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Loma Linda, CA 92354
Tel: +1 (302) 313-9984
LomaLindaPublishingCompany@gmail.com

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FCC TASKFORCE NEWSLETTER

The **first** international, multicenter collaborative initiative solely dedicated to **quality improvement in NICU Family-Centered Care**.

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- Supporting Families Beyond Discharge
- January '25 Webinar Summary
- Trauma-Informed Care Corner
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FAMILY-CENTERED CARE TASKFORCE

Subscribe to our mailing list and visit our website to learn more.

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Part Three: 'Aria's Journey: Connecting Through Our Shared Humanity' by Jessi Barnes, MSN, RN, RNC-NIC, NPD-BC, C-ELBW

Content Warning: The following is an artistic interpretation of what being a premature baby could be like. If you've experienced a preterm birth, please take care when reading.

"Today is the day! The helpers have been talking about my parents holding me skin-to-skin today. I am so excited. I've missed falling asleep while listening to my mom's body noises. I bet she is excited about today, too. I'm going to do my best to behave myself, I don't want to be so excited that I forget to breathe (they really don't like that around here)! I can hear the helpers talking with Mom and Dad about the plan. They sound nervous again. I wish I could tell them it will all be okay. We're going to be together again in just a few minutes! Mom and the helpers open up my spaceship (it's more fun if I think of it that way!), and Mom scoops me up onto her chest while the helper brings all of my accessories. This. Is. Amazing. I'm a little nervous, but Mom and Dad are here, so I know I'll be safe. I settle in while listening to Mom's heartbeat and Dad softly singing our song to me. This is where I'm supposed to be. I'm so lucky to have them. I know coming early made things scary, but I hope they know what a good job they are doing."

Practical tips for facilitating skin-to-skin care for infants like Aria in the NICU:

- Communicate with your patient's family. Keeping everyone informed and in agreement about when, where, and how skin-to-skin care happens helps support a smooth experience.
- Get support! It takes a team to care for families in the NICU, and skin-to-skin care is no exception. Ask a NICU nurse, neonatologist, respiratory therapist, and occupational or physical therapist to help families hold skin-to-skin. The team's shared goal should be a safe, enjoyable snuggle session.
- Consider a parent-led standing transfer. This video from UCSF is a wonderful resource!

For Part Two/Aria's Admission, catch up here.
For Part One/Aria's Birth, catch up here.

COMMUNICATION AS THE CORNERSTONE

WITH MIA MALCOLM, BS, CDFT, PHARM-D

As we reflect on 2024, it's apparent that language was a major theme in the FCC Taskforce's webinars and office hours sessions last year. **Effective communication is the cornerstone of patient- and family-centered care because words have both direct and indirect impacts on the people who hear and experience them.** Words like 'failure', 'misbehaving', 'difficult', 'absent', 'disengaged', and 'inattentive' are labels families can't escape or outrun. When used by healthcare professionals, these words may traumatize and haunt families for a lifetime.

Families in NICU spaces are experiencing varying levels of pain, trauma, oppression, discrimination, and stress. Language, words, and our ability to communicate are the most powerful tools we have as humans. Regardless of who we are, when we're born, or where we come from, we use language – verbal, body, or visual – to express our feelings and thoughts to others. So, when we are abusive or arrogant with our words, trust is broken. When our words are laced with assumptions or bias, when we are flippant, dismissive, or disrespectful with our words – especially in these vulnerable settings - we obliterate trust. **Trust is gained in drops and lost in buckets. One word can throw gallons of trust out the window – that's the power of our language.**

As we welcome 2025 let us all commit to taking a pause and taking inventory of our words, reflecting on the power they have to impact trust, outcomes, and collaboration with families. Because as Jay Z said, "when words fail, disease sets in," and it could be an incurable disease, so choose your words wisely. "A riot is the language of the unheard." ~ Rev. Dr. Martin Luther King Jr.

Free resources for communicating and building trust with NICU families:

- Building Trust and Transparency in Trauma-Informed Developmental Care: A Foundation for Healing, Caring Essentials Collaborative
- Effective Communication for Families in Crisis, InJoy Health Education
- Rules to Engagement: Families in the NICU, EI Excellence
- The Vital Role of Respect in the NICU: Building a Foundation of Trust and Compassion, Caring Essentials Collaborative

SUPPORTING FAMILIES BEYOND DISCHARGE

WITH JESS DAIGLE, MD, FAAP

For many NICU families, **transition home is filled with new anxieties, unexpected hurdles, and gaps in follow-up care**. As healthcare professionals, we have a unique opportunity to extend our support beyond the NICU walls in **three key areas**, ensuring families feel confident and capable as they navigate this new chapter.

1: ONGOING NAVIGATION

Discharge is often the beginning of a new, overwhelming chapter for families as they manage multiple health appointments, therapies, and specialist care. **A dedicated care coordinator can help families by guiding them through scheduling appointments, managing referrals, and understanding follow-up care plans.** This support not only alleviates logistical stress but also helps parents build confidence in meeting their baby's unique needs.

2: PROVIDING RESOURCES

Many parents leave the NICU overwhelmed by medical jargon, specialized equipment, and the fear of making mistakes. **Providing user-friendly tools such as customized care plans, educational materials, and workshops on topics like infant CPR and developmental milestones can help families feel more confident.** These resources allow parents to care for their child independently as they adjust to life without the round-the-clock support of the NICU team.

3: COMMUNITY SUPPORT

The NICU journey can feel isolating, and this isolation often deepens after discharge. **Peer support groups and mentorship programs—initiated in the unit and extending beyond discharge—can help families connect with others who understand their experiences.** These connections foster a sense of belonging, encouragement, and improved mental health for families as they navigate this challenging journey.

JANUARY '25 WEBINAR SUMMARY

"Optimizing Organizational Mindset to Support Skin-to-Skin and Evidence-Based Neuroprotective Care" with Elizabeth Rogers, MD

In her talk, Liz outlines how culture change can bring about improvements in patient care, specifically in neuroprotective care. Each NICU's culture is complex, and **change cannot occur without understanding the unit's cultural foundation** which consists of stories, feelings, and unwritten rules.

The team at University of California San Francisco (UCSF) surveyed staff about their unit's culture to identify areas of opportunity and growth as they worked to improve rates of skin-to-skin care occurrences in the first 72 hours of life. They formed committees to address areas of concern uncovered in the survey, such as burnout and the unit's safety climate, so that work to improve NICU culture could be done simultaneously with clinical QI efforts. In addition to improving their culture, USCF NICU created a unit-specific skin-to-skin protocol, provided widespread education on skin-to-skin, and developed an infant-readiness checklist. As a result of their efforts, UCSF improved rates of early skin-to-skin care occurrences and decreased the rate of intraventricular hemorrhage in their unit. In summary, **providing neuroprotective care for NICU babies relies on positive cultural transformation emphasizing a growth mindset and a supportive & nurturing environment for families & healthcare professionals**.

"The ABCs of Empathy, Hope and Clear Communication for NICU Parents" with Terri L. Major-Kincade, MD, MPH, FAAP

In her talk, Terri shares how **empathy is vital for supporting NICU parents** through their often challenging and traumatizing journeys. She describes **three core principles of empathy: Acknowledge, Breathe, and Curiosity**. Acknowledge involves establishing rapport, using preferred names, and respecting boundaries. Breathe encourages pausing before responding to allow for emotional connection between healthcare professionals and parents. Curiosity involves active listening and asking open-ended questions to understand the parents' perspective.

There are several roadblocks to providing empathetic care in the NICU including systemic barriers, location constraints, lack of staff time, and the inherent personal biases we all hold. Because of these roadblocks, families often feel disconnected from the medical team. The NICU environment can feel like a "war zone" with abrasive noises & alarms and frequent bad news, which can lead to chronic sorrow and Post Traumatic Stress Disorder. These challenges can be compounded by unintentional neglect bias, an example being a focus caring for premature infants at the expense of larger babies.

To improve communication, staff can use techniques like Parent-Led NICU Rounds, where parents actively contribute to the discussions about their infant's care, ensuring they feel valued and empowered. The **NURSE acronym (Naming, Understanding, Respecting, Supporting, Exploring)** is another helpful tool for providing empathy, while emphasis on posture—sitting instead of standing—can make interactions feel more inclusive and less hierarchical. Parents need to feel affirmed as good parents to better cope with the stress of the NICU. Validating their emotions, acknowledging their concerns, and providing reassurance that they are doing their best, fosters resilience and enhances parent-child bonding. Ultimately, empathy in action involves putting oneself in parents' shoes, listening attentively, and responding with compassion—something we can all strive to do more of.

To watch a recording of this event, click here!

TRAUMA-INFORMED CARE CORNER: TENDING TO THE WOUNDS WE CANNOT SEE

WITH MARY COUGHLIN, MS, NNP, NCC-E

What if we approached "less desirable" behaviors not with judgment, but with care? Imagine if, instead of labeling these actions as "bad" or "wrong," we recognized them as wounds—hidden, aching places in need of attention, compassion, and healing.

Just like a physical wound, these emotional wounds tell a story. They remind us of moments when we were hurt, unheard, or unseen. And just as we wouldn't ignore a cut that's bleeding or a burn that's festering, we shouldn't ignore the wounds that lie beneath the surface of human behavior. **When we treat behavior as a wound, the care we offer shifts dramatically:**

Clean the Wound: This is the first step—acknowledging the pain. We listen, ask questions, and seek to understand. What caused this behavior? What unmet need, fear, or hurt lies beneath it?

Debride When Necessary: Sometimes healing requires removing what no longer serves us—old patterns, limiting beliefs, or toxic environments. This process isn't easy, but it's essential.

Apply a Salve: Compassion and empathy are the balm for emotional wounds. These moments of kindness remind us that we are seen, valued, and worthy of care.

Change the Dressing: Healing isn't a one-time event. It's a process that requires monitoring, support, and consistent attention. We check in, reevaluate, and adapt our care as needed.

Prevent Infection: This is where community and connection come in. We heal best when we are surrounded by people who hold us accountable and uplift us.

Behavior, like a wound, is often a signal—not a definition of character. When we approach behavior with this understanding, we create a culture of healing, where judgment gives way to curiosity, shame to understanding, and alienation to connection. What wounds are you carrying today? What salve might you need? And how can we, together, create spaces where healing—not judgment—is the natural response to being human?

JANUARY POLL

Help us understand your unit's best practices around mental health screenings for NICU families so we can support units working toward implementing this crucial provision.

Does your unit screen NICU families for perinatal mood and anxiety disorders?

(ex. PMAD Ex Edinburgh Scale)

Click here to share!

Thank you!

Thank you for your insights! **To view all of the helpful polls and responses we've received, click here.**

Vol. 10 **01/2025**

UPDATE FROM FCC TASKFORCE FOUNDER MALATHI BALASUNDARAM, MD

Our **Year-End Update** is a testament to the FCC Taskforce's incredible year of strengthening Family-Centered Care in the NICU. These accomplishments would not have been possible without our Core Leadership Team, Executive Council, Committee Co-Chairs, Organizational Partners, Sponsors, and **YOU**. As we begin a new year, I'd like to share a few updates:

1. Our 2023 Small Group Quality Improvement Work was **accepted for publication in the Journal of Perinatology**! Keep an eye out for this publication, coming soon.
2. We selected **five fellows as FCC scholars** (pictured below) among 24 outstanding US and Canadian applicants. Thanks to the FCC Scholars Selection Committee for their blind review, which helped me select the deserving awardees to receive support to attend this year's Gravens Conference.
3. Our organization created **The Michael Hynan Fund to support family partner speakers** with travel expenses for their advocacy work at neonatal conferences. If you are interested in tax exempt donation to this cause, please reach out to me via email.
4. We've **established an EDIB (Equity, Diversity, Inclusion, and Belonging) Committee** led by co-chairs Mia Malcolm and Jessi Barnes (pictured below) so we can include an EDIB lens in all that we do.
5. Our Advocacy Committee led by Nicole Nyberg and Kerri Machut is working tirelessly on **creating a practical implementation toolkit based on the Presence Study and its recommendations**. The implementation toolkit will be published later this year.
6. Finally, **73 NICUs have committed to learning more about and improving their center's FCC practices**, click here to see if your unit is one of them and here to register your unit to participate!

"Each one of us can make a difference. Together we make change." - Barbara Mikulski

CONGRATULATIONS FCC SCHOLARS

Cameron N. Boyd, MD
Northwestern University, Feinberg School of Medicine
3rd Year Fellow

Emily Chi, MD
Oregon Health & Science University
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Caitlin Duncan, MD
Boston Children's Hospital
1st Year Fellow

Dhwani Oza, MD
University of Texas at Austin, Dell Medical School
2nd Year Fellow

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University of Texas, Southwestern Medical Center
2nd Year Fellow

Scholarships are made possible by Loma Linda Publishing Company and Perinatal Advisory Council: Leadership, Advocacy, and Consultation (PAC-LAC), our partners in receiving the Chiesi USA Independent Educational Grant to support this initiative.

FCC SCHOLARS SELECTION COMMITTEE

Pictured Left to Right, Top to Bottom:
Robert Cicco, MD
Jess Daigle, MD
Colby Day, MD
Morgan Kowalski
Mia Malcolm
Necole McRae
Ashley Omwando

EDIB COMMITTEE CO-CHAIRS

Jessi Barnes, MSN, RN, RNC-NIC, NPD-BC, C-ELBW

Mia Malcolm, BS, CDFT, Pharm D.

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FCC Taskforce

Core Leadership Team
Malathi Balasundaram, MD
Colby Day, MD
Keira Sorrells

Program Manager
Morgan Kowalski

Newsletter Committee

Co-Chairs
Vargabi Ghei, MD, MSHS
Morgan Kowalski

Contributors
Jessi Barnes, MSN, RN, RNC-NIC, NPD-BC, C-ELBW
Jess Daigle, MD, FAAP
Mary Coughlin, MS, NNP, NCC-E
Laura Hedli, MS
Mia Malcolm, BS, CDFT, Pharm-D

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Mission Statement

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

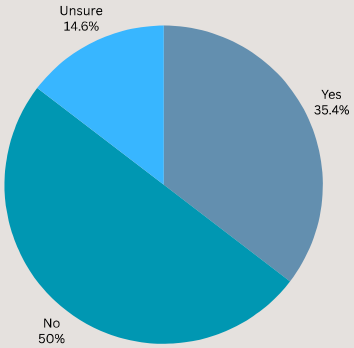
Why We Exist

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

Our key strength is equal partnership between clinicians and family partners in everything we do.

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

Does your NICU currently have an FCC Committee?



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Corresponding Author

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

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Should Infants Be Separated from Mothers with COVID-19?

FIRST DO NO HARM

SEPARATION may not prevent **INFECTION**.

SKIN to SKIN CARE supports newborns' physiology.

SEPARATION stresses parents and babies.

SEPARATION weakens immune protections.

SEPARATION disrupts breastfeeding putting babies' health at risk.

SEPARATING the DYAD doubles providers' workload, burdening systems.

BASED ON THE ARTICLE:

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

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