

NICU Family Advisory Council

nicu Family News



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...

you can plan something special for your NICU baby's "graduation day." Other NICU parents who felt the day their baby was going home from the hospital was a day to celebrate have had a personalized outfit made for them or brought a baby cap and gown to take photos in with the family. Do what feels right for you and feel free to be creative. It's your going-home-with-baby-day!

What Graduate NICU Parents Wish they Knew

We asked SBMC NICU parents whose baby/babies have been home from the NICU from 1 year to 10 years things they wish they knew while they were here. There were some similarities and they are listed below and when possible there is more information in italics about their wish so you can know NOW the things they wished they knew!

When my baby was in the NICU, I wish I knew:

...about the NICU Buddy Support Program and that I could have a NICU grad parent assigned to support me (and my spouse) via phone, email, text. The staff were supportive but an ex-NICU parent who had "been there" would have been great!

*There are yellow **Parent Buddy Program Brochures** in every blue and green NICU Welcome bag and in common areas of the NICU (library, lounge...). The brochure has detailed information about the program and the simple steps you can take to get matched with your very own NICU Parent Buddy. Don't wait, fill out the yellow insert in the brochure and give it to your baby's bedside nurse today! To get assigned a buddy, you can also reach out directly to Hayley.hirschmann@rwjbh.org.*

...what resources there were during our daughter's NICU stay

*Also in the NICU Welcome Bag is a **NICU Family Resource Guide** with lots of info about resources available to you while in the NICU. Useful NICU phone numbers are also listed on the back. While the hospital is still following COVID restrictions this guide is a blue sheet of paper in the welcome bag and is also available at the front desk when you arrive at the NICU.*

...what signs to look for to know if my child was going to have developmental delays

There is no way for any parent to be sure about this but having regularly scheduled visits to discuss milestones with the pediatrician and at our high risk infant follow up program (if the baby was born less than 1200 grams and/or earlier than 30 weeks) is very helpful. The NJ Department of Health Early Intervention Services (www.nj.gov/health/fhs/eis) encourages all families to view or download "Your Child's Development, Important Milestones from Birth to 36 Months," to see what is expected within "normal development." You can call them at 888-653-4463 to ask questions or request a home evaluation if your child seems more than just a little behind (which is fairly normal for premies up until the age of 2 years old with correcting for the prematurity).

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In honor of National Neonatal Nurses Week, September 14-20, we asked SBMC NICU nurses to share their favorite thing about being a NICU Nurse.



Donna Seyffart (NICU nurse 28 years)

"I love being able to see the kids when they come back to the Miracle Walk and seeing how we have impacted that life and that whole family."

Mackenzie Newnan (NICU nurse 2½ years)

"...loves seeing the 1st skin to skin baby has with mom and all the small victories that follow, especially with the real small babies"

Alyssa Devisser (NICU nurse 6 years)

"loves empowering families and helping them through a rough time in their lives..."

Pam Stone (NICU nurse 27 years)

"Loves watching the babies grow and go home with their families."

Jaclyn Susini (NICU nurse 2 years)

"Loves seeing the progress of all the small babies and seeing them growing and experiencing their first special moments with family... first feeding, first diaper change..."

Martha Dominique (26 years)

"Likes to see the good outcomes of the sick babies and the smiles on the parent's faces when they know they can take them home. Also, yesterday I helped a mom get her baby to latch for the first time and she was soooooo excited and so appreciative to have my help with this special occurrence and I was happy to be there to help her."

Ana Ruzic (NICU nurse here 3 years; 5 total)

"I love to see the babies getting bigger and getting better. also really like walking them out of the NICU when it is time for them to go home."

The 20th Annual Miracle Walk to benefit SBMC's NICU will be held virtually on Sunday, October 11, 2020.

We will not be able to all gather in person, but check out miraclewalk.com for more information. There are still t-shirts and activities planned from your computer and/or home. We are even collecting talent show admissions now. All of the details are on the website. Please register so we know you still support this great cause and so other people can support you and join your team and fund-raise too!!

To learn more, register for the walk, form a team or make a donation, visit:

miraclewalk.com | facebook.com/miraclewalk



Four Under Four

Our first child, a daughter, was born March 23, 2006 at 41 weeks. It was a fairly normal pregnancy following a few months of fertility help. At the time, my husband and I planned to have at least three children, but we were so happy when Emily was born healthy and happy.

After becoming pregnant with Emily, I was told I would need help again when we were ready for baby number two. The plan was to enjoy our baby girl and in a year or two try again...Fast forward nine weeks after Emily was born and we began our journey towards becoming a family of 4 in about 8 months. Our son was due to be born mid-March 2007, almost exactly a year apart from Emily. Plans were in place for our daughter's first birthday party as well as welcoming our baby boy.

I was teaching Kindergarten at the time and feeling great (a little tired but that was expected). What was not expected was that I would leave school on Friday, January 12 and not return for the year. That afternoon, I began feeling contractions and being extremely concerned, we called the doctor. We went to the hospital and I was immediately given medication to stop the labor and an injection to help my baby boy's lungs develop. I was sent home on modified bed rest which was not very easy when we had a nine month old baby at home.

I made it through the weekend, but by Wednesday, January 17, 2007 our son decided it was time for him to make his very early arrival. Even being born at 29 weeks, Brandon was over 4 lbs. He was immediately taken to the NICU at Saint Barnabas Medical Center (SBMC), where for the next few weeks, he received the best care we could have ever asked for. There were good days and bad ones, many ups and downs, but through it all, the nurses and doctors



who cared for Brandon were unbelievable. From the many calls (sometimes in the middle of the night), to the endless questions we had, someone was always there to ease our minds.

A few weeks later, in February, Brandon was released from the NICU and came home to join his big (not by much) sister. We have been grateful to the NICU for everything they did for our family. Brandon is now 13 years old, going into 8th grade. He and Emily just had their B'nai Mitzvah in December and decided to give back to the NICU as part of their Mitzvah project. Emily crocheted hats for the babies, and Brandon made take home bags for families currently there.

About two years after Brandon was born, we decided that we wanted to add to our young and happy family. This time it wasn't as easy, but we became pregnant with twins. Being that I was carrying twins and my history of delivering a premature baby, I was high risk and was watched very carefully. Each week that went by was one more week that our twins were growing and thriving. Each doctor visit showed our babies' heartbeats and development. By 30 weeks, I had surpassed the "danger zone" and although cautious, I felt comfort knowing that if my twins were born early, they would receive the same amazing care that Brandon got. We were much less worried, and being that they were twins, and our third and fourth children (in four years), we



assumed that they would be in the NICU for some amount of time.

At 35 weeks, on October 13, 2009, Addison and Samantha were born, weighing in at 3.8lbs and 4.2 lbs. Healthy and happy, they were brought to the NICU for observation and some feeding help. Samantha needed some help regulating her body temperature and Addison was mostly there for "sisterly support." The girls stayed in the NICU for 2 weeks and were sent home by the same wonderful nurse who was there for us throughout our time with Brandon. Leaving with our twin girls was bittersweet as we had been a part of the NICU for so many years. Each nurse and doctor who is there truly is special. Without them, our family would not be who we are today. Emily (14), Brandon (13), Addi (10) and Sammi (10), are all happy, healthy growing children and we have the NICU at SBMC to thank for that. It has been amazing to see the development of the NICU since our children were there. We know that they will continue to do the miracle work they do each and every day!

Thank you so much, Melissa R.

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

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973-322-9486

What Graduate NICU Parents Wish they Knew

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...the seriousness of having a micro-preemie and the amount of blood transfusions that might be needed during the NICU stay. I think our son had 3 or so. On those days his coloring was always off and I wasn't able to hold him because staff told me he would burn too many calories. Looking back, maybe if I knew that it would have helped me mentally prepare. It always made me so sad to not be able to hold him.

Actually, at this time, parents can hold their babies, even during a transfusion as long as some other medical issue does not stand in the way. If the baby is wrapped up well and kept warm, losing calories should not be a concern during a transfusion.

...more about the consequences of prematurity for a baby's long term health outcomes. I do realize it might not even be possible to know as each child is different but just milestone markers for prematurity versus full term child.

As mentioned above, regular pediatrician visits will help with this and you can refer to the Important Milestones brochure on the Early Interventions services website to be aware of these as your baby goes from birth to 36 months – keeping in mind the adjustment for age depending how premature they were.

...other moms who had been through something similar.

...what to expect at 3 months, at 6 months, and a year after going home

...what was normal and what was not.

...to always trust my instincts.

...the best places to go to address issues as they arose.

*The mom of twins who sent these five responses actually helped form a private FB group called **SBMC NICU Parents** to address some of these – check it out if you like! Also see responses above about getting a NICU Parent Buddy or the Early Intervention milestone pamphlet (from birth-36 months) available online.*

... that being in the NICU was actually a helpful experience because it enabled me to ease into Motherhood with great teachers showing me the way
Yay, a positive and it's true!

... to ask the nurses all of the questions I had because they are the best resource and are so available when you are in the NICU

Yes, ask away! Don't even be afraid to ask for clarification or ask a question again if you did not understand the answer. After all, most of the NICU parents don't have nursing / medical backgrounds.

... I could call the NICU any time of day or night to ask a nurse how my baby was doing. I did not know this until a few days after I went home from the hospital.

It's true, you can call anytime (except between 6:30-7:30 AM and PM because the nurses are focused on getting report for the shift change). Remember not to get worried if the nurses don't pick up right away or ask you to call back because your nurse is busy, as they usually have a few babies to care for on each shift.

...that it was ok to let staff know I wanted to hold / kangaroo my baby.

You may not believe it but you are your baby's best advocate so get used to that idea! If you want to hold / kangaroo your baby more, you need to let them know. They may assume that if you don't say anything you don't need their help with anything, so speak up. You and your baby will be glad you did!