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Once Upon a Design: HSHS St. John's NICU Design and Post Occupancy Findings

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"The national trend in NICU design toward all-private single-family rooms (SFR) has been widely embraced for good reasons. These units support family-centered care models, standardize operations, improve infection control, and promote equality by providing equal accommodations to all families. (1)"

Introduction:

The national trend in NICU design toward all-private single-family rooms (SFR) has been widely embraced for good reasons. These units support family-centered care models, standardize operations, improve infection control, and promote equality by providing equal accommodations to all families. (1) However, as research evolves and perspectives broaden, it is worth considering whether an exclusively private-room approach meets the needs of every patient, care model, and family. While private SFRs will continue to offer many advantages, they may not be optimal in all circumstances.

Recent research finds that private rooms may not support complex family needs and may be too isolating for some patients. As premature babies survive at increasingly high rates and NICU admissions increase overall, many NICUs nationwide face increased demand along with serious spatial constraints. (2,3) Alternative design solutions that include a mix of room types may be necessary to optimize bed counts while still providing patient and family-centered care, amenities, and efficient staff and clinical support spaces.

This article shares findings from a post-occupancy evaluation (POE) of the HSHS St. John's Level III NICU redesign, providing evidence and lessons learned for mixed-room-type units. (5) With a mix of room types, HSHS St. John's has found an increase in their resiliency to support diverse and changing needs while still maintaining high satisfaction scores for families and staff.

The HSHS St. John's Hospital NICU Renovation POE report, including diagrams and photos, is available here. https://www.kahlerslater.com/hshs-st-johns-hospital-nicu-renovation-post-occupancy-evaluation-report

Pre-Design Baseline:

At the outset of the project, HSHS St. John's Hospital NICU faced significant space constraints. As admissions increased, the average occupancy rate rose from 95.2% in 2017 to 111.8% in 2018. With approximately 15,000 square feet total, the existing NICU supported 40 beds at 333 square feet per bed, well below recommended benchmarks. The unit was arranged into six, six- to eight-bed pods, including two isolation rooms, each supported by a single care team station. The NICU lacked clinical support and storage space, which compromised workflows and staff efficiency. Milk and formula were mixed at the patient's bedside by nursing staff, taking time away from clinical care and raising concerns about accuracy and safety. Family amenities were very limited, and overnight stays were not allowed, which did not align with the hospital's Family Centered Care Model aspirations. To expand and modernize the unit, HSHS St. John's Hospital partnered with Kahler Slater and Smith Hager Bajo, Inc. to create a new vision and design for its NICU.

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Project Vision & Goals:

HSHS St. John's Hospital's vision for its NICU project focused on providing family-centered care and compassionately supporting the clinical care team in delivering high-quality critical care. This vision set requirements for the new NICU to be welcoming, comfortable, operationally efficient, and flexible. Early in the design concept phase, project drivers were defined to guide decision-making and create a framework for measuring design success. These project drivers were:

- **Patient and Family Privacy:** Give families the opportunity to bond, because small moments matter.
- **Ideal Patient and Family Experience:** Provide people-centered care, comfort, and support for families and patients alike.
- **A Culturally Supportive Environment:** Understand and support families with unique needs.
- **A Welcoming, Calming Environment: Create a space that is warm, restorative, and family-**centered.
- **Safe High-Quality Care:** Invite families to play an active role as part of our team.
- Find wonderment in the patients.
- **Access to Nature:** Reflect HSHS St. John's Hospital's faith through a serene, aesthetically pleasing design that

demonstrates God's presence in everything we do.

- **Ideal Staff & Provider Experience:** Enhance collaboration and workflows while supporting whole-person health and well-being.
- **Separate Flows:** Establish and clearly separate front-of-house and back-of-house flows.
- **Future Growth:** Provide flexibility to accommodate future growth and support resiliency.

In addition to the project drivers, measurable project goals were defined. These included: providing greater accommodation for families; decreasing infection and seven-day readmission rates, and average length of stay (ALOS); improving staff engagement. Both the design drivers and measurable project goals were used in the POE to evaluate the project's success.

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Design Process:

The NICU design process was highly inclusive, with multidisciplinary teams of physicians, nurses, infection prevention specialists, leadership, and other stakeholder representatives participating throughout. The design team led numerous activities to understand new care models, explore different concepts, and achieve consensus and buy-in. Key among these activities were benchmarking tours, puzzle play, and mockups.

- Benchmarking tours took stakeholders through peer facilities to provide an understanding of best practices and opportunities, and to gauge preferences for both aesthetic and functional design elements.
- Puzzle play invited participants to lay out the department and confirm space adjacencies, workflows, and sightlines during a hands-on design meeting. Scaled pieces were moved around a floor plan to illustrate a variety of options quickly.
- Full-size mockups of key spaces enabled stakeholders to understand the design better and test different clinical scenarios. Using affordable, lightweight materials such as rigid insulation board and additional furniture and equipment, the design team built a rough yet accurate model of the space, allowing stakeholders to walk through and simulate work activities.

HSHS. St. John's Hospital NICU's Clinical Liaison was a key factor in the success of this project. She began the project as the head nurse before transitioning into a leadership position dedicated to developing operational and clinical requirements for the new future-state models. Her leadership was instrumental in translating key concepts and requirements between the design team and the clinical staff, ensuring both designers and users spoke the same language. With new operational models implemented, the Clinical Liaison championed the change process, documented new standards, and set up training for a smooth transition into the new space. This role is highly recommended for any new design project implementing new care or operational models.

HSHS St. John's NICU Level III Design

Opened in March of 2021, the 36,000-square-foot phased renovation more than doubled the size of the previous NICU. Floor space was reclaimed by relocating the administrative and non-NICU clinical spaces that had filled the rest of the floorplate to more appropriate locations on campus. The expanded space accommodated 16 additional beds, bringing the total to 56, increasing capacity by 40%. Departmental square footage (DGSF) per bed also increased from 333 square feet to 652 square feet. In total, 47% of the space was devoted to patient care, 25% to staff support and administration, 16% to clinical support, and 14% to family amenities.

Although originally envisioned as an all-private room unit – in line with industry best practices at the time - the desire to design for future growth and flexibility required a mix of room types. Three SFR types included 18 private rooms (18 beds), five twin rooms (10 beds), and six couplet care rooms (12 beds). Additionally, a "suite" of sixteen semi-private bays (16 beds) offered semi-private accommodations. The mix of room types has given the NICU greater flexibility to accommodate diverse patient needs and clinical circumstances.

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The unit was organized into three neighborhoods: the green Woodlands, the purple Meadow, and the blue Garden. Each neighborhood optimized workflows around a set of patient rooms supported by rightsized, standardized clinical support and storage spaces, and was visually defined by its color. Front-of-house and back-of-house functions were separated as much as possible to improve workflows and satisfaction.

The design of the clinical support spaces included several strategic program elements to improve staff experience and patient care. These elements included:

- Storage: Numerous, dispersed, and spacious storage rooms throughout the unit created "space for everything" and reduced clutter in hallways, care team spaces, and patient rooms.
- Simulation Lab: A simulation and education space enabled staff, students, and residents to practice critical skills, in line with HSHS St. John's educational commitments. This space was equipped with a headwall identical to those in the patient rooms. It has provided overflow space during critical high-census times.
- Milk Room: A sterile environment for breast milk and formula mixing and fortification has been shown to improve patient safety, reduce feeding errors, and allow nursing staff more time to provide direct patient care and support families.

New family amenities were added to provide family members with spaces to spend time outside of the patient room, without leaving the unit. These amenities included a family lounge, sleep rooms, laundry facilities, and respite ("serenity") rooms. This programming created a space where clinical excellence was supported by comfort, efficiency, and flexibility to accommodate a wide variety of family shapes and preferences, care team needs, and patient census scenarios, without compromising essential clinical space.

"A POE is "the process of evaluating buildings systematically and rigorously after they have been built and occupied for some time." (6). The POE of HSHS St. John's NICU was informed by metrics associated with the project's design as well as POE criteria from the Center for Health Care Design's Clinical Design Post-Occupancy Evaluation Toolkit. (7)"

Kahler Slater + HSHS St. John's Post Occupancy Evaluation (POE) Method

A POE is "the process of evaluating buildings systematically and rigorously after they have been built and occupied for some time." (6). The POE of HSHS St. John's NICU was informed by metrics associated with the project's design as well as POE criteria from the Center for Health Care Design's Clinical Design Post-Occupancy Evaluation Toolkit. (7) This format aims to connect building design to outcomes and provide tangible, empirical findings that could inform similar future efforts.

Three and a half years after opening, Kahler Slater visited the NICU to conduct a visual audit of the different patient room types, care team stations, milk room, unit flow, and family amenities. The team interviewed leadership and conducted a staff survey to provide qualitative insights into quantitative findings on staff satisfaction, performance data, patient volumes, length of stay, and cost savings. This quantitative data was pulled from internal hospital data, public databases, and aggregated responses to the staff survey. The POE found that the NICU was generally well-received and facilitated a marked improvement across a range of performance metrics. It also revealed opportunities for improvement that can inform industry best practices.

POST-OCCUPANCY KEY FINDINGS

Key outcomes of the new unit include improved satisfaction, operational costs, and safety.

- The new design had a significant impact on the ALOS, which decreased by 8% in 2021 and by 29.4% in 2022, according to American Hospital Directory data.
- Shorter ALOS resulted in approximately $1,163 in daily savings in care costs, based on 2023 data from the American Hospital Directory.
- The dedicated Milk Room gave nurses an additional 1.75 hours per day for patient care and improved feeding errors, according to internal measures.
- Overall family satisfaction scores increased and are now in the 90th percentile, according to internal measures.

Alongside exemplary clinical practices, the POE team identified specific, replicable design choices that contributed to these positive outcomes.

"Given the diverse patient populations in NICUs, there is a strong need for spaces that accommodate a range of acuity levels and family needs. Standardization throughout the unit creates an environment that is adaptable, safe, and efficient."

Standardization:

Given the diverse patient populations in NICUs, there is a strong need for spaces that accommodate a range of acuity levels and family needs. Standardization throughout the unit creates an environment that is adaptable, safe, and efficient. At HSHS St. John's Hospital NICU, patient rooms and clinical support spaces are designed with similar equipment and layouts. This consistency contributes to greater patient safety, staff efficacy, and flexibility.

NICU patients often experience significant changes in acuity during their stay. Standardizing rooms, layouts, hookups, and equipment ensures that care can be adapted to the patient, rather than relocating the patient to a different room whenever their needs change. This goal was particularly important to the unit's providers and staff.

To achieve room standardization, every patient room in the HSHS St John's Hospital NICU was equipped with identical modular headwalls, a dedicated supply cart, a milk warmer, a diaper scale, and a milk refrigerator, all arranged in mirrored layouts. With every room capable of meeting a range of medical needs and acuities, patients could be roomed according to other considerations, such as developmental needs or family dynamics.

"This flexibility of room use also simplified surge planning. During surge events, adaptable rooms have increased clinical capacity and streamlined operations by offering charge nurses more unit configurations. When all the headwalls are dedicated to NICU bassinets, the unit can accommodate up to 56 babies."

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Standardization throughout the unit also supports safe and efficient work by minimizing mental fatigue and opportunities for error. Over the course of long, often stressful workdays, even small inconsistencies—such as outlets, hookups, and trash cans—can exacerbate mental fatigue by forcing staff and providers to think about actions that might otherwise be routine. These details must be considered not only in the architectural design but also in the construction and furnishing of any space.

"The original design scheme anticipated all single-family rooms in the NICU. Although initially considered a compromise, a mix of flexible patient rooms has proven essential to achieving three design drivers: designing for future growth, providing a culturally supportive environment, and offering an ideal family experience."

Room Type Mix:

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Single Family Rooms

Single-Patient Rooms (18 rooms)

The unit's 18 single-patient rooms have proven beneficial for many families. In line with the literature, parents and caregivers report greater comfort during breastfeeding, kangaroo care, and other intimate care in the private patient rooms. (8)

Twin Rooms (five rooms)

The unit's five twin rooms typically offer families of multiples similar benefits to single-patient rooms, as well as critical flexibility for the unit during high census times. When required, the twin rooms can serve as comfortable semi-private spaces for two unrelated patients and their families. To ensure comfortable shared accommodations, each bed has a separate, clean workspace with standard equipment and supplies for every patient. Curtains between the two beds create privacy when desired.

Couplet Care Rooms (six rooms)

Couplet care rooms are designed to care for both a healthy postpartum mother and a sick infant. As conceived, these rooms require two discrete headwalls: one with substantial medical gas hookups and monitors for the baby, and a somewhat simpler one for mom. This standard couplet care headwall configuration offers little flexibility in use. HSHS St. John's Hospital NICU representatives decided to challenge the standard by providing identical, higher-acuity headwalls for both mom and baby, achieving significant versatility.

For example, the couplet care rooms have been used to accommodate multiple related babies. In 2021, HSHS St. John's NICU swapped adult beds for bassinets in some couplet care rooms to create private rooms for each of the six sets of multiples whose admissions overlapped. Because bonding with family is so critical to newborn development, it is often preferable for siblings to share a patient room. Triplets were cared for in two adjoining rooms (a single-patient and twin room) linked by an internal door, which was initially designed for this purpose. The NICU has also adapted the couplet care rooms for multiple unrelated babies or healthy mom and healthy baby scenarios.

As the only room type in the unit with an integrated private toilet and shower room, couplet care rooms are well-suited to family needs. When HSHS St. John's Hospital's inpatient Mother/Baby Unit for healthy, newly postpartum moms and babies, located one floor below the NICU, has reached capacity, it has leveraged the couplet care rooms for overflow. The relatively large size of these rooms also renders them a dignified and spacious setting for palliative care, allowing families private space to gather and grieve.

Multifamily Rooms

The Suite (16 semi-private bays)

Emerging research suggests that shared spaces may have important benefits for some NICU patients. Infant development benefits from sensory input; for patients with limited family interactions, increased exposure to sound and touch from others may be essential. (9) The Suite comprises 16 semi-private bays,

designed with three hard-walls and an open front. Although smaller, each bay includes the same amenities as the SFRs and includes privacy curtains that allow families to personalize and have ownership of their space. The bays are arranged to maximize visibility across the Suite while providing privacy.

These semi-private spaces have yielded multiple benefits. For lower-acuity patients or those without frequent visitors, the gentle activity and ambient noise of the Suite provide beneficial stimulation. Nurses and providers can easily see and move across the Suite to monitor patients, help during code events, and support new staff and volunteers. Because they feel more comfortable interacting with the babies under supervision, NICU volunteers report a preference for engaging with infants in the Suite. Its open setting makes it easier to call for help. Similarly, the Suite provides heightened security when family dynamics require it. Far from a compromise, the Suite has come to be seen by staff and providers as a crucial option to deliver equitable care to all their patients and families.

"The design prioritized rightsizing clinical support and storage spaces to reduce clutter and improve operational efficiency. By organizing patient rooms along the perimeter of the floorplate, the design created "space for everything" within the substantial remaining interior space, which is ideal for back-of-house functions."

Support Space:

The design prioritized rightsizing clinical support and storage spaces to reduce clutter and improve operational efficiency. By organizing patient rooms along the perimeter of the floorplate, the design created "space for everything" within the substantial remaining interior space, which is ideal for back-of-house functions.

Storage Space

Each of the unit's three neighborhoods is supported by a designated clinical support space that includes a care team station and medication, clean supplies, and equipment rooms. A uniform design across each clinical support space has helped streamline workflows across the neighborhoods and reduce staff cognitive load. This lean design approach has significantly reduced staff time spent searching for items or tracking down equipment.

The storage spaces have proved particularly beneficial. Multiple spacious closets help reduce clutter in hallways, care team areas, and patient rooms. Ingeniously, the nursing staff conceived of a "broken equipment room" for items in need of repair, getting them out of the way while they await pickup by equipment engineering staff. In addition to improving workflow, removing clutter has noticeably increased staff and providers' reported sense of well-being.

Milk Room

Following the Milk Room Practicum at the University of Michigan Health, the staff implemented a new, centralized feeding operation based on a specialized, controlled, and sterile environment. The Milk Room has improved patient safety by reducing feeding errors and returned an estimated 1.75 hours per day to nursing staff for direct patient care and family support. The design follows the "Infant and Pediatric Feedings" Guidelines for Preparations of Human Milk and Formula in Health Care Facilities created by the Pediatric Nutrition Dietetic Practice Group of the Academy of Nutrition and Dietetics. (10)

"The Milk Room has improved patient safety by reducing feeding errors and returned an estimated 1.75 hours per day to nursing staff for direct patient care and family support."

Overall Unit Design:

Acoustics

Limiting babies' exposure to excessive noise requires intentional design consideration. Sounds from other patient rooms, such as infants crying or monitor alarms beeping, can interrupt sleep and contribute to deleterious health effects. (11) Contrarily, quiet patient rooms can promote rest and reduce stress. To achieve acoustic separation, special attention was given to the acoustic detailing across the unit.

Wall detailing, door and window gasketing, and material specifications all contributed to the overall success of the acoustic design of the spaces. Thicker, acoustically insulated headwalls help reduce sound transmission between rooms. Avoiding back-to-back openings (such as plugs and hookups) limits pathways for sound to leak between rooms. Soft finishes and furnishings, such as window curtains (as opposed to blinds), help absorb sound within the room itself. These details contribute to a more tranquil environment throughout the NICU.

Wayfinding

In addition to creating a calming, homelike environment, natural materials and biophilia-inspired design elements were used throughout the NICU for wayfinding. Color and nature-inspired imagery help families and staff intuitively navigate a fairly complex space. For example, staff use the neighborhood color identification system to clarify where to pick up and deliver items, reducing confusion and errors. Large windows in patient rooms and corridors allow natural light to serve as a point of reference. By integrating wayfinding into the interior design, designers created a strong sense of place in the NICU, which both eases navigation and promotes a sense of well-being.

Conclusion and Key Takeaways:

This POE of HSHS St. John's NICU demonstrates how a thoughtfully designed mixed-room unit can support a wide range of patient and family needs while enhancing clinical outcomes. A blend of private and semi-private rooms promotes privacy and family-centered care while enabling the unit to adapt to census surges and diverse care scenarios. Standardized layouts and rightsized support space contribute to a more efficient and less stressful work environment that improves staff workflows. Natural light, biophilic design elements, and intuitive wayfinding create a welcoming, calming space that feels both restorative and functional. Most importantly, the design supports safe, high-quality, family-centered care. As NICUs continue to evolve, this project offers a compelling case for moving beyond a one-size-fits-all model toward one that empowers flexibility, resiliency, and customization to each care team and patient population's unique needs.

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Patient & Family Privacy is achieved through the introduction of SFRs that support family-centered care models and walls designed to minimize sound transmission between spaces.

An Ideal Patient & Family Experience is achieved through investments in comfort: a variety of spaces with homelike furnishings and finishes that give families and caregivers a sense of choice and control.

Ideal Staff & Provider Experience is created by adding ample standardized clinical support spaces that optimize workflows and minimize avoidable stressors. Working with staff and care providers is essential to designing a space that works well for them.

A Culturally Supportive Environment includes a mix of room types that can flex to accommodate different family needs, patient acuity levels, and clinical circumstances. Understanding the unique culture of the health system and community is essential to designing spaces that are culturally respectful and reflective.

A Welcoming Calming Environment is shaped by homelike materials, with images and colors inspired by local surroundings, abundant natural light, and a variety of spaces that accommodate different family and staff needs.

Identical headwalls and equipment support safe, high-quality care in patient rooms and the milk room, and ensure uniformity across support spaces that help optimize workflows.

Access to Nature is provided by large windows that bring daylight into patient rooms and corridors, as well as nature-inspired finishes and imagery.

Separate Flows achieves front-of-house and back-of-house circulation separation, allowing the NICU to be restocked, serviced, and worked through efficiently without disturbing patients and families.

Future Growth is accommodated through flexible spaces designed for adaptation.

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Feasibility of Parent Education Intervention to Prevent Deformational Plagiocephaly and Neck Asymmetry in Neonates and Infants

Alexandra Buwalda, DPT, PCS, PhD Candidate, Jane K. Sweeney, PT, PhD, PCS, FAPTA

"Deformational plagiocephaly (DP) refers to the flattened, asymmetrical, or misshapen skull of infants due to positional molding from external forces. (1) Deformational plagiocephaly may occur in one in five infants in the USA, presenting at birth or in early infancy, and gradually peaking in the first four to six months of life. (2)"

Abstract:

Background:

Deformational plagiocephaly (DP) and early neck asymmetry are common in infancy and associated with modifiable positional risk factors during the first three months of life. Although prevention strategies are described in clinical guidelines, anticipatory guidance is inconsistently delivered in routine newborn care.

Objective:

To evaluate the feasibility and acceptability of a brochure-based parent education intervention designed to prevent deformational plagiocephaly and neck asymmetry in infants aged zero to three months.

Methods:

A single-group pre-post design was used in a feasibility pilot study of 10 caregiver-infant dyads (age ≤28 days at enrollment). During two home visits, separated by 4 to 6 weeks, caregivers completed an interview on familiarity with plagiocephaly and torticollis and received a detailed educational brochure with demonstrations and verbal instruction. Infant assessments included head circumference and cranial shape, cervical motion measurements, and observed positional preference. Parent-reported intervention adherence, perceived educational usefulness, infant tolerance, and observed changes in cranial asymmetry were evaluated in a follow-up assessment.

Introduction:

Deformational plagiocephaly (DP) refers to the flattened, asymmetrical, or misshapen skull of infants due to positional molding from external forces. (1) Deformational plagiocephaly may occur in one in five infants in the USA, presenting at birth or in early infancy, and gradually peaking in the first four to six months of life. (2) Although often described as mainly a cosmetic issue, DP has been associated with motor and cognitive differences in infancy and school age, particularly in cases of moderate to severe skull deformity. (3, 4) It remains unclear whether DP contributes to these developmental differences, whether early motor and cognitive differences predispose infants to developing DP, or whether both reflect shared underlying factors. Despite this uncertainty, prevention and early identification of positional asymmetry are widely recommended. (5, 6)

Early cervical range-of-motion limitations and head position preference are recognized risk factors for progressive cranial deformation during the first three months of life(7). Ninety-seven percent of infants with DP may have some form of torticollis, a persistent cervical asymmetry with or without muscle tightness. (8, 9) Additional modifiable risk factors include prolonged supine positioning during awake time, limited supervised prone positioning ("tummy time"), frequent infant seating device use, and side-biased feeding or carrying practices. (10, 11)

"The global increase in DP is an unanticipated consequence of the highly successful Back to Sleep campaign, initiated by the American Academy of Pediatrics (AAP) in the early 1990s to reduce sudden infant death syndrome (SIDS). (12) In response, the AAP incorporated "Tummy to Play" recommendations to encourage supervised prone positioning during wake time. Despite these recommendations, researchers continue to report inconsistent implementation of tummy time practices and limited parental understanding of prevention strategies. (13, 14) "

The global increase in DP is an unanticipated consequence of the highly successful Back to Sleep campaign, initiated by the American Academy of Pediatrics (AAP) in the early 1990s to reduce sudden infant death syndrome (SIDS). (12) In response, the AAP incorporated "Tummy to Play" recommendations to encourage supervised prone positioning during wake time. Despite these recommendations, researchers continue to report inconsistent implementation of tummy time practices and limited parental understanding of prevention strategies. (13, 14) Prevention messaging on plagiocephaly and neck asymmetry is

often delivered inconsistently, and many parents report receiving minimal guidance regarding positional asymmetry during the newborn period. (15-17)

In randomized, prospective studies, parent guidance and positioning protocols initiated in early infancy reduced the incidence and severity of DP. (17-19) Unfortunately, dissemination of preventive education on plagiocephaly and torticollis into routine pediatric and postpartum care remains variable. Limited evidence is reported on simple, low-cost educational tools designed for integration into standard newborn visits. In particular, the feasibility, acceptability, and preliminary impact of brochure-based education models delivered during the first months of life require further study.

"The first three months of life represent a critical window for prevention of positional asymmetries. During this period, infants have limited head control, high positional susceptibility, and rapidly changing motor patterns. (20) Early anticipatory guidance may influence daily infant positioning behaviors and preferences before asymmetry becomes established. (16)"

The first three months of life represent a critical window for prevention of positional asymmetries. During this period, infants have limited head control, high positional susceptibility, and rapidly changing motor patterns. (20) Early anticipatory guidance may influence daily infant positioning behaviors and preferences before asymmetry becomes established. (16) Understanding whether parents perceive such education as clear, feasible, and actionable is essential before larger controlled trials are conducted.

The purpose of this pilot feasibility study was to develop and evaluate a brochure-based parent education intervention to prevent deformational plagiocephaly and neck asymmetry in infants from birth to 3 months of age. The focus was on (1) assessing the feasibility and acceptability of implementing a structured educational brochure during the newborn period, (2) evaluating parental understanding and integration of recommended positioning strategies, and (3) describing preliminary changes in positional preference and cervical asymmetry over a four- to six-week period.

Methods:

Design

This prospective single-group feasibility pilot was designed to evaluate the feasibility, acceptability, and preliminary clinical observations associated with a structured brochure-based parent education model aimed at preventing DP and neck asymmetry during the first three months of life. A pre–post design was implemented without a comparison group. Consistent with feasibility study methodology, the primary objectives were to assess intervention acceptability, parent adherence, and practicality of delivery in this pilot phase. Secondary objectives included analysis of preliminary clinical findings. IRB approval was solicated but the intervention was determined to represent standard of care.

"The aim of this study was to evaluate several key domains relevant to the intervention's implementation and potential impact. The following domains were selected to capture both feasibility in real-world caregiving contexts and early indicators of behavioral and clinical change:"

Aim

The aim of this study was to evaluate several key domains relevant to the intervention's implementation and potential impact. The following domains were selected to capture both feasibility in real-world caregiving contexts and early indicators of behavioral and clinical change:

1. Acceptability: Parent perception of clarity, usefulness, and relevance of the brochure;
2. Practicality: Ease of integrating positioning and carrying strategies into daily routines;
3. Adherence: Parent-reported implementation of recommended positioning behaviors;
4. Preliminary clinical findings: Descriptive changes in head positional preference and cervical asymmetry over a four-to-six-week period.

Participants

A target sample of 10 participants was selected based on pragmatic considerations and alignment with commonly recommended pilot study sample sizes (n=8-12), sufficient to evaluate feasibility processes, recruitment logistics, and intervention delivery. (21) Caregiver-infant dyads were recruited through a pediatrician's office, midwife practice, and community-based parent network. Snowball sampling was also used, with participants invited to share information about the study within their own networks.

Dyads were eligible if their infants were healthy, born term or near term (≥35 weeks gestation), aged 30 days or younger at baseline, and had no prior diagnosis of deformational plagiocephaly or congenital muscular torticollis. Dyads were expected to participate in two home visits. Infants were excluded if they had known neuromuscular, genetic, or craniofacial conditions or a diagnosis of torticollis requiring active treatment prior to enrollment.

Twelve families enrolled in the study. Two infants were excluded from final analysis: one due to early clinical diagnosis of torticollis

requiring treatment, and one due to withdrawal prior to follow-up assessment. The final analytic sample included 10 infants.

Participant Characteristics

Ten mother-infant dyads (six male infants, four female infants) completed both study visits. Infants were assessed at a mean age of approximately 17 days (range 3–28 days) at baseline and 45 days (range 21–64 days) at follow-up. Gestational age at birth ranged between 37 weeks + 1 day and 41 weeks + 3 days.

Eight mothers gave birth in a hospital, and two mothers had home births. Six mothers had spontaneous vaginal deliveries, while two mothers had planned induced vaginal deliveries. One mother had a planned C-section, while another mother had a C-section due to poor progression following induced labor.

Two additional families were enrolled but excluded from the final analysis due to early clinical referral (n=1) and withdrawal prior to follow-up (n=1). Retention rate among eligible enrolled participants was 83% (10/12).

Ethical Considerations

In this minimal-risk pilot study, parents provided written informed consent prior to participation. Intervention consisted of non-invasive clinical observation and measurements of the infants, consistent with routine pediatric physical therapy assessment practices. Parents were interviewed during both sessions. No experimental interventions were administered.

"We developed a parent-focused brochure with content based on published evidence and clinical practice guidelines on the prevention of deformational plagiocephaly and torticollis. (16, 18, 22-24)The content emphasized early positioning strategies during common daily routines and was written in parent-friendly language. A copy of each page of the brochure is displayed in Appendix A."

Intervention: Brochure

We developed a parent-focused brochure with content based on published evidence and clinical practice guidelines on the prevention of deformational plagiocephaly and torticollis. (16, 18, 22-24)The content emphasized early positioning strategies during common daily routines and was written in parent-friendly language. A copy of each page of the brochure is displayed in Appendix A.

The brochure addressed five daily contexts. These contexts included sleep positioning, positioning during awake time (including prone and side-lying positions), feeding positioning (breast and bottle), infant equipment use, and professional referral indications. Specific recommendations on early positioning included alternating head orientation during sleep, incorporating early supervised tummy time and side lying, minimizing prolonged use of seating devices, alternating feeding sides, and encouraging midline development.

Existing literature and clinical guidelines informed content validity. Formal psychometric validation of the brochure was not performed because this study focused on feasibility.

"During the baseline home visit, the investigator verbally reviewed the brochure with the parent, demonstrated positioning strategies with the infant, answered the parent's questions, and encouraged the integration of strategies into daily routines."

Intervention Delivery and Procedure

Two 1-hour sessions were conducted in each participant's home. During the baseline home visit, the investigator verbally reviewed the brochure with the parent, demonstrated positioning strategies with the infant, answered the parent's questions, and encouraged the integration of strategies into daily routines. The baseline assessment (age 1 to 28 days) consisted of two parts. The first part included a structured interview of the parent assessing familiarity with plagiocephaly (0 to 5-point scale), familiarity with torticollis (0 to 5-point scale), information received upon discharge, and current positioning and handling practices. During the second part, the infants underwent a standardized clinical assessment including: head circumference (cm), cranial vault asymmetry index (CVAI), and cephalic index (CI) measured with calipers; passive cervical rotation and lateral flexion; and an observational assessment of head positional preference. Developmental screening of the infants was also conducted during the second part of the visit and included: sleep/activity level, muscle tone, visual and auditory alertness, and supine and prone movement patterns. Finally, a hip screening consistent with routine pediatric practice was performed (passive range of motion, skinfold asymmetry, Ortolani and Barlow maneuvers).

During the follow-up visit (4 to 6 weeks later), the infant's measurements and developmental observations were repeated. In the caregiver interview, the investigator assessed the implementation of the brochure recommendations, the perceived clarity and usefulness of the brochure, infant tolerance of the positioning strategies, and the suggested timing and provider for the brochure distribution.

Outcome Measures:

Primary Feasibility Outcomes

The primary feasibility outcomes included acceptability (parent perceptions of the brochure's clarity, usefulness, and relevance), practicality (ease of integrating positioning and carrying strategies

into daily routines), and adherence (parent-reported implementation of recommended positioning behaviors). Feasibility was achieved by three conditions: 1. 80% of parents reported the brochure to be clear and useful; 2. the majority of parents integrated at least three recommended positioning behaviors into daily routines, and 3. No adverse events were associated with the positioning strategies. The feasibility calculation required the completion of both study visits by 80% of enrolled parents.

Secondary Descriptive Clinical Outcomes

The focus of the secondary descriptive clinical outcomes was on preliminary changes in infant head shape and neck function over a 4- to 6-week period. These outcomes included the−presence and potential resolution of head positional preference identified at the initial session, as well as changes in cranial and postural asymmetries, passive cervical motion range, cranial vault asymmetry index (CVAI), and cranial index (CI).

Data Analysis

Descriptive statistics focused on means, ranges, and frequency distributions. Changes in positional preference were described by the proportion of infants demonstrating resolution between visits. No inferential statistical testing was conducted due to the small sample size and the focus on feasibility.

Results:

Baseline Parent Familiarity

At baseline, parent familiarity with plagiocephaly was moderate (mean score 2.6 on a 0-5 scale), while familiarity with torticollis was low (mean score 1.3). All parents were aware of helmet therapy as a treatment option for plagiocephaly. Few were familiar with specific preventive strategies or early risk factors for cervical asymmetry (Table 1).

7 of 10 parents reported receiving instruction on supine sleep positioning at hospital discharge. Two parents recounted receiving specific guidance regarding "tummy time" during the newborn period. No parents reported receiving education on the prevention of positional asymmetry beyond general safe sleep guidance (Table 2).

Feasibility Outcomes

Acceptability. All parents stated the brochure was clear and easy to understand. Parents described the content as relevant and appropriate for the newborn period. All families indicated that a brief verbal explanation from a healthcare provider enhanced understanding and the likelihood of use.

Practicality and adherence. All parents reported implementing at least several recommended positioning strategies. Commonly adopted practices included increased supervision of prone positioning, alternating head position during sleep, alternating feeding sides, and increased awareness of positional preference during carrying and diapering.

Side-lying positioning during awake time was initially unfamiliar to most parents but was adopted following instruction. Prone positioning on a caregiver's chest was described as particularly well tolerated. No adverse events related to positioning strategies were reported, and all infants tolerated the recommended positions. Caregivers did not express concerns related to discomfort or difficulty implementing the recommended strategies during daily routines. Three of ten parents initially noted infant resistance to prone positioning; however, tolerance reportedly improved over time.

Descriptive Clinical Outcomes

Head positional preference. At baseline, eight of ten infants demonstrated a mild head positional preference. At follow-

Table 1. Parent interview during initial screening: familiarity with plagiocephaly and torticollis.

Infant#	1	2	3	4	5	6	7	8	9	10	Range	Mean	Mode
Familiarity with plagiocephaly (0-5)	3	2	5	2	4	4	2	1	2	1	1-5	2.6	2
Familiarity with torticollis (0-5)	3	0	5	1	0	0	0	0	4	0	0-5	1.3	0

Abbreviations: 0-5: 0 not at all, 5 highly familiar.

Table 2. Parent interview during initial screening: information given upon discharge.

Infant#	1	2	3	4	5	6	7	8	9	10	Mode
Information given upon discharge on (y/n):											
• Sleeping position	n	y	y	y	y	y	n	y	y	n	y
• Feeding/nursing	y	y	y	y	y	y	y	y	y	y	y
• Tummy time	n	n	n	y	n	n	n	n	y	n	n
• Swaddling	y	n	y	y	n	n	n	y	y	y	y
• Car seat safety	n	y	y	n	y	y	n	n	n	y	y/n
• Other infant equipment	n	n	n	n	n	n	n	n	y	n	n
• Other	y	y	y	y	y	y	n	n	n	y	y

Abbreviations: y: yes; n: no

Table 3: Infant measurements

Infant	1	2	3	4	5	6	7	8	9	10
1st screening/ 2nd screening *unfavorable outcome										
Head circumference (cm)	35/40.5	35.5/38	35.5/39	37.5/40	38/39.5	35.5/39.5	34.5/37.5	36.5/37.5	36/39	34/37.5
Neck PROM WNL (y/n)										
• Rotation	y/y	y/y	y/y	y/y	y/y	y/y	y/y	y/y	y/y	y/y
• Lateral flexion	y/y	y/y	y/y	n*/y	y/y	y/y	y/y	y/y	y/y	y/y
Head shape (%)										
• CVAI (norm<3.5%)	1.6/0.80	1.7/2.1	1.7/1.5	2.4/2.3	2.3/1.6	0.85/0.85	1.7/1.6	3.3/2.5	2.4/0.80	0.90/2.50
• CI (norm < 90%)	80/79	78/80	89/83	84/88	81/83	83/78	83/84	83/81	83/74	80/82
Hip assessment WNL(y/n)										
• Abduction PROM	y/	y/	y/	y/	y/	y/	y/	y/	y/	y/
• Skinfold asymmetry	y/	y/	y/	y/	y/	y/	y/	y/	y/	y/
• Ortolani maneuver	y/	y/	y/	y/	y/	y/	y/	y/	y/	y/
• Barlow maneuver	y/	y/	y/	y/	y/	y/	y/	y/	y/	y/

Abbreviations: cm: centimeters; WNL: within normal limits; PROM: passive range of motion; CVAI: cranial vault asymmetry index; CI: cephalic index

Table 4: Infant Observations

Infant #	1	2	3	4	5	6	7	8	9	10
1st screening/ 2nd screening. *unfavorable outcome										
Developmental assessment WNL(y/n)										
• Sleep/activity level	y/y	y/y	y/y	y/y	y/y	y/y	y/y	y/y	y/y	y/y
• Muscle tone	y/y	y/y	y/y	y/y	y/y	y/y	y/y	y/y	y/y	n*/y
• Visual alertness/visual tracking	y/y	y/y	y/y	y/y	y/y	y/y	y/y	y/y	y/y	y/y
• Auditory response	y/y	y/y	y/y	y/y	y/y	y/y	y/y	y/y	y/y	y/y
• Physiological flexion/ balanced extension	y/y	y/y	y/y	y/y	n*/y	y/y	y/y	y/y	y/y	n*/y
• Supine (random mvt UE/LE, head rotation L/R)	y/y	y/y	y/y	y/y	y/y	y/y	y/y	y/y	y/y	y/y
• Prone: turns head L/R to clear airway	y/y	y/y	y/y	y/y	y/y	y/y	y/y	y/y	y/y	n*/y
Infant #	1	2	3	4	5	6	7	8	9	10
1st screening/ 2nd screening *unfavorable outcome										
• Asymmetries/ Preferences WNL (y/n):										
○ Head	y/y	n*/y	n*/y	n*/y	n*/y	n*/y	n*/n*	y/y	n*/y	n*/y
○ Trunk	y/y	y/y	y/y	y/y	n*/y	y/y	n*/y	y/y	y/y	y/y
○ Extremities	y/y	y/y	y/y	y/y	y/y	y/y	y/y	y/y	y/y	y/y

Abbreviations: WNL: within normal limits; mvt: movements; UE: upper extremities; LE: lower extremities; L: left; R: right

up, positional preference was no longer observed in 7 of the 8 infants. One infant continued to demonstrate head asymmetry at the second visit but showed resolution at a subsequent informal follow-up visit.

Cervical range of motion. Passive cervical rotation was within normal limits in all infants at both visits. One infant demonstrated reduced lateral flexion at baseline, which was within normal limits at follow-up.

Cranial measurements. All infants demonstrated head circumference growth consistent with age. Cranial vault asymmetry index (CVAI) and cephalic index (CI) values remained within normal reference ranges at both assessments for all participants.

Hip assessment. All infants passed a routine hip evaluation during the first session. Hips were not checked in detail during the second session because of typical outcomes during the initial session. Table 3 represents the infant measurements as described above.

Developmental observation. All infants demonstrated age-appropriate developmental behaviors at both visits. Mild asymmetries in trunk or head positioning observed at baseline resolved in all but one infant at follow-up. The observations are summarized in Table 4.

"When asked about optimal brochure distribution, parents identified primary care providers, such as pediatricians, as preferred providers to introduce the brochure during the first or second newborn visit."

Parent Recommendations for Dissemination

When asked about optimal brochure distribution, parents identified primary care providers, such as pediatricians, as preferred providers to introduce the brochure during the first or second newborn visit. A few parents suggested postpartum hospital discharge as a secondary opportunity, although some noted feeling overwhelmed immediately after birth. Other suggested distribution channels included midwives, lactation consultants, and community-based parent education settings. All parents considered a follow-up discussion about positioning practices useful.

Discussion:

This feasibility pilot study evaluated a brochure-based parent education model designed to prevent deformational plagiocephaly and early neck asymmetry during the first 3 months of life. Findings suggest that structured anticipatory guidance delivered during the newborn period is feasible, acceptable to parents, and readily integrated into daily caregiving routines. Parents reported increased awareness of positional behaviors, and most infants who demonstrated mild positional preference at baseline no longer showed preference at the four-to-six-week follow-up session.

Descriptive clinical observations align with prior evidence demonstrating that early positioning guidance may influence cranial symmetry outcomes. (22, 23) Randomized data from Aarnivala et al.(18) confirmed that structured parent guidance initiated in early infancy can reduce the incidence and severity of deformational plagiocephaly. The present study extends that work by exploring a low-cost, easily disseminated educational format suitable for integration into routine pediatric preventive care.

"Most caregivers were aware of helmet therapy as a treatment for plagiocephaly, but they were unfamiliar with prevention strategies. This gap highlights a paradox in pediatric care: interventions for established deformity are widely recognized, yet systematic prevention education is inconsistently implemented."

The Prevention Window: Birth to Three Months:

The first three months of life represent a period of heightened positional vulnerability. Infants have limited active head control and spend substantial time in the supine position. After cranial asymmetry becomes established beyond three to four months of age, correction may require prolonged physical therapy or a helmet orthosis (1, 25, 26). Preventive guidance delivered during the newborn period may therefore represent a critical public health opportunity.

Despite existing professional guidelines recommending supervised prone positioning and early detection of asymmetry, parents in this study reported receiving minimal anticipatory guidance beyond safe sleep instructions. Most caregivers were aware of helmet therapy as a treatment for plagiocephaly, but they were unfamiliar with prevention strategies. This gap highlights a paradox in pediatric care: interventions for established deformity are widely recognized, yet systematic prevention education is inconsistently implemented.

Feasibility and Clinical Integration:

All participating caregivers reported that the brochure was clear, actionable, and easily implemented. They emphasized that verbal reinforcement from a trusted healthcare provider increased the likelihood they would read and apply the positioning and play recommendations. This finding suggests that the effectiveness of written materials may depend not solely on content but also on context and provider endorsement.

From an efficient preventive care perspective, the educational model tested in this study required minimal time investment. A brief three to five-minute discussion during a newborn visit can meaningfully influence parental positioning practices. Pediatricians, nurse practitioners, midwives, lactation consultants, and postpartum nurses are uniquely positioned to introduce this guidance during early routine encounters.

The outcomes of this pilot study indicated that prevention messaging may be most effective when framed not as correction of a cosmetic concern, but as promotion of symmetrical motor development and early musculoskeletal health. This approach may better align with caregiver priorities and support greater engagement with recommended positioning and handling strategies.

Public Health Implications:

The rise in deformational plagiocephaly following the success of supine sleep campaigns underscores the unintended consequences that can accompany well-intentioned public health initiatives. Rather than reconsidering safe sleep recommendations, pediatric preventive care can evolve to integrate complementary positioning education. This approach may help mitigate the risk of developing plagiocephaly and associated neck asymmetry.

Given the low cost and scalability of brochure-based models, widespread dissemination is feasible. Digital adaptations, brochures integrated in electronic health record discharge materials, and QR-linked instructional videos may further enhance reach. Preventive education may reduce later referrals for helmet and physical therapy services, potentially resulting in healthcare cost savings.

Limitations:

Several limitations are acknowledged in this pilot study. The sample size was small and not powered for statistical analysis. The absence of a control group precluded causal inference. Outcomes relied partially on parent report, which may introduce recall or social desirability bias. A single clinician-investigator delivered the intervention, and results may differ in other settings. Additionally, follow-up was limited to four to six weeks, preventing evaluation of long-term cranial outcomes.

This study was conducted as a minimal-risk, educational pilot project and did not include randomization or formal psychometric validation of the educational tool. Conclusions are limited to feasibility and descriptive observations.

"Given the low cost and scalability of brochure-based models, widespread dissemination is feasible. Digital adaptations, brochures integrated in electronic health record discharge materials, and QR-linked instructional videos may further enhance reach."

Future Directions:

The positive feasibility findings of this pilot study support progression to a larger, controlled study examining the structured dissemination of preventive education materials within pediatric primary care settings. Future researchers should incorporate controlled comparison groups, extend follow-up periods to at least four to six months, and use standardized parent adherence measures. Studies should include more diverse socioeconomic populations and integrate implementation models into existing pediatric practice workflows.

Preventive musculoskeletal education in early infancy remains relatively underdeveloped compared to other areas of anticipatory guidance. Incorporating symmetrical positioning strategies into routine newborn counseling may represent an important advancement in pediatric preventive care, including guidance on alternating head position during sleep, promoting supervised prone positioning during awake periods, varying carrying and feeding positions, and minimizing prolonged time in equipment that restricts movement.

"Larger controlled studies are warranted to evaluate clinical effectiveness, implementation strategies within primary care settings, and long-term cranial and developmental outcomes."

Conclusion:

The results of this feasibility pilot study suggest that a structured, brochure-based parent education model delivered during the newborn period is acceptable, practical, and readily integrated into daily caregiving routines. Parents reported increased awareness of positioning behaviors associated with deformational plagiocephaly and neck asymmetry. Preliminary descriptive observations indicated that mild positional preferences resolved in most infants over a 4- to 6-week period.

Although the study was not designed to establish efficacy, the findings support the feasibility of integrating prevention strategies for plagiocephaly and early neck asymmetry into routine pediatric preventive care. Brief, provider-endorsed educational materials may represent a scalable, low-cost strategy to enhance early musculoskeletal health during a critical window of infant development.

Larger controlled studies are warranted to evaluate clinical effectiveness, implementation strategies within primary care settings, and long-term cranial and developmental outcomes. Such studies could also further define optimal timing, dosage, and delivery methods of preventive positioning education across early infancy.

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Appendix A: Brochure, pages 1 to 6

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WHILE YOUR BABY IS SLEEPING

- ✓ Always put your baby on the back to sleep; and on a flat surface.
- ✓ Take note of your baby's head position when going to sleep and switch to the other side next time when you put your baby down to sleep.
- ✓ Expose your baby to light or sound from different directions at different times:
  - ✓ *If your baby turns his head toward the light of the window, switch your baby's position in the crib (or the position of the crib) every night;*
  - ✓ *Talk to your baby from different sides if possible;*
  - ✓ *Or place your baby's head or feet in the direction of the window or your voice.*

Steps you can take to prevent your infant from getting a flat head and stiff neck during their first months.

WHEN YOUR BABY IS AWAKE

Tummy time:

- ✓ You can introduce tummy time for a few minutes each day within the first days of life. As your baby starts supporting his head, gradually increase tummy time to 15-30 minutes, a few times a day.
- ✓ Your baby can be on her tummy on your chest, across over your lap, on a playmat on the floor, or on the changing mat after each diaper change. Make sure you switch turning your baby's head every time you change positions.
- ✓ You can carry your baby while he is on his tummy.

WHILE FEEDING YOUR BABY

- ✓ Breast feeding will naturally switch your baby's head and body position.
- ✓ When bottle feeding, switch sides to feed her.
- ✓ When burping your baby upright over your shoulder after feedings, make sure you switch sides.

WHEN ON THE GO

- ✓ Only use baby equipment such as car seats, strollers and bouncers when necessary. Strollers should have a flat surface for your baby to lie on.

- ✓ Only use a car seat for transportation, don't leave your baby in the car seat when not in the car (or stroller).

- ✓ Be sure to switch your baby's head position when in a car seat or stroller every time you use it.
- ✓ As your baby gets stronger, always center your baby's head and body.
- ✓ Switch your baby's head to the other side every time you use a baby carrier.

Tummy time:

- ✓ After a few weeks you can place your baby on her tummy over a rolled towel or pillow to assist with lifting her head in the middle.
- ✓ Always supervise your baby when on tummy.

Side lying:

- ✓ Place your baby on his side, switch sides every time when you place your baby on his side.
- ✓ Lie next to your baby and have him look at your face or toys.

Promote midline development:

- ✓ As your baby develops more head control, encourage her head and body to look and point straight ahead. Use your baby's vision to keep her head in the middle: your baby will enjoy looking at your face or at bright toys.

WHEN TO CONTACT YOUR PEDIATRICIAN OR PEDIATRIC PHYSICAL THERAPIST

- ✓ If it is harder to nurse your baby on one side.
- ✓ If your baby develops a flat spot on the back or side of her head.
- ✓ If your baby consistently tilts her head to one side.
- ✓ If your baby avoids turning her head to one side.
- ✓ If any of the above mentioned activities and positions are poorly tolerated by your baby.

This brochure was developed by Alexandra Buwalda, a pediatric physical therapist in private practice, based in Brooklyn, New York. Alex has over 30 years of clinical experience working with infants and young children. She is currently a clinical doctorate student at Rocky Mountain University of Health Professions. The brochure is part of an infant care project to prevent flat head syndrome (plagiocephaly) and neck asymmetry (torticollis) in infants by actively engaging parents and caregivers.

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ROCKY MOUNTAIN UNIVERSITY OF HEALTH PROFESSIONS

May 16, 2021

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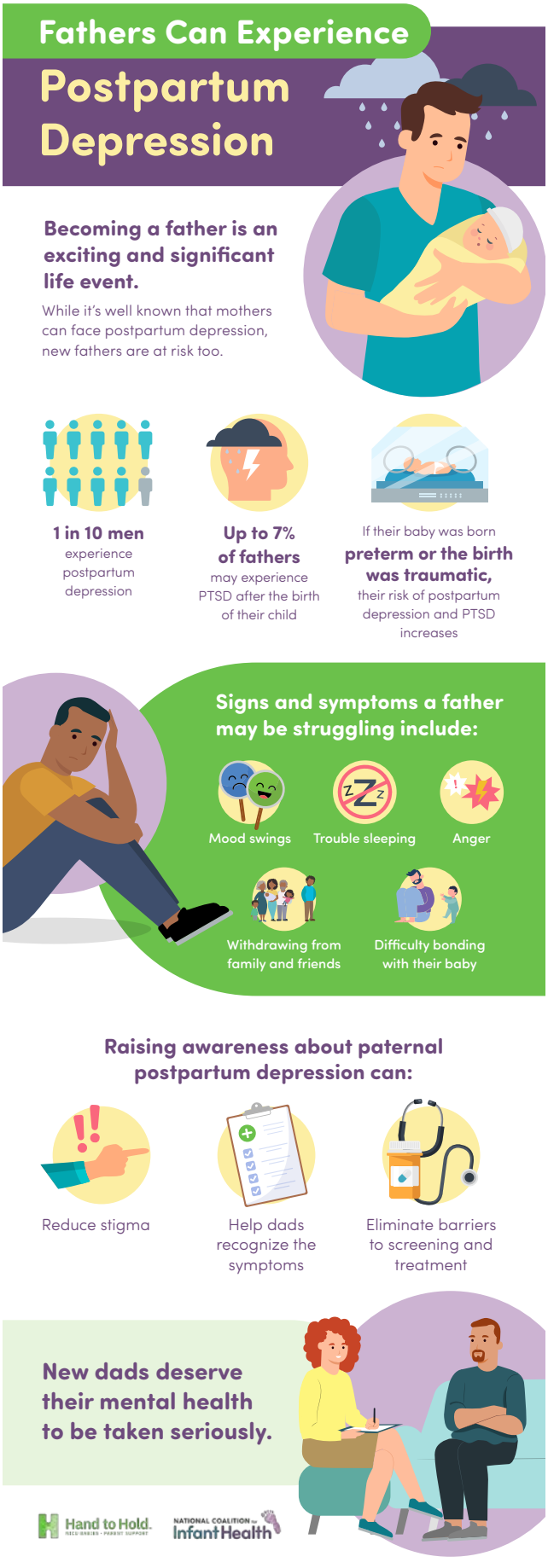

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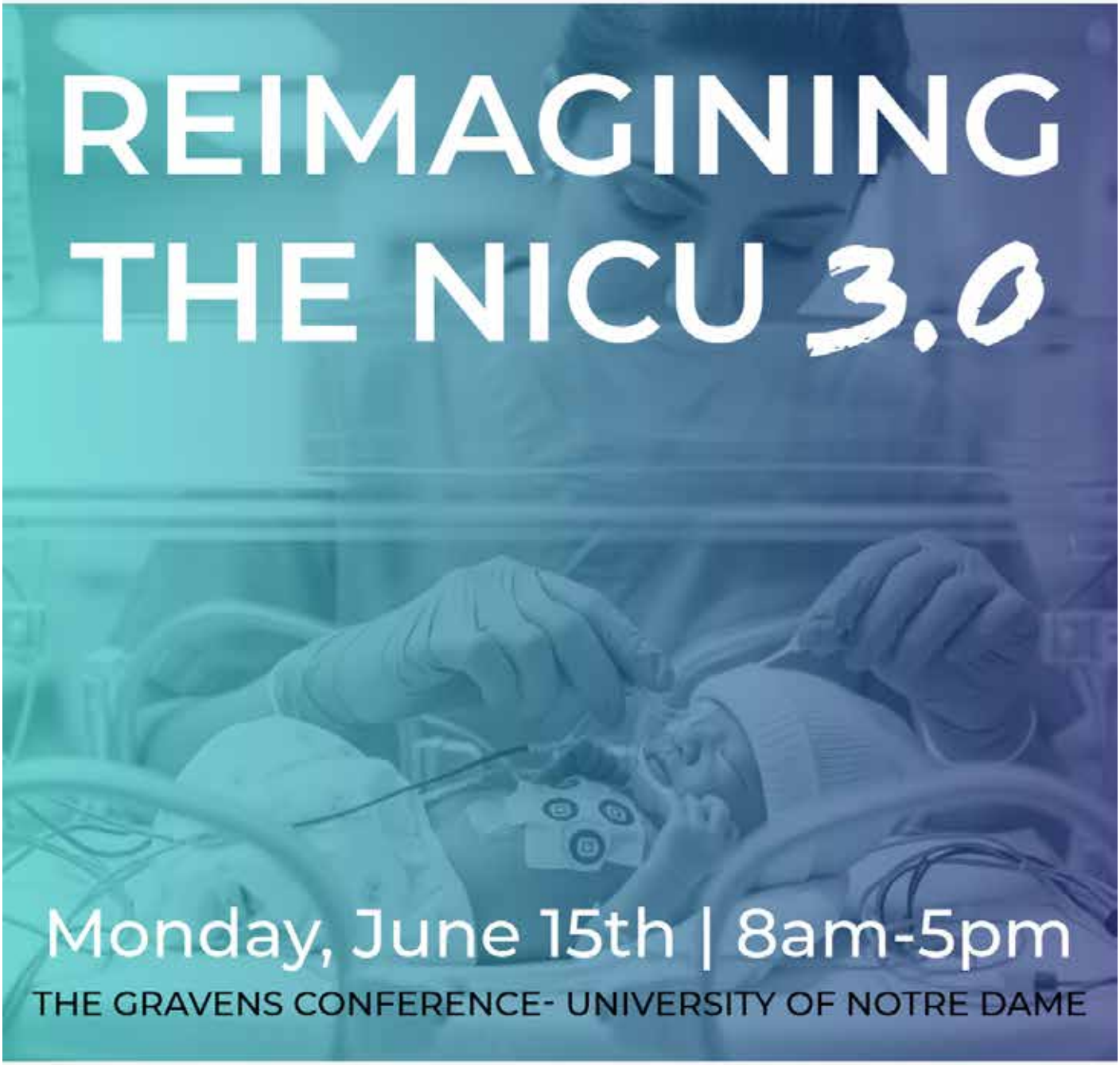
REIMAGINING THE NICU 3.0



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Historical Perspective: The Whoopee Cusion for Apnea of Prematurity(Plus, Adventures with ChatGPT)

Joseph B. Philips, III, MD, FAAP

Apnea of prematurity (AOP) is among the most common diagnoses in preterm infants, affecting virtually all those born <28 weeks of gestation with decreasing frequency as the infants become more mature. (1) Most infants cease having spells by the time they reach 34 to 36 weeks post-conceptual age. AOP is the result of immaturity of the respiratory control centers. Obstructive apnea occurs when the neuromuscular control of upper airway patency is lost, while central apnea occurs when the brainstem respiratory centers stop signaling the infant to breathe. Many infants manifest both obstructive and central apnea.

"Apnea of prematurity (AOP) is among the most common diagnoses in preterm infants, affecting virtually all those born <28 weeks of gestation with decreasing frequency as the infants become more mature."

Interest in using kinesthetic stimulation for the prevention or treatment of AOP began in the 1970s with the publication of a small study that randomized 10 premature infants to placement on a gently oscillating water mattress and 11 control infants. (2) The authors reported a significant reduction in AOP in the waterbed group. Kattwinkel and colleagues treated six infants, averaging 28 weeks' gestation, with gentle rubbing of the extremities for 5 minutes every 15 minutes for 3 hours, and compared AOP frequency with that of 12 comparable infants treated with continuous positive airway pressure (CPAP). (3) The cutaneous stimulation babies were reported to have a 35% reduction in apneas, compared to a 69% reduction in the CPAP group. Another study involving eight infants in a crossover design, where each spent 6 hours on an oscillating mattress and 6 hours off again, showed a reduction in apneas while on the mattresses. (4) Contrary to the prior reports, a small study of 14 infants found that they had more episodes of severe bradycardia while on an oscillating mattress than when not on it. (5) A further study comparing the effects of an oscillating waterbed (n=9) to those treated with theophylline (n=11) on apnea and bradycardia found theophylline to be associated with better reductions in episodes. (6) Korner, the author of two of the previous reports, published a letter indicating that the study of the effects of waterbeds was difficult and that results were hard to interpret. (7) She also mentioned that there was a proliferation of "bump beds" and water beds with different characteristics and argued for further randomized, controlled trials (RCTs) to address the use of these devices for treatment of AOP. Tuck and colleagues performed a crossover study in 12 premature infants with confirmed AOP using a rocking bed and found statistically significant reductions in spells when the beds were rocking compared to when they were still. (8)

These small studies spurred the widespread use of various devices for kinesthetic stimulation in the treatment or prevention of AOP. One such device is what was widely known as the "whoopee cushion." For those few who may not know what whoopee cushions are, they are gag devices that, when sat upon, emit a sound like flatulence. They were once all the rage but seem to be less so these days. The Rube Goldberg assembly widely used in NICUs usually consisted of a surgical glove connected to an intermittent positive-pressure respirator, such as the Bird Mark 7.

"These small studies spurred the widespread use of various devices for kinesthetic stimulation in the treatment or prevention of AOP. One such device is what was widely known as the 'whoopee cushion.'"

I asked one of our new AI overlords, ChatGPT, to produce an image of such a setup. Figure 1 is the result of the first attempt. I then asked it to place the glove under the baby and attach it to the respirator, and it produced Figure 2. The respirator in the

Figure 1. The first attempt of ChatGPT to depict the "whoopee cushion."

Figure 2. Result of the second attempt by ChatGPT when asked to modify Figure 2 by placing the glove under the baby and attaching it to the respirator.

previous two Figures is not a Bird Mark 7, so I asked to replace it with an image of a Mark 7 that I provided, and I received Figure 3. When I then asked ChatGPT to rotate the glove 90 degrees counterclockwise, shrink it by half, and connect the respirator to the glove, I got the hallucination shown in Figure 4, and I gave up on getting a better image. Anyhow, you get the idea. The glove was placed under the infant's back, connected to the respirator,

Figure 3. What I got when I asked Chat GPT to replace the incorrect respirator in Figure 3 with a correct image of a Bird Mark 7.

Figure 4. The image that ChatGPT produced when asked to rotate the glove shown in Figure 4 counterclockwise 90 degrees, shrink it by half and connect it to the respirator.

which was then set to deliver a small tidal volume between ten and 20 times per minute to provide kinesthetic stimulation. These things were everywhere in the late 1970s and early 1980s.

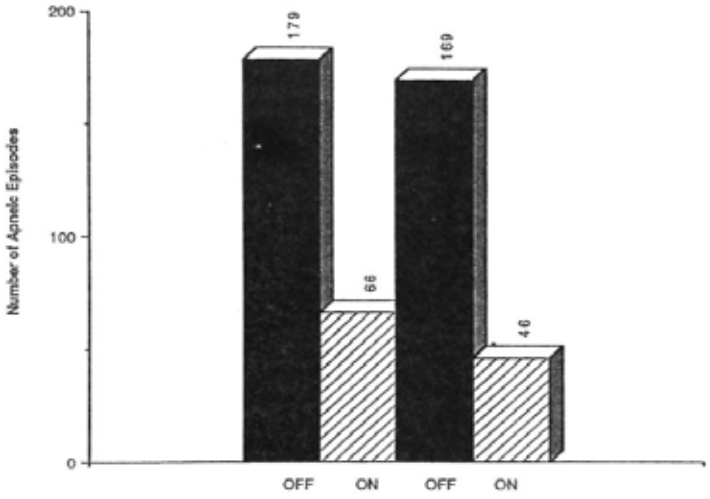
"In 1986, a larger RCT was published in which 59 preterm infants, averaging ~30 weeks of gestation, were assigned within 5 days of birth to an oscillating air mattress and compared with a similar group of 63 controls...No significant differences in apneas and/or bradycardias were found between the two groups, nor were there any significant differences in weight gain during the study or neurodevelopmental outcomes at six- and twelve-month corrected age. "

In 1986, a larger RCT was published in which 59 preterm infants, averaging ~30 weeks of gestation, were assigned within 5 days of birth to an oscillating air mattress and compared with a similar group of 63 controls. (9) The median duration of the study in both groups was about two and a half weeks. No significant differences in apneas and/or bradycardias were found between the two groups, nor were there any significant differences in weight gain during the study or neurodevelopmental outcomes at six- and twelve-month corrected age. The authors concluded "that the prophylactic use of an oscillating air mattress offers no benefits in reduction of apnea or enhanced growth and neurobehavioral performance.

Although we did not observe any adverse effects, its usefulness in the clinical management of preterm infants seems limited." The authors also speculated that the treatment failed because the infants had habituated to the short-term beneficial effects, leading to the disappearance of any longer-term effects. After publication of this report, along with the empirical observations of those using various kinesthetic stimulation devices that did not really help, their use faded away.

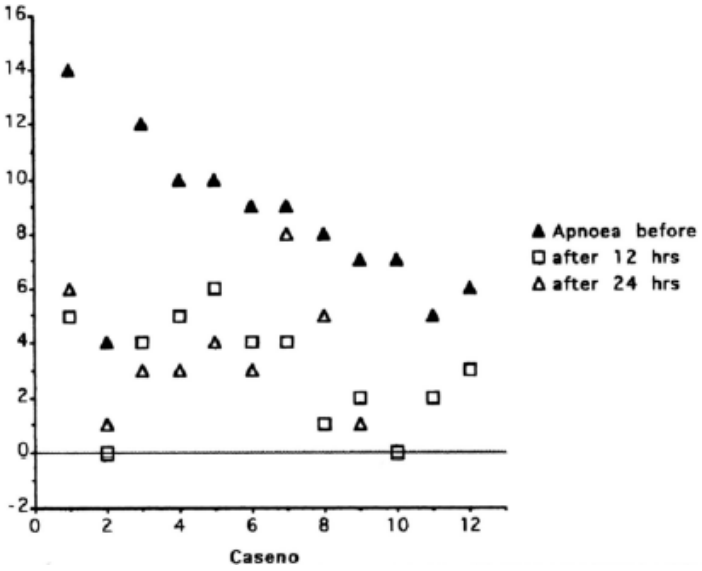
Nevertheless, interest in some form of kinesthetic stimulation continues. Jirapaet studied the effect of a vertical pulsating device consisting of a Bird Mark 8 respirator connected to an infant blood pressure cuff, cycling 16+4 times/minute and producing 1cm displacements, and found a significant reduction in spells when the device was turned on (Figure 5). (10)

Figure 5. Number of apnea episodes in 29 premature infants over four 6-hour intervals with a vertical pulsating device turned on or off. Used with permission. (10)



A 1995 study, which included 8 preterm infants with obstructive apnea, showed a reduction in spells with side-to-side rocking. (11) Another report combining an oscillating air mattress with high-frequency vibrations reported reductions at 12 and 24 hours in 12 premature infants with AOP (Figure 6). (12) An additional report involving 10 premature infants given small stochastic (random) displacements from a mattress embedded with actuators showed reduced variance in interbreath intervals and duration of oxygen desaturations; however, the study intervals were ten minutes with stimulation, then ten minutes off for a period of one hour, so long-term effects cannot be ascertained. (13) A follow-up to this study included 36 infants with a mean gestation of 30.5 weeks who received one or two alternating 30-minute periods of stochastic stimulation or no stimulation for three hours and found relatively similar results. (14) Again, however, the study durations were short, and no long-term inferences can be drawn. A more recent study using tactile, proprioceptive, and kinesthetic stimulation in 30 preterm infants with AOP showed a statistically significant decline in AOP in the treatment group. (15) A recent review entitled "Sensory stimulation for apnoea mitigation in preterm infants" reviewed all the modalities that have been tried,

Figure 6. Reductions in apnea spells at 12 and 24 hours in premature infants placed on an oscillating air mattress that also produced high-frequency vibrations. Used with permission. (12)



including tactile stimulation, generalized kinesthetic stimulation, CPAP with or without intermittent positive pressure ventilation, plus auditory and olfactory stimulation. (16) Of note, the authors presented a lengthy discussion noting that most of the published studies comprised relatively short study periods and emphasized the possibility of habituation in longer-term use of stimulators.

"A recent review entitled 'Sensory stimulation for apnoea mitigation in preterm infants' reviewed all the modalities that have been tried, including tactile stimulation, generalized kinesthetic stimulation, CPAP with or without intermittent positive pressure ventilation, plus auditory and olfactory stimulation. Of note, the authors presented a lengthy discussion noting that most of the published studies comprised relatively short study periods and emphasized the possibility of habituation in longer-term use of stimulators. As previously mentioned, the only longer-term study showed no benefit of an oscillating air mattress on AOP."

As previously mentioned, the only longer-term study showed no benefit of an oscillating air mattress on AOP. (9)

"At present, the only effective physical intervention for AOP is tactile stimulation provided by staff to terminate an episode...What if we could develop a method to predict when an AOP episode is about to occur and provide a stimulus to prevent it? Such a reactive delivery system would be ideal, providing a stimulus only when needed instead of continuously. Prediction systems using machine learning are being developed, which could then be linked to a device to deliver the intervention. So, the future of kinesthetic stimulation for treatment and prevention of AOP is bright."

So, where do we go from here? At present, the only effective physical intervention for AOP is tactile stimulation provided by staff to terminate an episode. I recall that, many years ago, when incubators had a small hole in the top, we would tie a length of umbilical tape to the baby's arm or leg and bring the other end out of the hole so we could gently shake the limb without having to enter the incubator. What if we could develop a method to predict when an AOP episode is about to occur and provide a stimulus to prevent it? Such a reactive delivery system would be ideal, providing a stimulus only when needed instead of continuously. Prediction systems using machine learning are being developed, which could then be linked to a device to deliver the intervention. (17, 18) So, the future of kinesthetic stimulation for treatment and prevention of AOP is bright.

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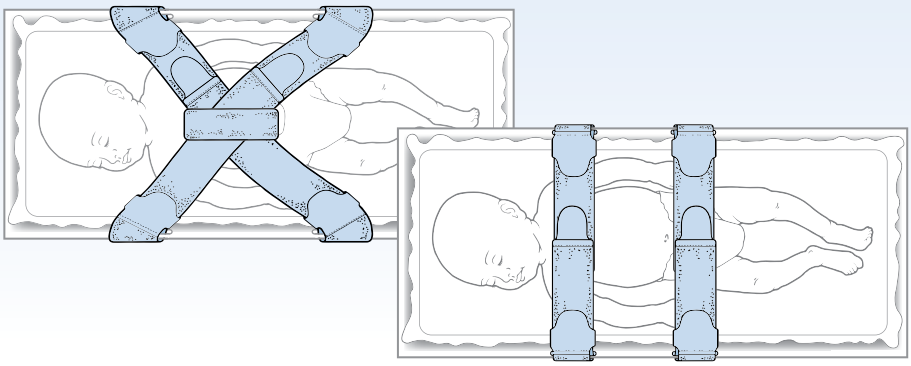

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From Surviving to Thriving: How Japan's Landmark Approval of Human Milk-Based Fortifiers Is Redefining Neonatal Care

Kate Tauber, MD, MA, CLC

Japan has long set the global standard for neonatal survival: between 80–90% of infants born at 22–24 weeks' gestation survive to discharge, with an overall NEC rate below 2% in very low birth weight (VLBW) infants. (1) Yet survival is only the beginning. Japanese clinicians recognized that, even with this impressive clinical success, neurodevelopmental outcomes could be improved with better early growth. Achieving that required solving a nutritional dilemma in Japan.

"Japan has long set the global standard for neonatal survival: between 80–90% of infants born at 22–24 weeks' gestation survive to discharge, with an overall NEC rate below 2% in very low birth weight (VLBW) infants."

Prior to a recent landmark regulatory decision, human milk-based fortifiers (HMBF) were not approved for use in Japan; only cow milk-based fortifiers (CMBF) were available. Concerns over the risks of CMBF in the smallest and most vulnerable infants led clinicians to routinely delay or avoid fortification, leaving those infants without adequate nutritional support during the most critical window of brain development. (2) Now, for the first time anywhere in the world, HMBF has been designated as a prescription drug with Japan's Ministry of Health, Labour and Welfare approving Prolacta Bioscience's fortifiers for use in VLBW and post-surgical infants. It is a decision that has the potential to transform not just Japanese neonatal care but the global standard.

"Concerns over the risks of CMBF in the smallest and most vulnerable infants led clinicians to routinely delay or avoid fortification, leaving those infants without adequate nutritional support during the most critical window of brain development."

The Neurodevelopmental Stakes:

The third trimester is the most dynamic period of neurological development in the entire human lifespan, one in which brain mass increases measurably week by week and approximately 250,000 neurons are formed every minute. (3, 4) For the very preterm infant, this extraordinary period of growth is happening outside the womb in the neonatal intensive care unit (NICU) with care teams managing the nutritional support that fuels it.

"The third trimester is the most dynamic period of neurological development in the entire human lifespan, one in which brain mass increases measurably week by week and approximately 250,000 neurons are formed every minute...The consequences of nutritional deficits during this window extend far beyond the NICU. Inadequate early nutrition reduces brain cells, myelin production, and synaptic connections, and has been associated with lasting cognitive impairment."

The consequences of nutritional deficits during this window extend far beyond the NICU. Inadequate early nutrition reduces brain cells, myelin production, and synaptic connections, and has been associated with lasting cognitive impairment. (5, 6) What we feed these infants in their first days and weeks of life can shape their long-term neurodevelopmental trajectory in ways that no intervention later in childhood can fully reverse. (7–11)

Why Japan's Fortification Practice Needed to Change:

Despite its exceptional survival rates, Japan's standard nutritional approach carried a critical limitation. The prevailing practice often relied on withholding or delaying CMBF and formulas, known to carry risks of complications in premature infants. (12) The recently published study on the Japan-led JASMINE trial describes the clinical reality plainly:

> Notably, Japan is a world leader in survival rates of extremely preterm infants, with 80–90% of infants 22–24 weeks surviving to discharge in 2022, and an overall NEC rate of 2% in VLBW infants. Despite these excellent outcomes, there is not yet wide availability of human donor milk (DM) and a great hesitancy to feed and fortify infants with cow milk-based products early, often leading to poor growth outcomes in Japanese infants. (13)

The result was inadequate nutrition and growth during the precise developmental window when the brain needs it the most. Japanese neonatologists were, in effect, winning on one metric while potentially compromising on another.

The JASMINE Trial: A Phase III Answer:

The JASMINE trial, *Growth and Safety Evaluation in Very Low Birth Weight Infants Receiving an Exclusive Human Milk Diet: A Phase III Randomized Control Trial in Japan,* was conducted across 11 Japanese NICUs and randomized very low birth weight infants to either an exclusive human milk diet (EHMD) with human milk-based fortifiers added to mother's own milk or donor milk, or the Standard Diet where CMBF or formula was delayed or avoided completely. Baseline characteristics were similar between groups, with a mean birth weight of 908.1 g in the EHMD group and 947.6 g in the standard diet group, and a mean gestational age of 27.05 weeks and 27.63 weeks, respectively. For clarity, findings are summarized from the per-protocol set (PPS; n=135), which included infants who remained on protocol through 34 weeks' gestational age (EHMD n=66; standard diet n=69) without a major protocol violation.

"The JASMINE trial,* Growth and Safety Evaluation in Very Low Birth Weight Infants Receiving an Exclusive Human Milk Diet: A Phase III Randomized Control Trial in Japan*, was conducted across 11 Japanese NICUs and randomized very low birth weight infants to either an exclusive human milk diet (EHMD) with human milk-based fortifiers added to mother's own milk or donor milk, or the Standard Diet where CMBF or formula was delayed or avoided completely."

The EHMD comprised three Prolacta products in the trial: Prolact+6 and Prolact+8, human milk-based fortifiers, and Prolact CR, a human milk-derived fat module added to mother's own milk or donor human milk. Prolact CR played a central role in the protocol; approximately 95% of infants in the EHMD arm received it, providing concentrated nutrition without substantially increasing feeding volumes.

The JASMINE results were compelling. In the per-protocol set (PPS), the EHMD group demonstrated significantly greater weight gain velocity than infants in the Standard Diet group (14.30 vs. 11.96 g/kg/day, p<0.0001). (13) Infants fed an EHMD also demonstrated significantly better length gain velocity compared to infants fed the Standard Diet (0.85 vs. 0.66 cm/week, p≤0.0016), and infants in the EHMD group achieved full feeding volumes faster. Notably, the EHMD group spent fewer days on antibiotics compared to the Standard Diet group, a meaningful indicator of infection resilience in a context where sepsis remains the leading acquired cause of neonatal death in Japan. (13) Although not statistically significant, head circumference growth was numerically improved in the human milk arm.

"In the per-protocol set (PPS), the EHMD group demonstrated significantly greater weight gain velocity than infants in the Standard Diet group (14.30 vs. 11.96 g/kg/day, p<0.0001). Infants fed an EHMD also demonstrated significantly better length gain velocity compared to infants fed the Standard Diet (0.85 vs. 0.66 cm/week, p≤0.0016), and infants in the EHMD group achieved full feeding volumes faster."

Critically, these growth gains came without compromising safety. There was a single NEC case in the EHMD group, consistent with Japan's low baseline NEC rates. Although randomized, the EHMD group included a higher proportion of infants born at 22–23 weeks' gestation than the Standard Diet group, making the superior growth outcomes even more meaningful.

"A randomized trial of infants 750–1,250 g showed that infants who received human milk-derived cream had superior weight gain (14.0 vs. 12.4 g/kg/day, p=0.03) and superior length gain (1.03 vs. 0.83 cm/week, p=0.02) compared to those who did not receive it. Cow milk-based products cannot replicate this bioactive profile, as intact MFGs are largely absent from CMBF."

"By contrast, processing methods such as homogenization and ultra-high-temperature (UHT) sterilization disrupt MFG membranes and additionally degrade key bioactive proteins. Immunoglobulins are reduced to nearly undetectable levels under UHT, and vascular/endothelial growth factor (VEGF), critical to gut and vascular development, is reduced by more than 60%."

Human Milk Fat and the Developing Brain:

For the preterm infant, fat is not simply a source of calories. The fat in human milk is uniquely structured to nourish the developing brain in ways that cow milk-based products cannot match. Human milk fat globules (MFGs) comprise approximately 98% of the fat in human milk and deliver 191 bioactive proteins, as well as long-chain polyunsaturated fatty acids, including DHA, which is critical for brain development. (14, 15) Premature infants miss approximately 80% of the DHA that would normally accumulate in the brain and tissues during the third trimester. (15) Prolact CR is composed of approximately 25% human milk fat and has been shown to increase weight and length velocity in VLBW infants significantly. A randomized trial of infants 750–1,250 g showed that infants who received human milk-derived cream had superior weight gain (14.0 vs. 12.4 g/kg/day, p=0.03) and superior length gain (1.03 vs. 0.83 cm/week, p=0.02) compared to those who did not receive it. (16) Cow milk-based products cannot replicate this bioactive profile, as intact MFGs are largely absent from CMBF.

Prolacta's vat pasteurization process preserves MFG integrity, maintaining the structural and functional properties of these bioactive components in their native state. (17–19) By contrast, processing methods such as homogenization and ultra-high-temperature (UHT) sterilization disrupt MFG membranes and additionally degrade key bioactive proteins. Immunoglobulins are reduced to nearly undetectable levels under UHT, and vascular/endothelial growth factor (VEGF), critical to gut and vascular development, is reduced by more than 60%. (18) The human milk-based products also preserve a wide spectrum of human milk oligosaccharides (HMOs), the third-most-abundant component in human milk, which guide the development of beneficial gut bacteria and, emerging research suggests, may directly influence neurodevelopmental processes in early brain development. (20–22)

The Long View: Neurodevelopmental Outcomes Beyond the NICU:

The JASMINE trial had a clear goal: to optimize early growth in the most vulnerable preterm infants to support better neurodevelopmental outcomes potentially. Evidence from EHMD use in other settings underscores the long-term benefits.

"The human milk-based products also preserve a wide spectrum of human milk oligosaccharides (HMOs), the third-most-abundant component in human milk, which guide the development of beneficial gut bacteria and, emerging research suggests, may directly influence neurodevelopmental processes in early brain development. "

A 2025 multicenter study by Chou and colleagues across 13 Kaiser Permanente Southern California NICUs involving more than 1,000 infants found that an EHMD was associated with 26% lower odds of motor skill delays at age 3, compared with infants fed cow milk-based products, despite EHMD infants being born approximately three weeks earlier and weighing more than 300 g less at birth. (23) Hair and colleagues reported that infants fed an EHMD had significantly higher cognitive scores and a trend toward improved language scores at 18–22 months corrected age compared to those fed cow milk-based diets. (24)

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A Landmark Decision with Global Implications:

Japan's prescription drug designation for Prolacta's human milk-based fortifiers is not simply a regulatory milestone; it is a clinical statement grounded in rigorous Phase III evidence that early fortification with an EHMD is achievable, beneficial, and safe for

VLBW infants.

For NICUs globally, this approval sets a powerful precedent that the evidence is strong enough and the safety profile clear enough that all NICUs should be using human milk-based products to fortify the enteral feeds of very preterm infants, not just to help premature infants survive but to help them thrive in the long term.

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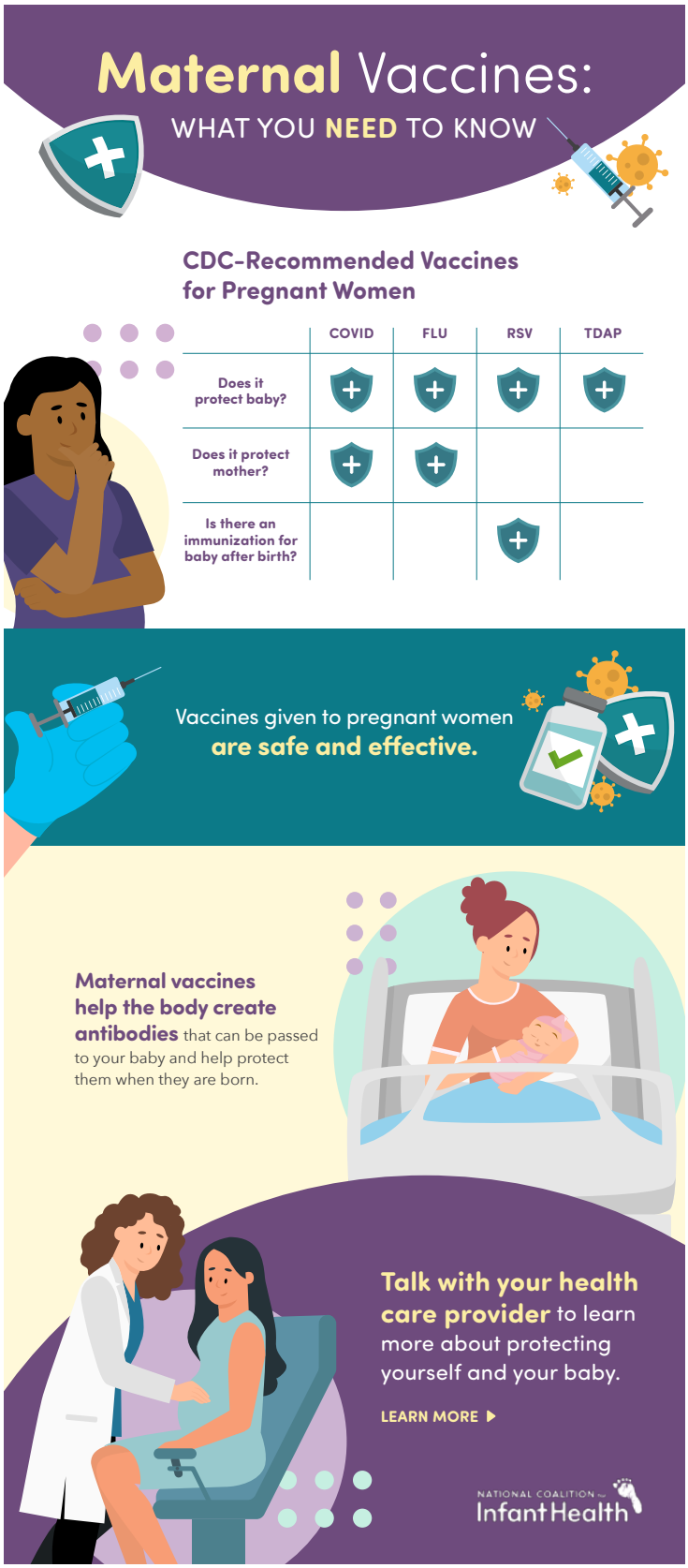

Mission

Since its inception in 1981, PAC/LAC has been a powerful catalyst for transformative change in perinatal care. As a dedicated non-profit organization, we champion advocacy, drive quality improvement, and promote equity among healthcare professionals, organizations, and systems.

Vision

We envision a future where the knowledge, skills, and experiences of healthcare professionals and community organizations caring for mothers, birthing individuals, infants, and families are continuously enriched, leading to dramatically improved perinatal health outcomes.

Our Overarching Goal

Our primary goal is to ensure a healthy start for every family by providing care delivered by the most skilled professionals in well-equipped healthcare settings. We achieve this through evidence-based education, tailored technical assistance, comprehensive resources, and strong leadership. Our commitment to quality improvement and excellence drives us to promote risk-appropriate perinatal care for all pregnant individuals and their infants.

Every family deserves unwavering support, confidence, and resources for a safe and fulfilling birth journey. By collaborating and networking with local communities and organizations, we are fiercely dedicated to treating all mothers, babies, and families with the highest respect, care, and access to unbiased, equitable health services.

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Merchak Monthly Neonatal Case Challenge June 2026 Edition – Case number 77

Assaad Merchak, MD

"We are pleased to present the June edition of the Merchak Monthly Case Challenge, designed to foster ongoing education and excellence in neonatal care. Each month, clinicians are invited to test their knowledge, engage with real-world scenarios, and compete for prizes."

Welcome Back.

We are pleased to present the June edition of the Merchak Monthly Case Challenge, designed to foster ongoing education and excellence in neonatal care. Each month, clinicians are invited to test their knowledge, engage with real-world scenarios, and compete for prizes.

"You are caring for Margaret. Margret is a 6-day-old female, born at 26 weeks GA via vaginal delivery due to preterm labor. Her mother's serology is negative, and she received one dose of antenatal steroids. Margaret is on Conventional Ventilation (CV), with Klebsiella Pneumonia sepsis. She is having frequent events of bradycardia on high ventilatory respiratory support. "

May Case Recap: Margaret is on the jet.

May's challenge featured a case in which we addressed the use of High-Frequency Jet Ventilation (HFJV) in neonates.

You are caring for Margaret. Margret is a 6-day-old female, born at 26 weeks GA via vaginal delivery due to preterm labor. Her mother's serology is negative, and she received one dose of antenatal steroids. Margaret is on Conventional Ventilation (CV), with Klebsiella Pneumonia sepsis. She is having frequent events of bradycardia on high ventilatory respiratory support. You are planning to support her respiratory status with the High-Frequency Jet Ventilator (HFJV).

"On HFJV, exhalation is both passive and continuous as air exhalation occurs because of the elastic recoil of the lungs, directing the passage of the gas from the side of the airway."

Key Learning Points:

- On HFJV, exhalation is both passive and continuous as air exhalation occurs because of the elastic recoil of the lungs, directing the passage of the gas from the side of the airway.
- The use of HFV may reduce exposure of the preterm infants' airways and alveoli to high inspiratory pressures and large tidal volumes.
- High-frequency jet ventilation (HFJV) may be used as the first intention ventilation modality in extremely preterm infants with respiratory distress syndrome.
- Extremely premature infants can undergo successful extubation directly from HFJV to noninvasive ventilation once they demonstrate a sustained respiratory drive.
- To learn more, visit the previous case presentation:

  https://www.takethequiz.us/prior-case-presentation

Congratulations: The gift card winner for May's challenge is Kathryn Moore, NNP. Carilion Children's NICU. Roanoke, VA

Next Challenge: Do you think she can come off the ventilator soon? Margaret's mother asks.

This case focuses on extubation readiness in premature infants

Sneak Peek Challenge question: True or false: When infants are on High-frequency ventilation, transition to conventional ventilation (MV) is necessary before extubation.

Test your knowledge and participate in the challenge by visiting: WWW.Takethequiz.US or scan this QR code:

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SESSION 2

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Advancing Neonatal Respiratory Care with AI-Driven Clinical Intelligence: The Emerging Value of Etiometry in the NICU

Evan Butler

"Respiratory instability remains one of the most prevalent and complex challenges in neonatal intensive care, particularly among preterm infants and those requiring mechanical ventilation. Despite continuous monitoring technologies such as pulse oximetry and ventilator-derived parameters, clinicians often lack integrated tools to synthesize these data streams and support review of oxygenation trends within hospital-defined workflows."

"This article reviews recent studies and clinical data highlighting the emerging value of Etiometry in neonatal care, with a focus on oxygen management, ventilation strategies, and non-invasive tracking of hypercapnia."

Introduction:

Respiratory instability remains one of the most prevalent and complex challenges in neonatal intensive care, particularly among preterm infants and those requiring mechanical ventilation. Despite continuous monitoring technologies such as pulse oximetry and ventilator-derived parameters, clinicians often lack integrated tools to synthesize these data streams and support review of oxygenation trends within hospital-defined workflows. In parallel, key aspects of respiratory management, particularly carbon dioxide monitoring, still rely on intermittent measurements and indirect indicators to guide clinical decision-making. These limitations can contribute to variability in care and increase the risk of complications, including bronchopulmonary dysplasia (BPD), retinopathy of prematurity (ROP), prolonged mechanical ventilation, and repeated invasive procedures.

Recent advances in clinical intelligence platforms have introduced the potential to transform continuously collected physiologic data into actionable insights. Etiometry's Clinical Intelligence Platform integrates high-frequency bedside monitoring data with advanced analytics and AI-based risk algorithms to support real-time clinical decision-making. A growing body of clinical evidence suggests that this approach may enhance the precision, safety, and efficiency of neonatal respiratory care.

This article reviews recent studies and clinical data highlighting the emerging value of Etiometry in neonatal care, with a focus on oxygen management, ventilation strategies, and non-invasive tracking of hypercapnia.

Optimizing Oxygen Therapy and Clinical Outcomes:

Maintaining oxygen saturation within a defined target range is a cornerstone of neonatal care, yet achieving consistent compliance remains difficult. Both hyperoxia and hypoxia are associated with adverse outcomes. Hyperoxia has been linked to the development of ROP, while fluctuations in oxygenation contribute to the pathogenesis of BPD. (1, 2)

A retrospective study utilizing Etiometry-derived data evaluated oxygen saturation (SpO_2) compliance in 879 preterm infants receiving oxygen therapy. The study found that mean compliance with target SpO_2 ranges was only 44.7%, highlighting the challenge of maintaining optimal oxygenation in routine practice. Hyperoxic events occurred more frequently than hypoxic events, and the number of clinically intervenable events increased with decreasing gestational age. Importantly, lower compliance with target ranges was associated with a higher incidence of both ROP and BPD, with odds ratios demonstrating significantly increased risk among infants with poor compliance. (3)

These findings underscore the importance of continuous, high-resolution monitoring of oxygenation beyond simple threshold alarms. By capturing SpO_2 and FiO_2 data continuously and identifying periods of deviation from target ranges, the Etiometry platform enables clinicians to recognize actionable patterns and intervene more effectively. This capability represents a shift toward proactive oxygen management, with potential implications for reducing long-term morbidity. (1)

Adjunctive CO_2 Risk Information to Support Clinician Review:

Continuous assessment of carbon dioxide levels remains a significant limitation in neonatal care. While pulse oximetry provides reliable oxygenation data, no equivalent non-invasive continuous standard exists for $pSpO_2$. Blood gas sampling, therefore, remains the primary method for assessment but is invasive, intermittent, and resource-intensive.

The IVCO2 Index provides additional information on the risk of inadequate carbon dioxide ventilation, using physiologic and laboratory inputs, supporting clinician review alongside primary clinical data. A recent retrospective cohort study in a Level IV NICU evaluated outcomes before and after implementation of this algorithm in 614 infants.

Following implementation, there was a statistically significant reduction in blood gas measurements per day (0.44 vs 0.40 per day, p=0.02), despite the post-implementation cohort

demonstrating higher acuity, including increased ventilator days and higher respiratory severity scores. Importantly, hypercapnia ($pSpO_2$ >60 mmHg) was detected unchanged. (4)

Enhancing Ventilation Management and Extubation Decisions:

Mechanical ventilation is essential in the management of neonatal respiratory failure but is associated with risks including ventilator-induced lung injury and prolonged hospitalization. Determining the appropriate timing for extubation is a critical and complex decision that requires careful assessment of respiratory readiness and the risk of failure.

"Recent studies have explored the role of Etiometry in optimizing ventilation strategies. A study conducted at Children's of Alabama and the University of Alabama at Birmingham demonstrated an association between the use of Etiometry's Clinical Intelligence Platform and a 30% reduction in mechanical ventilation duration in pediatric and neonatal patients undergoing automated spontaneous breathing trials. (5)

In addition, a multicenter study from Boston Children's Hospital evaluated Etiometry's risk analytics algorithms in patients undergoing congenital cardiac surgery. The study evaluated relationships between risk analytics outputs and extubation-failure outcomes, providing additional information for clinician review. (6)"

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In addition, a multicenter study from Boston Children's Hospital evaluated Etiometry's risk analytics algorithms in patients undergoing congenital cardiac surgery. The study evaluated relationships between risk analytics outputs and extubation-failure outcomes, providing additional information for clinician review. (6)

Together, these findings highlight how time-aligned physiologic data may support clinician review of respiratory trajectory during extubation-readiness workflows and their evaluations of reducing both premature extubation and unnecessary prolongation of mechanical ventilation. The platform provides adjunctive information to help clinicians evaluate SBT/ERT performance alongside other clinical data.

Advancing SpO_2 Risk Review in Neonatal Care:

Routinely collected physiologic data can provide useful context for reviewing carbon dioxide ventilation risk in neonatal care. A recent study published in the Journal of Perinatology [7] evaluated the use of Etiometry's platform to support the review of hypercapnia risk in neonates, demonstrating how physiologic data can help clinicians assess respiratory status alongside other clinical information.

This capability has been further supported by regulatory advancements, including U.S. Food and Drug Administration clearance of an adjunctive index that indicates an increasing risk of inadequate carbon dioxide ventilation in neonatal patients. The index is intended to bring the patient to the clinician's attention for review and should be interpreted alongside other clinical data when clinically appropriate.

"The integration of adjunctive respiratory-risk information into NICU workflows represents an important step toward broader adoption of AI-enabled clinical decision support. These tools may help care teams review patient status, support timely clinical awareness, and evaluate respiratory trends within existing hospital workflows."

The integration of adjunctive respiratory-risk information into NICU workflows represents an important step toward broader adoption of AI-enabled clinical decision support. These tools may help care teams review patient status, support timely clinical awareness, and evaluate respiratory trends within existing hospital workflows.

Discussion:

The growing body of evidence supporting Etiometry's Clinical Intelligence Platform suggests that it offers meaningful benefits across several domains of neonatal care. First, in oxygen management, the platform supports visualization of adherence to hospital-defined SpO_2 targets for clinician review. Associations between oxygenation patterns and ROP/BPD were reported in the literature and were observational.

Second, in ventilation management, the platform supports more precise and individualized decision-making by integrating continuous physiologic data with predictive analytics. This has been associated with reductions in mechanical ventilation duration

and improved assessment of extubation readiness.

Third, in carbon dioxide monitoring, the ability to predict hypercapnia non-invasively addresses a longstanding clinical challenge. In one retrospective cohort, blood gas measurement frequency was lower, whereas hypercapnia detection on blood gas analysis remained unchanged. The IVCO2 Index is an adjunct and not a substitute for blood samples.

Importantly, these benefits have been observed even in higher-acuity populations, suggesting that the platform is robust and adaptable across a range of clinical scenarios. Rather than replacing clinical judgment, Etiometry enhances it by providing a continuous, data-driven perspective that complements traditional monitoring approaches.

"Etiometry's Clinical Intelligence Platform represents a significant advancement in the application of artificial intelligence and data analytics in neonatal care. By transforming continuous physiologic data into actionable insights, it enables clinicians to deliver more precise, proactive, and patient-centered care."

Conclusion:

Etiometry's Clinical Intelligence Platform represents a significant advancement in the application of artificial intelligence and data analytics in neonatal care. By transforming continuous physiologic data into actionable insights, it enables clinicians to deliver more precise, proactive, and patient-centered care.

Current observational evidence suggests that platform-supported workflows may support clinician review of oxygenation trends, ventilation-related data, and adjunctive respiratory-risk information. As further studies are conducted and adoption expands, such technologies are likely to play an increasingly central role in the evolution of neonatal intensive care.

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When hope feels distant, let His words anchor your heart.

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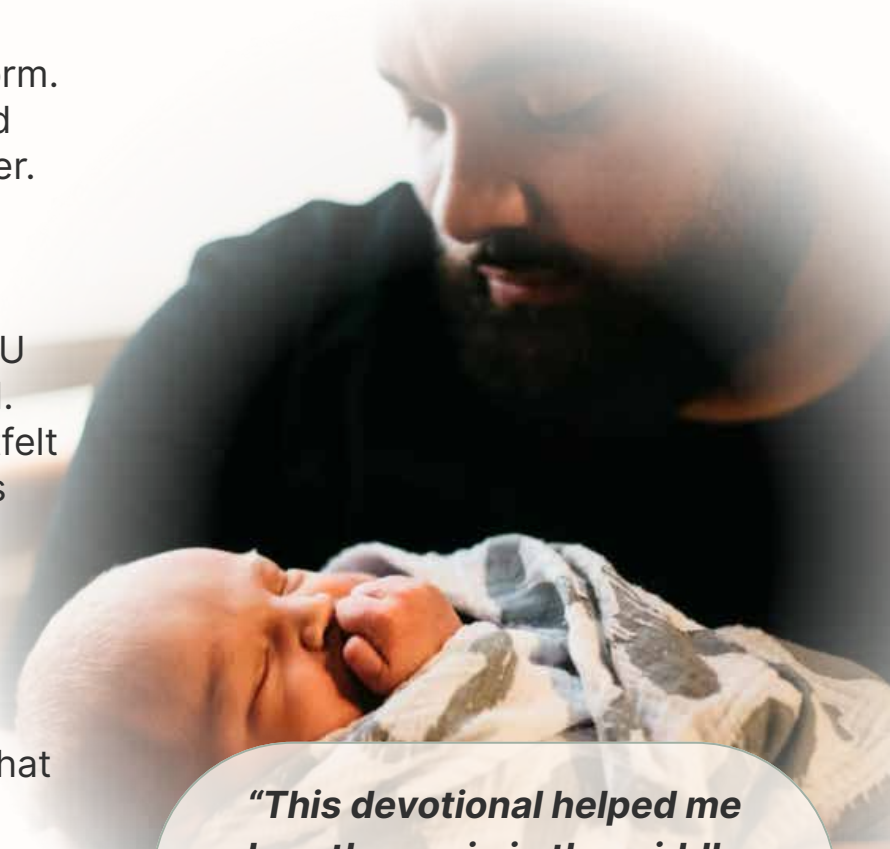
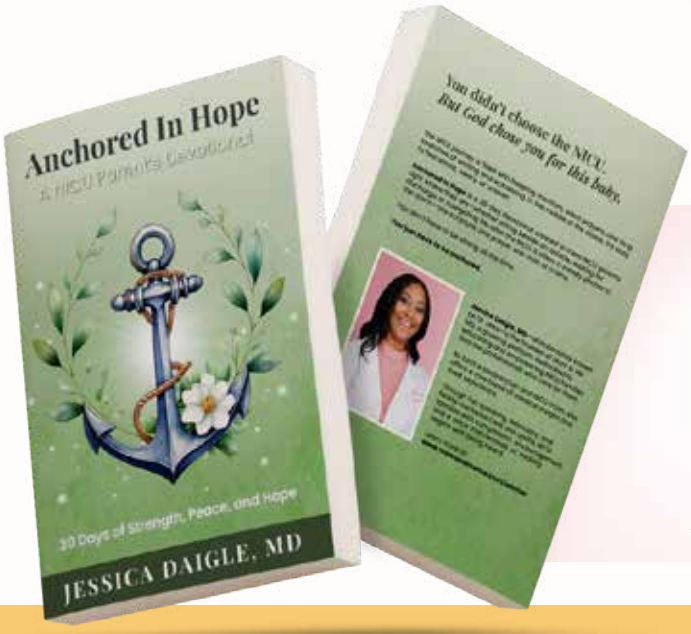


"This devotional helped me breathe again in the middle of our NICU storm."
— A NICU Mom & Dad



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Transpulmonary Pressure Equation in Neonatal Respiratory Care Using the Alveolar–Pleural Pressure Relationship to Interpret Bedside Physiology

Noel D Tan, MD, Alfredo Cartaya, MD, Peter-Paul U Nwokeji, MD

"Neonatal respiratory support is often described in terms of the device or ventilator mode used, yet the lung responds to a more fundamental relationship: the pressure gradient across it. The transpulmonary pressure equation describes this relationship, $P^L = P^A - Ppl$, where P^L is transpulmonary pressure, P^A is alveolar pressure, and Ppl is pleural pressure."

Abstract

Neonatal respiratory support is often described in terms of the device or ventilator mode used, yet the lung responds to a more fundamental relationship: the pressure gradient across it. The transpulmonary pressure equation describes this relationship, $P^L = P^A - Ppl$, where P^L is transpulmonary pressure, P^A is alveolar pressure, and Ppl is pleural pressure. In routine neonatal care, these pressures are not directly measured at the bedside. However, the equation remains clinically useful as a conceptual framework for interpreting respiratory signs, work of breathing, response to support, and the need for escalation or de-escalation. This review applies the equation to neonatal respiratory physiology, particularly respiratory distress syndrome, surfactant response, overdistension, air leak, and pleural interventions. Bedside signs are interpreted according to whether the infant is attempting to increase transpulmonary pressure, reduce excessive distension, or compensate for disruption of the pleural pressure environment.

"An increase in alveolar pressure increases transpulmonary pressure. A decrease in pleural pressure, meaning a more negative pleural pressure, also increases transpulmonary pressure."

Introduction:

The newborn lung expands when the pressure inside the alveoli exceeds the pressure in the pleural space surrounding the lung. This relationship is expressed as:

$P^L = P^A - Ppl$

An increase in alveolar pressure increases transpulmonary pressure. A decrease in pleural pressure, meaning a more negative pleural pressure, also increases transpulmonary pressure. Conversely, a decrease in alveolar pressure or an increase in pleural pressure (i.e., a less negative or more positive pleural pressure) reduces transpulmonary pressure and favors lung deflation.

This equation is central to neonatal respiratory physiology because the lung does not respond solely to airway pressure or to respiratory effort. The lung responds to the relationship between alveolar pressure and pleural pressure. A ventilator, CPAP device, or positive-pressure breath primarily changes P^A. The infant's own respiratory effort primarily changes Ppl. Pleural pathology, such as a pneumothorax or pleural effusion, disrupts the pleural pressure environment and thereby alters the effective pressure gradient across the lung.

Direct measurement of alveolar pressure and pleural pressure is not practical in routine neonatal care. For that reason, the equation should not be used as a bedside calculation in most clinical settings. Instead, it is best used as a conceptual model. It helps clinicians interpret the direction of physiologic change: whether transpulmonary pressure is insufficient, excessive, disrupted, or unevenly distributed.

"Direct measurement of alveolar pressure and pleural pressure is not practical in routine neonatal care. For that reason, the equation should not be used as a bedside calculation in most clinical settings."

This distinction is clinically important because the same general label, "respiratory distress," may reflect very different mechanical states. Some infants are distressed because they cannot generate or maintain enough transpulmonary pressure to keep the lung recruited. Others are distressed because transpulmonary pressure has become excessive, causing overdistension, impaired emptying, or hemodynamic compromise. Still others develop distress because the pleural pressure environment has been disrupted by air or fluid in the pleural space. These states may require opposite interventions.

Physiologic States Through the Equation:

In the normal newborn, a modest positive transpulmonary pressure is maintained at end-expiration. This preserves functional residual capacity and allows the next breath to begin from a stable lung volume. During inspiration, pleural pressure becomes slightly more negative. This increases transpulmonary pressure and efficiently produces tidal volume. The important feature of normal physiology is balance. The lung expands with relatively small pressure swings, and the work of breathing remains low.

In preterm respiratory distress syndrome, this balance is lost. Surfactant deficiency lowers lung compliance and promotes alveolar collapse. At baseline, transpulmonary pressure is insufficient to maintain adequate lung volume. The infant compensates by generating more negative pleural pressure during inspiration. As Ppl becomes more negative, P^L increases. This is the infant's attempt to recruit the lung and improve tidal volume.

"However, because compliance is low, a large increase in transpulmonary pressure may produce only a limited increase in lung volume. The infant, therefore, performs a large amount of work for a relatively small mechanical gain. Clinically, this appears as retractions, increased inspiratory effort, and fatigue if the process persists."

However, because compliance is low, a large increase in transpulmonary pressure may produce only a limited increase in lung volume. The infant, therefore, performs a large amount of work for a relatively small mechanical gain. Clinically, this appears as retractions, increased inspiratory effort, and fatigue if the process persists. Retractions reflect the infant's attempt to lower pleural pressure and increase transpulmonary pressure. Grunting reflects a different but related strategy: the infant partially closes the glottis during expiration to raise expiratory alveolar pressure, preserve end-expiratory transpulmonary pressure, and maintain lung volume between breaths.

Respiratory support in RDS primarily increases alveolar pressure. CPAP and PEEP raise end-expiratory P^A, thereby increasing baseline P^L and improving functional residual capacity. Once the lung is better recruited, the infant no longer needs to generate the same degree of negative pleural pressure with each breath. As a result, pleural pressure swings become smaller, work of breathing decreases, and respiratory distress improves. This explains why appropriate distending pressure can reduce retractions even when the applied pressure appears modest.

The equation also explains why the infant's condition can change rapidly after surfactant administration. Before surfactant, the same applied pressure may produce limited lung expansion because the lung is stiff and poorly compliant. After surfactant, lung compliance improves. The same P^A may now generate a much larger volume response. In other words, the measured pressure may not have changed, but its mechanical effect has changed substantially. What was previously appropriate support may become excessive support after compliance improves.

"This is a key reason de-escalation is often needed after surfactant. Improved chest expansion, better oxygenation, and reduced work of breathing may indicate successful recruitment, but they may also signal that the previously required pressure is now more than the infant needs."

This is a key reason de-escalation is often needed after surfactant. Improved chest expansion, better oxygenation, and reduced work of breathing may indicate successful recruitment, but they may also signal that the previously required pressure is now more than the infant needs. If applied pressure is not reduced, transpulmonary pressure may become excessive, leading to overdistension, air leak, impaired venous return, increased pulmonary vascular resistance, or reduced cardiac output.

Bedside Signs Interpreted Through the Equation:

Bedside signs should be interpreted according to which part of the equation the infant is attempting to modify.

Retractions reflect increased negative pleural pressure. When the chest wall retracts, the infant is attempting to lower Ppl and increase P^L. This is most consistent with a low-volume or under-recruited state, especially when accompanied by poor aeration, low functional residual capacity, hypoxemia, or radiographic atelectasis. In this setting, retractions indicate that the infant is trying to increase transpulmonary pressure to open the lung.

Grunting reflects an attempt to preserve alveolar pressure during expiration. By narrowing the glottis, the infant slows expiratory flow and maintains higher end-expiratory P^A. This preserves end-expiratory P^L and helps prevent alveolar collapse. Grunting can therefore be understood as a form of self-generated PEEP. It is most often seen when the infant is trying to maintain functional residual capacity in the setting of low lung volume or surfactant deficiency.

Prolonged expiration suggests a different mechanical problem. Instead of trying to recruit the lung, the infant may be trying to empty the lung. This is more consistent with overdistension, air trapping, or expiratory flow limitation. In this situation, the problem is not insufficient transpulmonary pressure but excessive effective distension or impaired lung emptying. The infant requires more time to reduce lung volume before the next breath.

Active abdominal effort during expiration also suggests an attempt to reduce distending pressure and facilitate emptying.

By increasing abdominal and pleural pressure, the infant makes Ppl less negative or more positive. This reduces P^L and promotes lung deflation. This pattern is more consistent with excessive lung volume or air trapping than with simple under-recruitment. It is physiologically different from retractions, which are an inspiratory strategy to make pleural pressure more negative.

"Reduced inspiratory excursion requires careful interpretation. It may occur because the infant is fatigued and can no longer generate an adequate decrease in pleural pressure. In that situation, P^L fails to rise sufficiently during inspiration. However, reduced excursion may also occur when the lung is already overdistended and additional pressure produces little additional volume change."

Reduced inspiratory excursion requires careful interpretation. It may occur because the infant is fatigued and can no longer generate an adequate decrease in pleural pressure. In that situation, P^L fails to rise sufficiently during inspiration. However, reduced excursion may also occur when the lung is already overdistended and additional pressure produces little additional volume change. The same bedside sign may therefore reflect either inadequate effort or excessive baseline distension. The equation reminds the clinician to interpret excursion in the context of lung volume, oxygenation, carbon dioxide clearance, chest radiography, ventilator graphics, and hemodynamic response.

A sudden increase in respiratory effort may indicate an abrupt loss of effective lung expansion. This may occur with air leak, worsening atelectasis, dislodgement of respiratory support, or sudden change in lung mechanics. In the case of pneumothorax, the pleural pressure environment is disrupted. The infant may respond by generating greater negative pleural pressure to restore the pressure gradient across the lung. Retractions in this setting are not simply evidence of ordinary RDS; they may represent an attempt to overcome a disrupted pleural space.

Oxygenation and Carbon Dioxide Through the Equation:

Gas exchange depends not only on the presence of pressure but on the appropriateness of transpulmonary pressure. If P^L is too low, alveoli collapse, oxygenation worsens, and ventilation may become inadequate. Hypercapnia may occur because tidal volume is insufficient or because too few alveoli participate in ventilation.

However, excessive P^L can also impair gas exchange. When the lung is overdistended, pulmonary blood flow may be reduced, dead space may increase, and carbon dioxide clearance may worsen despite high airway pressures. Oxygenation may also deteriorate if overdistension compromises perfusion or reduces cardiac output.

Therefore, hypoxemia or hypercapnia should not be inferred solely from airway pressure. High pressure does not always indicate adequate ventilation, and low pressure does not always indicate inadequate support. The more useful question is whether transpulmonary pressure is insufficient, excessive, poorly distributed, or disrupted.

"Excessive transpulmonary pressure can affect the cardiovascular system. As lung volume increases and intrathoracic pressure rises, venous return may decrease. Pulmonary vascular resistance may increase because overdistended alveoli compress pulmonary capillaries. Cardiac output may decrease. These effects are especially important in preterm infants, infants with poor myocardial reserve, and infants with pulmonary hypertension or transitional circulation."

Hemodynamic Effects of Excessive Transpulmonary Pressure:

Excessive transpulmonary pressure can affect the cardiovascular system. As lung volume increases and intrathoracic pressure rises, venous return may decrease. Pulmonary vascular resistance may increase because overdistended alveoli compress pulmonary capillaries. Cardiac output may decrease. These effects are especially important in preterm infants, infants with poor myocardial reserve, and infants with pulmonary hypertension or transitional circulation.

When respiratory support is escalated, improvement in oxygenation must therefore be weighed against signs of overdistension or hemodynamic compromise. If blood pressure worsens, perfusion declines, oxygen requirement rises despite higher pressure, or carbon dioxide clearance deteriorates, the possibility of excessive transpulmonary pressure should be considered. In that setting, further escalation may worsen the problem. De-escalation, reduction of distending pressure, adjustment of tidal volume, or correction of expiratory flow limitation may be more appropriate.

Pleural Pressure, Air Leak, Effusion, and Suction:

Pleural interventions also fit within the same equation because they act on Ppl. A pneumothorax or pleural effusion changes the pleural pressure environment and interferes with normal lung expansion. Drainage helps restore the lung's ability to expand by removing air or fluid from the pleural space.

Chest tube suction lowers pleural pressure. This can increase

transpulmonary pressure and promote lung re-expansion when air or fluid is preventing normal expansion. However, excessive negative pleural pressure may also increase the distending gradient across the lung. In the setting of an active air leak, excessive suction may increase flow across the fistula and potentially perpetuate the leak. Thus, pleural suction is not separate from ventilatory management. It is another way of changing the same pressure gradient.

"This is why ventilator settings and pleural suction should be interpreted together. Increasing airway pressure raises P^A. Increasing suction makes Ppl more negative. Both can increase P^L. If both are excessive, the infant may be exposed to a high distending gradient even if each intervention appears reasonable in isolation."

This is why ventilator settings and pleural suction should be interpreted together. Increasing airway pressure raises P^A. Increasing suction makes Ppl more negative. Both can increase P^L. If both are excessive, the infant may be exposed to a high distending gradient even if each intervention appears reasonable in isolation.

Escalation and De-escalation of Support

The transpulmonary pressure equation provides a practical way to organize management decisions.

When transpulmonary pressure is inadequate, the infant is usually attempting to increase it. Retractions, grunting, low lung volume, atelectasis, rising oxygen need, and inadequate ventilation may suggest that baseline P^L is too low. In this setting, support may need to be escalated by increasing alveolar pressure with CPAP, PEEP, or mean airway pressure, or by appropriately delivered positive-pressure ventilation. The goal is not simply to increase ventilator numbers but to restore functional residual capacity and reduce the infant's need to generate large negative pleural pressure swings.

When transpulmonary pressure is excessive, the infant may show signs of overdistension, impaired emptying, hemodynamic compromise, or worsening ventilation despite high pressures. Prolonged expiration, active abdominal expiratory effort, hyperinflation, reduced venous return, or increasing carbon dioxide despite apparently strong support may indicate that the lung is overdistended or unable to empty effectively. In this setting, the appropriate response is de-escalation or adjustment of support, not further escalation. This may include reducing distending pressure, lowering tidal volume, adjusting inspiratory time or expiratory time, reassessing PEEP or mean airway pressure, and evaluating for air trapping or air leak.

When the pleural pressure environment is disrupted, as in pneumothorax or pleural effusion, the problem is not simply too little or too much airway pressure. The pleural space itself must be corrected. Drainage, appropriate suction, and coordination with ventilator settings are needed to restore a functional transpulmonary pressure gradient without worsening lung injury.

"The transpulmonary pressure equation provides a unified framework for interpreting neonatal respiratory physiology. It explains why the lung responds to the difference between alveolar and pleural pressures rather than to airway pressure or respiratory effort alone. Although P^A and Ppl are not directly measured in routine neonatal care, the equation remains useful as a conceptual bedside tool."

Summary

The transpulmonary pressure equation provides a unified framework for interpreting neonatal respiratory physiology. It explains why the lung responds to the difference between alveolar and pleural pressures rather than to airway pressure or respiratory effort alone. Although P^A and Ppl are not directly measured in routine neonatal care, the equation remains useful as a conceptual bedside tool.

Retractions reflect an attempt to make pleural pressure more negative and increase transpulmonary pressure. Grunting reflects an attempt to preserve alveolar pressure and maintain end-expiratory lung volume. Prolonged expiration and active abdominal effort suggest an attempt to reduce excessive distension or promote lung emptying. Sudden increases in effort may indicate loss of effective lung expansion or disruption of the pleural pressure environment.

The central clinical question is whether transpulmonary pressure is inadequate, excessive, disrupted, or unevenly distributed. Effective management follows from this interpretation. Escalation is appropriate when the lung is under-recruited and transpulmonary pressure is insufficient. De-escalation is appropriate when transpulmonary pressure is excessive, leading to overdistension, air trapping, or hemodynamic compromise. Pleural interventions must be understood as part of the same equation because suction changes pleural pressure and, in turn, alters the pressure gradient across the lung.

By focusing on the direction and physiologic meaning of the pressure gradient, clinicians can interpret bedside respiratory signs more accurately and tailor support to the infant's actual mechanical state.

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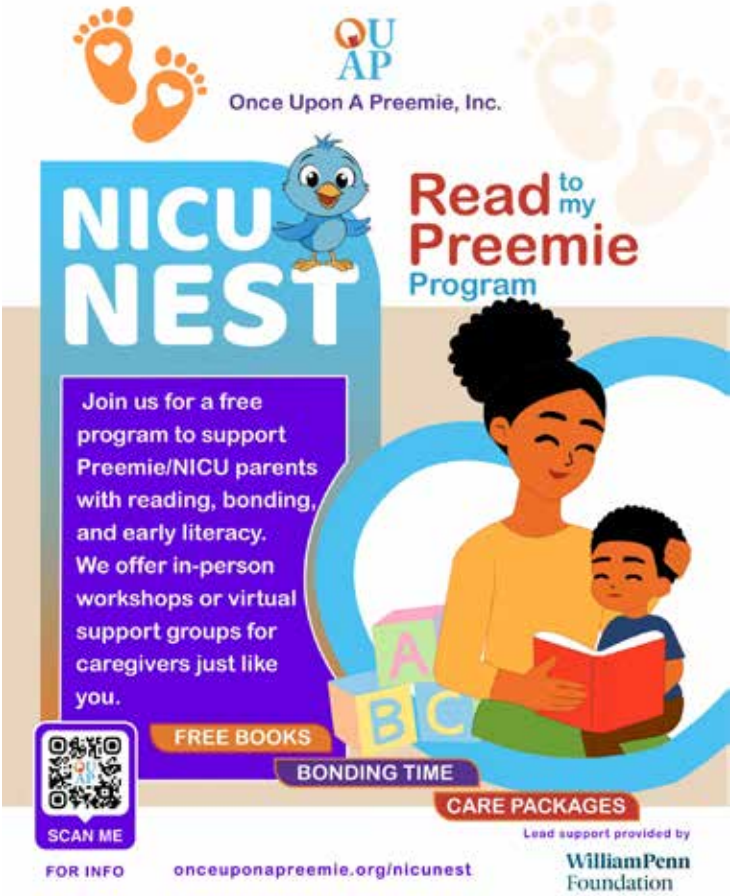

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Hyperfocus, Distraction and Situational Awareness: Blinded by the Plight

Rob Graham, RRT, NRCP

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

"Whether it is the remote, the keys, the cell phone, or the purse/wallet, the consequences are minor. Maybe you are a bit late for work, or you miss the start of your favorite show (does anyone even watch live TV anymore!?), but when a similar situation occurs in an unforgiving environment that demands full attention, consequences may be anything but minor. Aviation is a prime example. Medicine is another."

How many times have you exclaimed to someone in complete exasperation, "I've looked everywhere, and I just can't find it!", only to have them pick up said item (clearly in your line of sight) and ask, "Is this what you're looking for?"? Or, similarly, spotted it, plainly visible, hours after giving up the search? It happens to us all. We reassuringly say, "You'll find it as soon as you stop looking for it!" because our own experience validates the statement.

Whether it is the remote, the keys, the cell phone, or the purse/wallet, the consequences are minor. Maybe you are a bit late for work, or you miss the start of your favorite show (does anyone even watch live TV anymore!?), but when a similar situation occurs in an unforgiving environment that demands full attention, consequences may be anything but minor. Aviation is a prime example. Medicine is another.

Watershed Moments: improvements bought with blood

EAL-401

On December 29, 1972, Eastern Airlines Flight EAL-401 crashed in the Florida Everglades outside Miami. The plane was an almost-new Lockheed "Tri-Star" L-1011, registration N310EA, the model having been introduced into commercial service by Eastern Airlines in April, 1972, on the New York JFK to Miami route.

The L-1011, Lockheed's last passenger airliner, was described as "decades ahead of its time". It was the most modern, sophisticated aircraft in commercial service at the time. It was equipped with a host of avionics firsts, including the capability for fully automated flight from takeoff to landing, an early version of "fly-by-wire" control systems, and many flight augmentation systems that contributed in no small way to its being beloved by pilots and passengers alike. The L-1011 was incredibly reliable, and nearly bankrupted Lockheed. (Delays and development problems at engine supplier Rolls-Royce allowed rivals McDonnell-Douglas DC-10 and Boeing 747 to capture most of the market share for wide-bodied jets. Rolls-Royce declared bankruptcy as a result, before the L-1011 even began commercial service.)

So what happened? On its final approach into Miami after an unremarkable flight from New York, the nose landing gear position indicator light failed to illuminate after the landing gear was deployed. As is the case in most catastrophic accidents, this was the first of a series of events that led to the crash. The pilots did not fully understand the plane's sophisticated dual autopilot systems.*

"So what happened? On its final approach into Miami after an unremarkable flight from New York, the nose landing gear position indicator light failed to illuminate after the landing gear was deployed. As is the case in most catastrophic accidents, this was the first of a series of events that led to the crash. The pilots did not fully understand the plane's sophisticated dual autopilot systems."*

After activating the autopilot and setting the "altitude hold" feature at 2000 feet, the plane entered a holding pattern to allow the crew to investigate the problem as directed by air traffic control (ATC). While bending and reaching over to assist the first officer in removing the lens cover of the non-illuminated indicator, a threshold pressure of 15 pounds was exerted on the control column, causing the altitude hold to switch off. Due to the dual system's design, disengagement of altitude hold may not have been indicated on both sets of instruments, and since the autopilot had not been completely disabled, no warning sounded. Other flight control parameters were handled by the system, so the gradual descent was not felt. Completing the picture was a featureless landscape on a moonless night; it was so dark that the flight engineer sent into the electronics bay below the cockpit to inspect the nose gear visually could see nothing. (It appears the nosewheel well light meant to assist in visual verification of gear position was either not working, had not been turned on by

the Captain, or was not properly activated by the flight engineer.)*

Just over 6 minutes after notifying ATC of their problem, a half-second chime sounded, indicating that the altitude had deviated by more than 250 feet from the selected altitude.* No one in the cockpit heard it. In this aircraft's configuration, the continuously flashing amber warning light accompanying this chime is disabled below 2500 feet.* ATC noticed an indicated altitude of 900 feet on their radar seconds before inquiring about the flight's status, one minute and two seconds after the unheard warning chime, nothing was said that would cause the flight crew to check the plane's altitude.* Seven seconds later, the pilot initiated a turn to bring the plane back to final approach after indicating intentions to and receiving permission from ATC. Eighteen seconds later, the first officer noted the discrepancy between their selected altitude and the plane's actual altitude. Two seconds later, the Captain realised they were not at 2000 feet. Three seconds after that, the first of a series of radio altimeter warning beeps sounded, followed 2 seconds later by the sound of the aircraft striking the ground, as recorded on the cockpit voice recorder. It was traveling at an airspeed of 197 knots (226.7 mph, 364.84 kph) (1).

To spool up to takeoff power from flight idle would have taken the L-1011 5 seconds (2). Had the initial altitude warning chime been heard, or if ATC had drawn attention to the plane's altitude, no crash would have occurred. By the time the Captain saw what had happened, there was insufficient time to climb out. From the identification of a problem, it took only eight minutes and seven seconds to end 101 lives.

"Had the initial altitude warning chime been heard, or if ATC had drawn attention to the plane's altitude, no crash would have occurred. By the time the Captain saw what had happened, there was insufficient time to climb out. From the identification of a problem, it took only eight minutes and seven seconds to end 101 lives."

UA-173

In a hauntingly similar incident, on December 28, 1978, a McDonnell-Douglas DC-8-61, tail number N8082U, operating as United Airlines flight UA-173, crashed into a residential neighbourhood in Portland, Oregon. Upon lowering the landing gear on approach to Portland, the crew heard an unusually loud thump and felt a jolt as the gear descended. The first officer, who was piloting the plane, noticed a brief yaw (an aircraft's orientation on the horizontal plane) to the right, which he corrected. The left main landing gear and nose gear position lights both illuminated green, indicating a lowered and locked condition, but the right main gear indicator light did not illuminate, and a "landing gear unsafe" warning was illuminated.

What happened? The Captain was concerned that there may be a problem that could lead to a landing gear failure. ATC was informed at 17:12:20 PST that the flight intended to remain at 5000 feet and maintain 170 knots and wished to remain in contact with approach control rather than transfer to tower control. They were cleared to 5000 feet and at 17:14:43 given a heading to place them in a holding pattern to sort out their problem.

The crew spent the next 23 minutes discussing options and emergency procedures, checking secondary indicators of proper landing gear status (visible on the wings), and liaising with the cabin crew. The wing-top landing gear indicators showed proper deployment and locking.* They also contacted United Airlines maintenance in San Francisco and advised them of their problem, what they'd done, and that the cabin crew was preparing for an emergency evacuation. At that time, the Captain reported a fuel level of 7000 pounds, and that he would remain in a holding pattern for another 15-20 minutes so as not to "rush the girls" in their task of preparing the passengers. Maintenance asked whether this time frame was okay, and the Captain replied that it was. (The holding pattern kept the aircraft within 20 nautical miles (23 miles, 37km) of the airport.)

Commercial passenger aircraft are required to maintain a minimum amount of reserve fuel: enough to fly 45 minutes at normal cruise speed at an altitude of 25000 feet, or enough to hold at a clean speed (minimum safe speed with gear and flaps fully retracted) at an altitude of 5000 feet. The United Airlines operations manual for the DC-8 indicates a fuel requirement of 7800 pounds to "hold clean" at 5000 feet, with 8400 pounds required to maintain minimum landing reserve.

The Captain spent a few minutes discussing the state of preparation and crash-landing/evacuation procedures with the lead flight attendant. At 17:46:52, the first officer asked the flight engineer about their remaining fuel, and was told that about 5000 pounds remained. Two minutes later, the first officer asked the Captain about their fuel, to which the Captain replied, "5000 pounds." Shortly thereafter, the 5000 pounds estimate was validated by the fuel pump lights blinking, which occurs at the 5000 pounds fuel remaining level.*

"Two minutes later, the first officer asked the Captain about their fuel, to which the Captain replied, "5000 pounds." Shortly thereafter, the 5000 pounds estimate was validated by the fuel pump lights blinking, which occurs at the 5000 pounds fuel remaining level."*

The crew continued to discuss the landing gear situation until 17:50:20, when the Captain asked the flight engineer about the fuel status, requesting another 15 minutes of flying time. The flight engineer expressed his concern, stating that 15 minutes would leave them dangerously low on fuel. Shortly thereafter, he gave the fuel situation: 3,204 pounds. The plane was 18 nautical miles (20.71 miles, 33.34 km) south of the airport. At 17:51:35, the Captain asked the flight engineer to contact the United Airlines

representative in Portland and apprise them of the situation and that they would be landing with about 4,000 pounds of fuel remaining. The procedures and preparedness at the airport were discussed, and at 17:53:30, UA Portland operations asked if they'd be landing about 5 after. The Captain confirmed the arrival time. They were now 17 nautical miles (19.56 miles, 31.48km) south of the airport on a northeasterly heading.

At 17:55:04, the flight engineer announced the completion of the approach checklist, and just under 2 minutes later, the first officer asked the flight engineer how much fuel they had. The answer was 3000 pounds, 1000 in each of the 3 tanks.* The flight engineer was sent to the passenger cabin at 17:57:21 to check on preparations, and the Captain and first officer spent the next few minutes discussing procedures during landing, what to expect from braking, and giving the cabin crew ample time to prepare. At 18:01:34, the flight engineer reported the cabin would be fully prepared in 2-3 minutes. They were now 5 nautical miles (5.75 miles, 9.26km) southeast of the airport, turning to a southwesterly heading.

"At 17:55:04, the flight engineer announced the completion of the approach checklist, and just under 2 minutes later, the first officer asked the flight engineer how much fuel they had. The answer was 3000 pounds, 1000 in each of the 3 tanks.*"

The captain and flight engineer briefly discussed how the passengers were feeling until 18:02:22, when the flight engineer stated they had 3000 pounds of fuel remaining. They were now still 5 nautical miles south of the airport on a southwesterly heading. A brief reiteration of landing procedures was given, and at 18:02:44, Portland approach asked for a status report, which was given, and Portland was asked to have equipment standing by. At 18:03:14, the Portland approach asked when their approach would commence. The Captain replied that they were almost done in the cabin and that the approach would begin in 3-5 minutes. Recall that 1 minute earlier, the Captain was informed they had 3000 pounds of fuel remaining. They were now 8 nautical miles (9.2 miles, 14.82km) south of the airport on a southwesterly heading (heading away from the airport).

At 18:06:19, the lead flight attendant entered the cockpit and told the crew that they were ready. They were now 17 nautical miles (19.56 miles, 31.48 km) south of the airport, still on a southwesterly heading. At 18:06:40, the Captain said, "Okay, we're going to go in now; we should be landing in about 5 minutes." At the same time, the first officer stated that they had just lost the number 4 engine and told the flight engineer to "get some cross-feeds open there or something". At 18:06:46, he told the Captain they would lose an engine. Incredulously, the Captain asked why. At 18:06:49, the Captain was informed they were going to lose an engine, and he asked again why. The first officer responded, "Fuel."

The next few seconds on the cockpit voice recorder revealed confusion amongst the flight crew, and at 18:07:06 the first officer stated that the engine had flamed out. The Captain contacted Portland approach control requesting approach clearance "now". They were now in a left turn 19 nautical miles (21.86 miles, 35.19km) south-southwest of the airport, and were immediately given vectors for a visual approach.

"The next few seconds on the cockpit voice recorder revealed confusion amongst the flight crew, and at 18:07:06 the first officer stated that the engine had flamed out. The Captain contacted Portland approach control requesting approach clearance "now". They were now in a left turn 19 nautical miles (21.86 miles, 35.19km) south-southwest of the airport, and were immediately given vectors for a visual approach."

The following direct transcript of the cockpit voice recorder reveals the growing sense of desperation in the cockpit:

From 1807:27 until 1809:16, the following intra-cockpit

conversation took place:

18:07:27 - Flight Engineer: "We're going to lose number three in a minute, too."

18:07:31 - Flight Engineer: "It's showing zero."

Captain: "You got a thousand pounds. You got to."

Flight Engineer: "Five thousand in there... but we lost it."

Captain: "Alright."

18:07:38 - Flight Engineer: "Are you getting it back?"

18:07:40 - First Officer: "No number four. You got that cross-feed open?"

18:07:41 - Flight Engineer: "No, I haven't got it open. Which one?"

18:07:42 - Captain: "Open 'em both--get some fuel in there. Got some fuel pressure?"

Flight Engineer: "Yes, sir."

18:07:48 - Captain: "Rotation. Now she's coming."

18:07:52 - Captain: "Okay, watch one and two. We're showing down to zero or a thousand."

Flight Engineer: "Yeah"

Captain: "On number one?"

Flight Engineer: "Right"

18:08:08 - First Officer: “Still not getting it.”

18:08:ll - Captain: “Well, open all four cross-feeds.”

Flight Engineer: “All four?”

Captain: “Yeah.”

18:08:14 - First Officer: “Alright, now it’s coming.”

18:08:19 - First Officer: “It’s going to be on approach, though.”

Unknown Voice: “Yeah.”

18:08:42 - Captain: “You gotta keep ‘em running.”

Flight Engineer: “Yes, sir.”

18:08:45 - First Officer: “Get this. . .on the ground.”

Flight Engineer: “Yeah. It’s showing not very much more fuel.”

18:09:16 - Flight Engineer: “We’re down to one on the totalizer. Number two is empty.”

18:09:21 Captain: (to ATC) “United, seven three is going to turn toward the airport and come on in.” (Portland approach cleared visual approach)

18:10:17 -- Captain “reset that circuit breaker momentarily. See if we get gear lights.” (The flight engineer complied with the request.)

18:10:47 - Captain requested the flight’s distance from the airport. Portland approach responded, “I’d call it eighteen flying miles.”

18:12:42 -- Captain made another request for the distance. Portland Approach responded, “Twelve flying miles.” (The flight was then cleared to contact Portland tower.)

18:13:21 -- Flight engineer: “We’ve lost two engines, guys.”

18:13:25 – Flight Engineer: “We just lost two engines - one and two,”

18:13:38 – Captain: “They’re all going. We can’t make Troutdale.” (a small general aviation airport on the final approach path to runway 28L.)

First Officer: “We can’t make anything.”

18:13:46 -- Captain to First Officer, “Okay. Declare a mayday.”

18:13:50 -- First Officer: “Portland tower, United one seventy-three heavy, Mayday. We’re -- the engines are flaming out. We’re going down. We’re not going to be able to make the airport.”

(This was the last radio transmission from Flight 173.)

Less than 2 minutes later, the plane crashed into a wooded section of a Portland suburb, about 6 nautical miles (6.9 miles, 11.11km) east-southeast of the Portland airport. 10 people were killed, 23 suffered serious injuries, and, remarkably, 156 escaped with no or minor injuries.

The plane destroyed a house during the crash and landed on another. Fortunately, both were unoccupied. The plane avoided several occupied houses and apartment complexes in the area and crossed a street, severing telephone and high-tension wires. There were no ground casualties, and despite 5 of the 10 emergency exits being unusable and one partially obstructed, all were evacuated in 2 minutes. With no fuel remaining, there was no fire.

The National Transportation Safety Board investigation revealed that the bolt atop the right landing gear assembly rod was corroded and had separated, allowing the right landing gear assembly to free-fall. This is why the gear deployment sounded louder than usual: because the right gear was momentarily down before the left, the drag from it briefly yawed the aircraft to the right. The landing gear, while damaged, was found to be locked into place. The missing bolt would have prevented the landing gear from retracting, but it would not have affected its performance during landing. Indeed, the DC-8 manual indicates that if a landing gear lever down/landing gear unsafe condition exists, landing may commence at the Captain’s discretion upon secondary confirmation of landing gear status, which the crew had provided. There was no reason to remain in a holding pattern once gear down and locked confirmation was made.

“Less than 2 minutes later, the plane crashed into a wooded section of a Portland suburb, about 6 nautical miles (6.9 miles, 11.11km) east-southeast of the Portland airport. 10 people were killed, 23 suffered serious injuries, and, remarkably, 156 escaped with no or minor injuries.”

There may also have been confusion among the crew about what the fuel gauges were showing. One set required a multiplier of 100 to obtain the actual level, while another used a multiplier of 1000; as best as could be determined, the gauges were accurate. Be that as it may, the aircraft entered a hold at 17:14:43. 45 minutes of “clean hold” would give them until 17:59:43 *at the latest* to land with the minimum required fuel reserve, but *only if they had 8400 pounds of fuel at 17:14:20.* At 17:40:47, the Captain reported having 7000 pounds of fuel remaining. It was estimated that at the time the aircraft entered the hold, they had about 13,334 pounds of fuel. So far so good. At 17:49, 5000 pounds of fuel were reported to be remaining.

What the crew failed to take into account was that they were not holding clean but had the landing gear extended and the flaps at 15 degrees, not fully retracted. The added drag *doubled* their fuel consumption, so 8400 pounds of fuel would have given them 22.5 minutes of safe holding time, not 45. At a burn rate of 220 pounds/minute, they had a maximum of 1 hour of flight time when they entered the holding pattern. The plane’s engines flamed out right on schedule. Unfortunately, it was not the flight crew’s schedule.

Experienced and capable crews operated both flights, yet 111 lives were lost. Experience does not bestow infallibility in the cockpit, nor in a hospital.

NTSB recommendations

EAL-401

Two major recommendations emerged from the NTSB's investigation.

1 – A switch for the inspection light be installed in the nose gear well, and a sign or placard be installed near the optical sight explaining the operation thereof.

2 – The level hold deactivation light be modified in all Eastern Airlines L-1011 aircraft such that it operates continuously regardless of flight level.

Noting that all 3 members of the flight crew (and an additional flight engineer in the cockpit, not actively involved in the plane's operation) were preoccupied with the landing gear situation, it blamed the crash predominantly on pilot error.

The crash of EAL-401 is widely credited with major reforms in commercial aviation, namely the concept of cockpit crew resource management, now an integral part of pilot training.

"What the crew failed to take into account was that they were not holding clean but had the landing gear extended and the flaps at 15 degrees, not fully retracted. The added drag doubled their fuel consumption, so 8400 pounds of fuel would have given them 22.5 minutes of safe holding time, not 45."

UA-173

Once again, pilot error was cited as the primary cause of the crash, compounded by the fact that the 2 other members of the flight crew either failed to appreciate the gravity of the fuel issue or failed to communicate it adequately to the Captain.

The NTSB made the following recommendations:

1 -- "Issue an Operations Alert Bulletin to have FAA inspectors assure that crew training stresses differences in fuel-quantity measuring instruments and that crews flying with the new system are made aware of the possibility of misinterpretation of gauge readings. (Class II—Priority Action) (A-79-32)"

2 – "Emphasize to engineering personnel who approve aircraft engineering changes or issuance of Supplemental Type Certificates the need to consider cockpit configuration and instrumentation factors which can contribute to pilot confusion, such as the use of similar-appearing instruments with different scale factors. (Class II--Priority Action) (A-79-33)"

3 -- "Audit Supplemental Type Certificate SA3357 WE-D for completeness, especially in the area of system calibration after installation. (Class II--Priority .4ction) (X-79-33)"

4 -- "Issue an operations bulletin to all air carrier operations inspectors directing them to urge their assigned operators to ensure that their flightcrews are indoctrinated in principles of flightdeck resource management, with particular emphasis on the merits of participative management for captains and assertiveness training for other cockpit crewmembers. (Class II, Priority diction) (X-79-17)"

"Once again, pilot error was cited as the primary cause of the crash, compounded by the fact that the 2 other members of the flight crew either failed to appreciate the gravity of the fuel issue or failed to communicate it adequately to the Captain."

It is a hard-and-fast rule in aviation that someone is designated to monitor the aircraft's flight status at all times, including when the autopilot is engaged. The crew of EAL-401 did not assign this duty; this single action would have saved 101 lives. Aviate-Navigate-Communicate, and never allow the plane to go anywhere you have not already anticipated 10 minutes before.

Another hard rule in aviation (and one that we **MUST** improve upon in medicine) is to speak up and voice concerns. It is the monitoring pilot's duty to take control of the aircraft if the pilot flying fails to respond safely and appropriately. Rigid, military-style "top-down" command structures crash planes. They also kill patients.

Both of these incidents are reenacted in "Mayday" episodes. EAL-401 in Season 5 Episode 9 "Fatal Distraction" (https://www.youtube.com/watch?v=h1byJCeuyu4), and UA-173 in Season 12 Episode 8 "Focused on Failure" (https://www.youtube.com/watch?v=D_0K4c7Iha4).

Parts from the doomed L-1011 of EAL-401 were cannibalised and used in several other Eastern Airlines L-1011s. An urban legend has it that crews and passengers of planes with transplanted parts reported seeing the ghosts of EAL-401 crew members. The alleged sightings stopped when Eastern Airlines removed the parts from EAL-401. This story is told in the book "The Ghost of Flight 401" (4).

The reader may be wondering what my impetus for writing this column was. Not long ago, a baby under my care was very challenging to ventilate. Everyone involved in caring for this patient was engrossed in pulmonary issues and what to do with ventilatory parameters. Even the radiologist reviewing the baby's X-ray arrow marked up the position of an umbilical line, when right beside it was a feeding tube that had quite obviously perforated the esophagus and traveled into the peritoneal space. It was not until the nurse in charge that shift came in and announced the baby had a perforated esophagus that any of us noticed. A fresh set of eyes may see the obvious that another is blind.

Public Service Announcement

Federal regulations require all passengers to be able to evacuate a plane with more than 44 seats in 90 seconds. This is because

fuel vapors may reach a flashpoint within 2 minutes after a crash, completely engulfing the cabin in flames and rapidly filling it with extremely toxic, debilitating smoke and gases. One breath of this mixture is all it takes to incapacitate a person.

"Not long ago, a baby under my care was very challenging to ventilate. Everyone involved in caring for this patient was engrossed in pulmonary issues and what to do with ventilatory parameters. Even the radiologist reviewing the baby's X-ray arrow marked up the position of an umbilical line, when right beside it was a feeding tube that had quite obviously perforated the esophagus and traveled into the peritoneal space. It was not until the nurse in charge that shift came in and announced the baby had a perforated esophagus that any of us noticed. A fresh set of eyes may see the obvious that another is blind."

PLEASE! God forbid any of you ever have to evacuate an aircraft in an emergency, but if you do, ***leave everything behind!!!*** Your belongings can be replaced. Taking them with you ***may result in the deaths of those behind you***!

* Indicates a point at which the crash could have been avoided. Can you determine how?

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NT

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The Indirect Impact of **RSV**

NCfIH National Coalition for Infant Health
Protecting Access for Premature Infants through Age Two

OVERVIEW

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

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

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

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

RSV PARENT SURVEY

340 parents who had at least 1 child sick with RSV

67% of parents said their child was hospitalized for RSV

RSV HEALTH CARE PROVIDER SURVEY

175 health care providers across various pediatric and neonatal subspecialties

67% worked in an outpatient facility

33% worked in a hospital

RESULTS

FINANCIAL BURDEN

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

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

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

EMOTIONAL BURDEN

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

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

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

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

SOCIAL BURDEN

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

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

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

RESULTS

PARENT EDUCATION & AWARENESS

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

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

TREATMENT CHALLENGES

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

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

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

MISCONCEPTIONS

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

CONCLUSION

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

The virus may lead to:

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

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

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

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

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

A Commentary on Dr.Segal Hathi's Seeking a New Model of Maternal and Infant Care Delivery in Oregon Modeled Using Finland's Approach

T. Allen Merritt, MD, MHA, MBA, Mikko Hallman, MD, PhD, Sture Andersson, MD, PhD

"'Nine months of medical care, then almost nothing,' Oregon's Health Authority Director Sejal Hathi, M.D., wrote of her own experience as a new mother in a New York Times op-ed on May 25, 2026, to raise awareness of deficiencies in postpartum care for mothers of newborns, whether born healthy at birth or requiring NICU care."

"Nine months of medical care, then almost nothing," Oregon's Health Authority Director Sejal Hathi, M.D., wrote of her own experience as a new mother in a New York Times op-ed on May 25, 2026, to raise awareness of deficiencies in postpartum care for mothers of newborns, whether born healthy at birth or requiring NICU care. Her scathing analysis of the current model for providing for women's healthcare following the birth of her child should be a "wake-up" call for obstetricians; however, it has implications that include changing our current model of providing health care services for both infants and their mothers, including those infants requiring neonatal intensive care.

In her opinion editorial, Dr. Hathi, an internist, describes how pregnant women in the U.S. receive nine months of relatively intense supervision from Obstetricians, but "then she has the baby — and the system moves on." There is scant follow-up with mothers, who often face depression as well as physical issues such as vaginal tears separating their abdominal muscles, Hathi wrote. Further, mothers with problems during breastfeeding or having urinary incontinence from vaginal tears have relatively little medical care focused on their needs. She experienced these gaps in care firsthand, writing that "... the general OB clinic was stretched so thin it had stopped scheduling new postpartum patients. My primary care physician said postpartum recovery was outside her scope." Dr. Hathi noted she was required to "assemble[d] my own care: researching my symptoms, calling pelvic floor therapists, coordinating referrals." She added. "I am a physician who runs her state's health agency. I had good insurance, paid leave, and a fluency with institutions most new mothers should never need. What I did not have was a single provider who could serve as a quarterback for my care."

Dr. Hathi has called for revamping the prevailing model of care, including reimbursements, to treat "mother and infant as a single unit of care, both clinically and financially, through the first year of life." Soon after she began as Director of the Oregon Authority, she noted that the state's high rate of health insurance coverage did not translate into meaningful access to care. When she first moved to Oregon to start her job in early 2024, the earliest she could schedule a primary care check-up was 13 months away, according to her initial calls to providers. Even with the good news for maternal health, all states except one (Arkansas) have extended Medicaid postpartum coverage from 60 days to a full year after birth by September 2026. However, coverage is not the same as ensuring that mothers and their babies receive coordinated medical care. She proposes a model of care that treats mother and infant as a single unit of care, both clinically and financially, through the first year of life. This could start by having both maternal and pediatric services in the same location, or, in the case of an infant in a NICU, maternal care could be coordinated as part of Perinatal/Obstetric care within the same institution. Having neonatologists/pediatricians and other services in the same location, such as midwives, lactation consultants, mental health counselors, and pelvic floor therapists, within pediatric or perinatal units that often provided her obstetrical care, should provide a seamless model of care for her infant and her mother's health care needs. She notes, "better still would be taking advantage of babies' built-in schedule of check-ups to screen both mother and baby for common conditions at the same visit, such as screening for postpartum depression and lactation consultants available to assist mothers when needed." She notes that this model of care has existed in Finland for years and has improved maternal and infant health, which is the envy of most countries.

"She notes that this model of care has existed in Finland for years and has improved maternal and infant health, which is the envy of most countries."

Dr. Hathi suggests paying for both maternal postpartum care and pediatric collaborative services as a single unit of care (as is routine in Finland). "We should design a model that treats mother and infant as a single unit of care, both clinically and financially, through the first year of life." However, she notes that paying for collaboratives will require health system changes and a shift in how health care is delivered as a joint responsibility. She noted that in Finland, both mothers and infants are treated in public maternity clinics, and the same public health nurse provides care for both in the early years.

Mother's recovery from delivery, continued breastfeeding, and

ongoing emotional support matter as much as her newborn's growth and development. For infants requiring NICU care, Neonatal/Perinatal care offers a unique opportunity to provide care and, in addition, to reassure terrified parents that the mother's health care needs are being met and, if not, to arrange for the mother's care. Even when infants are transported to a Level III/IV unit, maternal care needs can be assessed and appropriate referrals made for the mother's ongoing medical care. Many training programs in Neonatal/Perinatal Fellowship emphasize that maternal care, as well as care for her infant, should be a priority in Neonatal/Perinatal practice. While most Neonatologists are not trained in Obstetrics, they may serve as a conduit for improved maternal care within their own health system or another. An opportunity exists in Neonatal Intensive Care units to endorse a philosophy of Family Centered Care, with greater vigilance for the health of mothers of infants requiring neonatal intensive care, while advocating for mothers of infants for whom they are providing care. An important contributor to Finland's success is that the maternal health care system in which Finnish women receive their pregnancy and postpartum care has been described as a decentralized network of primary health centers that serve local communities that markedly differs from the infrastructure of the U.S., which comprises medical centers and clinics rather than a community-based health care network that includes home visit by nurses, pediatric care for infants, and obstetrical/midwifery care for mothers. In Finland, the vast majority of normal vaginal deliveries are handled by midwives, not obstetricians. Obstetricians only deliver or assist with a fraction of the total babies, typically stepping in for roughly 20% of births that require medical intervention, such as cesarean sections or complex instrumental deliveries (2, 3, 4).

"However, she notes that paying for collaboratives will require health system changes and a shift in how health care is delivered as a joint responsibility. She noted that in Finland, both mothers and infants are treated in public maternity clinics, and the same public health nurse provides care for both in the early years."

A breakdown of Finland's maternity landscape highlights:

- **Total Deliveries:** Finland sees around 40,000 to 45,000 births annually. (3) and similar to Oregon's annual births.
- **Midwife-Led Care*:** The vast majority of care during the birthing process—even in hospitals—is midwife-led, contributing to Finland's world-renowned, low-intervention maternity metrics. (4)
- **Cesarean Sections:** The C-section rate in Finland hovers around 15% to 20%, meaning obstetricians are directly performing these surgical procedures. (4)
- **Instrumental Deliveries:** Obstetricians are also present and active during operative vaginal deliveries (like vacuum or forceps extractions), which account for another roughly 9-10 % of births. (4)
- *Midwives are certified by the Finnish Government and are similar to Certified Nurse Midwives in Oregon in terms of credentialing

The Finnish system has been associated with the lowest maternal and neonatal mortality rates worldwide, and its approach to maternal and infant care should be emulated by states seeking to improve their own systems.

"As Director of the Oregon Health Authority and the Oregon Health Plan (Medicaid), Dr. Hathi has significant influence over funding for maternal and infant care in Oregon. How she implements this newer model of care in Oregon will serve as a testing ground for it in the U.S. For many families, bringing a child home from the hospital is only the beginning of a new stage of care."

As Director of the Oregon Health Authority and the Oregon Health Plan (Medicaid), Dr. Hathi has significant influence over funding for maternal and infant care in Oregon. How she implements this newer model of care in Oregon will serve as a testing ground for it in the U.S. For many families, bringing a child home from the hospital is only the beginning of a new stage of care. After discharge, parents and caregivers may suddenly be responsible for managing supplies, learning new routines, communicating with providers, and coordinating with various medical offices and durable medical equipment suppliers to ensure their child has the products needed by both new mothers and infants. This transition can feel overwhelming, especially for families caring for children with ongoing medical needs or mothers with health problems owing to complications of pregnancy or delivery.

"The Finnish care model ties compensation for maternal and infant healthcare to a packaged fee paid to community-based programs or hospitals, which has proven highly effective and lower-cost in Finland (3). "

This model of health care includes care for both mothers and their infants, involving communication among providers and coordination of services among several healthcare providers

within community health centers (2) and University Hospitals. The Finnish care model ties compensation for maternal and infant healthcare to a packaged fee paid to community-based programs or hospitals, which has proven highly effective and lower-cost in Finland (3).

Dr. Hathi's concept of coupled maternal and infant care as a single unit of care for Oregon, and perhaps other states, may offer a model for improved care at lower cost by combining the two as a "unit of care." According to InfoFinland, infant care and postpartum care are described in Table I (4).

Table I.

Hospital Discharge and At-Home Care:

After giving birth, mothers and newborns typically spend 2 to 3 days in the maternity ward. Before returning home, the baby receives standard health checks, including hearing and metabolic screenings. Once home, the continuity of care is seamless: [

- **Follow-up at Home: Within 1 week of leaving the hospital, the same public health nurse who oversaw your prenatal care will visit you at home, give you a telephone call, and, when necessary, e.g.,** with your firstborn baby, a nurse will visit you at home.
- **Health Assessments:** The nurse checks the baby's weight gain, umbilical cord healing, and general well-being, and screens the mother for postpartum recovery and mental health.

Maternity and Child Welfare Clinics (*Neuvola*)

Postpartum care is fully integrated into Finland's municipal healthcare system and is virtually free.

- **Vaccinations & Growth:** Newborns are closely monitored through routine appointments at the local child welfare clinic (lasten neuvola) until age 6.
- **Postpartum Check-up:** Around 6 to 12 weeks after birth, the mother attends her own postpartum follow-up to ensure physical and psychological recovery.
- **Support System:** Clinics offer ongoing guidance on breastfeeding, sleep, and adjusting to parenthood, providing a crucial safety net for new families.

The Maternity Package (*Äitiyspakkaus*)

Every expectant parent in Finland who attends prenatal check-ups early in their pregnancy is eligible for the iconic Baby Box.

- **What's Included:** The box includes over 40 essential items, including clothing, bedding, diapers, and baby care products.
- **Safe Sleep:** The box is designed to serve as a newborn's first bed.
- **Cash Alternative:** Parents also have the option to receive a tax-free cash grant (currently valued at around €170) (~$200 U.S.) instead of the physical box.

Parental Leave

Finland offers one of the most generous parental leave systems in the world, heavily promoting dual-earning and co-parenting:

- **Allowance:** Both parents are entitled to a combined total of roughly 320 paid parental leave days.
- **Flexibility:** The leave can be divided equally between parents, with quotas specifically designed to encourage partners to take time off with the newborn.

Actionable Resources

To explore or register for these services, check the following official platforms:

- **Kela**: Finland's social security institution, where you apply for the baby box and parental allowances.
- InfoFinland: An official guide detailing municipal health services, interpreter options, and registration procedures for families.

"From a Finnish perspective, even with serious cuts to social programs, the public is nearly unanimous (regardless of political party) against any cuts to health benefits for mothers and children. The combination of general pregnancy and childhood follow-up (äitiys- ja lastenneuvola) is most satisfying to the public."

From a Finnish perspective, even with serious cuts to social programs, the public is nearly unanimous (regardless of political party) against any cuts to health benefits for mothers and children. The combination of general pregnancy and childhood follow-up (äitiys- ja lastenneuvola) is most satisfying to the public.

Finnish politicians and Universities believe that it is key to effective disease prevention during pregnancy and childhood. According to mothers, families, and the public, continuous contact with the same high-quality health care workers during pregnancy, infancy, and early childhood is key to success. This practice is both effective and cost-effective, saving significant resources.

Postpartum problems of the mother, as well as follow-up and instructions for the early life of the child and family, are interactive events, as most health care needs can be addressed without more costly specialty care within the same facility. The 'Neuvola' personnel, including health care workers, particularly

nurses with special education and supervising doctors (mostly pediatricians or general practitioners), are experienced and able to pick up more serious medical

problems for referral when needed. As a result, the child or the mother is effectively referred to appropriate diagnostics and treatment. In this way, the system reimburses the costs incurred by delayed medical treatment, inadequate referrals, or the lack of essential screening and prevention programs for the entire population.

Oregon has been a national innovator in health care delivery. There are current challenges to the delivery of maternal care in Oregon, with 8.3% of the state having maternity care deserts. Nearly half of Oregon's rural hospitals are at risk of closing or reducing obstetric services due to low delivery volumes, rising costs, and challenges

in recruiting and retaining obstetricians. These family physicians wish to provide obstetric services, and nurse-midwives in rural areas of Oregon. The Governor, the Oregon Legislature, the Oregon Health Authority, and the Hospital Association of Oregon have committed to investing millions of dollars to sustain rural care in Oregon and boost maternity and infant care payments (5). Dr. Hathi's disappointing postpartum care is documented in her editorial. Her suggestion of adopting a model more like that in Finland, with community-based clinics/hospitals providing for regional maternity and infant care using tele-maternal-fetal medicine consultation for high-risk and pregnancies allowing for management of complex cases, and earlier recognition of complication during pregnancy without having to travel to urban centers, and expansion of the program of the Oregon Perinatal Collaborative that brings hands-on emergency training directly to rural hospitals, their staff, and first responders will strengthen the safety net for maternal and infant care for Oregonians living in rural areas.

"Governor Kotek, Oregon's congressional delegation, the Oregon Health Authority (OHA), directed by Dr. Hathi, and the Hospital Association of Oregon, announced recently that the Centers for Medicare & Medicaid Services (CMS) approved Oregon's proposed state-directed payment to strengthen and stabilize maternity care services in rural Oregon communities (5). By matching state funding secured by Governor Kotek, these approved federal funds will result in a total investment of up to $37.5 million for 21 rural hospitals that provide maternity services for some of Oregon›s most remote communities."

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Addendum regarding cost of care: Maternal prenatal care and children's follow-up at the welfare clinic (up to age 6) are free of charge. The daily hospital charge is currently 71.50 € (about 82 USD/day). For a normal delivery, there will be a 2-3 day charge, i.e., a total of 143-214.50€ (166-249 USD). This sum includes all care during the stay, with no extra charge for c-sections, labs, special examinations, etc.

For adults, the healthcare payment ceiling is 815 € (945 USD) per year.

Children below 18 years have a payment limit of 7 hospital days per calendar year (the rest of the year is free).

In a worst-case scenario, with the mother requiring >11 days and the newborn ≥7 days of care, the total payment would be € 1,315.50 (USD 1,526). (source Dr. Sture Andersson, Emeritus Professor, Helsinki University

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- Are the baby and family central to the mission, values, environment, practice & care delivery of IFCDC in the unit?
- Are the parents of each baby fully integrated into the team and treated as essential partners in decision-making and care of the infant?
- What are the strategies and measurements used to improve and sustain IFCDC in the unit?

POSITIONING & TOUCH FOR THE NEWBORN

- Are the positioning plans therapeutic and individualized, given the care needs and development of the baby?
- Are the positioning and touch guidelines continually reviewed by the team, including the parents, and adapted to meet the changing comfort needs of the baby?

SLEEP AND AROUSAL INTERVENTIONS FOR THE NEWBORN

- Can the team confidently describe the "voice" or behavioral communication of the baby?
- Are the baby's unique patterns of rest, sleep, and activity documented by the team and protected in the plan of care?

SKIN-TO-SKIN CONTACT WITH INTIMATE FAMILY MEMBERS

- Is the practice of skin-to-skin contact supported and adjusted to the comfort needs of each baby, parent, & family member?
- Are the parents & family members supported to interact with the baby to calm, soothe, & connect?

REDUCING AND MANAGING PAIN AND STRESS IN NEWBORNS AND FAMILIES

- Are parents supported to be present and interactive during stressful procedures to provide non-pharmacologic comfort measures for the baby?
- Are there sufficient specialty professionals to support the wellbeing of the team, including parents, families, and staff? Examples include mental health, social, cultural, & spiritual specialists.

MANAGEMENT OF FEEDING, EATING AND NUTRITION DELIVERY

- Are the desires of the m/other central to the feeding plan? Is this consistently reflected in documentation with input of the m/other?
- Does the feeding management plan demonstrate a feeding & nutrition continuum from in-hospital care through the transition to home & home care?

WANT TO KNOW MORE ABOUT THE STANDARDS AND RECOMMENDATIONS?
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National Perinatal Association: 2026 National Perinatal Association Conference in Coeur d'Alene, Idaho

Chavis A. Patterson, PhD, Pamela A. Geller, PhD, Kristy Love

The National Perinatal Association (NPA)is an interdisciplinary organization that strives to be a leading voice for perinatal care in the United States. Our diverse membership is comprised of healthcare providers, parents & caregivers, educators, and service providers, all driven by their desire to give voice to and support babies and families at risk across the country.

Members of the NPA write a regular peer-reviewed column in Neonatology Today.

National Perinatal Association

Educate. Advocate. Integrate.

"The National Perinatal Association (NPA) Board of Directors would like to thank everyone who was able to attend the 2026 conference in beautiful Coeur d'Alene, Idaho. This year, our chosen theme was Advancing Rural-Urban Collaboration and Innovation in Perinatal and Infant Health; Uniting for Impact."

The National Perinatal Association (NPA) Board of Directors would like to thank everyone who was able to attend the 2026 conference in beautiful Coeur d'Alene, Idaho. This year, our chosen theme was *Advancing Rural-Urban Collaboration and Innovation in Perinatal and Infant Health; Uniting for Impact*. Based on feedback from you—attendees, presenters, and exhibitors—we are thrilled to share that the conference was a resounding success.

With a distinguished lineup of speakers across disciplines and specialty areas, as well as parent presenters, our goal was to introduce information to help foster rural and urban collaborations to advance perinatal and infant health, improve access to medical and psychosocial care in healthcare deserts, and offer examples of innovative technology and new models of care. We heard from many phenomenal speakers who traveled from as close as Washington state and as far as Florida, Pennsylvania, and Texas.

Zed Zha, MD, FAAP, opened the conference by sharing a personal story from her childhood, accompanied by artwork that illustrated her experiences. As a baby, Dr. Zha was labeled by doctors as "brain-damaged." Her life began in a locked hospital unit awaiting adoption, only to be "kidnapped" by her mother. Dr. Zha shared key elements of her life and current work that highlighted the range of challenges experienced by those living in rural communities.

In line with our conference theme, some of our presenters highlighted the use of technology to support rural and other communities. For example, Rachel Umoren, MB, ChB, MS, outlined ways to partner using tele-neonatology to improve outcomes in hospital settings, including remote areas, where there may not be specialists available onsite. She shared sample videos to demonstrate how this innovative approach can assist neonatal providers effectively and expeditiously.

Across our three-day conference, we showcased four incredible panels, each with a different focus. One panel entitled *Rural Innovation and Collaboration in the Inland Northwest* was presented by Katie Barcus-Kuka, MS CCC-SLP, Shari DePaulo, MSW, LICSW-A, PMH, Kimberley Polfer, Julie A. Wolter, PhD, CCC-SLP, and Liz Ann Morris, SMS, CCC-SLP (Moderator). They discussed the challenges faced by Native Americans in the Pacific Northwest regarding perinatal healthcare services, as well as the values, customs, and support that promote connection and wellbeing in these communities.

"In line with our conference theme, some of our presenters highlighted the use of technology to support rural and other communities. For example, Rachel Umoren, MB, ChB, MS, outlined ways to partner using tele-neonatology to improve outcomes in hospital settings, including remote areas, where there may not be specialists available onsite. She shared sample videos to demonstrate how this innovative approach can assist neonatal providers effectively and expeditiously."

The second panel spotlighted three NICU parent-led organizations - *Today is a Good Day* (Martha Sharkey), *NICU Alumni*

(Andrea Hickson), and *Hand to Hold* (Katrina Moline) - who offer in-person and virtual care to support families who have had or currently have a baby in the NICU. Each spoke about the forward-thinking work they are enacting in the community so that families do not have to experience the NICU journey alone. They also shared their thoughtful plans for service expansion.

The third panel included members of NPA's National Network of NICU Psychologists (Victoria Bacon, PhD; Brooke Yancey-Ward, PsyD; Brittany Hinkle-Salandy, PhD; Celeste Poe, PhD, PMH-C (Moderator) who discussed the value and importance of providing perinatal and NICU mental health services for all families across urban and low-resourced settings.

The fourth panel included leaders of three perinatal mental health intensive outpatient programs (IOPs), including *Piper Perinatal IOP* in Denver, CO, directed by Karen Longenecker, LCSW, PMH-C, IMH-E; *Anchor Perinatal Wellness in Chapel Hill, NC,* directed by Roxanne Rosenberg, LCHMC, PMH-C; and *Mother Baby Connections* at Drexel University in Philadelphia, PA, directed by Pamela A. Geller, PhD (Moderator). They discussed the value of introducing these intermediate levels of care in both rural and urban settings to address the high prevalence of postpartum depression and anxiety, including suicidality; the types of programming offered; and recommendations on how to build a program. Each panelist described their program and then outlined the steps they took to build and sustain it.

To invigorate student participation in NPA, Pamela A. Geller, PhD, and Brigette Desport, DPS, OTR/L, BCP, ATP, with the virtual assistance of Jerry Ballas, MD, gave an historical account of the National Perinatal Association Study Society (NPASS) and how an institution can go about establishing its own group. They announced that the NPA Board will be offering consultation to support the initiation of new programs.

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This year, we had another outstanding group of poster presentations, with nearly 40 posters highlighting approaches that supported rural communities. One of our newly adopted annual activities was an oral speed round of selected poster presentations on the main stage. Each presenter was given 10 minutes to share details of their project. These "flash talks" provided an excellent overview of some amazing work being conducted across the country. Based on peer review, four poster presenters were selected to receive NPA poster awards that included complementary registration for NPA's 2027 conference. Winners included the following:

- Sonia Torres, BSN, RN, for the *Policies & Initiatives* category for her poster entitled, "Mapping Needs, Building Equity: Preparing Mama Bexar for Rural Expansion."
- Daphne O. Darmanwan, MD, MBS, for the *Models of Care* category for her poster entitled, "Sound Therapy as an Innovative Model of NICU Care in Rural India."
- Seema Jacob, PsyD, for the *Original Research* category for her poster entitled, "Integrating Mental Health Support in the NICU: Early Lessons from a Quality Improvement Pilot."
- Madonna Ezeji for the newest category, the *Student Poster* award, for her poster entitled, "Examining Racial Bias in Patient-Provider Communication: A Review of Literature on Black Maternal Health."

We hope that during your time with us, you were able to network with fellow attendees, exchange ideas, and build meaningful connections. Additionally, we trust you had the chance to explore and enjoy the unique charm of Coeur d'Alene.

Your engagement and enthusiasm made this conference a memorable experience, and we are truly grateful for your support. Please know that your presence and active participation contributed greatly to the success of our event, and your excellent feedback is helping to shape our 2027 conference.

NPA certainly would not have been able to bring you this conference without our outstanding sponsors: Angel Eye, Keenova, Prolacta, and Sage Therapeutics/Biogen.

We look forward to staying connected, and we encourage you to attend our next conference on March 3-5, 2027, in St. Louis, MO, when we will be celebrating NPA's 50th year!

Next year's theme is ***Artificial Intelligence vs. Intelligence Amplified: Empowering Families with Knowledge through Connection and Technology.***

Thank you once again for being a part of this special event!

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Ethics and Wellness: Belonging: You are Welcome to Ask is Not an Invitation

Mitchell Goldstein, MD, MBA, CML

"There is a subtle but important distinction that many people seem determined to ignore: the difference between being told that you are welcome to ask and being invited. The two are often treated as interchangeable, but they are not."

There is a subtle but important distinction that many people seem determined to ignore: the difference between being told that you are welcome to ask and being invited. The two are often treated as interchangeable, but they are not. They communicate different intentions, create different expectations, and leave people with very different understandings of where they stand.

When someone says, "You're welcome to ask," they are offering permission. They are acknowledging that a request can be made. What they are not doing is expressing any particular desire regarding the outcome. Being allowed to ask is procedural. It is the bureaucratic equivalent of a shrug. It signals nothing about desire, nothing about inclusion, nothing about value. It is permission without endorsement—a hallway with the lights off. You may walk down it, certainly. Just do not expect anyone to greet you at the end. The answer may be yes. The answer may be no. The statement itself reveals nothing about what the person hopes will happen. It merely indicates that the question is not forbidden. (1)

"You may walk down it, certainly. Just do not expect anyone to greet you at the end. The answer may be yes. The answer may be no. The statement itself reveals nothing about what the person hopes will happen. It merely indicates that the question is not forbidden. (1)"

An invitation is fundamentally different. An invitation is not passive; it is active. It signals interest, desire, and intent. It communicates that someone's presence is not simply permissible but wanted. An invitation says, "We see you. We thought of you. We would like you to participate. We believe you belong here." It removes uncertainty rather than creating it. An invitation is directional. It carries intent. Confusing the two is not a minor semantic error—it is a convenient distortion that lets gatekeepers avoid accountability. (2)

Nevertheless, people blur the distinction between these two concepts. Perhaps this confusion is convenient. It allows individuals and institutions to appear welcoming without actually extending a welcome. It permits them to claim openness while avoiding the responsibility that comes with genuine inclusion.

How often have we heard some variation of the phrase, "Well, you could have asked"? It is usually offered as evidence that no exclusion occurred. The implication is that the person who was not invited bears some responsibility for their absence, having failed to seek permission to participate. However, this argument misses the point entirely. The issue is rarely whether participation was technically possible. The issue is whether participation was desired.

"The implication is that the person who was not invited bears some responsibility for their absence, having failed to seek permission to participate. However, this argument misses the point entirely. The issue is rarely whether participation was technically possible. The issue is whether participation was desired."

Most people understand this intuitively. We recognize the difference between being chosen and being tolerated. We know the difference between receiving an invitation and learning afterward that attendance would have been allowed if only we had inquired. The emotional experience is entirely different because the message being conveyed is entirely different. Although this concept has been mapped to perceived social strata, other markers of worthiness matter as well; individual self-esteem suffers. (3)

This is particularly true in professional settings, where invitations often carry significance beyond the immediate event or opportunity. Whether it involves joining a committee, participating in a project, contributing to a publication, speaking at a conference, or assuming a leadership role, an invitation communicates value. It tells the recipient that others considered them, sought them out, and concluded that their participation would be beneficial.

By contrast, being told that one could have asked places the burden entirely on the individual. It requires them to approach a situation without knowing whether their presence would be welcomed, merely tolerated, or quietly resented. It asks them to assume the social and professional risk of seeking entry into a space where they were not initially included. For those already inside the room, this distinction may seem trivial. For those standing outside, it can be profound. (1)

"It requires them to approach a situation without knowing whether their presence would be welcomed, merely tolerated, or quietly resented. It asks them to assume the social and professional risk of seeking entry into a space where they were not initially included."

Human beings are remarkably sensitive to signals of belonging. We spend our lives interpreting them. We understand when our presence is desired and when it is merely accepted. Although many people prefer to dismiss these realities as matters of ego or oversensitivity, they are deeply rooted in the way human relationships function, especially in self-esteem. (4) The absence of exclusion does not create belonging. It is created through intentional acts of inclusion.

"Human beings are remarkably sensitive to signals of belonging. We spend our lives interpreting them. We understand when our presence is desired and when it is merely accepted. Although many people prefer to dismiss these realities as matters of ego or oversensitivity, they are deeply rooted in the way human relationships function, especially in self-esteem. (4)"

That is why invitations matter. An invitation removes ambiguity. It replaces uncertainty with clarity. It allows the recipient to enter a space knowing that their presence has been requested rather than merely permitted. It establishes a foundation of mutual respect that permission alone cannot provide.

Of course, there are circumstances in which the distinction between asking and being invited becomes less important. In healthy organizations and healthy relationships, people often feel comfortable expressing interest, volunteering, or seeking opportunities without fear of embarrassment or rejection. In such environments, asking and being invited may frequently lead to the same result.

However, not all environments function this way. In many situations, the absence of an invitation conveys information. It reflects a decision, whether conscious or unconscious, about who was considered and who was not. Pretending otherwise does not eliminate the message. It simply obscures it behind a veneer of politeness.

"There are also circumstances in which someone is genuinely not wanted in a particular space. Not every committee can be expanded indefinitely. Not every project requires every participant."

There are also circumstances in which someone is genuinely not wanted in a particular space. Not every committee can be expanded indefinitely. Not every project requires every participant. Not every event can accommodate everyone who might be interested. There is nothing inherently wrong with making choices about participation. The problem arises when people refuse to acknowledge those choices honestly.

Instead, they retreat into the language of procedural openness. They point out that nobody was explicitly excluded. They note that questions could have been asked and that requests could have been made. While these statements may be technically true, they often avoid the more meaningful question: would the request have been welcomed?

That question lies at the heart of the distinction. Permission concerns the possibility. Invitation concerns desire. Permission says, "You may ask." The invitation says, "We hope you will join us." Permission leaves the initiative entirely in the hands of the outsider. An invitation reflects the effort by those already inside. One communicates tolerance; the other communicates belonging. In a sense, "opting in or opting out" parallels this distinction. (5) Directionality matters.

"The tendency to conflate these concepts reflects a broader discomfort with candor. Genuine invitations create accountability because they require people to make clear choices about whom they value and whom they wish to include."

The tendency to conflate these concepts reflects a broader discomfort with candor. Genuine invitations create accountability because they require people to make clear choices about whom they value and whom they wish to include. Simply allowing others

to ask avoids that responsibility while preserving the appearance of openness. The result is a culture in which many individuals find themselves wondering not whether they could participate, but whether they are wanted. (6) Those are not the same question, and treating them as such only deepens confusion and resentment.

Ultimately, people are far more perceptive than many leaders, organizations, and social groups seem willing to acknowledge. (3)They understand the difference between being welcomed and being tolerated. They understand the difference between being sought out and being allowed in. Most importantly, they understand that the absence of an invitation often carries meaning, even when others insist that it does not. (7)

"The solution is not complicated. If someone's participation is desired, invite them. If it is not, do not disguise indifference as generosity. Furthermore, if someone was never invited, resist the temptation to suggest that the outcome would have been the same had they asked, because it would not have been."

The solution is not complicated. If someone's participation is desired, invite them. If it is not, do not disguise indifference as generosity. Furthermore, if someone was never invited, resist the temptation to suggest that the outcome would have been the same had they asked, because it would not have been.

Permission is not inclusion. Tolerance is not belonging. Access is not a welcome. And being told that you are free to ask is not, and never will be, the same thing as being invited. (1)

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Navigating toward Neonatology: Interview with Dr. Cindy McEvoy

Benjamin Hopkins, DO, Cindy McEvoy, MD, MCR

"Welcome back to another installment. My name is Benjamin Hopkins, and I am currently a post-graduate year two pediatric resident at the University of California, San Francisco—Fresno. 'When I grow up, I want to be a Neonatologist.' Look at previous months' journals for my earlier articles, and follow along with this column as I navigate my way to becoming a neonatologist."

Welcome back to another installment. My name is Benjamin Hopkins, and I am a post-graduate year two pediatric resident at the University of California, San Francisco—Fresno. 'When I grow up,' I want to be a Neonatologist. Look at previous months' journals for my earlier articles and follow along with this column as I navigate my way to becoming a neonatologist.

I had the privilege of speaking with Dr. Cindy McEvoy, a practicing neonatologist, the Director of Child Health Research, and the Director of Neonatal Research at Oregon Health and Science University. We discussed her journey into neonatology, what makes an excellent neonatologist, what future neonatologists should prioritize, and her current academic and research projects.

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1. **What qualities are most essential to excel as a neonatologist?**

A good neonatologist is somebody who never stops learning and asking questions. Our patients are incredibly complex, and they're becoming more complex, especially as we lower the limit of viability, or get patients where we're intervening more often when they have complex fetal anomalies. Even with everything we know, we're always presented with situations at the bedside that don't neatly fit what we think or know, so the best clinicians are those who stay curious about what they see there.

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That's why I still love to work at the bedside even though I do a lot of research. Much of my research is informed by the questions that come up at the bedside, so bench-to-bedside and bedside-to-bench. Our field is unique because we can use those bedside observations as a starting point for questions and potential discoveries, such as oxygen needs, feeding intolerance, developmental outcomes, and respiratory outcomes, which allows us to go to the bench and back in translational studies.

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2. **What would you encourage a future neonatologist to prioritize and be involved in?**

The physiology of our patients is so unique. Having a priority of trying to build a deep understanding of the physiology while trying to get yourself as engaged as possible clinically, trying to increase your exposure to anything neonatology-focused. I encourage potential trainees to seek out experiences in translational and bench research, which can give them a different perspective on questions they might encounter at the bedside. It helps them move past questions like "What do I do next?" to questions like "Why is this happening?" and "Is there a better way to approach this?"

Get exposure to the nursery and some hands-on experience; going back to deliveries really solidifies the unique physiology happening right in front of your eyes. Partake in the procedures that are often incorporated into the practice. Even though the opportunities aren't quite as many as they used to be, if you make yourself available, you can avail yourself of those.

Another critical thing is to seek out good mentors; they can really help you think about your career. They can shape how you

approach problems, how you ask questions, and give you advice on how you can grow over time. Mentors can see certain qualities in people that you might not see in yourself.

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3. Should we track medical students toward neonatology because of the reduced opportunities to interest pediatric residents in the field?

We discuss this at our faculty level quite frequently. Reaching out to them, teaching some of their medical school classes, bringing them through the nursery, and sharing with them success stories that have happened. Speak with individuals who have been in the field for a while and can offer a perspective on the progress we've made and the questions we still have. Work to get them interested in the science, the pathophysiology, and the opportunity that still exists to make great strides in this area.

You need to capture learners' attention and excitement early. This is difficult because you need people who are focused on teaching in neonatology. You need teachers who will see something in someone when they say, "I might be interested," and they scoop you up. Then there's some self-selection among individuals who prefer hospital-based practices to outpatient clinics. I think that becomes pretty obvious to people during their training. However, the NICU can be a very intimidating environment, unless you've had exposure.

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4. What caused you to pursue a career in neonatology?

My path to neonatology really started during my pediatric residency, and that's also when I became interested in research. As a resident, I was lucky enough to get involved in a project one of our respiratory therapists was working on in collaboration with the parents of a set of premature triplets. As a parent of a premature triplet, he was very interested in the oxygenation patterns and also had a computer background. So, he developed this program to perform computerized analysis of pulse oximetry patterns, which at the time was quite novel. We examined the different patterns of intermittent hypoxemia, characterized and looked at those in preterm infants with evolving bronchopulmonary dysplasia. Then we looked at various interventions to reduce these episodes. I got excited about the research, and it's interesting because that question is still here. "What are episodes of intermittent hypoxemia? How should we be treating them?" It was a good question that we had even back then and a very difficult one to solve.

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For my fellowship, I chose a very high-volume, high-intensity training environment: LA County General Hospital. We had about 18,000 deliveries and 4 neonatology fellows covering all the calls. You can imagine it was very busy; we saw and did a lot, and it solidified my interest in clinical investigation. There were a large number of patients and extensive pathophysiology. I was able to ask many clinical questions, participate in clinical trials, and publish papers during my fellowship, which allowed me the opportunity to present those results at national meetings. One of my mentors was dually trained in neonatology and pediatric pulmonology, so I learned to perform neonatal pulmonary function tests and have continued that skill throughout my career. It's allowed me to quantify the physiologic responses to different medications we give to both preterm and term infants and to examine the perinatal origins of childhood lung disease through these pulmonary function tests, so it was a natural sequence of events.

5. What are you currently working on?

I have the good problem that I'm very busy, which is great. I have had NIH funding for about 20 years. Currently, I have two funded projects and a third that I'd like to fund, as I received a very good score. I focus on the perinatal origins of childhood respiratory health and disease and emphasize primary prevention that starts early. A major area in which I've worked is conducting two randomized trials in collaboration with investigators at the Oregon Primate Research Center.

Based on their foundation work, we randomized pregnant women who couldn't quit smoking to receive vitamin C or a placebo, and we found that the moms who received vitamin C seemed to protect their babies' lung development. It showed improved pulmonary function tests at 3 and 12 months, and at 5 years of age after delivery. We're now continuing to follow the most recent cohort through age 10. Currently, we're doing a high-resolution CT scan to quantify how their airways have been formed after exposure to in-utero nicotine with vitamin C.

Another study was looking at keeping stable premature babies who we would normally take off of CPAP in the NICU. We did

a randomized study where half of them stayed on CPAP for 2 more weeks, and half of them came off, which was our usual care. Then, when we studied them in the nursery and followed them up to 6 months of age, those who stayed on CPAP longer had bigger lungs at 6 months that worked better. There's evidence that mechanical distension from CPAP can stimulate lung growth and development. We're hoping that intervention in the nursery improves the trajectory of those babies' lungs and improves their lifelong lung function.

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There's no other therapy I know of in the NICU that can improve lung growth and development. Even the babies who don't have respiratory compromise when they come out, our feeders and growers, all have altered lung development. If you follow those kids after they go home, they have increased wheeze and respiratory tract infections, so those babies make up a big portion of the absolute numbers. Absolute numbers are far higher among babies born at 32, 33, and 34 weeks, who are also premature. If this therapy can improve lung and blood vessel growth and longer-term outcomes, it's a great intervention that could be life-changing.

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Long-term, when you look at the incidence of COPD throughout the world, it is increasing; it's the third leading cause of death. In the past, most investigators have thought that individuals who develop COPD are those who smoke or are exposed to different environmental toxins, which does make up part of that. However, 50% of the patients who develop COPD start low on their pulmonary function trajectory; people reach their maximum pulmonary function at about 22 years of age. If you're born preterm, you're starting at a lower level, and even if you have normal growth, you never meet your maximum potential. Just with the normal decline that we all have with age, those who were born premature are going to be more prone to developing COPD or lung disease as they age. Our former cohort of preterm infants is just reaching that age where individuals begin to manifest signs of COPD, so this is a focus now of the adult physicians to ask patients if they were born premature, which is a simple question to us, but not to adult physicians. Likewise, if you were born 30 years ago, you probably don't remember your mom saying you were premature, so I think it's about changing the paradigm.

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I'm also involved in another study as part of the Environmental Children's Health Outcome Consortium. This is a consortium across the United States composed of 50,000 moms and kids who have been followed from before delivery or right after, and we've been collecting data for about 10 years. This data examines exposure to different environmental issues, then goes one step further to examine how that exposure has impacted their health outcomes. We assess their respiratory, neurodevelopmental, obesity, and positive health trajectories—to look at these different factors, especially geocoding, environmental pollution, and wildfire effects. It's been a very rewarding experience for me to meet investigators across the country who are also following longitudinal cohorts. It's exciting to maximize data collection from cohorts, as these are the types of studies that inform protocol changes and what we recommend to the general public.

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6. What will be the next big innovation for neonatal patients?

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therapy, and of course, that's going to combine components of AI. This is going to be so important in the future of our medical treatment.

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Beyond the Incubator: Confronting the Semmelweis Reflex in the Interdependent Neonatal Intensive Care Unit

Colonel Robert Erick Ridout, U.S. Army, Retired

""Rather than being the main instigators of an accident, operators tend to be the inheritors of system defects created by designers, builders, paymasters, and managers. Their part is that of adding the final garnish to a lethal brew whose ingredients have already been long in the cooking." Dr. James Reason (1)"

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In the preceding columns of this series, "Beyond the Incubator: Growing a Culture of Interdependent Safety" and "The Nuclear Origins of Patient Safety", we established how a Neonatal Intensive Care Unit (NICU) can map its cultural evolution along the DuPont Bradley Curve, shifting from top-down "command and control" toward a resilient, interdependent ecosystem (2, 3). By examining the 1973 structural failure at Denmark›s Risø National Laboratory through the lens of Jens Rasmussen and James Reason, we explored how human fallibility naturally drifts toward an Efficiency-Thoroughness Trade-Off (ETTO), and how true safety requires building organizational layers of defense to intercept these inevitable human shortcuts.

However, as a NICU successfully matures into this Interdependent stage, where multidisciplinary teams operationalize mutual accountability, conduct safety huddles, and achieve universal RNC NICU certification, a deep-seated systemic paradox frequently emerges. While the collective unit has evolved to operate on the plane of flattened hierarchies, individual actors, particularly senior caregivers insulated by a traditional authority gradient, can remain stubbornly anchored in "The Way I Trained" (TWIT) or "How We (I) have always done it." When faced with new, evidence-based protocols that require moving from automatic, skill-based routines to exhaustive, knowledge-based analyses, these individuals often experience the **Semmelweis reflex**: an immediate, defensive rejection of empirical data that threatens their perceived clinical mastery (4, 5). This column examines the friction that occurs when an interdependent system clashes with individual cognitive entrenchment. We will explore how a single caregiver›s heuristic-driven shortcut can introduce a latent defect into an otherwise highly reliable care ecosystem.

To fully understand the destructive power of the Semmelweis reflex within an otherwise highly reliable, interdependent NICU, we must look at its origins and map it directly to the cognitive taxonomies established by Jens Rasmussen and James Reason. The term originates with Dr. Ignaz Semmelweis, a Hungarian physician who practiced in the maternity wards of the Vienna General Hospital in the 1840s. Dr. Semmelweis observed that women in the First Clinic, which was run exclusively by medical students and physicians, died of puerperal (childbed) fever at a rate three times higher than those in the Second Clinic, which midwives ran. Additionally, Semmelweis noted that the physicians and medical students would routinely conduct autopsies on victims of childbed fever and immediately proceed to the labor wards to deliver babies without performing hand hygiene. In 1847, after his close friend and colleague, Jakob Kolletschka, died of an infection following an accidental scalpel nick during an autopsy, Semmelweis recognized that "cadaveric particles" were the vector of transmission. When he mandated a strict, preventative chlorinated lime hand-washing protocol before any patient contact, the results were indisputable: mortality rates in the First Clinic plummeted from an atrocious 18% to less than 2%, eventually hitting 0% in subsequent months (6).

"Semmelweis noted that the physicians and medical students would routinely conduct autopsies on victims of childbed fever and immediately proceed to the labor wards to deliver babies without performing hand hygiene. In 1847, after his close friend and colleague, Jakob Kolletschka, died of an infection following an accidental scalpel nick during an autopsy, Semmelweis recognized that "cadaveric particles" were the vector of transmission. When he mandated a strict, preventative chlorinated lime hand-washing protocol before any patient contact, the results were indisputable: mortality rates in the First Clinic plummeted from an atrocious 18% to less than 2%, eventually hitting 0% in subsequent months (6)."

Despite empirical, quantifiable proof, the medical establishment of Europe violently and systematically rejected his findings. To understand why, we must examine the dominant medical paradigm of the era, which was anchored in the miasma theory, which is the belief that diseases were caused by the noxious exhalations of decaying organic matter or "bad air," combined with an imbalance in a patient's four bodily humors. Semmelweis's assertion that physicians' hands were mechanically transmitting a disease contradicted the leading scientific authorities of the day, including the world-renowned pathologist Rudolf Virchow, who dismissed Semmelweis›s data out of hand.

Furthermore, the establishment did not reject the data because they were indifferent to patient suffering; they rejected it because the discovery created an intolerable state of cognitive dissonance. In the 19th century, gentlemen and, by extension, upper-class clinicians were viewed as inherently clean. To accept Semmelweis›s truth meant accepting a horrific, unthinkable reality: that the clinicians themselves, through their lack of proper hygiene, had been the primary vectors of death for thousands of mothers and newborns.

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Instead of adopting the protocol, the medical community poured its energy into defensive rationalization and discrediting Semmelweis. He was ousted from Vienna General Hospital, his contracts were not renewed, and his peers in Budapest and Germany largely ignored his landmark 1861 treatise, *The Etiology, Concept, and Prophylaxis of Childbed Fever*. Overwhelmed by the systemic rejection and the ongoing, preventable loss of life, Semmelweis suffered a severe nervous breakdown. In a tragic historical irony, he was committed to an asylum in 1865, where he was severely beaten by guards and died at age 47 from the very sepsis he had spent his life trying to eradicate (7). It would take another two decades, and the independent bacteriological discoveries of Louis Pasteur and Robert Koch, for the medical community to finally validate his hand-washing protocol, proving that the establishment›s reflexive defensiveness had cost tens of thousands of lives (8).

In a modern, interdependent NICU, the Semmelweis reflex manifests not as a rejection of basic hygiene but as a rejection of systemic standardization that challenges legacy practices (TWIT: The Way I Trained). It represents the ultimate friction point between organizational maturity and individual ego. In the context of self-determination theory, clinical excellence is driven by the essential psychological nutrients of Autonomy, Competence (Mastery), and Relatedness (9, 10). While the interdependent team satisfies Relatedness through mutual accountability, the entrenched physician often derives their entire sense of Mastery and Autonomy from individual diagnostic brilliance and bespoke clinical judgment. When the unit introduces a standardized protocol, such as a rigid algorithm for enteral nutrition or strict antibiotic stewardship, the clinician's ego interprets this as an attack on clinical autonomy rather than simply a strategy to reduce clinical variation. The Semmelweis reflex acts as both psychological armor, protecting the ego, and cognitive armor, protective cognitive load. To protect their clinical autonomy, the clinician dismisses the rigid algorithm's standard work as "cookbook medicine" and retreats into the defensive silo of TWIT, operating under the flawed assumption that individual historical experience supersedes aggregated, multicenter empirical data (11, 12).

Using Jens Rasmussen›s Skill-Rule-Knowledge (SRK) taxonomy,

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we can isolate the exact cognitive mismatch that triggers this reflex during live operations. Senior clinicians are masters of efficiency; decades at the bedside allow them to operate primarily at effortless **Skill- and Rule-based levels**, utilizing rapid heuristics to manage complex patient loads. When a new protocol forces a change in practice, it abruptly demands that they ascend to the **Knowledge-based level**, which requires slow, methodical analysis and the painful synthesis of a new mental model (13). This state is characterized by high cognitive load (germane load) and mental fatigue. Here, the Semmelweis reflex serves as a cognitive escape hatch. Rather than enduring the mental exhaustion of rewriting their clinical habits, the clinician's brain invokes the Efficiency-Thoroughness Trade-Off (ETTO). They reject the new data because maintaining their legacy practice requires zero cognitive effort (14).

The ultimate danger of this reflex is that individual resistance does not occur in a vacuum; it introduces a massive latent defect into the organizational architecture. James Reason's Swiss Cheese model demonstrates that catastrophic active failures occur when systemic holes align. When an influential clinician selectively bypasses standardized protocols, they create an unapproved, highly

variable “Shadow System” within the unit (15).

This behavioral drift fundamentally undermines the unit’s psychological safety. If a bedside nurse or respiratory therapist utilizes a multidisciplinary huddle to proactively “Stop the Line” based on standard work, but is repeatedly met with a defensive, ego-driven rejection, the team-based ecosystem breaks down. The staff quickly calculates the interpersonal risk of challenging the authority gradient and stops speaking up. By silencing these frontline “sensors,” the senior clinician’s Semmelweis reflex systematically bores holes through the unit’s defensive layers, squelching the HRO principles of Deference to Expertise and Sensitivity to Operations (16, 17). The once-mature, interdependent team fragments back into a reactive posture, leaving the patient to inherit the lethal brew that is now, once again, long been cooking.

To neutralize the Semmelweis reflex, leadership cannot rely on top-down directives, which only increase defensiveness. Instead, the system must deploy Visible Felt Leadership and institutionalize a Questioning Attitude borrowed from High Reliability Organizations: **Make the Data the Authority:** Shift the focus entirely away from personal opinion. In clinical rounds, the question must never be, “What do you want to do?” but rather, “What is our prescribed standard work, and what objective bedside data verifies the patient’s actual condition?” Further, what care does the patient want to experience? (18) **Protect the Nutrients of Self-Determination Theory:** Frame adherence to evidence-based protocols not as a loss of clinical autonomy, but as the ultimate expression of collective Mastery and Relatedness, ensuring the team-based care is only ever delivering care that adds value. (10) **Empower the Cross-Check:** Ensure that the unit›s “Andon Cord” mechanisms are so structurally sound that even the most junior member of the care team can safely intercept a clinician’s cognitive drift, forcing a pause before the garnish of human error can ever be added to the patient’s care (19).

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Ultimately, the transformation of a Neonatal Intensive Care Unit into a highly reliable, interdependent ecosystem cannot endure if individual cognitive entrenchment undermines the collective architecture. The Semmelweis reflex remains a potent threat to modern medicine. The psychological armor of individual clinical autonomy and the cognitive escape hatch of reducing germane load naturally resist the friction of prescribed standardization. When senior caregivers retreat into the low-effort heuristics of “The Way I Trained,” they do not merely reject data; their practice increases the number and size of holes in James Reason›s layers of defense, blinding the unit›s frontline operational sensors and dismantling its psychological safety. Neutralizing this rigid reflex requires a deliberate shift from personal authority to objective, standard work, reframing collective compliance as the highest expression of shared mastery. Only by unleashing psychological safety, such as via an uncompromised ‘Andon Cord,’ can an organization flatten the traditional authority gradient. In doing so, we ensure that a mature, interdependent safety culture is nourished and robust, and that the care team returns to the bedside fully engaged, relentlessly delivering value-added, family-centered care for the patient—not *to* the patient.

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Erick Ridout, M.D., is blessed to be a husband, the dad to two amazing kids, granddaddy to three extraordinary grandsons and two granddaughters, and currently serves the babies, their families, and the caregivers in the Newborn ICU in Southwestern Utah, the Newborn ICU in Honolulu, Hawaii, and as Vermont Oxford Network Faculty. Additionally, Colonel Ridout proudly served in the United States Army for 23 years, including 11 years as the State Surgeon for the Nevada Army National Guard. He was among the first Army Medical Corps Officers to become a Lean Six Sigma Green Belt and has applied the learned principles to relentlessly eliminate patient, staff, and organizational harm in all its forms. He has lectured nationwide on Just Culture, Harm Reduction, Value-Added Care, and Servant Leadership. He passionately believes that all patients and caregivers deserve to experience care delivery free of harm. To that end, he seeks to influence MEDICINE to embrace the principles of servant leadership and team-based family-centered care, to send all members of the care team home each day feeling Safe, Valued, and Loved, returning to the bedside fully engaged with heart and mind, all the while seeking to only do for the patient and never to the patient.

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The Village Son

A Life's Journey

Iranian village to a university professor in the United States of America in this memoir. As a boy, his unruly behavior was sedated by scholastic challenges as a remedy. At age twelve, he left home for junior high school in a provincial capital. At first, a lack of self-esteem led him to stumble, but he soon found the courage to tackle his subjects with vigor. He became more curious about the world around him and began to yearn for a new life despite his financial limitations. Against all odds, he became one of the top students in Iran and earned a scholarship to study medicine in Europe. Even though he was culturally and socially naïve by European standards, an Italian family in Rome helped him thrive. The author never shied away from the challenges of learning Italian, and the generosity of Italy and its people became part and parcel of his formative years. By the time he left for the United States of America, he knew he could accomplish whatever he imagined.

Houchang D. Modanlou

First Candle: When the System Fails Families: A Case Study in What Safe Sleep Education Must Address

Alison Jacobson

first candle

Saving babies. Supporting families.

First Candle's efforts to support families during their most difficult times and provide new answers to help other families avoid the tragedy of the loss of their baby are without parallel.

"A one-month-old baby girl in Hernando County, Florida, died last November. The medical examiner ruled it an accident — accidental suffocation due to an unsafe sleep environment. Her mother, who had DCF caseworkers in her home twice a week for three months reviewing safe sleep at every visit, was arrested this month and charged with aggravated manslaughter."

A one-month-old baby girl in Hernando County, Florida, died last November. The medical examiner ruled it an accident — accidental suffocation due to an unsafe sleep environment. Her mother, who had DCF caseworkers in her home twice a week for three months reviewing safe sleep at every visit, was arrested this month and charged with aggravated manslaughter.

Before you judge: the vast majority of us have co-slept at least once, exhausted in the middle of the night, a baby who would not settle, a body that gave out. Most parents have been there. None of us is immune to this tragedy.

"This mother knew every guideline. She could recite them back. And she still co-slept because she was a mother in recovery, raising two children under two, navigating poverty and exhaustion that no checklist accounts for. Social determinants of health are not footnotes. They are the story. Moreover, when our systems ignore them, we lose babies."

This mother knew every guideline. She could recite them back. And she still co-slept because she was a mother in recovery, raising two children under two, navigating poverty and exhaustion that no checklist accounts for. Social determinants of health are not footnotes. They are the story. Moreover, when our systems ignore them, we lose babies.

"Furthermore, the families of these babies are often navigating compounded trauma: the fear of losing a fragile infant, disrupted bonding, breastfeeding challenges, financial strain, and the particular exhaustion of caring for a medically complex newborn. For these families, the transition home can be one of the most dangerous moments of an infant's life."

A Word to the Neonatology Community Specifically:

You see this vulnerability up close. Infants who spend time in the NICU are at significantly elevated risk for SUID after discharge. Furthermore, the families of these babies are often navigating

compounded trauma: the fear of losing a fragile infant, disrupted bonding, breastfeeding challenges, financial strain, and the particular exhaustion of caring for a medically complex newborn. For these families, the transition home can be one of the most dangerous moments of an infant's life. Safe sleep education delivered in a clinical setting, at discharge, under stress, is rarely enough.

DCF followed protocol. Nevertheless, this family needed a trusted community partner, someone whose presence felt like support, not surveillance. That is what research tells us works. That is what we keep failing to provide.

"We also have to name bias and racism. Families of color and families living in poverty are disproportionately criminalized when an infant death occurs. This is true in the general population, and it is compounded for NICU families, whose contact with institutional systems is already heightened. You cannot build equitable safe sleep education while ignoring the inequitable systems that surround it."

We also have to name bias and racism. Families of color and families living in poverty are disproportionately criminalized when an infant death occurs. This is true in the general population, and it is compounded for NICU families, whose contact with institutional systems is already heightened. You cannot build equitable safe sleep education while ignoring the inequitable systems that surround it.

"Furthermore, the trauma does not end with the loss. This mother woke up to find her baby unresponsive, called for help, and was later arrested. She has now lost her child and her freedom."

Furthermore, the trauma does not end with the loss. This mother woke up to find her baby unresponsive, called for help, and was later arrested. She has now lost her child and her freedom. First responders must be trained to understand what SUID is and to provide trauma-informed care from the moment they arrive. For a NICU family that has already endured weeks or months of medical crisis, the additional trauma of criminalization in the wake of loss is devastating and, unfortunately, it is not rare.

We have to do better.

This is not an outlier. It is a pattern. Furthermore, it is exactly why First Candle's work — community-centered education, first responder training, and advocacy for equity — is critical. We invite neonatology providers and NICUs to explore a partnership with us. Trusted community-based education, beginning before discharge and continuing at home, is how we close this gap.

Learn more at www.firstcandle.org.

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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www.firstcandle.org

About First Candle:

First Candle, based in New Canaan, CT, is a 501c (3) committed to eliminating Sudden Unexpected Infant Death while providing bereavement support for families who have suffered a loss. Sudden Unexpected Infant Death (SUID), which includes SIDS and Accidental Suffocation and Strangulation in Bed (ASSB), remains the leading cause of death for babies one month to one year of age, resulting in 3,700 infant deaths nationwide per year. It was also the host of the 2025 International Society for the Study and Prevention of Perinatal and Infant Death (ISPID) Conference in Houston from October 7 – 10.

firstcandle

LET'S TALK Community Chats IN THE NICU

We are thrilled to expand our ongoing efforts surrounding safe sleep in the Grady Memorial Hospital NICU by bringing Let's Talk Community Chats to our families. This is especially important given the significantly higher rates of Sudden Unexpected Infant Death in premature babies, and to help expand our work to ensure optimal health to all babies, both in the NICU and after discharge home."

Dr. Mattie Feasel Wolf,
Division of Neonatal-Perinatal Medicine
at Emory University School of Medicine

FEEDBACK FROM LET'S TALK COMMUNITY CHATS IN THE NICU:

- **Nearly all participants (98%) reported an increase in their confidence to apply safe sleep practices, and all also found the breastfeeding information provided to be helpful or very helpful (96%).**
- **Additionally, most participant (98%) felt that the products and recommendations shared were relevant to their needs.**
- **94% percent of respondents reported having a plan for where they would place their baby to sleep upon bringing them home after attending the event.**
- **All participants (100%) shared that they felt comfortable and supported, and that facilitators respected their cultural values.**
- **Almost all participants (82%) who had specific questions indicated that their specific questions and concerns were fully addressed.**

LEARN HOW YOU CAN BRING LET'S TALK TO YOUR NICU.

Email alison@firstcandle.org or scan the QR code for more information

Peer Reviewed

Advancing Neonatal-Perinatal Care: SONPM Chair Update: June 2026

Clara H. Song, MD, FAAP

"Your more-than-monthly update from SONPM to keep us all connected and informed!"

SONPM SHOUT OUT

Drs. Melissa Buck, Karen Gluck, Gaines Mimms, Thomas Murphy, Andy Schenkman, Christopher Stryker- the organizers of neoFORUM from MANA (Mid-Atlantic Neonatology Associates). This group of conference planning mavens has been hosting the magical meeting that is **neoFORUM** for the past 17 years!

Learn More

Coding Corner Update

CHA Webinar- Recording, presentation PDF, Q/A doc. Announcement

In May, Children's Hospital Association (CHA) experts Mitch Harris, PhD, and Amber Davidson, RHIA, CCS, CCS-P, presented us with information that gave us a clearer understanding of hospital payment methodologies tailored to the NICU.

Severity Happens: Decoding APR-DRG Assignment, SOI, ROM, and CMI for the NICU

View The Recording

Neonatal-Perinatal Medicine Fellowship Training

What are you thoughts on a 2-year pediatric subspecialty training model?

- SONPM, ONTPD and AANDD are partnering to take a deep dive into the potential consequences of an 2- versus 3-year fellowship training model in neonatal-perinatal medicine.
- A millions thanks to our representatives who are leading this effort:
- ONTPD (Organization of Neonatal Training Program Directors)- Drs. Melissa Scala and Brooke Vergales
- SONPM, Dr. Shetal Shah
- AANDD (Association of Academic Neonatal Division Directors)- Drs. Misty Good and Patrick McNamara

Qualtrics Survey | abp.org

Good Read: Farewell to PGY-6? Farewell to PGY-6? Addressing the realities of pediatric fellowship training

Read the following article on Journal of Perinatology.

Authored by

Satyan Lakshminrusimha, Clara Song & Robin H. Steinhorn.

Link to Article

Good Read: Compressing neonatal-perinatal medicine fellowship training: a critical appraisal of the American Board of Pediatrics proposed 2-year pathway

Read the following article on Journal of Perinatology.

Authored by:

Brooke Vergales, Melissa Scala, Christie Bruno, Cynthia Crabtree, Megan Gray, Suma Hoffman, Courtney McLean, Deirdre O'Reilly, Vilmaris Quinones Cardona, Erynn M. Bergner, Jennifer M. Brady, Lindsay Johnston, Patrick Myers, Misty Good, Patrick J. McNamara, Sara DeMauro, John Loyd, Jill Maron, Camilia R. Martin, Steven J. McElroy, Annemarie Stroustrup, Sarah N. Taylor, Trent E. Tipple, Ravi M. Patel, Shetal Shah, Clara Song, Alexis Davis, Munish Gupta, Marilyn Escobedo & Heather French.

Link to Article

SoNPM NCE Awardees

We will proudly congratulate our **Section on Neontal-Perinatal Medicine Awardees** at the 2026 National Convention & Exhibtion in **San Diego, California** on **Saturday, October 3, 2026.**

Their contributions to neonatology will continue for years to come.

Thank you!

MARIA DELIVORIA-PAPADOPOULOS LANDMARK AWARD

Founding members of AAP SONPM Trainees and Early Career Neonatologists (TECaN)

The Maria Delivoria-Papadopoulos Landmark Award highlights a seminal contribution that transformed neonatal-perinatal practice, acknowledging achievements that have stood the test of at least 15 years.

VIRGINIA APGAR AWARD

First RCT principal investigator for whole-body hypothermia in neonatal HIE

The Virginia Apgar Award is awarded to an individual whose career has had a profound and enduring impact on the well-being of newborn infants, continuing the legacy of Dr. Virginia Apgar's transformative contributions to medicine and public health.

AVROY FANAROFF NEONATAL EDUCATION AWARD

The Avroy Fanaroff Neonatology Education Award recognizes outstanding contributions to education in our field, honoring Dr. Fanaroff's lifelong commitment to advancing knowledge of newborns and their families.

On behalf of your #SONPMexec comm:

Past Chair Munish Gupta @munishguptamd

Chair Elect Alexis Davis @AlexisDNeoMD

District 1 Rep Wendy Timpson @TimpsonWendy

D2 Shetal Shah @NICUBatman

D3 Sara DeMauro

D4 Misty Good @mistygoodlab

D5 Heather Kaplan

D6 Emily Fishman

D7 John Loyd

D8 Jessica Davidson @JessDavMD

D9 Christine Bixby

D10 Ravi Patel @ravimpatelmd

Of Counsel Marilyn Escobedo @Mokcita

AAP Sr Manager Joie Frankovich

Chair Clara Song @songMD

Clara H. Song, MD, FAAP

Neonatal Intensivist | Southern California Permanente Medical Group

Chair | Academy of Pediatrics, Section on Neonatal-Perinatal Medicine

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Disclosures: No conflicts noted

NT

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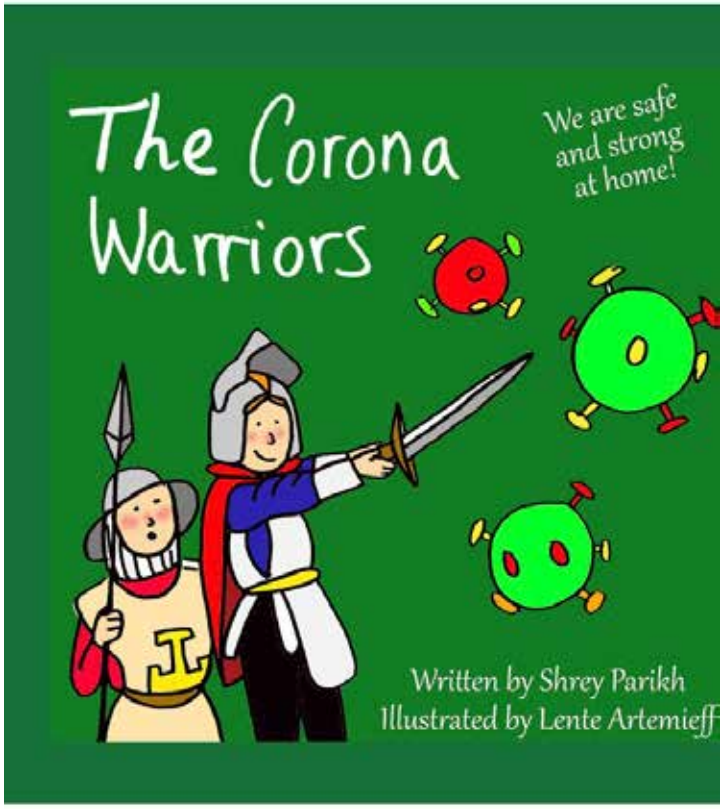
Chair, American Academy of Pediatrics, Section on Neonatal-Perinatal Medicine
Lean Six Sigma Black Belt
Email: E clara.h.song@kp.org



Request for Proposals (RFP)
AAP Chapter Grants to Advance the SONPM Fair Payment Agenda 2026–2027
Sponsored by: AAP Section of Neonatal-Perinatal Medicine (SONPM)
Application Deadline: June 30, 2026
Grant Period: September 1, 2026 – August 31, 2027

I. **Background and Purpose**
The AAP Section of Neonatal-Perinatal Medicine (SONPM) invites AAP Chapters to submit proposals that directly advance the SONPM Fair Payment Agenda. This agenda was established in response to growing concerns regarding the sustainability of neonatal practice, increasing workforce shortages, and persistent misalignment between the complexity of neonatal care and current payment structures.
Grant funding will support the development and implementation of practical, scalable tools that strengthen neonatal payment advocacy, improve coding accuracy, and promote optimized hospital and professional payments. Funded activities should empower neonatologists, neonatal advanced practice providers, trainees, and Chapter leaders with the knowledge and resources necessary to advocate effectively for fair, transparent, and sustainable payment models.

II. **Alignment with the SONPM Fair Payment Agenda**
Proposals must demonstrate clear alignment with one or more of the SONPM Fair Payment Agenda pillars:

- Payment Advocacy: Strengthening Chapter-level and clinician advocacy efforts related to neonatal payment policy, payer practices, and regulatory frameworks
- Coding Education: Improving knowledge and application of neonatal CPT, ICD-10, and documentation requirements to ensure accurate representation of care complexity
- Optimized Hospital and Professional Payments: Promoting strategies that align neonatal reimbursement with acuity, resource utilization, and quality of care delivered

III. **Funding Opportunity**
SONPM will award up to TWO (2) one-year grants of up to $6,000 each. Proposals should focus on high-impact, replicable initiatives that may be adapted by other Chapters or scaled nationally to support the Fair Payment Agenda.

IV. Priority and Eligible Activities

- Development of a neonatal payment and coding advocacy toolkit aligned with SONPM Fair Payment Agenda priorities
- Creation or expansion of Chapter-based neonatal payment, coding, or advocacy subcommittees
- Educational programming addressing neonatal documentation, coding accuracy, and payment optimization
- Workshops or webinars focused on advocacy skills related to payer negotiations, hospital alignment, or legislative issues
- Needs assessments evaluating payment and coding challenges impacting neonatal workforce sustainability
- Engagement of pediatric trainees and early career neonatologists in payment and advocacy
- education
- Collaboration with hospital administrators, coders, and revenue cycle leaders to promote
- shared understanding

V. **Allowable and Non-Allowable Expenses**
Grant funds may not be used to:

- Fund social activities outside of educational programming
- Raise general Chapter funds
- Offset expenses for activities or meetings that have already occurred

Funding limits for educational activities include:

- Speaker honoraria: maximum $2,000 per speaker
- Speaker travel expenses: maximum $700 per speaker
- Space rental: not to exceed $500 per day
- Audio-visual support: not to exceed $500 per day
- Marketing and distribution: not to exceed $5 per attendee
- Food and beverage (no alcohol): not to exceed 20% of total budget

VI**. Proposal Review and Selection Criteria**

The SONPM Executive Committee will evaluate proposals based on:

- alignment with the SONPM Fair Payment Agenda;
- potential to improve neonatal practice sustainability;
- feasibility and clarity of proposed activities;
- engagement of trainees and early career physicians; and
- consistency between the proposed activities and submitted budget.

VII. Reporting and Acknowledgment Requirements

Awardees must acknowledge the AAP Section of Neonatal-Perinatal Medicine on all materials produced. Grantees are required to submit a mid-point progress report and a final report within 30 days of the grant's conclusion. Reports must summarize activities implemented, budget expenditures, outcomes or evaluation data when available, Fair Payment Agenda pillars addressed, trainee engagement, and lessons learned. A short article highlighting the project's impact on neonatal payment advocacy is required for SONPM or Chapter communications.

VIII. Technical Assistance and Support

Each grantee will be paired with a SONPM member to provide strategic guidance related to neonatal payment advocacy and coding education. SONPM staff will also be available to provide administrative and logistical support throughout the grant period.

Submit applications to Laura Navarro at lnavarro@aap.org by **June 30, 2026**.

Call for Nominations!

Section on Neonatal-Perinatal Medicine Executive Committee: District Representatives from Districts III, VI, and IX

One of the most significant opportunities to engage with the Section on Neonatal-Perinatal Medicine (SONPM) is to serve on the SONPM Executive Committee (EC). The EC consists of one representative from each of the 10 AAP Districts, in addition to chair, chair-elect, past-chair, of-counsel advisor, and AAP section manager (currently Jim Couto). District representatives serve 3-year terms, and are eligible to serve a second term.

District representatives to the EC are responsible for representing all neonatologists working in their AAP districts. The district representative is a liaison between district neonatologists and the SONPM, providing members direct input into SONPM and conveying section activities and opportunities back to the members. More specifically, responsibilities of EC members include the following:

Within executive committee and SONPM broadly:

1. Attend two **required** EC meetings annually, at Scottsdale spring workshop and at NCE;
2. Attend the full SONPM program at Scottsdale spring workshop and NCE meetings annually;
3. Participate in periodic virtual SONPM EC meetings (generally once or twice per month);
4. Review and score abstract submissions to NCE and review poster and oral presentations at NCE meeting, including scoring for SONPM Young Investigator Award;
5. Suggest and select annual SONPM honorary lecturers, including the Cone, Merenstein, Butterfield and Silverman speakers;
6. Solicit and review nominations for annual SONPM awards, including the Apgar, Education, Landmark and Pioneer awards, and select awardees;
7. Participate in planning and execution of national meetings, including section program at NCE, Scottsdale conference, and NeoPREP;
8. Review applications and determine awardees for the Section Strategic Grant Program, currently offered every two years;
9. Review and provide feedback on AAP policy statements, clinical reports, and guidelines as they pertain to newborn care;
10. Participate in and support AAP and SONPM advocacy efforts, including AAP Days of Action;
11. Participate in section committees, groups, and task forces based on interest and need;
12. Participate in SONPM strategic leadership, including implementation of goals of strategic plan; and
13. Participate in SONPM administration, including maintenance and updating of section manual of operations and section budget planning.

Within district:

1. Solicit updates from district members for inclusion in section newsletter twice annually;
2. Allocate annual SONPM district grants by soliciting and evaluating grant proposals;
3. Provide regular updates to district members on relevant aspects of section activities;
4. Provide regular updates to section on district activities and needs of district members;
5. Actively participate in district activities, including attendance at regional conferences; and
6. Encourage AAP and SONPM membership from representative's district, including trainees.

The core executive committee is a productive group! Participation on the executive committee does require a commitment of time and effort, but it is a highly rewarding experience.

Letters to the Editor

Letter to the Editor: "Liquid Consciousness, Solid Gods: Pros and Cons of Artificial Intelligence (AI)"

June 9th, 2026.

Letter to the Editor.

We read with interest the excellent manuscript published in Neonatology Today by Sola and Goldstein, "Liquid Consciousness, Solid Gods: Pros and Cons of Artificial Intelligence (AI)," 2026;21(4):44-52.

"We consider the timing of this publication in your Journal to be fortunate, as the challenge posed by Artificial Intelligence (AI) affects more than just neonatology. The excellent April manuscript detailing the pros and cons of AI in neonatal medicine provides a vital foundation for a conversation that must urgently expand beyond clinical metrics, clinical workflows, and algorithms."

We consider the timing of this publication in your Journal to be fortunate, as the challenge posed by Artificial Intelligence (AI) affects more than just neonatology. The excellent April manuscript detailing the pros and cons of AI in neonatal medicine provides a vital foundation for a conversation that must urgently expand beyond clinical metrics, clinical workflows, and algorithms.

While AI offers undeniable promises in pattern recognition and predictive care within the NICU, its broader societal and scientific footprint presents a unique epistemic hazard: the degradation of objective reality through synthetic data and automated misinformation. edits

Very soon after Neonatology Today published this article, Pope Leo XIV and The New York Times chairman and publisher, Arthur G. Sulzberger, delivered very clear messages on May 15th and June 1st, 2026, addressing global concerns about AI, not just in the NICU, of course.

Both communications are definitely worth reading for anyone interested in the societal challenges posed by AI.

Pope Leo XIV, on May 15th, 2026, dedicated his encyclical letter, Magnifica Humanitas, given in Rome at Saint Peter's, on safeguarding the human person in the time of artificial intelligence. It is available in: https://www.vatican.va/content/leo-xiv/en/encyclicals/documents/20260515-magnifica-humanitas.html.

The New York Times chairman and publisher, Arthur G. Sulzberger, delivered a speech at the 77th WAN-IFRA World News Media Congress in Marseille on June 1st, 2026. In his speech, titled "AI, journalism and the uncertain future of the public square", he gave very solid and strong arguments for why publishers should fight AI platforms. It is available on the following sites:

- ✓ WAN-IFRA Organization Website: https://wan-ifra.org/2026/06/nyts-sulzberger-condemns-ai-giants-for-brazen-theft-of-intellectual-property/
- ✓ https://www.nytco.com/press/a-i-journalism-and-the-uncertain-future-of-the-public-square/
- ✓ https://reutersinstitute.politics.ox.ac.uk/news/new-york-times-publisher-g-sulzberger-why-and-how-news-publishers-should-fight-ai-platforms

"While AI offers undeniable promises in predictive care within the NICU, its broader footprint presents a unique epistemic hazard: the degradation of objective reality through synthetic data and automated misinformation."

While AI offers undeniable promises in predictive care within the NICU, its broader footprint presents a unique epistemic hazard: the degradation of objective reality through synthetic data and automated misinformation. This technological inflection point recalls the profound warning articulated by political theorist Hannah Arendt in her 1974 interview by reporter Roger Errera, published later in The New York Review of Books in 1978. She said, "*If everybody always lies to you, the consequence is not that you believe the lies, but rather that nobody believes anything any longer*". Arendt spoke these words at a time marked by the social and global impact of the Watergate scandal and government lies in the United States. She concluded by saying... "*And a people that no longer can believe anything cannot make up its mind. It is deprived not only of its capacity to act but also of its capacity to think and judge*."

"As medical professionals, our core duty relies on a collective trust in data, empirical truth, and shared evidence. The ultimate danger of unchecked AI is not merely that users will mistake an algorithmic hallucination for fact, but rather the resulting epistemic exhaustion."

As medical professionals, our core duty relies on a collective trust in data, empirical truth, and shared evidence. The ultimate danger of unchecked AI is not merely that users will mistake an algorithmic hallucination for fact, but rather the resulting epistemic exhaustion. When synthetic information becomes indistinguishable from reality, we risk losing faith in the integrity of data altogether, paralyzing our capacity to make sound medical decisions.

If nothing changes, we run the risk that Hannah Arendt's premonition will ultimately come true. By contextualizing the pros and cons of AI, the authors of the manuscript in Neonatology

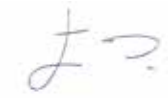
Today have opened a crucial door. We must recognize that the ethical deployment of AI requires safeguarding not just our clinical precision, but the very fabric of truth upon which all scientific inquiry and society as a whole rest.

Sincerely,

Maria Veronica Favareto
Assistant Professor in Neonatology at SIBEN

Marcelo Cardetti
Executive Director, and Professor at SIBEN

Ignacio Sosa
Assistant Professor in Neonatology at SIBEN



Taina Malena
Assistant Professor in Neonatology at SIBEN

Response from the Editor-in-Chief

We thank the authors for their thoughtful and timely letter regarding the article by Sola and Goldstein, *"Liquid Consciousness, Solid Gods: Pros and Cons of Artificial Intelligence (AI)."* Their observations appropriately broaden the discussion beyond the neonatal intensive care unit and into the larger societal, ethical, and epistemological questions that increasingly accompany the deployment of artificial intelligence.

The publication of the original article coincided with a period of intense international reflection on the role of AI in human affairs. As the authors note, recent statements by both Pope Leo XIV and Arthur G. Sulzberger underscore concerns that extend well beyond healthcare. Although these perspectives arise from different institutions and traditions, they share a common theme: the need to preserve human judgment, accountability, and trust in an era when machines can generate content at unprecedented scale and speed.

"The publication of the original article coincided with a period of intense international reflection on the role of AI in human affairs. As the authors note, recent statements by both Pope Leo XIV and Arthur G. Sulzberger underscore concerns that extend well beyond healthcare."

Medicine is fundamentally a discipline of evidence. Every diagnosis, treatment recommendation, quality improvement initiative, and scientific publication depends upon the integrity of data and the confidence that clinicians, researchers, patients, and families place in that evidence. The concern raised by the letter's authors—that synthetic information may become increasingly difficult to distinguish from authentic observations is therefore particularly relevant to healthcare. Scientific progress requires not only access to information but confidence in its provenance, validity, and reproducibility.

The reference to Hannah Arendt's warning about the consequences of pervasive falsehood is especially thought-provoking. Scientific inquiry depends upon a shared commitment to objective reality. If confidence in the reliability of information erodes, the consequences extend far beyond individual errors. The ability of clinicians, researchers, policymakers, and the public to make informed decisions becomes compromised. In this respect, the challenge posed by artificial intelligence is not solely technological but fundamentally human.

"The reference to Hannah Arendt's warning about the consequences of pervasive falsehood is especially thought-provoking. Scientific inquiry depends upon a shared commitment to objective reality. If confidence in the reliability of information erodes, the consequences extend far beyond individual errors. The ability of clinicians, researchers, policymakers, and the public to make informed decisions becomes compromised."

At the same time, it is important to recognize that the future of AI is not predetermined. Artificial intelligence remains a tool, and like all powerful tools, its impact depends upon the values, safeguards, and governance structures that guide its use. Within neonatology and medicine more broadly, AI offers tremendous opportunities to improve clinical decision support, identify subtle physiological patterns, enhance educational resources, accelerate research, and expand access to knowledge. The goal should not be to reject these advances but to ensure that they are implemented in ways that reinforce, rather than undermine, scientific integrity.

This responsibility extends to journals, publishers, academic institutions, and professional societies. Scientific publications must continue to strengthen standards for transparency, disclosure, authorship, peer review, and data verification. Researchers must develop methods to identify synthetic or manipulated content. Educators must train future clinicians not only to use AI effectively but also to evaluate its outputs critically. Most importantly, human expertise and judgment must remain central to clinical and scientific decision-making.

Neonatology Today has long embraced technological innovation while maintaining an unwavering commitment to scientific rigor and ethical publication practices. As artificial intelligence becomes

increasingly integrated into healthcare, education, and publishing, we believe ongoing dialogue such as that initiated by Sola and Goldstein and further expanded by this letter is essential. The questions raised are neither temporary nor confined to any single specialty. They strike at the heart of how knowledge is created, validated, and trusted.

We appreciate the authors for contributing to this important conversation and for reminding us that the ultimate challenge of artificial intelligence is not simply whether machines can think, but whether humanity can preserve the intellectual and ethical foundations necessary to distinguish truth from fabrication. The future of medicine, science, and society may depend upon our answer.

Sincerely,

Mitchell Goldstein, MD, MBA, CML

Editor in Chief

NT NEONATOLOGY TODAY

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c/o Mitchell Goldstein, MD

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Letters to the Editor

Carta al Editor: "Conciencias Líquidas, Dioses Sólidos: Pros y Contras de la Inteligencia Artificial (IA)"

9 de junio, 2026

Carta al editor

Hemos leído con interés el excelente manuscrito publicado en *Neonatology Today* por Sola y Goldstein: "Conciencias Líquidas, Dioses Sólidos: Pros y Contras de la Inteligencia Artificial (IA)", 2026;21(4):31-41.

Consideramos muy oportuno el momento de su publicación en su revista, ya que el desafío de la inteligencia artificial (IA) trasciende el ámbito de la neonatología. El excelente artículo de abril, que detalla las ventajas y desventajas de la IA en la medicina neonatal, sienta las bases fundamentales para un diálogo que debe extenderse con urgencia más allá de las métricas, los flujos de trabajo y los algoritmos de trabajo clínico.

"Consideramos muy oportuno el momento de su publicación en su revista, ya que el desafío de la inteligencia artificial (IA) trasciende el ámbito de la neonatología. El excelente artículo de abril, que detalla las ventajas y desventajas de la IA en la medicina neonatal, sienta las bases fundamentales para un diálogo que debe extenderse con urgencia más allá de las métricas, los flujos de trabajo y los algoritmos de trabajo clínico."

Si bien la IA ofrece perspectivas innegables en el reconocimiento de patrones y la atención predictiva dentro de la UCIN, su impacto más amplio, tanto social como científico, plantea un riesgo epistémico singular: la degradación de la realidad objetiva mediante datos sintéticos y desinformación automatizada.

Poco después de que Neonatology Today publicara este artículo, el Papa León XIV y Arthur G. Sulzberger, presidente y editor de The New York Times, emitieron mensajes muy claros el 15 de mayo y el 1 de junio de 2026, abordando las preocupaciones globales sobre la IA, mucho más allá de la UCIN, por supuesto.

Ambas comunicaciones son valiosas y recomendadas para cualquier persona interesada en los desafíos sociales que plantea la IA.

El Papa León XIV, el 15 de mayo de 2026, dedicó su encíclica Magnifica Humanitas en la Basílica de San Pedro, en Roma, a la protección de la persona humana en la era de la inteligencia artificial. Está disponible en: https://www.vatican.va/content/leo-xiv/es/encyclicals/documents/20260515-magnifica-humanitas.html

Arthur G. Sulzberger, presidente y editor de *The New York Times*, pronunció un discurso en el 77.º Congreso Mundial de Medios Informativos de WAN-IFRA, celebrado en Marsella el 1 de junio de 2026. En su intervención, titulada «La IA, el periodismo y el futuro incierto de la plaza pública», expuso argumentos sólidos y contundentes sobre por qué los editores deberían luchar contra las plataformas de IA. El texto íntegro y oficial del discurso en español no ha sido publicado en un único documento de libre acceso, ya que la organización del evento (WAN-IFRA) únicamente distribuyó la transcripción original en inglés en su sitio web: https://wan-ifra.org/2026/06/nyts-sulzberger-condemns-ai-giants-for-brazen-theft-of-intellectual-property/ Algunas Asociaciones de Medios como la Asociación de Entidades Periodísticas Argentinas (ADEPA) y la Alianza de Medios MX publicaron crónicas muy completas en español que traducen los puntos centrales y las advertencias de Sulzberger sobre el modelo de "búsquedas sin clics" y la sostenibilidad del periodismo.

"Como profesionales de la salud neonatal, nuestro deber fundamental se basa en la confianza colectiva en los datos, la evidencia empírica y la verdad compartida. El mayor peligro de una IA sin control no es simplemente que los usuarios confundan una alucinación algorítmica con un hecho real, sino el agotamiento epistémico resultante."

Este punto de inflexión tecnológico evoca la profunda advertencia formulada por la teórica política Hannah Arendt en la entrevista que le concedió al periodista Roger Errera en 1974, publicada posteriormente en *The New York Review of Books* en 1978. Ella afirmó: «*Si todo el mundo te miente constantemente, la consecuencia no es que creas las mentiras, sino más bien que nadie cree ya en nada*». Arendt pronunció estas palabras en una época marcada por el impacto social y mundial del escándalo de Watergate y por las mentiras gubernamentales en Estados Unidos. Concluyó diciendo... «*Y un pueblo que ya no puede creer en nada es incapaz de tomar decisiones. Se le priva no solo de su capacidad de actuar, sino también de su capacidad de pensar y de juzgar*».

Como profesionales de la salud neonatal, nuestro deber fundamental se basa en la confianza colectiva en los datos, la evidencia empírica y la verdad compartida. El mayor peligro de una IA sin control no es simplemente que los usuarios confundan una alucinación algorítmica con un hecho real, sino el agotamiento epistémico resultante. Cuando la información sintética se vuelve indistinguible de la realidad, corremos el riesgo de perder por completo la fe en la integridad de los datos, lo que paralizaría nuestra capacidad para tomar decisiones médicas acertadas.

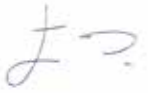
Si nada cambia, corremos el riesgo de que la premonición de Hannah Arendt termine haciéndose realidad. Al contextualizar las ventajas y desventajas de la IA, los autores del manuscrito en Neonatology Today han abierto una puerta crucial. Debemos reconocer que la implementación de la ética en la IA exige salvaguardar no solo nuestra precisión clínica, sino también el propio

tejido de la verdad sobre el que descansan toda la investigación científica y la sociedad en su conjunto.

Atentamente,

María Verónica Favareto
Profesor Asistente en Neonatología de SIBEN

Marcelo Cardetti
Profesor y Director Ejecutivo de SIBEN



Ignacio Sosa
Profesor Asistente en Neonatología de SIBEN

Taina Malena
Profesor Asistente en Neonatología de SIBEN

Respuesta del Editor en Jefe

Agradecemos a los autores por su carta reflexiva y oportuna respecto al artículo de Sola y Goldstein, *"Liquid Consciousness, Solid Gods: Pros and Cons of Artificial Intelligence (AI)"*. Sus observaciones amplían apropiadamente la discusión más allá de la unidad de cuidados intensivos neonatales y la sitúan en el ámbito de las cuestiones éticas, sociales y epistemológicas que acompañan cada vez más el despliegue de la inteligencia artificial.

"La publicación del artículo original coincidió con un período de intensa reflexión internacional sobre el papel de la IA en los asuntos humanos. Como señalan los autores, las recientes declaraciones tanto del Papa León XIV como de Arthur G. Sulzberger subrayan preocupaciones que trascienden ampliamente el ámbito de la atención sanitaria."

La publicación del artículo original coincidió con un período de intensa reflexión internacional sobre el papel de la IA en los asuntos humanos. Como señalan los autores, las recientes declaraciones tanto del Papa León XIV como de Arthur G. Sulzberger subrayan preocupaciones que trascienden ampliamente el ámbito de la atención sanitaria. Aunque estas perspectivas surgen de instituciones y tradiciones diferentes, comparten un tema común: la necesidad de preservar el juicio humano, la responsabilidad y la confianza en una era en la que las máquinas pueden generar contenido a una escala y a una velocidad sin precedentes.

La medicina es, fundamentalmente, una disciplina basada en la evidencia. Cada diagnóstico, recomendación terapéutica, iniciativa de mejora de la calidad y publicación científica depende de la integridad de los datos y de la confianza que los clínicos, investigadores, pacientes y familias depositan en dicha evidencia. Por ello, la preocupación planteada por los autores de la carta —que la información sintética pueda llegar a ser cada vez más difícil de distinguir de la observación auténtica— resulta particularmente relevante en la atención médica. El progreso científico requiere no solo el acceso a la información, sino también la confianza en su procedencia, validez y reproducibilidad.

La referencia a la advertencia de Hannah Arendt sobre las consecuencias de la falsedad generalizada resulta especialmente sugerente. La investigación científica depende de un compromiso compartido con la realidad objetiva. Si la confianza en la fiabilidad de la información se erosiona, las consecuencias trascienden los errores individuales. La capacidad de los clínicos, investigadores, responsables de políticas públicas y del público en general para tomar decisiones informadas se ve comprometida. En este sentido, el desafío planteado por la inteligencia artificial no es únicamente tecnológico, sino también profundamente humano.

"La referencia a la advertencia de Hannah Arendt sobre las consecuencias de la falsedad generalizada resulta especialmente sugerente. La investigación científica depende de un compromiso compartido con la realidad objetiva. Si la confianza en la fiabilidad de la información se erosiona, las consecuencias trascienden los errores individuales. La capacidad de los clínicos, investigadores, responsables de políticas públicas y del público en general para tomar decisiones informadas se ve comprometida."

Al mismo tiempo, es importante reconocer que el futuro de la IA no está predeterminado. La inteligencia artificial sigue siendo una herramienta y, como todas las herramientas poderosas, su impacto depende de los valores, las salvaguardas y las estructuras de gobernanza que orienten su uso. En la neonatología y en la medicina en general, la IA ofrece enormes oportunidades para mejorar el apoyo a la toma de decisiones clínicas, identificar patrones fisiológicos sutiles, enriquecer los recursos educativos, acelerar la investigación y ampliar el acceso al conocimiento. El objetivo no debe ser rechazar estos avances, sino garantizar que se implementen de modo que refuercen, en lugar de debilitar, la

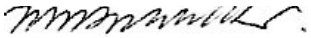
integridad científica.

Esta responsabilidad se extiende a las revistas científicas, los editores, las instituciones académicas y las sociedades profesionales. Las publicaciones científicas deben seguir fortaleciendo los estándares de transparencia, divulgación, autoría, revisión por pares y verificación de datos. Los investigadores deben desarrollar métodos para identificar contenido sintético o manipulado. Los educadores deben formar a las futuras generaciones de profesionales no solo para utilizar la IA de manera eficaz, sino también para evaluar críticamente sus resultados. Y, sobre todo, la experiencia y el juicio humanos deben seguir siendo el eje central de las decisiones clínicas y científicas.

Neonatology Today ha abrazado desde hace mucho tiempo la innovación tecnológica, manteniendo un compromiso inquebrantable con el rigor científico y con las prácticas éticas de publicación. A medida que la inteligencia artificial se integra cada vez más en la atención médica, la educación y la publicación científica, creemos que el diálogo continuo iniciado por Sola y Goldstein y ahora ampliado con esta carta es esencial. Las cuestiones planteadas no son temporales ni están limitadas a una única especialidad. Alcanzan el núcleo mismo de cómo se crea, se valida y se confía en el conocimiento.

Agradecemos a los autores su contribución a esta importante conversación y por recordarnos que el desafío último de la inteligencia artificial no consiste simplemente en determinar si las máquinas pueden pensar, sino en si la humanidad puede preservar los fundamentos intelectuales y éticos necesarios para distinguir la verdad de la fabricación. El futuro de la medicina, la ciencia y la sociedad puede depender de nuestra respuesta.

Sincerely,



Mitchell Goldstein, MD, MBA, CML

Editor en Jefe, Neonatology Today

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Erratum (Neonatology Today May, 2026

There are no erratum to report for May, 2026

Corrections can be sent directly to LomaLindaPublishingCompany@gmail.com. The most recent edition of Neonatology Today including any previously identified erratum may be downloaded from www.neonatologytoday.net.

NT

Neonatology Today welcomes your editorial commentary on previously published manuscripts, news items, and other academic material relevant to the fields of Neonatology and Perinatology.

Please address your response in the form of a letter. For further formatting questions and submissions, please contact Mitchell Goldstein, MD at LomaLindaPublishingCompany@gmail.com.

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pac-lac

Perinatal Advisory Council:
Leadership, Advocacy and Consultation

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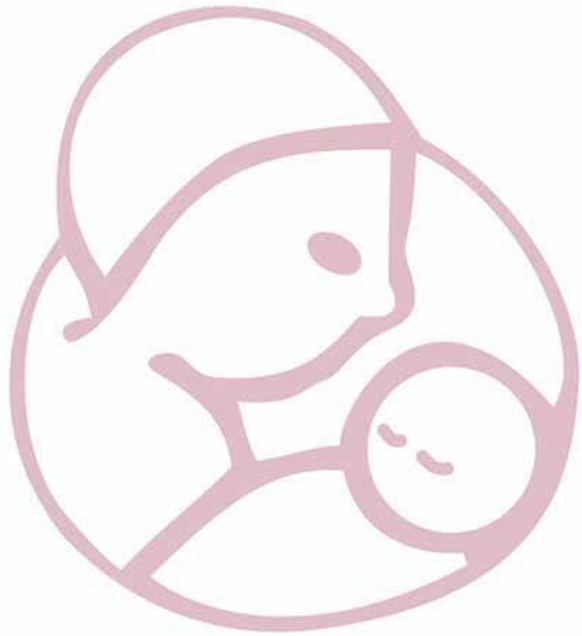

PAC/LAC's core values for improving maternal and child health have remained constant for over 30 years – a promise to lead, advocate and consult with others.

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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.

Peer Reviewed

Gravens by Design: Design Features of the 2026 Gravens Conference

Robert D. White, MD

The 39th annual Gravens Conference is coming to the University of Notre Dame from June 15-18th. One of the features of this meeting will be a full-day pre-conference workshop on "Reimagining the NICU," with a follow-up workshop to summarize the findings. A link to this summary workshop will be published in the July edition of Neonatology Today, along with links to several other Gravens workshops.

"The 39th annual Gravens Conference is coming to the University of Notre Dame from June 15-18th. One of the features of this meeting will be a full-day pre-conference workshop on 'Reimagining the NICU,' with a follow-up workshop to summarize the findings. A link to this summary workshop will be published in the July edition of Neonatology Today, along with links to several other Gravens workshops."

The plenary sessions on the first day of the Gravens meeting will feature several presentations on the environment of care, including an update from our Cochrane colleagues on "All Care is Brain Care," which will include updated reviews on the optimal sensory environment in the NICU. The second day of the Gravens Conference will include a full morning of design-related presentations, followed that afternoon by a tour of the NICU at Beacon Children's Hospital, the first in the US to offer couplet care and single-family rooms in the NICU. Photos, floor plans, and additional valuable design information from this NICU can be found in the May issue of Neonatology Today devoted to Therapeutic Design.

"Photos, floor plans, and additional valuable design information from this NICU can be found in the May issue of Neonatology Today devoted to Therapeutic Design"

"The Gravens Conference and Neonatology Today will continue to explore the science and experience that will inform optimal NICU design in the years to come as neonatal care evolves."

Perhaps the "hottest topic" in NICU design today is finding the proper balance between care delivered in couplet or single family rooms and that delivered in group care rooms, also referred to as "open bay" and "congregate care". There is no "one size fits all choice in this regard – an infant's condition and medical status evolve; so too do each family's needs, desires, and availability. How to best design a NICU that provides the optimal space for each baby and family at any given point in time will continue to be a topic of conversation for the future; it is probably safe to say that there are very few NICUs in the US today that provide the optimal setting of care for every baby and its family every day. The Gravens Conference and Neonatology Today will continue to explore the science and experience that will inform optimal NICU design in the years to come as neonatal care evolves.

Disclosures: *The author has no conflicts of interest.*

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Peer Reviewed

39th Annual Gravens Conference

On the Environment of Care for
High Risk Newborns and Their Families

June 15-18, 2026

"Sensitive Issues in Sensational Times"

Monday, June 15th
Let the Festivities Begin!

TIME	SESSION / EVENT	LOCATION
8:00 pm-4:00 pm	Reimagining the NICU - Troy Savage *Optional Pre Conference with Separate Registration*	
4:00 pm-7:00 pm	Registration Desk Open	
7:00 pm-9:00 pm	Welcome Reception *Cash Bar Only*	Podium at Embassy Suites

Tuesday, June 16th
Science & Application
Welcome, Breaks, Awards, and Closing Do Not Count for CME/CE

TIME	SESSION / EVENT	LOCATION
7:00 am-5:00 pm	Registration Desk Open	
7:00 am-8:00 am	Continental Breakfast Provided (1 hour)	
8:00 am-5:00 pm **Plenary Sessions** **Downes Ballroom - Corbett Family Hall** **Moderator: (Robert White and Joy Browne)**		
TIME	**SESSION / EVENT**	**PRESENTER**
8:00 am-8:15 am	Welcome & Introductions	Joy Browne
8:15 am-9:00 am	Family-Centered Collaborative Care Models that Support Families and Optimize Preterm Infant and Child Health Outcomes	Jessica DiBari
9:00 am-9:45 am	Care of the Mother is Care for the Baby	Heather Burris
9:45 am-10:15 am **Break (30 min)**		
10:15 am-11:00 am	Advocacy for Family Centered Care: An implementation Science Journey	Malathi Balasundaram
11:00 am-11:45 am	All Care is Brain Care: Lessons learned from an international quality improvement collaborative to improve brain health and outcomes (Part 1)	Roger Soll, Elizabeth Rogers, Sonia Bonifacio
11:45 am-1:00 pm **Lunch (75 min)**		
1:00 pm-2:30 pm	All Care is Brain Care: Lessons learned from an international quality improvement collaborative to improve brain health and outcomes (Part 2)	Roger Soll, Elizabeth Rogers, Sonia Bonifacio
2:30 pm-3:00 pm **Break (30 min)**		
3:00 pm-3:30 pm	Gravens Recognition Award Presentation	Mitch Goldstein
3:30 pm-4:15 pm	Sensitive Issues for Babies, Parents, and their Relationships	Joy Browne

4:15 pm-4:45 pm	Panel Discussion Among NICU Parents on Real-World Impact of Topics Presented	Molly Fraust-Wylie, Susanne Klawetter, Mia Malcolm, Alex Zavala
4:45 pm-5:00 pm	Family Centered-Care (FCC) Scholars Introduction	Malathi Balasundaram
5:00 pm-5:15 pm	Final Thoughts and Take-Home Messages	Robert White
6:30 pm-8:30 pm **Reception & Poster Walk** **Poster Session - Jordan Hall Galleria** *Substantial Snacks Provided* 7:00 pm-7:45 pm, Poster Authors Available 8:10 pm-8:30 pm, Door Prize Raffle: Vincent C. Smith		

Wednesday, June 17th
Themed Tracks

Welcome, Breaks, and Closing Do Not Count for CME/CE

TIME	SESSION / EVENT	LOCATION
6:30 am-7:15 am	Run, Walk, Skip Around Notre Dame Campus	
7:00 am-8:00 am	Continental Breakfast Provided / Networking Tables (1 hour)	
7:30 am-1:30 pm	Registration Desk Open	

8:00 am-1:00 pm
Themed Tracks

Track A **Infant and Family-Centered Developmental Care** **Jordan Hall Room 101** **Moderator: Joy Browne**		**Track B** **Newborn ICU Design** **Jordan Hall Room 105** **Moderator: Robert White**	
8:00 am-8:15 am	Introductions & Announcements	8:00 am-8:15 am	Introductions & Announcements
8:15 am-8:45 am	The Importance of a Developmental Point of View of Sensory Processes - Robert Lickliter	8:15 am-9:00 am	Therapeutic Design - Mardelle Shepley
8:45 am-9:30 am	Clinical Application from Chemosensory Research - Julie Mennella	9:00 am-9:45 am	Designing NICU Spaces for Ritual and Healing - Anya Vanacek and Julia Jude
9:30 am-10:15 am	Development and Clinical Application from Embodied Vocal Presence Research - Manuela Filippa	9:45 am-10:30 am	Soundscapes - Bobbi Pineda
10:15 am-10:45 am	Break (30 min)		
		10:30 am-11:00 am	Break (30 min)
10:45 am-11:30 am	Reflections on Sensory Developmental Ecology and Its Applications for Care - Jeff Alberts	*Exhibitors to Break Down*	
11:30 am-12:00 pm	Clinical Application of the Environment of Care from the NICU Parents' Perspective – Jessica DiBari, Mia Malcolm, Jessi Barnes	11:00 am-11:45 am	New Unit Presentation - Brianna Leigh, and Karizma Maxson
12:00 pm-12:05pm	Summary & Next Steps - Joy Browne	11:45 am-12:45 pm	Using AI for NICU Design - Troy Savage

12:05 pm-12:35pm	Break (30 min)	12:45 pm-1:00 pm	Summary & Next Steps - Robert White
12:35 pm -1:00 pm	Development and Clinical Application from Auditory Tactile Research - Nathalie Maitre *(This session is not designated for continuing education credit. This designation does not reflect the integrity or quality of the content.*		

1:00 pm-4:00 pm
Lunch, Rest, Play, Network, NICU Tour
Lunch Not Provided

Tour of the Beacon Children's Couplet Care/Single Family Room NICU

4:00 pm-4:45 pm
Welcome Back & Networking
Coffee and Light Snacks Provided

4:45 pm-6:00 pm
Workshops (75 min)

TIME	SESSION / EVENT	MODERATOR
4:45 pm-6:00 pm	A: Culture Club: Culture as a Foundation for Quality Improvement - Elizabeth Rogers and Sonia Bonifacio (Room: Jordan Hall 101)	**Mitch Goldstein**
	B: Taking Steps Toward Postpartum Care in the NICU - Heather Burris and Katey Mari (Room: Jordan Hall 105)	**Morgan Kowalski**
	C: Reimagining the NICU: Wrap Up - Troy Savage (Room: Jordan Hall 325)	**Robert White**
	D: Are We Really Seeing Delirium in Babies? A Conversation About Behavioral Assessment and Intervention - Jeff Alberts (Room: Jordan Hall 310)	**Kathleen Kolberg**
	E: Support for NICU Fathers and Non-Birthing Parents - Cameron Boyd, Alex Zavala, and Craig Garfield (Room: Jordan Hall 322)	**Molly Fraust-Wylie**
	F: Partnering with NICU parents and professionals: Methodological lessons from developing the PATH program - Susanne Klawetter (Room: Jordan Hall 326)	**Mardelle Shepley**

6:30 pm-9:00 pm
Dinner Banquet
Heritage Hall - Joyce Center
Included with Conference Registration

Thursday, June 18th
Family Topics & Reflections Abstracts & Workshops
Welcome, Breaks, and Closing Do Not Count for CME/CE

TIME	SESSION / EVENT	LOCATION
6:30 am-7:15 am	Run, Walk, Shuffle Around Notre Dame Campus	
7:00 am-8:00 am	Continental Breakfast Provided (1 hour)	

7:00 am-11:15 am	Registration Desk Open	
8:00 am-12:00 pm Plenary Session Downes Ballroom - Corbett Family Hall Moderators: (Vincent C. Smith and Molly Faust-Wylie)		
8:00 am-8:10 am	Introductions and Announcements	Vincent C. Smith & Molly Faust-Wylie
8:10 am-8:40 am	A NICU Dad's Perspective	Alex Zavala
8:40 am-9:15 am	Experiences of NICU Fathers and Non-Birthing Parents	Cameron Boyd
9:15 am-10:00 am	NICU Discharge Planning Considerations for NICU Fathers and Non-Birthing Parents	Craig Garfield
10:00 am-10:30 am Break (30 min)		
10:30 am-11:05 am	Audience Engagement Activity	Troy Savage
11:05 am-11:50 am	Parent Panel	Molly Fraust-Wylie & Mia Malcolm
11:50 am-12:00 pm	Acknowledgement & Celebration of Juneteenth Wrap Up/Warm Send Off	Joy Browne & Robert White
12:00 pm-1:15 pm *Planning Committee Meeting* **Lunch (75 min)**		
1:15 pm-2:30 pm Abstracts (75 min)		
TIME	**ABSTRACT**	**MODERATOR**
1:15 pm-2:30 pm	Developmental Care (Room: Jordan Hall 322): 1. Parent-Delivered Neurodevelopmental Care: Standardizing an Approach to Parent Education - Grace King, Tierney Morrison, Aimee Godett, Marge Day, Emily Whitesel (Abstract 30) 2. Interventions Designed to Improve the Postpartum Health and Wellbeing of Parents of Infants in the NICU: A Scoping Review - Sarah Verbiest, Wayne Price, Kimarie Bugg (Abstract 19) 3. Multidisciplinary Journey to Reliable Social Determinants of Health Screening for NICU Families: Navigating Barriers in the NICU Village - Rosanne Buck, Dory Ziperstein, Molly Faust-Wylie, Erika Sevieri, Gina Story, Emily Whitesel, Yarden Fraiman (Abstract 7)	**Vincent C. Smith**
	Family Support (A) (Room: Jordan Hall 101): 1. Harmonizing Developmental and Medical Communication in the NICU: A Dynamic Digital Platform to Augment Family-Centered Care - Ansul Asad, Yaya Ren, Bree Andrew (Abstract 36) 2. Early Parental Presence in the NICU: Social Determinants and Maternal Mental Health Shape Family Engagement for High Risk Infants - Jaclyn Ruggiero, Allison Davidson (Abstract 47)	**Malathi Balasundaram**

	3. Family-Centered Care: Increasing Positive Family Engagement and Interactions with Infants in the NICU - Terri Sandoval, Alison Smith, Jamie Lujan, Jennifer Guadalupe, Rachel Carlos, Candice Martinez (Abstract 4)	
	Developmental Care/Family-Centered Care (Room: Jordan Hall 310): 1. The Journey to a Developmental Care Continuum: An Interdisciplinary Collaborative Approach to Developmental Care in the NICU - Tiara Bolden, Lisa Miller, Cynthia Ruggles, Mary Beth Sanders, Laura Schacht, Lindsay Schuler, Kelly Crombie, Janet Dierstein, Susannah Dillender, Christine Houlihan, Amy Salisbury (Abstract 51) 2. Designing the NICU of the Future: National Survey Insights on Workforce Support, Digital Integration, and Family Partnership - Lisa Davenport, Jaylee Hilliard (Abstract 32) 3. Reimagining the NICU Environment of Care: Applying Human Factors and Ergonomics to Support Safe, Sustained Skin-to-Skin (Kangaroo) Care for High Risk Infants and Families - Yamile Jackson (Abstract 6)	**Molly Fraust-Wylie**
	Family Support (B) (Room: Jordan Hall 105): 1. Mapping Neonatal Transfer Patterns to Inform Family-Centered Care: Capacity and Distance Across Levels of Care - Amanda Luff, Emily Malloy, Veronica Fitzpatrick (Abstract 15) 2. Advancing Family Engagement in the NICU: A Qualitative Exploration of Barriers and Facilitators - Laura Rose, Kayla Schmittau, Kristen Schaffer, Alejandro Chavez, Katherine Lopez-Lepe, Linda Franck, Henry Lee (Abstract 8) 3. Effect of Parent Education Classes on Confidence and Stress of Parents of Infants Admitted to the NICU of a Tertiary Care Hospital in India - Pooja Dekhane, Puja Padbidri, Madhura Gandhi, Madhuri Patil, Eilish Byrne (Abstract 22)	**Mia Malcom**
	Potpourri (Room: Jordan Hall 325): 1. Reaching NICU Families: Feasibility of Recruiting High Risk Infants - Ashlee Vance, Eman Dannaway (Abstract 33) 2. Beyond Just Cuddles: Creating a Medical Student Cuddlers Program for an Evolving Level 4 NICU - Stephanie Bernard, Lauren Felzani, Rivky Barnetsky, Likhitha Patlolla, Jordan Bryan, Donessa Jenae Colley, Andrea Weintraub (Abstract 17) 3. Development of a Conceptual Framework for Financial Hardship in Neonatal Care - Ashlee Vance (Abstract 26)	**Joy Browne**
	Design (Room: Jordan Hall 326): 1. Acoustic Comfort in Newborn Intensive Care - Kathleen Philbin (Abstract 52) 2. Beyond Single-Family Rooms: A Hybrid NICU Model Responsive to Community Demographics - Zoraya Stern, Maria D'Souza, Whitney K. Fuessel (Abstract 24)	**Robert White**
2:30 pm-3:00 pm Break (30 min)		
3:00 pm-4:15 pm Workshops (75 min)		

3:00 pm-4:15 pm	A: Family-Centered Care in Action: Collaboration, Measurement, and Improvement- Malathi Balasundaram and Morgan Kowalski (Room: Jordan Hall 105)	**Malathi Balasundaram**
	B: Words Matter: Navigating Sensitive Situations with Intentional Language in the NICU - Ramya Kumar (Room: Jordan Hall 310)	**Judy Smith**
	C: Trauma-Informed Expectations for Gratitude in the NICU - Mia Malcolm and Jessica Barnes (Room: Jordan Hall 426)	**Mia Malcolm**
	D: D.R.I.V.E. Better Care: Developing Emotionally Present NICU Teams to Strengthen Family-Centered Care - Weston Brandon (Room: Jordan Hall 322)	**Mitch Goldstein**
	E: Relationships in the NICU: Will AI Foster or Hinder? - Jim Gray and Bridget Davern (Room: Jordan Hall 101)	**Vincent C. Smith**
	F: The Second Edition of the Infant and Family-Centered Developmental Care Standards: Discussion and Dissemination - Tiara Bolden, Carol Jaeger and Joy Browne (Room: Jordan Hall 325)	**Joy Browne**
4:15 pm	Safe Travels, See You at the Next Gravens Conference!	

Friday, June 19th
HAPPY JUNETEENTH!
Juneteenth is a United States federal holiday commemorating the end of slavery.

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RUSH

JOINTLY ACCREDITED PROVIDER™
INTERPROFESSIONAL CONTINUING EDUCATION

39th Annual Gravens Conference: On the Environment of Care for High-Risk Newborns and Their Families (live & virtual)
Dates: June 16-18, 2026
Location: Notre Dame University, Notre Dame, IN

Learning Objectives:

- Analyze the impact of the NICU sensory and caregiving environment on neonatal brain development and long-term neurodevelopmental outcomes.
- Apply evidence-based neuroprotective and developmental care strategies—including sleep protection, cue-based caregiving, and pain mitigation into routine clinical practice.
- Integrate family-centered and relationship-based care models by engaging parents as active participants in caregiving and clinical decision-making.
- Evaluate their local NICU environment, workflows, and culture to identify gaps between current practice and developmental care best practices.
- Develop and implement multidisciplinary quality improvement initiatives to advance neuroprotective care and measure their impact on clinical and developmental outcomes.

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Name	**Company(ies) and Nature of Relationship(s)**
Ramya Kumar	Consultant: Neotech; and Speaker: Mead Johnson
Brianna Leigh, MD	Advisor: SIME Diagnostics Ltd.

All other individuals in control of content have no relevant financial relationships with ineligible companies.

Raising Global Awareness of RSV

Global awareness about respiratory syncytial virus (RSV) is lacking. RSV is a relatively unknown virus that causes respiratory tract infections. It is currently the second leading cause of death – after malaria – during infancy in low- and middle-income countries.

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

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

RSV GOLD

A Global Mortality Database for Children with RSV Infection

The RSV awareness video was produced in collaboration with the Bill & Melinda Gates Foundation

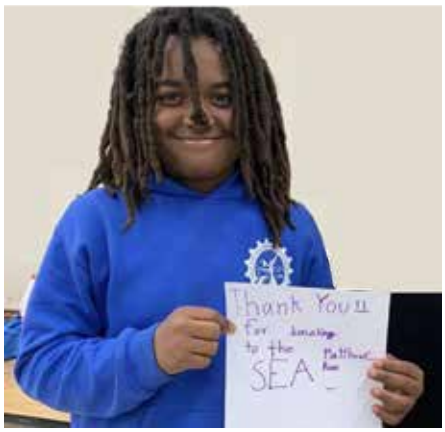
Thirteen-year-old Emily Rose Shane was tragically murdered on April 3, 2010 on Pacific Coast Highway in Malibu, CA. Our foundation exists to honor her memory.

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

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

Sponsor a Child in the SEA Program

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



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

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.

National Coalition for Infant Health: Spring Does Not Mean Respiratory Syncytial Virus is Gone

Kristen Santiago, MS

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.

Stay on Guard: RSV Stretches into Spring:

The arrival of spring usually ushers in a lower risk of severe respiratory infections. However, experts warn that this year's respiratory syncytial virus, or RSV, season may last longer than usual. (1, 2) The recommended window for RSV immunization had been extended through the end of April, but cases may persist into summer. (3, 4)

Protection is crucial while risks remain high. (5) For the most vulnerable population, infants, immunization with monoclonal antibodies offers indispensable protection. (6)

Preventing Hospitalizations:

RSV remains a leading cause of infant hospitalization in the United States. (7) The infection is often mild in older children and adults, but for the youngest and oldest patients, (8) severe complications

are common. Dehydration and difficulty breathing drive many into hospitals, at high fiscal and emotional cost.

Parents of infants in their first months of life should be aware of this unusual, extended risk of RSV infection. Access to preventive immunization reduces the likelihood of costly hospitalization, making it a sensible investment across health systems. (9)

The extended RSV season provides an urgent reminder that delaying protection can have severe, and sometimes deadly, consequences.

"Families are facing not just extended risk, but also confusion around recommendations for infant vaccinations more broadly. (10) Changes to federal vaccine guidance, timing, and eligibility have muddied the waters for parents as they educate themselves about options. (11)"

Clarity Matters for Families:

Families are facing not just extended risk, but also confusion around recommendations for infant vaccinations more broadly. (10) Changes to federal vaccine guidance, timing, and eligibility have muddied the waters for parents as they educate themselves about options. (11)

Expert recommendations, based on the best available empirical evidence, continue to recommend timely vaccination. The National Consumers League, the American Academy of Pediatrics, and other advocacy groups have expressed concern about the increased risk and support the extension of the RSV season through April. (12, 13)

"Even late in the season, preventive action can make a difference. Extended eligibility windows reflect ongoing risk: Infants will continue to stay vulnerable for weeks to come, and protection can be delivered now. When risk persists, prevention should follow."

Prevention Still Works:

Immunization remains essential to protecting children and the public at large from preventable illnesses.

Even late in the season, preventive action can make a difference. Extended eligibility windows reflect ongoing risk: Infants will continue to stay vulnerable for weeks to come, and protection can be delivered now. When risk persists, prevention should follow.

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3. https://www.cdc.gov/rsv/about/index.html
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12. https://nclnet.org/imported-tags/vaccines/
13. https://primaryimmune.org/resources/news-articles/foundation-supports-broad-rsv-vaccination-immunocompromised-adults

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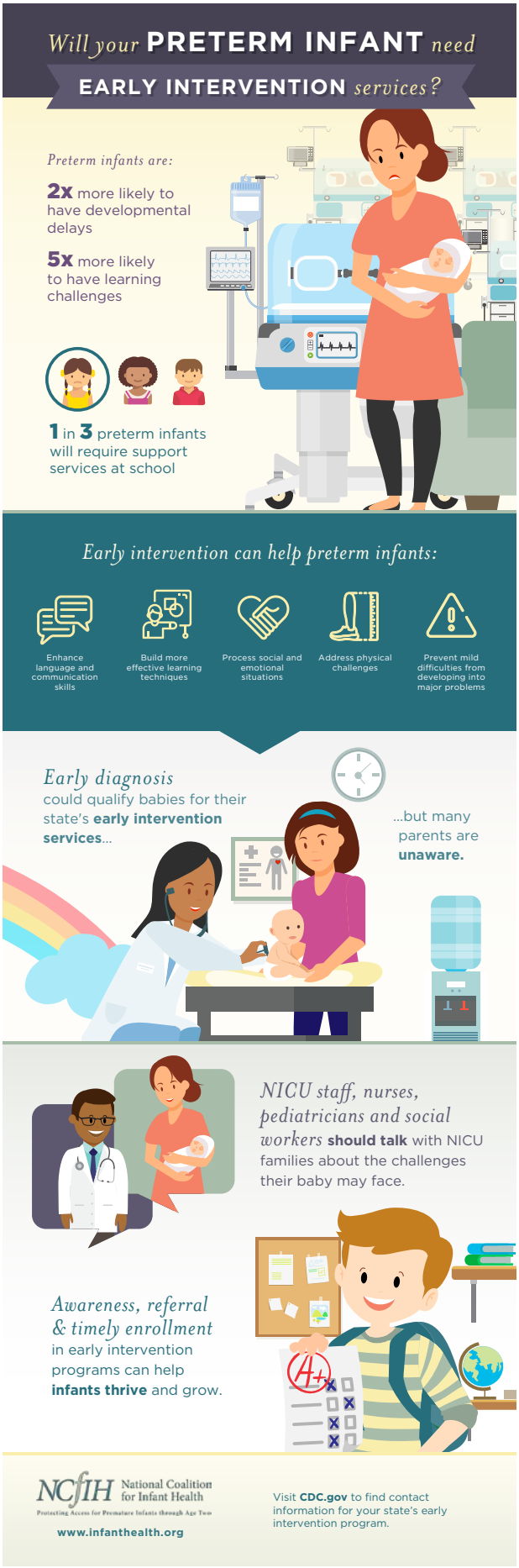
National Coalition for Infant Health Values (SANE)

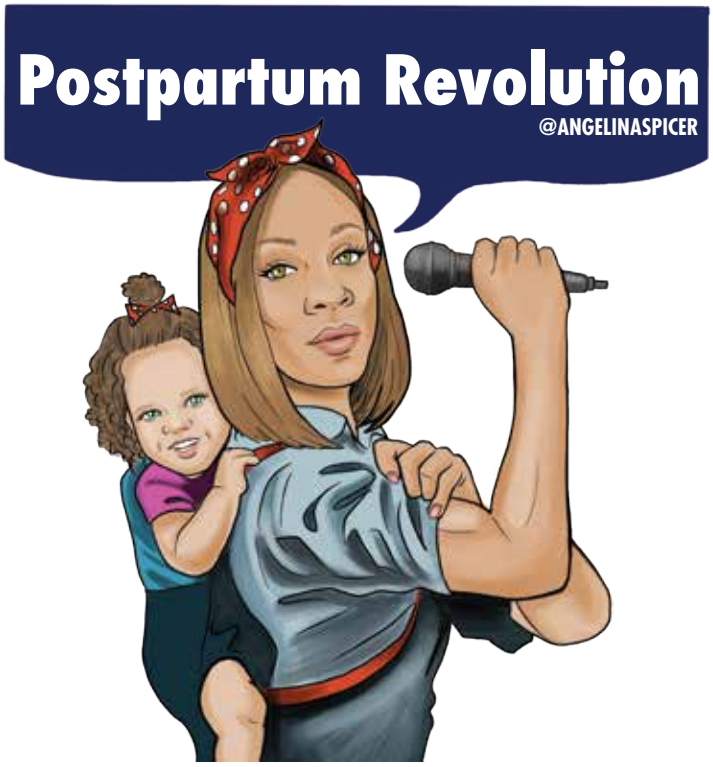
Safety. Premature infants are born vulnerable. Products, treatments and related public policies should prioritize these fragile infants' safety.

Access. Budget-driven health care policies should not preclude premature infants' access to preventative or necessary therapies.

Nutrition. Proper nutrition and full access to health care keep premature infants healthy after discharge from the NICU.

Equity. Prematurity and related vulnerabilities disproportionately impact minority and economically disadvantaged families. Restrictions on care and treatment should not worsen inherent disparities.





Your Pregnancy and Substance Use

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

Get Prenatal Care

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

Reduce Your Use

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

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

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

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

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

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

Take Good Care of Yourself

You deserve a healthy pregnancy & childbirth.

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

Your Health Matters

Academy of Perinatal Harm Reduction

National Perinatal Association

www.perinatalharmreduction.org | www.nationalperinatal.org

Fragile Infant Forums for Implementation of IFCDC Standards: From Evidence to Everyday Care: Implementing Neurodevelopmental Supportive Care in the Neonatal Intensive Care Unit

Welma Lubbe, PhD

Neurodevelopmental supportive care (NDSC) is widely recognized as beneficial for preterm and vulnerable infants, yet in many neonatal units it is still applied inconsistently or in fragmented ways (1, 2). The implementation challenge is therefore not whether NDSC matters but how to move it from good intentions and isolated practices to a sustained model of everyday care across different South African settings.

"Neurodevelopmental supportive care (NDSC) is widely recognized as beneficial for preterm and vulnerable infants, yet in many neonatal units it is still applied inconsistently or in fragmented ways. The implementation challenge is therefore not whether NDSC matters but how to move it from good intentions and isolated practices to a sustained model of everyday care across different South African settings."

This paper describes an implementation pathway developed to help neonatal units introduce, embed, and sustain NDSC in routine practice. The work was grounded in a practical question: how can neurodevelopmental care become standard care rather than an optional extra?

Why was implementation needed?

The starting point was a familiar gap between evidence and practice. Global and local experience shows that neurodevelopmental care improves short-term hospital outcomes (3), parent-infant bonding (4), and behavioral organization (5), but uptake remains uneven when staff lack a shared model, adequate training, or system support (1, 2).

"Global and local experience shows that neurodevelopmental care improves short-term hospital outcomes, parent-infant bonding, and behavioral organization, but uptake remains uneven when staff lack a shared model, adequate training, or system support."

The clinical problem is visible in everyday interactions. Preterm infants communicate stress and self-regulation needs through behavioral cues, but these cues are often missed when staff and families are not trained to interpret them consistently (6). This makes NDSC both a knowledge issue and a practice-change issue.

Learning from local barriers and enablers:

The implementation approach did not begin with education

"Key-informant interviews and preliminary focus group discussions highlighted recurring barriers: staff often believed they were already doing enough; knowledge deficits persisted; misconceptions shaped practice; staffing constraints limited continuity; and turnover or agency staffing weakened consistency."

alone. It first asked what helps units change and what gets in the way. Key-informant interviews and preliminary focus group discussions highlighted recurring barriers: staff often believed they were already doing enough; knowledge deficits persisted; misconceptions shaped practice; staffing constraints limited continuity; and turnover or agency staffing weakened consistency.

At the same time, units identified clear enablers for success. These included support from hospital and nursing management, medical buy-in, ongoing awareness activities, clearer follow-up indicators, and a stronger shared understanding of the model itself. This finding shaped the project's central lesson: implementation succeeds when it is treated as an organizational process rather than just a training event.

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The implementation model:

The intervention was built on South African best-practice guidelines for NDSC (7) and organized into practical domains that address the NICU environment, direct infant care, family involvement, and multidisciplinary teamwork. Each guideline was linked to evidence strength and to concrete clinical recommendations, making the material usable at the bedside rather than remaining theoretical (7).

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A champion-based strategy was used to drive change inside units. Hospital management and peers nominated project champions who were willing to lead the work, and leadership development drew on Kouzes and Posner's transformational leadership approach (8). This helped position champions not only as trainers but also as local facilitators of culture change, ownership, and accountability.

The implementation process followed phased objectives over time (see Table). Pre-work focused on awareness, hospital approvals, ethics requirements, and planning. Early implementation then introduced leadership training, readiness assessment, pre-implementation focus groups, baseline audit work using the INDeSC (implementation of neurodevelopmental supportive care) audit tool, document review, and introductory NDSC teaching for staff. Monthly thematic roll-out followed, covering neurosocial development, positioning and handling, kangaroo mother care and transport, family-centered care, environmental and sensory management, feeding and non-nutritive sucking, pain management, breastfeeding, discharge preparation, follow-up, and integration of NDSC into procedures. Post-implementation assessment, focus groups, hospital policy integration, orientation planning, and ongoing annual evaluation were included to support sustainability and scale-up.

Practical supports that made the change easier:

A key strength of the model was its integration of content with ongoing implementation support. Units were not expected to change after a once-off workshop. Instead, the project provided a website for refresher learning, access to project documentation, monthly online sessions, recordings for review, and slide decks that champions could reuse during in-service training.

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The project also created a collective vision for participating teams. In one site, participants articulated a shared commitment to "building and empowering a compassionate family-centred environment that supports the neurodevelopmental growth of every infant's unique path to a thriving future." They named their implementation project the "Siyakhula Project," meaning: "We are growing" in isiXhosa/Zulu, all of which demonstrated ownership. Stakeholder analysis, engagement planning, and appreciation

Table. Timeline for implementation of objectives for neurodevelopmental supportive care

OBJECTIVE	TIME FRAME	METHOD	
Objective 1: Awareness of NDSC implementation	Pre-work	Principles of Kouzes and Posner Translational Leadership will be utilised and participants will be supported to celebrate small achievements.	
Objective 2: Adopting the concept	Pre-work	Hospital approval, additional ethics approval, and planning meetings	
Objective 3: Taking ownership	Month 1	Leadership training (2 days) Organizational Readiness for Implementing Change (ORIC) Pre-implementation Focus Group Discussions Journaling training	
Objective 4: Evidence of practice	Month 2	Study overview (pre-assessments) Baseline assessment INDeSC audit tool Document analysis (at hospitals by champions/research assistants) Introductory NDSC training for team members	Champions and research team
	Month 3	**Neurosocial development (stress cues & reg)**	Champions
	Month 4	**Positioning, handling, KMC (& transport)**	Champions
	Month 5	**Individualised family-centered care (parents)**	Champions
	Month 6	**Environment & sensory Mx**	Champions
	Month 7	**Feeding and NNS**	Champions
	Month 8	**Pain Mx (non-pharmacological)**	Champions
	Month 9	**Breastfeeding in the NICU**	Champions
	Month 10	**Hospital-to-home: discharge preparation, follow-up, community care**	Champions
	Month 11	**Procedures using NDSC (integration), (& transport)**	Champions & PI (on-site)
Objective 5: Evidence of routine & integration	Month 12	Post-implementation assessment INDeSC audit tool Document analysis (at hospitals by champions/research assistants) Post-implementation FGD	Champions
Objective 6: Sustainable practice	Month 18	Policies, sustainability practices, e.g., orientation programs (from 6 months post-implementation)	
Objective 7: Expanding NDSC as model of care		Annual evaluation and monitoring	

strategies were used to maintain momentum and strengthen ownership.

What others can do:

Units wanting to implement NDSC do not need to start with a perfect programme; they need a structured process. A practical sequence would be to secure visible managerial support, identify credible local champions, assess readiness, conduct a baseline audit, and use a staged teaching plan tied to specific practice domains. Regular reinforcement is essential because awareness fades quickly when training is not repeated and embedded in systems.

Three principles stand out from this implementation journey. First, evidence must be translated into simple, bedside-ready guidance. Second, unit culture changes faster when champions are supported by leadership and multidisciplinary buy-in. Third, sustainability depends on integrating the work into policies, orientation, documentation, and routine monitoring rather than treating it as a short-term project.

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Implications for neonatal units:

This model shows that implementation research can bridge the long-standing gap between neonatal evidence and daily practice. For NDSC, success depends on more than proving benefit; it requires local adaptation, leadership development, repeated coaching, and systems that help staff convert knowledge into reliable habits.

"For NDSC, success depends on more than proving benefit; it requires local adaptation, leadership development, repeated coaching, and systems that help staff convert knowledge into reliable habits."

For neonatal teams in similar contexts, the message is practical: start with one shared framework, prepare champions well, support them continuously, and measure what changes. That is how evidence begins to look like everyday care.

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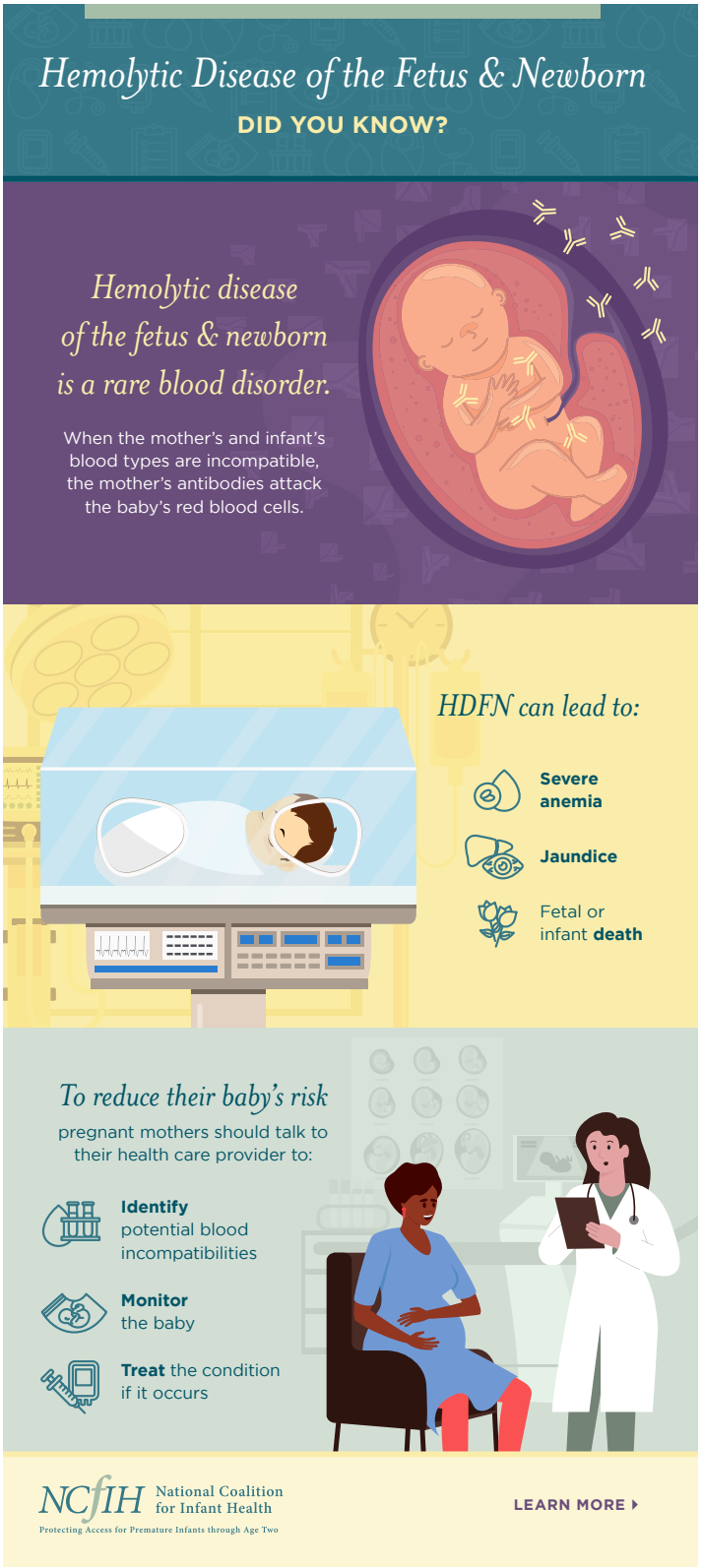

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A Multidisciplinary Approach to Perinatal Cardiology *Volume 1*

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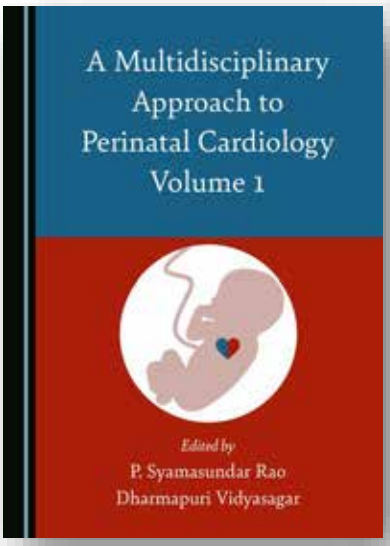

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Book Description

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

About the Editors

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

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

A Multidisciplinary Approach to Perinatal Cardiology Volume 1 is available now in Hardback from the Cambridge Scholars website, where you can also access a free 30-page sample.

Alliance for Patient Access: Supporting Safer Outcomes for Mothers and Babies

Josie Cooper

The Alliance for Patient Access (allianceforpatientaccess.org), founded in 2006, is a national network of physicians dedicated to ensuring patient access to approved therapies and appropriate clinical care. AfPA accomplishes this mission by recruiting, training and mobilizing policy-minded physicians to be effective advocates for patient access. AfPA is organized as a non-profit 501(c)(4) corporation and headed by an independent board of directors. Its physician leadership is supported by policy advocacy management and public affairs consultants. In 2012, AfPA established the Institute for Patient Access (IfPA), a related 501(c)(3) non-profit corporation. In keeping with its mission to promote a better understanding of the benefits of the physician-patient relationship in the provision of quality healthcare, IfPA sponsors policy research and educational programming.

AfPA | Alliance for Patient Access

IfPA | Institute for Patient Access

"New data from the Centers for Disease Control and Prevention, or CDC, show that maternal mortality in the United States declined in 2024 to 17.9 deaths per 100,000 live births — the lowest rate reported since 2018. While the decrease was modest and not statistically significant, the findings suggest that ongoing maternal health efforts may be making an impact."

New data from the Centers for Disease Control and Prevention, or CDC, show that maternal mortality in the United States declined in 2024 to 17.9 deaths per 100,000 live births — the lowest rate reported since 2018. While the decrease was modest and not statistically significant, the findings suggest that ongoing maternal health efforts may be making an impact.

At the same time, the data serves as a reminder that more work remains to be done. According to the CDC, more than 80% of pregnancy-related deaths are preventable. Delays in diagnosis, gaps in quality care, and limited follow-up during pregnancy and the postpartum period continue to put mothers at risk. Ensuring patients have access to timely, comprehensive care remains critical to improving outcomes for both mothers and infants.

"Despite recent progress, significant disparities in maternal health continue. Black women still experience maternal mortality rates three times higher than white women. Elevated risks also persist among older mothers and some Indigenous populations. These inequities reflect longstanding barriers to care, including differences in access to, treatment, and support services."

Why Continued Action Matters:

Despite recent progress, significant disparities in maternal health continue. Black women still experience maternal mortality rates three times higher than white women. Elevated risks also persist among older mothers and some Indigenous populations. These inequities reflect longstanding barriers to care, including differences in access to, treatment, and support services.

"The latest CDC findings are encouraging, but they are only one step forward. Continued investment in maternal health programs, improved access to care, and policies that address disparities can help reduce preventable deaths and support healthier pregnancies nationwide. Progress is possible, but sustained action will be needed to ensure safer outcomes for every mother and baby."

Addressing maternal mortality requires sustained, evidence-based solutions that support patients before, during, and after pregnancy. Policymakers, clinicians, and advocates continue to work to expand access to maternal health services, improve postpartum care, and strengthen early intervention efforts. Supporting mothers also means supporting newborns and families, helping to create healthier outcomes across communities.

Moving Maternal Health Forward:

The latest CDC findings are encouraging, but they are only one step forward. Continued investment in maternal health programs, improved access to care, and policies that address disparities can help reduce preventable deaths and support healthier pregnancies nationwide. Progress is possible, but sustained action will be needed to ensure safer outcomes for every mother and baby.

References:

1. https://www.cdc.gov/nchs/data/hestat/hestat113.htm
2. https://www.ajmc.com/view/black-maternal-health-week-highlights-persistent-disparities-and-policy-action

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

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Immunizing Yourself Against **COVID-19**

COVID-19 vaccines have been shown to:

- Lessen the severity of symptoms[1]
- Reduce disease transmission[3]
- Reduce risk of mortality[2]
- Make communities healthier and safer[4]

Understanding the Options

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

mRNA VACCINES

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

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

PROTEIN SUBUNIT VACCINES

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

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

VECTOR VACCINES

Used for decades against chickenpox, malaria and tuberculosis.

Use a modified virus, such as a common cold, to teach the body to fight off COVID.

COVID vaccines are recommended for everyone ages 6 months and older, and boosters for everyone ages 5 years and older, if eligible.[5]

Safe and Sound

COVID vaccines have been:

- **Thoroughly tested** through multi-phase trials with tens of thousands of participants[6]
- **Proven safe and effective** for adults as well as children[7]
- **Vetted and approved** by the US FDA and EMA and endorsed by the WHO[8-10]

Get Your Jab

Vaccines are available at your:

- **Doctor's office**
- **Neighborhood pharmacy**
- **Community health center**

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

1. https://www.mayoclinic.org/diseases-conditions/coronavirus/symptoms-causes/syc-20479963
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7. https://doh.wa.gov/emergencies/covid-19/vaccine-information/safety-and-effectiveness
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10. http://www.bccdc.ca/Health-Info-Site/Documents/COVID-19_vaccine/WHO-EUA-qualified-covid-vaccines.pdf

GAfPA Global Alliance for Patient Access

NCPA NATIONAL COMMUNITY PHARMACISTS ASSOCIATION

Still a **Preemie?**

Some preemies are born months early, at extremely low birthweights. They fight for each breath and face nearly insurmountable health obstacles.

But that's not every preemie's story.

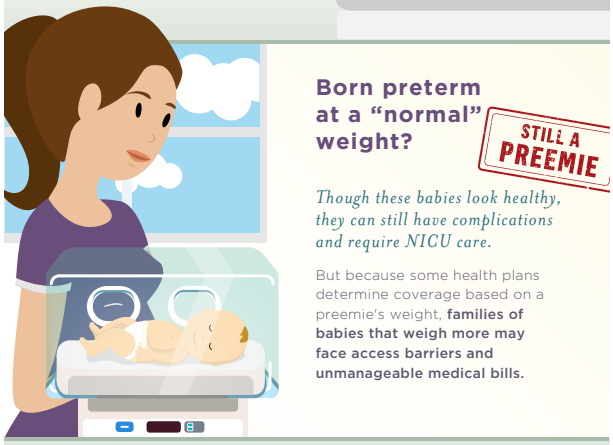
Born between 34 and 36 weeks' gestation?

STILL A PREEMIE

Just like preemies born much earlier, these "late preterm" infants can face:

Jaundice | Feeding issues | Respiratory problems

And their parents, like all parents of preemies, are at **risk for postpartum depression and PTSD.**



Born preterm at a "normal" weight?

STILL A PREEMIE

Though these babies look healthy, they can still have complications and require NICU care.

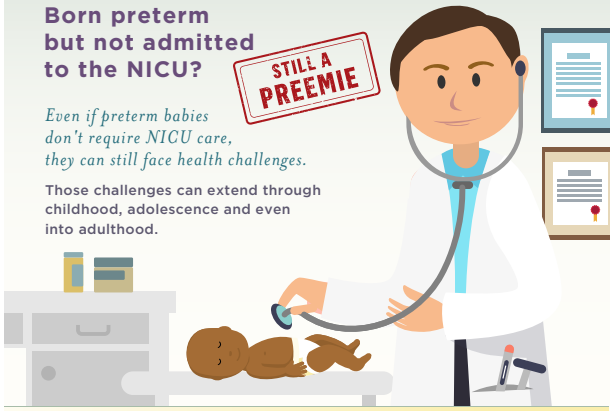
But because some health plans determine coverage based on a preemie's weight, **families of babies that weigh more may face access barriers and unmanageable medical bills.**

Born preterm but not admitted to the NICU?

STILL A PREEMIE

Even if preterm babies don't require NICU care, they can still face health challenges.

Those challenges can extend through childhood, adolescence and even into adulthood.



Some Preemies

- Will spend weeks in the hospital
- Will have lifelong health problems
- Are disadvantaged from birth

All Preemies

- Face health risks
- Deserve appropriate health coverage
- Need access to proper health care

NCfIH National Coalition for Infant Health

Protecting Access for Premature Infants through Age Two

www.infanthealth.org

The Gap Baby: An RSV Story

A collaborative of professional, clinical, community health, and family support organizations improving the lives of premature infants and their families through education and advocacy.

The National Coalition for Infant Health advocates for:

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

www.infanthealth.org

iCAN Update: iCAN Youth are in Full Bloom this June

Abby Clark

Get involved today and Join the iCAN Parent Council!

This May, iCAN youth members from around the world are taking charge of their stories and creating impact in their communities and beyond. As conversations about patient engagement become more prevalent in the global healthcare space, iCAN youth are making sure their voices ring loudly! The following newsletter showcases just a few examples of how iCAN youth members have helped grow global pediatric patient engagement efforts from a seed into a garden.

"As conversations about patient engagement become more prevalent in the global healthcare space, iCAN youth are making sure their voices ring loudly! The following newsletter showcases just a few examples of how iCAN youth members have helped grow global pediatric patient engagement efforts from a seed into a garden."

What is in this Issue of the iCAN Newsletter?

- What is iCAN?
- iCAN Impact - KIDS Walter Payton Featured in Local Newspaper
- Youth Member Spotlight - iCAN Youth Member Attends Patients as Partners EU
- KIDS Chapter Spotlight - KIDS Virginia Attends Science of Patient Engagement Summit
- Ask the Experts - Reflections on May's Episode and Upcoming Session
- iCAN Summit - Registration Open Until June 20!

"As a worldwide network of 40+ KIDS (Kids Impacting Disease through Science) advisory groups spanning four continents (and virtually), iCAN's dedicated youth member groups work in unison to provide a voice for children and families in medicine, research, science, and innovation."

What is iCAN?

Empowering Pediatric Patients Worldwide

iCAN, the International Children's Advisory Network, is the premier global pediatric platform working to empower the patient voice in healthcare, driven by youth for youth. As a worldwide network of 40+ KIDS (Kids Impacting Disease through Science) advisory groups spanning four continents (and virtually), iCAN's dedicated youth member groups work in unison to provide a voice for children and families in medicine, research, science, and innovation. To foster greater global understanding about the importance of the pediatric patient and caregiver voice in healthcare, clinical trials, and research, iCAN's young people continue to drive incredible change in the global health landscape.

"On average, our youth are between the ages of eight and eighteen years old, most of whom are living with chronic, rare, and complicated diagnoses; although, not all of iCAN's youth members have a medical diagnosis or medical condition."

On average, our youth are between the ages of eight and eighteen years old, most of whom are living with chronic, rare, and complicated diagnoses; although, not all of iCAN's youth members have a medical diagnosis or medical condition. iCAN celebrates the understanding that all patients, even the youngest, have valuable insights into improving the healthcare experience. All children, regardless of where they live, are welcome to participate in iCAN's programming. iCAN also supports young adults and the voices of parents and siblings. We continue to be an ecosystem of schools, children's hospitals, academia, and other like-minded non-profits.

"Our mission is to ensure that youth are placed in positions where their voices are heard and make a difference in pediatric healthcare through interactions with industry professionals, presenting original research at conferences, innovating new solutions, and sharing their stories."

Our mission is to ensure that youth are placed in positions where their voices are heard and make a difference in pediatric healthcare through interactions with industry professionals, presenting original research at conferences, innovating new solutions, and sharing their stories. iCAN continues to empower the pediatric patient voice through community partnerships with organizations such as the FDA, Everylife Foundation for Rare Diseases, PFMD, MRCT, iSPI, and AAP.

Whether a patient, family member, friend, healthcare professional, or just an individual looking to make a difference, you are welcome to visit our website at www.icanresearch.org to explore our mission, programs, and initiatives. Join us today in ensuring that every child's voice is enshrined in the effort to improve healthcare for all pediatric patients.

"We are so proud to share that one of our chapters, KIDS Walter Payton College Prep (WP), was featured on Page 8 of Skyline, a Chicago newspaper, for its incredible philanthropic project supporting kids at Ronald McDonald House Charities!"

iCAN Impact - KIDS Walter Payton Featured in Local Newspaper

We are so proud to share that one of our chapters, KIDS Walter Payton College Prep (WP), was featured on Page 8 of Skyline, a Chicago newspaper, for its incredible philanthropic project supporting kids at Ronald McDonald House Charities!

Through the generous support of the Hershey Company Service Project Grant, our WP chapter kids organized and donated backpacks filled with items for kids staying at Ronald McDonald House.

This meaningful initiative reflects the power of youth leadership, compassion, and community service. We are incredibly proud of our chapter for turning compassion into action and making a real

INSIDE PUBLICATIONS

Walter Payton students deliver Comfort Kits for families at Ronald McDonald House

On May 1, 175 teens contributed to the iCAN Deliver Hope at the Ronald McDonald House: Lurie Children's Hospital, 211 E. Grand Ave.

The youths were from Walter Payton College Preparatory High School ICAN Chapter, alongside their school's National Honor Society.

The youth-led initiative brought together student volunteers to assemble and deliver comfort kits for families staying at the Ronald McDonald House while their children received medical care.

The kits included essentials, comfort items, books, socks, stuffed animals, coloring books, and handmade cards created by students.

During their tour, students learned how the Ronald McDonald House operates and how young people can volunteer. They placed coloring books throughout the library and lounges and tucked their handmade cards into family mailboxes, hoping to bring a little comfort to those staying there.

The project took place during Youth Service Month and was supported through a grant from Youth Service America and The Hershey Co.

The youth-led initiative brought together student volunteers to assemble and deliver comfort kits for families staying at the Ronald McDonald House.

impact in its community. Congratulations on this well-deserved recognition in Skyline!

iCAN Youth Member Spotlight: iCAN Youth Member Attends Patients As Partners EU

This month, we are proud to spotlight iCAN Youth Member, Muminah (KIDS Moorfields Eye). She attended Patients as Partners EU 2026 and did an incredible job of sharing her voice as a young person while learning from experts in the field. She represented something that is too often missing from conversations surrounding improving patient engagement: the voices, perspectives, and questions of kids with lived experiences.

About Patients as Partners: The #PatientsEU2026 conference offers an unparalleled opportunity to hear from pharma R&D and patient advocacy together on how patient engagement gets done to drive greater efficiencies in clinical research and better outcomes. The conference prioritizes the patient voice to help pharma R&D make it easier for patients to find clinical research and achieve faster, more efficient clinical development.

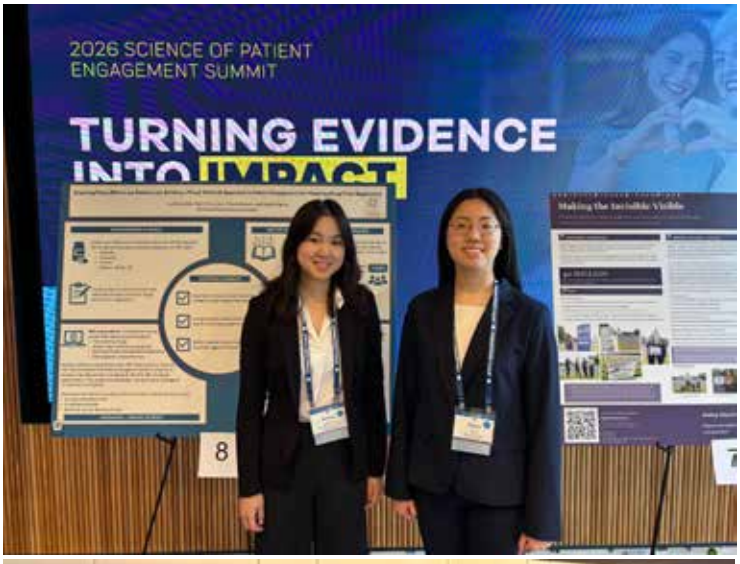
"... I really think I had an impact and sparked curiosity from a patient perspective that even large pharma companies like Pfizer could think of and were impressed by. This has shown me my potential and my drive, and also how I will continue to put in efforts to change the way patients are perceived in the medical field." (Muminah)

iCAN KIDS Chapter Spotlight: KIDS Virginia Attends Science of Patient Engagement Summit

Two youth members from KIDS Virginia took charge and represented their chapter and iCAN at the 2026 Science of Patient Engagement Summit in Arlington, Virginia. They did a fantastic job showcasing the professionalism, intelligence, and impact that young people have in a space often filled with representatives much older than them. They had the opportunity to meet Ms. Silke Schoch, Senior Director of Research & Programs, and Dr. Omar A. Escontrías, Chief Programs & Research Officer of the National Health Council.

"We heard speakers' personal experiences in making meaningful changes in healthcare. It was inspiring to see the impact patient advocacy can have on improving care and creating positive outcomes in research and clinical trials. The conversations resonated strongly with the work of iCAN on advocating for patient-centered research and ensuring that patients' voices and needs help shape outcomes in healthcare.

It was an amazing opportunity and an incredible experience for both of us. We are very grateful to iCAN and the National Health Council for giving us this opportunity."



iCAN Ask the Experts:

iCAN extends a huge thank you to guest speaker Dr. Maryanne Haddad and KIDS Member and ATE Host Piyush for an impactful "Ask the Experts" session! Through meaningful conversations on compassion, obesity medicine, resilience, mentorship, and patient-centered care, this session inspired our entire iCAN community. We are grateful for the honesty, wisdom, and empathy shared as we empower future healthcare leaders to lead with kindness and humanity.

Thank you for reminding us of the importance of listening, understanding, and advocating for compassionate healthcare for all.

From powerful conversations about compassion, obesity medicine, patient-centered care, and wellness, to honest reflections on resilience, mentorship, and empathy in healthcare, this discussion left a lasting impact on the entire iCAN community. Thank you for sharing your stories, experiences, and wisdom while encouraging the next generation of healthcare leaders to "be empathetic, be compassionate, be kind." We are so grateful for your time, authenticity, and dedication to improving healthcare with humanity and heart.

Next Episode: iCAN's ATE: From Survivor to National Advocate: The Inspiring Journey of Leia T. Hunt Toellner in Transforming Childhood Cancer Care, hosted by KIDS Summit Planning Committee Youth Member, Mary Rose.

Session Details: iCAN's ATE: From Survivor to National Advocate: The Inspiring Journey of Leia T. Hunt Toellner in Transforming Childhood Cancer Care

Date: Saturday, June 6, 2026

Time: 7:00 AM PST / 10:00 AM EST

"Leia T. Hunt Toellner is a two-time childhood cancer survivor. Leia's journey began when she was diagnosed with Retinoblastoma, a rare and aggressive form of eye cancer, at just two years old."

Speaker Bio:

Leia T. Hunt Toellner is a two-time childhood cancer survivor. Leia's journey began when she was diagnosed with Retinoblastoma, a rare and aggressive form of eye cancer, at just two years old. Her fight against the disease involved 26 surgical procedures, numerous rounds of chemotherapy, and the insertion of a radioactive isotope in her left eye. Although the radiation successfully eradicated the cancer, it also left Leia blind in that eye.

Despite these challenges, Leia's experiences fueled her passion to make a difference. At the age of 18, while still a senior in high school, she founded Leia's Kids, a 501(c)(3) non-profit organization dedicated to supporting families facing childhood cancer. Through Leia's Kids, Leia has provided financial assistance, advocacy, warrior parties, and mental health retreats for children, teens, and young adults across the nation.

In addition to her work with Leia's Kids, Leia is an inspirational speaker, podcast host, mental health advocate, educator, and author of several books, including What Is Cancer, My Battle Plan Journal, Princess Marygold and the Royal Tea Party, and Princess Marygold Coloring In the Castle. Her advocacy extends beyond her non-profit work, as she collaborates with organizations such as the Eye Tumor Research Foundation, the American Cancer Society, and the We C Hope Foundation. Leia works closely with Pharmaceutical companies and actively speaks at the Society for Clinical Research Sites (SCRS) global conference. Furthermore, she plays an active role in advocating for pediatric cancer research and awareness at both the state and federal levels, including speaking annually at the White House for the Cancer Moonshot initiative.

Leia's dedication and resilience have not only impacted countless lives but have also contributed to significant advancements in pediatric cancer legislation, ensuring that childhood cancer remains a priority in state cancer plans across the country.

"The 2026 iCAN Summit will be held July 12 (check-in) through July 17 (check-out), 2026, at Barretstown in Ireland (approximately one hour outside of Dublin), and will be hosted by KIDS RAiN CRAG. Set on beautiful, expansive grounds, Barretstown is a fully wheelchair-accessible SeriousFun therapeutic recreation camp, thoughtfully designed to support a wide range of physical and medical needs."

Ask the Experts brings in speakers every month to answer your questions about medicine, healthcare, research, innovation, and much more! Check out the ATE page on the iCAN Website to view previous recordings.

The 2026 iCAN Summit - Registration Open Until June 20!

Our annual Summit serves as a transformative platform for innovation, compassion, and collaboration in pediatric healthcare. As iCAN celebrates our 12th year of this incredible event, iCAN is so excited to announce that the iCAN Summit is back this summer in person. It is truly a testament to iCAN's dedicated and generous family that the Summit will continue to bring our young people together to change the global healthcare landscape. Registration is now open!

Link to Register: https://www.zeffy.com/en-US/ticketing/registration-for-icans-2026-summit

The 2026 iCAN Summit will be held July 12 (check-in) through July 17 (check-out), 2026, at Barretstown in Ireland (approximately one hour outside of Dublin), and will be hosted by KIDS RAiN CRAG. Set on beautiful, expansive grounds, Barretstown is a fully wheelchair-accessible SeriousFun therapeutic recreation camp, thoughtfully designed to support a wide range of physical and medical needs. In addition to collaborating directly with global industry leaders to advance meaningful change in pediatrics, our community will take part in exciting on-site experiences, including horseback riding, archery, canoeing, and team-building challenges, all intentionally adapted to ensure accessibility and inclusion for all participants (including those with medical and physical needs).

The lasting impact of this annual event on the youth who attend, the iCAN Network, and the wider healthcare community cannot be

measured. Together, we continue to impact pediatric healthcare in tangible ways. By giving every kid a seat at the table through discussion and co-creation, current and future pediatric patients are both empowered and transformed. We invite you to be part of this life-changing event by contributing in three meaningful ways:

1. Sponsor the 2026 Summit: Your sponsorship will play a crucial role in ensuring an

impactful experience for all attendees.

2. Sponsor a Child to Attend: Your sponsorship directly impacts a child's life by granting them the opportunity to attend the Summit in Canada. Your support will cover travel, accommodation, and participation, offering them a world of learning and empowerment.

"Together, we are shaping a brighter future for pediatric healthcare. Your contribution—big or small—makes a significant difference in prioritizing the patient voice and driving positive change."

Together, we are shaping a brighter future for pediatric healthcare. Your contribution—big or small—makes a significant difference in prioritizing the patient voice and driving positive change. Your generosity and dedication are deeply valued. Let's unite in Canada to create a summit experience that empowers the pediatric community for years to come.

3. Contribute to the GoFundMe for the iCAN 2026 Summit: We want our next Summit to be in person—and we can only do that with your support! Please share or donate to our GoFundMe:

- https://gofund.me/525439b3
- www.icanresearch.org

Let us work together to make our 2026 Summit even bigger by bringing more kids to share their voices! To contribute to the funding for next year's Summit, please click here to sponsor or make a donation.

Disclosures: *There are no reported disclosures*

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Pali Adventures
PORTO ELOUNDA
GOLF & SPA RESORT
WESTIN
HOTELS & RESORTS
The Westin Long Beach
MARRIOTT
Beverly Hills Marriott
DELTA HOTELS
MARRIOTT
Delta Hotels Montreal
cancúncards
Zachari Dunes
DOUBLETREE by Hilton
Ontario
SOUTH POINT
MIRACLE SPRINGS RESORT & SPA
PORTER VALLEY
COUNTRY CLUB
THE ACADEMY of MAGICAL ARTS
AT THE MAGIC CASTLE
PEJU
NAPA VALLEY
LA OPERA
Pacific Symphony
CARL ST.CLAIR MUSIC DIRECTOR
CRUISE COMPETE
Dunes West
GOLF & RIVER CLUB
AMERICA'S RAILROAD
DURANGO & SILVERTON
NARROW GAUGE RAILROAD
BEVERLY HILLS
Plastic Surgery Group
SABAN THEATRE
Powered by STERLING VENUE VENTURES
LONG BEACH
SYMPHONY
ECKART PREU, MUSIC DIRECTOR
FLAPPERS
COMEDY CLUB AND RESTAURANT
BURBANK
Pacific Chorale
GEFFEN PLAYHOUSE
LINKSOUL
CHANCE
THEATER @ Bette Aitken theater arts Center
lucky feet shoes
THE SORAYA
TAHOE DONNER
PEPPERDINE
Lisa Smith Wengler Center for the Arts
ISLAND PACKERS
citycruises
SMOKE HOUSE
Established 1948
VERDE CANYON RAILROAD
ILLUSION
MAGIC LOUNGE
LA MIRADA THEATRE
FOR THE PERFORMING ARTS
LAGUNA PLAYHOUSE
HAGAFEN
FAMILY OWNED
EST. 1979
Jack in the box
aNoiseWithin
Classic Theatre, Modern Magic
PASADENA PLAYHOUSE
DiscoveryCube
OC & LA
tieks
by Gavrieli
Murad
gorjana
RESTAURANT
GREEN STREET
WHEEL FUN RENTALS
USS Midway
MUSEUM
AMERICA'S LIVING SYMBOL OF FREEDOM
KINGS ICE
California
BOTANIC GARDEN
Bella Up
NEW WEST SYMPHONY
MICHAEL CHRISTIE | Music Director
Raising Cane's
CHICKEN FINGERS
BATTLESHIP
IOWA
LOS ANGELES
PHILHARMONIC SOCIETY presents
NEWPORT LANDING
THE MISSION INN FOUNDATION
RIVERSIDE
VISITOR CENTER + MUSEUM
Fiesta Village
Family Fun Park
WILLOWBROOK
THEATRICUM · BOTANICUM
CPH CORONADO PLAYHOUSE
Irvine Lanes
SIMMS
RESTAURANTS
THE HUNTINGTON
Hollywood
WAX MUSEUM
SANTA MONICA PLAYHOUSE
SANTA ANITA PARK
Go Kart World
OLIO E LIMONE
RISTORANTE
DOMENICO'S
RESTAURANT
ENJOY DELIGHT. YOU DESERVE IT.
Brent's
CHIPOTLE
MEXICAN GRILL
Panera
BREAD
Caroline Arnold, Author
BARK BOX
PETERSEN
AUTOMOTIVE MUSEUM

Join iCAN's Virtual Focus Group!

We warmly welcome all individuals within the age ranges of 8-10 and 12-18, including those with:

- Learning disabilities (example: dyslexia)
- Speech or language disabilities (examples: stuttering, understanding others, hearing)
- Physical disabilities (examples: epilepsy, cystic fibrosis)
- Autism Spectrum Disorder (ASD) or Attention-Deficit/Hyperactivity Disorder (ADHD)

Every voice counts!

It's a one-minute survey to see if you qualify for a one-hour focus group to be scheduled at a later date.

Survey Link: bit.ly/icanxkismet

Fill out the recruitment survey now and let your voice be heard! Together, we can make a real difference in pediatric healthcare!

iCAN
International Children's Advisory Network

Education.
Anytime, Anywhere.

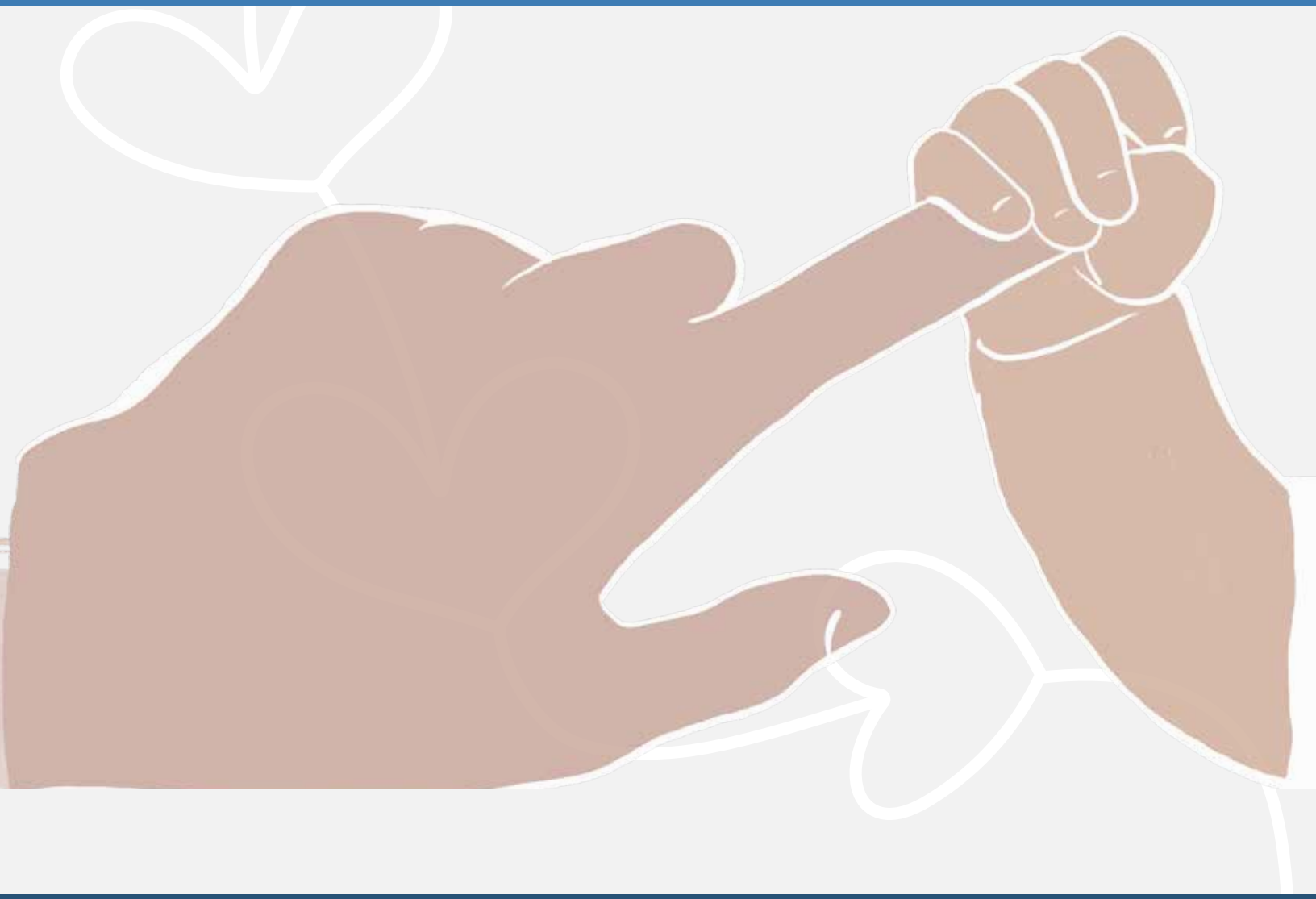
Academy of Neonatal Care

The Academy of Neonatal Care serves to educate Respiratory Therapists, Nurses, and Doctors in current and best practices in Neonatal ICU care. We prepare RT's new to NICU to fully function as a bedside NICU RT. Our goal is to enrich NICU care at all levels. Beginner to Advanced Practice, there is something for you at:

www.AcademyofNeonatalCare.org.

Every baby is part of a family.

Parents are their babies' primary caregivers.
Families are essential, equal, and integral members of the care team.



Parents and babies need each other.

National Network of NICU Psychologists

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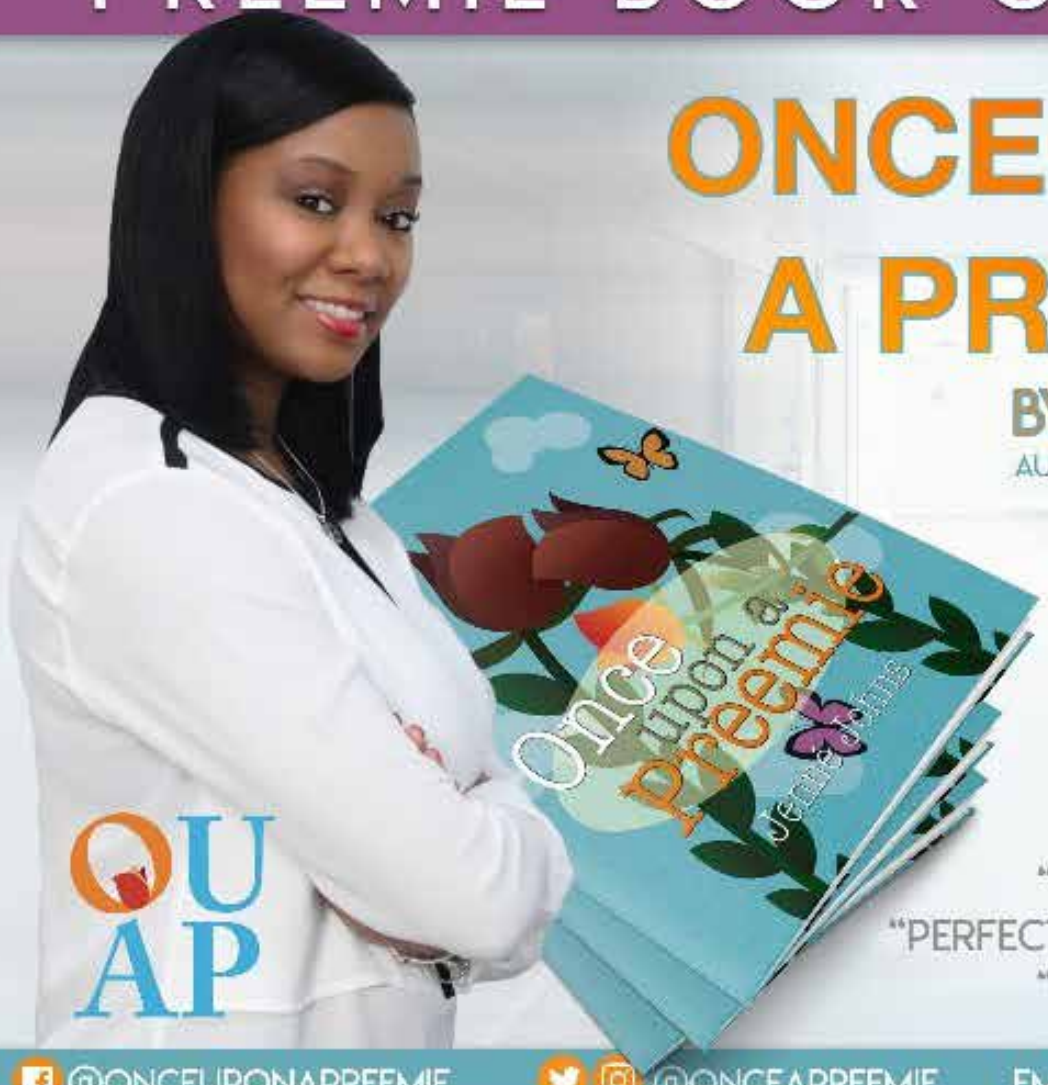

ONCE UPON A PREEMIE

BY JENNÉ JOHNS

AUTHOR | SPEAKER | ADVOCATE

QUAP

"ONE OF A KIND"
"PERFECT FOR PREEMIE FAMILIES"
"ENCOURAGING"

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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.

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Compiled and Reviewed by Benjamin Hopkins, DO

Government appeals AAP vaccine lawsuit ruling; loses bid to delay document release

NEWS PROVIDED BY

American Academy of Pediatrics

By Melissa Jenco

Study: **Government appeals AAP vaccine lawsuit ruling; loses bid to delay document release**

Current as of May 1, 2026

Federal health officials are appealing the historic court ruling blocking their overhauled immunization schedule that drastically reduced the number of routine vaccines for children.

Attorney Richard H. Hughes IV, J.D., who is representing the AAP and other medical groups who filed the lawsuit, said he is disappointed in the appeal and "we expect to prevail."

The government also recently asked U.S. District Court Judge Brian E. Murphy for permission to stop turning over administrative records to the AAP during the appeals process. The AAP opposed that move and the judge denied the government's request Friday.

The AAP and other medical groups filed the lawsuit against Health and Human Services (HHS) Secretary Robert F. Kennedy Jr. in July 2025 and have updated it several times as Kennedy continues to change vaccine recommendations without scientific evidence.

The lawsuit challenges Kennedy's decision to replace members of the Advisory Committee on Immunization Practices (ACIP), who advise the Centers for Disease Control and Prevention (CDC), with people who lack the credentials and required experience. It also challenges the CDC's January 2026 overhaul of the childhood immunization schedule that drastically reduced the number of routine vaccines for children and was announced without consulting ACIP.

In March, Murphy granted the AAP's request to block implementation of the new immunization schedule. He also found the new ACIP members likely were unlawfully appointed and halted their votes while the case continues.

Last month, Kennedy updated the ACIP charter, broadening the qualifications for members. It is unclear when he may name new appointees. The AAP and more than 100 other medical, public health and patient advocacy groups have spoken out against the new charter, which also puts more focus on rare vaccine injuries and adds liaison organizations known for spreading false information about vaccines.

The AAP continues to recommend routine vaccination to protect against 18 diseases in its 2026 immunization schedule. The AAP schedule has been endorsed by more than 12 national medical societies representing more than 1 million clinicians. A coalition of more than 230 medical, public health, parent and labor groups also have announced their support for the AAP's schedule.

Maternal RSV vaccination combined with infant immunization is safe

NEWS PROVIDED BY

American Academy of Pediatrics

By Melissa Jenco

Study: **Maternal RSV vaccination combined with infant immunization is safe**

Current as of May 5, 2026

Maternal respiratory syncytial virus (RSV) vaccination and infant immunization are safe and result in high levels of neutralizing antibodies whether they are given alone or in combination, a new clinical trial found.

"Either product is expected to provide high levels of protection for infants during these early months of life," co-author Christina A. Rostad, M.D., FAAP, said in a video abstract for "Maternal RSV Vaccination, Infant Nirsevimab or Both: Interim Analysis of a Randomized Trial," (Rostad CA, et al. Pediatrics. May 4, 2026)

Monoclonal antibody nirsevimab and maternal vaccination RSVpreF, which were approved in 2023, were thoroughly tested in separate clinical trials and most infants only need one for protection. However, both are called for in certain high-risk situations as well as when the vaccination status of the pregnant parent is unknown or when the infant is born less than 14 days after their pregnant parent was vaccinated.

To look at how the products perform when combined, researchers recruited 181 mother-infant pairs and randomized them into four groups — maternal vaccination, maternal vaccination and infant vaccination at birth, maternal vaccination and infant vaccination at 3 months or infant nirsevimab alone at birth.

The team plans to follow the infants for a year but reported interim data with up to four months of follow-up in its new study.

Neither the mothers nor infants in any of the groups experienced serious adverse events related to immunization, according to the study. Local and systemic reactions for infants receiving nirsevimab were mild to moderate. About 17% had a local reaction, most commonly injection site pain. About 60% had a systemic reaction, most commonly sleepiness/fatigue and irritability/crying.

"While most infants will not need to receive both products to be protected, our results suggest that maternal RSV vaccination and infant nirsevimab immunization may be safely sequentially administered," authors wrote.

The team also looked at levels of neutralizing antibody titers in infants and found significant increases in all four groups that remained high at 3 months of age despite some modest waning

from maternal vaccination alone.

Experts have not determined a minimum level of titers needed to protect infants from RSV. However, authors of the study noted antibody levels after maternal vaccination and/or infant immunization in their trial were similar to those found in clinical trials when the products were licensed. Those trials found each product to be highly effective in preventing medically attended infection and hospitalization.

The current trial had several limitations including that it only included uncomplicated pregnancies and the number of enrollees was too small to detect rare safety issues. The team also did not monitor infants for breakthrough RSV infections.

Authors noted maternal vaccination and infant immunization each have pros and cons. Maternal vaccination offers immediate protection and avoids an infant injection. However, the natural antibodies may wane more quickly. In addition, maternal vaccination only is given at 32 through 36 weeks' gestation from September through January.

Infant immunization produces antibodies that don't wane as quickly and there is more flexibility with timing. However, it comes with a higher price tag, could leave infants unprotected for months if not given at birth and has a small risk of adverse reactions. Last year, a second monoclonal antibody product, clesrovimab, also received federal approval. The AAP does not have a preference between nirsevimab and clesrovimab for infants under 8 months.

Authors of a related commentary said the safety findings for using maternal vaccination and infant immunization in combination are reassuring, although using both is too expensive for broader use. They indicated it will be useful to see which groups' antibodies persist at the 12-month follow-up.

Since the season began last fall, there have been 51,330 pediatric hospital admissions for RSV, most of which have been among children under 5 years, according to an AAP analysis of Health and Human Services data.

"RSV remains a primary cause of hospitalizations and early infection may lead to a lifetime of increased morbidity from a respiratory disease," authors of the commentary wrote. "These products represent tremendous advances in our ability to protect the most vulnerable infants."

Infant formula recalled due to toxin

NEWS PROVIDED BY

American Academy of Pediatrics

By Melissa Jenco

Study: **Infant formula recalled due to toxin**

Current as of May 5, 2026

Three batches of a2 Platinum Premium infant formula are being recalled due to the presence of a toxin produced by bacteria.

The milk-based powder with iron from the a2 Milk Company was distributed nationally through the manufacturer's website as well as Amazon and Meijer stores as part of the 2022 government effort to import formula in response to a shortage.

About 63,000 units are part of the recall, of which more than 16,000 were sold to consumers. The recalled products come in 31.7-ounce tins with batch numbers 2210269454 (use by July 15, 2026), 2210324609 (use by Jan. 21, 2027) and 2210321712 (use by Jan. 15, 2027). Importation rights expired at the end of 2025 and the product has been discontinued but may still be in people's homes.

Cereulide, a toxin produced by some strains of Bacillus cereus bacteria, was detected through testing in response to new guidance issued by New Zealand's food regulatory authority. An ingredient in the product likely is the source of the cereulide, according to the manufacturer.

Heating water when preparing the formula does not eliminate the toxin. It can cause symptoms including nausea and vomiting that typically start within 30 minutes to six hours after ingestion. Symptoms typically resolve within 24 hours but infants' developing immune systems can put them at risk for complications like dehydration. No illnesses related to the recalled formula have been reported.

Families in possession of the formula should dispose of it immediately or return it for a refund. They should seek immediate medical attention for an infant experiencing symptoms.

Illnesses also can be reported to the FDA's MedWatch system. Consumers with questions may contact a2MC at 844-422-6455.

Review: Tdap during pregnancy is safe, protects newborns from pertussis

NEWS PROVIDED BY

American Academy of Pediatrics

By Melissa Jenco

Study: **Review: Tdap during pregnancy is safe, protects newborns from pertussis**

Current as of May 15, 2026

Tetanus, diphtheria, and acellular pertussis (Tdap) vaccination during pregnancy is safe and protects newborns from pertussis (whooping cough), a new review confirmed.

"The data show that Tdap vaccination during pregnancy is an effective way to protect infants from a serious disease at a time when they are most at risk," said Rochelle Walensky, M.D., M.P.H., medical advisor for the Vaccine Integrity Project, which conducted the review. "The safety profile remains consistently strong across a large body of research, giving prospective parents confidence that they can safely protect their newborns from a serious disease that infected tens of thousands of people last year."

In 2025, there were 28,783 cases of pertussis including 16 deaths, according to provisional CDC data. Infants had the highest rate of severe disease. About 41% of those under 6 months who contracted pertussis were hospitalized. There already have been more than 13,000 cases across all ages this year.

The AAP, American College of Obstetricians and Gynecologists and Centers for Disease Control and

Prevention recommend Tdap vaccination during each pregnancy because infants do not begin pertussis vaccination until 2 months of age.

The Vaccine Integrity Project, an initiative of the University of Minnesota's Center for Infectious Disease Research and Policy, conducted the systematic review and meta-analysis of prenatal Tdap with the nonprofit Evidence Foundation. Project leaders said it comes in response to "recent public debate and policy uncertainty" as well as unfounded safety concerns about vaccination during pregnancy from federal vaccine advisers appointed by Health and Human Services Secretary Robert F. Kennedy Jr.

The review of 91 studies shows no evidence linking prenatal Tdap vaccination to increased risk of pregnancy outcomes like stillbirth, preterm birth, eclampsia, preeclampsia or gestational diabetes. There also was no evidence of increased risk to infants including congenital anomalies, neonatal intensive care admission, sepsis, low birth weight or death. While some adverse events may be too rare to capture in the studies, authors said they were reassured by the overall pattern as well as safety monitoring across multiple systems.

The team also found maternal Tdap vaccination is linked to a "probable reduction" in infant pertussis infections and severe disease. It lowers the rate of pertussis infection by an estimated 61 cases per 100,000 infants compared to no Tdap, the study found. When using the rate of infection before federal officials began recommending prenatal Tdap, it leads to 146 fewer cases per 100,000 infants.

Looking at severe disease, maternal Tdap vaccination reduces hospitalizations and emergency department visits for pertussis by an estimated 59 cases per 100,000 infants, according to the review.

Authors also noted infants whose pregnant parent was vaccinated have higher antibody levels at birth compared to their peers.

The Tdap review is one of several conducted by the Vaccine Integrity Project. Others have confirmed the safety and effectiveness of HPV vaccines, hepatitis B vaccines and COVID-19, flu and respiratory syncytial virus immunizations.

Nine Months of Medical Attention. Then Almost Nothing.

NEWS PROVIDED BY

The New York Times

By Sejal Hathi

Study: **Nine Months of Medical Attention. Then Almost Nothing.**

Current as of May 25, 2026

A pregnant woman in America receives more sustained medical attention than at almost any other point in her life. Her blood is drawn, her glucose monitored, her weight and blood pressure tracked. She sees a doctor every four weeks, then every two, then every week.

Then she has the baby — and the system moves on.

I know how quickly care recedes because I am living it. One year after my daughter's birth, I still begin most days in a body I no longer fully recognize. I sustained a third-degree tear during delivery and spent months dealing with urinary incontinence. Pregnancy separated my abdominal muscles, and their stubborn refusal to reknit rendered even the most ordinary movement, like lifting my daughter from her crib, a willful act.

I had nowhere obvious to turn. My obstetric specialist discharged me at six weeks after delivery, and the general OB clinic was stretched so thin it had stopped scheduling new postpartum patients. My primary care physician said postpartum recovery was outside her scope. So I assembled my own care: researching my symptoms, calling pelvic floor therapists, coordinating referrals.

I am a physician who runs her state's health agency. I had good insurance, paid leave and a fluency with institutions most new mothers should never need. What I did not have was a single provider who could serve as a quarterback for my care.

The dominant obstetric care model treats postpartum recovery as a brief coda to pregnancy: a short follow-up interval, punctuated by a three- to six-week clinic visit. Our reimbursement system reinforces that assumption, bundling prenatal care, delivery and immediate postpartum care into a single global fee, even as recovery extends months longer.

Beginning next year, the American Medical Association will replace that global fee with new codes that allow providers to bill for each piece of care separately. But fragmenting the bill may deepen the underlying problem: Beyond the first few weeks after delivery, no single clinician owns accountability for the mother's recovery and well-being. Her baby will see a pediatrician seven or more times in the first year of life. Whether the mother sees a doctor will depend largely on whether something goes wrong

That gap in care would matter in any era. It is especially consequential now, as the United States openly debates how to persuade women to have more children. The White House has called itself "the most pro-family administration in history," and Vice President JD Vance has said that the government should "make it easier for young moms and dads to afford to have kids."

But that postpartum year is when many families quietly decide whether to try again. Women who experience significant complications are up to 20 percent less likely to have another child, and when they do, they wait longer.

It is also a period of profound vulnerability. Mental illness spikes in the months following delivery. And for many women, the demands of caring for a baby and a lack of paid leave too often conspire to deter them from seeking necessary care. Two-thirds of pregnancy-related deaths in the United States happen in the year after giving birth, and more than 80 percent are preventable.

A mother and her newborn's health are inextricably intertwined. When a mother's depression goes untreated, infant cognitive development suffers. When her baby falls ill, she produces targeted antibodies in her breast milk to fight infection. States with the worst maternal mortality rates tend also to have the worst infant outcomes.

It's true that there has been some recent good news for maternal health. Most notably, all but one state will extend Medicaid postpartum coverage from 60 days to a full year after birth by the end of this summer. But coverage is not the same as ensuring that patients have ongoing, coordinated medical care. To achieve that, we should design a model that treats mother and infant as a single unit of care, both clinically and financially, through the first year of life.

This could start by having maternal and pediatric services in the same location,

such as placing midwives, mental health counselors and pelvic floor therapists inside pediatrician offices. After all, we know mothers reliably appear for their baby's appointments even when they neglect their own. Better still would be taking advantage of babies' built-in schedule of checkups to screen both mother and baby for common conditions at the same visit (some pediatric offices are already starting to screen mothers for postpartum depression).

Providers across maternal and pediatric services could be paid to work collaboratively and rewarded for keeping both patients healthy. That would require significant changes to the way the health system delivers and reimburses providers for care, but the deeper shift is conceptual: that medicine has a clear responsibility for both lives.

None of this is fanciful. Finland, for example, has long followed mother and child together at its public maternity clinics, assigning the same nurse to care for both patients through the early years. It's a system based around the simple truth that a mother's recovery matters as much as her newborn's growth.

My husband and I always imagined we would have more than one child. I understand more viscerally now why so many women stop at one — not because they don't want another child, but because they know how swiftly the system lets go once the baby arrives.

Tiny patients, big fight: NICU parents win leave in 2 states and push for more

NEWS PROVIDED BY

The Associated Press

By Alexandra Olson

Study: **Tiny patients, big fight: NICU parents win leave in 2 states and push for more**

Current as of May 17, 2026

As his daughter Olivia was born, Marlon White felt his wife's hand slacken as she fainted. The baby, born at 29 weeks and weighing about 2 pounds, wasn't making a sound as she was rushed to the neonatal intensive care unit. Terrified, he waited in the hall while the doctors stabilized his newborn and wife.

The next day, White, a welder, was back at work. Two days later, his wife, Farra Lanzer-White, was also back on the job, setting up a work station at the Denver hospital. For two months, first at one hospital then another, she kept up with emails and meetings as alarm bells went off each time Olivia stopped breathing, as she herself prepared for open-heart surgery for a condition discovered during her difficult pregnancy.

The Fort Collins, Colorado couple made a choice familiar to many parents with newborns in intensive care: Keep working while the baby is in the NICU to save any parental leave they might have for when the baby comes home. They are now part of a growing movement advocating for the adoption of NICU leave in the country's patchwork of family leave policies, which differ between states, cities and companies.

In January, seven months after Olivia was born, Colorado became the first U.S. state to adopt paid NICU leave, offering up to 12 weeks for parents with newborns in intensive care on top of the 12 weeks of parental leave under the state's family and medical leave program. A more modest policy will take effect next month in Illinois, guaranteeing between 10 and 20 days of unpaid leave to NICU parents.

While advocates want more states to adopt NICU leave, a major focus now is galvanizing support for a federal bill to add NICU leave to the Family and Medical Leave Act, the 1993 law that entitles eligible workers nationwide to take unpaid leave for family and medical reasons, said Inimai Chettiar, president of A Better Balance, a nonprofit that advocates for paid leave and other workplace policies in support of families.

"We think it's promising in terms of bipartisan support, because as we've approached people, it seems that they intuitively understand it," said Chettiar.

U.S. Rep. Brittany Pettersen, a Colorado Democrat who is drafting the federal bill said it would offer up to 12 weeks of NICU leave on top of the 12 weeks of parental leave available under the FMLA.

Push for bipartisan support

The U.S. has no federal law mandating paid family or parental leave, an issue that has long divided Democrats and Republicans. While FMLA leaves out many workers who can't afford to take unpaid leave, Pettersen said the goal is to win bipartisan support for the idea of NICU leave and bring it to the forefront of discussions surrounding parental leave.

The NICU leave bills passed in Colorado and Illinois offer mixed signals about the potential for bipartisanship. Colorado's paid leave passed mostly along party lines, while the shorter, unpaid leave adopted in Illinois had overwhelming bipartisan support.

Unlike Colorado, Illinois does not already have a paid family leave program in which it could incorporate NICU leave, said Illinois state Rep. Laura Faver Dias, a Democrat who introduced the bill and whose twin boys were born at 27 weeks in 2014 and stayed intensive care for three months.

Several Republican lawmakers became co-sponsors, including state Rep. Nicole La Ha, whose daughter spent 45 days in the NICU in 2017 after her water broke at almost 30 weeks.

"Unless you have had this experience, you can't fully understand why something like this is so meaningful," said La Ha. "You have an infant who is struggling to eat and breathe. The last thing you want to think about is work but unfortunately you have bills to pay."

While Colorado's bill lacked bipartisan support, Colorado State Sen. Jeff Bridges said "it was the quietest opposition you could hear," with few Republicans or business groups publicly speaking against it. Bridges introduced the bill a year after his son Kit was born two months early and weighing just 2 pounds.

"I wanted to share stories that were so moving that the lobbyists would look like monsters if they opposed it," Bridges said.

A handful of businesses step in

Nearly one out of 10 babies born in the U.S. are admitted to a NICU, according to the most recent figures from the Centers for Disease Control and Prevention.

While in the NICU, newborns are still learning to swallow, breath on their own and regulate their body temperature, said Dr. Karen Puopolo, section chief for Newborn Medicine at Pennsylvania Hospital and chair of the Committee on Fetus and Newborns of the American Academy of Pediatrics. Parental presence has a "multitude of advantages both ways," Puopolo said. Skin-to-skin contact slows down the baby's heart beat, improves their breathing and helps the mother with milk production.

In recent years, a smattering of companies have adopted dedicated paid NICU leave, including Morgan Stanley, Pinterest and the organic baby formula company Bobbie, while others have extended the length of parental leave or added policies like caregiving leave, which could also help NICU parents.

But mostly, the plight of NICU parents has been a blind spot, said Sahra Cahoon, executive director Love for Lily, a Colorado-based organization that supports NICU families and advocated for Colorado's new law.

Cahoon launched the organization after her daughter Lily, born at 24 weeks and five days, died after three-and-a-half months in the NICU. Cahoon, who owned a jewelry-making business at the time, said she worked, believing her daughter would survive.

"It's probably one of my biggest regrets," Cahoon said, though at the time she felt lucky to be able to work remotely from the hospital and didn't feel she could afford to give up her income. "We did not know that our story was going to end that way."

Feeling unprepared

When Rebeca Herrera-Moreno learned about Colorado's NICU leave law last year, it brought her back to her son's time in the NICU six years earlier and she decided to leap into advocacy for a similar provision in her home state of California.

When her son Nico was born at 32 weeks in 2020, Herrera-Moreno was already on disability leave, having entered preterm labor weeks earlier. Her husband, Martin Moreno, was entitled to six weeks of paid parental leave under California law at the time, but they decided he would save that time for when Nico could come home, which ended up being three weeks later.

She struggled to enjoy moments with her tiny son while holding him surrounded by machines, monitors and nurses. She would say "I love you" every day before leaving him while guilt swelled inside her that she hadn't developed that feeling yet. Weeks later at home, she opened to up to her husband, Martin Moreno, who confessed that he had felt the same way.

Moreno, a health director for a labor union, said he was consumed at the time with his job, which suddenly intensified as the COVID-19 pandemic swept the country. To this day, his most vivid memory of the period isn't with his son in the NICU, but of a video he helped produce to show workers how to properly wash their hands.

When he came home, he felt unprepared to care for Nico, who had to be fed on his side to prevent choking. He had been oblivious to his wife's emotional turmoil.

"I wish I would have had more preparation with the medical staff to really feel like I had everything set. And that's speaking to the medical piece of it — not even addressing being absent for Becky during so much of this," Moreno said.

Being present

Nearly 800 people have applied for neonatal care leave since Colorado's policy took effect in January, according to Tracy Marshall, director of Colorado's Family and Medical Leave Insurance Division.

Among the first were Chris and Stevie Madden, whose son was born almost eight weeks early on Jan. 11.

Stevie Madden, a mental health professional who had been rushed to the hospital after her blood pressure spiked and she began bleeding, said she panicked about how to handle the crisis and work when she realized she had planned to start her maternity leave much later.

A nurse at the hospital, however, told Chris Madden about the new NICU leave, which they both applied for.

Madden, an oil field mechanic, said he wouldn't have been able to keep him mind on his risky job while his son was fighting for his life. He said he learned how to handle his baby's delicate skin — press gently, don't rub — and gained the confidence he needed when Roczen stopped breathing once after returning home and had to be rushed the hospital.

He told every parent he met at hospital about NICU leave.

"It was life changing not to have to think about money and stress and just be present with your baby," Madden said.

Inside the High-Stakes Corporate Fight Over Feeding Preterm Babies

NEWS PROVIDED BY

KFF Health News

By David Hilzenrath

Study: **Inside the High-Stakes Corporate Fight Over Feeding Preterm Babies**

Current as of May 30, 2026

In 2013, a scientist at Abbott Laboratories saw study results with potentially big implications for the company's profits and the lives of some of the world's most fragile people: preterm infants.

The upshot, she wrote in an email: Babies fed rival Mead Johnson Nutrition's acidified liquid human milk fortifier — a nutritional supplement used in neonatal intensive care units — developed certain complications at higher rates than those given an Abbott fortifier, a researcher at the University of Nebraska had found.

At least one of those complications can be deadly.

The Abbott scientist, Bridget Barrett-Reis, described the results in the email to colleagues, using two exclamation points. Then she proposed that Abbott test the Mead Johnson fortifier, acidified for sterilization, against another Abbott product.

The clinical trial among preterm infants that Abbott subsequently sponsored, known as AL16, is a case study of corporate warfare in the high-stakes business of infant nutrition, wherein preemies have been coveted like commodities; their anxious, vulnerable parents have been — whether they know it or not — targets of calculated commercial pursuit; and scientific research has been used as a marketing tool.

In hospitals around the country, dozens of babies born an average of 11 weeks early were fed Mead Johnson's fortifier. Dozens of others were fed an Abbott fortifier that wasn't acidified.

The clinical trial became a boon for Abbott, which publicized the results to wrest market share from Mead Johnson. But for some of the babies enrolled, it didn't turn out so well, a KFF Health News investigation found.

Far more infants given Mead Johnson's product developed a buildup of acid in the blood called metabolic acidosis than those fed Abbott's product — 19 versus four, according to results published in the journal PharmacoEconomics.

Two outside doctors monitoring infants in the study became so alarmed that they refused to enroll any more babies, according to an April 2016 email one of them sent to Abbott.

In a related email to Abbott, neonatologist

Robert White of Memorial Hospital in South Bend, Indiana, and Pediatrix Medical Group — an investigator in the study — explained his concerns.

"We had another SAE" — serious adverse event — "today in which a child developed profound metabolic acidosis while on the study fortifier," White wrote. The severity was "unlike what we would see in most children with these issues."

A manager at Abbott replied that the company was "taking your concerns very seriously."

The study continued for almost a year.

At least some of the consent forms used to inform parents about risks did not mention metabolic acidosis or the often-fatal necrotizing enterocolitis, another condition identified in the 2013 email that led to the study.

In a November response to questions for this article, Abbott spokesperson Scott Stoffel said the clinical trial "was safe and ethical" and that the fortifiers it compared were "on the market and widely used."

The study was "led by 20 non-Abbott investigators," Stoffel said.

According to a federal website, Abbott's Barrett-Reis chaired the study.

Stoffel added that the study was approved "by 14 independent safety review boards at hospitals" and "published in a leading peer-reviewed scientific journal."

"It is reckless and not credible to suggest that these doctors and institutions conducted and then published the results of an unsafe or unethical study," Stoffel said.

A spokesperson for Mead Johnson, Jennifer O'Neill, did not comment on Abbott's clinical trial but said in a November statement to KFF Health News that existing studies "cannot responsibly support" any connection between the acidified fortifier and conditions such as necrotizing enterocolitis or metabolic acidosis.

Mead Johnson executive Cindy Hasseberg argued in a deposition that Abbott waged a "smear campaign" against the acidified fortifier that was "very hard to come back from."

In 2024, Mead Johnson discontinued the product.

Winning the 'Hospital War'

Behind their warm-and-fuzzy marketing, industry giants Abbott, maker of Similac products, and Mead Johnson, maker of the Enfamil line, have turned neonatal intensive care units into arenas of brutal competition.

This article quotes from and is based largely on records from three lawsuits against formula manufacturers that went to trial in 2024 and are now on appeal. The cases are Watson v. Mead Johnson, Gill v. Abbott Laboratories, and Whitfield v. St. Louis Children's Hospital. The records include emails, internal presentations, and other company documents used as exhibits in litigation, as well as court transcripts and witness testimony from depositions.

The records provide an inside view of the business of infant formula and fortifier, a nutritional supplement added to a mother's milk. For example, a Mead Johnson slide deck for a 2020 national sales meeting — later used in the Whitfield trial — outlined a plan for "Branding NICU Babies."

Urging employees to win more sales from neonatal intensive care units, the document said: "It is time to open up a can of 'Whoop Ass.'"

In internal documents and other material from litigation reviewed by KFF Health News, formula makers described hospitals as gateways to the much larger retail market because parents are likely to stick with the brand their babies started on. Products used in the NICU help win hospital contracts, and hospital contracts help establish brand loyalty, according to court records.

Manufacturers vie for contracts that can be "exclusive" or nearly so, according to records from the litigation, including company documents and testimony by people who have worked in management for the companies.

An undated Abbott presentation used in the Gill case, apparently referring to inroads with hospitals in its rivalry with Mead Johnson, boasted of "MJ Strongholds Broken!"

It saluted two employees who "Own 27K Babies Exclusively," and said another "Stole 600 formula feeders from MJ."

Still others were praised for "Playing in Mom's mailbox" or "kicking … and 'taking names.'"

In July 2024, Abbott CEO Robert Ford said in a conference call for investors that formula and fortifier for preterm infants generated total annual revenue of about $9 million — a small portion of Abbott's total sales of $42 billion in 2024 and its $2.2 billion of sales in the United States from pediatric nutritional products.

Industry documents cited in litigation provide a different perspective.

"'First Bottle Fed' drives our business," stated an Abbott training presentation from about a decade ago used in the Gill and Whitfield trials.

That described a baby's first formula feeding in the hospital, the document said. Over 74% of the time, an infant fed formula in the hospital stays on that brand at home, the document said.

Abbott's goal was that the first-bottle-fed strategy would help generate more than $1.5 billion in sales, the document showed. A staff training slide displayed during the Whitfield trial showed how that momentum could pay off in bonuses for Abbott sales representatives, leading to a "Happy Rep."

Mead Johnson has espoused a similar strategy.

The company rolled out a "Flip & Win" incentive plan with cash rewards for flipping hospitals from Abbott, according to a 2019 document marked for internal use by Mead Johnson and its parent company, England-based Reckitt Benckiser Group, and admitted into evidence in the Watson case.

"Winning in the NICU is critical to contract gains and acquisition," stated a company plan for 2022 that was cited in the Whitfield case.

One Abbott document shown in the Whitfield trial said more than half of first feedings happen at night, adding, "Nighttime is the right time to drive your business."

A "Mead Johnson University" training document described a scenario in which a sales rep overhears patient information in a NICU and encouraged the rep to promote the company's products. The document, titled "Advanced NICU Skills," was admitted as evidence in the Watson case.

"[Y]ou are walking back into your most important NICU," it said. "You overhear the HCP's" — health care providers, apparently — "stating all of the notes," it said. "There may be some information that may help you to position your products as a resource for this patient and to handle any objections that the HCP may present you with."

To win parents' business, companies have supplied formula to hospitals free or at a loss, court records show. That has resulted in such curiosities as a Mead Johnson "purchasing agreement" cited in the Watson case, listing the price for product

after product as “no charge.”

In a 2017 strategy document prepared for Mead Johnson, a consulting firm laid out a plan “to win hospital war.”

Why focus on hospitals? “INFLECTION POINT FOR VULNERABLE MOMS,” it explained.

The document was displayed in the Whitfield case.

In the market for preterm nutrition, Abbott and Mead Johnson compete with each other, not against the use of human milk, the companies told KFF Health News.

“Thus, references in documents about wanting to ‘win’ or ‘own’ the NICU refer to out-performing Mead Johnson by offering the highest-quality products,” Abbott’s Stoffel said in February.

Asked specific questions about business strategies and internal documents, Mead Johnson’s O’Neill said the company was “concerned that you are presenting a misleading and incomplete picture.”

Mead Johnson’s products “are safe, effective, and recommended by neonatologists when clinically appropriate,” O’Neill added.

On the Defensive

In courthouses around the country, Abbott and Mead Johnson are on the defensive — and have been for years.

In hundreds of lawsuits, parents of sickened or deceased preterm infants have alleged that formula designed for preemies has caused necrotizing enterocolitis, or NEC, a devastating condition in which immature intestinal tissue can become infected and die, spreading infection through the body.

Lawsuits also accuse the manufacturers of failing to warn parents of the risk.

One of the cases on which this article is based, Watson v. Mead Johnson, resulted in a $60 million judgment against Mead Johnson. Another, Gill v. Abbott Laboratories, et al., resulted in a $495 million judgment against Abbott. The third, Whitfield v. St. Louis Children’s Hospital, et al., resulted in a jury verdict in favor of Abbott and Mead Johnson, but the judge found errors and misconduct on the part of defense counsel, faulted his own performance, and granted the plaintiff a new trial.

The cases have involved children like Robynn Davis, who was born at 26 weeks, lost 75% to 80% of her intestine to NEC, suffered brain damage — and, at almost 3 years old, couldn’t walk, couldn’t really talk, and was eating through a tube, as Jacob Plattenberger, an attorney representing her, described in court in 2024.

An attorney for Abbott, James Hurst, said in court that Robynn suffered a catastrophic brain injury at birth, 10 days before she received any Abbott formula, and that her NEC resulted not from formula but from many health problems.

In at least three cases, a federal judge has granted summary judgment in favor of Abbott — ruling for the company before the lawsuits even reached trial.

The formula makers have repeatedly denied fault.

Addressing stock analysts in 2024, Abbott’s chief executive denounced as “without merit or scientific support” the theory that preterm infant formula or milk fortifier caused NEC.

In a joint statement issued in 2024, the FDA, the Centers for Disease Control and Prevention, and the National Institutes of Health said there was “no conclusive evidence that preterm infant formula causes NEC.”

Mead Johnson’s O’Neill said the scientific consensus is that there is no established causal link between the use of specialized preterm hospital nutrition products and NEC.

Neonatologists use the products routinely, O’Neill said.

O’Neill cited a statement by the American Academy of Pediatrics saying the causes of NEC “are multifaceted and not completely understood.”

In a legal brief filed with an Illinois appeals court in the Watson case, the company said “the NEC-related risks” of a formula for preterm infants “are the subject of medical debate,” adding that trial evidence “demonstrated, at a minimum, uncertainty as to the magnitude of the risk, as well as the causal role of various feeding options in the development of NEC.”

Manufacturers say formula is needed when mother’s milk or human donor milk isn’t an option. Fortifier, a product tailored to preemies, is meant to augment mother’s milk when babies are born prematurely and a mother’s milk alone doesn’t deliver enough nutrition. The Mead Johnson fortifier used in the head-to-head clinical trial sponsored by Abbott was acidified to prevent bacterial contamination.

In March 2025, Health and Human Services Secretary Robert F. Kennedy Jr. announced that his department, which encompasses the FDA, was undertaking a review of infant formula, dubbed “Operation Stork Speed.” It includes reassessing nutrient requirements and increasing testing for heavy metals and other contaminants, HHS said.

However, FDA oversight of infant formula is limited. The agency doesn’t approve the products or their labeling. Whether to report adverse events — illnesses or deaths potentially related to the products — to the FDA is largely at manufacturers’ discretion.

The business of infant formula further spotlights a central contradiction in the Trump administration’s health policies. When it comes to food and medical products, the administration has criticized industry-funded research as unworthy of trust. Yet under Kennedy, it has disrupted, defunded, or sought to cut government-funded research, which could leave industry-funded research with a larger and more influential role.

It “is entirely appropriate for the Department to scrutinize research design, conflicts of interest, and funding sources, particularly when research is used to inform public policy,” HHS spokesperson Andrew Nixon said.

‘At the Table’

Company emails cited in litigation shed light on the industry’s approach to research.

In a 2015 email, when Mead Johnson was considering supplying some of its formula to a researcher for a study, a company neonatologist expressed concern that the results could be spun to make the preemie product look unsafe.

“However, we are more likely to have control over final language if we provide the small support and are ‘at the table’ with him,” Mead Johnson’s Timothy Cooper added in the email, which was cited in the Watson trial.

In 2017, Abbott exchanged a series of messages with researchers at Johns Hopkins University about a study on how the composition of infant formula might affect NEC in mice. The email thread became an exhibit in the Whitfield case.

Abbott was both funding and collaborating on the work, a later publication in a scientific journal shows.

Forwarding a draft of the resulting paper to Abbott, David Hackam, chief of pediatric surgery at the Johns Hopkins University School of Medicine, said in one of the emails, “We hope you like it.” He also requested help from Abbott in filling in information.

"The manuscript looks great!" Abbott's Tapas Das wrote in May 2017, after a back-and-forth.

But Abbott had some changes, the email thread shows.

"We (VM & DT) made some edits in the text especially to soften a bit with the statement 'infant formula seems responsible for developing NEC,'" Das wrote.

"Instead, we thought if we could state as 'infant formula is linked to severity of NEC'. So we made changes throughout the text emphasizing on severity of NEC by infant formula rather than development of NEC by infant formula," Das wrote.

Das wrote that "other factors are involved for NEC development as described in the text."

Hackam did not respond to questions KFF Health News sent by email.

Efforts to reach Das and Cooper — including by phoning numbers and sending letters to addresses that appeared to be associated with them — were unsuccessful.

When Mead Johnson provided support to scientific researchers, the company would want to make sure they reported the results "in an honest way," Cooper said in a deposition played in the Watson trial.

The Abbott co-authors "proposed routine edits to the article for scientific accuracy and for the consideration of the other authors, some of the most well-respected NEC researchers in the world," Abbott's Stoffel said.

"Abbott regularly collaborates with and publishes studies with leading NEC scientists for the benefit of both premature infants and the entire scientific community," Stoffel said.

"The research studies Mead Johnson supports are conducted independently and appropriately, with full transparency," said O'Neill, the Mead Johnson spokesperson.

'In the Wrong Direction'

Transparency can be subjective.

More than a decade ago, Mead Johnson sponsored a clinical trial testing what was then a new acidified liquid fortifier against a powdered fortifier already on the market.

In the study, which enrolled 150 babies, 5% of infants fed the acidified liquid developed NEC compared with 1% of infants fed the powder, according to deposition testimony and a record of the clinical trial used in the Watson case.

That information was not included in a 2012 medical journal article that reported the study results.

The article, in the journal Pediatrics, whose authors included two Mead Johnson employees, concluded it was safe to use the new liquid fortifier instead of the powdered one. The article also said that, comparing babies fed the liquid with those fed the powder, the study observed no difference in the incidence of NEC.

The unpublished finding of 5% to 1% represented so few babies that it was not statistically significant.

Nonetheless, retired neonatologist Victor Herson, who ran a NICU in Connecticut and has studied fortifiers, said in an interview he would have wanted to see those numbers.

"The trend was in the wrong direction," Herson said, "and would have, I think, alerted the typical neonatologist that, well, maybe not to rush in and adopt" the new fortifier.

It's common for study publications to include tables showing complications even if they aren't statistically significant so that readers can draw their own conclusions, Herson said.

Neonatologist Fernando Moya, a co-author of the Pediatrics article, had a different perspective.

"You may not be very familiar with medical literature but when there are no 'statistically significant' differences, we do not comment on whether something was increased or decreased," Moya said by email. He referred questions to Mead Johnson.

Mead Johnson's O'Neill gave several reasons why "the data you cite was not included in the publication." She said the study was designed to examine infant nutrition and growth, NEC was a "secondary outcome," the NEC numbers weren't statistically significant, and the size of the study, "while appropriate, was not powered to draw any conclusions with respect to any potential differences in NEC."

In a deposition used in the Watson trial, Carol Lynn Berseth — a co-author of the paper and Mead Johnson's director of medical affairs for North America when the study was completed — testified that the article was peer-reviewed and that no reviewer asked for additional data.

"Had they asked for it, we would have shown it," Berseth testified.

Berseth did not respond to a phone message or to an email or letter sent to addresses apparently associated with her.

'It Should Not Be in a NICU'

The Abbott scientist who flagged research on Mead Johnson's acidified fortifier in 2013, Bridget Barrett-Reis, was later listed as chair of AL16, the follow-up clinical trial Abbott sponsored, and as a co-author of resulting publications.

In a deposition, she was asked why she conducted the study.

"I conducted that study because I thought [the acidified fortifier] could be dangerous," she said, "and I thought it would be a good idea to find out if it really was because nobody was doing anything about it."

Elaborating on the thinking behind the study, she testified: "It should not be in a NICU in the United States. That product should not be anywhere for preterm infants."

In her 2013 email recommending that Abbott conduct a study, Barrett-Reis cited findings by "an independent investigator," Ann Anderson-Berry, that showed, compared with preterm infants fed an Abbott powder, those on Mead Johnson's acidified liquid "had slower growth, higher incidence of metabolic acidosis and NEC!!"

Asked about the exclamation points, Barrett-Reis testified in a January 2024 deposition used in the Gill case that she wasn't excited about the findings. "I am known to put exclamation points instead of question marks and everything anywhere, so I have no idea at the time what those meant," she testified.

The research that caught her eye in 2013 reviewed patient records from the Nebraska Medical Center. The institution had switched to the acidified fortifier with high hopes but stopped using it after four months because it was concerned about patient outcomes, Anderson-Berry and Nebraska co-authors reported in January 2014.

In an interview, Anderson-Berry said she set out to analyze why, during those four months, babies' growth "fell apart in our hands."

Abbott was "very pleased" with Anderson-Berry's findings and paid her to go around the country discussing them, she said.

Metabolic acidosis can be fatal, Anderson-Berry said. But typically it can be managed, she said, adding that she didn't know of deaths from metabolic acidosis caused by the acidified fortifier.

Research has found that metabolic acidosis "is associated with poor developmental

and neurologic outcomes in very low birth weight infants," according to a paper Barrett-Reis co-authored. In addition, it is "a risk factor for neonatal necrotizing enterocolitis," the paper said.

Barrett-Reis did not respond to inquiries for this article, including a message sent via LinkedIn and a letter sent to an address that appeared to be associated with her.

In court, Abbott representative Robyn Spilker testified that metabolic acidosis can be a very serious condition and that nobody should knowingly put kids at risk for getting NEC in an effort to make money.

Before infants were enrolled in the AL16 study, their parents or guardians had to sign consent forms disclosing, among other things, the risks that clinical trial subjects would face.

International ethical principles for medical research on humans, known as the Declaration of Helsinki, say each participant must be adequately informed of the "potential risks."

Questioning Abbott's Spilker in litigation, plaintiff's attorney Timothy Cronin said, "Ma'am, despite the hypothesis going in, are you aware Abbott did not put metabolic acidosis on the informed consent form given to parents that signed their kids up for that study?" Spilker, who identified herself in court as a senior brand manager, said she didn't know what was on the consent forms.

Through a request under a Kentucky open-records law, KFF Health News obtained an informed consent form for the AL16 study used at a public institution, the University of Louisville. The form mentioned risks such as diarrhea, constipation, gas, and fussiness. It did not mention metabolic acidosis or NEC.

KFF Health News also reviewed an informed consent form for the AL16 study used at Memorial Hospital of South Bend. It was largely identical to the one used in Louisville and did not mention metabolic acidosis or NEC.

Cronin, the plaintiff's attorney, said in an interview that Abbott showed disregard for the health and safety of premature babies participating in the AL16 clinical trial.

"I think it's unethical to do a study if you know you are subjecting participants in the study to an increased risk of a potentially deadly disease and you don't at least tell them that," Cronin said.

Anderson-Berry told KFF Health News that Abbott was "ethically well positioned" to conduct the AL16 clinical trial because her paper was not definitive.

Yet she said she was unwilling to enroll any of her patients in the Abbott clinical trial because she didn't want to take the chance that they would be given the acidified liquid.

White, the neonatologist who stopped enrolling patients in the study, defended the decision to conduct it. In an interview, he said it was appropriate to conduct a large, properly controlled clinical trial to see whether concerns raised in earlier research were borne out. The two babies whose serious adverse events he reported to Abbott ended up doing fine, he said

But White, who went on to be listed as a co-author of the study, told KFF Health News that parents should have been informed that the risks included metabolic acidosis and NEC.

"In retrospect, obviously, that is something that we, I think, should have informed parents of," he said.

Abbott did not directly answer questions about the consent forms.

The results of AL16 were published in the Journal of Pediatrics in 2018. The conclusion: Infants fed the acidified product — in other words, the Mead Johnson fortifier — had higher rates of metabolic acidosis and poorer feeding tolerance. Plus, poorer "initial weight gain."

The title of the article trumpeted "Improved Outcomes in Preterm Infants Fed a Nonacidified Liquid Human Milk Fortifier" — in other words, the Abbott product.

Eight of the 78 infants receiving the Mead Johnson fortifier were treated for metabolic acidosis, compared with none of the 82 receiving the Abbott product, the article said. Four infants on Mead Johnson's product experienced serious adverse events, compared with one on the Abbott product, the article reported.

One infant receiving the Mead Johnson product died — from sepsis, the article said. One had a case of NEC, and infants on Mead Johnson's fortifier "had significantly more vomiting," the article said.

However, in a pair of letters to the editor published in the Journal of Pediatrics, doctors criticized the article as hyped. Writers said the article emphasized findings that were subjective and susceptible to bias.

In its business battle with Mead Johnson, Abbott deployed the study. It produced an annotated copy for its sales force, which was shown in the Whitfield trial.

Abbott's use of AL16 as a marketing tool worked.

In 2019, when Barrett-Reis applied for a promotion at Abbott, she wrote that the results of the study had been "leveraged to secure whole hospital contracts which have increased hospital share to > 70%."

Her letter was displayed in a deposition video filed in the Gill litigation.

Internally, Mead Johnson conceded it had been beaten in the fight over fortifiers. In the slide deck for a 2020 national sales meeting, the company said, "Abbott won the narrative."

Parents' Antidepressant Use Not Linked to Neurodevelopmental Disorders in Offspring

NEWS PROVIDED BY

Neurology Advisor

By HealthDay News

Study: **Parents' Antidepressant Use Not Linked to Neurodevelopmental Disorders in Offspring**

Current as of May 20, 2026

Antidepressant use during pregnancy does not cause an increased risk for neurodevelopmental disorders in offspring, according to a review published in the June issue of The Lancet Psychiatry.

Joe Kwun Nam Chan, Ph.D., from the University of Hong Kong, and colleagues conducted a systematic literature review to assess the risk for neurodevelopmental disorders following prenatal antidepressant exposure (before or during pregnancy) from mothers and fathers.

Based on 37 studies (648,626 antidepressant-exposed and nearly 25 million unexposed pregnancies), the researchers found that prenatal antidepressant use was associated with a modestly increased risk for neurodevelopmental disorders in offspring (relative risk [RR], 1.13), including

attention-deficit/hyperactivity disorder (ADHD; RR, 1.35) and autism spectrum disorder (ASD; RR, 1.69). No significant associations were seen for intellectual disabilities, motor disorders, or speech and language disorders. For ASD risk, there was no significant difference between high-dose and low-dose exposure. Additionally, paternal antidepressant use around conception was not linked to ASD. Similar associations were seen with preconception exposure. Associations were attenuated or became nonsignificant in sensitivity analyses when adjusting for confounding factors, including maternal mental disorders, familial or genetic influences, and misclassification. As a negative control, paternal antidepressant use during pregnancy was associated with increased ADHD risk (RR, 1.46) and ASD risk (RR, 1.28), suggesting the association reflects parental mental health and genetics rather than the medication itself.

"We know many parents-to-be worry about the potential impact of taking medication during pregnancy; our study provides reassuring evidence that commonly used antidepressants do not increase the risk of neurodevelopmental disorders such as autism and ADHD in children," coauthor Wing Chung Chang, M.D., also from the University of Hong Kong, said in a statement.

Judge sets up high stakes baby formula NEC trial vs Mead Johnson

NEWS PROVIDED BY

The Black Chronicle

By Black Chronicle News Service

Study: **Judge sets up high stakes baby formula NEC trial vs Mead Johnson**

Current as of May 17, 2026

A federal judge has potentially cleared the way for another trial against pharmaceutical and nutritional supplement maker Mead Johnson & Co. over claims their Enfamil-brand infant formula has harmed some babies.

On May 8, U.S. District Judge Rebecca Pallmeyer denied Mead Johnson's bid to bring a relatively quick end to a key lawsuit amid the thousands of others pending in the sprawling litigation.

The decision sets up a high-stakes trial, with potentially billions of dollars at stake.

Pallmeyer's new ruling marks a potentially significant win for trial lawyers who are seeking huge potential judgments and settlements in lawsuits against Mead Johnson and its frequent co-defendant, Abbott Laboratories. In those lawsuits, the plaintiffs accuse the companies of allegedly selling baby formula, including under the Similac and Enfamil brand names, despite allegedly knowing consumption of their cow's milk-based formulas increases the risk of babies suffering severe injuries or dying from the illness known as necrotizing enterocolitis, or NEC.

NEC is a condition which results in the death of bowel tissue and can lead to severe illness and death in newborns, particularly if they are born premature. NEC carries a fatality rate of around 15-40% in infants suffering from the condition.

The lawsuits have poured into courts by the thousands in state and federal courts throughout the U.S.

Specifically, they typically accuse the companies of allegedly failing to warn the public about the alleged enhanced NEC risks posed by the baby formulas, compared to human breast milk,

While hundreds of lawsuits are pending in Illinois state courts in Madison and St. Clair counties, more than 750 lawsuits have been consolidated before Judge Pallmeyer in Chicago federal district court.

As part of that action, Pallmeyer, in consultation with attorneys for both sides, selected four cases to serve as so-called "bellwether" cases. While pre-trial proceedings would continue to be consolidated for the other 700-plus cases, legal teams had prepared to take those four cases to trial.

To this point, the formula makers had succeeded in winning pre-trial judgments from Pallmeyer that had put the kibosh to trials planned in the first three bellwether cases.

To this point, the Chicago federal judge had sided entirely with formula makers on certain key questions at the heart of the litigation, and had granted their requests for summary judgment.

Mead Johnson had hoped to make it a clean sweep of all four cases.

In the fourth case, Mead Johnson had been sued by plaintiff Alexis Inman, an Indiana woman whose infant son died from NEC after consuming a nutritional regimen including Enfamil formula.

Pallmeyer, however, put an apparent end to those hopes in a decision that represented a reversal, of sorts, from her previous rulings.

In all three of the bellwether cases decided thus far, Pallmeyer agreed that evidence overwhelmingly favored formula makers' position that plaintiffs can't get past the benchmark holding that the benefits of their infant formula products — feeding newborns who would otherwise starve, for instance, in cases in which their mothers not be able to produce milk to feed their babies — outweigh the risks of possibly contracting NEC.

In a ruling in October 2025, for instance, Pallmeyer granted judgment in favor of Abbott Labs, saying trial lawyers can't show evidence that an alternative formula made from human milk could be mass produced in large enough amounts to prevent tens of thousands of babies from otherwise starving.

In her new ruling in the case against Mead Johnson, Pallmeyer reiterated her belief that the evidence shows formulas made from human milk don't amount to a viable commercial alternative that could form the basis of a lawsuit against formula makers for producing infant formula's from a cow's milk base.

However, Pallmeyer said, evidence may

show that formula makers could have instead produced a different kind of formula, which relies on the compound known as lactose "as the main source of carbohydrates, rather than corny syrup and maltodextrin."

In her decision, Pallmeyer noted some studies had shown such a lactose-based formula could reduce the risk of NEC in piglets.

In her decision, Pallmeyer said communications from scientists employed by Mead Johnson showed the company was at least aware of those studies since at least 2015.

The judge said this means, "Ms. Inman has presented evidence of a possible reformulation of Enfamil Premature that would have reduced the risk of NEC. Triable questions of fact remain regarding the safety, feasibility, and reasonableness of the possible reformulation as an alternative design…"

So, Pallmeyer said, Inman's case against Mead Johnson should proceed to trial to allow a jury to assess those facts and evidence.

The judge has not yet set a date for trial in the case.

Inman is represented by attorney Jose M. Rojas, of the firm of Levin Rojas Camassar & Reck, of Hartford, Connecticut.

Other attorneys representing plaintiffs in the consolidated actions and bellwether cases include attorneys from the firms of Levin Papantonio, of Pensacola, Florida; Johnson Becker, of St. Paul, Minnesota; Lieff Cabraser Heimann & Bernstein, of New York; DiCello Levitt, of Chicago and Birmingham, Alabama; and The Dixon Firm, of San Diego.

Mead Johnson is represented by attorney Paul W. Schmidt and others from the firm of Covington & Burling, of New York and Washington, D.C.

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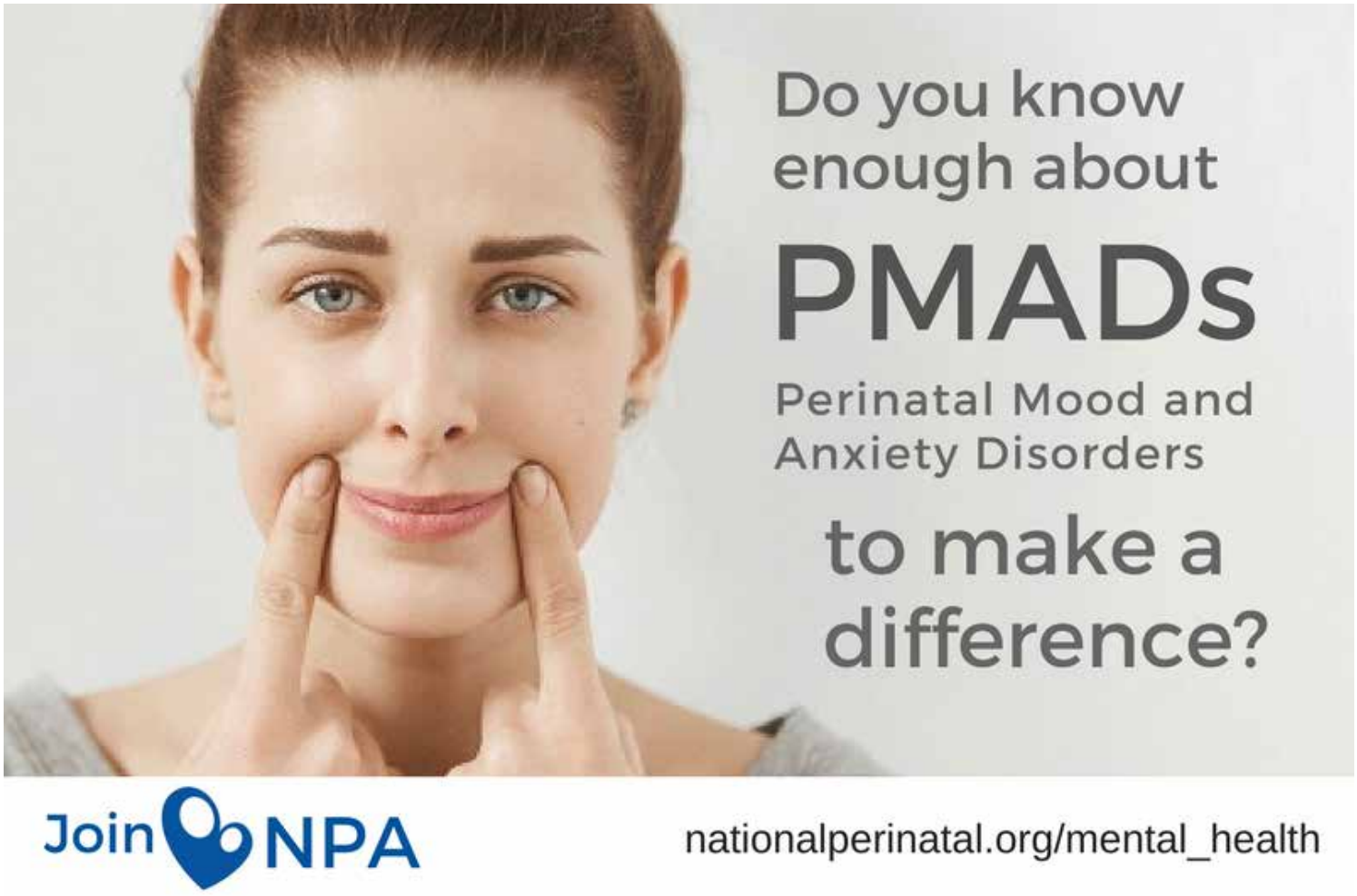

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Peer Reviewed

Genetics Corner: Silent at Birth, Devastating Later: Aicardi-Goutières Syndrome Masquerading as Post-Febrile Regression

Hua Wang, M.D., Ph.D

Abstract:

Background: *Aicardi-Goutières syndrome (AGS) is a rare genetic encephalopathy characterized by upregulation of type I interferons, mimicking congenital viral infection. It is caused by mutations in genes involved in nucleic acid metabolism, including ADAR.*

"Aicardi-Goutières syndrome (AGS) is a rare genetic encephalopathy characterized by upregulation of type I interferons, mimicking congenital viral infection. It is caused by mutations in genes involved in nucleic acid metabolism, including ADAR."

Case Presentation: *We report a 19-month-old male who presented with developmental regression following febrile seizures at 10 months of age. Initial epilepsy gene panel testing identified a pathogenic heterozygous variant in SCN9A and carrier status for AMT, which did not fully explain the clinical picture of hypotonia, dysphagia, and bilateral lentiform nuclei hyperintensity on MRI. Subsequent whole genome sequencing (WGS) revealed compound heterozygous likely pathogenic variants in ADAR (c.3337G>A and c.3384G>T), confirming a diagnosis of ADAR-related AGS type 6.*

Conclusion: *This case highlights the diagnostic challenge of AGS, in which clinical features can be misattributed to seizure sequelae or to other genetic incidental findings. It underscores the critical utility of WGS in complex neuro-regression cases to differentiate between pathogenic mimics and causative etiology, enabling precise management and genetic counseling.*

Introduction:

Aicardi-Goutières syndrome (AGS) is a genetically determined encephalopathy characterized by the upregulation of type I interferon, clinically mimicking congenital viral infections (pseudo-TORCH) in the neonatal period (1, 2). While neonatologists typically recognize AGS by the classic triad of basal ganglia calcifications, leukodystrophy, and systemic inflammation (hepatosplenomegaly, thrombocytopenia) present at birth, the phenotypic spectrum is far broader (3, 4). The 2021 EULAR/ACR points to consider for diagnosis and management of autoinflammatory type I interferonopathies emphasize that while patients with AGS typically present early in life, often within the first week, late-onset cases presenting as late as 5.6 years have been reported (5).

"While neonatologists typically recognize AGS by the classic triad of basal ganglia calcifications, leukodystrophy, and systemic inflammation (hepatosplenomegaly, thrombocytopenia) present at birth, the phenotypic spectrum is far broader. The 2021 EULAR/ACR points to consider for diagnosis and management of autoinflammatory type I interferonopathies emphasize that while patients with AGS typically present early in life, often within the first week, late-onset cases presenting as late as 5.6 years have been reported."

The ADAR gene (Adenosine Deaminase Acting on RNA) is a known cause of AGS (specifically AGS type 6), often presenting with a distinct "late-onset" phenotype characterized by subacute encephalopathy following a seizure or febrile illness after a period of normal development (6–8). This variability poses a significant diagnostic challenge. Neurologic manifestations in AGS include subacute or acute neurologic decline, unexplained developmental delay, progressive microcephaly, dystonia, spasticity, encephalopathy, irritability, and focal motor findings (5).

"This variability poses a significant diagnostic challenge. Neurologic manifestations in AGS include subacute or acute neurologic decline, unexplained developmental delay, progressive microcephaly, dystonia, spasticity, encephalopathy, irritability, and focal motor findings."

We present a case of a 19-month-old male with ADAR-related AGS whose diagnosis was obscured by a normal neonatal course and confounding genetic results—specifically, a pathogenic

SCN9A variant identified on an epilepsy panel. This case is particularly relevant to the neonatal community as it highlights the "silent" end of the interferonopathy spectrum. It serves as a critical reminder that a lack of neonatal "sepsis-like" features does not preclude a diagnosis of AGS. Furthermore, it underscores the need for whole-genome sequencing (WGS) over targeted panels to distinguish incidental findings from the true etiology of basal ganglia injury (9, 10).

"We present a case of a 19-month-old male with ADAR-related AGS whose diagnosis was obscured by a normal neonatal course and confounding genetic results—specifically, a pathogenic SCN9A variant identified on an epilepsy panel. This case is particularly relevant to the neonatal community as it highlights the 'silent' end of the interferonopathy spectrum. It serves as a critical reminder that a lack of neonatal 'sepsis-like' features does not preclude a diagnosis of AGS."

Case Presentation:

The patient is a 19-month-old male born to non-consanguineous parents of Mexican ancestry. Prenatal history was unremarkable; the pregnancy was detected at 4 weeks of gestation, and maternal serologies were non-contributory. He was born at 38 weeks via normal spontaneous vaginal delivery with a birth weight of 3.010 kg, length of 50.8 cm, and Apgar scores of 7 and 9. There were no postnatal complications, and he passed his newborn hearing screen.

The patient demonstrated normal developmental progression, including independent sitting and walking, until 10 months of age. In December 2024, he experienced a febrile illness associated with four seizures. Following this event, he exhibited marked developmental regression, losing the ability to sit, stand, and walk. By 16 months, he presented with severe hypotonia, inability to hold his head up, and asymmetric motor function with left-sided weakness and dystonic-like "jerky" movements. He developed significant oropharyngeal dysphagia with choking, requiring nasogastric (NG) tube feeding. Additional symptoms included sleep disturbance, irritability, and episodes of abnormal eye deviation ("zoning out"). Family history was non-contributory, with no reports of developmental delay, intellectual disability, early infant deaths, or multiple miscarriages. A three-generation pedigree is documented.

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At 16 months, the patient was alert but irritable and difficult to console. Growth parameters were within normal limits. HEENT examination noted a bulbous nose tip, mildly wide-spaced eyes, and significant drooling. Neurological examination revealed diffusely low axial and appendicular tone with head lag. He demonstrated dysmetric reaching, primarily using the left arm, and intermittent stiffening of the left side. MRI Brain (June 2025) revealed symmetric T1 hyperintensity within the bilateral lentiform nuclei and mild diffuse cerebral white matter volume loss. These findings were initially interpreted as potential sequelae of hypoxic, toxic, or metabolic insult. EEG (July 2025) was normal in wakefulness, drowsiness, and sleep, with no epileptogenic discharges identified. Initial genetic testing (July 2025), including chromosomal microarray and mitochondrial genome testing, was negative.

"MRI Brain revealed symmetric T1 hyperintensity within the bilateral lentiform nuclei and mild diffuse cerebral white matter volume loss. These findings were initially interpreted as potential sequelae of hypoxic, toxic, or metabolic insult."

Genetic Testing and Findings:

Initial testing utilized an Invitae Epilepsy Panel (302 genes). Due to an inconclusive phenotypic correlation, whole-genome sequencing (WGS) (GeneDx) was subsequently performed.

Invitae Epilepsy Panel (July 2025) identified SCN9A: c.902-2A>C (Splice acceptor), Heterozygous, Pathogenic, a gene associated with autosomal dominant epilepsy and pain disorders, and AMT: c.635T>C (p.Val212Ala), Heterozygous, Pathogenic, consistent with carrier status for autosomal recessive glycine encephalopathy. Whole Genome Sequencing (October 2025) identified variants in the ADAR gene (OMIM #146920): Variant 1: c.3337G>A (p.Asp1113Asn), Heterozygous, Likely Pathogenic, and Variant 2: c.3384G>T (p.Trp1128Cys), Heterozygous, Likely Pathogenic.

"Initial testing utilized an Invitae Epilepsy Panel (302 genes). Due to an inconclusive phenotypic correlation, whole-genome sequencing (WGS) (GeneDx) was subsequently performed. Whole Genome Sequencing identified variants in the ADAR gene (OMIM #146920): Variant 1: c.3337G>A (p.Asp1113Asn), Heterozygous, Likely Pathogenic, and Variant 2: c.3384G>T (p.Trp1128Cys), Heterozygous, Likely Pathogenic."

Segregation analysis confirmed the ADAR c.3337G>A variant was inherited from the mother, while the c.3384G>T variant occurred de novo. This biallelic finding confirms the diagnosis of autosomal recessive ADAR-related Aicardi-Goutières syndrome type 6.

Management and Outcome:

Management has been supportive and multidisciplinary. Given the significant dysphagia and risk of aspiration, the patient was transitioned to nasogastric feeding. Respiratory support includes monitoring for obstructive sleep apnea and restrictive lung disease.

While JAK inhibitor therapy has shown promise in some AGS patients (11–13), confirmation of AGS in this case enabled cessation of unnecessary metabolic workups and guides future therapeutic considerations for interferonopathies. The 2021 EULAR/ACR guidelines note that JAK inhibitors, particularly baricitinib, are widely used to treat patients with type I interferonopathies and have been reported to be beneficial for controlling inflammatory symptoms and preventing progression of end-organ damage (5). However, a recent multicenter retrospective study comparing treated versus untreated AGS patients found that while JAK1/2 inhibitors showed improvement in immunological and dermatological symptoms, the impact on neurological manifestations was limited and heterogeneous, with greater benefits in patients with mild or intermediate phenotypes and earlier treatment initiation (14).

Follow-Up and Outcome:

As of October 2025, the patient remains hypotonic with severe motor delays (unable to sit or walk). The clinical course has stabilized but has not shown significant recovery of lost milestones. The diagnosis provided closure regarding the etiology of the regression and facilitated genetic counseling.

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Discussion:

Clinical Features and Pathogenesis:

AGS is fundamentally a type I interferonopathy. In the neonatal period, this typically manifests as a "sterile infection" where the infant appears septic with negative cultures, often displaying microcephaly, sterile pyrexia, and irritability (1, 15). The pathology is driven by mutations in nucleic acid metabolic genes (like ADAR), leading to the accumulation of intracellular nucleic acid species that trigger an autoinflammatory response (2, 16). AGS may be caused by mutations in any one of nine genes (TREX1, RNASEH2A, RNASEH2B, RNASEH2C, SAMHD1, ADAR1, IFIH1, LSM11, and RNU7-1) that result in the accumulation of self-nucleic acids in the cytoplasm or aberrant sensing of self-nucleic acids,

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triggering overproduction of type I interferons (2). In our patient, this inflammation targeted the bilateral lentiform nuclei, a hallmark site of injury in metabolic and interferon-mediated disorders (17, 18).

"This case provides a vital contrast to the classic neonatal presentation. Classic neonatal AGS typically presents at birth with jitteriness, poor feeding, thrombocytopenia, and hepatosplenomegaly, with intracranial calcifications often visible on initial ultrasound or CT."

Neonatal vs. Late-Onset Phenotypes:

This case provides a vital contrast to the classic neonatal presentation. Classic neonatal AGS typically presents at birth with jitteriness, poor feeding, thrombocytopenia, and hepatosplenomegaly, with intracranial calcifications often visible on initial ultrasound or CT (19, 20). In contrast, our patient had an unremarkable prenatal and perinatal history, with normal Apgar scores and discharge to home without complications. He achieved normal milestones until 10 months of age. A recent characterization of late-onset AGS found that most individuals had a history of developmental delay and/or systemic symptoms, such as sterile pyrexias and chilblains, followed by a prodromal period associated with increasing symptoms, then an abrupt onset of neurological decline (fulminant phase), with a median onset at 1.33 years (4). Most individuals presented with a change in gross motor skills (97.0%), typically with increased tone (78.8%), and leukodystrophy was the most common MRI finding (40.0%), while calcifications were less common (12.9%) (4).

"A recent characterization of late-onset AGS found that most individuals had a history of developmental delay and/or systemic symptoms, such as sterile pyrexias and chilblains, followed by a prodromal period associated with increasing symptoms, then an abrupt onset of neurological decline (fulminant phase), with a median onset at 1.33 years. Most individuals presented with a change in gross motor skills (97.0%), typically with increased tone (78.8%), and leukodystrophy was the most common MRI finding (40.0%), while calcifications were less common (12.9%)."

The lesson: The absence of neonatal symptoms (calcifications, microcephaly) offered false reassurance. However, the subsequent precipitous regression triggered by a febrile event parallels the immune-trigger mechanism seen in neonates. This case illustrates that the "window of vulnerability" for interferonopathies extends beyond the NICU, and the diagnosis should be reconsidered in any infant with unexplained basal ganglia necrosis, regardless of a "clean" neonatal history (4, 7). Bilateral striatal necrosis has been specifically reported in patients with ADAR1 mutations (AGS6), expanding the neuroradiological phenotype of AGS (17).

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Genetic Insights:

The patient's initial workup was complicated by a pathogenic variant in SCN9A (associated with Dravet syndrome/epilepsy) and carrier status for AMT (glycine encephalopathy). Neither explained the symmetric basal ganglia hyperintensity seen on MRI. WGS was required to identify the compound heterozygous variants in ADAR: a maternally inherited c.3337G>A and a de novo c.3384G>T. For the neonatologist, this highlights a critical pitfall: standard epilepsy panels ordered for "seizures" may miss the underlying metabolic or inflammatory etiology (21, 22). Additionally, the identification of a de novo variant in a recessive condition significantly alters recurrence risk counseling for parents planning future pregnancies—a conversation that often begins in the neonatal or early infancy period. The diagnostic yield of WGS after non-diagnostic gene panels in developmental and epileptic encephalopathies has been demonstrated to be substantial, with WGS identifying diagnoses in 53–68% of previously undiagnosed cases (9).

"For the neonatologist, this highlights a critical pitfall: standard epilepsy panels ordered for 'seizures' may miss the underlying metabolic or inflammatory etiology. "

Neuroimaging Patterns in ADAR-Related AGS

Neuroimaging should be performed in individuals with a suspected diagnosis of an interferonopathy and neurologic symptoms, with brain MRI best for identifying white and grey matter changes (5). Basal ganglia or other intracerebral calcifications are overlapping neuroimaging findings in type I interferonopathies; they are more common, more severe, and typically present earlier in life in patients with AGS than in other interferonopathies (5). A comprehensive neuroradiologic characterization of 121 subjects with AGS found that brain calcifications were present in 90.9%, cerebral atrophy in 91.8%, and leukoencephalopathy in 99.2%, with three main patterns: frontotemporal, diffuse, and periventricular (18). White matter rarefaction was found in 50.0% of subjects, strongly associated with TREX1 mutations and early age at onset (18). A recent Middle Eastern case series found that initial neuroimaging revealed focal white matter disease in 76.9%, calcifications in 53.8%, hypomyelination in 38.5%, and basal ganglia involvement in 30.8% (23).

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Specific Therapeutics:

While supportive care remains the standard, the identification of the interferon signaling pathway has led to the off-label use of JAK inhibitors (e.g., baricitinib, ruxolitinib, tofacitinib) to dampen the immune response (11, 24, 25). The 2021 EULAR/ACR guidelines state that treatment with baricitinib resulted in significantly lower daily diary scores and a significant reduction in glucocorticoid use in patients with type I interferonopathies across different open-label trials, with 50% of patients with CANDLE/PRAAS achieving lasting remission (5). A beneficial effect of JAK inhibitors on inflammatory disease manifestations is also observed in patients with AGS, including in open-label trials, with treatment leading to a decrease in interferon signaling gene expression scores and improvement of AGS-related symptoms, including neurologic disability, crying, sleep disturbances, irritability, seizures, fever, and skin inflammation (5). However, in all instances, preexisting organ damage is irreversible (e.g., neurologic manifestations), underscoring the need for early treatment (5).

Recent evidence suggests that while JAK inhibitors show promise, their efficacy remains variable. A multicenter retrospective study

"A beneficial effect of JAK inhibitors on inflammatory disease manifestations is also observed in patients with AGS, including in open-label trials, with treatment leading to a decrease in interferon signaling gene expression scores and improvement of AGS-related symptoms, including neurologic disability, crying, sleep disturbances, irritability, seizures, fever, and skin inflammation...However, in all instances, preexisting organ damage is irreversible (e.g., neurologic manifestations), underscoring the need for early treatment."

comparing 12 treated patients with 20 untreated patients found that treatment improved immunological and dermatological symptoms, while its impact on neurological manifestations was limited and heterogeneous, with greater benefits in patients with mild or intermediate phenotypes and earlier treatment initiation (14). Notably, neuroimaging analyses in untreated patients showed radiological improvements equal to or greater than those observed in treated patients, raising questions about the true impact of JAK1/2 inhibitors on the neuroradiological course (14). Cerebrospinal fluid neopterin has been proposed as a biomarker of treatment response, with patients treated with JAK inhibitors demonstrating a median 81.5% reduction of CSF neopterin compared to a median 7% reduction in untreated patients (26).

While our patient presented late, earlier recognition of "atypical" or "late-onset" AGS could potentially allow for therapeutic intervention before irreversible striatal necrosis occurs. However, the efficacy of JAK inhibitors remains variable, with some patients showing modest improvements in systemic symptoms but limited

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neurological recovery (13, 27). Pharmacological evaluation using patient-derived neural stem cells suggests that glucocorticoids, JAK inhibitors (excluding pacritinib), and reverse transcriptase inhibitors are likely safe for neural stem cells of AGS patients, while caution is warranted with thioguanine and pacritinib (25).

Summary:

This case reinforces that ADAR-related AGS is a master mimic. It can present as a devastating neonatal encephalopathy or, as seen here, masquerade as "febrile seizures" with regression in a toddler. The presence of bilateral lentiform nuclei signal changes was the radiologic "red flag" that tied this older child's presentation back to the spectrum of disorders neonatologists treat. Recognizing this spectrum is essential for accurate diagnosis, prognosis, and genetic counseling.

"This case reinforces that ADAR-related AGS is a master mimic. It can present as a devastating neonatal encephalopathy or, as seen here, masquerade as 'febrile seizures' with regression in a toddler. The presence of bilateral lentiform nuclei signal changes was the radiologic 'red flag' that tied this older child's presentation back to the spectrum of disorders neonatologists treat. Recognizing this spectrum is essential for accurate diagnosis, prognosis, and genetic counseling."

Conclusion:

This case of ADAR-related Aicardi-Goutières syndrome illustrates the complexity of diagnosing neuro-regressive disorders in the genomic era. The presence of a "red herring" pathogenic variant in SCN9A on an epilepsy panel initially obscured the true diagnosis. The case contributes to the literature by documenting a compound heterozygous genotype with a de novo mutation and reinforcing the clinical phenotype of infection-triggered regression. For clinicians, this emphasizes that MRI patterns (specifically lentiform nuclei signal changes) should drive genetic testing strategies toward WGS when targeted panels are discordant with the clinical severity (9, 10).

Take-Home Messages for the Neonatologist:

- **Suspect AGS in "Cerebral Palsy" Mimics:** Consider Aicardi-Goutières syndrome in infants who exhibit developmental regression or dystonia following a febrile illness, particularly if they were previously developing normally.
- **Scrutinize the MRI:** Symmetric signal abnormalities in the basal ganglia (lentiform nuclei) and white matter rarefaction are hallmarks of mitochondrial or interferon-mediated damage and should prompt specific testing beyond standard epilepsy panels.
- **Look Beyond the First "Positive":** In the era of large panels, incidental pathogenic variants are common. Always ask whether the genotype fully explains the phenotype; if not, proceed to whole-genome sequencing.
- **Recurrence Risk Counseling:** Identifying de novo variants in compound heterozygous states dramatically alters genetic counseling for parents, as recurrence risk is significantly lower than the typical 25% for recessive disorders.
- **Consider Interferon Biomarkers:** Elevated interferon-stimulated gene expression in peripheral blood can serve as a useful biomarker for AGS and may guide therapeutic decisions.
- **Early Treatment Considerations:** JAK inhibitors show promise in controlling systemic and inflammatory symptoms, with greater benefits observed in patients with mild or intermediate phenotypes and earlier treatment initiation. However, preexisting neurologic damage is irreparable, emphasizing the critical importance of early recognition and intervention.

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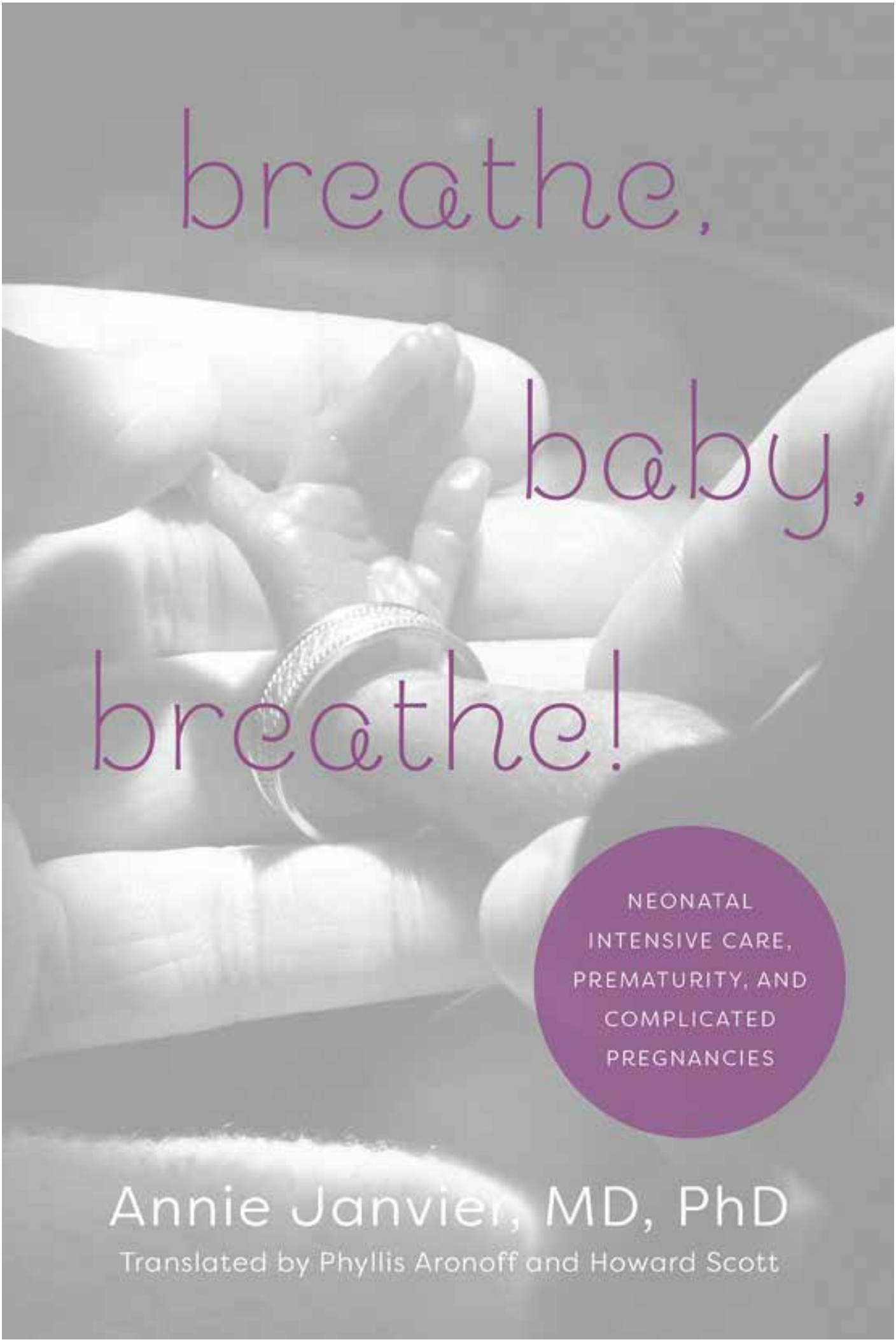

breathe, baby, breathe!

NEONATAL INTENSIVE CARE, PREMATURITY, AND COMPLICATED PREGNANCIES

Annie Janvier, MD, PhD

Translated by Phyllis Aronoff and Howard Scott

Summary of "Stigmatizing Language: Changing the Narrative", a Family-Centered Care Taskforce Webinar

Robert Cicco, MD

On May 14th, the Family-Centered Care (FCC) Taskforce hosted its 26th free, educational webinar titled "Stigmatizing Language: Changing the Narrative" with Veronica Barcelona, PhD, MSN, RN, FAAN, Jessi Barnes, MSN, RN, RNC-NIC, NPD-BC, C-ELBW, C-TIP, Rose Horton, MSM, RNC-OB, NEA-BC, FAAN, Adrienne McIntyre, DNP, RNC-NIC; and Cheniqua Morales, BSN, RNC-MNN, C-EFM, C-ONQS. The following is a summary of this meaningful presentation:

"We seem to be in constant search to identify why marked disparities exist in both the maternal and neonatal outcomes between different racial and ethnic groups. Data repeatedly show that these disparities cannot be explained by genetics and point more to social stressors and life-course experiences as the underlying causes."

We seem to be in constant search to identify why marked disparities exist in both the maternal and neonatal outcomes between different racial and ethnic groups. Data repeatedly show that these disparities cannot be explained by genetics and point more to social stressors and life-course experiences as the underlying causes. These experiences often affect how healthcare professionals communicate information. This webinar was presented by a distinguished group of experts who not only discussed why our words and actions matter but also offered thoughtful ways to use our communication to improve, rather than harm, our interactions. Some of the key messages in this powerful session included:

"This webinar was presented by a distinguished group of experts who not only discussed why our words and actions matter but also offered thoughtful ways to use our communication to improve, rather than harm, our interactions."

- With increasing education, pregnancy-related mortality drops dramatically for white women but remains essentially unchanged for black women.
- Racism, whether systemic, structural, or individual, is as much a social stress as economic stress.
- A CDC review in 2025 noted that 1/3 of pregnancy-related maternal deaths were associated with stigma, bias, or discrimination.
- Stigmatizing language conveys unintended meanings that can perpetuate power dynamics and bias. This can dramatically impact a patient's trust in either an individual provider or the healthcare system in general.
- Documentation in charts should be strength-based, patient-centered, and provide relevant clinical information. Charting should not be used to label or judge patients.
- Remember that you communicate not just through your written and spoken language. Your facial expression, body language, and attention are part of your language and can express feelings that are either strengthening or stigmatizing.
- Some examples of commonly used words in our "Medical Lingo" that are misconstrued and potentially harmful include "failure" (as in "failure to progress"), "incompetent" (as in "incompetent cervix"), or "fail" (as in "your baby failed their hearing test").
- People do not like to be referred to as a "condition"; They are not the "preeclamptic in Room 10" or the "24 weeker who was just admitted." Use patient and family names!
- In addition to learning the patient's and family's names, ask about preferences. Some people are ok with being called 'mom' or 'dad' by healthcare teams, some are not.
- Avoiding stigmatizing language is important, but no more important than identifying a person's strengths and using language that enhances those strengths.
- We should remember that how we communicate with babies can have both positive and negative effects. Part of essential developmental care is interacting positively every time we handle or talk to our babies.
- Avoiding stigmatizing language is an essential component of providing trauma-informed care. Remember that we should never be asking "What's wrong with you?" Instead, we should be asking "What

happened to you?" And then identify strengths that can help develop resiliency.

- No matter how hard we try, there will be times when we say the wrong thing, even without meaning to. We need to learn that it is good to apologize! Moreover, that apology will be easier for both you and the other person if you have already developed a trusting and respectful relationship.
- Eliminating the use of stigmatizing language in most cases requires a cultural shift, regardless of the healthcare setting. Tips for creating this culture change include:
    - Inspiring change instead of demanding it
    - Involving those whose behavior you are trying to change
    - Explaining the reasons why change is necessary
    - Documenting the progress of change in your workplace
    - Working on changing your own behaviors before asking others to change
    - Finding out who your early adopters, or your laggards, are
    - Remembering that change takes time and that it is important to celebrate small wins!

"Practicing trauma-informed care and avoiding stigmatizing language in our relationships may not eliminate the effect that social stresses have on disparities in perinatal outcomes, as those stresses also come from multiple sources outside of the healthcare setting."

Practicing trauma-informed care and avoiding stigmatizing language in our relationships may not eliminate the effect that social stresses have on disparities in perinatal outcomes, as those stresses also come from multiple sources outside of the healthcare setting. However, as this panel repeatedly emphasized, we must constantly strive to do our part in treating everyone fairly and with the respect they deserve. It is only then that we can effectively partner to achieve the common goal of improving outcomes for all patients.

To view a recording of this session on demand, click here.

Disclosure: *Mead Johnson Nutrition generously supports this work.*

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FCC TASKFORCE WEBINAR

JULY 9TH | 11:00 AM - 12:30 PM PT

Parent Perspectives: Clinician Communication

Latoya Blueford (she/her)
Founder & Executive Director,
The Skylar Project
NICU Parent of Skylar

Tracy Pella, MA, LMHP, EdS (she/her)
Co-Founder & President,
Connected Forever
Founder, Rooted Life Empowerment
NICU Parent of Cohen, Cooper, and Maybry

Breaking Bad News: Helping Families When They Need Us the Most

Anthony Orsini, D.O., FAAP
Section Chief of Neonatology,
Nicklaus Children's Hospital in Miami, Florida
President and CEO, The Orsini Way

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Family Centered Care: June 2026, FCC Taskforce Newsletter An international collaborative initiative solely dedicated to quality improvement in NICU Family-Centered Care.

Robert Cicco, MD, Morgan Kowalski

"Join us as we walk through the NICU through the lens of the parents. This is a stylized representation based on a combination of experiences shared by multiple NICU parents. As a professional in this space, we must attempt to gain insight from their perspective so we can continue to mold neonatal care from a foundation of equity-focused, family-centered, and trauma-informed care. Reflect on whatever comes up for you as you read this series and let it help shape your practice."

"The principle of equity in healthcare spaces, specifically in the NICU, aims to provide everyone with a fair and just opportunity to achieve their highest level of health. It requires removing obstacles like poverty, discrimination, and lack of access to quality care, ensuring that systemic barriers are addressed to eliminate health disparities based on social, economic, or environmental factors. In the NICU, an example might be lack of equity in transportation support. Charging NICU parents and families for parking means some families will face financial hardship to participate in their child's care or may not be able to participate at all."

Disclosures: *There are no reported disclosures*

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Volume 15

FCC TASKFORCE NEWSLETTER

An international collaborative initiative solely dedicated to **quality improvement in NICU Family-Centered Care**.

In This Issue

FAMILY-CENTERED CARE TASKFORCE

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Parenting in the NICU, Part 2

Jessi Barnes, MSN, RN, RNC-NIC, NPD-BC, C-ELBW

Content Warning: If you have experienced the NICU as a parent, please take care when reading.

The nurse shows us how to open the little doors on the box with our baby inside. My hands are shaking as I gently touch my tiny, sweet baby with the pad of my index finger. Avery seems impossibly small and a little bit sticky. Are babies supposed to be sticky? The nurse rushed to put her hand on mine and firmly said "Be gentle! They don't like stroking!" I wasn't stroking. I was shaking. I couldn't stop, so I removed my hand and squeezed my eyes tight to keep from crying. My partner, Cameron, meekly asked "Can we talk to him? Can he even hear us?" The nurse answers them, but I don't really hear it. All of my energy is focused on trying to be okay. I have no way to define what okay even means right now. It feels like a weight is pushing down on me, cementing me to the floor. I remind myself to smile and relax my face. They can't know how hard this is for me. It seems so easy for them. I need to be strong. The look on Cameron's face is cloudy. It's full of worry, fear, and confusion. We've weathered a lot over the last 10 years, but I've never seen this look before. Cameron grabs my hand and leans their head to mine as we both stand there absolutely shellshocked. The nurse comes back and says that I need to step out because they need to do something sterile for our baby. I feel guilty leaving Avery again. The nurse reminds me to pump when I get back to my hospital room so I can bring milk when I come back. "Your milk is medicine!" she cheerfully calls after us and my partner wheels me back to my hospital room.

Join us as we walk through the NICU through the lens of the parents. This is a stylized representation based on a combination of experiences shared by multiple NICU parents. **As a professional in this space, we must attempt to gain insight from their perspective so we can continue to mold neonatal care from a foundation of equity-focused, family-centered, and trauma-informed care**. Reflect on whatever comes up for you as you read this series and let it help shape your practice.

To read Part 1, click here.

SUPPORTING FAMILIES IN GRIEF

NAVIGATING GRIEF IN THE NICU

SAHRA CAHOON, LOVE FOR LILY &
ERIKA GOYER, NATIONAL PERINATAL ASSOCIATION

"Grief shows up in many ways, and we carry it in many forms… Grief is a complex, communal emotional response to a wide range of losses that extends beyond the death of an individual…"
-First Peoples Wellness Circle

Those of us who work in and around the neonatal intensive care unit (NICU) know that—in spite of tremendous, significant advancements in neonatal care—few patients and families leave the NICU unscathed. In fact, for many families a NICU stay can be marked by a series of losses, both anticipated and unanticipated, ambiguous and blunt. How we experience those losses shapes who we become as parents, caregivers, and advocates.

If you care for NICU families, you probably already understand that no one is guaranteed a "good outcome" in the neonatal intensive care unit. Sometimes bad things happen. Sometimes a diagnosis shatters the future a family has envisioned. Sometimes babies die. When this happens, we suffer—sometimes together—but often alone.

As parents who have lived through the deaths of our own babies, we bring experiential perspectives to the discussion of grief and loss. As advocates who have been the companions to other families in their grief, those views have broadened. And as witnesses to the suffering of our colleagues, we have been activated to try to improve the systems we all work within.

HERE'S WHERE WE'LL START

- **LISTEN** It sounds simple—and yet it can be so challenging. Sitting in someone else's puddle and hearing their sorrow can feel intense. One of the most powerful things that you can do is listen. When parents tell you how they feel, believe them. When they ask for a break or a moment, give them space. 💙 **We believe that there is no wrong way to grieve**.
- **USE THEIR BABY'S NAME** This tiny human often holds someone's whole world in their little body, and the name this family chose has meaning. Parents often find comfort in hearing their child's name and knowing they will be remembered.

See more tips here.

HERE'S WHERE WE'RE GOING NEXT

We are committed to learning together and exploring a deeper understanding of grief in the NICU and how we all experience and process it.

We are compiling a list of resources and articles to help you and your organization as you move towards more responsive, respectful, trauma-informed family-centered care practices.

We invite you to share your favorite resources, policies, and practices with us.

If there is a topic that you would like to see us cover, please email us:
Sahra at sahra@loveforlily.org and Erika at egoyer@nationalperinatal.org

MARCH '26 WEBINAR SUMMARY

BOB CICCO, MD

"Trust and Engagement in the AI Era: Advancing FCC Through Responsible Innovation" with James Barry, MD, MBA

Jim is a neonatologist and president of NeoMind-AI, a corporation whose mission is to advance the ethical integration of artificial intelligence in pediatric and neonatal medicine. **He presented a comprehensive overview of the developing impact of artificial intelligence (AI) on healthcare in general, and specifically in neonatal care.** Some key takeaways from his talk include:

- It's important for healthcare professionals to embrace new technology, but **we must learn how to use it properly**.
- AI deep learning models can be useful in helping clinicians to better evaluate vast amounts of digital data and better "connect the dots" of how to interpret this data.
- **AI can be a useful "assistant" to both healthcare professionals and families** in establishing diagnoses, cutting down on documentation time to allow for more face-to-face interaction, and allowing families to better understand their child's condition.
- Patients and families are accessing AI models to answer medical questions at a rapidly advancing pace. However, analysis shows AI answers were often "incorrect" when recommending a patient did not need to see a doctor or go to the ER.
- We must recognize that healthcare professionals do more than "diagnose." **There is a partnership between a patient/family and their healthcare team that transcends any value provided by deep learning AI models.** We cannot let AI interfere with either the human connection between a patient/family or the trust that develops between a provider and their patient/family.

This session was extremely enlightening for anyone unaware of how rapidly AI is progressing in the healthcare setting. The bottom line is that **we must accept and embrace that this new technology will continue to grow and we must ensure that, as it does, it is safe, effective, based in science, well evaluated, and integrated into our care with human authority.**

Did you miss this session? Watch the recording here.

CHECK OUT OUR NEW WEBSITE!

If you haven't checked it out yet, please visit our new and improved website. We hope you love the new look as much as we do, and we are grateful to smallTalk NICU Egg System for sponsoring this project.

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EDIBJ IN THE NICU

EQUALITY VS. EQUITY

JESSI BARNES, MSN, RN & MIA MALCOLM, BS, CDFT

Equality and equity are not the same thing. They don't want the same outcome and don't have the same intentions in the NICU space. Equality seeks to provide everyone with the same resources—and while that sounds "nice," it's not helpful or sustainable. **Equity acknowledges that families have different circumstances, needs, and starting points, and allocates the exact resources they need to reach the shared desired outcome.**

The principle of equity in healthcare spaces, specifically in the NICU, aims to provide everyone with a fair and just opportunity to achieve their highest level of health. It requires removing obstacles like poverty, discrimination, and lack of access to quality care, ensuring that systemic barriers are addressed to eliminate health disparities based on social, economic, or environmental factors. In the NICU, an example might be lack of equity in transportation support. Charging NICU parents and families for parking means some families will face financial hardship to participate in their child's care or may not be able to participate at all. Another example might be when parking vouchers are provided but only if families live 'X' number of miles away from the hospital. There's an assumption that proximity to the hospital somehow implies access or availability of resources. **Equity is the cornerstone of family-centered care. When families' needs are addressed on an individual basis, they are more likely to feel seen, heard, and supported to continue participation in their child's care.**

Reflect on this visual aid created by the Robert Wood Johnson Foundation that features a human-centered design based on feedback from the community they serve. Please visit their page to learn more about this image and the 'why' that led to them updating this visual.

CHECK OUT OUR POSITION STATEMENT

The Family-Centered Care (FCC) Taskforce affirms and advocates for the principles of equity, diversity, inclusion, belonging, and justice (EDIBJ) as foundational to high-quality, compassionate, and just neonatal care. **We believe that every family in the neonatal intensive care unit (NICU) deserves care that honors their identity, recognizes their individual needs, and promotes trust, healing, and resilience.**

Visit our website to learn more and explore how your unit can mitigate harm for marginalized families

TRAUMA-INFORMED CARE CORNER

EASE: A DIFFERENT WAY TO HOLD CARE

MARY COUGHLIN, MS, NNP, NCC-E, TRAUMA INFORMED PROFESSIONAL

In trauma-informed care, we often speak about safety, trust, and honoring choice. But there is another question that sits just beneath all of it, one we don't always name. Not *what or who is right* but: *do people have EASE (Equitable Access to Support and Education) for all care journeys*. **Because when we step into the realities of care, whether in infant feeding, the NICU, or beyond, we quickly realize that the conversations we tend to have are often shaped by tension.** Breastfeeding or formula. Policy or practice. Guidance or lived experience.

And yet, when we collapse complexity into these kinds of either/or frames, **we risk losing sight of what people actually need in the moments that matter most**. We know, without question, that breastfeeding offers profound biological and relational benefits. We also know that global organizations have worked to establish guidance intended to protect infant feeding practices and promote public health. And yet, at times, these **broader frameworks can feel distant from the realities clinicians and families are navigating every day where decisions are complex, resources are limited, and competing priorities are constant.**

Not all parents can breastfeed, not all infants can receive breastmilk, and **every family deserves to be met with support that is safe, informed, and free from judgment**. And then there is the reality of the systems we work within.

Many of the people leading, teaching, and shaping this work are doing so voluntarily, offering their time and energy because they believe deeply in what is possible in the NICU and the world. The infrastructure required to sustain organizations, education, and collaboration is real. It requires resources. It requires support. It requires decisions that are not always simple.

Even the most well-intended systems and guidelines cannot fully account for the lived realities unfolding at the bedside and in families' lives. At the same time, there is a growing call across our field to look more closely at alignment, transparency, and the conditions that shape care.

These are not opposing forces. They are the conditions of the landscape we are navigating. And this is where trauma-informed care stretches us. Because it does not ask us to simply notice complexity; it asks us to respond to it. It asks us to move from awareness into agency. If something feels misaligned, the work is not only to name it, but to wonder: what else might be possible here?

EASE (Equitable Access to Support and Education) invites us to look more closely at the conditions that make care possible. It invites us to ask:

- Is there equitable access to meaningful support?
- Is education clear, compassionate, and grounded in both science and lived experience?
- Are people being met with dignity, or with pressure and judgment?

EASE: A DIFFERENT WAY TO HOLD CARE

CONTINUED FROM PAGE 5

MARY COUGHLIN, MS, NNP, NCC-E, TRAUMA INFORMED PROFESSIONAL

When EASE is present, care in whatever form it takes can feel supported, informed, and grounded. When it is not, people can feel overwhelmed, judged, or alone. Clinicians can feel stretched, uncertain, or constrained by systems that do not fully reflect the realities they are navigating.

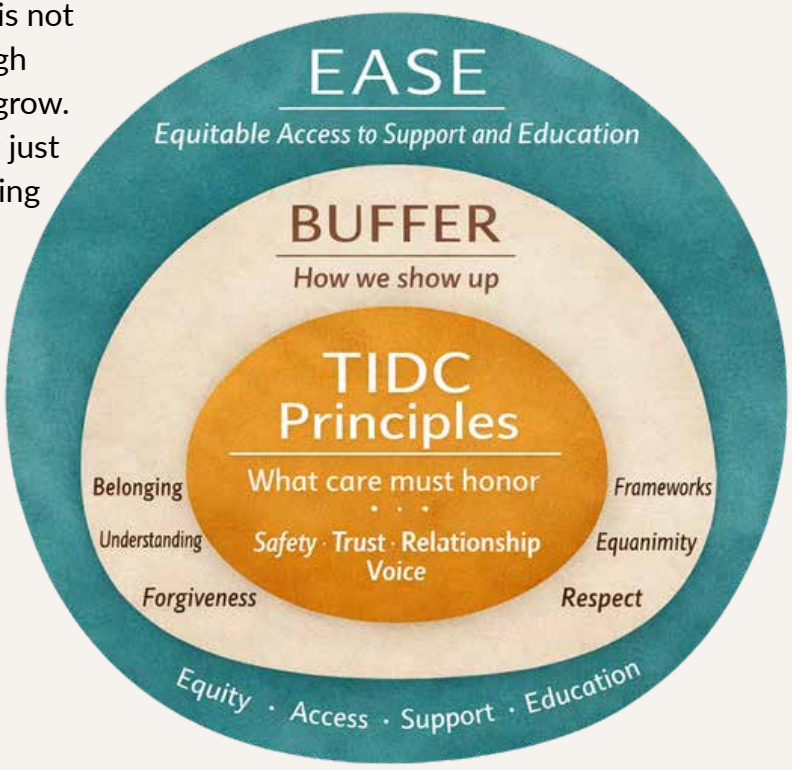
While EASE is explored here through the lens of infant feeding, it extends far beyond it. It reflects a broader condition of care; one that applies wherever individuals and systems intersect. Because **across all settings, the ability to provide thoughtful, responsive care depends not only on intention, but on whether equitable access to support and education is truly in place.**

In many ways, this reflects what we already know through the B.U.F.F.E.R. framework; that how we show up matters deeply. EASE extends that understanding, inviting us to **consider not only how we relate, but whether the conditions around us make that kind of care truly possible.**

Trauma-informed care not only asks us to recognize these gaps but to respond with creativity, courage, and a shared responsibility to build something better. Because this work is not about ideology. It is about people. It is about the parent making decisions under pressure, often with incomplete information and deep emotion. It is about the infant whose needs must be met in real time, without delay. It is about the clinician who is holding science, ethics, and humanity all at once.

Trauma-informed care asks us to meet each of them with dignity. With honesty. With presence. Not perfectly, but consciously. Because trust is not built on perfection. It is built over time, through transparency, reflection, and a willingness to grow. And perhaps this is the deeper invitation. Not just to navigate complexity…but to create something new within it.

Layers of Trauma-Informed Care:



A Reflection

- Where in your own work do you see EASE present?

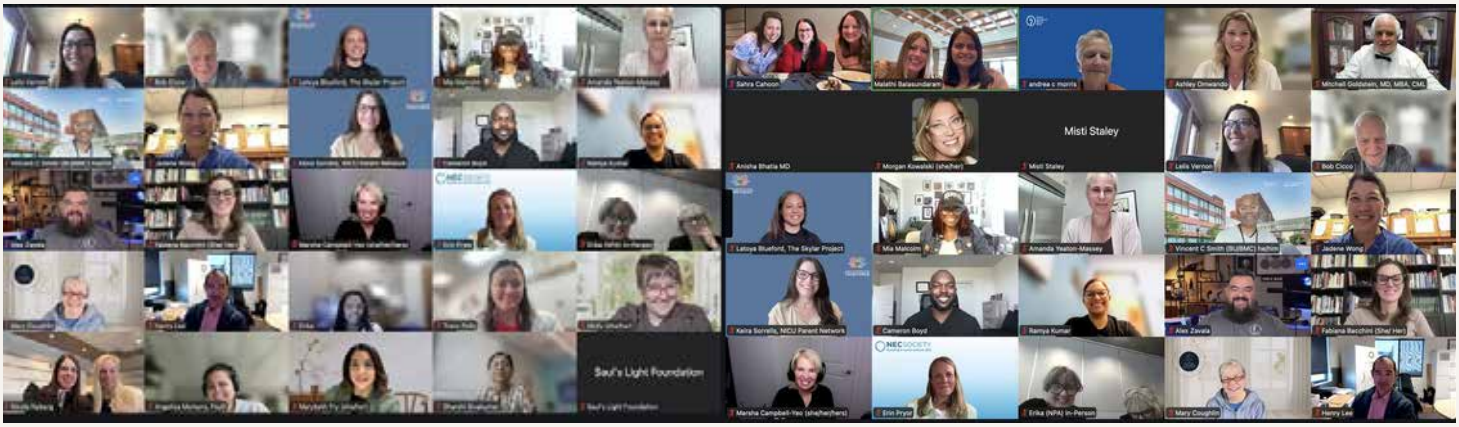
- And where might there be an opportunity to create more of it for the people you serve, for your colleagues, and for yourself?

With hugs and hope,
Mary

LEADERSHIP TEAM UPDATE

MALATHI BALASUNDARAM, MD & MORGAN KOWALSKI

The FCC Taskforce's Executive Council held its first quarterly meeting of 2026 on March 26th with 37 members joining virtually via Zoom and in-person at National Perinatal Association's conference in Coeur d'Alene, Idaho. Thank you to Kristy Love for accomodating our group!



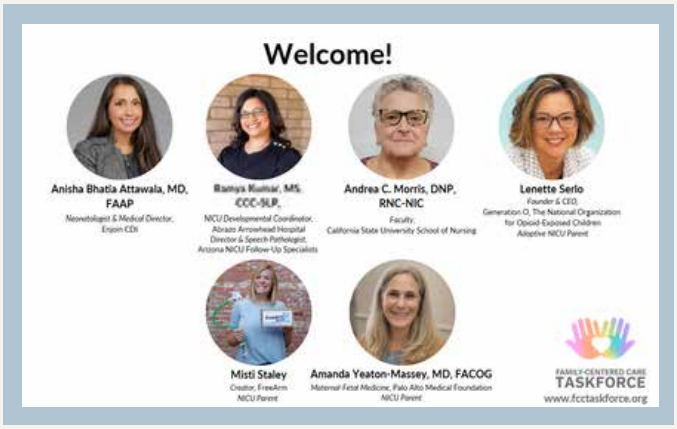
We are excited to introduce our new **Dads & Partners Engagement Committee** co-chaired by Cameron Boyd, MD and Alex Zavala of The NICU Dad! Together, they will **advance the inclusion, support, and engagement of dads, partners, and non-birthing parents in the NICU.**

Projects in Our Pipeline:

- Presence Study Toolkit
- FCC Scholars
- Quality Improvement Foundations Course for Family Partners - Thank you, VON!
- Dads and Partners Screening and Support Cohort
- Creation of Fiscal Stewardship Committee
- Silent Signals in the NICU Toolkit

It was so wonderful to be together in person in beautiful Coeur d'Alene!

We welcomed **six** new Executive Council members with dynamic areas of expertise and diverse lived experience!



THANK YOU FOR READING

FCC Taskforce Leadership

Malathi Balasundaram, MD
Founder & Executive Director

Morgan Kowalski, NICU Parent
Director of Operations

Keira Sorrells, NICU Parent
Director of Impact & Strategy

Organizational Partners

27 family-led organizations
50 healthcare-based organizations

Connect

Mission Statement

We support NICUs as they begin or strengthen Family-Centered Care in their units.

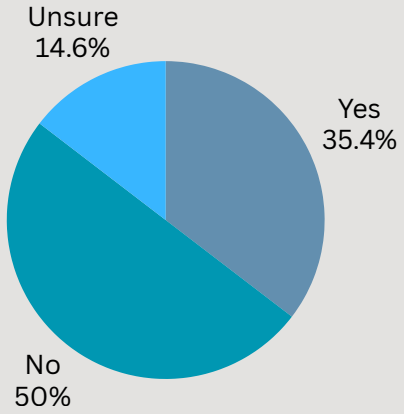
Why We Exist

To address the challenges that exist in implementing FCC practices, we offer free educational webinars with engaging, live Q&A sessions and free monthly FCC Community Exchange 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 active FCC Committee in their unit.

Does your NICU currently have an FCC Committee?



Membership

3,400+ members
49/50 U.S. States & Puerto Rico
9/10 Canadian Provinces
80 Countries
Join us, membership is free!

Our listserv is a closed and moderated, intended to foster meaningful collaboration and information sharing within our community. We are mindful of email fatigue and strive to keep communications thoughtful, relevant, and purposeful.

Newsletter Committee

Co-Chairs
Bob Cicco, MD
Morgan Kowalski

Contributors
Jessi Barnes, MSN, RN, RNC-NIC, NPD-BC
Sahra Cahoon
Mary Coughlin, MS, NNP, NCC-E
Erika Goyer, BS
Mia Malcolm, BS, CDFT
Jadene Wong, MD

We're grateful to our contributors who **donate their time and expertise** to our publication!

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FAMILY-CENTERED CARE TASKFORCE

Caring for Babies and their Families

Our online education gives Maternity, Labor & Delivery, NICU, and Postpartum staff the tools they need to bring care of parents, babies, and families to the next level.

Learn directly from patients and families. Hear their stories.
What they tell you will leave a lasting impression.

Timely

information to address our current challenges

Evidence-Based

education informed by the latest data

Story-Driven

lessons created in collaboration with family advocates, based on their real-life experiences

Trauma-Informed

content that addresses the unique psychosocial needs of families and staff

National Perinatal Association
and NICU Parent Network

Online continuing education created by parents and providers.

Peer Reviewed

Briefly Legal: Fetal Head Trauma versus Hypoxic-Ischemic Injury: Why Distinction Matters for Neonatologists: Beyond Cord Gases and Apgar Scores

Maureen E Sims, MD, Barry Schifrin, MD

A 21-year-old primigravida at 40.1 weeks' gestation with an unremarkable prenatal course was admitted to the hospital with spontaneous rupture of membranes and regular uterine contractions. She was 62.5 inches tall and weighed 135 pounds; her BMI was 24.6. She was experiencing fetal movements, and a fetal ultrasound showed a vertex presentation. Prenatal testing, including GBS status, was negative. Labor was prolonged despite augmentation with Pitocin. To better appreciate the details of contractions, an intrauterine pressure catheter (IUPC) was placed. Despite excessive uterine activity and fetal tachycardia, Pitocin was continued. After 33 hours of labor, the cervix became completely dilated with the fetus in the occiput transverse (OT) position—a malposition. An attempt to manually rotate the fetus to an occiput anterior (OA) position failed. The mother developed a fever to 38.8 °C, which was treated with antibiotics. After 3 hours of pushing with increasing frequency and depth of decelerations, the baby's head was delivered spontaneously, followed by difficulty in delivering the shoulders. Following McRoberts maneuver and suprapubic pressure the male infant was completely delivered and handed to the awaiting neonatal resuscitation team called in anticipation of problems with the delivery.

"At birth, the 3260-gram male infant appeared "stunned"; he was limp and showed no respiratory effort. Positive-pressure ventilation (PPV) with increasing inspired oxygen was initially provided, followed by CPAP. The Apgar scores were 2, 6, 6, 6, and 6 at 1 minute and 5 through 20 minutes, respectively."

At birth, the 3260-gram male infant appeared "stunned"; he was limp and showed no respiratory effort. Positive-pressure ventilation (PPV) with increasing inspired oxygen was initially provided, followed by CPAP. The Apgar scores were 2, 6, 6, 6, and 6 at 1 minute and 5 through 20 minutes, respectively. Umbilical cord gases were:

Venous pH 7.37/pCO_2 34/pO_2 32/BE -4

Arterial pH 7.31/pCO_2 42/pO_2 21/BE -4

Examination of the head showed significant bruising and scalp swelling with concerns for subgaleal hemorrhage (SGH). His length was 53 cm, and his head circumference was 35 cm. The ponderal index (PI) was 2.2.

"The infant was brought to the NICU on a nasal cannula, but after a couple of hours, he required intubation because of apnea. His physical examination showed a blood pressure (BP) of 60/31 mmHg and a heart rate (HR) of 173 bpm. A capillary blood gas, drawn at 20 minutes of life, showed a pH of 7.28, a pCO_2 of 40 mmHg, a pO_2 of 50 mmHg, a base excess of -7.5, and a lactate of 9.4 mmol/L."

The infant was brought to the NICU on a nasal cannula, but after a couple of hours, he required intubation because of apnea. His physical examination showed a blood pressure (BP) of 60/31 mmHg and a heart rate (HR) of 173 bpm. A capillary blood gas, drawn at 20 minutes of life, showed a pH of 7.28, a pCO_2 of 40 mmHg, a pO_2 of 50 mmHg, a base excess of -7.5, and a lactate of 9.4 mmol/L.

Therapeutic hypothermia was not considered since the physicians felt that prevailing criteria for treatment (acidosis) had not been met. His complete blood count was unremarkable. At 3 hours, en route to a CT scan, he had a seizure for which he was placed on phenobarbital; Dilantin was added subsequently. The CT scan showed a large subgaleal hemorrhage (SGH), a small subdural hematoma (SDH), and an intraventricular hemorrhage (IVH)

"Therapeutic hypothermia was not considered since the physicians felt that prevailing criteria for treatment (acidosis) had not been met...At 3 hours, en route to a CT scan, he had a seizure for which he was placed on phenobarbital; Dilantin was added subsequently. The CT scan showed a large subgaleal hemorrhage (SGH), a small subdural hematoma (SDH), and an intraventricular hemorrhage (IVH) in the occipital horn of the right lateral ventricle."

in the occipital horn of the right lateral ventricle. Neither mass shift nor dilated ventricles were present. A brain MRI on DOL 4 revealed extensive areas of cytotoxic edema throughout the cerebral hemispheres as well as involvement of the basal ganglia and cerebellar vermis. It also confirmed an IVH in the occipital horns bilaterally and a small SDH along the left posterior cerebral convexity.

Lactate levels at 9 and 14 hours of age showed a declining trend, with values of 6.6 and 2.4, respectively. Creatinine and liver enzymes, initially elevated, returned to normal by 48 hours. The baby developed anemia and a coagulopathy requiring blood products, including fresh frozen plasma. A lumbar puncture was unremarkable. HSV and bacterial cultures were negative. At 2 weeks, he was discharged nippling adequately and on room air (RA).

"Lactate levels at 9 and 14 hours of age showed a declining trend, with values of 6.6 and 2.4, respectively. Creatinine and liver enzymes, initially elevated, returned to normal by 48 hours. The baby developed anemia and a coagulopathy requiring blood products, including fresh frozen plasma."

The placenta was 377 grams and showed acute chorioamnionitis without cord involvement.

On follow-up examination at 3 years of age, he had a mixed pattern of cerebral palsy (spastic and extrapyramidal quadriparesis) and mixed communication with an ongoing seizure disorder.

The parents pursued a lawsuit against the physician, the nurses, and the hospital, alleging the following:

- **Failure to properly assess and respond to abnormalities of labor**
- **Failure to appreciate the improbability of safe vaginal delivery**
- **Failure to timely and properly assess and respond to abnormalities of the FHR tracing.**
- **Failure to properly assess and respond to signs of excessive uterine activity**
- **Failure to properly manage the administration of Pitocin—a black-label drug.**
- **The baby's brain injury was the direct result of the above, including direct trauma to the fetal head from failed rotation attempts, prolonged pushing in the 2nd stage.**

The defense maintained that the standard of care was met and that the injury was not preventable.

The case was settled prior to trial.

Discussion: Fetal Head Trauma:

There seems to be little doubt that the neurological injury suffered by the fetus was primarily ischemic, related to impaired cerebral circulation. This conclusion derives from the evolution of the FHR pattern, which is normal at the outset of labor and then progressively deteriorates to a Category III pattern and evidence of injury. This evolution occurs in the face of excessive uterine activity, a malposition of the fetal head, a failed manual rotation of the head, and a prolonged 2nd stage of labor with failure of the head to descend despite 3 hours of compulsive maternal pushing. The newborn is severely depressed and encephalopathic, initially requiring moderate respiratory support, but with near-normal umbilical blood gases. He is denied the benefits of cooling because his blood gases are normal, though his lactate level is markedly elevated. The requirement for respiratory support escalated within hours to assisted ventilation due to apnea and seizure activity. Neuroimaging demonstrated an extensive, multifocal pattern of intracranial injury, including SGH, SDH, and intraventricular hemorrhages, with parenchymal involvement of the cerebrum, basal ganglia, and cerebellum.

"There seems to be little doubt that the neurological injury suffered by the fetus was primarily ischemic, related to impaired cerebral circulation. This conclusion derives from the evolution of the FHR pattern, which is normal at the outset of labor and then progressively deteriorates to a Category III pattern and evidence of injury."

Fetal head trauma resulting in impaired cerebral blood flow and neurological injury sustained during labor and delivery often occur without concurrent *systemic* intrapartum hypoxia and variable problems of immediate neonatal adaptation.

"Fetal head trauma resulting in impaired cerebral blood flow and neurological injury sustained during labor and delivery often occur without concurrent systemic intrapartum hypoxia and variable problems of immediate neonatal adaptation."

Mechanism of fetal skull trauma causing brain injury:

Mechanical events affecting fetal cerebral blood flow (CBF) during labor and delivery should be considered as a potential explanation for adverse neonatal outcomes, particularly when significant changes occur in a previously normal fetal heart rate pattern and

umbilical pH remains within the normal range.

"Mechanical events affecting fetal cerebral blood flow (CBF) during labor and delivery should be considered as a potential explanation for adverse neonatal outcomes, particularly when significant changes occur in a previously normal fetal heart rate pattern and umbilical pH remains within the normal range."

A neonate who has sustained systemic intrapartum hypoxia typically presents with umbilical acidemia and varying degrees of depression, ranging from hypotonia and irregular respirations to requiring full resuscitation. In contrast, infants with neurologic injuries attributable to localized (regional) brain ischemia during labor and delivery present without significant umbilical acidemia and may be asymptomatic immediately after birth, depending on the degree of sustained intracranial trauma. These infants may not manifest clinically for hours, days, or longer after delivery. As cytotoxic edema accumulates and intracranial pressure (ICP) rises, eventually symptoms such as apnea, oxygen desaturations, or seizures may appear or more subtle neurologic signs later.

"In contrast, infants with neurologic injuries attributable to localized (regional) brain ischemia during labor and delivery present without significant umbilical acidemia and may be asymptomatic immediately after birth, depending on the degree of sustained intracranial trauma. These infants may not manifest clinically for hours, days, or longer after delivery. As cytotoxic edema accumulates and intracranial pressure (ICP) rises, eventually symptoms such as apnea, oxygen desaturations, or seizures may appear or more subtle neurologic signs later."

Fetal skull bones, not yet fused, are compliant, allowing the fetal head to mold and adapt to the birth canal and facilitating vaginal delivery. However, pressure generated by uterine contractions and pushing, which increases intraamniotic pressure by an average of 50%, is transmitted through the fetal skull, transiently elevating intracranial pressure (ICP) and potentially impairing cerebral perfusion.

Under normal circumstances, the fetus compensates by increasing systemic blood pressure (BP) proportionally during contractions, thereby maintaining adequate cerebral perfusion pressure. This response is further supported by two additional protective mechanisms: cerebrovascular autoregulation, the physiologic capacity to sustain cerebral blood flow (CBF) across a range of systemic BPs, and the Cushing response, in which a critical rise in ICP triggers a compensatory increase in mean arterial pressure (MAP) by increasing the peripheral resistance in non-essential organs.

Nevertheless, the neonatal cerebral circulation operates under inherent constraints. Because baseline arterial BP in the newborn is relatively low, cerebral perfusion pressure may already be functioning near the lower threshold of the autoregulatory curve, leaving limited physiologic reserve. When uterine contractions are excessively frequent, unduly intense, enhanced by maternal pushing, or associated with pathologically elevated baseline uterine tone, the cerebral circulation may be deprived of sufficient recovery time to restore oxygenated blood flow, ultimately precipitating cerebral ischemia. The fundamental hemodynamic relationship captures this vulnerability: **Cerebral Perfusion Pressure (CPP) = Mean Arterial Pressure (BP) – Intracranial pressure (ICP).**

"Because baseline arterial BP in the newborn is relatively low, cerebral perfusion pressure may already be functioning near the lower threshold of the autoregulatory curve, leaving limited physiologic reserve. When uterine contractions are excessively frequent, unduly intense, enhanced by maternal pushing, or associated with pathologically elevated baseline uterine tone, the cerebral circulation may be deprived of sufficient recovery time to restore oxygenated blood flow, ultimately precipitating cerebral ischemia."

A contraction-induced rise in ICP during pushing, superimposed on an already low neonatal MAP, can rapidly narrow the CPP margin, underscoring why even transient disruptions in this balance carry significant consequences for the developing brain.

Ischemic injury occurs when the fetus can no longer compensate for the forces compromising cerebral perfusion. It is an ischemic injury without the prerequisite of long-standing fetal hypoxia or acidemia. Because affected neonates may not be visibly depressed

"Ischemic injury occurs when the fetus can no longer compensate for the forces compromising cerebral perfusion. It is an ischemic injury without the prerequisite of long-standing fetal hypoxia or acidemia."

at birth (they are not acidotic), they may be transferred routinely to the nursery or placed with the mother, only to deteriorate hours to days later as cerebral edema progresses to the point of clinical decompensation. Without a thorough understanding of the *detailed* events of labor and delivery and a detailed understanding of the fetal responses, a neonatologist may struggle to explain the etiology of encephalopathy in a newborn with normal cord blood gases and no immediate postnatal depression. This often begins the search for a genetic or metabolic etiology. Specific mechanical factors include: prolonged labor, excessive uterine activity, fetal malposition, attempts at manual rotation, prolonged, compulsive pushing, and operative vaginal delivery (vacuum or forceps), shoulder dystocia, or difficulty extracting the fetus at cesarean section. An additional complicating factor is prolonged rupture of membranes, which eliminates the amniotic fluid cushion and increases fetal head molding by reducing the fetal head's diameter. It is a principle of physics that reducing the diameter of a sphere disproportionately increases the intracranial pressure when subjected to external force.

"Because affected neonates may not be visibly depressed at birth (they are not acidotic), they may be transferred routinely to the nursery or placed with the mother, only to deteriorate hours to days later as cerebral edema progresses to the point of clinical decompensation. Without a thorough understanding of the detailed events of labor and delivery and a detailed understanding of the fetal responses, a neonatologist may struggle to explain the etiology of encephalopathy in a newborn with normal cord blood gases and no immediate postnatal depression.."

The Intrapartum Challenge for Neonatologists:

Clinically, neonatologists distinguish intrapartum head trauma from systemic hypoxic-ischemic events using several key variables, though assembling a complete picture is rarely straightforward at the time of birth. Labor progression and fetal heart rate tracings are among the most difficult to assess, not because the data are inherently ambiguous but because neonatologists are typically summoned moments before delivery, allowing little time for a thorough handoff. As a result, critical intrapartum details may go unrecognized, such as a protracted labor with prolonged pushing, excessive uterine irritability with inadequate rest time between contractions, elevated resting tone, fetal malpositioning with or without attempted rotation, and assisted operative delivery via forceps or vacuum extraction. Compounding this, the urgency of neonatal stabilization after delivery routinely displaces retrospective review of intrapartum events, leaving the clinician to reconstruct an incomplete and often fragmented history.

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In addition, and in fairness, the obstetrical record usually provides little insight into the problems at hand. With such designations as fetal intolerance to labor, Category II tracing, prolonged labor, etc., there is little specificity to guide the neonatologist. It rarely includes the duration of pushing during the abnormal tracing or the presence of a malposition.

Umbilical cord gas:

Decelerations occur for reasons other than hypoxia. Decelerations occur when there is any impairment of intracerebral blood flow. Early in labor, this may manifest as early decelerations within contractions that do not affect the baseline fetal heart rate (FHR) or variability. With increasing impairment of the cerebral circulation, the decelerations become more angular and deeper (called variable decelerations). With further impairment, the FHR rises, and variability diminishes. In the 2nd stage of labor, these decelerations represent head compression, not cord compression. The failure to detect systemic asphyxia in the umbilical cord blood gases belies the impact of increased ICP on acidosis within

the brain. Experiments show that increased ICP indeed causes local acidosis that is NOT necessarily reflected in the systemic circulation.

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Lactate concentrations:

Once oxygen delivery fails and anaerobic metabolism kicks in, lactate begins rising within minutes. Under severe acute hypoxia (e.g., cord prolapse), lactate rises at 2–4 mmol/L per hour. Under sustained partial hypoxia (e.g., prolonged late decelerations, placental insufficiency), it rises more slowly, at about 0.5–1.5 mmol/L per hour. The lactate rise essentially mirrors the duration and depth of the hypoxic insult. In a compromised neonate who suffers poor cardiac output or liver dysfunction because of hypoxia, lactate clearance is dramatically slowed because the liver, which is the primary lactate-clearing organ, is hypoxically injured. Also, cardiac dysfunction reduces hepatic perfusion. Any ongoing anaerobic metabolism continues adding to the pool. The normal clearance rate of lactate is 1–2 mol/L/hour, and the half-life in healthy neonates is approximately 60–90 minutes. Base excess and lactate are related but are not interchangeable since lactate is only one contributor to the deficit. The general rule of thumb is that in pure lactic acidosis, each 1 mmol/L rise in lactate consumes approximately 1 mEq/L of bicarbonate, producing roughly 1 unit of negative base excess. Other contributors to the pool include unmeasured anions, ketones, and other organic acids.

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During systemic fetal hypoxia, lactate is produced predominantly in peripheral tissues that shift to anaerobic metabolism. Skeletal muscle is the largest contributor, followed by skin, peripheral soft tissues, kidneys, gut, and other non-vital organs. The placenta and fetal blood cells contribute to a lesser degree. In response to hypoxia, the fetus undergoes a "brain-sparing" redistribution of blood flow, preferentially maintaining perfusion to the brain, heart, and adrenal glands. When compensatory redistribution fails, as occurs with severe or prolonged hypoxia, the brain and heart themselves begin producing lactate, marking a transition to systemic lactate generation accompanied by worsening metabolic acidosis. This progression follows a recognizable pattern. Early compensated hypoxia generates lactate primarily from underperfused peripheral tissues, with vital organ function preserved. In severe, decompensated hypoxia, widespread tissue oxygen debt extends to vital organs, driving a rapid rise in both lactate and base deficit.

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An important clinical nuance is lactate mobilization after birth. Cord blood lactate may appear relatively low at delivery, despite significant tissue acidosis, because, during the Cushing response, peripheral vasoconstriction results in lactate accumulation within tissues rather than its free circulation. Once perfusion is restored after birth, this sequestered lactate is released into the systemic circulation, producing an apparently paradoxical rise in measured lactate and a fall in pH in the postnatal period, a pattern that should not be mistaken for new or ongoing injury. Indeed, the duration of the immediate neonatal tachycardia is a reflection of the severity of the acidosis sequestered in the periphery.

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In a situation of fetal head trauma, compression, bruising, cephalohematoma, and SGH increase intracranial lactate. Also, difficult deliveries trigger a major release of epinephrine and norepinephrine. A catecholamine surge during stressful deliveries stimulates glycolysis and lactate production, even when oxygen delivery remains adequate, a phenomenon referred to as "stress hyperlactatemia." Fetal struggling, prolonged pushing against the birth canal, or sustained contractions also increase fetal lactate production from their skeletal muscle.

Apgar Scores:

The Apgar score assesses five parameters: heart rate, respiratory effort, muscle tone, reflex irritability, and color. These assessments primarily reflect systemic cardiorespiratory and autonomic function. It was designed as a rapid snapshot of the newborn's overall physiologic transition at birth, not as an assessment of neurologic integrity.

When a fetus sustains a focal mechanical head injury, the impaired oxygenation (ischemia) may be confined entirely to the intracranial compartment. It is the anterior cerebral circulation, supplied by the carotid arteries and suffused with sympathetic innervation, which generally becomes ischemic when, as a last compensatory effort to supply the critical areas of the brain, the anterior cerebral circulation participates in the Cushing response. Lacking sympathetic innervation in the brain stem, particularly the reticular activating system and the cardiorespiratory centers of the medulla supplied by the vertebral/basilar system, may remain sufficiently perfused and oxygenated so that the neonate can still maintain heart rate and rhythm, initiate spontaneous respirations, and demonstrate muscle tone and reflexes. With these brain stem functions intact, the newborn may achieve normal or near-normal Apgar scores despite significant intracranial pathology. However, as cerebral perfusion decreases further, even brainstem functions controlling respirations, tone and other autonomic functions may be impaired. Indeed, neonates sustaining focal head trauma may appear intact or even hyperalert or stunned, a presentation attributable to catecholamine release and/or heightened sympathetic tone driven by pain from the injury. This alert state is not to be confused with neurologic intactness. In fact, the classification of neonatal encephalopathy recognizes a hyperalert phase in Stage I encephalopathy (1).

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Furthermore, when positive pressure ventilation or CPAP is provided to assist a newborn in establishing respirations, the resulting Apgar score is necessarily "assisted," and points awarded for respiratory effort must be explicitly acknowledged as such. Critically, there is a well-established sequence in which clinical signs recover in response to assisted ventilation: heart rate improves first, followed by color, then muscle tone, and finally reflex irritability. Accordingly, if points are assigned for reflex irritability before color or tone has been achieved, this temporal inconsistency strongly suggests errors in Apgar scoring.

Head and Ocular Examination in Neonates who have sustained fetal head trauma:

The scalp and skin should be systematically inspected for bruising, lacerations, and the characteristic parallel pressure marks of forceps blades or the circular chignon produced by vacuum extraction. Although bruises and lacerations may appear superficial and therefore benign, they can herald deeper pathology and warrant further assessment, including cranial ultrasound, skull radiographs, CT, or MRI as clinically indicated. A thorough evaluation at birth is essential: identifying marks, bruises, fractures, and the presence of retinal hemorrhages (RH) before discharge not only guides immediate management but may also prevent a child protection investigation arising from injuries discovered after the infant has left hospital. As an aside, RH and SDH are common findings in asymptomatic babies delivered vaginally.

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Scalp swellings must be carefully distinguished from one another, as their clinical significance differs substantially. Caput succedaneum presents as diffuse, pitting edema of the scalp soft tissue that crosses suture lines and typically resolves within the first few days of life. Cephalohematoma, by contrast, represents a subperiosteal hemorrhage strictly confined by suture lines, producing a firm, well-demarcated swelling that may take weeks to months to resolve and is prone to calcification. Bilirubin levels need to be closely followed since levels may easily exceed a safe range. The most clinically dangerous scalp finding is **subgaleal hemorrhage**, in which blood accumulates in the potential space

between the galea aponeurotica and the periosteum. Because this space can accommodate the entire neonate's circulating blood volume, hemorrhage may expand insidiously, presenting initially as diffuse, fluctuant, boggy swelling crossing suture lines before thermodynamic compromise becomes apparent, making early recognition critical.

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Underlying skull fractures, whether linear or depressed, may be detected on palpation as a step-off, bony crepitus, or a focal indentation of the calvarium. The anterior fontanel should be assessed when the infant is calm and held upright; a tense, bulging, or non-pulsatile fontanel suggests raised intracranial pressure and warrants urgent evaluation.

Ocular findings require active, systematic examination, as they are not apparent on casual inspection and carry significant diagnostic and medicolegal importance. Pupillary asymmetry, a fixed and dilated pupil, or sluggish and unequal reactivity to light may indicate transtentorial herniation or direct injury to the oculomotor nerve. Fundoscopic examination may reveal retinal hemorrhages appearing as flame-shaped, dot, or blot lesions reflecting transmitted intracranial hypertension or direct venous injury. Retinal and scleral hemorrhages must be carefully documented at birth, both for clinical management and to establish a clear contemporaneous record that may protect the family and clinicians alike should safeguarding concerns arise after discharge. Gaze abnormalities, including conjugate horizontal or vertical deviation, the sunset sign (forced downward gaze with upper lid retraction), or spontaneous nystagmus, may indicate injury to cortical gaze centers, the midbrain, or the cerebellum, and should prompt urgent neuroimaging.

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Differentiating injury from cerebral ischemia and systemic hypoxic-ischemia:

Distinguishing fetal injury from cerebral ischemia from hypoxic-ischemic injury is critical for neonatologists, as these two entities differ fundamentally in pathophysiology, acute management, neuroprotective eligibility, neuroimaging strategies and timing, prognosis, preventability, and medicolegal implications. However, both conditions may present similarly at birth, particularly when head trauma is severe, as in the case presented, or when the two conditions coexist, accurate differentiation remains essential. Correct diagnosis directly informs clinical management, guides accurate and meaningful parental counseling, shapes obstetric planning for future pregnancies, and supports quality improvement efforts for both physicians and hospital systems.

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Management:

Therapeutic hypothermia (TH) is the standard of care for moderate-to-severe hypoxic ischemic encephalopathy (HIE) and must be initiated within 6 hours of birth to provide neuroprotection. This therapy was validated specifically for encephalopathy caused by perinatal asphyxia. It has not been studied for neonates whose encephalopathy is primarily due to mechanical head trauma. We will not discuss the use of TH further in this newborn because he failed to meet pH criteria. Nevertheless, two issues seem critical to the discussion. First, the animal model of injury that supports neonatal cooling derives from experiments involving acute ischemia, not systemic hypoxia. (2) Second, the outcome of encephalopathic newborns is unrelated to the presence of acidosis in the umbilical cord at the time of birth (3).

Moreover, head trauma may require urgent volume and blood component resuscitation (e.g., SGH), urgent neurosurgical evaluation or intervention (subdural or epidural hematomas, depressed skull fractures). Trauma warrants an urgent CT scan to identify hemorrhage, skull fractures, or mass effect requiring immediate action. MRI, particularly diffusion-weighted imaging,

better characterizes HIE and is typically performed at 24–96 hours post-injury. HIE generally produces characteristic deep nuclear gray matter injury or watershed cortical injury patterns. A traumatic delivery may present as focal arterial infarction, isolated intraparenchymal or intraventricular hemorrhage, subdural hemorrhage, or skull fracture. These patterns suggest that the primary source of the injury is regional ischemia, not systemic hypoxia and acidemia. Significant head trauma with tissue damage and release of thromboplastins or severe hemorrhage can trigger consumptive coagulopathy or disseminated intravascular coagulation (DIC), requiring active monitoring and correction of clotting factors. While HIE also may trigger DIC, it is often not as severe as that in head trauma.

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Prevention:

Obstetrical personnel must continually evaluate the position of the fetal head in the birth canal, labor progress, the pattern of uterine contractions, and the fetus's response thereto using the fetus's responses on the fetal monitor. They must use uterine stimulants cautiously, avoiding excessive uterine activity and aggressive pushing. A helpful technique may be to have the mother push with every other contraction. The object is to avoid the need for urgent intervention.

Parental counseling:

Understanding the mechanism helps clinicians make more accurate predictions about survival, cognitive development, motor function, and quality of life. It should also trigger a discussion of the delivery route for subsequent deliveries. Parents want and deserve to understand the details of the delivery. Vague and inaccurate information increases parental anxiety or distrust. Mothers often internalize blame. Clarifying the etiology can meaningfully shape a family's emotional processing and reduce unwarranted self-blame. Although traumatic injury is generally not heritable, it may be linked to specific obstetric circumstances such as the size of the pelvic outlet. While not the primary focus of counseling, parents may have questions about whether the injury was preventable or whether standards of care were met. An accurate diagnosis ensures families receive truthful answers. It is helpful for the delivering obstetrician, parents, and neonatologist to conduct a joint conference to ensure that misleading narratives are not conveyed.

Finally, we acknowledge here the debate over whether head compression during labor causes injury (basically a medicolegal issue to deal with the lack of acidosis and symptoms at birth) and agree that fetal head compression during a properly managed, routine labor is an unlikely cause of injury. Even with a snug fit, the fetus's ability to compensate both anatomically and with systemic cardiovascular responses described above is often sufficient to prevent injury. These benign notions, however, are not persuasive in the face of excessive contractions, prolonged/obstructed labor with relentless pushing, fetal malposition, or difficult operative vaginal delivery, which are generally conceded to have the capability to cause fetal neurological injury.

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Peer Reviewed

Medical Legal Issues Surrounding Perinatal Arterial Ischemic Stroke

Jay P. Goldsmith, MD, Jonathan K. Muraskas, MD

Case:

A 37-year-old gravida 1 para 0 mother was admitted to the hospital in the early morning hours, complaining of spontaneous rupture of membranes at $40^{3}/_{7}$ weeks gestation. Pregnancy was complicated by gestational diabetes mellitus. Fetal monitoring started at about 0200 hours and appeared reassuring. Cytotec was given, and an epidural was placed later in the morning. Pitocin was started at 9 hours after admission, and the mother was complete and at 0 station by early afternoon. A prolonged deceleration occurred; Pitocin was stopped, and a fluid bolus and terbutaline were given. The fetal heart rate recovered to a Category I strip, and Pitocin was restarted with no further prolonged decelerations. Mother pushed for approximately 2.5 hours with the fetal head position noted as OP. Options for delivery were presented to the mother, and she elected to undergo a trial of vacuum delivery. A vacuum was attempted 3 times with 6 pulls, without any significant descent, and 1 pop-off was recorded. Mother was then taken to the OR for a cesarean section.

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A baby girl was born and assigned Apgar scores of 4 and 8 at 1 and 5 minutes, respectively. The baby was described initially as limp and apneic at birth and was suctioned for moderate meconium-stained secretions. She responded quickly to brief positive-pressure ventilation with bag and mask and was on room air by 5 minutes of age. Birth weight was 3350 grams, and head circumference was 35 cm. The arterial cord blood gas revealed a pH of 7.05, pCO_2 of 65, pO_2 of 15, and a base deficit of 14. The initial physical exam revealed some edema in the occipital area of the cranium but was otherwise normal, including a normal neurologic exam. The baby was evaluated by a neonatologist who felt this was serous fluid without significant blood or subgaleal hemorrhage.

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Over the next 36 hours, the baby continued to have normal neurological examinations. There were no seizures noted, and no signs of encephalopathy or multi-system organ dysfunction. Blood pressure was normal, and urine output was good. The hemoglobin and hematocrit remained stable over the first several days of life, indicating no significant blood loss into the subgaleal space. A cranial ultrasound on the third day of life to evaluate the extra-cranial edema revealed a suspicious echogenic area in the left periventricular white matter. The following day, an MRI was performed, which showed a large area of left middle cerebral artery (MCA) territory acute ischemia/infarction. An EEG was performed, which showed left hemispheric subclinical focal seizures. The baby was transferred to a Level 4 hospital for further

evaluation and workup. A thrombophilia workup was negative, and she was discharged at 12 days of age with diagnoses of left MCA stroke, seizures controlled on phenobarbital, and minimal subgaleal hemorrhage. Over the next 3½ years, she experienced problems with motor function, requiring bracing on the right side of her body, developmental delay, short attention span, dysphagia, and possible seizures. The parents filed a malpractice claim against the obstetrician and hospital, claiming that the stroke was secondary to hypoxia-ischemia and a traumatic birth secondary to a failed operative vaginal delivery.

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Incidence and Classification of Perinatal Stroke:

Arterial strokes generally occur in territories supplied by one of the six major penetrating cerebral arteries. As opposed to hemorrhagic strokes, which occur in older adults, fetal/neonatal strokes are generally ischemic and commonly conform to the vascular territory of the artery affected or essentially blocked. The first week of life is considered the most prevalent period of risk for perinatal arterial ischemic stroke (PAIS), with an incidence estimated at 1 in 1100–3000 live births. (1)

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"However, only about half of the newborns who have perinatal stroke have recognizable symptoms in the neonatal period. Moreover, there are few population-based studies of PAIS in the MRI era, potentially underestimating the true incidence. The increased vulnerability of newborns to ischemic central nervous system stroke is probably related to hypercoagulability during pregnancy and the activation of coagulant mechanisms at the time of parturition, presumably an evolutionary adaptation to lessen the risk of hemorrhage at this crucial time."

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Cerebral vascular events that occur between 20 weeks of pregnancy and 28 days of postnatal life are grouped under the classification of perinatal stroke. (3) Three groups are identified by the time of occurrence: fetal, neonatal, and presumed neonatal. The latter is a classification given to a clinical presentation of a static neurologic deficit in the first year of life, without a history of neonatal encephalopathy, and diagnosed by neuroimaging consistent with an arterial or venous territory infarction.

In neonates, the most common form of stroke is ischemic, arising from the vascular occlusion of a cerebral artery and accounting for 40–80% of all neonatal strokes. (4) Other types of stroke include hemorrhagic, cerebral sinovenous thrombosis, and periventricular venous infarction.

Causes:

The pathogenesis of perinatal arterial ischemic stroke (PAIS), the most common form of neonatal stroke, is considered to be most likely multifactorial by many experts. There are three physiologic mechanisms: thrombosis due to proven prothrombotic conditions or poor perfusion and cerebral hypotension; abnormalities of the cerebral arterial circulation; or embolisms from a distant site (most likely the placenta) transcardially into the cerebral circulation. In cases without meningitis, thrombophilia, or cerebral vascular instrumentation (e.g., ECMO), the etiology of PAIS is often difficult to determine and may involve multiple mechanisms.

"The pathogenesis of perinatal arterial ischemic stroke (PAIS), the most common form of neonatal stroke, is considered to be most likely multifactorial by many experts. There are three physiologic mechanisms: thrombosis due to proven prothrombotic conditions or poor perfusion and cerebral hypotension; abnormalities of the cerebral arterial circulation; or embolisms from a distant site (most likely the placenta) transcardially into the cerebral circulation."

Risk Factors:

Numerous risk factors have been associated with PAIS in retrospective literature reviews. (5) These factors and events are incompletely understood and are only viewed as associated with and not causative of PAIS. Maternal risk factors include autoimmune disease, diabetes mellitus, pre-eclampsia, cocaine abuse, placental abruption, smoking, prothrombotic abnormalities, and others. Intrapartum factors include chorioamnionitis, fetal heart rate abnormalities, prolonged second stage of labor, and operative vaginal delivery. Neonatal factors include hypoxia-ischemia, polycythemia, intrauterine growth restriction, hypoglycemia, sepsis, meningitis, DIC, dehydration, congenital heart disease, malpositioned intravascular catheters, and others.

"Numerous risk factors have been associated with PAIS in retrospective literature reviews. These factors and events are incompletely understood and are only viewed as associated with and not causative of PAIS."

Clinical presentation, diagnosis, workup, and initial treatment:

PAIS often presents with seizures or signs of encephalopathy (see article on neonatal seizures in March 2026 *Neonatology Today*). (6) In the modern perinatal unit, the presumed healthy newborn has limited exposure to medical personnel. Therefore, a report from a parent of apnea or cyanosis must be viewed as a potential seizure, and the appropriate CNS workup may be considered. Our mantra is that an apnea episode in a term infant is a seizure until proven otherwise. However, a significant number of strokes are totally asymptomatic in the neonatal period and are only discovered in infancy after the performance of neuroimaging for delayed milestones or hemiparesis. In the neonatal period, seizures are the presenting sign in 50–80% of cases. (7) Other signs of encephalopathy in the newborn may include abnormal tone, altered mental status, poor feeding, and asymmetry of spontaneous movements.

The diagnosis is confirmed by brain imaging, with MRI as the preferred modality. Often, ischemic strokes are missed on cranial ultrasound with one study showing 13% to 28% of strokes missed by this modality. (8) When a baby is not stable enough for an MRI, many neonatologists will do a rapid CT scan, although this modality has fallen out of favor due to increased ionizing radiation risks in the newborn. An MRI will define the vascular territory affected by the stroke and the presence or absence of hemorrhage. The middle cerebral artery is by far the most affected vascular territory of a PAIS, accounting for over 50% of the lesions.

"Therefore, a report from a parent of apnea or cyanosis must be viewed as a potential seizure, and the appropriate CNS workup may be considered. Our mantra is that an apnea episode in a term infant is a seizure until proven otherwise. However, a significant number of strokes are totally asymptomatic in the neonatal period and are only discovered in infancy after the performance of neuroimaging for delayed milestones or hemiparesis. In the neonatal period, seizures are the presenting sign in 50–80% of cases. Other signs of encephalopathy in the newborn may include abnormal tone, altered mental status, poor feeding, and asymmetry of spontaneous movements."

Early neonatal MRI can help distinguish PAIS, typically a well-demarcated territorial lesion, from hypoxic-ischemic encephalopathy (HIE), which more often shows diffuse diffusion abnormalities. In addition to brain imaging, echocardiography should assess for structural heart disease, shunt flow across the foramen ovale and ductus arteriosus, and (rarely) intracardiac thrombus. Placental pathology may show chorioamnionitis, thrombi in the umbilical cord or fetal vessels, or fetal vascular malperfusion. Although thrombophilia testing is commonly performed after PAIS is identified, inherited prothrombotic disorders (e.g., factor V Leiden and protein C or S deficiency) are found infrequently and, even when present, are not diagnostic and indicate only a weak association with PAIS.

The initial management of PAIS focuses on prevention of secondary

brain injury, particularly the vigilant diagnosis and aggressive treatment of seizures, especially status epilepticus. The use of continuous EEG monitoring is suggested since seizures are often not recognized clinically. There is controversy over whether seizures in themselves cause additional brain injury. However, it has been shown that prolonged seizures increase metabolic demands, increase inflammation, and promote the formation of reactive oxygen species, which may cause further edema and tissue damage. (9) Other treatments, such as thrombolysis or thrombectomy, are not recommended. (5)

"Early neonatal MRI can help distinguish PAIS, typically a well-demarcated territorial lesion, from hypoxic-ischemic encephalopathy (HIE), which more often shows diffuse diffusion abnormalities."

Medical Legal Issues:

A common issue regarding PAIS litigation is causation. Plaintiffs often claim (as in this case) that factors surrounding the birth (such as prolonged second stage of labor, use of forceps or vacuum, and/or hypoxia ischemia) caused the stroke. Since PAIS is an ischemic lesion, any factor that decreases arterial blood flow to the central nervous system (i.e., hypoxia-ischemia, hypotension, acidemia, or claimed stretching of the vasculature during operative vaginal delivery) could precipitate this event. Theoretically, there are several mechanisms by which intrauterine hypoxemia/acidemia during labor can cause and/or contribute to PAIS. Some experts may claim that vasospasm of cerebral arterial vessels can occur due to hypoxia-induced sympathetic activation, leading to compression of the cerebral arteries. This then leads to a reduction of blood flow and oxygen to that arterial territory. Altered cerebral perfusion pressure and blood flow can lead to ischemia and infarction. (10) However, there is only a weak association between HIE and stroke, and in these cases, there are often significant pathologic findings in the placenta. Moreover, if HIE causes stroke, there should be high rates of stroke in the multitude of therapeutic hypothermia studies for the treatment of HIE that have been published over the last 20 years. On the contrary, it is rare to have an HIE patient who has undergone therapeutic hypothermia reported as having suffered a stroke.

"The initial management of PAIS focuses on prevention of secondary brain injury, particularly the vigilant diagnosis and aggressive treatment of seizures, especially status epilepticus. The use of continuous EEG monitoring is suggested since seizures are often not recognized clinically."

It may also be claimed that trauma from external vascular compression, including head compression with prolonged second stage of labor, cephalopelvic disproportion, and attempted vacuum or forceps delivery, may result in perinatal stroke. Studies do not confirm this claim. (11) Other experts have claimed that PAIS can also occur by possible arterial dissection as an additional mechanism due to the rotation and pull of the vacuum or forceps on a mispositioned head. However, many published series of PAIS patients who have undergone magnetic resonance angiography have failed to demonstrate a single case of arterial dissection.

"Since PAIS is an ischemic lesion, any factor that decreases arterial blood flow to the central nervous system (i.e., hypoxia-ischemia, hypotension, acidemia, or claimed stretching of the vasculature during operative vaginal delivery) could precipitate this event."

The defense counters that unless there is documented HIE manifested by a diffuse pattern of partial prolonged asphyxia on MRI, systemic hypotension after birth, severe signs of laboratory (blood gas), other organ asphyxia, and clinical encephalopathy beyond clinical seizures, then the stroke is most likely the result of a placental thromboembolism. Moreover, altered cerebral perfusion pressure from external forces and stretching of the cerebral vessels have never been demonstrated in relation to stroke.

"The medical legal controversy continues because causation for PAIS cannot be found in most cases."

The medical legal controversy continues because causation for PAIS cannot be found in most cases. Thrombophilia has been suggested as a cause of a small percentage of PAIS and was examined in this case and found not to be present. Intrapartum factors, as suggested in this case, have been investigated in large studies and found not to be responsible for this lesion. Suggested associations of intrapartum management, including prolonged rupture of membranes, use of Pitocin, operative vaginal delivery, or attempted delivery with vacuum or forceps, have not been shown in the literature to be causative. The *Neonatal Encephalopathy and Neurologic Outcome* monograph, published in 2014 and reaffirmed in 2019 by the American College of Obstetrics and Gynecology and the American Academy of Pediatrics, makes this statement about the relationship between vacuum deliveries and stroke:

> *"Literature suggesting a direct association between vacuum deliveries and stroke consists of isolated cases that should not be mistaken for significant evidence of causation. There is no existing evidence supporting the biological plausibility that controlled, external mechanical*

manipulation could lead to clot formation in deep arterial structures resulting in arterial ischemic stroke." (12)

Other large studies, including the international neonatal stroke registry (13) and a NICHD workshop on stroke held in 2006, could not find a causal relationship between most intrapartum events and PAIS. (14) At present, the most generally accepted opinion on the causation of PAIS (absent infection, alteration of blood flow by a catheter such as an ECMO cannula, or significant trauma) is a thromboembolic event from the maternal placenta that crosses the foramen ovale or a septal defect in the heart to the cerebral arterial circulation, causing a blockage of arterial flow and leading to a territorial ischemia and infarction. Because of the flow characteristics in the MCA from the aorta, this is by far the most common vessel affected. Maternal thrombophilia or other thrombotic disorders are not a necessary condition for the placental clots that enter the fetal bloodstream.

"Other large studies, including the international neonatal stroke registry and a NICHD workshop on stroke held in 2006, could not find a causal relationship between most intrapartum events and PAIS. At present, the most generally accepted opinion on the causation of PAIS (absent infection, alteration of blood flow by a catheter such as an ECMO cannula, or significant trauma) is a thromboembolic event from the maternal placenta that crosses the foramen ovale or a septal defect in the heart to the cerebral arterial circulation, causing a blockage of arterial flow and leading to a territorial ischemia and infarction."

HIE vs. Stroke:

PAIS often has to be distinguished from HIE since the acute treatment of HIE (therapeutic hypothermia) is not indicated and may even be contraindicated in stroke (due to the effects of therapeutic hypothermia on the clotting cascade). Neonates with HIE typically present with very abnormal fetal heart rate tracings, low 5- and 10-minute Apgar scores, need for extensive resuscitation, abnormalities in tone, early seizures, and often abnormalities of other organ systems besides the brain (e.g., liver, kidney, bone marrow, heart, etc.). There may be overlap in presentations between stroke and HIE, but clinicians must move quickly to differentiate between the two if therapeutic hypothermia is to be started within the 6-hour window after birth. Using the criteria proposed by the American Academy of Pediatrics (15), the neonatal providers will review both the clinical aspects of encephalopathy (i.e., Sarnat or similar neurologic score) and the chemical criteria (cord and/or early neonatal blood gases). Later in the baby's hospital course, MRI evaluation may reveal progression of abnormal laboratory results (which may or may not be abnormal in the first 6 hours of life) and other findings that help distinguish between PAIS and HIE. In one 6-year retrospective study, stroke was found to be associated with later onset of seizures (usually after 12 hours of age) and increased platelet counts. It lacked association with common findings in HIE, such as emergency cesarean delivery, nonreassuring electronic fetal monitoring, sentinel obstetric events, low Apgar scores, and acidemia in the cord and early neonatal blood gases. (16)

"PAIS often has to be distinguished from HIE since the acute treatment of HIE (therapeutic hypothermia) is not indicated and may even be contraindicated in stroke (due to the effects of therapeutic hypothermia on the clotting cascade)."

Denouement of the case:

Each side presented reputable experts who opined that the stroke was secondary to hypoxia-ischemia and trauma caused by the failed vacuum extraction (plaintiff) or due to placental thromboembolism and not related to birth events, with no evidence of clinical asphyxia or HIE (defense). Unfortunately, there was no placenta to examine, as it was not sent to pathology after delivery. The case settled for an undisclosed amount prior to trial.

Take Home Messages:

- PAIS most commonly occurs in the left middle cerebral artery and usually presents with seizures after 12 hours of age in the neonatal period.
- About 50% of PAIS is asymptomatic and not recognized until later in infancy when an MRI is performed for developmental delay or hemiparesis.
- Acute care of PAIS is mainly seizure control, which is sometimes difficult. Thrombolysis is generally not recommended.
- The lack of clinical and/or laboratory signs of intrapartum asphyxia and the pattern of abnormal diffusion on an MRI in the first week of life make HIE an unlikely cause of PAIS. The International Pediatric Stroke Study found that only 8% of PAIS was associated with HIE. (13)
- Providers must attempt to distinguish HIE from PAIS early in the neonatal course in order to initiate therapeutic hypothermia for HIE within the 6-hour window for optimal efficacy.
- The stretching of deep cerebral arteries in response to head compression, prolonged second stage of labor, or operative vaginal delivery is an unlikely cause of PAIS.

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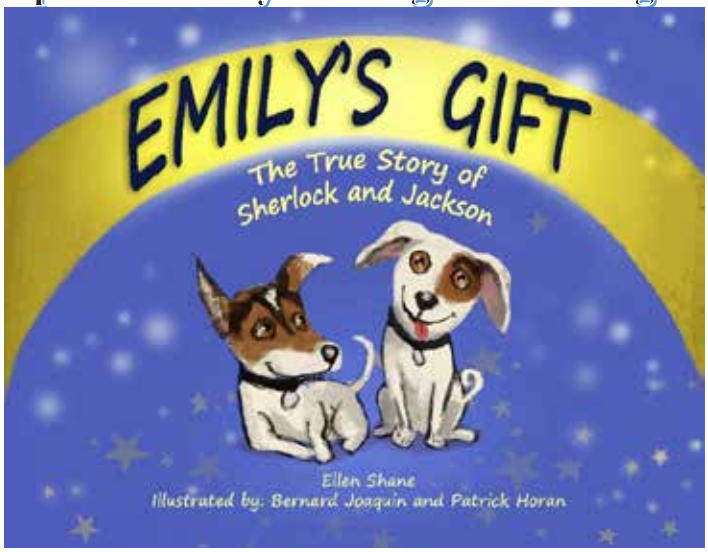

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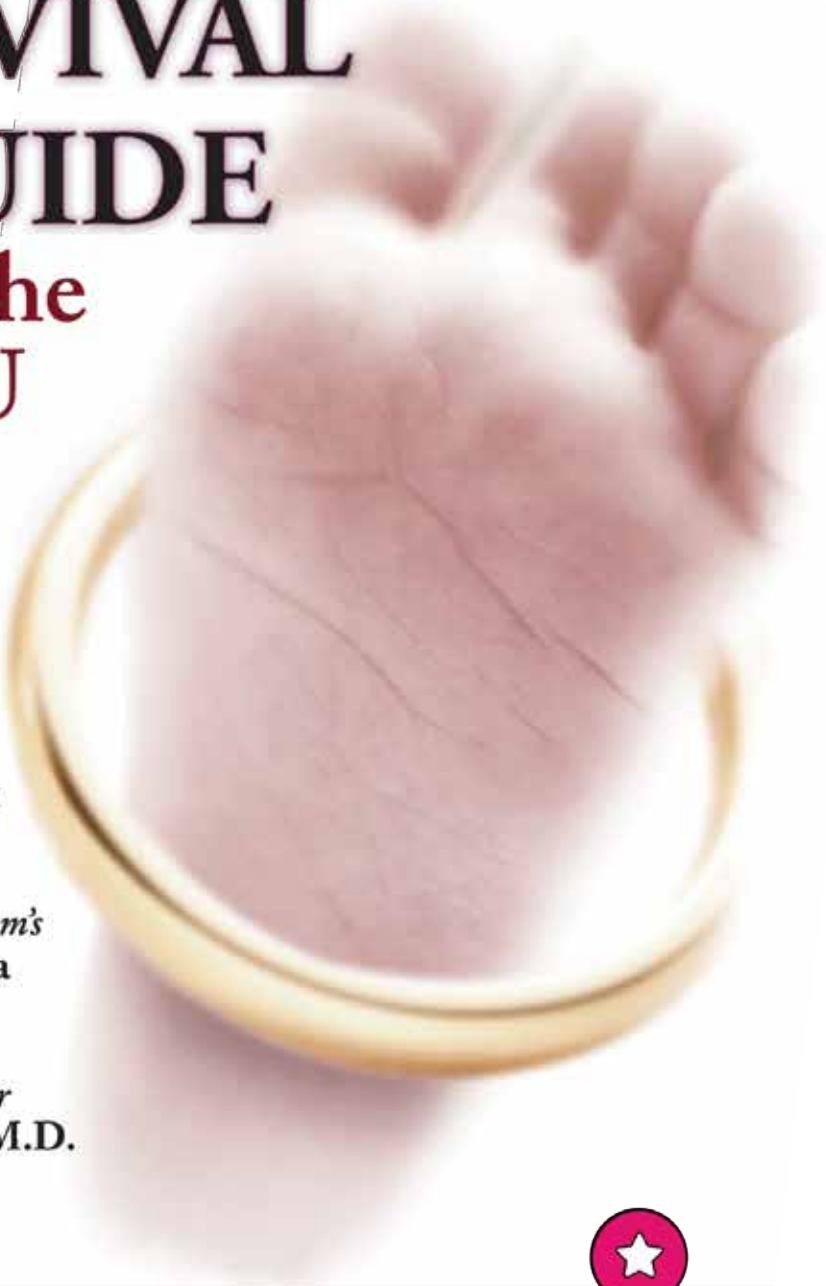

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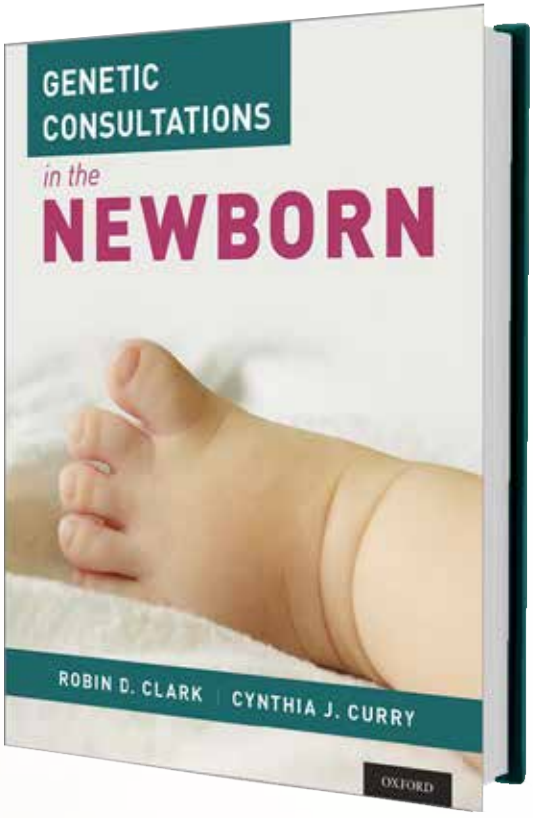

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Clinical Pearl: Antibiotic Resistance Genes Isolated from Newborn Stool at or Shortly after Birth

Joseph R. Hageman, MD, Mitchell Goldstein, MD, MBA, CML

"As I was reading headlines from articles in Healio (1), I came across a summary of a fascinating multidisciplinary research project by Ftergioti and colleagues in Greece, presented at the European Society of Clinical Microbiology and Infectious Diseases 2026 (ESCMID) (1,2)."

As I was reading headlines from articles in Healio (1), I came across a summary of a fascinating multidisciplinary research project by Ftergioti and colleagues in Greece, presented at the European Society of Clinical Microbiology and Infectious Diseases 2026 (ESCMID) (1,2). These investigators collected 105 meconium samples within 24 hours of birth from infants admitted to the neonatal intensive care unit (NICU) and DNA samples were extracted and analyzed for the presence of antibiotic resistance genes (ARG) "to capture the earliest snapshot of microbial and genetic exposure in newborns (2)". It was thought in the past that the first stool, meconium, that newborns passed was sterile, which is what I thought and taught. (3).

"The project included collaboration with pediatric infectious disease, neonatology, and molecular microbiology researchers (1,2). These samples were collected between July 2024 and July 2025. The collection and analysis resulted in a median number of 8 ARGs per sample as the researchers screened the samples for 56 different ARGs associated with commonly used antibiotics (2)."

The project included collaboration with pediatric infectious disease, neonatology, and molecular microbiology researchers (1,2). These samples were collected between July 2024 and July 2025. The collection and analysis resulted in a median number of 8 ARGs per sample as the researchers screened the samples for 56 different ARGs associated with commonly used antibiotics (2). Nearly all samples harbored ARGs for quinolones, and 1/3 to ½ of the samples contained beta-lactamases, which are the primary cause of resistance to beta-lactam antibiotics, including penicillin (1). In addition, genes linked to carbapenem resistance were detected in 21% of these samples (1).

What is also interesting is the list of the most common genes found in the analysis: *oqxA (98% of samples) and gnrS (96%),* which the investigators say have been associated with resistance to some commonly used antibiotics (4).

"Do these results suggest that collecting meconium samples and analyzing them for ARGs is a guideline for antibiotic choices in early-onset sepsis management? In discussion with colleagues, further study comparing ARGs in the stool of mothers with their infants might also be of value."

The investigators state that "at this stage, the collection of (antibiotic) resistance genes is mainly shaped by maternal transmission, delivery mode, and very early hospital exposures (1)". Dr. Ftergioti, who is leading this study, also states that "while further research is needed to understand how early carriage of resistance genes affects the microbiome development and infection risk, these findings highlight the importance of surveillance, infection prevention, and control in newborn care" (1). Do these results suggest that collecting meconium samples and analyzing them for ARGs is a guideline for antibiotic choices in early-onset sepsis management? In discussion with colleagues, further study comparing ARGs in the stool of mothers with their infants might also be of value (S Hageman, personal communication, May 2026).

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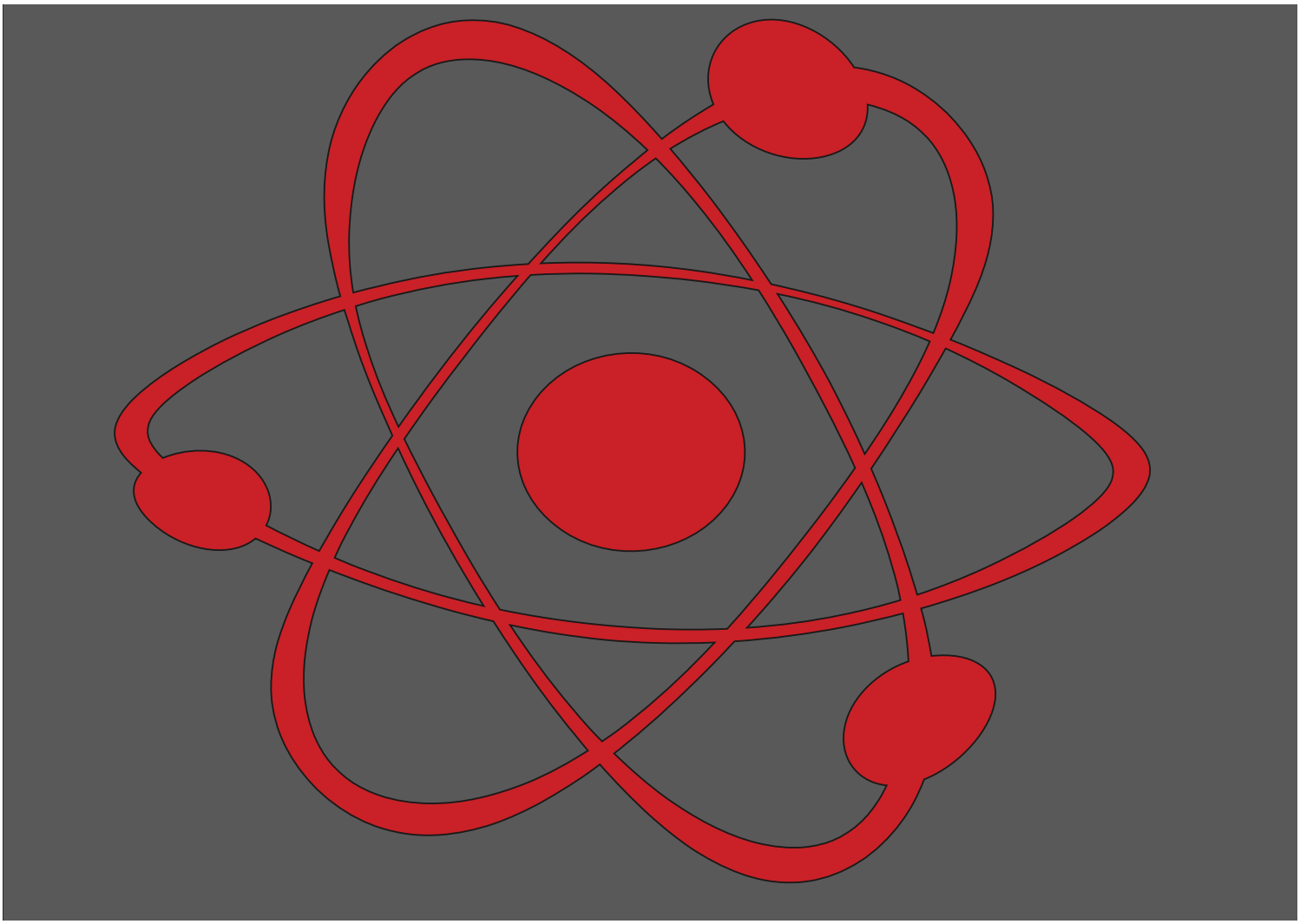

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Clinical Trial Center (Full-Time, Day Shift) - Research Coordinator

The Loma Linda University Health's Clinical Trial Center is actively seeking and recruiting top clinical research coordinator talent.

Our mission is to participate in Jesus Christ's ministry, bringing health, healing, and wholeness to humanity by Creating a supportive faculty practice framework that allows Loma Linda University School of Medicine physicians and surgeons to educate, conduct research, and deliver quality health care with optimum efficiency, deploying a motivated and competent workforce trained in customer service and whole-person care principles and providing safe, seamless and satisfying health care encounters for patients while upholding the highest standards of fiscal integrity and clinical ethics. Our core values are compassion, integrity, humility, excellence, justice, teamwork, and wholeness.

Able to read, write and speak with professional quality; use computer and software programs necessary to the position, e.g., Word, Excel, PowerPoint, Access; operate/troubleshoot basic office equipment required for the position. Able to relate and communicate positively, effectively, and professionally with others; provide leadership; be assertive and consistent in enforcing policies; work calmly and respond courteously when under pressure; lead, supervise, teach, and collaborate; accept direction. Able to communicate effectively in English in person, in writing, and on the telephone; think critically; work independently; perform basic math and statistical functions; manage multiple assignments; compose written material; work well under pressure; problem solve; organize and prioritize workload; recall information with accuracy; pay close attention to detail. Must have documented successful research administration experience focused on managing clinical trials function. Able to distinguish colors as necessary; hear sufficiently for general conversation in person and on the telephone; identify and distinguish various sounds associated with the workplace; see adequately to read computer screens and written documents necessary to the position. Active California Registered Nurse (RN) licensure preferred. Valid Driver's License required at time of hire.

The Clinical Trial Center is actively involved in many multi-center global pediatric trials, which span different Phases of research to advance health care in children. Please reach out to Jaclyn Lopez at 909-558-5830 or JANLopez@llu.edu with further interest. We would love to discuss the exciting research coordinator opportunities at our Clinical Trials Center.

Additional Information

- Organization: Loma Linda University Health Care
- Employee Status: Regular
- Schedule: Full-time
- Shift: Day Job
- Days of Week: Sunday, Monday, Tuesday, Wednesday, Thursday, Friday, Saturday

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LOMA LINDA UNIVERSITY
CHILDREN'S HOSPITAL

Loma Linda University Children's Hospital is hiring Neonatal Nurse Practitioners

Children's Hospital, centrally located in Southern California, has earned Magnet Recognition as part of the American Nurses Credentialing Center's (ANCC) Program.

We are looking for experienced or new graduate Neonatal Nurse Practitioners (NNPs) who are excited to join a cohesive team that practices in a collaborative, fast-paced, high-acuity setting.

- Full-time and part-time positions available
- Level IV, 84-bed Neonatal Intensive Care Unit (NICU)
- Regional referral center encompassing Tiny Baby unit, ECMO, Cardiac ICU, Neuro NICU and Surgical services
- Maternity services and delivery center
- 24/7 coverage by NNP team and Fellows
- Competitive employee benefit packages

*Offering a **sign-on bonus** with relocation reimbursement for full-time, direct applicants who meet requirements.

For more information, please contact:

Karin Colunga, MSN, RN, PNP-BC
Director of Advanced Practice Nursing
kecolunga@llu.edu | 909-558-4486

BEST CHILDREN'S HOSPITALS U.S.News & World Report NEONATOLOGY 2022-23

THELEAPFROGGROUP TOP CHILDREN'S HOSPITAL 2021

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CHILDREN'S HOSPITAL

WE ARE HIRING

NICU DIETICIAN SPECIALIST 2

Full job summary and link to apply below

https://egln.fa.us2.oraclecloud.com/hcmUI/CandidateExperience/en/sites/CX/job/2820/?utm_medium=jobshare

Qualifications:

- Bachlor's Degree or Master's degree in Nutrition and Dietetics or Nutrition-related field required
- Two years of clinical nutrition experience required
- One year in Pediatrics preferred
- RD/RDN required
- CCS paneling required within one year of hire date

Annette Gonzales | Recruiter | LLUH HRM| ACGonzales@llu.edu

NEONATOLOGY TODAY

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For more information, contact:

Melissa LaMarca

+1 (302) 313-9984 or

Melissa.LaMarca@neonatologytoday.net

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Neonatology Today's Policy on Animal and Human Research

Neonatology Today's policies ensure the protection and responsible use of animals and humans in all research articles under consideration. Authors are encouraged to follow the guidelines developed by the National Centre for the Replacement, Refinement & Reduction of Animals in Research (NC3R), International Committee of Medical Journal Editors, and the Guide for the Care and Use of Laboratory Animals and U.S. Public Health Service's Policy on Humane Care and Use of Laboratory Animals (PHS Policy). Authors are expected to demonstrate to their institutional review board or suitable proxy that ethical standards are met. If there is doubt whether research conducted was in accordance with ethical standards, then there must be verification that the institutional review body approved the uncertain aspects. Research not following these policies on participating animal and human subjects may be rejected. Researchers have a moral obligation towards the humane treatment of animals and ethical considerations for humans participating in research and are expected to consider their welfare when designing studies.

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Neonatology and the Arts

This section focuses on artistic work which is by those with an interest in Neonatology and Perinatology. The topics may be varied, but preference will be given to those works that focus on topics that are related to the fields of Neonatology, Pediatrics, and Perinatology. Contributions may include drawings, paintings, sketches, and other digital renderings. Photographs and video shorts may also be submitted. In order for the work to be considered, you must have the consent of any person whose photograph appears in the submission.

Works that have been published in another format are eligible for consideration as long as the contributor either owns the copyright or has secured copyright release prior to submission.

Logos and trademarks will usually not qualify for publication.

This month we continue to landscapes, feature artistic works created by our readers on the next to last page as well as photographs of birds on rear cover. Dr. Zahera Etter provides "Rows of Lavender" For this edition, our art was graciously provided by Colleen Kraft, MD. It is a work called "Eye of the Storm" done by her son Tim. Our bird is from Dr. Shah, "American Robin."

Lily Martorell, MD

Arts Editor
Associate Professor
Loma Linda University Children's Hospital
Loma Linda, CA

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Manuscript Submission: Instructions to Authors

1. Manuscripts are solicited by members of the Editorial Board or may be submitted by readers or other interested parties. Neonatology Today welcomes the submission of all academic manuscripts including randomized control trials, case reports, guidelines, best practice analysis, QI/QA, conference abstracts, and other important works. All content is subject to peer review.

2. All material should be emailed to: LomaLindaPublishingCompany@gmail.com in a Microsoft Word, Open Office, or XML format for the textual material and separate files (tif, eps, jpg, gif, ai, psd, SVG, or pdf) for each figure. Preferred formats are ai, SVG, psd, or pdf. tif and jpg images with sufficient resolution so as not to have visible pixilation for the intended dimension. In general, if acceptable for publication, submissions will be published within 3 months.

3. There is no charge for submission, publication (regardless of number of graphics and charts), use of color, or length. Published content will be freely available after publication. There is no charge for your manuscript to be published. NT does maintain a copyright of your published manuscript.

4. The title page should contain a brief title and full names of all authors, their professional degrees, their institutional affiliations, and any conflict of interest relevant to the manuscript. The principal author should be identified as the first author. Contact information for the principal author including phone number, fax number, e-mail address, and mailing address should be included.

5. A brief biographical sketch (very short paragraph) of the principal author including current position and academic titles as well as fellowship status in professional societies should be included. A picture of the principal (corresponding) author and supporting authors should be submitted if available.

6. An abstract may be submitted.

7. The main text of the article should be written in formal style using correct English. The length may be up to 10,000 words or longer with prior approval. Abbreviations which are commonplace in neonatology or in the lay literature may be used.

8. References should be included in standard "NLM" format (APA 7th is no longer acceptable). Bibliography Software should be used to facilitate formatting and to ensure that the correct formatting and abbreviations are used for references. EndNote X9 is suggested.

9. Figures should be submitted separately as individual separate electronic files. Numbered figure captions should be included in the main file after the references. Captions should be brief.

10. Only manuscripts that have not been published previously will be considered for publication except under special circumstances. Prior publication must be disclosed on submission. Published articles become the property of the Neonatology Today and may not be published, copied or reproduced elsewhere without permission from Neonatology Today.

11. NT recommends reading Recommendations for the Conduct, Reporting, Editing, and Publication of Scholarly Work in Medical Journals from ICMJE prior to submission if there is any question regarding the appropriateness of a manuscript. NT follows Principles of Transparency and Best Practice in Scholarly Publishing (a joint statement by COPE, DOAJ, WAME, and OASPA). Published articles become the property of the Neonatology Today and may not be published, copied or reproduced elsewhere without permission from Neonatology Today.

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NEONATOLOGY TODAY is interested in publishing manuscripts from Neonatologists, Fellows, NNPs and those involved in caring for neonates on case studies, research results, hospital news, meeting announcements, and other pertinent topics.

Please submit your manuscript to: LomaLindaPublishingCompany@gmail.com

Invitation to Apply:

Seeking content development experts for an AAP Project Advisory Committee (PAC)

The White Zone – Developing A Perinatal Loss Toolkit for LMICs

The Need: Over 2.4 million neonatal deaths and 2.6 million stillbirths occur each year; 98% occur in Low- and Middle-Income Countries (LMICs). While programs such as Helping Babies Breathe (HBB) and Essential Newborn Care (ENC 1 and 2) have revolutionized how providers in LMICs train in and provide neonatal resuscitation and post-delivery care for small and sick newborns, gaps remain in how to best offer end-of-life care and post-loss psychosocial care in these settings.

The Babies: HBB and ENC 1 begin with assessing if a baby is crying and conclude with the "Red Zone" where a baby who is unable to sustain an appropriate heart rate and/or respirations is provided with PPV support as someone attempts to get help. Within the HBB/ENC framework, we could imagine several babies for whom an extension of this framework to include palliative/perinatal loss guidelines could be helpful:

1. A stillbirth for whom no resuscitation is attempted. (Stillbirth)
2. A baby who proceeds through the red zone but never has a heartbeat or breathing despite the best resuscitative efforts of the team. (Stillbirth)
3. A baby who proceeds through the red zone who, after 20 or so minutes still has a very low heartbeat and/or gasping breathing. (Anticipated neonatal death)
4. A preterm baby who is too small for ongoing support, based on local resource constraints or resuscitation guidelines, despite a sustained heart rate and breathing. (Anticipated neonatal death)

The Approach: Create a suite of resources that could accompany ENC 1 and 2, focused on end-of-life care and perinatal loss. These resources would be less algorithmic than ENC, as local practices around death vary significantly – meaning there is not one "right" way to approach this care. Rather, the "White Zone Toolkit" would combine structured guidance about symptom management as well as reflective tools for implementing contextually and culturally appropriate post-loss care. This could consist of, but is not limited to, the following:

1. Structured guidance on what physiologic changes may happen at the end of life (ex: gasping) as well as pharmacologic and non-pharmacologic options for symptom management.
2. Reflective questions about if/when to offer seeing or holding of the baby.
    - Data shows that many women want to see and/or hold their infant following stillbirth or neonatal death but are often not offered that opportunity based on historic cultural norms.
3. Reflective questions about cultural traditions around loss and if/how these practices can be supported by those attending the delivery.
4. Anticipatory guidance guides on how mothers may still produce milk and how to manage those symptoms.
5. Anticipatory guidance on potential maternal mental health needs. Reflective questions on how to approach mental health and psychosocial support after loss.
6. Access to a set of adaptable practice scenarios that could help providers gain experience in handling perinatal loss and communicating with families surrounding perinatal loss.

NICU BABY'S *Bill of Rights*

1 The Right to *Advocacy*

My parents are **my voice** and **my family** are **my best advocates**.

My parents know me well. They are my voice and my best advocates. They need to be knowledgeable about my progress, medical needs, and prognosis, so they celebrate my achievements and support me when things get challenging.

2 The Right to *My Parents' Care*

Welcome my family and **include them** in everything we do.

My parents are my essential caregivers. In order to care for me, they need lots of opportunities to learn. Ensure that hospital policies and protocols, including hours & rounding, are as inclusive and expansive as possible. Then be patient with them.

3 The Right to *Bond With My Family*

Create opportunities for my family and me **to be together and bond**.

Bonding is crucial for my healthy growth and development. Support my parents so that we can practice skin-to-skin care as soon and as often as possible. Encourage them to read, sing, and talk to me.

4 The Right to *Neuroprotective Care*

Protect my **developing mind** and **senses**.

Protect me from things that startle, stress, or overwhelm me. Support things that calm me. Ensure I get as much sleep as possible. My brain is developing for the first time - and faster than it ever will again. The way I'm cared for today will affect me as I continue to grow & develop.

5 The Right to *Be Nourished*

Support our feeding decisions and **help us develop our skills**.

Encourage my parents to feed me at the breast or by bottle, whichever way works for us both. Support our feeding goals and make sure my parents know all the nutrition options available to meet my needs.

6 The Right to *Personhood*

Respect me as the **amazing, unique individual** that I am.

Use my name. Talk to me before touching me. If one of my siblings passes away, ask my family how we want to talk about and acknowledge them.

7 The Right to *Confident and Competent Care Giving*

Support my parents and caregivers.

The NICU may be a traumatic place for my parents. Ensure that they receive tender loving care, information, education, and as many resources as possible to help inform them about my unique needs, development, diagnoses, and more.

8 The Right to *Family-Centered Care*

Teach my family **how to care for me**.

Help me feel that I am a part of my own family. Teach my parents, grandparents, and siblings how to read my cues, how to care for me, and how to meet my needs. Encourage them to participate in or perform my daily care activities, such as bathing and diaper changes.

9 The Right to *Healthy and Supported Parents*

Care for our **mental health** and **wellbeing**.

My parents may be experiencing a range of new and challenging emotions. Be patient, listen to them, and lend your support. Share information with my family about resources such as counseling, support groups, & peer-to-peer programs, which can help reduce the impact of perinatal mood and anxiety disorders (PMADs).

10 The Right to *Inclusion and Belonging*

Celebrate what makes us special and unique.

Celebrate our diversity. Honor what makes us unique. Ensure that my parents, grandparents, siblings, and friends feel accepted and welcomed in the NICU, and respected and valued in all forms of engagement and communication.