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FCC TASKFORCE NEWSLETTER

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

In This Issue

FAMILY-CENTERED CARE TASKFORCE

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

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.

Since the last time we talked, I have mastered chestfeeding! It took us a while to get things sorted out, but my team of helpers really supported us through all the learning curves. Now I'm trying to figure out how to eat from a bottle. Who knew there were so many ways to eat? It feels different every time, and that makes it hard for me to learn what to do. It would be helpful if things could be more consistent. Mom can't be here all the time, and they said I have to figure this out if I want to go home. (I really want to go home.) They have special helpers who focus on teaching me how to eat from the bottle. They have special helpers for everything in here! Mom and Dad have been taking turns learning how to help me eat. This is the longest part, I think. Learning how to breathe was one thing, but eating is a whole other challenge! I know Mom and Dad are tired, but they are here supporting me through this last lesson. We'll get through it together!

Practical tips for supporting learning how to eat from a bottle:

- **Follow the baby's cues.** They will let you know if they are interested or capable of learning how to eat. They get to call all the shots!
- **Normalize the ups and downs of eating in discussions with families.** It can be one of the most frustrating times for parents. Their baby has made it through other challenges, but eating is a huge milestone that each baby conquers at a different time.
- **Be intentional about focusing on the baby's experience of eating rather than the volume eaten.** We want positive neuropathways around eating for these tiny people!

For Part One/Aria's birth, catch up here.
For Part Two/Aria's admission, catch up here.
For Part Three/Aria's first time skin-to-skin, catch up here.
For Part Four/Aria's first time breastfeeding, catch up here.

SUPPORTING FAMILIES BEYOND DISCHARGE

REIMAGINING NICU DISCHARGE THROUGH A FAMILY-CENTERED LENS

WITH JESS DAIGLE, MD, FAAP, NICU PARENT

In the NICU, discharge is not just a clinical milestone—it's an *emotional transition into the unknown.*

For families who've lived in a state of constant vigilance, where monitors replaced lullabies and updates came before sleep, discharge marks both freedom and fear. ***True family-centered discharge planning begins long before the paperwork.*** It's a gradual process of preparing, empowering, and honoring the family's voice.

I'll never forget one mom who stood quietly at her baby's bedside on the day of discharge. We had reviewed the feeding plan and the follow-up appointments, but before she left, she looked at me and said, "What if I don't wake up to feed him in time? The nurses won't be there anymore." She didn't need more instructions, ***she needed reassurance, presence, and a reminder that we believed in her***, too.

My reply to this parent sounded like, "You will. That instinct is already in you. **You've *been* showing up for your baby, and you'll keep showing up, just in a new rhythm.** Remember, it's not about being perfect, it's about being present."

Discharge planning means asking not only "Is this baby stable enough to go home?" but also "Have we equipped this family to feel confident and connected once they walk out the doors?" It's noticing who's missing from rounds, who's nodding without understanding, and who needs an extra day—not for the baby, but for themselves.

NICU professionals can support family-centered discharge in three major ways:

1. Start discharge conversations early.
Introduce the idea of going home at least 1-2 weeks in advance so families can emotionally and logistically prepare. Don't let it come as a surprise.

2. Teach in layers, not just once.
Spread out education on equipment use, feeding plans, and warning signs over time to improve retention and reduce overwhelm.

3. Ask, "What worries you most about going home?"
This simple question often reveals the unspoken fears that need your attention most.

Discharge from the NICU should never feel for families like they're being released—***it should feel like they're being carried forward with support, clarity, and compassion.*** That is what family-centered care looks like in practice—not just at the bedside, but at the threshold of home.

MAY '25 WEBINAR SUMMARY

WITH BOB CICCO, MD

Our May Webinar provided strategies for **safely and successfully increasing the utilization of skin-to-skin care** in all infants while overcoming barriers that exist in promoting this important practice. Watch a recording of this free educational webinar **here!**

"**Removing Barriers to Safer Skin-to-Skin Care" with Ashley Weber, PhD, RN, RNC-NIC and Yamile Jackson, PhD, PE, PMP**

The results of a survey taken prior to this talk showed that when parents show signs of drowsiness during skin-to-skin care, 64% of respondents wake the parent and reposition the baby and 41% stop the session and provide education and support. Furthermore, 54% of respondents reported not having a unit protocol to support safe skin-to-skin care. WHO recommends 8-24 hours of skin-to-skin care each day, which can be comprised of multiple sessions. As a point of reference, 3hr of Kangaroo Care is considered a longer session, however parents tend to become distracted and drowsy after roughly 45 minutes. Ashley and Yamile provide **insights to maintain safety while continuing to promote skin-to-skin care:**

- Our inability to develop strategies to address safety during skin-to-skin sessions is a roadblock in achieving longer sessions.
- If you're worried about safety during skin-to-skin care, the answer isn't to shorten sessions, but to strategize about how to safely support longer ones.
- Allowing longer sessions of skin-to-skin care requires more planning, but the benefits of this care make that planning worthwhile.
- Parental distractions and drowsiness will occur. **We should plan for how to manage these rather than forbid skin-to-skin care.**
- The risks of adverse events related to parents being distracted or falling asleep are real but can be reduced by instituting appropriate controls.
- It's essential to find ways to support the baby without the parents having to use their hands. This can include having the parents reclined and using kangaroo wraps.
- Safety control protocols must be monitored, evaluated, and modified if necessary to assure ongoing safety.
- It is better to control risk through education, stabilization, and monitoring than to avoid risk by not allowing skin-to-skin care.

"Engagement of Families in a State-Wide QI Initiative on Skin-to-Skin Care" with Susan Bowles, DNP, APRN-CNS, RNC and Lelis Vernon, SQIL

Sue and Lelis shared the results of a statewide quality improvement project focused on improving skin-to-skin care across Florida. This project was done through their state's Perinatal Quality Collaborative and emphasizes the **importance of family engagement and participation in achieving true quality improvement in care**. Some key results and takeaways from this project are:

- ANY QI project will benefit greatly from having parent consultants in order to assure that the project will promote change that is consistent with FCC principles.
- The primary drivers for this QI project were the pillars of FCC: Family Participation, Dignity and Respect, Collaboration and Information Sharing.
- Not only was prompt initiation of skin-to-skin care increased during the project, but there was also an increase in the use of mother's own milk at the time of discharge for all populations.
- Time to initiation of skin-to-skin care was most improved in Black and Hispanic populations.
- Skin-to-skin care was increased without any increase in unplanned extubations. All institutions developed a policy to have two staff members assist with transferring the baby to the parent's chest.
- Educating families on the value of skin-to-skin care reduces their fear of initiating it.
- With any QI project, it is important to track the changes that have be made to assure they are sustainable.

TRAUMA-INFORMED CARE CORNER

THE COURAGE TO BE GOOD: A CALL TO CARE WITH INTEGRITY

WITH MARY COUGHLIN, MS, NNP, NCC-E, TRAUMA INFORMED PROFESSIONAL

How hard is it to be good? It's a question that has echoed through my recent work — not as a moral dilemma, but as a trauma-informed inquiry. In a world that often rewards efficiency over empathy, and perfection over presence, being "good" — truly good — can feel like an act of quiet defiance.

In the NICU, goodness isn't abstract. It lives in the pause before a painful procedure. It's embedded in the choice to speak with respect to a family overwhelmed by fear. It shows up in our commitment to relational safety — even on the hardest days.

Trauma-informed care reminds us that every human behavior tells a story — including our own. And yet, we've been conditioned to separate the personal from the professional, to keep our griefs quiet and our hearts hidden. But goodness isn't sterile. It's relational.

To be good in this context is not just about clinical competence; it is about caring with integrity. It's about showing up consistently, compassionately, and consciously — even when we're tired, even when the system makes it hard. Goodness lives in our willingness to connect, to be seen, and to see others fully.

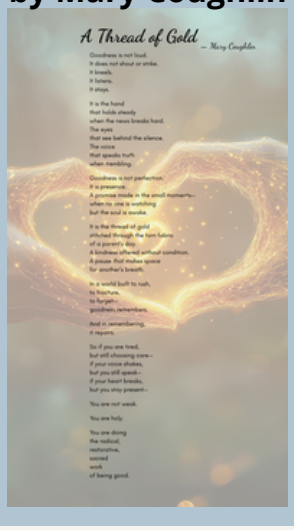
This is where the **B.U.F.F.E.R.™** framework meets real-life care:

- **Belonging** — because no one should feel like a visitor in their child's story.
- **Understanding** — because behavior is a reflection of experience, not worth.
- **Forgiveness** — because healing means we get to try again.
- **Frameworks** — because structure and soul are not mutually exclusive.
- **Equanimity** — because our calm becomes someone else's lifeline.
- **Respect** — because dignity is a birthright, not something earned.

So, how hard is it to be good?

Hard enough to require intention.
But beautiful enough to keep choosing it — again and again.

A Thread of Gold
by Mary Coughlin



Click here to enlarge

This Summer, **let's reclaim goodness not as a nicety, but as a clinical, ethical, and human imperative.** Let it be the throughline of every interaction, every decision, every moment of care.

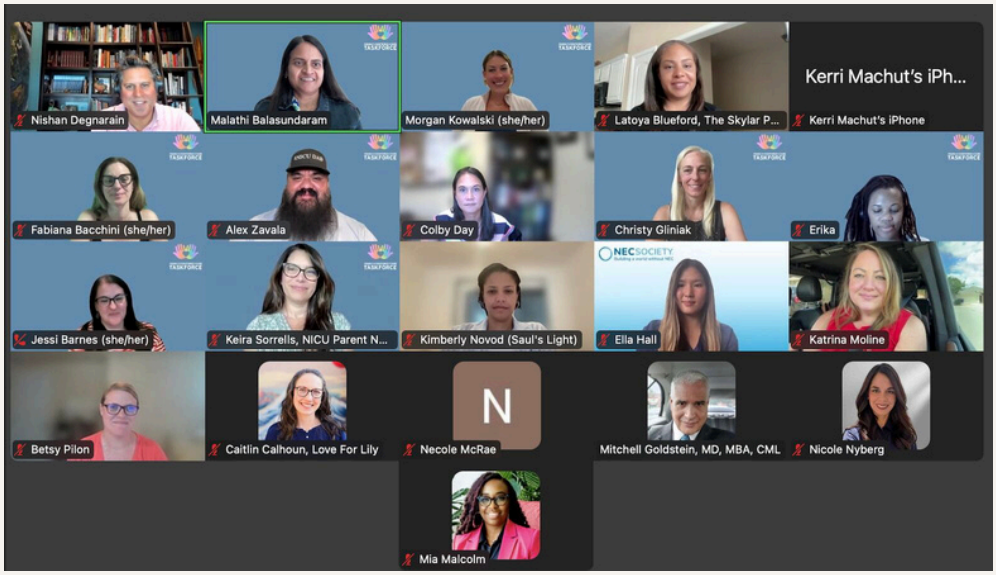
Because in a world that feels increasingly fractured, goodness is a radical act of repair. And we are the ones who carry the thread.

With heart, Mary

EXECUTIVE COUNCIL UPDATE

WITH MALATHI BALASUNDARAM, MD & MORGAN KOWALSKI

The FCC Taskforce's Executive Council held its second quarterly meeting of 2025 on June 24th with 21 members joining virtually via Zoom!

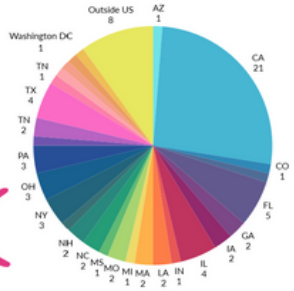


NICU FCC Measures Survey Update

- 96 centers have completed our REDCap Survey as of 2/25
- 59 centers have agreed to an interview with our Research Team (22 declined)
- 36 interviews have been scheduled with 28 completed

Research Team:
Malathi Balasundaram, MD
Colby Day, MD
Henry Lee, MD
Morgan Kowalski
Mia Malcolm, BS, CDFT
Keira Sorrells

July 31ST DEADLINE FOR PARTICIPATION



FAMILY-CENTERED CARE TASKFORCE
www.fcctaskforce.org

Asses your unit's performance in delivering Family-Centered Care. **Click here** to register for the survey!

We are grateful to the **16 family-led** and **22 healthcare-based** organizations supporting our work by sharing our free educational webinars and office hours sessions!

New Organizational Partnerships

Adaptive Parent Project
Care for NICU Families
GFONI global foundation for the care of newborn infants
NEWBORN BRAIN SOCIETY
phm NEWBORN HOSPITALISTS
New York State nyspQc Perinatal Quality Collaborative
Prevent Blindness
THE SKYLAR PROJECT
TIPQC Tennessee Initiative for Perinatal Quality Care

Welcome!

Marsha Campbell-Yeo, RN, BN, NNP-BC, PhD, FAAN
Neonatal Nurse Practitioner & Professor,
School of Nursing, Faculty of Health and IWK Health
Scientific Lead, MOMLINC Lab

Erika Mendence
Family Support Specialist,
Children's Mercy, Kansas City
NICU Parent

Elizabeth Simonton, JD
Co-Founder & Executive Director,
ICU baby
NICU Parent

Nishan Degnarain, MPA
Family Advisory Council Member,
California Perinatal Quality Care Collaborative
Family Advisory Council Member, Alta Bates NICU
NICU Parent

Katrina Moline
Executive Director,
Hand to Hold
NICU Parent

Kimberly Stobbe, LCSW
OB & MFM Social Worker,
Northwestern Medicine Huntley
Vice President,
National Association of Perinatal Social Workers

We're thrilled to welcome six new members to our Executive Council, and our first Healthcare Partner representing the social work community! Learn more about our Executive Council here.

THANK YOU FOR READING

FCC Taskforce

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

Program Manager
Morgan Kowalski , NICU Parent

Newsletter Committee

Co-Chairs
Bob Cicco, MD
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

Mission Statement

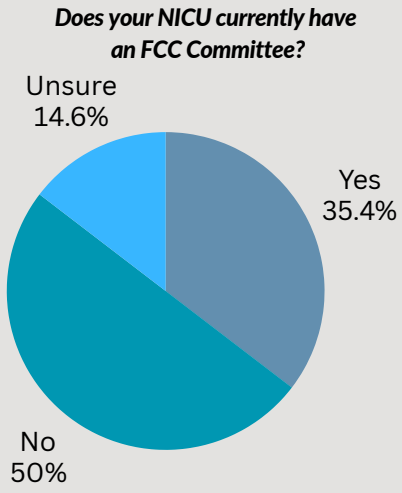
We exist to equip and support NICUs as they seek to begin or strengthen Family-Centered Care in their units.

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.



Membership

2400+ members
49/50 U.S. States & Puerto Rico
8/10 Canadian Provinces
70 Countries
Join us, membership is free!

Organizational Partners

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