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Beyond Sepsis: Neonatal Salmonella Meningitis: A Case Report

Alia Shaheen, MBBS, Fizza Jamil Rao, MBBS, Aliya Ayub, MBBS, Amna Saleh, MBBS, Arshad Khushdil, MBBS, Mamoon Rasheed, MBBS

"Neonatal Salmonella meningitis is rare but severe, associated with substantial death and disability, and a poor prognosis. It is most commonly seen in developing countries with scarce resources and limited treatment options."

Abstract:

Neonatal Salmonella meningitis is rare but severe, associated with substantial death and disability, and a poor prognosis. It is most commonly seen in developing countries with scarce resources and limited treatment options. Timely therapy is crucial but challenging due to rising antimicrobial resistance and the lack of a standardized regimen, with international guidelines falling short in the face of emerging resistant strains in endemic regions.

We report a rare case of neonatal Salmonella meningitis in a 14-day-old term male, highlighting the clinical presentation, diagnosis, and management. No distinguishing features were found in the clinical manifestations or CSF biochemistry, with CSF culture as the cornerstone of diagnosis.

This case underscores the importance of considering Salmonella as a potential etiology of neonatal meningitis, especially in endemic areas. Rapid recognition, prompt CSF studies, and early empirical treatment can improve outcomes. Close monitoring until complete recovery and watchfulness for deterioration are imperative to reduce relapse and improve survival.

Introduction:

Meningitis is an infection of the membranes surrounding the brain and spinal cord, associated with substantial mortality and morbidity. Due to an immature immune system and a more permeable blood-brain barrier, neonates are particularly susceptible, accounting for almost half of all cases of bacterial meningitis. The distribution of causative organisms differs by region, with viral meningitis more common in developed countries and gram-negative bacteria predominant in developing nations. Mortality is primarily associated with bacterial causes, with 24% fatality. (1-3)

Salmonella meningitis, caused by a gram-negative, facultatively anaerobic bacillus of the Enterobacteriaceae family, is rare but severe, accounting for 0.8-6% of all cases of bacterial meningitis, with 89.7% occurring in infants under 1 year of age. It invades the intestinal epithelium, breaches the abdominal barrier, and enters the bloodstream, ultimately reaching the meninges. The first report of meningitis caused by the genus Salmonella was published in 1907, and it has since been increasingly reported, particularly in tropical climates. (4-6)

The prognosis is generally poor, with a high risk of antimicrobial resistance and relapse. Serious neurological sequelae can arise due to its invasive nature, including developmental delay, auditory and visual impairment. Early treatment is essential but challenging since there is no consensus on the most appropriate approach, as all currently available regimens have been reported on a case-by-case basis. (4-5, 7)

"Serious neurological sequelae can arise due to its invasive nature, including developmental delay, auditory and visual impairment. Early treatment is essential, but challenging, since there is no consensus on the most appropriate approach, as all currently available regimens have been reported on a case-by-case basis. (4-5, 7)"

Prompt recognition and subsequent four to six weeks of empirical antibiotic therapy can improve outcomes. Given the emergence of methicillin-resistant *Staphylococcus aureus* (MRSA) and cephalosporin resistance, antibiogram surveillance is crucial to detect changes promptly. (1-2, 8)

We report a rare case of neonatal Salmonella meningitis, emphasizing the clinical presentation, diagnosis, and management.

Case Presentation:

A 14-day-old term male, with a birth weight of 3500 g, delivered via elective lower segment cesarean section (LSCS), with no known antenatal, natal, or postnatal complications, presented with a one-day history of fever, lethargy, and reluctance to feed. Inspection revealed jaundice, hypotonia, and sluggish neonatal reflexes (NNR). On initial examination, the neonate was afebrile, with a heart rate of 142 beats/min and a respiratory rate of 44 breaths/min. Occipitofrontal circumference (FOC) was 34.5 cm.

A preliminary diagnosis of late-onset neonatal sepsis (LONS) was made, and empiric, broad-spectrum, intravenous combination therapy with meropenem and vancomycin commenced while awaiting blood reports. Due to poor oral intake, the neonate was kept on a total fluid feed of 150 ml per day, with 75 ml per day administered parenterally and 75 ml per day given enterally via orogastric tube.

Baseline investigations from 28/03/2026 comprised a total lymphocyte count (TLC) of 4 x 10^9/L (61% neutrophils, 33% lymphocytes), hemoglobin (Hb) 15.4 g/dL, platelets (PLT) 221 x 109/L, and C-reactive protein (CRP) 292 mg/L. Liver function tests showed total serum bilirubin (S. Bil) 137 µmol/L (indirect 106 µmol/L, direct 31 µmol/L), alanine aminotransferase (ALT) 13 U/L, alkaline phosphatase (ALP) 117 U/L. Kidney function tests revealed urea 4.47 mmol/L, creatinine 46 umol/L, sodium 132 mmol/L, and potassium 6.0 mmol/L.

Lumbar puncture was performed, and cerebrospinal fluid (CSF) studies were done. CSF was turbid, with marked pleocytosis (76,350 cells/mm3), neutrophilic predominance (80% neutrophils, 20% lymphocytes), and increased globulins. A few red blood cells and degenerated neutrophils were also noted. Proteins were raised at 4095 mg/L, and glucose was reduced to 0.822 mmol/L. Ziehl-Neelsen (ZN) stain for acid-fast bacilli (AFB) and Gram stain for microorganisms were negative. An elevated CSF lactate level of 9.48 mmol/L led to a definitive diagnosis of acute bacterial meningitis.

On repeat panel on 31/03/2026, TLC climbed to 16.7 x 10^9 /L (20% neutrophils, 71% lymphocytes), with lymphocytic predominance, Hb and PLTs fell to 13.6 g/dL and 181 x 10^9 /L, respectively, and CRP improved to 120 mg/L. Renal profile demonstrated decreased urea 3 mmol/L and creatinine 46 µmol/L. Serum electrolytes were within normal range (sodium 141 mmol/L, potassium 4.8 mmol/L).

After 72 hours of incubation, CSF culture yielded isolates of Salmonella species, sensitive to Ampicillin, Azithromycin, Cefotaxime, Ceftriaxone, Cotrimoxazole, and Meropenem, and resistant to Ciprofloxacin and Levofloxacin. Antimicrobial regimen was tailored accordingly. Repeat studies were performed after 21 days of iv antimicrobial therapy, with levetiracetam injection added due to excessive jitteriness. A mother's blood culture was also performed, which showed no growth.

"After 72 hours of incubation, CSF culture yielded isolates of Salmonella species, sensitive to Ampicillin, Azithromycin, Cefotaxime, Ceftriaxone, Cotrimoxazole, and Meropenem, and resistant to Ciprofloxacin and Levofloxacin. Antimicrobial regimen was tailored accordingly."

Lumbar puncture was repeated on 16/04/2026. CSF was clear, with 96 cells/mm^3, showing lymphocytic predominance (lymphocytes 90%), and 1332 mg/L of proteins. CSF culture yielded no microorganism growth after 48 hours of incubation. On repeat CSF report, it was decided to complete 4 weeks of IV antibiotics.

A contrast-enhanced (CE) MRI brain performed on 14/04/2026 revealed diffuse patchy meningeal thickening along bilateral cerebral convexities and basal cisterns, along with prominent meningovascular enhancement along both frontoparietal lobes. Fairly defined, extra-axial, signal intensity areas around the frontal and temporal lobes, likely suggestive of subdural collections, were remarked upon. Benign enlargement of subarachnoid spaces of infancy (BESSI) was noticed as well. (Figures 1-2).

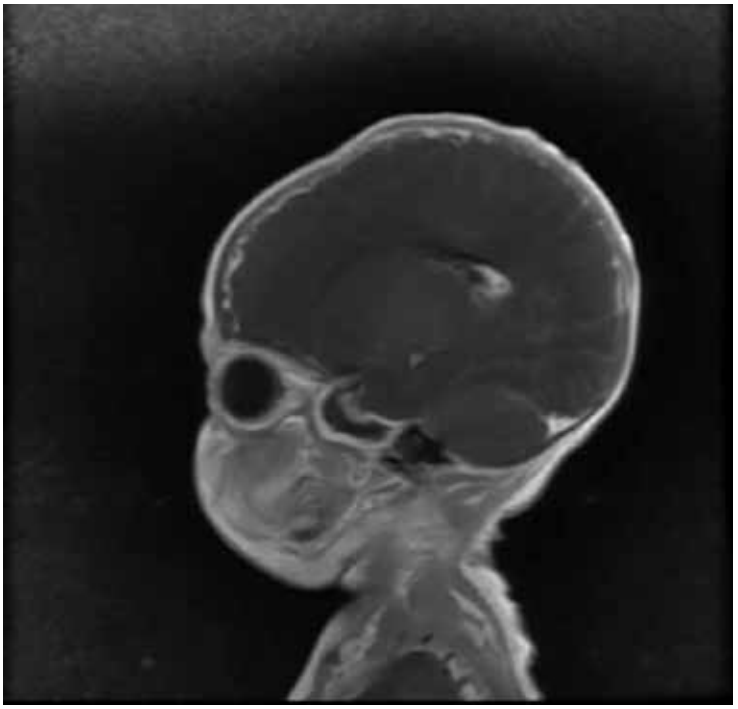

Figure 1: Sagittal contrast-enhanced MRI of the brain demonstrating diffuse meningeal enhancement along the cerebral convexities and basal cisterns, with associated extra-axial subdural collections.

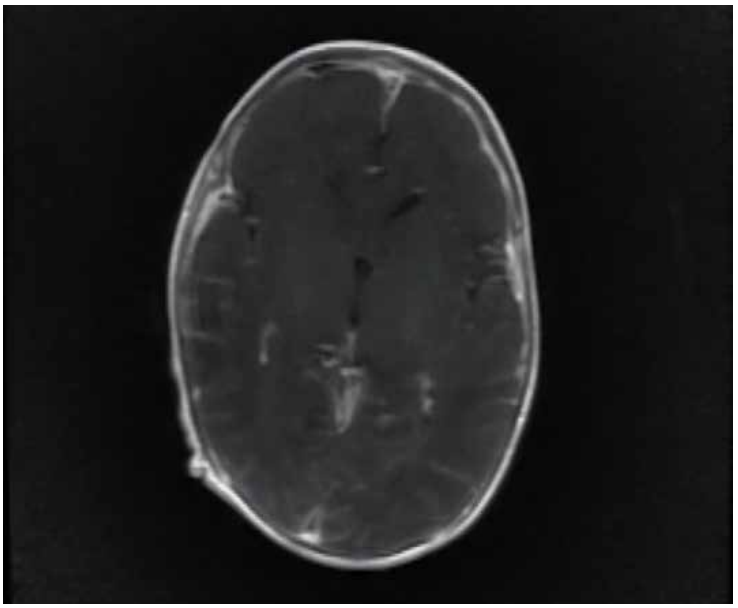

Figure 2: Axial contrast-enhanced MRI brain revealing bilateral leptomeningeal enhancement and extraaxial subdural collections consistent with inflammatory meningeal involvement.

Gradually, the patient's condition improved within a few days of starting treatment. His neonatal reflexes and activity were fair. No fits or any jitteriness observed. He was shifted to full oral feed. IV levetiracetam switched to oral Lerace. FOC monitoring was performed daily.

Patient was discharged on 30/04/2026, with hearing and neurodevelopmental assessments planned for follow-up. On baselines from 30/04/2026, TLC was 4.7 x 10^9 /L (32% neutrophils, 60% lymphocytes), Hb and PLTs were 9.2 g/dL and 249 x 10^9 /L, respectively, and CRP improved to 0.581 mg/L. Renal profile demonstrated urea 3 mmol/L and creatinine 25 µmol/L. Serum electrolytes were within normal range (sodium 141 mmol/L, potassium 4.8 mmol/L). Weight and FOC at discharge were 4520 g and 37 cm, respectively, within the appropriate range for age.

The patient was reassessed after 4 weeks on follow-up. The infant is now 2.5 months old and has achieved age-appropriate milestones. Growth parameters are within normal limits for age. Baby is active, alert, socially responsive, and feeding well. No developmental concerns were identified at the time of assessment. The infant is 2.5 months old and has achieved age-appropriate developmental milestones. Growth parameters were within normal limits for age. The baby is active, alert, socially responsive, and feeding well. No developmental concerns were identified at the time of assessment.

Discussion:

Gram-negative organisms, excluding Escherichia coli, accounted for 6% of all neonatal meningitis cases, with a median gestational age of 38.6 weeks, a median birth weight of 3100 g, and a median age of onset of 9 days. It was more common among preterm infants, making up almost 45% of cases. (1)(2) Signs and symptoms included temperature instability, irritability, lack of sucking, convulsions, impaired consciousness, and malnutrition, similar to those caused by other bacteria. (6) Our patient was a 14-day-old term male, weighing 3500 g, with fever, lethargy, and reluctance to feed, fitting the typical demographic profile.

Late-onset neonatal sepsis (LONS) occurs after 72 hrs of life; when the central nervous system is involved, the condition is classified as late-onset neonatal meningitis (LOMS). Empiric treatment for neonatal meningitis in most parts of the world includes ampicillin and gentamicin or a third-generation cephalosporin, with carbapenems reserved for resistant or relapsed cases. The majority of gram-negative organisms (63%) are now resistant to ampicillin, and 23% are resistant to third-generation cephalosporins; however, all isolates are susceptible to either vancomycin or fourth-generation cephalosporins. (1)(5) In light of above, dual therapy with meropenem and vancomycin was initiated.

Only a minority of patients had a TLC > 11 x 10^9 /L and > 70% polymorphonuclear cells. The majority had a TLC between 4-9 x 10^9 /L and between 40-68% polymorphonuclear cells. In another study, the mean Hb of the total respondents was 12.6 g/dL, the mean PLT count was 305 x 10^9 /L, and the mean CRP was 38.3. (9)(10) Compared to these, our case had more marked derangements in parameters. As our isolate was identified as a Salmonella species and not further serotyped, and given the rise of multi- and extensively drug-resistant strains in Pakistan, there is a possibility that it is a more aggressive and virulent strain. (11)

The CSF cell count ranged from 40-60 to 20,000-40,000 cells/mm^3, with polymorphs ranging from 70-90%, while lymphocytes ranged from 5-30%. Higher cell counts corresponded with higher polymorph and lower lymphocyte percentages. (10) This is in line with the CSF analysis in our case. The glucose in meningitis was significantly lower than in septicemia, while the protein was much higher. However, no specific biochemical features of CSF have been identified in Salmonella meningitis, and younger patients tend to present with atypical clinical manifestations. Thus, the keystone of diagnosis is CSF culture. (12)

"The American Academy of Pediatrics recommends cefotaxime or ceftriaxone, with or without a fluoroquinolone, for 4 weeks or more, but the emergence of resistant strains, especially in endemic regions of South Asia, requires therapeutic alternatives."

The American Academy of Pediatrics recommends cefotaxime or ceftriaxone, with or without a fluoroquinolone, for 4 weeks or more, but the emergence of resistant strains, especially in endemic regions of South Asia, requires therapeutic alternatives. In this regard, carbapenems have shown good outcomes due to favorable CSF pharmacokinetics and high cellular-to-extracellular concentration ratios. A treatment duration of greater than four weeks seems reasonable, as in our case. With multiple studies suggesting courses ranging from three to five weeks, however, further research is needed to inform the optimal duration. (9)(13)(14)

"Because of the risk of recurrence, neuroimaging is recommended for all, even if the clinical course is satisfactory. In our patient, a CE MRI brain showed leptomeningeal enhancement and subdural collections."

During hospitalization, many patients develop acute intracranial complications, including hydrocephalus (50%), subdural collections (42%), cerebral infarction (33%), ventriculitis (25%), empyema (13%), intracranial abscess (8%), and cranial nerve palsy (8%). After discharge, long-term neurologic sequelae can include motor, speech, and visual impairment, sensorineural hearing loss, intellectual disability, and epilepsy, necessitating continuing neurodevelopmental follow-up. Because of the risk of recurrence, neuroimaging is recommended for all, even if the clinical course is satisfactory. In our patient, a CE MRI brain showed leptomeningeal enhancement and subdural collections. Levetiracetam was administered for seizure prophylaxis, and hearing and neurodevelopment assessments were planned on follow-up. (15)

Conclusion:

We describe a rare case of neonatal Salmonella meningitis. A timely diagnosis based on recognition of acute neurological signs,

coupled with prompt and appropriate treatment, can improve outcomes. Patients should be monitored frequently until they have fully recovered, with detailed neurodevelopmental evaluation, and vigilant lookout for complications, to prevent and reduce the high risk of relapse and neurological sequelae.

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Informed Consent:

The patient's parents, his legal guardians, provided informed consent for the publication of this case report.

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Mission

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

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The Conversation I Did Not Hear

Philippe S. Friedlich, MD, MS Epi, MBA

There are conversations we remember because of what was said. Others remain with us because we only understand what the person may have been trying to tell us much later.

"There are conversations we remember because of what was said. Others remain with us because we only understand what the person may have been trying to tell us much later."

During my final year of fellowship, my mentor, Robert deLemos, suffered a stroke. Robert was a pioneer in neonatology, an internationally respected physician and an extraordinary teacher. His influence extended far beyond his own patients and trainees. Many of the physicians he trained went on to become leaders in our field.

I revered him. I also adored him.

Following his stroke, Robert became significantly depressed. One day in October, as we were washing our hands before entering the intensive care unit, he told me, quite simply, that I would replace him the following year, after I completed my fellowship.

I was stunned. Here was one of the pillars of neonatology telling a young fellow that I would take his place. At the time, I heard his words as an astonishing statement about my future. I did not understand that they might also have been a statement about his.

The following day, while I was rounding in the unit, I was called to the telephone. Robert had died by suicide.

That call changed my life.

In the years since, I have returned to our last conversation many times. I have wondered whether Robert was not merely telling me about my career but trying, in the only way he could at that moment, to reach out. I have wondered what might have happened if I had stopped, looked at him more carefully and asked, "What do you mean?" or simply, "Are you all right?"

Suicide is complex, and no single conversation or individual can bear responsibility for another person's death. I understand that intellectually. But I have also carried the enduring lesson that words may contain more than their literal meaning—and that listening requires more than hearing them.

"That call changed my life. In the years since, I have returned to our last conversation many times. I have wondered whether Robert was not merely telling me about my career but trying, in the only way he could at that moment, to reach out. I have wondered what might have happened if I had stopped, looked at him more carefully and asked, 'What do you mean?' or simply, 'Are you all right?'"

As physicians, we are trained to notice subtle changes in our patients. We recognize when a newborn's color, breathing, tone, or behavior is not quite right. We respond to small signals because we understand that they can precede profound deterioration.

Yet we do not always extend the same attentiveness to one another.

Medicine prizes endurance. Neonatology, in particular, asks us to work within an environment of uncertainty, grief and enormous responsibility. We care for critically ill newborns, support families through moments of unimaginable fear, make consequential decisions, and then move directly to the next bedside. We carry these experiences home while also managing illness, aging, family responsibilities, professional disappointments, and private struggles that may be invisible to those around us.

These pressures affect physicians at every stage of their careers. A trainee may feel overwhelmed but afraid that asking for help will be interpreted as a sign of weakness. A midcareer physician may be carrying clinical, administrative and family responsibilities that have become unsustainable. A senior physician may be confronting illness, loss of identity or the painful realization that a career built over decades is changing or approaching its conclusion.

Whether we are at the beginning, middle or end of our professional journey, we remain human first.

A second mentor, Istvan Seri, helped me understand that recognizing this humanity must be accompanied by meaningful

institutional support. As he prepared to leave Children's Hospital Los Angeles and I remained to assume new responsibilities, he gave me a piece of advice: find a way to incorporate a psychologist into the division.

"Whether we are at the beginning, middle or end of our professional journey, we remain human first."

Soon after I became division chief, I was introduced to Michael Wolkenfeld, a clinical psychologist with expertise in trauma who was also the father of children who had received care in a NICU. He understood the NICU both professionally and personally. The idea Istvan had proposed began to flourish, and in 2014 it became a reality within our division—well before embedding psychologists in clinical environments became a more widely recognized approach in medicine.

The original purpose was broader than providing support to patients and families. It was also to support the staff and physicians caring for them.

That distinction matters. Physicians may be reluctant to discuss emotional distress with a supervisor, particularly when that supervisor evaluates their performance, determines assignments or influences advancement. Even the most supportive leader cannot eliminate that concern. An embedded psychologist offers another doorway: a professional who understands the clinical environment but stands outside the usual chain of command.

To this day, I believe this structure helps bridge a critical gap. It allows physicians and other team members to speak with someone who understands trauma, grief, and the emotional realities of intensive care—and with whom they may feel more comfortable being candid.

"To this day, I believe this structure helps bridge a critical gap. It allows physicians and other team members to speak with someone who understands trauma, grief, and the emotional realities of intensive care—and with whom they may feel more comfortable being candid."

It also taught me an important lesson about leadership. We should encourage colleagues to reach out, but we cannot place the entire responsibility on the person who is struggling. Nor can we rely exclusively on informal acts of kindness. Institutions must create accessible and trusted pathways to support before a crisis occurs. The invitation to seek help has little meaning if people do not know where to turn, fear professional consequences, or believe that the only available person is their boss.

Recently, during a particularly demanding period in our division, I wrote to my colleagues asking them to take care of one another. I asked them to notice if someone seemed unusually quiet, overwhelmed, withdrawn, irritable, or simply not themselves. I encouraged them not to assume that somebody else would check in.

"Institutions must create accessible and trusted pathways to support before a crisis occurs. The invitation to seek help has little meaning if people do not know where to turn, fear professional consequences, or believe that the only available person is their boss."

Reach out. Ask how the person is doing. Then listen.

A brief conversation, a cup of coffee, or a simple expression of concern may be more meaningful than we realize. We do not need to diagnose a colleague or find the perfect words. We need to be present, attentive, and willing to tolerate an honest answer.

Sometimes "How are you?" is merely a greeting. At other times, asked with patience and genuine concern, it can open the door.

If the answer—or the silence that follows—causes concern, we should not look away. We can ask again. We can help the person connect with a trusted colleague, an embedded mental health professional, institutional resources, or outside care. When there is an immediate concern for someone's safety, we must act urgently rather than leave that individual to bear the burden alone.

Reaching out is not an intrusion. It is an expression of our shared responsibility for one another.

"Reaching out is not an intrusion. It is an expression of our shared responsibility for one another."

The same must be true when we are the ones struggling. Taking time to care for ourselves or our families is not weakness, disloyalty or a failure of professionalism. It is an acknowledgment that physicians cannot remain endlessly untouched by illness, grief, exhaustion and the emotional consequences of our work. Our patients deserve clinicians who are healthy, supported and able to bring their best selves to the bedside.

Creating such a culture requires more than wellness programs or occasional lectures. It requires daily permission to be human. It requires leaders who respond to vulnerability with support rather than judgment. It requires confidential and credible resources that clinicians can access without fear. It requires colleagues who recognize that professionalism includes knowing when to step forward—and when to step away.

Above all, it requires us to listen.

"Taking time to care for ourselves or our families is not weakness, disloyalty or a failure of professionalism. It is an acknowledgment that physicians cannot remain endlessly untouched by illness, grief, exhaustion and the emotional consequences of our work. Our patients deserve clinicians who are healthy, supported and able to bring their best selves to the bedside."

I cannot return to that sink outside the intensive care unit. I cannot ask Robert what he meant or tell him what his mentorship meant to me. I cannot change the conversation I did not fully hear.

But I can allow it to change how I listen today.

I can also honor Istvan's wisdom by helping to build a structure in which listening does not depend entirely on chance—one in which a struggling colleague has more than one person, and more than one doorway, through which to seek help.

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All of us will encounter a colleague whose words, behavior, or silence suggest that something is not right. We may never know whether reaching out altered the course of that person's life. That uncertainty should not prevent us from trying.

The gesture may seem small. The structure supporting it may be quiet and largely unseen. Both can have an impact that lasts a lifetime.

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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

Why Your Vote Matters
2026 American Academy of Pediatrics Election
September 2–16, 2026

Neonatology Today Editorial Election Advisory Committee

The American Academy of Pediatrics is more than a professional organization. Through its leadership, advocacy, clinical guidance, education, research, and public voice, the AAP helps shape the future of child health and the environment in which pediatricians practice.

"The American Academy of Pediatrics is more than a professional organization. Through its leadership, advocacy, clinical guidance, education, research, and public voice, the AAP helps shape the future of child health and the environment in which pediatricians practice."

The 2026 AAP presidential election allows every eligible member to help determine that future.

Why Participation Matters:

The issues facing pediatrics extend well beyond the bedside. They include access to care, Medicaid and CHIP, the pediatric workforce, evidence-based medicine, misinformation, immunization, health equity, family support, research, and public policy.

These issues are particularly relevant to neonatology. An infant's health depends not only on what happens in the NICU, but also on maternal and prenatal care, insurance coverage, specialty and developmental services, family resources, and reliable follow-up after discharge.

AAP election participation is often limited. When fewer members vote, a relatively small portion of the Academy determines its elected leadership and helps establish organizational priorities. If you are a practicing pediatrician in any specialty, we encourage you to join the AAP if you are not already a member.

Your vote is therefore an important form of professional participation.

Issues to Consider:

As you consider the election, think about the challenges facing pediatrics and the direction you believe the Academy should take:

- **Pediatric workforce:** Recruitment, retention, burnout, administrative burden, compensation, and the future of pediatric subspecialties.
- **Access to care:** Medicaid, CHIP, specialty services, and continuity of care for children with complex medical needs.
- **Science and evidence:** Maintaining evidence-based pediatric care and helping families navigate misinformation.
- **Families and equity:** Supporting families and addressing barriers related to poverty, geography, transportation, insurance, and access to services.
- **Advocacy and policy:** Ensuring that pediatric expertise informs decisions affecting children and families.
- **Innovation and collaboration:** Connecting pediatric specialties, research, education, clinical care, and policy to address emerging challenges.

Read the Statements. Make Your Own Decision.

The candidate statements that follow this informational provide the best opportunity to understand the candidates' experience, priorities, leadership approaches, and vision for the AAP.

We encourage every member to read both statements carefully, consider the issues that matter most to you and your patients, and make an informed decision.

This informational does **not endorse either candidate**.

The goal is simple: **informed participation.**

September 2–16, 2026

Read the statements.

Consider the issues.

Discuss with your colleagues.

And vote.

The future of the American Academy of Pediatrics should reflect an engaged and participating membership.

Your voice matters. Your vote matters.

Disclosures: *There are no relevant disclosures.*

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

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

"Wanda D. Barfield, MD, MPH, FAAP, RDML USPHS (ret.) is a candidate for the American Academy of Pediatrics president-elect. Voting for the next American Academy of Pediatrics (AAP) president-elect takes place from September 2 to September 16, 2026. The winner of this election will serve as the AAP president in 2028"

Every neonatologist understands that the first days of life can shape a child's entire future. We care for infants born too soon, too small, or critically ill, while guiding families through moments they never expected to face.

Yet neonatal outcomes are not determined solely by medicine. They are influenced by whether a mother has access to prenatal care, whether an infant has health coverage after discharge, and whether families can obtain medications, preventive and specialty services, developmental support, and reliable follow-up care.

That is why the priorities of the American Academy of Pediatrics should matter deeply to neonatologists—and why neonatologists must have a stronger voice in determining the Academy's future.

Medicaid and CHIP Are Essential to Neonatal Care:

Medicaid and the Children's Health Insurance Program (CHIP) are sometimes discussed as broad insurance or public-policy programs. (1) For neonatologists, however, they are part of the clinical infrastructure supporting newborns and their families.

Medicaid finances about 40% of births in the United States and is especially important for infants born prematurely, infants with complex medical conditions, and those requiring prolonged hospitalization. CHIP provides coverage for children in families whose incomes may be too high for Medicaid but who may still be unable to afford comprehensive insurance. (2, 3)

Together, these programs support prenatal and maternity care, neonatal intensive care, and newborn screening, medications, specialty consultations, therapies, home health services, medical equipment, and essential follow-up after NICU discharge.

They are also critical tools for reducing disparities. (3) Families facing poverty, unstable housing, limited transportation, rural isolation, or inadequate access to specialists are more vulnerable to gaps in care. Strong Medicaid and CHIP programs can help narrow those gaps by connecting infants with the services they need before, during, and after delivery, hospitalization, and the transition home.

For a medically fragile infant, coverage cannot end at discharge from the NICU. Survival is only the beginning. A premature infant may require ophthalmology, cardiology, pulmonology, audiology, developmental pediatrics, nutrition services, physical therapy, occupational therapy, early intervention, durable medical equipment, or home nursing.

When coverage is delayed, interrupted, or inadequate, the consequences become visible in our clinics and emergency departments. Appointments are missed. Prescriptions go unfilled. Developmental problems are identified later. Families already coping with the emotional and financial strain of a complicated birth are forced to navigate an increasingly fragmented system. Protecting Medicaid and CHIP is therefore not separate from neonatal advocacy. It is neonatal advocacy.

The Neonatology Pipeline Is at Risk:

Recruitment into pediatric subspecialties is a growing challenge. In the most recent fellowship match, more than one in five pediatric fellowship positions went unfilled (4), and residents weighing debt, training length, and pay are increasingly choosing other paths. (5) Neonatology is not immune. Rebuilding the pipeline requires stable graduate medical education funding, loan repayment that recognizes pediatric subspecialty service, and a profession that remains worth entering. Every unfilled fellowship position today is an uncovered call shift a few years from now. The Academy's advocacy on workforce will help determine whether the next generation of neonatologists is there when our patients need them.

Misinformation Is Reaching Families Before We Do:

Neonatologists are also witnessing the erosion of preventive care for newborns. In a recent three-center study of more than 93,000 newborns, refusal of the hepatitis B birth dose roughly doubled between 2018 and 2025, and refusal of vitamin K prophylaxis doubled as well. (6) Every neonatologist knows what follows: vitamin K deficiency bleeding and perinatal hepatitis B infection, harms we learned to prevent generations ago, returning one declined dose at a time. The Academy must lead with evidence families can trust, and it must equip the clinician standing at the bedside for that conversation.

My AAP Service Has Shaped My Leadership:

My commitment to the AAP has grown through years of service in neonatal medicine, public health, military medicine, research, education, and pediatric policy. I have served in leadership roles within the AAP Section on Neonatal-Perinatal Medicine and as an Armed Services representative to the Uniformed Services Section. I have also worked closely with the Committee on Fetus

and Newborn and served as a CDC liaison, connecting neonatal clinical expertise with public health evidence and national policy.

My research included leading a meta-analysis of 30 years of evidence examining outcomes among very preterm infants born outside hospitals with the highest levels of neonatal care. Published in *JAMA*, the study found higher mortality among very preterm infants born outside level III or higher facilities. (7) The findings helped inform my work as lead author in AAP policy concerning levels of neonatal care (8), which now accompanies standards for delivering high-risk infants in appropriately resourced facilities. (9) I also contributed to the seventh and eighth editions of *Guidelines for Perinatal Care*, the joint AAP and American College of Obstetricians and Gynecologists resource that helps establish standards for maternal, fetal, neonatal, and regionalized perinatal care.

My AAP service has extended beyond the NICU. Through the Uniformed Services Section, I helped address the needs of children in military families and contributed to the 2013 *Pediatrics* clinical report on children affected by parental military deployment. (10)

These experiences taught me that AAP policy is not abstract. It influences where high-risk infants are delivered, how neonatal systems are organized, how clinicians practice, how families are supported, and whether children receive the services they need.

Neonatologists Must Lead Beyond the NICU:

Neonatologists routinely make complex decisions under extraordinary pressure. We lead multidisciplinary teams, interpret rapidly changing clinical information, communicate with anxious and grieving families, and coordinate care across multiple specialties. Those same leadership skills are needed within the AAP.

The Academy's work directly affects maternal and infant health, insurance coverage, immunization, public health preparedness, injury prevention, safe sleep, substance use treatment, racial and geographic inequities, and the care of children with special health care needs. Each of these issues has important implications for neonatal outcomes and for the health of the infants and families we serve.

Two AAP resolutions considered in 2026 illustrate the connection between neonatology and broader pediatric policy. The first called for hospitals to model safe sleep practices for families before NICU discharge. The resolution was informed by evidence from the Pregnancy Risk Assessment Monitoring System (PRAMS), highlighted by neonatologists, showing that despite late preterm infants being at higher risk for sleep-associated death, they were less likely than term infants to be placed in safe sleep positions. (11) Neonatologists in Massachusetts subsequently developed a quality improvement collaborative to integrate safe sleep practices into NICU care for all birthing hospitals across the state. (12) The initiative's success contributed to the introduction of a state bill that required Massachusetts hospitals to provide safe sleep education to families of newborns before discharge. (13)

A second resolution supported paid family leave for parents of infants requiring intensive care. In Colorado, a state lawmaker whose family had experienced prolonged NICU hospitalization with the birth of their 29-week infant helped champion legislation that took effect in January 2026, providing an additional 12 weeks of paid family leave for eligible NICU families. (14) Although the safe sleep and paid family leave resolutions did not rank among the top 10 adopted resolutions, both resolutions drew support across the Academy, evidence that neonatal issues command attention within its broader policy agenda. (15)

Our responsibility does not end when an infant leaves the NICU. We must bring our clinical experience and understanding of families into advocacy, policy, research, education, and organizational leadership. That is the perspective I hope to bring to the presidency of the American Academy of Pediatrics.

Representation and Participation Matter:

The Section on Neonatal-Perinatal Medicine is one of the Academy's largest and most influential groups. Its members bring expertise in clinical care, quality improvement, ethics, research, education, family engagement, systems leadership, and public policy.

Despite that influence, participation in AAP elections is often low, both among pediatricians generally and among neonatologists specifically. Low turnout means that a small fraction of members determines who will help establish the Academy's priorities, represent pediatricians publicly, and guide its response to the most consequential issues affecting children.

Voting is not merely an administrative responsibility. It is an act of professional leadership. If elected, I would become the first neonatologist to serve as president of the AAP. That milestone would not belong to one individual. It would recognize the contributions neonatologists make across the Academy and throughout the continuum of child health. A neonatal perspective offers AAP leadership an essential understanding: children's health begins before birth, maternal and infant health are inseparable, and investments made early in life can yield benefits throughout an entire lifetime.

A Call to Vote:

I am asking neonatologists to learn about the issues in this election, discuss them with colleagues and trainees, and participate. I am one of two candidates for AAP President-elect; information about both candidates, including our position statements and answers to the candidate questions, is available at the AAP National Election Center on AAP.org. Voting is open **September 2-16**.

-Vote because Medicaid and CHIP are essential to the infants and families we serve.

-Vote because neonatal expertise should help shape national pediatric priorities.

-Vote because one of the Academy's largest sections should use its collective voice.

-Vote because our responsibility to children does not end when they leave the NICU.

The smallest patients require the strongest advocates. Neonatologists know this better than anyone. We must bring that same commitment to the future leadership of our professional home.

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Disclosures: *The author is a candidate for an elected position of the American Academy of Pediatrics. This letter reflects her platform and is not necessarily the official position of the Academy. The viewpoints expressed are those of the author and do not necessarily reflect the official position of the Centers for Disease Control and Prevention nor the Department of Health and Human Services.*

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Leading with Agility, Science, and Collaboration: A Shared Vision for Pediatrics

Lois K. Lee, MD, MPH

"Lois K. Lee, MD, MPH is a candidate for the American Academy of Pediatrics president-elect. Voting for the next American Academy of Pediatrics (AAP) president-elect takes place from September 2 to September 16, 2026. The winner of this election will serve as the AAP president in 2028"

As pediatricians, pediatric subspecialists, and surgical specialists, we share a singular, unwavering commitment: the health and well-being of all children, starting from birth. Yet today, our profession stands at a critical crossroads. We are confronting unprecedented systemic pressures—from health misinformation eroding bedside trust to increasing administrative friction, threats to Medicaid and CHIP, and acute workforce strains. We are being asked to do more with fewer resources while defending evidence-based care against unprecedented headwinds.

As I stand for election as President-elect of the American Academy of Pediatrics (AAP), I reflect on the deep ties that unite our diverse pediatric community, including neonatologists, primary care pediatricians, and pediatric medical and surgical subspecialists. My background as a Pediatric Emergency Medicine (PEM) physician, researcher, educator, advocate, and AAP leader offers a broad, integrative lens through which to lead our Academy. I am a Professor of Clinical Pediatrics at Harvard Medical School, immediate past Chair of the AAP Council on Injury, Violence, and Poison Prevention (COIVPP), and an elected member of the National Academy of Medicine.

In my clinical work, I care for a full spectrum of patients, from infancy to young adulthood, with a wide variety of medical and surgical conditions and backgrounds. I also work closely with pediatric subspecialists and trainees, giving me an important perspective on our profession. Like the NICU, the emergency department requires you to be ready for whatever the day brings, from caring for critically ill children to addressing social needs. You must also be able to lead your team, make informed decisions quickly, and communicate effectively with everyone.

A Background Rooted in Frontline Care and Policy:

In the emergency department, every shift reveals where social policy falls short—immigrant children who are uninsured and unhoused, unimmunized toddlers with preventable infections, and teens boarding in the ED for higher-level mental health care. But long before practicing in Boston, I grew up in Tallahassee, Florida. Then my medical training in the 1990s took me to West Philadelphia to the University of Pennsylvania for medical school and the Children's Hospital of Philadelphia for residency. Next, I completed my pediatric emergency medicine fellowship in Boston. During my training, I cared for children without insurance before CHIP and managed infections before modern vaccines transformed care. These experiences taught me that to protect the care delivered at the bedside, we must influence the systems that surround it.

Throughout my career, I have worked to advance child health equity and outcomes. I completed a health policy fellowship and, during part of that time, worked on the health policy staff for Senator Sheldon Whitehouse (D-RI). I was the inaugural Director of the Academic Pediatric Association's Health Policy Scholars Program, which created a faculty development program to promote advocacy and scholarship. My long-standing work in health equity has been recognized with my appointments as a Senior Faculty Advisor in the Office of Health Equity and as the Associate Director for Policy at the Fenwick Institute at Boston Children's Hospital. I am also conducting NIH-funded research to develop an AI-based real-time injury surveillance system.

In addition to COIVPP, my AAP leadership roles include serving as the Injury Prevention Committee Co-Chair for the Massachusetts Chapter of the AAP. I served on the Committee on Pediatric Emergency Medicine and have served as a liaison from the Society for Pediatric Research (SPR) to the AAP's Committee on Federal Government Affairs and the Committee on Pediatric Research. I have also been the lead author for several AAP technical reports and policy statements on mental health and injury prevention, including about firearms.

Core Platform: Protecting Our Workforce and Advancing Child Health:

If elected AAP President-elect, my platform rests on two foundational priorities:

1. **Fiercely Protecting Our Pediatric Workforce:** Our Academy must continue to address administrative friction, burnout, and financial pressures. We must advocate for fair payment models and pathways supporting pediatric careers from residency through retirement. This includes equipping all of us with the resources needed to keep practices sustainable and clinical care rewarding.

2. **Advancing Child Health with Upstream Pediatrics Grounded in Science:** Health does not begin in the clinic; it begins in safe homes, equitable neighborhoods, and sound public policy. We must defend evidence-based medicine, safeguard immunization standards, and fight for marginalized youth across every system. We must continue to advocate for robust Medicaid funding and policies to expand eligibility,

improve enrollment, support innovative payment structures, and standardize care for every child. The AAP must remain the authoritative, science-based anchor for child health, providing members with practical tools to counter false narratives.

Vision and Leadership Strengths for the AAP:

The care delivered in the NICU represents some of the most sophisticated, high-stakes medicine in the world. As a PEM physician, I regularly collaborate with pediatric subspecialists to navigate complex transitions of care, acute stabilization, and longitudinal management. I recognize that neonatal-perinatal specialists face distinct challenges—from subspecialty workforce shortages and research funding constraints to the complexities of high-acuity reimbursement and equitable, family-centered post-discharge care.

Three core strengths will guide my leadership:

- **Creative Problem-Solving:** I have a track record of leadership, whether developing national health policy curricula or convening the first national pediatric health equity and policy conference.
- **Connecting People and Ideas:** As co-chair of the first joint meeting between the SPR and the European SPR, I brought diverse global voices together to advance child health science. I will continue to foster cross-disciplinary bridges with partners within and outside the AAP.
- **Communicating Effectively:** As an AAP spokesperson on firearm injury prevention, I understand how to translate complex evidence into clear public discourse and actionable health policy.

We need an Academy that matches our members' everyday dedication with relentless action. I will bring this same collaborative focus to aligning academic centers, private practices, and subspecialty sections within the AAP. Together, we can transform today's systemic pressures into progress, ensuring a sustainable profession for clinicians and a healthy, equitable future for every child.

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Withdrawal of Care in a Preterm Neonate with Severe Hypoxic Ischemic Encephalopathy: An Ethical Dilemma and Case Report

Ahmad Asrar, MBBS, Ahsan Ali, MBBS, Omama Farooq, MBBS, Nasir Rashid, MD

"This case report highlights the importance of early intervention, open communication, and shared decision-making in the neonatal intensive care unit (NICU), highlighting the value of collaborative discussions between healthcare providers and parents in reaching decisions that prioritize the infant's best interests while respecting the family's values, preferences, and dignity at the end of life."

Introduction:

Neonatal Hypoxic Ischemic Encephalopathy (HIE) affects approximately 1.5 to 3 per 1000 live births in developed countries and accounts for 22% of neonatal deaths worldwide (1). It is a non-specific brain dysfunction caused by lack of blood flow and oxygen to the brain, also referred to as birth asphyxia. Although the precipitating events are not always identified, recognized risk factors include cord prolapse, uterine rupture, abruptio placentae, lack of prenatal care, and shoulder dystocia. It has been classified by severity using the modified Sarnat staging system as Mild HIE, Moderate HIE, and Severe HIE. The manifestations of HIE in early postnatal life include abnormal fetal heart rate, poor umbilical cord gases (pH <7.0 or base deficit > 12 mmol/L) (2), low APGAR scores, presence of meconium-stained amniotic fluid, need for respiratory support within the first several minutes of postnatal life, or neurological dysfunctions.

Multiple randomized controlled trials, including the TOBY and ICE trials, established therapeutic hypothermia as the standard of care for neonates with moderate-to-severe hypoxic-ischemic encephalopathy by demonstrating improved survival and neurodevelopmental outcomes when cooling is initiated within 6 hours of birth in eligible infants of gestational age equal to or > 36 weeks and birth weight equal to or > 1800 grams. (3). This case report highlights the importance of early intervention, open communication, and shared decision-making in the neonatal intensive care unit (NICU), highlighting the value of collaborative discussions between healthcare providers and parents in reaching decisions that prioritize the infant's best interests while respecting the family's values, preferences, and dignity at the end of life.

Case Presentation:

A 35-week, 5-day gestational age infant delivered vaginally to a 25-year-old G4P2 mother with no documented prenatal care and a history of methamphetamine use. She was brought to the ER with prolonged rupture of membranes, having a clear gush of fluid with no foul smell. The infant had a birth weight of 2800 g and an abnormal fetal heart rate prior to delivery. The APGAR scores remained critically low, with scores of 1 at 1 minute, 1 at 5 minutes, 1 at 10 minutes, and 2 at 15 minutes, consistent with severe perinatal compromise. Initial blood pressure at birth was 74/43 mmHg and mean blood pressure of 52 mmHg. At delivery, the neonate was flaccid and obtunded with fixed and dilated pupils in both eyes. Neurological examination revealed a stuporous infant with no spontaneous activity, decerebrate posturing, apnea, and absent Moro and suck reflexes, consistent with Sarnat Stage III (severe) HIE (5), (3). The skin appeared pale, with bruising noted over the right lower extremity.

The infant required extensive resuscitation at birth, including endotracheal intubation (ETT) and chest compressions in the delivery room during the code. Positive Pressure Ventilation was required. One dose of Epinephrine was given via ETT, and three doses were subsequently given via the intravenous route through the Umbilical venous catheter within 20 minutes. Respiratory support was initially maintained with high-frequency oscillatory ventilation and later transitioned to assist-control ventilation with volume guarantee settings (FiO_2 0.21, PEEP 8 cm H_2O, respiratory rate 40 breaths/minute).

The neonate received empiric prophylactic antibiotics, as needed, midazolam, and a loading dose of Phenobarbital at 20 mg/kg. The clinical course was complicated by multiorgan failure, including severe HIE, metabolic acidosis of the newborn, worsening renal failure, respiratory failure, and coagulopathy (5). Given the severity of the encephalopathy, therapeutic hypothermia with whole-body cooling was initiated within 30 minutes of the birth of the infant. The risks, benefits, and overall prognosis were thoroughly discussed with the parents by the neonatology team. The parents provided informed consent for a trial of therapeutic hypothermia, acknowledging potential benefits and associated risks to the infant (9). During whole-body cooling, the infant's condition remained critical and was consistent with brain death. Hypotension progressively worsened to 55/23 and mean blood pressure of 34 despite maximal hemodynamic support, including Dobutamine (20 mcg/kg/min), Dopamine (20 mcg/kg/min), Epinephrine (0.35 mcg/kg/min and maximized up to 2 mcg/kg/min), Hydrocortisone (1 mg/kg to 2 mg/kg) and Milrinone (0.35 mcg/kg/min and maximized up to 0.5 mcg/kg/min). After detailed discussions with the parents regarding prognosis, goals of care, and available management options, the parents elected to withdraw active life-sustaining treatment and proceed with comfort-focused care (4). Vasopressor support and mechanical ventilation were discontinued, and the infant passed away within one hour following withdrawal of active support.

Laboratory Evidence of Multiorgan Failure in Severe Hypoxic Ischemic Encephalopathy

Organ System	Laboratory Marker	Trend	Interpretation
Metabolic	CO_2/Bicarbonate	16 → 9 mmol/L	Severe Metabolic Acidosis
	Anion gap	32 → 36	High Anion Gap Acidosis
Renal	Creatinine	1.64 → 1.98 mg/dL	Acute Kidney Injury
	BUN	12 → 17.6 mg/dL	Worsening Renal Dysfunction
Hepatic	AST	719 → 698 U/L	Hypoxic Hepatic Injury
	ALT	114 → 125 U/L	Hepatocellular Injury
Cardiac	Troponin-I	971.1 ng/L	Myocardial Injury
Muscle Injury	CK	1897 U/L	Hypoxic Tissue Injury
Hematology	Platelets	48 → 229 → 142 k/μL	Thrombocytopenia with partial recovery and coagulopathy
	PT/INR	19.4 sec / 1.69	
	PTT	42.8 sec	
Electrolytes	Sodium	140 → 137 → 127 mmol/L	Developing Hyponatremia, hypocalcemia, and Stress Hyperglycemia
	Calcium	8.6 → 7.9 mg/dL	
	Glucose	162 → 266 mg/dL	

Table 1. Serial laboratory trends demonstrating multisystem organ dysfunction in a neonate with severe hypoxic-*ischemic encephalopathy (Sarnat Stage III) from* ***May 19, 2026 to May 20, 2026****. The table summarizes the affected organ systems, corresponding laboratory markers, temporal changes in laboratory values, and their clinical interpretation.*

Discussion:

Severe hypoxic-ischemic encephalopathy (HIE) remains a leading cause of neonatal mortality and lifelong neurodevelopmental impairment worldwide. Although advances in neonatal intensive care and the introduction of therapeutic hypothermia (TH) have improved outcomes for many infants with moderate to severe HIE, the prognosis remains poor in cases of profound hypoxic brain injury. In the present case, APGAR scores remained critically low at 1 at 1, 5, and 10 minutes, with only minimal improvement to 2 at 15 minutes despite prolonged and intensive resuscitation. The absence of neurological recovery following pro-active intervention indicated an extremely poor prognosis. Therapeutic hypothermia is recognized as the standard treatment for eligible neonates with moderate to severe HIE because it reduces mortality and improves long-term neurological outcomes. However, its neuroprotective effects are limited once extensive and irreversible cerebral injury has occurred. Despite timely initiation of TH and comprehensive intensive care, no meaningful neurological improvement was observed in this infant, prompting difficult discussions regarding the appropriateness of continuing life-sustaining treatment.

This case illustrates the complex ethical dilemmas that frequently arise in the neonatal intensive care unit (NICU), particularly when ongoing treatment may impose greater burdens than potential benefits. John D. Lantos describes many neonatal end-of-life decisions as existing within an ethical "gray zone," (4) where multiple ethically acceptable approaches may exist and decisions must be individualized. In such circumstances, ethical principles provide an essential framework for clinical decision-making. One of the most important lessons from this case was the need to recognize and address implicit bias among physicians. The parents initially presented with significant social challenges, including the absence of prenatal care, factors that could have unintentionally influenced assumptions about their understanding, engagement, or ability to participate in complex medical decisions. However, as honest and compassionate conversations progressed, they demonstrated a clear understanding of their infant's condition, asked thoughtful questions, and consistently prioritized their child's comfort and dignity (7). This experience emphasizes that socioeconomic circumstances should never influence clinicians' expectations of parental competence or commitment. Every family deserves respectful, unbiased communication and an equal opportunity to participate in shared decision-making regardless of their social background.

"This experience emphasizes that socioeconomic circumstances should never influence clinicians' expectations of parental competence or commitment. Every family deserves respectful, unbiased communication and an equal opportunity to participate in shared decision-making regardless of their social background."

The ethical principles of Beneficence and Non-Maleficence were central to the management of this case. Beneficence requires clinicians to act in ways that promote the patient's welfare, whereas Non-Maleficence requires avoidance of interventions that offer little likelihood of benefit while exposing the patient to unnecessary

harm or prolonged suffering. When treatment no longer has a realistic chance of improving the patient's condition and instead serves only to extend the dying process, continuing aggressive interventions may no longer be consistent with the infant's best interests. Because newborns lack decision-making capacity, parents serve as surrogate decision-makers and play a vital role in determining the goals of care. Consequently, shared decision-making becomes an essential component of ethically appropriate neonatal practice. In this case, the healthcare team engaged the parents in open, compassionate discussions regarding the infant's clinical status, prognosis, expected outcomes, and the limited likelihood of meaningful neurological recovery. These conversations enabled the family to make informed decisions that reflected both the infant's best interests and their own values.

Another important ethical issue highlighted by this case is the distinction between withholding and withdrawing life-sustaining treatment. Current ethical guidance considers these approaches morally equivalent when continued treatment no longer provides meaningful benefit (9). The ethical focus is not whether treatment is initiated or discontinued but whether its continuation remains justified in light of the patient's prognosis and overall welfare. In this case, the decision to withdraw pro-active interventions was not intended to hasten death but rather to prevent unnecessary suffering in an infant with irreversible neurological injury and an extremely poor prognosis (10). Importantly, withdrawal of life-sustaining treatment should never be interpreted as abandonment of care. Instead, the goals of treatment shift from life-prolonging interventions to comfort-focused care that prioritizes symptom relief, dignity, and family support. Such an approach acknowledges the limitations of medical therapy while ensuring compassionate care throughout the end-of-life process (4).

This case highlights the importance of early, honest communication and collaborative decision-making between healthcare professionals and families when caring for critically ill neonates. It demonstrates that ethically grounded, family-centered care can support decisions that prioritize the infant's best interests while respecting parental values, preserving dignity, and minimizing suffering at the end of life.

Conclusion:

This case highlights that through transparent communication and shared decision-making, the healthcare team and parents were able to decide to withdraw life-sustaining treatment in an extremely poor prognostic infant. Such a collaborative approach helps make ethically sound end-of-life decisions with compassion, while honoring family preferences and values.

"This case highlights that through transparent communication and shared decision-making, the healthcare team and parents were able to decide to withdraw life-sustaining treatment in an extremely poor prognostic infant."

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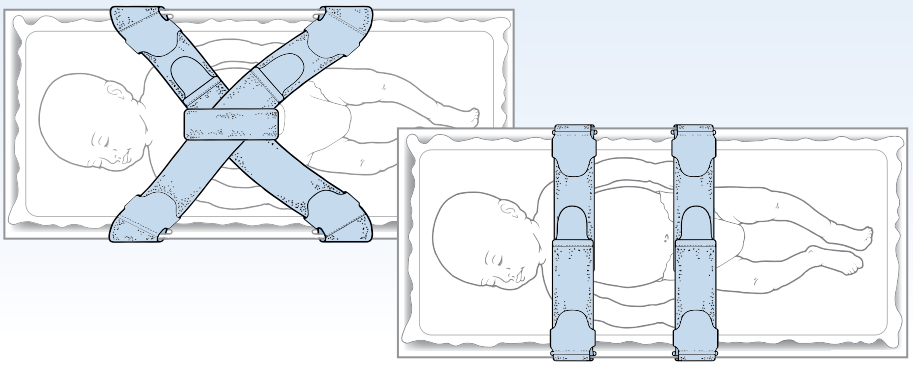

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Hemolytic Disease of the Fetus & Newborn

DID YOU KNOW?

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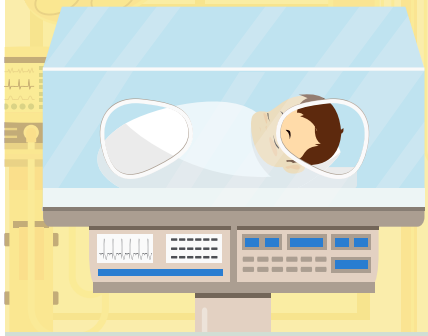
When the mother's and infant's blood types are incompatible, the mother's antibodies attack the baby's red blood cells.



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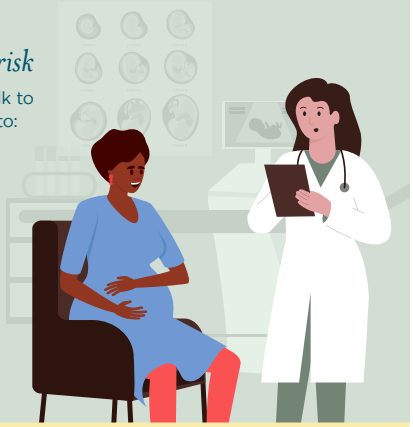
- **Severe anemia**
- **Jaundice**
- Fetal or infant **death**

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



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2024

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- Use alcohol-based sanitizers.

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- 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.

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Never Put a Mask on Your Baby

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- 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.
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Historial Perspective —Trisomy 13 and 18

Joseph B. Philips, III, MD, FAAP

"We recently had four babies in our main NICU with trisomy 13 or 18..."

Introduction:

We recently had four babies in our main NICU with trisomy 13 or 18, one of whom with trisomy 13 had cyclopia and a proboscis similar to the picture shown as Figure 1, (1) whose mother requested that we "do everything." This has prompted me to reflect on the changes in attitudes and care practices for these infants that have occurred over my practice lifetime. First, however, some historical background is in order.

Figure 1. A newborn infant with trisomy 13 manifesting cyclopia and a proboscis. (1) Courtesy of Chan et al. Licensed under CC BY 2.0 https://creativecommons.org/licenses/by/2.0 .

Background:

Human chromosomes were first described by Arnold in 1879. (2) However, the number of human chromosomes was uncertain until 1956, when Tjio and Levan in Sweden and Ford and Hamerton in Great Britain independently determined the correct number to be 46. (3, 4) This finding was confirmed by a study published in 1958 that concluded, "Studies have been made on chromosome number and morphology in somatic cells in tissue cultures derived from 34 normal human subjects including 29 American Whites, 4 American Negroes, and one of unknown race. The results indicate that regardless of race, sex, age, or tissue, in all cases the diploid chromosome number was 46." (5) Stern published a lengthy discourse on the history of chromosomes, highlighting that they are primarily composed of DNA, which he felt likely encoded genes and also raising the possibility of certain conditions resulting from aneuploidy. (6) Patau then proposed a classification system based on complex mathematics and chromosome characteristics (Figure 2). (7) Another proposed classification system, which came to be known as the Denver classification, came to similar conclusions except for using X and Y for the sex chromosomes instead of numbering them. (8) Patau was critical of this system in a subsequent publication, but it nevertheless became the world standard. (9)

Figure 2. Patau's proposed classification system for human chromosomes. (7) Used with permission.

The advent of fluorescent and Giemsa banding techniques then allowed for the labeling and definitive identification of each chromosome, leading to the conventional karyotype. (10, 11) The first definitive aneuploidy syndrome reported was the XXY Klinefelter's syndrome in January 1959, followed shortly thereafter by the identification of Down syndrome resulting from trisomy 21. (12, 13) Patau published a lengthy article in 1963 discussing the various ways in which aneuploidies can originate. (14)

"The advent of fluorescent and Giemsa banding techniques then allowed for the labeling and definitive identification of each chromosome, leading to the conventional karyotype."

Trisomy 13: Patau was the lead author of the first publication describing trisomy 13, which was published in 1960. (15) This occurred before the advent of banding techniques and the Denver classification, so the authors could only conclude that the extra chromosome was in the 13–15 or D group. However, we now know that it is chromosome 13 (Figure 3). (16) Interestingly, one of Patau's co-authors was the legendary David W. Smith, MD, who published the invaluable reference, *Recognizable Patterns of Human Malformation*, now in its eighth edition. (17)

Figure 3. Trisomy 13. Courtesy of CarloDiDio. (16) Licensed under Creative Commons Attribution-Share Alike 3.0 Unported.

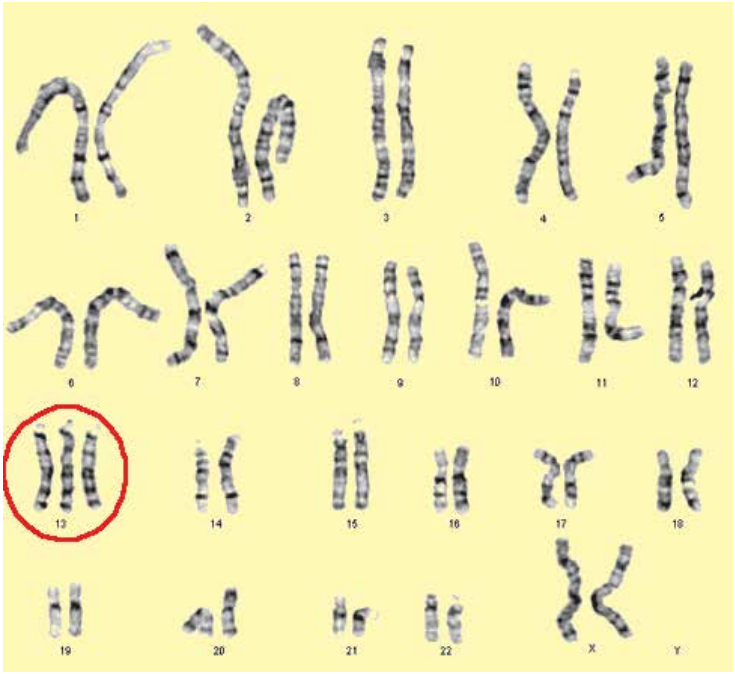
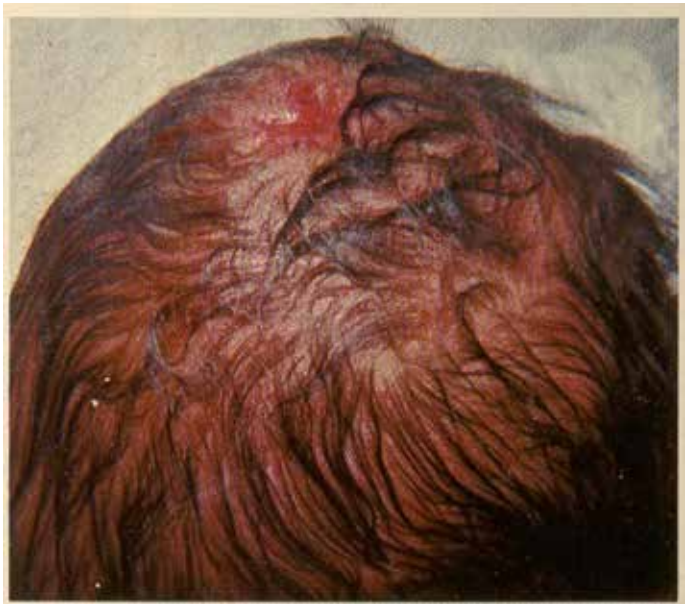


Figure 4. Scalp defect in an infant with trisomy 13. (22) Courtesy of the U.S. Dept. of Health, Education, and Welfare.



"Smith, Patau, et al. further elaborated on the malformations associated with trisomy 13 with illustrations of the common features, concluding, 'The D1 trisomy syndrome is recognizable as a pattern of numerous anomalies that is highly characteristic even though the combination of manifested anomalies and their degree of expression vary from case to case.'"

By the following year, Lubs et al. summarized the abnormalities associated with trisomy 13 from 6 reports. (18) Smith, Patau, et al. further elaborated on the malformations associated with trisomy 13 with illustrations of the common features, concluding, "The D1 trisomy syndrome is recognizable as a pattern of numerous anomalies that is highly characteristic even though the combination of manifested anomalies and their degree of expression vary from case to case." (19) Warkany and associates described mosaicism in a 6-year-old male with "mild mental retardation, poor expressive language performance, motor incoordination, and dysarthria with many congenital malformations," concluding that mosaicism resulted in a less severe phenotype than with full trisomy. (20) It was not until 1969 that scalp defects were discussed as a common feature of trisomy 13 (Figure 4). (21, 22) Cohen and colleagues then described the association of holoprosencephaly and facial dysmorphia, including cyclopia and a proboscis. (23) Table 1 lists the 15 most common malformations associated with trisomy 13, according to ChatGPT.

Trisomy 18:

Table 1. The 15 most common malformations found in trisomy 13, according to ChatGPT, in percent. (Prompt: What are the 15 most common malformations found in Trisomy 13?)

Cleft lip and/or palate	60–80
Postaxial polydactyly	60–75
Congenital heart defects	70–80
Scalp defects (aplasia cutis congenita)	40–60
Microphthalmia	40–70
Holoprosencephaly	30–50
Omphalocele	20–35
Renal anomalies (cystic kidneys, hydronephrosis, dysplasia)	30–45
Rocker-bottom feet	30–50
Cryptorchidism (males)	60–80
Single transverse palmar crease	25–45
Low-set, malformed ears	50–70
Microcephaly	50–70
Eye anomalies other than microphthalmia (coloboma, retinal dysplasia)	20–35
Neural tube defects (including spina bifida)	5–15

Trisomy of the 18th chromosome was also described by Edwards et al. in 1960, back-to-back in the same issue of The Lancet as the report by Patau on trisomy 13. (24) The authors erroneously concluded that the trisomy was for chromosome 17 and not 18. The characteristic overlapping of the index finger was described (Figure 5). (25) The following year, two articles including Patau and Smith as authors correctly identified the condition as being trisomy 18 (Figure 6). (26–29) Mosaicism for trisomy 18 was first reported in 1963. (30) Subsequent reports then documented the frequency of malformations associated with trisomy 18, including esophageal atresia with tracheoesophageal fistula. (31–33) The senior author on reference 32, Dr. Kurt Hirschhorn, was Chairman of the Department of Pediatrics at Mount Sinai School of Medicine when I was a house officer there in the mid-1970s. Table 2 lists the 15 most common malformations associated with trisomy 18, according to ChatGPT.

Discussion—from then until now:

Figure 5. Characteristic overlapping of digits in trisomy 18. (25) Courtesy of the Centers for Disease Control and Prevention.

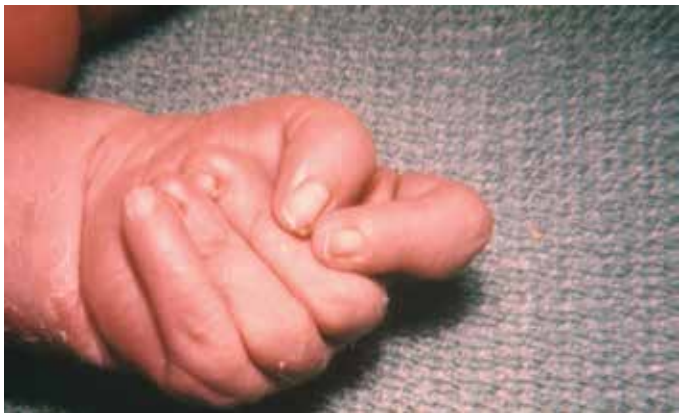


Figure 6. G-banded karyotype demonstrating trisomy 18 (47,+18). Image courtesy of Lebo et al. (29). Licensed under Creative Commons Attribution 4.0 International License (http://creativecommons.org/licenses/by/4.0/).

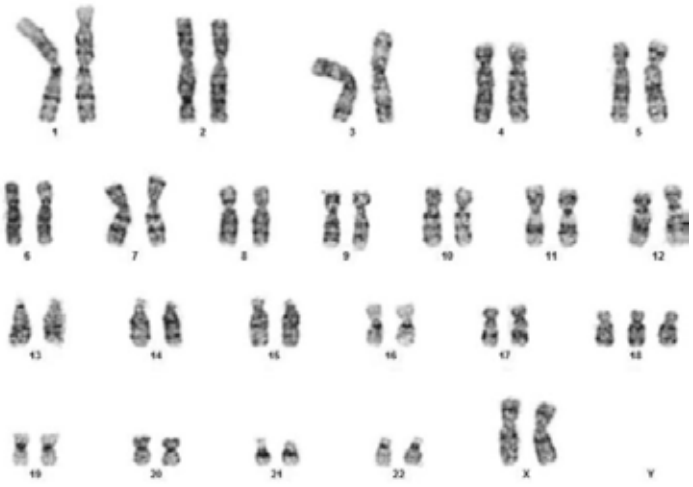


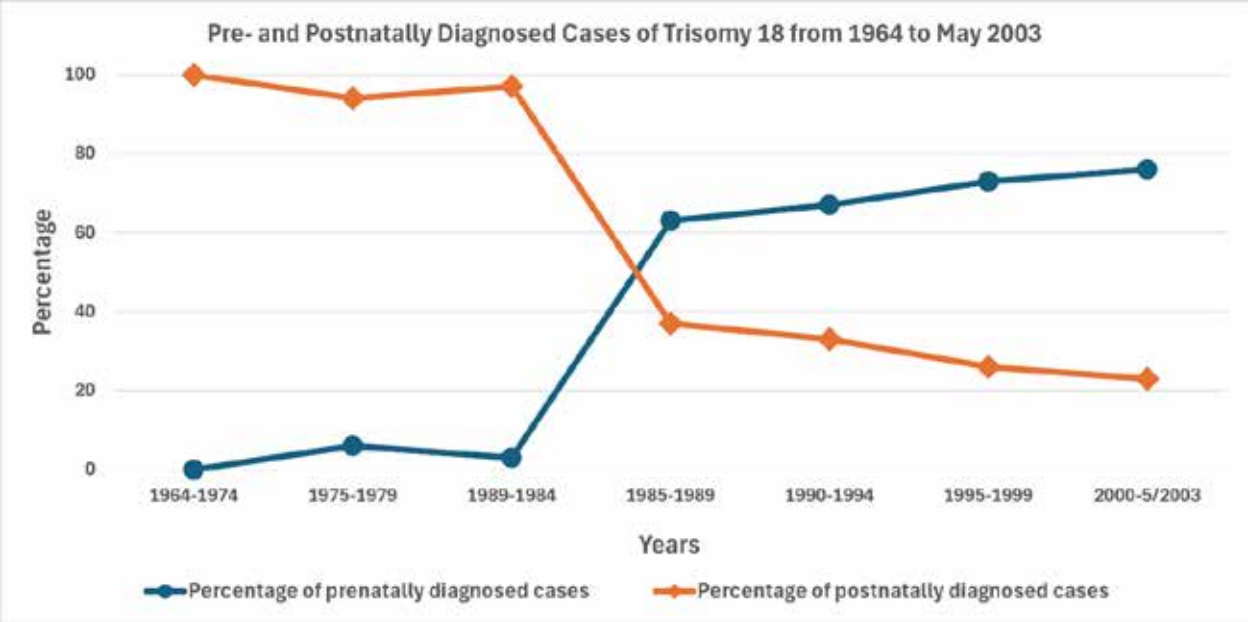
Table 2. The 15 most common malformations found in trisomy 18, according to ChatGPT, in percent. (Prompt: What are the 15 most common malformations found in Trisomy 18?)

Ventricular septal defect (VSD)	85–95
Patent ductus arteriosus (PDA)	75–90
Horseshoe kidney	55–70
Cerebellar hypoplasia	50–70
Atrial septal defect (ASD)	45–60
Omphalocele	20–40
Cleft lip and/or palate	15–30
Esophageal atresia ± tracheoesophageal fistula	15–25
Polycystic or dysplastic kidneys	15–25
Diaphragmatic hernia	10–20
Neural tube defects (including spina bifida)	5–15
Dandy–Walker malformation	5–15
Radial ray defects	5–10
Intestinal malrotation	5–10
Anorectal malformations (imperforate anus)	3–10

"From the discovery of trisomy 13 and 18 up through my training years in the mid to late 1970s, these conditions were considered lethal. Such infants were offered what we now call comfort care and were allowed to die. Ventilators were not offered, and surgeons would not operate. Most died within a few days. Some were not even given intravenous fluids or enteral nutrition. But sometime in the 1980s, things began to change gradually, only to accelerate in the twenty-first century."

From the discovery of trisomy 13 and 18 up through my training years in the mid to late 1970s, these conditions were considered lethal. Such infants were offered what we now call comfort care and were allowed to die. Ventilators were not offered, and surgeons would not operate. Most died within a few days. Some were not even given intravenous fluids or enteral nutrition. But sometime in the 1980s, things began to change gradually, only to accelerate in the twenty-first century. A major change was the increase in prenatal diagnosis. A Swiss study of 352 fetal and neonatal cases of trisomy 18 showed that virtually no cases were diagnosed prenatally until the mid-1980s when prenatal diagnosis rapidly overtook postnatal diagnosis (Figure 7). (34) The advent of prenatal diagnosis led to most affected fetuses being aborted. In my experience, the overturning of Roe v. Wade and the passage of laws restricting access to abortion in Alabama have led to an

Figure 7. Percentage of prenatally diagnosed versus postnatally diagnosed cases of trisomy 18 in Switzerland from 1964 until 2003. Graph created with data from Niedrist et al. (34)



increase in the numbers of infants born with both trisomy 13 and 18. In the Swiss study, 161 infants born alive with trisomy 18 lived a median of four days, with 32% dying in the first 24 hours, 40% surviving the first week, 22% the first month, and only 6% living until their first birthday. Females had a significant survival advantage over males.

"'These cases raise the most fundamental questions about the value of life, the meaning of personhood, and the limits of parental and professional authority. Deference to parents is generally the right course unless the infant is clearly suffering from ongoing treatment that is unlikely to be of benefit.'"

In 2011, the eminent pediatric ethicist, Dr. John D. Lantos, was the senior author of a report of a case of an infant with trisomy 18 and a ventricular septal defect (VSD) which asked two physicians and a parent the question "Should the parents be offered heart surgery to correct the VSD?" (35) The discussion is lengthy with the article concluding, "These cases raise the most fundamental questions about the value of life, the meaning of personhood, and the limits of parental and professional authority. Deference to parents is generally the right course unless the infant is clearly suffering from ongoing treatment that is unlikely to be of benefit." A 2012 article authored by my online friends, Drs. T. Allen Merritt, Mitchell Goldstein, and others, addressed many of these issues and provided a framework for caregivers and families to deal with the thorny issues surrounding decision-making for these infants. (36) The authors conclude the abstract with the following statement: "Education of parents regarding medical and developmental outcomes of affected infants, disclosure of values between physicians and parents, an understanding of the role and limitations of autonomy, transparency in the dialogue among all parties regarding the principle of 'best interest' for affected infants, and the medical axiom of not doing harm are essential components in the management decisions."

The development of social media on the internet has had a profound impact on attitudes towards infants with trisomy 13 and 18, particularly with parents. Janvier and colleagues surveyed a large number of families about this. (37) Respondents reported that they had been counseled "that their child was incompatible with life (87%), would live a life of suffering (57%), would be a vegetable (50%), or would ruin their family (23%)." However, 60% also reported that they had been told their child would live a short but meaningful life. Thirty percent of families requested full intervention. The authors concluded their article with the following: "Parents of children newly diagnosed with T13-18 who become integrated with social networks may acquire views, hopes, and expectations that are incongruous with those held by some of the clinicians they will encounter. Providers should be aware of the experiences of those families represented in this article. When parents request medical interventions, it may be because of what they have learned in their social networks." This has certainly been my experience over the past decade or so.

McCaffrey published an interesting article in 2016, noting that the newer approach to infants with trisomy 13 and 18 mirrored the earlier evolution of care for infants with Down syndrome, for whom full support was almost universal by then. (38) Our group here at UAB surveyed members of the American Academy of Pediatrics (AAP) Section on Neonatal-Perinatal Medicine (SONPM) regarding their opinions and attitudes toward liveborn infants with trisomy 18. (39) Although the response rate was low, the demographics of the 409 who did respond were similar to the membership of SONPM as a whole. The results indicated that, as a group, we are quite pessimistic about the future for these infants, with 83% agreeing or strongly agreeing that trisomy 18 is a lethal condition and 68%

"'The development of social media on the internet has had a profound impact on attitudes towards infants with trisomy 13 and 18, particularly with parents... Thirty percent of families requested full intervention. The authors concluded their article with the following: 'Parents of children newly diagnosed with T13-18 who become integrated with social networks may acquire views, hopes, and expectations that are incongruous with those held by some of the clinicians they will encounter. Providers should be aware of the experiences of those families represented in this article. When parents request medical interventions, it may be because of what they have learned in their social networks.'"

thinking that active treatment was futile. Only 15% felt that trisomy 18 is compatible with a meaningful life and fully 50% agreed that such infants should not be resuscitated. Of note, our group also reviewed the outcomes of 58 liveborn infants with trisomy 18 and compared the outcomes of those receiving non-aggressive care (n=13) with those receiving aggressive care (n=36). (40) The median survival was 30 days for those receiving non-aggressive care and 24 days for those receiving aggressive care, with very large variation in survival time as seen in Figure 8. The p value for the comparison was 0.9, indicating no significant difference in survival between the two groups. I share this information with families when I am doing prenatal counseling, but most families choose aggressive care.

Despite the long odds, some individuals with trisomy 13 and 18 survive into adulthood. Lebedoff and Carey report on 11 persons who reached adulthood with apparent non-mosaic trisomy 13 and interacted with their families. (41) Table 3 presents some of the comments of the parents.

"UAB surveyed members of the American Academy of Pediatrics Section on Neonatal-Perinatal Medicine regarding their opinions and attitudes toward liveborn infants with trisomy 18... The results indicated that, as a group, we are quite pessimistic about the future for these infants, with 83% agreeing or strongly agreeing that trisomy 18 is a lethal condition and 68% thinking that active treatment was futile. Only 15% felt that trisomy 18 is compatible with a meaningful life and fully 50% agreed that such infants should not be resuscitated."

Figure 8. Survival times for liveborn infants with trisomy 18 receiving aggressive or non-aggressive care. (40) The shaded areas represent 95% Hall–Wellner bands, displaying the 95% confidence boundaries along the curves. Used with permission.

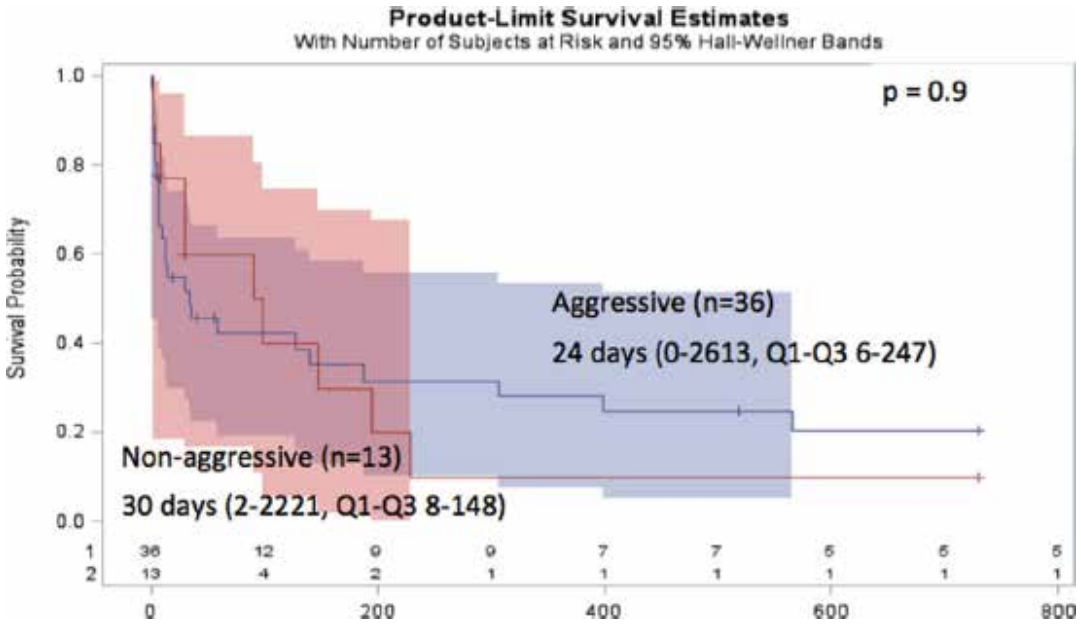


Table 3. Comments from parents of individuals with trisomy 13 who survive into adulthood. (41) Used with permission.

Parent comments
"There is definitely hope." "Don't settle for what the books say." "If I had done what they had told me, she would definitely not be alive."
"You cannot fully listen to what doctors say." "They always give you the worst-case scenario." "Take it day by day." "She reminds me of a toddler; she wants attention and is easy to please."
"First year it is pretty scary." "Living in rural America, there are not too many kids like him around." "I can help—live his life to the best of his ability."
"It's so overwhelming at first, but don't be afraid. Parents are their child's best advocate." "Don't be afraid to take 1 day at a time."
"They're still fun. It's worth the adventure."
"I wish we had a day program to be out in public more." "If you encourage things, they can happen." "Things have gotten a lot easier for us, we've kind of grown up together."
"She definitely fits in to our family." "It is hard if you're in a small area. There are more opportunities in urban areas."
"Fear of the unknown is so powerful, but you can grow with your children." "Even during harder times, you learn to deal with it, you learn to adjust."
"It was difficult to navigate therapies before he got in to school. It took a lot of my time." "There's a grieving period for the child you thought you would have. How can we move forward and make him a part of our family?" "We were his biggest advocate[s]. We brought people on board."
"They know love."

The Present:

So, here we are today in a time when the paternalistic days of patient care are largely in the past, and we are now in an era of parent-driven and joint decision-making. As most families choose aggressive care for infants born with trisomy 13 or 18, a series of guidelines has arisen. Weaver et al. published recommendations for the complex interdisciplinary care of such individuals, encompassing both medical and family guidelines, while Kepple et al. focused on surveillance guidelines for those with trisomy 13. (42, 43) Carvajal and colleagues surveyed the extant literature on cardiac surgery for these patients, concluding, "Cardiac surgery is feasible in children with trisomies 13 and 18 and can provide improved long-term results. However, this is a clinically complex population, and both physicians and caretakers should be aware of the long-term challenges these patients face following surgery when discussing treatment options." (44) Most recently, the joint committees Committee on Bioethics, Section on Neonatal-Perinatal Medicine, and Committee on Fetus and Newborn of the AAP published an article entitled "Guidance for Caring for Infants and Children With Trisomy 13 and Trisomy 18: Clinical Report," which discusses the ethical and clinical background surrounding the conditions as well as guidelines for the care of such individuals. (45) Of note, the article also addresses the moral distress that some clinicians experience in caring for these patients as well as the impact of social media on parent decision-making.

"Most recently, the joint committees Committee on Bioethics, Section on Neonatal-Perinatal Medicine, and Committee on Fetus and Newborn of the AAP published an article entitled 'Guidance for Caring for Infants and Children With Trisomy 13 and Trisomy 18: Clinical Report,' which discusses the ethical and clinical background surrounding the conditions as well as guidelines for the care of such individuals."

Conclusion:

Much has changed in the years since trisomy 13 and 18 were first identified in the early 1960s and considered universally lethal to today. While life expectancy is still reduced and the likelihood of normal neurodevelopmental outcome is virtually non-existent, individuals with these conditions can be loved and give love. Our responsibility as health care providers is to provide compassionate, informed counseling and care to these families and their children.

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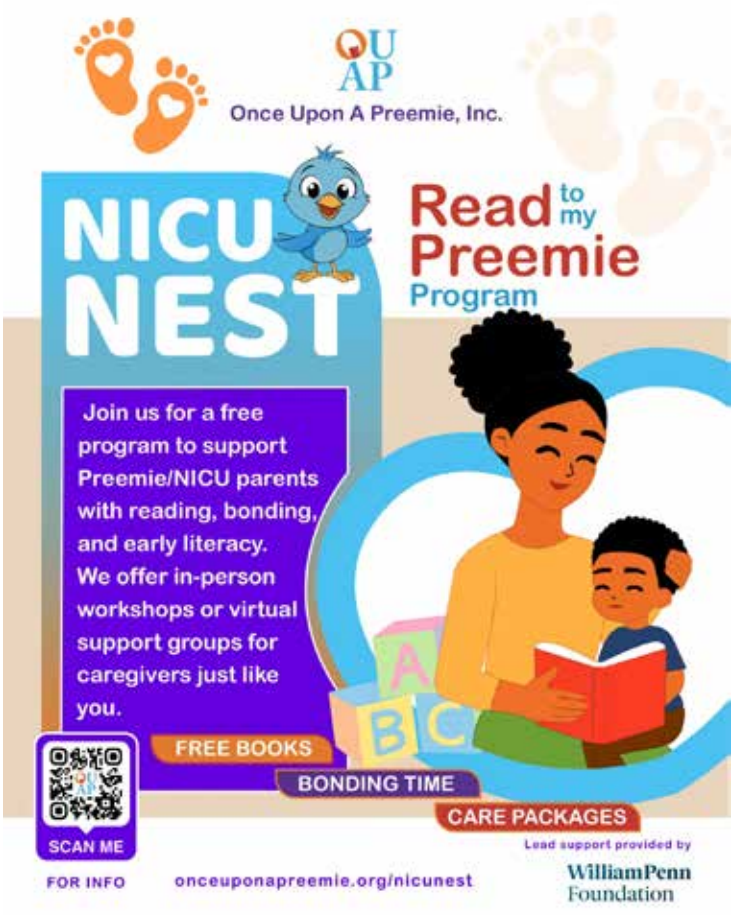

Maternal Vaccines:

WHAT YOU NEED TO KNOW

CDC-Recommended Vaccines for Pregnant Women

	COVID	FLU	RSV	TDAP
Does it protect baby?	+	+	+	+
Does it protect mother?	+	+		
Is there an immunization for baby after birth?			+	

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

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

*Source: Respirator Syncytial Virus and African Americans

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

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

AfPA Alliance for Patient Access

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Merchak Monthly Neonatal Case Challenge Page August 2026 Edition – Case number 80

Assaad Merchak, MD

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

Welcome Back.

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

"You are caring for Lauren. Lauren is a 10-week-old infant born at 24 weeks' gestational age. She spent 4 weeks on the ventilator and has a history of ruling out sepsis twice and ruling out Necrotizing Enterocolitis (NEC) once. Lauren is supported via Nasal CPAP, and she is receiving Breast milk with fortification via NG tube. Her medications are caffeine, diuretics, and iron supplementation. "

July Case Recap: Rickets?! How did she get Rickets? Lauren's mother asks you.

July's challenge featured a case where we address Metabolic Bone Disease of Prematurity (MBDP).

You are caring for Lauren. Lauren is a 10-week-old infant born at 24 weeks' gestational age. She spent 4 weeks on the ventilator and has a history of ruling out sepsis twice and ruling out Necrotizing Enterocolitis (NEC) once. Lauren is supported via Nasal CPAP, and she is receiving Breast milk with fortification via NG tube. Her medications are caffeine, diuretics, and iron supplementation. The radiologist calls you with findings of a rachitic rosary on her chest XR. Her most recent labs are as follows: Ionized Ca: 0.9 mmol/L, Calcium: 8.2 mg/dL, Phosphorus: 3.5 mg/dL, ALK Phos 843 U/L. Na: 139 mmol/L, K: 4.6 mmol/L, CL: 98 mmol/L, Co2: 27 mmol/dL. You are discussing the findings with the family.

" The radiologist calls you with findings of a rachitic rosary on her chest XR. Her most recent labs are as follows: Ionized Ca: 0.9 mmol/L, Calcium: 8.2 mg/dL, Phosphorus: 3.5 mg/dL, ALK Phos 843 U/L. Na: 139 mmol/L, K: 4.6 mmol/L, CL: 98 mmol/L, Co2: 27 mmol/dL. You are discussing the findings with the family."

Key Learning Points from last month's case:

- The incidence of MBDP is decreasing.
- The most significant factor is prematurity itself, due to missing most placental transfer of calcium and phosphate, which occurs in the third trimester of gestation and peaks between 32–36 weeks.
- Medications that increase bone mineral excretion, including loop diuretics, glucocorticoids, caffeine, and sodium bicarbonate, also increase the risk for MBD.

To learn more, visit the previous case presentation:

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

Congratulations: The gift card winner for July's challenge is Jessica Mazzariello, NICU, Tallahassee Memorial. Florida

Next Challenge # 80 for August 2026: Is that not enough to start Laura on antibiotics

This case focuses on ventilator-associated pneumonia in the neonates.

Sneak peek Challenge Question: **True or false**: Positive tracheal aspirate cultures alone are sufficient to diagnose ventilator-associated pneumonia in neonates.

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

Stay Connected

- Download the app for updates on new cases: https://www.jotform.com/app/223386358459166

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3. Case courtesy of Yaïr Glick, Radiopaedia.org, rID: 89657

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

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I want to learn to work in NICU... but how?

Academy of Neonatal Care has AARC-approved online courses

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Surfactant Administration - HFNC in the NICU - Neonatal Pneumonia and Sepsis - Oscillator basics - Neonatal Chest X-Rays - HFNC vs. CPAP - Apneas and Bradycardias - Intraventricular Hemorrhage - Neonatal Respiratory Distress Syndrome- Ventilator Waveforms IVH - Prove yourself as a NICU Newbie - The Honeymoon period - Accidental Extubations - Multi-Disciplinary Care in the NICU

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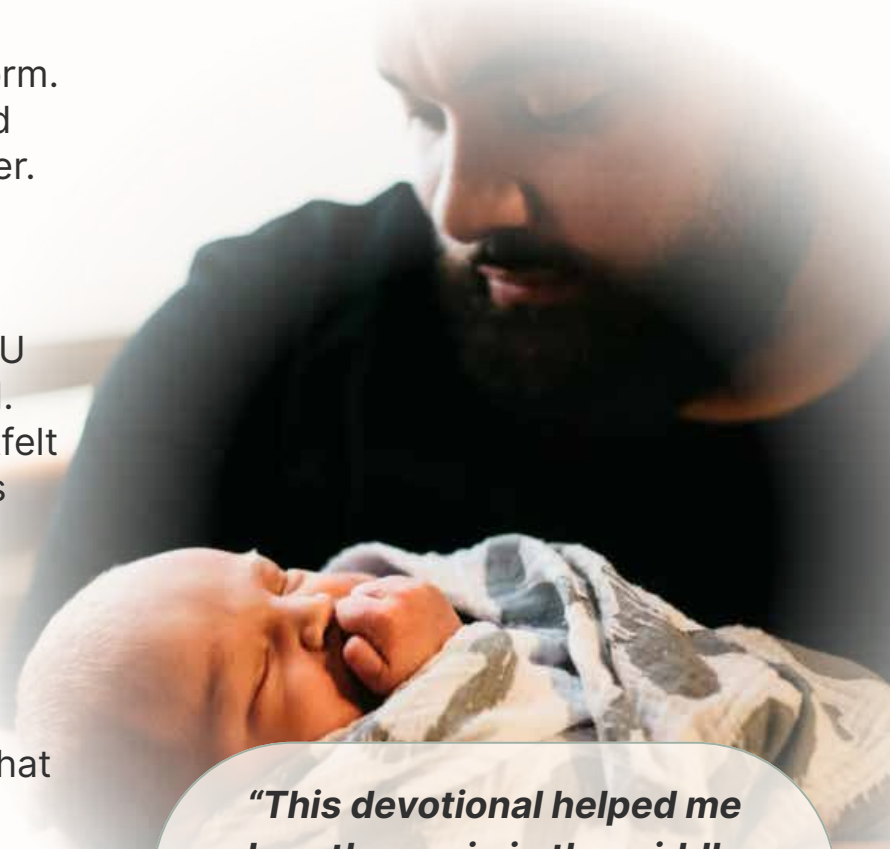
When hope feels distant, let His words anchor your heart.

A 30-Day Devotional for NICU Parents

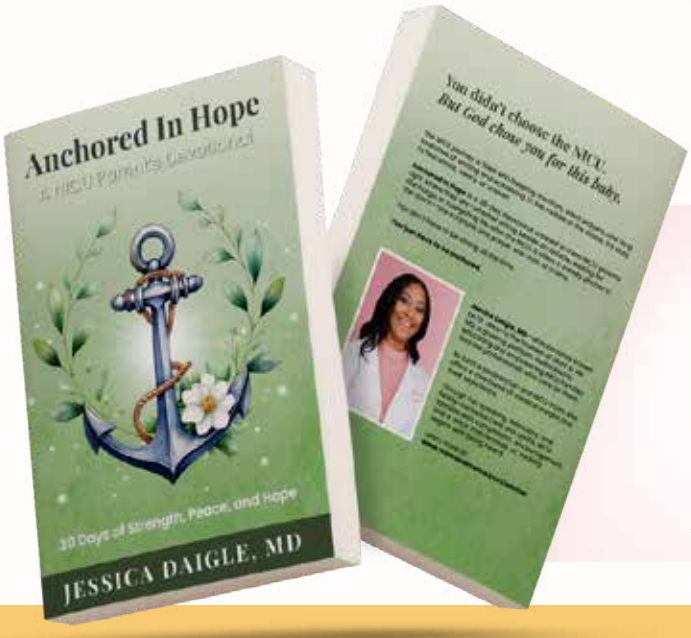
The NICU journey can feel like a storm. One filled with uncertainty, fear, and long nights that blur into one another. But even here, *you are not alone*.

Anchored In Hope was written by Dr. Jess, a physician and fellow NICU mom who knows this road firsthand. Through 30 days of scripture, heartfelt reflections, and guided prayers, this devotional helps NICU parents find calm, courage, and connection with God when life feels overwhelming.

Inside these pages, you'll feel **seen**, **understood**, and gently reminded that **hope is still present**. *Even here*.



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



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Crossing the Research Threshold: Determining When Clinical Innovation Requires Research Oversight Clinician Guidance Review

Rob Graham, RRT, NRCP

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

"The conventional distinction is purpose-based. Quality improvement seeks to improve care within a particular organization or clinical system, whereas research is a systematic investigation designed to develop or contribute to generalizable knowledge (1)."

Abstract:

Clinical practice depends on innovation. Physicians routinely modify treatment based on individual anatomy and physiology, prior treatment failures, emerging evidence, and local expertise. Most such decisions remain part of clinical care. However, a modification may cross into research when it is systematically assigned, prospectively evaluated, intended to answer a generalizable question, or exposes patients to uncertainty that exceeds ordinary clinical discretion. The boundary is especially difficult in quality improvement, learning health systems, off-label use, novel procedures, medical devices, software-driven care, and vulnerable populations.

No single feature—publication intent, statistical analysis, novelty, or off-label status—reliably determines whether an activity is research. A more useful approach is to examine the activity's purpose, design, intervention, risk, degree of clinician discretion, patient population, data plan, and intended use of the results. This guidance proposes a practical continuum from individualized clinical judgment through structured innovation and quality improvement to prospective clinical investigation.

The central recommendation is that physicians should not be expected to make difficult research-classification decisions alone. When an intervention is novel, protocolized, prospectively compared, applied to a new population, or dependent on an unvalidated biological or technological assumption, the appropriate response is not necessarily to prohibit its use. It is to obtain a documented institutional determination and oversight proportional to the uncertainty and risk. This guidance is grounded primarily in abstract-level evidence and should be interpreted alongside applicable institutional policy and jurisdiction-specific law.

Introduction:

Medicine advances because clinicians do not treat every patient identically. A surgeon alters an operative approach when anatomy differs from expectation. An intensivist modifies ventilator settings when standard parameters fail. An oncologist selects an off-label regimen when approved options are inadequate. A hospital introduces a new clinical pathway to reduce infections or treatment delays. These actions may represent appropriate clinical judgment, quality improvement, clinical innovation, or research. The difficulty is determining when one category becomes another.

The conventional distinction is purpose-based. Quality improvement seeks to improve care within a particular organization or clinical system, whereas research is a systematic investigation designed to develop or contribute to generalizable knowledge (1). This distinction is important but incomplete. Clinical activities commonly have mixed purposes. A physician may introduce a change to benefit current patients while also hoping to establish whether it should become standard practice. A hospital may implement a quality initiative locally but collect outcomes using a prospective comparative design. A device may already be marketed, yet the proposed use may involve a substantially different patient population, route, interface, or physiological assumption.

Published decision tools consistently examine project intent, design, and the nature of the intervention, but they vary in how those factors are weighted (2). Canadian institutions likewise differ in their pathways for quality-improvement ethics review, demonstrating that the boundary is not interpreted uniformly (3). The absence of a universal bright line does not mean the distinction is arbitrary. It means classification should be based on a structured assessment rather than a label chosen by the clinician conducting the activity.

"The absence of a universal bright line does not mean the distinction is arbitrary. It means classification should be based on a structured assessment rather than a label chosen by the clinician conducting the activity."

This paper provides a practical framework for physicians. It is not legal advice and does not replace formal institutional or regulatory review. Its purpose is to identify when a proposed clinical modification should be brought to a research ethics board, an institutional review board, a quality office, an innovation committee, a device committee, a privacy office, or a regulatory-affairs group for a documented determination.

The Clinical Innovation Continuum

Clinical care and research are often described as separate domains, but many activities lie along a continuum.

Individualized clinical judgment sits at one end. The primary purpose is therapeutic, the intervention is selected for a particular patient, and treatment remains responsive to that patient's condition. Examples include adjusting a medication dose outside a customary range, altering an operative technique because of unexpected anatomy, or using an approved device differently when standard settings are inadequate. Novelty alone does not necessarily convert care into research.

Clinical innovation begins when a physician introduces a substantially new technique, device use, procedure, or treatment strategy whose outcomes are less predictable than those of established practice. The intent may remain therapeutic, but uncertainty is greater. Innovation can be ethically appropriate without being formal research. It should, however, usually involve enhanced disclosure, expert consultation, careful documentation, and systematic outcome monitoring. Surgical literature has emphasized that early innovation may warrant institutional oversight even before a conventional trial is feasible (4).

"Clinical innovation begins when a physician introduces a substantially new technique, device use, procedure, or treatment strategy whose outcomes are less predictable than those of established practice."

The threshold begins to shift when the modification becomes a reproducible approach applied across patients. A written protocol, standard eligibility criteria, predetermined settings or escalation rules, prospective collection of defined outcomes, repeated use by multiple clinicians, and a plan to determine whether the approach performs better than current care are all signals of structured clinical innovation. At this stage, the activity may still be implementation or quality improvement, but it is no longer merely an isolated exercise of individualized discretion.

Quality improvement generally aims to make delivery of accepted care more reliable, timely, safe, or efficient. It commonly addresses implementation failure rather than unresolved biological efficacy. QI may use rigorous methods, comparison groups, statistical process control, and prospective data collection. Scientific rigor does not, in itself, make an activity research. Conversely, calling an activity "QI" does not exempt it from ethical obligations. Some projects are both QI and research, and some evolve into research as their objectives and design change (1).

At the far end is prospective clinical investigation. The activity has usually crossed the research threshold when patients are prospectively assigned to an intervention to answer a question about safety, efficacy, mechanism, or comparative performance. Randomization, concurrent control groups, sample-size calculations, prespecified hypotheses, inferential statistical testing, protocol-imposed limits on clinician discretion, and an intention to support a new indication or standard of care are strong indicators. Cluster randomization does not remove an activity from research; it changes the unit of assignment and requires ethics analysis tailored to a group-level design (5).

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When a Clinical Modification Crosses the Research Threshold:

No single question is sufficient. Classification should reflect the combined weight of several domains.

First, define the primary purpose. The key distinction is whether the activity is designed primarily to benefit the patient receiving the intervention, improve a local care process, or answer a generalizable question. A physician may learn from every encounter; incidental learning does not make treatment research. The threshold changes when generating knowledge becomes an explicit design objective, and patients are managed according to a plan created to answer that question. Publication intent is neither necessary nor sufficient. Legitimate clinical care and QI may be published, while an unpublished activity may still be research if it prospectively tests a hypothesis.

Second, determine whether the intervention is accepted or whether its safety and efficacy are themselves uncertain. QI ordinarily improves delivery of an intervention already supported as appropriate care. Research more often asks whether the intervention works, is safe, or should be used in a new population. Improving adherence to an established lung-protective ventilation protocol is likely QI; assigning patients to a new ventilator-control strategy to determine whether it reduces lung injury is more likely research. The concern is heightened where safety depends on an unvalidated physiological feedback pathway, algorithm, sensor, or developmental assumption.

Third, examine whether treatment is individualized or

systematically assigned. Clinical care preserves discretion. Research assignment follows a plan. Protocolization alone does not prove research, because clinical pathways are common and often beneficial. However, mandatory assignment, treatment allocation by schedule or algorithm, protocol-defined rescue criteria, crossover rules, blinding, or allocation driven by the needs of a comparison are powerful research signals.

Fourth, assess incremental risk relative to the care patients would otherwise receive. Additional risks can arise from a new invasive procedure, use in a more medically fragile population, delayed rescue treatment, withholding accepted care, additional imaging or sampling, unvalidated software, device performance outside tested conditions, or the collection of identifiable data. Whether consent is needed should be determined through a structured risk-benefit assessment by an appropriate review body, not solely on the judgment of those conducting the project (6).

Fifth, ask whether the population is materially different from the population in which the intervention was established. Moving from adults to children, term infants to extremely premature infants, stable patients to critically ill patients, noninvasive use to invasive use, or cognitively capable patients to those unable to consent may change mechanism, dose-response, safety margin, and device performance. A familiar intervention can become meaningfully novel when the evidence cannot reasonably be extrapolated.

Sixth, determine whether the activity is intended to establish a new product or performance claim. Off-label use in an individual patient does not automatically constitute research. The threshold changes when a standardized program is designed to establish safety or efficacy for a new indication, population, route, interface, operating range, software configuration, or device claim.

Finally, review the analytic plan. Routine outcome monitoring is part of responsible care. A defined primary endpoint, sample-size calculation, superiority or noninferiority hypothesis, interim efficacy analysis, causal model, prespecified subgroup analysis, or multisite pooling signals a systematic investigation rather than ordinary clinical observation.

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Quality Improvement and Learning Health Systems

The learning health system seeks to integrate evidence generation into clinical operations. This offers major benefits but can blur conventional boundaries. A hospital may continuously compare pathways, devices, staffing patterns, or decision-support systems. Some activities remain operational improvement; others are pragmatic clinical trials embedded in care. The fact that an intervention is delivered through a clinical system rather than a research center does not determine its classification.

A useful practical distinction is that QI asks, "How can we deliver care already considered appropriate more reliably here?" Research asks, "Which intervention should be considered appropriate, and for whom?" The distinction becomes less clear when the intervention itself is uncertain and the implementation strategy is being tested simultaneously.

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Quality and service-improvement research raises ethical questions that conventional categories do not fully resolve. One defensible approach is to apply established research-ethics principles when activities systematically generate knowledge beyond local process improvement (7). Some projects appropriately receive a hybrid determination: operational sponsorship through the quality office, with research ethics review of comparative, randomized, or knowledge-generating components.

The local-versus-generalizable distinction should not be treated mechanically. A local aim does not immunize an experimental intervention, and dissemination does not retroactively transform appropriate QI into research. Purpose, design, intervention, assignment, and risk must be evaluated together (1, 2).

Medical Devices, Software, Artificial Intelligence, and Off-Label Use

Technology increasingly separates the visible clinical action from the mechanisms that determine care. A clinician may perceive a change as merely selecting a different setting on an existing machine, while the relevant oversight question concerns a new intended use, population, control strategy, interface, or performance condition.

For medical devices, physicians should ask whether the device is authorized or validated for the intended population; whether the interface is invasive or noninvasive; whether patient weight, flow, pressure, volume, resistance, and compliance remain within tested ranges; whether accessories or software alter function; whether safety depends on a biological feedback mechanism not

validated in the population; and whether the activity is intended to support a new claim. When these questions remain unresolved, implementation should not be treated as a routine practice change merely because the hardware is already present in the hospital. The pediatric-device literature has specifically noted that devices are often adapted for children without sufficient evidence, resulting in inconsistent benefit-risk profiles (11).

Software and artificial intelligence can influence care through risk prediction, image interpretation, dosing, alarm prioritization, triage, and automated control. Research oversight becomes more likely when software produces patient-specific recommendations, changes treatment allocation, has not been validated in the local population, is retrained during deployment, adapts over time, or can cause clinically meaningful harm. "Silent" validation, in which output is not shown to clinicians, may lower direct clinical risk but still raises privacy and governance questions. Active deployment that changes treatment generally requires more extensive review.

"Research oversight becomes more likely when software produces patient-specific recommendations, changes treatment allocation, has not been validated in the local population, is retrained during deployment, adapts over time, or can cause clinically meaningful harm."

Off-label prescribing is common and may be clinically appropriate. The physician should nevertheless distinguish among individualized off-label care, a standardized off-label pathway, prospective comparison with standard care, and data collection to establish a new indication. Movement along that sequence increasingly resembles research. The same principle applies to device use outside labeling or validation. The relevant issue is not the label "off-label" itself, but whether the activity is individualized therapy or a systematic investigation designed to establish a broader claim.

Vulnerable Populations and Proportional Oversight

The research threshold does not necessarily change because a population is vulnerable, but the consequences of uncertainty do. Vulnerability may arise from inability to consent, medical fragility, dependency on institutional care, limited treatment alternatives, emergency circumstances, developmental immaturity, or socioeconomic and power disparities.

Neonatal and perinatal QI literature emphasizes that improvement activities should remain grounded in beneficence, nonmaleficence, justice, and respect for autonomy (8). Those principles apply equally to clinical innovation. A modification that might reasonably proceed with ordinary disclosure in a competent adult may warrant prior independent review in an extremely premature infant because uncertainty, small safety margins, inability to consent, and limited rescue capacity increase the need for prospective safeguards.

Proportional oversight may include independent expert consultation, enhanced disclosure to parents or substitute decision-makers, prospective eligibility criteria, real-time safety monitoring, conservative stopping rules, staged enrollment, initial feasibility cohorts, external safety oversight, independent outcome adjudication, and mandatory reporting of serious adverse events. The purpose is not to prevent innovation in vulnerable groups. It is to ensure that vulnerability is not used as a reason to lower the evidentiary or governance standard.

"Proportional oversight may include independent expert consultation, enhanced disclosure to parents or substitute decision-makers, prospective eligibility criteria, real-time safety monitoring, conservative stopping rules, staged enrollment, initial feasibility cohorts, external safety oversight, independent outcome adjudication, and mandatory reporting of serious adverse events. "

A Practical Decision Framework for Physicians:

Before introducing a clinical modification across multiple patients, physicians should complete a structured threshold assessment.

1. Define the intervention precisely. State what changes, what remains standard, who is eligible, who assigns treatment, whether hardware or software changes, whether the device is used within validated conditions, and how rescue decisions are made.
2. Define the purpose. Clarify whether the activity is intended primarily to treat an individual, improve local reliability, determine safety or efficacy, compare strategies, support adoption elsewhere, or establish a new product claim. Mixed purposes should be stated explicitly.
3. Assess novelty and uncertainty. Determine whether the intervention is established in the same population, disease, severity, route, interface, configuration, and physiological operating range. Multiple simultaneous gaps strongly favor formal review.
4. Examine assignment. Determine whether treatment is chosen case by case or assigned by protocol, schedule, unit, clinician, randomization, algorithm, or availability. Systematic assignment is one of the clearest research signals.
5. Examine the data plan. Identify primary outcomes, comparators, sample-size calculations, causal hypotheses, statistical testing, multisite pooling, and prospective plans to establish effectiveness.

6. Assess incremental risk. Identify physical, informational, psychological, and opportunity risks arising from the modification rather than from the underlying disease.

7. Consider vulnerability. Determine whether patients can consent, whether surrogates are under time pressure, and whether the population has a narrow safety margin.

8. Seek an institutional determination. When classification is uncertain, request a written decision from the appropriate body. The physician should not self-declare exemption when multiple research indicators are present.

Decision algorithms can help match protections and consent requirements to the design and risk of health-services research and QI (10). Their proper role is to prompt accountable consultation, not to authorize investigators to decide their own exemption.

Institutional Responsibilities:

Institutions should make consultation easier than avoidance. Confusing or slow pathways encourage clinicians either to abandon appropriate innovation or to proceed without adequate review.

"Decision algorithms can help match protections and consent requirements to the design and risk of health-services research and QI (10). Their proper role is to prompt accountable consultation, not to authorize investigators to decide their own exemption."

A mature governance system should provide a single entry point for uncertain projects; rapid preliminary classification; proportional review rather than automatic full-board referral; specialized expertise in devices, software, pediatrics, surgery, privacy, and QI; written determinations; and clear triggers for reassessment when design, risk, comparison, or dissemination plans change.

Institutional innovation committees can bridge the gap between unrestricted novelty and formal research review. Such committees may assess operator qualifications, scientific rationale, consent language, device status, feasibility, monitoring, and the point at which continued use must transition into a formal trial (4). Their role should complement rather than replace the IRB or research ethics board.

Institutional responsibility also includes protection from classification bias. Clinicians should not be rewarded for labeling an investigation as QI to avoid oversight, nor should low-risk operational work be burdened with unnecessary procedures. Consistency, transparency, and documented rationale are central. Reviews of research ethics systems suggest that refinement and more uniform application of existing standards may be more useful than continual proliferation of new rules (9).

Illustrative Cases:

"Reviews of research ethics systems suggest that refinement and more uniform application of existing standards may be more useful than continual proliferation of new rules (9)."

Case 1: Individualized off-label therapy. A physician prescribes an approved medication off-label to one patient after standard options fail. The decision is documented, risks and alternatives are discussed, and treatment is modified according to response. This is likely clinical care.

Case 2: Standardized off-label pathway. A department adopts the same off-label regimen for all eligible patients and prospectively tracks outcomes against historical experience. This is structured clinical innovation or QI requiring institutional determination. The intervention's evidence base, risk, and analytic plan determine whether research review is required.

Case 3: Concurrent comparative assignment. Eligible patients are assigned to the off-label regimen or to current care on alternating weeks. The team specifies a primary endpoint and calculates sample size. This is likely research even if described as service evaluation.

Case 4: Established infection-prevention bundle. A hospital implements a guideline-supported central-line checklist and monitors compliance and infection rates. This is likely QI, although privacy and governance review may still be required. Infection-control scholarship has noted that scientific methods and generalizable learning can arise in both QI and research, making streamlined institutional consultation preferable to self-classification (12).

Case 5: Novel ventilator mode in an extremely immature population. A ventilator mode used in adults or older infants is introduced invasively in extremely premature infants. Safety depends partly on a physiological feedback mechanism that has not been directly validated at that developmental stage, and outcomes are prospectively compared with current ventilation. This is likely a clinical investigation requiring ethics, device-regulatory, and institutional oversight.

Case 6: Artificial-intelligence sepsis alert. An algorithm is first run silently to assess accuracy without affecting care. This is data research or validation requiring privacy and ethics determination. The same algorithm is then activated, clinicians are expected to alter treatment, and outcomes are prospectively compared with a control period. The active phase is more likely prospective clinical investigation or hybrid implementation-effectiveness research.

Discussion:

The goal of oversight is not to create a presumption against innovation. A system that treats every deviation from routine care as research would be clinically unworkable and ethically undesirable. Physicians must retain discretion to respond to individual patients, particularly when standard care fails.

The opposite error is equally problematic: treating a systematic, hypothesis-driven intervention as ordinary care because it occurs in a clinical unit, uses a marketed device, or is labeled QI. The boundary among innovative procedures, QI, and research remains controversial. The literature suggests that a more consistent interpretation of existing principles may be more useful than continually adding new standards (9).

"The goal of oversight is not to create a presumption against innovation. A system that treats every deviation from routine care as research would be clinically unworkable and ethically undesirable. Physicians must retain discretion to respond to individual patients, particularly when standard care fails."

A proportional governance model offers a practical solution. Individualized therapeutic decisions remain within clinical care. Repeated novel interventions receive innovation oversight. Local process improvements receive QI governance. Prospective comparative evaluations receive research review. Device, software, and new-indication questions are subject to regulatory assessment. Vulnerable populations trigger stronger safeguards. An independent institutional body documents classification decisions.

Ethical review need not always mean full-board review or conventional written consent. Depending on risk and jurisdiction, oversight may result in a determination of non-research, exemption, waiver, expedited review, altered consent, notification, QI classification, or formal trial requirements. The essential point is that the decision should be made through an accountable process.

This paper is intentionally a guidance document rather than a systematic review. Its evidence base is predominantly abstract-level and therefore supports conceptual and operational guidance, not definitive jurisdiction-specific conclusions. Institutions should align the framework with current law, regulatory guidance, professional standards, and local policy. Older literature sometimes states that publication intent itself determines the need for IRB review (13); contemporary decision frameworks generally treat publication as neither necessary nor sufficient and instead emphasize purpose, design, intervention, and risk (1,2).

Conclusion:

Clinical innovation becomes more than a clinical modification when it changes from individualized judgment into a systematic intervention designed to answer a question about safety, efficacy, mechanism, comparative performance, or future practice.

The strongest research indicators are prospective assignment, concurrent comparison, randomization, hypothesis testing, predetermined outcomes, sample-size calculations, protocol-imposed limits on clinical discretion, new device claims, and use in populations where safety assumptions have not been validated. As an NICU clinician, the last point raises concerns about the use of invasive NAVA (neurally adjusted ventilatory assist) in the extremely premature/very low-birth-weight population. At the time of writing, evidence supporting its use in this population is lacking, and, to the best of my knowledge, it has not been directly compared with high-frequency oscillation (HFO), HFO with volume targeting (HFO/VG), or high-frequency jet ventilation (HFJV).

"Clinical innovation becomes more than a clinical modification when it changes from individualized judgment into a systematic intervention designed to answer a question about safety, efficacy, mechanism, comparative performance, or future practice."

No single feature is dispositive, and jurisdictional requirements differ. The appropriate response to uncertainty is therefore not automatic prohibition or automatic exemption. It is independent, documented, proportional review.

Clinicians should be encouraged to innovate—but they should not be required to decide alone when innovation has crossed the research threshold (nor should they assume they have not).

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Did Curiosity Kill the Cat? (or Make it Better?)

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.

"This mantra described human development long before being (allegedly) penned by Saint Jerome in the fourth century. Our innate curiosity and desire to improve have brought us to where we are today as a species and a society."

"**Good, better, best**

Never let it rest

'til your good is better

And your better is best"

(Attributed to Saint Jerome)

This mantra described human development long before being (allegedly) penned by Saint Jerome in the fourth century. Our innate curiosity and desire to improve have brought us to where we are today as a species and a society. When driven by a desire to improve the human condition, the results have met the intended goal; when driven by conflict, arguably, not so much. The discoveries of Ernest Rutherford laid the groundwork for those who followed, including Einstein and Oppenheimer, who gave us nuclear power, and the pursuit of nuclear fusion holds promise for limitless clean energy (albeit with a lot of money). Conversely, as many as 250k lost lives speaks to the cost of using the same discoveries in conflict; the constant fear, and very real possibility of our annihilation through thermonuclear war, continues to remind us.

Sometimes innovation is driven by curiosity, other times by necessity. In 1959, 36,223 lives were lost as a result of automobile collisions in the U.S. alone, a rate of 5.17 per million vehicle miles traveled (1). Many more suffered life-altering injuries and disfigurements. Given that most vehicles at the time had no occupant restraint systems whatsoever (and that they were rarely used even if so equipped), we can safely assume virtually all of these deaths did not involve the use of lap belts. Recognising this, in 1959 Volvo® designed a 3-point safety restraint and made the patent available to all manufacturers free of charge (2).

The most significant benefit of lap belts is to prevent ejection or partial ejection from the vehicle, which is well known to increase the risk of death. Compared to lap belts alone, the 3-point system reduces the risk of death by up to 48% in a crash (3). In 2024, 39,254 Americans died in vehicle crashes, but this is a rate of 1.9 deaths/VMD because that year there were 4.7 times more VMD than in 1959 (2). Even if we discount advances in vehicle design and passive safety systems, over 17k American lives could have been saved in 1959 had 3-point seatbelts been utilized. It is a travesty that it was not until 1968 that American passenger cars were required to have shoulder belts, and even then, they were not the more advanced type introduced in 1959. Rear seat 3-point restraints were not required until the late 1990s, and only for outboard passengers (4).

Today, at age 18, New Hampshire is the only U.S. state that preserves an adult's "freedom to die" by not wearing a seat belt (5). Apparently, New Hampshire takes its motto, "Live free or die," to the extreme. Ironically, it appears on their vehicle license plates to this day.

Vehicles are one thing. We have sophisticated crash test dummies and computer simulations to assess a vehicle's structural integrity and the injury risk occupants face in a crash. In medicine, simulations and sophisticated mannequins allow trainees to hone their skills (to a degree) without fear of harming an actual person. Unfortunately, we cannot use simulations to assess the safety and efficacy of a new mode of ventilation or a new drug. For this, we need actual human subjects.

"In medicine, simulations and sophisticated mannequins allow trainees to hone their skills (to a degree) without fear of harming an actual person. Unfortunately, we cannot use simulations to assess the safety and efficacy of a new mode of ventilation or a new drug. For this, we need actual human subjects."

In addition to the strong resistance that oft faces anything new in medicine, there is the real risk of causing harm, morbidity, or death, and the resulting litigation that usually results. The best of intentions are fine, but they carry with them no real safeguards, particularly if an investigator(s) is blinded by their own assuredness and/or bias.

In pediatrics, and neonatology in particular, the relatively small number of potential subjects available for clinical research affects

the research. Ethical constraints and informed consent are of course a good and necessary thing, but they further exacerbate the problem. Safeguards, while always in place, may not be activated. This is not necessarily an act of negligence; it may be because investigators are unaware of the potential adverse effects of a new treatment. Nevertheless, investigators stand on a very slippery slope if they independently decide that their work is not subject to those safeguards.

"In pediatrics, and neonatology in particular, the relatively small number of potential subjects available for clinical research affects the research. Ethical constraints and informed consent are of course a good and necessary thing, but they further exacerbate the problem."

How best to utilise limited financial resources and potential human subjects may be a philosophical debate, but clinicians must recognise that "good, better, best" ends in "best". Once interventions reach a very high level of success, the bar is very high when trying to establish another's superiority. Here, time, effort and money are more prudently spent seeking to improve areas that fall below that bar.

I have discussed in previous columns that improvements in pulmonary outcomes are far more evident when current ventilation practices result in poor outcomes, with non-invasive ventilation and early extubation being prime examples. Another centre's dramatic improvement must be viewed in the context of where they started from, and the final results. Going from awful to mediocre is a great improvement indeed, but a centre with existing excellent results should hardly strive to reach mediocre status. All that glitters is not gold, and new is not necessarily improved! Returning to the automobile world, I submit that touch screens are a prime example.

To that end, I submit this month a white paper to guide clinicians in their search for improvement. It is hoped that ethical and safety thresholds may be more easily recognised as a result.

The white paper was written in collaboration with Dr. David Graham of Graham Scientific, Germantown, MD, and references were verified using Graham Scientific's proprietary A.I. source-tracing software. I have no affiliation with Graham Scientific.

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The Indirect Impact of **RSV**

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

OVERVIEW

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

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

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

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

RSV PARENT SURVEY

340 parents who had at least 1 child sick with RSV

67% of parents said their child was hospitalized for RSV

RSV HEALTH CARE PROVIDER SURVEY

175 health care providers across various pediatric and neonatal subspecialties

67% worked in an outpatient facility

33% worked in a hospital

RESULTS

FINANCIAL BURDEN

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

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

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

EMOTIONAL BURDEN

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

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

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

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

SOCIAL BURDEN

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

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

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

RESULTS

PARENT EDUCATION & AWARENESS

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

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

TREATMENT CHALLENGES

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

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

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

MISCONCEPTIONS

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

CONCLUSION

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

The virus may lead to:

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

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

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

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

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

infanthealth.org

Fathers Can Experience

Postpartum Depression

Becoming a father is an exciting and significant life event.

While it's well known that mothers can face postpartum depression, new fathers are at risk too.

1 in 10 men experience postpartum depression

Up to 7% of fathers may experience PTSD after the birth of their child

If their baby was born **preterm or the birth was traumatic,** their risk of postpartum depression and PTSD increases

Signs and symptoms a father may be struggling include:

Mood swings

Trouble sleeping

Anger

Withdrawing from family and friends

Difficulty bonding with their baby

Raising awareness about paternal postpartum depression can:

Reduce stigma

Help dads recognize the symptoms

Eliminate barriers to screening and treatment

New dads deserve their mental health to be taken seriously.

Hand to Hold

National Coalition for Infant Health

INFANT AND FAMILY-CENTERED DEVELOPMENTAL CARE (IFCDC)

STANDARDS AND SAMPLE RECOMMENDATIONS FOR INFANTS IN THE INTENSIVE CARE UNIT

SYSTEMS THINKING IN COMPLEX ADAPTIVE SYSTEMS

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

POSITIONING & TOUCH FOR THE NEWBORN

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

SLEEP AND AROUSAL INTERVENTIONS FOR THE NEWBORN

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

SKIN-TO-SKIN CONTACT WITH INTIMATE FAMILY MEMBERS

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

REDUCING AND MANAGING PAIN AND STRESS IN NEWBORNS AND FAMILIES

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

MANAGEMENT OF FEEDING, EATING AND NUTRITION DELIVERY

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

WANT TO KNOW MORE ABOUT THE STANDARDS AND RECOMMENDATIONS? VISIT: HTTPS://NICUDESIGN.ND.EDU/NICU-CARE-STANDARDS/

Ethics and Wellness: The Power of "We," An Ethical Imperative in Neonatal Care

Mitchell Goldstein, MD, MBA, CML

"Few phrases are repeated more often in healthcare than 'There is no 'I' in team.' It reminds us that modern medicine is collaborative and that no individual possesses all the knowledge or skills required to care for our most vulnerable patients. The sentiment is sound, but perhaps it is incomplete."

Few phrases are repeated more often in healthcare than *"There is no 'I' in team."* It reminds us that modern medicine is collaborative and that no individual possesses all the knowledge or skills required to care for our most vulnerable patients. The sentiment is sound, but perhaps it is incomplete.

"A team is a collection of individuals with different roles, expertise, and perspectives. Teams deliberate. Teams debate. Teams occasionally disagree. Healthy disagreement is not a weakness; it is often the source of better clinical decisions."

After all, there is no "we" in *team* either. However, "we" may be the most powerful word available to neonatal clinicians. The distinction is subtle but important. A **team** is a collection of individuals with different roles, expertise, and perspectives. Teams deliberate. Teams debate. Teams occasionally disagree. Healthy disagreement is not a weakness; it is often the source of better clinical decisions. Neonatologists, nurses, respiratory therapists, pharmacists, dietitians, social workers, therapists, and consultants each bring unique insights that strengthen patient care. (1, 2)

Nevertheless, once those discussions have occurred, families deserve something more than evidence of collaboration. They deserve unity. That is where "we" becomes ethically significant.

Consider the difference between these two statements:

"The team decided that surgery is the best option."

versus

"We believe surgery is the best option."

The first sentence reports the outcome of a meeting. The second communicates shared ownership of the recommendation. One describes a process; the other conveys commitment. Parents entering a neonatal intensive care unit are rarely looking for evidence that professionals debated every nuance of care. They seek confidence, clarity, and reassurance that everyone caring for their child is working toward the same goal. "We" provides that reassurance.

Importantly, "we" is not intended to suppress disagreement or diminish professional autonomy. Ethical medical practice demands open discussion, respectful dissent, and thoughtful consideration of differing viewpoints. Robust dialogue behind closed doors is essential to sound decision-making. However, once a course of action has been established, continuing to project uncertainty unnecessarily can increase parental anxiety and undermine trust.

"Importantly, "we" is not intended to suppress disagreement or diminish professional autonomy. Ethical medical practice demands open discussion, respectful dissent, and thoughtful consideration of differing viewpoints. Robust dialogue behind closed doors is essential to sound decision-making. However, once a course of action has been established, continuing to project uncertainty unnecessarily can increase parental anxiety and undermine trust."

Language Matters:

When one clinician says, "I think," another says, "The consultant believes," and yet another says, "The team discussed," parents may begin to wonder whether anyone truly agrees. They may perceive uncertainty where there is actually consensus. Even when recommendations are evidence-based, fragmented

communication can unintentionally erode confidence.

Conversely, "we" signals alignment. It tells parents:

"We have reviewed your baby's condition carefully."

"We have considered the available options."

"We are committed to caring for your child together."

"Notice that none of these statements eliminates individual accountability. Rather, they emphasize collective responsibility. This distinction extends beyond conversations with families."

Notice that none of these statements eliminates individual accountability. Rather, they emphasize collective responsibility. This distinction extends beyond conversations with families.

Within the NICU, "we" strengthens interdisciplinary relationships. It reinforces that quality improvement is not the responsibility of one profession. Patient safety is not owned by one discipline. Family-centered care is not the exclusive domain of social workers or bedside nurses. Ethical practice is not limited to ethics committees. We own these responsibilities together. (3, 4)

The pronoun also has implications for professional wellness. Burnout often flourishes in environments where clinicians feel isolated. Physicians may feel that every difficult outcome rests solely on their shoulders. Nurses may feel unheard. Trainees may hesitate to voice concerns. The language of "I" can unintentionally reinforce these feelings of separation. (5)

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"We," on the other hand, reminds us that difficult decisions, emotional burdens, and clinical successes are shared. It acknowledges that no one carries the weight of neonatal care alone.

"There is another dimension worth considering. Some dismiss 'we' as the so-called 'royal we,' implying authority rather than collaboration. In healthcare, however, the opposite is true. Used thoughtfully, 'we' is not hierarchical: it is inclusive."

There is another dimension worth considering. Some dismiss "we" as the so-called "royal we," implying authority rather than collaboration. In healthcare, however, the opposite is true. Used thoughtfully, "we" is not hierarchical: it is inclusive. It welcomes every member of the care team into a common purpose while reassuring families that they are not navigating uncertainty alone. (6)

Perhaps the greatest strength of "we" is that it can extend beyond healthcare professionals. Imagine saying to parents: *"We will get through this together."* In that moment, "we" no longer refers only to clinicians. It includes the family. The relationship shifts from experts directing care to partners sharing a journey. This shift is the essence of family-centered care—not simply informing parents, but inviting them into a community united around their infant's well-being. (7)

Of course, "we" should never be used to obscure legitimate disagreement or avoid transparency. If meaningful differences of opinion exist that affect treatment options, honesty remains paramount. Ethical communication requires candor. Nevertheless, when a thoughtful consensus has been reached, presenting that recommendation with one voice serves patients and families better than highlighting every prior debate. (8)

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Words Shape Culture:

A NICU culture built around "we" fosters trust, psychological safety, shared accountability, and mutual respect. It encourages

clinicians to move beyond professional silos while helping families feel supported by an integrated community rather than a collection of independent experts. (9)

"However, there should be "we" in everything the team does. Because in the NICU, our greatest strength is not simply that we work together. It is that, after careful thought and compassionate discussion, we move forward together."

Perhaps we have been focusing on the wrong phrase all along. There may be no "I" in *team*, and there may be no "we" in the word team either. However, there should be "we" in everything the team does. Because in the NICU, our greatest strength is not simply that we work together. It is that, after careful thought and compassionate discussion, we move forward together.

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The Overloaded Clinician: Mapping Cognitive Load Theory to the POKE Ecosystem in the NICU

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

"Over the past series of columns, we have explored how a Newborn Intensive Care Unit (NICU) migrates down the DuPont Bradley Curve away from a top-down, "command and control" posture toward the pinnacle of cultural maturity: the Interdependent Stage. We established that in a mature POKE ecosystem, safety is a collective, non-negotiable precondition where team members are 100% accountable for their actions and 100% accountable for the actions occurring to their left and right (1)."

Over the past series of columns, we have explored how a Newborn Intensive Care Unit (NICU) migrates down the DuPont Bradley Curve away from a top-down, "command and control" posture toward the pinnacle of cultural maturity: the Interdependent Stage. We established that in a mature POKE ecosystem, safety is a collective, non-negotiable precondition where team members are 100% accountable for their actions and 100% accountable for the actions occurring to their left and right (1). By examining industrial tools like Toyota's Andon Cord and Jens Rasmussen's boundaries of systemic drift, we have built an architecture designed to intercept variation in practice before it reaches the bedside of any newborn intensive care unit patient (2, 3). However, a vital question remains: Why do highly trained, deeply committed clinicians repeatedly allow unstandardized practice variations to breach our systemic defenses?

The answer is not a failure of intent, vigilance, or baseline intelligence. Rather, it is an evolutionary limitation of human neurobiology. To truly understand why frontline caregivers succumb to the Efficiency-Thoroughness Trade-Off (ETTO) or fall back on "The Way I Trained" (TWIT) habits, we must cross-examine our clinical workflows through the lens of John Sweller's **Cognitive Load Theory (CLT) (4)**. Only by understanding the cognitive limits of human working memory can we position our POKE ecosystem defenses as true structural safeguards against mental and cognitive overload.

At the core of Cognitive Load Theory lies an important neurological reality: while human long-term memory is virtually infinite, our **working memory,** the mental workspace used to process immediate information, address patient-based variation, reason, and solve problems in real time, is exceptionally small, fragile, and easily overwhelmed. Research demonstrates that the conscious mind can hold only about four to seven distinct "chunks" of information at any given millisecond (5, 6) (Figure 1).

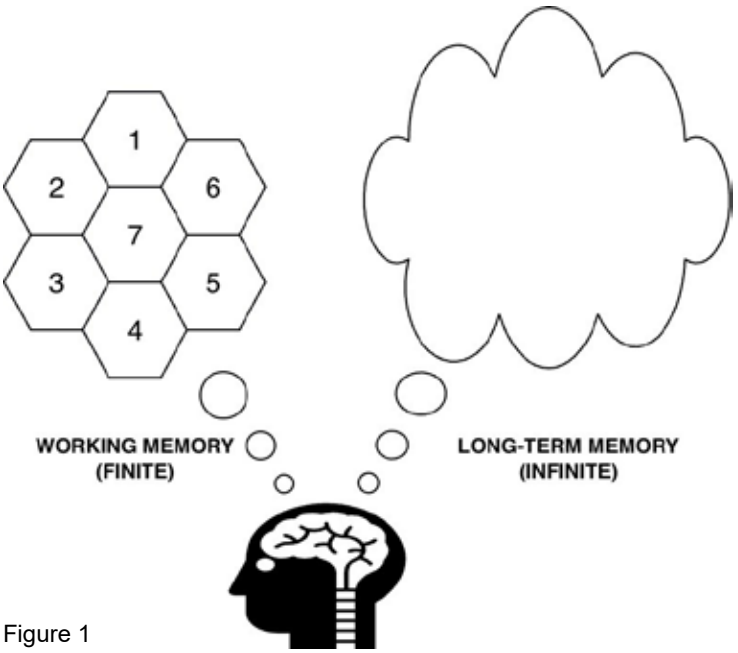

Figure 1

In a high-acuity environment like the NICU, a clinician's finite working memory budget is continuously bombarded by three distinct types of cognitive Load: Intrinsic Load, Extraneous Load, and Germane Load (7) (Figure 2). Patient safety in a POKE ecosystem is entirely an exercise in managing this total cognitive budget to prevent cognitive overload.

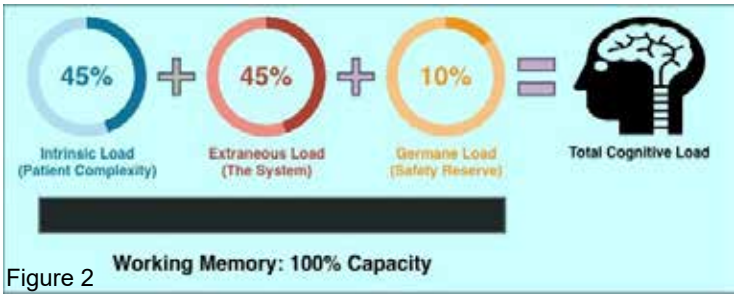

Figure 2

Intrinsic Load represents the baseline mental effort required to process the actual clinical challenge at hand. It is dictated entirely by the number of information elements that must be processed simultaneously and how heavily those elements interact with one

another. In our environment, you cannot artificially dilute or simplify the raw physiological complexity of a newborn with hypoxemic respiratory failure or a newly born 23-week extremely low birthweight infant. Clinical management of these patients, and their complex multi-organ physiologic and pathophysiologic disturbances, involves immense intrinsic Load. The clinician's brain is often required to concurrently consider a dynamic, multi-variable treatment regimen that may include vasoactive medication infusions, inhaled nitric oxide, adjustments to high-frequency ventilatory support based on assessed blood gas parameters, and interpretation of real-time echocardiographic findings. Each of these variables is deeply interdependent; changing one directly modifies another.

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The POKE ecosystem accepts that intrinsic Load cannot be engineered away. Instead, we intercept it through Core Clinical Mastery as Intellectual Capital. Through intensive, universal RNC-NICU certification and structured SBAR communication training, we structurally alter how this Load is handled. Advanced clinical expertise allows isolated, scattered pieces of clinical data to be consolidated into highly integrated, complex mental structures called **"schemas"** in long-term memory. When an experienced, certified neonatal nurse assesses a deteriorating infant, their brain does not exhaust working memory by analyzing ten separate, raw data streams (heart rate, saturation, perfusion, pressure). Instead, they instantly retrieve a unified "cardiovascular collapse" schema. This massive cognitive chunking offloads the working memory, transforming what would be an overwhelming intrinsic load for a novice into a manageable, structured cognitive state for the clinician striving for mastery (8).

Extraneous Load represents the mental waste and unnecessary cognitive friction generated by poor information presentation, task arrangement, or physical environment structure. Unlike intrinsic Load, extraneous Load adds absolutely zero clinical value to the infant. It is pure operational friction that voraciously consumes the precious, finite processing power that *should* serve the infant and their brain. In a poorly designed NICU, extraneous Load is rampant (9, 10). It is the heavy cognitive tax clinicians pay to non-intuitive electronic medical records (EMRs) that require fifteen disparate clicks across three menus to verify a critical lab value, determine intake/output, or sign a medication order. Continuous, non-actionable "cry-wolf" monitor alarms generate this and induce severe alarm fatigue, forcing the auditory cortex to expend subconscious energy constantly filtering out acoustic static. Chaotic physical layouts that place critical emergency supplies far from the bedside and in non-standard locations, frequent telephone interruptions during complex drug calculations, and ambiguous, unstructured handoffs exacerbate this. When a clinician is forced to battle an awkward user interface, navigate environmental noise, or fight through a poorly sequenced workflow, their immediate working memory budget is rapidly depleted or overloaded (Figure 3). But this external friction does not occur in a physiological vacuum. It compounds directly with **Allostatic Load**—the chronic, cumulative wear and tear on the human body and brain resulting from repeated exposure to systemic stress, circadian disruption, shift work, hyper-vigilance, and moral injury (11).

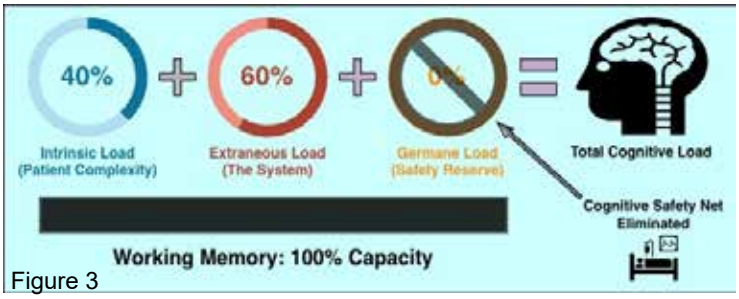

Figure 3

"While extraneous Load represents the external operational friction imposed by poorly designed systems, allostatic Load represents the internal physiological erosion of the clinician›s prefrontal cortex over time. Chronic neuroendocrine stress elevates baseline cortisol, disrupts neural plasticity, and fundamentally shrinks the overall baseline working memory vessel itself (12)."

While Extraneous Load represents the *external* operational friction imposed by poorly designed systems, allostatic Load represents the *internal* physiological erosion of the clinician's prefrontal cortex over time. Chronic neuroendocrine stress elevates baseline cortisol, disrupts neural plasticity, and fundamentally shrinks the overall baseline working memory vessel itself (12). Under high allostatic Load, a caregiver's tolerance for extraneous noise evaporates. An awkward EMR interface or a false alarm that a well-rested, low-stress clinician could easily brush off suddenly consumes 40% of an exhausted caregiver's remaining mental budget (Figure 4). This creates a catastrophic tipping point. Starved of cognitive reserves, the brain naturally slides down into

the Efficiency-Thoroughness Trade-Off (ETTO). To survive the shift, the overloaded clinician drops deliberate System 2 processing and substitutes tedious standard work with rapid, error-prone System 1 heuristics—creating the exact conditions where latent defects slip past undetected and reach the vulnerable infant (13).

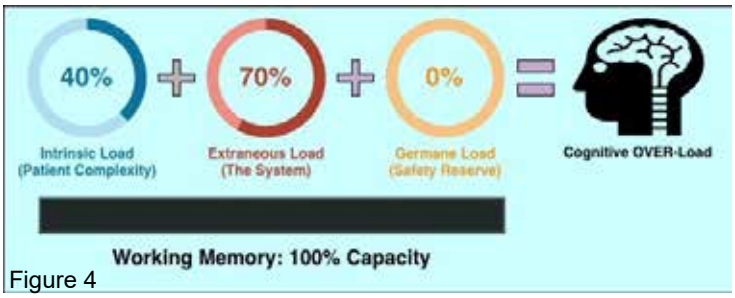

Figure 4

Germane Load is the beneficial, productive cognitive work dedicated to synthesizing information, constructing accurate real-time mental models, and integrating new data into deep, actionable understanding. In safety science, germane Load represents the vital cognitive reserve required to achieve a true Sensitivity to Operations—one of the foundational pillars of High Reliability Organizations (7, 14). It is the neurological bandwidth that allows a clinician to maintain acute situational awareness: to step back from immediate routine tasks, actively observe "work-as-done" versus "work-as-imagined," and detect the subtle, ominous clinical drift before it manifests as an adverse event. Germane Load is not a fixed asset, nor is it a guaranteed baseline; it is highly volatile and **exists strictly as a surplus**. It is the remaining processing space left over in working memory only after intrinsic patient complexity and extraneous systemic waste have taken their initial cuts.

"Germane Load is not a fixed asset, nor is it a guaranteed baseline; it is highly volatile and exists strictly as a surplus. It is the remaining processing space left over in working memory only after intrinsic patient complexity and extraneous systemic waste have taken their initial cuts."

The immediate, catastrophic threat to neonatal patient safety occurs when:

Intrinsic Load + Extraneous Load ≥ 100% of Cognitive Capacity:

When an infant's physiological instability and the system's operational friction consume 100% of the cognitive budget, **Germane Load drops to absolute zero**. When germane bandwidth reaches zero, the cognitive safety net completely evaporates (Figure 5). The clinical team loses its capacity for collective cross-checking, blind spots expand, and the shared mental model fractures into isolated, task-oriented silos. In this state of zero-surplus cognitive paralysis, the human brain loses its ability to process unexpected variations or question anomalies.

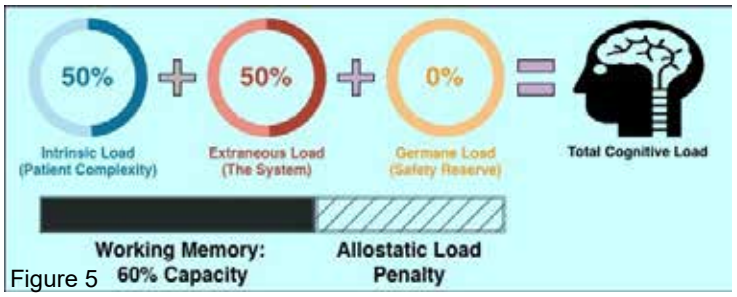

Figure 5

Under these zero-surplus conditions, the overburdened bedside nurse or physician bound to "The Way I Trained" (TWIT) habits may commit a heuristic error; the surrounding team lacks the cognitive bandwidth even to register the deviation. Because every brain at the bedside is fully occupied fighting the environment, no one possesses the mental capacity to execute a behavioral Andon Cord pull. The invisible boundaries of safety are crossed in silence, allowing the latent holes in James Reason's Swiss Cheese model to slide into perfect alignment, forcing a fragile infant with zero physiological reserve to inherit the harm (Figure 6).

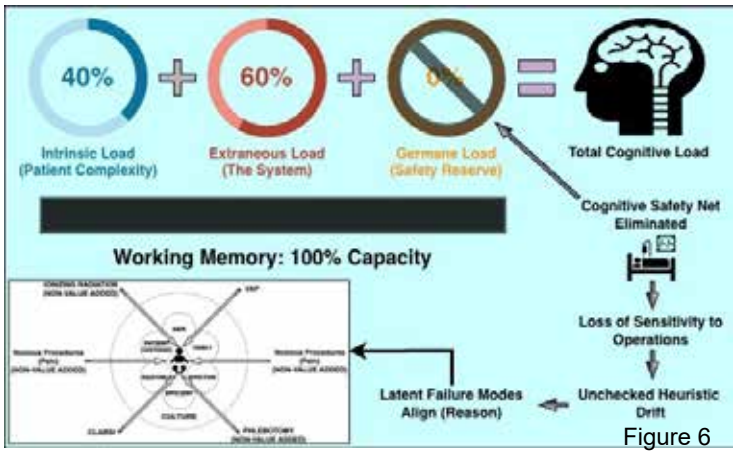

Figure 6

POKE Ecosystem Defenses as Cognitive Load Regulators - The core tools of our POKE safety culture are not merely bureaucratic compliance metrics or pleasant operational ideas. When viewed through the lens of neurobiology and cognitive psychology, they are explicitly designed to protect and offload human working memory, allow for margin, support germane Load, and enable the development of Skill-based performance. Among the myriad tactics we implemented, a few stand out.

1. **The Twice-Daily Huddle:** Off-Line Schema Building. By mapping out potential failures *before* they manifest at the bedside, the huddle allows the multidisciplinary team to utilize slow, analytical **System 2 processing** when stress and cognitive Load are exceptionally low. This process constructs highly organized mental "schemas" in long-term memory. When an emergency later occurs at the bedside, the team does not exhaust working memory trying to synthesize an ad hoc plan from scratch; they activate and execute the pre-built schema, preserving vital cognitive bandwidth.

2. **The Behavioral Andon Cord Pull:** Working Memory Reset. When a bedside nurse, respiratory therapist, or

neonatologist executes an Andon pull using a structured behavioral protocol—such as the Two-Challenge Rule or the escalating phrases of CUS (*Concerned, Uncomfortable, Safety*)—it acts as a macro-level cognitive circuit breaker (15). By forcing an immediate operational pause, it halts the compounding extraneous load of an unfolding clinical crisis. The team drops their automated, error-prone System 1 heuristics and is forced to ascend collectively to a deliberate, Knowledge-based level of processing, resetting their working memory bounds before proceeding.

3. **Systemic Redesign via Poka-Yoke (Mistake-Proofing):** Externalizing the Cognitive Load. Rasmussen argued that safety engineering must make invisible boundaries highly visible before an expert's shortcut can cross them. By institutionalizing rigid, binary defenses such as our physical "Rule of Two," we effectively externalize cognitive Load. Independent double-checks on high-risk infusions, analog pressure verifications on ventilation equipment, and computerized EMR hard-stops serve as auxiliary hard drives for the clinician's brain. If human working memory is overtaxed and misses a boundary, the physical system handles the processing and automatically intercepts the error.

"By aligning Daniel Kahneman's dual-system framework, Jens Rasmussen's safety boundaries, and John Sweller's cognitive limits, we transform the NICU from an environment of chaos into a structured, highly reliable ecosystem. It ensures that when human cognition inevitably encounters its limits under pressure, our collective safety architecture holds firm, sending everyone, from our fragile patients to our frontline caregivers, home at the end of the day Safe, Valued, and Loved."

We cannot reduce the intrinsic complexity and variation of a critically ill newborn, but we can ruthlessly eliminate the extraneous Load of our systems. When we clear cognitive waste, we preserve the germane bandwidth frontline caregivers need to think critically, develop mastery, communicate interdependently, and protect our vulnerable patients. Ultimately, managing cognitive Load is the ultimate "Public Victory" of an Interdependent unit. By aligning Daniel Kahneman's dual-system framework, Jens Rasmussen's safety boundaries, and John Sweller's cognitive limits, we transform the NICU from an environment of chaos into a structured, highly reliable ecosystem. It ensures that when human cognition inevitably encounters its limits under pressure, our collective safety architecture holds firm, sending everyone, from our fragile patients to our frontline caregivers, home at the end of the day **Safe, Valued, and Loved.**

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Disclosures: *The authors have no disclosures*

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

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

Your Pregnancy and Substance Use

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

Get Prenatal Care

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

Reduce Your Use

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

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

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

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

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

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

Take Good Care of Yourself

You deserve a healthy pregnancy & childbirth.

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

Your Health Matters

Academy of Perinatal Harm Reduction

National Perinatal Association

www.perinatalharmreduction.org | www.nationalperinatal.org

The Village Son

A Life's Journey

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

Houchang D. Modanlou

First Candle: First Candle's Let's Talk Community Chats Program has been Named a Promising Practice by the Association of Maternal and Child Health Programs (AMCHP)

Alison Jacobson

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.

"I am proud to share that First Candle's Let's Talk Community Chats program has been named a Promising Practice by the Association of Maternal and Child Health Programs (AMCHP). This designation is a genuine milestone as very few community-designed programs earn recognition at this level."

I am proud to share that First Candle's Let's Talk Community Chats program has been named a **Promising Practice** by the Association of Maternal and Child Health Programs (AMCHP). This designation is a genuine milestone as very few community-designed programs earn recognition at this level.

If you are not familiar with AMCHP, they are the national organization representing state maternal and child health leaders who shape MCH policy and programming across the country. Their Innovation Hub maintains a national database of practices that have shown real, replicable impact for families. Being included means AMCHP reviewed our model, outcomes, and approach, and is now recommending it to states and communities looking for programs that work.

For us, this recognition validates something we have believed from the start: **that safe sleep education only works when it comes from people families already trust.**

"We build a Community Action Network of local doulas, lactation consultants, faith leaders, and people with lived experience to understand what a community actually needs. Then we train facilitators who already look like and are trusted by the families they are reaching, to lead open, honest conversations about safe sleep, breastfeeding, perinatal mental health, and the real pressures shaping how families make decisions for their babies."

Let's Talk Community Chats is not a curriculum we bring in from outside. We build a Community Action Network of local doulas, lactation consultants, faith leaders, and people with lived experience to understand what a community actually needs. Then we train facilitators who already look like and are trusted by the families they are reaching, to lead open, honest conversations about safe sleep, breastfeeding, perinatal mental health, and the real pressures shaping how families make decisions for their babies.

The results speak for themselves:

- 98% of participants felt comfortable engaging with facilitators.
- 96% found the safe sleep and breastfeeding information helpful.
- Back sleeping increased from 40% to 60% within one month of attending.
- 80% reported making at least one positive change to their

baby's sleep environment.

This designation from AMCHP is not just an honor; it is a tool. It gives our affiliate partners, funders, and community collaborators independent confirmation that this model is worth investing in and worth replicating.

"This designation from AMCHP is not just an honor; it is a tool. It gives our affiliate partners, funders, and community collaborators independent confirmation that this model is worth investing in and worth replicating."

You can view our full listing in AMCHP's Innovation Hub here: https://amchp.org/database_entry/lets-talk-community-chats/

Thank you for being part of this work with us. Recognition like this belongs to every facilitator, partner, and parent who has trusted us along the way.

References:

1. https://amchp.org/database_entry/lets-talk-community-chats/
2. https://firstcandle.org/programs/lets-talk-community-chats/
3. https://amchp.org/database_entry/lets-talk-community-chats/

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

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About First Candle:

First Candle, based in New Canaan, CT, is a 501c (3) committed to eliminating Sudden Unexpected Infant Death while providing bereavement support for families who have suffered a loss. Sudden Unexpected Infant Death (SUID), which includes SIDS and Accidental Suffocation and Strangulation in Bed (ASSB), remains the leading cause of death for babies one month to one year of age, resulting in 3,700 infant deaths nationwide per year. It 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.

NEW LIVE VIRTUAL TRAINING

Trauma-Informed Bereavement Support for Hospital Teams

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

DATE
TUESDAY, OCTOBER 13, 2026

TIME
12:00 – 2:00 PM ET

FORMAT
Live Virtual Training

INCLUDES
Certificate of Completion

DESIGNED FOR

- Nurses
- Social Workers
- Physicians
- Chaplains
- Patient Experience Teams
- NICU & Labor & Delivery Staff

REGISTER TODAY! →

Better support.
Stronger teams.
Compassionate care.

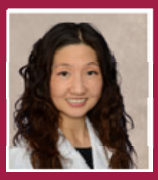
Peer Reviewed

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

Clara H. Song, MD, FAAP

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

SECTION ON NEONATAL-PERINATAL MEDICINE



SoNPM Chair Update

with Clara Song, M.D., FAAP

SONPM SHOUT OUT

Dr. Birju Shah, MD, MPH, MBA, FAAP

Dr. Birju Shah MD MPH MBA FAAP is one of the founding planning group members of the country's first and only conference that focuses on neonatal resuscitation, the Annual Neonatal Resuscitation #NeoResus Symposium! Birju is the Director of Clinical and Translational Research at the University of Oklahoma. He works alongside other neonatal resuscitation experts on the #NeoResus planning committee- check it out!

Neonatal Resuscitation Symposium

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

1

Submitted by

David Kanter, MD, MBA, CPC

on behalf of the

SONPM Coding Committee

Coding Corner #14: Transport Supervision

Presentation: a neonatologist at a fellowship GME teaching hospital agrees to accept a critical baby transfer from a referring hospital. The receiving hospital transport team (a neonatology fellow, nurse, and RT) spends 30 min with the baby at the referring hospital and 60 min with the baby in transit to the receiving hospital. The receiving, teaching physician (termed by CPT as the control physician) provides transport team supervision encompassing 15 min of initial team briefing before transport team departure from the receiving hospital, 10 minutes of phone communication with the team at the referring hospital, and 5 of minutes communication with the team while en route to the receiving hospital. How does the control physician bill transport services for supervision of the transport team inclusive of the fellow who is on transport?

CPT coding for the receiving neonatologist:

Service	CPT	Descriptor	Comment
Initial day admission care	99468	Initial day neonatal critical care ? 28d	
Transport services	99485	Control physician supervision of interfacility critical transport ? 24 months, first 30 min	Time-based service includes communication with transport team before transport, at the referring hospital, and during transport.

Rationale:

- Physicians and qualified health care professionals (QHP, such as nurse practitioners) may bill for face-to-face time with the critical patient during interfacility transport using 99466 for the first 30-74 minutes of hands-on care and 99467 for each additional 30 minutes. In the above scenario, the neonatal fellow is fulfilling training program responsibilities, is not moonlighting outside of training, and thus cannot separately bill for face-to-face transport services.
- CMS teaching physician guidelines allow the teaching physician to bill for services performed by the fellow so long as certain conditions are met including participation in key or critical portions of the service. Teaching physicians designate such services by appending modifier GC to the CPT code on the claim. Furthermore, for the teaching physician to bill for time-based services performed by the fellow, the teaching physician must be physically present throughout the length of billed time. Therefore, the teaching physician cannot bill 99466 face-to-face presence on behalf of the fellow because the teaching physician did not participate in key or critical portions of the service (in this case, physical presence) and was not physically present through the length of a time-based service.
- CPT 99485 represents the first 30-45 minutes of control physician supervision of a critical transport. An additional 99486 code is available for time that exceeds 45 minutes. Consistent with CPT guidance, unless otherwise specified in the code descriptor, a unit of time is attained when the midpoint is

passed. Thus, the control physician can bill 99485 for at least 16 minutes of communication time. 99485 accrued time is based on 2-way communication with the transport team during team briefing prior to transport, for team discussion when evaluating the baby at the referring hospital, and for team communication during transport back to the receiving hospital. 99485 represents

communication time and not total transport time. 99485 represents control physician communication with the transport team and does not include communication between the control physician and referring hospital staff. As with any time-based code, to bill 99485, the control physician would document in the baby's admit note the time spent on communication.

- Regarding 99485 transport supervision, CPT does not dictate staffing of the specialized transport team. In addition, CPT states: *"Services provided by the specialized transport team during non-face-to-face transport supervision are not reported by the control physician."* Unlike the Teaching Physician guidelines where CMS dictates when the teaching physician can bill for services performed by the resident, the 99485 vignette above is not a scenario where the control physician is acting as a teaching physician, and it is not a scenario where the control physician is billing a service performed by the resident. Instead, the control physician is billing a service solely performed by the control physician: supervision of the specialized team—regardless of team personnel. In this transport vignette, the fellow's time does not apply at all in calculating 99485 supervision time, and without a teaching physician present on transport, the fellow's face-to-face time is not 99466 billable—unless of course if the fellow instead was working as a contracted moonlighting physician outside of GME training.
- If the neonatology group had a scenario by which it was able to bill 99466 transport physical presence such as through transport presence of one of the group's employed physicians or QHPs, the group would not also bill 99485 supervision based on a CMS NCCI edit that prevents the concurrent billing of both those codes by the same group for the same patient's transfer.

Pediatric Subspecialty Survey

The Review Committee for Pediatrics is preparing to begin the major revision process for the pediatrics subspecialty Program Requirements, with an anticipated effective date of July 1, 2029. The Committee recognizes that this timeline differs from the American Board of Pediatrics (ABP)'s timeline for its new competency-based medical education model for certification. ACGME and Review Committee leadership are in communication with the ABP's leadership to discuss options that would allow fellows starting in July 2028 to pursue a two-year pathway toward ABP certification, before the revised Program Requirements take effect.

The Review Committee is seeking a high level of community input throughout the revision process, including through a survey and a summit with representatives from pediatrics and pediatrics subspecialty organizations. Feedback from the survey and summit will guide requirement development. A draft of the proposed new Program Requirements is expected to be posted for public review and comment in late 2027, prior to finalization by the Review Committee and approval by the ACGME Board of Directors.

Pediatric Subspecialty Survey - Open Through August 24

Learn More

Your Vote Matters

The AAP will host a virtual town hall at **7:00 PM CT 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. This one-hour session will feature remarks from the candidates and a live Q&A. Registration is required, and you'll have the opportunity to submit questions during that process.

Register Here!

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 - Fiscal Sustainability for Perinatal SUD Programs

Join AMCHP and our partners from Team Lily on **August 27, from 3:00 – 4:30 PM ET** for an interactive workshop on strategies, tools, and resources to support long-term program sustainability in the perinatal SUD space. This session will focus on fiscal sustainability and practical strategies to secure the resources needed for long-term program success.

What to Expect

Participants should:

- Be prepared to engage!
- Come with a particular perinatal SUD program or initiative in mind

Participants will:

- Learn about sustainability tools and resources to apply to your program.
- Hear real-world insights and lessons learned on sustaining perinatal SUD initiatives.
- Spend dedicated time in breakout groups with presenters.
- Explore strategies to strengthen the fiscal sustainability of your program.

Questions? Email hteizazu@amchp.org

Learn More and Register

AAP Training: GHEARD: From Learning to Leading

AAP is hosting "*GHEARD: From Learning to Leading*," a virtual GHEARD facilitator training, on Friday, August 28, 2026, from 10:00 AM–3:00 PM CT, and **registration is now open!** Please consider joining us and sharing this opportunity with members of your sections, councils, and committees.

This training is designed for global health professionals in any setting—especially those implementing GHEARD or interested in bringing the curriculum to their institution. You'll leave with concrete teaching and facilitation techniques, adaptable curricular resources, and strategies to build more equitable and collaborative global health partnerships! GHEARD was developed by the AAP, the Association of Pediatric Program Directors, and the Consortium of Universities for Global Health. It equips global health professionals with practical tools to address historical and current health inequities in global health training.

Through interactive activities, video-based case scenarios, and small-group discussions, participants will:

- Familiarize yourself with GHEARD content and activities.
- Define decolonization in global health education and analyze how colonial legacies have shaped power dynamics, equity, and ethical training practices.
- Apply principles and curricular elements from the Global Health Education for Equity, Anti-Racism, and Decolonization (GHEARD) curriculum to strengthen global public health practice.
- Earn up to 3.50 *AMA PRA Category 1 Credits*™

Workshop Information
Title**:** GHEARD: From Learning to Leading
Date: Friday, August 28th, 2026
Time: 10:00 AM – 3:00 PM CT
Location: Live Virtual Event
Cost**:** $100
Registration Link: https://www.aap.org/en/catalog/categories/advocacy-and-international-health/gheard-from-learning-to-leading/
Questions? Email: gheard@aap.org

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

Volunteer Opportunities

Making our voices count starts with having a seat at the table. Explore the volunteer opportunities below and consider how you can help make an impact.

American Medical Association Alternate Delegate Opportunity

The American Academy of Pediatrics has a delegation of AAP members who represent the Academy in the American Medical Association House of Delegates. The AAP Executive Committee is seeking nominations for an alternate delegate to serve beginning with the November 2026 AMA Interim meeting.

Criteria for appointment:

- Member of the AAP.
- Member of the AMA.
- Practicing pediatrician or academician.
- Involvement in AAP chapters, national committees, councils, or sections
- Involvement in AMA and State medical society activities.
- Excellent communication skills and public speaking skills.
- Strong leadership skills, including the ability to build consensus with issues.
- Knowledge and familiarity with AAP policies, technical/clinical reports, and manuals.
- Ability to respond to issues and requests promptly.
- Ability to represent the Academy at two in-person AMA meetings per year.
- Understanding of the child health care and medical education systems, and of the influences of social, economic, political, and cultural issues on the health and health care of children, youth and families.

Facts Sheet Member 2026

Delegation members are appointed by the AAP Executive Committee for a 3-year term and may be reappointed every three years for a total lifetime service of 24 years.

Interested candidates are asked to complete the attached fact sheet and provide their curriculum vitae. Please return both documents to Katie Friedman (kfriedman@aap.org) **by August 21, 2026.**

Please feel free to contact Katie if you have any questions.

Accreditation Council for Graduate Medical Education (ACGME)

The **Accreditation Council for Graduate Medical Education (ACGME)** is seeking nominations for an AAP member to serve on its **Review Committee for Pediatrics (RC-Peds)**. The six-year term will run from **July 1, 2027, through June 30, 2033**.

Eligible nominees should be board-certified pediatricians or pediatric subspecialists with significant graduate medical education leadership experience, including service as a program director, designated institutional official, or in a comparable role. Please refer to **RC-Peds Nominee Qualifications** for additional eligibility requirements.

To apply, we kindly request eligible candidates complete the RC-Peds Nominee Form and submit it, along with a current CV, to Natasha Karpasov at nkarpasov@aap.org no later than August 15, 2026.

The RC-Peds is responsible for establishing accreditation and recognition standards and conducting peer review of sponsoring institutions, residency programs, and fellowship programs. The ACGME's mission is to continuously improve graduate medical education by developing and monitoring professional educational standards that prepare physicians to provide safe, high-quality care. To learn more about the RC-Peds and the ACGME, please visit **www.acgme.org**.

Good Reads

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

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

Resuscitation of neonatal critical care: a call for identity and course correction

Read the following article on Journal of Perinatology.

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

ONTPD (Organization of Neonatal Training Program Directors)- Drs. Melissa Scala and Brooke Vergales

AANDD (Association of Academic Neonatal Division Directors)- Drs. Misty Good and Patrick McNamara

TECaN (Trainees and Early Career Neonatologists)- Dr. Theresa Urbina

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	***Action #2***	**Action #3**
Payment Transparency for Neonatal Codes	***Coding Education to Ensure Full Payment***	

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

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.

RG payments for optimal NICU payment

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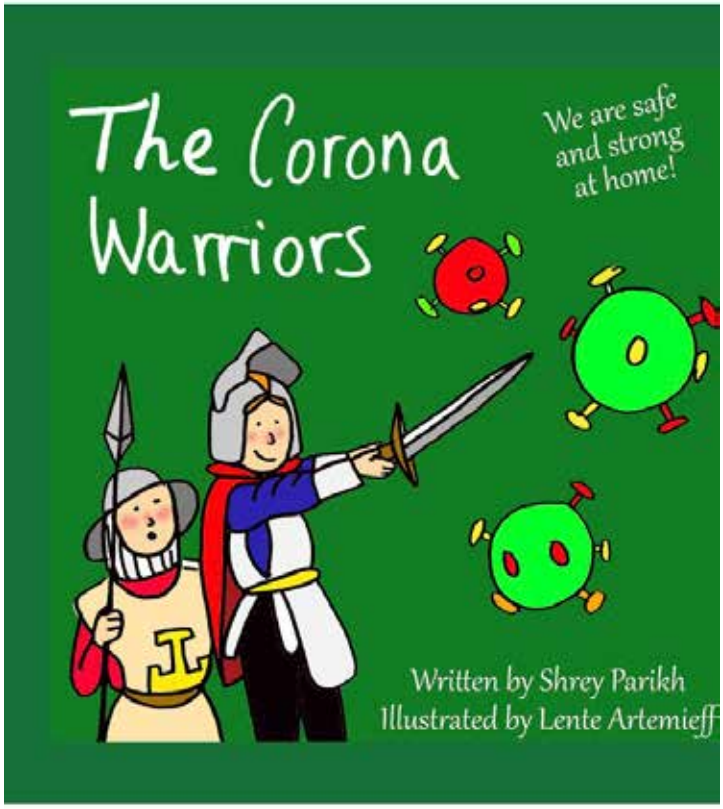

Call for Nominations!

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.

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Letters to the Editor

Letter to the Editor: "Neonatal Herpes: A Brief Review and Cautions for the Provider"

Dear Editor,

We thank the authors of the case study for a clinically important and thoughtfully presented contribution. We also thank the editorial team and Dr. Goldstein for the opportunity to explore the depth of neonatal herpes and write this commentary. It is a privilege to add to the discussion on a condition as consequential as neonatal herpes.

"On review, we found the paper to be an educationally and clinically significant piece whose central message is well-supported: neonatal HSV must remain on the differential even when maternal history is negative."

The case study described a preterm infant who developed disseminated HSV-1 infection and died on day of life 10 despite an entirely negative maternal herpes history — a course initially indistinguishable from bacterial sepsis. On review, we found the paper to be an educationally and clinically significant piece whose central message is well-supported: neonatal HSV must remain on the differential even when maternal history is negative. We also identified three areas that would strengthen it. First, the diagnostic presentation could be more complete — the case rests on a positive HSV culture without the fuller AAP/CDC/ACOG evaluation (surface swabs, blood cultures, ALT, cerebrospinal fluid PCR, and whole-blood PCR) or categorization into skin-eye-mouth, CNS, or disseminated disease, a distinction that matters because disseminated disease carries the highest mortality and may present with atypical multi-organ involvement. Second, the stated incidence of approximately 1 in 3200 deliveries overstates recent U.S. estimates of roughly 9.8 to 15.7 per 100,000. Third, while educational, the paper stops short of proposing a concrete framework—such as a specific trigger for empiric acyclovir—that could help establish a standard of care.

"Third, while educational, the paper stops short of proposing a concrete framework—such as a specific trigger for empiric acyclovir—that could help establish a standard of care."

These findings translate readily into practice. In the ill neonate after the first days of life, clinicians should obtain the complete HSV diagnostic panel and work to categorize the disease type rather than stopping at a single confirmatory test, since management and prognosis differ by category. Risk counseling and index of suspicion should be anchored to current epidemiology rather than older, higher incidence figures. Above all, providers should maintain a low and explicit threshold to begin empiric acyclovir while HSV testing is pending — irrespective of maternal history — as early diagnosis and early treatment remain the principal determinants of outcome.

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Hyeonung Cho, OMS-III

Western University of Health Sciences, Pomona, CA .

"Neonatal herpes simplex virus infection remains one of the most challenging diagnoses in neonatology precisely because its initial presentation can be deceptively nonspecific, and the consequences of delayed recognition can be devastating. "

Dear Hyeonung Cho,

Neonatal herpes simplex virus infection remains one of the most challenging diagnoses in neonatology precisely because its initial presentation can be deceptively nonspecific, and the consequences of delayed recognition can be devastating. The authors appropriately reinforce an important clinical principle: a negative maternal history does not meaningfully exclude neonatal

HSV infection, and clinicians caring for an ill newborn must maintain an appropriately high index of suspicion.

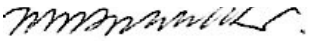
The letter also makes several useful contributions by identifying areas in the original case report that could have been developed further. In particular, the emphasis on distinguishing disseminated, central nervous system, and skin, eye, and mouth disease is clinically important, as these categories have implications for evaluation, treatment, and prognosis. The authors are also correct to highlight contemporary epidemiologic data and the danger of relying on older incidence estimates. Their recommendation that clinicians consider empiric acyclovir early in an appropriately concerning clinical presentation is particularly pertinent.

"While the principle is sound, neonatal HSV evaluation is inherently contextual, and a rigid algorithm may not adequately account for gestational age, clinical presentation, timing of illness, maternal and perinatal circumstances, laboratory findings, and the availability and expected turnaround time of diagnostic testing. Empiric treatment should be guided by the totality of the clinical picture rather than by a single finding or an overly prescriptive threshold. "

That said, I offer modest caution regarding the letter's characterization of a "specific trigger" for empiric acyclovir and its suggestion that providers maintain a universally "low and explicit threshold" for treatment. While the principle is sound, neonatal HSV evaluation is inherently contextual, and a rigid algorithm may not adequately account for gestational age, clinical presentation, timing of illness, maternal and perinatal circumstances, laboratory findings, and the availability and expected turnaround time of diagnostic testing. Empiric treatment should be guided by the totality of the clinical picture rather than by a single finding or an overly prescriptive threshold. The balance is important: missing neonatal HSV can be catastrophic, but indiscriminate treatment of every ill neonate also carries consequences.

Overall, this is a strong and worthwhile letter. It demonstrates the value of thoughtful critical review of the literature while translating epidemiologic and diagnostic considerations into practical bedside reasoning. I particularly commend Hyeonung Cho for approaching the subject with the maturity and clinical curiosity expected of a physician in training. His comments demonstrate that careful reading of the literature should not simply confirm what we already believe; it should prompt us to question assumptions, examine the evidence, and consider how our knowledge can improve clinical care. *Neonatology Today* is pleased to publish this contribution to the ongoing discussion of neonatal HSV and the continuing effort to recognize and treat this potentially devastating infection as early as possible.

Sincerely,



Mitchell Goldstein, MD, MBA, CML

Editor in Chief

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Erratum (Neonatology Today July, 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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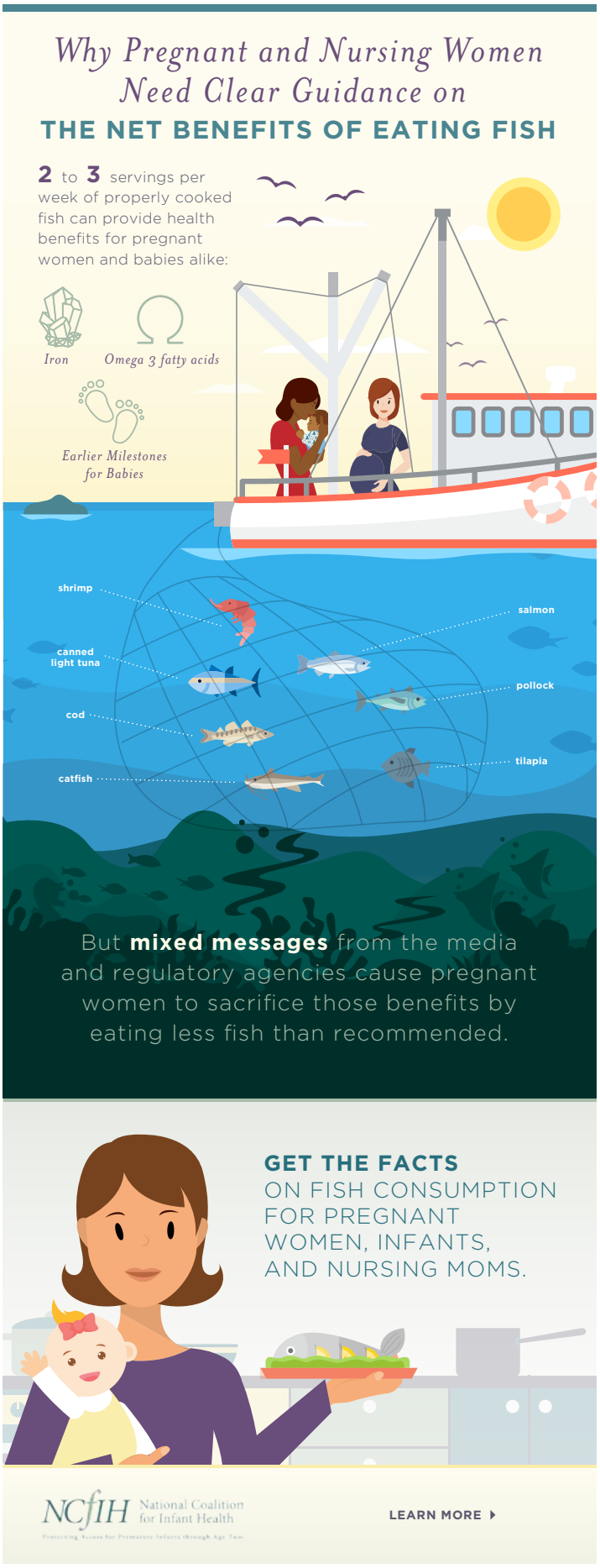
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Babies are just tiny adults, right? So ... half?
Infants need drugs tested and approved just for them.

Gravens by Design: Technology Defines the Modern NICU; the NICU Should be More Connected, Not Simply More Complicated

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

"Not very long ago, the technological centerpiece of most NICUs was a single bedside monitor connected to a ventilator and perhaps a computer in the corner of the unit that could access the internet over a painfully slow modem."

Not very long ago, the technological centerpiece of most NICUs was a single bedside monitor connected to a ventilator and perhaps a computer in the corner of the unit that could access the internet over a painfully slow modem. Today, virtually every infant is surrounded by a network of sophisticated devices that continuously collect physiologic information, communicate with hospital servers, document events in the electronic health record (EHR), and increasingly use artificial intelligence to help clinicians recognize subtle changes before they become clinically apparent. (1)

Technology has fundamentally changed how neonatal intensive care is delivered. Yet, in many ways, the digital infrastructure supporting these remarkable advances has not kept pace. We have become extraordinarily good at collecting information, but far less effective at sharing it securely, integrating it seamlessly, and using it to strengthen communication between caregivers and families.

The NICU of the future will not be defined simply by newer monitors or smarter ventilators. It will be defined by how well those technologies work together.

"The NICU of the future will not be defined simply by newer monitors or smarter ventilators. It will be defined by how well those technologies work together."

Beyond Pulse Oximetry

Perhaps no technology better illustrates this evolution than pulse oximetry. When pulse oximetry first entered the NICU, continuous measurement of arterial oxygen saturation was a remarkable advance. Today, pulse oximetry is almost taken for granted.

Modern systems, however, have moved well beyond measuring oxygen saturation alone. A non-invasive Pulse CO-Oximetry platform, for example, demonstrates how a familiar technology can evolve into a much richer source of physiologic information. Using multiple wavelengths of light, these monitors can continuously estimate total hemoglobin concentration (SpHb), carboxyhemoglobin, methemoglobin, and oxygen content in addition to conventional oxygen saturation. Although not intended to replace laboratory measurements in every circumstance, these continuous non-invasive trends provide clinicians with information that previously required repeated blood sampling. (2)

"For premature infants, where every milliliter of blood matters, this evolution is particularly meaningful. Continuous assessment of hemoglobin trends may reduce laboratory blood loss, enable earlier recognition of anemia or occult bleeding, and support more thoughtful transfusion practices."

For premature infants, where every milliliter of blood matters, this evolution is particularly meaningful. Continuous assessment of hemoglobin trends may reduce laboratory blood loss, enable earlier recognition of anemia or occult bleeding, and support more thoughtful transfusion practices. Monitoring methemoglobin has become increasingly important when nitric oxide therapy or oxidizing medications are used, while carboxyhemoglobin measurements may prove valuable in selected clinical situations involving smoke exposure or hemolysis. The future may not involve more blood tests—it may involve fewer. (3, 4)

Looking Beyond the Number

Similarly, clinicians are beginning to recognize that the waveform itself may be as valuable as the numeric value displayed on the monitor.

The Pleth Variability Index (PVI), derived from pulse oximetry, estimates perfusion index variation in the plethysmographic waveform and provides insight into intravascular volume responsiveness. Although its application in neonates continues to be investigated, technologies such as PVI illustrate an important principle: bedside monitors are evolving from simple measurement devices into sophisticated physiologic interpreters. (4)

Rather than asking, "What is the oxygen saturation?" clinicians may increasingly ask, "What does this integrated physiologic profile tell us about perfusion, oxygen delivery, and cardiovascular stability?" This shift represents a movement away from isolated measurements toward integrated physiology.

"The Pleth Variability Index (PVI), derived from pulse oximetry, estimates perfusion index variation in the plethysmographic waveform and provides insight into intravascular volume responsiveness. Although its application in neonates continues to be investigated, technologies such as PVI illustrate an important principle: bedside monitors are evolving from simple measurement devices into sophisticated physiologic interpreters. (4)"

Smarter Alarms Rather Than More Alarms

Alarm fatigue has become one of the defining challenges of modern intensive care. Hundreds of alarms may sound each day in a busy NICU, many of which do not require immediate intervention. The consequence is predictable: clinicians become desensitized, response times lengthen, and truly important alarms risk being overlooked.

The solution is not necessarily fewer alarms—it is smarter alarms.

"Three-dimensional alarm systems are beginning to demonstrate how technology can communicate urgency more effectively. Rather than relying solely on increasingly louder tones, 3D auditory alarms use spatial audio to indicate where an alarm originates and how critical it is. Combined with intelligent alarm prioritization and AI-assisted filtering, these systems may substantially reduce alarm fatigue while improving clinician situational awareness."

Three-dimensional alarm systems are beginning to demonstrate how technology can communicate urgency more effectively. Rather than relying solely on increasingly louder tones, 3D auditory alarms use spatial audio to indicate where an alarm originates and how critical it is. Combined with intelligent alarm prioritization and AI-assisted filtering, these systems may substantially reduce alarm fatigue while improving clinician situational awareness. Moreover, certain technologies can be adapted to better monitor the visual applicability of known parameters such as perfusion, although this may depend on standardization and the ability to recognize subtle changes in skin perfusion not related to skin coloration or maturity. (5)

Future systems may integrate multiple physiologic variables simultaneously before generating an alert. Instead of responding to isolated threshold violations, alarms could identify clinically meaningful patterns such as evolving sepsis, progressive respiratory failure, or impending hemodynamic instability. The monitor of the future will not simply report abnormalities; it will recognize them.

"Future systems may integrate multiple physiologic variables simultaneously before generating an alert. Instead of responding to isolated threshold violations, alarms could identify clinically meaningful patterns such as evolving sepsis, progressive respiratory failure, or impending hemodynamic instability. The monitor of the future will not simply report abnormalities; it will recognize them."

Family Presence Should Mean More Than Watching

Technology has also transformed the relationship between families and the NICU.

One of the most successful examples is AngelEye, which has shown that secure bedside video can reassure families who cannot be physically present with their infant. For many parents, especially those recovering from complicated deliveries or living long distances from tertiary referral centers, the ability to see their baby at any hour has become invaluable.

Programs such as AngelEye have consistently shown that remote viewing decreases parental anxiety, strengthens family engagement, and enhances satisfaction with care. Importantly, these systems have demonstrated that secure video communication can be implemented while maintaining patient privacy and institutional security.

However, watching is not the same as participating. Current camera systems remain largely one-directional. Parents observe their infant but rarely become active participants in the bedside experience.

The next step is obvious. Families should be able to join multidisciplinary rounds from home, participate in bedside discussions, meet consultants remotely, receive developmental

care instruction, and engage in discharge teaching regardless of geographic location. Grandparents serving as caregivers, deployed military parents, siblings unable to visit during respiratory virus season, and family members living internationally should all have opportunities to participate when appropriate. (6) Technology should allow families not simply to see their infant but to remain part of the infant's daily life.

The NICU as a Connected Digital Ecosystem

Achieving this vision requires more than installing cameras or upgrading wireless networks. It requires rethinking the NICU as an integrated digital ecosystem.

"Every connected device—from ventilators and infusion pumps to ultrasound machines, EEG systems, and bedside monitors—must communicate securely with the EHR and with one another. High-acuity Level IV NICUs increasingly transmit large imaging files, continuous waveform data, point-of-care ultrasound examinations, tele-echocardiography, and remote consultations in real time."

Every connected device—from ventilators and infusion pumps to ultrasound machines, EEG systems, and bedside monitors—must communicate securely with the EHR and with one another. High-acuity Level IV NICUs increasingly transmit large imaging files, continuous waveform data, point-of-care ultrasound examinations, tele-echocardiography, and remote consultations in real time. Artificial intelligence applications will add yet another layer of computational demand. (7)

This change requires robust, redundant, high-bandwidth networks designed specifically for clinical operations, not adapted from public hospital Wi-Fi. Single-family room NICUs, while offering tremendous developmental and privacy benefits, also present engineering challenges. Larger footprints require additional wireless access points, seamless roaming, redundancy, and continuous monitoring to eliminate coverage gaps. Infrastructure is no longer simply an information technology concern—it has become an essential component of patient safety. (8)

Trust Must Accompany Connectivity

As communication becomes increasingly digital, ensuring clinicians communicate with the correct individuals becomes equally important.

Artificial intelligence has introduced remarkable opportunities, but it has also introduced unprecedented risks. Voice cloning, deepfake video, and sophisticated identity spoofing mean that future communication platforms cannot assume that every participant is who they claim to be. (7)

Hospitals will increasingly need secure authentication systems incorporating multi-factor authentication, verified devices, encrypted communication channels, and role-based access controls. Family access should be straightforward but carefully verified. These safeguards should be incorporated directly into bedside communication platforms and the EHR rather than relying on consumer video applications. Trust must become a designed feature of the connected NICU.

"EWe should move beyond thinking of technology as a collection of individual devices and instead view it as an interconnected platform that supports every aspect of neonatal care. Continuous multimodal physiologic monitoring, non-invasive measurement of oxygen delivery and hemoglobin status, intelligent alarm management,"

A Path Forward:

The technological NICU of the next decade will not be built around any single innovation. It will emerge from the thoughtful integration of monitoring, communication, analytics, and family engagement into a cohesive whole.

We should move beyond thinking of technology as a collection of individual devices and instead view it as an interconnected platform that supports every aspect of neonatal care. Continuous multimodal physiologic monitoring, non-invasive measurement of oxygen delivery and hemoglobin status, intelligent alarm management, AI-assisted clinical decision support, secure telepresence, interoperable electronic health records, and robust cybersecurity are not separate initiatives—they are components of the same vision. (8)

Ultimately, the measure of technological progress will not be how many devices surround an infant's bedside, but whether those technologies improve outcomes, reduce clinician burden, strengthen communication, and keep families connected to their newborn when they need it most.

The technologically aware NICU is not one filled with gadgets. It is one in which every technology serves a clear purpose: delivering safer, smarter, more humane, and more connected care.

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Disclosures: *The authors have no conflicts of interest to disclose*

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

Leadership

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

Advocacy

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

Consultation

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

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

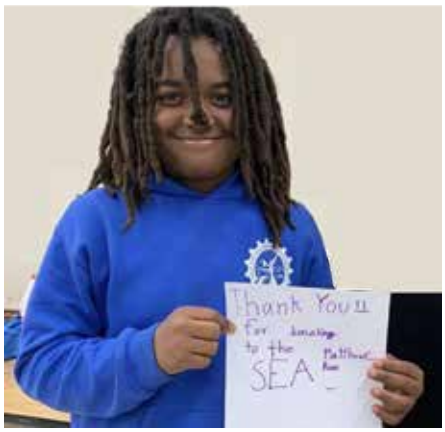
Thirteen-year-old Emily Rose Shane was tragically murdered on April 3, 2010 on Pacific Coast Highway in Malibu, CA. Our foundation exists to honor her memory.

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: Keeping the Focus on Congenital CMV:

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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Natasha Bonhomme	Expecting Health
Deb Discenza, MA	PreemieWorld
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Camille Torre, DNP, CCRN-N	The Council of International Neonatal Nurses

"June marked National Cytomegalovirus, or CMV, Awareness Month, bringing much-needed attention to a condition that remains unfamiliar to many families despite being one of the leading causes of congenital disabilities in the United States."

June marked National Cytomegalovirus, or CMV, Awareness Month, bringing much-needed attention to a condition that remains unfamiliar to many families despite being one of the leading causes of congenital disabilities in the United States. While the awareness month has ended, the need to educate families, improve newborn screening, and expand access to early intervention continues throughout the year.

Congenital CMV occurs when a pregnant person passes the common cytomegalovirus to their developing baby. For most healthy adults, CMV causes few or no symptoms. During pregnancy, however, the virus can lead to pregnancy loss, developmental disabilities, and lifelong medical conditions for the baby. According to the National CMV Foundation, congenital CMV affects approximately one in every 200 newborns and is the most common infectious cause of congenital disabilities in the United States. Hearing loss is among its most common long-term effects.

Why Screening Is Critical:

The first few weeks of life present a critical opportunity to identify congenital CMV. Because diagnosis must occur within the first 21 days after birth to confirm congenital infection, timely newborn screening allows clinicians

to monitor infants closely and begin interventions that may improve developmental outcomes. The National CMV Foundation's newborn screening resources highlight how early identification can connect families to hearing evaluations, developmental services and appropriate medical follow-up before symptoms worsen.

"The National CMV Foundation's newborn screening resources highlight how early identification can connect families to hearing evaluations, developmental services and appropriate medical follow-up before symptoms worsen."

Unfortunately, screening practices vary widely depending on where a baby is born. As the National CMV Foundation notes, a child's ZIP code should not determine whether they have access to an early diagnosis.

Expanding Access to Screening:

Awareness alone is not enough to improve outcomes. Policies that expand newborn screening, strengthen clinician education, and support research can help ensure more infants receive timely diagnoses and appropriate care. One example is the bipartisan Stop CMV Act, which would encourage hospitals to screen infants for congenital CMV within 21 days of birth while supporting data collection, research, and clinician training.

"Awareness alone is not enough to improve outcomes. Policies that expand newborn screening, strengthen clinician education, and support research can help ensure more infants receive timely diagnoses and appropriate care. One example is the bipartisan Stop CMV Act, which would encourage hospitals to screen infants for congenital CMV within 21 days of birth while supporting data collection, research, and clinician training. "

Congenital CMV Awareness Month may be over, but the work is far from finished. Continued education, expanded screening and evidence-based policy can help more children receive the early care they need to reach their full potential.

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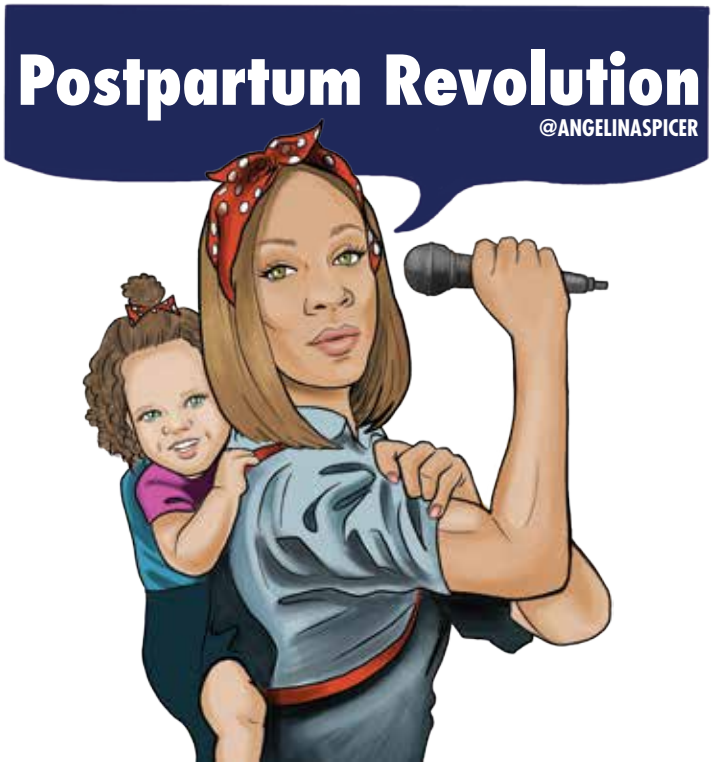
National Coalition for Infant Health Values (SANE)

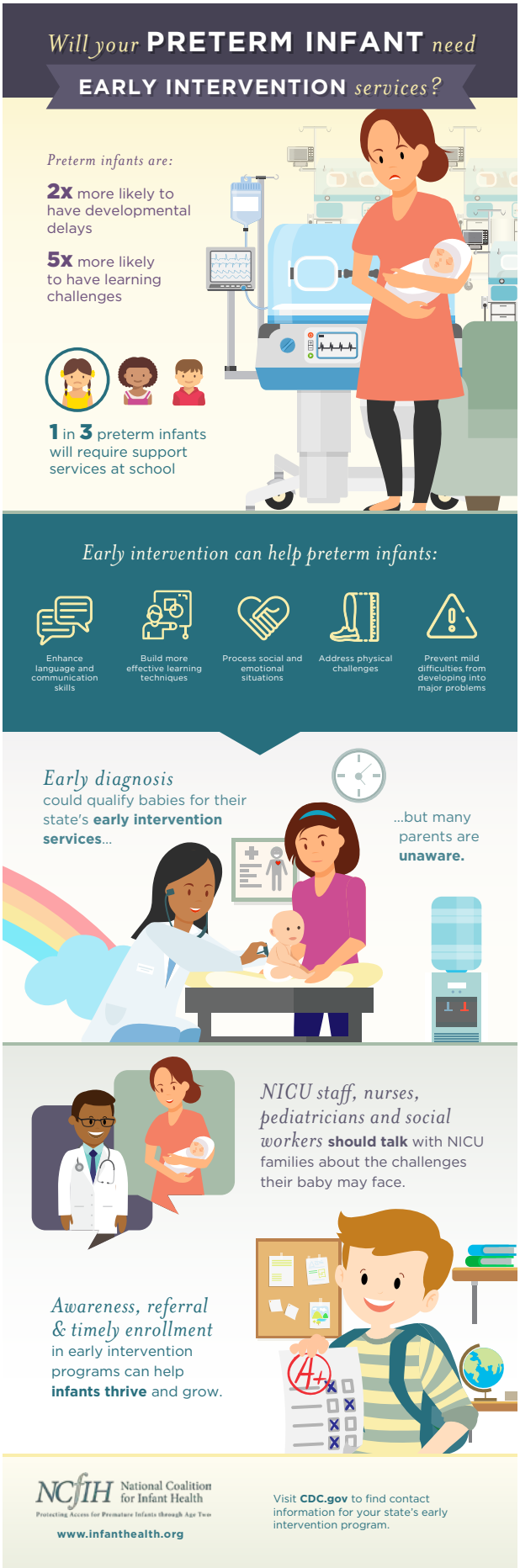
Safety. Premature infants are born vulnerable. Products, treatments and related public policies should prioritize these fragile infants' safety.

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 IFCDC Standards: Foundations of Development for growing babies in the NICU

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

Underlying the implementation of Infant and Family Centered Developmental Care (IFCDC) standards, competencies, and best practices (1, 2) (https://nicudesign.nd.edu/nicu-care-standards/) is a necessary understanding of babies' development. Early-born babies' development unfolds as a continuum, with the main determinants of physiology, behavior, and social/emotional aspects emerging with maturation. A focus on physiological changes during the baby's hospitalization is necessary in intensive care, yet behavioral organization and social/emotional development are emerging simultaneously. An informed approach to supporting all three aspects of development should be understood and applied, as they form the foundation essential for later developmental progress.

"A focus on physiological changes during the baby's hospitalization is necessary in intensive care, yet behavioral organization and social/emotional development are emerging simultaneously. An informed approach to supporting all three aspects of development should be understood and applied, as they form the foundation essential for later developmental progress."

Biophysiologic development in early born babies

Well-known physiologic adaptations accompany the shift at birth from fetal to newborn life and into a new environment. (3) Significant physiological and neurochemical autonomy and perceptual sensitivities at birth are known to influence later behavior. Weiss describes these shifts as "the most significant biobehavioral shift that an individual experiences in a lifetime." (4)

For the early-born baby, physiologic changes at birth are more challenging, necessitating medical and nursing interventions to ensure stability and optimal development. As the baby grows and approaches term, and in preparation for discharge, physiologic maturation is demonstrated by temperature regulation, feeding progression, and respiratory stability. (5)

Until recently, the physiologic development of very early-born babies had not been specifically described. Tan (6) has detailed four "biologic windows of prematurity across organ systems" of babies from early viability to term. He has also provided a perspective on how care must shift in line with understanding of these developmental changes. Newly identified physiological shifts reflect sensitive areas of development at each post-menstrual age and are most susceptible to environmental disruption.

"Newly identified physiological shifts reflect sensitive areas of development at each post-menstrual age and are most susceptible to environmental disruption."

Emerging behavioral development in the early born baby

Changes in behavior help identify sensitivities to environmental and social interactions, as well as emotional responsiveness, in babies of all post-menstrual ages. Heidelise Als described babies' behavioral communication and detailed the importance of identifying identifiable developmental goals. Her findings led to an understanding of emerging behavioral organization during the early weeks after birth. (7–9) Als's approach is especially important when considering the differences in severity of illness, environmental intrusiveness, and caregiving practices. Als's model does not identify aspects of behavior specific to post-menstrual age; instead, it describes how behavioral communication is individualized for each baby and situation. However, astute clinical observations by professionals clearly indicate that there is

a developmental progression in the regulation of behavior in most early-born babies.

"However, astute clinical observations by professionals clearly indicate that there is a developmental progression in the regulation of behavior in most early-born babies."

Emerging social and emotional development in the early born baby

Early social and emotional experiences have a lifetime influence on development, laying the foundations for all aspects of functioning, including physical health and attachment relationships. Research shows that the baby's brain development prepares them for both physical and social interactions, even in early-born babies. (4) Fetuses are known to respond to the mother's state, arousal, and motor activity that prepares them for socially oriented responsiveness and following the social cues of the mother. Chemosensory and auditory familiarity with the fetus's mother prepares them for attachment relationships and social interaction, with continuity from newborn experiences. (10–12) Although descriptions of social and emotional implications for the early-born baby are not readily available, there is a large body of research that lays a foundation for the need to address how the baby develops attachment and social relationships. When interrupted by preterm birth or medical complications, the impact of the altered social/emotional environment must be considered.

"When interrupted by preterm birth or medical complications, the impact of the altered social/emotional environment must be considered."

Integration of physiology, behavior, and social/emotional development in the early-born baby

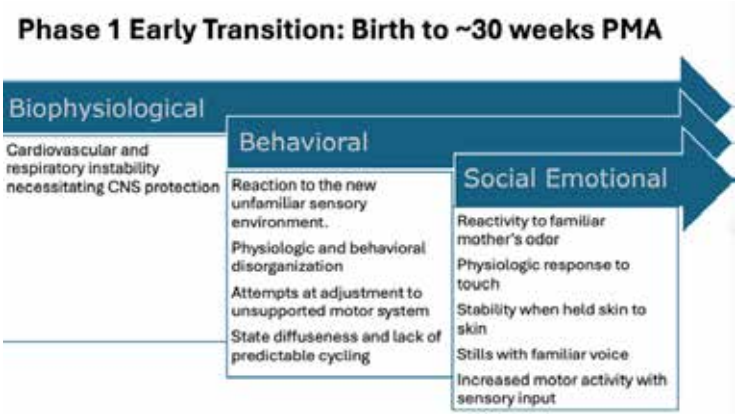
The conceptualization of physiologic developmental phases by Tan mentioned earlier provides a template for determining whether there were concomitant behavioral and social/emotional phases in the early-born baby. Using Tan's four-phase scaffold, the following integration of physiology, behavior, and social/emotional development was developed. It is important to note that, as in all developmental models, phases can be general categories, and that each baby may or may not exhibit characteristics of the "expected" phase. Many factors may contribute to a baby fitting or not fitting into the specific phase of a particular age range, such as chronic or episodic illness, environmental factors, parental presence, etc.

The following figures demonstrate the integration of physiologic, behavioral, and social-emotional development in early-born babies.

"The conceptualization of physiologic developmental phases by Tan mentioned earlier provides a template for determining whether there were concomitant behavioral and social/emotional phases in the early-born baby."

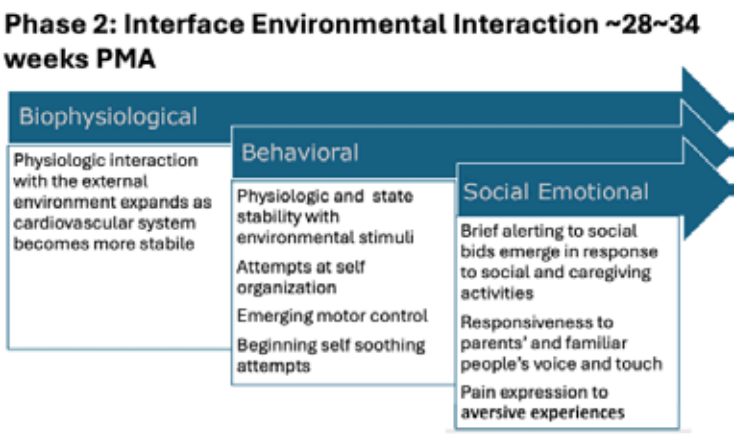
Phase 1 (Figure 1) represents the early transition from fetal to newborn life, during which significant recalibration of the baby's physiology, behavior, and social/emotional expectations must occur for survival. Without the familiar sensory environment and mother's regulation, the baby's survival depends on the external environment of the parents' bodies and/or on medical and nursing care.

Figure 1



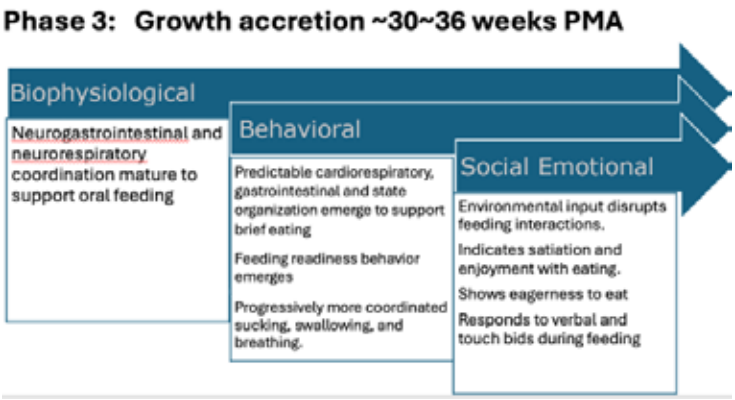
Phase 2 (Figure 2) represents the baby's increasing identifiable reactivity to caregiving and to the sensory environment. More stability in both physiology and behavior begins to emerge, if inconsistently, and represents the interface between the baby and the care provided.

Figure 2



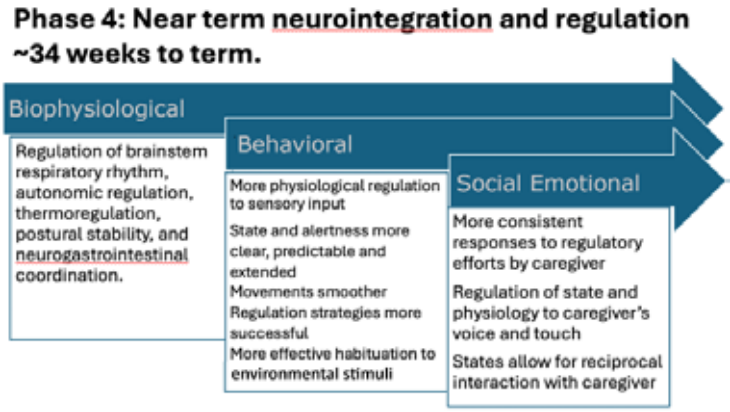
Phase 3 (Figure 3) focuses on increasing stability and coordination to support oral feeding and increasing weight gain. Both internal physiological processes and behavioral organization have matured, indicating preparation for successful and emotionally satisfying eating experiences.

Figure 3



Phase 4 (Figure 4) demonstrates increasing regulation in physiologic, behavioral, and social-emotional development, such that parents and providers can anticipate successful eating, sleeping, and social interactions to support survival and optimal development.

Figure 4



The four-phase model informs parents and providers about the important aspects of development for very early-born babies in intensive care. Importantly, it describes three essential elements of a baby's development and avoids a selective focus on only one aspect of care, instead advocating for integrating all three into caregiving practices. The model emphasizes that caregiving should develop and implement appropriate strategies to support all three integrated aspects to optimize overall outcomes.

Conclusions

Until recently, a description of physiologic, behavioral, and social/emotional development in very early-born babies has not been available. However, details of physiologic changes from extremely early birth to term have recently been proposed. An understanding of how behavioral and social/emotional aspects of development should be integrated with the identified physiological changes has been detailed and will contribute to a more comprehensive approach to the caregiving of early-born babies. The proposed model in this approach makes a first attempt to describe and integrate all three aspects of development and offers a framework for implementing comprehensive developmental care. As more research and clinical observations are applied to the model, it can become more robust, laying a foundation for informed caregiving and support for optimal developmental outcomes.

"An understanding of how behavioral and social/emotional aspects of development should be integrated with the identified physiological changes has been detailed and will contribute to a more comprehensive approach to the caregiving of early-born babies."

Acknowledgement

This approach was in part presented in a lecture at the 39th Gravens meeting on the Environment of Care for High-Risk Newborns and their Families, June, 2026, Notre Dame, Indiana.

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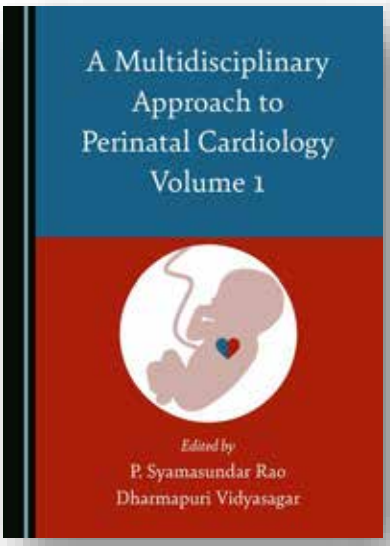
A Multidisciplinary Approach to Perinatal Cardiology *Volume 1*

Edited by P. Syamasundar Rao and Dharmapuri Vidyasagar



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Book Description

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

About the Editors

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

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

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: State Report Cards Rate Maternal Mental Health

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.

"Recent report cards paint a concerning picture of maternal health in the United States. The Policy Center for Maternal Mental Health, in collaboration with George Washington University's School of Public Health, has developed a nationwide maternal mental health report card. (1, 2)"

Recent report cards paint a concerning picture of maternal health in the United States. The Policy Center for Maternal Mental Health, in collaboration with George Washington University's School of Public Health, has developed a nationwide maternal mental health report card. (1, 2) By evaluating the policies and programs across all 50 states and across several domains that influence maternal mental health, (3) the report explores mothers' uneven access to mental and behavioral health services. States were evaluated on efforts to improve access, including clinician availability, insurance coverage, screening, support services, and parental support.

The report identifies significant gaps in resources and services available to families during pregnancy and the postpartum months. Researchers found that parents continue to encounter both mental health challenges and systemic barriers to accessing care. (4)

"The United States received an overall grade of C across all domains, a slight improvement from a C- in 2025. Although no state earned an A, for the first time in the report's history, no state earned an overall F. "

The United States received an overall grade of C across all domains, a slight improvement from a C- in 2025. Although no state earned an A, for the first time in the report's history, no state earned an overall F.

This year, a new "Parental Support" domain was introduced, measuring public paid parental leave, (5) childcare availability, and affordability and eligibility for childcare subsidies. The states collectively earned a failing grade in this domain. Using these report cards, states can make targeted, evidence-based efforts to address gaps in maternal mental health. (6)

"This year, a new "Parental Support" domain was introduced, measuring public paid parental leave, (5) childcare availability, and affordability and eligibility for childcare subsidies. The states collectively earned a failing grade in this domain. Using these report cards, states can make targeted, evidence-based efforts to address gaps in maternal mental health. (6)"

Babies Rely on Parents' Wellbeing:

When parents experience depression, anxiety, and other perinatal mental health concerns, the whole family may struggle. These difficulties can interfere with parent-child bonding, breastfeeding, and the routine care newborns require. (7, 8) For parents of premature or medically fragile infants, the emotional demands of a

NICU stay are associated with higher rates of anxiety, depression, and post-traumatic stress disorder symptoms. (9-13) Clinical support that strengthens parent-child attachment benefits the family long after discharge. (14, 15)

Federal Investment in Families:

Following the release of the report cards, a bipartisan group of lawmakers reintroduced the Moms Matter Act. (16) The Moms Matter Act increases investment in community-based programs that provide culturally responsive mental health services, empowering a health care workforce to improve the detection and treatment of mental health conditions during pregnancy and postpartum care. By expanding funds and training for care teams already working with underserved populations, the bill's funding would connect families with timely screening and prompt care within the communities they already trust. (17-20)

"These state report cards should serve as a roadmap for future policy improvements. The long-term value behind prioritizing healthy pregnancies and family bonds makes maternal mental health an essential investment for the future."

These state report cards should serve as a roadmap for future policy improvements. The long-term value behind prioritizing healthy pregnancies and family bonds makes maternal mental health an essential investment for the future.

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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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Immunizing Yourself Against **COVID-19**

COVID-19 vaccines have been shown to:

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

Understanding the Options

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

mRNA VACCINES

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

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

PROTEIN SUBUNIT VACCINES

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

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

VECTOR VACCINES

Used for decades against chickenpox, malaria and tuberculosis.

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

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

Safe and Sound

COVID vaccines have been:

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

Get Your Jab

Vaccines are available at your:

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

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

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6. https://doh.wa.gov/emergencies/covid-19/vaccine-information/safety-and-effectiveness
7. https://doh.wa.gov/emergencies/covid-19/vaccine-information/safety-and-effectiveness
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10. http://www.bccdc.ca/Health-Info-Site/Documents/COVID-19_vaccine/WHO-EUA-qualified-covid-vaccines.pdf

GAfPA Global Alliance for Patient Access

NCPA NATIONAL COMMUNITY PHARMACISTS ASSOCIATION

Still a **Preemie?**

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

But that's not every preemie's story.

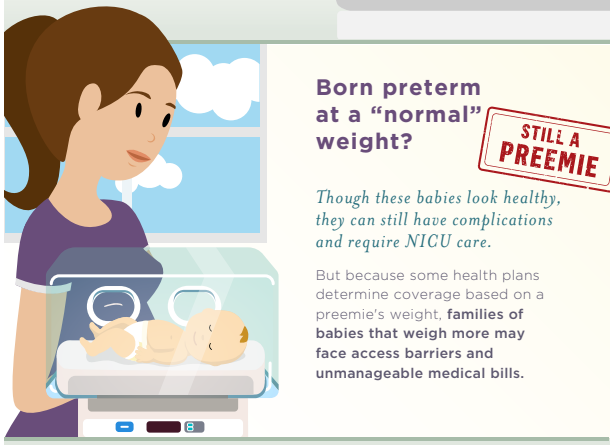
Born between 34 and 36 weeks' gestation?

STILL A PREEMIE

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

Jaundice | Feeding issues | Respiratory problems

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



Born preterm at a "normal" weight?

STILL A PREEMIE

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

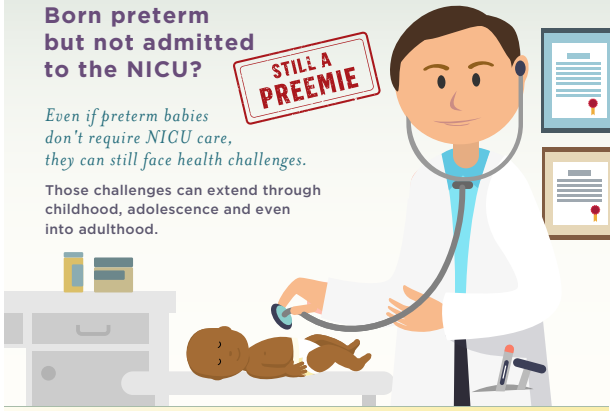
But because some health plans determine coverage based on a preemie's weight, **families of babies that weigh more may face access barriers and unmanageable medical bills.**

Born preterm but not admitted to the NICU?

STILL A PREEMIE

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

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



Some Preemies

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

All Preemies

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

NCfIH National Coalition for Infant Health

Protecting Access for Premature Infants through Age Two

www.infanthealth.org

The Gap Baby: An RSV Story

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

The National Coalition for Infant Health advocates for:

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

www.infanthealth.org

The Summit: 2026 Celebrating Youth-Driven Patient Centricity Around the World at the iCAN Summit!

Abby Clark

Get involved today and Join the iCAN Parent Council!

What is in this Issue of the iCAN Newsletter?

- What is iCAN?
- The 2026 iCAN Summit: A Kid-Driven Movement in Ireland!
- Looking Ahead: How Youth are Transforming the World of Healthcare Advocacy this Summer and Beyond
    - Ask the Experts: Featuring Joshua Sapienza, Creator of the Safe Hospital Finder
    - iCAN Impact: iCAN Youth Take on the 2026 CTIP Symposium
- iCAN 2027 Summit

"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 that spans four continents (as well as virtually), iCAN's dedicated youth member groups work in unison to provide a voice for children and families in medicine, research, science, and innovation."

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 that spans four continents (as well as virtually), iCAN's dedicated youth member groups work in unison to provide a voice for children and families in medicine, research, science, and innovation. To foster greater global understanding about the importance of the pediatric patient and caregiver voice in healthcare, clinical trials, and research, iCAN's young people continue to drive incredible change in the global health landscape.

On average, our youth are between the ages of eight and 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.

"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 that 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.

"iCAN continues to empower the pediatric patient voice through community partnerships with organizations such as the FDA, Everylife Foundation for Rare Diseases, PFMD, MRCT, iSPI, and AAP."

Whether a patient, family member, friend, healthcare professional, or just an individual looking to make a difference, you are welcome to visit our website at www.icanresearch.org to explore our mission, programs, and initiatives. Join us today in ensuring that every child's voice is enshrined in the effort to improve healthcare for all pediatric patients.

The 2026 iCAN Summit: A Kid-Driven Movement in Ireland!

Although the 12th iCAN Summit has closed its doors, the learnings and inspiration gleaned from this incredible event have continued to bear fruit in the world of pediatrics. Hosted from July 12th - 17th at Barretstown in Co. Kildare, Ireland, the iCAN Summit made incredible strides in empowering pediatric patients. During this week in July, the voices and insights of youth and families reverberated throughout the global healthcare community. Young people, clinicians, and regulatory representatives came together to exchange ideas, encourage cross-cultural connection, and identify lessons to propel healthcare advocacy into a new light. This year, iCAN is proud to say that what once started as a small dream and group of dedicated volunteers has turned into a leading global event - with an attendance of ~150 incredible and impassioned young people, clinicians, caregivers, industry leaders, and healthcare professionals representing 10 different countries.

The iCAN Summit challenges the traditional inclusion of patients

in healthcare by ensuring that youth are not only involved in the creation process but also are leading the charge. Thank you to our families and caregivers, our industry friends (researchers, clinicians, and healthcare innovators), community partners, and our youth and young people for guiding iCAN through another Summit of incredible change. Through your involvement, you have transformed the event and the healthcare landscape, ensuring that children's perspectives are valued and integrated into pediatric care.

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Day One Summit Highlights:

- We kicked the summit off with a strong start, celebrating the incredible work the iCAN community has accomplished throughout the year. Leanne West (iCAN's President of the Board) and Charlie Thompson (Founder and Chairman of the Board) welcomed Summit attendees with words of encouragement and excitement for the week ahead. Susa Benseler, Chief Academic Officer of Children's Health Ireland (CHI), gave the summit's opening keynote address!
- Jasmine Kincaide (Pediatric Alliance & Operational Lead), Erica Murphy (Patient Engagement Manager), and Tarja Nylund (Lead Study Manager) from Bayer kicked off our week of interactive industry sessions with their topic "Shaping Trial Result Summaries Together: What Matters to Young People and Parents." In this session, young people were able to provide insight on how best to communicate results from clinical trials to participants and their families - highlighting what can be possible when young people are given a seat at the table in shaping solutions made for them.
- Starting their week of deep dives into the caregiver role in a child's healthcare journey, Jen Degl (iCAN Parents Lead and Educator) and Dr. Mitchell Goldstein (Professor of Pediatrics at CHLA) led parent and adult attendees in their first session of the day, showcasing the need for a safe space to speak openly with other parents and connect with those who have faced similar challenges.

Day Two Summit Highlights:

- Day two featured incredible industry-led sessions from Pfizer (Building Trust in Research: Parent/Carer Perspectives on Recruitment Strategies and Study Locations), UCB (Transition of Care), Novartis, Fortrea (Research for Children and Young Adults), and Empath Labs (Designing Tools for Comfort and Calm in Clinical Trials)! These sessions showed summit attendees that their voices are fundamental to patient engagement, research, and development.
- Wrapping up day two, Fortrea gave the summit attendees a session to remember. Focused on both education and personal insights into clinical research, the session gave a brief overview of what clinical research is and why it is so important to include children and young adults. Throughout the session, the Fortrea team not only discussed clinical trials but also took the time to learn directly from iCAN youth how industry can make those trials more child- and young-adult-friendly. All of the summit attendees left the session inspired for the days to come!

Day Three Summit Highlights:

- Summit attendees had the opportunity to learn from an expert in clinical trial recruitment, Anita Amadi (Recruitment Strategist at Pfizer), and gain insight into how to improve study participation. Anita walked iCAN youth through a real-world clinical trial on migraines and identified current challenges: number of visits, daily diary completion, blood tests, physical examinations, and study length. From there, summit attendees broke into groups to discuss ways to mitigate those challenges. They touched on topics such as trial accessibility, ways to improve the challenges, and differing viewpoints on issues. As a group, the attendees were able to not only talk through challenging topics but also give Pfizer expert feedback as representatives of key populations.
- Summit attendees also had the opportunity to visit industry and academic exhibitors throughout the week! Each organization hosted activities at their table to create additional touchpoints with summit attendees. From live app development to medical device demonstrations, table activities were inclusive, interactive, and insightful! Thank you to our exhibitors: Bayer, Novartis, Georgia Tech, UCB, Biocryst, IQVIA, Neonatology Today, CSLifeSciences, Little Journey, NIHR, and Emapth Labs.

Day Four Summit Highlights:

- The last day of the summit brought together all the energy and work developed throughout the week! Day four featured incredible industry-led sessions from Biocryst (Mapping the Healthcare Trail: Carry What a Kid Carries and NIHR (The Next Chapter: Bringing Your Ideas To Life).

- Our youth took the stage to present their Activity of the Week project - a youth-created roadmap expanding the 2026 Summit project: *the International Position Paper on Youth Partnership in Healthcare*. Throughout the week, our youth, led by host chapter (KIDS RAiN) representatives, drafted a roadmap detailing the "how to" of implementing youth voices in health decisions (topic one on the 2025 position paper). Developed in just a matter of days, the roadmap breaks down the gargantuan tasks of "Involving Youth Voices and Perspectives in the Development and Implementation of Public Policy," "Bringing Decision Makers to Young People," and "Creating Youth Advisory Groups." The summit attendees tackled this task by breaking the topics down and developing actionable steps. Each group (combining a total of 75 youth members) presented their roadmaps to the whole of the summit. This project showed that, with collective action and global representation, the youth voice can drive significant change!

- We had two final presentations to wrap the 2026 iCAN Summit. One by Derick Mitchell (Executive Director at PFMD) and the other by Niall Muldoon (Ireland's Ombudsman for Children). Derek advised iCAN Youth on the trickier aspects of involving youth in the development and implementation of public policy, including how to form advisory groups and how to bring decision-makers to young voices, focusing on where power can be shared even when youth voices clash with adult ones. Niall's talk highlighted the work that the office of the Ombudsman has done and connected those local efforts to iCAN's global ones. He praised iCAN's youth for their exceptional work in making the global landscape of pediatrics a more equitable place for young people worldwide.

"We extend a warm thank you to Joshua Sapienza (creator of the Safe Hospital Finder) and our amazing KIDS Host (Joey) for makingAugust's Ask the Experts an incredible one! Josh took the time to share the story of the Safe HospitalFinder's creation and gave the iCAN community a live demo."

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

- **Ask the Experts:**

  - We extend a warm thank you to Joshua Sapienza (creator of the Safe Hospital Finder) and our amazing KIDS Host (Joey) for makingAugust's Ask the Experts an incredible one! Josh took the time to share the story of the Safe HospitalFinder's creation and gave the iCAN community a live demo. He touched on topics such as data accessibility and transparency and shared how a simple idea can create real change. "Youdon't have to be an expert to make an impact. You can start with a question, learn along the way, and build something that can make a difference for thousands of people"

  - Ask the Experts is a monthly webinar series hosted by iCAN, designed to connect our young people with changemakers and health experts. By engaging 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

  - Want to be part of our next *Ask the Experts* Session?

Please reach out to sabina@icanresearch.org.

iCAN Impact: iCAN Youth Take on the 2026 CTIP Symposium:

This past Friday, representatives from iCAN's KIDS Walter Payton chapter in Chicago, Illinois attended the 2026 CTIP Symposium. The CTIP Symposium is a forum dedicated to pediatric innovation and elevating standards of care for children nationwide, serving as a critical nexus for translating research into clinical practice and driving evidence-based advancements in pediatric medicine. As the youngest attendees at the conference (the Symposium's only high school students), the youth members were truly shining stars. This was an incredible opportunity for the youth members to experience their first professional conference and grow in their passions for healthcare and pediatric innovation. We are so proud of the KIDS Walter Payton representatives, and cannot wait to see the amazing things they will accomplish throughout the year!

"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 is immeasurable."

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 is immeasurable. 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 at a 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. Your generosity and dedication are deeply valued. 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 fund next year's summit, please click here to sponsor or donate.

Disclosures: *There are no reported disclosures*

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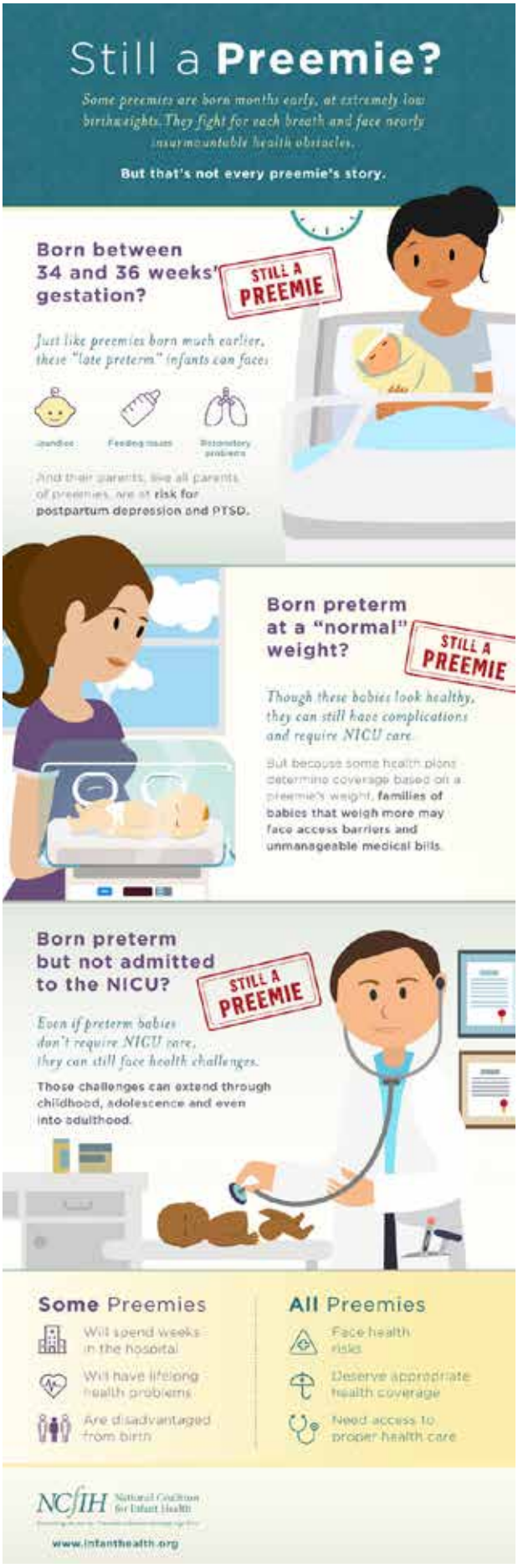
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Just like preemies born much earlier, these "late preterm" infants can face:
Jaundice
Feeding issues
Respiratory problems
And their parents, like all parents of preemies, are at risk for postpartum depression and PTSD.
Born preterm at a "normal" weight?
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Though these babies look healthy, they can still have complications and require NICU care.
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Will have lifelong health problems
Are disadvantaged from birth
All Preemies
Face health risks
Deserve appropriate health coverage
Need access to proper health care
NCfIH National Coalition for Infant Health
www.infanthealth.org


Thank You, from iCAN
Thank You, from iCAN Kids
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Continue to Support at iCAN.health


NT

PORTO ELOUNDA
GOLF & SPA RESORT

WESTIN
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The Westin Long Beach

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HOTELS
MARRIOTT
Delta Hotels Montreal

cancúncards

Zachari Dunes

DOUBLETREE
by Hilton
Ontario

SOUTH POINT

MIRACLE SPRINGS
RESORT & SPA

PORTER VALLEY
COUNTRY CLUB

THE ACADEMY of MAGICAL ARTS
AT THE MAGIC CASTLE

PEJU
NAPA VALLEY

LA OPERA

Pacific Symphony
CARL ST.CLAIR MUSIC DIRECTOR

CRUISE COMPETE

Dunes West
GOLF & RIVER CLUB

AMERICA'S RAILROAD
DURANGO & SILVERTON
NARROW GAUGE RAILROAD

BEVERLY HILLS
Plastic Surgery Group

SABAN THEATRE
Powered by STERLING VENUE VENTURES

LONG BEACH
SYMPHONY
ECKART PREU, MUSIC DIRECTOR

FLAPPERS
COMEDY CLUB
AND RESTAURANT
BURBANK

Pacific
Chorale

GEFFEN PLAYHOUSE

LINKSOUL

CHANCE
THEATER @ Bette Aitken theater arts Center

lucky feet
shoes

THE
SORAYA

TAHOE DONNER

PEPPERDINE
Lisa Smith Wengler Center for the Arts

SMOKE
HOUSE
Established 1948

VERDE CANYON
RAILROAD

ISLAND PACKERS

citycruises

ILLUSION
MAGIC LOUNGE

LA MIRADA THEATRE
FOR THE PERFORMING ARTS

LAGUNA
PLAYHOUSE

HAGAFEN
FAMILY OWNED
EST. 1979

Jack
in the box

aNoiseWithin
Classic Theatre, Modern Magic

PASADENA
PLAYHOUSE

DiscoveryCube
OC & LA

tieks
by Gavrieli

Murad

RESTAURANT
GREEN STREET

WHEEL FUN
RENTALS

gorjana

USS Midway
MUSEUM

AMERICA'S LIVING
SYMBOL OF FREEDOM

KINGS ICE

California
BOTANIC GARDEN

Betty Up

Raising
Cane's
CHICKEN FINGERS

BATTLESHIP
IOWA
LOS ANGELES

NEW WEST SYMPHONY
MICHAEL CHRISTIE | Music Director

PHILHARMONIC
SOCIETY
presents

NEWPORT
LANDING

THE MISSION INN FOUNDATION
RIVERSIDE
VISITOR CENTER + MUSEUM

Fiesta Village
Family Fun Park

WILLIAM
THEATRICUM · BOTANICUM

CPH CORONADO
PLAYHOUSE

Irvine Lanes

SIMMS
RESTAURANTS

THE HUNTINGTON

Hollywood
WAX MUSEUM

SANTA
MONICA
PLAYHOUSE

SANTA ANITA
PARK

Go Kart World

OLIO E LIMONE
RISTORANTE

DOMENICO'S
RESTAURANT

ENJOY DELIGHT. YOU DESERVE IT.

Brent's

CHIPOTLE
MEXICAN GRILL

Panera
BREAD

Caroline Arnold, Author

BARK
BOX

PETERSEN
AUTOMOTIVE MUSEUM

Peer Reviewed

An Unusual Presentation of Tuberculous Meningitis with Choreoathetoid Movements in a Malnourished Child

Hima Bindu Bhaskar, MD

"Approximately 10% of extrapulmonary tuberculosis cases involve the central nervous system, with tuberculous meningitis (TBM) being the most severe form associated with significant morbidity and mortality."

Introduction:

Approximately 10% of extrapulmonary tuberculosis cases involve the central nervous system, with tuberculous meningitis (TBM) being the most severe form associated with significant morbidity and mortality. In TB meningitis, there is a thick gelatinous exudate (1) around the sylvian fissures, basal cisterns, brainstem, and cerebellum. Hydrocephalus occurs as a consequence of obstruction of the basal cisterns, the outflow of the fourth ventricle, or the occlusion of the cerebral aqueduct.

Case Description:

An 18-month-old severely acute malnourished female child, second born to non-consanguineous parents, developmentally normal, presented with a history of fever for 3 days, one episode of convulsions on day 2 of fever, choreo-athetoid movements of the left upper and lower limbs for 2 days, and inability to sit and stand for 2 days. Past history was significant for two hospital admissions for fever lasting 2 months, on and off, 10 days back. On examination, the child had choreo-athetoid movements of the left upper and lower limbs. The child's father had an active case of pulmonary tuberculosis.

"An 18-month-old severely acute malnourished female child, second born to non-consanguineous parents, developmentally normal, presented with a history of fever for 3 days, one episode of convulsions on day 2 of fever, choreo-athetoid movements of the left upper and lower limbs for 2 days, and inability to sit and stand for 2 days."

Investigations:

CSF analysis revealed turbid CSF, elevated protein, low glucose levels, and elevated total cell count with lymphocytic predominance. ESR was 120 mm/hr, and Mantoux was positive. MRI brain showed severe obstructive hydrocephalus with periventricular white matter edema.

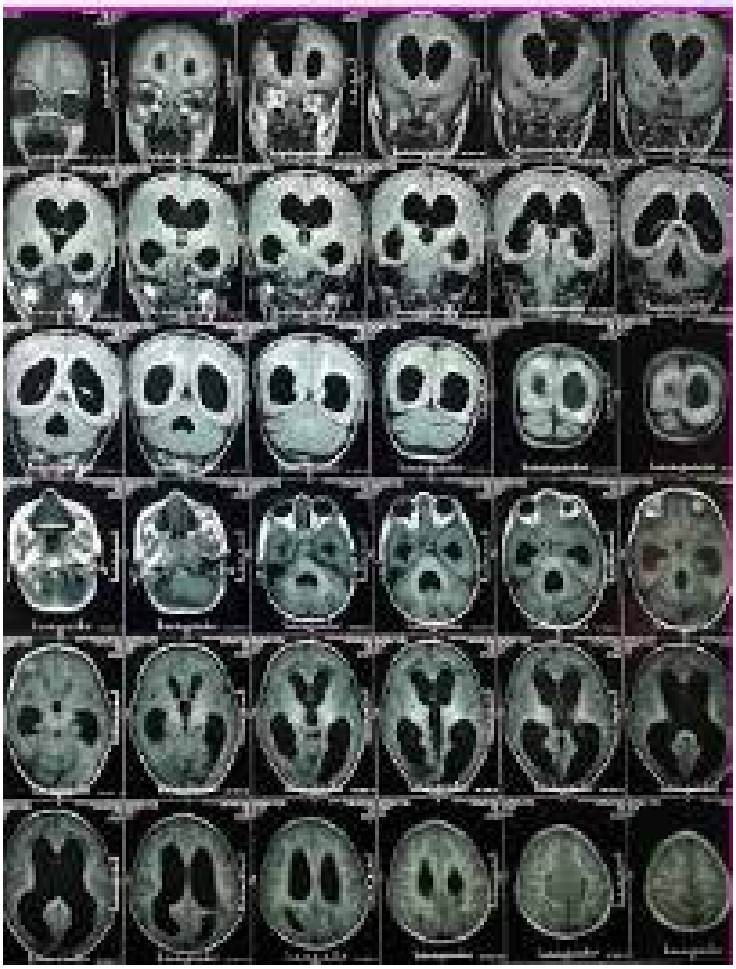

Image 1: MRI Brain showing dilated ventricles

Treatment:

The child was started on Category I antitubercular treatment, Systemic Steroids (2), and a ventriculoperitoneal shunt was performed. Child responded to treatment; on follow-up examinations, the Choreo-athetoid movements reduced, and the child is able to sit and stand.

"The child was started on Category I antitubercular treatment, Systemic Steroids (2), and a ventriculoperitoneal shunt was performed. Child responded to treatment; on follow-up examinations, the Choreo-athetoid movements reduced, and the child is able to sit and stand."

Image 2: A ventriculo-peritoneal Shunt was performed for TB meningitis with Hydrocephalus

Discussion:

Movement disorders may occur in TB meningitis. They may present as tremor, dystonia, myoclonus, chorea (3), and athetoid movements. Tremor is the most common movement disorder in TB meningitis. Deep vascular lesions are more common among patients with movement disorders (3). The brain tissue immediately underlying the tuberculous exudates shows varying degrees of edema, perivascular infiltration, and a microbial border—zone reaction. The basal exudates of TB are usually more severe in the vicinity of the circle of Willis (4) and produce a vasculitis-like syndrome. Recognition of these atypical neurological presentations is essential because delayed diagnosis may lead to hydrocephalus, neurological sequelae, and poor outcomes.

"Movement disorders may occur in TB meningitis. They may present as tremor, dystonia, myoclonus, chorea (3), and athetoid movements. Tremor is the most common movement disorder in TB meningitis. Deep vascular lesions are more common among patients with movement disorders (3)."

Conclusion:

Choreoathetoid movements are a rare manifestation of pediatric tuberculous meningitis and may contribute to diagnostic delay. Clinicians practicing in tuberculosis-endemic settings should maintain a high index of suspicion for TBM in children presenting with acute movement disorders, particularly in the presence of malnutrition and tuberculosis exposure. Early diagnosis and prompt initiation of therapy can significantly improve neurological outcomes (5).

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Artificial Intelligence for Predicting Neonatal Deterioration in the NICU: A Structured Literature Review

Rita-Nour Antoine Awad, MSIII

"The incidence of neonatal morbidity and mortality remains a serious problem worldwide, especially within the neonatal intensive care unit (NICU), where critical case care might be challenging, necessitating constant monitoring and immediate action."

Introduction:

The incidence of neonatal morbidity and mortality remains a serious problem worldwide, especially within the neonatal intensive care unit (NICU), where critical case care might be challenging, necessitating constant monitoring and immediate action. Detecting early deterioration is difficult in this population because neonatal clinical signs are often subtle and nonspecific (1,2).

Traditional diagnostic approaches are centered on clinical assessment, including vital signs and laboratory tests such as leukocyte counts, platelet counts, C-reactive protein (CRP), procalcitonin (PCT), and proinflammatory cytokines (IL-1, IL-6, IL-8, and TNF), as well as leukocyte surface proteins (CD64, presepsin)(3).

Recent advances in Artificial Intelligence (AI), Machine Learning (ML), and Deep Learning (DL) have opened new opportunities to improve the early detection of neonatal deterioration. AI-based models enable the analysis of complex patterns and large amounts of multidimensional data, including continuous vital signs, electronic health records, and laboratory parameters, thus enabling early diagnosis or detection of deterioration, enhancing monitoring during the NICU stay, and providing highly targeted treatment approaches enhance monitoring, and provide highly-targeted treatment approaches (4,5). Extensive research has evaluated the performance of AI systems in predicting early deterioration in NICU patients and associated outcomes, with promising results (3,6,7).

Although these advancements might seem promising, the use of AI in neonatal care is limited by several factors, including limited external validity, generalizability, and integration into clinical workflows, which may hinder widespread adoption and raise concerns among clinicians and researchers (2). It is essential to overcome these limitations to facilitate the implementation of these systems.

Focusing on validation and standardization in future research can make healthcare professionals feel optimistic about the reliable integration of AI models into NICU practice.

Method:

A structured literature review was conducted using a PubMed search to identify peer-reviewed articles on the role of artificial intelligence in predicting neonatal deterioration in the NICU. Advanced search terms included: artificial intelligence, machine learning, deep learning, neonatal care, NICU, clinical deterioration, sepsis, mortality, and prediction. Studies were limited to the neonatal population and to English-language articles published in the past 5 years. Relevant articles were screened based on title, abstract, and full text.

Results:

Types of AI Models

Both traditional and novel AI models have been studied in neonatal care. Starting with traditional approaches, machine learning (ML) and deep learning (DL) have been widely studied independently and in combination. Most studies used ML algorithms, including random forests, support vector machines (SVMs), logistic regression, and gradient-boosting techniques such as XGBoost (8–11). Random forests have proven effective in handling complex clinical datasets, making them the most used ML algorithm (10). Comparable effectiveness has been shown in deep learning models, especially convolutional neural networks (CNNs) and recurrent architectures such as long short-term memory (LSTM). These models enabled continuous analysis of physiological signals and time-series data (7,12).

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Additionally, studies showed that combining the LSTM method with Artificial Neural Networks (ANN) results in a hybrid model (LSTM-ANN) with improved predictive accuracy compared to individual models (12). Recent studies have explored graph-based models and bioinformatics-driven algorithms, which are novel AI methodologies for specific applications, such as distinguishing sepsis subtypes and identifying biomarkers (8,13). Overall, the selection of AI methodology depends on several criteria, including

the type and complexity of the input data, as well as a complete understanding of the model, its predictive performance, and validation results (13).

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Clinical Application:

1. **Sepsis Prediction:**

AI methods have been thoroughly studied in real-world NICU settings for sepsis prediction. For instance, ML models that combine multiple vital signs have achieved predictive performance with an area under the receiver operating characteristic curve (AUC) of approximately 0.82 up to 24 hours before clinical diagnosis, demonstrating the ability to detect neonatal sepsis hours to days before clinical suspicion (6). Similarly, studies have shown that late-onset sepsis can be predicted using deep learning approaches based on biosignals (7).

A study showed that combining clinical, laboratory, and demographic data, including birth weight, gestational age, and inflammatory biomarkers, significantly strengthens the performance and accuracy of predictive models more than using individual data sources alone (10,14). Similarly, another study showed that integrating electronic health record data improves diagnostic precision; for instance, with these data, they were able to differentiate between culture-negative and true sepsis (8).

2. **Mortality prediction:**

Studies have also investigated the role of AI in predicting overall neonatal disease risk and mortality. Although less studied than sepsis prediction, ML models identified high-risk neonates, facilitating early risk stratification and clinical decision-making based on clinical and demographic data (1,9). Multimodal data integration that combined time-series physiological data, including heart rate variability and oxygen saturation over hours/days, with clinical variables has demonstrated higher predictive accuracy, exceeding 80% in predicting neonatal outcomes (12).

3. **Deterioration Monitoring:**

To detect early signs of clinical deterioration, AI-based models enable continuous monitoring and analysis of vital signs, such as heart rate, respiratory rate, and oxygen saturation, and identify patterns associated with impending clinical events (6,7). Additionally, AI models can support physicians in generating clinical decisions that provide real-time assessments and guide treatment, including the type and dose of antibiotics (15). By helping detect early deterioration, AI models might shift neonatal care from reactive to proactive management (9,10).

Data used:

Neonatal care is a complex environment that requires a diverse combination of data sources for AI models. Continuous vital signs such as heart rate, respiratory rate, and oxygen saturation are particularly important for early detection of sepsis and deterioration (6,7). Patient demographics, clinical observations, and treatment history, which are referred to as Electronic Health Records (EHRs), may play a role in developing comprehensive predictive models (8,9). Additionally, multiple studies have demonstrated the significance of laboratory parameters and biomarkers, such as C-reactive protein, white blood cell count, and procalcitonin, for disease prediction (10,14).

More advanced approaches aim to enhance predictive accuracy by integrating genomic, bioinformatics, and molecular data, as well as novel data sources such as volatile organic compounds and biosignal-derived features (13,16). Overall, integrating diverse data has been shown to achieve higher efficacy and accuracy than individual data analysis by AI models. Although these might seem promising, many challenges, including variability in data quality, availability, and standardization across different clinical settings, remain, limiting the generalizability and implementation of these models (9,10).

"More advanced approaches aim to enhance predictive accuracy by integrating genomic, bioinformatics, and molecular data, as well as novel data sources such as volatile organic compounds and biosignal-derived features (13,16)."

Discussion:

Ongoing studies on AI models are showing promising advantages in neonatal care. The ability to detect underlying patterns and predict early signs of deterioration by continuously integrating and analyzing large amounts of data offers significant advantages in the care of newborn infants enhance monitoring, and provide highly-targeted treatment approaches (4,5).

Compared to traditional prediction approaches, which rely on a limited number of parameters, AI models have shown higher flexibility and performance. For instance, Machine Learning (ML) involves tools that integrate multiple data sources, enabling higher predictive accuracy in NICU settings (2,10).

AI models' success extended beyond disease prediction to support decision-making and optimizing treatment. Clinically, AI models can reduce unnecessary interventions, for example, inappropriate antibiotic use in neonatal sepsis, by guiding physicians' treatment plans. Additionally, this technology can generate a plan of care specific to each case based on the combined datasets (15).

While these results are encouraging, several factors are limiting the application of these AI systems in real-world NICU care. When applied across different populations, the same AI model showed

variability in data quality due to the use of retrospective datasets, resulting in reduced accuracy and efficacy, a lack of external validation, and limited generalizability (2,4,7).

"While these results are encouraging, several factors are limiting the application of these AI systems in real-world NICU care. When applied across different populations, the same AI model showed variability in data quality due to the use of retrospective datasets, resulting in reduced accuracy and efficacy, a lack of external validation, and limited generalizability (2,4,7)."

Furthermore, another barrier limiting the application of these systems in real-world NICU care is ethical concerns, including data privacy, potential biases in training data, and accountability in decision-making. Physicians did not trust many AI models due to their lack of transparency and interpretability in decision-making. Additionally, specialized training and a robust infrastructure are required before implementing these AI systems in clinical practice (5,17). As a result, most AI systems require careful reconsideration before implementation in routine clinical practice.

Future Directions:

Further research is needed to overcome the current limitations of implementing AI models in neonatal care. Replacing retrospective studies with large, multicenter prospective studies that evaluate these systems across diverse populations and clinical settings is essential to address the lack of generalizability and clinical applicability (9,10). Moreover, without standardized model evaluation methods, comparing and assessing the true clinical usefulness of AI models remains challenging. Achieving standardization requires defining consistent criteria and adopting a core set of evaluation metrics enhance monitoring, and provide highly-targeted treatment approaches.

Additionally, advances in this field will require transforming research models into clinically relevant tools that can be used in real time in NICU environments (17). One of the most important barriers to implementing these AI systems in real-world settings is ethical concerns. Transparency and data privacy should be carefully considered to ensure a safe and trustworthy implementation in clinical settings (4,5,17).

Overcoming these obstacles will ensure a safe and effective integration of AI into neonatal care. Still, it will also overcome the challenges seen today that limit the ability to respond to emergencies, thereby reducing the incidence of neonatal morbidity and mortality.

Conclusion:

The advancement of AI models is enabling the analysis of large, complex clinical datasets, allowing the identification of disease or deterioration before any apparent clinical signs or laboratory tests. This is particularly important, especially in the neonatal population, where clinical signs are often subtle and nonspecific. Although these results might look promising, they are still in the research phase and face many obstacles that limit their generalizability and validation for routine clinical use (1,9,10). Ensuring the standardization and validation of these models should be the focus of current studies to enable proper integration and benefit from them in clinical practice.

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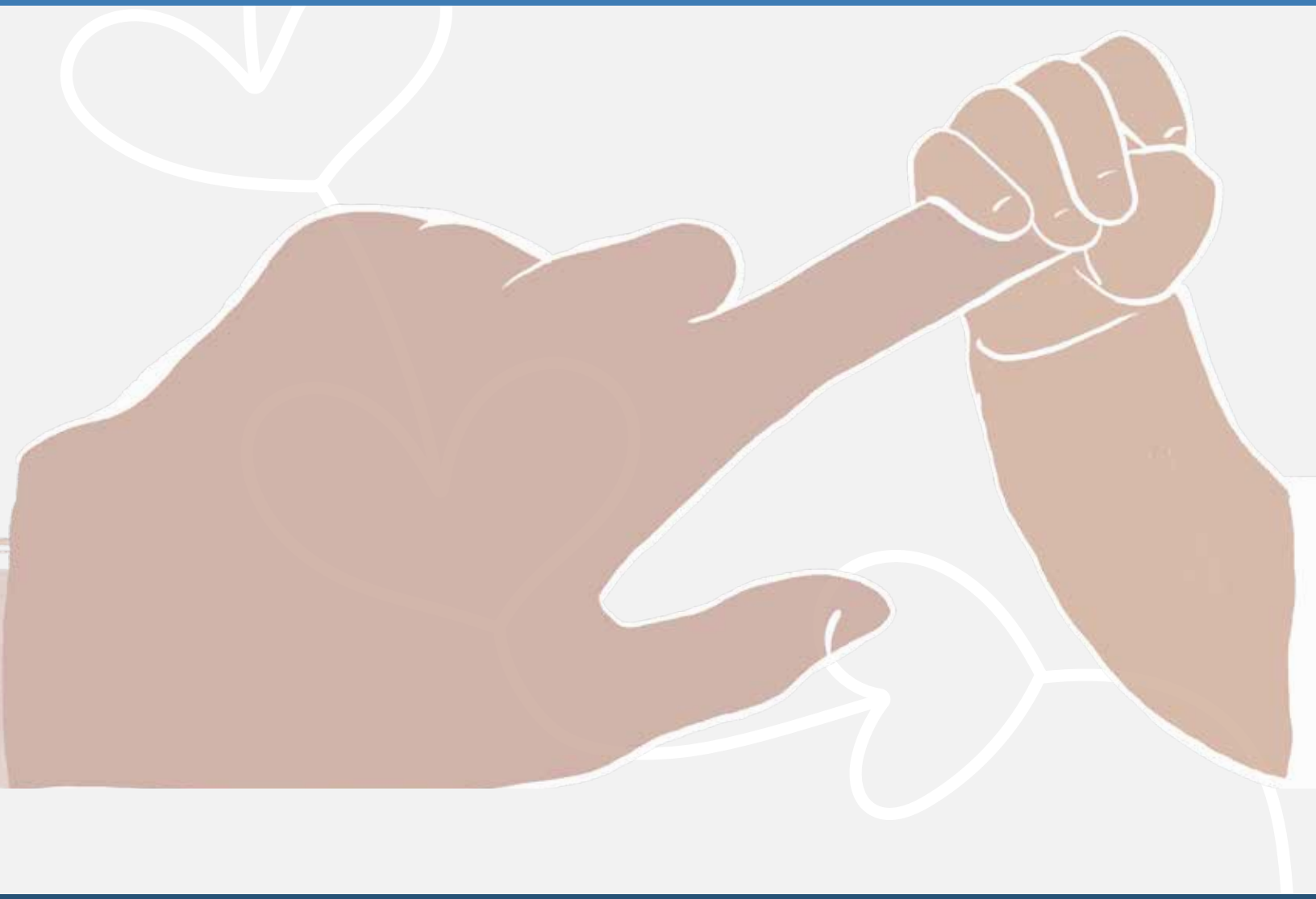

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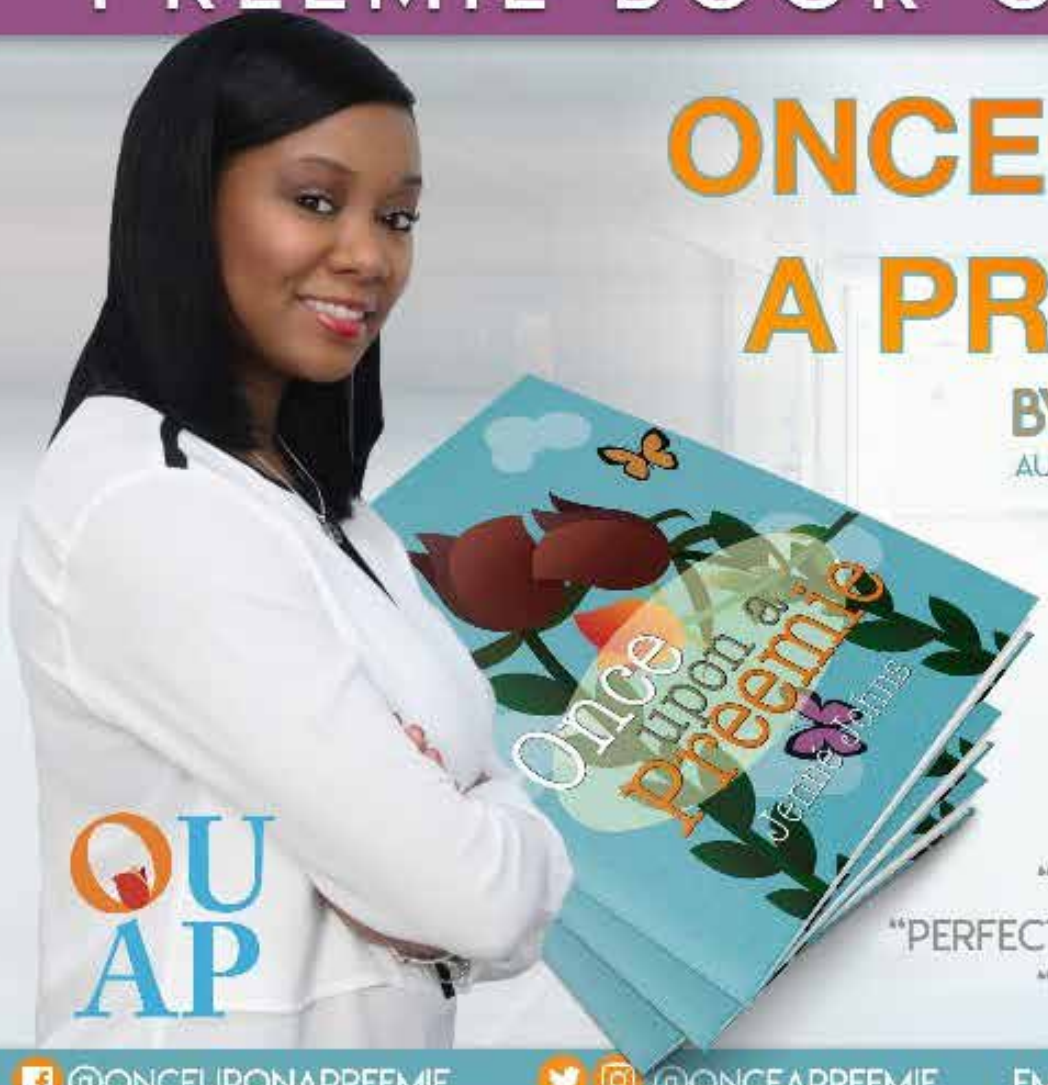

ONCE UPON A PREEMIE

BY JENNÉ JOHNS

AUTHOR | SPEAKER | ADVOCATE

QUAP

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AAP: Executive order to reduce childhood vaccines unscientific, dangerous

NEWS PROVIDED BY

American Academy of Pediatrics

By Melissa Jenco

Study: **AAP: Executive order to reduce childhood vaccines unscientific, dangerous**

Current as of August 11, 2026

A new Trump administration executive order that reduces and spaces out recommended childhood vaccines is unscientific and dangerous, AAP leaders said Monday.

Officials at an event announcing the order repeatedly suggested a link between vaccines and autism, though it was not mentioned in the order. Discouraging vaccination based on these false claims would leave children vulnerable to preventable diseases.

"There is no new evidence to justify significant changes to childhood immunization guidance," AAP President Andrew D. Racine, M.D., Ph.D., FAAP, said in a statement. "Dozens of studies involving millions of people show there is no link between vaccines and autism, and yet federal leaders continue to promote this outdated, disproven idea to scare families. Today's executive order will do nothing to support families of children with autism or advance understanding of the condition."

President Donald J. Trump's executive order recommends children get vaccines to protect them from 11 diseases, down from 18. The recommendations mirror those a federal judge struck down in March but administration officials said they hope states will implement them.

"The only thing I can see is going to happen as a result of the announcement today is the injection of greater amounts of uncertainty and fear and confusion where there doesn't need to be any," Dr. Racine said in a press conference.

Under the executive order, all children are recommended to be vaccinated against measles, mumps, rubella, diphtheria, tetanus, pertussis, polio, *Haemophilus influenzae* type b, pneumococcal disease, HPV and varicella.

Immunizations recommended by the executive order for children considered to be at high-risk are respiratory syncytial virus monoclonal antibodies, hepatitis A, hepatitis B, meningococcal B, meningococcal ACWY and dengue. Children also could get hepatitis A, hepatitis B, rotavirus, meningococcal disease, flu and COVID-19 vaccines based on shared clinical decision-making.

The AAP continues to recommend vaccines to protect against all 18 diseases in its 2026 immunization schedule.

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 and that they come as measles cases reach a 35-year high. Individual vaccines for measles, mumps and rubella have not been available in the United States since they were phased out of production in 2009.

"As measles cases reach a 35-year high in the U.S. and with cold and flu season quickly approaching, today's executive order on vaccines is not only disheartening but dangerous," Dr. Racine said. "Instead of ensuring every family can access life-saving vaccines for measles, influenza, RSV and more, federal leaders are once again spreading misleading claims."

The executive order also said states have an obligation to provide religious and medical exemptions from child and adolescent immunization 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.

In addition to billing the order as a means to reducing autism, Trump referred to European countries giving children fewer vaccines. However, many give a similar number to the U.S. and others have significantly different populations, disease burdens and health care systems.

"Vaccine recommendations from the American Academy of Pediatrics are tailored to the health of children living in the United States and are based on decades of research and systematic tracking of real-world experiences," Dr. Racine said. "Pediatricians recommend children receive certain vaccines at specific ages based on when children's immune systems will respond best and when they are most vulnerable to certain diseases."

He encouraged families to talk to their pediatricians if they have questions about the vaccines the AAP recommends for their children.

Resources

- AAP immunization schedule
- AAP Fact Checked articles on vaccine recommendations in the U.S. compared to other countries, receiving multiple vaccines, vaccine safety, aluminum in vaccines
- Information for parents from HealthyChildren.org on the AAP immunization schedule

FYI: New resources on children with special health care needs and newborn immunizations

NEWS PROVIDED BY

American Academy of Pediatrics

By Sean Stangland

Study: **FYI: New resources on children with special health care needs and newborn immunizations**

Current as of August 1, 2026

Resources for professionals who work with CYSHCN

A new AAP guide can help teams working with children and youth with special health care needs (CYSHCN) plan, implement and track system-level change. It outlines four phases of implementation and includes tools, technical assistance resources and case studies. Explore the guide at https://bit.ly/4amJZ19.

Also: A new video series from the AAP features parents and caregivers sharing their experiences caring for CYSHCN. Each video highlights part of a family's care journey and includes challenges faced and resources they found helpful. Watch the videos at https://bit.ly/3QlJwpl.

Newborns and immunizations

Neonatologists and hospital-based clinicians are 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 the hepatitis B vaccine, RSV immunization and vitamin K injection.

The materials available at https://bit.ly/4w1tK1K can be used at the point of care to guide immunization administration, support accurate documentation in the electronic health record, and answer frequently asked questions. Resources for families also are included.

Meet the teens helping to reshape youth suicide prevention

Every generation of teenagers faces new challenges. Young people today, however, are growing up in a radically different world, shaped by pandemic isolation, social media and AI. With donor support, the AAP Suicide Prevention Youth Leadership group helps ensure resources created by adults feel meaningful to adolescents. The group that has produced articles for HealthyChildren.org offers a perspective no adult could: what it's like to be a teenager in 2026.

Learn more about the leadership group and ways to support it at https://bit.ly/4xK2w1D.

Countries urged to strengthen breastfeeding support and health systems to give every child a healthy start in life

NEWS PROVIDED BY

World Health Organization

By WHO Media Team

Study: **Countries urged to strengthen breastfeeding support and health systems to give every child a healthy start in life**

Current as of June 31, 2026

Too many mothers and families around the world still lack access to services and interventions that enable and support breastfeeding.

Yet breastfeeding is one of the simplest and most powerful ways to protect a child's health. It provides infants and young children with essential nutrition, increases immunity, helps protect against serious illness, and supports cognitive development.

For mothers, breastfeeding brings important health benefits too, helping reduce the risk of noncommunicable diseases such as breast and ovarian cancers, and type 2 diabetes.

Encouragingly, breastfeeding rates around the world are going up. Exclusive breastfeeding in the first six months rose from around 37 per cent in 2012 to over 47 per cent today. In the past five years, the prevalence of breastfeeding up to two years of age rose from 38 per cent to 50 per cent.

These gains show that sustained investments in policies and programmes for mothers and families are working. Yet progress remains uneven, with many countries lagging behind global targets. Coverage of services supporting breastfeeding remains low, policies are inconsistently enforced, and service quality is often inadequate, especially in low-income, fragile, and humanitarian settings.

The evidence is clear: cost-effective interventions include skilled breastfeeding support in health systems, community-based counselling, maternity protection policies, and protection from the exploitative marketing of commercial milk formulas.

The returns are significant. Scaling up breastfeeding could prevent almost 400 000 child deaths and around 140 000 maternal deaths each year. Every US$ 1 invested in breastfeeding promotion generates an estimated US$ 59 in economic returns through lower health-care costs, improved cognitive development, higher educational attainment, and increased lifetime earnings.

This World Breastfeeding Week, under the theme, "Breastfeeding for a Sustainable Start in Life: Strengthen What Works," UNICEF and WHO are calling on countries to:

- strengthen health systems to provide quality breastfeeding support for mothers and newborns;
- expand community-based counselling and peer programmes;
- fully implement and enforce the International Code of Marketing of Breast-milk Substitutes;
- invest in paid maternity leave and supportive workplace policies.
- integrate breastfeeding interventions into antenatal, perinatal, and postnatal health-care services; and
- sustain breastfeeding support in humanitarian and fragile contexts.

Breastfeeding is vital. By investing in proven solutions, we can give every child the

best possible start in life and ensure every mother gets the care and services she needs.

Neocate Infant Formula Lawsuit Alleges Nutritional Defect Caused Rickets, Bone Fractures

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About Lawsuits

By Michael Adams

Study: **Neocate Infant Formula Lawsuit Alleges Nutritional Defect Caused Rickets, Bone Fractures**

Current as of August 5, 2026

An Illinois mother has filed a Neocate infant formula lawsuit on behalf of her three children, alleging nutritional deficiencies in the specialized formula caused them to develop rickets, weakened bones and repeated fractures.

The complaint (PDF) was brought by Susan Millner on behalf of her minor children, who were identified with the initials A.M., E.M. and S.M. The case was originally filed in Illinois state court on June 25, naming Nutricia North America Inc. and Danone North America LLC as defendants, but it was later removed to the U.S. District Court for the Northern District of Illinois on July 28.

Millner claims Neocate was marketed as a nutritionally complete formula for medically fragile infants, despite problems with the bioavailability of phosphorus that allegedly left some children unable to adequately absorb the mineral.

Neocate Nutritional Concerns

Neocate is an amino acid-based, hypoallergenic elemental formula manufactured by Nutricia, which is owned by Danone. The products are designed for infants and children with cow's milk protein allergies, gastrointestinal disorders and other feeding problems.

Because children who require elemental formulas may be unable to tolerate other sources of nutrition, Neocate is sometimes used as their primary or sole source of nourishment. However, prior studies and case reports have raised concerns that Neocate infant formula may contribute to rickets and bone fractures among infants and young children who rely on the product for nutrition.

These risks are separate from those presented by other products such as Abbott Laboratories' Similac and Mead Johnson's Enfamil cow's milk-based infant formulas. Concerns about premature infants developing necrotizing enterocolitis (NEC) from those products have resulted in hundreds of infant formula NEC lawsuits filed in federal courts nationwide.

Neocate Rickets and Bone Fracture Allegations

Millner's three children were born prematurely in March 2012 and spent about three months in neonatal intensive care. All three experienced feeding problems and milk allergies, resulting in the hospital giving them Neocate with calcium and phosphorus supplements shortly after birth.

By October 2012, each child showed signs of serious bone problems. A.M. was diagnosed with extensive rickets and widespread bone demineralization after suffering an unexplained clavicle injury, while E.M. and S.M. were diagnosed with osteopenia and hypophosphatemic rickets.

The complaint indicates all three children subsequently suffered multiple fractures involving their ribs, arms or legs despite receiving nutritional supplementation.

Millner claims the children continue to experience complications from their bone injuries. A.M. allegedly suffers chronic pain and gross motor impairments that require ongoing medical care, physical therapy and use of a wheelchair. E.M. continues to experience chronic pain and an increased risk of future fractures, while S.M. requires ongoing medical treatment, physical therapy, pain management and parental assistance.

"Defendants, as the manufacturers and/or sellers of the products at issue in this litigation, owed a duty to the consuming public in general, and Plaintiffs in particular, to manufacture, sell, and distribute their products in a manner that was not unreasonably dangerous." — Susan Millner et al. v. Nutricia North America Inc. et al.

The filing further alleges Nutricia marketed Neocate as a "nutritionally complete" formula for infants and children who may depend on it as their primary or sole source of nutrition, despite problems with phosphorus absorption.

Millner claims Nutricia and Danone knew or should have known about the risk of phosphate malabsorption but failed to adequately warn about hypophosphatemia, rickets, skeletal demineralization and fractures.

According to the complaint, published research eventually prompted Nutricia to recommend monitoring phosphate and other micronutrients among medically complex children who rely on Neocate as their sole source of nutrition. Millner maintains those warnings should have been provided earlier or the formula should have been changed to reduce the risk.

The lawsuit points to a 2017 multicenter study involving 51 infants and children who developed unexpected hypophosphatemia and bone disease while relying on Neocate products as their sole source of nutrition. Although the formulas appeared to provide adequate phosphorus, researchers found evidence that the mineral was not being properly absorbed.

Some children reportedly improved after discontinuing Neocate or switching formulas, while low phosphorus levels returned in certain cases after Neocate was reintroduced.

The lawsuit raises allegations of strict liability for design defect, failure to warn, negligence, intentional misrepresentation, negligent misrepresentation and breach of express and implied warranties. It seeks compensation on behalf of Millner's children for their injuries, medical care and other losses, as well as reimbursement for past and future medical and caretaking expenses.

Court Rejects Appeal in Similac Special Care Lawsuit Over NEC Warnings

NEWS PROVIDED BY

About Lawsuits

By Irvin Jackson

Study: **Court Rejects Appeal in Similac Special Care Lawsuit Over NEC Warnings**

Current as of July 30, 2026

A federal appeals court has refused to reinstate a Similac necrotizing enterocolitis (NEC) wrongful death lawsuit filed by the mother of a newborn who died after being fed the infant formula, indicating that the hospital had no other food to feed her child.

The lawsuit was brought by Ericka Mar on behalf of herself and her deceased infant, RaiLee Mar, who was born 12 weeks premature on New Year's Day in 2014. After RaiLee's mother was unable to provide human milk about a week after the child was born, the hospital began feeding her Similac infant formula.

The child contracted NEC and died a day later, which her mother blames on Similac side effects. She filed the lawsuit in January 2022, presenting claims of strict liability, design defect, negligence and failure to warn. However, Abbott was granted a motion for summary judgment by a federal judge after arguing the hospital had no alternatives for feeding the child, making the lack of a label warning moot.

Infant Formula NEC Risks

NEC is a dangerous condition that occurs when bacteria breaches the walls of the intestines, which can cause tissue inflammation and necrosis. Infants, particularly preterm, already face an increased risk of NEC due to their underdeveloped gastrointestinal systems, but health researchers worldwide warn that cow's milk-based formula, like Similac, carries a much higher risk of the condition than human milk.

Newborns with NEC often require emergency surgery that could involve the removal of parts of the intestinal tract, often leaving the child with life-long health problems. In many cases, the infant does not survive.

Mar's complaint is one of thousands of infant formula NEC lawsuits filed against Abbott Laboratories and its competitor, Mead Johnson, the makers of Enfamil. Each claim alleges the manufacturers placed profit ahead of infant safety by failing to provide adequate warnings of the products' true risks.

Infant NEC Injury Appeal

After U.S. District Judge Rebecca Pallmeyer dismissed the case in the Northern District of Illinois, Mar appealed to the U.S. Court of Appeals for the Seventh Circuit. Following oral arguments on May 20, the appeals court issued an opinion (PDF) on July 24 affirming the lower court's decision and refusing to reinstate Mar's wrongful death lawsuit.

Chief Judge Michael B. Brennan wrote the opinion, indicating that the hospital's policy and a lack of human donor milk at the time meant there was no other choice of food to give to RaiLee.

"The hospital turned to the Abbott formula at issue because it had no donor milk. Another patient at the hospital who had recently given birth offered to donate some of her breast milk to RaiLee. But hospital policy forbade sharing milk because diseases can be transmitted without first treating the milk." – Chief Judge Michael B. Brennan, U.S. Court of Appeals for the Seventh Circuit

According to the opinion, Mar argued that if Similac carried a stronger label warning, the hospital would have chosen to use the unpasteurized donor milk instead of putting RaiLee at risk of NEC. However, the judges disagreed, saying the hospital's policy of not sharing untested breast milk would not likely have changed.

Abbott also asked the judges to find there was insufficient evidence that Similac caused the child's fatal case of NEC, a ruling that could have affected other infant formula lawsuits. However, the panel declined to decide that issue, finding it was sufficient for the appeal to conclude that Mar's proposed alternative warning would not have prevented RaiLee's death.

Infant Formula NEC Lawsuits

Judge Pallmeyer, who dismissed Mar's lawsuit, is also overseeing the federal infant formula NEC litigation, where hundreds of similar claims have been consolidated for coordinated pretrial proceedings and discovery. She is expected to preside over a series of early bellwether trials involving representative cases, which are intended to help both sides evaluate how juries may respond to evidence and arguments that could arise throughout the litigation.

The first federal Enfamil NEC lawsuit trial began on July 6, involving claims filed by Alexis Inman. A second trial is scheduled to start on August 10, focusing on claims brought by Mary Kelton.

Several trials have already been held at the state level, including a 2024 trial in Missouri that led a jury to order Abbott to pay nearly $500 million to a woman whose daughter suffered brain damage due to NEC. Also in 2024, another Missouri case initially ended in a defense verdict. However, the judge ordered a new trial after finding Abbott improperly introduced certain evidence.

In April, a Cook County, Illinois, jury handed down a $70 million verdict in a Similac lawsuit. Another Cook County jury returned a $60 million verdict against Mead Johnson in a lawsuit involving Enfamil formula, yet an appeals court tossed that verdict out on June 12 and ordered a new trial.

While the results of these bellwether trials are not binding on other cases, the outcomes are being carefully watched since they could help attorneys reach a future Similac infant formula NEC settlement agreement. If the litigation is not resolved by the end of the bellwether trials or pretrial proceedings, Judge Pallmeyer is likely to begin remanding cases back to their originating federal districts for individual trial dates.

Marler Clark, The Food Safety Law Firm, Files First Infant Formula Botulism Case

NEWS PROVIDED BY

Marler Clark, Law Firm

By Marler Clark, Law Firm

Study: **Marler Clark, The Food Safety Law Firm, Files First Infant Formula Botulism Case**

Current as of July 23, 2026

A lawsuit was filed today in court on behalf of Stephen and Yurany Dexter, parents of E.D.(a minor), against ByHeart, Inc. The Dexter's are represented by Marler Clark, The Food Safety Law Firm and O'Steen, MacLeod & Combs PLC of Phoenix, Arizona. The case was filed in the United States District Court in the District of Arizona. Case filing # 2:25-at-99911

The Dexter's infant, E.D., was born on July 5th, 2025 and introduced to ByHeart baby formula as a supplement to breast milk. On August 21, 2025, E.D. began to experience stomach discomfort and gas, steadily decreasing her intake until after a week, despite seeming hungry, she refused to eat. Over the next several days, her parents attempted to feed her by syringe which was unsuccessful as she was unable to swallow.

Seeking medical attention, the Dexter's rushed her to Phoenix Children's Hospi-

tal and were informed that since botulism was so rare, a diagnosis of muscular dystrophy was more likely. E.D.'s symptoms worsened and she could not suck, swallow, smile, hold her head up, move her limbs normally, or cry with normal strength. Her cry was faint and weak. The Dexter's feared E.D. might die or might never recover fully. Their infant was treated with BabyBIG antitoxin, and began occupational, physical and speech therapy.

Several weeks later the Dexters brought E.D. home from the hospital with an IV feeding tube where she is still recovering and experiencing digestive and strength issues. The long-term effects of Botulism are not known for E.D., but after this trauma she has developed separation anxiety and requires constant contact with her caregivers.

Outbreak Facts and Public Health Actions

As of November 10, 2025, 15 infants with suspected or confirmed infant Botulism were identified by health officials from 12 states: Arizona 1, California 2, Illinois 2, Kentucky 1, Minnesota 1, North Carolina 1, New Jersey 1, Oregon 1, Pennsylvania 1, Rhode Island 1, Texas 2 and Washington 1. Illness onset for 14 of these cases started on August 9 to November 10, 2025. All 15 infants were fed ByHeart Whole Nutrition Powdered formula before getting sick. All 15 were hospitalized and treated with BabyBIG, an anti-toxin for botulism.

The FDA and CDC, in collaboration with state and local partners, are investigating this multi-state outbreak of infant Botulism. Lab results reported by the California Department of Public Health suggest the presence of bacteria that produce botulism toxin in an open can of ByHeart infant formula that was fed to a baby with who developed botulism. Additional testing is underway, and results are expected in the coming weeks.

The FDA has been in contact with ByHeart and has requested a recall expansion to include all ByHeart infant formulas on the market. On November 11, 2025, ByHeart expanded its recall to include all ByHeart formula nationwide, including cans and single-serve sticks.

Symptoms of Botulism in Infants

If your infant is experiencing any of these symptoms, please seek immediate medical attention.

• Constipation: Often the first sign, with stools that may become less frequent and harder.

• Weakness: A general lethargy or decreased muscle tone (hypotonia), often described as "floppy baby syndrome."

• Poor Feeding: Difficulty feeding or sucking.

• Cranial Nerve Dysfunction: This can lead to symptoms such as: Weak cry or inadequate vocalization. Difficulty swallowing. Drooping eyelids or poor eye movement.

• Respiratory Problems: In severe cases, difficulty breathing due to muscle weakness can occur.

• Weakness in Movement: Reduced ability to move arms and legs.

• Irritability or unusual crying.

Scientists expand list of infant formula hazards

NEWS PROVIDED BY

Food Safety News

By Joe Whitworth

Study: **Scientists expand list of infant formula hazards**

Current as of July 20, 2026

Recent illnesses highlight the need to include Clostridium botulinum spores and cereulide toxin as relevant hazards in powdered infant formula, according to scientists.

Ingestion of botulinum neurotoxin (BoNT)-producing clostridial spores can result in infant botulism. Cereulide production during the manufacture of arachidonic acid (ARA) oil, an optional ingredient in infant formula, has also been linked to illness.

Scientists at the Joint FAO/WHO Expert Meeting on Microbiological Risk Assessment (JEMRA) in Rome, Italy in June said powdered formula manufacturers should implement supplier risk management programs addressing BoNT-producing clostridia and cereulide toxin produced by Bacillus cereus in ingredients.

Past outbreaks and recalls of formula have been caused by spore-forming bacteria like Clostridium botulinum, as well as Cronobacter, Salmonella, and by cereulide toxin produced by Bacillus cereus.

Four cases of infant botulism have been linked to Nara Organics powdered infant formula in the United States while 48 infants fell sick in an outbreak traced to ByHeart formula in late 2025, also in the United States. In the cereulide incident, 144 cases were reported in 10 countries in January and February 2026. Nestlé, Lactalis and Danone were among companies that recalled products.

Experts updated safety advice after a request from the Codex Committee on Food Hygiene. Efforts will support Codex work to improve international food safety standards.

Key points to consider

Powdered formula is at risk of contamination with microbial pathogens or their toxins from multiple sources, including the ingredients and environmental sources throughout the processing chain, up to and including the point at which it is reconstituted and fed to infants and young children.

The expert group backed the importance of controlling moisture and limiting the use of wet sanitation in powdered formula manufacturing. Also, hygiene indicators such as Enterobacteriaceae do not replace or reduce the need for pathogen-specific testing during environmental monitoring.

Scientists included Abigail B. Snyder from Cornell University, Kristin M. Schill, from the University of Wisconsin-Madison, Caroline Le Maréchal from ANSES in France, and Emma Hartnett, of Risk Sciences International in Canada.

They said root cause analysis should be enhanced by industry and government agencies following process control failures, including contamination events.

Consumers often rely on social media for information about infant feeding, including time saving practices and feeding products. Experts said risk messaging on formula preparation, handling and storage needs to adapt to these behaviors.

Current preparation recommendations designed to reduce the risk posed by Salmonella and Cronobacter may not be effective for BoNT-producing clostridial spores and toxin production by Bacillus cereus.

BoNT-producing clostridial spores have previously been detected in powdered formula but not definitively linked to infant botulism cases before 2025.

Powdered formula production processes

are not designed to eliminate BoNT-producing clostridial spores. Mitigation steps can potentially reduce spores prior to drying.

Bacillus cereus, including emetic strains that can produce cereulide, have been detected in formula, but the origin of contamination is often unknown.

Controlling the growth and toxin production of Bacillus cereus is critical throughout all stages of production, processing, preparation and storage. Cereulide toxin is highly stable and is not inactivated by hygienic or control measures in manufacturing.

Court Revives Lawsuits Tying Tylenol Use in Pregnancy to Autism and A.D.H.D.

NEWS PROVIDED BY

New York Times

By Azeen Ghorayshi

Study: **Court Revives Lawsuits Tying Tylenol Use in Pregnancy to Autism and A.D.H.D.**

Current as of July 13, 2026

A U.S. appeals court on Monday reversed a trial judge's decision to dismiss lawsuits against the makers of Tylenol, reviving hundreds of cases filed by families who claim that their children developed autism or attention deficit hyperactivity disorder after their mothers took Tylenol during pregnancy.

The judges, all Democratic appointees, ruled that the lower court overstepped by excluding scientific evidence presented by expert witnesses on behalf of the plaintiffs. That expert testimony, the judges argued, was valid evidence about a scientific question that they said was still under dispute.

The decision came less than a year after President Trump and top health advisers warned that taking acetaminophen, the active painkiller in Tylenol, while pregnant could cause autism and A.D.H.D. in children. That link is unproven: While some studies have suggested that there may be a small increase in risk, large trials aiming to account for underlying genetics and other factors have found no evidence that the painkiller can cause neurodevelopmental disorders in children.

Major medical groups, including the American College of Obstetricians and Gynecologists, have consistently stressed that Tylenol is the safest option to treat pain or fever during pregnancy. Untreated fevers can pose risks to both the mother and the fetus, including neurodevelopmental issues.

The ruling acknowledged the national attention on the issue. The appeals "arise against the backdrop of significant debate in the relevant scientific communities," the judges wrote. "That debate has also become political. But the issue before us is not political."

At the center of the appeals court decision was the question of whether the scientific evidence presented by the plaintiffs held merit. The primary expert witness for the plaintiffs was Andrea Baccarelli, the dean of the Harvard T.H. Chan School of Public Health, who submitted a report claiming that "substantial evidence" supported a causal link between use of acetaminophen during pregnancy and neurodevelopmental disorders like autism and A.D.H.D. in children, especially when taken frequently at high doses.

In December 2024, U.S. District Judge Denise Cote sided with lawyers for the defendants and ruled that Dr. Baccarelli had "cherry-picked and misrepresented study results" in his testimony and was therefore "unreliable."

During the November 2025 hearing at the U.S. Court of Appeals for the Second Circuit, Judge Gerard Lynch argued that the scientific information presented was valid, even if it was under dispute. "Reasonable scientists do appear to disagree," he said.

Ashley Keller, a lawyer for the main law firm representing the plaintiffs, Keller Postman, said that Monday's ruling represented "vindication for the scientific evidence our clients have presented from the outset." He added, "We look forward to presenting that evidence to a jury."

The defendants in the suits are Kenvue, which has been the maker of Tylenol since it was spun off from Johnson & Johnson in 2023, and major retailers that sell generic versions of acetaminophen.

"The procedural ruling today does not change the fact that credible, independent science shows no proven link between taking acetaminophen and autism or attention deficit hyperactivity disorder," said Melissa Witt, a spokesperson for Kenvue. "Science matters, and we stand with the many public health and medical professionals who have reviewed the science on this topic and agree."

Mrs. Witt said that the company would continue to argue that the expert opinions should not be allowed in the case. "We stand behind the safety of our product and will continue to defend these cases," she said.

Dr. Baccarelli did not immediately reply to a request for comment.

Because acetaminophen passes into the brain and crosses the placenta during pregnancy, scientists have researched its possible effects on fetal brain development for more than a decade.

But it has been difficult to draw firm conclusions about the impacts of Tylenol use on fetal development in part because no randomized, controlled clinical trials — the gold standard in medical research — have been conducted to answer the question.

Large observational studies cannot entirely account for the underlying factors driving a possible association in the data. And because acetaminophen is considered the safest painkiller for use during pregnancy and is available over the counter, it is difficult for scientists to collect data on how much women are using and when it is being used.

In August 2025, Dr. Baccarelli, along with collaborators at the Icahn School of Medicine at Mount Sinai, published a review of 46 existing studies that concluded that there was an association between Tylenol use during pregnancy and autism and A.D.H.D. That article was cited by Mr. Trump's health advisers, who also consulted with Dr. Baccarelli directly, in their recommendation to women to avoid the painkiller during pregnancy except in cases of high fever.

But many scientists argued that this review, which did not include any new data, did not appropriately account for underlying factors. Another review published in the British medical journal The Lancet in January of this year gave more weight to studies that attempted to account for the role of genetics, comparing siblings born to the same mother. Genetics is known to be a major contributor to autism risk. That study found no evidence for a link between acetaminophen and autism.

In June, a new sibling-controlled study of more than 700,000 mothers and children in Hong Kong also found no evidence of an association between acetaminophen use during pregnancy and autism or A.D.H.D. in children.

On Monday, the judges cautioned that their ruling should not be interpreted as evidence of a causal relationship between acetaminophen use in pregnancy and neurodevelopmental disorders in children.

"We are not deciding whether there is a general causal relationship between acetaminophen and ADHD and/or ASD," the judges wrote. "We are also not deciding whether the manufacturers of acetaminophen must warn consumers about any alleged risk posed by such a potential causal relationship. And we are certainly not deciding the approach that policymakers concerned with protecting public health should take to regulating the use of acetaminophen."

Rather, they continued, "We are called upon to decide how closely a trial court may scrutinize a qualified expert's conclusions when that expert follows methodologies that are generally accepted in their field."

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Genetics Corner: Unexpected Identification of a Pathogenic BMPR1A Deletion Following Chromosomal Microarray for Congenital Heart Disease

Danielle Gee, BS, Jennifer Shin, MS, Hua Wang, MD, PhD

Abstract:

Hypoplastic left heart syndrome (HLHS) is a severe congenital heart defect with a genetically heterogeneous etiology. Although associated with chromosomal abnormalities and genetic syndromes, the underlying genetic cause remains unknown in most cases. We describe a one-month-old male born at 35 weeks and 3 days gestation with prenatally diagnosed HLHS. Chromosomal microarray identified a 275 kb pathogenic deletion at chromosome 10q23.2 involving BMPR1A. Pathogenic loss-of-function variants and deletions of BMPR1A are associated with autosomal dominant juvenile polyposis syndrome (JPS). Although the deletion did not provide an established genetic explanation for the patient's HLHS, it identified an unexpected and clinically important diagnosis with implications for long-term surveillance and cascade testing. This case highlights the importance of carefully evaluating pathogenic copy number variants identified during the genetic evaluation of neonates with congenital anomalies.

Keywords: *hypoplastic left heart syndrome; 10q23.2 deletion; BMPR1A deletion; incidental findings*

"We describe a one-month-old male born at 35 weeks and 3 days gestation with prenatally diagnosed HLHS. Chromosomal microarray identified a 275 kb pathogenic deletion at chromosome 10q23.2 involving BMPR1A. Pathogenic loss-of-function variants and deletions of BMPR1A are associated with autosomal dominant juvenile polyposis syndrome (JPS). Although the deletion did not provide an established genetic explanation for the patient's HLHS, it identified an unexpected and clinically important diagnosis with implications for long-term surveillance and cascade testing."

Introduction:

Chromosomal Microarray (CMA) is a diagnostic genetic test commonly used to detect copy number variants (CNVs) or chromosomal abnormalities in infants with congenital anomalies (1). In critically ill neonates, the diagnostic yield of this type of testing is about 10–20% (1).

Because CMA evaluates the genome for copy number variants (CNV), testing may reveal findings unrelated to the original clinical indication. Such incidental findings can carry important implications for the long-term medical management of both the patient and their family (2). When pathogenic, these unexpected results may provide clinically actionable information that extends well beyond the initial reason for testing.

"Chromosomal Microarray (CMA) is a diagnostic genetic test commonly used to detect copy number variants (CNVs) or chromosomal abnormalities in infants with congenital anomalies. In critically ill neonates, the diagnostic yield of this type of testing is about 10–20%."

In this study, we report a case of a one-month-old male infant born with HLHS and identified to have a pathogenic 10q23.2 deletion, resulting in a molecular diagnosis of Juvenile Polyposis syndrome.

Case Summary:

A one-month-old male born at 35 weeks 3 days with prenatally identified hypoplastic left heart syndrome (HLHS) was evaluated by the Pediatric Genetics service.

The patient was born to a 23-year-old G_1P_{0101} mother and 21-year-old father at 35 weeks and 3 days gestation by vaginal, spontaneous delivery. Prenatal care began in the third trimester. Prenatal ultrasound identified HLHS, but fetal echocardiogram was not performed due to premature birth. His Apgar scores were 3 and 8 at 1 and 5 minutes, respectively. His birth weight was 6 lb 5.9 oz (75^{th} percentile), birth length was 50 cm (92^{nd} percentile), and birth head circumference was 31 cm (20^{th} percentile).

Postnatal echocardiogram at less than one day old confirmed hypoplastic left heart syndrome with aortic and mitral hypoplasia; moderate hypoplasia of the left ventricle, moderate transverse arch hypoplasia; patent foramen ovale; moderate hypertrophy and dilatation of the right ventricle; large patent ductus arteriosus; and probable left arch with aberrant right subclavian. Ultrasound of the head was normal. Abdominal ultrasound showed mild right renal pelvocaliectasis. Physical exam identified slightly upslanting palpebral fissures; square-shaped ears that were slightly low set and posteriorly rotated; and redundant-appearing neck skin. Extremities, including nails, digits, and palmar creases, were normal, and the patient moved spontaneously during the examination.

At 13 days old, the patient underwent a Norwood procedure with the placement of a 5-mm Sano Shunt, atrial septectomy, and ligation of an aberrant right subclavian artery. His recovery was complicated by right ventricular dysfunction requiring a second bypass run and a delayed chest closure.

Family history was significant for autism spectrum disorder, learn-

ing difficulties, and colon cancer, as shown in Figure 1. Mother had a history of learning difficulties; father had a history of seizures; maternal grandmother had a history of colon polyps; mother's paternal first cousin had autism spectrum disorder; maternal great-aunt was diagnosed with colon cancer in her 50s; and father's paternal half-brother had autism spectrum disorder. The mother was of Mexican ancestry, and the father was of Mexican and Native American ancestry. Consanguinity was denied.

"Postnatal echocardiogram at less than one day old confirmed hypoplastic left heart syndrome with aortic and mitral hypoplasia; moderate hypoplasia of the left ventricle, moderate transverse arch hypoplasia; patent foramen ovale; moderate hypertrophy and dilatation of the right ventricle; large patent ductus arteriosus; and probable left arch with aberrant right subclavian."

Genetic Testing:

Chromosomal microarray identified a 275 kb pathogenic deletion of chromosome 10q23.2; arr[GRCh37] 10q23.2(88,428,502_88,703,466)x1. This deletion partially overlaps the region associated with chromosome 10q22.3-q23.2 microdeletion syndrome, in which the critical region is unknown. The deletion includes the entire *BMPR1A* gene. *LDB3* and *MMRN2* are partially deleted. *BMPR1A* is associated with autosomal dominant juvenile polyposis syndrome (JPS) (OMIM: 174900), in which haploinsufficiency is a known mechanism of disease. *LDB3* is associated with autosomal dominant dilated and hypertrophic cardiomyopathy, left ventricular noncompaction, and myofibrillar myopathy (OMIM: 605906). *MMRN2* currently has no established association with disease.

"Family history was significant for autism spectrum disorder, learning difficulties, and colon cancer."

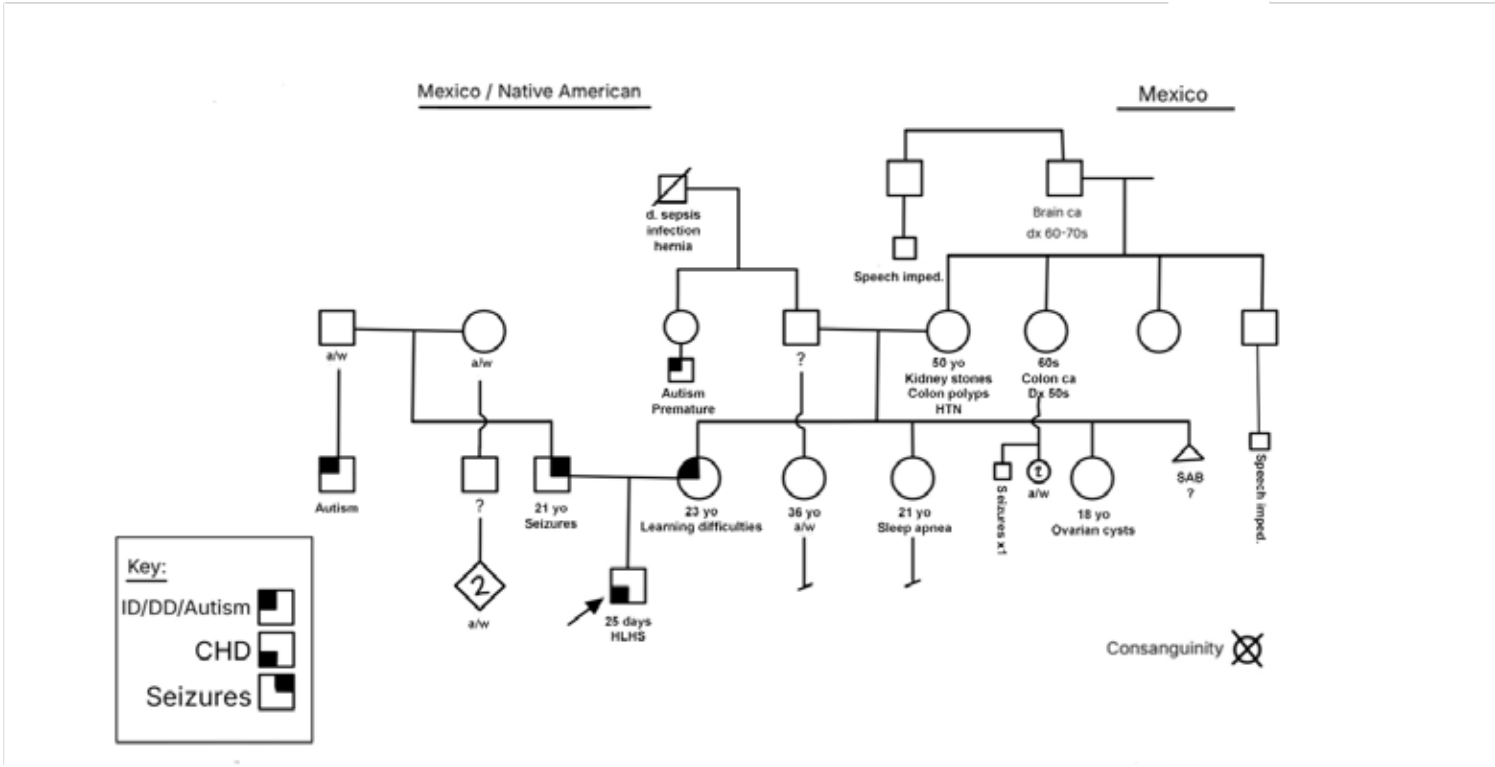
Patient was also identified to have two non-contiguous copy number gains involving chromosome 3p26.3, interpreted as a variant of uncertain significance (VUS); arr[GRCh37]3p26.3 (967,077__1,331,340)x3, 3p26.3(1,494,483_1,923,522)x3. The duplication includes the *CNTN6* gene, which currently has no well-established relationship with disease. However, there is preliminary evidence supporting an association with a neurodevelopmental disorder and, as a VUS, does not provide an established genetic explanation for the patient's HLHS (3–6).

Parental testing for both copy number variants was recommended but has not yet been completed. This is particularly relevant given the reported maternal family history of colon polyps and colon cancer.

Congenital Heart Defect and Heterotaxy panel was negative (Invitae).

Discussion:

Figure 1: Patient's maternal family history was significant for learning difficulties, autism spectrum disorder, and colon polyps.



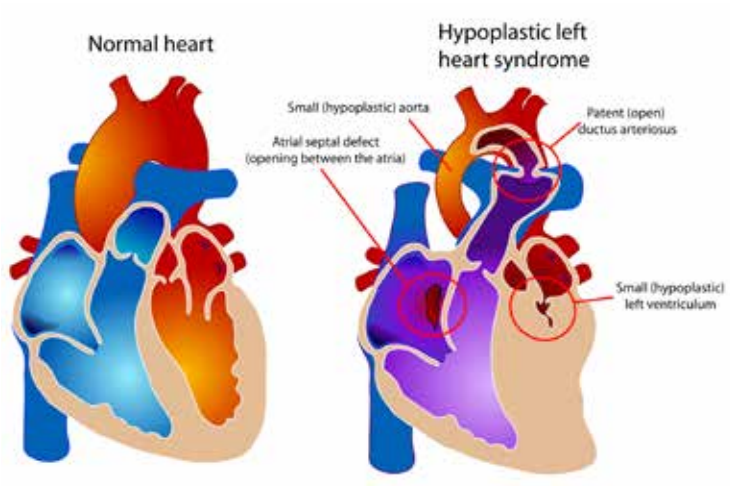
"The deletion includes the entire BMPR1A gene. LDB3 and MMRN2 are partially deleted. BMPR1A is associated with autosomal dominant juvenile polyposis syndrome (JPS)..."

Hypoplastic left heart syndrome is a severe, complex congenital heart defect occurring in approximately 2 out of every 10,000 live births. It is characterized by an underdeveloped left ventricle and is associated with left-sided cardiac defects, including abnormalities of the mitral valve, aortic valve, ascending aorta, and aortic arch. As shown in Figure 2, it encompasses a spectrum of anatomical subtypes based on the degree of atresia or stenosis of the mitral and aortic valves (e.g., mitral atresia/aortic atresia, mitral stenosis/aortic atresia, mitral stenosis/aortic stenosis). This congenital heart defect requires a series of surgeries to repair and is lethal without intervention (7).

Studies have shown that HLHS is heritable and has a genetically heterogeneous etiology (9, 10). However, in most cases the genetic cause remains unknown (9). It has been associated with chromosomal abnormalities and genetic syndromes, including monosomy X (Turner syndrome), trisomy 18, trisomy 13, terminal 11q deletion (Jacobsen syndrome), Holt-Oram syndrome, and others (7, 11). However, to our knowledge, no single gene has been identified as a monogenic cause of HLHS, although candidate genes including *NOTCH1*, *HAND1*, and *RBFOX2* have been identified (10).

The contribution of the 10q23.2 deletion involving *BMPR1A* to this patient's HLHS remains uncertain. *BMPR1A* is currently not established as a genetic cause of HLHS; however, pathogenic variants in BMPR1A have been reported in individuals with other congenital heart defects, including atrial and atrioventricular septal defects (12, 13). In addition, BMP signaling plays an important role in cardiac development (14). As a result, this deletion's potential contribution to the cardiac phenotype cannot be completely excluded. One study identified significant genetic linkage between HLHS and loci on chromosomes 10q22 and 6q23, further supporting the genetic heterogeneity and oligogenic inheritance of this complex heart defect (15).

Figure 2. Hypoplastic left heart syndrome with hypoplastic left ventricle, hypoplastic aorta, atrial septal defect, and patent ductus arteriosus. Reproduced from Mariana Ruiz (LadyofHats), Wikimedia Commons; public domain (8).



"Studies have shown that HLHS is heritable and has a genetically heterogeneous etiology. However, in most cases the genetic cause remains unknown."

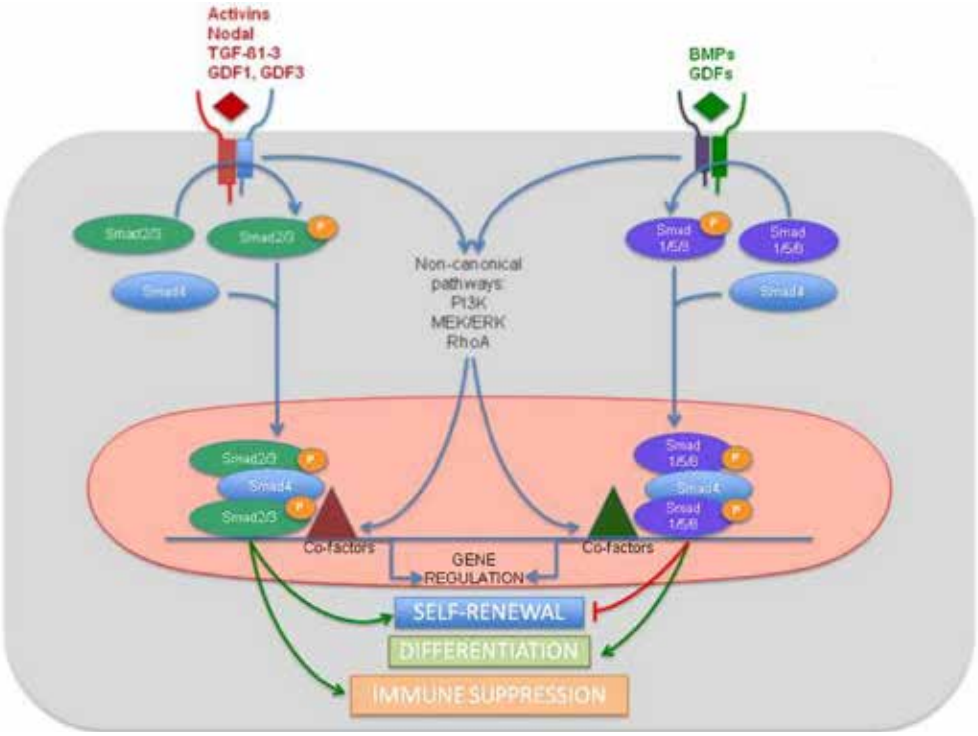
Although the 10q23.2 pathogenic deletion did not explain the patient's HLHS, it incidentally conferred a molecular diagnosis of JPS due to a pathogenic variant in the BMPR1A, or Bone Morphogenetic Protein Receptor Type A, gene. This gene encodes a type I receptor in the TGF-β/BMP signaling pathway shown in Figure 3. BMP ligand binding to its receptors initiates intracellular SMAD signaling, regulating the expression of genes involved in cellular growth and maintenance of intestinal tissue homeostasis. Decreased BMP signaling and impaired regulation of intestinal epithelial proliferation and differentiation, caused by germline loss-of-function variants or deletions of BMPR1A, increase the risk of developing hamartomatous polyps in the gastrointestinal tract and gastrointestinal (GI) malignancy (12, 17).

"BMPR1A is currently not established as a genetic cause of HLHS; however, pathogenic variants in BMPR1A have been reported in individuals with other congenital heart defects, including atrial and atrioventricular septal defects. In addition, BMP signaling plays an important role in cardiac development."

JPS is an autosomal dominant polyposis syndrome with an estimated incidence ranging from approximately 1 in 16,000 to 1 in 100,000—pathogenic variants in SMAD4 and BMPR1A cause it. Polyps may develop in any area of the GI tract, including the stomach, small intestine, colon, and rectum. Expressivity, including polyp number and age of onset, is highly variable even among family members. Some individuals develop polyps in infancy, while others develop them in adulthood. The number of polyps ranges between about five and more than 100. Most of the polyps in JPS are benign but may become malignant over time. Although the *SMAD4* pathogenic variants are associated with a higher risk of malignancy, surveillance of individuals with pathogenic variants in both genes is crucial for early detection (12).

The patient's deletion does not include the PTEN gene, located downstream of the *BMPR1A* gene on chromosome 10q23.31. *PTEN* is associated with autosomal dominant *PTEN* Hamartoma Tumor syndrome and is a known monogenic cause of autism and macrocephaly in children. Contiguous microdeletions that include both *PTEN* and *BMPR1A* can lead to a more severe phenotype known as juvenile polyposis of infancy (JPI) due to a synergistic

Figure 3: TGF-β/BMP signaling pathway. Reproduced from Caja et al. (16). Licensed under Creative Commmons 4.0 https://creativecommons.org/licenses/by/4.0/



effect caused by the deletion of both cancer predisposition genes. Symptoms typically present within the first two years of life and include diffuse pan-enteric polyposis, severe rectal bleeding, refractory anemia, protein-losing enteropathy with hypoalbuminemia, failure to thrive, macrocephaly, diarrhea, and anasarca. All documented cases have been sporadic or due to a *de novo* deletion (12, 18, 19).

"JPS is an autosomal dominant polyposis syndrome with an estimated incidence ranging from approximately 1 in 16,000 to 1 in 100,000—pathogenic variants in SMAD4 and BMPR1A cause it. Polyps may develop in any area of the GI tract, including the stomach, small intestine, colon, and rectum. "

According to the National Comprehensive Cancer Network Guidelines, surveillance by upper endoscopy with polypectomy and colonoscopy with polypectomy for individuals with a pathogenic *BMPR1A* variant starts at 12–15 years old (20). Earlier evaluation is indicated if symptoms such as gastrointestinal bleeding, unexplained anemia, diarrhea, abdominal pain, or other gastrointestinal concerns develop (12, 20). While this patient is currently too young for symptom onset or initiation of surveillance, his genetic test result carries significant implications for his long-term care. For cases like this, genetic counseling should be offered to the family to clarify the mode of inheritance and identify other relatives who may be at risk, regardless of family history.

"Contiguous microdeletions that include both PTEN and BMPR1A can lead to a more severe phenotype known as juvenile polyposis of infancy (JPI) due to a synergistic effect caused by the deletion of both cancer predisposition genes. Symptoms typically present within the first two years of life and include diffuse pan-enteric polyposis, severe rectal bleeding, refractory anemia, protein-losing enteropathy with hypoalbuminemia, failure to thrive, macrocephaly, diarrhea, and anasarca."

Conclusion:

Genetic testing was performed to investigate the genetic etiology of this patient's HLHS. Testing did not identify a genetic cause for his cardiac defect. However, a pathogenic 10q23.2 deletion involving *BMPR1A* was identified, establishing a molecular diagnosis of JPS. This incidental finding has important implications for long-term surveillance, genetic counseling, and family testing. This case illustrates that genetic testing in neonates with congenital anomalies may identify clinically significant findings beyond the original indication for testing and highlights the importance of carefully evaluating genes within pathogenic copy number variants.

"This case illustrates that genetic testing in neonates with congenital anomalies may identify clinically significant findings beyond the original indication for testing and highlights the importance of carefully evaluating genes within pathogenic copy number variants."

Practical Applications:

- Consider chromosomal microarray in neonates with congenital heart defects, as it can identify clinically significant copy number variants (CNVs).
- Pathogenic CNVs may not fully explain the patient's congenital anomaly but can still have important long-term implications for medical management and surveillance.
- When evaluating a CNV, it is important to determine which genes are deleted or duplicated, as specific gene involvement can influence the phenotype and guide appropriate management recommendations.
- Individuals with pathogenic deletions involving the *BMPR1A* gene should be referred to Genetic Counseling and Gastroenterology for appropriate screening and surveillance.
- Genetic counseling plays an important role in educating families, facilitating cascade testing, and addressing the psychosocial implications of a genetic diagnosis, especially when findings are unexpected.

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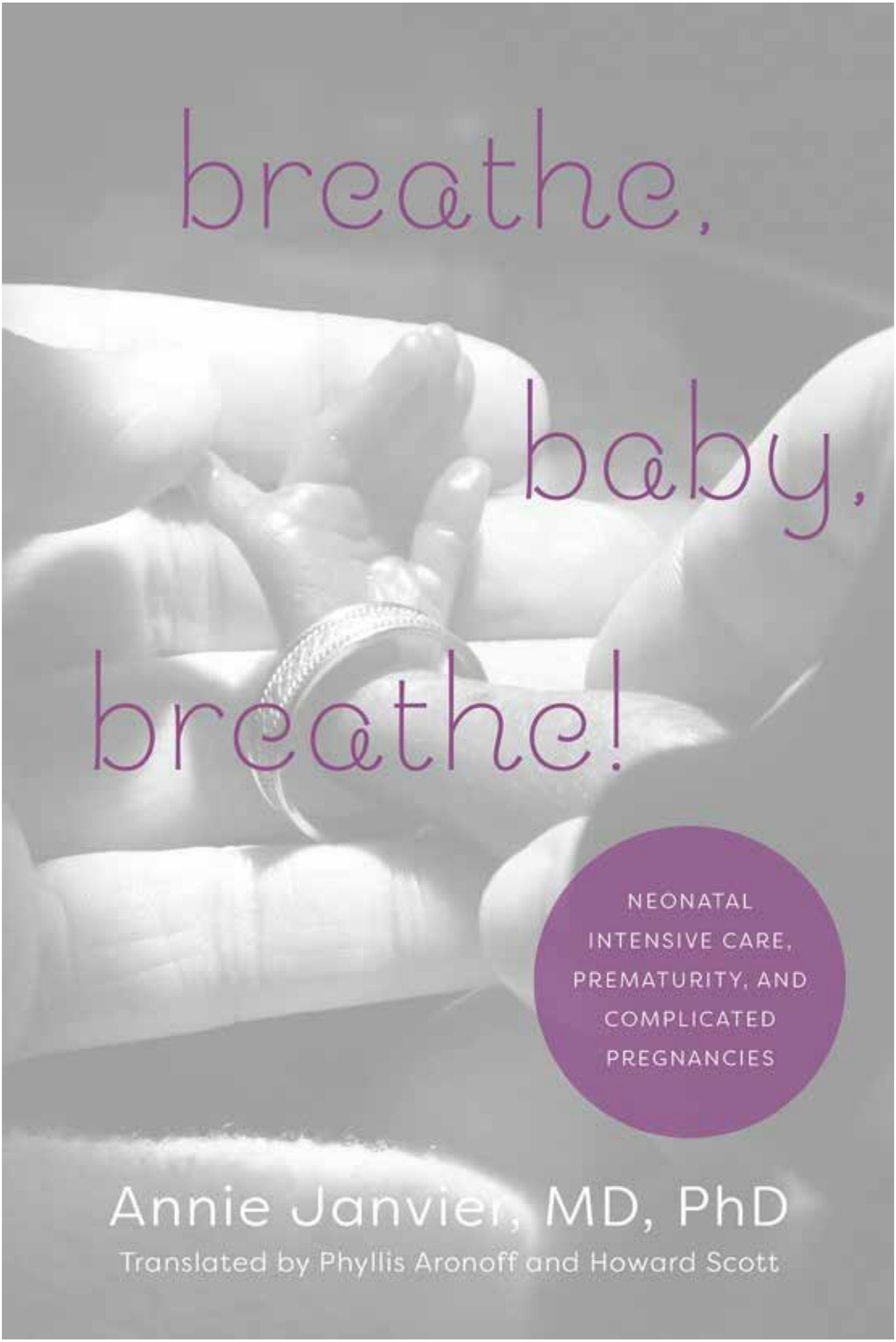
breathe,
baby,
breathe!
NEONATAL INTENSIVE CARE, PREMATURITY, AND COMPLICATED PREGNANCIES
Annie Janvier, MD, PhD
Translated by Phyllis Aronoff and Howard Scott

Peer Reviewed

Family-Centered Care Taskforce: 2026 FCC Scholars: Reflections

Malathi Balasundaram, MD, Morgan Kowalski

"The Family-Centered Care (FCC) Taskforce was delighted to support 11 FCC Scholars in attending Gravens Conference for the second year in a row. After supporting five neonatal fellows in 2025, the Taskforce was able to expand its reach and impact to include two Family Partners (former NICU parents engaging in peer support, quality improvement, and research), one early career neonatal nurse, and three early career neonatal therapists in addition to five neonatal fellows"

"Ultimately, 11 individuals were selected as FCC Scholars with nine invited to attend Gravens Conference in person and two to attend virtually. Support for in-person attendees included event registration, airfare, ground transportation, hotel, meals, etc., up to $2,000, while support for virtual attendees included event registration. "

Disclosure: *Mead Johnson Nutrition and Chiesi USAgenerously support this work.*

"Thank you to the Michael Hynan Fund and those webinar speakers who donated their honoraria over the last year to make two Family Partner scholarships possible. Thank you to Chiesi USA for their independent educational grant which supported eight scholarships, and to Mead Johnson Nutrition who provided support for one FCC Scholar. "

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2026 FCC SCHOLARS: REFLECTIONS

The Family-Centered Care (FCC) Taskforce was delighted to **support 11 FCC Scholars in attending Gravens Conference for the second year in a row**. After supporting five neonatal fellows in 2025, the Taskforce was able to expand its reach and impact to include two Family Partners (former NICU parents engaging in peer support, quality improvement, and research), one early career neonatal nurse, and three early career neonatal therapists in addition to five neonatal fellows.

When Dr. Malathi Balasundaram regularly attended Gravens Conference as early career faculty, her passion for collaborating with families in the care of their infants was sparked and ignited and led her to found the Family-Centered Care Taskforce at the 2022 event. The annual conference has remained significant to her over the years and is where she ultimately met Morgan Kowalski, NICU parent and FCC Taskforce Director of Operations, in 2023 and where they have co-presented FCC-related research and quality improvement work accomplished by the Taskforce ever since.

It has been long recognized that **NICU families enhance conferences** by sharing their lived experience and their unique expertise in supporting research and quality improvement work. While families are often invited to speak and co-present at medical conferences, **they lack the institutional funding necessary to attend**. In an effort to overcome this barrier to parent participation, Malathi and Morgan established a Family Partner fund with support from **Michael Hynan, PhD**, who is not only a giant in the field of neonatology but a NICU father as well. They also secured a Chiesi USA Independent Educational Grant and support from Mead Johnson Nutrition to fund this year's scholarships.

After advertising the FCC Scholars application with their 3,700+ community members, 79 organizational partners (including NICU Parent Network, National Association for Neonatal Nurses, National Association for Neonatal Therapists, and AAP's Trainees and Early Career Neonatologists (TECaN)), and in Neonatology Today, the FCC Taskforce **received over 60 impressive submissions** from applicants across the United States, Canada, India, and Ghana, and engaged a selection committee of 11 multidisciplinary NICU staff and family partners from their Executive and Advisory Councils to blindly review and score applications.

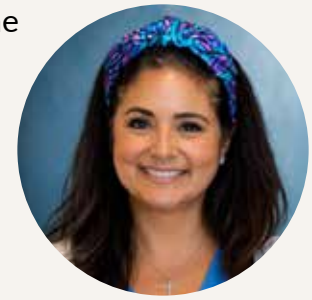
Ultimately, 11 individuals were selected as FCC Scholars with nine invited to attend Gravens Conference in person and two to attend virtually. Support for in-person attendees included event registration, airfare, ground transportation, hotel, meals, etc., up to $2,000, while support for virtual attendees included event registration. All the FCC Scholars expressed their appreciation to the FCC Taskforce for the opportunity to attend Gravens Conference and to the NICU parents who shared their stories. Below are some reflections on their time at Gravens:

FCC Scholars on First Day of Gravens Conference

Janna Andre
NICU Parent Advisory Committee,
Mount Sinai Hospital
NICU Parent

"I was especially struck by examples of parent collaboration that extended beyond traditional advisory roles and into true partnership, including units where parents train new staff and are included across all unit committees. . . . Parent voice belongs in the spaces where decisions are made that shape the daily reality of families in the NICU. . . . I was also **deeply touched by the conversations about fathers and non-birthing parents**, and the ways they can feel invisible while carrying fear, responsibility, and the pressure to be strong for everyone else. . . . Fathers and non-birthing parents also need to be invited in, reassured, and asked how they are doing. . . . I am grateful to bring these insights back into my work with a renewed commitment to strengthening parent partnership at both the bedside and the systems level, and to helping ensure that every parent feels welcomed, supported, and recognized as essential in their baby's care." **-Janna Andre**

"As both a NICU Family Support Specialist and a former NICU parent, I was deeply moved by the shared commitment of professionals from across the country who are dedicated to improving outcomes for infants and families. **Listening to NICU parents courageously share their journeys of hope, resilience, loss, and healing was one of the most impactful parts of the conference.** Their stories offered a powerful reminder of the lasting effects that trauma can have on families and reinforced the importance of providing compassionate, trauma-informed, family-centered care throughout the NICU journey. Two of my favorite learning experiences were the Support for NICU Fathers and Non-Birthing Parents Workshop. . . and the NICU tour at Beacon Children's Hospital. . . Inspired by what I learned, we are beginning a NICU Literacy Program to encourage early bonding through reading, developing a Just Dads Welcome Kit, and exploring additional ways to intentionally support and include fathers and birth partners throughout the NICU experience. " **-Valicitie Porrata-Rubino**



Valicitie Porrata-Rubino
NICU Family Support Specialist,
The Valley Hospital
NICU Parent

Isabella Massey, BSN, RNC-NIC
Knowledge & Innovation Council Chair
Cooper University Hospital

"What made the Gravens Conference especially meaningful was the **collaboration between every discipline connected to the NICU**: physicians, nurse practitioners, nurses, therapists, parents, family partners, architects, scientists, and so many others. **Every voice had a seat at the table, united by a shared commitment to NICU patients and their families.** I left the conference feeling energized and inspired, with countless innovative ideas that I am excited to bring back to my unit. The knowledge I gained, the conversations I had, and the connections I made will continue to shape and strengthen my practice as a NICU nurse for years to come." **-Isabella Massey**

"Whether through positive touch and sensory experiences, such as skin-to-skin care, or supporting parents as they participate in feeding and learn to read their infant's cues, families have a unique and important role in shaping their infant's development. As neonatal therapists, we have an opportunity to move beyond traditional models of care and empower families as confident participants rather than passive observers. The **conversations at Gravens challenged me to reflect on practices that have become routine and ask whether they truly serve infants and families** in the best way possible." **-Kelly Williamson**

Kelly Williamson, M.S. CCC-SLP
Speech-Language Pathologist
Johns Hopkins Bayview Medical Center

Dana Apkon, MD
Second Year Fellow,
Boston Children's Hospital
at Harvard

"**Gravens allowed me to really practice the family-partnered language that I can use and model in the NICU as a front-line provider.** I really appreciated hearing from families about what true "partnership" looks like to them, rather than "inclusion." I now actively look and advocate for ways to truly partner — thinking of how to involve families in holding and providing comfort during painful procedures, assessments, and discharge planning. Discussing these practical changes with families and other providers in attendance helped me to think critically about how we can implement these changes on a larger scale as well and to raise the bar of developmental care." -**Dana Apkon**

Daphne Darmawan, MD, MBS
Third Year Fellow
Stanford Lucile Packard
Children's Hospital

"One of my biggest reflections was the importance of caring for the whole family throughout the NICU journey, including the often overlooked "fourth trimester." I was struck by the emotional conflict parents face when they need to leave their baby's bedside to care for themselves postpartum, and it reinforced the need for systems that support parents not only as caregivers, but as individuals navigating recovery and uncertainty. I was also **inspired by the creativity around reimagining the NICU experience, including the involvement of architects and designers in creating spaces that better support families**. Discussions around sound protection, sibling inclusion, and NICU design challenged me to think critically about how our environment shapes connection and trust. . . . I leave Gravens motivated to continue questioning traditional practices and helping create NICUs where every family feels welcomed and supported." **-Daphne Darmawan**

Elizabeth Lee, MD
Second Year Fellow
Johns Hopkins Children's Center

"I will certainly take the lessons I learned from [NICU parent] stories back to my home practice, especially the **importance of intentionally involving NICU dads in care**. One quote that has stayed with me since the conference was the call to action to help infants and families move from surviving to thriving through intentional efforts to improve every aspect of care. . . . I hope to carry the teachings from this conference with me by continuing to work toward improving the experiences of NICU families, finding meaningful ways to involve parent voices in decision-making, and always striving to help our NICU infants and families move from surviving to thriving." **-Elizabeth Lee**

Trisha Mulamreddy, MD, MPH
First Year Fellow
University of California,
Los Angeles

"The lesson I will carry longest is that **our impact extends far beyond the NICU walls**. The weeks families spend with us shape how parents see themselves, how siblings process experiences they may not have words for yet, and how entire family systems find their footing long after discharge. That means our circle of care has to be wider than the mother-infant dyad we have traditionally centered. It has to include fathers, non-birthing parents, and siblings as equal participants in the story we are helping this family write. The NICU is where a whole family begins to form around a new life, and every member of that family deserves a place in it."
-Trisha Mulmareddy

Kelly MacPherson, MD, MS
First Year Fellow
Women & Infants Hospital,
Brown University

"My second child was born at 33 weeks' gestation, during my third year of pediatrics residency, and he spent two weeks in the NICU where I am currently completing fellowship training. Since then, I have been trying to find ways to incorporate my personal experience as a NICU parent into my training to better serve my patients and their families. **It was an absolute honor and privilege to learn from the families who shared their inspiring, but often distressing, stories of their neonate's journey through their early days, weeks and months of life in the ICU.** Their stories reminded me that, as medical providers, we may underestimate the overwhelming amount of mental, physical and emotional stress our birthing parents and their partners and support systems are going through as their little one enters our units. . . . It is our moral obligation to create an inclusive, supportive and informative space while they process their NICU journeys." **-Kelly MacPherson**

Sharath Hullumani
Pediatric & Neonatal Physiotherapist
Acharya Vinobhabve Rural Hospital,

"Despite attending from India, **I felt connected to a global community of clinicians, researchers, educators, and family advocates who share a common commitment to improving neonatal care**. . . . One of the most valuable lessons I gained was the importance of translating FCC principles into everyday clinical practice. The sessions highlighted practical approaches to strengthening communication, empowering parents as integral members of the care team, and creating healthcare environments where families feel heard, respected, and supported. . . . As a pediatric physiotherapist and researcher, these insights have further strengthened my commitment to advancing Family-Centered Care through clinical practice, education, and research, with a particular focus on developing culturally appropriate and sustainable FCC initiatives in India. . . . Having recently completed my Ph.D. with a research focus on Family-Centered Care in neonatal practice, this experience has reaffirmed my dedication to improving neonatal outcomes by fostering meaningful partnerships between healthcare professionals and families." **-Sharath Hullumani**

Niharika Mathur
Senior Physiotherapist
& PhD Scholar
All India Institute of
Medical Sciences

"**Attending. . . as a Virtual Scholar was quietly transformative.** As a neonatal therapist and PhD scholar, I came with the lived experience of an Indian NICU - its pace, its families, its complexities. Gravens. . . pushed me to think more intentionally about clustering care around the infant's neurodevelopmental needs and moving from informing families to truly partnering with them. Most significantly, it challenged how I think about who belongs in the NICU. In India, mothers carry the weight of infant care while fathers wait outside - present in the crisis, absent from the care. This is not a cultural inevitability; it is a gap. Involved fathers report stronger attachment, lower anxiety, and greater caregiving confidence. There is no clinical reason to leave them at the door - only habit, and habit can change. **Gravens also sparked something really important- the need for peer support among NICU families**. . . . A parents' group where one family's experience becomes another's anchor offers what no protocol can - the comfort of shared survival. In a setting where mental health support is scarce, this may be the most human and accessible intervention we can build. . . . I left with better questions than I arrived with - and that, in itself, felt like enough." **-Niharika Mathur**

Thank you to the **Michael Hynan Fund** and those webinar speakers who donated their honoraria over the last year to make two Family Partner scholarships possible. Thank you to **Chiesi USA** for their independent educational grant which supported eight scholarships, and to **Mead Johnson Nutrition** who provided support for one FCC Scholar. We also sincerely appreciate our selection committee for their time, support, and discernment:





Malathi Balasundaram, MD, **Jessi Barnes**, MSN, RN, RNC-NIC, NPD-BC, NICU Parent, **Latoya Blueford**, NICU Parent, **Sahra Cahoon**, NICU Parent, **Jessica Fry**, MD






Mitchell Goldstein, MD, **Morgan Kowalski**, NICU Parent, **Ramya Kumar**, MS, CCC-SLP, BCSS, CNT, IBCLC, NTMTC, SBCS, **Katrina Moline**, NICU Parent, **Vincent Smith**, MD, MPH, **Keira Sorrells**, NICU Parent

FCC Taskforce Leadership Team, Executive & Advisory Council Members, and FCC Scholars

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FCC TASKFORCE WEBINAR

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11:30AM - 12:30PM PT

PREGNANCY & DISABILITY: INTRODUCING THE ACCESSIBLE PREGNANCY ACTION PLAN

Kara Ayers, PhD (she/her)
Associate Professor,
Cincinnati Children's Hospital Medical Center
NICU Parent

SUPPORTING PARENTS WITH DISABILITIES: INCLUSIVE, MULTIDISCIPLINARY CARE FOR LACTATION & BEYOND

Alesha Thomas, BS, IBCLC (she/her)
Founder & Executive Director,
Adaptive Parent Project
NICU Parent of Nolan

RETHINKING DISABILITY IN THE NICU

Amy RL Rule, MD, MPH, FAAP (she/her)
Associate Professor of Pediatrics,
Newborn & Hospital Medicine
Director, GHOPE Pediatric Residency Track
Co-Director, Center for Maternal Infant Health

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information to address our current challenges

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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.

Placental Perforation and Fetal Hemorrhage Following Intrauterine Pressure Catheter Placement

Maureen Sims, MD, Barry Schifrin, MD

"At delivery, the 2,885-gram female infant was pale and lifeless. She underwent a full resuscitation including intubation and multiple doses of epinephrine first delivered via endotracheal tube, followed by several doses through an emergently placed umbilical venous catheter. Apgar scores were 0, 1, 1, and 3 at 1, 5, 10, and 15 minutes, respectively. She was also given a bolus of normal saline (10 mL/kg) and five aliquots of packed red blood cells (10 mL/kg each)."

27-year-old G2, P1 woman with an unremarkable prenatal course including ultrasound examinations which found the fetus to be of average size and the placenta located posteriorly and low. GBS status was negative.

At 39 2/7 weeks' gestation, an elective induction of labor was undertaken. Labor progressed unremarkably after artificial rupture of membranes revealed clear fluid. Two hours later, a midwife inserted an intrauterine pressure catheter (IUPC). Within 2 minutes of that insertion, there appeared a sudden fetal bradycardia to 50 beats per minute (bpm) that was unrelieved by various positional changes. An emergency was declared, and an operating team and pediatrics were mobilized for an emergency cesarean section, which was accomplished under spinal anesthesia within 18 minutes of the fetal bradycardia.

At delivery, the 2,885-gram female infant was pale and lifeless. She underwent a full resuscitation including intubation and multiple doses of epinephrine first delivered via endotracheal tube, followed by several doses through an emergently placed umbilical venous catheter. Apgar scores were 0, 1, 1, and 3 at 1, 5, 10, and 15 minutes, respectively. She was also given a bolus of normal saline (10 mL/kg) and five aliquots of packed red blood cells (10 mL/kg each).

At 40 minutes of age, the infant was transferred to the NICU on positive pressure ventilation (PPV), with a heart rate ranging from 60–100 bpm. Physical examination revealed an appropriately grown female, without dysmorphic features. Her length was 48.5 cm, and the head circumference (HC) was 34 cm. Ponderal index = 2.5

The admission blood pressure was 89/53 mmHg (mean 62 mmHg). The initial blood gas (capillary) at 40 minutes revealed a pH of 6.84, a pCO_2 of 87 mmHg, a pO_2 of 61 mmHg, a base deficit of 19, and a lactate of 13.7 mmol/L/ values reflecting a severe metabolic acidosis.

The infant underwent 72 hours of total body therapeutic hypothermia with the presumptive diagnosis of hypoxic-ischemic encephalopathy (HIE). Complete blood count showed a hematocrit of 63%, with an otherwise unremarkable white blood cell count and normal platelets. The remaining laboratory results were unremarkable except for mild coagulopathy and mild elevation of AST. During the NICU course, the infant developed seizures. A cranial ultrasound at 24 hours was read as normal. A brain MRI on day 4 showed no areas of abnormal diffusion restriction, though the study was limited by patient motion. The infant was discharged at 8 days of age on no medications and tolerated nipple feeds. Subsequent evaluations revealed gross motor impairment and expressive language delay.

"The infant underwent 72 hours of total body therapeutic hypothermia with the presumptive diagnosis of hypoxic-ischemic encephalopathy (HIE)... The infant was discharged at 8 days of age on no medications and tolerated nipple feeds. Subsequent evaluations revealed gross motor impairment and expressive language delay... The hospital was sued. The allegation asserted negligent application of the IUPC by the midwife causing rupture of a fetal vessel, fetal hemorrhage, and neurological injury resulting in subsequent handicap."

Placental Findings: Placental weight: 345 g (F/P=8.4) with acute sub-amniotic hemorrhage.

The hospital was sued. The allegation asserted negligent application of the IUPC by the midwife causing rupture of a fetal vessel, fetal hemorrhage, and neurological injury resulting in subsequent handicap. No defense was forthcoming from various defense experts other than the repeated notion that complications from IUPC insertion are rare; that no specific informed consent from the mother is required; and that even trained midwives may insert the device unsupervised. Furthermore, there was no requirement

that the position of the placenta or the fetus be ascertained prior to insertion. After discovery, the case was settled prior to trial.

Discussion:

Accurate determination of the timing, rhythm, frequency, and duration of uterine contractions is important for assessing labor progress, understanding fetal responses to contractions, and determining the feasibility of safe vaginal delivery.

Techniques for assessing uterine contractions include manual palpation, external tocodynamometry (TOCO), internal pressure monitoring with an IUPC, and, more recently, electrohysterography from the mother's abdominal wall. (1).

External palpation is quite subjective, especially for determining increased uterine tone, and requires the extended physical presence of a provider to perform frequent and sustained examinations. It is not reproducible, especially the assessment of tone and, to some extent, the duration of the contraction.

External Tocodynamometer (TOCO) is the most widely used device for recording contractions during labor. It provides an objective record (though sometimes erroneous) estimate of the frequency and duration of contractions without requiring the physical presence of a clinician. However, the absolute onset, offset, contraction strength, and baseline uterine tone cannot be quantified because the device measures relative changes in abdominal wall tension over the uterus. Its accuracy is limited, and frequent adjustments may be required to produce a reasonably consistent tracing, especially in patients who move, are obese, or are in the 2nd stage of labor.

"Electrohysterography is a noninvasive technology that detects uterine electrical activity using electrodes placed on the mother's abdomen. It appears more accurate than the TOCO and is less affected by maternal obesity, but is less accurate than the IUPC. Unlike the other techniques, it does not depict maternal pushing – a significant drawback."

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The Intrauterine Pressure Catheter (IUPC) overcomes many of these limitations as it provides a reliable, quantitative measure of uterine activity with minimal, determinable artifacts (2, 3). An IUPC can be used to estimate the exact onset and offset and strength of the contraction as well as intrauterine tone between contractions;

While the IUPC represents the current clinical gold standard for accurately measuring various contraction parameters and may be used electively as in this case, it is not routinely used for contraction surveillance during labor. Indeed, large studies suggest that routine use does not improve maternal or fetal outcomes [e.g., low Apgar scores, umbilical artery acidemia, neonatal intensive care unit admission, operative delivery, or hyperstimulation (4)) but does increase costs, complexity, and perhaps complications compared with external methods.

There are, however, clinical situations in which the TOCO is inoperative or difficult to maintain that the use of an IUPC is required if there is to be a reasonable assessment of uterine activity or to obtain access to the intrauterine cavity for amnioinfusion.

Its drawbacks include the need for ruptured membranes and sufficient cervical dilatation to admit the catheter tip in its introducer and the examiner's finger(s) to guide it; it must be introduced carefully and easily (without force) (19). and for appropriate indications. Rupture of the membranes, unless done early in association with oxytocin induction, does not reliably increase the speed of labor. Prolonged rupture of the membranes increases the risk of molding and fetal head trauma (20). Contraindications include known or suspected placenta previa, vasa previa, or low-lying placenta. Placement is also contraindicated in the 2nd stage of labor where the cervix is no longer palpable, and the fetal head is at a low station. Vaginal bleeding, suggestive of placental abruption, is also a contraindication. Some consider chorioamnionitis a contraindication, while others take advantage of the fluid used for amnioinfusion to remove bacteria from within the amniotic cavity. (see below)

"The introduction of the IUPC is associated with rare but serious risks of uterine perforation, placental abruption, extraovular placement (between the membranes and the uterine wall), disruption of fetal vessels and hemorrhage as in this case."

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Apparently paradoxically, it is yet unclear whether use of an IUPC is helpful for facilitating the diagnosis of uterine rupture in patients at higher risk for this complication (5-8). In a series of 39 cases of uterine rupture in which an IUPC was in place, the expected loss of intrauterine pressure was not observed in any patient (5). In two case reports, however, a stepwise, gradual decrease in uterine contraction amplitude (called the "staircase sign"), followed by the onset of severe variable decelerations, was observed after rupture (8).

Complications following IUPC placement are rare; some are inconsequential, while others are life-threatening, as in the above case. However, significant changes in the fetal heart rate pattern (usually bradycardia), bleeding from the IUPC or the vagina, or significant maternal pain should prompt immediate evaluation and likely intervention.

Extra-membranous placement involves extraovular insertion between the fetal membranes and decidua (19,26-28). Signs of extra-membranous placement include lack of fluid return and bloody return. Extra-membranous placement may be asymptomatic, or it can lacerate the placenta or cause an abruption manifest as a sudden fetal bradycardia and/or high contraction pressures from

the induction of uterine hypertonus. Detection usually begets removal. An extra-membranous catheter cannot be used for amnioinfusion.

Uterine perforation — If the tip of the catheter perforates the myometrium, there may be no signs at all. Under these circumstances, the tracing responds to maternal coughing but not to uterine contractions. More serious findings may include bloody insertion, abdominal pain, and/or systemic signs in the mother (eg, tachycardia, hypotension).

Umbilical cord prolapse can occur during IUPC placement, especially if the presenting part is dislodged during insertion of the introducer and catheter.

In very rare circumstances, amniotic fluid embolism (AFE) may occur immediately after IUPC placement (32, 33), resulting in obvious fetal bradycardia along with maternal respiratory difficulties and hypotension.

"Perforation of the umbilical cord, fetal blood vessels on the placental surface, or the placental parenchyma by the IUPC (19,26,27,34) may result in massive fetomaternal hemorrhage (35) that may NOT be associated with vaginal bleeding. This is associated with immediate frequent bradycardia, frequent uterine contractions, but absent systemic signs in the mother. Outcomes are frequently poor because the severity of the anemia is not promptly recognized and treated. Even with rapid cesarean section and volume replacement as in this case, the risk of death, seizures and long-term handicap is very high. (34)."

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Regarding the risk of infection with the IUPC, one systematic review of randomized trials comparing IUPC and TOCO found no increase in maternal or neonatal infection with IUPC (4). Other comparative trials have found that IUPC use was associated with a significant increase in surgical site infections (36). Given its frequent use with prolonged labor and prolonged ruptured membranes, the relationship between IUPC use and infection is probably indirect: it increases exposure of the uterine cavity to ascending bacteria while also being strongly linked to other risk factors for infection. **What remains troubling about the details of this case is the total lack of concern about the risks of IUPC placement, the lack of required knowledge of the location of the placenta, and the arbitrary insertion by the midwife when the TOCO device was properly registering contractions. The introduction of the IUPC would not in any meaningful or foreseeable way have changed the management of this patient.**

"What remains troubling about the details of this case is the total lack of concern about the risks of IUPC placement, the lack of required knowledge of the location of the placenta, and the arbitrary insertion by the midwife when the TOCO device was properly registering contractions. The introduction of the IUPC would not in any meaningful or foreseeable way have changed the management of this patient."

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Peer Reviewed

Medicolegal: Neonatal Herpes: A Brief Review and Cautions for the Provider

Jonathan Muraskas, MD, Jay P. Goldsmith, MD

"A 35 y/o G3 mother was transferred at 34 weeks gestation from a community hospital for "atypical pre-eclampsia." Mother had prenatal care and no significant past medical history, including infectious disease exposure... Mother gave no history of herpes, and no genital lesions were noted on physical examination."

Case:

A 35 y/o G3 mother was transferred at 34 weeks gestation from a community hospital for "atypical pre-eclampsia." Mother had prenatal care and no significant past medical history, including infectious disease exposure. She was seen by MFM physicians. Mother gave no history of herpes, and no genital lesions were noted on physical examination. Because of evidence of HELLP syndrome, a cesarean was performed at $34^{2}/_{7}$ weeks, resulting in the birth of a viable male with a birthweight of 2300 grams. Apgar scores were 8 and 9 at 1 and 5 minutes, respectively. Admitting physical exam was unremarkable, and the infant required 2 liters of high-flow with a low inspired oxygen concentration for mild respiratory distress. A routine septic workup was performed, and antibiotics were administered for 36 hours. The early NICU course was unremarkable; however, on the 10th day of life, the infant developed a temperature of 101°F rectally with evidence of evolving multiorgan failure. Liver function studies were drawn, revealing AST and ALT of 680 and 518, respectively. A workup for herpes was done, and acyclovir was initiated. Herpes cultures (HSV-1) were positive, and despite Acyclovir administration, the baby had rapid clinical deterioration and expired during the next 24 hours, consistent with disseminated herpes. After the baby's death, the mother admitted her partner might have herpes. This was confirmed by PCR testing of the parents.

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Herpes Simplex Disease in the Neonate:

Herpes simplex viruses (HSV) that are transmitted from a pregnant woman to infants can cause substantial neonatal morbidity and mortality. There are 2 distinct types of HSV, HSV-1 and HSV-2, both of which can be responsible for neonatal disease. Advances in diagnostic capabilities and antiviral treatment options have led to improved clinical outcomes in infected infants. However, significant morbidity and mortality remain in infants with invasive HSV disease, especially those with CNS (morbidity) or disseminated (mortality) involvement. Humans are the only known natural reservoir of HSV, and serial prevalence studies indicate that HSV-1 and HSV-2 infections are common worldwide, in both developed and developing countries. More than 90% of adults have acquired HSV-1 infection by their fifth decade of life, although only a minority develop clinically apparent disease at the time of acquisition. In the last decade, HSV-1 (as opposed to HSV-2) has become the predominant virus causing genital herpes, responsible for up to 80% of herpetic infections in some populations of young women. Risk factors for acquiring HSV genital infection include

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female gender, lower socioeconomic status, minority ethnic group, longer duration of sexual activity, prior history of other genital infections, and number of sexual partners. Neonatal HSV infections remain rare, occurring in approximately 1 in 3200 deliveries in the United States. Every year, approximately 14,000 newborns are affected worldwide (1–5).

Neonatal HSV infection can be acquired during one of the following 3 distinct times:

- In utero (5%)
- Peripartum (85%)
- Postpartum (10%)

"Peripartum transmission is the most common, and there is an increased transmission risk of 57% in infants born to women with first-episode primary genital infections, a 25% risk in infants born to women with first-episode non-primary infection, and only a 2% risk increase in those born to women with recurrent genital herpes. With primary genital maternal HSV infection, there is inadequate time for protective immunoglobulins against HSV to be passed transplacental to the fetus."

Intrauterine infection, which is rare, can present at birth or occur within 48 hours of life. Infected neonates typically present with cutaneous signs, eye damage, and central nervous system manifestations, which can include intracranial calcifications and microcephaly. Intrauterine HSV infection should also be in the differential of any newborn presenting with nonimmune hydrops with no obvious etiology. Postpartum acquisition can occur by direct contact with a family member or healthcare worker with an active HSV infection. Peripartum transmission is the most common, and there is an increased transmission risk of 57% in infants born to women with first-episode primary genital infections, a 25% risk in infants born to women with first-episode non-primary infection, and only a 2% risk increase in those born to women with recurrent genital herpes. With primary genital maternal HSV infection, there is inadequate time for protective immunoglobulins against HSV to be passed transplacental to the fetus. Significant risk factors for peripartal HSV infection include a longer duration of ruptured membranes, compromise of the integrity of the mucocutaneous barriers (fetal scalp probe, incisions, etc.), and mode of delivery (vaginal vs. operative) (6–8).

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Neonatal HSV infection acquired during the peripartum period can be categorized as follows:

- SEM (skin, eye, mouth) disease (45%)
- CNS disease (30%)
- Disseminated disease (25%)

Both SEM and disseminated disease are typically observed at an average of 9–11 days of life. CNS disease is somewhat later, with an average presentation on day of life 16–17. SEM disease does not involve the CNS or other organ systems. CNS disease can have mucocutaneous involvement, but this presentation does not

"CNS disease can have mucocutaneous involvement, but this presentation does not have evidence of any other organ system involvement. Mortality is usually the result of devastating brain destruction that can involve any area and often multiple parts of the brain, not just the temporal lobe."

have evidence of any other organ system involvement. Mortality is usually the result of devastating brain destruction that can involve any area and often multiple parts of the brain, not just the temporal lobe. The long-term neurodevelopmental outcomes in CNS disease remain unacceptably poor. Disseminated HSV infection may involve multiple organ systems including the liver, lungs, adrenals, gastrointestinal tract, skin, eyes, or mouth (9–11).

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The least common, but potentially the most devastating in terms of mortality, is disseminated neonatal HSV infection. The disease may be confused with bacterial sepsis because of an infant's ill appearance and multiorgan involvement. The differential in a newborn who has a relatively typical NICU course up until day of life 7 or greater would include late-onset bacterial sepsis, viral sepsis, cardiomyopathy, respiratory failure, or an inborn error of metabolism. The clinical presentation often involves nonspecific signs such as lethargy, apnea, irritability, poor p.o. intake, abdominal distention, and temperature instability. Cutaneous lesions can be a diagnostic clue, but as many as 35% of infants with HSV CNS disease do not have a vesicular rash identified. Similarly, in up to 40% of cases, newborns with disseminated disease never developed a vesicular rash during the course of their illness. However, disseminated infection can manifest as severe hepatitis, disseminated intravascular coagulation, pneumonitis, and possibly CNS involvement found in 60 to 75% of cases (12–15).

"The clinical presentation often involves nonspecific signs such as lethargy, apnea, irritability, poor p.o. intake, abdominal distention, and temperature instability. Cutaneous lesions can be a diagnostic clue, but as many as 35% of infants with HSV CNS disease do not have a vesicular rash identified. Similarly, in up to 40% of cases, newborns with disseminated disease never developed a vesicular rash during the course of their illness. However, disseminated infection can manifest as severe hepatitis, disseminated intravascular coagulation, pneumonitis, and possibly CNS involvement found in 60 to 75% of cases."

The current recommendations from the American Academy of Pediatrics for diagnostic evaluation of infants with suspected HSV infection include:

- Viral culture and polymerase chain reaction (PCR) from any mucocutaneous lesion concerning for HSV
- Viral culture and PCR of swabs of conjunctiva, nasal pharyngeal mucosa, oral mucosa, and anal mucosa
- Cerebrospinal fluid HSV PCR
- Whole blood HSV PCR
- Alanine aminotransferase (ALT) levels

An algorithm has been developed jointly by the American Academy of Pediatrics Committee on Infectious Diseases and the Committee on Fetus and Newborn that provides recommendations on risk stratification, diagnostic workup, and appropriate antiviral therapy for asymptomatic infants. The American Academy of Pediatrics and American College of Obstetricians and Gynecologists have published guidelines offering evidence-based recommendations on how to treat newborns born to mothers who have active genital herpes lesions. PCR test results are typically reported within 24 hours of sample collection (depending on laboratory availability), whereas viral culture results may take 2–5 days to be reported. A negative PCR result does not in and of itself rule out neonatal HSV disease. HSV infections have occurred despite cesarean delivery performed before the rupture of membranes (16–18).

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Although new antiviral agents continue to be studied for the treatment of HSV infections, acyclovir remains the current drug of choice for the treatment of neonatal HSV disease. Efforts to find

a prophylactic and therapeutic vaccine for both HSV-1 and HSV-2 are ongoing. Acyclovir given at 60 mg/kg/day in 3 divided doses has improved 1-year mortality rates to 29% and 4% in disseminated and CNS diseases, respectively. Disseminated and CNS disease should be treated for a minimum duration of 21 days, which could be extended if a repeat lumbar puncture remains positive. Infants with SEM disease should receive 14 days of treatment. Any newborn on acyclovir needs to be monitored for neutropenia as well as renal dysfunction. After intravenous therapy, infants are transitioned to oral suppressive therapy for 6 months (19, 20).

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Recommendations for providers:

1. Although most HSV post-delivery infections present when the neonate is 7–21 days of age, the provider initiating a septic workup for any neonate after day of life 3 should consider testing for and empirically treating for HSV infection. Failure to diagnose an HSV infection can result in devastating outcomes, including death.
2. In both preterm and late preterm/term newborns, temperature instability, especially fever, should put herpes on the radar.
3. Part of the septic workup during the neonatal window would include liver function tests, especially ALT, which usually will be significantly elevated with disseminated HSV infection
4. Clinicians should be aware of the dangers of HSV **even when there is no maternal history of herpes infection** because early diagnosis and early acyclovir treatment are keys to a better outcome.
5. Although the general principle of treatment in any infectious disease is that earlier administration of antimicrobials is preferred, there is no data that a delay of "x" hours increases the likelihood of a poor outcome in neonatal HSV infection.

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Book Review: Hope Before Thirty-Nine Hours: Patrick Bouvier Kennedy's Enduring Legacy

Nida Nasreen Ali, BS

"Rather than simply recounting the tragic death of President John F. Kennedy and First Lady Jacqueline Kennedy's youngest son, Levingston argues that Patrick's brief life became a turning point in neonatal medicine while simultaneously revealing the humanity hidden beneath the carefully cultivated image of Camelot. More importantly, Patrick's story demonstrates that legacy often begins long before death."

Steven Levingston's *Twilight of Camelot: The Short Life and Long Legacy of Patrick Bouvier Kennedy* explores how an infant who lived only thirty-nine hours permanently influenced American medicine, politics, and public memory. Rather than simply recounting the tragic death of President John F. Kennedy and First Lady Jacqueline Kennedy's youngest son, Levingston argues that Patrick's brief life became a turning point in neonatal medicine while simultaneously revealing the humanity hidden beneath the carefully cultivated image of Camelot. More importantly, Patrick's story demonstrates that legacy often begins long before death. Before his birth, Patrick represented hope and renewal within a marriage marked by repeated loss; after his death, he became a catalyst for medical innovation and a lasting reminder that even the briefest life can profoundly shape history.

One of the book's greatest strengths is its argument that the significance of a life cannot be measured by its duration. Although Patrick lived only thirty-nine hours, Levingston demonstrates that his influence extended far beyond those hours through the profound impact he had on his family, the nation's understanding of premature birth, and the evolution of neonatal medicine. Patrick's death occurred during a period when many treatments now considered routine for premature infants did not yet exist. While advances in neonatal care were already underway, his highly publicized struggle transformed prematurity from a largely medical concern into an issue of national attention. In doing so, Levingston challenges readers to reconsider how history assigns significance. Patrick's importance arose not from what he accomplished during his lifetime but from the changes his story inspired afterward.

Perhaps the book's most compelling contribution is its portrayal of Patrick as a source of hope before he became a symbol of tragedy. Before his anticipated birth, John and Jacqueline Kennedy's marriage had been strained by repeated miscarriages, the stillbirth of their daughter Arabella, John Kennedy's infidelities, and the relentless demands of political life. Against this backdrop, this pregnancy represented an unexpected period of optimism. Secret Service agent Clint Hill recalled that "everything was looking up" and that the Kennedys were "very happy...really looking forward to this child." Rather than presenting Patrick simply as another presidential child, Levingston argues that he embodied emotional renewal after years of disappointment.

"Although it is impossible to know whether Patrick's survival would have permanently transformed their marriage, Levingston presents persuasive evidence that both his anticipated arrival and his death strengthened the emotional bond between his parents."

Levingston further suggests that Patrick's influence continued even after his death. He writes that "expectation, then the sorrow" drove Jack and Jackie "into each other's arms as never before." During the weeks following their son's death at Brambletyde, friends observed Jack openly comforting Jackie and displaying a tenderness that had rarely been visible throughout their marriage. Theodore White later reflected that their "shared grief tore that wall down" and that they were finally "truly coming closer together." Although it is impossible to know whether Patrick's survival would have permanently transformed their marriage, Levingston presents persuasive evidence that both his anticipated arrival and his death strengthened the emotional bond between his parents.

The book notes that John and Jacqueline's "parenthood bound and bonded them," uniting them through "their nurturing of those who lived and their sorrow for those they lost." Levingston further observes that, after Patrick's death, John Kennedy became increasingly attentive to Jackie and their children, revealing how shared grief deepened their relationship. The tragedy became not only a devastating loss but also a turning point that allowed the couple to reconnect after years of emotional distance. The irony, however, is heartbreaking. Just as they began envisioning a healthier future together, President Kennedy was assassinated only a few months later. Looking back, Jackie reflected, "It took a very long time for us to work everything out, but we did. We were about to have a real life together."

TWILIGHT OF CAMELOT

THE SHORT LIFE AND LONG LEGACY OF PATRICK BOUVIER KENNEDY

STEVEN LEVINGSTON

One of the book's most memorable passages reinforces this central idea. Levingston writes that "Patrick came and went too quickly, but he was fully realized in his parents' hearts." I found this statement especially moving because it captures the book's larger message. Patrick's significance cannot be measured simply by the thirty-nine hours he lived. Long before his birth, he existed in his parents' hopes for healing and renewal. Long after his death, he continued to shape medicine, history, and public memory. In this sense, Patrick's legacy began before his life and endured far beyond it.

"Patrick's story also reshapes the traditional understanding of Camelot. Although the Kennedy presidency is often remembered for its glamour, youth, and optimism, Levingston reveals the vulnerability hidden beneath that carefully constructed image. The Kennedys were not immune to miscarriage, infant loss, marital struggles, or profound grief despite occupying the nation's highest office."

Patrick's story also reshapes the traditional understanding of Camelot. Although the Kennedy presidency is often remembered for its glamour, youth, and optimism, Levingston reveals the vulnerability hidden beneath that carefully constructed image. The Kennedys were not immune to miscarriage, infant loss, marital struggles, or profound grief despite occupying the nation's highest office. Rather than diminishing Camelot, these hardships deepen its emotional resonance. Patrick's death became another chapter in the succession of tragedies that defined the Kennedy family, reinforcing the reality that Camelot was always as fragile as it was inspiring. Levingston ultimately suggests that the true legacy of Camelot lies not in the illusion of perfection but in the resilience displayed amid repeated personal loss.

Levingston further deepens this portrait by examining the childhoods of John and Jacqueline Kennedy, illustrating how their early family experiences shaped their marriage and emotional responses as adults. Both were raised in households marked by infidelity, emotional distance, and family instability, experiences that influenced how they coped with conflict, vulnerability, and loss. Rather than portraying their marital struggles as isolated events, Levingston places them within the broader context of their upbringing, suggesting that many of the communication barriers they faced were rooted in long-established emotional patterns. I found this perspective especially insightful because it encouraged me to view the Kennedys with greater empathy. Understanding their childhood experiences helped explain why they often struggled to communicate openly during difficult moments and why Patrick's illness and death became such a pivotal turning point in their relationship.

The author's willingness to portray the Kennedys honestly rather than idealize them is another of the book's greatest strengths. He openly examines Jack Kennedy's repeated infidelities and the emotional pain they caused Jackie, preventing readers from romanticizing their marriage while also providing essential context for why this pregnancy represented such a meaningful opportunity for renewal. Likewise, Levingston's discussion of the stillbirth of the Kennedys' daughter, Arabella, demonstrates that Patrick's death was not an isolated tragedy but part of a heartbreaking pattern of pregnancy loss that had already shaped the family. By including Jack's initial hesitation to return home after learning of Arabella's stillbirth, Levingston resists simplistic characterizations. Rather than portraying Jack as merely indifferent, he explores his emotional immaturity, discomfort with grief, and difficulty confronting painful situations. I appreciated this balanced approach because it neither excuses Jack's shortcomings nor defines him entirely. Instead, the book presents both John and Jacqueline Kennedy as deeply human individuals whose strengths and flaws shaped the way they loved, grieved, and ultimately grew together.

"As someone who works in maternal-fetal and neonatal clinical research, I found Levingston's discussion of Patrick's medical legacy especially compelling. Rather than suggesting that Patrick's death single-handedly transformed neonatal medicine, Levingston presents his story as the catalyst that brought premature infant care into the national consciousness."

As someone who works in maternal-fetal and neonatal clinical research, I found Levingston's discussion of Patrick's medical legacy especially compelling. Rather than suggesting that Patrick's death single-handedly transformed neonatal medicine, Levingston presents his story as the catalyst that brought premature infant care into the national consciousness. Before Patrick's birth, he notes that the dangers of prematurity and hyaline membrane disease (HMD)—now known as neonatal respiratory distress syndrome—"rarely made news." Following Patrick's death, however, newspapers across the country explained the disease through headlines such as "Disease That Killed Kennedy Baby Is Biggest Danger in Premature Birth and Premature Infants Subject to HMD," bringing discussions of premature birth "to kitchen tables across the country." What had often been experienced as a private family tragedy suddenly became a national conversation.

The public response extended beyond newspaper coverage. Thousands of families wrote to the White House describing their own experiences with premature birth and infant loss, revealing that the Kennedys' grief resonated with parents across the country. In this way, Patrick's death narrowed the distance between the First Family and the American public. The tragedy humanized the Kennedys, reminding the nation that even those with extraordinary

wealth, influence, and access to the finest physicians remained vulnerable to the limitations of medicine.

Levingston also demonstrates that Patrick's influence extended beyond public awareness to research priorities. In the wake of his son's death, President Kennedy requested reports on hyaline membrane disease, neonatal research, and federal support for prematurity studies, encouraging greater collaboration among institutions and helping elevate prematurity as an important area of scientific investigation. Although Levingston does not claim that Patrick's death created the National Institute of Child Health and Human Development (NICHD) or initiated federal funding from scratch, he convincingly argues that it accelerated attention toward research already underway and strengthened support for innovations that would ultimately lead to surfactant replacement therapy, improved mechanical ventilation, continuous positive airway pressure (CPAP), and the development of modern neonatal intensive care units.

"Perhaps the book's greatest contribution is its distinction between direct and symbolic influence. Levingston acknowledges that advances in neonatal medicine were already in progress before 1963, making clear that Patrick did not personally transform neonatal care. Instead, his highly publicized death became the defining case that galvanized public interest, intensified scientific attention, and inspired physicians to challenge the limitations of existing treatments. "

Perhaps the book's greatest contribution is its distinction between direct and symbolic influence. Levingston acknowledges that advances in neonatal medicine were already in progress before 1963, making clear that Patrick did not personally transform neonatal care. Instead, his highly publicized death became the defining case that galvanized public interest, intensified scientific attention, and inspired physicians to challenge the limitations of existing treatments. As Levingston concludes, Patrick's "brief life and tragic death inspired a revolution in premature care." His legacy, therefore, lies not in a single medical breakthrough but in the momentum his story gave to an entire field dedicated to improving the survival of premature infants.

This distinction is one of the book's greatest strengths because it avoids overstating Patrick's historical influence while still recognizing its significance. Rather than attributing decades of medical progress to one tragic event, Levingston argues that Patrick's story accelerated conversations, research, and public investment that were already emerging. In doing so, he demonstrates how individual lives can shape history not only through direct action but also through the attention, empathy, and determination they inspire in others.

Levingston further illustrates that Patrick's death became inseparable from the public identity of the Kennedy presidency. The nation's response to Patrick's illness and death revealed John and Jacqueline Kennedy not simply as the President and first lady but as grieving parents confronting a loss shared by countless families. Americans followed Patrick's hospitalization through newspaper reports and television updates, while thousands of parents wrote to the White House describing their own experiences with premature birth and infant loss. In this sense, Patrick's death narrowed the distance between the First Family and the public, fostering empathy that transcended politics. Levingston demonstrates that while grief is universal, the experience of grieving is profoundly altered by public life. John and Jacqueline endured the same heartbreak as countless parents, yet they did so beneath relentless national scrutiny, illustrating the emotional cost of leadership and the sacrifices that accompany public service.

"Patrick's story also challenges conventional assumptions about privilege by revealing its limits in the face of tragedy. As the son of the President of the United States, Patrick received the finest medical care available, access to leading physicians, cutting-edge technology, and the full attention of the nation. Nevertheless, despite the Kennedy family's wealth, influence, and unprecedented resources, medicine in 1963 could not save him."

Patrick's story also challenges conventional assumptions about privilege by revealing its limits in the face of tragedy. As the son of the President of the United States, Patrick received the finest medical care available, access to leading physicians, cutting-edge technology, and the full attention of the nation. Nevertheless, despite the Kennedy family's wealth, influence, and unprecedented resources, medicine in 1963 could not save him. Levingston reminds readers that privilege cannot overcome the scientific limitations of its time or shield families from profound loss. Ironically, however, the same privilege that could not prevent Patrick's death amplified its impact. Because he was the President's son, his illness became front-page news, drawing national attention to premature birth and neonatal respiratory disease while strengthening public support for research that would benefit future generations. Patrick's story therefore demonstrates both the limitations and the power of privilege: it could not alter his outcome, but it ensured that his story helped shape the future of neonatal care.

"Another of Levingston's greatest strengths is his careful balance between emotional storytelling and historical scholarship. Rather than relying solely on sentiment, he builds his narrative through archival documents, government memoranda, newspaper accounts, interviews with family members, physicians, historians, and neonatologists, and an accessible explanation of the medical science surrounding neonatal respiratory distress syndrome."

Another of Levingston's greatest strengths is his careful balance between emotional storytelling and historical scholarship. Rather than relying solely on sentiment, he builds his narrative through archival documents, government memoranda, newspaper accounts, interviews with family members, physicians, historians, and neonatologists, and an accessible explanation of the medical science surrounding neonatal respiratory distress syndrome. Although the subject matter is deeply emotional, the book remains grounded in evidence. Even when Levingston reflects on the emotional significance of particular events, he distinguishes interpretation from documented fact, allowing readers to appreciate both the historical record and the humanity behind it. This balanced approach makes the book persuasive without becoming overly sentimental.

"Even when Levingston reflects on the emotional significance of particular events, he distinguishes interpretation from documented fact, allowing readers to appreciate both the historical record and the humanity behind it."

One passage near the conclusion of the book encapsulates Levingston's broader message. Reflecting on Patrick's brief life, he cites an editorial observing that pregnancy is "the waiting time" and that Patrick "did indeed have a life of his own," existing "prospectively, in the minds and imaginations of his parents." I found this observation especially powerful because it reinforces the idea that Patrick's legacy began long before his birth. Before he became associated with advances in neonatal medicine, he embodied hope, anticipation, and emotional renewal within his family. After his death, that same hope evolved into a lasting commitment to improving the care of premature infants, giving profound meaning to a life that lasted only thirty-nine hours.

Ultimately, *Twilight of Camelot* argues that Patrick Bouvier Kennedy's significance lies not in the brevity of his life but in the enduring influence of his story. His death challenged the illusion of Camelot's perfection, revealed the humanity behind one of America's most admired families, and helped bring national attention to premature infant care during a pivotal moment in medical history. Levingston reminds readers that history often assigns meaning retrospectively. Patrick was not born as a symbol of medical progress or national grief; he became one because later generations recognized the changes his life and death inspired.

"After his death, that same hope evolved into a lasting commitment to improving the care of premature infants, giving profound meaning to a life that lasted only thirty-nine hours."

Given my role at Loma Linda University Children's Hospital, I found this perspective especially meaningful. Clinical research is driven by the determination to learn from difficult outcomes so that future patients may benefit. Patrick's story illustrates that principle in a deeply human way. Although no single tragedy transforms medicine on its own, some losses become powerful catalysts that inspire greater awareness, collaboration, and scientific progress. Levingston's account reminded me that many of the advances now considered routine in neonatal care exist because physicians and researchers refused to accept the limitations exposed by families like the Kennedys.

"Levingston's careful blend of historical scholarship, medical history, and human compassion makes a persuasive case that Patrick's legacy should be measured not by the brevity of his life but by the enduring impact it had on his family, neonatal medicine, and generations of children who have benefited from the progress his story helped inspire."

Overall, I found *Twilight of Camelot* to be a compelling and thoughtfully researched account that successfully reframes a largely forgotten chapter of American history. Rather than presenting Patrick Bouvier Kennedy's story solely as one of tragedy, Levingston convincingly argues that it is ultimately a story of hope, resilience, and enduring influence. Patrick represented hope for his parents as they sought to rebuild their marriage, hope for a nation captivated by the promise of Camelot, and hope

for a medical community determined to improve the survival of premature infants. What stayed with me most was the realization that Patrick's greatest influence came not during the thirty-nine hours he lived but through the countless lives his story continued to touch afterward. Levingston's careful blend of historical scholarship, medical history, and human compassion makes a persuasive case that Patrick's legacy should be measured not by the brevity of his life but by the enduring impact it had on his family, neonatal medicine, and generations of children who have benefited from the progress his story helped inspire.

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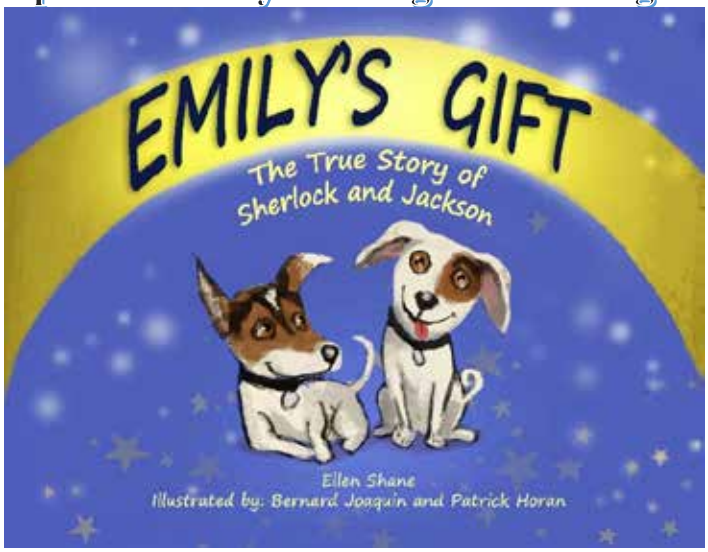

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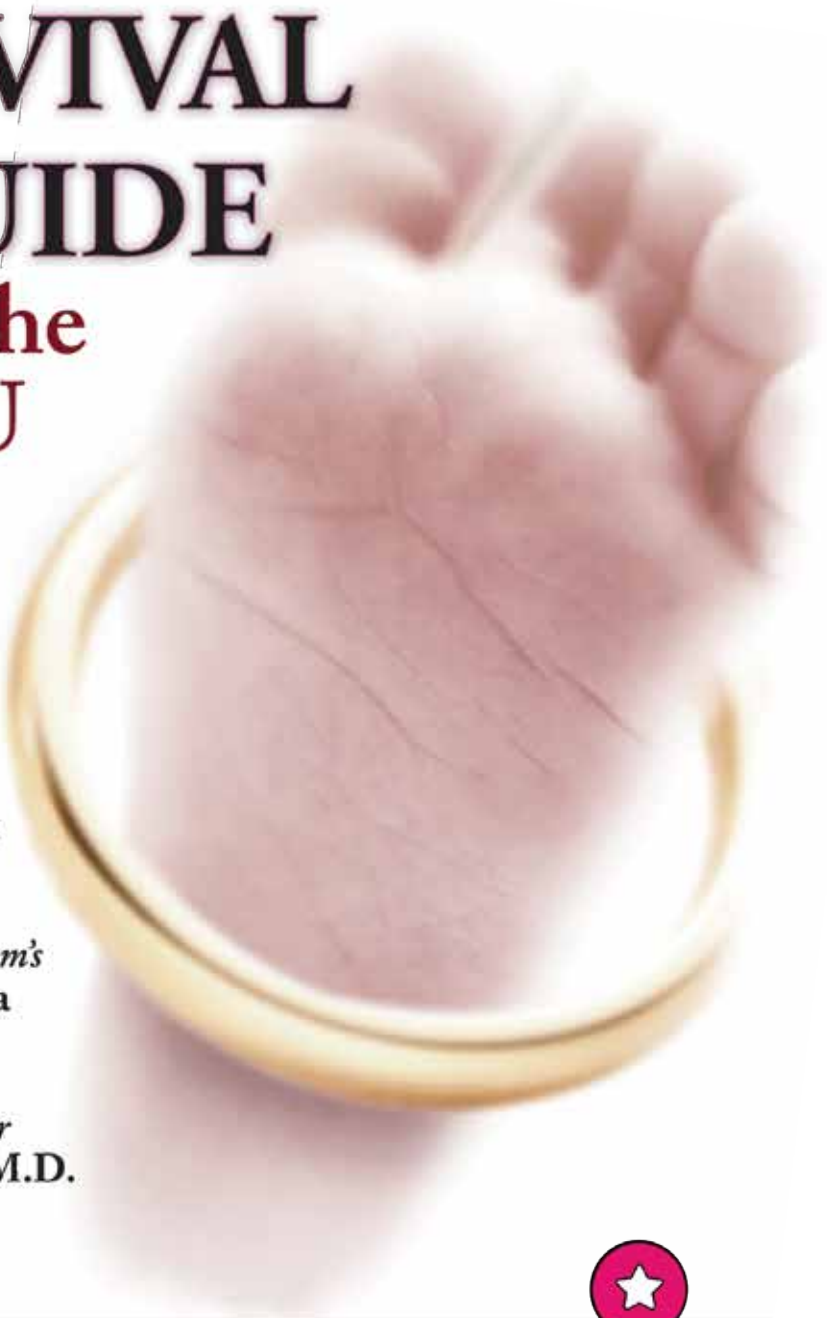

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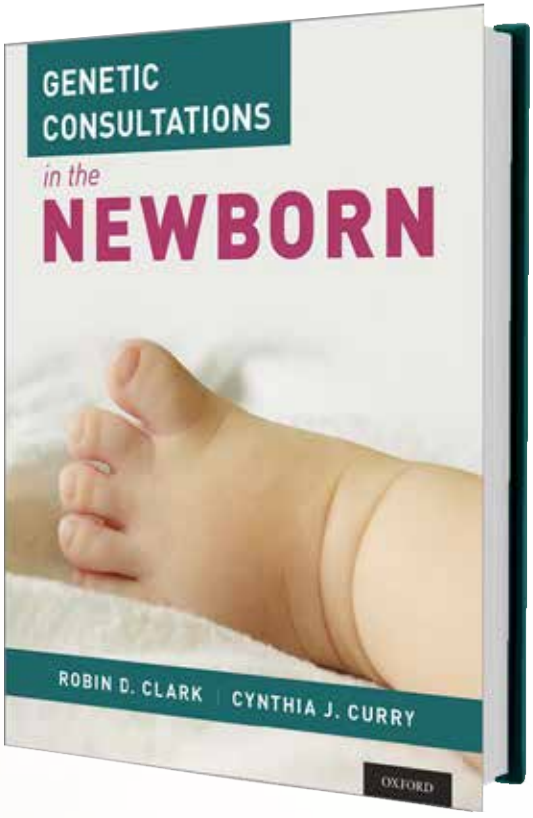

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Clinical Pearl: Prenatal Amnioinfusions for Fetuses with Anhydramnios Secondary to Renal Agenesis and Other Severe Renal Abnormalities: Neonatal Renal Physiology to Fetal Therapy: Reflections on the RAFT Trial

Joseph R. Hageman, MD, Mitchell Goldstein, MD, MBA, CML

"Ever since I was a medical student, I have had a particular interest in neonatal renal development, renal physiology, and the spectrum of congenital renal and urinary tract abnormalities encountered in newborns."

Ever since I was a medical student, I have had a particular interest in neonatal renal development, renal physiology, and the spectrum of congenital renal and urinary tract abnormalities encountered in newborns. The kidney is an extraordinary organ, and its development and function during the fetal and neonatal periods are fundamentally different from those of the older child and adult. These developmental differences have important implications for fluid and electrolyte homeostasis, blood pressure regulation, acid-base balance, and the response to illness. They also make the newborn particularly vulnerable when renal development or function is severely impaired.

My interest in neonatal nephrology began during my medical school training in 1975, when I had the opportunity to participate in a pediatric nephrology elective at the University of Illinois with Dr. Lorenzo Aschinberg, a pediatric nephrologist who profoundly influenced my early understanding of renal disease in children and newborns. The rotation was an important educational experience. I became particularly interested in the unique challenges of renal dysfunction in newborns, where relatively small changes in renal function can have profound physiologic consequences. During that experience, I had the opportunity to coauthor a review of neonatal acute renal failure (1). Looking back, that early exposure helped establish an interest that has remained with me throughout my career.

"During that experience, I had the opportunity to coauthor a review of neonatal acute renal failure (1). Looking back, that early exposure helped establish an interest that has remained with me throughout my career."

Decades later, that interest was rekindled and expanded through my work with pediatric residents. While serving as Director of Resident Research at Comer Children's Hospital at the University of Chicago, I had the opportunity to work with Dr. Shireen Hashmat, a pediatric nephrologist, and several pediatric residents on a project examining acute kidney injury (AKI). This experience provided another perspective on the evolving understanding of neonatal and pediatric kidney injury. Our work culminated in a poster presentation at the Illinois Chapter of the American Academy of Pediatrics annual conference, as well as a clinical pearl addressing neonatal AKI that we subsequently coauthored for *Neonatology Today* (2).

"The fetal kidney does much more than prepare the infant for life after birth. Fetal urine production is essential for maintaining amniotic fluid volume, and amniotic fluid, in turn, plays a critical role in normal pulmonary development."

These experiences have reinforced for me an important principle in neonatology: renal function cannot be considered in isolation from the developmental biology of the fetus and newborn. The fetal kidney does much more than prepare the infant for life after birth. Fetal urine production is essential for maintaining amniotic fluid volume, and amniotic fluid, in turn, plays a critical role in normal pulmonary development. This interrelationship between the kidney, amniotic fluid, and developing lung becomes particularly striking when fetal renal function is severely compromised.

"The RAFT trial represents a remarkable example of how an improved understanding of fetal physiology can lead to an innovative therapeutic approach to an otherwise devastating condition."

I was therefore very interested to read reports in *Contemporary Pediatrics* and Johns Hopkins Medicine describing the multicenter Renal Anhydramnios Fetal Therapy (RAFT) clinical trial led by Atkinson and colleagues (3–5). The RAFT trial represents a remarkable example of how an improved understanding of fetal physiology can lead to an innovative therapeutic approach to an otherwise devastating condition.

The trial addressed fetuses with severe renal failure resulting in anhydramnios, including cases caused by bilateral renal agenesis and other severe genitourinary abnormalities. In these

circumstances, the fetus produces little or no urine, resulting in profound oligohydramnios or anhydramnios. The absence of adequate amniotic fluid has consequences that extend well beyond the fetal kidneys. In particular, the developing lungs require an appropriate intrauterine environment for normal growth and maturation. Severe and prolonged anhydramnios can result in pulmonary hypoplasia, leaving affected newborns unable to achieve adequate respiratory function after delivery.

"Historically, this combination of severe renal abnormalities, anhydramnios, and pulmonary hypoplasia has been associated with an extremely poor prognosis. The clinical dilemma is profound: the fetal renal abnormality itself may not be correctable, but the consequences of absent amniotic fluid—particularly impaired lung development—might potentially be modifiable."

Historically, this combination of severe renal abnormalities, anhydramnios, and pulmonary hypoplasia has been associated with an extremely poor prognosis. The clinical dilemma is profound: the fetal renal abnormality itself may not be correctable, but the consequences of absent amniotic fluid—particularly impaired lung development—might potentially be modifiable.

"Could replacing the missing amniotic fluid during pregnancy provide the developing lungs with an environment sufficient to support meaningful pulmonary development?"

The RAFT investigators asked a straightforward but extraordinarily important question: **Could replacing the missing amniotic fluid during pregnancy provide the developing lungs with an environment sufficient to support meaningful pulmonary development?**

In the RAFT trial, repeated prenatal amnioinfusions were performed in 32 fetuses with renal failure and resulting anhydramnios due to bilateral renal agenesis or other severe genitourinary abnormalities. Rather than attempting to correct the underlying renal abnormality, the intervention sought to address one of its most devastating downstream consequences—the failure of normal lung development (3–5).

Dr. Meredith Atkinson, one of the trial's co-leaders, summarized the fundamental premise of the study particularly well: "The RAFT trial is a trial that looked at whether introducing fluid into the amniotic sac periodically during pregnancy in patients who had fetal anhydramnios due to renal failure could result in adequate lung development" (3).

The Renal Anhydramnios Fetal Therapy (RAFT) trial showed that serial prenatal amnioinfusions successfully mitigated lethal lung hypoplasia in fetuses with early-onset kidney failure and anhydramnios (lack of amniotic fluid), allowing 65.5% to 82% of live-born neonates to survive past 14 days and receive postnatal dialysis access.

That concept immediately captured my attention. As neonatologists, we routinely encounter the consequences of impaired pulmonary development, but we often encounter them only after birth, when therapeutic options are considerably more limited. The RAFT trial shifts the therapeutic window much earlier. Rather than accepting pulmonary hypoplasia as an inevitable consequence of fetal renal failure, the investigators asked whether the intrauterine environment itself could be modified sufficiently to alter the trajectory of lung development.

This is an important conceptual shift. It illustrates the increasingly blurred boundary between fetal medicine, neonatology, nephrology, and developmental biology. The fetus is not simply a small patient awaiting delivery. Fetal organ systems develop in an interconnected environment, and dysfunction in one organ can profoundly influence another. In the setting of severe fetal renal failure, the kidney alters the amniotic fluid environment, which, in turn, affects the developing lung. The RAFT trial attempts to intervene in that physiologic cascade.

For someone whose professional interest in neonatal renal disease began nearly five decades ago with an introduction to neonatal renal failure, the evolution of this field is particularly striking. In 1975, our understanding and therapeutic options for severe neonatal and fetal renal disease were extraordinarily limited compared with today. The concept that we could identify a fetus with renal failure, recognize the resulting anhydramnios, and then attempt to modify the intrauterine environment to improve lung development would have seemed remarkable.

"Of course, the RAFT trial does not mean that fetal renal failure has been solved. The underlying renal abnormalities remain profound, and surviving infants face substantial medical challenges."

The RAFT experience also raises broader questions about how we think about neonatal and fetal disease. Increasingly, some conditions traditionally considered "neonatal" are being recognized and potentially treated before birth. Advances in fetal imaging, molecular diagnosis, fetal intervention, maternal-fetal medicine, neonatal critical care, nephrology, and developmental biology are creating opportunities to intervene during critical periods of organ development rather than waiting until after birth.

Of course, the RAFT trial does not mean that fetal renal failure has been solved. The underlying renal abnormalities remain profound,

and surviving infants face substantial medical challenges. Questions regarding long-term renal replacement therapy, dialysis, transplantation, neurodevelopment, quality of life, and the ethical dimensions of fetal intervention remain critically important. Prenatal intervention also carries its own maternal and fetal risks and requires careful consideration of patient selection, procedural complications, timing, and long-term outcomes.

Nevertheless, the trial represents an important proof of concept and an extraordinary example of physiology informing clinical innovation. It reminds us that when we understand the developmental relationships among organ systems, we may identify therapeutic opportunities that are not immediately obvious when each organ is considered separately.

I was fascinated by these reports because they brought me full circle from my early exposure to neonatal renal disease as a medical student, through subsequent experiences with neonatal acute kidney injury, to a contemporary fetal intervention designed around the physiologic consequences of severe renal failure. More importantly, I believe the RAFT trial deserves broader attention among neonatologists, pediatricians, nephrologists, maternal-fetal medicine specialists, and others who care for infants with severe congenital renal disease.

The story also reminds us why curiosity remains so important in medicine. A question that begins with an observation about renal physiology can ultimately lead to an intervention directed at the lungs. The kidney may be the primary site of pathology, but the therapeutic opportunity may lie somewhere else in the developmental pathway. That is precisely the kind of interdisciplinary thinking that continues to advance fetal and neonatal medicine.

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- 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.

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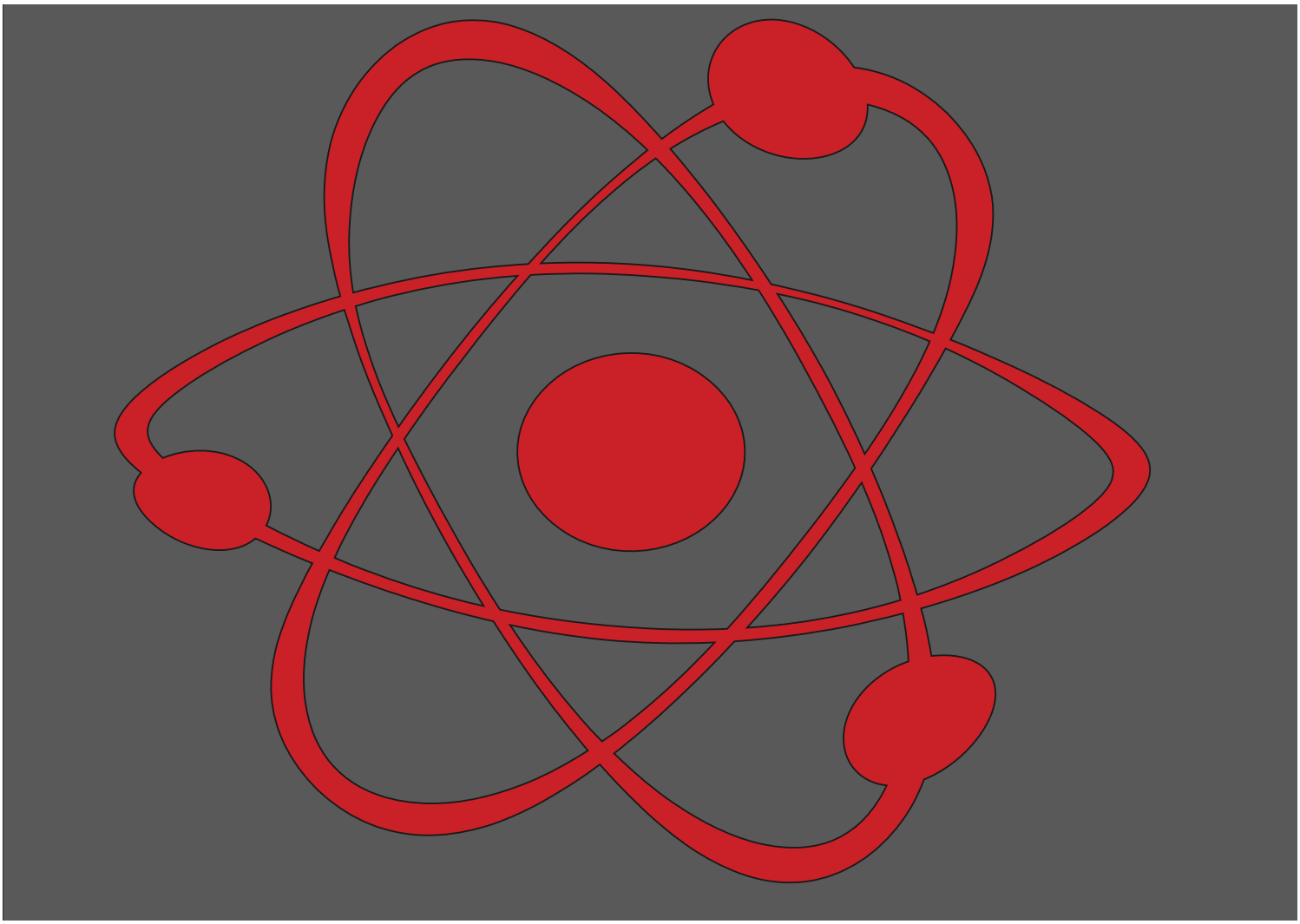

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The Loma Linda University Health's Clinical Trial Center is actively seeking and recruiting top clinical research coordinator talent.

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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 "Tour through Europe" For this edition, our art was graciously provided by Colleen Kraft, MD. It is a work called "All Eyes" done by her son Tim. Our bird is from Dr. Shah, "Dr. Mita Shah holding two parakeets."

Lily Martorell, MD

Arts Editor
Associate Professor
Loma Linda University Children's Hospital
Loma Linda, CA

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Manuscript Submission: Instructions to Authors

1. Manuscripts are solicited by members of the Editorial Board or may be submitted by readers or other interested parties. Neonatology Today welcomes the submission of all academic manuscripts including randomized control trials, case reports, guidelines, best practice analysis, QI/QA, conference abstracts, and other important works. All content is subject to peer review.

2. All material should be emailed to: LomaLindaPublishingCompany@gmail.com in a Microsoft Word, Open Office, or XML format for the textual material and separate files (tif, eps, jpg, gif, ai, psd, SVG, or pdf) for each figure. Preferred formats are ai, SVG, psd, or pdf. tif and jpg images with sufficient resolution so as not to have visible pixilation for the intended dimension. In general, if acceptable for publication, submissions will be published within 3 months.

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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.

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Seeking content development experts for an AAP Project Advisory Committee (PAC)

The White Zone – Developing A Perinatal Loss Toolkit for LMICs

The Need: Over 2.4 million neonatal deaths and 2.6 million stillbirths occur each year; 98% occur in Low- and Middle-Income Countries (LMICs). While programs such as Helping Babies Breathe (HBB) and Essential Newborn Care (ENC 1 and 2) have revolutionized how providers in LMICs train in and provide neonatal resuscitation and post-delivery care for small and sick newborns, gaps remain in how to best offer end-of-life care and post-loss psychosocial care in these settings.

The Babies: HBB and ENC 1 begin with assessing if a baby is crying and conclude with the "Red Zone" where a baby who is unable to sustain an appropriate heart rate and/or respirations is provided with PPV support as someone attempts to get help. Within the HBB/ENC framework, we could imagine several babies for whom an extension of this framework to include palliative/perinatal loss guidelines could be helpful:

1. A stillbirth for whom no resuscitation is attempted. (Stillbirth)
2. A baby who proceeds through the red zone but never has a heartbeat or breathing despite the best resuscitative efforts of the team. (Stillbirth)
3. A baby who proceeds through the red zone who, after 20 or so minutes still has a very low heartbeat and/or gasping breathing. (Anticipated neonatal death)
4. A preterm baby who is too small for ongoing support, based on local resource constraints or resuscitation guidelines, despite a sustained heart rate and breathing. (Anticipated neonatal death)

The Approach: Create a suite of resources that could accompany ENC 1 and 2, focused on end-of-life care and perinatal loss. These resources would be less algorithmic than ENC, as local practices around death vary significantly – meaning there is not one "right" way to approach this care. Rather, the "White Zone Toolkit" would combine structured guidance about symptom management as well as reflective tools for implementing contextually and culturally appropriate post-loss care. This could consist of, but is not limited to, the following:

1. Structured guidance on what physiologic changes may happen at the end of life (ex: gasping) as well as pharmacologic and non-pharmacologic options for symptom management.
2. Reflective questions about if/when to offer seeing or holding of the baby.
    - Data shows that many women want to see and/or hold their infant following stillbirth or neonatal death but are often not offered that opportunity based on historic cultural norms.
3. Reflective questions about cultural traditions around loss and if/how these practices can be supported by those attending the delivery.
4. Anticipatory guidance guides on how mothers may still produce milk and how to manage those symptoms.
5. Anticipatory guidance on potential maternal mental health needs. Reflective questions on how to approach mental health and psychosocial support after loss.
6. Access to a set of adaptable practice scenarios that could help providers gain experience in handling perinatal loss and communicating with families surrounding perinatal loss.

NICU BABY'S *Bill of Rights*

1 The Right to *Advocacy*

My parents are **my voice** and **my family** are **my best advocates**.

My parents know me well. They are my voice and my best advocates. They need to be knowledgeable about my progress, medical needs, and prognosis, so they celebrate my achievements and support me when things get challenging.

2 The Right to *My Parents' Care*

Welcome my family and **include them** in everything we do.

My parents are my essential caregivers. In order to care for me, they need lots of opportunities to learn. Ensure that hospital policies and protocols, including hours & rounding, are as inclusive and expansive as possible. Then be patient with them.

3 The Right to *Bond With My Family*

Create opportunities for my family and me **to be together and bond**.

Bonding is crucial for my healthy growth and development. Support my parents so that we can practice skin-to-skin care as soon and as often as possible. Encourage them to read, sing, and talk to me.

4 The Right to *Neuroprotective Care*

Protect my **developing mind** and **senses**.

Protect me from things that startle, stress, or overwhelm me. Support things that calm me. Ensure I get as much sleep as possible. My brain is developing for the first time - and faster than it ever will again. The way I'm cared for today will affect me as I continue to grow & develop.

5 The Right to *Be Nourished*

Support our feeding decisions and **help us develop our skills**.

Encourage my parents to feed me at the breast or by bottle, whichever way works for us both. Support our feeding goals and make sure my parents know all the nutrition options available to meet my needs.

6 The Right to *Personhood*

Respect me as the **amazing, unique individual** that I am.

Use my name. Talk to me before touching me. If one of my siblings passes away, ask my family how we want to talk about and acknowledge them.

7 The Right to *Confident and Competent Care Giving*

Support my parents and caregivers.

The NICU may be a traumatic place for my parents. Ensure that they receive tender loving care, information, education, and as many resources as possible to help inform them about my unique needs, development, diagnoses, and more.

8 The Right to *Family-Centered Care*

Teach my family **how to care for me**.

Help me feel that I am a part of my own family. Teach my parents, grandparents, and siblings how to read my cues, how to care for me, and how to meet my needs. Encourage them to participate in or perform my daily care activities, such as bathing and diaper changes.

9 The Right to *Healthy and Supported Parents*

Care for our **mental health** and **wellbeing**.

My parents may be experiencing a range of new and challenging emotions. Be patient, listen to them, and lend your support. Share information with my family about resources such as counseling, support groups, & peer-to-peer programs, which can help reduce the impact of perinatal mood and anxiety disorders (PMADs).

10 The Right to *Inclusion and Belonging*

Celebrate what makes us special and unique.

Celebrate our diversity. Honor what makes us unique. Ensure that my parents, grandparents, siblings, and friends feel accepted and welcomed in the NICU, and respected and valued in all forms of engagement and communication.