

From Us to You

A GUIDE TO THE NICU by Parents Who Have Been There



*Written with love by the
Saint Barnabas Medical Center
NICU Family Advisory Council*

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Dear NICU Family,

Congratulations on the birth of your baby!

As parents who also had babies in the Saint Barnabas Medical Center Neonatal Intensive Care Unit (NICU) we know firsthand that having a baby in the NICU can be one of the most stressful times in your life. Nothing can really prepare you for the experience. However, we hoped that writing this handbook based on our experiences and what we learned in the NICU might ease your transition to the NICU just a little.

This handbook was created to help orient you to the NICU and the hospital. There was nothing like this for us when our babies were here and we felt that this and other information (fact sheets, computer access...) could help parents understand some of the NICU experience better and faster. As a volunteer group of parents led by several NICU employees, we continue to work on projects and set goals to improve the overall experience of families that have infants in the NICU. It is meant to supplement the information your doctors and nurses give you, not replace it. **Any time you don't understand something they have told you, please ask questions of them until you do understand.** They know this is an overwhelming and confusing time and are happy to explain things to you.



PLEASE NOTE: We made a decision to refer to your baby as a male and a singleton throughout this handbook just to make reading it less awkward. If you delivered a girl, twins, triplets or more, please know that whenever applicable to your situation you should substitute the appropriate words ("she, your babies, they...") while reading. Also, policies and practices are often changing in the NICU. So, if the staff tell you something different than you read in the handbook, please listen to what they say and feel free to point out to them what you read here so we may change it in the future. We expect these instances will be rare but apologize in advance for any confusion it may cause.

Sincerely,

The NICU Family Advisory Council

Thank you!

Acknowledgements

We would like to thank **The Lehman Brothers Foundation** for their very generous grant for the production of this handbook. We appreciate their vision and understanding of how this handbook will make its mark on the families who have an experience in our NICU.

Our deepest thanks also go out to the parents who gave their time and shared their experiences in writing and editing this handbook.

Lastly our thanks go out to the staff members who graciously proofread and verified the accuracy of the content of this handbook.

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SECTION 1

Introduction to the NICU and Beyond

Your baby is one of approximately 1,300 babies treated in the Neonatal Intensive Care Unit (NICU) at Saint Barnabas Medical Center (SBMC), each year. The NICU is a special nursery for premature babies and babies with other medical issues. Many of us did not know this when our babies were treated here but, premature babies cared for in this unit have extremely high survival rates and very low disability rates. This is true even among the most fragile, low birth weight infants. Additionally, for several years the SBMC NICU has had one of the lowest chronic lung disease rates among over 500 NICUs in 27 countries.

It may seem like there are many rules and policies to keep in mind as you navigate the NICU. Keep in mind the NICU staff is always available to answer your questions or discuss any concerns. Also try to remember that NICU and hospital policies are intended to help provide the safest healing environment possible for your baby. What follows in this Chapter is some information to get you started on your NICU journey.

1.1 When can I spend time with my baby?

The NICU is open to parents all day, everyday, except between 6:30 and 7:30 a.m. and p.m. The 6:30 to 7:30 hours are shift changes for the nursing staff. They spend this time discussing your baby's condition over the last 12 hours and what they are likely going to need over the next 12 hours. They do this for several babies at a time and find it difficult to give parents the attention they need during this time so the unit is temporarily closed. The step-down unit (also called 3100), is also closed during this time. You may see your baby any other time and you can sit at his bedside for as long as you like. The frequency and length of your visits are completely up to you. Your baby will know you love him whether you're able to visit for two hours or 20 minutes.

Hand hygiene is the single most effective means of preventing your baby from getting an infection.



You may also call to check on your baby pretty much any time. **The phone number in the NICU is (973-322-5300) and (973-322-5310) in the step-down unit (3100).** At any time other than shift-changes, the nurses can update you by phone as to how your baby is doing. If you call and are told your baby's nurse is busy and can't come to the phone at that moment, ask when she might be free so you can call back and speak to her at that time.

1.2 What do I do when I get to the NICU?

You will need to use the phone system just outside the entrance to the NICU and 3100 to enter the locked unit. Pick up that phone and tell the staff person that answers your name and the last name of your baby. The staff person will release the lock on the door and it will open automatically for the main NICU. For entrance to 3100 you must open the door once the lock is released.

As soon as you enter the NICU, you should hang your coat, hat and umbrella in the closet located next to the main scrub sink. It is not advisable to leave purses, cameras, cell phones, or other valuables here. If available, secure those items in a locker in the NICU family lounge, or keep them with you. If you are dropping off breast milk, give the clearly labeled bottles to your baby's nurse or the nurse at the front desk before you wash your hands. She will place the milk in one of the unit's storage refrigerators (*more on breastfeeding and breast milk in Chapter 5*).

Next, you must "scrub in." This means you remove all jewelry (including watches) and wash your hands from your fingertips to your elbows for two full minutes. Detailed instructions on this very important practice are by the sinks in the main unit and on 3100. Please follow the guidelines carefully. **Hand hygiene is the single most effective means of preventing your baby from getting an infection.** In fact, studies have shown that simply improving hand washing improves infection rates in NICUs. Infections can be transmitted and spread through direct contact via the hands. Babies, particularly preterm and low birth-weight babies, are vulnerable to infections because they have immature immune systems. This two minute scrub should be done by ANYONE entering the NICU for the **first time each day** and **when entering the NICU again after leaving the hospital.**

You may use waterless antibacterial hand gel between visiting multiples, after changing a diaper, or touching areas around the baby's bedside. You can find this hand gel in pump bottles throughout the NICU and near your baby's bedside.

You should wash your hands with soap and water if you cannot tolerate alcohol based hand gel, whenever returning to the NICU after being in another area of the hospital, if your hands are visibly dirty, before and after eating, after using the restroom, after sneezing, coughing, blowing your nose, touching your hair, touching your face, placing fingers by or in mouth and whenever you feel a "build-up" on your hands from the alcohol based hand gel. Soap dispensers are located by the sinks throughout the NICU and on 3100.

As you proceed to your baby's bedside, try not to be alarmed if your baby is not where you last saw him. Babies are often moved to make room for new admissions.

HELPFUL TIP: *If you have multiples and one has an infection, it is advised that you visit the non-infected baby or babies first, and then wash your hands with soap and water before visiting the infected baby.*



1.3 Who can visit my baby?

You may bring anyone over the age of 18 to see your baby. Please keep in mind, however, that bringing many different people to see your baby exposes him to many different germs which could make him, or other babies in the NICU, sick. Usually, two people at a time may be at the bedside, and visitors must be accompanied by one of the baby's parents. Visitors should stop at the main desk on the ground floor of the hospital to get a pass, and should follow all of the NICU's rules and procedures, including those regarding hand washing.



Your baby's siblings, five years old and older, are the only children allowed to visit the unit. To do so, you must show proof of their immunizations and they must pass a health screening prior to each visit. Additionally, they can only visit once your baby has been moved out of the big room of the main NICU. This is because this room often contains very premature or sick babies who require a higher level of care and attention. Special visitation hours have been set up two nights a week and on Sundays for your children to see their sibling(s) in the NICU. Check with a staff member for specific times and a copy of the Sibling Visitation Guidelines.

Historically, siblings were not permitted to visit the NICU, but with the help of the Family Advisory Council, a sibling visitation policy is now in place. We believe it's important for siblings to see and bond with their newborn brothers and sisters. Many NICUs throughout the country permit sibling visitation in an effort to be more family centered. Research has shown that the presence of healthy, immunized children in the NICU does **not** increase infection rates. Involving siblings with their baby brothers and sisters is healthy for the family unit. Siblings five and older may visit the NICU with a parent. If you or your child have any concerns about visiting the NICU, our Nurse Manager or Clinical Coordinator can meet with them and prepare them for their visit. Just let a nurse know ahead of time. Additionally, if you have other children that do not meet the criteria to visit the baby in the NICU but want to see the baby, discuss it with your nurse and they can try to arrange a "visit" at one of the windows.

1.4 Can I be with my baby if I have a cold?

No one should enter the NICU if they have a fever above 100.5, diarrhea, vomiting, chicken pox or a communicable disease. This is because premature and low birth weight babies have weakened immune systems and are very susceptible to catching infections. If you have a cold, it is best to stay out of the unit. However, if you feel you must be there, try to limit your visit and ask a NICU staff member for a mask to wear during your visit. As always, make sure you do a complete two minute scrub before entering the unit. You should not allow visitors who have colds to accompany you into the NICU. Friends and relatives should understand you are doing what's best for your baby by keeping colds and germs away.

1.5 How long will my baby need to be in the NICU?

The short answer to this is "it depends." "It depends," because every baby in the NICU is different and has a different medical path. The slips and successes of each baby will vary greatly even if they are born at the exact same number of weeks gestation or are the same weight. However, there are a few requirements your baby is expected to meet before he can go home with you. First, he must be at least 34 weeks gestation and weigh about four pounds or more. He also needs to be eating well, maintaining his body temperature and free from apnea for a certain number of days (***more on this in Chapter 4***). You may also use the **Passport to Home Worksheet**, Appendix 8.1, to keep track of many specific things you, your baby and the staff will need to accomplish before discharge.



1.6 Will I ever be asked to leave my baby's bedside?

Surgical procedures may occur in the NICU with very little notice. Certain rooms may be closed during these procedures to keep the area sterile and provide as much space as possible to care for an infant during a crisis. Some of us came to the NICU to visit our babies and were told the unit was closed and we could not enter because a procedure was being performed on another baby. We understand it's disappointing and upsetting to be turned away when you've planned your day around your visit and have looked forward to seeing your baby. But take heart, often these closures don't last long. Go for a walk, grab a coffee or snack, head to the NICU lounge or resource library, or if you're short on time, return again later. Try to remember, you're helping another baby get well so he can go home with his family.

1.7 Can I donate blood if my baby needs a blood transfusion in the NICU?

Blood transfusions are often medically necessary for NICU babies, especially those who are premature. Your baby's doctor will discuss this further with you if blood needs to be given. Directed donation is a way for you and your family and friends to donate blood that might be used specifically for your baby. The directed donor must have a blood type compatible with the baby. Keep in mind that recently delivered mothers can not donate blood due to the health risks created by normal blood loss during delivery or medications they may have been given.

To donate blood for your baby, you must get a prescription from your baby's doctor. One prescription covers all family, friends and coworkers who want to donate.

To donate blood for your baby, you must get a prescription from your baby's doctor. One prescription covers all family, friends and coworkers who want to donate. Then you can phone the Blood Center of New Jersey, (973-676-4700) or (973-676-4751), to schedule an appointment at one of their sites. You may be asked to fax the prescription to the blood center and bring the hard copy when you give blood. Once your prescription is on file, anyone can call to schedule a donation for your baby.



Donated blood is tested and screened. All compatible blood is sent to the hospital, where it is usually available for your baby within two to three days. The hospital can store compatible blood for up to 35 days. Incompatible blood is earmarked for the general inventory. In some cases, the blood directed to your baby by family and friends will not be compatible, and your baby will receive blood from the blood bank. It should not be

cause for concern if your baby gets blood from the general inventory. All the blood is carefully screened and very safe. More information and statistics about this are available on the handout in the NICU titled "Administration of Blood or Blood Products." Please feel free to take a copy of it from the magazine rack on the right side of the door as you are about to exit the main NICU.

1.8 How does the NICU keep information about each baby private and confidential?

The NICU staff strives to keep all information private and will not give out specific information to anyone but parents or guardians. However, because of the open design of the unit, it may be impossible at times to keep conversations from being overheard. You might also develop relationships with other families in the unit. You are asked to respect the privacy of other families by not discussing any other family's circumstances and by staying at your own child's bedside unless you are invited by the parents to visit another baby. We have unofficially named this the "Mind Your Own Baby Rule." We ask that you let your baby's visitors know this as well. If parents have asked you to visit their baby, please be sure to wash your hands before leaving your baby's bedside and then again when you return to your baby.

1.9 What is a NICU Buddy?

A NICU Buddy is a parent who has had a baby in the SBMC NICU and has been trained to provide you with emotional and informational support, largely over the phone. Because these parents have had similar experiences to you they are often able to provide a unique form of support that only another parent who "has been there" can. If you are interested in being assigned a buddy, fill out the brief request form in the yellow pamphlet given to you by your social worker, or available by the door as you exit the main unit. Return the completed request form to the social worker or any nurse and an attempt will be made to "match" you with a buddy who had some similar NICU experiences. If you have any questions about this, you can leave a voicemail for the NICU Buddy Program Coordinator at 973-322-9753.

A NICU Buddy is a parent who has had a baby in the SBMC NICU and has been trained to provide you with emotional and informational support, largely over the phone.



1.10 What are some other things I should know about the hospital?

You may feel like everything you need to accomplish in the NICU requires a production team. Not so. In time you'll be navigating the hospital and the NICU so well you'll know exactly what to do and who to go to for help. In the meantime, here's some information to get you started.

- **Parking** is in the main visitor's lot in front of the hospital. Please remember to get your parking ticket stamped at the security desk on the ground floor if you're leaving the hospital but plan on returning later in the day. This way, you won't have to pay for parking twice. The maximum you should pay on any day is \$6 a car. **If your baby remains in the NICU for more than three weeks, free parking will be made available to you. Speak with one of the nurses or the clinical coordinator at that time and she will help you get a parking pass to use.**



- **Birth certificate** paperwork should be completed – with baby’s chosen name – signed and returned to the birth certificate office **before** mom is discharged from the hospital. Mom should have received the forms in her postpartum room in the maternity wing. Two days after mom is discharged, your baby’s information is sent to the Department of Health in Livingston. In order to receive the birth certificate, you will need to fill out a request for birth certificate form, a yellow card that was in mom’s admission packet, and send it with a self addressed, stamped envelope; copies of two forms of mom’s or dad’s ID; and \$10 cash or money order to the address on the form. If you have any further questions, the birth certificate office is on the third floor of the hospital and the phone number is (973-322-5327). They are open most days from 8am to 4pm.
- **Baptisms** can be performed at the request of the family by hospital clergy or the family’s minister or priest. They are typically performed in the NICU in extreme or emergent cases. Once a baby is baptized in the hospital, he is not baptized again after discharge.
- **Chaplains / Rabbis** are available to perform religious rituals, as well as provide emotional and spiritual support. You can call the Pastoral Care Office in the hospital (973-322-5015) to request a chaplain between 8am and 3pm. After hours or on weekends, they are available on an emergency basis and can be contacted by asking a nurse to have the on-call chaplain paged.
- **Circumcision** is usually performed in the unit a day or two before, or on the day of, discharge. It can be done by mom’s obstetrician or one of the neonatologists. By request, you may also have a bris for your baby while he is in the hospital. Arrangements can be discussed with the Nurse Manager or charge nurse.
- **The Hospital Interfaith Chapel** is open at all times as a place of meditation and prayer. It is located on the first floor of the hospital in Section B-2.
- **The Hospital Patient Park** is an outdoor area with benches, a pond, and a gazebo. You may go there to get some fresh air, sit and think or eat/drink something you brought with you. The NICU social workers and some other staff can direct you to it if you would like to use it.
- **The Hospital Cafeteria** is located on the ground floor near the main lobby and is open to the public. It is open for breakfast from 7-10am, lunch from 11:30am-2pm and dinner from 4:30-7pm. Additionally the Deli and Salad Bar in the cafeteria are open from 2-4:30pm.
- **Cup of Joe’s** is the coffee shop in the main lobby on the ground floor of the hospital. It is open from 6am-9pm every day and serves all kinds of hot teas, coffees and light snacks.
- **McDonald’s** is also located on the ground floor down the long hall past the cafeteria and is open 24/7.
- **The Hospital Gift Shop** is located in the main lobby and is open from 7:30am-9pm every day. They carry many items and often have a few items of premie clothing. You can always call them to see if they have something you are looking for (973-322-5239).



Tips

Being a parent to a baby in the NICU can be challenging to say the least. There is more information about this in Section 4. For now, here are some visiting tips to help you make the most of your time with your baby.

- Visit as often as possible and spend as much time as you can getting to know your baby. Even though your baby may be sick or premature, he recognizes your touch, voice and face.
- Try not to feel you are in the way of the medical staff. Talk to your baby's nurses about what you can do for your baby each time you come to see him.
- Hold your baby often. If he isn't stable enough to be held yet, you can talk or sing softly to him.
- Try not to be concerned with other babies around you. Keep your mind on your own little miracle.
- Pay close attention to your health and the health of other visitors. Your baby needs to be protected from contagious illnesses.
- It's okay to limit visits by friends and family members, or not allow them at all, if you're not ready to let others in.
- If you do choose to bring in other visitors, try not to be surprised by scared or shocked reactions they might have to the NICU and your baby.
- When bringing a sibling, it is a good idea to prepare them beforehand by explaining what they will see or showing them pictures.
- It's okay to take breaks away from the unit. You need rest too!

Section 2



The NICU and Its Equipment

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SECTION 2

The NICU and Its Equipment

Different hospital nurseries offer various levels of care. The Saint Barnabas Medical Center NICU can provide very high levels of care and is equipped to treat babies with a full range of serious medical conditions. This is why it is called a Regional Perinatal Center. Additionally, only experienced specialists are permitted to evaluate and treat babies here. Looking back on our infants' care we feel very fortunate that such excellent care was available to them.

2.1 How is a NICU different than a newborn nursery?

The NICU provides specialized, 24-hour care for premature and sick babies. Babies in the NICU must stay in the unit until a doctor discharges them to go home or transfers them to another unit in the hospital or on rare occasions, to another facility. However, parents can come spend time with their baby in the NICU almost 24 hours a day. While babies are in the NICU they are cared for by highly specialized doctors called neonatologists, and neonatal intensive care nurses.

2.2 Why are babies admitted to the NICU?

Babies may be admitted to the NICU for a number of reasons. They may have been born prematurely (more than four weeks before their due date) or have congenital anomalies, low Apgar scores, breathing problems, fast heart rate, low sugar levels, infection, or jaundice, just to name a few. Check with your baby's neonatologist to understand exactly why your baby is in the NICU.

The NICU cares for babies who need different amounts and types of medical attention. We hope you find comfort in knowing care is given on an individual basis which is determined by the baby's condition. Some babies may require care from two nurses at the same time, while others may have been born too early and just have some growing to do or may need to learn how to eat. You might hear these babies referred to as "growers and feeders."

2.3 Why is my baby in one room as opposed to another?

The majority of babies begin their stay in the NICU's Main Room, also known as Room 1 or "The Big Room." Babies who need some kind of surgery are also usually cared for in this room before and after their operation. In this room babies of various sizes and conditions are cared for in different types of beds. You will see and hear lots of medical equipment at work here. These are all helping your baby.

Most babies eventually graduate to one of the three other rooms located by the nurses' station and the main door of the NICU. These rooms, which are numbered 2, 3, and 4, are commonly referred to as "The Intermediate Rooms." These rooms are smaller, quieter, and often seem less intense than the "The Big Room," although much of the same equipment is still in use.





Two isolation rooms are located near the nurses' station. These rooms are sometimes used for babies with infections, babies admitted from home, or babies that have a weakened immune system and need to be specially protected from others. There are also times babies are placed in these rooms due to limited space in the unit.

Down the hall from the main NICU is 3100, or the "Step-Down Unit." This area may not be used if there is enough room to keep all of the NICU babies in the main unit. There is no particular order of rooms your baby needs to progress through before being discharged. Some babies may be in "The Big Room" for most of their stay, while others may spend time in a few different rooms. Additionally, your baby may be discharged from any room as long as he is ready to go home.

Babies may be moved at any time, day or night, for different reasons so try to stay calm if your baby is not where you last saw him. He may have simply been moved to another room. If this is the case, staff can easily direct you to your baby.

In some cases, it can actually be a good sign when your baby is moved. It may mean your baby has improved and is "stepping down" into one of the intermediate rooms. However, room changes often occur based on staffing and space issues in the unit. Keep in mind that all the rooms in the NICU and the Step-Down Unit (3100) are staffed by the same doctors and nurses so that all of the babies receive the same quality care, regardless of the room they are in. Also, don't be alarmed if your baby

Any time you are uncertain about what the equipment does or what an alarm means, feel free to ask your doctor or nurses as many questions as you need to understand.

moves back to the "Big Room." This *could* occur as a result of a change in the baby's condition or it could just be the result of additional babies being brought in to the NICU. Sometimes they are also brought back to that room for some medical procedure to be done. In this situation, try to take a deep breath and remember the nurses and doctors are there to answer any questions or concerns you might have, so ask them!

2.4 Why is my baby surrounded by so much equipment?

Equipment in the NICU is used to keep your baby warm, deliver oxygen, and administer nutrition, fluids, and medicine. It also helps the doctors and nurses monitor your baby's weight, heart rate, breathing rate, and blood pressure. Many babies have their oxygen saturation monitored as well. This tells doctors and nurses how well oxygen is getting to your baby's tissues.

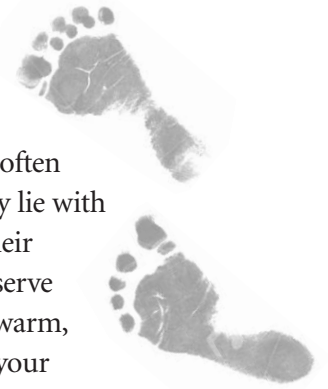
We know how scary and overwhelming it can be to see your baby connected to wires, tubes, and probes, especially when you hear the beeps and alarms that seem to constantly sound from this equipment. Although you may feel distracted or concerned by all of the medical devices, try to remember that the lights, cords, and monitors are there to provide your baby with the care needed to get well and go home with you.

As you sit by your baby's bedside, you will notice most of the equipment displays numbers on screens. The numbers have different meanings at various times during your baby's NICU stay. Your baby's nurses and doctors understand the numbers and are trained to give care accordingly. The equipment also has alarms, which will sometimes buzz or ring. While an alarm may cause your own heart rate to skyrocket, it usually signals the members of the NICU team to respond in order to avoid a problem. There are also times when they hear a buzz or ring but know it is NOT something they need to respond to right away. Many parents shared that they found the beeps and alarms very unnerving but felt learning what they meant was helpful in making them less startled and less worried when they heard them. Any time you are uncertain about what the equipment does or what an alarm means, feel free to ask your doctor or nurses as many questions as you need to understand.

2.5 What are some common types of medical equipment in the NICU?

- A **radiant warmer** helps keep your baby's body temperature normal. When babies first enter the NICU, they will often be placed on a radiant, or open, warmer. This special bed has an overhead heater to regulate body temperature and is open on all sides to allow the nurses and doctors easy access to care for babies while keeping them warm. You may feel varying amounts of heat depending on your baby's condition at any given time. The smallest preemies may even be under a cellophane blanket to avoid drafts, prevent evaporation of moisture from their skin, and increase their body temperature.
- The SBMC NICU has several **Giraffe® incubators**, which are generally used for the tiniest and most critical babies. The Giraffe® provides the benefits of a radiant warmer and an incubator in one piece of equipment. At the touch of a button the incubator converts to an open warmer, which allows easy access for x-rays, ultrasounds, and other tests without ever moving the baby from his bed. The Giraffe® also allows warmed humidity to be added to the inside of the incubator to help keep babies warm and prevent water loss through their skin. Lastly, sounds of the busy NICU are muffled by the walls of the Giraffe®, reducing the noise level for babies in it. You should know these state of the art incubators have all been purchased with money from the **Miracle Walksm**, a NICU fundraiser created and coordinated by families like you who have had personal NICU experiences. If you are interested, you can get more information at www.miraclewalk.com.
- An **isolette**, or **incubator**, is an enclosed bed where babies may be placed once they are growing and getting stronger. Nurses and doctors provide care to babies through "port holes," or openings, on the side of the isolette. You can touch your baby through these holes, but initially you should talk to a nurse about optimal times and ways to do so. Remember, your baby needs rest periods to sleep and grow without being touched or disturbed. Still, you and your baby can benefit from some gentle handholding. The isolettes have a side that opens to take your baby in and out for measurements and other needed care. There are many opportunities to participate in this care, but for your baby's safety please don't open or close the side of the isolette without a nurse or doctor there to assist.





- A **temperature probe** is used to help regulate your baby's body temperature. Extremely premature babies have almost no fat tissue to keep them warm, and they often need help achieving and maintaining a normal body temperature. These babies may lie with their arms and legs outstretched because they are too weak to bring them close to their bodies for warmth. Your baby's temperature needs to remain stable in order to conserve energy and grow. To prevent your baby from using too much energy trying to stay warm, the nurses attach a thin wire with an adhesive patch, called a temperature probe, to your baby's stomach, side, or back. This probe is connected to the bed which tells the warming device how much heat to give out based on the baby's temperature. The placement of the adhesive patch is changed regularly so your baby's skin doesn't become irritated. The nurses will suggest you take care not to cover the adhesive patch with a blanket, diaper or clothing, which will lead to a false temperature.

- A **cardio/respiratory monitor**, the most commonly used piece of equipment in the NICU, counts the number of times a baby's heart beats, as well as the number of times a baby breathes per minute. Three small patches, or electrodes, are put on your baby's chest and stomach and connected to a monitor. If your baby is very small at birth, the electrodes may initially be attached to his arms and legs. The electrodes count the heart rate and sense a baby's breathing by the rise and fall of the chest and stomach. If a baby has shallow breaths, is wrapped in blankets, or is lying on his stomach, the monitor may not detect the breathing movement and the monitor may alarm, but it is not always cause for concern.

- A **blood pressure monitor** measures a baby's blood pressure by inflating a small cuff around an arm or leg. Some babies may need to have their blood pressure monitored continuously from an intravenous (IV) line in an artery. If this is the case, the doctor will insert a small flexible tube into the umbilical artery, or an artery in the arm, leg, or scalp. This usually looks worse than it really is for the baby.

- A **pulse oximeter** calculates how much oxygen is getting to a baby's tissues. It tells doctors and nurses if a baby needs more or less oxygen, and it reduces the total number of times a baby will need to have blood taken. That is a good thing! Many NICU babies have a pulse oximeter. The

sensor, which has a red light that can be seen when it is in use, is placed on a baby's hands, fingers, wrists, toes, or feet and is secured with a soft, Velcro® closure. The oxygen saturation rate is displayed on a monitor near the baby's bed.



- A **scale** measures a baby's weight. A baby in the NICU may gain and lose weight from day to day. These weight changes are normal, especially in the first few days of life, and they should be expected. Nurses weigh babies when they are admitted to the NICU, and they routinely weigh them during the 6:30 p.m.-7:30 a.m. shift. This is important because doses of fluids, nutrition, and medication are based on knowing your baby's precise weight.

2.6 What is helping my baby breathe?

Often, babies in the NICU require supplemental oxygen. Room air, or the air we breathe, contains approximately 21% oxygen. The amount of oxygen that can be given to a baby ranges from 21% to 100% and may vary from day to day. You may notice members of the NICU staff adjusting the oxygen for a baby. This is based on signals from your baby's body and the monitor. It may be "normal" for a baby to require a higher percentage of oxygen while eating or during testing or other types of procedures.



Most of the time, the lungs of extremely premature babies (less than 28 weeks gestation) are not developed enough for them to breathe effectively on their own. Generally, these micro preemies need some kind of respiratory equipment to help them breathe well. Many will initially need the aid of a **respirator** (or **ventilator**). In these cases, an air tube is put in the baby's mouth or nose, down the throat, and into the trachea, or windpipe. Once the tube is in place, the baby is intubated. The baby's cries cannot be heard while this is in place because the tube passes between the vocal cords. The tube is connected to a respirator that regulates the flow of oxygen and air pressure. The ventilator can help the baby breathe more efficiently, or it can do all the breathing for the baby, if needed. On the other hand, some preemies may never need a respirator because they can breathe effectively on their own. The SBMC NICU often uses high frequency oscillatory ventilation, called the **oscillator**, for micro preemies. If your baby is on this type of ventilator, you will notice their chest vibrates or jiggles. A high frequency oscillator gives tiny breaths (smaller volumes) at a very fast rate. It is the goal of the NICU team to try to remove babies from the respirator as soon as possible to prevent conditions, such as chronic lung disease, that may develop as a result of prolonged respirator use. Keep in mind that chronic lung disease can also occur due to the prematurity of the lungs.

Many preemies are ready to breathe on their own within the first week after birth. As babies' lungs improve, they may be taken off the respirator and placed on **nasal Continuous Positive Airway Pressure (CPAP)** or a nasal cannula. Nasal CPAP provides a continuous flow of oxygen and air into the lungs and gently keeps the alveoli (air sacs) open to help babies breathe easier and more effectively. A baby on CPAP receives oxygen and air from tubing that enters the nostrils and is secured on their face or a small mask that covers the nose and mouth.

Respiratory management procedures are closely monitored by doctors, nurses, and respiratory therapists. The goal is to get your baby from the most invasive breathing devices to the least invasive as quickly as possible. As babies are weaned from nasal CPAP, they may be switched to a **nasal cannula**, which gives oxygen through small prongs, placed in the opening of each nostril.

Babies born full-term or near full-term with milder degrees of respiratory distress syndrome, cardiac illness, or infection may receive supplemental oxygen from an oxygen hood, or **oxyhood**. Humidified air with oxygen is pumped into a plastic box that is placed around the baby's head. Just as with the CPAP and the nasal cannula, the levels of oxygen delivered via the oxyhood are carefully monitored until the baby can breathe room air effectively.

2.7 What will my premature baby look like?

If you have no idea what a preemie or micro preemie looks like, you may not know what to expect when you see your baby for the first time. Not all premature babies look alike. Their appearances vary depending on the degree of prematurity and illness. For instance, the more critical and premature the baby, the more equipment and monitors will be needed. A baby born at 24 weeks' gestation will probably have a respirator and a lot of wires compared to a 35-week preemie, who might not even need supplemental oxygen to breathe. Babies who are very premature haven't had the chance to develop a fat layer under the skin, so their skin may be very red and papery thin—you may be able to see blood vessels and ribs through it. They may have no hair on their heads or any eyebrows, and they may still have soft body hair on their backs, arms, and foreheads (this is called lanugo, and it will eventually shed). Babies born three or more months early may not even have their eyes open yet; they may be fused shut. With each passing week these very premature babies will look more like average newborn babies. And, although the first sight of your baby might be upsetting, your love will be the same.

Parent Story



I will never forget the first time I walked into the NICU. It felt like I was walking onto a spaceship! All the beep, beep, beeps, different isolettes, and of course all the different sizes of babies! Our daughter, Lily, was born at 24 weeks' gestation and weighed 1lb. 9oz.

The first time we saw her she looked very scary! She was red and skinny; the skin on her hands and feet were transparent, and it seemed like every part of her tiny body was attached to something. It was a devastating experience for us. That first visit I had to walk out and all I did was cry all the way back to my room. I didn't think that this tiny little baby could ever survive, but she did! The SBMC NICU can do amazing things and Lily is proof! She had a four-month stay in the NICU with a PDA surgery, sepsis, and some other complications but conquered it all! Now she is two years old, almost 20 pounds and doing everything she should be doing. She is very active, runs all over the place, and is talking up a storm. She is truly a Miracle Baby! There is no question that having a premature baby is a very difficult life event. Seeing your baby in the isolette, attached to all the monitors, wires, lines, and oxygen can be extremely overwhelming and hard to comprehend. Each day Lily spent in the NICU was worrisome to my husband and I, but we tried to always remain hopeful. As parents, we found that becoming our baby's advocate made us a more effective part of the team. We realized we had to try to take a moment to recognize that by keeping ourselves well, we were providing good care to our baby. It's very difficult to

accept your baby is in the NICU and is not going home with you, but we trusted the doctors and nurses to take care of our baby and we got through it. (Lena E.)





Section 3



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SECTION 3

Who's Who in the NICU?

The first few times you sat by your baby's bedside, you probably noticed various medical professionals coming in to examine your baby and fiddle with his equipment. If you felt intimidated, you're certainly not alone. But fear not. The medical personnel you see passing through the unit make up the multidisciplinary team involved in your baby's care. Each member has a specific job to do to provide thorough and comprehensive medical attention to your baby. Those routinely around your baby are neonatologists, nurses, social workers, pharmacists, respiratory therapists, x-ray technicians and phlebotomists. In some cases, other pediatric specialists, such as surgeons, neurologists, ophthalmologists, physical/occupational therapists, and cardiologists, may be called to examine your baby. Though it may seem like the blur of people treating your baby are not connected, their responsibilities do, in fact connect. We know that in a heightened emotional state it can be difficult to keep track of the staff and understand each person's function in the NICU. So below we try to help you sort it out and hopefully answer some of your questions. Also, keep in mind you may ask anyone at any time what their role is in caring for your baby.

3.1 What is a neonatologist?

A neonatologist is a physician who specializes in the development, care and diseases of newborns. This medical doctor has special training and expertise in treating newborns with different types of medical problems. Typically, neonatologists treat premature babies born weighing less than five pounds, as well as bigger babies who have breathing difficulties and/or more severe health complications.

A neonatologist is a physician who specializes in the development, care and diseases of newborns.

The path to a career in neonatology is long and difficult. After four years of college and four years of medical school, neonatology hopefuls must complete three years of a pediatric internship and residency followed by another three years in a neonatology fellowship program.



3.2 The SBMC Neonatologists

At SBMC, one of nine full time neonatologists will take primary responsibility for the care of your baby until he is stable enough to leave the NICU. Your baby may have been directly admitted to the NICU and assigned to a neonatologist or your pediatrician may have referred your baby to the NICU and now one of our neonatologists is caring for him. Labeled pictures of each of them are here and on the wall just past the scrub sinks as you enter the main unit.

If the delivery of your baby was identified as “high risk”, you may remember a neonatologist and neonatal nurse present at his birth. They were the people who were caring for your newborn in the delivery room and then moved him to the NICU, where they administered immediate medical care. Research has shown that care in the first minutes of life can be vital to a premie’s outcomes. This is why a neonatologist and neonatal nurse are present at every high risk birth at SBMC.

As we mentioned earlier, outcomes

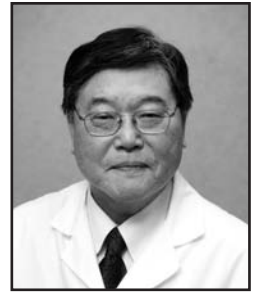
here are superior to those at other NICUs across the country. Infants with the lowest birth weights have survival rates more than double the average rate at NICUs internationally. For the years 2001-2006 a 23 week gestation infant born at SBMC has had a 65% chance of survival compared to the national average survival rate of 30%. This is partly due to the NICU team’s efforts in the first few minutes of life which is the most critical period for premature babies. Additionally, the unit does not employ any residents or interns which results in a staff of highly skilled and experienced neonatologists who work in the unit around the clock, even on weekends and holidays.



Dr. Shyan Sun
Director of Neonatology



Dr. V. Kamtorn
NICU Clinical Director



Dr. SoHun Ko
Neonatologist



Dr. Sandhya S. Ruben
Neonatologist



Dr. Maria Sanchez-Kanel
Neonatologist



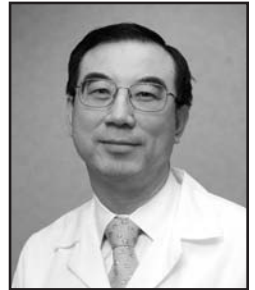
Dr. Jose Santo Domingo
Neonatologist



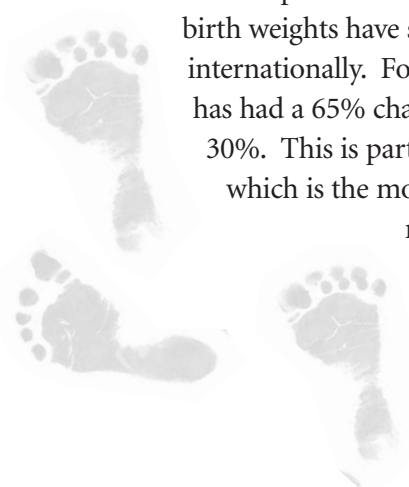
Dr. Agnes Soni
Neonatologist



Dr. Theresa Stec
Director— High Risk
Infant Follow UP



Dr. Huey Tien
Neonatologist



3.3 When does the neonatologist see my baby?

Every weekday morning, the neonatologists meet in an office to discuss current NICU patients, and review research and literature on the newest trends in neonatal medicine. Then they usually enter the unit sometime between 9:30 and 10 a.m. and see their patients during “rounds” over the next few hours. While on rounds, the doctor examines your baby and decides on a plan of care for the day, which might involve blood work, x-rays, feeding changes, or a decrease in oxygen, among other things. He also initiates and coordinates the efforts of other medical personnel who will be involved in your baby’s care. All orders are discussed with your baby’s neonatal nurse and written in the baby’s chart. When possible, you are encouraged to spend time with your baby during rounds to hear first hand from your baby’s doctor the plan for the day. If you are unable to be present during this time you may fill out a “Doctor and Family Communication Form” in the folder given to you when you first met your neonatologist.

On most days, your baby’s neonatologist remains in the hospital until about 4 p.m. Any time an issue arises, or there is a change in your baby’s condition, the doctor is notified and the baby is seen. If your baby has special problems or is in need of extraordinary care, the neonatologist will contact you to explain these problems.

3.4 What if my baby needs a doctor after 4 p.m., or even in the middle of the night?

While your baby is in the NICU he has quick access to a neonatologist whenever he needs one.

You might not feel confident about much at this moment, but you can be sure while your baby is in the NICU he has quick access to a neonatologist whenever he needs one, including in the wee hours of the morning. Usually, seven neonatologists work in the unit Monday through Friday from 7:30 a.m. to 4 p.m. One stays from 4 p.m. until the following morning, and is joined by an associate — a neonatologist or specially-trained pediatrician — to provide coverage through the night. If a problem surfaces or the number of babies in

the unit suddenly increases, as in the case of premature triplets being admitted, one of the unit chiefs — Dr. Sun or Dr. Kamtorn — may be called in. Here at Saint Barnabas Medical Center your baby is ALWAYS under the direct care of a neonatologist, not a fellow, resident or intern. Studies have found that NICUs that do not have neonatologists present 24 hours a day have higher mortality rates than those like SBMC that have neonatologists in the hospital at all times.



When possible, you are encouraged to spend time with your baby during rounds to hear first hand from your baby’s doctor the plan for the day.

3.5 When can I talk to my baby's neonatologist?

Some of you may feel as some of us did in the NICU— overwhelmed by the medical jargon, intimidated by the doctors, timid about intruding or overstepping your bounds, or unsure of the proper protocol. When you have a question about your baby's course of treatment, want clarification on a procedure, or just need an update on his condition, you are entitled to speak to your baby's physician. The neonatologists understand you are hungry for information and are happy to share it. You are welcome to phone your baby's neonatologist or ask for a meeting during the time you're with your baby in the unit.

It's not uncommon to feel helpless when so much of your baby's care seems out of your hands. Although the doctors and nurses in the NICU are running the show medically, you can become an educated partner in your baby's care. You are your child's strongest and most passionate advocate. You will not be perceived as a nag if you ask the same questions over and over again. You are not stepping on anyone's toes if you wish to speak with your baby's doctor often. Everyone in the unit expects you to be a parent to your child. Only you can give him the love and nurturing and attention he needs to thrive. YOU are the constant in your baby's life!

3.6 What is a NICU nurse?

The neonatal nurses are responsible for the minute-to-minute, individualized care of your baby. These nurses have training in and experience with the special needs of premature babies and full-term babies with complications. They serve as round-the-clock eyes and ears of the doctors, reporting changes in your baby's condition and carrying out the doctor's orders. All of the 100

Many of us counted on the nurses to give us honest and complete updates sprinkled with a whole lot of compassion.

plus nurses in the SBMC NICU are registered nurses who have completed, or are in the process of completing, an intensive orientation period, during which time they take classes and work closely with veteran staff nurses. Because the turnover rate is so low — less than 10 percent — the nursing staff remains relatively constant and experienced. With only a few nurses leaving the unit each year, there isn't much room for new hires. In fact, many of the nurses have worked in this NICU for more than 20 years

and all are NRP (Neonatal Resuscitation Program) certified.



3.7 What is the role of the NICU nurse?

NICU nurses have many duties. For one, they deliver daily, routine physical care to your baby. When a nurse begins her shift at 6:30 a.m. or 6:30 p.m., she first reviews your baby's chart and then performs a series of evaluations that she repeats throughout her 13-hour shift. She checks your baby's sensors and monitors that give heart rate, respiratory rate and body temperature information; observes your baby's skin tone and behavior; inspects your baby's IV insertion sites; and looks for any changes in your baby's physical condition. She also measures your baby's intake and output, and monitors and coordinates lab work, obtaining results and reporting them to the neonatologist. All data the nurse gathers about your baby is documented on the chart.



In addition to obvious tasks like feeding, bathing, and weighing your baby, the nurse is trained to administer medications, insert IV lines, draw blood samples, suction, and give CPR or use a resuscitation bag if necessary. If your baby shows signs of distress, the nurse is on-the-spot to provide care or call for a doctor when needed.

It's very likely that your baby's nurses are the people you will see and talk to the most in the NICU. They spend more time with your baby than anyone else in the unit, so they are a vital source of information about your baby. Not only can they give you up-to-the-minute progress reports, they may be able to help you understand your baby's development. They'll help guide you the first few times you handle, touch and feed your baby. They know your baby needs you just as much as you need him. Discuss with the nurse when your baby will be awake, bathed, changed, weighed and fed so you can be present at these times whenever possible.



Also, feel free to ask your baby's nurse to clarify any confusing medical terminology for you. Often, it's the nurse who will help you understand the doctor's comments. Many of us counted on the nurses to give us honest and complete updates sprinkled with a whole lot of compassion. We found we especially craved such comfort in the middle of the night when the "what ifs" played in our minds like a broken record or when we wished our babies were home, where we longed for them to be. These are the times you should never hesitate to call the NICU and ask to speak to the nurse who is assigned to your baby. A quick reassurance that all is well might be all it takes for you to get some rest.

3.8 Is it really okay to call from home to speak to my baby's nurse?

Absolutely! The nurses know that when you are away from your baby you may be worried. They understand that you may be itching to phone in for an update, or two or three. Feel free to call to speak with your baby's nurse any time of day or night, except during shift changes - from 6:30-7:30 a.m. and p.m. **Again, the phone number in the NICU is (973-322-5300) and (973-322-5310) in the step-down unit (also called 3100).**

3.9 What is a respiratory therapist?

A respiratory therapist is specially trained to assemble, calibrate, monitor and supervise the use of respiratory equipment in the NICU. If your baby needs oxygen, the respiratory therapist will set up the equipment, make sure it's functioning properly, and adjust the dials to the appropriate settings as prescribed by the doctor. Once the respiratory therapist has confirmed that the equipment is working as it should and the baby is getting exactly what has been prescribed, he will check the equipment every two to four hours and record the findings on a respiratory therapy chart at your baby's bedside.



Don't be alarmed if you see a respiratory therapist drawing blood from your baby. At times he may need to do so for a blood gas - a test that helps determine how effectively your baby is breathing. The respiratory therapist also ensures that all the respiratory equipment is cleaned and changed to help prevent any bacteria. At SBMC, a respiratory therapist is assigned to the NICU 24 hours a day so he can give immediate attention to any sudden respiratory problem.

3.10 What is a NICU social worker?

Two licensed clinical social workers are available to provide supportive counseling and assistance to you during your baby's stay in the NICU. You may have met the social workers when your baby first entered the unit. They typically introduce themselves to parents and explain that they are there to advocate for you as well as help you deal with the complex emotions associated with a NICU admission. They also get the ball rolling right away with your Supplemental Security Income application, if your baby is eligible for social security benefits.

The social workers follow each family in the unit and know the status of every baby. You can speak to them whenever you need guidance or an empathetic ear. You can also schedule individual or couples counseling sessions. Some of us found this to be invaluable. It's "normal" to be scared, angry, overwhelmed, confused, distracted, short-tempered, and easily brought to tears when your baby is in the NICU. It's also common

to feel disconnected from your spouse and other family members. By talking to the social workers, you may be able to lighten the load a bit, or at least find some validation, which can be very healing.

NICU 101 is an eight-week support/education group. One-hour session features guest speakers.



Not only can the social workers provide an emotional outlet, they can access community resources that you may need either while your baby is in the unit or after he is discharged. Additionally, they run an eight-week support/education group called “**NICU 101.**” Each one-hour session features a guest speaker who has expertise in a specific topic related to the NICU. Specialists who attend talk about breast feeding, developmental issues, medications used in the NICU and stress management. These meetings also serve to bring together families who are going through similar situations and can be a source of support. Some of us developed close and lasting friendships with parents we met in the NICU and at these meetings. We all felt like we were floundering when our babies came into the unit. Reaching out to other NICU families and the social workers can be an anchor.

3.11 Who else is involved in my baby's care?

There are other staff members you may not see every day who also play an important role in your baby's care. They include x-ray and laboratory technicians, case managers, lactation consultants and pharmacists, just to name a few.

- Most x-rays procedures are done in the unit at the babies' bedsides. The **X-ray Technicians** transport a portable x-ray machine to the NICU so the babies don't have to be moved.
- **Two Lactation Consultants** work in the NICU. They spend their days in the unit helping moms with breast pumping, breastfeeding and kangaroo care. They also visit the postpartum unit and give classes for postpartum patients. If you would like to speak to one of them just ask your nurse to page them. The lactation consultants also lead a weekly support and education group for NICU parents (*see Section 5.14*).
- Two nurses act as **Case Managers**. They communicate with insurance carriers to coordinate medical benefits, as well as arrange for any necessary equipment or services a baby may need when he goes home. Any financial concerns you have around caring for your baby and obtaining appropriate medical care for them when they leave the hospital should be discussed with the case managers.
- The **Quality and Research Coordinator** coordinates, plans and helps implement the quality improvement efforts in the NICU to ensure that NICU patients and families receive the safest, highest quality of care possible. This person also coordinates Vermont Oxford Network (VON) activities and projects, acts as a clinical resource to nursing staff, assists with education of nursing staff, and facilitates Family Advisory Council activities. This coordinator helps maintain communication with all NICU staff via a NICU Newsletter.

Two lactation consultants spend their days in the unit helping moms with breast pumping, breastfeeding and kangaroo care.



- The **Nurse Manager** is responsible for the daily delivery of patient care and overall operation of the unit. If you have an issue or concern you are unable to find a resolution for, you may contact the nurse manager at (973-322-5345.)
- The **Patient Care Coordinators** (PCC's) assist the nurse manager in the daily delivery of patient care and overall operation of the unit. The PCC can help you with any issues or concerns that you may have. There are two PCC on each shift and they act as the charge nurse when they are here. In the absence of a PCC on duty, there is always a charge nurse assigned to the unit that works under the guidance of a nursing supervisor.
- The **Clinical Coordinator** coordinates nursing care and practice in the NICU. She evaluates the practice of the staff, ensuring that all patients receive quality care. The clinical coordinator also assists with the development of patient care standards, orientation and staff continuing education. She also assists the manager with miscellaneous administrative duties.
- A **Pharmacist** is assigned to the unit for sixteen hours every day. This is an enormous benefit to your baby. Not all NICUs have their own pharmacist. A **NICU Pharmacist** is very familiar with NICU medications and is an expert at mixing medications to give to the young age and tiny weight of the patients. Plus, medications can be prepared and given to the baby quickly when there is a pharmacist in the unit.
- A **Speech Therapist** may be asked to come and work with your baby if issues around feeding have been identified.
- The **Physical Therapist** evaluates most micro preemies and helps with proper positioning.
- The **Technician** (tech) is responsible for cleaning equipment between patients to prevent the spread of germs. The tech also assists in making sure supplies are readily available for the nurses, doctors and other healthcare team members.

A pharmacist is assigned to the unit for sixteen hours every day. This is an enormous benefit to your baby. Not all NICUs have their own pharmacist.



Your baby's neonatologist may call in other doctors to treat your baby should they need a specialist. Here is a quick run-down of some specialists who commonly treat NICU babies:

- **Pediatric Cardiologists** diagnose and treat heart conditions in children.
- **Pediatric Ophthalmologists** diagnose and treat injuries or defects that affect a child's eyes. If your baby is going to be in the NICU for an extended period of time, a pediatric ophthalmologist will examine his eyes at around 32 weeks gestation. This is necessary to monitor for a condition called retinopathy of prematurity (ROP), which occurs in roughly one third of all preemies. Babies who have ROP are seen by the ophthalmologist every couple of weeks. The ophthalmologist passes his findings along to you through the neonatologist. However, if you have any questions or concerns, you can arrange for a meeting. It's also possible to coordinate your visit with the eye exam. Sometimes the nurses know when the ophthalmologist will be in the unit, so ask. If upon discharge your baby's retina and/or blood vessels are still not completely matured, the ophthalmologist will schedule follow-up visits in his office.
- **Pediatric Surgeons** evaluate and perform surgery on infants when necessary.
- **Pediatric Neurologists** diagnose and treat diseases of the nervous system in children.
- **Pediatric Hematologists** diagnose and treat blood disorders in children.

While it can be heart-wrenching and nerve-racking to leave the caretaking of your baby to complete strangers at the end of each visit, be assured your infant is receiving medical attention from extremely competent and experienced professionals. What's more, in time these complete strangers might feel like family.

While it can be heart-wrenching and nerve-racking to leave the caretaking of your baby to complete strangers at the end of each visit, be assured your infant is receiving medical attention from extremely competent and experienced professionals.



I first became a NICU nurse in 1983...

...and that is when the NICU became my home, my passion. I worked as a NICU staff nurse for 16 years on the night shift and loved providing the hands-on bedside care to many NICU infants. In the NICU, nurses do not only care for the babies but for their parents as well. I have always prided myself in being an advocate for my patients and their families. NICU patients cannot speak for themselves and need the trained eyes and ears that continually watch over them to speak up for what they need. As parents, you will get to know your baby by visiting often.



You will get to know what is normal for your baby and will know when “something is not right”. Sharing your observations with the NICU staff is very useful.

Today you may see me working throughout the NICU as the NICU Quality and Research Coordinator. I help to make changes in the unit to improve the care provided to NICU babies, to make the NICU a better place for parents and NICU families. You may see me in the NICU talking with staff or reviewing patient charts. Please feel free to stop me at any time if you have questions or concerns. I may not be able to answer specific questions about your baby but I can help direct you to the person that can. I am proud to be an active member of the NICU Family Advisory Council and find the input from family members that have lived the experience of having an infant in the NICU invaluable.

—Eileen Steffen, R.N.

Section 4



Parenting in the NICU

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SECTION 4

Parenting in the NICU

You are an important part of your baby's life and a valuable member of your baby's health care team. We know it's easy to lose sight of this when there seem to be so many people taking care of your baby. However, most babies, even very premature babies begin their interactions with their parents early on. If you are not able to hold your baby right away, don't shy away from parenting him. There are still many things you can do to get to know your baby, to soothe and comfort him, and to stay actively involved in his care. It is important to keep the lines of communication open with your baby's nurses because they will help you figure out the best ways to interact with your baby. Sometimes they will suggest you let your baby sleep when you are there because they know he has not slept well prior to your arrival and sometimes they will suggest you hold the baby because they know that is what you both need. After some time, you will know what your baby needs too. Try to be patient, watch and listen to your baby's cues and remember that your role as a parent is essential.

If you are not able to hold your baby right away, don't shy away from parenting him.





4.1 What can I expect and do during my baby's early development?

The following is a quick overview of how premature babies tend to develop in the early weeks of life. **Please use the chart only as a guideline and remember that all babies, healthy or sick, premature or full term, develop at their own speed:**

Week:	What to expect:	What you can do:
23	<ul style="list-style-type: none"> - eyes remain closed - little apparent responsiveness 	<ul style="list-style-type: none"> - place your hands softly and firmly on baby when suggested by nurse
24	<ul style="list-style-type: none"> - tiny response to voice and touch - little movements 	<ul style="list-style-type: none"> - talk softly to baby with your hand on him
25	<ul style="list-style-type: none"> - arms and legs are outstretched and limp 	<ul style="list-style-type: none"> - swaddle baby with arms and legs folded so muscles will be stronger
26	<ul style="list-style-type: none"> - eyes begin to open - baby still sleeps most of the time (19-22 hours a day early on) 	<ul style="list-style-type: none"> - shield your baby's eyes from bright lights - let him sleep as much as possible
27	<ul style="list-style-type: none"> - startles at loud noises - arms and legs are outstretched and limp 	<ul style="list-style-type: none"> - avoid sudden movements and noises - swaddle him to move and hold him
28	<ul style="list-style-type: none"> - sudden jerky movements of arms and legs are common - weak hand grasp and sucking reflex begin to appear 	<ul style="list-style-type: none"> - shield your baby from bright lights and loud noises - let your baby hold your finger - offer a pacifier or hold his hand near his mouth so he can suck on it
29	<ul style="list-style-type: none"> - sense of smell and hearing may help baby begin to recognize parents 	<ul style="list-style-type: none"> - speak to your baby as you approach - speak very slowly and in a calm and quiet tone
30	<ul style="list-style-type: none"> - baby may smile occasionally - begins to be awake more frequently 	<ul style="list-style-type: none"> - swaddle him when you hold him so he can concentrate more on looking at you than controlling his movements
31	<ul style="list-style-type: none"> - sometimes keeps eyes open wide - body begins to fill out a bit 	<ul style="list-style-type: none"> - try moving your face slowly back and forth as he looks at you to give him practice using his eyes
32	<ul style="list-style-type: none"> - may start to dislike feeding tube - enjoys pacifier during tube feedings 	<ul style="list-style-type: none"> - offer pacifier during tube feedings - hold pacifier during tube feedings if tolerated
33	<ul style="list-style-type: none"> - more moving about in isolette - sleep and wake times getting clearer 	<ul style="list-style-type: none"> - try to schedule your visits around your baby's awake times – usually right before a feeding
34	<ul style="list-style-type: none"> - enjoys sucking - breathing getting coordinated with sucking and swallowing 	<ul style="list-style-type: none"> - tolerates more interaction and light and sound - don't talk to him while he's trying to eat he really needs to concentrate on the feeding
35	<ul style="list-style-type: none"> - baby shows hunger and thirst - may cry to be fed or changed - eyes look at objects and people for short periods 	<ul style="list-style-type: none"> - spend time letting baby gaze at your face as you talk with him
36	<ul style="list-style-type: none"> - baby has longer quiet alert periods and begins to reveal a more dependable sleep-wake schedule - grasping while sucking may help him stay focused on eating 	<ul style="list-style-type: none"> - your face is still the most important visual stimulation and your voice the most important sound - he may also enjoy soft music or a mobile as well

4.2 How do I bond with my baby in the NICU?

Bonding can begin while your baby is confined to a warming table or isolette. All you need to start interacting with your baby are your touch, your voice, and your face. Research shows bonding isn't something that happens only in the first few days after birth, but is ongoing. And although your baby might not be stable enough to be held initially, bonding can start with other parental gestures.

- You can use touch to bond with your baby. If your baby is very premature (23-29 weeks) you may start by placing your warm hands softly and firmly around your baby's feet, back or head. This is sometimes called cupping or a "hand hug." Premature babies often like this better than being stroked because it is less jarring to their immature nervous systems. You may also gently place your finger in your baby's palm so he can curl his fingers around it.



Once your baby's doctors and nurses say he is stable enough to be held for short periods (usually around 15 to 20 minutes, otherwise your baby may use too many calories and could lose weight) there are two ways you can do so. While he is still attached to his monitors he

can be held either wrapped in blankets in your arms or by using Kangaroo Care. **Kangaroo Care** or **Skin-to-Skin Care** is a special way for parents to hold their baby up against their bare chest. If mom or dad are interested in Kangaroo Care it is suggested they wear a button down shirt to visit the NICU. During the visit, the baby, wearing only a diaper, will be placed in an upright position on the parent's bare chest with his head over your heart so he can listen to your heartbeat. Then, the baby is covered with your shirt and/or a blanket for additional warmth. Kangaroo Care can help your baby maintain his body temperature, regulate his heart and breathing rates, gain weight, spend more time in deep sleep, spend more time being quiet and alert and less time crying. Kangaroo care may also lead to a better chance of successful breastfeeding because it can help improve the mother's breast milk production.

- You can talk to your baby to bond with him. Talk softly to your baby to let him know you're there and you love him. It doesn't matter what you say; it's the sound and the soft tone of your voice that will stimulate and comfort him. Try not to use "baby talk" as it is not as soothing to your baby. You may also ask the nurses if your baby is ready for you to leave a small tape recorder so that when you're not there they can play a tape of you reading a story or singing a song.



4.3 How do I learn to care for my baby in the NICU?

Once your baby is stable enough, you will be encouraged to feed him, take his temperature, change his diapers and learn how to bathe him. Many of these things are done similarly to how they are done with all babies but may need a little adjusting due to the baby's stage of development or due to his attachment to wires and monitors. For example, many premature babies have difficulty coordinating sucking and swallowing. So, they are "tube fed" until they are big enough to suck on a bottle or mom's nipple. This means that the baby is fed through a small flexible tube that is passed through his mouth or nose and goes directly into his stomach. In situations such as these, you will be encouraged to hold your baby and the feeding tube during the feedings. Later on you will be able to bottle or breastfeed him. (*See Chapter 5 for more complete information on pumping breast milk and breastfeeding.*) The bedside nurses can help guide you in caring for your baby. If you are able to do some or all of these things, it can help you feel closer to your baby and know that you are helping too.



Additionally, a NICU nurse usually teaches an Infant Care Class about once a week during evening shift change (6:30-7:30 p.m.). It covers topics such as bathing, temperature taking, skin/cord care, and some basic child safety. It is suggested that you sign up for the class once your baby is off the respirator and is at least 32 weeks gestation. Sign-up sheets are posted in the main NICU near the hand washing sinks. Please ask your nurse for more information if you need it.

Parent Forum – Suggestions from us to you:

- Ask lots of questions.
- Talk to the doctors and nurses about your baby's condition and expectations.
- Write down questions and seek answers.
- Watch your baby. Notice how he sleeps and reacts to stimuli. Observing these patterns will help you know your baby's signals.
- Take notes on your baby's behavior, likes and dislikes (e.g. he likes to sleep on his left side, better than his right...)
- You may even want to keep a journal.
- Get informed and learn about your baby's condition. Every parent is different. Some may want more information, and others might only want information from the doctors.
- You can find more information on hospital "fact sheets" located to the right of the door as you exit the main unit.
- More information can also be found via the internet and books (**see Appendices 8.5 and 8.6**). Remember the more current the information is, the more accurate it will generally be. Also, different hospitals have different practices and outcomes (some of which are not nearly as good as SBMC and therefore sometimes misleading).
- Take things one day at a time!

4.4 What can I do to feel like my baby is part of the family while in the NICU?

You can personalize your baby's space by bringing in photos of the family or prayer cards to put in your baby's isolette. You may also want to make or design a card with your baby's name that's easily seen by all. If you have other children at home, this can be a special project for them to make for the baby.

You can also bring in receiving blankets for your baby's bed and a blanket to cover his isolette. This will help keep out some of the unwanted light and noise of the NICU. You may also bring in hats and booties for your baby. Talk to your nurse about bringing in tee shirts or sleepers for your baby once he is at least three pounds. For babies generally fed through a G-tube, it's easier if you bring in clothing that buttons or snaps in the front so the tube can be easily reached. Remember to wash your baby's clothes before you bring them in and take them home when they are soiled. The hospital does not provide laundry service for your baby's personal items.

If your baby is a "bigger baby" or is having a "longer stay" in the NICU, he may benefit from some additional stimulation from his environment. For example, ask your nurse if he is ready for a mobile, a bouncy seat or books to be read to him. Any of these items brought into the NICU should be wiped down with germicidal wipes – available in white and red round tubs throughout the unit – before being used with your baby.

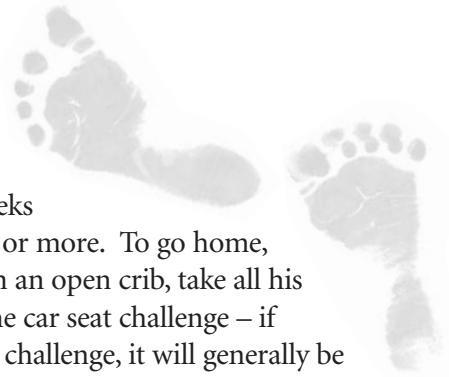


Parent Forum:

"I found it comforting to decorate my baby's bassinet with pictures of his older brother and a small stuffed animal. I also wrote his name on a piece of paper for the bassinet. It just felt more personal (the nurses knew his name, that he had a brother...) and a little more like home." J.G.

4.5 What else should I know about my baby?

- **Your baby cries** for the same reasons other babies do. He might be hungry, he might need his diaper changed, he might want his position changed or he might want to be held. If your baby is on a ventilator, you won't be able to hear him cry because the ventilator tube temporarily blocks the vocal chords.
- **Your baby's hearing** is stronger than his eyesight. He already knows your voice and will respond to it. Talk to him in a calm, soothing voice when you see him.
- **Your baby will be ready to go home** any time after he is 34 weeks gestation and weighs about 1,800 grams (almost four pounds) or more. To go home, the baby must also be able to maintain his body temperature in an open crib, take all his feedings by mouth while continuing to gain weight and pass the car seat challenge – if applicable. If your nurse tells you your baby needs the car seat challenge, it will generally be done within the week before discharge. The doctors and nurses will also want to see your baby free of apnea for a number of days before discharge (usually 7 or 8). If your baby has met all other milestones necessary for discharge but continues to have some episodes of apnea he may be discharged on an apnea monitor. If this is the case, staff will discuss this with you further and you will be trained on how to use the monitor.
- **As you watch your premature baby grow and develop**, he may seem delayed in some ways. This alone is not cause for concern because it can take up to a year or two for him to “catch up.” In fact, many doctors outside the hospital will refer to the baby by his adjusted or **corrected age**, which counts from the baby's due date, not the date he was born. So, for example, if the baby's due date was supposed to be January 20 but he was born on November 20, by March 20 he is actually 4 months old but his corrected age is 2 months.



Parent Forum:

“It scared me a lot when my daughter's eyes wandered and crossed. It worried me for days and then I finally asked the nurse about it. She explained that it was very normal and that as she developed, her eyesight and control over her eye movements would improve. She also explained to me that my baby liked to look at faces about 12 inches or more away which was helpful.”

– H.H.

4.6 How Do I Spread Myself Among Multiples?

When you have multiples in the NICU it can be overwhelming as you may feel you need to be in two or three places at one time. Some multiples will move along and progress in the NICU together allowing them to be in one room and on similar schedules. Other multiples will be in different areas and on different schedules. Here are some tips to help you with multiples in the NICU.

When Your Multiples are Together in the Same Room:

This sometimes makes handling multiples easier. You can sit between your babies and really be there for both of them. It is important that you always wash your hands between handling your babies. In addition, once they are ready for bottles try to notify the nurse ahead of time if you will be coming for a certain feeding so you can give each child a bottle. When you have multiples you can bring someone with you so they can hold one baby while you are feeding the other.

When Your Multiples are in Different Rooms:

This can be very overwhelming and scary. Obviously it is not possible to be in two places at the same time and no one expects this of you. So, don't expect it of yourself. It can be helpful in this situation if you can try to schedule longer periods of time for your visits. Also, if you and your spouse visit together, you can each spend time with one of your babies. If that is not possible, talk to the nurses about the schedules so you can arrange to give one baby a bottle, bath, etc. and then visit the other baby when that is complete. **Make sure you communicate with the nurses and inform them that you are in the NICU with one of your babies.** This way if another baby is ready for a feeding, etc. they can come get you.

Parent Forum:

“I had twins and while one was in Room 2 one was in Room 1. I felt very scared and unsure of how I would handle them in separate rooms. I made sure I was able to give each of them a bottle as well as bathe them. Even when only one of my girls was at that stage I would sit with the other so she knew I was there.”

– S.L.



Parent Forum:

“For me, it was important to keep reminding myself and my husband that we were only one mommy or one daddy with two hands.”

– K.L.K.



Section 5



Pumping and Breastfeeding

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SECTION 5

Pumping and Breastfeeding in the NICU

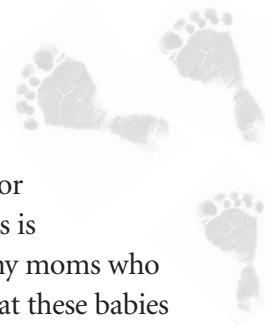
Mother's breast milk is recommended as the best source of food for all newborns. Breast milk is even more important for premature babies. When a baby is born prematurely, he doesn't receive many of the special nutrients that the placenta provides late in the pregnancy. Breast milk provides these nutrients and more. It may be hard to believe but nature actually creates "better" breast milk for preemies to make up for what they're missing. Mothers who give birth to premature babies have more of these nutrients in their milk than mothers of full term babies. Amazing, but true! So, providing breast milk for your premature baby is even more important than you might have thought.

5.1 *Why should I consider pumping breast milk even though I wasn't considering breastfeeding my baby?*

- It may result in a shorter hospital stay for your baby. Studies show that premature babies who receive breast milk may have shorter hospital stays, less infections, better bone development, better brain growth and intellectual development, and better vision than those babies fed formula.
- Your baby will likely tolerate it better than formula. Breast milk is easier for premature babies to digest and is often absorbed faster than formula.
- Pre-term breast milk is "customized" for your pre-term baby. Breast milk contains important immunity factors – while this is important for all babies, your premature baby is particularly vulnerable to infection. In fact, pre-term mother's milk contains more of these infection fighting components than full term milk.
- Your baby's growth and development will benefit. Breast milk has a higher concentration of nitrogen, sodium chloride, magnesium and iron, all important for premature babies' growth and development.
- It's empowering! Another factor that may help you decide to provide breast milk for your baby while in the NICU is the important role you will play in the care of your baby, a special gift that only you can provide. While so many others are taking care of your baby, this is one thing that only you can do. It really is quite empowering.

Mothers who give birth to premature babies have more of these nutrients in their milk than mothers of full term babies. Amazing, but true!





5.2 Can all mothers provide breast milk for their baby?

Not all mothers are able to provide breast milk due to medications they take or other health issues that may prevent them from producing breast milk. If this is the case in your situation, please know that you are not alone. There are many moms who came before you that had similar situations and the NICU staff made sure that these babies were fed appropriately and yours will be too! “It’s okay.” If this is something you continue to worry about, speak to your neonatologist to see if providing breast milk for your baby is still an option. If you are not able to provide breast milk but believe breast milk is the best thing for your baby, there may be other possibilities. There are breast milk banks that supply breast milk. If you are interested in banked breast milk, speak to your neonatologist and together you can explore the options.

5.3 How soon do I need to start pumping breast milk?

You’ll need to start pumping your breasts within 6-24 hours after giving birth to begin making milk. Ask your post-partum nurse to help you get started. The nurse will bring you a hospital grade pump that you can use during your stay in the hospital. She will also give you a personal breast pump kit that includes flanges (funnel or cup portion that is held against the breast), tubing and a supply of bottles for collection. At first, you will get very little milk and will probably wonder if you will ever have enough milk or if pumping is even working.

The thick, yellowish milk you get the first few days is called colostrum. Colostrum is rich in proteins and antibodies that a premature baby needs. Mature milk usually comes in a few days after birth; and you’ll begin to produce greater quantities of this milky-white breast milk. Don’t worry if your baby isn’t able to take all of the milk you are pumping. It can be frozen and fed to the baby when he is taking more breast milk.

5.4 How often do I need to pump?

To establish your milk supply, it is recommended that you pump every three hours around the clock (yes, this includes during the night initially).

In other words pump eight times every 24 hours for a total of 100 minutes. If your baby was with you, he would be eating that often!

Once your milk is established, you can sleep for six hours, skipping one pumping session. But remember, the more often you pump the more milk you will produce.

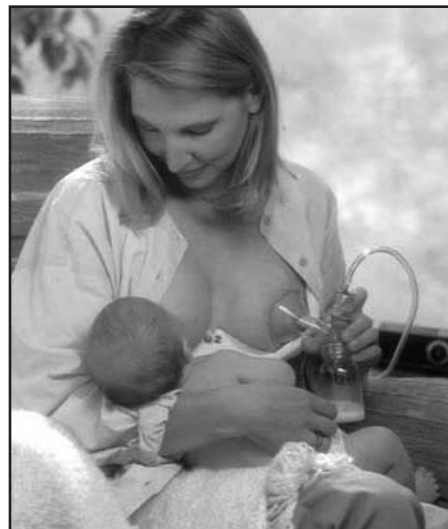
You’ll need to start pumping your breasts within 6-24 hours after giving birth to begin making milk.



5.5 How long do I need to pump each session?

If you pump both breasts at the same time - which is called double pumping - pump for 15-20 minutes each session. If you pump each breast separately - which is called single pumping - pump each side for 15-20 minutes for a total of 30-40 minutes each session. If you have multiple babies, you will need to pump more.

Double pumping will make your life much easier, as it will cut in half the amount of time it takes you to pump. Pumping both breasts at the same time may seem awkward at first but after you try it a few times it is easy to do. Ask a nurse or lactation consultant to show you how it's done. Your nurse can page a lactation consultant for you when you are in the NICU.



If you are interested in pumping hands-free, you may want to buy an “Easy Expression Bustier”. If you purchase this special pumping bra, all you have to do is insert the flanges from the breast pumping kit into holes in the pumping bra and turn the pump on. You don't have to hold the flanges to your breast, so you can read a book or a magazine or just relax. You can purchase the pumping bra and other breastfeeding items from the Women's Health Education Office located in the lobby of the 3rd floor, (973-322-5360).

5.6 Where do I pump in the hospital?

While you are still in the hospital, you can pump in your room or in the NICU. If your baby stays in the NICU after you are discharged, you'll want to pump both at home and in the NICU. Experts agree that pumping right after spending time with your baby increases your milk production. There are pumping stations in the NICU with hospital pumps and privacy curtains. Feel free to ask any nurse or lactation consultant where they are located. If you are going to use one of the NICU pumping stations you will not need to bring a pump from home, but you WILL need to bring the pumping kit to attach to the pump for use. Take your pumping kit home with you each day for sterilization and bring it back for use the following day.



5.7 Where can I get a breast pump to use at home?

You can rent or purchase a breast pump from the Women's Health Education Office (973-322-5360) weekdays 9 a.m.-4 p.m. If the hospital office is closed or out of rental pumps you can call 1-800-TELL YOU for help finding a pump. If you choose to purchase a pump on your own, a few recommendations are "Pump in Style" or "Purely Yours".

You can call your insurance company to see if they will provide coverage for pump rental or purchase. Once you are discharged from the hospital, you will need to continue to pump every three hours, so be sure to have a pump to use at home by the time you are discharged. If you can't afford to purchase or rent a pump, please speak with your social worker or case manager.

5.8 How do I clean the pump and breast pump kits?

Breast pump:

Before and after each use, wipe down the outside of the hospital pump with Germicidal Surface Wipes, found in the NICU pumping stations.

Breast pump kit parts:

1. After each use, clean the parts that come in contact with your breasts and your milk with hot soapy water, rinse, and air dry on a paper towel. You do not wash the tubing.
2. At home, sterilize the parts once a day in the dishwasher, boiling water for ten minutes, or the Medela® microwave sterilizing bags (follow directions carefully).



5.9 How do I label, store and transport my breast milk?

The hospital will provide you with boxes of small plastic bottles that attach directly to the pump flanges. Your nurse will also give you stickers to label the bottles. The white labels already have your baby's name and hospital identification information on them. The yellow labels are for you to write the date and time you finished pumping. Please use a ball point pen to write on the yellow labels.

You can combine the milk from the right and left breast at one pumping session. However, you do not want to combine newly pumped milk with refrigerated or frozen milk from a previous pumping session. Combining milk from multiple pumping sessions causes too much temperature fluctuation.

While you are a patient in the hospital, have someone take your labeled milk to the NICU within one hour after pumping. If you're using one of the pumping rooms in the NICU, you can bring the milk to your baby's nurse. When pumping at home, place your milk in the freezer for storage. Bring it with you the next time you come to the NICU in an insulated bag with an ice pack. You can store your milk in the freezer for three months if the freezer has a separate door and for six months in a deep freeze freezer.

Depending on the supply of breast milk already in the NICU for your baby, this newly pumped milk will be placed in the refrigerator or freezer by a NICU staff person. Please check with the nurse every few days to see how much breast milk is available in the NICU for your baby. Your nurse will let you know how much milk to bring in to the hospital.

Breast milk is never microwaved, as it can destroy some of the infection fighting benefits and can create "hotspots" that can burn the baby.

Before feeding, the nurse will thaw your breast milk in a container of warm water. Breast milk is never microwaved, as it can destroy some of the infection fighting benefits and can create "hotspots" that can burn the baby. Thawed milk must be used within 24 hours. When your baby first begins breast milk feedings he may only get a few drops every few hours. If this is true with your baby, when you pump try to fill the bottle with 15-30cc's to prevent wasting of thawed milk not used within the 24 hours.



Breast Milk	
Name: _____	
Pumped/Freezer	Refrigerator
Date:	Date:
Time:	Time:

5.10 How can I increase my milk supply?

- Pump more often and use a hospital-quality double pump.
- Keep a pumping diary to make sure you are pumping at least eight times a day or 100 minutes a day.
- Try not to watch the pumping process. Instead try to relax and think about your baby.
- Purchase larger flanges if pumping is painful even on the lowest setting.
- Kangaroo Care - Try snuggling with your baby skin to skin as this has been shown to increase milk production.
- Once your baby begins to bottle feed, try putting your baby to breast to stimulate your hormones.
- Try pumping in the NICU soon after contact with your baby.
- Make sure you are drinking plenty of fluids throughout the day, especially during warm weather.

5.11 Why do I feel cramping while I'm pumping?

It is normal to feel uterine cramps in the area of your abdomen the first two to three days of pumping. This occurs because the same hormone, oxytocin, that releases the milk helps the uterus contract back to it's pre-pregnancy size. You should also know the more pregnancies you have had, the stronger these cramps are likely to be.

Parent Forum:

"I didn't know it was okay to pump and dump. We had bottles in three families' freezers and finally ran out of room to store breast milk, so I stopped pumping and lost my milk supply. If I knew about pumping and dumping, where you throw out the pumped breast milk to keep your supply going until you can get the baby on the breast or have more space to store it, I would have done it." D.H.



Parent Forum:

“I had a lot of difficulty getting my baby to latch on after taking a bottle for so many weeks in the NICU. Nipple shields really helped me in this situation. I was able to breastfeed my baby immediately with no worries about latching on!” J.G.

5.12 How will my baby be fed in the NICU?

Most babies born at less than 34 weeks (and some babies born more than 34 weeks) cannot coordinate sucking with swallowing and breathing. In the NICU you may hear the staff refer to this as “suck, swallow and breathe”.

When your baby is ready for your milk, the first feedings may be given via a thin tube in the nose or mouth that goes directly into the stomach. If the tube is inserted through the nose it is called a NG (short for naso-gastric) tube and if it is inserted through the mouth it is called an OG (short for oral gastric) tube. Tube feedings may also be called gavage feedings. Once your baby begins to drink from a bottle, you can begin to try breastfeeding.

The nurses may add something called Human Milk Fortifier to your breast milk. Human Milk Fortifier gives your milk a little “extra boost” by providing extra calories, iron and vitamins that your baby needs.

You should also be aware that you may not make enough milk for every feeding and the nurses may have to supplement with formula. Your baby will still receive the benefits of breast milk even if they get formula supplements. If your baby receives breast milk for at least half of their feedings each day they will continue to reap the benefits breast milk provides.

5.13 If I decide to breastfeed, when and how do I start?

In most cases, once your baby is stable enough to bottle feed you may put him to the breast. Ask for assistance from the lactation consultant or the nurses. Remember it may be difficult in the beginning and your baby may do more licking and nuzzling than actual nursing. Getting the baby to latch on can be challenging, but practice makes perfect! If you are having a great deal of trouble, a nipple shield may make it easier for your baby to latch on. Ask the lactation consultant if a nipple shield would be helpful.

You can attend the hospital postpartum breastfeeding class to learn how to get your baby to latch on correctly and how to tell if your baby is getting milk from the breast. If you are interested, ask the lactation consultants when and where this class is held.

While learning to breastfeed, the baby will be offered some milk in a bottle after breastfeeding to make sure he is getting enough to eat. Getting comfortable with breastfeeding in the hospital will make for an easier transition to breastfeeding at home.

There is no “one size fits all” method for breastfeeding your baby, because each baby and each situation is different. Give your baby extra time to learn to breastfeed, and let the baby set the pace for learning. Learning to breastfeed effectively is a process that may take days or weeks. However, you and your baby have a better chance of becoming a breastfeeding team if you are patient, persistent, and maintain a positive attitude.

5.14 What is the NICU Mother's Milk Club?

This is a meeting for NICU parents led by the lactation consultants. During this meeting you can ask any questions you have about pumping and/or breastfeeding. They will also discuss a few common concerns each session. Such concerns might include how to increase your milk supply, how kangaroo care can help, what to know about breastfeeding your premature baby/babies and more. If you cannot attend but would like to call into the meeting, you may. More information about this is posted on signs around the NICU. As always, if you do not see information about the meeting, ask your baby's nurse about it. Also, you do not need to pre-register for this group and you are welcomed to bring a guest with you.

Parent Forum:

"I never gave any thought to breastfeeding before I had my preemie. Most women I knew had formula fed their babies and they seemed fine. I planned to do the same. I remember when the neonatologist came to my hospital room and said it could be helpful to my preemie if I started pumping breast milk for her right away. Even though she would only get a tiny bit at first, she told me I could freeze it and the nurses would give her more and more of it as she could tolerate it. Even though I never thought about pumping breast milk before and didn't know the first thing about it, I was sold. It made me feel just the tiniest bit less helpless while she spent the next three months in the NICU to be pumping breast milk for her." H.H.



Section 6



Coping

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SECTION 6

Coping

Having a baby in the NICU means learning to cope with many experiences and emotions you may never have expected even if you thought there was a chance you might deliver prematurely. Many parents of preemies are surprised by how upset they are by the early birth of their baby. It is important to know right away that it's normal to experience a confusing mix of feelings while your infant is in the NICU. The joy of having a newborn may be coupled with anger, guilt, fear and sadness that he is in the NICU. We also found our emotions changing dramatically from day to day, hour to hour, and even minute to minute. If you feel like your baby's journey through the NICU is like an emotional roller coaster ride, you are not alone. In general it will be important to give yourself time to process information and emotions. Below we try to answer some questions we recall having about coping while our babies were in the NICU.

6.1 How do I cope with going home without my baby?

Many of us found this to be a very emotional step. It was as if the act of leaving the hospital without our babies in our arms was the first of many strong reminders that our situation was not "normal." A handful of us found this was made harder by seeing other mothers sitting in the lobby in wheelchairs with babies waiting for a ride home. This may have been on our first day leaving our baby in the hospital or on one of the many days after that. For a few of us it got easier each time we saw this scene and for others the sadness was just as great every time until it was us sitting in the lobby with our baby waiting to go home.

Parent Forum:

"While going home without our babies was tough, having just gone through the surprise of having preemies and a C-section, it gave my wife and I time to prepare ourselves for what lay ahead." B.S.



Here are a few tips to try to help you get through this:

- It's helpful to try to stay positive. Think that it will be you sitting there getting ready to take your baby home one day.
- If it hurts, don't keep it to yourself. If you are sad or having other strong emotions find a good listener and tell them how you feel. This may be a spouse, friend, parent, priest/rabbi, or a NICU buddy who may have felt the same feelings.
- Remind yourself how good the care is that your baby is getting and it's all with the hope that he can go home with you as healthy as possible one day.

Parent Forum:

"At first I hated the idea of going home without my babies but then I realized there was no better place for them to be so I hated the idea a little less."

K.L-K.

Parent Forum:

"I didn't realize how difficult it would be to leave my baby in the hospital in the care of others while I went home. The best advice I can give to someone is to stay connected to the NICU as much as you can. I visited twice a day, so I could talk to the nurse that had him each shift. But if you can't be there, call and speak to the nurse who has your baby. They're always happy to give you an update on how your baby fed, his weight, etc. They never made me feel like I was bothering them or calling too much and that helped." J.G.

Then, there's being home without your baby. You may experience strong feelings of grief each time you walk past your baby's unfinished or empty room. You may also feel the loss of numerous rites of passage into parenthood: a specific kind of delivery, baby showers, childbirth classes, packing the hospital bag. You may feel awkward when others talk about their babies and the typical growth and development of their children. You may feel that you and your experiences just don't fit in. You are not alone! We felt these feelings too.

Whatever your situation, you'll have a long list of losses big and small that you need to acknowledge. The experts say that pinpointing and naming those losses makes it possible to know what you are grieving and makes the grief more manageable. They also say that grief is not a problem to be solved but rather a process that unfolds and going through it will help you heal. Your feelings of grief and sadness will likely increase and decrease from day to day. It can be impossible to predict how you will feel on any given day, or how long you will feel that way. Know that adjustment and healing WILL happen gradually over time. Your sadness and longing WILL soften and you'll be able to move ahead into the future. Your life will never be the same, but you'll reach a point where you can accept what happened, let go of "what might have been," and acquire a sense of peace.

6.2 How do I deal with having a sick or premature baby in the hospital?

It can be helpful to find ways to feel close to your baby. Early on, you may be frightened by all the medical equipment surrounding your baby. You may feel intimidated by hospital staff who seem so knowledgeable about how to care for your baby that you feel unsure about your role. It's even normal to be a little afraid to let yourself get close to a baby you fear might not survive. However, no matter what the future brings, letting yourself feel close to your baby will be helpful to you both. It will also help you build your confidence as a parent. Nurturing your baby can be a way to do something positive in a difficult situation. There is a lot more information on different ways to nurture your baby at different stages of his development in Chapter 4.

You should also know that there will likely be good days and bad days in the NICU. It can be helpful to try to focus on and celebrate your baby's small accomplishments such as weight gain, increase in feedings, maintaining body temperature, etc. Embracing all the little victories can help make this journey a bit more bearable. Many of us also found journaling and taking pictures very helpful. You may not want to share any of this with others right now, but may further down the road. It's also important to remember to keep the lines of communication open between you and your partner. Everyone has their own unique reaction to life in the NICU. Talking about how each of you feel can be helpful.

Coping With Grief

Grieving is a distressing process that entails facing your painful emotions and moving through them. Here are five key parts of coping with your grief:

- 1) Accept your need to grieve.
- 2) Identify the feelings you are experiencing.
- 3) Embrace your need to dwell on your baby.
- 4) Pursue those things that help you cope.
- 5) Have faith that eventually you will feel better.



6.3 How do I balance this trying ordeal with outside life?

You need to remember that even though your pregnancy may have ended early, during the first six weeks after you deliver, you are a postpartum mother whose body is going through all the normal physical and emotional changes that occur at the end of all pregnancies. Most women find they get tired pretty easily and are rather emotional during this time. If you had a c-section, you are also recovering from major abdominal surgery. Our point here is that even though you are likely to be very focused on your NICU baby you must make sure to take care of yourself and your other children as well. Look at it this way, if you do you'll be in better shape to take care of your baby when he comes home. Here are some tips we hope you find helpful:

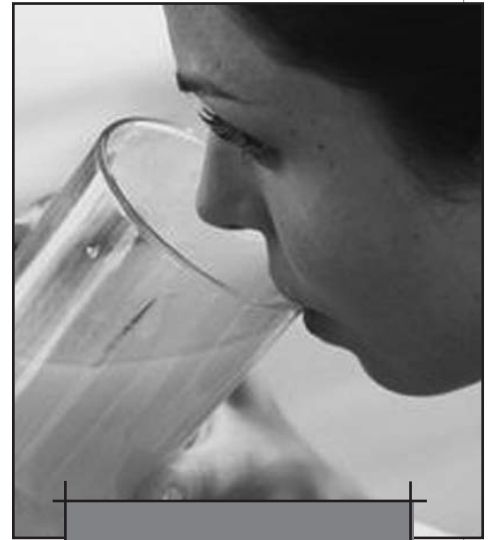
- **Get as much rest as possible.** This is a **must** especially while recuperating from the delivery. It's also important after your recovery because of the emotional energy having a NICU baby requires. If you need to go back to work and/or have other young children at home this can be very difficult. If at all possible, try to take one nap a day even if it's just for half an hour. Also, if you are pumping breastmilk, once your milk comes in you may want to pump more often during the day so you may sleep more during the night.
- **Eat nutritious meals.** You may not feel much like grocery shopping or cooking while your baby is in the NICU, but eating well is an important part of the recovery process. In the early weeks, friends and relatives can help with your shopping or by dropping off prepared meals. If you don't have any interest in fixing meals, try eating smaller meals or snacks throughout the day. Additionally, if you are pumping remember you will need to consume 500 more calories a day than you normally would for each baby you are pumping for or nursing.



In the early weeks, friends and relatives can help with your shopping or by dropping off prepared meals.



- **Make sure to drink enough fluids.** If you are pumping or nursing, you should be drinking at least 6-8 glasses of water or other caffeine-free fluids each day. Spending a lot of time in the NICU can not become an excuse for not taking care of yourself. Remember, in general, the more you drink the more breast milk you are likely to produce.
- **Accept practical offers of help.** Friends and family generally mean well and want to be helpful but they may not know how. Asking for and accepting help with things like meals, child care and household chores can create more time for you and your spouse to focus on your baby, your other children and each other. You may have a lot of people saying “let me know if there’s anything I can do,” because they don’t really know what to do but want to help. You will need to try to take them up on their offer and let them know specific ways they can help (i.e. watch your kids, make a meal...).
- **Limit the number of phone calls and/or visits you accept.** It can be exhausting retelling your baby’s status and progress to many people. Remember, you do not have to talk to everyone if you don’t feel up to it. You can set up a phone or e-mail chain where you update one person and then the others pass along the news regarding your baby. There is also a secure website called Care Pages (www.carepages.com) that you can use to communicate with others how you and your baby are doing.
- **Make the most of your hospital visits.** One good way to cope with the demands of a NICU baby and your other children or work is to try to plan your hospital visits around times when your baby is awake and alert. If your baby was very premature there may be very little of this time the first few weeks of his hospitalization. However, with time this will change. If you keep communicating with the nurses that you want to try to be there when your baby is awake, they can usually tell you when he will be fed or bathed so you can be there then too. This way you can make the most of the time you spend with your baby and minimize the time you need to take away from your other responsibilities. With other children at home it is also helpful to take turns with your spouse visiting your baby.
- **Above all, be patient with yourself.** You will heal in your own way and in your own time. Give yourself permission to fall apart at times if you need to. Many parents also feel a great deal of guilt at some point in their NICU journey. They ask themselves, “Why did this happen? Could I have done something differently?” These feelings are very common in NICU parents but it is important to remember that “feeling” and “being” are two different things. **Feeling guilty is not the same as being guilty. Feeling like a failure is not the same as being a failure.** Try to focus on the fact that you are doing the best that you can and your best can continue to get better and better.



Above all, be patient with yourself. You will heal in your own way and in your own time.

6.4 How come my partner and I seem to be coping so differently?

Many individual differences in personality, philosophy, coping mechanisms and hormones may affect how you cope with having a baby in the NICU. Moms and dads also grieve differently because they usually feel different levels of connection with the baby. Mom carried the baby in her body and her hormones are geared toward nurturing that child so she is naturally prone to feel more intense grief over the early ending of her pregnancy. Fathers often struggle with feeling helpless, unable to “fix” the situation.

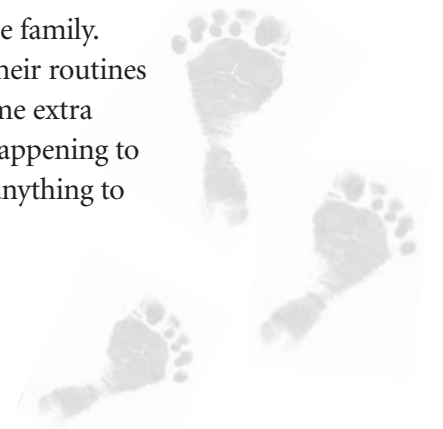
It is also not unusual for a sense of distance or isolation to develop between partners. Sometimes partners seem to take turns dealing with their emotions. When one is having a hard time, the other may put their grief aside to deal with life’s day-to-day demands. As a result the partners may feel further apart. You may not share your partner’s feelings or understand his or her reactions. However, by accepting each other’s differences, you provide the kind of support and understanding that can promote healing and help keep the relationship strong. Mutual respect and kindness is especially important during this period of intense stress. Keeping the lines of communication open during this time can be invaluable as well.

6.5 How do I handle friends or relatives who don’t seem to understand what we are going through?

You might be surprised how little people know about what prematurity means for a baby in the NICU and his parents. People may make hurtful comments when they truly mean to be comforting. They might say things like: “Lucky you, missing out on the last three months of pregnancy and getting so big.” Or “I wish my baby was born that small. I’ll bet the delivery was a breeze.” Or, “You should just enjoy sleeping through the night while the baby is in the hospital.” Or “Aren’t you over this yet? Your baby is doing fine and coming home soon.” All of the speakers here are trying to help by encouraging you to “look on the bright side.” They are mistakenly trying to ignore or erase your grief in an attempt to fix it. While you might find their comments isolating and hurtful, they really don’t mean them to be that way. Forgive your friends and relatives ignorance. If you choose, it can help to educate the people you trust and lean on most. Tell them, write them a note, give them a book to read or a website to visit (*book and website suggestions can be found in the Appendices*). You can also share with those who really want to support you that just being a good listener is helpful.

6.6 How do I handle my other children while my baby is in the NICU?

The trauma of premature birth is usually felt in some way by other children in the family. Depending on their age, they may be aware of your upset and the disruption of their routines and react by “acting up.” Although it can be difficult it is important to dig up some extra patience for them and explain to them in a simple, straightforward way what is happening to their little sibling. Some siblings may need to be reassured that they didn’t have anything to do with the baby’s prematurity and that your distress is not their fault either.



Other sibling tips:

- Try to spend some alone time with each of your other children during the week. Even if it's just for a few minutes, they'll know they are still important to you too.
- Read them books for children that explain prematurity. We have some in our NICU Resource Library you can read them and they are referenced for you in Appendix 8.6 as well.
- Short visits to the NICU window or unit, depending on the siblings age, could help them begin to bond with the baby.
- Get siblings involved by having them pose for pictures and make decorations for the baby's isolette in the hospital.

6.7 How do I cope with a loss?

This Section was written by and for parents whose beloved baby has died. It is not meant to cover all points about the complex emotional reactions people have in this situation. We suggest you speak with your social worker, close family supports, or a priest or rabbi for additional guidance. Additionally, the hospital has a Perinatal Bereavement Support Group for parents. Please call (973-322-5475) to find out more about it. There are also some suggested books and websites for grieving parents in the Appendix. *Preemies: The Essential Guide for Parents of Premature Babies* by Linden, Paroli and Doron has a good Chapter about losing a baby and dealing with the related necessary arrangements.

For parents whose baby spends days, weeks or months in the NICU death is an incredibly frightening possibility. If the unthinkable should happen to you, you may find that shock and numbness are the general feeling for the first few hours or even days. What comes next could be anger, guilt and/or vulnerability. All a cover for the enormous sadness and despair you are likely struggling with. You might wonder how you will ever get through this. You will. You will find that the path to adjusting to your baby's death and to eventual healing is by grieving. You will need to shed a certain number of tears and feel a certain amount of pain before you can come to terms with your baby's death. Every time you cry, and every time your heart aches, those particular tears or pains are behind you and you've moved along in your healing. No tear is wasted. Despite the unpredictable ups and down of this painful journey, you will discover that a time will come when you can remember your baby without falling apart. You'll never forget, your life will never be the same, but your broken heart will heal. Ours have.

Raising a surviving baby can bring both joy and pain. Your challenge is to find a healthy balance between parenting and grieving.

If your babies were twins, triplets or more and one or some of them died, you have the often confusing emotions of “multiple realities” to cope with. You may face many of these issues as you grieve:

- You grieve for the baby who died as well as for the chance to raise twins, triplets or more.*
- If one or more of your babies died earlier in your pregnancy, you will likely need to grieve for those babies even as you worry about your surviving baby in the NICU.*
- You may feel jealous of other parents of multiples in the NICU even if their babies are really struggling. This may be a difficult feeling to talk about.*
- Your need to devote much of your emotional energy toward caring for your surviving baby will complicate your grief for the one or more who did not make it. You may be so grateful that you still have one or more babies to take care of. On the other hand, you may feel you have no chance to grieve for the baby who died. Others may not give you the extra time you need to grieve either.*

Raising a surviving baby can bring both joy and pain. Your challenge is to find a healthy balance between parenting and grieving. You may be pulled into the future with the baby who lives even as you want to linger in the past with the baby you miss. As time passes, especially beyond the NICU, you’ll be able to find more opportunities to remember and say good-bye. Give yourself permission to grieve in the face of parenting and parent in the face of grief.



“It’s okay to cry.”

K.L-K.

6.8 How do I cope with the news of my baby going home?

By kicking up your heels and dancing, right? Maybe; maybe not. Sometimes the thought of taking your baby out of the safety of the hospital and into the “real world” is worrisome. It is very common to feel opposing emotions as discharge draws near: you may feel grateful and hopeful, but also anxious and unprepared. Some parents don’t realize how nervous and vulnerable they feel until actual discharge dates begin to be discussed. Others don’t realize their uneasiness until their baby is in their arms and ready to go home. Remember, it’s normal to feel a bit frightened about discharge, especially if your baby had medical complications while he was in the hospital. We found that whatever the conflicting emotions were, wanting our babies to come home always won!

Building your confidence in your ability to care for your baby can usually alleviate most concerns about bringing baby home. Here are some things you can do during your baby’s stay in the hospital (and beyond) that can help ease your worries about parenting your baby effectively at home:

- Start, or continue, to assert yourself as a parent. Tell staff how you like your baby dressed and participate in feedings, changing, and bathing. Be involved in decisions about his care.
- Try to spend as much time as you can with your baby in the days before discharge to get to know as much as you can about his patterns, temperament and care.
- Request that any necessary training (CPR, monitor, other specialized instruction) take place several days before discharge. This way, you have a little time to let the information sink in and can ask questions in the unit before you go.
- If you are feeling at all unsure about your abilities, tell the nurses that you would like to practice certain things with them watching and request their feedback or suggestions.
- If you have questions about your baby’s care, medical needs or follow up, ask them. Ask them again if you are not sure about the answers. Ask for information or instructions in writing if that helps. Don’t be afraid to go back to the doctors and the nurses and have them clarify anything you don’t understand.

Remember, going home is just what you and your baby need to do. It will give you more time and experience caring for your baby. This will help you build your faith in yourself as a strong and capable parent.

“It’s okay that the plan didn’t go as planned.”

K.L-K.



6.9 How do I cope with taking multiples home separately?

Many times multiples do not come home from the hospital together. This may cause you to feel both relieved and stressed at the same time. Although you don't want to leave anyone behind, separate homecomings can ease your anxiety about discharge by letting you "get the hang of each baby" individually. On the other hand, you are likely to feel pulled in ways you would not have believed possible before the baby came home.

It can be a real challenge for parents to take care of one twin in the hospital and one at home. Parents often don't trust anyone else to care for their newly discharged preemie. Unfortunately at least one partner might need to be at work as well. Know that the hospital staff expects, and you should also try to accept without guilt, that you won't be able to visit as often as before. If you can find someone you trust enough to leave at home, you might be able to visit your NICU baby for shorter periods than before. That's okay too. Do what you can and don't be too proud to enlist the help of family, friends, community outreach, or employed help.

Parent Forum:

"At first, it was a great concern for me to bring one baby home and leave one behind. I eventually came to look at it as a chance to practice with one baby so I would be ready for two." K.L-K.





Section 7

Our Personal NICU Stories

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Lucas

I remember the first time I saw my son Lucas. I had just recovered from nine hours of labor and was readying myself for my first peek at him in the NICU. This is where he was whisked away to as soon as he was born, 16 weeks' premature. Before the doctors left the birthing room with him, I knew two things for sure: One, my baby was strong, even though he was only one pound. I heard him crying soft little chirps like a baby bird. And two, my baby was a fighter. This I knew because he emerged into a world he wasn't ready for, breathing, a very rare feat for a 24-weeker. Puffed up by this knowledge, my husband and I went to see our little miracle. We scrubbed our hands thoroughly with hospital soap and found his incubator in a large, bright room, buzzing with the sounds of medical equipment. There he was, covered with something similar to Saran™ wrap, a tiny, dark red stick-figure surrounded by wires, tubes and probes. He looked like a miniature marionette. I stared and stared for what seemed like an hour, afraid if I opened my mouth to speak to him, all my anger, sorrow, and fear would come hurling out. I deflated. Everything I was so sure of an hour before hissed out of me like air from a helium balloon. I knew nothing. I couldn't imagine that Lucas would ever thrive. Now, seven years later, he is resilient, spirited, strong, and happy, all the things I wished for that very first day.

—Sharon S.





Hannah and Madison

There is such a strong bond between mothers and their children. It's a journey from the moment of conception, birth and beyond. My journey is like so many of yours. My wish is that I may bring comfort to those who may read this. Here is my story....

One evening, in July of 2000, my stretched out stomach was feeling strangely achy. Not like the usual achy-ness that I felt carrying my twin girls in my belly but feeling very "heavy". My next recollection is that I'm taking the ambulance to Saint Barnabas. That night, a bit after 8:00 p.m., I was awakened in the post op room to find that my baby girls had been born each weighing 1 lb. 3 oz. and 1 lb. 7.6 oz. I thought this was the hardest part. Oh, was I wrong! It was just the beginning.

During their time in the NICU, there were so many ups and downs. Mostly with many downs, our nurses and doctors were fantastic during those trying times. I remember decorating their isolettes, changing the first diaper (was I nervous!), being able to hold my daughters for the first time and so many other unforgettable memories.

After 114 and 99 days, my two little angels came home. Coming home was an experience for me. The monitors, the oxygen tanks. So many different medications. Would I be able to do this all?

My daughters, Hannah and Madison, just turned seven. Hannah is the sweetest girl a mom could hope for and can belt out an extremely great tune. Madison is quite the little competitive athlete and a bit adventurous.

To me, it was so worth it. My daughters are my best friends, my joys, my everthings.

Thank you, thank you, thank you to everyone in the NICU at Saint Barnabas Medical Center!

Fondly, Mari L.





Lauren



We are, and will forever be, incredibly grateful to the NICU staff at Saint Barnabas. We have learned that when you lose something dear to you, it makes you that much more appreciative for what still remains. This is our story.

Our twins Lauren and Matthew were born at 25 weeks gestation – each weighing 1 lb. 10 oz. They were by far, the tiniest babies we had ever seen or even imagined. The delivery was very traumatic for Matthew and he did not survive his first day of life. Lauren went on to spend the next 95 days of her life in the NICU. The medical care and attention she received during that time was also like nothing else we had ever seen. While other families involved themselves in Halloween festivities, Thanksgiving feasts and holiday cheer, we visited Lauren, prayed and waited for the day the doctors would say we could take her home. It was a very emotional time. She endured several infections, blood transfusions and eye surgery for Retinopathy Of Prematurity. She often showed us what a “fighter” she was starting very early on.

Today, Lauren is a bright and energetic seven year old. She is truly a miracle. She loves reading, sports, hip hop dance and her younger sister, Jessica.

— Hayley & Jonathan



Aaron



When my husband Rodney and I found out that we were expecting for the third time we were elated. When it was confirmed that we were going to have a little boy, we were ecstatic! For us, this was the last go around and it was a boy...mission accomplished!

Since my first two pregnancies were early deliveries by C-Section (*Shaylah my oldest was born at 34 weeks and Brianna, our middle child at 36 weeks*) we knew without a doubt that this pregnancy would not reach 40 weeks and ultimately would be a C-section too. With our expectations managed, we conservatively planned for a C-Section delivery at roughly 35 weeks...well, in life some things you cannot plan and our son's birth was going to be one of them.

Aaron Elijah B. was born on April 18, 2004 at 28 weeks and weighed only 2 lbs. 8 oz. It was a bumpy road to get him here, but we are truly blessed to have him. Although he was quite small for his gestational age, he came into this world a fighter...scoring an 8 on the Apgar Test (*I was told that's better than some full-term babies!*) So needless to say, we expect great things from him...the bar has been set!

Our baby boy spent four weeks in the NICU. Although it felt like a lifetime to be without him, we are thankful that he had no serious medical problems or concerns, he mainly needed to gain weight. The first couple of days were very rough, but we realized that the NICU was the best place for Aaron to be, to get the care that he needed to develop, grow and thrive. The NICU physicians and nurses provided such excellent care and my family and I are truly grateful.

Aaron is now three and he is no different from any other toddler...opinionated, moody, a bit mischievous and indifferent towards potty-training!



— Simone A-B.

Luke

On July 15, 2006 my water broke at 31 weeks. Without warning, I had a preemie. Yes, I had spent the last trimester of my first pregnancy on bed rest and medication expecting to deliver early but I never did. With this pregnancy things had been different. I didn't have the contractions signaling pre-term labor, so imagine my surprise when Luke decided to make a very early arrival.



This time it was so different than with our first son. I didn't get to hold him after giving birth, I had to wait till he was two days old. Unlike his brother who spent most of his time after birth in my room, I had to go visit Luke in the NICU. And worst of all, when it was time for me to go home, Luke had to stay.



At first, it seemed like every day we learned about something new. Luke and I had ABO incompatibility, he had a PDA, and then a VSD. After a while, it just came down to Luke learning how to eat and breathe at the same time! Well he kept desaturating (he came home with a monitor) but Luke finally learned how to “suck, swallow and breathe.” After six weeks in the NICU, he came home.

Luke is now an energetic, happy and healthy little boy who loves pizza, cars and trucks. At his last check-up he was in the 90th percentile for height and the 75th percentile for weight — talk about catching up!

— Jennifer G.



Jarrood and Harrison



On October 26, 2000, the Yankees beat the Mets in the World Series. For my husband, the Met Fan this day was bitter sweet. As for me, a Yankee fan, the day was a home run. Our sons Jarrood and Harrison were born 31 ½ weeks gestation. They weighed 4 lbs. 5 oz. and 2 lbs. 15 oz. respectively.

Throughout my pregnancy, I knew a NICU stay was a possibility. However, I never thought it was going to happen to me. The birth of my sons brought me great joy and a feeling of being “robbed” all at the same time. Jarrood and Harrison stayed in the NICU for 3 ½ and 4 weeks. We received wonderful care from the entire NICU staff. The staff became our family, our coaches, our mentors, and were the parents for our sons when we could not be there.

Today, Jarrood and Harrison are two very active and compassionate boys. They love playing, protecting, and teasing their little sister, Ava. Their days are filled with school, music and sports.

I believe “things happen for a reason”. Since leaving the NICU, I have learned why. During our stay and through being involved with the NICU Miracle Walk and the NICU Family Advisory Council, I have met and worked with many wonderful people. I have made great friends with several families and these friendships will last a lifetime.

— Kathleen L-K.



Jamie



My pregnancy was pretty typical. I had fertility problems, but once I became pregnant, everything seemed normal. However, by my 29th week, the baby seemed to move less and less every day. There were some days that I couldn't feel her at all. My obstetrician agreed to write me a prescription for an ultrasound, even though everything appeared normal. In my 31st week, on October 7th, 2004 I went with my husband to have an ultrasound. Afterwards, I headed to work. While on the road, I received the call that would change everything. My obstetrician informed me that my baby was only measuring at 26 weeks, and I needed to see a specialist that afternoon.

When I arrived at the perinatologist's office, I was worried, but figured I'd just have to go on bed rest. Once I had another ultrasound, the doctor told me, "your baby is fighting for its life, and wants to die.

If we don't get the baby out today, one or both of you isn't going to make it." So much for bed rest. My daughter

Jamie was delivered via emergency C-section a couple of hours later, weighing 1 pound 11 ounces. She was diagnosed with IUGR. I was diagnosed with severe preeclampsia, and remained in a magnesium induced haze for the next few days. I continued to have problems with my blood pressure, but finally returned to normal a few months later.

Over the next seven weeks, Jamie received three blood transfusions and needed oxygen at times, but basically spent time growing in the NICU. We brought her home weighing 4 lbs. 4 oz. She was on an apnea monitor for a few months, but has thrived since then. She is a happy, smart child, remains stronger than most kids her age. I guess when you come out fighting to survive, you're not going to let a little scrape or bruise slow you down.

— Michele L.

Georgie

My pregnancy was going well. I had some swelling in my feet but for the most part all was going along as expected. My due date was January 18, 2005.

I had 6 ½ weeks left to go. One morning I was sitting on the couch eating a bagel when I felt a gush of water. Upon the doctor's recommendation, we went to the hospital to see what had happened. Little did I know when I was admitted that I would be there "until the baby was delivered." My water had broken and the best they could do at this point was hope the baby would wait as long as she could. Georgie came the next morning after a difficult delivery.

Despite knowing that it was "too early," it was not until I saw her the next evening under the lights in the NICU did the thought occur to me that she was premature and that she might face complications and challenges. What those were or could be, however, we had no idea. We never looked into the possibility that our baby would be in the NICU or come early. We did not prepare ourselves for the possibility that you don't want to think about. Thankfully, she was in one of the best NICU's around.....Now, with all the requisite emotions and hormones I had to face the reality that she had some obstacles to face.

In retrospect, Georgie, compared to other NICU babies, was doing just fine. However, it's only your baby that matters to you. She was 4 ½ lbs and very jaundiced. She was not coming home with me. She only needed a bit of oxygen in the beginning but after that it was basically a "feed and grow" situation. Georgie was in the hospital for 3 ½ weeks.

She did have to come home on a heart monitor for apnea, a common condition with premature infants. That was stressful for the first few weeks as there were many false alarms.

Like anything else, once you learn the system, the language and what's what and who's who, your ability to deal with a stressful situation becomes a bit easier. However, no matter how big or small your problems and challenges are, what matters is how it affects you. Even a "routine feed and grow" situation is stressful if you do not understand the system or prepare yourself for what you have to face. Other than her petite size for her first 2 years, she finally made the charts at her 2 ½ year check-up, Georgie is flourishing and doing amazingly well. Thanks to the Saint Barnabas NICU Staff and the Family Advisory Council for their support.

— Allison G.



Christopher

Christopher was born on October 18, 2002 at 33 weeks gestation weighing 5 lbs. 2oz.

On the morning of October 18th I just felt like something was not right. I felt like my baby was moving around a lot, which wasn't unusual for him. He was very active, but the feeling that day was not the same as it had been in the past. After a phone call and short trip to my doctor's office, I was sent to the hospital. A biophysical

profile ultrasound was performed and detected severe fetal distress and an emergency c-section was performed. At birth, Christopher had no heartbeat, he was not breathing, and his limp, blue body did not respond to his airway being suctioned. By all measures, he was lifeless and had an apgar score of zero! Miraculously, after lifesaving techniques and round-the-clock care Christopher survived and spent four weeks in the NICU.

Today Christopher is a healthy, happy and energetic five-year-old. He enjoys riding his bike, playing ball, going to the beach, swimming and karate. He has, in less than a year, advanced through four levels in karate. On April 30, 2008 he excitedly became a big brother to 32 weeker, Gianna!

— Kim N.





Section 8

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SECTION 8

Appendices

8.1 Passport to Home Worksheet

As discussed in Section 4 there are several criteria your baby must meet to get discharged from the hospital. In short, he must be at least 34 weeks gestation, weigh about four pounds or more, be eating well, be maintaining body temperature and be free from apnea for several days.

Below are some things you can help make sure are done before your baby goes home. You may check them off and date them as they are done if you like. Many of them happen close to the time of discharge. If you have questions about any of these items, please just ask your doctor or nurse.

Date completed:

- _____ 1. **Breastfeeding** – When your baby is big enough and stable enough to start feeding with a bottle, you can breastfeed. If you need help getting started please ask to speak with one of our lactation consultants.
- _____ 2. **IEM Screening (formerly PKU)** – This routine screening for metabolic disorders is done for all newborns in the state of NJ within the first 24-48 hours of life. If the baby remains in the NICU, this screening is done again at 7 and 14 days of age and again at discharge or 42 days of age, whichever comes first. **PLEASE DO NOT BE ALARMED** if you receive a letter from the state saying your baby had an abnormal result for one of those screenings. About 80% of very low birth weight babies (about 3 lbs., 5 oz. and below) have at least one abnormal result. If an abnormal result is received, staff will discuss it with you and let you know if there is a need to take any further action.
- _____ 3. **Attend Infant Care Class** – Offered by a NICU nurse one night a week during shift change. Attend once your baby is at least 32 weeks gestation and is off the respirator.
- _____ 4. **Identify Private Pediatrician** – You need to choose a pediatrician for your baby to see once he is discharged from the hospital. Your neonatologist will usually recommend you set up your first appointment within 48-72 hours after discharge. If you have any difficulty finding a pediatrician who can see you that soon, talk to your neonatologist and see if they have any suggestions.
- _____ 5. **Attend CPR Class** – CPR is offered to all NICU parents, however, there is a limit of 12 participants per class. Classes are held on the first and third Tuesday of each month. Please call the phone number located near the scrub sinks to sign up for a class.
- _____ 6. **Hepatitis B Immunization** – It is recommended that babies receive their first Hep.B vaccine before leaving the NICU.
- _____ 7. **Other Vaccinations** – If your infant is in the NICU for more than eight weeks, there are additional immunizations he should get. Upon discharge, you will be given his immunization card which notes all vaccines received and the dates they were given.

- _____ **8. RSV “Vaccine” (Synagis)** – Infants born at less than 32 weeks gestation and discharged between October and March will receive Synagis, which helps protect high risk babies from severe RSV. Additional monthly doses of Synagis should be given by your pediatrician after discharge if it is between October and March.
- _____ **9. Hearing Screening** – All infants in the NICU have a routine hearing screening once they are in an open crib and do not need a feeding tube. Babies in the NICU longer than five days are required by the state to have a repeat test done by 36 months of age. The screening is non-invasive and involves taping three small wires to your baby’s head and sending a series of quiet sounds through a pair of “ear muffs.” The machine reads your baby’s response to the sounds and your baby either passes the test or is referred for further testing.
- _____ **10. Car Seat Challenge** – This is a test to see if your baby can tolerate being in a car seat for one hour. If it will take you longer than an hour to travel home with your baby, your test will be for that length of time. Most babies pass this test, but if a baby does not, the test is repeated in three to five days.
- _____ **11. Hospital Keepsake Photos** – When your baby is in an open crib and no longer has a feeding tube, a keepsake picture can be taken. The First Photo photographer is usually in the hospital in the evening, and calls the NICU to see if any babies need to have their picture taken. If you would like to bring in a special outfit for your baby to wear for the picture, please do so and let your baby’s nurse know.
- _____ **12 Monitor / Equipment Training** – If the baby is going home on an apnea monitor, oxygen or other equipment, you and other family members who will care for the baby will be trained to use the equipment. Some of these trainings are done by NICU staff and others by the company that will rent you the equipment. These trainings are scheduled on an individual basis in the hospital.
- _____ **13. Medication Administration Teaching** – If your baby is going to be discharged on medications, the nurse taking care of your baby will instruct you on how to administer them before you bring the baby home.
- _____ **14. Prescriptions Received** – If your baby is going to be discharged on medications, you will receive the prescriptions for the medications three to four days before discharge. You must have them filled and bring the medications back to the NICU so that the nurse caring for your infant and the NICU pharmacist can confirm that the medication and label dosage is correct.
- _____ **15. Circumcision** – If you would like your baby boy to have a circumcision, it can be performed in the unit by your OB or one of the neonatologists. A bris can also be performed in the NICU. Talk to your neonatologist for more information about this.
- _____ **16. Parent Satisfaction Survey** – Please fill out a Parent Satisfaction Survey before your baby goes home. We are always trying to improve the care in our NICU and we need your input and suggestions in order to do so.

8.2 Common NICU Abbreviations

A's and B's – Apnea and Bradycardia

BPD – Bronchopulmonary Dysplasia (also CLD)

CLD – Chronic Lung Disease (sometimes also called BPD)

CP – Cerebral Palsy

CPAP – Continuous Positive Airway Pressure

EEG – Electroencephalogram

EKG (or ECG) – Electrocardiogram

ELBW – Extremely Low Birth Weight; less than 1,000 grams or 2 lbs., 3 oz.

ENT – Ear, nose, and throat doctor (also called Otolaryngologist)

ET tube – Endotracheal Tube

FAC – Family Advisory Council

GERD – Gastroesophageal Reflux Disease

G-tube – Gastronomy tube

HMF – Human Milk Fortifier

IUGR – Intrauterine Growth Retardation

IV – Intravenous Catheter

IVH – Intraventricular Hemorrhage (also: brain bleed)

MRI – Magnetic Resonance Imaging

NEC – Necrotizing Enterocolitis

NG tube – Naso-Gastric Tube

NPO – nothing by mouth or no feedings until doctor changes the order

OG tube – Oro-Gastric Tube

PDA – Patent Ductus Arteriosus

PICC Line – Peripherally Inserted Central Catheter

PVL – Periventricular Leukomalacia

RDS – Respiratory Distress Syndrome

ROP – Retinopathy of Prematurity

RSV – Respiratory Syncytial Virus

TPN – Total Parenteral Nutrition

UAC (or UVC) – Umbilical Catheter

VLBW – Very Low Birth Weight; less than 1,500 grams or 3 lbs., 5 oz.

VSD – Ventricular Septal Defect

8.3 NICU Glossary

ABO Incompatibility — A problem that exists when the mother has Type O blood and the baby has Type A or B. This increases the likelihood of severe newborn anemia and jaundice.

Adjusted age (or corrected age) — The number of months since your baby's due date. Your baby missed out on some growth time inside the womb and the adjusted age takes that into account. For example: If your baby was born one month premature on January 1, on March 1 your baby's adjusted age is one month even though he was born two months ago. This is often used until the child is two years old for developmental expectations and at doctor's appointments.

Anemia — A condition in which certain levels in the blood are lower than normal and may result in the need for blood transfusions.

Antibiotics — Medications given to treat a possible or definite bacterial infection.

Apgar score — A score ranging from zero to 10 indicating a baby's physical condition immediately after birth.

Apnea — A pause in breathing lasting 20 seconds or longer. The heart rate often slows with apnea; this is called bradycardia.

Apnea Monitor — An instrument that may be used at home that monitors continuously for events of apnea or bradycardia. If an event occurs, it is recorded in the monitor's memory and an alarm sounds.

Bililights — Special bright lights used to treat jaundice (also called phototherapy).

Bilirubin — A yellow substance that is a normal waste product from the breakdown of red blood cells. An excess can cause a yellowing of the skin and/or eyes called jaundice.

Blood Culture — A blood sample to determine if bacteria is present in the blood.

Blood Gas — A blood sample from an artery or heel stick which helps determine current respiratory functioning.

Blood Transfusion — The administration of blood (red blood cells) supplied by the blood bank through an intravenous line. Used to improve oxygen carrying capability of the blood. Other blood products such as platelets and plasma can be transfused as well.

Bradycardia (Brady) — A slower than normal heart rate (below 80 to 100 beats per minute in infants). Bradys are usually associated with apnea in premature infants. During these spells the infant will stop breathing for at least 20 seconds and the heart rate will start to slow. This is also referred to as an "A&B" spell. Gentle touching or other stimulation almost always restarts the breathing and increases the heart rate. Caffeine may also be used to treat these spells.

Bronchopulmonary Dysplasia (BPD) — A lung disease that develops when the baby’s lungs do not work properly and there is trouble breathing. It is often diagnosed when a premature baby with respiratory problems continues to need additional oxygen after reaching 36 weeks gestational age. Also referred to as Chronic Lung Disease (CLD).

Caffeine — A drug which is often used to treat apnea of prematurity.

Cannula — Light, flexible tube used to give supplemental oxygen to a newborn. Oxygen flows through two prongs placed in the nostrils.

Catheter — A thin tube placed in a blood vessel for the purpose of administering fluids and/or obtaining blood samples.

Central Line — A type of intravenous tube threaded through a vein to a position as close to the heart as possible to give fluids and medications. The medical team may suggest placing a central line if your baby might need an IV for a long time because it can often stay in for several weeks or months.

Charge Nurse — The registered nurse who has general responsibility for coordinating the nursing care of all babies in a unit for a particular shift.

CAT Scan (CT scan) — A scanner which uses x-rays to generate cross-sectional pictures of the head or body.

Colostrum — The thick, yellowish breast milk produced in the first few days after delivery. This milk is especially rich in nutrients and antibodies.

Continuous Positive Airway Pressure (CPAP) — Pressurized air, often with additional oxygen, delivered to the baby’s lungs via small tubes placed in the nostrils or a soft mask placed over the nose and mouth. These tubes fit tighter inside the nostrils than those of a nasal cannula.

Cyanosis — Blue color of the skin caused by a low level of oxygen in the blood.

Desaturation (Desat) — A drop in the blood oxygen level. This is detected by a pulse oximeter or “sat monitor.”

Echocardiogram (Echo) — Ultrasound picture of the heart. This is a painless, non-invasive procedure which takes accurate pictures of almost all parts of the heart, looking at the structure and function of the heart.

Electrocardiogram (EKG or ECG) — A non-invasive and painless study in which electrodes are placed on the chest to record the electrical activity of the heart.

Electroencephalogram (EEG) — A non-invasive and painless study in which electrodes are placed on the scalp to record electrical activity of the brain.

Electrolytes (Lytes) — Minerals dissolved in the blood. Electrolytes are analyzed routinely by blood tests and include sodium, potassium, chloride, bicarbonate, calcium, phosphorus and magnesium.

Endotracheal Tube (ET Tube) — Tube placed through the mouth or nose and into the trachea and connected to a ventilator for the purpose of assisting breathing. The tube is taped in place to the skin around the mouth.

Extubation — Removal of the endotracheal tube.

Family Advisory Council (FAC) — The NICU has a Family Advisory Council made up of volunteers that had the first hand experience of having a child in the SBMC NICU. In gratitude for the care their babies received while in the NICU, these parents work with the NICU team to improve the experiences of current and future NICU babies and their families. These volunteers also work hand-in-hand with NICU staff to develop parent materials and NICU policies.

Gastroesophageal Reflux (GERD) — Condition where contents of the stomach back up into the esophagus. In some, reflux can irritate the lining of the esophagus and cause a form of heartburn which causes the baby to become irritable and uncomfortable. Mild forms of GERD are common in preemies, require no treatment and go away on their own over a period of months. However, it may be necessary to evaluate how severe the GERD is and whether or not it requires treatment.

Gavage feedings — Feedings given through a tube passed through the nose or mouth into the stomach.

Grasp reflex — A newborn's reflexive grab at an object, such as a finger, when it touches the hand.

G-Tube (Gastrostomy Tube) — A surgically inserted feeding tube that delivers nutrition directly into the stomach.

Hearing screen (BAER) — Test to examine the hearing of a newborn in which a machine monitors brain waves in response to clicking sounds played through headphones.

Heart murmur — An extra or unusual sound heard while listening to ones heartbeat with a stethoscope.

Heel stick — A small sample of blood for testing taken by pricking an infant's heel.

Hematocrit — Measures the number and size of red blood cells in the blood.

Human Milk Fortifier (HMF) — A powdered substance sometimes added to breastmilk in order to get more calories to a baby.

Hydrocephalus — An enlargement of the fluid filled (ventricles) spaces of the brain. It is sometimes known as “water on the brain.”

Intralipids (Lipids) — Fats that are given via IV to a baby that is not able to take enough calories/fats from milk (breast milk/formula) feedings. This is a white solution that is given along with TPN.

Intrauterine Growth Retardation (IUGR) — A condition where the baby doesn't grow as big as it should in the uterus. These babies are small for their gestational age, and their birth weight is below the 10th percentile.

Intravenous (IV) — A catheter (small tube) placed directly through the skin into the vein in a newborn's hand, arm, foot, leg or scalp. Nutrients, fluids and medications can flow through this tube. Newborn's veins are very fragile, so the location of the IV may need to be changed frequently.

Intraventricular Hemorrhage (IVH) — Bleeding into the fluid filled spaces (ventricles) of the brain or into the tissue around those spaces. There are four grades of IVH, indicating degree of severity. IVH is diagnosed by ultrasound examination of the brain.

Intubation — Insertion of a tube into the trachea (windpipe) to help the baby breathe.

Isolette — A clear, enclosed bassinette used to keep infants warm. Any baby can be in an isolette to be kept warm or for observation.

i-STAT — A small amount of blood taken and analyzed with results returned within minutes.

Jaundice — A yellowing of the skin and/or eyes caused by the accumulation of a natural waste product in the blood, bilirubin. It can usually be treated with phototherapy (special lights).

Kangaroo care — Skin-to-skin contact between parent and baby. During kangaroo care, the newborn dressed only in a diaper is placed on the parent's chest.

Lanugo — The fine, downy hair that often covers the shoulders, back, forehead and cheeks of a prematurely born newborn.

Lead wires — Wires connecting the sensors on the newborn's chest, arms or legs to the vital signs monitor.

Lumbar puncture (Spinal tap) — A procedure in which a fine needle is inserted between two bones at the base of the spine to remove a sample of spinal fluid for testing.

Magnetic Resonance Imaging (MRI) — A scan which uses magnetic fields to generate cross-sectional images of the head or body.

Meconium — A dark green, sticky substance present in the fetal intestinal tract before birth. It is the first stool passed by the newborn.

Meconium Aspiration Syndrome (MAS) — Meconium is passed by the infant before delivery and mixes with the amniotic fluid and is inhaled by the infant before birth.

Meningitis — An infection of the central nervous system. May be diagnosed by a lumbar puncture.

Nasogastric Tube (NG Tube) — Narrow, flexible tube inserted through the nostril, down the esophagus, and into the stomach. It is used to give food or to remove air or fluid from the stomach.

Necrotizing Enterocolitis (NEC) — Swelling and inflammation of the intestine usually caused by an infection or decreased blood supply to the intestine. The seriousness and treatment of NEC varies.

Patent Ductus Arteriosus (PDA) — The ductus arteriosus is a blood vessel connecting the pulmonary artery and the aorta. Before birth, this vessel allows the baby's blood to bypass the lungs because oxygen is supplied through the placenta. The ductus arteriosus should close soon after birth. If it does not, it is called PDA and may need to be treated with medications or surgery to close it.

Peripherally Inserted Central Catheter (PICC Line) — A type of IV line that can be used for longer periods of time. They are inserted through a peripheral vein, such as in the arm or leg.

Periventricular Leukomalacia (PVL) — A condition where areas of the brain are affected by lack of oxygen and/or blood which causes damage to brain tissue.

Pulse Oximeter (Pulse Ox) — A machine that uses a special light source to indirectly measure the oxygen getting to the baby's tissues/organs. Usually looks like a tape-like cuff wrapped around the baby's foot, hand or finger.

Residuals — The amount of undigested milk left in the stomach and is a measure of how the baby is tolerating feedings. This may be checked when a feeding is due to be given by pulling back on the feeding tube with a syringe.

Respiratory Distress Syndrome (RDS) — Respiratory problems due to lung immaturity.

Respiratory Syncytial Virus (RSV) — A common virus affecting the respiratory tracts and can be more serious in preemies. Symptoms include rapid breathing, coughing, wheezing and sometimes even respiratory failure. RSV season is usually from October to March.

Retinopathy of Prematurity (ROP) — A disease of the eyes (retina) in premature infants that sometimes leads to visual impairments.

Room Air — The air we breathe, contains 21% oxygen. Your baby's oxygen level can be adjusted from 21% to 100% as needed.

Saturation (O2 Sats) — An indication of the amount of oxygen getting to baby's tissues/organs.

Sepsis — A severe infection in the body that can spread to other areas of the body. A baby can be infected while still in the uterus, during delivery or after birth. The treatment is IV antibiotics.

Sonogram — Another name for ultrasound.

Suctioning — Removal of mucus or other fluid from the nose, mouth or endotracheal tube using a plastic tube attached to a suction device. This keeps your baby's breathing passages clear and makes him more comfortable.

Surfactant — A substance produced by the lungs that helps keep the small air sacs of the lungs open. Without surfactant, the air sacs tend to collapse or stick together. If a baby is not able to produce surfactant due to prematurity of the lungs he may be given some to help with breathing.

Tachycardia — A faster than normal heart rate. In an infant this is usually above 180 beats per minute.

Tachypnea — A faster than normal breathing rate. In an infant this is usually above 60 breaths per minute.

Total Parenteral Nutrition (TPN) — If your baby is not able to tolerate food he must still get the nutrients and calories he needs to grow. The calories, protein, vitamins and minerals he needs are given intravenously.

Ultrasound — Imaging of body parts using sound waves. The reflected sound waves are analyzed by computer and turned into pictures.

Umbilical Catheters (UAC or UVC) — Small plastic tube put into one of the arteries or the vein of the umbilical cord. They can be used to take blood samples, and give fluids and medications.

Ventilator (Vent or Respirator) — A machine that can assist the premature or sick baby with breathing.

Ventricular Septal Defect (VSD) — A hole in the wall between the two lower heart chambers. Often congenital VSD's close on their own, but sometimes they need to be repaired.

Vermont Oxford Network (VON) — The Vermont Oxford Network is a non-profit, voluntary collaboration of health care professionals dedicated to improving the quality and safety of medical care for newborn infants and their families. The Network maintains a database of information about the care and outcomes of high-risk newborns from over 700 NICUs around the world. The database provides reliable data to participating units for use in quality management, process improvement, internal audit and peer review.

Health care professionals participate in clinical trials, long-term follow-up studies and outcome research. Members can also participate in the Network's Quality Improvement Collaboratives, where multidisciplinary improvement teams work together to achieve measurable improvements in quality and safety. Our NICU has been involved with the VON since 1994 and continues to participate in their Quality Improvement Collaboratives.

8.4 Weight Conversion Table
(Pounds & Ounces to Grams)

	0 oz.	1 oz.	2 oz.	3 oz.	4 oz.	5 oz.	6 oz.	7 oz.	8 oz.	9 oz.	10 oz.	11 oz.	12 oz.	13 oz.	14 oz.	15 oz.
0 lb.	0	28	57	85	113	142	170	198	227	255	283	312	340	369	397	425
1 lb.	453	481	510	534	566	595	623	651	680	708	737	765	793	822	850	878
2 lbs.	907	936	964	992	1021	1049	1077	1106	1134	1162	1191	1219	1247	1276	1304	1332
3 lbs.	1361	1389	1417	1446	1474	1503	1531	1559	1588	1616	1644	1673	1701	1729	1758	1786
4 lbs.	1814	1843	1871	1899	1928	1956	1984	2013	2041	2070	2098	2126	2155	2183	2211	2240
5 lbs.	2268	2296	2325	2353	2381	2410	2438	2466	2495	2523	2551	2580	2608	2637	2665	2693
6 lbs.	2722	2750	2778	2807	2835	2863	2892	2920	2948	2977	3005	3033	3062	3090	3118	3147
7 lbs.	3175	3203	3232	3260	3289	3317	3345	3374	3402	3430	3459	3487	3515	3544	3572	3600
8 lbs.	3629	3657	3685	3714	3742	3770	3799	3827	3856	3884	3912	3941	3969	3997	4026	4054
9 lbs.	4082	4111	4139	4167	4196	4224	4252	4281	4309	4337	4366	4394	4423	4451	4479	4508
10 lbs.	4536	4564	4593	4621	4649	4678	4706	4734	4763	4791	4819	4848	4876	4904	4933	4961
11 lbs.	4990	5018	5046	5075	5103	5131	5160	5188	5216	5245	5273	5301	5330	5358	5386	5415

TO USE CHART:

1. Locate the grams that are closest to the weight you have been told your baby weighs.
2. Follow the line to the left to see the pounds (lbs.) for your baby.
3. Follow the line up to see the ounces (oz.) for your baby.

FOR EXAMPLE: If you are told your baby weighs 1,531 grams- follow to the left and you will see 3 lbs., then follow up and you will see 6 oz. That means your baby weighs 3 lbs. 6 oz. If you need help calculating your baby's weight, please feel free to ask your nurse.

8.5 Helpful Websites**

**Please note: All of the following websites are listed here because they were visited by former SBMC NICU parents and found to be helpful to them in some way. These sites are meant to be informational and are NOT meant to replace the medical advice of the doctors and nurses. If any of the information on these sites seems to conflict with anything the NICU staff has told you, please discuss it with them directly. Lastly, if the web site description is followed by *(Spanish)* it means the site has parts in Spanish as well as English.



Prematurity

www.comeunity.com — support and information for families of premature babies, special needs children and adopted kids

www.earlyarrivalinc.com — sells 72-page hardcover journal specifically for premature babies

www.keepkidshealthy.com/newborn/premature_babies.html — good current information on preemies and lots of topics through childhood

www.preemie.com — to order micro-preemie and preemie clothing from a business run by a preemie mom and her former preemie daughter

www.premature-infant.com — lots of preemie articles, resources and "Imagine..." threads that share the thoughts and feelings of parents of premature infants around the world

www.prematurelyyours.com — sells premature baby journal and birth announcements; also has online discussion boards

www.prematurity.org — lots of readable information on many preemie topics

www.preemiecare.org — info and stories on numerous preemie topics including RSV; online discussion forums too

www.preemie-l.org — provides support (via list serve and online discussion group) for parents of premature babies

www.preemiesrus.com — sells diapers, gifts, and lots of preemie clothes for babies 1 to 11 pounds

www.preemies.org — preemie links, stories and chat groups

www.preemieparenting.com — preemie articles and stories; discussion "corners" for moms and dads

Multiples:

www.bumboseat.com — to order an upright seat (for babies with head control), recommended by moms of multiples

www.MOSTonline.org — Mothers of Super Twins – international support network for multiple birth families that provides education, advocacy, networking and resources

www.multiplebirthsfamilies.com — education and support for multiple births, breastfeeding and bereavement

www.nomotc.org — National Organization of Mothers of Twins Clubs – for triplets and more too

www.preemietwins.com — info about multiples and info about “free stuff” for multiples too

www.tripletconnection.org — info on products, personal stories and quarterly magazine of same name

www.twinslist.org — list serve where you can post questions, lots of good links too

www.twinsmagazine.com — stories, products, message boards and TWINS™ Magazine info

Breastfeeding:

www.breastfeeding.com — practical, lighthearted site with tips, videos, music, blogs and ideas to entertain a toddler while breastfeeding

www.BreastfeedingMadeSimple.com — lots of information from book of same name

www.lalecheleague.org — lots of breastfeeding info, products and support (*Spanish*)

www.medela.com — info on all their products for pumping breast milk and where to purchase/rent them

www.nursingmothers.org — good info in nursing twins and common problems (*Spanish*)

Grief & Depression:

www.aplacetoremember.com — support materials and resources for those touched by a crisis in pregnancy or the death of a baby

www.climb-support.org — Center for Loss in Multiple Birth; information and resources about the effects of different loss situations on all family members (*Spanish*)

www.njspeakup.gov — info about symptoms and treatments for postpartum depression (*Spanish*)

www.postpartum.net — info about symptoms, support and treatment for postpartum depression (*Spanish*)

Health Challenges & Special Needs:

www.arcnj.org — the ARC of NJ for developmental disabilities and down syndrome (732-246-2525)

www.autismspeaks.org — information articles and message boards re: autism (212-252-8584)

www.autism-society.org — Autism Society of America - (*Spanish*) (NJ Chapter: 732-531-0454)

www.chadd.org — Children and Adults with Attention Deficit/Hyperactivity Disorder (800-233-4050)

www.cpofnj.org — info and services of Cerebral Palsy of NJ, Inc. (888-322-1918)

www.eparent.com — Exceptional Parent Magazine's site; lots of books, projects and resources for special needs children and their families

www.efnj.com — information and programs of the Epilepsy Foundation of NJ (800-336-5843)

www.firstsigns.org — First Signs, Inc. – Developmental delay vs. disorder vs. autism (978-346-4380)

www.hydroassoc.org — the Hydrocephalus Association offers education and support

www.hydrocephalus.org — the Hydrocephalus Foundation, Inc. provides support, education, resources and networking opportunities to patients and families affected by hydrocephalus: lots of links too

www.ldaamerica.org — Learning Disabilities Assoc. of America — info on signs of LDs at different ages and related websites, resources and local affiliates (973-265-4303)

www.nichcy.org — National Dissemination Center for Children with Disabilities (*Spanish*)

www.njcosac.org — NJ Center for Outreach & Services for the Autism Community — useful general and local information about diagnoses, services and programs (schools, camps, recreation...) for autistic children (*Spanish*) (1-800-4-AUTISM)

www.reflux.org — oldest and largest site devoted to pediatric Gastroesophageal Reflux Disorder

www.ropard.org — good info from the Association for Retinopathy Of Prematurity and related diseases

www.rsvinfo.com — good info about diagnoses and management of Respiratory Syncytial Virus

www.sbaa.org — Spina Bifida Association of America; fact sheets, helpful links and local chapters

www.specialchild.com — online publication for parents of children with special needs

www.tracheostomy.com — internet's leading tracheostomy resource (*Spanish*)

www.ucpa.org — information, articles and newsletters about cerebral palsy (*Spanish*)

Other:

www.aap.org — extensive information on many children’s health topics

www.carepages.com — allows you to create free personal web pages to communicate with your loved ones about your hospitalized family member; also has links to medical info and relevant blogs

www.dona.org — Doulas of North America; to locate a Doula, discussion boards and FAQ’s

www.infantmassage.com — site for International Institute of Infant Massage

www.infantmassageusa.org — teaches how and why; good resources too

www.miraclewalk.com — information about fundraising walk to benefit the SBMC NICU

www.njfamily.com — Family Magazine of Morris, Essex...County; lots of articles and resources for Special Needs and all New Jersey families (camps, schools...)

www.njsha.org — NJ Speech-Language-Hearing Association. (908-359-5308)

www.saintbarnabas.com — information on all departments and hospitals in the Saint Barnabas Health Care System

www.spannj.org — Statewide Parent Advocacy Network of NJ

www.state.nj.us/health/fhs/sch/sccase.shtml — Special Child Health Services – Early Intervention of NJ; contact information by county

www.state.nj.us/njded/specialed — State of NJ Department of Education, Office of Special Education Programs (609-292-4469)

www.webmd.com — all kinds of health related info with links to articles and blogs on specific topics



Miracle Walk

**Updated 3/08*

8.6 Resource Books

Many of these books have been donated to our NICU Resource Library by graduate NICU parents. Please visit the library to take a look at these books if you are interested. Most of them are also available on-line and at local bookstores.



PREMATURITY:

Albritton, Sara et al. (1998) *You are Not Alone*

Bradford, Nikki (2003) *Your Premature Baby – The First Five Years*

Clancy, Jo (2003) *Premature Birth: A Family Survival Guide*

Davis, D. & Stein, M. (2004) *Parenting Your Premature Baby and Child: The Emotional Journey*

Dickerson, MaryLou (2001) *Small Victories: Conversations about Prematurity, Disability, Vision Loss and Success*

Garcia-Prats, Joseph & Hornfischer, Sharon (2000) *What to Do When Your Baby is Premature: A Parent's Handbook for Coping with High-Risk Pregnancy and Caring for the Preterm Infant*

Hacker, P.H. & Ringo, C. *Early Passage: A Journal For Parents of Premies*

Hatcher, D., Lehman, K., & Johnson, M. (2000) *Baby Talk: For Parents Who Are Getting To Know Their Special Care Baby: Getting to Know Your Special Care Infant*

Hathorn, M. (2005) *A Mothers Diary: How to Survive the NICU*

Klein, A. H. & Ganon, J.A. (1998) *Caring for Your Premature Baby: A Complete Resource for Parents*

Linden, D.W., Paroli, E. T., & Doran, M.W. (2000) *Preemies: The Essential Guide For Parents of Premature Babies*

Madden, S. (2000) *The Premie Parents Companion: The Essential Guide to Caring for Your Premature Baby in the Hospital, at Home, and Through the First Years*

Manginello, F.P. & DiGeronimo, T.F. (1998) *Your Premature Baby: Everything You Need to Know About Childbirth, Treatment, and Parenting*

Powell, K. A. & Wilson, K. (2000) *Living Miracles: Stories of Hope from Parents of Premature Babies*

Sears, William & Sears, Martha (2004) *The Premature baby Book: Everything You Need to Know About Your Premature Baby From Birth to Age 1*

Smith, T. (1999) *Miracle Stories of Very Premature Babies: Little Thumbs Up*

Stanway & Stanway (1999) *Coping With Your Premature Baby*

Tracey, A. & Maroney, D. (1999) *Your Premature Baby and Child Helpful Answers and Advice for Parents*

Zaichkin (2002) *Newborn Intensive Care: What Every Parent Needs to Know*

MULTIPLES:

- Agnew, C., Klein, A., & Jill, A.G. (2006) *Twins! 2e: Pregnancy, Birth and The First Year of Life*
- Fierro, P. (2005) *Everything Twins, Triplets and More Book*
- Gromada, Kerkhoff, K. (1999) *Mothering Multiples: Breastfeeding and Caring For Twins or More*
- Lage, C. (2006) *Twinspiration: Real-life Advice From Pregnancy Through The 1st Year for Parents of Twins and Multiples*
- Laut, W. Benit, K., & Laut, S. (1999) *Raising Multiple Birth Children: A Parents Survival Guide*
- Lyons, E. (2003) *Ready or not...here we come! The Real Experts Cannot Live Without Guide to the 1st Year with Twins*
- Moskowinski, R. (2002) *Twins to Quints: The Complete Manual for Parents of Multiple Birth Children* *Twins Magazine*

BREAST FEEDING & KANGAROO CARE:

- Eiger, M. & Wendkos Olds, S. (1999) *The Complete Book of Breastfeeding – 3rd Edition*
- Fredregill, S. & Fredregill, R. (2002) *The Everything Breastfeeding Book – Basic Techniques and Reassuring Advice Every New Mother Needs to Know*
- Gotsch, Gwen (1999) *Breastfeeding Your Premature Baby*
- Huggins, K. (2005) *The Nursing Mothers Companion – 5th Revised Edition*
- La Leche League International (2004) *The Womanly Art of Breastfeeding: 7th Revised Edition*
- Ludington-Hoe, S. & Golant, S. K. (1993) *Kangaroo Care: The Best You Can Do for Your Preterm Infant*
- Mohrbacher, N. & Kendell-Tackett, K. (2005) *Breastfeeding Made Simple: Seven Natural Laws for Nursing Mothers*
- Newman, J. & Pitman, T. (2006) *The Ultimate Breastfeeding Book of Answers, Revised and updated*
- Pryor, G. (1996) *Nursing Mother, Working Mother: The Essential Guide For Breastfeeding and Staying Close to Your Baby After You Return to Work*

SPECIAL NEEDS/HEALTH CONCERNS:

Davenport, T. & Davenport N. (2004) *Making Life Better for a baby with Acid Reflux*

Klein, S. & Schive (2001) *You Will Dream New Dreams: Inspiring Personal Stories by Parents of Kids With Disabilities*

Loseff, J. (2001) *Special Kids Need Special Parents: A Resource for Parents of Children With Special Needs.*

Maclean, R. & McNeil, R. (2004) *Life on the Reflux Rollercoaster: Gastro Esophageal Reflux Disease in Infants and Children*

Parker, J. N. (2002) *The Official Parents Source book on Cerebral Palsy: A Revised & Updated Directory for the Internet Age*

Preschel, S. (2000) *A Parents Guide to Down Syndrome: Toward a Brighter Future, Revised*

Stallone, S. (2001) *The Parents guide to Childrens Congenital Heart Defects: What they are, how to treat them, and how to cope with them*

BOOKS FOR CHILDREN / SIBLINGS:

Amadeo, D. & Bladholm, C. (2005) *My Baby Sister Is a Premie – Helping Kids Heal*

Collins, Pat L. (1990) *Waiting for Baby Joe*

Duncan, D (1995) *When Molly Was in the Hospital: A Book for Brothers and Sisters of Hospitalized Children*

Hawkins-Walsh, E (2002) *Katie's Premature Brother*

Lafferty, L., Flood, & Young (1998) *Born Early: A Premature Baby's Story*

Maher, Nicola (2005) *The Tiniest Warrior of All: A Fairytale for Families With A Premature Baby*

Murphy-Melas, E. (1996) *Watching Bradley Grow: A Story About Premature Birth*

Pankow, V. (2004) *No Bigger Than My Teddy Bear*

Resta, B. & Harvill, K. (1995) *Believe in Katie Lynn*

Somers, S. (2004) *The Baby Who Couldn't Wait*

Wheat, P. (1985) *My Brother Got Here Early*

FOR DADS:

Brott, A. (2004) *The New Father: A Dads Guide to The First Year*

Marzollo, J. (1993) *Fathers and Babies: How Babies Grow and What They Need From You, from Birth to Eighteen Months*

Meyer, D., ed. (1995) *Uncommon Fathers: Reflections on Raising a Child with a Disability*

Stimpson, Jeff (2004) *Alex, The Fathering of a Premie*

Woodwell, W (2001) *Coming to Term: A Fathers Story of Birth, Loss and Survival*

INFANT MASSAGE:

McClure, V. S. (2000) *Infant Massage (Revised Edition): A Handbook For Loving Parents*

Reese, S. (2006) *Soothing Strokes For Healthy Growth*

Walker, P. (1996) *Baby Massage: A Practical Guide to Massage and Movement for Babies and Infants*

GRIEF / BEREAVEMENT:

Davis, D. (1996) *Empty Cradle, Broken Heart: Surviving the Death of Your Baby*

Levang, E. (1998) *When Men Grieve: Why Men Grieve Differently and How You Can Help*

Levang, E. & Ilse, S. *Remembering with Love: Messages of Hope for the First Year of Grieving & Beyond*

8.7 Important Phone Numbers

*Note: All hospital phone numbers begin 973-322. If you are calling any of them from a hospital phone, just dial 2 and the last four digits of the number.

While your baby is in the hospital...

NICU	973-322-5300
NICU Step-down (3100)	973-322-5310
Admissions	973-322-5165
Birth Certificate Office	973-322-5327
CPR Classes	973-322-5314
Main Hospital Number/ Information	973-322-5000
NICU Case Managers	973-322-2678
or	973-322-2045
NICU Nurse Managers	973-322-5345
NICU Social Workers	973-322-5503
or	973-322-8408
NICU Parent Buddy Program	973-322-9753
Neonatology Administration	973-322-5437
Neonatology Office (5th Floor)	973-322-5401
Pastoral Care	973-322-5015
Patient Satisfaction	973-322-5459
Perinatal Bereavement Support ...	973-322-5855
SBMC Medicaid Worker	973-322-8609
SBMC Post-partum depression Hotline	800-300-0628
Women's Health Education	973-322-5360

...and Beyond

Breastfeeding Support	800-La Leche
Early Intervention Services:	
Bergen County	201-634-2620
Essex County	973-395-8836
Hudson County	201-915-2514
Morris County	973-971-4155
Passaic County	973-523-6778
Union County	908-889-0950
Warren County	908-689-6000
	(x 258)
High-Risk Infant Follow Up & Apnea Clinic	973-322-2631
Low Income child-care assistance	973-733-4147
Miracle Walk	973-322-4305
NJ Kids Child Care (income based)	973-297-1114
NJ Family Healthline (info on WIC, parenting classes, Post Partum Depression	1-800-328-3838
Outpatient Speech and Hearing	973-322-7100
Pediatric Ophthalmology Follow-up	973-485-3186
Poison Information Hotline	1-800-222-1222
Post-partum depression Hotline	1-800-328-3838
Social Security Administration	1-800-722-1213

The NICU Family Advisory Council (FAC) is made up of a group of Saint Barnabas Medical Center (SBMC) NICU graduate parents. Combined, our babies were treated in the NICU for over 1,000 days. All of us are involved because we are grateful for the exceptional care our children received while in the SBMC NICU. The Council is dedicated to assisting the hospital achieve its goals, and to helping current and future NICU families. To that end, we prepared this handbook for you and hope it helps guide you through your NICU journey.



To reach the NICU, please call 973-322-5300



94 Old Short Hills Road, Livingston, New Jersey 07039
973-322-5000 or 1-888-SBHS-123