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
FCC Core Team

**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
Partners

NEONATOLOGY TODAY
Peer Reviewed Research, News, and Information in Neonatal and Perinatal Medicine
Agenda

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

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
Family Partners

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

- **No**: We are interested in working towards this as a goal - 17 responses (50.0%)
- **Yes**: It is somewhat active but has room for improvement - 12 responses
- **Yes**: It is very active - 5 responses

Graph showing the distribution of responses.
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.

![Graph showing the distribution of responses to the question about involving NICU families in a Family Partnership or Family Advisory Council. The graph includes categories for 'No - We are interested in working towards this as a goal', 'Yes - It is somewhat active but has room for improvement', 'Yes - It is very active', 'No - We are not interested in a Family Partnership or Family Advisory Council right now', and 'No response'. The percentages and number of responses are indicated on the graph.]

- No - We are interested in working towards this as a goal: 14 (41.2%)
- Yes - It is somewhat active but has room for improvement: 13
- Yes - It is very active: 4
- No - We are not interested in a Family Partnership or Family Advisory Council right now: 2
- No response: 1

Total number of responses: 36
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?

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

- 300+ listserv members from 90+ hospitals
- Padlet: Scan QR Code
Only ⅓ of California NICUs have an FAC

Less than ⅓ 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
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.
Poll results
Today’s webinar is dedicated to the NICU children of our speakers:
Sophia, Max, & Grace.
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!
Molly Fraust-Wylie, MA
BIDMC NICU Family Advisory

An Introduction and overview of our program
Hello!

I am Molly Fraust-Wylie

Former NICU Parent, now NICU Advocate

You can find me at mfwylie@bidmc.harvard.edu
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.
The Klarman Family NICU Philosophy of Care

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

Meals
- Create a schedule of meals so that dinners are taken care of. This might even include using an online resource for healthy milk bars.
- Local milk banks are a great option for these meals.

—

Protect Us From Germs
- Pray and support from a little white or brown bag, which can be a big deal to a newborn baby in the NICU. Stay away until you are comfortable with it.
- Help it off. Follow the latest mask guidelines and make sure you are up to date on your COVID-19 and influenza and Pertussis/Pneumococcal (PCV) vaccines.
- Spread the word and gently get other family members and friends about the issue, so that parents don’t have to feel guilty.
- Wash your hands and use hand sanitizer (make it and pump it out of our baby’s room) — we greatly appreciate it.

Helping Hands
- Offer to wash clothes on parents who spend time in the NICU, or even coordinate a schedule of visitors and family.
- Coordinate play dates for siblings.
- Offer to help drive children to and from the NICU.
- Offer to help drive children for hospitalization.
- Wash pets, feed them, or even take them to the vet.

We can also do things, especially in the carrots or small things in the world.
- Pray a little more with a don’t pound.
NICU CARES

Compassion  Advocacy  Respect  Empathy  Support
REMEMBER TO
CELEBRATE
THE LITTLE THINGS
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.
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
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
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, URMC, Rochester, NY

Creation of a Family Advisory Council
1. Parent input is critical to collaborative and effective care

Accomplishments of the Council
1. Improved patient outcomes and satisfaction
2. Parent involvement in making decisions and setting priorities
3. Improved communication between hospital staff and families
4. Improved patient outcomes and satisfaction

Why it Works
1. Parent input is critical to collaborative and effective care
2. Parent involvement in decision-making and setting priorities
3. Improved communication between hospital staff and families
4. Improved patient outcomes and satisfaction

Examples of Feedback
1. Recently returned from a NICU visit
2. Loved coming back to the NICU
3. We really appreciated the support
4. We really appreciated the support

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
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:
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 about fundraising activities that 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
### UR Medicine Golisano Children’s Hospital Family Connection Program:

Website: [https://www.urmc.rochester.edu/childrens-hospital/quality/patient-family-experience.aspx](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/xdv51h](https://redcap.link/xdv51h)

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)

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<tr>
<th>Description of opportunity</th>
<th>Quality Improvement Family Advisor</th>
<th>Buddy Programs (virtual)</th>
<th>Sharing with Public</th>
<th>Bereavement Advisors</th>
<th>Pediatric Family Advisory Council</th>
<th>Family Support (In-person)</th>
<th>Former name: Parent-to-Parent</th>
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| 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 virtually with 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 Programs: 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](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 which bereaved parents train Fellows how to share difficult | [https://www.urmc.rochester.edu/childrens-hospital/quality/patient-family-experience/pediatric-family-advisory-council.aspx](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. | [https://www.urmc.rochester.edu/childrens-hospital/quality/patient-family-experience/pediatric-family-advisory-council.aspx](https://www.urmc.rochester.edu/childrens-hospital/quality/patient-family-experience/pediatric-family-advisory-council.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
How should the Family Connection Program Exist?
- Virtually
- HIPAA Compliant
- Equitable fashion
- Reflecting our Values

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

DocuSign

UR Medicine
Golisano Children’s Hospital

Family Connection Program
Authentic Advocacy
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
Q&A

Moderated by:
Ashwini Lakshmanan, MD, MS, MPH &
Courtney Breault, RN, MS, CPHQ
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 Yost-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 Resp TC-FAN
Pronouns: she/her
NICU Children: Louis

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

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

Betty Pilans
Exec. Director, Hope for HIE
Pronouns: she/her
NICU children: Max

Evaluation Survey