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The Neonatal Early-Onset Sepsis Calculator and Its Impact at a Single Center: A Retrospective Cohort Study Pooja Rangan MBBS, MPH, Christine Wade, BSN, Becky Micetic, BSN, Suma Rao, MDPage 3	Family Centered Care Taskforce: Local NICU Parental Support: An Overview Dharshi Sivakumar MD, Michelle Wrench RN, CCRNPage 105
Letter to the Editor: Fragile Infant Forums for Implementation of IFCDC Standards: Neuroprotection - Protecting the Developing Brain Avis Ko, OMS-3, Elissa Port, OMS-3, Taryn Kawashima, OMS-3, Vivian Yu, OMS-3, MPH, Mitchell Goldstein, MD, MBA, CMLPage 11	Will Hepatitis C Testing for High-Risk Infants be Expanded? Michelle Winokur, DrPHPage 119
Letter to the Editor: Comment on "Health Equity Column: What is your Definition of Health Equity?" Sandeep Lankireddy, MS3, Mitchell Goldstein, MD, MBA, CMLPage 14	iCAN: Happy New Year from the International Children's Advisory Network! "Empowering Pediatric Patients Worldwide" Abby ClarkPage 124
Fellow's Column: Diagnostic and Treatment Challenges in Multisystem Inflammatory Syndrome in Neonates (MIS-N): A Success Story with Anakinra Kaydeen Morris-Whyte, MD, Robert Reid, MDPage 17	Medical News, Products & Information Compiled and Reviewed by Saba Saleem, BS, OMS 4Page 135
Engagement in High Reliability Organizing (HRO): The Individual Matters Daved van Stralen, MD, FAAP, Sean D. McKay, Thomas A. Mercer, RAdm, USN (Retired)Page 30	Genetics Corner: HACD1-Associated Congenital Myopathy in an Infant of Chaldean Ethnicity. Robin D. Clark, MDPage 148
Briefly Legal: Was Kernicterus the Cause of the Adverse Outcome? Maureen Sims, MD, Barry Schiffrin, MDPage 49	New Year, New Codes Kara Wong Ramsey, MD, Scott D. Duncan, MD, MHAPage 152
Gravens By Design: A Preview of Evidence-Based Programs for the Developmental and Family-Centered Care Track at the 36th Gravens Meeting Joy V. Browne, Ph.D., PCNS, IMH-EPage 57	The Indirect Impact of RSV Susan Hepworth, Suzanne Staebler, DNP, APRN, NNP-BC, FAANP, FAAN, Mitchell Goldstein, MD, MBA, CMLPage 158
Agenda for Evidence-Based Programs for the Developmental and Family-Centered Care Track at the 36th Gravens MeetingPage 61	Clinical Pearl: Understanding the Impact of Neonatal Acute Kidney Injury Kellie Barsotti, MD; Melanie Wielicka, MD PhDPage 166
Fragile Infant Forums for Implementation of IFCDC Standards: Systems Thinking and Implementation Carol Jaeger, DNP, RN, NNP-BC, Carole Kenner, PhD, RN, FAAN, FNAP, ANEFPage 69	Upcoming Meetings,Page 173
Back to Basics Rob Graham, R.R.T./N.R.C.P.Page 76	Subscriptions and Contact InformationPage 173
Highlights from the 39th Annual Conference: Advances in Therapeutics and Technology: Critical Care of Neonates, Children, and Adults Ontario, CA Donald Null, MDPage 81	Editorial BoardPage 179
The Importance of Seeing and Supporting the Maternal and Infant Health Needs of the United States Indigenous Populations Alison JacobsonPage 89	Animal and Human ResearchPage 181
Improvement of Maternal Morbidity and Mortality: Maternal Level of Care, Maternal Transport, and Regionalization Mary Fang, BS M.D. CandidatePage 98	Manuscript SubmissionPage 181
	Neonatology & the Arts Mita Shah, MDPage 181
	Cyclamen, Rabbit Ears Paula Whiteman, MDPage 184
	Swan Paula Whiteman, MDPage 185



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Family Centered Care Taskforce: Local NICU Parental Support: An Overview

Dharshi Sivakumar MD, Michelle Wrench RN, CCRN

The natural process of parent-infant attachment can be interrupted due to newborn intensive care unit (NICU) admission at birth. The attachment process comes from a developmental perspective on human life (1). Bonding with the parents or primary caregiver is fundamental to growth and development in children (2). Attachment and bonding have been used interchangeably, even though they should be defined separately in research.

“Bonding with the parents or primary caregiver is fundamental to growth and development in children (2). Attachment and bonding have been used interchangeably, even though they should be defined separately in research.”

Attachment between the parent and the high-risk infant in the NICU can be facilitated through protective factors such as nurturing touch, closeness, caregiving, sensitivity to the infant's cues, and responsiveness to the infant's needs (3,4). However, the early separation between parent and infant and a traumatic technological NICU environment interrupt the complex attachment process (5). Interventions to support or modify these factors during the NICU stay should help establish parent-infant attachment (6).

“ High-risk infants hospitalized in the NICU often receive life-saving interventions during a critical development period when their brain is susceptible to positive and negative environmental factors. This time is particularly challenging for families.”

High-risk infants hospitalized in the NICU often receive life-saving interventions during a critical development period when their brain is susceptible to positive and negative environmental factors. This time is particularly challenging for families. Parents of hospitalized newborns are likely to experience clinically significant symptoms of stress, anxiety, and depression. These symptoms can impact the nature and quality of the early parent-infant relationship and lead to long-term consequences for the family dynamic (7-10). Perinatal parent mental health represents a key factor that impacts neuro-developmental outcomes of high-risk infants. It is necessary to optimize the well-being of NICU infants and their families by increasing awareness and screening for parents' mental health in the NICU and building systems for support and early intervention (11).

Over the past couple of decades, the NICU philosophy and how we care for these infants have changed. With the introduction of

family-centered/integrated care, families are spending more time in the NICU and witnessing the ups and downs of their loved one's journey—the guilt, anxiety, and sadness of losing a normal pregnancy fuel the trauma and stress in mothers. Over time, this leads to postpartum depression, anxiety during NICU stay, and post-traumatic stress disorder a few months after discharge (12).

How can healthcare providers support these NICU families? Reviewing the literature, we could recognize a few common positive, supportive methods for the families (13,14).

“How can healthcare providers support these NICU families? Reviewing the literature, we could recognize a few common positive, supportive methods for the families (13,14).”

Meeting other parents in the unit during regular social and informative parent group sessions to give emotional support and gain confidence in participating in the care of their high-risk infant

- Providing access to well-established online groups to discuss common NICU issues with other past and present parents
- One-on-one support through a trained peer buddy program. Psychosocial and mental health screening and early psychological support for the vulnerable parents
- Bedside staff assigning simple activities to perform during parents' daily visits. Simple tasks like holding the infant, skin-to-skin care, reading, pumping at the bedside, selecting the clothes and dressing their infants, infant massage program, and following a well-designed developmental program with different staging
- Creating such opportunities for parent empowerment improves confidence in providing infant care and parental knowledge about an infant's development. These interventions are therapeutic to the parents and improve the infant's clinical and developmental outcomes(15-19).

The challenges in setting up parent support programs are different in each NICU

1. In tertiary care NICUs in children's hospitals or academic centers, the hospital administration and patient experience will love to support these measures as part of financial incentives to their institution. Funds will be provided to support different programs, and all the trainees in the NICU will readily participate in these projects. However, implementing such a program has its challenges, such as difficulty changing the culture, staff participation due to time constraints, cooperation with subspecialty providers and supporting the families living far from the hospital and visiting less often.
2. In a smaller level, 2 and 3 NICUs in community hospitals,

getting support from hospital administration and patient experience are crucial to developing parent support programs. The administration is unaware of these measures in these hospitals as they focus more on adult patients. The hospital administration support is necessary to receive funds that will help to support staff time and commitment. The staff are willing to support the families and have time. Most of the parents live close by and visit more often.

“No matter what the hospitalization entails for babies and families of the neonatal ICU, support from staff and other parents with similar experiences can ease the burden of trauma and optimize coping during the NICU journey.”

No matter what the hospitalization entails for babies and families of the neonatal ICU, support from staff and other parents with similar experiences can ease the burden of trauma and optimize coping during the NICU journey. Building a sense of community and a safe place to talk about shared experiences begins early at El Camino Health NICU. This is a 20-bed level 3 NICU in a community hospital staffed by academic neonatologists in the heart of Silicon Valley. We established a few parental support programs under the comprehensive family-centered care program.

1. **Parent Exchange Program:** We have been doing this support program for over a decade and did not stop during the pandemic. Our Parent Exchange Program meets monthly via zoom on a regularly scheduled day. Our team comprises two neonatal nurses (Michelle Wrench and Tammy Lee), FCC chair Dr. Malathi Balasundaram and a Family Partnership Council member. During this time, parents of current NICU babies can rely on having a safe environment to share their experiences, discuss concerns, and meet and connect with other NICU families. This is an excellent time for parents to inquire about and discuss discharge planning and what to expect while parenting a NICU baby long-term. We always have a former NICU parent in attendance to share their experiences of NICU parenting both during hospitalization and after discharge. The staff of Parent Exchange focuses on the importance of self-care, how to connect with their baby, and informing parents of their crucial role as part of their child's care team. Resources are offered to parents to connect with additional support through online platforms, including our own unique El Camino Hospital Slack Community.
2. **El Camino Health NICU Slack community:** Parents can connect exclusively with former El Camino Health NICU families to share stories, build a broader yet local NICU parent support system, get parenting tips and baby equipment recommendations as well as have an exciting place to share their

infant's progress as they grow! We have ~170 local veteran NICU families in this community. The FCC chair invites the current NICU families to join the Slack group if they are interested. They can read the stories of prior NICU families and their thriving babies or post questions to the group. It is created and run by former parents; no staff members except the FCC core team are part of this community.

3. **Parent activities and involvement:**
 - a. Early skin-to-skin (kangaroo) care
 - b. Early hand expression and oral care with mother's own milk by parents and staff
 - c. Reach out and read program
 - d. Infant massage program starting at 32 weeks

Interview Questions for Parent Buddy Applicants

1. Tell me a bit about your connection to El Camino Hospital. When was your baby born and at what gestation? What challenges did your baby face or overcome during their NICU stay? Did they face any challenges after graduating from the NICU? How old is your baby today? Tell us about them!
2. What do you imagine the role of a parent buddy to be?
3. Why are you interested in becoming a parent buddy?
4. What are 2 or 3 of your strengths you would bring as a parent buddy?
5. Tell me about a challenging or problem situation you had in coping with your baby's early birth and how you handled it.
6. Please give an example of how you prefer to communicate with health care professionals.
7. What is an example of how you manage or reduce your stress?
8. What time-commitment would you be able to make to being a parent buddy?

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Vision/Problem Statement:

Parents of infants in the Newborn Intensive Care Unit (NICU) will have access to a formal program of peer to peer support provided by trained, experienced parents, in addition to professional support. This support will help them cope with stress and anxiety, develop resilience, and gain practical parenting skills.

Background and Importance:

Parents are often overwhelmed and distressed when an infant is born prematurely or with a medical condition, especially if they are first time parents. NICU parents are well-documented to have higher rates of depression, posttraumatic stress disorder and anxiety than parents of healthy, term infants. They often experience sadness, a sense of loss and feelings of failure and powerlessness. When parents are distressed or depressed, their interactions with their infants may be impaired, they are less sensitive and attuned to their infant's needs, and this in turn leads to impaired social, emotional, cognitive and physical development in their infants. The evidence shows that supporting NICU parents leads to improved developmental outcomes for their infants.

Parent to parent support programs have been developed in many intensive care nurseries to provide the unique support that comes from peers. In 2012, the American Academy of Pediatrics recommended that health care professionals should facilitate and encourage peer support. Peer support and role modeling helps parents throughout every stage of their infants' hospitalizations, from giving them hope, to helping them begin to develop parental identity, to providing anticipatory guidance about taking their infants home. Research validates the value of parent to parent support in a NICU setting. NICU parents who receive peer support show:

- Increased confidence and well-being in their parenting
- Improved problem-solving capacity and adaptive coping
- Increased perception of social support, self-esteem, and acceptance of their situation
- Increased interactions and more nurturing behavior with their infants
- More frequent visits to the hospital
- Reduced stress, anxiety and depression

There is a business case for peer to peer as part of comprehensive family support. It results in shorter length of stay due to parents' increased competence at caregiving and ultimately results in lower hospital costs especially under DRG or bundled payment scenarios. It is likely to lead to lower hospital readmission rates for NICU babies, because parents are more competent and confident at caregiving by the time of hospital discharge. "Pay for performance," reimbursement rates are tied to patient satisfaction scores, which are impacted by competitive programs like these. In addition, young women are key drivers of traffic to healthcare systems so ensuring that mothers have a positive experience is crucial in ensuring their loyalty to the organization.

Goal/Target:

A functional parent to parent support program will be in place by Summer of 2019 serving at least 100% of parents. Recruiting, screening and training processes as well as evaluative components will be developed and documented.

Baseline/Current State/Condition:

Current parental psychosocial support in the El Camino NICU is provided by a social worker, as well as the bedside nurses and neonatologists. Parent hours are held monthly to provide opportunity for parents to connect. In addition, individual staff sometimes connect new parents with experienced parents with the goal of providing peer support. No formal processes, staff or training is in place and not all parents are given the opportunity. In addition, parents are sometimes referred to online peer communities that are specifically designed to support this population.

The ten member Family Advisory Board (FAB) in the NICU at El Camino has been active for 2 years. Among their other contributions has been an interest in creating a parent to parent support program. This interest is strongly shared by the unit and physician leadership. The Patient Experience Department of the hospital also desires the development of a program and will provide the assistance of a consultant with experience in starting and managing peer to peer programs.

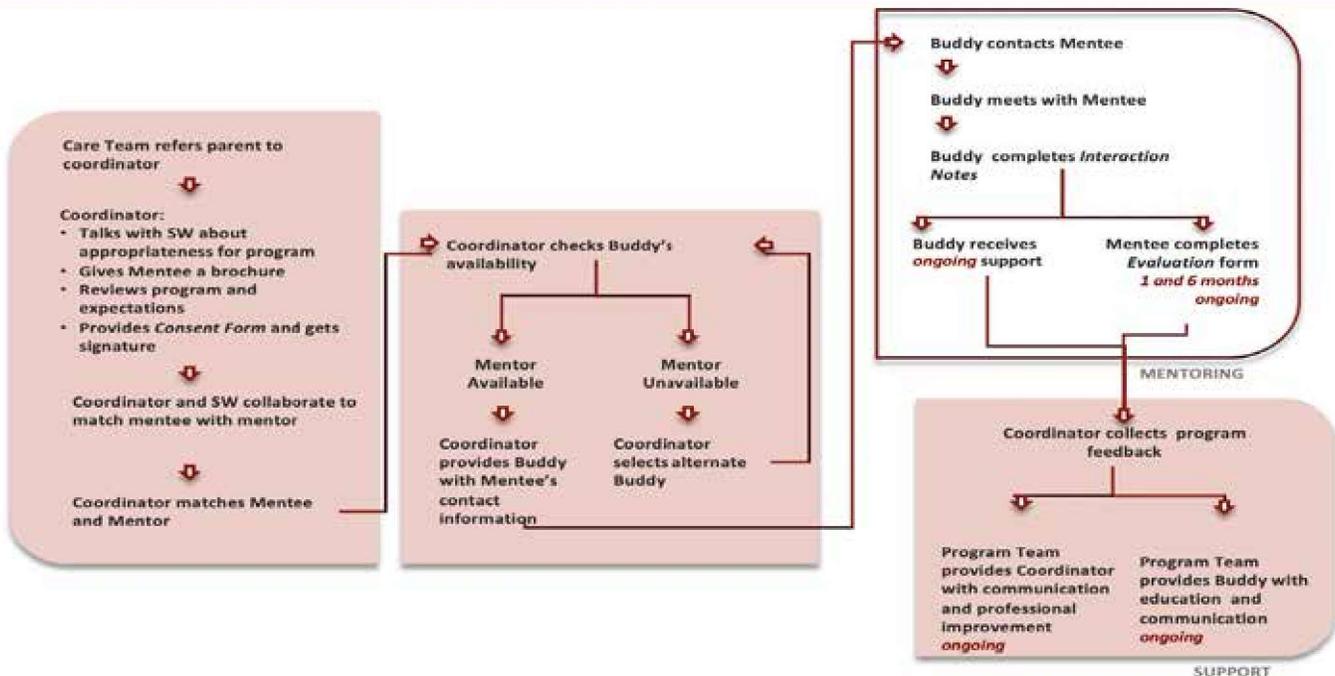
Risks/Mitigation:

Project Timeline/High-level Implementation Plan:

Goal/Target	Countermeasures/Tactics	Status
Validate need and support for program	<ul style="list-style-type: none"> • Review the literature for evidence of benefit to the target population. • Engage the FAB in identifying the need and requirements of a program. • Evaluate other modalities for parent to parent support. • Identify and engage program champions. • Identify essential team members and set meeting schedule. • Develop mechanism for communicating with related departments, such as volunteers or risk management. • Develop vision and guiding principles in alignment with organization's mission. • Determine specific model of peer support desired. • Explore national programs and any affiliations. • Agree on timeline for implementation. 	Complete
Institute planning process and make key decisions to drive program development.	<ul style="list-style-type: none"> • Integrate parent to parent with other patient and family centered initiatives, such as FAB and the parent hour. • Develop role descriptions, including all program personnel. • Document processes, ie matching protocol, based on best practices. • Identify methods of program evaluation and required data collection. • Create required forms. Review with Risk. 	In Progress
Secure support for the program and attain required resources.	<ul style="list-style-type: none"> • Identify all program stakeholders. Meet with individuals: educate, make needed modifications and gain commitment from multi-disciplinary leadership and staff. • Develop the business case and line item budget and gain approval. • Create program materials and conduct internal marketing campaign. 	In Progress
Implement program and collect data.	<ul style="list-style-type: none"> • Determine number of veteran parents mentors desired. • Recruit and identify first cohort of mentees to diversity. • Develop and provide training. • Provide ongoing support and education for mentors. 	In Progress
As program stabilizes and fundamental work is completed, begin further expansion of the program elements and size.	<ul style="list-style-type: none"> • Develop implementation plans and AS's to guide work. • Analyze and report program metrics. • Consider presentation and publication opportunities. 	In Progress

Follow up:

NICU Parent Buddy Program Process Flow



- e. Appropriate developmental care programs developed by rehabilitation therapists to start from the first week of life in the NICU, and staff are trained to perform and

The Parent Buddy Program will match and partner you with a parent of a NICU baby who faces similar challenges. As a participant in the program, you agree to release the following information to your buddy.

Name _____
 Address _____
 Gender _____ Baby's gestation and challenges _____

How would you like to be contacted by your buddy?
 Home phone _____ cell phone _____
 email address _____

Your signature below confirms your understanding that your buddy will need to discuss any serious safety and welfare concerns about you with your health care team.

Signature _____ Date _____

Mentee:
 Contact Date: _____ Contacted By: phone _____ email _____ in-person _____ Length of Contact: _____
 Information _____
 Support/encouragement _____
 Check in on peer _____
 Navigation _____
 Other _____

Agreements, Follow up and Next Steps _____

Requested follow-up (Please send email to team member and note here) _____

Additional Concerns and/or Comments _____

Buddy _____ Date _____

We need your help to make sure the NICU Parent Buddy Program meets your needs. Please respond to the following statements and provide comments to help us improve your experience. For each statement, circle the number that best represents your experience. Thank you!

	Strongly Disagree	Disagree	Neutral/Agree or Disagree	Agree	Strongly Agree
1. My Buddy provided me with emotional support and helped me feel connected. Comments _____					
2. My Buddy was a good match for me. Comments _____					
3. Having a buddy helped decrease my stress and/or anxiety. Comments _____					
4. My Buddy has helped me feel more empowered and active in my baby's care. Comments _____					
5. I am satisfied with the NICU Parent Buddy program in general. Comments _____					
6. I would recommend the NICU Parent Buddy program to another parent. Comments _____					

Additional comments and suggestions _____

Optional Name _____ Date _____

assist families

- f. Bedside binders for parents to track their infant's progress and significant milestones and disseminate important resource information.
 - g. Post-discharge follow-up phone call program
4. Parent buddy program: Parents are connected to compatible veteran parents to support the families during NICU stay and after discharge. In El Camino Health, we collected separate NICU-specific Press Ganey scores and solicited families to complete the survey after discharge. Nurses making follow-up phone calls reminded the families about the survey. We used the survey results and targeted better scores as an

incentive to win the administrator's support. The hospital patient experience and leadership team assisted the program by recruiting a parent buddy expert as a consultant and a trauma therapist from Maternal Outreach Mood Services (MOMS) to start this program. A parent buddy team with veteran parents, nursing staff, rehabilitation therapists, NICU nursing manager, physicians, and a maternal social worker was formed in September 2018. The team met monthly to discuss and develop goals, training, matching process, and program evaluation. Relevant documents such as mentee consent, mentor medical release form, mentor/mentee evaluation forms, and mentor education materials for online and in-person training were created over the next six months. We recruited a NICU nurse educator as a program coordinator. Due to time restraints, we did 2 hours of online training and 2 hours of in-person training for mentors. Six veteran parents on our family advisory board volunteered to become initial mentors and trained in March 2019. Following that, a second set of parents were trained three months later. The first mentor-mentee pair was matched in April 2019. Mentor training continued virtually during the pandemic, and we currently have 18 NICU veteran parents in the program. In supporting mentors, the FAB suggested starting a unit-specific Slack community. This now supports the parent buddy program and all other families in the NICU. We recruit new mentors during our annual NICU reunion program a couple of years after NICU discharge. Parents who benefited from the parent buddy program are willing to return the favor to other families, and we have several veteran parent volunteers to train annually. Plans are in progress to return to in-person training in 2023. As of today, we have 47 NICU parents supported by this program.

Evaluation comments from the mentees,

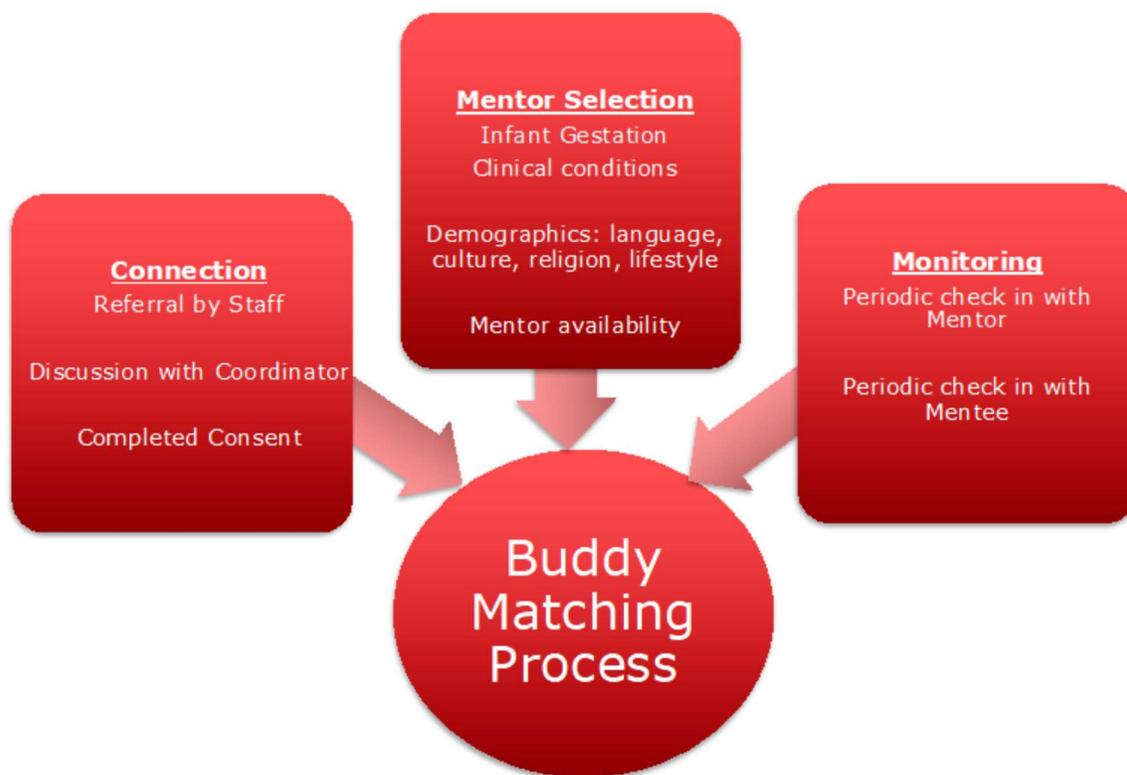
"I think this **needs to be structured as a friendship** as opposed to a Mentor/Mentee format. This is not an equal experience; therefore, you can never truly be "the Mentor" you are a friend who had your experience and may be able to relate and be empathetic at a few or many levels."

"Parenting in the NICU can be such a challenging and stressful experience for parents. Connecting through the El Camino Parent Buddy Program **gives experienced NICU parents a way to help others feel supported and understood during an emotional time** with the goal of helping them feel supported and empowered in the ways they need the most".

"At a time when everything feels crazy and out of our control, it's nice to know that something as simple as a **basic human connection can have a positive effect.**"

"Strongly recommend to NICU parents to provide moral support to mentees."

"Individual and group parental support, education, and resources will help the families confidently participate in the daily infant's care. These activities are therapeutic to the parents and improve the infant's clinical and neuro-developmental outcomes."



It is estimated that each year 10% of newborn infants require NICU admission due to being born sick and/or premature. Neonatal hospitalization can have a profound and pervasive negative impact on parents due to being separated from their infants and the unfamiliar and technological nature of the unit. As discussed above, every NICU can implement effective interventions when the infant is admitted to the NICU. In premature birth, interventions can be initiated at the time of the initial meeting during prenatal consultation. As maternal and neonatal health professionals, we are responsible for developing appropriate programs to support families in every NICU. Individual and group parental support, education, and resources will help the families confidently participate in the daily infant's care. These activities are therapeutic to the parents and improve the infant's clinical and neuro-developmental outcomes.

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