**NICU Family Advisory Council** 



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

#### DID YOU KNOW...

...you can plan something special for your NICU baby's "graduation day."
Some NICU parents feel the day their baby is going home from the hospital is a day to celebrate. They have had personalized outfits made for baby or brought in a mini cap and gown to take photos in with the family. Be sure to stop at the photo banner in the lobby to take a graduation pic to post too. Do what feels right for you and feel free to be creative. It's your going home with baby day!

## Cooperman Barnabas Medical Center



# *MICU*Family News

# NICU Discharge and CPR Classes Are Back!

Finally after several years of pandemic-related issues and limitations, our discharge and CPR classes for NICU parents are back. Here is what you need to know:

- Parents can take the NICU Discharge Class and/or the NICU CPR Classes at any time during their infant's hospital stay. Parents may attend as many times as they wish.
- Attending a discharge class early can help answer questions including ones about car seats, and may help parents choose the proper car seat for their baby. There are numerous discharge classes and parents can begin attending them when their baby is at least 32 weeks gestation.
- All class schedules are on the NICU Message Boards (flat screens in parent lounge and the welcome area near the handwashing sinks). They also are on the table in the Parent Lounge and emailed to parents via Crib Notes.
- Discharge Class Flip-Cards are an exact copy of the Discharge Class and are located in each pod at any time. Just ask your nurse for them. Discharge Class Flip-Cards in Spanish are coming soon!
- Parent "Homeward Bound" binders (in English and Spanish) are also coming soon and will be placed at the parent bedside tables.
   The Homeward Bound Checklist will help parents know what to expect in getting ready for discharge.
- We suggest you sign up early for a CPR Class since space is limited and it is usually only given twice a month. CPR Classes are usually held every other Wednesday evening at 5 pm. Call Angela at 973-322-2916 to sign up.
- Parents who can't attend an Infant CPR Class can ask any NICU staff for a CPR kit to take home and learn infant CPR.

# Interview With Veronica (Ronnie) Crawford, BSN, RNC, NICU Data Coordinator

#### Where did you do your education/training?

I returned to college at the age of 35 and graduated from the nursing program at William Paterson University on May 10, 1996 — 63 years to the day that my mom graduated from her nursing program!

How did you know you wanted to be a Nurse? Did you know you wanted to work specifically in the NICU?

I guess I was destined to become a nurse. My mom was a very well respected nurse and my childhood memories include her taking care of our disabled father at home. Also, my oldest daughter was born at 33 weeks in 1977, at a hospital in which the baby had to weigh 5 pounds before parents could visit in the same room and begin to provide care. At that time, I knew that when I did return to college, my nursing specialty of choice would be NICU. I knew that I wanted to help parents with all the things we were not helped with when my daughter was in a NICU, including bonding, education and hands-on care. I began my nursing career as a new grad in the NICU and I continue to hold a certification in NICU nursing.

#### Please describe what your role is in the NICU?

Two years ago, I retired from CBMC after 25 years as a NICU staff nurse. In July of 2022, I returned as NICU Data Coordinator. My job includes many behind the scenes office tasks, discharge patients calls, Multidisciplinary Rounds and NICU Policy and Procedure revision meetings. My main focus has been restarting our NICU Discharge and CPR Classes. These in-person classes had been on hold since the beginning of COVID, and have been a positive addition to our NICU discharge process. I am currently

Save-the-Date: 23rd Annual Miracle Walk October 8, 2023 | Verona Park

We are planning another great day of celebrating the miracle babies, families and staff — all to benefit the Cooperman Barnabas Medical Center NICU. We hope to see you there!

working on a High Risk Discharge Binder which will aid our nurses in discharging an infant with special needs, as well as providing parents with a bedside "Homeward which parents can check off tasks needed for a smooth discharge of their infant to home.



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

I have always loved working in the NICU, especially caring for a micro preemie infant from birth through discharge as a primary nurse. It is very rewarding to build a relationship with a family, while providing teaching for a smooth discharge home. With my current position teaching Discharge Class and CPR Class, I have the opportunity to meet many families and help them work toward their infant's discharge.

NICU staff are always working towards more neurodevelopmentally sensitive care (i.e., low voices, two-person care...) that is considered "protective," especially for the very premature babies. Do you have any thoughts about this?

Absolutely! NICU nurses learn that everything that we do to care for a premature infant can have a long-term effect on them. We "cluster" our care in order to provide the infant with time for rest and growth. Two-person care helps improve the infant's comfort and decrease their pain levels. Ask your nurses how you can be more involved in two-person care when you are here spending time with your baby.



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



## **Bella's Story**

We had been married for 12 years and, as parents who already experienced having a premature baby survive a one-month NICU stay, our goal was to remain a family of three. Interestingly, life had other plans for us, and we were pleasantly surprised when we found out we were pregnant with a new bundle of joy due to arrive November 2015. We were shocked, thrilled, excited, and nervous since we knew that I was considered high risk. From the start, the pregnancy brought us many uncertainties. Despite the uncertainties, we remained positive and hoped for the best outcome. As Jehovah's Witnesses, I knew that accepting a blood transfusion was something that I would not accept as part of my care. Therefore, early on, I reached out to the Blood Management/Bloodless Medicine Team at Barnabas for their guidance and assistance to make sure my blood levels remained normal. I also completed hospital paper work stating the non-blood treatment options I would be comfortable accepting if needed. I wanted to make sure that everything would be in place for a smooth delivery that took into account my wishes and religious beliefs.

By the time I reached around 23 weeks, I was admitted to the hospital for preeclampsia. After a few days, I was sent home only to be readmitted again due to more complications. At this point, my health and the baby's health were in such bad shape that I asked them to please keep me until the baby could be delivered. They agreed, but there was no guarantee that I would survive this and there was little hope for our daughter. My complications continued over the next few days in the hospital and at exactly 24 weeks, they had to deliver our little girl, Isabella, via C-section. This delivery was more complicated and scarier than my first. It was a miracle that I had survived as well as our baby, although she was in critical condition. Interestingly, as scary and traumatic as it was, my husband and I were at peace, because we knew we had done what we could for her delivery. In my room "the cell saver machine" was ready, just in case, and the doctors knew according to my Advance Directive and hospital paper work what alternatives to blood transfusion I would be willing to accept. We had a solid team that knew our wishes and respected them by giving us the assurance that they would do their best.

It was a day in mid-July of 2015 when our little Isabella was born at only 12.3 ounces and 10½ inches long. Although it was a moment of happiness and relief, I also knew that my husband and I would face many difficulties in the minutes, hours, days, months and years to come. Once again we entered the NICU doors, but this time it was different as Isabella was labeled "unstable and critical" from the start. The roller coaster we experienced with our daughter was beyond what words can describe. There were many times where we almost lost her and to this day it's hard to explain how this strong little girl pulled away from those near death experiences.





As Jehovah's Witness parents, we wanted the best care for our daughter without consenting to the use of blood or blood products. The Coordinator of Blood Management, Tanisha Reid-Davis (973-322-2950), was incredible in helping us understand NJ laws regarding minors and blood transfusions. She explained to us that that this was the best medical team in the state and they would try their best to honor our wishes. However, if a situation should arise and the medical team decided that blood transfusion was necessary to save Bella's life or to prevent serious injury, the physicians and hospital would legally be required to give her a blood transfusion. Hearing those words was stressful and very difficult. Tanisha acknowledged our feelings and helped us understand the NICU doctors approach to care and how we could respectfully express our concerns and still work together as a team. Thanks to all those conversations, my husband and I worked very well with the NICU team and really partnered with them for the well-being of the patient, our precious Bella.

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### **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

## Bella's Story (con't from page 3)

The NICU became our second home. They became our family. They understood the challenges we were facing as a family and the emotional effect it was having on every one of us. On days, when we struggled emotionally, the nurses did things to give us strength and make us smile. We were there every day and many times into the nights, doing whatever we could for Bella. We understood that this was her first home and as her family, we were right beside her to support her.

What we appreciated most about the NICU team was that when we were told how bad her outcome could be, we asked the team to please let us fight with her as long as she was willing to fight. They understood the deep love we had for our little girl and did their very best to give her the medical care she needed. We will always be thankful for this because they **never** gave up on our little girl. I still remember sitting in the Parent Lounge, so worried to hear Bella was in need of another surgery, as she just had surgery, and looking at Dr. Kamtorn and asking if she thought that our little Bella was strong enough for it. I can still see her face when she looked at me and said, we have to bite the bullet, then took my hand as we prayed to Jehovah to give us the wisdom to do what was best for our little girl. Her words touched me so deep and I will always be grateful for her compassion. We grew to truly appreciate all the NICU doctors. Their experience, wisdom and compassion made any hard news easier to hear.

After 243 days and several surgeries, we left the SBMC (now CBMC) NICU and went to Children's Specialized Hospital, with a tracheostomy and a gastrostomy. We were sent there to learn how to care for Bella, begin her needed therapies, and eventually transition home. In early July 2016, after a total of 334 days of care, we finally made it home with Bella. It was the sweetest feeling for my husband and me to finally be at home with our two children at once.

When we think back on this journey we can say that, thanks to all the staff at Barnabas who honored our choices and provided excellent care, we were able to be part of a solid care team for our baby girl. We were also able to build relationships that would last a life-time and truly understand one of my favorite quotes, "We don't grow when things are easy; we grow when we face challenges."

Despite the challenges we have faced, one thing we have always done is find normalcy throughout all of our circumstances and enjoy the moments making memories. Today, Isabella is a happy, active 7-year-old little girl full of personality. She loves to eat, play with her big brother, dance and sing. We look at her every day in awe and full of gratitude for the strength Jehovah gave us and for the wonderful care and understanding all of the CBMC staff gave us. - Liz and Pat