su validez, sin considerar si existen razones lógicas o pruebas que la respalden. Otro ejemplo es la falacia ad hoc. Este es un argumento que se introduce para salvar una teoría o hipótesis de ser refutada, a menudo añadiendo explicaciones o justificaciones que no son verificables ni generalizables. Proteger una idea, en lugar de aceptar que la idea pudiera ser incorrecta. Otro ejemplo de falacia es apelar a la autoridad. Sin embargo, Francis Bacon sustentó que el criterio de autoridad carece de valor. La idea de que algo es cierto porque lo dijo un sabio es un mal principio. Y Karl Popper sostuvo que la ciencia progresa a través de refutaciones. Sólo se puede demostrar el error, y toda certeza científica es conjetural por naturaleza.

En resumen, la identificación del error permite conclusiones más precisas y decisiones más seguras. También nos permite rechazar falacias y sofismas engañosos que beneficiarán a los pacientes. Lo más útil para la seguridad de los pacientes es adoptar una postura cuidadosamente crítica y utilizar un razonamiento sólido y crítico, antes que aceptar falacias y sofismas. Esperamos que este artículo contribuya a la seguridad de muchos niños. Porque nombrar bien también es una forma de cuidar. No dejemos que un mal nombre, o un error, nos convierta en profesionales "más o menos". Mejor denominarlo por lo que es realmente: catéter venoso periférico intermedio.

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"Innovation and access can go a long way toward saving infant lives."

Mitchell Goldstein, MD
Neonatologist

NCfIH National Coalition for Infant Health

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SEPARATION disrupts breastfeeding putting babies' health at risk.

SEPARATING the DYAD doubles providers' workload, burdening systems.

BASED ON THE ARTICLE:

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"Midline" and "Peripheral Line": Clinical Misunderstanding that Can Put the Patient at Risk

Bibiana Chinea Jiménez, PNP, PhD, Augusto Sola, MD

"The English term midline catheter, often translated into Spanish as "línea media," is conceptually misleading in the Spanish language as it suggests a central anatomical location. This semantic confusion is not harmless and can lead to severe clinical complications if the catheter is used as a central venous catheter (CVC) or a peripherally inserted central catheter (PICC), particularly in vulnerable populations such as neonates."

Abstract:

Introduction: *The English term* midline catheter*, often translated into Spanish as "línea media," is conceptually misleading in the Spanish language as it suggests a central anatomical location. This semantic confusion is not harmless and can lead to severe clinical complications if the catheter is used as a central venous catheter (CVC) or a peripherally inserted central catheter (PICC), particularly in vulnerable populations such as neonates.*

Objective: *To analyze the clinical consequences of the misinterpretation of the term "línea media," we propose a more accurate alternative and provide practical recommendations for its use in neonatal medicine in Spanish-speaking countries.*

Methods: *A reflective analysis of the use of a mistranslated term and the positioning of percutaneously inserted venous catheters.*

Results: *Studies show that the intermediate peripheral venous catheter, when used appropriately, is a safe and effective option. However, when misinterpreted as a central access device, it may be associated with an increased risk of complications such as extravasation, thrombosis, and medication administration errors.*

Conclusion: *We propose replacing the term "línea media" with "intermediate peripheral venous catheter" (IPVC), a designation that accurately reflects the device's nature, position, and limitations. Precise terminology is not a mere technicality—it is a means of protecting patients.*

Introduction:

The translation of the English term *"midline catheter " into Spanish as "línea media" is technically inaccurate and potentially hazard*ous. In health sciences, every term matters. When a term leads to misunderstanding, it can also misguide clinical practice. This is the case with the *midline catheter*, a peripherally inserted venous device with an intermediate position; its translation into Spanish has created fertile ground for clinical confusion.

Despite its name, the midline does not refer to the "midline" of the body, nor does it imply a central anatomical location. Instead, it is a peripheral access device whose length allows it to reach larger-caliber veins, such as the axillary vein, without ever reaching central veins. The literal translation into Spanish as "línea media" misleadingly suggests it is a central access device, which may significantly impact clinical decisions based on this assumption.

This ambiguity is especially concerning in neonatal and pediatric patients, where vascular fragility heightens the risks associated with access-related errors. The confusion is particularly critical in settings where these catheters may be mistaken for central venous catheters (CVCs) or PICCs (Peripherally Inserted Central Catheters), whose tips do reach central veins. This ambiguity is not harmless: it has practical implications for neonates, children, and adults alike. Beyond compromising therapeutic safety and effectiveness, it increases the risk of associated complications. Therefore, it is urgent to address both terminological precision and the clinical consequences of misusing this term.

"The objective of this article is to raise awareness of this terminological mismatch, analyze its clinical implications, and propose a more precise and safer alternative."

The objective of this article is to raise awareness of this terminological mismatch, analyze its clinical implications, and propose a more precise and safer alternative.

Nomenclature and Semantic Precision:

An intermediate peripheral venous catheter (IPVC) -that is, a percutaneously inserted venous catheter of intermediate length- is a peripheral venous access device whose length allows it to reach large proximal veins without entering the superior or inferior vena cava, nor the right atrium. For this reason, it should not be considered a central catheter. Nor should it be confused with a short peripheral catheter, which has a limited duration, or with a PICC (peripherally inserted central catheter). In adults and older children, it is usually inserted in arm veins such as the basilic or cephalic vein, and its tip is typically positioned in the axillary or proximal subclavian vein. In neonates, however, insertion sites vary depending on accessibility and patient size. In addition to the upper limb, the following sites have been used:

- **Scalp veins**, particularly the superficial temporal vein, are no

longer recommended. Their trajectory allows them to reach deep veins of the neck or skull base, such as the external or posterior jugular vein.

- **Lower limb veins**, such as the great saphenous vein, may advance to the femoral or even the external iliac vein depending on the catheter length and patient size.

These access routes enable prolonged catheterization without the need for a central catheter, but they require specific technical care and ultrasound-guided assessment to ensure correct tip placement and minimize the risk of complications.

For these reasons, the intermediate peripheral venous catheter (IPVC) should not be considered a central catheter. Nor should it be confused with a short peripheral catheter or a PICC, whose tip does reach the superior vena cava or right atrium.

"In English, the term midline refers to the catheter›s length, not its location. However, when translated as "línea media," it suggests a central or symmetrical anatomical position, leading to it being treated as a CVC. This can result in medication errors, non-sterile insertion techniques, and inappropriate catheter management."

In English, the term *midline* refers to the catheter›s **length**, not its **location**. However, when translated as "línea media," it suggests a central or symmetrical anatomical position, leading to it being treated as a CVC. This can result in medication errors, non-sterile insertion techniques, and inappropriate catheter management.

Therefore, we propose that in Spanish, the terms used should be:

- *Catéter venoso periférico intermedio (CVPI)* or
- *Catéter venoso periférico de longitud intermedia (CVPI)*.

These terms avoid semantic confusion and more accurately reflect the anatomical location of the tip and the device's function. They also enhance clinical communication more effectively (1–3).

Clinical Implications of Misusing the Term:

a) **Inappropriate Administration of Therapies and Medications:**

Confusion with a central catheter can lead to the administration of substances that are contraindicated for peripheral access—such as high-concentration vasopressors, total parenteral nutrition (TPN) with elevated glucose and protein levels, hyperosmolar solutions, or vesicant drugs. Since the catheter tip does not reach a central vein, the dilution capacity is limited, significantly increasing the risk of severe extravasation. This danger is especially pronounced in neonates and young children, where vascular tissues are fragile and consequences may be severe (3).

b) **Improper Insertion Technique:**

Mistaking it for a short peripheral catheter may lead healthcare providers to skip sterile techniques required for long-term devices. The WHO and various scientific societies recommend the use of full sterile technique during insertion—a standard that is not always followed, as the terminology often leads professionals to treat the catheter as "minor" (4–7).

c) **Inadequate Evaluation and Follow-up**

Protocols for care, monitoring, and removal vary between central and peripheral access sites. If the catheter is misclassified, checks for patency, signs of infection, or appropriate dwell time may be incorrectly performed or omitted, unnecessarily prolonging its use or fostering complications.

Practical and Language Recommendations:

To improve clinical clarity and safety, it is essential to:

1. **Eliminate the use of the term "línea media"** in Spanish scientific literature, clinical training, and institutional documentation.
2. **Officially adopt the terms:**
   - *Catéter venoso periférico intermedio (CVPI)*, or
   - *Catéter venoso periférico de longitud intermedia (CVPI)*
3. **Standardize clinical indications**, including permitted therapies, expected duration, and tip location.
4. **Train healthcare personnel** in ultrasound-guided insertion and sterile technique for this type of access (1–3, 8).
5. **Educate patients and families** using precise and understandable language, avoiding ambiguous terms in both verbal and written communication.

Conclusion and Final Comments:

Calling a catheter "línea media" in the Spanish language when it is not central is not a simple semantic confusion—it directly leads to real clinical errors, especially in vulnerable patients such as neonates. Misidentifying a peripherally located catheter as a central one can result in extravasation, thrombosis, unnecessary multiple punctures, and inappropriate therapies. In a field where every detail matters, we cannot afford terminological ambiguities.

To call a catheter "línea media" when it is not is to play with words—

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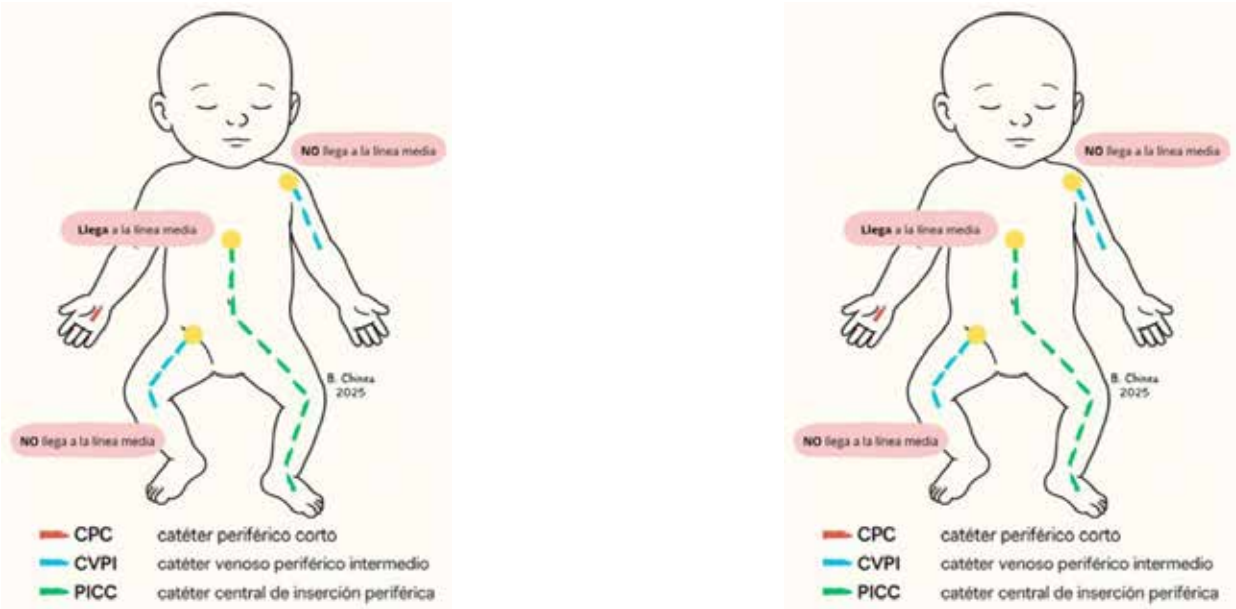
Figure 1. Potential confusion.
Abbreviation used. NPT: Total parenteral nutrition



Figures 2A and 2B: Anatomical illustration of possible venous accesses in neonatology
Figure 2A: Comparison between short peripheral catheter (SPC), two intermediate peripheral venous catheters (CVPI), and one peripherally inserted central catheter (PICC).
Figure 2B. Comparison between two conventionally surgically inserted central venous catheters (CVC) and a peripherally inserted central catheter (PICC)

and with patient safety. Medical language must be precise—not just to convey knowledge but to prevent mistakes. It must be clear, functional, and safe.

"Calling a catheter "línea media" in the Spanish language when it is not central is not a simple semantic confusion—it directly leads to real clinical errors, especially in vulnerable patients such as neonates. Misidentifying a peripherally located catheter as a central one can result in extravasation, thrombosis, unnecessary multiple punctures, and inappropriate therapies. In a field where every detail matters, we cannot afford terminological ambiguities."

To conclude, we offer a few brief reflections on errors and fallacies in the health sciences. The literature on this subject is extensive, and its causes have been thoroughly described by authors such as Gressens, Sola, Rodríguez, Ioannidis, Michael, and Chouris (9–15), among many others not cited here.

Ioannidis, who has dedicated his career to this subject, said: "A deep theory from Ancient Greek literature is that one must always pursue the truth, no matter what that truth is." He also demonstrated that "for most study designs, research findings are more likely to be false than true." In one publication, Chouris (15) states that there are fourteen types of fallacies.

"In summary, identifying errors allows for more accurate conclusions and safer decisions. It also enables us to reject misleading fallacies and sophisms that would otherwise harm patients. What is most beneficial for patient safety is to adopt a carefully critical stance and apply solid, logical reasoning—rather than accept fallacies or superficial logic."

Fallacies are erroneous ways of reasoning that have toxic effects, leading to inadequate medical decisions. Sophisms are false arguments with an appearance of truth. One example is the **appeal to tradition** (*argumentum ad antiquitatem*), a logical fallacy that holds something to be correct or true simply because it has been done or believed for a long time. The tradition or age of a practice or belief is mistakenly used as sufficient evidence of its validity, without considering whether there are logical reasons or supporting evidence.

Another example is the **ad hoc fallacy**—an argument introduced to save a theory or hypothesis from being refuted, often by adding explanations or justifications that are unverifiable and not generalizable. It aims to protect an idea instead of accepting that it may be incorrect. Another common fallacy is the **appeal to authority**. However, Francis Bacon argued that the authority of a person holds no weight on its own. The idea that something is true because a respected person said it is a flawed principle. Karl Popper also held that science progresses through **refutations**. Only error can be demonstrated, and all scientific certainty is conjectural by nature.

In summary, identifying errors allows for more accurate conclusions and safer decisions. It also enables us to reject misleading fallacies and sophisms that would otherwise harm patients. What is most beneficial for patient safety is to adopt a carefully critical stance and apply solid, logical reasoning—rather than accept fallacies or superficial logic.

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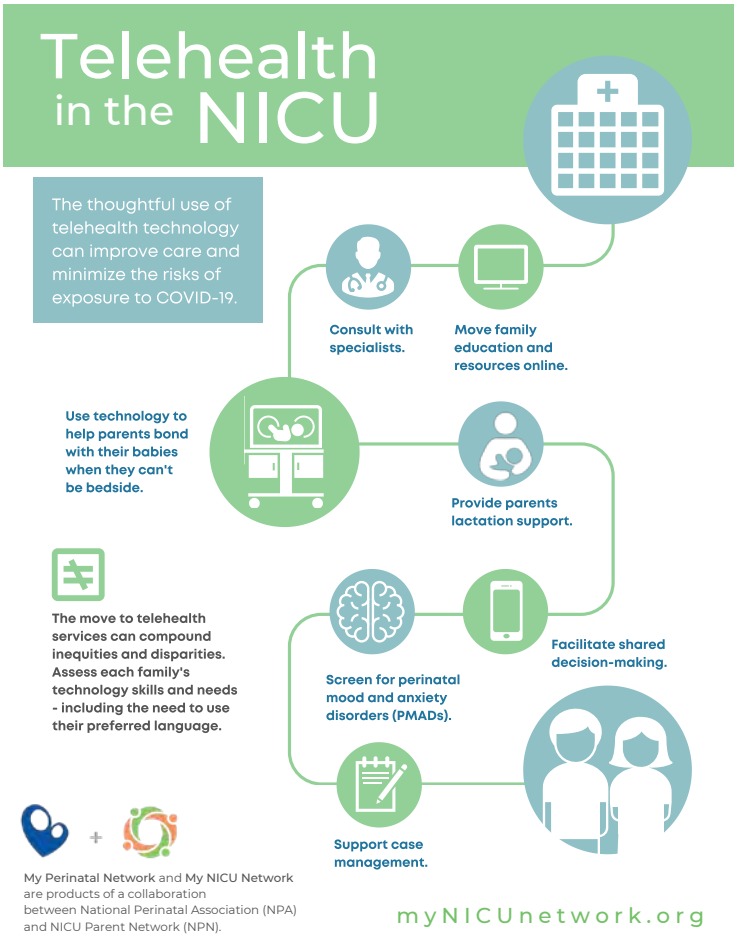

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- Struggling to Breathe
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- Difficulty Eating
- Lethargy
- Wheezing

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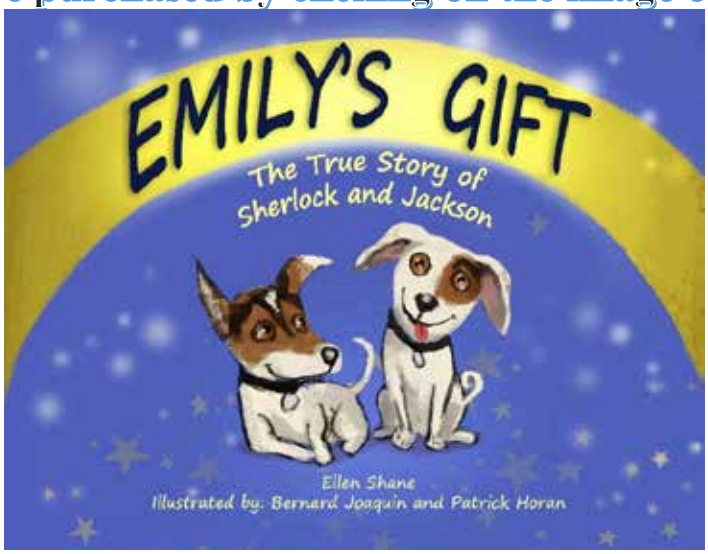

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Before AI Can Transform Healthcare, the Data Must Evolve

Sandro Shubladze

"Artificial intelligence could utterly reshape the way we care for patients and treat disease in the very near future, but one thing holds it back. We remain unable to unlock its full potential until we overcome the challenges surrounding healthcare data."

Artificial intelligence could utterly reshape the way we care for patients and treat disease in the very near future, but one thing holds it back. We remain unable to unlock its full potential until we overcome the challenges surrounding healthcare data.

AI's Potential in Healthcare Depends on Data:

The impact of AI on the healthcare sector has everyone excited, and for good reason. We see algorithms that analyze complex medical imaging to diagnose cancer or neurological disorders in seconds. (1) Headlines highlight AI platforms that shorten drug discovery timelines and identify potential compounds at a fraction of the cost of traditional methods. (2) We watch AI plow through genomic data and recommend treatment plans that match a patient's unique DNA profile. (3) We harness predictive analytics to forecast disease outbreaks and optimize the dwindling resources in our hospitals. (4)

However, these thrilling advances share one thing in common: they all depend on high-quality and accessible data. Without better data infrastructure, AI's capabilities remain capped, like a racecar stuck in rush-hour traffic.

Healthcare's Data Dilemma:

AI demands vast amounts of high-quality, well-integrated data to operate effectively. However, the actual state of healthcare data is far from being AI-ready. (5)

Healthcare data today is largely siloed. Patient information is stored in electronic health records, laboratory databases, pharmacy files, and insurance systems, but these systems rarely communicate across organizational boundaries. The data itself is often incomplete and non-standardized. Records often lack critical context or reside in formats incompatible with modern AI systems.

While compliance in the healthcare industry is critical, it also complicates the problem. Healthcare is one of the most tightly regulated industries, making data sharing particularly challenging. Data privacy concerns consistently necessitate a delicate balance between innovation and patient trust.

Fixing the Problem: A Blueprint for Better Healthcare Data:

The evolution of healthcare data requires systemic efforts from all players. Providers, researchers, policymakers, and tech companies must agree to adopt modern data architectures.

We must discover ways to make healthcare data far more accessible. For this to happen, we need systems that enable us to share data seamlessly across institutions and platforms.

AI thrives on big data, but healthcare organizations often lack the necessary infrastructure to store and process these large quantities of data. Legacy systems need to go. Healthcare organizations need to adopt scalable solutions that enable them to store and share this valuable healthcare information. New cloud-based platforms offer scalable means to store and process datasets. (6) Best of all, they enable real-time sharing among all stakeholders.

When it comes to sharing data, privacy and security remain top priorities in this industry, which is why the healthcare industry must focus on technology that prioritizes data security. Techniques like federated learning enable AI to train on decentralized data without the need for data transfer. (7) Advances like this can ensure that innovation continues without compromising compliance.

Inconsistent data remains one of the most significant roadblocks to interoperability. Only when healthcare organizations agree to implement a universal standard for collecting and annotating healthcare records will we be able to collaborate fully.

"When it comes to sharing data, privacy and security remain top priorities in this industry, which is why the healthcare industry must focus on technology that prioritizes data security. Techniques like federated learning enable AI to train on decentralized data without the need for data transfer. (7) Advances like this can ensure that innovation continues without compromising compliance."

Another part of ensuring consistent healthcare data requires everyone involved to invest in data cleaning. Automating the data-cleaning process can help healthcare organizations quickly pre-

pare their datasets for analysis while minimizing human error.

Errors and inconsistencies will continue to undermine AI-driven decisions until this issue is addressed. Only clean, standardized data will produce trustworthy AI outputs.

Once we establish a means to collect consistent healthcare data, pharmaceutical companies, hospitals, and insurers must dedicate themselves to sharing data freely. These organizations typically operate in isolation and guard their data due to competitive concerns. We must develop industry-wide coalitions and partnerships that address these concerns and facilitate secure data sharing.

Data Analysis Lessons from High-Regulation Industries:

Other highly regulated industries offer valuable lessons for healthcare's data challenges. Organizations in the financial sector utilize blockchain technologies to facilitate secure and transparent data sharing. (8) They have also adopted standards for recordkeeping and interoperability that allow them to exchange transactional data across borders while complying with international laws.

The aerospace industry excels at rigorous data maintenance. (9) Aircraft manufacturers and operators track millions of components using standardized identification systems and predictive analytics, ensuring that every part is accounted for — down to the bolt.

"Healthcare has a lot to learn from these industries. AI is transforming the sector, but a crumbling data foundation hinders its progress. Without a coordinated effort to modernize how we collect, share, and store data, AI's transformative potential will remain largely untapped."

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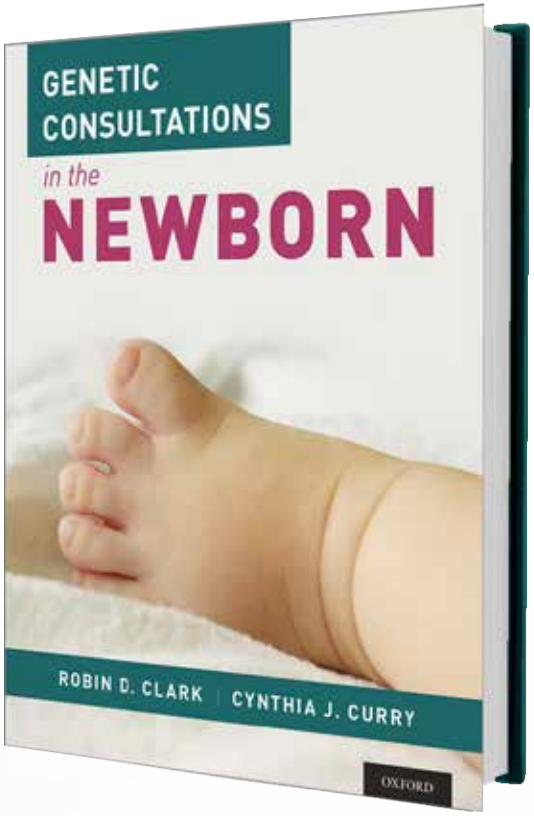

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Clinical Pearl: How Well Supported Do Parents of Neonatal Intensive Care Unit (NICU) infants with Chronic Critical Illness feel when transitioning from NICU to their Homes?

Joseph R. Hageman, MD, Mitchell Goldstein, MD, MBA, CML

"Most of them also required enteral feedings by tube or gastrostomy, some with elemental formulas. We also provided education for the families and caretakers so that they would feel more comfortable caring for their infants in the home environment. Most of them also required special insurance funding to provide home nursing and supportive care, which frequently took a long time to secure."

In a period from 1993 to 1995, I was the pediatric critical care attending in charge of a group of NICU infants with chronic critical illness (CCI) who were discharged from the NICU to our transitional care unit to their homes (1,2). Our job was to help stabilize each baby, almost all of whom were ventilator dependent with tracheostomies, and prepare them for discharge home with their parents and caretakers. Most of them also required enteral feedings by tube or gastrostomy, some with elemental formulas. We also provided education for the families and caretakers so that they would feel more comfortable caring for their infants in the home environment. Most of them also required special insurance funding to provide home nursing and supportive care, which frequently took a long time to secure. More recently, these infants and their families were discharged to out-of-hospital intermediate transitional care units as an additional step before being sent home.

The purpose of this pearl is to discuss an excellent longitudinal qualitative research study done in Boston at the Children's Hospital of interviews pre NICU discharge of 17 parents of 15 infants with CCI and 13 interviews of 11 infants (two home directly and nine home post stay in at a post-acute rehabilitation facility) discharge to qualify their parents' feelings of the level of support, unmet needs, and their recommendations to strengthen support pre and post discharge from the NICU (3). I believe that for all of us who have cared for these infants and their families during their longer NICU stays, understanding how we get to know and become close to our patients and their families, we can appreciate the importance and clinical value of this study (3). Some form of medical technology supported all 15 infants at the time of NICU discharge, including tracheostomy with mechanical ventilation (13-87%). (3) Most of these parents interviewed were mothers (88%) and married (55%). About one-quarter were Black (29%) or Latinx (24%) (3). The primary diagnoses of these infants included prematurity (6-40%), more than two body systems affected (6-40%), genetic syndrome (3-20%), lymphatic malformation 1-7%), multiple congenital anomalies (2-13%), aerodigestive (3-20%), pulmonary hypoplasia (1-7%), transesophageal fistula (1-7%), choanal atresia (1-7%) (3).

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The parents' narratives were analyzed by a data analysis team comprising experts in pediatric palliative care, pediatric complex care, pediatric hospital medicine, and qualitative methods (3). The methods were analyzed using inductive-deductive rapid qualitative analysis to identify key points and emergent themes (3).

The parents had an overall feeling of being highly supported during their NICU stay, but they felt significantly under-supported after discharge (3). The conclusions highlighted the need for additional hospital- and community-based supports to bridge the transition from the NICU to post-discharge home care (3).

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"Even with the limited number of parents pre- and post-discharge in this qualitative study, the information reflects a thoughtful approach and data collection, which I find reflective of my own clinical experience in the NICU and in the long-term care of infants with CCI (1-3)."

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Summarize the pearl for emphasis.

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2024

Keeping Your Baby Safe

from respiratory infections

RSV
COVID-19
colds
flu

How to protect your little one from germs and viruses

This year's cold and flu season may be a dangerous one - especially for vulnerable infants and children. Fortunately, there are proven protective measures that we can take to stay healthy.

Here's what you can do...

Wash Your Hands

- This is the single, most important thing you can do to stop the spread of viruses.
- Use soap.
- Wash for more than 20 seconds.
- Use alcohol-based sanitizers.

Limit Contact with Others

- Stay home when you can.
- Stay 6 feet apart when out.
- Wear a face mask when out.
- Change your clothes when you get home.
- Tell others what you're doing to stay safe.

Provide Protective Immunity

- Hold baby skin-to-skin.
- Give them your breast milk.
- Stay current with your family's immunizations.

Take Care of Yourself

- Stay connected with your family and friends.
- Sleep when you can.
- Drink more water and eat healthy foods.
- Seek mental health support.

Immunizations Vaccinations save lives. Protect your baby from flu, pertussis, RSV, and COVID-19 by getting your immunizations.

WARNING

Never Put a Mask on Your Baby

- Because babies have smaller airways, a mask makes it hard for them to breathe.
- Masks pose a risk of strangulation and suffocation.
- A baby can't remove their mask if they're suffocating.

If you are positive for COVID-19

- Wash with soap and water and put on fresh clothes before holding or feeding your baby.
- Wear a mask to help stop the virus from spreading.
- Watch out for symptoms like fever, confusion, or trouble breathing.
- Ask for help caring for your baby and yourself while you recover.

We can help protect each other.

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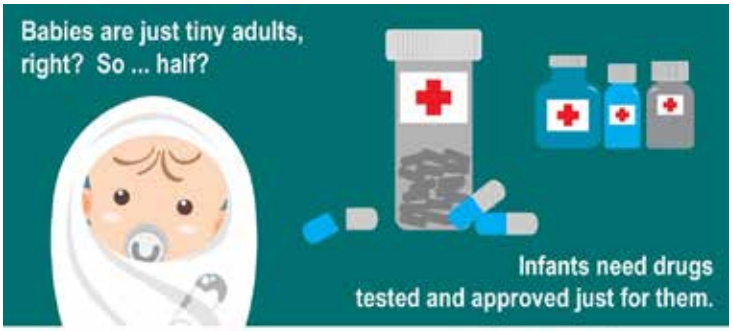

Coalition for Clinical Trials Awareness NCfIH

Which Infants are More Vulnerable *to Respiratory Syncytial Virus?*

RSV is a respiratory virus with cold-like symptoms that causes 90,000 hospitalizations and 4,500 deaths per year in children 5 and younger. It's 10 times more deadly than the flu. For premature babies with fragile immune systems and underdeveloped lungs, RSV proves especially dangerous.

But risk factors associated with RSV don't touch all infants equally.*

*Source: Respirator Syncytial Virus and African Americans

Caucasian Babies	Risk Factor	African American Babies
11.6%	Prematurity	18.3%
58.1%	Breastfeeding	50.2%
7.3%	Low Birth Weight	11.8%
60.1%	Siblings	71.6%
1%	Crowded Living Conditions	3%

AFRICAN AMERICAN BABIES bear the brunt of RSV. Yet the American Academy of Pediatrics' restrictive new guidlines limit their access to RSV preventative treatment, increasing these babies' risk.

AfPA Alliance for Patient Access

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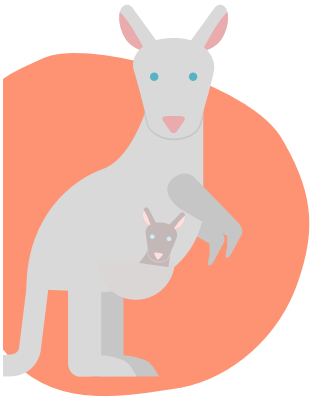

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work with your medical team to create a plan

GET CLEAN

WASH YOUR HANDS, ARMS, and CHEST

with soap and water for 20+ seconds. Dry well.

PUT ON FRESH CLOTHES

change into a clean gown or shirt.

IF COVID-19 + WEAR A MASK

and ask others to hold your baby when you can't be there

National Perinatal Association

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Telehealth in the NICU

The thoughtful use of telehealth technology can improve care and minimize the risks of exposure to COVID-19.

- Consult with specialists.
- Move family education and resources online.
- Provide parents lactation support.
- Facilitate shared decision-making.
- Screen for perinatal mood and anxiety disorders (PMADs).
- Support case management.
- Use technology to help parents bond with their babies when they can't be bedside.

The move to telehealth services can compound inequities and disparities. Assess each family's technology skills and needs - including the need to use their preferred language.

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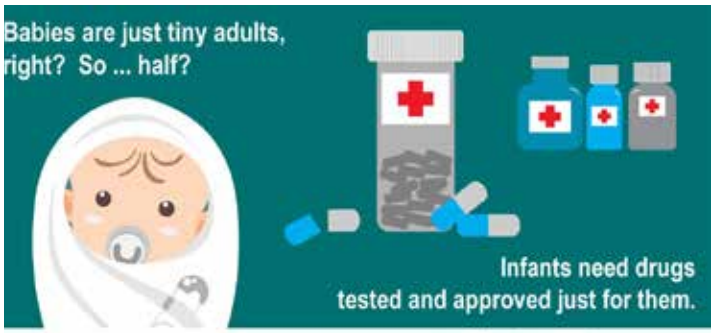

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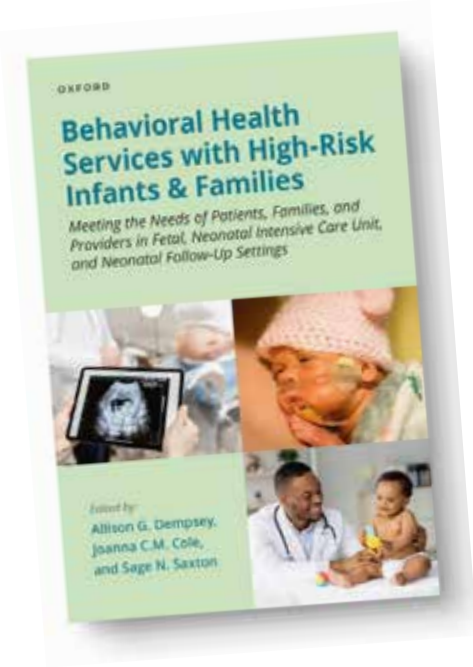

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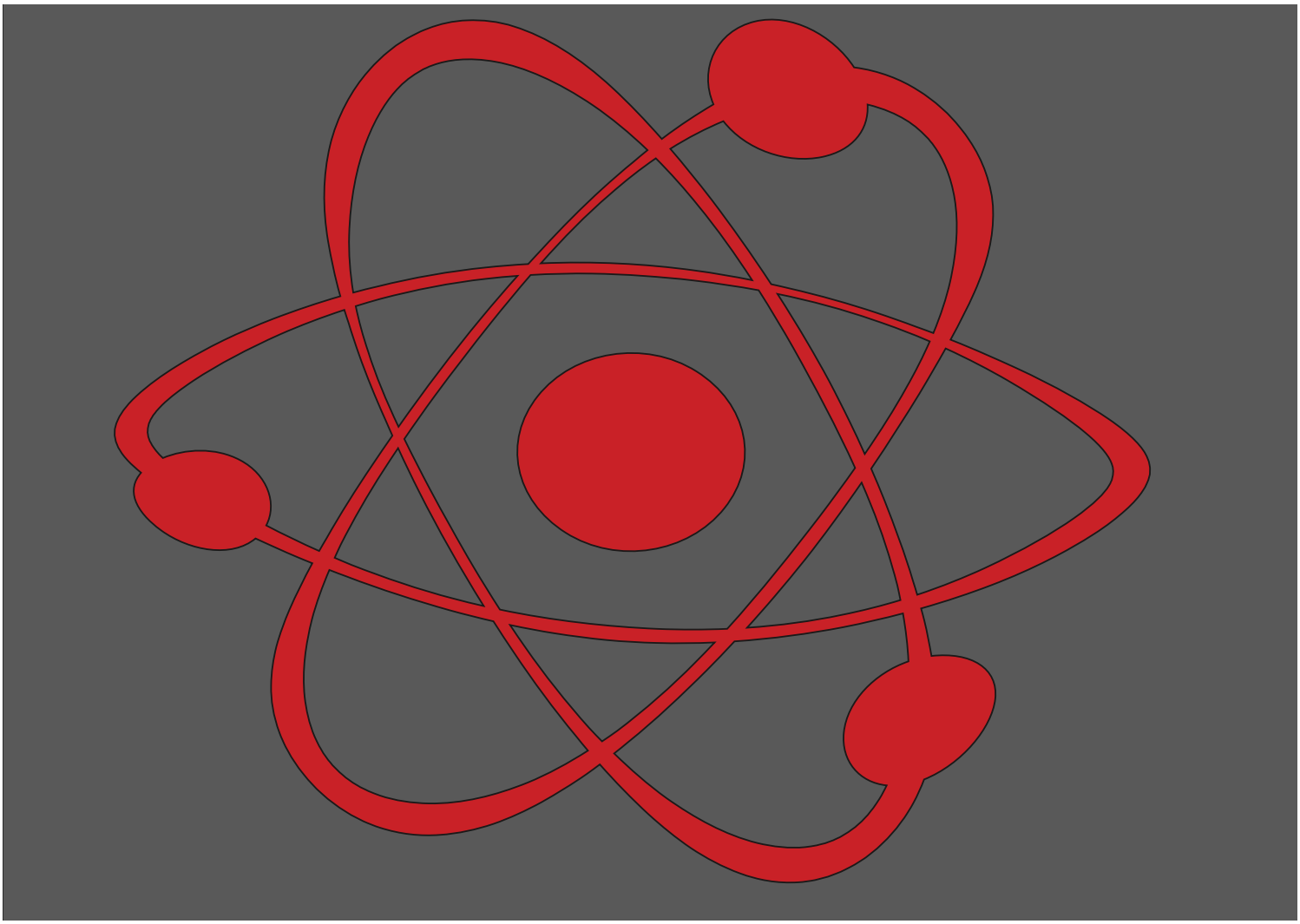

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2026 NeoCram Virtual Course
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National Perinatal Association
46th Annual Interdisciplinary Conference.
March 25 - 27, 2026
UNITING for IMPACT: Advancing Rural-Urban Collaboration and Innovation in Perinatal and Infant Health
The Coeur d'Alene Resort
Coeur d'Alene, Idaho
https://www.npaconference.org/

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April 24-27, 2026
Convention Center
Boston, MA
https://www.pas-meeting.org/

For up to date Meeting Information, visit NeonatologyToday.net and click on the events tab.

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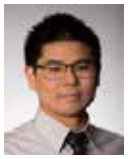

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Neonatology and the Arts

This section focuses on artistic work which is by those with an interest in Neonatology and Perinatology. The topics may be varied, but preference will be given to those works that focus on topics that are related to the fields of Neonatology, Pediatrics, and Perinatology. Contributions may include drawings, paintings, sketches, and other digital renderings. Photographs and video shorts may also be submitted. In order for the work to be considered, you must have the consent of any person whose photograph appears in the submission.

Works that have been published in another format are eligible for consideration as long as the contributor either owns the copyright or has secured copyright release prior to submission.

Logos and trademarks will usually not qualify for publication.

This month we continue to landscapes, feature artistic works created by our readers on the next to last page as well as photographs of birds on rear cover. Zahera Etter provides "Daffodils at the Base of Mount Fuji." For this edition, our art was graciously provided by Colleen Kraft, MD. It is a work called "Land and Sea" done by her son Tim. Our birds are from Dr. Shah, "A Snowy Egret on the Rocks."

Lily Martorell, MD

Arts Editor
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5. A brief biographical sketch (very short paragraph) of the principal author including current position and academic titles as well as fellowship status in professional societies should be included. A picture of the principal (corresponding) author and supporting authors should be submitted if available.

6. An abstract may be submitted.

7. The main text of the article should be written in formal style using correct English. The length may be up to 10,000 words or longer with prior approval. Abbreviations which are commonplace in neonatology or in the lay literature may be used.

8. References should be included in standard "NLM" format (APA 7th is no longer acceptable). Bibliography Software should be used to facilitate formatting and to ensure that the correct formatting and abbreviations are used for references. EndNote X9 is suggested.

X9 9. Figures should be submitted separately as individual separate electronic files. Numbered figure captions should be included in the main file after the references. Captions should be brief.

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Seeking content development experts for an AAP Project Advisory Committee (PAC)

The White Zone – Developing A Perinatal Loss Toolkit for LMICs

The Need: Over 2.4 million neonatal deaths and 2.6 million stillbirths occur each year; 98% occur in Low- and Middle-Income Countries (LMICs). While programs such as Helping Babies Breathe (HBB) and Essential Newborn Care (ENC 1 and 2) have revolutionized how providers in LMICs train in and provide neonatal resuscitation and post-delivery care for small and sick newborns, gaps remain in how to best offer end-of-life care and post-loss psychosocial care in these settings.

The Babies: HBB and ENC 1 begin with assessing if a baby is crying and conclude with the "Red Zone" where a baby who is unable to sustain an appropriate heart rate and/or respirations is provided with PPV support as someone attempts to get help. Within the HBB/ENC framework, we could imagine several babies for whom an extension of this framework to include palliative/perinatal loss guidelines could be helpful:

1. A stillbirth for whom no resuscitation is attempted. (Stillbirth)
2. A baby who proceeds through the red zone but never has a heartbeat or breathing despite the best resuscitative efforts of the team. (Stillbirth)
3. A baby who proceeds through the red zone who, after 20 or so minutes still has a very low heartbeat and/or gasping breathing. (Anticipated neonatal death)
4. A preterm baby who is too small for ongoing support, based on local resource constraints or resuscitation guidelines, despite a sustained heart rate and breathing. (Anticipated neonatal death)

The Approach: Create a suite of resources that could accompany ENC 1 and 2, focused on end-of-life care and perinatal loss. These resources would be less algorithmic than ENC, as local practices around death vary significantly – meaning there is not one "right" way to approach this care. Rather, the "White Zone Toolkit" would combine structured guidance about symptom management as well as reflective tools for implementing contextually and culturally appropriate post-loss care. This could consist of, but is not limited to, the following:

1. Structured guidance on what physiologic changes may happen at the end of life (ex: gasping) as well as pharmacologic and non-pharmacologic options for symptom management.
2. Reflective questions about if/when to offer seeing or holding of the baby.
    - Data shows that many women want to see and/or hold their infant following stillbirth or neonatal death but are often not offered that opportunity based on historic cultural norms.
3. Reflective questions about cultural traditions around loss and if/how these practices can be supported by those attending the delivery.
4. Anticipatory guidance guides on how mothers may still produce milk and how to manage those symptoms.
5. Anticipatory guidance on potential maternal mental health needs. Reflective questions on how to approach mental health and psychosocial support after loss.
6. Access to a set of adaptable practice scenarios that could help providers gain experience in handling perinatal loss and communicating with families surrounding perinatal loss.

NICU BABY'S *Bill of Rights*

1 The Right to *Advocacy*

My parents are **my voice** and **my family** are **my best advocates**.

My parents know me well. They are my voice and my best advocates. They need to be knowledgeable about my progress, medical needs, and prognosis, so they celebrate my achievements and support me when things get challenging.

2 The Right to *My Parents' Care*

Welcome my family and **include them** in everything we do.

My parents are my essential caregivers. In order to care for me, they need lots of opportunities to learn. Ensure that hospital policies and protocols, including hours & rounding, are as inclusive and expansive as possible. Then be patient with them.

3 The Right to *Bond With My Family*

Create opportunities for my family and me **to be together and bond**.

Bonding is crucial for my healthy growth and development. Support my parents so that we can practice skin-to-skin care as soon and as often as possible. Encourage them to read, sing, and talk to me.

4 The Right to *Neuroprotective Care*

Protect my **developing mind** and **senses**.

Protect me from things that startle, stress, or overwhelm me. Support things that calm me. Ensure I get as much sleep as possible. My brain is developing for the first time - and faster than it ever will again. The way I'm cared for today will affect me as I continue to grow & develop.

5 The Right to *Be Nourished*

Support our feeding decisions and **help us develop our skills**.

Encourage my parents to feed me at the breast or by bottle, whichever way works for us both. Support our feeding goals and make sure my parents know all the nutrition options available to meet my needs.

6 The Right to *Personhood*

Respect me as the **amazing, unique individual** that I am.

Use my name. Talk to me before touching me. If one of my siblings passes away, ask my family how we want to talk about and acknowledge them.

7 The Right to *Confident and Competent Care Giving*

Support my parents and caregivers.

The NICU may be a traumatic place for my parents. Ensure that they receive tender loving care, information, education, and as many resources as possible to help inform them about my unique needs, development, diagnoses, and more.

8 The Right to *Family-Centered Care*

Teach my family **how to care for me**.

Help me feel that I am a part of my own family. Teach my parents, grandparents, and siblings how to read my cues, how to care for me, and how to meet my needs. Encourage them to participate in or perform my daily care activities, such as bathing and diaper changes.

9 The Right to *Healthy and Supported Parents*

Care for our **mental health** and **wellbeing**.

My parents may be experiencing a range of new and challenging emotions. Be patient, listen to them, and lend your support. Share information with my family about resources such as counseling, support groups, & peer-to-peer programs, which can help reduce the impact of perinatal mood and anxiety disorders (PMADs).

10 The Right to *Inclusion and Belonging*

Celebrate what makes us special and unique.

Celebrate our diversity. Honor what makes us unique. Ensure that my parents, grandparents, siblings, and friends feel accepted and welcomed in the NICU, and respected and valued in all forms of engagement and communication.

NPN
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