



FAMILY-CENTERED CARE
TASK FORCE



How to Build & Strengthen Your NICU Family Advisory/Partnership Council

Malathi Balasundaram, MD
Colby Day, MD &
Caroline Toney Noland, MSc

CPQCC Educational Committee
Ashwini Lakshmanan, MD, MS, MPH
Courtney Breault, RN, MS, CPHQ &
Janine Bohnert, BS



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FCC Core Team



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Program Manager



Caroline Toney-Noland, MSc
*Program Manager,
CPQCC*

Co-Chairs



Malathi Balasundaram, MD
*Clinical Associate Professor
Stanford School of Medicine
FCC Committee Chair
El Camino Health, CA*



Colby Day, MD
*Assistant Professor of Neonatology
University of Rochester Medical Center
Associate Medical Director of Golisano
Children's Hospital NICU*



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Partners



NEONATOLOGY TODAY

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



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Agenda



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Taskforce & Small Group QI update: Malathi Balasundaram

Taskforce Member and CPQCC FAC Update: Caroline Toney-Noland

Speaker Introductions: Colby Day

Speakers: Marybeth Fry, Molly Fraust-Wylie, & Jennifer Johnson

Q & A: CPQCC Educational Committee Chair, Ashwini Lakshmanan & Associate Director of Quality, Courtney Breault

Closing & Feedback Survey: Malathi Balasundaram

Family Centered Care Task Force

Aim

To educate, create guidelines, and facilitate unit-based FCC interventions in NICU

Phase 1: 11/2021-4/2022: Program Development - Completed

1. Recruited physicians, nurses, therapists, advanced practice providers, and family partners (15) to form the task force & Executive Council
2. Formed small groups, connected with units that have an FCC program

Phase 2: 5/2022-5/2023: Building a Learning Community - Ongoing

1. Create networking opportunities for NICUs interested in FCC
2. Educate on the importance of family integration in the NICU through a series of 8 webinars
3. These webinars and recordings are also shared widely through our member listserv, flyers, and social media.

Phase 3: 12/2022- 11/2023: QI Collaborative

1. Facilitate 34 centers to build/strengthen their FCC committee and FPC in their local units



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Family Partners



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Jennifer Canvasser



Lelis Vernon



Necole McRae



Keira Sorrells



Marybeth Fry



Kimberly Novod



Michael Hynan



Nicholas Hall



*Molly
Fraust-Wylie*



Michelle Wrench



Betsy Pilon



Vishal Kapadia



Katherine Huber



Meegan Snyder



Kristy Love

New Executive Council Members



Emily Whitesel MD
Group 4 Co-lead
Attending Neonatologist
Director of Family Experience
Beth Israel Deaconess
Medical Center



Lori Gunther, MS, CPXP
Chief Executive Officer
Synova Associates
Advancing Nurse Leadership



Elizabeth Simonton
Co-Founder/CEO
ICU baby
Family Partner for Small
Group 1



Morgan Kowalski
Family Partner
U. Rochester
Family Partner for Small
Group 3



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Newsletter Committee
Chair



Dr. Vargabi Ghei
Attending
Neonatologist,
HCA East Florida
Northwest Medical
Center

Newsletter



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Vol. 01 08/31/2022

FCC TASK FORCE

NEWSLETTER

FCC Executive Board

Co-Chairs
Malathi Balasundaram MD
Colby Day MD

Program Manager
Caroline Toney-Noland MSc

Want to strengthen FCC in your NICU? Click this [link](#) or scan the QR code to join our FCC Task Force

Mission Statement

The Family Centered Care (FCC) Task Force aims to educate, create guidelines, and facilitate unit-based interventions related to FCC in the Neonatal Intensive Care Unit.

The Newsletter provides commentary on the latest publications related to FCC work, showcases a dedicated section for family partners to share expert insights, and shines a spotlight on practical unit-based FCC ideas.

Newsletter Committee

Chair
Vargabi Ghei MD, MSHS

Members
Robert White MD
Malathi Balasundaram MD
Colby Day MD
Daphna Barbeau MD
Caroline Toney-Noland MSc

Graphic Design
Kavya Wazhi

Follow us on twitter:
[@FccTaskforce](#)

Contact us:
familycenteredcaretaskforce@gmail.com

In this issue

Expert Insights — In promoting family centered care, it is imperative that we partner with families from the inception of our programs. Thusly, in our first newsletter, we've chosen to have our family partners speak for themselves.

Dedicated to their NICU children

Vol. 01 08/31/2022

EXPERT INSIGHTS

TRAUMA

"I was
terrified,
OVERWHELMED,
and
SCARED."

"After I gave birth at 24 weeks, I felt such
guilt.
I had
failed
the boys."

"I am not a good
mother.
I do not recognize my own
children."

"I blamed
myself."

"A lot of our birth parents are going through their own physical trauma... honoring and validating those lived experiences and feelings is such an important piece."



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Communication & Marketing Chair



Dr. Daphna Barbeau
Neonatologist HCA
University Hospital
Director, High Risk
Infant Follow up Clinic

Twitter



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... 🔔 Following

FCCTaskforce
@FccTaskforce

National Committee to distribute education, and create guidelines and standards, related to Family Centered and Family Integrated Care in the NICU.

📅 Joined June 2022

8 Following 62 Followers

👤 Followed by The Incubator Podcast, Jennifer Convasser, and Meg Parker

Tweets Tweets & replies Media Likes

 **FCCTaskforce** @FccTaskforce · Sep 13 ...
See you all THURSDAY for the next FCC Taskforce Webinar. Register at the link below!!
[#neoTwitter](#)

 **FCCTaskforce** @FccTaskforce · Sep 1
JOIN OUR NEXT WEBINAR!
[#neoTwitter](#) [#pedicu](#)

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@FCCTaskforce



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Terri Russell, DNP, APRN, NNP-BC	Abrazo Arrowhead Medical Center	Arizona
Rebecca Fish	Avera McKennan Hospital	South Dakota
Briana Meeks, RNC-NIC	Beacon Children's Hospital	Indiana
Emily Whitesel	BIDMC	Massachusetts
Ruth Ritzema	Bronson Children's Hospital	Michigan
Eric Raynal	CCHMC	Ohio
Kaitlin Ryan-Smith	Children's Hospital of the King's Daughters	Virginia
Dharshi Sivakumar, Malathi Balasundaram, Michelle Wrench, Katherine Huber	El Camino Health	California
Tamara Bledsoe	Envision Physician Services / Northwest Medical Center	Florida
Meredith Collins	HCA Clear Lake	Texas
Vargabi Ghei	HCA Florida Northwest Hospital	Florida
Daphna Yasova Barbeau	HCA University Hospital	Florida
Corinne Balint	Henrico Doctors' Hospital	Virginia
Ashley Osborne	Hospital of the University of Pennsylvania	Pennsylvania
Rafael Mendelsohn	Ichilov	Israel
Elizabeth Simonton	ICU baby	Florida
Kathryn Ponder	John Muir	California
Jessica Fry, Kerri Machut	Lurie Children's Hospital of Chicago	Illinois
Keira Sorrells	NICU Parent Network	Kentucky
Katherine Schwartz	Northwell	New York
Tamara Alexander	Oklahoma Children's Hospital at OU Health	Oklahoma
Timothy Palmer, MD	Penn State Hershey Children's Hospital	Pennsylvania
Ana Ribeiro	Rainbow Babies and Children's Hospital	Ohio
Robert Cicco	Retired. Answers below relate to the NICU I used to work in.	Pennsylvania
Priya Jegatheesan	Santa Clara Valley Medical Center	United States
Karen Anderson, Rachelle Sey, Jenny Koo	Sharp Mary Birch Hospital for Women & Newborns	California
Eric Horowitz	St. Peter's Hospital	New York
Amanda Rahman	Staten Island University Hospital	New York
Maya	Sunnybrook	Ontario, Canada
Ali Slone, Mina Hanna	UK, Kentucky Children's Hospital	Kentucky
Kavya Rao MD	University at Buffalo	New York
Sarah Swenson	University of Minnesota/M Health Fairview Masonic Children's Hospital	Minnesota
Colby Day, Morgan Kowalski	University of Rochester Medical Center, Golisano Children's Hospital	New York
Maria Franco Fuenmayor	University of Texas Medical Branch	Texas
Rashmi Gulati	University of south Alabama children's and women's hospital	Alabama
Radhika Narang	Valley Children's Healthcare	California
Laura Russell	Vanderbilt	Tennessee



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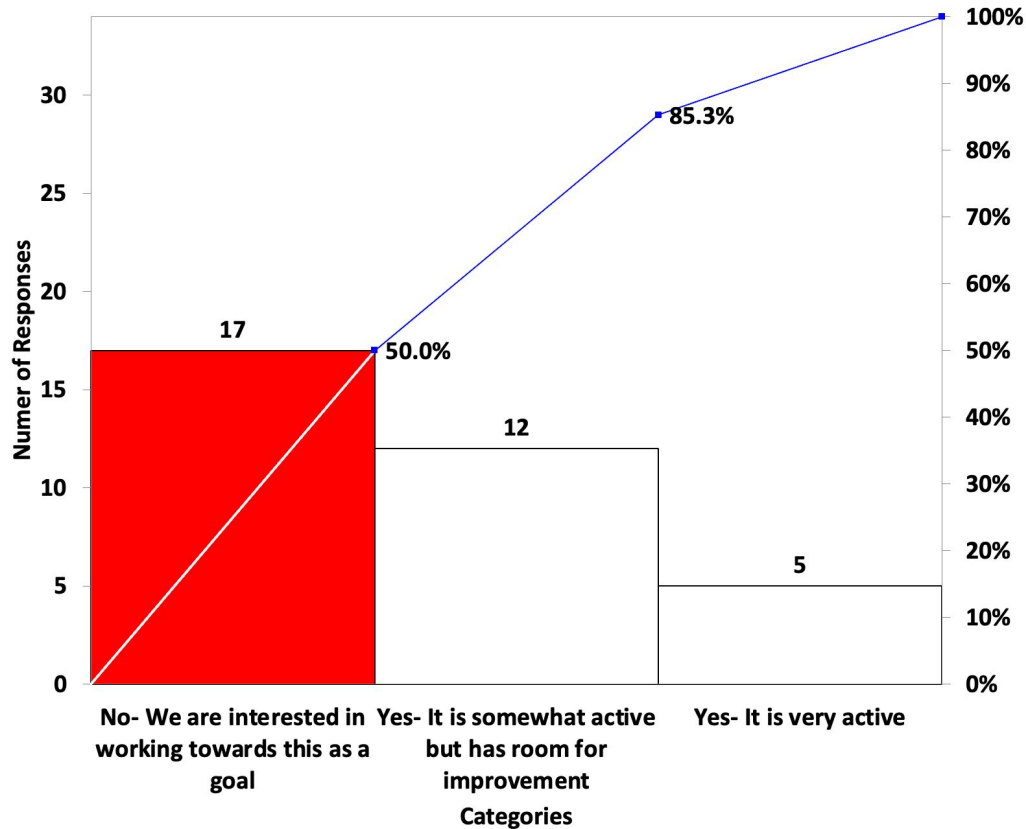


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Do you have a dedicated NICU-specific Family Centered Care (FCC) committee? This committee is defined as a multidisciplinary team that meets regularly whose goal is to empower family participation in the NICU.



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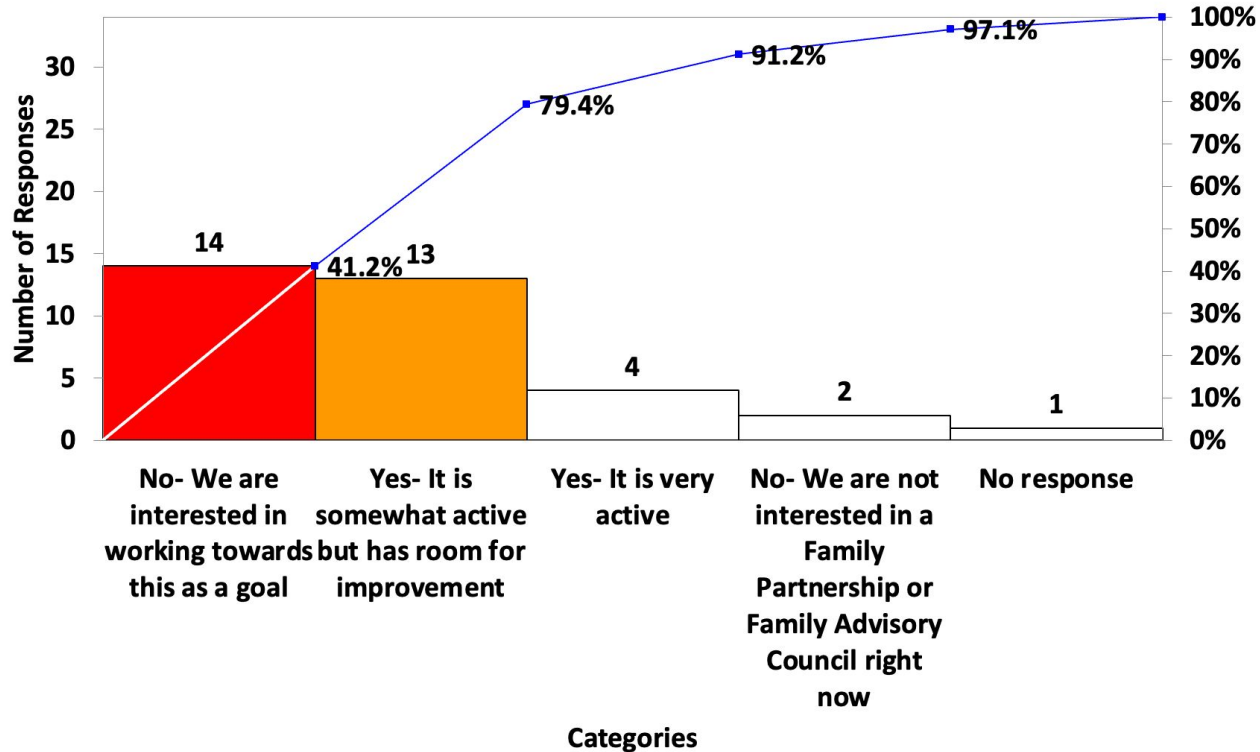


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Have you involved NICU families in a Family Partnership or Family Advisory Council? This could be a hospital-wide council that includes NICU family members or a NICU-specific council.



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Our SMART (Specific, Measurable, Achievable, Relevant, Time bound) aims are:

1. We aim to increase the percentage of NICUs who have a very active (defined as at least meeting quarterly) NICU-specific FCC Committee from a **baseline of 15% in Aug 2022 to 50%** by Nov 2023.
2. We aim to increase the percentage of NICUs who have a very active (at least meeting 1-2 times a year) Family Partnership Council from a **baseline of 12% in Aug 2022 to 50%** by Nov 2023.



In your unit, what were or are the barriers to implementing a Family Centered Care committee?

#	Answer	%	Count
1	Lack of leadership buy-in	6.12%	6
2	Lack of family-friendly environment (no comfortable chairs for skin to skin, no reading materials for reading program, etc)	7.14%	7
3	Others	6.12%	6
4	Need for a culture change	21.43%	21
5	Lack of staff time	29.59%	29
6	Parents live far away and are unable to come to the NICU to meet	18.37%	18
7	Financial factors	11.22%	11
	Total	100%	98

Small Group Leaders

Group 1:

Kerri Z. Machut, MD, Lurie Children's Hospital of Chicago

Jessica Fry, MD, Lurie Children's Hospital of Chicago

Elizabeth Simonton, Family partner



Group 2:

Dharshi Sivakumar MD, Stanford/El Camino Health NICU, CA

Vargabi Ghei MD, HCA East Florida Northwest Medical Center

Katherine Huber - Family Partner



Group 3:

Colby Day, MD, University of Rochester Medical Center

Daphna Barbeau MD, HCA University hospital, Davia

Morgan Kowalski - Family Partner





Small Group Leaders

Group 4:

Emily Whitesel MD, Beth Israel Deaconess
Medical Center

Timothy Palmer MD, Penn State University

Molly Wylie, Family Partner



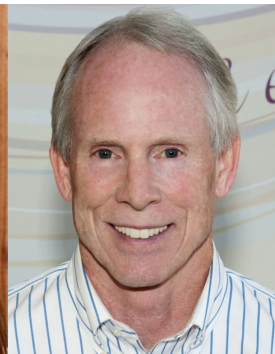
Group 5:

Robert White MD, Beacon Children's Hospital

Malathi Balasundaram MD, Stanford/ECH

Keira Sorrells- Family Partner

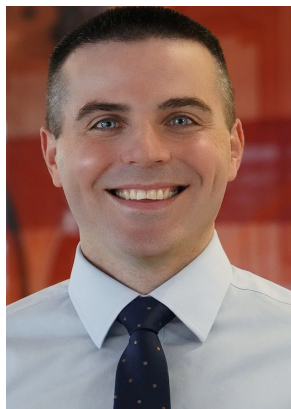
Michelle Wrench - Family Partner



QI Mentors



Wendy Timpson, MD
Attending Neonatologist
U. Massachusetts Memorial
Medical Center



Jeff Meyers, MD
Associate Professor of Pediatrics,
University of Rochester Medical Center
Medical Director, Golisano Children's
Hospital at Strong NICU



Henry Lee, MD
Clinical Professor
Stanford University School of
Medicine



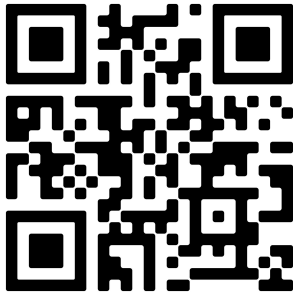
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Taskforce Member Update



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- 300+ listserv members from 90+ hospitals
- Padlet: Scan QR Code



Family Centered Care Taskforce

Taskforce Overview

FCC in the NICU is a key factor in improving infant health outcomes and family mental health outcomes, and in empowering family participation in their infant's care. Despite this, very few NICUs across the US have implemented a mode of NICU care focused on FCC. Our team has successfully garnered enthusiastic interest from 37 NICUs across the US to complete virtual trainings and engage in small group discussions from May 2022 to May 2023 around this topic.

Educational Webinars

Link for calendar invites & zoom information
[Click here!](#)

Upcoming Webinars
Sep 15th, 11-12:30 PM PDT- "How to build a Family Advisory Council in your local NICU" Molly from Beth Israel, Marybeth Fry from Akron's Children's Hospital, Jennifer Johnson from U. Rochester
Oct 13th, 2022, 11-12:30 PM PDT - "Providing supports to non-birthing NICU Partners" Dr. Chavis Patterson (CHOP Clinical Psychologist) "Late Preterm, Term baby Family Partner panel" Dr. Amanda Yeaton- Massey, Sha Sha, Betsy Pilon, and Michelle Wrench
Nov 10th, 11-12:30 PM PDT- "The need for more mental health professionals in the NICU" Dr. Mike Hynan; "Local Parental support" Dr. Sivakumar & Michelle Wrench "National Parental support" Meegan Snyder & Kiera

Resources and Past Webinars

July 2022 Webinar
"Why is it essential to provide FCC in the NICU; Pearls from Family Partners" Nicholas Hall, Jennifer Canvasser, Michelle Wrench, Meegan Snyder, Kimberly Novod, Dr. Mike Hynan. "How to provide FCC in the NICU?" Unit examples: Dr. Malathi Balasundaram, Dr. Dharshi Sivakumar from El Camino Health and Dr. Jessica Fry & Dr. Kerri Machut from Lurie Children's Hospital

- [Recording](#)
- [Slides](#)
- [Chat](#)

May 2022 Webinar
"Early Life Adversity in the NICU - The Critical Role of FCC" Mary Coughlin. "Why is it essential to provide FCC in the NICU; Pearls from Family Partners" Leilis Vernon, Katherine Huber, Keira Sorrells, Marybeth Fry, Molly Wylie, Nicole McRae

- [Recording](#)

Key Contacts

Co-Chairs
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Caroline Toney-Noland, MSc (Program Manager)
ctn@stanford.edu

Family Partners
We recruited multicultural, diverse, both birthing and non-birthing partners representing different states.

- **Keira Sorrells** - Founder, Executive Director, NICU Parent Network
- **Marybeth Fry** - NICU Family Care Coordinator, Akron Children's Hospital, Lead Family Faculty NICQ/NICQ, Vermont Oxford Network
- **Kimberly Novod** - Executive Director, Saul's light

Questions?

Ask your peers!
List serv: fcttaskforce@lists.stanford.edu
Want to join the list serv? [Click here!](#)

Tweet at Us!
[@FCCtaskforce](https://twitter.com/FCCtaskforce)

You can email
familycenteredcaretaskforce@gmail.com with any other questions you may have.



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CPQCC Family Advisory Council (FAC)

- Only $\frac{1}{3}$ of California NICUs have an FAC
- Less than $\frac{1}{3}$ formally involve family members in QI work
- Many developmental infant outcomes depend on family involvement
- Families can improve care at a systemic level by shaping programs and policies to meet the needs of families in the NICU as well as post-discharge





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CPQCC Family Advisory Council (FAC)

- CPQCC is currently seeking funding for a state-wide FAC to advise CPQCC activities as well as act as a catalyst for local FAC development
- The FAC will consist of 6-10 diverse NICU family members taking race, ethnicity, geography, language of preference, family structure, and other characteristics into consideration
- The CPQCC FAC will also create and curate educational materials to guide and support local NICUs in developing their own FACs and make these freely available on the CPQCC website.
- CPQCC will also offer \$5,000 mini-grants to CA NICUs to help kick start their FACs



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Poll results



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*Today's webinar is dedicated to the NICU children of
our speakers:
Sophia, Max, & Grace.*



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Marybeth Fry, M.Ed.

How to Build and Strengthen Your Family Advisory/Partnership Council in the NICU

Marybeth Fry, M.Ed.

Lead Family Partner - NICQ, iNICQ, EBCD

Vermont Oxford Network

NICU Family Care Coordinator

Akron Children's Hospital

Akron Children's Hospital

- ▶ Akron Children's Hospital - Akron, OH
 - ▶ Level IV regional transport NICU in free-standing children's hospital
 - ▶ 75 bed, single-patient room unit divided into 3 wings on 2 floors
 - ▶ Patient population - premature and sick newborn babies, as well as babies requiring surgical care and NAS/ESC treatment



About My Role

- ▶ NICU Family Care Coordinator
 - ▶ Volunteer/Parent Mentor/
NICU FACT member -
2009-2014
 - ▶ Paid Parent Position/
NICU FACT Lead -
2014-present





Family Advisory/Partnership Council

- Akron Children's Hospital Family Advisory Council
 - PICU FACT
 - Hematology FACT
 - NICU FACT
- FACT = Family Action Collaborative Team

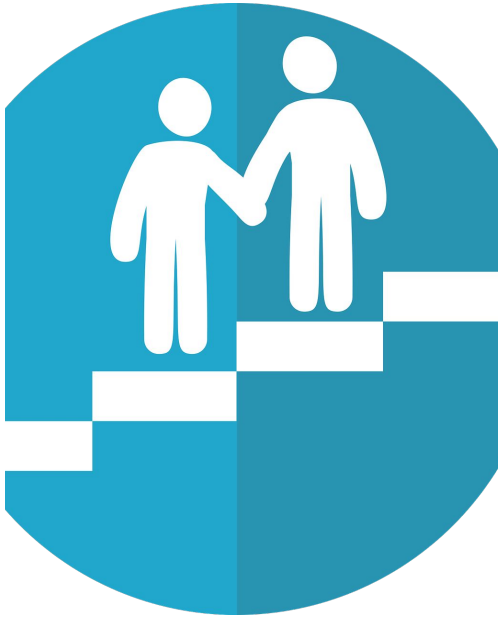
NICU Family Action Collaborative Team

“NICU FACT”

- ▶ Established by group of NICU graduate families in 2005
 - ▶ Volunteers; worked without Parent Mentor Coordinator to establish group
 - ▶ ACH employee group member/mentor
 - ▶ Report to larger hospital-wide FAC
 - ▶ Some members participated in Vermont Oxford over time with ACH



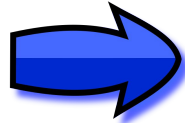
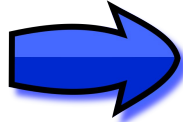
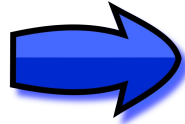
Projects Over Time



- ▶ Celebration & Support Dinners for NICU families
 - ▶ Financial Support
 - ▶ March of Dimes
 - ▶ Donor funds
 - ▶ Capital budget
- ▶ Review and development of educational materials
- ▶ Family Mentorship
 - ▶ Group and individual
 - ▶ Face-to-Face, phone calls, email communication

Challenges & Solutions

- Families growing, changing and relocating over time
- Leadership changes
- COVID-19 restrictions



- Active recruitment, terms of service
- Continue communication with role of group; seek meaningful projects
- Leverage online platforms to continue the work

Recruitment

Bedside staff

Events

- Reunions
- Fundraisers

Promotion of FAC work in unit

- Families see and experience the impact of the work and want to give back

***Membership should be reflective of your unit make-up!**



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Molly Fraust-Wylie, MA

BIDMC NICU Family Advisory

An Introduction and overview of our program

Klarman Family NICU



Beth Israel Deaconess
Medical Center

Beth Israel Lahey Health 



HARVARD MEDICAL SCHOOL
TEACHING HOSPITAL



Hello!

I am Molly Fraust-Wylie

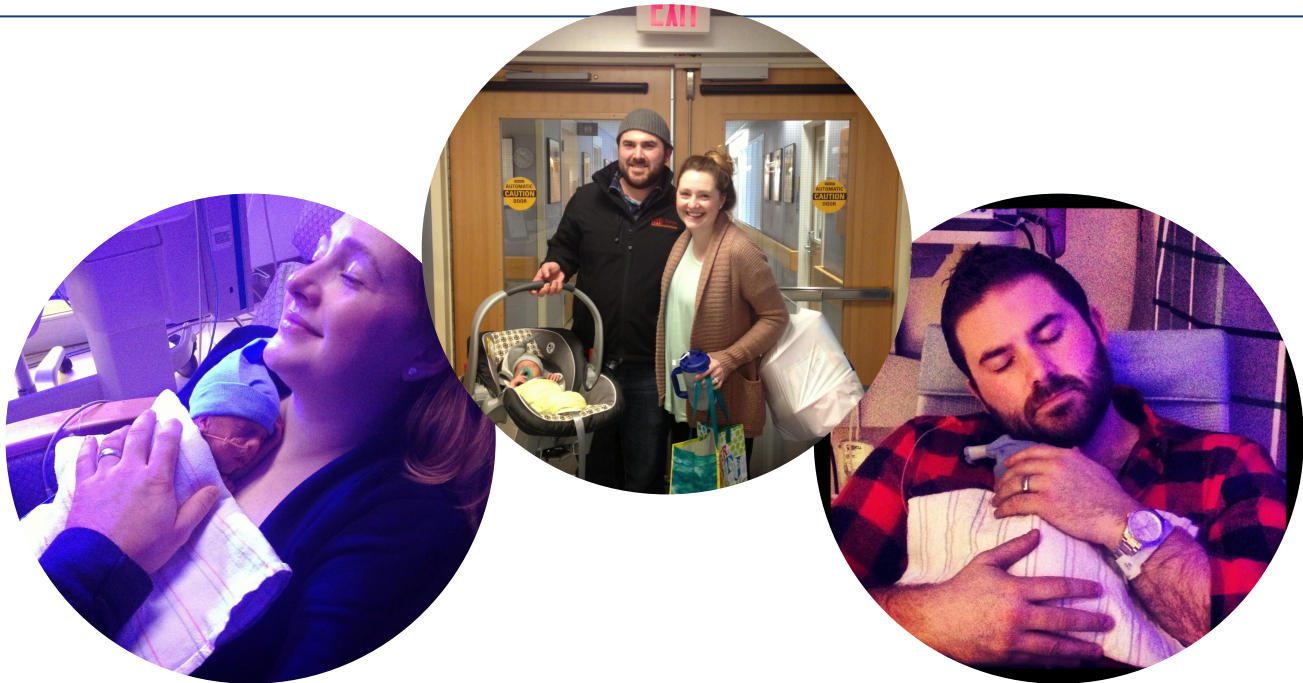
Former NICU Parent, now NICU Advocate

You can find me at mfwylie@bidmc.harvard.edu

A PICTURE IS WORTH A THOUSAND WORDS

This is the first time I met my first son, Max. He was born at 32 weeks (after 6 weeks of bed rest) and was on the BIDMC NICU.





He's 9.5, a 4th grader! Healthy, happy, and a big brother to Renzo, who is 6. Our experience on the NICU changed our life and now I work with other NICU Families like ours.



Welcome to the Klarman Family NICU.

Your Family is part of the care team.

Here we:

Value families and all the love and knowledge they bring.

Support the uniqueness of all families and cultures.



But what do you do?

Let's start with the NICU C.A.R.E.S. Program




NICU Family Support
Here's How You Can Help Us

Meals

- Create a schedule of meals so that dinners are taken care of. This might even include using an online resource for help. (mealtrain.com, takeamoment.com, letscelebratehands.com, mealibaby.com)
- Coordinate preparation of several frozen meals or casseroles in servings for one or two for easy storage and transport.
- Ask if you would like me to stop by the hospital for a "cheer me up" lunch, snack, or coffee break.
- Bake a batch of cookies, or another favorite pick me up food.

Protect Us From Germs

- Protect our baby from a little sniffle or stomach bug, which can be a big deal to a newborn baby in the NICU. Stay away until you are completely better.
- Play it safe. Follow the latest mask guidelines and make sure you're up to date on your COVID-19 and influenza and Pertussis/Whooping Cough (Tdap) vaccines.
- Spread the word and gently tell other family members and friends about this issue, so that parents don't have to feel guilty.
- Wash your hands and use hand sanitizer in and pump out of our baby's room – we greatly appreciate it.

Helping Hands

- Offer to watch siblings so parents can spend time in the NICU, or even coordinate a schedule of willing friends and family.
- Coordinate play dates for siblings.
- Offer to help drive children to/from childcare.
- Walk pets, feed them, or even keep them overnight. Change litter boxes. Organize pet boarding or trips to the veterinarian.
- Water indoor/outdoor plants, especially in the summer or shoveling snow in the winter.
- Run to a store with a list I provide.



Compassion

Advocacy

Respect

Empathy

Support





This program develops and coordinates social and informational programs to help families during their baby's hospitalization.



In addition, the NICU C.A.R.E.S. program helps families connect with other parents during and after their hospital stay



Involving Parents During & After Their Stay

- Parents at Rounds
- NICU Family Advisory Committee
- Parents on NICU Subcommittees
- Craft Nights for Alumni*
- Online Facebook Community for Graduate Parents
- Let's Get Together Today
- FICARE
- VON
- 1:1 virtual/in-person support
- MyNICU
- Music Therapy with Berklee College of Music*
- iPads & Kindles
- LTL Learners Program
- How Can We Help Document
- Alumni Events*
- Sibling Support*
- Meditation & Relaxation for parents
- Bereavement and Memorial Service



Why We Formed a NICU Family Advisory Committee- 2005

- Increase in programs through NICU C.A.R.E.S. for Families initiative
- Family Satisfaction Surveys
- Growing demand for parent involvement
- High value placed on parent perspective
- Need for funding



The mission of the BIDMC NICU Family Advisory Council is to touch the lives of each NICU family in a positive and lasting way. Our goal is to complement the NICUs outstanding clinical care and embrace the hospital's commitment to Family-Centered Care with programs and initiatives that acknowledge and support the family in a time of crisis, and to extend the relationship between the family and hospital well beyond discharge. The NICU Family Advisory Board will support this mission through representative feedback on existing and future programs, facility and policy enhancement, staff/family relations, development and fundraising and other issues related to the needs of NICU families.



Subcommittees

We also have 3-4 parents on *most* of our NICU Subcommittees

- 18 committees that are multidisciplinary working groups
- Meet monthly but we only ask parents to join at least 2-3 meetings virtually or in person as they can
- Generally we start talking about parent involvement 1 year post discharge. I talk to all the staff to see who they think might be a great fit to be involved.

But HOW?!

- Use multiple channels to connect with families: emails, phone calls, if you have an alumni group or a parent support person, engage there. Cast a wide net and know some families will express interest but not be able to commit
- Create a “stay in touch” document for discharged families that helps you understand where their interests lie and to what degree they want to be involved. Keep it active & updated.
- Families want to be a part of NICU QI work and giving them a way to help future families is a GREAT way for them to give back after their experience.



No really... how?!

- Relationship building. We cannot expect our NICU families to be vulnerable right away. We need to build trust and establish connection and a relationship. This starts at the bedside during their NICU stay and lasts for many, many years or in some cases, a lifetime.
- Trust in sharing experience is very important – families need to feel safe in sharing the good & the bad about their experiences. When sharing or disclosing clinical information with NICU families use content warnings as appropriate and understand they may have reactions to the language often used in NICU settings by clinicians.
- Talk to NICU Staff and nurses especially. Tell them about the project and see if they can think of families that might be a good fit.
- Flexibility- working families may not be able to meet regularly at 12 noon. Is Zoom an option? Can you do some nights? Can involvement happen over email or in a group online?
- Be up front about the ask. What is the time commitment? What staff will be involved? Will they connect with other NICU families?
- Compensate if you can!!! Budget for participation in your project to include paying parents for their time and expertise. We do not currently compensate our NFAC but we offer them free parking and meals during meetings (when in person) and for our NICU projects we try to give some compensation or small appreciation (hospital swag) if possible for their help and participation
- Utilize interpreters and if you can, have staff involved who speak the languages of the families you are engaging.
- Provide transportation, paid parking & childcare whenever possible – (we mainly provide childcare for things like focus groups and video projects)



Diversity in many ways

We should be prioritizing welcoming people from different backgrounds- like race & ethnicity.

- Consider not only race & ethnicity, but also sexual orientation, family structure, gender, financial situation, physical & mental ability, and education level.
- Diversity in family structure- Are you engaging LGBTQIA-headed families? Single parents?
- Cultural diversity- Families who do not speak the dominant language on your unit.



NFAC and Subcommittees and COVID

- Moved to virtual, quarterly Zoom calls
- Increased participation for NFAC – 20-25 family caregivers on our Zooms providing feedback and hearing updates about the NICU during COVID
- Decreased participation in subcommittee work
 - Less parents available to join monthly calls
 - Zoom fatigue
 - Emailed for feedback with documents, etc.



THANK YOU!
Contact info:
MFWylie@Bidmc.Harvard.Edu



Beth Israel Lahey Health 

Klarman Family NICU



Beth Israel Deaconess
Medical Center



HARVARD MEDICAL SCHOOL
TEACHING HOSPITAL



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Jennifer Johnson

Jennifer Johnson, Director of Family & Community Outreach



UR Medicine Golisano Children's Hospital Rochester, NY

8 story tower

NICU:

- 44 Private beds
- 24 beds in step-down unit
- Often at 100% capacity
- Only level 4 NICU in region



Video shows how to fortify breastmilk with formula powder according to the recipe provided at discharge: materials needed, steps of the process, and reminders about storage.

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How did you build the FAC/Family Partnership Council programs in your local NICU?

*Lots of credit to Social Work Clinical Manager Carla LeVant, L.M.S.W.

Carla's 2012 Poster

Using a Parent Advisory Council to Improve Family-Centered Care in the NICU
Carla LeVant, LMSW Golisano Children's Hospital, URM, Rochester, NY

Creation of a Family Advisory Council

- The NICU at Golisano is a 40-bed, level III unit and offers an 80% capacity or more
- Family Advisory Council was established in 2009 upon parental request for the unit's policies and procedures
- The 10th parent role and topic by hospital leadership has led to their impressive results

Accomplishments of the Council

- Expansion to 24-hour visitation by parents from previous 22-hour policy
- Parents were permitted to stay in unit during rounds and shift changes
- Creation of an admission handbook and welcome DVD to help families transition
- Establishment of a parent advocate/peer support volunteer position
- Improvements in discharge planning and follow-up
- Parent participation on hospital committees for planning and quality



Why it Works

- The NICU was prepared to address identified
- Parents identified through their feedback to address satisfaction survey of discharge
- Staff in both NICU and medical-surgical (e.g. Family Conference) in a hospital unit initiated
- Ongoing communication among all NICU staff (e.g. Social work, physicians and nursing)
- Representation by all three disciplines on the Family Advisory Council

Council Structure

- Co-facilitated by parent and a social worker
- Representation by parents of children with both lengthy and shorter stays with varying dependencies and requirements
- Representatives include Gen 3rd Network, New Building Planning and Quality and Safety
- Monthly meetings agenda typically include: concerns/requests, parent satisfaction data, changes in NICU practices and ongoing/needed communication by parents
- Parents participate in required hospital education training including safety, privacy and insurance issues
- All parents invited to peer support committee further Parent to Parent training



Examples of Feedback

- We really appreciated Dr. Smith's advice on staff to our home!
- Great discharge instructions as well as follow up phone call (we and nursing from discharging medicine)
- We received a phone call to check on us our son has done after we got home - much appreciated
- I loved the meeting to the room with us, I was also impressed that he attending called me to follow up 2 weeks later
- Doctor even called at home the next day. Never heard of a NICU MD doing this to check on our child at home ever and others. I was thankful to the medical field for their very warm interest about how good the doctor was. It was greatly appreciated.
- Have follow up phone call from discharge team. GREAT THANKS!
- Dr. Leonard called us at home to follow up. We were very appreciated!

Highlights:

*A Family Advisory Council was established to gain parental input for the NICU's policies and procedures.

*Expanding parent visiting hours and allowing parents to stay in unit during rounds and shift changes

*Establishment of a parent advocate/peer support volunteer position

*Improvements in discharge planning and follow-up

*Parent participation on hospital committees for planning and quality



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2011: Became mom to Grace. She taught me a lot!
2019: Joined hospital as Dir. of Family & Community Outreach
On our website...

Patient & Family Experience

Families are the center of a child's world so it makes sense that families have a role and are recognized as part of the decision-making process at Golisano Children's Hospital. It fits the mission of continually improving the overall experience for all of our patients and their families. Jennifer Johnson, the Director of Family and Community Outreach at Golisano Children's Hospital has experience as the mom of a patient ([2012 Miracle Kid Grace Esposito](#)) and is working to ensure the voice of parents and families go far beyond her own to include different diagnosis, different outcomes, social and ethnic backgrounds, genders, sexual orientations, geographic regions and physical abilities.

Family Connection Program

The Family Connection Program is one way voices of families are heard. The FCP is made of families who have all had either an extended stay or multiple stays at Golisano Children's Hospital or, in at least one case, may live in the Rochester, NY area but may have to travel outside the state to receive the necessary care. The ideas, insight and feedback from these families is invaluable. The FCP started in 2020 with four focuses:



Jennifer Johnson, Director Family & Community Outreach, Golisano Children's Hospital

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Family Connection Program Launch: January, 2020

Golisano Children's Hospital invites you to a launch meeting of the newly created

Family Connection Program

Wednesday, January 22nd, 5:30 – 7 pm
Bloch Advancement and Alumni Center
300 East River Road, Rochester, NY 14623

Meet Physician-in-Chief Dr. Patrick Brophy and enjoy some refreshments.

Please RSVP by January 15th to
Jennifer_Johnson@urmc.rochester.edu



Are you interested in:

- Telling the community at fundraising activities what the hospital means to you?
- Supporting a family with the same or a similar diagnosis?
- Giving online feedback to staff on instructional videos or brochures?
- Providing support to bereaved families?

Whether you have a little time, or a lot, we will provide you with options to become involved in our "hospital family"... a family that is stronger when we are connected.



Pre-Covid Engagement Opportunities:

- Family Advisory Council
- Quality Improvement
- Sharing stories for PR/Marketing/Advancement
- Bereavement Council

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UR Medicine Golisano Children's Hospital Family Connection Program:

Website: <https://www.urmc.rochester.edu/childrens-hospital/quality/patient-family-experience.aspx>

The FCP is the feeder program for several volunteer family engagement opportunities at GCH as mapped out here including requirements to participate. The FCP intake questionnaire at the link below helps us learn about interested families and their lived experience and how they might want to engage. **Intake Questionnaire:** <https://redcap.link/xdw51hly>

Contact: Jennifer Johnson: Jennifer_Johnson@URMC.Rochester.edu (Director of Family and Community Outreach)

or Carla Levant: Carla_LeVant@URMC.Rochester.edu (GCH Social Work Clinical Manager)

	Quality Improvement Family Advisor	Buddy Programs (virtual)	Sharing with Public	Bereavement Advisors	Pediatric Family Advisory Council	Family Support (in-person) <i>Former name: Parent-to-Parent</i>
Description of opportunity	Provide family perspective for healthcare team looking at an issue of the team's choosing. Must relate to your lived experience. Examples: workgroup, panel discussion or Small Baby Program	Parents/Guardians who have been through a health challenge with a child and are a few years out from the start of that challenge (a Buddy Mentor) are matched up <u>virtually with</u> a parent/guardian who is just beginning the journey (a Buddy Mentee). Buddy Programs as of Fall 2022: NICU Buddy Program: piloted in 2021 Trach Buddy Program: piloted in 2022 G-Tube Buddy Program: piloted in 2022 Bereavement Buddy Program: starting fall of 2022. Other Buddy Programs are in the beginning stages.	Individual stories are a great way to describe what happens at GCH. We're looking for families to do media interviews, talk in front of an audience at a fundraiser, show up at check presentation and/or submit pictures and written accounts for social media.	Bereavement website: https://www.urmc.rochester.edu/childrens-hospital/bereavement.aspx Advisors can contribute to the Advisory Board and/or participate in the Bereaved Parent Educator Program in <u>which bereaved</u> parents train Fellows how to share difficult	https://www.urmc.rochester.edu/childrens-hospital/quality/patient-family-experience/pediatric-family-advisory-council.aspx Medical staff may present an idea to the group for feedback.	Current NICU Program: https://www.urmc.rochester.edu/childrens-hospital/neonatology/nicu-family-support.aspx When visitation guidelines allow this is an in-person opportunity for families who have been in the NICU to support families there currently through

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How should the Family Connection Program Exist?

- Virtually
- HIPAA Compliant
- Equitable fashion
- Reflecting our Values



Resize font:
☐ | ☐

GCH Family Connection Program Questionnaire

Thank you for your interest in this program!

The information you share with us will be used to help get you involved and connect you to the GCH staff who are doing the work you are most interested in. We know life can get busy and your experience here may be an emotional one so please participate when and to the extent that you feel comfortable.

Families with different diagnoses, outcomes, racial and ethnic backgrounds, genders, sexual orientations, religions, geographic regions and physical abilities all provide important insight and perspective. Your lived experience and perspective matters.

Your first name

* must provide value

Your last name

* must provide value



Family Connection Program

Authentic Advocacy

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Did you have financial support? How are you planning to sustain this?



"Back-up needed!"...

Asked for Family Connection Program Coordinator in hospital budget

NICU pursuing a donor for a paid Parent Advisor position

Partnered with office that tracks on-site volunteers to help with virtual volunteers

Grand Rounds with Bev Johnson of Institute for Patient and Family-Centered Care

Update website



On behalf of our families, thank you for the opportunity to talk about this work!



Jennifer Johnson
Director of Family & Community Outreach at Golisano Children's Hospital
Jennifer_Johnson@urmc.rochester.edu

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FAMILY-CENTERED CARE
TASK FORCE



FAMILY-CENTERED CARE
TASK FORCE

Q&A

Moderated by:

Ashwini Lakshmanan, MD, MS, MPH &
Courtney Breault, RN, MS, CPHQ

CPQCC



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IMPROVEMENT PALOOZA 2022

families
as the foundation of high quality, inclusive NICU care



Scan below to join the
CPQCC mailing list!





FCC TASKFORCE WEBINAR

Join us on October 13, 11-12:30 PT

Speaker:



Dr. Chavis A. Patterson, PhD
Director of Psychosocial Services
Division of Neonatology
The Children's Hospital of Philadelphia
Pronouns: he/him



Register using the
QR code or this [link](#)

Providing support to non-birthing NICU Partners

Late Preterm & Term Family Partner Speakers:



Dr. Amanda Yeaton-Massey, MD
Clinical Assistant Professor,
Maternal-Fetal Medicine, UCSF
Pronouns: she/her
NICU Children: Simon, Willow



Sha Sha Chu
Pronouns: she/her
NICU Children: Simon, Willow



Dr. Theresa Urbina, D.O
Regional Fellow Rep TECaN
Pronouns: she/her
NICU child: Louis



Michelle Wrench, RN, CCRN
CPQCC Family Advisory Council Chair
Pronouns: she/her
NICU children: Elin, Mischa, Vivienne



Dr. Vishal Kapadia, D.O
Palliative Care Physician
NICU Parent Advocate
Pronouns: he/him
NICU children: Niyati, Nishtha



Betsy Pilon
Exec. Director, Hope for HIE
Pronouns: she/her
NICU child: Max



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Evaluation Survey

