

FCC TASKFORCE

NEWSLETTER

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

Mission Statement

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

Newsletter Committee

Chair

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New Website!

Be sure to visit our new website, fctaskforce.org, to view all past and upcoming webinars as well as shared resources.



Follow us on twitter: [@FCCTaskforce](https://twitter.com/FCCTaskforce)

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PARENT INSIGHTS

We were able to support seven small group leaders (SGL) to attend the Gravens Conference to build momentum and facilitate shared learning among FCC Taskforce small groups. The Gravens Conference offers a unique opportunity to connect with other family-centered initiatives around the world and hear how both community organizations and hospitals are improving the NICU environment. Below are thoughts from our SGLs on their takeaways and lessons learned from the conference:

- “Give parents a voice and make it be heard!”
- “Give **agency** to parents in their child’s care.”
- “Providing the highest level of care is helping parents **connect emotionally** with their babies; **bonding is brain-building.**”
- “Babies don’t need anything more than they need their parents.”
- “If parent is at bedside, infant shouldn’t be in bed.”
- “Ensure parental **mental and emotional resources** are being provided and supported.”
- “Facilitate understanding and empathy from caregivers to parents who are **showing up to play the most difficult role in the hospital** and showing up while experiencing immense stress and trauma.”
- “One of the key takeaways was a reaffirmation of the value and importance of family engagement in **decision-making processes** in the NICU. Involving families in the decision-making process has a positive impact on the well-being of the babies, their families, and on staff and the culture of care delivery in the NICU.”
- “Another significant lesson was the importance of **ongoing education and training for healthcare providers** in the NICU. Continuous education and training help healthcare providers engage with families and incorporate their perspectives into innovative, family-centered care plans. There is also a need for ongoing quality improvement initiatives in the NICU with a focus on involving families in the process to ensure that their needs and experiences are **taken into consideration.**”

PARENT INSIGHTS

- “Family Centered Care is not optional or a 'nice thing to do'. It is not too difficult or time consuming. Family Centered Care is about **being human to another human**- it is relating to a family who is suffering and rallying around them to **mitigate that suffering.**” -Keira Sorrells, Founder and Executive Director of NICU Parent Network
- “THIS ISN'T SCIENCE FOR US, THIS IS **LOVE!**” -Kimberly Novod Founder and Executive Director of Saul's Light
- “WE AREN'T SHOWING UP TO WORK. **WE'RE SHOWING UP TO TRAUMA!**” -Mia Malcolm PharmD, mother of 24 weeker
- The people with the most difficult job in the NICU, are the parents.”
-Michelle Wrench, CPQCC Family Advisory Council Chair
- “The only person who outranks everyone else on the team, is the baby.”
-Eric Rideout MD Neonatologist, Intermountain Healthcare St. George UT



Above: Some of the FCC Taskforce Executive Council Family Partners at the Gravens Conference; Right: Dr. Malathi Balasundaram presenting about the Taskforce



WEBINAR REVIEW

In our March 2023 FCC Taskforce Webinar, Dr. Vincent Smith and Kristin Love reviewed the inception of the most recent National Perinatal Association Discharge Guidelines and Dr. Malathi Balasundaram spoke about a quality improvement project at El Camino Health that sought to increase family satisfaction with discharge planning. **The recording and slides are available [here](#)**; thanks for Dr. Vargarbi Ghei for reviewing the content.

Discharge Guidelines

Dr. Smith reviewed the evolution of the discharge guidelines, describing the efforts of various experts and organizations that worked over the course of years to go through several drafts of the guidelines to ensure they include the most up to date evidence. The final guidelines aim to maximize discharge readiness for caregivers. The process of achieving this goal is outlined in the guideline and includes: recommendations for tailoring discharge education, improving the discharge summary, conducting a family and home and needs assessment and most importantly successfully executing the transition and coordination of care. Notably, for many families, Dr. Smith noted this is an area of weakness. To improve transition of care, NICU teams should aim to ensure that NICU families have a medical home after discharge. This would include contact with primary care providers as the infant nears discharge, contacting the family after discharge, assessing parental mental health, and providing community resources as appropriate. Here at [NICU to Home](#), companion website to the guidelines, units can find free resources to help with discharge planning.

The screenshot shows the top portion of the NICU to Home website. At the top, there is a navigation bar with five buttons: "Anticipatory Guidance" (teal), "Family + Home Needs Assessment" (light blue), "Transfer + Coordination of Care" (green), "More" (grey), and "NPA" (dark blue). Below the navigation bar is a light grey banner with the text "SUBSCRIBE for updates" and a bird icon. The main header area features the "NICU to Home" logo on the left and a grid of seven colorful icons on the right. The icons represent various aspects of discharge planning: a hospital building, a person with a heart, a stethoscope, a house with a tree, a person's feet, a person with a speech bubble, and a person with a stethoscope. At the bottom of the header area, there is a dark grey bar with the text "NICU Discharge Preparation and Transition Planning".

WEBINAR REVIEW

Increasing Parent Satisfaction with Discharge Planning ([article](#))

The main goal of the project was to increase discharge related patient satisfaction scores on the Press-Ganey survey from 47 to 70%. The main interventions included creating an e-book with standardized discharge educational content and a corresponding paper discharge teaching checklist completed by nurses. The e-book was later incorporated into the electronic health record (MyChart) allowing parents to check-off items on the Discharge Education Checklist. Ultimately, the Discharge Education Checklist was integrated into the EHR to be started upon admission. Lastly, the group started making follow-up phone calls to families after discharge to assess families' views of the discharge preparation process. The interventions proved impactful as the unit was successful in improving the patient satisfaction with discharge preparation from 47 to 70%. Dr. Balasundaram's work at El Camino NICU shows how starting the discharge process early (at admission) and leveraging technology as a discharge tool can help families feel more prepared for discharge.



Recommendations of the Quarter:

Looking for a NICU Family Leader for your FCC council? Reach out to those who don't look like you to ensure the full breadth of your NICU population is represented. And don't forget about full term NICU families! Aim for a variety of lived experiences.

Have you tried incorporating nature into your units? This can be achieved through windows and natural light, bringing nature indoors, or even including images of nature in your decor. Nature brings a calming effect to healing spaces.

When families leave the NICU, their lifelong journey with a medically fragile/complex child in many ways is just beginning. Intentionally seek out and build relationships with key community partners (beyond the follow-up clinic) that can provide emotional and practical support the families will need for years to come.

Remember, the day an infant passes away is a day few families have planned and none are truly prepared for. It is a day that can not be redone. Does your unit have a comprehensive bereavement program or a community bereavement partner to assist and support families on that day and in the weeks and months that follow?

Connecting with families comes second nature to some and for others, it requires additional training and education. Myperinatalnetwork.org has a full menu of online CE courses focused specifically on equipping you to support the psychosocial needs of maternity care and NICU families. You don't have to do this alone, there are resources and people to support YOU too!