



FAMILY-CENTERED CARE
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FCC Taskforce

May 2023

Family and QI in the NICU



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FCC Core Team



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Program Manager



Caroline Toney-Noland,
MSc Program Manager,
CPQCC



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

Co-Chairs



Keira Sorrells
Founder &
Executive Director,
NICU Parent Network



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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Agenda



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Taskforce Updates: Dr. Malathi Balasundaram

Speaker Introduction: Dr. Colby Day

Speakers: Dr. Meg Parker & Molly Wylie

Speaker Q&A: Dr. Colby Day

Speaker Introduction: Keira Sorrells

Speakers: Marybeth Fry & Lelis Vernon

Speaker Q&A: Keira Sorrells

Closing: Dr. Malathi Balasundaram



Organizational Partners



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NICU PARENT NETWORK

American Academy
of Pediatrics



DEDICATED TO THE HEALTH OF ALL CHILDREN®

Section on Neonatal Perinatal Medicine



california perinatal
quality care collaborative



Perinatal Advisory Council:
Leadership, Advocacy and Consultation

NEONATOLOGY TODAY

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



National
Association of
Neonatal
Nurses



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Acknowledgement

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&

Partially by “Prolacta Bioscience Foundation”

&

Gravens Luncheon session supported by independent educational grant by
Chiesi USA, Inc



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Small Groups



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Five small groups of 34 centers

Meeting regularly to help centers form active FCC/FPC in their local units

Next meeting for Group one June 8th

Group 2 May 15th

Group 3 May 17th

Group 4 May 17th

Group 5 on May 18th



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FCC TaskForce Committees



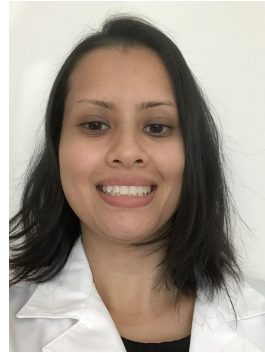
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Communication & Marketing Chair



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

Newsletter Committee Chair



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

Advocacy Committee Chair



Dr. Kerri Machut
*Attending
Neonatologist,
Lurie Children's
Hospital*



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New Executive Council Members



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Family Partners:



Alex Zavala



Dr. Yamille Jackson



Dr. Mia Malcolm

Healthcare Partners:



Luann Jones



Nicole Nyberg



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Executive Council - Family Partners



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Jennifer Canvasser



Lelis Vernon



Elizabeth Simonton



Kimberly Novod



Necole McRae



Nicholas Hall



Molly Faust-Wylie



Michelle Wrench



Betsy Pilon



Dr. Vishal Kapadia



Kathryn Huber



Dr. Yamille Jackson



Meegan Snyder



Kristy Love



Marybeth Fry



Dr. Mia Malcolm



Alex Zavala



Morgan Kowalski



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Executive Council Health Care Partners



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Dr. Dharshi Sivakumar



Dr. Bob White



Dr. Daphna Barbeau



Dr. Emily Whitesel



Dr. Robert Cicco



Dr. Kerri Machut



Dr. Jessica Fry



Dr. Vargabi Ghei



Dr. Henry Lee



Dr. Jeff Meyers



Dr. Tim Palmer



Dr. Joy Browne



Aida Simonian



Lori Gunther



Dr. Mitchell Goldstein



Dr. Jochen Profit



Luann Jones



Nicole Nyberg



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Family-Centered Care Taskforce

Improving family integration in NICU care



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Advocacy Work



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First advocacy effort - "Parents and family caregivers are not visitors"

Dr. Colby Day, Dr Kerri Machut, and Nicole Nyberg spearheading this effort

Acknowledgement - Dr. Munish Gupta and Dr. Lily Lo for their review and support from SONPM

We will share next steps and the outcome to all members as soon as available for your support

Resolution #	2023 Annual Leadership Forum
TITLE:	Parents and Family Caregivers are Not Visitors
SPONSORED BY:	Section on Neonatal-Perinatal Medicine
DATE:	March 31, 2023
DISPOSITION:	
Whereas,	consistent presence and engagement of parents or primary guardians, herein referred to as family caregivers, in neonatal and pediatric clinical settings positively impacts the child's overall health and long-term outcomes.
Whereas,	family caregivers who are actively involved in their child's care and shared decision-making have increased confidence, decreased stress, and improvement in the transition of clinical caretaking to the home environment.
Whereas,	during the COVID-19 pandemic, children and family caregivers were unnaturally separated from one another due to visitation restrictions since family caregivers were considered "visitors" rather than essential care team members.
RESOLVED,	that the American Academy of Pediatrics (AAP) recognize family caregivers as valued contributors to their child's health, declare family caregivers as parents, not visitors, and ensure children and family caregivers are not separated in clinical settings (while following appropriate infection control guidelines).
RESOLVED,	The AAP commits to this in the form of policy statements, recommended guidelines for care, and advocates for legislation for family caregiver rights in the healthcare system.



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FCC at PAS

Family Centered Care - State of Play

Speaker: Desiree Collins Bradley – ATW Health Solutions

Disparities and Family Centered Care - Opportunities and Pitfalls

Speaker: Alex Zavala – The NICU Dad

Family Centered Care - A Vision for the Future

Speaker: Lelis Vernon, SQIL – Stanford University School of Medicine

Barriers and Potential Solutions to Family Centered Care

Speaker: Jennifer M. Canvasser, MSW (she/her/hers) – NEC Society

To Improve We Have to Measure

Speaker: Malathi Balasundaram, MD (she/her/hers) – Stanford University School of Medicine





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Family Engagement in QI work:

Speakers:



Meg Parker, MD, MPH

- Academic Chief of Neonatology
- Professor of Pediatrics UMass Chan School of Medicine and UMass Memorial Medical Center
- Improvement Advisor at the Institute of Healthcare Improvement

Pronouns: she/her



Molly Fraust-Wylie

- NICU Family Program Manager at BIDMC
- Board Advisor Project Sweet Peas
- Chair of NeoQIC Family Advisory Leadership Committee

NICU Child: Max
Pronouns: she/her





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Family Engagement Examples at the National Level:

Speakers:



Lelis Vernon S.Q.I.L

- State Family Leader at Florida PQC
- Editorial Board of Pediatrics
- Clinical Advisor, QI Measures Task Force, AAP, SoNPM
- Faculty Family Leader, Vermont Oxford Network.

NICU Children: Charlie & Bobby



Marybeth Fry, M.Ed

- NICU Family Care Coordinator at Akron Children's Hospital
- Lead Family Faculty NICQ/iNICQ, Vermont Oxford Network

NICU Child: Sophia
Pronouns: she/her



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Future Webinars



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July 20

- “The I-Rainbow: A flexible, evidence-based care path for providing developmental care in the NICU” with **Dr. Melissa Scala & Dr. Eilish Byrne**
- “Connecting with families post discharge” with **Dr. Daphna Barbeau**
- “Mental Health Support” with Mammha founder **Ms. Maureen Fura**

September 28

- “Family Integrated Care” with **Dr. Karel O’Brien**
- Small Group Update

November 9

- “Helping Families Cope and the Ethics of FICare” with **Dr. Annie Janvier**
- “Family Integrated Care Interventions May Improve Preterm Infant and Maternal Outcomes Compared with Family-Centered Care in U.S. NICUs” with **Dr. Linda Franck**



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Good bye!! & Good luck!!



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Welcome Morgan



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Morgan Kowalski will be the new Program Manager for the FCC Taskforce beginning in June. She is a proud NICU Mom and has been an active and involved NICU Family Advisor at Golisano Children's Hospital in Rochester, NY NICU for several years. As a Family Partner with both VON and the FCC Taskforce, she will use her experience and expertise to serve the Taskforce well.

Welcome, Morgan!



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**Thank you
&
See you all in July 20th 11-12:30 PM PT**

