Saint Barnabas Medical Center NICU Family Advisory Council





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

DID YOU KNOW...

you can stay in touch with other SBMC NICU parents and "discuss" topics important to you and your baby's progress by liking our facebook page: www.facebook.com/SBMCNICU. What are you waiting for? Like us now. Thanks!

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The SBMC NICU is now on Facebook www.facebook.com/SBMCNICU



What is Early Intervention (EI) and Which Babies Need it?

A very common question many of our NICU families ask our staff as their baby/babies are getting close to going home is about whether or not their baby will need early intervention and how they will know if their baby needs it. Keep in mind that the majority of babies that graduate from our NICU do not need Early Intervention (EI) but some do, so what follows is some information we hope will help you with these questions.

In NJ, El is a statewide program that can evaluate and provide needed developmental services for youngsters from birth to 3 years old. A parent or doctor or other health care worker can request an evaluation for a child in this age range and an El worker can be scheduled to come to your house for an evaluation.

Since every baby develops at their own pace (and with preemies that pace may be delayed by roughly how early they were born), it is sometimes difficult to know if your baby is "developmentally delayed" and needs an evaluation. Skills such as taking a first step, smiling for the first time and waving bye-bye are called "developmental milestones" and when babies meet these milestones is important. However, some babies simply speak, crawl, walk and relate to others later than other babies, but there are some general things babies should be doing by certain ages and all pediatricians should be checking on these developmental milestones each time you take them for a check-up. So, it is important to keep regularly scheduled appointments with your pediatrician and ask them if they feel your baby is meeting their milestones in an acceptable time frame. You can also see a listing of these expected milestones, by age, in the El Pamphlets we have in the NICU Family Library or at www.cdc.gov (in English and Spanish). Because there are ranges of time for when babies/toddlers meet their milestones there is no set answer about some of this, especially early on (say in the first 3-6 months of life). However if you, or your doctor, have concerns about milestones seeming to be late in several areas or if your child seems very behind in one area reach out to Early Intervention for an evaluation. They can be contacted at 888-653-4463 and you can find out more about all of this at http://nj.gov/health/fhs/eis.

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Interview With NICU Nurse/Patient Care Coordinator: Marcie Varona, RN, BSN

Q: What is your background and how long have you been working in the NICU here?

A: I have a Bachelor of Science in Nursing from Seton Hall University. I have been a staff nurse here at SBMC's NICU for 15 years. Before this, I was a staff nurse for 2 years in the NICU at Jersey City Medical Center.

Q: How did you know you wanted to be a NICU nurse?

A: I have wanted to be a nurse for as long as I can remember. I absolutely love children, so when I started nursing school my goal was to be a Pediatric nurse. Then one day during my senior year of nursing school, I was given the opportunity to spend a day of observation in a NICU. From that moment on, I knew that I wanted to be a NICU nurse. I truly just felt it in my heart that this is where I was meant to be. I have never looked back.



A: My new position is Patient Care Coordinator (PCC). As PCC I have the best of both worlds here in the NICU. I give out staff assignments and help oversee all patient care. As PCC I still have the chance to do a lot of hands on patient care while still working with the entire management team and multidisciplinary team to continue to improve our quality of care.

Q: What do you like most about your job?

A: My favorite thing about working in the NICU is the opportunity it gives me to advocate for our tiny patients. The infants can't speak for themselves, therefore as a NICU nurse you must have excellent assessment skills and you must have the confidence to speak up on behalf of your patient when you know something is wrong.

Q: What are you most proud of working here?

A: I am most proud of our excellent outcomes. We have such an amazing group of professionals here that work so well together as a team; our results are proof of that. I am extremely proud to say that I work in a NICU that has one of the best survival rates in the nation.

Q: Have you seen any beneficial changes in the NICU since you have worked here?

A: I have seen many beneficial changes in the past 15 years. There have obviously been quite a few technological changes, some of which include new ways to ventilate our little babies, which in turn decreases our incidence of Chronic Lung Disease. However, the best change that I have seen since I started here is how the relationship between doctors and nurses continues to grow. There is a true camaraderie and mutual respect.

Q: What does Family Centered Care in the NICU mean to you?

A: Family Centered Care means to me that families are involved in every aspect of their infant's care from the time of admission until the day they are discharged. The more involved the families are, the easier it will be for them to build trust in the care that our dedicated team is trying to provide.



Q: What suggestions or advice do you have for NICU families?

A: To our NICU families I would say to remember to take it one day at a time and remember that you are going to have good days and you might have some bad days too. Please do not hesitate to ask questions, we are not insulted by your questions, we are honored to be taking care of your baby, and we are here to answer your questions, no matter how many times you ask them. Get to know your baby, try to become comfortable with your baby before you leave the NICU. Utilize all the resources that are offered to you... You don't have to do this alone. Ask for a NICU Parent Buddy too. It's always nice to know that someone has been where you are!

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Our Experience With Early Intervention

April 2010, my son Marcus arrived into the world three months early. He was a very little fellow weighing in at just 1lb, 2.5oz. He was immediately whisked away to the NICU where he spent



the next three months of his life. My family's NICU journey was filled with numerous serious medical concerns and complications, countless sleepless nights and many emotional highs and lows. As a new father, I was concerned about how his health concerns would impact the rest of his life. The nurses and neonatologists took the time to talk to me about the amazing growth and learning potential of the infant brain. They told me that positive, early experiences would help reduce developmental delays and make the most of my son's overall quality of life. To help with this, our NICU social worker arranged for us to have an Early Intervention (EI) evaluation immediately after discharge. Initially, the thought of having strangers come into our home to evaluate our baby boy was a little off-putting; however, we knew it was something we had to do. The El evaluation team was made up of a social worker, physical therapist and a speechlanguage pathologist. Together they reviewed my son's health history, helped get him qualified for services and arranged for weekly, in-home physical, occupational and speech therapy.

My son's El therapists were wonderful. They were always on time and professional as well as very kind and loving to my son. They not only tended to his

Marcus a few days after birth (left) and Marcus now almost 5 years old (below).

needs, but they also gave valuable support to us, as parents, as we transitioned

to home. They helped set practical, everyday goals and gave us exercises and activities that we could do to help him achieve these goals. We saw immediate improvements in his fine and gross motor skills and speech-language abilities.

My son "aged out" of El at 3 years of age. Prior

to this, his therapists helped us with his transition to preschool and armed us with numerous resources that we could refer to in the future. There were many tearful goodbyes when his therapists finished their final sessions. My son loved all of his therapists and still talks fondly about them to this day. As a result of Early Intervention, my son made tremendous strides in all areas of his development. My wife and I are so thankful the NICU staff recommended that we take early action, which was what our son really needed. Sometimes the NICU or pediatricians suggest more of a "watch and wait" approach for babies and toddlers, but they knew what was best for our son.





Save-The-Date: 15th Annual Miracle Walk
To Benefit the SBMC NICU

Sunday, 10/4/15

Verona Park, Verona, NJ

MIRACLEWALK.COM = 973-322-4259 = FACEBOOK.COM/MIRACLEWALK



Important Phone Numbers:

NICU 973-322-5300

NICU Step-down (3100) 973-322-5310

NICU Nurse Manager 973-322-8938

NICU Social Worker 973-322-5503

NICU Case Managers 973-322-2045 973-322-2678

Birth Certificate Office 973-322-5327

Lactation Consultants 973-322-5684

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. Contacts:

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What is Early Intervention (EI) and Which Babies Need it? continued

If the El team sends someone to your house to do an evaluation you will get information about your child's specific areas of development and they will help you decide if there is a need for ongoing early intervention services. During the evaluation they will look at specific skills the child is developing and they will suggest further services if the child is found to have a:

- 1. developmental delay of 25% or more in two areas of development OR
- 2. developmental delay of 33% or more in one area of development, OR
- 3. medically diagnosed physical or mental condition that typically results in a developmental delay (e.g. Down Syndrome, Cerebral Palsy...)

Families are often concerned with the cost of these services for their baby. Keep in mind, there is usually not any cost associated with having the EI team evaluate your baby and if they think the child needs services there are usually co-pays dependent on the families income and health insurance. They try to work with the families to get the most help to these children during these important first three years of life. Again, to learn more about any of this go to http://nj.gov/health/fhs/eis.

Tests Your Baby May Have in the NICU

Many of the following tests are commonly used to identify, or rule out, problems babies in the NICU might have.

Blood Tests - These often look for anemia, jaundice, electrolyte levels, low sugar, infections and more. They are done by taking a small sample of blood from the baby by a heel stick or artery.

CAT/CT Scan - These provide a closer look at the baby's organs and tissues. They use x-rays and computers to create detailed images for the nurses and doctors. The babies are often barely even touched during such scans.

Head Ultrasound - These check for any possible bleeding in the brain. A device is touched over the baby's head, using sound waves that make a picture for the doctors to examine.

Echocardiogram - This test examines heart structure and functioning using sound waves, much like in a head ultrasound.

Hearing Test - This tests the baby's hearing and brain activity by sending sound to the baby's ears through earphones and sound sensors placed on their head

Urine Test - This kind of test may be done to check kidney function or for infection.