



FAMILY-CENTERED CARE
TASK FORCE



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FCC Task Force

Inaugural Educational Session

Malathi Balasundaram, MD

&

Colby Day, MD



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Phase 1:



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Nov 2021- Apr 2022: Program Development

1. Partnered with AAP TECaN (Trainees and Early Career Neonatologists) Executive Council
2. Recruited physicians, nurses, and advanced practice providers passionate about FCC via survey link
3. Created a collaboration with 13 family partners
4. Formed five small cohort groups and connected with units that already have an FCC program

Currently we have 50 members in the FCC Task force representing 32 centers from 20 states and one international center!



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Aims



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The broad aims of this task force are:

1. To create networking opportunities for NICUs interested in family-centered care (FCC)
2. To facilitate the creation of FCC Committees/Family Partnership Councils at hospitals around the country/world
3. To educate on the importance of family integration in the NICU
4. To foster benchmarking on FCC measures between centers



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Co-Chairs



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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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Family Partners



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***Jennifer
Canvasser***
*Founder,
Executive
Director,
NECsociety*



Lelis Vernon
*NICU mom of
25 weeks g/a
twin boys,
healthcare
consultant*



Necole McRae
*Founder,
Free2Read-
Education
Recovery
Services*



Keira Sorrells
*Founder,
Executive
Director, NICU
Parent Network*



Marybeth Fry
*NICU Family Care
Coordinator, Akron
Children's Hospital,
Lead Family Faculty
NICQ/iNICQ,
Vermont Oxford
Network*



Molly Wylie
*NICU parent and
NICU Family
Program Manager
at Beth Israel
Deaconess Medical
Center*



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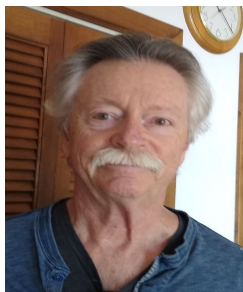
Family Partners



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**Kimberly
Novod**
*Executive
Director,
Saul's light*



Michael Hynan
*Father of
Christopher
Leslie-Hynan, who
spent 42 days in
the Milwaukee
NICU in 1980 and
Clinical
Psychologist*



**Nicholas
Hall**
*Founder and
President,
Graham's
Foundation*



**Katherine
Huber**
*Family Advisory
Council, El
Camino Health
& Mother of twin
8-year-old boys
born at 24 weeks*



Meegan Snyder
*Director,
Premie
Parent Mentor
Program,
Graham's
Foundation*



**Michelle
Wrench**, NICU
*nurse, FCC
Team
contributor,
Parent Exchange
co-chair at El
Camino Health*



Kristy Love
*Executive
Director,
National
Perinatal
Association*



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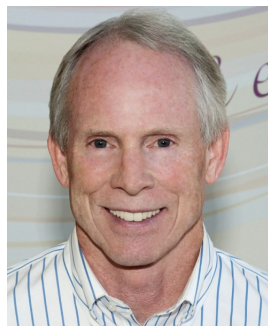
Planning Committee Mentors



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Dharshi Sivakumar MD,
Medical Director, El Camino Health, Clinical Professor, Stanford School of Medicine, CA



Robert White MD,
Director, Regional Newborn Program, Beacon Children's Hospital, South Bend, IN



Joy V. Browne, Ph.D., PCNS, IMH-E,
Clinical Professor of Pediatrics, University of Colorado School of Medicine, CO

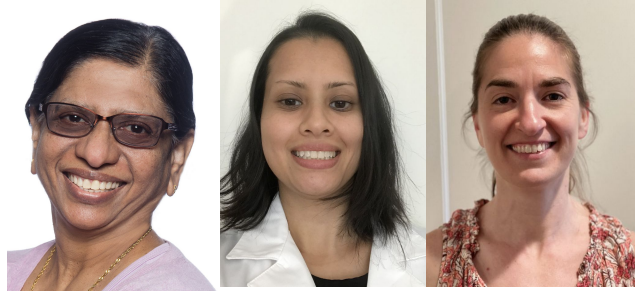


Michael Dunn MD, FRCPC,
Professor, Department of Pediatrics, University of Toronto, Sunnybrooks Health Sciences



Timothy Palmer MD, FAAP
Attending Neonatologist, Assistant Professor, Penn state University

Small Cohort Leaders



Group 1:

Kerri Z. Machut, MD, Assistant Professor, Feinberg School of Medicine, Northwestern University, Attending Neonatologist, Ann & Robert H.Lurie Children's Hospital of Chicago

Jessica Fry, MD, Assistant Professor, Feinberg School of Medicine, Northwestern University, Attending Neonatologist, Ann & Robert H.Lurie Children's Hospital of Chicago

Group 2:

Dharshi Sivakumar MD, Clinical Professor, Stanford School of Medicine, Medical Director, El Camino Health NICU, CA

Vargabi Ghei MD, Attending Neonatologist, HCA East Florida Northwest Medical Center

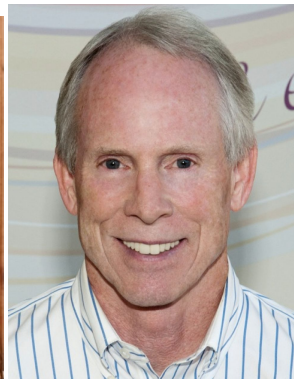
Katherine Huber - Family Partner

Group 3:

Colby Day, MD, Assistant Professor of Neonatology, University of Rochester Medical Center

Daphna Barbeau MD, Attending Neonatologist, HCA University hospital, Davia

Small Cohort Leaders



Group 4:

Jessica Davidson MD, Assistant Professor, Division of Neonatology, Medical Director Intermountain Medical Center Neonatal ICU

Timothy Palmer MD, Attending Neonatologist, Assistant Professor, Penn state University

Group 5:

Robert White MD, Director, Regional Newborn Program, Beacon Children's Hospital, South Bend, IN

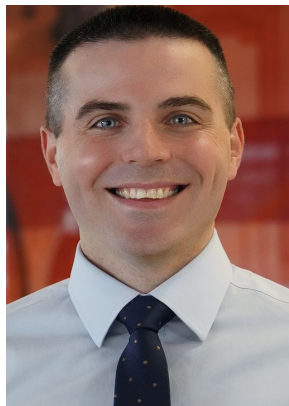
Malathi Balasundaram MD, Clinical Associate Professor, Stanford School of Medicine

Keira Sorrells, Michelle Wrench - Family Partners

QI mentors



Wendy Timpson, MD
Attending Neonatologist
Beth Israel Deaconess
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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Invited Faculty Speakers



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Vincent Smith, MD - Boston Medical Center

Mary Coughlin, MS, NNP, RNC-E - Caring Essentials
Collaborative, LLC

Bobbi Pineda, PhD - University of Southern California

Meg Parker, MD - Boston Medical Center

Jochen Profit, MD - Stanford School of Medicine



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FCC Newsletter Group



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Monthly newsletter - Focus on FCC publications, Pearls from
Family Partners

Vargabi Ghei

Malathi Balasundaram

Colby Day

Robert White

Daphna Barbeau

Family Partners



Learned from Family Partners

From “Parent Advisors” to “Family Partners”

- 1) Family: we moved away from *parent* to family to be more inclusive of the different types of caregivers, (this came up after the many efforts done on NAS nationwide) including grandparents, aunts, uncles, or older siblings, as well as surrogates and LGBTQ+ couples;
- 2) Partners: we have moved from just having a passive voice *advising* to partnering, which means having equal weight and role as team members and informing the co-design of a specific project (QI, research, etc)

From “NICU Graduates” to “NICU Children/Child”

More inclusive of “bereaved” families.

We aim to include the child/children who is/are no longer physically here with us but who continue to bring profound joy, influence, and meaning to their parent’s lives every day.

From calling NICU families/parents “visitors” to “essential caregivers”



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Flyer

Logo



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Dr. Daphna Barbeau

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FOR THE FIRST FAMILY CENTERED CARE TASKFORCE WEBINAR

Thursday, May 12th 11-12:30 PM PST (2-3:30 PM EST)!
[Zoom Link](#) Password: 983240

Featuring:

1. "Early Life Adversity in the NICU – the Critical role of Family Centered Care" by Mary Coughlin
2. Family partner panel

SPEAKER: MARY COUGHLIN MS, NNP, RNC-E



Mary is a global leader in neonatal nursing and has pioneered the concept of trauma informed, developmental care as a biologically relevant paradigm for babies, children and families

FAMILY PARTNERS:



Molly Fraust-Wylie
NICU Family Program,
Manager at BIDMC,
Board Advisor for Project
Sweet Peas,
Chair of NeoQIC Family
Advisory Leadership Committee
NICU Child: Max



Nicole McRae,
Vice President of
GloPreemies,
Executive Director of
Free2Read Education
Recovery Services
NICU Child: Ahmaari



Katherine Huber
Family Advisory Board at
El Camino Health
NICU Children: Finn &
Ethan



Keira Sorrells
Executive Director
NICU Parent Network
NICU Children: Zoe,
Avery & Lily



Lelis Vernon, S.Q.I.L
Healthcare Consultant
NICU Children:
Charlie & Bobby



Marybeth Fry, M.Ed
NICU Family Care
Coordinator
Akron Children's Hospital,
Lead Family Faculty
NICU/JNICU,
Vermont Oxford Network
NICU Child: Sophia

Kavya -
8th grader



Demographics of FCC Taskforce Members



AAP NICU level/designation	Taskforce Member Numbers (self-reported)
3	21 (64%)
4	12 (36%)
Number of beds in your unit	
<10	1 (3%)
11-40	11 (35%)
41-60	7 (23%)
61-90	8 (26%)
>100	4 (13%)



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Trainees in your unit	Taskforce Member Numbers
Yes	17 (55%)
No	14 (45%)
APPs in your unit	
Yes	26 (84%)
No	5 (16%)
Number of neos in your unit	
<10	16 (52%)
11-15	5 (16%)
16-20	2 (6%)
21-30	6 (19%)
>30	2 (6%)



Demographics of Taskforce Members



FCC Committee currently exists in your unit?	Taskforce Member Numbers (self-reported)
Yes	17 (55%)
No	14 (45%)
FAC Committee currently exists in your hospital?	
Yes	14 (45%)
No	17 (55%)



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Participating Centers 32 - Total 20 states and 1 international center



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HCA University Hospital Davia, Florida
Cincinnati Children's Hospital, Ohio
University of south Alabama children's and women's
hospital, Alabama
Hospital University of Pennsylvania, Pennsylvania
Penn State Hershey Children's Hospital, Pennsylvania
Intermountain Med center, Utah, Utah
Bronson Children's Hospital Kalamazoo MI,
Michigan
Beth Israel Deaconess Medical Center, Massachusetts
Banner Gateway Medical Center, AZ, Arizona
Tel Aviv Medical Center, Tel Aviv, Israel, N/A Israel
HCA Houston Healthcare Clear Lake, Texas
Henrico Doctors' Hospital, Richmond, VA, Virginia
Beacon Children's hospital, Indiana
Valley Children's Healthcare , CA, California
Children's Hospital of the King's Daughters in
Norfolk, Virginia

Health Fairview Masonic Children's Hospital, Minnesota
Staten Island University Hospital ,New York
University of Texas Medical Branch, Texas
Lurie Children's hospital Chicago, Illinois
Vanderbilt, Tennessee
Northwell (CCMC & NSUH), New York
University at Buffalo, Oishei Children's hospital, New York
Medical Center Alliance, Texas
John Muir Walnut Creek, California
Stanford/ El Camino Hospital, California
HCA East Florida Northwest Medical Center , Florida
Avera McKennan Hospital, South Dakota
Oklahoma Children's hospital, OUHSC, Oklahoma
University of Kentucky, Lexington, KY, Kentucky
University of Rochester , New York
WVU Medicine Children's, Morgantown WV3, West Virginia
Sharp Mary Birch, San Diego, CA



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Phase 2:

May 2022- May 2023: Program Initiation



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1. To create networking opportunities for NICUs interested in family centered care
2. To educate on the importance of family integration in the NICU (Webinars given by family partners and by faculty)
3. To facilitate the creation of Family Centered Care Committees/Family Partnership Councils (FPC) at hospitals around the country/world (32 centers from 20 states and 1 international center) as a multi-center QI initiative



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Upcoming Educational Sessions/Webinars



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1. May 12th, 11-12:30 PM PST - Inaugural first webinar!! **Early Life Adversity in the NICU - The Critical Role of FCC by Mary Coughlin. “Why is it important to provide FCC in the NICU; Pearls from Family Partners”** Lelis Vernon, Katherine Huber, Keira Sorrells, Marybeth Fry, Molly Wylie, Necole McRae
2. July 14th, 11-12:30 PM PST- **Why is it important to provide FCC in the NICU; Pearls from Family Partners II”** Nicholas Hall, Kristy Love, Michelle Wrench, Meegan Snyder, Kimberly Novod, Mike Hynan **How to provide FCC in the NICU?**
– Few units examples Dharshi Sivakumar & Malathi Balasundaram from El Camino Health; Jessica Fry & Kerri Machut from Lurie Children’s Hospital



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Upcoming Educational Sessions/Webinars



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3. Sep 15th, 11-12:30 PM PST- **How to build Family Partnership Council in your local NICU?** – Molly Wylie from Beth Israel, Marybeth Fry from Akron’s Children, Jennifer Johnson from U.Rochester NY

4. Nov 10th, 11-12:30 PM PST- **The need for more mental health professionals in the NICU** by Dr. Hynan, **Local Parental support** by Dr. Sivakumar & Michelle Wrench **Parental support @ national level** Meegan Snyder & Kiera Sorrells



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Upcoming Educational Sessions/Webinars



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5. Jan 12th, 2023 11-12 :30 PM PST - **How to do family integrated developmental care** by Bobbi Pineda and Joy Browne

6. Mar 16th, 2023 11-12:30 PM PST - **How to provide better home transition for NICU parents?** by Dr. Vincent Smith and Kristy Love-

7. May 11th, 2023 11-12:30 PM PST – **Family engagement and QI** by Meg Parker and Molly Wylie, **How to engage families in QI work** examples - Marybeth Fry, & Lelis Vernon-



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Lead Family Faculty
NICQ/iNICQ,
Vermont Oxford Network

NICU Child: Sophia



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Thank you for joining!



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Please fill out our brief feedback form!

<https://redcap.link/FCCTaskforceFeedback1>

If you are interested in receiving our newsletter and recordings, please join the Taskforce via our feedback form or by emailing Malathi or Colby.

If you are interested in learning from other centers and joining our QI effort, please join our small cohort groups via our feedback form or by emailing Malathi or Colby.

Malathi: malathib@stanford.edu; Colby: colby_richardson@urmc.rochester.edu

Next webinar: July 14th, 11-12:30 PM PST (2-3:30PM EST) - Why is it important to provide FCC in the NICU; Pearls from Family Partners II and How to provide FCC in the NICU?