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Antibiotic treatment of Chorioamnionitis-Exposed Neonates Based Only on Signs of Infection
John Wimmer, MD, Nicole Chandler, MD, Reese Clark, MD, Kaye Gable, MD
.....Page 3

National Perinatal Association 2024 Respiratory Syncytial Virus (RSV) Prevention Clinical Practice Guideline: Clinical Presentation, Prevention Strategies, and Social Impacts in Children: An Evidence-Based Interdisciplinary Collaboration
Mitchell Goldstein, MD, MBA, CML, Benjamin Hopkins, OSMIV, Munaf Kadri, MD, Elba Fayard, MD, Nicole Kraus, DO, Angela Patterson, MD, Melissa Scala, MD, Kristy Love, Cristal Grogan, Colleen Kraft, MD, MBA, Donald Null, MD, T. Allen Merritt, MD, MHA
.....Page 9

15 Trees to Negate the CO2 Effect of Living #15treesformylife
Minesh Khashu MD, MBBS, FRCPCH
.....Page 46

Ethics and Wellness Column: Grit and Wellness in Neonatology: The Path to Leadership and Career Fulfillment
Mitchell Goldstein, MD, MBA, CML, T. Allen Merritt, MD, MHA
.....Page 48

Letter to the Editor: "Prevalence of and Factors Associated with Neonatal Seizures in the United States, 2016-2020"
Grace Ahuja OMS-III, Melissa Kreutz OMS-III, Joshua Hernandez OMS-IV , Mitchell Goldstein, MD
.....Page 52

Navigating Toward Neonatology: Pediatric and Neonatal Seizure Considerations
Benjamin Hopkins, OSMIV, Elba Simon-Fayard, MD
.....Page 56

Fellows Column: Navigating Parental Psychiatric Illness in the NICU
Zeeruk Iqbal, MS4, Saba Saleem, DO, Darakshan Adam, MD
.....Page 62

High-Reliability Organizing Fundamentals: The Distinct Dimension of Time
Daved van Stralen, MD, FAAP; Sean D. McKay, Element Rescue, LLC; Thomas A. Mercer, RAdm, USN (Retired)
.....Page 68

Enhancing Neonatal Care: A Call for Industry-Wide Collaboration
Mitchell Goldstein, MD, MBA, CML, Suzanne Staebler, DNP, NNP-BC
.....Page 80

Collateral Damage: Is the Picture We Present Complete Without Discussing it?
Rob Graham, R.R.T./N.R.C.P.
.....Page 84

Gravens By Design: "Hands-Off" and "Hands-On" Care in the NICU: Can They Coexist and be Mutually Reinforcing in the NICU of the Future?
Robert White, MD
.....Page 99

Fragile Infant Forums for Implementation of IFCDC Standards: Key Cornerstone of Interventions for Pain and Stress in the Baby
Jean Powlesland, MS, RN, C-NNIC
.....Page 106

Neonatology Today Welcomes Carolyn TenEyck, RN as Advocacy Director on its All Volunteer Board
Mita Shah, MD
.....Page 121

40th Advances in Neonatal and Pediatric Cardiorespiratory Care Conference, Hilton Los Angeles North/Glendale, Glendale, CA. January 31 - February 1, 2024, Final Agenda
.....Page 124

CDC Calls for Infants to be Tested for Hepatitis C
Josie Cooper
.....Page 143

iCAN Chronicle: Nurturing Pediatric Voices, Global Insights, and Empowering Initiatives
Sabina Schmidt Goldstein-Becerra
.....Page 148

Briefly Legal: Parents Opt not to Pursue Further Surgical Treatment for their Child's Severe Congenital Heart Disease: A Nurse Threatens to Sue the Hospital, the Neonatologists, and the Parents for Withholding Care
Maureen E Sims, MD, Barry Schifrin, MD
.....Page 159

Medical News, Products & Information
Compiled and Reviewed by Sandeep Lankireddy, BA, OMS3
.....Page 165

Genetics Corner: A Premature Infant with Meconium Peritonitis Inspires an Update on the First Cases of In Utero Therapy for Meconium Ileus Due to Cystic Fibrosis
Robin Dawn Clark, MD
.....Page 179

Reducing Professional Liability in Neonatal Hypoglycemia
Jonathan K Muraskas, MD, Jay P Goldsmith, MD
.....Page 184

NICU Family Centered Care Program in a Safety Net Hospital
Sangeeta Balachandran Mallik, PhD, Dongli Song, MD, PhD, Sudha Rani Narasimhan, MD, Laura Berritto, Rupalee Patel, DNP, MS, BSN, C-PNP, C-PHN, IBCLC Priya Jegatheesan, MD
.....Page 192

Clinical Pearl: Artificial Intelligence, Machine Learning Models in Neonatology: Neonatal Acute Kidney Injury
Joseph R. Hageman, MD, Lolita Alkureishi, MD, Walid Hussain, MD, Mitchell Goldstein, MD, MBA, CML
.....Page 208

Upcoming Meetings
.....Page 215

Subscriptions and Contact Information
.....Page 215

Editorial Board
.....Page 220

Animal and Human Research
.....Page 222

Manuscript Submission
.....Page 222

Neonatology & the Arts
Mita Shah, MD
.....Page 222

Phoenix
Tim Kraft
.....Page 224

Bolsa Chica
Mita Shah, MD
.....Page 225

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Peer Reviewed

NICU Family Centered Care Program in a Safety Net Hospital

Sangeeta Balachandran Mallik, PhD, Dongli Song, MD, PhD, Sudha Rani Narasimhan, MD, Laura Berritto, Rupalee Patel, DNP, MS, BSN, C-PNP, C-PHN, IBCLC Priya Jegatheesan, MD

Introduction:

Family-centered care (FCC) is a critical part of NICU care. Families feel intense stress and anxiety during their infant's stay in the NICU (1–3). Many parents are ill-equipped to handle the adverse experience, which can lead to long-lasting negative impacts on parental well-being and their children's health and development. A family's need to be heard, understood, respected, and supported by NICU staff is the key to establishing a strong partnership between families and the NICU team. Family participation in routine infant care, positive parent-infant interaction, and shared decision-making with NICU staff are shown to decrease parental anxiety and stress levels, as well as later posttraumatic stress disorder (PTSD) (4–6). A supportive and nurturing environment improves the family's overall experience during NICU stay and the family's long-term outcomes, given the manifold early bonding and caring opportunities for families in the NICU with their infants (4, 7–9).

"Family-centered care (FCC) is a critical part of NICU care. Families feel intense stress and anxiety during their infant's stay in the NICU. Many parents are ill-equipped to handle the adverse experience, which can lead to long-lasting negative impacts on parental well-being and their children's health and development."

While increasing evidence has shown the benefits of family-centered and family-integrated care in NICU, establishing and incorporating a sustainable FCC program in routine clinical practice faces many challenges (10). In this paper, we describe how our NICU FCC program, in a safety net hospital, uniquely supports NICU families and how the FCC team, over the years, has become an integral part of the clinical care team, NICU care, and decision-making.

Context: NICU in a Safety Net Hospital Setting:

Santa Clara Valley Medical Center (SCVMC) NICU is an AAP level IV, California regional 40-bed NICU with 300–350 annual NICU admissions housed in a safety net hospital in San Jose, California. Safety net hospitals are committed to providing care for people with limited or no access to healthcare due to socioeconomic circumstances, insurance status, or health conditions. The mission of the Santa Clara County healthcare system is to provide high-quality, accessible healthcare and service to all persons in the county regardless of their socioeconomic status and ability to pay. This healthcare system comprises 3 Hospitals with associated Clinics and supports 20–25% of county births, with approximately 4,500 deliveries annually.

SCVMC FCC Program Development and Growth:

The FCC program journey at SCVMC NICU started in partnership with the March of Dimes program in 2009 when our site became one of their first ten NICU family support sites through a competitive grant application process. The program introduced FCC care into our NICU by providing patient education with a kiosk and staff education. Over the 15 years, the program's focus has been to promote a culture change incorporating FCC in every aspect of NICU care. Since 2012, the FCC program has been supported with extramural funding essential for continuous progress in the FCC and building a team of paid FCC team members in a safety net hospital.

"Since 2009, the FCC program at SCVMC NICU has grown to the current team of three family support specialists (FSS), a family education specialist (FES), and an FCC director (Figure 1)"

The FCC Team:

Since 2009, the FCC program at SCVMC NICU has grown to the current team of three family support specialists (FSS), a family education specialist (FES), and an FCC director (Figure 1).

Family support specialist

Peer support is a powerful tool to support families through a difficult journey in the NICU. NICUs need to address the psychosocial needs of families during their journey in the NICU. Peer support from NICU graduate parents can help mitigate some of the stressors the current NICU parents face after admission, through the hospital stay, and during the transition from the NICU

FAMILY-CENTERED CARE TASKFORCE

Dräger

Figure 1. SCVMC family-centered care program timeline
FCC – family-centered care, SUD – substance use disorder, MAT – medication-assisted treatment.

to home. In this peer support model, the NICU graduate parent shares a similar lived experience with the NICU parent, and the care provided usually involves sharing information/resources, emotional support, and encouragement. Peer support is flexible in its approach, i.e., services can be provided in person, by phone or email, in groups or individually, and in different settings.

"Peer support from NICU graduate parents can help mitigate some of the stressors the current NICU parents face after admission, through the hospital stay, and during the transition from the NICU to home. In this peer support model, the NICU graduate parent shares a similar lived experience with the NICU parent, and the care provided usually involves sharing information/resources, emotional support, and encouragement."

Our selection of FSS was based on the principle that they reflect the patient population served by the NICU. The first FSS is a Hispanic, bilingual, former NICU mother of a 27-week premature infant and a history of fetal loss. She proactively advocated for her daughter during her NICU stay. She helps primarily Spanish-speaking families, accounting for more than 30–50% of our NICU families. The next FSS is a former NICU mother of a 27-week preterm infant with a history of substance use disorder (SUD) who was in recovery at the time of delivery. She supports the NICU mothers with a history of SUD. As part of that support, she shares her lived experience with recovery programs in the county and has also helped NICU mothers tour residential programs in the county. The most recent FSS is a former NICU mother of a 24-week preterm infant. She is a strong advocate for maternal mental health support and supports English-speaking NICU families.

The FSSs support NICU families in many ways (Table 1). Upon admission, FSSs will reach out to families 1-2 days after admission, introduce themselves, and give them a self-care packet, breastmilk bag with icepacks, a NICU stay booklet that outlines caring for the baby in the NICU, coping as a NICU parent, getting ready for discharge etc., skin to skin brochure, and First 5 resource guides. FSSs connect with families in person or by phone once or twice weekly to support ongoing needs. They attend family conferences with the NICU team with the families' consent for their presence. In addition, they provide additional support to families when their babies are critically ill or dying. FSSs administer family satisfaction surveys 7–8 days after the infant is admitted into the NICU and around discharge time.

Furthermore, they often stay in touch with families following NICU discharge on an as-needed basis. They work closely with our home follow-up program and High-Risk Infant Follow-up program team. They reach out to the appropriate program staff to ensure that parental needs are met during NICU stay and after discharge.

Family Education Specialist

The bedside nurses provide education for families and training explicitly related to their infant's care at beside. However, learning in a stressful environment like NICU can be challenging and overwhelming. Based on the brain state model, learning is better when one is not in a survival or emotional state but in the executive state and ready to learn. To overcome this barrier, our designated FES provides individual and group family education and training away from patient care activities to ensure a calm and stress-free learning environment.

The FES is a former bedside nurse with the experience of having a preterm infant. She focuses on reviewing discharge teaching, including baby care and CPR classes. In addition, she facilitates

Table 1. Structure of FCC team and Roles of FSS

Understand our NICU families' needs and learn their strengths and challenges.
Provide peer support for NICU families by sharing their lived experiences.
Encourage families to express their needs, concerns, and suggestions and participate in their babies' care.
Encourage families to do skin-to-skin kangaroo care, comfort touch, read, breastmilk feeding, and pumping.
Organize activities to reduce families' anxiety and stress and connect NICU families.
Provide additional support to families when their babies are critically ill or dying.
Facilitate family-NICU staff partnership to improve family experience and infant outcomes.
Communicate with NICU leadership and staff to provide family feedback to improve NICU care.
Provide family's perspective to the NICU team by participating in NICU meetings.
Facilitate staff education on topics relevant to family-centered care.
Communicate with Home Follow-up and High-Risk Infant Follow-up program staff.

scrapbooking sessions that bring multiple NICU families together and allow them to connect as an informal support group.

"Based on the brain state model, learning is better when one is not in a survival or emotional state but in the executive state and ready to learn. To overcome this barrier, our designated FES provides individual and group family education and training away from patient care activities to ensure a calm and stress-free learning environment."

FCC Director

In the early years of our program, a NICU provider or a staff member served as the FCC director and worked closely with the FCC team. With the expansion of the FCC team and its activities, we recognized that the program required an FCC director whose sole responsibility is to lead and work with the FCC team to ensure the consistency and effectiveness of the FCC for sustaining success and program growth.

The director of our FCC program is a developmental psychologist with her own experience of pregnancy loss at 23 weeks. The director oversees weekly structured communication within the FCC team and between the FCC team and NICU staff. She plays a key role in improving team dynamics, accountability, and transparency of the FCC team's work, actively disseminating FCC achievements to NICU staff. Lastly, the director is also responsible for program building and expanding the breadth of services the team offers both within and outside the NICU.

Enriching Family Experience:

A fundamental goal of the FCC team is to enrich and bring reprieve from stress for NICU families and help build positive, lasting memories. Weekly scrapbooking sessions are one of the favorite activities for many of the families. The scrapbooking sessions away from the bedside help them relax in a calm environment as they connect and focus on creating positive memories of their NICU stay. In addition, the team organizes family-friendly activities to celebrate special occasions throughout the year, including Christmas, Thanksgiving, Halloween, New Year, Valentine's Day, Mother's Day, and Father's Day. They take photographs of babies in special holiday outfits and create mementos for the families. These occasions also provide opportunities to connect with other NICU families in a relaxing environment and to support each other. NICU family picnics and NICU reunions are occasions for current NICU families and graduate NICU families to interact with NICU staff and other families. In 2019, the FCC team worked with the March of Dimes to design and create a Wall of Hope that adorned the walls of our NICU. The "Wall of Hope" consists of several beautifully written stories of NICU babies who survived and thrived after their journey in the NICU. The stories and the pictures of the NICU graduates offer hope to new NICU families as they embark on what can sometimes be a scary journey.

"The director oversees weekly structured communication within the FCC team and between the FCC team and NICU staff. She plays a key role in improving team dynamics, accountability, and transparency of the FCC team's work, actively disseminating FCC achievements to NICU staff. Lastly, the director is also responsible for program building and expanding the breadth of services the team offers both within and outside the NICU. "

While these FCC activities likely occur in many other NICUs, our FCC team has overcome many barriers to provide them to underserved families in a safety net hospital consistently, weekly, year after year, over a decade.

"A fundamental goal of the FCC team is to enrich and bring reprieve from stress for NICU families and help build positive, lasting memories."

FCC Team as Clinical Care Partners:

The FCC team participates in regular clinical care meetings to advocate for the NICU families. They attend weekly NICU clinical rounds and multidisciplinary rounds. They remind the clinical care team of the trauma of the NICU family experience and advocate on behalf of the NICU families. The FCC team provides feedback from families to medical staff at the weekly meetings and shares findings from the patient satisfaction survey in monthly division meetings. The team members liaise regularly with the NICU social worker and work collaboratively to support family members. Thus, the FCC team and their feedback are considered critical to the NICU clinical care decision-making as we reflect the "voice of the family."

"The FCC team participates in regular clinical care meetings to advocate for the NICU families. They attend weekly NICU clinical rounds and multidisciplinary rounds...and advocate on behalf of the NICU families. The FCC team provides feedback from families to medical staff at the weekly meetings and shares findings from the patient satisfaction survey in monthly division meetings. The team members liaise regularly with the NICU social worker and work collaboratively to support family members."

The FCC team actively participates with NICU staff in unit improvement activities. They advocated for improving discharge readiness by highlighting the parents' feedback on being overwhelmed with information at discharge. They suggested addressing language barriers in non-English language Preference families and the educational needs of some families with limited literacy to understand the information in patient handouts. In 2022, the FCC team helped establish a Voice of the Patient (VOP) panel to engage with NICU leadership and staff to raise awareness about the family experience in the NICU and help create a culture of respect for our families. Based on the discussions with the VOP, recommendations were brought on how to communicate daily and effectively with families. In 2023, the FCC team helped establish a Family Staff Advisory Council (FSAC) that provides feedback on several issues pertaining to families, such as welcome to NICU videos for new families and family friendliness in handouts given to families. They educate staff on appropriate ways to communicate with and about families, given that families go through intense trauma during their journey in the NICU.

FCC Team Participates in Staff Education

A critical area that the FCC team participates in and contributes to is NICU staff education in the monthly division meeting. They helped educate NICU staff on appropriate ways to communicate with and about families, given that families may have histories of trauma and go through intense stress during the NICU journey.

The FCC team participates in FCC advocating activities and conferences organized by local, state, and national/international organizations, like March of Dimes, Vermont Oxford Network, California Perinatal Quality Care Collaborative (CPQCC) FCC taskforce, where they learn and share their experience both within and outside our institution. They share webinars and grand rounds from March of Dimes and other organizations on topics of trauma-informed care, staff burnout, and the trauma of NICU family experience.

"A critical area that the FCC team participates in and contributes to is NICU staff education in the monthly division meeting. They helped educate NICU staff on appropriate ways to communicate with and about families, given that families may have histories of trauma and go through intense stress during the NICU journey."

FCC Team Training and Education:

The professional growth of our FCC team is an essential component of program development. All FCC team members have received customer service training and informal training from the medical social worker on how to support the NICU families from the medical social worker. One FSS has undergone further training as a family advisory council member of CPQCC and parent-family partner training certification. The FSS is currently undergoing lactation educator training as well. Our goal is to standardize and provide additional training for all team members on how best to support the families.

Measuring Program Impact:

Ongoing data collection for measuring the impact and success of any program is critical to the program's sustainability. The FCC team collects such data regularly and submits this quarterly and annually to our funding agency. These data include:

- Process Measures: Demographics report to show how many families our FCC team supports.
- Outcome Measures: Breastmilk feeding rate at the time of discharge, any breastmilk feeding, and neonatal abstinence syndrome reports are outcomes that have been shown to improve with family-centered care.

Table 2 Family Satisfaction Survey Questions

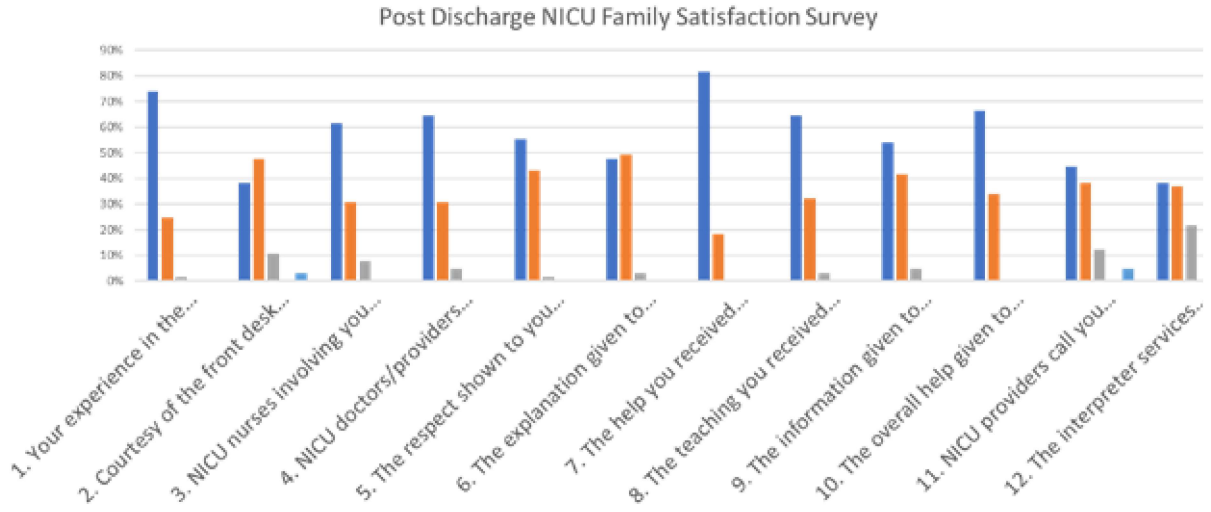
Overall, how satisfied were/are you with:
1. Your experience in the NICU?
2. Courtesy of the front desk staff?
3. NICU nurses involving you in the care of your infant?
4. NICU doctors/providers involving you in caring for your infant?
5. The respect shown to you and your family by the NICU staff?
6. The explanation given to you about why tests, procedures and/or medical treatments were performed on your infant?
7. The help you receive from our parent support/family-centered care (FCC) team?
8. The teaching you receive to take care of your infant after discharge?
9. What information did NICU staff give about you about your infant's follow-up appointments after discharge?
10. The overall help given to you by NICU staff?
11. NICU providers call you during rounds every day to give you daily updates on your baby.
12. Are interpreter services offered in the NICU (by a person or tablet)?

- Success Stories: The NICU families share details of their NICU journey with the FCC team. The team regularly collects this qualitative information in the form of quotes and/or success stories from NICU families that spotlight their experience in the NICU, what worked, what did not work, and how they felt overall about the support provided in the NICU.
- The Family Satisfaction Survey is administered twice by the FSS, a week after NICU admission and once after discharge. The questions on the satisfaction survey center around various topics, such as courtesy of front desk staff, how well nurses and providers treated families, and how well they were prepared for discharge on a Likert scale (very satisfied, satisfied, neither satisfied nor dissatisfied, dissatisfied, very dissatisfied). Table 2 shows the list of questions in the survey, and Figure 2 shows a recent summary of the results of the discharge survey.

Barriers to implementing FCC team:

NICU staff accepting the FCC team members as essential members of the clinical team is the key to the success of an FCC program. While our NICU staff acknowledged the importance of the FCC, it took time to recognize the role and value of a designated FCC team in the NICU. Initially, introducing our first FSS in the unit met resistance from nursing staff and medical social workers. There were concerns about confidentiality and confusion about the role of FSS. Nursing staff felt that they were the family advocates and that there was no need for FSS. Medical social workers were concerned that the FSS was not adequately trained to talk about social issues, especially when the FSS was helping mothers with SUD, informing them of the available treatment programs. We clarified the roles of the FCC team and arranged for them to get training from social workers. Participation in clinical meetings and close communication with NICU staff gave the FCC team opportunities to provide their

Figure 2 Post Discharge Family Satisfaction Survey result



perspective and input to address family/social issues. Over time, NICU staff recognized that families were more open to FSS and often felt more comfortable connecting and communicating with FSS, which helped establish trust and communication between families and NICU staff. Thus, staff came to accept FSS and value their services, often relying on them to communicate with families effectively. This change in the culture of seeing the FCC members as integral parts of the clinical team laid the foundation for the successful implementation of FCC in the NICU.

"NICU staff accepting the FCC team members as essential members of the clinical team is the key to the success of an FCC program. While our NICU staff acknowledged the importance of the FCC, it took time to recognize the role and value of a designated FCC team in the NICU."

Key Components of the FCC Program:

Establishing a well-integrated family-centered care system in a safety net NICU requires several components to be in place:

(1) a strong peer support presence in the NICU helps provide support to families through their NICU journey. Given the population served by our NICU, it is essential to have an FCC team that reflects the population served;
(2) equally significant, FCC members in safety net NICUs like ours must occupy paid positions sustainably. Indeed, we would argue that every NICU should consider having dedicated, paid FCC team members who are considered employees of the NICU;
(3) an essential component of this system is fostering program development. Given the busy workload of NICU staff, employing a dedicated program director is crucial to strengthening and growing the FCC program. The director is responsible for establishing accountability and transparency of the team's work with NICU leadership and fostering active, structured communication both within the team and between the team and NICU staff;
(4) integration of the FCC team into the clinical team is essential to maintain regular lines of communication and amplify the voice of the families. The FCC team should be considered to represent the true voice of the NICU families at weekly meetings;
(5) all QI activities must be informed and participated by NICU families, which has become a responsibility of our FCC team;
(6) continuous NICU staff education on the value of FCC to change unit culture; and
(7) a supportive hospital and NICU leadership that believe in the value of FCC is fundamental for the effectiveness and sustainability of FCC in clinical practice. Our future efforts will further emphasize the role of families in individualized medical and developmental care and provide qualifiable evidence to advocate for FCC as an integrated part of clinical practice in all NICUs.

Conclusion:

FCC is necessary for improving the quality of care and outcomes of high-risk infants and their families' well-being. Our 15-year journey has built a strong, effective, and sustainable FCC program that has transformed the culture of our unit and helped thousands of NICU families. A NICU mother best summarizes the impact of our FCC program: *"The memories of this place and what all the NICU staff did for me truly hit six months after discharge when your baby is hitting their milestones, and they are starting to become healthy. You look back and realize how much hope the NICU gave you. The stories that I heard from my Family Support Specialist and other mothers, and the encouragement that I received from the NICU staff was so profound when I got to the other side—I realized how much they carried me through that time when I was in the NICU."*

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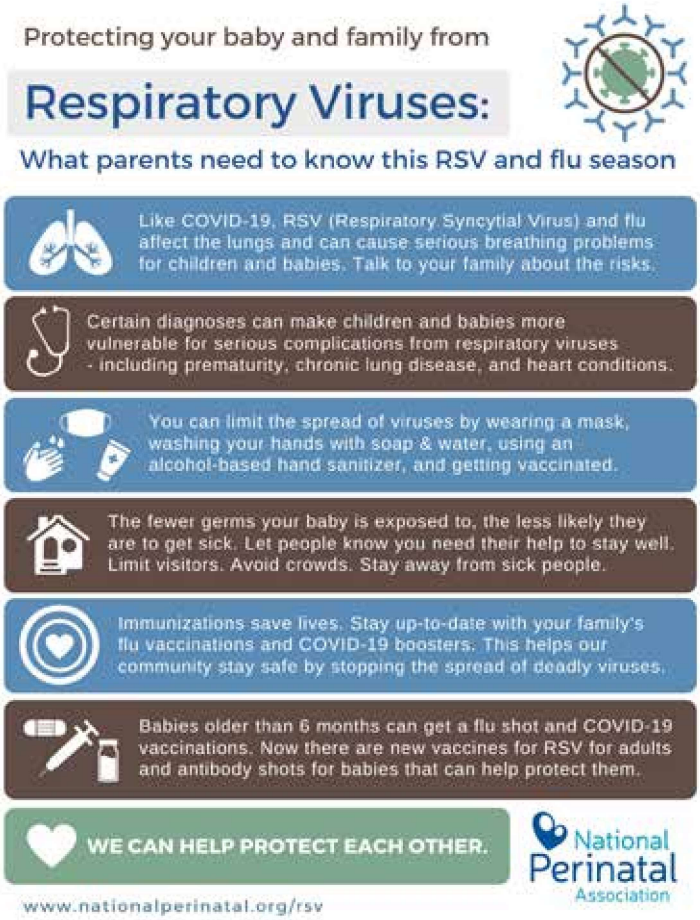

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