

NICU Family Advisory Council

NICU Family News



The NICU Family News is produced by the Cooperman Barnabas Medical Center (Neonatal Intensive Care Unit (NICU) Family Advisory Council. It is designed provide you with information we hope you will find useful during and after your family's NICU stay.

DID YOU KNOW...

..that to raise awareness about the benefits of skin-to-skin contact **May 15 is International Kangaroo Awareness Day?** Kangaroo care, also known as skin-to-skin care, encourages parents of newborns to hold their babies on their bare chest. This has been shown to help NICU babies regulate their breathing, heart rate, and temperature, and improve weight gain. For health and safety reasons, babies born less than 32 weeks and with other medical conditions /devices may have to wait until at least a few days after birth do skin to skin. Ask your nurse if you have any questions about this.

When Is Your NICU Baby Ready To Feed?

Some babies are ready to breast or bottle feed as soon as they get to the NICU while others are not ready yet and need to follow some guidelines that our staff use to help guide this process. The NICU staff work with the families and babies to help figure out what stage of being ready to feed they are at and when baby is ready for "pre-feeding" or feeding opportunities.

Every baby in the NICU is different but *usually* babies that are at least 32 weeks gestation, not intubated or on CPAP, and do not have a chest tube may be offered breast or bottle feedings. (If you have any questions about this at any point just ask your baby's nurse.)

General signs of the NICU baby being ready to feed include:

- being awake and alert before the feeding starts
- rooting or turning their head towards a nipple or bottle
- actively sucking on a pacifier or gloved finger
- actively sucking on the bottle/breast
- maintaining an "alert state" (awake and calm) during the feeding
- maintaining their oxygen saturations (as noted on the monitor they are hooked up to)

Babies are in the NICU for many different reasons. Some of them will need a consultation and/or treatment from one of the hospital speech and language pathologists. If needed, they will be called upon by your baby's NICU nurse or doctor. This is not an inclusive list, but premies having feeding difficulties and babies born with certain genetic and neurological disorders are often seen by a speech and language pathologist while in the NICU. If needed these trained therapists provide treatment interventions that help reduce oral sensitivity, improve range of motion and strength of muscles for sucking, increase oral motor organization, and activate reflex behaviors needed in sucking while feeding.

Please see the staff interview on the next page to learn more about one of the speech and language pathologist who comes to work with some of the NICU babies.

Let's Get to Know: Amariah Macatangay, MS, CCC-SLP Speech Language Pathologist

How long have you been working at CBMC and anywhere else doing this kind of work?

I have been working at CBMC for over 4 years. I actually was a student at CBMC back in 2019 and was hired as the department's first clinical fellow speech language pathologist later that year and obtained my certificate of clinical competency in 2020.

Please describe your role in the hospital and specifically in the NICU?

As a speech language pathologist, I provide bedside swallow evaluations, speech and language evaluations, and perform instrumental assessments to assess swallowing on infants, pediatrics, adults, and geriatrics. My role in the NICU is to assess the babies oral feeding readiness and note any cranio-facial abnormalities. Then I provide treatment interventions designed to reduce oral hypersensitivity, improve range of motion and strength of muscles for sucking, increase oral motor organization, and activate reflex behaviors that facilitate nutritive sucking.

What babies do you work with in the NICU and how do you get "called upon" to see one of the babies in this unit?

We work with any infants born prematurely who may have difficulty coordinating their sucking, swallowing, and breathing, or any infants with cleft lip/palate, genetic disorders, or neurological disorders. The NICU doctors (called neonatologists) will call us to see the baby in the NICU when they feel they may need feeding therapy or are having difficulty during their feedings. We also get called upon if the neonatologists see any craniofacial abnormalities. Sometimes the NICU nurses may ask for us to see the infant if they see these difficulties and notify the doctors who may order a consult from us if they feel it is appropriate.

How did you know you wanted to be a speech pathologist?

As someone who comes from a family of healthcare workers, I found interest in the rehabilitation side of this field and found an internship with a speech language



pathologist my senior year of high school. Although my internship was in a grade school, I researched more into the field, knew of the medical based setting, looked into pursuing that side of the field when entering college and found a passion for working with infants/pediatrics.

What do you like the most about working in the NICU?

Feeding, eating, and communicating are such important aspects of every individual's life. To be able to rehabilitate that is something that fills my cup every day. I am specifically drawn to the NICU, and find a lot of enjoyment in working with families and their infants and helping them foster growth and development in regards to feeding and meeting developmental milestones. To have a role in the NICU is so rewarding, and I enjoy working on the interdisciplinary team to encourage positive and quality oral feedings to promote feeding success in the NICU. Following the NICU babies I am assigned to up until their discharge gives me such a heartwarming feeling, knowing I played a role in their healing process.

Do you have any advice for NICU families?

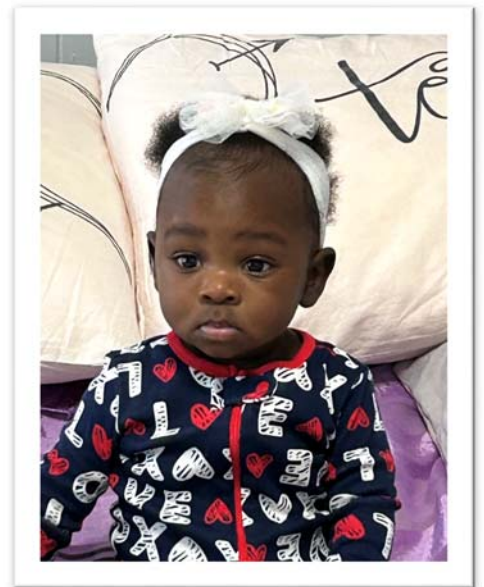
Having a baby in the NICU can be scary. Remember, you are your baby's biggest advocate. Try to make use of the resources available and always ask questions. If your baby needs a little extra help in terms of feeding and motor milestones, we have great resources to help you get the services you may need for your baby once you leave the hospital. We want you to feel as comfortable and confident as possible once you get the great news that your baby is being discharged! We want to make sure that all our interventions promote positive experiences to help nurture the development of our infants and want to help support our NICU families.

A Story of Gratitude

My pregnancy was going great...until it wasn't. Just that quickly, what was a normal experience turned into a medical drama. I woke up around 1:00 am on Wednesday, June 14, with a lingering pain in my chest. As someone who suffers with gallstones, I was familiar with the feeling. Normally, I would take over-the-counter pain meds and go on with my day. The problem this time was that I was 28 weeks pregnant! Wanting to be careful, I called my OB who said I should come to the hospital to be evaluated. Confident this would be a quick visit, I packed my work bag, asked my husband to drop me off and I would take ride share to work. I'm glad he didn't listen to me! I spent the next two weeks in the hospital followed by 5 weeks of daily visits to the NICU. In dramatic fashion, my daughter, Jordyn, was born at exactly 30 weeks on June 23. I was unconscious for the birth, but I am told she was quite lively and loud when she was born! My next memory is waking up and being rolled to the NICU in a hospital bed to see her briefly.



The first day I was able to see her was the hardest. She was in the incubator, with tubes and sensors covering her 2 pound, 12 ounce body. Her eyes were covered, but she was alert. We couldn't hold her yet, but could touch her through the slots in the incubator. The nurses were kind and let me know when they would be evaluating her during the day. This way, I could see her without her eye covering, take her temperature and change her diaper. The day nurse reassured me "by the time she leaves here, you will be doing my job!" Those moments changing her diaper and taking her temperature felt normal and I longed for each of them!



The second hardest day was when I was discharged from the hospital without her. After being discharged, I spent the rest of the day with her in the NICU, not wanting to leave her side. Her nurse that day encouraged me to go home and rest. "Soon, she will be coming home, our babies go home!" Those words were a glimmer of hope that I needed on the days when she lost a few ounces of weight or needed a new feeding tube or a blood transfusion.

The next memory I have is the day Jordyn was transferred from a pod to a private room. On this day, I arrived at her pod to find she wasn't there! What felt like forever was just a few seconds before a nurse took me by the hand and walked me to a room. "Jordyn has graduated, she is closer to the exit door, closer to going home!" I didn't see much through the tears that filled my eyes, but I followed her voice, holding on to her reassuring words until we stopped and I saw my daughter sleeping in her new room. I left her sleeping peacefully to get a coffee in the NICU Family Room. The Family Room was empty and I let the tears flow. Not knowing where Jordyn was, even for those few seconds, was an emotional rollercoaster ride. Soon, another NICU mom came and sat down in the Family Room too. She told me her daughter was born full term, but needed surgery, and her son had spent significant time in this NICU. "They are great here," she reassured me, "Jordyn will be fine!" We talked and cried and prayed together over coffee and water. We have kept in touch, but our first meeting was magical for me. I am forever grateful for that encounter and hope others utilize that space to connect as well.

(continues on page 4)

Important Phone Numbers

NICU: 973-322-5300

NICU Clinical Director:
973-322-8938

NICU Social Worker: 973-322-5503

NICU Case Managers:
973-322-5909/973-322-2678

Birth Certificate Office:
973-322-5327

Lactation Consultants:
973-322-9088

NICU High Risk Infant Follow-Up Program: 973-322-2631

Want to Help the Family Advisory Council?

The FAC is made up of graduate parents dedicated to helping new NICU parents. We meet monthly to discuss ways to do this. We're always looking for recent graduate parents to share their experiences and ideas to make our NICU the best it can be. We welcome your ideas and participation.

Contact: Hayley Hirschmann
FAC Coordinator
Hayley.Hirschmann@rwjbh.org
973-322-9486

A Story of Gratitude (cont'd from page 3)

I am also grateful to all the CBMC staff. I am grateful to the doctors who sat on my bed and let me cry because I was separated from my newborn baby. Thank you to the L&D nurses that asked how the baby was every time I came back to my hospital room. I am grateful for the apple and cookie they had waiting for me because I missed lunch and sometimes dinner. I am grateful to the doctors who visited me in the NICU so I could spend more time with Jordyn. Above all, I can't say thank you enough to the NICU Staff. Thank you to each nurse that wiped her down, brushed her hair and dressed her. I appreciate the nurses that warmed her feedings and gave her medications. Thank you to the doctors who explained everything that was happening and the milestones she needed to meet before being discharged. Thank you, Dr. Rani, for caring for my daughter's medical needs and making me aware of upcoming procedures so I could be there with her. For each person who cared for little Jordyn in my presence and in my absence, I am forever grateful.



On August 5, Jordyn left the NICU and came home with us just as the nurse said she would. One week later, during her first checkup, a hernia was discovered. She was readmitted to the NICU for surgery. I cried, but, this time, only briefly. A familiar face, a NICU nurse, reminded me, "Mom, you know we will take good care of her, she's in good hands!" and I wholeheartedly knew that she was!

The last few months, we have been donating some extra special snacks for families to enjoy in the NICU Family Lounge and I have been attending the NICU Family Advisory Council monthly meetings. I feel this helps me stay involved and keep finding ways to show and share my gratitude!

- With thanks, Jordyn's Parents

**24th Annual Miracle Walk
Sunday, October 6, 2024**

Please save the date for the 24th Annual Miracle Walk to benefit the Shyan Sun, MD Cooperman Barnabas Medical Center NICU. Held in beautiful Verona Park, there is always a DJ, fun activities and costumed characters for the kids!

Hope to see you and the whole family there in October!



To make a donation or for more information visit: miraclewalk.com or facebook.com/miraclewalk