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Moving on Up: Elevate Your NICU and US News and World Report Score With the Addition of a Psychologist

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Abstract

A designated psychologist in the Neonatal Intensive Care Unit (NICU) may seem like an obvious choice, given psychologists' expertise in trauma, attachment, neurodevelopment, mental health, and grief; however, few NICUs have a psychologist on staff. As National Network of NICU Psychologists members, we hope to increase access to psychology services as a routine part of care in NICUs. US News and World Reports (USNWR) ranks NICUs annually on multiple criteria, including having a "designated psychologist or psychiatrist" for consultations with families. We evaluated the psychology services provided by several NICUs of hospitals ranked in the top 50 by USNWR between 2015 and 2019. Many of these respondents had a designated NICU psychologist at varying capacities across the division of Neonatology. This indication should motivate other NICUs to hire a NICU psychologist as the standard of care for families and increase their overall USNWR score.

Key Words: NICU, Psychologist, US News and World Report

"A designated psychologist in the Neonatal Intensive Care Unit (NICU) may seem like an obvious choice, given psychologists' expertise in trauma, attachment, neurodevelopment, mental health, and grief; however, few NICUs have a psychologist on staff. As National Network of NICU Psychologists members, we hope to increase access to psychology services as a routine part of care in NICUs."

Integrating behavioral health into pediatric medical settings is paramount to fully addressing pediatric patients' and families' biopsychosocial needs. Historically, mental health needs have not been adequately addressed by the traditional role definitions of social work positions and their lack of specialty training in pediatric inpatient settings. With psychologists' doctoral-level training, they are well-positioned to provide behavioral health services within medical settings, allowing patients and families easier access to prevention, intervention, and evidence-based treatments for common mental health presentations (1). As medicine moves towards multidisciplinary collaboration and recognizes the inter-

play between the mind and body, there has been an expansion of psychology within various pediatric outpatient settings, including general pediatrics (2, 3), cardiology (4), and gastroenterology (5). Within inpatient settings, pediatric consultation liaison (C/L) psychology teams have seen increasing service demands, reflecting a growing need for medical teams to recognize and address mental health needs during medical admissions (6).

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A similar growing interest in pediatric psychology C/L services has been observed (7). Piazza-Waggoner et al. (2013) reported using a pediatric psychology C/L service within a larger medical center and observed nearly doubled annual services requested over five years. Psychology C/L received consults to address typical pediatric behavioral health concerns such as pain, adjustment, depression/anxiety, and treatment adherence. In addition to receiving consults where the child is the identified patient, psychology C/L services were also a frequent resource for caregiver concerns (e.g., adjustment, anxiety/depression). A majority of referrals came from neonatology, with presenting concerns primarily related to adjustment and depression for caregivers in the Neonatal Intensive Care Unit (NICU).

NICU Psychologists

The role of psychologists in the NICU began in the 1970s as a partnership to monitor developmental outcomes for NICU graduates. As the emphasis on "developmental care" and infant mental health garnered increasing attention in the field of neonatology, so did the role of psychologists as members of interdisciplinary teams to develop care plans incorporating an infant's developmental status, arousal level, medical condition, and continuing outpatient neurodevelopmental follow-up clinic needs (8). On the inpatient side, providers are increasingly acknowledging difficulties with adjustment and depression for caregivers even before NICU discharge.

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Parents of infants admitted to the NICU are at increased risk for developing stress disorders (e.g., adjustment disorders, posttraumatic stress disorder) along with perinatal mood and anxiety disorders (PMADs) (9). With the increasing incidence of PMADs and trauma-related disorders of parents with infants in the NICU, supporting caregiver coping warrants clinical attention. Psychologists in the NICU are best suited to provide dyadic intervention services to support infant mental health and attachment and reduce infant stress, which is especially pertinent with the growing focus on infant psychosocial health in the NICU (10, 11). Having a psychologist as part of the care team improves service efficacy and is often accompanied by increased patient satisfaction and improved outcomes (12-15). Embedding a psychologist directly in the NICU has the distinctive advantage of increasing the opportunity for informal collaboration among team members and proactive screening and intervention. Staff benefits, from access to psychological debriefing and staff support, cross-training opportunities with junior professionals (e.g., medical students and residents), and opportunities for research and quality improvement for NICU services, are all consistent with psychology offerings within similar departments like hematology/oncology (14).

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The National Perinatal Association (NPA), a leading organization in perinatal care, has recommended all NICUs have a psychologist as an integrated team member (17). The British Association of Perinatal Medicine (BAPM) Service and Quality Standards for

Provision of Neonatal Care in the UK (16) echoed this recommendation for psychologists as "essential members of the neonatal team" (p. 34). BAPM (16) developed staffing standards of 1 full-time psychologist per 20 beds with higher staffing requirements for units with additional risk factors. While some NICUs have embedded psychology successfully, there remains a dearth of NICU psychologist positions and training opportunities available in the United States.

Training, Education, and Certifications

Psychologists are doctoral-trained professionals qualified to provide therapy, conduct research, administer assessments, and participate in quality improvement, program development, and evaluation. Psychologists complete at least three years of full-time graduate-level education before completing a full-time, one-year pre-doctoral internship. Students are expected to complete psychology externships or practica in different settings (e.g., schools, hospitals) and a doctoral dissertation during their education. The pre-doctoral internship is the final year of formal clinical training for psychology students before graduation. In most states, an APA-accredited doctoral program and internship are required to become a licensed clinical psychologist. Most state licensing boards require supervised clinical hours following graduation and meeting state-specific requirements. Those requirements could include passing the national licensure exam (i.e., Examination for Professional Practice in Psychology), state jurisprudence exams, and oral examinations, amongst other requirements. A post-doctoral fellowship is a formalized method for accruing supervised post-graduate hours, including didactics, supervision, a research/ scholarly component, and clinical exposure to the specified population. While there are many specialties within the field of psychology, all clinical psychologists must have a basic understanding of research design and implementation, program development, test construction, psychological assessment, clinical interventions, and supervision.

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Following licensure, psychologists can choose to pursue board certification. This process is similar to medical board certifications; however, a difference is that this process is not required for clinical practice, and many psychologists curate advanced expertise without seeking board certification. The main benefit of this process is that it communicates to other psychologists, health service professionals, and the general public that the board-certified psychologist has advanced training and expertise in the specific

certification area. There are currently seventeen specialty boards offered through the American Board of Professional Psychology (ABPP). To date, there are no NICU-specific certifications for NICU psychologists. However, they might pursue further training and/or certification in other clinical areas (e.g., clinical neuropsychology, clinical health, clinical child and adolescent) to expand their knowledge and expertise in this highly specialized area. In addition to board certification through ABPP, several related certifications for NICU psychologists can include the Infant/Early Childhood Mental Health Endorsement (I/ECMH-E) sponsored by various infant mental health associations through The Alliance for Infant Mental Health or the Perinatal Mental Health Certification (PMH-C) sponsored by Postpartum Support International.

Psychology in the NICU

Perinatal Mood and Anxiety Disorders (PMADs):

A review of the literature shows an increased incidence of mental health concerns and diagnoses among parents of infants admitted to NICU as compared to parents of typical infants. Approximately 20–30% of NICU parents will meet the criteria for a mental health disorder, with many more experiencing sub-clinical yet still distressing symptoms (17). Common concerns include PMADs as well as trauma-related disorders. Parental mental health concerns can impact the infant in several ways, including reduced visitation/avoidance, diminished positive engagement with their infant and care team, and challenges related to reading and interpreting the infant's cues. These concerns can negatively impact the infant's long-term development and behavior. Therefore, NICU psychologists can directly impact the well-being of the family unit as a whole by addressing the parental mental health needs and the infants' social, emotional, and developmental needs.

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Many parents consider the NICU and/or their birth experience as traumatic or at least a very significant stressor. Chronic stress and

trauma may impact parents' behavior and regulation as outlined above, necessitating a trauma-informed care (TIC) approach. TIC involves: "(1) realizing the impact that trauma has on people and those reactions to a past trauma may inform the person's current response to a potentially traumatic situation; (2) recognizing the signs and symptoms of trauma in people and the staff caring for them; and (3) resisting re-traumatization, to prevent a situation that represents a tolerable stress from evolving into a toxic stress" (18). NICU psychologists provide TIC to families and can also help educate medical and administrative staff on how to practice TIC.

Infant Mental Health/Infant and Early Childhood Developmental Assessment:

Psychologists with infant mental health experience and training are specifically equipped to address the parent-infant dyad with a focus on early attachment and bonding, parental engagement, parental reflective capacity, adoption of the parental role, and grief related to the loss of the expected pregnancy and delivery experience. Many NICU parents report feeling as though they are limited in what they can do for their infants. As part of the NICU care team, psychologists can educate and coach parents around developmentally appropriate and relationship-enhancing activities such as kangaroo care, positive touch, hands-on care, and reciprocal interactions to improve the dyadic relationship and parental confidence and competence in caregiving. Psychologists can support parents in understanding their role in facilitating infant neurodevelopment through interactions that engage the sensory systems (e.g., talking, singing, reading, and scent). Positive, safe, and attuned relationships with parents can buffer the infant against the negative impacts of prematurity, NICU stress, and medical complexities (19).

"As part of the NICU care team, psychologists can educate and coach parents around developmentally appropriate and relationship-enhancing activities such as kangaroo care, positive touch, hands-on care, and reciprocal interactions to improve the dyadic relationship and parental confidence and competence in caregiving."

Early Childhood Developmental Assessment:

Premature and medically complex infants are at higher risk for neurodevelopmental complications and delays as compared to typically developing infants. Assessing, monitoring, and treating these concerns is largely a multidisciplinary effort occurring during NICU admission and in the months and years post-NICU stay. Psychologists have the training and expertise to administer, score, and interpret a variety of developmental assessments to support the infant's developmental course better and help educate families about their child's areas of strength and areas for growth. The

Bayley Scales of Infant and Toddler Development, Fourth Edition (20), is the gold standard in developmental assessment across domains. Additionally, many psychologists are utilizing the NICU Network Neurobehavioral Scale (21) to assess at-risk infants' neurological integrity and behavioral functioning. Results from assessments such as these allow for early identification of concerns, coordination amongst team members, and early referrals to support services, facilitating more comprehensive planning and education for families.

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USNWR Benefits for having a NICU Psychologist:

As outlined above, psychologists bring specific and necessary expertise to NICUs that positively affect patient and family care and staff and provider well-being. However, taking a systems-level view of this impact is also essential. Hospital systems and related entities are motivated by ranking systems such as the US News and World Reports Best Children's Hospital Report (USNWR). This is a premier ranking system that analyzes data on hospital services, specialties, clinical outcomes, coordination of care, and provision of resources. These annual rankings are used to inform patient and family decision-making and demonstrate excellence in reputation. They are often utilized in quality improvement efforts by hospitals and systems of care (22). Neonatology is one of the specialties USNWR ranks annually, and the availability of a psychologist or psychiatrist in the NICU boosts this score. USNWR awards points for having a "designated psychologist or psychiatrist available for referrals and consultation with parents." The designated psychologist is ambiguous and could include an embedded NICU psychologist or a C/L psychologist who rotates through the NICU.

Methods:

The number of top-ranked USNWR hospitals in Neonatology that have met the criteria of "designated psychologist or psychiatrist available for referrals and consultation with parents" is unknown. In this study, we sought to determine how many top-ranked Neonatology programs had a designated psychologist. We obtained a list of the top 50 ranking hospitals in the specialty of Neonatology from 2015–2019. From the list of 67 unique institutions, we identified contacts at 53 institutions, including psychologists, social workers, nursing directors, parent coordinators, and administrative staff. A 19-question survey was emailed to these contacts.

Participants were given a month to respond, and two reminders were emailed about the survey timeline. No incentives were provided to complete the survey.

Of the 53 institutions surveyed, 16 provided responses. Two respondents unintentionally completed the survey twice. The authors agreed on accepting the first response and deleting the second, as the responses did not significantly differ in the information provided, leaving a total n of 14. It is worth noting that almost all institutions that responded to the survey had psychology services available in their NICU or medical centers at varying capacities. Each institution was asked to respond to questions about the availability of psychology services provided within the NICU and other departments within neonatology. Given that NICU psychology is a new and growing field, it is not surprising that we were unable to gather more respondents. The 14 respondents indicate the need for more neonatology units to have a designated psychologist.

Results:

Data has been summarized in Table 1. Most hospitals (93%) were level 4 NICUs, and their bed capacity ranged from 30 to 250 beds, averaging 82. Most respondents reported having a psychologist in at least two service lines across inpatient and outpatient settings (i.e., NICU, NICU Follow Up Clinic, Fetal Care, Pediatric ICU, and Cardiac ICU). Although thirteen respondents reported having a fetal care center, only five reported having a designated psychologist in this department. Seventy-one percent of respondents reported having a designated psychologist in the NICU. The average percentage of clinical Full-Time Effort (FTE) within a workweek was 53%, ranging from 0% to 100%. Most psychologists within the NICU (71%) reported billing for their services. For psychologists who bill for services, 90% use Health and Behavior codes, and 20% use Psychotherapy codes (with some overlap depending on the setting where services are provided). Of the 14 respondents, 10 were funded, at least partially, by the hospital and/or academic department. Of the remaining respondents, philanthropic funds supported one, one was grant-supported, and a combination of sources funded two.

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reported having a designated
psychologist in the NICU."

Table 1: Summary of Survey Respondents' NICU Psychologist Service and Structure											
Institution		Level mber of	psycho	a NICU logist? % FTE I/NICU-related es	Clinical Service Line	Psychologist bills for services?	Billing codes used	Presence of FCC	Is there a dedicated psychologist in your FCC?	Psycholo- gist funding source(s)	Psychology training
Children's Medical Center Dallas	IV	47	Yes	100%	•NICU	Yes	•H&B Codes	Yes	No	•The medical/ academic dept	•Practicum •Internship •Fellowship
Johns Hopkins All Children's Hospital	IV	96	Yes	100%	•FCC •NICU •PICU/CICU •NICU FUC	Yes	•H&B Codes	Yes	Yes	•The hospital	•None
Nationwide Children's Hospital	IV	130 to 260	Yes	100%	•NICU •NICU FUC	Yes	•H&B Codes	Yes	No	•The hospital	•Internship •Fellowship
Oregon Health & Science University	IV	42	Yes	20%	•NICU •NICU FUC	No	•No billing	Yes	No	•The medical/ academic dept	•None
Duke University Medical Center	IV	65	No	10%	•NICU FUC	No	•No billing	Yes	No	•Grants •Teaching •Clinical receipts	•None
Children's Hospital of Philadelphia	IV	98	Yes	100%	•NICU •FCC •NICU FUC	Yes	•H&B Codes	Yes	Yes	•Each dept funds their respective psychologist	•Internship •Fellowship
University of Miami/ Jackson Memorial Hospital	IV	126	No	0%	•None	N/A	•N/A	Yes	No	•N/A	•None
University of Colorado Hospital/ UC Health System	III	50	Yes	90%	•NICU •Ante/L&D Unit •OP FIMC	Yes	•H&B Codes	Yes	No	•Grant(s)	•Fellowship
Children's Mercy Hospital - Kansas City	IV	84	Yes	30%	•FCC •NICU •PICU/CICU •NICU FUC	Yes	•Psych Codes •H&B Codes	Yes	Yes	•The hospital	•Practicum

Table 1 (continued): Summary of Survey Respondents' NICU Psychologist Service and Structure											
Institution	1	Level mber of	Chalagiet'/ % LIL in		Clinical Service Line	Psycholo- gist bills for ser- vices?	Billing codes used	Presence of FCC	Is there a dedicated psychologist in your FCC?	Psycholo- gist funding source(s)	Psychology training
Children's Hospital Los Angeles	IV	50	Yes	100%	•FCC •NICU •PICU/CICU •NICU FUC •Other hospital areas	Yes	•Psych Codes •No billing	Yes	Yes	•Private funder/Philan- thropy	•Fellowship
C.S. Mott Children's Hospital	IV	52	No	0%	•None	Yes	•H&B Codes	Yes	No	•The hospital •The medical school •Billing	•Fellowship
Cook Children's Medical Center	IV	98	No	0%	•NICU FUC	Yes	•H&B Codes •Unsure	No	N/A	•The hospital	•None
Boston Children's Hospital & Harvard Medical School	IV	30	Yes	80%	•PICU/CICU	No	•No billing	Yes	Yes	•All of the above (CICU)	•Practicum
Children's National Hospital	IV	60	Yes	10%	•NICU FUC	Yes	•H&B Codes	Yes		•The hospital	•None

*Note. Abbreviations: FCC = Fetal Care Center; PICU = Pediatric ICU; CICU = Cardiac ICU; NICU FUC = NICU Follow Up Clinic; Ante = Antepartum; L&D = Labor & Delivery; OP FIMC = Outpatient Clinic for Families of Infants with Medical Complexity; H&B = Health and Behavior; Psych = Psychotherapy

We assessed training opportunities for pre and post-doctoral psychology trainees. Eight respondents reported having a training program with trainee development levels ranging from externs/ practicum students to post-doctoral fellows. Of the training options, only one site endorsed offering training at all three levels (i.e., practicum/externship, internship, and fellowship). Five sites offered training at a single level (i.e., externship/practicum or fellowship); the remaining sites offered internship and fellowship training opportunities. Seven programs offered post-doctoral fellowships, the most advanced level of specialty training, and each of these institutions was also an institution where psychologists could bill for services provided.

Discussion:

Psychologists are integral to the NICU, providing clinical expertise for the infant's health and development and the family's overall well-being. NICU psychologists' contributions extend beyond direct patient care by enhancing interdisciplinary learning and heightening awareness of biopsychosocial factors that may affect decision-making and treatment planning, supporting the cultivation of family-integrated or family-centered care practice, imple-

menting trauma-informed care approaches, and promoting provider well-being through staff support. Additionally, having a NICU psychologist improves the expertise of clinical service, appeals to patients' and families' desires for top-ranked care, and contributes to a national reputation for excellence.

Including a psychologist within the NICU can improve a hospital's ranking within the US News and World Reports (USNWR) for that hospital's Neonatology division. This ranking system influences patient and family decision-making and is often utilized for quality improvement efforts within hospitals or larger systems of care (22). One of the specific factors assessed is if there is a "designated psychologist or psychiatrist," and a NICU's overall score is improved if such a clinician is on the care team. While this factor is not clarified more thoroughly (i.e., what defines presence), it seems that the USNWR recognizes the importance of having a professional present to address mental health concerns for this population.

Including a psychiatrist and/or psychologist within a NICU would benefit families and staff and improve care and outcomes. Despite the difference in training, psychologists and psychiatrists often work closely together to care for their patients. Both can provide in-depth/targeted assessment of mental health conditions, but treatments utilized generally differ. Psychiatrists are MDs (medical doctors) trained to understand the brain chemistry and biological aspects of mental health. Their training is less focused on psychotherapies, but some may utilize psychotherapy as a part of their approach. The inclusion of a psychiatrist as part of the treatment team would offer the unique benefit of having the option to utilize medication management for parents. The cost of integrating a psychiatrist is generally significantly greater than that of a psychologist, and the additional benefit of offering medication management may be less impactful as many new parents with an infant(s) in the NICU are often hesitant to utilize psychotropic medications as a first line of treatment. Families often worry that medications could impact milk supply, be dangerous for their infant(s), or be accompanied by undesirable side effects during what is already a vulnerable period. While psychiatrists may be trained in some psychotherapy techniques, to only access part of their skill set for the majority of patients they interact with would be an inefficient use of their clinical effort and challenging for many medical systems to justify financially. There are also systemic and medical-legal challenges related to documentation and prescribing medications when the identified patient is a neonate.

"Psychologists are integral to the NICU, providing clinical expertise for the infant's health and development and the family's overall well-being. NICU psychologists' contributions extend beyond direct patient care by enhancing interdisciplinary learning and heightening awareness of biopsychosocial factors that may affect decision-making and treatment planning, supporting the cultivation of family-integrated or familycentered care practice, implementing trauma-informed care approaches, and promoting provider well-being through staff support. Additionally, having a NICU psychologist improves the expertise of clinical service, appeals to patients' and families' desires for top-ranked care, and contributes to a national reputation for excellence."

Psychologists have expertise in psychological/neuropsychological assessment, brief interventions, evidence-based care, health-care system navigation, and research/program development. A psychologist's training focuses more specifically on understanding emotions and utilizing targeted therapeutic techniques (such as Cognitive Behavioral Therapy [CBT]) to address the mental

health needs of their patients. They are less costly to the NICU than a psychiatrist and can circumvent many medical-legal issues while operating at the top of their license. USMWR assigns credit when the psychologist collaborates with other subspecialties for neurodevelopmental programming and family services. A psychologist with a role in the NICU would be able to address all three of these areas with their single line of clinical effort while also engaging in program development, contributing to provider support and well-being efforts, supervising and teaching junior physicians and other trainees, and referring to psychiatric or other medical colleagues when appropriate.

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Despite a small sample size based on the availability of existing NICU psychologists, our survey results show that most respondents have a designated psychologist for NICU service lines. These institutions, highly ranked within the USNWR and wellrespected academic medical institutions, have set a standard of care that other institutions should model. This standard is often continuously rated highly across various domains important to patients, families, staff, and the greater community. Our survey also found considerable variability in the percentage of FTEs, clinical responsibilities, inpatient vs. outpatient work, funding resources within these institutions, and training opportunities. In preparation for expansion, it is vital to ensure adequate training opportunities at each level for up-and-coming psychologists to be prepared to serve in a neonatal environment. Greater than half of the highranking survey respondents demonstrated their dedication to future growth in this field, as indicated by their established training programs for future NICU psychologists. However, to adequately prepare for the growth of this service, more NICU psychologists are needed to expand the training programs for psychology students. Survey results indicate that institutions recognize that NICU psychologists are a value-added service, positively impacting long-term parental health, infant/child outcomes, the culture of the NICU itself, and reducing long-term financial costs. NICU psychologists are essential in pursuing excellence in neonatal care, and there is an increasing call for full-time psychologists in every NICU.

Future Directions:

The authors, members of the NNNP Advocacy Committee, plan to use the information gathered here to support expanding the availability of NICU psychology services in NICUs nationwide. Future directions for the NNNP Advocacy Committee include the creation of a NICU Psychologist toolkit. The purpose of this toolkit is twofold. The first is to assist individuals or units in providing a clear and concise rationale to hospital administration on the benefits of including a NICU psychologist within their NICU team. The second is to standardize the requirements for psychological support for NICU families. This toolkit will include a sample job description, guidance on identifying appropriate billing codes, possible funding sources to consider, education on infant mental health, and best practice recommendations for screening and intervention for PMADs. Finally, we want to encourage continued support for advancing NICU psychologists in more institutions to ensure the mental health needs of NICU families are addressed, maximizing the potential of and support for the developing infant.

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TG and LC created the format for the project, designed the survey, and distributed it. They also analyzed the data, created the outline, and participated in the manuscript's construction.

SE: Helped create the outline for the paper, analyzed the data, and participated in the manuscript's construction.

JK, BP, and MD: Helped create the outline for the paper and participated in the manuscript's construction.

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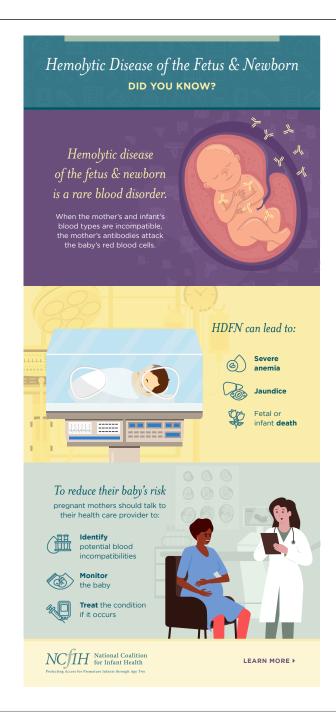
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Patient Safety Movement Foundation







Neonatal Duplicated Penis with Associated Complex Cardiac, Gastrointestinal, Renal, and Musculoskeletal Abnormalities

Larry Ngo, MD, Mark Baker, MD, Chaitra Manjunath, MD, Luis Fernando Rivera Melara, MD

Abstract:

Diphallia is an exceptionally rare genitourinary anomaly often associated with caudal duplication syndrome, which poses challenges in understanding its diverse nature. This case report presents a unique manifestation in a male infant born at 36 weeks to a mother with uncontrolled diabetes. The infant exhibited complete duplication of the penis, scrotum, testicles, urethra, bladder, sacrum, and right kidney, alongside major anomalies including Tetralogy of Fallot and lumbosacral spinal dysraphism with lipomyelomeningocele. Minor anomalies included abnormal ear creases, hypospadias, hydronephrosis, rectal-urethral fistulas, and a left club foot. This case represents the first documentation of such a complex constellation of supraumbilical presentation that includes abnormal ear creases and cardiac associations of Tetralogy of Fallot, right-sided aortic arch, and mirror aortic arch vessels.

"Diphallia is an exceptionally rare genitourinary anomaly often associated with caudal duplication syndrome, which poses challenges in understanding its diverse nature. This case report presents a unique manifestation in a male infant born at 36 weeks to a mother with uncontrolled diabetes. The infant exhibited complete duplication of the penis, scrotum, testicles, urethra, bladder, sacrum, and right kidney, alongside major anomalies including Tetralogy of Fallot and lumbosacral spinal dysraphism with lipomyelomeningocele."

Introduction

Diphallia, or duplicated penis, is an extremely rare genitourinary congenital anomaly that can present in newborn infants. Each case is unique in the degree of duplicated penile tissue and other associated congenital anomalies (1–3). Diphallia is usually associated with other genitourinary, gastrointestinal, and other congenital defects such that no two cases are exactly alike (1, 2). The exact etiology of diphallia is still unknown and is multifactorial in nature (1, 3, 4). Diphallia is often associated with caudal duplication syndrome (CDS), a constellation of a duplicated distal GI tract, urinary tract, genital organs, and/or lumbosacral spine, and other associated anomalies (5, 6). Given diphallia's rare and varied nature, additional case reports are necessary to identify risk factors, associated anomalies, appropriate screenings, and required surgical interventions.

"Diphallia, or duplicated penis, is an extremely rare genitourinary congenital anomaly that can present in newborn infants. Each case is unique in the degree of duplicated penile tissue and other associated congenital anomalies. Diphallia is usually associated with other genitourinary, gastrointestinal, and other congenital defects such that no two cases are exactly alike. The exact etiology of diphallia is still unknown and is multifactorial in nature."

In our case report, we present a unique presentation of diphallia and CDS from an infant boy born at 36 weeks. To our knowledge, this is the first case report with such a unique, complex constellation of multiple congenital anomalies for both CDS and isolated diphallia. This presentation includes previously unreported cardiac associations of Tetralogy of Fallot, right-sided aortic arch, and mirror image branching of aortic vessels.

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Figs. 1A and 1B: Ear anomalies, bilaterally folded helix with abnormal creasing.

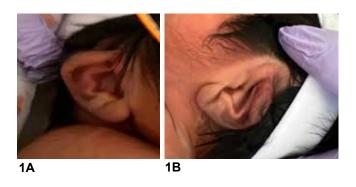


Fig. 3A: Left sided defect representing lipomyelomeningocele

Fig. 3B: Left shortened lower extremity and clubbed foot



Case

Our patient is a male infant born to a 36-year-old G₂P₂ woman with poorly controlled Type 2 diabetes, hypertension, and preeclampsia. The prenatal evaluation was significant for a 21-week fetal ultrasound that was concerning for multiple congenital anomalies, including spina bifida, Tetralogy of Fallot, and bilateral clubbed feet. The rest of her prenatal imaging, labs, and care were unremarkable.

The baby was delivered emergently at 36 weeks 6 days via C-Section due to severe maternal hypertension. Multiple obvious congenital anomalies were noted at birth. His physical exam was insignificant for abnormal ear findings, a completely duplicated penis, a duplicated scrotum, gluteal and sacral dimples, and left lower leg clubbing, as seen in Figures 1-3. The patient completed multiple imaging studies with abnormal congenital findings summarized in Table 1. His genetic evaluation was performed after completing a whole exome sequencing study. The study did not detect relevant sequence variants.

Due to the complex nature of the patient's condition and congenital anomalies, a multidisciplinary approach was required. Con-

Fig. 2A: Completely duplicated penis and scrotum.

Fig. 2B: Duplicated scrotum with abnormal midline scrotal tissue. Midline gluteal cleft with anatomically positioned anal sphincter. Left gluteal dimple without evidence of anal sphincter structures or fistula. Skin tag present







3B

sultation was obtained with pediatric urology, pediatric surgery, pediatric neurosurgery, pediatric orthopedic surgery, pediatric nephrology, pediatric cardiology, and genetics.

"Due to the complex nature of the patient's condition and congenital anomalies, a multidisciplinary approach was required. Consultation was obtained with pediatric urology, pediatric surgery, pediatric neurosurgery, pediatric orthopedic surgery, pediatric nephrology, pediatric cardiology, and genetics."

His prenatal diagnosis of Tetralogy of Fallot was confirmed with a

Table 1. The evaluation included examination under anesthesia, ultrasound, MRI, VCUG, retrograde pyelogram studies, upper GI, and barium enema.

Patient Evaluation fo	r Congenital Anomalies
HEENT	· Bilateral folded ear helix with abnormal ear creases
Genitourinary	 Complete duplicated penis, urethra, and bladder Glanular hypospadias of the right penis Duplicated scrotum with abnormal medial scrotal skin Complete testicular duplication; 4 testicles in total
Renal	 Ectopic left kidney transversely positioned at midline Crossed fused renal of the left kidney to the lower pole of the right kidney Duplicated right kidney Right grade 2 hydronephrosis Two rectal, urethral fistulas originating at the left penile urethra bladder neck
Cardiac	 Tetralogy of Fallot Right-sided aortic arch Mirror image branching of aortic vessels
Gastrointestinal	 Lateral anal-sacral dimple without fistula Sacral skin tag
Neurologic	 Tethered, duplicated cord at the level of L4 Lumbosacral spinal dysraphism with a lipomyelomeningocele and lipomyeloschisis Spinal syrinx extending from T12
Musculoskeletal	 Lower lumbar spine, sacrum, and coccyx dysgenesis Duplicated, dysplastic sacrum Hypoplastic left gluteus with abnormal fatty tissue Shortened left lower extremity Left club foot

postnatal echocardiogram. The baby remained stable and did not experience desaturations or tet spells during his time in the NICU. Serial echocardiograms were performed to assess his pulmonary stenosis. He required initiation of propranolol due to worsening pulmonary stenosis gradients. The patient was sent home with close outpatient follow-up with pediatric cardiology. At 4.5 months old, he underwent a PDA ligation and a transannular VSD patch closure. He has recovered very well from this surgery to date. Follow-up echocardiograms showed no residual ventricular level shunting, no right ventricular outflow obstruction, expected free pulmonary insufficiency, and normal biventricular systolic function. His Lasix and propranolol were weaned off by 8.5 months of life. He is expected to have a pulmonary valve replacement between 5 and 15 years, depending on his growth and clinical condition.

Our patient encountered challenges in achieving full feeds and required a G-tube placement before discharge. The presence of vesicoureteral reflux on the left side and bilateral hydronephrosis predisposed our patient to urinary tract infections caused by *Enterobacter* and *Klebsiella oxytoca*, subsequently leading to bacteremia and meningitis. This issue required a prolonged antibiotic treatment, and the infections responded appropriately.

Pediatric Urology advised correcting the recto-urethral fistula around 6 to 12 months, advising prophylactic amoxicillin until repair. They recommended a repeat outpatient pelvic MRI to better delineate his anatomy in preparation for surgical reconstruction of his duplicated phallus. The infant has developed one urinary tract infection at home, which presented with fevers to 103°F and gross hematuria while wiping the left urethra. His urine culture was positive for *Enterobacter cloacae* and *Enterococcus faecalis*, which

was treated with cefdinir. He resumed his prophylactic amoxicillin after the urine infection was appropriately treated.

Nephrology recommended repeating renal ultrasounds after discharge to monitor bilateral hydronephrosis. His central calyceal

"The presence of vesicoureteral reflux on the left side and bilateral hydronephrosis predisposed our patient to urinary tract infections caused by Enterobacter and Klebsiella oxytoca, subsequently leading to bacteremia and meningitis. This issue required a prolonged antibiotic treatment, and the infections responded appropriately. Pediatric Urology advised correcting the recto-urethral fistula around 6 to 12 months, advising prophylactic amoxicillin until repair."

dilation and ureteral dilation have improved, but the underlying

structural defects have remained unchanged.

Neurosurgery followed the neonate during and after his NICU stay due to his complex spinal anatomy. A spinal MRI at six months old showed increased conspicuity of the syrinx extending from T1–L2. The previously seen spinal, urinary, and genital structural abnormalities were noted and appeared unchanged. Surgical repair of these anomalies will be deferred until the patient is at least one year old. A repeat spinal/pelvic MRI will be repeated shortly before that time.

"Neurosurgery followed the neonate during and after his NICU stay due to his complex spinal anatomy. A spinal MRI at six months old showed increased conspicuity of the syrinx extending from T1–L2. The previously seen spinal, urinary, and genital structural abnormalities were noted and appeared unchanged. Surgical repair of these anomalies will be deferred until the patient is at least one year old."

An outpatient pediatric orthopedics evaluation was arranged. At nine months old, he received surgical repair of the left club foot and has recovered well so far.

His chromosomal microarray and whole exome sequencing results were within normal limits. The infant's routine newborn screening also yielded normal results.

"His chromosomal microarray and whole exome sequencing results were within normal limits. The infant's routine newborn screening also yielded normal results."

Discussion:

Diphallia is an extremely rare congenital genitourinary abnormality that is estimated to occur in 1 in 5–6 million live births (1–3). The first reported diphallia description was in 1609. Since then, there have only been about 100 cases reported in the literature, although the anomaly is likely underreported (1).

Establishing a definite cause for diphallia has been difficult, given how extremely rare and varied the presentation can be between patients. The cause of diphallia is multifactorial in most cases, with causes related to maternal exposure to teratogens, radiation, or infections; fetal injury; or an abnormal genome (3–5). While the embryologic cause of diphallia is hypothesized, several other theories have been proposed. Historic theories postulated that diphallia is due to a failure of normal fusion of the bilateral em-

bryonic anlagen, atavism, or a minor structural duplication (6). Recent studies in developmental anatomy suggest that diphallia may be due to duplication of the infra-umbilical cloacal structures, also known as caudal duplication syndrome (CDS), which leads to altered mesodermal migration and subsequent creation of two separate sets of genital structures (6–8).

A meta-analysis by Kendrick et al. evaluated 87 English-language, published case reports on diphallia presentation and associated congenital anomalies. The most common GU anomalies were single renal agenesis, horseshoe kidney, and duplicate ureters/ vesicoureteral reflux. The most common GI anomalies were imperforate anus, gastrointestinal tract duplication, and anorectal malformations. The most common non-GU/GI anomalies were inguinal hernias, limb agenesis/hypotrophy, wide diastasis of the pelvic bone, hemivertebra, and meningocele/umbilical hernia/talipes equinovarus/atrial septal defect (1).

"The most common GU anomalies were single renal agenesis, horseshoe kidney, and duplicate ureters/ vesicoureteral reflux. The most common GI anomalies were imperforate anus, gastrointestinal tract duplication, and anorectal malformations. The most common non-GU/GI anomalies were inguinal hernias, limb agenesis/ hypotrophy, wide diastasis of the pelvic bone, hemivertebra, and meningocele/ umbilical hernia/talipes equinovarus/ atrial septal defect."

Our case report presents a patient with a unique constellation of congenital anomalies. The patient had wholly duplicated phallic structures, a duplicated bladder, a right-sided kidney, fusion between the left and remaining right-sided kidneys, a bifid scrotum (each with two testicles), and two rectal-urethral fistulas. Other congenital anomalies included a tethered spinal cord, duplicated spinal cord at the T4 level, lipomyelomeningocele, lumbosacral spinal dysraphism, lumbosacral and pelvic dysgenesis, and a unilateral club foot/shortened leg. The unique congenital anomalies our patient presented included Tetralogy of Fallot, a right-sided aortic arch, and mirror image branching of aortic vessels.

Our patient's diphallia was likely related to CDS, given his associated genitourinary and spinal abnormalities. CDS is associated with various degrees of duplication of the genitourinary organs, lower spinal cord, and distal GI tract (9–11). Patients with CDS have sometimes been reported as having simple cardiac abnormalities like patent ductus arteriosus, atrial septal defect, and ventricular septal defect (10). However, patients with diphallia or CDS have not been reported with the more complex cardiac anomalies found in our patient. This makes our patient's cardiac abnormalities unique and an important addition to the existing literature.

"Patients with CDS have sometimes been reported as having simple cardiac abnormalities like patent ductus arteriosus, atrial septal defect, and ventricular septal defect (10). However, patients with diphallia or CDS have not been reported with the more complex cardiac anomalies found in our patient."

Given the wide variety of patient presentations, the treatment for diphallia CDS should be individually tailored to each patient. A detailed physical exam and imaging studies, including ultrasounds and magnetic resonance imaging, should be conducted to determine the anatomical abnormalities of the genitourinary, gastrointestinal, and musculoskeletal systems. In addition, there should be consideration for evaluation with an echocardiogram to assess for cardiac anomalies. Management often includes the discussion of surgical removal of the rudimentary/non-communicating phallus and appropriate reconstructive surgery (1-4). Patients with diphallia should receive appropriate screening and counseling for genitourinary, gastrointestinal, cardiac, extremity, and vertebral abnormalities. Minor asymptomatic abnormalities can be managed conservatively; however, additional surgical intervention may be required to address other major congenital anomalies that may be involved. Lower GI abnormalities commonly require surgical correction of anorectal malformations and duplicated gastrointestinal structures such that there is a single functioning, continent anus (5). Management of urinary tract duplications is generally more conservative, aiming to minimize urinary tract infections and maximize urinary continence (5). Even with adequate treatment, infants born with diphallia have an increased mortality rate from genitourinary and gastrointestinal infections and other complications (1, 2) The primary source of morbidity is spinal cord anomalies leading to urinary and gait disturbances in adulthood. The overall prognosis is favorable if the infant successfully survives all required surgeries. However, it is crucial to rule out chromosomal abnormalities when describing the prognosis to patients' families, as an underlying chromosomal genetic abnormality may have significant associated morbidities and mortality.

Conclusion:

Diphallia is a rare congenital developmental abnormality that presents differently with each patient. Our patient's presentation of diphallia suggests that the etiology may be related to CDS. But at this time, the pathogenesis of this congenital anomaly remains uncertain, and it may be multifactorial. Major congenital anomalies involve infra-umbilical structures of the genitourinary, gastrointestinal, musculoskeletal, and central nervous systems. Though previous reports have only described minor cardiac anomalies, our patient demonstrates that more complex cardiac abnormalities can be associated. Patients with diphallia or CDS should receive a complete cardiovascular and hemodynamic evaluation to successfully diagnose and manage all cardiac abnormalities.

Learning Points:

- Diphallia is a rare congenital urogenital abnormality occurring at a rate of 1 in 5–6 million live births.
- The developmental cause for diphallia is uncertain and likely multifactorial.
- Associated anomalies include urinary, musculoskeletal, gastrointestinal, anorectal malformations, central nervous system, and cardiac anomalies.
- 4. Management is individualized and should be completed with a multidisciplinary team.

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Patient Consent was obtained and granted from the patient's legal guardian through our institutional written consent form. Loma Linda University Children's Hospital - Authorization and Consent to Record Audio and/or Video, Photograph, Write and Publish.

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Celebrating Milestones and Advancements in Neonatal Care: All Pathways and Women In Neonatology June updates

Clara Song, MD

We extend warm greetings to our dedicated WiNners and Pathways friends. This month, we delve into the latest updates and upcoming events in the world of neonatal care, highlighting the continued progress and community spirit driving our field forward.

"We extend warm greetings to our dedicated WiNners and Pathways friends. This month, we delve into the latest updates and upcoming events in the world of neonatal care, highlighting the continued progress and community spirit driving our field forward."

Advancing Neonatal Education and Practice

Our #NeoGrandRounds series continues to be a cornerstone of neonatal education. On June 18, 2024, we hosted Dr. Satyan Lakshminrusimha, who presented on the Precision Medicine Approach to Persistent Pulmonary Hypertension of the Newborn (PPHN). This session was free and open to all, offering ABP Part 2 MOC and CME credits to attendees. This was a unique opportunity to gain insights from a leading expert and engage with peers in a collaborative learning environment.

"This year marks the 50th anniversary of the Section on Neonatal-Perinatal Medicine (SONPM). This milestone is a testament to the dedication and contributions of countless professionals who have shaped neonatal care over the past five decades."

Financial Health for Neonatal Professionals

Looking ahead, our next WiN Webinar on August 7, 2024, features Dr. Liz Bonachea, who will provide an update on managing finances for busy neonatal professionals. Financial literacy is crucial for ensuring the well-being of our practitioners, and this webinar promises to offer valuable tips and strategies.

Celebrating 50 Years of SONPM

This year marks the 50th anniversary of the Section on Neonatal-Perinatal Medicine (SONPM). This milestone is a testament to the

dedication and contributions of countless professionals who have shaped neonatal care over the past five decades. A commemorative video captures the journey and achievements of SONPM, reflecting on the past while looking forward to future innovations. https://youtu.be/2trcSaBjqw8?si=-SIQdUzf6NaxFc8a

Pioneering Immediate Kangaroo Mother Care (iKMC)

The iKMC project, supported by the American Academy of Pediatrics (AAP) and funded by The Bill & Melinda Gates Foundation, continues to promote zero separation between mothers and their newborns. Immediate skin-to-skin contact has proven benefits, and this initiative aims to make it a standard practice globally. The iKMC website serves as a central hub for resources, research, and updates on this transformative project. AAP iKMC https://www.aap.org/en/aap-global/immediate-kangaroo-mother-care-ikmc/ is the hub that includes highlighted articles and research about iKMC.

"The iKMC project, supported by the American Academy of Pediatrics (AAP) and funded by The Bill & Melinda Gates Foundation, continues to promote zero separation between mothers and their newborns. Immediate skin-to-skin contact has proven benefits, and this initiative aims to make it a standard practice globally."

Mark Your Calendars

- 7th Annual NeoResus Symposium: September 12-13, 2024
- SONPM h-program at NCE in Orlando: September 27-29, 2024, featuring sessions on AI, bioethics, palliative medicine, and more.

For all upcoming events and deadlines, the AAP Neonatal Calendar remains an essential resource.

Stay Connected

We encourage you to visit the #AAPneo photo gallery for highlights and moments from recent events. It's a wonderful way to stay connected with our community and celebrate our collective achievements.

Monthly Update

Here's a summary of what's happening in the coming months:

1. WiN Webinar: August 7, 2024, featuring Dr. Liz Bonachea

on financial updates for busy neonatal professionals.

- 2. NeoResus Symposium: September 12-13, 2024.
- **3. SONPM at NCE in Orlando**: September 27-29, 2024, focusing on AI, bioethics, and palliative medicine.
- **4. iKMC Project**: Continuing efforts to promote zero separation and immediate skin-to-skin contact between mothers and newborns, with resources available on the iKMC website.
- **5. SONPM's 50th Anniversary**: Celebrating five decades of contributions to neonatal-perinatal medicine.

For more detailed information, visit the AAP Neonatal Calendar and the #AAPneo photo gallery using the provided links. Check the #AAPneonatal Calendar for upcoming events and deadlines: AAPneonatal Calendar. Explore highlights in the #AAPneo photo gallery: AAPneo Photo Gallery, password: AAPneonatal.

"As we move forward, let's continue to support each other and drive advancements in neonatal care. Your engagement and dedication make a profound difference in the lives of newborns and their families."

As we move forward, let's continue to support each other and drive advancements in neonatal care. Your engagement and dedication make a profound difference in the lives of newborns and their families.

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

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Lean Six Sigma Black Belt

The Corona We are safe and strong at home!
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Figure 2. NANN Product Flyer





Neonatology Grand Rounds Series

The Pediatrix Center for Research, Education, Quality and Safety (CREQS) offers year-round **Neonatology Grand Rounds** webinars on topics that influence the clinical practice of newborn medicine. Join us in 2024 to review topics such as acute renal insufficiency, growth assessment in the NICU and many more.



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Paige Terrien Church, MD (she/her)

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- Assistant Professor, Harvard Medical School

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- NICU Parent of Gavin
- DEIB Facilitator and Consultant





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Book Review: Preterm Birth - Clinics in Perinatology June 2024

Gilbert I. Martin, MD

When I grew up, if someone mentioned the term "omics" to me, I would ask the sender to add a "c" to it so the word became "comics." I grew up with Blondie, Dennis the Menace and Superman. In this day and age, the term "omics" refers to branches of science and disciplines in biology. These branches, which end in the suffix "omics," include "genomics, proteomics, metabolomics, metagenomics, phenomics, and transcriptomics."

Bring back Dennis the Menace!!!!

The June 2024 issue of Clinics in Perinatology (Elsevier) titled "Preterm Birth" has a Consulting Editor in Lucky Jain and Editors who include Ronald J. Wong, Gary M. Shaw, and David K. Stevenson.

This issue of Clinics in Perinatology discusses the causes and interactions among well-defined factors that lead to preterm births. There are an additional 70+ contributors to this issue.

"This issue of Clinics in Perinatology discusses the causes and interactions among well-defined factors that lead to preterm births. There are an additional 70+ contributors to this issue."

The first paper is "Solving the Puzzle of Preterm Birth." The word puzzle is from the Medieval French "aposer, " meaning a sense of "perplex." As Doctor Stevenson and his group elaborate, there is an integration of the "omics profile (genome, epigenome, transcriptome, proteome, metabolome, immunome and microbiome)". Never have I been personally challenged with so many omics and biomes.

This encompassing treatise includes a general overview of preterm birth, a computational method for connecting the dots, an environmental and epidemiological approach, a suggestion of biomarkers, ethical consideration, and functional Taxonomy.

There is also a chapter that explores innovative solutions to preventing preterm births. Emerging therapies are presented that exhibit "promise" in mitigating inflammation and finally preventing preterm birth.

The complexities of preterm birth are extensive. Remember that the official derivation of the word "neonatology" was coined in 1960 by Alexander Shaffer, who stated, "Neonatology designates the art and science of diagnoses and treatment of the disorders of the newborn infant." We have come a long way since Dr. Shaffer's definition. Paradoxically, as maternal-fetal medicine, genet-

ics, and especially treatment of infection continue to improve, the incidence of preterm birth will necessarily increase.

The references presented in this volume are especially up-to-date in many areas. We, as neonatologists, are continually searching for "biomarkers" that will better define the issues we face daily.

I would encourage the reader to transition thinking and also include expansion to artificial intelligence (AI). As Shakespeare reminds us in Hamlet, "Speak the speech, I pray you, as I pronounc'd it to you, trippingly on the tongue." In today's verbiage, AI will become natural in our "dailyspeak."

"The references presented in this volume are especially up-to-date in many areas. We, as neonatologists, are continually searching for "biomarkers" that will better define the issues we face daily."

Again, I must mention the creed of Dr. Bill Silverman, one of our icons in neonatology. This creed stated: Guerir quelquefois, soulager souvent, consoler toujours. Cure sometimes; relieve often; comfort always. I believe this quote was initially attributed to Hippocrates and appeared in an article by Payne, L.M. Brit Med J 1967, (4) 47-48.

Disclosures: The authors have no disclosures

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Why Lily Lou, MD, Needs your Vote for American Academy of Pediatrics President in 2024

Mitchell Goldstein, MD, MBA, CML

The upcoming election for the AAP President is crucial. We can select a leader who will shape the future of neonatology and pediatric care. In recognition of her unwavering dedication to the care of neonates and younger pediatric patients throughout her career, I endorse Lily Lou's candidacy.

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pediatric patients throughout her career, I
endorse Lily Lou's candidacy."

Dr. Lily Lou is a Neonatologist and Director of Government Relations at UIC in Chicago. She is a member of the Illinois AAP Chapter. She attended UNC-Chapel Hill Medical School and was on the faculty at Yale. She has been in private practice in North Carolina and Alaska and academic practice in Connecticut, New Mexico, and Chicago. She is the past chair of the Neonatology Section and past president of the AAP-Alaska Chapter. Her role as chief medical officer for Alaska strengthened her belief that advocacy and health policy are vital to improving the welfare of all children.

"Dr. Lou's focus centers on three main themes: ensuring the inclusion of all pediatrician members, enhancing the advocacy voice to influence policy effectively, and identifying and bridging specific gaps to ensure equitable access to care for every child."

Dr. Lou's focus centers on three main themes: ensuring the inclusion of all pediatrician members, enhancing the advocacy voice to influence policy effectively, and identifying and bridging specific gaps to ensure equitable access to care for every child.

Subspecialists often see the AAP as an organization for general pediatricians, but we are all pediatricians! As a subspecialty section leader, chapter leader, and public health leader with diverse personal experience, Dr. Lou has witnessed the breadth of pediatric practice. Her career, characterized by varied experiences, has given her a broad perspective on the challenges and triumphs in

rural, suburban, and urban settings. She has seen firsthand the cultural and health equity challenges faced by American Indian/ Alaska Native populations and military families.

"Subspecialists often see the AAP as an organization for general pediatricians, but we are all pediatricians! As a subspecialty section leader, chapter leader, and public health leader with diverse personal experience, Dr. Lou has witnessed the breadth of pediatric practice."

Dr. Lou aims to strengthen the unity and inclusion of all pediatricians, regardless of subspecialty or generalist focus, rural or urban location, academic or private practice setting, and research or clinical roles. Goal 6 of the strategic plan of the AAP emphasizes engaging Sections, Councils, and Committees. The Alliances aim to streamline interactions among these groups, fostering collaboration among members with similar interests. We must embrace our membership's diversity and work synergistically across silos to achieve our common goal: optimizing the welfare of our children.

"Advocating for continual improvement in how we care for children in all settings has been a consistent theme in Dr. Lou's career. As a public health leader, she learned that expert voices at the bedside should inform policies shaping our country's health strategies."

Advocating for continual improvement in how we care for children in all settings has been a consistent theme in Dr. Lou's career. As a public health leader, she learned that expert voices at the bedside should inform policies shaping our country's health strategies. Pediatric leaders must comprehensively view the child health landscape to identify roadblocks and design opportunities to overcome them. Increasing the number of pediatricians with a voice and a seat at local and federal decision-making tables is crucial. The AAP excels at developing members' advocacy skills, as evidenced by the inspiring Advocacy Conference. We can employ similar strategies to enhance public health perspectives, health policy leadership, and sponsorship to marshal necessary resources for meaningful change.

Dr. Lou is proud to be part of an organization that is leading the rise of DEI in our national consciousness. We must understand

specific gaps to access target strategies effectively. Addressing racial disparities in maternal mortality in perinatal care is imperative. We must avoid race-based algorithms in inpatient treatment. There are gaps in geographic health resource availability, a severe shortage of some subspecialties, and social and political determinants of health, including legislated restrictions on evidence-based care. Environmental dangers disproportionately impact our population.

"There are various barriers to achieving equity. The SONPM's Women in Neonatology (WiN) group has worked collaboratively across the Academy to address gender pay and promotion equity. LGBTQ individuals deserve access to evidence-based care, and pediatricians of all gender identities deserve support and inclusion."

There are various barriers to achieving equity. The SONPM's Women in Neonatology (WiN) group has worked collaboratively across the Academy to address gender pay and promotion equity. LGBTQ individuals deserve access to evidence-based care, and pediatricians of all gender identities deserve support and inclusion. Fostering opportunities for members at all career stages is beneficial. Individuals from diverse training backgrounds, such as IMGs, significantly contribute to our community. Differently abled persons are valuable members of our society and deserve our care and support.

With experience in basic science research and clinical care, Dr. Lou understands the academic world's funding, publication, and promotion challenges. In private practice, she has navigated the scarcity of resources patients need outside a university medical center. She believes we must support the implementation of best practices and robust training for the next generation, including pipeline strategies for underrepresented groups. As ACGME requirements evolve, we must address emerging vulnerabilities to ensure that future pediatricians are well-prepared to meet the needs of patients and families. Equitable payment is crucial to fairly compensate every hardworking pediatrician and attract the best and brightest to the field of pediatrics.

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Dr. Lou believes we must be inclusive of all pediatricians and children, expand our health policy skills to amplify our voice, and have a comprehensive view of the gaps in our healthcare system to guide resource investment. She sees the AAP as capable of achieving these goals and serving as our professional home.

"Dr. Lou's experience as a public health leader provides her with a crucial health policy perspective. She believes the Academy can create opportunities for pediatricians to have influential roles in decision-making. With her unique blend of clinical and public health expertise, Dr. Lou is the best candidate for AAP president, ready to lead the Academy toward a more inclusive and effective future."

Finally, besides providing hands-on care for children, we need a comprehensive view of the child health landscape to understand specific gaps in access and drive effective strategies to address them. Dr. Lou's experience as a public health leader provides her with a crucial health policy perspective. She believes the Academy can create opportunities for pediatricians to have influential roles in decision-making. With her unique blend of clinical and public health expertise, Dr. Lou is the best candidate for AAP president, ready to lead the Academy toward a more inclusive and effective future.

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In Unity, Ashley, Deb & Jenny







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Fellows Column: Neonatal Respiratory Distress Syndrome in Near-Term to Full-Term Infants of Diabetic Mothers

Mona Singh, OSM IV, Mitchell Goldstein, MD, MBA, CML

Key Terms: IDM, NRDS, term, surfactant, DM, hyperinsulinemia Abstract

Neonatal Respiratory Distress Syndrome (NRDS) in infants of diabetic mothers (IDMs) is significantly influenced by maternal hyperglycemia and hyperinsulinemia, which impair surfactant production necessary for lung function. It is known that NRDS occurs in preterm infants, but research is limited on whether this occurs in near-term to full-term IDMS, which is what we discuss further in this paper. Studies indicate that maternal diabetes, both type 1 and type 2, increases the risk of NRDS, with hyperinsulinemia in the fetus inhibiting surfactant synthesis and contributing to respiratory complications. Furthermore, while insulin therapy manages maternal glucose levels, it can also be a risk factor for NRDS. Effective prenatal care, proper glycemic control, and further research into maternal HbA1C levels and insulin's role in surfactant production are essential for reducing NRDS incidence. Improved diagnostic criteria for gestational diabetes and enhanced management strategies can potentially prevent NRDS, benefiting neonatal outcomes globally.

"Effective prenatal care, proper glycemic control, and further research into maternal HbA1C levels and insulin's role in surfactant production are essential for reducing NRDS incidence. Improved diagnostic criteria for gestational diabetes and enhanced management strategies can potentially prevent NRDS, benefiting neonatal outcomes globally."

Introduction:

Neonatal Respiratory Distress Syndrome (NRDS) occurs secondary to either insufficient surfactant production or surfactant inactivation in the context of immature lungs. (Yadav, Lee, Kamity 2023). In respiratory distress syndrome (RDS), inadequate surfactant production decreases pulmonary compliance and increases surface tension. This increases the risk of alveoli collapse at expiration, followed by a reduction in total surface area for gaseous exchange and alveolar-capillary diffusion capacity. Hypoxia and hypercapnia develop due to the reduced surface area and alveolar-capillary diffusion capacity (Ma CC and Ma S 2012). Formerly, RDS was known as Hyaline Membrane Disease, and Avery and Mead first discovered the link between surfactant deficiency and clinical RDS in the 1950s.

When applied to a neonate, this is characterized as NRDS. NRDS is known to be a result of a preterm neonate being born before the age of 37 weeks, whether or not they are infants of diabetic mothers (IDMS). In 1959, Gellis and Hsia first described that IDMs had

increased mortality and morbidity due to RDS (Yildiz Atar, Baatz, Ryan 2021).

"There is a strong association between impaired glucose tolerance and diabetes during pregnancy with multiple fetal congenital anomalies, indicating that maternal hyperglycemia may be a significant teratogen to the growing fetus. Maternal HbA1C correlation with congenital malformations was found in seven cohort studies from 1997 pregnancies."

There is a strong association between impaired glucose tolerance and diabetes during pregnancy with multiple fetal congenital anomalies, indicating that maternal hyperglycemia may be a significant teratogen to the growing fetus. Maternal HbA $_{1C}$ correlation with congenital malformations was found in seven cohort studies from 1997 pregnancies. These pregnancies resulted in 117 live births with congenital anomalies. Maternal HbA $_{1C}$ ≥14% resulted in a 20% congenital malformation rate, while an HbA $_{1C}$ of 7.6% had a congenital malformation rate of approximately 4%. The other most common problems in IDMs include but are not limited to, hypoglycemia, hyperinsulinism, macrosomia, and RDS. (Yildiz Atar, Baatz, Ryan 2021). This shows that the higher the maternal HbA1c, the greater the risk of the neonate developing congenital anomalies. Notably, glucose may be a teratogen to the growing fetus and could be a reason for its involvement in other disease processes such as NRDS.

"This shows that the higher the maternal HbA1c, the greater the risk of the neonate developing congenital anomalies. Notably, glucose may be a teratogen to the growing fetus and could be a reason for its involvement in other disease processes such as NRDS."

Insulin has also been shown to contribute to the development of NRDS as it can potentially inhibit fetal lung maturation. It also affects components of surfactant. Surfactant is made of various surfactant proteins, mainly A and B. Surfactant Protein A (SP-A) has also been shown to regulate surfactant phospholipid synthesis, secretion, and reuptake.

Surfactant Protein B (SP-B) is a low molecular weight, hydropho-

bic protein that significantly increases surfactant phospholipid absorption. SP-B enhances the uptake of phospholipids by type II cells in vitro and, therefore, like SP-A, may play a role in surfactant recycling. Insulin has been shown to inhibit the accumulation of mRNA for SPs A, and B. Insulin can potentially decrease surfactant proteins at the molecular level, further contributing to the development of NRDS because this would affect surfactant and lung maturation.

"Insulin has been shown to inhibit the accumulation of mRNA for SPs A, and B. Insulin can potentially decrease surfactant proteins at the molecular level, further contributing to the development of NRDS because this would affect surfactant and lung maturation."

Etiology of NRDS in IDMs of both type 1 and type 2 diabetes:

Infants of Diabetic Mothers (IDMs) have about a six-fold increased risk of RDS when compared to infants of the same gestational age born to nondiabetic mothers (Shattuck and Huff UTMB).

This is independent of the route of delivery (vaginal vs. c-section). Another retrospective analysis by Robert et al. showed that after controlling for other confounder factors, including gestational age (GA) and delivery route, IDMs have a 5.6 times greater risk of developing RDS than infants of nondiabetic gestation. In a recent prospective study of late preterm infants born to a mother with Gestational Diabetes Mellitus (GDM), GDM was found to be a significant risk factor for severe RDS. Severe RDS in this study was defined as clinical signs of early respiratory distress occurring within the first two hours following birth, with consistent radiologic features and oxygen dependence requiring invasive and/or noninvasive mechanical ventilation with a fraction of inspired oxygen (FIO $_2$) >0.25 for a minimum of 24 h and admission to a neonatal intensive care unit (NICU).

"A systematic meta-analysis of studies performed throughout 1987–2008 compared fetal outcomes between type 1 and type 2 DM (total of 3781 and 7966 pregnancies, respectively) and did not reveal any statistically significant difference in NRDS. These results suggest that the type of diabetes does not influence NRDS outcome."

UK's Confidential Enquiry into Maternal and Child Health (CEMACH) study between 2002 and 2007 was the most extensive study to date to investigate outcomes of pregnant women with type 1 and type 2 Diabetes Mellitus (DM)(Yildiz Atar, Baatz, Ryan 2021). In this study, macrosomia, NRDS, and shoulder dystocia neonatal outcomes were not significantly different between

maternal type 1 and type 2 DM. A systematic meta-analysis of studies performed throughout 1987–2008 compared fetal outcomes between type 1 and type 2 DM (total of 3781 and 7966 pregnancies, respectively) and did not reveal any statistically significant difference in NRDS. These results suggest that the type of diabetes does not influence NRDS outcome.

"Glucose homeostasis affects fetal growth and development throughout pregnancy. Insulin resistance in the mother increases physiologically during pregnancy, especially in the last trimester. Increased insulin resistance results in maternal energy coming more from fat metabolism, sparing carbohydrate usage by the rapidly growing fetus."

Pathophysiology of NRDS in IDM:

Glucose homeostasis affects fetal growth and development throughout pregnancy. Insulin resistance in the mother increases physiologically during pregnancy, especially in the last trimester. Increased insulin resistance results in maternal energy coming more from fat metabolism, sparing carbohydrate usage by the rapidly growing fetus. This leads to both fetal hyperglycemia and hyperinsulinemia secondary to maternal diabetes (Yildiz Atar, Baatz, Ryan 2021). In order to compensate for the high levels of glucose in the mother, which transfer to the fetus through the placenta, the infant produces high levels of glucose as well as insulin as a result. Glucose is also an essential substrate for surfactant lipid synthesis. Insulin not only regulates glucose uptake to cells but also regulates surfactant synthesis. If insulin is high, it can inhibit components of surfactant synthesis. The fetal hyperinsulinemia secondary to maternal diabetes leads to decreased surfactant production and NRDS as a result (Yildiz Atar, Baatz, Ryan 2021). In IDMs, this compensation is exacerbated and, therefore, leads to hyperinsulinemia and NRDS as a result. Delayed lung maturation and increased risk of respiratory distress syndrome have been consistently observed among infants born to mothers with diabetes, and these findings are also observed in some rodent models of diabetes in pregnancy. (Azad et al., 2017).

"A study showed communication between trophoblasts and fetal lung epithelial tissue, causing fetal lung underdevelopment in mothers with GDM (Chen et al., 2023)."

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Accumulating evidence has proved that the placenta, as a selec-

epithelial cells and leading to FLUD.

tive barrier, makes adaptive changes to environmental and maternal factors and is involved in programming offspring health. It has been reported that pro-inflammatory responses and increased apoptotic rates in trophoblasts, increased trophoblast oxidative/nitrative stress, and reduced trophoblast mitochondrial respiration are related to the pathogenesis of GDM, which would lead to trophoblast dysfunction, impaired placenta development, restricted fetal growth, stillbirth, and neonatal respiratory distress syndrome (Chen et al., 2023).

"The study isolated and characterized the placenta-derived exosomes in normal and GDM umbilical cord blood plasma (NUB-exos and GDMUB-exos) and provided fresh evidence that the placenta-derived exosomes in GDM umbilical cord blood plasma can adversely affect the normal development of fetal lung by establishing in vitro, ex vivo and in vivo exosome exposure models."

The study isolated and characterized the placenta-derived exosomes in normal and GDM umbilical cord blood plasma (NUB-exos and GDMUB-exos) and provided fresh evidence that the placenta-derived exosomes in GDM umbilical cord blood plasma can adversely affect the normal development of fetal lung by establishing *in vitro*, *ex vivo* and *in vivo* exosome exposure models. Placenta-derived exosomes are a heterogeneous group of exosomes secreted by various placental cells, and most of them are released by the syncytiotrophoblastic layer. They cultured human trophoblast HTR-8/SVneo cells with D-glucose (5 mM or 25 mM) for 48 h and isolated the exosomes (NC-exos and HG-exos) in conditioned media to further confirm the adverse effects of trophoblasts on lung development. Our study indicated that GDMUB-exos and

HG-exos significantly inhibited lung cell proliferation and promoted apoptosis, disturbing the imbalance between lung cell proliferation and apoptosis and impairing fetal lung development (Chen et al., 2023).

Various signaling pathways and transcription factors are known to play roles in branching morphogenesis. Sox9 is a marker of distal epithelial progenitor cells. Briana E. Rockich et al. demonstrated that epithelial-specific loss and gain of Sox9 caused severe branching defects in the lung, which developed large, cyst-like structures at the distal epithelial branch tips at all developmental times examined. Moreover, with lung bud growth, Sox9+ progenitor cells gradually extended to distal portions stimulated by FGF10 secreted by mesenchymal cells. The ex vivo study also found that after exposure to GDMUB-exos or HG-exos, the terminal buds and superficial areas of lung explants decreased, and the terminal buds developed large, cyst-like structures (Chen et al., 2023). In addition, in their in vivo assays, they found that at 18 months and five days post coitum (E18.5), fetal lungs exposed to GDMUBexos or HG-exos showed lung morphology more comparable to that at E14.5-15.5, suggesting that GDMUB-exos or HG-exos result in delayed structural lung development. This shows that GDM can adversely affect trophoblasts and alter exosome contents, causing crosstalk disorder between trophoblasts and fetal lung "The study isolated and characterized the placenta-derived exosomes in normal and GDM umbilical cord blood plasma (NUB-exos and GDMUB-exos) and provided fresh evidence that the placenta-derived exosomes in GDM umbilical cord blood plasma can adversely affect the normal development of fetal lung by establishing in vitro, ex vivo and in vivo exosome exposure models."

Insulin Effect on Surfactant:

Increased insulin contributes to the development of NRDS by affecting surfactant components. Pulmonary surfactant is a complex molecule with a mixture of lipids (90%) and protein (10%) produced by type II alveolar epithelial cells (AEC2). Significant components of fetal lung maturation are the lecithin (PC)/sphingomyelin (L/S) ratio, presence of phosphatidylglycerol (PG), desaturated phosphatidylcholine (DSPC), and lamellar body count. The effect of different insulin and glucose concentrations on glucose uptake, glucose metabolism, and surfactant synthesis were examined in AEC2 cultures by Engle et al. AEC2s derived from fetal rat lungs at 19 days of gestation (term = 21) were cultured in different insulin and glucose concentrations. Adding 10 units/mL of insulin caused a 35% increase in surfactant PC synthesis. However, 100 units/mL of insulin reduced PC synthesis to below control levels. The exposure to insulin (3 h vs. 24 h) did not change the result. These results indicate that a physiological level of insulin is a stimulatory hormone in surfactant synthesis, but a high insulin level can inhibit surfactant PC synthesis.

"Increased systemic glucose and serum insulin concentrations in the fetus are potential inhibitors of fetal lung maturation and may contribute to the pathogenesis of NRDS in infants of DM mothers. Notably, it has been shown that increased insulin affects surfactant proteins A and B (Miakotina, Dekowski, Snyder 1998)."

Insulin Effect on Surface Proteins:

Increased systemic glucose and serum insulin concentrations in the fetus are potential inhibitors of fetal lung maturation and may contribute to the pathogenesis of NRDS in infants of DM mothers. Notably, it has been shown that increased insulin affects surfactant proteins A and B (Miakotina, Dekowski, Snyder 1998). Surfactant protein A (SP-A) is the major surfactant-associated protein and

may have a significant role in surfactant function and reutilization by type II cells. In addition to the developmental induction of surfactant glycerophospholipid synthesis, SP-A synthesis, and gene expression are initiated in fetal lung tissue (Mendelson, Acarregui, Odom, Boggaram 1991). SP-A has also been shown to regulate surfactant phospholipid synthesis, secretion, and reuptake. Surfactant Protein B (SP-B) is a low molecular weight, hydrophobic protein that significantly increases surfactant phospholipid absorption. SP-B enhances the uptake of phospholipids by type II cells in vitro and, therefore, like SP-A, may play a role in surfactant recycling. Insulin has been shown to inhibit mRNA accumulation for SPs A and B, although it has no effect on SP-C mRNA levels in human fetal lung tissue in vitro. Insulin can potentially decrease surfactant proteins at the molecular level, further contributing to the development of NRDS.

"NRDS due to surfactant deficiency can also occur in term or near-term infants in IDM. Eldeen et al. did a study where 1547 neonates were admitted to the NICU with a diagnosis of increased work of breathing for further management. One hundred seventeen cases of term and near-term neonates (mean GA = 36.8 wks) had a confirmed diagnosis of Surfactant deficiency respiratory distress syndrome (SRDS)."

NRDS in IDM: term vs preterm infants:

NRDS due to surfactant deficiency can also occur in term or nearterm infants in IDM. Eldeen et al. did a study where 1547 neonates were admitted to the NICU with a diagnosis of increased work of breathing for further management. One hundred seventeen cases of term and near-term neonates (mean GA = 36.8 wks) had a confirmed diagnosis of Surfactant deficiency respiratory distress syndrome (SRDS). Who compared 60 preterm neonates with NRDS less than 35 weeks gestation (mean GA 27.5 weeks) as a control. The mean birth weight was 2.8 kg vs 1.1 kg in the preterm group. SRDS occurs more among the male gender (58%), with CS in 78.6% of all diagnosed cases. No apparent cause was found in 28.2%. 37.6% of all cases of NRDS in neonates born full-term were born to mothers with diabetes mellitus. Surfactant deficiency leading to NRDS is not uncommon among full-term and near-term neonates (10/1000 live births). By far, the most common associated risk factors are maternal diabetes mellitus and cesarean section. Gestational glucose intolerance or diabetes is one of the main risk factors of NRDS in full-term neonates, as confirmed by a study in the Bayi Children's Hospital in China (Liu J, Yang N, Liu Y 2014). This is notable as it shows there are cases of NRDS of IDM not only nationally but globally. Since gestational glucose intolerance or diabetes is one of the main risk factors of NRDS in full-term neonates, if diagnosed late and not managed properly, infants can be at risk of IDM and NRDS. Managing with respiratory support and surfactant are treatments, but prevention is possible through adequate prenatal care with the OBGYN (Liu J, Yang N, Liu Y 2014).

A small prospective study with 18 type 1 DM pregnant women was designed to show improvement in maternal euglycemia

with continuous subcutaneous glucose monitoring and continuous insulin administration. Glucose monitoring was performed on two different occasions where diabetic women are prone to be hyperglycemic: 72 h after betamethasone administration and during labor. Infants were observed for hypoglycemia and RDS as primary outcomes; none of them had hypoglycemia or RDS. Even though preterm infants <34 weeks GA are more at risk of having NRDS, preterm infants in this study did not show NRDS after being managed with insulin administration, suggesting better glycemic control in diabetic pregnancies can improve neonatal outcomes. Therefore, managing glucose levels is beneficial to prevent NRDS. This shows that NRDS can be prevented in pregnant women diagnosed with DM if appropriately managed with insulin in preterm and possibly full-term neonates. Further research may show that this most likely would occur in both full-term and preterm neonates in type 1 and 2 DM.

Additionally, a prospectively collected (1995-2007) Israel National Very Low Birth Weight Infant Database was used to observe pregestational or gestational Maternal DM multivariable logistic regression analysis was used to assess the independent effect of maternal DM status on infant mortality, RDS, and other complications of prematurity. Mothers with DM were more likely to have received a complete course of prenatal steroids than control mothers. Infants of diabetic mothers (IDM) had a slightly higher gestational age and birth weight than non-IDMs (Bental et al., 2011). The distribution of birthweight percentiles and the mean birthweight z scores were similar. The study showed no significant differences between the two groups regarding delivery room mortality, RDS, and other significant complications of prematurity (Bental et al., 2011). Total mortality and bronchopulmonary dysplasia rates were significantly higher in the nondiabetic group. The adjusted odds ratios for mortality, RDS, bronchopulmonary dysplasia, etc., did not significantly increase in the IDM group (Bental et al., 2011). This is significant because it shows that with modern management and adequate prenatal care, IDM born with a very low birth weight do not seem to be at an excessive risk of developing RDS or other significant complications of prematurity compared with non-IDM.

"Total mortality and bronchopulmonary dysplasia rates were significantly higher in the nondiabetic group. The adjusted odds ratios for mortality, RDS, bronchopulmonary dysplasia, etc., did not significantly increase in the IDM group (Bental et al., 2011). This is significant because it shows that with modern management and adequate prenatal care, IDM born with a very low birth weight do not seem to be at an excessive risk of developing RDS or other significant complications of prematurity compared with non-IDM."

Furthermore, a prospective study demonstrated that gestational diabetes is particularly an independent risk factor of NRDS in the near term to term infants after 34 weeks of gestation (Mortier

et al., 2017). Women with singleton pregnancy in labor after 34 weeks of gestation or admitted for planned cesarean section and who had been systematically screened for GDM were eligible to participate in this prospective cohort study. Diagnosis of SRDS was defined by the association of clinical signs of early neonatal respiratory distress with consistent radiologic features and requiring mechanical ventilation with a fraction of inspired oxygen (FiO2) >0.25 for a minimum of 24 hours and admission to the neonatal intensive care unit. A total of 444 women were included. GD was diagnosed in 60 patients. A neonatal SRDS was diagnosed in 32 cases.

"Compared to others, neonatal SRDS was significantly more often seen in neonates from women diagnosed with GDM: 12 vs. 20, respectively (p < 0.001). Women who delivered neonates with SRDS were significantly more likely to be obese (p = 0.002), to have undergone a cesarean section (p < 0.001), and to have received corticosteroid therapy before 34 weeks (p = 0.013). In multivariate analysis, GD was identified as an independent risk factor of neonatal SRDS (aOR 3.6; 95% CI 1.5–8.6; p = 0.005)."

Compared to others, neonatal SRDS was significantly more often seen in neonates from women diagnosed with GDM: 12 vs. 20, respectively (p < 0.001). Women who delivered neonates with SRDS were significantly more likely to be obese (p = 0.002), to have undergone a cesarean section (p < 0.001), and to have received corticosteroid therapy before 34 weeks (p = 0.013). In multivariate analysis, GD was identified as an independent risk factor of neonatal SRDS (aOR 3.6; 95% CI 1.5–8.6; p = 0.005). Other risk factors were maternal obesity (aOR 2.8; 95% CI 1.1–7.1; p = 0.029) and assisted vaginal delivery (Mortier et al., 2017). The study showed that the diagnosis of GDM is an independent risk factor of neonates developing NRDS in near-term to-term infants. This is evidence that there are cases where NRDS does not only develop in preterm IDM but also in those who are near-term or full-term.

Insulin as a risk factor:

While insulin can be used to manage glucose levels, as mentioned above, studies show it can also be a risk factor. A retrospective study studied in a large retrospective cohort the relationship between maternal DM status (non-DM, insulin-treated DM (IT-DM), and non-insulin-treated DM (NIT-DM) and respiratory distress in term and near-term inborn singletons. Results: Among 18 095 singletons delivered at 34 weeks of gestation or later, 412 (2.3%) were admitted to the neonatal intensive care unit (NICU) for respiratory distress within the first hours of life (Becquet et al., 2015). The incidence of NICU admission due to respiratory distress groups was 2.2%, 5.7%, and 2.1% in the nonDM, IT-DM, and NIT-DM groups, respectively (Becquet et al., 2015). Insulin treatment of DM, together with several other perinatal factors, was associated with a significantly increased risk for respiratory distress in this

study, which is crucial to consider since insulin is a treatment of DM. Several markers of the severity of respiratory illness, including durations of mechanical ventilation and supplemental oxygen and hypertrophic cardiomyopathy, were also found to increase following IT-DM compared to NIT-DM (Becquet et al., 2015). In a multivariate model, we found that IT-DM, but not NIT-DM, was significantly associated with respiratory distress independent of gestational age and cesarean section, with an incidence rate ratio of 1.44 (1.00–2.08) (Becquet et al., 2015). This study shows that the treatment of maternal DM with insulin during pregnancy is an independent risk factor for respiratory distress in term and near-term newborns. (Becquet et al., 2015). It is essential for Mothers who are diagnosed with diabetes to control their glucose levels before they begin insulin therapy.

"Using HbA1c may lack specificity and sensitivity. Establishing diagnostic criteria for HbA1C during pregnancy might reduce the need for an oral glucose tolerance test (OGTT) among pregnant women and perhaps be more straightforward to test as it can be a one-step test, requiring less time than oral OGTT. Not relying on OGTT might encourage more women to test and not be lost to follow-up."

Discussion and Future Prospects:

Using HbA1c may lack specificity and sensitivity. Establishing diagnostic criteria for HbA_{1C} during pregnancy might reduce the need for an oral glucose tolerance test (OGTT) among pregnant women and perhaps be more straightforward to test as it can be a one-step test, requiring less time than oral OGTT. Not relying on OGTT might encourage more women to test and not be lost to follow-up. Randomized controlled trials in larger populations could improve our understanding of the role of HbA_{1C} during pregnancy. As we do not have a clear answer on how to use HbA_{1c} during pregnancy, OGTT remains the preferred diagnostic test for GDM. If more research is done on the topic, GDM can be diagnosed and better managed, and neonates would not be at risk of being an IDM and have less of a risk of developing NRDS. (Yildiz Atar H, Baatz JE, Ryan RM). Overall, more research needs to be done on this topic as it is crucial to understand how diabetes plays a role in developing NRDS.

Determining the blood glucose concentration that defines hypoglycemia in newborns remains a topic of debate. At birth, the mother's glucose levels influence an infant's blood glucose levels. The decline in blood glucose after birth is more rapid and pronounced in infants of diabetic mothers (IDM). Historically, hypoglycemia has been defined as blood glucose levels below 40 mg/dL, a threshold recently endorsed by the American Academy of Pediatrics (AAP). If hypoglycemia is suspected, blood glucose screening in asymptomatic IDM typically begins around one hour of life or sooner. Early oral feedings, whether breastfeeding or formula, prevent or correct neonatal hypoglycemia, though high rates of cesarean deliveries and other complications can hinder breastfeeding.

Data from a different study show that hypoglycemic episodes in the well baby nursery (WBN) occurred between one to four hours of life, most corrected through early breastfeeding or formula feeding (Cordero et al., 2014). The low recurrence of hypoglycemia suggests a potential benefit from early feedings. The preliminary data indicating a low incidence of hypoglycemia in exclusively breastfed IDM is encouraging. Higher breastfeeding initiation rates in the WBN compared to the Neonatal Intensive Care Unit (NICU) likely reflect more frequent maternal-infant interactions.

Over a decade, our institution saw a decline in NICU admissions for IDM from 47% to 25%, possibly due to improved maternal glucose control and efforts to promote maternal-infant contact and breastfeeding. NICU admissions often cite respiratory distress, prematurity, and hypoglycemia prevention. The high rate of transient tachypnea may be linked to cesarean deliveries, while the decrease in respiratory distress syndrome (RDS) indicates better delivery timing. Quick resolution of respiratory distress and successful initiation of oral feedings in late preterm infants may lead to shorter NICU stays and earlier returns to the WBN. (Cordero et al., 2014).

"In conclusion, we have demonstrated through a review that there is a risk of NRDS in IDM, which can occur in both near-term and full-term neonates. This is due in part to hyperinsulinemia in infants secondary to maternal diabetes. Hyperinsulinemia decreases surfactant production, further decreasing the L/S ratio, and the development of NRDS occurs as a result."

Conclusion:

In conclusion, we have demonstrated through a review that there is a risk of NRDS in IDM, which can occur in both near-term and full-term neonates. This is due in part to hyperinsulinemia in infants secondary to maternal diabetes. Hyperinsulinemia decreases surfactant production, further decreasing the L/S ratio, and the development of NRDS occurs as a result. Prenatal care to check for DM is essential for Mothers, and if diagnosed with DM type 1 or 2, adequate glycemic control would be beneficial and possibly preventative in developing NRDS in neonates. As there have been cases in the United States and China, this can have global impacts if further research is conducted on the topic since the current literature is limited on in-depth reasoning behind the estimated gestational age of IDM who develop NRDS. Insulin and GDM may impose a risk on the development of fetal lung development through a variety of molecular mechanisms. This demonstrates the cruciality of determining ways to manage NRDS, as treatment is typically done with respiratory support. Doing so will have positive health impacts on the medical community, families, and beyond.

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Burnout In Nursing: A National Crisis- Are NICU Nurses Immune?

Tiffany A Moore, PhD, RN, FAWHONN, Alyson E. Hanish, PhD, MSN, RN

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.

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"Burnout is an occupational syndrome characterized by overwhelming exhaustion, depersonalization (i.e., cynicism), and a low sense of professional efficacy. Workplace systems and associated societal, cultural, structural, and organizational factors lead to burnout among our health workforce."

Burnout is a longstanding nurse issue and was exacerbated by the COVID-19 pandemic. Burnout is an occupational syndrome characterized by overwhelm-

ing exhaustion, depersonalization (i.e., cynicism), and a low sense of professional efficacy. Workplace systems and associated societal, cultural, structural, and organizational factors lead to burnout among our health workforce. Examples include excessive workloads, administrative burdens (e.g., electronic medical records), and lack of organizational support. Burnout is an enduring and significant barrier to well-being. The National Academies of Sciences, Engineering, and Medicine and the Committee on the Future of Nursing 2020-2030 published a 'call to action' to improve nurses' personal and professional well-being. The health and well-being of nurses are affected by the demands of their workplace, and in turn, nurse wellbeing affects patient care and safety.

"Nurses are stressed, and not just those nearing their retirement. In May 2023, the American Nurses Foundation (ANF) conducted a follow-up Mental Health and Wellness survey. Of the 7,419 respondents, 56% reported experiencing burnout, and 40% reported their work as hectic and felt little control over their workload."

Nurses are stressed, and not just those nearing their retirement. In May 2023, the American Nurses Foundation (ANF) conducted a follow-up *Mental Health and Wellness* survey. Of the 7,419 respondents, 56% reported experiencing burnout, and 40% reported their work as hectic and felt little control over their workload. Over half of the nurses surveyed reported feeling 'stressed,' 'frustrated,' exhausted,' or 'overwhelmed,' yet only one-third of the nurses in the study received mental health support. Of interest, the nurses more likely

to be experiencing these burnout symptoms in their current role were the nurses with less nursing experience. Specifically, over 70% of nurses <35 years of age reported feeling stressed or exhausted in the past 14 days, with 43% reporting their stress continuum levels in the "injured" or "ill" categories. These staggering and sobering statistics offer a glimpse into the push behind national priorities for nurse wellness initiatives.

"Not only does burnout affect an individual's physical and mental health, but burnout is also a public health crisis. A significant consequence of burnout is its impact on the other 'crisis,' the nursing shortage. An estimated shortage of over 78,000 registered nurses (RNs) is expected in 2025. According to the National Council of State Boards of Nursing, 100,000 nurses left the workforce during the pandemic."

Not only does burnout affect an individual's physical and mental health, but burnout is also a public health crisis. A significant consequence of burnout is its impact on the other 'crisis,' the nursing shortage. An estimated shortage of over 78,000 registered nurses (RNs) is expected in 2025. According to the National Council of State Boards of Nursing, 100,000 nurses left the workforce during the pandemic. By 2027, almost 900,000, or almost one-fifth of 4.5 million registered nurses, intend to leave the workforce due to stress, burnout, and retirement. This means the nurses who stay in the field will be exposed to additional nursing shortages and excessive workloads, further contributing to burnout. This threatens the national healthcare system at large if solutions are not enacted.

But what about nurses in the Neonatal Intensive Care Unit (NICU)? Are they immune to burnout? One pre-pandemic multisite study reported that the average burnout rate among 2073 NICU providers was 26%, ranging from 8-54% across 44 NICUs in the United States. A recent publication on burnout in NICU nurses (n=136) reported high levels of accomplishment in the majority of their NICU nurses; however, most nurses also reported high/moderate (n=63/51) levels of emotional exhaustion and high/moderate (n=41/74) levels of depersonalization. Although the authors did not find a direct correlation between burnout scores and turnover rates, these pre-pandemic levels of burnout among NICU nurses are alarming and consistent with the current trends found by ANF. Another recent systematic review searched for relevant studies addressing burnout and coping in the NICU. The authors identified five studies that measured burnout in NICU nurses and concluded that nurses working in the NICU experience high rates of burnout with minimal resources to utilize their coping skills. Specifically, the review highlighted the lack of evidence-based coping mechanisms offered to NICU nurses, and the difference between 'just coping' and 'coping well' is not understood. So, the answer is no: NICU nurses are not immune to burnout. In fact, given the severe nature of the ICU environment, these critical care nurses are at an even higher risk of burnout.

"Between empirical data and mainstream headlines, well-being initiatives for the nursing workforce are a national priority. Many organizations (e.g., National Institutes of Health and Centers for Disease Control- National Institute for Occupational Safety and Health) continue identifying feasible and sustainable interventions to target burnout and well-being, incorporating individual and system-level interventions."

Between empirical data and mainstream headlines, well-being initiatives for the nursing workforce are a national priority. Many organizations (e.g., National Institutes of Health and Centers for Disease Control- National Institute for Occupational Safety and Health) continue identifying feasible and sustainable interventions to target burnout and well-being, incorporating individual and system-level interventions. There also is an increased drive for policy changes and legislation related to health workforce well-being. Highlighted below are example sentinel reports and legislation related to health workforce burnout.

In 2022, the Office of the Surgeon General released an advisory addressing health worker burnout. The advisory highlights the urgent need to address the health worker burnout crisis across the United States, including action items for healthcare organizations, federal, state, local, and tribal governments, health insurers and payers, healthcare technolog-

ical companies, academic institutions, accreditation bodies, as well as family, friends, co-workers, and health workers themselves. Dr. Vivek Murthy, Surgeon General of the United States, reflects on our choice to make this moment a collective commitment- where health workers can look ahead and see a future where their health, safety, and well-being are as much a priority as the people and communities in their care.

- The National Academy of Medicine released the National Plan for Health Workforce Well-Being, highlighting the need for taking collective action for the future of the nation's health system. This National Plan's vision is a thriving health workforce with an environment that fosters well-being as they improve population health, enhance the care experience, reduce costs, and advance health equity- thus achieving the quintuple aim. The plan highlights seven priority areas for health workforce well-being, including workforce culture and technology. It addresses compliance, regulatory, and policy barriers for daily work, with relevant goals, associated actors, and action items.
- The Dr. Lorna Breen Health Care Provider Protection Act is a landmark, first-of-its-kind legislation supporting health workforce mental health and well-being. Since its passage in 2022, the Lorna Breen Act has funded (through the Health Resources and Services Administration- HRSA) 44 health organizations \$103 million to implement evidence-informed strategies that reduce and prevent suicide, burnout, mental health conditions, and substance use disorders. As of June 2024, The Dr. Lorna Breen Health Care Provider Protection Act is up for re-authorization.

"Our grant, the Nebraska Collaborative Investment in Nurses, aims to deliver wellness-based interventions and resources to address and reduce burnout and mental health conditions for those working in rural and medically underserved areas (MUA) across Nebraska."

In 2022, HRSA funded our team through the inaugural cohort of grantees via the Dr. Lorna Breen Health Care Provider Protection Act. Our grant, the Nebraska Collaborative Investment in Nurses, aims to deliver wellness-based interventions and resources to address and reduce burnout and mental health conditions for those working in rural and medically underserved areas (MUA) across Nebraska. Here are a few strategies we have found to have a meaningful impact on our health workforce, including nurses, in and beyond Nebraska.

Burnout and mental health conditions are multidimensional, requiring integrated individual and system-level action. Our team found organizational partnerships, including partnerships with the Nebraska Center for Nursing and the Nebraska Board of Nursing, critical to our success and impact. One of our shared goals was to reduce the stigma of mental health. This partnership led to the Nebraska Board of Nurs-

ing as the first nursing recipient of the ALL IN: WellBeing First Champion Badge, indicating that the nursing licensing applications in Nebraska were free from overly broad and invasive mental health questions. Clinicians often avoid mental health care because of the fear of losing their licenses and credentials, as language on applications can be seen as broad and invasive.

- Our team identified the need for a broader nursing career focus on wellness to address burnout and mental health conditions. Our team implemented the Wellness How One Lives Effectively (WHOLE) program for nursing students (during orientation) and practicing professionals focusing on rural and medically underserved areas. The WHOLE program is an adaptive and flexible curriculum that utilizes Acceptance and Commitment Therapy, Mindfulness-Based Stress Reduction, Stress Management and Resiliency Training, and the Eight Dimensions of Wellness. Our programming aimed to create a psychologically safe space to share, build comradery, and learn from each other. In addition, our team delivered mental health first aid (students and faculty) and psychological first aid (health workforce) with associated certification options.
- 3. From 2022-2024, our team offered no-cost continuing education on topics identified by nurses. Our team implemented Heal the Healer summits, webinars, and in-person retreats, which were highly attended (1000+ participants). Topics included burnout, workforce well-being, workplace incivility and violence, compassion fatigue, communication techniques, NICU debriefing models, and systems-level burnout interventions, including return on investment calculations.

Leaders have tremendous responsibility and opportunity to address issues at the root of burnout. Addressing the factors contributing to burnout is fundamental to fostering professional well-being and a thriving health workforce. We must acknowledge a large gap between where we are with nurse workforce burnout and well-being and where we need to be. We must work collectively on our future of health workforce well-being.

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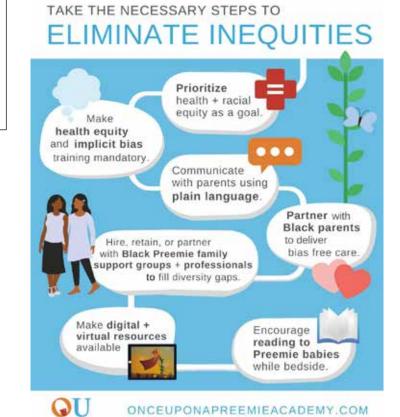


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The Indirect Impact of **RSV**



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

RESULTS

of providers agreed

that parents need

more information

RESULTS



FINANCIAL BURDEN

More than 3/3 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

(PP)

EMOTIONAL BURDEN

68%

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

SOCIAL BURDEN

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

TREATMENT CHALLENGES

PARENT EDUCATION & AWARENESS

Nearly 1/3

routine care.

86%

of providers said

they include RSV

education as part of

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

48%

99%

about RSV.

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.

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

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.



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Ethics and Wellness: Embracing the Full Spectrum of Intelligence in Neonatology Leadership

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

In the high stakes, often highly emotional world of a neonatologist, the role of a leader extends far beyond medical knowledge and technical expertise. A neonatologist must navigate the delicate balance of saving fragile lives, supporting anxious families, and managing a cohesive healthcare team while advocating with hospital administrations for additional funding. This requires a unique amalgamation of different types of intelligence, each contributing to leadership's overall efficacy and empathy. Among these, Intelligence Quotient (IQ), Emotional Intelligence (EQ), Spiritual Quotient (SQ), Creative Quotient (CQ), Adversity Quotient (AQ), Genius Quotient (GQ), and Business Quotient (BQ) stand out as essential elements.

"This requires a unique amalgamation of different types of intelligence, each contributing to leadership's overall efficacy and empathy. Among these, Intelligence Quotient (IQ), Emotional Intelligence (EQ), Spiritual Quotient (SQ), Creative Quotient (CQ), Adversity Quotient (AQ), Genius Quotient (GQ), and Business Quotient (BQ) stand out as essential elements."

The Pivotal Role of Adversity Quotient (AQ)

While each form of intelligence brings value, the ability to perform under adverse circumstances—reflected in a high Adversity Quotient (AQ)—is arguably the most crucial. Neonatology is a field fraught with unexpected challenges and high-pressure situations. A neonatologist with a high AQ can remain resilient, composed, and effective when faced with setbacks, ensuring the best possible outcomes for patients. This resilience supports personal well-being and serves as a beacon of strength and stability for the entire team, fostering a supportive and determined work environment. (1)

"While each form of intelligence brings value, the ability to perform under adverse circumstances—reflected in a high Adversity Quotient (AQ)—is arguably the most crucial."

The Interplay of EQ, SQ, and CQ in Patient Care:

Emotional Intelligence (EQ) is indispensable in Neonatology, where understanding and managing one's emotions and those of others is critical. High EQ enables a neonatologist to empathize with families, providing comfort and clarity during emotionally charged moments. It also helps build strong, trusting relationships with colleagues, essential for effective teamwork and communication. (2)

"Emotional Intelligence (EQ) is indispensable in Neonatology, where understanding and managing one's emotions and those of others is critical. High EQ enables a neonatologist to empathize with families, providing comfort and clarity during emotionally charged moments. It also helps build strong, trusting relationships with colleagues, essential for effective teamwork and communication. (2)"

Spiritual Quotient (SQ) contributes to a more profound sense of purpose and ethical grounding. In a field where moral dilemmas and end-of-life decisions are commonplace, a high SQ ensures that these decisions are made with compassion, integrity, and respect for the diverse beliefs of families and team members. (3)

"Having BQ or business acumen regarding the contribution of Neonatology to the institution's overall mission, ongoing commitment, gathering of philanthropy, and employee welfare at all levels requires both IQ and GQ but also training in business and the language of the CEO, CFO, and members of the Board of Directors. (4)"

Creative Quotient (CQ) fosters innovative thinking and problemsolving. Neonatologists often encounter complex cases that require out-of-the-box solutions. High CQ enables these healthcare professionals to devise new strategies and treatments, enhancing patient care and advancing medical practice.

Business Quotient (BQ) highlights the essential understanding of the institutional "bottom line" and how neonatologists and neonatal intensive care units contribute to the financial well-being of healthcare institutions that consume space, equipment, and required and essential staff. Having BQ or business acumen regarding the contribution of Neonatology to the institution's overall mission, ongoing commitment, gathering of philanthropy, and employee welfare at all levels requires both IQ and GQ but also training in business and the language of the CEO, CFO, and members of the Board of Directors. (4)

The Balancing Act of IQ and GQ:

Intelligence Quotient (IQ) remains a foundational element, reflecting the ability to acquire and apply knowledge. For a neonatologist, high IQ is essential for mastering the extensive medical knowledge required to diagnose and treat neonatal conditions effectively.

Genius Quotient (GQ), often associated with exceptional talent or brilliance, further elevates a neonatologist's capabilities. High GQ can drive breakthroughs in research, leading to advancements in neonatal care. However, those with high IQ or GQ can sometimes face jealousy or unfair treatment. A leader with a strong AQ can navigate these challenges gracefully, ensuring that their focus remains on patient care and team harmony rather than personal grievances. (5)

"This proposed quotient (ENQ) would prioritize fairness and ethical behavior, ensuring that all team members are treated respectfully and that their contributions are acknowledged. Such a quotient would be a natural extension of a high AQ, combined with EQ, fostering a culture of mutual respect and collaboration."

Towards a New Quotient: Equity and Nonmaleficence (ENQ):

Given the diverse demands of leadership in Neonatology, perhaps it is time to consider a new quotient that embodies equity, non-maleficence, rejection of bias, recognition of true merit, and the elevation of potential. This proposed quotient (ENQ) would prioritize fairness and ethical behavior, ensuring that all team members are treated respectfully and that their contributions are acknowledged. Such a quotient would be a natural extension of a high AQ, combined with EQ, fostering a culture of mutual respect and collaboration.

Conclusion:

Leadership in Neonatology requires various forms of intelligence, each contributing to the ability to provide exceptional care and effective management. While IQ and GQ are critical for medical

expertise and innovation, AQ stands out as the cornerstone of resilience and fair leadership. Coupled with high EQ, SQ, and CQ, a neonatologist can navigate the complexities of their role with empathy, creativity, and integrity. However, ENQ may be crucial. Embracing and cultivating these diverse forms of intelligence can lead to more equitable, compassionate, and effective neonatal care, ultimately benefiting patients, families, and healthcare teams.

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ELIMINATE INEQUITIES



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Letters to the Editor

Letter to the Editor: "Neonatal Outcomes After COVID-19 Vaccination in Pregnancy"

Dear Editor,

We want to thank and acknowledge the work done by Norman et al. for their study published in JAMA, "Neonatal Outcomes After COVID-19 Vaccination in Pregnancy." (1) During a period of great stress and uncertainty, it is essential to investigate if the suggested treatment during a global pandemic should continue to be accepted today if given a chance to start over. Investigating the consequences of our choices and learning how to improve our response to global health disasters is critical to improving patient outcomes, which this study accomplished precisely.

"During a period of great stress and uncertainty, it is essential to investigate if the suggested treatment during a global pandemic should continue to be accepted today if given a chance to start over. Investigating the consequences of our choices and learning how to improve our response to global health disasters is critical to improving patient outcomes, which this study accomplished precisely."

The population-based cohort study by Norman et al. included infants born between June 2021 to January 2023 in Norway and Sweden to mothers who received the mRNA vaccine at any point during their pregnancy, regardless of previous vaccination status (1). The study concluded that there was no increased risk of adverse neonatal outcomes with maternal COVID-19 vaccine exposure, even when controlling for various factors in the maternal population (1). We particularly commend the investigator's exhaustive list of covariates, which include but are not limited to the following: educational level, smoking status, body mass index (BMI), cardiovascular disease, diabetes, gestational diabetes, and SARS-CoV-2 infection before or during pregnancy (1). The following neonatal outcomes were measured: gestational age, infant sex, 5-minute APGAR scores, birth weight, small-for-gestationalage (SGA) or large-for-gestational-age (LGA), and neonatal ICU admissions (1). In addition to not finding an increased risk of adverse outcomes, the investigators found a decreased risk of neonatal nontraumatic intracranial hemorrhage, hypoxic-ischemic encephalopathy, and neonatal mortality (1). All previously stated findings continued to be seen when stratifying for vaccine manufacturers, Pfizer-BioNTech versus Moderna (1). However, it is unclear if this reduced risk may demonstrate an additional unrealized confounding variable.

This study has numerous strengths, including its large sample size, utilization of national registers to obtain data, numerous

covariate adjustments, longitudinal follow-up, and diversity of outcomes. First, the massive sample size of 196,470 infants increases the generalizability of statistical power and reduces the margin of error (1). Secondly, by utilizing a national register for data collection, the data can be considered accurate and reliable, further enhancing the study's generalizability and external validity. A key strength of this study is the exhaustive list of covariates. When discussing infant outcomes in the context of intrapartum maternal COVID-19 vaccination, numerous confounding factors can ultimately influence the final results. It is difficult to attribute a particular outcome to the vaccination itself unless there is robust analysis and foresight to account for all of the numerous confounding variables, which the authors were able to do.

"When discussing infant outcomes in the context of intrapartum maternal COVID-19 vaccination, numerous confounding factors can ultimately influence the final results. It is difficult to attribute a particular outcome to the vaccination itself unless there is robust analysis and foresight to account for all of the numerous confounding variables, which the authors were able to do."

Additionally, the ability to perform a four-week follow-up on the study participants added to the study results' usefulness. The initial weeks after birth are particularly eventful, and by choosing a shorter follow-up duration, specific outcomes may be missed, leading to inaccurate presentation of the data. Lastly, the study focuses on a diverse set of outcomes to help fully capture the effects of intrapartum maternal COVID-19 vaccination. Refraining from establishing a group of predetermined outcomes before beginning the study allowed the authors to address all outcomes rather than neglecting to address any unforeseen, albeit important, outcomes.

"Refraining from establishing a group of predetermined outcomes before beginning the study allowed the authors to address all outcomes rather than neglecting to address any unforeseen, albeit important, outcomes."

While the study has several strengths, as previously discussed, there are potential areas for improvement, such as the sample of interest, duration of follow-up, and gestational age when vaccinated. The study population is specific to children born in Sweden and Norway, which does not represent populations in countries with different morbidities and healthcare infrastructures. While

the authors successfully compared the study's findings to the historical data within their country, the generalizability of the study would improve if other geographical areas were incorporated. The study aimed to evaluate neonatal adverse outcomes in response to maternal COVID-19 vaccination during pregnancy; the study only followed the patients for 28 days. While these parameters will capture immediate outcomes, they fail to capture any adverse outcomes beyond this period. A growing concern has been post-vaccine myocarditis, an immune-mediated reaction that can take several weeks to appear in patients (2). Maternal antibody concentrations do not decline in their offspring until 3-6 months of age, indicating an extended study period is required (3).

"A growing concern has been postvaccine myocarditis, an immunemediated reaction that can take several weeks to appear in patients (2). Maternal antibody concentrations do not decline in their offspring until 3-6 months of age, indicating an extended study period is required (3)."

Additionally, this was a period when many parents feared exposing their young infants to the medical environment unnecessarily, which may have caused a delay in presentation. The overall impact on the child's health and development will be better understood by increasing the follow-up length. After extending the follow-up period, the authors can provide a more comprehensive understanding of the vaccine's safety profile. By incorporating the suggested improvements, the study can offer even more robust evidence regarding the safety and efficacy of COVID-19 vaccination during pregnancy, furthering an evidence-based approach to healthcare.

Concerning future studies, it would be interesting to investigate if the timing of vaccination, particularly during crucial first-trimester growth, impacts outcomes. An analysis incorporating vaccination timing, number of doses, and prior vaccine status could impact how providers advise their patients. Norman et al. conclude that antepartum mRNA (COVID-19) vaccination is not associated with an increased risk of adverse neonatal events within the first 28 days of life (1). Incorporating a randomized control study design with a study period greater than six months of life would lessen the possibility of committing a type II error.

As a society, we place great importance on the care of our vulnerable populations, pregnant women being one of our most vulnerable. We appreciate the authors' commitment to thoroughly investigate whether the accepted recommendation for COVID-19 vaccination during pregnancy yields the success and safety we depend on. Particularly in the United States, with growing vaccine

hesitancy among our general population and decreasing rates of childhood vaccinations, demonstrating the safety of vaccines by researchers outside of the pharmaceutical industry has never been as crucial as today (4,5). We are grateful for the work done by Norman et al. to demonstrate the vaccine's safety, which may consequently increase vaccine acceptance.

"With COVID-19 cases continuing to decrease across the country, the thought of a future pandemic continues to linger in the minds of hospitals and healthcare personnel worldwide. As new, aspiring physicians, it is essential to learn from our past actions to improve the lives of our future patients."

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Sincerely,

Alexandra Jones OMS-III, Dimplepreet Gill OMS-III, Parth Patel OMS-III, Michelle Booth OMS-III

Dear Alexandra Jones OMS-III, Dimplepreet Gill OMS-III, Parth Patel OMS-III, Michelle Booth OMS-III

The letter to the editor commendably recognizes the significant contributions of Norman et al. in their study "Neonatal Outcomes After COVID-19 Vaccination in Pregnancy." However, while the letter appropriately highlights the study's strengths, a more critical examination of its limitations is essential for a balanced perspective. (1)

"The letter to the editor commendably recognizes the significant contributions of Norman et al. in their study "Neonatal Outcomes After COVID-19 Vaccination in Pregnancy." However, while the letter appropriately highlights the study's strengths, a more critical examination of its limitations is essential for a balanced perspective. (1)"

First, the letter notes the study's large sample size of 196,470 infants, enhancing statistical power and generalizability. However, the sample's geographic limitation to Norway and Sweden may not reflect populations in countries with different healthcare infrastructures, economic conditions, and baseline health statuses. This limitation raises questions about the study's global applicability, and future research should consider including diverse populations to validate these findings across various settings. (1)

Moreover, while the study's use of national registers for data collection is praised for its accuracy and reliability, it is crucial to acknowledge potential biases inherent in such data sources. National registers, while comprehensive, may not capture all relevant health variables or nuances in maternal and infant care practices that could influence outcomes.

The letter also commends the exhaustive list of covariates considered by the study. While this is a strength, the possibility of unmeasured confounding variables remains. For example, the letter suggests that the observed reduction in specific adverse neonatal outcomes could indicate an unrealized confounding variable. This point warrants further investigation, as it is essential to ensure that all potential confounders are adequately addressed to draw defini-

tive conclusions about vaccine safety.

"Regarding the follow-up duration, the letter correctly identifies the limitation of a 28-day follow-up period. Immediate neonatal outcomes are essential, but they do not capture maternal vaccination's potential long-term effects on infant health. Extending the follow-up period would provide a more comprehensive understanding of the vaccine's safety profile."

Regarding the follow-up duration, the letter correctly identifies the limitation of a 28-day follow-up period. Immediate neonatal outcomes are essential, but they do not capture maternal vaccination's potential long-term effects on infant health. Extending the follow-up period would provide a more comprehensive understanding of the vaccine's safety profile. Additionally, concerns about post-vaccine myocarditis and the persistence of maternal antibodies suggest the need for more extended monitoring to detect delayed adverse events and assess sustained vaccine efficacy. (2)

"Furthermore, the letter suggests investigating the timing of vaccination during pregnancy, particularly during the first trimester. This is a valuable point, as different stages of fetal development may respond differently to maternal vaccination."

Furthermore, the letter suggests investigating the timing of vaccination during pregnancy, particularly during the first trimester. This is a valuable point, as different stages of fetal development may respond differently to maternal vaccination. Future studies should consider stratifying outcomes based on vaccination timing and dosage to provide more nuanced guidance for healthcare providers. (1)

Lastly, the letter rightly emphasizes the importance of independent research in demonstrating vaccine safety, especially in increasing vaccine hesitancy. However, it is also crucial to acknowledge and address the complex socio-political factors contributing to vaccine hesitancy. Transparent communication of research findings, active engagement with communities, and addressing misinformation are essential components of efforts to increase vaccine acceptance.

In conclusion, while the letter effectively highlights the strengths of Norman et al.'s study, a more critical perspective on its limitations and areas for future research is necessary. Addressing these

limitations will enhance our understanding of the safety and efficacy of COVID-19 vaccination during pregnancy and contribute to more informed healthcare decisions.

"In conclusion, while the letter effectively highlights the strengths of Norman et al.'s study, a more critical perspective on its limitations and areas for future research is necessary. Addressing these limitations will enhance our understanding of the safety and efficacy of COVID-19 vaccination during pregnancy and contribute to more informed healthcare decisions."

c/o Mitchell Goldstein, MD

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Sincerely,

mommile.

Mitchell Goldstein, MD, MBA, CML

Editor in Chief



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Erratum (Neonatology Today May, 2024)

There were no reported erratum for May 2024

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Keeping Your Baby Safe



COVID-19 colds

flu

How to protect your little one from germs and viruses

This year's cold and flu season may be a dangerous one - especially for vulnerable infants and children. Fortunately, there are proven protective measures that we can take to stay healthy.

Here's what you can do...

Wash Your Hands

- · This is the single, most important thing you can do to stop the spread of viruses.
- Use scap.
- Wash for more than 20 seconds
- Use alcoholbased sanitizers

Limit Contact with Others

- · Stay home when you can
- · Stay 6 feet apart when out.
- Wear a face mask when out.
- Change your clothes when you get home.
- Tell others what you're doing to stay safe.



Provide Protective Immunity

- Hold baby skin-to-skin.
 - Give them your breast milk
 - Stay current with your family's mmunizations



Take Care of Yourself

- Stay connected with your family and friends.
- Sleep when you can.
- Drink more water and eat healthy foods.
- Seek mental health support



Immunizations Vaccinations save lives. Protect your baby from flu, pertussis. RSV, and COVID-19 by getting your immunizations



Never Put a Mask on Your Baby

- · Because babies have smaller airways, a mask makes it hard for them to breathe.
- Masks pose a risk of strangulation and suffocation
- A baby can't remove their mask if they're suffocating

If you are positive for COVID-19

- · Wash with scap and water and put on fresh clothes before holding or feeding your baby.
- Wear a mask to help stop the virus from spreading.
- · Watch out for symptoms like fever, confusion, or trouble breathing
- Ask for help caring for your baby and yourself while you recover.

We can help protect each other.

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Should Infants Be Separated from Mothers with COVID-19?

FIRST DO NO HARM

SEPARATION

may not prevent

INFECTION.



SKIN to SKIN CARE

supports newborns' physiology.



SEPARATION

stresses parents and babies.





SEPARATION

weakens immune protections.





SEPARATION

disrupts breastfeeding putting babies' health at risk.



SEPARATING the DYAD

doubles providers' workload, burdening systems.



BASED ON THE ARTICLE.

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

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Gravens by Design: We Need Your Input! Ensuring Safe Spaces and Championing EDI at the Gravens Conference

Mitchell Goldstein, MD, MBA, CML, Robert White, MD

In an era marked by profound societal shifts and heightened awareness of equity, diversity, and inclusion (EDI), it is imperative that we critically evaluate the environments we create for our communities. The Gravens Conference, dedicated to caring for high-risk newborns and their families, must be a paragon of safety, inclusivity, and equity for all its attendees—newborns, families, and staff alike.

As the nation undergoes significant changes, certain groups increasingly feel unsafe and marginalized, particularly in specific regions. This reality underscores the necessity for the Gravens Conference to be a safe haven where everyone—regardless of race, gender, sexuality, or background—feels welcomed and valued. Since its inception, the conference has been held in South Florida, but tradition should not bind us if it compromises our commitment to EDI.

"This reality underscores the necessity for the Gravens Conference to be a safe haven where everyone—regardless of race, gender, sexuality, or background—feels welcomed and valued. Since its inception, the conference has been held in South Florida, but tradition should not bind us if it compromises our commitment to EDI."

Our guiding principle must be the well-being and comfort of our attendees. As we evaluate potential future venues, we must prioritize the sanctity and security of everyone involved. The criticality of safety extends beyond the walls of the conference venue. Attendees should feel secure and respected in nearby restaurants, parks, and beaches and during their travels to and from the conference. This holistic approach to safety ensures the experience is enriching and free from anxiety or discomfort.

Furthermore, accessibility is a cornerstone of our decision-making process. An ideal location would be near an accessible airport with affordable travel options, especially for our international attendees from Europe. This consideration is vital to maintaining the conference's global reach and ensuring diverse participation, which enriches our collective knowledge and understanding.

We have diligently provided a remote attendance option, recognizing the need for flexibility and inclusivity. This option has been crucial in accommodating those who cannot attend in person due

to various constraints. However, our goal is to avoid a scenario where those who would prefer to attend in person opt for the remote option solely due to concerns about the venue's safety or inclusivity.

"As such, we must continuously strive to create an environment that reflects our dedication to EDI. This means choosing a safe and inclusive venue and ensuring our programming, speakers, and materials represent our community's diverse voices and experiences."

The Gravens Conference is more than just a gathering; it is a community bound by shared values and a commitment to advancing the care of high-risk newborns and supporting their families. As such, we must continuously strive to create an environment that reflects our dedication to EDI. This means choosing a safe and inclusive venue and ensuring our programming, speakers, and materials represent our community's diverse voices and experiences.

While we have previously sought feedback, the evolving challenges and heightened awareness of EDI issues necessitate renewed input from our community. Ultimately, the decision rests with those who attend the conference. Should we remain in Florida, or is it time to explore new locations that better reflect our commitment to inclusivity and safety?

As we prepare for Gravens 2025 in South Florida, we have set September 1, 2024, as the deadline for deciding the venue for Gravens 2026. We urge you to share your thoughts and suggestions with us. Your voice is crucial in shaping the future of the conference. Through your feedback, we can ensure the Gravens Conference continues to be a beacon of safety, inclusivity, and support for all.

Please reach out to us directly at longlinealindapublishingcompany@gmail.com with your feedback. Together, we can ensure that the Gravens Conference not only meets but exceeds the expectations of our diverse and dedicated community.

By emphasizing the importance of safety, inclusivity, and EDI, we invite our community to partake in this critical decision-making process. Your input is invaluable in ensuring the Gravens Conference remains a safe, inclusive, and supportive environment for all.

Disclosures: The authors have no disclosures

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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)
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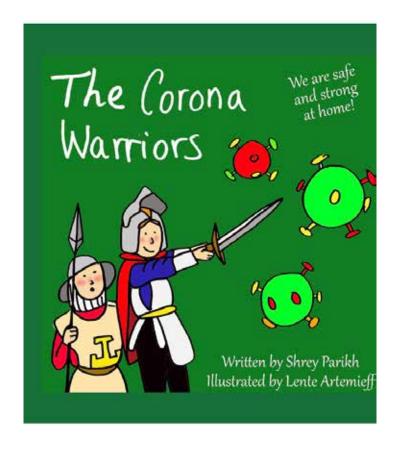
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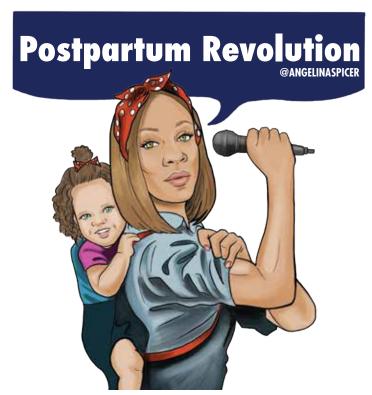
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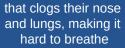


RSV can be deadly. If your baby has these symptoms, don't wait.
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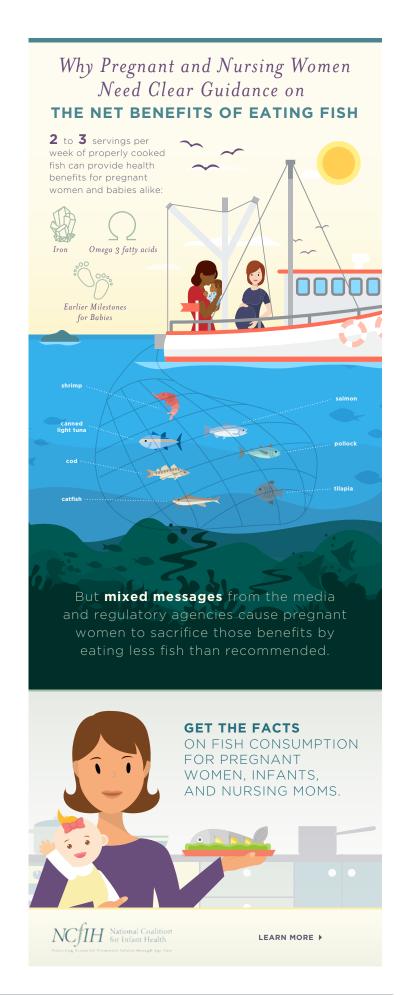
Fever that is more than 101° Fahrenheit



which is especially dangerous for babies younger that 3 months



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The Epigenetic Wild Card: Rethinking Current Practices for Future Safety

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

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

In the rapidly advancing field of medical science, what appears safe and benign today may prove to be not so in the future. This is particularly true when considering the intricate dance between our environment and our genetics—an interaction known as epigenetics. Epigenetics, the study of how behaviors and environmental factors can cause changes that affect gene expression, has unveiled the profound impact our surroundings can have on our DNA. These changes can sometimes lead to unforeseen health issues, turning what seemed like a minor risk into a significant threat over time.

"Epigenetics, the study of how behaviors and environmental factors can cause changes that affect gene expression, has unveiled the profound impact our surroundings can have on our DNA. These changes can sometimes lead to unforeseen health issues, turning what seemed like a minor risk into a significant threat over time."

One area where this is particularly concerning is the exposure to oxygen and its role in DNA damage. While oxygen is essential for life, high levels or prolonged exposure, particularly in medical settings, can lead to oxidative stress and DNA damage. This raises questions about the long-term safety of certain medical practices that involve high oxygen levels.

Chemical exposure from medical devices is another critical concern. For instance, certain plastics and coatings used in medical devices have been found to leach chemicals that may have epigenetic effects. These chemicals can disrupt normal gene expression, potentially leading to health issues later in life.

Therapeutic interventions such as pressure, steroids, and blood transfusions also warrant scrutiny. While often life-saving, these treatments can have profound and lasting impacts on gene expression. The potential long-term consequences of these interventions are not fully understood, making it imperative to balance immediate benefits with possible future risks.

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The Australian childhood cancer relative risks study highlights another dimension of this issue. The study suggests that some medical practices while addressing immediate health needs, may inadvertently increase the risk of cancer in children. For example, certain unavoidable conditions, such as prematurity, necessitate interventions that might carry long-term risks. However, other practices, such as elective Cesarean sections (C/S), warrant careful evaluation. The associations between these practices and increased cancer risks call for reevaluating their widespread use.

"Inhaled nitric oxide (iNO) therapy is a potent eye-opener in this context. iNO can be a lifesaver for treating persistent pulmonary hypertension in newborns (PPHN). However, its long-term safety remains under scrutiny. Should we consider more aggressive ventilation strategies before resorting to iNO?"

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Inhaled nitric oxide (iNO) therapy is a potent eye-opener in this context. iNO can be a lifesaver for treating persistent pulmonary hypertension in newborns (PPHN). However, its long-term safety remains under scrutiny. Should we consider more aggressive ventilation strategies before resorting to iNO? Moreover, if iNO is necessary, should it be weaned aggressively to the lowest possible dose and administered for the shortest possible time? These questions highlight the need for caution and a thorough evaluation of our current practices.

"Stress in and of itself has known epigenetic consequences. One of the earliest indicators of possible epigenetic triggers for homosexuality came from a German study. It found that those born in post-WWII Germany were more likely to identify as homosexual."

Stress in and of itself has known epigenetic consequences. One of the earliest indicators of possible epigenetic triggers for homosexuality came from a German study. It found that those born in post-WWII Germany were more likely to identify as homosexual. Living conditions at the time were akin to hell on earth, and maternal stress levels were invariably high. (Homosexual etiology was the topic of my first year psychology final essay.) We would later find that maternal stress in the first trimester could alter hormonal expression. Scans have shown that the brains of gay men have a similar reaction to women's when exposed to estrogen.

"The risks associated with early antibiotic exposure are adding up, but antibiotic stewardship notwithstanding, the use of antimicrobials can be all but eliminated through strict adherence to excellent infection control policies."

It could be argued that babies arrive in the NICU with epigenetic guns pre-loaded from intrauterine stress. Every procedure, sound, and bright light are added stressors that have the potential to alter gene expression later in life. The risks associated with early antibiotic exposure are adding up, but antibiotic stewardship notwithstanding, the use of antimicrobials can be all but eliminated through strict adherence to excellent infection control policies.

The evolving understanding of epigenetics underscores the importance of rethinking our medical interventions. We must consider not only the immediate benefits but also the potential long-term consequences. As we navigate this complex landscape, a more cautious and evaluative approach to medical practices may be necessary to safeguard future generations from unintended harm. A "hands-off" approach in the care of our patients may be the safest, most potent medicine we have to offer.

 Bembea MM, Ng DK, Carroll M, Roem JL, Groopman J, Caprarola SD, McElrath Schwartz J, Felling RJ, Salorio CF, Ellis G, Graham D, Everett AD. Cyclohexanone Exposure in Children on Extracorporeal Membrane Oxygenation Support. ASAIO J. 2022 Mar 1;68(3):419-425. doi: 10.1097/ MAT.0000000000001463. PMID: 33989209; PMCID: PMC8586036.

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. This article contains elements considered "off label" as well as maneuvers, which may sometimes be very effective but come with inherent risks. As with any therapy, the risk-benefit ratio must be carefully considered before they are initiated.

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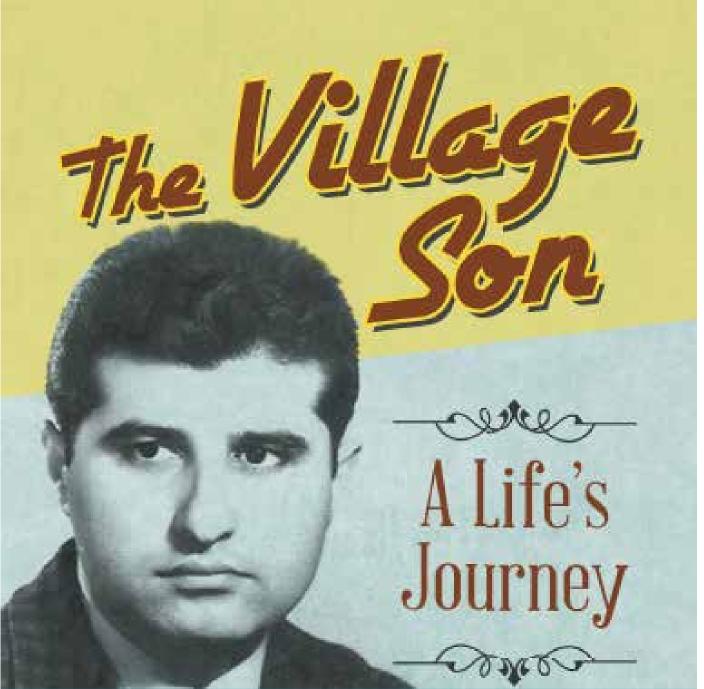
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1 week	\$30
1 month	\$120
1 semester	\$540
1 year	\$1,080
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Iranian village to a university professor in the United States of America in this memoir. As a boy, his unruly behavior was sedated by scholastic 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.

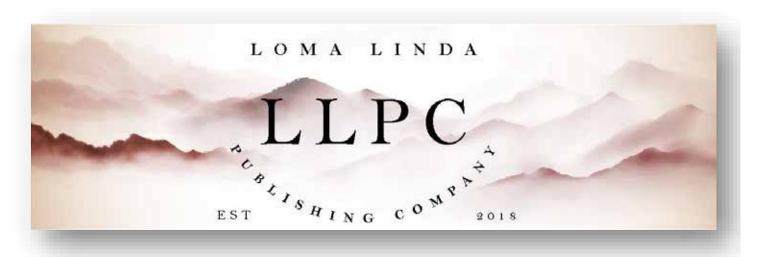
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when prescribing RSV prophylaxis

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and provide the supporting evidence



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First Candle: New Study Explores Nursing Students' Grasp of Racism and Health Disparities

Alison Jacobson



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"It is no secret that the U.S. has one of the highest rates of maternal mortality among the world's developed countries and that the rates for Black women (69.9 deaths/100,000 live births) are nearly three times higher than for White (26.6)."

It is no secret that the U.S. has one of the highest rates of maternal mortality among the world's developed countries and that the rates for Black women (69.9 deaths/100,000 live births) are nearly three times higher than for White (26.6).

Research continues to show that racism is a factor to be recognized and dealt with, and a recent study(1) looks at this from the perspective of nurses in training. The qualitative study looked at the perceptions of 16 White, Black, Hispanic and Asian maternal-

child nursing health students on the effects of bias and racism on health outcomes.

Five themes emerged from the findings:

Why are we so afraid to talk about race?

It's awkward; mistrust and fear of saying the wrong thing. There is a fear of being "shut down" if they bring up race, or of being called a racist. There is no provision for race discussion in the curriculum.

2. Whiteness, racism, and bias are learned behaviors

We learn from observation; nursing curriculum could perpetuate White supremacy; separate realities. Respondents cited family generational behaviors, recent sociopolitical (e.g. Black Lives Matter) coverage on social media among influences. They also felt nursing curriculum tends to be "average White American" focused as the norm, with little information about racial disparities and how to address them.

Racism was largely understood to be hostility toward others based on their appearance, and bias as unintentional and not fully understood.

3. I treat everyone the same.

Most felt that they could set aside any personal biases while caring for their patients, although they were aware that bias in general can affect patient outcomes.

4. I am just a nursing student.

The power structure within the clinical environment puts students in vulnerable positions, and they feel they need to gain experience and respect before challenging superiors on issues of race and bias.

5. We see racism and bias around us.

All study respondents reported having had direct or indirect exposure to racism or bias, in some cases toward themselves or their families and friends, and in other instances noticing different behaviors from providers and nurses toward those of their own race.

In addition, study authors found that the participants saw racism



Did you know that premature and low birth weight babies have a 4x greater risk for SIDS?

At First Candle we're educating parents, grandparents and caregivers about safer sleep to make sure all babies reach their first birthday. Learn more at firstcandle.org and bias from a personal level, but did not discuss it on an institutionalized or structural level, where affects social determinants of health and policies.

"Although small, the study shines a light on the gap between what is wanted and needed and what current realities seem to be. The American Association of Colleges of Nursing's nursing education core competencies calls for "nurses who are equipped to address systemic racism and pervasive inequities in health care."

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This study and the further research it could spur might lead to steps to broaden students' education around the effects of racism and bias on maternal health outcomes, and save lives.

References:

 Monika Costa, Michele K. Griswold, Lucinda Canty, Nursing student perceptions of racism and health disparities in the United States: A critical race theory perspective, Nursing Outlook, Volume 72, Issue 3, 2024. https://doi.org/10.1016/j. outlook.2024.102172.

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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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.

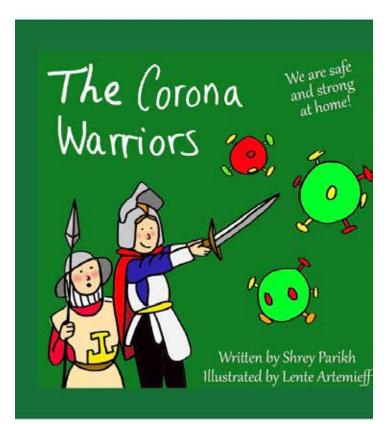
The RSV Research Group from professor Louis Bont, pediatric infectious disease specialist in the University Medical Centre Utrecht, the Netherlands, has recently launched an RSV Mortality Awareness Campaign during the 5th RSV Vaccines for the World Conference in Accra, Ghana.

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.





A Global Mortality Database for Children with RSV Infection



National Perinatal Association PERINATAL MENTAL HEALTH

nationalperinatal.org/position www.nationalperinatal.org/mental_health



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Thirteen-year-old Emily Rose Shane was tragically murdered on April 3, 2010 on Pacific Coast Highway in Malibu, CA. Our foundation exists to honor her memory.

In Loving Memory

August 9, 1996 - April 3, 2010



Each year, the Emily Shane Foundation SEA(Successful Educational Achievement)
Program provides academic and mentoring support to over 100 disadvantaged middle school students who risk failure and have no other recourse. We have served over 700 children across Los Angeles since our inception in the spring of 2012. Due to the COVID-19 outbreak, our work is in jeopardy, and the need for our work is greatly increased. The media has highlighted the dire impact online learning has caused for the very population we serve; those less fortunate. We need your help now more than ever to ensure another child is not left behind.

Make a Difference in the Life of a Student in Need Today! Please visit <u>emilyshane.org</u>

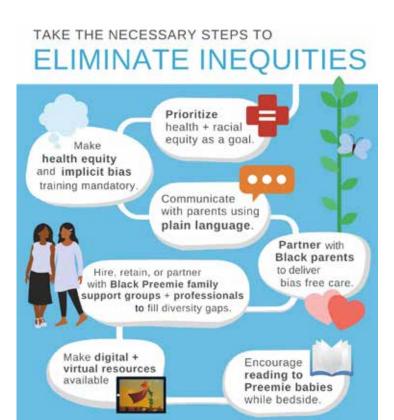
Sponsor a Child in the SEA Program

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.







Consult with specialists.

Support case



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education and resources online

Use technology to help parents bond with their babies when they can't be bedside









The move to telehealth services can compound inequities and disparities. Assess each family's technology skills and needs including the need to use their preferred language.



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National Coalition for Infant Health: The 2024 Steering Committee Meeting: A Collaborative Path Forward for Infant Health

Susan Hepworth, Mitchell Goldstein, MD, MBA, CML

tangible difference in the lives of infants and their families.



Protecting Access for Premature Infants through Age Two

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 morning of May 3rd began with a warm welcome from Dr. Mitchell Goldstein, the National Coalition for Infant Health Medical Director. His introduction set the stage for a day of significant discourse and planning. The first major agenda item, presented by Susan Hepworth, Executive Director of the National Coalition for Infant Health, focused on the coalition's education and advocacy priorities for 2024. Susan's insights underscored the importance of a unified approach in addressing the complex challenges facing infant health today. She highlighted key focus areas, such as improving access to neonatal care, advancing research on infant health issues, and promoting policies supporting families and healthcare providers. Her presentation set a tone of urgency and determination, reminding us that our collective efforts can make a

Steering Committee

The National Coalition for infant Health is supported by a volunteer steering committee, all of whom contribute significantly to lives of premature infants through work and parenting. Steering committee members represent national proporties, academic institutions, and parent organizations, and they provide leadership as well as help to mobilize partners in the field of corenaturity.

























"One of the most valuable aspects of our meeting was the opportunity for steering committee members to share updates from their respective organizations. Representatives from the American Academy of Pediatrics, the Association of Women's Health, Obstetric and Neonatal Nurses, and Expecting Health, among others, provided brief but impactful updates."

A Forum for Member Voices

One of the most valuable aspects of our meeting was the opportunity for steering committee members to share updates from their respective organizations. Representatives from the American Academy of Pediatrics, the Association of Women's Health, Obstetric and Neonatal Nurses, and Expecting Health, among others, provided brief but impactful updates. This exchange of information highlighted both the progress being made and the areas requiring increased attention and collaboration. For instance, the American Academy of Pediatrics discussed their recent initiatives to standardize neonatal care protocols nationwide, while the Association of Women's Health, Obstetric, and Neonatal Nurses emphasized the need for better training and support for neonatal nurses. Expecting Health shared their latest research findings on prenatal health education and its impact on birth outcomes. Each update served as a reminder of the diverse and multifaceted nature of infant health advocacy.

"Gavin Clingham, Senior Vice President at Woodberry Associates, provided a comprehensive overview of the current infant health policy landscape. His analysis was sobering and motivating, illustrating the critical need for continued advocacy and policy development support our youngest and most vulnerable citizens."

"These updates informed our discussions and reinforced the importance of industry collaboration in achieving our goals. Lindsay Hermany highlighted Merck's recent efforts to develop new vaccines for infants, while Cristal Grogan discussed Prolacta Bioscience's innovative approaches to enhancing neonatal nutrition through human milk-based products."

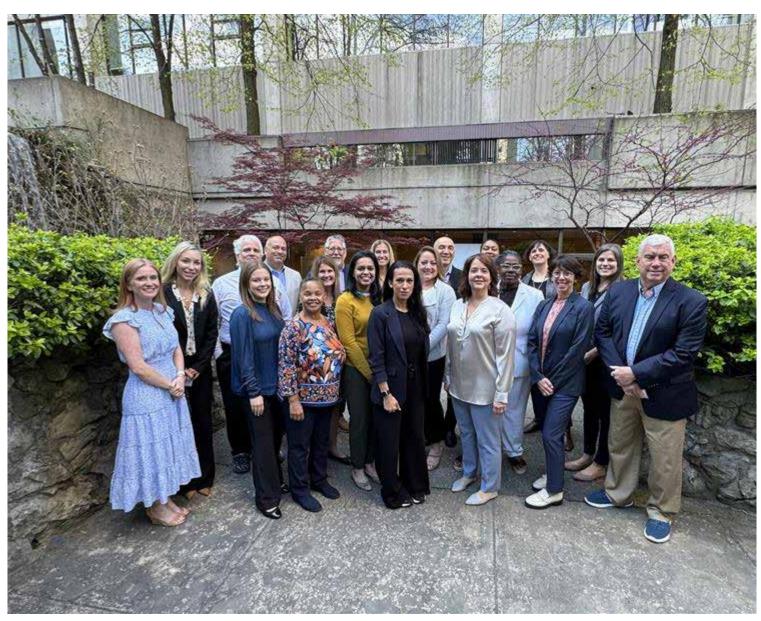
Understanding the Policy Landscape

Gavin Clingham, Senior Vice President at Woodberry Associates, provided a comprehensive overview of the current infant health

policy landscape. His analysis was sobering and motivating, illustrating the critical need for continued advocacy and policy development to support our youngest and most vulnerable citizens. Gavin highlighted the significant policy gaps, such as insufficient funding for neonatal research and the lack of standardized guidelines for infant care nationally. He also discussed recent legislative efforts to address these issues and encouraged the coalition to engage with policymakers actively. His presentation underscored the importance of staying informed and proactive in our advocacy efforts, reminding us that policy change is crucial to improving infant health outcomes.

Engaging with Industry Partners

Our meeting also included valuable contributions from our industry partners. Lindsay Hermany from Merck, Cristal Grogan from Prolacta Bioscience, and Chris Rizzo from Sanofi shared their companies' latest advancements and initiatives in infant health. These updates informed our discussions and reinforced the importance of industry collaboration in achieving our goals. Lindsay Hermany highlighted Merck's recent efforts to develop new vaccines for infants, while Cristal Grogan discussed Prolacta Bioscience's innovative approaches to enhancing neonatal nutrition through human milk-based products. Chris Rizzo provided an



overview of Sanofi's research on preventing and treating common neonatal infections. Their presentations demonstrated the critical role that industry partners play in advancing medical research and improving healthcare outcomes for infants.

"The subsequent sessions allowed for further updates from steering committee members, including representatives from PreemieWorld, NICU Parent Network, National Perinatal Association, Hand to Hold, GLO Preemies, National Association of Neonatal Nurses, National Black Nurses Association, and the National Association of Neonatal Therapists."

Continuing the Dialogue

The subsequent sessions allowed for further updates from steering committee members, including representatives from PreemieWorld, NICU Parent Network, National Perinatal Association, Hand to Hold, GLO Preemies, National Association of Neonatal Nurses, National Black Nurses Association, and the National Association of Neonatal Therapists. Each update was a reminder of the diverse and dedicated efforts being made across the board to improve infant health outcomes. For example, PreemieWorld discussed their ongoing advocacy for preterm infants and their families, while the NICU Parent Network shared stories of parental support and empowerment in neonatal intensive care units. The National Perinatal Association highlighted its initiatives to improve perinatal care standards, and Hand to Hold emphasized the importance of emotional support for families during and after a NICU stay. GLO Preemies, the National Association of Neonatal Nurses, the National Black Nurses Association, and the National Association of Neonatal Therapists each presented their unique contributions to the field, ranging from community outreach programs to specialized training for neonatal healthcare profession-

"Our collective dedication to advancing infant health is unwavering, and we are committed to working together to overcome the challenges ahead. The meeting reinforced the need for ongoing collaboration, continuous education, and relentless advocacy."

A Call to Action

As we concluded with lunch and adjourned the meeting at 12:30 p.m., it was clear that our work was far from over. The discussions and decisions during this meeting will serve as a blueprint for our

efforts in the coming year. Our collective dedication to advancing infant health is unwavering, and we are committed to working together to overcome the challenges ahead. The meeting reinforced the need for ongoing collaboration, continuous education, and relentless advocacy. It also highlighted the importance of listening to the voices of all stakeholders, including healthcare providers, researchers, industry partners, and, most importantly, the families and infants we serve.

"As we move forward, we must remain steadfast in our mission to ensure that every infant has the opportunity to thrive. Our future depends on the health and well-being of our youngest generation, and it is a responsibility we all share. The road ahead may be challenging, but our combined efforts and unwavering commitment can create a brighter and healthier future for all infants."

The 2024 Steering Committee Meeting was a testament to the power of collaboration. It reinforced the need for continued dialogue, shared knowledge, and joint action. As we move forward, we must remain steadfast in our mission to ensure that every infant has the opportunity to thrive. Our future depends on the health and well-being of our youngest generation, and it is a responsibility we all share. The road ahead may be challenging, but our combined efforts and unwavering commitment can create a brighter and healthier future for all infants.

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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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"Providing Safe Spaces for Babies, Families and Staff"

March 5-9, 2025

Sheraton Sand Key Resort Clearwater Beach, Florida For more information go to NeonatologyToday.net or PACLAC.org

Abstracts due September 30, 2024.





While common, **perinatal mood disorders** can be isolating and stigmatizing.

Parents need:



Support to manage their montal health



Access to screening



treatment



To care for their children,
PARENTS MUST ALSO CARE
FOR THEIR MENTAL HEALTH.

NCIH Nammal Cauthann
per Tailent Health

Your Pregnancy and Substance Use

4 Things you can do to improve your health and lower your risk for complications



Get Prenatal Care

Start early. Go to all your visits. Empower yourself with information so you can make smart decisions. Build relationships with providers who understand Substance Use Disorders (SUDs) and know how to help. Partner with them to reach your goals. But remember, you do not need to be abstinent from substance use to get care. Go now.



There are simple things you can do to limit the harm substances might do.

- Use fewer substances
- · Use smaller amounts
- Use less often
- · Learn how to use safer

Reducing or quitting smoking is a good place to start. Set your goals, then ask for help. One of the best things you can do is to stop using alcohol. We know that even small amounts are risky. And when combined with benzos and opioids, alcohol can kill.



Use Medications for Opioid Use Disorder (MOUD) if you are opioid dependent

Methadone and Buprenorphine (Subutex® or Suboxone®) are the "Standard of Care" during pregnancy because they:

- · Eliminate the risks of illicit use
- Reduce your risk for relapse
- Can be a positive step towards recovery



Take Good Care of Yourself

You deserve a healthy pregnancy & childbirth.

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

Your Health Matters





www.perinatalharmreduction.org | www.nationalperinatal.org

Why Pregnant and Nursing Women Need Clear Guidance on THE NET BENEFITS OF EATING FISH 2 to 3 servings per week of properly cooked fish can provide health benefits for pregnant women and babies alike: Omega 3 fatty acids Earlier Milestones for Babies But mixed messages from the media and regulatory agencies cause pregnant women to sacrifice those benefits by eating less fish than recommended. **GET THE FACTS** ON FISH CONSUMPTION FOR PREGNANT WOMEN, INFANTS, AND NURSING MOMS. NCTH National Coalition for Infant Health LEARN MORE ▶

Respiratory Therapists Enhance the Quality and Effectiveness of Interventions, Promoting Optimal Neurodevelopmental Outcomes

Kim Firestone, MS

The need for qualified and competent respiratory therapists (RTs) in the neonatal/pediatric arena is imperative, and the developmental care plan must be incorporated to establish a comprehensive neuroprotective strategy addressing the multifaceted needs of premature infants. RTs bring specialized expertise in respiratory physiology and management, making them integral multidisciplinary team members responsible for caring for preterm infants in the neonatal intensive care unit (NICU). Their involvement should be viewed not merely as an adjunct to care but as an essential component that enhances the quality and effectiveness of interventions promoting optimal neurodevelopmental outcomes.

"RTs bring specialized expertise in respiratory physiology and management, making them integral multidisciplinary team members responsible for caring for preterm infants in the neonatal intensive care unit (NICU). Their involvement should be viewed not merely as an adjunct to care but as an essential component that enhances the quality and effectiveness of interventions promoting optimal neurodevelopmental outcomes."

The neonatal respiratory therapist possesses a unique skill set that includes a deep understanding of respiratory mechanics, ventilation strategies, and airway management techniques explicitly tailored to the delicate physiology of premature infants. This specialized knowledge equips RTs to play a pivotal role in providing respiratory support, from conventional mechanical ventilation to advanced modalities such as high-frequency oscillatory and noninvasive ventilation. By actively participating in multidisciplinary care rounds and collaborative decision-making processes, RTs contribute valuable insights that contribute to developing and implementing individualized respiratory care plans tailored to each neonate's unique needs, creating a healing environment. Recommendations for positioning, oral feeding support, pain and stress management, skin care, and sensory stimulation can be incorporated into the plans.

Additionally, RTs bring to the table a wealth of experience in assessing and managing the respiratory consequences of common neonatal morbidities such as respiratory distress syndrome, bronchopulmonary dysplasia, and apnea of prematurity. Their ability to anticipate and promptly address respiratory complications is in-

strumental in mitigating the risk of adverse outcomes and optimizing long-term respiratory function in preterm infants. In addition to providing direct patient care, RTs play a vital role in caregiver education. Randomized clinical trials have shown that early discharge is possible without adverse health effects when discharged with preterm infants based on physiologic criteria. The RTs can empower parents to participate actively in the respiratory care of their infants and foster a supportive environment conducive to family-centered care.

"Randomized clinical trials have shown that early discharge is possible without adverse health effects when discharged with preterm infants based on physiologic criteria. The RTs can empower parents to participate actively in the respiratory care of their infants and foster a supportive environment conducive to family-centered care."

A hallmark practice in developmental care is kangaroo care, which involves prolonged skin-to-skin contact between infants and their parents. While the benefits of kangaroo care in promoting bonding, thermoregulation, and neurodevelopmental outcomes are well documented, emerging evidence suggests that this intervention may also positively impact respiratory function. Studies have shown that kangaroo care significantly reduces respiratory efforts in ventilated preterm infants, enhances the diaphragm's electrical activity, improves respiratory muscle strength, and reduces the duration of respiratory support required for preterm infants. RTs can help optimize respiratory outcomes while fostering parental involvement and confidence in caring for their infants by encouraging kangaroo care into routine caregiving practices and providing guidance on safe and effective positioning techniques. Education can be provided to families with bedside simulation with the RT and team to perform standing transfer, stabilization of equipment, and the endotracheal tube. Proper education reinforces confidence for all team members, including the parents.

Despite advances in neonatal respiratory care, unplanned extubation remains a significant concern in the NICU, posing both immediate risks to the infant's respiratory status and potential long-term consequences for neurodevelopment. Preventing unplanned extubation requires a multifaceted approach that addresses technical factors, such as securement methods and equipment selection, and human factors, such as caregiver education and vigilance. RTs are well positioned to contribute to developing and implementing comprehensive unplanned extubation prevention protocols, leveraging their expertise in airway management and

ventilator technology to identify risk factors and implement proactive strategies. By collaborating with families to educate them on the importance of maintaining a secure airway and providing ongoing support and reinforcement. RTs can help alleviate the risk of unplanned extubation and promote safe and effective respiratory care practices in the NICU.

"The involvement of respiratory therapists in developmental care initiatives for preterm infants is essential for optimizing respiratory outcomes and fostering holistic neurodevelopmental support. By providing their specialized knowledge, clinical expertise, and collaborative approach to care, RTs contribute valuable insights and interventions that complement the efforts of the multidisciplinary team. "

The involvement of respiratory therapists in developmental care initiatives for preterm infants is essential for optimizing respiratory outcomes and fostering holistic neurodevelopmental support. By providing their specialized knowledge, clinical expertise, and collaborative approach to care, RTs contribute valuable insights and interventions that complement the efforts of the multidisciplinary team. Through proactive engagement in respiratory care planning, caregiver education, and unplanned extubation prevention, RTs are necessary in promoting the health, well-being, and developmental potential of preterm infants in the NICU.

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SHARED DECISION-MAKING PROTECTS MOTHERS + INFANTS

DURING COVID-19

KEEPING MOTHERS + INFANTS TOGETHER

Means balancing the risks of...

- HORIZONTAL INFECTION
- SEPARATION AND TRAUMA







EVIDENCE

We encourage families and clinicians to remain diligent in learning up-to-date evidence.

PARTNERSHIP

What is the best for this unique dyad?

SHARED DECISION-MAKING

S EEK PARTICIPATION
HELP EXPLORE OPTIONS
A SSESS PREFERENCES
R EACH A DECISION

E VALUATE THE DECISION





TRAUMA-INFORMED

Both parents and providers are confronting significant...

- FEAR
- GRIEF
- UNCERTAINTY

LONGITUDINAL DATA

We need to understand more about outcomes for mothers and infants exposed to COVID-19, with special attention to:

MENTAL HEALTH
 POSTPARTUM CARE DELIVERY



NEW DATA EMERGE DAILY, NANN AND NPA ENCOURAGE PERINATAL CARE PROVIDERS TO ENGAGE IN CANDID CONVERSATIONS WITH PREGNANT PARENTS PRIOR TO DELIVERY REGARDING RISKS, BENEFITS, LIMITATIONS, AND REALISTIC EXPECTATIONS.

Partnering for patient-centered care when it matters most.





Fragile Infant Forums for Implementation of Infant and Family-Centered Developmental Care Standards: The Role of Clinical Social Work

Joan Hebert Cook MSW, ACSW, LCSW



"Clinical social workers have been integral to NICU interprofessional teams and adhere to the National Association of Social Workers (NASW) Standards for Social Work in Health Care Settings."

Introduction

The Infant and Family Centered Developmental Care (IFCDC) standards are designed to be used by all professionals who work with babies and families in intensive care. They recognize the primary importance of professionals adhering to their own guidelines and recommended clinical practice standards. (1) Clinical social workers have been integral to NICU interprofessional teams and adhere to the National Association of Social Workers (NASW) Standards for Social Work in Health Care Settings. (2) More specifically, they adhere to the National Association of Perinatal Social Work "Standards for social work services in the newborn intensive care unit" (3) (https://napsw.org/docs/NICU-standards_2.pdf—see Footnote 1). Adhering to social work standards and applying relevant IFCDC standards in providing care to babies and families utilize both an integrative approach to practice and add specificity to work with this population.

"Adhering to social work standards and applying relevant IFCDC standards in providing care to babies and families utilize both an integrative approach to practice and add specificity to work with this population."

Clinical social workers' role in the NICU

Social workers practice in most intensive care units and contribute significantly to the support babies and families need. Some articles regarding their special contributions have described how they can apply their education and perspectives to their role in IFCDC practice. (3–6)

As a current member of the IFDC Standards Consensus Panel, with over thirty years of experience as an NICU clinical social worker, I will provide a perspective on applying the IFCDC standards to the clinical social work role in newborn intensive care. The descriptions provided here identify how social work practice is consistent with and amplifies the implementation of current IFCDC standards.

The IFCDC Standards that are most aligned with NICU clinical social work practices

The six domains of IFCDC evidence-based standards (https://nicudesign.nd.edu/nicu-care-standards/) describe competencies and best practices for interprofessional work in intensive care. (1) A brief description of how the two perspectives complement each other follows.

Standard 1, Systems Thinking: The intensive care unit shall exhibit an infrastructure of leadership, mission, and a governance framework to guide the performance of the collaborative practice of IFCDC.

This IFCDC standard speaks clearly to the role of social work with families. Clinical social work practice uses systems thinking, apparent in evidence-based approaches, to address the problems families present and strive to implement effective solutions. Understanding clinical theories is essential to the social workers' role and allows exploration of specific origins of behavior seen in NICU families. Consistent biopsychosocial assessment by clinical social workers helps to understand each family's system, including respect for diversity, ethnic background, language, equity, and inclusion. (7) Attention to these values is a standard part of the family assessment and represents aspects of the National Association of Social Work (NASW) standards for best practice. (3)

"Understanding clinical theories is essential to the social workers' role and allows exploration of specific origins of behavior seen in NICU families. Consistent biopsychosocial assessment by clinical social workers helps to understand each family's system, including respect for diversity, ethnic background, language, equity, and inclusion."

Standard 2: The Intensive Care Unit shall provide a professionally competent interprofessional collaborative practice team to support the baby, parent, and family's holistic physical, developmental, and psychosocial needs from birth through hospital transition to discharge and assure continuity to follow-up care.

Clinical social work practice guides examining NICU families' conditions, beliefs, cultural contributions, and environmental factors to understand better the issues and hardships they may face. They add a dimension of assessment and appropriate exploration of resources for parents with additional mental health needs, providing essential elements for collaborative practice. Recognition of the myriad of mental health issues that often arise from the stress of a baby's hospitalization is often initially assessed by the clinical social worker in intensive care. The social worker is wellpositioned to refer to both in-hospital and home-based services and assure a smooth transition to appropriate interprofessional resources. The baby's developmental needs are best provided by a supportive family, which, in turn, often needs tangible financial support, housing, and relationship support from the hospital to the home. Social workers strive to find and provide appropriate resources so families can support the baby's development and avoid harm. (8)

"Recognition of the myriad of mental health issues that often arise from the stress of a baby's hospitalization is often initially assessed by the clinical social worker in intensive care. The social worker is well-positioned to refer to both in-hospital and home-based services and assure a smooth transition to appropriate interprofessional resources."

Competency 2.7: Team members shall demonstrate systems context sensitivity applicable across practice settings and show re-

spect for individual and collective professional skill sets.

Striving for best functioning interprofessional practice teams requires knowing what each profession in the unit does and understanding that role to assure interprofessional collaboration. Assumptions are often made about each other's professional role, like assumptions about families. Addressing this IFCDC standard can be accomplished with educational programs where professionals present their roles, ethics, and beliefs to each other, leading to the discovery of better ways to collaborate. (9)

While each discipline may not be involved in every aspect of care or project, essential contributions are often assumed but not recognized. For example, for some research projects, social workers are involved in soliciting information needed from families. Obtaining information from family members can facilitate getting essential information and provide families with accurate information about studies. Decisions to implement new programs in the unit necessitate how all the potentially impacted parties are included in the planning. In doing so, ancillary staff can provide necessary support to the primary activities or operations of the organization. (10)

"For example, for some research projects, social workers are involved in soliciting information needed from families. Obtaining information from family members can facilitate getting essential information and provide families with accurate information about studies. Decisions to implement new programs in the unit necessitate how all the potentially impacted parties are included in the planning."

Competency 2.8: Open and ongoing communication among team members, including parents and families, shall be encouraged.

As social workers are especially adept in obtaining family information, it behooves teams to consider and acknowledge their contributions carefully. Social workers who collaborate on areas within their role have valuable information to communicate to team members and assist the team in communicating with parents. Just as family capabilities and strengths can be overlooked, the abilities and contributions each other's professions provide are sometimes neglected. Often, the cause of neglect is a lack of communication. Providing an inclusive, collaborative effort emphasizes the roles involved, enhances collaboration, and obtains accurate information

Competency 2.9: Teams will manage real and potential conflict using an adopted defined process to negotiate an effective resolution

It is often difficult to distinguish similar family support roles, leading

to interprofessional conflict. Orientation to each NICU team member's responsibilities, observation, and shadowing of each other early on provides opportunities to understand how each functions in the unit and thus avoid role conflict. Although recent constraints on time and staff turnover have led to less time spent on how the professions can work together, these discussions are essential in promoting collaboration and avoiding conflict. Opportunities for discussion and delineating roles can increase professional satisfaction and, more importantly, decrease family confusion regarding who does what. Respecting what each staff member brings to the unit and developing a process to resolve problems contribute to effective program implementation, including effective change.

"Orientation to each NICU team member's responsibilities, observation, and shadowing of each other early on provides opportunities to understand how each functions in the unit and thus avoid role conflict."

Additional IFCDC clinical practice standards, competencies, and best practices

"Although many of the specific clinical standards and competencies do not apply to clinical social work roles, per se, the foundational IFCDC principles of a) the infant as an effective communicator, b) the primary parent-baby relationship, c) infant mental health practices, d) neuroprotective environments and relationships; e) individualized care; and e) neurophysiologic development should be well represented by all interprofessionals who practice in the NICU."

In addition to the overarching IFCDC standards of systems thinking, five evidence-based practice domains of the IFCDC standards (https://nicudesign.nd.edu/nicu-care-standards/) describe competencies and best practices needed for interprofessional clinical work in intensive care. Although many of the specific clinical standards and competencies do not apply to clinical social work roles, per se, the foundational IFCDC principles of a) the infant as an effective communicator, b) the primary parent-baby relationship, c) infant mental health practices, d) neuroprotective environments and relationships; e) individualized care; and e) neurophysiologic development should be well represented by all interprofessionals

who practice in the NICU. Current evidence-based clinically relevant practices identified by the interprofessional consensus panel include positioning and touch for the newborn, sleep and arousal interventions, skin-to-skin contact with intimate family members, reducing and managing pain and stress in newborns and families, and feeding, eating, and nutrition delivery.

Social workers are particularly adept at addressing stressful events and processes in parents and staff members, whether physical or psychosocial. Each IFCDC evidence-based practice has the potential to produce stress or stress regulation for babies, parents, and staff, and, as a result, it relates to social work practice. (11) When social workers are familiar with interprofessional best practice guidelines and can offer strategies for ameliorating stress, they can assist parents in understanding what is happening with their babies during the stress of hospitalization. (11, 12) Additionally, if parents perceive mixed messages among professional staff, resulting in parental confusion or frustration with what they are being told, social workers can assist with clarification and/or appropriate communication. (13)

Social workers familiar with IFCDC best practices regarding alleviating pain and stress in babies can help explain to parents what is done for pain and stress management as well as what babies need to thrive. In knowing how and what is provided to babies to reduce pain/stress, social workers can educate parents, find out their questions, and direct them to the discipline that can best answer them. (14) Questions about pain management can be discussed at the beginning of a baby's stay and be even more critical in the dying process. (15, 16) While others teach the science of all these skills, social workers are "cheerleaders" and "advocates" for parents in this and other aspects of involvement with their baby.

"While others teach the science of all these skills, social workers are 'cheerleaders' and 'advocates' for parents in this and other aspects of involvement with their baby."

In addition to individual work with families, groups are often led by social workers and offer a way of providing education and reducing stress and anxiety for parents around topics of concern. Some of the topics most often discussed when parent advocates work with new parents individually or in groups are issues around sleep, skin to skin, and feeding, as represented in the IFCDC standards.

Conclusion

Clinical social work is essential in supporting babies and families in intensive care. The guiding principles that The National Association of Perinatal Social Workers adheres to in healthcare settings demonstrate similar values represented in the IFCDC standards. In particular, both demonstrate a desire to address diversity, equity, and inclusion, a holistic view of the families served, an appreciation of systems thinking, alleviating stress in babies and their parents, and supporting families in the continuum from hospital to home. They are essential team members and healthcare providers, so their contributions to interprofessional planning and com-

munication are essential. Additionally, they are essential partners in the interprofessional team as they often add significant information and communication regarding family situations and needs. Communication with parents can be best assured when social work is included in the planning and executing of policies and programs that affect the families with whom they work. When clinical social workers are familiar with all the IFCDC practice standards and how they apply each standard to their clinical practice, they can best support the outcomes of babies and families in intensive care.

"The guiding principles that The National Association of Perinatal Social Workers adheres to in healthcare settings demonstrate similar values represented in the IFCDC standards. In particular, both demonstrate a desire to address diversity, equity, and inclusion, a holistic view of the families served, an appreciation of systems thinking, alleviating stress in babies and their parents, and supporting families in the continuum from hospital to home."

Footnote 1. "NAPSW Standards are to provide Standards related to the Perinatal Social Work service areas. The Standards are available on the NAPSW website in a read-only format. The Standards are available to NAPSW members. If a non-member is interested in copies, then the non-member would have to request copies of the Standards, and there is a fee for all eleven standards (\$30.00). Requests can be submitted to the Standards Committee on the website. All the Standards are copyrighted and cannot be copied.

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NT

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Orlando, Florida
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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.



The fewer germs your baby is exposed to, the less likely they are to get sick. Let people know you need their help to stay well. Limit visitors. Avoid crowds. Stay away from sick people.



Immunizations save lives. Stay up-to-date with your family's flu vaccinations and COVID-19 boosters. This helps our community stay safe by stopping the spread of deadly viruses.



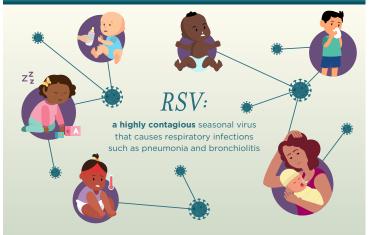
Babies older than 6 months can get a flu shot and COVID-19 vaccinations. There is no vaccine for RSV, but monthly antibody shots during RSV season can help protect them.



WE CAN HELP PROTECT EACH OTHER.

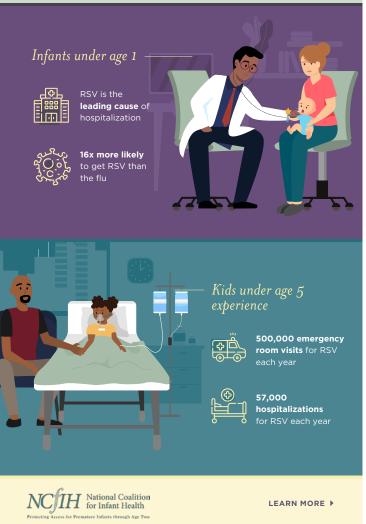


Respiratory Syncytial Virus



The Gap Baby: An RSV Story







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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 Cross-Ref and will assign DOI to all published material.

As we indicated last month, we look forward to a number of new features as well.

- 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.
- 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
- Sponsors will be able to sign up directly on the website and submit content for both the digital and PDF issues of Neonatology Today.

Neonatology Today will continue to promote our Academic True Open Model (ATOM), never a charge to publish and never a charge to subscribe.

If there are any questions about the new website, please email Dr. Chou directly at:

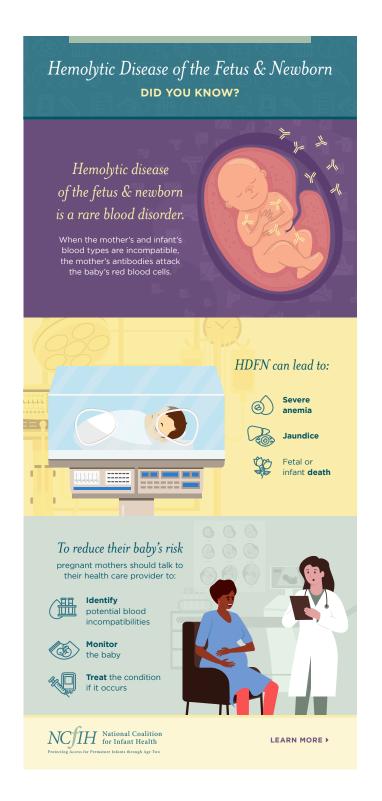
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Which Infants are More Vulnerable to Respiratory Syncytial Virus?

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.



FREE for our NICU COMMUNITY

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- · Bonding with Your Baby
- Caregivers Need Care Too





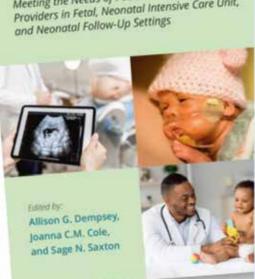






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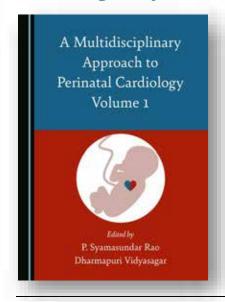
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A Multidisciplinary Approach to Perinatal Cardiology *Volume 1*

Edited by P. Syamasundar Rao and Dharmapuri Vidyasagar



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Book Description

Recent developments in diagnostic and therapeutic aspects of cardiac and neonatal issues have advanced the care of the newborn. To achieve excellence in cardiac care, however, close interaction and collaboration of the pediatric cardiologists with neonatologists, pediatricians, general/family practitioners (who care for children), anesthesiologists, cardiac surgeons, pediatric cardiac intensivists, and other subspecialty pediatricians is mandatory. This book provides the reader with up-to-date evidence-based information in three major areas of neonatology and prenatal and neonatal cardiology. First, it provides an overview of advances in the disciplines of neonatology, prenatal and neonatal cardiology, and neonatal cardiac surgery in making early diagnosis and offering treatment options. Secondly, it presents a multidisciplinary approach to managing infants with congenital heart defects. Finally, it provides evidence-based therapeutic approaches to successfully treat the fetus and the newborn with important neonatal issues and congenital cardiac lesions. This first volume specifically explores issues related to perinatal circulation, the fetus, ethics, changes in oxygen saturations at birth, and pulse oximetry screening, diagnosis, and management.

About the Editors

Dr P. Syamasundar Rao, MD, DCH, FAAP, FACC, FSCAI, is Professor of Pediatrics and Medicine and Emeritus Chief of Pediatric Cardiology at the University of Texas-Houston Medical School. He received his medical degree from Andhra Medical College, India, and subsequently received post-graduate training both in India and the USA before joining the faculty at the Medical College of Georgia, USA, in 1972. He has also served as Chairman of Pediatrics at King Faisal Specialist Hospital and Research Center, Saudi Arabia, and Professor and Director of the Division of Pediatric Cardiology at the University of Wisconsin and St. Louis University, USA. He has authored 400 papers, 16 books and 150 book chapters, and is a recipient of numerous honors and awards.

Dr Dharmapuri Vidyasagar, MD, MSc, FAAP, FCCM, PhD (Hon), is currently Professor Emeritus in Pediatrics at the University of Illinois, Chicago, where he served as Professor of Pediatrics for four decades. He is a graduate of Osmania Medical College, India. He has published over 250 papers and authored several books with a focus on prematurity, neonatal pulmonary diseases and neonatal ventilation. His goal is to reduce neonatal mortality in the USA and around the world, and he has received multiple awards and honors including the Ellis Island Award.

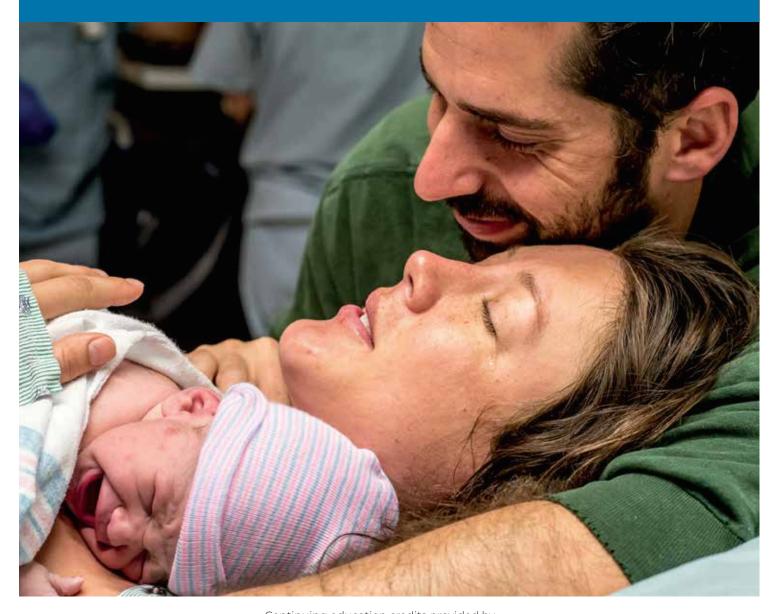


Online L&D Staff Education Program

Caring for Pregnant Patients & Their Families:

Providing Psychosocial Support During Pregnancy, Labor and Delivery

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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:

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Tracy Pella, MA

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Erin Thatcher, BA

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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.

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SHARED DECISION-MAKING 'PROTECTS MOTHERS + INFANTS

DURING COVID-19



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
F 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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Healthy Start Programs Receive \$105 Million to Reduce Maternal Mortality

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.





"Pregnancy and the birth of a child should be the cause of great joy. However, for too many, the event is tragic. More than 800 women died of maternal causes in 2022. (1)"

Pregnancy and the birth of a child should be the cause of great joy. However, for too many, the event is tragic. More than 800 women died of maternal causes in 2022. (1)

To improve maternal outcomes, in April, the U.S. Department of Health and Human Services announced that more than 100 community-based <u>Healthy Start</u> programs around the country would share **\$105 million** in funding. (2)

More Than 80% of Maternal Deaths are Preventable:

Local recipients of this funding will enroll women, infants, and children up to 18 months old in programs tailored to improve health outcomes during pregnancy and early childhood. Such interventions have <u>produced positive reductions</u> in excess mortality. (3)

Programs will concentrate outreach in communities experiencing

comparatively high rates of maternal and infant deaths – at least 1.5 times the national average. Black and Indigenous women and those living in under-resourced and rural communities are more likely to experience these tragic outcomes (4) partly due to inadequate access to prenatal health care. More than 80% of such maternal deaths are preventable. (5)

"Black and Indigenous women and those living in under-resourced and rural communities are more likely to experience these tragic outcomes (4) partly due to inadequate access to prenatal health care. More than 80% of such maternal deaths are preventable. (5)"

CDC data has tracked a <u>decrease in the maternal mortality rate</u> in 2022 after unusual spikes during the COVID-19 pandemic. (6) Race and wealth disparities persist, however.

"Healthy Start programs offer a range of support, from food assistance and nutrition counseling to birthing classes, transportation for medical appointments, and even housing assistance. The new funding can also be used to hire culturally responsive providers, giving expectant and new mothers the support of a counselor, therapist, doula, or social worker, according to their needs."

Tailored Support Helps Moms' Individual Needs

Healthy Start programs offer a range of support, from food assistance and nutrition counseling to birthing classes, transportation for medical appointments, and even housing assistance. The new funding can also be used to hire culturally responsive providers, giving expectant and new mothers the support of a counselor, therapist, doula, or social worker, according to their needs.

Services also include universal screening for intimate partner violence, a devastating but preventable factor that impacts <u>both maternal and infant health</u> and occurs at higher rates in communities impacted by poverty. (7)

"The recently announced Health Start funding is part of the Biden Administration's Blueprint for Addressing the Maternal Health Crisis. which aims to improve infant and maternal health."

The recently announced Health Start funding is part of the Biden Administration's Blueprint for Addressing the Maternal Health Crisis, which aims to improve infant and maternal health.

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

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Help Support a Child \$1,000

Help Our Youth Share Their Story

The International Children's Advisory Network, Inc., (iCAN) is a worldwide network of children's advisory groups, known as Kids Impacting Disease Through Science (KIDS) and Young Persons Advisory Groups (YPAGS). These dedicated youth member groups work in unison around the world to provide a voice for children and families in medicine, research, and innovation. Every year iCAN hosts a summit that brings these groups together in shared experience and camaraderie. ICAN is a tax exempt organization as described in Section 501(c)3 of the Internal Revenue Code.

We want as many children to come to the summitt as possible. However, attending the Summit is not always possible for our families who often experience financial hardships. So iCAN pays for lodging, most food, and a transportation stipend in addition to summit activities. As more youth join iCAN, we need your help more than ever! Your tax-deductible donation of \$1,000 will help bring a child to the Summit, to make it possible for that child to share their voice, and to interact with medical professionals and other kids like them. We will acknowledge you as an individual. donor or you may dedicate the donation in honor of a loved one, as you wish.



www.icanresearch.org #iCANMakeADifference in in in





Immunizing Yourself Against COVID-19

COVID-19 vaccines have been shown to:

- Lessen the severity of symptoms¹
- Reduce disease transmission³
- Reduce risk of mortality²
- Make communities healthier and safer⁴



COVID-19 vaccines are available for children, adolescents and adults. There are 3 types to choose from.



mRNA VACCINES

New to market, but research has been ongoing since the 1990s.



PROTEIN SUBUNIT VACCINES

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



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



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.

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

the immune system to the virus.

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 participants⁶



Proven safe and effective

for adults as well as children⁷



Vetted and approved by the US FDA and EMA and endorsed by the WHO⁸⁻¹⁰

Get Your Jab

Vaccines are available at your:



Doctor's office



Neighborhood pharmacy



Community health center

- https://www.mayoclinic.org/diseases-conditions/coronavirus/symptomscauses/syc-20479963
- 2. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8782520/
- https://www.nejm.org/doi/full/10.1056/nejmc2107717
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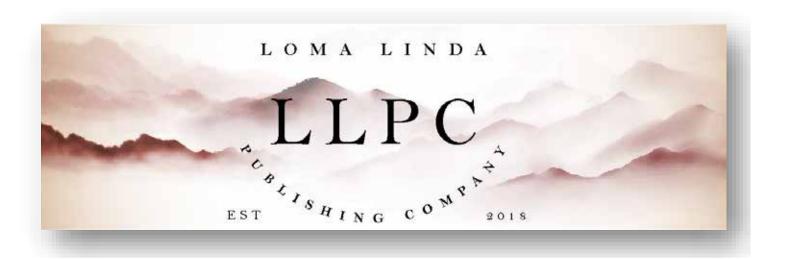
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- http://www.bccdc.ca/Health-Info-Site/Documents/COVID-19_vaccine/WH0-EUA-qualified-covid-vaccines.pdf



Talk to your health care provider or pharmacist about which vaccine is right for you.







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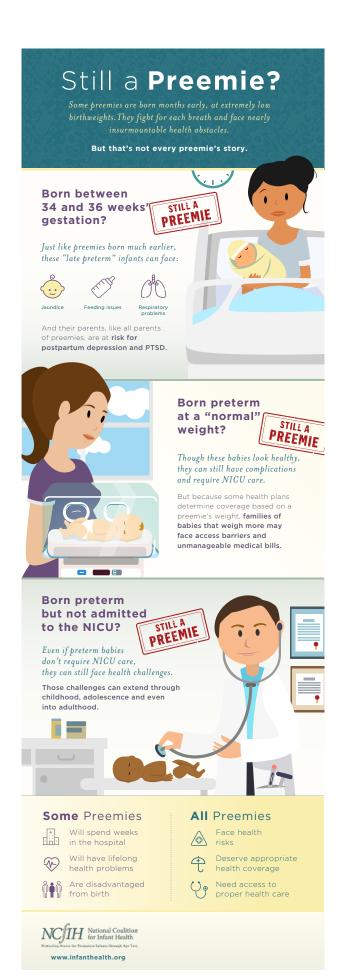


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- Increased emotional support resources for parents and caregivers suffering from PTSD/PPD
- Access to RSV preventive treatment for all premature infants as indicated on the FDA label
- Clear, science-based nutrition guidelines for pregnant and breastfeeding mothers
- Safe, accurate medical devices and products designed for the special needs of NICU patients

www.infanthealth.org

iCAN Chronicles: Empowering Youth Voices in Pediatric Healthcare: HypnoVR, Kismet Health, and iCAN's Global Impact

Sabina Schmidt Goldstein-Becerra



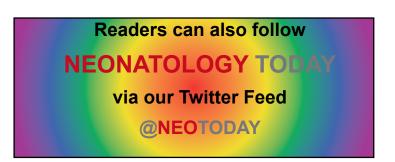
Get involved today and Join the iCAN Parent Council!

"CAN values and understands that all patients, even the youngest, often have ideas that can help improve their healthcare experiences. 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."

iCAN, the International Children's Advisory Network, is the premier global pediatric platform empowering the patient voice in health-care, 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. 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 to have their voices heard. Our amazing 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, 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.









Uma -8:39 AV

Hil I'm super interested in your work. I am in pediatric clinical research now, and my research group is hosting focus groups for the next two weeks. What suggestions/recommendations do you have to increase patient engagement and empower participants during focus groups? Also, do you think there is anything more that physicians and other healthcare providers should do to increase patient engagement and accessibility in clinical trials?



chloe 8:40 AM

I am currently trying to start a club at my high school for those who are interested in the medical field. I am located in New York but would you or your company be able to offer any opportunities for us?



1

"This feature is dedicated to the memory of our beloved youth member, Ilaria, who passed away on Saturday, June 8, at just 17 years old. Ilaria had been a cherished member of the Kids Bari group since 2020, where she contributed immensely despite bravely battling Schimke immuno-osseous dysplasia, a rare multisystem disorder."



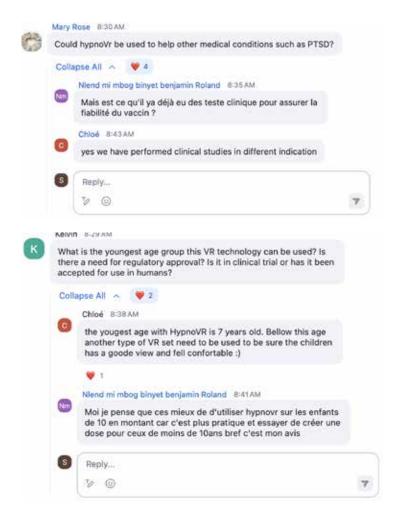
This feature is dedicated to the memory of our beloved youth member, Ilaria, who passed away on Saturday, June 8, at just 17 years old. Ilaria had been a cherished member of the Kids Bari group since 2020, where she contributed immensely despite bravely battling Schimke immuno-osseous dysplasia, a rare multisystem disorder. Ilaria was an exceptional individual and a promising artist whose creativity and vibrant spirit touched us deeply. Her legacy will endure through her beautiful artwork, which we will proudly feature on the 2024 iCAN Research and Advocacy Summit t-shirts featured above, ensuring she remains with us in spirit.

From KIDS Bari: "Ilaria was our waypoint for ideas, projects, and hearts, allowing us to be part of her unchosen journey, never losing her incredible smile and restless voice. Your voice will be our guidance; in quietness, it'll shine like the peak's sun."

June's Ask the Experts - June Recap and Looking Ahead

Spotlight on HypnoVR: Revolutionizing Medical Care with Virtual Reality





At this month's Ask the Experts session, we heard from two founders behind HypnoVR, Dr. Chloé Chauvin and Dr. Denis Graff. Dr. Chloé Chauvin is the Scientific Director specializing in anesthesia and paediatric intensive care at CHRU Hospital in Strasbourg. Both are anaesthesiologists with extensive backgrounds in ICU care and pain management. Meanwhile, Dr. Denis Graff focuses on anesthesia, intensive care, and pain management at a private clinic in the same city.

"HypnoVR has emerged as a widely adopted medical device accessible to everyone and classified as a category 1 device. It utilizes medical hypnosis through virtual reality to effectively alleviate patient pain and stress, significantly enhancing the quality of care in healthcare settings worldwide."

HypnoVR has emerged as a widely adopted medical device accessible to everyone and classified as a category 1 device. It utilizes medical hypnosis through virtual reality to effectively alleviate patient pain and stress, significantly enhancing the quality

of care in healthcare settings worldwide. Recognized as a leader in immersive digital therapies for pain and anxiety management, HypnoVR has already been integrated into over 300 hospitals and clinics globally. Its efficacy is supported by 18 clinical studies across various medical specialties, validating its non-medicated, user-friendly, and broadly applicable approach.

HypnoVR is particularly inspiring because Dr. Chloé Chauvin and Dr. Denis Graff took a bold leap into entrepreneurship to start this med-tech startup. Their passion for improving patient outcomes through innovative technology led them to develop HypnoVR, overcoming challenges and uncertainties.

We deeply appreciated Denis' insights on the excitement and challenges of pursuing a career in med tech—always aiming to make a meaningful impact on patient care. He emphasized the importance of staying curious, continuously learning, and abreast of innovations in this dynamic field.

Chloé's advice was equally valuable, highlighting that one should not be a doctor to contribute significantly to med tech. Expertise in cybersecurity, marketing, and intellectual property are essential pillars in driving innovation forward.

Their openness in sharing their experiences resonated deeply with our youth members. We look forward to collaborating further with Chloe and Denis to gather feedback from iCAN youth and to continue enhancing the impact of HypnoVR in medical care, with the potential to earn the iCAN seal of approval!

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

You are invited to another session of *Ask the Experts*! Join us on August 17, at 8 AM PST, 11 AM EST.

We are excited to spotlight one of our extraordinary teens, Alejandra Wells, at the next *Ask the Experts* and her inspiring journey as the founder of Hiya, an online jewelry boutique dedicated to promoting mental wellness among teens. She is a member of the University of Nebraska Medical Center and Children's Hospital and Medical Center's KIDS Nebraska, our advisory group for teens aged 13-18 that focuses on understanding, communicating, and improving medicine, research, and innovation for all children.

"We are excited to spotlight one of our extraordinary teens, Alejandra Wells, at the next Ask the Experts and her inspiring journey as the founder of Hiya, an online jewelry boutique dedicated to promoting mental wellness among teens."

Alejandra was also recently honored as Mentor Nebraska's Young Leader of the Year, demonstrating that even the youngest leaders can drive significant progress in mentoring and mental health advocacy. In her acceptance speech, Alejandra outlined her ambitious plans to launch a teen lifestyle magazine — a print and digital platform designed to amplify the voices of young change-

makers in her community. We cannot wait to have you at Ask the Experts, Alejandra!



Secure your spot by registering here today!

Save the dates for additional Ask the Experts:

September 21 with Ray Browning, CEO of Biomotum

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

As we look ahead, we remain committed to hosting empowering sessions of *Ask the Experts* for our youth members, where we will delve into critical topics and gain insights from inspiring leaders in their respective fields. Please let us know if you are interested in being a featured speaker on *Ask the Experts*!

<u>Transforming Pediatric Telehealth: Kismet Health x iCAN Youth</u> Members



Kelvin 12:38 PM

I am based in a rural town 100 km from Cape Town (south Africa) and we have used Zoom to now, connecting our youth chapter to scientists who cannot always travel over weekends. For example in one study scientists consulted with youth about gastric lavage procedure in children, across 100 km distance. I think we can certainly use a resource like Kismet in a research setting, because researchers can be very caught up in their academic world and don't always understand how to communicate with young people.



On June 25, we hosted a webinar with Kismet Health to discuss our youth's feedback on their telehealth platform, which features a drawing tool for therapy sessions. The call included insights from co-founder and COO Christie Sander and Head of Clinical Services Dr. Arwin Cotas-Girard. Christie described her role as one that encompasses a wide range of responsibilities, from investor meetings to team building and product shipping. She emphasized her enjoyment of the dynamic nature of her job. Dr. Cotas-Girard, a child psychologist, explained her role in ensuring the platform's features are clinically appropriate and beneficial for young patients. She also assists in marketing the platform to other providers.

"This principle, essential to their mission, sometimes slows development but ensures that patient concerns are addressed with utmost care."

During the webinar, Christie discussed the challenges faced in developing Kismet's technology, particularly around patient safety and privacy. She emphasized that while some features had to be delayed or de-scoped due to their complexity, Kismet remains steadfast in prioritizing patient safety. This principle, essential to their mission, sometimes slows development but ensures that patient concerns are addressed with utmost care. At iCAN, we also believe that patients should be at the forefront of healthcare decisions, empowering them as the drivers of their health journeys.

"Dr. Cotas-Girard highlighted how Kismet ensures that telehealth services are engaging and effective for young patients. They rely on professional experience and extensive research, including surveys of over 1,000 providers and direct feedback from kids and teens."

Dr. Cotas-Girard highlighted how Kismet ensures that telehealth services are engaging and effective for young patients. They rely on professional experience and extensive research, including surveys of over 1,000 providers and direct feedback from kids and teens. Our survey data showed that while our youth members found Kismet an engaging platform, they suggested improvements such as AI for users with limited fine motor skills and a broader selection of images for the drawing feature. Kismet Health responded positively, committing to implement many of these suggestions, some already underway. If these updates are successful, Kismet will earn the coveted iCAN Seal of Approval, indicating the product is "Kid Reviewed, Kid Approved." Kismet is also committed to ongoing engagement with our youth members to ensure the platform continues to meet their needs.

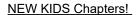
"Kismet plans to continue incorporating feedback through regular updates and possibly establishing a Kids Advisory Board. They aim to enhance accessibility and affordability, especially for underserved communities, and leverage emerging technologies like AI to improve their platform."

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iCAN Spotlight!

<u>Fiona and Sofia Kouwabunpat: Trailblazing Young Leaders in</u> Healthcare Host Benefit Concert







We are incredibly proud of these exceptional young women, Fiona Kouwabunpat and Sofia Kouwabunpat. As the daughters of a CHOC Children's primary care physician, they were inspired to pursue careers in healthcare and dedicate themselves to serving others.

"Last year, they were CHOC MI4 interns and helped launch our CHOC iCAN chapter. This year, they have excelled as chapter leads and, in a generous act of giving back, held a benefit concert to showcase their remarkable piano talents, which they also shared with CHOC patients at Seacrest Studios. They aimed to raise \$5,000 but surpassed it by raising \$7,200!"

Last year, they were CHOC MI4 interns and helped launch our CHOC iCAN chapter. This year, they have excelled as chapter leads and, in a generous act of giving back, held a benefit concert to showcase their remarkable piano talents, which they also shared with CHOC patients at Seacrest Studios. They aimed to raise \$5,000 but surpassed it by raising \$7,200!

Fiona and Sofia will travel to Bari, Italy, to represent the CHOC iCAN chapter at our international iCAN summit this summer.

Way to go, Fiona, Sofia, and the entire CHOC iCAN Chapter!



We are excited to announce the addition of new iCAN chapters! Welcome aboard KIDS Warsaw, KIDS Rare Hellas (Greece), and KIDS Kosovo to our growing global network!

We encourage you to contact us if you are interested in establishing your chapter, whether in collaboration with a hospital, university, or school. Let us collaborate to make a positive impact in pediatrics worldwide.



iCAN's 2024 Annual Research and Advocacy Summit

Presented by Jumo Health

July 15th-19th

To sponsor our Summit, visit bit.ly/iCANsponsorships

To register for our Summit, bit.ly/iCANSummit24Registration

Our upcoming 2024 Summit, Presented by Jumo Health, is just days away and will be held in Bari, Italy. Our network is beyond excited for this event, but we need your support to make it truly unforgettable!

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 2024 Summit: Your sponsorship plays a pivotal role in the organization of the Summit, ensuring an impactful experience for all attendees.
- Sponsor a Child to Attend: Your sponsorship directly impacts a child's life, allowing them to attend the Summit in Bari. Your support covers travel, accommodation, and participation, offering a world of learning and empowerment.

Together, we are shaping a brighter future for pediatric health-care. 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's unite in Bari, Italy, to create a summit experience that empowers the pediatric community for years to come!

Disclosures: There are no reported disclosures

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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!



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SHARED DECISION-MAKING **PROTECTS MOTHERS + INFANTS DURING COVID-19**

KEEPING **MOTHERS** + INFANTS TOGETHER

Means balancing...

Risk of infection





EVIDENCE

We encourage families and clinicians to remain diligent in learning up-to-date evidence.

PARTNERSHIP

SHARED DECISION-MAKING

What is the best for this unique dyad?

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.

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www.AcademyofNeonatalCare.org.

Keeping Your Baby Safe



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

WARNING

Vaccinations save lives. Protecting your baby from COVID-19, flu and pertussis lowers their risks for complications from respiratory infections.



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



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flu

coronavirus

pertussis

RSV



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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.







STAY AWAY FROM SICK PEOPLE

Avoid crowds. Protect vulnerable babies and children.



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While common, perinatal mood disorders can be isolating and stigmatizing.

Parents need:







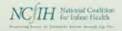
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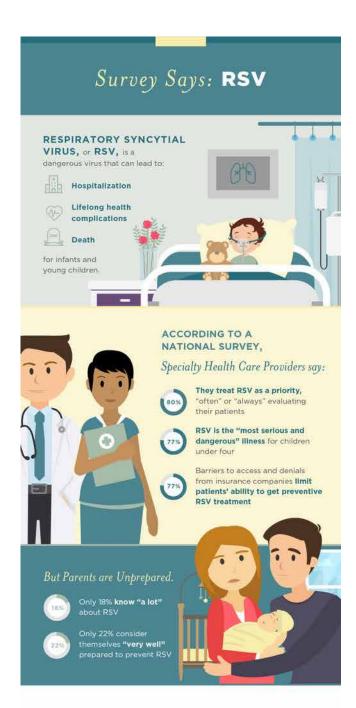
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To care for their children,
PARENTS MUST ALSO CARE
FOR THEIR MENTAL HEALTH.



World Sported or Built 4



RSV EDUCATION & AWARENESS CAN HELP

After parents learned more about RSV, they were:

65%

"More concerned" about their child contracting the disease

Likely to ask their doctor about RSV



NCTIH National Coalition for Infant Health for infant Access for Fernance Infant Access for Fernance Infant Access for Fernance Infant Infant

www.infantHealth.org/RSV

Electronic Fetal Monitoring

Barry S. Schifrin, MD; Maureen Sims, MD

"Electronic Fetal Monitoring [EFM], or cardiography [CTG], has been used worldwide for over half a century, making it the most common obstetric procedure. While financial investment in technology is considerable, there are repeated questions of whether the money is well spent and whether the technology is more harmful than beneficial. (1-3, 4-6)"

Malcolm Gladwell has said: The key to good decision-making is not knowledge. It is understanding. We are swimming in the former. We are desperately lacking in the latter._ Malcolm Gladwell (2008). "Outliers: The Story of Success", p.31, Hachette UK

Electronic Fetal Monitoring [EFM], or cardiography [CTG], has been used worldwide for over half a century, making it the most common obstetric procedure. While financial investment in technology is considerable, there are repeated questions of whether the money is well spent and whether the technology is more harmful than beneficial. (1-3, 4-6)

In these articles by Sartwelle, a malpractice lawyer, and others, including respected medical authors, they allege that research to date has shown that EFM has neither prevented adverse short or long-term outcomes nor has it ameliorated any measure of fetal adversity, including C.P. Further, they allege, that EFM has almost no scientific foundation and was untested by clinical trials. It comes "without an instruction manual, without premarket testing to support the expectations of efficacy, without clearly defined parameters for use, and proper informed consent from the patient." (7) In the face of such failures, the technology, by itself, has increased the C-section rate with its attendant risks and morbidity not only in the present pregnancy but for future pregnancies as well. (8) These authors question why EFM became a standard of care and why it is allowed to continue. Whether the authors are lawyers or physicians, the ratiocinations about the limitations of EFM inexorably lead to allegations of the predatory comportment of plaintiff attorneys and their experts in pursuing "brain-damaged baby" lawsuits alleging obstetrical negligence based on EFM.

They argue that the problem lies with the trial lawyers and their "experts" who use EFM-CP junk science to blame caregivers for causing C.P. In this scenario, ubiquitous experts abetted by unprincipled lawyers have helped create a worldwide litigation crisis threatening bankrupt healthcare systems. (9, 10, 11) Indeed, these allegations of obstetrical negligence have, in turn, created

an industry of defensive medicine that has diverted time, attention, and considerable expense to counter the allegations. This issue is highlighted by the recent disclosure from the United Kingdom of the extraordinary expenses related to payouts for alleged obstetrical negligence. National The situation has been called a lottery, a cash cow for lawyers and their experts." Sartwelle (3, 12, 13) We can agree, however, not that the awards are necessarily excessive or unjust, but that adverse outcomes need to be curtailed.

Mr. Sartwelle, a defense attorney, is one of the best-known assailants of EFM. He enumerates the scientific, clinical, ethical and judicial failures of EFM in various articles and discusses various solutions. - not so much to improve perinatal outcomes, but rather to protect the physician from allegations of negligence and the predations of lawyers and their experts. (12, 14-18) He questions why this litigation picture continues in the face of a technique (EFM) that he and others believe is based on junk science.

Where does the blame lie for this unhealthy, counterproductive situation? As these authors claim, does it lie with the purveyors of the technology or the medical societies? Or does it lie with the failure of the judicial system that continues to accept testimony about interpreting FHR patterns? Is it the fault of the ethical community or plaintiff experts in EFM who say that it must be someone's fault since there is a bad outcome? It is alleged that experts for the plaintiff become experts "after the fact when the outcome is known. (10-12, 17, 19) Is it the fault of defense experts who find exculpation for harm with the argument that whatever the doctor did was right because they would not have done it if it were not? Whatever happened to equipoise? Irrespective, there is little evidence that the problems of EFM and their potential for harm are being ignored or suppressed. (5, 9, 20, 21)

"From the medical standpoint, proposed solutions involve changing the classification of fetal heart rate patterns, modifying the scheme of management, abandoning the technique, or, perhaps more appealing, reengineering the interpretation of patterns such that the original, well-intentioned myths adopted prematurely by health care providers, litigators, and patients could be put into context. (22-27)"

There is no limit to the number and breadth of the proposed solutions. From the medical standpoint, proposed solutions involve changing the classification of fetal heart rate patterns, modifying the scheme of management, abandoning the technique, or, per-

haps more appealing, reengineering the interpretation of patterns such that the original, well-intentioned myths adopted prematurely by health care providers, litigators, and patients could be put into context. (22-27)

Legal solutions that have been put forth include no-fault, requiring patients to sign binding arbitration agreements, and giving up the right to sue for medical malpractice as a condition of care. (28) Sartwelle et al. claim that professional medical societies, such as the ACOG, might summarily curtail the use of EFM by declaring it as some unproven technique not yet justified in routine clinical practice. A partial concession has come with recommendations that in the "low-risk pregnancy," auscultation (presumably with EFM backup) is the desired form of fetal surveillance. There is no evidence that this approach is better overall, but at least the cesarean section rate seems lower.(29) Endorsing IA and removing EFM as the standard of care, presumably for any and all indications, need not forbid the use of EFM, but such a designation will allow the practitioner to use the technique. It helps litigation defense by removing the onus of not using the device.

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There are also recommendations that the testimony of plaintiffs' experts be challenged legally with Daubert or Frye constructs. The purpose of a Daubert challenge is to expose bias and selfinterest concerning the reliability and admissibility of expert opinions. A successful Daubert or Frye challenge seemingly permits the notion that, legally, EFM is "junk science." (8, 30, 31) Evaluating the challenge calls for trial judges to consider (1) whether the experts are proposing to testify about matters growing naturally and directly out of research they have conducted independent of the litigation, (2) whether their opinions were developed expressly to testify, and (3) if the testimony is not based on independent research, there is proof that the proffered conclusions have been subjected to scientific scrutiny through peer review and publication. Further, it emphasized that "differential diagnosis is a standard scientific technique of identifying the cause of a medical problem by eliminating the likely causes until the most probable one is isolated." (30) The methodology for establishing a differential diagnosis was summarized as follows: 1) The expert needs to compile a list of competing causes that are generally capable of causing the patient's adverse outcome. 2) After ruling in all potential causes that are generally capable of causing the outcome, the expert must eliminate potential causes based on a continuing examination of the evidence until the most likely cause is found. 3) The expert must provide reasons for rejecting alternative causes using scientific methods and procedures, and their elimination must be based on more than subjective beliefs or unsupported speculation.

This seemingly logical remedy partly fails because there is too much accepted science behind FHR patterns and too few alternatives. EFM has become the de facto, accepted standard of care required by most hospitals/institutions. Given their frequency of use and the attention and scientific underpinnings given to FHR patterns (as opposed to the management of these patterns), it seems complicated to reverse the position for litigation by attacking EFM as junk science. As a practical matter, there would seem to be no option for a Daubert challenge when a practitioner, with

proper informed consent from the mother (risks, benefits, alternatives), decides not to use EFM and writes a note stating that he/she understands that the standard of care prescribes the EFM, but with proper informed consent he is desisting. Nothing is limiting this option today – without a Daubert challenge.

Those who would curtail EFM in judicial litigation assume that intermittent auscultation (I.A.) is a scientifically proven alternative. Unfortunately, there is no evidence that auscultation is reliable, gives meaningful interpretations, or can be used as a reliable basis for intervention or review. A study of auscultation versus no surveillance found no difference in outcome. (32) Thus, carried to extremes, the lowest cesarean section rate would come from no monitoring. I.A. leaves no reliable record (a tracing) whose interpretation can be challenged. However, since there is no evidence that EFM will fail to detect hypoxia, it may be argued that I.A. failed to detect what would have been evident on EFM.

"Succinctly put, the classification of FHR patterns and the management scheme based on those patterns are attempting to protect the fetus from the problems of labor (excessive uterine activity, prolonged labor, malposition, etc.) while simultaneously using the same approach to protect the health care providers from allegations of negligence. Thus, the classification of FHR patterns (Categories I-III) is unworkable and widely disparaged. Management guidelines based on that classification prove vague, poorly reproducible, and of limited benefit. (7)"

There is an issue not articulated by any of the parties that seems fundamental to our present circumstances. Succinctly put, the classification of FHR patterns and the management scheme based on those patterns are attempting to protect the fetus from the problems of labor (excessive uterine activity, prolonged labor, malposition, etc.) while simultaneously using the same approach to protect the health care providers from allegations of negligence. Thus, the classification of FHR patterns (Categories I-III) is unworkable and widely disparaged. Management guidelines based on that classification prove vague, poorly reproducible, and of limited benefit. (7) To defend against allegations of negligence, the organization promulgated, in a widely disseminated monograph, (33) unrealistic and indefensible "essential criteria" for the relationship of intrapartum events and subsequent C.P. that would not (and did not) withstand a Daubert challenge. (33) Nevertheless, Sartwelle and others remain anchored to earlier notions of the mechanism(s) of injury when EFM was first promulgated, predicated on using FHR patterns to predict the severity of fetal acidosis. This mechanism did not apply to many, if not most, of those children injured during labor and delivery. (34) They use these issues of the classification and response to EFM patterns to camouflage their primary notion that C.P. and related handicaps are not preventable by the actions of the obstetrical care provider. (2, 12)

Do fetuses suffer preventable neurological consequences from the events of labor and delivery? The evidence seems inescapable that they do, and manifold evaluations from many countries involving experimental and human experience, even data from malpractice cases, affirm the compelling relationship of intrapartum events to subsequent, often devastating ones. These contributions also reveal the preventability of both fetal and maternal injury. Despite the limitations of implementation, these countervailing data gave practitioners backing for the continued use of EFM in the belief that it was helpful, if not perfect. The allegation that the practitioner continued using EFM "in the grossly mistaken and naive belief that EFM....was a defense to the rising tide of C.P. lawsuits. (10, 11, 17, 19) - a technology that caused more harm than good.

Paying attention to their allegations should have made Sartwelle and others realize that they and the ACOG were ("unintentional") co-conspirators. Both camps want to eliminate malpractice suits passionately. Given the role of EFM in such litigation, the question is not their shared objectives; they have different paths to the objective with very different constraints. Sartwelle does it by edict - legal, medical, or ethical. ACOG does it by vagueness or distractions – creating classifications of FHR patterns and management protocols that are so vague that they, in their perspective, offer the best opportunity to counter an allegation of negligence. (12, 14, 35-37)

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There can be no failure to recognize that the specialty, if not its society, began to publicly acknowledge EFM's flaws and limited benefits while still condoning its widespread use. In 2003, for example, Clark et al. (6) warned of the lack of benefit of EFM with "overwhelming evidence of EFM harm." His four remedies included a) publication of the lack of benefits; b) revision of EFM category II designation; c) official publication that C.P. litigation is

based on junk science; and 4) obstetricians need to realize EFM is based on myth, not reality. The demand for immunity is apparent. What is also clear is that his debatable criticisms and recommendations DO NOT call for the abandonment of the technique, to do more research, or to provide better training, and there was no call to revisit the original precepts for EFM. Indeed, Clark et al. later offered a reclassification of the scheme of managing Category II FHR patterns that was ultimately deemed unhelpful. (7, 38) They also found that since FHR patterns did not correlate well with fetal acidosis, the use of EFM was at fault, not the use of pH (see below). (39)

Unfortunately, EFM cannot be dismissed as "junk science." There is too much science behind the patterns; however, the management schemes are flawed. (40, 41) However, given the long-standing perspective on what it was expected to accomplish, there is not enough science behind its implementation (not the patterns) to simultaneously improve patient outcomes and reduce allegations of negligence.

There is a need to understand that EFM tells you about fetal behavior, including neurological responsiveness. It will not fail to tell you about hypoxia-ischemia, including stroke, infection, hemorrhage, and trauma. It cannot be used, however, without understanding the maternal condition and the feasibility of safe vaginal delivery - irrespective of FHR pattern. A normal pattern does not permit you to maintain labor when vaginal delivery is futile. Finally, EFM is an instrument of preventive care, not rescue.

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In these deliberations, several issues reflect mistaken notions. One such notion states that the expert sets the standard of care. Not quite; experts are only supposed to put forth opinions about the reasonable precepts of care as outlined in published guidelines of professional societies abetted by the enlightened interpretation of the literature in the context of the individual patient circumstances. They may not testify about their own standard of care or information they only know. They are there to opine on the propriety and reasonableness of the care in the light of the extant standards. It is inappropriate to believe that there is a single definable standard of care clinically and in courtrooms. Indeed, mutually exclusive options for care may each fall within a reasonable standard of care (elective cesarean section or attempted vaginal delivery) may each fall within an acceptable standard of care for

the fetus in breech presentation.

Another example of the problem of correlation is the notion that serious injury during labor will be manifested during the immediate neonatal period. From the time of Freud, but more obviously in recent times, it has been recognized that isolated cognitive defects can be related to adverse intrauterine environments during labor and delivery. Indeed, it is widely understood that "the outcome of neonatal encephalopathy includes cognitive deficits as a prominent feature, even in the absence of cerebral palsy, and that this is associated with the watershed pattern of injury and white-matter damage. (42)

Removing EFM as the standard of care, however, does not countermand its use. Given the inability to use A.I. as frequently as required, it might still be useful as a labor-saving monitoring device. Physicians could still make labor decisions based on EFM output. It simply requires a reversal of informed consent; now, informed consent must be obtained (not given) when using EFM since it is not *the* standard of care. If physicians explain how EFM might assist their decision-making, even if EFM is not the standard of care, many women, given a choice, will follow their doctor's advice. Will certification in FHR pattern interpretation still be required?

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The criticisms of plaintiffs' lawyers and their experts, the professional associations, the purveyors of equipment, the literature, etc, notwithstanding Sartwelle's efforts, go far beyond removing EFM from the clinical armamentarium. The fundamental reason behind these distractions about EFM's failures and limitations is that "we cannot prevent C.P." (43) He fails to give the profession credit for recognizing many potential causes of C.P. - including infection, trauma, coagulation disorders, malformations, and genetic disorders. Irrespective, asphyxia and hypoxic/ischemic injury are among the most common and potentially preventable causes. (44-46) Further, the newest version of the ACOG/AAP monograph (47) (2014) accepts the notion that injury can be attributed to labor events if there is an evolution in the EFM of a Category I pattern to a Category III pattern. Using similar logic that insists on a normal tracing at the outset of labor to establish previous normalcy (an uncommon prerequisite in most studies of EFM), various studies underscore not only the intrapartum timing of injury, but the duration of abnormality preceding harm and the likelihood of finding a low pH at the time of delivery. (25, 27, 48-51)

Ultimately, various authors have found that elective cesarean section has a beneficial effect on neonatal outcomes. (51-53) By eliminating labor, elective cesarean section eliminates many of

the risk factors for neonatal encephalopathy encountered during labor, including maternal fever, fetal malposition, and prolonged labor, along with other catastrophic events in labor. Ideally, EFM attempts to eliminate those differences by enhancing the safety of pursuing vaginal delivery. It seems perverse, therefore, to administer magnesium sulfate during labor to prevent neurological injury during labor and then argue that labor does not contribute to injury or that it is unpreventable. (54-56) The use of unvarnished, published "criteria" or data cobbled together by selective use of the literature by the experts of either side, clinically or in a courtroom, is not a substitute for an evidence-based, reliable weighting of the evidence. While careful reading of the literature easily refutes arguments to ban the monitor, it uncovers problems related to its implementation.

Thus, the proper interpretation of FHR patterns can provide the clinician with an opportunity to assess the potential for injury, but that assessment must rest with the establishment of certain prerequisites. The most obvious is that the baby is demonstrably normal on admission. As detailed above and elsewhere, (57) some babies are already injured on admission with no expectation that the conduct of delivery will prevent subsequent harm. Under circumstances where the initial tracing is demonstrably normal, EFM patterns almost invariably provide the window of opportunity for the obstetrician to understand the evolution to a threatened fetal environment irrespective of any confirmatory metabolic acidosis and the opportunity to moderate by conservative measures(if possible) the abnormal FHR patterns. If this fails to occur, tracings provide an understanding of the urgency of intervention if fetal decompensation and compromise are to be prevented. In published studies, this window ranges from minutes (occasionally) to hours (far more commonly), subject to the severity and nature of the compromise. In most cases, the window of opportunity to predict and confirm the asphyxial exposure tends to be longer rather than shorter. (24, 25, 58)

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There is persuasive evidence that obstetrical negligence during labor causes adverse outcomes, including C.P. It is not something to be proud of, but it is something to learn from, using the knowledge gained to improve care in the future. In a study of alleged malpractice during labor resulting in harm in Sweden between 1990 and 2005, Berglund reported 177 infants who suffered from severe asphyxia due to malpractice around labor, concluding that the most common causes of such obstetrical errors were failing to perform a timely delivery, increasing Pitocin in the presence of pathological FHR patterns, failing to supervise fetal well-being, overlooking signs of fetal asphyxia, and selection of a non-optimal choice of mode of delivery. ^{59,60} Our personal experience suggests that these circumstances still prevail a quarter-century later.

Despite the longevity of EFM, it is still recognized that outcomes will benefit from better training and education of clinicians in its use abetted by the implementation of unambiguous guidelines for the management of abnormal patterns, improved communication and collaboration between physicians and nurses, and implementation of special drills and training to teach personnel how to respond to emergencies. (61) EFM will come closer to achieving its

maximum potential when adequate training in relevant, uniform terminology and more rigorous standards are designed only to improve outcomes.

Hypoxic-ischemic brain damage comes in different forms, ranging from mild to severe, and varying combinations of hypoxia and ischemia. While the final outcome depends on the duration, the severity of the exposure, and the fetus' resources, the impact of such factors as the strength and frequency of uterine contractions and maternal pushing, the position and attitude of the fetal head during labor among other factors that likely influence fetal tolerance to the hypoxic and ischemic stresses encountered during labor and delivery. (62) It is also necessary to remember that the diagnosis of neurological injury acquired around the time of birth (and irrespective of the pH of the umbilical artery) has ramifications beyond medico-legal considerations. Neuroprotective therapies are capable of reducing the adverse effects of hypoxic-ischemic intrapartum injury. (63, 64) Ultimately, while similar degrees of insult may, in fact, not be similar at all - it will be up to the fetus, perhaps, to tell us what is and is not tolerable. (65, 66)

"Ultimately, it would seem that the interpretation of reliable, physiological information directly from the fetus must play a role in determining the urgency of intervention and the timing, mechanism, and preventability of intrapartum injury. Someone who understands its voice has to speak for the fetus."

Properly interpreted and with timely (preventive, early, not necessarily operative) intervention acted upon, the tracing benefits the current situation by improving the outcome and the defensibility of actions by diminishing the risk of adverse outcomes, the need for emergency delivery, and allegations of negligent care. Its deficiencies notwithstanding, it seems irresponsible to refer to EFM as "chicanery worthy of a snake oil salesman" and to encourage professional societies to call for its abandonment of EFM since doing so will make it easier to defend lawsuits. (43) Ultimately, it would seem that the interpretation of reliable, physiological information directly from the fetus must play a role in determining the urgency of intervention and the timing, mechanism, and preventability of intrapartum injury. Someone who understands its voice has to speak for the fetus.

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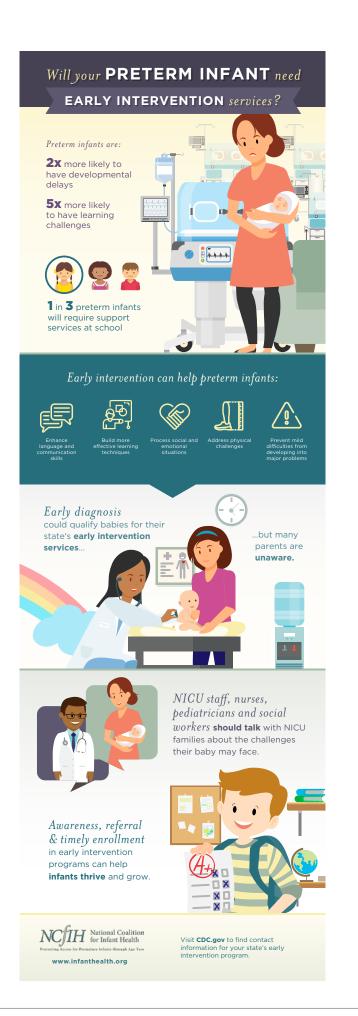


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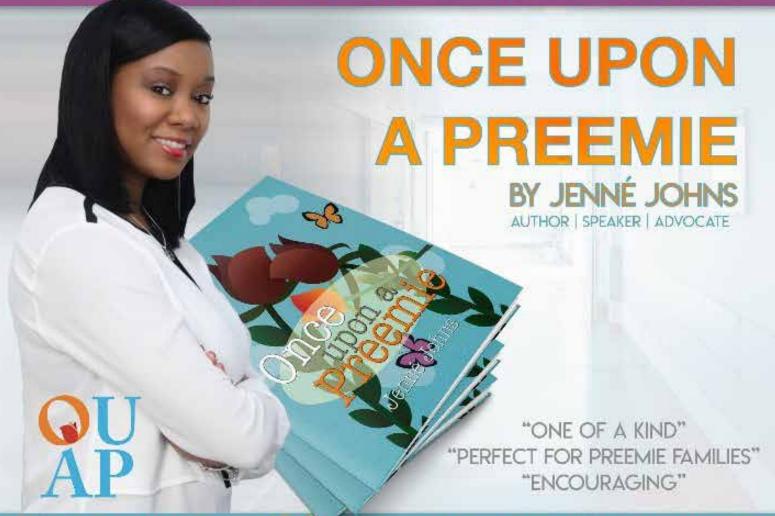
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PREEMIE BOOK ON SALE



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ONCE UPON A PREEMIE IS A BEAUTIFUL NEW WAY TO LOOK AT THE LIFE OF A PREEMIE BABY, IT EXPLORES THE PARENT AND CHILD NEONATAL INTENSIVE CARE UNIT (NICU) JOURNEY IN A UNIQUE AND UPLIFTING WAY.

SPEAKING ENGAGEMENTS

PREEMIE PARENT ALLIANCE SUMMIT NATIONAL ASSOCIATION OF PERINATAL SOCIAL WORKERS. CONGRESSIONAL BLACK CAUCUS ANNUAL LEGISLATIVE CONFERENCE NATIONAL MEDICAL ASSOCIATION ANNUAL CONFERENCE HUDSON VALLEY PERINATAL PUBLIC HEALTH CONFERENCE MATERNITY CARE COALITION ADVOCACY DAY





MEDIA APPEARANCES















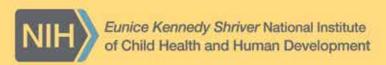
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You can help reduce the risk of Sudden Infant Death Syndrome (SIDS), the leading cause of death among infants between 1 month and 1 year of age. Take our free continuing education (CE) activity to stay up to date on the latest safe infant sleep recommendations. Approved for 1.5 contact hours.

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The CE activity explains safe infant sleep recommendations from the American Academy of Pediatrics and is approved by the Maryland Nurses Association, an accredited approver of the American Nurses Credentialing Center's Commission on Accreditation.







FIRST, DO NO HARM

11th Annual World Patient Safety, Science & Technology Summit

September 6-7, 2024 University of California, Irvine Student Center Pacific Ballroom

"Data is King, Action Out of Kindness is Godly."

Joe Kiani, Founder
Patient Safety Movement Foundation







The Masimo Foundation for Ethics, Innovation, and Competition in Healthcare

Our mission is to encourage and promote activities, programs, and research opportunities that improve patient safety and deliver advanced healthcare to people worldwide who may not otherwise have access to lifesaving technologies.





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CEO WELCOME MESSAGE

Dear Friends,

Welcome to the 11th Annual World Patient Safety, Science & Technology Summit! We are honored to host world-renowned patient safety experts who will address the latest challenges and opportunities in healthcare systems worldwide and discuss innovative solutions. Topics such as integration of real time data from electronic medical records, the role of artificial intelligence, and implementation of a culture of safety will be highlighted to show how we can achieve our goal of zero harm. Additionally, hearing moving patient stories throughout our program will remind us why we must remain committed to this cause.

Our main theme will adhere to the timeless words of Hippocrates from 2,500 years ago: "First, Do No Harm." We will emphasize that patient safety is a collaborative effort between healthcare workers, patients administrators and all involved to achieve optimal outcomes. We will tackle the challenges of implementing Actionable Evidence-Based Practices and highlight the positive transformations in healthcare systems when data transparency is practiced. To create meaningful change, it is crucial to know the facts about adverse events—such as the frequency of preventable patient harm, the categories of harm, and who are the most vulnerable patient populations—and to make this data publicly accessible. Physicians, nurses, pharmacists and the complete healthcare team absolutely are mortified when a patient experiences preventable harm during their care. They want proven solutions put in place immediately.

We are grateful for the diverse range of patient safety experts, patients and their families, physicians, nurses, healthcare system leaders, global safety organization leaders, academicians, MedTech executives, and politicians from around the world who are present at this summit. This is a unique opportunity to make lifelong connections and meet your partners in our journey to ZERO. As Joe Kiani said in his keynote speech at the WHO Ministerial Summit in February 2023, "Actions out of kindness are the most effective." Those who know him recognize his commitment to good, safe healthcare. If you see me or Sanaz,

please say hello. We want to meet you and learn how you are contributing to making healthcare safer. Rest assured, we are advancing patient safety faster than ever before, and it is because of your dedication, passion and the transparency of outcomes being made with global and importantly patient input.

Thank you for being here.

Mike Ramsay, MD, FRCA

CEO, Patient Safety Movement Foundation

DAY ONE FRIDAY, SEPTEMBER 6

7:30 am - 9:00 am

Registration

9:00 am - 12:00pm

First Morning Program

Welcome Message

Mike Ramsay, MD, FRCA Chief Executive Officer, Patient Safety Movement Foundation

State of the Movement

Joe Kiani, MS

Founder and Past Chairman, Patient Safety Movement Foundation, Founder, Chairman, and CEO, Masimo Corporation

Patient Story #1

Speaker

Donald M. Berwick, MD, MPP *Institute for Healthcare Improvement*

Panel 1:

The Role of the Board and C-Suite in Fostering a Culture of Safety

Joe Kiani Kimberly Cripe Chad Lefteris Tom Jackiewicz Dr. Marcus Schabacker

Break and Networking

Panel 2:

Using Real Time Data from Electronic Medical Records

Dr. Philip Lumb
Dr. Mark Konrad
Dr. David Stockwell
Drew Ladner
Ruth Ann Dorrill

Speaker

Dr. Diana Ramos

12:00 pm - 1:30 pm

Lunch & Movie

1:30 pm - 7:30 pm

First Afternoon Program

Panel 3:

Baylor Scott & White Healthcare System

Dr. Michael Ramsay Dr. Walter Peters Dr. Bret Stauffer Pete McCanna Dr. Elizabeth Papaila

Speaker

Dr. Craig Umschied

Speaker

Dr. Najm Meshkati

Speaker

Dr. Abby Towfigh

Break and Networking

Speaker

Dr. Michelle Schreiber

Speaker

Dr. Peter Ziese

Panel 4:

Resilience in Healthcare

Dr. Ed Kelley Robin Betts Dr. David Nash Dr. Patricia Mack Dr. Brandyn Lau

Speaker

Dr. Henrietta Hughes

Speaker

Dr. Evan Benjamin

Awards Ceremony

Networking Session

Movie

DAY TWO SATURDAY, SEPTEMBER 7

7:30 am - 9:00 am

Registration

9:00 am - 12:00pm

First Morning Program

Speech

Dr. Mike Durkin Chairman, Patient Safety

Movement Foundation

Patient Story #2

The Road Ahead

Dr. Sanaz Massoumi

Chief Operating Officer, Patient Safety Movement Foundation

Speaker

Dr. John Whyte

Panel 5: **Engaging Patient and Patient Family Members**

Dr. Steve Barker **Tracy Young** Dr. Joe Carmichael Vonda Vaden Bates Carole Hemmelgarn

Speaker

Dr. Tedros Ghebreyesus

Break and Networking

Speaker

Dr. Michael Stamos

Panel 6: **Global Patient Safety**

Dr. Mike Durkin

Dr. Ali Asery

Dr. Jannicke Mellin-Olsen

Dr. Carol Peden Dr. Anupam Sibal

Speaker

Dr. Ted Baker

12:00 pm - 12:45 pm Lunch 12:45 pm - 5:00 pm

Second Afternoon Program

Speaker

Dr. Peter Lachman

Speaker

D.A. Wallach

Speaker

Dr. Amy Ashcraft

Speaker

Dr. Ezequiel Garcia Elorrio

Speaker

Michael Millenson

Break and Networking

Panel

President Clinton and Joe Kiani

Awards Ceremony

Speech

Mike Ramsay, MD, FRCA Chief Executive Officer, Patient Safety Movement Foundation

Closing Video

Closing Remarks

Joe Kiani, MS

Founder and Past Chairman, Patient Safety Movement Foundation, Founder, Chairman, and CEO, Masimo Corporation

*The following speakers are confirmed.

KEYNOTE SPEAKERS



Joe Kiani



Dr. Don M. Berwick



Dr. Diana Ramos



Dr. Craig Umschied



Dr. Tedros Adhanom Ghebreyesus



Dr. John Whyte

"They say sunlight is a disinfectant, well transparency is the greatest disinfectant. We can learn from each other. It is unacceptable that we lack clarity on the true number of patient harm events.

Joe Kiani, Founder Patient Safety Movement Foundation

FEATURED SPEAKERS



Dr. Peter Ziese



Amy Ashcraft



Dr. Michelle Schreiber



Dr. Henrietta Hughes



Dr. Najm Meshkati



Dr. Abby Towfigh



Dr. Michael Stamos



Dr. Ezequiel García Elorrio



Dr. Peter Lachman



D.A. Wallach



Dr. Evan Benjamin



Dr. Ted Baker



Michael Millenson

Panel 1: The Role of the Board and C-Suite in Fostering a Culture of Safety

Moderator:

Joe Kiani

Panelists:

Kimberly Cripe
Chad Lefteris
Tom Jackiewicz
Dr. Marcus Schabacker

Panel 2: Using Real Time Data from Electronic Medical Records

Moderator:

Dr. Philip Lumb

Panelists:

Dr. Mark Konrad
Dr. David Stockwell
Drew Ladner
Ruth Ann Dorrill

Panel 3: Baylor Scott & White Health System

Moderator:

Dr. Michael Ramsay

Panelists:

Dr. Walter Peters

Dr. Bret Stauffer

Pete McCanna

Dr. Elizabeth Papaila

Panel 4: Resilience in Healthcare

Moderator:

Dr. Ed Kelley

Panelists:

Robin Betts

Dr. David Nash

Dr. Patricia Mack

Dr. Brandyn Lau

Panel 5: Engaging Patient and Patient Family Members

Moderator:

Dr. Steve Barker

Panelists:

Tracy Young
Dr. Joe Carmichael
Vonda Vaden Bates
Carole Hemmelgarn

Panel 6: Global Patient Safety

Moderator:

Dr. Mike Durkin

Panelists:

Dr. Ali Asery

Dr. Jannicke Mellin-Olsen

Dr. Anupam Sibal

Dr. Carol Peden

A Partnership Toward ZERO Harm

The Patient Safety Movement Foundation has been built on collaboration and partnership. These committed hospitals are using our Actionable Evidence-Based Practices in their efforts to reach ZERO preventable harm.



















Medical News, Products & Information

Compiled and Reviewed by Sandeep Lankireddy, BA, DO, Benjamin Hopkins. DO

Congenital cytomegalovirus infection linked to autism

NEWS PROVIDED BY

American Academy of Pediatrics

By Melissa Jenco

Study: Congenital cytomegalovirus infection linked to autism

Current as of May 30, 2024

Children with congenital cytomegalovirus (cCMV) infection are about 2.5 times more likely to be diagnosed with autism spectrum disorder (ASD) than their peers, according to a new study.

"Clinicians may want to be proactive in monitoring for early signs of ASD in children with a diagnosis of cCMV, especially those with hearing loss, the risk of which is elevated among both children with cCMV and those with ASD," authors wrote in "Autism Spectrum Disorder Diagnoses and Congenital Cytomegalovirus" (Pesch MH, et al. Pediatrics. May 29, 2024).

Previous studies have linked cCMV, the most common congenital infection in the U.S., to central nervous system anomalies. Researchers from the University of Michigan and Centers for Disease Control and Prevention set out to look more closely at possible ties to autism. They analyzed data on nearly 3 million children enrolled in Medicaid or the Children's Health Insurance Program from birth through 4-6 years.

Nearly half of those with cCMV had a central nervous system anomaly or injury, according to the study. About 64 of every 1,000 children with cCMV was diagnosed with autism compared to 25 of every 1,000 children without cCMV.

Researchers' adjusted calculations determined children with cCMV were 2.5 times more likely to be diagnosed with autism. Females with cCMV had 4.65 times the risk of autism and males had nearly 2 times the risk compared to their peers without cCMV.

"Maternal CMV infection can activate an inflammatory state which may, in turn, impact fetal brain development, thereby increasing the risk of ASD," authors wrote.

They noted brain anomalies accounted for some of the risk,



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but they also saw links between cCMV and autism in children without brain anomalies, preterm birth or low birth weight.

The links they found between the infection and autism could have been influenced in part by children with cCMV being monitored closely for neurodevelopmental issues. The data could not address whether other pregnancy factors played a role in their findings or whether they apply to children with asymptomatic cCMV infection.

To better understand the results, authors called for more study of children with cCMV identified through universal screening programs and followed long term.

NT

Crecelac, Farmalac infant formula recalleddose from 2011 to 2021

NEWS PROVIDED BY

American Academy of Pediatrics

By Melissa Jenco

Crecelac, Farmalac infant formula recalled

Current as of May 28, 2024

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Update 6/3/24: Cronobacter bacteria has been found in a sample of Crecelac Infant Powdered Goat Milk Infant Formula. Infants experiencing poor feeding, irritability, temperature changes, jaundice, grunting breaths, or abnormal body movements after consuming this formula should see a health care provider for immediate care.

Crecelac and Farmalac infant formulas are being recalled due to the manufacturer not complying with Food and Drug Administration (FDA) requirements.

Dairy Manufacturers Inc. is recalling Crecelac Infant 0-12 months, Farmalac 0-12 months and Farmalac 0-12 months low lactose. The formulas are packaged in 12.4-ounce cardboard and aluminum cans and were sold in Texas.

The products were not evaluated by the FDA to determine if they meet safety and nutritional standards, according to an announcement published by the FDA. No illnesses have been reported.

Customers who purchased the recalled formulas should stop using them and return them to the store where they were purchased for a refund.

Customers with questions can contact the manufacturer at 972-347-2341.

NT

Introducing peanut in infancy prevents peanut allergy into adolescence

NEWS PROVIDED BY

National Institute of Health

By Laura Leifman

Introducing peanut in infancy prevents peanut allergy into adolescence

Current as of May 28, 2024

NIH study finds protection lasts no matter how often kids eat peanut in later childhood.

Feeding children peanut products regularly from infancy to age 5 years reduced the rate of peanut allergy in adolescence by 71%, even when the children ate or avoided peanut products as desired for many years. These new findings, from a study sponsored and co-funded by the National Institutes of Health's National Institute of Allergy and Infectious Diseases (NIAID), provide conclusive evidence that achieving long-term prevention of peanut allergy is possible through early allergen consumption. The results were published today in the journal NEJM Evidence.

"Today's findings should reinforce parents' and caregivers' confidence that feeding their young children peanut products beginning in infancy according to established guidelines can provide lasting protection from peanut allergy," said NIAID Director Jeanne Marrazzo, M.D., M.P.H. "If widely implemented, this safe, simple strategy could prevent tens of thousands of cases of peanut allergy among the 3.6 million children born in the United States each year."

The new research findings come from the LEAP-Trio study, which builds on the seminal results of the Learning Early About Peanut Allergy (LEAP) clinical trial and the subsequent LEAP-On study, both sponsored and co-funded by NIAID.

During the LEAP trial, half of the participants regularly consumed peanut products from infancy until age 5 years, while the other half avoided peanut during that period. Researchers found that early introduction of peanut products reduced the risk of peanut allergy at age 5 by 81%. Subsequently, children from LEAP who participated in LEAP-On were asked to avoid eating peanut products from ages 5 to 6 years. Investigators found that most chil-

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.

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dren from the original peanut-consumption group remained protected from peanut allergy at age 6.

The LEAP investigators designed the LEAP-Trio study to test whether the protection gained from early consumption of peanut products would last into adolescence if the children could choose to eat peanut products in whatever amount and frequency they wanted. Those children who were allergic to peanut at age 6 were advised to continue avoiding it.

The study team enrolled 508 of the original 640 LEAP trial participants—nearly 80%—into the LEAP-Trio study. The children averaged 13 years of age at enrollment. Two hundred and fifty-five participants had been in the LEAP peanut-consumption group and 253 in the LEAP peanut-avoidance group.

The LEAP-Trio study team assessed the adolescents for peanut allergy primarily through an oral food challenge. This involved giving participants gradually increasing amounts of peanut in a carefully controlled setting to determine if they could safely consume at least 5 grams of peanut,

the equivalent of more than 20 peanuts. The study team also surveyed participants about their recent patterns of peanut consumption and verified the self-reports through measurements of peanut in dust from participants' beds, a technique previously validated by LEAP investigators.

The LEAP-Trio investigators found that 15.4% of participants from the early childhood peanut-avoidance group and 4.4% from the early childhood peanut-consumption group had peanut allergy at age 12 or older. These percentages reflected 38 of 246 participants from the peanut-avoidance group and 11 of 251 from the peanut-consumption group. (Complete data was unavailable for 11 of the 508 participants enrolled.) These results showed that regular, early peanut consumption reduced the risk of peanut allergy in adolescence by 71% compared to early peanut avoidance.

The researchers also found that although participants in the LEAP peanut-consumption group ate more peanut products throughout childhood than the other participants overall, the frequency and amount of peanut consumed varied widely in both

groups and included periods of not eating peanut products. This demonstrated that the protective effect of early peanut consumption lasted without the need to eat peanut products consistently throughout childhood and early adolescence.

For detailed advice on how to safety intro-









www.nationalperinatal.org/mental_health

duce peanut into an infant's diet, consult the Addendum Guidelines for the Prevention of Peanut Allergy in the United States.

NT

Self-pay accounts for nearly 20% of mental health visits by children

NEWS PROVIDED BY

American Academy of Pediatrics

By Carla Kemp

Current as of June 1, 2024

Overhage LN, et al. PS in Advance. https://

bit.ly/3Q6isGZ.

Nearly one-fifth of visits by children to mental health specialists were paid for by families out of pocket without insurance reimbursement, a recent study showed.

Furthermore, self-pay was more common among families with higher incomes, potentially exacerbating inequities in access, the authors said.

Studies have shown that children in families with lower incomes are less likely to receive mental health care than those with higher incomes. In addition, research has found that psychiatrists are less likely than physicians in other specialties to accept private insurance, and few take Medicaid.

The authors of this study sought to determine how often families self-pay for outpatient mental health care and assess if there are disparities based on income. To do so, they analyzed data from the Medical Expenditure Panel Survey from 2018-2020. They identified mental health visits by children ages 5-17 years to a psychiatrist, psychologist, social worker or mental

health counselor/family therapist and determined how many visits were not covered by insurance.

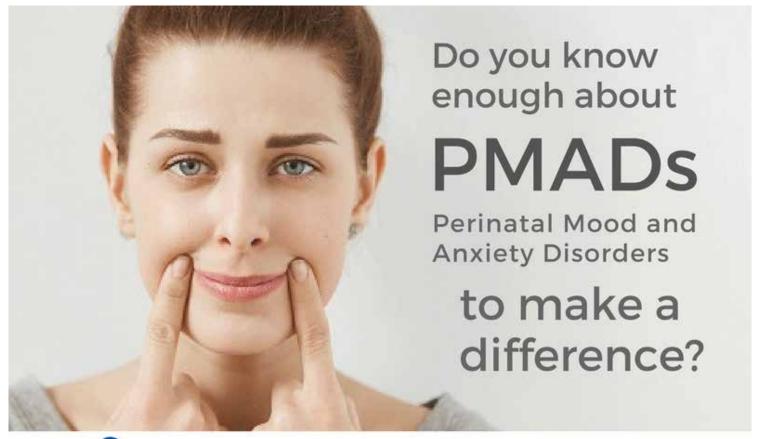
They also looked at the relationship between self-paying and family income.

Among the 9,911 children in the sample, 8% had at least one outpatient mental health specialist visit. Over the two-year period, there were 13,639 total visits.

Seven percent of visits by families with an annual income of less than \$28,000 were self-paid, and the median amount this group paid per visit was \$95. In comparison, 26% of visits by families who made \$110,000 a year or more were self-paid, and the median amount they paid was \$120.

Self-pay visits were more common with social workers (24% of visits) and psychologists (23%) compared to psychiatrists (17%) and counselors/family therapists (13%).

The median cost of a self-pay visit for all types of clinicians combined increased from \$86 in 2018 to \$145 in 2020.





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Keeping Your Baby Safe



from respiratory infections

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.



RSV

flu

Get Immunized

NARNING

Vaccinations save lives. Protecting your baby from RSV, COVID-19, flu, and pertussis lowers their risks for complications from respiratory infections.



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



"Our finding that the percentage of visits that were self-paid by families followed a strong income gradient suggests that self-pay mental health care potentially contributes to socioeconomic differences in access to mental health care for children," the authors concluded.

They also noted that "primary care providers will be key allies in improving equity in child mental health care."

NT

QI project improves safe sleep among hospitalized infants

NEWS PROVIDED BY

American Academy of Pediatrics

By Carla Kemp

QI project improves safe sleep among hospitalized infants

Current as of June 1, 2024

Butler SC, et al. J Pediatr Health Care.

https://bit.ly/4a0onVp.

A quality improvement (QI) project led to increased adherence to AAP safe sleep recommendations across 15 inpatient units at a large children's hospital.

Sudden unexpected infant death is the third leading cause of infant mortality, according to the Centers for Disease Control and Prevention. AAP safe sleep guidance, updated in 2022, calls for infants to be put to sleep on their backs on a flat, firm surface without any soft objects or loose bedding in the sleep area to prevent sudden infant deaths.

The authors of this study were concerned about adherence to the safe sleep guidelines at their hospital. Therefore, they used QI methodologies to increase knowledge of and adherence to the AAP guidelines among staff members caring for infants younger than 12 months in inpatient units.

Various interventions were implemented, including development of educational materials and videos for staff and family members, presentations by subject matter experts, documentation of safe sleep in the medical record, creation of exception orders for patients with medical complexity and use of sleep sacks for babies to keep extra linens out of beds.

All units conducted monthly audits to measure compliance with each component of safe sleep, including bed type (crib), sleep position (supine or able to roll independently), sleepwear/clothing (one swaddle blanket or sleep sack), head of bed elevation (flat) and objects in the sleep area (only crib sheet).

Fifteen units conducted 5,045 audits, which showed compliance with all aspects of safe sleep increased from 9% at baseline to 53% postintervention. Significant improvements also were seen in individual components of safe sleep, including flat head of bed (from a mean of 64% to 85%) and objects in sleep area/linens (from 51% to 70%).

Medically complex infants were less likely to adhere to all safe sleep practices. "Of importance, research is needed to clarify when an infant with a feeding tube can be in safe sleep, along with infants with aspiration risk, sedation wean, and need for





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supplemental oxygen," the authors wrote.

NT

Health Alerts: Laundry detergent packets, cribs, crib bumpers and more

NEWS PROVIDED BY

American Academy of Pediatrics

By Steve Schering

Health Alerts: Laundry detergent packets, cribs, crib bumpers and more

Current as of June 1, 2024

The U.S. Consumer Product Safety Commission (CPSC) has announced the recall of the following products. Consumers should stop using recalled products unless otherwise instructed. Consumers can submit reports of harm to the CPSC's searchable online product safety database at www.SaferProducts.gov. A searchable food and medical product recall database is available at www.fda. gov/Safety/Recalls/default.htm.

Laundry detergent packets

Procter & Gamble is recalling 8.2 million Tide Pods, Gain Flings, Ace Pods and Ariel Pods liquid laundry detergent packets in flexible film bags because the outer packaging can split open. Children can be injured if they swallow or touch the contents of the laundry detergent packets. The recalled detergent was sold at Big Lots, CVS, Family Dollar, Home Depot, Sam's Club, Target, Walmart and other major retailers and Amazon.com and other websites from September 2023 to April 2024 for \$5 to \$30. Call 833-347-5764 or visit https://www.pg.com/bags for refund and replacement information.

Youth bottles

Igloo Products is recalling 31,500 youth sipper bottles because the silicone cover can detach, and children can choke on it. The sipper bottles were sold at Academy Sports + Outdoors, Rural King and online by Igloo Coolers from April 2023 to March 2024 for \$13 to \$17. Call 800-273-7024 or email customerservice@ shop.igloocoolers.com for refund or replacement information.

Mario Kart racer

JAKKS Pacific is recalling 17,500 Mario Kart 24V ride-on racer cars because the acceleration pedal can stick and cause the battery-operated toy to crash. The cars were sold online and in stores by Target, Walmart, Entertainment Earth and Nebraska Furniture Mart and online by Amazon, Macy's and Game Stop from October 2022 to January 2024 for about \$400. Call 855-602-5464 or visit https://bit.ly/49Wxc2x for repair information.

Mini speakers

Yoto is recalling 251,165 mini speakers because the device's lithium-ion battery can overheat and cause burns or fires. The speakers were sold online by Yoto, Target, Amazon and Maisonette and in toy and gift stores nationwide from November 2021 to April 2024 for about \$70. Call 844-370-0426 or email minihelp@yotoplay.com for repair information.

Cribs

Crate & Barrel is recalling 3,200 Hampshire Cribs because the mattress support pins can come loose, and the mattress can fall. The cribs were sold online by Crate & Barrel from June 2022 to November 2023 for \$600 to \$800. Call 800-967-6696 or visit https://bit.ly/recallcbwalker for repair and refund information.

Crib bumpers

Zazaba International is recalling 795 Grão de Gente crib bumpers and bedding sets. Padded crib bumpers are banned under the Safe Sleep for Babies Act because infants can suffocate. The crib

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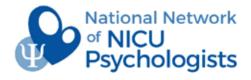
MISSION:

Optimizing care for all NICU infants and their families through

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VISION:

To be the leading voice and resource for mental health services in the NICU.





nationalperinatal.org/psychologists

nationalperinatal.org/membership

bumpers were sold online by Zazaba from March to August 2023 for \$24 to \$220. Call 855-425-4640 or email recall@graodegente.com for a refund.

Baby nests

Zazaba International is recalling 430 Grão de Gente baby nests because the product's head pillow is inclined at greater than 10 degrees, which violates the Safe Sleep for Babies Act. The baby nests were sold online by Zazaba from March to August 2023 for \$9 to \$110. Email recall@graodegente.com or visit https://bit.ly/3UqCOwc for a refund.

Children's pajamas

Several companies are recalling children's pajamas because the garments do not meet federal flammability standards.

Lovey & Grink is recalling 23,720 sets of children's two-piece pajamas and lounge dresses. The garments were sold at stores in California, New Jersey, New York, Connecticut and Florida and online by Lovey and Grink, Bloomingdale's, SAKS and Maisonette from September 2022 to January 2024 for \$38 to \$44. Call 877-360-5470 or email recall@loveyandgrink.com for a refund.

Skims Body is recalling 1,200 sets of SKIMS children's pajama sets. The sets were sold online by SKIMS from November 2023 to January 2024 for about \$54. Call 877-206-1172 or email pajamasets@realtimeresults.net for a refund.

Sant and Abel is recalling 935 sets of twopiece children's pajamas. The pajamas were sold online by Sant and Abel, Neiman Marcus, Maisonette, SAKS and Flip from January 2021 to February 2024 for about \$59. Call 213-328-2448 or email returns@ santandabel.com for a refund.

Zipline kits

Jugader is recalling 6,600 zipline kits because the stainless steel cable can break, and users can fall. The zipline kits were sold online by Amazon from March 2020 to

June 2023 for about \$140. Call 800-360-8078 or email support@jugader.com for a free repair kit.

Ski boots

Fischer Sports is recalling 1,460 junior ski boots because the lock mechanism can malfunction, causing falls or injuries. The ski boots were sold at ski gear stores nationwide and online by Fischer Sports from October 2022 to February 2024 for \$200 to \$275. Call 800-844-7810 or visit https://bit.ly/44onjt4 for a refund or repair information.

Fuel bottles

Two companies are recalling liquid fuel bottles because the containers are not child resistant, and children can be burned or poisoned if they drink the liquid.

Randder is recalling 1,830 liquid fuel bottles sold in packages of two on Amazon.com from September 2022 to November 2023 for \$26 for the 750 mL size and \$47 for the 1,500 mL size. Email catherine0216@outlook.comto receive a child-resistant cap.

BRS is recalling 1,600 liquid fuel bottles sold on Amazon.com from October 2018 to December 2023 for about \$15. Email chencaiyu1994@hotmail.com for a refund.

Rear-mounted bike seat

Thule is recalling 8,640 RideAlong rearmounted child bike seats because the harness padding contains a flame retardant, which is toxic if ingested or comes into contact with skin or eyes. The bike seats were sold at REI and baby stores nationwide and online by Amazon and Thule from May 2017 to October 2023 for about \$300. Call 888-816-0228 or email thuleridealong. americas@thule.com for replacement information.

Children's dressers

Rooms To Go is recalling 200 Mill Valley Jr. six-drawer youth dressers because the furniture can tip over. The dressers were sold by Rooms To Go in stores and online from December 2023 to January 2024 for

about \$450. Call 855-688-0919 or email productcare@roomstogo.com for replacement information.

Bicycle helmets

Chau River Sports Outdoors is recalling 200 multipurpose kids' bike helmets because the helmets can fail to protect users in the event of a crash. The helmets were sold online by Temu from June 2023 to January 2024 for \$16 to \$40. Email lexi_kuyou@163.com for a refund.

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Caring for Babies and their Families: Providing Psychosocial Support to NICU Parents

7- Module Online Course in NICU Staff Education



California to expand funding for children's hospitals, serve state's sickest kids

NEWS PROVIDED BY

Official website of the state of California, CA.Gov

California to expand funding for children's hospitals, serve state's sickest kids

Current as of June 25, 2024

Sacramento, California – Governor Gavin Newsom and the California Children's Hospital Association (CCHA) today announced an agreement to expand health care for children in the state. The agreement will provide additional funding for the Department of Health Care Services to support California children's hospitals now and in the future. This funding will help support medical care for critically ill children and those fighting the most serious and life-threatening diseases.

"In California, our children are not just our future – they are everything to the families that love them and the friends who play next to them. For the children suffering from the worst and most serious illnesses, we must support the hospitals that give them a fighting chance to live and thrive. I'm pleased we were able to provide this additional financial assistance and avoid a costly ballot initiative." - Governor Gavin Newsom

"State government leaders asked Children's Hospitals to think outside the box to maximize the use of federal money to achieve our goal of extending life-saving care to more critically ill children," said Ann-Louise Kuhns, President and CEO of CCHA. "We have found the best path to do so with less stress on the state's budget for public health, public safety, public education and public infrastructure."

This agreement is reflected in AB/SB 159. Once this legislation is passed by the Legislature, proponents of the "Affordable, Life-Saving Healthcare for Critically III Children" initiative eligible for the November 2024 ballot have agreed to withdraw their measure.

NT

Shipment of newest malaria vaccine, R21, to Central African Republic marks latest milestone for child survival

NEWS PROVIDED BY

World Health Organization

Shipment of newest malaria vaccine, R21, to Central African Republic marks latest milestone for child survival

Current as of May 24, 2024

With two recommended vaccines and expanded supply, Gavi, UNICEF, WHO are working closely with governments and partners to increase malaria prevention and protection for children

UNICEF delivered over 43 000 doses of the R21/Matrix-M malaria vaccine by air to Bangui, Central African Republic, today, with more than 120 000 doses to follow in the next days. It is the first country to receive the R21 malaria vaccine for use in routine childhood immunization, marking another step forward in preventing the disease and saving children's lives.

R21 is the second malaria vaccine to be recommended by WHO for children living in endemic areas. Along with the earlier WHO recommendation of the RTS,S vaccine, there is now sufficient vaccine supply to scale up malaria vaccination in Africa. The rollout of both vaccines is funded by Gavi, the Vaccine Alliance.

"With two products now available to countries, expanded supply of malaria vaccines is a game changer for child survival and health," said Director of UNICEF Supply Division Leila Pakkala. "Previous concerns about supply meeting demand are firmly behind us. Now our priority is for the vaccines to reach every child at risk."

The R21 and RTS,S vaccines are proven safe and effective in preventing malaria in children. The RTS,S vaccine was delivered to more than 2 million children in Ghana, Kenya, and Malawi in a four-year pilot programme that demonstrated a 13% reduction in all-cause mortality.

Malaria is one of the world's most lethal diseases, killing nearly half a million children under 5 years of age each year in Africa.

The Central African Republic has one of the highest rates of malaria incidence globally. In 2022, an estimated 1 733 000 malaria cases were reported in the country, averaging about 4747 cases a day. The disease also claimed around 5180 lives over the year, or 14 deaths each day.

"Having two safe and effective vaccines means we have greater supply security and can be more confident about meeting countries' needs," said Dr Sania Nishtar, CEO of Gavi, the Vaccine Alliance. "That is what matters most – that countries where our vaccines can be most impactful are able to access them, saving thousands of lives each year and offering relief to families, communities and entire health systems."

Central African Republic, along with Chad, Cote d'Ivoire, Democratic Republic of Congo, Mozambique, Nigeria, South Sudan, and Uganda, are preparing to receive R21 shipments.

Around 4.33 million doses of RTS,S have been delivered to 8 countries so far – Benin, Burkina Faso, Cameroon, Ghana, Kenya, Liberia, Malawi, and Sierra Leone – that are offering the vaccine in their routine child immunization programmes as part of national malaria control plans. Burundi and Niger are next on the list for RTS,S shipments.

Vaccine deliveries to countries that are funded through the Vaccine Alliance depend on government requests and readiness to include the vaccine in routine immunization programmes.

Gavi, UNICEF, WHO, and partners are supporting governments as they prepare to receive and introduce the vaccines. This involves supporting countries to develop vaccine implementation plans and communication strategies, conducting health worker trainings and community engagement, and ensuring sufficient cold chain capacity.

"Malaria vaccines, introduced as part of the tools available in comprehensive national malaria control plans, will substantially reduce early childhood deaths and can help revitalize the fight against malaria. With the R21 vaccine now joining RTS,S vaccine for use in country immunization programmes, scale up of malaria vaccine across parts of Africa, where malaria remains a major cause of childhood death will continue. The high community demand for malaria vaccines also provides an opportunity for children to receive other childhood vaccines that may be due, resulting in even more lives saved," said Dr Kate O'Brien, Director of WHO's Department of Immunization, Vaccines and Biologicals.

Malaria vaccines are an important addition to the fight against the disease. Careful planning is essential to ensure the successful introduction of the malaria vaccines and to combine them with other interventions including insecticide-treated bed nets or targeted indoor residual spraying, chemoprevention, diagnosis and prompt treatments to maximize the impact on public health.

NT

Sudan's children trapped in critical malnutrition crisis, warn UN agencies

NEWS PROVIDED BY

World Health Organization

By Joe English, Eva Hinds, Leni Kinzli, Isheeta Sumra

Sudan's children trapped in critical malnutrition crisis, warn UN agencies

Current as of May 30, 2024

Three United Nations agencies today issued a stark warning that all indications point to a significant deterioration of the nutrition situation for children and mothers in war-torn Sudan. The lives of Sudan's children are at stake and urgent action is needed to protect an entire generation from malnutrition, disease and death.

A recent analysis conducted by the UN Children's Fund (UNICEF), UN World Food Programme (WFP) and World Health Organization (WHO) highlights that the ongoing hostilities are worsening the drivers of child malnutrition. These include a lack of access to nutritious food, safe drinking water and sanitation, and increased risk of disease. The situation is compounded by massive population displacement, as large numbers of people flee the conflict. Sudan is facing an ever-increasing risk of conflict-induced famine that will have catastrophic consequences including the loss of life, especially among young children.

The year-long war is also severely impacting the delivery of humanitarian supplies, leaving countless women and children without access to vital food and nutritional support. The agencies have been struggling to deliver nutrition products as growing violence and bureaucratic procedures impede access to conflict affected areas.

Child malnutrition in Sudan is at emergency levels. In Central Darfur, acute malnutrition is estimated to be at 15.6 percent among children under 5, while in ZamZam camp it's close to 30%. The situation has deteriorated over recent months, with no sign of abating due to continued conflict and severely hindered humanitarian access. Acute malnutrition is life-threatening, with malnourished children up to 11 times more likely to die than a well-nourished child. Malnutrition and disease reinforce each other, with sick children becoming more easily malnourished and malnourished children becoming sick more easily, and suffering worse outcomes. Even when children recover, malnutrition can have lifelong effects on physical and cognitive development. Sudan risks a lost generation, with grave implications for the country's future.

Levels of malnutrition are particularly worrying among pregnant and breastfeeding mothers. For example, screening carried out last month by Medecins Sans Frontières in ZamZam camp, North Darfur, found over 33 percent of pregnant and breastfeeding women are malnourished, indicating that they are likely sacrificing their own needs to feed their children. This situation poses an incredible risk not only for the health of mothers, but also for the next generation of Sudan's children. As much as 30 percent of child malnutrition begins in utero, so children born to malnourished mothers are likely to be already malnourished themselves.

"Children in Sudan are experiencing horrific violence, displacement and trauma – and now they are confronted with potential famine," said UNICEF Executive Director Catherine Russell. "When children suffer from serious forms of malnutrition, it harms their physical and cognitive development and can leave life-long damage. Parties to the conflict must urgently allow humanitarian access so children can receive food, water, medical care and shelter. But most of all, children need peace."





The NUCDF is a non-profit organization dedicated to the identification, treatment and cure of urea cycle disorders. NUCDF is a nationally-recognized resource of information and education for families and healthcare professionals.

www.nucdf.org | Phone: (626) 578-0833

"Mothers and children across Sudan are wasting away from malnutrition. The ongoing war has stripped them of everything they need to survive – food, medical support and shelter. We need immediate and safe access to deliver the humanitarian assistance that they so desperately need. Without it, this crisis risks becoming the world's largest hunger emergency", said WFP Executive Director Cindy McCain. "Millions of lives are at stake and the international community must act now or we risk losing an entire generation of children."

"Malnutrition is not a one-time crisis. Malnourished children face a lifetime of developmental challenges and ill-health and are also more likely to die from infectious diseases", said WHO Director-General Tedros Adhanom Ghebreyesus. "The clock is ticking, edging Sudan's mothers and children closer to famine. WHO and partners are on the ground working to prevent and treat acute malnutrition to save precious lives but we need sustained humanitarian access and full financial backing to be able to do this."

The report acknowledges data gaps due to difficulties in gaining access to conflict hotspots. Despite this, the agencies fear that the situation is extremely critical, and continues to deteriorate. The data gaps in themselves are indicative of a lack of vital humanitarian access in the worst affected areas. All options must be utilized to reach those populations that are the most in need.

Over the coming months the situation for Sudan's children and mothers will only worsen: the rainy season, which will cut off communities and raise rates of disease, starts in June. Sudan is also entering the lean season, a time between harvests when food stocks traditionally run low. This is particularly pertinent this year, as reports are already indicating that agricultural production in 2023 was below normal, due to insecurity and displacement.

The agencies call for immediate, unimpeded and consistent access to communities who are suffering the worst effects of the brutal and lengthy conflict, through all possible crossline and cross-border routes with neighbouring countries, as well as a descalation of the situation in El Fasher and a nationwide ceasefire. We also count on a renewed and significant scaled up support from donors. The window to avert the worst is rapidly closing.

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Keeping Your Baby Safe





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.



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





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The Continuing Education Department at PAC/LAC is pleased to consider requests to be a joint provider of your CME activity. PAC/LAC is actively involved in direct and joint-providership of multiple continuing education activities and programs and works with our partners to ensure the highest standards of content and design. PAC/LAC is the recipient of the 2018 Cultural & Linguistic Competency Award. This award recognizes a CME provider that exemplifies the goal of integrating cultural and linguistic competency into overall program and individual activities and/or a physician who provides leadership, mentorship, vision, and commitment to reducing health care disparities

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- Licensed Educational Psychologists (LEP)
- Certified Health Education Specialists (CHES)
- Continuing Respiratory Care Education (CRCE)

www.paclac.org



PAC/LAC's core values for improving maternal and child health have remained constant for over 30 years – a promise to lead, advocate and consult with others.

Leadership

Providing guidance to healthcare professionals, hospitals and healthcare systems, stimulating higher levels of excellence and improving outcomes for mothers and babies.

Advocacy

Providing a voice for healthcare professionals and healthcare systems to improve public policy and state legislation on issues that impact the maternal, child and adolescent population.

Consultation

Providing and promoting dialogue among healthcare professionals with the expectation of shared excellence in the systems that care for women and children.

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Caring for Babies and their Families: Providing Psychosocial Support to NICU Parents

7- Module Online Course in NICU Staff Education



Section on Neonatal-Perinatal Medicine June Update – SONPM Updates: AAP NCE, SONPM, TECaN, AAP 2024 Awards, ACGME Pediatric Review Committee Nominations

Munish Gupta MD, MMSc, FAAP

Dear Colleagues,

Two quick time-sensitive announcements to share and a reminder:

HRSA pediatric subspecialty LRP applications are now open, and

Reminder – AAP National Conference and Exhibition, September 27 – October 1, 2024, Orlando.

"And a quick reminder: AAP NCE will be from September 27th to October 1st, 2024. Our SONPM program will be from September 27th to 29th. The section program looks terrific – the current agenda is attached. In addition to all the talks, sessions, abstracts, and awards, there will also be plenty of opportunities for connecting and networking." HRSA Pediatric Subspecialty Loan Repayment Program – Applications open through July 9th

HRSA (Health Resources & Services Administration) has opened this year's application cycle for their Pediatric Subspecialty Loan Repayment Program (LRP). This new program launched last year (after many years of AAP advocacy) provides up to \$100,000 in loan repayment for pediatric specialists who are training or working in a medically underserved area or with a medically underserved population. This is a different program than the longer-standing NIH LRP program. https://bhw.hrsa.gov/funding/apply-loan-repayment/pediatric-specialty-lrp

Reminder! Join the SONPM program at the AAP NCE in Orlando.

And a quick reminder: AAP NCE will be from September 27th to October 1st, 2024. Our SONPM program will be from September 27th to 29th. The section program looks terrific – the current agenda is attached. In addition to all the talks, sessions, abstracts, and awards, there will also be plenty of opportunities for connecting and networking. There are also a number of terrific neonatology-related sessions in the main conference schedule. The conference website with registration, hotel information, and schedule is here: https://aapexperience.org/.

Thanks all,

Munish

Disclosure: There are no reported conflicts.

More details:

NT



Corresponding Author



Munish Gupta MD, MMSc, FAAP Chair, AAP Section on Neonatal-Perinatal Medicine Assistant in Medicine, Division of Newborn Medicine Assistant Professor of Pediatrics, Harvard Medical School Department of Neonatology

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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.



Perinatal Association

www.perinatalharmreduction.org

www.nationalperinatal.org





SEPTEMBER 27 - OCTOBER 1, 2024 | AAPEXPERIENCE.ORG | AAP2024

H1015: Section on Neonatal Perinatal Medicine Program: Day 1

Friday, September 27

ONTPD Meeting

9:00 AM - Organization of Neonatal Training Program Directors (ONTPD) Meeting*

4:00 PM 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.

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)

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May 3, 2024

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AMA Section Council on Pediatrics

FROM: Melissa J. Garretson, MD, FAAP

Chairperson, AMA Section Council on Pediatrics

ABRAHAM JACOBI MEMORIAL AWARD

Deadline for Submissions: May 31, 2024

Call for Nominations: The American Academy of Pediatrics (AAP) is pleased to announce that nominations are being accepted for the **2024 Abraham Jacobi Award**, which will likely be presented during the 2024 National Conference and Exhibition. This is a joint AAP/ American Medical Association award honoring Abraham Jacobi, the Father of American Pediatrics.

About Abraham Jacobi: Born in Germany in 1830, Dr Jacobi arrived in New York in 1853. In 1860, he established the first children's clinic at the New York Medical College, and he was a teacher of pediatrics from 1857 until he was nearly 70 years old. He influenced the care of children in almost all medical institutions in New York City and was considered the focal point of all pediatric thought and teaching. In 1880, Dr Jacobi established the AMA Section on Pediatrics; Dr Jacobi was twice elected the president of the American Pediatric Society, the first time on its founding in 1889; he served as president of the Association of American Physicians (1896), the New York Academy of Medicine (1855-89), and the American Medical Association (1912-13). Abraham Jacobi died in 1916 at the age of 86.

2024 AAP Equity, Diversity, and Inclusion Excellence Award Nomination Form and Checklist

Please type a	l information requested below on this form. Thank you!	
Nominee Name	AAP ID #	
Title:		
Mailing Address	:	
City:	State: Zip Code:	
Office Phone:	Cell Phone: Fax:	
Home Phone:	Email:	
Nominator Nam	e:AAP ID #	
Title:		
Mailing Address	:	
City:	State: Zip Code:	
Office Phone:	Cell Phone: Fax:	
Home Phone:	Email:	
	<u>CHECKLIST</u> The nominator should include the following items along with this form and submit by <u>June 14, 2024</u>	
	 Nomination Letter (selection subcommittee will only accept one nomination letter) Four (4) page maximum Respond directly to the award criteria listed on the Call for Nominations. Please include the nominee's EDI contributions that are particularly significant. 	
	 1 Letter of Support Two (2) page maximum. The letter of support should be from an individual who can attest to the nominee's contributions to EDI. 	
	Nominee's Curriculum Vitae	
	Please send all materials via email to: sdiederich@aap.org Questions? Email mjones@aap.org	







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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

Coding: Clinical Documentation, Part II: Clinical Documentation Improvement Programs

Scott D. Duncan, MD, MHA

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.

"As noted in Part I, inaccurate documentation can impact patient care, quality metrics, administrative databases, and perceived patient complexity. Improper or poor documentation can result in adverse patient outcomes, communication gaps, revenue loss, and incorrect case-mix indexes."

As noted in Part I, inaccurate documentation can impact patient care, quality metrics, administrative databases, and perceived patient complexity. Improper or poor documentation can result in adverse patient outcomes, communication gaps, revenue loss, and incorrect case-mix indexes. Examples of the challenges clinicians face include choosing the correct ICD-10 diagnosis and/or Current Procedural Terminology (CPT®) codes and timely, accurate documentation. This may result from insufficient education, uncertainty related to the precise definition of the diagnosis, questions of the clinical significance of a diagnosis, and burdens related to the electronic medical record (EMR).

"Clinical documentation and proper coding can be improved! Traditional interventions may include didactic presentations, utilization of templates, and other learning aids. Emerging technology, such as artificial intelligence, speech recognition, and scribes, may improve clinical documentation."

Clinical documentation and proper coding can be improved! Traditional interventions may include didactic presentations, utilization of templates, and other learning aids. Emerging technology, such as artificial intelligence, speech recognition, and scribes, may im-

prove clinical documentation. Healthcare systems and/or physician practices can integrate multiple techniques, such as the ones noted above, as part of a Clinical Documentation Improvement (CDI) program.

The literature is replete with examples of CDI programs in adult medicine; however, pediatric CDI programs are emerging to enhance the case mix index and improve reimbursements. In many ways, a successful CDI program should mirror or incorporate similar quality improvement methodologies. The ultimate aim is to achieve accurate and thorough medical record documentation.

"In building a CDI program, the initial step is defining the complement and governance of the team. The team should include stakeholders with complementary skill sets. Members from clinical, administrative, health information management, quality, case management, utilization review, and revenue cycle departments should be considered. Specific roles can be defined for coders, clinical documentation specialists, physician advisors, and physician champions."

In building a CDI program, the initial step is defining the complement and governance of the team. The team should include stakeholders with complementary skill sets. Members from clinical, administrative, health information management, quality, case management, utilization review, and revenue cycle departments should be considered. Specific roles can be defined for coders, clinical documentation specialists, physician advisors, and physician champions. Clinical documentation specialists serve as a conduit between the clinician and the coder and review the medical record to collect and validate ICD-10 codes, amongst other roles. A physician advisor provides documentation education for clinical colleagues and trainees and education for coders, ancillary staff, and administrative personnel. A physician champion who understands the goal and mission of the CDI program can encourage colleagues and provide a link between the healthcare provider and the CDI team. An administrative sponsor provides leadership and support and is critical in developing a successful CDI program.

Like any quality improvement project, the next step is to evaluate the current state once the team is assembled. The initial assessment is critical to assessing provider documentation's accuracy, specificity, and completeness. Reviewing a sample of records may highlight areas upon which to focus efforts; this should include a review of the documentation processes, ICD-10 codes, and CPT® codes, focusing on the completeness and accuracy

of the documentation and coding. The CDI team should provide background information for providers to demonstrate the magnitude of the problem prior to defining interventions.

In addition to reviewing a sample of records, developing a process flow diagram, related to EMR documentation, coding, charge capture, record review, and inquiries may be useful. This will help determine what the CDI program's workflow and processes might look like and what interventions may be necessary. Is the current workflow for documentation, coding, and charge capture efficient? When are medical records and charge assignments analyzed? What is the process for provider inquiries?

"This is followed by a design phase, where the team develops an equivalent of the "AIM" statement, defines the program scope and approach with clear metrics for measuring successful outcomes, and creates SMART goals. Measurable metrics might include key performance indicators, the case mix index, length of stay, complications or comorbidities, revenue, denials, and/or other benchmarks."

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"The cornerstone of any CDI program is education. Audit findings should be communicated to the individual provider. Education components should include didactic components, as well as simulation-based training. Demonstration of best practices in clinical documentation should be mandatory for new clinical staff."

The cornerstone of any CDI program is education. Audit findings should be communicated to the individual provider. Education components should include didactic components, as well as simulation-based training. Demonstration of best practices in clinical documentation should be mandatory for new clinical staff. Due to the changing nature of coding and documentation, periodic updates should be provided to experienced providers. For example, new CPT® evaluation and management guidelines focus on medical decision-making (MDM) and time, creating a new standard for clinical documentation. While education is an essential program component, interventions may expand beyond educational activities to encompass technology such as natural language processing and computer-assisted coding.

Clearly defining goals and measuring specific progress indicators are required to obtain "buy-in." A communications plan should be developed as an essential part of the CDI program to provide timely updates to providers and stakeholders. This plan should include sharing objectives, best practices, timelines, desired outcomes, ongoing reviews, and, perhaps most importantly, program benefits. Ensuring sustainable progress requires continuous monitoring of program compliance, coding changes, and new carrier guidance while communicating successes and establishing new goals.

A CDI program should be ongoing. The CDI's performance data will reveal improvements in documentation and coding and eliminate interventions with limited results. Eliminating waste is a foundation of quality improvement methodology and will positively impact the CDI program itself. Ultimately, a well-designed CDI program will succeed in ensuring proper documentation and coding.

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Disclosures: Dr. Scott Duncan is a Fellow of the American Academy of Pediatrics and a member of the Coding Committee of the Section on Neonatal-Perinatal Medicine.

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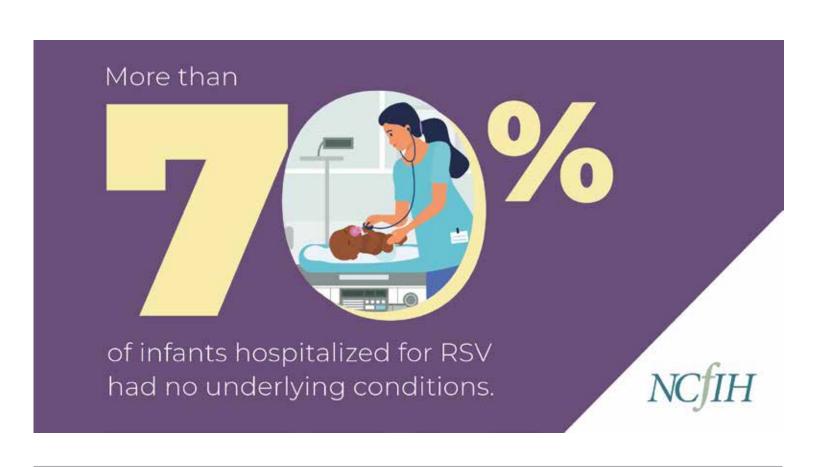
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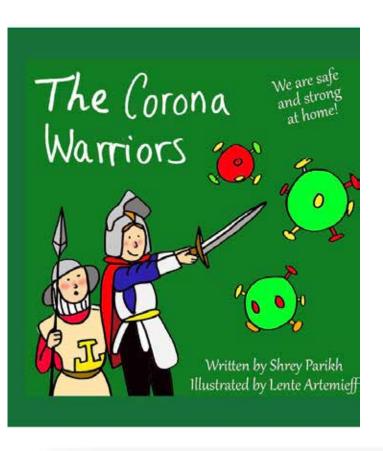
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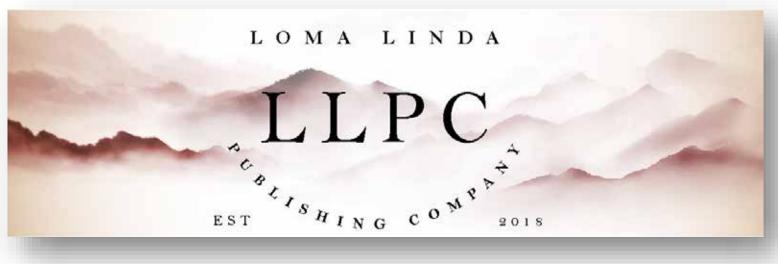
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Genetics Corner: A Consultation for Familial Polysyndactyly

Subhadra Ramanathan MSc, MS, Robin D. Clark MD

Clinical Summary:

A 7-month-old female was referred to Pediatric Genetics for preaxial polydactyly and syndactyly of both hands and feet (Figure 1a–c) and a positive family history of a similarly affected father. She was normocephalic (OFC at nine mos Z-score 1.05) with bilateral epicanthal folds and telecanthus. Her pediatrician had prescribed a helmet for plagiocephaly, which had resolved by the time of the visit. The exam and visit were completed by telehealth (video).

Imaging studies on the infant showed preaxial polydactyly of both feet. The first metatarsal of the left foot was associated with two sets of proximal and distal phalanges. The distal phalanx of the second digit was bifid with partial soft tissue fusion of the first and second digits and, possibly, third digits on the left and partial soft tissue fusion of the first, second, and third digits on the right.

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X-rays also showed preaxial polydactyly of both hands with bif first digits as well as soft tissue mass with punctate calcification arising off the fifth digit at the level of the proximal interphalangeal joint (postaxial polydactyly) on the left. There was partial soft tissue fusion of the first and second digits.

The infant was otherwise healthy, feeding well with normal stooling and voiding. No hearing or vision concerns were identified. She was developmentally on target.

The family history was significant for her father with similar preand postaxial polydactyly with broad thumbs, broad toes, and preaxial polydactyly of the right foot with syndactyly. He had prominent supraorbital ridges, downslanting palpebral fissures, and hypertelorism. While the paternal grandmother was reported to be asymptomatic, at least one of her family members had digit anomalies. Parents were of Hispanic ancestry; parental consanguinity was denied.

Figure 1a: Bilateral preaxial polydactyly/ syndactyly of the feet



Figure 1b and 1c: Preaxial polydactyly of hands bilaterally; post-axial polydactyly of left hand



The clinical features in the patient and her father—polydactyly and craniofacial dysmorphisms—were suggestive of Greig cephalopolysyndactyly syndrome (GCPS), inherited in an autosomal dominant manner due to pathogenic variants (mutations) in the *GLI3* gene. Molecular genetic testing confirmed the diagnosis and detected a pathogenic variant in *GLI3*, a deletion of exon 4, in our patient.

Discussion:

Polydactyly is the most common hereditary limb malformation, characterized by supernumerary fingers or toes. The estimated prevalence is 1/630 and 1/3300 among Caucasians and between 1/100 and 1/300 in African Americans. (1) While non-syndromic polydactyly can be multifactorial or inherited in an autosomal dominant manner, over 100 syndromes have also been associated with this birth defect.

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"The two most common types are postaxial polydactyly (PAP), with the extra digit at the fifth finger or toe (on the ulnar/ peroneal side), and preaxial polydactyly (PPD), having the extra digit attached on the greater toe or thumb side (radial/ medial). Isolated postaxial polydactyly is ten times more common in African Americans and is more common in males. Preaxial polydactyly is 3-4 times more common in Native Americans than in Caucasians or African Americans. It is more often unilateral and more common in females. It may be seen with other anomalies in infants of diabetic mothers. Mesoaxial (central) polydactyly, when there is duplication of the second, third, or fourth digits of the hands or feet, is very rare"

The two most common types are postaxial polydactyly (PAP), with the extra digit at the fifth finger or toe (on the ulnar/ peroneal side), and preaxial polydactyly (PPD), having the extra digit attached on the greater toe or thumb side (radial/ medial). Isolated postaxial polydactyly is ten times more common in African Americans and is more common in males. Preaxial polydactyly is 3–4 times more common in Native Americans than in Caucasians or African Americans. It is more often unilateral and more common in females. It may be seen with other anomalies in infants of diabetic mothers. (2) Mesoaxial (central) polydactyly, when there is duplication of the second, third, or fourth digits of the hands or feet, is very rare.

The limb buds appear at week 4, and the basic structures of the limbs (bones, muscle groups) are established by week 8 of gestation. The limbs' patterning, growth, and maturation occur along proximal-distal, anterior (rostral)-posterior (caudal), and dorsal-ventral axes of the developing embryo. Anterior-posterior patterning is determined by the Shh (Sonic Hedgehog) signaling. This protein is a well-studied morphogen that specifies digit identity by dose-dependent activation of target genes. *GLI3* encodes a zinc finger transcription factor that negatively regulates both the expression of *SHH* and its target genes and restricts the potential of a polydactylous limb to pentadactyly (Figure 2). (3, 4)

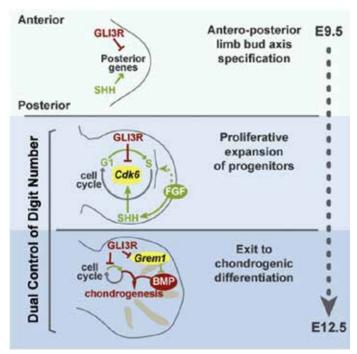
Pathogenic variants (mutations) in *GLI3* are associated with both non-syndromic and syndromic polydactyly: Grieg cephalopolysyndactyly syndrome (GCPS), Pallister-Hall syndrome, as well as isolated polydactyly classified as postaxial polydactyly types A1 and B and preaxial polydactyly, type IV. All of these are inherited in an autosomal dominant manner.

There are known genotype-phenotype correlations in *GLI3* (Figure 3). GCPS is caused by truncating mutations upstream or within of the zinc finger domain (ZFD) as well as missense and nonsense

variants in other parts of the gene that result in haploinsufficiency of the gene. (5) A small proportion of GCPS is associated with the deletion of the *GLI3* gene as part of a contiguous gene deletion on chromosome 7p14. (6)

"Pathogenic variants (mutations) in GLI3 are associated with both nonsyndromic and syndromic polydactyly: Grieg cephalopolysyndactyly syndrome (GCPS), Pallister-Hall syndrome, as well as isolated polydactyly classified as postaxial polydactyly types A1 and B and preaxial polydactyly, type IV. All of these are inherited in an autosomal dominant manner."

Figure 2: (Creative Commons License) graphical representation of GLI3 signaling and constraint of digit number in mice. (4)

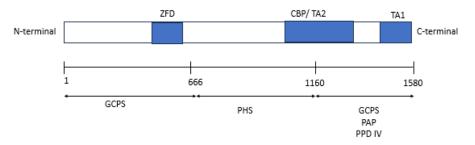


The exon 4 deletion in our patient is upstream of the ZFD in exon 12.

Pallister-Hall syndrome is caused by frameshift, nonsense, and splicing mutations in the middle third of the *GLI3* gene, corresponding to exon 14 and parts of exons 13 and 15.

GCPS is characterized by craniofacial features (Table 1), including macrocephaly, frontal bossing, prominent forehead, scaphocephaly, and hypertelorism associated with pre- and postaxial polydactyly. There may be broad or duplicated thumbs, broad or duplicated halluces, and cutaneous syndactyly of the fingers and toes. It is highly penetrant, meaning that those with mutations in the gene express clinical features in a family, but there can be inter- and intrafamilial phenotypic variability. (7) Less frequently, it can also include craniosynostosis, typically midline: metopic or

Figure 3: GL/3 genotype-phenotype correlations (adapted from Al-Qattan MM et al., 2017).



GLI3 protein domains and known genotype—phenotype correlations. ZFD, zinc finger domain; CBPD: cyclic AMPbinding protein-binding domain; TA 1 and 2, transactivation domain 1 and 2; GCPS: Greig cephalopolysyndactyly syndrome; PHS: Pallister—Hall syndrome; PAP: postaxial polydactyly A/B; PPD IV: preaxial polydactyly type IV.

sagittal. (8)

Developmental delay, intellectual disability, or seizures appear to be uncommon manifestations (~<10%) of GCPS and may be more common in individuals with large (>300-kb) deletions that encompass *GLI3*. Approximately 20% of individuals with GCPS have hypoplasia or agenesis of the corpus callosum.

Surveillance primarily involves reviewing head growth in infants and children; if faster than normal or neurologic concerns arise, a brain MRI is indicated.

"Developmental delay, intellectual disability, or seizures appear to be uncommon manifestations (~<10%) of GCPS and may be more common in individuals with large (>300-kb) deletions that encompass GLI3. Approximately 20% of individuals with GCPS have hypoplasia or agenesis of the corpus callosum."

Practical Applications:

- Evaluate for craniosynostosis when you suspect GCPS or syndromic polydactyly when there is complex polydactyly or syndactyly.
- Suspect a genetic etiology when there is a positive family history of polydactyly, even when isolated.
- Order chromosome microarray analysis if there are other anomalies and/or growth or developmental concerns to evaluate for a contiguous gene deletion syndrome
- Genotype-phenotype correlations in GLI3-associated polydactyly help distinguish diagnoses with overlapping clinical features and help guide clinical management.
- Understand the differences in the incidence of polydactyly based on ancestry: isolated postaxial polydactyly is quite common in African Americans, while preaxial polydactyly is common in Native Americans.
- 6. Isolated polydactyly can be sporadic and multifactorial. Post-axial polydactyly is seen more commonly in males.
- 7. Preaxial polydactyly is less common, and mesoaxial polydactyly is the least common.

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Table 1: Select Features of Greig Cephalopolysyndactyly Syndrome (9)

Feature	% of patients with feature	Comment
Macrocephaly	50	
Widely-spaced eyes	50	
Preaxial polydactyly	90	More common in the feet
Markedly broad hallux	25	
Markedly broad thumb	30	
Postaxial polydactyly	50	More common in hands
Cutaneous syndactyly	75	

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June 2024 Family Centered Care Taskforce

Morgan Kowalski

"The Family-Centered Care Taskforce stands as a pioneering force, being the FIRST international, multicenter, collaborative initiative solely dedicated to quality improvement in NICU Family-Centered Care."

The Family-Centered Care Taskforce stands as a pioneering force, being the FIRST international, multicenter, collaborative initiative solely dedicated to quality improvement in NICU Family-Centered Care. The Taskforce has over 1100 members and employs a small group quality improvement collaborative model by offering free monthly Office Hours for those looking to overcome barriers to implementing FCC and a large group model by offering free educational bi-monthly webinars. Our key strength is equal partnership between healthcare providers and Family Partners, enabling effective communication and facilitating change across various healthcare settings. By sharing evidence-based practices and critical family perspectives during webinars and promoting accountability through Office Hours, we are creating a forward movement to close the healthcare gap. Click here to sign up for Office Hours at no cost and visit our website, www.fcctaskforce. org, to subscribe to our mailing list and receive invitations to our webinars! Our next webinar takes place July 11th at 11 am PST.

As we celebrated our second anniversary of facilitating free educational webinars in May of this year, we cannot help but reflect on where we began. The Family-Centered Care Taskforce was founded by Malathi Balasundaram, MD, a Clinical Professor at Stanford School of Medicine and an attending neonatologist and

FCC Committee Chair at El Camino Health NICU. Malathi saw a need for an organization dedicated to quality improvement in NICU Family-Centered Care. She pitched her idea of creating the FCC Taskforce to colleagues at the Gravens Conference and the American Academy of Pediatrics (AAP), Trainees, and Early Career Neonatologists (TECaN) Executive Council. Shortly thereafter, a 'welcome to the Taskforce' email was sent to 50 dedicated members in February of 2022, and just over two years later, that number has grown to over 1,100 members from almost every U.S. State and 36 countries around the world.

"Our key strength is equal partnership between healthcare providers and Family Partners, enabling effective communication and facilitating change across various healthcare settings. By sharing evidence-based practices and critical family perspectives during webinars and promoting accountability through Office Hours, we are creating a forward movement to close the healthcare gap."

Colby Day, MD, Medical Director of Golisano Children's Hospital NICU, joined the Taskforce as a co-chair alongside Malathi at the Taskforce's inception. The pair invited Keira Sorrells, former NICU parent and Founder and Executive Director of NICU Parent Network, to join them on the Core Team in March of 2023 and recruit-



ed Morgan Kowalski, a former NICU parent, and Family Partner in her local unit, to serve as Program Manager in May of 2023 in the spirit of equal partnership between families and clinicians.

The Taskforce began our work by helping centers around the globe begin and strengthen FCC practices in their NICUs by recruiting and facilitating live bi-monthly webinars beginning in May of 2022, with speakers from diverse backgrounds and roles. In 2023, we continued these well-attended events and recruited 22 centers that wanted to overcome barriers in implementing FCC Committees and Family Partnership/Advisory Councils. These centers were split into five small groups based on AAP levels of care, and monthly meetings were held to discuss challenges around implementing FCC and strategies for overcoming them. These small group QI collaborative opportunities served participants well, with 59% creating an active FCC Committee and 45% creating an active Family Partnership/Advocacy Council in just one year. These advancements are significant, and we are continuing a similar but more inclusive opportunity for NICUs to brainstorm with others during our monthly Office Hours sessions in 2024.

Here are some testimonials from members who participated in small groups in 2023:

"Thank you for all your hard work in engaging NICU teams all around the country on this Taskforce! Our unit has been able to share our FCC team's efforts as well as availability of rich information-sharing that has helped us refine our family-centered care processes in our NICU."

Sangeeta, California

"The Taskforce began our work by helping centers around the globe begin and strengthen FCC practices in their NICUs by recruiting and facilitating live bi-monthly webinars beginning in May of 2022, with speakers from diverse backgrounds and roles."

"Our unit in Israel joined the FCC Taskforce a year and a half ago. We have attended general and small group sessions in which we have received mentoring from leading figures in the field of FCC. We have learned a lot! We now have a better understanding of the core elements of FCC and are learning about different and practical ways we can implement FCC in our unit. We could not have made this possible without the support of our mentors, and we are very grateful for them and for this amazing model of support."

— Rafi, Tel Aviv

"I am so proud to be on this Taskforce and to see the widespread change that is happening in units. I feel very fortunate to have the opportunity to connect with colleagues who share my passion for FCC. I learn something new in every webinar!"

— Maria, Texas

Our Executive Council of diverse Healthcare and Family Partners

supports the success of the FCC Taskforce in assisting NICUs. Healthcare Partners come from organizational, quality improvement, and multidisciplinary clinical backgrounds, some of whom are former NICU parents. Family Partners are diverse in their experiences, with full-term NICU journeys and non-birthing parent representation. They support their local NICUs, direct their organizations, contribute to nonprofits supporting NICU families, and hold esteemed positions in national QI collaboratives, respectively. Executive Council members facilitate Newsletters, Marketing and Communications, and Advocacy subcommittees, which help disseminate current best practices and create new ones. The Taskforce is also supported by esteemed national and international organizational partners. We are sharing the program overview below. Join us in strengthening FCC in your NICU.

"Our Executive Council of diverse Healthcare and Family Partners supports the success of the FCC Taskforce in assisting NICUs. Healthcare Partners come from organizational, quality improvement, and multidisciplinary clinical backgrounds, some of whom are former NICU parents. Family Partners are diverse in their experiences, with full-term NICU journeys and nonbirthing parent representation. They support their local NICUs, direct their organizations, contribute to nonprofits supporting NICU families, and hold esteemed positions in national QI collaboratives, respectively."

Disclosure: There are no reported conflicts.

NT

MEMBERSHIP



1100+ members across 43/50 U.S. States & 36+ Countries Join us, membership is free!





WEBSITE

Visit our <u>website</u> to learn more about our advocacy efforts, view testimonials from our members, view webinar recordings, and access free resources on all things Family-Centered Care.

FAMILY-CENTERED CARE TASKFORCE

THE **FIRST** INTERNATIONAL, MULTICENTER, COLLABORATIVE INITIATIVE SOLELY DEDICATED TO **QUALITY IMPROVEMENT IN NICU FAMILY-CENTERED CARE**

WHAT IS FAMILY-CENTERED CARE?

Family-Centered Care (FCC) ensures that caregivers are active, engaged team members throughout their NICU journey, and is a key factor in improving infant health and family mental health outcomes.

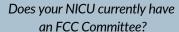
WHY WE EXIST

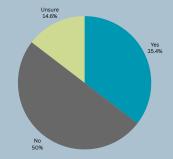
We exist to equip and support NICUs as they seek to begin or strengthen Family-Centered Care in their units.

To address the challenges that exist in implementing FCC practices, we offer free educational webinars with engaging, live Q&A sessions and free monthly office hours sessions.

Our key strength is equal partnership between clinicians and Family Partners in everything we do.

In a survey of 48 NICUs across the U.S., 65% said they don't have an FCC Committee in their unit.





STANFORD IMPACT LABS SEED PARTERSHIP

In June of 2024, the FCC Taskforce was awarded a <u>Seed Partnership</u> with Stanford Impact Labs to support our work, **Optimizing the Delivery of Family-Centered Care in the Neonatal Intensive Care Unit (NICU)**. We look forward to collaborating with <u>NICU Parent</u>
Network on this important initiative!

Our aim is to use quantitative and qualitative research methodologies to create an **FCC standard** and explore FCC practices at a scale that exceeds prior studies. This work will enable us to (1) develop first-ever FCC benchmarks in the NICU, and (2) identify ways to overcome barriers to FCC implementation.

FREE EDUCATIONAL WEBINARS

JULY 11TH

"Families as Neuroprotectors" with Paige Church, MD

"Delivering Hope Through Words: The Power of Effective Communication in the NICU" with Mia Malcolm, BS, CDFT

SEPTEMBER 12TH

"Improving Family Engagement in the NICU: The Colorado Experience" with Susan Hwang, MD, MPH, PhD

Title TBD with Elizabeth Simonton, JD and Co-Founder/CEO, ICU Baby

NOVEMBER 14TH

Title TBD with Rafi Mendelson, MD, Neonatologist, Tel Aviv

Title TBD with Fabiana Bacchini, Executive Director, Canadian **Premature Babies Foundation**

Subscribe to our mailing list to receive calendar invites and Zoom links for our free educational webinars!

OFFICE HOURS

The FCC Taskforce holds monthly Office Hours to discuss challenges around implementing FCC practices and provide strategies for overcoming them. Office Hours are facilitated by both clinicians and Family **Partners from our Executive** Council and includes a variety of topics relevant to beginning or strengthening FCC. Click here to register!

CONNECT

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July 11, 2024 11:00am - 12:30pm PT

FCC TASKFORCE

FAMILIES AS NEUROPROTECTORS IN THE NICU

Paige Terrien Church, MD (she/her)

- Director, NICU Grads Program, Boston Children's Hospital, Beth Israel Deaconess Medical Center
- Assistant Professor, Harvard Medical School

DELIVERING HOPE THROUGH WORDS: THE POWER OF EFFECTIVE COMMUNICATION IN THE NICU

Mia A. Malcolm, BS, CDFT (she/her)

- · NICU Parent of Gavin
- · DEIB Facilitator and Consultant









ORGANIZATIONAL PARTNERSHIPS



2023 QUALITY IMPROVEMENT WORK

We are thrilled to share that among the 22 global NICUs participating in our 2023 quality improvement work, we exceeded our goals by increasing the percentage of units with an active NICU-specific FCC Committee from 18% to 59%, and the percentage of NICUs with an active Family Advisory/Partnership Council from 18% to 45% in just 12 months! Units who had the most success consistently participated in small group benchmarking opportunities where they were encouraged to share their barriers to implementing FCC practices and brainstorm strategies for overcoming them, and attended our free educational webinars while encouraging their colleagues to do the same. Stay tuned for a publication on this quality improvement initiative!

SMALL GROUP 1

Kerri Z. Machut, MD Lurie Children's Hospital of Chicago Jessica Fry, MD Lurie Children's Hospital of Chicago Elizabeth Simonton, Family Partner CEO & Co-Founder, ICU Baby







SMALL GROUP 2

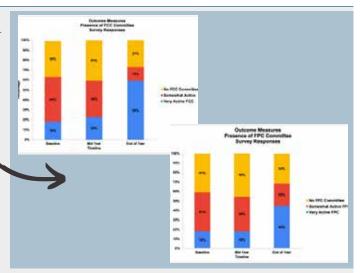
Dharshi Sivakumar ,MD
Stanford/El Camino Health NICU
Vargabi Ghei, MD
HCA East Florida Northwest Medical Center
Katherine Huber, Family Partner
FCC Committee, El Camino Health NICU
Alex Zavala, Family Partner
Founder, The NICU Dad and The NICU Dad Podcast











SMALL GROUP 4

Emily Whitesel, MD
Beth Israel Deaconess Medical Center
Robert Cicco, MD
Pennsylvania
Molly Fraust-Wylie, Family Partner
NICU Family Program Manager, Beth Israel
Deaconess Medical Center







SMALL GROUP 5

Robert White, MD
Beacon Children's Hospital
Malathi Balasundaram, MD
Stanford/El Camino Health NICU
Keira Sorrells, Family Partner
Founder & Executive Director,
NICU Parent Network
Michelle Wrench, Family Partner
Chair, Family Advisory Committee CPQCC









SMALL GROUP 3

Colby Day, MD
University of Rochester Medical Center
Daphna Barbeau, MD
HCA University Hospital Davia
Morgan Kowalski, Family Partner

University of Rochester Medical Center









FCC TASKFORCE WEBINAR

July 11, 2024

11:00am - 12:30pm PT



Paige Terrien Church, MD (she/her)

- Director, NICU Grads Program, Boston Children's Hospital, Beth Israel Deaconess Medical Center
- Assistant Professor, Harvard Medical School

DELIVERING HOPE THROUGH WORDS: THE POWER OF EFFECTIVE

COMMUNICATION IN THE NICU

Mia A. Malcolm, BS, CDFT (she/her)

- NICU Parent of Gavin
- DEIB Facilitator and Consultant





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Morgan Kowalski Program Manager Family Partner Golisano Children's Hospital NICU University of Rochester Medical Center









VACCINES

PREVENTIVE MONOCLONAL ANTIBODIES

Teach the body to create antibodies that fight off a specific disease.

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.

How does it work?

Introduce antibodies that are ready to ward off disease in the body.

Instead of teaching the body to create antibodies and defenses, they provide antibodies that are readily available.

Both support the immune system's defenses.

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



https://www.who.int/news-room/feature-stories/detail/how-do-vaccineswork#.-.text=Vaccines%20contain%20weakened%20or%20inactive,rather%20than%20 the%20antigen%20itself.

https://static1.squarespace.com/static/5523fcf7e4b0fef011e668e6/t/62445afd0134140ff
954f3f6/1648646910485/NCflH_Monoclonal+Antibodies+Inclusion+in+the+VFC+Program,
Position_Paner_Mara/2727.pdf

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.

Polio Measles COVID-19 And more



RSV COVID-19

Both can provide tailored protection from a variety of diseases.

Yes Is it safe?

Yes

Both vaccines and preventive monoclonal antibodies undergo extensive testing for safety and efficacy.

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

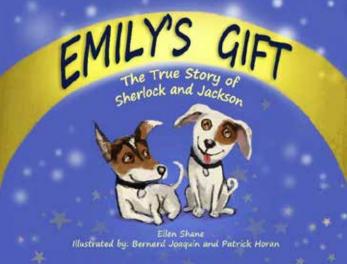
is a highly contagious seasonal virus that can lead to hospitalization for some babies and young children.

Know the Signs.



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Purchases of this engaging **true story** provide disadvantaged middle school students, risking academic failure, the opportunity to attain their best personal and academic potential.

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You can provide both reading entertainment for younger children, and make a difference in the lives of the disadvantaged middle schoolers we support.

Sales support our nonprofit charity's SEA Program. You can make a difference for these children!

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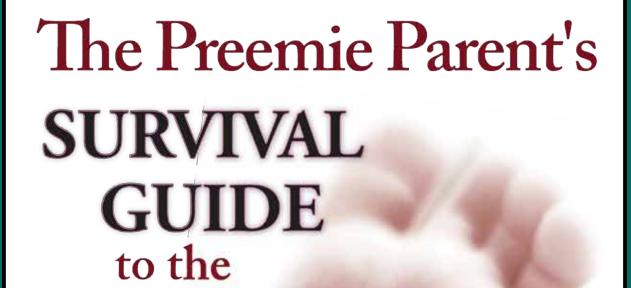
Direct SEA Support-Click Here





The Emily Shane Foundation is a 501(c)3 nonprofit charity. 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 fund the SEA Program, which make a difference in the lives of the students we serve.

For more information, please visit emilyshane.org.



By

NICU

little man's Nicole Conn

&

PreemieWorld.com's

Deb Discenza

with

Medical Editor Alan R. Spitzer, M.D.



HOW TO second edition
MAINTAIN YOUR SANITY
& CREATE A NEW NORMAL

Op-Ed: Pennsylvania Needs Paid Family Leave for NICU Families

Morgan Kowalski

"The stress, emotional toll, and financial burdens can be overwhelming, regardless of your infant's diagnosis or gestational age at birth. One of the most pressing issues for NICU families is the lack of paid family leave, which directly impacts infant health outcomes. It is time for Pennsylvania to take decisive action and pass paid family leave legislation."

As a former NICU parent and Program Manager of the Family-Centered Care Taskforce, I am acutely aware of the challenges families with infants face in the Neonatal Intensive Care Unit (NICU). The stress, emotional toll, and financial burdens can be overwhelming, regardless of your infant's diagnosis or gestational age at birth. One of the most pressing issues for NICU families is the lack of paid family leave, which directly impacts infant health outcomes. It is time for Pennsylvania to take decisive action and pass paid family leave legislation.

The absence of paid family leave exacerbates the difficulties faced by NICU families. Parents are often forced to choose between their jobs and their infant's well-being. This impossible choice can lead to prolonged hospital stays, increased health complications, and significant emotional distress. Paid family leave would allow parents to be present with their infants during these critical early days, promoting better health outcomes and offering much-needed support to families.

We are at a critical juncture. Our organization and the entire FCC Taskforce advocate for paid family leave in Pennsylvania. We are urging the governor and lawmakers to recognize the importance of this issue and take immediate action. We have initiated a letter of support and are collecting signatures to demonstrate the widespread demand for this essential policy. We invite everyone to take a moment to sign our letter via the linked Google Form. It takes less than a minute and can make a difference for countless families. The deadline for signatures is Thursday, June 27.

Moreover, our advocacy efforts extend beyond just paid family leave. We are working toward a resolution, "Parents and family caregivers are not visitors," which allows Zero Separation policies

"The absence of paid family leave exacerbates the difficulties faced by NICU families. Parents are often forced to choose between their jobs and their infant's well-being. This impossible choice can lead to prolonged hospital stays, increased health complications, and significant emotional distress. Paid family leave would allow parents to be present with their infants during these critical early days, promoting better health outcomes and offering muchneeded support to families."

to become the standard of care in NICUs across the U.S. In addition, we are seeking insights on how units have obtained senior leadership or administration buy-in for Family-Centered Care (FCC) practices. Your experiences and strategies are invaluable. Please contribute to our June poll to help us enhance our collective efforts to promote FCC practices.

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Our commitment to advocacy and support extends to organizing and participating in events that foster community and knowledge sharing. On Friday, July 12, our founder, Malathi Balasundaram, MD, and I will discuss the FCC Taskforce's efforts on the Canadian Premature Babies Foundation podcast, Preemie Chats. On

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July 24, join us for a session on establishing and sustaining effective Patient and Family Advisory Councils by IPFCC. We are excited about the 4th Annual Trauma Informed Developmental Care Conference from October 13-15th in Boston, MA, where professionals will converge to share insights and advancements in developmental care.

"Our commitment to advocacy and support extends to organizing and participating in events that foster community and knowledge sharing. On Friday, July 12, our founder, Malathi Balasundaram, MD, and I will discuss the FCC Taskforce's efforts on the Canadian Premature Babies Foundation podcast, Preemie Chats. On July 24, join us for a session on establishing and sustaining effective Patient and Family Advisory Councils by IPFCC. We are excited about the 4th Annual Trauma Informed Developmental Care Conference from October 13-15th in Boston, MA"

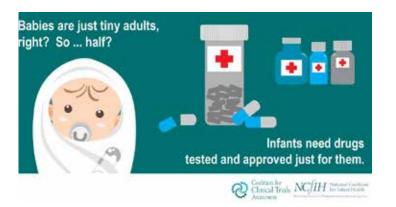
We thank our dedicated members and supporters for their unwavering commitment to Family-Centered Care. Your involvement and advocacy are what drive progress and change. Together, we can ensure that NICU families receive the support they need, including the critical provision of paid family leave.

Join the FCC Taskforce Mailing List, visit our website, follow us on Twitter, connect with us on LinkedIn, and subscribe to our You-Tube channel for updates and information.

Note: I work flexible hours and may send emails outside core hours of 9:00 a.m. - 5:00 p.m. EST. I do not expect you to read, action, or respond outside of your own working hours.

Disclosure: There are no reported conflicts.

NT



Corresponding Author



Morgan Kowalski Program Manager Family-Centered Care Taskforce email: morgankw@stanford.edu





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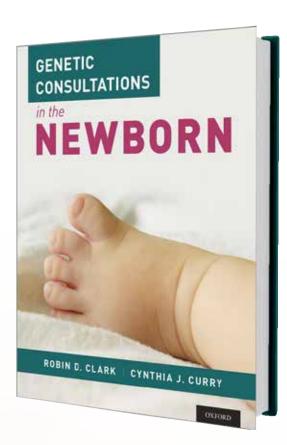


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Order now by clicking here.



Clinical Pearl: The Efficacy of Teaching Postpartum Mothers Proper Infant Positioning for Breast Feeding and Skin-to-Skin

Susan Wolf, RNC-NIC CCRP, Yuliya Vovchak MSN, RN, CBC, CCE, Katie Thedos, MS, BSN, RNC-OB, Michael Goodstein, MD, Mitchell Goldstein, MD, MBA, CML, Joseph R. Hageman, MD

"This SUPC-Prevention Safety Monitoring Program is comprised of staff education and maternal education reinforced by a written handout and an 8x10 colored poster in all postpartum rooms."

In Honor of Nancy Rodriguez, APN, PhD

Introduction:

Over the past seven years, we have been studying and writing about Sudden Unexpected Postnatal Collapse (SUPC) and have presented and published several presentations and papers (1-7). More recently, we have analyzed quality improvement data about Endeavor Health's copyrighted prevention program teaching mothers proper infant positioning (PIP) for breastfeeding and skin-to-skin care. - (6,7) * formerly NorthShore University Health-System (NSUHS)

This SUPC-Prevention Safety Monitoring Program is comprised of staff education and maternal education reinforced by a written handout and an 8x10 colored poster in all postpartum rooms

"In this study of 167 postpartum mothers at two of Endeavor Health's hospitals, we asked the mothers to rate their agreement with the following statements after their Proper Infant Positioning (PIP) training:"

Methods:

We asked mothers to complete a brief anonymous survey in the postpartum unit. They were not obligated to complete the survey but were told their feedback was vital so we could assess and revise/improve the PIP Program. They were instructed to place the completed survey in the attached envelope and seal it, then drop it

into a marked box at the nurse's station. The survey was available in English or Spanish.

In this study of 167 postpartum mothers at two of Endeavor Health's hospitals, we asked the mothers to rate their agreement with the following statements after their Proper Infant Positioning (PIP) training:

- 1. I feel confident in my ability to hold my infant properly during breastfeeding and skin-to-skin contact
- 2. I can demonstrate the six steps to ensure that my baby is properly positioned
- 3. PIP training interrupted time with my baby
- 4. Whoever is holding my baby (myself or others) should not be distracted by cell phone use and social media
- 5. I can recognize when I am fatigued and need to ask for help caring for my baby
- 6. PIP training encouraged me to breastfeed my baby often
- 7. I feel less anxious about breastfeeding or holding my baby skin-to-skin after PIP training.
- 8. I recommend the PIP training program
- 9. PIP training taught me things I did not know
- 10. I will remember the 10 PIP steps post-discharge

The results of each question are expressed using a Likert scale: Strongly agree, agree, undecided, disagree, strongly disagree, and no answer. Descriptive statistics are used, and a statistically significant result is p < 0.05.

Results:

I feel confident to hold my infant during breastfeeding and skin-to-skin:

Agree: 40/166=24%

Strongly agree: 122/166= 73%

Undecided 2/166= 1%

Disagree 1%

No Answer 1%

I can demonstrate the six steps to ensure that my baby is

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properly positioned:

Agree: 59/167= 35%

Strongly agree: 75/167= 46%

Undecided: 24/167= 14%

Disagree: 5/167= 3%

No answer: 4/167= 2%

PIP training interrupted time with my baby:

Agree 0/166= 0%

Strongly agree: 9/166= 5% Undecided: 17/166= 10% Disagree: 69/166= 42%

Strongly disagree: 64/166= 39%

No answer: 7/166= 4%

Whoever is holding my baby (myself or others) should not be distracted by cell phone use and social media:

Agree 32/167= 19%

Strongly agree 118/167= 71%

Undecided 7/167= 4% Disagree 3/167= 2%

No Answer 7/167= 4%

I can recognize when I am fatigued and need to ask for help caring for my baby:

Agree 28/167= 17%

Strongly agree 125/167= 75%

Undecided 3/167= 2% Disagree 3/167= 2%

No Answer 6/167= 4%

PIP training encouraged me to breastfeed my baby often:

Agree 42/167= 25%

Strongly agree 92/167= 55%

Undecided 23/167= 14%

Disagree 4/167= 2%

Strongly disagree 1/167= 0.5%

No Answer 5/167= 3%

I feel less anxious about breastfeeding or holding my baby skin-

to-skin after PIP training.

Agree 46/167= 28%

Strongly agree 96/167=59%

Undecided 17/167= 11%

Disagree 1/167= 0.6%

No answer 1/167= 0.6%

When the nurse came in to assess my baby's position, I felt it interfered with my breastfeeding or skin-to-skin session.

Agree 2/167=1%

Strongly agree 6/167=3.5%

Undecided 7/167= 4%

Disagree 66/167= 40%

Strongly disagree 80/167= 48%

No answer 6/167= 3.5%

Recommend PIP training:

Agree 45/163= 28%

Strongly agree 95/163= 58%

Undecided 14/163= 9%

Disagree 1/163= 0.6%

No Answer 8/163= 4%

PIP taught me things I did not know

Agree 55/167= 33%

Strongly agree 72/167= 43%

Undecided 25/167= 15%

Disagree 10/167= 6%

No answer 5/167= 3%

I will remember 10 PIP steps after discharge:

Agree 46/166= 28%

Strongly agree 77/166= 47%

Undecided 29/166= 17%

Disagree 5/166= 3%

Strongly disagree 2/166= 1%

No answer 7/166= 4%

Mothers were more confident in the proper positioning (97%) with skin-to-skin and breastfeeding of their newborn infants post-delivery (80%) and spent more time breastfeeding their infants (80%).

They discussed that PIP taught them things they did not know previously (76% agree/strongly agree vs. 21% undecided or disagree).

"A total of 86% of the mothers would recommend PIP training. In addition, 74% felt they would remember the 10 PIP steps post-discharge from the hospital."

A total of 86% of the mothers would recommend PIP training. In

addition, 74% felt they would remember the 10 PIP steps postdischarge from the hospital. (Table 1)

Proper Infant Positioning (PIP) Training Program:

Ten steps to keep your baby pink and positioned for distraction-free breastfeeding and skin-to-skin contact

- 1. My breast tissue does not cover my baby's nostrils
- My baby's head is turned to one side during skin-to-skin contact or directly facing my breast if I am breastfeeding, so I can easily see my baby's mouth and nostrils
- 3. My baby's chin is not tucked down into his/her chest, the neck is straight and not bent
- 4. My baby's shoulders and chest face me
- 5. My baby's lips are pink
- 6. If I cover my baby with a blanket, my baby's head is not covered so that I can always see his/her face and nose
- 7. If I am holding my baby, I will make sure not to get distracted by texting or posting social media updates, talking on the phone, reading, watching TV, or eating a meal. I will ask someone else to hold my baby or place him/her in the crib if I need to do any of these things.
- 8. I know that it is normal to feel fatigued after giving birth, and will make sure to ask the nurse for help if needed
- 9. I will use the fatigue scale to determine how tired I feel

Table 1: 10 PIP steps

10. If I feel very fatigued (score of 3 or higher on the fatigue scale) and am alone, I will call my nurse for assistance to place my baby back in the crib, positioned on his/her back, baby's safest position for sleep

Table 2: Maternal Fatigue Scale

Another important concept was that mothers would ask for relief when they felt fatigued when holding or feeding their baby (92%) (TABLE 2: Fatigue scale WellSpan). However, "nursing noted that not many - if any - patients specifically referred to the Fatigue Scale" when asking for relief (Y.Vovchak, personal communication, June 5, 2024).

"In addition, 90% felt it was important not to be distracted when holding or feeding their babies."

In addition, 90% felt it was important not to be distracted when holding or feeding their babies.

Discussion:

In general, the postpartum mothers felt that they benefited significantly from the education they received from their nurses, utilizing the PIP handout.

"The nursing staff is trained using the PIP training module devised by Dr. Nancy Rodriguez. This educational module is mandatory yearly for staff so everyone involved with the care of the newborn infant is educated in proper infant positioning and prevention of SUPC (1-7) and methods of maternal education. We are also summarizing our data about the efficacy of the educational module for staff for PIP and SUPC prevention."

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Lessons Learned:

While these findings were encouraging, there were potential missed opportunities for fewer "undecided" responses.

1. More strongly agree or agree responses could have been encouraged with slight revisions of some of the statements in the Mother's Survey. Statements 2 (demonstrate the six steps) and 11 (remember the Ten PIP steps) in the Mother's Survey had some of the highest percentages of "undecided" responses (14% and 17%, respectively). The tone of these statements might have been understood as requiring memorization and recitation of the six and Ten Steps. Similarly, statement 6 (breastfeed my baby often) also had 14% "undecided." PIP education does not directly encourage breastfeeding but rather confidence in the proper positioning of infants during breastfeeding and skin-to-skin holding. Asking pa-

tients to make this connection might have been too far-reaching. Patients might have been more inclined to respond positively if the statements had been worded differently.

2. The opportunity to continue to educate about PIP may have happened more frequently on one site as the mother moves floors from labor and delivery to postpartum. It may have been overlooked at other hospitals where patients do not change rooms/ units. Moms do not necessarily get "re-oriented" once they deliver their baby. The workflow is quite different, which may have accounted for some of the "undecided" responses to the survey.

"Finally, simplifying the "Proper Infant Positioning (PIP) Training Program: Ten Steps" handout by eliminating points 9 and 10 (the underutilized Fatigue Scale) could make the material easier to digest for new parents who are already being exposed to so much new information, often in the uncomfortable setting of labor pain."

Perhaps having the survey translated into other native languages may have captured even more data.

Finally, simplifying the "Proper Infant Positioning (PIP) Training Program: Ten Steps" handout by eliminating points 9 and 10 (the underutilized Fatigue Scale) could make the material easier to digest for new parents who are already being exposed to so much new information, often in the uncomfortable setting of labor pain.

References:

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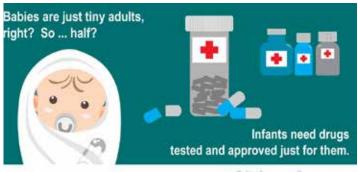
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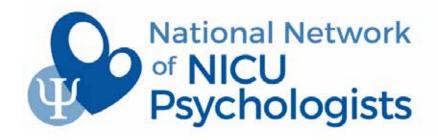
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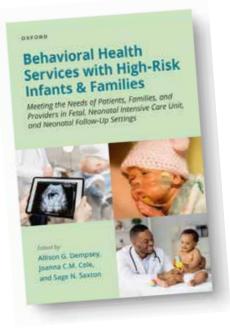


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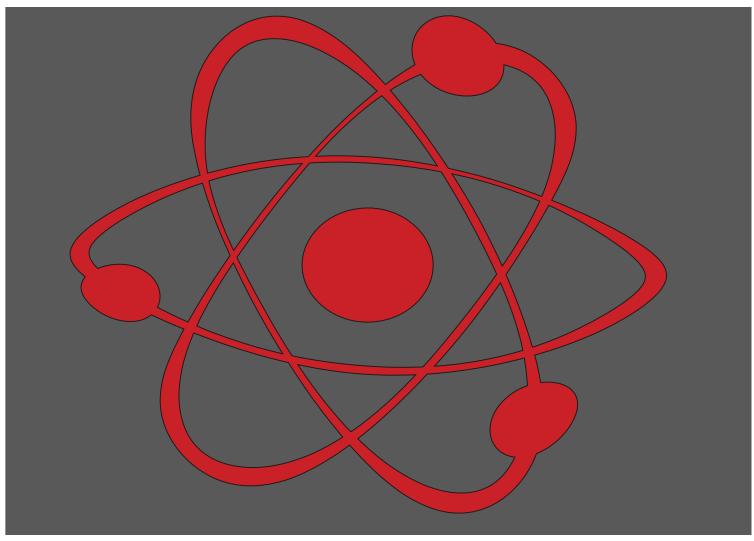
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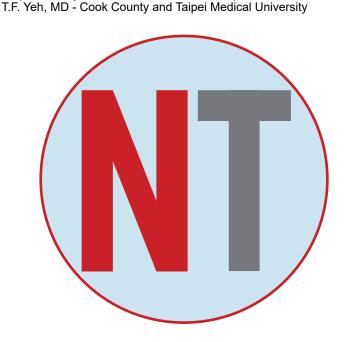


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This month we continue to feature artistic works created by our readers on the next to last page as well as photographs of birds on rear cover. For this edition, our art was again graciously provided by Colleen Kraft, MD. It is a work called "Solstice" done by her son Tim. Our Bird is from Dr. Mita Shah. It is an American Robin..



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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.

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