

**FCC TASKFORCE**

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# NEWSLETTER

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### 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](http://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)

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FAMILY-CENTERED CARE  
TASKFORCE

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# ANNIVERSARY REPORT

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The FCC Taskforce started with 50 individuals in May 2022 and has now expanded to 520+ individuals representing more than **230 NICUs** from **36 states** and **16 countries**, all committed to learning more about FCC in the NICU. The FCC Taskforce stands as a pioneering force, being the **FIRST** international, multicenter, collaborative initiative solely dedicated to quality improvement in family-centered care. Its core principle of **equal partnership between healthcare professionals and family partners** embodies a critical component of family-centered care, creating an environment where collaboration and shared decision-making thrive.

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 its global network of institutions, the Taskforce connects healthcare professionals, researchers, and family partners, fostering collaboration, knowledge sharing, and the dissemination of best practices. The Taskforce employs a **small group model and large group webinars** (nine so far and many more already scheduled), enabling effective communication and facilitating change across various healthcare settings.

One of the primary challenges with FCC is changing the mindset of healthcare professionals to view families as integral to the care team, so we've created five small groups of 25 centers, each led by two neonatologists and one to two family partners with a goal of increasing the percentage of units with a functioning FCC Committee (already a 12% increase in the first six months).

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## TESTIMONIALS FROM SMALL GROUP FCC AMBASSADORS

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"Our unit in Israel joined the FCC Taskforce a year and a half ago. We have attended general and small group sessions in which we have received mentoring from leading figures in the field of FCC. We have learned a lot! We now have a better understanding of the core elements of FCC and are learning about different and practical ways we can implement FCC in our unit. We could not have made this possible without the support of our mentors, and we are very grateful for them and for this amazing model of support." **-Rafi, Israel**

"Thank you for all your hard work in engaging NICU teams all around the country on this Taskforce! Our unit has been able to share our FCC team's efforts as well as availability of rich information-sharing that has helped us refine our family-centered care processes in our NICU." **-Sangeeta, California**

"I am so proud to be on this Taskforce and to see the widespread change that is happening in units. I feel very fortunate to have the opportunity to connect with colleagues who share my passion for FCC. I learn something new in every webinar!" **-Maria, Texas**

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## WEBINAR REVIEW

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### "The i-Rainbow: A flexible, evidence-based care path for providing developmental care in the NICU" by Melissa Scala, MD & Eilish Byrne, PhD

The i-Rainbow program is unique in that it prescribes developmentally appropriate ways for caregivers to interact with their infant based on the infant's physiological status. For example, a patient who is very unstable (Stage 1) would be stimulated only by a caregiver's smell, while a very stable patient (Stage 4), who tolerates holding for 15 minutes without physiological instability, would be deemed a suitable candidate for Kangaroo Care. The program has been used successfully at El Camino Health and Lucile Packard Children's Hospital NICUs.



### "Social Media: A tool for connecting with families" by Daphna Barbeau, MD

This webinar highlighted the importance of physician presence on social media for the purposes of dispelling misinformation and for better understanding the needs of current and former NICU families. Dr. Barbeau described how social media also gives physicians a channel to engage with families for research and advocacy purposes.

[@DoctorDaphnaMD](#)



### "How Mammha is Closing Gaps in Maternal Mental Health Care in NICUs" by Maureen Fura

[Mammha](#) connects NICU parents with mental health resources and provides a confidential, HIPAA-compliant remote depression screening tool for NICU parents. Those who screen positively are immediately connected with resources including no to low-cost mental health resources, education, CBT, and coping skills via text message as well as access to a care coordinator. Those who screen negatively are still offered resources in the form of links to educational materials and other opportunities to reach out for more mental health support.

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## SPOTLIGHT!

### RAFI MENDELSON, MD AND THE NICU TEAM AT ICHILOV-TEL AVIV MEDICAL CENTER

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NICUs participating in the Taskforce small groups are all working hard to improve their FCC practices. One ambitious and dedicated member, Dr. Mendelsohn from the Ichilov-Tel Medical Center, has been committed to attending all webinars and sharing the recordings with his team. He has been a devoted member of his Small Group 5 meetings, even attending them late at night due to the time difference, and often including his adorable children to make it family-inclusive. Dr. Mendelsohn painstakingly changed his unit's design plan to incorporate FCC with the help of an FCC Taskforce small group leader and has diligently worked towards changing the culture among staff to embrace family-centered care. We are incredibly proud of what he has accomplished in such a short amount of time and commend him for his leadership and perseverance to bring such an important aspect of care to patients and their families.

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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 family-centered care: **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 areas of focus and expertise come in many forms, from in-hospital program leaders to QI and research partners, as well as book authors, advocates, and organization leaders. As a way to get to know them better, our newsletters will profile one of our Family Partners in hopes to foster more collaboration with families in your unit!



### **YAMILE JACKSON, PHD, PE, PMP**

CEO, Nurtured by Design  
 Founder, Int'l Kangaroo Care Awareness Day  
 Parent of Zachary

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

*When Zach was 3 weeks old, weighing 2.5 lbs., Tropical Storm Allison hit Houston, TX, leaving the hospital and life-support equipment powerless. The NICU staff and we kept Zach alive "by touch" for 9 hours until he was evacuated. I held him skin-to-skin to keep him warm and calm, and Larry received a crash-course on "bagging," taking turns with the staff. In those dark hours, I promised Zachary that his pain and struggle to survive were not in vain and I would dedicate my life to supporting babies like him and families like ours. Zach is now healthy and in college.*

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

*We apply ergonomics engineering, risk management, and our personal and professional experiences in creating The Zaky® (products, consulting, and app) that are evidence-based, support families, zero-separation, aid kangaroo care, nonpharmacologic pain management, and individualized developmental and neuroprotection care.*

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

*Neonatologists with a multidisciplinary team can create a trauma-informed culture of family inclusion in the NICU. Parents have superpowers for natural healing and mental health support. The healthcare team provides medical care and enables families to bond. Work as a team and rely on each other's strengths.*

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

*The lack of parental leave in the USA, especially for families of NICU infants. Too much happens in the NICU; parents should be able to be there without barriers.*

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

*I like working with a taskforce that understands that families suffer when a baby is in the NICU, and the best way to support them is to include them in the care of their babies while in the hospital and beyond.*

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## FAMILY PARTNER COLUMN

### CONTINUED

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

*I am an advocate for trauma-informed kangaroo care. I know that everything important is "counted and analyzed," from the grams of weight of the babies to the drops of milk the baby eats. I hope we give more importance to analyzing kangaroo care and include it in "count what counts."*

**Fill in the blank: NICU and bereaved parents are traumatized but capable.**

**Fill in the blank: Healthcare partners are in a position to make or break the seamless inclusion of the baby into their own family.**




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## QUARTERLY RECOMMENDATIONS

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- We can **help families recognize milestones** by identifying small wins each week or periodically on rounds. The "Hope for HIE" team calls these "inchstones."
- Many units focus on families of preterm infants. Often, families of late-preterm or full-term babies can feel left out. **Review your unit's policies and signage to make them more inclusive for all infants.**
- Has your team had a hard week? Sometimes to care for families, we need to care for our teams too. Check in to see if **your team needs a pick-me-up** this week—free coffee, a group activity like a mindfulness coloring page, a sharing & listening meeting with each other, or someone from the community to offer mental health exercises. Be sure to NAME the stressor and recognize the hard work of your team.
- Does your 'C-suite' know what you are trying to achieve? Sometimes by sharing your vision (and needs!) with the people in power at your organization, you can find a shared vision and **new avenues for support and funding.**

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## ARTICLE REVIEW

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### "It Takes a Village to Implement Family-Centered Care in the Neonatal Intensive Care Unit" by Nesibe S. Kutahyalioğlu, PhD, RN, et al. (2023) ([link](#))

Nurses are critical for the successful implementation of FCC. NICU nurses may be aware of the benefits of parental participation in the care of the neonate, but they may hesitate to fully engage the family over concerns about giving up some of their power, control, and responsibilities. This study aimed to understand how NICU nurses can implement the FCC model into practice. The mixed-methods study began with an online survey of NICU nurses, followed by video-based dyadic interviews that were conducted with a subsample of 20 NICU nurses. Analysis of the interviews of the nurses revealed six main areas which help to facilitate FCC in the NICU. Each of the six areas aligned well with the 'it takes a village' metaphor and are listed below:

- **Equitable Relationships-** The care of a neonate in an FCC model requires a care team that includes nurses, parents, physicians, educators, and administrators. Each "village" member has a role to play with specific responsibilities; no individual is solely responsible for the infant's care.
- **Bond of Trust-** Individual FCC team members need trusted relationships, believing each provides the best possible care.
- **Knowledge Sharing-** Knowledge about best practices and FCC should be provided through institutional training. Several nurses noted the importance of institutional "buy-in" for continuing education.
- **Empowerment in the Workplace-** Members should share knowledge, engender trust, and guide others. Empowering others is not dictating what to do, instead the village may be more likely to achieve its goals when each member (e.g., parents and nurses) is empowered to engage.
- **Environment and Culture-** To successfully implement FCC, the NICU environment benefits from a no-fault policy. For example, if something goes awry, it is not seen as the fault of an individual but rather considered to be a systemic problem. The members of the village work together to ensure that similar issues do not occur in the future.
- **Regulations-** Variations within—and across—groups may prevent the accomplishment of goals. Most respondents noted a need to establish policies, protocols, and guidelines.

This study shows how many NICU nurses believe that FCC implementation is not an initiative for any specific group of personnel in the NICU. On the contrary, all staff have to participate. In other words, 'it takes a village' to achieve successful practice of FCC because of the complex interrelationships between care team members.

Reviewed by Malathi Balasundaram, MD & Vargabi Ghei, MD