

# nicu

## Family News



NICU Graduates Jaylin and Madelyn virtually celebrate their last day of Pre-School.

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...

.....there are many virtual and remote resources available to you as a NICU parent. All are listed on the blue handout in your NICU welcome bag or you can pick one up at the security/welcome desk on the third floor before entering the NICU. Be sure to check out information about how to attend any of the zoom-type meetings held every Wednesday (12:30 to 1:30 pm) and the first and third Sunday of each month (8:00 to 9:00 pm). There is also information about how to get your very own NICU buddy who has "graduated" from the NICU with their baby and can give you good info and support since they have walked a similar path in the past.

**Saint Barnabas Medical Center** | **RWJBarnabas HEALTH**

The SBMC NICU is now on Facebook  
[www.facebook.com/SBMCNICU](http://www.facebook.com/SBMCNICU)



94 Old Short Hills Road, Livingston, NJ 07039  
 1-888-724-7123 [rwjbh.org/sbmc](http://rwjbh.org/sbmc)

## Keep Distanced But Stay Social

You may be getting ready to take your NICU baby home and be wondering how to safely celebrate this milestone during this time of ongoing concern about the coronavirus. NICU graduate parents recommend a virtual celebration just like the many birthday parties and anniversaries you may have participated in over the last few months.

You can send paper or email invitations, decorate with balloons, put baby in a special outfit and "broadcast" from baby's new bedroom. You and others "in attendance" can share a special wish for baby and you can collect them and keep them somewhere for baby to see in the future (in a scrapbook or somewhere virtually; there are apps like VidHug, VidDay, and tribute.co for this). You can also take some screen shots of all on the "call" as a keepsake.

Another NICU graduate mom set up balloons and dressed her baby in a special outfit and then stood inside their glass front door while family and friends stopped by at assigned times to visit with their new baby from outside. They were even able to take pics of the new family at home through the door!

You also may be trying to keep older siblings busy at home and be in need of some fresh ideas. To follow are some recommendations from graduate NICU parents that work inside, outside and in both situations. All suggestions with friends can be done with 6 feet between people who are participating. It may also be good to remind kids (especially younger ones) why it's still important for them to keep the 6 feet of distance from others when playing/doing activities. Share a simple explanation of how staying apart keeps germs and sicknesses from spreading.

### Distanced Activity and Game Suggestions:

- walks and bike rides with family and/or friends
- buy little wood building kits from Lowe's to build with Daddy
- let kids pick a dinner and/or dessert recipe and make it together
- family movie night with the kids choice of movie and snack
- outdoor movie night if you are lucky enough to have an outdoor wall and player you can use/buy
- bake chocolate chip banana bread muffins together - or other yummy baked goods

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# Interview With Sandhya Ruben, MD

## Neonatologist, Saint Barnabas Medical Center (SBMC)



### Q: How long have you been working as a neonatologist?

A: I worked as a neonatologist in the special care nursery at St. Clares Hospital in Denville for 4 years and joined SBMC in 1999. I've been here for over 20 years now.

### Q: Please describe your role in the NICU?

A: I am an attending physician in this unit and am assigned to care for a certain number of premature and/or sick babies each day.

### Q: How did you know you wanted to be a doctor?

A: I knew I wanted to become a doctor very early on. My older sister, who is about a year and a half older than me, suffered from Polio when she was just a few months old. As a result, she has been handicapped for most of her life. Throughout my childhood, my parents put her in the same class with me at school so that I could help carry her school bag and help her climb staircases. With my help, she was able to complete the 12th grade. After that, I went on to pursue my desire to become a doctor. My sister started college but was unable to finish because of difficulties related to being disabled. Being with my disabled sister my whole childhood definitely motivated me to become a doctor and do all I could for sick children.

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

A: This NICU is very special because one neonatologist takes care of each baby from admission to discharge. This means

each baby has continuity of care without many changes in care from different doctors having different styles and methods. Also, the whole team of neonatologists discuss every baby's condition in detail at rounds every morning so that every doctor knows about all the babies in the unit.

### Q: What does Family Centered Care mean to you?

A: Family Centered Care (FCC) is a very important part of the baby's care. I like the parents to participate in their baby's care and it seems that since we started to increase our focus on FCC a few years ago, babies are recovering faster, feeding better, and going home earlier than they were before. It also empowers the parents so I feel it is very good for the health of the baby AND the parents.

### Q: Do you have any suggestions or advice for NICU families about being involved in the care of their babies?

A: I encourage the parents to spend time in the NICU, be involved in their baby's care and perform kangaroo care whenever they can.

### Q: Anything else you would like to say about your job or the NICU?

A: I am totally satisfied with my job in the NICU under the leadership of Dr. Kamtorn.



## The 20th Annual Miracle Walk to benefit the Saint Barnabas Medical Center NICU will be held virtually this year on Sunday, October 11, 2020.

We will not be able to all gather in person, but check out [miraclewalk.com](http://miraclewalk.com) for more information. There are still t-shirts and activities planned from your computer and/or home. We are even collecting talent show admissions now. All of the details are on the website.

Please register so we know you still support this great cause and so other people can support you and join your team and fundraise too!!

Learn More and Register:  
[miraclewalk.com](http://miraclewalk.com) ■ [facebook.com/miraclewalk](https://facebook.com/miraclewalk)

## A 20 Percent Chance

From the moment we found out we were having twins we were so excited! My husband and I were surprised and thrilled and quickly shared the news with all of our family and friends. We did a cupcake gender reveal party and started planning how perfectly and smoothly my pregnancy was going to be because in my family history a pregnancy complication was never heard of and we were of course always assuming the best outcome!

At 19 weeks, my doctor noticed my cervix was more open than usual and put me on medication with the hope of keeping my cervix from opening quicker. At almost 22 weeks, I started having complications and went to the emergency room. There I found out I was already dilating so they put me on hospital bed rest to try to keep the girls in longer. A couple of days before the 23 week mark, I met Dr. Bautista, a NICU doctor. She came into my room and assured me that in order for the girls to have a 20 percent chance of survival, I had to make it to the 23 week mark. Sure enough, at only 23 weeks, I gave birth to Jaylin and Madelyn. It was March 1, 2016, and each of the girls weighed 435 grams - that's less than 1 pound!

Jaylin and Madelyn were quickly wrapped in plastic and blankets, then into the incubators, and off to the NICU they went. On my first visit to the NICU to meet them, I saw them there intubated, eye masks and with such fragile skin that we refused to even touch them. It was hard to see them both depend on all those machines and was so overwhelming to see them so helpless. I was introduced to the girls' doctors, Dr. Tien and Dr. Bautista. From the moment I met them I felt comfortable and felt a feeling of trust. Although statistically they both gave them only a 20 percent chance of survival, which didn't sound promising, I felt their professionalism and concern to try their best and that they would take care of my children like they were their own.

After meeting the doctors that day, I chose to be 100 percent present every single day. I was there from 10:00 am through 3:00 pm every day and came back with my husband every night. My girls had unexpected breathing problems, and even had PDA surgery (for a heart condition that sometimes occurs with extreme prematurity) within the first three



Rocio and Edwin with Jaylin and Madelyn in the NICU.

weeks of their birth. I slowly began to adjust to hospital life and started to know the staff from the front desk and security, to the different nurses that cared for the girls. Nurses Marietta and Ruby cared for the girls a lot and were so kind and caring with them. But honestly every nurse I encountered always had a smile on their face and were ready to give me any updates about the girls. Besides taking care of my miracles the nurses made me feel like they were looking out for me too. They would tell me to take care of myself, to sleep before the girls got home, and to take lots of pictures so I could show them once they were older.

My time in the SBMC NICU was cut short when they were both diagnosed with serious retina problems and were transferred to University Hospital in Newark for eye surgery. My husband and I were devastated about being transferred to another

hospital after spending so much time with all these amazing doctors and nurses. We were concerned with moving the girls from one hospital to another but they reassured us that we could call them whenever we needed them. They were there literally with us until the moment we stepped foot into the other hospital. My girls spent 3 amazing months at Saint Barnabas Medical Center and we did another 2 months at University Hospital. Our stay was cut short at SBMC, but my heart never could part with all these amazing staff members. The hardest moments we had spent were there and it was my second home. I felt safe, loved, and understood. There aren't enough words to express my gratitude toward everyone that helped me stay sane and helped my children get as healthy as they are now.

The twins are now 4 years old. They are happy curious little girls that keep me very busy. They love singing Disney songs and saying their ABC's and 123's. They are very in touch with their feelings and are so loving. I love hearing their "Please, Thank You, Love You, and Excuse Me" phrases. I also have to mention I gave birth to another baby girl, Gwendolyn, 14 months later and she was a full term blessing that we weren't expecting.

I continue to be thankful for all the amazing NICU staff members. Without their incredible care I don't think my girls would have surpassed the outcome of their unlikely survival rate. I've tried writing my NICU experience several times but struggled. Every time, I tried expressing my emotions, I didn't know where to start or how to begin. Now I have done it! I hope to inspire another NICU graduate mom to write about their journey because it was helpful for me and I hope it is for you too. Thank you once again to the NICU staff for everything you do for all the babies every day!

**-Lots of Love Rocio and Edwin**

## Important Phone Numbers:

NICU  
973-322-5300

NICU Nurse Manager  
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. Contacts:

Eileen Steffen, RNC  
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973-322-9485

Hayley Hirschmann  
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## Keep Distanced But Stay Social... (continued from page 1)

- plan a socially distanced outdoor birthday party for a friend or relative
- clear out old items/toys in our house to donate for those in need
- go on a virtual zoo or museum tour
- virtual story hours from local libraries or other sites online
- LEGO battles - have the kids describe what they have created in a certain amount of time (can be taken outside)
- plant seeds or plants inside and / or out
- family chore sticks - kids pick a stick for the family to do together each week-end (e.g. wash the car, fold laundry, clean out the garage, help organize closets or a shared closet...)
- have a talent show - live or virtually
- Six Flags Great Adventure Drive through Safari, NJ
- blueberry picking at Alstede Farms, NJ
- play badminton or volleyball in the yard
- make designs or positive messages in chalk on the driveway or sidewalk
- make signs / cards for relatives and first responders
- make a list of things to find on a scavenger hunt in your yard or while out on a walk
- make a quarantine time capsule - find items that are unique to this social distancing time and add them to a time capsule. Seal it and then plan to reopen it in a few years to talk about it together.
- make an obstacle course and add new challenges to it daily/weekly...
- build a fort for hiding, reading or just relaxing
- plan a themed dinner (kids' choice) and make dishes and dress for it (superhero, 70's...)
- do cookie decorating at a large table or on a picnic blanket outside (with friends, each child gets their own small dish of frosting and toppings)
- Noodle Tag - just like tag but you tag each other with a pool noodle from about 6 feet away
- "Hot and Cold" - hide something in the yard or house and tell those searching for it when they are hot (near the item) or cold (not near the item) until they find it
- Kickball - can be played with more kids or more than one family
- "Freeze Dance" - you remember this one, have every one dance to the music until it goes off - the last one to stop dancing when it goes off has to do something silly or hard (i.e. 5 pushups, smile at all players for 20 seconds each...)
- "Simon Says" - it's a classic; look it up if you never heard of it
- have a field day with distanced challenges (pillow sack races, egg on spoon race)