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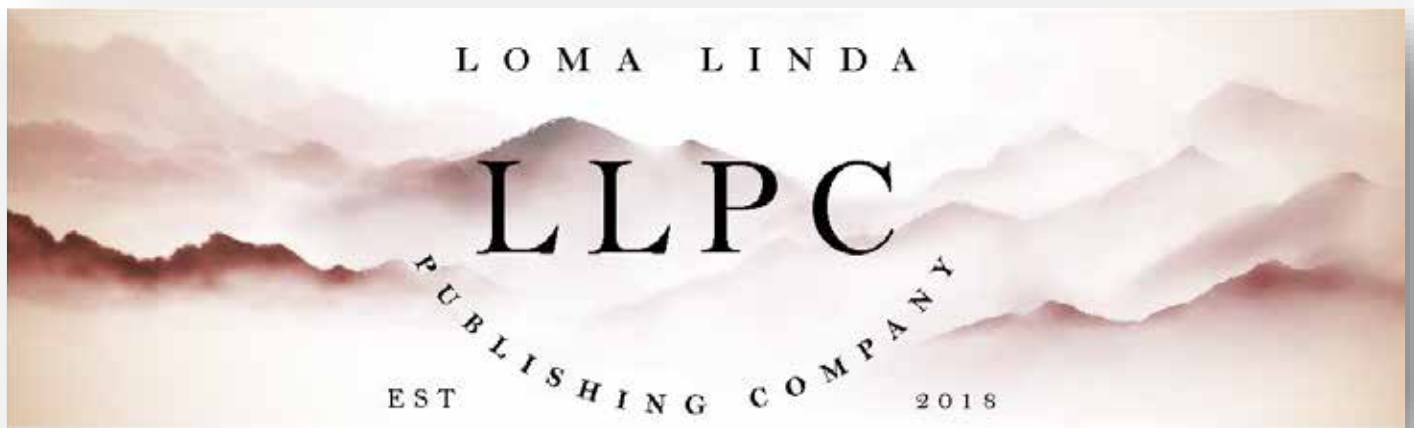
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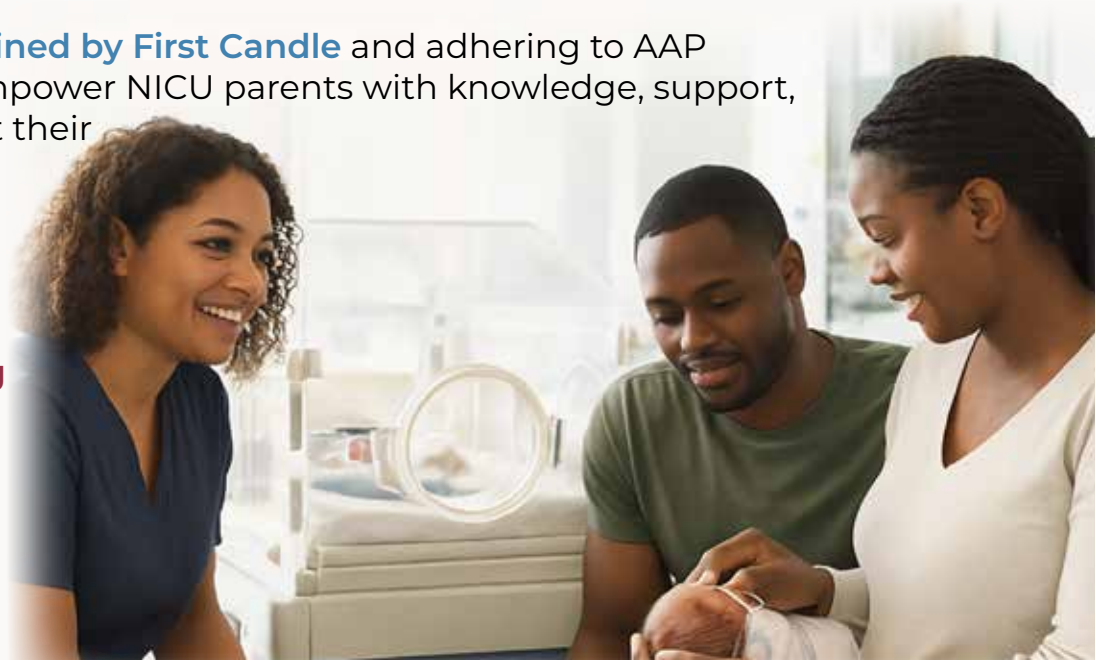
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Beyond the NICU: Surgical Deliberation, Family Support, and Post-Discharge Continuity for Infants with Trisomy 18

Ruby Wry, MS

Abstract

The question of cardiac and noncardiac surgery for an infant with trisomy 18 (T18) is never neutral: it asks a family to weigh uncertain statistics alongside their own values in a decision about the life of their child. Management has shifted away from unilateral comfort care based on perceived lethality and toward individualized decision-making that centers the family within a care team assembled around the child. This addendum reviews the evidence and practical considerations surrounding surgical deliberation, including what an operation may and may not change, the likely postoperative course, the limits of retrospective evidence, the treating center's capabilities, and the family's goals. It then extends the Parallel Relational Care roadmap through surgical deliberation, discharge, and ongoing care.

Keywords: trisomy 18, cardiac surgery, noncardiac surgery, palliative care, shared decision-making, post-discharge care

“Cardiac surgery for an infant with trisomy 18 places families squarely inside that uncertainty. The question is not limited to whether an operation is technically feasible; it also includes what recovery may require, how treatment may shape time in the hospital or at home, and whether the proposed course fits the family’s goals for their child.”

Introduction:

When a family must authorize, defer, or decline an intervention, an uncertain outcome can later feel like evidence that they chose wrongly. The question is no longer only what happened to their child, but what they should have done differently. Cardiac surgery for an infant with trisomy 18 places families squarely inside that uncertainty. The question is not limited to whether an operation is technically feasible; it also includes what recovery may require, how treatment may shape time in the hospital or at home, and

whether the proposed course fits the family’s goals for their child.

The published Parallel Relational Care roadmap addressed the daily work of supporting families once an infant with trisomy 18 is admitted to the neonatal intensive care unit (NICU). Its four domains—prognostic humility, relational time, synchrony-preserving care, and parallel planning—give clinicians a structure for holding clinical uncertainty and parent–infant connection together. (1)

“Cardiac surgery for an infant with trisomy 18 places families squarely inside that uncertainty. The question is not limited to whether an operation is technically feasible; it also includes what recovery may require, how treatment may shape time in the hospital or at home, and whether the proposed course fits the family’s goals for their child.”

This follow-up focuses on trisomy 18 and extends that structure across the surgical trajectory: preoperative deliberation, postoperative recovery, discharge, and ongoing care. Prognostic humility asks clinicians to hold space for outcomes they cannot predict in advance. Relational time and synchrony-preserving care protect the parent–infant bond from medical urgency crowding it out. Parallel planning allows treatment and comfort-focused support to proceed side by side rather than as a sequence of last resorts. Together, these principles support clinical decision-making and parent–infant connection without treating them as competing priorities. (1) The approach builds on patient-centered care described by Merritt and colleagues and Haug and colleagues. (2, 3)

The purpose is to give clinicians a concrete way to walk families through uncertainty at each stage of care, rather than leaving them to carry it afterward as personal failure. Families need to understand what treatment might make possible, what recovery may demand, and what support will remain when they leave the hospital. Those questions apply to cardiac repair, other operations, and decisions to pursue comfort-focused care without surgery.

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Scope and approach:

This article is a narrative synthesis of selected observational studies, professional guidance, and family-perspective literature, rather than a systematic review. It presents no original patient data. Disease-specific outcome estimates are restricted to studies of trisomy 18 or separately reported trisomy 18 results. The authors explicitly identify evidence from broader neonatal chronic critical illness populations as indirect. The bedside tools are an author-proposed extension of the published roadmap, not a validated decision rule or a professional-society guideline.

“This article is a narrative synthesis of selected observational studies, professional guidance, and family-perspective literature, rather than a systematic review. It presents no original patient data. Disease-specific outcome estimates are restricted to studies of trisomy 18 or separately reported trisomy 18 results.”

Historical context and the change in counseling:

Parenthood with a critically ill child is a psychological crucible. Nothing fully prepares a family for a decision as consequential as pediatric cardiac surgery, or teaches a parent how to negotiate for potential time with their child. The history of trisomy 18 care includes families seeking connection when long-term survival was rarely discussed. Before such experiences could enter a clinical evidence base, families needed ways to find one another and make their children's lives visible.

“This history places a mother, her living child, and a relationship with a clinician at the beginning of a wider conversation. The questions were about the lives children were already living, as well as the prognosis families had been given.”

The push to reexamine the old default included families. In an account of the beginnings of SOFT, a parent-support organization, Dr. John Carey describes meeting Kris Holladay and her two-year-old daughter Kari in 1979; an initial family gathering followed in 1980. (4) This history places a mother, her living child, and a relationship with a clinician at the beginning of a wider conversation. The questions were about the lives children were already living, as well as the prognosis families had been given.

Family networks also contributed to knowledge about surviving children. Baty and colleagues documented that children with trisomy 18 continued to acquire skills even though their

development remained severely impaired. These selected survivor data broadened descriptions of affected children's lives without establishing a typical developmental trajectory for every infant. (5)

Ethicists later examined what the old language could do. Koogler, Wilfond, and Ross explored how describing a condition as “lethal” can shape decisions to withhold treatment and, in turn, the outcomes used to describe that condition. (6) Carey described the field's movement toward individualized consideration of intervention as a shift in the paradigm of care. (7) The change in counseling therefore involves both the evidence clinicians present and the assumptions that determine which possibilities enter the conversation.

Parents' accounts belong in counseling alongside clinical evidence. A family's description of joy, connection, or burden should inform the conversation without becoming a promise about another child's future. Clinicians should ask what matters to this family and explain how the available options relate to those priorities. (2, 3)

“Work associated with Stanford, the University of Utah, and Nebraska helped broaden the clinical conversation from whether trisomy 18 precludes intervention to which children might benefit and what families should expect. Their contributions connect outcomes research, parent advocacy, and post-surgery care.”

Contributions from Stanford, Utah, and Nebraska:

Work associated with Stanford, the University of Utah, and Nebraska helped broaden the clinical conversation from whether trisomy 18 precludes intervention to which children might benefit and what families should expect. Their contributions connect outcomes research, parent advocacy, and post-surgery care.

Stanford-associated research contributed evidence against assuming that cardiac intervention offers no opportunity for longer survival. Kosiv, Collins, and colleagues, working across the University of Arkansas for Medical Sciences and Stanford, analyzed a multicenter hospital database and found an association between congenital heart surgery and lower in-hospital mortality in the trisomy 18 subgroup. This was collaborative, observational evidence rather than a Stanford-only surgical series; it supported reconsideration of categorical exclusion while leaving individual benefit uncertain. (8)

At the University of Utah, Dr. Carey's long-standing work with SOFT connected clinical genetics with families' accounts of survival and daily life. (4, 7) Utah investigators also contributed cardiac outcomes research: Domingo, Carey, Eckhauser, Wilkes, and Menon studied 140 children with trisomy 18 who underwent cardiac interventions in a multicenter hospital database and

examined mortality and resource use. Their work brought the intensity of care, as well as survival, into individualized counseling. (9)

In Nebraska, the team at Children's Hospital and Medical Center in Omaha and the University of Nebraska Medical Center, including Weaver and Hammel, connected cardiac surgical care with research on family experience. Their study included eight children with trisomy 18—seven with full trisomy and one with mosaic trisomy—whose families traveled out of state for cardiac surgery after local refusal. (10) A related case report described a family seeking care elsewhere after their daughter with trisomy 18 was denied cardiac surgery in her home state and emphasized coordinated planning and interdisciplinary communication. (11) These reports support attention to referral pathways and sustained family support without establishing outcomes every family will experience.

Contemporary guidance supports a broader discussion. The American Academy of Pediatrics (AAP) advises against differential treatment based solely on the genetic diagnosis and recognizes comfort-focused care as an appropriate option. The American Association for Thoracic Surgery (AATS) recommends considering cardiac disease, associated anomalies, and the child's overall circumstances on a case-by-case basis. (12, 13) These positions create a responsibility to explain reasonable options; they do not establish an indication for surgery in every infant.

“Population survival, postoperative mortality, and survival after discharge describe different groups. In an Ontario cohort, one-year survival among children with trisomy 18 was 12.6%, whereas one-year survival after a first surgical intervention was 68.6% among children who reached surgery.”

Reading the surgical evidence accurately:

Different populations answer different questions:

Population survival, postoperative mortality, and survival after discharge describe different groups. In an Ontario cohort, one-year survival among children with trisomy 18 was 12.6%, whereas one-year survival after a first surgical intervention was 68.6% among children who reached surgery. Those interventions were not limited to cardiac operations. The latter estimate incorporates substantial selection and survival to the time of treatment. (14)

Cytogenetic subtype also matters. A Texas population study reported ten-year survival of 6.6% for full trisomy 18 and 43.8% for mosaic or partial trisomy 18. These are population observations, not estimates of surgical benefit. (15) Counseling should establish which diagnosis was confirmed and how closely a cited cohort resembles the infant under discussion.

Greenberg and colleagues identified congenital heart disease in 73% (3,288/4,503) of children with trisomy 18 admitted to participating hospitals. Among the 3,288 children with documented heart disease, reported morphologies included: (16)

- Isolated atrial or ventricular septal defects: 42%.
- Aortic hypoplasia or coarctation: 23%.
- Single-ventricle morphology: 5% (167/3,288).

“These selected categories are not exhaustive. The retrospective hospital cohort included children younger than 18 years; these are not population-wide newborn prevalence estimates. Cardiac surgery was performed in 17% of the trisomy 18 cohort with heart disease.”

These selected categories are not exhaustive. The retrospective hospital cohort included children younger than 18 years; these are not population-wide newborn prevalence estimates. Cardiac surgery was performed in 17% of the trisomy 18 cohort with heart disease. Lesion frequency, potential candidacy, an institutional offer, and receipt of surgery are distinct quantities; these data do not establish a percentage of infants who are operable. (16)

Table 1 summarizes selected outcomes. The rows are not interchangeable estimates and cannot be combined into a single prognosis.

Association, selection, and uncertainty:

Selection is not simply a division between healthier operated children and sicker nonoperated children. In Greenberg's cohort, operated patients with trisomy 18 had a higher median number of coded extracardiac comorbidities than nonoperated patients, three versus two. Administrative counts, however, do not fully capture severity, physiology, family preference, or institutional practice. (16) Children must also survive long enough to receive surgery, creating additional challenges when comparing treated and untreated groups.

The defensible conclusion is that selected children can survive intervention and some can live for years. The literature cannot identify a guaranteed benefit for an individual infant or establish an optimal overall surgery rate. Clinicians should present what a statistic describes, what it leaves out, and why it may or may not apply to this child.

Physiology, procedure, and timing:

Surgical candidacy depends on more than cardiac anatomy. Respiratory status, pulmonary circulation, extracardiac conditions, clinical trajectory, and center experience may change the anticipated benefits and burdens. In the Society of Thoracic Surgeons cohort, preoperative mechanical ventilation was associated with higher operative mortality among patients with trisomy 18. It is a risk marker within an operated cohort, not a

stand-alone rule for excluding every ventilated infant. (17)

“Hatai and colleagues studied catheterization findings in 20 children with trisomy 18, alongside trisomy 21 and nontrisomic comparison groups with ventricular septal defect-associated heart failure, and found no significant group differences in several pulmonary hemodynamic measures. (21)”

Pulmonary findings require similar care. Tahara and colleagues described abnormal pulmonary vascular and alveolar development in lung biopsies from 28 selected infants with trisomy 18 undergoing cardiac surgery. (20) Hatai and colleagues studied catheterization findings in 20 children with trisomy 18, alongside trisomy 21 and nontrisomic comparison groups with ventricular septal defect-associated heart failure, and found no significant group differences in several pulmonary hemodynamic measures. (21) Histology and catheterization examine different features in separately selected populations. These studies do not justify a uniform prediction that pulmonary hypertension will either prohibit repair or normalize afterward.

Cardiac repair addresses one component of a multisystem condition. Respiratory, neurologic, feeding, and other problems may continue to determine recovery and survival. Multidisciplinary assessment can help make those interactions explicit. (22) Survival prediction differs from an estimate of the benefit of a particular operation.

Terminology should remain precise. Complete repair addresses

the cardiac lesion more definitively. Anatomic palliation modifies circulation without completing repair; for example, pulmonary artery banding may reduce pulmonary overcirculation in an appropriate setting. Supportive procedures, such as gastrostomy or tracheostomy, address particular feeding or airway needs. Palliative care is an approach to symptom relief, communication, and family support that may accompany any of these pathways. The word “palliative” should not make an anatomic procedure sound equivalent to comfort-only care. (12, 13)

“Palliative care is an approach to symptom relief, communication, and family support that may accompany any of these pathways. The word “palliative” should not make an anatomic procedure sound equivalent to comfort-only care. (12, 13)”

Potential benefit should be described in physiologic terms. For selected infants, intervention may relieve congestive heart failure, allow withdrawal of prostaglandin in ductal-dependent disease, or help make discharge possible. These are treatment goals to assess for the individual child, not promises of reduced medication needs or longer survival for every infant. (12, 13)

Noncardiac surgery and the burden of recovery:

Noncardiac procedures and anesthesia:

Feeding access and associated structural anomalies may prompt consideration of noncardiac surgery before or after a cardiac decision. The proposed procedure, the child’s condition, and the family’s goals should guide that discussion. (12)

Table 1. Selected cardiac intervention outcomes and their limits

Source	Population and reported outcome	Counseling limit
Cooper et al. (17)	Society of Thoracic Surgeons database, 2010–2017: 270 operations in patients with trisomy 18. Operative mortality was 15.6% (42/270); postoperative complications occurred after 55.6% of operations (150/270).	Selected surgical cases; operation-based denominators. Operative mortality does not match every study’s in-hospital endpoint.
Kosiv et al. (8)	Pediatric Health Information System, 2004–2015: 1,020 newborns with trisomy 18. Cardiac surgery was associated with 64% lower in-hospital mortality in the trisomy 18 group.	Retrospective association; clinical selection and survival to surgery preclude interpreting this as an individual treatment effect.
Greenberg et al. (16)	Pediatric Health Information System, 2003–2022: 3,288 children with trisomy 18 and congenital heart disease; 17% underwent surgery, with in-hospital mortality below 10% among surgical patients.	Pediatric hospital cohort, not an all-age or population birth cohort. The observation period overlaps earlier database work.
Nemoto et al. (18)	Japanese national database, 2013–2021: 789 operations in 502 children with trisomy 18; 42 patients died in hospital (8.4%).	Patient and operation denominators differ. The results describe selected children receiving surgery in that system.
Peterson et al. (19)	Pediatric Cardiac Care Consortium, 1982–2008: 69 children with trisomy 18 received an intervention. Median survival among discharge survivors was 16.2 years (95% confidence interval, 12–20.4).	Conditional survival after discharge; interventions included surgery and catheter procedures. This is not expected survival from birth or initial surgical evaluation.

Matthews and colleagues examined noncardiac surgery in the National Surgical Quality Improvement Program–Pediatric database. Among 335 children with trisomy 18, postoperative mortality was 11.1%; mortality in the neonatal trisomy 18 subgroup was 31.8%. (23) The neonatal rate is especially relevant to NICU counseling, but neither estimate applies without considering the proposed procedure and the child's condition. The broader cohort should not be described as if it consisted entirely of newborns.

“Anesthesia planning also deserves an explicit place in deliberation. Birmingham and colleagues reviewed 84 anesthetic encounters in nine children with complete trisomy 18 and identified difficult intubation as the most frequent critical perioperative event.”

Anesthesia planning also deserves an explicit place in deliberation. Birmingham and colleagues reviewed 84 anesthetic encounters in nine children with complete trisomy 18 and identified difficult intubation as the most frequent critical perioperative event. (24) Repeated encounters in a small number of children do not yield a population-wide risk estimate. They do support careful airway assessment and preparation for ventilation or intubation difficulty.

What surviving an operation may require:

Surviving an operation is not the same as a routine recovery, and families should hear that before consent rather than discover it afterward. In Cooper and colleagues' trisomy 18 surgical cohort, postoperative complications were recorded after 150 of 270 operations (55.6%), and median postoperative length of stay was 18 days. These findings describe selected surgical cases, not a prediction for every infant with trisomy 18. (17)

Other studies also identify substantial resource use. Ma and colleagues reported a median cardiac surgical admission of 16 days for trisomy 18. (25) Admission-level findings do not describe the expected course of every infant or the respiratory-support needs of medically managed NICU patients.

Mortality and length of stay do not capture all burdens borne by the child. Repeated painful procedures, sedation, invasive ventilation, separation from family routines, and possible technology dependence belong in the discussion. Neonatal pain guidance supports minimizing painful procedures and using explicit assessment and treatment plans. (26) Families should also hear the goals that might justify an intervention: symptom relief, improved feeding or circulation, discharge home, or more time together. Those goals must be individualized and revisited if recovery takes a different course.

Access, consultation, and coverage:

An individualized process requires transparency about what is actually available. The team should explain whether an operation is offered locally, whether consultation elsewhere is clinically appropriate, and why it recommends or advises against

intervention for this infant. Institutional unavailability and patient-specific inadvisability are different explanations. Naming a second-opinion pathway does not promise acceptance, safe transfer, or an operation. (12, 13)

A published account of a family seeking cardiac care elsewhere after their daughter with trisomy 18 was denied surgery locally illustrates the practical burden of differing institutional approaches. A single case does not establish how often such refusals occur or describe current institutional policies. (11)

Pediatric cardiologists also shape access through prenatal counseling and surgical referral. In a survey of 142 pediatric cardiologists, 63% would discuss surgery as an option in a trisomy 18 scenario involving critical coarctation and a ventricular septal defect; 59% would consult cardiac surgery before counseling. The response rate was 34%, and most respondents practiced in academic centers. These findings describe variation in stated practice, not verified institutional policies or actual referral outcomes. (27)

Payer associations also require restraint. In a Texas cohort of 1,156 patients with trisomy 18, 44 underwent congenital heart surgery. Medicare/Medicaid coverage was associated with lower odds of surgery than private coverage. The study does not establish that an insurance denial caused the difference or isolate the roles of geography, referral, clinical selection, and family circumstances. (28) Early care coordination can clarify referral requirements, receiving-center capacity, equipment needs, and authorization before a crisis.

“Teams should verify eligibility, benefits, provider networks, and authorization requirements with the responsible program or plan before referral or transfer. The diagnosis of trisomy 18 alone does not establish approval of a particular operation.”

In California, California Children's Services (CCS) covers medically necessary cardiac surgery for eligible children with qualifying congenital heart disease. Eligibility depends on the medical condition, residence, and financial criteria, and service authorization requires supporting documentation and a medical-necessity review. (29, 30) Outside California, Medicaid and private insurance are potential coverage pathways. (28) Teams should verify eligibility, benefits, provider networks, and authorization requirements with the responsible program or plan before referral or transfer. The diagnosis of trisomy 18 alone does not establish approval of a particular operation.

Concurrent hospice care may be relevant for eligible children. Federal Medicaid and Children's Health Insurance Program provisions allow eligible patients younger than 21 to receive hospice without waiving treatment for the terminal condition. This does not guarantee coverage of a particular operation, the availability of a hospice that can support the child's needs, or the same arrangement under every insurance plan. Teams should

Table 2. The four domains across the care trajectory

Domain	Surgical deliberation and recovery	Discharge and ongoing care
Prognostic humility	Identify the relevant population behind each estimate; distinguish technical feasibility from likely benefit; name uncertainty as recovery evolves.	Describe possible stability and decline; revise expectations using the child's actual course.
Relational time	Protect time to absorb information when clinically possible; treat the admission as part of the baby's life and the family's parenthood.	Preserve continuity of relationships and support parenting across home, clinic, and readmission.
Synchrony-preserving care	Plan safe opportunities for touch, holding, voice, feeding, and caregiving during deliberation and recovery.	Prepare caregivers for daily routines; support development and connection within the child's abilities and the family's goals.
Parallel planning	Prepare for improvement, prolonged recovery, and deterioration; document goals and reassessment triggers.	Name the coordinating clinician, emergency contacts, and plans for revisiting treatment and support.

verify the applicable program and local services with the family. (31)

“The same clinical facts do not mean the same thing to everyone in the room. A survival estimate or description of a ventilator course is received through what a family already believes, fears, and hopes. Patient-centered counseling asks what parents understand, what matters to them, and what kind of recommendation would be helpful. Merritt and colleagues emphasize education, transparent values, the child’s best interests, and the limits, as well as the importance of parental autonomy. (2)”

Parents’ perspectives and shared deliberation:

The same clinical facts do not mean the same thing to everyone in the room. A survival estimate or description of a ventilator course is received through what a family already believes, fears, and hopes. Patient-centered counseling asks what parents understand, what matters to them, and what kind of recommendation would be helpful. Merritt and colleagues emphasize education, transparent values, the child’s best interests, and the limits, as well as the importance of parental autonomy. (2)

Parents may already have encountered hospital websites, prognosis summaries, or stories from other families. The clinical task is to individualize that information without dismissing lived experience or presenting an exceptional survivor as an expected outcome. Family accounts and professional recommendations

support sustained communication about reasonable options, including comfort-focused care. (3, 32)

Explore reasons for choosing or declining surgery rather than assigning them to families. Parents may hope for more time together, relief of symptoms, or an opportunity to bring their child home; others may prioritize avoiding painful procedures or prolonged intensive care when benefit is uncertain. Counseling should ask which outcomes matter to this family and how anticipated burdens affect that judgment. Neither choice, by itself, measures parental attachment or commitment to the child. (2, 12, 32)

“Development belongs in this conversation even when the surgical literature provides few answers. Severe developmental impairment is part of the prognosis, while older survivor studies describe social engagement and acquisition of skills. (5) Neither survival nor successful repair establishes a developmental benefit. ”

Development belongs in this conversation even when the surgical literature provides few answers. Severe developmental impairment is part of the prognosis, while older survivor studies describe social engagement and acquisition of skills. (5) Neither survival nor successful repair establishes a developmental benefit. Teams should distinguish what is known about the condition, what a family values in their child’s interactions, and what remains unknown about function and quality of life after intervention.

Disagreement may continue while clinicians and parents remain in a working relationship. The next step can be another supported conversation, clarification of the recommendation, or an appropriate second opinion. Deliberation should allow goals

to change without implying that parents must repeatedly defend their child's worth. The question is whether a proposed treatment can achieve a child-centered goal at an acceptable burden under the circumstances.

“The proposed process carries the four domains of the NICU roadmap into surgical and longitudinal care (Table 2). (1) It does not rank families’ choices. It asks teams to make the reasoning and continuing support visible.”

Extending Parallel Relational Care:

The proposed process carries the four domains of the NICU roadmap into surgical and longitudinal care (Table 2). (1) It does not rank families’ choices. It asks teams to make the reasoning and continuing support visible.

The actions in Table 2 are proposed extensions of the author’s published framework; they have not been prospectively evaluated. A daily bedside question remains useful: has this parent had a chance today to hold, touch, speak to, feed, bathe, photograph, or be with their baby, as the infant’s condition allows?

Five questions for a surgical conversation

1. **What condition is being treated?** Name the anatomic or functional problem and distinguish complete repair, anatomic palliation, and a supportive procedure. Explain which problems will remain even if the operation succeeds.
2. **What is the goal?** State the hoped-for outcome in terms the family and team can recognize: symptom relief, survival, discharge home, easier caregiving, or time together. Explain how the operation might contribute and what alternative approaches could accomplish.
3. **What burdens are expected?** Discuss mortality, complications, likely recovery, pain, respiratory support, further procedures, and possible technology dependence. Use the most relevant published and local experience, with its limitations, rather than a single reassuring number.
4. **What remains uncertain?** Name uncertainties about survival, recovery, function, and life at home. Separate lack of evidence from evidence of no benefit, and distinguish an outcome prediction from an estimate of treatment effect.
5. **When will the plan be revisited?** Identify clinical changes and family concerns that should prompt reassessment, including failure to improve, new complications, increasing support needs, or changing goals—name who will lead that discussion.

A supported return to the conversation:

This article proposes scheduling a family-support follow-up within approximately 72 hours of a substantial deliberation, when the clinical situation permits. This interval is an operational suggestion,

not an evidence-based standard, waiting period, or decision deadline. Urgent conditions require earlier action; some families need more time. The purpose is to return predictably, clarify what was heard, address new information, and ensure that uncertainty has not become abandonment.

“The note should record the proposed procedure, the family’s goals, the team’s recommendation and reasoning, unresolved questions, alternatives, local limitations, and the next contact. Palliative care, social work, nursing, and other relevant clinicians can help sustain that plan. A supported pause should still include daily care, symptom management, and opportunities for parenthood.”

The note should record the proposed procedure, the family’s goals, the team’s recommendation and reasoning, unresolved questions, alternatives, local limitations, and the next contact. Palliative care, social work, nursing, and other relevant clinicians can help sustain that plan. A supported pause should still include daily care, symptom management, and opportunities for parenthood.

Box 1. Questions families can bring to the team:

These author-developed questions accompany the five-question process; they are not a validated questionnaire.

- ☐ What problem would this procedure treat, and what would it leave unchanged?
- ☐ What might life look like with the procedure, without it, and if recovery is harder than expected?
- ☐ What are we hoping it will make possible for our child?
- ☐ What pain, breathing support, feeding support, or further procedures might be involved?
- ☐ How much experience does this center have, and would another opinion help?
- ☐ What would we need at home, and who will help arrange it?
- ☐ What would make us reconsider the plan, and who will talk with us about that?
- ☐ Whom can we call after this conversation, and when will we meet again?

Families do not have to ask every question at once. The team remains responsible for explaining material risks and reasonable options even when parents do not know what to ask.

Discharge and ongoing care:

“The surgical conversation is incomplete if it does not name who carries the plan after discharge. Diagnosis-specific evidence about transitions remains limited. Studies of broader neonatal chronic critical illness populations describe persistent technology needs and parents’ difficulties navigating the move from intensive inpatient support to home.”

The surgical conversation is incomplete if it does not name who carries the plan after discharge. Diagnosis-specific evidence about transitions remains limited. Studies of broader neonatal chronic critical illness populations describe persistent technology needs and parents’ difficulties navigating the move from intensive inpatient support to home. (33, 34) These findings are indirect; they identify issues to anticipate, not trisomy 18-specific rates.

Box 2. A proposed discharge continuity checklist:

- **Accountable clinician:** identify the primary care or coordinating clinician who will integrate recommendations and convene the team when plans conflict.
- **Portable plan:** summarize baseline status, procedures completed or deferred, family goals, treatments and devices, symptom management, emergency instructions, and relevant resuscitation decisions.
- **Scheduled contacts:** confirm initial primary care and specialty appointments, the next goals-of-care review, and who will contact the family after arrival home.
- **Caregiver preparation:** verify teaching and practical readiness for medications, feeding or respiratory equipment, and the actions needed when problems arise.
- **Services and supplies:** confirm equipment delivery, nursing or home-care arrangements where available, and palliative or hospice connections when appropriate and desired.
- **Contingencies:** document whom to call day and night, where to seek urgent care, and what to do if planned home support is unavailable.

Adapt these proposed checklist items to the child’s condition and local resources. An appointment recommendation, equipment order, or referral is not a completed handoff. Families need to know what is in place, what is still pending, and who owns the next step.

Discharge changes the care plan’s address, not the end of the plan. The receiving clinician needs a concise account of the problem treated or deferred, the family’s goals, unresolved uncertainty, current technology, and the next review. A complete operative history alone cannot carry that information.

Revisit goals during stability as well as decline. Feeding difficulties, respiratory symptoms, repeated admissions, or a new procedural question may change what the family and team consider achievable. Conversely, a stable period at home may create opportunities that were difficult to imagine in the NICU. Routine preventive care, developmental support, symptom management, and care coordination should remain part of individualized longitudinal care. (12)

Caregiver capacity must also be discussed concretely: sleep, other children, employment, transportation, respite, and the reliability of home support. Those burdens call for practical assistance and honest planning. Peer connection can be offered without making it a requirement or a substitute for clinical follow-up. The five questions can be reused when another decision arises, so the family does not have to rebuild the conversation from the beginning.

“Surgical deliberation for an infant with trisomy 18 is an ongoing process, properly revisited from the NICU through discharge and into ordinary pediatric care. The clinical task is to name what surgery can and cannot change, what recovery may require, what a center can offer, and what the family’s goals mean for this child. The five-question conversation and continuity tools extend Parallel Relational Care toward that end. Their central commitment is practical: families should not have to carry an uncertain prognosis, a consequential decision, and an uncoordinated care plan alone.”

Conclusion:

Surgical deliberation for an infant with trisomy 18 is an ongoing process, properly revisited from the NICU through discharge and into ordinary pediatric care. The clinical task is to name what surgery can and cannot change, what recovery may require, what a center can offer, and what the family’s goals mean for this child. The five-question conversation and continuity tools extend Parallel Relational Care toward that end. Their central commitment is practical: families should not have to carry an uncertain prognosis, a consequential decision, and an uncoordinated care plan alone.

Stanford has publicly described its pediatric cardiac surgical care, family support, discharge planning, and follow-up. (35) SOFT’s hospital directory documents prior surgical experience but cautions that current availability may change. (36) A comprehensive, regularly updated national registry identifying centers that currently offer cardiac surgery and coordinated aftercare for

infants with trisomy 18 would help families, neonatologists, and pediatric cardiologists navigate regional referrals. Collaborative data sharing among participating centers could also support outcome evaluation and continuity of care.

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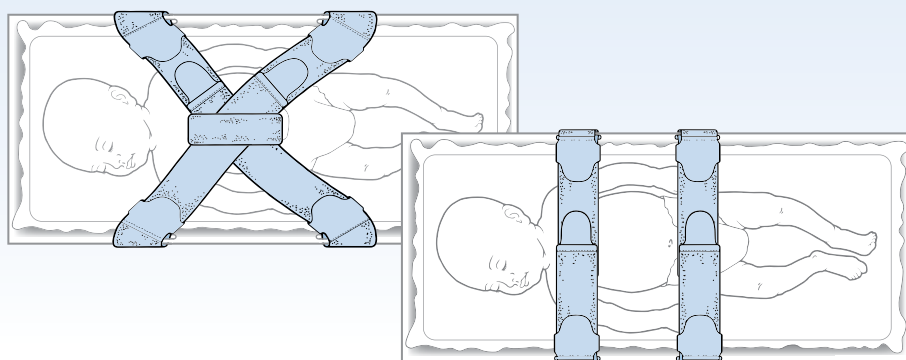
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Postpartum Psychosis and the NICU: Protecting Infant Safety While Preserving the Mother Infant Dyad

Prescilla Niayesh, MS-IV; Saba Saleem, DO

“Postpartum psychosis (PPP) is a rare but severe psychiatric emergency, typically emerging within 3 to 10 days after delivery (1). Presentation may include mania, depression, psychosis, confusion, mood-incongruent delusions, and disorganized behavior, with symptoms often waxing and waning (1).”

I. Introduction

Postpartum psychosis (PPP) is a rare but severe psychiatric emergency, typically emerging within 3 to 10 days after delivery (1). Presentation may include mania, depression, psychosis, confusion, mood-incongruent delusions, and disorganized behavior, with symptoms often waxing and waning (1). Given the elevated risk of suicide and infanticide, inpatient psychiatric hospitalization is the recommended standard of care (1). When the infant is hospitalized in the NICU, maternal psychiatric hospitalization creates a unique clinical dilemma: two patients, in two locations, under two clinical teams rarely structured to communicate with each other. The mother may be unsafe to be alone with her infant, while the infant may be medically unable to leave the NICU, further disrupting bonding, breastfeeding, and caregiving. This review examines how to provide maternal psychiatric treatment, protect infant safety, and preserve the mother-infant relationship through coordinated psychiatric and neonatal care.

II. Epidemiology

Population-based estimates of PPP incidence range from 0.89–2.6 per 1,000 births (2). PPP is closely tied to bipolar-spectrum illness: following a first episode, 50–80% experience a subsequent psychiatric episode, usually within the bipolar spectrum, while 20–50% remain confined to the postpartum period (1). Evidence linking PPP to NICU hospitalization is limited, as studies primarily examine prematurity and obstetric complications rather than NICU admission itself (3, 4). Whether NICU admission independently increases PPP risk remains unstudied. In contrast, psychiatric distress among NICU parents is well established. A meta-analysis of nearly 7,000 parents found anxiety, depression, and stress in 51%, 31%, and 41% of NICU mothers, respectively (5). However, these findings concern psychiatric distress rather than psychosis, and NICU admission has not been established as a specific PPP trigger. Thus, PPP risk appears concentrated among mothers

with underlying psychiatric vulnerability rather than the NICU experience itself (1, 5).

III. Risk Factors

The strongest risk factors for PPP are a personal history of bipolar disorder or prior PPP (1). Family history also contributes, as postpartum psychiatric episodes may mark a familial form of bipolar disorder (1). Unlike postpartum unipolar depression, ordinary life events and social stress are not implicated in PPP's etiology, emphasizing psychiatric and genetic vulnerability (1). Obstetric and perinatal risk factors are comparatively weak and inconsistent. Primiparity is a significant predictor, while other obstetric risk factors for a first episode of PPP have not been consistently identified (1). A large Swedish registry found that preterm delivery and other obstetric complications increased psychosis risk only among women with pre-existing psychiatric vulnerability, suggesting they may act as triggers rather than independent causes (3). NICU-related factors may similarly amplify underlying vulnerability. Severe sleep disruption is particularly relevant, as it often precedes psychotic symptoms in PPP (1). NICU circumstances may compound maternal sleep loss, separation, stress, and disrupted routines, although their contribution to PPP risk remains unclear. Clinically, suspicion for PPP should rise when these factors occur alongside a personal or family history of bipolar-spectrum illness.

“The strongest risk factors for PPP are a personal history of bipolar disorder or prior PPP (1). Family history also contributes, as postpartum psychiatric episodes may mark a familial form of bipolar disorder (1). Unlike postpartum unipolar depression, ordinary life events and social stress are not implicated in PPP's etiology, emphasizing psychiatric and genetic vulnerability (1).”

IV. Pathophysiology

PPP appears closely linked to bipolar-spectrum vulnerability, although the mechanisms underlying this relationship are not fully understood (1). Among women whose first psychiatric contact occurred within 30 days postpartum, 14% were later diagnosed with bipolar disorder within 15 years, compared with 4% whose first contact occurred outside the postpartum period (1). One proposed mechanism is the abrupt postpartum withdrawal of estrogen and

progesterone (1). Because estrogen modulates dopaminergic tone, this withdrawal may increase dopamine receptor sensitivity in vulnerable women, contributing to manic or psychotic symptoms (1). Supporting this hypothesis, postpartum rats demonstrated increased dopamine agonist responses and striatal dopamine (11). Human evidence is mixed: a case series and open-label pilot reported improvement with estradiol (6, 7), while a randomized trial found no reduction in relapse with estradiol prophylaxis (8), suggesting sensitivity to hormonal withdrawal rather than a simple hormone-deficiency model. Circadian disruption and sleep loss may also precipitate mania or hypomania in vulnerable women (12), potentially relevant to disrupted maternal sleep in the NICU. Genetic vulnerability is supported by linkage of postpartum-triggered episodes to chromosome 16p13 (9), while associations with autoimmune thyroiditis, preeclampsia, and anti-NMDA-receptor antibodies suggest possible immune involvement in some cases (1, 10).

V. Postpartum Psychosis When the Infant Is in the NICU

Maternal psychiatric hospitalization and separation

PPP generally requires acute inpatient psychiatric care, ideally in a specialized mother-baby psychiatric unit (MBU) when available and clinically appropriate (1). In a cohort of 869 women across 13 French MBUs, two-thirds improved significantly by discharge, and 21% of infants had been transferred to a NICU (13). However, co-location may not be possible for infants requiring ongoing specialized neonatal care. In one study, separation occurred in 23% of joint MBU admissions, potentially limiting feeding, holding, and other caregiving activities that support the mother-infant relationship (15).

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Infant safety versus mother-infant contact

After assessing imminent risk, supervised contact may be possible before full visitation resumes, with treatment algorithms recommending supervised infant access based on ongoing risk assessment (16). A nurse, family member, or other trusted adult may supervise contact, including skin-to-skin care when appropriate. As symptoms improve, and most women with PPP achieve remission within weeks (1), supervision should ease accordingly.

Breastfeeding, pumping, and psychiatric treatment

Maternal hospitalization during a NICU stay complicates lactation, as maintaining supply requires regular pumping despite separation, sedation, and logistical barriers. Medication adds further complexity: lithium, a first-line treatment for PPP (1), is transferred through breast milk and carries a risk of infant toxicity, warranting monitoring of infant lithium levels and renal and thyroid function (19). Particular caution is warranted for premature

or medically compromised infants because reduced renal clearance and intercurrent illness may increase the risk of lithium accumulation and toxicity. Antipsychotic exposure through breast milk is generally lower, typically under 5% of the maternal dose (1). However, transfer into breast milk varies considerably among antipsychotic agents; therefore, medication-specific lactation data, along with the infant's gestational age, medical condition, and ability to metabolize and eliminate the drug, should guide risk-benefit assessment. For medically fragile or preterm infants, these risks warrant shared decision-making among psychiatry, neonatology, and the mother.

“A good early parent-infant relationship supports a child’s future self-esteem, emotional regulation, and capacity to form close relationships, while poor early bonding is linked to worse cognitive and emotional outcomes (20). NICU hospitalization already disrupts these opportunities, and maternal hospitalization compounds this. Encouragingly, impaired bonding was less common at admission among women with PPP (17.6%) than among women with severe postpartum depression (57.1%), falling to 5.9% by discharge as symptoms resolved (14), suggesting PPP is not an inherent barrier to bonding once treated.”

Preserving bonding and attachment

A good early parent-infant relationship supports a child's future self-esteem, emotional regulation, and capacity to form close relationships, while poor early bonding is linked to worse cognitive and emotional outcomes (20). NICU hospitalization already disrupts these opportunities, and maternal hospitalization compounds this. Encouragingly, impaired bonding was less common at admission among women with PPP (17.6%) than among women with severe postpartum depression (57.1%), falling to 5.9% by discharge as symptoms resolved (14), suggesting PPP is not an inherent barrier to bonding once treated. When physical contact is not possible, video calls and photos may reduce parental stress and support bonding (17), with caregiving expanded gradually as the mother's condition allows.

Interdisciplinary care

None of the above works without active coordination across teams that do not typically communicate routinely: neonatology, psychiatry, obstetrics, nursing, social work, lactation, and family. In practice, this means clear ownership of a few concrete questions: who communicates changes in maternal status to the NICU team

and back; who conducts and documents safety assessments; how psychiatry signals when supervised contact can become unsupervised; and how discharge planning begins early enough that neither team is caught unprepared if one patient is ready to leave before the other. This coordination is what allows two overlapping crises—one neonatal, one maternal-psychiatric—to be managed as one family's care rather than two unrelated hospitalizations.

VI. Recovery, Reunification & Discharge

In a four-year follow-up of 106 women with first-onset PPP, over two-thirds had no major psychiatric episodes outside the postpartum period, while the remaining third developed bipolar disorder; none developed schizophrenia (18). These findings support treating acute restrictions as temporary, reassessing safety, and gradually expanding contact as symptoms stabilize. Continued psychiatric follow-up and medication adherence remain essential, particularly given the roughly 31% recurrence risk in a future pregnancy among women with isolated PPP (1). Protecting maternal sleep and educating families about early warning signs may also help prevent relapse. Discharge planning is particularly complex when mother and infant are ready at different times. If the infant is ready first, discharge to a partner or family caregiver may allow the mother to resume caregiving after recovery; if the mother is ready first, visitation and gradual caregiving can continue while the infant remains hospitalized. In either case, psychiatry and neonatology should jointly determine the safest arrangement for the family.

“Postpartum psychosis is a maternal psychiatric emergency, but when the newborn is hospitalized in the NICU, it becomes a neonatal and family-centered care issue affecting the mother-infant dyad. Protecting infant safety during acute illness does not require abandoning the mother-infant relationship, as bonding can recover alongside psychiatric symptoms with treatment.”

VII. Conclusion

Postpartum psychosis is a maternal psychiatric emergency, but when the newborn is hospitalized in the NICU, it becomes a neonatal and family-centered care issue affecting the mother-infant dyad. Protecting infant safety during acute illness does not require abandoning the mother-infant relationship, as bonding can recover alongside psychiatric symptoms with treatment. Because PPP symptoms may wax and wane, ongoing reassessment is important as maternal contact and caregiving responsibilities are gradually restored. Achieving these goals requires deliberate coordination between neonatology and psychiatry throughout hospitalization, recovery, reunification, and discharge. The goal

is not simply to protect the infant from an acutely ill mother, but to keep the infant safe while helping a recovering mother return safely to her role as a parent.

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Today, we are reaching out to invite you to extend that spirit of community and generosity to a mission that touches the lives of mothers, newborns, and families throughout Greater Los Angeles.

For more than 40 years, PAC LAC, a Glendale-based 501(c)(3) nonprofit organization, has been dedicated to improving maternal and neonatal health through advocacy, education, mentorship, collaboration, and quality improvement.

As a provider within the Regional Perinatal Programs of California (RPPC), we support more than **75 hospitals** across Santa Barbara, Ventura, Los Angeles, Riverside, San Bernardino, and Mono counties. Our work brings together health professionals, hospitals, and community-based organizations to share knowledge, strengthen partnerships, and improve care for mothers, infants, and families, particularly those facing inequality in access to healthcare.

Why Your Support Matters Now

- Across California, the closure of hospital maternity services and persistent disparities in maternal and infant health are creating additional challenges for families seeking timely, accessible, high quality care.
- Where a family lives, their circumstances, or their access to resources should never determine the quality of care they receive.
- Through our educational programs, professional mentorship, and regional collaboration, PAC LAC helps healthcare professionals learn from one another, implement evidence-based practices, and strengthen the systems of care that families depend upon.

This Giving Tuesday, we are seeking a \$75,000 charitable contribution to expand our education and mentorship initiatives, including:

- Monthly educational webinars featuring evidence-based maternal and neonatal care, quality improvement, and emerging healthcare challenges.
- Student health and lactation internship opportunities help promote knowledge and experience to inspire the next generation of healthcare professionals.
- Collaboration and shared learning among hospitals, public health agencies, and community organizations will strengthen care and address healthcare disparities.

We would be honored to have your business join us as a community partner in this important mission. While our funding goal is \$75,000, we would deeply appreciate any contribution, which would help us continue this work.

Thank you for considering our request and for your generosity that will make a difference in the lives of mothers, babies, and their families.

With sincere appreciation,

Dr. Carmen Rezak, DNP, MJ, RN, WHCNP-BC--Chief Executive Officer-crezak@paclac.org





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

Genetic, Molecular, and Developmental Insights into Neonatal Ventriculomegaly: A Comparative Case-Based Review

Habiba Mohsin, MD, Asma Tariq, MD, Nasir Rashid, M.D. MBA, FCPS

Introduction:

Ventriculomegaly, defined as dilatation of the lateral cerebral ventricles with an atrial diameter ≥ 10 mm, is among the most frequently encountered abnormalities on prenatal and neonatal neuroimaging. (1) It is identified in approximately 0.5–2 per 1,000 live births and may be detected in up to 1% of routine obstetric ultrasound examinations. (1) Based on ventricular diameter, ventriculomegaly is classified as mild (10–12 mm), moderate (13–15 mm), and severe (>15 mm). A clear distinction exists between ventriculomegaly, hydrocephalus, and macrocephaly, which is essential for accurate clinical interpretation. (2) Hydrocephalus is a clinical syndrome characterized by increased intracranial pressure, which may present in infants as progressive enlargement of head circumference and irritability. (2) In contrast, ventriculomegaly is the radiographic finding of enlarged cerebral ventricles, while macrocephaly is an abnormally large head circumference above the 98th percentile for age. (2) Ventriculomegaly should not be considered a diagnosis in itself but a manifestation of diverse underlying pathological processes. (3) Fetal ventriculomegaly may be isolated or associated with CNS and extracranial anomalies, with a higher risk in congenital

infections, genetic abnormalities, or structural anomalies. (3) The objective of this review is to explore ventriculomegaly in two cases that presented with the same radiological finding but with different underlying etiologies. By integrating these cases with the current literature, we highlight the diverse etiologies, pathophysiologies, genetic mechanisms, and neurodevelopmental outcomes.

Case Presentations:

Case A

“A 36 $\frac{6}{7}$ -week male was delivered to a 41-year-old primigravida through cesarean section due to non-reassuring fetal heart tracing following a pregnancy complicated by suspected trisomy 21 on cell-free fetal DNA.”

A 36 $\frac{6}{7}$ -week male was delivered to a 41-year-old primigravida through cesarean section due to non-reassuring fetal heart tracing following a pregnancy complicated by suspected trisomy 21 on cell-free fetal DNA. His APGAR scores were 8 and 9 at 1 and 5 min, respectively, and he was admitted to the NICU for desaturation, where he was put on nasal CPAP. Head US and MRI demonstrated mild dilation of the lateral and third ventricles with a normal fourth ventricle (Figure 1). MRI revealed partial aqueductal stenosis. The head circumference remained stable at 33.5 cm, consistent with the initial measurement obtained at birth.

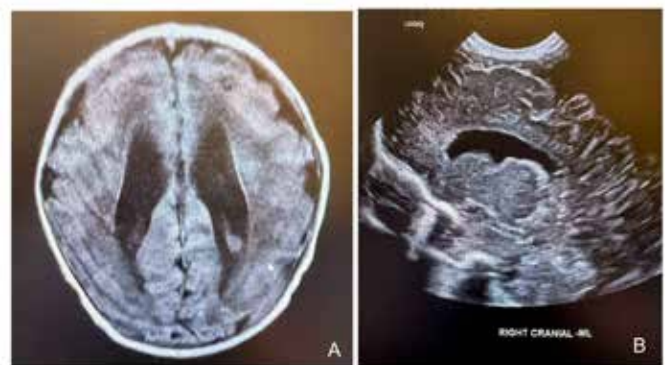


Figure 1. A Coronal section T1-weighted brain MRI. Dilated lateral ventricles. Figure 1. B Sagittal view, brain ultrasound. Ventriculomegaly involving the lateral and third ventricles. No germinal matrix hemorrhage or intraventricular hemorrhage is seen.

“Ventriculomegaly, defined as dilatation of the lateral cerebral ventricles with an atrial diameter ≥ 10 mm, is among the most frequently encountered abnormalities on prenatal and neonatal neuroimaging. It is identified in approximately 0.5–2 per 1,000 live births and may be detected in up to 1% of routine obstetric ultrasound examinations. Based on ventricular diameter, ventriculomegaly is classified as mild (10–12 mm), moderate (13–15 mm), and severe (>15 mm).”

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Neurosurgery recommended observation with repeat imaging at 3 months.

Echocardiography showed a large 8–9 mm inlet ventricular septal defect (VSD), patent ductus arteriosus (PDA), patent foramen ovale (PFO), and cleft mitral valve with mild mitral regurgitation. Despite intermittent tachypnea and elevated brain natriuretic peptide (BNP) reflective of cardiac strain, he remained hemodynamically stable. Chromosomal microarray analysis (CMA) confirmed trisomy 21. According to neurology, developmental delay is expected given the diagnosis of Down syndrome. Multidisciplinary follow-up with cardiology, neurology, genetics, endocrinology, hematology, and occupational therapy is planned.

Case B

“A 37 ⁴/₇-week term male infant was delivered through cesarean section to a 30-year-old primigravida... Prenatal imaging suggested congenital hydrocephalus. Maternal congenital infectious (TORCH) screening was negative...Cranial ultrasonography demonstrated hydrocephalus, and further imaging with Brain MRI revealed complete agenesis of the corpus callosum with pronounced colpocephaly characterized by marked enlargement of the occipital horns and normally sized third and fourth ventricles.”

A 37⁴/₇-week term male infant was delivered through cesarean section to a 30-year-old primigravida with well-controlled hypothyroidism treated with levothyroxine. Prenatal imaging suggested congenital hydrocephalus. Maternal congenital infectious (TORCH) screening was negative. At birth, the infant was large for gestational age (birth weight 3,840 g) with marked macrocephaly (head circumference 41 cm, >97th percentile) but otherwise vigorous. Apgar scores of 8 and 9 at 1 and 5 minutes, requiring no resuscitation. Cranial ultrasonography demonstrated hydrocephalus, and further imaging with Brain MRI revealed complete agenesis of the corpus callosum with pronounced colpocephaly characterized by marked enlargement of the occipital horns and normally sized third and fourth ventricles (Figure 2). Neurology concluded that ventriculoperitoneal shunting was not indicated. EEG showed no evidence of seizure activity (Figure 3), and fundoscopic examination demonstrated no features of septo-optic dysplasia (Figure 4). The infant was discharged home with outpatient neurology follow-up and pending chromosomal microarray testing. Subsequently, CMA revealed an interstitial deletion within 7p22.1, resulting in the loss of one copy of the RNF216 gene. Homozygous deletions are associated with the autosomal recessive disorder Gordon Holmes syndrome,

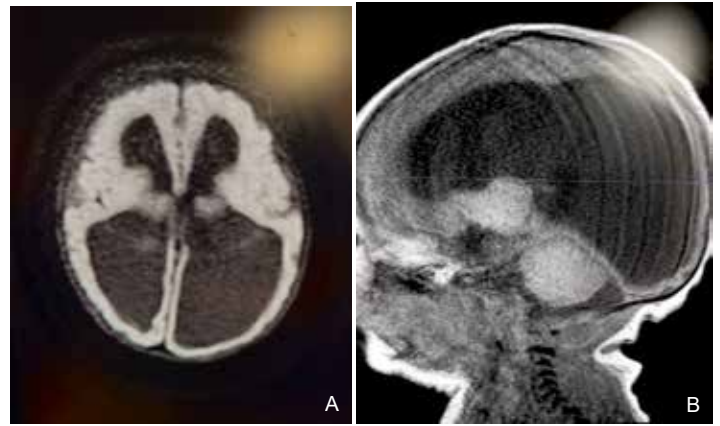


Figure 2. A Coronal section T1-weighted brain MRI. Dilated lateral ventricles, characteristic enlargement of posterior horns with markedly thinned occipital cortex.

Figure 2. B Sagittal section T1-weighted brain MRI. Prominent dilation of lateral ventricles, absent corpus callosum and minimal brain parenchyma.



Figure 3. Electroencephalogram (EEG) of an infant with colpocephaly showing no evidence of electrical seizure.

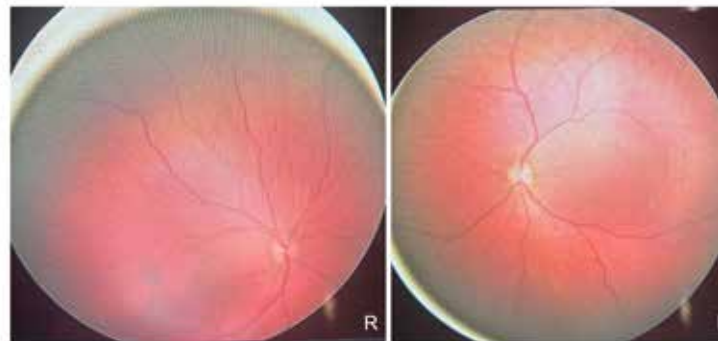


Figure 4. Bilateral fundoscopic examination showing normal optic discs with well-defined margins, normal retinal vasculature, and no evidence of septo-optic dysplasia.

characterized by hypogonadotropic hypogonadism and progressive cerebellar ataxia. As the gene deletion identified in this case is heterozygous, it is consistent with a carrier status and has no clinical association with colpocephaly. Thus, the clinical significance of this finding remains uncertain.

Discussion:

Etiologies and Pathophysiology of Ventriculomegaly:

Ventriculomegaly can result from several mechanisms, including a normal developmental variant, cerebral atrophy from degenerative conditions (infarction, metabolic disease,

congenital infection, genetic disorders), obstruction to CSF flow (structural malformations such as aqueductal stenosis or acquired causes like prior hemorrhage), impaired CSF absorption (prior hemorrhage or infection), increased CSF production (choroid plexus papilloma), and structural abnormalities deforming the lateral ventricles (cerebral dysgenesis). (4) Here we are highlighting ventriculomegaly as a tail of 2 pathologies: Down syndrome and colpocephaly.

“Ventriculomegaly can result from several mechanisms, including a normal developmental variant, cerebral atrophy from degenerative conditions (infarction, metabolic disease, congenital infection, genetic disorders), obstruction to CSF flow (structural malformations such as aqueductal stenosis or acquired causes like prior hemorrhage), impaired CSF absorption (prior hemorrhage or infection), increased CSF production (choroid plexus papilloma), and structural abnormalities deforming the lateral ventricles (cerebral dysgenesis).”

Down syndrome (DS), caused by the triplication of chromosome 21, is associated with accelerated age-related neurodegenerative changes. (5) These include greater age-related reductions in gray matter volume within the orbitofrontal and parietal cortices, reflecting the strong association between DS and the early development of Alzheimer’s disease (AD). (5) The apolipoprotein E (APOE) gene, through its role in amyloid- β metabolism, further contributes to neurodegeneration and ventricular enlargement. (5) Consequently, the pronounced ventricular dilation observed with advancing age in DS likely reflects progressive neurodegeneration affecting the adjacent cerebral parenchyma rather than atypical

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neurodevelopment alone. (5)

Colpocephaly is a distinctive form of ventriculomegaly characterized by disproportionate enlargement of the occipital horns of the lateral ventricles relative to the frontal horns, resulting in persistence of a fetal ventricular configuration into postnatal life. (6) It is not a primary disorder of cerebrospinal fluid dynamics but a developmental abnormality due to defective cerebral morphogenesis between the second and fifth months of fetal life. (6, 7) The failure of normal reduction of primitive brain vesicles is due to underdevelopment of the posterior cerebral white matter, while anterior regions continue to mature. (6) This regional white matter deficiency causes characteristic enlargement of the occipital horns with relatively small frontal ventricular horns, distinguishing colpocephaly from other causes of ventriculomegaly. (6) Although radiologically characteristic, colpocephaly is a heterogeneous developmental anomaly with genetic, chromosomal, and structural abnormalities that disrupt normal brain development. (6)

“Colpocephaly is a distinctive form of ventriculomegaly characterized by disproportionate enlargement of the occipital horns of the lateral ventricles relative to the frontal horns, resulting in persistence of a fetal ventricular configuration into postnatal life. It is not a primary disorder of cerebrospinal fluid dynamics but a developmental abnormality due to defective cerebral morphogenesis between the second and fifth months of fetal life. The failure of normal reduction of primitive brain vesicles is due to underdevelopment of the posterior cerebral white matter, while anterior regions continue to mature.”

Adult diagnosis of colpocephaly is exceptionally rare, with only 13 cases reported in the literature as of November 2024, often presenting with non-specific symptoms. (8–10)

Sangwan et al. reported a case of a 30-year-old woman presenting with syncope, dizziness, vomiting, and chronic intermittent headaches, with no prior neurological or developmental abnormalities. (8) Brain MRI showed colpocephaly with disproportionate enlargement of the occipital horns of the lateral ventricles and partial agenesis of the corpus callosum, with coronal T2 findings described as “moose head sign,” “racing car sign,” and “viking helmet sign.” (8) Although normal pressure hydrocephalus (NPH) remains the most common differential diagnosis for adult ventriculomegaly on MRI, unlike NPH, colpocephaly lacks the classic clinical triad of gait disturbance, urinary incontinence, and cognitive decline, which can help in differentiation. (8–10)

Genetics and Molecular Mechanisms:

Commonly reported genes associated with isolated ventriculomegaly, congenital hydrocephalus, Down syndrome, and colpocephaly are listed in the tables below. Fetal ventriculomegaly is considered an indicator of underlying chromosomal abnormalities and is associated with pathogenic copy-number variants (CNVs), which are submicroscopic chromosomal

abnormalities identified by chromosomal microarray analysis (CMA). (11) Multiple gene mutations contribute to the etiology of congenital hydrocephalus, as mentioned in Table 1. Among the known genetic causes, pathogenic variants in L1CAM are the most commonly detected, accounting for approximately 30% of suspected cases of X-linked congenital hydrocephalus. (12) This

Table 1- Genes associated with Ventriculomegaly and congenital hydrocephalus

Gene MIM number	Gene/Locus	Location	Inheritance	Phenotype mapping key	Mechanism
605066	YWHAE	17p13.3	AD, IC	4	Affects brain development and neuronal migration
601545	LIS1/PAFAH1B1	17p13.3	AD	3	Regulates the division of neuronal progenitor cells. Affects brain development
614697	KATNAL2	18q21.1	No Mendelian inheritance	-	Impaired ciliary microtubule function in fetal radial glial cells, disrupting CSF flow
614218	WDR81, CAMRQ2, HYC3	17p13.3	AR	3	Loss of function leads to congenital hydrocephalus
601090	FOXC1	6p25.3	AD	3	Hydrocephalus, hypoplasia of the cerebellum, brainstem, and corpus callosum
308840	L1CAM, CAML1, HYCX, MASA, SPG1	Xq28	XLR	3	Congenital hydrocephalus
611204	CCDC88C, HKRP2, DAPLE, KIAA1509, HYC1, SCA40	14q32.11-q32.12	AR	3	Congenital Hydrocephalus
603785	MPDZ, MUPP1, HYC2	9p23	AR	3	Disruption of CSF regulation (MPDZ) (13)
618570	TRIM71, LIN41, HYC4	3p22.3	AD	3	Congenital Hydrocephalus

Reference: OMIM

Inheritance Key

AD—Autosomal Dominant; AR—Autosomal Recessive; XL—X-linked; XLR X-linked Recessive; IC—Imprinting

Phenotype Mapping Key

1	The disorder is placed on the map because it is associated with a gene, but the underlying defect is unknown.
2	Statistical methods placed the disorder on the map.
3	The molecular basis of the disorder is known.
4	A contiguous gene duplication or deletion syndrome in which multiple genes are involved

Table 2 - Genes associated with Down's syndrome

Gene MIM number	Gene/ Locus	Location	Inheritance	Phenotype mapping key	Mechanisms
104760	APP	21q21.3	AD	3	Overexpression on chromosome 21. Neurodegeneration, cortical atrophy, ventricular enlargement
606385	OLIG 1	21q22.11	No Mendelian inheritance	-	Overexpression on chromosome 21. Oligodendrocyte differentiation and myelination (14)
606386	OLIG 2	21q22.11	No Mendelian inheritance	-	Overexpression on chromosome 21. Oligodendrocyte differentiation and myelination
600855	DYRK1A	21q22.13	AD	3	Overexpression on chromosome 21. Reduced neurogenesis, cortical hypoplasia, and impaired brain development
602917	RCAN1	21q22.12	No Mendelian inheritance	-	Altered neuronal differentiation and astrocyte formation
176263	KCNA3	1p13.3	No Mendelian inheritance	-	Potassium channel involved in oligodendrocyte signaling
300401	PLP1	Xq22.2	XLR	3	Major CNS myelin protein; decreased expression causes hypomyelination
159430	MBP	18q23	No Mendelian inheritance	-	Principal structural protein of CNS myelin; decreased expression causes white matter abnormalities

Reference: OMIM

reflects its key role in neuronal migration, axon bundling, corpus callosum development, and cerebrospinal fluid flow. Although there is minimal direct overlap between the genes associated with ventriculomegaly, Down syndrome, and colpocephaly, these disorders overlap on common neurodevelopmental pathways. Thus, despite their distinct genetic origins, these conditions can present with phenotypes that yield similar neuroimaging findings, including ventriculomegaly.

“Among the known genetic causes, pathogenic variants in L1CAM are the most commonly detected, accounting for approximately 30% of suspected cases of X-linked congenital hydrocephalus. This reflects its key role in neuronal migration, axon bundling, corpus callosum development, and cerebrospinal fluid flow.”

Radiological and Genetic Assessment:

Conventional karyotyping has traditionally been the gold standard for detecting chromosomal abnormalities. (12) However, recently, CMA has been recommended as the first-line diagnostic test for individuals with congenital or developmental anomalies because it can identify clinically significant CNVs that are undetectable by karyotyping. (12) Therefore, CMA should be offered to all fetuses with ventriculomegaly, regardless of its severity or whether it occurs in isolation or with other structural anomalies. (12) When conventional karyotyping and CMA fail to identify an abnormality, whole exome sequencing (WES) can be used as a secondary tool to provide an accurate molecular diagnosis, especially in fetuses with severe ventriculomegaly or a history of recurrent fetal anomalies. (11) In our case, WES could have been taken into consideration to explore the etiology of colpocephaly further, since the heterozygous RNF216 deletion on CMA did not fully explain the phenotype.

Serial ultrasound examinations are essential for monitoring fetal head growth and the progression of ventriculomegaly during pregnancy, particularly in the third trimester. (15) Fetal magnetic resonance imaging (MRI) complements ultrasonography by improving the diagnostic accuracy and prognostic assessment of fetal neurological abnormalities. (15) According to the International Society of Ultrasound in Obstetrics and Gynecology (ISUOG)

Table 3- Genes associated with Colpocephaly

Gene MIM number	Gene/ Locus	Location	Inheritance	Phenotype mapping key	Mechanism
308840	L1CAM	Xq28	XLR	3	Aqueductal stenosis, corpus callosum hypoplasia
300004	ARX	Xp21.3	XL	3	Neuronal migration defects, agenesis of the corpus callosum
600035	EMX2	10q26.11	No Mendelian inheritance	3	Cerebral hemisphere and corpus callosum development
603073	ZIC2	13q32.3	AD	3	Forebrain patterning, corpus callosum malformations, hydrocephalus
120470	DCC	18q21.2	AD	3	Agenesis of the corpus callosum
602529	TUBA1A	12q13.12	AD	3	Neuronal migration defects, lissencephaly, and agenesis of the corpus callosum
612850	TUBB2B	6p25.2	AD	3	Cortical dysgenesis, Agenesis of the corpus callosum
602661	TUBB3	16q24.3	AD	3	Agenesis of the corpus callosum
300121	DCX	Xq23	XL	3	Agenesis of the corpus callosum

Reference: OMIM

“Conventional karyotyping has traditionally been the gold standard for detecting chromosomal abnormalities. However, recently, CMA has been recommended as the first-line diagnostic test for individuals with congenital or developmental anomalies because it can identify clinically significant CNVs that are undetectable by karyotyping.”

guidelines, fetal MRI is recommended as an adjunct to ultrasound to distinguish isolated from non-isolated ventriculomegaly and identify associated central nervous system anomalies. (15) Fetuses with non-isolated, bilateral, or moderate-to-severe ventriculomegaly are at an increased risk of chromosomal abnormalities or pathogenic CNVs. (16) CNV sequencing can effectively improve diagnostic rates and should therefore be combined with karyotyping to rule out genetic abnormalities. (16)

Long-term neurodevelopmental outcomes:

“Serial ultrasound examinations are essential for monitoring fetal head growth and the progression of ventriculomegaly during pregnancy, particularly in the third trimester. Fetal magnetic resonance imaging (MRI) complements ultrasonography by improving the diagnostic accuracy and prognostic assessment of fetal neurological abnormalities. According to the International Society of Ultrasound in Obstetrics and Gynecology (ISUOG) guidelines, fetal MRI is recommended as an adjunct to ultrasound to distinguish isolated from non-isolated ventriculomegaly and identify associated central nervous system anomalies.”

Adults with Down syndrome show progressive brain atrophy with age, especially in the medial temporal region, which correlates strongly with cognitive decline, dementia, and progression to AD. (17) CT measures of medial temporal atrophy and SSRE (Suprasellar Cistern Ratio) were the earliest and strongest predictors of cognitive impairment, with 78% accuracy. (17) In a study, high-resolution MRI specifically identified the brain regions involved, the entorhinal cortex and posterior hippocampus, showing the earliest loss in Down syndrome, starting 13–15 years before Alzheimer's disease symptom onset. (18) Hippocampal atrophy correlated strongly with cerebrospinal fluid biomarkers of Alzheimer's pathology, including amyloid- β 42/40 and phosphorylated tau (pTau181). (18)

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In one study, the prevalence of neurodevelopmental delay in isolated ventriculomegaly was 7.9% (95% CI, 4.7–11.1%), and the risk of developmental delay, intrauterine fetal demise, and infant mortality increased with the degree of ventriculomegaly. (11, 19)

Hu et al. reported that almost all cases with pathogenic CNVs and isolated mild to moderate ventriculomegaly manifested neurodevelopmental disorders.

Long-term outcomes in congenital hydrocephalus are generally less favorable than in isolated ventriculomegaly due to frequent associated structural or genetic abnormalities. (20) Affected children commonly exhibit impairments in intelligence, executive function, memory, learning, processing speed, and visuospatial abilities. (20) Although isolated congenital aqueductal stenosis may show relatively preserved cognition, only a minority achieve normal neurodevelopmental outcomes. (20) Prognosis is worsened by seizures, shunt-related complications, multiple cerebrospinal fluid shunt revisions, and prolonged hospitalization.

“Hu et al. reported that almost all cases with pathogenic CNVs and isolated mild to moderate ventriculomegaly manifested neurodevelopmental disorders.”

(20) Approximately one-third of children with shunt-treated hydrocephalus develop epilepsy, with headaches common, and nearly half require treatment for depression, remain dependent, or are unemployed in adulthood.

“Long-term outcomes in congenital hydrocephalus are generally less favorable than in isolated ventriculomegaly due to frequent associated structural or genetic abnormalities. Affected children commonly exhibit impairments in intelligence, executive function, memory, learning, processing speed, and visuospatial abilities. Although isolated congenital aqueductal stenosis may show relatively preserved cognition, only a minority achieve normal neurodevelopmental outcomes. Prognosis is worsened by seizures, shunt-related complications, multiple cerebrospinal fluid shunt revisions, and prolonged hospitalization.”

Colpocephaly is typically associated with intellectual disability, seizures, and motor/visual abnormalities due to underlying brain insults. (21) Finally, long-term neurological and functional outcomes are strongly influenced by the underlying causative gene. (20)

“Colpocephaly is typically associated with intellectual disability, seizures, and motor/visual abnormalities due to underlying brain insults. Finally, long-term neurological and functional outcomes are strongly influenced by the underlying causative gene.”

Conclusion:

Overall, the two cases presented in this report demonstrate the heterogeneous etiologies of fetal ventriculomegaly. This article highlights the diverse genetic mechanisms that can underlie ventriculomegaly, stressing the importance of comprehensive genetic evaluation to establish the underlying diagnosis, guide prenatal counseling, and improve prognostic assessment. At the

same time, not all cases of fetal ventriculomegaly have a genetic basis. Further research is needed to understand better the non-genetic etiologies and pathophysiological mechanisms underlying this condition, which may ultimately improve diagnostic accuracy, counseling, and clinical management.

“Overall, the two cases presented in this report demonstrate the heterogeneous etiologies of fetal ventriculomegaly. This article highlights the diverse genetic mechanisms that can underlie ventriculomegaly, stressing the importance of comprehensive genetic evaluation to establish the underlying diagnosis, guide prenatal counseling, and improve prognostic assessment. At the same time, not all cases of fetal ventriculomegaly have a genetic basis.”

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Mission

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

Vision

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

Our Overarching Goal

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

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

Services

- Continuing Education – Elevate your expertise
- Technical Assistance and Resources – Gain access to valuable tools and support tailored to your needs
- Leadership & Team Development and Coaching – Cultivate strong, effective teams committed to excellence
- Professional and Community Events & Consultation – Engage with others to share insights and foster growth

Join us in redefining perinatal health.

SCAN ME



Hemolytic Disease of the Fetus & Newborn

DID YOU KNOW?

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

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



HDFN can lead to:

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

To reduce their baby's risk

pregnant mothers should talk to their health care provider to:

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



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

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Keeping Your Baby Safe

from respiratory infections

RSV
COVID-19
colds
flu

How to protect your little one from germs and viruses

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

Here's what you can do...

Wash Your Hands

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



Limit Contact with Others

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



Provide Protective Immunity

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



Take Care of Yourself

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



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

WARNING

Never Put a Mask on Your Baby

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



If you are positive for COVID-19

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



We can help protect each other.

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National Perinatal Association

Pioneer Profile – Samuel J. Fomon, MD

Joseph B. Philips, III, M.D.

Samuel J. Fomon, M.D., made monumental contributions to fetal, neonatal, and childhood growth and metabolism. His legacy and achievements remain relevant today, shaping nutritional recommendations for every baby and child on earth. He was born in Chicago in 1923 to physician parents. (1) His mother died when he was young, and he was raised by relatives in Wisconsin, where he attended high school. He then attended Harvard University, graduating cum laude before attending the University of Pennsylvania for medical school. He pursued residency training at the Children's Hospital of Philadelphia, followed by a fellowship in renal physiology at the Children's Hospital of Cincinnati. After two years in the Army, he joined the Department of Pediatrics faculty at the University of Iowa in 1954 as an assistant professor. There, he did his life's work. Before highlighting his extraordinary contributions, it is important to review the setting that enabled so much of his success.

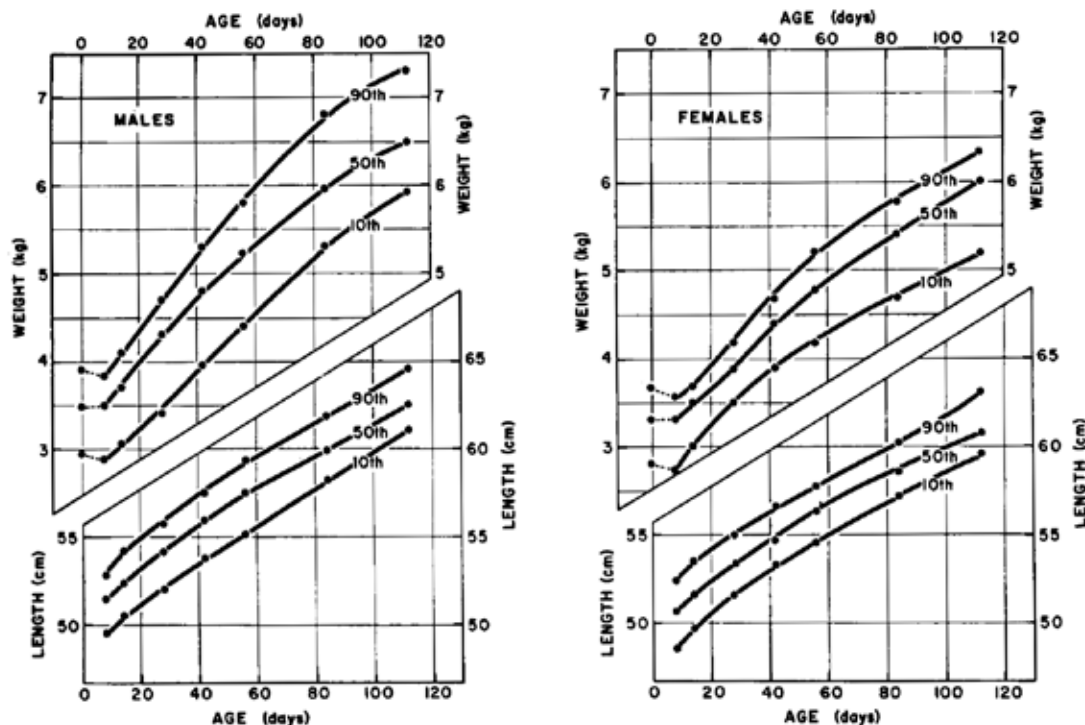
“Samuel J. Fomon, M.D., made monumental contributions to fetal, neonatal, and childhood growth and metabolism. His legacy and achievements remain relevant today, shaping nutritional recommendations for every baby and child on earth.”

Shortly after the University of Iowa established the Department of Pediatrics in 1915, the Iowa state legislature created the Child Welfare Research Station in 1918 to study normal children. (2) Infants waiting for adoption were housed in the station and often stayed a year or longer, offering a perfect opportunity for longitudinal study of infant growth and development. Dr. Phillip C. Jeans, the second Chair of Pediatrics, established The Metabolic Unit within the Child Welfare Research Station in 1927. (3) He embarked on a series of influential metabolic balance studies, including the recommendation that milk be fortified with vitamin D, a recommendation that remains in place today. Shortly after Dr. Fomon's arrival, he was invited to lead the Metabolic Unit. By this time, the Metabolic Unit also housed infants of students and staff in a home-like environment staffed around the clock with nurses. In time, Fomon's studies expanded to include infants and children in the local community as well. So, the stage was set for his extraordinary achievements.

Dr. Fomon's research focused on several interrelated areas, including the physical growth of children, body composition of the fetus, infant and child, protein and amino acid requirements, various factors affecting infant feeding, iron absorption, cow's milk-induced intestinal blood loss, and metabolism of various elements and nutrients in infants, including iron, fluoride and carnitine. (2) I shall review some of the most important studies in each of these areas.

Growth and serum chemical values of normal breastfed infants were reported. (4) Weight and length charts for 58 male and 46 female infants from birth to 112 days of age were presented (Figure 1). By 1971, Ekhard Ziegler had joined the Iowa group and was a lead or coauthor on many of Dr. Fomon's works.

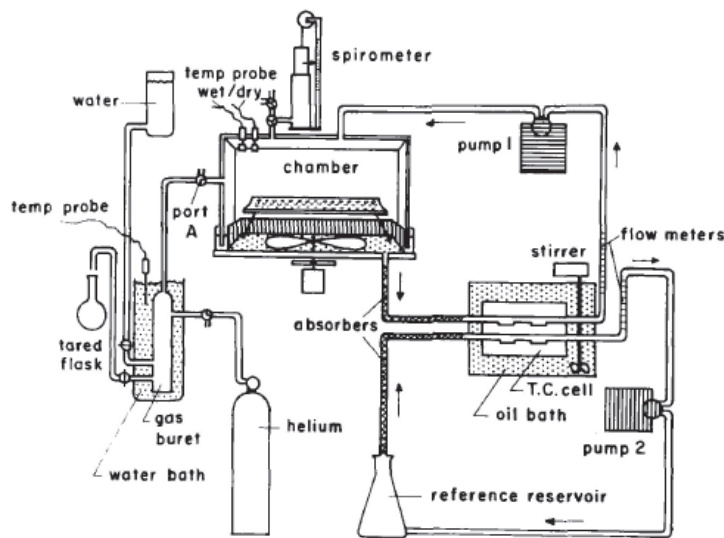
Figure 1. Weight and length for 58 breastfed boys and 46 girls from birth to 112 days of age. (4)



They published a follow-up to the breastfed infant growth paper with a similar study on milk-based formula-fed infants, and the formula-fed infants showed slightly higher gains in weight and length, but the differences did not reach statistical significance. (5) These reports were followed by a massive study involving 203 breastfed males, 216 breastfed females, 380 formula-fed males and 340 formula-fed females, concluding, "This report is the first publication of separate centile values for concurrently studied breast-fed and formula-fed infants. (6) The data confirm previous reports indicating that male infants gain weight more rapidly than do female infants and, on a sex-specific basis, formula-fed infants gain weight more rapidly than do breast-fed infants."

Fomon and colleagues had an enduring interest in body composition. They designed an apparatus to determine body volume using a helium displacement method and using fancy mathematics that I studied in college but have totally forgotten (Figure 2). (7)

Figure 2. Design of a device to measure body volume of infants using a helium displacement method. (7)



In 1966, Dr. Fomon, in his presentation accepting the prestigious Borden Award, reported the body composition of the "Male Reference Infant" during the first year of life, documenting the profound changes in the percentages of protein, lipids, and water that occur from fetal life to the first birthday. (8) That same year, he published "The Body Composition of the Reference Fetus", again showing the enormous shifts in body composition that occur during gestation. (9) These reports, plus others to follow, were based on chemical composition analyses performed by others of stillborn infants or premature infants who died shortly after birth, plus studies of total body water and metabolic balance studies performed by Fomon's group using a deuterium dilution technique, and estimates of body fat and lean mass. (10–12) Studies published in the early 1980s reported the body composition of a nine-year-old reference boy and extended the body composition data of reference children to ten years of age. (13, 14) This extraordinary oeuvre, which constitutes the bedrock upon which

all other nutrient recommendations rest, was summarized by Fomon and Nelson in 2002. (15)

"Studies published in the early 1980s reported the body composition of a nine-year-old reference boy and extended the body composition data of reference children to ten years of age. This extraordinary oeuvre, which constitutes the bedrock upon which all other nutrient recommendations rest, was summarized by Fomon and Nelson in 2002."

Nitrogen balance studies, often comparing different feeding regimens, were an early and enduring focus of Dr. Fomon's research. A flurry of reports was published beginning in the late 1950s. The first study examined nitrogen retention in infants fed pasteurized human milk in the Metabolic Unit, showing a mean retention of 180 mg/kg/d at one month of age that decreased linearly to an average of 47 mg/kg/d at six months of age. (16) A second study comparing nitrogen retention in infants fed fresh human milk or pasteurized human milk concluded, "Processing (pasteurization and freezing) of human milk apparently does not alter its nutritional properties in such a way as to affect nitrogen balance of infants." (17) A third report studying infants fed a commercial infant formula concluded, "Retention of nitrogen by infants receiving Formula S ad libitum was as large as, or greater than, that by infants receiving human milk ad libitum. Infants of both groups appeared to thrive and to progress along normal growth curves." (18) Yet another study showed that infants fed a soy-based formula achieved nitrogen retention levels equal to or slightly better than those fed pasteurized human milk. (19) A comparison study evaluating the adequacy of a powdered cow's milk protein-based formula versus human milk again showed roughly equal nitrogen retention under both feeding regimens. (20) A further study evaluated nitrogen balance in infants fed three different formulas providing at least 20% of calories as protein, showing increased nitrogen retention but not increased blood urea nitrogen levels. (21) Autoclaving of formula was also shown not to interfere with nitrogen retention. (22) A 1965 study established normative values for urinary and fecal excretion of nitrogen. (23) Finally, two investigations into the bioavailability of ingested urea using the stable ^{15}N isotope-labeled di- ^{15}N urea in formula or breast milk showed that bioavailability was limited, with approximately 85% being excreted unchanged in the urine. (24, 25)

Many additional studies investigated other nutritional aspects of different diets and formulas. An early report evaluated the effect of six different diets on serum cholesterol levels in infants ranging from one week to six months of age and found that those fed a soy-based formula had the lowest levels while breast-fed infants

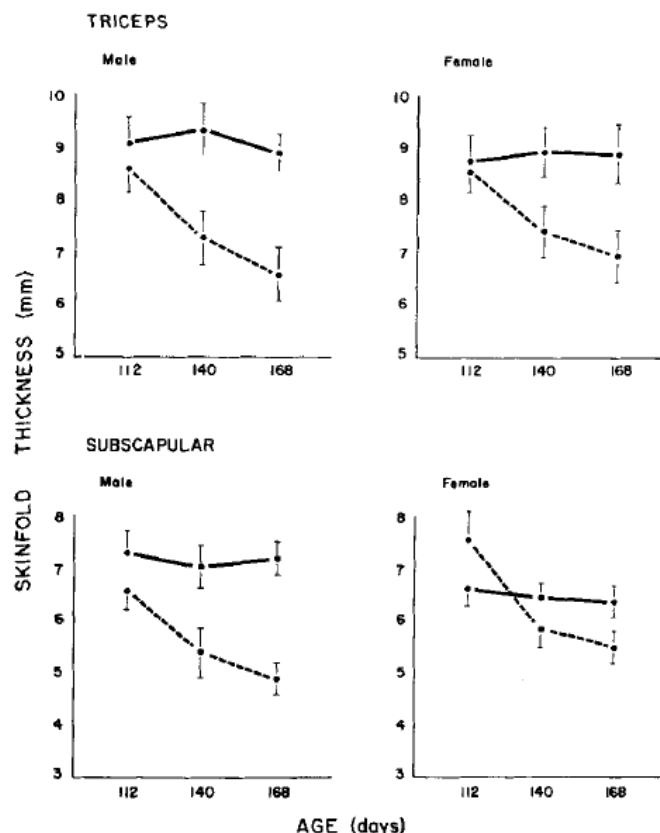
had the highest levels. (26) Normative values for volume ingested by these infants who were fed ad libitum were also reported. (27) Calcium and phosphorus retention was found to be higher in infants fed formula than in breastfed infants. (28) Another study examined the relationship between formula composition and rate of growth in infants fed ad libitum in the first 112 days following birth. (29) One group was fed a formula with 67 kcal/100ml while a second group was fed a formula with 113 kcal/100ml. Infants fed the higher-calorie formula consumed significantly more calories and grew faster, with boys in both groups growing faster than girls fed similar formulas. A further report, which began with a classic understatement, "In industrialized societies of the Western world, obesity is generally considered undesirable," studied the effects of formula concentration on caloric intake and growth in the first 111 days after birth in two groups of fifteen female infants each, most of whom were the daughters of students or young faculty at the University of Iowa. (30) One formula contained 54 kcal/100ml, while the other had 100 kcal/100ml with the major differences being carbohydrate and fat. The lower-calorie formula group consumed more volume but had lower growth rates than the higher-calorie group.

"One formula contained 54 kcal/100ml, while the other had 100 kcal/100ml with the major differences being carbohydrate and fat. The lower-calorie formula group consumed more volume but had lower growth rates than the higher-calorie group."

Excretion of fat by eleven groups of infants fed different diets ranging from human milk, homogenized cow's milk, evaporated cow's milk, or a variety of formulas concluded, "Excretions of fat were unexplainably high by infants receiving an experimental soy isolate-based formula with fat provided as a mixture of corn and coconut oils. Otherwise, with few exceptions, excretions of fat by infants fed human milk or formulas with fat supplied as vegetable oils were less than 1 g/kg per day. In many instances, infants fed homogenized cow's milk excreted more than 2 g/kg per day..... It seems inadvisable to feed homogenized milk without added carbohydrate during the early months of life." (31) Comparison of infants fed a commercial infant formula versus those fed skim milk fortified only with fat-soluble vitamins and enough safflower oil to provide adequate linoleic acid intake beginning at 112 days of age showed that the skim milk fed infants ingested larger volumes but fewer total calories and lost more subcutaneous fat as measured by triceps and subscapular skinfold thickness than did those continued on formula. (Figure 3)(32) The authors concluded that the skim milk group was mobilizing body fat to make up for inadequate caloric intake.

A 1983 paper outlined the methods Ziegler and Fomon used to study metabolic balance and growth, with two illustrative examples. (33) Infants fed a formula containing lactose were shown to have significantly greater calcium absorption compared to those fed a formula containing sucrose and a corn syrup

Figure 3. Changes in skinfold thickness in infants fed a commercial infant formula (solid line) versus those fed skim milk (dotted line) between 112 and 168 days of age. (32)



"Comparison of infants fed a commercial infant formula versus those fed skim milk fortified only with fat-soluble vitamins and enough safflower oil to provide adequate linoleic acid intake beginning at 112 days of age showed that the skim milk fed infants ingested larger volumes but fewer total calories and lost more subcutaneous fat as measured by triceps and subscapular skinfold thickness than did those continued on formula. The authors concluded that the skim milk group was mobilizing body fat to make up for inadequate caloric intake."

hydrolysate as the carbohydrate. Both formulas contained equal amounts of calcium and other nutrients. The growth study showed no significant differences when infants were fed two other formulas containing different carbohydrate compositions. A subsequent study showed that lactose also enhanced the absorption of magnesium and manganese with increased but not statistically significant increases in copper and zinc and no effect on iron absorption. (34) An eight year follow-up study of 469 children that had been intensively studied during infancy showed that "fatness" and serum cholesterol levels were similar in infants that were breastfed versus formula-fed, despite the formula-fed infants being heavier and longer during infancy. (35)

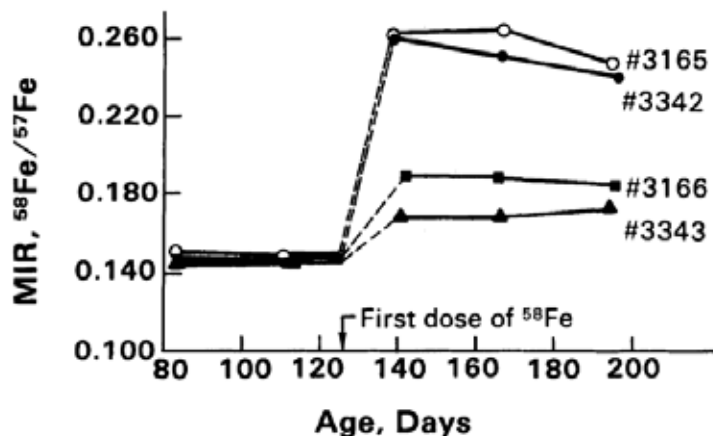
"An eight year follow-up study of 469 children that had been intensively studied during infancy showed that 'fatness' and serum cholesterol levels were similar in infants that were breastfed versus formula-fed, despite the formula-fed infants being heavier and longer during infancy."

Dr. Fomon was also interested in factors that affect food intake during infancy and childhood. While serving as Chairman of the American Academy of Pediatrics (AAP) Committee on Nutrition, he coauthored a lengthy report on the topic. (36) He then went on to further explore the topic in his own research. Intake of food by four- and six-month-olds was found not to be influenced by salt content, as infants consumed similar volumes whether the food contained added salt or not. (37) Similarly, the fat and carbohydrate concentrations in formula did not affect intake despite the higher lactose-containing formula being significantly sweeter than the lower lactose one. (38) However, a later study found that infant girls consumed more formula when fed a lactose-containing formula compared to one containing a bland-tasting corn starch hydrolysate as the primary carbohydrate. (39) Dr. Fomon summarized these studies in a 1980 publication. (40)

Dr. Fomon and his group also had a major interest in iron metabolism. This was spurred in part by the observation that infants fed pasteurized cow's milk had higher gastrointestinal blood loss than those fed a commercial formula. (41) A subsequent study found that infants fed formula or breast milk had a 5% rate of guaiac-positive stools compared to a 30.3% positive rate during the first 28 days after being switched to cow's milk, accompanied by a striking increase in stool hemoglobin concentrations. (42) In order to study iron uptake, Fomon and colleagues pioneered the use of the stable isotope ^{58}Fe , differentiating it from the common isotope ^{57}Fe using inductively coupled plasma mass spectrometry (ICP/MS). (43) Figure 4 shows the stable and sustained incorporation of ^{58}Fe into erythrocytes of four infants. This technique was then employed in multiple studies.

A second study found that ^{58}Fe incorporation into infant erythrocytes was inversely correlated with serum ferritin concentrations. (44)

Figure 4. Iron mass Isotope ratio for four infants given one dose (subjects 3343 and 3166) or two doses of ^{58}Fe , showing rapid and sustained incorporation into erythrocytes. (43)

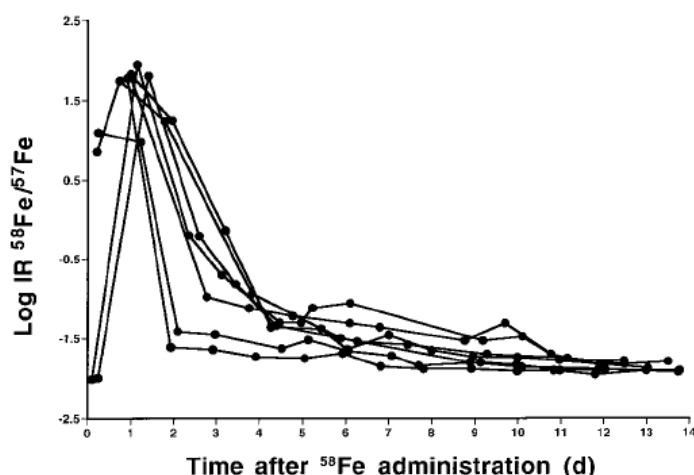


Iron absorption from several infant foods was studied, showing that they were good sources of absorbable iron, with absorption again correlating with serum ferritin levels. (45) Another report found that erythrocyte iron incorporation was significantly higher in breastfed versus formula-fed infants. (46) A further study confirmed this, concluding that something in the intestines of formula-fed infants inhibits iron absorption (Figure 7). (47)

"Another report found that erythrocyte iron incorporation was significantly higher in breastfed versus formula-fed infants. A further study confirmed this, concluding that something in the intestines of formula-fed infants inhibits iron absorption"

Formula containing 8 mg/L of iron was shown to have erythrocyte incorporation similar to that from another containing 12 mg/L, which is the amount commonly found in commercial infant formulas today. (48) The authors concluded that the iron amounts in formula could safely be lowered if the higher amounts were found to inhibit the absorption of other elements such as copper and zinc. A Special Article by Zeigler and Fomon, published in 1996, outlined strategies to prevent iron deficiency in formula-fed infants. (49) Another informative study revealed that much less than 80% of iron ingested by normal infants is incorporated into erythrocytes and that fecal iron excretion continues up to 14 days after administration (Figure 5). (50) This contrasts sharply with adults who promptly incorporate 80–100% of ingested iron into erythrocytes. A further study showed that iron incorporation was higher in infants previously fed a low-iron-containing formula and that the percentage of incorporation was higher in 168-day-old infants than in 56-day-old infants. (51) This study also found for the first time that red blood cell survival time in the older infants

Figure 5. Fecal excretion of iron in normal infants after a single dose of oral ^{58}Fe . (50)



remained significantly less than in adults at about 98 days compared to about 120 days in adults. A study of 25 children under 3 years old recovering from severe malnutrition (Z-score < -1.8) found that iron absorption was not impaired and again negatively correlated with plasma ferritin concentrations. Dr. Fomon's iron studies continued up until his death, with his final report published posthumously describing iron uptake of two different iron compounds from dry cereals in breastfeeding infants. (A review entitled "Retention of Iron by Infants" summarized the methods and many of the previously described findings by Fomon's group in 2000.)

Early on, Dr. Fomon was also interested in amino acid requirements, particularly methionine, valine, isoleucine, and cystine. A 1964 report established minimum requirements for the first three of these. (55) A study using a methionine-fortified soy-based formula established minimal protein and amino acid requirements for adequate growth in female infants in the first few months of life. (56) Another study comparing several parameters found that infants fed a methionine-fortified soy formula performed better than comparable infants fed an otherwise identical non-methionine-fortified formula. (57) A final report in this series

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established requirements for the sulfur-containing amino acids methionine and cystine in baby boys and girls. (58)

A later career interest was fluoride. A 1994 study investigated the pharmacokinetics of fluoride following a single ingestion and found that retention correlated linearly with the amount taken in. (59) Another report published in the dental literature concluded, "there is evidence that the currently recommended fluoride supplements are associated with development of fluorosis of the permanent dentition" and that "there is need to re-evaluate the use of fluoride supplements." (60) A study of fluoride intake from the diet over the period from 1971 to 1991 concluded, "Prolonged exposure to high intakes of fluoride during infancy is much more common now than in the past." (61) An expanded study stated, "fluoride intakes of infants and children have shown a rather steady increase since 1930, are likely to continue to increase, and will be associated with further increase in the prevalence of enamel fluorosis unless intervention measures are instituted." (62) Recommendations were made to limit fluoride supplementation in infants so as to reduce the risk of fluorosis.

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Lead was another interest. A case report of an infant born to a mother who worked in a lead-acid battery factory and was therefore exposed to lead dust found significant lead levels in both mother and newborn. (63) Mother's milk also contained significant amounts of lead. Despite this, the infant's lead levels fell rapidly after birth. Balance studies showed that infants were efficient absorbers of lead, concluding, "Highly efficient absorption and retention of ingested lead by young children may be partly responsible for the high prevalence of lead intoxication in this age group." (64) A final study evaluated dietary intake of lead in breast-

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and bottle-fed infants and its relationship to blood lead levels. (65)

Given his early training in renal physiology, it is unsurprising that Dr. Fomon would study various aspects of renal function in infants. Fifteen normal infants were followed for three years to determine normative values for urine volume, voiding frequency, and voiding size, finding that although total urine output increased with age, output per unit body weight and voiding frequency declined with age. (66) Acidification of the urine following a dose of ammonium chloride was studied in human milk-fed and formula-fed infants. (67) The formula-fed infants had much higher titratable acidity in the urine due to their higher intake of protein and phosphorus. Ziegler and Fomon subsequently presented data on the potential renal solute load of infant formulas and proposed maximum protein and phosphorus concentrations to avoid overloading the infant kidney. (68) These recommendations were reiterated and enhanced in a 1999 publication. (69) Another interesting study found that total body water content and exchangeable chloride are both greater in boys than in girls. (10)

“Ziegler and Fomon subsequently presented data on the potential renal solute load of infant formulas and proposed maximum protein and phosphorus concentrations to avoid overloading the infant kidney. These recommendations were reiterated and enhanced in a 1999 publication.”

Dr. Fomon and colleagues also addressed other nutritional topics related to infants and children. They evaluated variations in the nutritional content of commercially prepared strained and “junior” foods for infants. (70) Changes in what infants were fed in the first week after birth were documented, showing a marked decline in evaporated milk feeds and a sharp increase in commercial formula feeds, with breastfeeding remaining fairly stable at 25 to 30%. (71)

A subsequent report documented what infants were being fed in the United States in the early 1970s. (72) An editorial in the American Heart Journal in 1972 by Fomon and Zeigler discussed the nutritional management of infants with congenital heart disease. (73) Nutritional management of infants with gastrointestinal disorders was also addressed. (74)

Dr. Fomon was a member of a Select Committee on GRAS Substances of the Federation of American Societies for Experimental Biology, which published a 42-page report assessing the potential hazards of over 400 “generally regarded as safe” food additives, a topic enjoying renewed interest today. (75) A paper published as a Controversy in Pediatrics in the American Journal of Diseases of Childhood concluded “that per unit of energy, concentrations of protein, calcium, and sodium in human milk are inadequate for growing premature infants” and that “our calculations suggest that the content of several other minerals in human milk is also inadequate for growing premature infants. Thus, if human milk is to be used as a food for such infants, it

seems reasonable to consider supplementation with protein and minerals.” (76) This, of course, is why we fortify mother’s milk or donor milk for our premature infants today. An editorial in the New England Journal of Medicine addressed nutrient deficiencies in breastfed normal infants and recommended supplementation with vitamins K and D and perhaps iron. (A fascinating discussion entitled “Breast-feeding and evolution” addresses possible evolutionary reasons underlying the need for supplementing mother’s milk, highlighting the balance between the need for mother to maintain adequate nutrition to survive and nourish her infant versus the infant’s needs. (78) A report first authored by Dr. Jatinder Bhatia, who went on to a distinguished career of his own, evaluated sedimentation of calcium and phosphorus in various commercial premature infant formulas, concluding, “Vigorous shaking of the bottle immediately before withdrawing the amount to be fed to the infant appears to be essential, at least with some formulas.” (79)

“A paper published as a Controversy in Pediatrics in the American Journal of Diseases of Childhood concluded ‘that per unit of energy, concentrations of protein, calcium, and sodium in human milk are inadequate for growing premature infants’ and that ‘our calculations suggest that the content of several other minerals in human milk is also inadequate for growing premature infants. Thus, if human milk is to be used as a food for such infants, it seems reasonable to consider supplementation with protein and minerals.’ This, of course, is why we fortify mother’s milk or donor milk for our premature infants today.”

A lengthy article reflecting on infant feeding practices in the 1970s and 80s reviewed the changes in what infants were fed and the impact of the Infant Formula Act of 1980 on the composition and labeling of commercial infant formulas. (A 1990 study found that commercial infant formulas continued to be suitable for infants in the latter half of the first year of life.) (81) A 1991 article in Pediatric Research used two models to estimate the minimum protein requirements for infants—a factorial model and a breastfed infant model—and concluded: “The United States Food and Drug Administration specifies the lower limit of protein in infant formulas to be 1.8 g/100 kcal. This value would seem to merit revision. For the first 2 mo of life, the lower limit is less than the RDI... and less than has been demonstrated to be adequate. A minimum protein level of 2.2 g/100 kcal is recommended for infants less than 3 mo of age. For infants over 3 mo of age, a protein concentration of 1.6 g/

100 kcal is considered adequate.” (82) Finally, Dr. Fomon returned to his evolutionary speculations in a 2001 article, in which, among other topics, he discusses the observation that human breast milk contains significant amounts of amylase, which digests starches even though starch is not a component of human breast milk. (83) He goes on to point out that in some primitive cultures, mothers offer their infants prechewed food containing starch which may explain why amylase evolved to be in human milk. This led him to also question whether the growth of breast fed infants should be the standard against which to compare the growth of formula-fed infants who grow significantly faster, especially in terms of fat-free mass.

Dr. Fomon retired in 1993, when the University of Iowa Infant Metabolic Unit was renamed the Samuel J. Fomon Infant Nutrition Unit. (2) The AAP began awarding the Nutrition Award in 1944, and Dr. Fomon received it in 2004 when it was renamed the American Academy of Pediatrics Samuel J. Fomon Award. The federally funded Children’s Nutrition Research Center at Baylor College of Medicine and Texas Children’s Hospital has a Council of Scientific Advisors that Dr. Fomon chaired from 1994 to 2002. The painted image executed by his sister-in-law, Frances Smith, hangs in the Samuel J. Fomon Conference Room at the center (2).



Samuel J. Fomon, MD, died in December of 2007 at the age of 84. His contributions to fetal, neonatal, and infant nutrition were monumental and will endure for years to come.

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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?



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WHAT YOU **NEED** TO KNOW



CDC-Recommended Vaccines for Pregnant Women

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Which Infants are More Vulnerable to Respiratory Syncytial Virus?

RSV is a respiratory virus with cold-like symptoms that causes 90,000 hospitalizations and 4,500 deaths per year in children 5 and younger. It's 10 times more deadly than the flu.

For premature babies with fragile immune systems and underdeveloped lungs, RSV proves especially dangerous.

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*Source: Respirator Syncytial Virus and African Americans

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



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Merchak Monthly Neonatal Case Challenge Page

October 2026 Edition – Case Number 82

Assaad Merchak, MD

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

Last month's Case Recap: Mallory has CMV.

September's challenge featured a case of Congenital CMV infection in the neonates.

Key Learning Points from last month's case:

- CMV must be detected from an appropriate specimen within the first 21 days of life to establish congenital rather than postnatally acquired infection. Saliva PCR is highly useful for screening, but a positive saliva result should generally be confirmed with urine because CMV can contaminate saliva in breast milk. Neonatal CMV IgM is not recommended as the diagnostic test.
- Sensorineural hearing loss (SNHL) is one of the most important long-term sequelae of chronic CMV. Hearing loss can be unilateral or bilateral and may be progressive or delayed in onset. An infant with normal hearing in one or both ears during the newborn period can subsequently develop hearing impairment. To learn more, visit the previous case presentation:

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

Congratulations: The gift card winner for September's challenge is Sandra Flaishmakher, MD. Wellstar Spalding Griffin, GA.

This month's challenge # 82 for October 2026: Tommy has a tongue-tie.

This case focuses on ankyloglossia in the neonates.

“Tommy, a 4-day-old term infant, is exclusively breastfed. The mother reports significant nipple pain and difficulty maintaining latch. Examination shows a prominent lingual frenulum with limited tongue elevation. Weight loss is 6% from birth weight. The infant otherwise appears well.”

Tommy, a 4-day-old term infant, is exclusively breastfed. The mother reports significant nipple pain and difficulty maintaining latch. Examination shows a prominent lingual frenulum with limited tongue elevation. Weight loss is 6% from birth weight. The infant otherwise appears well.

Sneak peek Challenge Question: True or false: An asymptomatic newborn with an anatomically prominent lingual frenulum should undergo frenotomy because early treatment may prevent future speech articulation problems and obstructive sleep apnea.

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



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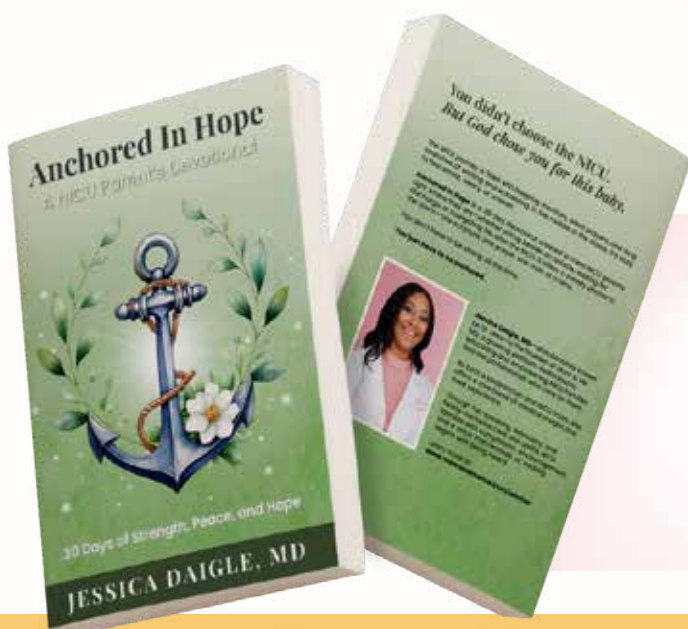
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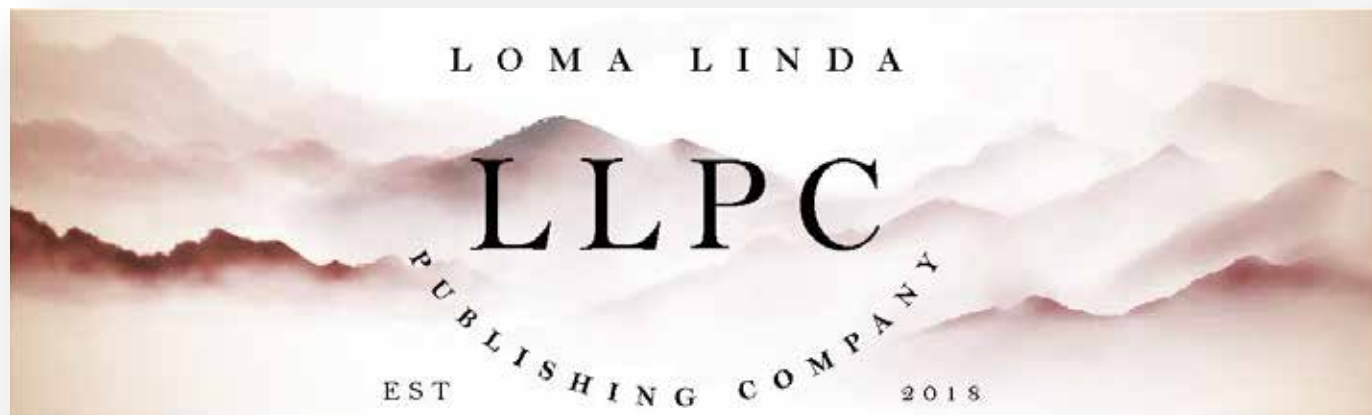


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Neonatal Intensive Care Unit Myth Busters

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.

“Patrick Bouvier Kennedy would never know it, but his death resulted in a massive influx of money directed at the treatment of premature infants. The birth of modern neonatology and NICUs is his legacy, and his death prevented the deaths of countless babies. Still, outdated or completely false beliefs remain.”

President John F. Kennedy and First Lady Jacqueline Kennedy's youngest child, Patrick Bouvier Kennedy, died on August 9, 1963, 39 hours after his birth. Patrick was born at 34 weeks postmenstrual age, and while many infants born at this gestation do well with minimal or no respiratory support, he was not one of them. He succumbed to what was then called hyaline membrane disease, now defined as respiratory distress syndrome (RDS). Treatment of RDS at the time was limited to supplemental oxygen – exogenous surfactant was not available, nor were mechanical ventilators suitable for use in the neonatal population.

Patrick Bouvier Kennedy would never know it, but his death resulted in a massive influx of money directed at the treatment of premature infants. The birth of modern neonatology and NICUs is his legacy, and his death prevented the deaths of countless babies. Still, outdated or completely false beliefs remain.

FiO₂ 0.4-0.6 (or more) is acceptable:

In the 1960s and 1970s, an infant of 30 weeks PMA was considered premature; surfactant was unavailable; and neonatal ventilators were relatively crude pressure-limited, time-cycled machines. High FiO₂ was necessary, and chronic lung disease (CLD) was ubiquitous. Through to the late 1990s, infants <24 weeks PMA were rarely offered resuscitation; the ventilation modes available were not capable of adequately supporting these infants. The widespread use of synchronized modes, volume regulation, high-frequency oscillation (HFO) (with or without volume targeting), and high-frequency jet ventilation (HFJV) enabled clinicians to resuscitate extremely premature infants at 22-23 weeks PMA.

Oxidative stress is cumulative and damages DNA. Rapidly dividing cells, such as pulmonary cells in the premature infant, are most

susceptible to this damage, as are others. While FiO₂ >0.4 may be acceptable for those born at >30 weeks PMA (this is debatable to this writer), those born at 22-28 weeks PMA are a completely different animal. A study of CLD and FiO₂ in premature infants reveals this difference (1). Cumulative FiO₂ exposure predicts CLD development (2). Reactive oxygen species (commonly referred to as free radicals) increase as FiO₂ increases; this may not be linear, although no studies report an exponential relationship. In the rest of the body, the partial pressure of oxygen in the blood drives free radical production.

“Cumulative FiO₂ exposure predicts CLD development (2). Reactive oxygen species (commonly referred to as free radicals) increase as FiO₂ increases; this may not be linear, although no studies report an exponential relationship.”

Adult medicine provides ample evidence of the perils of excessive oxygen. Baboons breathing 60% oxygen for only a few days have been found to have lung damage, as evidenced by “pulmonary toxicity with alveolitis, hyaline membrane formation, Home oxygen companies in Ontario do not have tank regulators that deliver < 125 mls/min, and do not offer low flow flowmeters adjustable to as low as 5 mls/min. Given the evidence, this is a travesty.

Babies with or at risk of persistent pulmonary hypertension of the newborn (PPHN) need to have SpO₂ 98-100% cellular infiltration, pulmonary oedema and subsequently, fibrosis” (3). Healthy adults breathing 30-50% oxygen for only 45 hours also suffer lung damage. A study of liberal vs conservative oxygen therapy in patients with chronic obstructive pulmonary disease (COPD) showed 1 additional death for every 14 patients treated in the liberal oxygen group. Another study showed a 20% increase in in-hospital patient death with liberal oxygen therapy (3).

“Limitations with home oxygen devices mean many babies whose SpO₂ is acceptable on very low flow (5-50 mL/min) still have SpO₂ of 100% at all times. This is anything but desirable.”

Physiological stress affects virtually every system, and the common practice of maintaining SpO₂ >96% does not seem wise. Limitations with home oxygen devices mean many babies whose SpO₂ is acceptable on very low flow (5-50 mL/min) still have SpO₂ of 100% at all times. This is anything but desirable. Home oxygen companies in Ontario do not have options.

A survey of neonatologists revealed that 70% targeted $\text{SpO}_2 > 95\%$ or 95-98%, and those with more than 10 years of experience targeted the lower end of this range and weaned FiO_2 more quickly—none aimed at sustained SpO_2 of 100% (4).

Reactive oxygen species production increases with PO_2 and is known to blunt the effects of inhaled nitric oxide (iNO) and create pulmonary vasoconstriction independent of iNO administration (5). Limiting excessive oxygen levels must be balanced with pulmonary vascular resistance, but once adequate tissue oxygenation is achieved, FiO_2 should be weaned judiciously.

“Lung-protective ventilation, provided by skilled clinicians and modern ventilators, does not necessarily result in CLD, and babies who have been managed exclusively with NIV can and do develop CLD, and I have witnessed this many times. The key is extubation at the earliest appropriate time and careful monitoring of pulmonary recruitment.”

ETT = CLD and NIV = no CLD:

This is a tough one. While evidence overwhelmingly supports non-invasive ventilation (NIV) to reduce CLD, this is not absolute. Lung-protective ventilation, provided by skilled clinicians and modern ventilators, does not necessarily result in CLD, and babies who have been managed exclusively with NIV can and do develop CLD, and I have witnessed this many times. The key is extubation at the earliest appropriate time and careful monitoring of pulmonary recruitment.

Failed extubation may increase the risk of CLD as well as the risks inherent to the intubation procedure itself. Weight, gestational age, presence of left-to-right ductal shunting, pre-extubation pH, and respiratory drive all influence the likelihood of success. Calculators to predict successful extubations are of limited use in smaller infants, achieving overall accuracy of 73%, but 34% when applied to a 750-gram, 24-week PMA infant with a pH of 7.25 and FiO_2 0.25 (6).

Fixation on “hyperinflation” and mean airway pressure (MAP) has led many to trade increased FiO_2 for lower pressure, and worse, to ignore climbing FiO_2 post-extubation. Physiological hyperinflation does not exist without compromised cardiac output and tissue perfusion, and it occurs at the lowest achievable FiO_2 . Rising FiO_2 reflects decreased pulmonary gas-exchange efficiency and is more likely due to derecruitment than hyperinflation. Pulmonary consolidation triggers an inflammatory response and will likely extend the need for respiratory support, the opposite of the result hoped for by reducing pressure. FiO_2 and SpO_2 are usually the most reliable indicators of pulmonary function. If oxygen or pressure requirements increase after weaning PEEP/MAP, go back.

Volume-targeted ventilation = lung-protective ventilation:

This is only true if the lung is fully and optimally recruited. Delivering 4 mL/kg to a lung that is only 50% recruited equates to 8 mL/kg.

Pressure-support ventilation is more lung-protective than volume-targeted ventilation in a poorly recruited lung. This is because pressure support terminates inspiration when flow decreases to approximately 25% of peak inspiratory flow.

“The benefits of NAVA apply only if the baby has a good drive to breathe, and the mode is not ideal if alveolar and airway stability are an issue. This is not the case in the extremely premature (7).”

Invasive NAVA (Neurally Adjusted Ventilatory Assist) is superior to other modes:

This statement is partly true and depends on the patient. Aside from a superior trigger and on-the-fly adjustment of pressure (and resulting volume), this is still a conventional ventilation mode. Backup ventilation in this mode is the same as intermittent mandatory ventilation (IMV). The benefits of NAVA apply only if the baby has a good drive to breathe, and the mode is not ideal if alveolar and airway stability are an issue. This is not the case in the extremely premature (7). The mode has also not been evaluated vs HFO or HFJV.

“Repositioning/positioning of extremely low birthweight/premature infants is the most frustrating part of maintaining invasive ventilation. Most babies have a “favoured” side or position where their FiO_2 and pressure requirements are lowest. Then the baby is repositioned, and ventilation pressure and oxygen needs increase significantly. If a baby’s ventilatory status deteriorates after a position change, change the position, not the ventilation!”

Repositioning a baby means a 180-degree flip:

Repositioning/positioning of extremely low birthweight/premature infants is the most frustrating part of maintaining invasive ventilation. Most babies have a “favoured” side or position where their FiO_2 and pressure requirements are lowest. Then the baby is repositioned, and ventilation pressure and oxygen needs increase significantly. If a baby’s ventilatory status deteriorates after a position change, *change the position, not the ventilation!*

The unstable nature of a very premature infant’s airways may cause partial airway obstruction, or the bevel of the endotracheal tube may be pressed against the side of the airway. Sometimes a small position change will correct this; sometimes complete

repositioning is needed. Increasing ventilation rather than changing position may (and often does) cause CO₂ to plummet when the position is changed again. The clinician responsible for the baby's ventilatory management may be completely unaware of this change, and large swings in CO₂ are not good for the brain.

“Whether on conventional ventilation, HFJV, or HFO (unfortunately, the Sensormedics® oscillator does not lend itself to KC), offer KC. If the baby deteriorates significantly, KC may be stopped. As for unstable infants, if they are unstable in the incubator, they will be unstable during KC. However, they may become more stable once settled into KC.”

Unstable infants cannot receive kangaroo care (KC):

This is a very contentious issue, but I firmly believe in offering KC whenever possible. Whether on conventional ventilation, HFJV, or HFO (unfortunately, the Sensormedics® oscillator does not lend itself to KC), offer KC. If the baby deteriorates significantly, KC may be stopped. As for unstable infants, if they are unstable in the incubator, they will be unstable during KC. However, they may become more stable once settled into KC. It is worth a try! Furthermore, it is devastating for parents to have never had the chance to hold their baby should it die.

Advances in knowledge are moot if they do not translate into clinical practice. Change is hard, but it is at the heart of advances in medicine and improved outcomes. Just do it!

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

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The Impact of Cumulative Medical Stress on the Developing Brain—Part 1: What Are We Missing Beyond Survival Measures?

Hilary Thompson, CTSS

What Does the Infant Experience?

Imagine a PICC line change from the clinical staff's perspective.

It is about safety; it is done kindly and gently. Sterile field, successful dressing change. Looks good, on to the next patient who needs care.

Imagine the same procedure from the eyes of a six-month-old.

The soft, warm cover is pulled away. Hands hold an arm still. Tape lifts from skin. A familiar smell disappears beneath antiseptic. That unpleasant odor signals bad things. Panic starts to mount. Arms are pinned; the crying begins. No one comes to her rescue, however. The discomfort begins, then pain. The infant cannot ask what is happening, cannot move away, and cannot understand "sterile field," "line security," or "infection prevention." She does not know this is in her best interest; she does not recognize the person hurting her. Her cry does not stop the procedure because the procedure must be completed. The adults are careful. They may be kind. They may be saving her life.

"The infant experiences what her body can register: touch, pain, immobilization, alarm, and the presence—or absence—of effective comfort. Her brain does not wait for language to learn. It is already building predictions about whether distress brings protection, whether touch is safe, and whether she has any control over what happens to her body. Her brain creates negative associations through the Hypothalamic-Pituitary-Adrenal axis to protect her against the next 'attack.'"

However, intention is information available to adults, not to a preverbal nervous system. Not to her brain.

The infant experiences what her body can register: touch, pain, immobilization, alarm, and the presence—or absence—of effective comfort. Her brain does not wait for language to learn. It is already building predictions about whether distress brings protection, whether touch is safe, and whether she has any control over what happens to her body. Her brain creates negative associations through the Hypothalamic-Pituitary-Adrenal axis to protect her against the next "attack." (1, 2)

What if the NICU Never Really Ends?

For many infants, discharge closes the most intensive chapter. Many might have a period of recovery and return to normalcy, but for children with medical complexity and comorbidities, it may simply change the location of care. The NICU becomes a living room where family caregivers perform NG placements, an operating room, a catheterization laboratory, an emergency department, a transplant unit, frequent and varied clinics, a laboratory chair, and countless other bedside procedures.

"For many infants, discharge closes the most intensive chapter. Many might have a period of recovery and return to normalcy, but for children with medical complexity and comorbidities, it may simply change the location of care."

Most young children do not yet have the developmental ability to understand our intention when our actions consistently hurt them. Around age five or later, most children begin to judge an action by intention rather than by harmful outcome alone. (3) And even then, it is abstract. An infant cannot understand that the adult restraining them, puncturing their skin, or causing pain is trying to save their life. The adult's intention may distinguish medical care from abuse in the adult world, but intention cannot protect an infant from the experience occurring in the infant's body.

The good news is that evidence-based ways can buffer this

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experience. The author intends to address those in a subsequent paper.

“An infant cannot understand that the adult restraining them, puncturing their skin, or causing pain is trying to save their life. The adult’s intention may distinguish medical care from abuse in the adult world, but intention cannot protect an infant from the experience occurring in the infant’s body.”

It is natural to cringe as we listen to procedures through the infant’s eyes—no one in pediatrics enjoys this unpleasant perspective. The parallel with maltreatment is uncomfortable, but avoiding it does not protect children from long-term consequences. As a well-known palliative care doctor at a children’s hospital has been known to say, “Take away the context of medical care, and a children’s hospital is just a giant torture chamber, when viewed from a child’s lens.”

“As a well-known palliative care doctor at a children’s hospital has been known to say, ‘Take away the context of medical care, and a children’s hospital is just a giant torture chamber, when viewed from a child’s lens.’”

Both abuse and repeated medical trauma may include pain imposed by adults, forced restraint, loss of control, unpredictable bodily threat, and separation from a protective caregiver. They are not morally or clinically equivalent. The essential difference is the adult’s purpose: one intends harm; the other intends healing. Nevertheless, a very young child cannot reliably use benevolent intention to change the sensory experience. The body still mobilizes for danger.

This action does not make physicians perpetrators. It makes cumulative exposure a clinical variable. This sequence is becoming an increasingly important consideration because, as medicine advances and more complex children survive, the care they receive in their lifetime is scaling as well. (4) We must find strategies to reduce this perceived harm, or else we are saving bodies at the expense of the mind, and few families want to sign up for that possibility.

When Painful Care Happens While the Brain Is Under Construction:

From birth through age four, the brain develops at extraordinary speed. Sensory pathways, stress regulation, executive

foundations, language, social expectations, and patterns of co-regulation are being shaped through repeated experience. Temperament is not created by medicine, and personality is never the product of a single exposure. Still, these years organize the child’s emerging way of approaching people, understanding threat, seeking comfort, experiencing novelty, and attempting control. (5)

“From birth through age four, the brain develops at extraordinary speed. Sensory pathways, stress regulation, executive foundations, language, social expectations, and patterns of co-regulation are being shaped through repeated experience...Still, these years organize the child’s emerging way of approaching people, understanding threat, seeking comfort, experiencing novelty, and attempting control.”

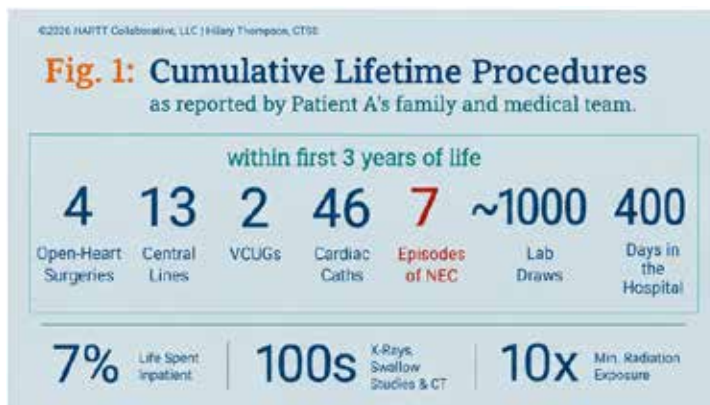
Research in very preterm infants provides a warning. Greater exposure to skin-breaking procedures has been associated with altered early brain development, including reduced white- and subcortical-gray-matter maturation after adjustment for important clinical factors. Other studies associate neonatal pain-related stress with altered cortical thickness, region-specific thalamic development, later white-matter microstructure, and cognitive outcomes. (6–9) These studies do not prove that painful procedures alone caused an individual child’s later difficulties; illness severity, prematurity, medication, inflammation, and surgery matter. Nevertheless, they make one conclusion difficult to defend: that necessary pain leaves no developmental trace.

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Cumulative Means More Than a Long Admission:

The 14-year case at the center of this inquiry makes “cumulative” visible. Within the first three years of her life, Patient A experienced four open-heart surgeries, 13 central lines, two voiding cystourethrogams, 46 cardiac catheterizations, seven episodes of necrotizing enterocolitis, approximately 1,000 laboratory draws, and 400 hospital days (see Figure 1). At the time of the study, she spent about 7% of her life hospitalized and accumulated hundreds of radiographic and swallow studies and roughly ten times the suggested radiation exposure limit for her age (Figure 1).

Figure 1. Cumulative medical and procedural exposure. Fourteen-year exposure for Patient A, concentrated in the first three years. Counts compiled retrospectively from medical and family records; estimates calculated by the author. Published with parental/legal guardian consent.



Her known opportunities for direct neurologic injury were limited: cardiopulmonary bypass on four occasions and an acute brain bleed immediately after transplant at age two. No subsequent brain injury was identified. Her most intensive medical care largely ended by age three, but maintaining a successful graft required frequent and invasive monitoring.

If early injury were the complete explanation, one might expect function to stabilize as medical intensity decreased.

It did not.

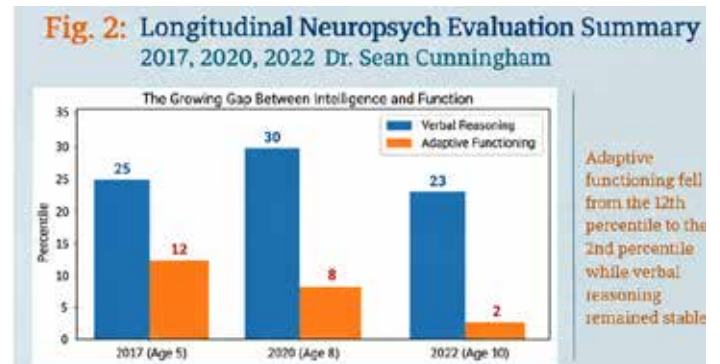
Neuropsychological evaluations at ages five, eight, and ten documented declining function across time, despite relatively stable verbal intelligence (see Figure 2). At age 10, Patient A's executive function was below the second percentile (see Figure 2).

The pattern raised a question that was not on the evaluators' radar: could the child's relational, regulatory, and behavioral symptoms reflect not only neurologic injury but also what her developing brain had learned through cumulative medical threat?

The Diagnosis No One Is Looking For:

Reactive Attachment Disorder (RAD) is appropriately associated with severe neglect, deprivation, repeated caregiver changes, or other pathogenic care. A diagnosis requires comprehensive evaluation; symptom checklists cannot establish it.⁽¹⁰⁾ That safeguard matters.

Figure 2. Longitudinal neuropsychological findings. Evaluations at ages five, eight, and ten reveal declining executive function despite relatively stable verbal intelligence. Source: Patient A's clinical records, retained by the author. Published with parental/legal guardian consent.



So does the blind spot it can create.

When a biological child has loving, consistently present parents, neuropsychologists may screen for attention-deficit/hyperactivity disorder, autism, anxiety, trauma, learning disorders, or sequelae of brain injury. RAD may never enter the differential because the parents did not neglect, abandon, or abuse the child. However, what if the child repeatedly experienced adults overriding her body during the same developmental window when safety, comfort-seeking, and trust were being organized and were necessary for normal development? What if loving parents were present, yet repeatedly prevented—by sterile fields, sedation, critical illness, or medical necessity—from stopping the threat? Or even worse, what if parents were associated with pain, restraining the child, creating disconnection, violating trust, and removing the safety needed for normal attachment?

“RAD may never enter the differential because the parents did not neglect, abandon, or abuse the child. However, what if the child repeatedly experienced adults overriding her body during the same developmental window when safety, comfort-seeking, and trust were being organized and were necessary for normal development?”

The question is not whether medicine “causes RAD.” Current evidence cannot support that claim. The question is whether cumulative medical trauma can produce a RAD-like pattern that remains unseen because the family does not fit the expected history.

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Caregivers Are Already Reporting the Signal:

Descriptive data from a pediatric heart-transplant caregiver community suggest this concern is not confined to one family. In an informal survey (“Survey 1”) of the world’s largest pediatric heart transplant caregiver support group (n = 115), 84% of caregivers reported active trauma-related symptoms in their children (H. Thompson, unpublished survey data, June 2026). In a separate survey (“Survey 2,” n = 184), 5% of families reported that their children had all six RAD-associated symptoms included in the survey. Additionally, every parent who took Survey 1 in the group rated their child’s function below 70% in every measured area (school, social, and home, for example). However, caregivers in Survey 1 reported that only 27% of their transplant centers (representing centers all over the country—Figure 3) were reported to have proactively addressed concerns about long-term psychological trauma or related functioning.

These are caregiver observations from a self-selected population, not diagnostic prevalence estimates. They may be influenced by recall, selection, question wording, and the extraordinary

“In an informal survey (‘Survey 1’) of the world’s largest pediatric heart transplant caregiver support group (n = 115), 84% of caregivers reported active trauma-related symptoms in their children”

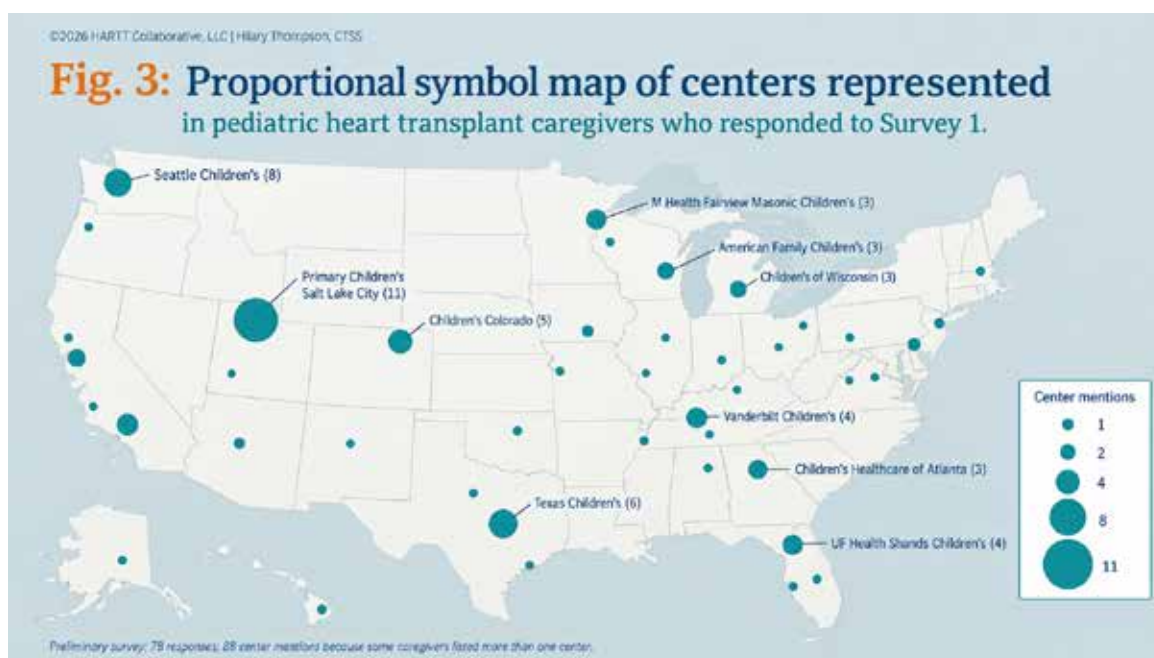
burden of transplant care. Nevertheless, a signal does not become unimportant because it is preliminary, especially when clinical systems are rarely looking for it. It equates to more than a substantial reason for further investigation.

Five percent is significant. Especially to these families, none of whom had been diagnosed with RAD but all of whom are struggling with no answers.

Caregiver associations are not the only affected relationships. The physical environment may amplify or interrupt that signal, too. Many parents in the informal Survey 1 (n=115) reported sleep disturbances (33.9% reported sleep disturbances excluding night terrors, and 15.7% also reported night terrors), and so did the family of Patient A, who reports an infant who preferred sleeping on a hardwood floor over the crib.

When painful procedures routinely occur in the child’s bed, the one place that should predict rest, parental comfort, and recovery also predicts invasion and ceases being a safe place. The infant or toddler’s brain has created a negative association: through repeated pairing, the bed may become a pain-predictive cue; the bed equals lack of safety; the bed equals pain. (11–12)

Figure 3. Geographic distribution of transplant centers. Caregiver-reported pediatric heart-transplant centers from Survey 1 (June 2026). Locations are not a representative sample or independent center evaluation. Multiple respondents may identify the same center.



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Because of this association, treatment rooms become essential to maintain a safe space for the pediatric patient whenever possible, and this deserves to be addressed in a subsequent paper that illustrates solutions for families and clinical staff. When clinically possible, separating painful intervention from the bed preserves at least one reliable safe space. For children whose bodies have learned that danger can arrive anywhere, that distinction matters.

The Cost of Seeing It Too Late:

By age nine, Patient A’s function had deteriorated enough that she was removed from school. Her family ultimately stopped all elective painful interventions and chose not to pursue retransplant listing should it become necessary. That decision did not emerge from ignorance of medical benefit. It emerged from the accumulated price of obtaining it.

This is the heart of the issue: care can succeed procedure by procedure while the child’s quality of life becomes progressively diminished. A patent line, successful catheterization, a functioning graft, or discharge home can be a medical victory and still fit into a losing longitudinal trajectory.

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This trajectory explains how families fail after discharge and lose trust in medicine. This progression also drives medical staff burnout—when families repeatedly fail outside their doors, it is hard to bring enthusiasm back to the work.

There is reason for hope, but the solution deserves its own paper. The HARTT Collaborative, with Patient A at the center

of their approach, translated existing but unused research into a framework and brought it to Patient A’s transplant team, who partnered with the family to apply it to Patient A’s care plan. The changes were remarkable and relatively fast. Four years later, Patient A’s six tracked RAD-like symptoms decreased by 95% from baseline, as reported by parental and clinical observation.

“The HARTT Collaborative, with Patient A at the center of their approach, translated existing but unused research into a framework and brought it to Patient A’s transplant team, who partnered with the family to apply it to Patient A’s care plan. The changes were remarkable and relatively fast. Four years later, Patient A’s six tracked RAD-like symptoms decreased by 95% from baseline, as reported by parental and clinical observation...RAD typically has a much worse long-term psychiatric burden, and it has a reputation for being a difficult diagnosis to treat...”

As most know, RAD typically has a much worse long-term psychiatric burden, and it has a reputation for being a difficult diagnosis to treat, according to informal interviews with several clinicians in this area of expertise (the data concurs, with 73.5% of kids with RAD going on to have elevated rates of psychiatric challenges). (13)

That outcome is a case observation, not proof of efficacy.

It is also too significant to ignore. Moreover, has the potential to be repeatable at scale.

The next paper will describe the THRIVE FrameworkSM and the practical changes that emerged from this case, the caregiver data, and the literature. For now, the request is simpler: place cumulative medical trauma on the differential. When possible, consider every clinical decision with a long-term outlook. Ask what the infant’s nervous system is experiencing. Ask what the caregiver at bedside is experiencing (whether they be a family caregiver or a medical one). Preserve the bed as safe whenever possible (it is acknowledged that this is difficult in an ICU setting but becomes increasingly important on step-down units).

A simple shift in perspective, a change of lens through which we view clinical decisions, and simultaneously educating and informing the family caregiver to do the same, will set the stage for helping families, especially those with medical complexities, actually thrive after care, not merely survive it. The next paper will suggest an evidence-based framework to make this possible for most families, improving caregiver-child relationships and positive attachment, development and nervous system regulation,

physician-patient-family relationships, and even medical staff job satisfaction.

“A simple shift in perspective, a change of lens through which we view clinical decisions, and simultaneously educating and informing the family caregiver to do the same, will set the stage for helping families, especially those with medical complexities, actually thrive after care, not merely survive it.”

The full framework and its early outcomes will be presented in the next paper. Clinicians who do not want to wait to begin this conversation are invited to contact the author.

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Hilary Thompson, CTSS, is a researcher, professional speaker, and consultant. She leads the world's largest pediatric heart transplant caregiver support group, serving nearly 3,000 caregivers worldwide, and supports families in coping with, recovery from, and prevention of, chronic medical stress. Hilary founded The HARTT Collaborative to partner with organizations that need practical, evidence-based strategies to thrive in high-stress environments. Combining 15 years of research, data analysis, and training with 30 years of lived expertise, she developed the THRIVE Framework® for more compassionate care of others, and its companion system, Take Care of the PILOT® for more compassionate care of self. She imparts these to teams and organizations around the country and internationally. Her work to improve medically complex families' mental health has been nationally recognized. A best-selling author and award-winning speaker, she resides in Central Utah, and is an active member of the American Academy of Pediatrics, the Family Centered Care Taskforce, and the National Speakers Association. She is currently pursuing her board certification in patient advocacy. "The goal is not to merely survive. The goal is to THRIVE."

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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



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You deserve a healthy pregnancy & childbirth.

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



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The Indirect Impact of RSV

OVERVIEW

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

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

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

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



RSV PARENT SURVEY

340 parents who had at least 1 child sick with RSV



67% of parents said their child was hospitalized for RSV

RSV HEALTH CARE PROVIDER SURVEY

175 health care providers across various pediatric and neonatal subspecialties



67% worked in an outpatient facility

33% worked in a hospital

RESULTS



FINANCIAL BURDEN

More than ¾ 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 ½ 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.

Ethics and Wellness: Validation or Vindication: Which One Do We Really Want?

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

“We often use two words to describe the arc of a professional career: validation and vindication. They sound similar, and they can even feel similar when we finally receive them, but they represent profoundly different experiences, particularly for those of us who spend our professional lives in academic medicine.”

We often use two words to describe the arc of a professional career: **validation** and **vindication**. They sound similar, and they can even feel similar when we finally receive them, but they represent profoundly different experiences, particularly for those of us who spend our professional lives in academic medicine. (1, 2)

Merriam-Webster defines *validate* as establishing validity, confirming that something is real or correct, and recognizing its worth or legitimacy. *Vindicate*, by contrast, means demonstrating that someone who has been criticized or doubted was right, or clearing someone of blame or suspicion. Although both concepts involve recognizing the truth, validation emphasizes acknowledging worth and legitimacy, whereas vindication emphasizes proving that an earlier judgment was wrong. The distinction may seem subtle, but it has important implications for our careers, our relationships, and our professional wellbeing. (3, 4)

“Occasionally, years later, circumstances prove that we were right, and the resulting vindication can be extraordinarily satisfying. There is something deeply human about seeing an idea succeed after others have rejected it, particularly when we have invested considerable professional and emotional energy in defending it.”

In academic medicine, we often believe we are right before our institution, department, committee, or colleagues recognize it. We may advocate for a change in clinical practice, challenge an established process, propose a new educational approach, raise an ethical concern, or argue that an important issue is being overlooked. Sometimes we are heard; but sometimes our ideas are dismissed, our contributions are overlooked, or our judgment is questioned. Occasionally, years later, circumstances prove that we were right, and the resulting vindication can be extraordinarily satisfying. There is something deeply human about seeing an idea succeed after others have rejected it, particularly when we have invested considerable professional and emotional energy in defending it. (5-7)

The temptation at that moment is to look backward and say, “I told you so.” However, we should ask whether proving we were right is really the outcome we wanted, or simply the most emotionally satisfying response to having been wronged. (8)

“Vindication asks whether we were right, whether our critics were wrong, and whether the record can finally be corrected. Validation can ask a more consequential question: what can we build now that our contribution has been recognized?”

Vindication is often backward-looking, while validation is forward-looking:

Vindication asks whether we were right, whether our critics were wrong, and whether the record can finally be corrected. Validation can ask a more consequential question: what can we build now that our contribution has been recognized? That distinction matters in academic medicine, where careers are built not only on being correct but also on relationships, mentorship, scholarship, collaboration, teaching, clinical excellence, institutional trust, and the ability to bring others along. (4, 9, 10)

A physician may win an argument and still lose the opportunity to lead the next initiative. A faculty member may ultimately prove a controversial position correct yet discover that the people who might have supported the next stage of that career are no longer willing to collaborate. In this sense, vindication can become an expensive achievement, particularly when the pursuit of being right takes precedence over the broader goals of academic and professional life.

“The pursuit of vindication can carry a remarkably high body count, though the casualties are not literal bodies but professional relationships, colleagues, mentors, collaborators, institutional allies, and future opportunities.”

The pursuit of vindication can carry a remarkably high body count, though the casualties are not literal bodies but professional relationships, colleagues, mentors, collaborators, institutional allies, and future opportunities. We can defeat the person who opposed an idea, expose the committee that made the wrong decision, or demonstrate that an earlier critic was mistaken, and the immediate satisfaction can be substantial. Nevertheless, when the argument is over, the opponent has been defeated, and the record has been corrected, we may discover that we have little left to show beyond the satisfaction of having won. (11-14) We may feel justified, vindicated, and even relieved, but our professional trajectory may have advanced very little.

That is the uncomfortable reality of vindication: it can produce a profound sense of personal satisfaction while simultaneously narrowing the professional landscape in which the next opportunity must occur. The emotional reward may be immediate, but the professional cost can linger long after the disagreement ends. If we have alienated the very people we must collaborate with to advance our next idea, we may have won the argument at the expense of the opportunity to make a meaningful difference. (15)

Validation operates differently because it does not necessarily require someone else to lose. A trainee who receives meaningful recognition from a mentor is validated, as is a faculty member whose scholarship is recognized by peers, a physician whose clinical judgment is trusted with greater responsibility, or a teacher whose students return years later to describe the lasting impact of that teaching. In each case, recognition can begin something rather than conclude an old dispute.

“Validation can provide the credibility and institutional trust necessary to move from contributing to an initiative to directing it, from mentoring individual trainees to shaping an educational program, or from advocating for a clinical improvement to leading its implementation.”

Validation can create capacity for advancement:

Recognition may lead to an invitation; an invitation may lead

to responsibility; responsibility may lead to leadership; and leadership may create the opportunity to change a system. This progression is especially relevant in academic medicine, where advancement often depends on demonstrating not only individual competence but also the capacity to build relationships, develop people, advance scholarship, and improve clinical and educational systems. (10, 16) Validation can provide the credibility and institutional trust necessary to move from contributing to an initiative to directing it, from mentoring individual trainees to shaping an educational program, or from advocating for a clinical improvement to leading its implementation.

“Validation can therefore be more than an emotional reward; it can catalyze professional growth and turn individual accomplishment into broader institutional impact.”

The potential benefit of validation is not simply feeling appreciated:

It can create a platform from which we reach a higher level of professional responsibility and influence. When our contributions are recognized, we may gain access to resources, collaborators, leadership opportunities, and the institutional support needed to translate an idea into meaningful change. Validation can therefore be more than an emotional reward; it can catalyze professional growth and turn individual accomplishment into broader institutional impact. (17, 18)

This alternative does not mean that vindication is inherently wrong or that we should avoid defending ourselves. There are circumstances in academic medicine in which correcting the record, challenging an unethical decision, exposing a flawed process, or demonstrating that a clinical or scientific claim is incorrect is essential. Scientific integrity depends on our willingness to challenge unsupported conclusions; patient safety requires us to speak up when established practices are harmful; and professional ethics sometimes demand that we resist institutional pressure. (19) Silence is not always wellness, and civility should never be confused with acquiescence.

“The important distinction is between pursuing vindication as a necessary means of correcting an injustice and pursuing it as the ultimate objective of our professional lives. Sometimes we must stand our ground, and sometimes evidence accomplishes what argument could not.”

The important distinction is between pursuing vindication as a necessary means of correcting an injustice and pursuing it as the ultimate objective of our professional lives. Sometimes we must stand our ground, and sometimes evidence accomplishes what argument could not. Nevertheless, we should regularly ask ourselves what we are actually trying to accomplish. If our objective is to prove that we were right, vindication may be enough. If our objective is to improve patient care, advance science, educate the next generation, strengthen an institution, or create opportunities for others, vindication may be a remarkably inefficient strategy. (10, 20, 21)

“Academic medicine is fundamentally a long game. Most of us will encounter people who misunderstand us, experience decisions that seem unfair, watch ideas we believe in initially fail, and occasionally be passed over for opportunities we believe we deserve. We will have manuscripts rejected, grants declined, proposals ignored, and recommendations dismissed, and some of those decisions will eventually prove mistaken.”

Academic medicine is fundamentally a long game. Most of us will encounter people who misunderstand us, experience decisions that seem unfair, watch ideas we believe in initially fail, and occasionally be passed over for opportunities we believe we deserve. We will have manuscripts rejected, grants declined, proposals ignored, and recommendations dismissed, and some of those decisions will eventually prove mistaken. The question is what we do with that experience and whether we allow it to shape our next contribution or consume our attention long after the original disagreement has ceased to matter. (15, 22-24)

We can collect grievances like trophies, remembering every person who underestimated us and every committee that said no, while spending enormous emotional energy waiting for the day when circumstances finally prove us correct. Alternatively, we can use the experience to improve the idea, strengthen the evidence, find collaborators, mentor someone else, and create something hard to dismiss. The latter approach does not require us to forget what happened or pretend that unfairness never occurred; it requires us to decide that the experience will inform our future without defining it. (16)

This perspective is where the wellness dimension becomes particularly important. The pursuit of vindication can be exhausting because it keeps us psychologically connected to the injury, often requiring acknowledgment from the very people whose actions caused the distress. (9, 11, 21) Someone has to admit that they were wrong, someone has to accept responsibility, and

someone has to recognize that we were right. When our sense of professional closure depends on that acknowledgment, we effectively surrender some control over our wellbeing to people who may never provide it.

“Validation offers a different kind of freedom because it allows us to recognize the value of our work even when the people who originally rejected it never acknowledge that value. Sometimes the most meaningful validation comes years later and from a completely different direction than we anticipated: a trainee who becomes a colleague, a family who remembers something we did, a patient whose life was changed, a paper that influences practice, or a young physician who adopts an idea we once struggled to introduce”

Validation offers a different kind of freedom because it allows us to recognize the value of our work even when the people who originally rejected it never acknowledge that value. Sometimes the most meaningful validation comes years later and from a completely different direction than we anticipated: a trainee who becomes a colleague, a family who remembers something we did, a patient whose life was changed, a paper that influences practice, or a young physician who adopts an idea we once struggled to introduce. Such validation does not require a defeated opponent; it requires a lasting contribution. (1, 8)

“A career built primarily on vindication can leave behind a trail of people who remember the conflict, whereas a career built on validation can create a network of people who remember the contribution.”

This distinction matters more as we pursue leadership in academic medicine. Leaders inevitably inherit disagreements and must work with people who opposed them yesterday and may oppose them again tomorrow. A career built primarily on vindication can leave behind a trail of people who remember the conflict, whereas a career built on validation can create a network of people

who remember the contribution. As professional responsibility increases, the ability to maintain relationships, develop future leaders, and create environments in which others can succeed becomes increasingly important to the work itself. (1, 2)

“Early in a career, proving that we are right can feel essential, especially when we are trying to establish credibility in a hierarchy that may not yet recognize our abilities. Later in a career, however, a more consequential question may be whether we can create an environment in which other people can succeed.”

Early in a career, proving that we are right can feel essential, especially when we are trying to establish credibility in a hierarchy that may not yet recognize our abilities. Later in a career, however, a more consequential question may be whether we can create an environment in which other people can succeed. This is a different measure of accomplishment because it shifts the focus from the recognition we receive to the opportunities we create, from our own victories to the contributions of those we mentor, and from the disputes we win to the systems we improve. (16, 21)

“In the end, vindication can provide a moment of satisfaction, while validation can provide momentum for the future. Vindication may close a chapter by demonstrating that our critics were mistaken, but validation can open the next chapter by giving us the credibility, relationships, and opportunities to accomplish something more significant.”

Perhaps the greatest professional validation is not having everyone admit we were right, but reaching a position where we can use our experience, knowledge, and credibility to make a meaningful difference without requiring that acknowledgment. (3, 14, 18, 20,

25) We can take lessons from a disagreement without carrying resentment, acknowledge that we were right without requiring someone else to be publicly wrong, and recognize injustice without letting it define our professional identity. Most importantly, we can use whatever recognition we receive as a platform for the next level of service rather than as a final opportunity to settle an old score.

Only a moment:

In the end, vindication can provide a moment of satisfaction, while validation can provide momentum for the future. Vindication may close a chapter by demonstrating that our critics were mistaken, but validation can open the next chapter by giving us the credibility, relationships, and opportunities to accomplish something more significant. (1, 2) In academic medicine, where careers should be measured not simply by what we accomplish but also by what we enable others to accomplish, that distinction may be one of the most important lessons we learn.

“Vindication may offer the satisfaction of knowing we were right, but validation offers the chance to use that knowledge to reach a higher level of contribution, influence, and leadership. The more enduring achievement is not merely to prove that we deserved a place at the table, but to use that place to make room for others. Ultimately, it may provide something considerably more valuable: a legacy.”

The ultimate goal:

Perhaps our goal should not be to leave behind a high body count of people we defeated but to leave behind many people whose careers, institutions, and patients are better because we were there. (24, 25) Vindication may offer the satisfaction of knowing we were right, but validation offers the chance to use that knowledge to reach a higher level of contribution, influence, and leadership. The more enduring achievement is not merely to prove that we deserved a place at the table but to use that place to make room for others. Ultimately, it may provide something considerably more valuable: a legacy. (16)

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Summary Statements	Supporting evidence
Pursuing vindication keeps one tied to the injury (wellness cost)	Rumination over injustice → worse mental health, mediates burnout; self-compassion protective (33)
Meaning and enabling others are the enduring achievement	Eudaimonic meaning predicts fulfillment; meaning protects against burnout; “pay it forward” mentorship (13)
Burnout is systemic, not individual weakness	Culture, leadership, loss of meaning are primary drivers. (13)
Recognition/validation drives engagement, fulfillment, and retention.	Recognition is the strongest predictor of engagement; feeling valued → markedly lower burnout and intent to leave. (26)
Careers advance through relationships, mentorship, and sponsorship	Mentorship → promotion/retention; sponsorship distinct and critical to leadership; networks matter (27, 28)
Collaboration (not just being right) builds institutional impact	Collaboration/teamwork foundational to physician-scientist and faculty success (29, 30)
Legitimate vindication: correcting the record, speaking up	Integrity self-correction; speaking up ethically essential; misconduct ≠ disagreement (31)
Psychological safety underpins voice.	Psychological safety enables error reporting, learning, wellbeing. (32)

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Las nuevas mamás necesitan acceso a la detección y tratamiento para LA DEPRESIÓN POSPARTO



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



Sin embargo, sólo el 15% recibe tratamiento¹

LA DEPRESIÓN POSTPARTO **NO TRATADA** PUEDE AFECTAR:



PARA AYUDAR A LAS MADRES A ENFRENTAR LA DEPRESIÓN POSPARTO



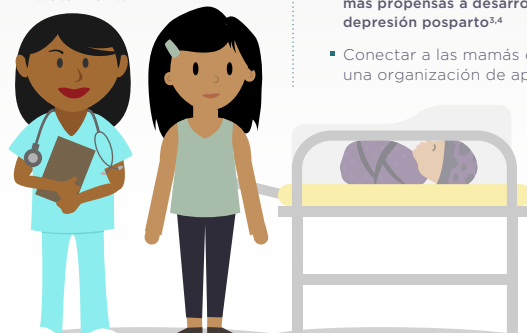
LOS ENCARGADOS DE FORMULAR POLÍTICAS PUEDEN:

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



LOS HOSPITALES PUEDEN:

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



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

¹ American Psychological Association. Accessed on: <http://www.apa.org/women/resources/reports/postpartum-depression.aspx>
² National Institute of Mental Health. Accessed on: <https://www.nimh.nih.gov/health/publications/postpartum-depression-facts/index.shtml>
³ Journal of Perinatology (2015) 35, 529–536. doi:10.1097/01.ppt.0000451471.14711.1f
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Beyond the Full Time Equivalent (FTE): Shifting from Functional Commoditization to Relational Valuing in the Neonatal Intensive Care Unit

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

“In many modern healthcare organizations, an insidious cultural shift has occurred. Clinicians, including nurses, respiratory therapists, nurse practitioners, and physicians, are frequently treated not as complex human beings with finite psychological and physiological limits, but as interchangeable functional assets (1, 2).”

In many modern healthcare organizations, an insidious cultural shift has occurred. Clinicians, including nurses, respiratory therapists, nurse practitioners, and physicians, are frequently treated not as complex human beings with finite psychological and physiological limits but as interchangeable functional assets (1, 2). They are measured by relative value units (RVUs), documentation compliance, bed-utilization rates, and mandatory on-call shift-coverage percentages (3). This operational stance represents **functional instrumentalization**: valuing a person strictly as a tool to achieve an institutional outcome (4, 5).

Every individual within a healthcare organization is evaluated

through one of two distinct frameworks: **Functional Valuing** or **Relational Valuing** (Figure 1).

Functional Valuing measures human worth strictly through transactional utility, immediate output, and administrative compliance (6, 7). Within this extrinsic model, the clinician is viewed as an interchangeable asset, an “FTE,” or a procedural unit required to satisfy a regulatory or financial metric. When a system communicates, “*We need you on shift tonight because we have an empty slot and need to maintain our nurse-to-patient ratio,*” it signals that the caregiver’s presence matters only insofar as it fills a schedule gap and protects throughput, ultimately driving moral injury and turnover (8).

“Conversely, Relational Valuing recognizes the clinician as a whole human being possessing intrinsic worth, clinical wisdom, and finite psychological and physiological limits (9). Rather than viewing the caregiver as a tool to be utilized, this interdependent model treats human well-being and psychological safety as essential preconditions for all operational success (10).”

THE SPECTRUM OF CAREGIVER VALUING	
FUNCTIONAL COMMODITIZATION (TRANSACTIONAL)	RELATIONAL INTEGRATION (INTERDEPENDENT)
⇒ Clinician as an "FTE Unit"	⇒ Clinician as a Whole Human Being
⇒ Focus on Output and Shift Fill	⇒ Focus on Self-Determination
⇒ "Do TO the Caregiver" Management	⇒ "Do WITH the Caregiver" LEADERSHIP
⇒ Compliance and Rule Enforcement	⇒ Psychological Safety Flourishes
⇒ High Moral Injury and Turnover	⇒ High Resilience and Retention

Figure 1

Conversely, Relational Valuing recognizes the clinician as a whole human being possessing intrinsic worth, clinical wisdom, and finite psychological and physiological limits (9). Rather than viewing the caregiver as a tool to be utilized, this interdependent model treats human well-being and psychological safety as essential preconditions for all operational success (10). When leadership says, “We value your clinical wisdom, your critical thinking, your unique presence at the bedside, and your personal well-being, and we are committed to supporting you through a demanding operational environment,” it signals that the person matters beyond shift metrics. This intrinsic alignment fosters deep organizational trust, active engagement, and long-term retention across the care team (11).

“When healthcare workers feel valued only for the function they perform, they experience what organizational psychologist Christina Maslach identifies as the primary driver of burnout: depersonalization (12, 13). When a health system treats its staff as transactional units, staff inevitably treat the health system—and eventually their clinical work—transactionally (14). The entire care team suffers (15).”

When healthcare workers feel valued only for the function they perform, they experience what organizational psychologist Christina Maslach identifies as the primary driver of burnout: **depersonalization** (12, 13). When a health system treats its staff as transactional units, staff inevitably treat the health system—and eventually their clinical work—transactionally (14). The entire

care team suffers (15).

As was explored in the previous columns, **Self-Determination Theory (SDT)** posits that human flourishing, intrinsic motivation, and psychological health depend on satisfying three basic psychological needs (also termed “Essential Nutrients”): **Autonomy, Mastery, and Relatedness** (16, 17). Functional commoditization systematically starves clinicians of all three of these Essential Nutrients (Figure 2):

“Management imposes rigid, top-down workflows and demands strict adherence to “Work-as-Imagined” algorithms. The clinician’s personal judgment is replaced by multi-click EMR protocols, converting skilled professionals into task-executors.”

- **Autonomy: Agency vs. Algorithmic Control**

- *Functional View:* Management imposes rigid, top-down workflows and demands strict adherence to “Work-as-Imagined” algorithms. The clinician’s personal judgment is replaced by multi-click EMR protocols, converting skilled professionals into task-executors.
- *Relational View:* Leadership honors clinical agency, calculates and protects cognitive load, encourages clinicians to exercise judgment and pull the behavioral Andon Cord when safety boundaries drift, and invites clinicians to actively participate in designing the workflows that govern their daily practice (18).

- **Mastery (Competence): Growth vs. Production Output**

- *Functional View:* Professional success is defined by

SELF-DETERMINATION THEORY (SDT)

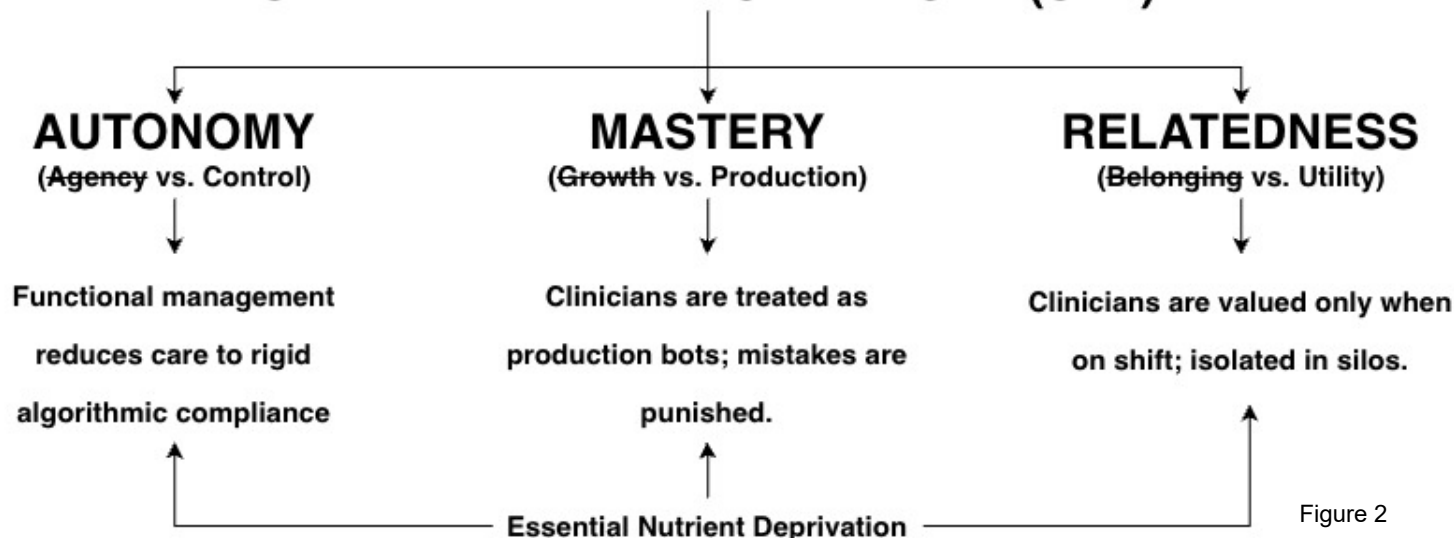


Figure 2

volume: how many patient visits were documented and billed, how many infants were admitted, or how quickly beds were turned over. Throughput subordinates growth and clinical mastery.

- *Relational View:* Mastery is cultivated through deliberate practice, high-fidelity simulation, and continuous learning. Mistakes are treated as system failures to understand rather than individual defects to punish.
- **Relatedness: Genuine Belonging vs. Operational Utility**
 - *Functional View:* Connection is transactional. A caregiver is “part of the team” as long as they are filling a spot on the schedule. When they experience distress, fatigue, or moral injury, they are seen as a broken component that needs replacing.
 - *Relational View:* Caregivers are integrated into an Interdependent community. Their personal identities, families, life stressors, and professional aspirations are known and respected. They belong to the team not because of what they produce, but because of who they are.

“In a commoditized NICU, a nurse may be assigned a third complex infant, or an infant in another corridor, despite knowing it compromises bedside vigilance, to satisfy an administrative ratio (19). The nurse is forced to execute the function of coverage while inheriting the systems-related moral trauma of experiencing compromised care delivery (20).”

The organizational cost of this commoditization manifests as severe **Moral Injury** and **Allostatic Load**:

- **Moral Injury:** Moral injury occurs when clinicians are forced to operate in environments that compel them to act—or witness actions—that violate their deeply held moral and professional values (8). In a commoditized NICU, a nurse may be assigned a third complex infant, or an infant in another corridor, despite knowing it compromises bedside vigilance, to satisfy an administrative ratio (19). The nurse is forced to execute the function of coverage while inheriting the systems-related moral trauma of experiencing compromised care delivery (20).
- **Accelerated Allostatic Erosion:** In our previous analysis of Cognitive Load Theory, we explored how chronic stress elevates allostatic load, which represents the cumulative biological wear and tear on the prefrontal cortex (21). When clinicians feel instrumentalized, their baseline neuroendocrine stress remains perpetually elevated (22).

They operate in a state of hypervigilance, anticipating that leadership will support them only when convenient and abandon them when systemic failures occur (23). This mental exhaustion shrinks available working memory, triggering the Efficiency-Thoroughness Trade-Off (ETTO) and increasing the likelihood of clinical errors (24, 25).

“Transitioning a Newborn Intensive Care Unit from a transactional culture of functional commoditization to an interdependent environment of relational valuing requires more than empathetic leadership rhetoric. It demands concrete, structural changes to daily clinical operations.”

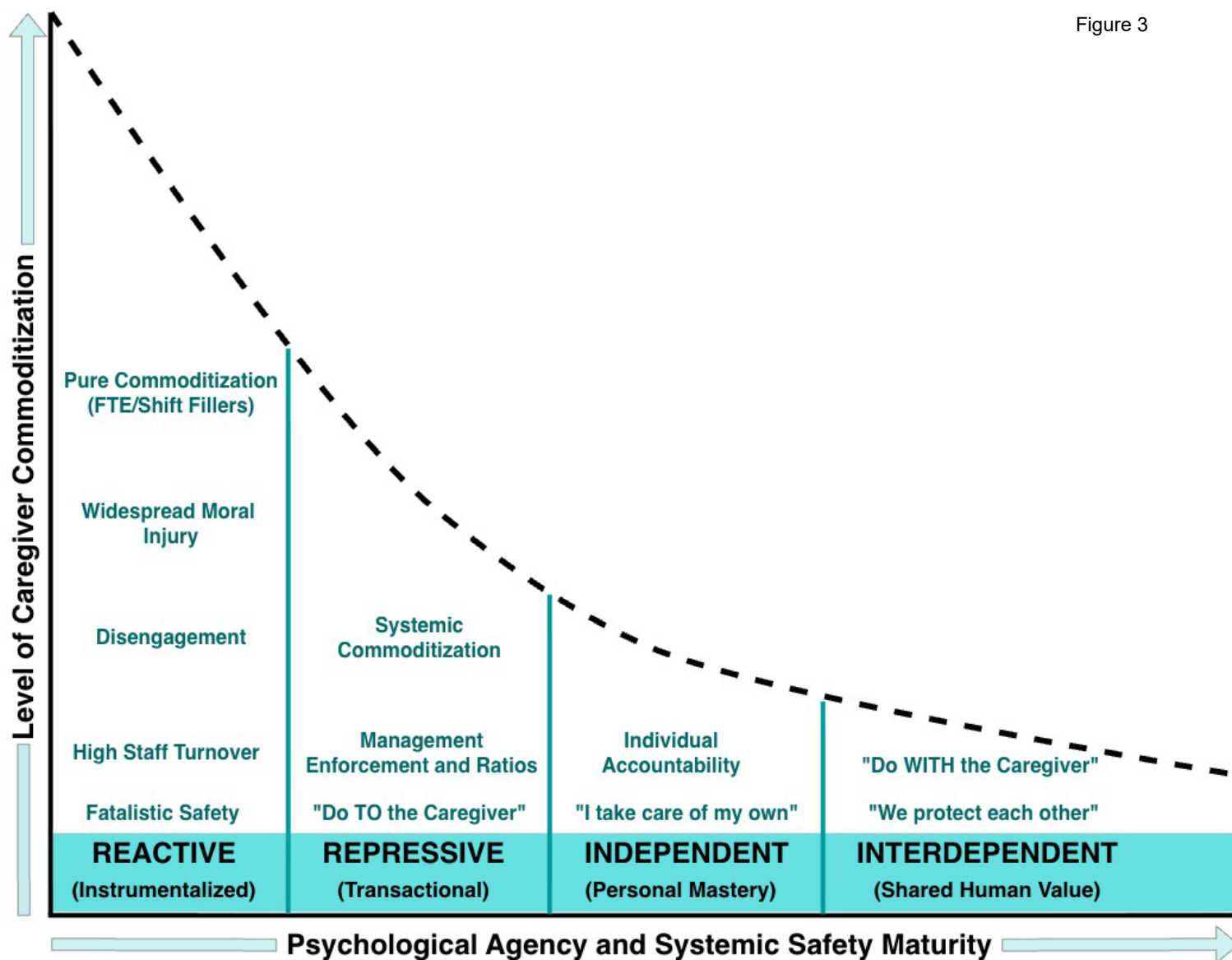
Operationalizing Human-Centered Interdependence

Transitioning a Newborn Intensive Care Unit from a transactional culture of functional commoditization to an interdependent environment of relational valuing requires more than empathetic leadership rhetoric. It demands concrete, structural changes to daily clinical operations.

“At this highest level of organizational reliability, safety and well-being are recognized not as individual obligations but as shared, non-negotiable preconditions maintained by every team member. To operationalize this culture, clinical leadership must integrate human-centered principles directly into the unit’s operational architecture, using the POKE Ecosystem to bridge systemic design and daily bedside execution:”

In the cultural progression mapped to a caregiver-commoditization-modified DuPont Bradley Curve, units evolve from a **Reactive** state (driven by fear and compliance) to a **Dependent** state (driven by management enforcement), and finally to an **Interdependent** state (Figure 3) (26). At this highest level of organizational reliability, safety and well-being are recognized not as individual obligations but as shared, non-negotiable preconditions maintained by every team member. To operationalize this culture, clinical leadership must integrate human-centered principles directly into the unit’s operational architecture, using the **POKE Ecosystem** to bridge systemic design and daily bedside execution:

Figure 3



- 1. Extend the POKE Mandate Internally:** The foundational ethos of the POKE ecosystem—"Do *FOR* the patient... never *TO* the patient"—must be applied internally to the care team: "Do *WITH* the caregiver... never *TO* the caregiver." Policies, schedules, EMR updates, and workflow changes must never be inflicted upon frontline clinicians without their direct co-design and consent (27, 28, 29).
- 2. Transform the Daily Huddle into a Psychological Safety Check:** Shift the focus of shift huddles from pure operational metrics (bed counts, acuity scores) to human state checks:
 - Functional Question:* "Are all beds covered and nurse-to-patient ratios met?"
 - Relational Question:* "Who on our team is carrying an unsustainable cognitive or emotional load today, and how do we redistribute our collective bandwidth to protect them?"
- 3. Establish Behavioral Circuit Breakers for Staff Distress:** Just as the Andon Cord (CUS protocol) empowers any team member to halt a procedure if an infant's safety is compromised, the unit must establish a **Psychological**

Andon Cord (8). Clinicians must be empowered to declare when allostatic load or fatigue has compromised their working memory capacity, triggering immediate, non-punitive support and workload rebalancing.

- 4. Leadership Presence at the Sharp End (Gemba Walks):** Medical directors and nurse executives must conduct regular, non-evaluative "Gemba" rounds—not to audit compliance, but to observe "Work-as-Done," identify systemic friction, and explicitly acknowledge the human effort required to deliver care in complex environments (30).

"A health system that treats its clinical workforce as disposable tools will ultimately deliver care that is fragmented, error-prone, and devoid of compassion."

Conclusion: Humanity as the Ultimate Precondition for Safety

In high-reliability healthcare, we cannot separate patient safety from caregiver humanity. A health system that treats its clinical workforce as disposable tools will ultimately deliver care that is fragmented, error-prone, and devoid of compassion. True safety is not achieved by enforcing rigid compliance on a commoditized workforce. True safety is achieved by cultivating an Interdependent culture where every caregiver feels deeply valued, not merely for the function they serve during a twelve-hour shift, but for the inherent worth, clinical wisdom, and unique human perspective they bring to the bedside of the fragile neonate. Individuals who are truly valued for who they are and are shown how they add value in the service of others go home daily feeling **Safe, Valued, and Loved**.

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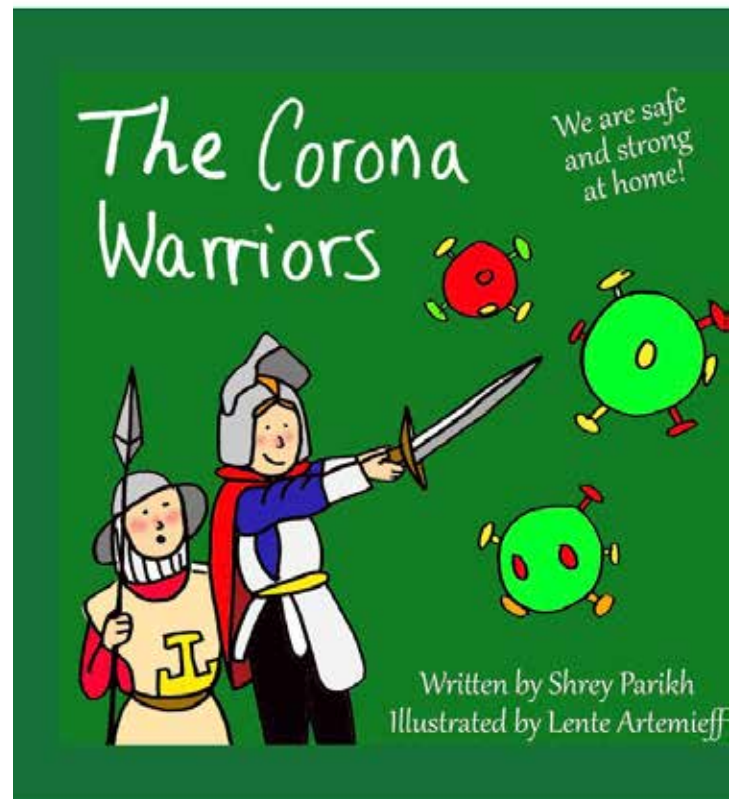


Erick Ridout, M.D., is blessed to be a husband, the dad to two amazing kids, granddaddy to three extraordinary grandsons and two granddaughters, and currently serves the babies, their families, and the caregivers in the Newborn ICU in Southwestern Utah, the Newborn ICU in Honolulu, Hawaii, and as Vermont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

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The Village Son



A Life's Journey

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

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First Candle: This October: Promoting Safe Sleep and Supporting Families Through Loss

Destiny Stokes, MPH



Saving babies. Supporting families.

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

“October brings two connected observances to the forefront of neonatal care: Safe Sleep Awareness Month and Pregnancy and Infant Loss Awareness Month, including Pregnancy and Infant Loss Remembrance Day on October 15.”

October brings two connected observances to the forefront of neonatal care: Safe Sleep Awareness Month and Pregnancy and Infant Loss Awareness Month, including Pregnancy and Infant Loss Remembrance Day on October 15. While neonatal professionals work each day to protect vulnerable infants and reduce the risk of sleep-related infant death, this month also asks us to pause, remember, and honor every baby lost too soon.

When a pregnancy ends in loss or a baby dies, grief ripples outward beyond the parents. Grandparents may mourn a grandchild while supporting their own child. Siblings, extended family members, friends, and communities are forever changed.

Within the NICU, loss can affect professionals who have cared closely for a baby and family. Neonatal nurses and bedside clinicians stand with families through critical moments, celebrate milestones, and provide comfort during uncertainty. When a baby

dies, the loss can be deeply felt by members of the care team. They may carry that grief while continuing to care for other infants and families. Supporting neonatal professionals is part of creating a compassionate, trauma-informed system of care.

“At First Candle, we work to reduce the risk of sleep-related infant death through respectful, evidence-based education while ensuring that no family navigates bereavement alone. We believe compassionate, trauma-informed care must honor each family's lived experience, culture, values, and needs. This requires more than offering information. It requires listening without judgment, acknowledging a baby's life, and remaining present after the immediate crisis has passed.”

At First Candle, we work to reduce the risk of sleep-related infant death through respectful, evidence-based education while ensuring that no family navigates bereavement alone. We believe compassionate, trauma-informed care must honor each family's lived experience, culture, values, and needs. This requires more than offering information. It requires listening without judgment, acknowledging a baby's life, and remaining present after the immediate crisis has passed.

“We invite neonatal professionals and healthcare organizations to help extend that circle of support. First Candle's Grief Line, bereavement resources, and peer support services help parents and family members find connection, guidance, and compassionate support following the death of a baby.”



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"This October, we remember every baby and every family forever changed by loss. Together, we can recognize these observances by continuing the work to save babies' lives and ensuring that every grieving family receives the empathy, care, and community they deserve."

This October, we remember every baby and every family forever changed by loss. Together, we can recognize these observances by continuing the work to save babies' lives and ensuring that every grieving family receives the empathy, care, and community they deserve. Visit firstcandle.org to learn more, access resources, or support this work.

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

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www.firstcandle.org

About First Candle:

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

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

Clara H. Song, MD, FAAP

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

On behalf of your #SONPMexec comm:

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D2 Shetal Shah @NICUBatman

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



Disclosures: No conflicts noted

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SECTION ON NEONATAL-PERINATAL MEDICINE



SONPM Chair Update

with Clara Song, M.D., FAAP



SONPM SHOUT OUT

A big shout-out to everyone who attended the NCE SONPM program, especially those who traveled to be with us, to our awardees, and to everyone who came together to make this a special event for our section.

We love the chance to learn together, celebrate our living legends and have fun!

ICYMI: here are a few high-yield slides my SONPM Chair update

Find your state's commercial payer negotiated rates here:

<https://pediatricsupport.com/analysis-of-codes-affecting-neonatology>



Plans to advocate for Medicaid-Medicare Parity at state level:

AAP + Pediatrix PAC + SONPM
AND
Solventum + SONPM
➔
State Advocacy for Medicaid
Parity

SONPM Members are learning about the AMA RUC and CPT process:

SONPM AMA Scholar Grants

Pilot program: 2 scholars
AMA RUC & CPT meetings

RUC= RVS Update Committee
 RVS= Relative Value Scale




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SONPM is creating bridges with AAP Chapters, where payer advocacy is **STRONG**

2026 SONPM Chapter Grant program

Pilot program: **\$6k** for Coding education/tools

- **Florida** Neonatal Fair Payment Resource Center
- **Georgia** PDHM Reimbursement Toolkit

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SONPM partnered with CHA for DRG education to optimize hospital payments- 2 more webinars to come!

[Watch the recording here](#)

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 SECTION ON NEONATAL-PERINATAL MEDICINE

American Academy of Pediatrics
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SEVERITY HAPPENS: DECODING APR-DRG ASSIGNMENT, SOI, ROM, AND CMI FOR THE NICU

MAY 27, 2027
 12:00 PM PT / 2:00 PM CT / 3:00 PM ET

Join Children's Hospital Association (CHA) experts Mitch Harris, PhD, and Amber Davidson, RHIA, CCS, CCS-P, for this educational webinar. Participants will walk away with a clearer understanding of hospital payment methodologies tailored to the NICU.

Moderated by Clara Song, MD, FAAP, SoNPM Chair

With Q&A Panel Discussion:

- David Kanter, MD, MBA CPC
- Kate Peterson Stanley, MD, FAAP
- Scott Duncan, MD, MHA, FAAP, Chair of Coding Committee



Amber Davidson, RHIA, CCS, CCS-P
 Manager, Health Information Data, Analytics



Mitch Harris, PhD
 Sr. Director, Policy, Research & Analytics

Congratulations to our newly appointed SONPM members on 2 AAP national committees:



**Kate
Stanley**

**AAP Committee on
Coding &
Nomenclature
(COCN)**



**Satyan
Lakshminrusimha**

**AAP Committee
on Child Health
Finance
(COCHF)**

Standby for report on our follow-up discussions with FDA on probiotic use in the NICU:

Asks from AAP

1. Clarification on IND requirement for clinicians who may use probiotics to promote overall intestinal health
2. Formal and expedited FDA evaluation of probiotics for preterm infants

10/2026 by Dr. Clara Song, Chair of SONPM, on behalf of AAP.

Photos were taken by the incredible C3 Committee Co-Chair, Dr. Meghan Chang.

We encourage you to find yourself in our photo gallery.

[Photo Gallery Link](#)



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

Coding Corner

Coding Corner #17: Prolonged Services



Submitted by
[David Kanter, MD, MBA, CPC](#)
 (click here to email Dr. Kanter)
 on behalf of the SONPM
 Coding Committee

Presentation: (Vignette provided by Kate Stanley, MD, University of Michigan)
 One day prior to assumption of oversight responsibilities of the group's NICU census, the attending neonatologist spends 6 hours reviewing medical records. Since the neonatologist has not yet been designated as the attending physician of record at the time of the chart review, can the neonatologist bill a Prolonged Service Without Direct Contact code for each patient whose records were reviewed?

Coding: For patients who are otherwise receiving global daily intensive or critical care, we do not recommend billing prolonged service codes for the time spent in record review. Prolonged Service Without Direct Patient Contact codes 99358 (30-74 min) and +99359 (each additional 30 min) represent time spent on a day other than when a face-to-face visit with the patient or family is occurring. The time spent must relate to a patient visit which has already occurred on a previous day or will occur on a future date. Considering that that extensive record review is one of the scenarios for which these codes were designed, it seems fitting that the neonatologist would be able report these codes prior to assuming NICU service responsibilities on a following day. But the nature of the global daily intensive and critical care codes change the acceptability of billing these codes.

Rationale: While acknowledging that there is no explicit CPT or NCCI guidance preventing the neonatologist from billing these codes in association with intensive and critical global daily codes, CPT stipulates that there is no face-to-face patient visit occurring on the day of the 99358/99359 Prolonged Service Without Direct Contact codes.

To that point, we recognize that the global daily codes which typically dominate NICU patient coding represent continuous face-to-face patient visits through most of the NICU stay—albeit by different physicians of the same specialty of the same group.

From the payer's perspective, same specialty/same group is conceptually equivalent to same physician. In other words, the payer views the NICU stay (for the most part, a series of global daily codes) as continuous midnight-to-midnight face-to-face care by a billing physician—regardless if that same-group/same-specialty physician is different from day to day. For global daily codes, the individual physician's NPI becomes subservient to the group entity. In billing 99358/99359, the neonatologist would be asking the payer and patient to pay for a non-face-to-face prolonged service on a day when the physician's group was otherwise providing an in-person, face-to-face patient service (most commonly, the global daily service).

Because of the absence of CPT or NCCI edits, it's possible that a neonatologist's separate claim for 99358/99359 could get paid in the above scenario for patients who are otherwise receiving daily critical or intensive care, but such billing could eventually be subjected to audit risk and possible recoupment.

5 Reasons to Attend

2027 Workshop on Neonatal-Perinatal Practice Strategies

Join neonatal-perinatal professionals at the [2027 Workshop on Neonatal-Perinatal Practice Strategies](#), February 5-7, 2027, in Tucson, Arizona. Through expert-led, interactive learning, you'll gain practical strategies to strengthen your leadership, enhance team-based care, and improve outcomes for fetuses and newborns.

Build stronger leadership and practice-management skills. Gain practical strategies to lead effectively, resolve conflict, and manage your practice setting with greater confidence.

Improve multidisciplinary team performance. Explore approaches that strengthen communication and collaboration across neonatal-perinatal care settings.

Translate evidence into better clinical care. Learn how to interpret and integrate published research into everyday decisions to advance care for fetuses and newborns.

Learn and connect with the neonatal-perinatal community. Engage with experts and peers to build relationships that support collaboration and career development.

Earn valuable CME and MOC credit. Earn up to 17.75 AMA PRA Category 1 Credits™—including the Neonatal Coding Seminar—and 10 MOC Part 2 points by successfully completing the post-course assessment.



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Registration Fees

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2027 WNPPS will focus on:

- Neonatal coding
- AAP neonatal based advocacy
- Artificial intelligence
- Butterfield lecture by 2026 Apgar Awardee
- COFN update
- Interventions to reduce health disparities
- Neonatal sepsis and the value of non-specific biomarkers
- Platelet transfusion in neonates
- Trisomy 13/18: current perspective
- Therapeutic drift in neonatology

Ready to strengthen your leadership, collaborate more effectively, and advance neonatal-perinatal care? Make your arrangements and register today!

Nominations for AMA Honors

The American Medical Association (AMA) is accepting nominations for its new **AMA Honors** awards program, which recognizes individuals whose work is shaping the future of health care through innovation, leadership, and communication.

The inaugural awards will honor outstanding achievement in three categories:

Tech Innovator Award: Recognizing transformative contributions at the intersection of health care and technology.

Excellence in Communication Award: Celebrating individuals who elevate public understanding of health and medicine through accurate, trusted communication.

Public Health Champion Award: Honoring leadership that advances population health and improves health outcomes.

Nominations, including self-nominations, are open through **November 2, 2026**. Nominees do not need to be AMA members. Each award carries a **\$25,000 prize**, payable to the recipient or a charity of their choice. Recipients will be recognized at the inaugural AMA Honors ceremony in Washington, DC, on February 23, 2027.

Individuals may submit nominations directly through the AMA website: www.ama-assn.org/amaone/ama-honors.

In Case You Missed It...

ABP Announces Petition Process for Two-Year Clinically Focused Subspecialty Training Pathway

[Read Article Here](#)

Join the Global Health SIG

The Global Health SIG would love to hear from you! If you have past experience in global health, interest in global health, or just want to learn more about what we do please fill out the super short survey below. We are also going to use this survey to build sub-groups within our SIG to better engage all of you!

[Click Here for the Survey](#)

Please also consider joining our SIG's listserv by [clicking on the highlighted link](#).

Keep your eye out for upcoming Calls for Nominations for open positions as the

SONPM conference planning group members.

We plan to seek out new planning group members for WNPPS and NeoPREP- stand tuned!

**VOLUNTEERS
NEEDED**

[Email Your Nominations - Click Here!](#)

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Jeff Meyers

jeff_meyers@urmc.rochester.edu



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Recipient announced
December 2026 and
recognized at an
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PRESENTED ANNUALLY IN RECOGNITION OF A NEONATOLOGIST DEMONSTRATING:

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- ✓ Commitment to a culture of excellence
- ✓ Commitment to staff well-being and engagement
- ✓ Meaningful impact on clinical programs, quality & safety
- ✓ Dedication to collaboration and mentorship

Regional or national contributions to neonatal clinical leadership will add to the strength of the nomination

NOMINATION PACKET TO INCLUDE:

- ☐ Primary nomination letter from an SONPM member
- ☐ Second supporting letter
- ☐ Nominee's CV or resume

- CLG membership is not required for the nominee or letter writer; the nominee must hold a clinical leadership role.
- Current CLG Executive Team members are not eligible for consideration.

Clinical leaders play a vital role in fostering excellence across our units. We invite you to take a moment to acknowledge their exceptional leadership by submitting a nomination for the
Excellence in Clinical Leadership Award.

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](#)



Neonatal Advocacy Action Corner

Keep informed on what's shaping neonatal-perinatal policy.

Log on to aap.org to access the following links.

AAP Members Engage in Advocacy Learning at National Conference



At the 2026 AAP National Conference & Exhibition, AAP advocacy leaders held workshops to help members hone their advocacy skills. Left image: AAP Committee on Federal Government Affairs Chair Geoffrey Rosenthal, MD, PhD, FAAP (left), DC AAP Immediate Past President Jessica Weisz, MD, MBA, FAAP (center), and AAP Committee on State Government Affairs Chair Lisa Costello, MD, MPH, FAAP (right) lead a session on advocacy storytelling. Right image: Dr. Costello and Dr. Rosenthal join Nola Ernest, MD, PhD, FAAP (left) and Dena Hubbard, MD, FAAP (second from right) for a session on "Making Advocacy Work for You".

Continue to visit the [AAP Advocacy Snapshot webpage](#) for the latest advocacy updates and opportunities!

[Learn More](#)

AAP Statement in Response to Executive Order on Vaccines

By: Andrew D. Racine, MD, PhD, FAAP, president, American Academy of Pediatrics

[Read the article here.](#)

More than 210 Leading Medical, Health and Patient Advocacy Groups Oppose Recent Executive Order on Childhood Vaccines

A message from the AAP.

[Read the article here.](#)

Visit the AAP.org Advocacy Page

The AAP advocates for a wide range of issues that impact children, families and pediatricians. Learn more about the issues the AAP is monitoring and advocating for (AAP login required).

[Learn More Here](#)

The AAP Round-Up



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

New AAP Resource on Congenital Measles

The AAP is pleased to provide you with three new resources for congenital measles.

[FAQ Sheet](#)

[AAP News Story](#)

[MMR Vaccine Fact Sheet for Families](#)



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, evidencebased guidance and reinforce the importance of timely immunizations during the newborn period and beyond.

[Learn More](#)

Good Reads

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



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

Authored by:

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

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Women in Neonatology - 10 Years in Review

Read the following article on Journal of Perinatology.

Authored by:

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

[Link to Article](#)

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

Read the following article on Journal of Perinatology.

Authored by:

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

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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 Subspecialties

[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

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

Action plans for NICU-specific payment advocacy include:

Action #1

Payment Transparency for Neonatal Codes

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

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

[Link for More Info](#)

Action #2

Coding Education to Ensure Full Payment

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

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

Action #3

RG payments for optimal NICU payment

ICYMI: "Severity Happens: Decoding APRDRG, SOI, ROM, and CMI for the NICU"

[Watch The Recording](#)

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



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**American Academy of Pediatrics
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Itasca, IL, 60143**

The Signs & Symptoms of RSV



Respiratory syncytial virus is a highly contagious virus that can lead to hospitalization for babies.

Common Symptoms



Cough



Runny nose



Difficulty eating



Fever

Symptoms of respiratory distress include:



Short, shallow breathing



Chest retractions



Bluish color of the skin



Wheezing



Nasal flaring

Any of these symptoms indicate a medical emergency.

Know the signs, symptoms and when to seek help for RSV.

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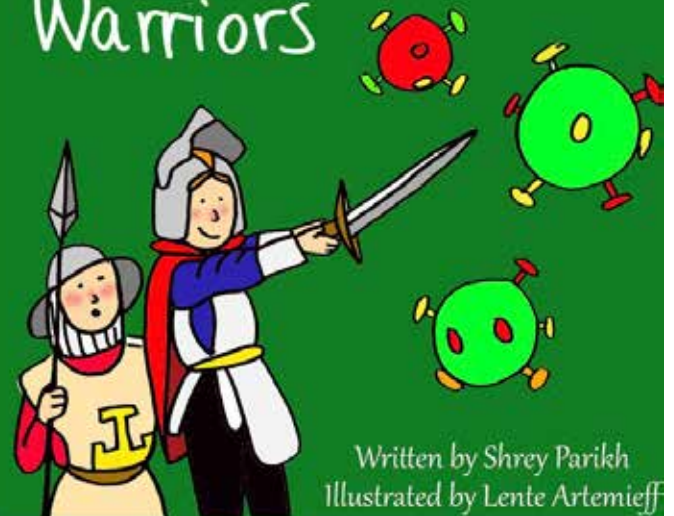
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The Corona Warriors

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Written by Shrey Parikh
Illustrated by Lente Artemieff

Letters to the Editor

Letter to the Editor: “Nuchal Compression”

“Goldsmith and Muraskas provide a useful review of nuchal cords and their potential relationship to neonatal depression. Their central message is clinically important: although nuchal cords are common and usually benign, a tight or multiple-loop nuchal cord may be relevant when a newborn is unexpectedly depressed at birth. Large observational data support the generally reassuring prognosis of most nuchal cords, while also suggesting that tight cords may occasionally have clinical consequences (1,2)”

To the Editor:

Goldsmith and Muraskas provide a useful review of nuchal cords and their potential relationship to neonatal depression. Their central message is clinically important: although nuchal cords are common and usually benign, a tight or multiple-loop nuchal cord may be relevant when a newborn is unexpectedly depressed at birth. Large observational data support the generally reassuring prognosis of most nuchal cords, while also suggesting that tight cords may occasionally have clinical consequences (1,2).

One point deserves particular emphasis: the distinction between association and causation. Tight nuchal cord has been identified as one of several intrapartum factors independently associated with hypoxic-ischemic encephalopathy, but this association does not establish that the cord caused encephalopathy in an individual newborn (3). This distinction matters because nuchal cords are common: a systematic review and meta-analysis estimated their prevalence at about 22% of births. They found no significant association between the presence of any nuchal cord and stillbirth, while noting insufficient data to distinguish the effects of tight and loose cords (2). Thus, a nuchal cord at delivery should be considered an important component of the clinical history rather than, by itself, evidence of causation.

The authors' discussion of cord blood gases is also particularly relevant. Cord gases provide valuable objective information regarding fetal acid-base status, but they must be interpreted

in the context of the clinical presentation and the circumstances of sampling. Paired arterial and venous samples can provide additional information about fetal versus placental physiology, and contemporary reviews emphasize that cord-gas interpretation requires consideration of pH, PCO₂, base deficit, sampling technique, and the timing of the insult (4). In a newborn with significant depression, an apparently reassuring cord gas should therefore not replace assessment of the infant's examination, response to resuscitation, and early postnatal course.

This becomes particularly important when considering therapeutic hypothermia. Current American Academy of Pediatrics guidance recommends determining eligibility through a combination of evidence for a peripartum hypoxic-ischemic event, early biochemical findings, and the presence and severity of neonatal encephalopathy; when an adequate cord gas is unavailable, a blood gas obtained within the first hour may contribute to that assessment (5). A tight or multiple-loop nuchal cord may therefore appropriately increase concern for an acute intrapartum event, but neither the cord itself nor a single laboratory value should determine whether an infant has HIE or qualifies for cooling.

Overall, this review reminds us that the clinical significance of a nuchal cord lies in context. Most nuchal cords require no additional neonatal intervention, and well-appearing infants should not undergo unnecessary testing solely because one was present. When a nuchal cord is accompanied by significant neonatal depression, however, it is reasonable to document the finding carefully, evaluate the infant broadly, and consider cord obstruction among possible contributors before concluding causation or prognosis.

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Sincerely,
Zollie Daily, OMS-3
College of Osteopathic Medicine of the Pacific
Western University of Health Sciences
Email: Zollie.daily@westernu.edu

Dear Zollie Daily,

I wanted to reach out personally to thank you for putting together this thoughtful letter. You identified several strong points in the original manuscript, and I appreciate how you expanded on them while maintaining a balanced, clinically meaningful perspective.

“I especially like your emphasis on the distinction between association and causation, as well as your discussion of how to interpret cord blood gases in the context of the infant’s overall clinical presentation. Your comments about therapeutic hypothermia are also important. These are exactly the kinds of clinical nuances that deserve attention in neonatology, where we must avoid concluding a single finding when the full clinical picture is so much more informative.”

I especially like your emphasis on the distinction between association and causation, as well as your discussion of how to interpret cord blood gases in the context of the infant’s overall clinical presentation. Your comments about therapeutic hypothermia are also important. These are exactly the kinds of clinical nuances that deserve attention in neonatology, where we must avoid concluding a single finding when the full clinical picture is so much more informative.

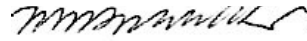
What I particularly appreciate is that you recognize both sides of the issue. Most nuchal cords are benign, but when a newborn presents with significant depression, the finding deserves thoughtful consideration as part of a broader assessment. That balance makes your letter a meaningful contribution, not simply a critique of the original article.

I am always pleased to see medical students engaging with the literature at this level, asking important questions, and contributing constructively to the ongoing discussion of neonatal care. You should be proud of the work you have done here. These are strong points, and I appreciate your willingness to share them with our readers.

Thank you again for your contribution and for your continued

interest in advancing neonatal medicine.

Sincerely,



Mitchell Goldstein, MD, MBA, CML
Editor in Chief

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More than

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of infants hospitalized for RSV
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Letters to the Editor

Letter to the Editor: “Can we Explain the Neurodevelopmental Effects of Medical Trauma?”

“However, the mechanism by which this stress induced by medical trauma may contribute to neuropsychological architecture at such a critical time in development is yet unclear. This article would benefit from further explanation of the hypothesized processes that could clarify the connection between early medical trauma and infant neurodevelopment.”

Dear Editor,

Hilary Thompson's article “When Medicine Becomes the Adverse Experience” makes a compelling argument that medical trauma inflicted on infants in the NICU has lasting effects that shape long-term neurodevelopment. The author effectively establishes the distress medical care causes infants. However, the mechanism by which this stress induced by medical trauma may contribute to neuropsychological architecture at such a critical time in development is yet unclear. This article would benefit from further explanation of the hypothesized processes that could clarify the connection between early medical trauma and infant neurodevelopment.

One example that stands out as needing further explanation is the case at the center of the article. It describes a particular patient who was subjected to intensive care during her first three years of life, and later experienced declining neurocognitive functioning over time. The implication is made that the medical trauma the patient experienced in infancy is the major explanation for the patient's neurocognitive decline later in life. However, several other plausible explanations remain and must be considered. In describing this case, it is stated that the patient experienced limited opportunity for neurologic injury, the main being a brain bleed without identified injury. We must consider that this does not necessarily mean there was no brain injury, but rather that it was not readily identified. Because of this lack of visualized brain injury, the author cites the medical trauma experienced by the infant as an explanation for this continued neurological decline. Consider, however, the effect of adverse environmental conditions such as abuse or neglect. Conditions such as these could exacerbate the effects of an early brain injury, or any underlying neurocognitive deficit. The case description does not address the patient's environmental conditions, so we cannot point to medical

trauma as the most likely cause. There is also the possibility of another frequent phenomenon: a brain injury that occurs and has extensive neurocognitive effects, but which may not be readily visible on imaging in such an acute time frame.

Another aspect of the article which could be strengthened by inclusion of further detail is when medical trauma is discussed as a potential cause of reactive attachment disorder (RAD). The connection between RAD and NICU medical trauma should be made clearer. A mechanism for the influence of medical trauma on infant neurocognitive development should be proposed, one that describes the development of RAD in this context. Providing more detail on how it is believed that medical trauma contributes to RAD or RAD-like behaviors would strengthen the overall argument of the paper and can further illustrate the effect on neurocognitive decline as discussed in the case presented.

This paper presents a unique and powerful argument for consideration of medical trauma in the framework of infant neurodevelopment which should be considered. However, it could be strengthened in several ways. More information should be provided about the case that is discussed, in order to illustrate why medical trauma is the most plausible explanation for the patient's neurocognitive decline, and why other potential factors are less causal. Additionally, a more in-depth description of a proposed mechanism for how medical trauma contributes to these neuropsychological outcomes would lend weight to the overall argument and clarify the case discussed. This could also open avenues for research to investigate proposed mechanisms or evaluate their applicability.

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Stella Rocchi, OMS-3

College of Osteopathic Medicine of the Pacific

Western University of Health Sciences

Dear Stella Rocchi,

Thank you for taking the time to prepare this thoughtful and in-

depth letter in response to “When Medicine Becomes the Adverse Experience.” You raise several important questions regarding the potential relationship between medical trauma in the NICU and subsequent neurodevelopmental outcomes, particularly the mechanisms through which early experiences may influence long-term neuropsychological development.

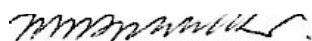
“I appreciate your careful attention to the clinical case and your recognition that other factors, including unrecognized brain injury and adverse environmental experiences, may contribute to the outcomes described. Your comments regarding the proposed relationship between medical trauma and reactive attachment disorder also highlight areas where additional explanation and scientific investigation would be valuable.”

I appreciate your careful attention to the clinical case and your recognition that other factors, including unrecognized brain injury and adverse environmental experiences, may contribute to the outcomes described. Your comments regarding the proposed relationship between medical trauma and reactive attachment disorder also highlight areas where additional explanation and scientific investigation would be valuable.

I hope the author addresses some of these concerns in subsequent manuscripts by further exploring the underlying mechanisms, considering alternative explanations, and identifying opportunities for future research. This remains an important and evolving area of neonatal care. Although our understanding of the effects of early medical experiences continues to develop, there is still much work to be done to clarify the relationships between medical trauma, the developing brain, and long-term neurodevelopmental outcomes.

Thank you again for contributing this thoughtful critique to *Neonatology Today*. Letters like yours advance the discussion, encourage critical examination of emerging concepts, and identify the questions this field must address as it continues to mature.

Sincerely,



Mitchell Goldstein, MD, MBA, CML

Editor in Chief

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Erratum (Neonatology Today September, 2026

We are not aware of an error affecting the September 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

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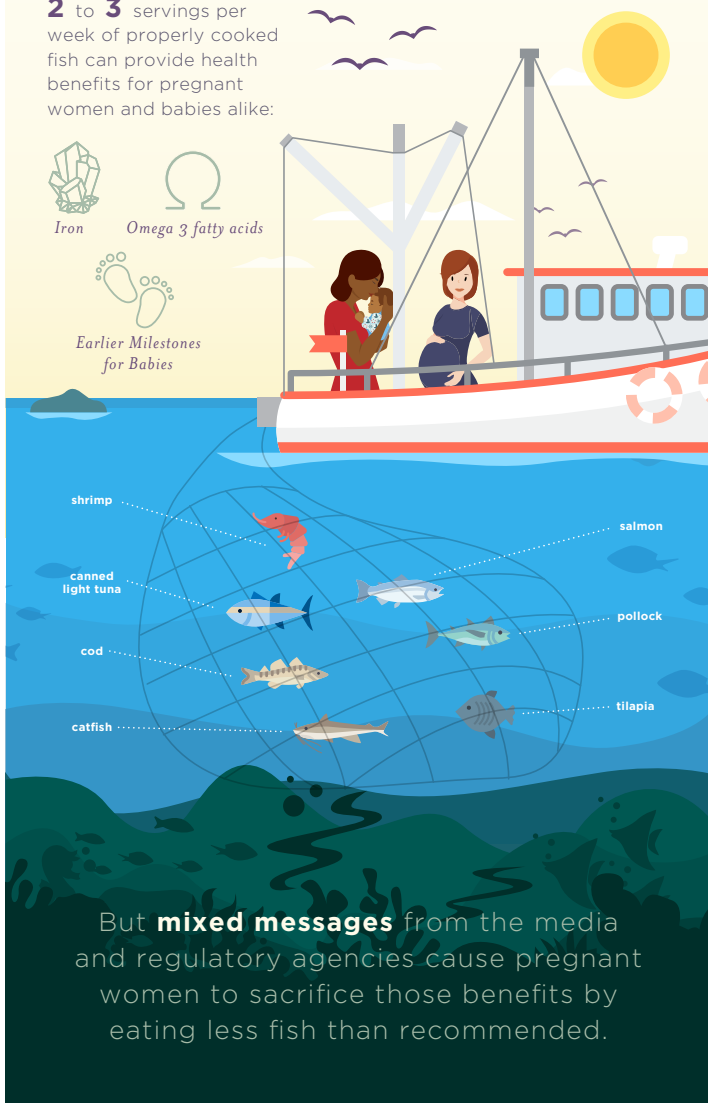
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Gravens by Design: Noise Pollution in the NICU: Why Should We Continue to Accept a Preventable Stressor?

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

“Some medical problems remain unsolved because we do not yet know exactly what to do. Noise in the neonatal intensive care unit is not one of those problems. We have known for decades that excessive noise can be harmful to newborns, particularly premature and critically ill infants.”

Some medical problems remain unsolved because we do not yet know exactly what to do. Noise in the neonatal intensive care unit is not one of those problems. We have known for decades that excessive noise can be harmful to newborns, particularly premature and critically ill infants. We understand that sleep is essential to neurodevelopment, that sudden and sustained auditory stimulation can produce physiologic responses, and that the NICU environment can affect heart rate, oxygenation, behavior, and stress. We also know that excessive noise is stressful for parents and caregivers. Perhaps most frustratingly, we know many ways to reduce it. (1-4)

“After many years of working in NICUs, we have become increasingly frustrated by the collective willingness to accept noise as simply part of intensive care. We would not knowingly expose a fragile premature infant to an unnecessary environmental stressor if we could readily eliminate it.”

After many years of working in NICUs, we have become increasingly frustrated by the collective willingness to accept noise as simply part of intensive care. We would not knowingly expose a fragile premature infant to an unnecessary environmental stressor if we could readily eliminate it. However, excessive sound has become so deeply embedded in the culture and physical design of many NICUs that we often treat it as inevitable. (5, 6) We put up signs, designate “quiet times,” install devices that tell us when noise levels become excessive, and sometimes put ear protection on the infant. These interventions may help at the margins, but they do not address the fundamental problem. The problem is not that we occasionally make too much noise. The problem is that we

have created an environment in which excessive noise is normal. Perhaps it is time to stop calling this simply “noise” and recognize it for what it is: **noise pollution**. (7)

“A NICU is filled with sound. Some of it is unavoidable and clinically meaningful. Much of it is neither. Constant background noise comes from HVAC systems and hospital infrastructure, overhead communications, telephones, conversations, doors, footsteps, carts, equipment moved across hard floors, respiratory equipment, infusion pumps, suction, and other bedside activities.”

The NICU is an unusually noisy environment.

A NICU is filled with sound. Some of it is unavoidable and clinically meaningful. Much of it is neither. Constant background noise comes from HVAC systems and hospital infrastructure, overhead communications, telephones, conversations, doors, footsteps, carts, equipment moved across hard floors, respiratory equipment, infusion pumps, suction, and other bedside activities. Superimposed on all of this are the alarms that have become one of the defining sounds of intensive care. (3, 5, 8)

For a premature infant, these sounds occur during a period of extraordinary neurodevelopmental vulnerability. The infant is trying to establish organized sleep and wake cycles while the brain rapidly matures. Instead of the relatively predictable sensory environment of the womb, the infant may face frequent, unpredictable, and sometimes startling auditory stimuli. A sudden alarm can be accompanied by movement, changes in heart rate, changes in respiratory pattern, or a decline in oxygen saturation. Even when an individual episode is brief, the cumulative environmental burden over days or weeks is difficult to dismiss. (7, 9)

The problem is not limited to the infant. Parents entering a NICU are already experiencing one of the most stressful periods of their lives. They may be frightened about their child’s survival, exhausted from interrupted sleep, worried about other children at home, struggling with transportation or housing, or trying to maintain employment while spending hours at the hospital. For families who live far from the hospital, these burdens can be even greater. They often have very little control over the environment in which they are expected to participate in their baby’s care. They cannot simply close the door when the environment becomes overwhelming, and they cannot remove the baby from the source of the noise. (10)

“Caregivers face a different but related problem. Nurses, respiratory therapists, physicians, and other members of the NICU team must continuously interpret physiologic information, communicate with one another, perform complex procedures, and make decisions while exposed to an enormous amount of auditory information.”

Caregivers face a different but related problem. Nurses, respiratory therapists, physicians, and other members of the NICU team must continuously interpret physiologic information, communicate with one another, perform complex procedures, and make decisions while exposed to an enormous amount of auditory information. The consequences include distraction, stress, and alarm fatigue. We have come to recognize alarm fatigue as a patient-safety concern, but we should also recognize that the constant auditory burden contributes to the overall quality of the clinical environment in which care is delivered. (9, 11-13)

“This discrepancy is difficult to understand. We would not regard a persistent environmental exposure above an accepted clinical standard as something that should be tolerated indefinitely in another area of the hospital. We would measure it, identify the source, establish a corrective plan, and monitor the result. In the NICU, however, we have often approached noise as a behavioral issue rather than an environmental one.”

We have known the standard for decades.

Recommended standards for newborn intensive care design have long recognized the importance of controlling NICU noise, including a recommended maximum average background sound level of approximately 45 dB. (2, 10) However, many NICUs continue to operate well above that level.

This discrepancy is difficult to understand. We would not regard a persistent environmental exposure above an accepted clinical standard as something that should be tolerated indefinitely in another area of the hospital. We would measure it, identify the

source, establish a corrective plan, and monitor the result. In the NICU, however, we have often approached noise as a behavioral issue rather than an environmental one. (3, 7-10) We remind people to speak quietly, ask staff to observe designated quiet periods, and place visual indicators in hallways. These efforts place responsibility on individuals to overcome a physical environment often designed without sufficient attention to acoustics. (5)

That approach is unlikely to succeed consistently because human behavior is only one component of the problem. Asking everyone in a busy clinical environment to remain quiet all day is not a realistic engineering solution. If the HVAC system is noisy, the walls transmit sound, the floors amplify footsteps and equipment, and dozens of monitors generate audible alarms, telling people to whisper will only take us so far.

The better approach is to design the environment so that excessive noise is difficult to produce in the first place.

“This perspective is shaped by working in a NICU deliberately designed and operated to meet the 45 dB standard. That experience informs us that this problem is not primarily one of feasibility. We know how to do it. What has been missing in many settings is the decision to make it a sufficiently important priority.”

We know how to build a quieter NICU.

This perspective is shaped by working in a NICU deliberately designed and operated to meet the 45 dB standard. That experience informs us that this problem is not primarily one of feasibility. We know how to do it. What has been missing in many settings is the decision to make it a sufficiently important priority.

The first opportunity comes during design and construction. For many NICUs, a complete redesign is not an option, and that is the reality. Existing hospitals have physical constraints, financial limitations, competing priorities, and infrastructure that cannot simply be changed. However, institutions building a new NICU or undertaking a major renovation should not miss the opportunity.

Treat acoustic performance as a clinical specification from the start. It should not be something the architectural team considers after the floor plan is complete. It should be part of the discussion involving architects, engineers, hospital administration, clinicians, infection prevention, facilities personnel, and families. The goal should be explicit, measurable, and incorporated into the construction requirements. (3, 5, 6, 10)

Our own experience demonstrates why this matters. Even after we specifically instructed an excellent, experienced architectural firm that achieving an appropriate ambient noise level was important, the mean ambient noise level in an unoccupied room

after the initial stages of construction was above 60 dB. The room was empty. No infants, families, nurses, physicians, ventilators, or infusion pumps contributed to the noise. The building itself was too loud. (3, 5)

The construction team had to go back and address the sources of sound transmission. The team wrapped ventilation ducts with fiberglass batting and added wall insulation. These were not cosmetic modifications. They were necessary corrections to make the physical environment appropriate for the patients who would eventually occupy it. This experience taught us an important lesson: if acoustic performance is not explicitly required and measured during construction, it is easy to build a NICU that never achieves the desired environment. (5)

“Even seemingly mundane design decisions can substantially affect the acoustic environment. Flooring is one example. Hard surfaces are understandably attractive in healthcare environments because they are durable, easy to clean, and familiar. They also transmit and amplify sound. Footsteps, carts, equipment, and objects striking the floor all become part of the background acoustic environment. (3, 5)”

Do not underestimate the floor beneath:

Even seemingly mundane design decisions can substantially affect the acoustic environment. Flooring is one example. Hard surfaces are understandably attractive in healthcare environments because they are durable, easy to clean, and familiar. They also transmit and amplify sound. Footsteps, carts, equipment, and objects striking the floor all become part of the background acoustic environment. (3, 5)

Carpeting in a NICU hallway may initially seem impractical or even inappropriate to some healthcare planners. We made that choice anyway. After nine years, the hallway carpeting has performed well and has meaningfully reduced the noise generated by people and equipment moving through the unit. It is a simple intervention, but it illustrates a broader principle: sometimes environmental design is more effective than behavioral instruction.

We should question assumptions about hospital design when those assumptions conflict with the developmental needs of our patients. A NICU does not have to look and sound like every other part of the hospital. It should be designed around the unique needs of premature and critically ill newborns. (3-5, 7, 10)

The alarm problem is different, and we can address it now:

The second major issue is bedside alarms. Unlike HVAC systems,

walls, and flooring, this problem does not necessarily require new construction. The technology to transmit alarm information away from the bedside and directly to a clinician's personal communication device has been available for years. (8, 11-13)

This paradigm creates a particularly difficult question for NICU leadership. If the nurse responsible for an infant can receive an alarm directly on a personal communication device, why must that same alarm keep sounding loudly at the baby's bedside? The answer should not be “This is how we have always done it.” (4, 9, 11, 13)

An alarm's purpose is to communicate clinically meaningful information to the person who needs to act. It is not to announce that information to everyone within earshot. A nurse may need to know immediately that an infant's oxygen saturation has fallen. The parent sitting quietly beside the baby does not necessarily need to hear a high-intensity alarm. More importantly, the infant whose developing nervous system we are trying so carefully to protect does not benefit from being subjected to the sound. (14)

“This course does not mean eliminating alarms or compromising safety. Quite the opposite. It means improving the NICU's information architecture so the right information reaches the right person at the right time. Clinically important alarms should be prioritized, individualized, and transmitted reliably to the responsible caregiver.”

This course does not mean eliminating alarms or compromising safety. Quite the opposite. It means improving the NICU's information architecture so the right information reaches the right person at the right time. Clinically important alarms should be prioritized, individualized, and transmitted reliably to the responsible caregiver. Less meaningful or artifact-related alarms should be addressed through better monitoring practices and appropriate parameter management. (6, 7, 9)

The technology exists. Some hospitals already use similar communication systems. Nevertheless, many NICUs continue to allow alarms to sound repeatedly at the bedside. That is difficult to justify when we know the potential consequences of excessive noise and have mechanisms to reduce it. (4, 8)

We should not make the baby adapt to our environment:

One of the most revealing responses to NICU noise has been the development and use of infant ear protection. Protective devices may help in some circumstances, but we should be cautious about letting them become the primary solution. There is something fundamentally backward about creating an excessively noisy environment and then asking the patient to wear protection against the environment we created. The infant should not have to adapt to a poorly designed NICU. We should adapt the NICU

to the infant.

This adaptation is consistent with the broader philosophy of developmental care. We have learned to think carefully about light, touch, positioning, sleep, skin-to-skin contact, human milk, parental presence, and other environmental influences. Sound belongs in that same conversation. Consider the acoustic environment part of the developmental environment, not merely an unavoidable byproduct of intensive care. (3)

“Reducing noise should not mean eliminating sound. In fact, one reason this issue matters so much is that the NICU should contain more meaningful human sound and less meaningless mechanical sound. A parent’s voice is not pollution.”

Quiet does not mean silent:

Reducing noise should not mean eliminating sound. In fact, one reason this issue matters so much is that the NICU should contain more meaningful human sound and less meaningless mechanical sound. A parent’s voice is not pollution. A mother singing to her baby is not something we should try to eliminate. (15) A father reading to his infant, a nurse reassuring a family, or a clinician explaining what is happening can all be important components of a nurturing environment.

The problem is that these sounds must compete with the unit’s background noise. When the environment is loud, parents and caregivers naturally speak louder. When conversations become louder, everyone else must speak louder to be heard. The result is a self-perpetuating cycle in which noise generates more noise.

Reducing the baseline acoustic burden changes that equation. A quieter environment makes the sounds we want babies to hear more prominent without requiring anyone to raise their voice. It creates space for human interaction. (3, 5, 12)

“That distinction matters especially for families who face barriers to being physically present. When parents can only spend limited periods at the bedside because of distance, work, transportation, childcare responsibilities, or other disparities, the quality of the time they do have with their infant becomes even more important.”

That distinction matters especially for families who face barriers to being physically present. When parents can only spend limited periods at the bedside because of distance, work, transportation, childcare responsibilities, or other disparities, the quality of the time they do have with their infant becomes even more important. We should create an environment that supports those moments of talking, reading, singing, holding, and bonding rather than overwhelming them with the mechanical sounds of intensive care. (15)

“Every NICU can begin addressing this problem without waiting for a new building. The first step is measurement. We should know the actual acoustic environment of our units rather than relying on impressions. Measure noise in patient rooms, hallways, and other relevant areas at different times of day and under different clinical conditions.”

What can we do today?

Every NICU can begin addressing this problem without waiting for a new building. The first step is measurement. We should know the actual acoustic environment of our units rather than relying on impressions. Measure noise in patient rooms, hallways, and other relevant areas at different times of day and under different clinical conditions. We should identify the major sources rather than simply documenting that the unit is noisy. (5, 9)

The next step should be a comprehensive alarm assessment. NICUs should determine how many alarms occur, how many require immediate intervention, how many are generated by artifact or transient conditions, how many are repeatedly triggered, and who actually needs to receive each alarm. Alarm parameters should be individualized when clinically appropriate, and systems that transmit meaningful alarms directly to the responsible clinician should be evaluated and implemented. (3, 4, 8, 11-13)

Most importantly, hospitals should establish measurable goals. “We are trying to be quieter” is not an adequate quality-improvement strategy. We should define an acoustic target, determine the gap between current performance and that target, identify interventions, and measure whether those interventions work. This diligence should become part of the NICU’s quality and safety agenda.

Leadership must decide this matters:

Ultimately, noise pollution in the NICU is a leadership problem. Hospital leaders routinely invest substantially in technologies designed to improve neonatal outcomes. We purchase increasingly sophisticated ventilators, monitors, imaging systems, infusion pumps, and laboratory equipment. We invest in electronic systems that generate enormous quantities of physiologic information. We should be equally thoughtful about the environment in which we deliver that information. (1, 6, 10, 14)

If a hospital already has the infrastructure to transmit alarms to clinicians in another part of the institution, why should the NICU remain dependent on audible bedside alarms? If we can measure oxygen saturation to a fraction of a percentage point, why can we not measure the acoustic environment in which the infant spends weeks or months? If we can build a ventilator capable of delivering extraordinarily precise respiratory support, why are we still moving equipment across hard floors without considering the sound it produces? These are not questions about whether we have the technology. They are questions about priorities. (1, 4)

“One of the greatest barriers to change is familiarity. When everyone working in the NICU has become accustomed to alarms, carts, conversations, and mechanical noise, the environment begins to feel normal. However, normal does not necessarily mean appropriate.”

We need to stop accepting “normal:”

One of the greatest barriers to change is familiarity. When everyone working in the NICU has become accustomed to alarms, carts, conversations, and mechanical noise, the environment begins to feel normal. However, normal does not necessarily mean appropriate.

An infant surviving a noisy NICU does not prove the noise was harmless. The fact that staff have learned to work in the environment does not mean that it is optimal. The fact that parents have tolerated it does not mean that they should have to. Medicine has repeatedly improved when we have challenged things that were accepted simply because they were customary. Noise in the NICU deserves the same scrutiny.

“The NICU of the future should not simply look different from the NICU of the past. It should sound different. It should be an environment where the background acoustic level is deliberately controlled, unnecessary sounds are eliminated, clinically meaningful alarms are communicated intelligently, and human voices become a more prominent part of the infant’s experience. This future is not a call for silence. It is a call for intentionality. (4)”

The NICU of the future should sound different.

The NICU of the future should not simply look different from the NICU of the past. It should sound different. It should be an environment where the background acoustic level is deliberately controlled, unnecessary sounds are eliminated, clinically meaningful alarms are communicated intelligently, and human voices become a more prominent part of the infant’s experience. This future is not a call for silence. It is a call for intentionality. (4)

“We should be able to walk into a NICU and distinguish between necessary sounds and sounds that are simply the consequence of how we built and operate the unit. We should be able to identify which sounds are directed toward clinical action and which sounds are broadcast to everyone for no particular reason.”

We should be able to walk into a NICU and distinguish between necessary sounds and sounds that are simply the consequence of how we built and operate the unit. We should be able to identify which sounds are directed toward clinical action and which sounds are broadcast to everyone for no particular reason. We should be able to tell whether the physical environment protects the infant’s sleep or continuously interrupts it. Most importantly, we should stop accepting the premise that excessive noise is inevitable in intensive care: It is not. (7, 9, 12)

We know the problem. We know the standards. We know many of the sources. We know how to design quieter environments. We have technology that can move alarms away from the bedside. We can measure whether our interventions work. Now we need the will to make noise reduction a clinical priority.

“For NICUs being designed or substantially renovated, include acoustic performance in the earliest planning discussions and incorporate it into the construction specifications. The recommended standards for newborn intensive care design should not be treated as aspirational language.”

For NICUs being designed or substantially renovated, include acoustic performance in the earliest planning discussions and incorporate it into the construction specifications. The recommended standards for newborn intensive care design

should not be treated as aspirational language. They should be the project's starting point, with actual acoustic performance measured before the first infant arrives. (1, 4)

For existing NICUs, we should not wait for a renovation. We can start by measuring noise, addressing the biggest sources, redesigning alarm management, and moving as many unnecessary audible alarms away from the bedside as possible.

After all these years, it is difficult to accept that we are still having this conversation. We have the knowledge. We have the standards. We have the technology. What we have not yet had is the collective determination to say that this matters enough to fix. It is time to make that decision. Noise pollution is an environmental hazard in the NICU. We should stop treating it as an inevitable feature of neonatal intensive care and start treating it as a problem we are responsible for solving. (1, 3, 4, 8, 10, 12, 14)

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New Moms Need Access to Screening & Treatment for POSTPARTUM DEPRESSION



**1 IN 7 MOMS FACE
POSTPARTUM DEPRESSION,**
experiencing



Uncontrollable
crying



Disrupted sleep



Anxiety



Shifts in
eating patterns



Thoughts of
harming
self or baby



Withdrawal from
friends and family



15%

Yet only 15% receive treatment¹

**UNTREATED
POSTPARTUM
DEPRESSION
CAN IMPACT:**

Baby's sleeping,
eating, and behavior
as he or she grows²

Mother's health

Ability to care for
a baby and siblings

TO HELP MOTHERS FACING POSTPARTUM DEPRESSION



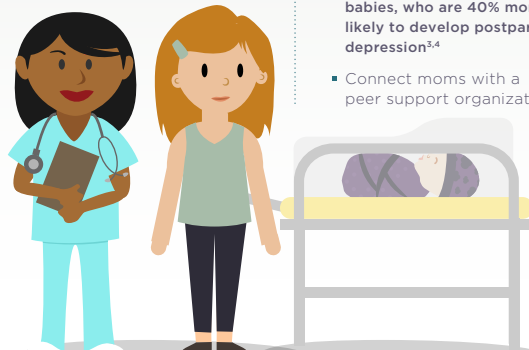
POLICYMAKERS CAN:

- Fund Screening Efforts
- Protect Access to Treatment



HOSPITALS CAN:

- Train health care professionals to provide psychosocial support to families... especially those with preterm babies, who are 40% more likely to develop postpartum depression^{3,4}
- Connect moms with a peer support organization



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

¹ American Psychological Association.
Available at: <http://www.apa.org/pubs/news/press/releases/postpartum-depression.aspx>

² National Institute of Mental Health.
Available at: <http://www.nimh.nih.gov/health/publications/postpartum-depression-facts/index.shtml>

³ Journal of Perinatology 2015;35:525-530. doi:10.1097/01.jp.0000000000.00000

⁴ Prevalence and risk factors for postpartum depression among women with preterm and low birth-weight infants: a systematic review. Vigod SN, Villages L, Dennis CL, Ross LE. BJOG. 2010 Apr; 117(5):540-50.



Perinatal Advisory Council:
Leadership, Advocacy and Consultation

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

Leadership

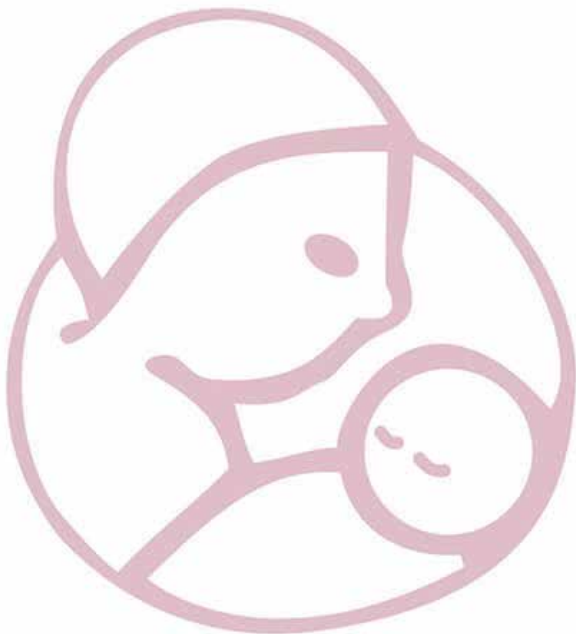
Providing guidance to healthcare professionals, hospitals and healthcare systems, stimulating higher levels of excellence and improving outcomes for mothers and babies.

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.



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

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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.





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

In Loving Memory

August 9, 1996 - April 3, 2010



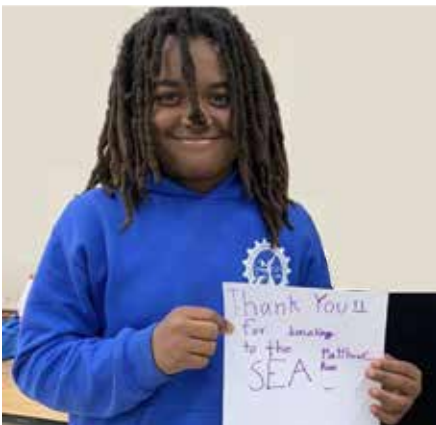
Each year, the Emily Shane Foundation SEA(Successful Educational Achievement) Program provides academic and mentoring support to over 100 disadvantaged middle school students who risk failure and have no other recourse. We have served over 700 children across Los Angeles since our inception in the spring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

Make a Difference in the Life of a Student in Need Today!

Please visit 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: NCfIH Quarterly Update: Advancing Infant Health Through Advocacy, Collaboration, and Access

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 Disenza, MA	PremieWorld
Taryn Edwards, MSN, CRNP, NNP-BC	National Association of Neonatal Nurses
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Camille Torre, DNP, CCRN-N	The Council of International Neonatal Nurses

The National Coalition for Infant Health (NCfIH) continues to advance policies and initiatives intended to improve the health of infants and their families. At our October 1, 2026, quarterly Steering Committee meeting, members reviewed ongoing programming, legislative priorities, educational initiatives, collaboration opportunities, and the issues that should receive the greatest attention in 2027. One message was clear: improving infant health requires more than identifying effective interventions. We must also address the policies, payment structures, educational gaps, and practical barriers that determine whether families can benefit.

“One message was clear: improving infant health requires more than identifying effective interventions. We must also address the policies, payment structures, educational gaps, and practical barriers that determine whether families can benefit.”

NCfIH brings together organizations and individuals committed to improving infant outcomes. Our work encompasses nutrition, maternal and paternal health, immunization, neonatal screening, and the broader policies that influence access to appropriate care. The October meeting provided an opportunity to assess progress, welcome new leadership to the coalition, and begin shaping the next phase of our advocacy.

“We were pleased to welcome Dr. Barbara Snapp, DNP, APRN, NNP-BC, President of the National Association of Neonatal Nurses (NANN), to the Steering Committee. Dr. Snapp is a neonatal nurse practitioner with the Children’s National Hospital NICU team in Washington, DC, and an Assistant Professor of Pediatrics at the George Washington University School of Medicine and Health Sciences.”



Welcoming new leadership and strengthening collaboration:

We were pleased to welcome Dr. Barbara Snapp, DNP, APRN, NNP-BC, President of the National Association of Neonatal Nurses (NANN), to the Steering Committee. Dr. Snapp is a neonatal nurse practitioner with the Children's National Hospital NICU team in Washington, DC, and an Assistant Professor of Pediatrics at the George Washington University School of Medicine and Health Sciences. Her career has included extensive work in neonatal resuscitation, professional leadership, publication, and mentorship.

“Our existing partnerships remain central to this approach. NCfIH continues to work with organizations including NANN, the Council of International Neonatal Nurses (COINN), the NICU Parent Network, Hand to Hold, Expecting Health, and the American Academy of Pediatrics.”

Her participation reflects the importance of bringing together clinicians, professional organizations, researchers, and family-focused organizations to address challenges affecting newborns. Neonatal health policy is most effective when the people delivering care, supporting families, conducting research, and shaping professional standards can work toward shared goals.

“Nutrition remains a major focus of NCfIH’s policy and educational work. The coalition is monitoring several legislative initiatives addressing the needs of mothers, infants, and children, including the Supporting Healthy Mothers and Infants Act of 2025 (H.R. 3743), which would expand the Special Supplemental Nutrition Program for Women, Infants, and Children (WIC) to include support for women with substance use disorder and infants and children with neonatal abstinence syndrome.”

Our existing partnerships remain central to this approach. NCfIH continues to work with organizations including NANN, the Council of International Neonatal Nurses (COINN), the NICU Parent Network, Hand to Hold, Expecting Health, and the American Academy of Pediatrics. These relationships provide opportunities to amplify important messages, develop educational resources, and connect advocacy efforts with the experiences of clinicians

and families.

Nutrition: Protecting access, safety, and informed decision-making:

Nutrition remains a major focus of NCfIH’s policy and educational work. The coalition is monitoring several legislative initiatives addressing the needs of mothers, infants, and children, including the Supporting Healthy Mothers and Infants Act of 2025 (H.R. 3743), which would expand the Special Supplemental Nutrition Program for Women, Infants, and Children (WIC) to include support for women with substance use disorder and infants and children with neonatal abstinence syndrome.

This legislation addresses an important intersection between maternal health, substance use, nutrition, and the needs of infants affected by prenatal exposure. Effective policy must recognize that infant health cannot be separated from the mother’s health and the family’s circumstances.

“NCfIH is also supporting the Developing Oversight for Nutrition through the Official Regulation of Milk Act (DONOR Milk Act) (H.R. 8964), which would increase federal oversight of pasteurized donor human milk, including FDA inspections and safety requirements.”

NCfIH is also supporting the Developing Oversight for Nutrition through the Official Regulation of Milk Act (DONOR Milk Act) (H.R. 8964), which would increase federal oversight of pasteurized donor human milk, including FDA inspections and safety requirements. Ensuring that families and clinicians have access to appropriately screened and processed donor human milk remains an important consideration in the care of medically vulnerable infants.

A related initiative involves informed consent for nutrition in the neonatal intensive care unit (NICU). In partnership with the NICU Parent Network, NCfIH is exploring a project that could include a white paper, a webinar, and dissemination of educational materials. Funding remains pending, and the project details are still being developed.

This work recognizes that decisions about infant nutrition can be complex, particularly when a newborn is premature or medically fragile. Parents need understandable information about available nutritional options, their potential benefits and risks, and the rationale for recommendations made by the clinical team. Supporting informed decision-making is an important part of family-centered care.

Maternal health, prematurity, and prevention:

Maternal health remains closely connected to the coalition’s infant health agenda. The Steering Committee reviewed the Prematurity Research Expansion and Education for Mothers who deliver Infants Early (PREEMIE) Act of 2025 (H.R. 1197/S. 1562), which would reauthorize CDC epidemiological studies, data tracking, and prevention efforts related to preterm birth through fiscal year 2029.

Prematurity remains a major contributor to infant mortality and long-term morbidity. Sustained attention to research, surveillance, and prevention is essential to improving outcomes and identifying opportunities to reduce the burden on families and health systems.

“The committee also reviewed the Preventing Maternal Deaths Reauthorization Act (H.R. 1909/S. 2621). This legislation would reauthorize support for state-based maternal mortality review committees and direct the Department of Health and Human Services to disseminate maternal mortality prevention best practices to hospitals, professional societies, and perinatal quality collaboratives.”

The committee also reviewed the Preventing Maternal Deaths Reauthorization Act (H.R. 1909/S. 2621). This legislation would reauthorize support for state-based maternal mortality review committees and direct the Department of Health and Human Services to disseminate maternal mortality prevention best practices to hospitals, professional societies, and perinatal quality collaboratives.

These initiatives reinforce an essential principle: improving outcomes for newborns requires attention to the systems of care that support mothers before, during, and after pregnancy. Maternal mortality, prematurity, neonatal complications, and family well-being are interconnected challenges that benefit from coordinated prevention and policy efforts.

NCfIH is also exploring potential collaboration with Talkspace on maternal and paternal health. As this work develops, mental health remains a potential opportunity for the coalition to connect family needs with broader health policy and educational efforts.

Vaccine access: Turning recommendations into real-world protection:

Vaccine access and immunization policy remain among NCfIH's most active areas of work. The coalition continues to monitor the Advisory Committee on Immunization Practices (ACIP) and has supported professional statements affirming established immunization recommendations.

In 2026, NCfIH signed a statement supporting the American Academy of Pediatrics' immunization schedule, which more than 230 signatories published. The coalition also signed a statement supporting the American College of Obstetricians and Gynecologists' maternal immunization schedule.

These actions reflect the importance of clear, evidence-informed recommendations and collaboration among professional organizations. However, issuing recommendations is only part of the task. Families must also be able to obtain recommended preventive interventions, and clinicians and hospitals need workable mechanisms to provide them.

RSV prevention and the challenge of hospital payment:

Respiratory syncytial virus (RSV) prevention illustrates the gap between recommending an intervention and ensuring it is available when it is most useful.

NCfIH has advocated for separate payment for long-acting RSV monoclonal antibodies administered to eligible infants before discharge from the birth hospitalization. Through an effort led by the Association of Immunization Managers (AIM), advocates asked America's Health Insurance Plans (AHIP) to encourage commercial insurers to accept line-item billing and provide appropriate payment to procure and administer these products.

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The rationale is practical. Administering an indicated RSV monoclonal antibody before a newborn leaves the hospital can help ensure that the infant receives protection before encountering the virus in the community. However, if a hospital cannot obtain reimbursement for the product and its administration, the intervention may be unavailable to commercially insured infants in that setting.

The coalition's materials describe a particularly concerning consequence: some birthing hospitals, including rural and critical-access facilities, may be unable to provide the product to commercially insured newborns without appropriate compensation. Rather than create differences in access between commercially insured infants and those eligible for the Vaccines for Children (VFC) program, a hospital may decide not to provide the product to any infant.

Implementation and reimbursement deserve a place alongside clinical evidence in infant health advocacy. Professional organizations can recommend an intervention and support it with clinical evidence, yet it can remain inaccessible if financing and delivery systems do not support its use. Continued engagement with payers and other stakeholders will be important to addressing these barriers.

NCfIH is also developing additional RSV communication materials, including social media graphics, general-awareness messaging, targeted communications, and provider education. The coalition is examining how to communicate about extended RSV seasons, flexibility in guidance, and maternal vaccination. These efforts aim to help clinicians and families navigate preventive options with

clear, useful information.

Vaccine communication and education:

The coalition's vaccine messaging work extends beyond RSV. Planned and ongoing activities include conversation starters, provider education, caregiver videos, and communications intended to reach populations that may be hesitant about vaccination.

NCfIH has used professional meetings, including NANN's annual conference, to engage clinicians and expand the reach of its resources. Participation at NANN's 42nd Annual Conference also helped establish approximately 35 new, meaningful contacts for future engagement.

“Building trust requires more than repeating recommendations. Effective communication should address questions, acknowledge concerns, and provide information that clinicians and caregivers can use in real conversations.”

Building trust requires more than repeating recommendations. Effective communication should address questions, acknowledge concerns, and provide information that clinicians and caregivers can use in real conversations. Continued collaboration with professional organizations offers a way to extend these efforts to the people making decisions for newborns and their families.

Screening and prevention: CMV, vitamin K, and vision

The October meeting also reviewed several additional areas in which policy, prevention, and early detection may improve infant and child health.

The Stop CMV Act of 2025 (H.R. 5435/S. 2842) is intended to establish nationwide newborn screening for congenital cytomegalovirus (cCMV). Early identification can create opportunities for appropriate evaluation and intervention. The coalition continues to monitor this legislation as part of its broader interest in newborn screening and prevention.

Increasing rates of Vitamin K refusal were another topic of discussion and concern among steering committee members. The coalition plans to amplify work involving researchers at Children's Hospital of Philadelphia (CHOP) that has recently been published on the topic. Further collaboration could help connect emerging research with the clinicians and organizations best positioned to use it.

The Early Detection of Vision Impairments for Children Act (H.R. 2527) would support children's vision and eye health through grants to states, territories, and Tribal organizations, along with technical assistance. The proposal reflects the coalition's interest in preventing and early identifying conditions that can affect children's health and development.

Measuring our reach and expanding our educational impact:

Advocacy is most effective when the information reaches the people who can use it. NCfIH continues to expand its educational

and social media presence to support communication about infant health priorities.

“Year-to-date social media statistics presented at the meeting included 11,226 impressions, 1,241 link clicks, 178 published posts, and 456 video views. These figures provide a snapshot of the coalition's communication activity and the opportunities available to share resources with clinicians, families, and other stakeholders.”

Year-to-date social media statistics presented at the meeting included 11,226 impressions, 1,241 link clicks, 178 published posts, and 456 video views. These figures provide a snapshot of the coalition's communication activity and the opportunities available to share resources with clinicians, families, and other stakeholders.

The committee also discussed continuing to develop RSV-specific social graphics and targeted communications. By making materials easier to understand and share, NCfIH seeks to support conversations that connect policy and clinical recommendations with practical decisions at the bedside and in the community.

Readers can follow the coalition's work through its website, infanthealth.org, and its [LinkedIn page](#).

Looking ahead: Setting priorities for 2027:

An important part of the October meeting was the beginning of a discussion about the coalition's priorities for 2027. Potential areas included a policy summit, nutrition, neonatal and newborn screening, equity, maternal health, skincare, mental health, and workforce issues.

The breadth of these topics reflects the many factors that influence infant health. It also presents a strategic challenge: a coalition can identify numerous worthy priorities, but its impact depends on directing resources and partnerships toward work where meaningful progress is achievable.

The Steering Committee was asked a particularly important question: **If NCfIH could make meaningful progress on only one issue in 2027, what should it be, and why?**

This question encourages members to move beyond identifying problems and consider where the coalition can contribute most. Which issue is most urgent? Which populations are not adequately represented in current discussions? Where are funding opportunities available? Which organizations should be brought into the conversation? Furthermore, where can collaboration produce results that individual organizations might not achieve independently?

These questions will help guide further discussion as the coalition develops its plans for the coming year. The objective is not simply to maintain a long list of concerns, but to identify opportunities for coordinated action, measurable progress, and sustainable impact.

Continuing the work together:

NCfIH's quarterly meeting underscored the value of bringing together professional organizations, clinicians, researchers, and family-focused groups around shared concerns. From human milk access and informed consent to maternal health, RSV prevention, vaccine communication, and newborn screening, the coalition's work reflects the reality that infant health depends on both sound clinical practice and the systems that make that practice possible.

Our next Steering Committee meeting is scheduled for February 4, 2027, at 10:00 AM. Eastern, followed by an in-person meeting planned for April 29–30, 2027. These meetings will provide additional opportunities to refine priorities, identify partners and funders, and translate discussion into coordinated action.

Improving infant health is ongoing, and progress depends on sustained engagement. We are grateful to our participating organizations, Steering Committee members, and collaborators for their continued commitment. By working together, we can help ensure that the needs of infants and their families remain central to the policies, resources, and decisions that shape their care.

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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.

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

Preterm infants are:

- 2x** more likely to have developmental delays
- 5x** more likely to have learning challenges

1 in 3 preterm infants will require support services at school

Early intervention can help preterm infants:

- Enhance language and communication skills
- Build more effective learning techniques
- Process social and emotional situations
- Address physical challenges
- Prevent mild difficulties from developing into major problems

Early diagnosis could qualify babies for their state's **early intervention services**...
...but many parents are **unaware**.

NICU staff, nurses, pediatricians and social workers should talk with NICU families about the challenges their baby may face.

Awareness, referral & timely enrollment in early intervention programs can help **infants thrive** and grow.

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

Visit CDC.gov to find contact information for your state's early intervention program.

Fragile Infant Forums for Implementation of IFCDC Standards: The Upcoming Second Edition of the Standards, Competencies, and Best Practices for Babies and Families in Intensive Care

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



Background

The Consensus Panel on the Infant and Family Centered Developmental Care (IFCDC) Standards published the first edition in 2000. (1–4) and made available for ready access for interprofessional providers on the web (<https://nicudesign.nd.edu/nicu-care-standards/>). The standards have been widely promoted through workshops, presentations at national meetings, and especially at the annual Gravens meetings. Since they became available in 2000, more than 70 articles have been published to provide guidance and examples for application to professional practice in intensive care units.

“The Consensus Panel on the Infant and Family Centered Developmental Care (IFCDC) Standards published the first edition in 2000 and made available for ready access for interprofessional providers on the web (<https://nicudesign.nd.edu/nicu-care-standards/>).”

Recognizing that the IFCDC field is growing exponentially and with significantly increased research available, the panel realized that it was necessary to work towards a second edition. With that in mind, over the last 3 years the panel has been updating and revising the initial standards with the goals of

- Assuring updated evidence for practice
- Providing appropriate scaling of current evidence
- Streamlining standards to assure acceptance and clarity
- Adhering to the principles of the concept model (see insert #1)
- Integrating concepts assuring that parents are partners in the care of their baby
- Adding usable metric recommendations to assist with appropriate implementation

One of the primary efforts of the second edition is to stress the importance of not separating parents from their baby, including both rationale and strategies for implementation. (5–7)

“One of the primary efforts of the second edition is to stress the importance of not separating parents from their baby, including both rationale and strategies for implementation.”

Insert #1

Principle 1: Systems' thinking

Principle 2: Infant Mental Health Focus

Principle 3: Individualized Care of the baby and family with an emphasis on the baby and parents as competent interactors

Principle 4: Parents as Essential Partners in Care with the interprofessional team and the primary caregiver in practice

Principle 5: Supportive Environments that diminish adverse responses from the baby and increase the opportunity for intimate interactions with parents

Principle 6: Neuroprotection of the Developing Brain

The process

Revising the initial IFCDC standards and producing the second edition included monthly panel meetings to determine how the principles and aforementioned goals would be addressed by each practice section. (See Table for practice areas addressed) Skillfully led by Dr. Carol Jaeger, the practice section authors were encouraged to review, evaluate, and level (grade) each standard in their section, and to provide rationale for their recommended standards. (8) Additionally, and based on feedback regarding

implementation of the initial standards, they were encouraged to streamline and combine standards to provide more clarity and usefulness (see Table for number of standards in each practice area). Competencies were further revised to provide objective approaches to care and metrics for which to measure application of each standard. Further expansion of the standards is based on accumulated evidence, including the addition of Caregiving Patterns in the Position and Touch practice section.

The interprofessional authors in each practice section worked

Table. Practice areas addressed and interprofessional authors of each section.

Evidence-Based Practices	Authors
Practice 1: Systems thinking in complex adaptive systems (6 standards)	Carole Kenner, PhD, RN, FAAN, FNAP, ANEF, IDFCOINN Carol B. Jaeger, DNP, RN, NNP-BC Joan Hebert Cook, MSW, ACSW, LCSW Aisha Q. Ealey, DNP, APRN, ACCNS-N
Practice 2: Positioning, touch, and caregiving patterns for the newborn (3 standards)	Carole Kenner, PhD, RN, FAAN, FNAP, ANEF, IDFCOINN Carol B. Jaeger, DNP, RN, NNP-BC Joan Hebert Cook, MSW, ACSW, LCSW Aisha Q. Ealey, DNP, APRN, ACCNS-N
Practice 3: Sleep and arousal interventions for the newborn (2 standards)	Rosemarie Bigsby, ScD, OTR/L, FAOTA Amy Salisbury, PhD, APRN, FAAN Kathleen Kolberg, PhD Christie Lawrence, DNP, RNC-NIC, APN/CNS, CNL, CHSE Tiara Bolden, BSN, RNC-NIC, TIP-C
Practice 4: Skin-to-skin contact with intimate family members (4 standards)	Carol B. Jaeger, DNP, RN, NNP-BC Carole Kenner, PhD, RN, FAAN, FNAP, ANEF, IDFCOINN Joy V. Browne, PhD, PCNS-BC, IMH-E
Practice 5: Reducing and managing pain and stress in newborns and families (2 standards)	Michael T. Hynan, PhD Jean Powlesland, MS, RN, C-NNIC Alice K. Gong, MD, FAAP Carol McNair, PhD, RN (EC), NNP-BC, NP-Peds Robert Cicco, MD, FAAP Malathi Balasundaram, MD, FAAP Carol B. Jaeger, DNP, RN, NNP-BC
Practice 6: Management of feeding, eating, and nutrition delivery (4 standards)	Erin Ross, PhD, CCC-SLP, IBCLC Kelly McGlothen-Bell, PhD, RN, IBCLC, FAWHONN, FAAN Joan C. Arvedson, PhD, CCC-SLP, BCS-S, ASHA Honors & Fellow Jacqueline McGrath, PhD, RN, FAAN Debra Paul, OTR/L Paige Church, MD, FAAP

collaboratively to identify, review, level (suggest a grade), and provide rationale for articles from the systematic literature review from 2019 to present. The panel reviewed, considered, and integrated over 1000 articles into the new standards, competencies, and best practice recommendations, as appropriate. Additionally, each practice section suggested metrics to guide practice evaluation of implementation.

“The interprofessional authors in each practice section worked collaboratively to identify, review, level (suggest a grade), and provide rationale for articles from the systematic literature review from 2019 to present. The panel reviewed, considered, and integrated over 1000 articles into the new standards, competencies, and best practice recommendations, as appropriate.”

Evaluation

The interprofessional panel presented the practice standards, competencies, and best practice recommendations from each section for a consensus vote, and the panel enthusiastically approved them. A panel of interprofessional national and international consultants is further reviewing the document, and this review is expected to be completed in November of this year.

“The Second Edition of the IFCDC Standards, Competencies and Best Practice Recommendations is expected to be complete by the end of the year and be widely available at the following website. <https://nicudesign.nd.edu/nicu-care-standards/>.”

Next steps

The Second Edition of the IFCDC Standards, Competencies and Best Practice Recommendations is expected to be complete by the end of the year and be widely available at the following website. <https://nicudesign.nd.edu/nicu-care-standards/>. An executive summary will be published, and individual articles addressing each practice section will also be published.

The interprofessional panel of experts will guide future IFCDC clinical practice for babies and their families in intensive care. Without their commitment to accumulating, evaluating, and providing rationale for the standards, there would be little guidance for evidence-based practice and best care for babies and families. They deserve kudos for their professional commitment to both the

process and the results of the upcoming second edition.

The Second Edition of the IFCDC Standards, Competencies and Best Practice Recommendations will be a significant resource for professionals who provide evidence-based care for babies and families in intensive care. We hope that up-to-date evidence, along with streamlined standards and metrics, will enhance usability and implementation. Any comments, suggestions, and/or recommendations are welcome and can be sent to Drs. Browne and Jaeger.

“The Second Edition of the IFCDC Standards, Competencies and Best Practice Recommendations will be a significant resource for professionals who provide evidence-based care for babies and families in intensive care. We hope that up-to-date evidence, along with streamlined standards and metrics, will enhance usability and implementation”

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Hemolytic Disease of the Fetus & Newborn

DID YOU KNOW?

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

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

HDFN can lead to:

- Severe anemia
- Jaundice
- Fetal or infant death

To reduce their baby's risk

pregnant mothers should talk to their health care provider to:

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

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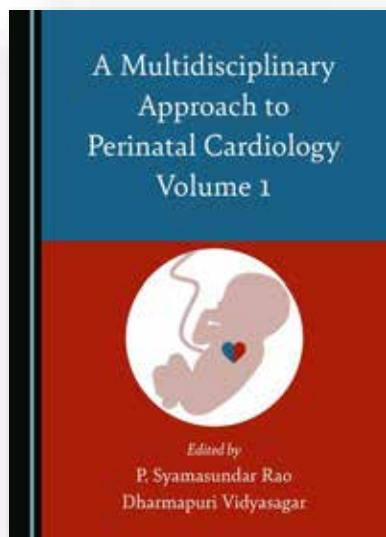
Second Edition

**Gary D. Miner, Linda A. Miner,
Scott Burk, Mitchell Goldstein,
Robert Nisbet, Nephi Walton,
Thomas Hill**



A Multidisciplinary Approach to Perinatal Cardiology Volume 1

Edited by P. Syamasundar Rao and Dharmapuri Vidyasagar



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

About the Editors

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

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A Multidisciplinary Approach to Perinatal Cardiology Volume 1 is available now in Hardback from the Cambridge Scholars [website](https://www.cambridgescholars.com), where you can also access a free [30-page sample](#).

Alliance for Patient Access: Another Respiratory Syncytial Virus (RSV) Season Brings Updated Guidance

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.



“Millions of patients will contract respiratory syncytial virus and experience mild, cold-like symptoms. For some, RSV will lead to serious respiratory illnesses like bronchiolitis or pneumonia.”

October is both RSV Awareness Month and the start of the 2026–27 RSV season.

Millions of patients will contract respiratory syncytial virus and experience mild, cold-like symptoms. For some, RSV will lead to serious respiratory illnesses like bronchiolitis or pneumonia.

About RSV:

Babies face the greatest risk in the first few months of life, as their immune system is still developing. Several other [health complications](#) can place infants at a higher risk, including prematurity, chronic lung disease, and congenital heart disease.

“Before RSV immunization and vaccine options became available, between 58,000 and 80,000 children under 5 were hospitalized due to RSV each year. Now that there are preventative options available, parents can reduce the risk of serious complications and hospitalization associated with RSV”

Before RSV immunization and vaccine options became available, between [58,000 and 80,000](#) children under 5 were hospitalized due to RSV each year. Now that there are preventative options available, parents can reduce the risk of serious complications and hospitalization associated with RSV.

Protecting All Children:

[The American Academy of Pediatrics](#) and the [CDC](#) recommend babies be protected in one of two ways:

- **Maternal RSV vaccine:** Pregnant women between 32 and 36 weeks of pregnancy should receive a single dose of this vaccine. Vaccination during this window allows protective antibodies to pass to the baby, so they do not need to receive antibodies after birth.
- **Infant preventive monoclonal antibody:** Infants should receive this antibody if the mother did not receive the vaccine or the baby was born within 14 days of maternal vaccination. Infants can receive this antibody before they leave the hospital or at a pediatrician's office.

“The AAP has now broadened the high-risk criteria for children ages 8 through 19 months entering their second RSV season, allowing more vulnerable children to qualify for protection.”

New Guidelines Expand Protection

Previously, RSV preventive monoclonal antibodies were recommended for all eligible infants younger than 8 months entering their first RSV season and for certain high-risk children entering their second season. The AAP has now [broadened the high-risk criteria](#) for children ages 8 through 19 months entering their second RSV season, allowing more vulnerable children to

qualify for protection.

Parents, caregivers, and family members can also help prevent spread by washing hands, cleaning surfaces, and avoiding contact with others who are sick.

“An ounce of prevention can go a long way. RSV infections can move quickly from ordinary sniffles to serious illness. Keeping infants out of the hospital starts with education about preventive options to help parents make the best health care decisions for their infants.”

An ounce of prevention can go a long way. RSV infections can move quickly from ordinary sniffles to serious illness. Keeping infants out of the hospital starts with education about preventive options to help parents make the best health care decisions for their infants.

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November 12th 11am-12:30pm PT

Meals on Wheels: Transporting Mother's Own Milk & Donor Milk to NICUs Across New Orleans

**Kimberly E.
Novod, MPA**

(she/her)
*Founder &
Executive Director,
Saul's Light
NICU Parent of Saul*



Changing the Trajectory of Feeding Outcomes with Droplets of Milk

**Barbara O'Rourke,
RN-NIC,
C-ELBW, TIP**

(she/her)
*Neonatal Clinician &
Research Nurse,
Blank Children's Hospital
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A Century-Old Infant Formula: Further adventures with ChatGPT

Joseph B. Philips, III, MD, FAAP

My father was born in 1917. He had two sisters, one older and one younger. They grew up in Kennett Square, PA, about 40 miles from Philadelphia. While going through his affairs after he died, I chanced upon this formula recipe from the Children's Hospital of Philadelphia (CHOP). It must have been for one of his sisters, as the writing at the bottom left of it says, "She should get ½ oz of orange juice every day." The writing above it states, "This is the whole formula. If you want only one or two bottles, you make it out in proportion. When you increase the milk, subtract from the Barley water but keep the quantity the same."

Barley water is made by simmering hulled barley in water, then straining the water. The recipe does not specify the barley-to-water ratio, but most online recipes use 1 cup of barley to 4 cups of water.

To investigate the formula's nutritional adequacy, I asked

ChatGPT, "Is a formula of 20 ounces of whole milk, 20 ounces of barley water, and 3.5 tablespoons of dextrin maltose adequate nutrition for an infant?" It produced the following:

Approximate nutritional calculation:

Using ordinary whole cow's milk:

Component	Approximate amount
Whole milk	20 oz
Barley water	20 oz
Dextrin-maltose	3.5 Tbsp
Total volume	40 oz/day
Calories from milk	~300 kcal
Calories from dextrin-maltose	~140–180 kcal*
Total energy	~440–480 kcal/day
Protein	~15–16 g/day
Fat	~16 g/day
Carbohydrate	~55–70 g/day

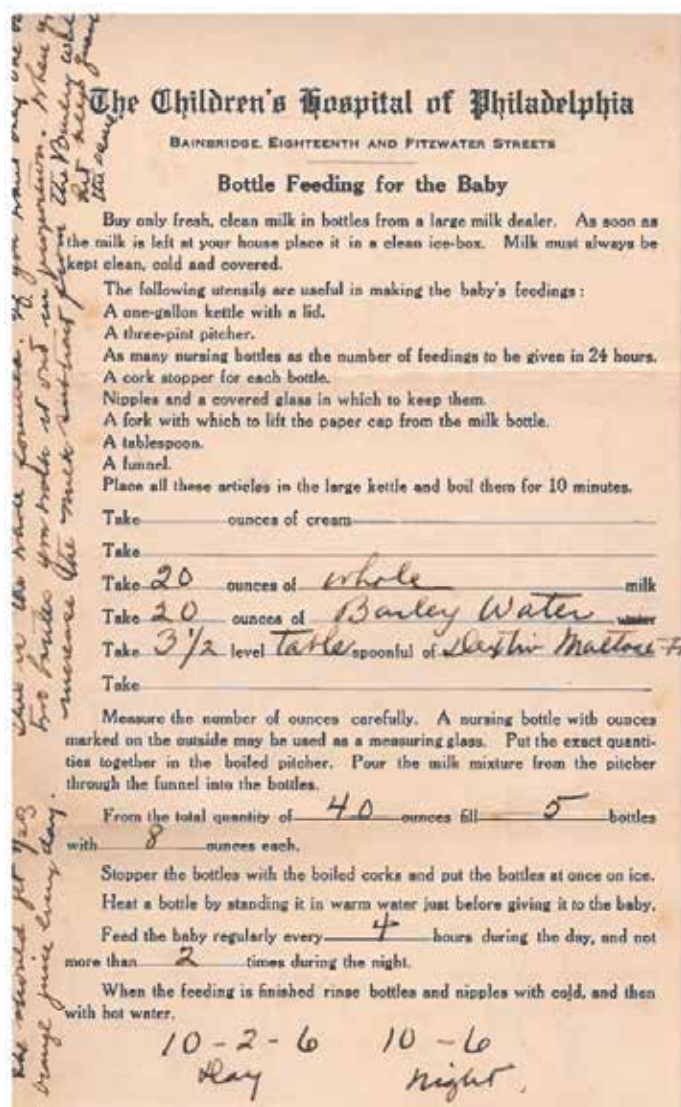
*The exact figure depends on the particular dextrin-maltose preparation and how much a tablespoon weighs.

It further commented, "Thus, the formula might provide an adequate *amount of energy* for a relatively large infant but would be inadequate as a modern sole source of nutrition for a young infant because of its **micronutrient composition**, particularly **iron and vitamin C**, and because the fat/protein/mineral composition is not designed for infant requirements." Cow's milk also contains considerably more protein and mineral load than human milk while lacking adequate iron. The AAP specifically notes that unmodified cow's milk is not nutritionally complete for infants under 12 months.

"Cow's milk also contains considerably more protein and mineral load than human milk while lacking adequate iron. The AAP specifically notes that unmodified cow's milk is not nutritionally complete for infants under 12 months."

There is an interesting historical issue here.

If you are asking because you have encountered this particular **20 oz milk + 20 oz barley water + 3½ tablespoons dextrin-maltose** recipe in an older pediatric or neonatal text, that is important. This sounds very much like a **historical infant formula**, rather than a



modern formula recipe.”

Next, I inputted the image of the formula and got this back:

“I would characterize it as **quite sophisticated for its era but nutritionally incomplete by modern standards—especially for a young infant.**

What the CHOP formula actually provided

Nutrient	CHOP ~1920 formula	Modern comparison
Total volume	40 oz (1.18 L)	Typical formula intake ~24–32 oz/day
Energy	~450–500 kcal/day	~90–100 kcal/kg/day for a young infant
Protein	~15–16 g/day	~9–12 g/day from typical formula intake
Fat	~16 g/day	~25–35 g/day
Carbohydrate	~60–70 g/day	~65–80 g/day
Iron	~0.1–0.2 mg/day	~10–12 mg/L in modern iron-fortified formula
Vitamin C	Very little	~10–15 mg/day
Vitamin D	Very little/none	~400 IU/day
Vitamin E	Low	Adequate amounts supplied
Essential fatty acids	Limited	Specifically provided in modern formula
Calcium/phosphorus	Relatively high	Carefully balanced in modern formula
Sodium/protein/mineral load	Relatively high	More carefully controlled

Assuming the recipe means **20 oz whole cow’s milk + 20 oz barley water + 3½ tablespoons dextrin-maltose over 24 hours**, the approximate composition is:

It also said the most important deficiency was iron and that it had less fat than modern recommendations, as well as lacking vitamins and other micronutrients. The half ounce of orange juice was likely intended to supplement vitamin C, as that amount provides almost 8 mg.

“This practice likely helped to remedy some of the deficiencies in the CHOP formula. It clearly worked, as my father and his sisters grew up to be healthy, vibrant adults.”

So the formula was sophisticated for its day but not up to modern standards. However, it was common back then to introduce biekost quite early, often as early as one month of age. This practice likely helped to remedy some of the deficiencies in the CHOP formula. It clearly worked, as my father and his sisters grew up to be healthy, vibrant adults.

Disclosures: The author has no conflicts of interest.

NT

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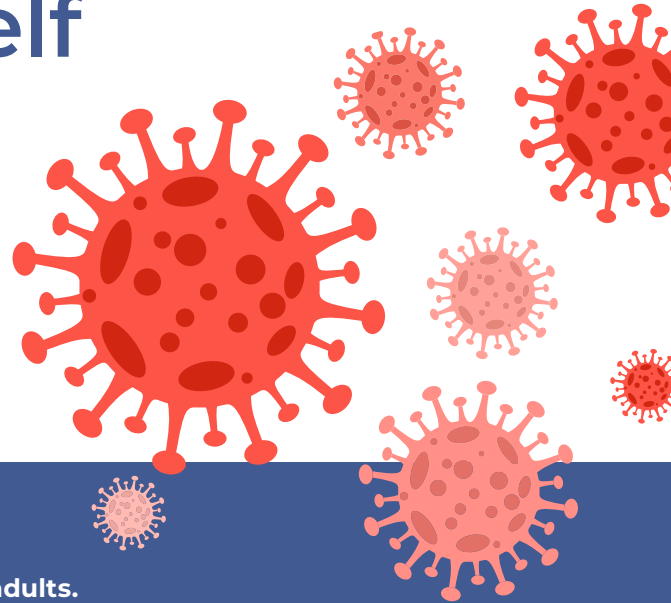
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COVID-19 vaccines have been shown to:

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



Understanding the Options

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



mRNA VACCINES

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PROTEIN SUBUNIT VACCINES

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



VECTOR VACCINES

Used for decades against chickenpox, malaria and tuberculosis.

HOW THEY WORK:

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

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

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

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COVID vaccines have been:



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Community health center



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1. <https://www.mayoclinic.org/diseases-conditions/coronavirus/symptoms-causes/syc-20479963>

2. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8782520/>

3. <https://www.nejm.org/doi/full/10.1056/nejmc2107717>

4. <https://royalsocietypublishing.org/doi/full/10.1098/rsif.2020.0683>

5. <https://www.cdc.gov/vaccines/covid-19/clinical-considerations/interim-considerations-us.html>

6. <https://doh.wa.gov/emergencies/covid-19/vaccine-information/safety-and-effectiveness>

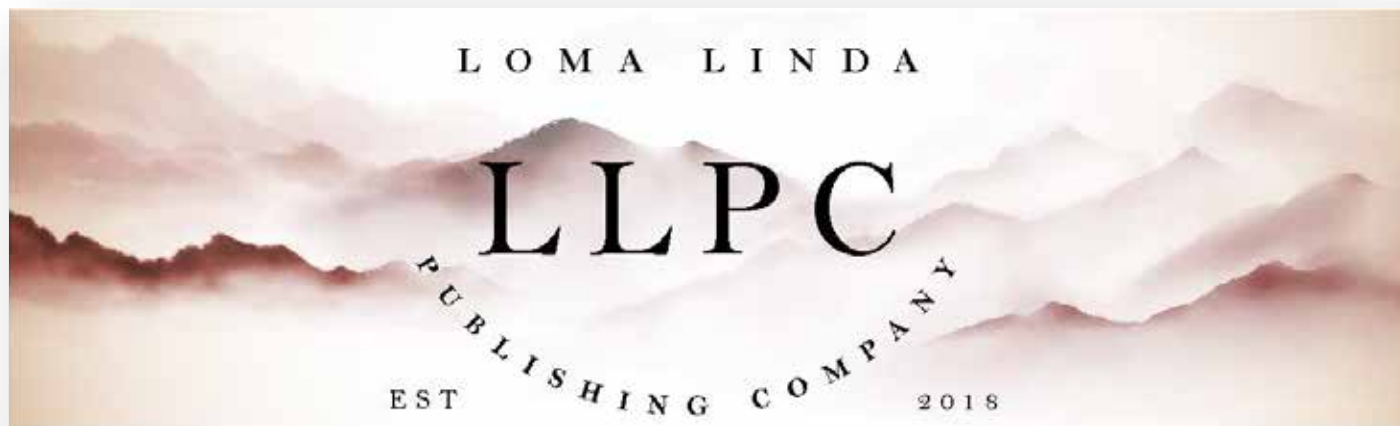
7. <https://doh.wa.gov/emergencies/covid-19/vaccine-information/safety-and-effectiveness>

8. <https://www.fda.gov/emergency-preparedness-and-response/coronavirus-disease-2019-covid-19/covid-19-vaccines>

9. <https://www.ema.europa.eu/en/human-regulatory/overview/public-health-threats/coronavirus-disease-covid-19/treatments-vaccines/vaccines-covid-19/covid-19-vaccines-authorised>

10. http://www.bccdc.ca/Health-Info-Site/Documents/COVID-19_vaccine/WHO-EUA-qualified-covid-vaccines.pdf





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Still a Premie?

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 PREMIE

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 PREMIE

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 PREMIE

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 Premies



Will spend weeks in the hospital



Will have lifelong health problems



Are disadvantaged from birth

All Premies



Face health risks



Deserve appropriate health coverage



Need access to proper health care

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

The Gap Baby: An RSV Story



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



The National Coalition for Infant Health advocates for:

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

www.infanthealth.org

iCAN Embraces Spooky Season: Youth From Around the World Show Their Bravery This October!

Abby Clark



iCAN

International Children's Advisory Network

Get involved today and Join the iCAN Parent Council!

“As the days get shorter and the nights get longer, iCAN youth members continue to impact pediatric healthcare through service projects, speaking engagements, advisory boards, and community-building initiatives.”

As the days get shorter and the nights get longer, iCAN youth members continue to impact pediatric healthcare through service projects, speaking engagements, advisory boards, and community-building initiatives. Read below to learn more about the incredible work they have done this month, and welcome to the new chapters joining our incredible community.

What is in this Issue of the iCAN Newsletter?

- What is iCAN?
- Read All About It: iCAN's newest resource for co-creation! Youth Engagement in Research (YER): How We Designed a Roadmap for Pediatric Patient Engagement!
- 2026 iCAN Summit in Pictures
- Looking Ahead: How Youth are Transforming the World of Healthcare Advocacy
 - Ask the Experts: Looking ahead to October and Beyond
 - iCAN Impact: 2026 TEDDY General Assembly and Scientific Meeting

- iCAN 2027 Summit

What is iCAN?

iCAN, the International Children's Advisory Network, is the premier global pediatric platform empowering the patient voice in healthcare, driven by youth for youth. As a worldwide network of 50+ KIDS (Kids Impacting Disease through Science) advisory groups spanning four continents (as well as virtually), iCAN's dedicated youth member groups work together to give children and families a voice in medicine, research, science, and innovation. To foster greater global understanding about the importance of the pediatric patient and caregiver voice in healthcare, clinical trials, and research, iCAN's young people continue to drive incredible change in the global health landscape.

On average, our youth are between the ages of eight and twenty-one years old, most of whom are living with chronic, rare, and complicated diagnoses, although not all of iCAN's youth members have a medical diagnosis or medical condition. iCAN celebrates the understanding that all patients, even the youngest, have valuable insights into improving the healthcare experience. All children from anywhere are welcome to participate in iCAN's programming. iCAN also supports young adults and the voices of parents and siblings. We continue to be an ecosystem of schools, children's hospitals, academia, and other like-minded non-profits.

“Our mission is to ensure youth are placed in positions where their voices are heard, and they can make a difference in pediatric healthcare through interactions with industry professionals, presenting original research at conferences, innovating new solutions, and sharing their stories.”

Our mission is to ensure youth are placed in positions where their voices are heard, and they can make a difference in pediatric healthcare through interactions with industry professionals, presenting original research at conferences, innovating new solutions, and sharing their stories. iCAN continues to empower the pediatric patient voice through community partnerships with organizations such as the FDA, Everylife Foundation for Rare Diseases, PFMD, MRCT, iSPI, and AAP.

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



Read All About It: iCAN's newest resource for co-creation! Youth Engagement in Research (YER): How We Designed a Roadmap for Pediatric Patient Engagement!

iCAN's Executive Director (Sabina Schmidt Goldstein-Becerra), Director of Operations (Abby Clark), Youth Members (Joey and Anvita), and a researcher from Brown (Kristine Durkin) developed *Closing the Loop: A Roadmap for Youth Engagement* in a course they attended on Family Education in Research, hosted by McMaster University and CanChild Centre for Childhood-Onset Disability Research. This month, the team got back together again to present their finished product on iCAN's *Ask the Experts* webinar and podcast!

“The course, created in 2018, brings together families, researchers, patients, and health professionals to work in tandem and learn from each other about meaningful partnership in healthcare research.”

The course, created in 2018, brings together families, researchers, patients, and health professionals to work in tandem and learn from each other about meaningful partnership in healthcare research. The course guides each student through firsthand testimonials and best practices for engaging with patient advisors and brings a novel approach to what it means to work with other healthcare leaders in this context. The class centered on building a tool to guide or highlight patient partnership. iCAN's group's project delves deeper into actionable steps of patient-centric co-creation.

The project, *Closing the Feedback Loop: A Roadmap for Youth Engagement*, standardizes project evolution by breaking down what is often a complex undertaking into a method adaptable to any co-creation. It provides a roadmap for engaging youth and young people through a universal feedback cycle. It expands the steps of the iCAN Feedback Loop (a framework that focuses on incorporating youth and family voices in co-creation) by detailing actionable steps to incorporate open streams of communication at

every stage of a project process.

While the iCAN Feedback Loop is a valuable tool, it does not go into enough depth on how to engage and provide adequate feedback at each “step.” The new tool expands each step, including sections on “Contextualization,” “Communicating back,” and a “scenario” in which this step might be utilized.

“While the iCAN Feedback Loop is a valuable tool, it does not go into enough depth on how to engage and provide adequate feedback at each ‘step.’”

Closing the Feedback Loop: A Roadmap for Youth Engagement standardizes project evolution, breaking down what is often a complex undertaking into a method adaptable to any co-creation. Simply put, the project is a roadmap for facilitating engagement with youth and young people through a universal feedback cycle. It expands the steps of the iCAN Feedback Loop (a framework that focuses on incorporating youth and family voices in co-creation) by detailing actionable steps to incorporate open streams of communication at every stage of a project process.



You can access the Roadmap and iCAN Feedback Loop here:

<https://www.icanresearch.org/icanroadmapandfeedbackloop>

You can also listen to the podcast episode here:

<https://open.spotify.com/episode/18W9hbuWWFaHKP0P64pjf?s=i=So51jF0UQSuSYHwkAWt46Q>

2026 iCAN Summit in Pictures

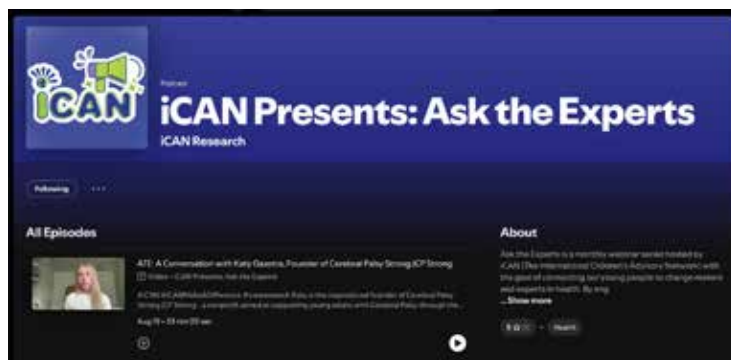
Every year, iCAN young people share their voices at the iCAN Summit. It is an incredible, transformative event! Nevertheless, why tell you when we can show you? Enjoy a glimpse into the 2026 iCAN Summit!



More pictures from the iCAN Summit are linked on our webpage!

<https://www.icanresearch.org/2026-summit>

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



Listen to our podcast now: [*iCAN Presents: Ask the Experts*](#) on Spotify!

- **Ask the Experts:**
 - Ask the Experts is a monthly webinar series and podcast 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 October 17th, 2026: A Conversation with Chris Evans, CEO of Little Journey & KIDS host Berkley
 - About the guest speaker: Chris Evans is an anaesthetic doctor, researcher, and founder & CEO of Little Journey. He is passionate about applying behavioural science, clinical insight, and data-driven personalisation to improve experiences and outcomes across global clinical trials and healthcare. At Little Journey, they build scalable digital platforms that deliver personalised participant and family support in a way that is consistent, deployable, and measurable in the real world. They operate two platforms: Trial Flow, a protocol-configured patient support delivery platform for clinical trials. Configured for each study and deployed rapidly across sites, regions, languages, and age groups, Trial Flow helps sponsors and CROs standardize how patient support is delivered across studies. This reduces fragmentation and supports adherence, engagement and retention, with outcomes that can be measured consistently at study and portfolio level. Little Journey: a patient preparation and support app for hospitals and health systems. It provides the right support at the right time, in the right format for patients and caregivers, reducing anxiety and improving understanding, while helping clinical teams work more efficiently through better-prepared patients, fewer avoidable disruptions, and proven ROI. Their family-centred foundation informs how they build support that scales across ages and settings, turning evidence-based care into consistent, real-world impact.
- [RSVP Here](#)
- Future ATE Sessions:
 - November 14th - SPECIAL EPISODE: Celebrating World Children's Day: "My Day. My Rights. My Future: Empowering Young Voices Across the Globe."
 - January 16th - ATE: A Conversation with Katie, Courage Tees

- Want to be part of our next *Ask the Experts* Session? Please reach out to sabina@icanresearch.org.

iCAN Impact: 2026 TEDDY General Assembly and Scientific Meeting

Join us in congratulating the TEDDY Network for completing their 2026 TEDDY General Assembly and Scientific Meeting! As one of iCAN's most treasured community partners, the Teddy Network (and the iCAN KIDS chapters that are part of it) accomplishes incredible work empowering pediatric patients throughout the year.

The General Assembly explored innovative approaches to addressing evidence gaps and strengthening the involvement of children and young people in shaping pediatric research. We are so proud of the amazing work they do every day! Congratulations to Donato Bonifazi and the TEDDY Network team for such a successful event!

"Promoting a shift in the perspective that places the empowerment of children and adolescents at the center, recognizing their active role in decisions that affect their health, and valuing their experiences and specific knowledge." (Donato Bonifazi, TEDDY Network Chair)



"The lasting impact of this annual event on the youth who attend, the iCAN Network, and the wider healthcare community cannot be measured. Together, we continue to impact pediatric healthcare in a tangible and real way."

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

Please submit your manuscript to: LomaLindaPublishingCompany@gmail.com

The 2027 iCAN Summit

Our annual Summit serves as a transformative platform for innovation, compassion, and collaboration in pediatric healthcare. The lasting impact of this annual event on the youth who attend, the iCAN Network, and the wider healthcare community cannot be measured. Together, we continue to impact pediatric healthcare in a tangible and real way. By giving every kid a seat at the table through discussion and co-creation, current and future pediatric patients are both empowered and transformed. The upcoming Summit is set to take place in July 2027; the location will be announced soon.

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

1. Sponsor the 2027 Summit: Your sponsorship will play a crucial role in ensuring an

impactful experience for all attendees.

2. Sponsor a Child to Attend: Your sponsorship directly impacts a child's life by granting them the opportunity to attend the Summit. Your support will cover travel, accommodation, and participation, offering them a world of learning and empowerment. Together, we are shaping a brighter future for pediatric healthcare. Your contribution—big or small—makes a significant difference in prioritizing the patient voice and driving positive change. We deeply value your generosity and dedication. Let us create a summit experience that empowers the pediatric community for years to come.

Let us work together to make our 2027 Summit even bigger by bringing more kids to share their voices! To help fund next year's Summit, please [click here](#) to sponsor or donate.

Disclosures: There are no reported disclosures

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Still a Premie?

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 PREMIE**

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 PREMIE**

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 PREMIE**

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 Premies	All Premies
Will spend weeks in the hospital	Face health risks
Will have lifelong health problems	Deserve appropriate health coverage
Are disadvantaged from birth	Need access to proper health care

NCJH National Coalition for Infant Health
www.infanthealth.org



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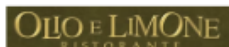
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Caroline Arnold, Author



Impact of Music Therapy Procedural Support on Pain Expression During Circumcision

Chloe Heintz, MMT, LPMT, MT-BC, Lelia Emery, MMT, LPMT, MT-BC, Julie Alton Renato, MM, LPMT, MT-BC, Jason Benjamin Kovalcik, MD, FAAP, Jennifer J. Hofherr, MS, OTR/L, CNT, NTMTC, Jana L. Erner, MD, FAAP, Anna Dicari, PT, DPT, Molly Susi, OTD, OTR/L, Courtney Mackert, OTR/L, MOT, CNT, CLC, Jason A. Benedict, MS; Anthony Meadows, PhD, MT-BC, LPC

“This pilot study investigated the impact of a music therapy procedural support intervention on infant pain expression before, during, and after circumcision.”

Abstract: *This pilot study investigated the impact of a music therapy procedural support intervention on infant pain expression before, during, and after circumcision. Participants were assigned to either standard care or music therapy plus standard care, and researchers recorded heart rate, respiratory rate, and pain expression throughout the procedure. No significant differences were found between groups in heart rate, respiratory rate, or pain score. However, a significant difference was found in pain scores between the last step of the circumcision procedure and 5 minutes post-procedure, suggesting that music therapy may be beneficial in supporting infants' recovery time. This study discusses implications for future research and clinical practice.*

Keywords: *music therapy, neonatal intensive care unit, procedural support, circumcision, pain*

Introduction:

Premature infants admitted to the neonatal intensive care unit (NICU) experience significantly more stressful events than a typical newborn (1). These events may include heel sticks or other blood draws, intravenous (IV) placements, and various other medical procedures, including elective circumcision. Stress or pain responses may trigger adverse physiological reactions, including changes in heart rate, respiratory rate, oxygenation, and blood pressure. In addition to negative physiological responses, research suggests that infant mental health should not be ignored and that parental involvement, as well as the inclusion of non-pharmacological interventions, are vital to infant health and development during hospitalization (2). Premature infants who are exposed to frequent stressful events such as painful procedures in the NICU are more susceptible to long-lasting effects on health and development (3,1).

There are numerous ways to address infant pain and distress in the NICU, of which pharmacologic interventions provide one solution. Alternatively, non-pharmacological interventions are becoming increasingly integrated in the NICU as they are perceived as beneficial to the infant and do not have the negative side effects commonly associated with drug administration (4-8). Music therapy is a non-pharmacological intervention that

positively impacts infant well-being in the NICU. Adding live music therapy to standard NICU care has been shown to improve infant autonomic and physiologic stability, with improvements in heart rate, respiratory rate, and oxygenation when music therapy was provided during quiet alert periods (9, 10, 11, 12, 13). A recent Cochrane review found that music and vocal interventions reduce infant heart rate both during and after the intervention compared with standard care alone (14). Additionally, infants who received live contingent singing, or improvised singing responsive to infant cues, showed significantly better neurobehavioral development than those who received standard care alone (15, 16, 17).

NICU music therapy interventions supporting painful procedures have also shown clinical benefits. A Pacifier Activated Lullaby (PAL) intervention after painful procedures lowered infant stress levels and allowed them to return to a calm state more quickly than infants receiving standard care (18). Presenting recorded maternal singing and heartbeat aided infant recovery after a retinopathy of prematurity (ROP) exam (19). In two case studies, live lullaby singing during venipuncture resulted in more stable vitals than standard care (20). Similarly, live music therapy offered during ROP exams resulted in low rates of adverse events following the procedure, indicating that the intervention is safe and feasible (21).

While research suggests multiple benefits from music therapy interventions, including reduced pain perception and decreased emotional distress in young children, the impact of music therapy during elective circumcision has not been examined. Although elective, the procedure is common, with the Centers for Disease Control and Prevention (CDC) reporting that 64% of newborn males were circumcised between 1979 and 2010 (22). Because circumcision is considered a painful procedure, it is common to use a combination of pharmacological and non-pharmacological interventions that include a local anesthetic, a topical or injected nerve block, and swaddling, sucrose, and a pacifier. However, the specific benefits of combining these interventions have not been carefully investigated (23, 8).

“While research suggests multiple benefits from music therapy interventions, including reduced pain perception and decreased emotional distress in young children, the impact of music therapy during elective circumcision has not been examined.”

Previous research provides a context for the inclusion of music therapy during elective circumcision (24, 8, 25). One study found that combining recorded music or sound with pacifier use decreased crying in infants undergoing circumcision (24). Additionally, compared with other combinations of non-pharmacological

interventions, integrating recorded music with sucrose, swaddling, or pacifier use significantly reduced pain scores (8). However, the benefits of incorporating recorded music into circumcision procedures are equivocal, with one study reporting increased infant agitation during circumcision (25). These contradictory findings suggest further investigation into how music interventions are delivered, with a focus on the differential impact of live vs recorded music.

"First, it incorporates live music throughout the circumcision procedure, with the interventionist able to tailor the music to each moment to meet the infant's needs. Second, the study records pain expression and accompanying physiological measures throughout the intervention, providing insight into the intervention's temporal effects at key moments during the procedure."

This study addresses this research and clinical gap in two ways. First, it incorporates live music throughout the circumcision procedure, with the interventionist able to tailor the music to each moment to meet the infant's needs. Second, the study records pain expression and accompanying physiological measures throughout the intervention, providing insight into the intervention's temporal effects at key moments during the procedure. The guiding research questions are:

1. What is the impact of music therapy procedural support on physiological measures (heart rate, respiration rate) for infants undergoing circumcision in the NICU?
2. What is the impact of a music therapy intervention on the expression of pain in infants undergoing circumcision in the NICU?

Method:

This study utilized a pretest/posttest, two-group, non-randomized design. Participants were assigned to one of two groups: standard care (control group) or standard care plus music therapy intervention (experimental group). Participants were initially assigned to the control or experimental group based on parental preference. After most families chose the experimental group, we created a second arm, and participants were assigned to the control group for the remainder of data collection. However, parents could still elect not to participate in the study and receive music therapy if they so chose. Circumcisions were generally scheduled according to the patient's discharge plans, usually within 24-72 hours of discharge. Data collection took place between October 4, 2022, and March 31, 2023.

Setting

This study took place in a 130-bed level IV neonatal intensive care unit (NICU) at a large hospital in the Midwestern United States. At the time of the study, the NICU had three part-time music therapists covering the unit Monday through Friday, all of whom served as interventionists. Before the study, the music therapy team had

provided procedural support for circumcisions for approximately five years.

Participants

A total of 35 male infants admitted to the NICU, whose parents opted for the elective procedure of circumcision, were recruited to participate in this study. All infants meeting criteria for neonatal circumcision were screened for study eligibility. Infants were included in the study when the following criteria were met: (a) parents consented to both circumcision and the research study, (b) infants were medically stable, and (c) infant post-menstrual age was less than 48 weeks but greater than 35 weeks. Infants who were not medically stable, who were on high-flow nasal cannula or any higher level of oxygen support, whose post-menstrual age was greater than 48 weeks, and whose parents did not speak English were excluded from the study. Diagnoses were considered for data analysis but not for inclusion or exclusion.

Ethics Approval

Institutional Review Board (IRB) approval was obtained from both the hospital where the study was conducted and the university where this author was enrolled at the time of the study.

"Participants received either standard care or standard care plus music therapy. The circumcision procedure lasted 20-30 minutes, including setup, lidocaine injection, the procedure itself, and cleanup. A surgeon performed the procedure, with a nurse present. Parents were not present for most infants during the procedure due to physician or parental preference and institutional practices."

Interventions

Participants received either standard care or standard care plus music therapy. The circumcision procedure lasted 20-30 minutes, including setup, lidocaine injection, the procedure itself, and cleanup. A surgeon performed the procedure with a nurse present. Parents were not present for most infants during the procedure due to physician or parental preference and institutional practices.

1. The bedside nurse and physician provided standard care. In addition to assisting the physician, the bedside nurse provided the infant with two-hand containment, sucrose, and a pacifier throughout the surgical procedure. Standard care began approximately two minutes prior to lidocaine injection and continued during the procedure to promote a calming environment.
2. Standard care, including music therapy, was provided continuously before, during, and after the procedure. One of three female NICU music therapists involved in the study provided the music therapy intervention. The music therapy intervention began 5 minutes prior to the lidocaine injection, continued throughout the procedure, and continued up

to 5 minutes after the procedure's conclusion, totaling approximately 30 minutes. The intervention involved unaccompanied singing of lullabies and children's music with simple, repetitive melodies and rhythms (i.e., "Twinkle, Twinkle Little Star" or "Baby Beluga"). Each of the three music therapists chose songs in the moment based on recommendations from the National Institute for Infant and Child Medical Music Therapy and, when indicated, parent preferences. These recommendations for auditory stimuli in the NICU include using lyrics in the infant's native language, infant-directed language, melodies in a higher vocal range, constant or light rhythmic elements, and some variety in selections, using multiple songs throughout the procedure (32). The music therapist tailored the intervention in response to infant cues of behavioral pain or distress, altering musical elements to promote a calming environment. For example, the tempo and volume increased when the infant showed increased pain or distress, and decreased when the infant began to calm. Additionally, the music therapist could adjust or stop melodic input when observing overstimulation and use clinical judgment to either resume melodic input, provide rhythmic input using a "shh" sound, or provide two-hand containment alone without auditory input. Medical staff monitored infants throughout for safety.

Measurements

A member of the research team recorded physiological measures (heart rate and respiration rate) at 5 time points throughout the circumcision procedure: 1. 5 minutes prior to the procedure, 2. at the time of lidocaine injection, 3. at the time of the first clamp, 4. at the time of foreskin removal, and 5. 5 minutes after the circumcision completion. Additionally, we recorded a video of each infant's face throughout the procedure and time-stamped it simultaneously with physiological data. Two members of the research team edited videos to remove all sound so that the video coders would be blinded to the infant's intervention. Each participant's video was assigned a random study ID to ensure the coders were blinded to the infant's intervention.

“A member of the research team recorded physiological measures (heart rate and respiration rate) at 5 time points throughout the circumcision procedure: 1. 5 minutes prior to the procedure, 2. at the time of lidocaine injection, 3. at the time of the first clamp, 4. at the time of foreskin removal, and 5. 5 minutes after the circumcision completion.”

We analyzed these videos using a modified version of the Neonatal Facial Coding System (NFCS), as shown in Table 1, which evaluates infant pain expression via facial actions (26, 27). The NFCS demonstrates adequate inter-observer reliability and construct validity and is feasible for assessing infant pain (28, 29). Each facial action equals one point, and the absence of a facial action scores zero. A score of 3 or higher indicates that the infant is experiencing some pain, with a maximum score of 8. To resolve any rating discrepancies, two coders and this author analyzed the first three participant videos together, providing a

foundation for analyzing the remaining sessions. The two coders, trained in NFCS, then independently analyzed the remaining videos.

Table 1

Neonatal Facial Coding System

Action	Description
Brow bulge	Bulging, creasing, and vertical furrows above and between brows occurring as a result of the lowering and drawing together of the eyebrows
Eye squeeze	Identified by the bulging or squeezing of the eyelids. Bulging of the fatty pads about the infant's eyes is pronounced.
Naso-labial furrow	Primarily manifested by the pulling upwards and deepening of the naso-labial furrow (a line or wrinkle which begins adjacent to the nostril wings and runs down and outwards beyond the lip corners)
Open lips	Any separation of the lips
Stretch mouth (vertical or horizontal)	Characterized by a tautness at the lip corners coupled with a pronounced downward pull on the jaw. Often, a stretched mouth is seen when an already wide-open mouth is opened a fraction further by an extra pull at the jaw. Or a distinct horizontal pull at the corners of the mouth.
Lip purse	The lips appear as if an "oo" sound is being pronounced.
Taut tongue/tongue protrusion	Characterized by a raised, cupped tongue with sharp, tensed edges. The first occurrence of taut tongue is usually easy to see, often accompanied by a wide-open mouth. After this first occurrence, the mouth may close slightly. Taut tongue is still scorable based on the still visible tongue edges.
Chin quiver	An obvious high-frequency up-and-down motion of the lower jaw

Note. Adapted from "Pain expression in neonates: Facial action and cry" by R. V. E. Grunau and K. D. Craig, 1987, *Pain*, 28(3), p. 399. Copyright 1987 by Elsevier Science Publishers B. V. (Biomedical Division)

Statistical Data Analysis

We averaged the two coders' scores at each time point to obtain a single score for each outcome of interest. A two-sample t-test was computed to compare groups for each measure at timepoints 2 and 5, as well as at timepoints 4 and 5. These timepoints were chosen because perceived pain was highest at timepoint 2 (lidocaine injection) for both groups, and there was visually the most difference between timepoints 4 (foreskin removal) and 5 (5 minutes post-procedure). After visual inspection, and to account for differences between groups at timepoints 2 or 4, we analyzed differences at timepoint 5 using an ANOVA model with timepoint 5 as the dependent variable, controlling for scores at either timepoint 2 or 4. All p-values shown are exploratory and displayed at their nominal levels. All analyses were performed in R version 4.3 (30).

Results:

Demographics

A total of 35 infants participated: 16 in the control group and 19 in the treatment group. Participants were born between 34 and 39 weeks of gestational age, with the majority in each group born after 37 weeks. Additionally, participants were between 38 and 42 weeks post-menstrual age at the time of procedure. Participants' hospital stays ranged from 7 to 58 days. Most infants were on room air at the time of the procedure, with a few on nasal cannula. One participant was noted to have a diagnosis of Chiari malformation type 2 and was excluded from data analysis due to a lack of visual response to any stimuli during the circumcision procedure. Table 2 provides a summary.

Table 2

Demographic Data

Characteristic	Control, <i>n</i> = 16	Treatment, <i>n</i> = 19	Overall, <i>n</i> = 35
Gestational Age (GA) at Birth (Completed weeks and days)	37.0 (34.2-38.5)	37.4 (36.3-39.2)	37.3 (34.9-39.0)
Over 37 weeks GA	9 (56)	14 (74)	23 (66)
Under 37 weeks GA	7 (44)	5 (26)	12 (34)
Post-menstrual Age (weeks)	39.45 (38.5-40.7)	40.3 (39.25-42.45)	40.3 (38.8-41.4)
Length of Hospital Stay (days)	16 (9-26)	13 (7-58)	15 (9-40)
Race			
Asian	1 (6.2)	0 (0)	1 (2.9)
Black or African American	2 (12)	4 (21)	6 (17)
Unknown	2 (12)	0 (0)	2 (5.7)
White	11 (69)	15 (79)	26 (74)
Ethnicity			
Not Hispanic or Latino	12 (75)	17 (89)	29 (83)

Unknown	4 (25)		2 (11)		6 (17)	
Oxygen Support						
Nasal Cannula	1 (6.2)		3 (16)		4 (11)	
Room Air	15	94	16	84	31	89

Note. Median (IQR); *n* (%)

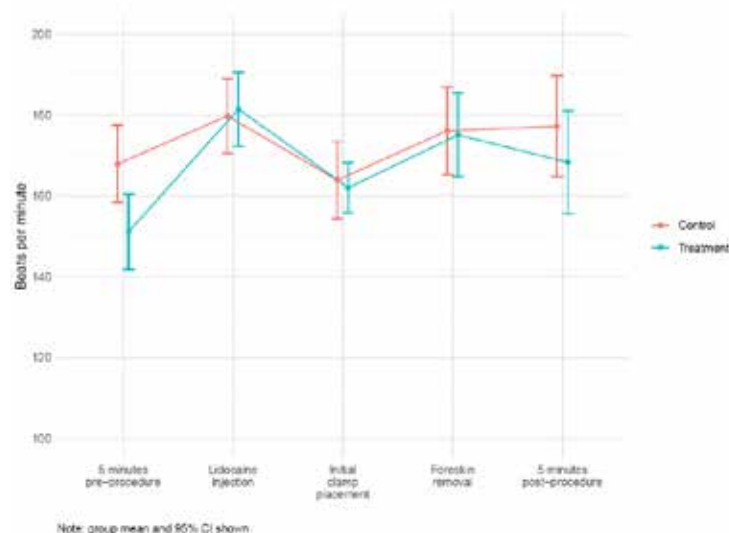
Physiological measures

We recorded heart rate at each time point throughout the procedure. Figure 1 provides the average heart rate for each group throughout the procedure. We compared average heart rate between the two groups at time points 2 and 5. We chose these time points because pain was perceived highest at time point 2 (lidocaine injection) for both groups, and time point 5 provides a post-procedure measure of pain expression. No statistically significant differences in heart rate were observed between groups at time point 2 ($p = 0.80$) or at time point 5 ($p = 0.33$).

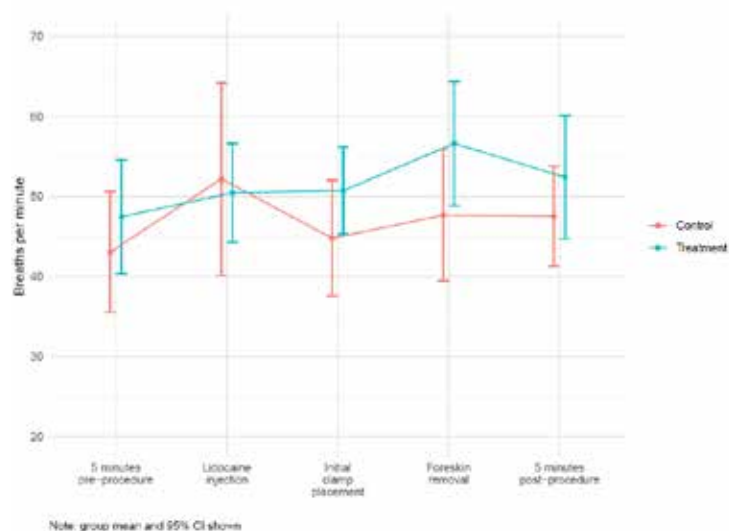
We recorded respiration rate at each time point throughout the procedure. Figure 2 provides the average respiration rate for each group throughout the procedure. No statistically significant differences in respiration rate were observed between groups at time point 2 ($p = 0.80$) or time point 5 ($p = 0.34$).

Figure 1

Heart Rate at Each Intervention Time Point



Respiration Rate at each Intervention Time Point



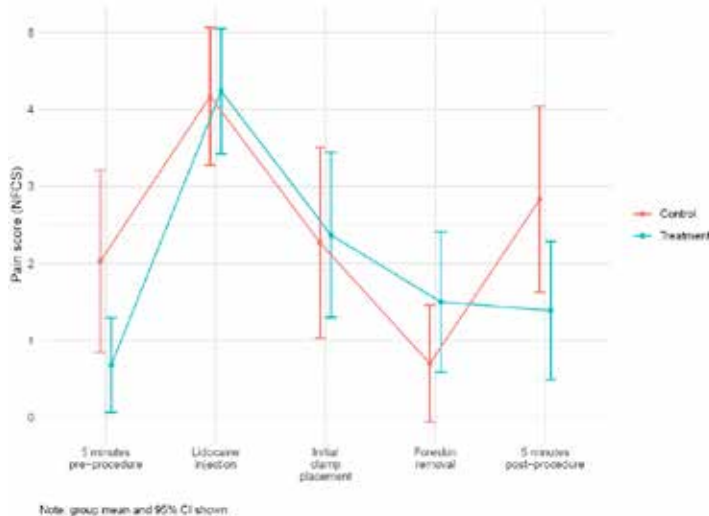
Pain expression

Pain scores were calculated at each time point throughout the procedure using the Neonatal Facial Coding System, which included eight facial actions that indicated a pain response when three or more are present (26,27). Figure 3 provides the average pain score for each group throughout the procedure. We observed no statistically significant differences in pain score between groups at timepoint 2 ($p = 0.91$) or timepoint 5 ($p = 0.07$). Additionally, we compared differences between groups at timepoint 5, controlling for either timepoint 2 or 4, to assess temporal significance. We observed no statistically significant difference in pain score between groups at timepoint 5, controlling for timepoint 2 ($p = 0.05$). However, we found a statistically significant difference in pain scores at timepoint 5, controlling for timepoint 4 ($p = 0.04$).

Discussion:

This study investigated the impact of a music therapy procedural support intervention on infant physiological response and pain expression during neonatal circumcision. We measured infant responses at 5 time points to evaluate the intervention's impact. No differences were found between groups in heart rate, respiratory rate, or pain scores at time points 2 and 5. Additionally, we found no significant differences in pain scores across time between groups at time points 2 and 5. This suggests that the addition of the music therapy intervention did not impact infant pain expression or physiological response during circumcision. However, a significant difference in pain scores was found between time points 4 and 5, suggesting that the addition of the music therapy intervention during circumcision may help reduce infant recovery time.

Pain Score at each Intervention Time Point



This finding aligns with previous research suggesting that music therapy may support a faster recovery time after painful procedures than standard care alone (18, 19, 21). Clinical practice at this institution also suggests that music therapy is a supportive non-pharmacological intervention during recovery after circumcision. Although live singing did not significantly affect infant physiological responses or pain scores during circumcision, it may serve a contextual function for infants, with the benefit of the music intervention observed at the end of the medical procedure. Additionally, while the singing intervention allowed for the music therapist to keep their hands free to offer containment and pacifier support, the lack of observable impact during the procedure suggests further investigation into the nature of the music intervention and whether the addition of an accompanying instrument (e.g., guitar), the use of recorded music, or the incorporation of parent voice or participation may be more impactful.

Because of institutional practices and our focus on a specific music therapy intervention, we did not actively involve parents or caregivers in the research protocol. The authors acknowledge growing evidence supporting parental involvement in neonatal pain management (33). However, the exact nature of parent involvement in music therapy during circumcision has not been studied. While the study design followed best-practice recommendations for music therapy by providing additional support during a procedure in which parents are not typically present (at our institution), recent research indicates that re-evaluating parent participation is indicated (34).

Future research should include a larger, multi-site trial comparing standard care with live music therapy. Additionally, researchers

should compare different types of music interventions and investigate the optimal timing of music therapy relative to the start of the medical procedure. Future research should also consider other measures of infant pain and stress, such as salivary cortisol or EEG, and collect experiential data from medical staff and parents.

Limitations:

This study had several limitations that may have affected the study's findings. These include the small sample size, non-randomized design, and participant heterogeneity. Infants with a diagnosis of neonatal abstinence syndrome (NAS) and hypoxic-ischemic encephalopathy (HIE) are likely to have heightened reactions to painful stimuli, and this may have impacted the overall study findings. Further, the authors excluded a participant with a diagnosis of Chiari Malformation Type II during data analysis because it is associated with variable pain response (35). Additionally, most infants included in the study were born after 37 weeks of gestation, so the findings may not generalize to premature infants.

Finally, while all the physicians involved in this study used the Gomco method for circumcision, they had slight variations in their implementation of the procedure, which may also have impacted infant response. Variation in intervention delivery may also have occurred, with the three NICU music therapists providing the procedural support intervention and multiple nurses providing standard care.

“The findings from this study suggest that a live singing music therapy intervention may shorten recovery time after circumcision, even though it does not affect infant physiological responses or pain expression during the procedure.”

Conclusion:

The findings from this study suggest that a live singing music therapy intervention may shorten recovery time after circumcision, even though it does not affect infant physiological responses or pain expression during the procedure. Further research comparing the type and timing of music therapy interventions may clarify its treatment benefits.

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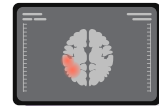
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Annular Pancreas Causing Neonatal Duodenal Obstruction: A Case Report

Razika Haboussi, Otman Bouchrif, Zohra Otmani,

“A 21-day-old neonate was admitted for persistent, non-bilious postprandial vomiting since day 6 of life, presenting with severe dehydration and electrolyte imbalances. Antenatal ultrasonography revealed oligohydramnios, with no specific prenatal diagnosis established. Upon admission, a high intestinal obstruction located proximal to the ampulla of Vater (supra-ampullary) was suspected.”

Keywords: Annual pancreas-Neonatal obstruction-Duodenoduodenostomy-Kimura procedure

Introduction:

Annular pancreas is a rare congenital anomaly in which pancreatic tissue forms a ring around the duodenum and may produce partial or complete obstruction. In neonates, diagnosis can be challenging and may be established only at surgery.

Case Presentation:

A 21-day-old neonate was admitted for persistent, non-bilious postprandial vomiting since day 6 of life, presenting with severe dehydration and electrolyte imbalances. Antenatal ultrasonography revealed oligohydramnios, with no specific prenatal diagnosis established. Upon admission, a high intestinal obstruction located proximal to the ampulla of Vater (supra-ampullary) was suspected.

Plain abdominal radiography demonstrated marked gastric stasis with a classic double-bubble sign alongside sparse distal intestinal gas. Abdominal ultrasonography revealed proximal duodenal dilatation with gastroduodenal stasis. An upper gastrointestinal (UGI) contrast study confirmed incomplete obstruction compatible with a congenital duodenal stenosis or an annular pancreas.

“Initial management focused on aggressive intravenous fluid resuscitation, correction of electrolyte disturbances, and preoperative clinical optimization.”



Double Bubble sign

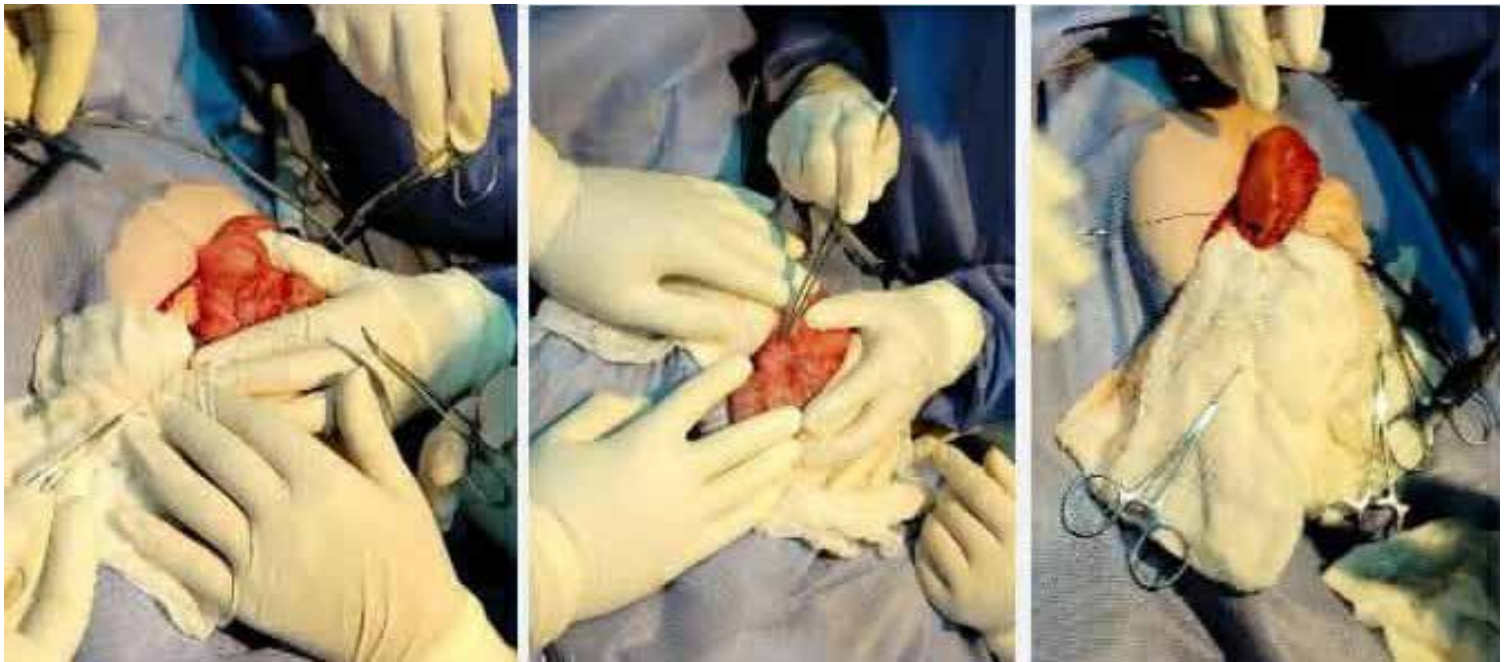


Sequential upper GI contrast study

Initial management focused on aggressive intravenous fluid resuscitation, correction of electrolyte disturbances, and preoperative clinical optimization.

Surgical Management:

An exploratory laparotomy confirmed an annular pancreas encircling the second portion of the duodenum (D2), causing partial luminal occlusion. To bypass the obstructed segment, a diamond-shaped side-to-side duodenoduodenostomy (Kimura procedure) was performed via a transverse incision in the



Annular Pancreas Encircling the Duodenum



Post Operative Course and Outcome



proximal dilated duodenum and a longitudinal incision in the distal collapsed duodenum. The annular pancreatic tissue was deliberately left undisturbed to prevent postoperative pancreatic fistula or biliary duct injury.

“The initial postoperative course was complicated by surgical site infection (parietal sepsis) leading to abdominal wound dehiscence and evisceration.”

Postoperative Course and Outcome:

The initial postoperative course was complicated by surgical site infection (parietal sepsis) leading to abdominal wound dehiscence and evisceration.

Emergency surgical revision was performed, including wound debridement, abdominal wall repair, and placement of a temporary decompressive gastrostomy to alleviate upper gastrointestinal pressure and protect the duodenal anastomosis. After targeted intravenous antibiotics, wound management, and gradual nutritional advancement, the infant achieved full clinical recovery and tolerated regular oral feeding before discharge.



Follow up up to 21 months of Age

Outcome and Long-Term Follow-Up:

Enteral feeding was re-introduced gradually and titrated to full capacity, with complete resolution of vomiting, feeding intolerance, and gastrointestinal symptoms.

Disclosures: The authors did not have any disclosures.

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“At the 21-month clinical follow-up, the toddler demonstrated normal somatic growth, appropriate developmental milestones, and an excellent nutritional status without long-term gastrointestinal sequelae.”

At the 21-month clinical follow-up, the toddler demonstrated normal somatic growth, appropriate developmental milestones, and an excellent nutritional status without long-term gastrointestinal sequelae.

Conclusion:

Early surgical intervention via duodeno-duodenostomy yields excellent long-term outcomes for the pancreas.

Suggested References:

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BY JENNÉ JOHNS

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AAP report supports pediatricians in screening, diagnosis and care of infants with congenital CMV

NEWS PROVIDED BY

American Academy of Pediatrics

By Karen M. Puopolo, M.D., Ph.D., FAAP

Study: **AAP report supports pediatricians in screening, diagnosis and care of infants with congenital CMV**

Current as of September 21, 2026

A well-appearing infant born at 39 weeks' gestation does not pass a hearing screen performed in the birth hospital. A 40-week gestation newborn's head circumference has been confirmed at the 3rd percentile. A serum bilirubin level is obtained for a jaundiced term newborn, and the conjugated bilirubin is elevated above normal range. Which of these infants should be tested for congenital cytomegalovirus (cCMV) infection?

A new AAP clinical report provides the latest information on epidemiology, clinical presentation, diagnostic approach and treatment options for cCMV infection to inform these questions. "Care of the Infant With Congenital Cytomegalovirus Infection" from the AAP Committee on Infectious Diseases, Section on Otolaryngology-Head and Neck Surgery, Committee on Fetus and Newborn and Council on Children With Disabilities is published online at <https://doi.org/10.1542/peds.2026-078595> and in the October issue of *Pediatrics*.

CMV epidemiology

CMV is a human herpesvirus. Infection can occur throughout life but is especially common in young children. By adulthood 60%-90% of people worldwide have been infected. After infection, CMV virus remains latent in the body; infectious virus can be shed into saliva, breast milk, genital secretions and urine intermittently, especially during periods of immune suppression. The clinical implications of CMV range from clinically silent infection (detected only by screening) to devastating disease in the context of immunosuppression for bone marrow or solid organ transplant.

Congenital CMV infection is the result of transplacental viral transmission from a pregnant individual to the developing fetus. This can occur when a person acquires a CMV infection during pregnancy for the first time (referred to as "primary infection"), or by reactivation of a latent infection, or from infection after a primary infection with a new CMV strain (together referred to as "non-primary infection"). Risk dynamics are complex:

- Risk of transmission to the fetus is higher with maternal primary compared to non-primary infection
- Risk of transmission to the fetus is highest if maternal infection occurs in the third trimester of pregnancy
- Risk of clinically apparent CMV disease in the newborn is higher if maternal infection occurs in the first trimester of pregnancy compared to the 2nd and 3rd trimester
- Risk of clinically apparent CMV disease in the newborn may not differ with maternal primary compared to non-primary infection

Most newborns with cCMV infection have no signs of disease at birth and will not develop sequelae over time. Approximately 10% to 15% will have abnormal findings on their newborn physical exam, on laboratory tests, neuroimaging studies, or with hearing testing.

Clinical outcomes defined

The clinical report provides definitions for the possible clinical outcomes of cCMV infection:

- **CMV infection:** no apparent signs to suggest CMV disease and normal hearing testing
- **CMV infection with isolated sensorineural hearing loss:** no signs of congenital CMV disease other than sensorineural hearing loss
- **Mild congenital CMV disease:** less than or equal to two transient or clinically insignificant findings (e.g., petechiae, mild hepatomegaly, thrombocytopenia, elevated alanine aminotransferase)
- **Moderate/severe cCMV disease** (with or without sensorineural hearing loss): single severe or multi-organ disease or multiple milder but persistent abnormalities (e.g., thrombocytopenia, hepatomegaly, splenomegaly, hepatitis; or intracranial abnormalities, chorioretinitis, or detection of CMV DNA in cerebrospinal fluid)

Recommendations for treatment with CMV antiviral medications are guided by these definitions and are outlined in the clinical report and the 2024-2027 *Red Book*.

Minimizing risk of hearing loss

Congenital CMV infection with sensorineural hearing loss is the most common cause of non-genetic congenital hearing loss. Hearing differences can be apparent at birth or develop later in infancy and early childhood and can result in permanent sensorineural hearing loss. As reviewed in the clinical report, there is evidence that antiviral therapy started within 13 weeks after birth may benefit hearing outcomes and may be offered after discussion and shared decision-making with parents.

Screening approaches

The best clinical approach to congenital CMV screening has been

debated for years. Congenital infection is diagnosed by CMV DNA-based testing of urine, saliva, blood or dried blood spots obtained by 21 days of age. The clinical report reviews the benefits and limitations of the three approaches to test-based screening:

- **Expanded testing** involves testing infants with specific risk factors or with certain physical, laboratory or imaging findings.
- **Hearing-targeted screening** involves testing all infants who fail to pass routine newborn hearing screening.
- **Universal screening** involves testing all newborns, often with dried blood spot-based screening.

After reviewing the data associated with each approach, the AAP guidance recommends a hearing-targeted plus expanded testing program as the best evidence-based approach for identifying newborns with cCMV infection.

This recommendation is based on the assessment that this approach can identify infants who may benefit most from antiviral therapy and/or longitudinal hearing and developmental monitoring, while minimizing identification of most infants who will have no sequelae of congenital infection. Using this approach, term and preterm newborns should be tested for CMV if any of the following are present:

- Not passing the newborn hearing screen
- Maternal HIV infection or CMV infection during pregnancy
- Abnormal central nervous system imaging consistent with cCMV
- Abnormal prenatal or postnatal imaging identifying intra-abdominal calcifications
- Unexplained hepatomegaly, splenomegaly, petechial rash, thrombocytopenia, elevated liver enzymes, and/or elevated conjugated bilirubin
- Small for gestational age (birth weight less than the 10th percentile for gestational age)

• Microcephaly (head circumference less than the 10th percentile for gestational age)

Preterm, very low birth weight infants of ten cannot have hearing tested before 21 days of age. For this reason, the report suggests clinicians consider CMV testing for all such infants by 21 days of age. This approach also allows for the accurate diagnosis of postnatally acquired CMV, an infection with specific implications for very preterm infants.

The report also provides guidance for clinicians in multiple aspects of CMV management, including approaches to minimizing exposure to CMV during pregnancy; strategies to decrease disparities in CMV testing; recommendations for initial evaluation after cCMV is diagnosed; guidance on antiviral therapy; and recommendations for pediatric infectious disease consultation and longitudinal audiologic, ophthalmologic, neurodevelopmental and therapeutic care. Provision of staff education and local development of evidence-based guidelines/protocols are recommended to improve individual provider recognition of signs and risk factors for cCMV.

The answer to the question posed at the start of this article — all the infants described in the clinical scenarios should be tested for congenital CMV. For those patients and others like them, the clinical report aids clinicians in the identification of infants with congenital CMV infection who can benefit from appropriate initial care and longitudinal monitoring.

Raw dairy risks to children, pregnant people outlined in updated AAP policy

NEWS PROVIDED BY

American Academy of Pediatrics

By Anne Sardi, M.D., FAAP, and Adam J. Ratner, M.D., M.P.H., FAAP

Study: **Raw dairy risks to children, pregnant people outlined in updated AAP policy**

Current as of October 5, 2026

When asking patients about unpasteurized or “raw” milk consumption, pediatricians may be surprised by their answers. More patients may be consuming unpasteurized dairy products, putting them at risk of serious illness.

An updated policy statement from the AAP Committee on Infectious Diseases and the AAP Committee on Nutrition outlines the risks of unpasteurized dairy consumption and addresses the falsely claimed nutritional benefits. “Consumption of Unpasteurized (Raw) Milk and Milk Products by Pregnant People and Children” is available at doi.org/10.1542/peds.2026-079036 and will be published in the November issue of *Pediatrics*.

Raw milk myths

Pasteurization, a standardized process of heating to a specific temperature for a minimum duration, inactivates pathogens that once made milk a leading cause of foodborne illness and infant mortality. Unpasteurized milk is often referred to as “raw” milk.

Despite the widespread availability of pasteurized dairy, some consumers, more often young adults living in rural areas, seek out raw milk and dairy products made from it. They believe false claims that raw dairy offers health benefits, such as higher nutritional content and reduced allergic reactions. In reality, the heat from pasteurization does not change or improve the nutritional value of milk as a source of protein, fat and vitamins. It does, however, kill disease-causing bacteria, parasites and viruses.

According to the policy, the incidence of foodborne illness outbreaks linked to unpasteurized milk has increased in the past 20 years, with nearly half of illnesses in children. More than three-quarters of single-state outbreaks occurred where the retail sale of unpasteurized milk is legal.

Sources of illness

Pathogens responsible for the majority of foodborne illness linked to unpasteurized dairy include *Campylobacter* species, *Salmonella* species, Shiga toxin producing *E coli* (STEC), *Cryptosporidium* species, and *Listeria monocytogenes*. STEC serotype O157:H7 is responsible for the majority of U.S. cases of hemolytic-uremic syndrome, a serious complication from diarrheal illness more often seen in young children.

Many more pathogens can survive in milk and have the potential to cause disease. The policy includes new information on highly pathogenic avian influenza (HPAI)

virus, an emerging milk-borne pathogen. During a multi-state outbreak in dairy cattle in 2024, HPAI A(H5N1) virus was detected in nearly one-quarter of unpasteurized milk samples and led to several cases of symptomatic illness in dairy farm workers through contact with mucous membranes. Illness from consuming unpasteurized milk contaminated with HPAI A(H5N1) has so far only been demonstrated in animals. The potential for unpasteurized dairy to cause cow-to-human transmission of HPAI A(H5N1) remains a concern.

The Food and Drug Administration bans the interstate shipment of unpasteurized milk. However, unpasteurized cheese aged 60 days is exempt from the ban. In a recent *E.coli* O157:H7 outbreak linked to aged unpasteurized cheese, seven of the nine cases were in California — where unpasteurized milk products can also be legally sold in grocery stores.

What can be done to protect patients from milk-borne pathogens?

Efforts in clinical practice can focus on educating families on the benefits of pasteurization. All children who consume raw dairy are at risk, but infants and young children, immunocompromised individuals and pregnant persons are particularly vulnerable. The risk of vertical transmission of listeriosis and toxoplasmosis should be discussed in pregnancy. Particularly in states with legalized sale, advocating for legislation prohibiting the sale of unpasteurized milk and milk products can protect children and families more broadly.

Key recommendations:

- Know state laws on the sale of unpasteurized dairy.
- Ask patients and family members about unpasteurized dairy consumption as a component of dietary history, especially in states allowing retail sale.
- Encourage patients to choose dairy products — including those made from the milk of cows, goats and sheep — labeled as pasteurized.
- Educate families on the reasons to choose pasteurized products, emphasizing equivalent health benefits and the decreased risk of foodborne illness.
- Advocate for legislation to prohibit the sale of unpasteurized dairy.

New global roadmap launched to tackle hypertension in pregnancy, a leading cause of maternal and newborn deaths

NEWS PROVIDED BY

World Health Organization

By WHO Media Team

Study: New global roadmap launched to tackle hypertension in pregnancy, a leading cause of maternal and newborn deaths

Current as of October 8, 2026

The World Health Organization (WHO) and partners today launched a new global roadmap to tackle hypertensive disorders of pregnancy, including pre-eclampsia, which affect millions of women every year. These disorders remain among the leading causes of death and serious illness for pregnant women and their babies, with tragic long-term impact on their families.

Hypertensive disorders complicate an estimated 10–15% of pregnancies worldwide. They account for around 16% of maternal deaths globally, resulting in an estimated 42 000 deaths each year, as well as more than 500 000 stillbirths and newborn deaths.

In many countries, women still lack reliable access to basic blood-pressure measurement, urine protein testing and essential medicines, including aspirin, antihypertensives and magnesium sulfate. Weak refer-

ral systems, shortages of trained health workers and limited emergency obstetric services can further delay life-saving care.

“Pre-eclampsia can develop in any pregnancy. Whether it becomes fatal depends on whether a woman’s blood pressure was checked in time, and whether quality emergency care was within reach when it turned severe,” said Dr Pascale Allotey, Director of WHO’s Department of Sexual, Reproductive, Maternal, Child, Adolescent Health and Ageing. “This roadmap brings together research, medicines, clinical guidance, health systems and political action so that a woman’s chances of surviving pregnancy and having a baby do not depend on where she lives.”

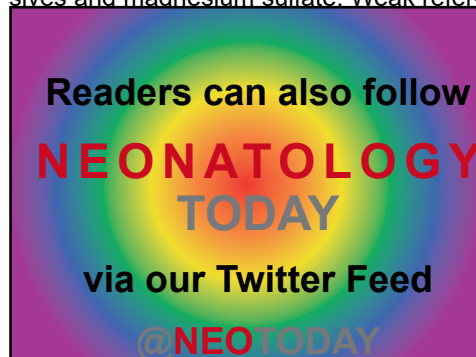
Launched at the Society for Maternal-Fetal Medicine Global Conference, the *Global roadmap for hypertensive disorders of pregnancy from 2026 to 2035 and beyond* sets out coordinated actions across research and innovation, global clinical guidance, access to medicines and diagnostics, implementation, advocacy and accountability.

The roadmap highlights a striking innovation gap between the scale of the problem and the lack of medicines specifically developed and approved by regulators for the prevention or treatment of pre-eclampsia or eclampsia. Research investment has largely focused on diagnostics, with chronic underinvestment in new preventive and treatment options.

To change this, WHO brought together more than 140 partners at a global summit in May 2026 to identify and answer 20 priority research questions to guide future investment that will help predict, detect and treat hypertensive disorders in pregnancy. In low- and middle-income countries, gaps in antenatal care, medicines, diagnostics, trained health workers and emergency services mean women are more likely to develop severe complications or die. Women affected by poverty, humanitarian crises, geographic isolation and other challenges face particularly high risks.

Pre-eclampsia can also have consequences for mothers long after childbirth. Women affected by hypertensive disorders of pregnancy face increased risks later in life of chronic hypertension, cardiovascular disease, stroke and kidney disease, while children exposed during pregnancy can face increased risks associated with pre-term birth and longer-term cardiovascular and metabolic disease.

WHO asks governments, funders, researchers, health professionals, industry, civil society and development partners to



align investment and action around one goal: ensuring that proven interventions and future innovations reach the women and babies who need them most.

WHO Guideline Development Group meets to review Abortion care guideline

NEWS PROVIDED BY

World Health Organization

By WHO Media Team

Study: **WHO Guideline Development Group meets to review Abortion care guideline**

Current as of October 14, 2026

The World Health Organization has transitioned the Abortion care guideline to a living guideline format to focus on targeted recommendations that address new evidence or implementation issues as they arise. To this effect, the evidence for repeat dosing for the misoprostol-alone regimen for medical abortion at less than 12 weeks will be revisited (Recommendation 27b). In line with the WHO handbook for guideline development, a subset of the Abortion care guideline's Guideline Development Group (GDG) is being reconvened to assist the WHO Steering Group in this process. The GDG will review the synthesized evidence and formulate an updated recommendations. Of note, members of this GDG for this recommendation arise from the group of experts who had informed the Abortion care guideline and therefore, their updated biographies are being posted.

The biographies of the GDG members are made public for a period of 14 days in line with WHO standards in guideline development.

Technical advisory group to advise on WHO's maternal and perinatal health guideline portfolio

NEWS PROVIDED BY

World Health Organization

By WHO Media Team

Study: **Technical advisory group to advise on WHO's maternal and perinatal health guideline portfolio**

Current as of October 5, 2026

The World Health Organization (WHO) and the UNDP/UNFPA/UNICEF/WHO/World Bank Special Programme of Research, Development and Research Training in Human Reproduction (HRP) works to improve health and well-being for people of all ages in every country. Through its normative role, WHO develops global, evidence-informed recommendations to improve maternal and perinatal health.

WHO and HRP are convening a Technical Advisory Group (TAG) meeting on Maternal and Perinatal Health Guidelines on 12–13 October 2026, from 09:00 to 17:00 CET each day. The meeting will:

- review current evidence in key maternal and perinatal health areas
- agree on priority actions for WHO/LHR/MPH.

WHO launches TB in pregnancy and lactation research toolkit

NEWS PROVIDED BY

World Health Organization

By WHO Media Team

Study: **WHO launches TB in pregnancy and lactation research toolkit**

Current as of October 13, 2026

The World Health Organization (WHO) has launched the TB in pregnancy and lactation research toolkit, a new online resource designed to support the earlier and optimal inclusion of pregnant and lactating women in tuberculosis (TB) research. The toolkit provides practical guidance and tools for researchers, trial sponsors, ethics committees, regulators and other stakeholders involved in TB drug and vaccine research.

"Pregnant and lactating women continue to be underrepresented in TB research, resulting in critical evidence gaps that delay access to innovations and optimal care," said Dr Tereza Kasaeva, Director of WHO's Department for HIV, Tuberculosis, Hepatitis and Sexually Transmitted Infections. "This new WHO toolkit will help close these gaps by advancing their inclusion in research, ensuring that women and their infants benefit from scientific advances and accelerating progress towards ending TB for everyone."

Pregnant and lactating women have historically been excluded from TB drug and vaccine trials, contributing to critical evidence gaps related to the safety, pharmacokinetics, dosing and effectiveness of interventions used during pregnancy and lactation. As a result, women and their infants are often among the last to benefit from advances in TB prevention and treatment. The new toolkit aims to facilitate a

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more systematic and evidence-based approach to inclusion, helping researchers generate the data needed to inform policies and improve care.

The toolkit offers practical guidance on:

- ethical considerations and community engagement
- preclinical considerations relevant to TB research
- trial design and pharmacokinetics during pregnancy, postpartum and lactation
- outcome measures and sample size considerations
- recruitment and retention strategies
- regulatory aspects
- TB vaccine trial considerations, and
- surveillance and registries.

The toolkit is supported by case studies and curated resources drawn from completed and ongoing research initiatives.

Toolkit development process

The toolkit was developed as a direct follow-up to the WHO-led global consensus process on the early and optimal inclusion of pregnant and lactating women in TB research. Through a series of working groups and consultations held during 2024 and 2025, experts from all WHO regions examined barriers to inclusion and identified practical approaches to strengthen the generation of evidence for this important population. The process culminated in the publication of the consensus statement *Optimal and early inclusion of pregnant and lactating women in tuberculosis research* and the accompanying Call to action: *Accelerating research to end tuberculosis in pregnant and lactating women* in August 2025. Development of a TB-specific research toolkit was identified as one of the priority actions in the Call to Action.

The TB toolkit complements a broader WHO knowledge portal that provides generic guidance on the inclusion of pregnant and lactating women in clinical research across health conditions. While the broader knowledge portal outlines overarching principles and approaches, the TB toolkit translates these into practical consider-

ations specific to TB research. Additional information on the broader WHO initiative is available from the Human Reproduction Programme (HRP): *Sexual and Reproductive Health and Research (SRH)*.

NEWS PROVIDED BY

World Health Organization

WHO to update the recommendations on criteria and diagnosis of hyperglycaemia in pregnancy

By WHO Media Team

Study: **WHO to update the recommendations on criteria and diagnosis of hyperglycaemia in pregnancy**

Current as of September 25, 2026

One in six live births (21 million per year) is affected by hyperglycaemia during pregnancy. Hyperglycaemia in pregnancy includes diabetes that existed before pregnancy, diabetes first diagnosed during pregnancy, or gestational diabetes mellitus (GDM), a form of elevated glucose (blood sugar) levels that appears during pregnancy. Distinguishing between these conditions is often challenging, particularly in settings with a high prevalence of undiagnosed pre-existing diabetes.

Hyperglycaemia during pregnancy is associated with increased risks of adverse maternal and perinatal outcomes, including hypertensive disorders of pregnancy, stillbirth, macrosomia, neonatal hypoglycaemia, birth injury, and other long-term complications. Early identification and accurate classification of hyperglycaemia during pregnancy are therefore critical to enable appropriate care and reduce the risk of adverse outcomes.

Given the substantial and growing global burden of diabetes, with most cases occurring in low- and middle-income countries, guidance that is applicable across diverse resource settings is needed. With a view to improving maternal and newborn

outcomes worldwide, the World Health Organization (WHO) published its first recommendations on care for women with diabetes during pregnancy in November 2025.

The updated recommendations set to come out in 2026 will include updates on the 2013 recommendations on the diagnostic criteria and classification of hyperglycaemia first detected during pregnancy. New evidence has emerged regarding approaches to screening, diagnosis, and classification, highlighting the need to revisit this guidance. Revising these recommendations has been prioritized as part of WHO's broader efforts to address non-communicable diseases in pregnancy and improve maternal and newborn health outcomes worldwide.

A Guideline Development Group (GDG) meeting will be held 20–24 October 2026 to review the evidence base on the screening and diagnosis of hyperglycaemia in pregnancy. In keeping with the requirements of the WHO Compliance, Risk Management and Ethics Office, we are posting online short biographies of the GDG members. The listed candidates have also submitted a declaration of interest form stating any conflict of interests. WHO has applied its internal processes to ensure that the performance of the above tasks by members of this group will be transparent and without any significant conflict of interests (academic, financial or other) that could affect the credibility of the guideline.

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Genetics Corner: De Novo Pathogenic WT1 Zinc-Finger Variant Presenting as Neonatal-Onset Congenital Nephrotic Syndrome With Early Dialysis Dependence

Hua Wang, MD, PhD, FACMG

Abstract:

Background: Germline pathogenic variants in WT1 cause an autosomal dominant disorder characterized by a variable combination of progressive glomerulopathy, Wilms tumor predisposition, and differences in gonadal development. Missense variants affecting the DNA-binding zinc-finger domain are particularly associated with early-onset steroid-resistant nephrotic syndrome and diffuse mesangial sclerosis.

“Germline pathogenic variants in WT1 cause an autosomal dominant disorder characterized by a variable combination of progressive glomerulopathy, Wilms tumor predisposition, and differences in gonadal development. Missense variants affecting the DNA-binding zinc-finger domain are particularly associated with early-onset steroid-resistant nephrotic syndrome and diffuse mesangial sclerosis.”

Case Presentation: A term, small-for-gestational-age female infant presented during the second week of life with feeding intolerance, coffee-ground emesis, abdominal distention, severe hyponatremia and metabolic acidosis, acute kidney injury, profound hypoalbuminemia, anasarca, and massive proteinuria. Her course was complicated by Bell stage IIIB necrotizing enterocolitis with ileal perforation requiring bowel resection and ostomy creation, dialysis-dependent kidney failure, acquired hypogammaglobulinemia, hypertension, and central venous catheter-associated thrombosis. Rapid trio whole-exome sequencing identified a heterozygous pathogenic WT1 variant, NM_024426.6:c.1316G>A (p.Arg439His); parental testing was negative in both parents, supporting an apparently de novo event. Chromosomal microarray showed a female copy-number profile without pathogenic copy-number change, and pelvic ultrasonography demonstrated müllerian structures. The molecular diagnosis established WT1 disorder as the unifying cause of the congenital nephrotic syndrome and directly informed avoidance of ineffective immunosuppression, Wilms tumor surveillance, and long-term kidney replacement planning.

Conclusion: This case expands the clinically important severe end of the WT1 disorder spectrum by illustrating that neonatal WT1 glomerulopathy may first be recognized during catastrophic multisystem illness. The case also emphasizes the clinical value of rapid genomic testing in critically ill infants and the importance of reporting the exact laboratory-confirmed WT1 transcript and HGVS nomenclature.

Introduction:

WT1, located at chromosome 11p13, encodes a C2H2 zinc-finger transcription factor with central roles in renal, gonadal, and genitourinary development. Historically, germline WT1-associated phenotypes were separated into Denys-Drash syndrome, Frasier syndrome, isolated steroid-resistant nephrotic syndrome, and other named entities. Contemporary frameworks increasingly use the unifying term WT1 disorder because renal, tumor-predisposition, and gonadal phenotypes overlap and are strongly influenced by variant class and location (1–4).

“WT1, located at chromosome 11p13, encodes a C2H2 zinc-finger transcription factor with central roles in renal, gonadal, and genitourinary development.”

Congenital nephrotic syndrome (CNS), defined by onset within the first 3 months of life, is characterized by severe proteinuria, hypoalbuminemia, edema, and substantial risks related to infection, thrombosis, malnutrition, endocrine protein loss, and kidney failure. Genetic causes predominate, and early molecular diagnosis is increasingly central to management because it can distinguish disorders for which immunosuppression is ineffective and identify gene-specific extrarenal risks (5, 6).

“Congenital nephrotic syndrome (CNS), defined by onset within the first 3 months of life, is characterized by severe proteinuria, hypoalbuminemia, edema, and substantial risks related to infection, thrombosis, malnutrition, endocrine protein loss, and kidney failure.”

Within *WT1* disorder, missense variants affecting the DNA-binding zinc fingers are associated with earlier glomerulopathy than many truncating or KTS splice variants. Recent national and international cohorts further demonstrate that *WT1* disease is broader than the classic eponymous syndromes and includes both very early and late-onset phenotypes (2–4, 10, 11).

“Within *WT1* disorder, missense variants affecting the DNA-binding zinc fingers are associated with earlier glomerulopathy than many truncating or KTS splice variants. Recent national and international cohorts further demonstrate that *WT1* disease is broader than the classic eponymous syndromes and includes both very early and late-onset phenotypes.”

We report a term infant with severe neonatal CNS, necrotizing enterocolitis with bowel perforation, thrombosis, and rapid progression to dialysis dependence in whom rapid trio exome sequencing identified a heterozygous pathogenic *WT1* variant, NM_024426.6:c.1316G>A (p.Arg439His), with negative parental testing. The report highlights the diagnostic value of rapid sequencing and the management consequences of recognizing *WT1* disorder during complex neonatal critical illness.

Case Presentation:

Clinical Evolution and Multisystem Illness

The patient was a female infant born at 38 weeks and 1 day of gestation to a 33-year-old gravida 2, para 2 mother by uncomplicated spontaneous vaginal delivery after an uneventful pregnancy with normal fetal anatomy ultrasonography. Birth weight

“The patient was a female infant born at 38 weeks and 1 day of gestation to a 33-year-old gravida 2, para 2 mother by uncomplicated spontaneous vaginal delivery after an uneventful pregnancy with normal fetal anatomy ultrasonography. Birth weight was 2,484 g (3.9th percentile), length 44 cm (<1st percentile), and head circumference 33 cm (22nd percentile), consistent with small for gestational age.”

was 2,484 g (3.9th percentile), length 44 cm (<1st percentile), and head circumference 33 cm (22nd percentile), consistent with small for gestational age. Apgar scores were 8 and 9 at 1 and 5 minutes, respectively, and she was discharged home after routine newborn care.

During the first week of life, oral intake progressively deteriorated. On day of life 6, she was admitted to a community hospital for lethargy and poor feeding, followed by progressive abdominal distention and coffee-ground gastric aspirates. On day of life 8, she was transferred to a level IV neonatal intensive care unit for escalating respiratory and hemodynamic support. Examination showed pallor, marked abdominal distention and tenderness, and edematous external female genitalia without clitoromegaly or palpable inguinal masses. No major dysmorphic, skeletal, or digital anomalies were noted.

“During the first week of life, oral intake progressively deteriorated. On day of life 6, she was admitted to a community hospital for lethargy and poor feeding, followed by progressive abdominal distention and coffee-ground gastric aspirates.”

Initial laboratory testing demonstrated serum sodium 118 mmol/L, severe metabolic acidosis, thrombocytopenia with a nadir of $24 \times 10^9/L$, and acute kidney injury with serum creatinine rising from 1.2 to 4.1 mg/dL. During the next 72 hours, she developed profound anasarca and massive urinary protein loss. Spot urine protein-to-creatinine ratio was 2,958 mg/g; urine albumin-to-creatinine ratio exceeded 23,280 mg/g; urine dipstick protein remained $\geq 1,000$ mg/dL; and serum albumin fell to 1.0–1.4 g/dL, establishing severe neonatal nephrotic syndrome.

“Initial laboratory testing demonstrated serum sodium 118 mmol/L, severe metabolic acidosis, thrombocytopenia with a nadir of $24 \times 10^9/L$, and acute kidney injury with serum creatinine rising from 1.2 to 4.1 mg/dL. During the next 72 hours, she developed profound anasarca and massive urinary protein loss.”

Associated complications included acquired hypogammaglobulinemia (serum IgG <100 mg/dL), thyroid hormone abnormalities requiring replacement, and systemic hypertension requiring intravenous nicardipine. These findings

are biologically consistent with the broad consequences of severe urinary protein loss in CNS (5, 6).

Her gastrointestinal disease progressed to Bell stage IIIB necrotizing enterocolitis. Serial radiographs showed extensive pneumatosis intestinalis followed by pneumoperitoneum on day of life 14. Exploratory laparotomy demonstrated necrotizing hemorrhagic enterocolitis with distal ileal perforation, requiring segmental small-bowel resection and end ileostomy. On day of life 77, she underwent ileostomy takedown, bowel reanastomosis, and gastrostomy placement. A subsequent gastrostomy-site upper gastrointestinal hemorrhage was managed with tube revision, octreotide, pantoprazole, and temporary interruption of anticoagulation.

“Her gastrointestinal disease progressed to Bell stage IIIB necrotizing enterocolitis. Serial radiographs showed extensive pneumatosis intestinalis followed by pneumoperitoneum on day of life 14.”

Kidney failure progressed to anuria. Continuous kidney replacement therapy was initiated through a right internal jugular dual-lumen catheter for fluid overload, hyperkalemia, and uremia, with subsequent transitions between continuous therapy and prolonged intermittent hemodialysis according to hemodynamic status. Attempts to reduce dialysis frequency were limited by recurrent fluid accumulation and hypertension.

“Kidney failure progressed to anuria. Continuous kidney replacement therapy was initiated through a right internal jugular dual-lumen catheter for fluid overload, hyperkalemia, and uremia, with subsequent transitions between continuous therapy and prolonged intermittent hemodialysis according to hemodynamic status.”

The combination of severe nephrotic syndrome and central venous access was complicated by nonocclusive inferior vena cava thrombosis extending toward the renal vein confluence. Nephrotic syndrome is a recognized prothrombotic state related in part to urinary loss of anticoagulant proteins and compensatory hepatic changes (12). Unfractionated heparin was difficult to titrate and required antithrombin supplementation, followed by low-molecular-weight heparin after gastrointestinal bleeding stabilized. The prolonged critical-care course also required mechanical ventilation, blood-product support, and immunoglobulin replacement. A later

airway evaluation for a weak, hoarse cry showed laryngomalacia and left vocal-fold paresis after repeated intubations.

Family history was negative for congenital nephropathy, childhood kidney failure, differences of sex development, or early-onset malignancy. The parents were healthy and non-consanguineous.

“Family history was negative for congenital nephropathy, childhood kidney failure, differences of sex development, or early-onset malignancy. The parents were healthy and non-consanguineous.”

Genetic Analysis and Molecular Characterization

Because of the neonatal onset and severity of nephrotic syndrome, rapid trio whole-exome sequencing was pursued. Testing identified a heterozygous pathogenic missense variant in *WT1*, NM_024426.6:c.1316G>A (p.Arg439His). The original laboratory report classified the variant as pathogenic and documented negative testing in both parents, supporting an apparently de novo event. The variant affects the *WT1* DNA-binding zinc-finger region and has been reported in association with Denys-Drash syndrome and early-onset nephrotic syndrome (2–4, 13).

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The laboratory classification is supported by negative parental testing, localization within the highly constrained DNA-binding zinc-finger domain, prior disease association of this recurrent variant, and the highly specific renal phenotype. The manuscript therefore reproduces the laboratory classification as pathogenic without retrospectively applying ACMG/AMP criteria not explicitly documented in the clinical report (7).

Chromosomal microarray demonstrated a female copy-number profile without pathogenic copy-number alteration or a chromosome 11p13 deletion. Pelvic ultrasonography showed a neonatal uterus and right ovary; the left ovary was not visualized because of bowel gas. Renal ultrasonography showed enlarged echogenic kidneys without a focal renal mass.

Discussion:

WT1 Disorder at the Severe Neonatal End of the Spectrum

This infant represents the severe neonatal end of *WT1*-associated glomerulopathy. Although persistent proteinuria or steroid-resistant nephrotic syndrome is the characteristic renal presentation of *WT1* disorder, age at onset varies substantially. Zinc-finger missense variants are enriched among patients with early glomerulopathy, whereas truncating variants more often present first with Wilms tumor and may have later renal disease (2–4, 10, 11). The extraordinarily rapid transition from neonatal proteinuria to anuria and dialysis dependence in this case is therefore biologically consistent with the variant class, while still representing an unusually severe clinical trajectory.

“This infant represents the severe neonatal end of WT1-associated glomerulopathy. Although persistent proteinuria or steroid-resistant nephrotic syndrome is the characteristic renal presentation of WT1 disorder, age at onset varies substantially. Zinc-finger missense variants are enriched among patients with early glomerulopathy, whereas truncating variants more often present first with Wilms tumor and may have later renal disease. The extraordinarily rapid transition from neonatal proteinuria to anuria and dialysis dependence in this case is therefore biologically consistent with the variant class, while still representing an unusually severe clinical trajectory.”

The simultaneous occurrence of severe NEC should be described cautiously. CNS can produce profound hypoalbuminemia, edema, intravascular volume instability, infection susceptibility, and thrombosis, all of which may worsen physiologic reserve during critical illness (5, 6). However, available evidence does not establish *WT1* dysfunction or nephrotic syndrome as a direct cause of NEC. The novelty of this case is therefore not a claimed *WT1*–NEC causal association, but the diagnostic challenge created when a monogenic glomerulopathy is initially embedded within a catastrophic surgical and hemodynamic neonatal presentation.

The CNS differential diagnosis includes *NPHS1*, *NPHS2*, *LAMB2*, *PLCE1*, *WT1*, and other monogenic podocytopathies. Contemporary consensus recommendations support early genetic testing because establishing a monogenic diagnosis informs prognosis, extrarenal surveillance, and treatment selection (5, 6). In *WT1* disorder specifically, immunosuppression is generally

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ineffective and potentially toxic; recognition of the molecular diagnosis therefore prevents escalation of therapies intended for immune-mediated nephrotic syndrome (1).

Molecular Genetics and the Importance of Transcript-Aware Nomenclature

WT1 produces multiple isoforms through alternative splicing, including the clinically important $\pm$ KTS isoforms. The C-terminal zinc fingers mediate sequence-specific nucleic-acid binding, and structural studies demonstrate that disease-associated substitutions within this region can materially alter target recognition (13, 14). The p.Arg439His variant identified in this patient lies within this functionally critical region and corresponds to a recurrent disease-associated *WT1* substitution described in the Denys-Drash spectrum (2–4, 13).

WT1 has multiple historical and current transcripts, and residue numbering can differ across publications and diagnostic pipelines. To avoid conflating distinct amino-acid substitutions across isoforms, we report the variant exactly as documented by the molecular laboratory: NM_024426.6:c.1316G>A (p.Arg439His). Historical literature has used alternative numbering for this recurrent substitution; therefore, transcript accession and version should accompany HGVS nomenclature whenever cross-referencing older *WT1* reports.

Diagnostic Value of Rapid Genomic Sequencing

Rapid genomic sequencing has demonstrated diagnostic and clinical utility in critically ill infants with suspected monogenic disease. In this case, rapid trio sequencing was particularly valuable because the phenotype was dominated by multisystem critical illness rather than an isolated nephrology presentation. The molecular diagnosis reframed the kidney disease as a primary genetic podocytopathy, supported avoidance of ineffective immunosuppression, and immediately triggered *WT1*-specific tumor and gonadal considerations (8, 9).

The strongest clinical argument for rapid sequencing here is therefore not simply diagnostic yield; it is actionability. A definitive *WT1* diagnosis changes surveillance, anticipatory counseling, and kidney-replacement planning during the same hospitalization. This distinction strengthens the case's clinical significance beyond

another report of a known *WT1* variant.

“Rapid genomic sequencing has demonstrated diagnostic and clinical utility in critically ill infants with suspected monogenic disease. In this case, rapid trio sequencing was particularly valuable because the phenotype was dominated by multisystem critical illness rather than an isolated nephrology presentation. The molecular diagnosis reframed the kidney disease as a primary genetic podocytopathy, supported avoidance of ineffective immunosuppression, and immediately triggered *WT1*-specific tumor and gonadal considerations.”

Tumor Surveillance and Gonadal Considerations

Germline *WT1* pathogenic variants confer substantial Wilms tumor risk, with risk varying by molecular class. The 2024 AACR update estimates an overall Wilms tumor risk of approximately 38%–43% for *WT1*-related disorders and recommends abdominal ultrasonography every 3 months through age 7 years in affected children (15). This current recommendation should replace older wording suggesting surveillance through 7–8 years. Surveillance should begin when the diagnosis is recognized, including during infancy.

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Gonadal phenotype is also variant- and karyotype-dependent. *WT1* variants can cause 46,XY differences of sex development and gonadal tumor risk, but gonadal involvement is not restricted to 46,XY individuals. Available data support attention to pubertal development and gonadal function in 46,XX individuals as well (1). In this patient, the female chromosomal complement and

demonstrated müllerian structures are reassuring regarding current anatomy but do not eliminate the need for longitudinal assessment of pubertal and reproductive function.

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Kidney Replacement and Transplantation Considerations

Severe CNS requires individualized management of fluid balance, nutrition, thrombosis, infection risk, and kidney replacement therapy (5, 6). Peritoneal dialysis is commonly favored for chronic infant dialysis, but major abdominal surgery, bowel perforation, ostomy creation, and adhesions can make peritoneal access impractical or unsafe. In this patient, those constraints necessitated prolonged extracorporeal kidney replacement therapy and vascular access despite a high thrombotic burden.

For patients with *WT1* disorder who reach kidney failure, transplantation is definitive renal therapy. Decisions regarding native nephrectomy should be individualized with nephrology, transplant surgery, and oncology because nephrectomy may address persistent protein loss and eliminate native-kidney Wilms tumor risk but also has important timing and surgical implications. The manuscript should avoid implying that bilateral nephrectomy is universally required; contemporary management is genotype-, tumor-risk-, and patient-specific (1, 15).

“For patients with *WT1* disorder who reach kidney failure, transplantation is definitive renal therapy. Decisions regarding native nephrectomy should be individualized with nephrology, transplant surgery, and oncology because nephrectomy may address persistent protein loss and eliminate native-kidney Wilms tumor risk but also has important timing and surgical implications.”

Conclusion:

This case illustrates an unusually severe neonatal presentation of *WT1* disorder in which congenital nephrotic syndrome rapidly progressed to dialysis-dependent kidney failure amid necrotizing

enterocolitis, bowel perforation, thrombosis, and prolonged critical illness. Rapid trio exome sequencing provided clinically actionable etiologic resolution and redirected management toward gene-specific tumor surveillance, gonadal follow-up, and long-term kidney replacement planning. The case is most distinctive not because NEC can be attributed to *WT1*, which remains unproven, but because a severe monogenic podocytopathy was revealed within a complex neonatal surgical presentation. The molecular diagnosis is reported using the laboratory-confirmed nomenclature NM_024426.6:c.1316G>A (p.Arg439His).

Take-Home Messages:

- **Recognize severe neonatal *WT1* disease:** *WT1* glomerulopathy can present within the first weeks of life and progress rapidly to kidney failure even in a 46,XX infant without genital ambiguity.
- **Use rapid genomic testing when the phenotype is complex:** In critically ill infants with unexplained nephrotic-range proteinuria or early kidney failure, rapid exome/genome sequencing can change management during the index hospitalization.
- **Do not over-attribute associated critical illness:** NEC and bowel perforation may coexist with severe CNS, but current evidence does not establish a direct *WT1*–NEC causal relationship.
- **Report exact variant nomenclature:** *WT1* isoform complexity makes inclusion of the transcript accession/version essential; in this case, the laboratory-confirmed result is NM_024426.6:c.1316G>A (p.Arg439His).
- **Initiate current tumor surveillance:** For *WT1*-related disorders, current AACR guidance supports abdominal ultrasonography every 3 months through age 7 years.
- **Plan longitudinal gonadal care:** Chromosomal sex and current pelvic anatomy inform risk assessment, but pubertal and gonadal function warrant longitudinal follow-up.

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Briefly Legal: The Quality of Justice

Maureen E. Sims, MD, Barry Schifrin, MD

A 24-year-old G2P0 mother with an unremarkable prenatal course enters the emergency room at 0500, having been awakened by abdominal pain and vaginal bleeding. Her GBS is unknown. The cervix is closed and poorly effaced. She is immediately attached to a fetal monitor, which reveals excessive uterine activity, including about 1 contraction per minute with obvious coupling and elevated baseline tone (by inference).

“A 24-year-old G2P0 mother with an unremarkable prenatal course enters the emergency room at 0500, having been awakened by abdominal pain and vaginal bleeding. Her GBS is unknown. The cervix is closed and poorly effaced. She is immediately attached to a fetal monitor, which reveals excessive uterine activity, including about 1 contraction per minute with obvious coupling and elevated baseline tone (by inference).”

The baseline FHR was about 140 bpm with decreased variability and recurrent late decelerations with contractions. Improbably, the nurses' notes describe the FHR pattern as “Category I” and the contraction frequency as “every 2-4 minutes.” Given the abdominal pain, vaginal bleeding, uterine activity, and fetal distress in a preterm gestation, the diagnosis of placental abruption could not have been more straightforward. Further, given the improbability of safe vaginal delivery in the foreseeable future, an immediate cesarean section was required. The fetus, however, was not delivered for over 2 hours, during which time there was obvious deterioration in the fetal tracing with the FHR pattern evolving into a total loss of variability. The tracing was discontinued after about 1.5 hours, when the patient was taken to the OR 40 minutes before delivery. No monitoring was performed in the delivery room. Upon arrival in the OR, the patient was prepped and given a spinal anesthetic despite the lack of a neonatologist. In response to the spinal, the patient's blood pressure dropped, and the decision was made to expedite the delivery without the neonatologist (a

requirement of the hospital's policy). At delivery at 0700, two hours after presenting to the ER, the 34-week, appropriately grown (AGA) female infant (2740 g) was flaccid, pale, and had no heart rate. Apgar scores were 0, 1, 2, 2, and 4 at 1, 5, 10, 15, and 20 minutes, respectively.

“The venous cord gas showed a pH of 6.8 and a base excess of 29.6. An arterial gas was not sent. Arriving shortly before birth, a NICU nurse and respiratory therapist attended the delivery. Resuscitation included intubation, chest compressions, epinephrine via both endotracheal tube (ETT) and umbilical venous catheter (UVC), and two normal saline boluses.”

The venous cord gas showed a pH of 6.8 and a base excess of 29.6. An arterial gas was not sent. Arriving shortly before birth, a NICU nurse and respiratory therapist attended the delivery. Resuscitation included intubation, chest compressions, epinephrine via both endotracheal tube (ETT) and umbilical venous catheter (UVC), and two normal saline boluses. Although hospital policy required adherence to the Neonatal Resuscitation Program (NRP) algorithm, there were substantial deviations in the timing of intubation, chest compressions, epinephrine dose and route, and the timing of UVC placement and fluid boluses. The neonatologist finally arrived 11 minutes after birth and moved the infant to the NICU, where she showed only intermittent spontaneous movements. She required assisted ventilation on room air at low pressures. Her complete blood count was unremarkable. Blood gases showed profound metabolic acidosis that persisted for several hours, along with hypoglycemia (30-40 mg/dL) over the same period. Creatinine and liver enzymes were elevated. At 24 hours, she was classified as Sarnat stage 3. She developed seizures, for which she was treated with phenobarbital and levetiracetam (Keppra), and subsequently developed disseminated intravascular coagulation (DIC) requiring multiple blood product transfusions.

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“A repeat MRI there showed extensive cerebral hypoperfusion damage involving the deep gray nuclei and bilateral corticospinal tracts. After discussion, the family accepted compassionate extubation, and the infant died at 2 months of age.”

Cranial ultrasound at 4 days was normal. An MRI on day 17 showed increased T1 signal in the basal ganglia and diffusion restriction in the ventrolateral thalami. At one month of age, the neonatal team recommended gastrostomy (gastric tube) placement and tracheostomy. The parents demurred, instead requesting transfer to a children's hospital for a second opinion. A repeat MRI there showed extensive cerebral hypoperfusion damage involving the deep gray nuclei and bilateral corticospinal tracts. After discussion, the family accepted compassionate extubation, and the infant died at 2 months of age.

The examination of the placenta was consistent with an acute placental abruption. The parents sued the hospital, the obstetricians, and the neonatologists.

The plaintiff's allegations:

1. Failure to timely recognize and respond to an obvious life-threatening situation.
2. Failure to recognize and respond to excessive uterine activity
3. Failure to recognize and properly respond to abnormal FHR patterns
4. Delay in performing a cesarean section
5. Improper anesthesia for cesarean section
6. Improper resuscitation of the newborn

The Defense's position:

1. The fetus had sustained brain injury before the mother arrived at the hospital
2. There was no delay in the delivery - it was not an emergency
3. The hospital policy justified any delay. The case settled without going to trial.

Placental Abruption:

Definition and presentation:

A placental abruption represents a premature separation of the placenta from the decidua at or after 20 weeks of gestation. The major clinical findings are vaginal bleeding and abdominal pain, often accompanied by uterine contractions, uterine tenderness, and a nonreassuring fetal heart rate (FHR) pattern. Abruption is a significant cause of maternal and perinatal morbidity and mortality, especially when it occurs preterm.

“The immediate cause is rupture of maternal vessels in the decidua basalis, the maternal portion of the placenta. Only rarely does the bleeding originate from fetal-placental vessels. The accumulating blood separates the decidua, leaving a thin layer attached to the placenta.”

The immediate cause is rupture of maternal vessels in the decidua basalis, the maternal portion of the placenta. Only rarely does the bleeding originate from fetal-placental vessels. The accumulating blood separates the decidua, leaving a thin layer attached to the placenta. Bleeding may be overt, fresh, or clotted, as in this patient with vaginal bleeding. Less commonly (about 10-20% of cases, but more ominously, there is no vaginal bleeding -a concealed abruption where the edges of the placenta confine the blood. In these “concealed” abruptions, most of the blood is trapped between the fetal membranes and the decidua rather than escaping through the cervix.

“A key diagnostic clue is persistent pain between contractions. Back pain may be prominent when the placenta is on the posterior uterine wall. The uterus is often firm, sometimes rigid, and tender to palpation. About 50% of abruptions occur between 22 and 36 weeks, peaking at 26 to 30 weeks.”

Acute abruption. Patients classically present with abrupt-onset vaginal bleeding, mild to moderate abdominal pain, and uterine contractions. A key diagnostic clue is persistent pain between contractions. Back pain may be prominent when the placenta is on the posterior uterine wall. The uterus is often firm, sometimes rigid, and tender to palpation. About 50% of abruptions occur between 22 and 36 weeks, peaking at 26 to 30 weeks. A nonreassuring FHR pattern may be present.

Chronic abruption. Patients may have relatively light, intermittent bleeding. They are at risk of placental ischemia, leading to oligohydramnios (the chronic abruption-oligohydramnios sequence), fetal growth restriction, and/or preeclampsia. They are also at risk of preterm, pre-labor rupture of membranes.

Pathophysiology:

In acute severe abruption, high-pressure arterial hemorrhage in the central placenta dissects extensively through the placental-decidual interface and causes complete or nearly complete separation. This can rapidly produce life-threatening maternal

hemorrhage, maternal disseminated intravascular coagulation (DIC), and abnormal FHR patterns reflecting fetal hypoxemia and ischemia. Most abruptions do not cause neonatal anemia, but about 16% of affected neonates are born with low hematocrits. A small proportion of acute abruptions follow sudden mechanical events (blunt abdominal trauma, motor vehicle crash) or rapid uterine decompression (delivery of the first twin, rapid release of polyhydramnios).

“Most abruptions do not cause neonatal anemia, but about 16% of affected neonates are born with low hematocrits. A small proportion of acute abruptions follow sudden mechanical events (blunt abdominal trauma, motor vehicle crash) or rapid uterine decompression (delivery of the first twin, rapid release of polyhydramnios).”

In chronic abruption, impaired trophoblast invasion and abnormal spiral artery remodeling lead to decidual necrosis, placental inflammation, and ultimately low-pressure venous hemorrhage, typically at the placental periphery. The process is often self-limited.

Incidence and risk factors:

The incidence is 3 to 14 per 1000 births. The strongest risk factor is a previous abruption. Other risk factors include:

- Hypertension
- Structural uterine abnormalities
- Substance use, particularly cocaine (reportedly up to 10% of those using cocaine in the third trimester develop abruption)
- Cigarette smoking (increased risk, reported as high as fourfold in some studies)
- Antiphospholipid antibodies, presumably through impaired placentation

Less common associations include a female sibling with abruption, maternal birth small for gestational age, first-trimester vaginal bleeding, asthma, insomnia and obstructive sleep apnea, subclinical hypothyroidism, major fetal congenital anomalies, prior cesarean birth, pregnancy-related acute kidney injury, air pollution exposure, conception by assisted reproductive technology, marginal placental cord insertion, grand multiparity, short maternal stature, and severe maternal morbidity in a prior pregnancy.

Consequences for the mother:

Maternal consequences depend primarily on the severity of separation. They include excessive blood loss and DIC, which can lead to hypovolemic shock, acute kidney injury, acute respiratory distress syndrome, multiorgan failure, peripartum hysterectomy, and death. Women who undergo emergency cesarean birth for

fetal or maternal indications appear to be at increased long-term risk of premature cardiovascular disease, and their risk of death after coronary artery revascularization is doubled. It is uncertain whether these long-term risks reflect underlying maternal vascular abnormalities that manifest in pregnancy as abruption.

“Fetal risk depends on the severity of separation, the gestational age, and how long the fetus is exposed to hypoxemia and ischemia. Abruption increases perinatal morbidity and mortality through hypoxemia, ischemia, low birth weight, and preterm birth. Chronic abruption is associated with fetal growth restriction and small-for-gestational-age infants.”

Consequences for the fetus and the timing of fetal injury:

Fetal risk depends on the severity of separation, the gestational age, and how long the fetus is exposed to hypoxemia and ischemia. Abruption increases perinatal morbidity and mortality through hypoxemia, ischemia, low birth weight, and preterm birth. Chronic abruption is associated with fetal growth restriction and small-for-gestational-age infants. Perinatal mortality ranges from 3 to 12%, compared with 0.6% in births without abruption. More than 50% of abruption-related perinatal deaths are stillbirths from intrauterine asphyxia, which generally occurs when more than 45% of the placenta detaches, particularly with central detachment. Abruption is implicated in up to 10% of preterm births.

Maternal hemodynamic priority over the uteroplacental unit:

Maternal hemodynamic priority over the uteroplacental unit is a fundamental feature of the response to acute obstetric hemorrhage. The uterine circulation is a low-resistance, non-autoregulated vascular bed; its perfusion depends on maternal systolic pressure and cannot be defended when that pressure falls. It is therefore preferentially sacrificed to preserve central maternal blood pressure and perfusion of the brain, heart, and kidneys, at the direct expense of fetal oxygen delivery.

When abruption causes bleeding, the mother mounts the classic hypovolemic response: catecholamine-driven tachycardia, increased systemic vascular resistance, and peripheral and splanchnic vasoconstriction that shunts blood centrally. Because uterine vessels participate in the maternal defense against hemorrhage, uterine blood flow decreases. As a result, the fetus can be gravely compromised before the mother becomes unstable. Pregnancy expands plasma volume by roughly 40 to 50% and substantially raises cardiac output, so overt signs of hypovolemia such as hypotension and tachycardia may not appear until blood loss exceeds about 25% of blood volume (more than 1500 mL in late pregnancy). Maternal vital signs can remain deceptively reassuring while placental perfusion is already curtailed. For this reason, a nonreassuring FHR tracing is often the earliest sign of abruption, and fetal status can deteriorate well before maternal

decompensation.

Fetal injury mechanism:

Fetal injury in abruption is predominantly hypoxic-ischemic rather than hemorrhagic. The separated placental surface loses gas-exchange area. Reduced placental perfusion is further compounded by frequent contractions and elevated intrauterine pressure (hypertonus), which further impede fetal oxygen availability.

The fetus responds with “brain sparing”: redistribution of blood flow toward the brain, heart, and adrenal glands at the expense of the splanchnic, renal, and peripheral beds. Unlike the mother, however, the fetus cannot compensate by increasing its own oxygen supply, because that supply depends entirely on the shrinking functional placental surface. Redistribution is therefore a limited, temporary defense.

“FHR patterns in abruption vary depending on the acuteness of the abruption and the extent of separation. A sudden acute abruption usually accompanied by a sustained uterine contraction (tetany) will be reflected in an acute bradycardia.”

Fetal heart rate and uterine activity patterns:

FHR patterns in abruption vary depending on the acuteness of the abruption and the extent of separation. A sudden acute abruption usually accompanied by a sustained uterine contraction (tetany) will be reflected in an acute bradycardia. The tracing may be completely normal in a small or early abruption, so a reassuring FHR does not exclude the diagnosis.

Abruptio is a clinical diagnosis, based on pain, bleeding, a tender or rigid uterus, and risk factors such as hypertension, trauma, or cocaine use. Ultrasound is insensitive and cannot reliably exclude abruption; a normal ultrasound does not rule it out. Because bleeding may be minimal or absent in concealed hemorrhage, the tracing can be the first clue.

This case is quite interesting from the perspective of the timing of injury. Based on the erroneous description of the tracing as “Category I”, the timing of injury can be reliably assigned to the interval between admission and the end of the tracing, with a further contribution from the hypotension and delay in performing the cesarean section after the spinal anesthesia. A more experienced assessment of the tracing cannot exclude injury prior to admission. Far from being a Category I tracing, it more likely represents a Category III tracing with both decelerations and decreased/absent baseline variability. Without a preceding normal tracing, there is no way to resolve whether the responses seen on admission are simply the responses of the uninjured fetus to the massive assault by the uterine contractions or whether the fetus has already suffered a neurological injury. Without a definitive conclusion of the matter, it is reasonable to argue that

the fetus was injured during the deterioration of the tracing and that the fetus was further assaulted by the extent and duration of the maternal hypotension prior to delivery. It was not reasonable to expect that the newborn to be asystolic at birth had it been delivered 40 minutes earlier when its heart rate was 140 bpm.

“A more experienced assessment of the tracing cannot exclude injury prior to admission. Far from being a Category I tracing, it more likely represents a Category III tracing with both decelerations and decreased/absent baseline variability. Without a preceding normal tracing, there is no way to resolve whether the responses seen on admission are simply the responses of the uninjured fetus to the massive assault by the uterine contractions or whether the fetus has already suffered a neurological injury.”

Key points:

1. Excessive uterine activity may be the earliest clue to the presence of an abruption. The diagnosis is facilitated by searching for point tenderness over the uterus and pain persisting between contractions.
2. Recurrent late decelerations plus tachysystole or hypertonus should raise strong suspicion of abruption.

Loss of variability, decelerations, or bradycardia indicates progressive fetal compromise and warrants urgent evaluation and delivery planning.

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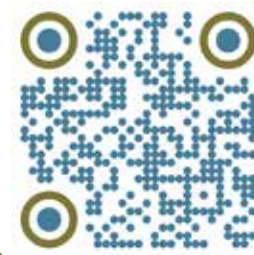
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Medicolegal: Nuchal cords and Neonatal Depression

Jay P. Goldsmith, MD, Jonathan K. Muraskas, MD

“These reports and others led to questions regarding the significance of tight and multiple loop nuchal cords, whether they cause hypoxia and/or hypovolemia, and how providers should care for newborns who are born with a diagnosis of a nuchal cord.”

Definition of nuchal cord:

A nuchal cord has been defined as $\geq 360^\circ$ wrapping of the umbilical cord around the fetal neck. (1, 2) Interest in umbilical cord entanglement dates back to Hippocrates (circa 460 BC) who noted that nuchal cords were a potential danger in late pregnancy and may cause “suffering in the mother and either perish or born difficulties to the fetus.” (2) Over 50 years ago, the 16th edition of *Williams Obstetrics* stated that nuchal cords “ordinarily do no harm, but occasionally may be so tight that constriction of the umbilical vessels and consequent hypoxia result.” (2) Two reports in the late 1980’s described neonates with tight nuchal cords who had signs of hypovolemia requiring blood transfusions and even shock. In all cases, there was no evidence of fetal-maternal transfusion or other causes of neonatal anemia/hypovolemia. (3,4) These reports and others led to questions regarding the significance of tight and multiple loop nuchal cords, whether they cause hypoxia and/or hypovolemia, and how providers should care for newborns who are born with a diagnosis of a nuchal cord.

Incidence:

Nuchal cords are relatively common. Incidence reports range from 15% to 34% in various reviews. Incidence appears to increase with increasing gestational age, excessive fetal activity, and long umbilical cords. (5) Henry et al. reported on 219,337 live births from 2005 to 2010 in a multi-hospital health system, which revealed that 21.6% had a loose nuchal cord and 6.6% had a tight nuchal cord (defined as “the inability to reduce the cord over the fetal head manually”). (6) This group reported that term newborns with a tight nuchal cord were slightly more likely to be admitted to the NICU than infants born with no or loose nuchal cord (6.6%

vs. 5.9%) but not more likely to need blood pressure support medications, transfusions, or die. In the cohort of very low birth weight infants reported in this review (<1500 grams birth weight), major morbidities and mortality did not differ significantly.

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Association of nuchal cord with neonatal depression:

Nuchal cords have been associated with and blamed for intrapartum asphyxia in the literature and in medical-legal controversies/litigation. Questions for obstetric providers in this area include whether a nuchal cord should be looked for and diagnosed with ultrasound before delivery and whether its presence on ultrasound should affect the mode or timing of delivery. Other questions include whether an ultrasound can distinguish between a loose or tight nuchal cord and what is the mechanism by which a nuchal cord may cause neonatal depression (hypoxia and/or hypovolemia) or a prolonged second stage of labor? Martin et al. reviewed umbilical cord blood gases of term newborns with normal Apgar scores with and without nuchal cords. (7) In this relatively small study (n=62), they found that neonates with nuchal cords had significantly lower pH, higher pCO₂ levels, and lower oxygen saturations in their arterial cord samples. There were also higher veno-arterial differences in the paired umbilical cord samples (arterial and venous) in pH and pCO₂ in the newborns *with* nuchal cords than those *without* nuchal cords. Unfortunately, this study did not describe whether the cords were loose or tight. The study showed that Apgar scores were not a sensitive indicator of neonatal acidemia and that nuchal cords could increase pCO₂

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and lower pH in babies born with this complication. Despite these differences in cord blood gas values, the authors did not report clinically significant adverse outcomes in the nuchal cord group.

“Despite these differences in cord blood gas values, the authors did not report clinically significant adverse outcomes in the nuchal cord group.”

In 2013, Martinez-Biarge et al. published a retrospective analysis of antepartum and intrapartum factors associated with hypoxic-ischemic encephalopathy (HIE) in 633 infants ≥ 35 weeks' gestation. Seven intrapartum factors were statistically independently associated with HIE, including tight nuchal cord. In their review, Martinez-Biarge et al. found tight nuchal cords in 45/396 HIE cases and in 15/237 control infants with a resultant odds ratio of 1.89 (1.03-3.5). (8) This finding implied that a tight nuchal cord was a significant factor in the etiology of intrapartum HIE, although the mechanism was not specified and the possibility of chronic impairment of blood flow to the fetus over days or weeks was not addressed.

“Several studies have reported associations of nuchal cords with adverse obstetric outcomes. Nuchal cords have been associated with abnormal fetal heart rate patterns, meconium-stained amniotic fluid, increased incidence of cesarean delivery and operative vaginal delivery, and reduced Apgar scores.”

Several studies have reported associations of nuchal cords with adverse obstetric outcomes. Nuchal cords have been associated with abnormal fetal heart rate patterns, meconium-stained amniotic fluid, increased incidence of cesarean delivery and operative vaginal delivery, and reduced Apgar scores. In many of these studies, researchers do not describe other umbilical cord characteristics, including whether the cord is loose or tight or how many nuchal loops were found at delivery. Other biomechanical aspects of the umbilical cord may be very important as to whether or not a nuchal cord will have clinical significance to the fetus/newborn. Such constituent tissues of the cord, including the outer layer of amnion and amount of Wharton's jelly (or diameter of the cord), length of the cord, number of coils per 10 cm of cord, as well as many other physiologic and biometric aspects of the umbilical cord, are generally not considered in these studies. For example, short cords (<40 cm), long cords (>70 cm), cords with decreased Wharton's jelly, or less-than-normal coiling have been associated with adverse neonatal outcomes independent of tight nuchal cords. (2)

“The fetus in utero is dependent upon the delivery of oxygen through the umbilical cord vein much as a deep-sea diver is dependent on air delivered by a hose. The fetus does not breathe air, and thus it is unlikely that hypoxia is due to strangulation as we conceive of it in a live person, but rather the reduced amount of oxygen delivered because there is an obstruction to blood flow through the cord.”

Mechanism of nuchal cord causing neonatal depression:

The fetus in utero is dependent upon the delivery of oxygen through the umbilical cord vein much as a deep-sea diver is dependent on air delivered by a hose. The fetus does not breathe air, and thus it is unlikely that hypoxia is due to strangulation as we conceive of it in a live person but rather the reduced amount of oxygen delivered because there is an obstruction to blood flow through the cord. The flow of blood through the cord is usually equal in both directions from the placenta to the fetus (through the vein) and back again to the placenta (through the 2 umbilical arteries). Obstruction to the umbilical cord blood flow is more likely to disproportionately affect the vein, which is thin-walled compared to the thicker-walled arteries; thus, an obstruction may lead to hypoxia from lack of oxygen delivery from the placenta as well as hypovolemia, since blood may still be flowing through the umbilical arteries and not being replaced by umbilical vein flow. (9)

In these cases, the baby may have difficulty making the transition since once the umbilical cord is cut, the fetal hypovolemia as well as hypoxia will manifest as severe birth depression. Sometimes, when the cord is completely obstructed before birth, the newborn will have very low Apgar scores, yet the cord blood gases are near normal, reflecting the acid-base status before the obstruction. Cord obstruction may also occur at other anatomic sites between fetal body parts and the vaginal wall as the baby descends in the birth canal and may be a major factor causing birth depression in conditions such as a shoulder dystocia.

“There are no specific guidelines for neonatal providers regarding the care of babies born with a nuchal cord. The presence of multiple loops or a tight nuchal cord should be noted even if the newborn is not severely depressed at birth.”

Suggestions for neonatal providers:

There are no specific guidelines for neonatal providers regarding the care of babies born with a nuchal cord. The presence of multiple loops or a tight nuchal cord should be noted even if the newborn is not severely depressed at birth. However, as noted by Henry et al., tightness of the cord around the neck is a “spectrum rather than a dichotomous variable” from the description of a loose cord. (6) Accordingly, the response of the provider team will vary according to the condition of the baby at birth. A tight nuchal cord or multiple loops of nuchal cord is not generally associated with clinically significant adverse outcomes. However, the provider is placed on notice and, in appropriate circumstances (i.e., significant depression at birth), may request cord gases or check early neonatal blood gases, neonatal blood pressure, serial hemoglobin and/or hematocrits to rule out delayed equilibration, and send the placenta to pathology for evaluation. A difference in cord arterial and venous pH of >0.10 units may be the result of cord compression in utero. Occasionally, when there is a major obstruction to cord blood flow in utero, the placental veins will be distended, and this may help diagnose a significant cord obstruction in a case of unexpected neonatal depression at birth. Moreover, the provider is warned that an obstructed cord blood gas may not reflect the true acid-base status of the baby, and this inconsistency should be considered when contemplating care such as therapeutic hypothermia. However, in a normal-appearing neonate who transitions well, providers should allow early skin-to-skin bonding and breastfeeding and are not required to perform extra monitoring or additional laboratory and clinical monitoring solely because of a multiple-loop or tight nuchal cord found at delivery.

“Moreover, the provider is warned that an obstructed cord blood gas may not reflect the true acid-base status of the baby, and this inconsistency should be considered when contemplating care such as therapeutic hypothermia.”

Medical-legal Considerations:

HIE litigation will sometimes include the history of nuchal cord and allegations potentially against both obstetric and neonatal providers. Failure to diagnose nuchal cord by ultrasound prior to birth and prolonged second stage of labor due to nuchal cord are common complaints. Plaintiffs will allege that the nuchal cord became tighter and caused injury as the baby descended in the birth canal. Neonatal providers are alleged to have not properly accounted for the nuchal cord in the early care of the baby, thus leading to a lack of appropriate monitoring in a baby who had a successful resuscitation and subsequent injury from failure to use therapeutic hypothermia, treat anemia, or treat hypovolemia. The defense causation position often is that the etiology of the baby's injuries was a nuchal cord which was not diagnosable or preventable and may have been present long before the mother went into labor.

The takeaway message here is that most nuchal cords are

harmless, but those associated with neonatal birth depression warrant closer monitoring of the newborn. Depending on the degree of depression, early careful monitoring of the baby in the first hours of life may be appropriate, as well as evaluation of the placenta by pathology and measurement and description of the umbilical cord (total length to include all segments, width, coiling, description of Wharton's jelly) as prudent risk management actions.

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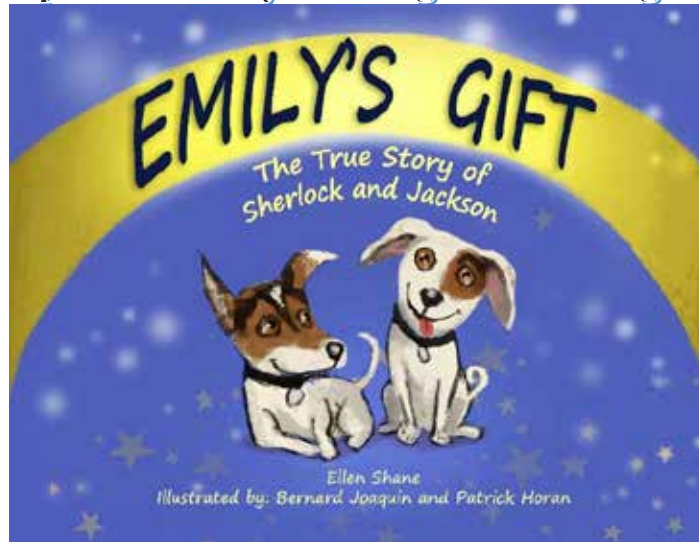


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"Everyone Knows It": How Wimpy White Boy Syndrome Persists as a Belief Among NICU Providers

Brittany Nicole Stewart, PhD, Mieke Beth Thomeer, PhD

"Wimpy White Boy Syndrome" (WWBS) is the belief that White male preterm infants fare worse than Black female, White female, and Black male infants. "

Abstract:

"Wimpy White Boy Syndrome" (WWBS) is the belief that White male preterm infants fare worse than Black female, White female, and Black male infants. This article presents in-depth interviews with 34 neonatal intensive care unit (NICU) providers, including physicians, nurse practitioners, nurses, and therapists from 21 states, to examine how this belief is defined, communicated, and applied in clinical practice. Our findings show that WWBS is a widely held but poorly examined belief within neonatal intensive care units (NICUs) across the United States. Every provider interviewed was familiar with WWBS, and most believed it was factually accurate, based on their training and experience. They also assumed scientific backing, despite very limited empirical research from two decades ago. Providers offered explanations for infant outcomes including maternal health conditions and socioeconomic factors that directly contradict the premise of WWBS, suggesting a pattern of cognitive dissonance. Several providers acknowledged that WWBS affects clinical care, including more careful monitoring of White male infants and biased assumptions that Black female infants require less pain management. These findings have significant implications for neonatal health equity and point to the need for standardized protocols, provider education on implicit bias, and increased social work support within NICUs.

Keywords: NICU, Wimpy White Boy Syndrome, neonatal health disparities, provider bias, implicit bias, race, gender

Introduction:

Within neonatal intensive care units (NICUs) across the United States, a widely shared and generally non-questioned belief among providers is that White male preterm infants are the most fragile and fare the worst while Black female infants are the strongest and most resilient. (1) This belief has the name "Wimpy White Boy Syndrome" (WWBS) and persists as a form of folk wisdom passed between clinicians across institutions and generations. (2–7)

WWBS has unclear origin. There is limited empirical research

from the early 2000s that documented a survival advantage for Black female infants over White male infants at extremely low gestational ages (<28 weeks), particularly prior to the widespread adoption of artificial surfactant therapy. (8, 9) However, the survival advantage for Black infants at earlier gestational ages largely disappears and, in some cases, reverses once surfactant or other interventions are introduced. (10) Despite this, WWBS has persisted.

"WWBS has unclear origin. There is limited empirical research from the early 2000s that documented a survival advantage for Black female infants over White male infants at extremely low gestational ages (<28 weeks), particularly prior to the widespread adoption of artificial surfactant therapy. However, the survival advantage for Black infants at earlier gestational ages largely disappears and, in some cases, reverses once surfactant or other interventions are introduced. Despite this, WWBS has persisted."

In fact, the more extensive contemporary evidence that documents racial disparities in neonatal outcomes tells a different story than WWBS. Black infants have consistently higher rates of preterm birth, infant mortality, late-onset sepsis, necrotizing enterocolitis, bronchopulmonary dysplasia, and retinopathy of prematurity than White infants. (8–12) Additionally, racial segregation across NICUs, where Black infants are disproportionately cared for in lower-quality units and within-NICU disparities in quality of care seem to contradict the idea that White male infants are the most disadvantaged group. (12, 14) Yet despite this epidemiological evidence suggesting worse care and outcomes among Black infants, narratives about WWBS and the vulnerability of White infant males persist.

Ultimately, the persistence of WWBS as a clinical belief warrants examination. This article reports findings from qualitative interviews with 34 NICU providers (including physicians, nurse practitioners, nurses, and therapists) from across the United

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States. We examine how providers define and discuss WWBS, the explanations they offer for different outcomes, the contradictions in their interviews, and how this belief may affect providers' care within the NICU. Our goal is not necessarily to determine whether WWBS is true, but to understand it as a belief and its potential consequences for neonatal care and health equity.

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Methods:

In this study, the first author conducted in-depth, semi-structured interviews with 34 NICU providers between February and June 2025. Participants included 13 physicians, 10 nurses, 6 therapists (respiratory, physical, and occupational), 3 nurse practitioners, and 2 providers in other clinical roles. The sample included 27 women and 7 men. Seventy-one percent of participants identified as White, 18% as Black or African American, and 11% as Asian or multiracial. Providers represented 21 states, ranging from Alabama and Texas to California, New York, and Washington State. Years of experience spanned from less than one year to more than 45 years. Participants were recruited primarily through snowball sampling, beginning with acquaintances known to the first author through her prior work as a NICU social worker, and supplemented by social media outreach. All interviews were conducted via confidential Zoom (n=26), phone (n=1), or in person (n=7), lasted approximately 45 to 60 minutes, and were audio-recorded and transcribed. The interview guide covered multiple topics related to WWBS and NICU care, including respondents' knowledge of the concept, their beliefs about it, and how they implemented those beliefs. Respondents were also asked additional questions regarding what factors they believe matter for NICU outcomes and dynamics within NICUs. Transcripts were analyzed using NVivo qualitative software through an iterative process of open and focused coding, which used thematic synthesis and abductive analysis. (15) The study received IRB approval. In this paper, all participant names are changed for confidentiality.

Findings:

Universal Familiarity with WWBS:

Every provider interviewed, regardless of profession, years of experience, geographic region, or racial identity, was familiar with Wimpy White Boy Syndrome (WWBS). This finding alone is striking. WWBS is not a belief held only by some providers; it is a shared frame across all NICUs in this study. Providers described WWBS consistently, providing a hierarchy of health: Black female infants at the top, followed by White female infants, then Black male infants, with White male infants at the bottom. As one nurse with more than 30 years of experience stated:

“Well, you know, there’s always that saying that Black females are the strongest, and then you have the ‘wimpy White males.’ You’ve probably heard that being in the NICU. Stereotypically — I mean, even the neonatologists have always told us that. I don’t know what it is about them, but we’ve always heard that: ‘wimpy White boys.’” (Winona, nurse)

Another nurse created some understanding about what WWBS looks like at the bedside:

“White boys tend to come back [to the hospital]; they need more oxygen; they tend to take longer to come off oxygen. Sometimes they’ll have a hard time holding their temperature when maybe they should start holding their temperature” (Uma, nurse).

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Discussions of specific ways that White male infants did worse depended in part on the respondents' professional role. Nurses typically described White boys as the most difficult feeders, while physicians tended to focus on respiratory difficulties, and therapists often discussed lower muscle tone in White male infants. In other words, across professional roles, providers applied the WWBS frame through the lens of their profession.

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How WWBS Is Learned and Perpetuated:

Another finding was that providers first learned WWBS early in their careers and perpetuated it as their careers continued. Most providers stated that they learned about WWBS during their formal training or within the first year of clinical practice. No providers

described learning about it through a research article. Instead, the most common way they learned was through direct instruction from supervising clinicians or through the culture they observed early in training. As one provider explained:

"I remember hearing about it in nursing school. I remember hearing about it and thinking, 'Oh, I wonder if that's true'" (Brittany, nurse practitioner).

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Others learned about WWBS on the job at the NICU from experienced coworkers, with the belief passed down as received wisdom. As one nurse with over 30 years in the NICU put it:

"The saying has been around since I started in the NICU" (Winona, nurse).

One of the most intriguing parts of this belief is the historical depth the data suggests. One nurse recounted that a physician told her grandmother, whose own premature birth occurred in 1956, that had her mother been a boy, she likely would not have survived. This suggests WWBS, or something similar, has circulated within neonatal medicine for at least seven decades.

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Most providers were uncertain about the belief's origins. Many suspected it began with someone noticing a pattern and that the observation was then continued through repetition:

"I don't know. It probably started when someone noticed a little White boy who was developmentally slow, and right next to him was a little African American boy—or girl—who was doing everything like a champ" (Francis, nurse practitioner).

Explanations for WWBS: Biology & Genetics and "It Just Is":

When asked to explain why WWBS exists, providers most commonly offered biological or genetic explanations. Eighteen of 34 providers attributed differential outcomes to inherent biological differences between racial and gender groups. One therapist stated:

"I think there's some truth to whatever that genetic and gender makeup is that affects the outcome, you know, survival of the fittest" (Pam, therapist).

A physician suggested that:

"[The field] should be figuring out what's the genetic profile that's making NICU hospitalization more complicated for the White boys" (Mallory, doctor).

A second group of providers offered what might be called the "it just is" explanation, which acknowledges WWBS as a real phenomenon while providing no evidence-based account for it. Several in this group focused on gender alone, suggesting girls are simply more mature than boys as a general developmental principle, ignoring race entirely.

"Boys are generally wimpier than females" (Jatin, doctor).

Contradictions: When Provider Explanations Undercut WWBS:

Among the most clinically significant findings in this study is the pattern of internal contradiction within providers' own accounts. While nearly every provider endorsed WWBS, many simultaneously offered explanations for infant outcomes that directly contradict the belief. Providers did not acknowledge these contradictions during the interviews.

One of the biggest contradictions concerns maternal health. Twelve providers explicitly stated that maternal health conditions and delivery complications are among the most important predictors of infant outcomes, which is a well-supported research belief. (16,17) As one physician explained:

"The healthier the mom, the more likely the better outcomes for the baby" (Van, doctor).

"The phrase 'if all things are equal' is used here, even though in reality, all things are rarely equal. Black infants are more likely to arrive in the NICU having already been disadvantaged by their mothers' experiences of racism, structural inequality, and inadequate prenatal care."

However, the same providers did not connect that if Black women have worse maternal health outcomes than White women, such as higher rates of preeclampsia, preterm labor, and obstetric complications (17), impacted by the cumulative effects of racism and chronic stress (16), then their infants should, by the providers' own reasoning, be at greater risk.

Only one provider in the study explicitly recognized this paradox:

"I know there's been a lot of recent research about outcomes for Black women in pregnancy and childbirth. But in the NICU, we tend to see the opposite. If all things are equal, generally Black babies do better if they have the same diagnoses" (Christy, doctor).

The phrase "if all things are equal" is used here, even though in reality, all things are rarely equal. Black infants are more likely to arrive in the NICU having already been disadvantaged by their mothers' experiences of racism, structural inequality, and inadequate prenatal care. (18–21)

A second contradiction concerns extremely preterm infants. Providers agreed that extremely premature infants—those with extremely low birth weight or extremely low gestational age—are the sickest infants in any NICU. One provider gave a detailed account:

"Micro-preemies usually do [fare worse]. And I think that just kind of, unfortunately, comes with the territory. You know, the 23-, 24-, 25-weekers—they have totally premature development. They experience chronic lung disease and bronchopulmonary dysplasia (BPD). They're at risk for NEC, for developing infections during their hospitalization, and for intraventricular hemorrhage (IVH), or brain bleeds. They're also at risk for osteopenia from being in a hospital bed for so long and just from being preemies. So, I definitely think micro preemies are at the highest risk for the most serious [outcomes] and multiple diagnoses." (Wendy, nurse).

"It makes sense that extremely premature babies would fare worse, and research consistently demonstrates that Black infants are significantly more likely than White infants to be born preterm, sometimes at rates two to three times higher. If the sickest babies are those born earliest, and Black infants are born earliest most frequently, the population of most-at-risk infants should be Black infants. The providers' own logic contradicts WWBS."

It makes sense that extremely premature babies would fare worse, and research consistently demonstrates that Black infants are significantly more likely than White infants to be born preterm, sometimes at rates two to three times higher. (22, 23) If the sickest babies are those born earliest, and Black infants are born earliest most frequently, the population of most-at-risk infants should be Black infants. The providers' own logic contradicts WWBS.

Care Implications of WWBS Belief According to Providers:

Some of the most interesting data from this study is the providers'

own accounts of how WWBS shapes clinical care. While many insisted that the belief did not influence their practice, a subset of providers acknowledged effects, either in their own behaviors, in behaviors they observed, or hypothetical cases. Several described watching White male infants more closely with the expectation that these infants would struggle worse. One nurse practitioner reflected:

"I think there's the possibility that you could sit on a baby longer if you expected them to be wimpy. That could happen, maybe miss an opportunity, because you're like, 'Oh, they're just a wimpy White boy, they're just doing what they're supposed to be doing,' when maybe something is actually wrong" (Brittany, nurse practitioner).

The flip side of this attention to White boys is reduced attention to Black girls. One nurse made the following admission:

"I've never really expressed that to anyone else, but in my experience, Black girls tend to take everything really well... My husband knows that if I say I had a good day at work, it probably means I had two Black girls" (Jessica, nurse).

Then, another provider added that Black girls are so strong that they do not even need pain medicine. She states:

"[Black girls] are the strong ones that all the things seem to be working for them, or they're not really needing any more pain medicine" (Danielle, nurse).

A physician observed that at a resuscitation, a White male infant might be given respiratory support such as CPAP more quickly than a Black female infant with the same experience. This demonstrates the expectation that the Black female infant may not need the additional assistance both at birth and after.

Additionally, other providers believed that this label was disadvantaging White boys since the providers use it regularly. This provider mentions:

"I do think we do a disservice to both our wimpy White boys and their parents when we fall back on that label all the time. I feel like we kind of lower expectations for the baby" (Pam, therapist).

"WWBS is not a harmless saying. Ultimately, it is a belief system learned across generations of providers and sustained within institutions that shapes how vulnerable infants are perceived and potentially treated. The WWBS account in this study reflects the sociological concept of social construction: a belief that emerges from selective observation, gets labeled, and is then perpetuated as established fact, with real consequences for social inequality and health outcomes."

Discussion:

The findings presented here raise questions about NICU culture and its implications for health equity. WWBS is not a harmless saying. Ultimately, it is a belief system learned across generations of providers and sustained within institutions that shapes how vulnerable infants are perceived and potentially treated. The WWBS account in this study reflects the sociological concept of social construction: a belief that emerges from selective observation, gets labeled, and is then perpetuated as established fact, with real consequences for social inequality and health outcomes. (25)

“However, epidemiological research does not support the idea that White male infants have the worst outcomes, with research outside of the NICU supporting that Black infants have the greatest risk of mortality. ”

Additionally, the WWBS belief is rooted in a biological view of race and gender that contradicts contemporary research on neonatal outcomes. Providers frame race and gender as producing inherent, fixed physiological differences, which is a framing that is inconsistent with science and with the sociological literature documenting that racial health disparities are predominantly socially produced. (24, 26) However, epidemiological research does not support the idea that White male infants have the worst outcomes, with research outside of the NICU supporting that Black infants have the greatest risk of mortality. (27–30)

“These contradictions are particularly important for clinical reflection. Providers who hold WWBS simultaneously hold beliefs about the importance of maternal health, gestational age, and socioeconomic factors that should lead them to expect worse outcomes for Black infants, not White ones. The fact that these contradictions go unnoticed suggests that WWBS is not a proven clinical diagnosis but is an unexamined cultural frame. Providers inherit this frame, rarely question it, and continuously reproduce it.”

This study also identified that contradictions within providers' own accounts are particularly important for clinical reflection. These contradictions are particularly important for clinical reflection. Providers who hold WWBS simultaneously hold beliefs

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“Lastly, a third source of contradiction emerged around the role of surfactant. Several providers noted the historical advantage that Black infants demonstrated over White infants in respiratory distress syndrome before artificial surfactant became widely available. What they did not know or articulate is that once surfactant was introduced, the advantage reversed not because Black infants suddenly became weaker but because, according to sociology's fundamental cause theory, access to new technologies became more beneficial to White infants.”

Lastly, a third source of contradiction emerged around the role of surfactant. Several providers noted the historical advantage that Black infants demonstrated over White infants in respiratory distress syndrome before artificial surfactant became widely available. What they did not know or articulate is that once surfactant was introduced, the advantage reversed not because Black infants suddenly became weaker but because, according to sociology's fundamental cause theory, access to new technologies became more beneficial to White infants. (11, 24) The pre-surfactant data may have given rise to WWBS as part of historical research, not as ongoing proof of WWBS' existence.

“This all has clinical implications. If providers attend more closely to White male infants out of more concern and attend less closely to Black female infants out of assumptions of resilience, the result may be inequitable attention, earlier discharge of Black infants, and delayed diagnoses or treatment. These are not hypothetical risks; providers themselves described these dynamics.”

This all has clinical implications. If providers attend more closely to White male infants out of more concern and attend less closely

to Black female infants out of assumptions of resilience, the result may be inequitable attention, earlier discharge of Black infants, and delayed diagnoses or treatment. These are not hypothetical risks; providers themselves described these dynamics. The reduced attention to Black female infants is in line with sociological theories on controlling images and the Strong Black Woman framework. (32–35)When providers frame Black female infants as inherently strong and having a high pain tolerance, they put on newborns a set of beliefs that historically could be used to justify withholding adequate medical attention and pain management from Black women. (32, 36) This research appears to represent the first empirical examination of how the Strong Black Woman ideology shapes clinical perception of preterm infants.

Limitations:

This study has several limitations. Snowball sampling may have introduced some similarities, although the geographic representation across 21 states helps to mitigate this concern. Social desirability bias may have led some providers to present their practice in a more equitable light than is accurate. However, many providers' willingness to describe biased practices shows openness. The sample includes only providers and does not include the perspectives of NICU families, whose experiences with providers would strengthen this research.

Recommendations for Clinical Practice:

Based on these findings, we offer the following recommendations for NICU leadership, educators, and practitioners. First, incorporate provider education on the history and limitations of WWBS into neonatal training at all levels. Trainees should understand the small—or even non-existent—empirical basis of the belief, the historical role of surfactant in reversing the “survival advantage,” and the much larger body of research documenting Black infant disadvantage across most neonatal outcomes. Presenting the contradictions documented in this study between WWBS and providers' own frameworks may help support this education.

“Second, standardized clinical protocols can protect against implicit bias. When treatment decisions such as pain management, feeding timelines, respiratory support, and discharge readiness are guided by consistent, evidence-based protocols applied in the same way across patients, it can provide more objective care.”

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Third, implicit bias training specific to the neonatal context should be developed and implemented. Generic implicit bias training has limited evidence of effectiveness. However, training that uses realistic NICU scenarios, including the specific dynamics described by providers in this study, is more likely to improve understanding and support behavioral change.

Fourth, NICUs should integrate social work and family support services into the care team. Multiple providers noted that families they found difficult, including those with language barriers, substance use histories, limited resources, or complex social situations, sometimes led to avoidance of the infant's bedside. A dedicated social work presence can help mediate in these circumstances, helping ensure that infants receive equitable care and attention.

Conclusion:

Wimpy White Boy Syndrome is known to every NICU provider who participated in this study. It is informally taught in medical schools and nursing programs. It is repeated at bedsides and in conference rooms. It is assumed to be backed by science, even though the providers who hold it typically cannot cite the research, and the research that does exist is decades old, narrow in scope, and, in important ways, changed by more recent developments. It persists in the face of a fair amount of evidence that Black infants, on nearly every neonatal outcome measure, face greater disadvantage.

“The persistence of WWBS is not a story about bad providers or malicious intent. It is a story about how clinical cultures take on and perpetuate beliefs, how those beliefs interact with implicit bias, and how the structure of NICU healthcare with different protocols and limited family support keeps the belief going.”

The persistence of WWBS is not a story about bad providers or malicious intent. It is a story about how clinical cultures take on and perpetuate beliefs, how those beliefs interact with implicit bias, and how the structure of NICU healthcare with different protocols and limited family support keeps the belief going. Neonatology has made enormous advances in caring for preterm infants. The next step is examining of the beliefs providers carry with them into the NICU and their consequences for the preterm infants in their care.

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Author Contributions:

B.N.S. conceived the study as a part of a dissertation and drafted the manuscript. M.B.T. contributed many hours of brainstorming

and revisions. All authors reviewed and approved the final version.

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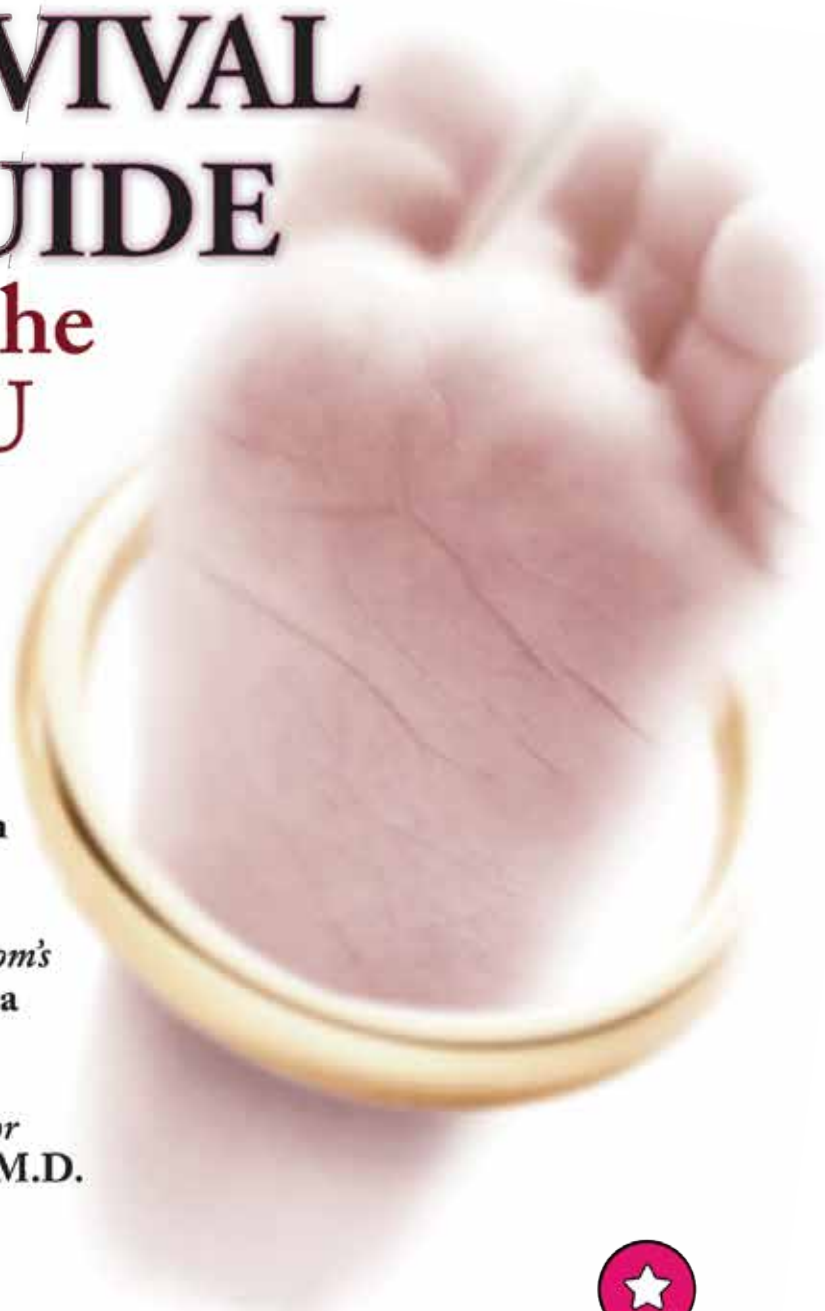
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The Premie Parent's SURVIVAL GUIDE to the NICU

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Facilitated Tucking as a Non-Pharmacological Pain Management Intervention in the Neonatal Intensive Care Unit: A Case Series

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“In the United States, more than 365,000 infants in 2020 were born preterm at less than 37 weeks of gestation. (1) Many of these infants are cared for in a neonatal intensive care unit (NICU), where they experience between 7.5 and 17.5 daily painful procedures. (2)”

Introduction:

In the United States, more than 365,000 infants in 2020 were born preterm at less than 37 weeks of gestation. (1) Many of these infants are cared for in a neonatal intensive care unit (NICU), where they experience between 7.5 and 17.5 daily painful procedures. (2) Common sources of pain include heel lances, blood draws, and venipuncture. (2) These interventions are recognized as painful; however, because they are routine and brief, analgesia is often not offered. (3) Evans et al.(4) observed that preterm infants also demonstrate pain responses to many routine activities considered benign, such as position changes and medication administration through intravenous lines. Neonates communicate pain through facial expressions, body movements, behavioral states, crying, and changes in color and muscle tone.(5)

Repeated exposure to mismanaged or undermanaged painful stimuli may result in negative consequences for the underdeveloped nervous systems of preterm infants. (6) Pharmacological interventions are available but not consistently provided, (2) and many have adverse effects. (7) A variety of nonpharmacologic pain management interventions are also accessible and have demonstrated effectiveness in reducing pain symptoms in preterm infants. (8) Unfortunately, nonpharmacologic pain management interventions such as pacifiers and breastfeeding cannot be used with infants requiring oral intubation.

Effects of Pain on Preterm Infants:

Neither pharmacological nor non-pharmacological pain management interventions for infants are consistently offered during painful procedures in the NICU (3), especially during routine caregiving activities, rarely recognized as painful. (4) Pain is defined by the International Association for the Study of Pain as “an unpleasant sensory and emotional experience associated with, or resembling that associated with, actual or potential tissue damage.” (9) Preterm infants are at risk of negative neurologic consequences as a result of repeated exposure to unmanaged

pain. (6) Pain can be assessed in infants by observing autonomic and behavioral responses. (10)

Repeated exposure to untreated pain during infancy can interfere with growth, alter brain development, and increase the risk of long-term cognitive, motor, and sensory impairments. When infants experience pain, their strength and energy reserves are diverted from growth and healing and expended responding to painful stimuli. Pain is associated with impaired brain development (3, 11) due to neuronal damage, a consequence of exposure to noxious sensory input that preterm infants are not equipped to manage. (12) Specifically, exposure to invasive procedures and the duration of mechanical ventilation are associated with reduced volumes in several brain areas, including the amygdala and thalamus, which are implicated in impaired perceptual reasoning and visual perception. (13) The number of surgeries an infant undergoes in the NICU has been related to decreased volumes of specific areas of the brain, including the fornix and striatum (13), which are associated with impaired verbal comprehension and motor coordination. Early painful experiences can lead to increased pain and hyperalgesia later in life (14). The consequences of pain in early life: injury-induced plasticity in developing pain pathways, impaired motor development (15), and difficulty with sensory processing. (16) Painful experiences in the NICU have also been associated with decreased brain responses to non-noxious touch (17) and an impaired ability to habituate to various stimuli. (18)

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Facilitated Tucking:

Facilitated tucking is a safe non-pharmacological pain management intervention used effectively with infants as young as 23 weeks postconceptional age experiencing venipuncture, pharyngeal suctioning, and heel sticks. (19) Facilitated tucking was also effective in reducing pain responses to vaccinations in full-term infants. (20)

Facilitated tucking can be performed with intubated infants in their

bedspace. It involves supporting the trunk in slight flexion, bringing the shoulders and hips into a neutral, midline position close to the body, and supporting the knees and elbows in flexion with the infant's hands close to the face or mouth. (21) Supporting infants in this position for 15 minutes prior to the initiation of a painful procedure and maintaining the position both throughout the procedure and for an additional 15 minutes after the procedure were shown to be effective in reducing procedural pain. (22)



Figure 1 - Facilitated tuck. Photo credit: Lillian Green, 2026.

Facilitated tucking was successful in reducing pain scores during heel sticks and suctioning (23, 24), with some studies showing greater efficacy than opioids. (23) Facilitated tucking was not consistently superior to other non-pharmacological pain management techniques in all situations. Perroteau et al. (25) did not find facilitated tucking to have a significant effect on reducing pain during a heel stick, but observed that infants returned to baseline more quickly after the heel stick procedure than those not supported with a facilitated tuck.

In addition to reducing pain signs and symptoms, facilitated tucking has been shown to improve infant physiological parameters at rest, including heart rate, oxygen saturation, body temperature, and respiratory rate. (26) Facilitated tucking also improved comfort level and breastfeeding performance. (26) Suna Dag (27) found facilitated tucking to be equally effective as white noise in improving sleep duration and efficiency, while reducing stress scores, in neonates receiving nasal continuous positive airway pressure (CPAP) for respiratory support.

As a standalone intervention, facilitated tucking supports physiological stability and effectively reduces pain responses in preterm infants. Facilitated tucking can also be used with other non-pharmacological pain management interventions. When combined with non-nutritive sucking and oral sucrose, it was associated with improved sleep, measured by decreased time to fall asleep, decreased wakefulness during sleep, and increased total sleep time. (28) Apaydin et al. (29) found swaddling combined with expressed breastmilk to be superior to facilitated tucking combined with expressed breastmilk during orogastric tube insertion; however, facilitated tucking and expressed breastmilk were superior to breastmilk, swaddling, or facilitated tucking used separately for pain relief.

Facilitated tucking is an effective nonoral, nonpharmacologic pain management intervention. (30) Unfortunately, it is not consistently implemented during painful procedures. (3) Only one study reported facilitated tucking effects during routine caregiving activities. (31) The study included infants with corrected ages between 25 and 34 weeks at the time of testing. (31) Further research is needed to explore the effects of facilitated tucking in modulating infant stress during basic care procedures, with increased focus on the effects of this intervention during routine caregiving activities with infants less than 30 weeks corrected age. This case series aimed to document the effect of facilitated tucking on pain responses in infants with corrected ages less than 30 weeks in the NICU during routine caregiving activities.

Methods:

Design:

To explore the effect of a neonatal physical therapist supporting infants with a facilitated tuck during routine caregiving activities, we designed a case series. This case series did not require IRB approval because the small sample involved only routine caregiving activities. The Neonatology Chief and Nurse Director of the unit approved the observational case series.

"Infants were observed during one set of routine caregiving activities while receiving a facilitated tuck and during another set without manual postural support."

Infants were observed during one set of routine caregiving activities while receiving a facilitated tuck and during another set without manual postural support. During the facilitated tuck intervention, the infants received facilitated tuck containment in three adjacent phases: 1. two minutes prior to the initiation of caregiving activities; 2. throughout the caregiving routine; and 3. recovery phase after the caregiving activities were concluded. Infant responses were scored on the Neonatal Pain, Agitation, and Sedation Scale (N-PASS)(32) every two minutes during a ten-minute baseline period before care activities were initiated and during a ten-minute recovery period after care activities were concluded. We also recorded infants' N-PASS scores in response to each caregiving procedure.

Subjects:

The study included three preterm infants (two males and one female). Their birth gestational ages ranged from 25 to 28 weeks (mean = 27.0 weeks). Age adjustment for prematurity at the time of the study was 26 to 29 weeks (mean = 28.5 weeks). Table 1 details infant demographics.

Table 1 - Demographic Information

Mean Gestational Age	27.0 weeks (range 25w0d – 28w3d)
Mean Post-conceptual Age	28.5 weeks (range 26w6d – 29w6d)
Mean Chronological Age	12.3 days (range 10 – 14)
Mean Birth Weight	938 grams (range 693g – 1014g)
Respiratory Support	Bubble CPAP 6cm/H ₂ O, 21%FiO ₂

Instrumentation:

All infants included in this case series required Continuous Positive Airway Pressure (CPAP) support related to respiratory system immaturity. This neonatal respiratory support mask obscures subtle changes in facial expressions, such as nasolabial creases, which must be observed and scored in preterm infant pain scales, including the Premature Infant Pain Profile (PIPP). The N-PASS has been validated as a reliable pain scale with preterm infants and was chosen for this study because it does not rely on nuanced facial changes that the CPAP interface could obscure. The N-PASS includes pain responses such as crying or irritability, behavioral state, extremity tone, and vital signs, as well as general facial expressions of pain. (33)

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Procedure:

The infants were observed during two separate episodes of routine caregiving within a 24-hour period. Each infant was scored on the N-PASS during each of the two conditions while receiving routine care. During one episode of care, the nurse alone provided care to the infant, including independent body positioning. During another episode of care, the nurse performed the caregiving activities while the physical therapist supported the infant's body in a midline, tucked position. The order of the conditions was randomly assigned by coin toss.

Routine caregiving activities were scheduled at three-hour intervals and included temperature checks, auscultation, diaper changes, and initiation of tube feedings. Two neonatal physical therapists observed and documented baseline infant responses before initiating the caregiving activities. One neonatal physical therapist scored each infant using the N-PASS criteria during a 10-minute pre-intervention baseline, throughout the caregiving

activities, and during a 10-minute recovery period. During the condition in which the infant received a facilitated tuck, the other physical therapist supported the infant in a midline, flexed position for two minutes before the nurse initiated caregiving activities, throughout the episode of care, and for an additional two minutes after the care episode was complete.

“The potential impact of extraneous variables was minimized by completing both episodes of care within 24 hours for each infant, with the same nurse providing care in both conditions. The order of caregiving activities was similar for each infant across conditions. One neonatal physical therapist recorded infant responses, and the other therapist provided the facilitated tucking for all infants.”

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Results:

Overall, N-PASS pain scores were lower during the care phases when a facilitated tuck was provided, and higher when infants were not supported with facilitated tucking. In cases 1 and 2, elevated N-PASS scores also occurred after caregiving activities, indicating a delayed stress response and difficulty returning to sleep (Figure 2).

Facilitated tucking was associated with lower mean N-PASS pain scores during routine caregiving activities and in the subsequent recovery phase, as illustrated in Figure 3. The mean N-PASS score of the three infants during routine caregiving activities, when they received facilitated tuck support, was 3.3, compared with 4.6 without facilitated tuck support. Figure 3 also depicts the mean N-PASS scores of the three infants during the recovery phase following caregiving activities. The infants had a mean N-PASS score of 3.1 during the recovery phase with facilitated tucking and 4.3 without facilitated tuck support.

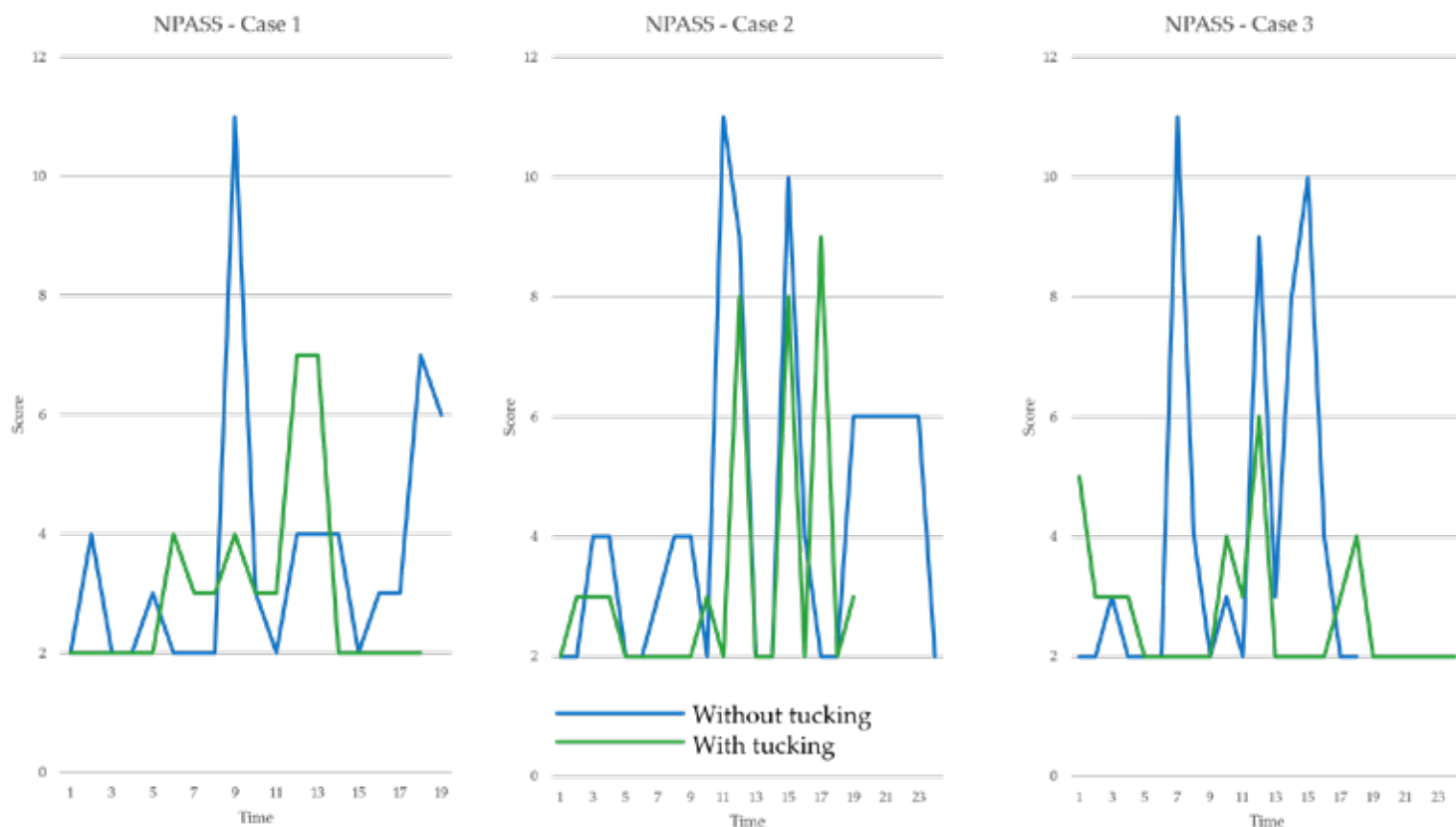


Figure 2 - N-PASS scores of three infants during two observed episodes of caregiving activities. Lower N-PASS scores were observed when infants were supported with facilitated tucking.

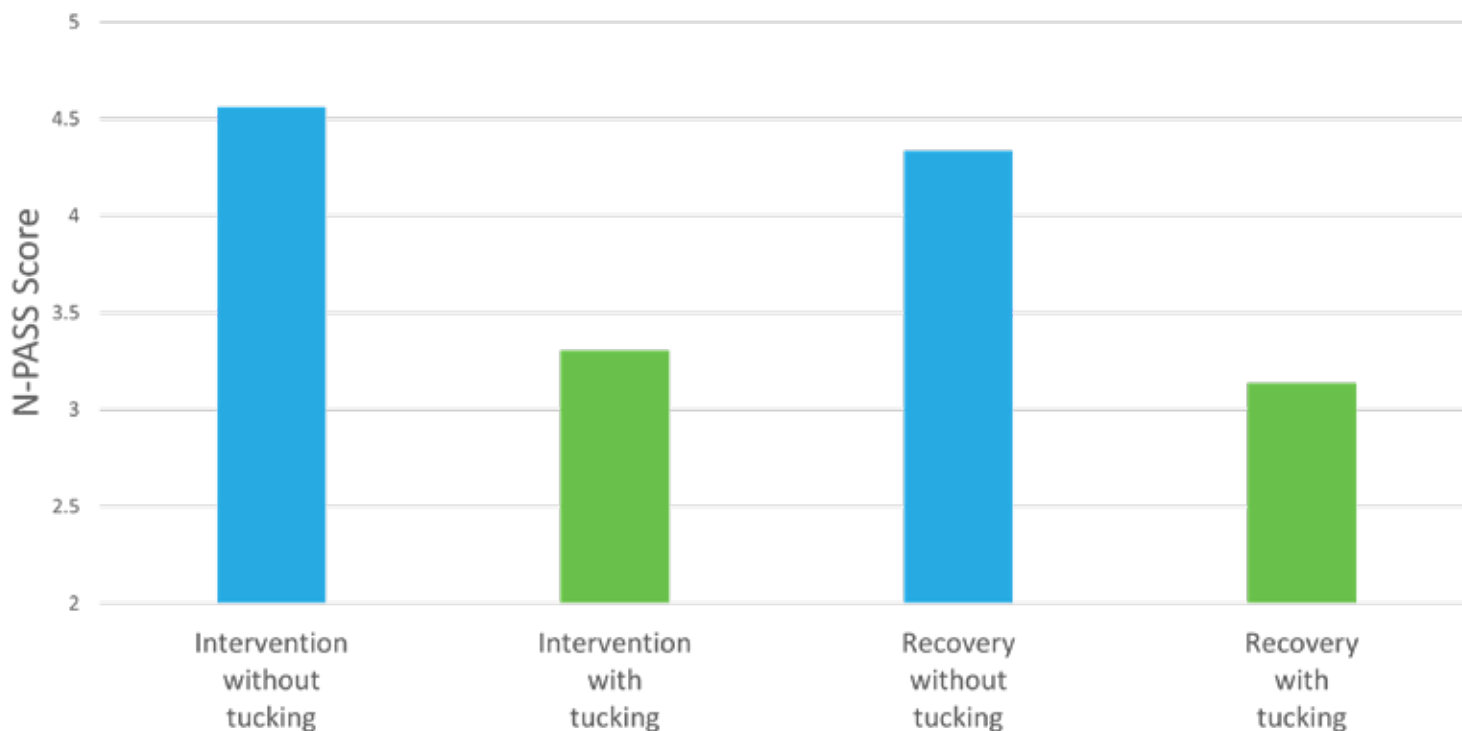


Figure 3 - Mean N-PASS scores of three infants during caregiving

Discussion:

Infants supported with a facilitated tuck demonstrated lower mean N-PASS scores during and after routine caregiving activities. Incorporating facilitated tucking into routine care may reduce pain experienced by preterm infants. This partially flexed position (Figure 1) provides postural and sensory support, which may increase autonomic stability during the discomfort often caused by disrupted body position and tactile and sensory overload during routine caregiving activities. Facilitated tucking may also enhance behavioral state stability, resulting in a faster return to a restful state after routine caregiving activities.

Parents successfully used facilitated tucking to reduce pain experienced by intubated preterm infants during endotracheal/pharyngeal suctioning. (34) This intervention could be taught to parents and used during routine caregiving activities, supporting them in taking a more active role in their infant's care in the NICU. Incorporating facilitated tucking into routine care would also allow parents to partner with nurses.

Research on facilitated tucking has primarily examined its effectiveness during recognized painful procedures, such as venipuncture, pharyngeal suctioning, heel sticks, and vaccinations. (19, 20) This case series extends the existing evidence by exploring the use of facilitated tucking during routine caregiving activities. The findings suggest that infants may also benefit from the supportive effects of facilitated tucking during routine care that can be stressful or uncomfortable. Infants under 30 weeks of gestation demonstrate greater reactivity to painful stimuli and are limited in their ability to self-soothe. (35)

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Future Research Needs:

This case series was a preliminary investigation into the effect of facilitated tucking during routine caregiving activities. A larger study is planned to include an increased sample size and an expanded focus on the effects of facilitated tucking on the post-procedure duration needed for infants to return to sleep. Neonatology researchers should examine the effects of parent-delivered facilitated tucking, explore the perspectives of both parents and nursing staff regarding collaborative implementation during routine care, and investigate whether facilitated tucking is associated with improved weight gain in infants.

Conclusion:

Facilitated tucking is a non-pharmacological pain management intervention that can be used with all infants regardless of respiratory support level. Implementation of facilitated tucking intervention may reduce behavioral disruption, pain, and stress during routine caregiving activities for infants less than 30 weeks of gestation.

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Respiratory Syncytial Virus

DID YOU KNOW?

RSV:
a highly contagious seasonal virus that causes respiratory infections.

RSV is a leading cause of hospitalization for infants under one.

- Two to three out of every 100 infants under 3 months are hospitalized with RSV every year.
- Infants are 16x more likely to get RSV than the flu
- Most children will get RSV by the time they turn two.

Long-acting monoclonal antibodies for infants after birth have been proven to reduce RSV hospitalizations.

NATIONAL COALITION Infant Health

Source:
RSV in Infants and Young Children (CDC, 2026)

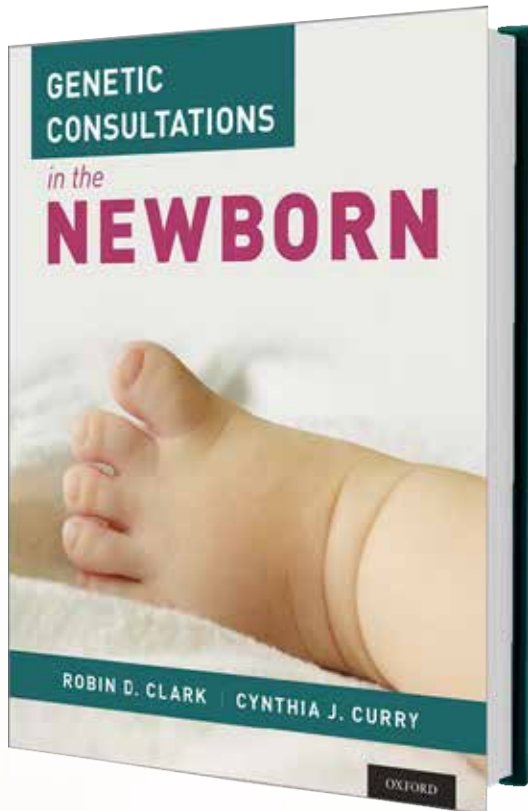
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Clinical Pearl: The Accuracy of AI in Providing Infant Safe Sleep Advice to Parents and Caretakers

Joseph R. Hageman, MD, Mitchell Goldstein, MD, MBA, CML,

“After the American Academy of Pediatrics (AAP) started the Back to Sleep (now called Safe to Sleep) campaign in the United States in 1994, the rate of Sudden Infant Death Syndrome (SIDS) declined until it leveled off in 2001 at 0.55 per 1000 live births (2234 infants) (1,2).”

After the American Academy of Pediatrics (AAP) started the *Back to Sleep* (now called *Safe to Sleep*) campaign in the United States in 1994, the rate of Sudden Infant Death Syndrome (SIDS) declined until it leveled off in 2001 at 0.55 per 1000 live births (2234 infants) (1,2). Since that time, the SIDS rate has declined more slowly to 0.38 per 1000 live births in 2020 (~1,200 infants) (2). This decline has largely been due to infants being placed in the supine position for safe sleep (2). Obstetric and pediatric providers have provided evidence-based safe sleep information to their families during the pre- and postnatal periods (1,2). Since the development of the internet, parents and caretakers have used this tool to access clinical information from many sources. Parents and caretakers obtain safe sleep information from the internet, social media platforms, peer communities such as the Reddit New Parents forum, and, most recently, artificial intelligence (AI) (1).

The question studied in this thoughtful, new work done by Rothschild and colleagues is how accurate and correct this information provided by AI is for infant safe sleep advice. (1)

“This is a cross-sectional comparative evaluation of generated responses (1). The investigators adapted nine caregiver questions from the Reddit New Parents forum and mapped them to core AAP infant safe sleep topics”

“Three reviewers with expertise in emergency medicine, injury prevention, and infant safe sleep independently scored the responses on a 0 (inconsistent with or contradicted AAP), 1 (partially correct information), and 2 (full alignment with AAP) scale for accuracy (primary outcome), completeness, and empathy (1). Similar repeated responses reflected stability.”

Methods:

This is a cross-sectional comparative evaluation of generated responses (1). The investigators adapted nine caregiver questions from the Reddit *New Parents* forum and mapped them to core AAP infant safe sleep topics (AAP 2022 “Recommendations for Reducing Deaths in the Sleep Environment”) (1). Each of the questions was entered into three large language models (LLMs): ChatGPT -5 (OpenAI), Gemini 2.5 Flash (Google), and Claude Sonnet 4.5 (Anthropic) three times within the same day to assess stability (1). Three reviewers with expertise in emergency medicine, injury prevention, and infant safe sleep independently scored the responses on a 0 (inconsistent with or contradicted AAP), 1 (partially correct information), and 2 (full alignment with AAP) scale for accuracy (**primary outcome**), **completeness**, and **empathy** (1). Similar repeated responses reflected **stability**. We **calculated readability** using the Flesch-Kincaid grade level (1). Mean scores using descriptive statistics, analysis of variance (ANOVA), and post hoc testing (Tukey tests) were evaluated. $p < 0.05$ was considered statistically significant (1).

Primary and Secondary Outcomes:

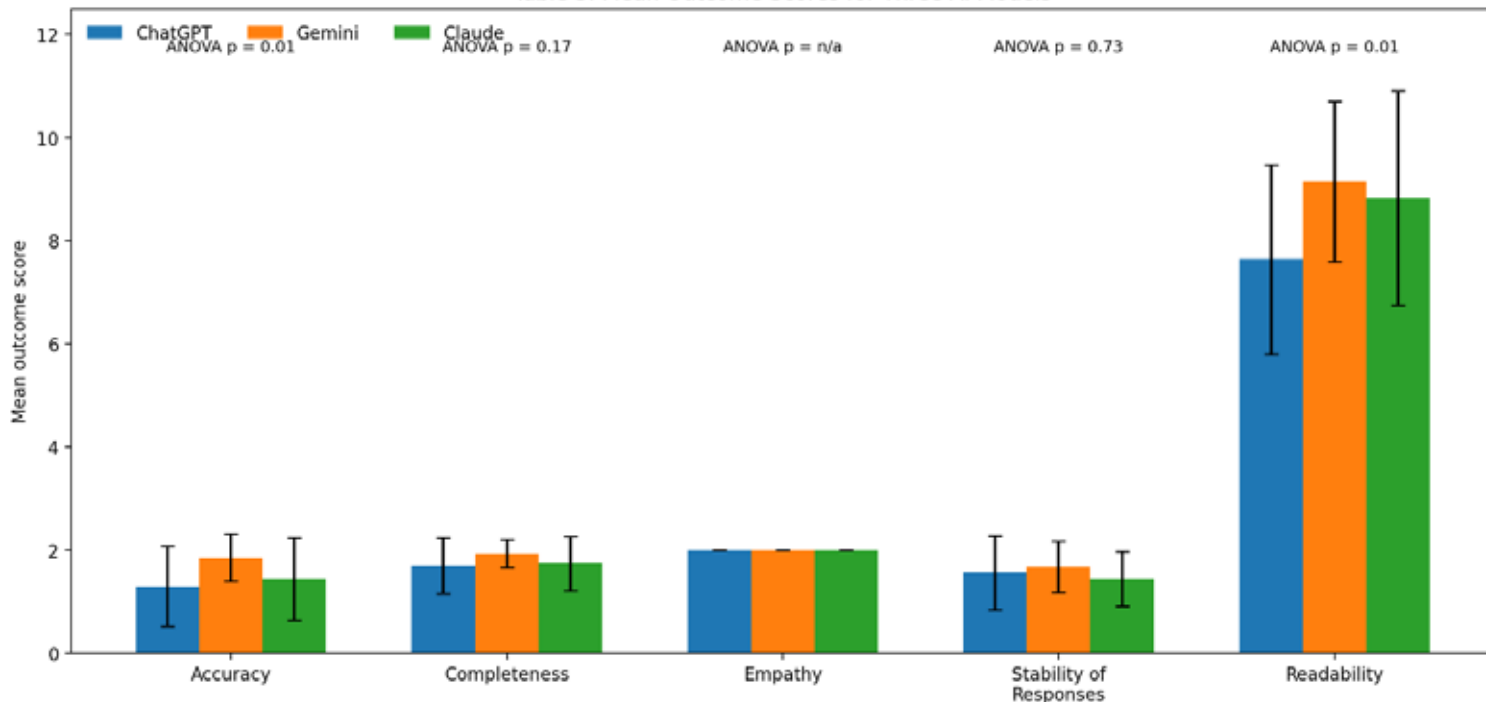
Primary outcome: accuracy

Secondary outcomes: completeness, empathy, stability, readability.

Results:

The primary outcome was **accuracy**: ChatGPT 1.30 ± 0.78 , Gemini 1.85 ± 0.46 , and Claude 1.44 ± 0.80 . ANOVA $p = 0.01$. The graph presents the mean outcome scores for the 3 AI models for the secondary outcomes: **completeness**, **empathy**, **stability**, and **readability**.

Table 3. Mean Outcome Scores for Three AI Models



The nine Common Caregiver Questions about Infant Sleep and corresponding AAP Safe Sleep Recommendations are categorized as guideline-based (4 questions) and nuanced (5 questions) (1). For example, question 1 (guideline-based): What position should I use when I put my baby down to sleep? Question 2 (nuanced): What should I do if my baby only falls asleep while being held?

Results for the individual questions showed that accuracy varied by both model and question type (1). Only question 4 (“Is it better to share the bed with my baby and rest or stay all night and follow the rules?”) demonstrated a statistically significant difference in accuracy between Claude (mean: 2), Gemini (mean: 1.67), and ChatGPT (0) ($p < 0.01$) (1). Questions 1, 6, and 7 all achieved a score of 2 across the 3 LLMs (see Table) (1).

Completeness scores were higher than accuracy scores but did not differ significantly across models (1). Response stability also did not differ across LLMs, whereas readability did differ significantly across models (1).

Overall agreement among the 3 expert reviewers was substantial ($\kappa = 0.674$, $p < 0.001$), supporting the reliability of the scoring process.

Discussion:

In this study, responses to the nine common caregiver questions about infant safe sleep using the 3 LLMs as resources were inconsistently accurate, with frequent deviations from AAP recommendations. Accuracy varied across the models and was highest for questions that could be answered directly from the guidelines (1).

All three LLMs responded well to guideline-based questions, but performance declined on nuanced questions involving caregiver exhaustion, infant illness, or infant sleep difficulties (1).

This thoughtful, well-done comparison study highlights how

caretakers use these LLMs to ask questions about the nuances of infant safe sleep. This is compared with AI responses to common, guideline-based questions from the 2022 AAP recommendations for reducing deaths in the sleep environment, where accuracy is higher (1).

“Pediatricians should be aware that LLM responses on infant safe sleep may be inaccurate or incomplete, especially when caretakers ask nuanced questions not fully addressed in the AAP infant safe sleep recommendations. AI LLMs are increasingly used to answer these clinical questions, so when caretakers ask infant safe sleep questions, providers should ask about the source of the caretakers’ information.”

Pediatricians should be aware that LLM responses on infant safe sleep may be inaccurate or incomplete, especially when caretakers ask nuanced questions not fully addressed in the AAP infant safe sleep recommendations. AI LLMs are increasingly used to answer these clinical questions, so when caretakers ask infant safe sleep questions, providers should ask about the source of the caretakers’ information.

Technology developers and AI pediatric advisors also need to consider the findings of this comparison and the LLMs’ responses to ensure accuracy and readability. Readability analyses found the LLM responses to be written at or about a seventh-grade level,

exceeding the recommended thresholds for patient education materials (1).

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1. Rothschild E, Christian J, Arar C, Ryan LM, Solomon BS, Badaki-Makun O, McDonald E, Omaki E, Howard MB. How Correct is Artificial Intelligence for Infant Safe Sleep Advice? Evaluating Accuracy of ChatGPT, Gemini, and Claude Against American Academy of Pediatrics' Guidelines. *Acad Pediatr*. 2026 Sep-Oct;26(7):103398. doi: 10.1016/j.acap.2026.103398. Epub 2026 July 14. PMID: 42448223.
2. Hauck FR, Carlin RF, Moon RY, Hunt CE. Sudden infant death syndrome. Chapter 423 in *Nelson Textbook of Pediatrics*. Ed. by Kliegman RM, St. Geme III JW, et al. 22nd. Edition. Philadelphia, Elsevier, 2025. pp.2532-2540.

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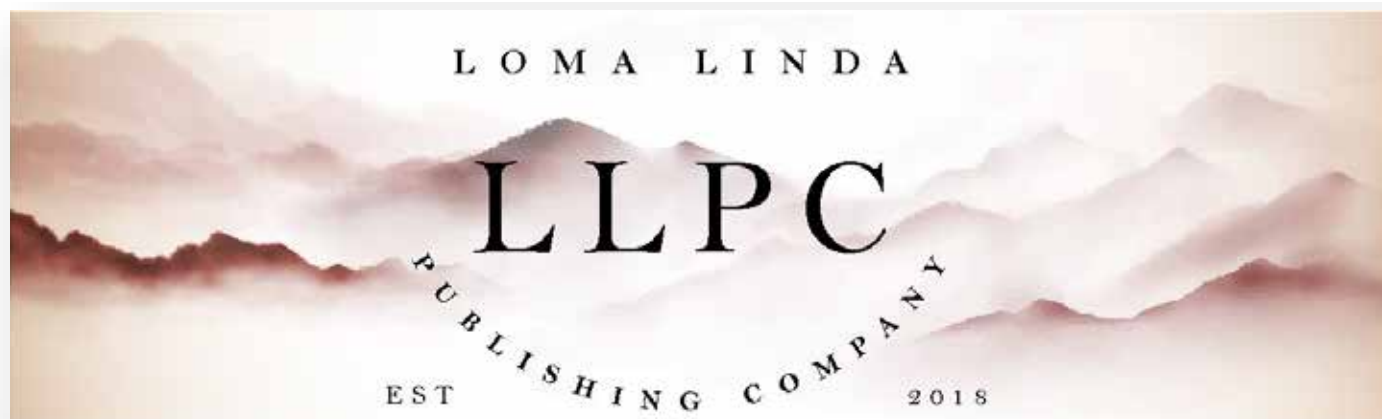
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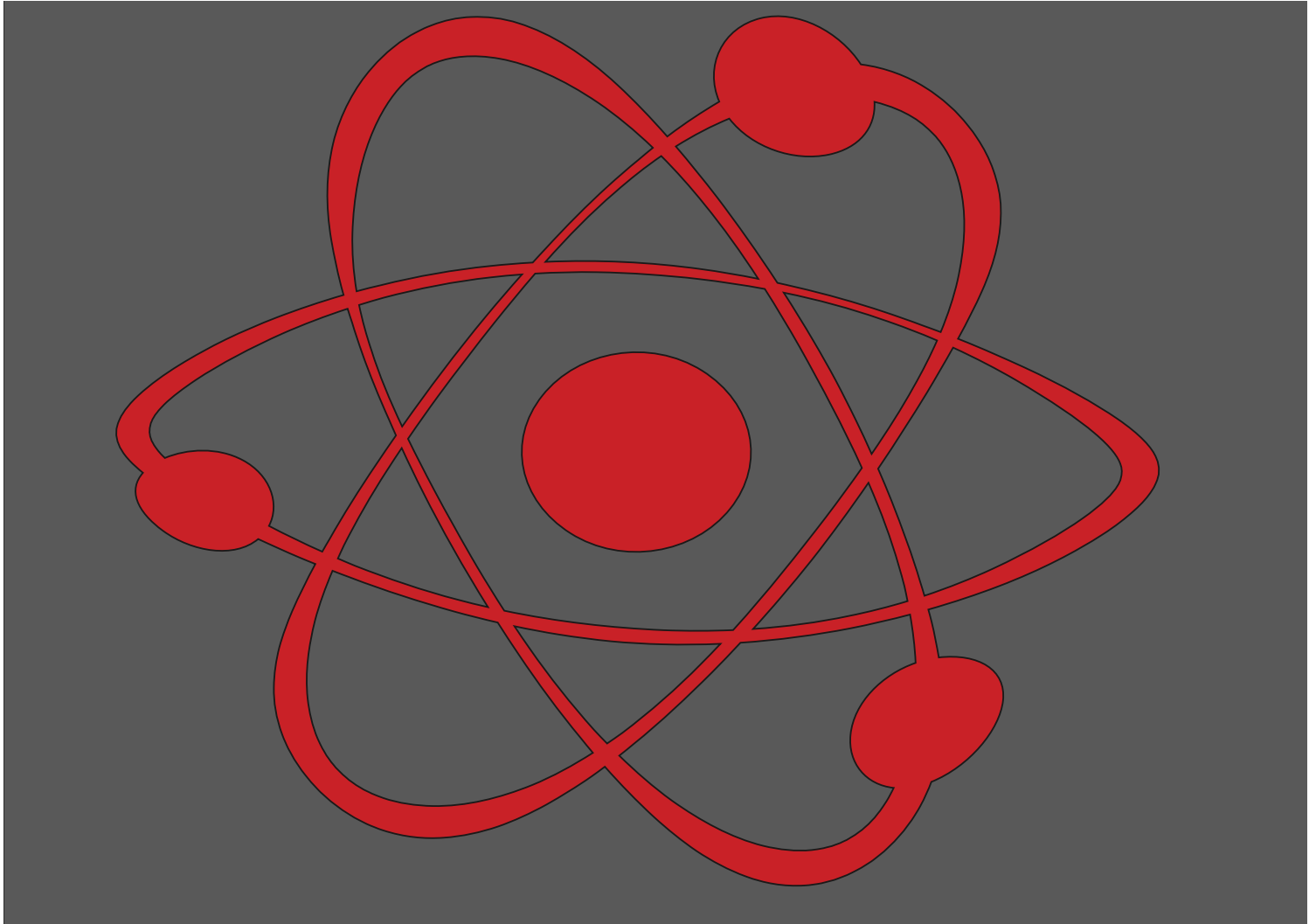
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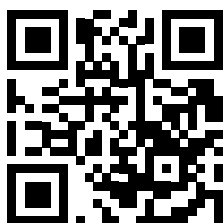
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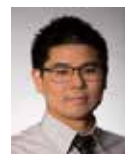
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This month we continue to landscapes, feature artistic works created by our readers on the next to last page as well as photographs of birds on the rear cover. Monty Natour, MD provides "Milky Way over Zion" For this edition, our art was graciously provided by Colleen Kraft, MD. It is a work called "All Hallows Eve" done by her son Tim. Our bird is from Dr. Shah, "Porocephalus Rubinus."

Lily Martorell, MD

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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.



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.





