Saint Barnabas Medical Center NICU Family Advisory Council



Learn more about NICU Graduate Lauretta Rose, now a preschooler, and her mom Rose on page 3.

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 request a NICU Parent Buddy? This is a parent who has already had a baby (or babies) in the SBMC NICU and can give you emotional and informational support. Because they have had NICU experiences similar to yours, they can give very special support that only another parent who "has been there" can. You can request a "Buddy" by calling the program coordinator at 973-214-6970 or by filling out a yellow NICU Parent Buddy Program info sheet (found in the NICU Social Workers office).

### 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 With the Stress of COVID-19

For years NICU parents, like you, have been practicing excellent handwashing and "social distancing," in the form of limiting visitors, to help keep their ill and premature babies as healthy as possible. In this era of COVID-19, the rest of the world has finally joined us in these habits, so we are not "strange" or alone anymore. For years, NICU parents have had to deal with worries about our babies struggles to eat, to grow, and breathe. But now, there are also worries about our and all of our loved-ones' health, possibly being out of work or having reduced income, homeschooling our other children, lifestyle changes and more due to COVID-19. We are challenged with the uncertainties of the NICU and the world as a whole. It's clearly an even more difficult time than ever to be a NICU parent due to all the stressors and worries that are being juggled. So, what can you do?

- 1. Remember you are not alone in your feelings. A certain amount of worry, and even grief, as a NICU parent is normal, especially the first few weeks your baby is in the NICU. However, 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. Let your OB/GYN, internist, and NICU staff know if you are struggling emotionally. There are currently many therapists and psychiatrists offering virtual appointments for people who need them so ask a professional about this. People can't help you if they don't know you need help and they can't read your mind.
- 2. The NICU Social Worker (973-322-5503) can help you while you are in the NICU and can help you find resources for help outside the NICU if needed. Call her or ask a NICU nurse to direct you to her office.
- 3. The NICU Family Advisory Council Coordinator (Hayley, 973-214-6970) is currently offering virtual zoom-type groups to provide information and support for the current NICU families.

Groups take place every Wednesday from 12:30 to 2:00 pm and the first and third Sunday of each month from 8:00 to 9:00 pm. Please use codes provided to the right to join.





Wednesday

Sunday

# Interview With Sarah Ambio, RRT

## Respiratory Therapist, Saint Barnabas Medical Center (SBMC)

### Q: How long have you been working at SBMC?

A: I have been working as a respiratory therapist at SBMC for almost 8 years now.

### Q: Please describe what your role is in the NICU and what you do?

A: I help babies with different lung illnesses. Due to their prematurity, some of the babies in the NICU are born with compromised lung functioning. This requires me to use a number of different, state-of-the-art breathing machines we have in the NICU to help them overcome their illnesses. Basically, any time an infant needs oxygen to help them breathe, I play a role in their treatment. I am also always available when I'm here to help the staff move a baby on respiratory equipment to be able to be held skin to skin by a parent.

### Q: How did you know you wanted to be a respiratory therapist? Did you know you wanted to do this work specifically with infants and is there special training for this?

A: I always knew I wanted to work with children or babies and was drawn to working in a medical field since I was a teenager. I started out taking classes in the pre-med and pre-nursing direction. My personal life led me down a different path of starting my own family but I eventually found my way to the medical field through respiratory therapy. Once I became a registered respiratory therapist (RRT) I did study and take the exam for the Neonatal/Pediatric Specialty (NPS) so I could work mostly with babies and children at SBMC.

### Q: What do you like the most about working in the NICU?

A: I like working with the babies and especially like getting to see their conditions improve. It's very special to see babies who are so critical at birth go on to survive and thrive. I also really enjoy working hand in hand with the rest of the dedicated NICU staff.

### Q: In recent years the NICU staff have been learning more about the possible benefits of more neurodevelopmentally sensitive care (i.e. low lighting, low voices, two person cares). What do you think about this?

A: I think this kind of care is amazing for the babies because it tries to reproduce more of an the in utero environment that

Sarah Ambio, RRT

the baby came from. As much as we can try to create this environment in the NICU, I think we should keep working to do so.

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

A: To me, this means caring for the whole family, not just the babies. I think it's important to foster as much communication as possible with the families and try to include them in their baby's treatment as much as they are able to be involved.

### Q: Do you have any suggestions or advice for NICU families in general and/or about being involved in their care/holding their babies?

A: I would say to the parents to try to not be too afraid to hold their babies even if they are on breathing equipment because the nurses and respiratory therapist will help them. The staff will manage the equipment so all the parent has to think about is taking a deep breath and holding their baby.

### Q: Any other personal or fun facts you would be willing to share?

A: I have 3 kids (who range in age from 16-22 years old) and an American Bulldoa!



Miracle Walk To Benefit the SBMC NICU Save-The-Date 20th Annual Miracle Walk Sunday, October 11, 2020 9:00 am at Verona Park

> Learn More and Register: miraclewalk.com 973-322-4259 ■ facebook.com/miraclewalk



# A Mom's Story

"It's a girl... you have a beautiful baby girl Mrs. S."

The experience of childbirth is one like no other. Regardless of the incredible support of the physician, L&D nurses, staff and your spouse or partner, a woman in childbirth is alone in her mind, physical body and spirit. Nothing prepares you for such an intense but beautiful experience. While it all happens in the blink of an eye, the aftermath of emotional intensity is a force to be reckoned with.

"Can I hold her?" I remember asking while still shaking and trying to compose myself.

My little Lauretta Rose was born at 36 weeks and 3 days. Balloon induction. Maternal Intrahepatic Cholestasis of Pregnancy... aka torture. While no two pregnancies and deliveries are the same, nothing prepared me for my daughter's 10-day stay in the NICU at Saint Barnabas Medical Center, or what I endured for 5 weeks before her induction.

Cholestasis is a liver condition that occurs late in pregnancy. The condition triggers intense itching with complications to the mother and baby. Extensive monitoring is a must and early delivery is typically required as part of treatment. With that, a baby's lungs tend to be underdeveloped as a result. Thankfully, my intense itching stopped immediately after childbirth and my body no longer felt on fire. But I was feeling other things. Lauretta needed to go directly to the NICU because she wasn't breathing well and my wish of holding my baby airl was short lived. It had been 5 weeks of medications, counting kicks that started to slow as time progressed, itching to the point of bruising and



NICU Graduate Lauretta Rose together with her mom Rose on her first day of pre-school (left) and back when she was in the NICU.

cutting myself on my palms and ankles, and 4 steroid shots in my backside to name a few. What did they mean I couldn't hold her?

Off she went into the NICU. While trying to rest, heal and regain strength I knew she was in God's hands with the best care possible. This allowed me to take care of myself (LADIES, I SUG-GEST YOU USE THIS TO YOUR ADVANTAGE). The first time I was able to see Lauretta, she seemed covered in tubes that were helping her breathe. I wanted to die. I thought she was dead. All of these crazy emotions were running through my head and I knew this was not what I expected for the delivery of my baby. I actually ran... OK, walked very fast... 1day post-partum back to my room. In my head I was running. When I was discharged without her, I took myself to the mall and attempted to feel normal again. The sales associates thought I was nuts! I was 5 days postpartum but was on a mission.

Being discharged without your baby is probably one of the most difficult things a mother can go through. In my experience, I would say it was the worst part of it all except for any physical pain. To know my baby was not coming home with me after 8 months of carrying her was devastating. I felt like an empty shell. If you're a NICU mom reading this, please know you

aren't alone. Many other NICU moms have gone through the experience of returning home without their little one right away; an empty car seat or an empty crib - it can be really painful. Talk to people, ask for support in the NICU and beyond, ask for a ride or groceries, a hot meal... anything. You need nurturing during that time more than ever. There is always someone to listen if you reach out. Friends, family, NICU staff, I even found good resources at www.postpartum.net

For 10 days as a post-partum mother, I pumped around the clock to keep my milk supply up. Reading that breast milk was the best thing for a NICU baby, I was determined to get it to her and be there for her as much as I physically and mentally could. Back and forth to the hospital I went. Oddly enough, even though the pumping was exhausting, it was the thing that helped me be strong and present for Lauretta and it was the thing that I believe made her strong too. I feel blessed beyond compare that she is here with us today, almost 3 ½ years later. I try to hold her now, even more than ever.

Remember NICU parents, "You've got this!"

Fondly Written By: Rose F. S.



# 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... (continued from page 1)

4. Try to maintain good self-care and improve your sense of control. The NICU and all the COVID-19 changes in the world can really ruin your sense of control over your daily life. It's important to try to maintain some balance wherever possible (get enough sleep, try to eat healthy, get some physical exercise as many days of the week as you can, avoid drugs and alcohol, accept circumstances that you cannot change and focus on what you can, practice the belief that you can get through this).

Interestingly, many of the tips that NICU graduate parents have shared in past newsletters to help you cope with the "NICU roller-coaster ride" are as powerful today in these times of COVID-19. They are reprinted here:

- If possible, try to stay positive and think about getting ready to take your baby home one day.
- 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!
- 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 power-nap sitting at your baby's bedside.
- Eat nutritious meals. 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 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 you accept. It can be exhausting to retell your baby's status/progress each day to many people. Consider using group texts or emails 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 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.