

FCC TASKFORCE WEBINAR

November 13th, 2025

11-12:30pm PT

The Butterfly Project:
Supporting Families After Co-Twin Baby Loss



Professor Nicholas Embleton (he/him)
Newcastle NHS Hospitals
Newcastle University, UK



Keira Sorrells (she/her)
Founder & Executive Director,
NICU Parent Network
NICU Parent of Lily, Avery, and Zoe

Newborn Individualized Developmental Care and
Assessment Program (NIDCAP):
Nurturing and Being Nurtured



Deborah Buehler, PhD (she/her)
Assistant Professor,
Department of Pediatrics, UCSF
President, Member of the Board,
NIDCAP Federation International

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This Webinar is Dedicated to Avery, Lily, and Zoe



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.



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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New Organizational Partnerships



National Network
of **NICU**
Psychologists



THE **NICU DAD**



Organizational Partners



FCC Taskforce Core Leadership Team

Co-Chairs

Program Manager



Malathi Balasundaram, MD

*Clinical Professor,
Stanford School of Medicine
Attending Neonatologist &
FCC Committee Chair,
El Camino Health, CA*



Keira Sorrells

*Founder &
Executive Director,
NICU Parent Network
Trauma-Informed
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Colby Day, MD

*Associate Professor of Pediatrics &
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NICU Parent*



Morgan Kowalski

*Family Liaison,
American Academy of
Pediatrics Committee
on Hospital Care
NICU Parent*

Executive Council of Family Partners



Fabiana Bacchini



Lelis Bauzá Vernon



Latoya Blueford



Sahra Cahoon



Jennifer Canvasser



Nishan Degnarain, MPA



Amy Finn



Molly Fraust-Wylie



Marybeth Fry



Yamille Jackson, PhD



Erika Goyer



Mia Malcolm



Necole McRae



Erika Mendence



Katrina Moline



Kimberly Novod



Betsy Pilon



Elizabeth Simonton



Alex Zavala

Executive Council of Healthcare Partners



Daphna Barbeau, MD



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



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



Robert Cicco, MD



Mary Coughlin,
MS, NNP, NCC-E



Jessica Daigle, MD



Jessica Fry, MD



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



Mitchell Goldstein, MD



Luann Jones,
DNP, APRN, NNP-BC, NE-BC



Henry Lee, MD



Lily Lou, MD, FAAP



Kerri Machut, MD



Nicole Nyberg,
MSN, APRN, NNP-BC



Dharshi Sivakumar, MD



Vincent Smith, MD, MPH



Kimberly Stobbe, LCSW



Bob White, MD



Emily Whitesel, MD

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 **2,800** members
- **49/50** U.S. States & Puerto Rico
- **9/10** Canadian Provinces
- **76** Countries!!!



Advocacy Committee

Co-Chairs

Kerri Machut, MD

*Attending Neonatologist,
Lurie Children's Hospital
Associate Professor*

*Feinberg School of Medicine at
Northwestern University*

Nicole Nyberg, MSN, APRN, NNP-BC

*Neonatal Nurse Practitioner,
Cone Health*

Founder,

*Empowering NICU Parents &
Empowering NICU Parents Podcast*



Presence Study Toolkit

The spark:

The negative impact of restrictive parental presence policies in NICUs during the COVID-19 pandemic.

Dilemma

- Hospitals restricted parental access, leaving babies without a parent or a support person, even during extreme illness or death.
- Significant variations existed in parental access policies, even in the same city.
- Parents reported higher negative health outcomes during the visit.

The response:

Co-created best evidence practice recommendations regarding parental in NICUs during pandemics caused by respiratory pathogens such as COVID-19

How we got there:

Consensus Panel: Ad-hoc group of individuals with expertise related to the project.

Values, preferences, and evidence guided our recommendations

1. Gathered input into a national survey, parent caregivers, healthcare providers, and NICU.
2. Identified 50 potential recommendations.
3. Conducted two rounds of Delphi surveys. Participants (n=20) rated and ranked each item on importance.
4. Round 1: Rated 50 items on a scale of 1-5.
5. Round 2: Rated the top 20 items of Round 1.
6. Presented rapid evidence synthesis of the top 20 items to the panel.
7. Consensus Panel: Each item was a Strategic Care recommendation, based on strength of evidence.
8. Award panel members. Do you agree with this item as a national recommendation?

Consensus recommendations based 80% of the panel agreement



Consensus practice recommendations regarding parental presence in NICUs during pandemics caused by respiratory pathogens such as COVID-19

Parents/Caregivers should have:

- 1. Status for parent/caregiver(s) as essential caregivers
- 2. Unrestricted access to provide skin-to-skin contact for their infant in the NICU
- 3. Unrestricted access to breastfeed and to receive breastfeeding supports (lactating only, non-breastfeeding, pumping, lactation encouragement, and lactation support) for their infant in the NICU
- 4. Unrestricted access to mental health and psychosocial support services while their infant is admitted to the NICU
- 5. Unrestricted access to attend medical rounds while their infant is admitted to the NICU
- 6. Inclusion in co-decisioning/decision-making for parent-requested NICU policies (e.g., infection control, medical staffing, housing/NICU cleanliness and advocates)
- 7. Unrestricted access to provide feeding touch for their infant in the NICU
- 8. Unrestricted access to provide holding touch for their infant in the NICU
- 9. Unrestricted, in-person access to attend medical rounds while their infant is admitted to the NICU. Virtual care services may be preferred. Contact on the local context or if parent health or preference warrants it.
- 10. Unrestricted, in-person access to attend medical rounds and psychosocial support services while their infant is admitted to the NICU. Virtual care services may be preferred, based on the local context of parent/caregiver preference warrants it.
- 11. Unrestricted access for two parent/caregivers to be present while their infant is admitted to the NICU
- 12. Unrestricted access to fractional allocated space to visit/attend to their infant is admitted to the NICU
- 13. Unrestricted access to use communication devices that are on hospital devices for remote communication and support (text/pictures, video, phone, etc.) while their infant is in the NICU (with "heat off")

Call to Action: Consensus practice recommendations regarding parental presence in NICUs during pandemics caused by respiratory pathogens such as COVID-19. Consensus recommendations should be implemented to support the health and well-being of infants and their parents, ensure equitable care, and optimize future infection control clinics.

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Equity, Diversity, Inclusion, & Belonging Committee

Co-Chairs

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

*Neonatal Outreach Coordinator,
Atlanta Perinatal Region*
Emory University School of Medicine,
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Mia Malcolm, BS, CDFT

*Community Outreach & Programs Care Manager,
Ollie Hinkle Heart Foundation*
*Senior Research Coordinator,
Washington University School of Medicine*
*Clinical Research Coordinator,
Stanford University School of Medicine*

Work in Progress:

- Executive Council Demographics Survey
- Equity, Diversity, Inclusion, and Belonging Position Paper
- Silent Signals in the NICU

**Toolkit supported by an
independent educational grant
from Chiesi**



Marketing & Communications Committee

Co-Chairs



Daphna Barbeau, MD
*Attending Neonatologist,
Director, Neurodevelopment &
Palliative Care,
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Director,
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Alex Zavala, Family Partner
*Founder,
The NICU Dad &
The NICU Dad Podcast
PFAC Chair,
Dell Ascension NICU Network
Family Leader,
Vermont Oxford Network*



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How You Can Help:

- **Follow us!** Even if you're not active on social media, giving The FCC Taskforce a follow boosts engagement and drives traffic to our profiles!
- **Tag us!** Tagging us makes it faster and easier to share and repost your content.



Newsletter Committee

Co-Chairs

Bob Cicco, MD

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

Morgan Kowalski, Family Partner

*Program Manager,
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Contributors:

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Jess Daigle, MD, FAAP

Mary Coughlin, MS, NNP, NCC-E

Laura Hedli, MS

Mia Malcolm, BS, CDFT, Pharm-D

All Issues



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Monthly Poll

Our November Poll is centered around supporting units working toward **implementing Trauma-Informed Care for NICU professionals.**

Respond Here:



All poll responses
can be found here!



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FCC Taskforce Office Hours

Who?

Facilitated by one Healthcare Partner and one Family Partner from our Executive Council and attended by members like you!

What?

An informal meeting where members can bring their unit's specific challenges and barriers around implementing family-centered care practices and brainstorm solutions for overcoming them with their peers.

Where?

Zoom! These sessions are not recorded so folks can feel safe sharing.

Why?

Don't reinvent the wheel! Modify what's worked for other units to suit your own.

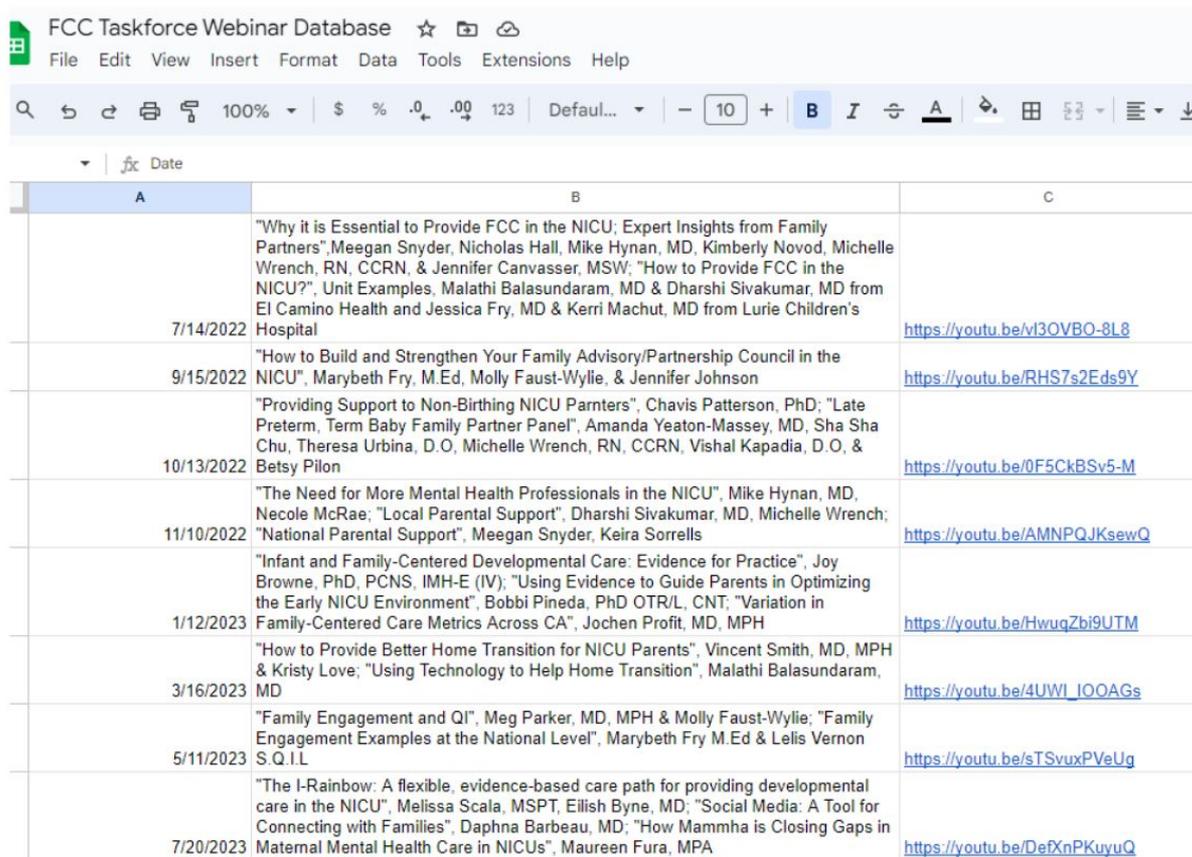
Heard from Members: **"Hearing real life experiences is so impactful for us all as clinicians who have never lived in the shoes of NICU families!** Thank you all for your vulnerabilities and sharing so that we can all learn."

Register Here



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Database of Webinar Recordings & Topics



A	B	C
7/14/2022	"Why it is Essential to Provide FCC in the NICU; Expert Insights from Family Partners", Meegan Snyder, Nicholas Hall, Mike Hynan, MD, Kimberly Novod, Michelle Wrench, RN, CCRN, & Jennifer Convasser, MSW; "How to Provide FCC in the NICU?", Unit Examples, Malathi Balasundaram, MD & Dharshi Sivakumar, MD from El Camino Health and Jessica Fry, MD & Kerri Machut, MD from Lurie Children's Hospital	https://youtu.be/vI3OVBO-8L8
9/15/2022	"How to Build and Strengthen Your Family Advisory/Partnership Council in the NICU", Marybeth Fry, M.Ed, Molly Faust-Wylie, & Jennifer Johnson	https://youtu.be/RHS7s2Eds9Y
10/13/2022	"Providing Support to Non-Birthing NICU Parnters", Chavis Patterson, PhD; "Late Preterm, Term Baby Family Partner Panel", Amanda Yeaton-Massey, MD, Sha Sha Chu, Theresa Urbina, D.O, Michelle Wrench, RN, CCRN, Vishal Kapadia, D.O, & Betsy Pilon	https://youtu.be/0F5CkBSv5-M
11/10/2022	"The Need for More Mental Health Professionals in the NICU", Mike Hynan, MD, Necole McRae; "Local Parental Support", Dharshi Sivakumar, MD, Michelle Wrench; "National Parental Support", Meegan Snyder, Keira Sorrells	https://youtu.be/AMNPQJKsewQ
1/12/2023	"Infant and Family-Centered Developmental Care: Evidence for Practice", Joy Browne, PhD, PCNS, IMH-E (IV); "Using Evidence to Guide Parents in Optimizing the Early NICU Environment", Bobbi Pineda, PhD OTR/L, CNT; "Variation in Family-Centered Care Metrics Across CA", Jochen Proff, MD, MPH	https://youtu.be/HwuqZbi9UTM
3/16/2023	"How to Provide Better Home Transition for NICU Parents", Vincent Smith, MD, MPH & Kristy Love; "Using Technology to Help Home Transition", Malathi Balasundaram, MD	https://youtu.be/4UWI_JOOAGs
5/11/2023	"Family Engagement and QI", Meg Parker, MD, MPH & Molly Faust-Wylie; "Family Engagement Examples at the National Level", Marybeth Fry M.Ed & Lelis Vernon S.Q.I.L	https://youtu.be/sTSvuxPVeUg
7/20/2023	"The I-Rainbow: A flexible, evidence-based care path for providing developmental care in the NICU", Melissa Scala, MSPT, Eilish Byne, MD; "Social Media: A Tool for Connecting with Families", Daphna Barbeau, MD; "How Mamma is Closing Gaps in Maternal Mental Health Care in NICUs", Maureen Fura, MPA	https://youtu.be/DefXnPKuyUQ



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at University of Notre Dame
Notre Dame, Indiana

Pictured: Baby Kole with his Dad



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**Abstracts Due
February 15th, 2026**

To learn more and register,
visit our website:

