FCC TASKFORCE
MARCH 2024 WEBINAR

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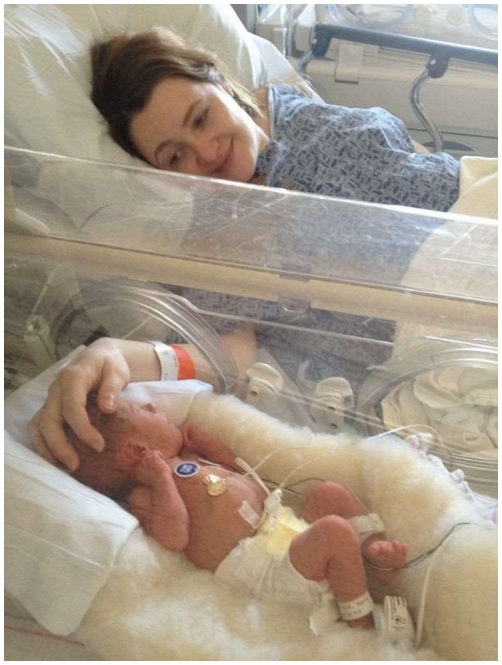
THIS WEBINAR IS DEDICATED TO

MAX OLIVER FRAUST-WYLIE



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"Care for babies like never before"

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All-In Meeting

- → Break down the hierarchy
- → Integrate patient-families
- → Prioritize funds to support patient-families
- → Intentionally elevate the voices of women, diverse groups, and individuals with rare or unique experiences
- → Make it relevant and personal
- → Provide support to disabled individuals during in-person meetings
- → Invest in building relationships
- → Support and include breastfeeding mothers/parents
- → Demonstrate the impact, progress, and opportunities
- → Capitalize on the expertise in the room
- → Remain receptive and responsive to constructive criticism

ALL-IN MEETING

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FCC Taskforce Core Team

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Malathi Balasundaram, MD
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Stanford School of Medicine
Attending Neonatologist &
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El Camino Health, CA

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Founder & Executive
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Program Manager

Morgan Kowalski
Family Partner

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Kerri Machut, MD

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Jochen Profit, MD

Aida Simonian,
MSN, RNC-NIC, SCM, SRN

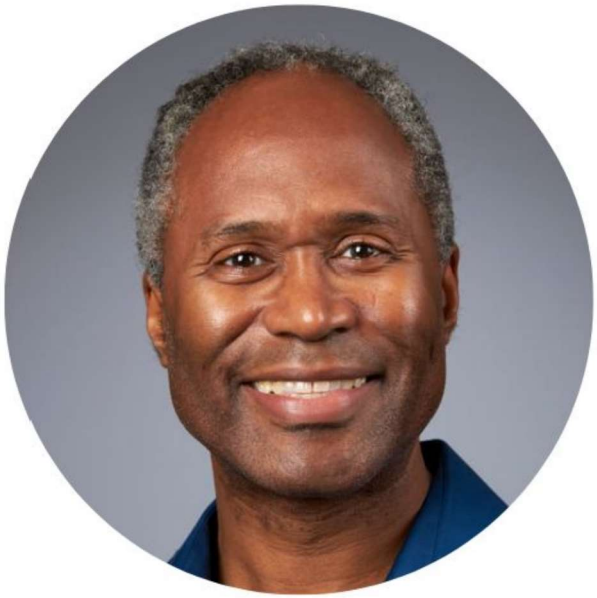
Dharshi Sivakumar, MD

Bob White, MD

Emily Whitesel, MD

Welcome New Executive Council Members!

Kelli Kelley
Founder & CEO, Hand to Hold



Vincent Smith, MD
Division Chief of Newborn Medicine, Boston Medical Center

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Marketing & Communications Committee Co-Chairs

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Director,
High Risk Infant Follow Up Clinic

Alex Zavala, Family Partner

Founder,
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The NICU Dad Podcast
PFAC Chair,
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Family Advisor,
Vermont Oxford Network

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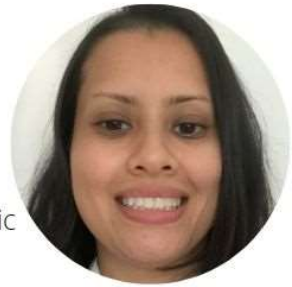

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Neonatal Nurse Practitioner,
Cone Health
Founder,
Empowering NICU Parents &
The Empowering NICU Parents
Podcast

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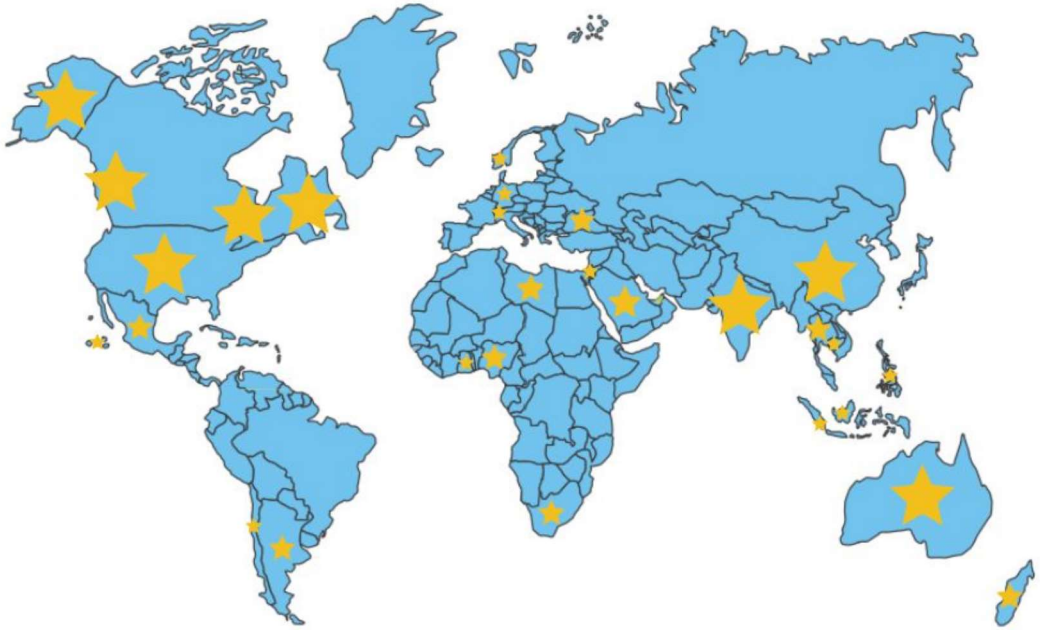
Family-Centered Care Across the Globe!



Over 800 memberss!
43/50 U.S. States
30+ Countries

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February 2024 Poll

Accepting responses now through March 31st!

Typically, centers ask NICU parents to wait 1-1.5 years after discharge to join a Family Advisory Council. Considering this, how long should a family who had a neonatal loss journey wait when they are eager to join?

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March 2024 Poll

Help us understand how your unit includes Family Partners in charting and meetings with families!

We want to know if Family Partners (i.e. former NICU parents who are paid or unpaid and who are assisting in current activities on the unit) are able to use electronic medical records (EMR) to document updates on the current NICU families they are supporting as well as attend meetings with families with healthcare providers, social workers, etc.

All poll responses can be found here!

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FCC Taskforce Office Hours

Join us for Office Hours **Thursday, 3/28 at 9am PT** to with Colby Day, MD and Morgan Kowalski, Family Partner!

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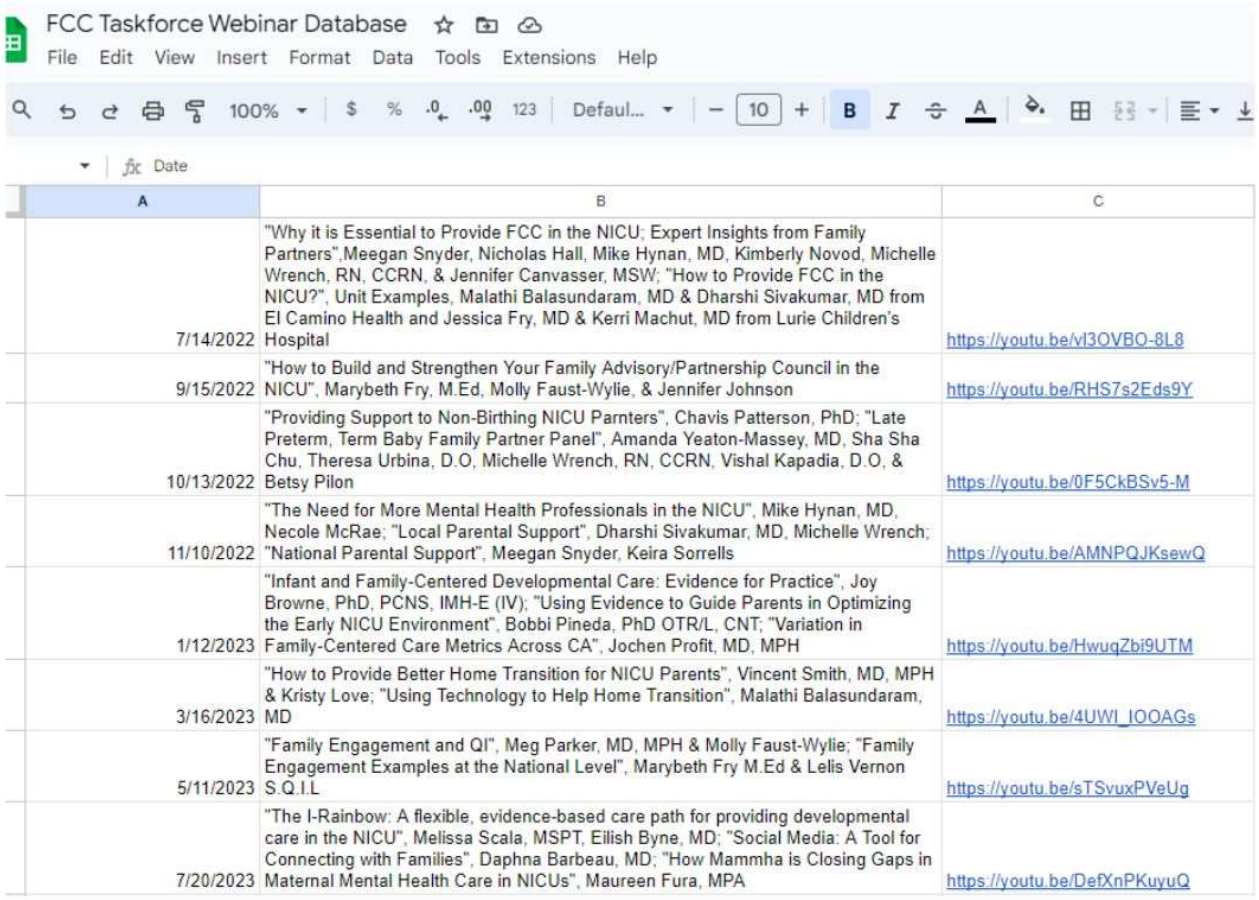
Database of Webinar Recordings & Topics


FCC Taskforce Webinar Database

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Date

A	B	C
7/14/2022	"Why it is Essential to Provide FCC in the NICU; Expert Insights from Family Partners",Meegan Snyder, Nicholas Hall, Mike Hynan, MD, Kimberly Novod, Michelle Wrench, RN, CCRN, & Jennifer Canvasser, MSW; "How to Provide FCC in the NICU?", Unit Examples, Malathi Balasundaram, MD & Dharshi Sivakumar, MD from El Camino Health and Jessica Fry, MD & Kerri Machut, MD from Lurie Children's Hospital	https://youtu.be/vl3OVBO-8L8
9/15/2022	"How to Build and Strengthen Your Family Advisory/Partnership Council in the NICU", Marybeth Fry, M.Ed, Molly Faust-Wylie, & Jennifer Johnson	https://youtu.be/RHS7s2Eds9Y
10/13/2022	"Providing Support to Non-Birthing NICU Parnters", Chavis Patterson, PhD; "Late Preterm, Term Baby Family Partner Panel", Amanda Yeaton-Massey, MD, Sha Sha Chu, Theresa Urbina, D.O, Michelle Wrench, RN, CCRN, Vishal Kapadia, D.O, & Betsy Pilon	https://youtu.be/0F5CkBSv5-M
11/10/2022	"The Need for More Mental Health Professionals in the NICU", Mike Hynan, MD, Necole McRae; "Local Parental Support", Dharshi Sivakumar, MD, Michelle Wrench; "National Parental Support", Meegan Snyder, Keira Sorrells	https://youtu.be/AMNPQJKsewQ
1/12/2023	"Infant and Family-Centered Developmental Care: Evidence for Practice", Joy Browne, PhD, PCNS, IMH-E (IV); "Using Evidence to Guide Parents in Optimizing the Early NICU Environment", Bobbi Pineda, PhD OTR/L, CNT; "Variation in Family-Centered Care Metrics Across CA", Jochen Profit, MD, MPH	https://youtu.be/HwuqZbi9UTM
3/16/2023	"How to Provide Better Home Transition for NICU Parents", Vincent Smith, MD, MPH & Kristy Love; "Using Technology to Help Home Transition", Malathi Balasundaram, MD	https://youtu.be/4UWI_IOOAGs
5/11/2023	"Family Engagement and QI", Meg Parker, MD, MPH & Molly Faust-Wylie; "Family Engagement Examples at the National Level", Marybeth Fry M.Ed & Lelis Vernon S.Q.I.L	https://youtu.be/sTSvuxPVeUg
7/20/2023	"The I-Rainbow: A flexible, evidence-based care path for providing developmental care in the NICU", Melissa Scala, MSPT, Eilish Byne, MD; "Social Media: A Tool for Connecting with Families", Daphna Barbeau, MD; "How Mammha is Closing Gaps in Maternal Mental Health Care in NICUs", Maureen Fura, MPA	https://youtu.be/DefXnPKuyuQ

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FCC TASKFORCE MARCH WEBINAR

3.14.24 @ 11AM PT

IMPROVING SKIN-TO-SKIN AND FAMILY-CENTERED CARE IN A COMMUNITY LEVEL 3 NICU

Tamara Bledsoe, MS, NNP, APRN-BC, C-ONQS
(she/her)
Envision Healthcare

Vargabi Ghei, MD, MSHS
(she/her)
Envision Healthcare, HCA Northwest Hospital

Pamela Torreblanca, RN, Clinical Nurse Coordinator
(she/her)
HCA Northwest Hospital

FAMILY INTEGRATED CARE: FROM PILOT TO PRACTICE IN A BUSY LEVEL 3 NICU

Emily Whitesel, MD
(she/her)
Attending Neonatologist, Beth Israel Deaconess Medical Center (BIDMC)

Molly Fraust-Wylie
(she/her)
NICU Family Program Manager, The Klarman Family NICU, BIDMC
NICU Child: Max

Kathleen Tolland, DNP, RN
(she/her)
NICU Nursing Director, BIDMC

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Initiative to Improve Skin-to-Skin and Family Centered Care at a Community Hospital NICU

Pamela Torreblanca, RN - Clinical Nurse Coordinator at HCA Northwest

Tamara Bledsoe APRN - Director of Quality at Envision Healthcare

Vargabi Ghei, MD MSHS - NICU Medical Director at HCA Northwest

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Envision PHYSICIAN SERVICES

Objectives

Share our experience and journey of increasing skin to skin care in a community hospital NICU

Share our successful and not so successful interventions

Lessons we learned that we want to share with other community-hospital based NICUs

Our NICU

- Main pediatric service located within a medium sized community hospital
- We care for all gestational ages, have sub-specialist availability through telehealth
- NICU Consists of 3 Rooms
  - Two rooms are Open Bay Concept (11 beds)
  - Special Care Nursery (6 beds)
- Average Daily Census 11-12
- Neonatologist in-house 24 hours/day and NNP or PA available 8 hours/day (dayshift)
- Respiratory Therapist in the NICU 24 hours/day

2021-2022 Context/Local Problem

- Limited Caregiver Presence
- Minimal Participation of Parents on Rounds
- Low Rate of Skin-to-Skin Care

Barriers

COVID-19

- Number of caregivers limited at bedside
- Increase in staff turnover and many travelers
- Harder for families to come to NICU due to lack of childcare, worsening socioeconomic barriers

Unit Culture

- No official unit skin-to-skin policy
- Practice variation among different providers and nurses
- Some nurses comfortable with skin-to-skin for patients with umbilical lines, while others were unsure if it was safe

Education

- No staff in-service or training done to teach how to perform skin-to-skin for more complex patients (intubated, with umbilical lines)
- Concerns about healthcare acquired infections

Physical Barriers

- Limited space
- Not enough chairs
- No uniform way to wrap baby on caregiver

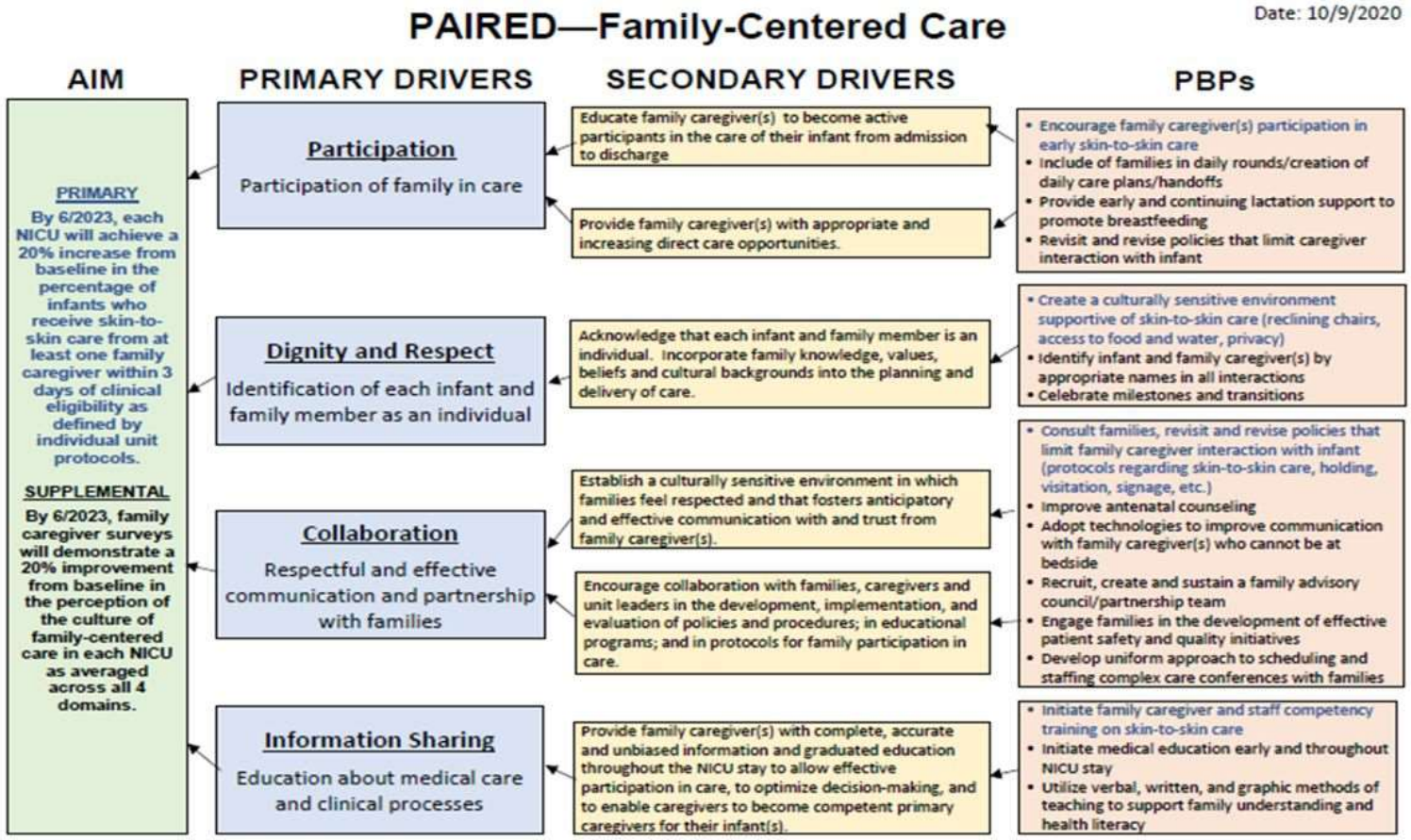
Fears/Anxiety

- We were not sure if it was safe to do skin to skin care for micropreemies
- We were afraid that patients who were intubated would extubate during skin-to-skin care
- We thought that babies were more likely to have events or become hypothermic while doing skin-to-skin care
- We thought that we shouldn't interrupt the babies sleep to perform skin-to-skin care
- We were concerned about the risk of IVH while performing skin-to-skin care

Case # 1

We had a 24 wk baby admitted into the NICU.
He was intubated and had umbilical lines, at the time we didn't offer skin to skin.
Hand hugs weren't something we were teaching parents yet.
Baby was small but stable until day 5 of life and he suddenly decompensated and passed away within 5 hours while mother was not present in the NICU.
Mom was never able to hold or touch skin to skin until after he had already passed.

FPQC PAIRED Initiative Key Driver Diagram



Family-centered care is defined as a shared approach to the planning, delivery, and evaluation of healthcare that is based upon a partnership between healthcare professionals and family caregiver(s). There are four essential domains of FCC: 1) family participation in care, 2) dignity and respect, 3) family collaboration, and 4) information sharing.

Our Goals

Change culture and beliefs around skin-to-skin in the unit to make it the “norm” rather than the exception

Implement processes that supported family centered care

Interdisciplinary Team

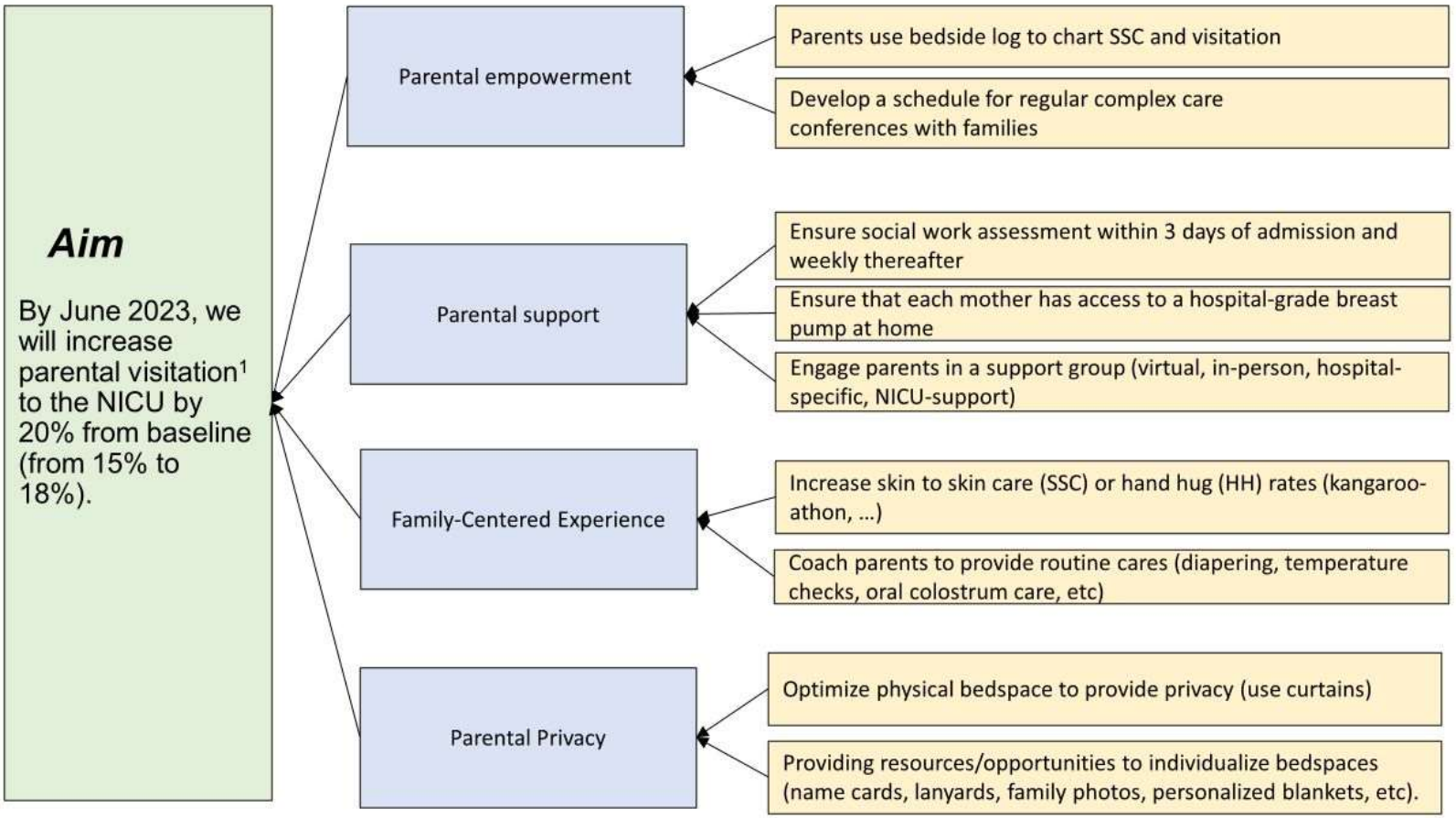
Nursing Champions (3)

Neonatologist Champions (3)

Hospital Leader Champion (1)

Data Champion (1)

Respiratory Therapy Champions (1)

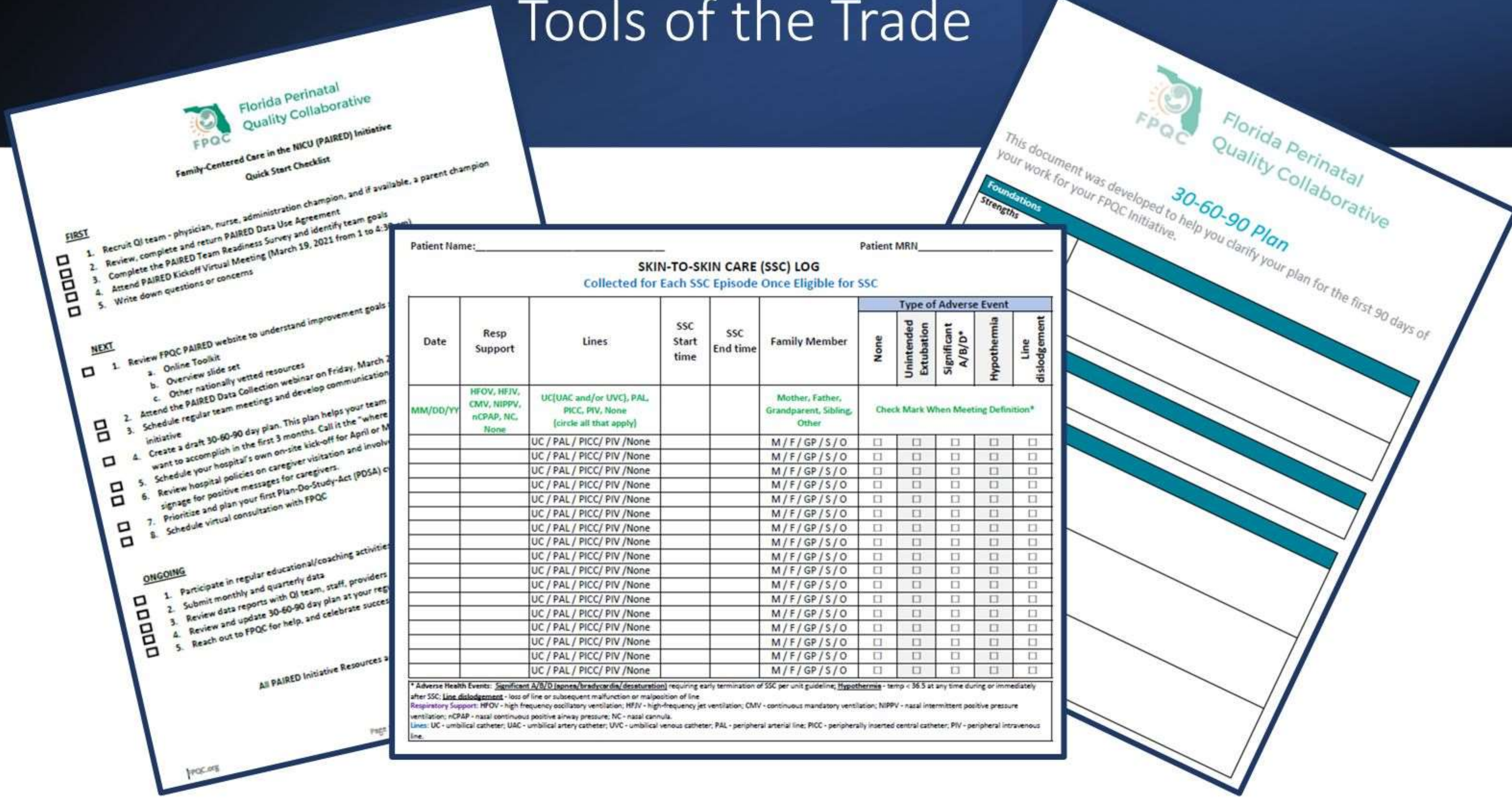


[1] * Any parent or caregiver present in-person in the NICU within a calendar day.

Balancing measure: Percent of adverse events (AE) during SSC (# of adverse events during SSC/# of total SSC events); AE = unplanned extubation and/or dislodged central line

Process Measure: Percent of patients receiving HH or SSC (# of patients receiving either HH or SSC on any given day/total daily NICU census that day)

Tools of the Trade



Patient Name:________________ Patient MRN____________

SKIN-TO-SKIN CARE (SSC) LOG

Collected for Each SSC Episode Once Eligible for SSC

Date	Resp Support	Lines	SSC Start time	SSC End time	Family Member	Type of Adverse Event				
						None	Unintended Extubation	Significant A/B/D*	Hypothermia	Line dislodgement
MM/DD/YY	HFOV, HFJV, CMV, NIPPV, nCPAP, NC, None	UC[UAC and/or UVC], PAL, PICC, PIV, None (circle all that apply)			Mother, Father, Grandparent, Sibling, Other	Check Mark When Meeting Definition*				
		UC / PAL / PICC/ PIV /None			M / F / GP / S / O	☐	☐	☐	☐	☐
		UC / PAL / PICC/ PIV /None			M / F / GP / S / O	☐	☐	☐	☐	☐
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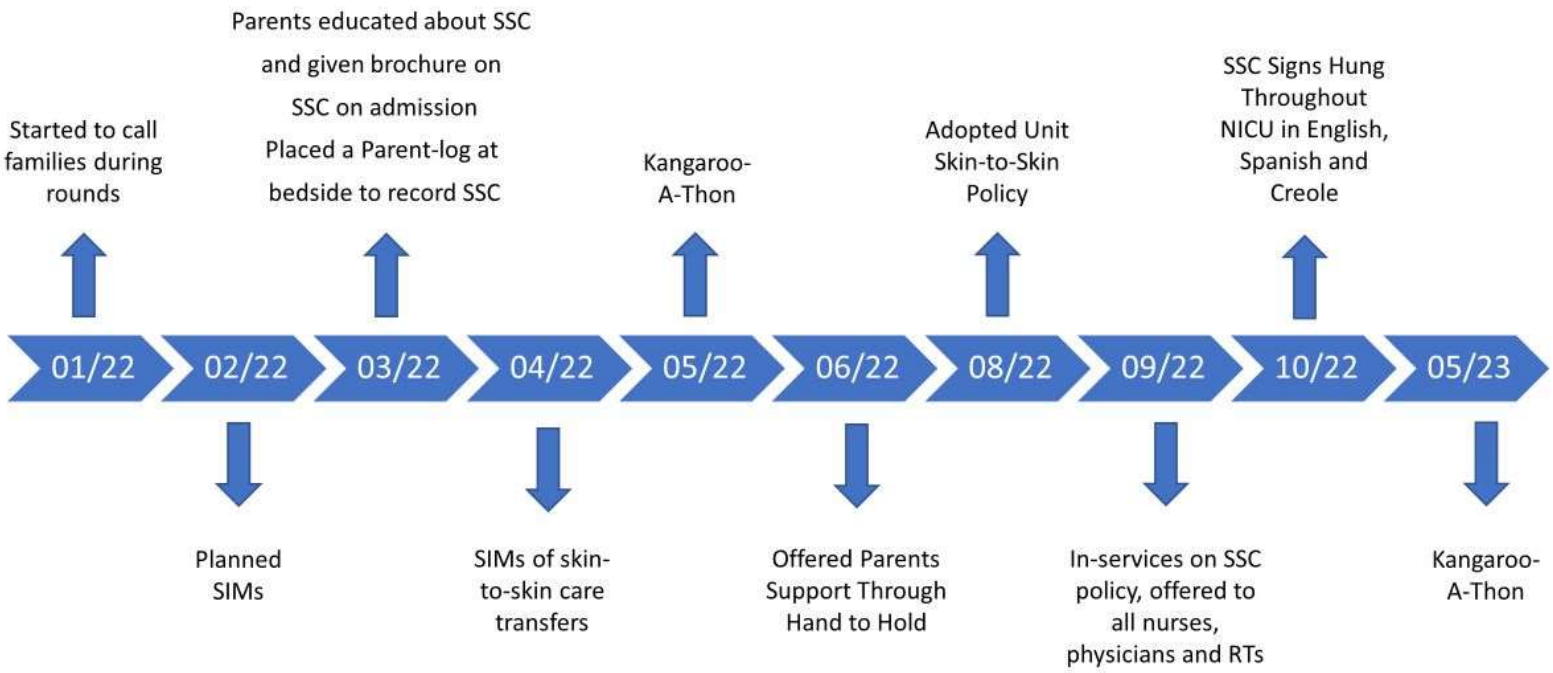
* Adverse Health Events: Significant A/B/D (apnea/bradycardia/desaturation) requiring early termination of SSC per unit guideline; Hypothermia - temp < 36.5 at any time during or immediately after SSC; Line dislodgement - loss of line or subsequent malfunction or malposition of line

Respiratory Support: HFOV - high frequency oscillatory ventilation; HFJV - high-frequency jet ventilation; CMV - continuous mandatory ventilation; NIPPV - nasal intermittent positive pressure ventilation; nCPAP - nasal continuous positive airway pressure; NC - nasal cannula.

Lines: UC - umbilical catheter; UAC - umbilical artery catheter; UVC - umbilical venous catheter; PAL - peripheral arterial line; PICC - peripherally inserted central catheter; PIV - peripheral intravenous line.

Timeline


01/22
Started to call families during rounds
02/22
Planned SIMs
03/22
Parents educated about SSC and given brochure on SSC on admission
Placed a Parent-log at bedside to record SSC
04/22
SIMs of skin-to-skin care transfers
05/22
Kangaroo-A-Thon
06/22
Offered Parents Support Through Hand to Hold
08/22
Adopted Unit Skin-to-Skin Policy
09/22
In-services on SSC policy, offered to all nurses, physicians and RTs
10/22
SSC Signs Hung Throughout NICU in English, Spanish and Creole
05/23
Kangaroo-A-Thon

Simulation

Fear

Confidence

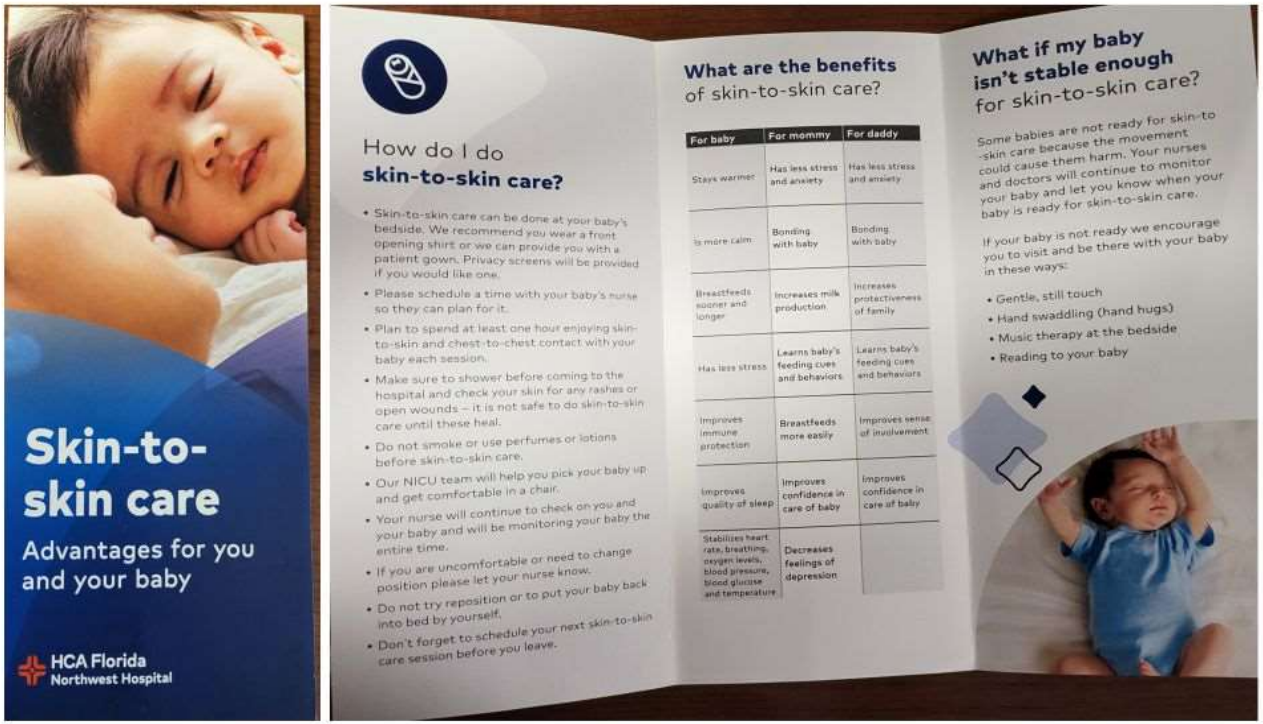
Transferring intubated baby RN/RT to parent

Standing transfer parent with RN/RT assistance

Staff

Families

Caregiver Education



Skin-to-skin care

Advantages for you and your baby

HCA Florida Northwest Hospital

How do I do skin-to-skin care?

- Skin-to-skin care can be done at your baby's bedside. We recommend you wear a front opening shirt or we can provide you with a patient gown. Privacy screens will be provided if you would like one.
- Please schedule a time with your baby's nurse so they can plan for it.
- Plan to spend at least one hour enjoying skin-to-skin and chest-to-chest contact with your baby each session.
- Make sure to shower before coming to the hospital and check your skin for any rashes or open wounds – it is not safe to do skin-to-skin care until these heal.
- Do not smoke or use perfumes or lotions before skin-to-skin care.
- Our NICU team will help you pick your baby up and get comfortable in a chair.
- Your nurse will continue to check on you and your baby and will be monitoring your baby the entire time.
- If you are uncomfortable or need to change position please let your nurse know.
- Do not try reposition or to put your baby back into bed by yourself.
- Don't forget to schedule your next skin-to-skin care session before you leave.

What are the benefits of skin-to-skin care?

For baby	For mommy	For daddy
Stays warmer	Has less stress and anxiety	Has less stress and anxiety
Is more calm	Bonding with baby	Bonding with baby
Breastfeeds sooner and longer	Increases milk production	Increases protectiveness of family
Has less stress	Learns baby's feeding cues and behaviors	Learns baby's feeding cues and behaviors
Improves immune protection	Breastfeeds more easily	Improves sense of involvement
Improves quality of sleep	Improves confidence in care of baby	Improves confidence in care of baby
Stabilizes heart rate, breathing, oxygen levels, blood pressure, blood glucose and temperature	Decreases feelings of depression	

What if my baby isn't stable enough for skin-to-skin care?

Some babies are not ready for skin-to-skin care because the movement could cause them harm. Your nurses and doctors will continue to monitor your baby and let you know when your baby is ready for skin-to-skin care.

If your baby is not ready we encourage you to visit and be there with your baby in these ways:

- Gentle, still touch
- Hand swaddling (hand hugs)
- Music therapy at the bedside
- Reading to your baby

Skin-to-skin Policy

Purpose:
To provide all clinical staff with the criteria and procedure to effectively and safely promote and provide skin-to-skin (STSC) to infants and parents in the neonatal intensive care unit. Skin-to-skin contact between an infant and parent can be used to enhance bonding, lower the infant's oxygen requirements, improve tolerance to feeds, improve tolerance to feeds, improve milk production in breastfeeding mothers, improve weight gain, and shorten length of stay.

Patient Population:
Skin-to-skin Care will be promoted provided to all infants who have maintained cardiopulmonary stability for at least 24 hours. All eligible infants are to participate in STSC within 72 hours of eligibility.

- Exclusion:
  - During first 72-hour Neuro Protection Bundle
  - If infant has humidity in isolette, limit to 1 hour per day.
  - Infants requiring Therapeutic Hypothermia
  - Surgical necrotizing enterocolitis
  - Hypotension with use of vasopressors
  - Chest tube in place
  - Hyperbilirubinemia that is high risk and is unable to be managed with a Bili blanket.
  - Acute or sudden deterioration in clinical condition within the past 24 hours
  - Persistent pulmonary hypertension
  - Arterial lines (Peripheral, and Umbilical, arterial lines)
  - Parents with contagious skin lesions or other communicable diseases
  - Drains
  - Urinary catheter

Exceptions can be made on a case-by-case basis with a physician's order.

Education:
Staff will provide STSC flier as well as verbal and video instructions to parents regarding how to provide Skin-to-skin care for their infant. STSC sessions should be pre-scheduled whenever possible.

Equipment:

- Comfortable, reclining chair.
- Front opening shirt or patient gown for the parent
- Privacy screens as needed.
- Pillow/s
- Warm blankets and hat for infant

Procedure:

1. Provide education to parents.
2. Document the infant's baseline assessment, including vital signs and respiratory support, before initiating Skin-to-skin care. Be aware of the infant's neurobehavioral stability.
3. Perform any necessary procedures that may later interrupt STSC if possible.
4. Ensure RN and a minimum of 1 additional staff member present to assist with infant transfer.
5. Respiratory therapist must be at bedside for all patients requiring respiratory support.
6. Ensure the reclining chair is present and available.
7. Remove infant's clothing except for diaper, socks, and hat.
8. Position parent to perform standing transfer.
9. Assist parent with standing transfer and ensure infant is placed on parent's bare chest between the breasts, upright with head above parent's heart.
10. Assist parent into comfortable sitting position in reclining chair.
11. Upon completion of STSC, RN and RT as needed, will assist parent into standing position assist with transfer of infant into isolette.
12. Schedule next STSC session with parent

Assessment:
Evaluate and document heart rate, respiratory rate, oxygen saturation, temperature, and pain score prior to STSC and 15 minutes after initiation and maintain monitors throughout. Skin-to-skin Care will be performed for a minimum of 60 minutes and can be performed as tolerated by infant or determined by MD/NNP/PA based on patient acuity.

Feeding:
If feeding is due during STSC put infant at breast if appropriate. Place infant near mother's nipple if feeding is being provided via feeding tube or bottle. Assist mother with first breastfeeding as appropriate, once effective latch has been achieved, allow for breastfeeding with STSC.

Documentation:
Nurse is to document STSC session in medical record including start and stop time along with patient response and or adverse events to STSC.
For patients receiving respiratory support, respiratory therapist will document respiratory assessment before and after STSC.

References:
Ludington-Hoe, S.M., PhD, CNM, FAAN, Morgan, K., BSN, CNNP, RN, & Abouelfettoh, A., PhD, RN. (2008). A Clinical Guideline for Implementation of Kangaroo Care with Premature Infants of 30 or more weeks Postmenstrual Age. Advances in Neonatal Care, 8(3S), S3-S23.

Hardin, J.S., Jones, N.A., Mize, K.D., & Platt, M. (2020). Parent-Training with Kangaroo Care Impacts Infant Neurophysiological Development & Mother-Infant Neuroendocrine Activity. Infant behavior & Development. DOI: 10.1016/j infbeh 2019 101416.

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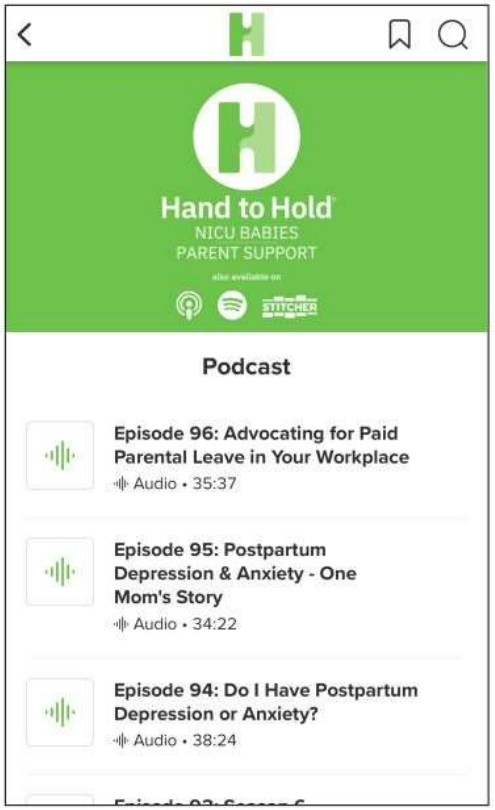
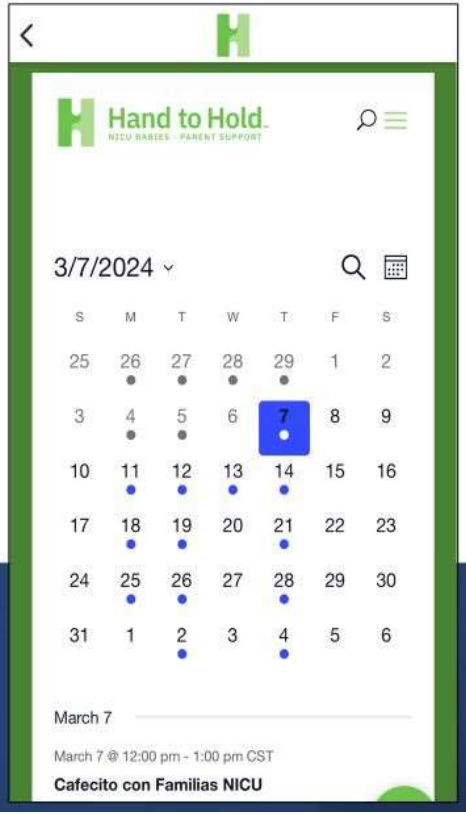
NICU BABIES · PARENT SUPPORT

https://handtohold.org/

The Hand to Hold mobile app provides convenience, compassion and connection to help support NICU parents' emotional needs during their journey. "Creating a mobile app is essential to help eliminate barriers to support for all NICU parents," said Kelli Kelley, Hand to Hold Founder and CEO and NICU parent.





Signage

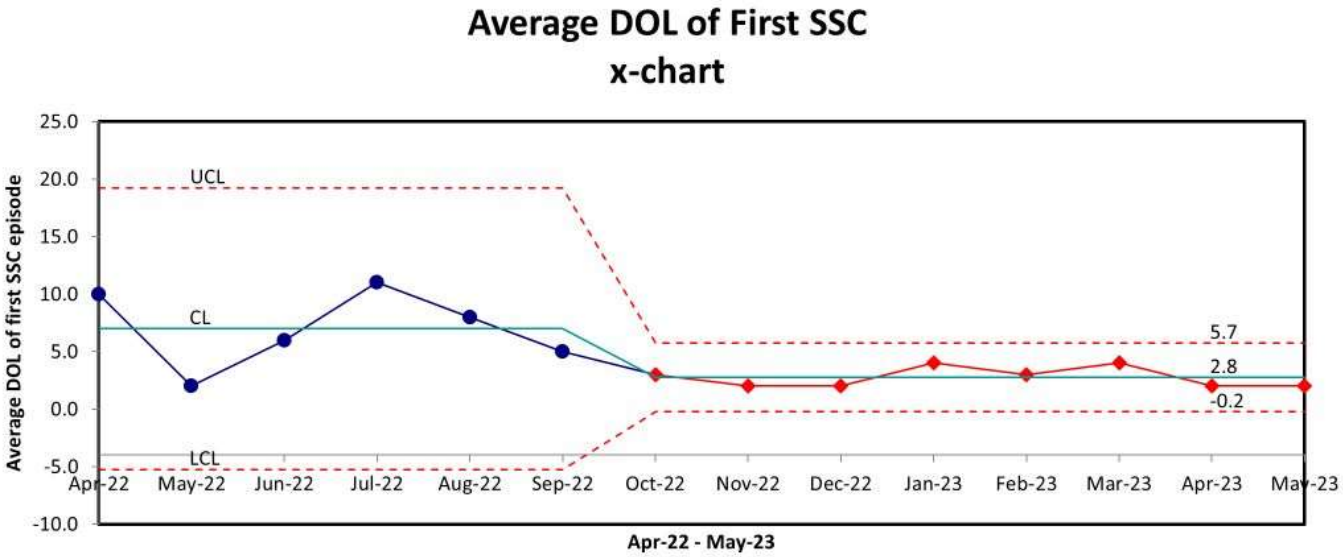
English

Spanish

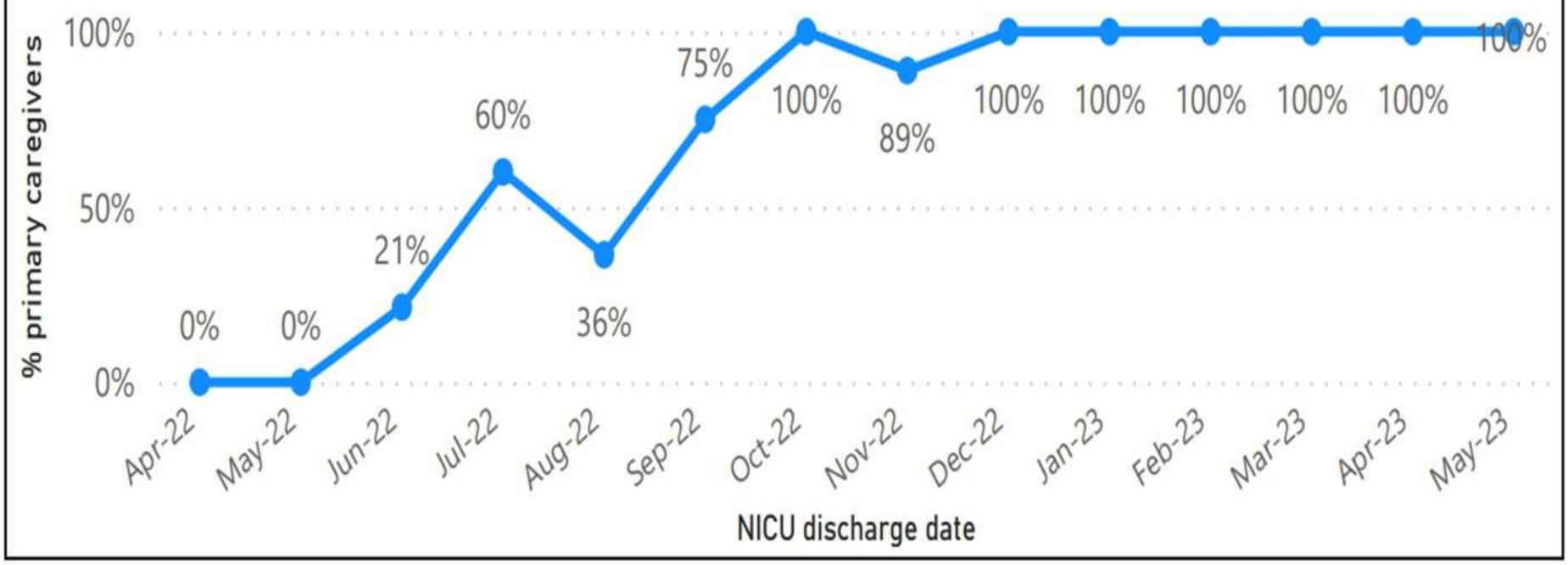
Creole

Results

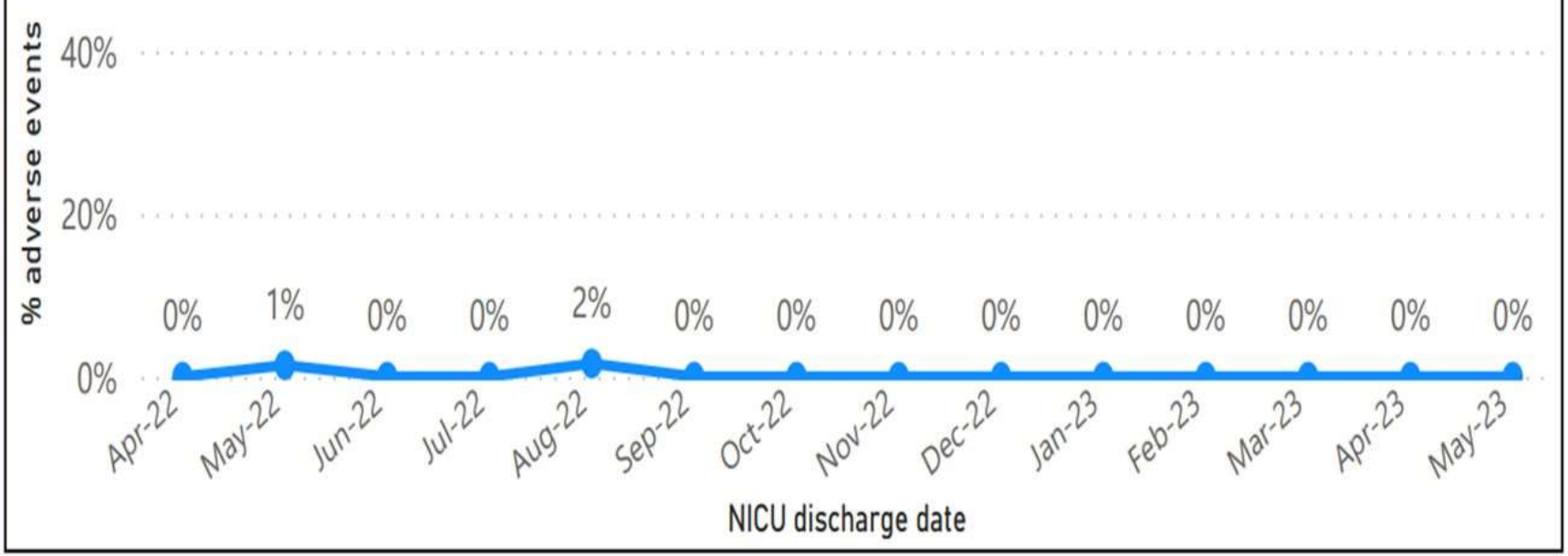
Decrease in Average DOL of First SSC from DOL 7 to DOL 2.8

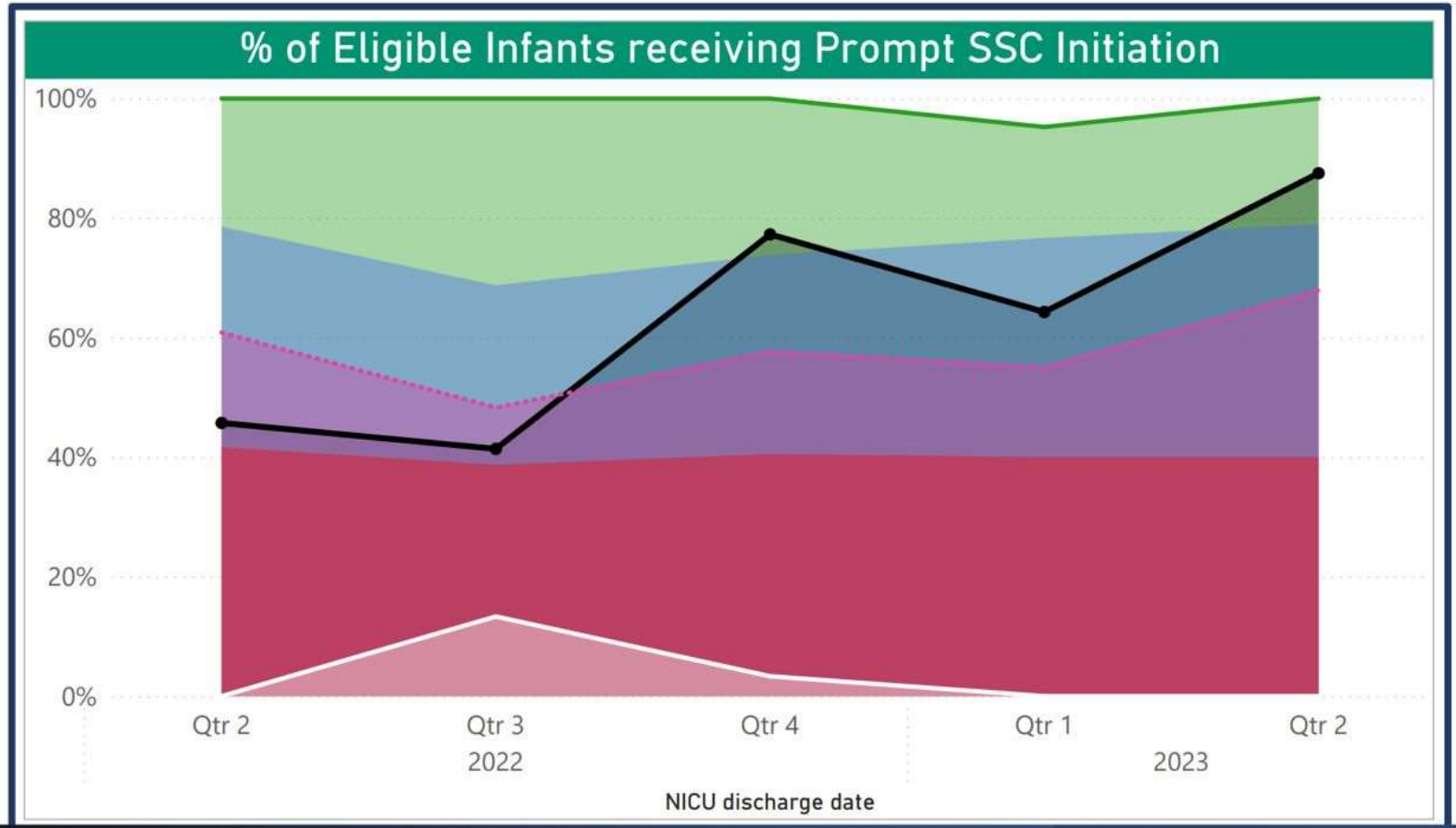


SSC education



Total unplanned adverse events




% of Eligible Infants receiving Prompt SSC Initiation
100%
80%
60%
40%
20%
0%
Qtr 2
Qtr 3
2022
Qtr 4
Qtr 1
2023
Qtr 2
NICU discharge date

Case # 2

Mommy came in every day and night, at first did lots of Hand Hugs because baby was unstable and couldn't be held. Once baby was stable enough, mom and dad got a chance to give STSC. This helped so much with bonding and EBM production. It helped baby to grow and be weaned off respiratory support right on target. The only thing that prolonged his stay a little was bottle feeding. Mom kept producing lots of EBM until after he went home.

Quotes from staff

"It is not unusual for patients who are intubated to do SSC with parents" Peter Voltaire, RT

"We include parents more in shared-decision making after the PAIRED initiative" Dr. Aviles-Medina, Physician Champion

“Having an official Skin-to-Skin Policy is great because we can refer to it easily if anyone has any questions,” Amy Cleveland, NICU Nurse

"Parents are asking for SSC more often because we educate them more about it." Ericka Laurent, NICU Nurse

“Parents feel a deep sense of comfort when they’re able to do skin-to-skin with their baby,“ Whitney Sager, NICU Nurse

Conclusions

- Over the course of a year, we were able to improve the prompt initiation of SSC from an average of DOL 7 to an average of DOL 2.8
- Our most impactful interventions were on-going staff education about SSC
- Overall, staff were felt they were more educated about SSC and felt more comfortable offering SSC with infants who were more critical
- During our participation in the PAIRED initiative, our staff also felt that our care became more family centered
- This is only the first step in our journey of making our NICU more family centered and creating a culture of excellence

Future Directions

- Kangaroo-A-Thons!
- In-House Support Programs and Classes for Parents
- Family Advisors

Thank you

FPQC – Sue Bowles

FCC Taskforce (Malathi, Colby and Morgan)

All the PAIRED Initiative Champions at HCA Northwest

Our patients and their families!

HCA Florida Healthcare®

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FAMILY-CENTERED CARE TASKFORCE

www.fcctaskforce.org

Family Integrated Care: From pilot to practice in a busy level 3 NICU

Kathy Tolland, DNP, RN
NICU Nursing Director

Emily Whitesel, MD
Neonatologist
Director Clinical Operations

Molly Fraust-Wylie, MA
NICU Family Program Manager

Beth Israel Lahey Health

Klarman Family NICU

Beth Israel Deaconess Medical Center

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Disclosures

We have nothing to disclose

Learning Objectives

1. Review value of Family Integrated Care

2. How to Create a Family Integrated Care program through collaboration with graduate families and providers

3. Review challenges of adapting family programs within the limitations of our current health care system

Approach to Care

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Beth Israel Deaconess Medical Center (BIDMC)

- 63 level III NICU in large academic center
- 1,100 NICU admissions per year
- Growing Network
- Full subspecialty support by adjacent children's hospital

Family Integrated Care: Overview

- The Neonatal Intensive Care Unit (NICU) is a highly technical healthcare environment designed to support preterm and term newborn infants.

- Despite efforts to encourage family-centered care, parents continue to report anxiety, depression, and a feeling of being unprepared for discharge.

- Family Integrated Care is a model that incorporates families as equal partners in the NICU care team

Family Integrated Care: Evidence

The purpose of this program is to create a philosophy that places families at the center of their infant's care. Nurses are coaches, promoting family-infant interactions.

This program has been shown to:

- Improve caregiver confidence and preparedness at time of discharge.
- Decrease caregiver stress and anxiety.
- Improve communication with medical team.
- Decrease the length of stay in the NICU.
- Improve average daily weight gain
- Increase breastfeeding and breast milk at discharge.

Family Integrated Care: Goals

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- To fully integrate parents into the care team
- To facilitate partnership and collaboration between parents and nursing staff
- Nurses as coaches and educators
- To promote parent-infant interactions
- To build parent confidence
- To decrease parental stress and anxiety

BIDMC was awarded an Innovation Grant to develop a family integrated care program for our NICU and determine feasibility in the new Stoneman Special Care Nursery (SCN)

Developing a Pilot Program at BIDMC: Steering Committee

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NICU Nurse Lead: **Jamie Perkins**, Laura Hart, and Kelly Chelofsky

Graduate Family co-leads: **Jamie Bull, Joanne Keith**

NICU Family Program Managers: Molly Fraust-Wylie, Marge Day

Nursing Leadership

- Nursing Director: Kathy Tolland
- Assistant Nursing Directors: Karen Waldo, Jamie Perkins

Attending Neonatologist: Emily Whitesel

Other staff involvement:

- Lactation Consultant: Ellen Cooper, Radka Arnold, and Melissa Machinist
- Occupational Therapy: Erin Macintosh

During our initial phases of planning, our development team has met biweekly to determine how to best pilot family integrated care at the BIDMC NICU.

Family Co-Leads

Hailey Bull
Born at 29 weeks 1 day
2lb 7oz
81 days in the NICU

August Harrison Keith
Born at 33 weeks 6 days
3lbs 15oz
21 days in the NICU

Pilot Program Development

Tool Kit Creation:

- Curriculum for parents
- Newborn Documentation Form
- Adaptation of rounding Guides – parents present on rounds
- Skills checklist
- Nursing vs. Parent responsibility
- Enrollment Form

Staff Education

- MyPath tutorial for nurses
- Audio overview
- Posted documents
- Committee meetings with staff
- 1 on 1 education in the SCN
- Baseline nursing survey

Measures

- IRB Waiver
- Redcap Database

FICare Curriculum

Caring for your baby

Infant Safety

- Whenever positioning your baby back to sleep in their crib, please always ensure the side rails or isolette doors are up and secure.
- Always position your baby back to sleep when developmentally appropriate.
- Never walk away and leave your baby unattended on a raised surface, such as a bath cart or in the crib with the side rail down.
- Please do not silence alarms. Never leave your baby unattended without the proper monitoring in place.
- We encourage you to hold your baby. Please do not hold the baby if you are sleepy, dizzy, or faint.
- Do not ever shake your baby. Please ask someone to help you soothe the baby.

Taking Your Baby's Temperature

CAREGIVER SKILLS CHECKLIST
TIER 1

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Caring for your Baby					
Caregiver Skills	**Date of initial teaching:**	**Date caregiver demonstrated skill:**	**Caregiver initials/date:**	**Caregiver initials/date:**	**Staff initials:**
Infant safety (back to sleep, side rails, alarms)					
I can check my baby's temperature					
I can dress and swaddle my infant					
I can take my baby in and out of crib or isolette while swaddled					
I can change my baby's diaper					
I can do eye, mouth, and neck care					
I can change the bed linen					
I can turn the feeding pump off and disconnect the feeding tube.					
I understand my baby's stress signals (sneezing, finger splaying etc.)					
Medications					
Caregiver Skills	**Date of initial teaching:**	**Date caregiver demonstrated skill:**	**Caregiver initials/date:**	**Caregiver initials/date:**	**Staff initials:**
I know about my baby's medications					
With my nurse, I can administer my baby's medications					

CAREGIVER SKILLS CHECKLIST
TIER 2

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Caring for your baby					
Skills	**Date of initial teaching:**	**Date caregiver demonstrated skill:**	**Caregiver initials/date:**	**Caregiver initials/date:**	**Staff Initial:**
I understand the normal heart rate, respiratory rate, and saturation					
I can change the leads and oxygen saturation probe					
I can recognize spells (apnea, bradycardia, or desaturation)					
I can provide my baby skin to skin care safely					
I can bathe my infant safely					
I can weigh my baby					
I am able to provide tummy time and time in play positions					
I feel comfortable stimulating my baby if necessary					

Beth Israel Lahey Health

CAREGIVER SKILLS CHECKLIST
TIER 3

NG tube feedings					
Caregiver Skills	**Date of initial teaching:**	**Caregiver demonstrated skill:**	**Caregiver initials/date:**	**Caregiver initials/date:**	**Staff Initial:**
OPTIONAL: I can place NG tube properly and check placement of feeding tube		☐ ☐ ☐			
I can draw up feeding into syringe, attach tubing, and connect to infant		☐ ☐ ☐			
I can turn the pump on, program to the proper setting, start feeding, and turn off pump		☐ ☐ ☐			

Introduction to the NICU staff

Attending Neonatologist
Neonatologists are pediatricians who specialize in caring for newborn infants. Neonatologists at BIDMC are members of the Division of Newborn Medicine at Children's Hospital. As faculty of Harvard Medical School, they also teach and conduct research in the field of neonatology. An attending neonatologist is in the hospital 24 hours a day and is responsible for patient care in the NICU/SCN.

Neonatology Fellow
Neonatology fellows are pediatricians who are in advanced training to become neonatologists.

NICU DICTIONARY

This is a list of the most common terms you may hear while your baby is in the NewbornIntensive Care Unit (NICU). Please ask if there is anything you do not understand.

Anemia	Fewer red blood cells than normal. In preemies, anemia cancause breathing problems, low energy, and poor growth. Measured by a hematocrit.
Apnea	A pause in a baby's breathing, often accompanied by a slowheart rate (see "Bradycardia") and a dip in oxygen saturation(see "Oximeter"). Apnea of Prematurity, also referred to as "spells," is common while a baby is premature.
Bilirubin	See Jaundice

Initial Pilot Implementation: June 2019 – February 2020

- Enrollment criteria
  - Participate in feedback sessions
  - Maintain record of learning with the skills checklist and basic documentation
  - Present at bedside for 2 care times (initially 6 hours)
  - Participate in medical rounds when able
  - Provide care to the infant when present:

Data: June 2019 – February 2020

	Family Integrated Care
Number enrolled in pilot	18
Gestational Age, weeks: Median (range – SD)	30.7 (24.4-34.6 +/- 3.01)
Birth Weight, grams: Median (range – SD)	1360 (490-2780 +/- 661)
Birth Weight %ile: Median (range – SD)	50.5 (2-91 +/-28.71)
Female	66.7%
PMA at discharge, weeks: Median (range – SD)	38.2 (35.3-45.4 +/- 2.84)

Trends: Breastfeeding at Discharge

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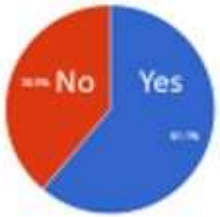
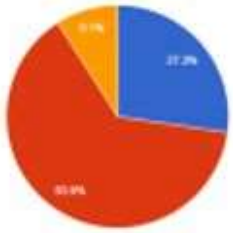
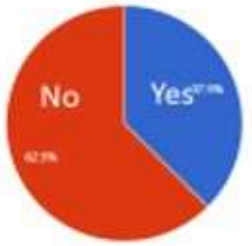
FAMILY INTEGRATED CARE





- Any Breastfeeding at Discharge:
- If Breastfeeding at Discharge, how many times per day:
  - Blue = 1 time/day
  - Red = 2-3 times/day
  - Orange = >3 times/day

ROUNDTINE CARE



Any Breast Milk at Discharge

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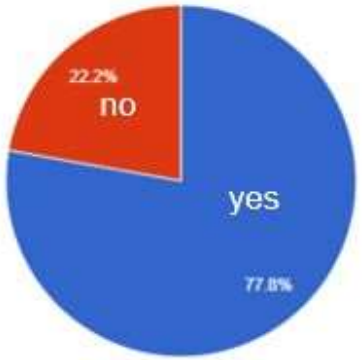
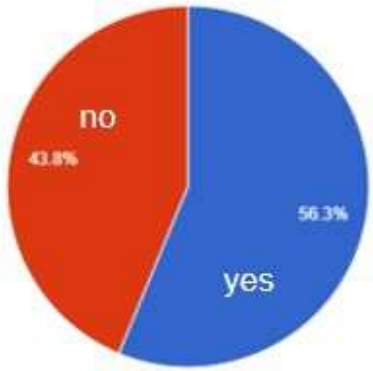
Family Integrated Care



Routine Care



How emotionally prepared is the family to be discharged?

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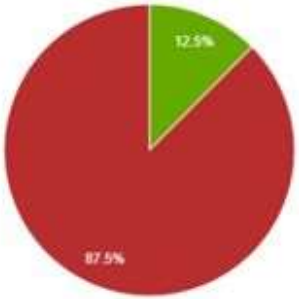
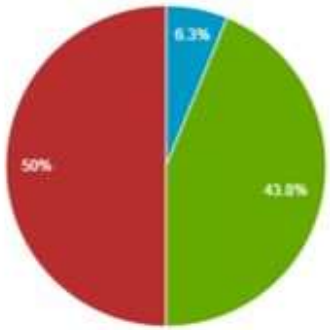
Family Integrated Care



Scale of 1-9
(1=not at all prepared;
9 = very prepared)

- Red = 9
- Green = 8
- Blue = 6

Routine Care



Overall, how technically prepared is the family for discharge

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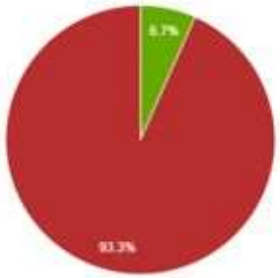
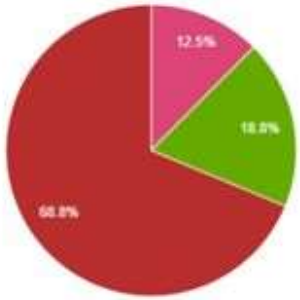
Family Integrated Care



Scale of 1-9
(1=not at all prepared;
9 = very prepared)

- Red = 9
- Green = 8
- Pink = 7

Routine Care



Caregiver Quotes

"Understanding more about everything has made us less nervous and more confident taking care of her."

"Even when we don't know the nurse, it is nice that we can still take the lead and share the responsibilities!"

"Before I felt like a spectator but now I feel like a participant in my baby's care."

"I actually feel like her parent now. When we go to rounds, changes are being made because of things we say. Now, we know what to ask at rounds"

"This program can given parents hope, a sense of empowerment, a sense of control, and, very importantly, confidence. NICU nurses are the superheroes here but us moms like to feel like we wear a piece of the cape too."

Lessons Learned: Program to Approach

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- Binder Documents – too much
- Rounding prompts overwhelming
- Transition from to an approach rather than program:
  - How do you change culture?
  - **Inclusion vs. Exclusion?**

COVID surge --> PAUSE

From Pilot to Standard of Care

- Updated staff education
- Room checklists
  - Caregiver checklist
  - Nurse and Caregiver responsibilities guide
- MyNICU will include updated content to reinforce information for caregivers
- Parent driven rounding sheets
- Content added to orientation and a future skills day
- Offer materials in multiple languages through MyNICU
- All can participate with no time commitment
- Education at the bedside and in person

Parent rounding guide

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Parent Led Rounds

_____ born at _____ weeks,
name

is now _____weeks and _____days. My baby's weight is

now _____, up / down _____grams from yesterday.

I feel the baby is appearing_____

_____

(i.e. well/unwell, comfortable/uncomfortable, alert/sleepy, etc.)

Recent Milestones, Changes, or Challenges

Over the last day / several days_____

_____

(i.e. more/less feeding, more/less diapers, more/less oxygen, losing/gaining weight, sleeping more/less, more/less active, etc.)

Today's Goals:

_____

_____

_____

Today's Questions:

_____

_____

_____

Rounds in the NICU: In the NICU patient rounds occur daily starting in the morning. At rounds, you and your care team will talk about your baby's progress and plan of care.

We value your thoughts and questions. We would like to encourage caregivers to attend rounds. Caregivers play an important role in rounds. Caregivers can attend in person, by phone or by relaying questions to your nurse. Please let your baby's nurse know if you are able to attend and/or present at rounds. The goal is to review the previous 24 hours and your baby's current plan. *Longer conversations will happen at the bedside after rounds.*

Who participates in rounds?

Caregiver: Caregivers are the baby's identified family.

Neonatologist: Neonatologists are pediatricians who specialize in caring for newborn babies.

NICU nurse: The NICU nurse will coordinate with you and the team your baby's care for the day.

Respiratory therapist: Respiratory therapists assist with your baby's care if he/she needs supplemental (extra) oxygen or the assistance of a ventilator.

Nurse practitioner: Nurse Practitioners (NPs) are registered nurses who have received advanced education and training in the care of newborns that work with the Neonatologist to provide care to the babies in the NICU.

Neonatology fellows: Neonatology fellows are pediatricians who are in advanced training to become neonatologists.

Hospitalist: Pediatric hospitalists are pediatricians who work primarily in hospitals. They will be working alongside an attending neonatologist.

NICU Pharmacist: The pharmacists work closely with the NICU care team to ensure the effectiveness and safety of medications.

NICU Dietician: The dieticians work closely with the NICU care team to ensure your baby's optimal nutrition and growth.

Bedside caregiver guide

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Caregiver Responsibilities	Nursing Responsibilities
Skin to Skin	
• Speak to RN about providing skin to skin as often as you would like as tolerated by your baby Practice in accordance with NICU guidelines • Never fall asleep while holding your baby	• Provide education on skin to skin • Assist with infant transfer if needed • Reinforce safe holding practices • Document in medical record
Temperature	
• Check your baby's temperature at the beginning of the care time, right after unwrapping the baby from the swaddle • Report temperature to the nurse	• Educate caregivers • Document in medical record
Spells/Desaturations	
• Recognize a spell • Provide stimulation if necessary • Call a nurse for help if needed	• Assess baby and provide intervention when necessary • Document spells in the medical record
Monitors	
• Reposition ECG leads and oxygen probe • **DO NOT** silence alarms or change alarm limits	• Record vital signs in medical record • Respond to and silence alarms
Bathing	
• Check in with RN and prepare supplies • Make sure water temperature is safe • Remove leads/probe from baby • Never leave your baby alone while off the monitor or in bath • Wash, rinse, and dry baby • Replace leads/probe and swaddle baby	• Educate caregivers on keeping baby warm • Place monitor on standby mode • Assist with bath if necessary • Confirm proper placement of leads/probe • Confirm monitor is on • Document bath in medical record • Plan next bath if appropriate
Feedings	
• Remove milk and warm to appropriate temperature using milk warmer • Verify milk with RN before administration • Confirm amount of milk to be fed to your baby • Place on pump after checking with the RN that the tube is in the proper place • Track milk supply	• Double check name and volume of milk being given to the baby • Verify proper placement of feeding tube • Document in the medical record
Medications	
• Be aware of your baby's medications • Speak with your RN about the purpose of your baby's medications • Administer medications with RN	• Provide education on medication and proper administration • Supervise administration of medications • Document in medical record
Oxygen	
• Adjust nasal cannula prongs • **DO NOT** adjust the oxygen concentration	• Assist with cannula prongs if needed • Adjust oxygen as needed and document

Ways to Engage in Your Baby's Care

Welcome to the NICU. This checklist is used to guide you throughout your NICU stay. This guide identifies ways to engage in your baby's care. Not everyone will check off every box! That is ok! Your care team will teach you skills that you can use to interact with your baby during your NICU stay.

Each day the caregivers and the nurse will discuss the activities for the day using the above list as a guide to support your comfort level in caring for your infant.

	Skills	Ready	Caregiver 1	Caregiver 2
	I can do hand hugs			
	I can do skin to skin care safely			
	I can do eye care, mouth care and neck care			
	I can do colostrum care			
	I can take a temperature			
	I can change my baby's diaper			
	I can recognize and discuss a spell			
	I can give a sponge bath			
	I can change the leads and oxygen saturation probe			
	I can remove milk from the fridge and verify it with the nurse			
	I can use the milk warmer to heat my baby's milk			
	I can draw up a feeding into the syringe, attach tubing, and connect to infant appropriately			
	I can turn the feeding pump off and disconnect the feeding tube when it's finished			
	I can administer medications once the nurse has verified them			
	I have reviewed tummy time			
	I can read / sing to my baby (>32 weeks)			
	I can take my baby in and out of the crib or rocker while swaddled			
	I can bathe my baby safely			
	I can weigh my baby			
	I can give my baby a massage			
	I can dress my baby			
	I can check placement of the feeding tube			
	I can turn the feeding pump on, program it to the proper setting and start the feeding			
	I can mix milk and/or formula at the bedside			
	I can breastfeed and/or bottle my baby independently			
	I can place my baby in stroller and go for a walk			

Beth Israel Lahey Health

Staff Education for expansion of FICare

Beth Israel Deaconess Medical Center

HARVARD MEDICAL SCHOOL TEACHING HOSPITAL

- In 2019, our NICU team at Beth Israel Deaconess Medical Center (BIDMC) piloted the family-centered care model known as Family integrated care (FICare). Family integrated care has been shown to improve family experiences in the NICU.
- A literature review revealed variability in family-centered care models and in the current practice of family-centered care (Bruce & Ritchie, 1997; Franck et al., 2021).
- Studies also identified gaps in staff knowledge and the continued need to define clinician and family roles in family-centered care and the evolving model, family integrated care (FICare).
- Nursing staff stated in surveys, focus groups, and interviews that they required and benefited from further education and understanding of both expectations and role definitions of nurses and families in the FICare model.

Methods

- Data from a FICare pilot program (2019) in the NICU.
- Family centered care questionnaire – revised (FCCQ-R) was answered by staff to assess staff understanding of family centered care.
- Interviews with staff that participated in the pilot program also informed educational modules.
- Education was developed and distributed to clinical staff.
- Surveys and staff educational development took place between January 2022 – May 2022. Education distributed to staff in October 2022.

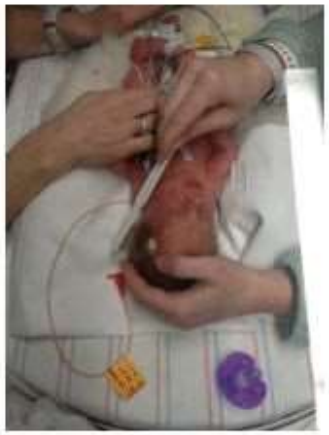
Creating the education

- Program
  - Three educational modules were created:
    - Becoming a NICU parent
    - Family centered care
    - Clinician role in Family integrated care
  - Questions on content and evaluations were included.
  - Goal - 75% of staff finish the education

Module 1 Objectives – Becoming a NICU parent

- Define prenatal and postnatal attachment and bonding
- Transition to parenthood
- Define family experience on entrance to the NICU
- Parenting in the NICU
- Staff involvement and role in attachment and bonding
- Engaging families in infant care
- Introduction to Family Integrated Care

Disconnection From Infant



- The NICU's high technology, physical setting, and intense staff involvement contribute to a feeling that the staff has usurped the parental role, increasing stress for parents and preterm infant.

- A NICU admission creates dependence on other people and the environment that they enter. There are physical barriers between the family and infant, and they are deprived of the expected birth experience.

Families feel detached and uninvolved in their infant's care due to limited opportunities to be with their baby.

The absence of time to interact with and freely touch and cuddle their infant may adversely affect the emerging parent-child relationship.

"They took my little child away from me, and until I saw her the next day, I did not digest the birth. It was a weird situation in a sense. Yes, a delivery, but an artificial one"

Parental Role

Caregiver

- Caregivers feel they can not take care of their infant in the NICU, they feel like outsiders.
- They feel "ambivalent" about parenthood.
- Experience feelings of loss associated with their anticipated experience of parenthood.

Staff role

- Assigning a specific role or task encourages parental role attainment.
- Encouraging the parental role by modelling interactions with infants and increasing parental contact.
- Communicating with caregivers about their infant's status and care.
- Providing contact with infant in a private setting to experience a family connection.

Engaging Families In Infant Care

- Provide moments for bonding and attachment
- Skin to skin holding
- Teaching hand hugs and soothing techniques
- Providing time and space for family and infant to be together
- Communicate with families and follow a family integrated care model where families partner in the care of their infant

Module 2 Objectives– Family Centered Care in the NICU

- Define family and patient centered care
- Principles of family centered care
- History of Family centered care in BIDMC NICU
- BIDMC current state of Family centered care
- BIDMC NICU staff survey result
- Family Integrated Care basics
- Why Family Integrated Care
- BIDMC FICare pilot program results

Current Family Centered Care Strengths

Beth Israel Deaconess Medical Center

HARVARD MEDICAL SCHOOL TEACHING HOSPITAL

Explanations are presented to families using a variety of techniques depending on the individual needs and learning styles of the family.
4.0(±0.87)

Staff maintain familiar routines for each child and family.
4.06(±0.73)

Staff work with families to determine the level of participation in direct care and decision-making that suits the family's needs best.
4.28(±0.69)

Staff encourage parents and siblings to come and go any time that meets the family's needs.
4.27(±0.90)

Staff determine the child's needs in consultation with the family and other health professionals.
4.21(±0.72)

Current Family Centered Care Weaknesses

Beth Israel Deaconess Medical Center

HARVARD MEDICAL SCHOOL TEACHING HOSPITAL

The hospital recognizes and rewards special knowledge and skills that are needed to care for children and families.

2.49(±1.06)

Any family member significantly involved in the child's care is encouraged to discuss or chart information about the care of their child.

3.34(±1.23)

Parents contribute to the development and review of hospital policies and practices.

2.72(±1.01)

Parents and siblings are involved in staff orientation and continuing education programs.

2.34(±1.07)

All written materials for families is available in English and Spanish versions.

3.04(±1.30)

A written summary of relevant information about the child is available in the primary official language of the family.

2.31(±1.26)

What Staff Identified as Needed to Provide Family Centered Care

"Better consistency of care. Families develop trust and gain confidence when they have a consistent team of providers rather than a different person every day."

"Time to educate all staff on the difference between family integrated care and family centered care, and why we are moving towards family centered care for all our patients".

"All discharge and handouts translated in multiple languages especially NG, and O2 teaching. such a struggle for information for non-English speaking families".

"Better services for families that do not speak/read English."

Module 3 Objectives – The NICU clinician role in Family integrated Care

- Outline the Family Integrated Care (FICare) program
- Myths of FICare
- The clinician role in FICare
- The caregiver role in FICare
- The importance of family at rounds
- Challenges with FICare
- Communication strategies
- Embracing the clinical team and family partnership

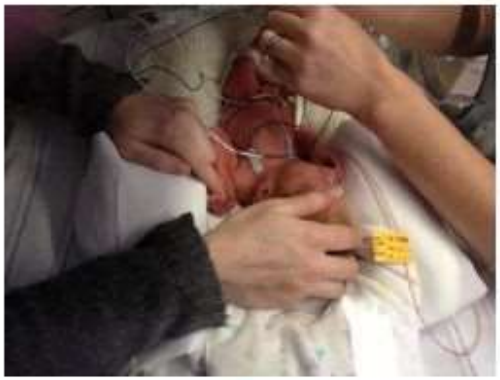
The NICU Clinician Role in FICare

Focus on	Focus on caregiver education and support so that parents provide bedside care to their infant.
Encourage	Encourage caregivers to participate in any education sessions provided in the unit.
Support	Support caregivers in attending and presenting at rounds.
Encourage	Encourage caregivers to partner with the RN when documenting any skill they feel comfortable performing

Myths About FiCare

Myth:

FICare decreases the need for nurses or nursing care.



Truth:

Nursing patient assignments remain the same.

The nurse may focus more time teaching the caregiver.

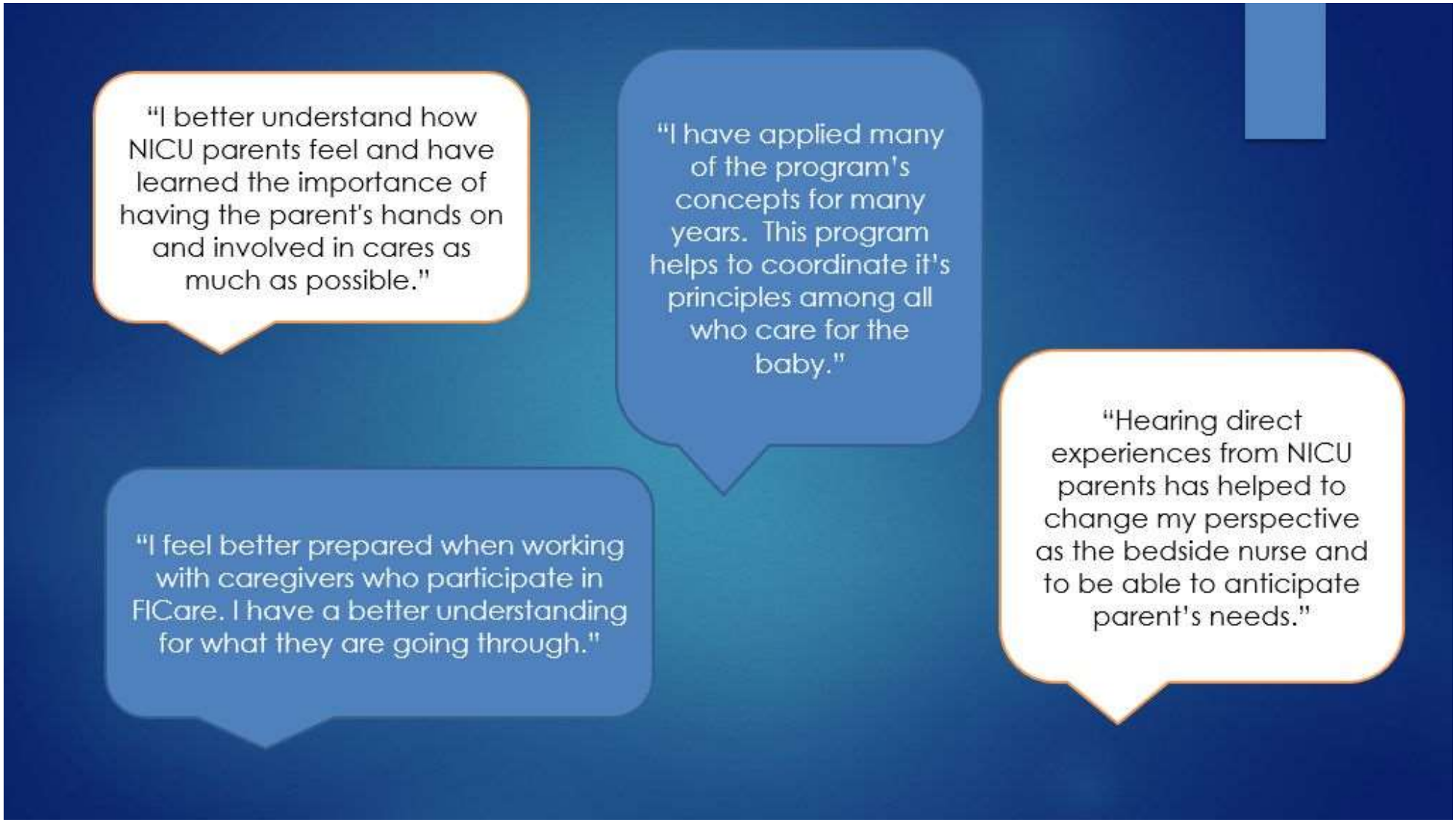
Approaching discharge, the caregiver should be doing most of the infant care.

Caregiver vs Nursing Responsibilities

CAREGIVER RESPONSIBILITIES	NURSE RESPONSIBILITIES
SPELLS / DESATURATIONS	
❖ Recognize a spell ❖ Provide stimulation if necessary ❖ Call a nurse for help if needed	❖ Assess infant and provide intervention when necessary ❖ Explain event to parent ❖ Document in medical record
MONITORS	
❖ Reposition ECG leads and oxygen probe ❖ **DO NOT** silence alarms or change alarm limits	❖ Record vital signs in medical record. ❖ Respond to and silence alarms

Outcomes

- 145(65%) clinical staff completed the staff education modules and answered questions related to the content.
- 93-98% of participants ranked their understanding of the content of all three modules as above average and excellent. The average mean for content evaluation questions was 4.5. (Likert scale)
- 96% of staff answered that they had enough information to change their practice, professional development, or patient outcomes.
- March 2024 update – 198 staff have finished the education. The average mean for content evaluation is 4.4. 94% of staff having enough information to change their practice, professional development, or patient outcomes.


"I better understand how NICU parents feel and have learned the importance of having the parent's hands on and involved in cares as much as possible."
"I have applied many of the program's concepts for many years. This program helps to coordinate it's principles among all who care for the baby."
"Hearing direct experiences from NICU parents has helped to change my perspective as the bedside nurse and to be able to anticipate parent's needs."
"I feel better prepared when working with caregivers who participate in FICare. I have a better understanding for what they are going through."

Current survey

1.Did you complete FICare education? - YES = 100%

2. Have you referred to the skills checklist with families when providing care? Yes = 35%, Sometimes = 44%

3. Would reinstituting the FICare binder help you as a clinician provide Family integrated care? Yes=18%, Maybe, As needed for a family = 70%

4. There is a new guide for families attending rounds. Have you had a family use the guide for rounds? A majority have not used the rounding guide with families.

5. Families that have participated in FICare feel more prepared to be home. Do you feel like we prepare families to be independent before discharge? Yes prepared - 57%, Sometimes – 43%

Where we are and where we are going:

- FICare as a standard approach!
- Working on increasing participation
- Metrics: family satisfaction and discharge readiness
- Translation of materials

Thank you!

Questions?

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Upcoming Webinars

May 9th:

⟶ Family-Team Dynamics in the NICU: How Bias Can Threaten Optimal Communication
Tamorah Lewis, MD, PhD

⟶ Supporting NICU Families
Kelli Kelly, Founder & CEO of Hand to Hold

July 11th:

⟶ Parents as Partners in the NICU
Mia Malcolm, PhD

⟶ Impact of FiCare on Toddler Behavior
Paige Church, MD

September 12th:

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

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

November 14th:

⟶ Title TBD
Rafi Mendelson, MD

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

Subscribe to join at no cost!

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