

NEONATOLOGY TODAY

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



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June 2024 Family Centered Care Taskforce

Morgan Kowalski

“The Family-Centered Care Taskforce stands as a pioneering force, being the FIRST international, multicenter, collaborative initiative solely dedicated to quality improvement in NICU Family-Centered Care.”

The Family-Centered Care Taskforce stands as a pioneering force, being the FIRST international, multicenter, collaborative initiative solely dedicated to quality improvement in NICU Family-Centered Care. The Taskforce has over 1100 members and employs a small group quality improvement collaborative model by offering free monthly Office Hours for those looking to overcome barriers to implementing FCC and a large group model by offering free educational bi-monthly webinars. Our key strength is equal partnership between healthcare providers and Family Partners, enabling effective communication and facilitating change across various healthcare settings. By sharing evidence-based practices and critical family perspectives during webinars and promoting accountability through Office Hours, we are creating a forward movement to close the healthcare gap. Click [here](#) to sign up for Office Hours at no cost and visit our website, www.fctaskforce.org, to subscribe to our mailing list and receive invitations to our webinars! Our next webinar takes place July 11th at 11 am PST.

As we celebrated our second anniversary of facilitating free educational webinars in May of this year, we cannot help but reflect on where we began. The Family-Centered Care Taskforce was founded by Malathi Balasundaram, MD, a Clinical Professor at Stanford School of Medicine and an attending neonatologist and

FCC Committee Chair at El Camino Health NICU. Malathi saw a need for an organization dedicated to quality improvement in NICU Family-Centered Care. She pitched her idea of creating the FCC Taskforce to colleagues at the Gravens Conference and the American Academy of Pediatrics (AAP), Trainees, and Early Career Neonatologists (TECaN) Executive Council. Shortly thereafter, a ‘welcome to the Taskforce’ email was sent to 50 dedicated members in February of 2022, and just over two years later, that number has grown to over 1,100 members from almost every U.S. State and 36 countries around the world.

“Our key strength is equal partnership between healthcare providers and Family Partners, enabling effective communication and facilitating change across various healthcare settings. By sharing evidence-based practices and critical family perspectives during webinars and promoting accountability through Office Hours, we are creating a forward movement to close the healthcare gap.”

Colby Day, MD, Medical Director of Golisano Children’s Hospital NICU, joined the Taskforce as a co-chair alongside Malathi at the Taskforce’s inception. The pair invited Keira Sorrells, former NICU parent and Founder and Executive Director of NICU Parent Network, to join them on the Core Team in March of 2023 and recruit-

Organizational Partners



ed Morgan Kowalski, a former NICU parent, and Family Partner in her local unit, to serve as Program Manager in May of 2023 in the spirit of equal partnership between families and clinicians.

The Taskforce began our work by helping centers around the globe begin and strengthen FCC practices in their NICUs by recruiting and facilitating live bi-monthly webinars beginning in May of 2022, with speakers from diverse backgrounds and roles. In 2023, we continued these well-attended events and recruited 22 centers that wanted to overcome barriers in implementing FCC Committees and Family Partnership/Advisory Councils. These centers were split into five small groups based on AAP levels of care, and monthly meetings were held to discuss challenges around implementing FCC and strategies for overcoming them. These small group QI collaborative opportunities served participants well, with 59% creating an active FCC Committee and 45% creating an active Family Partnership/Advocacy Council in just one year. These advancements are significant, and we are continuing a similar but more inclusive opportunity for NICUs to brainstorm with others during our monthly Office Hours sessions in 2024.

Here are some testimonials from members who participated in small groups in 2023:

“Thank you for all your hard work in engaging NICU teams all around the country on this Taskforce! Our unit has been able to share our FCC team’s efforts as well as availability of rich information-sharing that has helped us refine our family-centered care processes in our NICU.”

— Sangeeta, California

“The Taskforce began our work by helping centers around the globe begin and strengthen FCC practices in their NICUs by recruiting and facilitating live bi-monthly webinars beginning in May of 2022, with speakers from diverse backgrounds and roles.”

“Our unit in Israel joined the FCC Taskforce a year and a half ago. We have attended general and small group sessions in which we have received mentoring from leading figures in the field of FCC. We have learned a lot! We now have a better understanding of the core elements of FCC and are learning about different and practical ways we can implement FCC in our unit. We could not have made this possible without the support of our mentors, and we are very grateful for them and for this amazing model of support.”

— Rafi, Tel Aviv

“I am so proud to be on this Taskforce and to see the widespread change that is happening in units. I feel very fortunate to have the opportunity to connect with colleagues who share my passion for FCC. I learn something new in every webinar!”

— Maria, Texas

Our Executive Council of diverse Healthcare and Family Partners

supports the success of the FCC Taskforce in assisting NICUs. Healthcare Partners come from organizational, quality improvement, and multidisciplinary clinical backgrounds, some of whom are former NICU parents. Family Partners are diverse in their experiences, with full-term NICU journeys and non-birthing parent representation. They support their local NICUs, direct their organizations, contribute to nonprofits supporting NICU families, and hold esteemed positions in national QI collaboratives, respectively. Executive Council members facilitate Newsletters, Marketing and Communications, and Advocacy subcommittees, which help disseminate current best practices and create new ones. The Taskforce is also supported by esteemed national and international organizational partners. We are sharing the program overview below. Join us in strengthening FCC in your NICU.

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Disclosure: There are no reported conflicts.

NT

FAMILY-CENTERED CARE TASKFORCE

THE **FIRST** INTERNATIONAL, MULTICENTER, COLLABORATIVE INITIATIVE SOLELY DEDICATED TO **QUALITY IMPROVEMENT IN NICU FAMILY-CENTERED CARE**

WHAT IS FAMILY-CENTERED CARE?

Family-Centered Care (FCC) ensures that caregivers are active, engaged team members throughout their NICU journey, and is a key factor in improving infant health and family mental health outcomes.

WHY WE EXIST

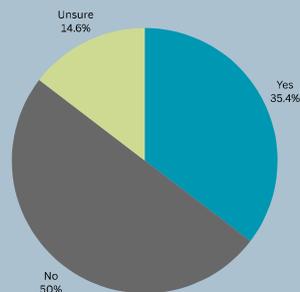
We exist to equip and support NICUs as they seek to begin or strengthen Family-Centered Care in their units.

To address the challenges that exist in implementing FCC practices, we offer free educational webinars with engaging, live Q&A sessions and free monthly office hours sessions.

Our key strength is equal partnership between clinicians and Family Partners in everything we do.

In a survey of 48 NICUs across the U.S., 65% said they don't have an FCC Committee in their unit.

Does your NICU currently have an FCC Committee?



MEMBERSHIP



1100+ members across
43/50 U.S. States &
36+ Countries
Join us, membership is free!



WEBSITE

Visit our [website](#) to learn more about our advocacy efforts, view testimonials from our members, view webinar recordings, and access free resources on all things Family-Centered Care.

STANFORD IMPACT LABS SEED PARTERSHIP

In June of 2024, the FCC Taskforce was awarded a Seed Partnership with Stanford Impact Labs to support our work, **Optimizing the Delivery of Family-Centered Care in the Neonatal Intensive Care Unit (NICU)**. We look forward to collaborating with NICU Parent Network on this important initiative!

Our aim is to use quantitative and qualitative research methodologies to create an **FCC standard** and explore FCC practices at a scale that exceeds prior studies. This work will enable us to (1) develop first-ever FCC benchmarks in the NICU, and (2) identify ways to overcome barriers to FCC implementation.

FREE EDUCATIONAL WEBINARS

JULY 11TH

“Families as Neuroprotectors” with Paige Church, MD

“Delivering Hope Through Words: The Power of Effective Communication in the NICU” with Mia Malcolm, BS, CDFT

SEPTEMBER 12TH

“Improving Family Engagement in the NICU: The Colorado Experience” with Susan Hwang, MD, MPH, PhD

Title TBD with Elizabeth Simonton, JD and Co-Founder/CEO, ICU Baby

NOVEMBER 14TH

Title TBD with Rafi Mendelson, MD, Neonatologist, Tel Aviv

Title TBD with Fabiana Bacchini, Executive Director, Canadian Premature Babies Foundation

OFFICE HOURS

The FCC Taskforce holds monthly Office Hours to discuss challenges around implementing FCC practices and provide strategies for overcoming them. **Office Hours are facilitated by both clinicians and Family Partners from our Executive Council and includes a variety of topics relevant to beginning or strengthening FCC.** Click [here](#) to register!

CONNECT

Email	Twitter
Website	Facebook
YouTube	Instagram
LinkedIn	

FCC TASKFORCE WEBINAR
July 11, 2024
 11:00am - 12:30pm PT

FAMILIES AS NEUROPROTECTORS IN THE NICU
Paige Terrien Church, MD (she/her)
 • Director, NICU Grads Program, Boston Children’s Hospital, Beth Israel Deaconess Medical Center
 • Assistant Professor, Harvard Medical School

DELIVERING HOPE THROUGH WORDS: THE POWER OF EFFECTIVE COMMUNICATION IN THE NICU
Mia A. Malcolm, BS, CDFT (she/her)
 • NICU Parent of Gavin
 • DEIB Facilitator and Consultant

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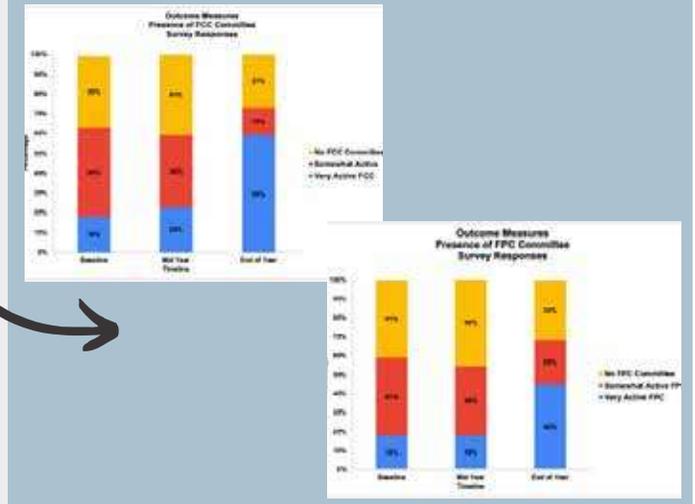
Subscribe to our mailing list to receive calendar invites and Zoom links for our free educational webinars!



ORGANIZATIONAL PARTNERSHIPS

2023 QUALITY IMPROVEMENT WORK

We are thrilled to share that among the 22 global NICUs participating in our 2023 quality improvement work, we exceeded our goals by increasing the percentage of units with an active NICU-specific FCC Committee from 18% to 59%, and the percentage of NICUs with an active Family Advisory/Partnership Council from 18% to 45% in just 12 months! Units who had the most success consistently participated in **small group benchmarking opportunities** where they were encouraged to share their barriers to implementing FCC practices and brainstorm strategies for overcoming them, and attended our free educational webinars while encouraging their colleagues to do the same. **Stay tuned for a publication on this quality improvement initiative!**



SMALL 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

CEO & Co-Founder, ICU Baby



SMALL GROUP 2

Dharshi Sivakumar, MD

Stanford/El Camino Health NICU

Vargabi Ghei, MD

HCA East Florida Northwest Medical Center

Katherine Huber, Family Partner

FCC Committee, El Camino Health NICU

Alex Zavala, Family Partner

Founder, The NICU Dad and The NICU Dad Podcast



SMALL GROUP 3

Colby Day, MD

University of Rochester Medical Center

Daphna Barbeau, MD

HCA University Hospital Davia

Morgan Kowalski, Family Partner

University of Rochester Medical Center



SMALL GROUP 4

Emily Whitesel, MD

Beth Israel Deaconess Medical Center

Robert Cicco, MD

Pennsylvania

Molly Fraust-Wylie, Family Partner

NICU Family Program Manager, Beth Israel

Deaconess Medical Center



SMALL GROUP 5

Robert White, MD

Beacon Children's Hospital

Malathi Balasundaram, MD

Stanford/El Camino Health NICU

Keira Sorrells, Family Partner

Founder & Executive Director,

NICU Parent Network

Michelle Wrench, Family Partner

Chair, Family Advisory Committee CPQCC



**FAMILY-CENTERED CARE
TASKFORCE**

Corresponding Author



Morgan Kowalski
 Program Manager
 Family Partner
 Golisano Children's Hospital NICU
 University of Rochester Medical Center



Vaccines and Preventive Monoclonal Antibodies

WHAT'S THE DIFFERENCE?

The Importance of Immunization

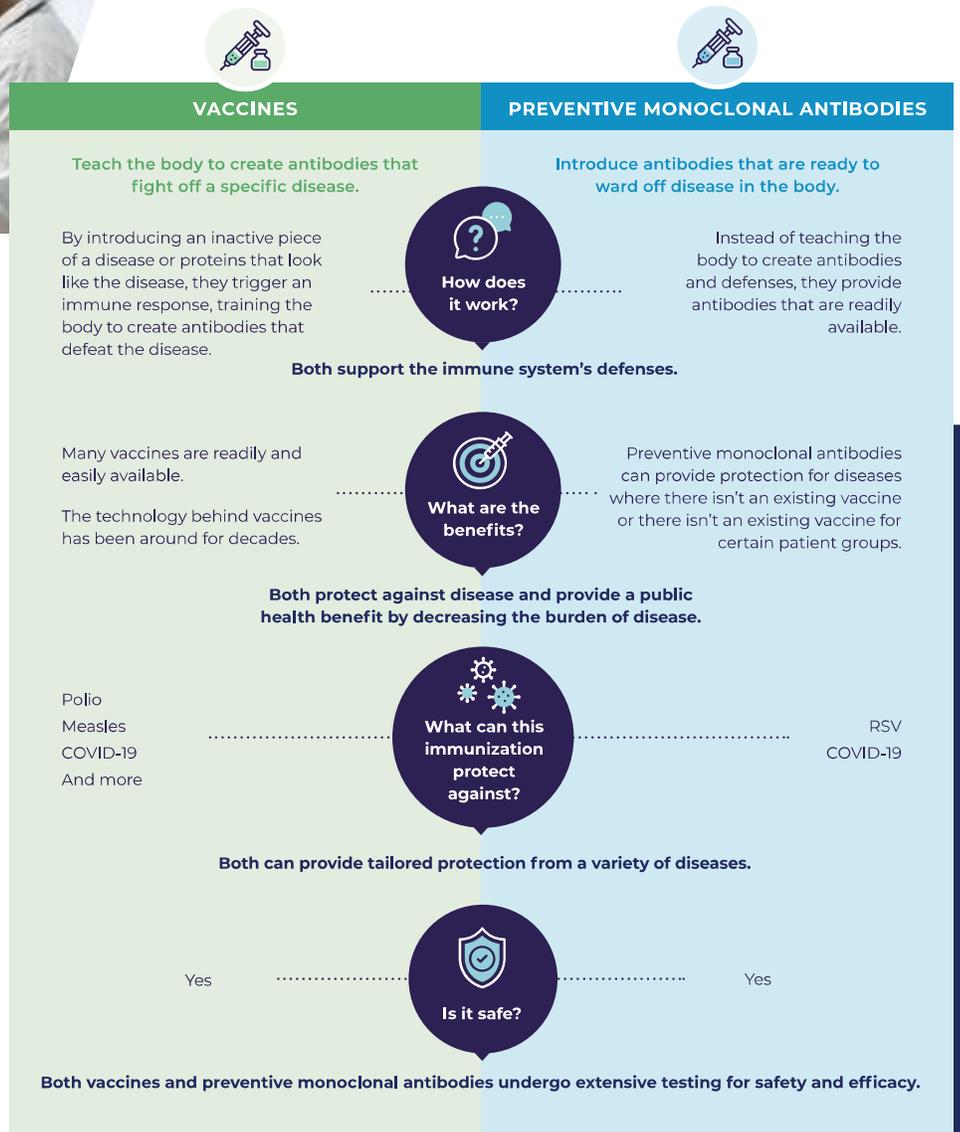
Vaccines and preventive monoclonal antibodies are two different types of immunization. While they function differently, they both serve the same purpose: protecting people from serious illnesses and diseases.

Different Technology, Same Protective Value



<https://www.who.int/news-room/feature-stories/detail/how-do-vaccines-work#:~:text=Vaccines%20contain%20weakened%20or%20inactive,rather%20than%20the%20antigen%20itself.>

https://static1.squarespace.com/static/5523cf7e4b0fe011e668e67/62445af0d0134140f95413f6/164864910485/NCIH_Monoclonal+Antibodies+Inclusion+in+the+VFC+Program_Position+Paper_Mar+2022.pdf



Op-Ed: Pennsylvania Needs Paid Family Leave for NICU Families

Morgan Kowalski

“The stress, emotional toll, and financial burdens can be overwhelming, regardless of your infant’s diagnosis or gestational age at birth. One of the most pressing issues for NICU families is the lack of paid family leave, which directly impacts infant health outcomes. It is time for Pennsylvania to take decisive action and pass paid family leave legislation.”

As a former NICU parent and Program Manager of the Family-Centered Care Taskforce, I am acutely aware of the challenges families with infants face in the Neonatal Intensive Care Unit (NICU). The stress, emotional toll, and financial burdens can be overwhelming, regardless of your infant’s diagnosis or gestational age at birth. One of the most pressing issues for NICU families is the lack of paid family leave, which directly impacts infant health outcomes. It is time for Pennsylvania to take decisive action and pass paid family leave legislation.

The absence of paid family leave exacerbates the difficulties faced by NICU families. Parents are often forced to choose between their jobs and their infant’s well-being. This impossible choice can lead to prolonged hospital stays, increased health complications, and significant emotional distress. Paid family leave would allow parents to be present with their infants during these critical early days, promoting better health outcomes and offering much-needed support to families.

We are at a critical juncture. Our organization and the entire FCC Taskforce advocate for paid family leave in Pennsylvania. We are urging the governor and lawmakers to recognize the importance of this issue and take immediate action. We have initiated a letter of support and are collecting signatures to demonstrate the widespread demand for this essential policy. We invite everyone to take a moment to sign our letter via the linked Google Form. It takes less than a minute and can make a difference for countless families. The deadline for signatures is Thursday, June 27.

Moreover, our advocacy efforts extend beyond just paid family leave. We are working toward a resolution, “Parents and family caregivers are not visitors,” which allows Zero Separation policies

“The absence of paid family leave exacerbates the difficulties faced by NICU families. Parents are often forced to choose between their jobs and their infant’s well-being. This impossible choice can lead to prolonged hospital stays, increased health complications, and significant emotional distress. Paid family leave would allow parents to be present with their infants during these critical early days, promoting better health outcomes and offering much-needed support to families.”

to become the standard of care in NICUs across the U.S. In addition, we are seeking insights on how units have obtained senior leadership or administration buy-in for Family-Centered Care (FCC) practices. Your experiences and strategies are invaluable. Please contribute to our June poll to help us enhance our collective efforts to promote FCC practices.

“In addition, we are seeking insights on how units have obtained senior leadership or administration buy-in for Family-Centered Care (FCC) practices. Your experiences and strategies are invaluable. Please contribute to our June poll to help us enhance our collective efforts to promote FCC practices.”

Our commitment to advocacy and support extends to organizing and participating in events that foster community and knowledge sharing. On Friday, July 12, our founder, Malathi Balasundaram, MD, and I will discuss the FCC Taskforce’s efforts on the Canadian Premature Babies Foundation podcast, Preemie Chats. On

NEONATOLOGY TODAY is interested in publishing manuscripts from Neonatologists, Fellows, NNPs and those involved in caring for neonates on case studies, research results, hospital news, meeting announcements, and other pertinent topics.

Please submit your manuscript to: LomaLindaPublishingCompany@gmail.com

July 24, join us for a session on establishing and sustaining effective Patient and Family Advisory Councils by IPFCC. We are excited about the 4th Annual Trauma Informed Developmental Care Conference from October 13-15th in Boston, MA, where professionals will converge to share insights and advancements in developmental care.

“Our commitment to advocacy and support extends to organizing and participating in events that foster community and knowledge sharing. On Friday, July 12, our founder, Malathi Balasundaram, MD, and I will discuss the FCC Taskforce’s efforts on the Canadian Premature Babies Foundation podcast, Premie Chats. On July 24, join us for a session on establishing and sustaining effective Patient and Family Advisory Councils by IPFCC. We are excited about the 4th Annual Trauma Informed Developmental Care Conference from October 13-15th in Boston, MA”

We thank our dedicated members and supporters for their unwavering commitment to Family-Centered Care. Your involvement and advocacy are what drive progress and change. Together, we can ensure that NICU families receive the support they need, including the critical provision of paid family leave.

Join the FCC Taskforce Mailing List, visit our website, follow us on Twitter, connect with us on LinkedIn, and subscribe to our YouTube channel for updates and information.

Note: I work flexible hours and may send emails outside core hours of 9:00 a.m. - 5:00 p.m. EST. I do not expect you to read, action, or respond outside of your own working hours.

Disclosure: There are no reported conflicts.

NT

Babies are just tiny adults, right? So ... half?

Infants need drugs tested and approved just for them.

Center for Clinical Trials and Biometrics | NCI/NIH National Institutes of Health

Corresponding Author



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Program Manager
Family-Centered Care Taskforce
email: morgankw@stanford.edu

DeEtta's RSV Story

"As a first-time mom, I didn't know much about RSV."

"But when my 4-month-old stopped eating and her breathing became shallow, it was terrifying."

"When the doctor said he wanted to admit her to the hospital, I became even more concerned."

"Our baby girl being admitted to the hospital will forever be ingrained in my mind."

RSV places a real burden on babies and families like DeEtta's.

NCI/NIH National Institutes of Health

DeEtta (OTARA, KANSAS)

LEARN MORE