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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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Generously supported by Mead Johnson Nutrition

Part Four: '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.

"I get to try something new (again) today! My favorite helper said Mom and Dad are here, and I'm going to try using my mouth to eat. I wonder if that means they will get rid of this thing in my nose. Don't get me wrong, it's way better than when it was in my mouth, but it tickles and makes me sneeze. Don't get me started about when they put it in! Do all people have to have one of these in the beginning? There has got to be a better way! Maybe this mouth thing is it. After Dad changes my diaper, Mom scoops me up onto her chest. I love snuggling with her, but I am super hungry. My helper is talking to Mom and Dad about what we'll be doing. Mom holds me against her in a different way. It's weird, but I'll get used to it. I just really want to eat! It smells like her, and that makes me feel calm. One thing I know is we'll figure this out together, just like everything else!"

Practical tips for facilitating breastfeeding/chestfeeding for the first time:

- Everyone will be nervous, and the baby could be cranky or unsure of what to do. Share your calm! It helps bring the stress down in the room. Normalize the jitters and make a plan together.
- Frame the first feeding at the breast/chest as a shared learning experience. We are all in this together and learning along the way.
- Just like with cue-based interaction, focus on the experience rather than the quantification.
- If your unit has access to a lactation consultant, utilize their support!

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.

SUPPORTING FAMILIES BEYOND DISCHARGE

WITH JESS DAIGLE, MD, FAAP, NICU PARENT

Discharge day is often seen as the happy ending in a NICU story, but for many families it's the beginning of an entirely new chapter. As a physician and a NICU mom, I've come to understand that the journey home is layered with relief, joy, fear, and an invisible weight that is rarely acknowledged outside of NICU walls. **I wish more people knew what it's really like to bring a NICU baby home:**

1. **Discharge doesn't mean the journey is over.** Leaving the NICU is not the end of care—it's a transition. Families are sent home with follow-up appointments, feeding plans, therapy referrals, and lingering questions about their baby's development and future.
2. **You're excited—but terrified.** For weeks (or months), parents have had the safety net of machines, monitors, and medical teams. Home is quieter, but it can also feel lonelier and scarier. Every sound, every missed feeding, every pause in breathing feels high stakes.
3. **Feeding, sleep, and milestones become stressors.** Feeding often remains a challenge due to reflux, fatigue, or coordination issues. Sleep is fragmented, not just because of the baby, but because parents are hypervigilant. And developmental milestones don't feel like boxes to check—they feel like potential red flags.
4. **Grief can sneak in, even where there's joy.** Parents still grieve the birth experience they didn't get, the time they missed while their infant was in the NICU, and the uncertainty they still carry. The NICU experience is traumatic for many, and trauma doesn't disappear at discharge.
5. **Just because we're home doesn't mean we're "fine."** Friends and family often expect things to return to "normal" after discharge. But the truth is, families are still healing—physically, emotionally, and mentally. They need ongoing support, not just congratulations.

As members of the healthcare team, we must recognize that **discharge isn't a destination—it's a handoff. True family-centered care continues beyond the hospital walls.** That means preparing parents not just with supplies and appointments, but with validation, education, and emotional support. **We can empower families by:**

- Normalizing anxiety and emotional shifts after discharge
- Offering resources like parent support groups, therapists, or NICU follow-up clinics
- Collaborating with pediatricians and specialists to ensure seamless care
- Encouraging honest conversations about fears and expectations

NICU parents are doing more than surviving—they're carrying the weight of uncertainty, trauma, and fierce love. When we acknowledge that, we help carry that weight with them. As healthcare professionals, **our compassion doesn't end when a family leaves our unit, it lives in the way we prepare them, follow up with them, and advocate for better systems of support—from hospital to home.**

MARCH '25 WEBINAR SUMMARY

WITH BOB CICCO, MD

Our March Webinar (watch **HERE**) emphasized the need for healthcare professionals and the healthcare system itself to recognize that their roles go far beyond treating the medical conditions that bring a baby and family to the NICU. If we are going to ensure that all babies reach their maximum potential in life, we must do everything possible to provide compassionate care that allows parents and their babies to grow together in their quest towards self actualization.

"Cultivating Compassion: Enhancing NICU Family Experiences and Addressing Bias in Healthcare" with Jess Daigle, MD, FAAP

Jess emphasized quality care is not only meeting the medical needs of babies in the NICU, but **providing compassionate care that addresses families' mental, social, emotional, financial and cultural needs.** The following are some of the many highlights from her talk:

- While a history and physical exam provide medical data, it's equally **important to obtain and understand every family's unique lived experiences in order to effectively partner with them on their NICU journey.**
- Compassion is not the same as empathy. Compassion is not only feeling and understanding another's experience but taking action to help.
- People are not born with or without compassion. **Compassion can be developed and cultivated.**
- The words we use matter. It's important to be respectful and honest when we speak, and to be active listeners who are attentive to what is being said to us.
- Even the best communicators sometimes say things that are hurtful. We should always apologize, even if it just a misunderstanding. It still hurts!
- Everyone has biases! We should not deny our biases but try to understand them and learn how not to make unwarranted assumptions about others.
- Address bias by remembering to **P.A.U.S.E. P**ay attention to your reactions. **A**cknowledge assumptions. **U**nderstand your perspective. **S**eek different viewpoints. **E**xamine & adjust your approach.
- Cultivate compassion by engaging in **C.A.R.E. C**ontinuous self-reflection. **A**sk for feedback. **R**ecognize cultural differences. **E**ngage in mindfulness. For more of Jess' guidelines on cultivating compassion, click here

"Self Actualization: Live Highest Potential as Parents" with Colonel Erick Ridout, USA, Medical Corps (Retired)

Erick's presentation provided a detailed summary of the importance of striving to achieve self actualization and how it can be accomplished for families in the NICU. Some of the vital lessons Erick imparted in his talk include:

- Every healthcare professional should remember: **"We provide care FOR a baby, not TO a baby!"**
- It's not enough to only address physical, developmental, and emotional needs of infants in the NICU. **Healthcare professionals must also support parents by encouraging their ongoing growth in taking care of their baby**, allowing them self actualize.
- **Self actualization is achieved through autonomy** (being in control of our decisions), **mastery** (getting better at something that matters) **and purpose** (finding meaning our lives).
- Self actualization is not just important for parents, but also for healthcare professionals AND babies.
- Autonomy does not mean one has to go it alone. Family-Centered Care requires interdependence of all team members, including parents. With increasing autonomy, there is increasing interdependence and accountability.
- **Babies are not totally dependent - they have a voice. They desire and deserve care that has value to them. Care provided to both babies and families that does not have value is harmful.**

TRAUMA-INFORMED CARE CORNER

REIMAGINING FCC: A TAPESTRY OF TRANSITIONS, CONTEXT, AND CONNECTION

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

Family-Centered Care is often described as a partnership—one that honors dignity, voice, and collaboration. But how often does that partnership reach beneath the surface, into the lived experiences of families and clinicians navigating uncertain terrain?

In trauma-informed developmental care, we recognize that every NICU admission is more than a medical event—it's a profound transition. Drawing from Afaf Meleis' Transitions Theory, we are reminded that identity, relationships, and roles are in flux—and that **healing requires more than interventions; it requires presence.** Layering in Bronfenbrenner's Ecological Systems Theory, we acknowledge that **care doesn't happen in a vacuum**. Families are shaped by complex systems—policies, cultures, inequities—that ripple through the bedside experience. **Context matters. Language, access, and belonging all shape the story of care.**

And so, FCC must evolve. It must become more than a philosophy—it must become a practice of relational safety. This is where the **B.U.F.F.E.R.™** framework lives: **B**elonging, **U**nderstanding, **F**orgiveness, **F**rameworks, **E**quanimity, and **R**espect. **These aren't soft skills; they are clinical imperatives. They shape trust. They buffer stress. They transform outcomes.**

As we move forward, let us ask:

- What transitions are the families—and staff—moving through?
- What systems support or harm those journeys?
- And how can our care reflect not just what we know, but who we choose to be?

FCC, at its best, is not a checklist—it is a commitment. One that begins with us.

Click here to enlarge this graphic!

MAY POLL

Tell us about your unit's protocol & guidelines around fingernail length, artificial nails, and nail polish for staff & families!

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.**

EXECUTIVE COUNCIL UPDATE

WITH MORGAN KOWALSKI

The FCC Taskforce's Executive Council held its first quarterly meeting of 2025 on March 6, with 19 members gathering in person at the Gravens Conference and 6 joining virtually via Zoom!

There was a lot to talk about!

Journal of Perinatology publishes our quality improvement work

Read here with open access!

Journal of Perinatology www.nature.com/jp

QUALITY IMPROVEMENT ARTICLE OPEN

Improving commitment to family-centered care in the NICU: a multicenter collaborative quality improvement project

Malathi Balasundaram[1,2✉], Henry C. Lee[3], Laura C. Hedli[1], Kerri Z. Machut[4], Dharshi Sivakumar[1,2], Morgan Kowalski[1], Rafael Mendelsohn[5], Keira Sorrells[6] and Colby Day[7]

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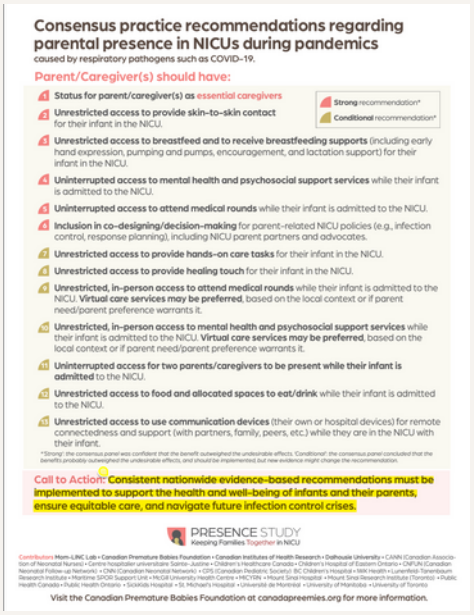
OBJECTIVE: Despite evidence demonstrating the positive impact of family-centered care (FCC) in the neonatal intensive care unit (NICU), FCC is not standard of care. This multi-center, quality improvement initiative aimed to increase the percentage of NICUs with FCC committees and Family Partnership Councils (FPCs).
STUDY DESIGN: Participating NICUs were divided into small groups for collaborative mentoring. A key driver diagram and Pareto charts evaluated barriers to FCC and directed interventions. The primary outcome measure was development of an FCC committee and/or FPC. Process measures were views of bi-monthly educational webinars, evaluated using Statistical Process Control charts.
RESULT: Across 22 NICUs, the percentage with FCC committees and FPCs increased from 18% to 59% and 18% to 45%, respectively. Average webinar views increased from 28 to 182 views/webinar with clear signal on XmR chart.
CONCLUSION: A collaborative mentoring model and focused education achieved the goal of increasing NICU FCC committees and FPCs.

Journal of Perinatology; https://doi.org/10.1038/s41372-025-02232-1

Presence Study provides guidelines for parental presence in NICUs during pandemics. We're creating a toolkit based on this amazing work!



Consensus practice recommendations regarding parental presence in NICUs during pandemics

caused by respiratory pathogens such as COVID-19.

Parent/Caregiver(s) should have:

- Status for parent/caregiver(s) as essential caregivers
- Unrestricted access to provide skin-to-skin contact for their infant in the NICU.
- Unrestricted access to breastfeed and to receive breastfeeding supports (including early hand expression, pumping and pumps, encouragement, and lactation support) for their infant in the NICU.
- Uninterrupted access to mental health and psychosocial support services while their infant is admitted to the NICU.
- Uninterrupted access to attend medical rounds while their infant is admitted to the NICU.
- Inclusion in co-designing/decision-making for parent-related NICU policies (e.g., infection control, response planning), including NICU parent partners and advocates.
- Unrestricted access to provide hands-on care tasks for their infant in the NICU.
- Unrestricted access to provide healing touch for their infant in the NICU.
- Unrestricted, in-person access to attend medical rounds while their infant is admitted to the NICU. Virtual care services may be preferred, based on the local context or if parent need/parent preference warrants it.
- Unrestricted, in-person access to mental health and psychosocial support services while their infant is admitted to the NICU. Virtual care services may be preferred, based on the local context or if parent need/parent preference warrants it.
- Uninterrupted access for two parents/caregivers to be present while their infant is admitted to the NICU.
- Unrestricted access to food and allocated spaces to eat/drink while their infant is admitted to the NICU.
- Unrestricted access to use communication devices (their own or hospital devices) for remote connectedness and support (with partners, family, peers, etc.) while they are in the NICU with their infant.

Strong recommendation* Conditional recommendation*

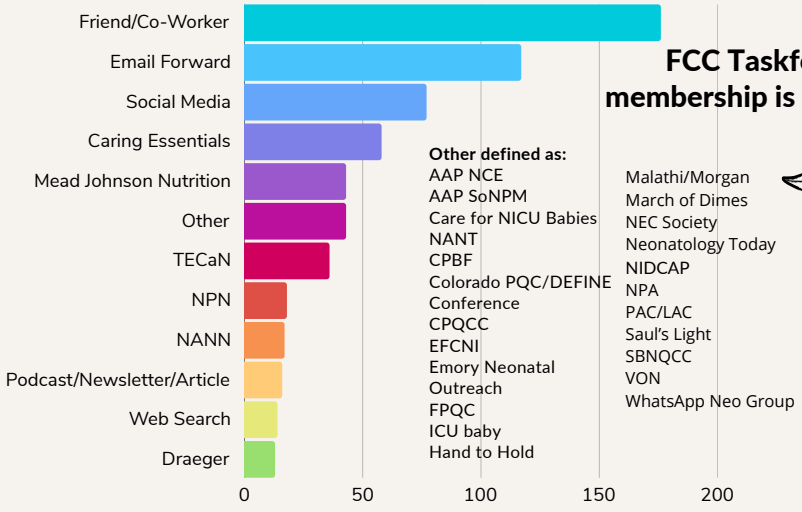
*'Strong': the consensus panel was confident that the benefit outweighed the undesirable effects. 'Conditional': the consensus panel concluded that the benefits probably outweighed the undesirable effects, and should be implemented, but new evidence might change the recommendation.

Call to Action: Consistent nationwide evidence-based recommendations must be implemented to support the health and well-being of infants and their parents, ensure equitable care, and navigate future infection control crises.

PRESENCE STUDY Keeping Families Together in NICU

Contributors Mom-LINC Lab • Canadian Premature Babies Foundation • Canadian Institutes of Health Research • Dalhousie University • CANN (Canadian Association of Neonatal Nurses) • Centre hospitalier universitaire Sainte-Justine • Children's Healthcare Canada • Children's Hospital of Eastern Ontario • CNFUN (Canadian Neonatal Follow-up Network) • CNN (Canadian Neonatal Network) • CPS (Canadian Pediatric Society) • BC Children's Hospital • IWK Health • Lunenfeld-Tanenbaum Research Institute • Maritime SPOR Support Unit • McGill University Health Centre • MICYRN • Mount Sinai Hospital • Mount Sinai Research Institute (Toronto) • Public Health Canada • Public Health Ontario • SickKids Hospital • St. Michael's Hospital • Université de Montréal • University of Manitoba • University of Toronto

Visit the Canadian Premature Babies Foundation at canadapreemies.org for more information.



FCC Taskforce membership is growing!

Other defined as:
AAP NCE
AAP SoNPM
Care for NICU Babies
NANT
CPBF
Colorado PQC/DEFINE Conference
CPQCC
EFCNI
Emory Neonatal Outreach
FPQC
ICU baby
Hand to Hold
Malathi/Morgan
March of Dimes
NEC Society
Neonatology Today
NIDCAP
NPA
PAC/LAC
Saul's Light
SBNQCC
VON
WhatsApp Neo Group

FCC Taskforce Now on Bluesky!

Click Here to follow us!

THANK YOU FOR READING

Mission Statement

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

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

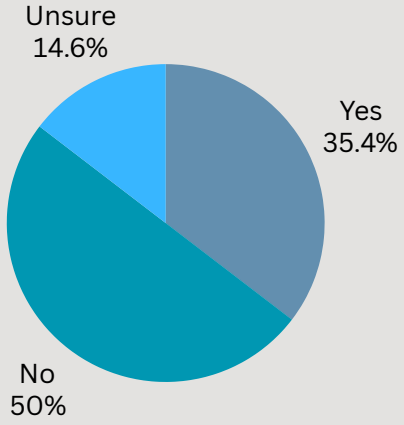
Why We Exist

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?



Membership

2100+ members
49/50 U.S. States & Puerto Rico
8/10 Canadian Provinces
66 Countries
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