This book has information that will help you from admission through discharge. We encourage you to take it home to read, but please bring it each time you return so we can check off your progress.

My baby is in Pod:

Bed number:

The NICU Direct Parent phone number:

(757) 668-7449

For more information about the NICU, visit

CHKD.org/NICU
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Welcome to the CHKD NICU

Dear NICU Parents,

Congratulations on your baby! We know this is a very scary time, but an exciting time as well. On behalf of the neonatal intensive care unit (NICU) at Children’s Hospital of The King’s Daughters, we would like to welcome you to our unit.

We consider parents to be valuable members of our NICU medical team and we encourage your involvement. Although initially you may be limited in what you are able to do for your baby, your presence here is invaluable. You are the only mom or dad your baby has!

In addition to your baby’s medical team, we have a strong support team to help you through the typical ups and downs of your NICU journey. We also offer a number of parent programs that are both educational and supportive. We welcome your questions and your participation in daily interdisciplinary medical rounds. We are available to assist you as needed.

Sincerely,

Dr. Jamil Khan, Neonatologist
NICU Medical Director

Laura Biava, RN, MSN
NICU Director

NICU Family Advisory Council
New to the NICU
My NICU orientation checklist

Please be sure to check off the following items as you complete them.

☐ I have learned about hand washing and how to prevent the spread of infection.

☐ I have learned about the NICU’s visitation guidelines.

☐ I have filled out my visitor/parent contact card.

☐ I have learned about the best times to call the NICU for updates on my baby.

☐ I understand the NICU’s cell phone guidelines.

☐ I have received education on the medical equipment being used to help my baby get better.

☐ I have been to the admitting office to confirm insurance and receive my parking card and KD Café discount card.

☐ I have met with my social worker.

☐ I have signed my NICU partnership agreement.

☐ I have met with a lactation consultant.

☐ I have met with a parent support coordinator.

☐ I have participated in NICU classes and activities.

☐ I have started my journey beads.
Who should I go to for help at admission?

Here are some members of your support team you will meet around admission time:

- Doctors and nurses will help you learn about your baby’s medical needs and how you can care for your baby.
- Social workers and parent support coordinators are available to help with resources and with the emotional stress of the NICU.
- Lactation consultants can help you successfully pump and breastfeed, if that is your goal.
- Chaplains offer support as a member of the team.
- If your baby is admitted over the weekend or overnight, you can speak with the charge nurse if you have questions about resources.

What should I do first?

As soon as possible after admission, please visit the admitting office on the first floor, across from the ATM. There you will confirm insurance and receive a parking pass and KD Café discount card. Remember to add your baby to your insurance as soon as possible. Once you have your baby added, take your baby’s hospital proof of birth letter and insurance information to the admitting office to register them in the CHKD system.

Under certain circumstances, you may be able to stay overnight at the Ronald McDonald House. On weekdays, ask your social worker for more information. On weekends, ask the charge nurse.

If you plan to pump and/or breastfeed, speak with one of our lactation consultants as soon as possible to help establish your milk supply. See the pumping and breastfeeding section of this binder for more information on pumping and obtaining a hospital-grade breast pump.

Hand Washing

While your baby is in the NICU, he or she can be very susceptible to infection. To help decrease the spread of germs, we must all take special care. Hand washing/hygiene is one of the MOST effective ways to prevent the spread of germs. In the NICU, you will use antiseptic soap and alcohol hand sanitizers to help remove and kill germs on your hands, wrists and arms. Before going to your baby’s bedside, remove all jewelry from the elbow down and follow these hand washing guidelines posted at the sink:

1. Wash hands with soap and water, paying special attention to cleaning under your nails and between your fingers.
2. Dry your arms and hands with a paper towel.
3. Apply two squirts of Purell Surgical Scrub in the palm of one hand and work the scrub from fingertips to elbow. Repeat this procedure on the opposite hand and arm. Rub until completely dry. Do not rinse off.
**Spending time with your baby**

Parents are encouraged to spend as much time with their baby as possible, and we offer 24-hour visitation. However, for the protection of your baby, the NICU is a locked unit. When you arrive, the receptionist or secretary will call your baby’s nurse to be sure you can come to the bedside. Occasionally, you may have to wait during shift change (6:30-7 a.m. and p.m.) or if there is procedure occurring in the pod.

Only two people at a time may visit the baby. An exception to this is made if the baby’s siblings visit. In this case, the sibling may visit with both parents. Siblings must be over the age of two, and parents must provide a copy of his or her immunization record. As with all visitors, the siblings must be free of illness. Non-sibling visitors must be at least 12 years old.

Parents will fill out a visitor list card which is placed at the bedside. In addition to phone contact info for the parents, the card contains the following visitation information:

- A list of four family members or friends allowed to visit your baby without you. Any other visitors must be accompanied by one of the baby’s parents.
- Two adults are able to receive phone updates. Usually these are the parents.
- Please do not visit if you have a temperature over 100.5 degrees. You must wear a mask if you have a cough, runny nose or cold sore.
- Finally, the NICU does not have sleep rooms for parents, nor are parents able to sleep at the bedside or in the family waiting room. Please speak with your social worker or the charge nurse if you have any questions.

**Calling the NICU**

We encourage parents to call for updates on their baby if they are not able to visit or attend medical rounds. At admission, parents will receive a pass code which you will need to receive any information by phone. Parents should not share their pass code with anyone.

The BEST times to call are:

- 6 a.m. or p.m.: This is before shift change when the nurse who was there all day or night can give you a thorough update.
- 9-10:30 a.m. or p.m.: This gives the nurse coming on shift time to assess your baby and perform the 8 o’clock hand-on.
- Noon and midnight: This is after the 11 o’clock hands-on and before quiet hour begins.
- 1:30 a.m. or p.m.: This is after quiet hour but before hands-on.
- 3-5 a.m. or p.m.: This is between the 2 o’clock and 5 o’clock hands-on.
- Early afternoon: This is after medical rounds (usually around noon) and can be a good time to check on any changes made during rounds

The nurse MIGHT NOT be able to answer the phone at the following times:

- During hands-on (8, 11, 2 and 5 a.m. or p.m.)
- During quiet hour (12:30-1:30 a.m. or p.m.)

The nurse WILL NOT be able to answer the phone at the following times:

- During shift change (6:30-7 a.m. or p.m.)
Shift Change

- From 6:30-7 in the morning and evening the nurses will be giving report on your baby to the nurse coming on duty. You may see your baby during this time, but we ask that you arrive before 6:30.
- If you are visiting your baby during shift change, please keep in mind that important information is exchanged during this time and interruptions can be distracting. Please refrain from asking questions until the report is completed.
- Outside phone calls will not be connected to the pods until after 7:30.

Rounds and Privacy Issues

- Medical rounds take place every morning between 9 a.m. and noon. Parents are encouraged to attend and participate. This is an opportunity to ask questions and learn more about the plan of care for your baby.
- During rounds and shift report you may hear information concerning other patients and families. We ask that you keep this information to yourself. As medical professionals, we are held to a standard that respects the rights and privacy of each patient. As partners of our medical team, we hold you to the same standard.

Cell Phones

- All visitors must put their phone in a plastic bag as they enter the NICU to help prevent the spread of germs.
- Please do not touch or hold your phone when you are holding your baby. Your baby’s nurse would be happy to take a photo if you wish. Your baby deserves 100% of your attention while you are holding him, and it is important to use both hands to support while holding.
- Please do not place your phone on any equipment or charge it at the bedside.
- Text rather than talk. If you must talk, please do so quietly or take the call in the family waiting room (not in hallway).
- Set your cell phone on vibrate or a soft tone so as not to disturb the patients and families.
- Taking pictures or video of your baby is encouraged, but please keep your phone in the bag.
- Use hand sanitizer often when using your phone.

The NICU can be very overwhelming. Please look through the information in these first sections soon after admission to help adjust to your new environment.
Case management

Every NICU baby is assigned a case manager who keeps your insurance company updated on your baby’s progress throughout his or her hospitalization. The NICU has three case managers, and they are located in the “fishbowl” - the glass office across from pod H.

In order to be sure your baby’s stay is covered by insurance:

- As soon as possible after admission, **within a few days**, please be sure to:
  1. Add your baby to your insurance.
  2. Stop by the admitting office on the first floor. They will confirm that your baby has been added to your insurance and give you a parking card and cafeteria discount card.
- Your baby may qualify for SSI Medicaid or long term hospitalization Medicaid (hospitalized for over 30 days). Your social worker can help you apply for these programs.
- Please let the admitting office know as soon as possible if there are any changes to your insurance or address during your baby’s hospitalization.
- Please stop by the fishbowl and speak with your baby’s case manager if you have questions about any bills you may receive during your baby’s hospitalization.
- Your baby’s case manager can help you with paperwork if you apply for FMLA or EFMP (the military exceptional family member program).

Your case management team phone number:

**(757) 668-7449**
Your case manager will also provide **discharge planning coordination** for your child and family as the time comes to go home.

- Your case manager will ensure all necessary training has been completed with your family in preparation for discharge.
- Prior to discharge, your case manager will arrange follow-up appointments with your baby’s pediatrician and any needed specialists.
- Your case manager will work with you to set up any needed home care equipment while working with your insurance company to ensure adequate coverage.
- If your child is discharged with medical equipment, skilled nursing visits will be arranged to assist with safe transition to home.
- Depending on the medical needs of your child at the time of discharge, your case manager will provide referrals to available community resources and programs to assist with the care of your child at home. This would include screening your child as appropriate for Medicaid waivers to provide private duty in-home nursing.
- You will be provided a discharge summary for your records and to bring to your pediatrician’s office. Keep your copy readily available in case you need to seek emergency care for your child.
- If you have additional questions regarding the discharge process, please contact your case manager.
Give yourself time to develop a new routine in the NICU. Asking about the following items can help you understand your baby’s medical status and become part of the NICU Team.

**Medical Team Rounds**

Medical rounds occur daily between 9 a.m. and noon, and parents are encouraged to participate. This is a great opportunity to meet the members of the medical team, ask questions and learn the plan of care for your baby.

Your infant will be assigned to either the Red or Blue team. Each team is headed by an attending neonatologist. In addition to that neonatologist, the Red Team includes neonatal nurse practitioners and the Blue Team is made up of pediatric residents.

Other members of the medical team who participate in rounds are pharmacists, dietitians, social workers, therapists and other specialists and consultants as needed.

**Family Meetings**

A care conference is a meeting between a baby’s parents and the medical team, separate from rounds. This is an opportunity for parents and members of the medical team to discuss concerns, answer questions and review the plan of care. Parents can request a care conference at any time during their baby’s hospitalization, but care conferences are particularly advised if there is a change in the baby’s status or if specialists are involved in his or her care. Talk to your social worker if you would like a family meeting.

**Primary Nursing**

Primary nursing involves one or more nurses who care for your infant on a regular basis. The advantage of this is that the nurse gets to know you and your infant very well. The nurse can be an advocate for your infant when you are not available and provide continuity of care.

If you need help obtaining a primary nurse, please speak with your baby’s social worker or one of the parent support coordinators.
Monitors and alarms

All infants in the NICU have monitors that continuously track their heart rate, respiratory rate and the amount of oxygen in their blood. The probes on these monitors are very sensitive and may alarm with movement. They will also alarm if the infant’s heart rate, respiratory rate or saturation briefly falls outside the normal limits. In either case, these alarms are different from the alarm sound of a true emergency. Your baby’s nurse is very familiar with the different alarms and will know when it is necessary to go to the bedside and check on the infant.

**EKG Monitor**

This monitor records your baby’s heart rate and respiratory rate by using three wires with probes that can be placed on the skin. If an infant’s heart rate or respiratory rate is too fast or too slow, an alarm will sound to alert the staff.

**Pulse Oximeter**

This equipment measures the level of oxygen in the blood; also referred to as oxygen saturation. A probe (similar to an adhesive bandage) is placed on the infant’s hand or foot. A red glow lets you know it’s working. The heart rate is also monitored with the oxygen saturation. As with the EKG monitor, an alarm will sound if the infant’s oxygen saturation falls outside the normal limits. There is a central monitor that provides continuous information on all the infants in the pod. This is another way for the nurse to know how your baby is doing. Remember, if the nurse doesn’t look worried, you needn’t worry.

Staff will make every effort to silence alarms promptly. We ask that parents do not touch or adjust the monitors and other equipment.
### Assessing a newborn’s weight

Please use this chart to help convert your baby's weight from grams to pounds and ounces.

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Who’s who in the NICU

**Neonatologists** – Pediatricians who have advanced training and are certified in the care of the premature and sick newborn infants.

**Resident Physicians** – Doctors who are in advanced training in the care of infants and children.

**Consulting Physicians** – Doctors with specialized training in other areas of pediatric medicine such as cardiology, infectious disease and surgery.

**Neonatal Nurse Practitioners** – Registered nurses with advanced training who work with the neonatologists to care for the medical needs of your infant.

**Registered Nurses** – Nurses who are specially trained in the care of premature and critically ill infants.

**Respiratory Therapists** – Individuals specially trained in the operation of ventilators and other devices that deliver oxygen and assist infants with breathing.

**Developmental Care Specialist** – A registered nurse with advanced training in infant development.

**Pediatric Advanced Care Team Coordinator** – A registered nurse with advanced training in infant pain and comfort measures.

**Pharmacists** – Individuals with special training in the dosing and management of infant medications.

**Social Workers** – Each NICU family is assigned a clinical social worker who is specially trained to assist parents with the emotional and stressful issues associated with a premature or sick newborn infant.

**Speech, Occupational and Physical Therapists** – Individuals with advanced training to assist your infant’s development in the following areas: language skills, fine and gross motor skills, cognitive skills and social skills.

**Case Managers** – Registered nurses specially trained to assist with insurance needs and other questions that arise. They coordinate medical follow-up and home care needs at the time of discharge.

**Lactation Consultants** – Registered nurses with advanced training to help mothers meet breastfeeding goals. The lactation consultant is available for questions and with information on how to obtain a hospital-grade breast pump for home use. Your baby’s bedside nurse can page the lactation consultant on your behalf, or you can reach them by calling (757) 668-7405.

**Registered Dietitian** - During your baby’s NICU stay, you will work with a registered dietitian (RD). Sometimes called a nutritionist, the dietitian manages the calories, protein, vitamins and minerals that your baby needs to grow and heal. The dietitian will plot your baby on a growth chart to monitor your baby’s weight gain, head growth and body length throughout their NICU stay. At discharge, the dietitian will teach you how to prepare any breast milk or formula at home.

**Parent Support Coordinators** – Our support coordinators are parents who have gone through the experience of a hospitalized infant in the NICU themselves and are now using that experience to help other NICU parents.

**Chaplains** – The chaplains role is to meet your spiritual and emotional needs and to offer support to you, your family and your child.

**Others** – Other members of the medical team include: nursing care partners (NCP), x-ray techs, NICU educators, secretaries, NICU managers, child life specialists and volunteers.
Who’s who on your NICU support team

LeeAnn Apker, IBCLC  
Lactation Consultant

Pam Fasciocco, RN  
NICU Case Manager

Lisa McGonagle, RN  
NICU Case Manager

Martine Sallee, RN  
NICU Case Manager

Jessica Black, RN, IBCLC  
Lactation Consultant

Kitty Katz, RN, IBCLC  
Lactation Consultant

Sharon Cooke, MSW  
NICU Social Worker

Rachel Houck, MSW, LCSW  
NICU Social Worker

Denise Willford, MSW, LCSW  
NICU Social Worker

Elizabeth Moll, MSN, RN, CPNP, CIMI, NICU Developmental Care Specialist

Marnie Dyer  
NICU Parent Support Coordinator

Maureen Heald  
NICU Parent Support Coordinator
Pumping and breastfeeding in the NICU
When do I start pumping my milk if my baby cannot feed at the breast?

As soon as possible, ideally within the first 24 hours after delivery. Research shows establishing your milk supply in the first two to three weeks after giving birth is an important window of time to stimulate the hormones that make milk. Please let your nurse or lactation consultant know you want to pump.

How often do I need to pump?

You need to pump with a hospital grade pump every 2 to 3 hours, or 8 - 10 times in 24 hours. This will include once or twice during the night. This is the minimum number of times newborns breastfeed.

How do I obtain a breast pump for home use?

We have breast pumps for you to use here, but you WILL need one for home also. Call your insurance company or WIC. We can provide you with a WIC letter. We also have a list of locations that rent breast pumps. Ronald McDonald House has a hospital grade breast pump you may use if staying there.

I am taking medications. Can I still pump?

YES. There are very few medications that are not safe. We will be happy to review your medications for you. If we are not available, continue to pump and label your containers with the medication(s) until we can check them for you.

If at any time you notice a decrease in your milk supply, pain with pumping, or have any other concerns/questions, please come see us or leave a message if we are not here.

Where can I pump?

There are three pump rooms located in the hallway across from the parent support coordinator’s desk. These rooms are supplied with electric breast pumps and provide a place for moms to express milk. You may also pump at the bedside. Your baby’s nurse or one of the lactation consultants can help you get set up at the bedside.

Your lactation team
phone number:

(757) 668-7405
The importance of breastmilk

The American Academy of Pediatrics has recommended that all preterm infants receive human milk. Mother’s own milk is preferred, but if she is not able to supply enough milk for her baby, pasteurized donor human milk is the next best option.

Pasteurized donor human milk has been safely used in Europe for over a century and in the United States for more than 60 years.

Pasteurized donor human milk in the NICU has been found to improve the outcomes of preterm babies in the NICU by:

- Providing antibodies that help prevent infection and devastating bowel diseases
- Providing growth hormones to optimize development
- Improving feeding tolerance
- Aiding in the maturation of the gastrointestinal tract
- Decreasing the chance of allergy development
- Providing anti-inflammatory and healing proteins
- Improving eye and brain development

Human milk treatments also benefit babies and children in the following ways:

- Lower rates of severe retinopathy of prematurity
- Fewer hospital re-admissions after NICU discharge
- At least 58% decrease in risk of necrotizing enterocolitis (NEC)
- 36% decrease in risk for sudden infant death syndrome (SIDS)
- 27% decrease in risk for asthma, skin disorders and eczema
- Up to a 30% reduction in type 1 diabetes
- 15-20% decrease in the risk for specific leukemia-related cancers
- Decrease in risk for irritable bowel syndrome by 31%
- 52% decreased in risk for celiac disease
- Decrease in risk for obesity later in life
- Higher intelligence scores noted at 8 years of age for patients who received mother’s milk as infants in the NICU

Donor human milk is provided to our NICU by the King’s Daughters Milk Bank. This milk goes through a rigorous pasteurization process and lab testing to ensure it is safe for our most critically ill babies.
Breastfeeding basics

Getting started

Your body has been getting ready to feed your baby throughout your pregnancy. Human milk is specially made for your baby. Consider the first few weeks a learning period for you and your baby. Give yourself time to recuperate from birth. With time and practice, you will become a coordinated team. You will not see or measure how much milk your baby takes in, but you and your baby will show signs that your baby is getting enough milk. CHKD Lactation is available in the NICU to assist you with getting started.

Mother’s signs

- Breasts feel full and heavy as milk comes in around day 2 to 4. Leaking milk is normal and pads inside your bra may be helpful.
- Breasts should feel fuller before feedings and softer after feedings. Listen for your baby’s swallowing.
- ‘Let-down’ is the milk ejection reflex that starts milk flowing toward the nipple. Some mothers experience a pins and needles sensation and some don’t. This is normal.
- You may experience some nipple tenderness when your baby latches on. This normal and usually disappears at the end of the first week. If tenderness persists or worsens, please call (757) 668-7405 to contact a certified lactation consultant.

Baby’s signs

- Baby should latch on deeply and suckle rhythmically for at least 15 minutes on the first side, then switch sides. Baby may pause to rest and you will hear him swallowing. Your baby is finished when he pulls off or falls asleep.
- Baby should breastfeed 8 to 12 times in 24 hours, or about every 1 ½ to 3 hours. You may need to wake your baby to feed if she does not wake up to eat after four hours.
- Baby should be content between feedings. If your baby is often fussy or crying, contact your physician.
- The color of your baby’s stools will change from thick black meconium to dark green to yellow cottage cheese/mustard milk stools over the first 4 to 5 days. Baby should have four or more stools per day after the fourth day of life.
Breast pump kit care

Good hygiene will help protect the breastmilk that you give to your baby. For the best protection when handling your breast milk, wash your hands with soap and water, and follow the guidelines below for cleaning, drying and storing your kit. If your baby is premature or ill, consult with your healthcare provider for further cleaning and storage instructions.

How do I clean my kit?

1. Finish pumping.
   - While the pump is still running, disconnect tubing from breast shields.
   - Continue to let pump run for two minutes with tubing attached. This will eliminate condensation that naturally results from humidity.

2. Take apart kit and store breastmilk.
   - With tubing still connected to pump, separate all parts of your kit that come in contact with your breast or breastmilk.

3. Wash kit.
   - Rinse all separated parts in cool water to remove breast milk.
   - Wash all separated parts in warm soapy water or dishwasher.
   - Place all separated parts on top rack if using dishwasher.
   - Rinse all separated parts with clear water.

If sanitizing your kit, separate all parts that come in contact with your breast or breast milk and boil for 10 minutes. At CHKD, we provide you with Medela Quick Clean Micro-Steam™ bags.

Drying and storing

Allow all breast pump kit parts to air dry in a clean area and store dry parts when not in use. Do NOT store wet or damp parts.

When do I care for my tubing?

If your tubing comes in contact with breastmilk, clean it by following these directions:
   - Rinse and run water through tubing to remove breastmilk.
   - Dry tubing by attaching it to pump and running for two minutes or until dry. This will eliminate condensation that naturally results from humidity.
NICU Social Work
Dear NICU Parents,

Clinical social workers in the NICU are part of the team of people working to care for your baby and for you. Every family with an infant in the NICU is assigned a clinical social worker who will follow you and your family while your child is at CHKD.

Clinical social workers talk with families about their social and emotional needs and provide information about things that may help you and your family while your baby is at CHKD and after your baby goes home. Clinical social workers are also here for support and counseling and can talk with you and your family about what it is like to have a baby in the NICU and what can be done to help you feel more comfortable.

If at any time you have questions or concerns you would like to share with your clinical social worker, or if you would like more information, please feel free to contact your social worker directly, or ask your nurse or doctor to contact your social worker for you.

Sincerely,

Your Clinical Social Work Team
Common parent reactions to the NICU

The NICU is a wealth of sensory input. You may be overwhelmed by the amount of equipment. Many of these machines have unique operating noises and alarms that may frighten you or make you feel something is not right with your baby. The NICU staff are specially trained to interpret and respond to any concerning alarms and explain what they mean. As you spend more time in the NICU, you too will begin to distinguish among various alarm sounds.

Depending on the time of day, the unit may be a flurry of activity. More people tend to be in the NICU during the day because this is when most physicians, nurse practitioners and physician assistants make rounds (visit each patient) and most diagnostic testing is performed. Many different healthcare providers involved in your baby’s care will introduce themselves to you. Don’t worry about remembering their names or what they do.

The staff understands that you are taking in a lot of new information and will continue to introduce themselves as you get to know each other and develop your NICU partnership.

Parents report a range of reactions and emotions following their first moments in the NICU. How you feel may depend on whether you were expecting your infant to need NICU care after birth, your baby’s condition, your own condition and if you have had any past NICU experience. Your NICU social worker can help you understand some of these common reactions and emotions.

Fear

Fear is a normal reaction to the unknown. Most parents have little previous experience with sick newborns; many are uncomfortable in the NICU environment and concerned about their baby. As a parent, you may also fear the possibility of serious illness, disability or even death. You may even begin to question your own ability to take care of your ill or premature baby.

Some parents also fear their friends’ and relatives’ response to the birth. Mothers sometimes fear their partner will blame them for a complicated birth and fear the loss of the relationship. Often mothers feel that their mother or their partner’s mother is judging them as responsible for the baby’s problems. It helps to know that most pregnancy and birth complications are not anyone’s fault and many NICU admissions are unforeseen. Fears and misgivings usually decrease over time, but most NICU parents feel apprehensive in the early part of their NICU stay.

Anger

Anger is also a common reaction to the initial NICU experience. Many parents feel angry at the hospital staff - both the labor and delivery staff and the NICU staff. You may feel angry that your birth experience did not go as expected, or you may be angry at your inability to control events in the NICU (“They just don’t know what they’re doing”), at your family and friends (“They just don’t understand”), and even your partner (“How can he go to work and just forget about the baby?”). You may even be angry at yourself (“Why couldn’t I carry this baby to term?” or “What did I do/not do to make this happen to my baby?”). As uncomfortable as it may be, you may also feel angry at your baby (“Why couldn’t you have waited for just a few more weeks?”).

Most parents of NICU babies feel some anger, and they express it in different ways. Some are openly angry, demanding and looking to blame others. Some want to retreat or run and keep their anger hidden inside. It may be difficult to acknowledge any anger, especially if that anger is directed toward your baby or partner.
To cope with anger, begin by acknowledging it to yourself, your partner and those around you. Realize that anger is a normal, expected emotion common to most NICU parents. By discussing your feelings with NICU staff, you may begin to understand why you feel this way. Are you upset with someone in particular, or is the situation itself the problem? By discussing your feelings, you can begin to make a plan to address the problems you want to confront or things you want to try to change.

Anger requires a tremendous amount of energy. As NICU parents, you will spend a great amount of energy just getting through each day - getting to and from the hospital, absorbing the vast amounts of information you receive, spending time with your baby, caring for yourself and your household, and coping with the common emotional ups and downs of having an sick or premature baby. Dealing with your anger can give you more energy to care for yourself and your baby.

**Guilt**

“It took us a long time to resolve our guilt. We asked the ‘what if’ and ‘why us’ questions for months. But we did nothing wrong. We had good prenatal care. What happened to us was nobody’s fault.”

Most parents express feelings of guilt after the birth of a sick or premature baby. You may ask yourself, “What did I do to cause this?” or “What could I have done to prevent this?” And nearly every parent unnecessarily laments, “If only I hadn’t ....” Mothers especially, examine their lives since the day they became pregnant, wondering if they could have changed the outcome by making different decisions or if their circumstances had been different.

For most babies in the NICU, the reasons they were born sick or premature are not known. Letting go of guilty feelings will give you more energy to care for yourself and your new baby. It is also important to share these feelings with the NICU team. Often the NICU team can provide answers and comfort.

**Loss**

Throughout your pregnancy, you probably had an image of your baby. For most parents, this picture was of a healthy full-term infant. Seeing your premature or ill baby for the first time may lead to feelings of loss for what you had expected. Most mothers of term infants report that they are glad their pregnancy is over; however, mothers of premature babies often mourn the end of their pregnancy. Mothers of premature babies frequently find that they miss feeling the baby inside of them and did not feel ready to give birth. NICU mothers may also feel jealous of women who are still pregnant, or mothers who have given birth to healthy term babies.

If your birth didn’t happen as you planned, you and your partner may also mourn the loss of that planned birth experience. Many couples today plan who will attend the birth, how the environment will look, how they will manage the labor process, and how much medical intervention they desire. Some write detailed birth plans to convey their desires to their care providers. Unfortunately, your preterm or complicated birth may have required an abrupt, unplanned change to your experience.

You may also feel the loss of your parenting role. Throughout pregnancy, you envisioned yourself as a parent. You pictured yourself and your partner playing with and caring for your baby. Now you must spend time with your baby in a foreign environment, touch your baby through an incubator porthole, and wait for someone else to tell you when it’s appropriate for you to hold or feed your baby. Letting go of what has been lost is an important part of your transition. Now you must develop a new dream of your growing family and different goals for marking progress. These new goals may be quite different (such as weaning off of oxygen or breastfeeding for the first time), and parents cannot set these new goals until they let go of the old dream of a healthy full-term infant.

It may take time to get over these feelings of loss. Many revisit these feelings frequently, sometimes for years, often around the time of their baby’s birth. Again, this is a normal reaction for many NICU families. As with anger, it often helps to discuss and acknowledge these feelings of loss. You may find it helpful to talk with other parents who have had a baby in the NICU. Your NICU team can help you identify possible support in your area.
**Powerlessness**

You find yourself in a strange environment, surrounded by high-tech equipment and a multitude of people caring for your baby. You want to comfort your baby, but you may not know what to do. These feelings of powerlessness are common in the NICU.

Begin by understanding that most NICU parents feel powerless, and acknowledge those feelings. If you are not yet comfortable with your baby’s nurses, you might begin by making observations and asking questions like, “My baby looks uncomfortable. What can I do to help her?” or “My baby’s lips are dry. What can I use to moisten them?” As you become more comfortable with the NICU environment and have experience touching and interacting with your baby, feelings of confidence will begin to replace your initial feelings of powerlessness.

Discuss your feelings with your baby’s nursing staff. They can often suggest unique ways for you to communicate with the NICU team and participate in your baby’s care. For example, providing breast milk for your baby is an important contribution to your baby’s care. Even if you had planned to formula feed later, you may want to consider breastfeeding now. Breast milk is especially important for sick or premature infants because it provides ideal nutrition and other benefits that help your baby heal and grow.

**Feeling “on display”**

Unlike most hospital rooms for children and adults, several NICU babies and their parents may share space in the same large room. Some parents say that this exposure makes them feel like ‘fish in a tank’ during their early experiences in the NICU. You may feel that others are watching your every move, and this loss of privacy can be stressful. The staff in the NICU are observing you to help you learn to care for your baby. They have special training with premature and ill infants and can observe the baby for signs of stress that you may not yet understand. In addition, other NICU parents may be watching you to identify you with your baby and to compare your circumstances to theirs. This socialization is part of the getting-to-know-you process in the NICU. The more familiar you become with the environment, the more comfortable you will be with the NICU staff, the routines and your ability to care for your baby. Your care and presence are known by your baby and are vital to your baby’s growth and healing.
ANXIETY and DEPRESSION

These illnesses affect up to 1 in 5 women during pregnancy or the first year postpartum. They are caused by changes in biology, psychology, hormones, and environment.

You are not alone. You are not to blame. With help, you will be well.

WOMEN EXPERIENCING THESE ILLNESSES SAY:

I’m supposed to be happy…why do I feel so sad?
I worry all the time.
Why am I such a failure?
I feel like the worst mother in the world.
Everything would be better if I got a good night’s sleep.
I’m having thoughts that are upsetting or scary.
Why can’t I ‘snap out of it’?
I want to run away.

SIGNS and SYMPTOMS

Overwhelmed
Anxious
Angry
Sad
Guilty
Irritable
Hopeless
Exhausted but can’t sleep

FREE Postpartum Support Group
Healthy Mommy Healthy Baby
The Children’s Hospital of The King’s Daughters
• 1st Tuesday afternoon of every month - specifically for NICU Moms
• 3rd Wednesday evening of every month - open to all Moms

Contact
HealthyMommyHealthyBaby@CHKD.org
(757) 668-7165
Meet other mothers - Learn coping skills
Identify resources

Postpartum Support Virginia (PSVAs)
helps new and expectant mothers and their families overcome anxiety and depression by providing FREE support, information and resources.
Visit Postpartum Support Virginia’s website to find:
• Support volunteers and support group
• Self-help and coping techniques
• Mental health professionals
• Additional resources

www.postpartumva.org
P.O. Box 7521, Arlington, VA 22207
703-829-7152

Children’s Hospital of The King’s Daughters
Social security low birth weight program

The social security low birth weight program is available to all families with babies weighing 1199 grams or less at birth. The CHKD NICU is fortunate to have an SSI representative who comes to the unit twice a month to help parents sign up for the program. Please be sure to check the monthly calendar for dates and times.

When you arrive in the NICU waiting room, please sign up on the registration sheet at 12:30 p.m. The representative will call parents in the order they sign up. Items to bring with you include:

- The completed form given to you by your social worker
- Your birth hospital proof of birth letter
- Picture identification for the parent (preferably a state issued driver’s license or a state issued personal identification card)
- Voided check or account routing information to arrange direct deposit (if possible or money will be put on a debit card)

If you are unable to attend a Wednesday session, you can contact your local social security office to begin the process. The social security web site is www.socialsecurity.gov.

After enrolling, please go downstairs to the CHKD Eligibility Office that same day to complete an application for the SSI VA Medicaid with Nancy Monroe, Doris Branch or Arnold Harrell. Please bring these items to this meeting:

- Proof of birth letter
- Picture ID
- Any insurance information you may have

Long term hospitalization Medicaid

Babies may be eligible for Medicaid through the long term hospitalization program if they are hospitalized more than 30 days. Please speak with your social worker for details on this program.

Transportation with Medicaid cabs and mileage reimbursement

If you or your baby is eligible for Medicaid, a Medicaid cab can be made available to you for transportation to the NICU. The phone number for contacting the cab is listed on the back of your Medicaid card. When calling, you will need to provide your Medicaid number, your destination (CHKD NICU) and explain that you need to meet with members of the medical team.

Transportation can then be arranged for you to go to and from the NICU on weekdays, generally during business hours, and possibly on weekends depending on available drivers. These cabs typically need 48-72 hours advance notice.

Mileage reimbursement may also be available through your insurance. You can call the number on the back of your Medicaid card or speak with your NICU social worker for more information.

Virginia Department of Medical Assistance Services Health Insurance Premium Programs (HIPP)

HIPP is a premium assistance program that may be available to people with Medicaid that helps pay part or all of their health insurance premiums. To contact DMAS for information regarding these programs or to submit an application, you may send an email to HIPPCustomerservice@dmas.virginia.gov. Application forms and additional information is available on the web at: http://dmasva.dmas.gov/Content_pgs/rcp-hipp.aspx
Developmental Care
Dear NICU Parents,

Congratulations on the birth of your new baby! I imagine you are feeling a little overwhelmed right now. Delivering a premature or medically fragile baby is unexpected and scary. You and your baby are going to learn a lot about each other over the next few months. One of the first things you will learn is how to read your baby’s behavior. Babies talk to us through their behavior. By watching their behavior, we can tell when they are feeling good and want to interact or when they are feeling bad and want to be left alone.

A baby’s brain does a lot of growing and developing between 24 and 40 weeks of gestation. To encourage normal brain growth and development, it’s important that your baby is comfortable, relaxed and stable. When your baby is stressed and uncomfortable, the brain can’t grow and develop normally. It’s important to recognize behaviors that tell us the baby is stressed so we can help them return to a non-stressed or stable state.

The next few pages show examples of the different behaviors your baby will exhibit. Also included are things you can do to help your baby feel better. I look forward to meeting you and your new baby!

Sincerely,

Your Developmental Care Specialist
The role of the developmental care specialist (DCS) is to promote normal growth and development of the preterm and term infant. This is achieved by providing developmentally supportive care. This includes:

- Recognizing behavior that indicates the preemie is stressed (unstable) and providing interventions that help the preemie return to a stable state.
- Ensuring the preemie is positioned flexed and midline by using positioning devices. This will prevent the development of abnormal movement patterns and promote self-regulation.
- Modifying the environment to decrease environmental stressors (bright lights, loud noise, frequent handling and interrupted sleep).
- Involving therapy services when appropriate to help the infant meet developmental milestones.
- Encouraging parents to provide daily skin-to-skin care because of the positive sensory stimulation it provides - as well as its neuroprotective properties.
- Involving parents in medical decisions, team rounds and daily care throughout the infant’s hospitalization.
- Maximizing the infant’s developmental potential within the constraints of the infant’s hospital course.
Parenting your premature baby in the NICU

One thing you are told as soon as you enter the NICU is that premature babies are not like term babies. They don't act the same way or want the same things. Nothing you already know about taking care of or soothing a baby is very useful right now. All of that knowledge will be handy someday, when your baby goes home, but what about now? How can you possibly parent this tiny baby? In addition to these suggestions about what you can do for your baby at various stages of development, your baby's nurse can provide additional guidance or instruction if needed.

Less than 26 weeks gestation

Even at this very young and fragile stage, your baby knows your voice and smell. Hearing your voice will soothe your baby. But be sure to keep your voice quiet. Your baby’s hearing is very sensitive.

Touching and holding:

- Hold your baby’s hand using gentle pressure. At this age, your baby will not like being rubbed or even lightly stroked. Your hand cupping his head (not stroking it) is a soothing touch.
- Place your finger in your baby’s hand for him to hold on to.
- You may not be able to hold your baby at this age.

Feeding:

- Begin collecting breastmilk as soon as possible if you plan to provide breastmilk for your baby.
- If your baby is given breast milk or formula at this age, it will be through a tube placed in his nose or mouth.

Sight, hearing and smell:

- Open the incubator door slowly so light changes are gradual. Your baby’s eyes and ears are extremely sensitive. Shield your baby’s eyes from bright or direct lights. Avoid loud sounds around your baby.
- Provide only one sensory input at a time, such as only touching or only talking softly, but not both at the same time.
- Protect your baby from strong odors such as perfume or scented lotions.

26-29 weeks gestation

Touching and holding:

- Touch slowly and gently without any sudden movements.
- Hold your baby’s hand using gentle pressure. Your baby will still not enjoy being rubbed or even lightly stroked at this age. Continue to provide containment for his arms and legs.
- Place your finger in your baby’s hand for him to hold on to.
- Kangaroo care (skin to skin contact) is recommended at this age as your baby becomes ready.
Feeding:

- Consider placing a cloth scented with mother’s milk in your baby’s bed during tube feedings. Be sure to clean this cloth just like other blankets and bedding.
- Offer a pacifier for very short periods. Baby will need help keeping the pacifier in his or her mouth.
- Your baby will still not bottle feed at this age.

Sight, hearing and smell:

- Avoid bright lights directed toward your baby’s eyes.
- Avoid loud sounds.
- Use a quiet voice when talking to your baby.
- Protect your baby from strong odors.

30-32 weeks gestation

Touching and holding:

- Prepare baby for touch with a soft voice.
- Do not stroke baby’s skin. Provide continuous, gentle pressure to his legs, upper body and head.
- Babies do not tolerate rocking at this age.
- Kangaroo care is recommended at this age.

Feeding:

- Provide opportunities for your baby to suck a pacifier as tolerated. This is in preparation for bottle or breastfeeding and is called non-nutritive stimulation.
- The environment should be calm.
- Baby may be put to breast in preparation for later breastfeeding. Speak with your baby’s doctor if you are interested in trying this.

Sight, hearing and smell:

- Talking, interacting and care should be done when your baby is awake or in a light sleep.
- Let your baby sleep whenever possible. They need this deep sleep to grow and get stronger.
- Avoid bright lights.
- Remain still when your baby is awake, as she is not yet ready to look at moving objects.
32-36 weeks gestation

**Touching and holding:**

- Continue to use continuous, gentle pressure when touching.
- Hold your baby still rather than rocking.
- Talk or sing in a quiet voice.
- Kangaroo care is recommended.

**Feeding:**

- If tube-feeding, continue to provide opportunities to suck a pacifier during feedings. Also, provide an opportunity to smell milk.
- Your baby will begin to work with occupational therapy in preparation to feed by mouth (PO feed).
- If baby is beginning to breastfeed, mom should continue to pump as well. The environment should be calm. Burp your baby gently without excessive patting.
- As baby begins to bottle feed, you will work with occupational therapy on the technique that works best. Hold baby mostly upright, so he can control how often he swallows. You will not hold a preemie in the traditional reclined position to feed. Keep the nipple still. Pause to gently burp as needed.

**Sight, hearing and smell:**

- Interact with baby when awake.
- Develop a regular pattern of care for feeding, diaper change and sleep in preparation for home.
- Provide dim light at bedspace during the day and darkness at night.

*From: Parenting Based on the Developmental Progression of Preterm Infants, 2006 Children's Medical Ventures, a subsidiary of Respironis, Inc.*
The benefits of Skin to Skin Care (S2S Care)

What is S2S Care?

- S2S Care is a special way of holding your baby.
- The baby, wearing only a diaper, is placed ‘skin to skin’ against your bare chest.
- A blanket or your clothes cover the baby’s back to help create a thermal pocket.

Benefits of S2S Care for baby

- Regulates baby’s heart rate and breathing – the rise and fall of your chest relaxes baby.
- Baby’s body temperature remains normal because your body adjusts to keep baby at the right temperature.
- Infections are decreased because antibodies created from S2S Care are passed to the baby via breast milk.
- Decreases crying and encourages a more restful quiet sleep. Babies in deep sleep use fewer calories, so the overall growth rate increases.
- More successful breastfeeding.

Benefits of S2S Care for parents

- Increases bond between you and your baby.
- Enhances parent confidence. S2S Care is something only parents can do.
- Less breast engorgement. Babies that experience S2S Care early breastfeed 50 percent longer and tend to breastfeed exclusively.

What parents need to know

- Both parents can do S2S Care.
- Many babies can begin S2S Care at a very early age. Discuss with your nurse when it’s best to begin.
- Wear a loose shirt or blouse that opens in the front.
- Prior to S2S Care, use the restroom, have a snack and drink and wash your hands.
- Your nurse will help you transfer your baby.
- A change in the baby’s vital signs may occur with the transfer but will return to baseline during S2S Care.
- Try to allow for 65 minutes of S2S Care so your baby can complete one sleep cycle.
- Call at the beginning of the shift and schedule a time to S2S Care.
- If baby is going to nuzzle at the breast, empty your breast prior to S2S Care.
What is quiet hour?

- Quiet hour is a designated time each day when the preemie is allowed one hour of uninterrupted sleep.
- No treatments or procedures are allowed unless it’s an emergency.
- No lab draws or x-rays are allowed.
- Lights are dimmed and noise levels are kept to a minimum.
- Parents may ‘kangaroo’ but should be in their chair before quiet hour begins and remain there the entire hour.

Facts:

- A preemie's sleep is interrupted an average of 132 times per day.
- Preemies spend less than 20 minutes a day in deep sleep and are essentially sleep deprived.
- Sleep deprivation can lead to high blood pressure, apnea, desaturations and feeding problems.

What are the benefits of quiet hour?

- It promotes deep sleep.
- It supports physiologic stability.
- It encourages growth and repair of brain tissue.

Quiet hour times:

12:30-1:30 a.m.
and
12:30-1:30 p.m.
Certified child life specialists

A certified child life specialist (CCLS) in the NICU is able to provide developmental play for your hospitalized baby. It is important that babies continue to have opportunities for play and exploration to meet milestones. The NICU CCLS can also provide support to siblings who are having a difficult time understanding why their brother or sister is hospitalized. The CCLS can identify specific ways to help the sibling feel involved and feel like a part of the team caring for your baby. Lastly, the NICU CCLS can provide legacy-building opportunities for your family. Even though your baby is hospitalized, it is important to document milestones (big and small).

Speech pathologists and occupational therapists

The role of the speech pathologist (ST) and occupational therapist (OT) in the NICU is to assess an infant’s pre-feeding skills and to assist when an infant is ready to begin, or is having difficulty, transitioning to oral feeding. Services provided by ST and OT include the following:

- Pre-feeding or non-nutritive evaluations
- Oral motor stimulation home programs
- Collaboration with the medical team for feeding readiness
- Feeding intervention (i.e. nipple adaptations, positional recommendations, therapeutic facilitation)
- Parent and caregiver education
- Determine the need for further intervention if patient continues to demonstrate difficulty transitioning to feeds (i.e. video swallow study, long-term non-oral feeding)

Speech pathologists and occupational therapists who work with medically fragile infants in the NICU have specific training to provide developmentally supportive care and support of infants in the transition to oral feeds.

Additionally, occupational therapists can provide passive range of motion support and splints to the upper extremities if needed.

Physical therapists

The role of the physical therapist (PT) in the NICU is to assess an infant of less than 32 weeks post-conceptual age (PCA) that may require assistance with state control, positioning, range of motion and developmental interventions. Services provided by PT include the following:

- State control: Helping baby tolerate being handled and to achieve quiet alert state with minimal stress signs
- Positioning: Involves encouraging midline positioning, preventing cervical rotation preferences and assisting with adaptive seating as appropriate
- Range of motion: Used to prevent or reduce contractures (increased muscle tone, clubbed feet, etc.) and torticollis
- Developmental interventions: Assisting with development of age-appropriate motor skills (i.e. head control, midline, tracking, tummy time, reaching and grasping and rolling)
- Parent and caregiver education
- Assessing the need for further interventions: Facilitating therapy services (ST/OT) as needed including recommendations for early intervention services upon discharge
- Car seat program: All PT and OT staff are child passenger safety certified technicians and assist with car seat needs as appropriate
Parent to Parent Support
Dear NICU Parents,

Welcome to the NICU from your parent support coordinators. We are two members of your support team who have walked in your shoes. We both had premature babies – Marnie had 28-week triplets and Maureen had 28-week twins – so we understand the emotions you are feeling, even if the circumstances of your baby’s hospitalization are different than ours.

We know how scary it is to walk into the NICU for the first time, how powerless to protect your baby you feel, how lost you feel at the bedside as the ‘experts’ care for your child. We know the guilt and even at times the anger, and we know the loss. The loss of a perfect pregnancy, the loss of a perfect delivery, the loss of bonding after birth, and the loss of being discharged without your baby.

So we are here for you. Whether you need to talk, want to find a primary nurse, need advice on advocating during medical rounds, or are confused about who’s who in this big unit, please stop by our “nook” across from the pump rooms, or ask your nurse to page us. We can help you learn your way.

We are also a part of many of the classes offered daily in the NICU. In addition to providing education about your baby, these classes are designed to help you meet and connect with other NICU families. No one knows what it’s like to be a NICU parent better than another NICU parent. Please pick up a calendar today and start coming to our many classes.

In addition to classes, we offer many programs to help normalize this very un-normal place: we have weekly scrapbooking, ways to earn NICU bucks to spend in our NICU store, or you can start your NICU journey beads.

So stop by any time to chat. We look forward to meeting you soon!

Sincerely,

Your Parent Support Coordinators

Your NICU Parent Support Coordinator
phone number:

(757) 668-8016
When your baby is admitted to the NICU, one of the most important things you can do is learn all you can about his or her care. NICU University was created to help you learn. We have the ability to text you reminders about classes and groups. If you have not signed up to receive text reminders about classes, see your social worker or one of the parent support coordinators to sign up.

Below is a listing of our regularly scheduled NICU classes. Occasionally additional topics are offered, so be sure to pick up a calendar in the NICU waiting room for complete details.

**Dine & Discover**

Dine & Discover is our twice monthly support dinner for families. Each dinner features a NICU topic to help you learn more about the unit. We provide dinner and give you the chance to get to know some other NICU families. Look for signs throughout the unit with the topic and location details. All are welcome. No pre-registration needed.

**Just Keep Swimming!**

Ever feel like you’re swimming upstream? Learn to cope with the ups and downs of the NICU from a mom who’s been there.

**Welcome to the NICU orientation**

Whether you’re a new parent or have been here for a while, please join us in the NICU waiting room every Monday at 11 a.m. to get to know your fellow NICU parents. No one understands what it’s like to be a NICU parent better than another NICU parent. You can also meet graduate parents who can give you some helpful hints.

**Discharge Q&A**

At Discharge Q&A, you will have the opportunity to ask one of our discharge planners all the questions you have about discharge. Whether your baby is still in an isolette and you’re wondering about the process, or if you’re close to actually going home, this class is for any NICU parent.

**Mommy Care**

Mommy Care is a group just for moms. Some topics include: Guilt, Grief and Moving Forward: This is NOT What I Expected, Celebrate Your Baby and Can’t Shake Those Baby Blues. Mommy Care will help you recognize the losses associated with your baby’s birth and hospitalization and all the many emotions you might experience along the way, including sadness, guilt, anxiety, grief and powerlessness.
Healthy Mommy, Healthy Baby postpartum support group (facilitated by NICU social workers)

The number one complication of pregnancy and childbirth is anxiety and depression. Join us the first Tuesday of each month for support, to meet other moms and to learn coping skills. You are not alone. You are not to blame. With help, you will be well.

Cues & Signals and Skin 2 Skin

By using non-verbal communication, your baby can tell you when he's stressed, alert, calm or in pain. In this class, you will learn to read those cues and signals, so you can soothe your baby if he's over-stimulated or interact effectively if he's alert. You will learn about infant brain development including all the benefits of holding your baby skin to skin. This class is taught by our NICU developmental care specialist.

CPR and Infant Safety

This class is required for discharge. You will be contacted to schedule it as you get closer to going home, or you can sign up for a class at any time with the NICU receptionist.

Scrapbooking

Scrapbooking is offered every Friday during the day. All supplies (except your photos) are provided.

NICU Bucks

NICU bucks are certificates you can spend in our NICU store. You can find baby clothes, toys, blankets, books, hats and more in our store, which is open every Wednesday.

Every time you come to any of our NICU classes, groups or activities, you can earn one NICU buck. The more you learn, the more you earn.

Check out our calendar and get involved in NICU University today.
NICU journey bead program

Over the course of your baby’s time here, your family will endure ups and downs, overcome challenges and celebrate milestones. Your baby may be here for days or months. Each baby’s journey is unique and should be celebrated and honored.

Our journey bead program gives you the chance to document your baby’s stay in the NICU through colorful beads that tell his or her story. Over time, the necklace you create will become a testament of your baby’s individual experience in the NICU.

Participation in our journey bead program is completely voluntary. If you wish to participate, please let your social worker or one of the parent support coordinators know, and they will help you get started, or help you add to your bead story as you journey through the NICU.

Each participating family will receive:

- A length of cord for the beads
- A CHKD admission bead
- Letter beads for your baby’s name

You will then earn beads for many NICU firsts and milestones, like pumping, changing a diaper, bottle feeding, respiratory support, wearing clothes, moving to an open crib and many more.

At the time of discharge, you will complete your string with beads for passing the car seat test, a graduation cap and number of days in the NICU.

Please use your journey beads to help explain to friends and family all ups and downs of your baby’s NICU experience.
The NICU has a very active family advisory council, made up of parents of NICU grads and bedside nurses. They work together to make positive changes in the NICU. Some of their projects include the NICU wall of fame, the NICU reunion, the journey bead program, and NICU University.

Here is some advice to you from our family advisory council parents:

- Stay connected, it will help you bond with your baby ... visit as much as possible and call when you can’t visit. Try to establish a routine.
- When you call, ask for the schedule for the day including the best time to come in (during hands-on to participate) or the best time to kangaroo.
- Write down questions; keep an ongoing list with you. A journal is also helpful and therapeutic.
- Meet the medical team and participate in rounds as often as possible. You will learn the plan and can advocate for your baby. Ask your baby’s nurse to help you come up with questions to ask at rounds.
- Take care of yourself.
- Ask the nurse to help you learn. This will help develop a trusting relationship with the nurses and give you confidence to care for your baby. You can change diapers, take temperatures, help change the isolette, perform oral care and much more as your baby gets stronger.
- Watch your baby ... learn her signals so you can recognize when something isn’t right.
- Participate, practice and observe. This will give you confidence when your baby goes home.
Planning for discharge
My checklist to go home

Please be sure to check off the following items as you complete them.

☐ I have completed CPR/infant safety.

☐ I have bathed, diapered and dressed my baby.

☐ I know how to take a temperature.

☐ I have successfully given medication to my baby, know the dose, how often to give the medication and what the medication is for.

☐ I have fed my baby and feel comfortable feeding my baby.

☐ I have received the recipe to fortify the milk and understand how to fortify breast milk or formula.

☐ I have brought in a car seat, and I understand that my baby will need to pass a car seat test before discharge.

☐ I have selected a pediatrician for my baby and informed my case manager of my selection.

☐ I am familiar with any specialized equipment or care my baby may need and have received adequate training on that equipment.

☐ I understand that I need to bring a copy of my driver’s license or ID on the day of discharge.

☐ I understand my baby will be administered a hearing screen before discharge and I will be informed of the results.

Questions I still have about going home:

1.

2.

3.

4.
Choosing your baby’s pediatrician

As a parent, you make countless choices that affect the health and well-being of your baby. Among the most important is the selection of a pediatrician. At CHKD, we offer a free physician referral service to help parents find the very best pediatric care for their child.

Children's Health Line has complete information on the region's pediatricians and pediatric specialists. Through our extensive referral system, we can recommend the doctor who best meets your child's specific needs and your needs. Children's Health Line can be accessed by calling (757) 668-7500 or by email at healthline@chkd.org. You can also get a list of CHKD pediatricians in the waiting room of the NICU or in the fishbowl office.

Families differ when it comes to what matters most when choosing a pediatrician, but here are some things to consider:

- What training does the provider have? Is he/she a board-certified pediatrician?
- Is the pediatrician’s office located near your home or work? Are the office hours convenient to your schedule?
- What do you do if your child is sick or injured when the office is closed?
- Is the doctor in a group practice with other physicians? Will you see the same physician each time you visit?
- Is the practice accepting new patients? Do they take your insurance?
- How are visits for illnesses handled? Are you able to make an appointment on short notice if your child needs to see the pediatrician because of a sore throat, fever or earache?
- Does the doctor communicate clearly and make an effort to ensure that all your questions are answered?
- Is the office staff friendly, courteous and helpful?
- If your child ever develops a condition that requires the care of specialists, will your pediatrician coordinate care among all the doctors providing treatment?
- Most importantly, are you comfortable with the doctor’s style and philosophy of care? Your pediatrician will be your partner and advisor in the care of your new baby. You should feel that you can ask anything and your concerns will be handled with respect and compassion.

The process of selecting a pediatrician isn't difficult, but it's a good idea to start early so you can take your time and make the best decision for your family. Many pediatric practices offer free visits, or special events, for parents to tour the office, meet providers and staff, and ask questions.

Important: As soon as you select a pediatrician, let your social worker or case manager know the physician's name and practice.
Selecting a daycare

There are many factors that go into choosing a daycare for your baby. It is important to find a provider that fits your budget, but finding a daycare that is safe and nurturing is also essential.

In addition, it is important to remember that many NICU graduates benefit from a smaller daycare setting where germs may be less prevalent. When interviewing potential providers, please consider the following questions:

• Is the environment safe?
• Will it contribute to my child’s development – socially and educationally?
• Are caregivers trained in CPR and infant safety?
• Do caregivers practice safe sleep techniques?
• Are background checks conducted on all employees?
• Do you require or provide child development training for your employees?
• What is the baby to teacher ratio?
• Is the business licensed or accredited?
• What is the licensed capacity of your daycare?
• How do you communicate with parents?
• Do you utilize good hand hygiene?
• How often are toys cleaned?
• What is the policy when children get sick?
• Are you able to accommodate my child’s special medical needs (if applicable)?
Before going home

Hearing screen

Hearing screens are performed prior to discharge from the NICU. This hearing screen is required by the Commonwealth of Virginia, and it is the first step in identifying potential hearing problems. If additional follow up is required post-discharge, an appointment with a hearing specialist will be made for you by your discharge planner.

Vision screen

Preemies are at a greater risk for retinopathy of prematurity (ROP). This is an eye disease which results from the abnormal development of blood vessels in the retina (the lining inside the back of the eye). Preemies born at less than 28 weeks gestation are at the greatest risk for ROP. Detecting problems early can lead to better outcomes, so our preemies’ eyes are followed very closely while they are patients in the NICU. A pediatric ophthalmologist will continue to follow preemies’ eyes after discharge. An appointment will be made for you by your discharge planner.

Car seat test

Most babies discharged from the NICU will be evaluated for 90 minutes in a car seat that you provide. Your baby will successfully pass this car seat test if he fits properly in the seat and does not have any apnea or bradycardia during the 90 minutes. If your baby does not meet these criteria, an occupational therapy consult will be ordered and the therapist will make suggestions so your baby can safely go home.

CPR and infant safety

Please plan to attend a CPR and infant safety class prior to your baby’s discharge. Anyone caring for your baby is welcome and encouraged to attend this educational class. Classes are offered Tuesdays and Thursdays at 10 a.m. and twice a month at 5 p.m. on Wednesdays. You can sign up for a class with the receptionist.

ALTE Watch

As your baby gets closer to discharge, you will hear the health care team mention an ALTE Watch. This stands for acute life threatening event. During an ALTE, your baby may experience a drop in heart rate, saturation or respiration, either by itself or all at one time. This is also known as apnea and bradycardia. Your baby must free from apnea and bradycardia for seven days prior to discharge. If your baby has an event during this watch period, the watch will be reset and the seven-day count started over.
Breast Milk/Formula Preparation

As you approach discharge, please ask your baby’s nurse and his dietitian to teach you the proper way to fortify breast milk or mix formula to the proper calorie level. This is a very important step in your discharge learning process, so ask to practice it at the bedside until you feel comfortable.

Immunizations

Your baby begins to receive immunizations while in the NICU based on the age recommendations of the Centers for Disease Control. You will receive information on each immunization, so please let the medical team know if you have any questions. Your discharge planner will make your first pediatrician appointment for you following your baby’s discharge from the NICU, and your pediatrician will continue the immunization schedule.

Rooming in

Once your baby is on full feeds and you have completed a CPR and infant safety class, you are able to room-in with your baby prior to discharge if you choose to do so. Rooming in gives you the opportunity to independently care for your baby before going home.

Rooming in is from 8 p.m. to 8 a.m., and you will provide all care to your baby overnight, while she is monitored remotely by a nurse. You must remain with your baby at all times while you room in.

Arrangements can be made for rooming in with the charge nurse or your bedside nurse.

Equipment needs

If your baby will be going home with any equipment, like oxygen or a feeding pump, you will receive extra training on those items. Your case manager will coordinate with a home health agency to deliver the equipment to the hospital and train you on how they work. They will also deliver supplies to your home. In many cases, it’s a good idea to room-in with your baby using the equipment you will have at home to help you gain confidence in providing that care.

Discharge paperwork

On the day of discharge, you will review any specialized teaching, including mixing formula/fortifying breast milk, with the nurse. The recipe for mixing the formula and/or breast milk will be included in your paperwork. You will also review drawing up to the correct dose and giving any medications your baby may need, including vitamins. You should bring your baby’s medications with you on the day of discharge.

You will also receive a discharge summary. This document is a summary of every issue your baby has encountered since birth and whether it is resolved or ongoing. Please be sure to keep a copy of this summary with you as you go to first appointments with caregivers outside the hospital.

Your case manager will make of all of your baby’s first appointments for you, and you will receive a list of these scheduled visits on the day of discharge. This includes the name of the provider and the date, time and address for the following:

- Pediatrician appointment
- Any specialist appointments, including ophthalmology
- A date for a NICU follow-up clinic appointment, if your baby qualifies
NICU follow-up clinic

The NICU runs a follow-up clinic to monitor the development of babies born prematurely or with other complications/diagnoses. If your baby is identified as a candidate for the clinic, your first appointment will be about a month after discharge.

The clinic is staffed by NICU registered nurses, a neonatologist, a neonatal nurse practitioner, a social worker and a developmental pediatrician. For the first few years of life, this team will do developmental testing to be sure your baby is receiving all the services he needs to catch up developmentally, and to be sure you are coping with the stress of bringing home your NICU baby.

Early intervention

Early intervention (EI) services are provided to babies who are born prematurely or with other diagnoses. If your baby qualifies for EI services, you will be asked to sign a consent for the NICU to send your baby’s medical record to the EI office in your home city. Then, once your baby goes home, your local EI office will call to schedule an assessment to determine eligibility for services. Services can include PT, OT and/or ST, depending on the needs of your child. If your child qualifies for services, your therapists will come to your home and teach you various techniques to help your child progress. This program is available through age three.

Care Connection

Care Connection for Children, sponsored by the Virginia Department of Health, is a statewide network of regional programs that provides healthcare services, community support and resources to children with special healthcare needs. The team-based approach pulls together case managers, medical personnel educators and family members to determine how children with special healthcare needs can reach their maximum potential. Care coordinators connect families with local healthcare providers, specialized health insurance programs, resources from the community and other families experiencing similar situations. You can reach Care Connection for Children at (757) 668-7132.
Discharge reminders for babies receiving SSI

If you applied for SSI (low birth weight program) for your baby, you must contact your local social security office when your baby is discharged and notify them of the discharge date. If you continue to receive SSI and Medicaid when you are not eligible, you will be required to pay the money back.

In addition, if you applied for SSI or if your baby is already receiving SSI, you must go to your local social security office after your baby goes home in order to determine continued eligibility. This is important because you may receive an increase in benefits once your baby is home.

When you go to your local social security office, please bring these items:

- Your baby’s discharge summary
- Your baby’s social security number
- Pay stubs to show your income
- Any bank account statements you have
- Information on any other income you receive
- Your personal identification

This must be done within 30 days of discharge. Remember, to re-apply you must go into the social security office to see a claims representative. This cannot be done over the phone. Be sure to write down who you talked with and when.

Phone number for SSI questions:

1 (800) 772-1213

website:

SSA.gov
Caring for your baby at home
Congratulations on taking your baby home! Here are answers to some questions that are commonly asked by parents of NICU graduates:

**What are the most common reasons to take my baby to the pediatrician or the emergency room?**

At any time in the first month, you should take your infant to the pediatrician or emergency room for the following:

- Dehydration – your baby should have 6-8 wet diapers per day
- Feeding issues – when your baby doesn’t get enough calories to gain weight and grow
- Fever – a rectal temperature of over 100.3 degrees

*Always call your pediatrician with questions or concerns about your baby.*

**Most common reasons for readmission to the hospital:**

- Respiratory issues
- GI (stomach) issues

**What can I do to help keep my baby healthy?**

Expect to live quietly with your infant at first. Their immune systems (primarily preemies) are still developing and they are at risk for infections.

- Limit visits from friends and family
- Practice good hand washing habits for all individuals in contact with your infant
- Avoid public places with preemies
- Always keep your infant’s immunizations current

**How often does my baby need to eat, and how can I tell if he’s getting enough breastmilk or formula?**

- Feed your infant about eight times a day
- Monitor for voiding and stooling patterns, and if they change, discuss with your pediatrician. Infant’s usually have 6-8 or more wet diapers a day and usually stool at least once a day. Breastfed babies stool more often.
Can I let my baby sleep on her tummy?

- Always put your baby to sleep on her back and alone in a crib, or in a safety approved pack 'n play or bassinet.
- Remember front to play for your infant and back to sleep.

I really enjoyed kangaroo care in the NICU. Is my baby too big to do skin to skin once I take him home?

You can still practice kangaroo care at home.

- In a warm room in your home, dress your infant in only a diaper then place the baby on your chest and turn your baby's head to one side so that his or her ear is against your heart. This enhances bonding and promotes health and breastfeeding success.

Respiratory Syncytial Virus (RSV)

What is RSV?

RSV is a virus that causes cold-like symptoms in people of all ages. RSV can cause a serious lung infection in infants and young children. RSV is most common during the winter months. Most children will get RSV by the age of two.

How can my child get RSV?

RSV, like other cold viruses, is easily spread by touching, kissing and shaking hands. Sometimes it can be spread by close contact with a person who is sneezing or coughing or touching things that have RSV on them. The most common way to spread RSV is by hand contact. People catch RSV from other people who have colds caused by RSV.

Who is at risk?

- Premature infants born ≥ four weeks early
- Babies born under 5.5 pounds
- Infants who attend daycare
- Infants who live with school-age siblings
- Infants with a history of chronic lung disease
- Serious heart disease
- Neuromuscular disease
- Family history of asthma
- Exposure to smoke

What are the symptoms of RSV?

- Runny nose
- Coughing that does not stop
- Fussiness
- Increased tiredness, less activity
- Lack of appetite
- Loud or fast breathing
- Wheezing (a tight whistling or musical sound heard when your child breathes)
- Your child’s chest sinks in or his nostrils flare with each breath
- Low grade fever in some children
- Difficulty breathing, gasping for breath, bluish color around mouth or fingernails
• **Worsening symptoms can be life-threatening, so it is important to prevent RSV.**

**How can I prevent my child from getting RSV?**

Take these steps to prevent the spread of RSV:

- Always wash your hands before touching your baby
- Ask other people to wash their hands before touching your baby
- Wash with soap and water or alcohol rub
- Keep your baby away from crowds
- Keep your baby away from people with colds
- Wash your baby’s toys and bedding often
- Keep your baby away from smoke
- Protect your baby with a medication called palivizumab (Synagis®)

**What is Palivizumab (Synagis®)?**

It is a medicine to help prevent RSV infections and is given as a shot into the baby’s thigh muscle.

**How does it work?**

Each dose helps the body’s immune system fight viral infections for about one month.

**How often is it given?**

It is usually given in 1-5 shots each month, depending on your child’s age during the RSV season.

• **It is important for your baby to get all the required doses.**

**Will Synagis® hurt my baby?**

There are very few side effects of this medication. There will be some discomfort with the injection. As with any other shot, you may notice warmth, redness or a little pain at the injection site.
Important phone numbers

Keep any important phone numbers handy at all times. Here are some numbers that you may want to include in your list:

- Poison control
- Pediatrician
- Other specialists
- Care Connection for Children: (757) 668-7132 or (800)-864-8903
- Early intervention
- NICU follow-up clinic: (757) 668-9410
- Insurance provider
- WIC
- Medicaid transportation: (757) 668-8000

Follow-up appointments

It is very important that you keep all of your follow-up appointments after discharge. Please list your baby’s first appointments after leaving hospital below:

1. 
2. 
3. 
4. 
5. 
Glossary of terms
Glossary of terms

**Anemia** - Abnormally low number of red blood cells.

**Apnea** - When breathing stops for 15 seconds or more. Sometimes the heart rate drops also. The nurse may rub or pat the infant to stimulate breathing.

**Aspiration** - Breathing or inhaling fluid such as amniotic fluid, meconium or formula into the lungs.

**Alarms** - All the equipment has some type of alarm system to alert staff of potential problems. With that said, if the nurse isn’t worried, you needn’t worry. The desk area has a central monitor where the bedside nurse can monitor your infant. She can also monitor your infant at another patient’s bedside by pulling up that information on the monitor screen.

**Bilirubin** - A byproduct from the breakdown of red blood cells that can cause a yellow coloring of the skin called jaundice.

**Blood Gas Test** - Measurement of levels of oxygen, carbon dioxide and pH using a small amount of blood. Results are used to monitor how well the infant is responding to therapy.

**Bradycardia** - A slow heart rate, usually less than 100 beats per minute. Sometimes the infant needs stimulation to bring the heart rate back up.

**Culture** - A lab test done on blood, mucus, urine or spinal fluid to test for the presence of infection.

**Dextrostick** - A test to measure glucose or sugar in the blood. The blood is usually obtained from a heel prick.

**Endotracheal (ET) Tube** - A clear plastic tube that is passed through the mouth between the vocal cords and then into the windpipe. Breaths from the ventilator are given and mucus can be removed through this tube.

**Gestational Age** - An estimate of an infant’s age in weeks from the time of conception.

**Post Conceptual Age (PCA)** – Gestational age plus chronological age (age in weeks since birth). Example: an infant is delivered at 24 weeks gestation and is now 4 weeks old. Infant’s PCA is 28.

**Corrected Age or Adjusted Age** - Chronological age in months minus the number of months premature. For example, if an infant is now four months old, but was born three months early, the corrected age is one month.

**Hyperalimentation (TPN)** - A special IV solution that contains vitamins, glucose and nutrients that is given to infants who are not feeding or are only feeding small amounts.

**Intralipids** - An IV solution that contains fat used to provide calories during hyperalimentation.

**Intraventricular Hemorrhage (IVH)** - Bleeding occurring in the inner part of the brain, near the ventricles, where blood vessels that are very fragile are prone to rupture and bleed.
Nasal Continuous Positive Airway Pressure (NCPAP) - Special prongs are placed in the infant’s nose for air and oxygen to be given at a certain pressure. The pressure helps keep the small air sacs in the lungs open, helping the infant breathe easier.

Necrotizing Enterocolitis (NEC) - An intestinal disease in which portions of the bowel are damaged or destroyed because of poor blood flow, inflammation or infection.

NPO - Abbreviation for the words “nothing by mouth” which means the infant is not taking any milk or formula.

Patent Ductus Arteriosus (PDA) - An open blood vessel near the heart and lungs which is a necessary part of a fetus’ circulation. A PDA should normally close a few days after birth. If it lingers it can cause breathing difficulties and some heart failure.

Percutaneous Intravenous Central Catheter (PICC line) - An intravenous line (IV) fed through a vein to a location close to the heart. The line can remain in place for up to 30 days.

Pneumothorax - Refers to air or gas in the chest cavity that result in collapse of the lung on the affected side.

Premature Infant - An infant with a gestational age less than 37 weeks.

Reflux - A backward flow of stomach contents into the throat.

Respiratory Distress Syndrome (RDS) - A common lung disorder of premature infants in which there is a tendency for the tiny air sacs in the lungs to collapse.

Retinopathy of Prematurity (ROP) - An eye disease of preemies in which new blood vessels grow abnormally near the retina causing temporary or permanent damage.

Sepsis - An infection in the blood or tissues that may require antibiotics.

Suction - Removal of gas or fluid by mechanical means.

Ventilator - A special machine that helps an infant breathe when they can’t breathe on their own. Air and oxygen are given through an endotracheal tube (ET tube) which rests in the infant’s windpipe. Settings on the ventilator are adjusted based on the infant’s blood gases.

Vital Signs - Refers to the measurement of temperature, pulse, respirations and blood pressure.