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...

... May 15 is International Kangaroo Care Awareness Day? Doing this kind of skin-to-skin holding with your baby is good for you and for them. Talk to your nurse and get in on the Kangaroo-a-thon contest we are having from May 15 to 30. During this time, Kangaroo with your baby as much as possible (for at least an hour at a time), to win a prize! Good luck!

### Saint Barnabas **Medical Center**



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



94 Old Short Hills Road, Livingston, NJ 07039 1-888-724-7123 rwjbh.org/sbmc

# - 111CU Family News

### Coping in the NICU and Beyond

Having a baby or babies in the NICU is scary right? Well yes, but it can also feel downright terrifying for some! NICU parents often watch their babies struggle to eat, to grow, and often just to breathe. It's no wonder a number of recent online articles and medical journal articles reveal higher rates of depression, anxiety and even post-traumatic stress disorder in NICU moms and yes, in dads too. They also show these rates to be higher for up to a year after NICU babies come home. These parents are often jugaling numerous stressors (e.g. being out of work, costs of hospitalization or spending extended time at the hospital) on top of worrying about their baby and their future.

Almost all NICU parents experience some grief which can be supported and talked about and generally lessens once they can sleep better, eat better, see the baby improving, and are hopeful about taking them home. Sometimes though it does not improve, and indeed it worsens and turns into clinical depression and/or anxiety which they feel they cannot control and may need the help of medication and/or psychotherapy. The most important thing you can do as a parent is to be open and honest with medical providers and friends/family about how you feel. No one can help you get the services you need unless you tell them. Often for women it is their OBGYN that needs to hear about their mood at follow up visits. Please don't assume because you feel like you "seem sad" when visiting the NICU that will translate to your doctor knowing how you are feeling. You must tell them what you are thinking and feeling beyond just the initial terrified feelings we mentioned earlier. If they are not listening or do not seem to think your low mood as a NICU parent is as serious as you do, check in with your regular doctor as well.

In recognition of May being Mental Health Awareness month, NICU graduate parents will be posting on the hospital NICU facebook page (SBMCNICU) about mental health in general and after having a NICU baby. Feel free to check it out and join in the conversation.

Graduate NICU parents from SBMC have also shared these emotional tips, based on their experiences, to try to help you get through "the NICU roller-coaster ride:"

■ If possible, try to stay positive and think about getting ready to take your baby home one day.

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### Interview With Laura Romeo, BSN, RNC

### Saint Barnabas Medical Center NICU Nurse

### Q: How long have you been working in the NICU?

A: I have been at SBMC 32 years this June. I have been in the NICU for 31 years. This is my first job since graduating nursing school. I started in 1987 as a Maternal Child Float and transferred to NICU after one year. Working as a maternal child float was a great way to start my career because it made me realize how much I wanted to work in the NICU.

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

A: Like most nurses, I have wanted to be a nurse since I was a child.

## Q: What have you liked the most about working in the NICU?

A: That is very hard to answer, because it is hard to pick just one thing. However, I really enjoy attending the Miracle Walk fundraiser that benefits our NICU because it's so nice to see our graduates progress and thrive through the years. The walk is held every October and people can go to www.miraclewalk.com to find out more about it if they are interested.

# Q: Recently the NICU staff have been learning more about the possible short and long term benefits of more neuro-developmentally sensitive care that is considered "protective," especially for the very premature babies. What are your thoughts about this?

A: In 2017, I attended the Vermont Oxford Network (VON) Conference with some members of our NICU VON team. One of the speakers was a NICU parent of a former preemie. She spoke in detail of her daughter's sensitivity to noise and other issues since her very premature beginnings. This had a very big impact on me. I think that this is a very important thing that we can continue to

improve upon in our care to protect our infants and improve their outcomes.

# Q: What do you think is the most important component of this kind of care?

A: All of the components are important. I think it is important to maintain a quiet environment. The Mom that spoke at the VON Conference



showed a picture of her middle-school aged daughter covering her ears as she flushed the toilet with her foot to get farther away from the sound. The child had such a pained look on her face. That stressed the importance of this component to me.

#### Q: What does Family Centered Care mean to you?

A: Family Centered Care means that the family and the medical staff work together for their baby or babies; we are a team from day one. This can start at a hand hug and progress as the infant is able to tolerate more. It means involving the families in all aspects of their baby's care.

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

A: There are many informal "classes" offered in the NICU. There is NICU 101, weekly discharge classes, breastfeeding classes and infant CPR. The classes offer a lot of really good/practical information for new parents and allow families to meet other families they can relate to. I strongly suggest NICU parents try to attend as many of these classes as possible.

# 19th Annual Miracle Walk To Benefit the SBMC NICU

Sunday, October 13, 2019 9:00 am at Verona Park

**LEARN MORE AND REGISTER:** 

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



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### **Katheryn's Story**

On April 1, 2018, Katheryn Delsy R. was born.

It was Good Friday, March 30 when it all began. I was getting up to go to the bathroom and as I got up noticed my water broke. I was only 24 weeks, 6 days into my pregnancy, and I was scared. I went to the Pre-Evaluation Testing (PET) Unit at Saint Barnabas Medical Center (SBMC). There, I was immediately put on magnesium and antibiotics, and was then given a steroid shot to help my baby's very premature lungs. That Saturday night at 11:30 pm, I felt contractions and told the nurse they were happening every seven minutes and quickly moved to every four minutes.

It was now Easter Sunday, April 1, 2018, at 12:00 am. Katheryn was now 25 weeks, 0 days. An epidural relieved the contractions but I was really shaken up not knowing what to expect. The nurses were amazing in Labor and Delivery and in the PET unit. They assured me I would be ok. At 4:01 am my Little Warrior Katheryn was born at 25 weeks, weighing 1 pound, 7 ounces. I was scared about what would happen next when I didn't hear her cry. I looked when a nurse said, "She's moving her arms." Then I saw her briefly and off she went to the NICU.

A little after 7:00 am, I saw my baby girl in the NICU hooked to all those wires and the oxygen machine. I was able to touch her briefly and I remember it being the best feeling ever!

Three days later, she had a head ultrasound test which came back all clear and we breathed a sigh of relief!

Six days later, I held her for the first time with the help of the amazing nurses in the NICU. I was scared and excited but I finally got to hold my baby. While many get to

hold their babies right away or the next day, I had to wait until 6 days later. It felt like I waited forever but, it was the best feeling to finally hold and feel my little girl. Eleven days later was Daddy's first chance to hold his baby girl. He was so scared because she was so small and fragile. But after that day Daddy always wanted to hold her.

When Katheryn was 1 month old, she pulled her feeding tube out. It was Mother's Day and my other 3 beautiful daughters were at the NICU to take a family picture for the occasion. I think Katheryn was trying to show off in front of her big sisters. LOL!

After three months and 11 days, Katheryn graduated from the NICU and came home with us!

The nurses had helped me so much, even on the roller coaster days when Katheryn needed blood transfusions (she had 3), or when her oxygen would have to be increased, or she was having a bad feeding day. They always tried to educate me on how things are different with a preemie and how she will get older and get better. And, she has! If there was anything I wasn't sure about they would even print articles for me to read. The lactation nurses were so patient and wonderful with helping me understand any concern I had. Being in the NICU this long takes a toll mentally but we worked at staying strong with prayers and much love from many friends and relatives. The NICU became our family. There were many nurses who gave us and Katheryn the love and support we needed to survive our NICU journey.

Thank you to all our angels in the NICU, Irma N. and family



Daddy's First Father's Day
With His Princess



Mother's Day



Katheryn is going home today!



# Important Phone Numbers:

NICU 973-322-5300

NICU Nurse Manager 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

### Coping in the NICU and Beyond (continued from page 1)

- If it hurts, don't keep it to yourself. If you are sad or having other powerful emotions find a good listener and tell them how you feel. This may be a spouse, friend, parent, religious leader, or a NICU buddy who may have felt the same feelings you are.
- Remind yourself how good the care is that your baby is getting at SBMC and that the doctors and nurses are doing everything they can in an effort to have your baby go home as healthy as possible one day!

# Graduate parents, who are where you are now, also had these suggestions for trying to balance NICU life with outside life:

- Try to get as much rest as possible. This is a MUST, especially for moms recovering from delivery and pumping breastmilk or breastfeeding. Don't be opposed to a quick nap sitting at your baby's bedside, even if you were never much of a nap person before.
- Eat nutritious meals. You may not feel much like grocery shopping or cooking while your baby is in the NICU but eating well is an important part of the recovery process. Also, you will need to take in about 500 calories more a day than usual for each baby you are pumping or nursing for. Eat more smaller meals if you don't have a big appetite and do take friends/families up on offers to cook for you if you are lucky enough to get them.
- Make sure to drink enough fluids. If you are pumping or nursing you should be drinking at least 6-8 glasses of water or other non-caffeinated drinks each day.
- Accept practical offers of help. Sometimes friends and family offer to help but don't know how. Asking them to help with things like meals, child care or household chores could create more time for you and your spouse to focus on your NICU baby, your other children and each other.
- Limit the number of phone calls and/or visits you accept. It can be exhausting to retell your baby's status/progress each day to many people. Consider using email or text groups to reach out to many people at once. Or you can choose one person to update and then have them update others you want to have information.
- Try to make the most of the time when you are here in the NICU. If you are on a tight schedule with time (due to work and/or needs of other children at home...) try to spend time at the NICU when your baby is awake and alert. Whenever you see your baby's nurses let them know you want to try to be there when your baby is awake and they can usually tell you when they will be fed or bathed so you can be there too.
- Above all, be patient with your baby and with yourself. You and your baby will heal in your own way and your own time. A common feeling NICU parents experience is guilt but remember "feeling" and "being" are two different things. Feeling guilty or feeling like a failure is not the same as being guilty or being a failure. Try to focus on the idea that you are doing the best you can and your best can get better with patience, practice, self-care, and professional help if needed.