

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....?

...lots of good hand washing is the best way to keep your baby from getting sick. Do it and insist others who come in contact with your baby do it too. You will be glad you did!

What to Know About RSV

RSV, which stands for Respiratory Syncytial Virus, is an easily spread virus most common from fall to spring. While most babies who get RSV just get what seems like a cold, it can cause pneumonia and other lung problems. In severe cases it can sometimes even lead to death.

Babies born prematurely (at 35 weeks or less) and babies born with heart disease or chronic lung disease are at greater risk for RSV.

Signs of RSV include stuffy/runny nose, sneezing and a fever. Severe RSV can include wheezing, coughing, and trouble breathing. You might also see difficulty eating, drinking or sleeping. If the baby's skin color is blue or gray or you see any of these other severe symptoms, let your doctor know right away.

The best protection against RSV is to have everyone wash their hands before touching your baby. You can also:

- Keep people who have colds away from your baby, including siblings
- Keep your baby away from crowds
- Wash baby's toys and bedding often
- Be sure to NOT share pacifiers, bottles, cups, forks, spoons, towels or washcloths
- Be sure to NOT smoke around your baby

A medication called Synagis® is available to help protect high-risk babies from severe RSV and can be given via injection by your nurse or doctor. Babies who need Synagis will get monthly shots during RSV season.

Insurance coverage for Synagis outside the hospital varies by insurance plan and can be a frustrating process. Working with your doctor is a great plan of action. For some helpful hints you can also go to <http://synagis.com/insurance.aspx>

1. Synagis Reimbursement Hotline (1-877-480-8082)
2. MedImmune Assistance Program (1-877-480-8082)
3. Patient Access Network Foundation (1-866-316-7263)

You can obtain more information about RSV and Synagis through your baby's doctor, the NICU Family Resource Library, or by calling 1-877-633-4411.

94 Old Short Hills Road
Livingston, NJ 07039
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Interview with Claudia Garrity, LCSW

Claudia Garrity, LCSW, has been a social worker in the Saint Barnabas Medical Center NICU since 1993.



Social Worker Claudia Garrity, LCSW

Q: Why did you become a social worker in the NICU?

A: A passion for people and a deep desire to somehow ease despair and suffering led me to the social work profession. I have always thrived in intense environments and wanted to be in a place where my professional role would be meaningful and valued by the people I served. A busy Level 3 NICU like the one at Saint Barnabas is just that environment.

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

A: I love the opportunity that the NICU environment provides for inspiring hope and outreach to families during what is often such an overwhelming and frightening time in their lives

Q: What are you most proud of?

A: I am proud of being part of such a talented and dedicated team of health care professionals. The never-ending dedication of the team and their constant quest for perfection in giving struggling NICU babies the best possible outcomes is personally and professionally inspiring. I am filled with pride and often tears each time a family takes their beloved baby home with them. I am proud to have walked with the families on such a challenging and significant road in life.

Q: What do you think of Family Centered Care, or what does that mean to you?

A: In so many ways Family Centered Care (FCC) is a dream come true for a professional social worker. In FCC, the role of the parent becomes one of partner with the health care team. We are currently working to create an environment where parents are no longer treated like visitors but as an important part of their baby's care.

Q: Can you share some of the SBMC NICU changes that you have seen over the years?

A: In my 15 years as social worker in the NICU, I have seen much change. However, the most dramatic changes have happened very recently. Over the last three years, family involvement and the concept of Family Centered Care has come to the forefront. Our NICU Team has accepted the challenge to implement Family Centered Care and is working to make this happen by improving communication with parents, creating parent advisors, providing

more comfortable facilities and distributing educational materials among other things. The goal is to make this new model for care a reality which will create an environment of inclusion and partnership with parents.

Q: Do you have any suggestions for parents?

A: Take part in the education and support programs we offer. In addition to learning some good information on a number of subjects related to your baby's care, this is also a chance to meet some of the other parents in the unit that may be dealing with many of the same issues and worries that you are. I have heard from many parents that these relationships often help in getting through the daily ups and downs of the NICU experience. Also, let your social worker know if you are upset, depressed or in need of a listening ear.



Parent Story

Getting pregnant wasn't as easy as I expected and being pregnant was not nearly what I expected, being a Mom, however, is so much more than I ever expected. I went into pre-term labor and was hospital-

ized 19 weeks into my pregnancy. It was one of the most terrifying days of my life. The next seven weeks of bed rest and medication gave my children a chance at surviving

Dylan Anthony and Cassidy Nicole came into this world on November 26, 2007, at 26 weeks and 1 day gestation. Born 14 weeks early and weighing 1 lb., 13.5 oz. and 1 lb., 13 oz., they both came out fighting for their lives and they both came out crying. Cassidy spent 88 days in the NICU and Dylan 80 days. I still grieve the loss of a "normal" pregnancy and delivery.

Dylan and Cassidy both had their "ups and downs" while in the NICU. Within the first 24 hours Dylan suffered a brain bleed and a Pneumothorax that required a chest tube. Both

babies needed several blood transfusions from donors that I wish I could find to thank. My daughter and son struggled to breathe and fought to eat; they had to learn all of the things that most babies just know. I watched my children have episodes of apnea and bradycardia. I watched them as they were intubated and extubated. Even on the scariest of NICU days, I also saw them progress. I read them books through their isolettes; I sang them my favorite songs; I told them stories of the world outside of the NICU. I spent their first Christmas and New Years by their side in the hospital. I prayed so hard I knew God would hear me.

Today I get stopped by strangers who want to know more about my twins. They say, "you sure have your hands full"; my response is always "full of love". I share Dylan and Cassidy's story often, so that people know that they are in the presence of greatness...that they are in the presence of miracles. The doctors and nurses at the Saint Barnabas Medical Center NICU saved my children. They cared for them and loved them as if they were their own. I am now the proud mother of two happy and healthy one-year-olds.

-April Quartell Erck

MIRACLE WALK UPDATE

On October 5, 2008, close to 2,000 people participated in the 8th Annual Miracle Walk to raise funds for the SBMC NICU. 130 teams made up of NICU graduates and their grateful families and friends, took part in the day. This year also saw an increase in recent NICU graduate involvement and teams made up of families with a baby still in the NICU. It was truly heartwarming to see all the new babies alongside the many older graduate children. Many participants said it was a wonderful day and a great way to "give something back" to the incredible staff that cared for their babies.

Over \$440,000 was raised for the NICU which represents the most money in a single year. It brings the total, since the walk began eight years ago, to \$2.5 million. Just as in the past, the money raised will help purchase special state-of-the-art equipment for the NICU (i.e. Giraffe™ Omnibeds™, NeoPuff infant resuscitators, and Draeger Air-Shields® Isolette® Infant Transporters).



In addition to the walk, participants enjoyed entertainment from local balloon artists, face painters, costume characters, and a great DJ. Food and refreshments were provided, as were gift bags for all that walked.

**The 9th Annual Miracle Walk
will take place on
Sunday, October 4, 2009,
in Verona Park.**

**To learn more or to sign up for the walk:
Visit: www.miraclegwalk.com
Email: miraclegwalk@sbhcs.com
Phone: 973-322-4259**

Important Phone Numbers:

NICU

973-322-5300

NICU Step-down (3100)

973-322-5310

NICU Social Workers

973-322-5503 or 8408

Birth Certificate Office:

973-322-5327

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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Holiday Tips from a NICU Parent



We don't have family in the area and my family was unable to travel to us, so it was just my husband and me at home for the holidays last year. If you had asked me at the time, I would have told you that the holidays were the last thing we were concerned with. However, we did manage to find a few ways to make the holidays as good as they could be even though we

weren't all home together. It made for some nice memories of our daughter's first Thanksgiving and Christmas.



Everyone feels differently, but here are some helpful tips based on our experiences:

Even though you might feel tempted, don't ignore the holidays.

- Find some way, even if it's a small one, to recognize the time of year, but keep it simple. Chances are you're exhausted from the haze that is life when you have a child/children in the NICU.
- For the holidays, I pre-ordered food for my husband and me at the grocery store and picked it up on my way home from my morning visit to the NICU.

Take people up on their offers to help.

- For Christmas, we took a friend's offer to stop by "whenever" and if "we were up to it." Usually, I would feel I had to commit one way or the other, but I realized they really did want us to come if we could, but didn't want to add stress if it didn't work out. We did manage to make it as they were sitting down to eat, and enjoyed a much needed break for a couple of hours.
- If you have other children to buy gifts for, make lists and ask those who offer help to do the shopping AND wrapping. Often, people really want to help but just don't know what to do.

Talk to your nurse about how to celebrate with your child/children.

- You may be able to dress your baby/babies in a special outfit, or hang cards on their isolettes.
- Ask staff to take pictures of you as a family.

Take care of yourself.

- You are the best gift you can give your child/children. Don't over-commit yourself or try to do more than you can.
- As always, eat and drink healthy and get enough rest.

- Mom of NICU graduate, Lily

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