NEONATOLOGY TODAY

Peer Reviewed Research, News and Information in Neonatal and Perinatal Medicine

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Volume 19 / Issue 8 August 2024

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NEONATOLOGY TODAY

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ISSN: 1932-7137 (Online), 1932-7129 (Print)
All editions of the Journal and associated manuscripts are available on-line:
www.NeonatologyToday.net
www.Twitter.com/NeoToday

NT

Loma Linda Publishing Company
A Delaware "not for profit" 501(C) 3 Corporation.
c/o Mitchell Goldstein, MD
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Peer Reviewed

Newborn Screening for Congenital Cytomegalovirus (cCMV) Infection: Universal, Targeted, Expanded-Targeted, or None-of-the-Above?

Mark R. Schleiss, MD

Key Words:

Congenital CMV; newborn screening; TORCH infection; antiviral therapy

Abbreviations:

AAP – American Academy of Pediatrics

cCMV – Congenital CMV infection

DBS – Dried blood spot

MDH – Minnesota Department of Health

NHS – Newborn hearing screening

SNHL – Sensorineural hearing loss

"Congenital cytomegalovirus (cCMV) infection is the most common cause of neurodevelopmental sequelae in the United States (US). The most common long-term disability associated with cCMV is sensorineural hearing loss (SNHL)."

Abstract:

Congenital cytomegalovirus (cCMV) infection is the most common cause of neurodevelopmental sequelae in the United States (US). The most common long-term disability associated with cCMV is sensorineural hearing loss (SNHL). Among children with cCMV-associated SNHL, over 40% will pass their newborn hearing screen (NHS). Therefore, to maximize the identification of infants at risk for SNHL, there is a strong rationale for universal cCMV screening. Early identification of cCMV also allows for the timely commencement of antiviral therapies for some infants, which in turn can improve clinical outcomes. Congenital infection must be diagnosed in the newborn infant in the first 21 days of life since demonstration of CMV infection beyond this time point commonly reflects postnatal acquisition, typically from breastfeeding. Although many advocates are enthusiastic about universal cCMV screening (1–3), other experts express hesitancy in embracing such a policy recommendation until there is more evidence of cost-effectiveness. Moreover, since most infants with cCMV are asymptomatic and have a good prognosis for normal neurodevelopmental outcomes, there is concern that universal screening may raise undue anxiety for parents of infants with asymptomatic cCMV infection (4). This review considers the pros and cons of different cCMV screening approaches, emphasizing enhancing awareness of new and emerging approaches for neonatologists in clinical practice.

"Early identification of cCMV also allows for the timely commencement of antiviral therapies for some infants, which in turn can improve clinical outcomes. Congenital infection must be diagnosed in the newborn infant in the first 21 days of life since demonstration of CMV infection beyond this time point commonly reflects postnatal acquisition, typically from breastfeeding."

Background: Congenital CMV Infection

The overall prevalence of cCMV infection has been reported to range from 0.2% to 2.5% (5, 6), with an overall prevalence of 0.64% estimated in a meta-analysis (7). The economic burden is substantial (8). Congenital transmission rates are higher in low- and middle-income countries (9) and vary substantially worldwide (10). The likelihood that cCMV will complicate a pregnancy is directly proportional to maternal seroprevalence rates in the population being studied (11). As noted in the accompanying manuscript in this issue of *Neonatology Today* by Hillyer and

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colleagues (Hillyer et al., 2024), cCMV infection is a disease of health disparities that disproportionately impact black and multiracial infants (12–16).

"The overall prevalence of cCMV infection has been reported to range from 0.2% to 2.5%, with an overall prevalence of 0.64% estimated in a meta-analysis. The economic burden is substantial. Congenital transmission rates are higher in low- and middle-income countries and vary substantially worldwide. The likelihood that cCMV will complicate a pregnancy is directly proportional to maternal seroprevalence rates in the population being studied."

Infants with cCMV are at risk for developmental disabilities, in particular, and SNHL. Indeed, of all infectious diseases, cCMV is the most common cause of disability in the US and probably globally. Most cCMV infections are not clinically apparent, and only 12.7% of infants are reported to have symptoms at birth (5). Isolated SNHL occurring in the setting of cCMV, in the absence of any other clinical, laboratory, or neuroimaging evidence of infection, was defined by an international consensus panel as "asymptomatic" cCMV (17). These definitions are in flux, and European expert consensus statements have defined cCMV-associated SNHL as a "symptomatic" congenital infection (18, 19). Both symptomatic and clinically inapparent cCMV infections can result in SNHL. Approximately 30–50% of those children with clinically apparent cCMV disease (symptomatic infants) and 8–12% of those children who are born with clinically inapparent infections (asymptomatic infants) due to cCMV will either be born with or will subsequently go on to develop SNHL (20). Morton and Nance have noted that 21% of cases of SNHL at birth and 25% of cases of SNHL that occur by five years of age are caused by cCMV (21). The challenge for physicians who care for newborn infants is that over 40% of pediatric SNHL due to cCMV infection is **not present at birth** and, therefore, is missed by the NHS (22–25). The fact that SNHL may be delayed in onset and may occur in the absence of other clinically evident manifestations of the disease becomes a compelling reason to pursue newborn screening programs for cCMV. Early identification of cCMV provides the opportunity to carefully perform serial audiological monitoring of infants toward the early identification of SNHL. Early identification of SNHL, in turn, can prompt corrective interventions that will optimize speech and language outcomes (26).

"Approximately 30–50% of those children with clinically apparent cCMV disease (symptomatic infants) and 8–12% of those children who are born with clinically inapparent infections (asymptomatic infants) due to cCMV will either be born with or will subsequently go on to develop SNHL. Morton and Nance have noted that 21% of cases of SNHL at birth and 25% of cases of SNHL that occur by five years of age are caused by cCMV."

"The challenge for physicians who care for newborn infants is that over 40% of pediatric SNHL due to cCMV infection is not present at birth and, therefore, is missed by the NHS. The fact that SNHL may be delayed in onset and may occur in the absence of other clinically evident manifestations of the disease becomes a compelling reason to pursue newborn screening programs for cCMV. Early identification of cCMV provides the opportunity to carefully perform serial audiological monitoring of infants toward the early identification of SNHL. Early identification of SNHL, in turn, can prompt corrective interventions that will optimize speech and language outcomes."

CMV Screening Approaches: Targeted, Expanded-Targeted, and Universal

SNHL is a major driving force behind cCMV screening. However, NHS is inadequate for finding all babies destined to have CMV-associated audiologic difficulties, given the frequently delayed-onset pattern of cCMV-associated SNHL. In the absence of cCMV screening, many cases of cCMV-associated SNHL will be missed. For those infants with cCMV that have delayed-onset SNHL, waiting until a child demonstrates evidence of hearing loss to test for CMV is not acceptable. There are three issues to consider:

1. Finding evidence of an active CMV infection in an infant beyond 21 days of age cannot be presumed to represent

in-utero transmission of the virus since postnatal acquisition of CMV, most commonly from breast milk, is ubiquitous in breast-fed infants (27), and this mode of infection is not associated with SNHL. To be sure, postnatal acquisition of CMV infection in premature infants from breast milk is a particular concern for practicing neonatologists. Premature infants in the NICU setting may acquire CMV from breast milk, and subsequently, these infants may begin to shed the virus from infections acquired from maternal milk, sometimes after weeks of hospitalization and often asymptomatically. Since pasteurization destroys viral infectivity, donor milk does not pose this risk, although pasteurization does modify salutary components of milk (lactoferrin, defensins, leukocytes, etc.). Although such postnatal infections may be associated with disease, generally, they are not of great clinical significance (28), and there is no evidence to suggest that they carry a risk of neurodevelopmental sequelae such as SNHL. Therefore, and as noted in the accompanying manuscript, in this issue of *Neonatology Today* by Pesch et al., cCMV may be a particularly important diagnosis to rule out through newborn screening in the NICU.

2. Second and more significantly, waiting until a child has delayed-onset SNHL before consideration of the diagnosis of cCMV represents a "missed opportunity" where early surveillance and monitoring could have improved speech and language outcomes.

3. Third, the practicing neonatologist needs to recognize that the most recent edition (2024–2027 edition) of the Red Book published by the American Academy of Pediatrics (AAP) now suggests a change in the valganciclovir treatment approach for cCMV infection (29). If SNHL can be demonstrated, even without other signs and symptoms, a six-week course of oral valganciclovir is now recommended. This new development, driven by the results of the CONCERT study in The Netherlands, represents a substantial change in clinical practice in 2024 (30, 31).

If cCMV screening is warranted, what should be the approach to such a screening program (Table 1)? An approach that has gained momentum throughout the US and Canada in recent years is so-called ***targeted screening*** (also known as "hearing-targeted" screening). This type of screening is driven by the finding of a

Table 1. *Hearing-Targeted, Expanded-Targeted, and Universal cCMV Screening Approaches: Pros and Cons.*

Screening Approach	Pro	Con
Targeted Screening	• Identifies up to 7% of cCMV cases. • Cost-savings: requires testing for fewer newborns. • Enables early diagnosis for etiology of SNHL; allows antivirals to be commenced in a timely fashion.	• Misses most cases of cCMV. • Most infants that "refer" on NHS have normal hearing on audiological follow-up.
Expanded Targeted Screening	• Captures cases of cCMV that might have been otherwise been overlooked. • Enables early diagnosis of cCMV and allows antivirals to be commenced in a timely fashion.	• Misses most cases of cCMV. • Criteria for screening incompletely defined; cost-effectiveness not studied.
Universal Screening	• By definition, it is more sensitive than targeted or expanded-targeted screening. • Identifies clinically inapparent cCMV cases in infants at risk for sequelae, particularly SNHL. • Early identification facilitates comprehensive diagnostic evaluation. • Amenable to high-throughput testing using DBS.	• Most infants are asymptomatic with a good prognosis; this may raise undue anxiety ("vulnerable child syndrome"). • Risk of unwarranted antivirals with attendant toxicities. • If saliva is used for screening, the potential for false-positives. • If DBS is used for screening, there is potential for false negatives.

"refer" or "fail" status on the NHS. A CMV test can be ordered for these newborns that fail the NHS (32-41), and such a test can be ordered to evaluate whether congenital infection is present. Targeted screening has been implemented in several states in the US. The American Academy of Audiology endorsed targeted screening in a publication in 2023 (42). A concern with respect to targeted cCMV screening is the intrinsically high failure rate for NHS; most infants who "refer" on the NHS have normal hearing (43). The expected percentage of targeted screening tests that are positive for cCMV in infants that fail the NHS is not known with certainty but appears to fall between 1.5–3% (33, 44, 45).

In addition to infants that fail the NHS, the targeted screening definition has been expanded to include a category of ***expanded targeted screening***. In this approach, suggestive clinical findings, such as abnormal head size, small-for-gestational-age status, low birth weight status, petechial rash, and other findings (44, 46, 47), trigger a targeted screening test. Although it might be argued that experienced clinicians know when to consider a diagnosis of cCMV infection (48), often there are classic signs and symptoms that are overlooked, and cases of cCMV infection are missed (49–51). Of importance to neonatologists is the issue of whether newborns that are SGA, IUGR, or have unexplained premature birth should be included in the expanded targeted screening approach. The diagnosis of cCMV should probably be considered in all infants with unexplained premature birth since there appears to be a higher cCMV prevalence in premature infants (52, 53).

"Of importance to neonatologists is the issue of whether newborns that are SGA, IUGR, or have unexplained premature birth should be included in the expanded targeted screening approach. The diagnosis of cCMV should probably be considered in all infants with unexplained premature birth since there appears to be a higher cCMV prevalence in premature infants."

Given the substantial percentage of infants with cCMV who have delayed SNHL, the utility of targeted and expanded-targeted cCMV screening is unclear: there is still concern that many babies destined to have cCMV-associated hearing loss will be missed. Pesch et al. argue that ***universal screening*** is the most appropriate solution. With universal screening, no cases are missed (assuming a sufficiently sensitive screening test). Recently, advances in technology have made the dried blood spot (DBS) a tenable source for newborn screening, a cost-effective strategy insofar as the DBS is already routinely collected for the panoply of other newborn screening tests that are an intrinsic part of newborn care. Enhanced extraction techniques yield a sensitivity of the DBS PCR (for a two-primer-pair comparison) in the ~85% range (54). Moreover, and as pointed out by the two other articles in this edition of *Neonatology Today* (Pesch et al., 2024; Hillyer et al., 2024), universal screening helps to ensure health equity since, in principle, every newborn gets tested in a universal screening program.

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What do expert groups opine about universal cCMV screening? More recently, the American Academy of Otolaryngology and Head and Neck Surgeons endorsed the concept of implementation of a universal cCMV screening approach (55). This seems to be the path forward and should be considered for implementation as a part of the standard NICU admission order set (Pesch et al., 2024). The AAP has not yet taken a position on newborn screening for cCMV, although an updated practice guideline for managing cCMV is expected in 2024–2025 and may address this question.

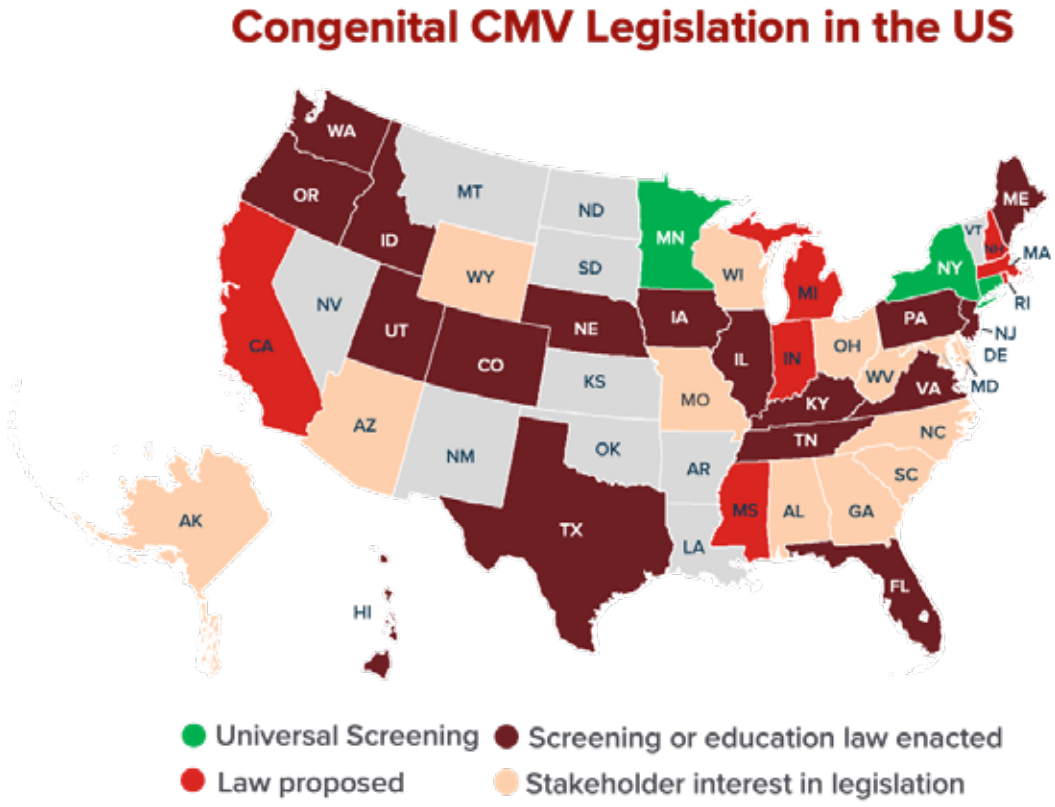
CMV Screening Approaches: Is There a Downside?

The potential "downsides" of cCMV screening chiefly center around the issue of whether such testing meets the classic Wilson and Jungner (56) criteria for a newborn screenable disorder: specifically, the question of the sensitivity of the screening test; the cost-effectiveness of newborn screening; and the efficacy of inventions for infants found to have the infection. The demonstration of enhanced sensitivity of the DBS PCR through methodologic improvements shown in recent studies (55) has engendered enthusiasm for incorporating cCMV into newborn DBS-based screening programs. Recent reports of high-throughput universal cCMV screening using a pooled saliva technique also offer the promise of enhanced sensitivity at reduced costs (57), although it is essential to be mindful of the risks of false positive PCR results (due to colostrum/breast milk) when saliva is used as the screening template (58). Minnesota commenced universal DBS-based cCMV screening in 2023, and preliminary results from the first year of screening have been reported (59). New York State is currently screening all newborns for cCMV, using the DBS as a template, under the aegis of a NICHD-sponsored study, and universal screening is likely to continue as standard practice beyond the study period. Connecticut also passed legislation in 2023 that will mandate universal screening, which is expected to commence in 2025.

Two other "downsides" of cCMV screening, particularly universal screening, merit discussion. First, there is concern that universal screening may create unwarranted parental anxiety (a "vulnerable child syndrome"). This stems from the fact that most infants identified with cCMV by universal screening are expected to have clinically inapparent infections and are predicted to be asymptomatic with a good prognosis for a normal outcome (60). Pesch et al. challenged the concern regarding excessive parental anxiety (61), and, given a choice, most parents would prefer to know about their child's cCMV infection, even if sequelae never ensued (62). Surveys of women of child-bearing potential support universal cCMV screening (63). Second, the concern for over-treatment with antivirals (ganciclovir and valganciclovir) is important, particularly for asymptomatic/clinically inapparent infections. Although the AAP has recently expanded the indications for antiviral therapy (29) to include treatment of otherwise-asymptomatic infants with isolated SNHL, universal newborn screening might increase the number of asymptomatic children with cCMV receiving antivirals on an unwarranted basis. There is a lack of data on the long-term safety of ganciclovir and valganciclovir (64), but even though no human cancers have been linked to these drugs, the concerns about the carcinogenic potential of these agents warrant continued surveillance.

"Although the AAP has recently expanded the indications for antiviral therapy to include treatment of otherwise-asymptomatic infants with isolated SNHL, universal newborn screening might increase the number of asymptomatic children with cCMV receiving antivirals on an unwarranted basis. There is a lack of data on the long-term safety of ganciclovir and valganciclovir, but even though no human cancers have been linked to these drugs, the concerns about the carcinogenic potential of these agents warrant continued surveillance."

Figure 1. *Map of states in the US that currently either conduct targeted or universal cCMV screening, states that have legislation pending or under consideration, and states where there is stakeholder interest in legislation. Three states have universal cCMV screening: Minnesota, which commenced screening through legislation (the Vivian Act) in 2023; New York, which currently conducts universal cCMV screening through a NICHD-sponsored program, with a plan to incorporate screening permanently into the newborn screening program; and Connecticut, which passed legislation in 2023 (HB8821) to commence universal screening in 2025. All three states base the universal cCMV screen on DBS PCR analysis. (adapted from* https://www.nationalcmv.org/about-us/advocacy)



"In conclusion, the era of cCMV screening is here! Of the cCMV screening options before us—universal, targeted, expanded-targeted, or none-of-the-above—the only alternative that is not acceptable is "none-of-the-above." Even when confronted with uncertainty in prognosis and long-term outcomes, parents prefer to have the knowledge that their infant has a cCMV infection."

Conclusion:

In conclusion, the era of cCMV screening is here! Of the cCMV screening options before us—universal, targeted, expanded-targeted, or none-of-the-above—the only alternative that is not acceptable is "none-of-the-above." Even when confronted with uncertainty in prognosis and long-term outcomes, parents prefer to have the knowledge that their infant has a cCMV infection (63). Screening will only become more commonplace in the years ahead. Two provinces in Canada—Ontario and Saskatchewan—have commenced universal cCMV screening, and two states in the US also screen all newborns for this infection—Minnesota, through legislative action (the "Vivian Act") that commissioned the Minnesota Department of Health (MDH) to begin screening in 2023 (59), and New York, which currently screens all newborn through an NICHD-funded program. New York will almost certainly continue screening after the research program has concluded. Connecticut has also passed legislation to begin universal cCMV screening in 2025. Many US states currently conduct targeted screening for cCMV if infants refer (fail) on the NHS or expanded targeted screening if other risk factors are present. The states in the US that have either commenced screening or have legislation either submitted or under consideration by stakeholders in cCMV research and advocacy are shown in Figure 1 (65). Federal legislation, the "Stop CMV Act," has been introduced in the US Senate (S.3864) by Senators Richard Blumenthal (D-CT), Chris Murphy (D-CT), and Roger Marshall (R-KS), and in the US House by Representatives (H.R.7542) by Mike Lawler (R-NY) and Greg Landsman (D-OH). The bill authorizes funding to states for hospitals and other healthcare entities caring for infants to administer congenital CMV tests and to provide standards and procedures for these tests (65). This would be a welcome development, and the pediatric and neonatology communities should advocate for this legislation.

As screening moves forward, it is imperative that state legislatures that pass bills directing health departments to perform targeted or universal screening adequately fund such programs. In Minnesota, the fees in the Vivian Act legislation were generated, in part, by increasing the "per specimen" fee for screening by $43 to a total of $220 per specimen (Minnesota.gov statutes, 2023). Additional funds were earmarked to fund personnel costs required in administration and follow-up. Indeed, the cost of a DBS PCR assay is nominal, particularly if the test is included in the costs of other screening assays routinely performed in newborns. Instead, the costs are associated with the long-term neurodevelopmental and audiology follow-up required for screen-positive infants with confirmed cCMV. Despite the costs associated with a cCMV newborn screening program, a recent analysis demonstrated that universal cCMV screening was more cost-effective and averted more cases of severe hearing loss than did targeted cCMV testing—even in areas of low overall CMV prevalence (66). These observations are encouraging, but more data is needed on the cost-effectiveness of screening, parental acceptance of screening, the ideal substrate for testing (DBS or saliva), and the efficacy of and indications for antiviral treatments. As clinical practice evolves, health equity is also critical, as Hillyer et al. discussed in this *Neonatology Today* issue (Hillyer et al., 2024). Even as newborn screening moves forward, maternal education programs and preconception vaccines are needed to help reduce the disease and disability burdens associated with cCMV.

"Despite the costs associated with a cCMV newborn screening program, a recent analysis demonstrated that universal cCMV screening was more cost-effective and averted more cases of severe hearing loss than did targeted cCMV testing—even in areas of low overall CMV prevalence."

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Acknowledgments: *Financial Support. Funding support from the University of South Carolina's Research and Dissemination Center (DRDC), through its Cooperative Agreement (Number 6U19DD001218) with the Centers for Disease Control and Prevention (CDC), and from the NIH, R01 HD099866, is acknowledged.*

Disclosures**:** *Mark R. Schleiss is the UMN site PI for the Moderna mRNA-1647 CMV vaccine trial, which provides research support for the UMN but no personal honoraria for the PI. Dr Schleiss also reported grants from the CDC, the National Institutes of Health (R01 HD099866) and the University of South Carolina's Disability Research and Dissemination Center (DRDC); and consultant fees from Sanofi Vaccines and GlaxoSmithKline Vaccines outside of the submitted work.*

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Dr. Mark R. Schleiss, Professor of Pediatrics, did his training in Pediatrics at the Oregon Health and Sciences University in Portland, Oregon, followed by Fellowship Training in Pediatric Infectious Diseases at Seattle Children's Hospital at the University of Washington in Seattle, Washington. He holds the American Legion and Auxiliary Heart Research Foundation Endowed Chair at the University of Minnesota (UMN) Medical School. His laboratory studies vaccines for preventing congenital cytomegalovirus (cCMV) infection, and he provides expertise nationally and internationally in evaluating and managing cCMV. The NIH and the CDC fund his research program, and he advocates universal cCMV screening. His work with the Minnesota Legislature, in collaboration with families with children with cCMV, led to the successful implementation in 2023 of the "Vivian Act," novel legislation that enabled universal CMV screening in Minnesota newborns. Minnesota is the first state in the USA to adopt universal cCMV screening. He is also the principal investigator of a CDC-funded MAT-LINK site in Minnesota that is currently engaged in cCMV surveillance and follow-up (https://ctsi.umn.edu/news/ctsi-part-team-studying-follow-infants-cmv-infections). His laboratory also studies the immunology and molecular virology of congenital and post-natally acquired CMV infections in preterm infants and the long-term audiologic and neurodevelopmental impact of such infections.

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A Call to Action: Embracing Universal Congenital CMV Screening in NICUs

Megan Honor Pesch, MD; Mary Uran, MPH; Khaliah Fleming, EdD

The mission of the National CMV Foundation is to prevent pregnancy loss, childhood death, and disability due to congenital CMV. Congenital cytomegalovirus (cCMV) is the most common congenital infection in North America, impacting 1 in every 200 live-born infants, which is three times more common than Down syndrome or 16x more common than cystic fibrosis. (1–3) Those numbers are staggering compared to the number of infants diagnosed yearly, which is as few as 1 in 10 of those infected. (4, 5) Congenital CMV can lead to a spectrum of sequelae or none. (6) Neonatal diagnosis, treatment, and follow-up can mitigate some of the risks of those sequelae; however, treatment is impossible without first diagnosing this often silent condition. As members of the Executive Committee of the National CMV Foundation, a non-profit organization dedicated to ending this often devastating condition, we urge neonatologists to consider the compelling evidence supporting universal screening as the superior strategy for early detection, comprehensive care, and improved long-term outcomes.

"Congenital cytomegalovirus (cCMV) is the most common congenital infection in North America, impacting 1 in every 200 live-born infants, which is three times more common than Down syndrome or 16x more common than cystic fibrosis."

Why Screen for CMV at All?

Infants with congenital CMV rarely present with the "classic" triad of findings (jaundice, hepatosplenomegaly, and petechiae) that many memorized in their medical training. (5) In fact, most children present with no signs or symptoms at birth at all. As such, congenital CMV screening programs in the US and internationally have gained momentum over the last decade. (7, 8) Such programs can be targeted (screening only a subset of infants) or universal (screening all infants). Herein, we present arguments for why all infants should be screened for congenital CMV.

Screening Methods

Screening for congenital CMV involves testing urine, saliva, or blood samples using polymerase chain reaction (PCR) to detect the presence of the virus. This testing must be conducted within the first 21 days of life to accurately diagnose congenital CMV, as later detection could indicate a postnatally-acquired infection. (9, 10) Saliva PCR is often preferred due to its non-invasive nature and ease of collection, while urine PCR remains a reliable alternative. Dried blood spot screening has the advantage of being easier to implement on a large scale but has the drawback of lower sensitivity. (11) Implementing a universal screening protocol ensures timely and accurate identification of CMV, allowing for immediate intervention and timely follow-up.

"Screening for congenital CMV involves testing urine, saliva, or blood samples using polymerase chain reaction (PCR) to detect the presence of the virus. This testing must be conducted within the first 21 days of life to accurately diagnose congenital CMV, as later detection could indicate a postnatally-acquired infection."

Potential Sequelae and Urgency of Antiviral Therapy

The potential sequelae of congenital CMV are extensive and can be severe, including hearing loss, developmental delays, cerebral palsy, autism, and vision loss. It is estimated that roughly 1 in 4 infants with congenital CMV will have a long-term disability. (12–15) The urgency of starting antiviral therapy as soon as possible in symptomatic infants, as well as those with isolated hearing loss, cannot be overstated. Antiviral treatment, when initiated early, has been shown to improve hearing and developmental outcomes, reducing the burden of these long-term complications. (16, 17) For infants diagnosed through universal screening, this immediate intervention may be critical in altering the trajectory of their health and development.

Comprehensive Detection Beyond Hearing Loss

Hearing-targeted screening for congenital CMV focuses on identifying infants referred to their newborn hearing screen, as hearing loss is a common yet not exclusive symptom of congenital CMV infection. While this approach successfully identifies a significant subset of affected infants, it misses those who are

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asymptomatic or exhibit non-auditory symptoms at birth. A study by Fowler et al. found that hearing-targeted congenital CMV screening only detected 7% of those with congenital CMV, and 57% of those infants would develop hearing loss by two months of age. (18) Furthermore, hearing-targeted congenital CMV screening could also lead to late detection in the NICU population who receive their hearing screen weeks to months after birth. Universal screening, on the other hand, ensures that all infants are tested, allowing for the identification of those who may develop serious complications such as neurodevelopmental delays, vision loss, and seizures. By broadening our detection scope, we can intervene earlier and more effectively, ultimately improving the prognosis for these infants.

"A study by Fowler et al. found that hearing-targeted congenital CMV screening only detected 7% of those with congenital CMV, and 57% of those infants would develop hearing loss by two months of age."

Early Intervention and Treatment

Early detection through universal screening facilitates prompt antiviral treatment, which has been shown to improve outcomes modestly in infants with symptomatic congenital CMV infection and those with isolated hearing loss. The most crucial benefit of screening is for those who might develop symptoms later, such as progressive hearing loss or developmental delays, as early identification allows for closer monitoring and timely intervention. Data is mixed on whether congenital CMV is or is not more common in the preterm versus term population. (19, 20) However, a proactive approach is crucial in the NICU setting, where infants are already at high risk for complications. Ensuring that no infected infant is overlooked enhances our ability to mitigate the long-term impacts of the virus and support their families.

To be sure, there are risks of universal congenital CMV screening that must be considered as well. For instance, in general, most infants with congenital CMV will go on to develop no symptoms at all, although this may not apply to those requiring NICU-level care. While CNS involvement is a predictor of epilepsy, cerebral palsy, and intellectual disabilities,(21) other more subtle sequelae, such as hearing loss or autism, are more challenging to predict. (22) While some worry about the risk of parental anxiety, data from studies of parent perspectives on congenital CMV testing resoundingly support their desire to know their infants' status and protectively take steps to support their child's development. (23–25) The fact is that congenital CMV and its risk of long-term sequelae will not disappear, even if we continue to ignore them.

Reducing Healthcare Disparities

Universal screening helps address healthcare disparities by providing equal opportunity for early detection and intervention (26), regardless of an infant's initial presentation. In contrast, targeted screening may inadvertently perpetuate inequalities by failing to identify asymptomatic infants who may come from disadvantaged backgrounds and lack access to follow-up care or only be implemented in resource-abundant settings. Ensuring every infant in the NICU is screened for CMV promotes a more equitable healthcare system where all infants receive the comprehensive care they need from the outset.

Economic Considerations

While universal screening may initially appear more costly than hearing-targeted screening, it is essential to consider the long-term economic benefits. (27) Early detection and intervention may prevent or reduce the severity of congenital CMV-related complications, decreasing the need for costly treatments and supportive services later in life. There are also often unmeasured yet important costs of congenital CMV to caregivers, families, and society at large (28) that may be lessened if complications of the infection could be mitigated.

"While universal screening may initially appear more costly than hearing-targeted screening, it is essential to consider the long-term economic benefits. Early detection and intervention may prevent or reduce the severity of congenital CMV-related complications, decreasing the need for costly treatments and supportive services later in life. "

Conclusion

As neonatologists, you are entrusted with safeguarding the health and development of our youngest and most vulnerable patients. Universal congenital CMV screening is more effective and equitable than hearing-targeted screening, particularly in the NICU population. By ensuring comprehensive detection, enabling early intervention, and addressing healthcare disparities, universal screening aligns with our shared mission to provide the highest standard of care. It is time for the neonatal community to embrace universal congenital CMV screening as the gold standard for protecting our patients from the potentially devastating effects of this common congenital infection.

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Disclosure: *The authors have no conflicts of interests to disclose.*

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Editorial: Congenital Cytomegalovirus: Do Not Miss an Opportunity for Detection and Treatment

Kimberly Hillyer, Ph.D., RN, DNP; T. Allen Merritt, MD, MHA; Mitchell Goldstein, MD, MBA

Health inequities and racial disparities in maternal and infant mortality and morbidity of non-Hispanic Blacks and Hispanics, Native Americans, and Native Hawaiians compared with non-Hispanic Whites have been the focus of multiple efforts by the Centers for Disease Control and Prevention (CDC), the March of Dimes, and various states to reduce this racial gap or social determinant of health. Identifying and taking action to reduce these disparities and efforts to mitigate them requires a concerted effort among federal, state, and local governments as well as maternal and infant health care providers. For example, significant efforts have been undertaken to reduce maternal deaths among Black and Hispanic mothers during and after pregnancy and to reduce rates of prematurity and infant mortality, which continue to represent significant gaps among various groups and the social determinants of health. The March of Dimes and the CDC have emphasized providing more comprehensive care and expanding healthcare coverage through the expansion of Medicaid (1).

"A racial disparity exists in congenital cytomegalovirus (cCMV) prevalence. In most studies, its impact on infant hearing, language acquisition, and childhood development represents a major determinant among non-Hispanic Black infants versus White infants."

A racial disparity exists in congenital cytomegalovirus (cCMV) prevalence. In most studies, its impact on infant hearing, language acquisition, and childhood development represents a major determinant among non-Hispanic Black infants versus White infants. Further, opportunities for treatment have been promising using antiviral therapy. However, early detection of congenital CMV depends on identifying infants most at risk for the devastating effects, including sensorineural hearing loss in infancy and later childhood, by early screening and careful observation for clinical signs of infection in infants. Lantos et al. (2) reported that among infants born in North Carolina, CMV seropositivity was significantly more common among African Americans compared to Whites (odds ratios 3.31). They identified clusters of high and low CMV odds, primarily explained by race, and this disparity persisted across the lifespan. In the US, CMV immunoglobulin G seropositivity among women 20–49 years was greater than 85% among non-Hispanic Black individuals and approximately 50% for non-Hispanic White individuals (3). Congenital cCMV infections occur in an estimated 4.5 per 1000 live births in the US, and substantial racial and ethnic differences in prevalence exist, with non-Hispanic Black infants having a rate of nearly twice that of non-Hispanic White infants (4).

"Congenital cCMV infections occur in an estimated 4.5 per 1000 live births in the US, and substantial racial and ethnic differences in prevalence exist, with non-Hispanic Black infants having a rate of nearly twice that of non-Hispanic White infants."

However, in studies from Minnesota from 2106 to 2021, nearly 20,000 infants were screened for cCMV using dried blood spots and saliva collected within two weeks of birth with urine-confirmed nucleic acid amplification testing to corroborate positive saliva or dried blood spots. The cCMV prevalence among newborns of non-Hispanic Black and non-Hispanic White mothers was 5.1 and 4.6/1000, respectively, in contrast to prior estimates of 9.5 and 2.7 per 1000, respectively (5). Microcephaly, a prominent clinical

"The cCMV prevalence among newborns of non-Hispanic Black and non-Hispanic White mothers was 5.1 and 4.6/1000, respectively, in contrast to prior estimates of 9.5 and 2.7 per 1000, respectively. Microcephaly, a prominent clinical sign of cCMV infection, is reported to be seven-fold higher among non-Hispanic Black Americans compared to infants classified as White by Messinger et al. in 2020."

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sign of cCMV infection, is reported to be seven-fold higher among non-Hispanic Black Americans compared to infants classified as White by Messinger et al. in 2020 (6). Lucas et al. report that higher Neighborhood-level poverty found primarily among Black women in their study was primarily associated with maternal CMV positivity rates (7), although poverty alone also predicted an increased prevalence of maternal CMV positivity.

"Microcephaly, a prominent clinical sign of cCMV infection, is reported to be seven-fold higher among non-Hispanic Black Americans compared to infants classified as White by Messinger et al. in 2020."

Many state newborn screening programs are inundated by the increased burden of pregnancy-associated cytomegalovirus infection among African American mothers by testing during pregnancy. In about 1:200 of all infants born (0.5%) in the US, or ~21,000 infants annually, there is a disproportionate overrepresentation of infants with cCMV in minority populations. Among non-Hispanic Black infants, this rate is 7% in a recent report by Messinger et al. comparing infants born with microcephaly (symptomatic cCMV) among various racial groups (6). However, many infants (75%) will be generally asymptomatic at or soon after birth, with 20–25% of infants with cCMV neurosensory hearing loss identified on newborn hearing screens in one or both ears or later in childhood. As cCMV is the most significant non-genetic cause of hearing loss in infants and children, this healthcare disparity persists in many states not testing for cCMV, thus exacerbating the health inequity gap, placing Black infants at greater risk for delays in language acquisition and developmental delay detection and treatment.

"However, many infants (75%) will be generally asymptomatic at or soon after birth, with 20–25% of infants with cCMV neurosensory hearing loss identified on newborn hearing screens in one or both ears or later in childhood. As cCMV is the most significant non-genetic cause of hearing loss in infants and children, this healthcare disparity persists in many states not testing for cCMV, thus exacerbating the health inequity gap, placing Black infants at greater risk for delays in language acquisition and developmental delay detection and treatment."

In an era where promising antiviral therapies for congenital CMV result in lessening of sensorineual hearing loss, infants are neither screened for cCMV with neonatal blood spot testing nor considered for expanded targeted CMV testing despite being "referred" following initial newborn hearing screening. Several states have chosen to screen for CMV as a part of the newborn

"Targeted screening unfortunately misses up to 39% of infants who may pass the newborn hearing screening but develop sensorineural hearing loss later in childhood."

blood spot screen, while others have more targeted screening using infant saliva or urine based on symptoms and/or results of the newborn hearing screen. Targeted screening unfortunately misses up to 39% of infants who may pass the newborn hearing screening but develop sensorineural hearing loss later in childhood (8). While some states have focused on enhanced parental education regarding CMV during pregnancy, many others have embraced either universal screening using newborn blood spot analysis or targeted or enhanced screening of infants referred on their hearing screening exam and/or having clinical signs consistent with congenital viral infections such as microcephaly, prematurity, intrauterine growth restriction, unexplained jaundice, liver enlargement or thrombocytopenia.

"Many states have chosen to screen for much rarer hereditary and primarily metabolic conditions or very rare conditions, such as disorders of fatty acid oxidation with an incidence varying from 0.9 to 15.2 per 100,000 live births, but do not include cCMV as a part of their newborn screening panels."

Many states have chosen to screen for much rarer hereditary and primarily metabolic conditions or very rare conditions, such as disorders of fatty acid oxidation with an incidence varying from 0.9 to 15.2 per 100,000 live births, but do not include cCMV as a part of their newborn screening panels (8). While newborn blood spot screening is invaluable in detecting many conditions that are treatable in the newborn, it is unclear why cCMV has not been included. Whether these states have a bias or subtle systematic racism in their selection of tests included in their newborn screening panel is unknown. However, by June 2024, the Secretary of Health and Human Services has not placed cCMV testing on the approved screening list (although Krabbe disease [1:70:000 births] is included) despite its having been approved by the Health Resources and Services Administration.

Utah was the first state to use expanded targeting CMV testing of newborns based on clinical presentation (prematurity, intrauterine growth restriction, microcephaly, or unexplained jaundice OR failing their newborn hearing screening OR both). Several states

have followed Utah's example, the most recent of which was Colorado in 2024. Many other states are now expanding targeted screens. Minnesota and other states have taken a broader approach by universally screening all infants for CMV as a part of the newborn blood spot testing procedure and offering options for treatment. A national randomized clinical trial discussed in this issue is under way to demonstrate further the efficacy of antiviral therapy in reducing hearing loss. These efforts to identify congenitally-acquired CMV are the focus of peer-reviewed reviews in this month's *Neonatology Today*.

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Neonatal care providers and parents of cCMV infants have advocated for their infants diagnosed with congenital CMV regarding options for treatment that, in most studies, confirm a reduction of hearing loss, improved language acquisition, and decreased developmental delay. Since cCMV may be diagnosed using nucleic acid amplification testing from dried blood spots, urine, or saliva with high degrees of accuracy, as documented by Schleiss et al., failure to test for cCMV using either universal screening or expanded targeted screening exacerbates perinatal healthcare disparities affecting the most vulnerable and disadvantaged mothers and infants in our society. While more and more states have chosen to screen infants soon after birth (many using expanded targeted screening for CMV), unfortunately, many have not focused either on parent education about cCMV or not made early identification a priority. Based on the insightful articles

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in this issue by Schleiss et al. and by Pesch (former president of the National CMV Foundation), we believe there is a need for a concerted "call to action" for maternal and neonatal care providers in states and territories and their state public health agencies that do not screen for cCMV. We contend that screening newborns for cCMV soon after birth using either a universal or an expanded targeted approach will seriously narrow this racial disparity in providing improved care for all newborns, not only through case identification but also treatment with antivirals, hearing amplification, and cochlear implants to improve development during infancy and childhood.

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Disclosure: *The authors have no conflicts of interests to disclose.*

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Happy Labor Day Weekend, WiNners and Pathways Friends!

Clara Song, MD

"As we gear up for the holiday weekend, we wanted to take a moment to bring you all up to speed with the latest updates and upcoming events in our neonatal community. A lot is happening, so let us dive right in!"

As we gear up for the holiday weekend, we wanted to take a moment to bring you all up to speed with the latest updates and upcoming events in our neonatal community. A lot is happening, so let us dive right in!

AAP Elections Are Approaching:

It is that time of year again! The **AAP Elections** are just around the corner, running from September 11-25, 2024. These elections are vital to our professional community, and your participation ensures that our collective voice is heard. Voting allows us to shape the future direction of neonatology and advocate for the issues that matter most to us. So, watch your email for the voting link, and be ready to cast your vote when the time comes. Every vote counts in making a difference!

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Upcoming #NeoGrandRounds:

We are excited to announce the next session in our #NeoGrandRounds series, scheduled for September 17, 2024. This month, we have the privilege of hearing from Dr. Joseph Turek, who will be discussing a groundbreaking topic: "Partial Heart Transplant after Circulatory Collapse in the NICU." Dr. Turek is the Chief of Pediatric Cardiac Surgery at Duke Children's and the Executive Co-Director of the Pediatric & Congenital Heart Center. His work is at the cutting edge of pediatric heart surgery, and his insights will undoubtedly be invaluable for anyone involved in neonatal care.

This session is a fantastic opportunity for continuing education and professional development. Moreover, it is open to all, with no cost to attend. Participants can earn ABP Part 2 MOC and CME credits if they join in real time. So, please mark your calendars for Tuesday, September 17, 2024, at 12:15 PM PT / 1:15 PM MT / 2:15 PM CT / 3:15 PM ET, and make sure to join us for what promises to be a truly enlightening discussion.

"For those of you who could not attend the last few sessions, do not worry—we have got you covered. Recordings of our #NeoGrandRounds from June, July, and August 2024 are available to review at your convenience."

In Case You Missed It (#ICYMI):

For those of you who could not attend the last few sessions, do not worry—we have got you covered. Recordings of our **#NeoGrandRounds** from June, July, and August 2024 are available to review at your convenience. These sessions featured some of the leading voices in our field:

- **June 2024:** Dr. Satyan delivered an insightful presentation that delved into critical neonatal issues and the latest research.
- **July 2024:** Dr. Matt Harer shared his expertise, offering new perspectives on neonatal care and treatment strategies.
- **August 2024:** Dr. Rita Ryan's session was particularly impactful, discussing innovative approaches in neonatology that have the potential to transform patient care.

"Looking ahead, we are also excited about the 7th Annual #NeoResus Symposium, happening on September 12-13, 2024. This event has become a cornerstone for those of us focused on neonatal resuscitation and critical care. The symposium will feature various sessions designed to deepen our understanding and refine our skills in neonatal resuscitation."

All these recordings are available on Microsoft Teams and the Women Neonatologists YouTube channel. If you have not had a

chance to watch them yet, I highly recommend setting aside some time to do so. Each session has valuable insights and practical takeaways that can enhance your practice.

7th Annual #NeoResus Symposium:

Looking ahead, we are also excited about the **7th Annual #NeoResus Symposium**, happening on September 12-13, 2024. This event has become a cornerstone for those of us focused on neonatal resuscitation and critical care. The symposium will feature various sessions designed to deepen our understanding and refine our skills in neonatal resuscitation.

This year's symposium starts with a pre-symposium workshop on SALSA (Simulation-Assisted Life Support and Assessment), which promises to be a hands-on, interactive experience that will provide practical skills applicable to everyday clinical practice. Whether you are a seasoned professional or newer to the field, this symposium offers something for everyone. It is an incredible opportunity to engage with experts, learn about the latest advancements and network with colleagues who share your passion for neonatal care.

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#NeoIntensivists at NCE 2024 in Orlando:

This year's **NCE 2024 in Orlando** is shaping up to be a must-attend event for **#NeoIntensivists**. There is a packed agenda that's sure to offer something for everyone:

- **September 27, 2024:** The NRP Current Issues Seminar will kick off the event. This seminar is a crucial opportunity to stay updated on the latest developments and discussions in neonatal resuscitation practices. More details can be found here.
- **September 27-29, 2024:** The SONPM program will run throughout the weekend, featuring sessions on Artificial Intelligence in neonatology, Bioethics, Palliative Medicine, and more. This program will also include a special WiN session on Sunday to explore the intersection of women in neonatology and emerging trends in the field.
- **September 30, 2024:** Do not miss the AAP Business Lunch, where Dr. Lou Halamek will receive the prestigious 2024 AAP Education Award. This recognition highlights Dr. Halamek's significant contributions to neonatal education, and it is sure to be an inspiring moment for all attendees.

August WiN Webinar Recap:

We also want to take a moment to highlight the **August WiN Webinar**, which featured Dr. Liz Bonachea. Dr. Bonachea provided a comprehensive update on financial strategies tailored to busy neonatologists. Her presentation covered the basics of retirement accounts, effective strategies for long-term financial planning, and practical tips for managing finances amidst a demanding career. If you missed it, I strongly encourage you to watch the recording. It is packed with helpful advice to help you make informed financial decisions and plan for a secure future.



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Stay Informed:

As we head into the fall, there is plenty more on the horizon. Be sure to stay informed by regularly checking the **#AAPneonatal Calendar**. This is your go-to resource for all upcoming events, deadlines, and important updates in our community. Whether you are looking to participate in a webinar, attend a symposium, or stay connected with your peers, the calendar has all the details you need.

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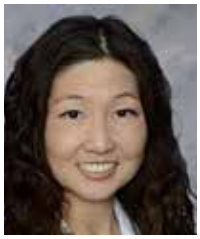
That is all for this month! Enjoy your weekend, rest well, and we will catch up again soon. Together, let us continue to advance our field and positively impact the lives of the newborns we care for.

Your #WomenNeo and #AllPath Leaders

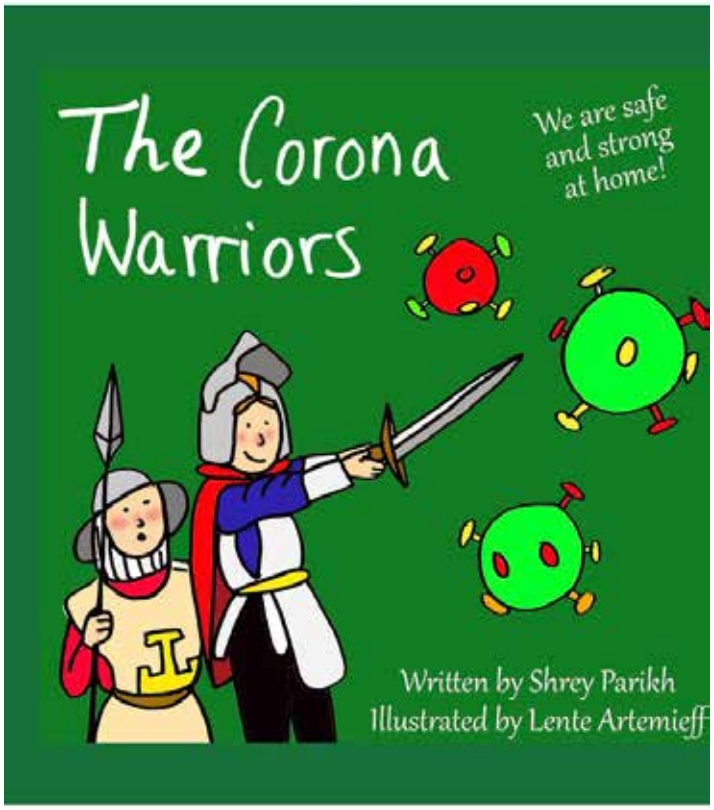
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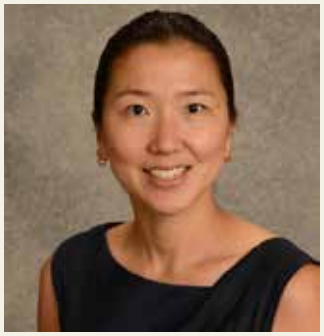
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September 12, 2024

11:00am-12:30pm PT

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Improving Family Engagement in the NICU: The Colorado Experience



Sunah Susan Hwang, MD, MPH, PhD (she/her)

The Lula O. Lubchenco Chair in Neonatal-Perinatal Medicine, University of Colorado School of Medicine

ICU baby's Work to Optimize NICU Health Literacy & Transportation Support



Elizabeth Simonton, JD (she/her)

Co-Founder & CEO, ICU baby

NICU Parent of Benedict

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FCC Taskforce Program Overview

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Feature on Mission and Key Objectives of the National CMV Foundation

T. Allen Merritt, MD, MHA, Mitchell Goldstein, MD, MBA, CML

Introduction: A New Mission to Prevent Congenital Cytomegalovirus (CMV):

In November 2020, the National CMV Foundation updated its mission and launched a new strategic plan. This marked the first revision in its six-year history, expanding the organization's initial goal from 2014, which focused on raising awareness and educating women of childbearing age about congenital CMV. As the largest national advocacy organization dedicated to congenital CMV, they are now prepared to tackle the broader challenge of eliminating CMV, the most common infectious cause of birth defects in the United States.

"As the largest national advocacy organization dedicated to congenital CMV, they are now prepared to tackle the broader challenge of eliminating CMV, the most common infectious cause of birth defects in the United States."

Their revised mission aligns with an urgent need. With public health and infectious disease being key concerns, the Foundation leverages new scientific advancements to reach its goal. This summary outlines the organization's updated vision, mission, values, and strategic goals shaping their work in the years ahead.

Vision:

To eliminate congenital cytomegalovirus (CMV) in the United States for the next generation.

Mission:

To prevent pregnancy loss, childhood death, and disability caused by congenital CMV.

"The National CMV Foundation's work is built on a foundation of five core values: leadership, passion, innovation, excellence, and integrity. Leadership involves advancing scientific understanding through collaboration, while passion drives their advocacy for the CMV community. The organization fosters innovation by seeking fresh ideas and disrupting old norms."

Values:

The National CMV Foundation's work is built on a foundation of five core values: leadership, passion, innovation, excellence, and integrity. Leadership involves advancing scientific understanding through collaboration, while passion drives their advocacy for the CMV community. The organization fosters innovation by seeking fresh ideas and disrupting old norms. Excellence is a non-negotiable standard, ensuring credibility and impact. Integrity underpins their transparency and accountability as they work to form partnerships that move the mission forward.

Strategic Goals and Key Activities:

The National CMV Foundation has developed five primary strategic

goals designed to further its mission and improve outcomes for families affected by congenital CMV.

"The Foundation is committed to increasing awareness of congenital CMV through federal, state, and local advocacy. They plan to resubmit the RUSP (Recommended Uniform Screening Panel) application, advocate for creating a national CMV patient registry, and push for newborn screening studies."

Raise Awareness through Advocacy:

The Foundation is committed to increasing awareness of congenital CMV through federal, state, and local advocacy. They plan to resubmit the RUSP (Recommended Uniform Screening Panel) application, advocate for creating a national CMV patient registry, and push for newborn screening studies. They will also collaborate with federal agencies to improve the distribution of CMV-related information.

"The Foundation is committed to increasing awareness of congenital CMV through federal, state, and local advocacy. They plan to resubmit the RUSP (Recommended Uniform Screening Panel) application, advocate for creating a national CMV patient registry, and push for newborn screening studies."

Accelerate Mission-Driven Research:

Establishing itself as a leader in CMV research, the Foundation will prioritize studies focused on pregnancy loss, childhood death, and disability prevention due to CMV. They are dedicated to funding high-impact research, partnering with other organizations to advance research priorities, and addressing disparities in CMV outcomes. The Foundation will also reconvene the International CMV Consensus Group to refine research goals.

Target Education Programs:

The Foundation aims to enhance its influence among healthcare providers and policymakers by promoting CMV prevention and newborn screening. They are positioning themselves as a premier source for reliable CMV information and will expand their CMV Community Alliance Program to increase outreach. They seek to improve access to CMV resources and support services in collaboration with national and international partners.

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Grow Resources in Support of the Mission:

The Foundation is focused on increasing revenue and building organizational infrastructure to sustain growth. They will invest in capacity-building for staff, volunteers, and board members while adhering to best governance practices. Expanding their donor base through diverse fundraising efforts is crucial to ensure continued mission-driven growth.

Demonstrate Commitment to Diversity, Equity, and Inclusion:

The Foundation is committed to promoting diversity, equity, and inclusion in all aspects of its work. They will ensure that their programs, resources, and educational materials are culturally and linguistically appropriate. The Foundation also plans to increase the representation of marginalized communities in their CMV Family Database and prioritize research into disparities in CMV outcomes. By bringing a broader range of voices and perspectives into leadership, they will continue building an inclusive and accessible environment.

"The National CMV Foundation's updated mission and strategic plan provide a clear roadmap for the organization's work through 2024. Guided by a commitment to awareness, research, education, resource growth, and inclusion, they are driven to make congenital CMV preventable. With the support of their network of advocates, donors, and partners, the Foundation is well-positioned to lead the way in eliminating CMV and safeguarding the health of future generations."

Conclusion:

The National CMV Foundation's updated mission and strategic plan provide a clear roadmap for the organization's work through 2024. Guided by a commitment to awareness, research, education, resource growth, and inclusion, they are driven to make congenital CMV preventable. With the support of their network of advocates, donors, and partners, the Foundation is well-positioned to lead the way in eliminating CMV and safeguarding the health of future generations.

***Disclosures**: The authors have no relevant disclosures.*

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Feature on Hands & Voices: Advocacy for Children with Hearing Loss

T. Allen Merritt, MD, MHA, Mitchell Goldstein, MD, MBA, CML



"In addition to the National CMV Foundation, we are delighted to highlight the work of Hands & Voices, an organization dedicated to supporting families of children who are deaf or hard of hearing."

Our August 2024 edition of Neonatology Today highlights newborn and childhood deafness associated with congenital cytomegalovirus (CMV), the most prevalent cause of non-genetic hearing loss that can extend into childhood and contribute to developmental delays. As part of our commitment to supporting early detection and intervention, we are proud to feature non-profit advocacy groups that are making a significant impact. In addition to the National CMV Foundation, we are delighted to highlight the work of Hands & Voices (https://www.handsandvoices.org/), an organization dedicated to supporting families of children who are deaf or hard of hearing.

About Hands & Voices

Hands & Voices is an international non-profit organization driven by a simple but powerful mission: to support families with children who are deaf or hard of hearing, regardless of the communication methods they choose. Their mission is to provide parents with the information, support, and encouragement they need to make informed decisions for their children, fostering the potential of every child to thrive in a world full of possibilities.

"Hands & Voices is an international non-profit organization driven by a simple but powerful mission: to support families with children who are deaf or hard of hearing, regardless of the communication methods they choose. Their mission is to provide parents with the information, support, and encouragement they need to make informed decisions for their children, fostering the potential of every child to thrive in a world full of possibilities."

Founded by parents, Hands & Voices has grown into a global network of chapters and members who share a common goal—to ensure that deaf and hard-of-hearing children have access to the resources they need to reach their highest potential. The organization operates with a philosophy of non-biased support, emphasizing the importance of informed decision-making and empowering families to advocate for their children.

Vision and Reach

The vision of Hands & Voices is to see a world where all children who are deaf or hard of hearing have access to a full and productive life. Their work spans early intervention, educational advocacy, and family support, offering a lifeline to parents navigating the challenges of raising a child with hearing loss. Whether through personalized support, educational resources, or connecting families with local communities, Hands & Voices ensures that no family walks this journey alone.

With chapters across the United States and internationally, Hands & Voices is a beacon of hope for families, providing tailored support and resources that reflect the diverse needs and experiences of the deaf and hard-of-hearing community.

"As we advocate for universal newborn screening for congenital CMV and raise awareness of its impact on childhood hearing loss, we honor Hands & Voices' involvement in this vital conversation."

Join Us in Advocacy

As we advocate for universal newborn screening for congenital CMV and raise awareness of its impact on childhood hearing loss, we honor Hands & Voices' involvement in this vital conversation. By sharing their mission, vision, and the work of their chapters, we can amplify our collective efforts to ensure that every child, regardless of hearing ability, has the opportunity to thrive. Together, we can make a difference in the lives of children and families impacted by hearing loss.

***Disclosures**: The authors have no relevant disclosures.*

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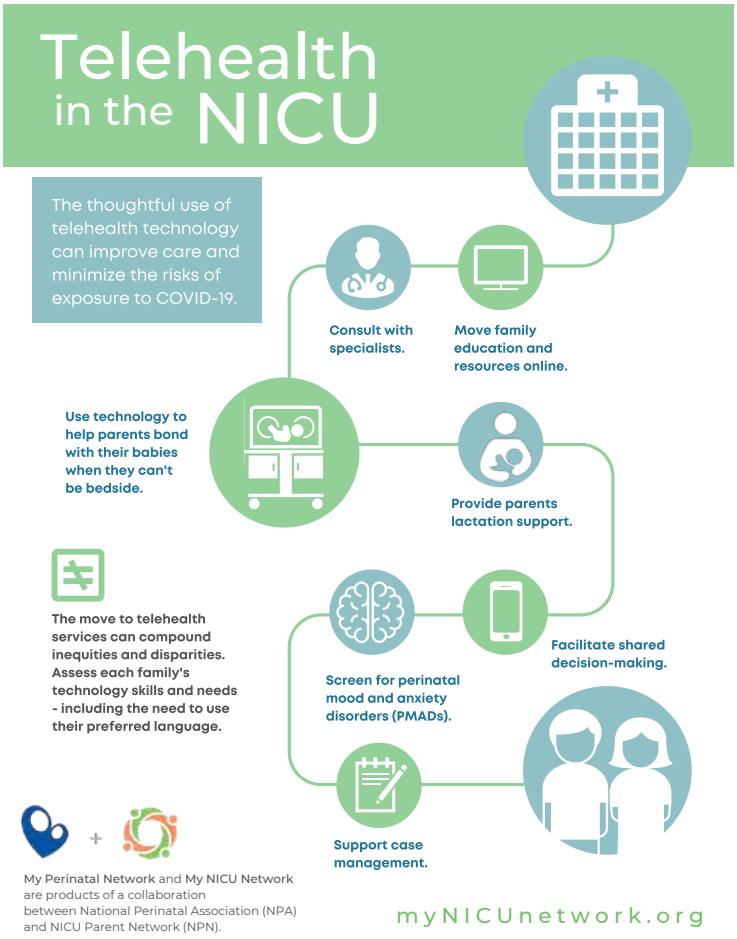


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Next-Level Perinatal Palliative Care Live Training Course

September 18-20, 2024

Columbia University Irving Medical Center

New York, NY

REGISTER TODAY!

Perinatal palliative care offers a plan for improving quality of life of infants who are affected by life-limiting conditions with a potential of short life expectancy.

This training is designed for the entire perinatal team: physicians, nurses, midwifes, nurse practitioners, physician assistants and other allied health professionals practicing in the perinatal arena (obstetrics and neonatology) interested in improving the practice of perinatal palliative care, both nationally and internationally. The course faculty will discuss evidence-based rationale, practical aspects and strategies to provide support for families and achieve a state of comfort for newborns with life-limiting conditions.

The 3-day course will include didactic presentations followed by live Q & A sessions to cover all aspects of perinatal palliative care.

Training Objectives

1. Identify the essential elements of prenatal and neonatal palliative consult.
2. Describe pregnancy and delivery management with fetal diagnosis of life limiting condition when mothers elect to continue the pregnancy.
3. Identify newborns' basic needs and apply strategies to successfully achieve a state of comfort for newborns with life-limiting or life-threatening conditions.
4. Identify families' needs and apply strategies to successfully achieve support when they have a newborn with a life-limiting condition.

Continuing Medical Education (CME)
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CME and CNE credits have been requested.

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NEONATAL Comfort Care PROGRAM

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2024 Next-Level Perinatal Palliative Care Training Course, September 18-20, 2024, Columbia University Irving Medical Center

Elvira Parravicini, MD

"Perinatal detection of congenital anomalies leads to the identification of women facing a fetal diagnosis of a life-limiting condition who elect to continue the pregnancy and deliver infants with a short life expectancy."

Program description and objectives

Perinatal detection of congenital anomalies leads to the identification of women facing a fetal diagnosis of a life-limiting condition who elect to continue the pregnancy and deliver infants with a short life expectancy. Perinatal palliative care offers a plan for improving the quality of life of the infant and the family when extending the baby's life is no longer the goal of care. The evidence base for perinatal palliative care continues to grow. However, there is no consensus about the best clinical practice for promoting support for the family or comfort for the neonate. Support for the family is achieved through appropriate pre- and postnatal consults, shared decision-making, and advanced care planning. A state of comfort for the neonate is achieved when relational basic needs such as bonding, maintaining body temperature, relief of hunger/thirst, and alleviating pain/discomfort are met.

This course will include information about the successful experiences of the Neonatal Comfort Care Program in providing perinatal palliative care for over a decade at Columbia University Irving Medical Center (CUIMC). Moreover, the course faculty will discuss the evidence-based rationale, practical aspects, and strategies for implementing and applying CUIMC to support families and comfort newborns with life-limiting conditions.

"This course will include information about the successful experiences of the Neonatal Comfort Care Program in providing perinatal palliative care for over a decade at Columbia University Irving Medical Center (CUIMC)."

This three-day course will cover virtually all aspects of perinatal palliative care. Topics include 1) the current state of the science on perinatal palliative care, 2) obstetric management of women who elect to continue their pregnancy with fetal life-limiting diagnoses, 3) definition and roles of the members of the interdisciplinary team, 4) essential elements of perinatal palliative consult, 5) advance care planning, 6) essential elements of a neonatal comfort care plan, 7) evidence-based interventions in the prenatal, intrapartum and postnatal periods that promote the health of the mother and family, 8) ethical elements of perinatal palliative care.

The three-day course will include didactic presentations, practical applications, hands-on training, role-play, videos, and Q&A sessions. An extensive syllabus will be provided. After this three-day course the following objectives will be met: Participants will 1) identify the evidence-base to implement perinatal palliative care within their organization, 2) list interventions that promote the health of women with fetal life-limiting diagnoses during pregnancy, labor, and delivery, 3) recognize members of the interdisciplinary team, 4) apply four essential elements into a perinatal palliative consult, 5) develop a mechanism to guide advance care planning, 6) formulate a comprehensive neonatal comfort plan, 7) list interventions that promote the health of the mother and the family during the prenatal, intrapartum and postnatal periods, 8) list ethical principles associated with perinatal palliative care.

This activity is designed for the entire perinatal team: physicians, nurses, nurse practitioners, physician assistants, and other allied health professionals practicing in the perinatal arena (obstetric and neonatology) interested in improving the practice of perinatal palliative care, both nationally and internationally.

***Disclosures**: The authors have no relevant disclosures.*

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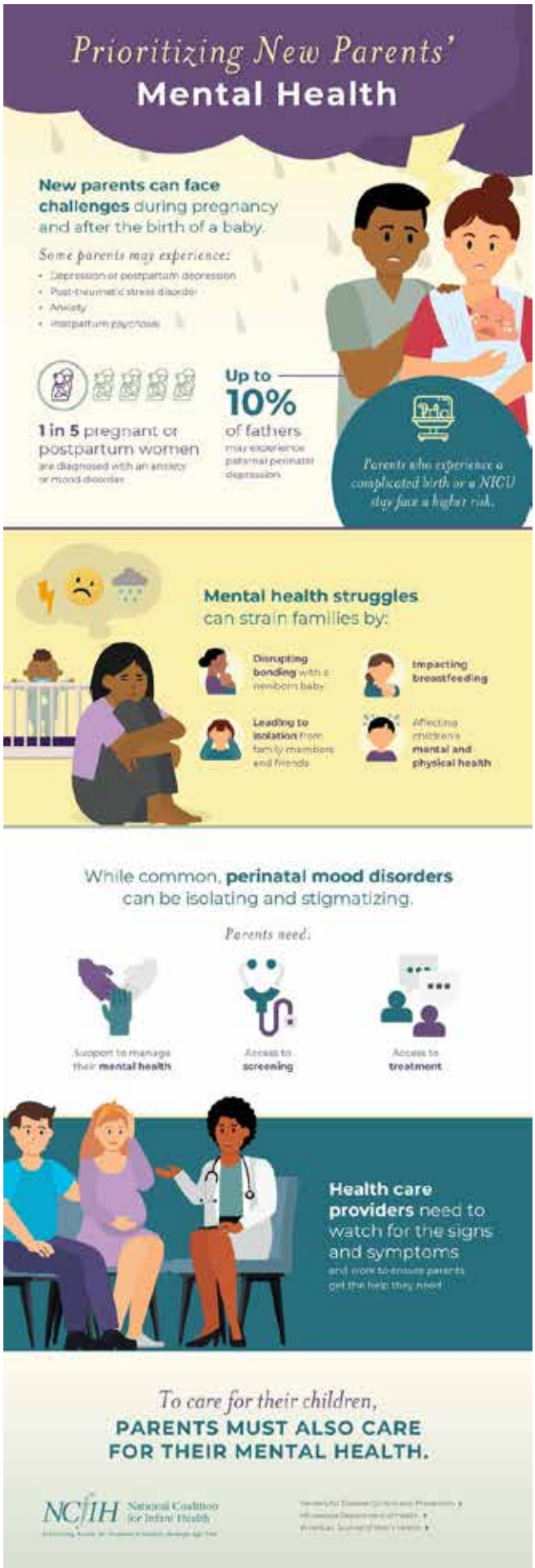
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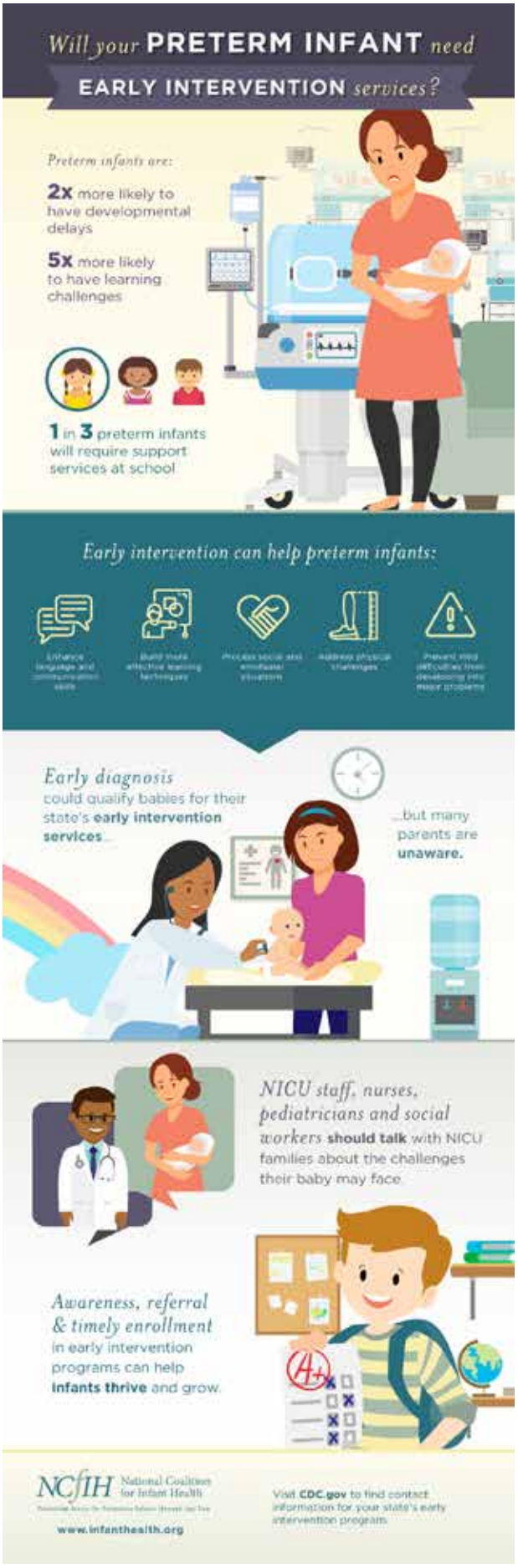
Additional Information

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Attendance by complete physician-nurse-respiratory therapist teams is strongly recommended


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


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:
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
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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.

infanthealth.org

Ethics and Wellness: The Delicate Balance of Competition and Collaboration in Neonatology Academic Practice

Mitchell Goldstein, MD, MBA, CM , Lily Martorell-Bendezu, MD

" Academic practice in this field is no exception, and competition can drive innovation, pushing clinicians and researchers to develop new treatments, refine techniques, and improve outcomes. However, there is a fine line between healthy competition that fosters progress and destructive rivalry that undermines the very mission of patient care. (1,2,3)"

In the high-stakes world of neonatology, where the lives of the most vulnerable patients hang in the balance, the pressure to excel is intense. Academic practice in this field is no exception, and competition can drive innovation, pushing clinicians and researchers to develop new treatments, refine techniques, and improve outcomes. However, there is a fine line between healthy competition that fosters progress and destructive rivalry that undermines the very mission of patient care. (1,2,3)

"When channeled effectively, competition can be a powerful catalyst for positive change. It encourages the pursuit of excellence, motivates individuals to go the extra mile, and can lead to breakthroughs that benefit patients and families"

When channeled effectively, competition can be a powerful catalyst for positive change. It encourages the pursuit of excellence, motivates individuals to go the extra mile, and can lead to breakthroughs that benefit patients and families. Within an academic setting, it can spur advancements in research, prompt the adoption of best practices, and elevate the overall standard of care. This kind of competition, grounded in a collective goal to improve outcomes for neonates, is invaluable. (2, 4)

However, competition for its own sake, or when taken too far, can become detrimental. When the focus shifts from patient-centered care to personal or institutional gain, the dynamics of a team can be severely compromised. It becomes easy for someone to be marginalized simply because they are not perceived as "competitive" enough, leading to a toxic environment where collaboration is stifled, and the quality of care suffers.

"When the focus shifts from patient-centered care to personal or institutional gain, the dynamics of a team can be severely compromised. It becomes easy for someone to be marginalized simply because they are not perceived as 'competitive' enough, leading to a toxic environment where collaboration is stifled, and the quality of care suffers."

At its most extreme, unchecked competition can devolve into warfare within the team. Vendettas and retaliation—whether overt or subtle—can surface, creating a counterproductive cycle of conflict and division. This harms those directly involved and casts a shadow over the entire practice, eroding trust and morale. (5)

"Even in the face of adversity, ethical behavior must prevail, including maintaining transparency in all questionable or marginal circumstances."

It is in these moments that the importance of optics cannot be overstated. Even if someone feels wronged or treated poorly, retaliation—no matter how justified it may seem—is never the answer. It is unethical and perpetuates a harmful culture that ultimately detracts from patient care. Even in the face of adversity, ethical behavior must prevail, including maintaining transparency in all questionable or marginal circumstances.

" In a field as critical as neonatology, where collaboration and trust are essential, upholding ethical standards is not just a matter of professional integrity but a fundamental requirement for delivering the best possible care to our patients. (7)"

Transparency, in particular, is crucial in fostering an environment where everyone is treated with equity and respect.(6) It ensures

that decisions are made openly and fairly, reducing the risk of misunderstandings and resentment. In a field as critical as neonatology, where collaboration and trust are essential, upholding ethical standards is not just a matter of professional integrity but a fundamental requirement for delivering the best possible care to our patients. (7)

"Ultimately, the goal should be to create an ethical environment where competition drives progress, but not at the expense of the team or the patients. In such an environment, every team member is valued, collaboration is encouraged, and the focus remains squarely on providing the highest quality care."

Ultimately, the goal should be to create an ethical environment where competition drives progress, but not at the expense of the team or the patients. In such an environment, every team member is valued, collaboration is encouraged, and the focus remains squarely on providing the highest quality care. Only then can we honestly say that we are fulfilling our mission as neonatologists. (8)

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Disclosures: The authors have no disclosures

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Fellows Column: A Neonatal Case of False Negative Rectal Biopsy

Arun Kharel, MD, Parama Sahoo, MD, MBA, Shabih Manzar, MD, MPH

"We describe a case of a neonate who had persistent abdominal distension and difficulty in passing stool without assistance. The differential diagnosis and management are presented with a particular focus on rectal biopsy (RB) in diagnosing Hirschsprung's disease. Although RB is deemed a valuable test, it could also be a false negative test with low sensitivity."

Abstract:

We describe a case of a neonate who had persistent abdominal distension and difficulty in passing stool without assistance. The differential diagnosis and management are presented with a particular focus on rectal biopsy (RB) in diagnosing Hirschsprung's disease. Although RB is deemed a valuable test, it could also be a false negative test with low sensitivity.

Keywords:

Delayed passage of meconium, Rectal biopsy, Hirschsprung Disease, Neonate, False negative

"Of the many discrete criteria that we establish for an infant to be discharged from the NICU or the nursery – one of the most critical criteria remains to be the passage of meconium within the first 24 to 48 hours of birth."

Introduction:

Of the many discrete criteria that we establish for an infant to be discharged from the NICU or the nursery – one of the most critical criteria remains to be the passage of meconium within the first 24 to 48 hours of birth. While up to 99% of full-term infants are expected to pass meconium within the first 24 hours, the timeline increases to the first 48 hours for preterm infants (1). Failure to pass meconium in the backdrop of abdominal distension, as noted in our case, leads to an extensive list of differential diagnoses. These predominantly stem from concerns of a physical intestinal obstruction and can range from large to small bowel obstruction. We present a case of Hirschsprung's disease that baffled the team with his clinical course.

Case Presentation

A 4-day-old male neonate was transferred to our NICU from lower tier NICU for concerns of abdominal distension and failure to pass meconium. He was delivered via cesarean section to a G3, now P0121 mother at 36 weeks and 1 day due to maternal indications of gestational hypertension and pre-eclampsia, with APGARs of 6 at 1 minute and 8 at 5 minutes.

"A 4-day-old male neonate was transferred to our NICU from lower tier NICU for concerns of abdominal distension and failure to pass meconium. He was delivered via cesarean section to a G3, now P0121 mother at 36 weeks and 1 day due to maternal indications of gestational hypertension and pre-eclampsia, with APGARs of 6 at 1 minute and 8 at 5 minutes."

While the other NICU had noted some bowel movements on the second day of life, they quickly noticed that the child had progressively increasing abdominal distension and intolerance of feeding. A nasogastric tube and green-colored aspirates were suctioned back, causing concerns for intestinal obstruction. The infant's vitals were noted to be within normal limits. Significant abdominal distension was noted on physical examination, with no palpable masses or hernias. An anal inspection was performed, which showed a patent anus with no associated anomalies. His laboratory testing revealed an elevated magnesium level of 4.3 mg/dL (normal range between 1.6-2.6 mg/dL) except for a urine drug screen positive for barbiturates as the mother had received a combination medication for pain control during delivery, which included the drug butalbital. A plain abdomen X-ray showed dilated bowel loops with no air-fluid levels (Figure 1- A).



Figure 1-A: Serial abdominal X-rays: A – day of life 4

The infant was placed NPO, a nasogastric tube was placed for gastric decompression, and the infant was started on maintenance intravenous fluids followed by a transition to total parenteral nutrition. The infant received empiric ampicillin and gentamicin; blood cultures were sent, which showed no growth at five days. Pediatric surgery was consulted, and a contrast enema was used as a first step. The enema revealed a rectum smaller than the sigmoid colon, with findings concerning for Hirschsprung's disease. An upper gastrointestinal (GI) follow-through imaging revealed no abnormalities of the upper GI. Significant gaseous dilatation of the bowel loops with residual contrast in the rectum was noted, once again, to be possibly seen with distal obstruction – specifically Hirschsprung's.

"Initial rectal biopsy failed due to copious amounts of meconium present upon introduction of the biopsy probe. A repeat rectal biopsy successfully obtained approximately 2.5 cm above the dentate line was sent to pathology."

Initial rectal biopsy failed due to copious amounts of meconium present upon introduction of the biopsy probe. A repeat rectal biopsy successfully obtained approximately 2.5 cm above the dentate line was sent to pathology. The specimen obtained showed positive ganglion cells and mucosal neurites in the tissue specimen, ruling out Hirschsprung's Disease. (Figures 2 and 3) The infant had several spontaneous bowel movements following rectal biopsy. The infant did not continue to have spontaneous bowel movements after this. He developed progressive abdominal distension once again and required either glycerin suppositories or rectal stimulation to have a bowel movement. The follow-up x-rays on days 15 and 29 of life showed persistently dilated loops (Figure 1 - B and C). The infant was transferred to a higher care center for further evaluation, where he had a repeat rectal biopsy of 2 cm and 3 cm from the anal verge. Pathology noted rare ganglion cells on routine hematoxylin and eosin-stained sections at 2 cm and none at 3 cm. Marginally hypertrophic nerve trunks were also seen. A calretinin immunostain highlighted rare linear and punctate positivity at 2 cm, but expression overall was markedly reduced and was essentially absent at 3 cm. These findings confirmed a diagnosis of ultrashort-segment Hirschsprung's disease. The infant was sent home with the parents trained on rectal irrigation with scheduled follow-up with Pediatric surgery and gastroenterologist.

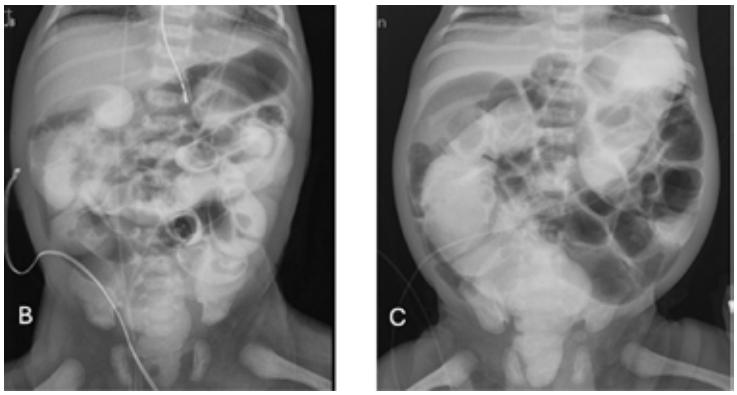


Figure 1-B, C: Serial abdominal X-rays: B – day of life 15, C – day of life 29

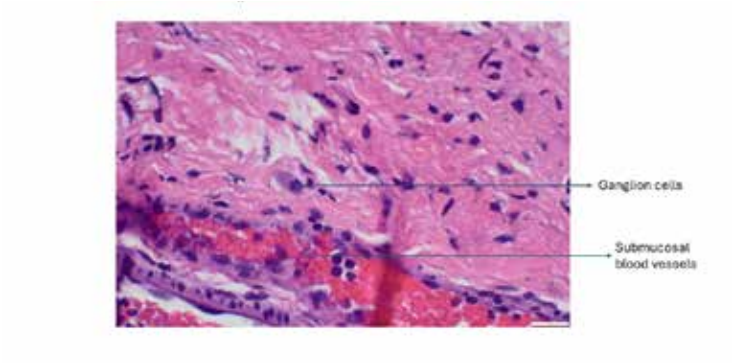


Figure 2: Magnified histopathology view of the rectal specimen

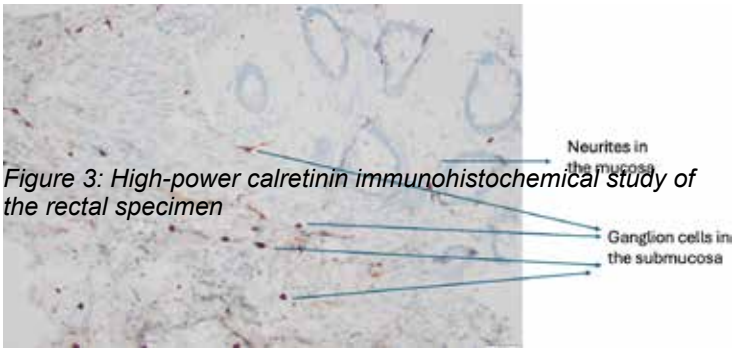


Figure 3: High-power calretinin immunohistochemical study of the rectal specimen

Discussion:

Up to 20-25% of neonatal bowel obstruction is attributable to Hirschsprung's, and this continues to remain a leading diagnosis in an infant that presented like our case (2). Aganglionosis is pathognomonic for Hirschsprung's, and the initial biopsy performed would ideally have picked up on the most familiar type of Hirschsprung's – the "short-segment disease" which is limited to the rectum and sigmoid colon. This accounts for 80-85% of all Hirschsprung cases (3). While this can often pick up on the aganglionosis involving a greater segment proximally to the sigmoid colon (long-segment disease) and the rare total colonic aganglionosis (3) – this misses the equally rare ultrashort-segment disease (3, 4).

Of paramount importance here is to, first and foremost, develop an excellent clinical picture by examining the infant daily and closely watching bowel movements, the amounts, as well as frequency. As in our infant, the passage of meconium or the intermittent passage of stools is not enough to pinpoint a diagnosis. At the same time, intermittent tolerance of feeds, initial examination/passage of meconium, and imaging were enough to exclude the diagnosis of intestinal obstructions at various points (for instance, duodenal or other intestinal atresias, gut malrotations, intestinal volvulus) or obstructions due to etiologies such as meconium ileus and meconium plug. Furthermore, it is imperative to ensure a patent and proper anal opening, as opposed to an anal malformation such as a fistula.

As those are excluded, further differentials of infant dyschezia,

colonic dysmotility, or anal achalasia should be considered. As noted above, a repeat biopsy at a lower level has a significant predictive value in including or excluding Hirschsprung's and should be performed to ensure the presence or absence of ganglion cells.

"Although rare, it is critical to diagnose and treat ultrashort-segment Hirschsprung's. The complications of intestinal obstruction can be just as critical as short-segment Hirschsprung's. Infants may present with life-threatening enterocolitis, sepsis, volvulus, progression to toxic megacolon, and rarely neonatal appendicitis and appendiceal perforation (5-8)."

Although rare, it is critical to diagnose and treat ultrashort-segment Hirschsprung's. The complications of intestinal obstruction can be just as critical as short-segment Hirschsprung's. Infants may present with life-threatening enterocolitis, sepsis, volvulus, progression to toxic megacolon, and rarely neonatal appendicitis and appendiceal perforation (5-8).

Conclusion:

In conclusion, the development of a differential diagnosis is critical to the evolving management of an infant admitted to the NICU for concerns of abdominal distension. While laboratory testing can help guide the infant's clinical management, imaging is imperative to shed light on the status of the bowels and indicate the need for emergent surgical management in situations such as intestinal obstructions, volvulus, or emergent complications of Hirschsprung's, as discussed above.

Furthermore, keeping in mind that almost 25% of neonatal obstructions can be attributed to Hirschsprung's, lower anal segment differentials should not be excluded simply after a normal rectal biopsy at a high level or after intermittent passage of stools. There is great value in doing a repeat biopsy at a lower level to ensure the visualization of ganglion cells through the entirety of the colonic tract, as the management differs significantly. However, always remember that a rectal biopsy could be a false negative with a low sensitivity.

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Acknowledgment: *We thank Dr. Kshitij Arora, Assistant Professor, Department of Pathology, Louisiana State University Health Shreveport, for providing us with the slides.*

Disclosures: The authors have no relevant disclosures.

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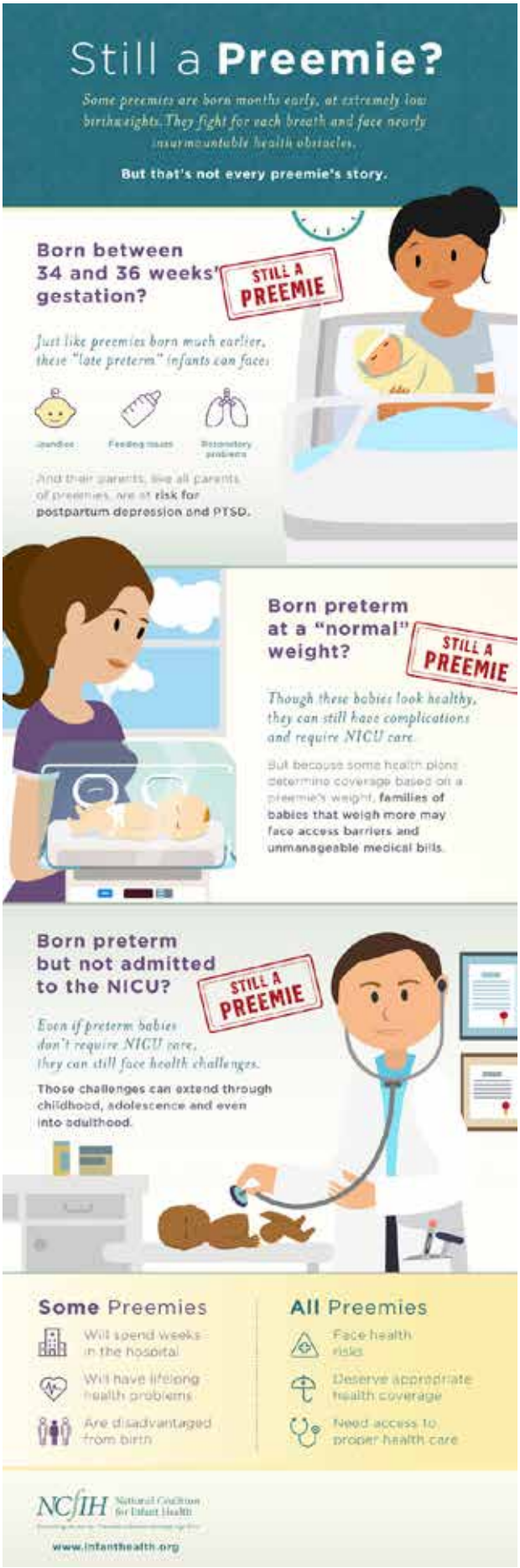
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AngelEye Health Services Driving Quadruple Aim Objectives in Neonatal Units

Nicole Nyberg, MSN, APRN, NNP-BC, Christopher Rand, Jaylee Hilliard, MSN, RN, NEA-BC, CPXP



In today's healthcare landscape, the Quadruple Aim framework has become integral for guiding improvements in healthcare systems. Developed by the Institute for Healthcare Improvement, this framework focuses on enhancing the patient and family experience, improving population health, reducing costs, and supporting healthcare team well-being. In neonatal and pediatric departments, leveraging services that promote family engagement is one powerful strategy to meet these objectives effectively. By enhancing the family experience, streamlining care delivery, minimizing costs, and improving health outcomes, AngelEye Health aligns with the Quadruple Aim framework to achieve comprehensive healthcare improvements for staff and families, fostering a supportive healthcare environment for all stakeholders.

AngelEye Health's Commitment To Family-Integrated Care

AngelEye Health is dedicated to promoting family-integrated care, particularly in neonatal settings. Our HIPAA-compliant Family Engagement services, including NICU2Home™, CameraSystem™, and MilkTracker™, actively incorporate parents into their child's care team, fostering a collaborative environment that benefits the family and the care team. Technology-supported services improve the family experience by establishing a continuous, reassuring connection and contribute to better health outcomes through more informed, engaged, and competent families. (1)

"Our HIPAA-compliant Family Engagement services, including NICU2Home™, CameraSystem™, and MilkTracker™, actively incorporate parents into their child's care team, fostering a collaborative environment that benefits the family and the care team."

NICU2Home:

NICU2Home is the first evidence-based NICU navigation and discharge coordination solution to support families and care teams. It is designed to enhance neonatal outcomes by providing families with continuous education, information, and support from their initial moments in the NICU through their hospital stay and extending six months post-discharge. The solution's seamless integration with electronic health records (EHR) ensures that the information provided to parents is tailored to each infant's unique journey. Additionally, the comprehensive platform supports health

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literacy by being available in 70 languages and simplified to a 5th-grade reading level. This comprehensive support system improves parental competence, facilitating a smoother transition to home, leading to better health outcomes, improved parent satisfaction, and reduced hospital costs.

"The solution's seamless integration with electronic health records (EHR) ensures that the information provided to parents is tailored to each infant's unique journey."

Furthermore, NICU2Home proactively addresses social determinants of health (SDOH) by notifying the NICU care team about families requiring extra support and resources. With its user-friendly dashboard, NICU2Home enables clinicians to track parental progress, helping to minimize discharge delays efficiently. Delivering comprehensive coverage of essential educational content increases the care team's satisfaction.

Improving Health Outcomes:

The NICU2Home solution aims to improve neonatal outcomes by enhancing parental understanding of their infant's clinical condition, boosting their confidence, and reducing parental traumatic stress. This integrated support structure equips families with the knowledge and confidence needed to care for their child, ensuring a smoother transition to home and ultimately improving overall health outcomes (1)

"Furthermore, NICU2Home proactively addresses social determinants of health (SDOH) by notifying the NICU care team about families requiring extra support and resources. With its user-friendly dashboard, NICU2Home enables clinicians to track parental progress, helping to minimize discharge delays efficiently."

NICU interventions that include key components like improved parent-infant interactions, education, guided observations, active involvement, and tailored support reduce maternal stress and depression, improve infant growth and development, and enhance interactive behaviors (2) significantly. A quasi-experimental study showed that integrating family-centered and developmental care enhances neurodevelopmental outcomes and reduces hospitalization for high-risk neonates compared to standard care. (3) Additionally, implementing FCC contributes positively to neonatal growth, early development, and long-term health outcomes, including children's psychological, emotional, and neurobehavioral development. (2) Overall, NICU2Home improves health outcomes by enhancing parental understanding of their child's condition and increasing engagement, leading to more effective care and better developmental outcomes for high-risk neonates.

Improving Patient and Family Experience:

The NICU2Home solution fosters a seamless experience from the infant's NICU admission through six months post-discharge. This increased parental education and engagement reduces anxiety and empowers families with the confidence to care for their children. In a 2022 study by Garfield et al., parents who utilized NICU2Home reported higher parental self-efficacy in the NICU and post-discharge. By fostering a more seamless experience, NICU2Home markedly improves patient outcomes and enhances the family experience.

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Clear and effective communication is crucial in neonatal care, as it alleviates family stress and fosters trust between healthcare providers and families. Clear, consistent, and readily available communication in the family's native language supports a nurturing environment where parents feel well-informed and actively involved in their child's care.

Reducing Costs:

The financial burden of neonatal and pediatric hospital stays is significant, making cost reduction a priority for healthcare leaders. Enhanced parental engagement and confidence result in fewer readmissions of NICU patients. The streamlined discharge processes reduce discharge delays and associated costs. Research shows that the NICU2Home platform boosts parental competence, can shorten hospital stays, and lower readmission rates, leading to significant cost savings (4) Unplanned hospital readmissions for extremely low birth weight infants are the most expensive compared to all other types of patients, with a mean cost of $25,295 (5) This finding underscores the potential for targeted interventions, like NICU2Home, to significantly reduce healthcare costs for this group.

Improving Provider Satisfaction:

One challenge in the discharge process is the lack of standardized education provided throughout the NICU journey. NICU clinicians often become frustrated by their inability to track where families are in the process due to the absence of a consistent method or comprehensive solution. Consequently, clinicians spend more time getting families up to speed in the last 48–72 hours before discharge, which can ultimately lead to some families falling through the cracks.

"The streamlined discharge processes reduce discharge delays and associated costs. Research shows that the NICU2Home platform boosts parental competence, can shorten hospital stays, and lower readmission rates, leading to significant cost savings."

The automated, patient-specific information sent to families throughout the NICU stay allows clinicians to focus on more immediate hands-on educational opportunities. NICU2Home enables clinicians to standardize and streamline their discharge education process, alleviating variables and ensuring consistent communication with the family.

NICU2Home's user-friendly dashboard empowers clinicians to monitor parental progress efficiently, reducing discharge delays. Ensuring that critical educational content is consistently covered increases the care team's satisfaction, reinforcing their confidence in delivering high-quality patient care.

CameraSystem

Parents with a child admitted to the NICU often face psychological distress, altered parental roles, and disruptions in parent-infant bonding. A 2016 study by Baía found that parents experienced heightened stress levels due to separation from their infants, the inability to provide care, and disrupted bonding, which added to the already significant stress of the NICU environment and all its demands.(6) Poor parental mental health further exacerbates the challenges of bonding in the NICU setting.

AngelEye Health's CameraSystem provides parents with live-streaming video access to their children. This innovative solution allows care teams to share patient-specific updates and memorable moments through real-time texts, photos, and videos. By integrating these features, the CameraSystem helps alleviate the anxiety experienced by NICU parents, promote parental engagement, and foster stronger connections even when they cannot be physically present at the hospital (7)

Improving Health Outcomes:

When parents can bond with their infants despite their physical presence, they experience less distress, have improved mental well-being, and form stronger attachments, leading to better long-term outcomes for both the infant and the family. Forming solid attachments is fundamental for optimal infant growth and brain development in the first two years of life. (8) Interventions that promote parent-infant attachment are effective in relieving maternal traumatic stress, maternal depression, infant weight growth, and infant development (2) Additionally, deeper parent-infant connections promote the use of maternal milk and enhance parental participation in care, contributing to better health outcomes.

"AngelEye Health's CameraSystem provides parents with live-streaming video access to their children. This innovative solution allows care teams to share patient-specific updates and memorable moments through real-time texts, photos, and videos. "



Improving Patient and Family Experience:

Family engagement solutions such as AngelEye Health's CameraSystem play a crucial role in reducing parental distress by establishing vital visual connections during an infant's hospital stay. These tools enhance collaboration between families and healthcare teams by fostering transparency and trust. They also enable extended family members and siblings to track the infant's progress, providing them with a sense of involvement. Visual access to the infant for extended family members and friends also enhances their ability to support the mother-baby dyad, especially since many NICUs restrict the number of in-person support persons. Moreover, the ability for care team members to send HIPAA-compliant photos, videos, and messages in the family's native language improves communication, further increasing parental satisfaction.

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Reducing Costs:

Infants who have spent time in the NICU face an increased risk of readmission within their first year, posing a significant financial burden on the healthcare system. Improved parental well-being is crucial for an infant's long-term growth and development, especially for preterm children (9) Parents who experience enhanced bonding and engagement are more confident in caring for their infants in the NICU and after discharge, which helps minimize readmission risks. Additionally, the effective communication facilitated by the CameraSystem reduces misunderstandings and errors, contributing to shorter hospital stays and lower readmission rates, ultimately leading to significant cost savings for healthcare facilities.

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Improving Provider Satisfaction:

The CameraSystem enhances communication, collaboration, and trust between healthcare providers and families. Additionally, it enhances the efficiency of the hardworking staff by keeping parents engaged as essential care team members. The ease with which NICU care team members can update parents and foster attachment improves their efficiency and workflow, increasing satisfaction and reducing burnout.

MilkTracker

AngelEye Health's MilkTracker solution supports families throughout their lactation journey by involving them in the care process and encouraging continued breastfeeding and pumping post-discharge. The user-friendly solution provides in-hospital lactation support and enhances safety by preventing maladministration of milk and formula. It seamlessly integrates with the EHR to automate data flow and order validation. MilkTracker optimizes inventory and minimizes waste while tracking donor milk and human-milk-derived fortifiers to ensure best practices. With MilkTracker, the care team can provide education and resources while gaining real-time insights into parents' pumping activities, allowing for proactive intervention.

"[Milk Tracker] provides in-hospital lactation support and enhances safety by preventing maladministration of milk and formula. It seamlessly integrates with the EHR to automate data flow and order validation."

Improving Health Outcomes:

AngelEye Health's MilkTracker solution supports parents and promotes the use of maternal breast milk, which is linked to improved neonatal outcomes such as better growth and reduced infection rates. Research consistently highlights the benefits of human milk for both short- and long-term health. (10–12) Specifically, Cartagena et al. (2022) found that mother's own milk (MOM) yields superior outcomes in infant growth and gut microbiome diversity compared to donor human milk (DHM). Despite these benefits, systemic challenges remain in providing equitable access to breast milk, particularly among Black and Native American families, those with public insurance, and individuals with limited transportation. Dedicated lactation support systems in NICUs have proven pivotal in increasing breast milk utilization among infants. (13) Strengthening social and hospital support frameworks is crucial for closing gaps in breast milk utilization within NICU settings. Leveraging solutions like AngelEye Health's MilkTracker can play a pivotal role in this endeavor, offering robust support throughout the breastfeeding journey and encouraging continued pumping or breastfeeding post-discharge. Additionally, by enhancing patient safety and reducing feeding and preparation errors, MilkTracker improves infant health outcomes by ensuring that infants receive accurate nutrition, minimizing the risk of complications, and supporting optimal growth and development.

Improving Patient and Family Experience:

MilkTracker enhances the family experience by providing a seamless and efficient way to manage milk feeding, reducing stress, and increasing their confidence. The integration of two-way messaging enables lactation support services to connect with families beyond the bedside, fostering a supportive environment.

Families are uniquely engaged in their infant's feeding journey through the visibility of pumping logs and data, which support early intervention. The easy-to-use MilkChat feature allows bi-directional communication with lactation resources and facilitates sharing photos, videos, and text messages to encourage families and promote proper pumping.

Reducing Costs:

AngelEye Health's MilkTracker solution reduces hospital costs by optimizing breast milk inventory management while providing parental support and encouragement to continue breastfeeding, decreasing the need for costly donor milk. MilkTracker improves staff efficiency by streamlining processes, leading to significant cost savings. The feeding management solution also enhances patient safety by preventing maladministration at every step of milk and formula management. Reducing errors minimizes potential adverse impacts, such as clinical consequences, financial burdens, negative reviews, and the need for additional maternal and neonatal blood work.

Additionally, MilkTracker fosters a more engaging experience for families through two-way messaging with in-hospital lactation support. The improved communication and support help reduce readmission rates and associated costs, making feeding a safer, more efficient, and inclusive experience for all.

Improving Provider Satisfaction:

MilkTracker enhances breast milk inventory management, saving clinical staff time and resources. Minimizing errors that lead to clinical and financial consequences, such as adverse outcomes and increased staff workload, achieves significant cost savings for healthcare facilities.

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The streamlined milk management process provided by MilkTracker boosts staff efficiency, allowing more time for direct patient care, which enhances provider satisfaction and reduces burnout. MilkTracker's ability to integrate with orders adds an extra layer of safety by ensuring accuracy at every stage of milk handling, from receiving and preparation to administration and discharge, thereby minimizing human error.

Conclusion

AngelEye Health's family-integrated services, including NICU2Home, CameraSystem, and MilkTracker, provide a transformative approach to achieving the Quadruple Aim by enhancing the family experience, improving population health, reducing costs, and supporting the well-being of the healthcare team. By actively involving families in the care process, these solutions provide a comprehensive solution to modern healthcare challenges.

AngelEye Health is at the forefront of this movement, providing innovative solutions that seamlessly integrate into existing workflows and deliver measurable outcomes and benefits. NICU2Home offers educational resources and guidance from admission to beyond the hospital stay that empowers families, streamlines discharge processes, and reduces readmission rates. The CameraSystem fosters emotional connections and parental engagement through live-streaming video access, real-time updates, and multimedia sharing, ultimately alleviating parental anxiety and promoting better long-term health outcomes for infants. MilkTracker optimizes breast milk management and provides seamless integration with electronic health records, improving patient safety, enhancing family experience, and reducing healthcare costs by minimizing errors and improving inventory management.

"AngelEye Health's family-integrated services, including NICU2Home, CameraSystem, and MilkTracker, provide a transformative approach to achieving the Quadruple Aim by enhancing the family experience, improving population health, reducing costs, and supporting the well-being of the healthcare team."

Together, these solutions improve clinical outcomes and parent satisfaction and enhance operational efficiency. By leveraging these services, healthcare facilities can achieve excellence in healthcare delivery, ensuring holistic support for families from the hospital to home.

AngelEye Health is leading the way in creating more integrated, effective, and compassionate care in neonatal and pediatric settings by prioritizing family engagement and collaboration. This comprehensive approach improves health outcomes and contributes to significant cost savings and increased provider satisfaction, ultimately enhancing healthcare facilities' overall quality of care.

Are you interested in learning more about AngelEye's comprehensive services? Visit angeleyehealth.com.

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Disclosure: *The authors are employees of AngelEye Health*

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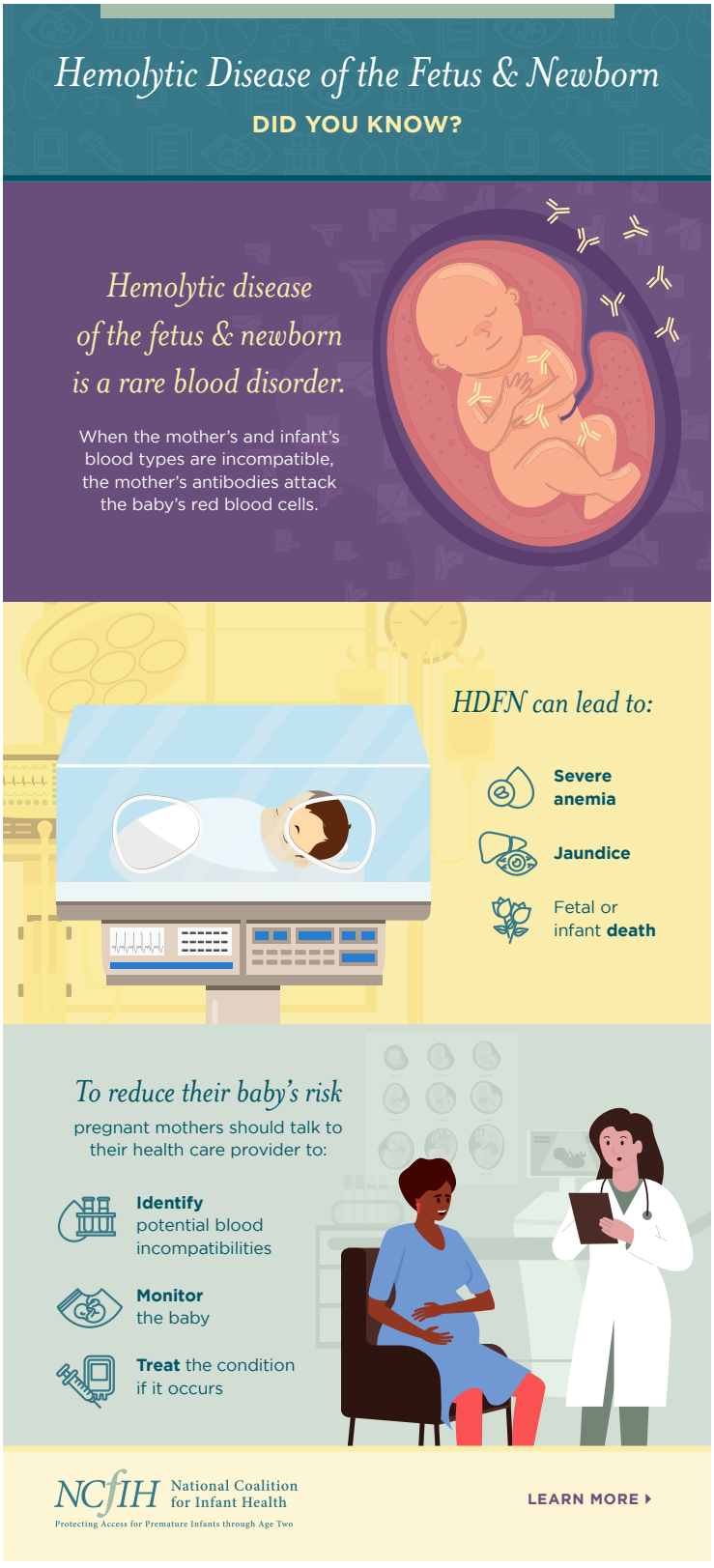
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National Perinatal Association, "Towards Trauma-Responsive Perinatal Care," May 15-17, 2024 Anaheim, CA

Jerry Ballas, MD, MPH, Cristal Grogan

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.

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"Trauma-informed care identifies and acknowledges the effects of trauma, whether it be direct or shared, on the health and well-being of individuals, their families, and vulnerable populations. "

Trauma-informed care identifies and acknowledges the effects of trauma, whether it be direct or shared, on the health and well-being of individuals, their families, and vulnerable populations. Trauma-*responsive* care is the act of creating equitable, proactive, and multifaceted systems of care that not only address specific trauma but also work to ensure such trauma can be mitigated or eliminated for future generations.

"Trauma-responsive care is the act of creating equitable, proactive, and multifaceted systems of care that not only address specific trauma but also work to ensure such trauma can be mitigated or eliminated for future generations. "

The National Perinatal Association held its annual "Towards Trauma-Responsive Perinatal Care" meeting to a near-capacity audience this past May in Anaheim, CA. From the inspirational keynote address by Mary Coughlin, MS, NNP, RNC-E entitled "All We Need is Love: Trauma-Responsive Living," to the poignant and timely final plenary by Dr. Krishelle Marc-Aurele entitled "Three Reasons to Stop Saying *Not Compatible with Life*," attendees learned first-hand the full spectrum of trauma-responsive models of care through a multidisciplinary mix of plenaries, breakout sessions, poster presentations and podium talks that have become hallmarks of NPA conferences. Whether it was personal stories of trauma transformed into resilience or evidence-based protocols aimed at providing targeted therapies, there was something for everyone to take back with them to their lives and practices.

"Whether it was personal stories of trauma transformed into resilience or evidence-based protocols aimed at providing targeted therapies, there was something for everyone to take back with them to their lives and practices. "

"From basic and applied research to the newest policies and innovative models of care, such organic, grassroots exchange of information and ideas between presenters and attendees has long been part of NPA's mission to educate, advocate, and integrate knowledge across the full spectrum of perinatal care."

At the conference's core was the opportunity for learners and luminaries to network and interact through poster presentations and abstract podium talks. From basic and applied research to the newest policies and innovative models of care, such organic, grassroots exchange of information and ideas between presenters and attendees has long been part of NPA's mission to educate, advocate, and integrate knowledge across the full spectrum of perinatal care. Each year, awards are given to posters that best exemplify the spirit of each abstract domain. This year's winners were:

1. Innovative Model of Care: Errica Capossela, et al. The Cherry Blossom Family: Evaluating the Impact of a Bereavement and Lactation Support Program for Grieving Mothers after a Perinatal Loss
2. Applied or Basic Research:
    - Leah B. Sodwick, et al.: "We Feel It Too:" A Qualitative Examination of Secondary Traumatic Stress and Coping Strategies in NICU Nurses.
    - Maggie Runyon et al.: Perinatal Trauma-Informed Care Education Associated with Decreased Nurse Secondary Traumatic Stress
3. Policies and Initiatives: Jaclyn Del

"In the spirit of ongoing networking, you can find these presentations all the abstracts presented and contact information at the following link: https://www.npaconference.org/2024posters."

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By keeping patients and their families at the center of our work and providing space for contemporary ideas to be shared in a safe and collegial setting, NPA moved the field forward by transforming what is known about trauma-informed care into actionable initiatives and trauma-responsive tools for perinatal providers.

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For more details about conference speakers and topics and to learn more about how you can become part of NPA, click on the following link: https://www.nationalperinatal.org/ or https://www.npaconference.org/

Disclosure: *The author has no conflicts of interests to disclose.*

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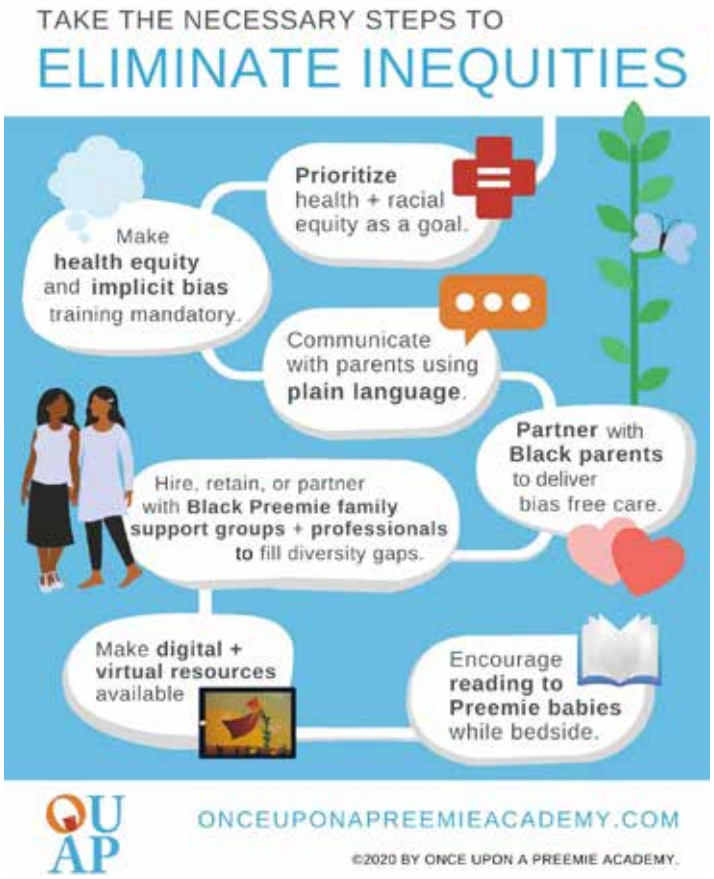
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Peer Reviewed

SONPM Updates: CDC Alert on Oropouche Virus, New Red Book Resources, Donor Milk toolkit, RDS QI Grant Opportunity, First 1000 days Opportunities

Munish Gupta, MD, FAAP

Hi everyone,

It has been a busier summer than usual, and we have got several important updates and announcements that I wanted to share with you:

"The CDC has recently issued a Health Advisory about increased cases of Oropouche virus disease. This virus, usually found in the Amazon basin, has spread to other parts of South America and the Caribbean. We are now even seeing some travel-related cases here in the US."

1. CDC Alert on Oropouche Virus and Perinatal Transmission

The CDC has recently issued a Health Advisory about increased cases of Oropouche virus disease. This virus, usually found in the Amazon basin, has spread to other parts of South America and the Caribbean. We are now even seeing some travel-related cases here in the US. What is especially concerning is that the virus poses risks during pregnancy, with the potential for vertical transmission from mother to baby.

If you are looking for more detailed information, the CDC has put together some great resources:

- You can read the complete CDC advisory here: CDC Advisory.
- For guidance on managing the Oropouche virus during pregnancy, check out this link: Clinical Guidance for Pregnancy.
- Moreover, this page is helpful for information on caring for newborns who might be affected: Clinical Guidance for Newborns.

2. New Red Book Resources: Respiratory Virus Season Webinars and Syphilis Management Algorithm

The AAP's Red Book Online has released some new resources that could be useful as we gear up for the respiratory virus season. Sean O'Leary, Chair of the AAP Committee on Infectious Diseases, presents a short, two-part webinar series. The webinars cover essential updates, including:

- **COVID-19 vaccine recommendations** for the upcoming season.
- **Nirsevimab recommendations** for RSV prevention.

These webinars are quick and to the point—one is 13 minutes long, and the other is just 11 minutes. If you are interested, you can watch them here: Red Book Online Webinars.

"In addition to the webinars, there is also a new online, step-by-step algorithm that can help guide you through the management of infants born to mothers who tested positive for syphilis. This tool is based on the latest Red Book recommendations and could be a valuable resource for your practice."

In addition to the webinars, there is also a new online, step-by-step algorithm that can help guide you through the management of infants born to mothers who tested positive for syphilis. This tool is based on the latest Red Book recommendations and could be a valuable resource for your practice. You can access the algorithm online. The webinars are available here (with link: Red Book Online Webinars | Red Book Online | American Academy of Pediatrics (aap.org)). Second, they have also developed an online step-by-step algorithm to help with the management of infants born to mothers with positive syphilis tests. The algorithm is based on Red Book recommendations. The algorithm is available here (with link: Red Book Interactive Algorithms | Red Book Online | American Academy of Pediatrics (aap.org)).

"For those of you exploring or considering implementing a donor milk program, Alison Wolf and Lisa Stellwagen, directors of the UC Health Milk Bank, have developed a comprehensive toolkit to assist hospitals in this process."

3. Donor Milk Toolkit from UCSD

For those of you exploring or considering implementing a donor milk program, Alison Wolf and Lisa Stellwagen, directors of the UC Health Milk Bank, have developed a comprehensive toolkit to assist hospitals in this process. While the toolkit targets NICUs in California, many materials can easily be adapted for use in other locations.

I have attached the toolkit for you, but if you are starting and want to find a local milk bank, that is a great first step. You can locate your nearest milk bank here: Find a Milk Bank.

"Chiesi USA once again offers grants for quality improvement projects focusing on neonatal Respiratory Distress Syndrome (RDS). This year, there is an added focus on ensuring that the projects explicitly address health equity. They offer two grants of up to $25,000 each, which is a fantastic opportunity if you are working on or considering starting a project in this area."

4. Grant Opportunity from Chiesi USA for QI Projects on RDS: Applications Due September 30

Chiesi USA once again offers grants for quality improvement projects focusing on neonatal Respiratory Distress Syndrome (RDS). This year, there is an added focus on ensuring that the projects explicitly address health equity. They offer two grants of up to $25,000 each, which is a fantastic opportunity if you are working on or considering starting a project in this area.

The application deadline is September 30, so if you are interested, you should start preparing your proposal soon. The complete Request for Proposals (RFP) is attached. You can find additional details and submit your application here: Grant Submission Website.

"The AAP is looking for editors to help develop new modules for their "First 1,000 Days Knowledge Center," an online resource dedicated to best practices for child health during the first three years of life. They are particularly interested in expanding content on newborn topics, so if you have expertise in this area, this could be a great way to contribute."

5. Editor Opportunities for AAP First 1,000 Days Knowledge Center

The AAP is looking for editors to help develop new modules for their "First 1,000 Days Knowledge Center," an online resource dedicated to best practices for child health during the first three years of life. They are particularly interested in expanding content on newborn topics, so if you have expertise in this area, this could be a great way to contribute.

As a module editor, you would select key articles, chapters, and other content that pediatric professionals need to be up-to-date on specific topics. You would also write short guidance notes, including an introductory paragraph for the module and brief notes for each selected piece to highlight its importance. The AAP will provide a content survey and examples of previous module drafts, giving you plenty of support. If this sounds like something you would be interested in, you can find more information and indicate your interest here: Editor Opportunities.

Moreover, just a quick reminder—if you have not already, there is still time to join us at the AAP Experience: National Conference & Exhibition (NCE) in Orlando from September 27 to October 1, 2024. It will be a great event, and I hope to see many of you there!

Thanks for all your hard work and dedication. Let us keep up the great momentum as we head into the fall!

Best,

Munish

Disclosures: No conflicts noted

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Letters to the Editor

Letter to the Editor: "Physiological and Behavioral Stress in Preterm Infants During NICU Clothing Application: A Case Series"

Dear Editor,

We thank and acknowledge Carrie Crozier-Arena, PT, DPT, NTMC, CNT, DCS, for her publication "Physiological and Behavioral Stress in Preterm Infants During NICU Clothing Application: A Case Series." Exploring variables in neonatal care that no one else has yet to consider is a testament to the significance of this work. Her piece opens the gate for further research and questions on fundamental methods used to care for preterm infants. Reconsidering and researching core techniques will impact preterm infant care outcomes, further improving neonatal intensive care units (NICUs') efficiency and effectiveness in delivering quality care for preterm infants.

" Her piece opens the gate for further research and questions on fundamental methods used to care for preterm infants. Reconsidering and researching core techniques will impact preterm infant care outcomes, further improving neonatal intensive care units (NICUs') efficiency and effectiveness in delivering quality care for preterm infants."

Validity/reliability of the Neonatal Pain, Agitation, and Sedation Scale (N-PASS)

This paper's use of the N-PASS plays a critical role in the assessment of "Swaddling" vs. "Clothing" preterm infants. We appreciated using this scoring system due to its crucial role in NICU patients. N-PASS aids providers in gauging a newborn's discomfort to ensure pain is appropriately managed with sedatives. Since its conception in 2008 (1), N-PASS scores have guided care for the most critically ill and needy infants in the NICU.

Pain is an inherently subjective experience; therefore, scales designed to measure it often fall prey to issues with validity and reliability. The Neonatal Pain, Agitation, and Sedation Scale (N-PASS) are not immune to this. Although the N-PASS is widely regarded as a reliable tool for assessing neonatal pain, agitation, and sedation, it still has some significant limitations. It has high inter-rater variability due to little or no training provided to the healthcare providers doing the ratings (2). In addition, the assessment also hinges on subjective observations of behaviors and physiological signs, which may be biased due to the observer's perceptions. We believe future studies can consider implementing several scoring tools to capture these different aspects of neonatal pain.

Future research in neonate attire can focus on the impact of several variables within a neonate's N-PASS score. Skin-to-skin time, clothing material, and environmental temperature are just a few aspects of neonatal care that can be explored. These variables have already been investigated in different capacities regarding neonatal life outcomes. This paper has not necessarily touched on the specific impacts of these variables within neonatal intensive care units. Further exploration in these areas may shape future care standards for neonates being cared for within NICUs globally.

"This paper has not necessarily touched on the specific impacts of these variables within neonatal intensive care units. Further exploration in these areas may shape future care standards for neonates being cared for within NICUs globally."

For instance, this study could explore whether the difference in physiological responses between the bodysuit and the swaddle is due to the swaddle's reduced barrier between the infant and the mother during contact or if it is just the nature of the material being tight. Research has previously shown that respiratory and heart rate variability improves when infants are placed skin-to-skin with their mothers (3). The close, intimate contact and the hormonal changes in this process contribute to a relaxed state in the infant, helping to mitigate the stress associated with prematurity. By investigating this aspect, a better understanding could be achieved of whether the minimization of barriers between the infant and mother impacts the physiological stress responses observed. Moreover, different measures could be studied to add to the study's credibility, such as how clothing affects sleep, nutrition, and temperature and the long-term implications of clothing on infants' cognitive and neuronal development.

"This small technique can make a significant difference in the NICU, helping reduce stress for infants under considerable strain. Swaddling can be a simple yet impactful change, unlike using tight clothing. Even minor adjustments like this can contribute to a long-term improvement in the infants' comfort and well-being."

This small technique can make a significant difference in the NICU, helping reduce stress for infants under considerable strain. Swaddling can be a simple yet impactful change, unlike using tight clothing. Even minor adjustments like this can contribute to a long-term improvement in the infants' comfort and well-being. By providing a sense of security, swaddling promotes better sleep and reduces physiological strain, ensuring better health outcomes for

these infants' future.

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Sincerely,

Phillip Mouradkhanian, OSM III, Ilana Radparvar, OSM III, Katlin Wieselthier, OSM III, Fatima Iqbal, OSM III

Western University

Pomona, CA

Dear Phillip Mouradkhanian, Ilana Radparvar; Katlin Wieselthier, Fatima Iqbal

Thank you for your insightful review of Carrie Crozier-Arena's publication, "Physiological and Behavioral Stress in Preterm Infants During NICU Clothing Application: A Case Series." It is evident that you have invested significant time and effort in understanding the nuances of this study, and your engagement with such an important and underexplored aspect of neonatal care is commendable.

"As a critical tool in this study, the Neonatal Pain, Agitation, and Sedation Scale (N-PASS) demonstrate the challenges involved in neonatal pain assessment. Identifying the inherent subjectivity of the N-PASS and the potential for inter-rater variability due to inconsistent training is essential. "

As a critical tool in this study, the Neonatal Pain, Agitation, and Sedation Scale (N-PASS) demonstrate the challenges involved in neonatal pain assessment. Identifying the inherent subjectivity of the N-PASS and the potential for inter-rater variability due to inconsistent training is essential. There are considerations in evaluating the reliability of studies that rely on such tools. This evaluation can be further explored by looking at potential strategies that future researchers could implement to address these limitations. For instance, how could additional training protocols or multiple assessment tools improve the accuracy and consistency of pain assessment in the NICU? Discussing these possibilities would enhance the analysis and demonstrate an ability to think critically about improving research.

"For instance, how could additional training protocols or multiple assessment tools improve the accuracy and consistency of pain assessment in the NICU? Discussing these possibilities would enhance the analysis and demonstrate an ability to think critically about improving research. "

The suggestion to investigate additional variables such as skin-to-skin contact, clothing material, and environmental temperature is essential. These factors are indeed critical in understanding the full scope of neonatal care. The ability to identify these variables reflects a strong awareness of the broader context in which neonatal outcomes are shaped. This discussion can be deepened by integrating examples from the literature or proposing specific hypotheses about how these factors could influence the outcomes observed in Crozier-Arena's study. Doing so can add more value to the analysis and demonstrate a sophisticated understanding of the subject matter.

" This discussion can be deepened by integrating examples from the literature or proposing specific hypotheses about how these factors could influence the outcomes observed in Crozier-Arena's study. Doing so can add more value to the analysis and demonstrate a sophisticated understanding of the subject matter."

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Attention to the long-term outcomes of neonatal interventions, such as the effects of clothing on sleep, nutrition, and neurodevelopment, is particularly insightful. This topic is a critical area of research that is often overlooked in favor of more immediate outcomes. Perhaps this point can be expanded by considering how future research could be designed to evaluate these long-term effects systematically. What specific measures would be most helpful in tracking developmental outcomes over time, and how could these findings inform best practices in the NICU? Additional thoughts on these questions could lead to a richer and more comprehensive manuscript.

"Perhaps this point can be expanded by considering how future research could be designed to evaluate these long-term effects systematically. What specific measures would be most helpful in tracking developmental outcomes over time, and how could these findings inform best practices in the NICU? Additional thoughts on these questions could lead to a richer and more comprehensive manuscript."

Overall, This is an impressive analysis and thoughtful approach to this review. This work demonstrates a strong foundation in critical thinking and a clear commitment to understanding and improving neonatal care.

Sincerely,

Mitchell Goldstein, MD, MBA, CML

Editor in Chief

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c/o Mitchell Goldstein, MD

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Published monthly.

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Erratum (Neonatology Today July, 2024)

There were no reported erratum for July, 2024

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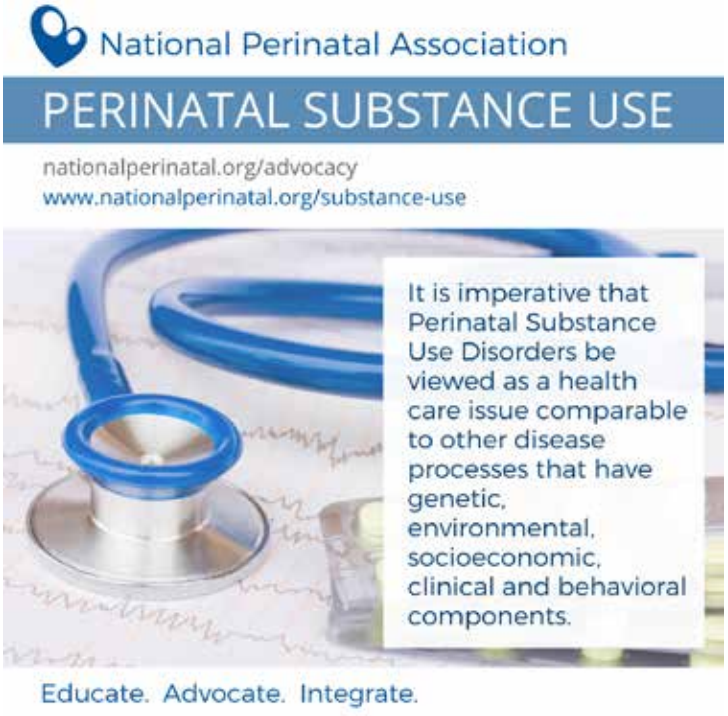


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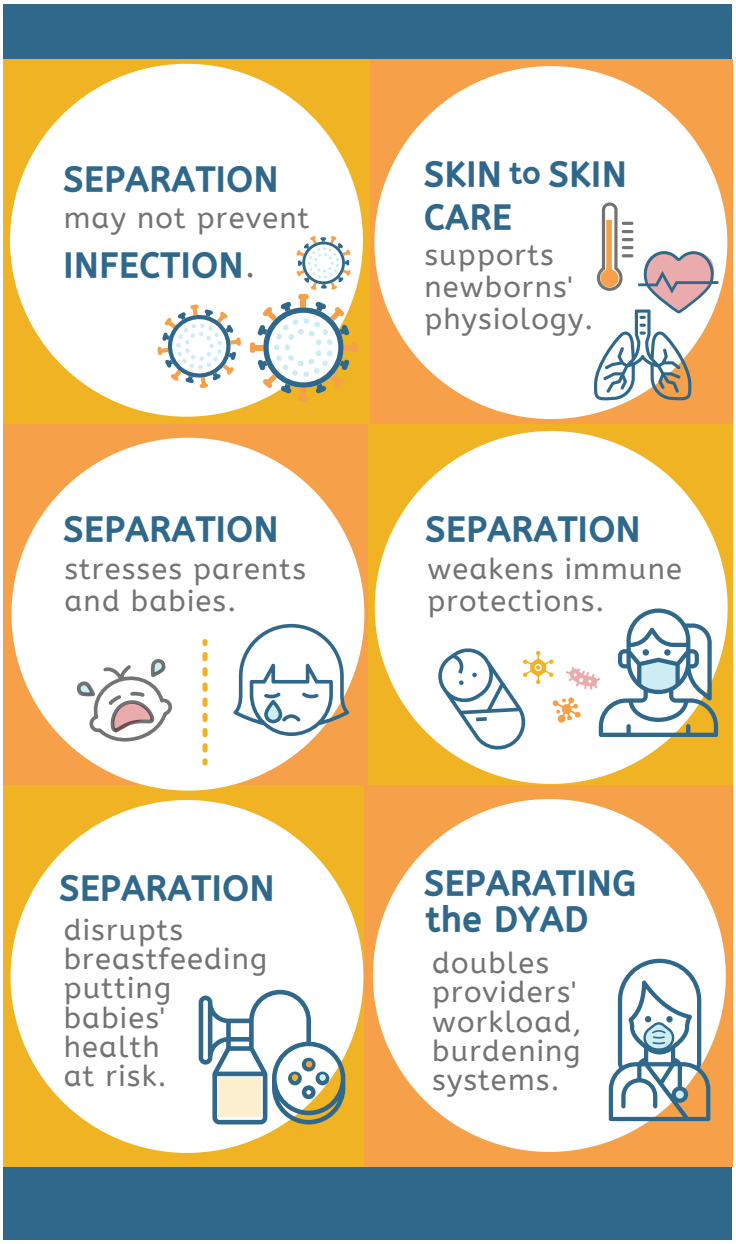
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Should Infants Be Separated from Mothers with COVID-19?

FIRST DO NO HARM



BASED ON THE ARTICLE:

Should Infants Be Separated from Mothers with COVID-19? First, Do No Harm

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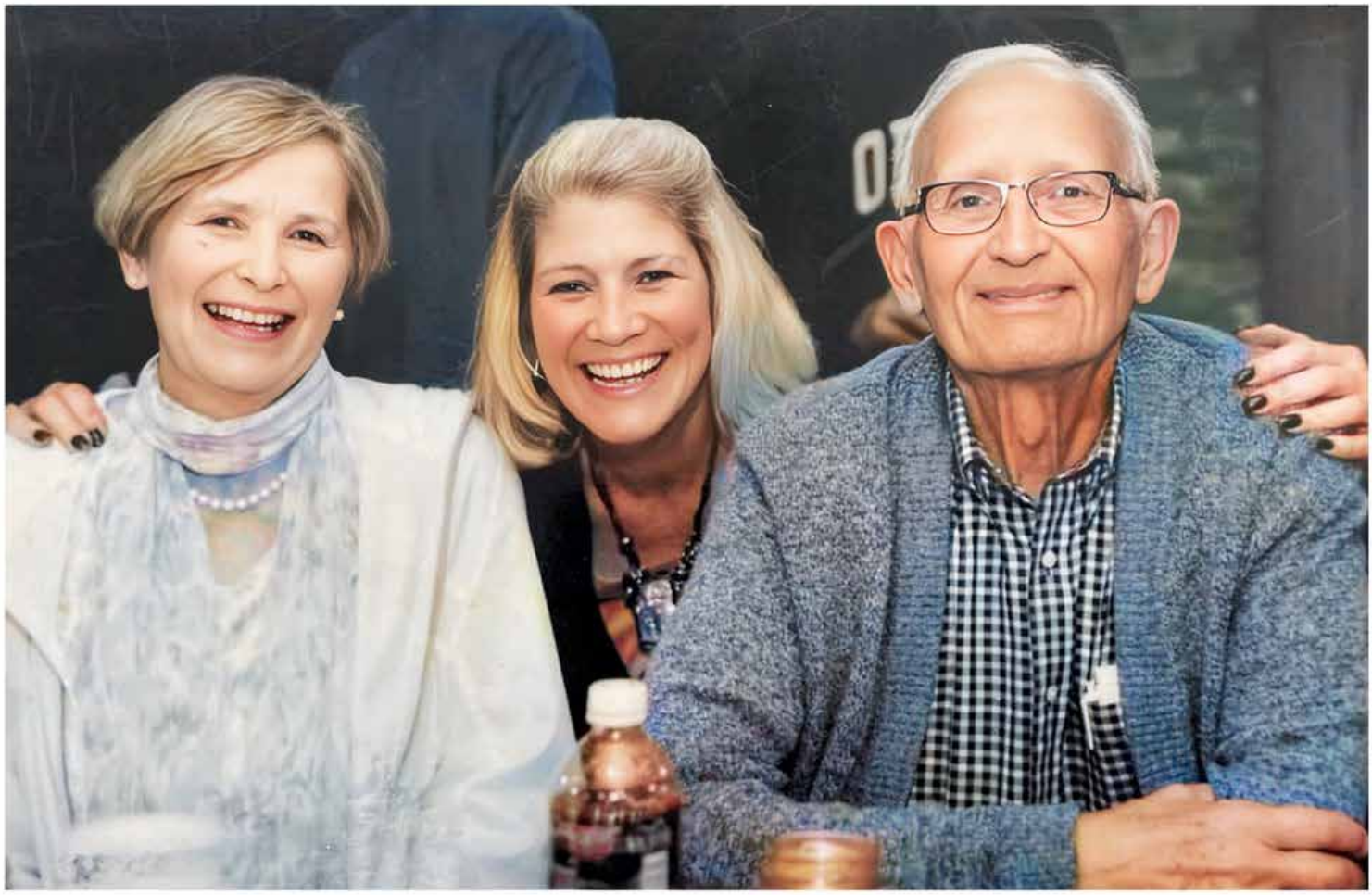
Kari Graven

" His compassion extended to every baby he cared for in the neonatal unit and their worried parents. He brought hope to families who needed it most, and each night, he returned home to the warmth of his own family, where love and faith were the pillars of his life."

My Uncle Stan was a man who wore many hats, but the one he cherished most was that of a neonatologist. He saw life in its most fragile and miraculous form in his work each day. His compassion extended to every baby he cared for in the neonatal unit and their worried parents. He brought hope to families who needed it most, and each night, he returned home to the warmth of his own family, where love and faith were the pillars of his life.

He was so proud of the care, innovation, and work of his team. I visited him in the neonatal center in Sioux Falls. His inspiration and insight into what was important and vital to newborns left a lasting impression on me as a person and even more as a mother. The newborn and human need for touching, holding, lighting, sounds, talking, music, and the joy and miracle of life itself.

What made Uncle Stan remarkable wasn't just his skill with the tiniest of patients but his ability to see something special in everyone he met.



Mavis, Kari and Stan Graven

Whether it was a nurse on his team, a friend down the street, or a relative, Uncle Stan had a gift for finding the hidden talents in people. He'd spot a spark in someone's eyes and gently coax it into a flame, always encouraging them to shine in their own unique way.

"Whether it was a nurse on his team, a friend down the street, or a relative, Uncle Stan had a gift for finding the hidden talents in people. He'd spot a spark in someone's eyes and gently coax it into a flame, always encouraging them to shine in their own unique way."

Uncle Stan had a gift for storytelling. He could captivate an audience with his knowledge and understanding of people and tales of life experiences. He had a knack for coming up with ideas that were ahead of their time, like when he thought that South Dakota needed more bagels long before they became popular. He had a vision of opening a bagel shop, convinced the community would benefit. This was just one of the many ways Uncle Stan showed his love for people—always thinking about how to bring something good into their lives.

"He had a knack for coming up with ideas that were ahead of their time, like when he thought that South Dakota needed more bagels long before they became popular. He had a vision of opening a bagel shop, convinced the community would benefit."

Reading my dad's college letters recently, I discovered more about the man Uncle Stan was. Returning after a weekend away to St. Olaf, where my parents attended as well… in a new shirt, there was a "choir" of "ohs and ahs" from all the gals. (He had not yet met Mavis- not until he went to Wartburg) He was "the looker" of the family—proof of his charm and warmth. Uncle Stan was undeniably handsome, with a special smile and twinkle in his eye.

"Family was everything to Uncle Stan. He loved his children fiercely and extended that love to his entire family, embracing everyone with open arms. He was, without apology, loyal to his family, taking immense pride in being a Graven."

Family was everything to Uncle Stan. He loved his children fiercely and extended that love to his entire family, embracing everyone with open arms. He was, without apology, loyal to his family, taking immense pride in being a Graven.

"His inspiration and insight into what was important and vital to newborns left a lasting impression on me as a person and even more as a mother. The newborn and human need for touching, holding, lighting, sounds, talking, music, and the joy and miracle of life itself."

What happened at my parents' wedding was a testament to the bond he shared with his family. As the best man, Uncle Stan wasn't just there for the ceremony—he was there for my dad and my mom, who was stressed out because other wedding party members decided to "steal my dad away." My mom ended up with hives, and Uncle Stan convinced them to return my dad to the ceremony. Later and over the years, there were other deeply sad events for my parents, like a stillborn baby--Stan offered comfort during the most difficult times. And in those times, his presence was a source of strength and solace. My Dad described Uncle Stan as a "really good brother," someone who was always there, dependable, and kind. But he was more than just a good brother; he was a good uncle, a devoted husband, a father, and a dedicated doctor.

"Later and over the years, there were other deeply sad events for my parents, like a stillborn baby--Stan offered comfort during the most difficult times. And in those times, his presence was a source of strength and solace."

Uncle Stan was a man of many endearing qualities to me also, from him calling me "old Kar," a nickname that always brought a smile to my face, and saying I had "pulchritudinous." He holds a special place in my heart, not just for the lives he saved or the people he inspired, but for the moment that changed everything for me. When I was eleven, my entire family was in a car accident. Tragically, my mom passed away.

"It was Uncle Stan who gently broke the news to me. In that moment, he did something profoundly difficult with such grace and compassion that I will never forget."



It was Uncle Stan who gently broke the news to me. In that moment, he did something profoundly difficult with such grace and compassion that I will never forget. I needed to be transported from the hospital in Mason City, Iowa, back home to Minneapolis with my leg in traction from a broken femur. He arranged everything and even had them pull into my elementary school parking lot so that I could see my friends. I always knew I could turn to him, whether for medical advice or simply a comforting word. I trusted him to be there for me and knew he would help me in any way he could. When I was attending the University of Wisconsin-Madison as a transfer student from St. Olaf, Stan and Mavis gave me a place to be; "a home away from home," a meal, and a place to feel the love and comfort of family.

"Together, they were a force of nature, a beacon of kindness and dedication in their work, community, and church. Their marriage was a partnership of equals, grounded in mutual respect, unwavering support, and a deep, abiding love."

Uncle Stan wasn't alone on his journey. By his side, always, was Aunt Mavis. She was his partner in every sense-- at work, at home, and in life, they shared a love and passion for helping infants and children that was almost palpable. Together, they were a force of nature, a beacon of kindness and dedication in their work, community, and church. Their marriage was a partnership of equals, grounded in mutual respect, unwavering support, and a deep, abiding love.

Uncle Stan and Aunt Mavis were very proud of their cabin in Ely, Minnesota. Growing up, we would spend time in the beautiful, pristine northern woods and on the glistening crystal-clear lake. Stan would tell us how they built the cabin and how much they loved it there—an early appreciation for nature and how we can take care of our planet. The call of the loon, catching fish, the tall trees, and the infinite stars in the night sky -paint pictures in my mind to this day.



Kari, her brother Mark, Stan's daughter Nadine and Grand dad Henry is holding Mike, Stan's oldest son

Uncle Stan believed in the power of education, in the strength of community, and in the importance of giving back. His strong faith and beliefs provided the pillars of his life that guided him in all things. He lived by example, and above all, he was a servant at heart. He put others first, always looking for ways to help, heal, and bring joy. His life was a testament to the power of love, faith, and selflessness, leaving a legacy that will continue to inspire those who knew him.

"He lived by example, and above all, he was a servant at heart. He put others first, always looking for ways to help, heal, and bring joy. His life was a testament to the power of love, faith, and selflessness, leaving a legacy that will continue to inspire those who knew him."

I will continue to tell his stories… with love. I am proud to be his niece and a Graven.

"Old Kar" misses you.

Disclosure: *The author has no conflicts of interests to disclose.*

NT

Corresponding Author



Kari Graven
Oldest niece of Stanley Graven
Daughter of David Graven (Stan's oldest brother)
Albuquerque, NM, The Land of Enchantment



Grandparents from Norway

Norway



Brothers and sisters a la Graven

Lloyd Annelise David Mavis Stan Grands



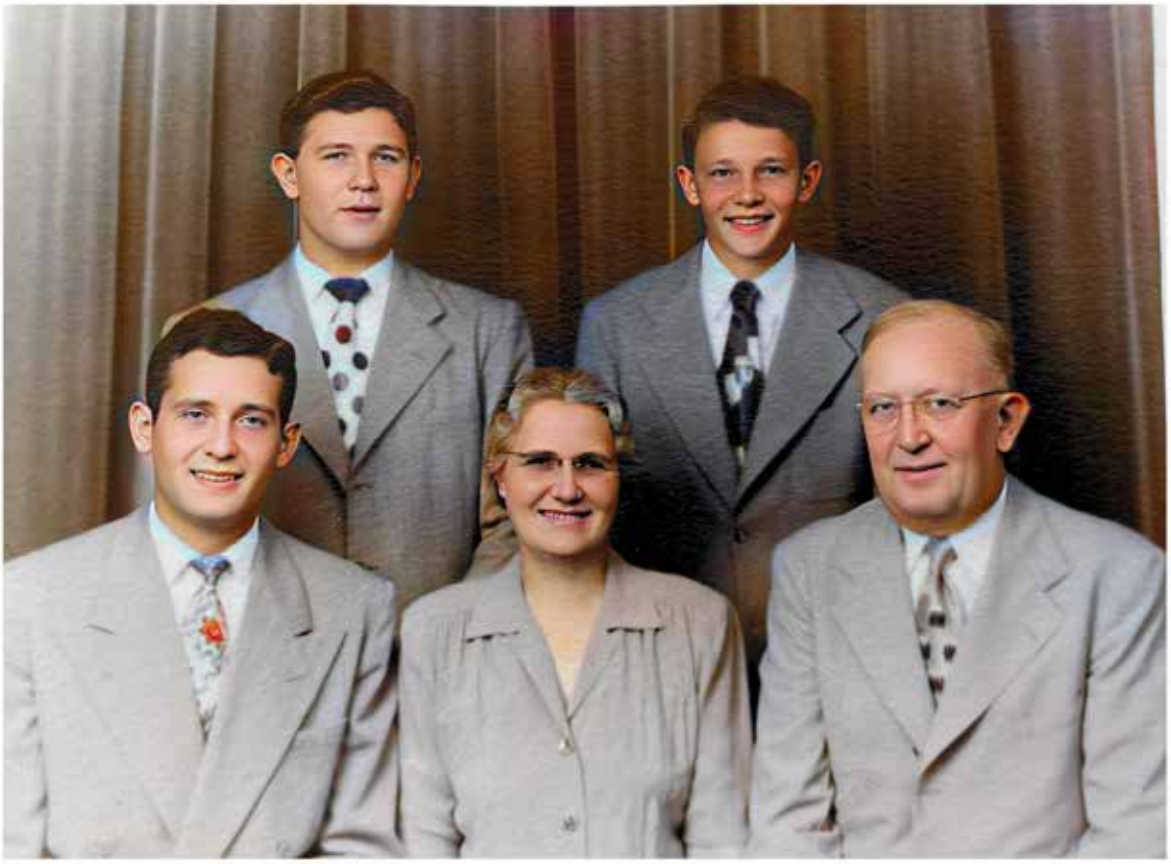
Graven home in Greene,IA



Stan 1 year, David 2 ½ years



Stan with hat on, sibs, friends and dog.



Gravens family. Stan David Lloyd and parents

Peer Reviewed

Gravens by Design: A Tribute to Stanley Norman Graven, MD: A Comprehensive Legacy Early Life and Education, in Memoriam

Mitchell Goldstein, MD, MBA, CML, Joy V. Browne, Ph.D. PCNS, IMH-E

"Dr. Graven furthered his training with pediatric residencies at The Children's Hospital in Cincinnati, Ohio, and the State University of Iowa in Iowa City, where he received extensive training in pediatric care."

Stanley Norman Graven, MD, was born in the United States on May 20, 1932. His early academic journey began at Wartburg College in Waverly, Iowa, where he earned his Bachelor of Science degree in 1955. His pursuit of medical knowledge continued at the University of Iowa College of Medicine, where he graduated with his M.D. in 1956. His formative years in medicine were marked by an internship at Madigan Army Hospital, Tacoma, Washington, from 1956 to 1957. Dr. Graven furthered his training with pediatric residencies at The Children's Hospital in Cincinnati, Ohio, and the State University of Iowa in Iowa City, where he received extensive training in pediatric care.

Military Service and Early Research Contributions

Dr. Graven's service in the U.S. Air Force from 1960 to 1964 gave him significant opportunities to advance pediatric care. As Chief of Pediatric Services at USAF Hospital-Fairchild AFB, Washington, he established a new pediatric ward that became a model for future pediatric care facilities. His research during this period included pioneering studies on the relationship between cholesterol, lysolecithin, and bilirubin in breast-fed versus bottle-fed infants, contributing to a better understanding of neonatal nutrition and metabolism.

"Dr. Graven's service in the U.S. Air Force from 1960 to 1964 gave him significant opportunities to advance pediatric care. As Chief of Pediatric Services at USAF Hospital-Fairchild AFB, Washington, he established a new pediatric ward that became a model for future pediatric care facilities."

At Wilford Hall USAF Hospital in San Antonio, Texas, he led the newborn service and made groundbreaking advancements, including creating the first special care nursery for newborns in the military. Dr. Graven's work here involved the innovative use of ventilators and intravenous therapy in preterm infants with Respiratory Distress Syndrome (RDS). His research on fibrinolysin therapy for RDS and the genetic basis for RDS in preterm infants was instrumental in improving treatment outcomes. Additionally, he studied the effects of television viewing on children's fatigue and somatic symptoms, providing insights into the impact of environmental factors on child health.

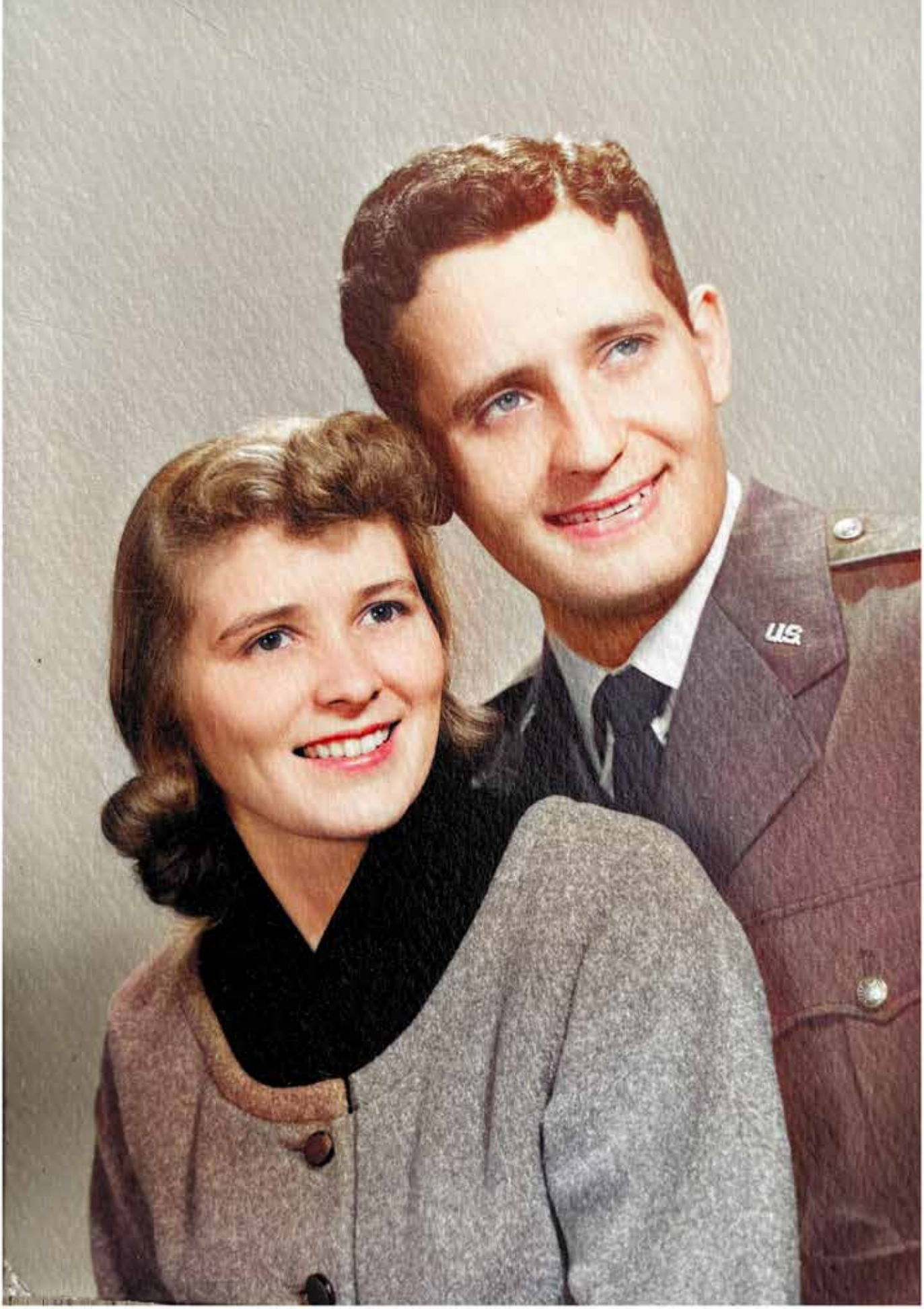
"His research on fibrinolysin therapy for RDS and the genetic basis for RDS in preterm infants was instrumental in improving treatment outcomes. Additionally, he studied the effects of television viewing on children's fatigue and somatic symptoms, providing insights into the impact of environmental factors on child health."

Academic and Research Career

In 1964, Dr. Graven began his academic career at the University of Wisconsin-Madison as a Research Associate in the Department of Pediatrics and the Institute for Enzyme Research. Under the mentorship of Professor Lardy, he focused on the biochemistry of mitochondrial function, which contributed significantly to the field of enzymology and mitochondrial research. His work during this period included crucial findings on the role of mitochondria in cellular metabolism.

Dr. Graven's academic ascent continued as he became an Assistant Professor in 1966 and later an Associate Professor and Professor. During his tenure, he was a driving force behind the establishment of Wisconsin's first neonatal intensive care unit (NICU) and the Wisconsin Perinatal Program. This regionalized perinatal care system was pioneering, offering data on its impact on fetal and infant mortality and setting a precedent for similar programs across the U.S. His research on lecithin and sphingomyelin levels in amniotic fluid provided critical insights into prenatal development and neonatal health markers.

As Chairman of the Committee for Sub-specialty Certification in Neonatology, American Board of Pediatrics, and later Chair of the Sub-Board of Neonatal-Perinatal Medicine, Dr. Graven played a critical role in defining the standards and scope of neonatal care and certification. His efforts to establish the first neonatal nurse



Mavis and Stan

clinician program in the United States and publish groundbreaking research on lecithin/sphingomyelin ratios in amniotic fluid were seminal in advancing neonatal care practices.

"As Chairman of the Committee for Subspecialty Certification in Neonatology, American Board of Pediatrics, and later Chair of the Sub-Board of Neonatal-Perinatal Medicine, Dr. Graven played a critical role in defining the standards and scope of neonatal care and certification."

Leadership and Contributions to Public Health

Dr. Graven's transition to Medical Director for Maternal-Child Health at the South Dakota Department of Health in 1976 marked a new phase in his career. His leadership led to the creation of a statewide perinatal program, a comprehensive prenatal and parenting education system, and the establishment of the National Perinatal Association. He also established a neonatal nurse clinician program and developed the Children's Comprehensive Health Care System, which aimed to improve pediatric care infrastructure across South Dakota.

At the University of South Dakota, where he served as a Professor in the Departments of Pediatrics and Obstetrics/Gynecology, Dr. Graven spearheaded the creation of a new NICU with full-time neonatologists and neonatal nurse clinicians. He also initiated a series of pediatric subspecialty clinics, including those for cardiology, neurology, gastroenterology, and child development. His role as Program Director and Senior Program Consultant for the Rural Infant Care Program and the Egyptian Newborn Care Program highlighted his commitment to improving neonatal care globally. The latter program was instrumental in reducing neonatal mortality related to tetanus in Egypt by legalizing and training traditional midwives.



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Impact at the University of Missouri and University of South Florida

In 1980, Dr. Graven joined the University of Missouri-Columbia as a Professor in the Department of Pediatrics. His contributions included creating an Infant Development Unit designed to control environmental factors affecting infant development, such as light and sound. His role as a consultant to Missouri's maternal and child health programs and the organization of a multidisciplinary study group on early infant and child development were pivotal in advancing care practices.

"Dr. Graven's tenure at the University of South Florida, starting in 1984, was marked by significant achievements. As a Professor and later Chair of the Department of Community and Family Health, he built the department from two faculty members to a robust team of eleven academic and thirty-two total staff members."

Dr. Graven's tenure at the University of South Florida, starting in 1984, was marked by significant achievements. As a Professor and later Chair of the Department of Community and Family

Health, he built the department from two faculty members to a robust team of eleven academic and thirty-two total staff members. He developed and expanded academic programs, including MPH, MsPH, and PhD programs, and led the creation of the Healthy Beginnings Program. This program aimed to improve public health practices and optimize Medicaid spending for maternal and child health. The Gravens Conference was established to inform and educate about the importance of environmental factors on infant development. Dr. Graven also served as a principal investigator for over fifty grants and contracts, securing over $4.5 million in funding.

As director of The Lawton and Rhea Chiles Center for Healthy Mothers and Babies from 2000 to 2003, he oversaw initiatives to improve maternal and child health outcomes. As Interim Dean of the College of Public Health from 2003 to 2004, he managed the college's academic and research functions, further cementing his leadership in public health.

"The Gravens Conference was established to inform and educate about the importance of environmental factors on infant development."

Comprehensive Impact of Dr. Graven's Research in Perinatal and Neonatal Health

Dr. Graven's research covered a wide range of perinatal and neonatal health topics. Graven's early studies made significant strides in understanding the nutritional management of celiac disease in children. In 1958, Graven and Tomsovic investigated the effectiveness of a gluten-free diet in treating celiac disease, providing crucial insights into dietary interventions for managing this condition. This early work laid the foundation for Graven's future research endeavors.

In the early 1960s, Graven's research expanded to address the challenges of ABO blood group incompatibility and its impact on neonatal health. The 1960 study examined the implications of blood group incompatibility, offering valuable information on its management. In 1964, Graven and Mann focused on the pathophysiology and treatment strategies for hemolytic disease in newborns. This period also saw collaboration with Gomez to explore the use of fibrinolysin as a treatment for respiratory distress syndrome, further advancing the field.

Graven's investigation into neonatal hyperbilirubinemia in 1965, particularly his study on the role of phospholipids, provided new insights into the biochemical mechanisms underlying this condition. His concurrent research on blood lactate levels in respiratory distress syndrome highlighted the importance of metabolic factors in neonatal respiratory conditions.

In the late 1960s, Graven delved into the effects of mitochondrial function and antibiotic use on oxidative phosphorylation. This research was pivotal in understanding the biochemical impacts of antibiotics on neonatal health and mitochondrial function. His exploration of maternal factors and their association with respiratory distress syndrome risk contributed significantly to the field, revealing critical links between prenatal conditions and neonatal outcomes.

In the 1970s, Graven's focus shifted towards developing and implementing perinatal health care programs. His 1973 study emphasized the benefits of regionalized OB/GYN care systems, advocating for a structured approach to improving perinatal outcomes. Subsequent research in 1974-1975 examined amniotic fluid analysis for assessing fetal maturity, which played a key role in advancing diagnostic methods for evaluating fetal development.

The 1974-1976 period was marked by Graven's work on the lecithin/sphingomyelin ratio, a crucial indicator of fetal pulmonary maturity. This research provided valuable benchmarks for assessing the readiness of the fetal lungs for birth, influencing clinical practices related to neonatal respiratory care.

During the late 1970s and early 1980s, Graven concentrated on enhancing neonatal intensive care practices and developing statewide perinatal outreach programs. His efforts in 1978-1980 to evaluate and improve perinatal care systems highlighted the importance of coordinated care strategies in reducing neonatal morbidity and mortality. In 1991, Graven's research on prenatal nutrition and educational services underscored the impact of maternal health interventions on birth outcomes, contributing to a broader understanding of how prenatal factors influence neonatal health.

In the 2000s, Graven's research shifted towards sensory development in neonates, emphasizing the critical role of early sensory experiences on cognitive and physical development. His studies during this period provided insights into how environmental factors and sensory stimulation affect neonatal development, shaping approaches to early childhood care.

Graven's comprehensive contributions also include developing educational materials on perinatal care and organizing nursery services. His 1983 work provided foundational knowledge for neonatal-perinatal medicine, offering guidance for best practices in neonatal care and program organization.

Overall, Graven's extensive research has significantly advanced the field of neonatal and perinatal health. His work spans decades and includes crucial findings on neonatal care practices, perinatal health care systems, biochemical mechanisms, and developmental outcomes, reflecting a commitment to improving neonatal health through rigorous research and practical applications.

NT



Recognition and Awards

Dr. Graven's contributions to pediatric medicine and public health have been recognized with numerous awards. He received the Bordon Undergraduate Medical Research Award in 1956 and was honored as a John and Mary Markle Scholar in 1968. The Stanley N. Graven Award, established by the National Perinatal Association, and the Virginia Apgar Award from the American Academy of Pediatrics are among the many accolades that reflect his significant impact on the field. In 2005, he was awarded the Distinguished Service Award from the University of Missouri-Columbia, and in 2006, the Stanley & Mavis Graven Award was named in his honor.

"The Stanley N. Graven Award, established by the National Perinatal Association, and the Virginia Apgar Award from the American Academy of Pediatrics are among the many accolades that reflect his significant impact on the field. In 2005, he was awarded the Distinguished Service Award from the University of Missouri-Columbia, and in 2006, the Stanley & Mavis Graven Award was named in his honor."

Professional Affiliations and Activities

Dr. Graven's professional affiliations include membership in Sigma XI, the American Academy of Pediatrics, the Society for Pediatric Research, and the American Public Health Association. His leadership roles have encompassed chairing and participating in various committees and task forces on perinatal care, including serving as President of the Wisconsin Association for Perinatal Health Care and consulting for international health programs.

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Community and Church Involvement

Beyond his professional achievements, Dr. Graven has been actively involved in community and church activities. His service on the Board of Missions for the American Lutheran Church, the Board of Regents for Wartburg College, and various other church-related organizations highlights his commitment to community service and faith-based initiatives.

Courses and Teaching

At the University of South Florida, Dr. Graven taught a wide range

of courses in the College of Public Health, including Introduction to Maternal Child Health, Program Development and Change Process, and Child Development and Public Health. His dedication to education and mentoring has shaped the careers of many future pediatric and public health professionals.

"His dedication to pediatric medicine and maternal-child health has been evident throughout his career, marked by significant advancements in neonatal care and public health initiatives. Today, Dr. Graven continues to be a respected figure in his field, influencing the next generation of healthcare professionals and contributing to the ongoing evolution of pediatric care."

Personal Life and Legacy

Dr. Graven was married to Mavis Graven for over 70 years. They had four children together. His dedication to pediatric medicine and maternal-child health has been evident throughout his career, marked by significant advancements in neonatal care and public health initiatives. Today, Dr. Graven continues to be a respected figure in his field, influencing the next generation of healthcare professionals and contributing to the ongoing evolution of pediatric care.

"Dr. Stanley Norman Graven's career is a testament to his enduring commitment to advancing pediatric medicine and public health. His pioneering work in neonatal care, leadership in public health programs, and dedication to education have profoundly impacted the field."

Dr. Stanley Norman Graven's career is a testament to his enduring commitment to advancing pediatric medicine and public health. His pioneering work in neonatal care, leadership in public health programs, and dedication to education have profoundly impacted the field. His legacy continues through the institutions he helped build, the policies he influenced, and the lives he has improved through his work.

Stanley Norman Graven, MD passed away on July 8, 2024, in Dallas, Oregon. He was 92.

Disclosure: *The authors have no conflicts of interests to disclose.*

NT

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Gratitude for the Contributions of Stan Graven, MD

My introduction to Stan was in the mid-1970's when he was presenting at conferences and guiding us through the value of an organized transport system of preterm and sick newborns from less acute care facilities to acute and surgical centers. He spoke in a strong, clear, calm, and factual manner, and was never hesitant to use the power of his voice combined with knowledge to speak on behalf of babies and parents. And he was inclusive of the multidisciplinary healthcare team that offered specialty support to the baby and parents. Stan taught the physiologic advancement of clinical care, the value of technical support to augment care, the unique individuality of each baby, AND he emphasized the strength of parent presence for the neurodevelopment of the baby while growing and maturing in the NICU.

Stan's wife, Mavis, was a strong contributor to the maturation and behavior of babies through her focus on infant and child development. She and Stan were a team guiding us to learn, translate the evidence into practice, monitor the outcomes, disseminate findings, listen to the parents and include them in decision-making, and care with compassion. It sounded so simple and natural, and yet I/we discovered that the doing was harder than the envisioning.

I was able to work with Stan in the late 1980's and beyond as an early and continuing member of the NICU Design Consensus Committee, chaired by Bob White. The committee published the evidence-based guidelines that standardize the physical space as a healing environment for acute care nurseries. Stan could have easily become the informal leader, but he chose to participate, listening to the experience, evidence, and insights of others. When asked Stan thoughtfully offered wise counsel and insight. The group become a cornerstone of an annual meeting known as the Gravens Conference on the Environment of Care for High Risk Newborns. Stan and Mavis welcomed each attendee, faculty, and committee member with a smile, kind words, and warm hug. They knew everyone! Stan and Mavis showed us how innovators and early adopters could energize the change of the NICU physical, clinical, and cultural environment to support the physical and neurodevelopmental outcome of the preterm and sick newborn and the wellbeing of parents and families.

In a natural progression and with the proliferation of neurodevelopmental evidence, Stan and the Gravens Planning Committee facilitated the initiation of the Infant and Family Centered Developmental Care Consensus Committee in 2014, chaired by Joy Browne. It has been my great fortunate to work with this extraordinary group of neonatal interdisciplinary healthcare experts to build evidence-based neuroprotective standards to guide the delivery of baby and family centered care in an intensive care environment. The foundation and direction that Stan provided continues to support the tenants of this work.

Stan's legacy is extensive and lasting. His presence will be felt as we continue to inquire, learn, listen, study, practice, monitor the outcomes, and challenge ourselves to change for the sake of improving the growth, development, and wellbeing of babies, parents, and families. Stan has been a friend, mentor, innovator, teacher, and author. I am grateful for the gifts that he has given me/us as I/we carry his inquiring spirit forward.

With Gratitude,

Carol Jaeger, DNP, RN, NNP-BC

July 2024

NT

Dr. Graven was an inspired and positive force and, happily for me, believed in the power of design to support wellbeing. He leaves a remarkable legacy.

Mardelle

Mardelle M. Shepley <mshepley@cornell.edu>

NT

Dear Joy

I just read the news that Stanley Graven has passed. I know that you worked with him for a long time and I wanted to express my condolences to you and his family.

To my mind come so many souvenirs when assisting at the Gravens Conference. I think that he was always with Mavis. Not when he was speaking to the audience but the rest of the time, I think I see them as a couple with a deep warmful relationship and radiating their love.

When I was walking on the beach, I was meeting them from time to time, but every single time, they would be so kind as to say hello and ask how I found the conference.

What to say about his talks? I never ever had such a brilliant talker who could explain some very confusing subjects (confusing to me) with such clarity. I was leaving his talks with the feeling I had learned something new and understood clearly difficult concepts.

It is such a skill to be a good communicator and help many to learn. He was one of those.

And I did not know him. So I can only imagine how his direct colleagues, family members, friends are deeply touched by his death.

Warmest Love to you

K!k!

Kiki Rémont <kiki.remont@gmail.com>

NT

Thank you, Joy, for sharing his legendary contributions to neonatology with us. I was unfortunate not to have the honor of meeting him in person, but I can imagine him and his beautiful life by reading his obituary. The FCC Taskforce was born because of this conference, and his and Mavis Graven's legacy will live forever through the impact they made in my life and others through this conference.

Thanks again

Malathi

Malathi Balasundaram <malathib@stanford.edu>

NT

I first got to know this remarkable leader while working on NICU design standards many decades ago. He had the warmest smile and quiet demeanor that turned into fierce passion when speaking about his beliefs and research. From our early encounters, I recall that our design committee and his namesake Gravens Conference planning committee listened carefully and respectfully when he spoke, and with good reason. He was already one of the wisest and most genuine icons in neonatology and public health. As I got to know him more over the years, I realized that one of his many attributes was his perfect balance of seriousness and playfulness. For example, he'd wear his colorful, signature children's neckties while presenting groundbreaking, complex scientific research. His well-balanced approach to life was as inspirational as his work.

Judy Smith

Judy Smith <jsmith@shbajo.com>

NT

Hi to all

Joy, thank you for sharing. I am so very sad and appreciative to have gotten the chance to learn from Dr Graven and to meet him. He was a gentle man and a giant in my world and I will forever admire him (and his beautiful wife). The work of Gravens Conference is all the more important as his (and Mavis') legacy.

Church, Paige (HMFP - HMFP Neonatology) <pchurch1@bidmc.harvard.edu>

NT

Hello, everyone:

I have had a chance to speak with Dr. Graven's son Douglas and niece, Kari. They were kind enough to provide information about the plans for a celebration of life and Dr. Graven's obituary. You will find details about the celebration in the obituary.

For those of you who do face book, here is a link.: https://www.facebook.com/stanleyngraven . *I have also attached a copy for those of us who don't use FB very well (like me!).*

I am also accumulating some photos that I hope can be used for a NT article as well as in a tribute at next year's Gravens meeting. As I have looked through them, I am reminded of all of his many contributions to our work. The obituary gives some hints of what those were.

Joyy

Browne, Joy <JOY.BROWNE@CUANSCHUTZ.EDU>

NT

Dear Joy,

Thank you for letting me know. He certainly had a huge impact on neonatal care that was felt around the world. You and Bob have done a great deal to make sure his legacy lives on, and I applaud you for that.

Sending love and appreciation,

Raylene

Phillips, Raylene <RPhillips@llu.edu>

NT

Thank you for sharing, Joy. What beautiful family and legacy.

Christie

Christie Lawrence <Christie_Lawrence@rush.edu>

NT

Sad to hear, but his immense contributions have formed the foundation for so much positive change in care environments and services for sick and preterm infants and their families. It's been an honor to be associated with his work through the Gravens Conference interprofessional consensus committee. Sending gratitude and sympathy to his wife and family. Rose

Bigsby, Rosemarie <rosemarie_bigsby@brown.edu>

NT

The depth and breadth of Dr. Graven's leadership and contributions at so many levels and in so many areas related to NICU/infant care are immeasurable. His legacy will live on to influence clinicians and researchers for years to come. I was privileged to meet him at my first Gravens Conference a number of years ago. My heart goes out to the family. With prayers, Joan Arvedson

Joan C. Arvedson, PhD, CCC-SLP, BCS-S, ASHA Honors & Fellow

Joan C Arvedson <jcarved@aol.com>

NT

The Gravens Conference

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Stan Graven loved to take a big idea and make it become a reality. From basic science to NICU regionalization and then to the National Perinatal Association, Stan sought to assure the best care for babies by challenging assumptions and systems to change. One of the stories he told us was that he and Mavis, his partner and the love of his life, observed that parents could not be with their babies in intensive care. Stan and Mavis set out to change the attitudes about families being with their babies; they understood the importance of the environment of care for babies and young children and helped design care practices that would optimize their development

Stan had already been lauded as a leader and a creative thinker when the last chapter of his professional career emerged at the University of South Florida. That is when his interests and ours began to gel into a collaborative effort to change NICU environments. Along with Judy Smith, an architect, we set out to understand the impact of the design of NICUs on babies and families and change perceptions about what was optimal for our patients and their caregivers. Stan gathered the research about the impact of the sensory environment on babies' physiologic responses and outcomes, then brought together a wide group of basic science and clinical professionals to evaluate the current literature on sound, light, odor, temperature, and other sensory inputs on babies' outcomes. By the time that group gathered, over 30,000 references had been accumulated for all to access. This collection spurred interest from a wide variety of basic scientists and stimulated further research into the impact of the environment on babies and families. The parallel process of the impact of the sensory environment and the need for design change provided a powerful platform for communicating the science of how the environment affects babies and families.

Stan was a teacher, so his next big undertaking was to bring NICU professionals and families together in an annual scientific meeting on the "Environment of Care for High-Risk Newborns and their Families," now planning its 38th year. As an "umbrella" for developmental, family-centered, and design initiatives, the Gravens meeting has led the way to the dramatic changes in how we care for newborns and their families, both through our care practices and through international Design Standards, now in the 10th version. These standards, promulgated in collaboration with the Gravens Conference, are now referenced and largely have become incorporated into governmental standards. Throughout Stan's career, both the Conference and the Standards have been instrumental in leading the worldwide shift from crowded, noisy rooms caring for many intensive care babies with limited family access, to a much more supportive NICU design and care practices, with full integration of families into the care of their babies.

Along the way, Stan emphasized the importance of understanding the science of systems change. We designed a Gravens meeting preconference on that topic, thinking a few people would be attending an additional day. Surprisingly, the preconference was a "standing room only" session. That set the scene for expanding the meeting to meet the needs of professionals interested in ensuring infant and family-centered developmental care becomes "institutionalized" with an expectation of integration into all medical and nursing care.

Stan had a way of understanding critical issues in the care of babies and families. He also had a knack for identifying people who had a passion for supporting babies and families and an ability to advance the field. He often drew them into discussion and to a leadership role and supported them as they grew professionally, as he did for both of us. He had a wonderful ability to gently challenge thinking in a way that made the recipient feel valued and stimulated to respond creatively to the challenge. His ability to provide a platform from which global change could happen is unparalleled.

Stan's mentorship, leadership, and creativity is a model for how we now try to support those who may need just that little opening of the door to do great things. We have benefited exponentially in learning from him how to make change happen and how to advance the field. He leaves an amazing legacy to all of us who were fortunate to know, learn from, and love him.

Joy Browne and Bob White

NT

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Review Committee for Pediatrics (RC-Peds) Nominee Qualifications

To qualify to be nominated to the RC-Peds for this position, the candidate:

- must be a board-certified pediatrician or pediatric subspecialist with a background in education and expertise in graduate medical education.
- should have at least three years of experience as a program director of an ACGME-accredited pediatrics residency program or pediatric subspecialty fellowship or three years of experience as a designated institutional official. The nominee's program must be in good standing with a status of Continued Accreditation.
- must have a current or past association with graduate medical education.
- should participate in major specialty societies.
- must be skilled in the use of computers (communication with staff is primarily through email, and members will use electronic systems for receipt of agenda materials, program reviews, reimbursement of expenses, and peer evaluations).
- must demonstrate fairness, the ability to work collaboratively, and express views clearly and concisely.
- must be able to attend an observation meeting, April 10-11, 2025, prior to the start of the term.
- must devote sufficient time to prepare for and participate in three RC meetings per year (January, April, and September), two-three days per meeting, as well as contribute to RC-Peds subcommittee work as assigned.
- ideally, will not hold the same subspecialty certifications as the members of the RC-Peds at the time of appointment. The RC-Peds strives to maintain a balance of specialties; it is preferable that individuals from the following specialties are not nominated:
    - General Pediatrics
    - Internal-Medicine Pediatrics
    - Pediatric Hospital Medicine
    - Pediatric Emergency Medicine
    - Neonatal-Perinatal Medicine
    - Pediatric Critical Care Medicine
    - Pediatric Endocrinology
- must not be at the same institution as any member of the RC-Peds at the time of appointment.
    - *Same-Institution Disqualification: Although the RC-Peds may have multiple members from the same state, they may not be from the same institution. Accordingly, individuals must not be nominated from the following institutions:*
        - UC Davis (Davis, CA)
        - Stanford University (Stanford, CA)
        - University of Colorado (Aurora, CO)
        - Advocate Children's Hospital (Park Ridge, IL)
        - Mayo Clinic (Rochester, MN)
        - Columbia University College of Physicians & Surgeons (Yonkers, NY)
        - Goryeb Children's Hospital-Atlantic Health System (Morristown, NJ)
        - University of North Carolina School of Medicine (Chapel Hill, NC)
        - Cincinnati Children’s Hospital Medical Center (Cincinnati, OH)
        - University of Texas Health San Antonio (San Antonio, TX)
        - University of Washington/Seattle Children's (Seattle, WA)

The RC-Peds expects the AAP to consider diversity and inclusion when submitting its nominations.

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Respiratory Syncytial Virus

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Breathing that causes their ribcage to "cave-in"

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

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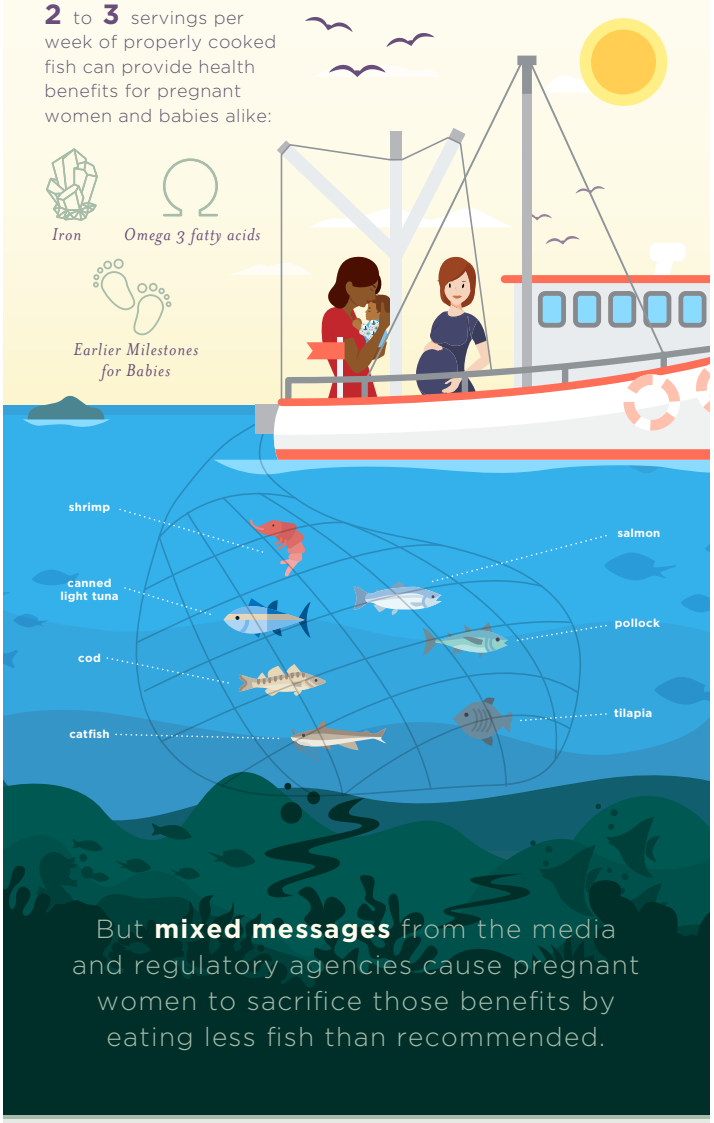
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Antenatal Steroids: A Game of Chance

Rob Graham, RRT, NRCP

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 benefits of steroid administration were first demonstrated in the late 1960s in experiments using sheep (1), followed by several human trials, which demonstrated a significant decrease in the instance and severity of respiratory distress syndrome (RDS) (2, 3). Since these studies originated in New Zealand, it is not surprising that Australia and New Zealand adopted widespread administration of antenatal steroids (AS) earlier than the rest of the world, with the majority of at-risk women receiving them in the 1980s (4). In contrast, by the early 1990s, less than 20% of eligible women received AS in the U.S. and U.K.. This changed rapidly following the National Institutes of Health (NIH) consensus statement in 1994 (5).

"The benefits of steroid administration were first demonstrated in the late 1960s in experiments using sheep (1), followed by several human trials, which demonstrated a significant decrease in the instance and severity of respiratory distress syndrome (RDS)."

The administration of AS is often said to mimic a stress response in the fetus and, in doing so, spur pulmonary development, but their mechanism of action is far more complex. Antioxidant production is increased, surfactant production is stimulated, and structural maturation is accelerated. In addition, severe intraventricular hemorrhages are significantly decreased in the 23–25 week PMA cohort (6).

The vast majority of infants born today prematurely have been exposed to at least one course of AS, time permitting, and many to 2 or more. The benefits to infants receiving AS when born prematurely are incontrovertible, but that benefit decreases as PMA increases (7). The risk of pulmonary complications decreases (but is not eliminated) with pulmonary maturation, so this only makes sense.

"The administration of AS is often said to mimic a stress response in the fetus and, in doing so, spur pulmonary development, but their mechanism of action is far more complex. Antioxidant production is increased, surfactant production is stimulated, and structural maturation is accelerated. In addition, severe intraventricular hemorrhages are significantly decreased in the 23–25 week PMA cohort."

There is a big "but" here. Steroid exposure, whether pre or post-natal, is not without risk, and the wisdom of giving more than one course is controversial. When delivered prematurely, steroid exposure significantly reduces the risks associated with prematurity, but as many as 40% of mothers in threatened preterm labour (TPTL) go on to deliver at term or near term. By association, their babies are more likely to:

- Have adverse health issues in the short and long term (8)
- Develop an infection (including sepsis) in their 1st year of life (this includes term and preterm infants, with term infants more at risk than the preterm) (8)
- Be admitted to NICU (8)
- Have breathing problems (8)

"Steroid exposure, whether pre or post-natal, is not without risk, and the wisdom of giving more than one course is controversial. When delivered prematurely, steroid exposure significantly reduces the risks associated with prematurity, but as many as 40% of mothers in threatened preterm labour (TPTL) go on to deliver at term or near term."

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- Have poor growth (8)
- Be hypoglycemic (7)

Recent investigations in Ontario, Canada, have revealed more disturbing trends. Ontario's public health care system gives access to information through the Ontario Health Insurance Plan (OHIP) billing codes. Although preliminary, alarm bells sound, questioning the liberal use of AS. When born at term, AS-exposed infants were more likely to require healthcare services for those born prematurely, such as:

- Audiometry testing (9)
- Vision testing (9)
- Neurocognitive investigation (9)

These infants were exposed to a *single course* of AS (9). Multiple courses can reasonably be expected to increase this association, but a similar investigation has not been conducted. Canadian investigations have found multiple courses of AS to be associated with significant increases in adverse outcomes and are thus no longer recommended (10). In the U.S., 2017 guidelines allow for additional courses of AS in certain circumstances (11), and repeat AS administration is still common (12). Mounting evidence against multiple courses will surely change recommendations.

"Canadian investigations have found multiple courses of AS to be associated with significant increases in adverse outcomes and are thus no longer recommended."

Other potential sequelae of AS, such as cardiovascular disease and hypertension, are the subject of continued investigation (13). Thus far, conclusions are inconclusive, and most evidence is derived from animal studies. The cited paper found no association between AS exposure and adverse long-term outcomes (13).

The use of post-natal steroids (PNS) has increased of late with the introduction of the "DART" protocol (14). Not long ago, position papers advised PNS to be approached with extreme caution, secondary to concerns about brain development. Dosing regimens were much higher than what is currently recommended.

"In the absence of a clinical crystal ball to predict whether or not TPTL will progress to premature delivery, the clinician's best guess is as good as the prediction gets. Improving the safety, efficacy, and timing of AS will ultimately depend on follow-up studies and an improved ability to predict premature delivery."

Nevertheless, it should be no surprise the use of AS comes with consequences".

In the absence of a clinical crystal ball to predict whether or not TPTL will progress to premature delivery, the clinician's best guess is as good as the prediction gets. Improving the safety, efficacy, and timing of AS will ultimately depend on follow-up studies and an improved ability to predict premature delivery.

In the interim, caution is advised.

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Disclosures: *The author receives compensation from Bunnell Inc for teaching and training users of the LifePulse HFJV in Canada. He is not involved in sales or marketing of the device nor does he receive more than per diem compensation. Also, while the author practices within Sunnybrook H.S.C., this paper should not be construed as Sunnybrook policy per se.*

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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.

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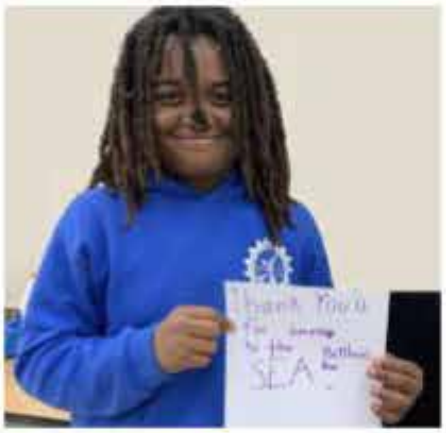


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The Village Son



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.

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Alison Jacobson

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"For those of us who have experienced the death of our precious babies, we desperately want answers, yet Sudden Infant Death Syndrome (SIDS) remains a mystery."

For those of us who have experienced the death of our precious babies, we desperately want answers, yet Sudden Infant Death Syndrome (SIDS) remains a mystery.

While research continues, new researchers must carry on the work of some of the pre-eminent researchers around the globe.

Fortunately, one young man, Adam Nack, whose sister Jessica died of SIDS, has decided to tackle the mystery. This summer, Adam, a pre-med student at Binghamton University, conducted an independent research project under the supervision of Dr. Robin Haynes at Boston Children's Hospital.

"The goal of Adam's project was to examine the hippocampus of SIDS infants for evidence of seizure activity prior to death."

The goal of Adam's project was to examine the hippocampus of SIDS infants for evidence of seizure activity prior to death. During his time at Boston Children's, Adam investigated two proteins of interest in the hippocampus: neuropeptide Y (NPY) and dynorphin. These proteins are expressed in the hippocampus and have previously been found at increased levels in animal models with seizures and in patients with temporal lobe epilepsy. Until now, their hippocampal expression in SIDS infants has been unknown. If NPY and dynorphin expression are increased in the hippocampus of SIDS infants, then data could suggest that seizure activity was present in some SIDS infants prior to death.

In order to do this work, Adam needed a grant to cover tissue samples and laboratory supplies. Through the generosity of one of our donors, Adam worked with nearly 200 samples of hippocampal tissue using antibodies and other essential laboratory supplies.

Over the next several months, he will continue digitizing his laboratory slides and performing quantitation and statistical analysis remotely to publish his findings in an academic journal. In 2025, Adam will present his work at the Seattle Children's and Microsoft SIDS Research Summit and hopes to also present at the International Society for the Study and Prevention of Perinatal and Infant Death (ISPID) Conference in San Diego next year.

As a side note, Adam was also one of our Team First Candle NYC Marathon runners last year!

"One way of helping to support Adam and other young researchers at next year's ISPID Conference is by becoming a sponsor. Learn more here."

We are so excited to see SIDS siblings and other young researchers tackling the mystery of SIDS so that one day, we will have the answers we so desperately want.

One way of helping to support Adam and other young researchers at next year's ISPID Conference is by becoming a sponsor. Learn

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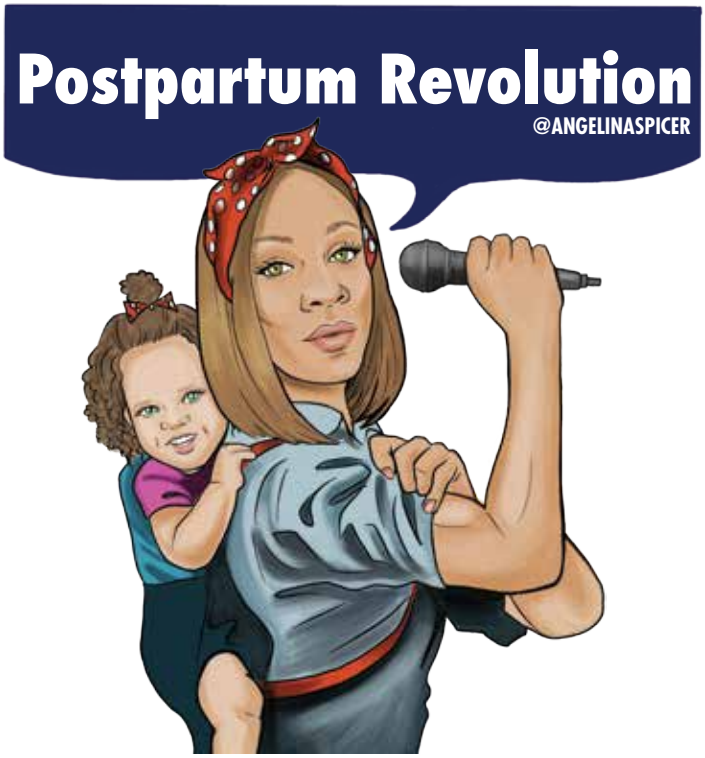
Disclosure: The author is the Executive Director and Chief Executive Officer of First Candle, a Connecticut-based not-for-profit 501(c3) corporation.

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About First Candle

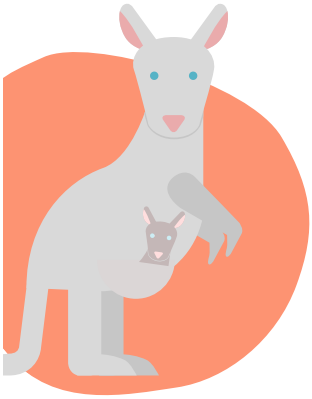
First Candle, based in New Canaan, CT, is a 501c (3) committed to eliminating Sudden Unexpected Infant Death while providing bereavement support for families who have suffered a loss. Sudden Unexpected Infant Death (SUID), which includes SIDS and Accidental Suffocation and Strangulation in Bed (ASSB), remains the leading cause of death for babies one month to one year of age, resulting in 3,500 infant deaths nationwide per year.





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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



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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.

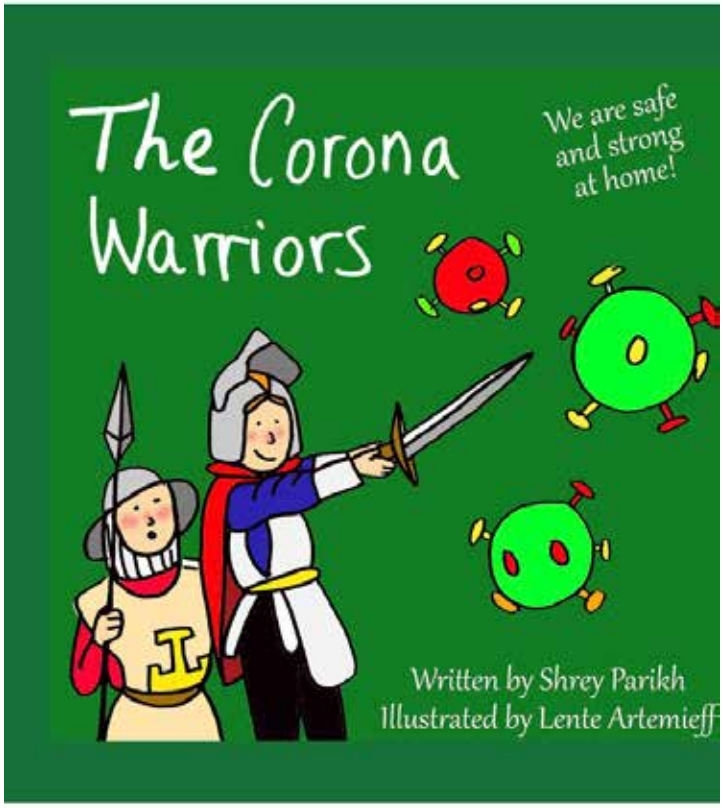
They have produced a personal video entitled "*Why we should all know about RSV*" about Simone van Wyck, a mother who lost her son due to RSV. The video is available at www.rsvgold.com/awareness and can also be watched using the QR code on this page. Please share the video with your colleagues, family, 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.

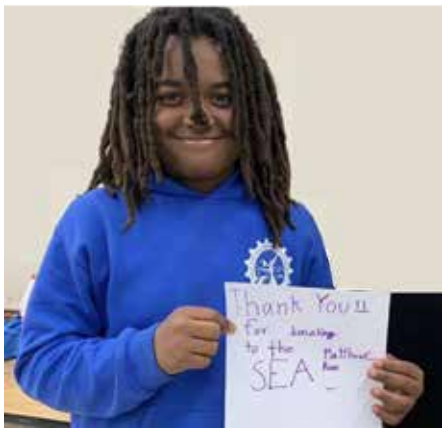


Each year, the Emily Shane Foundation SEA(Successful Educational Achievement) Program provides academic and mentoring support to over 100 disadvantaged middle school students who risk failure and have no other recourse. We have served over 700 children across Los Angeles since our inception in the spring 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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Sponsor a Child in the SEA Program

The average cost for the program to provide a mentor/ tutor for one child is listed below.

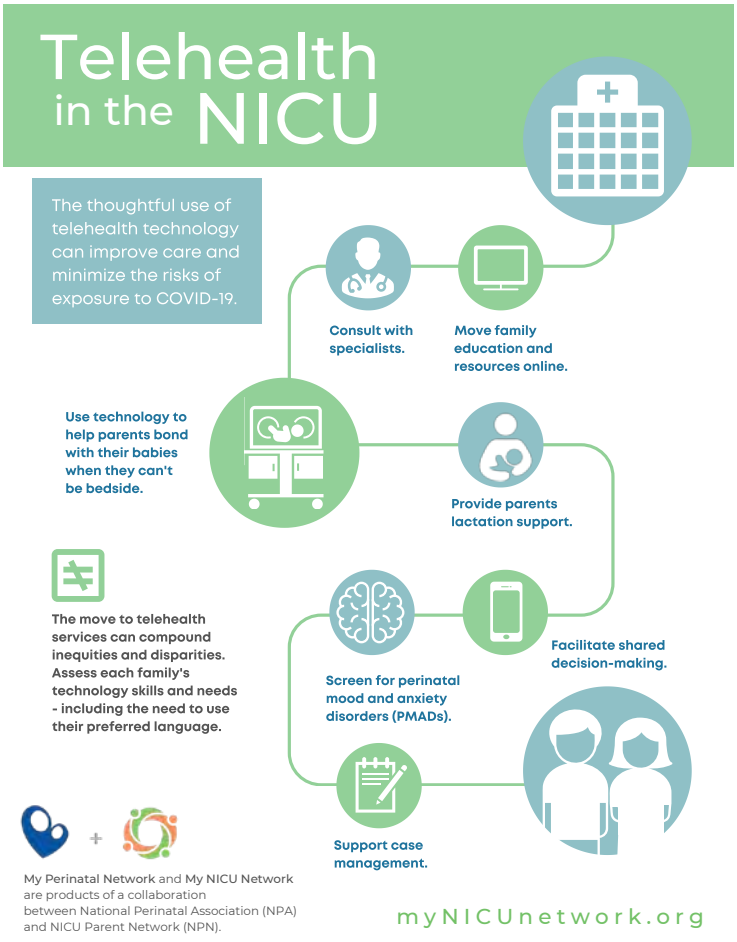


1 session	$15
1 week	$30
1 month	$120
1 semester	$540
1 year	$1,080
Middle School	$3,240

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.







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National Coalition for Infant Health: Feeding and Premature Infants

Susan Hepworth, Mitchell Goldstein, MD, MBA, CML

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.

The National Coalition for Infant Health (NCfIH) will release an important statement in response to the growing trend and heightened focus on infant formula use in neonatal care. The NCfIH extends its deepest empathy to the families navigating these challenging decisions, acknowledging the stress and concern that accompany nutritional choices for preterm infants.

The NCfIH underscores that the nutritional needs of preterm infants are highly individualized and complex. It is crucial to recognize that not all preterm babies are alike. For instance, what may be a suitable nutritional option for an infant weighing 2500 grams born at 34 weeks gestation could be entirely inappropriate for a much smaller, more vulnerable infant weighing 680 grams at 26 weeks.



This distinction highlights the necessity of tailoring nutritional strategies to each infant's specific needs and developmental stages.

"The National Coalition for Infant Health (NCfIH) will release an important statement in response to the growing trend and heightened focus on infant formula use in neonatal care. The NCfIH extends its deepest empathy to the families navigating these challenging decisions, acknowledging the stress and concern that accompany nutritional choices for preterm infants."

For preterm infants born later in gestation and at a larger birth weight, specialized preterm infant formulas play an essential role in their care. However, the evidence is unequivocal for extremely low birth weight (ELBW) infants, particularly those weighing less than 1250 grams at birth: an exclusive human milk diet (EHMD) is the gold standard. Extensive research demonstrates that an EHMD offers the best outcomes for these fragile infants, significantly reducing the risk of life-threatening conditions such as necrotizing enterocolitis (NEC) and promoting better overall health until they reach 34 weeks gestation.

"This comprehensive discussion should encompass each option's potential risks and benefits, enabling parents to make informed decisions about their baby's care. Informed consent is only possible when parents clearly understand the implications of each feeding choice."

The NCfIH stresses the importance of transparent and thorough communication between healthcare providers and families. Physicians are responsible for ensuring that parents are fully informed of all nutritional options available in the NICU, including human milk-based formulas and fortifiers. This comprehensive discussion should encompass each option's potential risks and benefits, enabling parents to make informed decisions about their baby's care. Informed consent is only possible when parents clearly understand the implications of each feeding choice.

Given the current body of evidence, the NCfIH calls on physicians to exercise the utmost caution when considering cow's milk-based

formulas for infants weighing less than 1250 grams until they reach 34 weeks gestation. These infants are particularly vulnerable, and the risks associated with cow's milk-based products, including a higher incidence of NEC, cannot be ignored. Healthcare providers must carefully deliberate and prioritize using an EHMD for these infants in line with the best available evidence.

"The focus should always be on delivering the safest and most effective care, tailored to the unique needs of each infant and grounded in the best scientific evidence available."

In conclusion, the NCfIH urges the medical community to prioritize the well-being of these fragile infants, ensuring that all decisions are made with complete transparency and in collaboration with the families involved. The focus should always be on delivering the safest and most effective care, tailored to the unique needs of each infant and grounded in the best scientific evidence available.

Disclosures: The authors have no relevant disclosures.

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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.

Equality. 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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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.

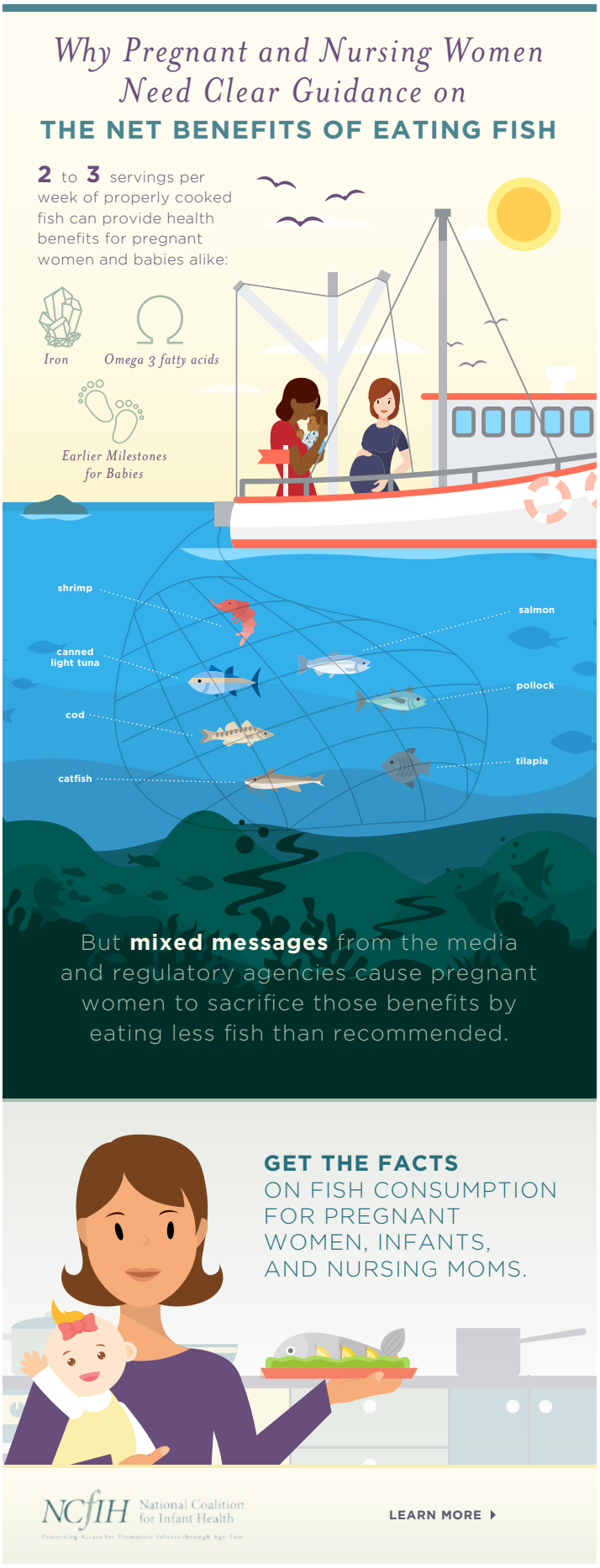
- Eat healthy and take your prenatal vitamins
- Find the right balance of rest and exercise
- Surround yourself with people who care

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Academy of Perinatal Harm Reduction

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Peer Reviewed

Social Responsibility in the NICU: The Power of Language in Educating Families and Cultivating Compassion

Jessica Daigle, MD, FAAP

The neonatal intensive care unit (NICU) is a critical environment for caring for the most vulnerable infants. Within this space, healthcare professionals not only provide lifesaving medical interventions but also play an essential role in educating and supporting families during an incredibly challenging and often traumatic time. This article explores the social responsibility of NICU staff, emphasizing the significance of compassionate communication and the mindful use of language in fostering positive outcomes for infants and their families.

"The concept of social responsibility in healthcare extends beyond clinical care to include ethical practices that respect the dignity, rights, and culture of patients and their families. In the NICU, this responsibility is magnified due to the fragility of the patients and the heightened emotional state of their families. NICU staff deliver high-quality medical care and provide emotional support, accurate information, and compassionate communication."

Social Responsibility in the NICU:

The concept of social responsibility in healthcare extends beyond clinical care to include ethical practices that respect the dignity, rights, and culture of patients and their families. In the NICU, this responsibility is magnified due to the fragility of the patients and the heightened emotional state of their families. NICU staff deliver high-quality medical care and provide emotional support, accurate information, and compassionate communication. This holistic approach ensures that families are well-informed and emotionally supported, contributing to their overall well-being and ability to care for their babies (1,2). It is, therefore, vital that NICU units build family-centered care into their practices and serve as examples for all staff who care for these medically fragile patients and their families (3).

The Importance of Language in the NICU:

Language is a powerful tool that can shape perceptions, influence emotions, and impact decision-making processes. In the NICU, the words chosen by healthcare professionals carry significant weight. Positive and compassionate language can provide comfort and hope, while negative or insensitive language can cause additional stress and anxiety for families already in distress (4).

Phrases like "At least your baby is alive" or "Your situation could be worse" are often said to provide perspective but can be dismissive of the family's current pain and struggles. Each family's situation is unique, and this type of comment can invalidate theirspecific challenges, making them feel that their concerns are not fully acknowledged. Therefore, NICU staff must be mindful of their language and strive to communicate in ways that are supportive, empowering, and truthful (4,5).

"Each family's situation is unique, and this type of comment can invalidate theirspecific challenges, making them feel that their concerns are not fully acknowledged. Therefore, NICU staff must be mindful of their language and strive to communicate in ways that are supportive, empowering, and truthful (4,5)."

Educating Families with Compassion:

Educating families in the NICU involves conveying complex medical information understandably and compassionately. Clear, empathetic communication helps families grasp their child's condition and the necessary medical interventions while being mindful of the impact this information can have (6). Understanding their baby's condition is crucial for parents to make informed decisions about their infant's care. However, this information must be delivered sensitively to the family's emotional state.

"Understanding their baby's condition is crucial for parents to make informed decisions about their infant's care. However, this information must be delivered sensitively to the family's emotional state."

One effective strategy is using person-first language, even using the child's name, which emphasizes the individual before their condition. For example, saying "Baby XYZ, an infant with a congenital heart defect" rather than "a heart-defect baby" acknowledges the child as a person first and foremost. This approach helps humanize the patient and can mitigate feelings of alienation or stigma (4).

Moreover, avoiding jargon and using plain language ensures that parents can comprehend the information being shared (3). It is also important to encourage questions and provide opportunities for parents to express their concerns. This two-way communication fosters trust and collaboration between families and healthcare providers (1,2).

Cultivating Compassion Through Language:

Cultivating compassion in the NICU begins with recognizing the immense emotional burden carried by families. The language used by healthcare professionals can either alleviate or exacerbate this burden. Compassionate communication involves not only the words chosen but also the tone, body language, and overall approach to family interactions (4).

"Empathy, an essential component of compassionate care, can be conveyed through language by acknowledging the parents' emotions and validating their experiences."

Empathy, an essential component of compassionate care, can be conveyed through language by acknowledging the parents' emotions and validating their experiences. Simple phrases such as "I can see how much you love your baby" or "I recognize this is very difficult for you" can make a significant difference in how supported parents feel (5).

Additionally, providing consistent and honest updates, even when the news is difficult, builds trust and helps families feel more in control. Avoiding false reassurance while offering realistic hope is a delicate balance that requires careful consideration of the words and approach used (6).

Conclusion:

The social responsibility of NICU staff encompasses not only the provision of medical care but also compassionate and mindful communication with families. The language used by healthcare professionals plays a critical role in educating parents, alleviating stress, and fostering a supportive environment. By prioritizing compassionate communication and recognizing the power of their words, NICU staff can significantly enhance families' emotional well-being, thereby contributing to better overall outcomes for the infants in their care.

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Disclosure: *The author has no conflicts of interests to disclose.*

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- SEPARATION AND TRAUMA





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PARTNERSHIP

What is the best for this unique dyad?

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- **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
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Infant and Family-Centered Developmental Care Standards Implementation: Historical Perspectives on the Emergence of Evidence-Based IFCDC Standards: Part 2

Joy V. Browne, Ph.D. PCNS, IMH-E



Introduction to Part 2 of the two-part series:

Part 1 of this series traced the historical perspectives of medical and nursing neonatal care practices in the United States. The discussion focused on the emergence of neonatal intensive care primarily directed to the protection and survival of early-born and medically compromised babies. Exclusion of developmental support and restrictions of parents from participation in babies' care were the norm.

Part 2 focuses on how emerging interest and research contributed to developmental or neuroprotective care in neonatal intensive care units (NICUs). Four theoretically based and empirically supported approaches include 1) sensory stimulation and the impact of sensory environments; 2) appropriate nurturing environments; 3) caregiving using the baby's behavioral communication to determine appropriate and individualized interventions; and 4) family integration in their baby's caregiving. As a result, evidence-based Infant and Family-Centered Developmental Care (IFCDC) Standards, Competencies, and Best Practices for Infants in Intensive Care have recently been developed. They promote the infusion of IFCDC principles into interprofessional clinical practice in newborn intensive care.

Early conceptualization of the impact of sensory environments on babies.

As described in Part 1, Historically, the focus of newborn intensive care was aimed at protection from infection, thermoregulation, and early birth babies' survival. Aside from nursing care that included hygiene and reduced access to babies, there was little attention to babies' behavior or developmental progress in the newly emerging NICUs. The use of incubators and restrictions on parents' being with their babies created a perspective that babies were "sensory deprived." Basic science studies of sensory deprivation and maternal separation introduced in the early 1970s (1) led to providing "extra sensory stimulation" to enhance the developmental outcomes of typically born babies. (2) An extension of this perspective to preterm babies soon followed, as babies in NICUs were seen to be deprived of stimulation that would enhance development. Scarr-Salapatek initiated an early approach that provided extra sensory stimulation for preterm babies up to a year, demonstrating positive outcomes. (3) Other studies that provided extra stimulation to babies in the intensive care unit or after discharge from the hospital were also initiated. (4-6)

"Basic science studies of sensory deprivation and maternal separation introduced in the early 1970s (1) led to providing "extra sensory stimulation" to enhance the developmental outcomes of typically born babies. (2) "

Other notable early 1970s strategies to influence outcomes and increase growth used extra kinesthetic stimulation using water beds and auditory stimuli (7, 8). Korner introduced the oscillating waterbed to reduce apnea and bradycardic episodes and enhance outcomes. (9-11) Field introduced tactile stimulation in the form of touch and massage (12), and Thoman introduced the "breathing bear," which examined the baby's ability to use self-regulatory skills and ultimately affect neurodevelopment. (13, 14) Research continued to be published in the 1970s and into the 1980s--including those providing extra stimulation—and were generally thought to be beneficial. (15)

As noted in Part 1 of this series, parents were still not available to their infants for extended periods, if at all, in many 1980 and 1990 NICUs. The sensory interventions in the studies were done primarily by professionals who had designed the studies. Extra stimulation, either uni or multimodal, was done in addition to the current care practices rather than integrated into the entire care plan. Overall, the extra stimulation studies appear to have been done "to" rather than "with" the baby, in addition to the sensory input of the NICU and caregiving, and devoid of familiar parental multimodal sensory input.

A change in perspective to babies receiving too much sensory input:

Complex technology and enhanced medical and nursing procedures made survival more likely for babies born preterm and with significant birth challenges. However, more equipment, increasing numbers and complexity of procedures, and more professionals in the environment made most NICUs busy and overwhelming spaces. Open bays, alarms, increasing equipment, bright lights, and crowding added to the sensory environment for

babies. Recognizing the impact of the environment and caregiving on babies, Gottlieb and Gaiter published the book "Infant Stress Under Intensive Care" in 1985. (16) Their studies implicated the environment and procedures as detrimental to babies' short and long-term organization and outcomes. With increasing available technological support, the physiologic effects of caregiving on the baby were more apparent to the caregiver. For example, Long and Lucey identified that caregiving procedures and environmental input affect the stability of many physiologic parameters. (17)

With similar concerns, in the late 1980s, Dr. Stanley Graven initiated study groups of professionals to address the then-current literature on sensory environments and caregiving practices in NICUs. (18, 19) He also invited developmental basic scientists to help address what was known at the time about the development of sensory systems and the impact of early environments on babies' behavior and outcomes. Most of the studies by basic scientists were done with animal models, so implications for human infant development were considered cautiously. (20-25) However, some studies examining the impact of the environment and caregiving were done with human babies. With various naturalistic sensory exposures, babies demonstrated responsivity, preferences, overstimulation, and influences on early attachment relationships. As a result, there was renewed attention to the effects of the sensory and nurturing environment on preterm babies and their parents. New insights into sensory development, sensory interference, and optimal sensory development ultimately influenced and identified the impact on developmental outcomes.

"...there was renewed attention to the effects of the sensory and nurturing environment on preterm babies and their parents. New insights into sensory development, sensory interference, and optimal sensory development ultimately influenced and identified the impact on developmental outcomes."

Sensory environments and NICU design:

Also, in the late 1980s, a group of professionals concerned with the findings reviewed above gathered the support and encouragement of Judy Smith and Robert White to examine the evidence and develop standards for NICU environments. The first edition of the NICU design standards was published in 1992. (26) Since then, the standards have been globally acclaimed in their 10th revision (27).

The *Gravens Meeting on the Environment of Care for High-Risk Newborns and Their Families, B*ased on available research on Developmental Care and the interest in NICU Design, the *Gravens Meeting on the Environment of Care for High-Risk Newborns and Their Families* first met in 1987 and is now holding its 38th annual meeting in 2025. thegravensconference.org

Emergence of a new construct: individualized developmental care:

Parallel to the efforts of Dr. Graven to address environmental and caregiving issues and their impact on babies, Dr. Heidelise Als offered a different perspective of development in the form of the "synactive theory." At the theory's core was the reconceptualization of developmental care based on understanding the behavioral communication of the baby.

Developmental approaches in the 1980s recognized the importance of an individualized approach for the best understanding of the child's experience. Wolke describes in 1987 a practical approach to individualized interventions (27) by observing before, during, and after procedures to see how the child reacts. Then, an individual care plan should be designed to reduce stress and pain and support behavioral regulation. Als adapted this approach to babies in intensive care. Interpreting the stressful or organizing behavior that the environment and caregiving elicit leads to a developmental care plan that is individualized for that baby's expressed behavior and developmental goals. (28-31)

A series of short- and long-term studies examined outcomes from individualized developmental caregiving (the Newborn Individualized Developmental Care and Assessment Program--NIDCAP). Als provided evidence for the benefit of incorporating developmentally supportive approaches to medical care that resulted in optimized medical and neurodevelopmental outcomes.

"Dr. Als' developmental approaches to caregiving and the evidence in her outcome studies have laid the foundation for conceptualizing subsequent developmental care studies (28, 32-36)."

Dr. Als' developmental approaches to caregiving and the evidence in her outcome studies have laid the foundation for conceptualizing subsequent developmental care studies (28, 32-36). Although in its early days, it was resisted as "non-essential" or "fluff" for the care of babies, it gradually became recognized as evidence-based and essential for influencing babies' medical and developmental outcomes and providing benefits for parents.

"...medical outcomes could benefit from the addition of sensitive developmental care and proposed using these approaches as a new standard in NICUs"

Recognition of the lingering neurodevelopmental impact on babies born preterm and evidence of developmental care optimizing neurodevelopmental outcomes became recognized as integral in neonatal care. Dr. Gerry Merenstein, an early neonatology leader, recognized that medical outcomes could benefit from the addition of sensitive developmental care and proposed using these approaches as a new standard in NICUs

> "This is not a glamorous, high-technology form of neonatal intensive care. It does not dramatically rescue babies who are at immediate risk of death, as high-frequency ventilation, inhaled nitric oxide, or extracorporeal membrane oxygenation do. These high-technology interventions are widely used despite lack of well-controlled trials demonstrating their efficacy and safety. Will individualized developmental care for the very low-birth-weight infant be as widely accepted

and implemented"? p 891 (37)

The decade of the brain:

The 1990s ushered in the "decade of the brain" (38), which expanded previous notions of the need for extra sensory stimulation in preterm infants. The effects of the environment on the developing brain, now better measured by non-invasive technology, allow for further understanding of the need for protection from noxious sensory input and provision of appropriate sensory input. In particular, there were implications for the preterm newborn whose brain develops in a very different sensory environment than they would have if carried to term. Additional studies of the physiologic impact of the environment and caregiving on babies' organization provided more evidence for modifications in care practices. The effects have generally resulted in attention to the NICU environment's impact on the developing newborn brain. Common strategies to address these findings included reducing overstimulation, including dimmed lights, lowered sound, and "minimal stimulation" protocols.

Family-centered care and family involvement begin to evolve:

The early 1990s ushered in a change in how patients and families were acknowledged and incorporated into the care of their family members. Beverley Johnson began to explore what is now known as "Family Centered Care" (FCC). (39, 40) Levin's Humane Neonatal Care developed similar efforts to include parents in care in Europe. (41) Johnson's efforts to raise the consciousness of hospitals and organizations to advocate for parent involvement in NICUs were some of the Institute for Family-Centered Care's initial initiatives. https://www.ipfcc.org/about/. Gradual changes from parent restrictions for "visiting hours" have led to open access to their babies 24/7 and parents being integral to the care of their babies. (42-45) Since those initial efforts, the role of parents and families in caring for their babies and family members has become the standard for care not only in NICUs but hospital-wide. NICU design standards have also been adapted to assure parents comfort, access to their baby, and advocacy for their baby's care. (46, 47) Further environment changes and practices included single-family room NICU designs. There is a current effort to provide rooms and opportunities for "couplet care" To keep babies and parents together without interruption. These varied approaches facilitate and enhance developmental and family-centered care. (48, 49)

Kangaroo mother care as a driver for physiologic stability and improved outcomes:

Anderson initially proposed the concept of parents as primary caregivers, which was foundational to FCC in 1977 (50), but with restrictive policies for parents to be with their babies, the effort did not survive. However, it has resurfaced with the findings of the benefits for both mother and baby. Kangaroo Mother Care (KMC, often called Skin to Skin Care—STS) research, highlights the practice's physiological, behavioral, and psychological benefits for term and preterm infants and their mothers. (50-52) KMC/STS is frequently recommended in the approach by AIs, and promoting early mother/baby emotional connection proposed by Welch, KMC/STS is used as a vehicle to establish an emotional connection (53, 54) between babies and their mothers. Both research programs show beneficial behavioral as well as neurophysiological outcomes.

Multiple disciplines in increasingly complex systems:

In the last few decades, NICUs have successfully grown in number and have been effective in treating early-born and sick babies. The model of physicians and nurses as primary professionals involved in planning care has expanded to include subspecialty medical, social work, therapy providers, and, increasingly, parent support advocates.

Influenced by studies showing neurodevelopmental and mental health sequelae babies and parents experience, there is a broader awareness of the need to provide infant and family-centered developmental care as a standard of practice for all disciplines. As central to the care of newborns and parents in the NICU, nursing practice has expanded its scope and guidelines to include developmental care principles. A description of best practice is best exemplified by Kenner and McGrath's recent "Developmental Care of Newborns and Infants" (55)

Various other disciplines now involved in intensive care bring expertise in their particular practice area. As a result, unidisciplinary professional standards, guidelines, and competencies for practice have evolved to meet the needs of professionals who work with high-risk babies and their parents. (56-59) https://www.asha.org/policy/ks2004-00080/ . In addition to single discipline guidelines and standards, descriptions of interprofessional practice in NICUs have been developed (60-64) and typically document overlapping skills of Occupational, Physical, and Speech/Language therapists. Infused into the various practice guidelines are principles of developmental and family-centered care and neuroprotective strategies.

"Influenced by studies showing neurodevelopmental and mental health sequelae babies and parents experience, there is a broader awareness of the need to provide infant and family-centered developmental care as a standard of practice for all disciplines. "

An expanding variety of definitions, approaches, and programs designed to address developmental care has led professional organizations, governments, and family members to develop guidelines specific to the global application of developmental care. (See box with examples)

The emergence of Infant and Family-Centered Developmental Care (IFCDC): evidence-based standards, competencies and best practices for the care of babies in intensive care:

The time has come. A statement by Gartner (65) in his review of the history of the establishment of neonatal intensive care units cites Victor Hugo, who reportedly said, "Nothing is so strong as an idea whose time has come." Gartner was referring to the founding of NICUs as an "idea whose time has come." In recent decades, the time was right for the emergence of infant and family-centered developmental care practices. From 2015 on, the need to establish IFCDC standards and competencies based on the best evidence available was the right time. (66, 67)

The rationale and process for the development of IFCDC standards:

As more emphasis has been put on evidence-based practices in healthcare settings, appropriate research has been needed to substantiate any new technique, medication, or procedure, and developmental and family-centered care is no different.

Examples of global developmental guidelines and policies for NICU care

Developing countries:

Handbook of Healthcare in the Arab World: Developmental Care Practices at Neonatal Intensive Care Units in Developing Countries World https://link.springer.com/referenceworkentry/10.1007/978-3-030-36811-1_146

National Health Service Great Britain:

NHS Greater Glasgow and Clyde NHSGGC Paediatrics for Health Professionals: Developmental Care Guidelines https://www.clinicalguidelines.scot.nhs.uk/nhsggc-guidelines/nhsggc-guidelines/neonatology/developmental-cae-guideline/

East of England Neonatal Neonatal Operational Delivery Network: Developmental Care Guideline

https://eoeneonatalpccsicnetwork.nhs.uk/neonatal/downloads/developmental-care guideline/

Australia:

New South Wales Government Sydney Childrens Hospitals Network: Developmentally Supportive Care for Newborn Infants Practice Guideline Guideline https://resources.schn.health.nsw.gov.au/policies/policies/pdf/2006-0027.pdf

Australian Capital Territory Government Canberra Health Services: Developmental Care in the Neonatal Intensive Care Unit and Special Care Nursery https://www.canberrahealthservices.act.gov.au

Safer Care Victoria Australia Best practice and. Improvement: Developmental care for neonates https://www.safercare.vic.gov.au/best-practice-improvement/clinical-guidance/neonatal/developmental-care-for-neonates

Government of Western Australia Child and Adolescent Health Services: Neonatology Guideline Developmental Care: Reducing environmental stimuli https://cahs.health.wa.gov.au/~/media/HSPs/CAHS/Documents/Health-Professionals/Neonatology-guidelines/Developmental-Care-Reducing-Environmental-Stimuli.pdf?thn=0

Canadian Guidelines:

Joint Position Statement From the CANN, CAPWHN, NANN, and COINN: Canadian Guidelines for the Institutional Implementation of Developmental Neuroprotective Care in the NICU. Part B: Recommendations and Justification https://sddsenc.com/img/client/PDFC/GuidelinesB.pdf.

European Foundation for the Care of Newborn Infants (EFCNI):

: European Standards of care for newborn health: Infant and family-centered developmental care. https://newborn-health-standards.org/standards/standards-english/infant-family-centred-developmental-care/

American Academy of Pediatrics:

Standards for Levels of Neonatal Care: II, III, and IV Https://Publications.aap.org/pediatrics/article/151/6/E2023061957/191305/standards-for-levels-of-nonatal-care-II-III-and?autologincheckk=redirected.

Until recently, appropriate synthesis and grading of the various studies has not been available, making evidence for standards, competencies, and best practices elusive.

"In recent decades, the time was right for the emergence of infant and family-centered developmental care practices."

A group of interprofessional leaders and experts representing major NICU disciplines gathered to develop an approach to identify, review, and critique available evidence supporting IFCDC in intensive care. Developing a comprehensive review of available data, they established evidence-based standards, competencies, and best practices. Their work was supported by the Gravens meeting administration, now led by Dr. Mitch Goldstein at Loma Linda Publishing Company and Loma Linda Division of Neonatology. NICU parents initiated a similar evidence-based, interprofessional approach in Europe under the European Foundation for Care of Newborn Infants (EFCNI, see box)

Conclusion:

Although the field of neonatology is relatively young, it has shown dramatic success in the outcomes of babies and families. It has embraced not just the medical and nursing needs of babies and families but has also recognized the developmental and mental health needs of families who experience intensive care. The historical perspective offered in this two-part series has traced the significant evolution of care for babies and families in intensive care and encourages ongoing research, standards of care, and implementation toward robust IFCDC.

As the field grew, the need for sensitive and evidence-based developmental care, including parents as caregivers, became apparent. Research studies began to ask about the optimal physical and caregiving environments for the developing baby and proposed programs and interventions to address these questions. In recent decades, contributions from various disciplines, basic scientists, and family members have increased momentum to include infant- and family-centered developmental care in NICUs globally. The most recent effort is to develop evidence-based standards of care that reflect the growing body of research substantiating infant and family-centered developmental care for babies and families in intensive care.

"The historical perspective offered in this two-part series has traced the significant evolution of care for babies and families in intensive care and encourages ongoing research, standards of care, and implementation toward robust IFCDC."

IFCDC-- to the future:

The work is not complete and will continue. An emphasis on evidence-based practice and adaptation to new knowledge, technology, and practice will need ongoing review. Continual awareness of challenges with implementing and providing

evidence-based developmental support is of prime importance. As the field grows, future work should include attention to emerging science and the opportunities that result from appropriate clinical implementation. Continuity in applying IFCDC perspectives to preconception, perinatal, delivery, intensive care, community support, early education, and adulthood can and should be the goal.

Including parents in their baby's care and providing support for their physical and mental health for all families is essential not only for theirs but also for their baby's outcome. Babies and their parents should be seen as a physiological/psychological unit rather than a separate focus of caregiving. Interprofessional practice that includes non-separating parents from their babies must be the norm rather than the exception.

Environments should be adapted to provide safe and nurturing spaces for babies, families, and staff. Practices that assure their physical and mental health and well-being must be a priority. The future should respect and recognize all individuals: babies, parents, and families, regardless of their backgrounds, resources, or perspectives. Furthermore, these principles and standards of care should be expanded into other places where babies and families receive care.

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Disclosure: *The author has no conflicts of interests to disclose.*

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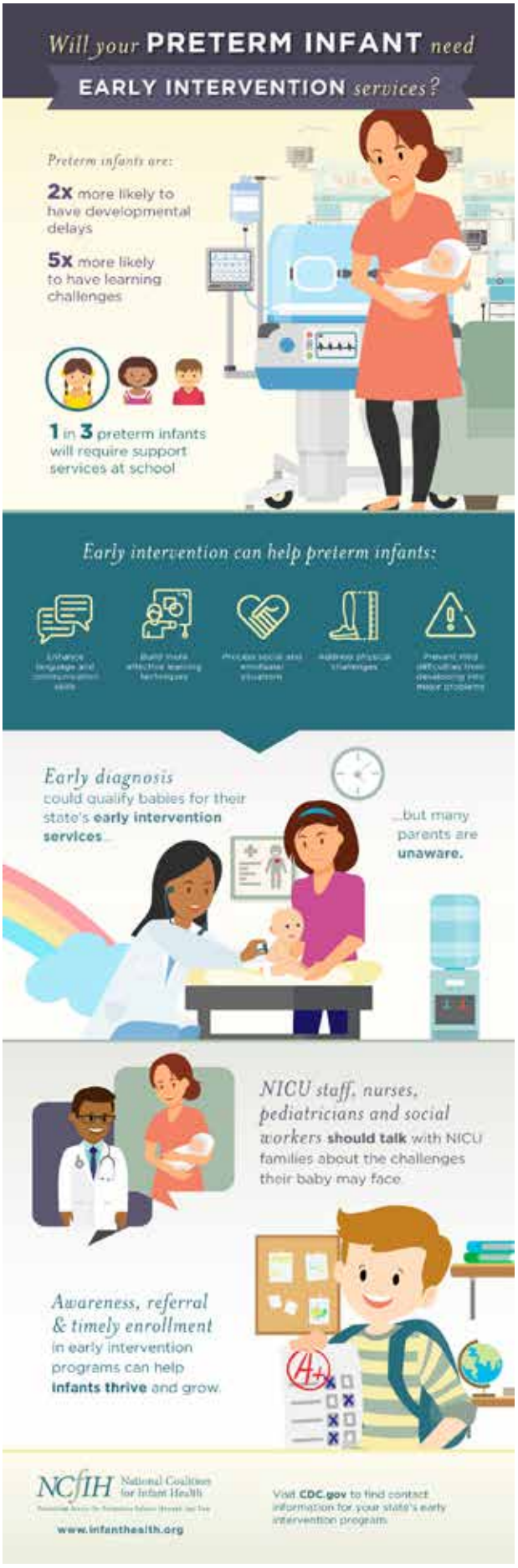
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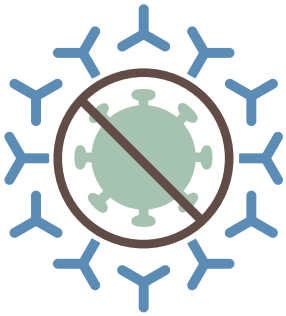
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Protecting your baby and family from

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.

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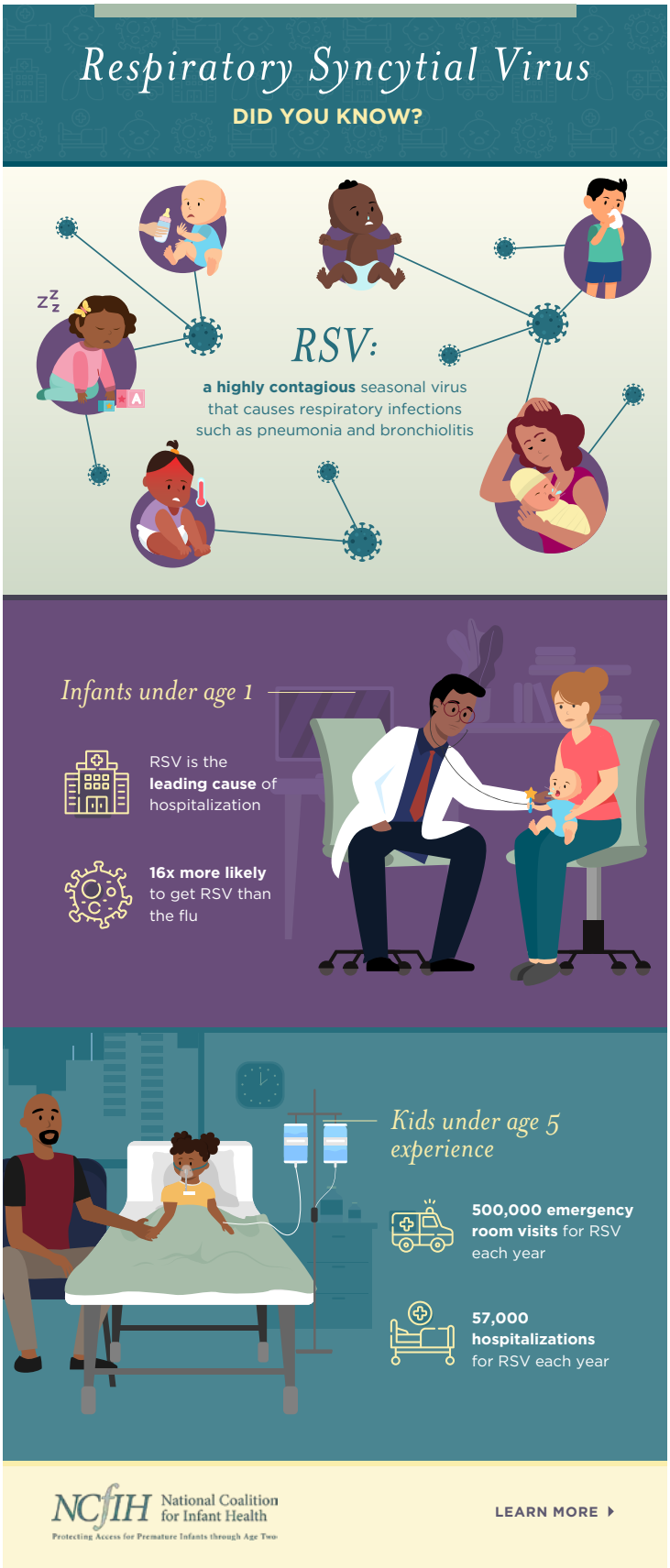
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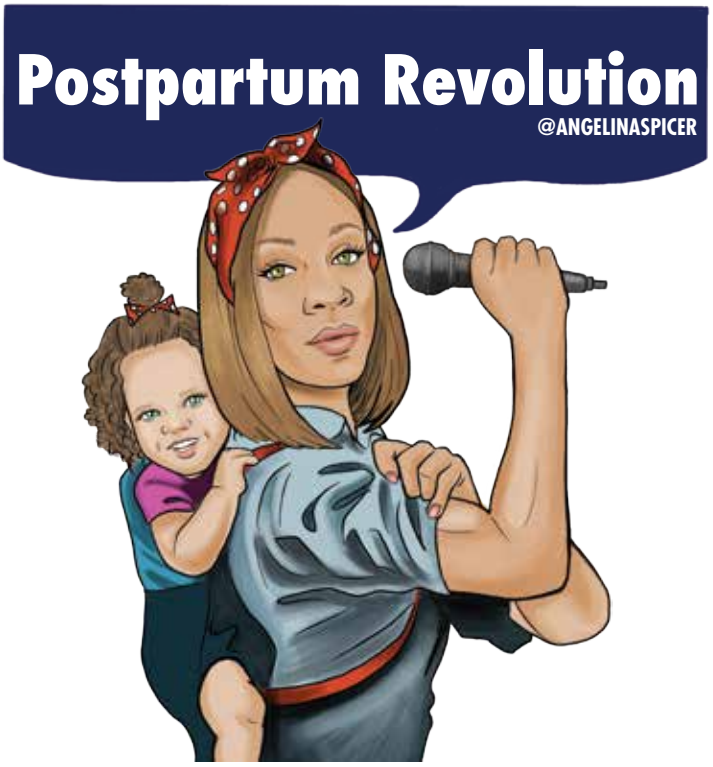
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Dan L. Stewart, MD
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University of Louisville School of Medicine
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Louisville, KY

Preventing Retinopathy of Prematurity

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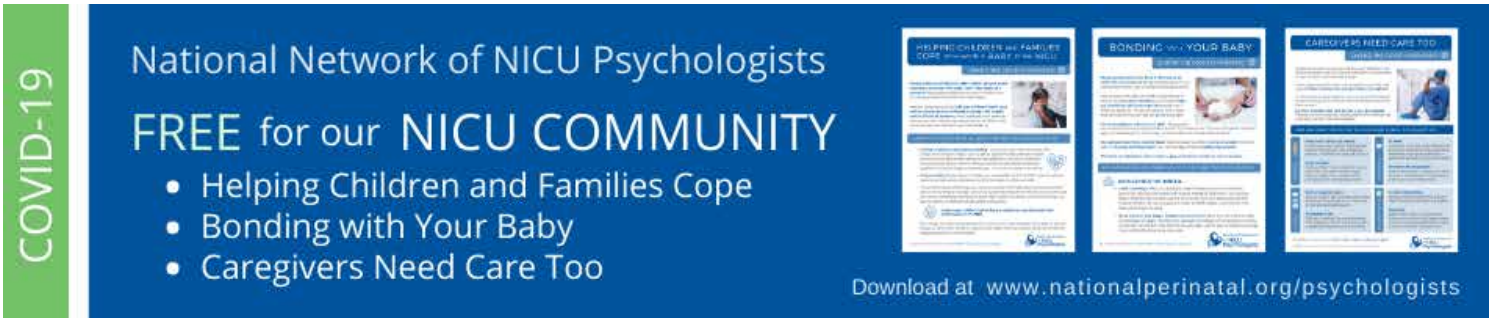
Jonathan R. Swanson, MD, MSc
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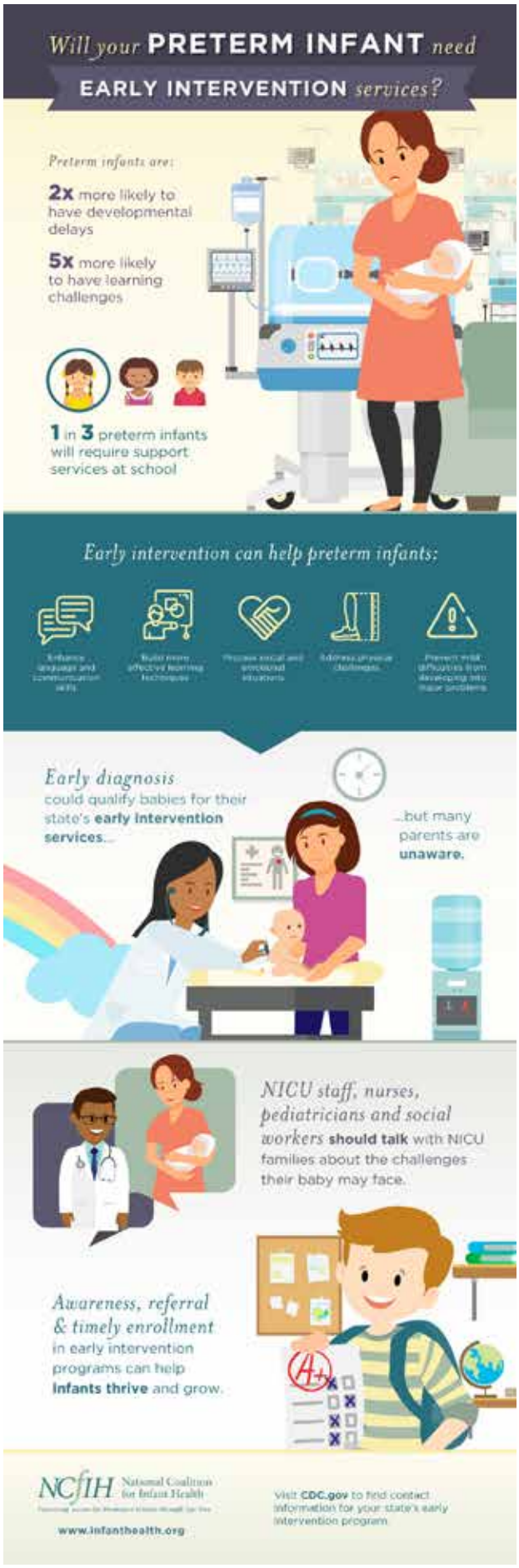
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Neonatology Today's Digital Presence

Neonatology Today's now has a digital presence. The site is operational now and defines the future look of our digital web presence. By clicking on this https://www.neonatologytoday.org/web/., researchers can download individual manuscripts both in digital format and as part of the original PDF (print journal). While the PDF version of Neonatology Today will continue in its present form, we envision that the entire website will be migrated to this format in the next several months. We encourage you to take a look, "kick the wheels," and let us know where we still need to improve.. We are working towards making the website more functional for subscribers, reviewers, authors and anyone else. Although we have not yet applied for inclusion in the National Library of Medicine Database (Pub-Med), this new format meets several of the important metrics for this ultimate goal. As of December, 2020, NT has its own account with CrossRef and will assign DOI to all published material.

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:

fu-sheng.chou@neonatologytoday.net

Readers can also follow

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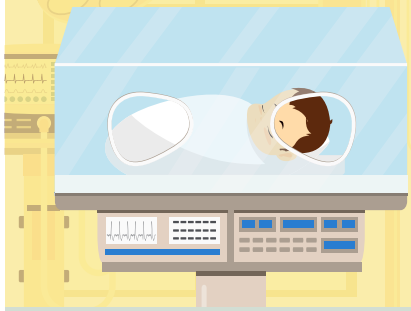
Hemolytic Disease of the Fetus & Newborn

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.





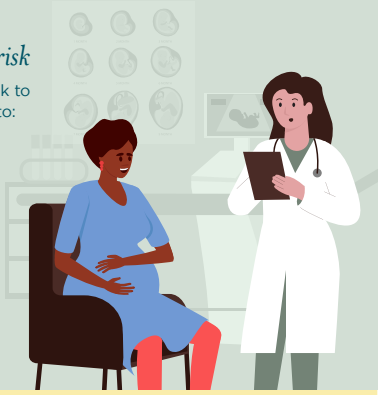
HDFN can lead to:

- **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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- Helping Children and Families Cope
- Bonding with Your Baby
- Caregivers Need Care Too



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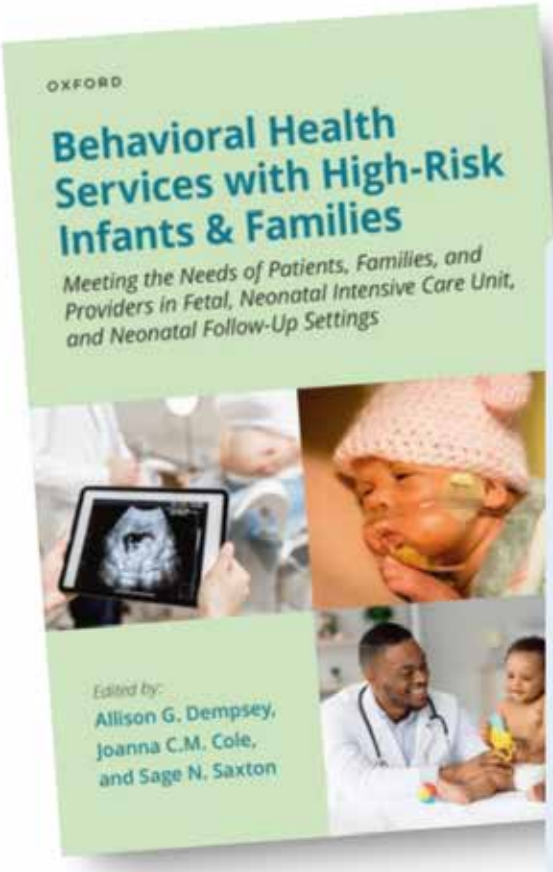
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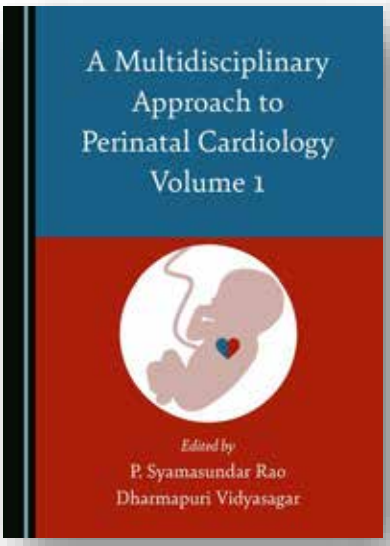
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A Multidisciplinary Approach to Perinatal Cardiology *Volume 1*

Edited by P. Syamasundar Rao and Dharmapuri Vidyasagar



Hardback

ISBN-13:
978-1-5275-6722-1

ISBN-10:
1-5275-6722-2

Date of Publication:
24/04/2021

Pages / Size:
794 / A5

Price:
£99.99

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

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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
Founder, Bryce's NICU Project, San Antonio, TX.

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.

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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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Medicaid Rule Changes Poised to Improve Postpartum Care for New Moms

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.

AfPA | Alliance for Patient Access

IfPA | Institute for Patient Access

"Federal Medicaid officials announced an extension of postpartum coverage and expanded eligibility for people who may have trouble accessing public health coverage, along with rule changes aimed at improving obstetric care at key hospitals and increasing access to care for underserved communities."

Federal Medicaid officials announced an extension of postpartum coverage and expanded eligibility for people who may have trouble accessing public health coverage, along with rule changes aimed at improving obstetric care at key hospitals and increasing access to care for underserved communities.

The updates, announced in mid-July, along with the White House's *Blueprint for Addressing the Maternal Health Crisis,* are part of a broader effort to reduce pregnancy and birth-related deaths in the U.S., where rates far exceed other highly developed nations. (1,2)

"While maternal mortality rates have declined since the spikes during the COVID-19 pandemic, (3) provisional data from the CDC show that around 680 women died in childbirth in 2023."

Maternal Deaths are Unequally Distributed – and Most are Preventable:

While maternal mortality rates have declined since the spikes during the COVID-19 pandemic, (3) provisional data from the CDC show that around 680 women died in childbirth in 2023. (4) Such deaths are more common among American Indian, Alaska Native, and Black mothers, who also experience higher disparities in access to pre- and post-natal care. (5, 6)

However, research shows that more than 80% of maternal deaths are preventable. (7)

"This is especially important for those facilities designed as 'critical access' for their service to high-risk populations. The changes announced last month proposed closer tracking of these hospitals' staffing, training, emergency preparedness, care delivery, and cultural competencies."

Ensuring hospitals meet minimum safety and care standards is one change that could make a difference. This is especially important for those facilities designed as "critical access" for their service to high-risk populations. The changes announced last month proposed closer tracking of these hospitals' staffing, training, emergency preparedness, care delivery, and cultural competencies.

Officials expect the changes to "improve the safety, quality, and timeliness of the care that hospitals provide pregnant women." (8)

Expanded Access and New Outreach:

Last month's announcement also outlined exceptions to the federal "four walls rule," which prohibits Medicaid from reimbursing for services outside the facility. This change encourages outreach to mothers in rural areas, including those served by the Indian Health Service and tribal area clinics who may require follow-up

postpartum care. (9)

Mothers previously incarcerated will also see their access to covered care improve under the new rules. (10)

"The recently announced changes and other government and community-led efforts can potentially move the country off the bottom rung among its peers regarding maternal mortality."

The recently announced changes and other government and community-led efforts can potentially move the country off the bottom rung among its peers regarding maternal mortality.

References:

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2. https://www.commonwealthfund.org/publications/issue-briefs/2024/jun/insights-us-maternal-mortality-crisis-international-comparison
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4. https://www.cdc.gov/nchs/nvss/vsrr/provisional-maternal-deaths-rates.htm
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10. https://nationalpartnership.org/report/incarceration-harms-moms-and-babies/

Disclosure: Josie Cooper is the Executive Director of the Alliance for Patient Access. This article was also published at healthpolicytoday.org.

NT

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Email: jcooper@woodberryassociates.com



Immunizing Yourself Against **COVID-19**

COVID-19 vaccines have been shown to:

- Lessen the severity of symptoms[1]
- Reduce disease transmission[3]
- Reduce risk of mortality[2]
- 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.

HOW THEY WORK: **Instruct cells to make COVID-like proteins that trigger the immune system to fight the virus.**

PROTEIN SUBUNIT VACCINES

Used for three decades against the flu, whooping cough and hepatitis B.

Deliver harmless versions of the COVID protein that train the immune system to fight the virus.

VECTOR VACCINES

Used for decades against chickenpox, malaria and tuberculosis.

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
2. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8782520/
3. https://www.nejm.org/doi/full/10.1056/nejmc2107717
4. https://royalsocietypublishing.org/doi/full/10.1098/rsif.2020.0683
5. https://www.cdc.gov/vaccines/covid-19/clinical-considerations/interim-considerations-us.html
6. https://doh.wa.gov/emergencies/covid-19/vaccine-information/safety-and-effectiveness
7. https://doh.wa.gov/emergencies/covid-19/vaccine-information/safety-and-effectiveness
8. https://www.fda.gov/emergency-preparedness-and-response/coronavirus-disease-2019-covid-19/covid-19-vaccines
9. https://www.ema.europa.eu/en/human-regulatory/overview/public-health-threats/coronavirus-disease-covid-19/treatments-vaccines/vaccines-covid-19/covid-19-vaccines-authorised
10. http://www.bccdc.ca/Health-Info-Site/Documents/COVID-19_vaccine/WHO-EUA-qualified-covid-vaccines.pdf

GAfPA Global Alliance for Patient Access

NCPA NATIONAL COMMUNITY PHARMACISTS ASSOCIATION

LOMA LINDA
LLPC
PUBLISHING COMPANY
EST 2018

Supporting NICU Staff so they can support families



Providing online education that is...

- Story-Driven
- Trauma-Informed
- Evidence-Based

National Perinatal Association

NPN NICU PARENT NETWORK

The preeminent provider of compelling perinatal education on psychosocial support created through interprofessional collaboration

www.mynicunetwork.org

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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.

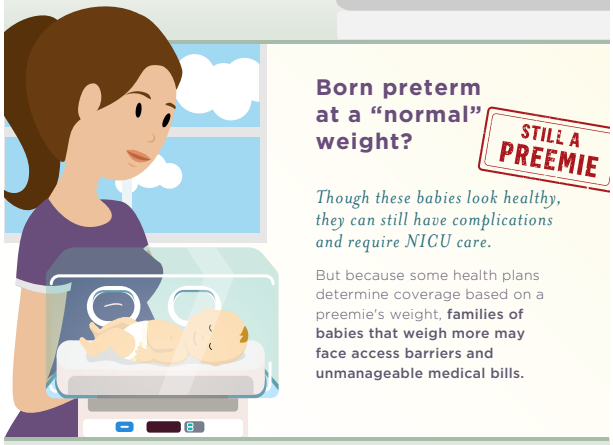
Born between 34 and 36 weeks' gestation?

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.

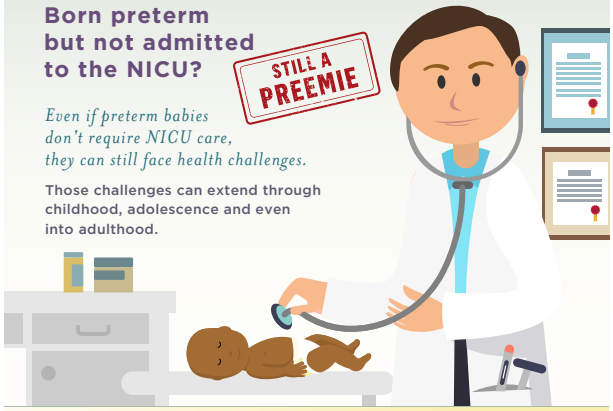
But because some health plans determine coverage based on a preemie's weight, **families of babies that weigh more may face access barriers and unmanageable medical bills.**

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

Empowering Youth Voices in Pediatric Healthcare: Annual Summit and More

Sabina Schmidt Goldstein-Becerra

iCAN, the International Children's Advisory Network, is the premier global pediatric platform empowering the patient voice in healthcare, driven by youth for youth. As a worldwide consortium of 36 KIDS' (Kids Impacting Disease through Science) advisory groups spanning four continents, including one virtual chapter, iCAN's dedicated youth member groups work in unison around the world 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. On average, our youth are ages 8-18 years old, most of whom are living with chronic, rare, and complicated diagnoses, though a few of our youth have no medical diagnoses or medical conditions. iCAN values and understands that all patients, even the youngest, often have ideas that can help improve their healthcare experiences.

Get involved today and Join the iCAN Parent Council!

"iCAN, the International Children's Advisory Network, is the premier global pediatric platform empowering the patient voice in healthcare, driven by youth for youth. As a worldwide consortium of 36 KIDS' (Kids Impacting Disease through Science) advisory groups spanning four continents, including one virtual chapter, iCAN's dedicated youth member groups work in unison around the world 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."

"We continue to be a collaboration between the American Academy of Pediatrics (AAP) Section on Advances in Therapeutics and Technology (SOATT), Georgia Institute of Technology (the GT Pediatric Innovation Network), local AAP Chapters, children's hospitals, local academia, and other non-profits. We aim to get our youth where they need to be and have their voices heard."

To foster diversity, all children from anywhere may freely join iCAN. iCAN also supports young adults and the voice of parents, many of whom have young people who cannot share their voices. We continue to be a collaboration between the American Academy of Pediatrics (AAP) Section on Advances in Therapeutics and Technology (SOATT), Georgia Institute of Technology (the GT Pediatric Innovation Network), local AAP Chapters, children's hospitals, local academia, and other non-profits. We aim to get our youth where they need to be and have their voices heard. Our fantastic youth make a difference in pediatric healthcare through interactions with industry, by presenting original research at conferences, by innovating new solutions, by empowering the pediatric patient voice in healthcare worldwide, and by telling their stories at conferences and to organizations like the FDA, iACT,

Readers can also follow

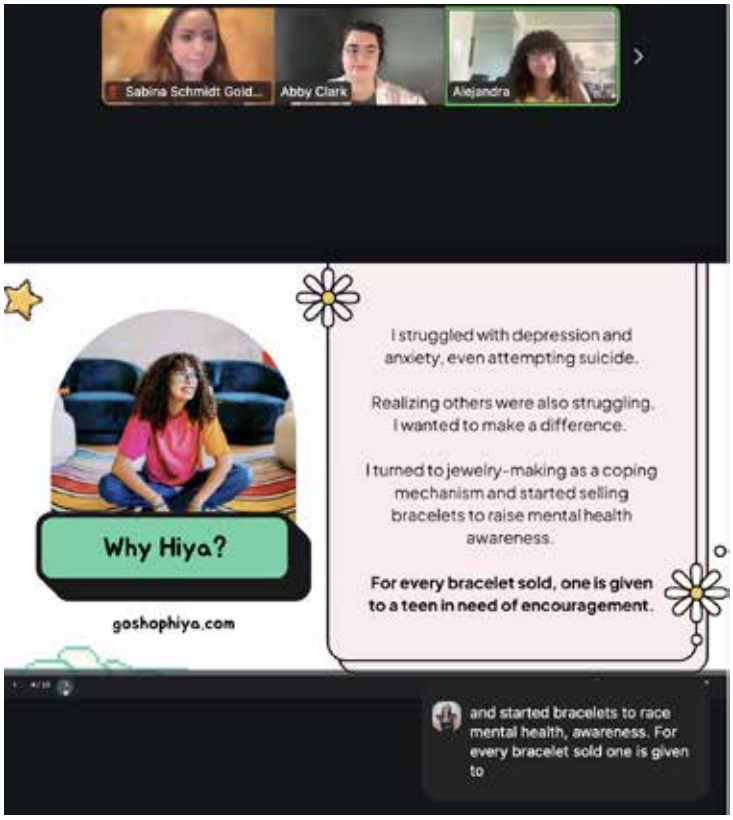
NEONATOLOGY TODAY

via our Twitter Feed

@NEOTODAY

NIH, NORD, CDC, and AAP. Whether you are a patient, family member, healthcare professional, or supporter of the cause, we welcome you to visit our website at icanresearch.org to learn more about our mission, various programs, and initiatives. Join us to ensure that every child's voice is heard and that their unique experiences are taken into account to improve healthcare outcomes for all pediatric patients.

Empowering the Next Generation: Alejandra Wells on Mental Wellness and Advocacy at iCAN's Ask the Experts Event





At our recent "Ask the Experts" event, we featured Alejandra Wells, a remarkable young entrepreneur, advocate, and iCAN KIDS member, as our expert speaker. Alejandra's journey, from starting her jewelry business, Hiya, to promoting mental wellness among teens, is a testament to young leaders' impact when they are empowered to use their voices.

Alejandra's words during the webinar—"Staying positive, checking on your people, advocating for yourself, and being loud about what you want"—resonated deeply with our audience. Our community needed to hear these powerful messages, aligning perfectly with iCAN's mission to support and empower the next generation of changemakers.

Throughout the event, Alejandra shared how creative outlets, like her jewelry business, have helped her cope with mental health challenges. Hiya is more than just a business; it is a platform for raising awareness and supporting others facing similar struggles. Alejandra's dedication to this cause shines through her advocacy work, mentoring, and passion for making a difference.

Sabina and Abby joined the conversation by emphasizing the importance of networking and communication in growing a business. They highlighted how sharing one's voice and passion can attract support, which is essential for any young entrepreneur. Alejandra, Abby, and Sabina also stressed the importance of providing resources and support for mental health awareness and the critical role of open communication and feedback in ensuring that these resources are accessible and practical.

"Alejandra, Abby, and Sabina also stressed the importance of providing resources and support for mental health awareness and the critical role of open communication and feedback in ensuring that these resources are accessible and practical."

Feedback from attendees has been overwhelmingly positive, with many expressing their gratitude for Alejandra's perspectives and actionable ideas. Her work is empowering and inspiring, and it's clear that she is helping shape a brighter future for the next generation.

As Alejandra continues her incredible work, including her exciting plans for her teen lifestyle magazine, we are reminded of the importance of supporting young leaders like her. At iCAN, we are incredibly proud to have Alejandra as part of our family, and we are honored by her commitment to promoting mental wellness and empowering teens.

"As Alejandra continues her incredible work, including her exciting plans for her teen lifestyle magazine, we are reminded of the importance of supporting young leaders like her. At iCAN, we are incredibly proud to have Alejandra as part of our family, and we are honored by her commitment to promoting mental wellness and empowering teens."

Thank you, Alejandra, for being a beacon of positivity and strength. Your contribution made this event a resounding success, and we are excited to see where your journey will take you next.

Mark your calendars- iCAN invites you to another installment of Ask the Experts on September 21!

Ask the Experts Series: Featuring Ray Browning, CEO of Biomotum



We are excited to announce that Ray Browning will join us for our next *Ask the Experts* session on September 21 at 8 AM PST, 11 AM EST, and 5 PM CET! Ray is an accomplished Research and Product Development professional with an impressive background in both industry and academia. With athletic engineering, human performance, and clinical science expertise, Ray has delivered high-impact innovations throughout his career. He is also a 7-time Ironman winner, showcasing his dedication to pushing the limits of human performance.

"Throughout the week, our kids participated in an engaging and creative process. They sang songs, drew vibrant pictures, and meticulously cut out their artwork. Guided by the experts, they then pieced together all these elements into an impressive video that captures the rich diversity and collaborative spirit of iCAN."

In this special session, Ray will share his journey, from his inspiring career to the factors that drive his passion for innovation. He will also discuss how the feedback from our iCAN KIDS has played a pivotal role in shaping his latest product developments. Through this collaborative approach, Ray is working closely with iCAN to incorporate our kids' insights into the product development cycle, ensuring their voices are heard when creating new solutions.

Join us for this exciting event as Ray Browning offers an insight into his career, his vision for the future, and how our iCAN kids are making a tangible impact on the innovation process!

Secure your spot by registering here today!

Save the dates for the next *Ask the Experts*:

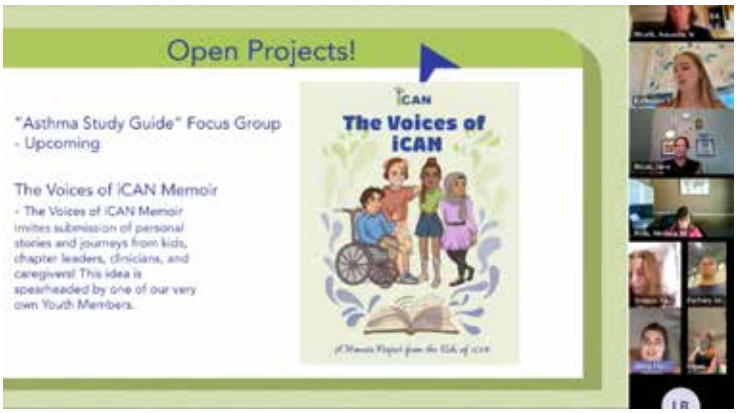
October 19 with Mary Jo Klein, iCAN Parent and Professor of Bioethics

November 18 with Harvey Castro, AI in Healthcare Expert

Empowering New Voices: iCAN's Director of Operations, Abby Clark, Connects with KIDS Kansas City







Abby recently joined a call with KIDS Kansas City, where she connected with their new members and introduced them to our mission. She emphasized iCAN's commitment to prioritizing pediatric patients in all our initiatives, from advising to research. Abby shared insights on how we empower young people to lead innovation, medicine, and research in pediatric healthcare. She also highlighted opportunities for collaboration, including

engaging in feedback phases, advising efforts, and developing patient-centered materials. Abby ensured the new members felt welcomed and informed about how they could contribute to iCAN's mission of prioritizing pediatric patients and driving positive change. Welcome to our new members at KIDS Kansas City!

Sylvia Baedorf Kassis, MPH Engages with iCAN's KIDS Virtual– Championing Health Literacy in Clinical Research





Sylvia Baedorf Kassis, MPH, a Program Director at the Multi-Regional Clinical Trials (MRCT) Center of Brigham and Women's Hospital and Harvard, has been at the forefront of making clinical research more understandable and accessible for over 20 years. Her work simplifies complex medical concepts and ensures that research is accessible to everyone through initiatives like the Health Literacy in Clinical Research program and the plain language Clinical Research Glossary.

Sylvia recently joined our iCAN KIDS Virtual chapter meeting, engaging directly with our youth members. During this interactive session, she presented the Clinical Research Glossary, a tool designed to translate difficult clinical research terms into plain language. Our kids provided invaluable feedback, suggesting features that would make the glossary even more inclusive. Ideas included adding a reader function for those who struggle with literacy, increasing font sizes to accommodate visual impairments, adding kid-friendly animations for those who may not understand the clinical language, and adjusting font colors to improve readability.

Sylvia's commitment to enhancing patient understanding aligns with iCAN's mission to empower the next generation of patient advocates. Her collaboration with our youth members highlights the importance of including diverse voices in the conversation around health literacy, and we are excited to continue this partnership to drive meaningful change in clinical research.

"The virtual chapter is vital to iCAN's efforts to connect young patients and advocates with industry leaders and experts like Sylvia. These sessions allow our members to contribute to essential initiatives actively, ensuring that young people's perspectives are included in developing patient-focused resources. If you want to engage with the virtual chapter, please contact us!"

The virtual chapter is vital to iCAN's efforts to connect young patients and advocates with industry leaders and experts like Sylvia. These sessions allow our members to contribute to essential initiatives actively, ensuring that young people's perspectives are included in developing patient-focused resources. If you want to engage with the virtual chapter, please contact us!

iCAN KIDS Spotlight

Feature: Spotlight on iCAN Youth Council Co-Leader, Ella





Ella took center stage at our 10th Annual iCAN Research and Advocacy Summit in Bari, Italy, presenting her cross-sectional study, "The Social Perceptions of Chronic Illness." Conducted as part of her Capstone Project for Trinity College's Global Health Humanities Gateway Program and through her role as Co-Chair of iCAN's Youth Council, Ella's research delved into the complex perceptions surrounding chronic illness and its profound impact on individuals.

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Her study involved over 200 participants, who shared their perspectives and experiences, contributing valuable insights to this critical topic. This engagement was instrumental in ensuring that the research reflected diverse viewpoints on chronic illness.

"A special thanks also goes to Meghan Herrington, who played a pivotal role as a research assistant, and to the iCAN Youth Council for their continuous involvement, ensuring the study resonated with those who live with chronic illness and those who do not."

Ella extends her heartfelt gratitude to her mentors, Kirsten Sherman Cervati, Leanne West, and Dr. Erin Frymire, for guiding her through the research process. A special thanks also goes to Meghan Herrington, who played a pivotal role as a research assistant, and to the iCAN Youth Council for their continuous involvement, ensuring the study resonated with those who live with chronic illness and those who do not.

Reflecting on her experience, Ella shared, "Leading this study was meaningful — not only did I learn tremendously about the topic at hand, but also about the research process. I am grateful to have had this incredible opportunity."



Ella first began her journey with iCAN through KIDS Walter Payton and plans to continue her commitment to the organization. Her work exemplifies the passion and dedication of iCAN's youth members, whose efforts are driving meaningful change in pediatric health worldwide.

iCAN's 2025 Annual Research and Advocacy Summit

Presented by Jumo Health

July 14-18, 2025

To sponsor our Summit, visit bit.ly/iCANsponsorships

We are so excited to announce that our next Summit will take place in Canada from July 14 to 18th, 2025, hosted by KIDS Canada Francais. Please save the date! Additional details will be shared later this year. Here is the video announcing the location, which was played at our annual Summit.

Our annual Summit is a transformative platform for nurturing innovation, compassion, and collaboration in pediatric healthcare among all stakeholders. We invite you to join us in this life-changing event and contribute in two meaningful ways:

1. Sponsor the 2025 Summit: Your sponsorship plays a pivotal role in organizing the Summit, ensuring an impactful experience for all attendees.
2. Sponsor a Child to Attend: Your sponsorship directly impacts a child's life, allowing them to attend the Summit in Canada. Your support covers travel, accommodation, and participation, offering a world of learning and empowerment.

Together, we are shaping a brighter future for pediatric healthcare. Regardless of size, your contribution makes a significant difference in prioritizing the patient's voice and fostering positive change. Your generosity and dedication are deeply valued. Let us unite in Canada to create a summit experience that will empower the pediatric community for years! Let us work together to make next year's 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 donate.

Disclosures: *There are no reported disclosures*

NT

Corresponding Author



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OPIOIDS and NAS
When reporting on mothers, babies, and substance use
LANGUAGE MATTERS

I am not an addict.
I was exposed to substances in utero. I am not addicted. Addiction is a set of behaviors associated with having a Substance Use Disorder (SUD).

I was exposed to opioids.
While I was in the womb my mother and I shared a blood supply. I was exposed to the medications and substances she used. I may have become physiologically dependent on some of those substances.

NAS is a temporary and treatable condition.
There are evidence-based pharmacological and non-pharmacological treatments for Neonatal Abstinence Syndrome.

My mother may have a SUD.
She might be receiving Medication-Assisted Treatment (MAT). My NAS may be a side effect of her appropriate medical care. It is not evidence of abuse or mistreatment.

My potential is limitless.



I am so much more than my NAS diagnosis. My drug exposure will not determine my long-term outcomes. But how you treat me will. When you invest in my family's health and wellbeing by supporting Medicaid and Early Childhood Education you can expect that I will do as well as any of my peers!

Learn more about
Neonatal Abstinence Syndrome
at www.nationalperinatal.org

National Perinatal Association



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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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.

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

International Children's Advisory Network, Inc. (iCAN)
15921 Bahama Street, North Hills, CA 91343
www.icanresearch.org
info@icanresearch.org

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iCAN, the International Children's Advisory Network, is a 501(c)(3) nonprofit organization comprising 90% youth with medically rare or complex diagnoses from around the world, with 10% not having any diagnoses but wanting to contribute to change in pediatrics. For over a decade, iCAN has consistently advocated for the representation of children and families in the realms of pediatric medicine, research, and innovation. iCAN is the platform for empowering young individuals to contribute their insights and experiences, directly influencing the landscape of pediatric medical research and innovation. Through various initiatives and events, iCAN strives to enhance the involvement of children and families in healthcare decision-making processes with clinicians, researchers, the FDA, and industry to foster patient-centric advancements in pediatric healthcare.

On behalf of iCAN, we extend an invitation for you to contribute an in-kind donation to our upcoming online auction event scheduled for October 24-October 31, 2024, where buyers across the continental US will support us in raising funds for our kids. Your generous contribution not only provides life-changing opportunities but also empowers these children to actively shape the future of pediatric healthcare.

Your valuable contribution to this auction directly supports our fundraising efforts, enabling us to sponsor children from around the world who do not have the financial means to attend our annual Research and Advocacy Summit. This upcoming year, the iCAN Summit will be hosted by our Canada chapter and is scheduled for July of 2025. The proceeds specifically cover global travel and accommodation expenses to bring together pediatric participants from around the world. Throughout the interactive and educational week-long event, children will engage with industry, work in a university medical lab and on projects, share research findings from the past year, and perform a service project with the local children's hospital.

Exclusive recognition for your contributions will be provided during this event, such as acknowledgment on our social media platforms, recognition on our website under "Auction Donors," and mentions in our promotional materials for the auction. Your dedication to our cause will be prominently highlighted within our network of supporters.

To confirm your generous donation, including coverage of shipping costs to our organization, we have enclosed an in-kind donation form specifying the item you intend to contribute. You can also sponsor the Summit as well. Please take a moment to complete this form and return it to us via email at goldsteinmd@icanresearch.org by September 30, 2024. Your prompt response will ensure the accurate acknowledgment of your donation or sponsorship for tax purposes.

Your consideration and support are highly valued. By contributing to our cause, you play a crucial role in making a tangible difference in the lives of children everywhere. Together, we can amplify these young voices and contribute to groundbreaking advancements in pediatric medicine and healthcare, recognizing the patient as the most important stakeholder.

We look forward to your partnership!

Sincerely,

Charles A. Thompson, MD FAAP

Founder/Chairman, International Children's Advisory Network

Sponsorship and Donation Request Form

___ Champion Sponsor ($100,000)

___ Titan Sponsor ($75,000)

___ Warrior Sponsor ($50,000)

___ Guardian Sponsor ($25,000)

___ Defender Sponsor ($15,000)

___ Protector Sponsor ($10,000)

___ Patron Sponsor (< $10,000)

Company Name:_____

Contact Person: _____

Title:_____

Email Address:_____

Phone Number:_____

Address:_____

Description of In-Kind Donation:

- ☐ Product(s)
- ☐ Gift Certificate
- ☐ Other (please specify)

Quantity/Value of Donation: _____

Expiration Date (if applicable):_____

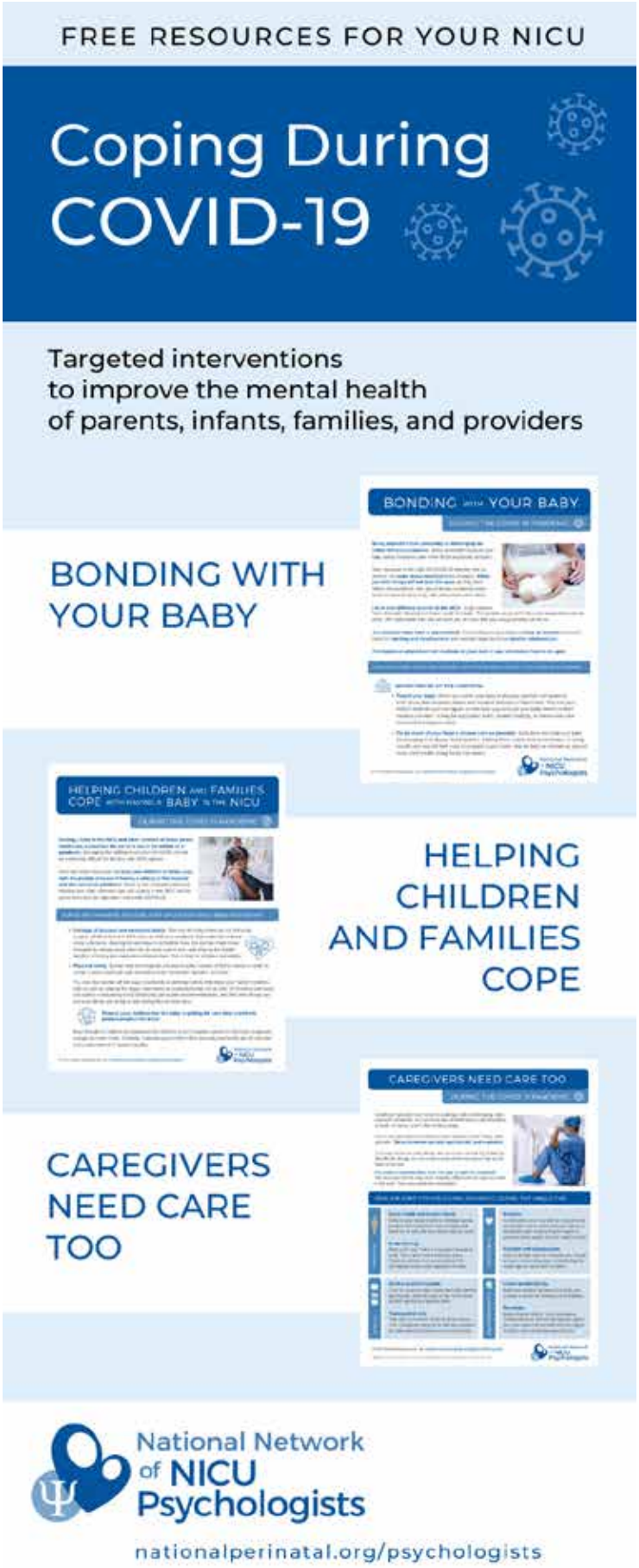
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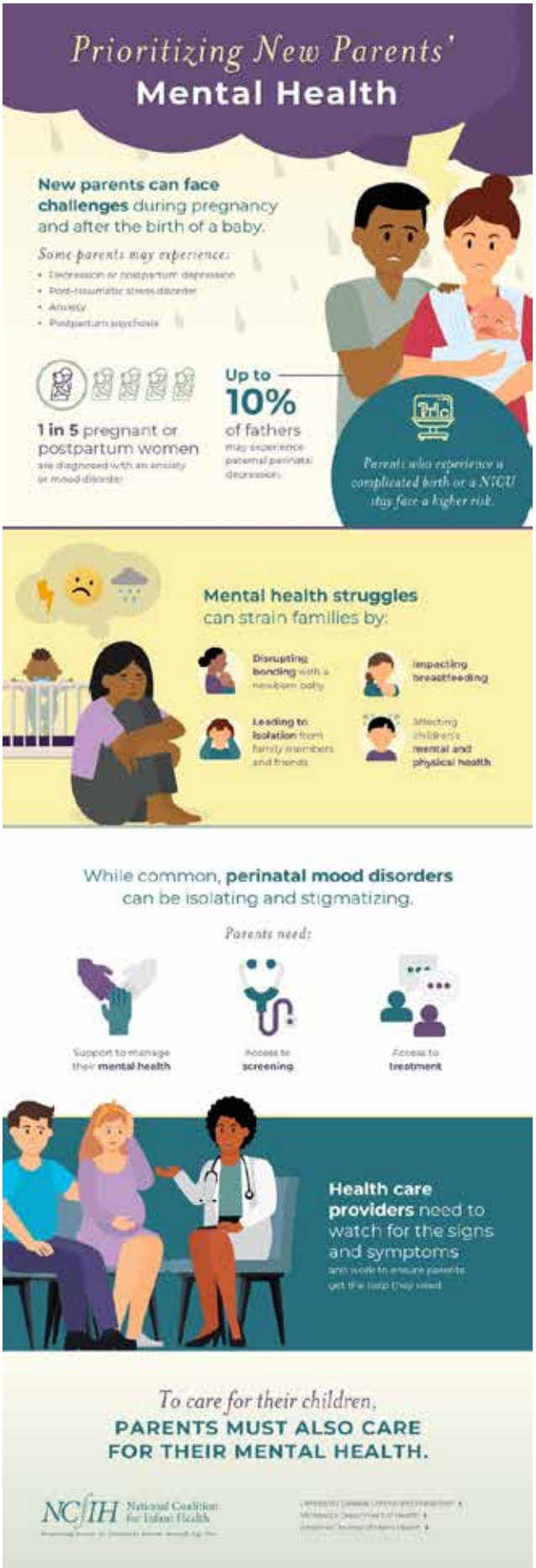
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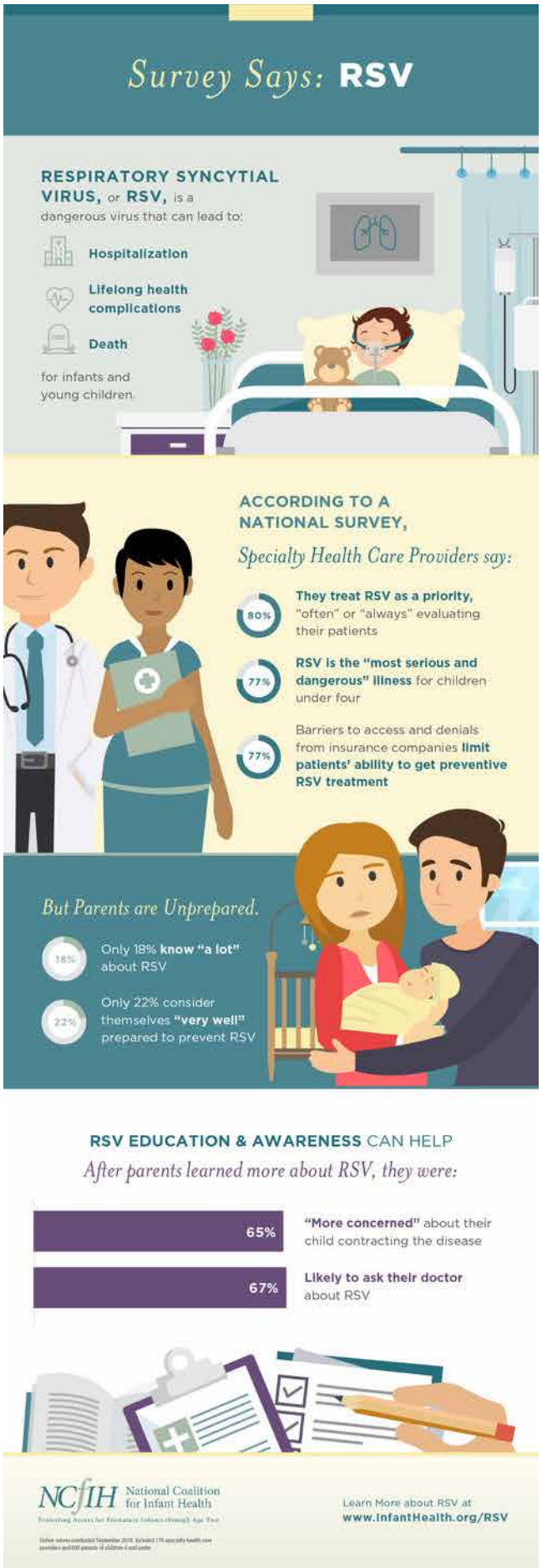
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- ☐ UPS/FedEx

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PROTECT YOUR FAMILY FROM
RESPIRATORY VIRUSES
flu
coronavirus
pertussis
RSV
SOAP
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


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.
NCIH 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
NCIH National Coalition for Infant Health
Learn More about RSV at www.InfantHealth.org/RSV

Peer Reviewed

Briefly Legal: Presumed Perinatal Stroke – Issues Beyond Malpractice

Maureen Sims, MD, Barry Schifrin, MD

At the time of her pregnancy, the patient was a 20-year-old, single, Hispanic woman who was 5'2", weighed 105 pounds, and worked as a waitress. She gained 47 pounds during the pregnancy but remained normotensive. She attended every prenatal appointment. At 16.6 weeks gestation, she was seen in the ED for nausea, vomiting, and diarrhea over the last 24 hours. Her pulse was 137, and she had a fever of 38.2° C. IV hydration, and Zofran were administered, and she was discharged home. She later reported this episode as "food poisoning."

At 36.4 weeks, urine culture was positive for GBS. After 38.3 weeks gestation, the patient was seen on multiple occasions in OB triage for complaints of abdominal pain. Contractions were found to be 5-10 minutes apart with a normal fetal heart rate (FHR) pattern. In each case, "false labor" was diagnosed, and she was discharged home.

At 40.4 weeks, she was seen for similar complaints, but on this occasion, she was admitted to the hospital for induction/augmentation of labor. On admission, her BP was 136/81, and her pulse was 118 bpm. She remained somewhat tachycardic but not hypertensive. The drug screen was negative. The cervix was dilated 1-2 cm. and 80% effaced, soft, and anterior with the presenting part at -2 station.

"Labor was augmented with Cytotec, and GBS prophylaxis was provided. After about 5 hours, epidural anesthesia was placed. After about 6 hours of labor, in response to a very prolonged FHR deceleration, the patient received an IV fluid bolus, oxygen via face mask, and position change, but the nurses failed to notify the attending physician about the episode, and the labor continued. The tracing improved, and some 2 hours later, a 'reassuring FHR' was noted."

Labor was augmented with Cytotec, and GBS prophylaxis was provided. After about 5 hours, epidural anesthesia was placed. After about 6 hours of labor, in response to a very prolonged FHR deceleration, the patient received an IV fluid bolus, oxygen via face mask, and position change, but the nurses failed to notify the attending physician about the episode, and the labor continued. The tracing improved, and some 2 hours later, a "reassuring FHR" was noted.

At 5cm dilatation with the fetus in the OP position (a malposition), artificial rupture of membranes (AROM) revealed a moderate amount of clear amniotic fluid. Pitocin was initiated with an order "to produce three good contractions in 10 minutes." The attending physician left the hospital because of personal issues and did not contact another physician. With the use of Pitocin, there ensued persistent, excessive uterine activity along with intermittent abnormalities of the FHR tracing. Later in labor, there was a loss of the fetal tracing and then a persistent episode where the (rapid) maternal heart rate (MHR), not the FHR, was being recorded.

"The attending physician left the hospital because of personal issues and did not contact another physician. With the use of Pitocin, there ensued persistent, excessive uterine activity along with intermittent abnormalities of the FHR tracing. Later in labor, there was a loss of the fetal tracing and then a persistent episode where the (rapid) maternal heart rate (MHR), not the FHR, was being recorded."

Immediately before delivery, the nurse notes that she "went into the patient's room to check on the patient, who expressed the urge to have a BM." In her note, the nurse described the fetal head at +1 station and the patient pushing" out of control and the visitors all screaming," She further noted that she attempted to calm everyone down, instructing the patient "to listen to only me." With no effort to summon an available physician, she then instructed the patient to push, resulting in delivery by the RN. During this sequence, the FHR pattern deteriorated further, including a rise in baseline FHR and the appearance of decelerations and overshooting with absent variability, which is an FHR pattern consistent with neurological injury.

This sequence was captured on a video taken by the patient's

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mother. In contrast to the statements by the nurse, the video not only showed no evidence of the patient being "out of control" or the visitors "all screaming," but the nurse appeared verbally abusive to the patient and seemed committed to performing the delivery herself: she made no effort to contact a physician. Further, the FHR recording indicated prolonged and sustained pushing for over 5 minutes before delivery.

"This sequence was captured on a video taken by the patient's mother. In contrast to the statements by the nurse, the video not only showed no evidence of the patient being 'out of control' or the visitors 'all screaming,' but the nurse appeared verbally abusive to the patient and seemed committed to performing the delivery herself: she made no effort to contact a physician. Further, the FHR recording indicated prolonged and sustained pushing for over 5 minutes before delivery."

The male infant weighed 3107 gm. (10-50th percentile) and was 20" long at delivery. He received Apgar scores of 7 and 9 at 1 and 5 minutes, respectively. Examination of the baby revealed significant caput succedaneum, molding, and bruising of the fetal head. He was examined by a pediatrician and was kept in the normal nursery. Irrespective, there were feeding difficulties related to the baby's inability to latch. The baby was discharged with the mother at three days of age, having undergone an uncomplicated circumcision. There was facial drooping

At eight months, various concerns, including facial drooping, prompted a visit to a pediatric neurologist. A neurological workup, including an MRI/MRA, revealed a right periventricular leukomalacia (PVL) with periventricular white matter volume loss. The neurologist thought the lesions were the result of an injury during labor and delivery and, sotto voce, suggested that the patient seek an attorney. Over time, there was obvious developmental delay and significant physical disability. He underwent physical and occupational therapy. Ultimately the child carried the diagnosis of spastic CP and left hemiplegia thought to be related to perinatal ischemic stroke.

The patient's first encounter with a lawyer occurred when the mother was 21, and the baby was one year old. After 14 years, the case would go to trial. Part of the delay was to determine the later effects of the injury on the child's development and school performance.

The allegations

1. Failure to properly use Pitocin and respond to excessive uterine activity. Pitocin was increased inappropriately in the face of excessive uterine activity and progress in labor.
2. Failure to recognize the decreased probability of safe vaginal delivery given the prolonged dilatation, protracted descent, and a malposition (OP) of the fetal head
3. Failure to properly recognize and respond to abnormalities of the FHR tracing, including prolonged decelerations, loss of tracing, and maternal recording
4. Failure to notify the responsible attending physician resulted in a traumatic delivery performed by the nurse.
5. Failure to provide continuity of medical care by the timely and proper transfer of care by the attending physician who was required to leave the hospital
6. Improper nursing instructions to the patient to push continuously

The pleadings of the case focused heavily on the conduct of the nurse who performed the delivery. Not only did she fail to properly and timely notify the physician about the problems and the progress, but she also misused the Pitocin, encouraged an inappropriate, forced delivery, and appeared quite abusive to the patient.

"The pleadings of the case focused heavily on the conduct of the nurse who performed the delivery. Not only did she fail to properly and timely notify the physician about the problems and the progress, but she also misused the Pitocin, encouraged an inappropriate, forced delivery, and appeared quite abusive to the patient."

The defense position

1. The timing and mechanism of the child's stroke is unknown.
2. The cause of the injury was the brief episode of dehydration (less than two days) experienced by the mother at about 16 weeks gestation.
3. The plaintiff's notion that mechanical forces acting on the fetal head was not an accepted theory of fetal neurological injury; it had no scientific support.
4. Any hypoxic-ischemic injury that might have occurred during labor would have shown immediate handicap at the time of delivery.

Each of these positions was successfully rebutted at the time of trial.

While the patient was indeed treated with intravenous hydration at 16 weeks gestation, the episode was short-lived, and she was sent home without a diagnosis of dehydration. Further, the pediatric neurologists from both sides testified that the brain cells affected in the stroke were not yet present in the fetus at 16 weeks gestation. This mechanism could not be responsible for the child's injury.

Throughout the pregnancy, fetal growth, fetal behavior, and amniotic fluid volume remained normal, and numerous reactive

and reassuring tracings were observed later in the pregnancy. The abnormalities of labor, coupled with the excessive uterine activity and exaggerated pushing efforts, subjected the fetus's brain to excessive intracranial force and pressure. It is known that such forces can cause asymmetric ischemic brain injury, as was evidenced by the subsequent MRI that showed right-sided periventricular leukomalacia. (1) This was supported by the tell-tale changes in the FHR pattern, which permitted a reliable determination of the timing and mechanism of any ischemic injury. (2) The course of labor was prolonged; pushing had produced minimal descent of the fetal head until the extraordinary efforts just prior to vaginal delivery.

The risk of stroke is high during the perinatal period; indeed, the individual will not be at a similar risk of stroke for another 5 or 6 decades. Mercifully, the survivors of perinatal stroke survive for many more years than older patients with stroke. While many newborns with stroke present clinically with obvious abnormalities of adaptation, including seizures, they are rarely acidotic at birth. **(3, 4, 5-7)**`

"The problem in identifying the timing and mechanism of infant stroke in these children is the widespread recognition that some of these injuries, received during labor and delivery, may not show signs of injury nor umbilical acidemia at the time of birth, and there may be no obvious need for neonatal brain imaging or umbilical cord blood gases."

The problem in identifying the timing and mechanism of infant stroke in these children is the widespread recognition that some of these injuries, received during labor and delivery, may not show signs of injury nor umbilical acidemia at the time of birth, and there may be no obvious need for neonatal brain imaging or umbilical cord blood gases. Alternatively, brain images taken may not be sensitive enough to diagnose ischemic injuries. Thus, the diagnosis of ischemic perinatal stroke may be delayed weeks to months, even for years, before the appearance of sufficient signs and symptoms promotes neuroradiological examination. This underdiagnosed sequence, widely acknowledged in the literature, has been designated *presumed perinatal ischemic stroke*.

It is of interest that contemporary estimates of the incidence of perinatal stroke suggest a risk of perhaps 1 per thousand, a number which seems to represent a severalfold increase (from about 1 per 4000 deliveries) over the past several decades. One explanation for the apparent increase in incidence is the availability and utilization of neuroradiological assessment. With the recent focus on extending the course of labor before resorting to cesarean section, it is also possible that changes in the conduct of labor may contribute. There is now sufficient evidence that the prolongation of pushing in the 2nd stage of labor is associated with an increased risk of seizures and the diagnosis of HIE and perinatal stroke. (1) (8)

With the demonstration of PAIS, various causes other than fetal hypoxia are routinely sought but are rarely contributory to the diagnosis. The risk for recurrence and mortality appears to be low, as is the likelihood of finding any genetic or hematological (clotting issue) abnormality. Indeed, in this case, no other putative cause was found. Frequently, the notion that perinatal strokes arise from placental embolus surfaces in medico-legal cases; however, there appears to be little convincing evidence that this is common.

Regarding the allegation that mechanical forces were involved in the pathogenesis of injury, one of the defense experts offered evidence that this mechanism of hypoxic-ischemic injury was not scientifically proven and deserved no weight in the deliberation of the child's injury. This expert had no opinion on the conduct of labor, the interpretation of the FHR tracing, or the cause of this child's hypoxic-ischemic brain injury and became agitated during cross-examination.

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Curiously and unprecedented in the author's experience, the trial court admitted testimony from a character witness for the plaintiff's obstetrical expert who upheld the integrity of the expert.

After a brief deliberation, the jury returned a plaintiff verdict in excess of $35 million.

"When the case came to trial, the child was 16 years old. Almost 15 years had elapsed since the initial approach to a lawyer. The mother, a free-spirited, unmarried 20-year-old at the time of birth and unsure of the child's father, was now a college-educated, attentive mother in a stable and loving marital relationship. Though bullied by the defense, she made a thoughtful, intelligent, sympathetic witness."

When the case came to trial, the child was 16 years old. Almost 15 years had elapsed since the initial approach to a lawyer. The mother, a free-spirited, unmarried 20-year-old at the time of birth and unsure of the child's father, was now a college-educated, attentive mother in a stable and loving marital relationship. Though bullied by the defense, she made a thoughtful, intelligent, sympathetic witness. The proceedings of the trial, especially the videotape during the delivery, might be understood if you were dealing with an irresponsible, uncontrollable 20-year-old. However, it could never be understood for the poised, educated individual testifying before the jury one and a half decades later. More incomprehensible in the conduct of the trial was the defense's decision to show, in their final summation, a video of a competition of handicapped athletes in the Special Olympics. It drove the mother out of the courtroom.

"This brings us to the amount of the verdict; before trial, the plaintiffs had offered to settle the case for $6,500,000. This amount was rejected, presumably based on the defense posture outlined above. The deliberations of the jury are secret; the reader, however, may choose to consider whether the jury reached this verdict based exclusively on the child's long-standing injury and suffering, including the suffering of his parents, or whether the comportment of the defense, the offering of either an implausible explanation of the cause of injury (dehydration at 16 weeks) or the abnegation of the universally accepted notion of injury related to the mechanical forces of labor and delivery) also impacted the jury's deliberations. "

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"Our experience in such verdicts suggests that the conduct of the defense contributes to such verdicts. The size of the award is the only mechanism available to the jury to show their disapproval of the tactics and the honorability of the defense."

Further, did the unprofessional conduct of the nurse, evident on the videotape, impel the jury to a higher award? Or was it the video of the Special Olympics and the mother's response that contributed to the size of the award? Our experience in such verdicts suggests that the conduct of the defense contributes to such verdicts. The size of the award is the only mechanism available to the jury to show their disapproval of the tactics and the honorability of the defense.

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Disclosures: *There are no reported disclosures*

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Will your **PRETERM INFANT** *need* **EARLY INTERVENTION** *services?*

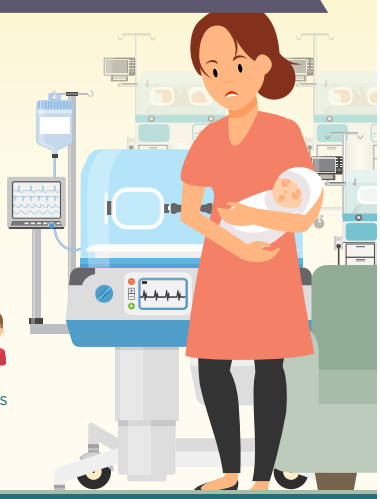
Preterm infants are:

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

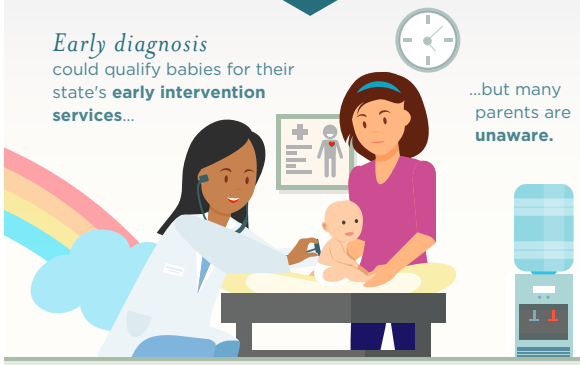


Early intervention can help preterm infants:

- 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.



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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**

1 DE CADA **7** MADRES AFRONTA LA DEPRESIÓN POSPARTO, *experimentando*

- 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*

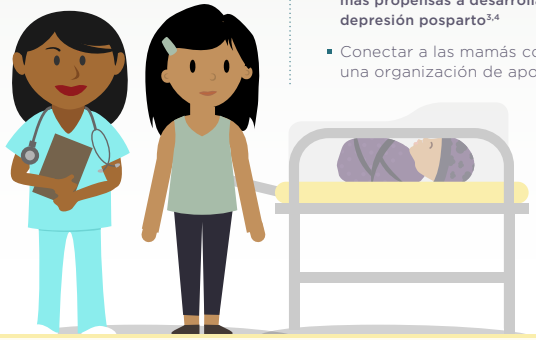
PARA AYUDAR **A LAS MADRES A ENFRENTAR LA DEPRESIÓN POSPARTO**

LOS ENCARGADOS DE FORMULAR POLÍTICAS PUEDEN:

- Financiar los esfuerzos de despistaje y diagnostico
- Proteger el acceso al tratamiento

LOS HOSPITALES PUEDEN:

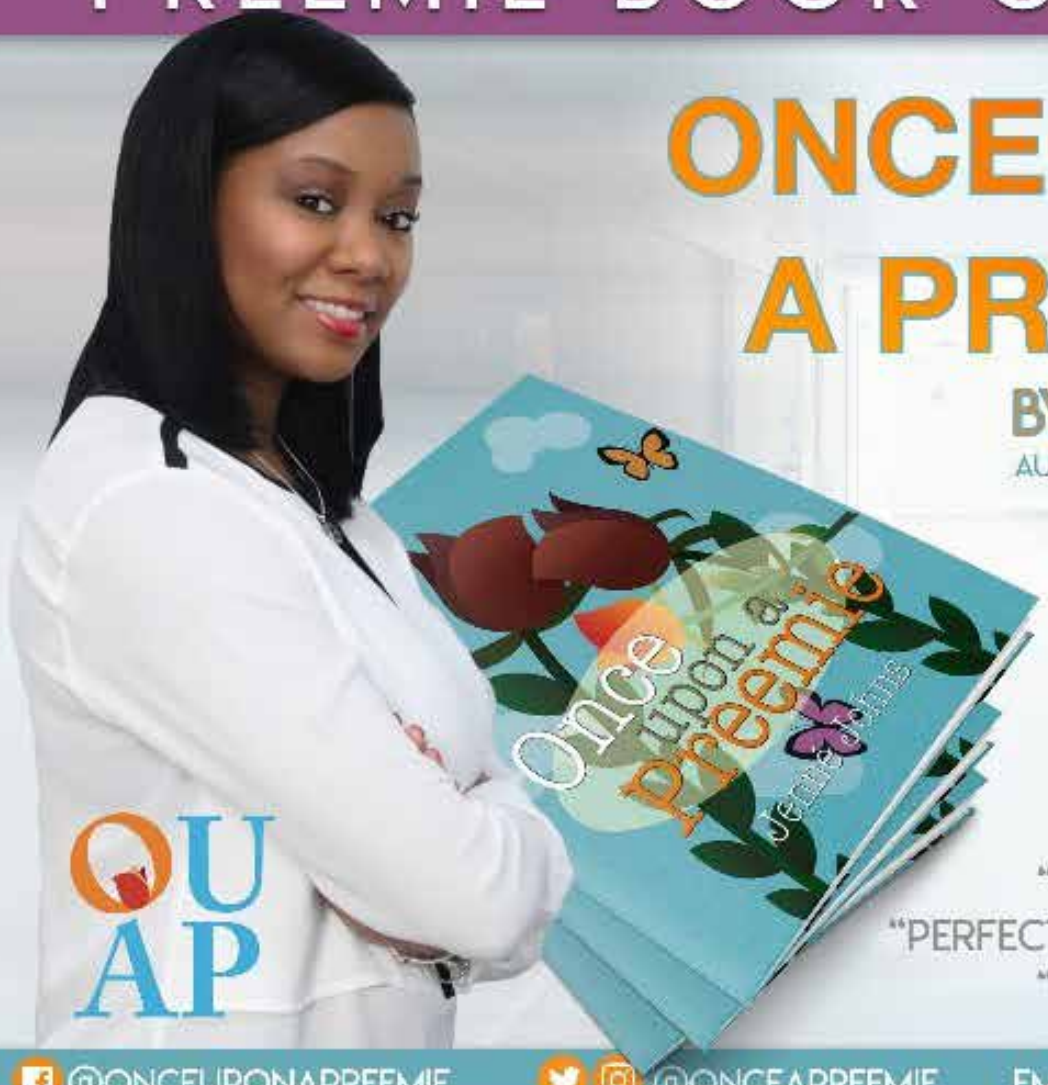
- Capacitar a los profesionales de la salud para proporcionar apoyo psicosocial a las familias... **Especialmente aquellas con bebés prematuros, que son 40% más propensas a desarrollar depresión posparto**[3,4]
- Conectar a las mamás con una organización de apoyo



NCFIH National Coalition for Infant Health
Protecting Access for Premature Infants through Age Two
www.infanthealth.org

[1] American Psychological Association. Accessible on: http://www.apa.org/pi/women/resources/reports/postpartum-depression.aspx
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BY JENNÉ JOHNS

AUTHOR | SPEAKER | ADVOCATE

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"PERFECT FOR PREEMIE FAMILIES"
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Compiled and Reviewed by Benjamin Hopkins, DO

Childhood vaccines prevented 1.13 million deaths, saved $2.7 trillion over 3 decades

NEWS PROVIDED BY

American Academy of Pediatrics

By Melissa Jenco

Current as of August 8, 2024

Vaccines prevented more than 500 million illnesses and 1.13 million deaths among children born over the last three decades, according to a new study.

"Childhood immunizations continue to provide substantial health and economic benefits, while promoting health equity," researchers from the Centers for Disease Control and Prevention (CDC) wrote in a new *Morbidity and Mortality Weekly Report*.

The team looked at the impact of nine vaccines among the 117 million children born from 1994-2023. Vaccines included diphtheria and tetanus toxoids and acellular pertussis; *Haemophilus influenzae* type b conjugate; oral and inactivated poliovirus; measles, mumps and rubella; hepatitis B; varicella; pneumococcal conjugate; hepatitis A and rotavirus.

Researchers calculated that these vaccines prevented 508 million lifetime illnesses, 32 million hospitalizations and 1.13 million deaths. Measles and varicella vaccines each prevented just over 100 million illnesses, according to the study. Measles vaccines also prevented the highest number of hospitalizations at 13.2 million. Diphtheria vaccines prevented an estimated 752,800 deaths.

The analysis also found a net savings of $540 billion in direct costs, which considered medical and nonmedical costs of having an infection. There also was $2.7 trillion in savings to society.

Many of the vaccines in the study had coverage rates near or above 90%. Authors credited the Vaccines for Children (VFC) program with helping vaccinate millions of children and contributing to cost savings. The VFC program provides free vaccines to children who are Medicaid-eligible, uninsured, underinsured, American Indian or Alaska Native.

"The VFC program reduces financial and logistical barriers for eligible children who otherwise might not have reasonable access to immunization, thereby promoting health equity and contributing substantially to these high coverage levels," they wrote.

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RSV immunization guidance not changing; AAP continues work on logistical hurdles

NEWS PROVIDED BY

American Academy of Pediatrics

By Melissa Jenco

Current as of August 8, 2024

AAP experts are optimistic the use of nirsevimab (Beyfortus) to protect infants from respiratory syncytial virus (RSV) will be smoother in the upcoming season, although some logistical hurdles remain.

The AAP is continuing to work on the remaining challenges that plagued the rollout of the long-awaited RSV immunization last fall. It also is reminding clinicians to review the clinical guidance, which will remain the same.

RSV causes about 50,000 to 80,000 hospitalizations and 100 to 300 deaths per year in children under 5 years, according to the Centers for Disease Control and Prevention (CDC). The AAP recommends all infants be protected from RSV by receiving nirsevimab or through vaccination of their pregnant parent with RSVpreF (Abrysvo).

About half of children born during the 2023-'24 RSV season were protected, according to the CDC.

Data from the first season show nirsevimab was 91%-98% effective at preventing RSV-associated hospitalizations.

"I think if we are able to deliver this product in a timely fashion, we're going to see a significant impact on the RSV season this coming year," said Sean T. O'Leary, M.D., M.P.H., FAAP, chair of the AAP Committee on Infectious Diseases.

Clinical guidance

Nirsevimab is recommended for infants under 8 months during their first RSV season. They should be immunized regardless of whether they have high-risk conditions. The ideal timing is during the first week of life for those born shortly before or during the RSV season. In most of the continental U.S., the season typically runs from October through March. Infants whose pregnant parent received RSVpreF vaccine at least 14 days before giving birth do not need nirsevimab.

The AAP also recommends nirsevimab for infants and children 8 months through 19 months of age who are at increased risk of severe RSV disease when entering their second season. These children should be immunized in season two regardless of whether their pregnant parent was vaccinated or whether they received nirsevimab in their first season.

While palivizumab previously was the primary means of protec-

tion for high-risk infants, Dr. O'Leary said clinicians should prioritize nirsevimab because it can be given in a single dose and likely provides more protection. The AAP continues to recommend palivizumab if nirsevimab is not available.

Eligible infants and children can be immunized shortly before the RSV season begins if a clinician is concerned the child may not return.

Logistical hurdles

While supply shortages plagued the first season of nirsevimab use, Sanofi has implemented a reservation program it hopes will mitigate those issues.

Customers participating in the reservation program should receive reserved shipments in September and throughout the season. Those not participating in the program can order nirsevimab from October 2024 through February 2025 via http://www.vaccineshop.com.

The degree to which providers face other logistical challenges may depend on where they practice. Issues around billing and integration into immunization information systems have improved for many. Sanofi has created an immunization card hospitals can give to parents to show their baby received nirsevimab. However, clinicians in some areas may have to take extra steps to find out if a child was immunized in the hospital or if the child's pregnant parent was vaccinated.

"For pediatricians working in primary care, it's good to be familiar with the practices of the delivering hospitals in your area," Dr. O'Leary said. He added that no safety concerns are expected if the pregnant parent was vaccinated and the child receives nirsevimab.

There also are ongoing issues around birthing hospitals enrolling in the Vaccines for Children (VFC) program and payment for hospital-based administration of nirsevimab.

The CDC is allowing flexibility in the VFC program regarding inventory requirements and borrowing nirsevimab from private stock through August 2025, although CDC guidance does not supersede jurisdictional policies.

The AAP is continuing to advocate for steps to ease the logistical concerns and has been working with the CDC, Sanofi and other partners.

NT

When breastfeeding problems arise in infant with tongue-tie, don't jump to surgery

NEWS PROVIDED BY

American Academy of Pediatrics

By Jennifer Thomas

Current as of July 29, 2024

The parents of a 5-day-old infant come in for a preventive care visit. The mother is committed to breastfeeding but says she is having pain when the baby latches. One lactation consultant in the hospital said the baby has a tongue-tie, but another said the baby does not. The mother's online communities keep asking her if the baby has been "checked for ties." The family has searched online for information on tongue-, lip- and cheek-ties but are overwhelmed. They ask you to help with the next steps.

Studies show a growing number of infants are being diagnosed with ankyloglossia, a congenitally tight lingual frenulum that limits the motion of the tongue. Performance of frenotomy to release tongue-ties also is rising.

The increased rate of frenotomy is fueled partly by economic incentives for health care providers, which has led to a surge in the number of clinics and specialists offering tongue-tie surgeries. In addition, social media has increased awareness of ankyloglossia, and online communities often pressure parents to seek surgical procedures when breastfeeding difficulties arise.

Many medical professionals, however, have expressed concerns regarding the overdiagnosis of tongue-tie and surgeries that may not always resolve breastfeeding issues.

The AAP has released new evidence-based guidance to help pediatricians care for mothers and infants with breastfeeding problems. It recommends prioritizing nonsurgical interventions and fostering a collaborative care model to help ensure successful breastfeeding outcomes.

The clinical report *Identification and Management of Ankyloglossia and its Effect on Breastfeeding in Infants* is a multidisciplinary effort from the AAP Section on Breastfeeding, Council on Quality Improvement and Patient Safety, Section on Oral Health, Committee on Fetus and Newborn, and Section on Otolaryngology-Head and Neck Surgery. It is available at https://doi.org/10.1542/peds.2024-067605 and will be published in the August issue of *Pediatrics.*

Is tongue-tie a problem?

The AAP recommends exclusive breastfeeding for about six months, with continuation for two years or longer as mutually desired by mother and infant. Breastfeeding problems are common, so pediatricians should be able to provide practical advice on techniques or refer to lactation specialists when necessary.

Maternal pain is one of the most common complaints and can occur if the infant's tongue cannot extend and elevate due to a restrictive lingual frenulum. Pain can lead to poor milk transfer and insufficient growth as well as premature cessation of breastfeeding.

Most difficulties with breastfeeding, including pain, are not due to ankyloglossia, and the differential diagnosis of feeding problems in newborns is extensive.

A pediatrician considering the diagnosis of ankyloglossia should start with the differential diagnosis of poor weight gain and ineffective latch. Feeding problems in newborns should be evaluated in the medical home. Families often seek the help of lactation specialists. Therefore, a team approach is best.

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If a restrictive lingual frenulum causes breastfeeding problems that do not improve with lactation support, a diagnosis of symptomatic ankyloglossia can be made. The clinical report includes an algorithm to aid in the evaluation, which requires an observation of breastfeeding to assess the functional dynamic movement of the tongue. Tools to assess the severity of ankyloglossia have been published in peer-reviewed journals, but none have been validated.

Management options

If breastfeeding problems continue after other causes have been evaluated and treated, surgical intervention for ankyloglossia by a trained professional is a reasonable option. Despite the widespread use of lasers for frenotomy, no studies support their use over scissor clipping in infants younger than 6 months.

Parents with breastfeeding problems also face considerable pressure to have labial frenula (lip) or buccal frenula (cheek) addressed. They are *normal* oral structures, and intervention to release these ties is not supported by evidence.

The Academy of Breastfeeding Medicine and the American Academy of Otolaryngologists-Head and Neck Surgeons recommend frenotomy for tongue-tie under limited circumstances but do not recommend intervention for labial or buccal frenula.

Recommendations

Following are key findings and recommendations in the clinical report:

- Early identification of feeding problems is crucial to support successful breastfeeding outcomes and should take place in the medical home.
- Comprehensive care for infants with tongue-tie requires collaboration with lactation consultants, speech-language pathologists and other specialists.
- Frenotomy should be reserved for cases where significant functional impairments are observed and non-surgical interventions have failed. The procedure is safe, and poor outcomes are rare. The post-procedure care of the infant should ensure symptoms have improved.
- No evidence supports laser over other methods of frenotomy.
- Increasingly, parents are influenced by online communities advocating for surgical interventions for tongue-tie. It is essential to guide them toward evidence-based practices.
- The evidence supporting frenotomy is limited. While it may alleviate maternal nipple pain, its broader efficacy for other diagnoses remains uncertain.
- There is no support for interventions on labial and buccal frenae.
- Postoperative "stretching" exercises to prevent reattachment are not recommended.

Dr. Thomas is a lead author of the clinical report and a member of the AAP Section on Breastfeeding Executive Committee.

NT

NIH-funded study finds long COVID affects adolescents differently than younger children

NEWS PROVIDED BY

National Institute of Health

By NHLBI Newsroom

Current as of August 21, 2024

Adolescents were most likely to experience low energy/tiredness while children were most likely to report headache.

Scientists investigating long COVID in youth found similar but distinguishable patterns between school-age children (ages 6-11 years) and adolescents (ages 12-17 years) and identified their most common symptoms. The study, supported by the National Institutes of Health (NIH) and published in *JAMA*, comes from research conducted through the NIH's Researching COVID to Enhance Recovery (RECOVER) Initiative(link is external), a wide-reaching effort to understand, diagnose, treat, and prevent long COVID, a condition marked by symptoms and health problems that linger after an infection with SARS-CoV-2, the virus that causes COVID-19.

Children and adolescents were found to experience prolonged symptoms after SARS-CoV-2 infection in almost every organ system with most having symptoms affecting more than one system.

"Most research characterizing long COVID symptoms is focused on adults, which can lead to the misperception that long COVID in children is rare or that their symptoms are like those of adults," said David Goff, M.D., Ph.D., division director for the Division of Cardiovascular Sciences at the NIH's National Heart, Lung, and Blood Institute. "Because the symptoms can vary from child to child or present in different patterns, without a proper characterization of symptoms across the life span, it's difficult to know how to optimize care for affected children and adolescents."

The observational study included 3,860 children and adolescents with a SARS-CoV-2 infection history at more than 60 sites across the United States between March 2022 and December 2023. A comparison group of 1,516 children and adolescents with no history of a SARS-CoV-2 infection were also included to disentangle whether prolonged symptoms of those who had experienced COVID-19 were related to SARS-CoV-2 itself or more broadly related to the effects of the pandemic.

Caregivers completed a comprehensive symptom survey that asked about 75 prolonged symptoms in all major body systems that occurred at least 90 days after an initial SARS-CoV-2 infection and lasted for at least a month. They also completed a survey asking for their perception of the child's overall health, physical health, and quality of life. The researchers then employed a commonly used statistical technique to identify which symptoms were best at differentiating participants who did

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and did not have history of SARS-CoV-2 infection. They identified combinations of symptoms distinct for each age group that together generated a long COVID research index, which indicates the likely condition of long COVID.

Researchers identified 18 prolonged symptoms that were more common in school-age children, including headache (57%), followed by trouble with memory or focusing (44%), trouble sleeping (44%), and stomach pain (43%). Other common symptoms in school-age children not included in the research index included body, muscle, and joint pain; daytime tiredness/sleepiness or low energy; and feeling anxious.

In adolescents, 17 symptoms were more common, including daytime tiredness/sleepiness or low energy (80%); body, muscle, or joint pain (60%); headaches (55%); and trouble with memory or focusing (47%). Feeling anxious and trouble sleeping were other commonly reported symptoms that were not included in the research index.

"The symptoms that make up the research index are not the only symptoms a child may have and they're not the most severe, but they are most predictive in determining who may have long COVID," said Rachel Gross, M.D., associate professor in the departments of pediatrics and population health at New York University Grossman School of Medicine and lead author on the study.

Fourteen symptoms overlapped between the age groups. Comparing previous research on long COVID in adults, the new study found that adults and adolescents had a greater overlap in symptoms, such as loss of or change in smell or taste. Researchers found less overlap between adults and school-age children, underscoring the importance of age-based long COVID research.

The study identified separate research indexes for school-age children and adolescents along with overlapping, but distinguishable symptom patterns in each group. Of the 751 school-age children that had COVID-19, 20% met the long COVID research index threshold. Of the 3,109 adolescent children with a history of SARS-CoV-2 infection, 14% met the research index threshold, though researchers noted that these numbers should not be used as measures of incidence in the general population, since their study may have included more children with long COVID than the overall population.

Scientists note that the research index provides a framework for looking at common symptoms for research purposes – not necessarily as a guide for clinical care – and will likely be refined as researchers study more children with and without long COVID.

"Our next step is to study children ages 5 years and younger so we can better understand long COVID in the very young," said Gross.

In compliance with NIH's Data Sharing and Management Policy, a dataset containing RECOVER Pediatric Observational Cohort Study data collected through June 15, 2024 – which includes data used for this publication – will be released on NHLBI BioData Catalyst® this fall.

Research reported in this press release was supported by NIH under award numbers OT2HL161841, OT2HL161847, and OT2HL156812. Additional support came from grant R01 HL162373. The content is solely the responsibility of the authors and does not necessarily represent the official views of the NIH. For more information on RECOVER, visit https://recovercovid.org(link is external).

NT

Vaccines for Children Program Celebrates 30 Years of Providing Lifesaving Vaccines to Children at No Cost

NEWS PROVIDED BY

Center for Disease Control

By CDC Media Relations

Current as of August 13, 2024

When the Vaccines for Children (VFC) legislation was passed 30 years ago, it was a historic step in improving children's lives by providing recommended vaccines at no cost to eligible children.

Routine vaccinations are the best defense against illnesses. The VFC program was established to ensure that children below the federal poverty level and those without health insurance have access to critical, lifesaving vaccines that can protect their health throughout their lives.

"For 30 years, the Vaccines for Children program has been providing lifesaving vaccines to our nation's children at no cost," said CDC Chief Medical Officer Dr. Deb Houry. "Because of congressional support and dedicated partners across the country, we have prevented more than 1.1 million deaths in kids born during the VFC era. There is no better time than now, as families are planning for returning to school, to continue this effort that keeps our children safe from disease and prepares them for the fall and winter virus season."

Almost 90% of VFC-eligible children born during 2011–2020 received the measles, mumps, and rubella (MMR) vaccine, according to a new CDC *Vital Signs* report. There were no differences in receipt of the MMR vaccine found among VFC-eligible children born in 2020 by race and ethnicity, poverty status, and urban-rural residency. This highlights VFC program efforts in achieving and maintaining measles elimination status in the U.S.

In addition, the new CDC *Vital Signs* report shows routine childhood rotavirus vaccination increased from 65% to 71% among children born in 2011–2020, which shows progress toward achieving high vaccination coverage (proportion of children vaccinated) for all routine immunizations.

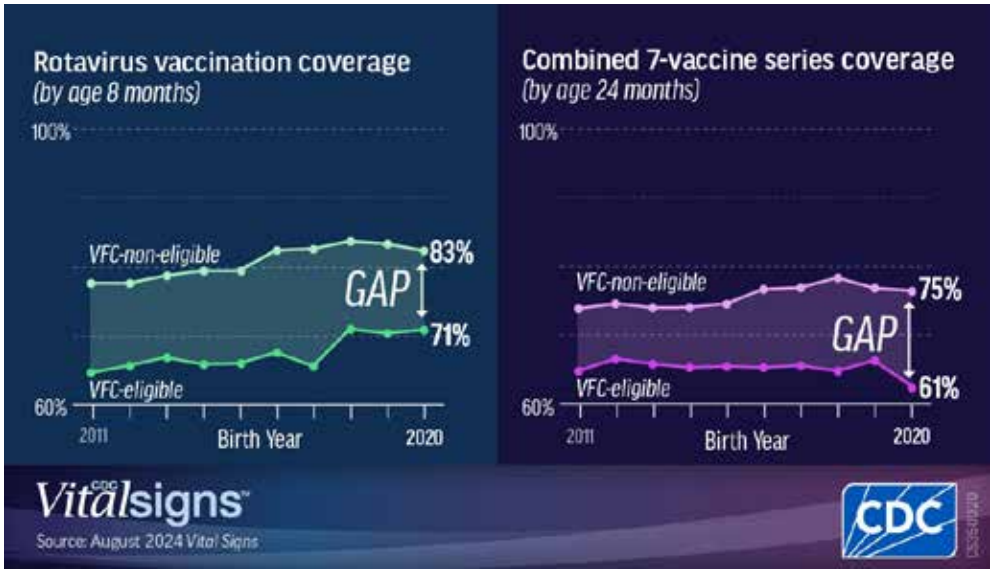
Furthermore, a CDC report, issued on August 8, 2024, found that for children born during 1994–2023, routine childhood vaccinations will have prevented approximately 508 million cases of illness, 32 million hospitalizations, and 1,129,000 deaths, resulting in societal savings of nearly $2.7 trillion, including a direct savings of $540 billion.

Despite these successes, the new CDC *Vital Signs* report shows there is still a need to increase the number of children who complete their vaccine series and a need to reach children living below the poverty level and those without health insurance.

- Only 61% of VFC-eligible children (born in 2020) received 7 selected vaccines (the "combined 7-vaccine series") by their second birthday. This series includes all recommended doses of diphtheria and tetanus toxoids and acellular pertussis (DTaP) vaccine, poliovirus vaccine, measles-containing vaccine, *Haemophilus influenzae* type b conjugate vaccine (Hib), hepatitis B vaccine, varicella

vaccine, and pneumococcal conjugate vaccine (PCV). Of these vaccines, coverage among VFC-eligible children born in 2020 was about 90% for first doses of vaccines (varicella, MMR) and for series given earlier in life (poliovirus, hepatitis B vaccine).

- Vaccination coverage was lowest (74%-77%) for vaccines that require multiple doses, with at least one dose recommended after 12 months of age (DTaP, PCV, and Hib). This suggests children face challenges to receiving vaccines that require multiple doses as well as doses in the second year of life.
- Vaccination coverage was lower among uninsured children than among Medicaid-insured children. Uninsured children are more likely to live at or below the federal poverty level and have not seen a healthcare provider in the past year. They are less likely to complete vaccine series that require multiple doses.
- VFC-eligible children living below the federal poverty level had lower coverage for rotavirus vaccine and the combined 7-vaccine series compared with VFC-eligible children living at or above the poverty level. Although the VFC program provides recommended childhood vaccines at no cost, non-Medicaid VFC-eligible children, including those who are uninsured, can be charged a vaccine administration fee, and there may also be fees for an office visit or non-vaccine services received during the visit.



In the birth year 2020, rotavirus vaccination coverage (by age 8 months) was 83% VFC-non-eligible versus 71% VFC-eligible. In the birth year 2020, combined 7-vaccine series coverage (by age 24 months) was 75% VFC-non-eligible versus 61% VFC-eligible.

Healthcare providers can help reduce missed opportunities for vaccination by giving catch-up vaccinations to all children who are behind. The VFC program plays a vital role in increasing and sustaining vaccination coverage for all vaccinations, including flu and COVID-19 vaccinations. Heightened efforts must ensure those eligible for the VFC program are aware of, have confidence in, and are able to receive all recommended vaccines.

Healthcare providers can:

- Offer accurate information on vaccination benefits.
- Give catch-up vaccines and review for needed vaccines, including those that protect children in the fall virus season that includes flu and other respiratory viruses.
- Strengthen relationships with families.
- Use reminder/recall systems to inform parents of upcoming or missed shots.

The Vaccines for Children program is administered nationally by CDC, which provides operational funding to 61 state, local, and territorial immunization programs. Funding recipients implement and oversee the VFC program in their respective areas. The federal government purchases pediatric vaccines at a discount and ships them directly to enrolled VFC vaccine providers to ease the fiscal burden of vaccine purchase and distribution. The VFC program ensures that all children have a better chance of getting their recommended vaccinations on schedule which means healthier children, families, and communities.

For more information on VFC eligibility for children, go to Vaccines for Children (VFC) Program: Information for Parents | VFC Program | CDC.

If you are a healthcare provider interested in enrolling in the VFC program to help ensure all families can get the vaccines they need, please visit Vaccines For Children (VFC) Program Information for Providers | CDC.

For more information about this report, go to www.cdc.gov/vitalsigns.

NT

Biden-Harris Administration Awards Over $558 Million to Improve Maternal Health, including $440 Million to Support Pregnant and New Moms, Infants, and Children through Voluntary Home Visiting Programs Proven to Improve Maternal and Child Health, Child Development,

and School Readiness

NEWS PROVIDED BY

Center for Disease Control

By CDC Media Relations

Current as of August 27, 2024

Today, the U.S. Department of Health and Human Services (HHS) announced more than $558 million in funding to improve maternal health, building on the Biden-Harris Administration's commitment to reducing the nation's high maternal mortality rate through the White House Blueprint for Addressing the Maternal Health Crisis. The Health Resources and Services Administration (HRSA), an agency of HHS, is awarding more than $440 million in funding to expand voluntary, evidence-based maternal, infant, and early childhood home visiting services for eligible families across the country. In addition, the Centers for Disease Control and Prevention (CDC) announced a new investment of $118.5 million, over five years, to 46 states, six territories and freely associated statesto continue building the public health infrastructure to better identify and prevent pregnancy-related deaths.

In 2022, President Biden signed bipartisan legislation that doubles funding for the Maternal, Infant, and Early Childhood Home Visiting program over five years – the first expansion of the federal home visiting program in nearly 10 years. Through this program, local organizations can provide home visits from nurses, social workers, and other trained health workers who work with families on early and ongoing engagement in prenatal care and postpartum support. They provide support on breastfeeding, safe sleep for babies, learning and communications practices that promote early language development, developmental screening, getting children ready to succeed in school, and connecting with key services and resources in the community – like affordable childcare or job and educational opportunities. The awards announced today reflect the first opportunity for states and jurisdictions to receive federal matching funds in addition to their base grants. Every single state and U.S. territory has seen an increase in funding to their home visiting program since the start of the Biden-Harris Administration.

"As someone who has spent my entire career fighting for the health and wellbeing of women and children, I am committed to addressing a maternal health crisis in which women across America are dying before, during, and after childbirth at higher rates than in any other developed nation. That is why I called on states to extend Medicaid postpartum coverage from two months to 12 months and announced the launch of the White House Blueprint for Addressing the Maternal Health Crisis, an unprecedented whole-of-government strategy to improving maternal care," said Vice President Harris. "Today, we are building on this lifesaving work by awarding more than $558 million to improve maternal health across America. This includes a critical $440 million to support pregnant women, new mothers, and their children through home visiting programs that will improve health outcomes, child development, and access to resources for years to come."

"Bringing home a baby can be stressful. Many new parents face additional challenges such as housing, or income insecurity, which can make the whole situation even more daunting. But we know from decades of research that home visits work – from helping with school readiness and achievement for children to improving health for women," said HHS Secretary Xavier Becerra. "President Biden and Vice President Harris know how important it is to support children in their most crucial years of development so they can grow up to be healthy, happy adults. We will continue to make resources and support available, and elevate maternal health issues so that more women and families know that help is available."

"At the Health Resources and Services Administration, we are deeply committed to removing barriers to care for expectant and new moms and babies who face too many hurdles getting the support that they need," said HRSA Administrator Carole Johnson. "That's why – thanks to the leadership of the President and Vice President – we were able to work closely with bipartisan leaders in Congress to grow the home visiting program to give more moms and babies a trusted home visiting partner to help their families in ways large and small to be healthy, feel supported, access health care services, nurture their child's development, and give families every opportunity to thrive."

HRSA Administrator Carole Johnson announced the awards in conjunction with HRSA's *Enhancing Maternal Health Initiative*convening at Wayne State University, in Detroit, Michigan. The Initiative is bringing together moms and babies served by HRSA programs with maternal and infant health community leaders, health officials, HRSA-supported community providers, and others to advance the goals of the White House Blueprint to Address the Maternal Health Crisis.

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The home visiting program funds states, jurisdictions, and tribal entities to develop and implement evidence-based, voluntary programs that best meet the needs of their communities. Families choose to participate in home visiting programs from pregnancy up to kindergarten and partner with health, social services, and child development professionals who provide resources, support, and skills to help families and children be physically, socially, and emotionally healthy. The program has demonstrated significant benefits, including improved school readiness and achievement of children, improved health for women, increased health insurance coverage, and prevented child injuries, abuse, and neglect.

For a complete list of Maternal, Infant, and Early Childhood Home Visiting Program awardees, visit https://mchb.hrsa.gov/programs-impact/programs/home-visiting/maternal-infant-early-childhood-home-visiting-miechv-program/fy24-awards.

The CDC's new $118.5 million five-year investment will continue building the public health infrastructure to better identify and prevent pregnancy-related deaths. This new investment expands support to Maternal Mortality Review Committees (MMRCs) from 46 to 52 states and U.S. territories and freely associated states. MRCs are state- and territory-based multidisciplinary groups that review deaths that have occurred within 1 year of the end of a pregnancy, determine if those pregnancy-related deaths were preventable, and recommend ways to prevent them in the future. This new investment in the Enhancing Reviews and Surveillance to Eliminate Maternal Mortality (ERASE MM) program also advances progress on implementing the White House Blueprint for Addressing the Maternal Health Crisis. CDC began the ERASE MM program in 2019 to invest in MMRCs and to strengthen and standardize their efforts to review deaths.

"Every pregnancy-related death is a tragedy for the family and the community," said Wanda Barfield, MD, MPH, director of CDC's Division of Reproductive Health. "Thanks to MMRCs, we know more about the causes and circumstances around pregnancy-related deaths, and we have

actionable recommendations to prevent future deaths. This investment will support more jurisdictions in their critical work to save mothers' lives."

Together, these efforts build on both HHS' and the broader Administration's efforts to implement the White House Blueprint to Address the Maternal Health Crisis as described in the following Fact Sheet: White House Blueprint to Address the Maternal Health Crisis: Two Years of Progress.

NT

On World Breastfeeding Week, UNICEF and WHO call for equal access to breastfeeding support

NEWS PROVIDED BY

World Health Organization

By Laura Keenen and Nadie Samie-Jacobs

Current as of July 31, 2024

Statement by Catherine Russell (UNICEF Executive Director) and Tedros Adhanom Ghebreyesus (WHO Director-General)

In the last 12 years, the number of infants under six months of age globally who are exclusively breastfed has increased by more than 10%. This means 48% of infants worldwide now benefit from this healthy start in life. It translates to hundreds of thousands of babies whose lives have been saved by breastfeeding.

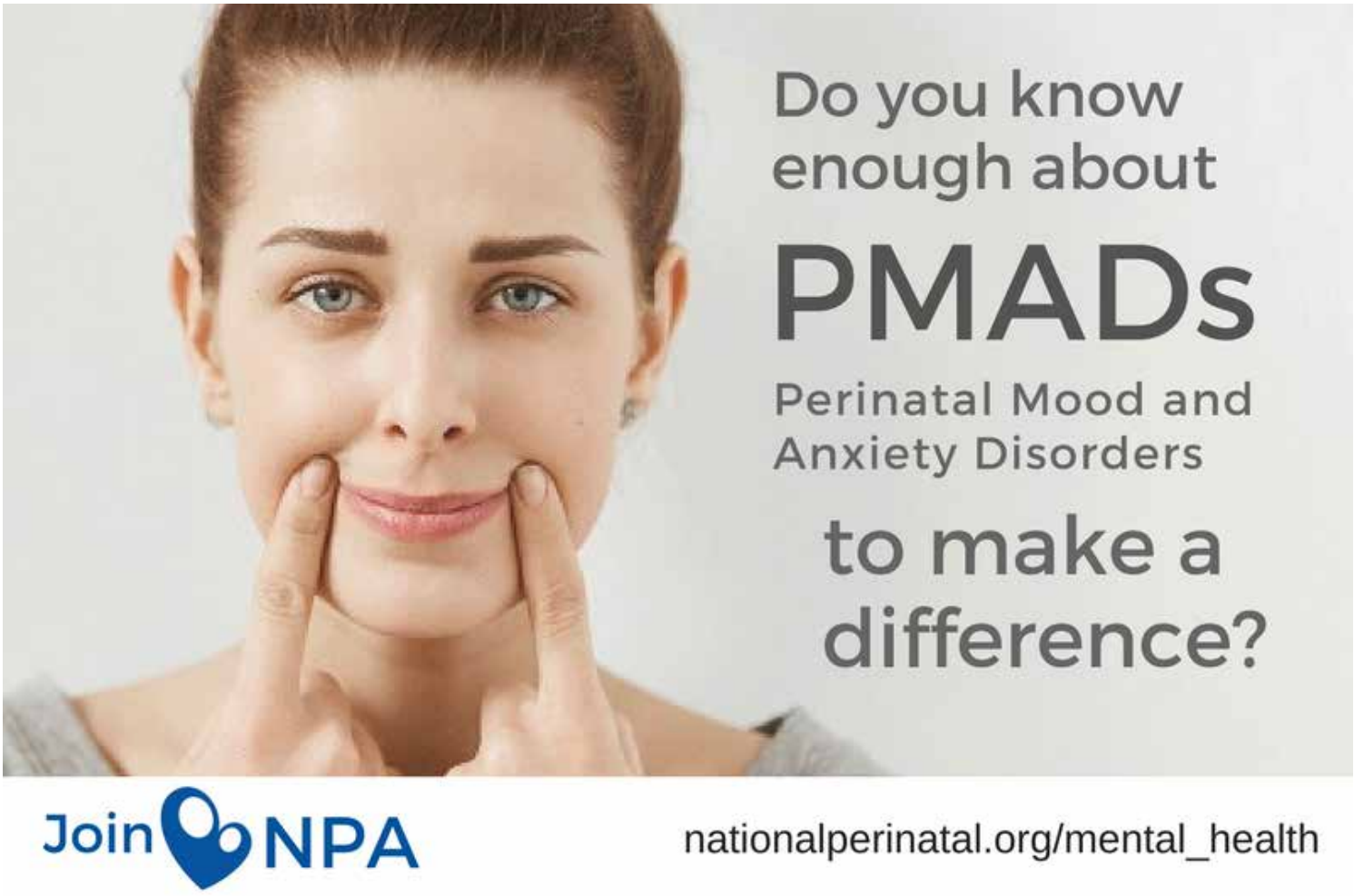
While this significant leap brings us closer to the World Health Organization target of increasing exclusive breastfeeding to at least 50% by 2025, there are persistent challenges that must be addressed.

When mothers receive the support they need to breastfeed their babies, everyone benefits. Improving breastfeeding rates could save over 820 000 children's lives each year, according to the latest available data.

During this critical period of early growth and development, the antibodies in breastmilk protect babies against illness and death. This is especially important during emergencies, when breastfeeding guarantees a safe, nutritious, and accessible food source for infants and young children. Breastfeeding reduces the burden of childhood illness, and the risk of certain types of cancers and noncommunicable diseases for mothers.

This World Breastfeeding Week, under the theme "Closing the gap: Breastfeeding

NT



Keeping Your Baby Safe
from respiratory infections

RSV
COVID-19
colds
flu

How to protect your little ones from germs and viruses

Cold and flu season can be dangerous - 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 hand sanitizers.



Limit Contact with Others



- Stay home when you can.
- Avoid sick people.
- 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 RSV, 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 can make it harder for them to breathe.
- Face masks and their straps pose a risk of suffocation and strangulation.
- Remember, a baby can't remove their mask if they're having trouble breathing.



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 viruses 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

Peer Reviewed

The Immediate Response to Abrupt Change by High-Reliability Organizations (HRO) is Related to Animal Personality

Daved van Stralen, MD, FAAP; Sean D. McKay, Element Rescue, LLC; Thomas A. Mercer, RAdm, USN (Retired)

"Before assessment, before full awareness, people respond to abrupt changes in their immediate environment. This trait, shared by a wide variety of animal phyla, is "animal personality" that covers three behavioral syndromes: boldness to shyness, exploration to avoidance, and level of activity."

Abstract

Before assessment, before full awareness, people respond to abrupt changes in their immediate environment. This trait, shared by a wide variety of animal phyla, is "animal personality" that covers three behavioral syndromes: boldness to shyness, exploration to avoidance, and level of activity. These phenotypic syndromes shape the animal's immediate response to the environment, even as the environment shapes the phenotypic expression of these behaviors. The larger ecological environment shapes the behaviors of humans, mammals, and birds, converging several types of behaviors toward common behaviors. Animal personality and ecological convergence illustrate the influence of the environment on behavior, the constriction of the environment on behaviors, and the influence of fitness of these responses to the environment. HRO may not be as much the initial response to a crisis as the flux of continuing iterations of responses. There is no wrong first action toward enactment. There may be wrong in creating an expectation of what happens in that first moment or a consequence of not responding to the environment responding to the person's response.

Introduction:

It is transient. It is too transient for us to know or remember. A person responds to the environment momentarily, without appraisal, and not in an aroused state. In this ephemeral moment, an individual begins a cascading series of actions, self-organizing improvisation (1), that bumps along through events as the person seeks control while seeking information.

Theory does not prepare us for decision-making in these stochastic situations. Response to our actions guides our subsequent response. Each act creates a "different" situation. The "sensed" situation we create from these reciprocal decisions ceases to exist seconds after we act. It will never be available for review (2).

Only the "monitored" situation will exist. This is what we remember, but what we remember will coincide with what we were told is essential. Descriptions of the episode mask the reality. This is how the individual will recall events.

"Only the "monitored" situation will exist. This is what we remember, but what we remember will coincide with what we were told is essential. Descriptions of the episode mask the reality. This is how the individual will recall events."

The authors have been present at events where the environment abruptly and catastrophically changed events. In the first moments of these events, they observed the actions of individuals. They listened to these individuals during the incident and later as the individual recounted what happened.

Examples include heroic actions, yet the individual said they were "in denial" that anything was wrong; immediate and effective engagement described as "I had to do something;" ingenious decisions that were simply "I must have learned it somewhere;" and laments of "I screwed up" yet the person had saved the day.

Equally, the authors have observed maladaptive actions. Those who learn from these will be quiet and non-talkative. Through "investigative coaching," the authors help interpret events – " you can only see so much; you made the best decision with what you had."

> Early in his fire rescue ambulance service, one of the authors [DvS] had the following experience with a firefighter, also new to the service:
>
> They responded to a motor vehicle collision blocking several highway lanes during rush hour traffic. The firefighter recommended pulling the door outward to allow the victim to leave the vehicle, which made sense as the victim had no visible injuries. The fire department responds to a ladder truck, two fire engines, and a battalion chief for a victim extrication at a traffic collision.
>
> The victim began turning gray and stopped talking, an early sign of a heart attack that may have led to the accident or occurred after the accident. Paramedics are also at least twenty minutes away. The victim was transported to the hospital emergency department, where he died fourteen hours later from a heart attack.
>
> That evening, the Captain called the author into the office and thanked him for his work. He said the author was the fire department's most qualified medic for the call. There may have been more qualified medics, but they were not available. The department would support the author and everything he did. He then asked what could be done differently next time.

A coaching session ensued, and the Captain identified several improvements. The Captain finished by telling the author he was the most qualified medic for the assignment; the department would stand behind him, not to worry.

The Captain concluded with, "There are a thousand things happening at a scene. You can only see a hundred. You can only act on ten. I may see a different hundred. I may act on a different ten. That doesn't mean I'm better than you; only that I'm different."

Even if engaged side by side, people have different experiences.

"This remains, to me, one of your more powerful, rich experiences. One can dwell on its implications for a long time." Karl Weick, personal communication.

Then some muckle things up, emerging proudly as everyone's saviors. Moreover, they tell us about it.

Human reaction time is about 0.20 seconds. This is the time interval when a salient signal hits our attention. Recognition to action is less than a second. We can stand next to each other yet have distinctly different experiences. However, sensing those first moments will be lost in subsequent events, the urge to understand and explain, and the necessity to conform – such as reporting the person was in denial even as they engaged heroically.

From a relaxed state to emergency engagement, this period occurs in seconds and is challenging to study. Researchers cannot reproduce the situation for ethical studies. They rarely have extensive experience in this environment. Experienced veterans do not have the necessary body of knowledge to communicate with academicians. Neither group, academicians nor veterans, share a lexicon for effective communication. Below, we present several vignettes that demonstrate these behaviors. This will focus on natural behaviors.

"Human reaction time is about 0.20 seconds. This is the time interval when a salient signal hits our attention. Recognition to action is less than a second. We can stand next to each other yet have distinctly different experiences."

Perhaps understanding animal personality can help us appreciate how the behavior of two people standing side-by-side differs – because their environments differ. More fundamentally, possibly we explain how people respond to danger as quickly as they do – while becoming more effective as they act.

HRO Is a Natural Response for People:

A combat medic treated American and allied soldiers after an artillery barrage hit their compound and damaged the perimeter. Treating the more seriously wounded soldiers used up his antibiotics. The allied soldiers made direct threats for him to treat the other wounded with antibiotics. Since the evening was approaching, the area commander denied helicopter pilots permission to evacuate the wounded. That would wait for the morning. Enemy soldiers were 800 meters out. He thought he would be killed one way or another.

A kindergarten teacher, on her first day at the school, stood at the door of her classroom as all of her students ran out of each of the four exit doors. The sky was black. The school had just received a tornado alert, followed by an announcement to move students to the designated shelter. Nearby teachers could not assist her because they were escorting their students to the shelter. She lost her students; now she thought she would lose her job (personal communication from the medic and teacher, DvS).

Despite the command, helicopter pilots lifted off from their base to evacuate the wounded. Despite responsibility for their young students, the teachers gathered the scattering kindergarteners. The medic later understood he had a standard supply of antibiotics and learned they were victims of friendly fire. The teacher learned that a tornado hit the school the year before, killing three students who were friends of her kindergarteners. The children ran away from fear.

One of the authors (DvS) asked the army medic how he and his experience differed from the teacher and her experience. There was no difference, the medic answered. It was not the fault of either person. The helping responders were not supposed to help. Nevertheless, they spontaneously came together to help. He observed that he and the teacher had the same brain and had the same response.

Upon hearing three rapid, evenly spaced pops, elementary school teachers evacuated their students toward the edge of the playground's grassy area. For some classrooms, this was the opposite direction for a fire drill. The teachers wordlessly moved their students to the back gate, where they decided to leave the school grounds. Upon opening the gate, the first arriving police officer drove his motorcycle through.

There had been no announcement to evacuate. There had been no discussions between teachers during the evacuation. They had neither received 'active shooter' training nor did the school have an active shooter plan. Some students thought they were going on a field trip. School staff had quietly evacuated about 400 children in less than six minutes (3, 4).

"One of the authors (DvS) asked the army medic how he and his experience differed from the teacher and her experience. There was no difference, the medic answered. It was not the fault of either person. The helping responders were not supposed to help. Nevertheless, they spontaneously came together to help. He observed that he and the teacher had the same brain and had the same response."

A passenger ship with 581 guests and crew sailed into 40-knot winds and 9m-high (30ft) waves, began drifting sideways into the waves and listing back and forth. It was late at night. Chairs began sliding. Passengers moved to sit on the floor. A guitarist observed

crew members wearing life jackets racing aft. The lights went out, replaced by emergency lighting. The cruise director reported that the Captain had said they should prepare to abandon the ship. Not hearing instructions from the crew, the guitarist and a magician went below decks to learn more. They reached a bulkhead sealed off by water-tight doors. The ship must be taking on water. There had been no announcement, no alarm sounded. The guitarist could hear the sound of water flowing. The ship was sinking (4, 5).

The guitarist, cruise director, and the magician, now joined by another magician and a few other mostly female entertainment staff, figured out how to release the lifeboats. They carried out the evacuation of guests. Passengers stopped asking about the ship's officers, realizing the entertainers were now in charge. After the launch of the last lifeboat, 220 people remained on board (6, 7).

By then, the navy had arrived, initiating a helicopter evacuation of the remaining passengers. The guitarist, bass player-singer, and the cruise director worked together on deck for this evacuation. One magician remained on the bridge for radio contact. Another magician joined a navy rescue diver in a Zodiac inflatable boat to rescue anyone who fell or jumped into the sea.

"The guitarist, cruise director, and the magician, now joined by another magician and a few other mostly female entertainment staff, figured out how to release the lifeboats. They carried out the evacuation of guests. Passengers stopped asking about the ship's officers, realizing the entertainers were now in charge. After the launch of the last lifeboat, 220 people remained on board (6, 7)."

The Captain was one of the first people rescued by helicopter, stepping in front of elderly passengers. He stated he needed to direct the rescue from land (8). No lives were lost in the sinking of the passenger ship.

> [The Captain remains with the ship because the Captain knows the capability of the crew and ship, understands and has monitored the damage, and has the knowledge of the ship to direct damage control, salvage, and rescue operations. The crew cannot jettison lifeboats without the Captain's order to abandon the ship because the Captain needs the entire crew to save the ship. Passengers are safer on the ship than in lifeboats. It would be considered mutiny for the crew to leave the ship on lifeboats without the Captain's orders (TAM).]

These vignettes represent common patterns – people will come together to find a solution. Various small unit actions self-organize, merging to improvise solutions on the spot rapidly. This is "self-organizing improvisation" (1).

This coming together without individuals having the "big picture," they do not work from a plan, and most importantly, they engage the environment without knowing the extent of the threat. It becomes easy to see why they report reasons likely to have greater social acceptance than "I don't know."

Oddly, their responses have similar patterns to responses to the environment by various animals. These responses to the environment are consistent over time and context. Animal behavior researchers call this "animal personality."

"These vignettes represent common patterns – people will come together to find a solution. Various small unit actions self-organize, merging to improvise solutions on the spot rapidly. This is "self-organizing improvisation" (1)."

Animal Personalities:

For survival, animals rely on behaviors and genetically determined reaction norms. However, these are behaviors that evolved under past conditions. Personality creates plasticity of these evolved traits, allowing survival in novel or rapidly changing conditions (9). Animal personality supports allostatic change.

People and animals adapt to the current environment, whether that environment developed from slow change, emerged from forcing functions, or appeared as an abrupt catastrophe. In these circumstances, the system or organization gains stability through change, which is the fundamental principle of allostasis. The quickest way to change is by behavior. Animal adaptations that produce allostasis emerge from those behaviors used to cope with adverse environments. Nobel laureate Niko Tinbergen (10) recognized this, "Every animal has to cope in numerous ways with a hostile, at least uncooperative environment." He identified that behavior gives the animal the ability to cope and survive.

Tinbergen did not describe whether these behaviors are specific to a situation or derive from a restricted repertoire – suites of behavior or whether all animals share the same few suites versus phylum-dependent behaviors.

Those who have spent extensive time around animals recognize that different animals of the same species have consistent but different behaviors. These consistent behaviors come with the animal rather than being a product of training or the animal's experiences. These behaviors form "animal personality." "Animal" differentiates this personality type and its ultimate function from "human personality."

As described by Tinbergen, behaviors are an essential factor that influences fitness, allowing an animal to survive and adapt to a "hostile, at least uncooperative environment." Behaviors must be dependable and consistent and must support variability during a crisis. Animal personality is defined as a suite of individual differences in behavior that are consistent over time or contexts. Personality operates as an emergent behavioral phenomenon by reacting to environmental challenges (11).

Personality differences within a group may derive from genetics, phenotypic plasticity related to the environment, or a combination.

Favorable behavioral phenotypes may be moderate (12).

In behavioral ecology, an animal's repeatable behavior is called a trait, a more concrete definition than psychology's more abstract use of the term (13). Behavioral ecologists in the past considered these personality behaviors to be noise and, therefore, easily disregarded (12).

Characteristics and Phenotypes

With further observation and investigation, animal behaviorists found that what they thought was noise had structured differences and occurred over a diverse range of animal species (12). Consistent differences in behavioral tendencies of animals include aggressiveness, boldness, activity level cooperativeness, fearfulness, dispersal tendency, exploration tendency, docility, impulsivity, sociability, responsiveness to environmental stimuli, and coping styles (12). These behaviors form a spectrum and are heritable.

"As described by Tinbergen, behaviors are an essential factor that influences fitness, allowing an animal to survive and adapt to a "hostile, at least uncooperative environment." Behaviors must be dependable and consistent and must support variability during a crisis. Animal personality is defined as a suite of individual differences in behavior that are consistent over time or contexts. Personality operates as an emergent behavioral phenomenon by reacting to environmental challenges (11)."

The framework for the structure includes five major personality trait categories (boldness/shyness, exploration/avoidance, activity, sociability, and aggression). *Current personality and behavioral syndromes investigations use boldness/ shyness, exploration/ avoidance, and activity* [Table 1](14).

Table 1: Standard Personality Axes

Boldness/ Shyness
Exploration/ Avoidance
Activity

Personality behaviors can influence an individual's survival and reproductive success because they are responses to the environment. Personality can also influence adaptability in a changing environment (11). Animal personality then supports rapid behavioral response in an adverse environment, which is the function of behavior that Niko Tinbergen described (15).

Animal personality is structured with various suites of behaviors consistent across various animal species. It is consistent over time, context, and across different situations. Animal personality influences fitness and adaptability in a changing environment (11, 12).

The importance of animal personality is shown in the findings of personality in amphibians. In wild populations of amphibians, personality differences can persist when offspring are raised in captivity. Personality in amphibians also persists across metamorphosis (11).

Similarity across Phyla

Animal personality is consistent across numerous phyla in the animal kingdom. Animal personality traits have been documented in vertebrates such as salamanders, fish, lizards, rodents, mink, and bighorn sheep (12, 16). Frogs, toads, salamanders, and newts show personality along the three behavioral axes of boldness, exploration, and activity (11).

"Animal personality is structured with various suites of behaviors consistent across various animal species. It is consistent over time, context, and across different situations. Animal personality influences fitness and adaptability in a changing environment (11, 12)."

Invertebrates also show animal personality, including drosophila fruit flies, crickets and locusts, larvae (damselfly, sawfly), cockroaches, ants, Fishing spiders (shy-to-bold males), cephalopods (octopus, squid), crab, worms, and snails [Table 2] (17).

Table 2: Invertebrates with Animal Personality

Drosophila fruit flies	Gene-environment interactions cause behavior that is consistent over context and time.
Crickets, locust	
Larvae – damselfly, sawfly,	
Cockroach	
Ants	
Fishing spiders	Passive or aggressive males (Shy-bold continuum)
Spiders	A single spider species: Riparian spiders fearful; grassland spiders aggressive
Crab	
Cephalopods – octopus, squid	
Worms, snails,	

Proximate and Ultimate Causation

To evaluate behavior, we look to the proximate and ultimate causes. What happened immediately prior to the behavior is the proximate *causation*, generally a mechanistic process. What the animal achieves through its behavior is the ultimate *function*, an

adaptive process. The function of behavior is to adapt to the current environment. Proximate mechanistic causes and ultimate adaptive functions operate at different levels of analysis (18). Animal personality research has focused on whether animal personalities exist, the characterization of their structure, and the proximate and ultimate causes of personality differences (12).

The environment operates on phenotype. However, animal personality phenotypes are expressed across various contexts and situations and in diverse environmental stressors. Personality influences the optimal behavior for varying environments (11). This creates difficulty in identifying phenotypic distributions of personality traits, suites of behavior, and fitness (19).

It is easy to think that behavioral plasticity, rather than animal personality, causes the phenotypic variation in those behaviors that respond to the environment. However, animals have limited behavioral plasticity, and the same animal will have differing responses toward the same environmental stimuli (19).

However, this seems odd. Having behavioral plasticity for quickly changing behaviors in an uncertain environment would make sense. However, animals have limited behavioral plasticity, and individuals often respond differently to the same environmental stimulus (19). It also makes sense to have behaviors specific to responding to the environment. Nevertheless, the behaviors from animal personalities are limited, structured suites of behaviors. That is the paradox: we find behavioral plasticity to be restrictive for uncertainty while animal personality is limited.

Genotypes:

Single components of animal personality, such as aggressiveness, have moderate heritability and remain relatively stable throughout the individual's life. Strong genetic correlations can generate phenotypic correlations between components of personality (e.g., between aggressiveness and boldness) (20). From 20 to 50 percent of phenotypic has a genetic basis. We do not know why it is present and how it is maintained (21). The response to selection depends on different selective environments (12).

Two cattle populations were measured for flight distance to a human approacher and social separation. The most likely determinant of the differences was a dopamine receptor.

Animal personality is beginning to influence the well-being of farm animals. For humans, personality variation appears to be in a dopamine gene and serotonin transporter gene. The 7R allele at a dopamine gene is associated with higher levels of novelty seeking. In human populations, population pattern is associated with population migration distances in prehistoric times. Populations near their origins have fewer 7R alleles (22).

"The environment operates on phenotype. However, animal personality phenotypes are expressed across various contexts and situations and in diverse environmental stressors. Personality influences the optimal behavior for varying environments (11)."

Environment and Stress:

Environmental factors can modify personality even though personality is partially heritable. Different environments lead to different personality types, even with the same genotype (11, 23, 24). Animals' behavioral response to environmental change varies due to behavioral plasticity (25). During early-life growth, physical and social factors can influence an animal's development (11).

Stress responsiveness to the environment through the hypothalamic–pituitary–adrenal axis is linked with animal behavioral personality measures. Those with a more robust stress response, measured by hormone levels, tend to be less bold (26).

The habitat for a funnel web spider is dry grassland and moist riparian habitats. The grasslands have lower prey availability and lower predation from birds. Riparian habitats have high predation and high food availability. The grassland spiders are aggressive, while the spiders in the riparian habitats are shy, spending more time hiding. This is an inheritable trait on the shy-bold axis (17).

Response to Stressors

Exposed to a stressor, the priority of specific behaviors and physiological functions change for an animal. This reprioritization varies in an individual animal due to different behavioral or physiological characteristics such as bold versus shy personality or differing metabolic rates. Differential sensitivity to a stressor further increases the observed phenotypic variation of traits (26).

Environmental stressors are commonly measured on or characterized as a gradient. While the gradient may be suitable for an aggregate of animals, a single point along a gradient quickly becomes a stressor for an individual animal (26). This is like the line worker engaged with a situation in granular circumstances. The person who made the plan likely used aggregate data to prepare the program. The program would then be reproduced for various incidents or modified for types of incidents. The supervisor, far from events, too quickly dismisses the seriousness of the situation.

"Environmental factors can modify personality even though personality is partially heritable. Different environments lead to different personality types, even with the same genotype (11, 23, 24)."

This is a continuing problem with humans, and it is the influence of personality on abrupt stress. In the 1970s, one of the authors [DvS] served as a medic on a fire rescue ambulance. Medics and fire companies would arrive on the scene, decide there was no emergency, and then depart. They had kept themselves removed from the situation the citizens were experiencing. The circumstances that led the citizens to call the fire department had not changed. He continued to experience this in healthcare and working with EMS, sometimes with grim results.

Bruce Spurlock, an internist, described this personality response to a. stressor within the same environment. He would request surgical consults for his patients experiencing severe abdominal pain that he did not understand. The surgeons would diagnose "not a surgical abdomen," only recommending an internal medicine con-

sultation. Not finding this disease in the *International Classification of Diseases,* Spurlock took it upon himself to identify the entity as "NASA Syndrome" – Not A Surgical Abdomen (27).

This article describes animal personality as an individual's immediate, unfiltered response to the environment. A demonstration of personality followed as a response to the problem. A surgeon (22) had responded to Spurlock: "Perhaps the surgical consultant should have directed definitive studies, exacted a diagnosis, and provided treatment. However, then why would we need internists? Perhaps Spurlock's apparent contempt/ insecurity/ whatever needs some adjustment?"

"Environmental stressors are commonly measured on or characterized as a gradient. While the gradient may be suitable for an aggregate of animals, a single point along a gradient quickly becomes a stressor for an individual animal (26)."

We do not make light of this. As described above, spectators (who are often higher rank than the operator) too readily use aggregate data that has been decontextualized from the situation. This increased physical distance and being removed from local imperatives too quickly drives insufficient attention to the problem. The result is a diminished appreciation for how the engaged individual experiences the event. In Spurlock's situation, the consultant does not enter the patient's environment. The consultant becomes a spectator—a spectator with an opinion.

Time has a dimension when we respond to a situation, which is lost with increasing distance from the situation (28, 29). We must leave the Euclidean space of three fixed dimensions to respond to the environment. We do not have the luxury of points creating lines of hierarchy. A single point no longer serves as a reference, the central or absolute point from which we can measure and compare actions. The Euclidean space does not need personality. Those at the absolute point of reference, where time starts, have the authority.

When responding *within* the environment, there is no single environment within which we respond. The predator can become prey during predation – much like the fish on the hook, swallowed by a larger fish, and so on. The animal and person in this environment move forward, seeking to bring control over uncontrollability. At the same time, they are in an uncontrolled environment that seeks to control them.

The two environments in which they operate are not the same. The individual embraces an immediate local environment within an independent and larger environment. As in the vignette about the motor vehicle collision, each person standing alongside the individual will experience a different environment. We need a requisite *diversity* of personalities for these environments. There are not two points of view, as supervisors are fond of saying. There are multiple points of view, and each person has multiple yet simultaneous frames of reference.

When we do not consider an individual's frame of reference, we cannot identify the source of a person's response. The belief in the same environment masks the reasons for personality responses, and we too easily view their behavior as improper.

Convergence of Behaviors:

We can easily think that collective behavior results from interactions with similar individuals sharing similar situations within the same environment. It is more likely that the environment constrains behavior Toman Barsbai, Dieter Lukas, and Andreas Pondorfer (25) analyzed an ethnographic database of 339 human hunter-gatherer populations worldwide. They also identified all mammal and bird species living in the exact location.

Foraging human populations, mammal, and bird species show high levels of similarity in their foraging, reproductive, and social behavior when they live in the same area. Strong associations developed between human and non-human animals for diet composition, reliance on food storage (hoarding food for animals), short-term movements to acquire resources, and long-term movements between resource locations.

Animal personality describes how the environment shapes animal behavior, calling on only a few survival behaviors. It now appears that "lifestyle" behaviors also converge amongst various animal species, shaped by the environment. The environment shapes and constrains behavior, apparently independent of the organism. The authors suggest a tendency for a specific set of behavioral solutions to environmental challenges.

Conclusion:

The HRO Study Group from the University of California, Berkeley, developed the concept of the High-Reliability Organization from initial studies of the USS Carl Vinson, a Nimitz-class aircraft carrier. One of the authors (TAM) was the Captain who had invited the Berkeley academicians to study the crew's performance.

Less than a year after commissioning, Carl Vinson departed on a seven-month homeport change and around-the-world cruise. The author (TAM) reported as Captain to the ship in Perth, Australia, three months into the cruise. Carl Vinson maintained heavy training cycles. Meetings were kept to an absolute minimum.

"When we do not consider an individual's frame of reference, we cannot identify the source of a person's response. The belief in the same environment masks the reasons for personality responses, and we too easily view their behavior as improper."

Over the next three years and two extended deployments, Carl Vinson operated free of aircraft accidents and major injuries, receiving significant aviation safety and operational readiness awards, including the Admiral Flatley Memorial Award for the best Navy-wide aircraft carrier and air wing safety record (38).

The author describes one approach to safety for a nuclear aircraft carrier – keep the ship at dock and the planes on deck. As described in the previous paragraph, the author had an impeccable safety record *because* he took the ship out to sea and kept the planes in the air.

HRO described an operational approach to entering a hazardous

environment. HRO works because humans engage in emergent problems within adverse environments. We can only accomplish this through action…the *function* of behaviors.

Animal personality describes suites of behaviors utilized by animals to survive adverse environments. In some sense, animal personality is the *function* of the three behavior axes: boldness/shyness, exploration/avoidance, and level of activity.

Some significance lies in the three types of behavior that compel an animal to respond to the environment. They are found across diverse animal phyla, within diverse environments, and forming behavioral responses to the environment. They also function to increase fitness and adaptation.

"Animal personality describes how the environment shapes animal behavior, calling on only a few survival behaviors. It now appears that "lifestyle" behaviors also converge amongst various animal species, shaped by the environment. The environment shapes and constrains behavior, apparently independent of the organism. The authors suggest a tendency for a specific set of behavioral solutions to environmental challenges."

We have also seen that the environment influences personality, causing a convergence of behaviors across humans, other mammals, and birds. Nature seems to have presented us with an adverse environment that influences our personality behaviors. Also, animals have a set of behaviors constrained by the environment even as they increase fitness for that environment.

Nowhere in this domain of animal personality, responsiveness to the environment, and environmental influence on behaviors do we see rules, protocols, hierarchy, and rigid structure.

"HRO described an operational approach to entering a hazardous environment. HRO works because humans engage in emergent problems within adverse environments. We can only accomplish this through action… the function of behaviors."

We may have lost focus on the function of behavior when operating in an adverse environment and as an HRO. Self-organization emerges from the nonlinear interactions of a few simple rules at the local level. Self-organization creates order out of disorder. Improvisation is acceptance of what you are given and then using it to create the next step toward order. Improvisation as a form of directed self-organization creates something new that will influence fitness.

The Carl Vinson went out to see and put planes in the air. Animals go out into adverse environments where boldness or shyness makes the animal the most fit. It may be good to return to the function of HRO.

One aircraft carrier can stay safe at the dock with its planes on deck. Another aircraft carrier can go to sea and keep its planes in the air. Outwardly, both ships may look the same. From the shore, it would appear prudent and safer to stay near the dock. That is until we encounter a forcing function or abrupt catastrophe. That is the function of HRO.

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Raymond Novaco, PhD.

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Errol van Stralen, Ancora Education

Disclosures: The authors have no disclosures

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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

Cold and flu season can be dangerous - 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 hand sanitizers.



Limit Contact with Others



- Stay home when you can.
- Avoid sick people.
- 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 RSV, 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 can make it harder for them to breathe.
- Face masks and their straps pose a risk of suffocation and strangulation.
- Remember, a baby can't remove their mask if they're having trouble breathing.



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 viruses from spreading.
- Watch out for symptoms like fever, confusion, or trouble breathing.
- Ask for help caring for your baby and yourself while you recover.



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How to Care for a Baby with Signs of Withdrawal

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.

Academy of Perinatal Harm Reduction
www.perinatalharmreduction.org

National Perinatal Association
www.nationalperinatal.org

H1015: Section on Neonatal Perinatal Medicine Program: Day 1

Friday, September 27

ONTPD Meeting

9:00 AM – 4:00 PM	**Organization of Neonatal Training Program Directors (ONTPD) Meeting***
	Megan Gray and Deirdre O'Reilly – ONTPD Co-Chairs

Opening Session

4:00 PM	**Welcome and Opening Remarks***
	Brian Hackett – Program Chair
4:10 PM	**Section on Neonatal Perinatal Medicine Update***
	Munish Gupta – SONPM Executive Committee Chair
4:30 PM	**Thomas Cone Lecture**
	Evidence, Experience, Emotions, and Egos: a History of Evidence-Based Neonatology
	Kanekal Gautham
	Sponsored by Abbott
5:15 PM	**Gerald Merenstein Lecture**
	Big Data, Big Challenges: Navigating the Landscape and Landmines of Neonatal Genomic Sequencing
	Jill Maron
	Sponsored by Abbott
6:00 PM	**Adjourn**

**This portion of the agenda is not designated for CME credit.*



H2012: Section on Neonatal Perinatal Medicine Program: Day 2

Saturday, September 28

Artificial Intelligence in the NICU

8:00 AM	**Introduction of Session***
	Moderator: James Barry
8:05 AM	**Bytes, Babies, and Bots: Charting Artificial Intelligence in the NICU**
	Kristyn Beam
8:50 AM	**AI-Powered Risk Prediction for Early Detection of Neonatal Sepsis**
	Brynne Sullivan
9:35 AM	**Break***
9:45 AM	**Using AI to Analyze Biological Big Data from the NICU**
	Thomas Hooven
10:30 AM	**Ready or Not: Is AI Poised to Revolutionize the NICU?**
	Ryan McAdams
11:05 AM	**Panel Discussion and Questions**
	Kristyn Beam, Brynne Sullivan, Thomas Hooven, Ryan McAdams
11:45 AM	**Adjourn***

SONPM Poster Fair

12:00 PM to 1:30 PM	**SoNPM Poster Fair***

Original Abstracts

1:40 PM	**Welcome and Opening Remarks***
	Alexis Davis – Abstract Chair
1:45 PM	**Scientific Abstract Oral Presentations**
	Best abstracts sponsored by Reckitt Mead Johnson
3:00 PM	**Presentation of Marshall Klaus Research Awards***
	Hendrik Wëitkamp – SONPM Research Chair
	Awards sponsored by: Reckitt Mead Johnson, Section on Neonatal Perinatal Medicine, Beth Israel Deaconess Medical Center Department of Neonatology
3:15 PM	**Break***
3:30 PM	**Scientific Abstract Oral Presentations**
	Best abstracts sponsored by Reckitt Mead Johnson

**This portion of the agenda is not designated for CME credit.*

H2012: Section on Neonatal Perinatal Medicine Program: Day 2 (continued)

Saturday, September 28

Section Awards

4:45 PM	**Section on Neonatal Perinatal Medicine Awards***
	Munish Gupta – SONPM Executive Committee Chair
4:55 PM	**Presentation of the Avroy Fanaroff Neonatal Education Award**
	Presenter: Gil Martin
	Awardee: Stephen Pearlman
	Sponsored by Reckitt Mead Johnson
5:10 PM	**Presentation of the Neonatal Landmark Award**
	Presenter: Henry Lee and Jochen Profit
	Awardee: Jeffrey Gould
	Sponsored by Reckitt Mead Johnson
5:25 PM	**Presentation of the Virginia Apgar Award**
	Presenter: Eric Eichenwald
	Awardee: Ann Stark
	Sponsored by Abbott
5:40 PM	**Adjourn**

**This portion of the agenda is not designated for CME credit.*

H3003: Joint Program: Section on Bioethics, Section on Hospice and Palliative Care Medicine, and Section on Neonatal Perinatal Medicine

Sunday, September 29

When External Factors Limit Options: Caring for Birthing Families

8:00 AM	**Announcement of SONPM Young Investigator Awards***
	Alexis Davis – Abstract Chair
	Sponsored by Reckitt Mead Johnson
8:05 AM	**Presentation of William G. Bartholome Award for Ethical Excellence***
	Presenter: Steven Leuthner
	Awardee: Brian S. Carter
8:35 AM	**Introduction of Session**
	Moderators: Amy Trowbridge, Dalia Feltman, Brian Hackett
8:40 AM	**Constraints on Available Neonatal-Perinatal Care Options**
	DonnaMaria Cortezzo
9:15 AM	**Ethical and Moral Implications of Constraints in Neonatal Perinatal Care Options**
	April Dworetz
9:50 AM	**Update from AAP staff on advocacy for shared decision making and physician support**
10:00 AM	**Break***
10:20 AM	**The Dance of Shared Decision-Making: How Honest Human Connection Can Make All the Difference**
	Ashley Waddell Tingstad, Courageous Parents Network
10:55 AM	**Catalysts and Constraints to Shared Decision-Making—Helping Birthing Families Create a Path Forward**
	Terri Major-Kincade
11:30 AM	**Panel Discussion and Audience Q&A**
	Terri Major-Kincade, Ashley Waddell Tingstad, April Dworetz, DonnaMaria Cortezzo
12:15 PM	**Adjourn**

**This portion of the agenda is not designated for CME credit.*

H3038: Section on Neonatal Perinatal Medicine Program: Day 3

Sunday, September 29

Women in Neonatology (WiN): WiNning together: rising stronger with goal setting, coaching, mentorship, allyship

1:00 PM	**WiNning together: rising stronger with goal setting, coaching, mentorship, allyship** *Gina Geiss*
2:00 PM	**Career development part I: Craft your WiNning circle: rising stronger with coaches, mentors, and allies** *Marilyn Escobedo*
3:00 PM	**Career development part II: WiNning at goal setting: rising stronger through personal strategy development** *Kris Reber*
4:00 PM	**WiN Reception*** *Sponsored by Reckitt/Mead Johnson Nutrition*

**This portion of the agenda is not designated for CME credit.*

Review Committee for Pediatrics (RC-Peds) Nominee Qualifications

To qualify to be nominated to the RC-Peds for this position, the candidate:

- must be a board-certified pediatrician or pediatric subspecialist with a background in education and expertise in graduate medical education.
- should have at least three years of experience as a program director of an ACGME-accredited pediatrics residency program or pediatric subspecialty fellowship or three years of experience as a designated institutional official. The nominee's program must be in good standing with a status of Continued Accreditation.
- must have a current or past association with graduate medical education.
- should participate in major specialty societies.
- must be skilled in the use of computers (communication with staff is primarily through email, and members will use electronic systems for receipt of agenda materials, program reviews, reimbursement of expenses, and peer evaluations).
- must demonstrate fairness, the ability to work collaboratively, and express views clearly and concisely.
- must be able to attend an observation meeting, April 10-11, 2025, prior to the start of the term.
- must devote sufficient time to prepare for and participate in three RC meetings per year (January, April, and September), two-three days per meeting, as well as contribute to RC-Peds subcommittee work as assigned.
- ideally, will not hold the same subspecialty certifications as the members of the RC-Peds at the time of appointment. The RC-Peds strives to maintain a balance of specialties; it is preferable that individuals from the following specialties are not nominated:
    - General Pediatrics
    - Internal-Medicine Pediatrics
    - Pediatric Hospital Medicine
    - Pediatric Emergency Medicine
    - Neonatal-Perinatal Medicine
    - Pediatric Critical Care Medicine
    - Pediatric Endocrinology
- must not be at the same institution as any member of the RC-Peds at the time of appointment.
    - *Same-Institution Disqualification: Although the RC-Peds may have multiple members from the same state, they may not be from the same institution. Accordingly, individuals must not be nominated from the following institutions:*
        - UC Davis (Davis, CA)
        - Stanford University (Stanford, CA)
        - University of Colorado (Aurora, CO)
        - Advocate Children's Hospital (Park Ridge, IL)
        - Mayo Clinic (Rochester, MN)
        - Columbia University College of Physicians & Surgeons (Yonkers, NY)
        - Goryeb Children's Hospital-Atlantic Health System (Morristown, NJ)
        - University of North Carolina School of Medicine (Chapel Hill, NC)
        - Cincinnati Children’s Hospital Medical Center (Cincinnati, OH)
        - University of Texas Health San Antonio (San Antonio, TX)
        - University of Washington/Seattle Children's (Seattle, WA)

The RC-Peds expects the AAP to consider diversity and inclusion when submitting its nominations.



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Coding: Coding for Summer Travel

Kate Peterson Stanley, MD, FAAP

The SONPM Coding Committee recently presented a Coding Workshop and a Deep Dive into Coding at the 2024 Perinatal Practice Strategies meeting in Scottsdale, March 22-24, the latter of which included topics related to clinical documentation. The first article of this two-part series was dedicated to clinical documentation, emphasizing the importance of clinical documentation and reviewing common errors. This article will focus on clinical documentation improvement programs.

"The first article of this two-part series was dedicated to clinical documentation, emphasizing the importance of clinical documentation and reviewing common errors. This article will focus on clinical documentation improvement programs."

Summer is the season for vacation travel. This year, a software upgrade stopped airline travel, forcing many travelers, including myself, to adjust their plans. While waiting for my delayed flight in the airport at 2 am with my sleepy teenager, I wondered if medical transports were caught up in the snafu. This reminded me of neonatologists' vital role in ensuring safe and expedient medical transports. Over 68,000 neonatal transports occur annually. As part of a transport team, all practicing neonatologists participate in some component of the process, including referral, acceptance, and medical management by phone or in-person care. Knowing how to be reimbursed for this work is essential. So, in the spirit of the summer travel season, this article will review the neonatal interfacility transport Current Procedural Terminology (CPT) codes and how to apply them. Let us begin with a scenario:

"As part of a transport team, all practicing neonatologists participate in some component of the process, including referral, acceptance, and medical management by phone or in-person care. Knowing how to be reimbursed for this work is essential."

A preterm female infant is delivered precipitously in a community hospital ER after a woman presents in active labor. A pediatrician on-site resuscitated and successfully intubated the infant. The ER team calls the regional neonatal ICU for emergency transport while the pediatrician provides positive pressure ventilation using a self-inflating bag. Meanwhile, at the regional NICU, the neonatologist spends 15 minutes providing medical support to the ER team via telephone. She then spends 15 minutes assembling and dispatching the transport team, including a neonatal nurse practitioner (NNP), respiratory therapist, and neonatal flight nurse. The NNP is part of the physician's practice and independently bills for her services. The transport team arrives at the community ER and receives a handoff from the pediatrician at 3:15 am. After confirming endotracheal tube placement with a chest radiograph, surfactant is provided by the NNP and respiratory therapist. The infant is transitioned to a transport ventilator. The NNP also places an umbilical venous line and adjusts the intravenous fluids. Stat laboratory studies showed that the infant was euglycemic and ventilating appropriately. The time spent performing the procedures was 20 minutes. The NNP spends 15 minutes updating and reviewing the radiograph and data with the neonatologist by phone. The team returns to the regional NICU at 5:15 am. The neonatologist accepts care of the patient and admits him to the NICU.

Which CPT codes are submitted for the interfacility transport services?

A. **99466**: Critical care face-to-face services, during an interfacility transport, critically ill or injured pediatric patient ≤ 24 months age, first 30-74 minutes hands-on care during transport (each additional 30 minutes: **99467**).
B. **99485**: Supervision by a control physician for interfacility transport care of a critically ill or injured pediatric patient ≤ 24 months of age, first 30 minutes (each additional 30 minutes: **99486**)
C. **99288**: Physician or other qualified health care professional direction of emergency medical systems emergency care, advanced life support
D. **99291**: Critical care, E/M of the critically ill or critically injured patient, first 30-74 minutes (each additional 30 minutes **99292**).



Answer A: 99466, 99467: Critical care face-to-face services during an interfacility transport, critically ill or injured pediatric patient ≤ 24 months age, first 30-74 minutes hands-on care during transport (each additional 30 minutes: 99467).

Several factors determine which CPT code is used to report transport services. These include the patient's condition, the personnel performing the transport, and the time spent providing services. The patient's condition must meet the CPT definition for critical care to report face-to-face transport services (99466/67) or supervision of transport by a control physician (99485/86). A patient is critically ill if there is acute impairment of one or more vital organ systems where there is a high probability of imminent or life-threatening deterioration. The medical treatment involves high-complexity medical decision-making to manage organ failure and prevent additional life-threatening deterioration. (1)

"Several factors determine which CPT code is used to report transport services. These include the patient's condition, the personnel performing the transport, and the time spent providing services. The patient's condition must meet the CPT definition for critical care to report face-to-face transport services (99466/67) or supervision of transport by a control physician (99485/86)."

Next, code choice is affected by the personnel providing services. Face-to-face transport services (99466/67) must be provided by a "medically qualified professional." This includes a physician and an advanced practice provider (APP) in most states. To report this code, the APP must be a member of the physician group and be allowed to bill independently by the state. Additionally, the provided services must be within the AAP's scope of practice. If the hospital employs the APP rather than the physician's practice, the hospital may report the face-to-face transport codes (99466/67). In many practices, house officers and nurse transporters provide face-to-face transport medical services under the indirect supervision of a physician. However, house officers and nurse transporters are not considered "medically qualified professionals" by CMS and most payers, so the face-to-face transport codes (9966/67) cannot be applied. In this situation, the physician who served as medical control and supervised the transport team can report CPT codes 99485/86. These codes are used to provide non-face-to-face supervisory services during critical care transport. It includes two-way communication with the transport team when the team is preparing for dispatch, providing care at the referring hospital, and during the transport itself.

The supervisory codes (99485/86) are appropriate when a physician supervises non-qualified medical personnel, and the face-to-face transport codes (99466/67) cannot be utilized. Note that the face-to-face transport codes (99466/87) cannot be reported together with the supervisory transport codes (99485/86) for the same encounter by the same group practice. However, if the APP is employed by the hospital, and the hospital submits a code for an APP's face-to-face transport services (99466/67), the separate physician group can report the supervision transport code (99485/86) if applicable.

"The supervisory codes (99485/86) are appropriate when a physician supervises non-qualified medical personnel, and the face-to-face transport codes (99466/67) cannot be utilized. Note that the face-to-face transport codes (99466/87) cannot be reported together with the supervisory transport codes (99485/86) for the same encounter by the same group practice."

Finally, code selection is determined by the time required to provide transport services. The face-to-face transport code 99466 is used for the first 30-74 minutes of critical care. Code 99467 is used for each additional 30 minutes. Time begins when the medical provider is delegated patient care responsibilities at the referring institution. Time ends when the receiving hospital accepts care of the patient. Only face-to-face time with the patient is counted. Time spent performing unbundled procedures is counted separately and should not be included in the time spent providing transport services. Documentation in the medical record should include the time spent providing services, a description of the critical condition of the patient and care provided, and a description of the unbundled procedures performed. When reporting the supervisory transport codes (99485/86), 16- 30 minutes must be spent providing services to use code 99485. Code 99486 is added for each additional 30 minutes.

"The NNP may submit transport codes 99466 and 99467 in the scenario above. The patient meets the definition of critical care based on the infant's diagnosis of respiratory failure and RDS. The NNP is a member of the neonatology group, is privileged to provide medical transport services, and is allowed to bill independently in her state."

The NNP may submit transport codes 99466 and 99467 in the scenario above. The patient meets the definition of critical care based on the infant's diagnosis of respiratory failure and RDS. The NNP is a member of the neonatology group, is privileged to provide medical transport services, and is allowed to bill independently in her state. The total time she spent providing face-to-face critical care during the transport was 100 minutes. She can submit code 99466 for the first 30-74 minutes and code 99467 for the additional 26 minutes of critical care. Time spent performing unbundled procedures is not included in the critical care transport time; therefore, she cannot include the

20 minutes of time she spent assisting the respiratory therapist with surfactant administration and placing an umbilical line. However, she can report the CPT codes for both procedures, including 36510 for umbilical vein catheterization and 94610 for surfactant administration.

"The neonatologist in the scenario above does not report a code for transport services. Although the neonatologist spent 30 minutes serving as medical control, she cannot report the transport supervision codes (99485/85) because the NNP from her practice is reporting codes 99466/67 for the face-to-face transport services."

The neonatologist in the scenario above does not report a code for transport services. Although the neonatologist spent 30 minutes serving as medical control, she cannot report the transport supervision codes (99485/85) because the NNP from her practice is reporting codes 99466/67 for the face-to-face transport services. If a house officer or nurse transporter replaces the NNP as the medical provider on the transport, the neonatologist can report 99486 for the 30 minutes she spent supervising the transport.

In contrast to the transport services, the neonatologist should report the neonatal initial day critical care code (99468) for admitting the transported patient to her facility. Modifier 25 is added to face-to-face transport code 99466 submitted by the NNP to indicate that transport and admission are two separate identifiable E/M services performed on the same day by the same group practice. Since the neonatologist is the accepting physician of interfacility transport, she utilizes the global critical care codes to report the admission. The referring pediatrician in the above scenario uses the time-based critical care codes (99291,99292) to report the critical care he provided to the patient before handing over responsibilities to the transport team. The pediatrician should also report the CPT codes 99465 for delivery room resuscitation and 31500 for endotracheal intubation.

"Often, neonatologists advise referring physicians by phone to assist with patient stabilization prior to transport. The transport code 99288 is used for the professional direction of emergency medical care or advanced life support by a physician or other qualified healthcare professional via two-way communication."

Often, neonatologists advise referring physicians by phone to assist with patient stabilization prior to transport. The transport code 99288 is used for the professional direction of emergency medical care or advanced life support by a physician or other qualified healthcare professional via two-way communication. There are no time requirements for this code; therefore, it can be used if the time criteria are not met (<16 minutes) when providing supervisory transport services (99485). The code 99288 does not have an assigned RVU value. Medicare does not recognize this code as a separate service and does not provide payment for it. Reimbursement by other payers, including state Medicaid programs, varies.

Unlike my experience with vacation travel this summer, coding for "neonatal travel" is not complicated. Three questions can assist medical providers with choosing the appropriate code:

1. Does the patient's condition meet the definition of critical care?
2. Is the person providing face-to-face medical care during the transport a "qualified medical professional"?
3. What is the total time spent providing services?
4. Be safe and happy traveling this summer!

References:

1. COCN American Academy of Pediatrics. *Coding for Pediatrics 2022*. American Academy of Pediatrics. 2022.

Disclosures: *No conflicts of interest indicated.*

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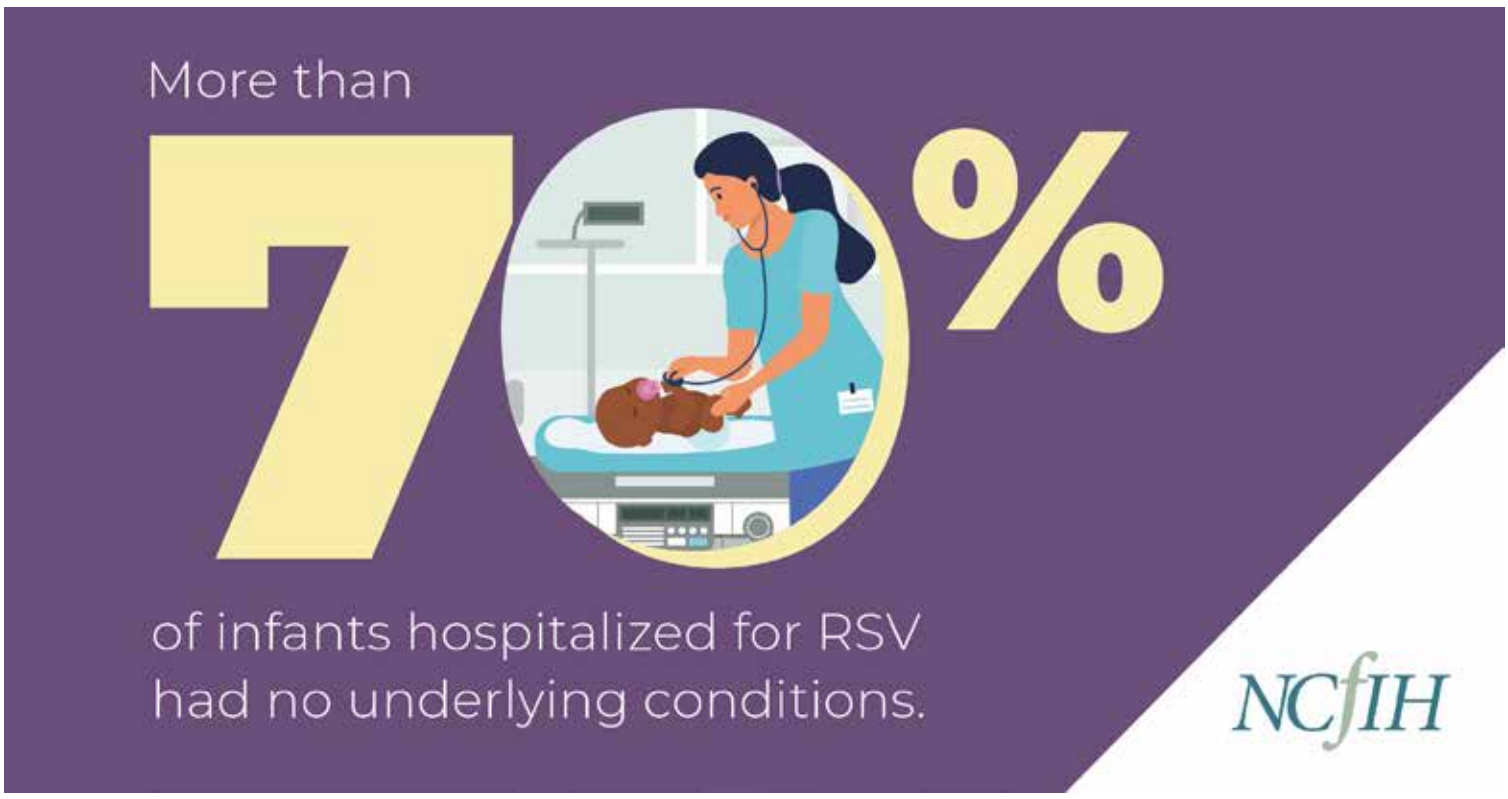
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2024

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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.

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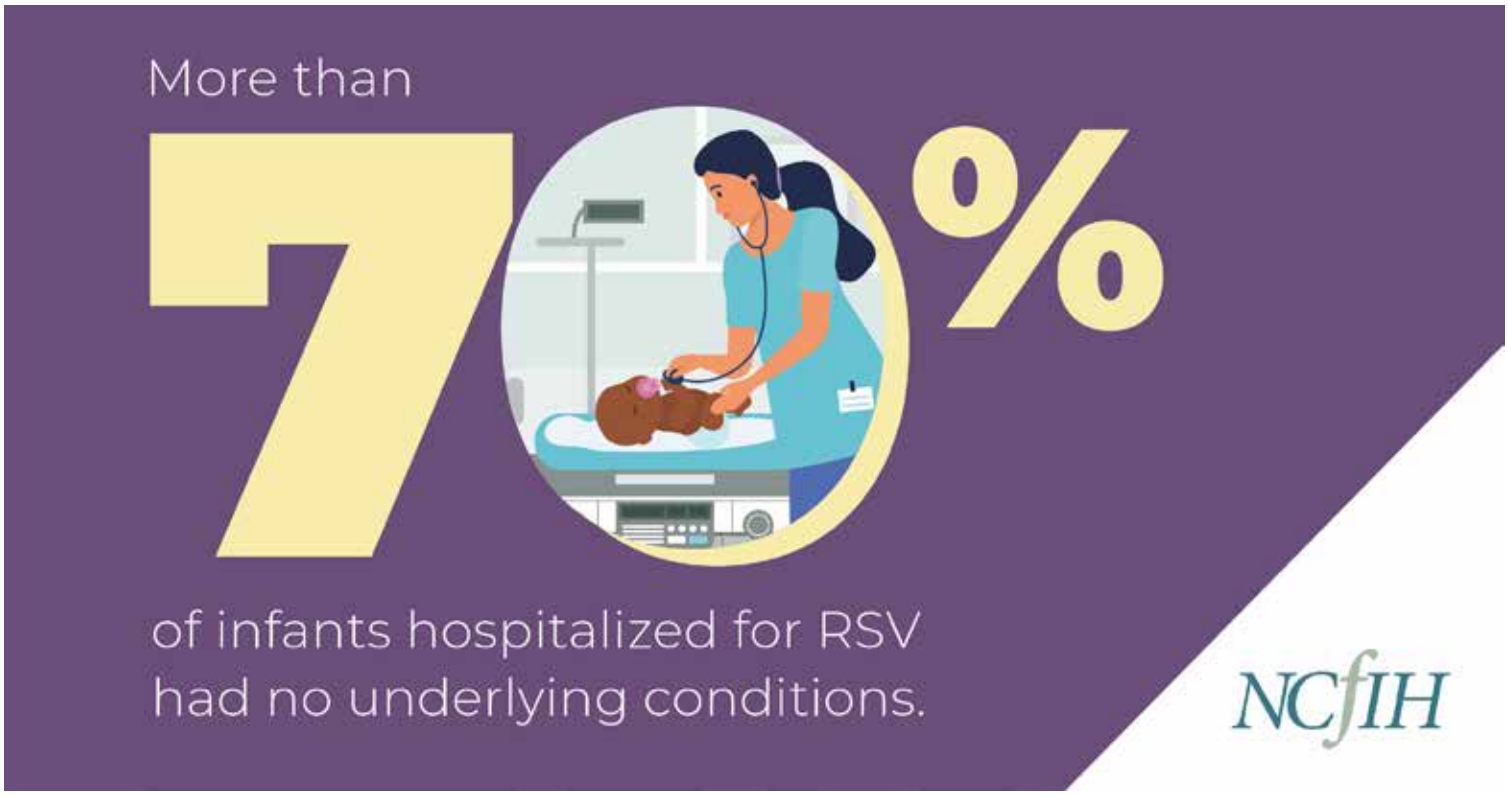
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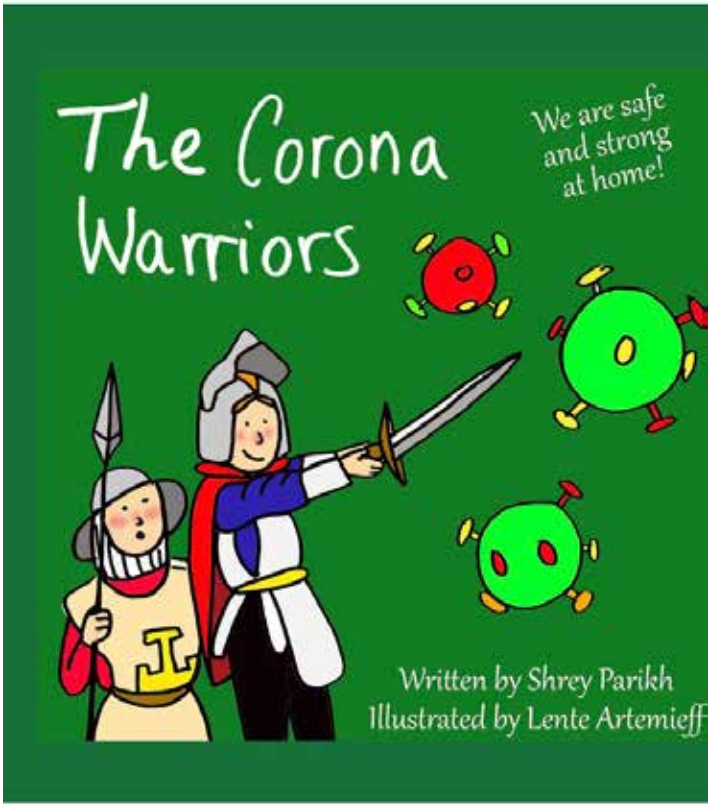
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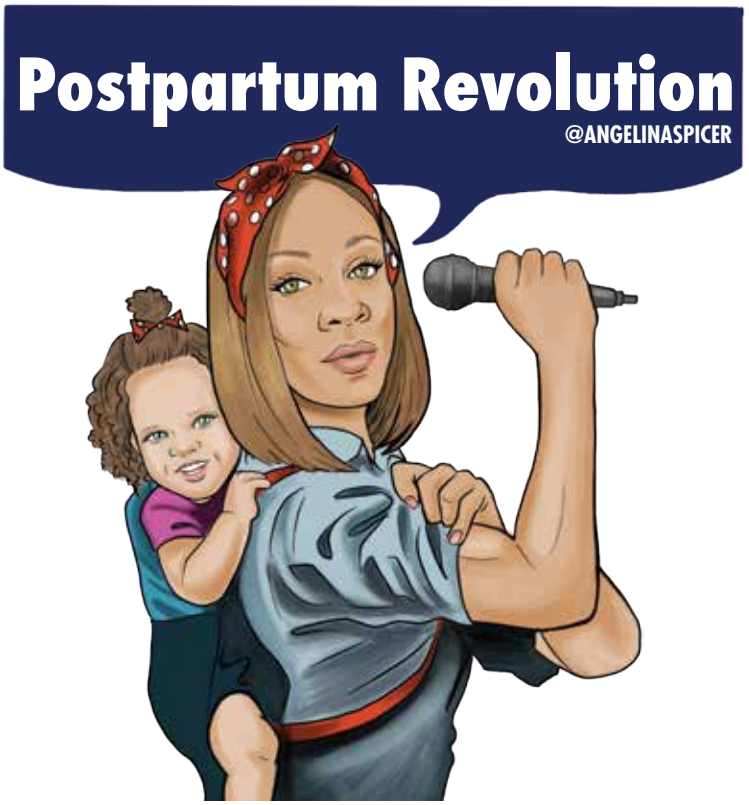


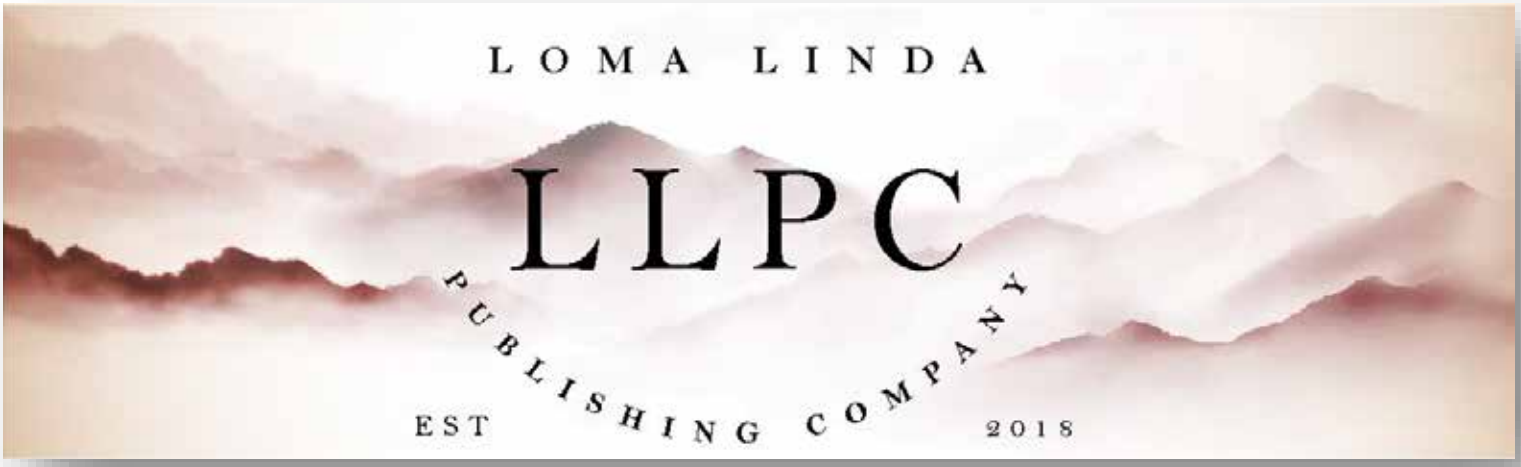
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Genetics Corner: X-linked ZC4H2-Associated Rare Disorder in a Female with Arthrogryposis Multiplex Congenita

Jennifer Shin, MS, Hayley Bottino, MS, Laura Wilson, MD

Case Summary:

A 1-day-old female born at term with arthrogryposis multiplex congenita was evaluated by the Pediatric Genetics service after whole exome sequencing on amniocentesis identified a *de novo* pathogenic *ZC4H2* variant associated with *ZC4H2*-related neurodevelopmental disorder with multiple congenital anomalies.

"A 1-day-old female born at term with arthrogryposis multiplex congenita was evaluated by the Pediatric Genetics service after whole exome sequencing on amniocentesis identified a de novo pathogenic ZC4H2 variant associated with ZC4H2-related neurodevelopmental disorder with multiple congenital anomalies."

The patient was born to a 32-year-old G_5P_{4014} mother at 39 weeks and 2 days. Pregnancy was complicated by fetal findings of arthrogryposis, including bilateral club feet and hyper-flexed hands, a suspected ventricular septal defect, and maternal obesity. The mother has two healthy daughters from a previous partnership. Before the patient, the mother's and father's pregnancy history includes a spontaneous abortion at 8 weeks gestation and an uncomplicated term delivery of a healthy son, who is currently 15 months of age. Family history was not significant for congenital anomalies, neurodevelopmental delay, hearing loss, vision loss, sudden infant death, or recurrent miscarriages.

An amniocentesis was performed at 20 weeks gestation. Amniotic fluid alpha-fetoprotein was within normal limits. Both karyotype and microarray reported normal female. Spinal muscular atrophy, fetal analysis reported negative. Whole exome sequencing revealed an X-linked *de novo* pathogenic nonsense variant in the *ZC4H2* gene (c.487C>T; p.Q163*) consistent with a *ZC4H2*-related neurodevelopmental disorder with multiple congenital anomalies.

Upon birth, a physical exam revealed retrognathia with a protruding upper lip and bilateral distal contractures of the upper and lower extremities with limited movement of the elbows, wrists, hips, knees, ankles, and digits. Fingers were flexed with overlapping 2nd and 3rd fingers, unable to extend passively. Her thumbs were partially flexed. Her right foot was internally deviated with medially deviated toes. Her left lower extremity was externally rotated, and the ankle was dorsiflexed with overlapping toes.

An echocardiogram revealed a moderate ostium atrial septal defect. An MRI of the L-spine identified a low-lying conus terminating at L4–L5, which was concerning for tethered cord. There was no evidence of spina bifida. The head ultrasound and electroencephalogram were unremarkable.

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The patient was initially placed on continuous positive airway pressure due to concerns about meconium aspiration. The evaluation revealed inspiratory stridor and mild laryngomalacia. The patient underwent supraglottoplasty nine days after birth and was subsequently weaned to room air eight days later. A

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swallow study showed the patient was at risk for aspiration due to dysphagia and ultimately required gastrostomy tube placement.

Discussion:

With an incidence of 1 in 12,000 births, arthrogryposis multiplex congenita (AMC) is defined as multiple joint contractures involving at least two different areas of the body (1). The most common cause of AMC is secondary to a lack of fetal movement in-utero. Fetal movement coordinates the cartilage and bone development needed to form a functioning joint. Fetal akinesia and the resulting joint contractures may be secondary disorders of the central or peripheral nervous system, the neuromuscular junction, myopathies, or restricted space, such as with multiple births.

"With an incidence of 1 in 12,000 births, arthrogryposis multiplex congenita (AMC) is defined as multiple joint contractures involving at least two different areas of the body. The most common cause of AMC is secondary to a lack of fetal movement in-utero. Fetal movement coordinates the cartilage and bone development needed to form a functioning joint. Fetal akinesia and the resulting joint contractures may be secondary disorders of the central or peripheral nervous system, the neuromuscular junction, myopathies, or restricted space, such as with multiple births."

Located on the long arm of chromosome X (Xq11.2), the *ZC4H2* gene is *a* zinc-finger protein belonging to the family of proteins with a C-terminal zinc-finger domain characterized by four cysteine and two histidine residues. The *ZC4H2* proteins are essential in neural stem cell development, proliferation and differentiation, ventral spinal patterning, and central noradrenergic development (OMIM# 300897) (2, 3). Decreased *ZC4H2* expression is associated with reduced growth and survival of neural crest cells caused by oxidative phosphorylation disruption (4).

Pathogenic variants in the *ZC4H2* gene are associated with a spectrum of allelic syndromes known as *ZC4H2*-Associated Rare Disorders (ZARD). In the 1990s, these conditions were previously referred to as Miles-Carpenter syndrome and Wieacker-Wolff syndrome (WRWF), an X-linked neurodevelopmental disorder characterized by the in-utero onset of fetal akinesia and AMC.

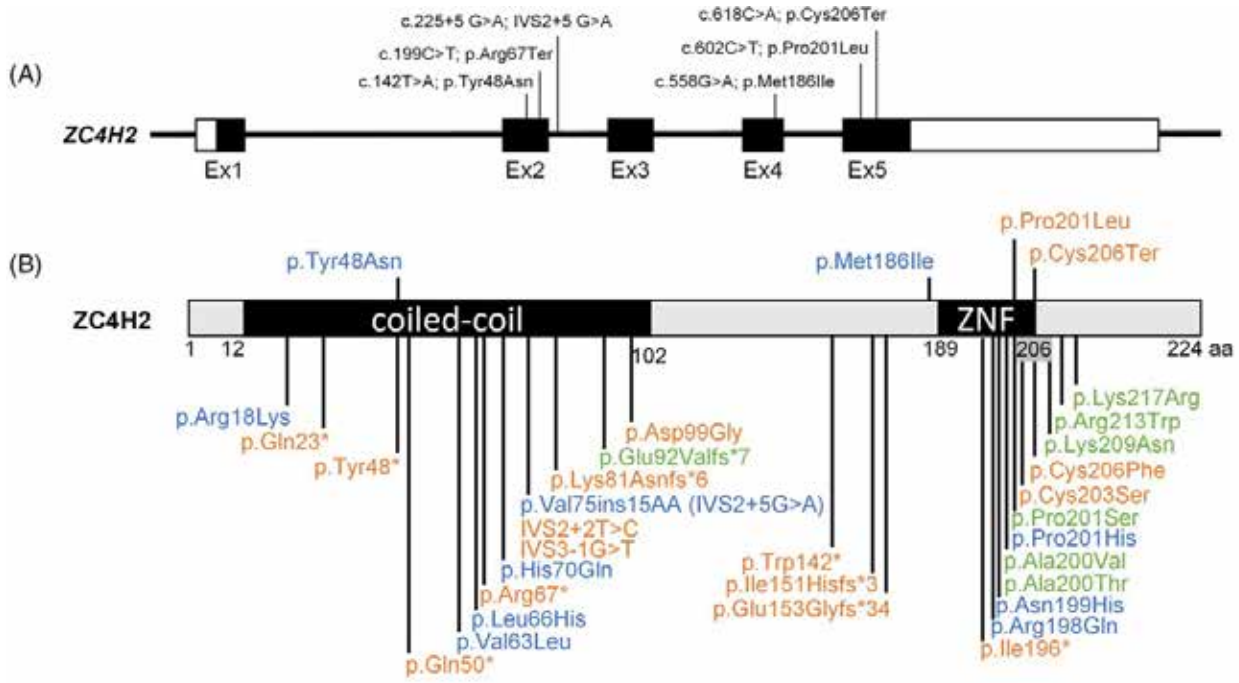
The central and peripheral nervous system involvement is characteristic of *ZC4H2*-associated disorders. In addition to AMC, symptoms may include distal muscle weakness, craniofacial features, ptosis, and poor feeding with an increased risk of aspiration. Varying degrees of central involvement may be characterized by microcephaly, apnea, oculomotor apraxia, spasticity, and seizures. Intellectual disability is commonly reported in childhood (5).

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After the first week of life, our patient continued to require noninvasive airway support with CPAP. ENT was involved in surgical intervention to improve upper airway obstruction, but the risk of neuromuscular disease, including central apnea, remained a prominent concern and prompted consideration of tracheostomy. The molecular diagnosis proved helpful in the decision to hold off on tracheostomy placement. We ultimately relied on several case reports and case series suggesting the condition has an overall static or slow progressive neurologic course.

"The ZC4H2-gene is found on the X-chromosome. Like males in other X-linked conditions, males and females typically present with different phenotypes. In ZC4H2-associated disorders, males are more severely affected than females and usually present with characteristic facial features, poor growth, profound neurodevelopmental delays, hypotonia, microcephaly, tethered cord, and skeletal anomalies. Compared to males, females are less severely affected or asymptomatic carriers. They present more variable features, which may be explained by skewed X-inactivation."

Figure 1: This diagram by Wongkittichote et al. (2022) is (A) a schematic representation of the *ZC4H2* gene and reported pathogenic variants in (A) their study and (B) other reported *ZC4H2* variants in symptomatic individuals. Blue variants were reported in males, orange variants in females, and green variants in males and females (3). Our patient's variant is p.Q163*, in exon 4, shown in red.



The *ZC4H2*-gene is found on the X-chromosome. Like males in other X-linked conditions, males and females typically present with different phenotypes. In *ZC4H2*-associated disorders, males are more severely affected than females and usually present with characteristic facial features, poor growth, profound neurodevelopmental delays, hypotonia, microcephaly, tethered cord, and skeletal anomalies. Compared to males, females are less severely affected or asymptomatic carriers. They present more variable features, which may be explained by skewed X-inactivation. However, normal X-inactivation patterns have been observed in severely affected females (3).

Affected males generally present with *de novo* or maternally inherited missense variants. Most pathogenic variants identified in males do not lead to a truncated or completely absent *ZC4H2* protein. Inherited variants were generally passed down from an asymptomatic or only mildly affected mother. Affected females usually present with *de novo* splicing, frameshift, nonsense, or partial deletion variants predicted to be loss-of-function alleles. This suggests that *ZC4H2* deficiency is the pathological mechanism leading to an X-linked dominant phenotype (6).

Figure 1 above shows pathogenic variants identified in both affected females and males (3). Our patient's variant is a nonsense variant (c. 487C>T; p.Q163*) in exon 4.

Practical Applications

1. Arthrogryposis multiplex congenita occurs secondary to fetal akinesia/hypokinesia and may be linked to genetic or environmental causes. Early involvement of a neurologist and a geneticist can help with timely diagnosis and treatment planning.
2. An early molecular diagnosis can help guide treatment planning. Our patient avoided excessive early intervention with a tracheostomy due to the molecular diagnosis and multiple case reports suggesting a relatively static neurologic course.
3. An X-linked disorder does *not* mean that only males are affected. More commonly, disorders with X-linked inheritance show different phenotypes in males versus females. Females that inherit an X-linked disorder from a parent may show variable expressivity due to skewed X-inactivation.

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Disclosure: *The authors have no conflicts of interests to disclose.*

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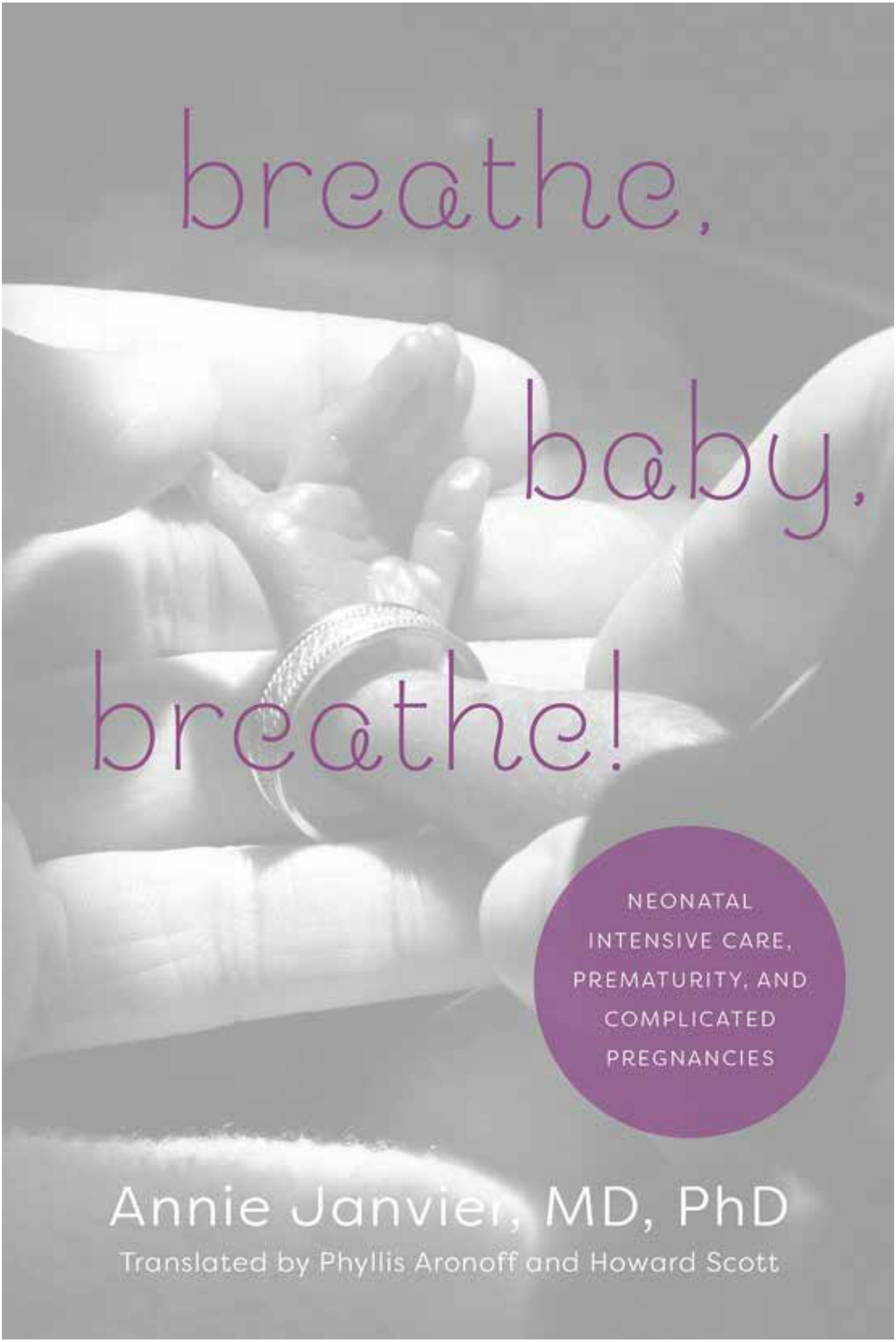


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Formula Use in the NICU and Risk for Necrotizing Enterocolitis: The Need for Informed Consent

Mitchell Goldstein, M.D, MBA, T. Allen Merritt, M.D, MHA

"The recent court decision of Gill v. Abbott, 2322-CC01251, Missouri 22nd Judicial Circuit (St. Louis), Missouri, in July 2024 found Abbott Laboratories, the maker of premature infant formulas and fortifiers advertised for use in premature infants, found Abbott Laboratories liable for both punitive damages and economic damages totaling $495 million."

The recent court decision of Gill v. Abbott, 2322-CC01251, Missouri 22nd Judicial Circuit (St. Louis), Missouri, in July 2024 found Abbott Laboratories, the maker of premature infant formulas and fortifiers advertised for use in premature infants, found Abbott Laboratories liable for both punitive damages and economic damages totaling $495 million. This judgment was awarded to a mother whose infant developed necrotizing enterocolitis (NEC) and who unfortunately died (1). Earlier, on March 15, 2024, in the case of Jasmine Watson v Mead-Johnson, an Illinois jury awarded $60 million to a mother whose infant died from NEC after using an Enfamil premature formula (2). Executives from Abbott defended their product as safe and effective and stated that they are considering pulling their premature infant formulas from the market (3). Both court decisions have been appealed.The FDA considers infant formulas for premature babies "exempt infant formulas." These formulas are designed to support the growth and development of premature babies, who may have missed part or all of the third trimester of pregnancy when bone formation usually occurs.Preterm formulas contain more calories, protein, vitamins, and minerals per ounce than formulas for full-term babies and also have higher levels of calcium and phosphorous to support bone growth (4). Unlike pharmaceuticals, nutritional products are not FDA approved; however, there is regulatory oversight of their manufacturing and labeling; however, prior to any company or person manufacturing and marketing a new exempt infant formula or any infant formula, specific practices, procedures, and processes must be followed (Section 412 of the Federal Food, Drug, and Cosmetic Act). For exempt infant formulas, some specific terms and conditions must also be met (21 CFR 107.50). The following list provides all of the products classified as exempt infant formulas that the FDA believes are currently available (to date) on the U.S. retail market (4).

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While neonatologists are unlikely to be the primary litigation targets, hospitals and their purchasing agents will probably face substantial liability. Hospital purchasers and administrators should have known that cow's milk formulas for premature infants have been associated with a nearly 3-fold increased risk of developing NEC (5-7). Their failure to adequately address the known association between cow's milk formula and necrotizing enterocolitis (NEC) may have been based on economics, as using donor breast milk when needed and using a human milk-based fortifier have significantly higher costs. Further, some hospitals and their staff fail to notify parents of this increased risk of cow's milk-based formula compared to the use of mother's milk or donor human breast milk, among others, as preventative strategies to reduce the occurrence of NEC (8).

The scientific evidence is mounting that compared to human milk use in premature infants use of cow's milk-derived premature formulas was reported in *Pediatrics* (the official journal of the American Academy of Pediatrics) that an extensive meta-analysis of multiple studies comparing human milk-fed premature infants to those receiving human milk had a 2.99 odds ratio (95% confidence intervals 1.75-5.11) of an increased occurrence of NEC, but not overall mortality, cognitive-neurodevelopmental or growth (7). Moak and coworkers explored the links between NEC and cow's milk protein allergy in preterm infants and reported that in many cases of NEC, cow's milk protein intolerance may be the underly-

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ing diagnosis associated with NEC (9). Quigley and coworkers (2019) reviewed formula versus pasteurized donor breast milk for preterm or low birth weight infants and found that use of formula increased the occurrence of NEC (OR 1.87 95% CI 1.23-2.85) (10).

"The inference of casualty, rather than association in public health, focuses on Bradford-Hill's criteria that support causal association from epidemiological data. These factors include plausibility, consistency, Temporality, Strength, Specificity, and Change in risk factors."

The inference of casualty, rather than association in public health, focuses on Bradford-Hill's criteria that support causal association from epidemiological data. These factors include plausibility, consistency, Temporality, Strength, Specificity, and Change in risk factors. Multiple studies cited in the mentioned meta-analysis, among others, add credence that cow's milk protein substantially contributes to the risk of NEC (11,12). Allana and coworkers established that using donor breast milk when the mother's milk was low or unavailable, was associated with earlier initiation of enteral feeding, faster return to birth weight, and a reduced incidence of NEC (13). However, not all studies, including the observational study using feeding and fortifier epochs with changes in feeding substrate, did not find a reduction of NEC when using donor human milk or a human milk-derived fortifier and lower early weight gain (14,15). A recent multicenter, randomized controlled trial from Sweden comparing human milk-derived fortifiers to bovine fortifiers to infants 22 to 27 +6 weeks gestation receiving exclusively mother's or donor human milk failed to demonstrate a significant reduction of NEC stage II, III, culture-proven sepsis and mortality from inclusion to discharge (15). We agree with Barrington (2020) that "the only justification for giving a preterm baby at risk for NEC artificial formula, rather than donor human milk, if it is available, is parental refusal. And even then, if a parent refused for a baby at very high risk, I (Dr. Barrington) think it is questionable whether such a refusal should be accepted" (17). Furthermore, the economic and clinical impact of using a human milk-derived fortifier in very low birth weight infants at the University of Southern California/s NCU led to a 6.8-day reduction in NICU stay and a cost savings of $31,815 per infant without short-term morbidity. The estimated financial impact over two years, excluding insurance reimbursement, was $16,032 per infant, combining the cost avoidance from adverse clinical outcomes (18).

In the context of nutritional products that are not prescribed by physicians but are instead chosen based on hospital preference, the responsibility falls heavily on hospital administration, purchasing agents, nutrition services, and nursing leadership in their choice of formulas and fortifiers or securing donor breast milk from donor breast milk banks to feed premature infants when maternal milk is not available. These entities will be held accountable, particularly if the use of such formulas is enshrined in the hospital's policies or procedures. This administrative oversight is critical, as it directly influences the care provided to vulnerable infants in the NICU. The physician's major role is to inform parents of the additional risk of NEC if the mother does not provide human milk or donor breast milk is not approved (informed denial) for use in their infant. In the 2016 Policy Statement of the American Academy of Pediatrics, the Committee on Bioethics stresses that informed consent incorporates three duties: disclosure of information to patients or their surrogates for medical decision-making and obtaining informed consent before treatments and interventions (19).

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The implications for legal action are profound. Lawyers are expected to vigorously represent parents whose infants either developed NEC or were administered these formulas without their knowledge of added risk, thereby increasing their infant's risk of morbidity without the provision of informed consent or informed declination. The legal strategy will likely focus on the hospitals' negligence in failing to inform parents of the potential risks associated with cow's milk formula and not seeking alternative nutritional options, as well as the company's manufacturing specialized formulas for premature infants who continue to market them as "safe and effective."

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The jury's award of substantial non-punitive damages reflects the extensive costs associated with the fallout from these cases. These costs include the additional hospital and physician/surgeon billing expenses related to extended NICU stays, the profound emotional distress experienced by parents, and the long-term gastrointestinal issues that affected infants may face. The financial impact on Abbott, Mead Johnson, and other manufacturers could be monumental, with potential costs running into billions of

dollars. These cases underscore the critical importance of hospital policies and procedures in administering nutritional products in the NICU. Hospitals must prioritize informed consent and risk assessment when selecting formulas for their most vulnerable patients. Failure to do so not only potentially endangers the health and well-being of infants but also exposes the hospital to significant legal and financial repercussions and manufacturers to product liability litigation.

"Hospitals must prioritize informed consent and risk assessment when selecting formulas for their most vulnerable patients. Failure to do so not only potentially endangers the health and well-being of infants but also exposes the hospital to significant legal and financial repercussions and manufacturers to product liability litigation."

Moreover, these cases highlight the broader implications for hospital networks and their approach to cost-saving measures, such as accepting a "free" formula for use and for parents at discharge. While such practices may appear financially advantageous in the short term, the long-term risks and potential liabilities can far outweigh any initial savings. Hospitals must carefully weigh these considerations and prioritize patient safety and informed consent in their decision-making processes.

In conclusion, the Abbott and Mead-Johnson cases serve as a reminder of the critical importance of informed consent, diligent risk assessment, and the careful selection of nutritional products in the NICU. Hospitals and their administrative and nursing leadership must take proactive steps to mitigate risks and ensure the safety and well-being of their patients. As reported by Lopez and coworkers at Johns Hopkins University, "Strong data suggests the utility of preventative strategies (for NEC) that include administration of human-milk based diet, standardized feeding strategies, while clinical evidence also supports the use of antenatal steroids and probiotics in certain circumstances" (20). It is reasonable to assume that the criteria of Daubert (21) have been met. Under the Daubert Standard, trial courts consider the following factors in determining whether an expert witness methodology is valid: whether the technique or theory in question can be and has been tested; whether it has been subjected to publication and peer review; its known or potential error rate; the existence and maintenance of standards controlling its operation; and whether it has attracted widespread acceptance within a relevant scientific community.

The NEC Society (22) stated Watson v Mead Johnson, stating, "With or without MOM (mother's own milk) or PDHM (pasteurized donor human milk), premature and medically fragile infants must receive adequate nutrition to support their complex and exceptional nutritional needs. The ICU is inherently risky for infants, and NEC is one of many devastating health risks. In the ICU, feeding decisions are medical decisions. Medical decisions must be made by those who practice medicine in partnership with patient families. In collaboration with patient families, the medical team should decide how babies are fed in the ICU. These medical feeding decisions aim to protect against NEC while providing optimal nutrition for discharge and long-term health outcomes." Unfortunately, some healthcare institutions have chosen to restrict or make unavailable human milk-derived premature infant fortifiers. Thus, these "medical decisions" have been replaced by "institutional or administrative decisions" that may not be consistent with the current evidence regarding the added risk associated with artificial milk formulations in premature infants.

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Based on the evidence presented and the conclusion that the Daubert standard has been met in terms of the relationship with the use of cow's milk-based premature formulas as one of the causes of NEC, and further that experts testifying regarding cow's milk formula used in premature infants for feeding without informed consent contribute to NEC, many juries will continue to support parents in their product liability decisions.

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Disclosure: *The authors have no conflicts of interests to disclose.*

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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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Family-Centered Care (FCC) Taskforce NICU FCC Measures Survey

Morgan Kowalski

The FCC Taskforce intends to create a universally accepted, standardized way to measure FCC in the NICU, gather information to inform each NICU about its current status in delivering FCC practices and identify potential opportunities for quality improvement collaboration between NICU sites.

The FCC Taskforce is the first international, multicenter, collaborative initiative dedicated to quality improvement in NICU Family-Centered Care. Our organization's key strength is the equal partnership between multidisciplinary healthcare providers and family partners who are diverse in their lived experiences and backgrounds. Our membership comprises over 1,300 individuals across 48/50 U.S. States, Puerto Rico, and 43 countries worldwide who benefit from and contribute to our free educational webinars and resources.

Why We Created This Survey:

Optimal care for a premature or sick newborn in the NICU requires family presence, trust, and respect between a family and their clinicians, whereby the parents/primary caregivers are integrated as members of the care team. While decades of research have shown that Family-Centered Care(FCC) supports the best possible outcomes for these infants, FCC practices vary significantly across NICUs.

No universally accepted, standardized way to measure FCC in the NICU exists. Additionally, there is a lack of consensus on priority areas when measuring or comparing FCC practices across NICUs. Even when FCC priorities are identified, families are rarely included in determining what is most meaningful to them and their infants. Ensuring NICU families are given a voice to share what matters most to them is foundational in determining how clinicians measure FCC.

How We Created This Survey:

The FCC Taskforce Executive Council of Family Partners created this comprehensive REDCap survey. It is diverse in their lived experience, race, ethnicity, gender, and background, alongside multidisciplinary clinicians and researchers, with careful consideration of FCC best practices.

Why Your NICU Should Participate:

1. Each NICU site will receive a summary of its unit findings immediately after the survey and a de-identified summary across all NICU sites after this project is completed in early 2025.
2. Each NICU site will have the opportunity to collaborate and work with NICUs that perform at the highest level of FCC, using scoring to implement NICU site-specific quality improvement processes.
3. In the next phase of this project, each NICU site will have the opportunity to collaborate with the FCC Taskforce on topic-specific quality improvement projects.

Survey Makeup:

1. NICU Framework/Infrastructure (9 Questions)
2. Family Support (19 Questions)
3. Family Integration into Care (16 Questions)
4. Family Integration into QI and Processes (1 Question)
5. NICU Environment (7 Questions)
6. Staff Education (2 Questions)
7. Balancing Measures (4 Questions)

How we will distribute the survey:

We will share the survey link with unit leaders to avoid duplicate responses. Your center clinical leader/QI leader/FCC Champion will receive the PDF copy of the entire survey and online survey link. We ask you to collaborate with your team and complete the PDF. Once you gather the information, transcribe the results to an online link. You can save the online survey in the middle and come back later. We would be happy to schedule a meeting with your team by Zoom or phone to help complete the survey on your behalf. After completion, you can meet with the FCC TaskForce core team to review your unit's performance and scores in each category.

If you are interested in participating in this survey, please submit your information using the QR Code below. Thank you for your time and your commitment to FCC in the NICU!

Disclosure: *This work is supported by an educational grant from Chiesi Inc. USA and a Seed 1 Partnership Award from Stanford Impact Labs. Thank you to Reckitt/Mead Johnson for supporting our work.*

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Vaccines and Preventive Monoclonal Antibodies

WHAT'S THE DIFFERENCE?

The Importance of Immunization

Vaccines and preventive monoclonal antibodies are two different types of immunization. While they function differently, they both serve the same purpose: protecting people from serious illnesses and diseases.

Different Technology, Same Protective Value

	VACCINES	PREVENTIVE MONOCLONAL ANTIBODIES
	Teach the body to create antibodies that fight off a specific disease.	Introduce antibodies that are ready to ward off disease in the body.
How does it work?	By introducing an inactive piece of a disease or proteins that look like the disease, they trigger an immune response, training the body to create antibodies that defeat the disease.	Instead of teaching the body to create antibodies and defenses, they provide antibodies that are readily available.
	Both support the immune system's defenses.	
What are the benefits?	Many vaccines are readily and easily available. The technology behind vaccines has been around for decades.	Preventive monoclonal antibodies can provide protection for diseases where there isn't an existing vaccine or there isn't an existing vaccine for certain patient groups.
	Both protect against disease and provide a public health benefit by decreasing the burden of disease.	
What can this immunization protect against?	Polio Measles COVID-19 And more	RSV COVID-19
	Both can provide tailored protection from a variety of diseases.	
Is it safe?	Yes	Yes
	Both vaccines and preventive monoclonal antibodies undergo extensive testing for safety and efficacy.	

https://www.who.int/news-room/feature-stories/detail/how-do-vaccines-work#:~:text=Vaccines%20contain%20weakened%20or%20inactive,rather%20than%20the%20antigen%20itself.

https://static1.squarespace.com/static/5523fcf7e4b0fef011e668e6/t/62445afd0134140ff954f3f6/1648646910485/NCIH_Monoclonal+Antibodies+Inclusion+in+the+VFC+Program_Position+Paper_Mar+2022.pdf

The Signs & Symptoms of RSV

RESPIRATORY SYNCYTIAL VIRUS

Know the Signs & Symptoms of RSV

- Cough
- Runny Nose
- Struggling to Breathe *(breastbone sinks inward when breathing)*
- Difficulty Eating
- Lethargy
- Wheezing

RESPIRATORY SYNCYTIAL VIRUS
is a highly contagious seasonal virus that can lead to hospitalization for some babies and young children.

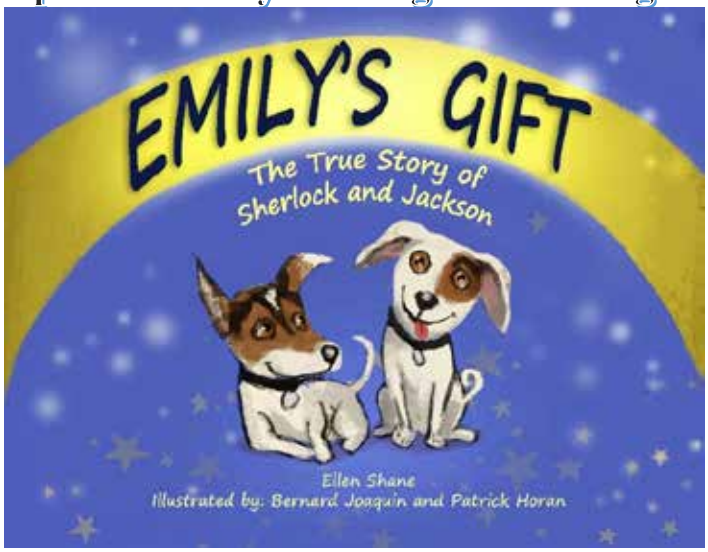
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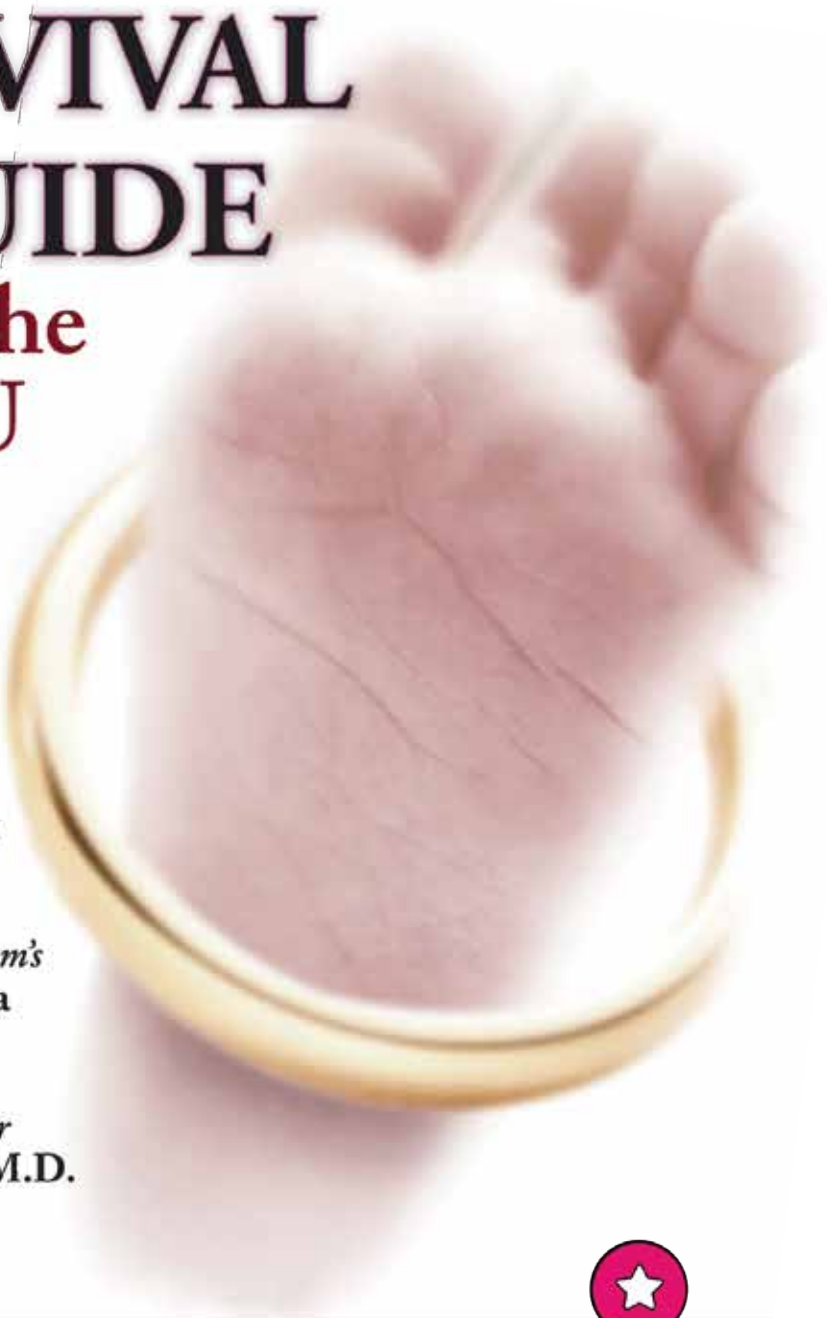




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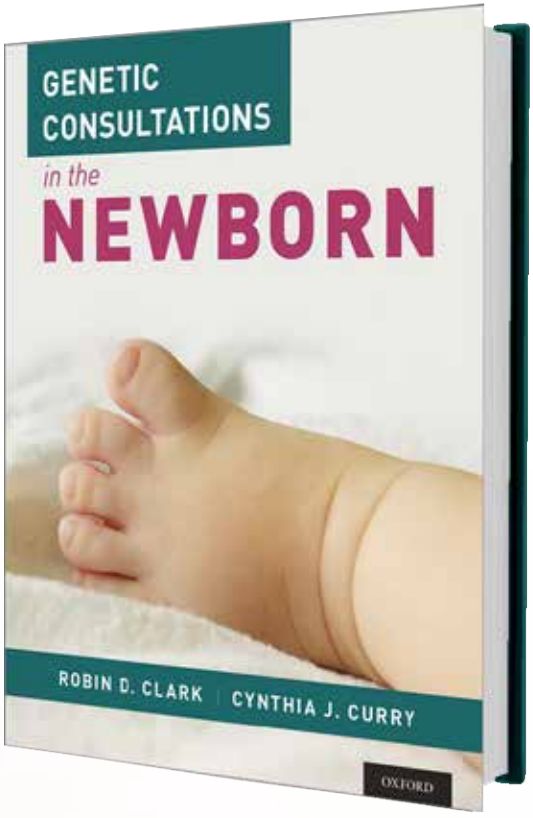
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Clinical Pearl: Necrotizing Enterocolitis and Fortified Formula for Premature Infants: Successful Suits Against Mead Johnson and Abbott Laboratories

Joseph R. Hageman, MD, Lolita Alkureishi, MD, Wally Hussain, MD, Kshama Shah, MD, Gustave Falciglia, MD

"There has been a lot of clinical research into the relative risk for the development of necrotizing enterocolitis (NEC) in premature infants who have been fed the special fortified cow's milk formula (1-7)."

There has been a lot of clinical research into the relative risk for the development of necrotizing enterocolitis (NEC) in premature infants who have been fed the special fortified cow's milk formula (1-7). Many studies have demonstrated a significant increase in the incidence of NEC in premature infants who have received the special fortified cow's milk formula compared with those premature infants who have received their mother's or donor breast milk (2-5). In a review by Hay and Hendrickson, "numerous studies and at least two Cochrane reviews have documented improved growth with preterm formulas (2), but there is a concern for increased risks of NEC, possibly from cow milk antigen in the formulas or from different gut microbiomes, increased duration of TPN, and increased rates of sepsis in infants receiving preterm formulas (7)". In another review by Quigley et al., "formula feeding increased the risk of necrotising enterocolitis (typical risk ratio (RR) 1.87, 95% CI 1.23 to 2.85; risk difference (RD) 0.03, 95% CI 0.01 to 0.05; number needed to treat for an additional harmful outcome (NNTH) 33, 95% CI 20 to 100; 9 studies, 1675 infants)" (2). Finally, Christofalo and colleagues found in their study that "In extremely preterm infants given exclusive diets of preterm formula vs. human milk, there was a significantly greater duration of parenteral nutrition and a higher rate of surgical NEC in infants receiving preterm formula. This trial supports using an exclusive human milk diet to nourish extremely preterm infants in the neonatal intensive care unit (3)".

"According to this article in AAP News, hundreds of other pending cases are also dealing with this issue, and the controversy continues."

The issue we are dealing with now is a medical-legal issue regarding suits that have been filed and judgments that because these premature infants who were fed the special fortified cow's milk formula developed NEC, a jury in Missouri has ruled against Abbott Laboratories and awarded 95 million dollars in compensatory damages and $400 million in punitive damages and another jury in Illinois ruled against Mead Johnson and awarded $60 million in damages (1). According to this article in *AAP News*, hundreds of other pending cases are also dealing with this issue, and the controversy continues. The lawsuits allege that the formula companies "failed to warn of the risk of NEC posed by its product" (1), although both formula makers denied that there was any increased NEC risk related to its product (1).

"The issue we are dealing with now is a medical-legal issue regarding suits that have been filed and judgments that because these premature infants who were fed the special fortified cow's milk formula developed NEC, a jury in Missouri has ruled against Abbott Laboratories and awarded 95 million dollars in compensatory damages and $400 million in punitive damages and another jury in Illinois ruled against Mead Johnson and awarded $60 million in damages (1). "

Dr. Benjamin Hoffman, President of the American Academy of Pediatrics, suggests that courtrooms are not "the best place to determine clinical recommendations for the care of infants. Clinicians and families should make feeding decisions. These need to be individualized in the context of human milk availability, specific patient needs, and individual family preferences (1)".

We need to summarize and review the available data in this area, then present the information to our colleagues and the families of premature infants to make a thoughtful decision regarding their infant's clinical status and nutritional needs.

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Disclosures: The authors have no disclosures

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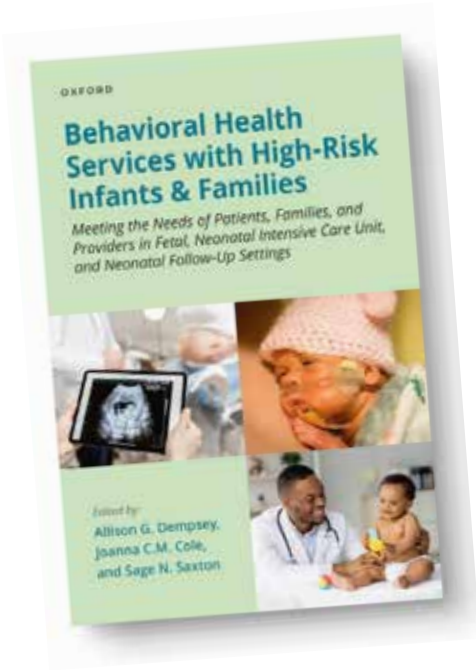
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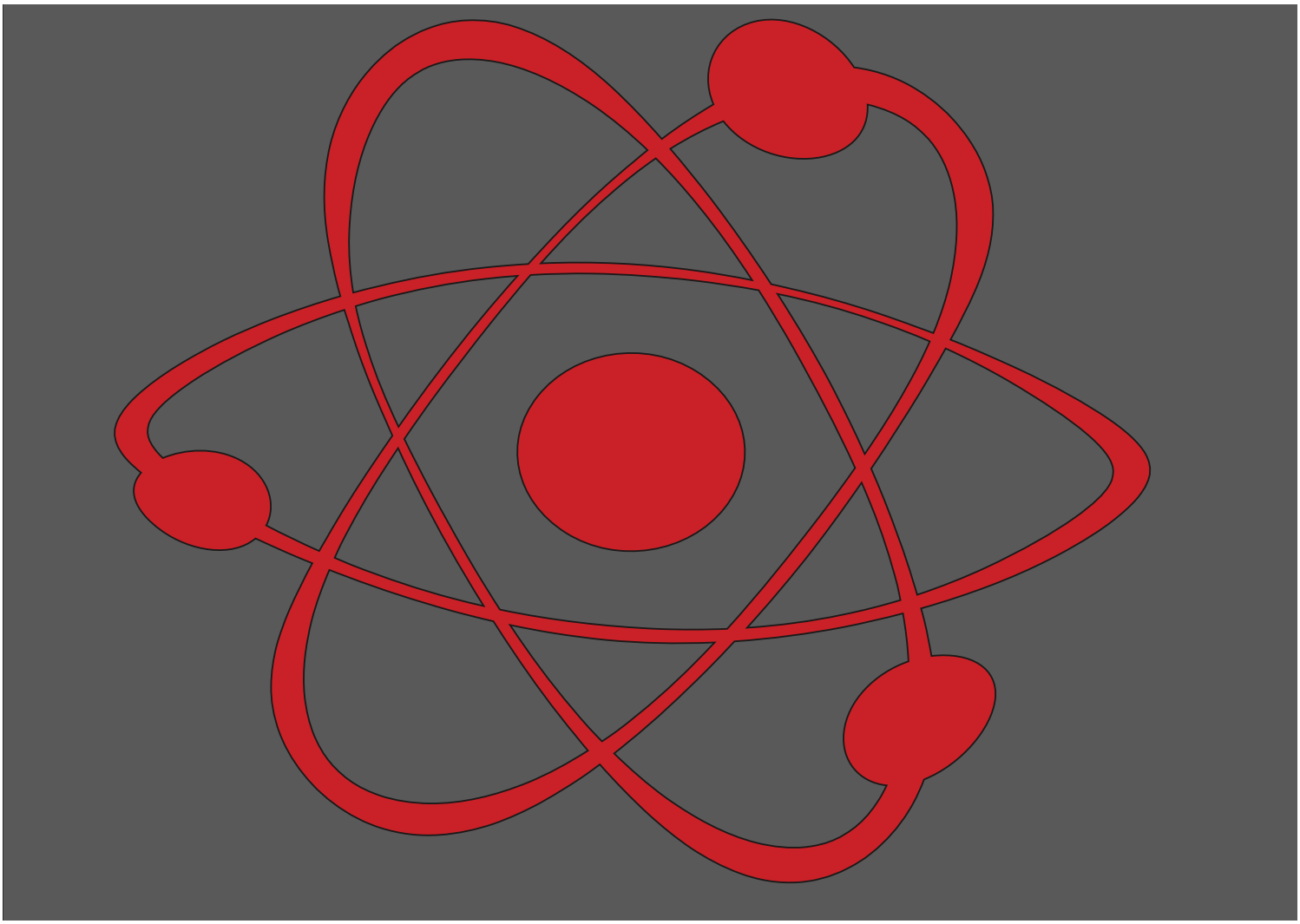
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https://worldneonatology.com/2024/

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Publication
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Our mission is to participate in Jesus Christ's ministry, bringing health, healing, and wholeness to humanity by Creating a supportive faculty practice framework that allows Loma Linda University School of Medicine physicians and surgeons to educate, conduct research, and deliver quality health care with optimum efficiency, deploying a motivated and competent workforce trained in customer service and whole-person care principles and providing safe, seamless and satisfying health care encounters for patients while upholding the highest standards of fiscal integrity and clinical ethics. Our core values are compassion, integrity, humility, excellence, justice, teamwork, and wholeness.

Able to read, write and speak with professional quality; use computer and software programs necessary to the position, e.g., Word, Excel, PowerPoint, Access; operate/troubleshoot basic office equipment required for the position. Able to relate and communicate positively, effectively, and professionally with others; provide leadership; be assertive and consistent in enforcing policies; work calmly and respond courteously when under pressure; lead, supervise, teach, and collaborate; accept direction. Able to communicate effectively in English in person, in writing, and on the telephone; think critically; work independently; perform basic math and statistical functions; manage multiple assignments; compose written material; work well under pressure; problem solve; organize and prioritize workload; recall information with accuracy; pay close attention to detail. Must have documented successful research administration experience focused on managing clinical trials function. Able to distinguish colors as necessary; hear sufficiently for general conversation in person and on the telephone; identify and distinguish various sounds associated with the workplace; see adequately to read computer screens and written documents necessary to the position. Active California Registered Nurse (RN) licensure preferred. Valid Driver's License required at time of hire.

The Clinical Trial Center is actively involved in many multi-center global pediatric trials, which span different Phases of research to advance health care in children. Please reach out to Jaclyn Lopez at 909-558-5830 or JANLopez@llu.edu with further interest. We would love to discuss the exciting research coordinator opportunities at our Clinical Trials Center.

Additional Information

- Organization: Loma Linda University Health Care
- Employee Status: Regular
- Schedule: Full-time
- Shift: Day Job
- Days of Week: Sunday, Monday, Tuesday, Wednesday, Thursday, Friday, Saturday

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Loma Linda University Children's Hospital is hiring Neonatal Nurse Practitioners

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For more information, please contact:

Karin Colunga, MSN, RN, PNP-BC
Director of Advanced Practice Nursing
kecolunga@llu.edu | 909-558-4486

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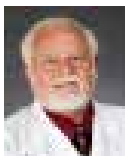
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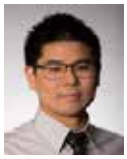
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Neonatology and the Arts

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 feature artistic works created by our readers on the next to last page as well as photographs of birds on rear cover. For this edition, our art was again graciously provided by Colleen Kraft, MD. It is a work called "Family" done by her son Tim. Our Bird is an Eagle from Ramsey Samara, PhD taken at William L. Finley National Wildlife Refuge near Corvallis, Oregon.



Lily Martorell, MD
Arts Editor
Associate Professor
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Manuscript Submission: Instructions to Authors

1. Manuscripts are solicited by members of the Editorial Board or may be submitted by readers or other interested parties. Neonatology Today welcomes the submission of all academic manuscripts including randomized control trials, case reports, guidelines, best practice analysis, QI/QA, conference abstracts, and other important works. All content is subject to peer review.

2. All material should be emailed to: LomaLindaPublishingCompany@gmail.com in a Microsoft Word, Open Office, or XML format for the textual material and separate files (tif, eps, jpg, gif, ai, psd, SVG, or pdf) for each figure. Preferred formats are ai, SVG, psd, or pdf. tif and jpg images with sufficient resolution so as not to have visible pixilation for the intended dimension. In general, if acceptable for publication, submissions will be published within 3 months.

3. There is no charge for submission, publication (regardless of number of graphics and charts), use of color, or length. Published content will be freely available after publication. There is no charge for your manuscript to be published. NT does maintain a copyright of your published manuscript.

4. The title page should contain a brief title and full names of all authors, their professional degrees, their institutional affiliations, and any conflict of interest relevant to the manuscript. The principal author should be identified as the first author. Contact information for the principal author including phone number, fax number, e-mail address, and mailing address should be included.

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. 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.

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.

10. Only manuscripts that have not been published previously will be considered for publication except under special circumstances. Prior publication must be disclosed on submission. Published articles become the property of the Neonatology Today and may not be published, copied or reproduced elsewhere without permission from Neonatology Today.

11. NT recommends reading Recommendations for the Conduct, Reporting, Editing, and Publication of Scholarly Work in Medical Journals from ICMJE prior to submission if there is any question regarding the appropriateness of a manuscript. NT follows Principles of Transparency and Best Practice in Scholarly Publishing(a joint statement by COPE, DOAJ, WAME, and OASPA). Published articles become the property of the Neonatology Today and may not be published, copied or reproduced elsewhere without permission from Neonatology Today.

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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

NICU Baby's Bill of Rights

1- The Right to Advocacy
My parents know me well. They are my voice and my best advocates. They need to be knowledgeable about my progress, medical records, and prognosis, so they celebrate my achievements and support me when things get challenging.

2- The Right to My Parents' Care
In order to meet my unique needs, my parents need to learn about my developmental needs. Be patient with them and teach them well. Make sure hospital policies and protocols, including visiting hours and rounding, are as inclusive as possible.

3- The Right to Bond with My Family
Bonding is crucial for my sleep and neuroprotection. Encourage my parents to practice skin-to-skin contact as soon as and as often as possible and to read, sing, and talk to me each time they visit.

4- The Right to Neuroprotective Care
Protect me from things that startle, stress, or overwhelm me and my brain. 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 am cared for today will help my brain when I grow up. Connect me with my parents for the best opportunities to help my brain develop.

5- The Right to be Nourished
Encourage my parents to feed me at the breast or by bottle, whichever way works for us both. Also, let my parents know that donor milk may be an option for me.

6- The Right to Personhood
Address me by my name when possible, communicate with me before touching me, and if I or one of my siblings pass away while in the NICU, continue referring to us as multiples (twin/triplets/quads, and more). It is important to acknowledge our lives.

7- The Right to Confident and Competent Care Giving
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 educate them about my unique needs, development, diagnoses, and more.

8- The Right to Family-Centered Care
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
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 parents about resources such as peer-to-peer support programs, support groups, and counseling, which can help reduce PMAD, PPD, PTSD, anxiety and depression, and more.

10- The Right to Inclusion and Belonging
Celebrate my family's diversity and mine; including our religion, race, and culture. Ensure that my parents, grandparents, and siblings feel accepted and welcomed in the NICU, and respected and valued in all forms of engagement and communication.

Presented by:

NPN
NICU PARENT NETWORK

NICU Parent Network

Visit nicuparentnetwork.org to identify national, state, and local NICU family support programs.

*** The information provided on the NICU Baby's Bill of Rights does not, and is not intended to, constitute legal or medical advice. Always consult with your NICU care team for all matters concerning the care of your baby.**

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- Inflatables
- Carnival Games
- Art Station
- Face Painting

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- Vendor Tables **Details Here!**
- Community Organization Tables **Details Here!**

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- Art Installation by Acclaimed Malibu Artist Ann Krasner
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