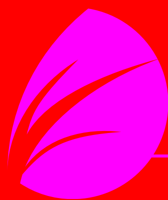

REGIONAL MEDICAL CENTER

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Dear Parents,

Welcome to Overland Park Regional Medical Center. For over 30 years our hospital has prided itself on delivering the finest health care available to our patients. As a community hospital, our physicians, nurses and staff consider it an honor and a privilege to care for you — our neighbors, friends and family members.

Our highly trained staff will provide your child with the highest level of service and care in the safest environment. In addition, you will receive all of the information you need to make important healthcare decisions. We encourage you to participate in your baby's care by asking questions and making sure you have the explanations and support you need. Please don't hesitate to address any concerns or questions about your baby's care with OPRMC staff members.

Our goal during your stay is not limited to an excellent patient experience. OPRMC also wants to provide the tools and information you need after you the leave hospital. We hope that this will be an invaluable guide in answering questions, addressing concerns and providing resources. Don't hesitate to contact us otherwise at (913) 541-5562, day or night.

From the OPRMC family to you, thank you for entrusting your family's care to us. We're honored to be your hospital of choice and your partner in delivering quality healthcare.

Warmly,

Damond Boatwright, CEO

Dear Parents,

Welcome to the Neonatal Intensive Care Unit (NICU) at Overland Park Regional Medical Center (OPRMC). We understand this may be an emotional time for you and your family and would like to ensure in every way possible your infant's stay with us is exceptional. Please take time to review the information in this guide, and let us know if you have any questions regarding the care your baby is receiving from our experienced NICU team.

The NICU at OPRMC is a state-of-the-art, Level III Unit, the highest level of neonatal care, with expert neonatology support and the latest in evidence-based practices. Our highly trained neonatologists, neonatal nurse practitioners, registered nurses, respiratory therapists, occupational therapists, speech therapists, lactation consultants, dietitians and social workers are compassionate and dedicated to the care they provide to your baby. We work very closely as a team, and your family is a very important part of this team.

Please count on our support throughout your journey, and thank you for the privilege of caring for you and your child.

Margaret Meier, RN, BSN, MSL
NICU Director

"You almost feel like you are leaving your children with family."

– Lawrence Tynes, NY Giants Kicker,
Two-Time Super Bowl Champ, and Father of Former
Overland Park Regional NICU Patients, Jaden and Caleb

TO LEARN MORE ABOUT THE TYNES STORY AND OUR NICU, VISIT OPRMC.COM/NICU

Hospital Main Number:
(913) 541-5000

Hospital Visiting Hours:
8 a.m. to 8 p.m.

NICU Visiting Hours:
24 hours a day for parents. Siblings may visit during non-flu season, typically May – October.

NICU Number(s): 913-541-5275 or toll-free at 1-800-765-8975.

Patient E-mails: delivered 9 a.m. to 3 p.m. daily. Find information on how to send emails to patients at oprmc.com, under Patients and Visitors.

Security: 541-5066 or 541-5405. Security is available after hours to walk visitors to their cars.

Overnight Accommodations: Please let your nurses know if you or a family member needs assistance in securing overnight accommodations.

Gift Shop: Contact our gift shop at (913) 541-5366 or contact the Gift Shop Manager at (913) 541-5304 for custom orders or gift ideas. The gift shop is open Monday through Saturday and closed on Sundays and holidays. Hours vary.

Valet Parking: Free of charge for patients and visitors from 7 a.m. to 8 p.m. After 8 p.m., call security at extension 5066 for retrieval of your car. Tipping is optional.

Chaplain: A chaplain is on-call 24 hours a day. Please let your nurses know if you want a chaplain to visit. The chaplain's direct line is 913-541-5442. The interfaith Chapel is located on the 2nd floor of the hospital, in the ICU waiting area and is open 24/7.

Sunflower Café: The café is on the main level of the hospital. Meals and grab-and-go snacks are available daily. Operating hours vary — please check signage outside café. Vending machines available 24 hours a day.

Welcome to the NICU at Overland Park Regional Medical Center. We hope this guide will answer many of the questions you may have about your infant's care.

For more than 20 years, our Level III NICU has been providing the highest level of neonatal care in Johnson County and the surrounding areas. We have a highly skilled team of NICU experts who will provide specialized care to your baby and help your family throughout the NICU experience.

While we are continually improving our approach to care, we stay grounded in solid, evidence-based practices and technology. Specialized care, combined with medical innovations, provides your newborn with a greater chance of getting better today than ever before.

Please feel free to ask questions of the staff at any time and know that we are here to provide the best care possible for your baby.

Image courtesy of Jessica Strom Photography, Overland Park, Kan. (jessicastrom.net.)

LACTATION SUPPORT AT OPRMC

Even though breastfeeding is a natural process, some mothers find themselves facing challenges. Our lactation consultants are registered nurses who will work with you to prevent and solve problems. ***Call (913) 541-5208 to speak to a lactation consultant.***

MAILBOXES

In your baby's room, there is a mailbox located near the gray bulletin board. This is specifically for your use. Check this mailbox each time you come to the NICU. You may find current NICU information, outside mail and important communication from your baby's care team.

CHECK THE BULLETIN BOARDS IN THE PARENT ROOM AND THE MAILBOX IN YOUR BABY'S ROOM FOR UPCOMING ACTIVITIES AND CLASSES INCLUDING:

- NICU 101 — Everything you need to know about the NICU
- The Happiest Baby on the Block
- Scrapbooking
- Infant Massage
- Homeward Bound — The Discharge Class
- CPR

Image courtesy of Jessica Strom Photography, Overland Park, Kan. (jessicastrom.net.)

Parents are welcome in the NICU and are an integral part of the health care team. Parent interaction with their infant is vital to family bonding. Even while your infant requires intensive care, we want you to learn about your infant's condition. Your infant's nurse will guide you in becoming an active participant in your baby's care.

Because your infant has an increased risk for infection and a low tolerance for stimulation, please follow these visiting guidelines:

HAND WASHING AND INFECTION CONTROL

- Proper hand washing is the best protection against the spread of infection. The NICU staff will instruct you on proper scrubbing techniques.
- Remove ALL jewelry (rings bracelets, watches, etc.) during your visit. Long sleeves must be pulled up to the elbows and remain there during your visit.
- Cell phones, purses, bags, etc. are not allowed on the baby's bedside table. These items can transfer dirt and bacteria to tables, which in turn, can contaminate anything that comes in contact with your baby.
- Remember to set cell phones to vibrate. **ALWAYS WASH YOUR HANDS AFTER USING YOUR CELL PHONE.**
- You and your visitors must complete the NICU WELLNESS SCREENING TOOL (health questionnaire) every day.
- You and your visitors MUST be free of infection and communicable diseases (colds, flu, fever, cough, runny nose, rash, sore throat, diarrhea, cold sores, exposure to chicken pox, etc.)
- NO food or drink is allowed in your baby's room at any time.
- Visitors and family members must wear shoes or slippers at all times.

- Parents or designated support person may be at the baby's bedside at any time.
- No children under the age of 14 are allowed to visit, with the exception of siblings.
- The total number of people allowed at the bedside is 4, including parents. The number of visitors at the bedside is always at the discretion of the baby's nurse. Quiet visits are required as an ill infant is very sensitive to stimuli and noise.
- Your baby's care is our first priority, and any visitor may be asked to leave in the event of treatments, procedures or emergencies.
- Visitors are to stay with their infant and not visit or inquire about other babies.
- ALL visitors, *excluding parents*, must step out of the NICU for the nursing bedside report from 6:30 – 7:30 a.m. and p.m. each day.
- Each family may choose 4 primary visitors for the entire hospital stay. Primary visitors may visit without a parent present.
- Primary visitors **MUST HAVE IDENTIFICATION** and may not bring other visitors with them.
- Only parents can hold their baby at first. The nursing staff will guide you when your baby is ready. Once your baby is in an open crib, primary visitors may hold with parent permission.

INFANT/FAMILY PRIVACY

Infant information is confidential and is given only to parents or a designated support person, either directly or by phone. Your infant will receive a personal pass code upon admission. The pass code is for parents and the designated support person. This pass code is required in order to receive information by phone.

BROTHER AND SISTER VISITS

Brothers and sisters of the infant can visit with parents. Parents must complete the NICU Wellness Screening Tool for each sibling prior to the visit. Immediate families with more than 4 members may visit together. This visit must be arranged with your bedside nurse. **Please keep visits to 10 - 20 minutes. Siblings under age five, may become restless if visits are prolonged. An adult must supervise siblings less than 14 years of age at all times.**

Daily shift change is 6:30 - 7:30 a.m. and p.m. Only parents are allowed to remain at bedside during shift change. We are available for urgent or emergent needs but any non-emergent needs must wait until shift change and safety checks are completed. We are not able to answer phone calls during shift change.

Laptops using battery power are allowed in the NICU and a wireless connection is available. Headphones are required to alleviate noise.

Cell phones are allowed in the unit, but must be on vibrate. Limit cell phone use to photos and email. **NO CALLS OR TEXT MESSAGING** due to possible interference with our equipment.

Dr. Robert Holcomb, OPRMC Neonatologist, and former NICU patients, Caleb and Jaden Tynes.

THE PEOPLE WHO MAKE UP THE NICU CARE TEAM INCLUDE:

- Neonatologists: pediatricians specializing in the care of premature or ill newborns.
- Neonatal Nurse Practitioners (NNP): advanced-practice nurses that specialize in neonatal care.
- Neonatal Nurses: nurses who specialize in the care of premature or ill newborns.
- Respiratory Therapists: specialized healthcare practitioners who treat and monitor newborns with breathing disorders or issues.
- Family Support Social Workers: practitioners who advise and educate families on social service options, and support families throughout the NICU experience.
- Parent Educators/Discharge Planners: nurses who teach classes and parents individually about the special needs of their baby. They guide the discharge process for a smooth transition home.
- Lactation Consultants: registered nurses who educate and help resolve breastfeeding issues.

- Registered Dietitian: nutrition specialist who works with premature or ill newborns who have special dietary needs.
- Secretaries: support NICU operations and administration.
- Nurse Interns: nurses in training for the neonatology specialty.
- Patient Care Technicians: health-care assistants who support neonatologists, NNPs and nurses in patient care.
- Women's Services Case Manager: a professional who works with your insurance company
- Occupational and Physical Therapists: therapists who provide specialized neonatal developmental, functional and physical therapy services.
- Speech Language Pathologists: therapists who devise a special feeding plan for your baby and assist with feeding problems as needed.
- Other specialty doctors, such as cardiologists and neurologists.

- Turn off or put your cell phone on vibrate. No texting or phone calls while in the NICU.
- Stay at your infant's bedside to preserve privacy and confidentiality for other families.
- Speak softly, and be aware of cues of over-stimulation from your infant. Please ask others to speak softly around your baby, as well.
- Have siblings visit for short periods of time, bring small, quiet activities to keep them busy (no food or drink) and please monitor their noise level, as infants in the NICU are especially sensitive.
- If a visitor is ill or recovering from illness, ask them to visit another day when they are fully recovered.
- Feel free to take advantage of the parent room when you need a break. It includes a refrigerator, a microwave and snacks. A computer is also available for your use.
- Remind your visitors that 6:30 – 7:30 a.m. and p.m. are reserved for bedside reports with parents, safety checks and nursing shift changes.

Image courtesy of Jessica Strom Photography, Overland Park, Kan. (jessicastrom.net.)

You are an integral part of your baby's life and member of your baby's health care team. It can be easy to lose sight of this when there are so many people caring for your infant. Even if you aren't able to hold your baby right away, there are still many things you can do.

Talk to your NICU nurses. They will help you learn the best ways to interact with your baby. They will know when to let your baby sleep or when your baby needs to be held. After some time, you will know what your baby needs, too. Remember that your role as a parent is essential.

The following tips will help you make the most of your parenting time in the NICU:

BE HERE AS MUCH AS POSSIBLE

- Visit your baby often and get to know your baby's NICU Team. Call us for updates when you aren't here.
- We encourage you to participate in your baby's care by taking his or her temperature, changing diapers and holding as much as your baby will tolerate. It is important to also allow your infant to rest in between care and feeding to allow for essential deep sleep.
- Attend classes taught by the Parent Educators/NICU Family Support Social Workers.

WORK WITH THE CARE STAFF AND PARTICIPATE IN YOUR BABY'S CARE

- Moms, wear your Snoedel (a sleeping and bonding aid) and bring it to the NICU to place with your baby.
- Take your baby's temperature and change diapers.
- Hold your baby as often as his or her condition will allow.

- Pump breast milk if nursing, and give the milk to your NICU nurse for proper storage.
- Feed your baby when he or she is able to try.
- Bring your home bottle system to the hospital. This should include a 2 – 4 oz. bottle, a slow-flow or preemie nipple and a bottle brush.
- Offer a pacifier or try other calming techniques when your baby is fussy.
- If possible, be there to comfort your baby after a procedure.
- Learn other ways to care for your baby, for example: bathing, range of motion exercises, infant massage.
- Bring in a portable musical device with calming music and/or a soothing recording of your voice.
- When your baby is old enough, learn and use developmental play techniques.

PERSONALIZE YOUR BABY'S ROOM

- Bring in family photos, prayer cards or pictures made by siblings for the baby.
- Attend the NICU scrapbooking class and bring your creations to hang on the bulletin board in your baby's room.
- Personalize the Parent Mailbox in your infant's room.
- Bring in larger blankets to cover the isolette and receiving blankets to use as bed sheets.
- Bring onsies, sleepers, gowns, socks and hats for your baby once he or she is able to wear clothes. Please avoid clothes with zippers or items that close in the back.
- Gather dirty clothing and blankets, and take home frequently for washing.
- Use fragrance-free and dye-free soap and rinse twice after washing. *Many popular baby soaps contain fragrance and dyes.*

KANGAROO CARE

Kangaroo Care is a special skin-to-skin way to hold your baby up against your bare chest when the infant is ready for this type of touch. This allows your baby to easily maintain his or her body temperature by sharing yours. It is an opportunity for him or her to reconnect with your natural rhythms (heart beat and breathing). Studies show that it promotes infant weight gain and reduces stress. This increased rest and relaxation allows for a deeper sleep, supporting your baby's development. As your baby settles in, you may see an improvement in his or her oxygen saturations and a lower resting heart rate.

Kangaroo Care allows you to develop a close bond with your baby and offers an essential positive experience that only a parent can provide. For the nursing mom, your breast milk production may increase following a holding session. Kangaroo Care will help you learn things about your baby you may not discover otherwise.

HOW TO PROVIDE KANGAROO CARE

- In your baby's room, close the curtains for privacy.
- Sit in a reclining chair and open your shirt in the front.
- Your baby will be transferred to you by your nurse and possibly a respiratory therapist.
- To minimize stress for your baby, hold for a minimum of one hour, preferably longer if possible.
- Kangaroo Care is typically provided during a feed or care time to promote uninterrupted sleep for your baby.
- Make sure you take care of your needs, like using the bathroom, prior to holding.

BE YOUR CHILD'S ADVOCATE

Your child has no voice, so you must be that voice for your baby. Knowledge is empowering and can bring you comfort.

- Get to know your baby well enough to be able to anticipate his or her needs, and learn how your baby communicates with you in each and every way. Spend as much time in the NICU as possible and participate in your baby's care. You will also get to know your baby's care team.
- Be a consistent caregiver in your baby's life, in any way you can.
- Learn as much as you can about everything your child faces now, and in the future (use only reliable information sources).
- If you don't understand what a doctor, nurse, or other professional has explained, have them explain it in other ways until you fully understand.
- If you don't feel comfortable with something, ask for another explanation or opinion.
- If you feel you are not being heard regarding your baby's needs, speak up and find a NICU staff member who will listen and get you the help that you need.
- Help your baby grow, develop, and progress by being fully involved, aware and empowered.

You will get to know your baby best by spending each and every day with him or her, and learning what normal is fosr your baby. If anything changes or doesn't work, whether it be a treatment, a medication schedule, etc., don't hesitate to address it with your baby's doctor.

ORAL FEEDINGS

- The NICU Care Team will advise you when it is time to feed your baby by mouth, either at the breast or by bottle. Try to be patient, as learning how to nurse or bottle feed can be a long and difficult process. When the time comes, the nurses and lactation consultants will be happy to assist you.
- The best chance for success when breast or bottle feeding is following a cue-based feeding pattern. This simply means offering the breast or bottle when your baby is awake, alert and hungry. Be flexible in the times you come to feed your baby initially, as he or she will be awake at different times each day. After a while, you will know when the best time is to feed your baby.
- Every oral feeding session will be stopped when your baby becomes too sleepy or at 30 minutes, whichever comes first. After this time, your baby uses more calories than he or she is consuming, which can lead to weight loss. Sleepy premature babies also tend to choke more frequently.

PAIN AND MEDICATION

Our NICU care team strives to promptly recognize and treat pain as quickly and as effectively as possible. There are many types of medicines that we can use to ease pain and discomfort. The type of pain, how long it may last and the reason for the pain, determines which type of pain medicine is the best choice for your baby.

Your nurses use a scoring system to evaluate and track your baby's pain level. Some procedures that may cause pain include heel sticks and starting IVs. Surgical procedures cause pain, and being on a breathing machine may be uncomfortable to some infants. You are an important part of the team and can help your baby deal with new and difficult situations. Please let your doctor and nurse know if you think your baby's pain is not being treated effectively.

THE FOLLOWING ARE SIGNS THAT YOUR BABY MAY BE IN PAIN:

- Crying
- Rigid or tense body
- Lack of sleep
- Higher than normal heart rate and blood pressure
- Worried face with a grimace or a frown
- Oxygen levels may fall when they are touched or handled
- Tightly fisted hands and feet

- Holding, rocking and talking to your baby
- Giving your baby a pacifier
- Wrapping your baby snuggly
- Shading baby's eyes from light
- Massaging your baby
- Keeping the bed area quiet

Some babies like minimal interaction because they cannot handle touch, sound or an increase in light. Your baby's nurse will help you figure out what works best. This may change as your baby's condition changes.

The nurse can also give your baby a specific sugar solution called "Sweet-Ease" for painful procedures. Studies have proven that babies who taste this special solution as well as suck on a pacifier will feel less pain. However, do NOT give your baby sugar or other sweeteners, such as honey, at home. This is dangerous and can cause serious problems. For pain after discharge, speak to your pediatrician.

Babies who have been on pain medications for more than a week will need to be weaned slowly as stopping quickly can be irritating. This does not mean that your baby is addicted to the medicine, only that your baby has gotten used to it.

NOTES

A premature baby is not able to digest food effectively; therefore, your NICU doctor will begin feeding your baby slowly and cautiously. If your baby has difficulty digesting his food, he may be placed back on IV fluids to allow the intestinal tract to rest. This can happen several times before your baby's body is able to successfully digest oral food. This process of starting and stopping is sometimes necessary to jump start your baby's digestion.

Your baby will begin with very small infrequent feedings; for example, 1 ml every 12 hours (30 mls is equal to 1 ounce). Once the NICU Care Team has determined your baby can handle more, feedings will be increased to a full amount every three hours.

Initially, your baby will likely be fed through a feeding tube inserted into his mouth (OG), or his nose (NG). This tube goes directly to the stomach and is secured to either your baby's chin or cheek. The milk flows from a syringe, through the tube, and into the stomach by gravity. Sometimes a special pump is used to help control the speed of the feeding to the stomach. This tube will remain in place until your baby is able to eat every single feed by mouth easily for 48 hours. It will be changed by the nurse periodically.

Once your baby can consume a full volume, extra calories may be added to the breast milk or formula to promote growth. This is called *fortifying the breast milk or formula*.

FACTORS THAT HELP DECIDE IF YOUR BABY IS TOLERATING FEEDINGS:

- Residuals (what is left in the stomach after a period of time has elapsed to allow for digestion). Not all residuals are abnormal.
- Stooling patterns
- Abdominal measurements
- Spitting up — some is normal but we evaluate color, volume, and consistency
- Abdominal pain

Bottle feeding your premature baby may be both your greatest happiness and biggest concern. Holding your baby will be a pleasure, but you may worry that your baby is not drinking enough milk to grow, or has a hard time learning to swallow properly.

YOUR NICU NURSE WILL HELP YOU, BUT KEEP IN MIND THE FOLLOWING AS YOU LEARN HOW TO BOTTLE FEED YOUR BABY:

- The suck, swallow and breathe reflex forms around 32-34 weeks of gestational age, so don't try to feed your baby before he or she is ready.
- A premature baby will be uncoordinated at first, and get better with practice, while building endurance.
- You may notice your baby is consistently sucking and swallowing but not pausing to breathe. To prevent choking, pace your baby. (See following page.)
- Be patient: a premature baby may take a long time to take a small amount.
- A premature baby does not have a strong suck.
- A slow flow nipple is best because premature babies cannot handle a fast flow or large volume of milk at once without choking.
- It is normal for a premature baby to take one feed well, and then forget how to eat at the next feed.
- The side-lying position is usually better for premature infants. This prevents choking by limiting the pooling of milk in the back of their throats.

Some babies will wake up for feedings and cry when they are hungry, and some will need to be woken up to eat. When first learning how to eat, babies will only bottle feed once or twice a day and usually not two feedings in a row, because they tire easily.

Sometimes swaddling helps to "organize" your baby. Make sure not to rock your baby while eating, as this is a sure way to put a preemie to sleep quickly!

Some babies are uncoordinated at first when bottle feeding, and may choke occasionally. If your baby sputters and coughs, turns pale or blue, or suddenly falls asleep or becomes limp, remove the bottle, sit him upright, and pat his back. The heart monitor may go off also, but don't worry, the nurses are watching and are there to help.

PACING

If your baby is an enthusiastic eater and forgets to take a breath; you can set a safe pace. After 5-8 sucks and swallows, tip the bottle so only air fills the nipple.

BURPING YOUR BABY

There are two ways to burp your baby. The best way is to place your baby in a sitting position on one of your legs. Then with one hand, support him or her under each armpit, as well as under the chin. Use your other hand to pat the back.

The more traditional way is to hold your baby up on your shoulder. However, it is more difficult to see his or her face, and encourages sleepy snuggling. Also, keep in mind most premature babies will spit up with burping. If you use the shoulder burping technique, you may end up "wearing" some of the feeding.

Usually a baby is burped about half way through a feed, although some babies may require more frequent burping. If your baby doesn't burp within a few minutes, he probably hasn't swallowed any air and you can continue feeding. Once your baby has finished eating, burp one final time.

NOTES

The lactation consultants at OPRMC are here to support you and your baby as you breastfeed. They provide information and guidance on how to breastfeed, build your milk supply and continue successfully breastfeeding at home.

The OPRMC Lactation Department is staffed with full-time International Board Certified RN Lactation Consultants who are at the hospital on weekdays, weekends and holidays. The NICU has its own dedicated full-time lactation consultant.

Call the Lactation Department at (913) 541-5208 or let your baby's NICU nurse know that you would like to speak with them.

BREASTFEEDING YOUR PREMATURE BABY IN THE NICU

Your NICU nurse will help you prepare your baby for breastfeeding by using one or more of the following methods:

Breastfeeding Friendly Oral Stimulation: Baby sucks on your clean finger or pacifier. Taste therapy is important when approved by the Neonatologist. To initiate taste therapy, place a drop or two of breast milk on the pacifier and place in your baby's mouth. Or with help from your baby's nurse, drip some breast milk from a syringe into the baby's cheek.

Smell: Place a Snoedel doll in your baby's bed for your baby to smell after you have worn it on your chest. You may also place drops of breast milk on it, a gauze pad or a clean breast pad for your baby to smell during a feeding. Change twice a day.

Kangaroo Care: Being close to your baby skin-to-skin connects you with your baby; it stabilizes your baby's vital signs and improves your milk supply. Your baby is able to smell you and this helps you learn to respond to your baby's cues. A baby who travels to the nipple may be ready to feed. Fathers can also Kangaroo and are encouraged to do so.

BREASTFEEDING STAGES

- Increased Alertness, Stronger Oral Reflexes and Hand-to-Mouth Movements: Coordinated sucking, swallowing and breathing; usually between gestational ages of 32 – 34 weeks.
- Licks and Light Sucks: Pump before putting your baby to the breast. Expect licks, light sucks and an occasional swallow; this can happen for several days. Your baby's nurse will observe your baby's suck, swallow, and breathing pattern to assess progress.
- Suckles and Short Bursts of Sucks: When ready, your baby will grasp your nipple, latch on the areola, and begin to suckle. Milk transfer increases as your baby gets stronger and the suckling pattern matures.
- Partial Breastfeeding: Your baby latches on and breastfeeds for a few minutes, then tires. Your baby will need a feeding supplement to complete the feeding.
- Full Breastfeeding: You must be available to breastfeed your baby and respond to your baby's feeding cues. You will learn how to assess the quality of the feeding by hearing baby's swallows, seeing milk in baby's mouth, and by the softening of your breast afterwards.

BASIC STEPS FOR SUCCESSFUL BREASTFEEDING

- Pump 8 times in 24 hours to bring in and maintain a full milk supply.
- Kangaroo Care (skin-to-skin holding with mom and baby).
- Cue led breastfeeding focusing on baby's instincts.
- Allow baby to organize instincts and learn how to use them.
- Once your baby is able to feed, offer the breast at every opportunity you have for an oral feeding. When possible, start breastfeeding before bottles are given.
- Be patient while baby learns and gains the energy to breastfeed.
- Make a breastfeeding plan with the lactation consultant before discharge.
- Room in with your baby before discharge.
- Attend educational opportunities provided by the NICU to increase your knowledge on how to care for your baby.
- Be aware of community resources available to you after discharge

USING THE MEDELA SYMPHONY PREEMIE/STANDARD PUMP PATTERNS

The Preemie/Standard pump provides 2 programs for breast pumping:

1. Preemie Pattern-used for stimulating your milk supply
2. Standard or Symphony II pattern-made for expressing your milk

PREEMIE PATTERN:

- Press the ON button on the left (the button with a circle on it).
- Press the "let down" button on the right with the arrow/drops on it.
- Adjust the suction with the large center dial to find a strong but still comfortable suction level. This can be adjusted during each pumping. The strength of suction is indicated by the number of drops seen across the display.
- The pump will run for 15 minutes with several variations in speed. It will include 2 short pauses and the display will say "Pause". The display will say "Done" when finished and will turn itself off.
- Use this pattern until you have more milk coming in. When you have 20 mls or more twice, switch to the Standard/Symphony II pattern.

STANDARD/SYMPHONY II PATTERN

- Press the ON button. (Press the same ON button to turn the pump OFF.)
- Pump will run fast for 2 minutes on 3 drops of suction, and then it automatically slows and adds 3 more bars of suction. Adjust the suction to increase comfort at any time.
- As your milk flows, press the "let down" button to stimulate your breasts by pumping fast again for 2 minutes. The pump does not shut itself off in this pattern.
- Use for 15 minutes or more if needed for relief of breast fullness.

HOW TO USE YOUR BREAST PUMP

- Wash your hands thoroughly. Use a warm compress on your breasts five minutes prior to pumping. Sit in a comfortable chair and relax. Have a glass of water or juice nearby.
- Pump about 15 minutes total using double set up (*double pumping takes less time and produces more milk)* or 15 minutes per side if single pumping. Begin with suction level set on pump to 3 drops. After 24 hours, you may gradually increase the suction. Keep within your comfort level. Pumping should not hurt! Speak to a lactation consultant if it is painful.
- Pump 8 to 10 times in a 24-hour period; pumping every 2-3 hours when you are awake and every 3-4 hours at night. After your milk is in, pump to empty. This may lengthen your pumping time.

- When you begin to use the breast pump, you may see little milk. Don't be discouraged! Milk production is based on supply and demand; the more you pump the more milk you produce. Also, your baby (if nursing well) does a better job of milking your breasts than the pump; therefore pumped milk is not an accurate measure of how much your baby would get naturally.
- Put your breast milk in containers supplied by the hospital. Mark the label with your name, date, and time you pumped. All breast milk should be taken to the NICU or refrigerated within 60 minutes. Ask your baby's nurse or your nurse for collection containers and labels.
- Wash the pump parts in dishwashing liquid and warm water; rinsing well and drying immediately. Or, you may use the special microwave bags supplied by the hospital.
- If you have any questions concerning the set up or use of the electric pump, please ask your nurse or call the lactation consultants at 913-541-5208.

CLEANING PUMP PARTS IN THE NICU

Wash pump parts with dish soap and water soon after pumping. Hold the parts in your hands as you wash them. *Avoid touching the sink*. Do not leave pump parts out to dry in the NICU. Dry the parts immediately and store them in your baby's room or wherever it's most convenient for you.

MICRO-STEAM BAG

Sterilize the pump supplies after each use by using the micro-steam bag. Read the instructions for use on the back of the bag. Nipple shields can be steamed in the bag with the pump parts. Microwave for 3 minutes in the designated microwave in the parent break room. **CAUTION: USE OVEN MITT WITH HOT MICRO-STEAM BAG TO PREVENT BURNS!**

Drain the bag carefully through the orange colored vent in the side of the bag; leave the parts in the open bag to air dry. Wash your hands before removing the sterilized parts. When the bag is near 20 uses, ask your baby's nurse for a new micro-steam bag.

If you place your purse or bag on the floor, keep these items on the floor. Do not move something from the floor to the working countertop, sinks or table surfaces. Purses, laptops, bags, etc. can transfer dirt and bacteria to tables, which in turn can contaminate anything that comes in contact with your baby.

GUIDELINES FOR COLLECTING, STORING, AND DEFROSTING BREAST MILK

- Wash hands before handling breast milk.
- Fresh breast milk can be stored in the refrigerator for 48 hours. Breast milk can be frozen for 3 months in a side by side freezer or a freezer that is above the refrigerator. It can be stored in a deep freezer for one year as long as the temperature is 0 degrees Fahrenheit.
- Store pumped/expressed milk in plastic containers or bottles. Make sure the container is very sturdy and that it can be well sealed. Do not use glass containers or bottles as certain components in breast milk cling to glass.
- Do not use plastic bottle liner bags to store breast milk if your baby is in the NICU.
- Store breast milk in appropriate amounts for the baby in order to minimize waste. The following are suggested guidelines:
  0 – 2 months: 2 – 4 ounces
  2 – 4 months: 3 – 5 ounces
  4 – 6 months: 4 – 5 ounces
  6 – 8 months: 6 – 8 ounces

Defrost breast milk by putting the frozen milk in a pan of lukewarm water. *The defrosting process should take 15-30 minutes* to insure the greatest preservation of immunities and other milk components. Breast milk from the refrigerator can be warmed in water or brought to room temperature in 15-20 minutes.

- **DO NOT MICROWAVE BREAST MILK OR PLACE IT UNDER HOT RUNNING WATER.** This will alter the breast milk composition. Do not vigorously shake breast milk.
- Defrosted milk can keep in the refrigerator for 24 hours. Do not put used breast milk from a bottle back into the refrigerator after the baby has sucked from the bottle.
- Breast milk will vary in color, consistency and odor depending on the current age of the milk. Human milk has a cream layer which may become more visible when the milk is chilled or frozen.
- Breast milk can be pumped or expressed at any time and the supply will quickly be replenished. Build up a supply by pumping after your baby has nursed or when your baby leaves a full or partially full breast. Express milk for storage in between feedings if your baby is sleeping for longer stretches of time, such as 4 – 6 hours. Most mothers find that their milk supply is greatest early in the morning and lowest in the late afternoon.

There are some health problems in babies that can make it harder to breastfeed. Yet breast milk and early breastfeeding are still best for the health of both you and your baby — even more so if your baby is premature or sick. Even if your baby cannot breastfeed directly from you, it's best to express or pump your milk and give it to your baby with a cup or dropper.

JAUNDICE

- Jaundice is caused by an excess of Bilirubin, a substance that is in the blood usually in very small amounts. In the newborn period, Bilirubin can build up faster than it can be removed from the intestinal track. Jaundice can appear as a yellowing of the skin and eyes. It affects most newborns to some degree, appearing between the second and third day of life. The jaundice usually clears up by two weeks of age and is not harmful.
- Two types of jaundice can affect breastfed infants — breastfeeding jaundice and breast milk jaundice.
- Breastfeeding jaundice can occur when a breast feeding baby is not getting enough breast milk. This can happen either because of breastfeeding challenges or because the mother's milk hasn't yet come in. This is not caused by a problem with the breast milk itself.
- Breast milk jaundice may be caused by substances in the mother's milk that prevents Bilirubin from being excreted from the body. Such jaundice appears in some healthy, breastfed babies after about one week of age. It may last for a month or more and it is usually not harmful.

Your baby's doctor may monitor your baby's Bilirubin level with blood tests. Jaundice is best treated by breastfeeding more frequently or for longer periods of time. It is crucial to have a health care provider help you make sure the baby is latching on and removing milk well. This is usually all that is needed for the infant's body to rid itself of excess Bilirubin.

Some babies will also need phototherapy — treatment with a special light. This light helps break down Bilirubin into a form that can be removed from the body easily. If you are having trouble latching your baby to the breast, it is important that you pump or hand express to ensure a good milk supply. The same is true if the baby needs formula for a short time — pumping or hand expressing will make sure the baby has enough milk when you return to breastfeeding.

It is important to keep in mind that breastfeeding is best for your baby. Even if your baby experiences jaundice, this is not something that you caused. Your health care providers can help you make sure that your baby is eating well and that the jaundice goes away.

REFLUX DISEASE

Some babies have a condition called gastroesophageal reflux disease (GERD), which occurs when the muscle at the opening of the stomach opens at the wrong times. This allows milk and food to come back up into the esophagus, the tube in the throat.

Some symptoms of GERD can include:

- Severe spitting up, or spitting up after every feeding or hours after eating
- Projectile vomiting, where the milk shoots out of the mouth
- Inconsolable crying as if in discomfort
- Arching of the back as if in pain
- Refusal to eat or pulling away from the breast during feeding
- Waking up often at night
- Slow weight gain
- Gagging or choking, or problems swallowing

Many healthy babies might have some of these symptoms and not have GERD. But there are babies who might only have a few of these symptoms and have a severe case of GERD. Not all babies with GERD spit up or vomit. More severe cases of GERD may need to be treated with medication if the baby refuses to nurse, gains weight poorly or is losing weight, or has periods of gagging or choking.

See your baby's doctor if he or she spits up after every feeding and has any of the other symptoms mentioned here. If your baby has GERD, it is important to continue breastfeeding. Breast milk is more easily digested than infant formula.

CLEFT PALATE AND CLEFT LIP

Cleft palate and cleft lip are some of the most common birth defects that happen as a baby is developing in the womb. A cleft, or opening in either the palate or lip, can happen together or separately, and both can be corrected through surgery. Both conditions can prevent babies from forming a good seal around the nipple and areola with his or her mouth or effectively removing milk from the breast. A mother can try different breastfeeding positions and use her thumb or breast to help fill in the opening left by the lip to form a seal around the breast.

Right after birth, a mother whose baby has a cleft palate can try to breastfeed her baby. She can also start expressing her milk right away to keep up her supply. Even if her baby can't latch on well to her breast, the baby can be fed breast milk by cup. In some hospitals, babies with cleft palate are fitted with a mouthpiece called an *obturator* that fits into the cleft and

seals it for easier feeding. The baby should be able to exclusively breastfeed after his or her surgery.

If your baby is born with a cleft palate or cleft lip, talk with a lactation consultant in the hospital. Breast milk is still best for your baby's health.

PREMATURE AND/OR LOW BIRTH WEIGHT

Premature birth is when a baby is born before 37 weeks' gestation. Prematurity often will mean that the baby is born at a low birth weight, defined as less than 5½ pounds. Low birth weight can also be caused by malnourishment in the mother. Arriving early or being small can make for a tough adjustment, especially if the baby has to stay in the hospital for extra care. But keep in mind that breast milk has been shown to help premature babies grow and ward off illness.

Most babies who are low birth weight but born after 37 weeks (full term) can begin breastfeeding right away. They will need more skin-to-skin contact with mom and dad to help keep them warm. These smaller babies may also need more frequent feedings, and they may get sleepier during those feedings.

Many babies born prematurely are often not able to breastfeed at first, but they do benefit from expressed milk. You can express *colostrum* (liquid secreted for a few days after birth characterized by high protein and antibody content) by hand or pump as soon as you can in the hospital. You can talk to the hospital staff about renting a hospital-grade electric pump. Call your insurance company or local WIC Office to find out if you can get reimbursed for this type of pump. You will need to express milk as often as you would have breastfed, so about 8 times in a 24-hour period.

Once your baby is ready to breastfeed directly, skin-to-skin contact can be very calming and a great start to your first feeding. Be sure to work with a lactation consultant on proper latch and positioning. It may take some time for you and the baby to get into a good routine.

If you leave the hospital before your baby, you can express milk for the hospital staff to give your baby by feeding tube.

TWINS OR MULTIPLES

The benefits of human milk to mothers of multiples and their babies are the same as for all mothers and babies — possibly greater, because many multiples are born early. Although the idea may seem overwhelming, many of these moms find breastfeeding easier than other feeding methods because there is nothing to prepare. Many mothers have overcome challenges to successfully breastfeed twins and more even after going back to work.

BEING PREPARED

It will help to learn as much as you can about breastfeeding during your pregnancy.

- Take a breastfeeding class. Find online resource for beastfeeding (see page 51).
- Join a breastfeeding support group. OPRMC offers a weekly support group each Tuesday.
- Let your health care provider and family members know that you plan to breastfeed.
- Keep in mind that even if your babies need to spend time in the NICU, breastfeeding is still possible, with some adjustments.
- Visit with one of the OPRMC lactation consultants before your babies are born. Call OPRMC Lactation Department at (913) 541-5208.

MAKING ENOUGH MILK

Most mothers are able to make plenty of milk for twins. Many mothers fully breastfeed or provide milk for triplets or quadruplets.

Keep these tips in mind:

- Breastfeeding soon after birth and often is helpful for multiples the same way it is for one baby. The more milk that is effectively removed, the more milk a mother's body will make.
- If the babies are born early, double pumping often will help the mother make more milk.
- Weight checks can tell you if your babies are getting enough breast milk. You can also track wet diapers and bowel movements to tell if your babies are getting enough.
- It helps to have each baby feed from both breasts. You can "assign" a breast to each baby for a feeding and switch at the next feeding. Or, you can assign a breast to each baby for a day and switch the next day. Switching breasts helps keep milk production up if one baby isn't eating as well. It also prevents babies from favoring one side.

There are certain goals your baby must meet in order for the NICU team to determine if he or she is ready for discharge from the hospital. These include:

- Maintaining body temperature in a crib
- Taking all feedings by mouth easily, without distress, and minimal or no spells
- Consistent weight gain
- Breathing easily on their own, without spontaneous spells for 5 days or more (some babies may go home with oxygen and an apnea monitor)
- Your baby may also have additional needs, special to him or her, that must be met in order to go home.

As your baby meets these goals, the NICU team may be able to give you a best-guess estimate of a date for discharge. However, please know that this is only an estimate, and can change at any time depending upon what is happening with your baby each day.

WHAT CAN I EXPECT THE WEEK OF MY BABY'S DISCHARGE?

This week you will be doing as much of your baby's care as possible, to ensure you are prepared to do so at home. This will include:

- Performing all care (feeding, diapering, bathing, etc.)
- Training for any special equipment and arranging for delivery to your home
- Making baby's pediatrician appointments
- Medication training and filling prescriptions
- Rooming in with your baby if necessary
- Bringing in your car seat with the base and watching a car-seat safety video
- Begin taking home belongings and breast milk

THIS WEEK YOUR BABY WILL HAVE THE FOLLOWING:

- Angle Tolerance Test in his or her car seat to ensure safety and proper fit
- The NATUS hearing screening
- Hepatitis B vaccine if desired and appropriate
- Congenital Cardiac Screening
- Boys: circumcision if desired
- Hospital pictures taken if desired

ROOMING-IN WITH YOUR BABY

You can choose to room-in with your baby prior to his or her discharge. This provides you with the chance to care for your infant as you will at home. You will be responsible for maintaining your baby's feeding and medication schedule, feeding, medicating, bathing, changing and doing anything else your baby requires at that time (such as managing a monitor or oxygen). You will pretend the NICU staff is not there to care for your baby, although we are close by if you should need us for any reason. Both you and your partner are encouraged to participate.

You may room-in during the day or overnight, at the baby's bedside, or use a private room in the hospital, depending upon availability. Your nurse will let you know if a private room is an option. **If you are taking your baby to a private room, you or your partner must remain with your baby in the room at all times.** For safety, siblings are not allowed to stay overnight with you during this time, unless they are the baby's twin or triplet.

Please sign and see the **PARENT GUIDE FOR ROOMING-IN**, included in this guide, for more information.

NOTES

DISCHARGE FROM NICU

When the happy day arrives and your baby is finally going home from the NICU, please be prepared by reading the following:

WHAT TO BRING:

- ID bracelets and photo ID
- Cooler for breast milk transportation
- Two receiving blankets and one washcloth for the car seat
- Blankets appropriate for the weather to place over the baby
- Car seat — please have base installed in the car already
- Outfit appropriate for the weather (including hat and socks) for the baby
- Bag to bring home any belongings
- Your camera

The doctor *and* the nurse practitioner will give your baby a complete exam, and then write a discharge order. Typically, you will be able to leave by mid-afternoon. It's best to coordinate your departure with your baby's feeding schedule.

DISCHARGE SUMMARY AND INSTRUCTIONS

If your baby has had an extended or complicated hospital stay, we will provide you with a discharge summary. This discharge summary is a condensed version of everything that happened during your baby's stay. Keep copies of the discharge summary in each car, and in your diaper bag, to take with you in an emergency, and for any doctor requesting the baby's history.

The discharge instructions from the doctor are essential for your baby's continued progress and growth at home. Pay attention to the details and follow the instructions carefully. Start following the instructions even before leaving the hospital, and continue the routine once you are home. Carefully doing so can prevent problems. These instructions may be revised by your baby's physician specialists.

REFERENCE CHARTS

Please use the “My Medications” reference sheet in your dischcarge packet to list your baby’s medicines correctly. Also complete the “My Daily Schedule” chart to track what medications have been given for the day (page 49). Not following the prescribed dose and schedule of each medicine can lead to serious health problems requiring medical attention.

APNEA MONITOR AND OXYGEN USE

If your baby uses an apnea monitor, do not turn it off or take it off unless directed by the neonatologist (except when bathing). Your doctor will use the information from the monitor to make critical decisions about your baby’s care.

Do not remove or change your baby’s oxygen liter flow. Oxygen is a prescribed medication and must be used as directed. If you feel a change is needed, call the NICU and speak with a neonatologist, or call the NICU clinic at (913) 541-5022.

If any of your baby’s discharge instructions are difficult to follow, or if you have questions:

- Call the NICU at **(913) 541-5275.**
- Call the NICU Clinic at **(913) 541-5022** if your baby is being followed in the NICU Follow-Up Clinic, or has not yet been seen by your pediatrician.
- Call your pediatrician if your baby is not being followed in our clinic, and you have already been seen by the pediatrician.

NOTES

HOME OXYGEN AND APNEA MONITOR INFORMATION

- If your baby needs oxygen at home, keep him on oxygen at all times. Do not take the oxygen off for any reason until your baby is seen in the NICU Clinic a month after discharge. Don't be alarmed if your baby pulls the oxygen tubing out of his nose. It will happen at some point. Just put the cannula back in and tape it securely. Babies who go home on oxygen also use apnea monitors as a "back-up" safety system. If your baby's oxygen comes out of his nose and he is having trouble with breathing, the alarm will sound.
- Never change the oxygen liter flow without instructions from your doctor.
- Call the electric company so that in the case of a power outage, your house will be one of the first to have the power restored. Also contact the nearest fire station to let them know that you have a premature baby at home on oxygen. If you call 911, they will know that this is a home with special medical needs and oxygen in use, which is flammable.
- Make sure your baby's oxygen tank is full before leaving your house and always carry an extra tank with you.
- Secure the extra oxygen tank in the trunk of your car wrapped in a blanket. Take it out of the car when you return home; never leave it in the hot sun all day.
- Be careful not to trip on your baby's oxygen or apnea monitor tubing, especially going up and down stairs.
- If your baby needs an apnea monitor, this should also stay on your baby as directed until he is seen in the NICU Clinic, one month after discharge. If you have issues with the monitor, please call your monitor company to help you resolve the problem.
- Keep the apnea monitor away from your baby's ears. The alarms are loud (to wake you up) and can damage your baby's hearing. Make sure that you can hear the monitor in every room of your home. When showering, take your baby monitor in the bathroom with you so that you can hear the alarm.
- Oxygen is flammable. Do not let anyone smoke around your baby. Keep your baby away from a gas stove while cooking.
- If your baby is on oxygen and gets a cold, he may have to have the oxygen flow increased. Likewise, if your baby is off of oxygen and gets sick, he may have to go back on oxygen until he recovers. Call your baby's doctor for instructions.

SIGNS AND SYMPTOMS OF BREATHING TROUBLE:

- Increased respiratory (breathing) rate
- Skin color change - pale, dusky, or blue
- Baby not feeding well or taking longer to finish a bottle

- Pulling away from the bottle or breast to catch his breath
- Nasal flaring
- Retractions or seeming to work harder to breathe
- Sleeping more than usual or not sleeping as much
- Increase in fussiness
- If baby is on an apnea monitor, there may be more apnea alarms

The NICU Follow-Up Clinic provides medical follow-up for babies who go home on oxygen, apnea monitors, or have other special needs or lingering medical issues. Usually the first appointment is about one month after discharge, but this can vary.

NICU staff will make this appointment for you before your baby's discharge. Staff will also call you about a week before the appointment to remind you and to give you directions to the clinic.

At the clinic appointment, a nurse and a neonatologist will evaluate your baby and determine if your baby can be weaned off of oxygen. They will also analyze the apnea monitor download and decide if your baby can discontinue using the monitor. As long as your baby is on oxygen, he or she will remain on the monitor for safety. The nurse will weigh your baby, see how your baby is growing, and discuss your concerns. Labs may be drawn, medication doses may be adjusted, and your baby may be referred to a specialist, if needed.

NICU FOLLOW-UP CLINIC

The Doctor's Medical Building
10550 Quivira Rd., Suite 520
Overland Park, Kansas 66215

- Appointments are on Thursdays only and fill up quickly, so please do not cancel or reschedule your time if at all possible.
- Please be sure that NICU has your current phone numbers and emails prior to discharge.
- Do not schedule other doctor appointments including Home Health on the same day as your clinic appointment. Insurance will not pay for multiple health visits on the same day. Spread these appointments out so that your baby can be seen more often.

If you have questions or concerns, you may:

- **Call the NICU at 913-541-5275 and speak with a nurse practitioner**
- **Call the NICU Clinic at 913-541-5022**
- **Call your pediatrician, after your baby's first appointment**

A LETTER TO YOUR FAMILY AND FRIENDS

Bringing home your infant will be a special occasion and it is natural for your family and friends to want to share that with you. However, too much company too quickly will not only exhaust you as your baby acclimates to life at home, it can also be harmful in terms of spreading illness to your baby. We recommend sharing the following letter with visitors.

Dear family and friends,

I am so happy that I am finally going home! Getting to know all of the special people in my life is very important to me. I look forward to spending time with each and every one of you.

Although the doctors say that I am strong and healthy enough to go home, I still need time to adjust. Thank you so much for your patience while my family and I take time to settle into our new life together.

I am still recuperating and facing new challenges every day. Coming home may be a tough transition for me. My parents and I have a unique journey ahead in figuring out our new schedule and the best way to take care of all my special needs. So, visiting with each of you a little at a time will help.

To be sure I don't get sick, please protect yourself from getting sick. Wash your hands thoroughly and frequently. If you or someone close to you is sick, please reschedule your visit. Please limit my time spent with other children. Please wash your hands or use hand sanitizer any time you are near me.

I may need time before we can visit, but my parents welcome your help and support! They may need help around the house, getting to my doctor appointments and with meals.

Thank you for your help and understanding. You are all special to me, and I cannot wait to meet you!

SIBLINGS

As visiting policies allow, have your older children visit your baby in the NICU as much as possible. Bring one other adult with you to help maintain their attention. Siblings will accept the new baby when they have the chance to spend time together. If visits are not possible, encourage your children to be involved from home, such as drawing pictures for the baby's room in the NICU. Or, have them make a scrapbook of any pictures you take in the NICU so they are able to follow your baby's progress.

In the weeks before discharge, it is important to prepare siblings for changes after your baby comes home. Help them understand that even though the baby will need a great deal of your attention, they are still important and loved. They may enjoy helping get the baby's room ready or drawing welcome pictures. If you can, arrange a gift from the new baby to the sibling, or vice versa. Above all, *be patient with them*. Adjusting to this new life can be difficult and stressful. Children may act out differently, and possibly regress to infant-like behavior in order to gain attention. Spending time with each sibling will ease the transition, and let them know they are still a valuable member of the family.

PETS

Pets can need time to adjust to a new baby at home and may also show their anxiety by acting out. Prior to discharge, take a blanket or a hat that the baby has slept with and introduce the new scent to your pet. Once home, allow your pet to be curious and sniff the baby. However, do not allow your pet to lick your baby, especially on the face and hands. If necessary, keep the pet and the baby in separate rooms; never leave your baby unattended with the pet. If your baby is on oxygen and/or a monitor; prevent your pet from chewing on, or becoming entangled with, the tubing and wires. If you have any questions or concerns about having pets in the house with your new baby, talk with your health care provider and your veterinarian.

VISITORS

Maintain the same strict NICU guidelines for visitors once you have your baby at home. Your baby has met the criteria for discharge, but still requires more rest and recuperation than a healthy, full-term baby. Your baby still has a weak immune system. A simple cold could readmit your baby to the hospital.

Continue your strict hand washing guidelines before touching your baby. Clean hands are the best defense against an illness. Keep hand sanitizer on you at all times to prevent you and your baby from getting sick. Give the Family and Friends Letter (page 34) to anyone who may want to visit just before your baby's discharge. This is not the time for big family get-togethers, or for flying on an airplane. Your pediatrician will let you know when your baby is strong enough to handle those experiences.

It is also important for your health to limit visitors. You need to rest throughout the day. Set expectations for friends and family visits early to prevent hurt feelings later. Have them visit you and your baby in the NICU just before discharge. Ask for time to adjust to having a preemie with special needs before visiting. Let a close friend schedule visitors for you.

LEAVING THE HOUSE WITH YOUR BABY

1. Make sure your baby is up for the extra stimulation that comes with venturing out.
2. Choose places that will not put your baby at risk. Until your baby's immune system strengthens, avoid crowded areas such as grocery stores, churches and shopping centers. Also, do not go to a house where someone is, or has recently been, sick.
3. Do not go anywhere that someone is or has been smoking. Smoke inhalation causes the airway to constrict, making it very difficult for a baby to breathe. Smoking is especially dangerous for babies on oxygen, because oxygen is extremely flammable and combustible.
4. Bring everything you should need and pack extras in case you are delayed in returning home. Prepack a bag to make leaving the house easier. Each time you use something, replace it when you get home to save time. Here is a list of essentials to pack and have ready:
    - Feeding supplies (bottles, pre-measured formula, water to mix dry formula)
    - Bibs and burp cloths, breastfeeding cover
    - 2 extra changes of clothes for baby
    - Diapers, wipes, diaper cream
    - Extra blankets
    - Hat and socks
    - Bulb syringe
    - Shirt for yourself … just in case
    - Hand sanitizer
    - Any extra supplies specific to your baby (ex: leads for the monitor, etc.)

TAKE TIME FOR YOURSELF

It's very important to take time out for yourself, away from the care of your baby, to rejuvenate. In order to stay healthy, get plenty of rest, eat a balanced diet, drink plenty of water, and take time out of each day to do something that relaxes you. The stress that comes with the NICU experience is hard on you. Take time for yourself so you are able to focus on your baby. Parents of NICU graduates recommend having a date night just before your baby comes home.

Once at home, train a trusted person to care for your baby and give you a break from time to time. Even though finally having your baby at home is rewarding, it can also be stressful on the family and on your relationship with your partner. Make an effort to spend time alone together and focus on each other.

HOW FAMILY AND FRIENDS CAN HELP

Your time and energy will be dedicated to your baby and family. Ask a few close family members or friends for help when your baby comes home. They will want to help, so assign them duties. Ask for help doing housework, VIP time for your other children, meals, etc. You may want to assign a close friend or family member to be your "go to" person. Refer all offers for help to this person. Have them maintain a calendar and schedule people to help out in some way. There are calendar resources available including **carecalendar.org**. Find Care Calendar information on the family bulletin boards and in the parent room.

Another way your "go to" person can help you is to set up your website for updating friends and family. Two frequently used sites are **shareyourstory.org** and **caringbridge.org**. These sites reduce frequent update calls from friends and family. Have your "go to" person email out instructions to access pictures and updates as they are posted. This service will allow you to concentrate more on your baby instead of managing phone calls.

SOOTHING YOUR FUSSY BABY

All babies cry, but some cry more than others. They cry when they're hungry, bored, uncomfortable, or frightened. They also cry when they need a diaper changed, hear a loud noise, meet a new person — or for no apparent reason. Crying is one of the few ways your baby can communicate.

His or her crying is no reflection on your parenting. But it can be very frustrating when your baby cries and, despite your best efforts, doesn't stop. You can try to soothe a crying baby by feeding him, changing his diaper, swaddling, dimming the lights, rocking, singing and walking.

Some studies show that premature babies are more likely than term babies to be fussy. They may be harder to soothe, cry often, and have irregular eating and sleeping patterns. But each child is different, so this may or may not apply to your baby. If your baby is fussy, it may be comforting to know that you are not alone. Your baby will soon outgrow this difficult phase.

Some babies who have been in the NICU have trouble adjusting to the quiet of home. Your baby may sleep better with some background music or a low level of noise. Your baby may also sleep better with a night light on (since the NICU always had lights on).

As you get to know your baby, you'll learn how much crying is normal for him or her and what you can do to soothe him. If your baby cries longer than usual, and nothing you do soothes him or her, call your baby's health care provider to see if there is a medical reason.

The most important thing to remember is to put the baby down if you start to feel tense and stressed. Your baby can read your cues, and will become stressed as well. If you feel you are getting to this point, place him or her in his a crib, and take a few moments to regroup. Identify a friend or family member you can call to relieve you, so you can take a break. If nothing else works, put the baby in his or her crib on his back, close the door and check back *in 10 minutes*.

Visit **purplecrying.info** for more information about your baby's crying and ways to help, soothe and cope.

IF YOUR BABY WON'T STOP CRYING

- Check to make sure he isn't hungry, or needs a clean diaper.
- Look for signs of illness or pain, such as fever, swollen gums or an ear infection.
- Take your baby into a quiet/dark room. Hold baby close to your body. Breathe calmly and slowly.
- Rock the baby, or walk with him or her. Sing or talk to the baby quietly.
- Offer a pacifier or a toy. Take the baby for a stroller ride.
- Swaddle the baby snuggly in a blanket.
- Turn on music but make sure the sound is low and soothing.
- Run the vacuum, dish washer, or clothes dryer. Some babies like these rhythmic noises.

CHOOSING A PEDIATRICIAN

There are many factors to consider when selecting your baby's doctor.

- Match your baby's health condition to the expertise of the doctor. Babies with special medical needs visit the doctor's office more often and require more parent advocacy. Pediatricians concentrate their knowledge on infants and children.
- Make sure that whomever you choose is comfortable taking care of a premature infant with the more complex medical issues involved.
- Pick a doctor whose personality and philosophies match yours.
- Find a doctor who interacts well with you and considers your point of view on topics such as breastfeeding verses bottle feeding, immunizations, circumcision, and prescribing antibiotics. Ask the doctor about something if you feel strongly about it.
- Location: Remember that infants (especially preemies) visit the doctor more frequently than toddlers and older children. The location has to be convenient.
- Is the pediatrician board certified? This means that the doctor has had 4 years of medical school, 3 years of residency in pediatrics, and has passed a national test on core competency in pediatrics. Select a doctor who maintains yearly continuing education and the latest knowledge.
- How big is the practice? Are there many doctors in the practice or just one? The bigger the practice, the more expertise, but there may be longer wait times or impersonal service. Does the doctor have one office or several?
- Other things to consider: How easy is it to get an appointment on short notice? What are the office hours? Do they have an urgent care clinic before or after hours? Is there a way to communicate with the doctor without an appointment?

Visit **oprmc.com** and search our physician directory by name, location and specialty or call our physician referral line at (913) 541-5562.

IT IS VERY IMPORTANT TO MEET YOUR CHILD'S POTENTIAL DOCTOR

Here are a few questions to ask at your "meet and greet":

- Is the doctor taking new patients?
- Has the doctor taken care of premature babies before and feels comfortable doing so?
- Is he or she willing to refer to a specialist (GI, ENT, etc.)? How quickly?
- Does he or she specialize in a certain area, for example, asthma?
- Does he or she take your insurance?
- Who answers calls and gives advice? Registered nurses on staff or medical assistants?

- Is there an after-hours answering service?
- Is there a charge for weekend phone calls?
- How does the doctor stay current on updated medical practices?
- How open is he or she to your ideas and parenting decisions?
- Does he or she follow the “Better Safe than Sorry” or “Less Cost” philosophies when ordering tests, etc.?

- Was the staff pleasant, courteous, and helpful?
- Is this a child-friendly place?
- Were there toys and books in the waiting area?
- Did the doctor wear a tie with cartoon characters on it?
- Did the staff wear colored scrubs?
- Did the doctor and nurses put children at ease?
- How was the doctor’s bedside manner?
- Was the staff friendly and smiling?

WHEN TO CALL THE DOCTOR

If your baby has just been discharged, and has not had a follow-up appointment with the pediatrician, call the NICU at 913-541-5275 for advice. Once your baby has been seen by the pediatrician, refer all questions to the pediatrician. At that time the pediatrician will have the most updated information about your baby to best address the issue.

Call the doctor if your baby is experiencing one or more of the following:

- Temperature of 100.4˚F (38.0 C) or higher (make sure baby is not overdressed).
- Cannot maintain a temperature above 97.6˚ F (36.4˚C), despite warming efforts.
- Low energy and less active (lethargic).
- Difficulty breathing (faster than usual, pausing 20 seconds or more, working harder to take each breath, wheezing, more ribs visible than usual with each breath, nasal flaring, head bobbing).
- Has one or more apnea spells (more than typical for your baby).
- Blue, grey or pale color around the nose and mouth, or throughout the body.
- Refusal to eat, not enough energy to finish a feed.
- Vomiting (more than a wet burp or spit up), especially if projectile or green in color.

- Has more than several diarrhea diapers, or the stools change dramatically in color and consistency (normal stools may be loose and seedy in nature, diarrhea has a watery consistency and can have an atypical foul odor).
- Has 4 or less wet diapers per day (begin to pay close attention at less than 6).
- Is more irritable than usual (possibly arching his/her back or pulling knees to the chest when upset) and you are unable to soothe.
- Becomes more yellow in color (jaundice).
- Redness, swelling or drainage at umbilical cord, circumcision or any surgical incision site.
- New or changing rash.
- Not acting normal — the feeling that something is just not “right”.

WHAT IS RSV?

Respiratory Syncytial Virus (RSV) is a very common virus. RSV usually causes moderate to severe cold symptoms in adults and children. But in high-risk children, such as premature infants or babies born with certain heart problems or chronic lung disease, RSV is very serious.

Each year, an estimated 125,000 infants in the United States are hospitalized with severe RSV, the leading cause of hospitalization for children under 1 year of age. Severe RSV can cause up to 500 infant deaths annually in the United States. RSV may also cause long-term health problems, such as asthma.

Premature babies have a high risk of getting very sick if they catch RSV because their lungs are not fully developed. Also, because they were born early, they may not have received enough virus-fighting substances or *antibodies* from their mothers to protect them from RSV and other viruses.

RSV season usually starts in the fall and runs through the spring. In some areas of the United States, RSV season may last all year. Ask your healthcare provider when RSV season occurs in your area. If your baby is at high risk for severe RSV, discuss protective steps you can take with your baby's healthcare provider.

CALL YOUR HEALTHCARE PROVIDER IMMEDIATELY IF YOUR BABY HAS ANY OF THESE SYMPTOMS:

- Fever greater than 100.4° F
- Persistent coughing
- Wheezing
- Rapid breathing
- Problems breathing or gasping for breath
- Blue lips or around the mouth

ADDITIONAL RISK FACTORS FOR PREMATURE INFANTS MAY INCLUDE:

- Being in daycare or spending more than 4 hours per week with other children
- Having school-age siblings
- Young chronological age (12 weeks of age or younger at the beginning of RSV season)

- Living with 4 or more family members
- Exposure to tobacco smoke or other air pollutants
- Low birth weight (less than 5.5 pounds)
- Family history of wheezing or asthma
- Being a twin, triplet or other multiple
- Severe neuromuscular disease
- Born with abnormal airways

WHAT IS INFLUENZA (ALSO CALLED FLU)?

The flu is a contagious respiratory illness caused by influenza viruses. It can cause mild to severe illness, and at times can lead to death. The best way to prevent seasonal flu is by getting a seasonal flu vaccination each year.

EVERY YEAR IN THE UNITED STATES:

- 5% to 20% of the population gets the flu
- More than 200,000 people are hospitalized from flu-related complications
- About 36,000 people die from flu-related causes

The flu can be a very serious illness for high-risk children, such as premature infants or babies born with certain heart problems or chronic lung disease. The elderly, young children, pregnant women and people with health conditions (such as asthma, diabetes, or heart disease), are also at increased risk for serious complications from the seasonal flu.

FLU COMPLICATIONS

Flu complications can include bacterial pneumonia, ear infections, sinus infections, dehydration, and worsening of chronic medical conditions, such as congestive heart failure, asthma or diabetes.

HOW FLU SPREADS

Flu viruses spread mainly from person to person through coughing or sneezing. Sometimes people become infected by touching something with flu viruses on it, and then touching their mouth or nose. Most healthy adults are able to infect others beginning 1 day before symptoms develop, and up to 5-7 days after becoming sick. That means that you may be able to pass on the flu to someone else before you know you are sick, as well as while you are sick.

PREVENTING SEASONAL FLU: GET VACCINATED

- The "flu shot" — an inactivated vaccine (containing killed virus) that is injected with a needle. The seasonal flu shot is approved for use in people 6 months of age and older, including healthy people and people with chronic medical conditions.
- The nasal-spray flu vaccine — a vaccine made with live, weakened flu viruses that do not cause the flu (sometimes called LAIV for "Live Attenuated Influenza Vaccine"). LAIV is approved for use in healthy people 2 to 49 years of age who are not pregnant.

About two weeks after vaccination, antibodies develop that protect against influenza virus infection. Flu vaccines will not protect against flu-like illnesses caused by non-influenza viruses.

SYMPTOMS OF FLU

- Fever (often high)
- Headache
- Extreme fatigue
- Dry cough
- Sore throat
- Runny or stuffy nose
- Muscle aches
- Nausea, vomiting, and diarrhea can occur in both children and adults. Some people who have been infected with the new H1N1 flu virus have also reported diarrhea and vomiting.

PROTECT YOUR NEWBORN FROM CIGARETTE SMOKE

Did you know that second-hand and third-hand smoke is even worse for babies than it is for adults? Now that your newborn is home, it's crucial to keep your baby away from cigarette smoke. You may have quit smoking when you found out you were pregnant. If not, it's still not too late. Protect the baby from anyone who smokes including grandparents, friends and babysitters.

HOW CIGARETTE SMOKE CAN HARM YOUR BABY

- Asthma or other lifelong breathing problems
- Worsening of colds or other respiratory problems
- Poor growth and development, both mentally and physically
- Higher chance of SIDS (Sudden Infant Death Syndrome)

HOW TO PROTECT YOUR BABY FROM SMOKE

If someone in your household smokes and isn't ready to quit, you must still protect your baby. Ban smoking inside the house. Any smoker (including you, if you smoke) should smoke only outside, away from windows and doors. Wear a jacket or sweatshirt while smoking that you remove before holding the baby. Never let anyone smoke around the baby. And never take the baby into an area where people are smoking. If you have visitors who smoke, explain your smoking rules before they come over, so they know what is required.

QUITTING IS BEST FOR YOUR BABY

If you smoke, quitting is the BEST thing for you and your baby. Quitting is hard, but you can do it!

- Tape a picture of your newborn to your pack of cigarettes. Look at it each time you smoke. This will remind you of the best reason to quit.
- Join a group or smoking cessation class to give you the support and skills you need to quit smoking. You may even meet other parents in the same situation. If you need help finding a group or class in your area, call your healthcare provider.
- Ask other smokers in the family to quit with you. This way you can support each other.
- If you don't succeed the first time, try again! Many people have to try more than once before they quit for good. Just remember, you're doing it for your baby.

NOTES

NAME: ______________________________

Date	Weight in Grams	Weight in lbs/oz	Length/Head Measurements

This measurement is equal to …	This measurement
1 cc	1 milliliters (ml)
5 cc	1 **TEA**spoon
15 cc	1 **TABLE**spoon
30 cc	1 ounce (oz)
60 cc	2 ounces
90 cc	3 ounces
120 cc	4 ounces

* *Make sure you have a full set of measuring spoons at home for adding extra calories to formula or breast milk.*
* *Remember to ask for extra syringes when filling a prescription at the pharmacy.*

NOTES

NAME: ______________________________ **DATE:** ______________

Use this chart (one per day) to keep track of feedings, temperatures, diaper changes and medications at home. *Tip: Pencil in feeding times and medications as reminders for when they are due, then add a check mark when you give them. Take several completed days with you to your baby's doctor appointment to show him/her what a typical day is like for your baby.*

Time	Feeding/Amount	Temp	Diaper	Medications Given √

Taking a temperature

- ☐ Know the normal range and be able to react appropriately if out of normal range
- ☐ Axillary (under the arm)
- ☐ Rectal
- ☐ Verbalize the temperature range to maintain in your home

Bathing

- ☐ Demonstrate both a sponge and tub bath
- ☐ Know what temperature the bath water should be and how to tell

Changing a diaper

- ☐ Recognize signs of a diaper rash and be able to care for
- ☐ Thorough cleaning with each change
- ☐ Recognize a change in urination and stool frequency, as well as abnormal changes in both

Use of the bulb syringe

☐ When to use ☐ How to use ☐ Use of saline

Feeding

- ☐ How to breastfeed your baby
- ☐ Mixing formula and added calories correctly
- ☐ Proper handling and storage of breast milk and formula
- ☐ Proper cleaning of feeding supplies
- ☐ Warming milk
- ☐ How to resolve choking and spells
- ☐ Maintaining a schedule

Medications

- ☐ How to measure and draw up the proper dose
- ☐ Maintaining a medication schedule
- ☐ How to properly give each different medication
- ☐ Know the purpose of each medication, as well as any special considerations or instructions
- ☐ Fill prescriptions a few days before discharge and practice giving in the NICU setting

Car seat

☐ Read and familiarize yourself with your car seat
☐ Be able to adjust any straps or settings for your baby
☐ Be able to secure your baby correctly in the car seat
☐ Know how to install the car seat correctly in your vehicle
☐ Watch the NICU car seat video

When to call the doctor

☐ Recognize abnormal changes with your baby
☐ Have emergency contact information on hand at all times (doctor's phone number, copy of discharge summary)
☐ Verbalize signs and symptoms of an emergency
☐ Complete an infant CPR course (This is not required for all parents, though highly recommended. The NICU care team will inform you if it is a requirement for you.)

Infant Safety

☐ Become familiar with key points in this resource book and attend the discharge class

Special equipment training (if applicable)

☐ Oxygen
☐ Apnea monitor
☐ Any other equipment specific to your baby

SIDS & Shaken Baby Syndrome

☐ Understand the risk factors
☐ Demonstrate prevention measures

Schedule Follow- up Appointments

☐ Pediatrician
☐ All other (cardiologist, retina specialist, feeding team, etc.)

Prepare your home

☐ Clean
☐ Smoke-free environment
☐ Organize baby items
☐ Prepare siblings, family and pets for the baby's arrival

NICU

If you have questions or concerns after your baby's stay, call the NICU at 913-541-5275 or call the NICU Clinc at 913-541-5022.

LACTATION INFORMATION

In addition to speaking with our lactation consultants (913-541-5022), we also recommend these comprehensive breastfeeding websites: **llli.org, breastfeedinginc.ca, womenshealth.gov, kellymom.com., newborns.stanford.edu, and lowmilksupply.org.**

CIRCLE OF HOPE NICU FOUNDATION

The mission of the Circle of Hope NICU Foundation is to support and strengthen families by providing services that contribute to the emotional, social and financial health and vitality of parents while their babies are in the NICU at Overland Park Regional Medical Center (OPRMC).

The Circle of Hope, a nonprofit organization, includes parents of NICU graduates. They serve as Parent Members on the Board of Directors alongside the NICU social workers and discharge planning nurses, who serve on the Board in an advisory capacity.

The NICU Foundation is committed to:

- Providing NICU family support through interactive programs such as parent-to-parent, bereavement services and meal support services.
- Promoting a better understanding of the principles of family centered healthcare as well as the services and policies of OPRMC for NICU patients, families and staff.
- Being active consultants with regard to decisions and plans that affect OPRMC NICU patients, their families and staff.
- Continually improving the facilities available to OPRMC NICU patients and families.

For more information on services available to you through the Circle of Hope or if you are interested getting in involved, please contact the NICU Family Support Social Workers Elaine Riordan, 541-5882, or Tiffany Crabtree, 541-3219.

MARCH OF DIMES

March of Dimes works to provide all babies a fighting chance against threats to their health, including prematurity, birth defects and low birth weight. Visit, **marchofdimes.com/kansas** for more information about resources and events in the Kansas City area.

WOMEN'S SERVICES AT OPRMC

Overland Park Regional Medical Center offers a wide range of women's health services, an outstanding team of gynecologists and surgeons, as well as an experienced team of nurses and support staff skilled in caring for women. Visit **midwestcareforwomen.com** or call 913-541-5540 for information about our services.

EMERGENCY SERVICES AT OPRMC

In an emergency, every second matters. That's why OPRMC offers emergency care 24 hours a day, seven days a week for people of all ages. We have board-certified physicians in Emergency Medicine, critical care nurses and staff trained to meet your trauma needs.

NURSES ON-CALL

Call 800-386-9355 to speak directly with experienced registered nurses. Nurses On-Call provide comprehensive health information and answer questions to help you make informed healthcare decisions. Nurses-On-Call can also refer you to OPRMC physicians.

POISON CONTROL

Hotline pharmacists, nurses and poison control specialists are available 24/7 at 1-800-222-1222.

PARENTS AS TEACHERS

A FREE, voluntary service for any family with children from birth to age three. Excellent child development information is offered through home visits, group activities and developmental screenings. Call your school district for more information about the program in your area.

THE FAMILY CONSERVANCY

The Family Conservancy offers child development information and counseling services for individuals, couples and families related to family life, as well as a metro-wide parenting classes. Visit the **thefamilyconservancy.org** for program details.

PERIOD OF PURPLE CRYING

This website helps parents understand and effectively deal with crying. Visit **purplecrying.info** for more information about your baby's crying and ways to help, soothe and cope.

THE PREGNANCY AND POSTPARTUM RESOURCE CENTER

The center offers resources, information and support groups for women experiencing the "baby blues" or pregnancy or postpartum depression (PPD). Visit **kansasppd.org** for more information or call 866-363-1300 for help anytime day or night.

CAR SEAT SAFEY

These websites offer good information about a variety of carseat issues and guidelines: **nhtsa.gov, boosterseat.gov, ntsb.gov, chop.edu/carseat, iihs.org and safekids.org.**