## CONVERSION CHARTS

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WELCOME TO THE NEIGHBORHOOD!

Welcome to the state-of-the-art Neonatal Intensive Care Unit (NICU) at Kentucky Children’s Hospital (KCH). The NICU has six neighborhoods designed to meet the special needs of our tiniest patients and their families. KCH has more special care neighborhoods outside the NICU, as babies move from special care to home.

We know having a baby in the NICU is stressful. We have a dedicated care team to support you, your family and your baby. We want to make your stay as safe and comfortable as possible.

This guide will help answer some common questions and help you know what to expect in the NICU. If you have any questions or concerns, feel free to ask any member of your baby’s care team at any point in your journey.

You play an important role in your baby’s care. You are part of the team. We are grateful to partner with you to care for your baby.

OUR PROMISE TO YOU

We promise to treat your baby with as much care as we would our own. We will treat you with respect and will keep you informed of the care plan for your baby each day. Your baby needs you to help with his or her care. We will do all we can to support you. Our goal is to get your baby home as quickly and safely as possible. To do this, we will prepare you to care for your baby. We promise to teach you how to help your baby thrive.

Neighborhoods are shown in order – below is north to south: Blackberry, Squirrel, Fish on north side; Warbler, Elk and Coneflower on the south.
**BEING WITH BABY**

Parents or Guardians are welcome any time. The first time you arrive, the clerk at the check-in station will ask for a photo identification that shows you are the parent or guardian. After checking, the clerk will hand you a blue sticker. Please wear the sticker the entire time while you are in the NICU. It lets the health care team know who are parents and guardians. Each time you come, please stop at the check-in desk to get a blue sticker. These steps are important for the safety and security of your baby.

**Having Guests**

Special Support Guests are two people whom you as parent(s) or guardian(s) identify to us. They will remain the same during your baby’s NICU stay. Support guests are people who can hold and help care for your baby. They cannot make medical decisions. They may receive only a short update on the baby. Support guests are welcome between 9 a.m. and 9 p.m. They will need to show a photo identification on the first visit. After the first visit, they must stop at the check-in desk to receive a green sticker to let them visit. Support guests are good to have because they let you as parents or guardians take a break. They can care for your baby when you are unable to make it.

Grandparents (this includes grandparents, great grandparents and step grandparents) are welcome to visit with parents at any time between 9 a.m. and 9 p.m. They do not need a green sticker to do so. Parents or guardians may choose grandparents to be special support guests. If grandparents are special support guests, then they will need a photo ID and must wear a green sticker to visit when a parent or guardian is not present.

Some parents or guardians want several people to be able to visit their baby. In that case, you may not want to make grandparents support guests because of the limitation of only two identified support guests.

It is important for your baby that we maintain a calm environment. We understand families want to be able to see the baby together, but we must limit visitors to only three people in the room at a time.

To decrease the risk of infection, we strongly recommend you limit the number of people who visit your baby.

**Brothers and sisters**

We welcome siblings to see their new brother or sister. We have information to help older children understand the ups and downs of a NICU environment.

Siblings ages 3 through 12 require a 24-hour notice for the first time. Let the nurse know when you plan to bring a sibling. This notice lets the nurse tell the Child Life Specialist, who will meet with your child/children before seeing the baby. A trained Child Life Specialist uses dolls, medical supplies and photos to help your older child/children understand why their brother or sister is in the NICU.

After this meeting, a sticker is placed in your baby’s chart and your older child/children can visit between 9 a.m. and 9 p.m. Guidelines may change during flu season or if other health safety requirements are in place.

Because the babies are small and often have complicated health conditions, we need your help to decrease the number of illnesses brought into the NICU. To decrease risks of getting your baby or other babies sick, we will complete a health screen on children under the age of 13.
The health screen consists of the following:

- Parents bring updated immunizations records.
- All siblings must have had the chicken pox or received the vaccine.
- Children cannot have a fever, cough, runny nose, rash or stomach illness.
- Temperature will be taken by a nursing tech.

This important health screen will help protect your children, yourselves and the health care team.

As you know, younger children have shorter attention spans. A calm environment is important for your baby to rest and heal. Plan on sibling visits to last one hour or less. We recommend parent(s) or guardian(s) read a book or enjoy other quiet activities to bond with your child/children in the moment. (The Pediatric Health Education Center has books and additional resources that may be helpful.)

Siblings who are 13 years and older may visit with parents or guardians before 9 p.m. Please make sure children have no cough, runny nose, colds, rash or stomach illness. You are welcome to share health information with your children. If you need or would like help explaining, please ask a member of the healthcare team.

**Hand washing**

Please remind all visitors to thoroughly wash their hands when entering your baby’s room (basins are located inside the door). Handwashing will reduce germs and risk of infection.

**Flu season**

For everyone’s safety, October to March visitation is limited to parents or guardians, grandparents and two support guests. Limiting visitors protects your baby, you and the health care team.

**WAYS TO STAY IN TOUCH**

We know there may be times when you cannot be here. There are ways you can stay connected to your baby.

On your first visit, your nurse will ask you to select a passcode. You will use it when you call to check on your baby. We can only give information about the baby to a parent or legal guardian over the phone. Please do not give your passcode to others.

**How to call your nurse**

- To call your nurse, you must call the NICU clerk first at 859-562-1010.
- The clerk will then transfer you to the nurse caring for your baby.
- If the nurse cannot pick up the phone, please call back. The nursing phone system does not let the phones transfer back to the clerk. If you call the clerk again, you may be transferred to a hallway phone to try to reach a team member close to your baby.

**NicView cameras**

We have cameras in every patient’s room. These allow parents, guardians and their families to check on their baby when they are away from the hospital. To set this up, please check in at the NICU clerk’s desk. They will give you login information for this service.

If you have any questions or concerns about your baby’s camera, please call 1-855-642-8439 (this is the camera company).
Since it is our goal to provide an encouraging and healing place, we must respect the space and each other. It is important we all work together to keep every baby safe.

The map provided shows a layout of the main NICU. As you can see, it is divided into six neighborhoods with individual rooms and shared family space. Restrooms are located throughout the unit. Your nurse or a staff member can help you locate areas.

Your baby will have a private room. One parent will be able to stay in the room with your baby if you would like. Each room has a bed and chair and a breast pump for mom’s use. The bed functions as a couch during the day, and there is a TV in every room. A curtain is available for privacy when sleeping or pumping breast milk. However, you should keep in mind that the room has glass doors and that the NICU is a public area. You will want to wear clothing suitable for public areas. For your own safety and comfort, you should always wear shoes in the hospital.

We want you to be part of your baby’s care while you are here. Please be up and ready for your baby’s first care in the mornings (usually 8 a.m. or 9 a.m.).

We know that taking breaks is important for parents and families. You may use the family area or visit one of our cafes for your meals. Food and drinks other than water in sealed containers cannot be in the baby’s room. This is important to keep a clean and sanitary space for your baby to get better.

For your comfort and convenience, our NICU has shared family space. It includes two family lounges with TVs, a kitchenette, showers and a laundry facility. The kitchenette has a microwave, refrigerator, and an ice and water machine you can use. The areas are open and available for use 24 hours a day, every day.

You may store food in the storage bins provided next to the cabinets or in the refrigerator. Please mark or label your items with your baby’s name and write the date that you place them there. The area is cleaned on a regular basis, and unmarked items will be discarded. We want to keep the space clean for everyone to use.

The showers and laundry facilities are next to the kitchenette. Towels, washcloths and toiletries are available for showering, and detergent is available for doing laundry. Ask a nurse or clerk where to find these items.

Behavior expectations
UK HealthCare is committed to the safety and well-being of our patients, visitors and staff. Our focus is to ensure a healing environment. It should be free from behavior that is wrong or disruptive – anything that would interfere with giving safe, quality patient care.

This “Your Safety First” approach puts a priority on keeping everyone safe. It includes a Zero-
Tolerance Policy for disruptive or aggressive behaviors. Examples of these behaviors include, but are not limited to, any verbal abuse or harassment, angry outbursts, physical aggression, threats of violence, or fighting. We take these very seriously. We have procedures that guide our healthcare team on how to respond properly and report when these types of behaviors happen.

As parents/guardians of a pediatric patient at UK HealthCare, you will receive information about “Behavioral Expectations.” It will explain your responsibilities as parents/guardians and our responsibilities as your healthcare provider. When you sign the form, you agree that you understand your responsibilities.

If the parent/guardian does not meet these expectations, the hospital can take action. To maintain a safe, calm healing environment it is possible that the parent/guardian would be restricted from entering the NICU and would not be allowed to visit.

**Partners in Care**
An unfamiliar place can cause us to feel anxious or unsettled. There are several things to keep in mind that will help decrease stress and anxiety. Your baby and you need rest. Take time to care for yourself. It is OK to take breaks or ask for help or support. As a parent in the NICU, you have access to a member of the Family Support Team who has resources and can offer creative and relaxing activities. If you are interested, please ask a member of your care team, and they will be able to connect you to a support team member.

If you need a break, the hospital offers places where you can go to relax. You may wish to visit the large **KCH lobby outside the NICU, the atrium on the ground floor, one of our courtyards or chapels.**

Our dining areas, or exhibits within the hospital offered through our Arts in Healthcare program. Your baby in the NICU is special and comes with particular needs — let your nurse help show you how to care for your baby. Nurses are excellent at making a routine that includes care, feeding and a quiet space.

As parents, your help is needed to establish a routine for your baby. The nurses will ask you to help care for your baby. This will help you get comfortable and confident with providing what your baby needs. (See section [link] on Caring For Your Baby.) However, let your nurse be your guide. Before you pick up or accidently overstimulate the baby, talk to the nurse. Interruptions may cause medical stress to your baby. **Caring for a NICU baby** is often overwhelming. Let the team teach you to reduce stress for your baby and for you.

You are your baby’s advocate and biggest voice. It is OK to ask any questions and to speak up for your baby when you have concerns. As a member of your baby’s health care team, we want you to be involved in the daily multidisciplinary rounds. Daily rounds are a time when all your baby’s caregivers meet to talk about your baby’s health. This will give you a chance to ask questions about your baby’s care and progress. It also lets you have input into the plan of care. These rounds are usually between 9 a.m. and noon every day.
Things to remember

Please keep the following in mind as we work together to keep our neighborhoods safe and nurturing for everyone.

- If you use tobacco products, you may not know that after use, chemicals stick to your clothes and body (also known as “third-hand” smoke). This is not healthy for your baby. Resources are available to help you stop the use of tobacco products (including dip, chew, cigarettes and e-cigarettes). Ask your nurse if you would like information about these resources. If you do use tobacco products, please put on a gown and wash your hands for the safety and health of your baby.

- Safety is a priority in the NICU. For the safety of everyone please do not charge lithium ion batteries. Small appliances including curling irons and straighteners (or anything that could get hot) cannot be in the baby’s room. There is a risk of fire with these devices. We want to protect all of our babies and their special equipment from any potential risks, dangers or anything that may prevent the best care possible.

- Your baby has special medical equipment to provide the best care possible. Your nurse or provider can explain what the equipment is for, answer any questions and address concerns you might have. If you hear alarms or other beeping sounds, the nurse or provider must turn them off so any issues can be taken care of and addressed by the health care team.

- Our patient rooms have special lighting that helps your baby develop. The lights automatically change to mimic day time and night time. It is important to leave them on their current setting and not change them.

- To prevent the spread of germs, we ask that you avoid visiting other babies’ rooms. This will protect both your baby and the other babies. You are welcome to visit with other parents in the family lounge, waiting areas or areas outside of the NICU space.

- To protect the privacy of all babies and families, we are unable to answer questions about other babies.

- The best way to prevent spread of germs is to wash your hands often. Always wash them before touching your baby.

- Cell phones carry germs. Ask your nurse how to sanitize your phone before taking pictures, after phone conversations and before touching your baby.
Photos in the NICU
You may want to take photos or videos of your baby to keep and to share with family and friends. You are welcome to do this at any time. However, if any other person (such as a staff member) will be in the photograph or video, our hospital policy requires that you get permission from that person. Because of this, we ask that you please be mindful of your surroundings when you are taking pictures.

Posting information online
You may want to post pictures of your baby on a personal website or a social networking site. If you want to include anyone else from the NICU (such as a staff member, another baby or another parent), you must have permission to take the picture and to post it online. Please help us protect the privacy of staff, patients and families by not putting pictures or names of other people on the internet without their permission.
Your care team will come to your baby’s room each day to meet and talk about his or her health and progress. This meeting is called “Rounds.” Multidisciplinary rounds is the time when multiple team members, each with their own special perspective and training, meet to discuss your baby. You have an important role during rounds to ask questions and understand updates and next steps for your baby. Daily rounds are between 9 a.m. and noon.

Caregivers you might see on Rounds

Advanced practice providers (APP): APPs are either neonatal nurse practitioners (NNP) or physician assistants (PA) who are specially trained to take care of babies. They work with the attending physicians and the fellows to make decisions about the care of babies in the NICU.

Attending physician (neonatologist): Neonatologists are doctors who are specially trained to take care of babies. They are in charge of all of the babies in the NICU. Your baby’s attending physician will introduce themselves, and their name is written on the white communication board in the room for your reference. The attending physicians rotate.

Nurse case managers: Nurse case managers help prepare you and your baby for the transition to home. They will arrange for any equipment your baby may need at home along with training for you on how to use the equipment. They arrange and schedule follow-up appointments that your baby will need after discharge from the NICU.

Neonatology fellow: Fellows are doctors who have finished their pediatric residency. They are taking an added step in their education for three years to become neonatologists. The fellows rotate monthly.

NICU nurse: NICU nurses spend the most time at the baby’s bedside, watching them closely and caring for them. They also support parents and show them how to care for baby. They are your primary contact person in the NICU since you will see them the most.

Pharmacist: NICU pharmacists are specially trained to prepare medicines for babies. They also keep track of all of the medicines a baby gets to make sure they are safe.

Resident: Residents are doctors who have finished medical school and are training to be pediatricians. They may be interns or second or third-year residents.

Respiratory therapists (RT): Respiratory therapists are trained to care for babies with breathing problems. They give breathing treatments and make sure the equipment that helps babies breathe works properly.

Registered dietitians (RD): Registered dietitians are nutrition experts who work to make sure babies get the nutrition they need for healthy growth. They may work with a lactation consultant for new nursing moms.

Certified child life specialist (CCLS): CCLSSs are trained specifically in child development and in providing support to patients and their families, siblings included, during their NICU stay. A CCLS understands the unique stress the hospital can bring and works to provide many positive ways of coping.

Caregivers who can help during your stay

Certified child life specialist (CCLS): CCLSSs are trained specifically in child development and in providing support to patients and their families, siblings included, during their NICU stay. A CCLS understands the unique stress the hospital can bring and works to provide many positive ways of coping.
Chaplain: Chaplains work together to provide spiritual and emotional support to patients and families. They are there to talk and listen any time, with compassion and without judgment. Chaplains are available for everyone, regardless of faith tradition or belief system, and support is based on the patient’s own values. They are clinically trained to understand the needs of parents and families of neonatal patients.

Interpreters: UKHC provides language resources including qualified medical interpreters for spoken languages and American Sign Language. They ensure effective communication for patients and families. Interpreting services are always available at no cost to the patient or family. (At times a phone service may be used for interpreting.)

Lactation consultant (LC): These professionals work with new moms to help them meet their breastfeeding goals. They help moms with using a breast pump and provide guidance when babies are ready to nurse.

Music therapist (MT-BC): The music therapist is a qualified clinician who can help you and your baby cope, bond and develop through music. They have special training in approaches that research shows can help you.

Nursing care technician (NCT): The nursing care tech in the NICU is a second set of hands for the RN. They respond to family call lights, prepare rooms for admissions, stock supplies, help feed and calm babies and help in multiple ways within the NICU.

Occupational therapists (OT)/Physical therapists (PT): Occupational therapists and physical therapists are specialists who assess the physical development and movements of babies.

Patient care manager (PCM) and assistant patient care manager (APCM): The nursing managers are skilled in nursing education, team management and the overall operations of the NICU. You can find the name of the nursing manager on the white board in your baby’s room.

Patient financial advocate: The patient financial advocate meets with families to get insurance information and to help add your baby to your insurance. They also help with the application for the Social Security Administration’s Supplemental Security Income (SSI).

Social worker (SW): Social workers can support your family during your NICU stay. They may also be able to provide resource and support information to you as needed. All families are assigned a primary social worker.

Speech language pathologists (SLP): These specialists are trained in speech and language problems. They are also trained in swallowing difficulties and will assess babies for feeding problems.

Team manager (TM): The team manager is a nurse (RN) in charge of the flow of babies through the NICU. The TM helps take babies to procedures and attends high-risk births.

X-ray technicians (X-ray tech)/Ultrasound technician: The technicians come into the NICU to take images of your baby that help your healthcare team care for your baby.
CARING FOR YOUR BABY

Often parents feel helpless or fearful when they have a baby in the NICU. You are the most important person in your baby’s life. Even before birth, your baby came to know your voice and your heartbeat. Your child knows the feel of your skin, your scent and your special touch. Your presence will be comforting. We want to help you learn how best to care for your baby while in the NICU.

But first, caring for your baby means taking care of you, too. Parents as well as babies need rest. Take time to care for you.

It is important that you care for your emotions and mental health. Having a baby in the NICU can be stressful and lead to a wide range of emotions. You are not alone. There are people who can help support you and your family. Identify your personal support network – people who can help support you during this time, who can help at home or listen as you share thoughts and feelings.

Take advantage of resources available to you and ask about groups and programming that can help. If you are feeling more anxious, worried or stressed than feels normal to you, you may want to discuss your concerns with your personal or OB/GYN physician. In the hospital, chaplains and social workers are available to talk and to listen anytime.

We understand circumstances may not allow you to stay with your baby as long or as often as you would like. You may live too far from the hospital, have other children or need to return to work. Your care team can work with you to help you find ways to spend as much time as possible with your baby.

Your baby in the NICU is special. Even though you may have other children, NICU babies need a different level and kind of care, feeding, attention and routine. This includes maintaining a quiet environment.

As parents, you are essential in helping maintain the routine. Interruptions in routine may cause medical stress to your baby. Before you pick up or stimulate the baby, talk to your nurse.

While you may not be able to hold your baby and do all the care right away, there are things you can do. One thing is just being at the bedside. Your baby benefits from your presence. You can be in the room and write down new things that you and your baby do and celebrate new experiences or start a scrapbook.

At first, it may feel scary or intimidating to think about caring for your baby in the NICU setting. Our staff will support you. Let your nurse be your guide and help you with ideas on ways to be part of the care from the start. You will soon be able to touch and talk to your baby and help with changing diapers, checking temperature and handling feedings. Your voice will comfort your baby, and you will be able to read books to your baby. As your baby’s health gets better, you can take on more and more of the care.

You are welcome to bring in items for your baby. You may want to bring clothes, stuffed animals, books or even pictures or wall decorations. Many times parents and staff find creative ways to make your baby’s room feel warm and special.

If your baby has a long stay in the NICU, members of the care team can help you learn how to care for all your baby’s growth and development needs.
Learning your baby’s cues
Spending time with your baby will help you learn your child’s cues. There are times when talking and contact are positive and times when it may be better to take a “time out.”

Some of the positive cues are:
- Quiet, alert, eyes open
- Hands centered
- Hands to mouth

Some “time-out” cues are:
- Fingers splaying
- Arms extended, hands up (as if to say, “Stop!”)
- Hiccups
- Eyes closed
- As & Bs (apnea and bradycardia—see terms for more information)

The best time to interact with your baby is when you see positive cues. For your baby’s growth and well-being, try not to interact when you see negative cues or during sleep. Ask your baby’s nurse about these cues and what to do to help promote positive cues.

Your baby will react differently to different types of touch. A gentle firm touch will be more comforting to your baby rather than stroking, which may upset your baby.

One way to support your baby and help with calming is to offer a form of containment holding by placing your hands gently over baby’s trunk.

Or, you may place your hands gently over your baby’s head and feet.

Sometimes, you can offer a calming touch by simply grasping their hand gently around your finger.

Feeding
Breast milk is the best choice for your baby’s first food. Breast milk provides essential nutrients babies need for healthy growth and development, especially if they are preterm or ill.

If breastfeeding your baby is not possible right away, you can pump and store milk for your baby. If you are unable to provide breast milk, donor breast milk may be an option if your baby is less than 32 weeks gestation. The team will discuss the options with you.

The NICU has lactation consultants who will provide early and continuing support and education for mothers to start breast milk expression, breastfeeding, and pumping and storing milk. You may ask your nurse to contact a lactation consultant if you would like help or if you need to borrow a breast pump for home use. Breast milk is stored in the Infant Nutrition Center. You can get labels for your breast milk at the “milk kiosks” (computer stations) in the family lounges.

We will respect your choice, whether you choose to provide breast milk or not.
Kangaroo care
This is skin-to-skin contact between baby and parents. This special care lets your baby hear your heartbeat, feel your warmth and touch your skin. Kangaroo care improves bonding, breastfeeding, weight gain, baby’s stability and length of stay in the hospital. It can help parents feel closer to their babies.

Skin-to-skin care can help to stabilize baby’s heart rate, blood oxygen levels, breathing rate, body temperature and blood sugar levels. Frequent skin-to-skin contact can improve baby’s weight gain and can help moms produce more breast milk.

Skin-to-skin care involves holding your baby skin-to-skin against your bare chest, while your clothes or a blanket create a pouch to keep your baby secure and warm. Studies have shown that skin-to-skin care helps babies sleep better and grow faster. Also, many moms and dads have said that skin-to-skin care helps them feel closer to their baby and more confident giving care. It also can help promote successful breastfeeding and increase breast milk supply. Ask your baby’s nurse if your baby is stable enough for skin-to-skin care. The nurse will be able to help you.
Once your baby is stable, you can hold your baby. The nurse will help place your baby, dressed in only a diaper and maybe a hat, on your bare chest under your shirt and a blanket.

For your baby’s health and comfort, your skin should be clean and dry. You can prepare for kangaroo care by showering and being free of cigarette smoke, perfume, cologne or powder.

After your baby has been checked and cleared for kangaroo care, you can tell the nursing staff you want to do kangaroo care when you visit. Kangaroo care can be done throughout your baby’s stay in the NICU, no matter how big your baby is. The more you do kangaroo care, the more it helps your baby.

Read more about kangaroo care at the Kangaroo Care Project at [https://www.uky.edu/chs/pas/resources/kangaroo-care](https://www.uky.edu/chs/pas/resources/kangaroo-care)
6 WAYS TO SUPPORT YOUR NICU BABY

Wash Your Hands
Always wash your hands before touching your preemie. This will help protect them from outside bugs and infections.

Kangaroo Care
Your baby loves to be held. Kangaroo care (skin-to-skin) for at least 30 minutes can help keep baby calm and help stabilize breathing, heart rate and temperature. It can also help mom with milk production.

Express Your Milk
If you plan to breastfeed, try and express your milk at least eight times a day. Even a tiny bit is OK. If you have trouble, talk to your nurse about our lactation specialists.

Positive Touch
Preemies can go through a lot in a short time. Try to give your baby positive touch experiences by using gentle, firm containment holding and a quiet, comforting voice.

Reduce Stimulation
Your baby needs quiet time to sleep and grow. A dark, quiet space helps the brain grow and develop. Talk with your nurse about what might be best for your baby’s development.

Look After You
Being a parent of a NICU baby can be exhausting and overwhelming. You may be on a long journey to get your baby home. Make sure you look after yourself. Eat properly and get rest when you can.

TIPS FROM VETERAN PARENTS

Parent advice from parents who have been where you are

“I would encourage parents to remember that every NICU stay is different, and each baby has a unique experience with different challenges. While it can be helpful to talk with other families in the unit, it can also be discouraging to hear that your child is not making as much progress as their neighbor. I would encourage parents to celebrate their child’s victories, even if they look different than the gains of others.”

“New parents come from all walks of life, varying levels of education and experience; but one thing we share is a love for our babies. With that comes a strong desire to advocate for them, so do exactly that: be there when the care team rounds, take notes, ask questions, and lean into your baby’s nurses for understanding.”

“During this time, there are plenty of reasons to be scared, but try not to let your fear rob you of the opportunity to bond with your baby. Hold their hand if you can’t pick them up, sing them a song if you can’t find the words to say, and tell them how much you love them no matter how unnatural the NICU feels.”

“Your child is in incredibly capable, skilled caring hands. Know that the people caring for your child truly do care and want what’s best for them. As difficult as this experience is, your child needs you to take the best care of yourself that you can. You are the only one that can fulfill this role for them – get sleep, eat, drink lots of water. Trust those capable hands caring for your child and breathe.”

Note: Quotes are from the NICU/Mother/Baby Parent Advisors.
WORDS YOU MIGHT HEAR

When talking about your baby's health or care, a nurse or doctor in the NICU may use a word or term that is new to you. Here is a list of some common words that may be used.

How we may describe your baby

Gestational age: A baby’s age in weeks from conception to present. The age of the baby during pregnancy.

Premature infant (or “preemie”): A baby born before the 37th week of pregnancy.

Words about breathing and helping the lungs

Respiration: This term describes how a baby is breathing. The health care team will look at respiratory rate (how many breaths in one minute) to talk about how much work a baby is putting into their breathing and if they are struggling to breath.

Tachypnea: Breathing rate of more than 60 breaths a minute.

Desaturation event (or “a desat”): A drop in the oxygen level in the baby's blood. It is usually because of poor breathing.

Oxygen saturation (or O2 saturation): This is the percentage of oxygen that is in the baby’s blood stream with 100 being the highest possible number. We use a different goal range, depending on your baby’s age and medical conditions, but in general high numbers are better.

Retractions: Hard breathing in which the ribs show and the breastbone sinks. It is a symptom of respiratory distress syndrome.

Apnea: A pause in breathing that lasts more than 20 seconds.

As & Bs: When a baby has apnea and bradycardia at the same time.

Cyanosis: Bluish skin color because of low oxygen in the blood. It is also called “duskeness.”

Endotracheal tube (or ET tube): The tube placed from the mouth that extends down into your baby’s lungs. Used with a ventilator to help your baby breathe.

Intubate: When an endotracheal tube is placed. Used with a ventilator to help your baby breathe.

Ventilator: The equipment that helps your baby breathe when your baby is not ready to breath on his or her own.

Extubate: When an endotracheal tube is removed. This likely means the baby is “off the ventilator.”

Surfactant: This liquid covers the lining of the air sacs in the lungs. It lets the lungs expand in a normal way while breathing. Premature babies do not make this liquid. We may need to give a dose of surfactant through the ET tube to help your baby’s lungs work better. Your baby may need more than one dose.

Pneumothorax: When air gets in the space between the lung and chest, causing the lung to collapse. In most cases, a chest tube is needed to deal with the issue.

Chest tube: A tube placed in the chest and hooked up to a suction machine to remove air trapped outside the lung (pneumothorax).

Words about heart rate

Bradycardia: When the heart rate slows to less than 80 beats a minute.

Tachycardia: Heart rate of more than 180 beats a minute.

Words about feeding and eating

Ad lib: The term ad lib feeding comes from the Latin phrase ad libitum, meaning “at will.” It refers to feeding babies “as desired,” meaning when they’re hungry, rather than on a schedule.

Calories: These are the building blocks of food that allow for growth. They can be given in formula, breast milk, or IV nutrition. This can be adjusted based on how your baby is growing.
Aspirate (or residual): This may be checked on a baby who is getting breast milk or formula into the stomach from a feeding tube. It tells us how they are digesting the milk. This is not regularly checked, but if it is high it means your baby is not digesting the milk well and a lot of milk is still sitting in the stomach instead of moving through the intestine. High residuals can be a sign of feeding intolerance.

mLs (or milliliters): The measurement we use for the amount of fluid or feeding we give your baby. For example, 30 mLs equals one fluid ounce.

Feeding intolerance: This is a general term used to describe ways a baby may not be handling their milk well. This might include high aspirates (residuals), increased size of the belly, green vomit or increased amount of vomiting. If this happens, we will likely stop feeding your baby for a short time or change the type of milk to help your baby tolerate it better.

Fortifier: This may be added to breast milk to increase calories and protein and to help babies gain weight.

Gavage feeding: A way to feed a baby formula or breast milk. The food goes through a tube passed from the mouth (OG) or nose (NG) into the stomach.

NPO: Nothing by mouth — no oral feedings. Nothing should go into the stomach or gastrointestinal tract.

TPN and lipids: The solution of protein, sugar and fat that provides nutrition. Given into the body through the veins.

Blood labs that we measure

Bilirubin (bili): Substance in the blood that causes jaundice. It is made when red bloods cells break down.

Blood culture: This test looks for infection in the bloodstream.

Glucose: The main energy or fuel for the body. It is also called “blood sugar.”

Hematocrit: The percentage of the blood made up of red blood cells. Red blood cells carry oxygen through the body.

Blood gas: Test done on a small amount of blood taken from the heel, vein or artery. It tells how well the baby is breathing.

White blood cells (WBC): These are the cells in the blood stream that help your baby fight infection. Sometimes when the white blood cell number goes up, it tells us whether or not to treat your baby for an infection. There are several types of white blood cells helpful in different kinds of infection or illness.

Problems we test for with these blood tests

Jaundice: When the skin and eyes become yellow from high bilirubin in the blood. Also known as hyperbilirubinemia, it is treated with “bili lights.”

Sepsis: An infection of the blood. This is treated with antibiotics.

Hypoglycemia: A low level of sugar in the blood. We will give extra sugar when this happens.

Anemia: A low percentage of red blood cells. Many premature babies need blood transfusions to add red blood cells.

Other words you may hear

Kangaroo care: Holding a baby close to your chest so there is skin-to-skin contact.

Meconium: A baby’s first bowel movement. It is thick and blackish-green, and it looks like tar.

Rounds: A time when the neonatologist and care team check on the baby and plan care.

Suction: Clearing mucus and secretions from the mouth, nose or airway. This makes it easier for your baby to breathe. We may use bulb suction or a machine from the wall. If your baby needs a breathing tube, a small tube can be used to suction through the breathing tube into the airway.
Precautions: (Usually “contact precautions” or “droplet precautions.”) This is extra protection including a gown, gloves and sometimes a mask. This personal protective equipment (PPE) is worn by providers and guests to enter the room of a patient known or suspected to be infected or colonized with specific bacteria or viruses that may easily spread to others through touching (contact) or coughing or sneezing (droplet). The nurse will let parents know what, if any, PPE they must wear.

**COMMON TESTS AND PROCEDURES**

Here is a list of some common tests and procedures that your baby may need while in the NICU.

**Blood testing:** We may have to take blood from your baby’s heel, vein or arterial line and send it to the lab. Blood tests help us find out more about your baby’s health and which treatment will work best.

**Car seat observation:** Babies born before 37 weeks will need to be checked while sitting in their own car seat before going home. We need to make sure they don’t have low heart rates or oxygen levels while in their car seat.

**Chest tube placement:** This is a tube placed into the chest between the ribs when a baby has a collapsed lung or fluid in the chest.

**Echo (echocardiogram):** An echo is an ultrasound of the heart.

**ROP exam:** An eye doctor (ophthalmologist) checks the eyes of babies that are born early, because they may have eye problems. One of these problems is called retinopathy of prematurity or ROP.

**Hearing test:** An ALGO hearing test is done on all babies. It is done by placing headphones on the baby’s ears and seeing if the brain registers the sounds.

**Intubation:** This procedure is when a special tube is placed in the baby’s windpipe to help with breathing.

**Lumbar puncture:** A needle is inserted into the spine to take a sample of the fluid. This is done to check for infection or to relieve pressure on the brain.

**MRI:** This is a type of study that uses large magnets and radio waves to take a detailed look inside different parts of the body.

**Sepsis workup:** If we think a baby might have an infection, we do tests to look for bacteria in the blood, urine and spinal fluid. We also start antibiotics to fight the infection.

**Ultrasound:** This test uses sound waves to look at the inside of the body. In the NICU we often use this to look for bleeding in the baby’s brain.

**X-Rays:** These are pictures of the inside of the body. In the NICU, we bring an X-ray machine to the baby’s bedside to take these pictures.
NICU EQUIPMENT

We use special equipment in the NICU to give your baby the best care. Here is a list of common equipment your baby might need.

Ways we monitor how your baby is doing

Cardiorespiratory monitor: This equipment tracks your baby’s heart rate, breathing rate, oxygen level and blood pressure. The monitor is connected to your baby by leads placed on the chest and belly, with a blood pressure cuff on the arm or leg.

Pulse oximeter (or pulse ox): This is a sensor that wraps around your baby’s hand or foot. It measures how much oxygen is in their blood (also called oxygen saturation).

Where we keep your new baby

Incubator: This is a bed that keeps your baby warm and keeps germs and noise away. Humid air may also be added for very small babies.

Isolette: This is the special bed that looks like a plastic box. Premature babies must stay in it help keep them warm and healthy when they are too small to keep their temperature normal on their own.

Bassinet: This type of bed is open to surrounding air and does not have a warmer in it. Your baby may graduate to a bassinet or crib before going home.

Ways we provide fluids, medicines and nutrition

IV line: This is a line that goes into a vein in your baby’s arm, leg or scalp. It is used to give your baby fluids and medicine.

Peripherally Inserted Central Catheter (PICC) line: It is often called a “central line” based on its location in the body. This long IV line goes into a vein in your baby’s arm or leg. It can be used longer than a regular IV line. It is used to give your baby fluids, medicine and nutrition.

Umbilical line: It is often called a “central line” based on its location in the body. This is an IV line that goes into either an artery or vein in your baby’s umbilical cord. These lines can be used to give fluids, nutrition and medicine. We can also use them to check blood pressure or take blood for tests.

Nasogastric (NG) tube: This is a tube inserted in the nose (naso-) going to the stomach (gastric). It lets your baby get breast milk or formula as well as medicines, even if your baby cannot eat by mouth.

Orogastric (OG) tube: This is a tube inserted in the mouth (oro-) going to the stomach (gastric). It lets your baby get breast milk or formula as well as medicines, even if your baby cannot eat by mouth.
STEP DOWN NEONATAL UNIT

As your baby continues to improve and needs less critical care, he or she may move to our “step-down” unit called the Yellowwood Neighborhood.

You will stay involved in your baby’s care with the same health care team that you know. However, you may meet new NICU trained nurses.

This neighborhood is on the third floor. Yellowwood is different from the first floor neighborhoods in many ways, but the same in others.

Please continue to check in at the first floor NICU Welcome Desk to get your visitation sticker. The clerk will give directions to the Yellowwood neighborhood. The visitation policies are the same as the other neighborhoods. Parents are welcome to visit 24/7.

The Yellowwood neighborhood does not have private rooms. There may be 8 babies in the same room. We understand that having multiple babies in a room may be a cause for concern. But you can expect the same level of safe quality care as the other neighborhoods. If you live within driving distance, we encourage you to go home and rest at night as you prepare to take your baby home. We understand many of you live too far away to travel back and forth. Please talk to your care team to make plans to rest.

You are welcome to be at the crib side and spend time caring for your baby. We encourage you to take breaks and relax.

You are welcome to take advantage of the Ronald McDonald Family Room on the fourth floor (Room 461) for coffee and light snacks. You may be familiar with this space as where you can obtain Lunches with Love. There is a small kitchenette and laundry facilities near this room (Room 448, across from the PICU/CPICU entrance and PICU/CPICU clerk’s desk). The PICU clerk can get laundry detergent for you if needed.

You are always welcome to ask questions or share concerns with any member of your health care team.
GOING HOME

Parents often wonder, “How will I know when my baby is ready to go home?” Your care team will be keeping you up to date on your baby’s progress and goals for going home.

The health care team will help you develop skills to build confidence so you can care for your baby at home.

Important goals are that your baby will be able to stay warm by keeping his or her own temperature (97 degree F for 24-48 hours) and be able to get enough from feedings to have consistent weight gain.

We know that taking care of your baby all on your own can feel like an overwhelming or even scary task. We are here to help. Before you leave, Nursing Case Managers and the rest of your care team will learn your needs and plan how to meet them. You will take Discharge Classes before you leave to prepare you for going home. The nurses also will help you learn what you need to know as time gets closer to take your baby home. You can find sign-up sheets for the Discharge Classes at the clerk’s desk.

Sometimes your baby may need extra support to get home. You will get chances to practice taking care of your child before leaving the hospital. This is called Care-by-Parent. We have special rooms to let you do all the care on your own and help you to feel confident in your ability to fully care for your baby. Practicing the care before you go home gives you support if needed, since nurses will be here if you have questions or concerns.

PREPARING FOR LIFE AT HOME

Pediatrician/primary care provider

You may have a pediatrician or primary care physician (PCP) whom you currently work with or plan to work with after your baby goes home. Please tell your nurse your choice as soon as possible. This information will be helpful as the time gets closer to when you can take your baby home. The Nurse Case Manager will help with the move home by making the first follow-up appointments for you. If you do not have a pediatrician or primary care physician yet, you should begin thinking about who to choose early in your stay.

Training videos

Ask your nurse about any informational or training videos that may be helpful to watch before going home. Videos include “Safe Sleep Saves Lives” and “Hope for Tomorrow.”

Circumcision

If you have a baby boy, you may choose to have him circumcised. If this is your decision, please let your provider know so that it can be scheduled before you take your child home.

As you get ready to take your child home, it is helpful to gather records and paperwork you will need to keep. You will be given a Discharge Folder to help you keep track of papers and information.

Immunizations

With your consent, your baby will get needed immunizations before going home. Keep the immunization record with your Discharge Folder for safekeeping. Bring this with you to follow-up appointments.
**Screening results**
Your baby may have some basic screenings while in the hospital. Ask for the results of your baby’s hearing screening and CCHD screening (Congenital Cardiac Heart Defect screening). Place those in your Discharge Folder to take to your pediatrician or primary care physician appointment.

**Formula**
If you qualify for or are already receiving services through WIC, please make sure you receive a form for formula before leaving the hospital.

**Medicines**
You should get all of your baby’s prescriptions and vitamin recommendations from the health care team before going home. We will make sure you know what each medicine is for as well as when and how to give it. You might have the chance to practice giving medicines as you care for your baby in the NICU so you will feel comfortable when it’s time to go home. When the day arrives for going home, we have a program that might make it easier for you by delivering your needed prescriptions directly to the bedside. It is called the “Meds to Beds” program. Please ask your nurse or pharmacist if you are interested in this convenient program.

**Breastfeeding moms**
Before you go home, please bring a cooler and gel ice packs for your breast milk to the INC (Infant Nutrition Center) the week or day you want your breast milk packed to take home. Please label the cooler with your name. If you cannot bring a cooler and ice packs, let us know. Review the care and thawing process for once you are home. We will do our best to help you.

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**SPECIAL CARE**

**Extra follow-up care**
Many babies born very early will need more appointments for medical or developmental help after going home. If your baby needs these services, we will discuss them with you and schedule your first follow-up appointments. These appointments will be here in Lexington and may involve long days. Please plan to be at these important follow-up clinics for at least two hours. You will see many different caregivers at one time (such as physicians, dietitians, social workers and therapists).

**Special equipment**
If your baby needs special equipment such as a monitor or oxygen, your Nurse Case Manager will arrange for you to get them through a special company (Durable Medical Equipment or DME) that handles these items. You will be taught how to use the equipment and who and when to call if you have problems. Any supplies needed (such as catheters or ostomy supplies) for your baby also will be arranged in the same way.

If your baby has special medical equipment, contact your fire department, emergency medical service and the local utilities to let them know. In case of a power outage, your neighborhood can be prioritized when fixing utility problems.
TRANSPORTATION HOME – CAR SEAT

Be sure you have an approved car seat. All babies must travel in a safe car seat. Car seats should be rear facing, have never been in an accident and be made for your baby’s weight when he or she goes home. Car seats have an expiration date, which is often six years from the date it was made. It is important that your car seat not be expired. When in doubt, the easiest thing to do is to call the manufacturer and ask. Your nurse will be happy to discuss options for car seats with you, especially if you will need to buy a new one. If your baby is very small, you may need a seat designed for infants weighing four pounds.

Learn how to use the car seat by reading the manual before you take the baby home. Some fire departments or police departments offer a car seat installation check. Call ahead to the fire or police department to find out how to get a check in your hometown. Many babies will need a “car seat challenge” before going home. The baby will be monitored for a period of time in the car seat to make sure they are safe riding in it.

SAFETY AT HOME

• Put your baby to sleep on their back to reduce the risk of Sudden Unexpected Infant Death (SUID). Talk to your health care provider about tummy time when the baby is awake.

• Keep emergency phone numbers next to all the phones in your home and store in your cell phones as well.

• Clean your house of dust, pet hairs, paint smell, tobacco smoke or other smells that may bother your baby’s eyes, nose and lungs. Find out if any other precautions may be needed if someone in your home or a visitor to your home is a smoker.

• Ask what precautions visitors should take and when no one should visit.

• Find out how soon you can take your baby out in public.
RESOURCES

Infant Nutrition Center
Located within the NICU (Room HA1283). Open daily 8 a.m.–3:30 p.m. and 5:30 p.m.–8:30 p.m.

The Infant Nutrition Center is where all breast milk is stored for our patients. The technicians who work there are responsible for safely preparing milk and formula for your infant. If you are pumping, please bring your milk to the Infant Nutrition Center window often to ensure that your infant gets the freshest, most nutritious milk possible. Remember, kiosks for labeling your milk are in the family lounges.

For more information, visit UK Infant Nutrition Center (INC) Quick Tips for Parents in Appendix.

Ronald McDonald House
The Ronald McDonald House offers a place to stay for families of sick children from outside the area who may not be able to afford long-term stay elsewhere. If you think this is a service you will need, talk to your social worker. The social worker will discuss the specific criteria with you and who can make a referral if needed. The Ronald McDonald House will run a criminal records background check on every guest over the age of 18 who wishes to stay there. All parties who are 18 years old are required to have a valid picture identification.

The Ronald McDonald House staff makes the final decision on whom they accept. If you do not meet their criteria, there may be other housing options your social worker can discuss with you. If the Ronald McDonald House is full, a family can be placed on their waiting list, and the Ronald McDonald House will contact the family when a room becomes available.

The house has 21 rooms that can house up to four guests at a time. Only one room is allowed per family. There is no cost to use the Ronald McDonald House, although a $10 a night donation is suggested. No family is turned away for inability to make this donation. The Ronald McDonald House also offers dinner nightly (provided by volunteers) for its guests, as well as toiletries and access to laundry facilities.

Other places to stay
A variety of hotels and motels are within a short distance of the UK HealthCare campus. For information on these hotels or motels, please see any information desk or the Customer Relations Office located in Pavilion H, near the main entrance, for a complete list. Please contact the hotel of your choice directly for reservations and rate information.

Information desks
The staff at the information desks can provide information on local restaurants and local activities.

They have information about LexTran bus routes and can help you figure out how to get around Lexington and the area around the hospital. A bus that can take you to local shopping areas and restaurants stops in front of the hospital.

Ask a guest relations specialist about taking a self-guided tour of the art in the hospital.

Public spaces (places to sit and relax)
Staying in the NICU for long periods can be very tiring. There are several places in the hospital where you can sit and relax:

- Ronald McDonald Family Room®. This waiting room is located in Kentucky Children’s Hospital on the fourth floor of Pavilion H (across from Pediatric ICU). It is open 9 a.m. – 9 p.m. There are light snacks and coffee available for families. Children need to be accompanied by an adult.
• **KCH Main Lobby.** Open space and seating. There is an interactive play wall for children.

• **KCH Ground Floor Lobby.** Open space and seating. Quiet play activities for children are available.

• **Atrium Lobby (ground floor of Pavilion A).** Comfortable seating areas allow visitors to rest and have quiet conversation. There is often music during the days,

• **Courtyard.** The garden setting outside of the Pavilion A Atrium off the ground floor provides intimate seating areas and benches built into the natural limestone wall. There is also a courtyard dining area next to the main cafeteria on the first floor of Pavilion A.

• **Labyrinth.** The walking labyrinth offers patients, visitors and hospital staff a quiet place to focus and gather their thoughts. It is located on the ground floor of Pavilion A Atrium.

• **Chapel.** There are two non-denominational chapel spaces available. The Myra Leigh Tobin Chapel is located on the ground floor of Pavilion A in the hallway behind the ground floor registration area. Pastoral care offices are located just across the hall. The Pavilion H Chapel is located on the first floor of Pavilion H in Room H122. Both are open 24 hours a day for prayer, meditation or just some quiet time alone. Chaplains are available at all times. Have your baby’s nurse page a chaplain if you would like to talk to someone.

For the convenience of Muslim patients and families, prayer rugs are available in each chapel.

Non-denominational services are offered on Sundays at 10 a.m. in the Myra Leigh Tobin Chapel in Pavilion A and at 11 a.m. in the Pavilion H Chapel.

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**MEAL ASSISTANCE**

If you need help with meals, please ask to speak to a social worker. The Lunches with Love program also is available to serve families.

**Lunches with Love**

Lunches with Love is a free bagged meal program of the Ronald McDonald House Charities® of the Bluegrass. Lunches with Love are shelf stable and contain an entrée (such as Chef Boyardee, cup of noodles, tuna packet or mac & cheese cup), a fruit cup (apple sauce or diced fruit), a sweet treat (cookie or snack cake), a drink (water or juice box), plastic silverware, napkin and a note of encouragement. Family members of patients within Kentucky Children’s Hospital are eligible for up to two Lunches with Love per day for each family. Lunches with Love is located in the Ronald McDonald Family Room® located on the fourth floor of Kentucky Children’s Hospital, Room H461, near the PICU.
AMENITIES

Dining
Our cafeteria is located on the first floor of Pavilion A near the patient elevators. Cash and credit are accepted. A wide variety of menu items and snack food is available. Call 859-257-1168 for daily menus. The cafeteria is open 22 hours a day; closed 5-6 a.m. and 10-11 a.m. for meal changes.

• Courtyard Café: This grab-and-go café is located in Pavilion A on the ground floor next to the auditorium. It offers coffee, beverages, pastries, soups, salads and sandwiches. Open weekdays.

• Starbucks: Kentucky Clinic. Located on the first floor of the Kentucky Clinic. Open weekdays.

• Wildcat Café: Located on the third floor of the Kentucky Clinic near the pedestrian bridge from Pavilion H. Open weekdays.

• Vending machines: Located on the first floor of Pavilion H around the corner from the KCH Lobby. Accessible 24 hours a day; a microwave is available.

Parking
The UK HealthCare Parking Garage is located at 110 Transcript Ave., directly across S. Limestone from UK Chandler Hospital. The garage entrance is on Transcript Avenue.

There is a fee for parking. Rates are posted at the garage entrance.

Extended-stay (7-day) parking passes are available for purchase in the parking office on Level A (ground floor) of the hospital parking garage. Passes cost $20 a week for the first and second weeks. Once you buy 2 consecutive 7-day passes, there will be no charge for the remainder of your visit. Contact the parking office at 859-257-5757 or toll free 800-441-0555.

Internet access
You are welcome to connect to UK HealthCare’s free wi-fi:

• Connect to UK-Guest and create an account.

• Check your email or text for credentials and sign in with credentials.

• It will be important to renew your credentials every 5 days.

• If you have questions or need assistance with connecting to our wi-fi, please call UK HealthCare Information Technology Support Services at 859-218-4357 or visit www.uky.edu/wifihelp.

We also welcome you to ask a member of your healthcare team for assistance.

ATM locations
• Pavilion A: First floor to the right of the information desk

• Pavilion H: Left of the registration desk on right side of the hall

• Chandler Emergency Department: Pediatric waiting area.

Gift shops
A children’s gift shop is located in the Kentucky Children’s Hospital Lobby.

Gift shops are also located on the first floor of Pavilion H near the lobby and the first floor of Pavilion A near the information desk.
EDUCATIONAL RESOURCES

Don and Cathy Jacobs
Pediatric Health Education Center
The Don and Cathy Jacobs Pediatric Health Education Center is located in the lobby of the Kentucky Children’s Hospital. It offers patients and families a place to get educational materials. These materials are available free for families, so that they will have the information they need to take care of their child when they return home. The center also offers families use of computers and other business center needs. It has medical models for patients and families to look at, and even practice some skills as needed.

Don and Cathy Jacobs Health Education Center
The staff at the Don and Cathy Jacobs Health Education Center is available to help families find reliable health information.

The center offers these free resources:

• Computers with internet access.
• Books and pamphlets.
• Videos and audiobooks.
• Health models.
• Free copying and faxing.

Located on the first floor of Pavilion A near the concourse bridge, the Health Education Center is open Monday – Friday, 9 a.m. – 4:30 p.m. This resource is open to patients and their loved ones. It offers books, videos, brochures and computers with internet access as a means of adding to the information provided by your doctor or nurse. Visitors to the center may also check email and copy or fax documents. Please call 859-323-7808 if you have any questions about available resources or services.

ADDITIONAL SUPPORT

Websites
Some helpful websites for parents of a baby in the NICU:

• medlineplus.gov/prematurebabies.html
• www.marchofdimes.org
• handtohold.org
• support4nicuparents.org
• nationalperinatal.org
• kidshealth.org/en/parents/nicu-caring.html
• preemeandyou.com

Helpful apps
• My NICU Baby App
  (March of Dimes)
• Breast Beginnings App
  (University of Kentucky)
• My Preemie App for Preemie Parents
  (Graham’s Foundation)

Postpartum Support International
Postpartum Support International provides resources for families and trained professionals and provides a bridge to connect them. One in seven moms and one in 10 dads suffer from postpartum depression.

For more information, visit www.postpartum.net

Or call or text the HelpLine: 1-800-944-4773 (4PPD)
English and Spanish; or text 503-894-9453.

Available 24 hours a day, you will be asked to leave a confidential message. A trained and caring volunteer will return your call or text. They will listen, answer questions, offer encouragement and connect you with local resources as needed.
FINANCIAL RESOURCES

SUPPLEMENTAL SECURITY INCOME

Dedication
This section of the guide explaining financial assistance is dedicated in loving memory of sisters Evelyn Diana Ying and Roselyn Elizabeth Ling Gatton-Hallen, who were patients in the NICU in October and November 2015. Their parents hope their experience will help other NICU families. They also want your family to know that you are not alone.

Introduction
When a baby is in the NICU, the focus should and will be on care for the baby and the family. But Evelyn and Roselyn’s parents helped us understand that families also need information about the possible financial help available through the Social Security Administration’s Supplemental Security Income (SSI) and Medicaid programs. This may cover part or all of the cost of your baby’s NICU care.

While you are not required to apply for these government programs, you should consider applying for them if your baby has certain conditions or disabilities. Our staff is here to help you apply for these programs, and they can answer any questions you may have throughout the process.

SSI AND MEDICAID

Information and Qualifying Factors
If it looks like your baby may qualify for SSI or Medicaid benefits, a member of our staff will meet with you. If you think your baby may qualify and no one has talked with you about this benefit, please contact the patient financial advocate at 859-323-5769.

Conditions that may qualify babies for SSI and Medicaid benefits include but are not limited to:
- HIV (human immunodeficiency virus) infection.
- Total blindness.
- Total deafness.
- Cerebral palsy.
- Down syndrome.
- Muscular dystrophy.
- Severe intellectual disability.
- Birth weight below 2 pounds, 10 ounces.

How to apply for SSI and Medicaid
If you decide to apply for benefits for your baby, we will help you gather the needed paperwork. We will take completed paperwork to the Social Security office to start the application. The Lexington branch of the Social Security office will contact you to schedule a phone interview to complete the application. We can help you with this call.

The Social Security office or the Cabinet for Health and Family Services may mail you a request for more information. If you have questions along the way, your hospital social worker can help. Call the social worker at 859-323-5769.

If your baby qualifies for SSI, your out-of-pocket payment will be $30 a month while your baby is in the hospital. In Kentucky, babies who qualify for SSI automatically qualify for Medicaid. This may cover part or all the cost of your baby’s care both while in the NICU and after he or she goes home.
Once your baby is well enough to go home, the Social Security office will decide if your child still qualifies for benefits. At that time, you will need to call the Social Security office at 800-772-1213 to let them know you are home with your baby. If benefits continue, there may also be other programs to help you and your family. To learn more about these programs, visit the Cabinet for Health and Family Services website at chfs.ky.gov.

**Getting ready to leave the NICU**
As you get ready to go home, you may keep working with a social worker or patient financial advocate. That person can help you learn more about other assistance programs. If the hospital sends you bills that you do not understand or that you feel you should not need to pay, please call 859-323-5769.
INFANT NUTRITION CENTER (INC):
QUICK TIPS FOR PARENTS

What is the INC?
• The INC provides a secure, clean location to store and prepare breast milk and formula for your child.
• The INC follows a “no touch” technique to prepare breast milk and formula. This helps reduce the risk of contamination.
• Formula and breast milk are not prepared at the same time.
• Breast milk preparation is from 12 p.m. (noon) to 4:30 p.m.
  * Please make sure we have your milk before this to ensure your baby gets fresh milk.

What do I do with my expressed breast milk?
• In the hospital, your expressed breast milk should be stored in food-grade plastic containers. If you do not have plastic containers, ask your nurse or lactation consultant to provide them. Please don’t use breast milk storage bags in the hospital as they can leak easily and are hard to handle during preparation.
• Leave some space at the top of the breast milk container. This will let the milk expand during freezing and prevent the container from breaking.
• Use Timeless printed labels on each breast milk container. Write the date and time of expression. Make sure each label has the correct name for your infant. If your nurse prints labels for you, make sure they list the correct name.
• You are welcome to print your own labels by using the electronic mother kiosks in the NICU family lounge areas. You will use your phone number to log in. You can also view and edit your personal information for receiving text/e-mail messages for when the INC supply of your milk is running low.
• It is safest for you as mom/parent to take the breast milk containers to the INC window yourself because that ensures that your milk is handled by fewer people.
• When you drop your breast milk off at the INC window, the INC techs will check each bottle to check if it is labeled correctly before you leave.
• If you bring breast milk to the NICU when the INC is closed, place your breast milk in the refrigerator (also known as the “penguin”) in your room. The Nurse Care Tech will take your milk to the INC once open if you are not available to.
• If you bring in frozen breast milk to the NICU, please take it to the INC as soon as possible or tell your nurse before it thaws. Thawed breast milk cannot be refrozen.
• When transporting frozen breast milk to and from home, please store it in a tightly packed cooler or insulated bag with freezer gel packs.
• Fresh expressed breast milk will expire in 72 hours (3 days) from the date/time expressed (for NICU standards). The INC cannot take it after that.

How can I take milk home?
• The INC will store an adequate supply of your breast milk in the INC freezers. If the INC supply of your milk goes over what we can store, the INC will ask you to take some milk home with you. Taking milk home will save you time and stress later. It also lets us have enough freezer space for all of our infants in the NICU.
• Before you go home, please bring a cooler and gel ice packs for your breast milk to the INC the week or day you want your breast milk packed to take home. Please label the cooler with your name. If you cannot bring a cooler and ice packs, let us know. We will do our best to help you.
**Human milk storage/expiration guidelines in the INC**

<table>
<thead>
<tr>
<th>Type of human milk</th>
<th>Refrigerator (&lt; 39°F)</th>
<th>Freezer (&lt; -4°F)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Freshly expressed or pumped</td>
<td>72 hours (3 days) from date/time expressed</td>
<td>12 months from date expressed</td>
</tr>
<tr>
<td>Fresh expressed milk with additives</td>
<td>24 hours (1 day) after preparation</td>
<td>Never refreeze human milk after it has been thawed.</td>
</tr>
<tr>
<td>Thawed, previously frozen</td>
<td>24 hours (1 day) after thawing</td>
<td>Never refreeze human milk after it has been thawed.</td>
</tr>
</tbody>
</table>

* Note: Human milk storage/expiration guidelines in the INC may differ from the recommendations you are given to follow at home. Please ask your lactation consultant for home storage guidelines.

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**Infant Nutrition Center (INC)**

Hours of operation: 8 a.m. - 8:30 p.m.  *INC is closed from 3:30 p.m. - 5:30 p.m. for delivery
Room number: HA01283 (located in the NICU)  | Phone number: **859-562-1108**