

NICU Family Advisory Council


 The logo for NICU Family News features the word "nicu" in a large, blue, lowercase, sans-serif font with a dot above the "i". Below it, the words "Family News" are written in a smaller, blue, uppercase, sans-serif font.


NICU Graduates Maya and Sienna.

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...

...doing skin to skin care with your baby in the NICU has a number of benefits for baby and is one of the most comforting things a parent can do for their child. No NICU equipment can substitute for doing skin to skin care. Talk to your nurse to see if your baby is able to do skin to skin with you (for babies born less than 32 weeks gestation, you will have to wait until after their first three days of life).

Read To Your Baby

In Support of the National NICU Read-a-Thon

Former NICU parents often say how helpless they felt at times while their baby was in the NICU. The nurses at SBMC have been focusing in recent years on encouraging and supporting parents to hold their babies and be involved in their care whenever possible, to try to cut down on this feeling. Also, in the last few years, research has shown that reading out loud to sick and premature babies brings extra special benefits to the babies as well as their parents.

This year, to show our support for reading to babies, our NICU will be participating in a **National NICU Read-A-Thon event** with more than 100 other NICUs from around the U.S.! From **September 13 to 23**, staff will be giving out board books and encouraging all families to read to their babies every time they are together in the NICU. We also hope bringing awareness about the many benefits of reading will keep families reading to their babies often once they are home from the NICU. All families and staff who participate in the Read-A-Thon will be entered to win a prize which will be drawn at the end of the event.

For NICU parents, reading out loud to baby is a way to be involved with them in a positive way that is not medical but rather a "normal" thing a parent would do with a baby. Often, reading this way to babies in the NICU helps parents bond and feel a little bit "closer" to their baby. It's also something the parents can do for their baby at a time when they may feel as if there might not be much more they can do.

Very important research also shows that babies in the NICU have important brain development going on and reading to these babies helps aid in this development. Believe or not, it seems it is helpful to both speak to your baby AND read out loud to them. Neonatologists at a NICU in Boston found it so important that they set a goal for parents, or other family members, to read to their NICU baby at least once every day. Research also shows that from birth and beyond, in addition to advancing brain development, language skills, and vocabulary, reading out loud can also build listening and memory skills over time.

(continues on page 4)

Interview With Dr. Rudolph Wagner, Pediatric Ophthalmologist

Dr. Rudolph Wagner has been caring for babies in our NICU since the early 1990's. He also treats babies and children of all ages through his private practice.

What are the criteria for you to do an eye exam on a baby in the NICU? All babies born at 32 weeks or less and/or 1500 grams or less need eye exams according to criteria established by the American Academy of Pediatrics and the American Academy of Ophthalmology. I usually see these babies in our NICU at four weeks of age. Larger and older babies may be examined as well if they have a suspected disease or genetic disorder, or have been on oxygen for more than a few days.

What is this exam like? The exam takes about 3 to 5 minutes for both eyes. We don't need to sedate the babies since they handle it pretty well. The nurses carefully monitor the babies during the exam because sometimes their heart rate lessens and the oxygen saturation decreases slightly. We do place a small device in the eye to keep the lids open during the exam. This allows us to complete the exam in less time, as I look through the dilated pupils at the retina with a lens held in my hand and a light source (indirect ophthalmoscope) on my head. I often warn the parents that this doesn't look very pleasant, and advise some not to watch the exam. I think watching the exam hurts the parents or family more than the exam affects the baby.

When do you come back to do repeat eye exams and about how often does this happen? Usually 2 weeks after the initial exam, a second exam is done. Depending on the findings we may need weekly exams in higher-risk

cases. We follow these babies until the retina is fully vascularized to the periphery in both eyes. Then the baby is no longer considered at risk for Retinopathy of Prematurity (ROP).

In simple terms for parents, what is Retinopathy of Prematurity (ROP) and how common is it? ROP is a vascular or blood vessel developmental disorder in which the normal growth of retinal arteries and veins is interrupted in very premature babies. Prematurity is the cause and exposure to high levels of oxygen (which is necessary for survival) may lead to progression of the disease in some babies. We are not sure why it occurs in some babies and not others. The problem is that abnormal fragile blood vessels can grow in the premature retina and can cause bleeding, scarring and retinal detachments. A small percentage of babies go on to require laser therapy or injections of medicine for treatment into the eyes, and some of those require retinal surgery.

Why did you become a pediatric ophthalmologist to begin with? I enjoy helping children and recognize that early treatment for many eye disorders can have life-long benefits for these kids and their families. I really like to see the kids as they grow up and to hear about their accomplishments. That might be the best part.

(continues on page 4)



21th Annual Miracle Walk to benefit the SBMC NICU: Sunday, October 10, 2021

Visit us online to learn more about this year's walk, including details and information about registration and fundraising.

Don't wait! Check out it out and register now:
miraclewalk.com | facebook.com/miraclewalk



Maya and Sienna – Twin Rainbow Babies

After a difficult road with IVF and pregnancy loss, we were thrilled to be expecting twin “rainbow babies.” I had a normal 13-week checkup with our high-risk doctor before we headed off to our annual family beach vacation to relax.

On the last night of vacation, I began experiencing spotting. I checked in with both my obstetrician and high-risk physician by phone and came in for an appointment as soon as I could, but I had a feeling that something was wrong. My instinct turned out to be right. At my next checkup, our high-risk doctor told us Baby A had low fluid and they did not know why. At 18 weeks, Baby A was officially diagnosed with **pre-term premature rupture of membranes (PPROM)**, and Baby B was diagnosed with chronic placental abruption.

As parents-to-be, we suddenly felt our world crashing down on us. We made the decision to try everything we could. Life on the 3200 unit at Saint Barnabas Medical Center (SBMC) became a whirlwind of steroid shots, magnesium, and taking it one day at a time to try to reach a point where the babies could survive. Incredibly, our Baby A resealed and regained normal fluid for a few weeks!

On November 13, 2018, at 30 weeks gestational age, our two pound, strong-willed daughters, Maya and Sienna, were born screaming along to the song “Bohemian Rhapsody.” We were amazed at how hard they had fought and how much they had already overcome, but also knew our daughters had a long road ahead.

Despite all the beeping noises, tubes, and wires, the NICU became a comfortable place very quickly. We settled into a routine as a family and watched our palm-sized girls grow and thrive with the care of their outstanding nurses and neonatologists. They answered all our questions and always made us feel comfortable. They put up with Maya's tricks when she hit 3 pounds and repeatedly pulled out her feeding tube and tried to roll out of her bed. They became part of our family, especially as our stay coincided with the holidays.

Sienna, our sweet Baby B, came home after 51 days. The most stressful part of our NICU experience was having one baby home and one still in the NICU. Maya, our feisty Baby A, joined us at home after another 15 days, at day 66.



NICU Graduates Maya and Sienna in the NICU and now!



Today, Maya and Sienna are healthy, happy almost-three-year olds who love singing, reading, and playing outside. Our twins are, without a doubt, the best thing that has happened to us. We will always be grateful for the care our family has received through SBMC.

-Andrea and Jordan L.

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. Contact:

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

Read to Your Baby (continued from page 1)

So, bring a few books to the NICU and try to read to your baby each day. You will be glad you did! If you want to read out loud to your baby in your native language, please do so. There are many wonderful books available to read to your baby. Here are some favorites some of our NICU graduate parents recommend:

- | | |
|--|----------------------------------|
| 1. Goodnight Moon | 7. Where is Spot? |
| 2. The Very Hungry Caterpillar | 8. Jamberry |
| 3. Guess How much I love You? | 9. Good Night Gorilla |
| 4. Five Little Monkeys | 10. Moo, Baa, La, La, La! |
| 5. Llama Llama Nighty-Night | 11. The Colors of Us |
| 6. Brown Bear, Brown Bear,
What Do You See? | 12. If You Give a Mouse a Cookie |

Interview with Dr. Wagner... (continued from page 2)

What do you like most about working with the patients in the NICU?

First of all, helping the babies and their families, but here at SBMC in particular working with the staff. The doctors, nurses, respiratory therapists, social workers, pharmacists and others are of the highest level and provide the very best care to these little patients.

Have you seen any beneficial changes in the NICU since you have worked here? There are many, but I like that the doctors and nurses try to establish a consistent relationship with the families. The technological advances including the newest Giraffe isolettes and monitoring capabilities are outstanding and rank with any NICU in the world. Recently, we have obtained a state of the art retinal camera, called the RetCam thanks to very generous donors. This device allows us to take pictures of the babies' retinas so we can monitor any changes which can help in our treatment decisions. In some cases, we can show the images to the parents to help them better understand why we may need to treat their baby. Very few NICUs have this technology available.

Do you have any suggestions or advice for NICU families? Sure, don't be afraid to ask questions. All of us enjoy what we do so it's rewarding to be able explain our role and why we do what we do for the babies. This way the parents can better understand what's going on.

Anything else parents might not otherwise know about you that you would like to share? I am the Director of Pediatric Ophthalmology at the NJ Medical School which has been part of Rutgers since 2013. There I teach residents and medical students. I am the editor of the *Journal of Pediatric Ophthalmology and Strabismus* and completed a textbook on Pediatric Ophthalmology for the Pediatrician in 2014.