

FCC TASKFORCE

SEPTEMBER 2023 WEBINAR

FCC TASKFORCE WEBINAR
September 28
11-12:30pm PT

FAMILY INTEGRATED CARE: WHERE ARE WE NOW?
Karel O'Brien, MD (she/her)

- Staff Neonatologist, Mount Sinai Hospital
- Professor of Pediatrics, University of Toronto

NICU DAD PERSPECTIVE: DISPARITIES IN FAMILY-CENTERED CARE
Alex Zavala (he/him)

- Founder, The NICU Dad & The NICU Dad Podcast
- VON Family Advisor
- Dell Children's Ascension NICU Network PFAC Chair
- NICU Children: Emerson & Mia

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WEBINAR DEDICATED TO MIA & EMERSON ZAVALA

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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
- 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



FCC Taskforce Core Team

Co-Chairs

Program Manager



Malathi Balasundaram, MD

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



Keira Sorrells

Founder & Executive
Director,
NICU Parent Network



Colby Day, MD

Assistant Professor of Pediatrics &
Medical Director,
Golisano Children's Hospital NICU
University of Rochester
Medical Center



Morgan Kowalski

Family Partner



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Organizational Partners

American Academy
of Pediatrics



DEDICATED TO THE HEALTH OF ALL CHILDREN™

Section on Neonatal Perinatal Medicine

CPQCC

california perinatal
quality care collaborative

HOPE
for HIE



National
Association of
Neonatal
Nurses

NEONATOLOGY
TODAY

Peer Reviewed Research, News and Information
in Neonatal and Perinatal Medicine



National Association of Neonatal Therapists®
supporting neonatal therapists and the babies they serve

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Perinatal Advisory Council:
Leadership, Advocacy and Consultation

NPN
NICU PARENT NETWORK



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Acknowledgements

Phase 3 QI Work Supported By:

"A grant from Genentech,
a member of the Roche Group"

&

Partially funded by "Prolacta Bioscience Foundation"



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“Care for babies
like never before”



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Executive Council - Family Partners



Jennifer Canvasser



Molly Faust-Wylie



Marybeth Fry



Nicholas Hall



Katherine Huber



Yamille Jackson, PhD



Vishal Kapadia, MD



Morgan Kowalski



Kristy Love



Mia Malcolm



Necole McRae



Kimberly Novod



Betsy Pilon



Elizabeth Simonton



Meegan Snyder



Lelis Vernon



Michelle Wrench



Alex Zavala

Executive Council - Healthcare Partners



Daphna Barbeau, MD



Joy Browne, PhD



Robert Cicco, MD



Jessica Fry, MD



Vargabi Ghei, MD



Mitchell Goldstein, MD



Lori Gunther, MS, CPXP



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



Henry Lee, MD



Kerri Machut, MD



Jeff Meyers, MD



**Nicole Nyberg,
MSN, APRN, NNP-BS**



Tim Palmer, MD



Jochen Profit, MD



**Aida Simonian,
MSN, RNC-NIC, SCM, SRN**



Dharshi Sivakumar, MD



Bob White, MD



Emily Whitesel, MD

FCC Taskforce Committee Chairs

**Marketing & Communications
Committee Chair**



Daphna Barbeau, MD
Attending Neonatologist,
HCA University Hospital
Director,
High Risk Infant Follow Up Clinic

**Newsletter Committee
Chair**



Vargabi Ghei, MD
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HCA East Florida
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**Advocacy Committee
Chair**



Kerri Machut, MD
Attending Neonatologist,
Lurie Children's Hospital
Associate Professor,
Feinberg School of Medicine,
Northwestern University



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FCC Taskforce Website

16 months ago, we had 50 individuals participating in the Family-Centered Care Taskforce. Involvement has grown to 600+ individuals representing more than 230 NICUs from 36 states and 14 countries committed to learning more about Family-Centered Care.



Follow us @FCCTaskforce



FAMILY-CENTERED CARE
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Database of Webinar Recordings & Topics

FCC Taskforce Webinar Database ☆ 📁 ☁

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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 Canvasser, 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-Wyllie, & 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 Profit, MD, MPH	https://youtu.be/HwuuqZbi9UTM
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_I0OAGs
5/11/2023	"Family Engagement and QI", Meg Parker, MD, MPH & Molly Faust-Wyllie; "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 Mammha is Closing Gaps in Maternal Mental Health Care in NICUs", Maureen Fura, MPA	https://youtu.be/DefXnPKuyuQ



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September 2023 Poll

Centers in our Small Groups shared their barriers to forming a Family-Centered Care Committee; **lack of staff time was identified as a top barrier**. Of the FCC Taskforce's 600+ members, some of you have a well-established FCC Committee. **Please share your insights on overcoming the 'lack of staff time' barrier using the QR Code below:**





Small Group Spotlight



Read full newsletter here!

SPOTLIGHT!

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

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.

3

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2024 Gravens Conference

Gravens Conference offers and opportunity to share your work and experiences with colleagues.

The theme of the 2024 Gravens Conference is "The Power of Voice: Using Your Voice for Babies, Family, Staff and Beyond.

Abstracts may include any applicable NICU topic, please use the QR code below for more information.



Join Us!
**For the 37th International
GRAVENS meeting on the
Environment of Care for
High Risk Newborns and
their Families**

March 6-9, 2024



Sheraton Sand Key Resort
Clearwater Beach, Florida

For more information go to <https://paclac.org/https-paclac-org-gravens-conference/> or PACLAC.org
Abstracts due October 1, 2023



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Tell us how you were activated to advocate for and support NICU families?

After our NICU stay with our youngest, we were compelled to give back. We started with bringing baked goods for the NICU staff on holidays. This grew to joining the NICU PFAC. We then became an ambassador family for Ronald McDonald House Charities, March of Dimes, Hand to Hold, and other NICU family support organizations. I later was asked to host NICU Dads Groups in our NICU. This is where I discovered the gap in NICU dad support, and prompted me to create thenicudad.com.

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

One of the main things I observe is the need to close the gap in disparities in the support of birthing and non-birthing parents.

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

I created The NICU Dad and The NICU Dad Podcast to help fill the gap in NICU dad support. I try to bring information and resources to current and former NICU dads. I am a peer to peer mentor for NICU dads. I am an advocate for NICU dad support.

Alex Zavala

FCC Taskforce

Executive Council Member



NICU and bereaved parents are...

some of the strongest people on the planet.

Healthcare partners are...

strangers that later become family.

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

My greatest wish is that FCC Taskforce members will have a positive impact in always making vast improvements in helping make NICU stays easier and less traumatic for both NICU parents and NICU babies.

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

Being a part of the FCC Taskforce is a huge honor for me. The group of NICU All Stars is incredible and it excites me to know that I am part of a group that makes such a difference in NICU family support.

Anything else you want our community to know?

Of all the hats I wear, my favorite hat to wear is my dad hat, but even more than that is my NICU dad hat.





Disparities in Family Centered Care A NICU Dad Perspective

Alex Zavala

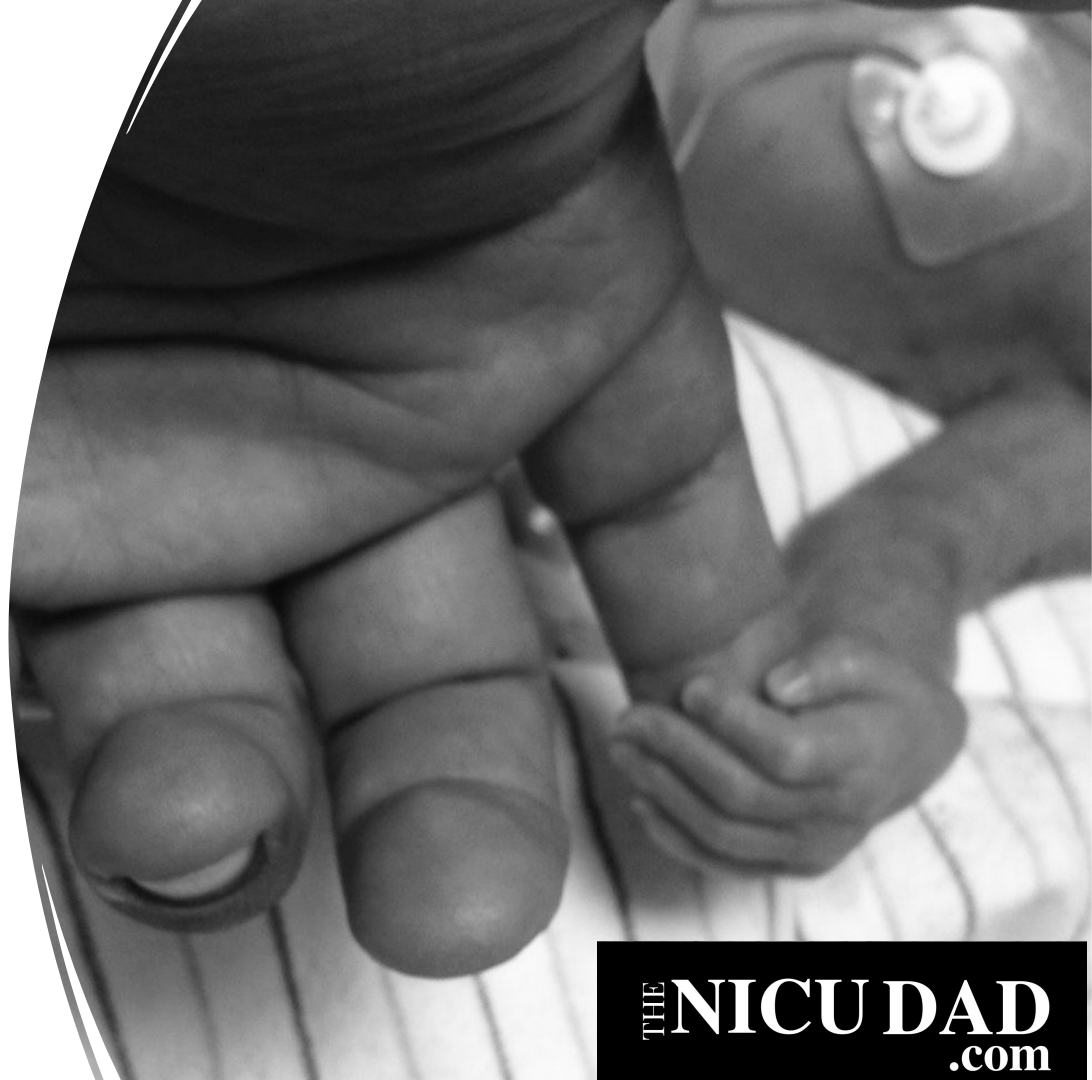


Our NICU Journey

- December 2012 we found out we were pregnant
- High risk pregnancy
 - 9 Years earlier our oldest, my stepdaughter, was born at 30 wks
- We did everything to try to go full term
 - Seeing specialists
 - Ultrasounds
 - Progesterone shots
 - fFN Test- Negative

- Monday morning

- Wife went to work, daughter went to grandma's, I went to work
- 9 a.m. phone call
- Ride to hospital
- Baby breech
- Emergency C-section



-
- Baby born around 12 p.m.
 - NICU Dad Shuffle
 - Baby transported to another hospital around 2 p.m.



- Arrived at NICU- 7 p.m.
- 67 Days in the NICU
 - NICU, work, NICU, home





-
- Bringing baby home
 - Series of doctors' visits and evaluations
 - Therapies- physical and occupational
 - Stay at home dad
 - Social distanced for 1 year





My Health

- STRESSED!!!!
- Gained almost 100 lbs.
- High Blood Pressure
- Hypertension
- Type 2 Diabetes
- ZERO Self Care
- No Medical Check-up

Disparities in Family Centered Care

CONDITIONED TO SIT IN THE CORNER

- Starts in early doctors' visits
- System that doesn't look at things from the Dad/NBP perspective
- Unknown amount of trauma/ mental health
- NO CHART = NO CARE



Causes Dads to withdraw
Causes Dads to hesitate to
participate
Causes a lack of trust
Causes more trauma



Define role/ responsibilities

- Husband/ Caretaker
- Parent/ Dad
- Employee/ Work
- Homeowner
- Facilitator of Information
- Nurse/ Therapist- Mental & Physical Caretaker
- Driver/ Delivery Guy



Solutions

- Change Culture
 - Change stereotypes
- Create Awareness
 - More platforms
- Promote Inclusion
 - More than just being in the room



Real Help

- Focus on self care in the NICU
 - Mental & Physical
 - Exercise & Nutrition
- Focus on getting in shape for life after the NICU
 - Mental & Physical
- Peer to Peer Mentoring
- Counseling





THE NICU DAD

Returning the favor

The NICU Dad

The NICU Dad Podcast

Dell Children's Medical Center PFAC

Dell Children's Ascension NICU Network PFAC- Chair

Dell Children's Medical Center NICU Quality Council

Vermont Oxford Network Family Partner

Family Centered Care Taskforce Executive Council

Family Centered Care Taskforce Small Group Leader

Peer to Peer Mentor

Host Dad Groups

NICU Dad Advocate



THE NICU DAD
.com



THE NICU DAD
.com

Future Webinar Sponsored by **Dräger**

November 9th:

- "Helping Parents Cope in the NICU" with **Annie Janvier, MD, PhD**
- "Next Level FCC: How FICare Can Benefit US NICUs" with **Linda Franck, RN, PhD, FRCPCH, FAAN**



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Helping Parents Cope in the NICU
Annie Janvier, MD, PhD

- Professor of Pediatrics and Clinical Ethics at Université de Montréal
- Neonatologist and Clinical Ethicist at CHU Sainte-Justine

Next Level FCC: How FICare Can Benefit US NICUs
Linda S. Franck, RN, PhD, FRCPCH, FAAN (she/her)

- Professor & Jack and Elaine Koehn Endowed Chair in Pediatric Nursing
- University of California San Francisco Department of Family Health Care Nursing

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Future Webinars 2024

January 11th:

- Social Determinants of Health Screening with **Erika (Gaby) Cordova Ramos, MD**
- SafetyNet NICU's Comprehensive Family-Centered Care Program with **Priya Jegatheesan, MD and Sangeeta Malik, PhD**

March 14th:

- Family-Centered Care Curriculum with Beth Isreal Deaconess Medical Center's **Emily Whitesel, MD, Molly Faust-Wylie, Kathleen Tolland, DNP, RN, NICU Nursing Director**
- Skin to Skin Care with **Vargabi Ghei, MD**



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