

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

DID YOU KNOW...

... August is World Breastfeeding Month! Try breastfeeding today. Breastmilk is best for your baby and breastfeeding has benefits for you too (www.babycenter.com).

"Designated Support People" Program Begins in the NICU

At the suggestion of numerous past NICU families, current NICU parents can now identify support people that will be allowed into the unit without them. In the past, visitors could only see and spend time with a NICU baby if one of the baby's parents were present. However, families have shared that sometimes it would be helpful if a grandparent or aunt/uncle could spend time with their baby when they could not be in the unit (home sick, back at work, unable to drive, etc.). The NICU staff heard these concerns and, with the help of graduate NICU families, developed a set of guidelines allowing up to four people to be named by the family to spend time with their baby/babies without them.

"Support people" will need to follow all the existing NICU visitation guidelines and some others, including that they:

- must follow all hand washing guidelines to prevent infection in the NICU
- must be at least 18 years old
- may not bring additional visitors to the NICU who are not on the support person list
- must not come to the unit if they are sick, not feeling well or showing signs of flu symptoms
- must be identified by the NICU family and photographed for an ID badge
- must wear their photo ID badge at all times in the NICU
- will only be given general medical information and must respect the confidentiality of all babies in the unit by not asking questions about or taking pictures of any baby other than the one(s) they are designated to visit
- will respect the family and nurses decisions about what level of involvement is appropriate for the baby each day and understand that this could change from day to day depending on the baby's condition
- need to step away from the bedside during procedures or emergencies if asked to do so by NICU staff
- understand that this program could be suspended at any time to ensure the safety of the babies (i.e., during a bad flu season)

Think about if you would like for any of your family or close friends to be able to visit your baby in the NICU at times when you are not there. This is not for every one, but if you are interested in having Designated Support People for your baby talk to your baby's bedside nurse or social worker about filling out the necessary form.

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



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BARNABAS HEALTH
Saint Barnabas Medical Center

Interview With Rudolph (Rudy) Wagner, MD Pediatric Ophthalmologist

Dr. Wagner has been consulting in our NICU since the early 1990's after being recruited by Dr. Sun who he knew from Children's Hospital of NJ. Dr. Sun told Dr. Wagner of the need for pediatric ophthalmology in the NICU and because of his great respect for Dr. Sun and his work, and his staff, he began to see babies in the NICU.

Q: What are the criteria for you to be called in to do an eye exam on a baby?

A: 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. These babies are usually seen at four weeks of age. Larger and older babies may be examined as well if they have a suspected disease or genetic disorder.

Q: What is this exam like?

A: The actual exam takes 3 to 5 minutes for both eyes. We don't need to sedate the babies since they tolerate it pretty well. The nurses carefully monitor the babies during the exam as it is not unusual for the heart rate to lessen and the oxygen saturation to decrease 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 about this as it 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 hurts the baby!

Q: Under what circumstances do you come back to do repeat eye exams and about how often does this happen?

A: 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 they are no longer considered at risk for Retinopathy of Prematurity (ROP).

Q: In simple terms for parents, what is Retinopathy of Prematurity (ROP) and how common is it?

A: ROP is a vascular or blood vessel developmental disorder in which the normal growth of retinal arteries



Rudolph Wagner, MD

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 and some of those require retinal surgery.

Q: Why did you become a pediatric ophthalmologist to begin with?

A: I enjoy helping children and recognize that early treatment for many eye disorders can have life long consequences and benefits to 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.

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

A: 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.

Q: Have you seen any beneficial changes in the NICU since you have worked here?

A: There are too many to name them all, but I like the fact that the doctors and nurses try to establish a consistent relationship with the families. The technological advances including the newest isolettes and monitoring capabilities are outstanding and rank with any NICU in the world.

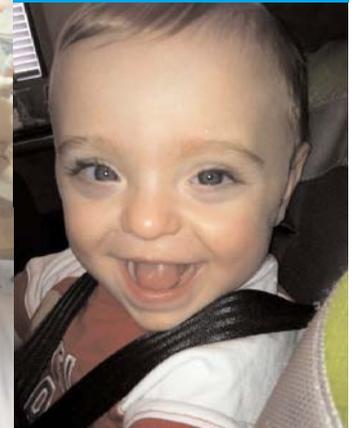
(continues on page 4)

John Michael's NICU Story

We were all surprised and terrified when after only 23 weeks the doctors told us that because of my preeclampsia, my baby had to come. Hours later John Michael arrived, tipping the scales at just 1 lb., 2 oz. This was the start of a long, bumpy road called NICU life. John Michael's lungs were always his kryptonite. Every time we went to the NICU his doctor told us of more difficulties and problems. "We had to put him on an oscillating ventilator." "We had to give him some nitric oxide to help open up his lungs." "He has too much air leaking from his lungs so we'll need to insert a chest tube." "I think that he may benefit from steroids but we need to wait until he's old enough." "He's showing some progress with the steroids, but we need to discontinue them because they are causing other problems." Minutes turned into hours, hours turned into days, days turned into weeks and our little angel was still alive!

John Michael taught us many lessons. We learned not to take anything for granted. Each day is truly a gift. We were excited about changing his dirty diaper and giving him a "bath" just so we could touch him. We longed for every time we could "kangaroo" with him and patiently waited for his first cry.

The first month was by far the hardest, but in time John Michael started gaining weight and even learned how to breathe on his own. After 2 ½ months, John was finally able to come off the ventilator. John's NICU stay was filled with plenty more bumps, twists and turns. He never took to the whole feeding thing either and needed to have a g-tube placed in order to come home. It's always difficult to accept the fact that your child cannot eat by mouth, especially when



John Michael in the NICU and all smiles today!

you're a speech therapist. After 221 days, John Michael was finally able to breathe well enough to come home to us. It was hard to believe that our 14 lb., 13 oz. moose of a baby was ever a micro preemie.

Our days are now filled with weekly follow up appointments for different doctors and specialists. John Michael is in therapy each day to help with feeding and physical delays due to his extreme prematurity. It brings tears to my eyes to see him reach his developmental milestones at his pace. Every day is filled with more smiles and hope.

We can never begin to repay Saint Barnabas NICU for all they have done for our family. They gave our son the true miracle of life. Other parents and the NICU community gave us hope when there was none. The biggest miracle of all is that one day our little baby who once clung to life will be a typical little boy running with the rest of the pack!

Save-The-Date

13th Annual Miracle Walk
To Benefit the SBMC NICU

**SATURDAY,
September 28, 2013**

Verona Park, Verona, NJ



To learn more or register:
MIRACLEWALK.COM ■ 973-322-4259

Find MIRACLE WALK on FACEBOOK
FACEBOOK.COM/MIRACLEWALK

Important Phone Numbers:

NICU
973-322-5300

NICU Step-down (3100)
973-322-5310

NICU Nurse Manager
973-322-8938

NICU Social Workers
973-322-5503 or 8408

NICU Case Managers
973-322-2045
973-322-2678

Birth Certificate Office
973-322-5327

Lactation Consultants
973-322-5684

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:

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New NICU Facebook Page www.facebook.com/SBMCNICU

In recent months, with the help of the hospital, the NICU Family Advisory Council has created a Facebook page aimed at parents here in our NICU and beyond.

Every Day,
Extraordinary.



The Facebook page was developed in response to our NICU graduates who have said it would be helpful to have a place to share information and ask questions of other NICU families upon leaving the NICU as well as during the first months and years at home. So far, the page has numerous personal stories and information and tips that might be helpful. If you have something to share or just want to check it out, please go to www.facebook.com/SBMCNICU and like it today!

Interview With Dr. Wagner, MD (continued from page 2)

Q: Do you have any suggestions or advice for NICU families?

A: 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 the diseases we encounter. This way the parents have a greater understanding of what's going on.

Q: Anything else folks might not otherwise know about you that you would like to share?

A: I am the Director of Pediatric Ophthalmology at the New Jersey Medical School which will be part of Rutgers as of July 1, 2013. There I teach residents and medical students. I am the editor of the *Journal of Pediatric Ophthalmology and Strabismus* and have just about completed a textbook on Pediatric Ophthalmology for the Pediatrician, which should be published early in 2014.

Also, I enjoy international ophthalmology and most recently traveled to Ulaan Batar, Mongolia, where I taught and operated. There we saw many babies with birth weights greater than 2000 grams and gestational ages greater than 30 weeks with severe ROP. We never see babies with that large of a birth weight with this disease here because of the excellent NICU care and monitoring we have available here. I have also been in countries where there are no patients with ROP, because they are unable to save babies born with birth weights less than 2000 grams!