

# FCC TASKFORCE

# NEWSLETTER

## FCC Core Team

### Co-Chairs

Malathi Balasundaram, MD  
Colby Day, MD  
Keira Sorrells

### Program Manager

Morgan Kowalski



## Want to strengthen FCC in your NICU?

Click this [link](#) or scan the QR code to join the FCC Taskforce for access to free webinars & resources.

## Newsletter Committee

### Chair

Vargabi Ghei, MD, MSHS

### Members

Malathi Balasundaram, MD  
Daphna Barbeau, MD  
Colby Day, MD  
Morgan Kowalski  
Keira Sorrells  
Robert White, MD

### Graphic Design

Kavya Wazhi

## Mission Statement

The Family-Centered Care (FCC) Taskforce aims to educate, create guidelines, and facilitate unit-based interventions related to FCC in the NICU.

## Check Out Our Website!

Be sure to visit our website, [fcctaskforce.org](https://fcctaskforce.org) to view all past and upcoming webinars as well as shared resources.

Follow Us on Twitter: [@FCCTaskforce](https://twitter.com/FCCTaskforce)

Contact Us: [familycenteredcaretaskforce@gmail.com](mailto:familycenteredcaretaskforce@gmail.com)

## In This Issue

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- FCC Taskforce End of Year Update
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- How to Provide Intentional Care
- Quarterly Recommendations

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FAMILY-CENTERED CARE  
TASKFORCE

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## WEBINAR REVIEW

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### **“Family Integrated Care: Where are we now?” with Karel O’Brien, MD (she/her), neonatologist at Mount Sinai Hospital and Professor of Pediatrics at the University of Toronto**

Karel discussed the family integrated care (FICare) model, which can provide a structure that supports the implementation of FCC. She highlighted the principles of FICare: 1) parent education & support, 2) staff education & support, 3) environmental support, and 4) psychosocial support. For infants, FICare improves growth, breastfeeding success, discharge readiness, self-regulation at 18 months’ corrected age, and motor development. For parents, FICare improves hands-on skills, emotional bonding, and stress management.

The guiding concept of FICare is that parents are true partners in their baby’s care – they are the primary caregivers and NICU staff act as mentors. Unit leadership can start the journey towards FICare by creating a FICare steering committee (ideally with participation from parents, administrators, physicians, bedside nurses, healthcare providers, nurses, and hospital administrators). They can assess the current state of FICare in their NICU and obtain organizational buy-in through incremental change. Page 6 has some tips!

### **“NICU Dad Perspective: Disparities in Family Centered Care” with Alex Zavala (he/him), founder of The NICU Dad and The NICU Dad Podcast, VON Family Advisor, Dell Children’s Ascension NICU Network PFAC Chair, and a former NICU parent of Emerson (30-weeker) and Mia (27-weeker)**

Alex, with bravery and courage, shared his experience as a NICU dad and the lack of support he received in his role as a non-birthing parent. He spoke about the challenges of caring for his wife who had just given birth and youngest daughter in the NICU while also being the primary parent for his older daughter at home. He aptly coined this the “NICU Dad Shuffle.” Alex shared his mental load during this medical crisis was significant. He was responsible for keeping his business afloat, taking care of his home, caring for pets, sharing information between providers and his family, making NICU visits a positive experience for his older daughter, and acting as a nurse, therapist, driver, and delivery guy, among other tasks!

“No one checked on me,” Alex said after describing his 100-pound weight gain, diagnosis of hypertension, type II diabetes, and declining mental health during his youngest daughter’s NICU stay. Alex fights to change NICU culture and stereotypes around dads being uninvolved. “Dads are no longer smoking cigars in the lobby,” Alex said. “They are in the delivery room. They are involved!” By creating awareness of the struggles of non-birthing parents, Alex invites dads to share their stories and promotes the inclusion of all parents. Alex left us with these impactful words: **“Family-Centered Care should include the whole family.”**

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# FCC TASKFORCE

## END OF YEAR UPDATE

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*The FCC Taskforce stands as a pioneering force, being the FIRST international, multi-center, collaborative initiative solely dedicated to family-centered care. Our work is guided by a core principle: equal partnership between healthcare professionals and family partners. One of the key strengths of the FCC Taskforce lies in its ability to break down the silos that often hinder progress in healthcare. Through our global network of institutions, the Taskforce fosters collaboration between NICU stakeholders, encourages knowledge sharing, and leads QI/research on best FCC practices. We want to take a moment to thank you for your interest in our work and share a snapshot of how we've grown over the course of the year.*

### 2023 Accomplishments

- Deepened our inclusion of family partners in planning, implementing, and **leading** FCC efforts with healthcare professionals
- Ensured our Executive Council of healthcare partners and family partners features **diverse** perspectives
- Provided **six free educational webinars** featuring FCC work by healthcare partners, researchers, and family partners. These have received robust attendance live and recordings are widely shared and viewed.
- Successfully mentored five small groups that meet bi-monthly to discuss barriers to FCC and successes in overcoming them

### 2023 Impact

- **Increase** in the percentage of centers that have FCC Committees **from 20% to 32%** in six months
- **Increase** in the percentage of centers that have Family Partnership Councils **from 16% to 20%** in six months

### 2023 Outreach

- More than doubled listserv membership, now at **700+**!
- Partnered with several esteemed national organizations including American Academy of Pediatrics: Section on Neonatal Perinatal Medicine and Trainees and Early Career Neonatologists, California Perinatal Quality Care Collaborative (CPQCC), Perinatal Advisory Council: Leadership, Advocacy, and Consultation (PAC-LAC), Neonatology Today, Loma Linda Publishing Company, National Association of Neonatal Nurses (NANN), National Association of Neonatal Therapists (NANT), NICU Parent Network, and Hope for HIE
- Website, YouTube Channel, and Twitter account continually show improved engagement and are updated many times each month
- Six free educational webinars scheduled for 2024

### 2023 Support

FCC Taskforce Phase 3 QI work is supported by a grant from Genentech, a member of the Roche Group & partially funded by Prolacta Bioscience Foundation. The 2023 Gravens Conference luncheon was supported by an independent educational grant by Chiesi USA, Inc. We have received webinar sponsorship from Draeger. Thank you to all for supporting this critical work.

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## FAMILY PARTNER COLUMN

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NICU Family Partners play an important role in facilitating and supporting the principles and practices of FCC: **to ensure every family is an essential and integral member of their baby's care team, and that no family has to navigate the NICU alone.** Their range of expertise is broad: some serve as in-hospital program leaders or QI and research partners, while others are authors, advocates, and organization leaders. As a way to get to know them better, our newsletters profile one of our NICU Family Partners. We hope their stories inspire you to foster collaboration with families in your unit!



### **ELIZABETH SIMONTON**

CEO, ICU Baby  
Parent of Benedict

#### **How were you personally activated to advocate for and support NICU families?**

*My son was in the NICU after I experienced, a high risk pregnancy with polyhydramnios. His time in the NICU felt like the longest seconds of our lives, but in hindsight, it was a short stay compared to what so many others experience. While I was there, I saw many parents struggle. Their babies were very premature or had more complicated conditions than my son. Many of those parents struggled to be at their babies' bedside and had to deal with the roller coaster of the NICU. Seeing this, I knew I wanted to help NICU families.*

#### **How does your organization/company/hospital support NICU families?**

*ICU Baby unites NICU families and offers emotional, financial, and informational support so babies and their families can thrive in the NICU. We offer mentorship programs, peer-to-peer support, meals, packs with NICU supplies, informational programming, and financial support to cover transportation costs.*

#### **What insight or advice do you have for healthcare partners who want to implement/strengthen FCC practices in their hospital?**

*I think it is critical to engage former NICU parents in driving FCC practices. Those parents have the lived experience in that specific hospital and can guide, advise, and even serve as mentors to future NICU parents. Their insights are critical!*

#### **What are the greatest needs of families in maternal-infant health you observe through your work?**

*NICU parents have significant mental health issues, yet there is little support for them. If screenings are done, they are typically done early in the NICU stay and not again. As the baby's time in the NICU progresses, parents struggle more and have nowhere to turn.*

#### **What does being part of the FCC Taskforce mean to you personally?**

*The FCC Taskforce is really laying the groundwork for future care in the NICU across the nation. As the movement to build FCC grows, I am proud that I can share what ICU Baby has learned and the resources we have found helpful with other teams. I'm also excited to hear about others' best practices.*

#### **What is your greatest wish in terms of the positive impact the FCC Taskforce members can make together in maternal-infant health?**

*My wish would be that parents would never have to leave their baby's NICU bedside and they would feel fully informed, empowered, and confident while there.*

#### **Anything else you want our community to know?**

*This work is critical to ensure the wellbeing of NICU parents. We have seen FCC practices in motion and they change the entire ecosystem of the NICU for the better. ICU baby is so grateful to be meaningfully supporting NICU families here in South Florida.*

**NICU & bereaved parents are... BRAVE.**

**Healthcare partners are... HEROS.**

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## SMALL GROUP SPOTLIGHT

### MARIA FRANCO-FUENMAYOR, MD

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*NICUs participating in the Taskforce's small groups are working hard to improve their FCC practices. Here's a recent success story submitted by Small Group 1 Leader Jessica Fry, MD.*



#### **Maria Franco-Fuenmayor, MD**

Assistant Professor of Pediatrics,  
University of Texas Medical Branch, Galveston TX

When she was a NICU fellow at University of Texas Medical Branch in Galveston, Maria Franco-Fuenmayor, MD developed and led a local "HOME SAFE" team that tackled both discharge practices and family-centered care. After immense growth, the group decided to create separate committees, one to improve discharge readiness and another to strengthen FCC. Maria leads the latter, now as a faculty member, and has directed the development of multiple initiatives. These include the use of first names in the EMR, revamped holiday celebrations with collage pictures that families can take home (a favorite of families!), creation of an FCC dashboard for easy viewing by all teams, and improved documentation of communication with families (at 24 and 72 hours post birth, and during hospitalization). The committee has also initiated "goals of care" meetings at specific timepoints (usually at 4 weeks in the NICU and 36 weeks post menstrual age) to discuss each infant's course and discharge requirements.

In addition to her work on the unit, Maria has taken on a special role within the FCC Taskforce's small group. With the support of small group leaders and other team members, she is currently leading a scoping review of the literature on FCC within the NICU. We hope to have more updates on this project soon. We are grateful to partner with Maria. Her enthusiasm and commitment to the work have already brought amazing results, and we know she will continue to advance the work and the field!

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## HOW TO PROVIDE INTENTIONAL CARE

### SUE LUDWIG, *TINY HUMANS, BIG LESSONS*

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#### 5 Second Rule of Intention

**Second One:** Pause and breathe. As you step into the baby's bed space, use that transition as a cue to hit pause on your busyness and take a deep breath.

**Second Two:** Check your baggage. Consciously check any personal or professional baggage you may have in tow.

**Second Three:** Address the baby by name. This is to respect the baby as an individual. It also serves to grade the sensory input - first a verbal cue, then touch.

**Second Four:** Provide human touch. Before doing any 'procedural touch,' take a moment and provide the baby with a gentle but firm hand hug.

**Second Five:** Set your intention. While providing that human touch, set the intention for the session. For example, "I intend to decrease Nia's stress while she has a new IV placed."

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# QUARTERLY RECOMMENDATIONS

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Recently, we asked our small groups about barriers in implementing FCC practices, and many indicated that time is a significant hurdle. In our September poll, we asked you for recommendations about how to improve engagement in FCC practices when timing is tight. Check out some of our favorites below! We also share suggestions for how to support and engage non-birthing parents, to build on the themes from our most recent webinar.

## Tips for implementing FCC:

- Educate your team on how having engaged family at bedside can be a time saver. (Share Taskforce webinar recordings!)
- Let FCC/education be a part of your workflow, not an additional task. Engage families in the care processes, teaching as you go.
- Share parent feedback and stories with the team and your administration.
- Create small subcommittees for different projects, instead of one large group taking on all projects.
- Recruit a family leader, discharge coordinator, nurse educator, social worker, or child life specialist to assist in FCC duties.
- Celebrate small wins.

## Suggestions for supporting non-birthing parents:

- Help prevent what's been coined the "NICU dad shuffle," when the non-birthing parent has TWO (or more!) patients to care for. This is especially critical in the first 24 hours after birth. Recognize and acknowledge that this time might be overwhelming for non-birthing parents.
- Non-birthing parents should be considered equal care partners to birthing parents. Often, they are left out of care processes and don't receive updates or resources. We can work to change this.
- All parents suffer from stress, anxiety, and trauma in the NICU, and all deserve mental health resources whether they gave birth or not.
- There are existing resources and support groups for dads! Consider including these in your unit resources:
  - The NICU Dad [website](#) and [podcast](#)
  - [Hand to Hold](#) weekly dad support groups
  - [The DadPad](#) guide for new Dads
- Remember to not refer to parents as "Mom" or "Dad." Always ask parents by what name or title they want to be addressed.