

FCC TASKFORCE WEBINAR

JULY 9TH | 11:00 AM - 12:30 PM PT

Parent Perspectives: Clinician Communication



Latoya Blueford
(she/her)
Founder & Executive
Director,
The Skylar Project
NICU Parent of Skylar



Tracy Pella, MA,
LMHP, EdS (she/her)
Co-Founder &
President,
Connected Forever
Founder, Rooted Life
Empowerment
NICU Parent of Cohen,
Cooper, and Maybry

*Breaking Bad News: Helping Families When
They Need Us the Most*



Anthony Orsini, D.O., FAAP
Section Chief of Neonatology,
Nicklaus Children's Hospital in Miami, Florida
President and CEO, The Orsini Way

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Webinar Etiquette

Thank you for helping us make FCC Taskforce Webinars a safe & brave space for all!

By participating, you are agreeing to the following guidelines:

1. Please mute your microphone when you aren't speaking
2. Please turn off your camera if multitasking
3. All questions & comments spoken and written in the chat should be respectful, non-discriminatory, and non-judgmental

Topics discussed may illicit strong emotions and feelings. Please reach out to us if you need support.



July is Bereaved Parents Awareness Month

Bereaved Parents Awareness Month is recognized annually in July and is dedicated to **raising awareness about the profound grief parents endure after losing a child**, whether through miscarriage, stillbirth, infant loss, or the death of a child at any age.



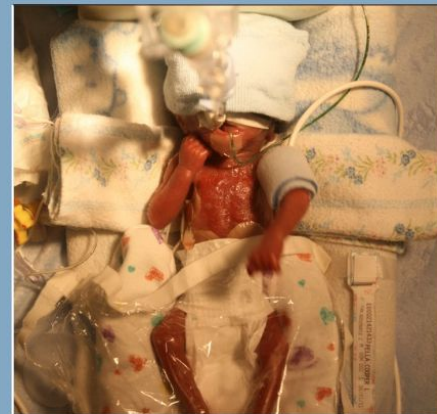
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This Webinar is Dedicated to Skylar



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This Webinar is Dedicated to Cohen, Cooper, and Maybry



All-In Meeting

- Break down the hierarchy
- Integrate patient-families
- Prioritize funds to support patient-families
- Intentionally elevate the voices of women, diverse groups, and individuals with rare or unique experiences
- Make it relevant and personal
- Provide support to disabled individuals during in-person meetings
- Invest in building relationships
- Support and include breastfeeding mothers/parents
- Demonstrate the impact, progress, and opportunities
- Capitalize on the expertise in the room
- Remain receptive and responsive to constructive criticism



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PROTECT, HEAL AND
NURTURE IN THE PURSUIT
OF A HEALTHIER WORLD



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Connecting Babies and Families in the NICU

Developed by a neonatologist with support from the National Institutes of Health, **The smallTalk® NICU Egg™ System helps families stay connected with their babies during NICU stays.** Families make recordings for their babies that are played by the care team when they can't be there. Recordings are automatically played at a NICU-safe volume and duration.



smallTalk



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Family-Led Organizational Partners

- Adaptive Parent Project
- Adult Premie Advocacy Network
- Cooper Steinhauer Foundation
- Alliance for Black NICU Families
- Canadian Premature Babies Foundation
- Connected Forever
- Empowering NICU Parents
- FreeArm
- Generation O
- GLO Premies
- Graham's Foundation
- Hand to Hold
- Hope for HIE (Hypoxic Eschemic Encephalopathy)
- ICU baby
- Love for Lily
- Miracle Babies Foundation
- NEC Society (Necrotizing Enterocolitis)
- NICU Alumni
- The NICU Dad
- NICU Neuroscience by Leo's
- NICU Parent Network
- PPRM Foundation (Preterm Premature Rupture of Membranes)
- PremieWorld
- Saul's Light
- Project NICU
- Skylar Project
- Today is a Good Day
- The Zaky (Nurtured by Design, Inc.)



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Healthcare-Based Organizational Partners

- 4th Trimester Project
- AAP Organization of Neonatal Training Program Directors (ONTPD)
- AAP Section on Neonatal Perinatal Medicine (SoNPM)
- AAP Section on Newborn Pediatric Hospital Medicine Hospitalists (nPHM)
- AAP Trainees and Early Career Neonatologists (TECaN)
- California Association of Neonatology (CAN)
- California Perinatal Quality Care Collaborative (CPQCC)
- Care for NICU Families
- Caring Essentials Collaborative
- Children's Hospital Neonatal Consortium (CHNC)
- Colorado Perinatal Care Quality Collaborative (CPCQC)
- Council of International Neonatal Nurses, Inc. (COINN)
- Creative Therapy Consultants
- DEFINE Colorado
- Developmental Care
- Engage, Grow, Thrive
- Georgia Perinatal Quality Collaborative (GAPQC)
- Global Foundation for the Care of Newborn Infants (GFCNI)
- Illinois Perinatal Quality Collaborative (ILPQC)
- Institute for Patient- and Family-Centered Care (IFPCC)
- Irish Neonatal Health Alliance (INHA)
- March of Dimes
- Measure the Placenta
- Missouri Perinatal Quality Collaborative (MOPQC)
- National Association of Neonatal Nurses (NANN)
- National Association of Neonatal Therapists (NANT)
- National Association of Perinatal Social Workers (NAPSW)
- National Coalition for Infant Health
- National Institute for Children's Health Quality (NICHQ)
- National Network of Neonatal Psychologists (NNNP)
- National Perinatal Association (NPA)
- Nebraska Perinatal Quality Improvement Collaborative (NPQIC)
- Neonatal Butterfly Project
- Neonatal Research Network of Japan
- Neonatology Today
- New York State Perinatal Quality Collaborative (NYSPQC)
- Newborn Brain Society
- NIDCAP Federation International, Inc. (Newborn Individualized Developmental Care and Assessment Program)
- Not on My Watch
- Prematuridade
- Perinatal Advisory Council: Leadership, Advocacy, and Consultation (PAC/LAC)
- Perinatal-Neonatal Quality Improvement Network of Massachusetts (PNQIN)
- Perinatal Resource Collaborative (PRC)
- Preventing Blindness
- Sensory Beginnings
- South Dakota Perinatal Quality Collaborative (SDPQC)
- Synapse Care Solutions
- Tennessee Initiative for Perinatal Quality Care (TIPQC)
- Tiny Baby Collaborative
- Union of European Neonatal and Perinatal Societies (UENPS)



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New Organizational Partnerships



Equal Representation in Leadership

Leadership Team



Malathi Balasundaram, MD
Founder & Executive Director
Neonatologist



Morgan Kowalski
Director of Operations
NICU Parent



Keira Sorrells
Director of Impact & Strategy
NICU Parent

Executive Council of Family Partners



Fabiana Bacchini



Leilis Bauzá Vernon, SQIL



Latoya Blueford



Sahra Cahoon



Jennifer Canvasser, MSW



Tracy Pella, MA, EdS, LMHP



Marybeth Fry, M.Ed.



Yamille Jackson, PhD,
PE, PMP



Erika Goyer



Mia Malcolm, BS, CDFT



Erika Mendence



Lenette Serlo



Misti Staley



Katrina Moline



Kimberly Novod, MPH



Betsy Pilon



Alex Zavala

Executive Council of Healthcare Partners



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



Anisha Bhatia Attawala,
MD, FAAP



Cameron N. Boyd, MD



Marsha Campbell-Yeo, RN,
BN, NNP-BC, PhD, FAAN



Mary Coughlin, MS,
NNP, NCC-E



Jessica Daigle, MD



Christy Gliniak, PhD,
OTR/L, CNT, CPXP, NTMTC



Henry Lee, MD



Ramya Kumar, MS, CCC-SLP,
BCSS, CNT, IBCLC, NTMTC, SBCS



Lily Lou, MD, FAAP



Alon Metrikin-Gold



Angelica Moreyra, PsyD



Andrea C Morris, DNP,
RNC-NIC, CCRN-K, CNS



Nicole Nyberg, MSN,
APRN, NNP-BC



Amanda Yeaton-
Massey, MD, FACOG

Thank You!



Colby Day, MD
Chief of Pediatrics,
University of Florida
NICU Parent



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Board of Directors



Robert Cicco, MD
*Retired Neonatologist,
Pittsburgh, PA
Former Associate Director,
West Penn Hospital NICU*



Mitchell Goldstein, MD, MBA, CML
*Professor of Pediatrics
USC Keck School of Medicine
Division of Neonatology
Children's Hospital Los Angeles
Editor in Chief,
Neonatology Today*



Ashley Omwando, MBA
*FCC Committee Member
El Camino Health NICU
NICU Parent*



Jadene Wong, MD
*Neonatal Hospitalist,
Lucile Packard Children's Hospital
Clinical Associate Professor,
Stanford School of Medicine*



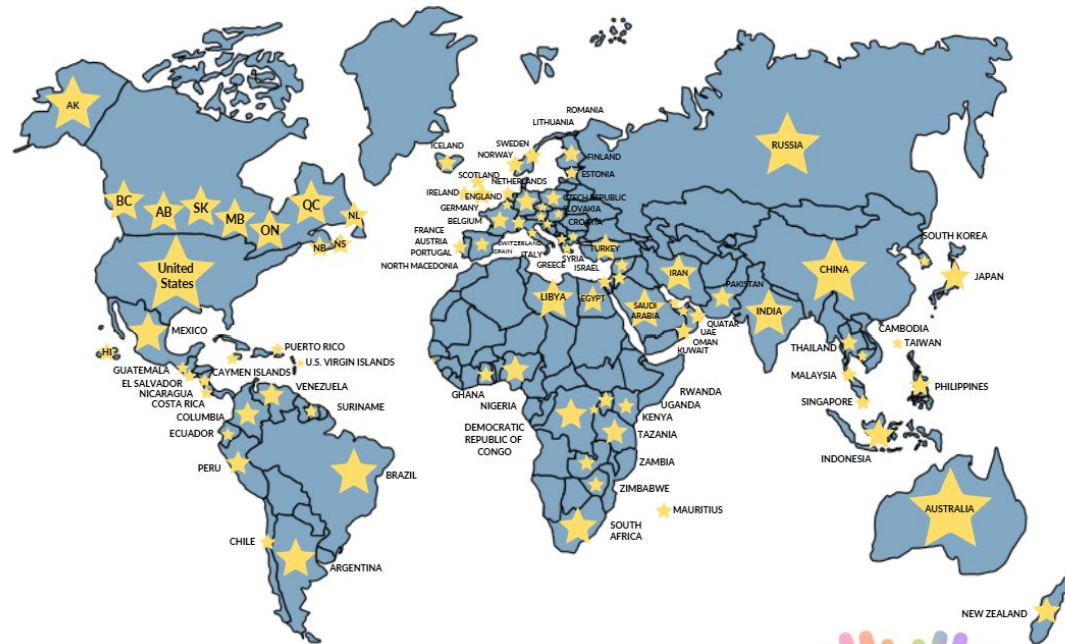
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Family-Centered Care Around the Globe!

The FCC Taskforce began in February 2022 with just 50 members.

Over the last three years,
our membership has increased to:

- more than **3,600** members
- **50** U.S. States & Puerto Rico
- **9/10** Canadian Provinces
- **80** Countries!!!



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Monthly Poll

July POLL

Help us support NICUs establishing policies that preserve milestones or 'firsts' for family caregivers.



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FCC COMMUNITY EXCHANGE OPEN FORUM

JULY 16, 11AM PT/2PM EST

IMPLEMENTING FAMILY-CENTERED ROUNDS IN THE NICU
FACILITATED BY:



Robert Cicco, MD
*Retired Neonatologist,
Pittsburgh, PA
Former Associate Director,
West Penn Hospital NICU*



Erika Mendence
*Patient & Family Engagement Specialist,
Children's Mercy NICU
NICU Parent of Birdie*



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A Multicenter, Collaborative Initiative Dedicated to Quality Improvement in NICU Family-Centered Care



JOIN THE TASKFORCE!



Our Network

3018

Members Worldwide

79

Countries

49

United States

9

Canadian Provinces



Thank You

smallTalk[®]
NICU Egg[™] System

Presence Study Toolkit Release: It's Here!!!



Recognizing
parents as essential
partners in care,
strengthening their
role at the bedside,
and prioritizing both
infant outcomes and
family well-being

Presence Study Toolkit

Support for adopting a true
family-centered approach

- NICU teams • Healthcare organizations
- Educators • Family support networks



Toolkit developed collaboratively by family and healthcare partners from the Family-Centered Care Taskforce, the MOM-LINC Lab, and the Canadian Premature Babies Foundation's Presence Study team

The Toolkit is designed to:

- *Support more consistent, informed care*
- *Bring research into real-world use*
- *Reflect both clinical and family perspectives*
- *Be practical, not theoretical*
- *Be shared across teams, sites, and systems*

Recognizing parents as essential
partners in care, strengthening
their role at the bedside, and
prioritizing both infant outcomes
and family well-being



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CPBF Canadian Premature
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Equity, Diversity, Inclusion, Belonging, and Justice Position Statement



Family-Centered Care Taskforce Equity, Diversity, Inclusion, Belonging, and Justice Position Statement

Position Statement

The Family-Centered Care (FCC) Taskforce affirms and advocates for the principles of **equity, diversity, inclusion, belonging, and justice (EDIBJ)** as foundational to high-quality, compassionate, and just neonatal care. We believe that every family in the neonatal intensive care unit (NICU) deserves care that honors their identity, recognizes their individual needs, and promotes trust, healing, and resilience.

Background

Having an infant in the NICU is universally traumatic, exhausting, and emotionally taxing. However, for families that have been intentionally and historically marginalized, this experience is often compounded by systemic inequities (i.e., racism, classism, misogyny, etc.), bias, and cultural disconnects. When families do not see themselves represented among the medical team caring for their baby, it can create mistrust, fear, and a sense of alienation—emotions that hinder the foundation of family-centered care.

Disparities based on race, gender identity, language, family composition, socioeconomic status, and other dimensions of identity can lead to additional harm. Families who feel unseen, undervalued, and/or misunderstood often experience isolation, defensiveness, and exhaustion. At this critical moment in time—when identities are being denied, families are being divided, and inclusion is under threat—the neonatal community must rise to protect our most vulnerable patients and their families.

The FCC Taskforce therefore reaffirms its unwavering commitment to equity, diversity, inclusion, belonging, and justice in all aspects of NICU care, culture, and education.

Equity

Equity means providing individuals and families with **what they need** to achieve optimal outcomes—not necessarily providing the same resources or support to everyone. Equality assumes sameness; equity recognizes difference.

Just as precision medicine tailors treatments to each patient's biological needs, family-centered care must respond to each family's social, cultural, and emotional needs. True fairness emerges not from identical treatment, but from intentional and individualized support. By identifying and addressing systemic inequities, we can begin to level the playing field for all NICU families. Each family's journey is unique, and our care must reflect that truth.

Ultimately, family-centered care is rooted in centering the individual needs of each family and providing culturally conscious, concordant care that allows families to achieve the best possible outcomes for their infants.

Figure 1 on Page 2 uses a street-crossing analogy to illustrate the difference between equality and equity. In the NICU, this same concept applies to many care practices, such as safe sleep, that are often taught and discussed in a strict binary way (i.e., right or wrong). This approach of either/or framing takes away our ability to see the fullness of a family's experience—their abilities, capabilities, beliefs, cultural practices, fears, community/familial norms—rendering equity impossible.

The FCC Taskforce affirms and advocates for the principles of equity, diversity, inclusion, belonging, and justice (EDIBJ) as foundational to high-quality, compassionate, and just neonatal care.

We encourage you to read and share this information with your team and explore how your unit can mitigate harm for marginalized families.



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FCC Scholars @ Gravens Conference



Janna Andre
*NICU Parent Advisory Committee,
Mount Sinai Hospital
NICU Parent*



Valicitie Porrata-Rubino
*NICU Family Support Specialist,
The Valley Hospital
NICU Parent*



Dana Apkon, MD
*Second Year Fellow,
Boston Children's Hospital
at Harvard*



Daphne Darmawan, MD, MBS
*Third Year Fellow
Stanford Lucile Packard Children's
Hospital*



Elizabeth Lee, MD
*Second Year Fellow
Johns Hopkins Children's Center*



Trisha Mulamreddy, MD, MPH
*First Year Fellow
University of California,
Los Angeles*



Kelly MacPherson, MD, MS
*First Year Fellow
Women & Infants Hospital,
Brown University*



Isabella Massey, BSN, RNC-NIC
*Knowledge & Innovation Council Chair
Cooper University Hospital*



Kelly Williamson, M.S. CCC-SLP
*Speech-Language Pathologist
Johns Hopkins Bayview Medical Center*



Sharath Hullumani
*Pediatric & Neonatal Physiotherapist
Acharya Vinobhabve Rural Hospital,*



Niharika Mathur
*Senior Physiotherapist & PhD Scholar
All India Institute of Medical Sciences*



Family Partner FCC Scholars are generously supported by The **Michael Hynan Fund**. Eight FCC Scholars are generously supported by a **Chiesi Independent Educational Grant**. One FCC Scholar is generously supported by **Mead Johnson Nutrition**.

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2026 Impact

Family-Centered Care Taskforce Impact Report, January-June 2026



Our Mission

We support NICUs as they begin or strengthen family-centered care in their units by offering **free resources**.

Membership

+685 in 2026!

- 3591 Members
- 80 Countries
- 50 United States
- 9 Canadian Provinces

Educational Events

- Jan Webinar: **218 Live, 266 Views**
- Jan Community Exchange: **130 Live**
- Feb Community Exchange: **185 Live, 143 Views**
- March Webinar: **139 Live, 68 Views**
- March Community Exchange: **131 Live**
- April Community Exchange: **184 Live, 143 Views**
- May Webinar: **159 Live, 88 Views**
- May Community Exchange: **143 Live**

Monthly Polls

January – May: **211 Total Respondents**

Publications

- Winter & Spring Newsletters
- January – June FCC Columns

Social Media

1,919 Followers Across Six Platforms

[YouTube](#) • [LinkedIn](#) • [Facebook](#) • [Instagram](#) • [Bluesky](#) • [X](#)

Our Values

Equal partnership between NICU families and multidisciplinary healthcare professionals **in everything we do**.

Organizational Partnerships

78 Esteemed National & International Healthcare-Based and Family-Led Organizations Supporting our Work

- 50 Healthcare-Based Orgs
- 28 Family-Led Orgs

Completed Projects

Presence Study Toolkit
FREE to Download!



ED/BJ Position Statement
FREE to Download!



11 FCC Scholars Attended Gravens Conference!



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