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...

...there are some great resources for you and your family in your black NICU Welcome Bag. Take a look and start using them right away! Every bag has:

- A small NICU Resource Guide with all the NICU phone numbers and groups/ classes we offer.
- A welcome kit with a NICU Journal, breast milk storage bottles and a cooler bag with ice packs for transporting breast milk.
- Scent cloths, a brochure about the NICU Parent Buddy Program, a hospital patient guide and a board book you can start reading to your baby RIGHT THIS MINUTE!



NICUFamily News

What Graduate NICU Parents Wish They Knew

We asked CBMC NICU parents whose baby/babies have been home from the NICU from 1 year to 10 years things they wish they knew while they were here. There were some similarities and they are listed below and when possible there is more information in italics about their wish so you can know NOW the things they wished they knew!

When my baby was in the NICU, I wish I knew:

... I could call the NICU any time of day or night to ask a nurse how my baby was doing. I did not know this until a few days after I went home from the hospital.

It's true, you can call the NICU at 973-322-5300 at anytime (except between 6:30-7:30 AM and PM because the nurses are focused on getting report for the shift change). Remember not to get worried if the nurses don't pick up right away or ask you to call back because your nurse is busy, as they usually have a few babies to care for on each shift.

...that it was ok to let staff know I wanted to hold / kangaroo my baby. You may not believe it but you are your baby's best advocate so get used to that idea! If you want to hold / kangaroo your baby more, you need to let them know. They may assume that if you don't say anything you don't need their help with anything, so speak up. You and your baby will be glad you did!

...about the NICU Buddy Support Program and that I could have a NICU grad parent assigned to support me (and my spouse) via phone, email, text. The staff were supportive but an ex-NICU parent who had "been there" would have been great!

There are yellow Parent Buddy Program Brochures in every **black NICU Welcome Bag** and in common areas of the NICU (library, lounge...). The brochure has detailed information about the program and the simple steps you can take to get matched with your very own NICU Parent Buddy. Don't wait, fill out the yellow insert in the brochure and give it to your baby's bedside nurse today! To get assigned a buddy, you can also reach out directly to Hayley.hirschmann@rwjbh.org.

...what signs to look for to know if my child was going to have developmental delays.

There is no way for any parent to be sure about this but having regularly scheduled visits to discuss milestones with the baby's pediatrician and keeping high risk infant follow up program appointments (if the baby was born less than 1500 grams) is very helpful. (continues on page 4)



Anna & Cooper: A Magical Friendship

Anna, pictured top left, was born in April of 2018 at 35-weeks gestation. She spent her first 9 days in the NICU at Cooperman Barnabas Medical Center (CBMC). As first-time parents, we were very nervous and worried about our baby girl, but every single NICU nurse put our minds and hearts at ease. We are extremely thankful for the level of care, professionalism, intelligence, compassion and skill of all of them. Anna is now 5 years old and is strong, beautiful, smart and thriving! We will always remember the hard work and dedication of the NICU nurses and doctors at CBMC as Anna continues to grow each day.



Cooper, pictured bottom left, was born in January of 2018 at 28-weeks gestation. As first-time parents we were scared and totally unaware of the NICU world. Every nurse and staff member there made us feel loved, comfortable and safe. We were able to experience first-hand, all that they do, not just for the babies but for the families as well. The NICU nurses are such heroes and we are extremely grateful to them all for supporting us those first few months in the NICU with Cooper. He is now 5 years old and recently started kindergarten. They NICU Team all said time would fly by and it has, but we always remember where it all began.

Anna and Cooper met in their first year of preschool. Slowly they built a friendship. As parents, we were excited to see our kids forming a bond so we got to talking and found out that these two had more in common than we thought. They both started their journey of life in the NICU! Yes, it was at slightly different times, as Anna was born soon after Cooper went home from the NICU.

23rd Annual Miracle Walk

The 23rd Annual Miracle Walk to benefit the Cooperman Barnabas Medical Center NICU was held on Sunday, October 8 in beautiful Verona Park. There were balloon artists, face painters, costumed characters and a DJ. If you are interested in supporting the NICU, donations can be made by visiting miraclewalk.com.



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From the start, Anna and Cooper have always been looking out for each other. They are always there to share a hug and always seem to just be standing next to each other. Our families have come together in such an amazing way because of them! Did we mention we live in walking distance from each other?!

This year, Cooper and Anna started kindergarten and seem to look forward to seeing each other every morning before school. It definitely puts a smile on their faces as well as on all of ours! Some days, they like to schedule play dates with each other for after school and enjoy walking home together along with their parents. As parents, we love to see these young kids living their fullest lives and enjoying every moment of it.

We think it's a little bit of *NICU*Magic that these two have found such a beautiful friendship and we hope it lasts forever!

With much love and appreciation, Anna and Cooper's Families









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

What Graduate NICU Parents Wish They Knew (con't from page 1)

The NJ Department of Health Early Intervention Services (www.nj.gov/health/fuss/eyes) encourages all families to view or download "Your Child's Development, Important Milestones from Birth to 36 Months," to see what is expected within "normal development." You can call them at 888-653-4463 to ask questions or request a home evaluation if your child seems more than just a little behind (which is fairly normal for preemies up until the age of 2 years old with correcting for the prematurity).

...the seriousness of having a micro-preemie and the amount of blood transfusions that might be needed during the NICU stay. I think our son had 3 or so. On those days his coloring was always off and I wasn't able to hold him because staff told me he would burn too many calories. Looking back, maybe if I knew that it would have helped me mentally prepare. It always made me so sad to not be able to hold him.

Actually, at this time, parents can hold their babies, even during a transfusion as long as some other medical issue does not stand in the way. If the baby is wrapped up well and kept warm, losing calories should not be a concern during a transfusion.

...more about the consequences of prematurity for a baby's long term health outcomes. I do realize it might not even be possible to know as each child is different but just milestone markers for prematurity versus full term child. As mentioned above, regular pediatrician visits will help with this and you can refer to the Important Milestones brochure on the Early Interventions services website to be aware of these as your baby goes from birth to 36 months — keeping in mind the adjustment for age depending how premature they were.

- ...other moms who had been through something similar.
- ...what to expect at 3 months, at 6 months, and a year after going home
- ...what was normal and what was not.
- ...to always trust my instincts.
- ...the best places to go to address issues as they arose.

The mom of twins who sent these five responses actually helped form a private FB group called **CBMC NICU Parents** to address some of these – check it out if you like! Also see responses above about getting a NICU Parent Buddy or the Early Intervention milestone pamphlet (from birth-36 months) available online.

... that being in the NICU was actually a helpful experience because it enabled me to ease into Motherhood with great teachers showing me the way Yay, a positive and it's true!