## **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 request to have a NICU Parent Buddy? This is a parent who has already had a baby (or babies) in the NICU and can give you emotional and informational support. Because they have had NICU experiences similar to you, they can give very special support that only another parent who "has been there" can. To request a "Buddy," fill out a yellow NICU Parent Buddy Program sheet (found in the NICU Library or top drawer in the NICU Parent Lounge) and give it to any nurse.

## Cooperman Barnabas Medical Center



# *MICU*Family News

## **Keeping Baby Healthy at Home**

With any newborn at home, you want to try to avoid having common colds in your home. But from about October to April/May, you also want to avoid Respiratory Syncytial Virus (RSV), an easily spread cold virus that attacks the respiratory tract. This can be especially serious for preemies because of their immature lungs. Some high-risk babies will get a monthly shot of Synagis (http://synagis.com/insurance.aspx) to help protect them from severe RSV. This shot is recommended and prescribed by your babies doctor **only** if they meet the criteria that say they need it. You can ask your babies neonatologist about this if you have any questions.

### Other things you can do to help keep baby well include:

- Washing hands often and using antibacterial gel
- Keeping your baby away from crowds for several months
- Not allowing your baby to put other children's toys near their mouth
- Asking visitors (and strangers) not to touch your baby's hands or mouth to help prevent the spread of germs
- Washing baby's bedding and items she mouths often
- NOT smoking around your baby

## Our tips for keeping your NICU baby healthy around school-age siblings:

- Have siblings wash hands when they first come home from school
- Have them take off their shoes in the house
- Maybe even change clothes from school outfit to play outfit
- If they are sick, try to have them stay at least six feet away from the baby and cover their mouth/nose when coughing/sneezing
- Encourage the use of antibacterial gel and keep it in several easyto-reach places the child can get to
- Let the school know you have a preemie at home and ask them to alert you to any illnesses that may be floating around the school
- For younger school kids, maybe a show and tell about his/her siblings (either with pictures) and tell the class the importance of hand washing and hygiene
- Set up more play dates outside the home than in the home (and wash those hands!)

## Interview Mackenzie Newman, RN, BSN NICU Staff Nurse

### How long have you worked here?

I started working in the CBMC NICU right after graduating from nursing school about 4 ½ years ago.

#### How did you decide to become a NICU nurse?

I always loved kids and working with them even before becoming a nurse. Then, the opportunity came to me to work in the NICU so I took a chance to try this as a new nurse, and it turned out I had just as much of a passion for the neonatal population as I did kids!

## What do you think is your favorite thing about being a NICU nurse?

I think the best part is probably helping parents do the first kangaroo care with their tiny preemies. In this kind of care, parents are helped by the nurses to hold their baby directly on their chest (skin to skin). Many times you can just feel the emotion of that moment in the room as they hold their babies for the first time. NICU graduations, where baby gets to go home with their parents, are a close second!

#### What does family centered care mean to you?

To me this means encouraging families to spend time with their baby in the NICU and begin to be families while we help care for their babies. It also means

working together so we can help provide the care their babies need while they still have opportunities for involvement and positive bonding and experiences.



In recent years the NICU staff have been learning more about the short- and long- term benefits of more neurodevelopmentally sensitive care that is considered "protective," especially for the very premature babies, i.e., low lighting, low voices, two person cares, etc. Do you have any thoughts about this to share?

Neurodevlopemental care is so, so important! I work hard to group or cluster cares together that need to get done each shift (diapering, temperatures, feedings, other tests...) along with other neuroprotective measures you mentioned. That way the babies are disrupted from their sleeping and growing needs fewer times a day. It seems very helpful for the babies and especially the very tiny ones. And, as important as these measures are, it's important to involve parents in care. So, I try to balance both together and encourage parents to be involved in their babies care whenever possible.

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# A Successful 22nd Annual Miracle Walk

The 22nd Annual Miracle Walk to benefit the Cooperman Barnabas Medical Center NICU was held in beautiful Verona Park on October 9, 2022. This was the first in-person event since the pandemic and was a great success with over \$175,000 raised. We hope to have as fantastic an event next year in the park again in October and hope to see you there!



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



## JD's Story

Jonathan David, means God's Gift, Beloved One. We were so excited to know a rainbow baby was on his way. Our pregnancy was going amazing. JD as we lovingly call him, kept reminding me that he was the boss of my cravings and was the most active when Mommy was ready to go to sleep. We never expected that just 14 days after our gender reveal, our little blessing would make an early entrance.

It was quite an adventure, walking into L&D and hearing about the possibilities. I became overwhelmed. My husband was downstairs getting our daughter situated in Starbucks and arrived just in time to remind me of the great faith I always carried in my heart. It was then I knew we were about to enter a season of a lot of changes, but the story would end in our favor.

April 27 at 10:35 am, Jonathan David came into the world at 24 weeks gestation, at 1 pounds, 7 ounces and 11% inches. He was the strongest little warrior I have ever known. I got to hold him the very next day. He was our miracle!

Our honeymoon period at the NICU was short lived and the test of faith came quick. We saw our boy fight for his life so many times and the roller coaster we were warned about was so real. Good thing Mom loves a great thrill ride, but even then the uncertainty was so real. We fought through meningitis, infantile spasms, GI issues, hydrocephalus due to the meningitis, and many blood transfusions and PICC lines. On paper, all these things would convince anyone, our boy, would surely have a tough long road ahead of him, but with every storm, our boy showed that he was truly God-Strong! He healed on, fought harder, and came through it all stronger.



We never stopped praying, we never stopped holding on to our faith. Long days and nights were spent with our NICU family. We sang to him, we prayed with him, and we read to him, everyday. We had the best Pod in the NICU. The "Pod 1 Crew" as we called them! Our support in and out of the NICU was God-sent. To be honest, the support was so needed. Our boy didn't have nurses, he had Aunties. They were our family and we became theirs. They were our angels and they reminded us we were theirs too. His room was filled with peace, love and a lot of smiles. We brought love and received it day in and out.

JD, the "chillest baby in the NICU," fought hard. From Cooperman Barnabas NICU, he was transferred to Boston Children's to finish off the road to recovery. We left with the biggest crowd of support around us, and our journey home came in early November 2021!

Today JD, is still showing how God -Strong he is. Doing things we could never have imagined he would accomplish. A strong healthy, miracle boy, JD is now 18 months old. He currently is cruising along everything he can hold onto and loves to eat, but mac and cheese holds his heart, especially when he gets to feed himself. When he really wants to get our attention, he will use sign language for milk or food. He absolutely adores *Ms. Rachel* on YouTube. He dances and sings along with her, and so do we. It's amazing to be able to enjoy this life with our miracle.

To every family who is on this journey now, the storm may seem intense, but hold on and the sun will come shining through. Your little one is going to shock you and bring you and your family a new sense of strength, hope, and love.



## **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

## **Calling All Interested NICU Parents**

You may not have known this but there are a number of ways that CBMC NICU parents stay involved with this very special unit after their babies are discharged. These interested parents, who call themselves "graduate parents," help current NICU parents and staff in many ways throughout the year. To get involved in any way fill out the short 3 question form at discharge that your nurse should give you. You can also get involved or get more information by emailing: Hayley.Hirschmann@rwjbh.org.

Ways to help range in different commitment levels. Some parents just get on the mailing list and help out with a special project or deliver treats once a year. Others attend some, or all, of our monthly Family Advisory Council Wednesday night meetings. You can also write your personal NICU story for the NICU newsletter!

Some graduate parents even become fully-trained hospital volunteers who lend support (largely by phone, text and email) to current NICU parents. This is called being a NICU Parent Buddy. Parent Buddies attend a 4-5 hour training to become experienced listeners who can give special emotional and informational support to parents who are in the NICU right now. Parents need to be out of the NICU for close to a year before they can be considered for the training. After this, you could be a great source of peace and understanding for another current NICU family. The NICU Parent Buddy program coordinator matches trained parents with a family requesting support and they reach out to them to start the buddy relationship.

For more information about any of these ways to help after you leave the NICU, or to get more information about Miracle Walk, our yearly fundraiser, reach out to Hayley.Hirschmann@rwjbh.org.

## Interview With Mackenzie Newman, RN, BSN

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#### Do you have any suggestions for the NICU families?

I'm not sure I have any specific advice but, I do often suggest to families that they try to take the experience of the NICU "one day at a time." I also suggest they try to "be present" while they are here spending time with their babies. Lastly, I tell them to remember that victories are still victories, no matter how small they are.

Is there a personal or fun fact about you that you are willing to share?

A fun little fact about me is I that I love travelling during my time off and it's on my "bucket list" is to visit all 50 states!