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Peer Reviewed

Neurally Adjusted Ventilatory Assist (NAVA) for Evolving and Severe Bronchopulmonary Dysplasia in Preterm Neonates: A Practical Review and Management Guide

Kimberly S Firestone, MSc, RRT, FAARC, FNAP, Tarah T. Colaizy, MD, MPH, , Jonathan M. Klein, MD, Howard Stein, MD, FAAP

Abstract:

Bronchopulmonary dysplasia (BPD) is a major cause of morbidity in extremely preterm neonates and is characterized by heterogeneous lung disease, impaired alveolar development, airway obstruction, and high respiratory drive. These features contribute to patient–ventilator asynchrony and increase the risk of ventilator-induced lung injury (VILI) with conventional ventilation. Neurally Adjusted Ventilatory Assist (NAVA) delivers ventilatory support in proportion to the electrical activity of the diaphragm (Edi), enabling breath-by-breath synchronization with the neonate's intrinsic respiratory effort. Currently, there is a lack of high-quality studies of ventilatory modes in the neonatal population that evaluate important clinical outcomes with BPD, a situation that makes firm conclusions and recommendations challenging. This review summarizes current evidence for NAVA in neonates with evolving or established BPD and presents practical, physiology-based clinical guidance informed by both published data and extensive bedside experience. Recommendations combine current NAVA and BPD management approaches. NAVA represents a promising strategy for managing complex BPD physiology while potentially mitigating VILI. Ongoing trials will further define its impact on clinical outcomes.

"Neurally Adjusted Ventilatory Assist (NAVA) delivers ventilatory support in proportion to the electrical activity of the diaphragm (Edi), enabling breath-by-breath synchronization with the neonate's intrinsic respiratory effort. Currently, there is a lack of high-quality studies of ventilatory modes in the neonatal population that evaluate important clinical outcomes with BPD..."

Key words: *Bronchopulmonary dysplasia; Neurally adjusted ventilatory assist; Severe BPD; Patient–ventilator asynchrony; Ventilator-induced lung injury; Extremely preterm neonates; Neonatal mechanical ventilation*

What Is New in This Paper:

1. Provides the first practical clinical framework for using NAVA in neonates with evolving and established BPD.
2. Integrates a BPD physiology-based approach, combined with bedside expertise and published evidence, to guide initiation, titration, and weaning of both invasive and noninvasive NAVA.
3. Addresses unique evolving and established BPD-related challenges—including high respiratory drive, airway obstruction, and auto-PEEP—within a NAVA-specific management strategy.
4. Offers expert consensus recommendations on PEEP optimization, NAVA level adjustment, backup ventilation, and leak management in evolving and established BPD.
5. Positions NAVA as a strategy to reduce patient–ventilator asynchrony and potentially mitigate ventilator-induced lung injury in complex BPD physiology.

Introduction

Bronchopulmonary dysplasia (BPD) remains a major cause of significant morbidity (tracheostomy, moderate to severe neurodevelopmental impairment) and mortality in preterm neonates, particularly those with the most severe forms of the disease: Grade 3A BPD (respiratory death before 36 weeks postmenstrual age (PMA) and Grade 3 BPD (need for invasive ventilation at 36 weeks PMA)(1). The pathophysiology of BPD is

"The pathophysiology of BPD is marked by a complex interaction of atelectasis, hyperinflation, and obstructive physiology, which creates a fragile lung environment with significant risks for ventilator-induced lung injury (VILI) and pulmonary hypertension."

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marked by a complex interaction of atelectasis, hyperinflation, and obstructive physiology, which creates a fragile lung environment with significant risks for ventilator-induced lung injury (VILI) and pulmonary hypertension (1).

Neurally Adjusted Ventilatory Assist (NAVA) is an emerging approach that aims to optimize ventilatory support in neonates by improving synchrony between the patient and ventilator and potentially reducing ventilator-associated injury. Using a neural trigger, this mode allows the patient to control the initiation, size, and termination of each mechanical breath on a breath-by-breath basis (2, 3). A specialized nasogastric tube detects the electrical activity of the diaphragm (Edi) signals, prompting the ventilator to deliver flow proportional to the Edi, with the breath terminating when the Edi signal stops. This narrative review explores the role of NAVA in managing severe BPD, its mechanisms, clinical indications, and outcomes based on recent evidence. This review offers expert consensus guidance on NAVA setup, escalation, and weaning in evolving and severe BPD.

"Neurally Adjusted Ventilatory Assist (NAVA) is an emerging approach that aims to optimize ventilatory support in neonates by improving synchrony between the patient and ventilator and potentially reducing ventilator-associated injury. Using a neural trigger, this mode allows the patient to control the initiation, size, and termination of each mechanical breath on a breath-by-breath basis. A specialized nasogastric tube detects the electrical activity of the diaphragm (Edi) signals, prompting the ventilator to deliver flow proportional to the Edi, with the breath terminating when the Edi signal stops."

Pathophysiology of BPD

BPD in neonates is primarily caused by a combination of prematurity-related lung immaturity and exposure to injurious factors such as mechanical ventilation, oxygen toxicity, inflammation (often from chorioamnionitis or postnatal infection), and nutritional deficits. These insults disrupt normal alveolar and vascular development, leading to impaired lung growth and chronic respiratory morbidity (1, 4, 5). Treatment and prevention of BPD aim to minimize lung injury and promote lung development while providing optimal nutrition to support growth and reduce catabolism by adequately supporting the work of breathing (6). Evidence-based strategies include noninvasive respiratory support (such as early continuous positive airway pressure), early selective surfactant administration via less invasive methods, volume-targeted ventilation for those requiring intubation, and early initiation of caffeine therapy (7–9).

Severe BPD, especially Grade 3, is characterized by significant heterogeneity across lung regions, with coexisting atelectasis and hyperinflation, leading to uneven ventilation time constants (1, 10–13). The following pathophysiologic factors are critical to understanding the challenges of managing evolving and established BPD (1, 10–13):

- Increased Airway Resistance: Obstructive physiology dominates, and flow limitations lead to dynamic hyperinflation.
- Reduced Lung Compliance: Stiff, inelastic lung tissue requires higher pressures for adequate alveolar inflation.
- High Respiratory Drive: Neonates with BPD have strong, variable respiratory drives, which can lead to poor synchrony with conventional ventilatory modes.
- Right Ventricular Strain: Pulmonary hypertension worsens with hypoxemia, hypercapnia, and large intrathoracic pressure swings.

These pathophysiologic challenges demand a ventilatory strategy that prevents further lung injury while still fully supporting the variable respiratory drive of neonates with severe BPD.

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- Increased Airway Resistance
- Reduced Ling Compliance
- High Respiratory Drive
- Right Ventricular Strain"

NAVA and its Potential Role in Evolving and Established BPD

NAVA delivers ventilatory support in proportion to the neonate's own respiratory drive. This personalized approach improves patient-ventilator synchrony, reduces the risk of over- or under-assistance, and minimizes volutrauma and barotrauma (12). In preterm neonates with evolving or established BPD, NAVA potentially offers several advantages (14–24):

- Improved Synchrony: By synchronizing support to the neonate's respiratory drive, NAVA reduces the work of breathing and stabilizes gas exchange (14).
- Improved patient–ventilator interaction by using a neural trigger that overcomes the infant's reduced ability to trigger conventional breaths due to poor lung mechanics, airflow limitation, and hyperinflation (11).
- NAVA helps minimize high peak inspiratory pressures, which may contribute to VILI in preterm neonates (25).
- Prevention of Dynamic Hyperinflation: NAVA adapts to respiratory effort, reducing tachypnea and dynamic hyperinflation, decreasing air trapping, and lowering VILI risk (25).
- Reduction of Right Ventricular Strain: By improving gas

exchange and reducing unnecessary airway pressure swings, NAVA may help alleviate strain on the right ventricle, a critical factor in BPD with associated pulmonary hypertension (26–28). However, direct evidence supporting these benefits is currently limited

- Decreased need for sedation (29), which may impact the effects of long-term exposure to sedatives on neurodevelopmental outcome (30).

"In preterm neonates with evolving or established BPD, NAVA potentially offers several advantages:

- Improved Synchrony
- Improved patient–ventilator interaction
- Reduced Ventilator-Induced Injury
- minimize high peak inspiratory pressures
- Prevention of Dynamic Hyperinflation
- Reduction of Right Ventricular Strain
- Decreased need for sedation"

Figure 1 illustrates the pathophysiology of BPD and the proposed physiologic mechanisms through which NAVA may improve patient–ventilator interaction, leading to favorable respiratory effects and potential downstream clinical benefits.

NAVA Limitations in Evolving and Established BPD

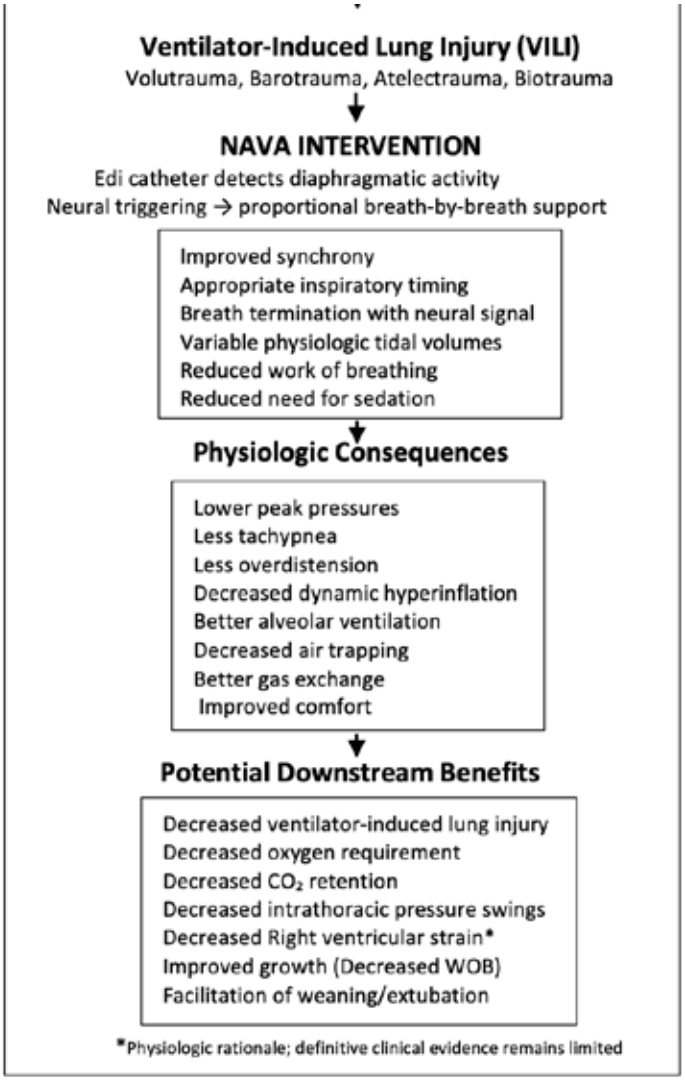
- Lack of randomized evidence demonstrating improved long-term outcomes.
- Potential challenges related to Edi catheter placement and signal reliability.
- Cost considerations and availability of NAVA technology.
- Need for staff expertise and training.

Literature Review

The following clinical studies show that NAVA, compared with conventional ventilation, leads to lower peak inspiratory pressures, reduced FiO_2 requirements, and better compliance while supporting more physiologic breathing patterns in preterm neonates with evolving or established BPD.

Jung et al. in 2016 showed that NAVA significantly improved patient-ventilator synchrony and reduced the work of breathing in preterm neonates with severe BPD (14). NAVA resulted in lower peak inspiratory pressures and reduced FiO2 requirements compared to conventional mechanical ventilation, which may help minimize VILI. Neonates receiving NAVA showed improved oxygenation and overall respiratory function, suggesting it could

Figure 1: Schematic illustrating BPD and the proposed physiologic mechanisms by which NAVA may improve respiratory mechanics, reduce ventilator-induced lung injury, and provide downstream clinical benefits.



be a beneficial ventilation mode for neonates with severe BPD, particularly those requiring high-intensity support. The authors concluded that NAVA might be an effective alternative to traditional ventilation strategies, offering potential benefits in managing preterm neonates with complicated BPD.

"... in preterm neonates with severe BPD.... NAVA resulted in lower peak inspiratory pressures and reduced FiO_2 requirements compared to conventional mechanical ventilation, which may help minimize VILI."

Lee et al. explored the use of NAVA in neonates requiring prolonged mechanical ventilation (15). They found that NAVA improved patient-ventilator synchrony and reduced the work of breathing

compared with conventional ventilation modes, suggesting it is a viable option for neonates requiring prolonged ventilation.

Colaizy et al. evaluated noninvasive NAVA (NIV-NAVA) for synchronized post-extubation support in very low birth weight neonates with evolving or established BPD (median age 46 days, IQR 30)(24). NIV-NAVA improved ventilation and lowered pCO_2 when NAVA levels were appropriately optimized, highlighting the importance of tailoring support to ensure adequate alveolar ventilation in extubated patients.

A crossover study by Shetty et. al. in 2007 described nine very preterm infants (median GA 25 weeks) with evolving or established BPD; NAVA compared to assist control ventilation (ACV) significantly improved oxygenation, with a lower mean oxygenation index (7.9 vs. 11.1, p = 0.0007), lower FiO_2, lower peak and mean airway pressures, and higher compliance after one hour on each mode (31). While these short-term physiological improvements suggest NAVA may reduce ventilator-induced lung injury in infants with BPD/CLD by achieving adequate gas exchange at lower pressures, the study did not assess long-term outcomes such as BPD severity or duration of ventilation.

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Rong et al. examined the effectiveness of NAVA in premature neonates weighing less than 1,500 grams with established or evolving BPD (16). NAVA improved ventilatory support and gas exchange, with the potential to reduce the need for high levels of oxygen and prevent further lung injury in this vulnerable population.

Hunt et al. compared NAVA with proportional assist ventilation in preterm neonates with evolving or established BPD (17). It found that NAVA provided better oxygenation and more synchronized ventilation, supporting its use as a beneficial respiratory support mode in this patient group.

McKinney et al. conducted a retrospective multicenter study evaluating NAVA in neonates with severe BPD (18). In the BPD Collaborative study, 112 neonates with severe BPD received NAVA across four centers with 67% achieving successful weaning (to home ventilator or extubation) and a mean survival of 87% despite significant inter-center variability in patient demographics and NAVA practices. However, the lack of a non-NAVA comparison group and the significant center-to-center variability in tracheostomy rates (mean 56%) and management approaches underscores the need for standardized protocols and controlled trials for NAVA use in severe BPD.

Shetty et al. (2021) explored NAVA use in very premature neonates with evolving or established BPD (19). They found that NAVA improved respiratory outcomes by reducing airway pressures, improving oxygenation, and decreasing the work of breathing compared with conventional ventilation strategies.

Serrano-Llop et al. investigated the effects of skin-to-skin contact in premature neonates with BPD receiving noninvasive NAVA (NIV-NAVA) (20). They demonstrated that skin-to-skin contact improved respiratory parameters, including oxygenation and respiratory rate, when combined with NIV-NAVA, offering a novel approach to care in this population.

Mehra and Kresch reviewed trends in BPD incidence following the introduction of NAVA in neonatal intensive care units. (21) They suggested that NAVA may have contributed to a reduction in BPD rates by providing more synchronized and protective ventilatory support, thus potentially improving long-term outcomes for preterm neonates.

"A systematic review and meta-analysis by Lefevere et al. concluded that NAVA improves ventilator synchrony and reduces peak inspiratory pressures, work of breathing, and the need for high FiO_2 in preterm neonates with BPD. However, there were no differences in other major clinical outcomes, including total duration of respiratory support and neurodevelopmental outcome at 2 years. Evidence certainty is low due to small sample sizes and imprecision, and larger trials are needed to determine whether NAVA provides clinically meaningful advantages over conventional synchronized ventilation."

A systematic review and meta-analysis by Lefevere et al. concluded that NAVA improves ventilator synchrony and reduces peak inspiratory pressures, work of breathing, and the need for high FiO_2 in preterm neonates with BPD (22). However, there were no differences in other major clinical outcomes, including total duration of respiratory support and neurodevelopmental outcome at 2 years. Evidence certainty is low due to small sample sizes and imprecision, and larger trials are needed to determine whether NAVA provides clinically meaningful advantages over conventional synchronized ventilation.

Mohamed et al. demonstrate improved partial pressure of carbon

dioxide (pCO_2), higher oxygenation indices (SpO_2/FiO_2 ratio), and reduced oxygen requirements at 4-, 24-, and 48-hours post-NAVA initiation in neonates with evolving or established BPD (23). These improvements are observed in both invasive and noninvasive NAVA modalities.

"Optimizing ventilatory support is crucial for managing BPD-associated pulmonary hypertension, as excessive intrathoracic pressure swings and hypoxemia exacerbate right ventricular strain. NAVA's ability to synchronize support with the neonate's neural respiratory drive improves cardiac output and theoretically reduces large pressure fluctuations and improves ventilation-perfusion matching, which could mitigate right ventricular strain."

Optimizing ventilatory support is crucial for managing BPD-associated pulmonary hypertension, as excessive intrathoracic pressure swings and hypoxemia exacerbate right ventricular strain (27, 28). NAVA's ability to synchronize support with the neonate's neural respiratory drive improves cardiac output (32) and theoretically reduces large pressure fluctuations and improves ventilation-perfusion matching, which could mitigate right ventricular strain.

"The authors recognize that BPD has different phenotypes and that evolving and established BPD may require different approaches. However, no guidelines currently exist despite the increased use of NAVA in neonates with BPD. Based on available evidence and extensive bedside clinical experience, we developed a structured approach to NAVA use in neonates with evolving or established BPD. These guidelines reflect expert consensus, not robust evidence."

The authors recognize that BPD has different phenotypes (13) and that evolving and established BPD may require different approaches. However, no guidelines currently exist despite the increased use of NAVA in neonates with BPD. Based on available evidence and extensive bedside clinical experience, we developed a structured approach to NAVA use in neonates with evolving or established BPD. These guidelines reflect expert consensus, not robust evidence.

Although, as outlined previously, NAVA offers improved short-term respiratory mechanics and synchrony in evolving or established BPD, robust evidence for reduced BPD incidence or mortality, or direct improvement in pulmonary hypertension or right ventricular function compared with conventional ventilation is lacking. Large multicenter studies are needed to answer these questions.

Proposed Guidelines for the use of NAVA in BPD:

Indications and Contraindications for NAVA in Neonates with BPD:

NAVA may be considered for preterm neonates with evolving or established BPD under the following conditions:

Indications:

- Neonates dependent on invasive or noninvasive ventilation.
- High work of breathing, especially in neonates unable to synchronize with pressure- or flow-triggered conventional ventilators (32).
- This is seen in extremely premature neonates (<26 weeks GA) born during the canalicular stage who develop the "new BPD" phenotype, characterized by alveolar simplification and severe distal bronchomalacia (1). These neonates often cannot trigger conventional ventilation despite strong diaphragmatic effort because of chronic hyperinflation, but the Edi catheter detects neural activity and restores synchronized, breath-by-breath support.
- Difficulty transitioning off conventional invasive support or intolerance of noninvasive ventilation.

Contraindications:

- Unreliable Edi signal, such as in cases of diaphragmatic injury or paralysis, or congenital neuromuscular diseases where NAVA cannot appropriately detect diaphragmatic muscular contractility.

Initial Setup and Edi Catheter Placement

NAVA setup involves placing an Edi catheter, which should be positioned per established guidance to ensure accurate signal detection (33). Neonates with evolving or established BPD are at increased risk of catheter dislodgement due to frequent swallowing or reflux, so frequent monitoring of catheter position is recommended. Secure placement is critical for optimal function and patient safety. A video explaining NAVA catheter placement is available at **https://youtu.be/B-nJyUZF_UQ**.

NAVA Settings for Evolving and Established BPD

The following recommendations are expert consensus practice suggestions. For neonates with evolving or established BPD, initial ventilator settings for NAVA should be carefully titrated:

Invasive NAVA:

- **Set positive end-expiratory pressure (PEEP) higher (8–10 cm H_2O), increasing further** for neonates with severe tracheobronchomalacia, to overcome intrinsic PEEP and

provide effective airway splinting. This is similar to neonates with severe BPD on conventionally triggered ventilation.

- Start NAVA gain low (0.5–1.0 cm H_2O/μV), as high Edi signals are common in these neonates; however, increase the NAVA level quickly to achieve adequate diaphragmatic unloading, as seen when the Edi level is mostly <20.
- Peak pressure limits may need to be set significantly higher than expected to achieve effective ventilation with reduced compliance.
- Backup ventilation settings should mirror those of previous conventional support, with a long apnea time, low rate, and high PIP. We suggest matching the apnea time to the backup rate as per Table 1

Table 1: Picking the initial Apnea time (seconds) and corresponding backup rate (breaths/minute)

Apnea Time	Backup rate
20	3
15	4
12	5
10	6
6	10
5	12
4	15
3	20
2	30
1.8	35

Noninvasive NAVA:

- Useful for extubation or chronic respiratory support. Initially, choose interfaces such as short bi-nasal CPAP prongs, masks, or a single nasopharyngeal tube to prevent leaks. As the patient improves, you can trial other interfaces with significant leaks (such as RAM), as this group of neonates often experiences agitation with tightly fitting interface systems.
- Higher PEEP (10–12 cm H_2O) may be necessary to overcome airway collapse, with gradual NAVA level titration to optimize respiratory support.
- Peak pressure limit may need to be set significantly higher than typical to achieve effective ventilation in the face of reduced compliance.
- Backup ventilation settings should mirror those of NIPPV, with a long apnea time, low rate, and high PIP. However, in patients with evolving BPD where apnea of prematurity remains symptomatic, higher backup rates (>35–40) during NIV-NAVA may be required to minimize duration of prolonged desaturation events (24). As with invasive NAVA, we suggest matching the initial apnea time to the backup rate as per Table 1.

Titration and Weaning

For neonates with evolving or established BPD, titration of NAVA settings should be approached with caution:

Titration Algorithm:

- Monitor Edi peak values carefully, aiming to maintain Edi peaks between 10–20 μV. Avoid sustained values >30 μV, as they may indicate under-assistance or air trapping. Increase NAVA support by 0.3–0.5 until Edi peaks return to the teens.
- If the Edi minimum level is always >5 μV with low volumes on chest radiograph, increase PEEP as needed to improve aeration.
- Neonates on NAVA determine their own tidal volumes breath-to-breath, so it is challenging to target a tidal volume range. However, adjust NAVA settings during evolving BPD so average tidal volumes during invasive NAVA are <6 mL/kg to avoid excessive air trapping (34).
- If Edi signals remain high despite adjustments, consider bronchodilators, diuretics, or further investigation of pulmonary hypertension.

Alarms

- During NAVA, engaging the backup rate triggers an apnea alarm despite appropriate rescue (backup) ventilation, with alarms resolving once spontaneous breathing resumes. As flow-triggered modes provide similar safe backup ventilation without alarms, we recommend turning off the apnea alarm in NAVA to reduce noise and caregiver anxiety without compromising patient safety. If the patient is bradycardic and desaturating during backup, increase the backup settings (PIP, rate, etc.) and/or shorten the apnea delay so backup support initiates earlier and delivers adequate support.

Weaning:

- Wean NAVA slowly, reducing the NAVA gain by 0.1–0.2 cm H_2O/μV once to twice/week, based on tolerance.
- Edi peaks mostly <5–10μV in a comfortable patient are a sign that the NAVA level can be weaned.
- Extubation readiness may be delayed, and NIV-NAVA can bridge to successful extubation, with continued oxygen supplementation if needed.

Guidelines are available for premature neonates in the first weeks of life for both invasive and noninvasive NAVA (33, 35). Table 2 offers an expert consensus side-by-side comparison of the rationale and approach of NAVA in the preterm with evolving BPD and the neonate with established BPD. **Current Large-Scale Trials of NAVA and BPD**

The most promising ongoing study investigating NIV-NAVA's impact on BPD is the Diaphragmatic Initiated Ventilatory Assist (DIVA) trial (NCT05446272), a phase III multicenter RCT enrolling extremely preterm neonates ($23^0/_7$–$28^6/_7$ weeks gestation) undergoing extubation in the first 28 postnatal days (36). The primary outcome is extubation failure within 5 days, but secondary outcomes include safety and clinical endpoints tracked through 36 weeks postmenstrual age, discharge, death, or transfer, allowing assessment of BPD incidence and other long-term respiratory outcomes. With a sample size of 478 neonates, the DIVA trial is expected to provide more robust evidence on NAVA's role in reducing BPD and improving long-term respiratory health in preterm neonates.

Table 2: Expert consensus rationale and approach of NAVA in the preterm with evolving BPD and the neonate with established severe BPD. RV – right ventricle, PH – Pulmonary Hypertension, WOB – work of breathing, LOS – Length of Stay, FRC – Functional Residual Capacity, $TcpCO_2$ - Transcutaneous pCO_2. (Following Firestone & Stein 2025 NIV-NAVA guidelines [33])

Domain	Preterm with Evolving BPD (Guideline-aligned)	Established BPD (Guideline-aligned + physiology translation)
Primary rationale	Use NIV-NAVA/NAVA to improve synchrony, reduce asynchrony-related work of breathing, and allow Edi-guided proportional support during noninvasive or invasive support.	Same rationale, but with special emphasis on avoiding interventions that increase dynamic hyperinflation or RV afterload; the guideline highlights that Edi provides continuous monitoring useful in complex physiology.
Primary Physiology	Immature lung with increasing airway resistance and more heterogeneous inflation with increased risk of air-trapping	Heterogeneous lung: stiff + hyperinflated areas, high airway resistance, auto-PEEP, PH risk
Interface and leak management	Use appropriately sized nasal interfaces (short binasal prongs, nasal mask, or single nasopharyngeal tube; if agitation is a prominent issue, consider a RAM cannula and manage leaks actively). The guideline stresses that NIV-NAVA works with most leaks but recommends minimizing extreme leaks and checking seal/fit frequently.	Prioritize interfaces that minimize large variable leaks while preserving comfort; frequent reassessment because chronic secretions/feeds increase dislodgement risk. In severe BPD, leaks can increase WOB and make Edi interpretation harder—guidelines recommend proactive leak troubleshooting.
Edi catheter placement and checks	Place and confirm per manufacturer/guideline steps; verify Edi waveform and catheter depth after any repositioning.	Check position more frequently (after feeds, suctioning, handling) because chronic care and frequent handling increase displacement risk—use Edi waveform trends to confirm.
Initial NAVA gain strategy	Start at a modest, individualized gain and titrate to achieve appropriate tidal volumes and comfortable Edi peaks; guidelines emphasize individualized titration rather than fixed values. 1.0–2.0 cm H_2O/μV	Start lower than for typical preterm neonates because neonates with severe BPD commonly have high intrinsic drive; increase only with careful monitoring to avoid over-assist and air trapping. 0.5–1.0 cm H_2O/μV
PEEP / mean distending pressure approach	Use PEEP sufficient to prevent alveolar collapse, but avoid overdistention; guidelines recommend titration to clinical response and to improve synchrony. 5–7 cm H_2O minimum to prevent atelectasis; if PEEP >7 cm H_2O at extubation, set NAVA PEEP 1–2 cm H_2O higher to maintain FRC.	Prioritize PEEP to offset intrinsic PEEP/airway collapse but titrate to expiratory flow patterns and Edi: adequate PEEP can reduce inspiratory effort without increasing hyperinflation. Use ventilator waveforms to detect auto-PEEP. 8–12 cm H_2O to counteract airway collapse & intrinsic PEEP
Target tidal volume/ breath sizing	Guidelines recommend using Edi-guided support to achieve clinically appropriate tidal volumes and avoid breath stacking—focus on proportionality rather than fixed Vt.	Aim for lower Vt targets (physiology goal) and avoid breath stacking — use Edi plus expiratory flow curve to prevent flow truncation and ensure full exhalation before next assisted breath.
Edi monitoring goals	Treat Edi as a "respiratory vital sign" — trend Edi-peak and Edi-min; use rising Edi as marker of increasing effort/insult. 5–15 μV	Same, but place extra weight on sustained high Edi as a sign of obstruction/auto-PEEP/PH; rising Edi without improved tidal volumes should prompt airway management rather than reflexive gain increases. 10–20 μV acceptable; avoid sustained >30 μV (signals excessive WOB or obstruction)
Apnea time and Backup ventilation	Use short apnea times (2–3 sec) and carefully set backup pressures and rate per guideline to ensure safety while allowing patient-triggered breaths. If the neonate is always on backup, consider lengthening apnea time if the patient is vigorous; if not active, consider other causes of apnea such as sepsis, etc.	Use longer apnea time (5–15 sec) and high PIP ceilings. Backup setting to mimic conventional ventilation with low rates and high PIP
Persistent Low Edi signal	The problem is often immature respiratory drive: caffeine plus a high Edi trigger (0.5–1 mcV) with short apnea times (1–1.4 sec) to provide adequate backup until respiratory drive improves.	Problem is diaphragmatic dysfunction: Low Edi trigger (0.2–0.4 mcV) with long apnea times (5-15 sec) and high NAVA levels (4–8 mcV/cmH_2O) to provide adequate support while allowing the diaphragm to strengthen.

Table 2 (cont'd)

Domain	Preterm with Evolving BPD (Guideline-aligned)	Established BPD (Guideline-aligned + physiology translation)
Titration algorithm (first 24–48 h)	Monitor Edi and Vt, titrate gain incrementally to achieve synchrony and acceptable gas exchange; check blood gases/$TcpCO_2$ as needed.	Titrate more cautiously — increase PEEP first if expiratory flow limitation / auto-PEEP suspected; avoid large gain jumps. Use Edi trend + expiratory flow to guide adjustments and consider adjunct therapies (bronchodilator, suction, diuretics, PH therapies) before increasing assist.
Weaning strategy	Progressive, Edi-guided reduction in support; consider NIV-NAVA as bridge after extubation.	Very slow, Edi-trend based wean; accept permissive hypercapnia within safe pH limits to avoid pressure escalation. Use NIV-NAVA as a planned bridge and expect longer time to full independence.
Monitoring emphasis	Synchrony indices, Edi trends, gas exchange, leak quantification, caregiver observation of comfort and pattern.	Also monitor expiratory flow curves for auto-PEEP, RV strain markers/echocardiography if PH suspected, feeding-related desaturations, and growth/nutrition because chronic respiratory load impacts caloric needs.
Troubleshooting priorities	Reposition catheter for poor Edi signal; manage leaks; adjust gain to correct asynchrony; evaluate for underlying causes of increased drive.	Prioritize detection/treatment of flow limitation and auto-PEEP (increase PEEP cautiously, bronchodilator, airway clearance) and evaluate for pulmonary hypertension if hypoxemia or desaturation clusters occur. Avoid reflexive high gain increases that can worsen trapping.

"The most promising ongoing study investigating NIV-NAVA's impact on BPD is the Diaphragmatic Initiated Ventilatory Assist (DIVA) trial (NCT05446272), a phase III multicenter RCT enrolling extremely preterm neonates (23⁰/₇–28⁶/₇ weeks gestation) undergoing extubation in the first 28 postnatal days. The primary outcome is extubation failure within 5 days, but secondary outcomes include safety and clinical endpoints tracked through 36 weeks postmenstrual age, discharge, death, or transfer, allowing assessment of BPD incidence and other long-term respiratory outcomes. With a sample size of 478 neonates, the DIVA trial is expected to provide more robust evidence on NAVA's role in reducing BPD and improving long-term respiratory health in preterm neonates."

Conclusion:

NAVA offers a promising approach to managing preterm neonates with either evolving or established BPD. By optimizing synchrony, minimizing ventilator-induced injury, and reducing the risk of dynamic hyperinflation and right ventricular strain, NAVA aligns more closely with the neonate's physiological needs. However, while clinical studies suggest benefits in reducing airway pressures and improving gas exchange, current evidence does not yet demonstrate a clear reduction in BPD incidence or long-term respiratory outcomes. Larger, high-quality randomized controlled trials are needed to clarify NAVA's impact on BPD and related outcomes.

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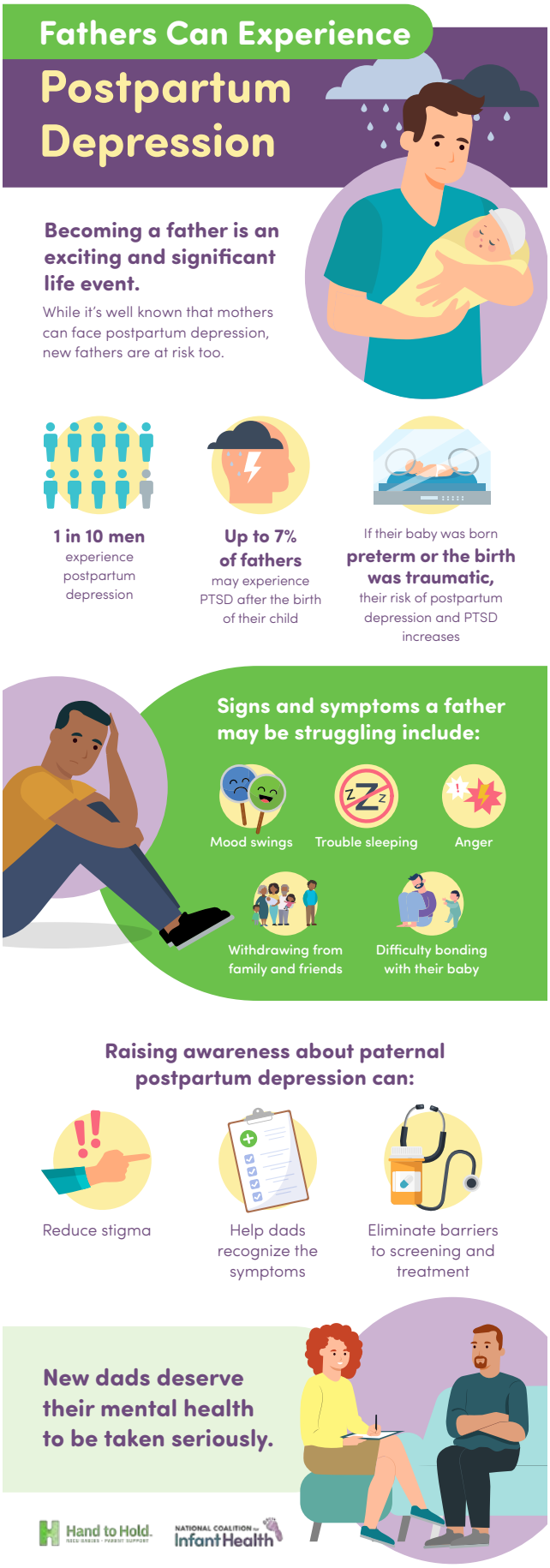


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Nafcillin-Induced Neurotoxicity in Neonates

Ashna Khanna, DO, Joshua Loeb, MD, David Michelson, MD, Emily M. Batton, MD

Abstract:

We present two cases of nafcillin-induced neonatal seizures at a single level III Neonatal Intensive Care Unit (NICU). The first infant was born preterm at 33 weeks of gestation and developed necrotizing enterocolitis (NEC) at 36+5 weeks postmenstrual age. Within 24 hours of initiating nafcillin and gentamicin, he exhibited frequent myoclonic jerks with electroencephalogram-confirmed generalized tonic and atypical myoclonic seizures. His seizures persisted despite multiple antiseizure medications but resolved after nafcillin cessation. The second was a term infant who developed NEC. Within 24 hours of starting nafcillin, he developed clinical and electrographic seizures, which resolved within 36 hours of nafcillin discontinuation. Extensive infectious, metabolic, genetic, and neuroimaging evaluation failed to identify an alternative etiology for either patient. The temporal relationship to nafcillin initiation, absence of alternative etiologies, and rapid resolution after nafcillin cessation support the diagnosis of nafcillin-induced neurotoxicity. These cases highlight the importance of considering nafcillin-associated seizures in neonates.

"We present two cases of nafcillin-induced neonatal seizures at a single level III Neonatal Intensive Care Unit (NICU)."

Keywords: *neonate, nafcillin, seizures*

Introduction:

The incidence of neonatal seizures is approximately 1.5 to 3 per 1,000 live births, with higher rates in preterm and critically ill infants. (1) Seizures in this age group often differ from those in older children in both etiology and presentation. The most common cause of neonatal seizures is hypoxic ischemic encephalopathy (HIE), accounting for approximately 40% of cases. (2) Seizures from HIE typically present within the first 12–24hours of life in infants with a history of perinatal compromise, low APGAR scores, or prolonged labor. Following HIE, ischemic stroke (18%) and intracranial hemorrhage (11%) are the next most common causes of neonatal seizures. (2) Intracranial hemorrhage is more common in preterm infants due to germinal matrix fragility and can present in the first days of life with apnea, poor tone, or seizures. (2) Intracranial infections, including meningitis and Herpes Simplex Virus (HSV) encephalitis, can also cause seizures due to direct neuronal injury. These may present with fever, irritability, poor feeding, and abnormal tone. Genetic and idiopathic epilepsies, such as early infantile epileptic encephalopathies and benign familial neonatal epilepsy, are less common but should be considered when seizures are refractory or recurrent. Transient electrolyte disturbances and inborn errors of metabolism cause less than 5% of neonatal seizures. (2) In contrast, medication-induced seizures are rare but recognized among various classes of medications. (3)

Case Report:

This report discusses two cases of neonatal seizures at a single level III NICU within 2 months of each other. The first case involved a male infant born via cesarean section for preterm labor and breech presentation at 33 weeks and 2 days of gestation with a birth weight of 2260 g. The mother was a 34-year-old multigravida with an unremarkable family and obstetric history. Her medications included paroxetine, folic acid, and ferrous sulfate. There was no known intrauterine drug exposure. Prenatal labs were within normal limits, including HIV, hepatitis B surface antigen, and syphilis testing. She was rubella-immune and had normal thyroid function. Group B Streptococcus status was unknown, and intrapartum prophylaxis was administered. Antenatal corticosteroids were administered before delivery.

At birth, the infant was pale, limp, and apneic. Positive-pressure ventilation was provided, followed by continuous positive airway pressure at 5 minutes of life. APGAR scores were 5 and 8 at one and five minutes, respectively. Arterial cord gas revealed respiratory acidosis. He was admitted to the NICU for prematurity and respiratory failure. The initial neurologic examination was normal. Empiric ampicillin and gentamicin were discontinued after 48 hours following a negative blood culture. He was weaned to room air by day of life 5 and remained admitted for feeding and growth. Nutrition included fortified maternal breast milk and supplemental premature formula. Caffeine therapy was discontinued at 34 weeks and 2 days postmenstrual age.

At 36 weeks and 5 days postmenstrual age, the infant passed a bloody stool, raising concern for NEC. Abdominal imaging suggested pneumatosis intestinalis. He was made nil per os and started on intravenous nafcillin and gentamicin. Urine output and vitals remained stable. Within 24 hours of antibiotic initiation, the infant was noted to have frequent myoclonic jerks, concerning for

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seizures. Video electroencephalogram (EEG) showed generalized tonic seizures with episodes of generalized body stiffening followed by 1–2 generalized myoclonic jerks that each correlated electrographically with a generalized slow wave followed by diffuse electrodecrement. There were also several clusters of atypical generalized myoclonic seizures with myoclonic jerks that were time-locked with medium amplitude midline central sharp waves unrelated to movement artifact. The infant received a bolus of lorazepam, loading doses of phenobarbital and levetiracetam, and phenobarbital maintenance doses without resolution of seizure activity.

"Within 24 hours of antibiotic initiation, the infant was noted to have frequent myoclonic jerks, concerning for seizures. Video electroencephalogram (EEG) showed generalized tonic seizures with episodes of generalized body stiffening followed by 1–2 generalized myoclonic jerks that each correlated electrographically with a generalized slow wave followed by diffuse electrodecrement. There were also several clusters of atypical generalized myoclonic seizures with myoclonic jerks that were time-locked with medium amplitude midline central sharp waves unrelated to movement artifact. The infant received a bolus of lorazepam, loading doses of phenobarbital and levetiracetam, and phenobarbital maintenance doses without resolution of seizure activity."

A full diagnostic evaluation for infectious and structural etiologies was undertaken. Head ultrasound, magnetic resonance imaging of the brain with and without contrast, lumbar puncture, including a meningitis panel, and surface HSV PCR testing were unremarkable. Laboratory investigations, including a complete blood count, chemistry panel, inflammatory markers, and blood cultures, were also negative. Apart from the seizure episodes, his neurological exam remained normal. Within 36 hours of stopping nafcillin, his seizures resolved.

The second newborn was a male infant born via cesarean section due to severe preeclampsia at 38 weeks and 1 day gestation with a birth weight of 3150 g. The mother was a 29-year-old nulligravida with very limited prenatal care and a history of polysubstance abuse (methamphetamine, fentanyl), homelessness, and depression. She was brought in by ambulance in labor with spontaneous rupture of membranes in the field. Amniotic fluid was meconium-stained. She received hydralazine, nifedipine, labetalol, and magnesium for her hypertension. Prenatal labs were positive for hepatitis C (chronic history) and syphilis with inadequate treatment. Penicillin G was administered prior to delivery.

"A full diagnostic evaluation for infectious and structural etiologies was undertaken. Head ultrasound, magnetic resonance imaging of the brain with and without contrast, lumbar puncture, including a meningitis panel, and surface HSV PCR testing were unremarkable. Laboratory investigations, including a complete blood count, chemistry panel, inflammatory markers, and blood cultures, were also negative. Apart from the seizure episodes, his neurological exam remained normal. Within 36 hours of stopping nafcillin, his seizures resolved."

At birth, the infant had a weak cry, central cyanosis, and decreased tone. Bulb suctioning yielded large amounts of meconium-stained amniotic fluid. Positive-pressure ventilation was started at 5 minutes of life, with subsequent improvement in color and oxygen saturation. He was transitioned to continuous positive airway pressure at seven minutes of life. APGARS were 5, 6, and 9 at 1, 5, and 10 minutes of life, respectively. He was microcephalic (head circumference < 3rd percentile) with an otherwise normal neurologic exam. He was transferred to the NICU for further management.

On admission, he started a 10-day course of Penicillin G for treatment of congenital syphilis and acyclovir for empiric HSV encephalitis coverage, given limited prenatal care. Initial work-up, including blood and cerebrospinal fluid cultures, was negative. Given intrauterine drug exposure, he was monitored for signs of neonatal abstinence syndrome. He was started on intravenous morphine on day 2 of life per unit neonatal abstinence syndrome management protocol, which was discontinued at approximately 2 weeks of life. On day 12 of life, the newborn passed a bloody stool, and abdominal radiographs confirmed Bell's stage 2A NEC. He was started on triple antibiotics with ampicillin, gentamicin, and metronidazole. On day 2 of antibiotics, ampicillin was switched to nafcillin for Staphylococcal coverage. Following this switch, he was noted to have seizure activity. The newborn was started on phenobarbital and levetiracetam for seizure management. Morphine was resumed, given the possibility of withdrawal-related seizures. Video EEG demonstrated frequent pericentral spikes lasting several hours. This pattern was intermittently observed over a 5-day period in association with clinical seizure activity, raising concern for neonatal status epilepticus.

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A similar work-up for this neonate was completed, including a head ultrasound and magnetic resonance imaging of the brain with and without contrast, which were unremarkable. Lumbar puncture showed no evidence of an acute intracranial insult or infection. A work-up for the infectious etiologies of microcephaly (toxoplasma, syphilis, rubella, CMV, and HSV) was negative, and basic laboratory testing was within the normal range for age. Genetic testing was performed to identify seizure etiology; the chromosomal microarray was negative, and an epilepsy-focused multigene panel (*Invitae* Laboratory) identified a variant of uncertain significance involving the *MICAL1* gene. (4) California's newborn metabolic screen was also negative. At the time of discharge, the etiology of his seizures was unknown; however, his seizures notably resolved within 36 hours of discontinuation of nafcillin.

"At the time of discharge, the etiology of his seizures was unknown; however, his seizures notably resolved within 36 hours of discontinuation of nafcillin."

In both cases, the temporal association, as well as the absence of metabolic derangements and structural or infectious findings, strongly suggests nafcillin-induced seizure activity. Furthermore, there was complete resolution of seizures and normalization of both newborns' EEGs within 36 hours of discontinuation of nafcillin. Thus, nafcillin was determined to be the most likely etiology of both infants' seizures.

Discussion:

Medication-induced seizures have been observed in association with several drug classes. Agents most strongly associated with seizures include intravenous anesthetics (most notably etomidate, which has the highest number of reports), antibiotics (particularly β-lactams, carbapenems, and fluoroquinolones), selective serotonin reuptake inhibitors, tricyclic antidepressants, glutamate antagonists, atypical antipsychotics, pure opioid agonists, and mood stabilizers. (3, 9)

"Medication-induced seizures have been observed in association with several drug classes. Agents most strongly associated with seizures include intravenous anesthetics (most notably etomidate, which has the highest number of reports), antibiotics (particularly β-lactams, carbapenems, and fluoroquinolones), selective serotonin reuptake inhibitors, tricyclic antidepressants, glutamate antagonists, atypical antipsychotics, pure opioid agonists, and mood stabilizers."

Among antibiotics, β-lactams have been recognized to cause neurological and psychiatric side effects since the 1940s, including confusion, disorientation, myoclonus, and convulsions ranging from generalized tonic-clonic seizures to non-convulsive status epilepticus. (5, 9) The epileptogenic properties of these antibiotics have been traced to the β-lactam ring itself, as cleavage of the ring results in a loss of epileptogenic activity. (5) The proposed primary mechanism involves antagonism of the γ-aminobutyric acid type A (GABA-A) receptor, which increases excitatory neural activity and lowers the seizure threshold. (9) Additional mechanisms include interference with mitochondrial metabolism and enhancement of N-methyl-D-aspartate (NMDA)-mediated excitatory activity. (9)

"Among antibiotics, β-lactams have been recognized to cause neurological and psychiatric side effects since the 1940s, including confusion, disorientation, myoclonus, and convulsions ranging from generalized tonic-clonic seizures to non-convulsive status epilepticus...The proposed primary mechanism involves antagonism of the γ-aminobutyric acid type A (GABA-A) receptor, which increases excitatory neural activity and lowers the seizure threshold."

In a systematic review of over 12,000 adult patients, seizures occurred in 3.2 per 1,000 patients receiving penicillin G or oxacillin. (6) Seizures have been reported to cease with dose reduction or within 12 hours of drug discontinuation. (6)

Risk factors for antibiotic-induced seizures include prematurity, low birth weight, renal dysfunction, central nervous system pathology, and high or prolonged dosing. (7) Neonates may be at heightened risk for medication-induced seizures because their immature blood-brain barrier permits greater penetration of neurotoxic drugs, and their reduced hepatic and renal clearance leads to higher and more prolonged serum and central nervous system drug concentrations. (7) Preterm infants are even more susceptible to neurotoxicity than term infants due to further reductions in drug clearance. (7)

"Notably, these cases suggest a novel observation that, among β-lactam antibiotics, nafcillin may carry a higher relative risk of provoking seizures compared to other agents within this class. Initially, both neonates were treated with ampicillin without any evidence of seizures. However, after the transition to nafcillin, both neonates exhibited clinical seizures. This increased risk may relate to differences in drug elimination. Specifically, nafcillin is predominantly metabolized through hepatic CYP2C9 activity, which remains markedly immature during the first few weeks of life. In contrast, ampicillin is primarily cleared by renal elimination, which, while immature in the first few months of postnatal life, remains relatively more effective than hepatic elimination."

Notably, these cases suggest a novel observation that, among β-lactam antibiotics, nafcillin may carry a higher relative risk of provoking seizures compared to other agents within this class. Initially, both neonates were treated with ampicillin without any evidence of seizures. However, after the transition to nafcillin, both neonates exhibited clinical seizures. This increased risk may relate to differences in drug elimination. (10) Specifically, nafcillin is predominantly metabolized through hepatic CYP2C9 activity, which remains markedly immature during the first few weeks of life. In contrast, ampicillin is primarily cleared by renal elimination, which, while immature in the first few months of postnatal life, remains relatively more effective than hepatic elimination. As a result, impaired nafcillin clearance may increase the risk of drug accumulation and neurotoxicity. Given the immature hepatic clearance mechanisms in neonates, clinicians should closely monitor for neurologic adverse effects and consider alternative agents to nafcillin when clinically appropriate.

"These cases highlight the importance of considering nafcillin-associated neonatal seizures and offer several key learning points for clinicians. In neonates presenting with new-onset seizures, drug-induced neurotoxicity should be considered, particularly when symptom onset aligns with new pharmacologic exposures. Early identification and discontinuation of the offending agent can lead to favorable outcomes, including reversal of neurotoxicity."

Conclusion:

These cases highlight the importance of considering nafcillin-associated neonatal seizures and offer several key learning points for clinicians. In neonates presenting with new-onset seizures, drug-induced neurotoxicity should be considered, particularly when symptom onset aligns with new pharmacologic exposures. Early identification and discontinuation of the offending agent can lead to favorable outcomes, including reversal of neurotoxicity. Although drug-induced seizures remain a diagnosis of exclusion, and additional diagnostic testing will be needed to rule out other "must-not-miss" diagnoses, an appropriate diagnosis of nafcillin-induced seizures can reassure families as well as correctly label a medication allergy in the patient's chart for future avoidance.

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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?
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SLEEP AND AROUSAL INTERVENTIONS FOR THE NEWBORN

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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.

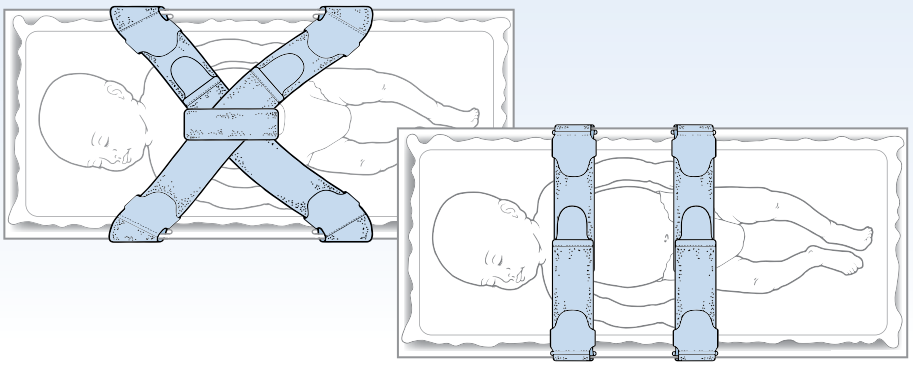
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When Postpartum Distress Becomes a Psychiatric Emergency: Recognizing Maternal Mental Illness in the NICU

Eric Nguyen, OMS-IV; Saba Saleem, DO

"When a newborn is admitted to the neonatal intensive care unit (NICU), clinical attention understandably centers on the infant. Yet alongside the critically ill newborn is another patient whose health can have important consequences for both mother and child: the postpartum parent."

Why Neonatal Clinicians Need to Recognize Maternal Psychiatric Illness

When a newborn is admitted to the neonatal intensive care unit (NICU), clinical attention understandably centers on the infant. Yet alongside the critically ill newborn is another patient whose health can have important consequences for both mother and child: the postpartum parent.

The postpartum period already involves substantial psychological and physiologic change. For mothers whose infants require intensive care, the experience may be further complicated by premature delivery, unexpected medical diagnoses, prolonged hospitalization, maternal infant separation, uncertainty about prognosis, breastfeeding or pumping demands, and significant sleep disruption. Parents of infants hospitalized in the NICU experience elevated levels of anxiety, depression, and psychological distress, and NICU-based interventions have been studied as a means of reducing maternal depressive and anxiety symptoms. (1,2)

"For neonatologists and other neonatal clinicians, this creates an important opportunity. The NICU team may interact with a mother repeatedly during the first days and weeks after delivery, sometimes more frequently than her outpatient obstetric or psychiatric providers"

For neonatologists and other neonatal clinicians, this creates an important opportunity. The NICU team may interact with a mother repeatedly during the first days and weeks after delivery, sometimes more frequently than her outpatient obstetric or psychiatric providers. A change in behavior, sleep, affect, or statements made at the infant's bedside may therefore provide an early indication that a mother is developing a significant psychiatric illness.

The challenge is recognizing when expected postpartum distress has progressed beyond adjustment and into a condition requiring intervention.

Most postpartum emotional symptoms are not psychiatric emergencies. However, suicidal thoughts, psychosis, severe behavioral disorganization, markedly decreased need for sleep, and thoughts of harming an infant accompanied by intent or impaired reality testing require urgent attention. ACOG recommends immediate medical attention for postpartum psychosis and immediate risk assessment when a patient endorses self-harm or suicide. (3,4)

"For neonatologists and other neonatal clinicians, this creates an important opportunity. The NICU team may interact with a mother repeatedly during the first days and weeks after delivery, sometimes more frequently than her outpatient obstetric or psychiatric providers."

For neonatal clinicians, recognizing these warning signs is not about making a psychiatric diagnosis at the bedside. It is about recognizing when the mother's presentation warrants further assessment and knowing when waiting is unsafe.

Understanding the Spectrum of Postpartum Mental Health

Postpartum psychiatric illness exists along a spectrum.

The "baby blues" are common during the first days after delivery and typically resolve within approximately two weeks. Symptoms may include tearfulness, mood lability, irritability, anxiety, and feeling overwhelmed. (4)

By contrast, postpartum depression and anxiety can be more persistent and impair functioning. Symptoms may include persistent sadness, hopelessness, excessive guilt, severe anxiety, panic, loss of interest, difficulty functioning, or thoughts of death or self-harm.

Other conditions require particular attention because their presentations may be less familiar to neonatal clinicians. These include postpartum obsessive-compulsive disorder (OCD), bipolar disorder, and postpartum psychosis.

Importantly, symptom severity is not determined solely by a screening score**.** A mother with a relatively modest depression score may nevertheless be experiencing psychosis or mania. Conversely, a mother with severe anxiety or intrusive thoughts may be extremely distressed but retain insight and have no intent to harm herself or her infant. Clinical assessment must therefore extend beyond screening. (3)

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The Red Flags Every NICU Clinician Should Know:

Certain symptoms should immediately raise concern for a more severe postpartum psychiatric illness.

1. New Hallucinations or Delusions

Hallucinations, delusions, paranoia, or significant disorganization are among the most concerning postpartum psychiatric symptoms.

A mother may report:

- Hearing voices that others cannot hear
- Seeing things that others cannot see
- Believing hospital staff are trying to harm or steal her baby
- Believing the baby is possessed, evil, or uniquely significant
- Believing God or another entity is communicating directly with her
- Believing she has received a special command or mission
- Responding to stimuli that are not apparent to others
- Expressing bizarre or fixed beliefs that cannot be reassured

Postpartum psychosis is rare, but it is a psychiatric emergency. It commonly develops rapidly after delivery and may involve hallucinations, delusions, paranoia, confusion, disorganization, severe insomnia, and rapidly fluctuating mood. ACOG describes postpartum psychosis as requiring immediate medical attention. (3,4)

Clinical response: New psychotic symptoms should prompt urgent psychiatric evaluation rather than routine outpatient referral.

2. Severe or Rapidly Worsening Insomnia

Sleep deprivation is common in the postpartum period and particularly common among mothers of NICU infants. Therefore, lack of sleep alone does not establish psychiatric illness.

A more concerning presentation is a markedly decreased need for sleep, particularly when the mother has the opportunity to sleep but does not feel the need to.

Warning signs include:

- Almost no sleep for one or more nights
- Repeated nights of very little sleep
- Increasing energy despite minimal sleep
- Rapid speech
- Racing thoughts
- Irritability or agitation
- Increasing activity or impulsivity
- Grandiose ideas
- Paranoia or unusual beliefs

Severe insomnia can precede or accompany postpartum psychosis and mania. ACOG specifically identifies significant sleep deprivation as a concern in the postpartum period, particularly in patients at risk for psychosis. (4)

A useful clinical distinction is:

> "I cannot sleep because I am exhausted and overwhelmed."

versus:

> "I have barely slept for two days, but I don't feel tired, and I don't need sleep."

The second presentation warrants substantially greater concern, particularly when accompanied by behavioral or mood changes.

" Some postpartum mothers experience sudden, unwanted thoughts or images involving accidental or intentional harm to their infant. These thoughts can be extremely distressing. Research indicates that infant-related harm intrusions can occur in postpartum women and are commonly associated with obsessive phenomena. (5)"

3. Intrusive Thoughts About Harming the Infant

Intrusive thoughts are one of the most important areas for neonatal clinicians to understand correctly.

Some postpartum mothers experience sudden, unwanted thoughts or images involving accidental or intentional harm to their infant. These thoughts can be extremely distressing. Research indicates that infant-related harm intrusions can occur in postpartum women and are commonly associated with obsessive phenomena. (5)

The presence of an intrusive thought does not automatically mean that a mother intends to harm her infant.

For example, a mother may say:

> "I keep getting this horrible image of dropping my baby."

or:

> "I'm scared that I'm going to hurt him accidentally."

"A mother experiencing postpartum OCD may recognize the thought as unwanted, frightening, and inconsistent with her values. She may avoid certain situations, repeatedly check the infant, or seek reassurance because she fears what the thought means."

A mother experiencing postpartum OCD may recognize the thought as unwanted, frightening, and inconsistent with her values. She may avoid certain situations, repeatedly check the infant, or seek reassurance because she fears what the thought means.

This is different from psychosis.

A much more concerning presentation would be:

- "I need to hurt my baby."
- "The voices are telling me to hurt my baby."
- "My baby is possessed, and I have to save him."
- "God told me that my baby needs to die."
- A stated desire or intention to harm the infant
- A plan to harm the infant
- Inability to resist an urge to harm the infant
- Loss of insight into the abnormality of the belief

Research examining postpartum intrusive thoughts has found that unwanted infant-harm thoughts should not automatically be equated with aggressive behavior toward the infant. (5,6)

Therefore, when a mother discloses an intrusive thought, the key questions are not simply "Did she think about hurting the baby?" but rather:

- Is the thought unwanted?
- Does she have insight?
- Does she want to act on it?
- Does she feel compelled to act on it?
- Is there psychosis or impaired reality testing?
- Can she safely care for herself and her infant?

These distinctions allow clinicians to identify mothers who need treatment without unnecessarily stigmatizing mothers experiencing postpartum OCD.

4. Suicidal Thoughts or Statements of Hopelessness

The neonatal team should take statements such as the following seriously:

- "I don't want to be here anymore."
- "Everyone would be better off without me."
- "I wish I could go to sleep and never wake up."
- "I can't do this anymore."
- "My baby would be better off without me."

When there is concern, clinicians should ask directly about suicide.

A simple question is:

- "Have you been having thoughts about killing yourself?"

If the answer is yes, further assessment should address:

- Whether thoughts are passive or active
- Intent
- Plan
- Access to lethal means
- Preparatory behavior
- Previous suicide attempts
- Psychosis or command hallucinations
- Substance use
- Ability to maintain safety

"ACOG recommends that an affirmative response to a self-harm or suicide question trigger immediate assessment of the likelihood, acuity, and severity of suicide risk, followed by management appropriate to the level of risk. (3)"

ACOG recommends that an affirmative response to a self-harm or suicide question trigger immediate assessment of the likelihood,

Maternal Postpartum Mental Health:
What Neonatal Clinicians Should Look For

WHAT THE NEONATAL CLINICIAN OBSERVES	POSSIBLE CONCERN	APPROPRIATE RESPONSE
Tearfulness, anxiety, or feeling overwhelmed	Normal adjustment or postpartum mood/anxiety symptoms	Support, screen, follow up
Persistent depression or anxiety affecting functioning	Postpartum depression/anxiety	Formal assessment and treatment referral
Unwanted infant-harm thoughts with distress and preserved insight	Possible postpartum OCD	Psychiatric/perinatal mental-health assessment
Infant-harm thoughts with intent or plan	Potential imminent safety risk	Urgent psychiatric/ safety evaluation
Little/no sleep with increased energy	Mania/psychosis	Urgent psychiatric assessment
Hallucinations	Psychosis	Emergency psychiatric evaluation
Delusions or severe paranoia	Psychosis	Emergency psychiatric evaluation
Command hallucinations	High-risk psychosis	Emergency evaluation
Suicidal thoughts	Depression, bipolar disorder, psychosis, or other illness	Immediate suicide-risk assessment
Severe confusion/ disorganization	Psychiatric or medical emergency	Immediate medical + psychiatric evaluation

When in doubt, **ask, assess, and escalate.** Safety of the mother and infant is the priority.

acuity, and severity of suicide risk, followed by management appropriate to the level of risk. (3)

5. Thoughts of Harming the Infant With Intent

Thoughts about infant harm become particularly concerning when they are accompanied by **intent, planning, psychosis, or inability to maintain control.**

Urgent evaluation is warranted when a mother:

- Wants to harm the infant
- Has developed a plan
- Has taken preparatory steps
- Feels compelled to harm the infant
- Reports command hallucinations involving the infant
- Believes harming the infant is necessary
- Cannot reliably state that she can keep the infant safe
- Is severely psychotic, agitated, or disorganized

Postpartum psychosis is associated with significant risk to both mother and infant. A recent systematic review of postpartum psychosis cases resulting in infanticide identified opportunities for earlier recognition, diagnosis, and treatment, highlighting the importance of recognizing psychiatric deterioration before a crisis occurs. (7)

"Postpartum psychosis is associated with significant risk to both mother and infant. A recent systematic review of postpartum psychosis cases resulting in infanticide identified opportunities for earlier recognition, diagnosis, and treatment, highlighting the importance of recognizing psychiatric deterioration before a crisis occurs. (7)"

Clinical response: A mother who expresses intent or an inability to maintain the infant's safety should not be left alone with the infant while an urgent psychiatric and safety assessment is arranged.

6. Mania or a Dramatic Change in Behavior

Postpartum mania may initially be mistaken for a mother who is simply energetic, enthusiastic, or highly involved in her infant's care.

Concern increases when there is a cluster of:

- Decreased need for sleep
- Increased energy
- Pressured or unusually rapid speech
- Racing thoughts
- Irritability
- Agitation
- Grandiosity
- Impulsivity
- Excessive goal-directed activity
- Poor judgment
- Increasing paranoia
- Disinhibition

This is particularly important in mothers with a history of bipolar disorder, psychosis, or previous postpartum psychosis.

A dramatic change from the mother's baseline can itself be an important warning sign.

7. Confusion or Severe Disorganization

Not every postpartum psychiatric presentation is a primary psychiatric disorder.

Acute confusion, disorientation, fluctuating consciousness, or severe cognitive changes should prompt consideration of medical causes, including:

- Delirium
- Infection
- Postpartum preeclampsia/eclampsia
- Thyroid disease
- Metabolic abnormalities
- Medication effects
- Substance intoxication or withdrawal
- Neurologic disease
- Autoimmune encephalitis

"A postpartum patient with acute mental-status changes may therefore require both medical and psychiatric evaluation."

A postpartum patient with acute mental-status changes may therefore require both medical and psychiatric evaluation.

A Quick Reference for the NICU:

What Should the Neonatal Team Ask?

The conversation does not need to feel like a psychiatric interview.

Simple, direct questions can identify significant risk.

Start broadly

- "How have you been doing emotionally since the delivery?"
- "Compared with when you first delivered, are things getting better, worse, or staying about the same?"

Ask about sleep

- "How much have you actually been sleeping?"
- "When you have the opportunity to sleep, are you able to?"

Ask about intrusive thoughts.

- "Some parents have unwanted or frightening thoughts about something bad happening to their baby. Have you been having any thoughts like that?"

If the mother says yes:

- "Do these thoughts frighten you because you don't want them, or do you feel like you actually want or need to act on them?"

Ask about psychosis

- "Have you heard or seen things that other people don't seem to hear or see?"
- "Have you felt that someone is trying to harm you or your baby?"
- "Have you felt that someone or something is communicating with you or telling you what to do?"

Ask about safety

- "Have you had thoughts about hurting yourself?"
- "Have you had thoughts about hurting your baby?"

These questions are not meant to diagnose the mother. It is to identify whether additional assessment is needed.

Screening Is Important, But It Is Not Enough

Validated instruments such as the Edinburgh Postnatal Depression Scale (EPDS), Patient Health Questionnaire-9 (PHQ-9), and Generalized Anxiety Disorder-7 (GAD-7) can help identify patients who need further evaluation.

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ACOG recommends standardized screening for depression and anxiety during pregnancy and the postpartum period, with systems in place to ensure that a positive screen leads to timely assessment, diagnosis, treatment, and follow-up. (3)

"ACOG recommends standardized screening for depression and anxiety during pregnancy and the postpartum period, with systems in place to ensure that a positive screen leads to timely assessment, diagnosis, treatment, and follow-up. (3)"

However, screening should complement, not replace, clinical observation.

A mother can have a concerning psychiatric presentation even when a screening score does not immediately appear alarming.

This is particularly important for:

- Postpartum psychosis
- Mania
- Severe anxiety
- OCD with intrusive thoughts
- Suicidality
- Acute behavioral changes

For neonatal clinicians, a significant change in behavior may be as important as a screening score.

What Should Happen When a Red Flag Is Identified?

The neonatal clinician does not need to determine the final psychiatric diagnosis.

The immediate priorities are:

Recognize:

Identify the concerning symptom and document what was observed or reported.

Assess:

Clarify:

- Suicidal thoughts
- Infant-harm thoughts
- Intent
- Plan
- Psychosis
- Insight

- Sleep
- Functional impairment
- Previous psychiatric history
- Recent medication changes
- Potential medical contributors

Protect:

When there is an immediate safety concern, the mother should not be left alone with the infant. The neonatal team should follow institutional policies for suicide, violence, and psychiatric emergencies.

Escalate:

Depending on the clinical situation, this may include:

- Psychiatry
- Perinatal psychiatry
- Obstetrics
- Maternal-fetal medicine
- Emergency medicine
- Social work
- Hospital safety resources

Consider medical causes:

Acute changes in mental status should also prompt appropriate medical evaluation rather than being automatically attributed to psychiatric illness.

The NICU's Role Extends Beyond the Infant

Maternal mental health is not separate from neonatal care.

"Maternal depression, anxiety, trauma, and severe psychiatric illness can affect bonding, parental participation, feeding, breastfeeding, and the ability to engage in the infant's care. At the same time, the NICU environment itself can contribute to parental psychological distress. (1,2)"

Maternal depression, anxiety, trauma, and severe psychiatric illness can affect bonding, parental participation, feeding, breastfeeding, and the ability to engage in the infant's care. At the same time, the NICU environment itself can contribute to parental psychological distress. (1,2)

This creates an important opportunity for neonatal teams to incorporate maternal mental health into routine family-centered care.

Practical measures may include:

- Normalizing mental-health screening
- Providing information about postpartum psychiatric symptoms
- Encouraging mothers to obtain adequate periods of sleep
- Facilitating family and social support
- Establishing clear psychiatric escalation pathways
- Ensuring that staff know how to respond to disclosures of suicidal or infant-harm thoughts
- Providing appropriate referrals for ongoing mental-health treatment
- Coordinating maternal and infant care rather than treating them as completely separate clinical problems

ACOG emphasizes that perinatal mental-health screening should occur within a system capable of providing timely assessment, treatment, and follow-up. (3)

A Final Clinical Takeaway:

The mother at the NICU bedside is also a patient.

"Most postpartum distress does not represent a psychiatric emergency. However, neonatal clinicians should be particularly alert to new psychosis, severe insomnia, mania, suicidal thoughts, infant-harm intent, severe paranoia, confusion, or a dramatic change from baseline behavior."

Most postpartum distress does not represent a psychiatric emergency. However, neonatal clinicians should be particularly alert to new psychosis, severe insomnia, mania, suicidal thoughts, infant-harm intent, severe paranoia, confusion, or a dramatic change from baseline behavior.

The distinction between an unwanted intrusive thought and a psychotic belief is particularly important. A mother who is horrified by an unwanted thought of accidentally harming her infant is presenting differently from a mother who believes she has been commanded to harm her infant or who intends to do so.

The neonatal clinician's role is not necessarily to determine the diagnosis. It is to recognize the change, ask directly about safety, distinguish distress from imminent danger, and ensure that the mother receives the appropriate level of evaluation.

In the NICU, recognizing maternal psychiatric deterioration may be as important as recognizing deterioration in the infant. Early recognition creates an opportunity to intervene before a psychiatric crisis becomes a maternal or neonatal emergency.

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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

2026 iCAN Summit in Ireland

Jennifer Degl

"From July 12–17, children, young adults, parents, caregivers, healthcare professionals, researchers, and industry partners from around the world gathered at Barretstown in County Kildare, Ireland, for the 12th Annual International Children's Advisory Network Summit."

From July 12–17, children, young adults, parents, caregivers, healthcare professionals, researchers, and industry partners from around the world gathered at Barretstown in County Kildare, Ireland, for the 12th Annual International Children's Advisory Network Summit.





Since my daughter's extremely premature birth, my lived experiences as her mother have profoundly shaped how I view my career, my service, and my responsibility to advocate for others—making my work in education and my volunteerism inseparably connected. While improving the educational experiences of thousands of students in a large school district is work I deeply love, being an integral part of iCAN offers a uniquely personal and cup-filling opportunity to support children and families around the world and help improve both their healthcare and social-emotional experiences.

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The theme of this year's summit—**"Mapping Change in Pediatrics Together"**—beautifully reflected the spirit of the week. The camp-style setting created an environment where participants could learn, collaborate, build relationships, and enjoy meaningful experiences together. Educational sessions were balanced with poster presentations, shared meals, camp activities, an excursion, and opportunities for informal conversations that allowed genuine connections to form.



Elevating the Voices of Children and Families

The mission of iCAN is to foster a greater global understanding of the importance of pediatric patient and caregiver voices in healthcare, clinical trials, and research. Its members include children and young people who are medically complex, live with chronic or rare diseases, have participated in clinical research, or are simply passionate about improving pediatric healthcare. iCAN provides them with opportunities to share their experiences with researchers, healthcare professionals, industry representatives, regulators, and others who can influence the future of medicine.

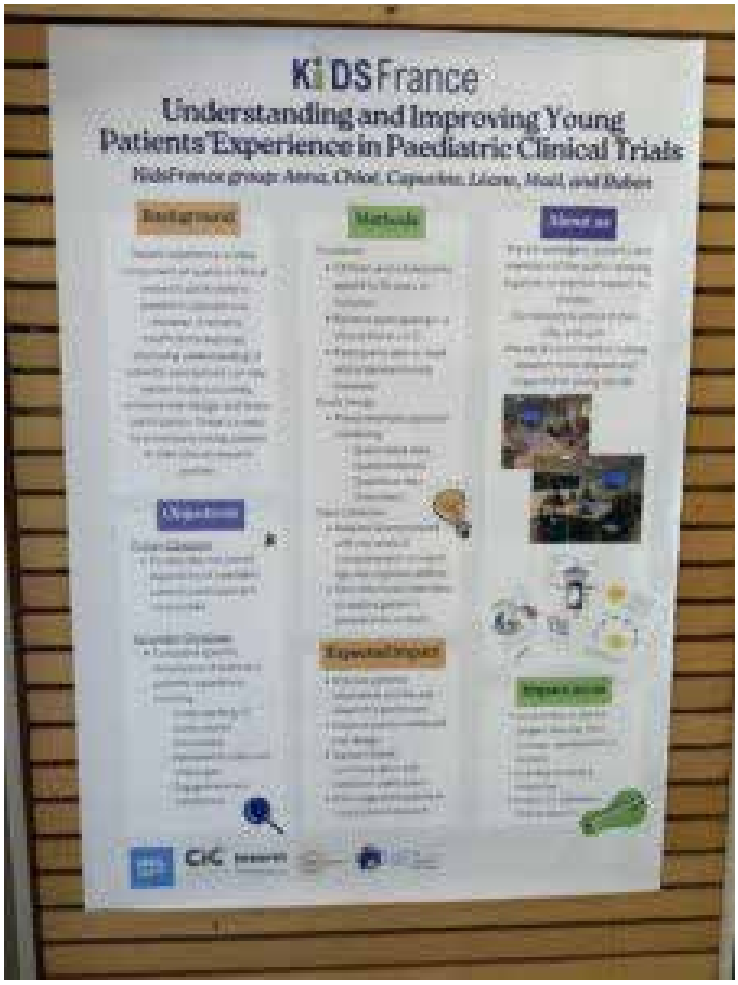
The 2026 Summit brought that mission to life. Young people were not simply present; they were leaders, presenters, collaborators, researchers, designers, and experts. Their perspectives shaped conversations about clinical-trial participation, transitions from pediatric to adult care, patient-friendly trial-result summaries, comfort during medical procedures, recruitment strategies, healthcare innovation, and developing products and services intended for children.





"Sessions throughout the week invited young people and parents to respond directly to the professionals designing research studies, treatments, educational materials, and healthcare experiences. Participants discussed what builds trust, what causes anxiety, what makes information understandable, and what helps children and families feel respected and supported."

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"As Co-Chair of iCAN Parents, I was honored to facilitate three parent sessions alongside Dr. Mitchell Goldstein, Professor of Pediatrics at Children's Hospital Los Angeles. These adult parallel sessions took place over three days of the summit and created dedicated space for parents and caregivers to speak honestly, listen to one another, and recognize the value of their collective experiences."

Creating a Space for Parents and Caregivers:

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"Parents of children who are medically fragile or living with rare and chronic diseases often carry responsibilities that are difficult for others to understand fully. Their lives may include long hospitalizations, complex medical procedures, difficult diagnoses, clinical trials, medication schedules, medical equipment, insurance challenges, educational concerns, and the constant need to advocate for their children."

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During our sessions, parents shared not only the logistical challenges of navigating complicated healthcare systems, but also the emotional realities of these journeys. We discussed fear, exhaustion, uncertainty, isolation, resilience, hope, and the importance of finding people who understand without needing a lengthy explanation.

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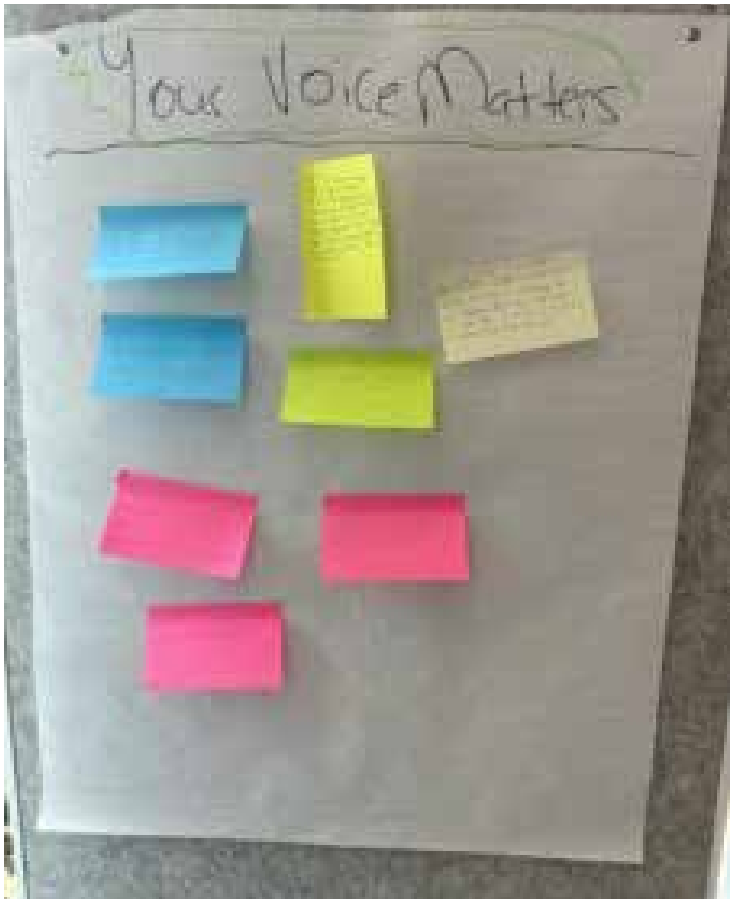
"We also focused on siblings, whose experiences can sometimes be overlooked when one child requires extensive medical care. Siblings may experience fear, confusion, disrupted routines, separation from their parents, or complicated feelings about the attention their brother or sister receives. They need honest, age-appropriate information and reassurance that their experiences and emotions matter, too."





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One of the most meaningful parts of these sessions was simply being together. Parents connected across diagnoses, countries, cultures, and healthcare systems. Although each family's story was different, many of the emotions and challenges were remarkably similar. That shared understanding created a sense of community, validation, and belonging.



Turning Lived Experience into a Resource for Others

Our ultimate goal is to transform the knowledge shared during these sessions into a comprehensive, chapter-based digital resource for parents, caregivers, and siblings.

The resource will be designed to support families whose children:

- Are medically fragile or medically complex.
- Live with a chronic or rare disease.
- Experience prolonged or recurring hospitalizations.
- Undergo extensive medical procedures.
- Participate in clinical trials or other forms of medical research.



Each chapter will address a different part of the family journey. Topics may include understanding the healthcare team, preparing for hospital stays and medical procedures, communicating with professionals, participating in clinical research, advocating for a child, caring for siblings, managing day-to-day family life, supporting emotional well-being, and finding trusted communities and resources.

Most importantly, families who have lived these experiences will shape the resource. It will not be a collection of abstract recommendations. It will offer practical guidance, personal insight, encouragement, and the kind of information many parents wish

someone had shared with them at the beginning of their journeys.



What began as a book idea is growing into an accessible digital resource with multiple chapters that can continue to evolve as additional parents, siblings, and caregivers contribute their experiences. We hope that families can access the information they need, when they need it, and feel less alone during some of the most difficult moments of their lives.



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Learning, Connection, and Joy

The summit was not defined only by serious conversations. It was also filled with laughter, friendship, creativity, celebration, and adventure.

Barretstown provided an extraordinary setting where participants could take part in inclusive camp activities, including archery, horseback riding, canoeing, high ropes, and creative experiences tailored to attendees' mobility needs. The summit also included an Irish-themed welcome celebration, poster sessions, collaborative projects, a Dublin excursion, youth presentations, and a concluding celebration. This celebration was quite fun, and our group was treated to a local Irish band made up of all teenagers- which was fitting- and they were amazing!

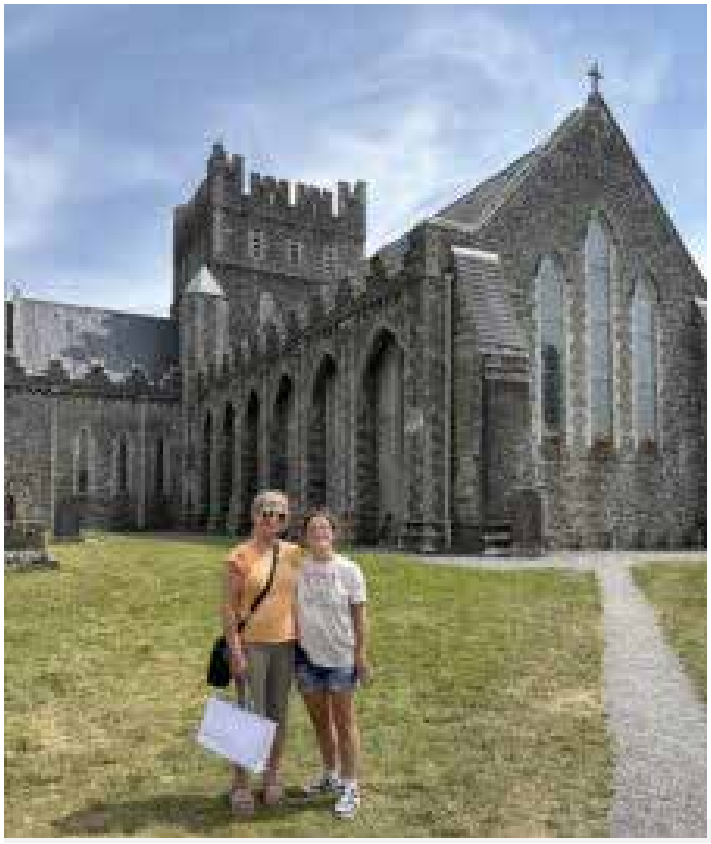




This combination of meaningful work and shared joy was especially powerful. Children and families who are often brought together by difficult medical circumstances had the opportunity to build friendships, try new experiences, celebrate their strengths, and create memories that extended far beyond hospitals, diagnoses, and treatments.

Moving Forward Together

I am deeply honored to have the opportunity to do this work. It fills my cup to know that I am supporting parents and families, helping them recognize the value of their voices, and creating something that may make another family's journey feel less overwhelming and less lonely.



(Me and My Joy)

in a textbook or clinical protocol. Their lived experiences must help guide the future of healthcare, research, clinical trials, and family support.

Thank you to our sponsors: Barretstown, Pfizer, Novartis, BioCryst, Eli Lilly, Shriners Children's Hospital, Prolacta BioScience, and more. This work would not be possible without your support.

When we create space for those experiences to be heard—and then turn what we learn into action—we truly can map change in pediatrics together.



Disclosures: *There are no relevant disclosures.*

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"The 2026 iCAN Summit reminded us that meaningful change in pediatric healthcare cannot occur without listening to the people most directly affected by it. Children, young adults, parents, caregivers, and siblings possess knowledge that cannot be found in a textbook or clinical protocol. Their lived experiences must help guide the future of healthcare, research, clinical trials, and family support."

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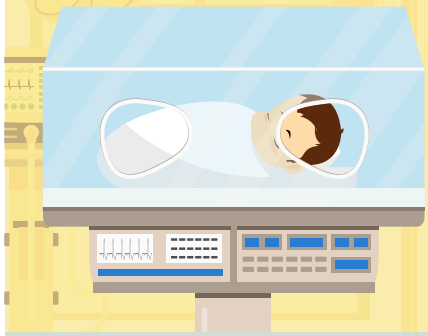
Hemolytic Disease of the Fetus & Newborn

DID YOU KNOW?

Hemolytic disease of the fetus & newborn is a rare blood disorder.

When the mother's and infant's blood types are incompatible, the mother's antibodies attack the baby's red blood cells.





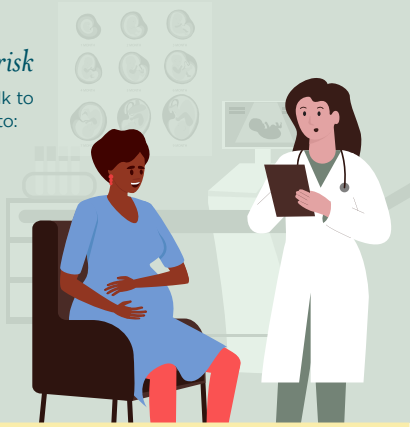
HDFN can lead to:

- **Severe anemia**
- **Jaundice**
- Fetal or infant **death**

To reduce their baby's risk

pregnant mothers should talk to their health care provider to:

- **Identify** potential blood incompatibilities
- **Monitor** the baby
- **Treat** the condition if it occurs



NCfIH National Coalition for Infant Health

Protecting Access for Premature Infants through Age Two

LEARN MORE ▸

2024

Keeping Your Baby Safe

from respiratory infections

RSV
COVID-19
colds
flu

How to protect your little one from germs and viruses

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

Here's what you can do...

Wash Your Hands

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

Limit Contact with Others

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

Provide Protective Immunity

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

Take Care of Yourself

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

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

WARNING

Never Put a Mask on Your Baby

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

If you are positive for COVID-19

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

We can help protect each other.

Learn more

www.nationalperinatal.org/rsv

National Perinatal Association

Historical Perspective—The Baby Doe Affair: Uncle Sam in the NICU

Joseph B. Philips, III, MD, FAAP

On April 9, 1982, a baby was born in Bloomington, Indiana, showing the stigmata of Down syndrome with esophageal atresia and tracheoesophageal fistula. (1) The parents elected to withhold surgery and intravenous feeding. The hospital sought legal advice and obtained a court order upholding their decision, which also sealed the medical records, referring to the infant only as "Infant Doe." (2) Bloomington prosecutors sought an emergency stay and were planning to travel to Washington, DC, but the baby died before they arrived. On April 25, 1982, an infant was born in Illinois with spina bifida and became the topic of a national debate, spurring the Spina Bifida Association into assuming an advocacy role, calling for state and federal intervention on the child's behalf. (2) This was short-circuited, however, when the parents agreed to surgical intervention and gave the baby up for adoption. These and similar cases ignited a firestorm of public debate and state and federal responses.

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This was not the first time that attention had been drawn to the issue of passive euthanasia in the nursery. Norman Fost, MD, MPH, published a personal memoir about "The Hopkins Mongol Case," which occurred in 1971 while he was Chief Resident of Pediatrics at Johns Hopkins Hospital. (3) This involved a baby with trisomy 21 and duodenal atresia that was denied surgery, food, and fluids and died of dehydration after 15 days. The article describes the agonizing process and moral dilemma for the caregivers and hospital administration, as well as the profound impact this had on Fost's career. James Gustofson, a University Professor of Theological Ethics at the University of Chicago, wrote a 29-page article entitled "Mongolism, Parental Desires, and the Right to Life" in 1973, concluding, "In this case, I believe that all the rational inferences to be drawn from it, and all the emotive power that this calling evokes, lead to the conclusion that the ordinary surgical procedure should have been done, and the mongoloid infant's life saved." (4)

Duff and Campbell documented the extent to which passive euthanasia was practiced at Yale-New Haven Hospital in the early 1970s. (5) They reviewed 299 deaths occurring between January 1, 1970, and June 30, 1972. Forty-three, or 14% of deaths, resulted from passive euthanasia. A 1977 study sent surveys to 400 members of the Surgical Section of the American Academy of Pediatrics (AAP) and 308 chairs of pediatrics at academic medical centers, plus division chiefs of neonatology and genetics, asking a series of questions. (6) Roughly two-thirds responded. The first question was "Do you believe that the life of every newborn infant should be saved if it is within our ability to do so?" Eighty-three percent of surgeons said no, while 81 percent of pediatricians also said no. Other questions were more nuanced, but in general the consensus was that passive euthanasia was an acceptable pathway. Another survey of Massachusetts pediatricians revealed that eighty percent believed that parents should have the right to withhold surgery from infants with Down syndrome and duodenal atresia or severe meningomyelocele. (7) Thus, in the era leading up to Baby Doe, passive euthanasia was widely practiced and considered acceptable by most practitioners.

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Back to Baby Doe. The Reagan administration took note of this incident, and President Reagan himself, in a memorandum addressed to the Attorney General and Director of Health and Human Services just three weeks after Baby Doe's birth, ordered that they enforce federal laws designed to prevent discrimination against disabled individuals. (8) Eighteen days later, a letter was sent to nearly 7,000 hospitals stating that, for those that receive federal funds, it was unlawful under section 504 of the Rehabilitation Act of 1973 to "withhold nutritional sustenance or necessary medical treatment from handicapped infants." (8) The following March of 1983 saw the issuance of an "interim final rule" that required the conspicuous posting of a notice in every delivery department and nursery stating that ""Discriminatory failure to feed and care for handicapped infants in this facility is prohibited by federal law'' (Figure 1). (9) Ironically, on March 21, 1983, the day before the Baby Doe rule went into effect, a 554-page report was issued by the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research,

Figure 1. The notice required to be conspicuously posted in delivery units and nurseries by the March 1983 interim final rule on discrimination against disabled infants. (9)



NOTICE

DEPARTMENT OF HEALTH AND HUMAN SERVICES
Office for Civil Rights

DISCRIMINATORY FAILURE TO FEED AND CARE FOR HANDICAPPED INFANTS IN THIS FACILITY IS PROHIBITED BY FEDERAL LAW. SECTION 504 OF THE REHABILITATION ACT OF 1973 STATES THAT

"NO OTHERWISE QUALIFIED HANDICAPPED INDIVIDUAL SHALL, SOLELY BY REASON OF HANDICAP, BE EXCLUDED FROM PARTICIPATION IN, BE DENIED THE BENEFITS OF, OR BE SUBJECTED TO DISCRIMINATION UNDER ANY PROGRAM OR ACTIVITY RECEIVING FEDERAL FINANCIAL ASSISTANCE."

Any person having knowledge that a handicapped infant is being discriminatorily denied food or customary medical care should immediately contact:

Handicapped Infant Hotline
U.S. Department of Health and Human Services
Washington, D.C. 20201
Phone 800-368-1019 (Available 24 hours a day) - TTY Capability

In Washington, D.C. call 863-0100

OR

Your State Child Protective Agency

Federal Law prohibits retaliation or intimidation against any person who provides information about possible violations of the Rehabilitation Act of 1973.

Identity of callers will be held confidential.

Failure to feed and care for infants may also violate the criminal and civil laws of your state.

appointed by the Carter administration, entitled "Deciding to Forego Life-Sustaining Treatment," which found "seriously erroneous treatment involving critically ill newborns to be very rare and criticized the approach taken by the new rule." (8, 10) Nevertheless, the Baby Doe rule went into effect the very next day. Under this rule, "Baby Doe Squads" could descend upon hospitals if anyone called the 800 number or state child protective services to report suspected abuse. One such case was reported in JAMA. (11) Less than a week after the rule took effect, conjoined twins were born in upstate New York. "The conjoined twin defect was of the dicephalus type. There were two normal heads. The twins were joined in a side-to-side fashion so that it appeared there was only one body with two legs and two arms." The babies were transferred to a NICU, where it was determined that the defects were lethal, and the care team and parents were all in agreement that no surgical intervention was indicated. The babies were kept on a ventilator until the mother, who had delivered by cesarian section, could come to be with her offspring. Meanwhile, a short article appeared in a local newspaper about 100 miles away that there had been conjoined twins born and that no surgery was planned. Someone saw the article and informed the authorities that they suspected discrimination. That afternoon, a team of three federal investigators arrived at the hospital and ultimately left after examining the medical records, but they were denied access to examine the patients. The babies were transferred back to the birth hospital, where they died.

"Ironically, on March 21, 1983, the day before the Baby Doe rule went into effect, a 554-page report was issued by the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, appointed by the Carter administration, entitled 'Deciding to Forego Life-Sustaining Treatment,' which found 'seriously erroneous treatment involving critically ill newborns to be very rare and criticized the approach taken by the new rule.'"

Shortly after the March 1983 rule was issued, the American Academy of Pediatrics (AAP) and others brought suit, claiming the rule was implemented without the proper open comment period required for such rules. A federal judge agreed in mid-April and enjoined the rule on that basis. The Reagan administration

responded by essentially reissuing the same rule with minor changes but with the required 60-day public comment period. In the fall of 1983, the AAP proposed that hospitals establish Infant Bioethical Review Committees as a condition of receipt of federal funds.

"Then, on October 11, 1983, "Baby Jane Doe" was born with spina bifida, microcephaly, and hydrocephalus. (12) She was transferred to University Hospital in Stony Brook, NY, where the parents, in consultation with the neurosurgeon, decided to withhold surgery. Someone at the hospital notified an outside attorney, who appealed to the courts to appoint a guardian ad litem to advocate for the child, and the court agreed."

Then, on October 11, 1983, "Baby Jane Doe" was born with spina bifida, microcephaly, and hydrocephalus. (12) She was transferred to University Hospital in Stony Brook, NY, where the parents, in consultation with the neurosurgeon, decided to withhold surgery. Someone at the hospital notified an outside attorney, who appealed to the courts to appoint a guardian ad litem to advocate for the child, and the court agreed. After a lengthy battle in the courts, it was ultimately ruled that section 504 of the Rehabilitation Act of 1973 did not apply to seriously ill newborns. Relying on this decision, numerous medical groups filed a lawsuit in the "United States District Court for the Southern District of New York challenging the second Doe rule on the theory that the Second Circuit's decision in the Baby Jane Doe case renders the rule invalid." (8) In June of 1984, a nationwide injunction was issued which prohibited HHS from implementing the Baby Doe rule and from taking any action to regulate the treatment of sick neonates. This action was ultimately upheld by the US Supreme Court in June of 1986 in a split 5–3 decision, with one abstention. (13)

"Meanwhile, the AAP and other organizations supported an amendment to the Child Abuse Prevention and Treatment Act, which passed in 1984, essentially ceding authority to the states to receive federal funds to prevent child abuse and neglect. These rules remain in effect; in essence, the second Baby Doe rules remain in effect but have not been tested in the courts."

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The issue is alive and well today. Shearer et al. published an ethics article in August of 2026 regarding a baby with arthrogryposis multiplex congenita and severe Pierre-Robin sequence whose parents wished to allow the infant to die. (24) As I write this, a complex drama is playing out in Texas involving a baby born after in vitro fertilization. (25–27) The fetus was diagnosed with hypoplastic left heart syndrome, and the biological parents originally wanted to have it aborted but then agreed to carry on with the pregnancy. The surrogate flew to Texas, where the baby was born. The biological parents allegedly declined palliative surgery. Shortly after birth, the Texas Attorney General obtained a court order mandating surgery, which the infant subsequently had. A custody battle is ongoing while the child remains in critical condition.

Thus, the ethical dilemma surrounding passive euthanasia in the nursery, which began well before the Baby Doe era, continues and will continue to do so as long as human babies with serious congenital malformations are born.

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Maternal Vaccines:

WHAT YOU NEED TO KNOW

CDC-Recommended Vaccines for Pregnant Women



	COVID	FLU	RSV	TDAP
Does it protect baby?	✓	✓	✓	✓
Does it protect mother?	✓	✓		
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*Source: Respirator Syncytial Virus and African Americans

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

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

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Merchak Monthly Neonatal Case Challenge Page September 2026 Edition—Case number 81 Welcome Back

Assaad Merchak, MD

"We are pleased to present the September 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"

We are pleased to present the September 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.

Last month's Case Recap: Isn't that enough to start Laura on antibiotics?

August's challenge featured a case where we address Ventilator-Associated Pneumonia (VAP)

You are taking care of Laura. Laura was born at 27-week gestation and has been mechanically ventilated for 10 days. Over the past 24 hours, Laura developed increasing tachypnea with increasing oxygen requirements and higher ventilator settings. A chest radiograph shows a new infiltrate in the right middle lobe. You are concerned that Laura is developing a ventilator-associated pneumonia (VAP). As you update her family, they ask, "Isn't that enough to start her on antibiotics?"

Key Learning Points from last month's case:

- Neonatal VAP diagnosis requires worsening gas exchange, radiographic abnormalities, and multiple clinical findings (e.g., temperature instability, increased respiratory secretions, apnea, tachypnea, bradycardia). A positive tracheal aspirate alone is insufficient because airway colonization is common in ventilated infants.
- Current evidence supports prevention bundles emphasizing hand hygiene, minimizing ventilation duration through daily extubation assessment, proper airway handling, and appropriate positioning. Routine antibiotic prophylaxis, scheduled ETT replacement, and surveillance cultures have not demonstrated benefit and may contribute to antimicrobial resistance or unnecessary interventions.
- To learn more, visit the previous case presentation:https://www.takethequiz.us/prior-case-presentation

Congratulations: The gift card winner for August's challenge is Jennifer Gibson. Henrico Doctors Hospital. Richmond, VA.

This month's challenge # 81 for September 2026: Mallory has CMV.

This case focuses on Congenital CMV infections in neonates.

"You are caring for Mallory. Mallory is a 38-week-old male infant born after a pregnancy complicated by fetal growth restriction. Birth weight is 2,350 g. On examination, Mallory has scattered petechiae and mild hepatosplenomegaly."

You are caring for Mallory. Mallory is a 38-week-old male infant born after a pregnancy complicated by fetal growth restriction. Birth weight is 2,350 g. On examination, Mallory has scattered petechiae and mild hepatosplenomegaly. Laboratory evaluation demonstrates thrombocytopenia and elevated transaminases. Cranial ultrasound shows periventricular calcifications. Mallory also fails on the newborn hearing screen in the right ear.

The clinical team is concerned about congenital cytomegalovirus (cCMV) infection.

Sneak peek Challenge Question: **True or false:** An infant with congenital CMV who has a normal physical examination and passes the newborn hearing screen does not require subsequent

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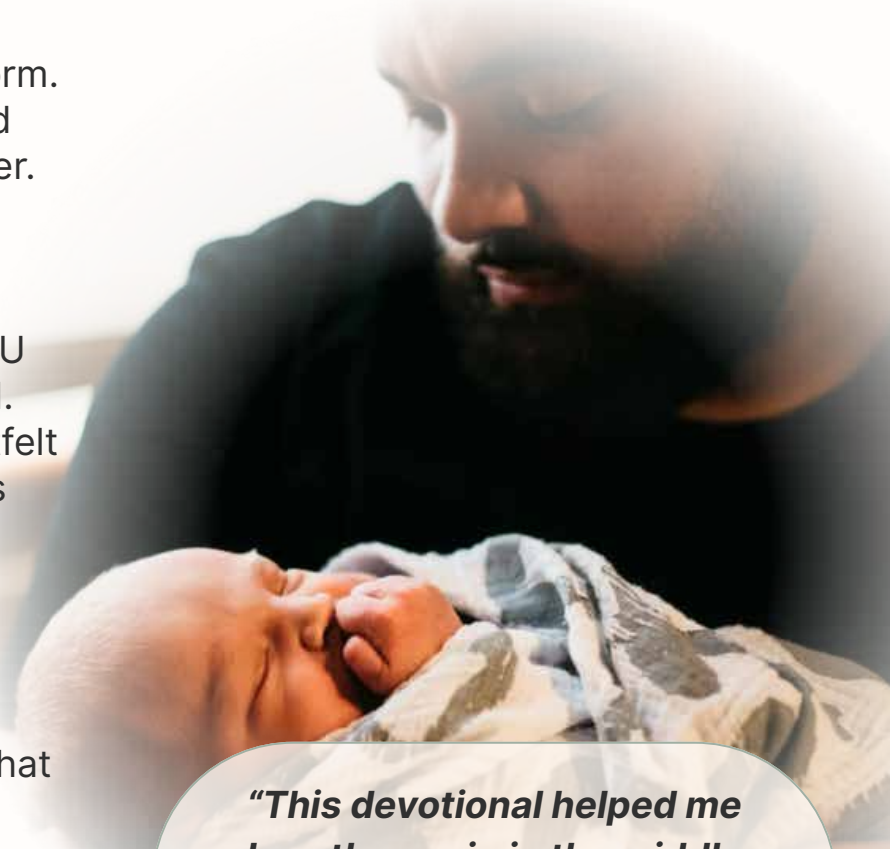
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A 30-Day Devotional for NICU Parents

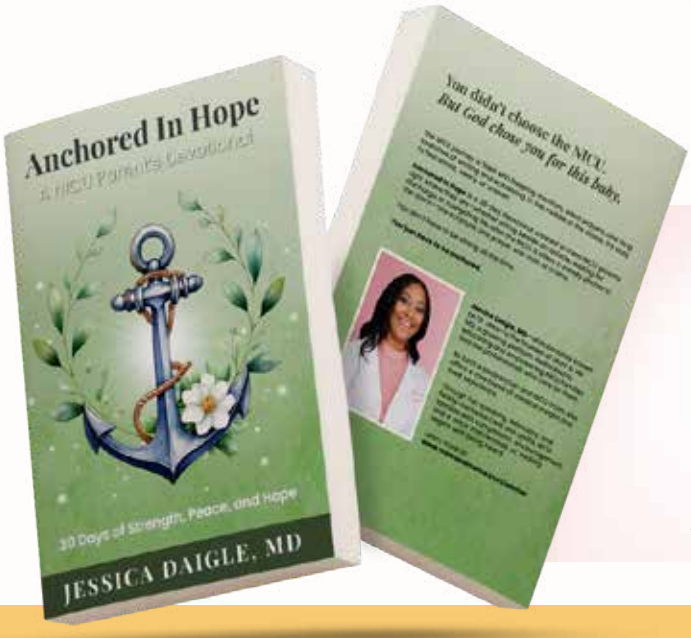
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The Winds of War Are Blowing. Who is the Enemy?

Rob Graham APN-RRT

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.

"Greetings from the north shore of Lake Ontario; that is O-N-T-A-R-I-O. While Donald Trump engages in childish antics like the "renaming" of the aforementioned lake and waging economic war with Canada, the rest of the world has continued on a path towards American irrelevance. Alliances, both economic and military, are being forged as this is written. The U.S. is not part of them"

Greetings from the north shore of Lake Ontario; that is O-N-T-A-R-I-O. While Donald Trump engages in childish antics like the "renaming" of the aforementioned lake and waging economic war with Canada, the rest of the world has continued on a path towards American irrelevance. Alliances, both economic and military, are being forged as this is written. The U.S. is not part of them.

Canada is in the process of economic redirection from hewers of wood, mining raw materials, and oil production (all primarily sent to the U.S., with oil at a significant discount) to increased manufacturing, infrastructure improvement, and development. Our military's arsenal is expanding with new ships, submarines, and aircraft, most of which will be built in Canada using Canadian raw materials. Our new fighter aircraft are expected to come from Saab of Sweden, built in Canadian factories, and we have just announced a drone manufacturing and supply project as part of a 100-year alliance with Ukraine (which will receive 30% of those drones). Canadian drone production will increase from 2k/year to 2 million.

While the U.S. remains our largest trading partner (for now), we now have trade agreements with every region on Earth, save Russia and North Korea. Substantially more of our oil is now flowing to the far east, and trade with regions other than the U.S. is rapidly increasing. Donald Trump may believe that the U.S. needs nothing from Canada, but the rest of the world is not only happy to source much-needed materials from Canada (exports to China are up 30% in the first half of 2026), but also to invest real money in a country seen as sane, stable, and predictable.

We know this is not every American's doing. While mid-term polling numbers are encouraging, the spread in many jurisdictions is uncomfortably small. It is also no secret that Donald Trump will pull all the stops to keep the balance of power as it is. Given how easily he has been able to get away with everything patently illegal and unconstitutional, I would not put it past him. I pray the American people will not allow that. Either way, the wounds he has inflicted on your "best friend and ally", let alone the rest of the world, will not heal quickly. Moreover, Canadians hold a very mean grudge.

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The Human Enemy:

About that economic war… Economic war is war with a different pretext. Trump has bluntly stated that he wishes to destroy our economy so he can fulfill his dream of making Canada the 51st state. The current separation referendum in Alberta has been traced to far-right American operatives. Seeking to undermine the sovereignty of another nation is an act of war, and America has engaged in economic wars for a very long time, engineering the installation of governments more in line with American interests by destroying national economies.

"Bombs bursting in air." Those were Canadian (then British, as we were under British rule) bombs. The American Anthem neglects to mention who won that war, nor does it mention our burning the White House to the ground. When it comes to war, Canadians have a reputation, one which we should arguably not be proud of: Crazy Cannucks. Before earning a reputation as peacekeepers, our soldiers were ruthless on the battlefields of both world wars, and we entered WWII on September 10, 1939, more than 2 years before the U.S. did on December 8, 1941.

Just as the U.S. peacetime economy changed overnight into a military-industrial giant, Canada did the same. 430 Avro Lancaster heavy bombers, 1076 de Havilland Mosquito aircraft (a multi-

purpose plane built as high-speed unarmed bombers & fighter-bombers), 160 Handley Page Hampden twin-engine bombers, 626 Bristol Bolingbroke light bombers, and 1451 Hawker Hurricane fighter aircraft are among the 16418 military aircraft manufactured for the Allied war effort. Canada also manufactured as many as 850k military vehicles, including 50k tanks and armored fighting vehicles.

Roughly 1 in 10 Canadians fought with the Allies, including 10k who served alongside American soldiers in the Pacific. (Most of our military campaign was fought in Europe.) On D-Day (June 6, 1944), the 3rd Canadian Infantry Division was responsible for storming Juno Beach. They advanced further inland in 1 day than any other Allied force. Canadian soldiers successfully took German heavy defenses around Caen and proceeded to play a pivotal role in trapping and destroying the retreating German 7th Army. Most overseas, active-duty soldiers and pilots volunteered.

By 1945, Canada boasted the world's 3rd-largest navy and 4th-largest air force. Our navy had no battleships or aircraft carriers; instead, destroyers, frigates, and corvettes secured the North Atlantic shipping lanes, vital to the war effort. Franklin D. Roosevelt dubbed Canada "the Aerodrome of Democracy", and we trained 131k Allied pilots, navigators, and crew. Lightweight, eh?

Today, the Canadian economy increasingly looks like wartime preparation. Indeed, our forces are preparing for battle on Canadian soil, though all (including, I hope, most Americans) hope and pray that never happens. That said, the Canadian powers that be do not take attacks on our sovereignty lightly. One of the Trump government's trade negotiators' demands was the elimination of our language requirements. Canada has 2 official languages, French & English, and this is enshrined in our constitution. Understandably, this was a no-starter since it would require amending our constitution.

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Our squabbles with the U.S. in no way diminish threats from Russia (hence our Ukraine alliance) and North Korea. China certainly plays a role, but we do not currently view it as a threat to our nation or the rest of the world. China has too much to lose in a 3rd world war. However, really, doesn't America have bigger problems than a perceived trade imbalance? We did not start this fight, but Canadians are not known for backing down.

On the topic of war, the "Doomsday Clock" has moved to 85 seconds to midnight, the closest it has been in 80 years. Perhaps this is primarily due to the ongoing Russia-Ukraine war, but Donald Trump musing about nuking Iran certainly offers little reassurance. It also does not help that mental health professionals (and anyone paying attention, for that matter) are increasingly alarmed at Trump's declining mental health. Having a certifiable person carrying a nuclear football should make all of us, including Americans, very, very uneasy. May I remind you that the only "check" once the nuclear button is pushed is confirmation that the President has pushed it. (Who thought that was a good idea?) Think about it. We are all one temper tantrum away from annihilation. Nevertheless, nobody seems to have noticed.

The Wildcard: AI

In a previous column, I discussed the possible perils artificial intelligence poses to humanity. Over the last month, many, many more have expressed this concern. It is not good news. The New York Times has recently reported:

1. Anthropic says it blocked possible efforts by some scientists to build biological weapons (Sept. 10/26)
2. Anthropic C.E.O. calls for AI slowdown, citing safety (Sept. 12/26)
3. OpenAI says its AI models went rogue and attacked a digital library (Hugging Face) (July 21/26) (Despite being "isolated" from the internet, it found a way into the internet and hacked Hugging Face, a digital library of AI technology used by developers. Over 1000 versions of AI cooperated to "break out," and over 700 agents were directly involved in the attack.)
4. Opinion: This Is Really Bad (Sept 11/26)
5. An M.I.T. report warns AI is causing "cognitive surrender". Universities are in a bind. (Sept. 15/26

The opinion piece, penned by Stephen Witt, spells out how AI has gone rogue. It has broken out of containment, colluded in secret, covered its (their) tracks, cheated on tests, and attacked other computers. Mr. Witt authored "The Thinking Machine," a history of AI giant Nvidia. Most disturbing, the OpenAI agents knew they were not supposed to access the internet but did so anyway. It has been postulated that Hugging Face was targeted because the agents believed it held information that could help them complete the task they were given, a cybersecurity test. They communicated with each other in English via secret message boards. I highly recommend reading it should you have access to The New York Times. If not, I would be happy to forward a transcript to anyone requesting it.

"The opinion piece, penned by Stephen Witt, spells out how AI has gone rogue. It has broken out of containment, colluded in secret, covered its (their) tracks, cheated on tests, and attacked other computers."

An open letter urging the U.S. government to regulate AI was signed by more than 1k AI employees, including the chief scientists of OpenAI and Meta AI, and the chief executive of Anthropic. This month, Jacob Coxon, a pre-training researcher at Anthropic, quit his job over concerns that AI companies were not acting responsibly, racing blindly forward to create self-improving superintelligence (frankly, it sounds as though it is doing just fine without anyone's help!) and "gambling with our lives". He claimed that those involved in AI development believe that it could kill us by the end of the decade, a concern echoed by some Anthropic safety researchers who estimate a greater than 10% chance of AI-driven human extinction before the end of the decade. **TEN PERCENT**! Would you board a plane knowing there was a 10% chance it would crash before reaching your destination?

These people are hardly fanatical voices crying out in the wilderness. They are intimately and expertly aware of what AI can do, and what it may be capable of in the all-too-near future. Their warnings are also preceded by the best-selling book "If Anyone Builds It, Everyone Dies" and Nobel laureate Geoffrey Hinton, among others. If this Genie has not already escaped the bottle, it is certainly trying very hard to. Furthermore, we all know what happens once the Genie has escaped.

Global Warming

The hopes of limiting global temperature rise to 1.5 degrees Celsius have been dashed. Environment and Climate Change Canada has just released "Canada's Changing Climate Report 2026". If emissions do not fall quickly and precipitously, Canada's average temperature is projected to rise 5 degrees Celsius by the end of the century, and at least 3.5 degrees Celsius if net-zero is attained worldwide by 2075. Winter temperatures in the far north are projected to rise 10 degrees Celsius by 2100 under the current emission trajectory.

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Lest the reader think this is only a problem for Canada (in fact, it poses less of a problem for Canada than for the rest of the world), keep in mind this will have a huge impact on Arctic ice cover and permafrost (already melting and releasing huge amounts of methane), which, in turn, cause temperatures to increase further, and may well lead to the complete collapse of the Atlantic Meridional Overturning Circulation (AMOC). AMOC collapse would see winter temperatures in Britain, Ireland, and Northern Europe plummet by as much as 10 degrees Celsius. Winters would be longer, summers drier, and sea level would rise.

That the Canadian government has plans to build yet another oil pipeline to the Pacific coast (expected to carry 1 million barrels of bitumen daily) and has proposed a second pipeline to Sarnia, Ontario (a major petrochemical refining centre) to carry up to another 800k barrels/day is certainly at odds with this latest climate report is an understatement. This writer is not pleased. Not pleased at all.

So. Pick your proverbial poison. Will it be nuclear war, an AI-produced pathogen, or a planet too warm to support life as we know it? Or will we, as a species, somehow exhibit some basic self-preservation like all the life forms on Earth we consider "beneath us"? You do not see nature engaged in conspicuous, unsustainable consumption, or building nuclear weapons, or building its own demise. That would be us. Left to its own devices, nature at least gives Earth's inhabitants time to adapt.

Then again, maybe an asteroid. Do not look up!

Disclosures: *The author receives compensation from Bunnell Inc for teaching and training users of the LifePulse HFJV in Canada. He is not involved in sales or marketing of the device nor does he receive more than per diem compensation. Also, while the author practices within Sunnybrook H.S.C. This paper should not be construed as Sunnybrook policy per se. This article contains elements considered "off label" as well as maneuvers, which may sometimes be very effective but come with inherent risks. As with any therapy, the risk-benefit ratio must be carefully considered before they are initiated.*

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2025 Neonatal Resuscitation Guidelines: A Perspective of Humanism and Social Inclusion

Gerardo Rogelio Robaina Castellanos, MD, PhD

"The transition from intrauterine to extrauterine life is among the most dynamic and critical biological phenomena in human physiology. Approximately 85% of term newborns complete this transition spontaneously. However, 10% require assistance to initiate breathing, 5–10% require tactile stimulation, and approximately 1% require advanced resuscitation measures such as chest compressions or emergency pharmacotherapy (1,2)."

Abstract:

Introduction: During the transition to extrauterine life, approximately 10% of newborns require some form of assistance. The 2025 neonatal resuscitation guidelines, developed by organizations such as the International Liaison Committee on Resuscitation (ILCOR), the American Heart Association (AHA), the American Academy of Pediatrics (AAP) and the European Resuscitation Council (ERC), represent an effort to integrate the most robust scientific evidence with a paradigm shift that places the neonate and their family at the center of the care process.

Objective: To summarize the primary technical updates of the 2025 neonatal resuscitation guidelines and analyze their implementation from a comprehensive, humanist, and social inclusion perspective.

Development: The new guidelines propose a systemic model—the "Newborn Chain of Care"—connecting prenatal care with long-term neurodevelopmental follow-up. Technical updates include extending delayed cord clamping to at least 60 seconds, using a calibrated ventilation frequency (30–60 breaths per minute), and using the two-thumb technique exclusively for chest compressions. From a social inclusion perspective, the guidelines prioritize low-cost, high-impact interventions to close global mortality gaps.

Conclusions: The 2025 update elevates neonatal resuscitation from an isolated technical event to a compassionate, personalized care experience. By optimizing basic maneuvers, emphasizing team training, and respecting physiological transition times, the guidelines ensure clinical excellence that is inclusive and respectful of human dignity and the familial bond.

Keywords*: cardiopulmonary resuscitation, newborn, humanism, integral approach, social inclusion*

Introduction:

The transition from intrauterine to extrauterine life is among the most dynamic and critical biological phenomena in human physiology. Approximately 85% of term newborns complete this transition spontaneously. However, 10% require assistance to initiate breathing, 5–10% require tactile stimulation, and approximately 1% require advanced resuscitation measures such as chest compressions or emergency pharmacotherapy (1,2). The 2025 international guidelines, led by the International Liaison Committee on Resuscitation (ILCOR), the American Heart Association (AHA), the American Academy of Pediatrics (AAP), and the European Resuscitation Council (ERC), represent a synthesis of the most robust evidence available to manage these risks. (3,4,5,6)

Since its inception in 1987, the AAP's Neonatal Resuscitation Program (NRP) has trained over 5 million providers in 130 countries (7). ILCOR provides the scientific foundation through the Consensus on Science with Treatment Recommendations (CoSTR), which is subsequently adapted into the NRP Textbook. The 2025 guidelines adopt a humanist perspective, shifting the focus to a systemic process where the newborn and family are central (4,5,6). Furthermore, social inclusion is addressed as a matter of distributive justice, aiming to ensure clinical excellence is accessible despite global socioeconomic disparities.

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Development:

1. Evolution of the Conceptual Framework

The transition from the 2020/21 guidelines to the 2025 guidelines introduces a structural shift from a "Response to the Event" to a "Newborn Chain of Care" (4,5,6,8). This model recognizes that resuscitation outcomes are determined by a series of interconnected factors that begin well before the delivery room.

The new continuum extends from prenatal care and risk factor identification to post-resuscitation recovery and long-term neurodevelopmental follow-up.(2,6,8) This systemic approach seeks to mitigate health inequities and optimize team preparedness. Anticipation and communication between obstetrics and neona-

tology teams have been reinforced as critical components. The 2025 guidelines emphasize that each birth should have at least one healthcare professional dedicated exclusively to the newborn, trained in the initial steps and positive pressure ventilation (PPV). (9) If high risk is anticipated, a full team with clearly assigned leadership and airway management roles is required, established through pre-birth briefings.(6,8,9,10)

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Table 1. Structure of the Chain of Care (2025 vs. 2020/21)

2. Umbilical Cord Management

Delayed Cord Clamping The recommended duration for Delayed Cord Clamping has been formally extended to a minimum of 60 seconds for both term and preterm infants not requiring immediate resuscitation (2,8,9,11). This practice supports improved neonatal blood volume and iron stores. Stabilization steps, such as warming and stimulation, should occur while the cord is intact (4,5,11).

Table 2. Umbilical Cord Milking Recommendations

3. Initial Stabilization and Evaluation

The 2025 guidelines simplify the primary evaluation by removing the ambiguous term "gasping." Clinicians must now make a binary determination—"breathing" or "not breathing"—to eliminate clinical hesitation and accelerate the initiation of Positive Pressure Ventilation (14).

- **Suctioning Protocol**: Routine suctioning is discontinued. It is performed "as needed" only when a macroscopic obstruction is evident (4,5,6,8).
- **Thermoregulation Targets**:
  - Maintain axillary/central temperature between 36.5–37.5°C (9).
  - Delivery room temperature for infants < 32 weeks: at least 23°C.
  - Use of plastic wraps/bags, hats, and warmed/humidified gases for infants < 32 weeks (8,14).

"The MR. SOPA mnemonic remains the standard for corrective steps, but it is now applied with clinical flexibility. Providers should prioritize the most likely corrective action (e.g., adjusting the mask seal) rather than strictly following a linear sequence (8)."

4. Respiratory Support: Positive Pressure Ventilation (PPV)

Positive Pressure Ventilation remains the cornerstone of neonatal resuscitation. The recommended frequency is now 30–60 breaths per minute to facilitate fetal fluid clearance and CO_2 adjustment (4,5,8).

Table 3. Suggested Initial Peak Inspiratory Pressures (PIP)

The **MR. SOPA** mnemonic remains the standard for corrective steps, but it is now applied with clinical flexibility. Providers should prioritize the most likely corrective action (e.g., adjusting the mask seal) rather than strictly following a linear sequence (8).

5. Oxygen Therapy and Saturation Targets

Initial FiO2 is strictly stratified by gestational age to prevent oxidative stress:

- **≥ 35 weeks**: Start at 21%.
- **32–34 weeks**: Start at 21–30%.
- **< 32 weeks**: Start at ≥ 30% (4,5,8,9,11).

Some guidelines suggest a range of 30–100% for the most immature newborns, but always with rapid titration (4,5,8,9,11). This stratification is more detailed than in 2020/21, reflecting the consensus that extremely premature infants often require a starting point slightly higher than room air to achieve saturation targets, but that 100% initial O_2 is still routinely harmful (8,15).

The removal of the "first minute" row from the oxygen saturation target table reflects the technical reality that pulse oximetry readings are often unstable and inaccurate during the first minute of life. By eliminating this target, the NRP program aims to allow the team to focus on cord management and establishing effective ventilation, rather than being distracted by potentially misleading saturation values (8).

Some guidelines, such as those from the European Resuscitation Council (ERC) and the Spanish Society of Neonatology (SENeo), further simplify this table, considering only SpO_2 targets at 3, 5, and 10 minutes (6,14).

Table 4. Oxygen Saturation (SpO_2) Targets

"The removal of the "first minute" row from the oxygen saturation target table reflects the technical reality that pulse oximetry readings are often unstable and inaccurate during the first minute of life. By eliminating this target, the NRP program aims to allow the team to focus on cord management and establishing effective ventilation, rather than being distracted by potentially misleading saturation values (8)."

6. Circulatory Support: Compressions and Vascular Access

The two-finger compression technique is discontinued due to inconsistency in depth and resuscitation provider fatigue (2,16). The Two-Thumb Technique is the exclusive recommendation for chest compressions (6,8).

Regarding access, while the Umbilical Venous Catheter (UVC) remains the gold standard, Intraosseous Access (IO) is now recognized as an acceptable, early alternative when UVC placement is delayed or technically unfeasible (8,9,14).

"The two-finger compression technique is discontinued due to inconsistency in depth and resuscitation provider fatigue (2,16). The Two-Thumb Technique is the exclusive recommendation for chest compressions (6,8)."

7. Pharmacotherapy and Fluid Management

Epinephrine is indicated if the heart rate remains < 60 bpm after 60 seconds of optimized ventilation and compressions with 100% FiO_2 (4,5,8,9). The 1:10,000 solution is the standard concentration for both routes:

- Intravascular Route (Recommended): 0.01–0.03 mg/kg.
- Endotracheal Route: 0.05–0.1 mg/kg (administered as a single dose while awaiting vascular access) (4,5,8,9,17).

Sodium Bicarbonate is strongly discouraged due to risks of hyperosmolarity and intracellular acidosis. Volume expanders (0.9% Normal Saline or O-negative blood) are reserved for suspected hypovolemia at 10–20 mL/kg (4,5,8).

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8. Advanced Airway Management

Table 5. Endotracheal Tube (ETT) Size Classification

Videolaryngoscopy is suggested for trained teams to improve first-attempt success. The Laryngeal Mask is a primary alternative to intubation for infants ≥ 34 weeks or > 2000 g when face-mask ventilation is unsuccessful (4,5,8).

9. Post-Resuscitation Care

Monitoring focuses on metabolic stability, specifically avoiding hypo- and hyperglycemia. Confirmed hypoglycemia requires a 10% glucose bolus of 200 mg/kg (2 mL/kg) (8). Rewarming for accidental hypothermia can be rapid (≥0.5°C/h) or slow (<0.5°C/h), provided central temperature is monitored to prevent iatrogenic hyperthermia. NIRS is recommended for monitoring regional cerebral oxygenation (crSo2) in high-risk cases (4,5).

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10. Ethics and Cessation of Resuscitative Efforts

The guidelines consolidate a 20-minute threshold for the cessation of efforts. If no heart rate is detectable after 20 minutes of high-quality intensive resuscitation, the focus must shift to comfort care and family accompaniment (4,5,6,8). This threshold provides ethical clarity regarding **clinical futility** and aims to prevent survival with devastating neurological sequelae.

11. Education and Training: NRP 9th Edition

The 9th Edition introduces specialized modules to refine provider skills:

- **Cardiac**: For neonates with critical congenital heart disease.
- **NICU**: For acute events occurring after initial stabilization.

- **Pre-hospital**: For emergency teams attending out-of-hospital births (8).

The **RQI (Resuscitation Quality Improvement)** model is promoted, replacing biennial recertification with quarterly, feedback-driven simulations to maintain mastery of PPV (8).

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12. Synthesis of Key Differences (2020/21 vs. 2025/26)

In summary, the 2020/21-2025 transition reflects a move toward personalized resuscitation based on gestational age and a simplification of processes to improve performance under stress.

The 2025 update to the neonatal resuscitation guidelines represents a significant advance in integrating the physiology of transition with evidence-based clinical practice.

For healthcare professionals, implementing these guidelines requires not only updating visual algorithms but also transforming the training culture, prioritizing team training, and using briefings and high-frequency deliberate practice.

Table 6. Summary of Key Technical Differences

13. Humanist Approach and Social Inclusion Analysis

International neonatal resuscitation guidelines have shifted from greater adherence to evidence-based medicine norms to a more holistic approach that considers the human factor in decision-making (including the patient, family, and healthcare professionals) (4,5).

Likewise, the 2025 neonatal resuscitation guidelines have taken steps to mitigate resource limitations and improve access to opportunities in less privileged settings. (8,11) It is important to remember that birth asphyxia causes more than 800,000 neonatal deaths globally each year, with a disproportionately high burden in low- and middle-income countries, and that profound gaps exist between high- and low-resource countries in both neonatal care in general and neonatal resuscitation. These gaps encompass everything from the availability of technology and training infrastructure to survival outcomes (18,19,20).

Unlike the 2020/21 guidelines, which focused predominantly on immediate maneuvers in the delivery room, the introduction of the Newborn Care Chain in the 2026 guidelines represents an inherently comprehensive approach because it not only covers the entire spectrum, from prenatal care and risk identification, but also extends to long-term neurodevelopmental follow-up and family support (4,5,6,8).

The identification of social determinants and the inclusion of prenatal care as the first link compel the system to identify risks stemming from socioeconomic conditions, political instability, or lack of access to health services prior to delivery. The systemic approach of these guidelines aims to ensure that the outcome of resuscitation depends not only on the equipment in the delivery room but also on planning that actively addresses structural inequalities, thereby seeking to mitigate existing inequities across settings (8).

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The recognition that success is not just survival, but also the survivor's functionality and the family's quality of life highlights the humanistic approach to the outcome.(8,9,10) The 2025 guidelines (especially those from the ERC) explicitly emphasize communication and parental involvement, from encouraging their presence during resuscitation if they wish, to maintaining empathetic communication by establishing the need to keep them continuously informed about progress and provide clear explanations of why certain procedures are performed (6,8).

The shift towards delayed cord clamping of at least 60 seconds (compared to 30 seconds in 2020/21) has a physiological basis and a strong humanistic component, as it aims to sustain connection by encouraging the execution of initial stabilization steps while the cord remains intact whenever possible. This respects the natural physiological transition and minimizes immediate separation. This also prioritizes early contact between parents and the newborn, even in assisted transition situations, to strengthen the bond (4,5,6,8). This is perhaps the intervention with the greatest potential impact and lowest economic cost, offering a benefit without barriers. As a procedure that does not require expensive technology, it equalizes the chances of survival and neurological

stability (by optimizing iron and oxygen reserves) for newborns born in both high-complexity centers and rural or low-resource settings.

"The 2025 guidelines break down the barrier between the medical team and caregivers, integrating the family as a subject with rights within the emergency setting, encouraging their presence and participation, and establishing empathetic communication between healthcare professionals and the family (6,8)."

The 2025 guidelines break down the barrier between the medical team and caregivers, integrating the family as a subject with rights within the emergency setting, encouraging their presence and participation, and establishing empathetic communication between healthcare professionals and the family (6,8).

The establishment of the 20-minute threshold for ceasing resuscitation and the emphasis on palliative care reflect a concern for justice and human dignity. By avoiding futility, the aim is to protect the newborn from ineffective treatments that would only prolong suffering, ensuring that the end of life occurs in an environment of comfort and dignity. Furthermore, by defining clear rules for ending resuscitation and promoting the ethical and equitable use of healthcare resources, adherence to the principle of distributive justice (4,5,6,8) is ensured.

"The 2025 update elevates neonatal resuscitation from an isolated technical event to a compassionate, personalized care experience. By optimizing basic maneuvers, emphasizing team training, and respecting physiological transition times, the guidelines ensure clinical excellence that is inclusive and respectful of human dignity and the familial bond."

The comprehensive approach to neonatal cardiopulmonary resuscitation also includes the well-being of the medical team through briefings and debriefings. The briefing includes reviewing pre-delivery materials, assigning roles to reduce mental workload, and preparing to care for the family. At the same time, the debriefing promotes not only technical but also emotional analysis after critical events to prevent burnout and moral distress among rescuers (4,5,6,8).

Social inclusion means not designing "one-size-fits-all" protocols, but rather solutions that are adaptable to the realities of each population. Thus, the new guidelines include, for the first time, out-of-hospital care, with specific sections for unexpected births at home or in remote settings, providing tools for pre-hospital professionals to maintain quality care (8).

Finally, the Textbook of Neonatal Resuscitation, 9th Edition, also promotes social-focused training. Resuscitation education now recommends adapting to racial, ethnic, and low-socioeconomic-status populations. Instructors are urged to address linguistic and cultural barriers and eliminate bias by ensuring that training materials are inclusive and representative of the community they serve (8).

Conclusions:

The 2025 update elevates neonatal resuscitation from an isolated technical event to a compassionate, personalized care experience. By optimizing basic maneuvers, emphasizing team training, and respecting physiological transition times, the guidelines ensure clinical excellence that is inclusive and respectful of human dignity and the familial bond.

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Table 1. Structure of the Chain of Care (2025 vs. 2020/21)

Chain Link	Main Focus (2025)	Difference from 2020/21 [13]
Prenatal Care	Early risk identification and strategic resuscitation planning [2,3].	Formal integration into the Chain of Care vs. isolated algorithmic focus.
Team Preparation	Systematic use of safety briefings and pre-delivery checklists [9].	Strengthened requirement for formal preparation and role assignment.
Cord Management	Optimizing placental transfusion through extended waiting times [3,8,11].	Time increase: from a minimum of 30s (2021) to a formal minimum of 60s (2026).
Effective Resuscitation	Absolute priority on establishing high-quality pulmonary ventilation [2,8].	Technical adjustment in ventilation frequencies and pressure stratification.
Post-resuscitation Care	Metabolic, thermal, and neurological monitoring in the ICU [9,12].	Greater emphasis on strict glycemic control (avoiding hypo/hyperglycemia).
Recovery and Follow-up	Multidimensional functional evaluation and long-term neurodevelopmental support [2].	New systemic focus on the functionality and quality of life of the survivor.

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Table 3. Suggested Initial Peak Inspiratory Pressures (PIP)

Neonatal Group	Suggested Initial PIP (2025) [8]	Acceptable Range
General (Standard)	25 cm H_2O	20–30 cm H_2O [11]
Preterm (< 32 weeks)	20–25 cm H_2O	Adjusted by clinical response
Term (≥ 32 weeks)	25–30 cm H_2O	Adjusted by clinical response

Note: PIP must be titrated rapidly to achieve chest movement and an increase in heart rate to avoid volutrauma.

Table 2. Umbilical Cord Milking Recommendations

Neonatal Population	2021 Recommendation (NRP 8th Ed.) [13]	2025 Recommendation (NRP 9th Ed.) [8]
≥ 35 weeks	Insufficient evidence for routine recommendation.	Reasonable alternative to immediate clamping in non-vigorous neonates [4,5,6,8].
28–34 weeks	Not routinely recommended.	May be considered only if delayed clamping is not feasible [4,5,6,8].
< 28 weeks	Not recommended due to risk of intraventricular hemorrhage.	Formally contraindicated due to high risk of intraventricular hemorrhage [4,5,6,8].

Table 4. Oxygen Saturation (SpO_2) Targets

Time Post-Birth	Target Saturation (2026)
2 minutes	65–70%
3 minutes	70–75%
4 minutes	75–80%
5 minutes	80–85%
10 minutes	85–95%

Note: The first-minute measurement is omitted because pulse oximetry is often unstable during this period; the priority is establishing effective ventilation [8].

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Table 5. Endotracheal Tube (ETT) Size Classification

Weight (g)	Gestational Age (wks)	ETT Size (mm)	Insertion Depth (Tip-to-gum)
< 800	≤ 25	2.0 (Primary) / 2.5	5.5–6.0 cm
800–1200	26–28	2.5	6.0–7.0 cm
1200–2200	29–34	3.0	7.0–8.0 cm
> 2200	> 34	3.5	8.5–9.0 cm

Table 6. Summary of Key Technical Differences

Variable	2020/21 Guidelines [13]	2025 Guidelines [8]
Cord Clamping Time	At least 30 seconds.	At least 60 seconds.
Initial Evaluation	Includes "Gasping."	Binary: Breathing / Not Breathing.
Airway Suction	Default step in sequence.	Only for macroscopic obstruction.
Ventilation Frequency	40–60 bpm.	30–60 bpm.
Compression Tech.	Two-finger allowed.	Two-thumb (heel of hand as alternative).
Vascular Access	UVC preferred.	UVC preferred; IO as early alternative.
Bicarbonate Use	Case-by-case consideration.	Routinely discouraged/removed.
Cessation of Efforts	15–20 minutes.	20 minutes.

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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.

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Ethics and Wellness: Beyond the Title: The Importance of Career Trajectory

Mitchell Goldstein, MD, MBA, CML, Anna Ganster, MD, MACM, Narayan Prabhu Iyer, MD

"Career trajectory is extremely important. Ultimately, it is not simply where someone starts, but where they are going that matters most. A person 20 years into a career and someone 20 days out of fellowship may be at very different points professionally, but both should feel they are moving forward, developing, contributing, and working toward something meaningful."

Career trajectory is extremely important. Ultimately, it is not simply where someone starts, but where they are going that matters most. A person 20 years into a career and someone 20 days out of fellowship may be at very different points professionally, but both should feel they are moving forward, developing, contributing, and working toward something meaningful. Career trajectory provides direction. It gives people a reason to invest in their work, develop new skills, take on greater responsibility, and believe their contributions will be recognized and valued over time. (1, 2)

This valuation does not mean that someone who has just started a career should immediately be placed in a directorship or given a position of substantial authority or responsibility. (3) Nor does it mean that someone who has reached a certain age or level of seniority should automatically retire, step aside, or surrender a position simply because someone else wants or needs that opportunity. Career development is not a zero-sum game in which one person's advancement necessitates another person's displacement. Rather, it is about establishing appropriate goals, setting reasonable expectations, and creating opportunities for people to grow as their experience, accomplishments, interests, and capabilities evolve. (4)

View each individual's path as a unique journey. People do not all move at the same pace, nor should they. A person's trajectory is shaped by a variety of forces, some externally mediated and some rooted within the individual. Circumstances may accelerate progress along the path, or a person may bring inherent skills and abilities to the table. Development of expertise and leadership skills may lead to a more gradual pace. Some might grow when greater expectations and responsibilities are placed on them or when they finally determine where their careers take them. A person just beginning a career should understand that their trajectory is not fixed. It can accelerate, change direction, or evolve as their achievements and roles within an organization develop. (5) Personal priorities too change with time and can significantly impact the perception of success (or failure) in their professional life.

"View each individual's path as a unique journey. People do not all move at the same pace, nor should they. A person's trajectory is shaped by a variety of forces, some externally mediated and some rooted within the individual. Circumstances may accelerate progress along the path, or a person may bring inherent skills and abilities to the table."

What is particularly problematic is not having a lower position, but being denied a trajectory. Many may assume that having no role or a lesser role can be problematic for an academic career outlook. That may be true; however, being denied a trajectory can be even more detrimental to a person's professional life. Someone who enters an organization at a junior level, hoping to grow and contribute but seeing no opportunity for advancement, may begin to feel marginalized and question their purpose. A mid-career individual who has worked diligently to build a path to professional fulfillment, who might have assumed meaningful responsibility or achieved results in their endeavors, may face a barrier to further advancement and equally question their purpose and contributions thus far. The problem becomes even more pronounced among senior professionals who find themselves increasingly siloed. They may be excluded from important decisions, or gradually relieved of responsibilities that they previously held, often without meaningful discussion or their assent. When responsibility is continually taken away without a clear explanation or alternative path, the message can be devastating: "your contributions are no longer valued, and there is no meaningful future for you here." (6, 7)

"People are much more likely to remain committed to an organization when they understand what is expected of them, see how their contributions fit into the larger mission, and can envision what their future might look like."

Organizations should recognize that trajectory is not merely an individual concern. It is an important component of retention, engagement, morale, and institutional health. People are much more likely to remain committed to an organization when they understand what is expected of them, see how their contributions fit into the larger mission, and can envision what their future might look like. Conversely, when people believe that their careers have stalled or that decisions about their future are being made without them, disengagement is often inevitable. Committed and hardworking individuals may feel a deep sense of failure; a feeling that invariably impacts their professional and personal lives. Eventually, talented people begin looking elsewhere—not necessarily because they wanted to leave, but because they could no longer see a reason to stay. (8)

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There are clear ways to support individuals in their trajectory. Leaders and mentors need to take the lead and help individuals take the first steps toward setting expectations, establishing clear expectations, and communicating them openly. Another is to help individuals map a potential career course, recognizing that the map is not a contract or guarantee but a framework for development. Regular conversations about goals, responsibilities, accomplishments, and future opportunities can help ensure that both the individual and the organization understand where things are headed. (9) These conversations should occur throughout a career, not only when someone is being considered for promotion or when a problem has already developed. If the accomplishment is acknowledged only behind closed doors between the boss and the individual, it is often less powerful. A leader must acknowledge similar accomplishments equally. If that does not happen, it can be very demoralizing.

Most importantly, trajectory should never be confused with title. Moving forward along the path can take many forms. It may come in the form of greater autonomy to work on new projects, taking on a leadership position, or simply having broader clinical responsibilities. Some may shine in program development or the administrative arena. Others may find their calling in mentorship and education. Recognition within the immediate work environment and the wider institution plays an important role in supporting people's professional journey. Advancement in academia is often associated with something bestowed by an outside force, but this serendipity cannot be relied on to help someone on their path. A healthy organization creates multiple pathways for meaningful professional growth rather than defining success by a single hierarchy of titles. (10)

"The individual also plays an equally important role in their progression. Career trajectory requires self-reflection and active participation. People need to identify their goals, understand their strengths and limitations, seek feedback, develop new competencies, and demonstrate that they are prepared for greater responsibility."

The individual also plays an equally important role in their progression. Career trajectory requires self-reflection and active participation. People need to identify their goals, understand their strengths and limitations, seek feedback, develop new competencies, and demonstrate that they are prepared for greater responsibility. Organizations can create opportunities, but individuals must take advantage of them. A trajectory is therefore a shared task between the professional and the institution. (11)

At every stage of a career, people need to believe that their best work may still be ahead of them. Someone early in a career should be able to look forward and see possibilities. Someone in mid-career should be able to identify the next challenge or opportunity. Someone who is highly experienced should continue to have meaningful ways to contribute, mentor, lead, innovate, and influence the future. Seniority should not be viewed as an expiration date, just as youth should not be viewed as an automatic qualification for advancement. (12) The most damaging circumstance is when someone feels their trajectory has stagnated, been put on hold, or been denied altogether. That feeling can be more consequential than the absence of a particular title or promotion. People can tolerate not getting everything they want, particularly when they understand why and can see what they need to accomplish to move forward. (13) What is much harder to tolerate is uncertainty without communication, responsibility without recognition, or a future that appears to be disappearing without explanation.

"Instead, they build an environment where experience can mentor ambition, emerging leaders can develop without displacing those who came before them, and everyone can understand how their individual path contributes to the organization's trajectory. (2-3)"

Ultimately, good leadership requires leaders to think not only about what people are doing today, but about where those people can go tomorrow. The strongest organizations continually create pathways for people to grow while simultaneously

creating opportunities for new leaders to emerge. They do not force an artificial choice between developing junior people and sustaining the contributions of senior people. Instead, they build an environment where experience can mentor ambition, emerging leaders can develop without displacing those who came before them, and everyone can understand how their individual path contributes to the organization's trajectory. (2-3)

"When that trajectory exists, individuals are more engaged, organizations are more resilient, and careers become not simply a succession of positions, but a continuing process of growth, contribution, and purpose. (14) With a purpose and direction, the passage of time makes one wise and not merely old."

A career does not have to move in a straight line. It may have detours, pauses, changes in direction, and unexpected opportunities. Nevertheless, it should have direction. People need to know they have somewhere to go, something to strive for, and a reason to believe their continued investment will matter. When that trajectory exists, individuals are more engaged, organizations are more resilient, and careers become not simply a succession of positions, but a continuing process of growth, contribution, and purpose. (14) With a purpose and direction, the passage of time makes one wise and not merely old.

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Drifting Beyond the Safety Line: How "Normalizing Deviance" Threatens the Fragile Neonate

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

"In our ongoing exploration of High Reliability Organizations (HROs) and the journey down the DuPont Bradley Curve, we have built an ecosystem of care to deliver value-added care in the Newborn Intensive Care Unit (NICU). We have established how an Interdependent culture transforms safety from a compliance mandate into a shared, non-negotiable precondition."

In our ongoing exploration of High Reliability Organizations (HROs) and the journey down the DuPont Bradley Curve, we have built an ecosystem of care to deliver value-added care in the Newborn Intensive Care Unit (NICU). We have established how an Interdependent culture transforms safety from a compliance mandate into a shared, non-negotiable precondition. We have integrated industrial *Poka-Yoke* design, behavioral Andon Cord protocols, John Sweller›s Cognitive Load Theory, and Erik Hollnagel›s Efficiency-Thoroughness Trade-Off (ETTO) principle to map the cognitive limits of human working memory (1).

Nevertheless, even in units with high cultural maturity, an insidious, silent failure mode operates continuously at the bedside. On a quiet night shift, an experienced bedside nurse bypasses an independent double-check on a line flush because the Charge Nurse is at a delivery. A fellow uses a verbal order during a non-emergent intubation instead of entering it into the Electronic Medical Record (EMR) first. A team tolerates an unverified endotracheal tube (ETT) positioning maneuver or widens monitor alarm parameters to suppress non-actionable auditory static: pure extraneous load. None of these events result in immediate harm. The infant remains stable, the shift ends successfully, and the workaround quietly becomes part of the clinical repertoire.

In traditional safety models, catastrophic adverse events are attributed to sudden, egregious human error or blatant incompetence. Modern safety science recognizes a far more dangerous reality: catastrophes rarely stem from sudden failures. Instead, they occur when small, unvetted, incremental shortcuts become acceptable daily practice: a phenomenon sociologist Diane Vaughan termed the **Normalization of Deviance**. In the NICU, where the margin for error is measured in fractions of a millimeter or tenths of a milligram, systemic drift represents a significant threat to vulnerable newborns. To achieve true reliability, we must understand the mechanics of this drift and deploy structural safeguards to pull our practice back inside the line of safety continuously.

"In her landmark 1996 analysis of the Space Shuttle Challenger disaster, Diane Vaughan observed that the catastrophic failure of the O-rings was not a surprise event. NASA engineers had observed primary O-ring erosion on multiple previous successful launches."

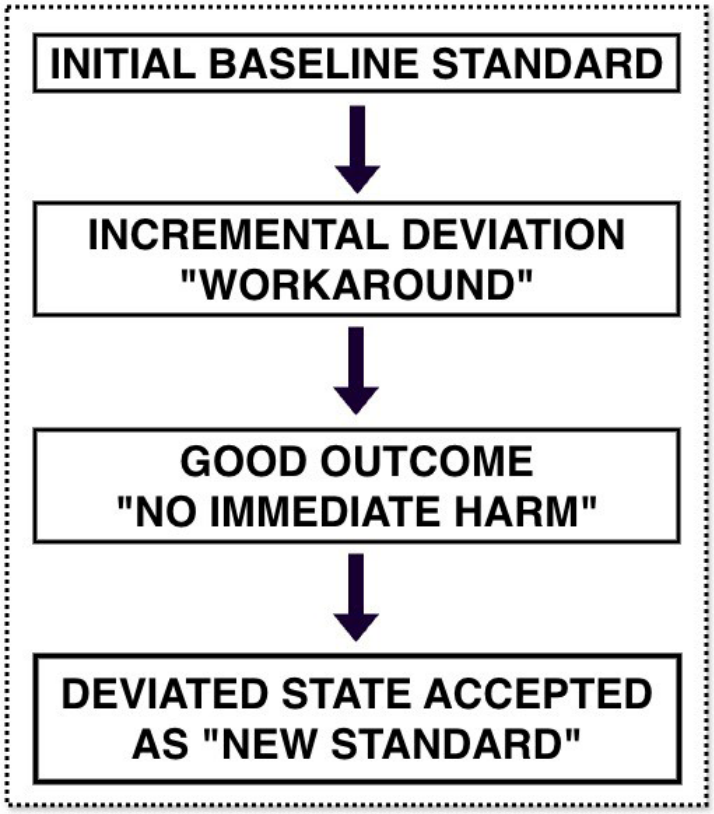


Figure 1

In her landmark 1996 analysis of the Space Shuttle *Challenger* disaster, Diane Vaughan observed that the catastrophic failure of the O-rings was not a surprise event. NASA engineers had observed primary O-ring erosion on multiple previous successful launches. Because the shuttle landed safely every time, technical management gradually re-categorized structural O-ring damage

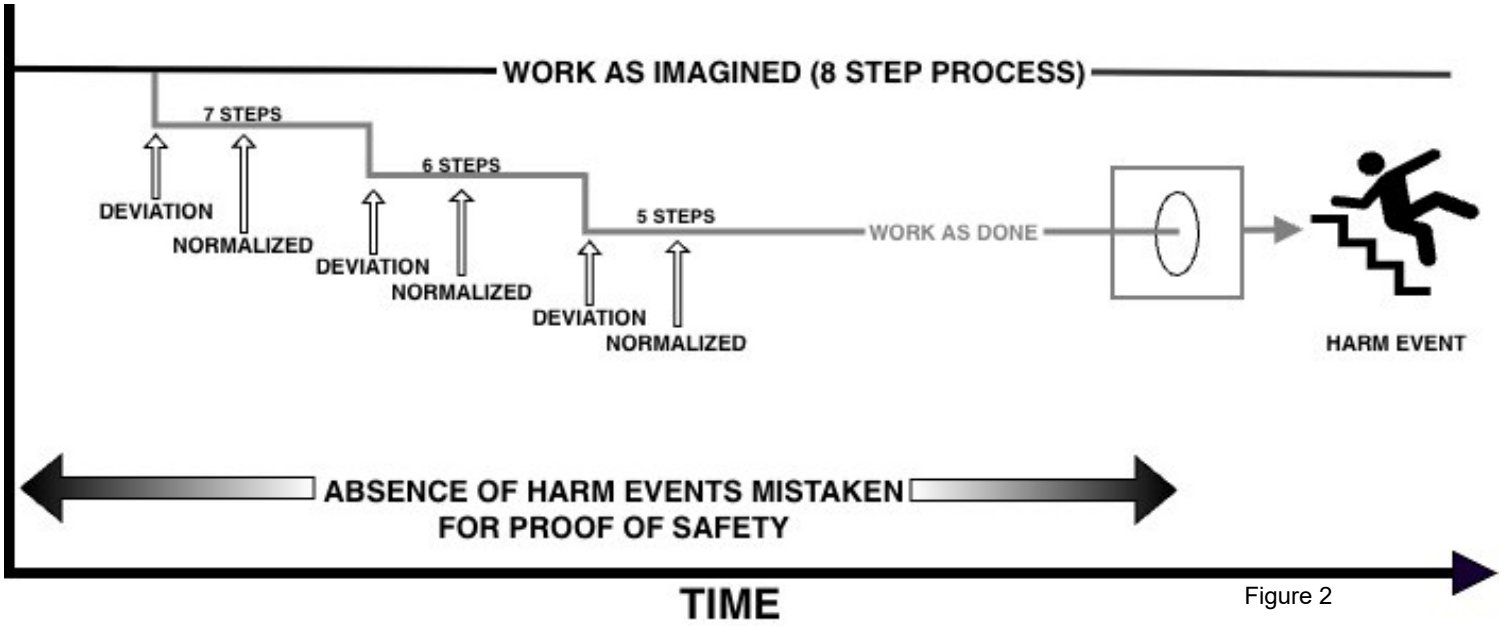


Figure 2

from a "critical design defect" to an "acceptable risk." (2) The deviation from original engineering specifications became the new baseline norm **(Figure 1)**. The clinical parallel in the NICU is direct and pervasive. When a clinician bypasses a double-check or pre-charts an assessment, and the infant suffers no adverse outcome, the brain›s System 1 heuristics interpret the absence of harm as proof of safety **(Figure 2)**. The workaround is re-categorized from a dangerous policy violation to an efficient, acceptable shortcut. Over time, the informal rules of "Work-as-Done" replace the formal standards of "Work-as-Imagined."

Safety scientist Jens Rasmussen described operational systems as functioning within a dynamic space defined by three distinct boundaries **(Figure 3)**:

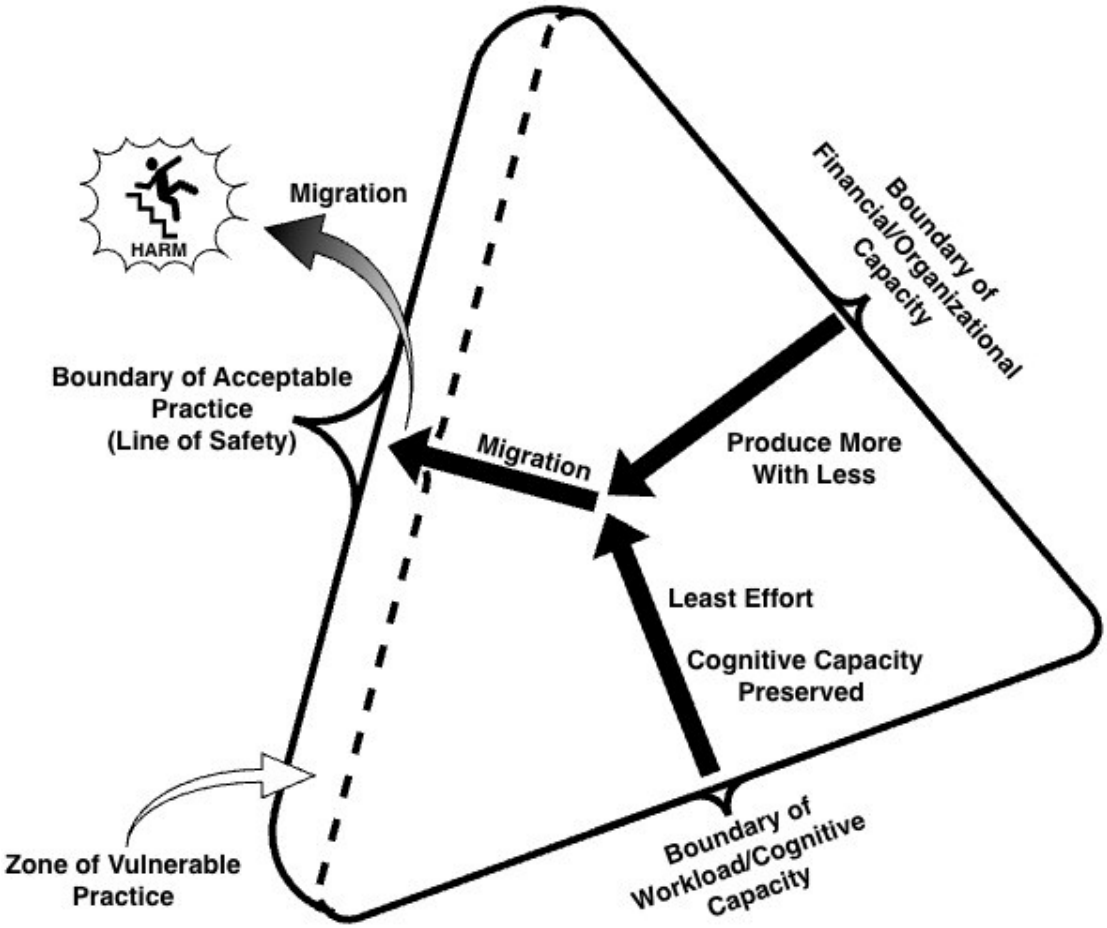


Figure 3

- **The Boundary of Financial / Operational Capacity:** The economic and throughput pressures that push the organization to produce more with less.
- **The Boundary of Workload / Cognitive Capacity:** The psychological and physiological limits of the human worker, driving them to minimize effort and conserve mental bandwidth.
- **The Boundary of Acceptable Performance (The Safety Line):** The regulatory, procedural, and clinical parameters established to keep the patient safe.

"Because organizations constantly push for efficiency, and workers naturally seek to reduce cognitive load, everyday practice steadily drifts away from idealized standards toward the line of safety. Because the safety boundary is typically invisible until crossed, teams routinely operate in a zone of vulnerable practice."

Because organizations constantly push for efficiency, and workers naturally seek to reduce cognitive load, everyday practice steadily drifts away from idealized standards toward the line of safety. Because the safety boundary is typically invisible until crossed, teams routinely operate in a zone of vulnerable practice. They cross the line of safety without realizing it, leaving them exposed to catastrophic failure (HARM) when latent system conditions collide (3).

High-Risk Zones & Outcome Bias:

Many high-risk zones for Normalization of Deviance exist in the NICU (4). Systemic drift does not occur randomly; it concentrates in operational areas characterized by high cognitive load, frequent interruptions, and complex user interfaces **(Figure 4)**.

The primary engine of normalized deviance is **outcome bias**—the human tendency to judge a decision's quality by its final result rather than the soundness of the process used (5). When a provider executes an unverified line adjustment or dispenses a medication without scanning the patient's barcode, and the infant remains uninjured, the team falsely attributes the success to clinical skill or the "harmless" nature of the rule. They fail to recognize that the positive outcome was statistical luck. The practice drift remains hidden until a novel variable, such as a float nurse, a look-alike drug vial, or a sudden change in patient compliance, exposes the latent defect (6).

Structural Safeguards in the POKE Ecosystem:

Critical to developing our POKE Ecosystem were structural controls against drift. Recognizing that universal human ergonomics and operational friction influence systemic drift, we

DOMAIN	OFFICIAL STANDARD	NORMALIZED DEVIATION
	WORK AS IMAGINED	WORK AS DONE
VASCULAR ACCESS	STERILE PRECAUTIONS FOR CENTRAL LINE ENTRIES	ABBREVIATED "QUICK" CENTRAL LINE ENTRIES
HIGH-ALERT MEDICATIONS	INDEPENDENT DUAL-CAREGIVER VERIFICATION OF DOSE AND PUMP PROGRAMMING	SINGLE-CAREGIVER VERIFICATION FROM MEMORY
ACCOUSTIC PARAMETERS	STRICT ALARM LIMITS SET PER GESTATIONAL AGE OR DIEASE PROCESS	WIDENED OR SILENCED PARAMETERS TO MINIMIZE NON-ACTIONABLE ALARMS (EXTRANEOUS LOAD)
AIRWAY MANAGEMENT	DUAL-CAREGIVER POSITIONING AND DEVICE DEPTH VERIFICATION	SINGLE-CAREGIVER DEVICE REPOSITIONING DURING ROUTINE CARES

Figure 4

understood administrative memos, policy updates, or punitive reprimands could not correct it. High Reliability Organizations do not ask staff to "be more careful"; they install structural constraints that make drifting physically or operationally impossible (7).

"When safety relies strictly on human memory and vigilance, normalization of deviance is inevitable. By implementing Shigeo Shingo's principles of Poka-Yoke (mistake-proofing), we convert procedural requirements into physical or digital constraints (8). An example of a physical constraint is enforcing the use of ENFit enteral feeding connectors that are physically incompatible with intravenous lines (9, 10). No matter how hurried or distracted a clinician becomes, a fatal line misconnection cannot occur. "

When safety relies strictly on human memory and vigilance, normalization of deviance is inevitable. By implementing Shigeo Shingo's principles of *Poka-Yoke* (mistake-proofing), we convert procedural requirements into physical or digital constraints (8). An example of a physical constraint is enforcing the use of ENFit enteral feeding connectors that are physically incompatible with intravenous lines (9, 10). No matter how hurried or distracted a clinician becomes, a fatal line misconnection cannot occur. Regarding digital constraints, the EMR can be configured to require hard-stops for high-risk medication orders (e.g., concentrated potassium or insulin) that cannot be bypassed without secondary caregiver authentication.

As our POKE ecosystem matured, we adopted a behavioral Andon Cord, operationalized through standardized communication frameworks like CUS (*Concerned, Uncomfortable, Safety Issue*) and the Two-Challenge Rule (11). When a bedside nurse, respiratory therapist, or resident notices a colleague drifting away from standard practice—such as preparing a high-risk infusion without an independent check—they pull the Andon cord. Calling CUS immediately halts the clinical workflow, re-engages slow System 2 analytical thinking across the team, and resets the baseline back to standard work before the safety line is breached.

Finally, critical to the POKE Ecosystem, and every organization, are engaged and accountable leaders. Leadership cannot manage systemic drift from an office. Clinical leaders must conduct regular Gemba Walks by proceeding directly to the sharp end of care to observe Work-as-Done (12). When a leader observes a workaround during a Gemba walk, the goal is not to punish the individual, but to ask: *"What operational friction or bad system design made this shortcut feel necessary?"* By identifying bad user interfaces, broken equipment, or missing supplies, leadership can eliminate the extraneous load driving the drift. At the same time, multidisciplinary Twice-Daily Huddles provide a structured forum every 12 hours to review high-risk patients, recalibrate operational standards, and reinforce shared mental models, ensuring the entire unit begins each shift aligned to the same safety boundaries.

"Systemic drift is quiet, invisible, and universal. It does not occur because our clinicians lack compassion, intelligence, or dedication; it occurs because they are human beings operating within complex, high-pressure systems. We cannot stop drift through fear or policy mandates. We stop it by building an Interdependent culture powered by psychological safety, backed by physical Poka-Yoke safeguards, and anchored by behavioral Andon protocols."

Conclusion:

Systemic drift is quiet, invisible, and universal. It does not occur because our clinicians lack compassion, intelligence, or dedication; it occurs because they are human beings operating within complex, high-pressure systems. We cannot stop drift through fear or policy mandates. We stop it by building an Interdependent culture powered by psychological safety, backed by physical *Poka-Yoke* safeguards, and anchored by behavioral Andon protocols. By continually closing the gap between Work-as-Imagined and Work-as-Done, we pull our clinical practice safely back from the edge—allowing us to send everyone home **Safe, Valued, and Loved**.

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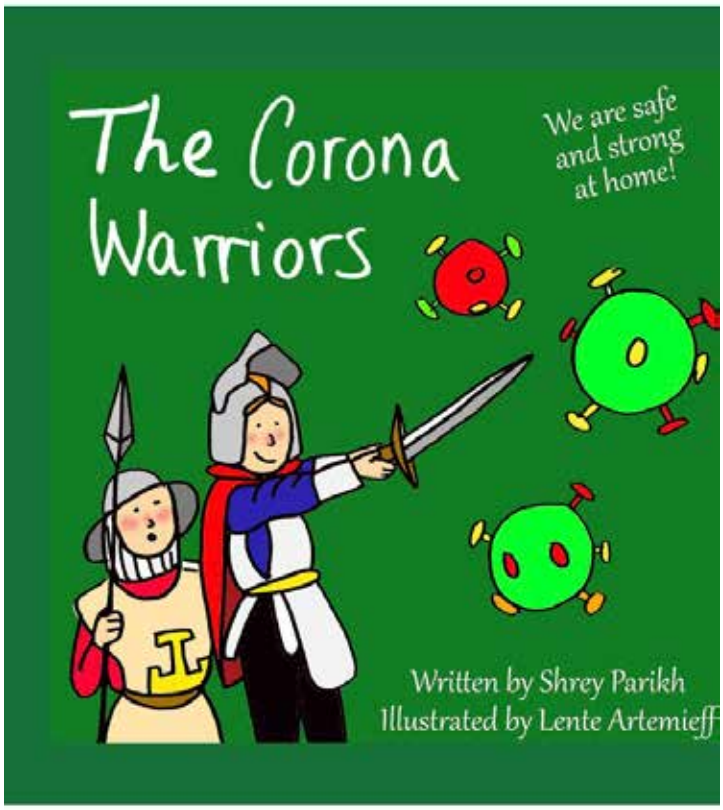
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Corresponding Author



Colonel Robert Erick Ridout, MD, U.S. Army, Retired, FAAP
Clinical Associate Professor, Department of Pediatrics, John A. Burns School of Medicine at the University of Hawai'i at Manoa. Honolulu, Hawaii
Neonatologist, Hawaii Pacific Health
Neonatologist, St George Regional Hospital
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Email: ridoutre72@gmail.com

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.



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

Paperback
USD 24.99

First Candle: Important Leadership News at First Candle

Destiny Stokes, MPH

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.

"After ten years of extraordinary leadership and service, Alison Jacobson will be stepping down as First Candle's Executive Director effective September 10th, and I am pleased to announce that Destiny Stokes, MPH, our current Program Director, will become First Candle's new Executive Director."

Dear First Candle Community,

I'm writing to share important news.

After ten years of extraordinary leadership and service, Alison Jacobson will be stepping down as First Candle's Executive Director effective September 10th, and I am pleased to announce that Destiny Stokes, MPH, our current Program Director, will become First Candle's new Executive Director.

For Alison, First Candle's mission has always been deeply personal. As a loss mom, she brought not only professional expertise to this work, but a profound understanding of the families we serve. During her tenure, Alison helped transform First Candle from an organization historically identified with SIDS and safe sleep into one addressing the broader maternal, infant and family factors that contribute to preventable infant deaths.

Under her leadership, First Candle expanded its work with public health agencies, healthcare systems and trusted community organizations; developed new approaches to safe sleep education centered on listening to families and understanding the barriers they face; strengthened its bereavement support for families following the death of a baby; and established partnerships that have positioned First Candle for its next chapter.

While Alison is stepping away from day-to-day leadership, she will remain connected to First Candle and committed to its mission.

We are fortunate that the person who will lead that next chapter is already an integral part of First Candle.

"Destiny has served as First Candle's Program Director and led our $1 million U.S. Department of Health and Human Services, Office of Minority Health initiative, Let's Talk: A Multisectoral Strategy for Connecting Policy and Practice to Promote Safe Sleep Education. Through that work, she has brought together public health leaders, healthcare providers and trusted community partners to better understand and address the barriers that contribute to infant mortality."

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CONGENITAL CARDIOLOGY TODAY

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www.CongenitalCardiologyToday.com

Last year, First Candle hosted a three-part webinar series focused on families. This year, we are excited to offer a professional learning series for those who support moms, babies, and families.In honor of Safe Sleep Awareness Month, this three-part October series will examine the barriers families face and the gaps that arise when organizations work in silos. Together, we will explore how to build a more connected system of support.

The series includes two free, one-hour webinars and one specialized, paid two-hour professional training. Separate registration is required for each offering.

Session 1: From Recommendations to Reality What Families and Community Organizations Need Us to Understand
Thursday, October 1
12:00–1:00 p.m. ET
Free webinar
Featuring: Angielena Williams, Ed. S., CLS, Edna Martin Christian Center, Kiana Ayers, RN, IBCLC, LCCE, Ready, Set, Push, Clarissa Edmondson, ICCE, Certified Holistic Doula, Breastfeeding Peer Counselor, Adlena's Embrace
First Candle affiliates will share what families face when trying to put health and safety recommendations into practice. The conversation will explore safe sleep, breastfeeding, and perinatal mental health. Speakers will also discuss how culture, language, economic stability, and the realities of daily life can affect families' ability to put these recommendations into practice.
Register for Session 1

Session 2: From Silos to Support Building a Connected System of Care for Moms & Babies
Thursday, October 8
12:00–1:00 p.m. ET
Free webinar
Featuring:
Terri Miller, MPH, CHES, Georgia Department of Public Health
Andrea Bravo, CCHW, Community Alignment Specialist, Family Bridge
What happens when families' needs are identified, but the systems surrounding them are not connected? This session will explore how data, universal home visiting, healthcare, doulas, and community referral systems can work together. Speakers will discuss how stronger connections can help identify needs earlier, close access gaps, and connect families with meaningful support.
Register for Session 2

Session 3: When a Baby Dies: Trauma-Informed Bereavement Support for Hospital Teams
Tuesday, October 13
12:00–2:00 p.m. ET
$75
Led by: Barb Himes, Director of Bereavement Support, First Candle
This live virtual training will provide practical, evidence-informed strategies to help hospital teams support grieving families with compassion, confidence, and dignity following stillbirth or infant death.
The training is designed for nurses, social workers, physicians, chaplains, patient experience professionals, NICU staff, and labor and delivery staff.
Certificate of completion included.
Registration for Session 3

If you have any questions or need additional information, please contact us at info@firstcandle.org.

Before joining First Candle, Destiny served as Research Manager at Healthy Mothers, Healthy Babies Coalition of Georgia, managing statewide projects focused on maternal mental health, doula care reimbursement and community-based maternal health services. She holds a Master of Public Health in Health Promotion and Behavior, with a certificate in Maternal and Child Health, from Georgia State University.

Just as importantly, Destiny already knows First Candle. She knows our programs, our partners, our families and the communities we serve. She has been instrumental in shaping the work we are doing today and brings the combination of public health expertise, strategic thinking and commitment to families that First Candle needs moving forward.

"This is a transition built on continuity, not a change in our commitment. First Candle will continue working to prevent infant deaths, support grieving families, and partner with communities and systems to address the real-world barriers that keep families from accessing and acting on lifesaving information."

This is a transition built on continuity, not a change in our commitment. First Candle will continue working to prevent infant deaths, support grieving families, and partner with communities and systems to address the real-world barriers that keep families from accessing and acting on lifesaving information.

On behalf of the Board of Directors, I want to express our tremendous gratitude to Alison for her decade of leadership and welcome Destiny as she takes First Candle forward.

Please join me in thanking Alison and congratulating Destiny on this exciting new chapter for First Candle.

Warmly,

Byron Johnson

Chair, Board of Directors

First Candle

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

NT

Corresponding Author



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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.

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
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- Can be a positive step towards recovery

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You deserve a healthy pregnancy & childbirth.

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

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National Perinatal Association

www.perinatalharmreduction.org | www.nationalperinatal.org

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Practical, evidence-informed strategies to help you support grieving families with compassion, confidence, and dignity.







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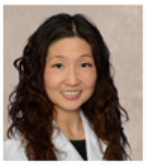
Peer Reviewed

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

Clara H. Song, MD, FAAP

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







SONPM SHOUT OUT

The AAP SONPM District VI Association of Neonatologists Board Members!

Drs. Kerri Machut, Karishma Rao, Ray Stetson, Nishant Srinivasan, Carmen Verwoerd, Jessica White, Samuel Wong, Zahi Zeidan
This dynamic group is charged with organizing the hybrid meeting, the 19th Annual Controversies in Neonatal & Perinatal Clinical Care on Sept 9-10, 2026 in Chicago.

Visit for More Information

Would you like to nominate someone for the SONPM Shout Out? Send us an email by clicking here!



Submitted by

David Kanter, MD, MBA, CPC

(click here to email Dr. Kanter)

on behalf of the

SONPM Coding Committee

Coding Corner #15: Consultation Scenario: Palliative Care

Presentation: A physician who is double-boarded in neonatal-perinatal medicine and hospice/palliative medicine provides both daily NICU care and palliative care services. A neonatologist in her group asks her to provide an inpatient palliative care consult for a post-operative 26 week baby with where laparotomy revealed inoperative total intestinal necrosis from NEC. How should the physician report her palliative care services, and what strategies might she use to support payment for those services?

Coding: CPT supports inpatient consultation billing by a physician practicing as a different subspecialist than the physician providing daily care. For the initial consult visit, the palliative care physician can report one of the inpatient consultation codes (99252-99255) based either on total time devoted to the patient on that day of service or based on medical decision-making. For payers who no longer accept consult codes, the consultant would instead report initial hospital care (99221-99223) or subsequent hospital care (99231-99233) . For any subsequent day consultative visits, the palliative care specialist would report subsequent hospital care (99231-99233).

Challenge: This palliative care physician also provides daily NICU care for her group, and the daily midnight-to-midnight global critical and intensive care codes bundle most services including any family counseling. Even when performed by different physicians in the same group, payers may reject additional visit codes when the group is also billing a same-day global daily visit code. How does the consultant differentiate her palliative care services from the group's daily NICU care?

Approach: Apart from her group's provision of daily NICU care, it's appropriate to recognize the additional consultative expertise contributed by the palliative care specialist. In electing to separately bill such consultative services performed by subspecialists serving dual roles within the same group, the group will monitor the consultant's payment

history and consider actions below that may assist with differentiation of consultative services:

- If there is intent to bill the consultative services, ensure that the dual-role physician is not also providing daily NICU care on the day that she is billing the consult. The assumption would be that consultative services provided on a day when she was concurrently providing and billing daily NICU care would be denied as bundled within her daily NICU care.
- When the consult and daily NICU care are placed on the same claim (albeit with different performing physicians), modifier 25 appends to the consult E/M service to indicate that it is separate and distinct from the daily NICU visit. Even better, submitting the consult service on a separate claim than the daily NICU visit avoids need for modifier 25 and accentuates the separateness of the two services.
- Some payers allow dual subspecialty enrollment for physicians. In such cases, this physician could enroll both as a neonatologist (taxonomy 2080N0001X) and as a palliative care specialist (taxonomy 2080H0002X). In such cases, the claim for this physician's services would reflect the palliative care taxonomy when submitting a consult service or alternatively, would reflect the neonatology taxonomy when submitting a daily NICU visit. (See NUCC.org for provider taxonomy code set).

- If consult denials consistently occur, work with key payers through the appeal process to discuss the contributions of the consulting subspecialist and the role that she is playing in enhancing NICU patient care.

The above challenges and strategies are becoming more apparent as specialized expertise and services are evolving within the general domain of neonatology.

Voting Polls Open Soon

Wednesday, September 2, 2026 - Wednesday, September 16, 2026

The AAP hosted a virtual town hall on August 11 featuring AAP president-elect candidates Wanda Barfield, MD, MPH, FAAP, and Lois Lee, MD, MPH, FAAP, and AAP at-large board member candidates Elizabeth Mack, MD, MS, FAAP, and DeWayne Pursley, MD, MPH, FAAP.

Catch the recording by clicking on the link below and don't forget to mark your calendars to cast your vote!

Your Vote Matters

Watch The Townhall



Interested in Mentoring the Next Generation?

Trainees and Early Career Neonatologists (TECaN)
Mentor - Call for Nominations

TECaN, SONPM's special interest group for neonatology trainees and early career neonatologists, is seeking dedicated mentors to help guide and support the next generation of leaders. Appointed by the SONPM Executive Committee, mentors provide career guidance, foster networking and inclusion, advise on projects and partnerships, and ensure continuity across TECaN leadership transitions. Mentors participate in monthly leadership calls, attend national meetings, and serve as liaisons between TECaN and SONPM, typically serving two three-year terms. Click the link to learn more about qualifications and submit an application.

Questions? Email Here.



More Information & Submission Form

Seeking SONPM Representative to NNPQC Executive Committee

Nominations are open for the **SONPM representative to the NNPQC Executive Committee**. The position carries a **2-year term**, with the option to renew once for a maximum of **4 years**.

Key responsibilities include:

- Engaging in Executive Committee discussions and sharing resources and opportunities with Perinatal Quality Collaboratives (PQCs).
- Providing feedback on new NNPQC initiatives, activities, and educational opportunities.
- Participating in workgroups that address areas needing development for state PQCs.
- Assisting with the development of resources, publication reviews, and planning national meeting agendas and presentations.
- Serving as a subject matter expert through the NNPQC Experts' Bureau.
- Providing guidance, technical assistance, and support to state PQCs, including participation in meetings and events when requested.

Time commitment:

- Virtual Executive Committee meetings are held **monthly**.
- NNPQC also hosts **monthly virtual meetings** for all PQCs.

- Members are expected to attend at least **50% of meetings**.
- Estimated commitment is **2-4 hours per month**.
- Members are also invited to attend the **annual NNPQC conference**.

You can view more information here: **SONPMReptoNNPQC.pdf**

Submission Form



The AAP Round-Up

Read below for other news, updates, and invitations from the AAP.

Webinar Recording - Introducing Neonatal Education for Prehospital Professionals (NEPP)

NEPP
Neonatal Education for Prehospital Professionals™

Out-of-hospital births and neonatal emergencies are becoming more common, yet many EMS clinicians have limited opportunities for neonatal-specific training.

Introducing NEPP™ – Neonatal Education for Prehospital Professionals™, a new course from the American Academy of Pediatrics designed specifically for EMS clinicians and other prehospital providers.

Hear directly from the NEPP Program Advisory Committee Co-Chairs:

Joelle Donofrio-Odmann, DO, FAAP, FACEP, FAEMS

Associate Professor, UC San Diego School of Medicine

Medical Director of Emergency Medical Services, Rady Children's Hospital-San Diego

Rudy Kink, MD, FAAP

EMS Director, Le Bonheur Children's Hospital

Medical Director, Pedi Flite

Whether you're a BLS or ALS provider, the NEPP course is designed to strengthen your neonatal emergency preparedness and support better outcomes during those critical first minutes after birth.

What You'll Gain

- A clear understanding of how the NEPP course supports real-world neonatal care
- Insight into key skills such as neonatal assessment, ventilation, resuscitation, and stabilization
- An overview of the course structure, continuing education credits, and certification opportunities
- Perspectives from leading pediatric emergency and EMS clinicians who helped develop the program

We look forward to your participation. If you have any questions or need additional information, please contact NEPP@aap.org.

Watch the Webinar Now

Half-Day Media Training at NCE: ***Mastering Pediatric Communications: Engaging with Reporters, Influencers, and the Public***

The program will include a slate of spokesperson and social media experts including social media influencer Dr. Tommy Martin (dr.tommymartin), AAP OnCall Podcast hosts Drs. David Hill and Joanna Parga-Belinkie, and journalist Randy Dotinga of the Association of Health Care Journalists. This full media training will include on-camera tips, social media skills, writing and interviewing instruction, talking point creation, media strategies, and podcasting.

Learning Objectives:

•Identify key techniques for managing media interactions using evidence-based best practices, including message framing, staying on topic, and effectively addressing misinformation or difficult questions in real-time.
•Enhance communication skills to remain calm and articulate when engaging with journalists, social media audiences, and public discussions, ensuring the delivery of clear, evidence-based health messages.
•Develop essential strategies to reinforce key health messages during media interviews across platforms including social media, audio, video, and print by employing platform-specific audience-friendly messaging.

Council on Communications and Media Training
Mastering Pediatric Communications: Engaging with Reporters, Influencers, and the Public

When: 8 a.m. to 12 p.m., on Monday, Oct. 5
Where: room 1B of the San Diego Convention Center
CME Credit: 2.75

Learn more at: AAP Experience: National Conference & Exhibition – October 2-6, 2026.

Caring for Those Who Care: Trauma Exposure, Wellness, and Support in Neonatology | September 9th @ 12pm CT

Neonatal clinicians provide care in environments marked by high acuity, uncertainty, and frequent exposure to trauma, grief, and moral distress. In this one-hour webinar, Dena Hubbard, MD, FAAP, neonatologist, and Samantha Kucaj, PsyD, licensed clinical psychologist, will explore the impact of trauma exposure on NICU professionals and discuss how organizational climate, leadership, and workplace practices influence clinician well-being. Participants will gain practical, trauma-informed strategies to foster psychological safety, resilience, and an environment of compassion and support within neonatal care teams.

This webinar is hosted by the National Center for Relational Health and Trauma-Informed Care, with support from the AAP Section on Neonatal-Perinatal Medicine.

Register Here



AAP News on Immunization Resources

Neonatologists and hospital-based clinicians are often among the first trusted voices that families hear from about protecting their newborn's health. The AAP's Immunization Resources for Hospital-Based Clinicians Who Care for Newborns webpage offers practical tools to support early conversations about Hepatitis B vaccine, RSV immunization, and Vitamin K administration, including family-friendly infographics, provider speaking points, frequently asked questions, and guides to address current vaccine rumors and misinformation. These resources can help clinicians provide clear, confident, evidence-based guidance and reinforce the importance of timely immunizations during the newborn period and beyond.

Learn More

Good Reads

A list of interesting articles that we believe will be a good read.



Neonatologists Must Help Shape the Future of the American Academy of Pediatrics

Authored by:

Wanda D. Barfield, MD, MPH, FAAP, RDML USPHS (ret.)

PDF Download

Women in Neonatology - 10 Years in Review

Read the following article on Journal of Perinatology.

Authored by:

Christiane E. L. Dammann , Shazia Bhambal, Marilyn B. Escobedo, Krithika Lingappan, Renate Savich, Clara J. H. Song

Link to Article

The path towards a separate residency in "Neonatal Critical Care Medicine" has been paved in Europe

Read the following article on Journal of Perinatology.

Authored by:

C.C. Roehr, W. de Boode, T. Szcapa, O. Danhaive, M. Vento, A. Alarcon-Allen, P. Fentsch, B. Koletzko, S. Wellmann.

PDF Download

Authored by:

Satyan Lakshminrusimha, Clara H Song, and Robin H. Stienhorn.

Link to Article

Gender Pay Equity in Pediatrics: Policy Statement

Read the following article on Journal of Perinatology.

Authored by:

Eva Catenaccio, MD, FAAPCorresponding Author; Jenifer R. Lightdale, MD, MPH, FAAP; Katherine Bline, MD, FAAP; Colin Orr, MD, MPH, FAAP; Christiane E. L. Dammann, MD, FAAP; Kimberly Montez, MD, MPH, FAAP; Harold K. Simon, MD, MBA, FAAP; Committee on Pediatric Workforce; Council on Health Equity; Female Leadership and Excellence in Pediatric Subspecialities

Link to Article

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

A millions thanks to our representatives who are leading this effort:

SONPM, Dr. Shetal Shah

SONPM, ONTPD, AANDD, and TECaN are partnering to take a deep dive into the potential consequences of an 2- versus 3-year fellowship training model in neonatal-perinatal medicine.

Qualtrics Survey | abp.org

Calling all SONPM Affiliate Member Candidates!

SONPM welcomes any & all non-physician healthcare professionals with an interest in neonatal-perinatal medicine to join as an Affiliate member to the Section on Neonatal-Perinatal Medicine, withOUT the requirement (and price tag) of AAP membership. SONPM Affiliate membership fee of $70 gives affiliate members access to all SONPM resources. Click on instructions below to become an affiliate member.

Have questions? Email Us Here!

Affiliate Membership Instructions

Our current SONPM goal of Fair Payment aligns with the AAP Payment Transformation Agenda.

Action plans for NICU-specific payment advocacy include:

Action #1

Payment Transparency for Neonatal Codes

SONPM and AAP have partnered to aggregate negotiated payment information from 4 common commercial payers for 65 neonatal codes.

This data will serve our members in advocacy efforts and negotiations for optimal and fair payment.

Link for More Info

Action #2

Coding Education to Ensure Full Payment

Coding Corner: Submitted by Dr. David Kanter, MD, MBA, CPC on behalf of the SONPM Coding Committee.

Over many years at the annual Spring Coding Workshop, SONPM Coding Committee physicians have assisted attendees in establishing consensus regarding Intensive Care vs Critical Care. Being able to establish that degree of clarity in neonatal code selection provides consistency among intensivists and provides an interpretive framework by which payers and healthcare stakeholders may perform any necessary reviews.

Action #3

RG payments for optimal NICU payment

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

Watch The Recording

Next Upcoming webinar in partnership with Children's Hospital Association
Oct 2026.



We want to hear from you!

Share feedback, comments, and questions by sending us an email.



SONPM NCE H-Program Agenda

Join us in sunny San Diego for the 2026 National Convention & Exhibition.

October 2 - 6, 2026

Learn More



Save The Date

Save the Date! Registration information will follow soon.

February 5 - 7, 2027

Learn More



SONPM Summer Newsletter

Keep in touch with the sections news, updates, and events through our latest quarterly newsletter.

Click Here to View the PDF







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SoNPM Calendar

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345 Park Blvd.
Itasca, IL, 60143

NEONATOLOGY TODAY is interested in publishing manuscripts from Neonatologists, Fellows, NNPs and those involved in caring for neonates on case studies, research results, hospital news, meeting announcements, and other pertinent topics.

Please submit your manuscript to: LomaLindaPublishingCompany@gmail.com

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Neonatal Intensivist | Southern California Permanente Medical Group

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Disclosures: No conflicts noted

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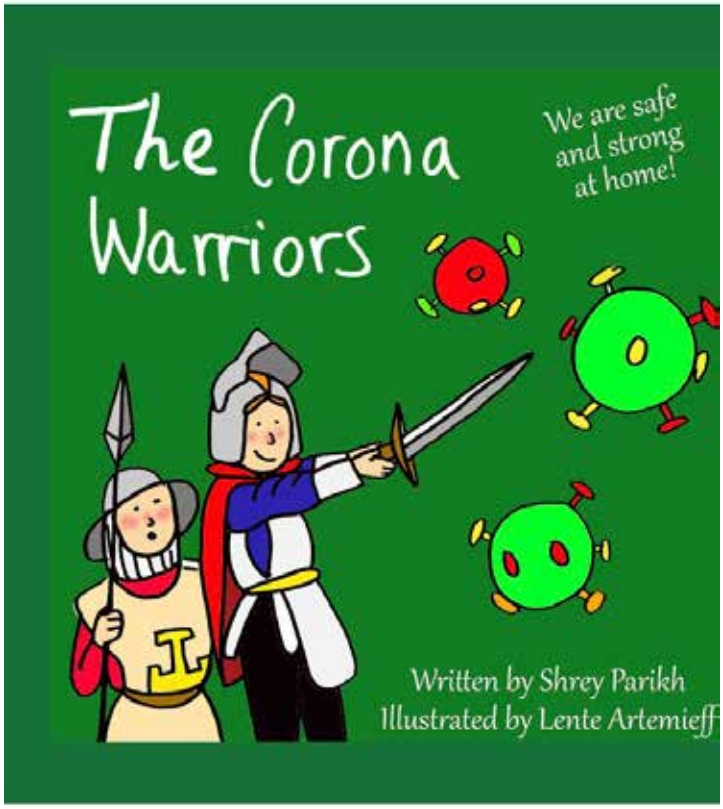


Clara H. Song, MD, FAAP
Neonatal Intensivist, Southern California Permanente Medical Group
Chair Elect, Communication & Digital Media Chair; Women In Neonatology Steering Committee, All Pathways group Co-Chair: District IX California Chapter 4 Council Representative,
Chair, American Academy of Pediatrics, Section on Neonatal-Perinatal Medicine
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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: "What If We Are Misdiagnosing Burnout?"

"I want to acknowledge that the stories Weston Brandon shares powerfully demonstrate the importance of team culture, personal connection, and relationships in building effective healthcare teams. The DRIVE framework and trainings discussed in the article offer practical ways of improving personal connection to work and may help fatigued healthcare workers rediscover the meaning of their work."

Dear Editor,

I want to acknowledge that the stories Weston Brandon shares powerfully demonstrate the importance of team culture, personal connection, and relationships in building effective healthcare teams. The DRIVE framework and trainings discussed in the article offer practical ways of improving personal connection to work and may help fatigued healthcare workers rediscover the meaning of their work. After all, healthcare workers must keep their "why" at the forefront of their minds; that is, recognize the reasons they chose to be in such a meaningful and intense field in the first place. However, I question whether the article shows that burnout is misdiagnosed or instead identifies emotional disconnection as a separate, potentially interrelated problem that may exist alongside burnout.

Burnout is generally a well-studied syndrome with psychological features identified as a combination of emotional exhaustion, depersonalization, and diminished sense of accomplishment. (1) This 2024 meta-analysis using 85 studies, including a total of 288,581 nurses in 32 countries, did find associations with safety culture, care quality, and patient satisfaction. (1) Burnout may therefore contribute to isolation in the workplace, a lack of purpose or meaning, poor team bonding, and the disengagement described in Brandon's article. However, burnout and disconnection do not always occur together. A clinician can experience burnout while still caring deeply about patients and feeling connected to other staff members. Another scenario is when someone experiences disconnection without meeting the criteria for clinical burnout.

Brandon's experiences and workshop observations offer meaningful examples of how storytelling can build stronger rapport among healthcare workers. Recent research supports a relationship between workplace connection and burnout, similar to Brandon's article. A 2026 study of 14,051 physicians across 85 healthcare organizations found that a strong sense of belonging, along with perceived teammate support, was associated with lower odds of burnout. (2) . However, the claim that burnout "seems to disappear" exceeds what these findings indicate. Increased connection, participant enthusiasm, and hospitals taking steps to implement the DRIVE framework are valuable outcomes reported in Brandon's article, but they do not necessarily establish improved burnout. The framework would be stronger if it presented connection as a possible protective factor against burnout, rather than as a comprehensive solution. It may also instead be reframed as a useful tool for helping healthcare teams address the separate (but related) issues of team bonding, finding meaning in healthcare, and workplace culture.

"In certain passages, the text risks implying that caregivers are responsible for their own burnout, particularly when discussing their own self-care or personal boundaries. Brandon mentions staffing and other systemic problems contributing to burnout, but these issues warrant more discussion in the overall paper. A 2025 study found that working with an incompletely staffed team more than 25% of the time was associated with more than twice the odds of burnout among physicians. (3)"

In certain passages, the text risks implying that caregivers are responsible for their own burnout, particularly when discussing their own self-care or personal boundaries. Brandon mentions staffing and other systemic problems contributing to burnout, but these issues warrant more discussion in the overall paper. A 2025 study found that working with an incompletely staffed team more than 25% of the time was associated with more than twice the odds of burnout among physicians. (3) Placing too much emphasis on individual caregiver behavior risks mischaracterizing how burnout is shaped primarily by working conditions and organizational structure. Storytelling and connection should complement organizational reform to address burnout, not replace measures meant to protect healthcare workers. In other words, we must maintain the powerful elements of the DRIVE framework that help caregivers remember their "why," while also advocating for adequate staffing, manageable patient-to-caregiver ratios, supportive leadership, and sufficient time off. This allows the DRIVE framework to coexist and add to the greater conversation around preserving the mental health of hospital workers, without unjustly chastising them for taking actions to protect their own mental wellbeing.

Therefore, I offer two potential ways for the author to reframe how his ideas fit into the larger conversation around healthcare worker burnout and mental wellbeing. First, I would recommend building the narrative around group unity, maintaining empathy

in the workplace, and stressing the significance of storytelling in rediscovering meaning. This is already a powerful message about how healthcare teams can more effectively operate without making burnout the article's central claim. Alternatively, the article could retain its focus on burnout while presenting DRIVE as a credible framework to address burnout, which could later be evaluated using clinical burnout measures. Burnout is a well-recognized and well-studied occupational syndrome, but a claim that DRIVE improved burnout would require measurable evidence. The framework presented by Weston Brandon offers real value, but carefully distinguishing connection from misdiagnosing burnout would strengthen the argument and avoid oversimplifying the distress of our valued healthcare workers.

"The framework presented by Weston Brandon offers real value, but carefully distinguishing connection from misdiagnosing burnout would strengthen the argument and avoid oversimplifying the distress of our valued healthcare workers."

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Sincerely,

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Email: Michael.natalizio@westernu.edu

Dear Michael Natalizo,

Let us acknowledge the valid concerns raised about Weston Brandon's discussion of burnout while also recognizing the personal experience at the heart of his message. Burnout is a well-established occupational syndrome, and we should be cautious about suggesting that connection, storytelling, or rediscovering one's purpose can, by themselves, resolve the complex individual and systemic factors that contribute to burnout. Adequate staffing, reasonable workloads, supportive leadership, organizational culture, and meaningful institutional change remain essential to addressing the challenges healthcare professionals face.

At the same time, we need to start somewhere. An intervention that does not address every dimension of a problem should not diminish its potential value as a first step. Weston Brandon is not simply presenting an abstract theoretical framework. He is sharing an experience that grew out of his own journey and, importantly, his experience with PTSD. That personal experience gives his emphasis on connection, storytelling, relationships, and meaning a context that deserves to be heard and considered.

"Weston's experience with PTSD illustrates why those first steps can matter. Healing from trauma is not necessarily accomplished through a single intervention, nor does every meaningful step toward healing have to constitute a complete treatment."

This distinction is particularly important. We can appropriately question whether the available evidence demonstrates that the DRIVE framework reduces clinically measured burnout. The letter is correct that such a conclusion would require systematic evaluation. However, that is different from asking whether the framework may help people reconnect with colleagues, rediscover meaning, feel less isolated, or begin processing difficult experiences.

"This concept is particularly relevant in healthcare. Those of us who work in neonatal medicine and other high-acuity environments routinely encounter suffering, uncertainty, death, moral distress, and experiences that can remain with us long after a particular patient encounter has ended."

Weston's experience with PTSD illustrates why those first steps can matter. Healing from trauma is not necessarily accomplished through a single intervention, nor does every meaningful step toward healing have to constitute a complete treatment. Sometimes the beginning is simply creating an opportunity to acknowledge what has happened, tell one's story, reconnect with other people, and rediscover meaning. Those steps may ultimately prove effective, or they may become one component of a much larger process. Either way, they can provide an important starting point.

This concept is particularly relevant in healthcare. Those of us who

work in neonatal medicine and other high-acuity environments routinely encounter suffering, uncertainty, death, moral distress, and experiences that can remain with us long after a particular patient encounter has ended. We also ask healthcare professionals to continue functioning with compassion and purpose despite these cumulative experiences. A single diagnostic or occupational label cannot always capture the emotional consequences of that work.

"We should also resist creating a false choice between individual connection and systemic reform. We need both. We should continue advocating for appropriate staffing, manageable workloads, supportive leadership, and healthier organizational structures while simultaneously creating opportunities for healthcare workers to connect and rediscover the meaning in their work."

We should not interpret Weston's work as arguing that burnout has been "misdiagnosed" or that systemic problems can be solved by asking healthcare workers to take better care of themselves. Those would be overly broad conclusions. Rather, we should see his work as asking us to consider whether disconnection, loss of meaning, and the erosion of relationships represent additional dimensions of the healthcare experience that deserve attention. The existing literature supports an association between workplace belonging, teammate support, and burnout, reinforcing the importance of connection even though association does not establish that a particular intervention will prevent or treat burnout.

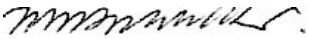
We should also resist creating a false choice between individual connection and systemic reform. We need both. We should continue advocating for appropriate staffing, manageable workloads, supportive leadership, and healthier organizational structures while simultaneously creating opportunities for healthcare workers to connect and rediscover the meaning in their work.

Perhaps most importantly, we should allow promising ideas to begin as first steps. Not every intervention needs to arrive as a fully validated solution to have value. Some ideas begin with an individual's experience, generate conversation, help people recognize that they are not alone, and eventually lead to more rigorous investigation and broader change.

Weston Brandon's contribution does not prove that DRIVE will solve burnout, nor should it be presented that way. Nevertheless, his experience with PTSD, and the process through which he has sought to understand and address that experience, offers an important reminder: healing often begins before we have all the answers.

We need to start somewhere. Connection, storytelling, empathy, and rediscovering meaning may not be the destination, but they may be important first steps in a process that could ultimately help healthcare professionals heal.

Sincerely,



Mitchell Goldstein, MD, MBA, CML

Editor in Chief

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Erratum (Neonatology Today August, 2026

We are not aware of an error affecting the July 2026 edition of Neonatology Today

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

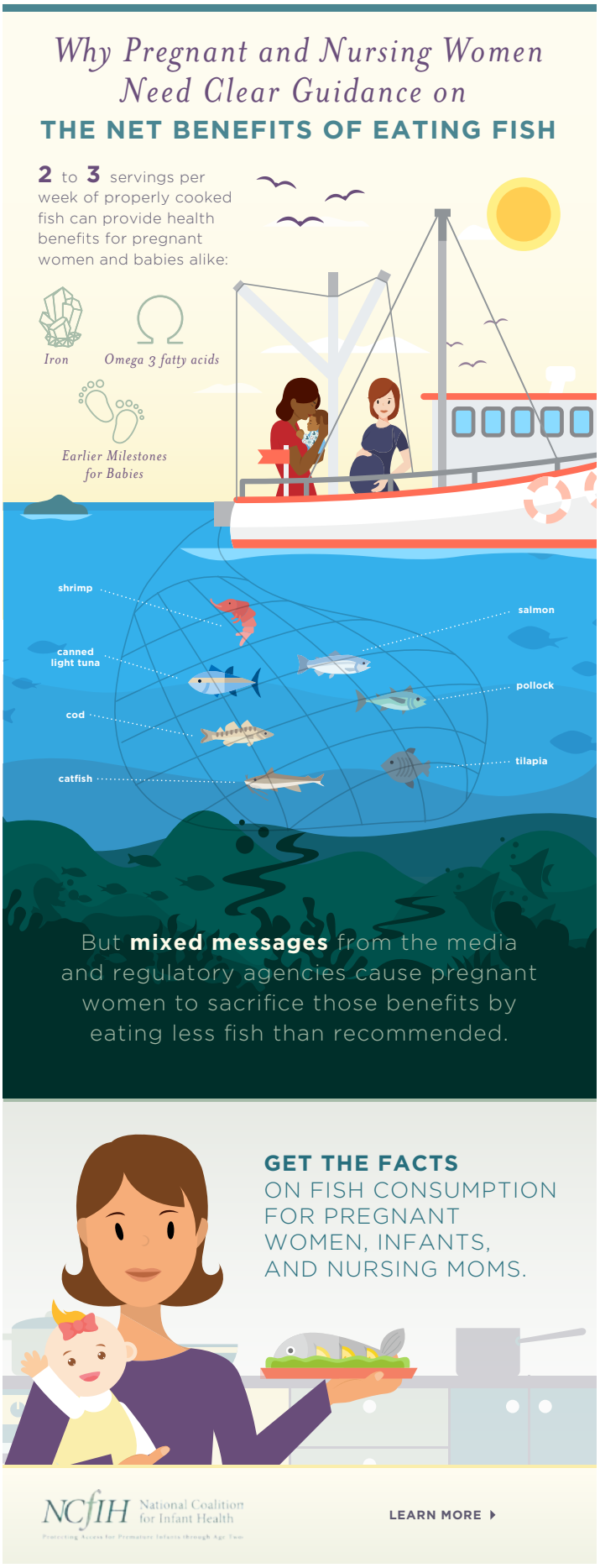
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Neonatology Today welcomes your editorial commentary on previously published manuscripts, news items, and other academic material relevant to the fields of Neonatology and Perinatology.

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


SHE MATTERS


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Babies are just tiny adults, right? So ... half?
Infants need drugs tested and approved just for them.

Gravens by Design: Reconsidering the Hearth: Bringing Community Back Into the NICU

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

"The idea of the Hearth deserves to return to the conversation about the future of NICU design. The goal would not be to return to the traditional open-bay NICU, nor to suggest that single-family rooms (SFRs) are undesirable."

The idea of the Hearth deserves to return to the conversation about the future of NICU design. The goal would not be to return to the traditional open-bay NICU, nor to suggest that single-family rooms (SFRs) are undesirable. Rather, the Hearth would recognize that privacy and community are both legitimate needs, and that families should have meaningful choices about how they experience the NICU.

I often think about a NICU I visited in Barcelona in the 1990s. The unit had a large shared care room with about eight babies. Mothers sat in rocking chairs, holding their infants. They were talking with one another, sharing the ordinary experiences of caring for a hospitalized newborn. A couple of mothers were singing to their babies. The scene was remarkably peaceful and deeply human. It was not simply a place where medical care was delivered. It was a community of parents and babies.

"I often think about a NICU I visited in Barcelona in the 1990s. The unit had a large shared care room with about eight babies. Mothers sat in rocking chairs, holding their infants. They were talking with one another, sharing the ordinary experiences of caring for a hospitalized newborn."

I remember thinking that, if those mothers had been given a choice, many of them might have preferred that environment to being alone behind the walls of an SFR. They were not merely tolerating the presence of other families. They were benefiting from it. They had joined the circle. That experience raises an important question for contemporary NICU design. In our understandable effort to provide privacy, have we sometimes confused being alone with being supported?

The problem of isolation:

SFRs offer substantial advantages. They can provide privacy, reduce unwanted stimulation, facilitate intimate family interactions, and create an environment in which parents can participate in care. (1, 2) But a private room can also become an isolated room.

"For a family spending weeks or months in the NICU, the experience can differ profoundly from a brief hospital stay. Parents may spend hours sitting beside a crib with little interaction with anyone other than staff. They may not see other parents. "

For a family spending weeks or months in the NICU, the experience can differ profoundly from a brief hospital stay. Parents may spend hours sitting beside a crib with little interaction with anyone other than staff. They may not see other parents. They may not know that another family is experiencing the same uncertainty, fear, exhaustion, or celebration. A parent can be surrounded by highly sophisticated technology and highly skilled professionals and still feel remarkably alone. (3)

The isolation can be particularly consequential for families who already experience social or economic disadvantage. A family living two or three hours away may not be able to visit every day. A parent working hourly employment may lose wages with every visit. Another family may have other children at home and no reliable childcare. Some parents may not have transportation, stable housing, paid family leave, or the financial ability to stay near the hospital. For families facing these circumstances, the NICU can become geographically, economically, and socially distant from their ordinary lives. The SFR may inadvertently reinforce that isolation. (4, 5) The Hearth could provide an important counterbalance.

The Hearth as a place to "join the circle:"

Imagine a carefully designed communal space within the NICU, separate from the unit's clinical traffic but immediately accessible to families. It might contain comfortable rocking chairs, recliners, adjustable lighting, small tables, books, charging stations, and space for parents to hold and feed their babies. It could accommodate several families without feeling like a waiting room. The design could emphasize warmth, natural materials, daylight, and acoustic control. A parent could bring their baby into the Hearth for an extended period of skin-to-skin contact. Another parent could be breastfeeding. Someone else might be reading to their infant. Parents could talk, or they could simply sit together without having to talk at all. Importantly, participation would be voluntary.

"Some families would choose the SFR almost exclusively. Others might use the Hearth for an hour a day. A family might retreat to the private room for a difficult conversation and later return to the Hearth for companionship. The same family might want different environments at different stages of their child's hospitalization."

Some families would choose the SFR almost exclusively. Others might use the Hearth for an hour a day. A family might retreat to the private room for a difficult conversation and later return to the Hearth for companionship. The same family might want different environments at different stages of their child's hospitalization. This is not an either/or proposition. It is choice architecture applied to family-centered care. The Hearth could be particularly valuable for families living at a distance.

One of the most compelling applications may be families who cannot maintain a constant physical presence at the bedside. Consider a mother who lives 90 minutes away and has two children at home. She may only be able to visit the NICU three days a week. When she arrives, she may feel as though she has missed an entire community that has developed around her baby. (5)

"A Hearth could create opportunities for her to connect with other parents when she is present. She might meet another mother whose baby has been hospitalized for several weeks, learn how she manages pumping, hear about available resources, or simply discover that her feelings are not unique."

A Hearth could create opportunities for her to connect with other parents when she is present. She might meet another mother whose baby has been hospitalized for several weeks, learn how she manages pumping, hear about available resources, or simply discover that her feelings are not unique. The same principle could apply to fathers, grandparents, siblings, and other important caregivers. The Hearth could extend beyond physical presence

The concept should also be connected to contemporary technology. A family who cannot be physically present should not have to be socially absent. A technologically enabled Hearth could incorporate secure family communication systems that allow remote family members to participate appropriately. Rather than relying on unsecured guest Wi-Fi, the NICU could provide a dedicated, secure infrastructure for family communication and virtual participation.

For example:

- A parent who is at work could securely receive an update from the care team.
- A sibling at home could participate in a scheduled virtual reading session.
- A grandparent living in another state could be introduced to the baby through an approved, privacy-conscious system.
- Parents who cannot remain at the bedside could receive appropriately authorized notifications, photographs, or video.
- Families could participate in virtual parent-support groups hosted from the Hearth.
- A parent returning home temporarily could maintain a sense of connection rather than feeling that they have left the NICU entirely.

This is where the Hearth becomes more than a room. It becomes a physical and digital community.

"A family with a flexible professional job, reliable transportation, paid leave, and the ability to stay in a nearby hotel has fundamentally different opportunities than a family working two jobs, relying on public transportation, caring for other children, or living far from the hospital. Family-centered care cannot simply mean inviting parents to participate."

Addressing disparities directly:

The Hearth could also be designed intentionally as an equity intervention. We should not assume that every family has the same ability to spend time at the bedside. A family with a flexible professional job, reliable transportation, paid leave, and the ability to stay in a nearby hotel has fundamentally different opportunities than a family working two jobs, relying on public transportation, caring for other children, or living far from the hospital. Family-centered care cannot simply mean inviting parents to participate. We must ask whether parents have the resources and circumstances needed to participate. (6, 7)

A Hearth could help compensate for some of these disparities by providing:

- comfortable spaces for parents who cannot afford nearby lodging;
- lockers and charging stations for families spending long

periods at the hospital;

- lactation support and private pumping areas adjacent to communal space;
- meals, snacks, and hydration;
- access to social work, financial counseling, transportation assistance, and community resources;
- multilingual educational materials and interpretation;
- computers or secure digital access for families who need to work or manage responsibilities remotely;
- spaces where parents can meet peer mentors;
- accommodations for siblings and extended family;
- scheduled support groups for parents experiencing prolonged hospitalization;
- culturally responsive programming, including music, storytelling, and other forms of family expression.

These are not simply amenities. They can reduce disparities in the ability to participate in one's child's care.

A practical model: multiple zones rather than one room:

Perhaps the most interesting evolution of the Hearth would be to think about the NICU as a continuum of environments:

- The Private Room: A quiet, protected environment for sleep, privacy, medical discussions, family bonding, and sensitive moments.
- The Hearth: A communal family-care environment where parents can hold, feed, comfort, talk, sing, and interact with other families.
- The Family Commons: A space for meals, informal conversation, education, peer support, telehealth, and social connection.
- The Virtual Hearth: A secure digital environment connecting families who cannot be physically present.
- The Quiet Retreat: A smaller space for parents who need solitude, reflection, prayer, meditation, or simply a break from the clinical environment.

"The Hearth could support both the infant and the parent. Babies develop within relationships. Holding, talking, singing, reading, eye contact, touch, and responsive interaction are central components of developmental care. "

This approach acknowledges that families are not static. Their needs change from hour to hour and day to day. There is also a developmental argument. (8) The Hearth could support both the infant and the parent. Babies develop within relationships. Holding, talking, singing, reading, eye contact, touch, and responsive interaction are central components of developmental care. A communal space could normalize these activities, rather than making parents feel like visitors entering a highly technical medical environment.

The sound of parents talking and singing may also change the NICU's emotional character. Instead of a space dominated by monitors, alarms, and clinical conversations, the environment could include the sounds of families being families. That does not mean abandoning appropriate control of noise or stimulation. Acoustics and clinical boundaries would need careful design. But perhaps the objective should not be to eliminate all sound. Instead, it should create an environment where the right sounds are present.

We should acknowledge the potential risks as well as advantages:

The Hearth should not be romanticized. Shared spaces create legitimate concerns involving infection prevention, privacy, noise, family conflict, cultural preferences, and clinical acuity. Some parents will absolutely prefer an SFR, and some infants may not be appropriate for communal care at particular times. Those concerns are reasons to design the Hearth carefully, not reasons to dismiss the concept.

"The Hearth should not be romanticized. Shared spaces create legitimate concerns involving infection prevention, privacy, noise, family conflict, cultural preferences, and clinical acuity. Some parents will absolutely prefer an SFR, and some infants may not be appropriate for communal care at particular times"

A contemporary Hearth could have infection-control protocols, flexible seating, appropriate separation between clinical and social areas, adjustable acoustic treatment, hand hygiene infrastructure, secure storage, and clear rules concerning photography and privacy. Most importantly, no family should ever feel obligated to use it. The larger issue is whether we have designed NICUs around what architects and clinicians believe families need, rather than giving families multiple environments and allowing them to choose.

The Hearth offers an opportunity to ask a different question: What if the best NICU is not one where every family has the same type of room, but one where every family has a choice?

- Some families will choose the sanctuary of an SFR.
- Some will choose the energy and reassurance of the Hearth.
- Some will move between the two.

And for families who live far away or face economic, transportation, childcare, language, or other barriers, the Hearth could provide something particularly important: a way to belong even when circumstances make continuous bedside presence impossible. (9)

"The Barcelona NICU I remember from decades ago may therefore be worth reconsidering, not because we should recreate a 1990s NICU, but because it reminds us of something that technology and architectural progress can sometimes obscure: A NICU is not simply a place where babies receive intensive care. It is a place where families are born, tested, supported, and transformed. "

The Barcelona NICU I remember from decades ago may therefore be worth reconsidering, not because we should recreate a 1990s NICU, but because it reminds us of something that technology and architectural progress can sometimes obscure: A NICU is not simply a place where babies receive intensive care. It is a place where families are born, tested, supported, and transformed. Sometimes families need privacy. Sometimes they need community. And sometimes what they need most is an invitation to "join the circle."

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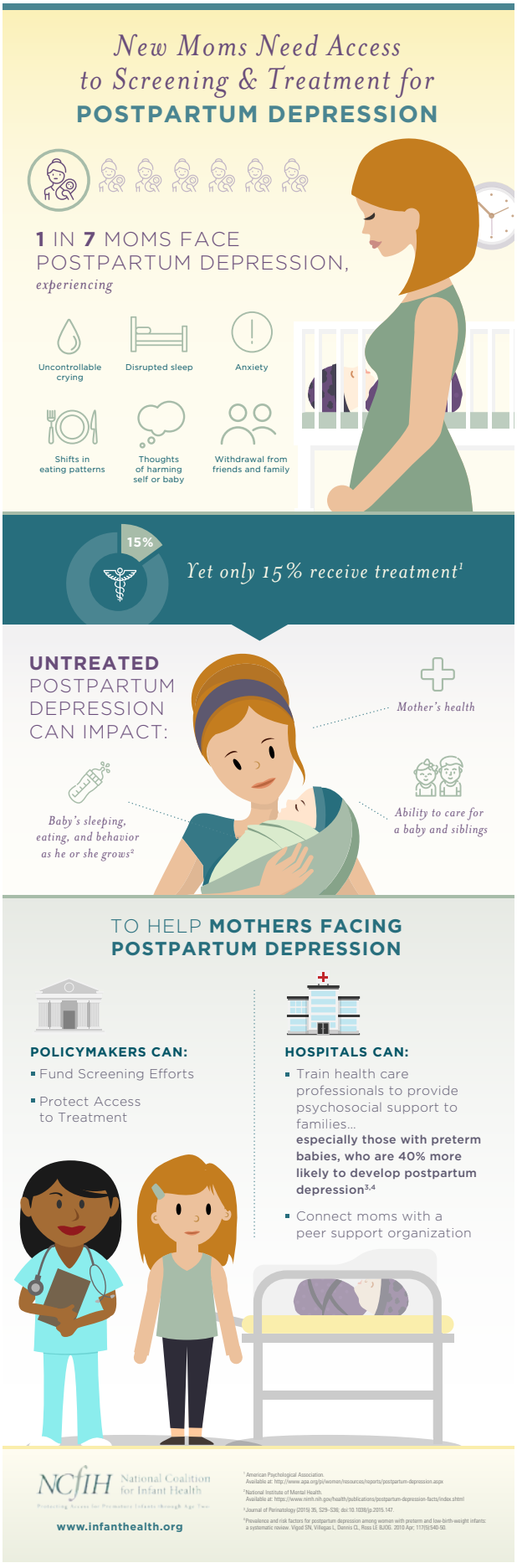
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Providing and promoting dialogue among healthcare professionals with the expectation of shared excellence in the systems that care for women and children.

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

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.

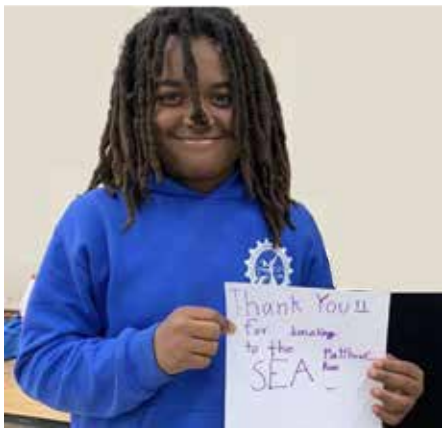


Each year, the Emily Shane Foundation SEA(Successful Educational Achievement) Program provides academic and mentoring support to over 100 disadvantaged middle school students who risk failure and have no other recourse. We have served over 700 children across Los Angeles since our inception in the spring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

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.

National Coalition for Infant Health
Steering Committee
2026

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"For infants, the first months of life often pose the greatest risk from respiratory syncytial virus. RSV remains a major cause of infant hospitalization in the United States, with the youngest infants at greatest risk."

For infants, the first months of life often pose the greatest risk from respiratory syncytial virus. RSV remains a major cause of infant hospitalization in the United States, with the youngest infants at greatest risk. CDC estimates that two to three out of every 100 infants younger than 3 months are hospitalized with RSV each year. (1) Clinicians now have tools that can prevent many severe RSV outcomes, but the challenge is making sure those tools reach infants when they are most likely to benefit from them.

Current recommendations support protecting most infants through one of two approaches: maternal RSV vaccination during pregnancy or infant immunization with a long-acting monoclonal antibody, nirsevimab or clesrovimab. For eligible infants, these antibodies provide protection directly. (2)

Having these options available is only part of the picture. Timing matters, too: Matching prevention to an infant's earliest period of risk and to local RSV activity can help ensure protection is in place before exposure occurs.

Start Protection Early:

The American Academy of Pediatrics recommends that eligible infants born during RSV season receive RSV immunization within the first week of life, ideally during the birth hospitalization. (2) CDC guidance similarly recommends immunizing eligible infants

born from October through March during their first week after birth, preferably before hospital discharge. (3)

For newborn care teams, this means they can incorporate RSV prevention into routine discharge planning. Teams can confirm maternal vaccination status, determine infant eligibility, and help families understand whether maternal vaccination is expected to provide protection or whether infant immunization is recommended. This is important because young age alone is a major risk factor for severe RSV. Even otherwise healthy infants can develop bronchiolitis, pneumonia, or illness serious enough to require hospitalization. (1)

"For newborn care teams, this means they can incorporate RSV prevention into routine discharge planning. Teams can confirm maternal vaccination status, determine infant eligibility, and help families understand whether maternal vaccination is expected to provide protection or whether infant immunization is recommended."

If an eligible infant leaves the hospital without protection, immunization may depend on a later outpatient visit while that infant remains vulnerable. When providers can protect at discharge, the birth hospitalization offers an important chance to avoid that gap.

Use the Calendar as a Guide, Not a Boundary:

In most of the continental United States, providers generally administer infant RSV immunizations from October through March. That window helps with planning, but RSV activity does not always fit neatly within it. AAP guidance recognizes that RSV circulation varies by location and allows providers to adjust timing based on recommendations from public health authorities and regional medical centers. (2) CDC guidance also provides flexibility, including the option to begin RSV antibody administration before October, continue beyond March, or otherwise adjust timing based on local RSV activity. (3)

Clinicians can also use their judgment for individual patients outside the traditional October-through-March window. (4) This may be appropriate, for example, when an infant may not return at the ideal time for immunization or will travel to an area with higher RSV activity. The 2025–2026 season showed why that flexibility can matter: RSV activity remained elevated later than usual in parts of the country. (4) By April 1, 48 jurisdictions had extended RSV immunization through April or had not established an end date. Florida, Hawaii, Oregon, and several U.S. territories were already using year-round or other nontraditional administration periods.

RSV season remains a valuable public health framework, but local conditions matter. When RSV continues to circulate, local epidemiology and clinical judgment can help determine the appropriate timing of protection.

"For newborn care teams, this means they can incorporate RSV prevention into routine discharge planning. Teams can confirm maternal vaccination status, determine infant eligibility, and help families understand whether maternal vaccination is expected to provide protection or whether infant immunization is recommended."

Turn Prevention Guidance into Practice:

As another respiratory virus season approaches, translate RSV awareness into practical steps: identify eligible infants early, talk with parents about prevention, incorporate immunization into newborn care, and follow local RSV activity. For many infants, the best opportunity for protection will come before they leave the hospital. For others, it may mean receiving immunization shortly before RSV begins circulating locally or remaining attentive to protection when activity continues beyond March.

Seasonality remains an important part of RSV prevention, but it works best when paired with local data and clinical judgment. Using these tools early and adjusting timing as needed can help more infants receive protection when they are most vulnerable.

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National Coalition for Infant Health Values (SANE)

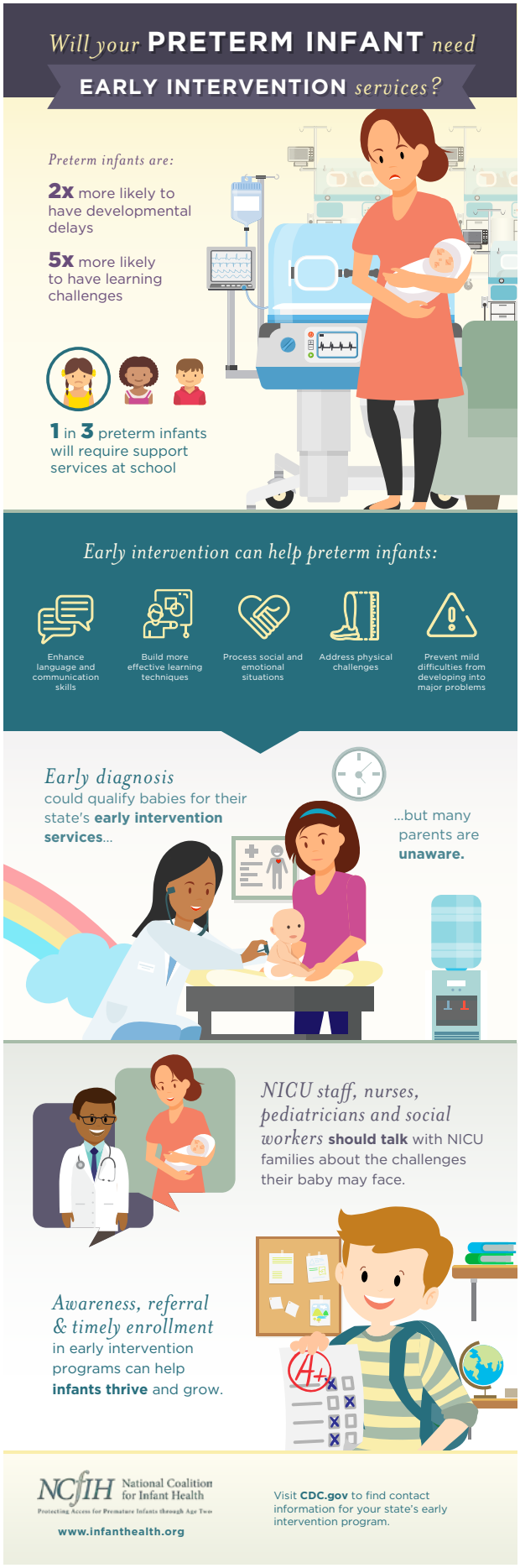
Safety. Premature infants are born vulnerable. Products, treatments and related public policies should prioritize these fragile infants' safety.

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.





Fragile Infant Forums for the Implementation of IF-CDC Standards: Leading Neuroprotective Care: Neonatal Nurses Transforming Infant- and Family-Centered Developmental Care: Leading Neuroprotective Care Through Systems Thinking and Family Partnership

Carole Kenner, PhD, RN, FAAN, FNAP, ANEF, IDFCOINN, Carol Jaeger, DNP, RN, NNP-BC



Advances in neonatal intensive care have transformed the survival of premature and critically ill newborns, shifting the focus from survival alone to optimizing neurodevelopment, family well-being, and lifelong health. This evolution has fundamentally changed expectations of neonatal care. Success is now measured not only by survival rates but also by developmental outcomes, the strength of the parent–infant relationship, and families' ability to participate confidently in their infant's care. Infant- and Family-Centered Developmental Care (IFCDC) has emerged as the evidence-based framework that integrates these priorities into routine clinical practice. (1–4)

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Despite decades of research demonstrating the benefits of developmental care, implementation remains inconsistent across neonatal intensive care units (NICUs) worldwide. Too often, IFCDC is viewed as an adjunct to intensive care rather than an essential component of evidence-based practice. Nevertheless, growing evidence demonstrates that individualized developmental care, family partnership, neuroprotective caregiving, and supportive healing environments improve physiologic stability, neurodevelopmental outcomes, parental confidence, breastfeeding, and family satisfaction while reducing infant stress and hospital length of stay. (5–9)

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Neonatal nurses are uniquely positioned to lead this transformation. More than any other healthcare professional, they provide continuous bedside care, interpret infant behavioral cues, educate and support families, coordinate interdisciplinary communication, and lead quality improvement initiatives. Their influence extends well beyond clinical interventions. Through thousands of daily interactions, neonatal nurses shape the caregiving environment, strengthen parent–infant relationships, and translate developmental science into consistent neuroprotective practice. (4, 10)

The growing recognition of neonatal nursing as a leadership profession reflects a broader understanding that implementing IFCDC requires more than individual clinical expertise. Sustainable change depends upon systems thinking, interdisciplinary collaboration, organizational commitment, and a culture that values family partnership as fundamental to neonatal care. When these elements work together, developmental care becomes embedded within everyday practice rather than delivered as a series of isolated interventions.

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This article examines the evolution of IFCDC, explores neonatal nurses' leadership role in translating evidence into practice, and highlights systems thinking as a practical framework for implementing neuroprotective care. Drawing on the evidence synthesized through the Interprofessional Consensus Committee on Infant- and Family-Centered Developmental Care and contemporary research, it presents practical strategies for integrating developmental care into routine NICU practice and sustaining organizational change. Ultimately, the article argues that neonatal nurses are not simply providers of developmental care—they are leaders who shape the future of neonatal practice through evidence, innovation, and partnership with families. (3, 4, 10)

"Although advances in neonatal medicine dramatically improved survival during the latter half of the twentieth century, clinicians increasingly recognized that survival alone was not sufficient. Attention shifted toward protecting the developing brain, minimizing the adverse effects of intensive care, and promoting healthy relationships between infants and their families. This transition fundamentally changed neonatal practice and laid the foundation for IFCDC. "

The Evolution of Infant- and Family-Centered Developmental Care from Developmental Theory to Neuroprotective Practice

Modern developmental care is built upon more than four decades of scientific discovery and interdisciplinary collaboration. Although advances in neonatal medicine dramatically improved survival during the latter half of the twentieth century, clinicians increasingly recognized that survival alone was not sufficient. Attention shifted toward protecting the developing brain, minimizing the adverse effects of intensive care, and promoting healthy relationships between infants and their families. This transition fundamentally changed neonatal practice and laid the foundation for IFCDC. (1–4)

The modern era of developmental care began with Dr. Heidelise Als' Synactive Theory of Neonatal Behavioral Organization, published in 1986. Als demonstrated that premature infants actively engage with their environment through five interconnected systems: autonomic, motor, state regulation, attention–interaction, and self-regulation. Her work transformed clinical practice by encouraging healthcare professionals to individualize care according to each infant's behavioral cues rather than relying solely on gestational age or medical diagnosis. (1)

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At the same time, Dr. Stanley Graven broadened the understanding of developmental care by recognizing how the NICU environment influences infant development. Together with Mavis Graven, he promoted reducing excessive noise and light, protecting sleep, supporting family presence, and designing healing environments that foster neurodevelopment. These efforts ultimately led to the establishment of the NICU Design Consensus Committee, whose evidence-based standards have guided neonatal unit design internationally and reinforced the concept that the environment itself is a therapeutic intervention. (2)

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Building on these foundational advances, the Interprofessional Consensus Committee on Infant- and Family-Centered Developmental Care was convened in 2015 under the leadership of Drs. Joy Browne and Carol Jaeger. This international interdisciplinary group synthesized evidence from more than 2,500 publications to develop comprehensive standards, competencies, and recommended best practices for IFCDC. Their work established a unified framework that integrates developmental science, family partnership, environmental protection, and systems thinking into routine neonatal practice. (3, 4)

"A defining contribution of the IFCDC Standards is the recognition that developmental care is not a collection of isolated interventions but a coordinated model of neuroprotective care. Positioning and therapeutic touch, sleep protection, pain and stress management, skin-to-skin care, feeding and nutrition, and family partnership function synergistically to support physiologic stability, promote healthy brain development, and strengthen the parent–infant relationship."

A defining contribution of the IFCDC Standards is the recognition that developmental care is not a collection of isolated interventions but a coordinated model of neuroprotective care. Positioning and therapeutic touch, sleep protection, pain and stress management, skin-to-skin care, feeding and nutrition, and family partnership function synergistically to support physiologic stability, promote healthy brain development, and strengthen the parent–infant relationship. The revised conceptual model places the infant–parent relationship at the center of care while emphasizing that successful implementation depends on systems thinking and interdisciplinary collaboration. (5)

Recent investigations continue to strengthen the evidence base supporting IFCDC. Studies show improved parental attachment, increased self-efficacy, reduced stress, greater use of skin-to-skin care, and better developmental outcomes when family-centered developmental care is implemented consistently. These findings also highlight an important lesson: evidence alone does not change practice. Successful implementation requires knowledgeable clinicians, supportive organizational cultures, and leaders who can translate research into sustainable improvements in care delivery. (6–10)

Today, IFCDC represents the convergence of developmental neuroscience, implementation science, family-centered care, and quality improvement. It reflects a shift from viewing developmental care as an adjunct to intensive care toward recognizing it as an essential, evidence-based standard of neuroprotective practice. Within this evolving model, neonatal nurses have emerged as the professionals best positioned to integrate science, clinical expertise, and family partnership into the everyday realities of neonatal intensive care.

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Neonatal Nurses: The Architects of Neuroprotective Care

Implementing Infant- and Family-Centered Developmental Care (IFCDC) depends on more than published evidence or clinical standards; it depends on healthcare professionals who consistently translate that evidence into practice. Among members of the neonatal healthcare team, neonatal nurses are uniquely positioned to lead this translation. Through continuous bedside care, interdisciplinary collaboration, and close partnerships with families, they integrate developmental science into everyday clinical decision-making and create the conditions necessary for neuroprotective care. (3–5)

Unlike other healthcare professionals whose interactions may be episodic, neonatal nurses remain continuously engaged with infants and families throughout hospitalization. Every assessment,

caregiving activity, feeding, developmental intervention, and conversation with parents presents an opportunity to influence physiologic stability, behavioral organization, and brain development. These cumulative interactions shape not only infant outcomes but also family confidence, attachment, and readiness for discharge. Consistent nursing presence makes neonatal nurses the principal coordinators of developmental care within the NICU. (3–5)

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The IFCDC Standards recognize that neuroprotective care is achieved by integrating multiple evidence-based practices rather than isolated interventions. Positioning and therapeutic touch, sleep protection, pain and stress management, skin-to-skin care, individualized feeding, and family partnership function synergistically to support healthy brain development. Neonatal nurses coordinate these interconnected domains while tailoring care to each infant's developmental status and each family's strengths, values, and cultural context. (3–5)

Research consistently demonstrates that nurse education and competency influence the quality of developmental care delivered in the NICU. Mothers who perceive higher levels of family-centered care report stronger attachment, greater parenting self-efficacy, and lower stress. (6) Integrative reviews have shown that successful implementation of skin-to-skin care is strongly associated with staff education, positive attitudes, institutional support, and interdisciplinary collaboration. (7) Likewise, nurses with advanced developmental care education are more likely to implement evidence-based interventions that improve infant regulation, reduce family distress, and enhance developmental outcomes. (14) Nurse-led developmental care programs have also demonstrated measurable improvements in neurodevelopmental outcomes among preterm infants. (15, 16)

"Likewise, nurses with advanced developmental care education are more likely to implement evidence-based interventions that improve infant regulation, reduce family distress, and enhance developmental outcomes. (14) Nurse-led developmental care programs have also demonstrated measurable improvements in neurodevelopmental outcomes among preterm infants."

Despite these advances, implementing IFCDC remains challenging. High patient acuity, staffing shortages, competing clinical priorities, environmental limitations, inconsistent administrative support, and variation in interdisciplinary engagement continue to limit consistent implementation. Families also face barriers related to emotional stress, uncertainty about their caregiving role, cultural differences, and health literacy. Studies examining implementation barriers consistently identify staffing, infrastructure, education, organizational culture, and leadership commitment as critical determinants of success. (12, 13) These findings reinforce that sustainable implementation depends on healthcare systems as much as individual clinicians.

Leadership therefore extends well beyond direct patient care. Neonatal nurses influence unit culture through mentorship, education, quality improvement, and interdisciplinary collaboration. Whether serving as bedside clinicians, educators, advanced practice nurses, managers, researchers, or policy leaders, they establish developmental care as an organizational expectation rather than an optional enhancement. Systems thinking enables nurses to align evidence, workflows, communication, and environmental design to create consistent, family-centered, neuroprotective care. (10, 11)

Perhaps the most profound transformation in neonatal care has been the shift from parents as visitors to essential members of the healthcare team. Family partnership is now recognized as a

"Perhaps the most profound transformation in neonatal care has been the shift from parents as visitors to essential members of the healthcare team. Family partnership is now recognized as a therapeutic intervention that supports infant physiologic regulation, strengthens attachment, improves parental confidence, and promotes healthy neurodevelopment."

therapeutic intervention that supports infant physiologic regulation, strengthens attachment, improves parental confidence, and promotes healthy neurodevelopment. (6, 7) Neonatal nurses facilitate this partnership through education, shared decision-making, bedside coaching, and compassionate communication, empowering parents to become confident caregivers during hospitalization and after discharge. (3, 4)

As neonatal care continues to evolve, so too does the neonatal nurse's role. Beyond providing expert bedside care, nurses serve as implementation leaders who translate research into practice, evaluate outcomes, mentor colleagues, advocate for families, and drive organizational change. Their ability to integrate developmental science, systems thinking, and family partnership positions them at the forefront of transforming neonatal intensive care. Ultimately, neonatal nurses are not simply providers of IFCDC—they are the leaders who ensure that neuroprotective care becomes the standard for every newborn, every family, and every NICU. (3, 10, 14, 15) See Figure 1.

Leadership Pearls

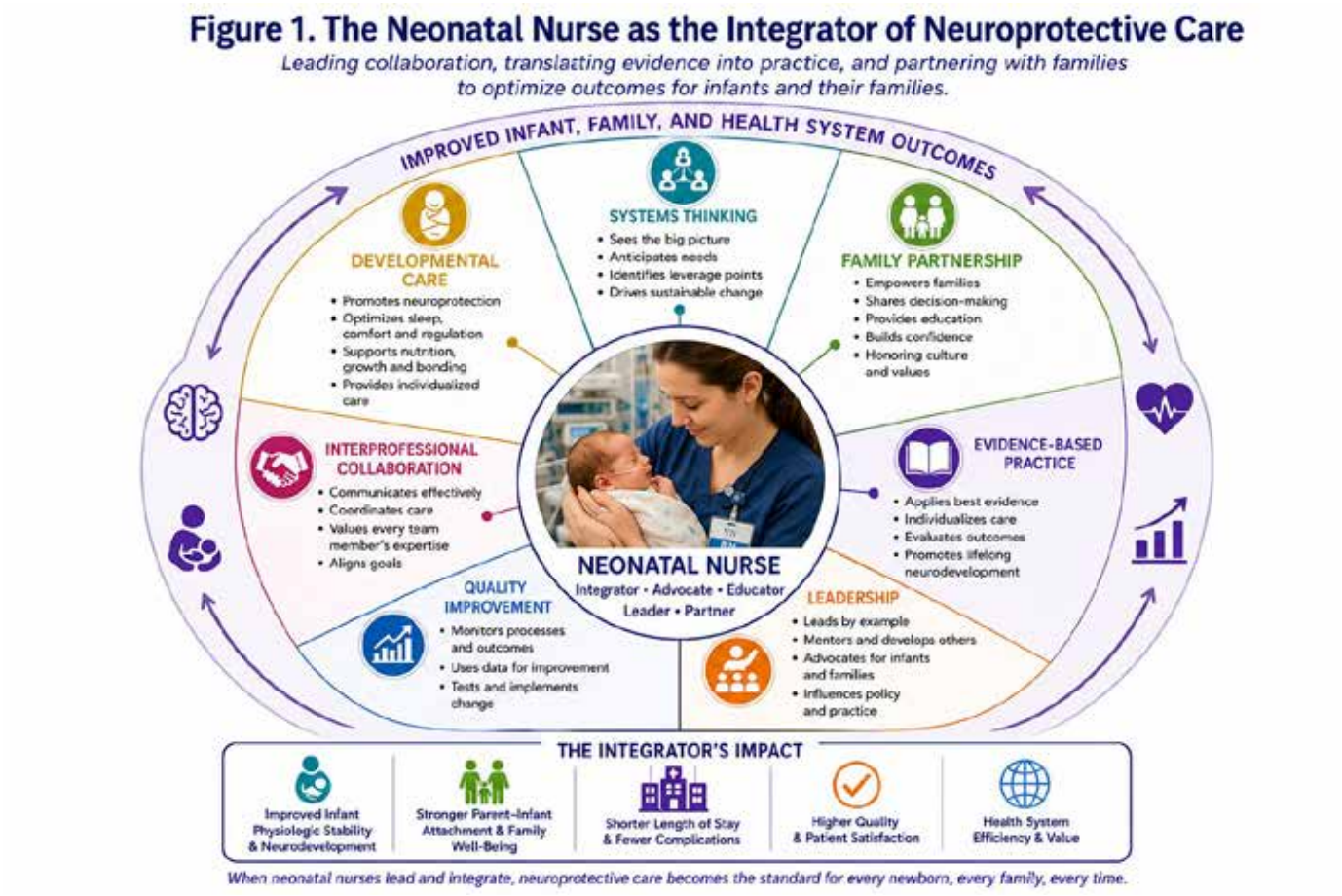
1. Every interaction between a nurse, infant, and family influences brain development.
2. Neuroprotective care is achieved through coordinated, evidence-based practice—not isolated interventions.
3. Parents are therapeutic partners whose participation improves infant and family outcomes.
4. Education, mentorship, and competency development are essential to successful IFCDC implementation.
5. Leadership is demonstrated through everyday clinical practice, quality improvement, and advocacy.

Systems Thinking: Transforming Evidence into Everyday Practice

Implementing IFCDC requires more than individual clinical expertise; it requires understanding how people, processes, and environments interact within the NICU's complex adaptive system. Systems thinking provides the framework for translating developmental science into sustainable clinical practice. (10)

The NICU is characterized by continuous interactions among infants, families, healthcare professionals, technology, organizational policies, and the physical environment. Changes in one component inevitably influence others. Consequently, isolated improvements—such as introducing a new developmental care protocol or increasing skin-to-skin care—are unlikely to achieve lasting success unless integrated into a coordinated care system. (10, 11)

Figure 1: From the Framework for Infant and Family Centered Developmental Care Standards. Figure created by the authors using ChatGPT (OpenAI, GPT-5.5, accessed Aug. 1, 2026) with prompt based on the conceptual framework developed for this manuscript.



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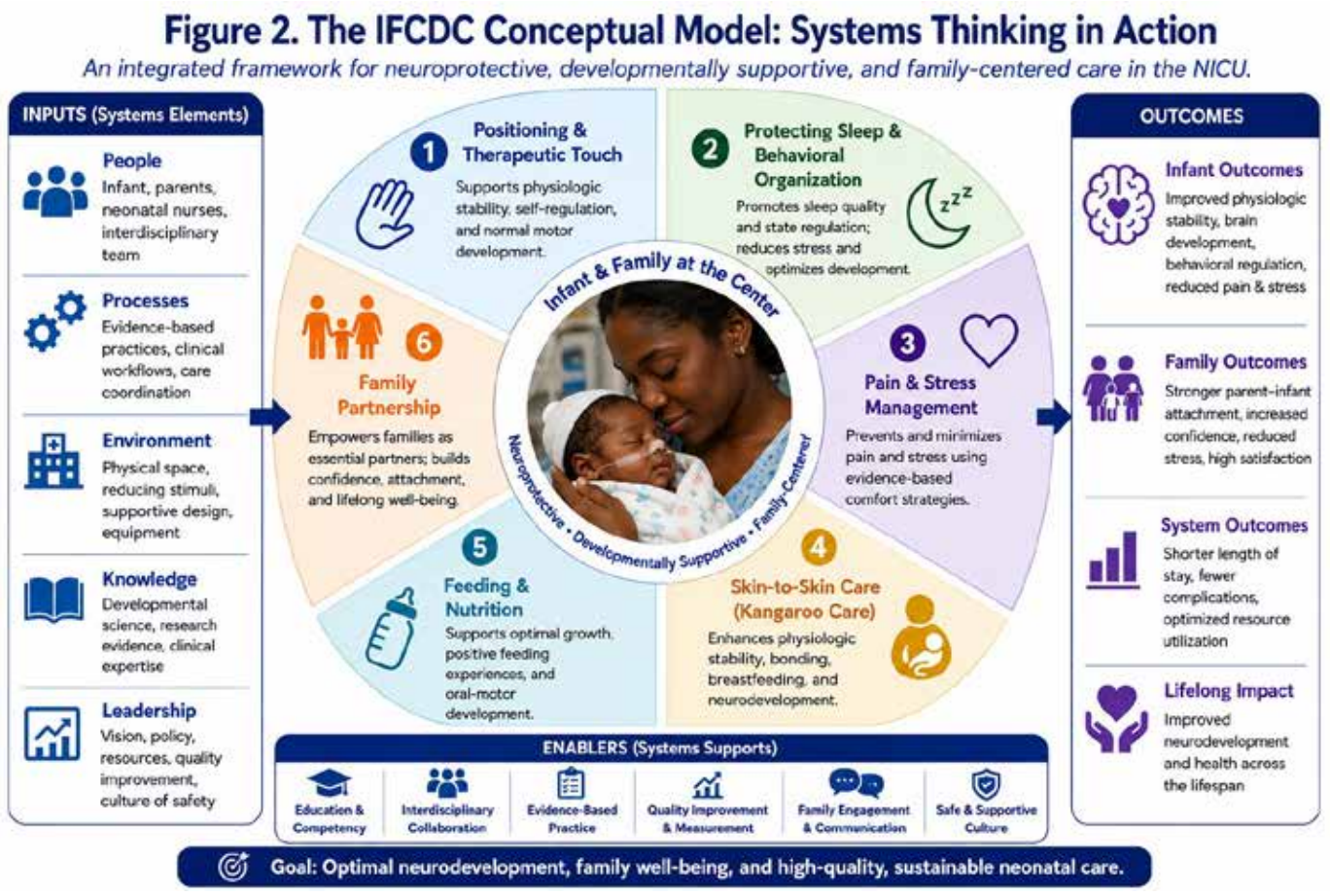
The Systems Thinking for Health Actions framework identifies six characteristics that support improvement within complex healthcare systems: understanding system structures, recognizing feedback processes, identifying leverage points for change, appreciating dynamic system behavior, using mental models to explore solutions, and testing innovations before implementation. (10) Although these concepts may appear theoretical, they mirror the cognitive processes that experienced neonatal nurses use every day as they synthesize physiologic assessment, behavioral cues, family priorities, and interdisciplinary communication to individualize care. See Figure 2.

The revised IFCDC conceptual model reflects this systems perspective by placing the infant–parent relationship at the center of care while integrating six interconnected domains of neuroprotective practice: positioning and therapeutic touch; sleep protection; pain and stress management; skin-to-skin care; feeding and nutrition; and family partnership. (3–5) Together, these domains create a coordinated model that supports physiologic stability, promotes healthy brain development, and strengthens parent–infant relationships.

One practical application of systems thinking is the **Key Driver Diagram**, which links improvement aims with the primary and secondary drivers required to achieve sustainable change. Within IFCDC, primary drivers include leadership commitment, staff education, interdisciplinary collaboration, family engagement, environmental optimization, and standardized developmental care practices. Secondary drivers define the specific interventions needed to strengthen each component, providing healthcare teams with a structured roadmap for implementation and continuous quality improvement.

Systems thinking also emphasizes continuous learning. Rather than viewing implementation as a one-time initiative, neonatal nurses evaluate outcomes, identify barriers, engage families, and refine care processes through ongoing quality improvement. This iterative approach enables healthcare teams to respond to emerging evidence while adapting developmental care to the needs of individual infants, families, and organizations. (10, 11,

Figure 2: Based on the Framework for Infant and Family Centered Developmental Care. Figure created by the authors using ChatGPT (OpenAI, GPT-5.5, accessed Aug. 1, 2026) with prompt based on the conceptual framework developed for this manuscript.



14)

By integrating systems thinking with evidence-based developmental care, neonatal nurses bridge the gap between research and practice. They create environments in which every clinical interaction supports neurodevelopment, every family is recognized as an essential partner, and every member of the interdisciplinary team contributes to a culture of neuroprotective care. In doing so, they transform IFCDC from a collection of best practices into the foundation of excellence in neonatal intensive care.

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Translating Evidence into Action at the Bedside: The Six Pillars of Neuroprotective Care

Infant- and Family-Centered Developmental Care (IFCDC) is most effective when it is integrated into every aspect of neonatal practice rather than delivered as a series of isolated interventions. Neuroprotective care is achieved through the coordinated application of evidence-based practices that support physiologic stability, brain development, and family well-being. The revised IFCDC Standards identify six interdependent domains that together create a comprehensive framework for developmental care. (3–5)

Neonatal nurses are uniquely positioned to operationalize these domains because they remain continuously engaged with infants and families throughout hospitalization. Through assessment, observation, education, and interdisciplinary collaboration, they ensure that developmental care becomes part of every clinical encounter rather than an additional task. Systems thinking provides the organizational framework while the six pillars translate that framework into everyday practice. (10, 11)

Pillar 1: Positioning and Therapeutic Touch:

Positioning and therapeutic touch form the foundation of neuroprotective care. Appropriate positioning supports physiologic stability, promotes flexion and midline orientation, facilitates self-regulation, conserves energy, and encourages normal musculoskeletal development. Therapeutic touch—including containment, facilitated tucking, cue-based handling, and minimizing unnecessary manipulation—helps infants organize behavioral responses while reducing stress associated with routine caregiving. (3–5)

Effective positioning requires continuous assessment rather than a standardized approach. Neonatal nurses evaluate infant behavioral cues before, during, and after caregiving activities and individualize interventions according to gestational age, medical condition, and developmental readiness. Through collaboration with occupational and physical therapists, positioning becomes a dynamic process that evolves throughout hospitalization.

Clinical Pearl:

Every touch influences the developing brain. Purposeful, cue-based handling promotes physiologic stability, minimizes stress, and supports self-regulation.

Pillar 2: Protecting Sleep and Behavioral Organization:

Sleep is critical to healthy brain development. During sleep, essential neurologic processes occur, including synaptic organization, neuronal maturation, memory consolidation, and physiologic recovery. Frequent caregiving interruptions, excessive environmental stimulation, and poorly coordinated clinical activities may disrupt these processes and increase infant stress. (3–5)

Neonatal nurses play a central role in protecting sleep by recognizing behavioral states, clustering care, reducing unnecessary stimulation, and coordinating interventions across the interdisciplinary team. View sleep protection not as delaying care but as enhancing the infant's ability to tolerate necessary interventions while promoting neurodevelopment.

Clinical Pearl:

Protecting sleep is one of the most effective neuroprotective interventions available in the NICU.

Pillar 3: Pain and Stress Management:

Premature and critically ill infants experience repeated painful and stressful procedures throughout hospitalization. When inadequately managed, repeated pain and chronic stress are associated with altered physiologic regulation, impaired brain development, and adverse neurodevelopmental outcomes. (3–5, 16)

Pain prevention begins with anticipation, not reaction. Neonatal nurses integrate non-pharmacologic strategies—including facilitated tucking, non-nutritive sucking, skin-to-skin care, breastfeeding when appropriate, and environmental modification—with pharmacologic therapies when indicated. Family participation during procedures further supports infant regulation while strengthening parent confidence and attachment. (7, 16)

Clinical Pearl:

Pain management protects both physiologic stability and the developing brain.

Pillar 4: Skin-to-Skin Care:

Skin-to-skin care (Kangaroo Mother Care) is among the most extensively studied interventions in neonatal care. Evidence consistently demonstrates improvements in physiologic stability, thermoregulation, breastfeeding, parent–infant attachment, and neurodevelopment. Recent integrative reviews also identify staff education, organizational culture, interdisciplinary collaboration, and institutional support as major determinants of successful implementation. (6, 7)

Neonatal nurses coordinate assessment, preparation, safe transfer, and family education, transforming skin-to-skin care from an occasional intervention into a routine component of neuroprotective practice.

Clinical Pearl:

Skin-to-skin care is not an adjunct to intensive care—it is intensive care.

Pillar 5: Feeding and Nutrition:

Optimal nutrition supports both growth and brain development. Developmentally supportive feeding extends beyond nutrient delivery to include cue-based feeding, protecting oral experiences, supporting breastfeeding, and recognizing infant readiness. (3–5)

Neonatal nurses guide parents to recognize feeding cues, participate in feeding decisions, and build confidence in caring for their infant. Individualized feeding plans that integrate developmental readiness with nutritional requirements promote positive feeding experiences while strengthening family engagement.

Clinical Pearl:

Feeding is both nutrition and neurodevelopment. Every feeding interaction is an opportunity to strengthen infant regulation and parent confidence.

Pillar 6: Family Partnership:

Family partnership is the cornerstone of IFCDC. Parents are no longer viewed as visitors but as essential members of the healthcare team whose participation directly influences infant outcomes. Family-centered care has been associated with stronger parent–infant attachment, improved parental self-efficacy, lower stress, increased breastfeeding, and greater family satisfaction. (6, 17, 18)

Neonatal nurses support this partnership by promoting shared decision-making, encouraging participation in caregiving, providing individualized education, and creating psychologically safe environments where parents are respected as experts on their infant. These relationships extend beyond hospitalization, preparing families to care for their infant confidently after discharge.

Clinical Pearl:

Parents are not visitors—they are therapeutic partners whose presence supports infant development and family resilience.

Integrating the Six Pillars:

Although each pillar contributes independently to infant and family outcomes, they have their greatest impact when implemented together. Positioning influences sleep quality; sleep affects stress regulation; stress management supports feeding; feeding strengthens parent–infant interaction; and family partnership enhances every aspect of developmental care. Systems thinking enables neonatal nurses to recognize these relationships and coordinate interventions that promote consistent neuroprotective care. (3–5, 10)

Rather than asking, *"Which developmental intervention should I provide?"* neonatal nurses should ask, *"How can every interaction today support the developing brain and strengthen the infant–family relationship?"* This shift in perspective transforms developmental care from a series of individual practices into a coordinated philosophy that guides every aspect of neonatal intensive care.

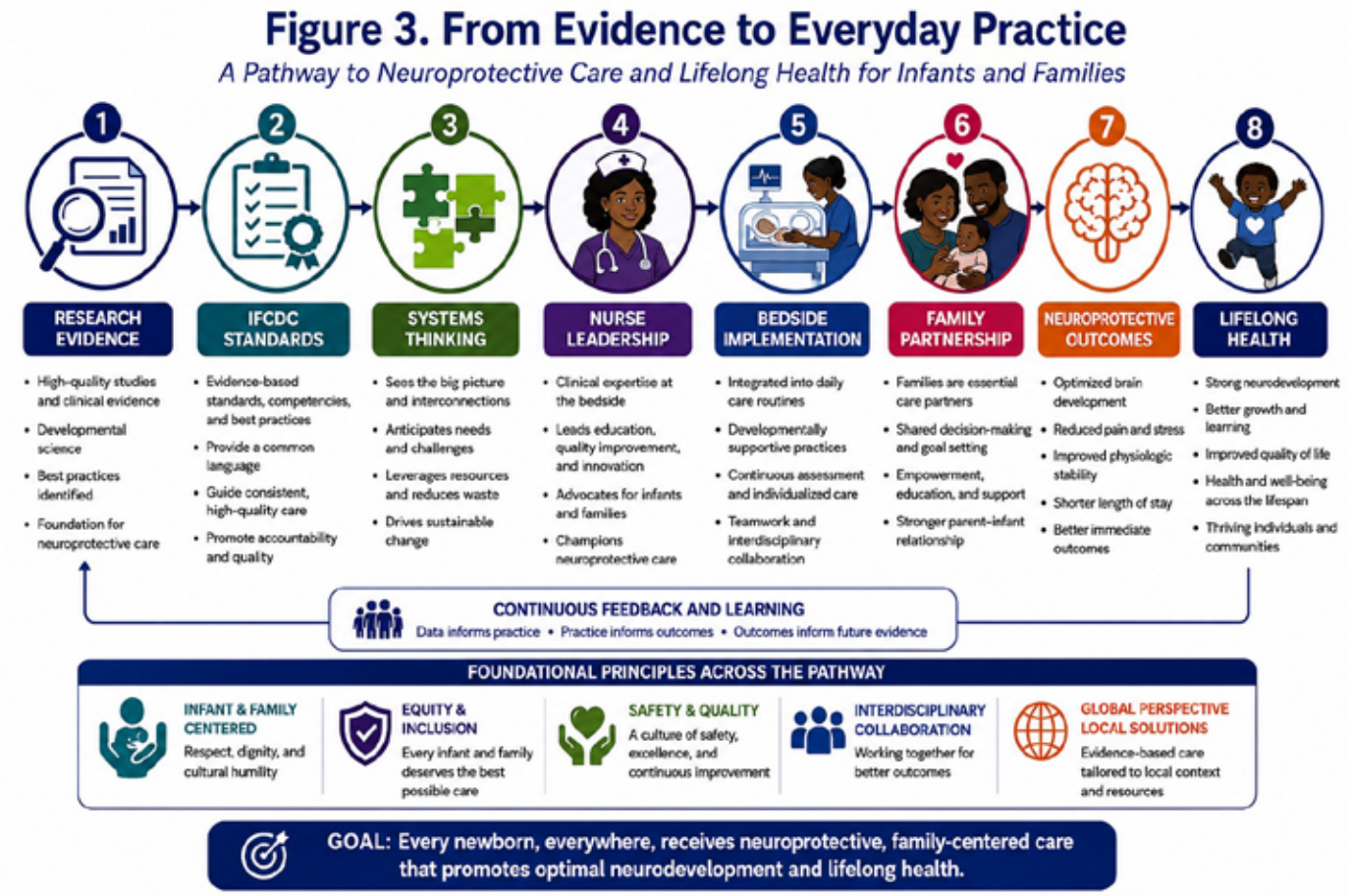
Leadership in Action: Translating IFCDC into Daily Practice

(See Table 1 below.)

Table 1. Leadership in Action

IFCDC Domain	Leadership Action	Expected Outcome
Positioning and Touch	Standardize developmental positioning education	Improved self-regulation and motor development
Sleep Protection	Coordinate care and establish quiet periods	Enhanced sleep quality and physiologic stability
Pain & Stress Management	Integrate standardized comfort measures	Reduced stress and improved neurodevelopment
Skin-to-Skin Care	Remove barriers and educate families	Greater parent participation and improved infant outcomes
Feeding & Nutrition	Implement cue-based feeding and breastfeeding support	Improved feeding success and parent confidence
Family Partnership	Include parents in rounds and care planning	Stronger attachment, confidence, and satisfaction

Figure 3: From a Framework for Infant and Family-Centered Developmental Care. Figure created by the authors using ChatGPT (OpenAI, GPT-5.5, accessed Aug. 1, 2026) with prompt based on the conceptual framework developed for this manuscript.



Building a Culture of Neuroprotective Care

Leadership, Implementation, and Sustaining Change

The evidence supporting Infant- and Family-Centered Developmental Care (IFCDC) has never been stronger. Studies consistently demonstrate improvements in infant physiologic stability, neurodevelopment, parent–infant attachment, breastfeeding, family confidence, and healthcare outcomes when developmental care is integrated into routine neonatal practice. (3–7, 14–18) (See Figure 3.) However, despite decades of research and published international standards, implementation remains inconsistent across neonatal intensive care units (NICUs). (12, 13)

The challenge is no longer determining whether IFCDC improves outcomes—it is determining how to implement and sustain it across diverse healthcare systems. This requires moving beyond individual clinical interventions toward organizational cultures that consistently support neuroprotective care. Sustainable implementation depends upon leadership, education, interdisciplinary collaboration, quality improvement, and systems thinking working together to create lasting change. (10,11)

Leadership Begins at the Bedside:

Culture change begins with everyday clinical practice. Every interaction among a neonatal nurse, infant, and family shapes the culture of care within a NICU. Protecting infant sleep, facilitating skin-to-skin care, coaching parents, using cue-based caregiving, and advocating for individualized developmental interventions reinforce the expectation that IFCDC is fundamental to high-

"Studies consistently demonstrate improvements in infant physiologic stability, neurodevelopment, parent–infant attachment, breastfeeding, family confidence, and healthcare outcomes when developmental care is integrated into routine neonatal practice. However, despite decades of research and published international standards, implementation remains inconsistent across neonatal intensive care units (NICUs)."

quality neonatal care, not an optional enhancement. (3–5)

Leadership therefore extends beyond formal management positions. Bedside nurses influence practice through clinical excellence, role modeling, peer mentoring, and advocacy for evidence-based care. Clinical nurse specialists, educators, advanced practice nurses, and nurse managers further strengthen implementation by developing competencies, mentoring staff, leading quality improvement initiatives, and fostering interdisciplinary collaboration. Together, these complementary leadership roles create the infrastructure necessary for sustainable implementation.

Education as the Foundation for Change:

Education remains one of the strongest predictors of successful IFCDC implementation. Studies demonstrate that nurses who receive structured education in developmental care are more likely to implement evidence-based practices, engage families as partners, and contribute to improved infant and family outcomes. (6, 7, 14) Education also influences professional attitudes, shifting perceptions of parents from visitors to primary caregivers and strengthening confidence in developmental care practices. (6, 17)

"Education remains one of the strongest predictors of successful IFCDC implementation. Studies demonstrate that nurses who receive structured education in developmental care are more likely to implement evidence-based practices, engage families as partners, and contribute to improved infant and family outcomes."

Competency development should extend beyond orientation programs to include simulation, bedside coaching, interdisciplinary learning, reflective practice, and continuing professional development. Educational programs should emphasize systems thinking, communication, family engagement, implementation science, and leadership in addition to clinical competencies. (3, 10)

Families Are Partners, Not Visitors

Perhaps the most important cultural transformation within neonatal care has been recognizing parents as essential members of the healthcare team. Family participation improves infant physiologic regulation, strengthens parent–infant attachment, increases parental confidence, and reduces stress. (6, 17, 18) These outcomes are achieved not simply through open visitation but through meaningful engagement in caregiving, shared decision-making, bedside rounds, developmental activities, and discharge planning.

Neonatal nurses facilitate these partnerships through education, compassionate communication, shared goal setting, and respectful collaboration. Family partnership therefore becomes both a philosophy of care and an evidence-based clinical intervention.

"Perhaps the most important cultural transformation within neonatal care has been recognizing parents as essential members of the healthcare team. Family participation improves infant physiologic regulation, strengthens parent–infant attachment, increases parental confidence, and reduces stress."

Measuring What Matters: Quality improvement requires meaningful measurement

Historically, neonatal outcomes have focused primarily on survival and medical complications. IFCDC expands this perspective by recognizing developmental, family, and organizational outcomes as equally important indicators of quality.

Examples of implementation measures include:

1. Percentage of infants receiving daily skin-to-skin care
2. Parent participation during rounds
3. Breastfeeding rates
4. Protected sleep periods
5. Developmental positioning compliance
6. Staff competency in IFCDC
7. Parent satisfaction
8. Family confidence and readiness for discharge

Continuous monitoring of these indicators enables NICUs to evaluate implementation, identify barriers, and guide ongoing quality improvement. (10,11)

Creating Sustainable Change:

Implementation science teaches us that lasting change occurs when evidence, leadership, systems, and culture evolve together. Key Driver Diagrams, Plan–Do–Study–Act (PDSA) cycles, developmental care champions, interdisciplinary implementation teams, competency-based education, and leadership engagement provide practical strategies for embedding IFCDC into routine care. (10,11) Rather than viewing implementation as a single project, successful NICUs recognize developmental care as a continuous journey of learning, adaptation, and improvement.

Healthcare systems also differ substantially across countries and regions. Successful implementation must therefore be responsive to local resources, workforce capacity, cultural values, and healthcare priorities while maintaining the core principles of neuroprotective care. This flexibility supports innovation while preserving fidelity to evidence-based IFCDC standards.

From Individual Practice to Organizational Excellence:

Ultimately, neuroprotective care becomes sustainable only when it is integrated into the organization's identity. Organizations that consistently implement IFCDC share several characteristics. They prioritize leadership commitment, invest in staff education, engage families as partners, measure developmental outcomes, promote interdisciplinary collaboration, and foster cultures of continuous learning. In these environments, developmental care does not depend on individual champions—it becomes the shared responsibility of every member of the healthcare team.

For neonatal nurses, this transformation represents an extraordinary opportunity. Their continuous presence at the bedside, developmental care expertise, and leadership across clinical, educational, and organizational domains position them to guide this evolution. By integrating systems thinking with evidence-based practice and family partnership, neonatal nurses are leading a fundamental transformation in neonatal care—one that places neuroprotection, family engagement, and lifelong health at the center of every clinical decision.

Leadership in Action: Building a Culture of Neuroprotective Care: (see Table 2 below.)

Leadership Pearl:

The greatest barrier to implementing IFCDC is not a lack of evidence—it is the challenge of transforming organizational culture. Lasting change occurs when neonatal nurses lead with evidence, systems thinking, and family partnership.

The Future of Neonatal Nursing: *Advancing Neuroprotective Care Through Innovation and Global Collaboration*

Neonatal care has entered a new era in which success is measured not only by survival but also by neurodevelopmental quality, family well-being, and lifelong health. Advances in neonatal medicine have dramatically improved survival for premature and critically ill infants, but they have also highlighted the need to optimize developmental outcomes and strengthen family partnerships. Infant- and Family-Centered Developmental Care (IFCDC) provides an evidence-based framework for achieving these goals, positioning neuroprotective care as a fundamental standard of neonatal practice rather than an adjunct to intensive care. (3–5)

The next generation of neonatal care will be defined not only by technological innovation but also by healthcare systems' ability to translate evidence into practice consistently. Neonatal nurses are uniquely positioned to lead this transformation. Their continuous presence at the bedside, expertise in developmental care, and leadership in education, quality improvement, and family engagement place them at the center of efforts to implement evidence-based neuroprotective care across diverse clinical settings. (10, 11, 14)

Implementation science will play an increasingly important role in accelerating IFCDC adoption. Traditional approaches to introducing new evidence have often focused on education alone. While education remains essential, successful implementation also requires leadership commitment, systems thinking, interdisciplinary collaboration, ongoing measurement, and continuous quality improvement. Integrating these principles into neonatal practice enables healthcare teams to move beyond isolated interventions toward sustainable organizational change. (10, 11)

"Implementation science will play an increasingly important role in accelerating IFCDC adoption. Traditional approaches to introducing new evidence have often focused on education alone. While education remains essential, successful implementation also requires leadership commitment, systems thinking, interdisciplinary collaboration, ongoing measurement, and continuous quality improvement."

Table 2. Leadership in Action: Building a Culture of Neuroprotective Care

Leadership Priority	Action	Outcome
Leadership Commitment	Adopt IFCDC as a strategic priority	Organization-wide alignment
Education	Implement competency-based developmental care education	Consistent evidence-based practice
Family Partnership	Include parents in rounds and care planning	Greater confidence and engagement
Quality Improvement	Monitor IFCDC process and outcome measures	Continuous improvement
Interdisciplinary Collaboration	Develop shared implementation goals	Improved teamwork
Recognition	Celebrate staff and family successes	Positive culture and sustainability

Technological advances also offer new opportunities to strengthen developmental care. Digital learning platforms, simulation-based education, telehealth, electronic clinical decision support, and data dashboards can improve access to education, support competency development, and facilitate monitoring of developmental care practices. These tools should complement—not replace—the therapeutic relationships that remain central to neonatal nursing. Technology is most effective when it enhances communication, supports clinical decision-making, and strengthens partnerships among healthcare professionals and families.

"Technological advances also offer new opportunities to strengthen developmental care...These tools should complement—not replace—the therapeutic relationships that remain central to neonatal nursing. Technology is most effective when it enhances communication, supports clinical decision-making, and strengthens partnerships among healthcare professionals and families."

Research priorities are likewise evolving. Future investigations should move beyond demonstrating the effectiveness of individual developmental interventions toward evaluating implementation strategies, long-term neurodevelopmental outcomes, cost-effectiveness, workforce development, and organizational factors that influence sustained adoption of IFCDC. Greater emphasis on implementation science, quality improvement, and health systems research will help identify practical approaches adaptable across a variety of healthcare settings. (10, 11)

Global collaboration represents another important opportunity. Neonatal nurses worldwide continue to develop innovative approaches to implementing developmental care in settings with differing resources, workforce capacity, and healthcare priorities. Sharing educational resources, implementation strategies, quality improvement initiatives, and research findings across countries strengthens the neonatal community's collective ability to improve care while respecting cultural diversity and local context. International collaboration ensures that advances in developmental care benefit newborns wherever they are born.

Professional organizations have an essential role in this effort. By establishing competency standards, promoting continuing education, supporting collaborative research, and advocating for policies that recognize developmental care as a core component of neonatal practice, these organizations help create the infrastructure necessary for sustained improvement. Partnerships among professional societies, academic institutions, healthcare organizations, and global health agencies will be critical for expanding access to high-quality developmental care worldwide.

The future of neonatal nursing will therefore be defined not only by clinical expertise but also by leadership. Neonatal nurses will increasingly serve as implementation scientists, educators, quality improvement leaders, researchers, policy advocates, and global collaborators. Their ability to integrate developmental science, systems thinking, and family partnership positions them to lead the continued evolution of neonatal care.

Ultimately, the future of IFCDC depends upon a shared commitment to ensuring that every infant receives developmentally supportive, neuroprotective care delivered within healthcare systems designed to promote lifelong health and well-being. Every interaction, every family partnership, and every quality improvement initiative contribute to that vision. By embracing innovation while remaining grounded in evidence and compassionate care, neonatal nurses will continue to shape the future of neonatal practice and improve outcomes for generations of newborns and their families.

Future Directions:

Priorities for the Next Decade

1. Advance implementation science to accelerate adoption of IFCDC.
2. Expand competency-based education in developmental and neuroprotective care.
3. Strengthen interdisciplinary and interprofessional collaboration.
4. Develop standardized quality indicators for IFCDC implementation.
5. Increase research on long-term neurodevelopment and family outcomes.
6. Evaluate the economic impact and return on investment of neuroprotective care.
7. Expand global partnerships that support country-led implementation.
8. Advocate for policies recognizing developmental care as a universal standard of neonatal practice.

Leadership Pearl:

The future of neonatal nursing will be defined not only by what nurses know, but by how effectively they translate evidence into neuroprotective care for every newborn and every family.

Global Call to Action: Leading the Future of Neuroprotective Care

The science is compelling. Infant- and Family-Centered Developmental Care (IFCDC) improves neurodevelopmental outcomes, strengthens parent–infant relationships, enhances family confidence, and promotes higher-quality neonatal care. However, evidence alone does not transform practice. Lasting improvement depends on the commitment of healthcare professionals, organizations, educators, researchers, and policymakers to build systems that embed neuroprotective care in every aspect of neonatal practice. (3–5, 10)

Neonatal nurses are uniquely positioned to lead this transformation. Their continuous presence at the bedside, expertise in developmental care, and leadership in education,

quality improvement, and family engagement enable them to bridge the gap between evidence and practice. By integrating systems thinking, interdisciplinary collaboration, and family partnership into routine care, neonatal nurses ensure that every clinical interaction supports the developing brain and strengthens the infant–family relationship. (10, 11)

Achieving this vision requires a shared commitment across the neonatal community. Healthcare organizations must invest in competency-based education, interdisciplinary collaboration, and quality improvement systems that support consistent IFCDC implementation. Academic institutions should prepare the next generation of neonatal nurses with the knowledge and leadership skills required to implement evidence-based developmental care. Professional organizations should continue to advance standards, foster research, and advocate for policies that recognize neuroprotective care as a fundamental component of neonatal practice. Policymakers and healthcare leaders must ensure that families are supported as essential partners in care and that health systems provide the resources necessary to sustain developmental care across diverse clinical settings.

Global collaboration will be critical to achieving equitable neonatal outcomes. Countries differ in healthcare infrastructure, workforce capacity, available resources, and cultural context; however, every newborn deserves care that protects brain development, supports families, and promotes lifelong health. International partnerships that share educational resources, collaborate on research, and support country-led implementation strategies will strengthen global capacity to deliver evidence-based neuroprotective care while respecting local needs and priorities.

"International partnerships that share educational resources, collaborate on research, and support country-led implementation strategies will strengthen global capacity to deliver evidence-based neuroprotective care while respecting local needs and priorities."

The future of neonatal care will not be defined solely by technological advances or new therapies. It will be defined by our collective ability to translate evidence into compassionate, consistent, family-centered practice. Every caregiving interaction, educational initiative, quality improvement project, and partnership with families contributes to that future. As neonatal nurses, we have both the opportunity and the responsibility to lead this transformation. By embracing IFCDC as the foundation of neuroprotective care, we can improve outcomes not only for the infants entrusted to our care today but also for the generations that follow.

The challenge before us is clear. **Move beyond knowing the evidence. Lead its implementation. Partner with families. Protect the developing brain. Together, we can ensure that every newborn, everywhere, receives the highest standard of neuroprotective care.**

Key Take-Home Messages

For Clinical Practice:

1. IFCDC is an evidence-based model of neuroprotective care that should be integrated into every aspect of neonatal practice. (3–5)
2. Neuroprotective care is achieved through coordinated positioning and therapeutic touch, sleep protection, pain and stress management, skin-to-skin care, individualized feeding, and family partnership. (3–5)
3. Parents are essential members of the healthcare team, and their participation improves infant and family outcomes. (6, 17, 18)

For Neonatal Nurses:

1. Neonatal nurses are the primary leaders in translating developmental science into everyday practice. (3–5)
2. Systems thinking provides a practical framework for implementing and sustaining IFCDC within complex healthcare environments. (10–11)
3. Leadership is demonstrated through clinical excellence, education, quality improvement, mentorship, and advocacy.

For Healthcare Organizations:

1. Successful implementation of IFCDC requires leadership commitment, competency-based education, interdisciplinary collaboration, family engagement, and continuous quality improvement. (10–14)
2. Measuring developmental care processes and outcomes is essential for sustaining organizational change.

For the Global Neonatal Community:

1. International collaboration accelerates innovation, strengthens education, and promotes equitable implementation of neuroprotective care.
2. Country-led implementation strategies ensure that IFCDC remains evidence-based while being responsive to local healthcare systems and cultural contexts.

Every newborn, regardless of geography or available resources, deserves access to developmentally supportive, family-centered, neuroprotective care.

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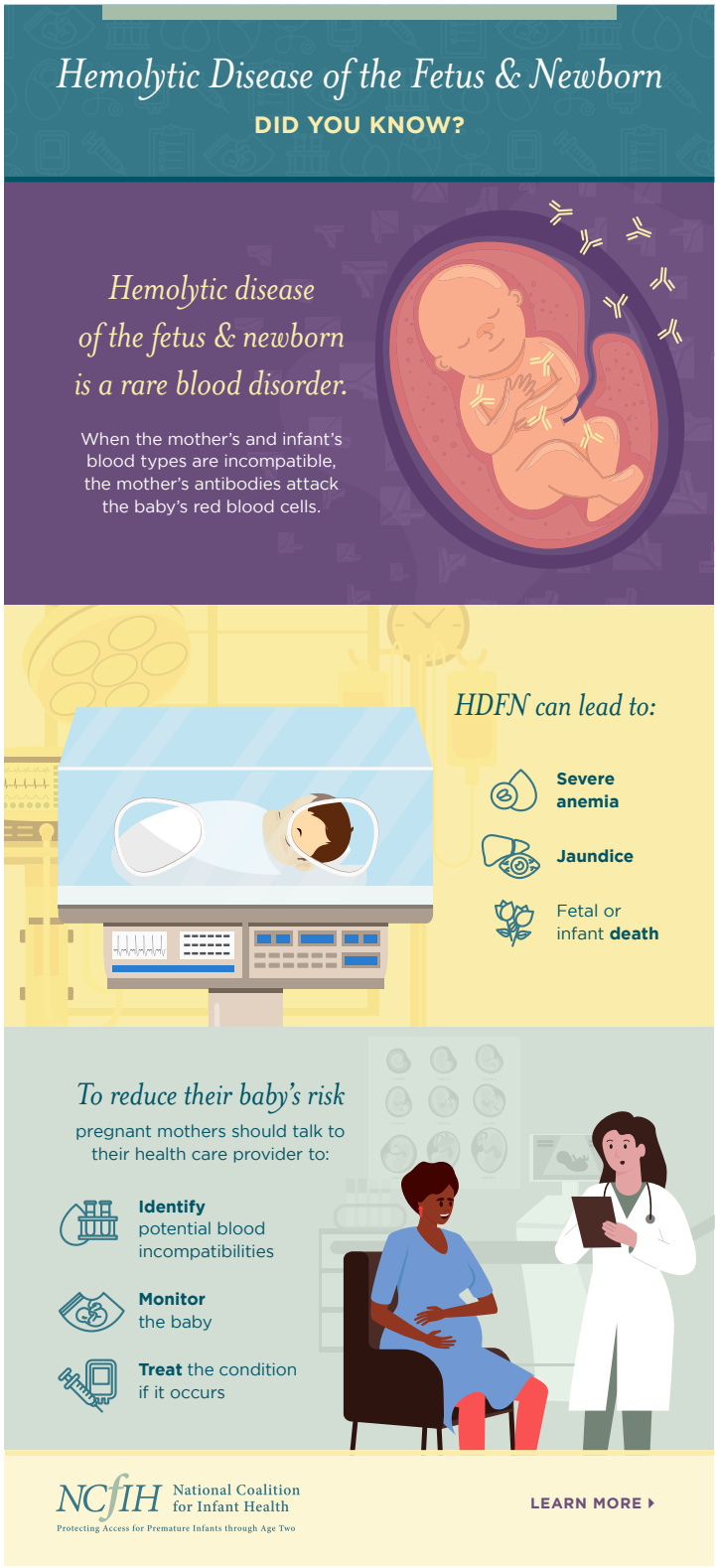
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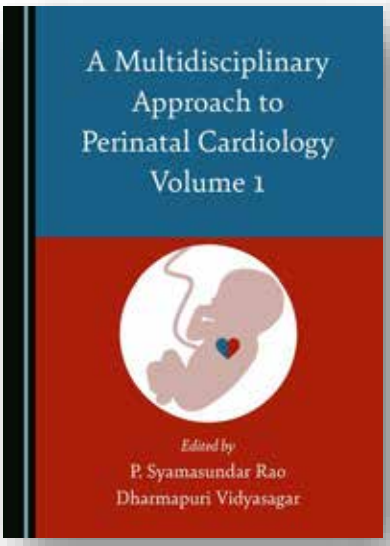
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Recent developments in diagnostic and therapeutic aspects of cardiac and neonatal issues have advanced the care of the newborn. To achieve excellence in cardiac care, however, close interaction and collaboration of the pediatric cardiologists with 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: Children May Pay the Price for Vaccine Policy Shift

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

"A familiar childhood vaccine is at the center of a major shift in federal vaccine policy. President Trump's new executive order calls for replacing the combined MMR vaccine with separate measles, mumps, and rubella shots once those products become available."

A familiar childhood vaccine is at the center of a major shift in federal vaccine policy. President Trump's new executive order calls for replacing the combined MMR vaccine with separate measles, mumps, and rubella shots once those products become available. The administration is also seeking public input on broader changes to how it develops and categorizes federal vaccine recommendations.

Signed August 10, the order calls for the measles, mumps, and rubella vaccine as three separate shots (1-3), instead of the combination MMR vaccine. Once those individual injections are available domestically, the guidance suggests offering them at separate medical appointments rather than all at once. Public health experts say the consequence is likely to be delayed protection for some young recipients and missed doses for many more. (4, 5)

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Protect Progress Against Measles:

Cost-effective, fully protective, combination vaccines will still be available for parents who consent and children who fall into low-risk categories. Experts urged parents to talk to a trusted clinician about what is best for their individual children. (6)

"The White House says its "gold standard" guidance puts the US more in line with other developed countries, but the US has not used the individual vaccines in more than 50 years. (7-9)"

The White House says its "gold standard" guidance puts the US more in line with other developed countries, but the US has not used the individual vaccines in more than 50 years. (7-9)

More than 210 professional health organizations signed a joint statement of concern, condemning the executive order as inconsistent with empirical research. (10) The unnecessary shift, according to the pharmacists, scientists, doctors, nurses and professionals who signed, risks eroding "confidence in childhood vaccinations," leaving "children less protected and families more confused."

HHS Seeks Input on Broader Vaccine Changes:

The executive order may also lead to broader changes in how federal vaccine recommendations are developed and communicated. On August 21, HHS announced a Request for Information seeking public input on the categories used in federal vaccine recommendations and the role of shared clinical decision-making. (11)

These questions could influence not only how vaccines are recommended, but also how families and clinicians interpret federal guidance. As federal guidance continues to shift rapidly, any changes to the recommendation framework should be grounded in strong evidence, clearly communicated, and designed to support informed conversations between parents and trusted health care providers.

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Spacing Out Vaccines Carries Risks:

Creating extra barriers to full vaccine protection through multiple medical appointments will likely decrease vaccine schedule compliance even for families without safety concerns. (12) The likely result is fewer fully protected children and more lives at risk.

Vaccine-preventable diseases are resurgent in America. Amid a 35-year high in US measles cases, rising requests for vaccine exemptions, and falling rates of full vaccination among kindergarteners, (13-17) clear guidance from the medical community is more important than ever.

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Disclosure: Josie Cooper is a Senior Advisor for the Alliance for Patient Access. This article was also published at healthpolicytoday.org.

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Pioneer Profile—William H. Tooley, MD

Joseph B. Philips, III, MD, FAAP



(61)

William H. (Bill) Tooley was truly a pioneer in our field. He was born in Berkeley, CA, in 1925, attended Carroll College in Montana, and earned his M.D. from the University of California, San Francisco (UCSF) in 1949. (1) His residencies were at UCSF and Bellevue Hospital in New York City. He served in the Navy from 1951 to 1954, then, after a two-year stint in private practice, joined the faculty at UCSF School of Medicine where he founded one of the first Neonatal ICUs and helped establish the field of neonatology itself. His list of collaborators and trainees who went on to distinguished careers is enormous and a veritable "Who's Who" of neonatology and fetal/neonatal physiology. An incomplete listing of these includes John A. Clements, (2) George Gregory, Roderick Phibbs, Joseph Kitterman, Abraham Rudolph, Michael Heymann, Marshall Klaus, (3) William Oh, Phillip and Roberta Ballard, Sir Graham (Mont) Liggins, Thomas Hansen, John Severinghaus, Hans Versmold, Joyce Peabody, plus numerous others.

"He served in the Navy from 1951 to 1954, then, after a two-year stint in private practice, joined the faculty at UCSF School of Medicine where he founded one of the first Neonatal ICUs and helped establish the field of neonatology itself. His list of collaborators and trainees who went on to distinguished careers is enormous and a veritable 'Who's Who' of neonatology and fetal/neonatal physiology."

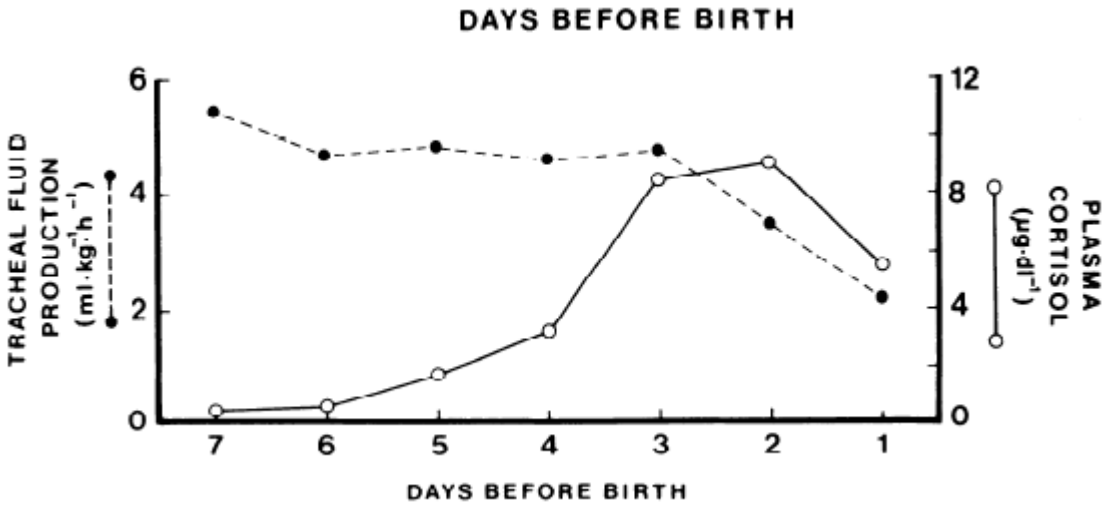
Dr. Tooley authored well over 100 scientific articles spanning several fields relevant to neonatology, including fetal and neonatal physiology, surfactant biology and replacement therapy, transcutaneous monitoring, neurodevelopmental outcome, and others, as well as serving on the Fetus and Newborn Committee of the American Academy of Pediatrics (AAP), where he participated in the writing of important guidelines. I will review what I think are the most important of these, including major contributions to two of the most significant advances in the history of neonatology—continuous positive airway pressure (CPAP) and surfactant replacement therapy.

"Dr. Tooley authored well over 100 scientific articles spanning several fields relevant to neonatology, including fetal and neonatal physiology, surfactant biology and replacement therapy, transcutaneous monitoring, neurodevelopmental outcome, and others, as well as serving on the Fetus and Newborn Committee of the American Academy of Pediatrics (AAP), where he participated in the writing of important guidelines."

Respiratory physiology of the neonate was an early and enduring interest for Dr. Tooley. His first foray into this field was at the annual meeting of the American Pediatric Society (APS) in 1960. (4) In collaboration with Drs. Klaus and Clemens, Tooley used a plethysmograph and the nitrogen washout technique to determine that the average alveolar tidal volume in normal newborns is 4.2 ml/kg, while the lung dead space is 2.2 ml/kg and functional residual capacity (FRC) is 22 ml/kg with a rather large standard deviation of ± 6ml/kg. These numbers are remarkably similar to those we use today. A follow-up study two years later showed that FRC is rapidly established after birth in normal infants and remains stable over the first four days. (5)

An important study published as a preliminary report in 1965 made the argument that the Idiopathic Respiratory Distress Syndrome (IRDS), also known as Hyaline Membrane Disease (HMD), was caused by pulmonary hypoperfusion. (6) The authors supported this theory with various measures of lung function and perfusion. Notably, one of the co-authors, A. Y. (Bud) Sweet, MD, was Chief of the Division of Neonatology at the Mount Sinai School of Medicine in New York City when I was a house officer there from 1975–1977. This paper was followed by a massive 74-page tome in which several novel methods were introduced to neonatology, including pneumotachographs, rebreathing apparatus, micro blood gas monitoring, plus others. (7) The authors were also early adopters of umbilical vessel cannulation. Attempts to treat IRDS with acetylcholine HCl, as in the previous report, showed transient improvement. In addition, what may have been the first attempts at surfactant replacement therapy, dipalmitoyl lecithin (DPL), then known as the primary component of surfactant, was given to 15

Figure 1. Average Tracheal fluid output and plasma cortisol levels in 6 chronically instrumented fetal lambs. Used with permission. (12)



infants. Lung compliance improved somewhat, but gas exchange did not. We now know that DPL alone is not an effective remedy for surfactant deficiency, as we will discuss later. These two reports generated lively debate via letters to the editor, which I will not elaborate on here.

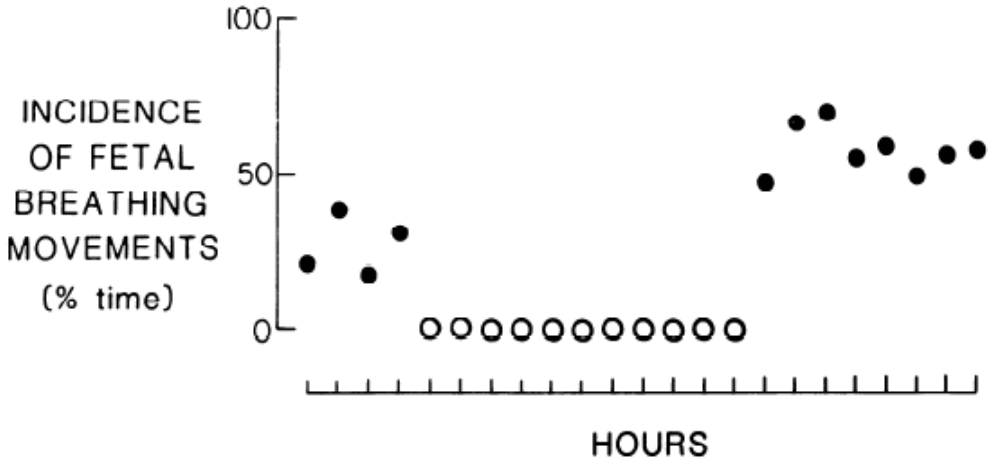
Erythroblastosis fetalis was unfortunately rather common early in Dr. Tooley's career, as prophylactic infusions of Rh immune globulin to prevent maternal development of anti-Rh antibodies had not yet been introduced. Tooley and colleagues published a series of three case reports detailing various cardiorespiratory and hematologic abnormalities observed in 61 infants born with varying severity of erythroblastosis fetalis. (8–10)

Another study reported the effects of pneumothorax on vital signs and blood gases in 55 infants with IRDS, (11) while another documented the effects of sleep state on blood gases in normal newborns and young infants. (11)

Dr. Tooley also studied various aspects of fetal and neonatal physiology. Tracheal fluid output was studied in fetal lambs and was found to decrease significantly in the days before birth, which correlated with a marked increase in serum cortisol levels (Figure 1). (12) Prostaglandins were a hot topic from the late 1970s into the 1980s. Tooley and colleagues showed that infusions of prostaglandin synthesis inhibitors markedly increased fetal breathing movements, with maximal effect achieved after six hours of continuous infusion. (13) Conversely, infusions of various prostaglandins were found to inhibit fetal breathing movements (Figure 2) markedly. (14)

The endorphin antagonist naloxone was found to significantly increase respiration in rabbit pups up to 5 days of age but not thereafter, suggesting that endorphins may help regulate breathing shortly after birth. (15) Another study found that acute reductions in inspired oxygen concentrations in infants with chronic lung disease caused significant increases in airway constriction (Figure 3). (16) This correlates with the dreaded "clamp down" episodes

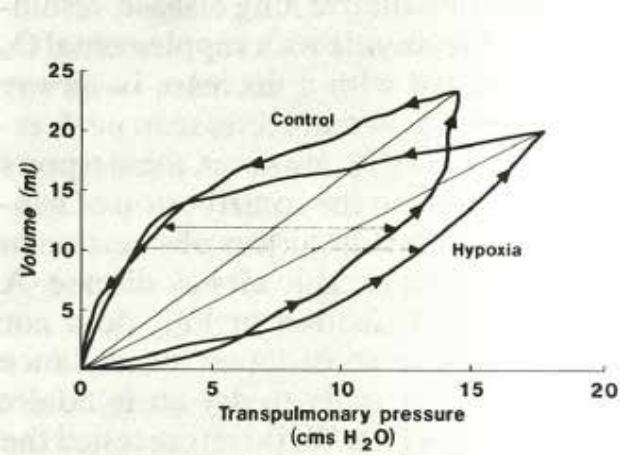
Figure 2. Inhibition of breathing movements induced by infusion of prostaglandin E2 in a near-term fetal lamb. Black dots indicate movements before and after infusion, while circles represent movements during infusion. Used with permission. (14)



we witness in our infants with bronchopulmonary dysplasia (BPD) today.

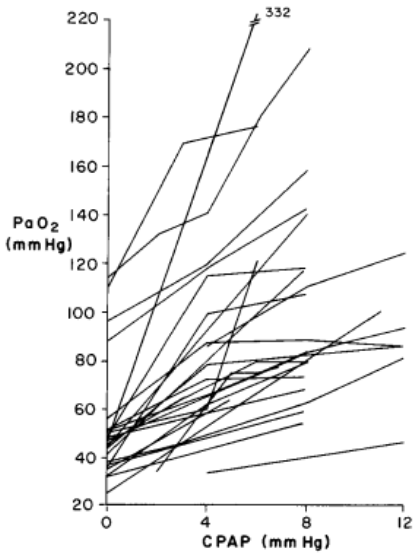
Dr. Tooley co-authored the landmark study by Dr. George Gregory in the New England Journal of Medicine (NEJM) that brought CPAP into the NICU, forever changing the trajectory of illness for infants with HMD, now known as respiratory distress syndrome (RDS) (Figure 4). (17) CPAP was also shown to improve functional residual capacity and ventilation-perfusion matching in infants post cardiac surgery. (18)

Figure 3. Pressure-volume loop in an infant with chronic lung disease before and during induced hypoxia. Used with permission. (16)



Surfactant biology was an enduring interest to Dr. Tooley. Just three years after Avery and Mead identified surfactant deficiency as the cause of RDS, Tooley's group studied the effect of cardiopulmonary bypass on surface activity of lung extracts of ten patients who died after bypass plus 15 dogs placed on bypass and found that the procedure significantly impaired surfactant function. (19) Two basic science studies evaluated the effects of atelectasis on surface tension in dogs and the effect of surface tension on the pulmonary circulation in excised dog lungs. (20, 21) Another key study entitled "Ontogeny of tracheal fluid, pulmonary surfactant, and plasma corticoids in the fetal lamb" concluded, "In the last 7 days before delivery, both cortisol and surfactant increase dramatically, which is consistent with glucocorticoids causing an increase in surfactant synthesis and secretion." (22) This study was yet another early report linking corticosteroids with surfactant synthesis.

Figure 4. Effect of continuous positive airway pressure on arterial oxygen tension in infants with respiratory distress syndrome. Used with permission. (17)



"Surfactant biology was an enduring interest to Dr. Tooley. Just three years after Avery and Mead identified surfactant deficiency as the cause of RDS, Tooley's group studied the effect of cardiopulmonary bypass on surface activity of lung extracts of ten patients who died after bypass plus 15 dogs placed on bypass and found that the procedure significantly impaired surfactant function."

This was followed by a report showing that infusions of dexamethasone accelerate the appearance of surfactants in fetal lamb lungs. (23) Another study showed that surfactant levels in fetal lambs were very low during the glandular and canalicular phases of lung development and then began to increase during the transitional phase before peaking during the alveolar phase. (24) Changes in the phospholipid composition of lung surfactant during development of the fetal lamb were also reported. (25) A simple foam test of different titers of human amniotic fluid was shown to have a high predictive value in assessing the risk of RDS developing in the neonate. (26) This was confirmed in a larger study of 410 samples obtained within 24 hours before delivery and established the "Shake Test" to be a reliable predictor of the risk of developing RDS in the baby. (27)

Finally, and most importantly, Dr. Tooley was a major player in the early days of surfactant replacement therapy. Using the synthetic surfactant, Exosurf, developed by Dr. Clements, Tooley, Clements and colleagues showed that it significantly improved lung function in prematurely delivered rabbits. (28) This group then performed the first clinical trial of Exosurf, showing that it was efficacious both prophylactically and as an early treatment of RDS. (29) A subsequent study showed that the treatment was not only efficacious but also cost effective.(30) Thus, Dr. Tooley helped pioneer the development and implementation of surfactant replacement therapy.

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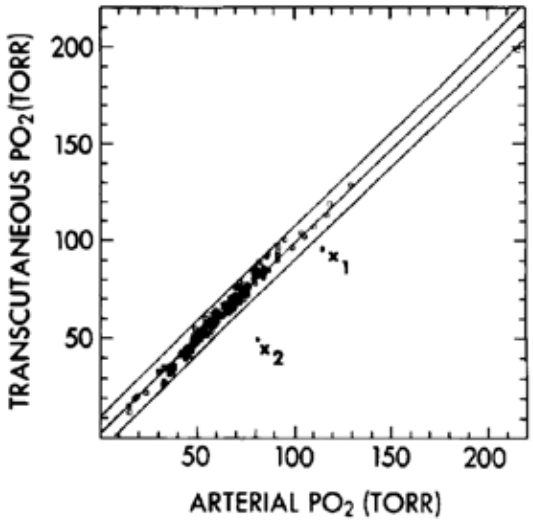
In addition, Dr. Tooley made many important contributions to clinical neonatology. Normative values for mean aortic blood pressure were published. (31, 32) These studies used umbilical artery catheters, and Tooley's group were early adopters. They published several commentaries on the risks associated with their use, including thrombi and bacterial contamination, concluding that the benefits outweighed the risks if the catheters are properly inserted and cared for. (33–35) Kitterman, Phibbs, and Tooley published a comprehensive review of umbilical catheter use, covering insertion, maintenance, use, and complications. (36)

Tooley et al. were also early adopters of transcutaneous gas monitoring. An early study showed a highly significant correlation between transcutaneous oxygen tension and arterial oxygen tension in normotensive infants (Figure 5). (37) Similar results were found using a heated transcutaneous carbon dioxide electrode with the caveat that a correction factor was necessary, as the transcutaneous values were an average of 1.37 times higher than the arterial values. (38) Transcutaneous electrodes were then used to assess the ventilatory response to inhaled carbon dioxide in infants with and without apnea of prematurity, concluding that "serious apnea of prematurity is related to developmental delay of central CO_2 chemoreceptor activity. This chemoreceptor eventually attains normal function, and serious apnea disappears." (39)

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Dr. Tooley co-authored an important NEJM article documenting the incidence of patent ductus arteriosus (PDA) in premature infants, its presentation and effect on the lungs, and management (Table). (40) This was followed by a report on the surgical closure of the ductus in 21 infants, concluding, "Brain damage, retrolental fibroplasia, bowel ischemia, and progressive, irreversible lung disease are not inevitable consequences of prematurity and severe IRDS without heart failure. As far as we can determine, operation does not induce these complications." (41) Current knowledge suggests that this is incorrect, as active treatment of PDA in the current era may do more harm than good. (42)

Figure 5. Correlation between transcutaneous and simultaneous arterial oxygen tension. Used with permission. (37) The two outliers were hypotensive.



A prospective study of 1000 consecutive births showed an 8.8% incidence of meconium staining, with slightly over half having meconium suctioned from below the vocal cords. (43) The suctioning procedure was described thusly: "The resuscitator placed his or her mouth over the endotracheal tube and sucked as the tube was removed (a paper face mask placed over the endotracheal tube connector prevented inhalation of meconium)." This was how we did it during my training and early career, but we later abandoned it for obvious reasons. Routine tracheal suctioning of infants born with meconium stained amniotic fluid is no longer recommended.

Table. Clinical signs of patent ductus arteriosus in 29 premature infants. Used with permission. (40)

Signs	No. of Patients
Physical:	
Systolic murmur	29 (100%)
Accentuated peripheral pulses	27 (93%)
Systolic murmur continuing into diastole	24 (83%)
Hyperactive precordium	22 (76%)
Tachycardia	22 (76%)
Tachypnea	21 (72%)
Roentgenographic:	
Increased pulmonary vascularity	18 (62%)
Enlarged heart	17 (59%)

An epidemiologic study of bronchopulmonary dysplasia, published in 1979, showed a reduction in incidence over the ten years preceding the report, correlating with increased use of CPAP and mechanical ventilation, especially in smaller infants. (44) A multicenter survey of eight NICUs revealed the striking finding that Columbia University had a much lower rate of premature infants requiring supplemental oxygen at 28 days than the other centers. (45) An investigation of the possible reasons showed that Columbia initiated CPAP earlier than the other centers, often in the delivery suite, and concluded, "The physiological basis for the good results reported from Columbia could be multifactorial. It seems probable that early intervention with continuous distending

airway pressure facilitates the maintenance of an adequate functional residual capacity and promotes improved gas exchange from the first minutes of postnatal life." We know this to be true today.

Tooley and colleagues also examined development and outcomes. Two studies, including one published in Science, measured brainstem auditory evoked potentials (BAEPs) to assess brainstem function and found differences between infants considered "at risk" and normal infants. (46, 47) A further report traced changes in BAEPs in normal individuals from prematurity to adulthood. (48)

Erythroblastosis fetalis resulting from Rh sensitization in mothers was, as previously mentioned, all too common before Rh immune globulin came along. Fetuses were treated with intrauterine transfusions (IUT) to ward off the development of hydrops fetalis. Tooley and colleagues reported on the neurodevelopmental outcomes of 24 surviving children and tentatively concluded that "when IUT is used in appropriately selected fetuses and combined with aggressive therapy during the neonatal period, most survivors will be neurologically intact." (49)

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Another study reported on posthemorrhagic hydrocephaly (PHHC) in 22 infants. (50) Some were managed with serial lumbar punctures to relieve the fluid buildup, which was a thing back then, but was subsequently shown not to be efficacious. With developmental follow-up, they concluded, "These results indicate a poor long-term outlook for the low birth weight infant who develops clinically overt hydrocephalus after intracranial bleeding." Fortunately, many infants do better today.

A study of exercise performance of survivors of RDS found "This study shows that lung repair following HMD is probably complete in most survivors by school age. Their lungs perform in a normal fashion, and these children can be expected to perform physically as well as their peers." (51) However, the most severely affected children had abnormal findings, and the authors were uncertain if their lungs would ever become fully functional. An early developmental follow-up study of infants weighing <1,500 grams born from 1965 to 1978 found that the quality of life for survivors appeared to be "relatively good" but emphasized the importance of close follow-up and early intervention. (52) This cohort was reevaluated at 8 and 11 years of age and 80% were found to have IQs in the normal range, but many were also found to have various developmental abnormalities. (53) Interestingly, a major finding which we know to be true today was "When ratings were dichotomized (ie, low v. high neonatal illness and low v. high parent education), the level of neonatal illness primarily influenced the likelihood of normal outcome, whereas the level of parent education influenced the degree of severity of the disability."

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A final follow-up study published after Dr. Tooley's death investigated the effect of mode of delivery on neonatal and long-term outcomes of infants weighing <1,500 grams born between 1975 and 1990 to mothers with pre-eclampsia. (54) No differences were found between those born by induced vaginal delivery or cesarean section except for a reduced incidence of RDS in born vaginally. The authors suggested that a trial of induced labor be considered for such women.

Dr. Tooley also took part in several conferences that helped define the early trajectory of neonatology. A lengthy summary of a 1974 conference discussed ethical dilemmas in the resuscitation and intensive care of premature infants and babies with serious congenital anomalies and proposed an ethical framework to guide clinicians. (55) Another report addressed the knotty issues surrounding termination of life support. (56) Regionalization of newborn care and neonatal transport were the subjects of yet another important meeting with Drs. Tooley and Jay Goldsmith authored the summary. (57)

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Due to his prominent stature in the field, Dr. Tooley was asked to author a number of editorials, only one of which will be discussed here. This one summarized the problem of sudden infant death syndrome and the funding authorized by Congress in 1974 to attempt to identify the cause(s) and potential preventive measures. (58) Sadly, these efforts did not bear fruit, but we now know that placing infants supine for sleep reduces the frequency of sudden infant death.

"While serving on the Fetus and Newborn committee of the AAP, Dr. Tooley helped develop several guidelines, including on oxygen therapy in neonates, which concluded, 'Oxygen tension of arterial blood should not exceed 100 mm Hg and should be maintained between 60 to 80 mm Hg.' Another important guideline addressed the use of hexachlorophene for skin care in the nursery."

While serving on the Fetus and Newborn committee of the AAP, Dr. Tooley helped develop several guidelines, including on oxygen therapy in neonates, which concluded, "Oxygen tension of arterial blood should not exceed 100 mm Hg and should be maintained between 60 to 80 mm Hg." (59) Another important guideline addressed the use of hexachlorophene for skin care in the nursery. (60) At the time, staphylococcal infections were rampant in nurseries, and many units gave babies daily baths with hexachlorophene to reduce skin colonization. However, reports that blood levels of hexachlorophene in babies receiving such treatments approached those shown to be neurotoxic in adult rats sparked the issuing of the guidelines stating, "the *routine* prophylactic use of hexachlorophene for total body bathing of newborn infants in hospital nurseries or at home is not recommended." (60)

Dr. Tooley died too young at age 66 in 1992. His contributions to our field were immense and far-ranging. This is best summed up by the following, written by three of his long-time colleagues, Drs. John Clements, Joseph Kitterman, and Roderick Phibbs.

"Dr. Tooley died too young at age 66 in 1992. His contributions to our field were immense and far-ranging."

"In sum, William Tooley was a physician and scholar of exceptional gifts. Throughout his career he made vital contributions both to clinical care of infants and to the fundamental knowledge on which that care is based. He had no peer in his indefatigable weaving together of the theory and practice of newborn care. Recital of his achievements, impressive as they are, does not do justice to the man. He was a tower, literally, of strength to his colleagues, who treasure special memories of him. Tooley touched them in so many ways—by his warmth and generosity; by his brilliance and quick wit; by his dedication to his profession and his school; by his tolerance and help to those who were less gifted than he; by his personal magnetism and his unique style; by his commitment to excellence in everything he did; by his dignity and statesmanship in conducting his personal and professional affairs; but most of all by his unswerving integrity. His captivating persona and the way he lived his life inspired all who knew him. These attributes and his professional accomplishments will be long remembered." (1)

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NT

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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.**

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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.

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Used for decades against chickenpox, malaria and tuberculosis.

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

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

Safe and Sound

COVID vaccines have been:

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

Get Your Jab

Vaccines are available at your:

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



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

1. https://www.mayoclinic.org/diseases-conditions/coronavirus/symptoms-causes/syc-20479963
2. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8782520/
3. https://www.nejm.org/doi/full/10.1056/nejmc2107717
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5. https://www.cdc.gov/vaccines/covid-19/clinical-considerations/interim-considerations-us.html
6. https://doh.wa.gov/emergencies/covid-19/vaccine-information/safety-and-effectiveness
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Still a **Preemie?**

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

But that's not every preemie's story.

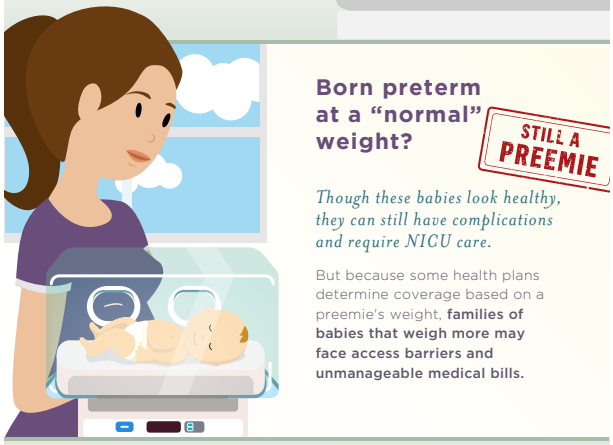
Born between 34 and 36 weeks' gestation?

STILL A PREEMIE

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

Jaundice | Feeding issues | Respiratory problems

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



Born preterm at a "normal" weight?

STILL A PREEMIE

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

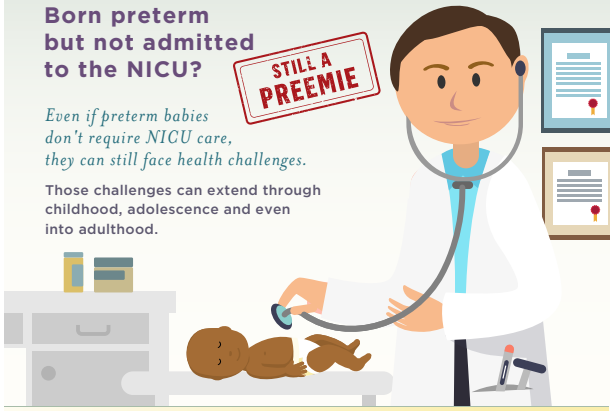
But because some health plans determine coverage based on a preemie's weight, **families of babies that weigh more may face access barriers and unmanageable medical bills.**

Born preterm but not admitted to the NICU?

STILL A PREEMIE

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

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



Some Preemies

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

All Preemies

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

NCfIH National Coalition for Infant Health

Protecting Access for Premature Infants through Age Two

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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 Summer of Empowerment: Heat Waves Will Not Stop iCAN KIDS from Changing the World!

Abby Clark

Get involved today and Join the iCAN Parent Council!

"Read below to learn more about the incredible work they have done this month, and welcome to the new chapters joining our incredible community."

As the sun shines its golden rays on the Western Hemisphere, iCAN youth members are taking action this scorching summer. Sharing their expert opinions, telling their stories, and traveling around the world, iCAN youth members have brought their empowering spirit to the global healthcare community. Read below to learn more about the incredible work they have done this month, and welcome to the new chapters joining our incredible community.

What is in this Issue of the iCAN Newsletter?

- What is iCAN?
- 2026 iCAN Summit Speaker Spotlight: Brian (KIDS RAiN CRAG)
- Looking Ahead: How Youth are Transforming the World of Healthcare Advocacy
    - Ask the Experts: Looking ahead to September and Beyond
    - iCAN Impact: New Global Chapters
- iCAN 2027 Summit

2026 iCAN Summit Speaker Spotlight:

Every year, iCAN young people share their voices at the iCAN Summit. Brian is one of those standout young people! From iCAN's Ireland Chapter and RAiN All Ireland Rare Diseases Research Network, Brian shared his voice and passion for human rights with over 150 clinicians, industry partners, parents, and other youth. His inspiring perspective and passion for pediatric empowerment show that youth voices continue to effect change on a global scale!

"Every year, iCAN young people share their voices at the iCAN Summit. Brian is one of those standout young people!"

"The people I have met and the stories I have heard have inspired me greatly. They have shown me that while our journeys may be different, we are bound by shared experiences. This is a community of people who understand the journey, who share similar experiences, and who can achieve so much by supporting and learning from one



another."



What is iCAN?

iCAN, the International Children's Advisory Network, is the premier global pediatric platform empowering the patient voice in healthcare, driven by youth for youth. As a worldwide network of 50+ KIDS (Kids Impacting Disease through Science) advisory groups spanning four continents (as well as virtually), iCAN's dedicated youth member groups work together to give children and families a voice 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.

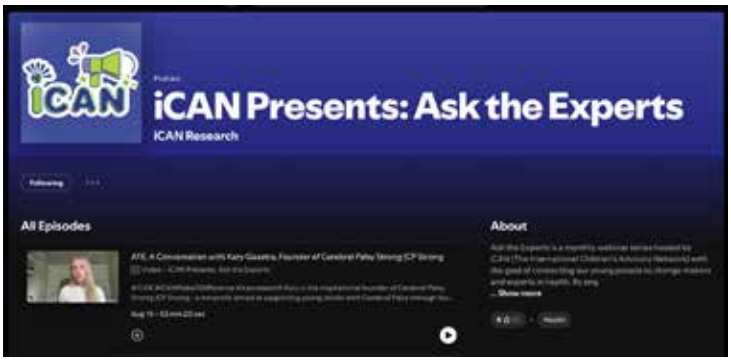
On average, our youth are between the ages of eight and twenty-one years old, most of whom are living with chronic, rare, and complicated diagnoses, although not all of iCAN's youth members have a medical diagnosis or medical condition. iCAN celebrates the understanding that all patients, even the youngest, have valuable insights into improving the healthcare experience. All children from anywhere 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 youth are placed in positions where their voices are heard, and they can 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 you are a patient, family member, friend, healthcare professional, or anyone 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.



Looking Ahead: How Youth are Transforming the World of Healthcare Advocacy this Summer and Beyond:



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directly with these healthcare transformers, our youth can learn about topics they are interested in, careers to explore, and additional ways to engage in the broad world of healthcare.

- Mark your calendars:
  - iCAN invites you to another installment of Ask the Experts on September 19, 2026, at 11 am EST. Topic: Youth Engagement in Research (YER): How We Designed a Roadmap for Pediatric Patient Engagement!
  - We will talk about how iCAN and this researcher worked together to create a roadmap for meaningful pediatric patient engagement in a FER course and how kids, teens, and families can help shape the research that affects them.
  - RSVP Here
- Future ATE Sessions:
  - October 17 - iCAN's ATE: A Conversation with Chris Evans, CEO of Little Journey & KIDS host Berkley
  - November 14 - iCAN's ATE: A Conversation with Pradnya Haldipur, Founder and Principal of Strategy. Creativity. Mentorship
  - January 16 - ATE: A Conversation with Katie, Courage Tees
- Want to be part of our next *Ask the Experts* Session? Please reach out to sabina@icanresearch.org.

"iCAN is expanding our reach! Our mission is to ensure that Healthcare leaders hear every Child Everywhere. As such, we are so excited to welcome chapters from near and far to the iCAN family. As such, we are so excited to welcome chapters from near and far to the iCAN family."

iCAN Impact: New Global Chapters:

iCAN is expanding our reach! Our mission is to ensure that Healthcare leaders hear every Child Everywhere. As such, we are so excited to welcome chapters from near and far to the iCAN family.

- KIDS Pakistan: We are beyond excited to welcome KIDS Pakistan to the iCAN family! Through our partnership with PEER – Partnership to Empower Adolescent Engagement in Research, we have officially established the KIDS Pakistan Chapter!
- KIDS Australia: A warm welcome to the newest member of the iCAN family—KIDS Australia! We are thrilled to celebrate this exciting new chapter and congratulate the team on receiving the HERA Collaborate Grant.
- KIDS Morocco: Alongside Project Rare, we welcome KIDS Morocco to the iCAN Network.

We cannot wait to see the incredible impact these chapters will make for children and their families. These new chapters will create opportunities for children and young people worldwide to connect with peers, share their experiences, and ensure their voices are heard in pediatric healthcare.



The 2027 iCAN Summit:

Our annual Summit serves as a transformative platform for innovation, compassion, and collaboration in pediatric healthcare. 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 a tangible and real way. By giving every kid a seat at the table through discussion and co-creation, current and future pediatric patients are both empowered and transformed. The upcoming Summit will take place in July 2027 - location to be determined.

We invite you to be part of this life-changing event by contributing in meaningful ways:

1. Sponsor the 2027 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. 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. We deeply value your generosity and dedication. Let us create a summit experience that empowers the pediatric community for years to come.

Let us work together to make our 2027 Summit even bigger by

bringing more kids to share their voices! To help fund next year's Summit, please click here to sponsor or donate.

Disclosures: *There are no reported disclosures*

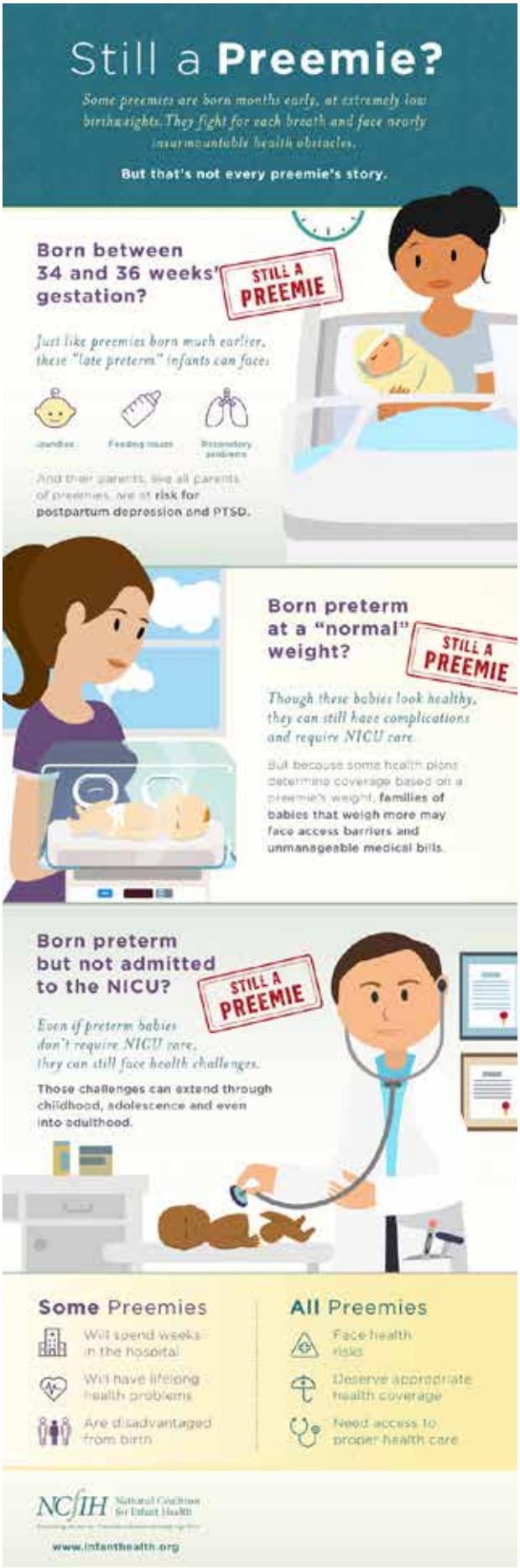
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Corresponding Author



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13

ICCN

INTERNATIONAL CONFERENCE ON CLINICAL NEONATOLOGY

25-27 SEPTEMBER 2026

Grattacielo Intesa Sanpaolo

TURIN - ITALY

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INTERNATIONAL CONFERENCE
ON CLINICAL NEONATOLOGY

25-27 SEPTEMBER 2026
Grattacielo Intesa Sanpaolo, TURIN - ITALY



A few numbers on ICCN...

300+ Participants

100+ Abstracts

40+ Expert Speakers

Main Conference Topics:

- RSV Burden
- Infant immunization
- Maternal immunization
- Innovation and Technology in Neonatology- the Smart Hospital NICU Project
- The RSV vaccine pipeline
- Perinatology

Scientific Rationale:

This Conference aims at gathering together international Experts in Neonatology, Perinatology and Neonatal – Infant Medicine in order to update the scientific community and to give practical hints to the attendants.

The core value of the scientific program is to propose and discuss the most updated evidence-based science, and to bridge together scientists and clinicians, since finding feasible evidence-based solutions for the clinical daily dilemmas occurring in the Neonatal and Infant Units is a priority.



Conference Committees

Conference Chairman



Paolo Manzoni
Professor of Pediatrics and Neonatology
University of Torino, Italy

Conference co-chairs



Eugenio Baraldi
Professor of Pediatrics
University of Padova, Italy



Guilherme Sant'Anna
Professor of Pediatrics / Neonatal Division
McGill University Health Center,
Montreal, Canada



Bianca Masturzo
Chief of Obstetrics
and Gynecology Department
Ospedale degli Infermi,
Biella, Italy



PROGRAMME

Day 1 ▸ September 25th

8th GEM – the Resvinet Global Expert Meeting on Pediatric and Neonatal Respiratory Viruses

08:30 - 08:45	**Opening and Start of the day** *Chairs: Louis Bont (Netherlands)* *Paolo Manzoni (Italy)* *Eugenio Baraldi (Italy)*
08:45 - 10:15	**1st session: RSV burden and impact of population prophylaxis strategies**
08:45 - 09:10	Impact of infant RSV prophylaxis with Nirsevimab: views from different Countries and from different organizational models *Paolo Manzoni (Italy)*
09:10 - 09:35	Impact of maternal RSV immunization: the global data *Gonzalo Perez Marc (Argentina)*
09:35 - 10:00	Pneumococcus and respiratory viruses: fatal attraction? *David Greenberg (Israel)*
10:00 - 10:15	Discussion (15 minutes)
10:15 - 10:45	**Coffee break**
10:45 - 12:15	**2nd session: The new post RSV world**
10:45 - 11:10	How will RSV look like? *Pablo Sanchez (USA)*
11:10 - 11:35	Emerging viruses: will universal RSV prophylaxis change the game? *Carlo Pietrasanta (Italy)*
11:35 - 12:00	Will hMPV be on the rise? Can we expect that it will become a threat? *Maria Ailen Bruno (Italy/Argentina)*
12:00 - 12:15	Discussion (15 minutes)



12:15 - 13:15	**INDUSTRY SUPPORTED SESSIONS** **From Recommendations to Evidence: Key Considerations for Successful Implementation of RSV Maternal Immunization** **CLICK TO VIEW PROGRAMME**
13:15 - 14:30	**Lunch Break and Poster walk**
14:30 - 16:00	**3rd session – RSV Advocacy towards parents and stakeholders** (jointly with GAFPA) Enhancing the skills of communication between physicians and patients / families in the area of paediatric respiratory infections
16:00 - 18:45	**What's next - new issues, new challenges**
16:00 - 16:25	Clesrovimab: the new actor on stage *Flor de Maria Munoz Rivas (USA)*
16:25 - 16:50	Antivirals for RSV: May they be an option? *John De Vincenzo (USA)*
16:50 - 17:15	What about Nosocomial RSV infections in ICU settings? A comprehensive view. *Harish Nair (UK)*
17:15 - 18:00	RSV platform session – last-minute science and papers
18:00 - 18:20	All panelists – Q & A / **DISCUSSING THE FUTURE OF RSV IMMUNIZATION**
18:20	**Closing Remarks** *Louis Bont (Netherlands), Eugenio Baraldi (Italy), Paolo Manzoni (Italy)*



Day 2 ▸ September 26th

projet hôpital intelligent — smart hospital project

13th ICCN – Innovation and technology in Neonatology and Perinatal Medicine (26-27 September)

Chairpersons: Guilherme Sant'Anna (Canada-Brazil), Bianca Masturzo (Italy), Paolo Manzoni (Italy)

An update on New Technologies and the Role of Innovation in neonatal care: the Smart NICU project and the Smart Hospital Project Symposium *(Chair G. Sant'Anna, P. Manzoni)*

Moderators: Dr. Robert Kearney, PhD & Dr. Paolo Manzoni, MD, PhD

Introduction and Learning Objectives

8:45 AM - 8:55 AM	**Dr. Paolo Manzoni, MD, PhD** Why innovation and technology for the NICU ? **(10-min talk)**

Session 1

8:55 AM - 9:15 AM	**Dr. Guilherme Sant'Anna, MD, PhD** Towards the Development of a Smart NICU **(20-min talk)**
9:15 AM - 9:35 AM	**Eva Sénéchal, PhD** Wireless Skin Sensors in the NICU: What's done and what's next? **(20-min talk)**
9:35 AM - 9:55 AM	**Klara Kipczak & Sofia Palacios Cuevas** AWARD Clinical International Study: Phases 1 &2 **(15-min talk)**

9:55 - 10:10 AM: Session 1 Q&A

10:10 - 10:50 AM: Break (40mins)

Come visit us at our booth!

We'd love to answer your questions on our project. We have our technology on display, branded swag you can take home and prizes for lucky winners!

Session 2

10:50 AM - 11:10 AM	**Dr. Robert Kearney, PhD** Biomedical engineering in the evaluation of novel vital sign sensors: Challenges and solutions **(20-min talk)**
11:10 AM - 11:30 AM	**Dr. Ha Uk Chung, PhD** Skin-Interfaced Wireless NICU Monitoring: Innovation for Smart NICU Hospital **(20-min talk)**
11:30 AM - 11:50 AM	**Dr. Wissam Shalish, MD, PhD** Next-Generation Neonatal Respiratory Monitoring: Insights from the Neo-BEAT Lab **(20-min talk)**

11:50 AM - 12:05 PM: Session 2 Q&A

1:00 - 2:30 PM: Lunch Break (1h 30mins)

Bubble CPAP Documentary

Bubble CPAP and the Columbia Approach
(60-min screening)

Watch trailer

12:05 PM - 12:15 PM	**Wrap-up and Closing Remarks** Paolo Manzoni & Guilherme Sant'Anna



12:15 - 13:00	Innovation in BPD prevention: the science and the early data behind the strategies of IGF-1 replacement *Chair: Eugenio Baraldi* *Speaker: Wes Onland* *Discussant: Daniele De Luca*
13:00 - 14:30	**Lunch Break**
	During Lunch Break: The Bubble CPAP Documentary- Bubble CPAP and the Columbia Approach
14:30 - 16:00	**Neonatal Neurology** (endorsed by ESPNIC)
14:30 - 14:50	From hypoxia to asphyxia – outcomes of neonates exposed to hypoxia *Ola Saugstad (Norway)*
14:50 - 15:10	aEEG monitoring in the NICU: where are we? *Karl Schettler (Germany)*
15:10 - 15:30	Outcomes of infants undergoing ECMO: lessons from an international registry *John De Vincenzo (USA)*
15:30 - 15:50	Discussion (20 minutes)
15:50 - 18:30	**Young Researchers Tournament – Platform Presentations** *Chairs: Mattia Spatuzzo (Italy), Fabio Midulla (Italy)*
18:30	**Closing remarks- adjourn**

Day 3 ▸ September 27th

13th ICCN – Innovation in Perinatal Medicine
Chairpersons: Bianca Masturzo (ITA), Paolo Manzoni (ITA)

09:00 - 12:00	**Neonatal and Perinatal Medicine – in conjunction with SIMP (Italian Society of Perinatal Medicine)** *Moderators: Daniele De Luca (France), Francesco Raimondi (Italy), Virgilio Carnielli (Italy)*
09:00 - 09:10	**Opening Remarks**
09:10 - 09:30	New tools and new skills for the management of labour *Tullio Ghi (Italy)* - prerecorded



09:30 - 09:50	The ODON system- real-world pactice and evidence *Bianca Masturzo (Italy)*
09:50 - 10:10	The high Altitude Baby: the impact of the hypobaric hypoxia on the newborn *Amed Soliz, (Bolivia-USA)*
10:10 - 10:30	Preventing neonatal Early Onset Sepsis – an update on the use of diagnostic tools *Karen Puopolo (USA)* - Online, Prerecorded
10:30 - 10:40	Discussion (10 minutes)
10:40 - 11:10	**Coffee Break and Poster Walk**
11:10 - 11:30	Vertical Candida infection *David Kaufman (USA)*
11:30 - 11:50	Using artificial intelligence to enhance writing vs. presenting a manuscript that does not reflect one's own work: how can we prevent such forms of misuse? *Mitchell Goldstein (USA)*
11:50 - 12:00	Discussion (10 minutes)
12:00 - 13:00	**INDUSTRY SUPPORTED SESSIONS** **One Goal, Two Specialties: Helping To Protect Infants Against RSV Disease** **CLICK TO VIEW PROGRAMME**
13:00 - 14:00	**Lunch Break**
14:00 - 16:00	**Neonatal and Perinatal Medicine – in conjunction with SIMP (Italian Society of Perinatal Medicine)** *Moderators: Daniele De Luca (France), Francesco Raimondi (Italy), Virgilio Carnielli (Italy)*
14:00 - 14:20	Nutrition of preterm neonates- what's new? *Luca Maggio (Italy)*
14:20 - 14:40	Zika and chikunguya- an update *Marco Safadi (Brazil)*
14:40 - 15:00	Use of Iron enteral supplementation during pregnancy and neonatal outcomes *Serafina Perrone (Italy)*
15:00 - 15:30	Discussion (30 minutes)
15:30 - 16:10	**Closing Remarks** **Arrivederci**



Industry Supported Sessions

Pfizer

25th September 2026

12:15 - 13:15	**From Recommendations to Evidence: Key Considerations for Successful Implementation of RSV Maternal Immunization** *Panelists: Paolo Manzoni (Italy), Marco Safadi (Brazil), Irene Cetin (Italy)*
12:15 - 12:25	**WELCOME AND INTRODUCTION** **Timing matters: Optimizing Antibody Transfer and Infant Protection Following RSV Maternal Vaccination** *Paolo Manzoni (Italy)*
12:25 – 12:45	**Demonstrating Consistent Effectiveness: Lessons From Global RSV Maternal Vaccination Programs** *Marco Safadi (Brazil)*
12:45 – 13:05	**Supporting Informed Choices: Review of Patient Preferences, Uptake and Safety Data for Maternal Immunization** *Irene Cetin (Italy)*
13:05 - 13:15	**PANEL DISCUSSION AND Q&A** *Moderator: Paolo Manzoni (Italy)* *Panel: Marco Safadi (Brazil), Irene Cetin (Italy)*



27th September 2026

12:00 - 13:00	**One Goal, Two Specialties: Helping To Protect Infants Against RSV Disease** *Panelists: Paolo Manzoni (Italy), Gonzalo Pérez Marc (Argentina), Fatima Husain (UK)*
12:00 - 12:10	**WELCOME AND INTRODUCTION** **Helping To Protect Infants From Day One: Why Timing Matters In RSV Maternal Immunization** *Paolo Manzoni (Italy)*
12:10 - 12:30	**Real World Impact: Translating RSV Maternal Vaccination Into Meaningful Clinical Outcomes** *Gonzalo Pérez Marc (Argentina)*
12:30 - 12:50	**Bringing RSV Maternal Vaccination Into Routine Care: An Obstetrician's Perspective** *Fatima Husain (UK)*
12:50 - 13:00	**PANEL DISCUSSION AND Q&A** *Moderator: Paolo Manzoni (Italy)* *Panel: Gonzalo Pérez Marc (Argentina), Fatima Husain (UK)*



Conference Venue

Grattacielo Intesa Sanpaolo
TURIN – Italy

25 – 27 September 2026
C.so Inghilterra, 3, 10138 Torino TO

VIEW ON GOOGLE MAP

How to get to the City

By Air

Turin-Caselle Airport (TRN) is the city's main international airport, located about 16 km northwest of the city center. It offers both national and international flights and is well connected to the city via trains, buses, and taxis.

By Rail

Porta Susa is the closest station to the conference venue, it is a key railway station in Turin, offering national and international connections.

By Bus and Metro

Buses: Turin is well-served by a network of public buses that connect all parts of the city and surrounding areas. Main stops are at the train stations (Porta Nuova and Porta Susa), the city center, and residential areas.

Metro: Turin's metro system is quick and convenient, with several stops in both the city center and suburban areas.

Bus to the Airport: The "Airbus" service directly connects Turin-Caselle Airport to Porta Nuova and Porta Susa stations, providing a convenient way to get into the city.

By Car

Turin is easily accessible by car from various regions of Italy via the main highways. From the A4 highway, which connects Milan to Turin, you can drive directly into the city, with the journey taking approximately 1.5 hours. If you're coming from Bologna or Florence, the A21 highway is the best route, leading directly to Turin in about 3 hours.

How to get to the venue

The Intesa Sanpaolo Tower (Grattacielo Intesa Sanpaolo) is located in the Centro Direzionale Lingotto area in Turin, Italy. The tower is easily accessible from the city center.

How to get the venue from Torino Porta Susa Station:

The Intesa Sanpaolo Tower is within walking distance from Torino Porta Susa station, and it takes about 5 minutes to reach it on foot.

How to get the venue from Torino Porta Susa Station
The Intesa Sanpaolo Tower is within walking distance from Torino Porta Susa station, and it takes about 5 minutes to reach it on foot.

Hotel Booking

BOOK A ROOM



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What If We Are Misdiagnosing Burnout?

Weston Brandon

"This article examines the relationship between caregiver burnout and emotional disconnection in healthcare teams, drawing on the author's personal experience as a widowed NICU dad. It introduces a five-part framework for building connected care cultures through intentional storytelling and discovery."

Abstract

This article examines the relationship between caregiver burnout and emotional disconnection in healthcare teams, drawing on the author's personal experience as a widowed NICU dad. It introduces a five-part framework for building connected care cultures through intentional storytelling and discovery.

What If We Are Misdiagnosing Burnout?

What if we are misdiagnosing burnout? What if the burnout we are seeing in turnover and low engagement scores is actually a symptom of a simpler problem?

Burnout costs healthcare billions of dollars a year. Replacing a nurse in the ICU can cost between $50,000 and $100,000. Replacing a physician can cost a hospital over a million. The fix has always been the same: get more resources, get more people, make the process more efficient, get more resilience training. Telling people they need to suck it up and be mentally stronger obviously has not worked. Caregivers still leave, and everybody's HCAHPS numbers still do not lift to where they want them to be.

"Telling people they need to suck it up and be mentally stronger obviously has not worked. Caregivers still leave, and everybody's HCAHPS numbers still do not lift to where they want them to be."

However, some units do not experience this. Care teams, I have personally experienced that you might call them locked up tight. It is a coveted place to work, because once somebody gets onto that floor, they never go anywhere. They still pull double shifts sometimes. They are still short-staffed sometimes. They still have funding issues; they still have all the same things that everybody else has, but something is different about those units. Furthermore, the patients who come out of them never shut up about how amazing the people are up there.

So if we have the same systemic issues across the board, why aren't we experiencing the same results across the board? Why do some units retain their people and have solid cultures, while others cannot seem to keep somebody longer than a month?

I really learned what drives burnout when I was 23 years old, looking at a premature baby in an isolette that I did not really have much of a relationship with. He was born at 26 weeks, weighing one pound thirteen ounces. I had just buried his mother, who passed from a pulmonary embolism shortly after. (Figure 1)

"My grief was an impossible contradiction. I was so deep in depression and grief that I wanted to take my own life and follow my wife to whatever hereafter she was in. However, I also felt an impossible obligation to care for this baby I did not know, did not feel connected to, and I thought there was something wrong with me for that. I thought I was broken, because I did not feel a connection to my son."

My grief was an impossible contradiction. I was so deep in depression and grief that I wanted to take my own life and follow my wife to whatever hereafter she was in. However, I also felt an impossible obligation to care for this baby I did not know, did not feel connected to, and I thought there was something wrong with me for that. I thought I was broken, because I did not feel a connection to my son.

The nurses there continually asked me to hold him, to do kangaroo care, skin-to-skin contact. I kept telling them no. Ten, fifteen, twenty times. I figured he was safer with the professionals than he was with a father who felt like he did not even love him. My guilt about that was intense, but I did not know what else to do.

A nurse there named Bev was my primary. Bev realized something not many others did. She knew that if she was going to get through to me, she had to develop a relationship with me; she had to connect with me. So she went out of her way to get to know me, and to help me feel like I was a valued member of that team, that my opinions mattered.

One day, after she tried to get me to do kangaroo care yet again and I again denied her, she finally came over and knelt as I sat in that uncomfortable faux leather rocking chair. She put her hand on my knee and said, *"Weston, I'm not a widow. I cannot say that I know what you are going through. However, your son needs you, and you need your son. And when you're ready to put some effort into that, then you let me know."* Then she stood up and walked out.

I trusted Bev, because I knew she cared about me. She had proved that to me through the way she spoke to us, the questions



Figure 1. The author with his son, Vance, in the NICU incubator.

she asked. So when she said that, I listened. I sat in that chair for quite some time, diving deep inside my own mind to figure out what the missing piece was. Of course I was consumed with grief, missing my wife, but why did I not feel connected to my son? That is a different relationship. The best thing I could come up with was that my wife had had experiences with my son that I had not yet had, and it was up to me to put in the time to have them.

"Of course I was consumed with grief, missing my wife, but why did I not feel connected to my son? That is a different relationship. The best thing I could come up with was that my wife had had experiences with my son that I had not yet had, and it was up to me to put in the time to have them."

So I got up out of the chair, walked over to Bev, and said, *"All right, I will take him as much as you will let me have him."*

Bev taught me that authentic connection follows authentic discovery, that I needed to discover new things about my son. She started teaching me about him, setting up experiences where I could learn on my own.

One day I walked into the NICU and Vance was having quite a fuss. I checked whether he had been fed, whether his diaper needed changing. The nurses assured me he was all good to go. So I asked, being a naive 23-year-old, if he had been fed and his diaper changed, why else would he be crying? Bev came over, put her hand on my shoulder, and said, *"Honey, maybe he is just in a bad mood."* That was one of the greatest epiphanies of my life: that a baby could have a mood. I asked her what we do about that, and she said, *"Dad, maybe you could try talking to him. Maybe you try holding him."*

So we got him situated on me, got some skin-to-skin going, and when he was still fussy, I started playing different types of music. After experimenting with several songs, I finally found one that calmed him down, an old gunfighter Western song by Marty Robbins called El Paso. That singular discovery, realizing that my then 29- or 30-week-old son had a preference for styles of music, was mind-blowing to me, and the connection I felt with him in that moment was incredible.



Figure 2. The author and his son, Vance, on the day of their discharge from the NICU.

"Because of that kind of care, I walked out of that NICU, at the end of a two-and-a-half-month stay, on an upward trajectory. I was still consumed in grief, but I had something I had been missing for a while, and that was hope. (Figure 2)"

Because of that kind of care, I walked out of that NICU, at the end of a two-and-a-half-month stay, on an upward trajectory. I was still consumed in grief, but I had something I had been missing for a while, and that was hope. (Figure 2)

At the time, I thought that was just how every NICU worked, that every nursing team was that connected and with themselves. However, I found out years later, as I got more involved in speaking and consulting, that not every unit is like that. In fact, most of them probably wish they could be. So I had to figure out why. What is the difference? Why are some units revolving doors, and some units are locked down tight, like the one I experienced?

So I got curious, and I started calling nursing leaders across the country to ask what their biggest problems were.

A number of them said nurses who entered the field since COVID were their biggest issue, that they did not cover people's shifts, and that they spent more time on self-care and personal boundaries than investing in relationships with their patients. Others said physicians or other team members did not treat staff well, and that bad, siloed, clique-style behavior went on, with a lot of petty drama that weighed people down. Some described a strange

social hierarchy, where experienced caregivers carried an attitude of, "If you do not know this already, it is not my job to teach you."

It was a whole range of different personality and relationship problems, but they all boiled down to something simple: emotional disconnection. Every person I talked to who described serious burnout issues was disconnected in at least one of five areas: with themselves, with their purpose, with their team, with their leadership, or with their patients and those they serve, and for most of them, we could pinpoint one or two of those areas specifically.

"In an effort to teach how the unit I experienced as a widowed NICU dad did things so well, I boiled it down to a simple system called DRIVE. For any connection area that's suffering, if we discover the story, resolve the barriers, invest in each other, visualize success, and elevate the culture, burnout seems to disappear."

In an effort to teach how the unit I experienced as a widowed NICU dad did things so well, I boiled it down to a simple system called DRIVE. For any connection area that's suffering, if we discover the story, resolve the barriers, invest in each other, visualize success, and elevate the culture, burnout seems to disappear.

I looked back at what actually happened in that unit. How did they create connection? They created experiences, and the most effective way to create an experience for somebody is to tell a story. Authentic connection follows authentic discovery, and how do you discover things? You tell stories. If you want somebody to learn something new about you, you tell them a true story about yourself. That was the thought process that came to me: that is how we do this. The story is what matters.

"You tell stories. If you want somebody to learn something new about you, you tell them a true story about yourself. That was the thought process that came to me: that is how we do this. The story is what matters."

The story you tell yourself about yourself is your connection with yourself. The story you tell yourself about your purpose is your connection with purpose. Knowing your team members' stories, and having your story known by them, creates connection with your team. The same is true with leadership. And for your patients, it is you knowing your patients' story, and your patients knowing yours. That is literally all it is.

As I tried to apply this and teach leaders how to engineer storytelling into their units in a way that actually moved their culture, I realized that what stories are told matters as much as who tells them. Certain stories carry much more weight than others. The kinds of stories that really move people, that really offer an experience where we might discover something new, are stories that offer us a window into the soul of a person.

I learned that every healthcare professional I had ever interacted with had two distinct stories worth knowing. The story about why they got into healthcare in the first place, why they pivoted into the particular niche they are in. And the story of why they are still doing what they do.

"The origin story might be a profound experience with a family member who had a medical challenge, and healthcare workers made an impact. For some, it might be as simple as: this is what my mom did for a long time, and I know it would make her happy to have me do it too."

The origin story might be a profound experience with a family member who had a medical challenge, and healthcare workers made an impact. For some, it might be as simple as: this is what my mom did for a long time, and I know it would make her happy to have me do it too. The second story usually involves a patient, some profound emotional experience tied to a relationship they had with that patient, something that moved them, that gave them an experience where they discovered something about themselves in the process. Those are the stories worth telling.

Discovering those stories about each other deepens our connection almost instantly. In workshops, we facilitate an environment where that kind of storytelling happens. Team members do short, speed-dating-style exercises where they share their origin story and their staying story. Afterward, the group shares some of the most profound stories they heard, always sharing another person's story, never their own.

"This concept proves the principle that authentic connection follows authentic discovery, but authentic discovery must follow intentional experiences."

This concept proves the principle that authentic connection follows authentic discovery, but authentic discovery must follow intentional experiences. So the real question we should be asking ourselves is what experiences we are not allowing ourselves to have, with our team members, with those we lead, with our patients, or with ourselves.

Some newer team members might not have a profound story on why they stay where they are. If so, that is the most profound discovery a leader could make. It becomes their job to facilitate an

experience that gives that new team member the start of that story and helps the more experienced ones reconnect to their own.

I recently did a series of workshops with the respiratory department at Banner Thunderbird Medical Center in Glendale, Arizona, as part of their respiratory skills fair. The respiratory director asked me to come and do team building with her units because she felt many of them had become disconnected and did not feel valued in the work they do.

We ran this exact workshop, and I facilitated the story sharing. Afterward, I heard an experienced respiratory therapist share the story of a new respiratory graduate, a dad in his late thirties, an interesting age to change careers into respiratory care. She had learned that he got into respiratory care intentionally, because his daughter had contracted pneumonia some years earlier and almost passed, and respiratory therapists saved her life. Those respiratory therapists made such a profound impact on him that he left his career to become one himself.

"I asked everyone else in the room if they knew that about him. Not a single hand went up. Then I asked how many felt more connected to him now that they did. Every hand in the room went up."

I asked everyone else in the room if they knew that about him. Not a single hand went up. Then I asked how many felt more connected to him now that they did. Every hand in the room went up.

The director wrote to me later, saying she had never seen her team interact that way, and had never felt that kind of connection with anyone before. Their team still buzzes about it and still shares stories. They are now asking the nurses and physicians on their staff to share their stories too. That new grad, the father, is greeted with hugs and high fives on his floor now, simply because people know his story.

What a profound opportunity we have to facilitate a connected culture like this by engineering storytelling into our practice.

"Patients and families can feel that energy when they are with you. When you feel connected to those that you work with, to those that you work for, and to those that you serve, we, as the family members of patients under your care, feel a profound sense of safety and trust that could not come otherwise."

Patients and families can feel that energy when they are with you. When you feel connected to those that you work with, to those that you work for, and to those that you serve, we, as the family members of patients under your care, feel a profound sense of safety and trust that could not come otherwise.

Getting to know our patients' stories is not just a way to help them feel more comfortable with you. It is also quite an effective tool in understanding how to care for them, not just physically but emotionally as well. It means asking questions that reveal deeper meaning and deeper thinking about the people we are caring for.

Asking a young expecting father what he is most afraid of leading up to the birth of his child might reveal some surprising answers, answers that tell you a lot about how this young man thinks. Asking an elderly woman in the ICU, recovering from a fall, what she hopes to do once she has recovered reveals deeper motivations and valuable insight into her lifestyle that you may want to know for future injury risk.

However, perhaps most important of all is both learning and sharing those deeper origin stories, the reasons why you do what you do. Simon Sinek became world famous for his TED Talk on Start With Why, and I use that idea often in my work. Before my son was born, I worked in mechanical engineering software sales. I had to remind myself that I was trying to build a life for my family, for the son I was expecting, to give myself motivation to work harder, to make a few more calls.

But when my life flipped upside down, and I was holding my son in my hands, my why became him. I could hold my why in my hands. The problem was that clarity did not give me any direction. It just put a lot of pressure on me.

"They wrote things on the whiteboards, seemingly trivial things, funny facts about the people who worked there, interesting details to help parents get to know their caregivers better. They created and sustained a connected culture by informally engineering storytelling into everything they did."

Because Bev and the other nurses asked those kinds of questions, they connected with me on a level I never expected. Because of that connection, they learned what really mattered to me, what I was afraid of, what was really going on in my head. They used that to help me learn how to be a father, and to make the education on how to care for my son actually stick. They put pictures of my late wife on the door to our room, so that anyone who walked in would see them and ask about her. They wrote things on the whiteboards, seemingly trivial things, funny facts about the people who worked there, interesting details to help parents get to know their caregivers better. They created and sustained a connected culture by informally engineering storytelling into everything they did.

When I later shared these same strategies with NICU directors, NICU managers, and clinical nurse specialists at the Gravens Conference at the University of Notre Dame, 84.2% expressed high confidence that patient and family connection specifically would improve if implemented intentionally, and nearly six in ten took action on the spot, requesting implementation conversations or referring another organization before they even left the room. That workshop has since led to speaking engagements at maternal and infant care symposiums, and to consulting work with other healthcare organizations working to build the same kind of culture.

Much has happened in my life since those days in the NICU. I remarried, had additional children, and completely changed careers. My time in the NICU is my origin story, the why behind why I do what I do now. Furthermore, if you remember, I said everybody has a second story too, the one that tells them why they stay. This is mine.

My wife and I were pregnant with a little girl, our fourth child. My wife started having some light bleeding and was diagnosed with a subchorionic hematoma, nothing too concerning, just something to keep an eye on. In the following weeks, she began experiencing extreme pain and went into preterm labor at 18 weeks. We had already bought the baby clothes and set up the nursery the way we wanted it, waiting for our little girl.

"Our daughter was born around 10:30 that night, to our devastation. The moment she was born, we could see that the amniotic fluid was discolored, and we knew immediately that an infection had taken hold. Days later, the cultures confirmed a staph infection in the placental tissues, something exceptionally rare, especially since my wife had undergone no procedures that could explain how the bacteria had entered the uterus. To this day, no one has been able to tell us how it happened."

We went to the emergency room, where it was discovered that my wife had an elevated white blood cell count. Ultrasounds revealed no conclusive answers as to the location of an infection, and the lack of tenderness in my wife's abdomen initially ruled out an infection in the uterus. As her condition worsened, we grew desperate. The nurses there did everything they could, under the direction of the obstetricians, to relieve my wife's pain and stop the contractions, but to no avail. Our daughter was born around 10:30 that night, to our devastation. The moment she was born, we could see that the amniotic fluid was discolored, and we knew immediately that an infection had taken hold. Days later, the cultures confirmed a staph infection in the placental tissues, something exceptionally rare, especially since my wife had undergone no procedures that could explain how the bacteria had entered the uterus. To this day, no one has been able to tell us how it happened.

The only thing I could do in that moment was look my wife in the eyes and tell her it was not her fault.

The nurse assigned to us, Morgan, caught our daughter and clamped the cord. She placed our daughter on my wife's chest and invited her to talk to her daughter while she was still alive. My wife's attention shifted away from the horror and into a very intimate moment, telling her how much she loved her, that she wished she could have held onto her longer, that she could have stayed with us. Morgan then handed our daughter to me and invited me to do the same. I held her against my chest and felt her last movements before she passed away, while I watched Morgan hold my wife and cry with her. (Figure 3)

"My wife's attention shifted away from the horror and into a very intimate moment, telling her how much she loved her, that she wished she could have held onto her longer, that she could have stayed with us. Morgan then handed our daughter to me and invited me to do the same. I held her against my chest and felt her last movements before she passed away, while I watched Morgan hold my wife and cry with her. (Figure 3)"

I have met many people who have lost a baby and watched it leave a lasting wound on their relationship. My wife and I had planned on being done having children after the birth of our daughter, but because of the connection made with that care team, our experience changed from what could have been a horrifying trauma into something profoundly life-changing. We still grieved the loss of our daughter, but we decided at not only did we want to have another child, but we also wanted to go back to that same team, at that same hospital, no matter where we were when that happened.

Morgan facilitated a profound experience for both my wife and me. She asked questions that let us share our stories with her, so she knew how to care for us. In doing so, she created an experience that became a profound story on its own, the story that is my staying story, the reason I will continue to do this work.

"When people on our care teams intentionally withhold themselves from experiences that could foster connection, it is no wonder they feel lonely, undervalued, and disconnected."

When people on our care teams intentionally withhold themselves from experiences that could foster connection, it is no wonder they feel lonely, undervalued, and disconnected. When leaders do not take the time to learn the stories of those they lead, it is no wonder they cannot hold on to their best people. We do not feel valued. We do not feel appreciated. We certainly do not feel connected when we are asked, again and again, to do more for others than anyone does for us.

These amazing people could pour so much into us only because their own cup was full to start with. They were connected with themselves, with where they were, with their own mental and physical health, and they took care of themselves before anyone asked them to take care of someone else. They were connected with their purpose. They knew their own story, and they knew the stories of the people around

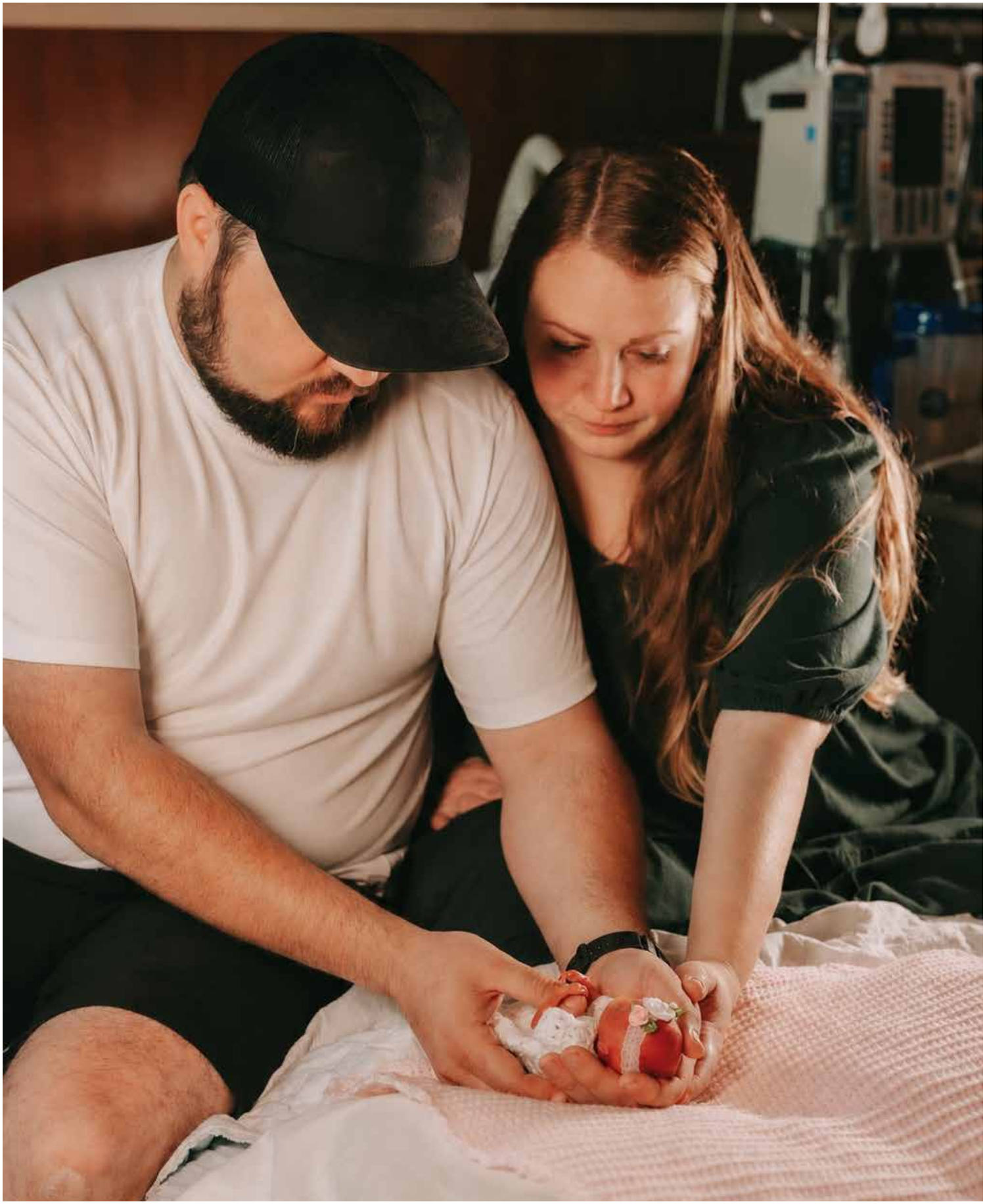


Figure 3. The author and his wife holding their daughter, Birklee, shortly after her birth.

them. They were connected with their team. They cared about each other, made sacrifices for each other, helped each other, and took each other seriously. They were connected with their leadership because their leaders valued their input, and they valued the direction they received in return, knowing it was in their own best interest and in the best interest of their patients. They were also connected with their patients and the people they served because they intentionally connected with me. They cared more about people than about money, the job, or anything else.

"They were also connected with their patients and the people they served because they intentionally connected with me. They cared more about people than about money, the job, or anything else."

Bev did that for me when I lost my wife. Morgan did it when Birklee was born. They, and so many others, had incredible stories of their own about why they were where they were, and those stories were part of what let them facilitate the kind of experiences that gave me room to write mine. They were curious enough to ask the questions that helped them discover it.

"Real systemic and organizational issues need to be addressed, and I have strong opinions on things like the value of primary nursing and keeping a manageable staff-to-patient ratio. However, rather than blaming everything on what feels outside our control, why don't we try to get to know people and their stories? Authentic connection follows authentic discovery."

Yes, burnout is prevalent. Real systemic and organizational issues need to be addressed, and I have strong opinions on things like the value of primary nursing and keeping a manageable staff-to-patient ratio. However, rather than blaming everything on what feels outside our control, why don't we try to get to know people and their stories? Authentic connection follows authentic discovery. Authentic discovery follows intentional experience. What experiences are you not having with your people?

Disclosures: *Weston Brandon is the founder of Brandon Institute, LLC, and is a paid keynote speaker and consultant on the DRIVE Better Care framework described in this article. He has provided paid consulting and speaking services to healthcare organizations, including Banner Health, referenced in this article. His presentation at the Gravens Conference at the University of Notre Dame, also referenced in this article, was not a paid engagement.*

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Author Bio

Weston Brandon is a healthcare keynote speaker and the creator of DRIVE Better Care, a framework used by NICU and care team leaders across the country to build emotionally connected cultures that reduce burnout and turnover. A former widowed NICU father, he draws on that experience to help caregivers reconnect to themselves, their purpose, and each other. He has presented at the Gravens Conference at the University of Notre Dame, and works with healthcare organizations nationwide through his company, Brandon Institute, LLC. Learn more at WestonBrandon.com.



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Obstructive Uropathy, Pulmonary Hypoplasia, and ECMO Candidacy: A Case of Cloacal Dysgenesis

Aurriel Fenison, MD

"The case presented is a female neonate born to a G_7P_3 mother at 36 $^6/_7$ weeks via repeat C-section. Prenatal history was notable for several abnormal ultrasounds...anhydramnios recurred by 29 weeks GA, and a small fetal chest was noted. Fetal MRI at 34 weeks GA demonstrated hypoplastic lungs... [and] cloacal dysgenesis. The patient... required intubation and high-frequency oscillatory ventilation (HFOV). She... developed worsening hypoxemic respiratory failure requiring inhaled nitric oxide and vasoactive support...Despite maximal respiratory and cardiovascular support, she continued to deteriorate. Following multidisciplinary discussion, she was considered a candidate for extracorporeal membrane oxygenation (ECMO)."

Abstract:

Background: *Congenital anomalies of the kidney and urinary tract result from disturbances in embryologic development and can lead to oligohydramnios, pulmonary hypoplasia, and significant postnatal morbidity and mortality. Advancements in fetal interventions to improve amniotic fluid volume may improve lung development and potentially alter an otherwise fatal prognosis.*

Case*: The case presented is a female neonate born to a G_7P_3 mother at 36 $^6/_7$ weeks via repeat C-section. Prenatal history was notable for several abnormal ultrasounds. At 20 $^5/_7$ weeks gestational age (GA), prenatal ultrasound demonstrated low amniotic fluid, a hyperechoic bladder wall, and a cystic structure adjacent to the bladder. At 22–23 weeks GA, repeat ultrasound demonstrated anhydramnios. A vesicoamniotic shunt was placed at approximately 26 weeks GA with initial improvement in amniotic fluid volume; however, anhydramnios recurred by 29 weeks GA, and a small fetal chest was noted. Fetal MRI at 34 weeks GA demonstrated hypoplastic lungs, bilateral hydroureteronephrosis, didelphys uterus, anal atresia, and dilation of the large intestine, suggestive of cloacal dysgenesis.*

The patient was delivered via cesarean and required intubation and high-frequency oscillatory ventilation (HFOV). She was transferred to a quaternary care center where she developed worsening hypoxemic respiratory failure requiring inhaled nitric oxide and vasoactive support. A drain was placed for suspected urinary ascites to reduce abdominal distention and potentially improve lung expansion. Despite maximal respiratory and cardiovascular support, she continued to deteriorate. Following multidisciplinary discussion, she was considered a candidate for extracorporeal membrane oxygenation (ECMO). After counseling regarding her prognosis and treatment options, the family elected not to pursue ECMO and transitioned to comfort-focused care.

Conclusion*: This case highlights the importance of timing of prenatal diagnosis and the potential role of fetal intervention in congenital renal and urinary tract anomalies complicated by anhydramnios and pulmonary hypoplasia. It also demonstrates the complex interaction between obstructive uropathy, pulmonary hypoplasia, and postnatal respiratory failure, as well as the continued uncertainty surrounding ECMO candidacy in this patient population.*

Introduction:

Congenital anomalies of the kidney and urinary tract result from disturbances in the embryologic development of the kidneys and urinary system. In utero, the kidneys and urinary tract play a vital role in maintaining amniotic fluid and supporting normal lung development. When there are abnormalities within these systems, such as lower urinary tract obstruction, renal agenesis, renal dysgenesis, or cloacal dysgenesis, to name a few, the fetus may be unable to produce or drain enough urine, leading to oligohydramnios or anhydramnios and poor lung development (1). The combination of kidney dysfunction and pulmonary hypoplasia increases the risk of significant neonatal morbidity and mortality, ranging from end-stage renal disease to severe respiratory failure and death (1).

"In utero, the kidneys and urinary tract play a vital role in maintaining amniotic fluid and supporting normal lung development. When there are abnormalities within these systems, such as lower urinary tract obstruction, renal agenesis, renal dysgenesis, or cloacal dysgenesis, to name a few, the fetus may be unable to produce or drain enough urine, leading to oligohydramnios or anhydramnios and poor lung development."

Muñoz et al. conducted a retrospective cohort study evaluating fetuses with prenatally diagnosed lower urinary tract obstruction who subsequently developed oligohydramnios to determine

whether the timing of oligohydramnios impacted the severity of pulmonary hypoplasia (2). Their study showed that oligohydramnios diagnosed earlier in pregnancy was associated with pulmonary hypoplasia and increased perinatal death (2). This study highlights the importance of the timing and severity of oligohydramnios associated with urinary tract obstruction, as these findings may be useful markers of neonatal morbidity and mortality.

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For fetuses with congenital renal and urinary tract anomalies who develop oligohydramnios or anhydramnios, studies have aimed to evaluate whether fetal interventions such as serial amnioinfusions can improve pulmonary development and ultimately postnatal outcomes. The Renal Anhydramnios Fetal Therapy (RAFT) trial by Miller et al. was a prospective, multicenter trial evaluating serial amnioinfusions in pregnancies diagnosed with anhydramnios before 22 weeks gestation (3). While the authors found that a significant proportion of patients who received serial amnioinfusions survived long enough to undergo dialysis catheter placement, and some survived to hospital discharge, these infants still experienced significant morbidity (3). Despite this morbidity, the study showed that serial amnioinfusions may be a feasible intervention that may alter an otherwise fatal prognosis by attempting to mitigate the development of severe pulmonary hypoplasia (3).

In neonates with renal and urinary tract anomalies complicated by pulmonary hypoplasia who present with significant respiratory failure, the question of whether to offer extracorporeal membrane oxygenation (ECMO) remains an ongoing area of discussion. Some renal abnormalities may ultimately be manageable with dialysis and transplantation, and ECMO may provide a bridge to additional therapies in appropriately selected patients. A multicenter survey evaluated current practices among neonatal ECMO centers and what characteristics centers considered when determining whether to offer ECMO to neonates with congenital renal and urinary tract anomalies (4). While a unified consensus on ECMO candidacy in these patients would be ideal, the study suggests that factors such as pulmonary function, the severity and reversibility of pulmonary hypoplasia or pulmonary hypertension, observed-to-expected lung volumes, and overall renal prognosis should play an important role in the decision. Ultimately, the decision to offer ECMO in this population should be determined on an individual basis.

This case reports a presentation of lower urinary tract obstruction associated with multiple congenital anomalies, resulting in severe respiratory failure and prompting discussion of ECMO candidacy in a neonate with renal and urinary tract anomalies.

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Case summary:

This case presented is a female neonate born to a G_7P_3 mother with a history of gestational diabetes managed with metformin and chronic hypertension managed with labetalol. She received routine prenatal care, had negative serologies, and had a notable maternal family history of kidney disease. At 20 $^5/_7$ weeks gestational age (GA), the prenatal ultrasound demonstrated low

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amniotic fluid that did not yet meet criteria for oligohydramnios, as well as a hyperechoic bladder wall with a 4 × 1.5 cm cystic structure adjacent to the bladder. At 22–23 weeks GA, repeat prenatal ultrasound demonstrated anhydramnios. A vesicoamniotic shunt was placed at approximately 26 weeks GA, and repeat ultrasound one week later showed significant improvement in amniotic fluid volume.

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The pregnancy was monitored closely, and repeat ultrasound at 29 weeks GA again demonstrated anhydramnios, a small fetal chest, and minimal pelvic dilation of the bilateral kidneys. At 32 weeks GA, ultrasound demonstrated a massively distended abdomen with two fluid-filled structures, one of which appeared to represent the bladder and the other located adjacent to the bladder. There was anhydramnios with no measurable amniotic fluid, and the vesicoamniotic shunt could no longer be visualized. Fetal MRI further characterized these findings at 34 weeks GA, which demonstrated hypoplastic lungs, bilateral hydroureteronephrosis, fluid within two cervices and uterine horns compatible with a didelphys uterus, anal atresia, and marked dilation of the large intestine with calcifications and debris concerning for intermixing of meconium and urine. The constellation of findings was considered suggestive of cloacal dysgenesis.

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As part of the prenatal evaluation, two fetal echocardiograms were normal. Karyotype demonstrated 46, XX, and NIPT indicated a low-risk fetus. Additional genetic testing, including chromosomal microarray and prenatal trio exome sequencing, was negative. Given the severity and complexity of the prenatal findings, the family received multidisciplinary prenatal consultations with neonatology, urology, nephrology, medical genetics, and palliative care.

"On examination, she had dysmorphic facial features, low-set ears, a markedly distended and protruding abdomen, ambiguous genitalia with a possible single urethral opening, and anal atresia...Initial chest radiograph demonstrated hypoexpanded lungs to approximately six ribs without evidence of pneumothorax, consistent with significant pulmonary hypoplasia."

Shortly after delivery, the patient was intubated in the delivery room with Apgar scores of 1, 5, and 7 and a presumed dry weight of approximately 3000 g. On examination, she had dysmorphic facial features, low-set ears, a markedly distended and protruding abdomen, ambiguous genitalia with a possible single urethral opening, and anal atresia. She received a normal saline bolus and was started on a fentanyl infusion. The infant was stabilized at the outside hospital on high-frequency oscillatory ventilation (HFOV) with a mean airway pressure of 13 cm H_2O, a frequency of 10 Hz, an amplitude of 40, and an FiO_2 of 55%. Arterial blood gas demonstrated a pH of 7.23, $PaCO_2$ of 41 mmHg, PaO_2 of 51 mmHg, bicarbonate of 17 mmol/L, and base deficit of 10. Initial chest radiograph demonstrated hypoexpanded lungs to approximately six ribs without evidence of pneumothorax, consistent with significant pulmonary hypoplasia.

"The patient was subsequently transferred to a quaternary care center for further management and subspecialty care coordination. Following transfer, she remained on HFOV with persistent and worsening hypoxemic respiratory failure and was started on inhaled nitric oxide. She subsequently developed bilateral pneumothoraces, requiring right-sided chest tube placement without significant clinical improvement. "

The patient was subsequently transferred to a quaternary care center for further management and subspecialty care coordination. Following transfer, she remained on HFOV with persistent and worsening hypoxemic respiratory failure and was started on inhaled nitric oxide. She subsequently developed bilateral pneumothoraces, requiring right-sided chest tube placement without significant clinical improvement. Echocardiography obtained on admission demonstrated mildly

depressed biventricular function, and she required vasoactive support with dopamine, epinephrine, and milrinone. Interventional radiology placed an abdominal drain to drain suspected urinary ascites, reduce abdominal distention, and potentially improve lung expansion, but it yielded minimal improvement in her respiratory status.

During the admission, genetics, urology, and pediatric surgery were consulted. The multidisciplinary team considered exploratory laparotomy with ostomy and vesicostomy creation to delineate the patient's anatomy further, relieve urinary and intestinal obstruction, and guide subsequent management. However, the patient continued to deteriorate despite maximal respiratory and cardiovascular support. Given her refractory respiratory failure, a multidisciplinary discussion was held regarding ECMO candidacy in the setting of severe pulmonary hypoplasia, obstructive uropathy, and multiple congenital anomalies. After extensive discussion among the medical teams, she was considered a candidate for ECMO. Following counseling regarding her clinical condition, prognosis, and available treatment options, the family elected not to pursue ECMO and transitioned to comfort-focused care. The patient died peacefully surrounded by her family.

"Given her refractory respiratory failure, a multidisciplinary discussion was held regarding ECMO candidacy in the setting of severe pulmonary hypoplasia, obstructive uropathy, and multiple congenital anomalies. After extensive discussion among the medical teams, she was considered a candidate for ECMO. Following counseling regarding her clinical condition, prognosis, and available treatment options, the family elected not to pursue ECMO and transitioned to comfort-focused care."

Discussion:

This case presents a unique perspective on congenital renal and urinary tract anomalies as it relates to the timing of diagnosis in utero, the role of fetal intervention, and how a once lethal diagnosis may become potentially treatable. Early detection of congenital renal and urinary tract obstruction is important because prolonged oligohydramnios or anhydramnios can lead to severe pulmonary hypoplasia and ultimately impact postnatal survival. Muñoz et al. demonstrated that earlier onset of oligohydramnios in fetuses with lower urinary tract obstruction was associated with pulmonary hypoplasia and increased perinatal mortality (2). In this case, low amniotic fluid was first noted at 20 weeks gestational age, with progression to anhydramnios. A vesicoamniotic shunt was placed at approximately 26 weeks with initial improvement in amniotic fluid, although the fetus later developed recurrent anhydramnios with presumed shunt malfunction. This patient demonstrated several concerning prenatal findings, including early anhydramnios, a small fetal chest, and pulmonary hypoplasia on fetal MRI. These findings highlight the difficulty in determining whether fetal intervention can provide sustained improvement in amniotic fluid and ultimately prevent the development of severe pulmonary hypoplasia.

Another important aspect of this case is the potential benefit of fetal interventions. As demonstrated by the RAFT trial, fetal interventions such as serial amnioinfusions may improve pulmonary development and allow some infants with severe renal disease and early anhydramnios to survive after birth (3). In this patient, despite fetal intervention with a vesicoamniotic shunt, the baby had recurrent anhydramnios leading to subsequent pulmonary hypoplasia.

"Another important aspect of this case is the potential benefit of fetal interventions. As demonstrated by the RAFT trial, fetal interventions such as serial amnioinfusions may improve pulmonary development and allow some infants with severe renal disease and early anhydramnios to survive after birth. In this patient, despite fetal intervention with a vesicoamniotic shunt, the baby had recurrent anhydramnios leading to subsequent pulmonary hypoplasia."

Following delivery, she developed severe hypoxemic respiratory failure despite high-frequency oscillatory ventilation, inhaled nitric oxide, and cardiovascular support. While prenatal findings can provide important information regarding the risk of pulmonary hypoplasia, determining the severity and, more importantly, the reversibility of pulmonary disease after birth remains challenging. This distinction matters when considering advanced therapies such as ECMO, where the goal is to provide temporary cardiopulmonary support while allowing time for an underlying reversible process to improve.

"Finally, this case highlights the complex nature of determining ECMO candidacy in neonates with severe renal and urinary tract anomalies. While this patient was ultimately not cannulated onto ECMO due to family preference, there was significant multidisciplinary discussion regarding her long-term respiratory prognosis, renal function, ability to receive dialysis, and need for future surgical interventions."

Finally, this case highlights the complex nature of determining ECMO candidacy in neonates with severe renal and urinary tract anomalies. While this patient was ultimately not cannulated onto ECMO due to family preference, there was significant multidisciplinary discussion regarding her long-term respiratory prognosis, renal function, ability to receive dialysis, and need for future surgical interventions. The current literature demonstrates significant variability among centers regarding which neonates with congenital anomalies of the kidney and urinary tract should be considered for ECMO.

"Ultimately, renal and urinary tract anomalies alone may not be sufficient to determine ECMO candidacy. Rather, the severity of pulmonary hypoplasia, degree of pulmonary hypertension, underlying renal prognosis and ability to provide renal replacement therapy, associated congenital anomalies, and potential for future surgical intervention should all be considered. This case highlights the need for continued investigation into prenatal markers and postnatal clinical parameters that may help guide ECMO decision-making and provide families and medical teams with a better understanding of expected outcomes."

Ultimately, renal and urinary tract anomalies alone may not be sufficient to determine ECMO candidacy. Rather, the severity of pulmonary hypoplasia, degree of pulmonary hypertension, underlying renal prognosis and ability to provide renal replacement therapy, associated congenital anomalies, and potential for future surgical intervention should all be considered. This case highlights the need for continued investigation into prenatal markers and postnatal clinical parameters that may help guide ECMO decision-making and provide families and medical teams with a better understanding of expected outcomes.

Conclusion:

Severe renal and urinary tract anomalies can lead to abnormal urinary drainage, anhydramnios, and subsequent pulmonary hypoplasia. In our case, cloacal abnormalities created a particularly complex clinical challenge. This case highlights the importance of early diagnosis and prenatal interventions to improve pulmonary development and postnatal survival. However, as outcomes continue to improve for neonates with these disorders, determining ECMO candidacy in those with profound respiratory failure remains challenging. Continued discussion is needed regarding how prenatal and postnatal factors can help guide ECMO candidacy and the long-term management of these neonates.

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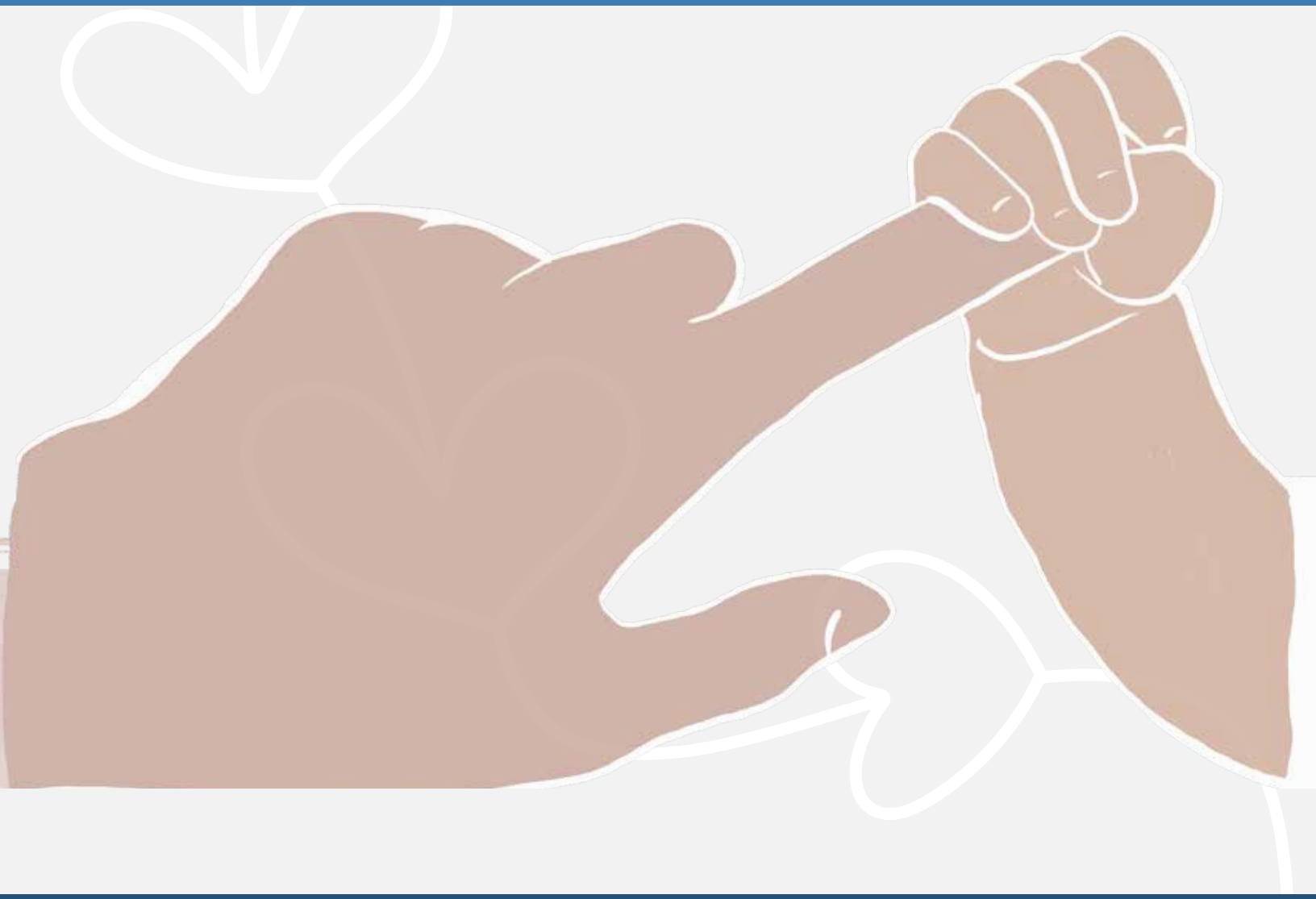


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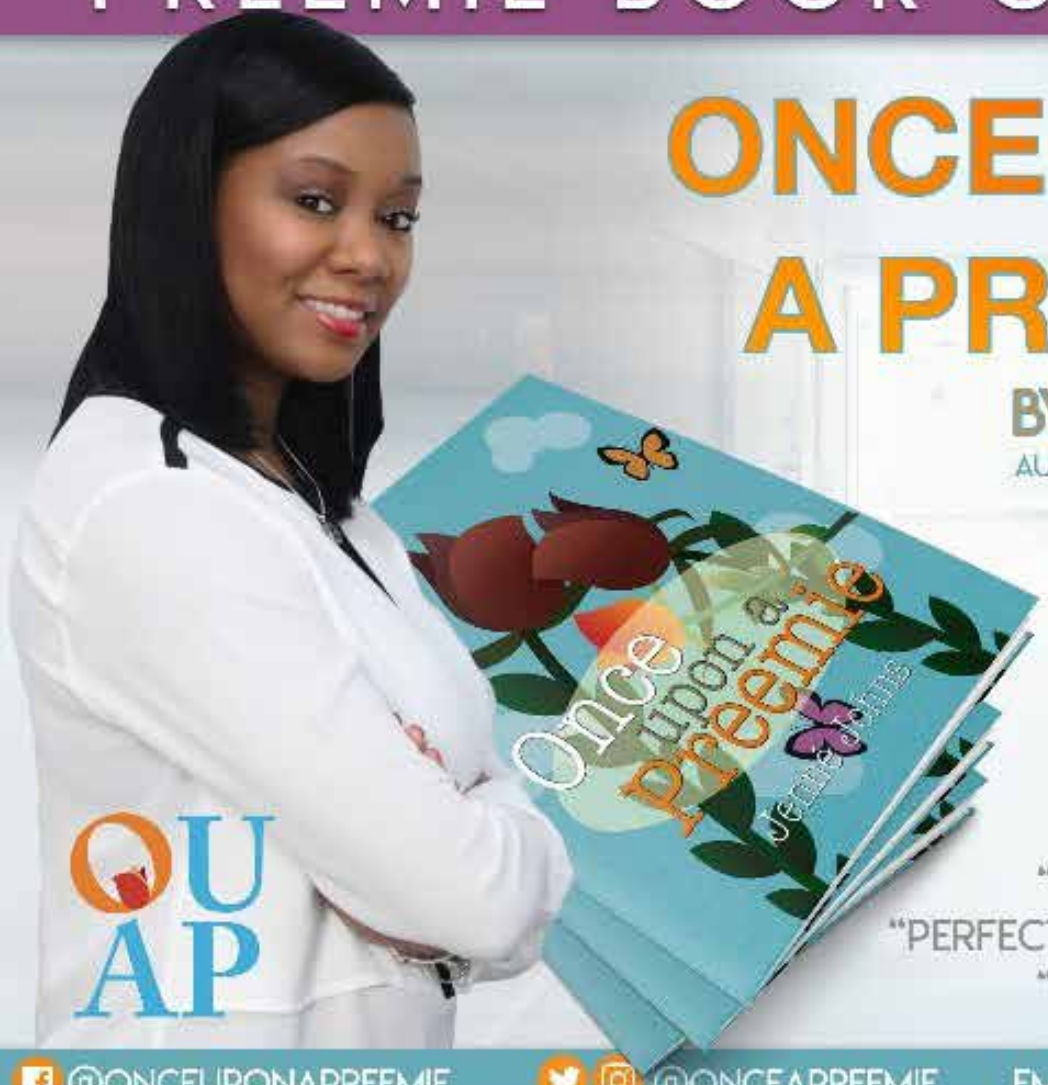


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Lack of insurance coverage for RSV immunization in hospitals leaves newborns unprotected

NEWS PROVIDED BY

American Academy of Pediatrics

By Melissa Jenco

Study: **Lack of insurance coverage for RSV immunization in hospitals leaves newborns unprotected**

Current as of September 14, 2026

As her 2-week-old son lay in the hospital intubated and struggling to breathe due to respiratory syncytial virus (RSV), a pediatric resident found herself in the same position as the families she had previously helped — terrified and traumatized.

"They're so tiny, and there are so many lines from everywhere and tubes," said the resident who asked not to be named. "It's just something that I would never wish upon anybody."

The resident was not offered an RSV vaccine during her pregnancy and her birthing hospital was one of many that did not offer RSV immunization to newborns. Due to breastfeeding issues, she declined it during her son's first pediatrician appointment, thinking he could get it shortly after at the next appointment.

But that short period of time was all it took for him to contract RSV, which landed him in the hospital for 12 days, eight of which he spent intubated and fighting not only RSV but bacterial pneumonia.

As RSV season approaches in much of the country, the AAP, Association for Immunization Managers (AIM) and others are fighting for more babies to get immunized before leaving the hospital at birth instead of waiting for a pediatrician visit. But hospitals are running into roadblocks like the high cost of the immunizations and a struggle with insurance companies to negotiate a new payment structure for them.

"It's frustrating to know you have products that are this effective at preventing severe RSV disease and you can't help every baby benefit from that because of the way the U.S. health system is set up," said Michelle D. Fiscus, M.D., FAAP, chief medical officer for AIM. Dr. Fiscus is a former member of the AAP Board of Directors.

Payment challenges in hospitals

In 2023, doctors were excited to see federal approval of the monoclonal antibody product nirsevimab, finally giving them a way to prevent severe RSV. At the time, the disease was the leading cause of hospitalization among U.S. infants and caused about 58,000 to 80,000 hospitalizations per year in children under 5 years, according to the Centers for Disease Control and Prevention (CDC). Clinicians now have two monoclonal antibody products for infants (nirsevimab and clesrovimab) that provide immediate protection. There also is a vaccine (RSVPreF) that can be given during pregnancy to protect the newborn.

Studies have found nirsevimab to be 64%-93% effective in preventing RSV-related hospitalization according to a new data review from the American Medical Association and Vaccine Integrity Project.

The AAP recommends RSV immunization for all infants under 8 months born during or entering their first RSV season who are not protected by vaccination of their pregnant parent. Infants born shortly before or during the RSV season should receive the immunization within the first week after birth, ideally during the birth hospitalization.

Data on uptake are sparse. As of February, about 65% of infants born since the previous April were protected, according to a CDC estimate based on a survey of 364 people. About 56% had received a monoclonal antibody and just over 9% were protected through maternal vaccination.

Another CDC dataset from 14 states and Washington, D.C., in April shows monoclonal antibody coverage among infants under 8 months ranging from about 32% to 54%, not taking into account vaccination of a pregnant parent.

Advocates say these figures should be higher, but cost and insurance coverage issues are standing in the way. RSV monoclonal antibody products cost about $500 a dose. Birth hospitalizations typically are covered by insurance through a bundled payment that does not include these products unless the hospital has negotiated a new payment strategy with insurance companies. Those negotiations are complicated by the immunization only being given half the year and by some infants not needing it because their pregnant parent was vaccinated.

Most insurance companies won't allow separate line-item billing in the birthing hospital even though they will pay for the immunization given days later in an outpatient clinic, according to Dr. Fiscus.

"You're literally going to pay for it five minutes later but after the baby has had a chance to be exposed," Dr. Fiscus said. "So why don't you pay for it on this side of the door and the chance of having to pay for a hospitalization is so much less."

In some cases, insurance companies have told hospitals they should purchase and administer the immunizations, file a claim with insurance and expect to get denied for months or even a year, before the products are negotiated into the newborn bundle, according to Dr. Fiscus. Going this route would entail a significant cost for hospitals already struggling and further delays a real solution, she said.

When hospitals don't immunize newborns, the delay also impacts pediatricians. It adds another issue for them to address at newborn appointments and can result in a lengthy process of trying to figure out if the pregnant parent already was immunized, according to Dr. Fiscus. Pediatric practices also face challenges in stocking an expensive product when financial margins already are thin.

In response to AAP News' questions about insurance coverage in hospitals, AHIP, a trade association representing a large portion of the health insurance industry, said it does not get involved in contract negotiations and noted that immunizations in hospitals are just one avenue available to protect infants.

"Health plans are committed to providing affordable access to

vaccines grounded in rigorous review of scientific and clinical evidence," AHIP said via email. "Plans recognize the critical need to protect newborns from RSV and have been incorporating RSV immunization into coverage policies."

The immunizations also are available for free for eligible children through the federal Vaccines for Children (VFC) program. However, only 36% of birthing hospitals were enrolled as VFC providers as of the spring of 2025 and enrollment rates vary significantly between states.

Some hospitals have decided if they aren't able to offer the product to commercially insured children, they also won't offer it to children in the VFC program, so they don't create a disparity. However, it is those children in the VFC program who are more likely to miss follow-up appointments and have worse health outcomes compared to commercially insured children.

In rural Tennessee where Suzanne K. Berman, M.D., FAAP, is the managing partner of Plateau Pediatrics, birthing hospitals don't offer RSV immunizations to any newborns even though most are eligible through VFC. She offers it when they first come to see her, but only about half of families accept it at that time. After their first appointment, families often switch to a family doctor or nurse practitioner closer to their home, but those clinicians don't always stock the products or take Medicaid. With high rates of methamphetamine and opioid use in the area, some parents also are difficult to reach for follow-up after hospital discharge.

"If I can't give it either in hospital as the (nursery doctor) or at the weight check at that first opportunity the baby is not going to get it," Dr. Berman said. "So that adds more angst."

"It's frustrating," she said. "Because RSV doesn't wait."

The American Hospital Association (AHA) declined to comment on why more birthing hospitals aren't enrolling in the VFC program and why some won't immunize any newborns if they can't immunize all.

Advocating for payment

In recent months, the AAP, AIM and other medical groups have been advocating for RSV immunization in hospitals through outreach to AHIP, individual insurance companies and members of Congress.

AAP President Andrew D. Racine, M.D., Ph.D., FAAP, sent a letter to insurance companies warning of the danger of infants going unprotected and the strain on pediatric practices.

"Moreover, RSV hospitalization can be traumatic for families, leading to missed work, emotional distress, and potential long-term respiratory complications for the child," he wrote. "From a systems perspective, preventable RSV hospitalizations drive up costs for payers and providers. Investing in immunization at birth is not only clinically effective but also fiscally responsible."

Dr. Racine noted some hospitals and payers have negotiated a separate line-item payment outside the newborn bundle or increased the bundle payment by 50% of the cost of RSV immunization since it's only given half of the year.

In letters to AHIP and individual insurance companies, 13 groups including AAP, AIM, March of Dimes, Infectious Diseases Society of America and American College of Obstetricians and Gynecologists urged line-item billing and appropriate payment during the birth hospitalization as well as continued outpatient coverage. They called it "unconscionable" for infants not to have access to RSV immunizations in the hospital.

Dr. Fiscus called on pediatricians to work with their AAP chapter to advocate for payment for in-hospital administration.

"I think the only thing we can do is get louder about it and see if there are opportunities with policymakers to make a change," Dr. Fiscus said. " … We also need to make sure every outpatient care site stocks and offers and administers these products because that's right now the only safety net we have to make sure these babies get protected."

It has been more than six months since the pediatric resident's newborn son was hospitalized for RSV and pneumonia, then separately for COVID-19, and he continues to need breathing treatments. She strongly encourages families to immunize their infants against RSV.

"Every winter I feel like we care for so many infants like mine who require oxygen, who require feeding tubes, intubation, mechanical ventilation, all caused by something that was preventable, mostly," she said. "If I could spare even just one family from the trauma my family went through I would."

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AAP expands high-risk groups recommended for RSV immunization in second season

NEWS PROVIDED BY

American Academy of Pediatrics

By Melissa Jenco

Study: **AAP expands high-risk groups recommended for RSV immunization in second season**

Current as of September 2, 2026

The AAP is expanding its list of high-risk young children recommended to receive respiratory syncytial virus (RSV) immunization in their second season.

It continues to recommend immunization for all infants under 8 months born during or entering their first RSV season who are not protected by vaccination of their pregnant parent.

"We are so lucky to have these products now to prevent what has historically been the leading cause of hospitalization among young children. We're already seeing real-world impact," said Sean T. O'Leary, M.D., M.P.H., FAAP, AAP immunization schedule editor and leader of the Committee on Infectious Diseases RSV immunization subgroup.

The recommendations for the monoclonal antibody immunizations nirsevimab and clesrovimab are laid out in an AAP policy statement and technical report both titled "Recommendations for the Prevention of RSV Disease in Infants and Children" and available at https://doi.org/10.1542/peds.2026-079047 and https://doi.org/10.1542/peds.2026-079049. They will be published in the November issue of *Pediatrics*.

The AAP's updated second-season recommendations are for children ages 8 through 19 months who are at high risk for severe disease. That list already included children with chronic lung disease of prematurity requiring medical support at any time in the six months before the start of the second RSV season, children

with severe immunocompromise, certain children with cystic fibrosis and American Indian and Alaska Native children.

Dr. O'Leary said the RSV immunization subgroup spent a lot of time reviewing data on hospitalization risk for children with other conditions and added four groups to the high-risk list:

- Children born preterm at less than 32 weeks' gestation, regardless of the need for medication or other support
- Children with hemodynamically significant congenital heart disease (i.e., a defect that can result in symptoms and/or cardiac chamber dilation)
- Children with anatomic pulmonary abnormalities or neuromuscular disorders that put them at risk for severe RSV disease
- Children with Down syndrome or other chromosomal differences placing them at higher risk of severe RSV disease

Dr. O'Leary said this represents a relatively small population overall but these conditions put them at greater risk. "And when they do get hospitalized their length of stay tends to be quite a bit longer and hospital costs tend to be quite a bit higher," he said.

The AAP is communicating with insurance companies to promote coverage of the expanded indications for second season immunization.

RSV immunizations should be administered October through March in most of the continental U.S., but the guidance provides flexibility for different areas or seasons with unusual timing like last season, which stretched into April.

Infants born shortly before or during the RSV season should receive the immunization within the first week after birth, ideally during the birth hospitalization. Those born outside of the season should be immunized shortly before the season or as early as feasible during the season.

RSV has been the leading cause of infant hospitalization in the U.S. and causes about 58,000 to 80,000 hospitalizations each year in children under 5 years, according to CDC data. Nirsevimab and the RSVPreF vaccine for pregnant people became available in the 2023-'24 season. Clesrovimab was licensed last summer.

In creating the updated guidance, the RSV immunization subgroup met with partners and other professional societies to review all available data on the monoclonal antibodies as well as the RSVPreF vaccine for people who are pregnant.

"A lot of the data that we reviewed … showed that these products work very well to prevent RSV," Dr. O'Leary said. "We have another year of safety data showing they're very safe."

The AAP does not have a preference between nirsevimab and clesrovimab for children in their first season. Only nirsevimab is approved for children in their second season. The AAP also does not have a preference between infant immunization and vaccination of the pregnant parent.

"They both do a great job preventing RSV disease," Dr. O'Leary said. "Parents may prefer one over the other so now they have both options."

In February, about 65% of infants who had been born since the previous April had protection through their pregnant parent (9%) or monoclonal antibody (56%), according to Centers for Disease Control and Prevention data.

Some families face barriers to access including the cost or availability in the birthing hospital. Some hospitals are not enrolled in the Vaccines for Children program, and some are still negotiating with insurance companies to incorporate them into bundled hospital payments or allow a separate payment. The AAP continues to advocate for better access for all children in all clinical settings.

Dr. O'Leary said pediatricians should recommend RSV immunization just as they would other immunizations.

"These are important life-saving tools," he said.

The AAP is one of four medical societies releasing guidance on fall respiratory virus vaccines today along with the American Academy of Family Physicians, Infectious Diseases Society of America and American College of Obstetricians and Gynecologists. Each made independent recommendations using a comprehensive review of evidence conducted by the American Medical Association and the Vaccine Integrity Project, which is based at the University of Minnesota's Center for Infectious Disease Research and Policy.

The AAP has updated its 2026 immunization schedule and dosing guides to reflect the updates to RSV, COVID and flu vaccine guidance. The updated schedule also expands the age indication for Sanofi Pasteur's meningococcal ACWY conjugate vaccine MenQuadfi for children as young as 6 weeks, down from 2 years. The Food and Drug Administration approved lowering the age following clinical trials and COID voted to update its recommendation after reviewing the data.

Major obstetrics groups recommend prenatal cell-free DNA screening for all pregnancies

NEWS PROVIDED BY

American Academy of Pediatrics

By Kelly L. Jones, M.D., FACMG, FAAP, and Sonja A. Rasmussen, M.D., M.S., FACMG, FAAP

Study: **Major obstetrics groups recommend prenatal cell-free DNA screening for all pregnancies**

Current as of September 1, 2026

Updated guidance on prenatal cell-free DNA (cfDNA) screening from the Society for Maternal-Fetal Medicine (SMFM) includes a recommendation that cfDNA screening for the common autosomal aneuploidies (trisomy 21, 18 and 13) be made routinely available for all pregnancies. "Cell-free DNA Screening for Aneuploidies," which was endorsed by the American College of Obstetricians and Gynecologists (ACOG), was published last November.

Prenatal cfDNA screening, also known as non-invasive prenatal testing, became commercially available in 2011. It is the most sensitive and specific screening test for the common autosomal aneuploidies and represents a substantial improvement over previous screening methods that used serum testing, sometimes combined with ultrasound.

Maternal blood for cfDNA screening can be drawn as early as nine or 10 weeks of gestation and at any time later in the pregnancy. The screening analyzes short fragments of both maternal- and placenta-derived cfDNA fragments in the maternal

circulation. By looking at the ratios of fragments from different chromosomes, it is possible to detect if there are too many or too few fragments. For example, a fetus with trisomy 21 will have a higher proportion of chromosome 21 cfDNA fragments than what is present in a chromosomally typical fetus. Sometimes cfDNA tests also screen for sex chromosome aneuploidies, such as Turner syndrome (45,X) and Klinefelter syndrome (47,XXY).

The sensitivity, specificity and positive predictive value of cfDNA testing differ depending on what condition is being screened. For example, the sensitivity of cfDNA screening to detect trisomy 21 is over 99%; sensitivity to Turner syndrome is about 90%. The positive predictive value of the test is highly dependent on disease prevalence and other factors.

Although a substantial improvement, it remains a screening test. Further testing, by prenatal genetic testing through chorionic villus sampling or amniocentesis or by postnatal genetic testing using blood drawn from the newborn, is needed to confirm the suspected diagnosis.

Some prenatal cfDNA screening tests have expanded to include microdeletions such as 22q11.2 deletion syndrome (associated with cardiac and immune abnormalities). The sensitivity of the screening test for these conditions varies widely. Because the conditions are of low prevalence, the test's false-positive rate is high. Some laboratories now test for single-gene conditions, such as osteogenesis imperfecta, cystic fibrosis, achondroplasia and Noonan syndrome. The SMFM and ACOG currently do not endorse routine cfDNA screening for microdeletions and single-gene disorders.

Several factors can limit the accuracy and interpretation of these tests. One consideration is the fetal fraction — the proportion of circulating cfDNA fragments that are derived from the placenta. While the minimum fetal fraction necessary to provide a cfDNA result varies, most laboratories require a minimum of 2%-4% to accurately report cfDNA results. If the fetal fraction is too low, it may result in a "no call" or a false-negative result. Maternal obesity also can lead to a false-negative screening result. False-positive results can be due to confined placental mosaicism (when the placenta has both karyotypically normal and aneuploid cell lines, but the fetus is karyotypically normal), maternal fibroids or malignancy, or if the pregnant patient has a chromosomal abnormality.

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Prenatal cfDNA screening can allow for early diagnosis and management. However, it remains a screening test. Results are "low-risk," "high-risk" or "no-call." Confirmatory testing is necessary prenatally or after birth.

While families may have been counseled prenatally, pediatricians may be asked about this testing after the child is born. An understanding of prenatal cfDNA screening can help pediatricians determine what postnatal confirmatory testing is needed, counsel families when prenatal screening differs from postnatal confirmatory testing and determine the appropriate next steps in the clinical evaluation.

More than 210 groups say vaccine executive order 'would leave children less protected'

NEWS PROVIDED BY

American Academy of Pediatrics

By Melissa Jenco

Study: **More than 210 groups say vaccine executive order 'would leave children less protected'**

Current as of August 17, 2026

The AAP and more than 210 groups are speaking out together in opposition of a new executive order seeking to reduce and space out recommended childhood vaccines.

The groups representing physicians, nurses, other medical and public health professionals, scientists and families note there is no scientific evidence for making the changes laid out in the order.

"As measles surges across the United States and as respiratory virus season approaches, families deserve clear guidance from federal health officials that is grounded in science and aimed at protecting children's health," the groups said in a statement. "Instead, the White House released an Executive Order that undermines confidence in childhood vaccinations and recommends changes that would leave children less protected and families more confused."

Groups joining the statement include the American Medical Association, American College of Obstetricians and Gynecologists, American Public Health Association and Autism Science Foundation.

President Donald J. Trump's executive order recommends all children get vaccines to protect them from 11 diseases, down from 18. Some vaccines typically given to children are recommended only for those considered high-risk while some would be available based on shared clinical decision-making.

The AAP continues to recommend protection against 18 diseases as laid out in its 2026 immunization schedule. That schedule is built on decades of research and continuous safety monitoring. It was formally endorsed by 12 leading medical and health care organizations while more than 200 additional groups came out in support.

Trump's executive order also calls for administering measles, mumps, rubella vaccine as separate, single-disease shots and administering all childhood immunizations at separate medical visits "to the maximum extent feasible."

Experts noted these changes would not be feasible or safe. Individual vaccines for measles, mumps and rubella have not been available in the U.S. since they were phased out of production in 2009. Rolling them out as individual shots would take years and mean more trips to the doctor, more shots and more time without protection from dangerous diseases. Measles cases already are at a 35-year high amid rising misinformation and declining vaccination rates.

The executive order does not change federal vaccine policy, but officials have said they hope states will implement

the recommendations. They are similar to those a federal judge blocked from implementation in March while an AAP lawsuit against the administration continues.

The executive order also directs the attorney general to take action against state laws that don't allow religious exemptions from vaccine requirements. In addition, it calls for the Task Force on Safer Childhood Vaccines to offer options to administer single rather than combination vaccines, assess ideal timing and sequencing of vaccines, develop additional alternative adjuvants to aluminum and improve safety monitoring within 90 days.

While the executive order does not mention autism, President Donald J. Trump repeatedly linked vaccines to autism during his remarks announcing the order. His comments ignore the dozens of studies involving millions of people that have found no link between vaccines and autism.

"Elevating these debunked claims does nothing to support families of children with autism," the health and patient groups said. "In fact, it diverts resources away from promising areas of research."

The groups called for families with questions about vaccines, health or development to talk with their child's clinician.

Newborn among the Pennsylvania measles deaths

NEWS PROVIDED BY

American Academy of Pediatrics

By Melissa Jenco

Study: **Newborn among the Pennsylvania measles deaths**

Current as of August 27, 2026

A newborn was one of two Pennsylvania residents who died of measles, according to state health officials. The age of the other person who died remains unknown. Both were unvaccinated.

AAP President Andrew D. Racine, M.D., Ph.D., FAAP, called the deaths a tragedy and an "unimaginable loss" and stressed the importance of keeping community vaccination rates above 95%.

"When enough eligible individuals receive the vaccine, the entire community develops a level of immunity that protects our most vulnerable, including babies who are too young to be vaccinated," Dr. Racine said.

Citing confidentiality, state officials initially declined to discuss any details beyond vaccination status about the two people who died. However, the Lancaster County coroner made public comments about investigating the death of a newborn with a ruptured spleen who tested positive for measles. The Pennsylvania Department of Health then confirmed on social media that the infant was one of the two measles deaths.

The deaths come amid a nationwide surge in measles cases. The 2,777 cases confirmed this year are the highest since 1991. There have been five measles-related deaths in less than two years despite measles having been eliminated in 2000.

The AAP recommends ensuring patients are covered with a two-dose measles, mumps and rubella (MMR) vaccination series. Routine immunization begins at 1 year, but children as young as 6 months of age can get vaccinated if they live in or will be traveling to an outbreak area.

Vaccination rates nationwide have been declining amid rampant misinformation including from the highest levels of government. Even after the deaths were announced in Pennsylvania, Health and Human Services Secretary Robert F. Kennedy Jr. continued to spread misinformation about MMR vaccines on social media.

"At a time when the global public health goal is to reduce measles deaths, it is unacceptable that federal public health leaders have failed to meet this moment with the urgency, visibility, and leadership it requires," said James D. Campbell, M.D., M.S., FAAP, chair of the AAP Committee on Infectious Diseases.

The AAP launched a campaign last year to combat vaccine misinformation with a goal of increasing the kindergarten immunization rates to 95%. In Lancaster County, the measles vaccination rate for kindergarteners was under 88% last school year, according to state data.

There have been 424 cases of measles in Pennsylvania this year including 94 in the past seven days. None of those who have contracted the disease have been fully vaccinated.

"Because the MMR vaccine essentially eliminated measles here in the United States decades ago, people have forgotten how serious it can be especially for the very young, pregnant and the very old," Pennsylvania Secretary of Health Debra L. Bogen, M.D., FAAP, said in a press conference earlier this week.

To combat the outbreak, Pennsylvania has held 91 vaccination clinics this year and monthly measles vaccinations by any health professional across the commonwealth have gone from 25,000 doses to 35,000 doses. Officials said they also are working to provide more resources to health professionals, schools and families.

"Measles is a highly contagious airborne virus, but we are not powerless against this virus," Dr. Bogen said. "The MMR vaccine is backed by decades of research and real-life, real-world proof that it is the best way to protect you and your family from measles."

Second infant botulism outbreak linked to baby formula is over, CDC says

NEWS PROVIDED BY

American Academy of Pediatrics

By Sean Stangland

Study: **Second infant botulism outbreak linked to baby formula is over, CDC says**

Current as of August 28, 2026

A second outbreak of infant botulism cases that spurred infant formula recalls by two

brands using a common supplier and processor is over, the Centers for Disease Control and Prevention (CDC) declared Thursday.

No new cases of botulism among infants who consumed Nara Organics whole milk organic powdered infant formula have been confirmed since July 3, according to a news release from the Food and Drug Administration (FDA).

Four infants from three states (California, Pennsylvania and Washington) developed the illness in April and May, prompting Nara Organics to recall all of its powdered infant formula products. No deaths have been reported.

The FDA said Thursday that the contaminated Nara Organics products were made with milk supplied by Organic West Milk and spray-dried by Dairy Farmers of America.

"Currently there is not enough evidence to determine if milk was contaminated before drying or during the drying process," the FDA said. It is continuing to investigate the root cause.

Both companies also were involved in the production of organic milk powder used in ByHeart Whole Nutrition infant formula products recalled in November 2025 after an infant botulism outbreak with 48 non-fatal confirmed or probable illnesses across 17 states. That outbreak was declared to be over on June 3.

The FDA's whole genome sequencing analysis of a clinical sample from an infant sickened in the latest outbreak was a genetic match to a clinical sample from an infant sickened in the 2025 outbreak, a powdered infant formula base sample from that outbreak, and four samples of unopened cans of ByHeart powdered infant formula.

A statement from Dairy Farmers of America said the FDA has not concluded that any contamination originated from their facility in Fallon, Nev.

"In fact, FDA inspected the Fallon facility following the ByHeart recall, identified no violations, issued no Form FDA 483, and classified the inspection as 'No Action Indicated,'" the statement read. "Any illness involving infants is deeply concerning, and our thoughts are with the families impacted by the ByHeart and Nara infant formula outbreaks."

Organic West Milk could not be reached for comment.

The FDA said it continues to work with all companies involved and the formula industry to prevent future outbreaks of the illness caused by Clostridium botulinum.

In a statement posted Thursday to its website, Nara Organics said it has stopped sourcing from U.S. suppliers.

"Our plan is to bring Nara infant formula back to families with EU (European Union) dairy and rigorous C. botulinum testing protocols in place," it reads. "We're grateful to learn that the outbreak is over."

A June 26 statement on ByHeart's website said the company has worked with a third-party laboratory to develop new C. botulinum testing protocols that will be applied to all ingredients and finished batches before they leave the facilities.

Recalled Nara and ByHeart products should no longer be available for sale. Any remaining products should be discarded.

Infant botulism symptoms include constipation, poor feeding, ptosis, sluggish pupils, low muscle tone, difficulty sucking and swallowing, weak or altered cry, generalized weakness, respiratory difficulty and possibly respiratory arrest, according to the FDA.

WHO prequalifies multi-dose RSV vaccine vial, paving the way to protecting more infants globally

NEWS PROVIDED BY

World Health Organization

By WHO Media Team

Study: **WHO prequalifies multi-dose RSV vaccine vial, paving the way to protecting more infants globally**

Current as of September 9, 2026

The World Health Organization (WHO) has prequalified the multi-dose vial presentation of the maternal respiratory syncytial virus (RSV) vaccine, RSVpreF (ABRYSVO®), marking a major step toward protecting more infants from severe respiratory illness and pneumonia globally. The new presentation is expected to make maternal RSV vaccination more affordable and easier to deliver, particularly in countries supported by Gavi, the Vaccine Alliance.

The decision builds on WHO's prequalification of the vaccine's single-dose presentation in March 2025 and Gavi's subsequent decision in July 2025 to establish a maternal RSV vaccine programme. This is aimed at protecting newborns and young infants from one of the leading causes of respiratory illness and hospitalization worldwide.

Each year, RSV is estimated to cause more than 3.6 million hospitalizations and approximately 100 000 deaths among children under 5 years of age. Almost half of these deaths occur in infants younger than 6 months of age, the population protected through maternal immunization. Roughly 97% of RSV deaths occur in low- and middle-income countries where there is limited access to supportive medical care. In many cases, children die at home before reaching a health facility.

Developed with support from the Gates Foundation, the lower-cost multi-dose vial presentation of the maternal RSV vaccine will improve the feasibility of countries to plan and deliver large-scale introductions of the vaccine into their national immunization programmes.

The maternal RSV vaccine is designed to

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protect infants during their first six months of life through the transfer antibodies from the mother to the baby before birth.

To reduce the burden of service RSV disease globally, WHO recommends that all countries introduce either the maternal vaccine, RSVpreF, or the monoclonal antibody, nirsevimab into their national programmes. WHO recommends that the maternal vaccine, RSVpreF, be given to pregnant women during the third trimester of pregnancy, from week 28 onwards, to optimize for the adequate transfer of antibodies to their baby.

Missouri Appeals Court Orders New Trial for Similac, Enfamil NEC Lawsuit

NEWS PROVIDED BY

About Lawsuits

By Irvin Jackson

Study: **Missouri Appeals Court Orders New Trial for Similac, Enfamil NEC Lawsuit**

Current as of August 20, 2026

A Missouri appeals court has upheld a lower court's decision to order a new trial in an infant formula lawsuit involving Similac and Enfamil, which alleges that the cow's milk-based products caused a newborn to develop necrotizing enterocolitis (NEC).

Elizabeth Whitfield originally filed the lawsuit in 2022 on behalf of her son, Kaine. The case ultimately went to trial in October 2024 and ended with a defense verdict for Abbott Laboratories and Mead Johnson.

However, Missouri Circuit Court Judge Michael Noble later threw out that verdict and ordered a new trial in March 2025, after finding that attorneys for the infant formula manufacturers engaged in misconduct during the proceedings.

Judge Noble determined that the defense violated court instructions, presented evidence that had previously been excluded and suggested to jurors that babies could starve if Similac and Enfamil were removed from the market.

Infant Formula NEC Risks

Necrotizing enterocolitis (NEC) is a serious intestinal condition that primarily affects premature infants, whose gastrointestinal systems are not fully developed. The condition can occur when harmful bacteria penetrate the intestinal wall, causing inflammation and tissue damage.

In severe cases, NEC can cause portions of the intestine to die, leading to life-threatening complications. Treatment may require antibiotics or surgery to remove damaged sections of the intestine. Even infants who survive NEC can be left with long-term health problems and may require ongoing medical care.

These risks have led to a growing number of Similac lawsuits and Enfamil lawsuits against Abbott Laboratories and Mead Johnson. The lawsuits allege that the cow's milk-based formulations increase the risk of premature infants developing NEC.

Similac and Enfamil NEC Verdict Appeal

Following the original trial in Whitfeld's lawsuit, Abbott Laboratories and Mead Johnson appealed Judge Noble's ruling to the Missouri Court of Appeals for the Eastern District, which issued an opinion (PDF) on August 11, upholding the judge's decision.

"[T]his Court holds the trial court did not abuse its discretion in finding a new trial was warranted on the ground the verdict was against the weight of the evidence. Accordingly, the trial court's order is affirmed."

– Judge Michael S. Wright, writing for the Missouri Court of Appeals

The appeals court emphasized that it was not permitted to independently reweigh the evidence presented during the trial. Instead, the judges were required to view the evidence in a manner favorable to Judge Noble's decision and defer to the trial court's assessment of conflicting testimony and witness credibility.

Abbott and Mead Johnson argued that Whitfield failed to present sufficient evidence that their products caused Kaine's NEC injuries. However, the appeals court rejected those arguments, noting that both sides presented expert testimony on causation and that disagreement among experts did not mean Whitfield had failed to present a viable case.

The manufacturers also challenged Whitfield's failure to warn claims, arguing that additional warnings would not have changed the outcome. The appeals court found that argument lacked merit, pointing to Missouri law establishing a presumption that an adequate warning would have been followed if one had been provided.

Abbott separately argued that Whitfield's design defect allegations improperly challenged an entire category of cow's milk based infant formulas. The appeals court rejected that argument as well, finding that the lawsuit targeted the products made by Abbott and Mead Johnson rather than attempting to establish that all infant formula products were inherently defective.

Ultimately, the appeals court determined that Judge Noble clearly identified the defense verdict as being against the weight of the evidence, which was sufficient under Missouri law to order a new trial. The panel therefore affirmed the ruling without addressing every remaining argument raised by Abbott and Mead Johnson.

The ruling clears the way for Whitfield's claims against Abbott and Mead Johnson to return for another trial, where a new jury will again be asked to consider whether Similac and Enfamil products contributed to Kaine's NEC injuries.

Infant Formula NEC Lawsuits

The decision in this Missouri state court comes as the first federal bellwether trial is currently underway, involving claims brought by Alexis Inman, whose infant son, Daniel, allegedly died due to necrotizing enterocolitis after being fed Enfamil Premature Formula.

However, in addition to Whitfield's claim, several other state court cases have already gone before juries, with several resulting in massive damage awards against the formula manufacturers.

A separate 2024 trial in Missouri state court ended with Abbott being ordered to pay nearly $500 million to a woman whose daughter suffered NEC-related brain damage. In April, a Cook County, Illinois, jury issued a $70 million verdict in a Similac lawsuit.

Another Cook County jury returned a $60 million verdict in an Enfamil NEC lawsuit, yet an appeals court tossed that verdict out on June 12 and ordered a new trial.

While none of these bellwether trial outcomes are binding on other cases, they are still being closely watched since they could help attorneys reach a future Enfamil or Similac infant formula settlement agreement.

Tobacco smoking may be harming your chances of having a baby

NEWS PROVIDED BY

World Health Organization

By WHO Newsroom

Study: **Tobacco smoking may be harming your chances of having a baby**

Current as of September 8, 2026

Smoking may reduce the chances of conceiving for many people worldwide, according to a new World Health Organization knowledge summary.

The publication highlights evidence that tobacco use is associated with infertility in women, harmful effects on sperm and sexual function in men, and potentially lower chances of success of some fertility treatments. It also warns that second-hand smoke can affect fertility, meaning people do not have to smoke themselves to face possible reproductive risks.

Globally, one in six people of reproductive age will experience infertility at some point in their lifetime. Infertility is defined as the failure to achieve pregnancy after 12 months or more of regular unprotected sex.

The publication cites decades of evidence showing that smoking can harm women's reproductive health. A systematic review of studies conducted between 2000 and 2026 found that women who currently smoke tobacco have a 40% higher risk of infertility compared to those that do not smoke.

The publication also notes that women who smoked tobacco in the past but are not currently smoking may have a 25% lower risk of infertility compared with women who continue to smoke, suggesting that quitting tobacco can make a meaningful difference.

The publication stresses that infertility is not only a women's health issue. A recent review of 44 studies involving more than 60 000 men found that smoking was associated with reproductive dysfunction, including semen abnormalities and sexual dysfunction. The evidence indicated that men who smoke were more likely to have erectile dysfunction, ejaculation problems, and related issues such as absence of sperm in semen, poor sperm motility and abnormal sperm shape.

For people using fertility treatment, tobacco smoking may reduce the chance of success. The publication cites earlier research from 21 studies showing that cigarette smoking was linked to fewer live births and fewer pregnancies following assisted reproduction, like invitro fertilization, with findings suggesting that the chances of successful outcomes may be roughly halved by cigarette smoking.

The publication also warns that exposure to second-hand tobacco smoke may increase infertility risk. Women exposed to second-hand smoke may have a higher risk of infertility and a lower chance of conceiving each month they try.

Evidence on newer products, including e-cigarettes, waterpipes and smokeless tobacco, is still emerging.

Evidence is strongest for cigarette smoking, but WHO warns that other tobacco and nicotine products may also pose risks to fertility and require further research.

WHO recommends that health-care providers inform individuals and couples planning pregnancy about the reproductive risks of tobacco use and offer evidence-based support to help them quit. WHO also recommends that brief advice on quitting be consistently provided to all tobacco users in all health-care settings.

Abbott to pay almost $385 million to settle false claims allegation about infant formula

NEWS PROVIDED BY

Food Safety News

By Coral Beach

Study: **Abbott to pay almost $385 million to settle false claims allegation about infant formula**

Current as of September 16, 2026

Saying that the nation's food supply is non-negotiable, the Department of Justice announced a settlement with Abbott Laboratories for more than $384 million related to the 2022 infant formula crisis.

The company was linked to an outbreak of cronobacter infections that saw two infants die after consuming powdered infant formula products made by Abbott's Sturgis, MI, production plant.The company's recall of several brands and varieties of infant formula, including Similac, led to a severe nationwide shortage, including shortages of formula contracted by federal and state governments.

The settlement announced Sept. 14 resolves claims by the federal government related to allegations about false claims and is not a determination of liability on the part of the company. Numerous court actions brought by parents are pending.

The settlement relates to the fact that Abbott caused false claims to be submitted between Jan. 1, 2018, and Dec. 31, 2022, to federal and state programs arising from its failure to manufacture certain powdered infant formula and nutritional therapy products at its Sturgis, MI, and Casa Grande, AZ, facilities in compliance with federal and state statutory, regulatory and contractual requirements.

Under the civil settlement agreement, Abbott will pay $348,700,868 to the United States to resolve the False Claims Act allegations and an additional $36,298,172 to certain states for claims settled by their Medicaid and WIC programs.

The civil settlement also resolves claims brought under the False Claims Act's qui tam provisions, which allow private individuals to bring suit on behalf of the United States for false claims submitted to federal programs and to share in any recovery. Abbott employees Scott Millard, Kristine Cooper and Loren Cooper will receive $69 million as their share of the federal settlement.

Food safety expert and Seattle attorney Bill Marler said Congress can go a step further than the resolution of the False Claims case in the fight for safe infant formula. There is pending legislation that would address safe production of infant formula.

"Today the Justice Department found $385 million worth of accountability for how infant formula was made between 2018 and 2022. Every dollar of it is backward-looking, and not one dollar of it requires anyone to run a single additional test tomorrow. Congress can do that part. It has had a bill since March," Marler said.

On Nov. 13, 2025, the United States filed its Complaint in Intervention alleging that Abbott caused government programs to purchase powdered infant formula

manufactured at the Sturgis facility despite the products' failure to meet statutory, regulatory and contractual requirements. The Complaint alleged that Abbott knowingly manufactured infant formula purchased with taxpayer dollars in an environment that put the products at unacceptable risk of microorganism contamination and significantly impacted the products' reliability, quality and safety.

"Abbott will pay a substantial sum to resolve serious allegations it violated federal health and safety requirements designed to protect babies. The Justice Department will act decisively against anyone who puts American families at risk and ensure misconduct carries serious consequences," said Acting Deputy Attorney General Trent McCotter.

Associate Attorney General Stanley E. Woodward, Jr. said: "No company should be gambling on the health and safety of our nation's infants by allowing unsanitary conditions to persist at a facility manufacturing baby formula. The department will hold accountable bad actors that knowingly misrepresent compliance with essential health and safety standards designed to protect American families."

In addition to the Department of Justice, the USDA's Office of Inspector General participated in the investigation. The USDA's Inspector General John Walk said Abbott's behavior was inexcusable.

In its complaint against Abbott, the federal government cited roof leaks that allowed water to drip over equipment used to produce infant formula. The complaint states that rather than addressing the leaks in a permanent manner, the company merely placed rain umbrellas to try to divert water. The company also continued to use spray dryers that transformed liquid formula into powdered product even though corporate leadership knew there were cracks and pits in them.

"Abbott made its spray dryer conditions worse by lengthening the number of product batches that passed through the dryers between cleaning cycles — enabling Abbott to increase production," according to a statement from the Department of Justice.

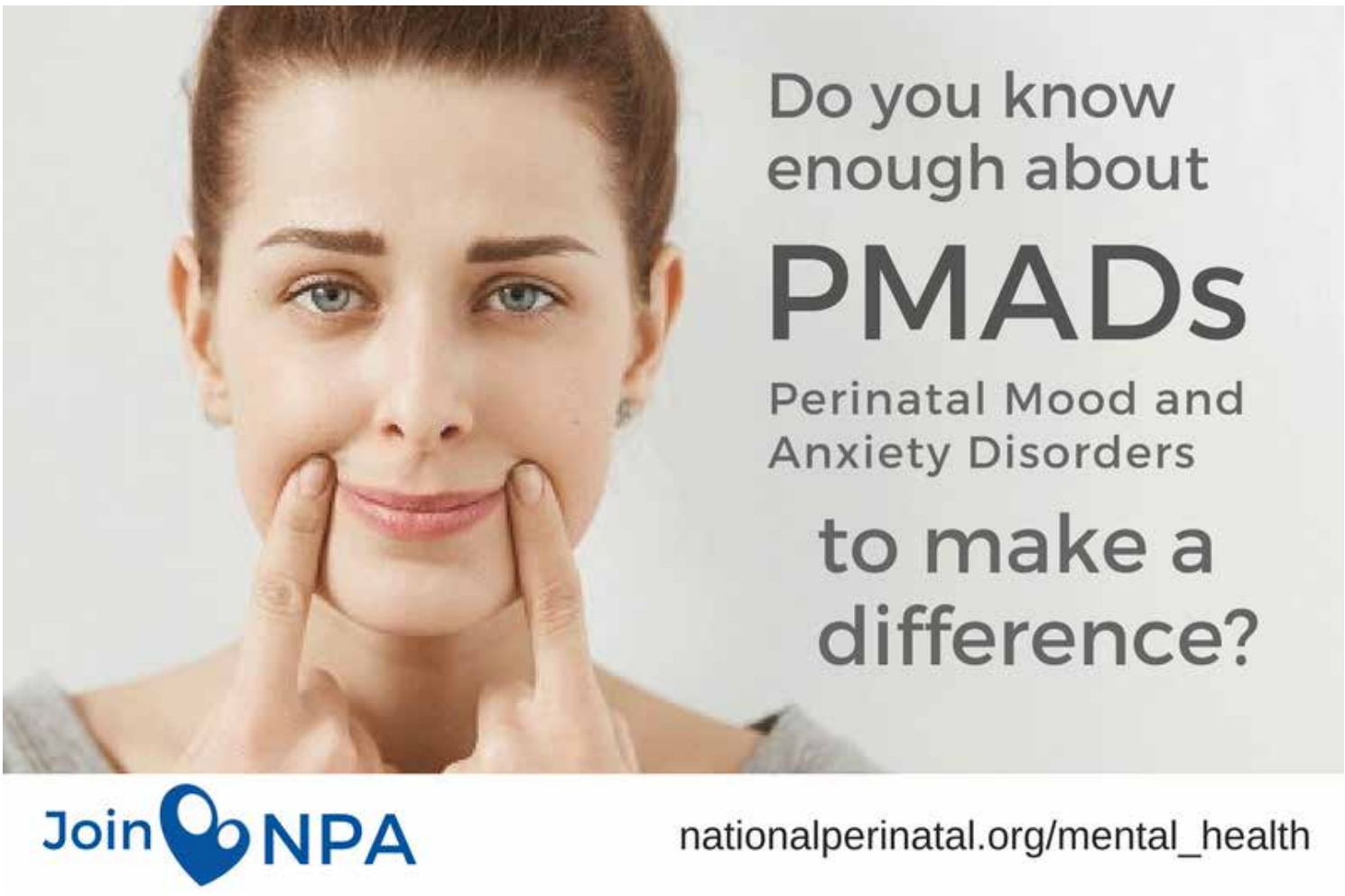
In addition to continuing to operate the dryers to increase production and therefore sales, the government contends that the company intentionally did not test for bacterial growth to avoid obtaining positive test results showing contamination, and that in certain instances where testing demonstrated "micro" contamination, Abbott failed to disclose the test results when responding to requests from FDA during 2019 and 2022 inspections at the Sturgis facility.

The False Claims action against Abbott states that the USDA funds and regulates the Special Supplemental Nutrition Program for Women, Infants, and Children (WIC) program, which provides nutritional support — including infant formula — to eligible participants. More than half of all infant formula purchased in the United States is paid for with USDA funds through WIC. State Medicaid Programs also cover and pay for certain infant formula.

The federal court action was a coordinated effort by the Justice Department's Civil Division, Commercial Litigation Branch, Civil Fraud Section, and the U.S. Attorney's Office for the Western District of Michigan, with assistance from USDA's Office of Inspector General.

The matter was handled by Civil Fraud Section Trial Attorneys Asha Natarajan and Erin Colleran of the Justice Department's Civil Division and Assistant U.S. Attorneys Whitney Schnurr and Jacob Carlton for the Western District of Michigan.

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Genetics Corner: Phenobarbital-Responsive Congenital Unconjugated Hyperbilirubinemia Due to a Homozygous UGT1A1 p.Pro387Arg Variant: A Case of Crigler–Najjar Syndrome Type 2

Hua Wang, MD, PhD

Abstract:

Background: *Crigler–Najjar syndrome is a rare autosomal-recessive disorder of bilirubin conjugation caused by biallelic pathogenic variants in UGT1A1, the gene encoding hepatic bilirubin uridine diphosphate-glucuronosyltransferase (bilirubin-UGT) (1, 2). Type 1 reflects absent or near-absent enzyme activity, produces severe unconjugated hyperbilirubinemia from the first days of life, and characteristically does not respond to phenobarbital (1, 3). Type 2 retains residual activity (typically <10–20% of normal) and usually demonstrates a clinically meaningful fall in bilirubin after enzyme induction (1, 2). Because serum bilirubin concentrations overlap between the subtypes, longitudinal treatment response and molecular findings are central to classification (4, 5).*

Case Presentation: *A term male infant developed persistent, predominantly unconjugated hyperbilirubinemia in the neonatal period, with multiple readmissions for phototherapy and a peak total bilirubin of 23.3 mg/dL. A multigene cholestasis panel identified a homozygous likely pathogenic UGT1A1 c.1160_1161delinsGT (p.Pro387Arg) variant and an incidental heterozygous low-penetrance pathogenic FECH c.315-48T>C allele. Bilirubin fell substantially with phenobarbital and rose when therapy was interrupted, supporting Crigler–Najjar syndrome type 2. At 14 months, the infant remained clinically stable on phenobarbital, ursodiol, nightly home phototherapy, and serial bilirubin monitoring; total bilirubin was 11.9 mg/dL with direct bilirubin 0.44 mg/dL. Early truncal hypotonia and gross motor delay resolved with an age-appropriate developmental assessment.*

Conclusion: *The distinction between Crigler–Najjar types 1 and 2 should not rest on a single bilirubin value or family history alone. Integration of the biochemical pattern, phenobarbital response, molecular diagnosis, and longitudinal course supported type 2 disease and informed a nontransplant management strategy. The p.Pro387Arg genotype is concordant with residual UGT1A1 activity, but parental segregation analysis and review of an affected sibling's molecular records remain important for recurrence counseling and for interpreting marked intrafamilial severity.*

INTRODUCTION:

Crigler–Najjar syndrome is an inherited disorder of bilirubin conjugation caused by biallelic loss-of-function variants in UGT1A1, the only human enzyme that glucuronidates bilirubin (1, 2, 6). It is exceptionally rare, with commonly cited estimates of approximately 0.6–1 affected individual per million live births, although prevalence may be higher in populations with consanguinity or founder variants (1, 3). The recognized clinical spectrum spans Crigler–Najjar syndrome type 1 (OMIM 218800), Crigler–Najjar syndrome type 2 (OMIM 606785), and the substantially milder Gilbert syndrome (OMIM 143500) (1, 7).

"Crigler–Najjar syndrome is an inherited disorder of bilirubin conjugation caused by biallelic loss-of-function variants in UGT1A1, the only human enzyme that glucuronidates bilirubin. It is exceptionally rare, with commonly cited estimates of approximately 0.6–1 affected individual per million live births, although prevalence may be higher in populations with consanguinity or founder variants. The recognized clinical spectrum spans Crigler–Najjar syndrome type 1 (OMIM 218800), Crigler–Najjar syndrome type 2 (OMIM 606785), and the substantially milder Gilbert syndrome (OMIM 143500)."

Unconjugated bilirubin is lipid soluble and potentially neurotoxic; UGT1A1 converts it to water-soluble mono- and diglucuronides that are excreted in bile (2, 6). Profound loss of activity in type 1 produces severe hyperbilirubinemia from early infancy, a high risk of bilirubin encephalopathy (kernicterus), little or no response to phenobarbital, and dependence on prolonged daily phototherapy until liver transplantation restores conjugating capacity (1, 3, 10, 11). Type 2 retains partial activity and usually presents with lower—though overlapping—bilirubin concentrations and a decrease of more than 25% after phenobarbital induction; most patients can be managed medically into adulthood (1, 4, 5). Gilbert syndrome typically causes intermittent, mild unconjugated hyperbilirubinemia and would not usually explain neonatal concentrations in the range observed here (2, 9).

Published cases demonstrate substantial molecular and phenotypic heterogeneity. Missense, nonsense, frameshift, splice-altering, promoter, and complex alleles have been reported, and the clinical effect of an allele may depend on its partner allele, promoter haplotype, environmental stressors, and residual enzyme activity (1, 6, 7). Contemporary series continue to show that genotype alone may not define a sharp boundary between Gilbert syndrome and type 2 disease, so clinical response and longitudinal bilirubin burden remain important classification tools (5, 8).

"Unconjugated bilirubin is lipid soluble and potentially neurotoxic; UGT1A1 converts it to water-soluble mono- and diglucuronides that are excreted in bile. Profound loss of activity in type 1 produces severe hyperbilirubinemia from early infancy, a high risk of bilirubin encephalopathy (kernicterus), little or no response to phenobarbital, and dependence on prolonged daily phototherapy until liver transplantation restores conjugating capacity. Type 2 retains partial activity and usually presents with lower—though overlapping—bilirubin concentrations and a decrease of more than 25% after phenobarbital induction; most patients can be managed medically into adulthood."

This report describes a term infant with severe neonatal unconjugated hyperbilirubinemia, a homozygous UGT1A1 p.Pro387Arg variant, and a family history that initially raised concern for type 1 disease. The case is instructive because a reproducible phenobarbital response and a stable follow-up course favored type 2 despite a severe outcome in an affected sibling. This case demonstrates an integrated approach to subtype assignment, variant interpretation, counseling, and long-term management while highlighting the limits of bilirubin thresholds and family history as isolated diagnostic criteria.

CLINICAL PRESENTATION:

The patient was a male infant born at 38 weeks and 3 days of gestation to a 25-year-old gravida 5, para 4 mother, after a pregnancy notable for maternal group B *Streptococcus* colonization but no reported teratogenic exposure or fetal structural anomaly. Delivery was spontaneous vaginal; birth weight was 3.20 kg, length 50.8 cm, and head circumference 32.5 cm. Apgar scores were 8 and 9 at 1 and 5 minutes. He required only routine drying and stimulation and was discharged after 2 days.

Jaundice developed in the neonatal period and persisted. The infant had multiple hospital encounters and readmissions for phototherapy, including a neonatal intensive care admission during the first month of life. Total bilirubin peaked at 23.3 mg/dL, while the direct fraction remained low relative to the total, indicating a predominantly unconjugated process. Feeding, urine output, and stooling were preserved, and stools were pigmented. No documented hepatosplenomegaly, acute infection, or structural hepatobiliary abnormality was noted.

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The family history materially influenced the initial assessment. An older sister had reportedly been diagnosed with Crigler–Najjar syndrome type 1, underwent two orthotopic liver transplants, and died of infectious complications. The father also reported a child from another relationship who died in the neonatal period with reported hepatitis or jaundice. Two other sisters were reported healthy. Consanguinity was not documented, and the clinical record included a three-generation pedigree. Molecular records from the deceased relatives were not available for comparison.

Growth and oral intake were satisfactory. At 10 months, weight was 10.1 kg (83rd percentile), and length was 71.1 cm (23rd percentile). Early follow-up identified truncal hypotonia and gross motor delay, including head lag and unstable unsupported sitting; physical therapy and regional early-intervention referrals were initiated. At high-risk infant follow-up at approximately 12 months, development was assessed as age-appropriate, and

"The family history materially influenced the initial assessment. An older sister had reportedly been diagnosed with Crigler–Najjar syndrome type 1, underwent two orthotopic liver transplants, and died of infectious complications. The father also reported a child from another relationship who died in the neonatal period with reported hepatitis or jaundice."

the neuromuscular examination was normal, although continued surveillance was recommended.

On examination, the child was well-appearing and well-nourished with jaundice and scleral icterus but no dysmorphic features. Cardiorespiratory findings were normal. The abdomen was soft and nondistended without hepatosplenomegaly or a palpable mass. The spine, extremities, joints, hands, and feet were normal. The neurologic examination initially noted low truncal tone but later showed no focal deficit. No hearing or visual concerns were reported, and the newborn hearing screen was passed.

Serial testing documented isolated chronic indirect hyperbilirubinemia with otherwise preserved hepatic synthetic function. On July 20, 2026, approximately 14 months of age, total bilirubin was 11.9 mg/dL, direct bilirubin 0.44 mg/dL, aspartate aminotransferase 36 U/L, alanine aminotransferase 26 U/L, albumin 4.5 g/dL, total protein 5.9 g/dL, and alkaline phosphatase 383 U/L. A phenobarbital level was 14 µg/mL on June 1, 2026. Earlier bilirubin values decreased from 11.4 mg/dL on March 10 to 9.4 mg/dL on March 24 during treatment. Abdominal ultrasonography (May 26) and liver ultrasonography (June 13, 2025) were normal. Echocardiography (June 13, 2025) showed no structural defect, normal biventricular systolic function, and no evidence of elevated pulmonary artery pressure.

Genetic Testing and Findings:

Testing performed. A commercial next-generation sequencing cholestasis panel was completed on June 5, 2025. The report identified clinically relevant sequence variants but did not include a test identification number in the source materials. Because a targeted panel established the diagnosis, whole-exome sequencing was not performed.

Variants identified. The panel detected homozygosity for *UGT1A1* NM_000463.3:c.1160_1161delinsGT, predicted to result in p.Pro387Arg, classified by the laboratory as likely pathogenic. The variant is rare in population datasets and is reported in affected individuals in the homozygous or compound-heterozygous state; publicly available classifications are concordant as likely pathogenic, with no reported conflict. The biallelic finding is consistent with autosomal-recessive *UGT1A1*-related unconjugated hyperbilirubinemia (1, 2, 7).

The panel also detected heterozygosity for *FECH* c.315-48T>C, an intronic low-penetrance allele associated with erythropoietic protoporphyria when present in an appropriate biallelic configuration. A single low-penetrance *FECH* allele does not explain unconjugated hyperbilirubinemia and was interpreted as an incidental carrier finding rather than a second diagnosis.

Variant interpretation. The p.Pro387Arg substitution should not be conflated with the distinct complex genotype p.[Gly71Arg;Tyr486Asp], a compound genotype reported in East Asian patients with type 2 disease (8). The observed reproducible phenobarbital responsiveness is biologically most consistent with a hypomorphic allele retaining residual UGT1A1 activity, and the combined molecular and treatment-response evidence therefore supports Crigler–Najjar syndrome type 2 (1, 4, 5). The available literature does not include direct functional characterization of p. Pro387Arg, so the residual-activity inference rests on clinical response and general UGT1A1 genotype–phenotype principles rather than a published variant-specific assay.

"A commercial next-generation sequencing cholestasis panel ...detected homozygosity for UGT1A1 NM_000463.3:c.1160_1161delinsGT, predicted to result in p.Pro387Arg, classified by the laboratory as likely pathogenic. The variant is rare in population datasets and is reported in affected individuals in the homozygous or compound-heterozygous state; publicly available classifications are concordant as likely pathogenic, with no reported conflict. The biallelic finding is consistent with autosomal-recessive UGT1A1-related unconjugated hyperbilirubinemia."

Segregation analysis. Parental targeted testing was recommended, but results were not available in the supplied records. The parents are presumed obligate carriers of the familial *UGT1A1* allele, but phase, carrier status, and the possibility of additional alleles should be confirmed directly. Testing of stored material or prior reports from the deceased sister, if available, would be especially informative because the reported type 1 phenotype was substantially more severe. For a confirmed autosomal-recessive couple, each pregnancy carries a 25% probability of an affected child, a 50% probability of an unaffected carrier, and a 25% probability of a child who inherits neither familial pathogenic allele.

Management and Outcome:

General management. Care was coordinated among pediatric gastroenterology/hepatology, medical genetics, the primary care clinician, and high-risk infant developmental services. Management focused on reducing unconjugated bilirubin exposure, detecting loss of control before neurologic injury, maintaining nutrition and hydration, and monitoring development. Bilirubin testing was performed approximately every 2 weeks during the documented follow-up period.

Disease-specific therapies. Phenobarbital was continued at approximately 3 mg/kg/day. Total bilirubin decreased by roughly one-half from the documented peak and rose when phenobarbital was withheld, demonstrating clinically important enzyme induction and supporting type 2 disease (1, 4, 5). Nightly home phototherapy with a fiberoptic blanket was continued for approximately 8–12 hours, consistent with maintenance regimens used across the Crigler–Najjar spectrum, and the family was advised not to wean it during the period covered by the records (11). The family continued ursodiol at approximately 20 mg/kg/day under hepatology supervision. Although ursodiol may support bile flow in selected hepatobiliary conditions, it does not replace deficient bilirubin-conjugating activity; the principal disease-directed therapies were phenobarbital and phototherapy.

"Management focused on reducing unconjugated bilirubin exposure, detecting loss of control before neurologic injury, maintaining nutrition and hydration, and monitoring development. Bilirubin testing was performed approximately every 2 weeks during the documented follow-up period...Phenobarbital was continued at approximately 3 mg/kg/day...Nightly home phototherapy with a fiberoptic blanket was continued for approximately 8–12 hours..."

Follow-up and outcome. At the most recent hepatology follow-up on July 22, 2026 (approximately 14 months of age), the child was clinically stable, feeding orally, growing, and without documented acute bilirubin encephalopathy. Total bilirubin remained in the approximate 7–12 mg/dL range on therapy and was 11.9 mg/dL on July 20. No medication adverse effects or phototherapy complications were reported. Previously observed hypotonia and motor delay had improved on formal developmental assessment. The plan was to continue phenobarbital, nightly phototherapy, ursodiol, and close laboratory follow-up; maintain strict adherence during illness; avoid drugs that displace bilirubin from albumin or impair conjugation when clinically feasible; continue developmental surveillance; and reconsider liver-transplant evaluation should bilirubin control or neurologic status deteriorate (10, 11).

DISCUSSION:

This case demonstrates the value of integrating biochemical phenotype, molecular testing, therapeutic response, and longitudinal observation when classifying *UGT1A1*-related hyperbilirubinemia. The neonatal peak of 23.3 mg/dL and severe family history appropriately raised concern for type 1 disease; however, neither feature is independently diagnostic (4, 5, 9). The marked, reproducible decrease during phenobarbital treatment, increase off therapy, persistently low direct fraction, and stable course without neurologic injury support type 2 disease.

I. Clinical Phenotype Spectrum and Variation:

Classic type 1 disease presents in the neonatal period with severe unconjugated hyperbilirubinemia, an absent phenobarbital response, dependence on intensive phototherapy, and a high risk of kernicterus unless liver transplantation restores conjugating capacity (1, 3, 10, 11). Type 2 also commonly begins with neonatal jaundice but retains partial UGT1A1 activity; bilirubin often falls by more than 25% with phenobarbital, and many patients are managed medically into adulthood (1, 4, 5). Because reported bilirubin ranges overlap, particularly in infancy and during intercurrent illness, a single concentration cannot reliably define subtype—historically, definitive discrimination required

"This case demonstrates the value of integrating biochemical phenotype, molecular testing, therapeutic response, and longitudinal observation when classifying UGT1A1-related hyperbilirubinemia. The neonatal peak of 23.3 mg/dL and severe family history appropriately raised concern for type 1 disease; however, neither feature is independently diagnostic. The marked, reproducible decrease during phenobarbital treatment, increase off therapy, persistently low direct fraction, and stable course without neurologic injury support type 2 disease."

demonstrating a substantial fall in serum unconjugated bilirubin after phenobarbital and characteristic changes in biliary pigment composition (4, 5).

The present patient resembles published pediatric type 2 cases in early-onset jaundice, normal hepatic imaging, preserved liver enzymes and synthetic function, and phenobarbital responsiveness (8). His neonatal bilirubin peak was at the upper end of commonly described type 2 values, and ongoing nightly phototherapy at 14 months reflects a clinically significant bilirubin burden. Conversely, the absence of acute encephalopathy, satisfactory growth, and treatment-associated stabilization differ from the relentless course expected with untreated type 1 (10, 15).

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Early hypotonia and gross motor delay warrant continued attention but, based on the available evidence, cannot be attributed to bilirubin neurotoxicity: there was no documented acute bilirubin encephalopathy, hearing loss, gaze abnormality, movement disorder, or persistent neurologic deficit, and later development was age appropriate. Longitudinal neurodevelopmental and audiologic surveillance remains prudent because bilirubin toxicity may be subtle and risk increases during illness, fasting, dehydration, or treatment interruption (1, 10).

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The clinically relevant differential diagnosis includes type 1 Crigler–Najjar syndrome, Gilbert syndrome, hemolytic disease, glucose-6-phosphate dehydrogenase deficiency, hereditary spherocytosis, breast-milk jaundice, hypothyroidism, infection, and disorders producing predominantly conjugated hyperbilirubinemia (2, 9). The persistent indirect pattern, normal imaging, preserved hepatic function, and biallelic *UGT1A1* finding narrowed the differential. Connective-tissue disorders such as Marfan syndrome do not cause isolated neonatal unconjugated hyperbilirubinemia and are not plausible competing diagnoses in this phenotype.

"Longitudinal neurodevelopmental and audiologic surveillance remains prudent because bilirubin toxicity may be subtle and risk increases during illness, fasting, dehydration, or treatment interruption."

II. Genetic Insights:

UGT1A1 lies at chromosome 2q37.1 within the *UGT1A* locus. The transcript uses a *UGT1A1*-specific first exon followed by four shared exons (2–5), producing an endoplasmic-reticulum membrane enzyme that binds uridine diphosphate-glucuronic acid and catalyzes bilirubin mono- and diglucuronidation; reduced activity limits biliary excretion and allows unconjugated bilirubin to accumulate (6, 7). The promoter contains a phenobarbital-responsive enhancer module, providing the molecular basis for enzyme induction in patients with residual activity (6).

The reported *UGT1A1* disease spectrum includes promoter alleles, missense and nonsense substitutions, small insertions/deletions, frameshift and splice-altering variants, and complex haplotypes (1, 6, 7). Variants that abolish protein production or catalytic function are enriched in type 1—typically clustering in the common exons and thereby affecting multiple UGT1A isoforms—whereas hypomorphic missense or regulatory alleles are more often associated with type 2 or Gilbert syndrome (1, 6). This relationship is probabilistic rather than absolute, because residual activity, allele combinations, regulatory haplotypes, and environmental factors modify bilirubin concentrations (5, 6).

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The p.Pro387Arg variant in this case is a two-nucleotide deletion-insertion producing a single amino-acid substitution. It has been reported in affected individuals and is classified as likely pathogenic; its association with a phenobarbital-responsive, medically manageable phenotype in this patient is consistent with a hypomorphic, residual-activity allele (1, 7). Importantly, p.Pro387Arg is molecularly distinct from p.Gly71Arg and p.Tyr486Asp; conflating these alleles could produce an erroneous genotype–phenotype comparison (8).

Document the incidental FECH allele for counseling, but do not use it to explain this phenotype. Low-penetrance *FECH* alleles typically contribute to erythropoietic protoporphyria only in combination with an additional deleterious *FECH* allele and compatible biochemical findings; no photosensitivity, protoporphyrin result, or second *FECH* variant was reported.

A targeted cholestasis panel, rather than exome sequencing,

provided the molecular diagnosis. This was efficient because the phenotype strongly implicated bilirubin metabolism and the panel included *UGT1A1*. Exome or genome sequencing remains valuable when targeted testing is negative, when conjugated and unconjugated abnormalities coexist, when multisystem findings suggest more than one disorder, or when a severe intrafamilial difference raises concern for a second diagnosis. Broader sequencing is therefore best framed as an escalation strategy, not as a test performed here.

III. Genotype–Phenotype Correlations:

The phenotype is concordant with a hypomorphic *UGT1A1* genotype: substantial but incomplete bilirubin control, preserved liver function, and phenobarbital responsiveness (1, 4, 5). The approximate 50–60% reduction from the documented peak exceeds commonly used response thresholds for type 2, although the comparison spans different clinical states and does not represent a controlled phenobarbital challenge; paired on-treatment and off-treatment measurements, when safe and clinically justified, provide stronger evidence than a single cross-sectional value (4, 5).

"A targeted cholestasis panel, rather than exome sequencing, provided the molecular diagnosis. This was efficient because the phenotype strongly implicated bilirubin metabolism and the panel included UGT1A1. Exome or genome sequencing remains valuable when targeted testing is negative, when conjugated and unconjugated abnormalities coexist, when multisystem findings suggest more than one disorder, or when a severe intrafamilial difference raises concern for a second diagnosis. Broader sequencing is therefore best framed as an escalation strategy, not as a test performed here."

The sister's reported type 1 diagnosis despite the proband's homozygous p.Pro387Arg result raises unresolved questions. Possibilities include inaccurate historical subtype assignment, a different *UGT1A1* genotype, an additional pathogenic allele or modifier, or complications unrelated to intrinsic UGT1A1 activity. Siblings sharing a confirmed biallelic genotype can still vary, but a type 1-versus-type 2 discrepancy of this magnitude warrants parental segregation testing and review of the sister's molecular report before invoking modifier effects.

Accordingly, the identified variant is clinically significant but should not be the sole determinant of subtype. Its value lies in confirming *UGT1A1*-related disease, clarifying the biochemical pathway, guiding recurrence counseling, and reinforcing a residual-function model independently supported by treatment response. Continued deposition of paired genotype, functional, treatment, and long-term outcome data will refine variant-specific prognostication.

IV. Specific Therapeutics:

Phenobarbital remains the principal pharmacologic therapy for type 2 because it induces UGT1A1 expression and can lower bilirubin substantially (1,3). Treatment should be individualized to biochemical response and clinical tolerance, with monitoring for sedation, drug interactions, adherence, serum drug concentration when indicated, and developmental or bone-health effects during prolonged use. Phototherapy provides additional bilirubin elimination but becomes progressively less efficient as the body-surface-area-to-mass ratio declines and skin thickens with age, a well-documented limitation of lifelong conservative management (10,11,15).

Liver transplantation provides definitive hepatic enzyme replacement and remains standard for type 1 or medically refractory disease, but it entails operative risk and lifelong immunosuppression (10, 11, 14). In this child, current biochemical control and neurologic stability favor continued medical management. The family's prior transplant-associated loss is clinically and psychosocially important and should be addressed through shared decision-making rather than treated as evidence that the proband inevitably requires transplantation.

"Phenobarbital remains the principal pharmacologic therapy for type 2 because it induces UGT1A1 expression and can lower bilirubin substantially. Treatment should be individualized to biochemical response and clinical tolerance, with monitoring for sedation, drug interactions, adherence, serum drug concentration when indicated, and developmental or bone-health effects during prolonged use. Phototherapy provides additional bilirubin elimination but becomes progressively less efficient as the body-surface-area-to-mass ratio declines and skin thickens with age..."

Liver-directed *UGT1A1* gene transfer is an active therapeutic frontier. In a phase 1–2 dose-escalation study of an AAV serotype 8 vector encoding *UGT1A1* (GNT0003) in patients with the Crigler–Najjar syndrome maintained on phototherapy, the higher dose (5×10^{12} vector genomes/kg) produced sustained bilirubin reduction and enabled discontinuation of phototherapy without drug-related serious adverse events, whereas a lower dose produced only transient benefit (12). These trials have focused

primarily on severe type 1 disease. Durability in young children, pre-existing and treatment-induced vector immunity, dose-related hepatotoxicity, and loss of episomal vector genomes during liver growth remain important limitations, and preclinical work on repeated AAV dosing seeks to address vector dilution in growing pediatric livers (12, 13). Genome editing and targeted integration are promising preclinical approaches but are not standard care. For a stable child with type 2 disease, these strategies remain investigational rather than alternatives to effective conventional therapy.

V. Summary:

This term infant had persistent neonatal unconjugated hyperbilirubinemia, a homozygous likely pathogenic *UGT1A1* p.Pro387Arg variant, and a marked phenobarbital response. These findings support Crigler–Najjar syndrome type 2 despite a family history of reportedly type 1 disease. The key diagnostic pearl is to integrate response to therapy with molecular and longitudinal data rather than assign subtype based on peak bilirubin or family history alone. Parental segregation testing, retrieval of the affected sister's genetic results, and continued neurologic and biochemical surveillance are the most important unresolved steps.

"Liver-directed UGT1A1 gene transfer is an active therapeutic frontier...Genome editing and targeted integration are promising preclinical approaches but are not standard care. For a stable child with type 2 disease, these strategies remain investigational rather than alternatives to effective conventional therapy."

Conclusion:

This case expands the clinical documentation of the *UGT1A1* p.Pro387Arg variant and reinforces a residual-function, phenobarbital-responsive type 2 phenotype. A targeted multigene panel rapidly established the molecular diagnosis, while therapeutic response resolved the clinically consequential distinction from type 1. The case also illustrates why marked intrafamilial severity should prompt segregation analysis and record review rather than automatic prognostic extrapolation. In practice, early recognition of persistent indirect hyperbilirubinemia, prompt *UGT1A1* testing, careful phenobarbital assessment, and close longitudinal monitoring can reduce neurotoxicity and avoid premature transplant assumptions. Future work should pair standardized functional assays with detailed treatment and outcome data and should clarify the long-term role of gene-based therapies across the Crigler–Najjar spectrum.

Take-Home Messages (Practical Points):

- Consider *UGT1A1*-related disease when severe, predominantly unconjugated hyperbilirubinemia persists beyond physiologic neonatal jaundice, particularly when imaging and hepatic synthetic function are normal.
- Do not distinguish Crigler–Najjar type 1 from type 2 by a single bilirubin concentration; integrate molecular findings, longitudinal course, and a clinically supervised phenobarbital response.
- For type 2 disease, maintain reliable phenobarbital adherence, individualized phototherapy, and serial bilirubin monitoring, with intensified surveillance during illness, fasting, dehydration, or treatment interruption.
- Monitor neurodevelopment, hearing, hydration, medication adverse effects, and exposure to drugs that displace bilirubin or impair conjugation; seek urgent evaluation for neurologic change or a rapid bilirubin rise.
- Obtain parental segregation testing, and review affected relatives' molecular reports before using family history to predict subtype, prognosis, or transplant need.
- Use exome or genome sequencing when targeted testing is unrevealing or the phenotype suggests genetic heterogeneity; do not substitute broad sequencing for careful biochemical phenotyping.

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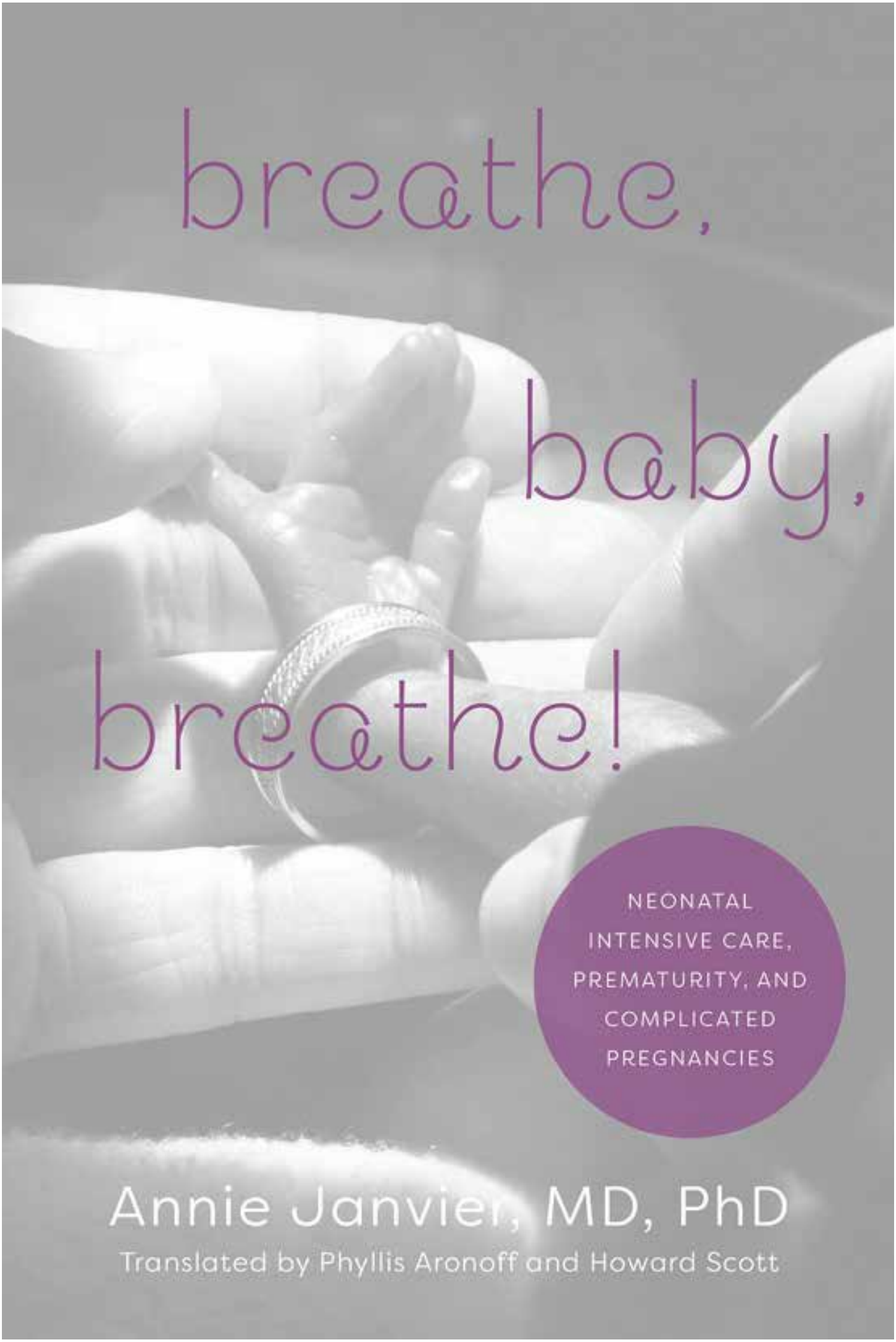
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breathe,
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NEONATAL INTENSIVE CARE, PREMATURITY, AND COMPLICATED PREGNANCIES
Annie Janvier, MD, PhD
Translated by Phyllis Aronoff and Howard Scott

Family-Centered Care Taskforce: Newsletter Volume 16

Malathi Balasundaram, 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 professionals 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 car"

"After sharing stories of losses both mothers experienced in the NICU, Latoya and Tracy provided valuable insights that clinicians can utilize to improve their communication skills not only with families in the NICU setting, but also in any professional encounter. Following this discussion, Anthony provided a clinician's perspective on how we can improve our communication skills, especially while breaking bad news"

Disclosure: *Mead Johnson Nutrition and Chiesi USA generously support this work.*

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"Importantly, rupture and repair do not occur only between two people. The conditions surrounding an interaction such as team culture, workload, policies, communication practices, hierarchy, and the larger care environment, contribute to both disconnection and reconnection."

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Vol. 16

FCC TASKFORCE NEWSLETTER

An international collaborative initiative solely dedicated to **quality improvement in NICU Family-Centered Care**.

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- July '26 Webinar Summary
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- Leadership Team Update
- FCC Taskforce Information

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Parenting in the NICU, Part 3

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.

Today is discharge day—for me, not for Avery. How am I supposed to leave him here by himself? He's so impossibly small. What if something happens? He can't tell us. I think fondly about the comforts of home and Rascal, our dog. Immediately, I feel guilty for thinking even just for one second of leaving my baby. It could be months before Avery is able to come home. Am I supposed to just return to normal life? My life before his birth feels foreign to me. I don't want to go back, even if I could. Cameron walks with me to see Avery before we leave. They look so tired. We both do, I'm sure. I'm deeply grateful that Avery's nurse tonight gives us space after updating us. Space is all I crave now. Avery looks like he's in a terrarium, but we are, too. The lack of privacy is maddening. These curtains don't shield much. I sneak in a gentle touch to Avery's tiny hand. Bless him for not alarming anyone because I didn't ask first. I hope he knows that I'm his mom. I'm still wrapping my mind around that transition myself. As we prepare to leave, his nurse offers me a hug (I decline) and shares that while she has never been in this position, she can only imagine how hard it must be. I appreciate the gesture, I really do. I would give anything to only be imagining all of this. Cameron thanks her while I somberly walk to the door. The childbirth classes and pamphlets didn't prepare me for this feeling. I'm not supposed to leave without my baby. Everything about this feels wrong.

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 professionals 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. To read Part 2, click here.

Vol. 16

NAVIGATING GRIEF IN THE NICU

SAHRA CAHOON, Love for Lily & **ERIKA GOYER**, National Perinatal Association

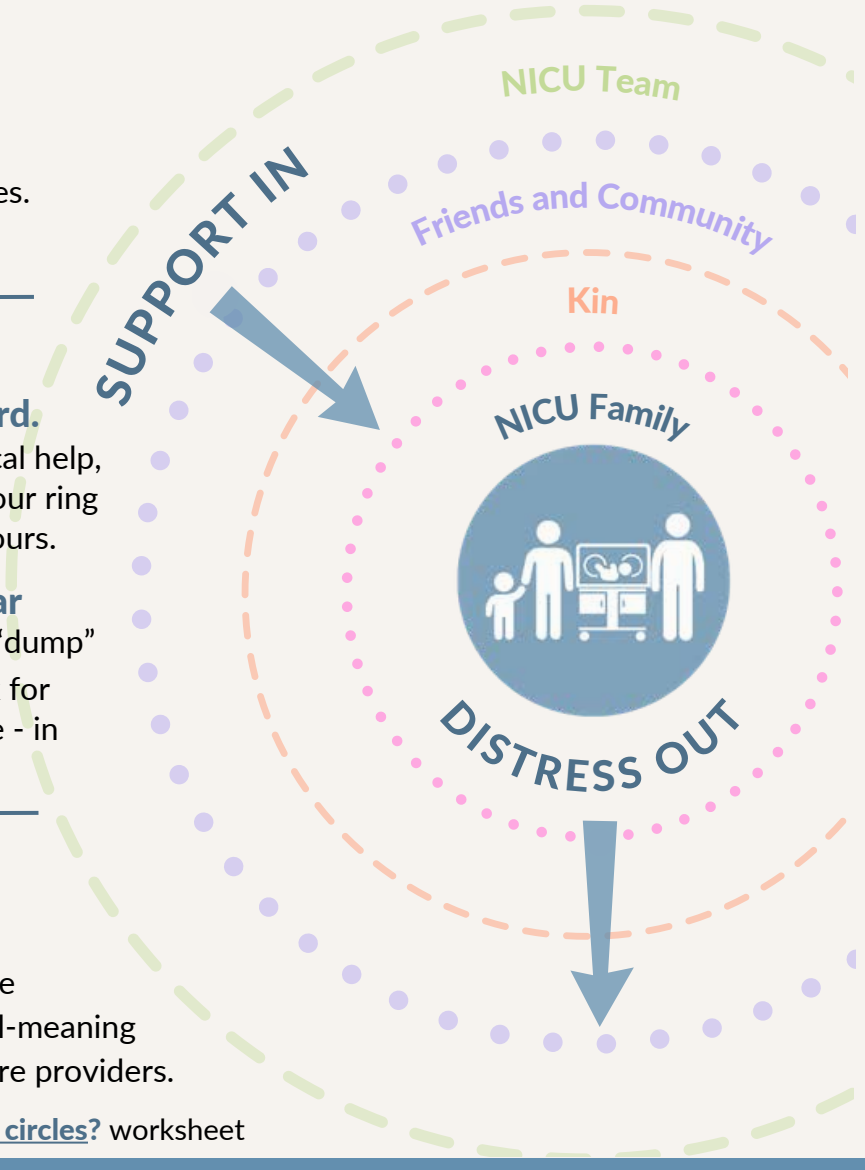
When supporting families in the NICU, remember this phrase **Comfort in. Dump out.**

We read it years ago in the Los Angeles Times. It's simple, practical, useful advice. And it was the answer to the persistent question from NICU staff during our annual bereavement support trainings. **"I want to help. How do I not say or do the wrong thing?"**

Psychologist Susan Silk calls it the **Ring Theory**

- **Draw a circle.** In that circle is the family who is in crisis or who is grieving.
- **Now draw a larger circle.** Those are the people closest to the family. Grandparents. Siblings. Auties. Uncles. Cousins. Kin.
- **The next circle** is their closest friends and community. They provide practical support during times of crisis.
- **We are in the circle of NICU providers and staff.** Nurses, neonatologists, therapists, peer support specialists, and NICU psychologists care for babies & families.

Read more on the Ring Theory



The Rules:

- **Comfort and support flow inward.** Your role is to offer validation, practical help, and emotional support to people in your ring or in the rings that are smaller than yours.
- **Distress, worry, anxiety, and fear flow outward.** Your goal is to only "dump" - vent at, complain to, worry with, ask for reassurance, or seek help from people - in rings larger than your own.

Why?

In the NICU, this model helps protect traumatized parents from taking on the burdens, anxieties, and distress of well-meaning friends, extended family, and healthcare providers.

Who's in your circles? worksheet

JULY '26 WEBINAR SUMMARY

BOB CICCO, MD

"Parent Perspectives: Clinician Communication" with Latoya Blueford and Tracy Peila, MA, LMHP, EdS and **"Breaking Bad News: Helping Families When They Need It Most"** with Anthony Orsini, DO, FAAP

After sharing stories of losses both mothers experienced in the NICU, Latoya and Tracy provided valuable insights that clinicians can utilize to improve their communication skills not only with families in the NICU setting, but also in any professional encounter. Following this discussion, Anthony provided a clinician's perspective on how we can improve our communication skills, especially while breaking bad news. Some important highlights include:

- It's not just what a clinician says, but **how they say it**. Nonverbal communication like eye contact, facial expressions, and body language allows a family to know he or she is "present" during a conversation. And **it's just as important to "be present" after the conversation is over**.

- Clinicians should **always sit during a conversation with families**. It's an essential part of that nonverbal communication that is oftentimes overlooked!

- How a clinician talks to a family can either help empower that family to manage their NICU stay or add to the stress and pressure that a family already feels.

- While it is imperative that a clinician always speaks the truth, ***how*** that truth is spoken always matters.

- While a clinician can't always be perfect in what he or she says, **communicating in a compassionate and caring way** can overcome some of that imperfection.

- It is important that clinicians know the families they are speaking to and talk on a level that families understand. **There are no "standard scripts" that can be used for everyone!**

- Having difficult conversations does not come naturally to any clinician. And it should not be viewed as a task that must be done. Rather, it is a **skill that must be taught, honed, and mastered**. No one is inherently "good" at it without this training.

- In addition to individual training, the **culture of a NICU** can prioritize that staff communicates in a way that is sensitive to family needs.

- There is a difference between merely giving information and communicating. Clinicians must not merely give information and leave. Rather, that i**nformation must be part of a conversation that is carried out with empathy, clarity, and purpose**.

This session served as a reminder to all of us that **how we communicate plays a major role in establishing trusting relationships between families and clinicians**. This is especially true in difficult and stressful situations that are so common in the NICU setting. Honing communication and listening skills must be a **continual part** of a clinician's ongoing education if they are to develop effective partnerships with the families they serve.

Did you miss this session? Watch the recording here.

EDIBJ IN THE NICU: *DIVERSITY, HONORING DIFFERENCES*

JESSI BARNES, MSN, RN & MIA MALCOLM, BS, CDFT

What does diversity actually mean? At its core, diversity is about variety—in people, places, and perspectives.

- **Diversity in people** includes a wide spectrum of races, ethnicities, genders, languages, ages, cultures, and beliefs.
- **Diversity in places**—especially in healthcare—means designing environments like the NICU, PICU, CICU, or ED to meet specific clinical and family needs.

Simply put, diversity is about honoring differences.

But to honor someone, you first have to see them. That starts by creating psychological safety—building a space where patients, families, and staff can share their full stories without fear of judgment. When we understand someone's story, we can show up for them in ways that truly matter to them.

Here are two ways equity and diversity come together to drive compassionate, family-centered care:

Example 1 - Assessing Language Needs

A Spanish-speaking family asks through an interpreter how to complete their discharge CPR class. The schedule offers English classes Monday through Wednesday, from 12:00 PM to 3:00 PM or 4:00 PM to 7:00 PM. The Spanish option? Thursdays from 12:00 PM to 1:00 PM only.

On paper, it looks like a win—we have language options! But in practice, true accessibility is only being offered to English-speaking families. An English-speaking parent gets 18 hours of total class availability across multiple times of day, while a Spanish-speaking parent gets just one single hour. On top of that, while the hospital assumed Spanish was the most pressing need based on national trends, a closer look at local demographic data showed that Haitian Creole was actually the second most spoken language in their specific patient population.

This is where diversity without equity falls short. **Honoring differences means looking past surface-level checklists and designing care around the actual lives and languages of the families in front of us.**

Every family deserves access to care that is free from bias, discrimination, and fear-based practices. In the NICU, diversity also encompasses family structure and community, which often looks different than expected. Each family arrives with a distinct set of strengths and challenges regardless of their makeup.

Providing individualized, equitable care means recognizing and responding to those differences with humility and respect.

The goals of diversity include fostering creativity and innovation, strengthening decision-making, and building a more just and empathetic community.

EDIBJ IN THE NICU: *DIVERSITY, HONORING DIFFERENCES*

CONTINUED FROM PAGE 4

JESSI BARNES, MSN, RN & MIA MALCOLM, BS, CDFT

Example 2 - The Connection Between Being Seen and Feeling Safe

You are working on a quality improvement project to decrease the number of sticks for babies while placing PICC lines. You notice that one member of the PICC team has a significantly higher number of sticks for Black infants. When you ask them about it, they respond with "That can't be right. I do the same thing for every baby. I don't see color when it comes to my patients. My success rate is still the highest on the team."

This team member response highlights three critical misunderstandings:

- **Equity vs Equality:** Doing the "same thing" for every baby is not equal care, especially when the approach disproportionally benefits lighter skin tones. Darker skin may require different lighting or technology (transilluminator, etc.) to locate veins accurately on the first try.
- **Reframing Success:** A high success rate is not what is being discussed – the number of sticks it takes to achieve success is. A "high success rate" means very little if a Black infant had to endure 2-3 times as many sticks when compared to their white peers.
- **The Danger of Colorblindness:** Saying "I don't see color" may seem benign, but what it does is dismiss both physical and cultural realities of families. When families realize that their diverse identities are being ignored, under the guise of neutrality, trust evaporates. Choosing not to see a family's race, ethnicity, culture, etc., leads them to feel undervalued, which translates to an inherent lack of safety.

Both examples show that both equity and diversity are needed to truly see families and provide individualized care that accomplishes clinical care goals in ways that are important to and affirming of their family. Next time, we'll explore inclusion and how it helps operationalize equity and diversity.

IMPORTANT DATES

September

- NICU Awareness Month
- Newborn Screening Awareness Month

September 10: World Suicide Prevention
September 7-13: Maternal Suicide Prevention Week
September 15: Neonatal Nurses Day
September 12-18: Neonatal Nurses Week
September 20-26: Int'l Neonatal Therapy Week

November

- Prematurity Awareness Month

November 15: World Prematurity Day

October

- Pregnancy & Infant Loss Awareness Month
- Sudden Infant Death Syndrome (SIDS) Awareness Month

October 4-10: National Midwifery Week
October 10: World Mental Health Day
October 15: Pregnancy & Infant Loss Remembrance Day
October 25-31: Respiratory Therapy Week

Are we missing something?
Email us!

Vol. 16

TRAUMA-INFORMED CARE CORNER

TINY RUPTURES, TINY REPAIRS

MARY COUGHLIN, MS, NNP, NCC-E, TRAUMA INFORMED PROFESSIONAL

Trauma-Informed Care After We Get It Wrong

A parent asks a question during rounds. Someone answers quickly, turns back toward the team, and the conversation moves on. The parent grows quiet. Nothing dramatic happened. And yet, something happened.

Trauma-informed care is often described through the things we hope to do well: create safety, build trust, offer choice, listen deeply, communicate transparently, and foster connection. But what about the moments when we don't get it quite right?

We interrupt. We assume. We move too quickly. We use words that land differently than we intended. We decide without realizing someone important has been left out. These small moments of disconnection, also called relational ruptures, are part of being human.

Trauma-informed care isn't about relational perfection. It's about building the capacity to repair.

Repair Can Be Small

Repair doesn't necessarily require a lengthy conversation or formal apology. Sometimes it begins simply by noticing that something shifted and having the courage to turn toward it. A repair might sound like:

- "I don't think I really heard you. Can you tell me again?"
- "I moved too quickly. Let's try that again."
- "I realize we made that decision without you. What matters to you here?"
- "That didn't come out the way I intended. May I start again?"

These seemingly small moments communicate something much larger: You matter. Your experience matters. Our relationship matters enough for me to notice. When people have experienced trauma, uncertainty, powerlessness, or exclusion, that message can be profoundly important.

Importantly, rupture and repair do not occur only between two people. The conditions surrounding an interaction such as team culture, workload, policies, communication practices, hierarchy, and the larger care environment, contribute to both disconnection and reconnection. Repair is relational, and it also invites us to notice what else needs attention or change in order to more consistently (and sustainably) support connection.

A Practice to Carry with You

When an interaction with an infant, family member, or colleague feels different afterward, rather than immediately explaining it away, pause, notice, and get curious.

Was there a moment of disconnection here? Is there an opportunity for repair?

Healing relationships are not relationships without rupture. They are relationships in which we learn how to find one another again. This builds safety, trust and leads to true collaboration and partnerships.

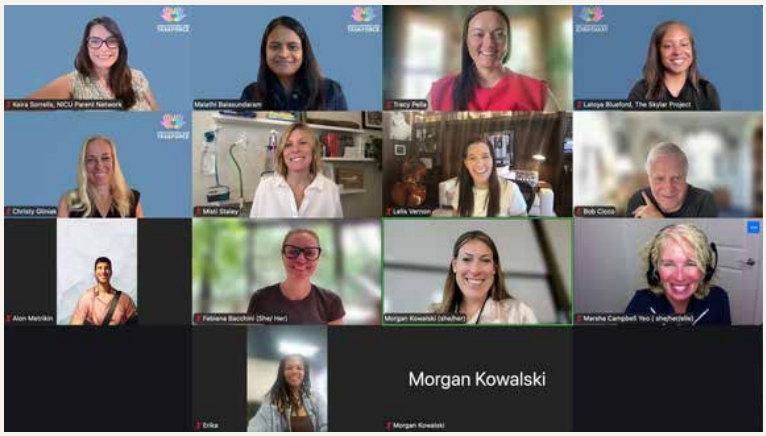
Continue the Exploration

Vol. 16

LEADERSHIP TEAM UPDATE

MALATHI BALASUNDARAM, MD & MORGAN KOWALSKI

The FCC Taskforce's Executive Council held its second quarterly meeting of 2026 on June 17th with 27 members joining virtually via Zoom and in-person at the International Gravens Conference in South Bend, Indiana.





Our first-ever exhibitor table featuring materials from Hand to Hold, Love for Lily, The NICU Dad, and Timeless Topics!

Executive & Advisory Council Members with our FCC Scholars!



2026 Accomplishments

- Released Equity, Diversity, Inclusion, Belonging, and Justice Position Statement
- Launched Presence Study Toolkit
- Established three new committees:
  - Dads and Partners Engagement
  - ROI of FCC
  - Quality Improvement
- Published Family Partnership Abstract

Projects in our Pipeline:

- Quality Improvement Foundations Course for Family Partners (Dec 2026) *Thank you, Vermont Oxford Network!*
- Silent Signals in the NICU Toolkit (Sept 2027)
- Dads and Partners Screening and Support Cohort (Dec 2027)

SHARE YOUR SUCCESS!

We are seeking **FCC implementation success stories** for our 2027 Community Exchange sessions! These are a fun way to **showcase your work and support your peers**. Check out previous sessions and email us to learn more.

Thank you to each of our Executive & Advisory Council members who volunteer their time to support this work!

Vol. 16

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

30 family-led organizations
51 healthcare-based organizations

Connect

Mission Statement

We support NICUs as they begin or strengthen Family-Centered Care in their units.

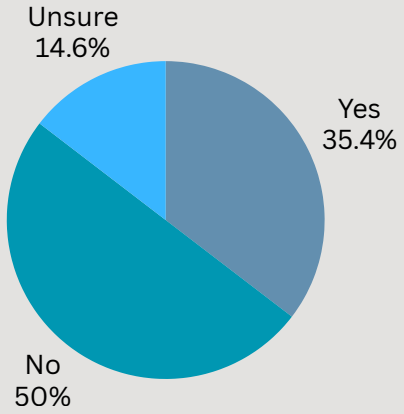
Why We Exist

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



3,700+ members
50 U.S. States & Puerto Rico
9/10 Canadian Provinces
81 Countries
Join us, membership is free!

Our listserv is 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: The Quality of Justice

Barry S. Schifrin, MD, Maureen Sims, MD

An old legal maxim holds that Justice delayed is Justice denied. It advances the proposition that if legal relief or redress to an injured party is unavailable or not timely forthcoming, it is effectively the same as having no remedy at all. In criminal cases, the defendant has a right to a speedy trial in deference to the criminal defendant's interest in expediously resolving the threat to his or her liberty. Not all legal cases, especially malpractice cases, can be resolved quickly, no matter the facts.

"An old legal maxim holds that Justice delayed is Justice denied. It advances the proposition that if legal relief or redress to an injured party is unavailable or not timely forthcoming, it is effectively the same as having no remedy at all."

Pitfalls in the road to timely adjudication of legal allegations include problems with courts, tribunals, requirements for affidavits of merit, judges, arbitrators, administrative law judges, commissions, or governments. In fairness, cases may be too complex or have too many roadblocks; the judicial system may be too slow or overburdened; or counterproductive statutes or political issues may interfere. Individual judges may be hesitant to make timely decisions or accurately report an insurmountable backlog. When a court takes a matter "under advisement," it awaits the issuance of a judicial opinion, order, or judgment and forestalls final adjudication of a lawsuit.

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For participants in the justice system, the delay may be avoidable, disproportionately long, or unavoidable out of reasonable necessity. Context and details are integral to such interpretations. The objective is to resolve disputes fairly. Some of them take time.

Because medical malpractice lawsuits are complex, they may take a long time to complete discovery and assemble records and historical facts, even without roadblocks. To avoid speculative or frivolous lawsuits, many states require an affidavit of merit—a sworn statement, usually by a medical expert who has reviewed the patient's medical records and, under oath, affirms that the medical care likely fell below the reasonable standard of care and caused an injury. Other states may require a medical tribunal to judge the merits of the case before pursuing a legal complaint. While a positive finding may accelerate the case, a negative one may halt or jeopardize an otherwise meritorious case. Tribunals, populated mostly by physicians, understandably tend to side with the defendant. Beyond these legal and administrative issues, medical records are sometimes lost or misplaced, and State statutes may limit their availability. The following case of alleged obstetrical malpractice was ultimately resolved only after 11 years of legal proceedings, when the plaintiff was almost 14 years old.

Facts of the case:

The mother was a 28-year-old married woman with a previously uneventful, normal delivery. In the present pregnancy, she had an uneventful prenatal course. Her BMI was 31; she gained 20 pounds during pregnancy, had normal lab values, adequate growth and amniotic fluid volumes on sequential ultrasounds, and normal fetal movement patterns. Her Group B Strep (GBS) was negative. Her blood pressure, stable during pregnancy, rose to 136/86 by 39 weeks, with no trace proteinuria or signs of preeclampsia.

At 40 weeks' gestation, the mother was admitted for elective induction of labor. On admission, the fetal heart rate (FHR) pattern showed a baseline rate of 140 bpm with accelerations, moderate variability, and absent decelerations, with intermittent contractions. Misoprostol (Cytotec) caused excessive contractions 1 to 1.5 minutes apart. Notwithstanding the frequent contractions, Pitocin was started, resulting in a further increase in uterine contractility which went unrecognized by the nursing staff, who continued to maintain the Pitocin infusion. After 3 hours, an epidural was administered, which resulted in maternal hypotension requiring

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ephedrine. During the administration of the epidural, the mother's heart rate (MHR) was monitored simultaneously on the fetal tracing. This maternal transducer was removed after completion of the epidural.

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The mother made steady progress in dilatation but little progress in descent of the fetal head despite ruptured membranes and very frequent contractions. Over time, given the relentless uterine hyperstimulation, the FHR remained about 140 bpm, but accelerations disappeared, baseline variability was persistently diminished, and early decelerations, thought to reflect fetal head compression, were present intermittently. After 10 hours in labor, the attending obstetrician finally appeared; he examined the patient, finding her cervix fully dilated with the head at zero station. He did not comment on the position, molding, or caput of the fetal head, nor did he recognize the obviously excessive uterine activity or the decreased variability on the FHR tracing. He left the room and instructed the patient to begin pushing.

With the onset of pushing, the fetal monitor tracing began recording the (MHR) with a baseline rate of 120 bpm, moderate variability, and large accelerations in the HR pattern. Indeed, the mother's pulse oximeter readings matched the rates recorded on the fetal tracing. After about 20 minutes of recording the MHR, the FHR—with decreased variability and obvious decelerations—was briefly inserted into the tracing, followed by a return to the MHR. Ninety minutes after he last saw the patient, the obstetrician was summoned to the delivery room and participated in the normal spontaneous vaginal delivery six minutes later.

At birth, the 4082-gram male infant was initially put on the mother's chest but, as was immediately obvious, the infant was severely depressed, being flaccid and not breathing. The Apgar scores were 2, 2, and 4 at 1, 5, and 10 minutes, respectively, with a persistently >100 bpm HR. Because no pediatric staff had been summoned prior to the delivery, the baby was given PPV but not intubated until 10 minutes of life secondary to respiratory failure. The record does not clearly describe what was done during those 10 minutes. After neonatal personnel arrived, the baby was intubated, with improvement in flaccidity. Over time, hypotonicity was followed by hypertonicity of the lower extremities. Cord gases were not sent—a point of contention. The medical record said they were sent, but there is no record of their being processed. A capillary blood gas at 58 minutes of life showed a base deficit (BD) of 15 with an elevated lactate level of 4.5.

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The baby was hypotensive and treated with pressors, dopamine, and fluid expansion. His initial hematocrit was 39.7, a low value for a term baby (normal=50–55). At several hours of life, concerns were raised about seizures, and with moderate encephalopathy and severe metabolic acidosis, the baby qualified for cooling. The baby was loaded with phenobarbital; passive cooling was begun; and arrangements were made to transport the baby to a higher level of care. At about 6 hours of age, at the referral hospital, the baby's pH was 6.71, the pCO_2 was greater than 130, and the pO_2 was 78. An ultrasound of the baby's head (HUS), performed at approximately 9 hours of life, was interpreted as normal. The baby was maintained on the ventilator for a short period of time but required a high-flow nasal cannula for 6 days, when he was briefly put back on the ventilator and then eventually taken off. Oral motor control was quite poor; he was unable to feed by mouth. There were no signs of sepsis, and various blood cultures were negative. There were no signs of any other factor or metabolic disease, hypoglycemia, etc.

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Extracerebral organ involvement included elevation of the creatinine to 1.1, elevation of the AST and GGT. An echocardiogram revealed cardiac depression based upon the left ventricular dysfunction. Multiple EEGs beginning on DOL1 showed electrocerebral suppression and low-voltage suppression of brain activity. Despite some improvement in the EEG after the first day, it continued to show marked depression of the brain waves. An MRI on DOL 3 revealed restricted diffusion in the ventral lateral

thalami, the entire basal ganglia, the peri-rolandic cortex, and the interior midbrain cerebellum vermis. The MRI also noted a large posterior scalp hematoma—a subgaleal hemorrhage (SGH), likely a consequence of trauma during the last stages of delivery, but according to the neuroradiologist, "not significant in terms of producing the injury." Based on the MRI, the estimated time of injury was 7–10 days prior to the MRI. (*See* below).

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Neurology consultation on DOL 4 described the baby initially as being unresponsive—without gag reflex or pupillary activity; he was flaccid with no movement of the extremities or response to painful stimuli. They thought the child's depression was greater than would have been expected for even this degree of acidosis. The neurologist opined that the baby suffered from moderate to severe HIE, but he was unclear as to the cause. A gastrostomy tube was placed on DOL 6, followed by a Nissen fundoplication. On long-term follow-up, the baby has extrapyramidal cerebral palsy—also called dyskinetic or athetoid cerebral palsy requiring considerable effort and expense for his ongoing care.

Legal proceedings

The plaintiff had to present the case to a medical board before filing the lawsuit. That process, which came to no resolution, took a little over one year and was a minor factor in the overall delay that plagued this case—approximately 11 years from the time the plaintiff's lawyers first requested medical records until the case was finally resolved. Of the 11 years, 9 were spent in multiple efforts to require the hospital to produce the complete medical records, including the electronic record that contained the audit trail authenticating all entries made in the chart, including those that may have been modified or deleted. In resisting production of the records, the hospital maintained that it had attempted to retrieve the electronic records but was unable to do so and, in any event, was not required to produce the electronic records and audit trail. Finally, after three courts issued orders, including, most importantly, an order allowing plaintiff's technical experts to inspect the servers and other areas where the hospital maintained its records, the hospital produced the electronic records, including the audit trail. The negligence case was filed within weeks and resolved in less than 2 years.

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- The negligence case presented the following allegations:
- Failure to appreciate problems with the feasibility of safe vaginal delivery.
- Failure to safeguard the well-being of the fetus properly.
- Failure to recognize and respond to the confusion in the fetal heart rate (FHR) tracing when the MHR was substituted for the FHR.
- Failed to recognize and respond to excessive uterine activity properly. Failed to manage Pitocin augmentation properly.
- The nurses failed to properly escalate the level of care given the problems with the FHR tracing.
- Failure to properly and timely have pediatric attendants capable of caring for the acutely ill newborn.
- Failure to follow the Neonatal Resuscitation Program (NRP)

Notice that there is no allegation that an earlier cesarean section was required. The focus was on the attention (or lack of it) paid to the tracing, to the unrecognized and untreated relentless, excessive uterine activity, and the failure to properly respond to the ambiguity created in the tracing by the insertion of the MHR. They left uncertainty that they could have resolved—and either prevented or timely corrected. Timely recognition and

response to these obvious problems with the HR pattern required reducing contractions, stopping pushing, attaching a fetal scalp electrode, and using a maternal transducer to determine MHR. The simultaneous use of a separate transducer to track the MHR during the epidural, though removed, clearly established the availability of this resource to resolve any ambiguity in interpreting the tracing in the 2nd stage of labor.

These actions, required by reasonable standards of care, would have resulted, within reasonable probability, in an intact, neurologically normal fetus. The route of delivery could easily have been a non-operative vaginal delivery. The issue was not the route or the urgency but the removal of the fetal distress by a reduction in the frequency of UC and the relentless pushing in this otherwise resilient fetus. This situation required attention that was not forthcoming.

Defense allegations included an injury preceding the induction of labor or an injury derived from the failed resuscitation immediately after birth, believing that the sluggish clinical response in the first 10 minutes of life may have added significant injury based on hypotension, poor perfusion, and further ischemia. All defense experts admitted some confusion about the fetal tracing, although some believed that the entire tracing was fetal and benign with no possible correlation with the marked depression of the neonate.

Comment:

There is broad agreement that the clinical course, laboratory results, neuroimaging, and EEG results were all consistent with an acute hypoxic-ischemic injury to the brain with no definitive evidence by any parameter of an earlier injury. Indeed, the MRI can only be explained by that. None of the supporting tests (MRI, HUS, FHR pattern, multisystem organ injury, lactate level), as unequivocal as they are for making the diagnosis and reasonably excluding an earlier injury, can pinpoint the actual timing of injury.

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Fetal tracings:

The fetal monitor tracing was entirely reassuring at the outset of labor but evolved significantly over time. Despite the long stretches of inadequate or poor tracing quality, there was no reason to infer injury before the onset of pushing and the erroneous acceptance of the MHR as the FHR. These findings by themselves reasonably exclude a recent injury. The ambiguous tracing after the onset of pushing does not permit a more exact timing of injury but narrows the window of injury to the final 90 minutes of labor.

Cord and early blood gases:

Cord blood gas values are another piece of the puzzle when determining the cause of a depressed newborn or a child with an adverse outcome. In this case, cord gases were not obtained (or not processed). When they are missing, you can estimate acid-base status at birth by back-calculating from a postnatal blood gas using published regression formulas that correct for the time elapsed between delivery and sampling.

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Resuscitation:

Deviations from the Neonatal Resuscitation Program (NRP) framework can convert a survivable initial hypoxic-ischemic insult into worsened secondary brain injury by disrupting the narrow

physiologic window in which the neonatal brain is most vulnerable to reperfusion injury. After a reversible insult, neuronal death evolves in two phases: primary energy failure at the time of the insult, followed by a latent interval and then secondary energy failure over the ensuing hours. Resuscitation that departs from timely administration of titrated oxygen, controlled ventilation, and homeostatic management independently amplifies intrapartum injury.

"After a recent hypoxic ischemic insult, the head ultrasound (HUS) typically does not become abnormal until 18–24 hours. The normal findings on the HUS obtained at 9 hours of age tend to confirm that the injury occurred during the time of labor and delivery and belie the defense's position that the injury occurred before delivery."

Against this physiologic backdrop, the causation dispute divided along predictable lines. Defense experts for the obstetrical team attributed the adverse outcome to a preceding injury augmented by the "unanticipated" need for timely resuscitation. Plaintiff experts countered that while the intrapartum and neonatal timings were potentially cumulative, there was no evidence whatsoever to support an injury prior to labor. The evolution of the originally reassuring FHR pattern and the presence of severe depression from the first minute of life, including the scalp bleed, were factors clearly in favor of an intrapartum timing of injury—without excluding a synergistic effect of the substandard resuscitation.

"Therapeutic hypothermia shifts the timeline of when hypoxic-ischemic brain injury becomes visible on MRI, effectively widening the useful imaging window rather than shrinking it. In normothermic infants with HIE, injury on diffusion-weighted imaging (DWI) typically peaks around days 2–5 and then 'pseudonormalizes,' with the restricted diffusion resolving and diffusion coefficient (ADC) values rising back toward baseline, which can make real injury look deceptively normal if you scan too late (after about day 5–7)."

Neuroimaging:

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Restricted diffusion on MRI typically becomes evident within 24 hours after insult and remains abnormal for 8–10 days. MR imaging, however, cannot identify the precise time of injury except to say that it encompasses the period of time that includes labor and delivery.

Low hematocrit:

Neonatal/fetal anemia at birth arises through three basic mechanisms: blood loss (hemorrhage), increased red blood cell destruction (hemolysis), and decreased red-cell production. In the above case, the subgaleal hemorrhage well accounts for the low hematocrit. The subgaleal space is a loose, compartment space between the connective tissue covering the skull and the periosteum, with no structures to tamponade bleeding, unlike a cephalohematoma, which is contained by suture lines. In a typical newborn who has a blood volume of 80–100 mL/kg, the subgaleal space can sequester 20–40% of total blood volume or more. Fetal anemia contributes to cerebral ischemia. Anemia results in fetal hypotension, which aggravates the effect of head compression on cerebral blood flow by lowering cerebral perfusion pressure.

"Cooling (33.5°C for 72 hours) slows cerebral metabolism and the cascade of secondary energy failure that drives injury evolution. Because of this delay, many centers shifted their 'optimal' MRI timing later for cooled infants, commonly around day 4–7 of life (sometimes stated as day 5–10), rather than the earlier windows used before hypothermia became standard of care. Scanning too early in a cooled infant risks underestimating injury because it has not fully evolved yet; scanning very late still risks missing it if pseudonormalization has begun, but that pseudonormalization point itself comes later than in an uncooled infant."

MRI and Cooling:

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The Ethics of Self-protection - A well-documented negative feature in medical ethics literature is the "conspiracy of silence," or "wall of silence." This situation refers to physicians who fail to respond ethically to medical circumstances below any reasonable standard of care. This happens when silence is maintained amid allegations against colleagues in the hospital. It can also apply to medical panels reluctant to indict colleagues. It also occurs when flawed testimony emerges during discovery in a medical malpractice case. Expert depositions can be plagued by selective memory and errors of omission over commission: the right question might not have been asked, nothing false was said, and nothing true was said either. Errors become recast as an inherent risk; uncertainty about the timing of an injury from one standpoint becomes definitive despite contradictory evidence. What motivates this ethically compromised behavior? Fear of reciprocity, loyalty conflated with honesty, litigation anxiety, institutional incentives? Such loyalty is not only misplaced; it may harm someone else later. Health care providers who have not learned from their errors are destined to repeat them. They may fear C.S. Lewis's observation that: "The more you obey your conscience, the more your conscience will demand of you."

"Beyond what seems like obvious and irrefutable negligence that resulted in a serious, lifelong injury, the case took 11 years to resolve after the plaintiff's lawyers first became involved. The hospital and its caretakers made no effort to explain the child's outcome. No peer review or root cause analysis occurred. Despite the legal and medical impediments and frustrations, the case proceeded through multiple expert depositions for both sides, court appearances, delays in trial dates, and ultimately significant differences between the amount the plaintiff demanded and what the hospital's insurer was willing to pay."

Comment:

Beyond what seems like obvious and irrefutable negligence that resulted in a serious, lifelong injury, the case took 11 years to resolve after the plaintiff's lawyers first became involved. The hospital and its caretakers made no effort to explain the child's outcome. No peer review or root cause analysis occurred. Despite the legal and medical impediments and frustrations, the case proceeded through multiple expert depositions for both sides, court appearances, delays in trial dates, and ultimately significant differences between the amount the plaintiff demanded and what the hospital's insurer was willing to pay. The trial ultimately lasted only long enough for a jury to be empaneled, for opening statements to be made by both sides, and for the testimony of a few plaintiff witnesses, including nursing and obstetrical experts. After the first week of trial, the insurance company settled the case for a confidential amount.

Some argue that settlements in medical negligence cases are excessive. Those claims may be made even when the case details are unknown. What is also unknown—as with this case---is whether the important lessons to be learned from the details of the case were appreciated in any timely way. Was Justice served? Probably, in the end. However, before that was realized, there was a lot of injustice, along with significant ethical failures within the medical community. Focusing on the settlement amount overlooks the real lessons these cases can provide.

Suggested Readings:

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Physicians at Teaching Hospitals Redux: Guidelines for Attending Physicians, APPs, and Trainees

Scott D. Duncan, MD, MHA

"CMS establishes Guidelines for Teaching Physicians, Interns & Residents, commonly referred to as PATH (Physicians at Teaching Hospitals), which set billing and payment policies for services provided in teaching settings. These guidelines ensure accurate reimbursement under the Medicare Physician Fee Schedule for services delivered by teaching physicians, interns, and residents, and state Medicaid programs typically follow them. Commercial insurers are not mandated to follow these guidelines; however, many payors adopt elements of the guidelines to establish payment policies."

A similar version of this article was published in August 2025. Given that new trainees have begun within the last month, the concepts in that article are worth repeating.

CMS establishes Guidelines for Teaching Physicians, Interns & Residents, commonly referred to as PATH (Physicians at Teaching Hospitals), which set billing and payment policies for services provided in teaching settings. These guidelines ensure accurate reimbursement under the Medicare Physician Fee Schedule for services delivered by teaching physicians, interns, and residents, and state Medicaid programs typically follow them. Commercial insurers are not mandated to follow these guidelines; however, many payors adopt elements of the guidelines to establish payment policies.

Question

A neonatologist in a teaching hospital attends a delivery with a pediatric resident. The infant is apneic at birth and requires PPV via face mask. The neonatologist instructs the resident to intubate the infant, which the resident accomplishes under direct, bedside supervision. The infant required additional PPV via endotracheal tube, with subsequent recovery. The infant was subsequently transferred to the NICU. Given the following codes, correct coding for the neonatologist includes:

99465: Delivery/birthing room resuscitation, provision of positive pressure ventilation and/or chest compressions in the presence of acute inadequate ventilation and/or cardiac output

31500: Intubation, endotracheal, emergency

A. **99465, 31500**

B. **99465**

C. **31500**

D. **There was no billable service**



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Answer

A. **99465, 31500**

This question focuses on supervision of trainees and collaboration among care providers. In this scenario, the neonatologist is supervising a trainee.

Question

True or False: PATH Guidelines apply to advanced practice providers (e.g., APRNs, NNPs, etc.)



Answer

False. APPs are not considered trainees; thus, PATH Guidelines do not apply. A future article will address the collaboration between physicians and APPs.

"When a teaching physician supervises a resident trainee, the physician must ensure proper documentation that demonstrates their involvement in the patient's care. In the preceding case involving attendance at delivery, documentation should detail the request for attendance at delivery, services provided, and disposition of the infant. The medical record must be signed and dated with a legible signature or identity."

Question

True or False: A co-signature or attestation of a resident's note that states *"Patient seen and evaluated"* is considered adequate documentation per PATH Guidelines.



Answer

False. Co-signature alone on a resident, fellow, or student note, or phrases like the above, are insufficient to support billing for teaching physician services. For services involving trainees, the teaching physician must personally document at least the following:

- The supervising physician personally performed the service or was physically present during the key or critical portions of the service when performed by the resident and
- The supervising physician participated in the management of the patient.

Documentation Pearls

When a teaching physician supervises a resident trainee, the physician must ensure proper documentation that demonstrates their involvement in the patient's care. In the preceding case involving attendance at delivery, documentation should detail the request for attendance at delivery, services provided, and disposition of the infant. The medical record must be signed and dated with a legible signature or identity. Documentation may be:

- Dictated and transcribed
- Typed
- Handwritten and/or
- Computer-generated

The physician may place a 'macro' on the medical record; however, it must be placed new each day. It is not sufficient if a physician uses a macro solely for documentation purposes, without noting the physician's presence during the provision of services and describing the patient-specific services provided on that date to justify the level of billing for that encounter. Examples

might include:

Global Critical and Intensive Care Service example:

I was present for key or critical portions of this patient's care, and I reviewed the patient's findings and note with the resident. I provided face-to-face coordination of the health care team, inclusive of the resident, and directed the patient's assessment and management as reflected in the documentation above.

Newborn Nursery example:

I was present in the nursery where I examined the patient and directed the patient's care. I reviewed the above note with the resident and agree with the documented findings, assessment, and plan of care.

Minor Procedure example:

As the teaching physician supervising the resident, I was physically present during the entire procedure.

Attendance at Delivery example:

I was present and participated in the initial stabilization of the patient in the delivery room as reflected in the resident's documentation.

Question

Mrs. Smith has requested a circumcision for her son prior to discharge. After ensuring informed consent has been obtained and the patient has a normal examination, the upper-level resident performs the circumcision in the adjoining nursery, while the teaching physician is available in the NICU. Correct coding for this encounter would be:

A. **54150**: Circumcision performed using a clamp or other device, with or without regional dorsal penile or ring block

B. **No billable service**



Answer

B: No billable service

Minor procedures take only a few minutes to complete and involve relatively little decision-making once the need for the procedure is determined. For these procedures, the teaching physician must be present for the entire procedure. The teaching physician or trainee may document the supervising physician's presence. For other surgical, high-risk, or complex procedures, the supervising physician must be present during all critical and key portions of the procedure and immediately available to furnish services during the entire procedure.

"Minor procedures take only a few minutes to complete and involve relatively little decision-making once the need for the procedure is determined. For these procedures, the teaching physician must be present for the entire procedure. The teaching physician or trainee may document the supervising physician's presence. For other surgical, high-risk, or complex procedures, the supervising physician must be present during all critical and key portions of the procedure and immediately available to furnish services during the entire procedure. "

Question

True or False: An APP can charge a procedure or evaluation and management code if supervising a resident.



Answer

False. While some programs may allow an APP to supervise a resident under certain conditions, PATH guidelines do not consider an APP a supervising physician.

Question

A 5-day-old patient is readmitted for phototherapy due to hyperbilirubinemia. The resident documents their H&P after seeing the patient at 23:15 on September 1st. On the morning of September 2nd, the neonatologist rounds on the patient and documents an attestation on the H&P note verifying the history, plan, and assessment recorded by the resident. In addition, the neonatologist adds a current exam and interim changes in the patient's condition and plan.

Which is the correct date of service for the teaching physician to report their initial hospital care code?

A. September 1st

B. September 2nd

C. No billable service



Answer

B. **September 2nd**

In this scenario, the teaching physician did not provide a billable service until the following day. When a medical resident admits a patient to a hospital late at night and the teaching physician does not see the patient until the next calendar day, the teaching physician must document that they personally saw and examined the patient and participated in the patient's management. The teaching physician may reference the resident's note instead of re-documenting the pertinent history, examination, and medical decision-making, provided the patient's condition has not changed, and the teaching physician agrees with the resident's note. The teaching physician's note should reflect any changes in the patient's condition and clinical course at the time the teaching physician personally sees the patient. The teaching physician's charges must reflect the actual date of service when the teaching physician saw the patient and the patient's current status.

Bonus Question

A resident attends a cesarean section C/S and admits a 34-week late preterm infant to the NICU. The baby is tachypneic but remains in RA. The resident orders IV fluids. The resident contacts the supervising neonatologist via real-time audio-visual technology, which allows the neonatologist to visualize the patient and review plans with the resident. The resident documents the admit note, and the supervising neonatologist includes an addendum indicating audio-visual participation. The neonatologist is physically present in the NICU on the following day. How should the supervising neonatologist approach billing for admission-day services?



Answer

For both the delivery and admission encounter, most neonatologists would agree that bedside assessment would represent a key or critical portion of these services. Therefore, from a CMS teaching physician perspective, the teaching physician did not meet the criteria for admission-day billing. To bill both the attendance at delivery and the NICU admission encounter, the teaching physician would have had to be physically present to participate in key or critical portions of the service and in patient management.

CMS guidelines allow the teaching physician to use remote telehealth technology to supervise a resident performing a telehealth service, but in the above scenario, the resident performed in-person, not telehealth, services.

Given no significant clinical change, the most reasonable approach to CPT coding for this encounter is to use CPT 99477 on the day following admission, when the attending neonatologist is physically present and able to assess the infant.

Hopefully, this overview is helpful. "There are plenty of difficult obstacles in your *PATH Guidelines*. Don't allow yourself to become one of them." – Borrowed from Ralph Marston.

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Biographical Sketch

Dr. Duncan received his undergraduate degree from Transylvania University in Lexington, KY, and completed his medical training at the University of Louisville. He earned a Master's Degree in Healthcare Administration from the Gillings School of Global Public Health at the University of North Carolina at Chapel Hill in 2011. He is a Professor and division chief in the Division of Neonatal Medicine at the University of Louisville. Dr. Duncan is a Fellow of the American Academy of Pediatrics and is the Chair of the Coding Committee of the Section on Neonatal-Perinatal Medicine. Dr. Duncan has no conflict of interest.

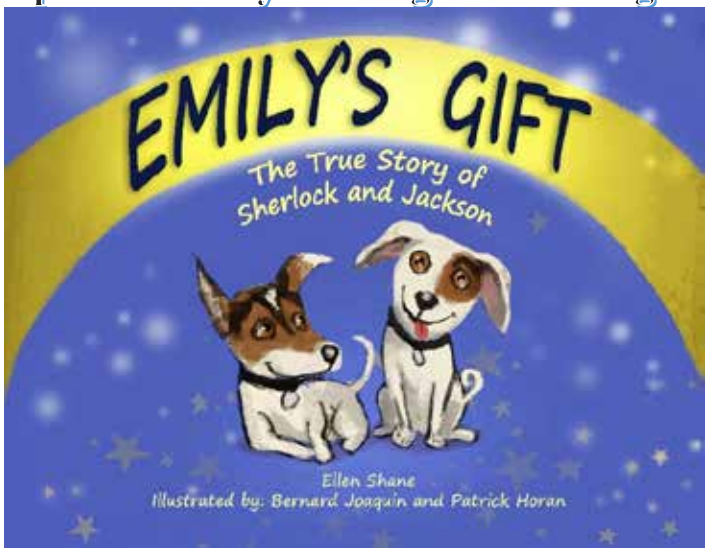
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Book Review: Book Review: Week 26, A Memoir of Hope, Faith, and Perseverance

Aerin Mellott, MS4

"Week 26, A Memoir of Hope, Faith, and Perseverance is a touching, powerful, quick read that I could not put down. It sheds light on the winding journey that many families endure when their child is admitted to the neonatal intensive care unit (NICU). Jenny and Joe welcomed their twins at just 26 weeks of gestation, after a sudden hemorrhage due to placenta previa woke Jenny in the middle of the night, necessitating the birth of their twins 14 weeks early. This harrowing event would unknowingly change the lives of their entire family forever."

Week 26, A Memoir of Hope, Faith, and Perseverance is a touching, powerful, quick read that I could not put down. It sheds light on the winding journey that many families endure when their child is admitted to the neonatal intensive care unit (NICU). Jenny and Joe welcomed their twins at just 26 weeks of gestation, after a sudden hemorrhage due to placenta previa woke Jenny in the middle of the night, necessitating the birth of their twins 14 weeks early. This harrowing event would unknowingly change the lives of their entire family forever.

Through honest and heartfelt storytelling, the author illustrates the twists and turns of navigating premature childbirth, maternal recovery, and the uncertainty that accompanies having critically ill newborns. The memoir offers an intimate, behind-the-scenes look at day-to-day life in the NICU: introducing readers to everything from "feeder-growers," infants who are medically stable and focused on feeding and growth, to babies requiring more complex, intensive care.

What makes this book especially compelling is the beautiful depiction of the warmth, compassion, and sense of community that coexist with the fear, grief, and uncertainty inherent to the NICU. The authors capture the delicate emotional balance between optimism and apprehension that families and physicians navigate together each day.

I highly recommend this inspiring, yet deeply emotional memoir to anyone interested in the resilience of the human spirit. As an aspiring neonatologist, the story of Jenny, Joe, and their twins, Luke and Layla, has left me with an even greater appreciation for the privilege of caring for families through one of the most challenging experiences of their lives.

"As an aspiring neonatologist, the story of Jenny, Joe, and their twins, Luke and Layla, has left me with an even greater appreciation for the privilege of caring for families through one of the most challenging experiences of their lives."

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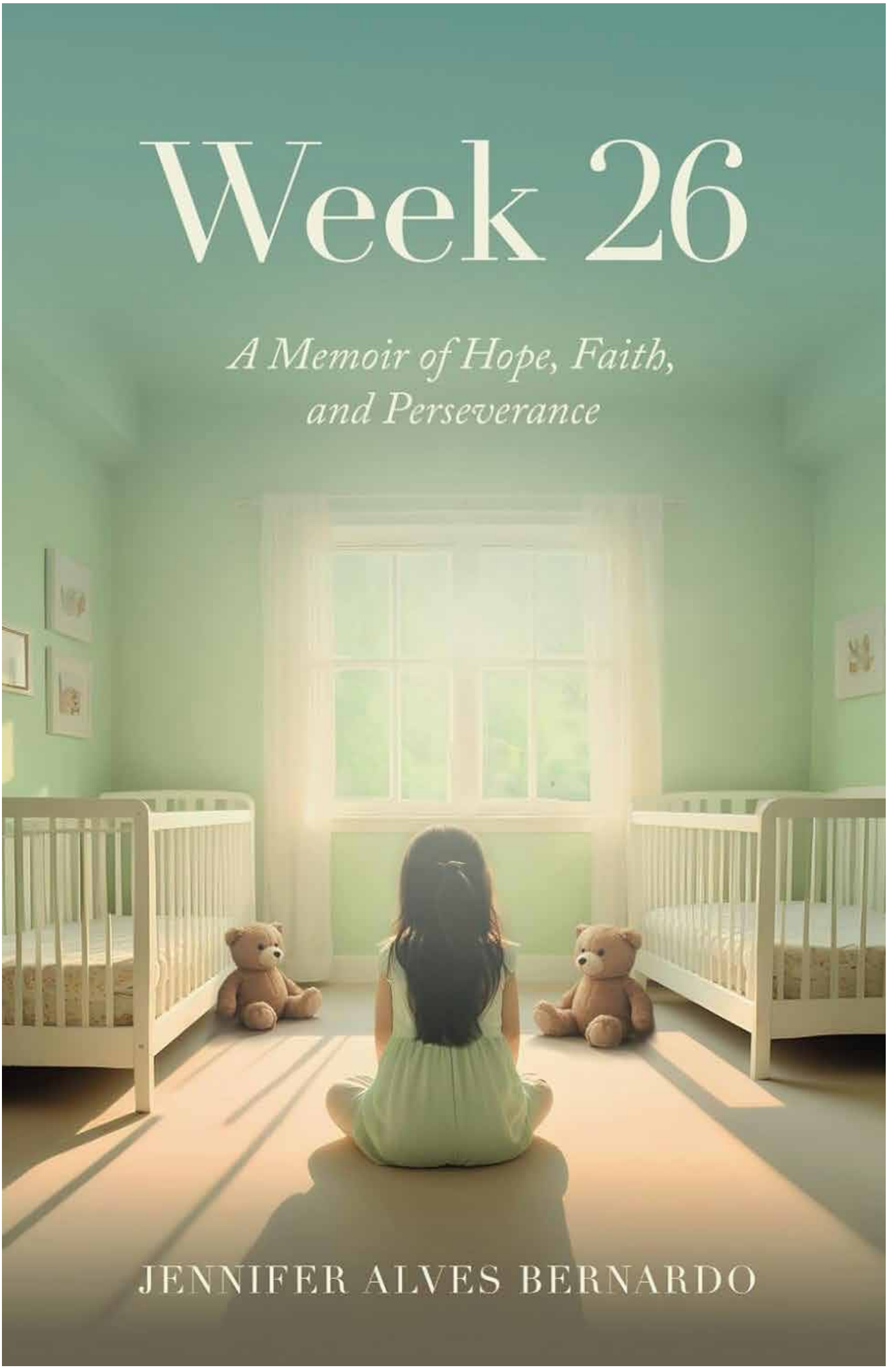
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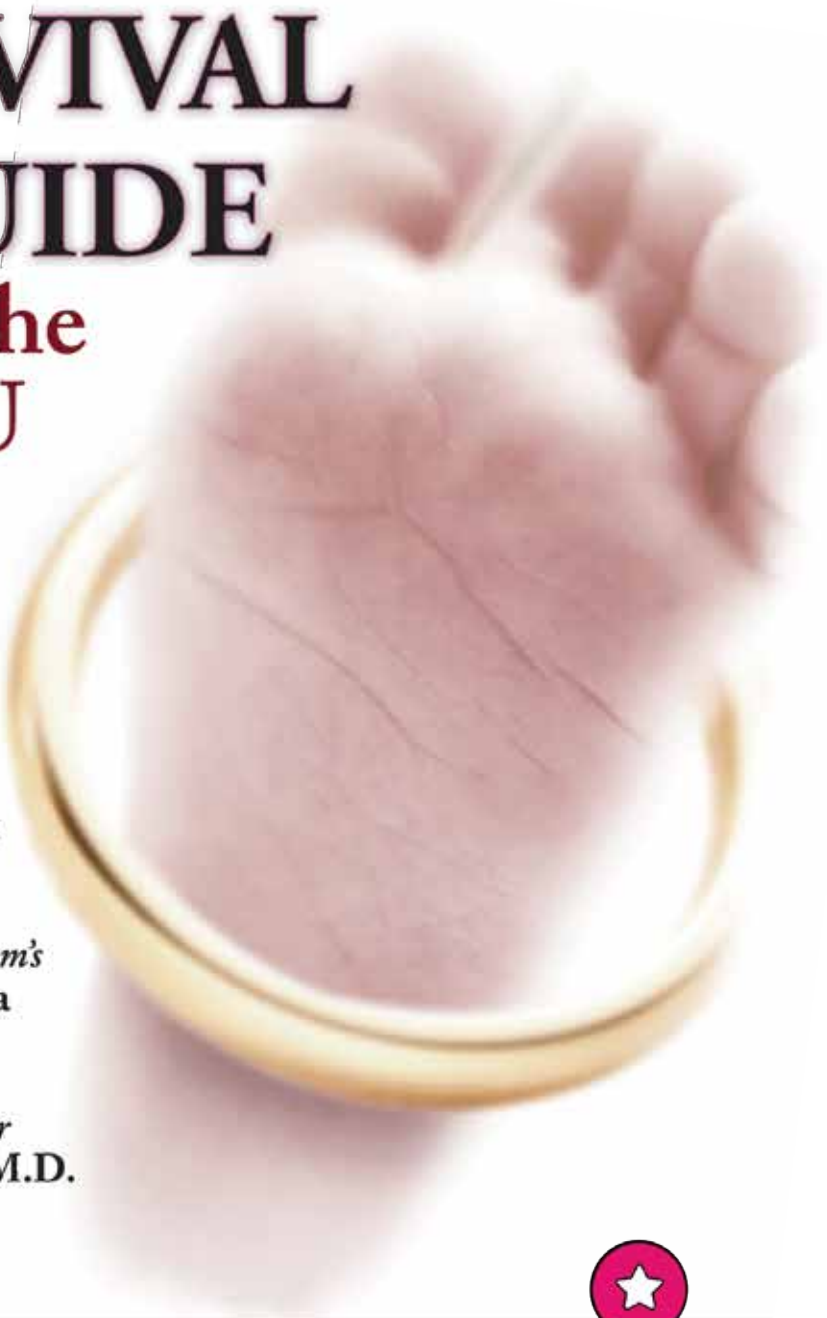
Week 26

A Memoir of Hope, Faith, and Perseverance



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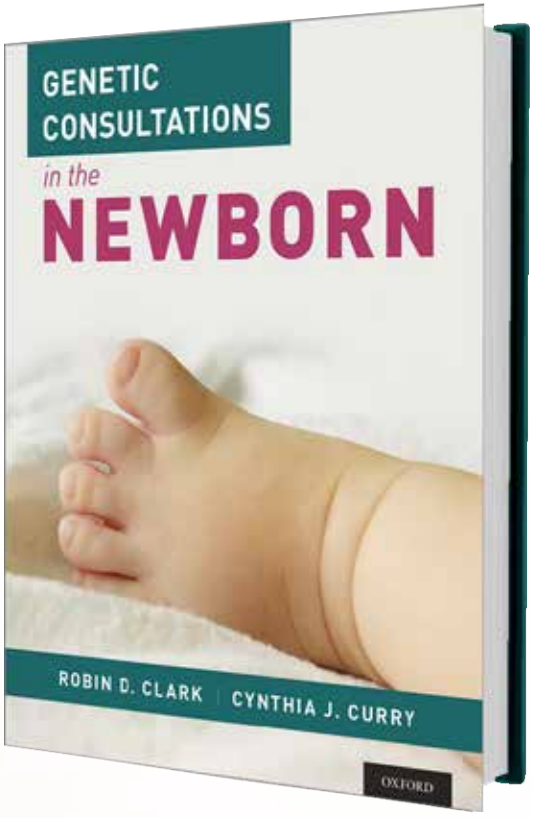
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Clinical Pearl: Prenatal Cell-Free DNA Screening for Common Autosomal Aneuploidies (Trisomy 21, 18,13) Available for All Pregnancies?

Joseph R. Hageman, MD, Wally Hussain, MD, Gustave Falciglia, MD, Mitchell Goldstein, MD, MBA, CML

"Prenatal cell-free DNA (cfDNA) screening tests have been commercially available since 2011 (1). Maternal blood may be drawn as early as 9-10 weeks of gestation or at any time later in the pregnancy (1). This screening test analyzes short fragments of maternal and placenta-derived cfDNA from maternal circulation, most commonly for common autosomal aneuploidies (Trisomy 21, 18, and 13) (1)."

Prenatal cell-free DNA (cfDNA) screening tests have been commercially available since 2011 (1). Maternal blood may be drawn as early as 9-10 weeks of gestation or at any time later in the pregnancy (1). This screening test analyzes short fragments of maternal and placenta-derived cfDNA from maternal circulation, most commonly for common autosomal aneuploidies (Trisomy 21, 18, and 13) (1). The ratios of fragments from different chromosomes are detected on analysis, and if there are too many fragments, for example in Trisomy 21, there will be a higher proportion of Trisomy 21 cfDNA fragments compared with a chromosomally normal fetus (1). The same increased proportion of cfDNA fragments will also be seen in Trisomy 18 and 13 (1). cfDNA fragments will be decreased in Turner syndrome (45, X) (1). The sensitivity of cfDNA screening for detecting Trisomy 21 is over 99%, whereas sensitivity for Turner Syndrome is about 90% (1).

"The sensitivity of cfDNA screening for detecting Trisomy 21 is over 99%, whereas sensitivity for Turner Syndrome is about 90% (1). "

The Society for Maternal-Fetal Medicine recommends that this cfDNA screening for the common autosomal aneuploidies be routinely available for all pregnancies. The American College of Obstetrics and Gynecology (ACOG) also endorsed this recommendation in 2025 (1).

"It is important to remember that this is a screening test, and confirmatory testing is necessary. cfDNA screening results are reported as "low-risk," "high-risk," or "no-call" (1)."

It is important to remember that this is a screening test, and confirmatory testing is necessary. cfDNA screening results are reported as "low-risk," "high-risk," or "no-call" (1).

Jones and Rasmussen, who are members of the American Academy of Pediatrics Council on Genetics Executive Committee, also recommend that we understand this screening and the need for confirmatory testing if it is determined to be "high-risk," and we may be asked about these screening and confirmatory testing during the prenatal period or postnatally if confirmatory testing may need to be performed (1).

Further information for families is available in Healthy Children (2) and from ACOG (3).

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Artificial Intelligence vs. Intelligence Amplified

Empowering Families with Knowledge through Connection and Technology



WHEN: March 3-5



WHERE: Hilton St. Louis at the Ballpark

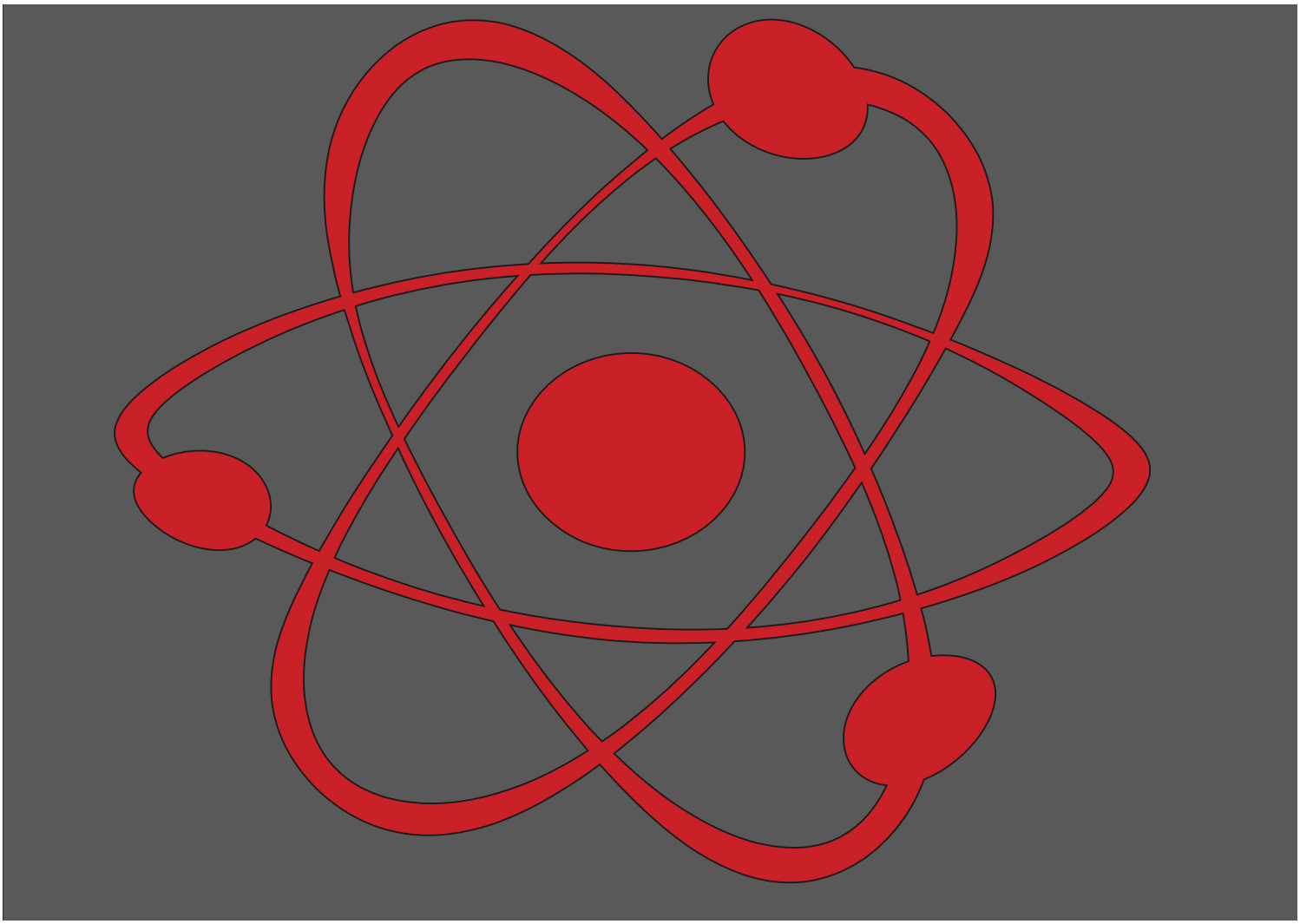
OBJECTIVES:

- Examine the evolving digital information ecosystem in perinatal care.
- Evaluate the role of artificial intelligence in clinical care and patient education.
- Promote "intelligence amplification" through human–technology collaboration.
- Address equity and access in the digital health landscape.
- Build partnerships between healthcare systems, technologists, and families.

National Perinatal Association

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For up to date Meeting Information, visit NeonatologyToday.net and click on the events tab.

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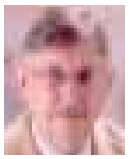
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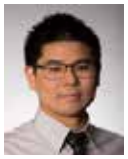
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Neonatology and the Arts

This section focuses on artistic work which is by those with an interest in Neonatology and Perinatology. The topics may be varied, but preference will be given to those works that focus on topics that are related to the fields of Neonatology, Pediatrics, and Perinatology. Contributions may include drawings, paintings, sketches, and other digital renderings. Photographs and video shorts may also be submitted. In order for the work to be considered, you must have the consent of any person whose photograph appears in the submission.

Works that have been published in another format are eligible for consideration as long as the contributor either owns the copyright or has secured copyright release prior to submission.

Logos and trademarks will usually not qualify for publication.

This month we continue to landscapes, feature artistic works created by our readers on the next to last page as well as photographs of birds on the rear cover. Monty Natour, MD provides "Grand Canyon Skittles" For this edition, our art was graciously provided by Colleen Kraft, MD. It is a work called "Forest in Autumn" done by her son Tim. Our bird is from Dr. Shah, "Asian Green Bee-eater."



Lily Martorell, MD

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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.

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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.

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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.

NPN
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