#### **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 provide you with information we hope you will find useful during and after your family's stay in the NICU.

#### DID YOU KNOW...

....during this time of ongoing COVID restrictions there are many virtual and remote resources available to you as a NICU parent. All are listed on the blue handout in your NICU welcome bag or you can pick one up at the security/welcome desk on the third floor before entering the NICU. Be sure to check out information about how to attend any of the zoom-type meetings held every Wednesday (12:30 to 1:30 pm) and the first and third Sunday of each month (8:00 to 9:00 pm). There is also information about how to get your very own NICU buddy who has "graduated" from the NICU with their baby and can give you good info.

# *NICU*Family News

# 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, EI 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 EI worker can be scheduled to come to your house for an evaluation.

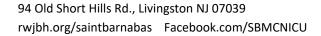
Since every baby develops at their own pace (and with preemies that pace may be delayed by roughly how early they were born), it is sometimes difficult to know if your baby is "developmentally delayed" and needs an evaluation. Skills such as taking a first step, smiling for the first time and waving 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 EI 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.

(continues on page 4)









### Interview With Jamie Beins, MSN, RNC-NIC, **Neonatal ICU Nurse**

#### Q: How long have you worked here and in what roles?

A: I have been working at Saint Barnabas for 16 years in the NICU as a bedside nurse. When I decided to become a nurse. I knew the NICU was exactly where I wanted to begin my career. I interviewed for a job in the SBMC NICU and was hired as a new graduate at 22 years old.

## Q: Where did you do your nursing education and train-

A: I received my RN license after an accelerated nursing program through The County College of Morris in 2004 and started my career immediately. A few of years later, I got married and started having children. When my third child was 3, I decided to further my education in nursing. I started an online nursing program at Western Governors University and received my bachelor's degree in 2017. I decided to continue my education and started the master of science in nursing program at the same school. While in school, I had my fourth child and competed the program in 2018. I also received my NICU certification.

#### Q: What is your role and what are your responsibilities in the NICU?

A: My role in the NICU is a bedside staff nurse. I care for all NICU babies but have a special passion for those that are critically ill and/or extremely premature. I am involved in the NICU Council, co-chair the NICU Breastfeeding/Breastmilk Committee where we work to improve anything related to breastfeeding and breastmilk, and am one of the day shift charge nurses that oversees the NICU and the nurses working for my assigned shift.

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

A: Coming out of high school, I wasn't quite sure what I wanted to be. Upon attending a career workshop at County College of Morris, I completed



a questionnaire to help me choose a career path. The only answer I received in response to my questionnaire was a registered nurse. From that moment, I just knew nursing was my calling. Deciding on working in the NICU was easy because I have always been obsessed with babies. When I toured the NICU during nursing school, I was amazed and immediately fell in love. Later, I learned that my grandmother was a NICU nurse for her entire career. What a coincidence. It all just came together like the NICU was where I was meant to be. As far as special training for the NICU, you do receive an extended training period compared to nurses on other units. This is due to NICU being such a specialized unit. Included in this training are required NICU specific classes and education taught by our NICU educator.

#### Q: What is your favorite thing about working in the NICU?

**A:** What I love most is knowing that I have the ability to help people. I have such passion for helping families and comforting them to get through some of the most scary and challenging times in their lives. Watching and helping the babies grow, getting to know them and their families, and watching them walk out of the NICU together, as one, is so rewarding especially knowing I helped make that possible.

(continues on page 4)

#### 20th Annual Miracle Walk Held Virtually

On Sunday, October 11, 2020, for the first time ever, the 20<sup>th</sup> Annual Miracle Walk to benefit the Saint Barnabas NICU happened virtually. That day, grateful families, like "Team Christina," pictured, were encouraged to walk for the cause from wherever they were (home, school, a local park, etc.). The event raised close to \$200,000 for the NICU. If you, or anyone you know, want to get the fundraising totals up over that amazing goal, you can go to miraclewalk.com to make a donation until the end of the year. You can also still watch the event kickoff video there with a special tribute to Shyan Sun, MD.







## Twice The Birthday Celebrations

We had our list of names narrowed down to 6 or 7, but we thought we had several weeks left to make the final decision. I was keeping the names a secret from family, but planned to share the top 3 with a close friend who would give honest, impartial feedback and help us choose.

At 30 weeks and 1 day, I woke up at my usual time for work – but was just not feeling well. I'd been rundown the past few days and even texted my manager the night before that I was probably not making it in to work on Monday morning.

I tried to go back to sleep but a few moments later, labor started really quickly and I was soon yelling for my husband. I hadn't even packed my bag yet — that was on the to-do list for the following weekend. Somehow, I pulled together contact lenses and extra pis and we were off.

The first thing I remember at Saint Barnabas Medical Center (SBMC) was a nurse saying, "We're giving you medicines to try to stop labor. You're going to stay with us here until you have a baby, and that might be several weeks". She was very calm and reassuring, but even without labor pains I had a strong feeling our baby was not going to wait. A few hours later, I was headed into an emergency c-section.

My husband Lee was amazing at not passing out during the surgery, and he followed our baby and the team to get him stabilized while I went to the recovery room. After a few hours, I was awake and I heard our little one was doing OK. I couldn't get out of bed yet... but I could text my friend. "So we need to speed up the timeline on the name feedback... my baby arrived early today!" I could keep this one part of my day lighthearted in contrast to all the worry and drama at the hospital. My friend promised to have the name review complete by the next morning. Once she did, Lee and I got to look at our baby and decided he should be called "Nico".

The recovery and NICU nurses were so helpful and reassuring at every step. It's a scary yet beautiful gift to see your baby's development almost 10 weeks before they are supposed to enter the world. In addition to some breathing issues and frightening desaturation events, Nico had an infection 8 days in, and needed a ventilator for several days and then lower-level breathing support for weeks after. The nurses and doctors walked us through each step and decision in his care. Additionally, the NICU Family Support Group helped me process and make decisions about how to spend time at the hospital,



Nico in the NICU and now at 16 months old!

handle my recovery, and choose whether to go back to work after my own recovery while Nico stayed in the hospital.

After several weeks of very slow improvements, Nico received a blood transfusion. While this wasn't the first line treatment to try for his conditions, it ended up being the right one and the turning point for him. Within a few days, his desaturation episodes began to get better. He was gaining weight and improving all around. Soon, we could start transitioning him from a feeding tube to bottle and within a few more weeks he was ready to come home, just a couple days before his original due date. A few weeks later, we were at the Miracle Walk, to benefit the SBMC NICU, feeling the love from all the other NICU grad families, reuniting with the SBMC doctors, nurses, and staff.

Nico is almost 18 months now and thriving. Although in 2020 there are no group toddler soccer lessons, he can throw and kick the ball and is ready for next summer. He loves music, books, and playing outside. And, we get to celebrate his birthday twice every year, on his birthday and on his due date birthday, with an extra party in the middle for his homecoming anniversary.

Special thanks to the entire SBMC NICU team for getting Nico off to such a strong start, to the NICU Family Coordinator, and to all the other grad families in the SBMC NICU Facebook group for creating the community and friendships we have today.

- Anne



#### **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. Contacts:

Eileen Steffen, RNC NICU Quality & Research Coordinator Eileen.Steffen@rwjbh.org 973-322-9485

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

#### What is Early Intervention (EI)... (continued from page 1)

If the EI team sends someone to your home to do an evaluation, they will gather information from the family and from observing the child in several areas of development (such as communication, feeding, behavior, walking/movement, vision, and hearing). That trained professional will then determine if the child is significantly delayed compared to other children the same age and in need of services. They will also recommend the types and amounts of services needed.

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.

#### Interview With Jamie Beins (continued from page 2)

- Q: Have you ever been a preceptor where new nurses shadow you before they can become a NICU nurse?
- A: I have been a preceptor for new nurses for many years now. It can be quite a challenge, but what I like about the experience is getting to use my knowledge to help shape someone into the best NICU nurse they can be.
- Q: What does Family Centered Care mean to you?
- A: Family Centered Care to me means making the family part of our team. Having them be involved in decision making, in their babies care when possible, and supporting their needs along with their babies. Just like I try to make the babies comfortable, I also try to make the family comfortable and the least stressed as possible.
- Q: Do you have any suggestions for the NICU families?
- A: Yes, communicate with us. We are here for you and your babies. If you want to hold the baby and be involved in their care, please speak up. Sometimes we get a little busy but we understand how important it is for you to hold, bond, and participate in your babies care. If you're nervous, let us know. We are happy to try to ease your anxiety. Also, remember every nurse will do things a little differently and have a different personality. You will naturally bond with each nurse a little bit differently and that's okay. If you feel really comfortable with someone let them know. Maybe they would be willing to take care of your baby more often. Also, one thing I always tell parents is if you don't see me panicking, don't panic yourself. There are many scary monitor alarms and noises in the NICU but not all of them are always bad. If you are worried or wondering what they are, ask your nurse. We are here to help you.

#### Q: Is there a personal or fun fact you would be willing to share?

A. Yes, I have a history before kids, of being a great Texas Hold'em poker player! Years ago, my husband and I used to play in a poker league several days a week. We did so well we took 1st and 2nd place in a tournament with about 200 people. I miss it of course, but get to play a little online and in the casinos here and there.