NICU Family Advisory Council



Colton (ex-23 weeker) and Family

The NICU Family News is produced by the Cooperman Barnabas Medical Center Neonatal Intensive Care Unit (NICU) Family Advisory Council. It is designed to provide you with information we hope you will find useful during and after your family's NICU stay.

DID YOU KNOW?

The NICU has its own Family Library that is open 24/7?

It is right across the hall from the NICU Family Lounge as you walk towards Pod 1. The library has three work stations and you can find some special things just for NICU Families there. There are some resource books about NICU babies, multiples and prematurity. There are also hand-crafted baby hats and scent cloths if you are looking for extras or a different size or color. While you are there, feel free to check out the NICU Baby Milestone Cards so you can choose the ones that mark your baby's milestones when they come up! There is also a large TV and magazines to help pass the time or catch something you didn't want to miss on TV.

NICUFamily News

Parents Guide to Supporting NICU Siblings

If you can, come spend time in the NICU with your other children. A short visit can be very helpful for siblings. Seeing what it is like here in the hospital is usually less upsetting than what they imagine is happening (unless the baby is very tiny or very sick). You can also try to bring them to a NICU Sibling hour, held two Tuesdays a month (4:30 to 5:30 pm), and/or NICU Family Pizza Night, one Sunday night a month (6 to 7:30 pm). Exact dates for these are always on the table in the NICU Family Lounge and on the NICU electronic message boards.

For the safety of all the NICU babies, only big brothers and sisters, age four and older are able to visit the NICU right now. It's also possible that if the rates of childhood Covid, flu and RSV are high this winter/spring, we may have to close the NICU temporarily to all children to make the unit a little safer. We will try to give the families as much warning as possible if that is the case.

As a new NICU parent, you will likely have many of your own feelings to manage about having a baby in the NICU. It is also important to support your other children at home and make sure they know they are loved and cared for too. Knowing why a sick or premature sibling is in the NICU can be helpful but should be explained simply and with only a few details. You might also let them know the baby is being well cared for by the doctors and nurses.

Depending on their age, siblings may need to talk about their feelings about having a baby sister or brother in the hospital. Some kids may also show behavior changes, like acting out to get your attention or relieve stress; complaining about feeling sick, nauseous, hurt, or in pain; withdrawing; bed wetting; or acting younger than their age. If these changes last a long time or get worse, talk to your child's pediatrician for suggested ways to help.

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Let's Get to Know: Megan Rosa (Norton), BSN, RN

NICU Bedside Nurse

How long have you been working at CBMC and in the NICU?

My first nursing job was in the CBMC NICU and I have been here for a little over two years now!

Where did you do your nursing education and training? I received my BSN degree from Caldwell University in May 2022.

How did you know you wanted to be a nurse?

I always knew I wanted to be a nurse because I love to help others and wanted to be in a field where I could learn more every day. I started the first few weeks of my life in this very NICU, born prematurely. I want to be able to make a difference for babies and their families just as the nurses did at the start of my life.

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

I love being able to see the strength and progress our little babies make over the duration of their NICU stay. I love seeing the tiny, fragile babies overcome large obstacles. I also love seeing the once scared and anxious families walk out the door confident to take their baby/babies home at time of discharge.

What does family centered care mean to you?

To me, family centered care is the team approach and ongoing communication between the family, nurses, doctors and interdisciplinary staff here in the NICU. One of my favorite things about working for the neonate population is being able to give their parents autonomy and comfort. One day, a family will remember a NICU nurse's smile, kindness, patience and strength on their worst days.



What is the Daisy Award and how did it feel to receive it back in May of 2023?

The Daisy Award is a national organization that recognizes nurses for their work. Nurses who get the award are nominated by patients, families, and co-workers as a way to thank them for the care and kindness they provide. Earning a Daisy Award had been a career goal of mine that I set before beginning my nursing career. I was so grateful to receive this award in my first year of being a nurse. It validated to me that it's not only the big things that we do to help our patients that make a difference, but also the "small everyday things" that can make a large impact.

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

Yes, the NICU journey does not always go in a straight line, and is not always a short one for that matter. I like to encourage families to try to be patient in the NICU and keep a notebook at the bedside to write milestones their baby achieved as a way to remember the positive moments -- even if they feel very small at that time. Those milestones will build every day or week, until baby goes home.



Colton's NICU Journey

On April 2, 2021, around 10:00 am, I was in an ambulance on my way to Cooperman Barnabas Medical Center (CBMC), praying that I did not deliver my son in the back of it. I had gone into labor the night before and went to our local hospital, where I found out I was already dilated. My husband and I listened to the doctor who came in and told us all of the things that could be wrong with a baby born at 23 weeks, IF he lived! He suggested comfort care. That meant deliver our baby and hold him as he took his last breaths. This would include no medical interventions, as this hospital was not equipped to care for such an early baby. They left the room for us to talk it over and decide. I said, 'I mean we have to at least try, right?' My husband agreed. The doctors gave me meds to stop the labor from progressing. The next morning the doctors thought I was stable enough to be transported to CBMC since they had a NICU that could help our baby when he was born.

About 2 hours after we got to CBMC I continued to dilate and our baby flipped himself up and was coming out feet first. Minutes later, I was on my way to a C-section. Our son, Colton, was born at 2:26 pm ... all 1 pound, 8 ounces of him!

Colton was born at 23 weeks and 4 days. He was what they refer to as a micro preemie. He faced many challenges. The first 3 days were crucial. I don't think I can put into words the feeling that you have as a mom looking at your tiny baby hooked up to all of these machines, knowing that they're keeping him alive. Anyone who has had a NICU journey can tell you that it is a rollercoaster ride filled with the highest highs and the lowest lows. We learned this lesson quickly in the first 5 days. At 3 days, they did a scan of Colton's brain to check for bleeding. We were thrilled to find out that there was minimal bleeding. It was our first highest high. Two days later, we hit one of our lowest lows when we found out Colton had pneumonia. We were terrified. We knew Colton was already having breathing problems due to underdeveloped lungs and that having pneumonia was only going to make it more difficult for him. He was already fighting for his life and I couldn't even imagine how much more difficult this was making it for him. This was the most terrifying time of our NICU journey.

Luckily, Colton responded well to antibiotics and from there they focused on strengthening his lungs. He had two rounds of steroids to try to help. It was a long road with Colton's lungs and respiratory system. His oxygen levels were so up and down that it took us almost a month to be able to hold him. I'll never forget how it felt when I finally could. Aside from his struggles with oxygen, he also had multiple blood transfusions, retinopathy of prematurity (ROP) surgery



for his eyes (which he was transported to CHOP for), hernia surgery, and multiple other day-to-day hurdles. Eventually he was diagnosed with chronic lung disease.

We spent 156 days in the NICU. It became a second home and we built relationships with some of the staff that I believe will last forever. The NICU is filled with amazing doctors and nurses that we owe our baby boy's life to. Not only did they take such wonderful care of Colton, they also took great care of my husband and me. They explained things we didn't understand over and over again as we needed, they comforted us when we were worried, they hugged me when I cried, and they celebrated with us when Colton reached another milestone. To say I feel blessed that we ended up at CBMC with the doctors, nurses, and support system that we had is SUCH an understatement. I truly can't put into words the love, admiration, and gratitude that I have for them all.

Today Colton is a healthy, adventurous, stubborn 3-year-old, who loves all things superheroes, going to the park, school, and playing with his big brother and sister! I can't even count the number of times that people have told me how incredible he is as they look at him in awe of where he started. If you weren't there to experience this time in our lives with us you would have no idea that his life began the way it did.



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

Supporting NICU Siblings (cont'd from page 1)

Listed are some NICU parent graduate and staff suggestions of ways to help NICU siblings.

- Talk to your children using words they can understand.
- Let your children talk to you, ask questions and share feelings.
- Share some of your own feelings, but perhaps not too intensely.
- Reassure your children that they are not to blame for the baby's hospitalization.
- Try to keep as many scheduled routines as possible from before the NICU baby was born. Keeping familiar routines of school or playdates/classes can help children feel a sense of control and reduce some of their anxiety.
- Try to schedule "special time" with each sibling if even for a short while so they feel they have your full attention for periods of time.
 Here are things you can do to tune into your children's feelings:
 - Read a book together; could *
 be about having a NICU sibling (some are in the NICU library) *
 - * Take a walk or a ride in the car together
 - * Go for a treat
 - Shop for a gift for the baby from the sibling (and maybe a small gift for the sibling)
 - * Draw pictures
 - * Tell or write stories
 - * Play their favorite game
 - Have some cuddle time
 - Look at their baby book or pictures of them as a baby and share stories/feelings about that special time

- Let them draw a picture or take a picture to hang in/ near the baby's isolette
- Give your child a picture of their baby sister/brother to show others if they want
- Practice stress-reducing activities together, like exercising, deep breathing, dancing or singing together to music (or encourage them to)
- Let them choose an activity you used to enjoy together before the NICU baby's birth (i.e. bake cookies, go shopping, plant flowers, eat a meal, etc.)

Miracle Walk

The 24th Annual Miracle Walk to benefit the Cooperman Barnabas Medical Center NICU was held in October at Verona Park. It was a beautiful day and we are thankful for such a GREAT turnout! The walk was a big success and raised almost \$236,000 for the NICU!

Save the date for the big 25th annual event on October 5, 2025!

To make a donation or learn more, visit: miraclewalk.com or facebook.com/miraclewalk

