Baby Steps to Home:
A Guide to Prepare NICU Parents for Home
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Home Medical Equipment

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Tracheostomy

Medications at Home

Albuterol (Proventil, Ventolin)

Budesonide (Pulmicort)

Caffeine Citrate

Chlorothiazide (Diuril)

Compounding Pharmacy

Digoxin (Lanoxin)

Ferrous Sulfate (Elemental Iron)

Fluticasone (Flovent)

Lansoprazole (Prevacid)

Multivitamins

Omeprazole (Prilosec)

Phenobarbital

Ranitidine (Zantac)

Vitamin D (Ergocalciferol, Cholecalciferol)

Follow-Up Appointment

Cardiology

Cardiothoracic Surgery

Dermatology

Early Intervention or Early Childhood Intervention

Endocrinology

Gastroenterology

Genetics

Hematology

High-Risk Infant Follow-Up (Neuro Brain Developmental Follow-Up)

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Introduction

How to Use This Guide
Many families feel overwhelmed by the neonatal intensive care unit (NICU) experience. Although they long for the day when they can take their baby home, they may feel apprehensive and unprepared when that day finally arrives. Baby Steps to Home was created to standardize the discharge pathway and parent teaching that happens during the baby’s stay in the NICU. It is designed to provide parents with information appropriate for their baby’s condition and progress toward discharge.

Each topic is presented in two parts. The first section is written specifically for nurses but can be used by anyone on the NICU team. Current, evidence-based content is provided, along with references to consult for more information. The second section, written for parents, presents the content in easy-to-understand language that promotes consistent messaging between the parent and nurse sections. The parent-focused content discusses common issues and diagnoses parents may encounter while their baby is in the NICU, suggests questions to ask their baby’s provider, and provides practical information and tips parents will need now and after discharge.

The parent-focused sections of Baby Steps to Home can be modified and printed so each unit can add their hospital’s logo and other specific directions or information before handing the information to a parent.

Parents are essential to maximizing the long-term outcomes of NICU patients. This guide will be a useful tool in the education and preparation of parents for discharge, so that all parents of NICU babies feel prepared and ready to care for their babies at home.

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Step 1
Breastfeeding Overview

In a summary of the Agency for Healthcare Research and Quality’s (AHRQ) evidence report on breastfeeding in developed countries, Ip, Chung, Raman, Trikalinos, and Lau (2009) concluded that breastfeeding is associated with a reduced risk for many diseases in infants and mothers. “The magnitude of health benefits linked to breastfeeding is vastly underappreciated. Breastfeeding is a public health issue” (Bartick & Reinhold, 2010, p. 1048). For the premature or ill infant, the use of mother’s milk has even greater importance. Numerous studies demonstrate improved short- and long-term outcomes for the premature infant who is fed breast milk. These benefits include achieving full enteral feedings more rapidly, significantly lower rates of necrotizing enterocolitis (NEC), lower rates of nosocomial infections, and improved neurocognitive and visual acuity scores, to name a few (Patel, Meier, & Engstrom, 2007; Rodriguez, Miracle, & Meier, 2005; Meier, Engstrom, Patel, Jegier, & Bruns, 2010).

Improved outcomes translate to shorter hospital stays and cost savings for families and healthcare facilities. In a 2010 study published in Pediatrics, researchers analyzed the data cited by AHRQ on health outcomes related to breastfeeding for 10 pediatric diseases. The researchers found that if 90% of families in the United States complied with the recommendations to breastfeed exclusively for 6 months, the United States would save approximately $13 billion per year in healthcare costs (Bartick & Reinhold, 2010).

Successful breastfeeding at discharge begins when the infant is admitted to the NICU and continues throughout the hospital stay. Establishing a good milk supply is the key to successful breastfeeding and requires early initiation of pumping. When a mother and her baby are separated, the healthcare professional may be hesitant to discuss pumping if the mother is undecided on breastfeeding or if she is recovering from the birth experience. Mothers who deliver a premature or ill infant need information on the science of breast milk so they can make the best decision for them with regard to providing breast milk for their infant (Rodriguez, Miracle, & Meier, 2005). During this time, the nurse will want to distinguish between providing expressed breast milk (EBM) and breastfeeding. Some mothers will choose to pump for their infant but do not plan on feeding at the breast. The mother needs to know why her milk is important and the specifics related to use of an electric breast pump, collection of EBM, and the storage and transport of EBM.

The healthcare professional can explain that nutrition for the infant begins in the womb when the infant swallows amniotic fluid. Amniotic fluid contains growth factors, stem cells, and immunoglobulins. All mammals swallow amniotic fluid, which provides the essential growth factors to develop the gut and mature organs. During the last trimester, the infant swallows approximately 750 mL of amniotic fluid per day (Sangild et al., 2002; Meier, Engstrom, Patel, Jegier, & Bruns, 2010). The growth factors in the swallowed amniotic fluid more than double the weight of the intestinal mucosa (2010). The healthcare professional also can explain to the mother that her colostrum is more like amniotic fluid than milk and will help the gut develop and mature after delivering prematurely. This may help her understand the importance of early pumping and feeding colostrum to her baby.

It is important to remember that mucous membranes are the defense system against all kinds of infection. Mother’s milk will help to develop a healthy gastrointestinal tract, which is essential to a healthy immune system.

It is beneficial to tell the mother that although feeding her baby breast milk exclusively provides the greatest protection for her premature infant, even providing the mother’s breast milk for 50% of daily feedings reduces the risk of infection by one-half (Rodriguez, Miracle, & Meier, 2005).

Pumping and Milk Storage

When a mother is separated from her infant, it is necessary to initiate pumping as early as possible, preferably within the first 6 hours after delivery. The mother should
receive instructions on breast massage and manual expression techniques, which can be done prior to using the electric breast pump. Combining hand expression with pumping has been found to increase milk volume (Morton et al., 2009). Providing the mother with an opportunity to put her infant skin to skin with her as early as possible has many benefits, including improved milk production and increased duration of breastfeeding (Moore, Anderson, Bergman, & Dowswell, 2012). In addition, skin-to-skin contact enhances an enteromammary response to produce immunoglobulins that protect the infant from the bacteria and viruses in the hospital environment (Calais, Dalbye, Nyqvist, & Berg, 2010).

The following guidelines should be provided to the new mother:

- Instruct the mother to pump every 2–3 hours in the daytime and at least once at night, for a total of eight or more pumping sessions in a 24-hour period.
- Provide an opportunity for pumping at the infant’s bedside. Instruct the mother on pumping techniques, including hand washing; cleaning pump equipment; and storage, labeling, and transport of EBM.
- Provide the mother with a log to keep track of her milk volume and pump sessions.
- Instruct the mother to inform the neonatologist or neonatal nurse practitioner (NNP) if she is taking any medication while providing milk for her infant in the NICU. The provider, with the lactation consultant, will need to assess the compatibility of maternal medications with breastfeeding and use of EBM.

### Storage of Human Milk for NICU and High-Risk Infants

- Freshly expressed human milk is safe at room temperature for 4 hours.
- Milk can safely be refrigerated for 2–4 days.
- Time in freezer: 1–3 months; time in deep freezer: ≤ 12 months
- Human milk that is previously frozen and cold thawed but not warm: ≤ 24 hours in refrigerator
- Milk that is being fed to an infant via continuous feeding can be safely administered over a 4-hour period.
- Storage of fortified human milk: Milk with fortifiers should be given as soon as possible after the fortifier is added and as quickly as tolerated. Time in refrigerator: ≤ 24 hours

Refer to Best Practice for Expressing, Storing and Handling Human Milk (2011) from the Human Milk Banking Association of North America for additional information (www.hmbana.org).

References


Breastfeeding Overview: Information for Parents

The benefits of breast milk for preterm infants include fewer infections, shortened length of stay in the NICU, and decreased risk of developing an allergy.

Pacifier Use for the Preterm or Ill Infant
Nonnutritive sucking, or sucking without taking milk, has been shown to have many benefits for preterm or compromised infants, especially when provided during gavage (tube) feedings. Nonnutritive sucking may be provided with a pacifier or at the emptied breast (called nuzzling). Although pacifier use during the early postbirth period has been linked with breastfeeding problems in the healthy full-term infant, pacifier use during tube feedings for preterm or compromised infants does not cause problems. Discuss nuzzling during tube feedings with your infant’s provider or NNP.

Protecting Your Milk Supply
In the early weeks following your baby’s birth, the breast pump did the work of maintaining your milk supply. It is natural to think that once your baby starts to feed at the breast, you can stop pumping. In fact, most mothers cannot wait to stop pumping. They are anxious to get rid of the pump and just breastfeed. Remember, your baby may not be strong enough to empty your breast, and you have worked so hard to get your milk supply where it is. It is important to continue to pump your breasts after your premature baby has nursed to make sure that your breasts are empty. This will make sure you continue to make enough milk. Stopping too quickly may cause your milk to dry up.

Maintaining Your Milk Supply
Consider the following ideas for maintaining your milk supply:

- Start a pumping schedule that matches your baby’s feeding schedule. Pump every 2 to 3 hours during the day and 3 to 4 hours during the night.
- Pump for about 10 to 15 minutes or until you have completely emptied both breasts. Continue to pump another 2 minutes once your milk flow has stopped.
- Drink plenty of fluids and eat three healthy meals a day.
- Keep going through the ups and downs of your milk supply.
- If your supply remains low, you might want to consider renting a hospital grade pump.

This journey you have been on toward successfully breastfeeding may be very difficult at times. You may even wonder if it is all worth the effort. Every study shows that it is worth it. Your gift of love will have health benefits for you and your baby that last for years to come.

Tips for Storing Your Milk for Your Infant at Home

- Wash your hands with warm water and soap before handling pump parts or breast milk.
- Use clean bottles or plastic nursing bags to store your breast milk.
- Write the date and time on each new bottle of pumped milk.
- Once at home, freshly expressed breast milk is safe at room temperature for 4–6 hours.
- Frozen milk can be stored in the freezer for 3–6 months.
- Thaw frozen milk in the refrigerator or in cold water and use within 24 hours.
- Do not store expressed milk in the refrigerator or freezer door; temperature variation is considered warmer inside door space.
- Do not add fresh milk to milk that is already frozen.
- Do not thaw or warm breast milk in the microwave.
Getting Information from the Healthcare Team

Studies have shown that parents who are included in care giving and decision making are less likely to suffer from depression and anxiety, are less likely to experience a loss of trust in their healthcare providers, and are more likely to feel connected with their baby (Obeidat, Bond, & Callister, 2009). Multiple stakeholders have expressed the importance of family-centered care and the importance of family inclusion as partners in care (National Association of Neonatal Nurses, 2011; American Academy of Pediatrics, 2003; Maizes, 2009).

Each member of the NICU should consider the unit’s physical layout and ability to maintain confidentiality when determining how best to include parents in rounds and exchange information about their infant. Parents should be presented not with a list of restrictions but instead with a list of options and opportunities to participate in both care and decision making. Parents should be recognized as both experts about and advocates for their child.

The following are suggestions for parental participation:

- Encourage parents to be consistent caregivers in any ways they can.
- Encourage parents to learn as much as possible about their child’s health.
- Encourage parents to ask questions, include them in rounds when possible, and encourage them to participate.
- Encourage parents to keep a journal or write down their questions.
- Encourage parents to care for themselves, too (Gracey, 2002).

References
Getting Information from the Healthcare Team: Information for Parents

You are the most important people in your baby’s life and in their care. Your baby’s healthcare team needs you to help us provide your baby’s care. There are many ways that you can do this:

- Come to the NICU as soon as you can after your baby is born. Get to know your baby. Help us learn about his or her patterns, likes, dislikes, and communication. Let your baby hear your voice and feel your touch—they are comforting and familiar to your baby.
- Learn what care you can provide for your infant (for example, taking his or her temperature, diaper changes, bathing, feeding, and calming your baby).
- If we use words you don’t understand, ask for a time out and ask us to explain what we mean.
- Talk with your baby’s caregivers often. It helps to write down questions, anything that worries you, or things about your baby to share. Talk with your baby’s bedside nurse and the doctor or nurse practitioner.
- Learn everything you can about your baby’s strengths and differences.

In this unit, the best way/time to participate is ______________. We ask that you respect the privacy of other babies and not ask questions about them or discuss them with others.

It’s important to take care of yourself, because your baby needs you. Spend time talking with your family and friends each day. Discuss your feelings and concerns. Find friends or family who can help with other things to be done or offer support. It might help to talk to a social worker or chaplain. Tell the staff if you are having difficulty eating or sleeping.

Don’t forget to ask your NICU team for information about support groups or websites that might be helpful.
Step 2
Thermoregulation is an important aspect of neonatal care that affects healthy newborns, as well as sick or premature infants. Infants need assistance with maintaining a neutral thermal environment, in which the least amount of an infant’s energy is needed to maintain a normal body temperature. Maintaining this temperature requires a balance between heat that the infant produces and heat that is lost.

At birth, an infant loses heat rapidly due to exposure in a cold delivery room (convection) or through the evaporation of fluid from the infant’s skin. An infant’s core body temperature can drop 2 °C to 3 °C in the first 30 minutes of life. An infant may lose heat quickly when placed directly on cold surfaces, such as a scale or an X-ray plate (conduction), as well as through radiation, such as through walls or windows. In order to maintain temperature after delivery, an infant will metabolize brown fat stores, glycogen stores, or both. Infants who are born early have fewer brown fat stores than healthy newborns. By being exposed to heat losses for an extended period of time, these stores may become depleted, causing the infant to develop cold stress. When an infant experiences cold stress, blood vessels throughout the body will constrict, causing systemic vasoconstriction. Vasoconstriction prevents blood flow and oxygen from being delivered to tissues, which increases the risk for organ and tissue damage. This can lead to increased oxygen needs, hypoglycemia, increased risk for blood pressure alterations, and potentially intraventricular hemorrhage when rewarmed.

Here are some ways to minimize heat loss in an infant:

- Increase the temperature of the delivery room and use prewarmed surfaces while stabilizing the infant.
- Heat respiratory gases (oxygen being breathed in from a ventilator or nasal cannula).
- Place a warm blanket on a scale or X-ray plate prior to use.
- Use a radiant warmer or double-walled isolette (shown at right) to reduce radiant heat losses.
- Use humidity for very premature infants to reduce heat loss through evaporation.
- Use developmental care, including facilitated tucking, to minimize surface area exposure.

When an infant is able to maintain temperature without radiant heat, he or she can be dressed in clothes and a hat, swaddled, and placed in an open crib.

It is also important to avoid overheating the infant while trying to maintain an infant’s neutral thermal environment. If an infant is too warm or warmed up too quickly after being cold, he or she may experience further physiological changes such as increased heart rate and
respiratory rate and the risk of dehydration and altered acid-base status. A sustained increase in body temperature can cause apnea, bradycardia, and oxygen desaturation.

Bibliography
Temperature Control: Information for Parents

Babies can sometimes have a hard time keeping their temperature in the normal range. Full-term babies have a layer of fat under their skin that helps them stay warm. When babies are born early, they don’t have as much fat under their skin.

Right after birth, your baby can get cold really fast. The best way to keep your baby warm is to dry your baby; give your baby a warm, dry bed; and place a hat on his or her head.

In the neonatal intensive care unit (NICU), one of the beds that can be used is called a radiant warmer. It is like an open crib, with a heater on it that helps your baby stay warm. Another bed your baby may use is called an isolette or incubator. This gives a preemie or sick baby extra heat to help keep his or her temperature where it should be.

When your baby is older and bigger, he or she can be dressed in clothes or a t-shirt, wrapped in a blanket, and put in an open crib or bassinet. This is one of the milestones along the journey to go home.

It is also important to make sure your baby doesn’t get too warm. Dressing your baby in too many clothes, covering your baby in too many blankets, or covering your baby’s face can make him or her too warm. For more information related to this subject, see also Safe Sleep.

Things to remember when going home:

- If your baby’s body temperature is lower than 97 °F (36 °C), undress your baby, place him or her skin to skin on your chest, wrap yourselves in blankets, and call your baby’s provider. You should also call the provider if your baby’s temperature is higher than 100.4 °F (38 °C).
- If your baby’s hands or feet are cool or look pale or blue, warm them with a blanket. You can also add a layer of clothing. If the color of your baby’s hands and feet does not improve, call your baby’s provider.
• Dress your baby in layers. To avoid overheating, add only one more layer of clothing than you are wearing if the temperature is cool, and remove a layer of clothing if your baby is warm. Use sleepers when you can.
• Remove clothes when they are wet or dirty.
• Keep your baby away from drafts and windows as much as possible.
• Keep the crib away from drafts, windows, and outside walls by placing your baby's crib on the inner wall of the room.
• Always place a hat on your baby when you go outside in cool or windy weather.
Infants born sick or premature who are admitted to the NICU frequently endure painful procedures during their stay. Procedures such as routine care, heel pricks, blood draws, intravenous catheter insertion, respiratory interventions (suctioning or intubation), and surgical procedures are painful stimuli that can have negative effects on the infant. There is a growing body of evidence showing that infants may develop long-term consequences as a result of experiencing repeated painful stimuli including emotional, behavioral, and learning difficulties. In addition, parents of infants receiving care in the NICU report that one of the greatest sources of parental stress is the worry that their baby is experiencing pain.

The prevention or reduction of pain an infant experiences should be the goal for all caregivers, as well as an expectation of the parents. Pain assessment tools are used to measure pain responses in neonates because of the infant’s inability to report pain. These tools may measure physiological indicators (e.g., heart rate, respiratory changes) and behavioral indicators (e.g., facial expressions, body movements, crying). An infant’s pain should be assessed routinely, as well as before and after procedures.

Pain prevention strategies in neonates include nonpharmacological interventions, as well as the use of pharmacologic agents such as opioids or other analgesic agents such as acetaminophen. The most effective way to alleviate pain is to reduce or eliminate unnecessary procedures. Other methods to reduce pain include developmental interventions performed by the caregiver or a parent. For routine care procedures, nonpharmacological interventions may be sufficient to reduce or prevent pain in an infant.

Nonpharmacological interventions include
- containment or facilitated tucking (swaddling, positioning)
- nonnutritive sucking (use of pacifier with oral sucrose or breast milk)
- kangaroo care or skin-to-skin contact with mother
- maternal presence during procedure
- decreasing light and noise to provide calming environment.

Bibliography
Pain Management: Information for Parents

Pain management is an important part of care in the neonatal intensive care unit (NICU). While your baby is in the NICU, the doctors and nurses are doing everything they can to make sure your baby is comfortable and not in any pain. Although it is natural for you to be worried that your baby is hurting, there are many ways to prevent pain and make potentially painful procedures more comfortable.

There are many ways to lower pain without using medications. This is called nonpharmacological pain management. This includes
- swaddling the baby snugly in a blanket
- holding the baby skin to skin, also called kangaroo care
- offering the baby a pacifier to suck on
- letting the baby nurse at the breast before, during, and after a painful procedure
- keeping the baby distracted with rocking, gentle touch, soft sounds, and low light
- giving the baby a solution of sugar water on their tongue or on a pacifier.

If your baby’s providers think that a procedure they need to do will cause more pain, they can use many safe and effective medications to help relieve that pain. This includes everything from applying numbing cream to the skin to offering medicines to stop the pain.

If you’re worried that your baby is in pain, you can ask the NICU nurses to help you learn how to tell if your baby needs something (Is your baby hungry? Does he or she need a diaper change?) or if he or she is hurting. After going home, you can continue following these tips to help your baby if you think he or she is in pain:
- Wrap your baby in a blanket to provide comfort and to help him or her feel safe.
- Give your baby a pacifier or offer breastfeeding.
- Provide skin-to-skin care by holding your baby with their bare skin up against yours (kangaroo care).
- Keep lights and noise down to provide calm.
- Talk to your baby’s provider about medicines that can help with pain.
Developmental Care

What Is It and Why Is It Important?
Preterm infants are hospitalized in a care environment, which is very different from the maternal womb, where optimal growth and development of the fetus occurs. Therefore, the application of developmental care principles in the NICU is critical to improve neurodevelopmental outcomes of preterm infants. Developmental care is a strategy to help reduce the amount of environmental and sensory stress that a premature infant is exposed to after birth.

Developmental care practices can be predictive of long-term neurobehavioral outcomes in preterm infants. In one study (Montirosso et al., 2012), infants from NICUs with high scores in infant-centered care had higher attention and regulation, less excitability, less hypotonicity, and lower stress scores than infants discharged from lower scoring units.

There are many aspects of developmental care. These include family-centered care principles such as
- open visitation and kangaroo care (shown below)
- infant behavioral or “cue” monitoring
- positioning (providing boundaries and avoiding “W” placement of extremities [shown at top right])
- handling (avoiding the “preemie flip,” when infants are turned rapidly; telling infants when they will be touched)
- bathing (should be a family intervention)
- helping infants regulate themselves.

Remember, there is no time when developmental care is not appropriate, because routine care is never innocuous to neonates.
Reference

Bibliography
As a preemie, your baby needs special care and attention. While your baby is in the neonatal intensive care unit (NICU), the staff will try to create an environment that is safe, quiet, and more like being in the womb than being in a noisy, busy hospital. They will do this by keeping the lights low, using soft voices, and positioning your baby’s body so that it is cradled in the isolette. Bright lights and loud noises may bother your baby, especially if he or she is very premature or very sick.

The staff will be very gentle with your baby. This is because a premature baby’s skin can be very fragile and sensitive to touch. You also may find that your baby needs to be held or positioned in certain ways to be calm and comfortable. Learning the best way to care for your baby now can help him or her grow and develop down the road.

Most of the time, preemies and sick babies are asleep. It is best to avoid waking them because they need sleep to grow and get well. As babies get closer to full term and get stronger, they will be able to stay awake for longer periods of time. Preemies and sick babies are very sensitive to overstimulation. Try to focus on one of your baby’s senses at a time. For example, touch your baby and then talk to him—not both at the same time.

Babies develop the sense of touch early so they can be very sensitive. Ask your baby’s nurse to help you use touch in a positive way. This might include

- using a constant, firm but gentle touch; a back-and-forth touch like stroking or massaging can be too much for a premature baby
- gently cupping one hand under the head and another hand on the bottoms of the feet to support a fetal position
- using skin-to-skin contact (also called kangaroo care) as soon as your baby is ready, putting your finger in your baby’s hand so he or she can hold it.

Babies use taste and smell to know who their parents are while they are in the womb. They continue to use these senses to get to know you during their NICU stay as well. Be sure to not wear perfumes or scented lotions. Some mothers can place a cloth that smells like their breast milk in their baby’s isolette. This smell is unique to you and can help your baby connect and bond with you.

Over time you also will learn to read your baby’s cues. Cues are things your baby does that show what he or she is feeling. Ask your NICU nurses to teach you what your baby is saying by the way he or she is acting. Learning to read your baby’s cues will help you care for your baby when you go home together. For example, you will learn the difference between the angry cry and the hungry cry. Also, you’ll know whether your baby, when given a pacifier, either just doesn’t like it or needs you to hold it in his or her mouth. Eventually, you will be the expert and will know what your baby needs to grow and develop.
Having an infant in the NICU can be a stressful time for parents. Infants are admitted to the NICU for a variety of reasons, including prematurity, infection, and respiratory complications. Most of these are unexpected and distressing for the family. Parents of a sick or premature infant can experience many emotions and display different responses to their baby being in the NICU.

Some common emotions and responses to having an infant in the NICU can include:

- fear of the unknown
- guilt for having the baby early or feeling responsible for what happened
- grieving the loss of a typical birth experience and not having a healthy baby
- feeling helpless to comfort their infant
- fears their infant will experience pain
- frustration over being separated from their infant
- fear of the future and the financial burden a NICU admission can cause.

Parents can see the NICU as a foreign and overwhelming environment, and many have reported that the inability to hold their baby and protect them from experiencing pain is a great source of stress. It is important to help reduce parents’ stress by giving them opportunities to be involved and to have some control in their infant’s care. Remember, parents often don’t know what to ask and can be so distraught that they don’t remember what was said to them. Be patient—parents may ask the same question several times.

Parents can be involved in their infant’s care by:

- asking questions (multiple times, if needed)
- providing routine care, such as taking their baby’s temperature and changing his or her diaper
- being present and placing their hands on the baby to help console him or her during painful procedures
- providing skin-to-skin contact (kangaroo care)
- holding or feeding their baby, when he or she is medically stable.

It has been shown that facilitating quality parent-infant interaction during the infant’s stay in the NICU can help parents acquire a sense of confidence when taking their infant home.

Remember, too, that it is important to include fathers. Although fathers may have some of the same feelings about having a sick baby, they will outwardly react differently in most cases. Just because the father appears to have it all together does not mean he does.

Bibliography


Parenting in the NICU: Information for Parents

Having a baby born very early or sick can be distressing for parents. The neonatal intensive care unit (NICU) can be a scary place because of all of the sounds and machines that are used. You may have many overwhelming feelings about your baby being sick: you may be feeling sad, guilty, scared, or worried about your baby and what is going to happen. Mothers and fathers often have many of the same feelings about having a sick baby, but they will show those feelings differently—and that’s okay. Be patient with each other. It’s okay to ask questions—and you can ask the same question again if you don’t understand or don’t remember the answer.

At first, your baby may be too sick to hold, and noise and lights may be too much for them. One way you can help your baby is to gently touch or talk to him or her in a quiet voice. You play a very important role in your baby’s care and ongoing development. Your presence at the bedside is very comforting to your baby, who knows your voice and scent. Your voice can help your baby be calm so he or she can grow and get better. Once your baby is feeling better, your nurse will show you how you can place your hands on your infant to help your baby feel secure.

As your baby feels better, the nurse will let you know when you can help with your baby’s care. Being involved in your baby’s NICU care will help you feel more comfortable caring for your baby once you go home. There are many ways you can interact with your baby during the NICU stay, including talking, reading, and singing. You can change your baby’s diaper, take his or her temperature, and possibly hold your baby. You (mom or dad) can also give your baby skin-to-skin care, called kangaroo care. This will help you get to know your baby and help your baby be calm and quiet.

As your baby gets bigger and stronger, you will get to hold your baby more and feed him or her. When your baby is able to do these things, you are one step closer to going home!
**Newborn Screening**

Newborn screening tests look for serious developmental, genetic, and metabolic disorders so action can be taken during the critical time before symptoms develop. Most of these illnesses are very rare but treatable if caught early.

In the United States, individual states regulate newborn screening, so the diseases screened for vary considerably from state to state. Most states require three to eight tests, but organizations such as the March of Dimes and the American College of Medical Genetics suggest more than two dozen additional tests.

The most thorough screening panel checks for about 40 disorders. All 50 states screen for congenital hypothyroidism, galactosemia, and phenylketonuria (PKU).

Screening tests do not diagnose illnesses. They identify which babies need additional testing to confirm or rule out illnesses. Remember, a negative screen does not mean that the disease is not present—it may mean that the baby was screened too early or that there were insufficient amounts of metabolites in the blood to reach the threshold for a positive result (sensitivity of the test). If the baby is showing signs and symptoms of concern, always do follow-up testing. If follow-up testing confirms that the infant has a disease, appropriate treatment can be started right away, before symptoms appear.

Normal values for each screening test may vary depending on how the test is performed. Each state laboratory should have established “normal ranges” for the newborn screening program and individual tests.

Each state has independent screening programs. To find out specifics on your state screening program, visit http://genes-r-us.uthscsa.edu.

Screening tests in state programs may include

- amino acid metabolism disorders
  - arginosuccinic acidemia
  - citrullinemia
  - homocystinuria
  - maple syrup urine disease
  - PKU
  - Tyrosinemia type I
  - biotinidase deficiency
  - congenital adrenal hyperplasia
  - congenital hypothyroidism
  - cystic fibrosis (see also neonatal cystic fibrosis screening)
  - fatty acid metabolism disorders
    - carnitine uptake deficiency
    - long-chain L-3-hydroxyacyl-CoA dehydrogenase deficiency
    - medium-chain acyl-CoA dehydrogenase (MCAD) deficiency
    - trifunctional protein deficiency
    - very long-chain acyl-CoA dehydrogenase deficiency (VLCAD)
  - galactosemia
  - glucose-6-phosphate dehydrogenase deficiency (G6PD)
  - organic acid metabolism disorders
    - 3-hydroxy-3-methylglutaric aciduria (HMG)
    - 3-methylcrotonyl-CoA carboxylase deficiency (3MCC)
    - beta ketothiolase deficiency
    - glutaric acidemia type I
    - isovaleric acidemia
    - methylmalonic acidemia
    - multiple carboxylase deficiency
    - propionic acidemia
  - sickle cell disease and other hemoglobinopathy disorders and traits.

**Bibliography**


Newborn Screening: Information for Parents

All newborn babies are given tests before they leave the hospital to identify possible serious or life-threatening conditions that they may have, even if they don’t have symptoms. Serious diseases are rare. Some disorders can slow down an infant’s normal physical and mental development in a variety of ways. Parents can pass along the gene for a certain disorder without even knowing that they carry the gene. Most disorders can be treated if found early, but not all disorders found during screening can be treated.

The following are excellent resources if you need more information about genetic screening:

- National Newborn Screening and Genetics Resource Center: www.genes-r-us.uthscsa.edu
- American College of Medical Genetics: www.acmg.net
- March of Dimes: www.marchofdimes.com/pnhec
- Baby’s First Test: www.babysfirsttest.org

Most tests use a few drops of blood collected on a special sheet of paper by pricking the baby’s heel. If a screening test suggests a problem, your baby’s provider will follow up with more testing. If those tests confirm a problem, the provider may refer you to a specialist for treatment. Even though these conditions are considered rare and most babies are given a clean bill of health, finding disorders early and giving proper treatment can make the difference between lifelong challenges and healthy development for your child.

Although individual states may not perform all screening tests, parents can have additional tests done by qualified laboratories at large medical centers. Private laboratories also offer newborn screening. Parents can find out about extra newborn screening tests from their provider or the hospital where their baby was born, as well as through organizations such as the March of Dimes.

An abnormal result means that the baby should have additional testing to confirm or rule out the condition, but remember, normal value ranges may vary slightly among different laboratories. Talk to your baby’s provider about the meaning of your specific test results.
Step 3
Kangaroo Care

*Kangaroo care*, or skin-to-skin care, involves having an unclothed infant (wearing diapers only) lay directly on a parent’s chest. Instruct the parent to remove all jewelry and not wear any perfume, and discourage the use of cell phones during this time. If a parent is a smoker, ask him or her to bring a clean shirt to the hospital and change into it before participating in skin-to-skin care. You may have to ask them to wash their chest prior to kangaroo care, as well. A standing transfer is preferred because it is less disruptive for the baby. The family member can prepare himself or herself while the nurse prepares the baby. The process of providing kangaroo care will take at least 1 hour, so the infant and family member should be prepared for this extended experience.

Nurse preparations are as follows: change the diaper, then assess and record the infant’s status, including temperature, oxygen saturations, vital signs, breath sounds, and position of indwelling tubes. Suction the endotracheal tube if necessary. Place a blanket under the infant and position supine next to the door of the isolette. The family member can then open his or her shirt, place their hands under the blanket, and draw the baby toward his or her chest. If the infant is intubated, ask for help from another nurse or a respiratory therapist to help maintain tubes and lines in place. Disconnecting briefly from the ventilator during the transfer process is advised.

Alternatively, the family member can be seated and the nurse can perform the transfer, placing the infant on the family member’s chest. The infant is then covered with a warm blanket and a hat is placed on the infant’s head. Position the baby flexed with the head in a sniffing position to maintain the baby’s airway. Help the family member get into a comfortable position.

Once the baby has settled into place, continue to frequently monitor the baby, including vital signs and respiratory status. Set the isolette temperature to maintain a neutral thermal environment until the baby is returned to the bed. Benefits of this activity include pleasant sensory stimulation to the infant, increased oxygenation, stability of respirations, and enhanced bonding. Other benefits include regulation of heart rate, temperature, and a decrease in infections. This activity can be continued at home after the infant is discharged.

**Bibliography**


Kangaroo Care: Information for Parents

Kangaroo care is a way of holding a sick baby so that there is skin-to-skin contact with the parent. It is used to help form the special mother-baby bond following sudden separation during the birth experience. Kangaroo care is important for fathers, too!

There are many benefits to kangaroo care. These include keeping your baby warm, helping your baby gain weight, improving your baby’s heart rate and oxygen level, and increasing mom’s milk supply, as well as increasing the special antibodies in the breast milk that help protect your baby from infection. Some research shows long-term effects include helping with your baby’s brain function and growth.

Here’s what you need to know about kangaroo care:

• This type of holding your baby usually begins before a feeding and continues for the duration of the feeding. Talk to your nurse about how kangaroo care is done in your baby’s unit.
• You will hold your baby for at least 1 hour and up to 3 hours.
• Use the bathroom before kangaroo care.
• Mom or dad will open his or her shirt. (Button-down shirts work well and can be left at the bedside. Mom will want to remove her bra.)
• A standing transfer is easiest for the baby. The nurse will initially assist you in preparing the baby for transfer. He or she will place a blanket under the baby and secure any tubes that may be necessary. You will stand next to the baby’s isolette, place your hands under the blanket, and draw the baby toward your chest while the team assists you with maintaining secure tubes and lines. Once you have the baby secure against your chest, you can step backwards toward the chair and sit. Alternatively, the nurse will place your baby on your chest after you sit down. Some units may have special chairs designed just for kangaroo care.
• Your baby will be covered snuggly with a blanket.
• Do not wear chains or necklaces.
• No loud conversations with visitors should take place during this time.
• For the safety of your baby, please do not sleep while holding your baby. Your nurse will check on you and your baby frequently during kangaroo care. Use of cell phones is not recommended during your visit in the NICU.

As soon as your baby is stable enough to hold, you may start kangaroo care. We strongly encourage this special type of holding at least once per day. The wonderful thing about kangaroo care is that you can continue it even after you are home.
Skin Care

Promoting skin integrity in the neonate is a priority for the neonatal nurse. The premature infant’s skin is thinner than that of a full-term infant, making it more susceptible to problems. The neonatal nurse must therefore exercise caution when handling and cleansing the neonate’s skin. One of the most important steps a nurse and visitors in the NICU can take is to wash their hands with antibacterial cleansers before making contact with the premature infant (Gardner, Carter, Enzman-Hines, & Hernandez, 2011). This helps decrease the spread of all infections, especially methicillin-resistant *Staphylococcus aureus* (MRSA). The nurse should perform a thorough skin assessment at least once a day to identify any skin breakdown and to promote skin integrity.

**Bathing**

The tub that is used for bathing the neonate should be disinfected before and after each use. When bathing an infant, create a neutral thermal environment so that the infant is less likely to lose heat. Precautions such as keeping the bath water temperature between 38 °C and 40 °C, keeping the room temperature warm, and using prewarmed towels prevent the infant from becoming hypothermic. The length of the bath should be kept to a minimum to ensure that the infant stays physiologically stable (Association of Women’s Health, Obstetric and Neonatal Nurses [AWHONN], 2007). The cleansing agent used for bathing should have a neutral pH and minimal dyes. Further, the infant should be bathed no more than every other day (Gardner, Carter, Enzman-Hines, & Hernandez, 2011); this ensures that the skin does not become overly dry. It is also recommended that preterm infants less than 32 weeks old should be cleansed with warm-water baths only during the first week of life, and rubbing the skin should be avoided during the bath to maintain skin integrity (AWHONN, 2007).

**Vernix**

Residual vernix does not have to be removed after birth, because it acts as a protective skin barrier and allows the infant to better adapt to the dry extrauterine environment. The World Health Organization (WHO) recommends leaving vernix intact after the infant is initially dried following birth. Vernix helps to protect against infection, is a natural water-containing barrier cream, helps with wound healing, and does not affect auxiliary temperature readings. Vernix should be left in place to naturally wear off with normal care (AWHONN, 2007). Scrubbing vernix after delivery may cause skin breakdown by damaging the fragile epidermis of the neonate.

**Cord Care**

After birth, the neonate’s cord should be cleansed with tap water to remove debris and thoroughly dried. The routine use of antimicrobial sprays, creams, or powders on the umbilical stump has not been shown to be more effective in preventing infection than allowing the cord to dry naturally (Gardner et al., 2011). If the cord becomes soiled, it can be cleaned with water and dried with absorbent gauze to remove excess water. The diaper should be folded down and away from the umbilical stump to keep the stump clean and dry. Current evidence shows that cord separation time is shorter with dry cord care than by applying isopropyl alcohol to the cord daily. Research also shows that triple dye on the umbilical stump had the longest separation time compared with dry cord care and alcohol cord care (AWHONN, 2007). Further, triple dye can cause skin necrosis when used on the umbilical stump (AWHONN, 2007).

**Emollients**

Emollients help protect the integrity of the neonate’s skin by keeping it hydrated and should be used at the first sign of dryness. The emollient should be applied gently to the skin to prevent skin irritation and breakdown (AWHONN, 2007). The container should be kept away from contamination and the contents kept sterile.
Transepidermal Water Loss (TEWL)

Because preterm infants have a smaller stratum corneum, which controls evaporative heat loss, they are more likely to develop transepidermal water loss (TEWL; Gardner et al., 2011). The preterm infant who is less than 28 weeks gestation can be placed in a polyethylene wrap immediately after birth to help maintain body temperature. The infant should not be dried before being placed in the bag from the shoulders down. The wrap should be removed after the infant has stabilized in the NICU (AWHONN, 2007). Humidity set at 70% to 90% for the first 7 days of life should also be used to reduce TEWL and evaporative heat loss, with servo-controlled isolettes recommended. The level of humidity should then be gradually decreased to 50% until the infant is 28 days old; evidence shows that this helps to mature the skin faster with no increased risk of dehydration or hyponatremia (AWHONN, 2007).

Skin Disinfection

Decontamination of the infant’s skin before invasive procedures is a common practice in the NICU. Due to the fragile nature of the neonate’s skin, there have been reports of skin injury and chemical burns from using such substances as 2% chlorhexidine gluconate in 70% isopropyl alcohol on very-low-birth-weight infants (AWHONN, 2007). Further, when iodine is used as a cleansing agent, it can be absorbed through the infant’s thin skin, which can affect the thyroid gland. Some disinfectants must be removed after the procedure has been completed. One such disinfectant is chlorhexidine gluconate (AWHONN, 2007). In such cases, sterile water or saline should be used to prevent adverse outcomes (further skin absorption or chemical burns). Isopropyl alcohol should be avoided as a primary disinfectant, because it can cause drying to the skin and chemical burns (AWHONN, 2007). No disinfectant agent comes without risks, but it is important that the nurse understands the possible risks and uses the most current evidence to guide his or her nursing practice.

Adhesives

Adhesives can alter skin barrier function when they are removed and strip the epidermis and cause skin breakdown (AWHONN, 2007). Therefore, adhesives should be used sparingly, and a thin barrier should be applied before applying the adhesive. To prevent skin trauma from adhesive use, the nurse should consider minimizing the use of tape, applying cotton to the back of tape prior to application, and delaying adhesive removal until adherence has decreased. Pectin barrier removal should similarly be delayed until adherence has decreased, as well (Gardner et al., 2011).

To reduce skin trauma, the nurse should remove the adhesive slowly with water-soaked cotton balls or gauze and pull the tape close to the skin surface while holding the skin in place. Adhesive-removing solvent should not be used in the newborn due to the risk of absorption. Bonding agents can also cause damage to the infant’s skin upon removal (AWHONN, 2007).
Penile Care
With an uncircumcised penis, the foreskin should not be forcibly retracted; doing so can cause tearing, which can lead to adhesions (AWHONN, 2007). After a circumcision has been performed, the nurse should closely inspect the skin and remove any skin disinfectant still present with sterile water or saline. Following the circumcision, the penis should be covered with petroleum gauze for at least 24 hours to promote healing. With a circumcision that involves a plastic device, petroleum use should be determined by the provider doing the procedure. Some believe it should not be used, because it may cause the device to move out of place; others will suggest the use of petroleum to prevent adhesions. Once the plastic device falls off, place petroleum jelly over the tip. This will keep the foreskin lubricated while healing.

The newly circumcised penis should be cleansed with water only for the first 3–4 days, because soaps can be more irritating to the skin.

Diaper Dermatitis
Diaper rash can occur after 1–3 weeks of life and can be caused by prolonged contact of the skin with urine and feces. To care for a diaper rash, use soft cloths and water or disposable diaper wipes that have no added detergents or alcohol (AWHONN, 2007). Encouraging breastfeeding also decreases the chances of diaper rash, because breastfed infants have stools that are less caustic to their skin than formula-fed infants. Petroleum-based lubricants or barriers can provide a layer that protects the skin from injury (AWHONN, 2007). Keep in mind that vigorous rubbing to remove traces of these barriers should be avoided because doing so can cause more damage to the skin. Diaper dermatitis can be complicated with a fungal infection and should be treated accordingly with antifungal ointments or creams. The use of powders should be avoided due to the risk of promoting bacterial and yeast growth (AWHONN, 2007). Most important to preventing diaper dermatitis is keeping the skin dry and maintaining a normal skin pH (Gardner et al., 2011). This means that frequent diaper changing is necessary.

Skin Excoriations
Specific measures that can minimize the risk of skin breakdown include using devices (such as gelled mattresses, pads, and sheepskins) to help prevent pressure sores, applying transparent dressings over bony prominences (knees and elbows), and applying petroleum ointments to the groin and thigh of very-low-birthweight infants (AWHONN, 2007). Skin excoriations can be cleansed with warmed sterile water or saline to gently debride the wound, and moistening helps with the healing process. Ointments may be used on the excoriation, along with transparent dressings on uninfected wounds (Gardner et al., 2011).

References
Skin Care: Information for Parents

While your baby is in this unit, he or she will have special doctors and nurses. Your baby’s nurses will look at your baby’s skin to make sure it is not broken or red. Your baby has very fragile skin that has to be touched gently. As your baby gets older, his or her skin will not be as fragile. Talk with your baby’s nurses about ways to move your baby that protect his or her skin.

Remember to always wash your hands with soap and water for at least 15 seconds before touching your baby. You should scrub your hands very well while washing them and clean underneath your fingernails. Also, clean between each of your fingers and the top of your hands. You should also wash your hands after changing your baby’s diaper and before you make your baby’s bottle. Washing your hands will help prevent your baby from getting an infection. Those caring for your baby will be doing this, too.

Your baby’s nurses will tell you about the different things that they will do to or use on your baby’s skin. The nurses will also show you how you can help take care of your baby’s skin until you go home.

Bathing
You may see your baby’s nurses clean the bathtub before and after a bath. This is done to help prevent infection. The soap you use on your baby should be fragrance-free to help protect his or her skin. You may also find that your baby’s nurses use only water when giving your baby a bath. This is because your baby was born early, and soap is not needed right now. Later on, your baby will get a bath with soap. You do not need to give your baby a bath more than once every few days. By not bathing your baby every day, you are helping to keep his or her fragile skin safe and not dried out.

Vernix
Your baby may have a white, cheesy covering on his or her skin called vernix (ver-nicks). This is normal and is a natural covering to keep your baby’s skin moist and free from infection. Sometimes this covering is left on your baby’s skin. This will help to keep your baby’s skin moist and intact. It is not necessary to scrub this covering off of your baby’s skin. This can hurt your baby’s fragile skin. Instead, the covering is left in place until it comes off by itself.

Cord Care
After your baby is born, the umbilical cord is clamped and cut, leaving a stump. If it becomes dirty, this stump can be cleaned with water and dried well. It is not necessary to use alcohol wipes to clean the cord. The best way to keep your baby’s cord free from infection is to make sure that it does not get dirty from your baby’s diaper. You should fold the front of the baby’s diaper down when changing him or her to make sure the stump does not get wet. You should also look at the cord daily to make sure it is not red or hot or has any drainage. These are signs of infection, and you should tell your baby’s providers or nurses if you see them.

Cream to Protect Your Baby’s Skin
The nurses may put a clear cream on your baby’s skin. This helps to keep your baby’s skin from becoming too dry. When your baby’s skin is too dry, it can crack more easily. Talk with your baby’s nurse or medical provider about creams or lotions that can be used on your baby’s skin. If you apply the clear cream to your baby’s skin, make sure the container does not get dirty, because this can raise the risk of a skin infection.

Water Loss
Your baby’s skin is very thin and fragile. Because of this, your baby’s skin can dry out very easily. Depending on how early your baby was born, your baby may have been wrapped in a plastic bag from the shoulders down right after he or she was born. This helps to keep the baby warm and to keep his or her skin moist. Remember that your baby can get cold very easily. The plastic bag will also help to prevent that. Your baby might also have been placed into an isolette, which is a special “house” that keeps your baby warm and lets the nurses keep track of your baby’s temperature. Sometimes when your baby is in the isolette, the nurses will keep the air humid inside of
Keeping Your Baby Free from Infection
Your baby may need to have his or her skin cleaned with a special cleansing agent before certain procedures are performed. You may see your baby’s skin cleaned with different types of cleansing wipes. This helps protect your baby from an infection. Feel free to ask any questions that you may have about the special cleansing agents or the procedures being performed.

Tape
You may see your baby’s nurses use different kinds of tape on your baby. The nurses may put a protective piece of tape on your baby’s skin and then put another kind of tape on top of that. This helps to keep your baby’s skin intact. Since your baby has very fragile skin, the nurses will help keep it safe with different kinds of tape. When the nurses remove the tape, they will do it slowly and may use water to keep your baby’s skin from breaking. Your baby’s nurses may also leave the tape in place even though your baby may not need it anymore. This is because your baby’s nurses are waiting for the tape to come off by itself. This will help keep your baby’s fragile skin intact and protect your baby from getting an infection.

For Baby Boys
You may or may not decide to have your baby boy circumcised (sir-cum-sized). This procedure is used to remove skin toward the tip of the penis. Caring for your son differs based on whether or not you choose to have your son circumcised. For a natural penis, you should not pull the skin down to clean around your baby’s penis. This can cause your baby’s skin to tear. Instead, leave the skin in place and gently clean around the penis if needed.

For a circumcised penis, make sure that you cover the penis with a petroleum product (such as Vaseline®) and gauze with each diaper change for as long as your baby’s nurses tell you to do so. Sometimes, depending on how your baby’s provider performed the circumcision, your baby’s nurses may tell you not to use petroleum and gauze on your baby. Be sure to ask questions about caring for your baby’s circumcision.

For circumcised boys, the tip of the penis may seem raw or yellowish. When gauze is used, it should be changed with each diapering to reduce the risk of infection. Use petroleum jelly to keep the gauze from sticking to the diaper. Sometimes a plastic ring is used for circumcision. This should drop off within 5–8 days. It may be recommended that you use petroleum jelly on the tip of the penis with either procedure to keep the foreskin lubricated; be sure to follow the instructions from the hospital. The penis should be fully healed about 7–10 days after circumcision.

Diaper Rash
Diaper rash is when your baby has redness and irritation around his or her buttocks. To prevent a diaper rash, frequently change your baby’s diaper, especially after they poop. To care for a diaper rash, clean the area with soft cloths and water. You can also clean the area with diaper wipes that are chemical-free. Your baby may also have a special cream that should be applied each time the diaper is changed. Sometimes, your nurses will tell you not to wipe off all of the cream, but to only gently wipe around the buttocks. This will keep your baby’s skin intact and allow it to heal.

Other Skin Information
Depending on how early your baby was born, you may see your baby’s nurses use special techniques to keep your baby’s skin from tearing, including placing special pads underneath your baby or placing clear coverings on your baby’s knees or elbows. Clear creams also help to keep your baby’s skin moist and stop it from being torn. Ask your baby’s nurses about ways you can help keep your baby’s skin from tearing.
Newborn Jaundice

Newborn jaundice, or hyperbilirubinemia, develops when red blood cells (RBCs) are broken down and release bilirubin. The liver helps metabolize bilirubin so that it can be excreted in urine or stool, but when the rate of RBC breakdown exceeds the rate of elimination, it results in a buildup of bilirubin in the body. Jaundice can be the result of excessive numbers of RBCs breaking down (as in Rh or ABO incompatibility), bruising, polycythemia, or from a slow rate of metabolism and elimination, as can occur with an infection, lack of enzyme activity, dehydration, or constipation. Bilirubin build up can manifest itself as a yellowish color of the sclera and skin of an infant. This skin color progresses in a cephalocaudal pattern (head to toe). Jaundice becomes particularly harmful when the level of the bilirubin in the blood is too high because it can cross the blood-brain barrier and deposit into the cells of the brain and spinal cord, resulting in bilirubin encephalopathy. The goals of assessment and therapy are to initiate phototherapy and prevent the bilirubin from climbing to dangerous levels. In the event that it rises and approaches critical levels, an exchange transfusion can be done. This process consists of removing small volumes of blood while replacing them with fresh, whole donor blood or normal saline (in the case of polycythemia). Infants of Chinese, Japanese, Korean, Native American, and Greek descent are at higher risk for having hyperbilirubinemia. Methods to determine the level of bilirubin present include transcutaneous instruments and sampling the serum. The transcutaneous assessments have not proven reliable beyond a certain level and thus have limitations associated with the instrument. Serum assessment is more reliable when the levels are elevated. Visual inspection alone is not sufficient to determine bilirubin levels. Even if a test is in the normal range, based on the infant’s age (in hours) and the rate of increase, the bilirubin level can rise and cross into a dangerous zone (see figure on next page).

An infant with significant risk factors and climbing levels is not a candidate for early discharge. When an infant is discharged, it is necessary for parents to keep appointments for jaundice evaluation and further bilirubin tests. It is important to give regular feedings (every 2–3 hours) to promote an active pattern of stooling and to provide adequate hydration and elimination. Parents need to be informed of signs indicating that the bilirubin level is too high, including fussiness, limp or floppy tone, stiffness in arms or legs, arching of the neck or back, high-pitched cries, or sleepiness. Any change in level of response (consciousness) should be reported immediately.

Bibliography
Hyperbilirubinemia Levels

* Use total bilirubin. Do not subtract direct reacting or conjugated bilirubin.
* Risk factors = isoimmune hemolytic disease, G6PD deficiency, asphyxia, significant lethargy, temperature instability, sepsis, acidosis, or albumin < 3.0g/dL (if measured)
* For well infants 35-37 6/7 wk can adjust TSB levels for intervention around the medium risk line. It is an option to intervene at lower TSB levels for infants closer to 35 wks and at higher TSB levels for those closer to 37 6/7 wk.
* It is an option to provide conventional phototherapy in hospital or at home at TSB levels 2-3 mg/dL (35-50mmol/L) below those shown but home phototherapy should not be used in any infant with risk factors.

Newborn Jaundice: Information for Parents

When an infant’s skin has a yellowish or orange color, this is known as **jaundice**. Jaundice occurs when red blood cells are broken down. This gives the baby’s skin a yellowish color. Bilirubin is released from the red blood cells. The liver helps break down the bilirubin so it can be removed from the body in the stool. Sometimes special blue lights are used on infants whose levels are high. This is called **phototherapy**. These lights work by helping to break down bilirubin in the skin. The infant is placed under artificial light in a warm, enclosed bed to maintain constant temperature. The baby will wear only a diaper and special eye shades to protect the eyes. Treatment can last 1 to 2 days and further testing called a bilirubin test will be done. Babies who were born early, bruised during delivery, or have a different blood type from their mothers have a higher risk of getting jaundice. Jaundice becomes harmful when the level of bilirubin in the blood is very high.

The only way to know the level of bilirubin in the blood is to test the baby’s blood. Even if a test is normal, the bilirubin level can sometimes rise. When a baby is sent home, a follow-up appointment with your baby’s provider will be made. This appointment will help decide if an additional bilirubin test is needed.

If your baby is more mature and able to feed normally, it is important to feed your baby every 2–3 hours. Frequent feedings will help your baby poop more often so that the bilirubin is removed from his or her body. You can check for jaundice by pressing a fingertip on your baby’s nose, cheek, or forehead. When you remove your fingertip, the pressed area should look lighter for a few seconds before turning pink. If the area is yellow after your fingertip is removed, this shows that your baby has jaundice. This process can be repeated on the upper chest and tummy area. Jaundice starts in the face, moves down to the tummy area, and then spreads to the legs and feet.

Look for signs that show that your baby’s bilirubin might be too high, including fussiness, stiffness in arms or legs, arching of the neck or back, high-pitched cries, or sleepiness. Phototherapy is used to prevent your baby’s bilirubin from rising. The light waves in phototherapy change the bilirubin in the skin to a substance that is easily removed in the urine or stool. If your baby is under the lights, it is important to keep his or her eyes covered (to protect him or her from the light) and have as much skin exposed as possible. Phototherapy is safe and can sometimes be done at home.
Step 4
Basic Baby Care

Basic baby care incorporates the daily routines of elimination, cord care, and bathing. It is an essential part of discharge education, but it includes a lot of information that may overwhelm parents. When teaching basic care, it may be a good idea to break up the content and set priorities by following the parents’ cues.

Elimination
Elimination patterns will be determined by breastfeeding or formula-feeding patterns of the infant. It is important to be aware of elimination patterns to distinguish problem signs from normal elimination. Normal elimination includes six to eight voids per day. Changes in the color and consistency of the stools will depend on feeding type. Formula-fed infants will have fewer stools compared with breastfed infants. The stools of formula-fed infants are pasty to semiformed; breastfed infants’ stools will be looser, with some consistency in the texture. Instruct parents to cleanse the genitals daily and with diaper changes, noting any skin irritations. Infrequent diaper changes and diarrhea can contribute to diaper rash, so diapers should be checked often. Over-the-counter zinc oxide ointments may be used if diaper rash is noted.

Cord Care
The umbilical cord should be kept clean and dry. In recent years, the use of triple dye and alcohol for cord care has been shown to prolong separation time. Signs of infection should be noted with each diaper change, and the cord should fall off around 10–14 days after birth. A granuloma is often seen once the cord separates, appearing as a small, raw, red polyp. The granuloma may need to be treated with silver nitrate by the infant’s provider if it does not heal on its own.

Bathing and Skin Care
Bathing is an opportunity to observe the infant’s skin condition. Daily bathing is not recommended because it alters the skin’s pH, disrupts the integrity of the skin, and may cause excessive dryness. The infant’s age will determine if a sponge bath or tub bath is appropriate. All infants should be sponge bathed until their cord falls off and heals.

Unscented, mild baby soap (avoid alkaline soaps) should be used for cleansing the skin to protect the pH. The newborn’s skin has an acid mantle that is formed from the epidermis, superficial fat, and amniotic fluid, which can be a medium for bacterial growth when altered by alkaline soaps. Steps to prevent heat loss are an important part of bath time. If the infant is stable, immersion bathing is appropriate and has been found to lessen heat loss as well as crying. Developmental bathing, in which the infant is swaddled while in the tub, with only one body part unwrapped at any one time, is recommended for premature infants. Dry the infant immediately after bathing to prevent further heat loss.

Bathing is one of those tasks that allows parents to bond with and get to know their infant. This increases parental feelings of competency and confidence and will lower overall anxiety. Bath time is also a good opportunity for parent-infant interaction. Parents should talk to their infant and engage their infant in play activities.

Clothing
A common concern parents have is how to dress their infant. It is best to recommend that parents dress infants as they would dress themselves. Keep in mind that overdressing may cause overheating and is linked to increased risk of sudden infant death syndrome, and an uncovered head leads to excessive heat loss in cold weather.

Bibliography
Basic Baby Care: Information for Parents

It is important to understand how to care for your baby to meet his or her basic needs. Basic care activities such as diaper changes, cord care, and bathing are a good time for parent-baby interaction and will be part of your daily routine with your baby. While caring for your baby, you can talk and play with your baby. We want you to care for your baby while in the neonatal intensive care unit (NICU) so you are ready to continue caring for your baby when you go home. The nurses will help teach you how.

Elimination and Diaper Changes
Your baby will need his or her diaper changed several times a day. You should check your baby’s diaper often and with each feeding. The number of bowel movements and stool consistency depends on your baby’s feeding method.

- Formula-fed babies may have as few as one bowel movement every other day and poops may be pasty to semiformed in consistency.
- Breastfed babies may have three or more bowel movements a day and stools may be loose in consistency, like mustard mixed with cottage cheese.
- You can expect six to eight wet diapers a day.
- Clean the genitals daily and as needed with each diaper change using unscented, non-alcohol based, mild soap, baby wipes, or a washcloth and water. For girls, clean the genitals by separating the labia and gently washing and rinsing from the pubic area to the anus. For uncircumcised boys, gently wash and rinse the tip of the penis. When a gauze is used for circumcised boys, it should be changed with each diaper to reduce the risk of infection. Use petroleum jelly to keep the bandage from sticking to the diaper.
- Secure the diaper with the tabs, making sure the diaper does not cover the cord.
- Wash your hands after each diaper change.

Cord Care
- Clean around the base of the cord where it joins the skin with soap and water.
- Keep the cord dry.
- Do not bathe your baby in a tub until the cord falls off and is healed.
- You can expect the cord to fall off between 10–14 days after birth.
- Inspect the cord for signs of infection (foul odor, redness, drainage) and report them to your baby’s provider.

Bathing and Skin Care
Bathing gives you a chance to clean and observe the condition of your baby’s skin. Your baby’s skin is sensitive. Use unscented, mild baby soap for bathing. Sponge or spot bathing is often done until your baby’s umbilical cord falls off and heals. As your baby gets older, you can give your baby a tub bath. A daily bath is not necessary, but you should clean the face, behind the ears, neck, and diaper area daily. While your baby is in the NICU, talk to your baby’s nurse if you want to give your baby a bath. The nurses will help you coordinate a time for the bath.

Here are some tips for giving your baby a bath:
- Make sure the room is warm and free of drafts.
- Gather your supplies (soap, washcloth, drying towel, receiving blanket, diaper, and clothes).
- Bring your baby to the bathing area when the supplies are ready.
- Never leave your baby alone on a bathing surface or in bath water.
- Water temperature should feel pleasantly warm to the inner wrist. Do not hold your baby under running water. The temperature can change and your baby could be scalded or chilled quickly.
- When sponge bathing, undress your baby and swaddle in a towel with the head exposed. Uncover the parts of the body you are washing, taking care to keep the rest of your baby covered to prevent him or her from getting cold. As you bathe, wash, rinse, and dry each part of the body.
- If tub bathing, position your baby on his or her back in the tub with just enough water to touch the chest.
• Start by washing your baby’s face. Do not use soap on the face. Wet the wash cloth. Wash the eyes from the inner edge of the eye (by the nose) to the outer edge. Use a separate part of the washcloth for each eye. Report any eye drainage to your baby’s nurse or provider.

• Wash the rest of the face. Clean the ears and nose with the washcloth. Do not use cotton-tipped swabs, because they can cause injury.

• Add soap to the washcloth and wash the body with soap.

• Lift your baby’s shoulders to expose the back of the neck (be sure to hold the head) and clean between the skinfolds. Gently lay your baby on his or her back and lift the chin to expose the front of the neck. Clean between the skinfolds.

• Wash the arms and legs and be sure to clean between the fingers and toes.

• Wash the chest and back. Be sure to support the head and neck.

• Wash the diaper area last and be sure to clean between the skinfolds.

• If the hair is to be washed, you may wrap your baby in a warm towel with the head exposed. Hold your baby in a football position supporting the head and neck with one hand and using your other hand to wash the hair with soap. Rinse soap completely and dry with a towel.

• Unscented, non-alcohol–based lotion may be used after bathing. Ask your baby’s provider for suggestions on skin care products.

• Newborn fingernails and toenails are usually soft and flexible. You should use a nail file or emery board to shorten and smooth the nails once a week or as needed. This is the safest method.

**Clothing**

Dress your baby as you would dress yourself. Add or take away clothes as necessary. Your baby’s clothes should be washed separately using an unscented, mild laundry detergent to protect his or her sensitive skin. Your baby is also prone to sunburn and should be kept out of direct sunlight. Ask your baby’s provider about the use of sunscreen.
Choosing Your Baby’s Provider

The American Academy of Pediatrics recommends that every infant with special healthcare needs have a medical home. They use the term medical home to describe an individual or team of providers that is prepared to coordinate the many needs of infants in a way that is family-centered and culturally effective, while providing education and making use of community resources (American Academy of Pediatrics, n.d.).

All infants need a healthcare provider or group to be their primary care provider and provide the services of a medical home. Depending on where the infant lives and what his or her care needs are, this provider may be a pediatrician, a physician who provides family care, or a nurse practitioner. When an infant is born prematurely, parents may not have had time to choose a primary care provider. Parents should begin their search as early as possible and meet the primary care provider before discharge, if possible. When picking a provider, parents should consider the following issues:

- Does the provider accept their insurance or form of payment? Are they accepting new patients?
- Where is the provider located? Does the family have appropriate transportation to reach the provider?
- Does the provider understand the parents’ culture and beliefs? Is the provider easily able to communicate with the parents?
- Does the provider have the knowledge and skills to care for the infant? Is the provider willing to coordinate potentially complex care needs? With which hospitals is the provider affiliated? With which hospitals are they on staff and can provide in-patient care if needed?
- Does the provider have separate “sick” and “well” waiting areas, or does the provider schedule fragile patients at specific times?
- How long does it take to get an appointment? What if the parents just need advice? Is there a “nurse line” parents can call with questions?
- Does the provider offer lactation support after discharge through the office?
- Will parents always see their primary care provider?
- How do caregivers contact the provider after hours or on weekends?

Reference

Bibliography
Choosing Your Baby’s Provider: Information for Parents

Picking a provider—whether a doctor or nurse practitioner—to care for your baby after discharge is an important decision. You may need to see this person often, and you will be dependent on him or her for advice, medical care, and help as you coordinate your baby’s care. Start looking for a provider before your baby is ready to go home. This will give you time to find someone you are comfortable working with to make taking your baby home less stressful.

Here are some things to consider when picking a provider:

- What types of providers are close to home? Are there pediatricians, family practice doctors, or nurse practitioners?
- How far are you willing to travel to see a provider? Ask your baby’s nurse what kind of special care your baby might need when he or she goes home.
- Consider asking friends and family for suggestions. The doctors or nurse practitioners in the NICU might also be able to help you identify a few providers to consider.

Here are some questions to ask potential providers:

- Is the provider on your insurance plan? Is the provider accepting new patients?
- Can you set up an appointment and meet the provider before bringing your infant home?
- Does the provider have experience caring for infants with your child’s conditions, such as prematurity, feeding problems, or lung issues? Is the provider comfortable coordinating the specialty care your child may need after going home?
- Does the provider have separate “sick” and “well” waiting areas or another way to make sure your infant stays well while at the office?
- With which hospitals is the provider working? Will they care for your baby if he or she has to be admitted to the hospital again?
- What are the provider’s hours? If the provider is part of a group, do you always see your own doctor or nurse practitioner? How long is a typical appointment? Are weekend hours available?
- What if you need to talk with someone after hours? Does the provider offer a “nurse line” for questions?
- How are emergency calls handled?
- While you are breastfeeding, is there someone at the office who can help you with questions or provide support?

Discussing these topics with your provider before bringing your baby home can make you more comfortable with your provider and make coming home less stressful. Don’t forget to schedule your first appointment within a few days of going home. Once you choose your provider and make your appointment, make sure to give that information to the NICU team so they can share information about your baby with your new provider.
Home Safety: Information for Parents

Below are some tips and warnings to help ensure your baby’s safety when you return home. Be sure to check that all electrical outlets are working.

Medications
- Keep your baby’s medicine bottles away from other small children.
- Discuss any home medications with other caregivers and share instructions on the medication sheet you received.

CPR
- Enroll all caregivers in a cardiopulmonary resuscitation (CPR) class.

Bathtub Safety
- Don’t rely on baby bathtubs, bathtub rings, pool noodles, floaties, or other air-filled toys to keep your baby above water. These items cannot replace adult supervision.
- Before you begin bathing, have all supplies within arm’s reach.
- Prevent your baby from being burned by the water by testing bath water temperature with your inner wrist or a bath thermometer. The water should be luke-warm or no warmer than (37.7 °C to 40 °C [100 °F to 104 °F]) and deep enough to allow your baby to settle into the water with his or her body well covered. Move your hand through the tub to mix any hot spots. Wash your baby’s face with clean water only (Don’t use soap on face until they are older—your provider will tell you when it is alright to do so.). Clean your baby’s body and then shampoo the hair with a new clean cloth.

Kitchen safety
- Put your baby down before handling hot objects.
- Do not hold your baby while cooking.
- Always follow the instructions for how to prepare formula. Formula that has been warmed up in the microwave can burn a baby’s mouth. Test the warmth of the formula on your wrist before giving it to your baby.
- Your baby’s food should be barely warm.
- Keep hot items, such as coffee, out of reach.
- For burns, run cool water over the burn right away, then call your baby’s provider.

Nursery Safety
Babies spend much of their time sleeping; therefore, the nursery should be the safest room in the house.
- Your baby should sleep in a crib, not in your bed. The crib should hold a firm mattress with tight-fitting sheets.
- The crib should not have any soft surfaces, including waterbeds, sheepskins, comforters, or fluffy quilts.

- Remove any loose blankets, toys, pillows, or stuffed animals from the crib.
- When your baby is awake, give him or her at least an hour of tummy time each day.
- Never leave your baby on a bed, couch, or changing table due to the risk of falling.
- Keep the sides of the crib raised. If the bars of the crib are not close enough, a baby’s head can get caught between the bars. You can check to see if your crib is safe by taking an upright soda can and placing it between the bars. If you are not able to push the can through the bars, your baby’s head will not fit through.
• Check the paint on the crib. Peeling paint could be harmful if swallowed.
• Keep the crib away from windows. Keep window blind cords, rosaries, or strings away from the crib.
• Do not put your baby to bed with a bottle.
• Do not attach a pacifier to a string or chain while in bed.

When buying a new crib, ensure that the crib is safe. However, if you are getting a used crib from a store or a friend, be sure to check the following:
• It is not recalled (see www.cpsc.gov).
• It meets all current federal industry standards.
• Mattress support is securely attached to the crib headboard and footboard.
• There are no cutout areas on the headboard or footboard.
• Slats are not missing, loose, splintered, or cracked. Slats should 2-3/8 in. apart or less; a soda can will not fit through. (If it does, a baby’s head could, too.)
• The mattress fits snugly against the frame. It should allow no more than two fingers between the edge of the mattress and the crib side.
• The sides of the crib are at least 22 in. above the mattress.
• There are no sharp corners, jagged edges, or projections, such as posts. Corner posts should be 1/16 of an inch high or less.
• No parts are broken, cracked, or loose.
• Screws or bolts holding the crib together are tight and not missing.
• Drop-side latches should be too difficult to be released by a young child.
• Regularly check the crib’s hardware. If any screws or slats loosen again after tightening, it’s best to replace the crib.
• Place the crib at least 2 ft away from heating vents, windows, window-blind cords, drapery, or wall lamps and 1 ft from walls and furniture.
• Cover the mattress with a snug-fitting crib sheet with elastic corners and nothing more. Do not use a sheet, or part of one, from a larger bed.

Fire Safety
• Test the smoke alarms monthly and replace the battery when you change the clock for daylight savings time.
• Create a fire escape plan and practice it. If the door is blocked or on fire, is there another way out? Do you need a window ladder? Who will get the baby? Where will you meet outside?
• Do not put electric cords under rugs. Do not overload sockets.
• Keep space heaters away from anything that can catch fire. Never use the oven to heat your home. Blow out candles when you leave the room.
• Keep a fire extinguisher in the kitchen. Post emergency numbers near the phone.
• Do not let anyone smoke in your home. If you smoke, go outside, but never leave your baby alone.
• In case of a fire, take your baby to a neighbor’s home and call 911.

Babysitters
When leaving your baby with a babysitter, place emergency phone numbers near the phone and show them to the babysitter. Tell the babysitter how to reach you. Include the following:
• emergency contact name and number
• emergency 911
• Poison Control Center 800.222.1222
• your baby’s provider and phone number
• your baby’s birth date
• your baby’s health insurance information, which hospital to use, and consent for emergency medical treatment if you are away overnight.

Sun and Outdoor Safety
Babies who are younger than 6 months old should stay out of the sun. Use a hat and a carriage cover but no sunscreen.
• Use netting on the stroller to protect your baby from bug bites.
• Before you put your baby into a car seat, make sure the car seat is not too hot from the sun. A hot car seat can hurt your baby.
• Use the car seat every time your baby rides in a car or taxi. Use sunshades for car windows to protect babies from the sun.

**Water Safety**
As your baby grows, remember these things:
• Because toddlers can drown in 1 in. of water, empty wading pools or buckets and turn them upside down when not using them.
• Many drownings of young children occur in bathtubs, usually when the caregiver leaves “for just a minute.” Never leave a child in the tub, even with a sibling.
• In a household with toddlers, always put the toilet lid down and use toilet locks. Keep bathroom doors closed and latched so children can’t play in the bathroom.
• Plan ahead and buy latches for cabinets, drawers, doors, and toilets. Cover electrical outlets with safety covers.

**Additional Resources**
Centers for Disease Control and Prevention: Water Injuries
www.cdc.gov/HomeandRecreationalSafety/Water-Safety/waterinjuries-factsheet.html

Healthy Children: Safety for Your Child Birth to 6 Months
www.healthychildren.org/English/tips-tools/Pages/Safety-for-Your-Child-Birth-to-6-Months.aspx

Healthy Children: Bathing Your Newborn
Step 5
Oral Feedings

Assessment of oral feeding readiness traditionally begins once a baby nears 34 weeks gestation, although in some instances this assessment may begin sooner. Babies whose mothers plan to breastfeed may already be nuzzling at the breast; others who aren’t being breastfed are receiving oral stimulation with a pacifier. Both of these methods are used during gavage feedings.

Oral stimulation and nonnutritive sucking promote feeding success and develop positive feeding experiences. Oral stimulation is best achieved when the infant accepts the pacifier, rather than inserting the pacifier into the mouth when the mouth is closed and the infant is not rooting. Oral care for infants who are not eating by mouth (NPO) or are intubated should be provided gently by letting the infant allow entrance when his or her mouth is open. When cleaning the lips, the use of the mother’s pumped breast milk or donor milk with a 2-in. x 2-in. gauze pad or swab stick may be preferred over commercial saline wipes, which may be “taste” aversive to the infant.

As the baby begins weaning off of intravenous fluids and feedings are being initiated, this is a good time to start discussing oral feeding and feeding readiness with parents. Some hospital institutions have developed parent education about infant-driven feeding or cue-based feeding protocols; other institutions rely on feeding orders for volume and how many times per shift a baby may take a bottle or breastfeed. Whatever the case may be at your institution, early discussions of oral feeding with parents facilitates improved comfort levels once oral feedings begin.

Feeding assessment, which includes hunger cues and physiologic stability, consists of factors that indicate whether a baby is ready to feed. Observing for desaturations and stress cues such as hiccoughs, bradycardia, or fingers splayed before, during, and after oral feeding are important assessment criteria. These stress cues determine the start of a feed, the need for pacing during a feed, and the end of a feed. Remember not to push an infant to suck and swallow if they fall asleep during a feed. This is usually a sign that they are finished, even if they have not completed the volume. Parents should be instructed in how to identify physiologic signs and be involved as much as possible. Medical staff should encourage consistent parent participation.

The assessment skills that you have learned regarding feeding readiness and stress cues will help you determine the significance of feeding difficulties, should they arise. Infants who have been hospitalized long term or have chronic lung disease, those born with cleft lip and palate, and those who remained NPO for long periods of time due to gastroschisis or other gastrointestinal complications are considered to be at risk for feeding difficulties. When identifying potential problems, lactation, speech and language therapy, and occupational therapy referrals should be made as a proactive approach to ensure babies continue to safely advance with oral feedings. Identifying feeding problems and initiating safe interventions early will allow the baby to continue to progress, having fewer opportunities for oral aversion and less chance of a physiologic setback.

Bibliography
Oral Feedings: Information for Parents

You will learn a lot about feeding your baby. You play an important part in your baby’s feedings.

Your baby is getting your breast milk, donor milk, or special formula through a tube that goes into the mouth or nose and ends in his or her stomach. A pacifier may be dipped into milk and given to your baby during feeding times. A pacifier dipped into milk makes your baby happy during the tube feeding. Sucking on a pacifier gives your baby practice for either the bottle or your breast. Never force the pacifier into your baby’s mouth.

Feeding should always be a happy time for you and your baby. If your baby is not ready to suck from a bottle or your breast, there are other things your baby can do. Your baby can rest his or her mouth at your breast if you want to breastfeed. Your baby can rest his or her body skin to skin with mom or dad during the tube feeding.

Your baby has to learn how to coordinate sucking, swallowing, and breathing when eating. Your baby may not begin to learn how to do this until they are close to 34 weeks gestation. The nurses and feeding therapists in the neonatal intensive care unit (NICU) will work with you to teach you how to feed your baby safely. You will also learn about feeding readiness. If your baby is stable, you and the nurse will decide if your baby is awake and moving around enough to eat from a bottle or breast. Both parents and caregivers should be comfortable with bottle feeding. Mothers should be comfortable with breastfeeding. Your baby should gain weight every day and finish the full feeding by bottle or breastfeeding. Once they can do these things, they can go home.

If your baby has problems during breastfeeding, the nurse will call a special nurse who may be able to help. If your baby has problems bottle feeding, the nurse will call the feeding specialist. If problems are found, the NICU team will work together to help your baby eat better. A video of your baby while swallowing may be made to see if the mouth or throat is not working right. The video will also show if food is going into the baby’s lungs (also called aspiration). The fluid may just be going up and down the baby’s throat (also called reflux). During the video, milk may be thickened like a milkshake. The best thickness will show no reflux or aspiration on the video. Your baby’s provider may decide to let your baby rest and go back to tube feedings until your baby is a little older. He or she may decide that a thickened feeding will help keep your baby safe. If your baby needs thickened feedings, as they grow and get a little older the video will be done again.

Once oral feedings are started, it will be very important for parents to visit as much as possible. As parents, you will be the ones feeding your baby once you go home. If you plan to have other caregivers help you at home, they need to come to the NICU with you to learn how to feed your baby. Once you are home, contact your baby’s provider for any feeding issues your baby might have. Things like not eating well for more than two feedings in a row, spitting up more than usual, not waking up for a feeding, or not breathing during a feeding need to be shared with your baby’s provider as soon as possible.
Hearing Screening

Because early detection of hearing loss is so critical to positive outcomes, the National Institutes of Health made a statement in 1993 recommending universal newborn hearing screenings within the first 3 months of life for all NICU patients as well as full-term infants. Since this statement, 43 states and territories including Puerto Rico and the District of Columbia have mandated hearing screens for all infants. Universal hearing screening is also a recommendation of the American Academy of Pediatrics. Early detection of hearing loss is key in preventing later speech and communication disorders, as well as any potential developmental problems stemming from poor speech and hearing loss.

There are two types of hearing loss, conductive and sensorineural, though a mixture of the two is also possible. Conductive hearing loss usually occurs when fluid in the outer or middle ear blocks sound or when there is a structural abnormality of the outer or middle ear. Sensorineural hearing loss involves the inner ear or damage to the nerves from the inner ear that carry sound to the brain. Sensorineural hearing loss may be caused by structural abnormalities to the inner ear, maternal infections such as cytomegalovirus and rubella, or a genetic condition passed on to the baby from a parent. Hereditary causes are the main source of sensorineural hearing loss. It is very important for family history to be reviewed, especially any family history of hearing loss, prior to the hearing screen.

There are currently two forms of hearing screen testing: the Otoacoustic Emissions (OAE) and the Auditory Brainstem Response (ABR). The OAE involves placing small probes in both ear canals, which release external sounds and stimuli and then measure internal cochlear sounds. If the cochlea is not functioning, there will either be no internal sounds recorded or the sounds will be too low to be recorded. The ABR involves placing earphones on both ears and electrodes all over the baby’s head. Sounds are released and electrical signals across the electrodes are recorded. If hearing is present in the baby, the responses are recorded as low-level stimuli. With hearing loss, the responses are recorded as high-level stimuli. Your hospital or institution has chosen at least one of these testing measures for universal hearing screening for all newborns.

The best testing results occur when the baby is sleeping or not active. Parent education should focus on the type of hearing test used at your institution (OAE vs. ABR), test time, an explanation that the procedure is pain free, and the importance of follow-up testing at outside referral centers when further testing is required. According to data analyzed by The National Institute on Deafness and Other Communication Disorders (National Institutes of Health, 1993), as many as 50% of babies who fail the in-hospital screening are lost to follow up. Hospital staff plays a critical role in improving these odds. Reinforce with parents that even though their infant passed the hospital hearing screen, hearing may change due to illness or medications used while hospitalized, or both. Routine screenings throughout childhood are important.

Reference

Bibliography
Hearing is very important for the normal development of all babies. Every year, about 12,000 babies are born with hearing loss in the United States. Even a small hearing loss in one ear can affect your baby’s communication skills. When babies cannot hear well, they may develop problems talking and understanding words. For this reason, all babies will have a hearing test before going home.

The hearing test is a painless procedure that is done when your baby is sleeping or still and quiet. This test measures how well the outer and inner ear work. It takes 10–20 minutes, unless the test has to be repeated. Special probes or earphones are placed in or around both of your baby’s ears and connected to the hearing screening machine. This will be used to test both ears.

The hearing test will determine if both ears can hear. If your baby does not pass the first hearing test, it will be repeated. If your baby is awake and moving too much or if your baby has fluid in his or her ears, the test will need to be repeated. If your baby does not pass the hearing test, your baby’s provider will refer you to someone who specializes in infant hearing. This specialist is called a pediatric audiologist. The audiologist has special skills and experience giving hearing tests and explaining what the results mean. Be sure to make and keep all appointments with your baby’s primary provider, as well as any hearing test appointments. Although hearing loss is serious, the sooner you know about it the sooner you can find help—and the better the outcome will be for your baby. If you need help and information, contact your state’s early hearing detection and intervention program.

Your baby’s hearing continues to develop over time. Even if your baby has passed the hearing test in the hospital, you will still need to watch your baby’s milestones of development. Some babies will require periodic hearing tests after they go home from the hospital. Talk to your provider about the milestones of development for hearing and talking. You can find more information at www.healthychildren.org. Under the tab “ages and stages,” select baby 0–12 months. Visit www.babyhearing.org for more information.
Immunizations

The Centers for Disease Control and Prevention (CDC) and the American Academy of Pediatrics have worked together over the years to develop an immunization vaccination schedule based on long-standing practice and current evidence-based research.

According to the CDC, “Vaccines are the best defense we have against infectious diseases; however, no vaccine is 100% safe or effective. Differences in the way individual immune systems react to a vaccine account for rare occasions when people are not protected following immunization or when they experience side effects” (CDC, 2013). Vaccines are tested and then approved by the U.S. Food and Drug Administration.

The National Childhood Vaccine Injury Act (NCVIA) was passed by Congress in 1986 to provide the public with information regarding vaccine safety and health concerns and to reduce government liability (CDC). The NCVIA also gave the medical community resources and guidelines for administering immunizations and reporting vaccine reactions. The resources developed include the vaccine information sheet (VIS), which all healthcare providers must provide to parents before requesting consent for each scheduled immunization. Each VIS contains a brief description of the disease as well as the risks and benefits of the vaccine. The CDC develops and distributes the VIS to state and local health departments and posts it on the CDC website. The NCVIA also calls for a compensation program to assist those who have been injured from immunizations and a review committee to monitor information on vaccine side effects (CDC).

It is important for healthcare providers to educate parents about diseases and viruses, which may be harmful to children. It is important for parents to remember that breastmilk has immunologic benefits to help as well. It is also important that the mother receives pertussis vaccination during pregnancy or at delivery to protect the baby. All family members and caregivers of infants younger than 6 months of age should receive the flu vaccine as well.

Newborns are immune to many diseases because they have antibodies from their mothers and these antibodies increase with breastfeeding. However, this immunity lessens during the first year of life. Infants and young children do not have “maternal immunity” against some diseases, such as whooping cough. Immunizing individual children also helps to protect the health of our community, especially those who cannot be immunized. That population includes children who are too young to be vaccinated (e.g., children younger than 1 year cannot receive the measles vaccine but can be infected by the measles virus), who cannot be vaccinated for medical reasons (e.g., children with leukemia), and those for whom vaccination is not successful.

By visiting www.cdc.gov/vaccines, healthcare providers can review information about preventable diseases and vaccines that prevent them. Content is designated specifically for healthcare providers and parents of infants and toddlers.

Immunization schedules may be printed directly from the CDC website and given to parents. Copies of immunization records and immunization injection dates should be included in the electronic health record printed discharge instructions and given to parents to share with their pediatric provider.

Reference
Immunizations: Information for Parents

The diseases that immunizations (vaccines) prevent can be dangerous—or even deadly. Vaccines reduce the risk of infection by helping the body’s natural defenses to develop immunity (or resistance) to disease.

When germs, such as bacteria or viruses, invade the body, they attack and multiply, causing an infection. The immune system (our natural system of defenses) has to fight the infection, but once this happens, the fighting cells can remember that infection to fight it in the future. Vaccines help develop these fighting cells (immunity) by imitating an infection, but this imitation infection doesn’t cause illness. It causes the immune system to have the same fighting response as though it were a real infection, so the body can recognize it and fight it in the future. Sometimes, the vaccine can cause minor symptoms, such as fever. These minor symptoms are normal and should be expected as the body builds immunity.

Like any medication, vaccines can cause side effects. The most common side effects are mild (such as redness and swelling where the shot was given) and go away within a few days. If your baby experiences redness, soreness, and swelling where the shot was given, you can ease those symptoms with a cool, wet cloth. Pay extra attention to your baby for a few days after vaccination. If you see something that concerns you, call your baby’s provider.

While your baby is in the hospital, the NICU team will follow the vaccine schedule for your baby and make any necessary changes due to your baby being born early. The vaccine recommendations for the first 6 years of life are shown below.

A medicine called Synagis (palivizumab) will also be recommended if your baby was premature and born before 35 weeks to help prevent your baby from getting a respiratory virus called RSV.

The nurses will give you information on the specific shots your baby needs that will explain the possible side effects. They will ask for your written permission before giving your baby any shots.

A vaccine shot schedule and a record of the shots your baby received while in the hospital will be given to you before you go home. Vaccine shot records will be needed for public day care centers and public schools. It’s very
important that you make routine well-child appointments for your baby to see his or her provider. They will help manage your baby’s vaccines and make sure the shots are given when they are needed. One of the best ways you can build your baby’s immune system is to follow up and ensure that your baby receives all of the shots and medicines recommended for his or her age.
Step 6
Car Seat Testing and Safety

When discharge is anticipated, the infant’s nurse notifies the family of the need to bring the car safety seat to be used for transportation upon discharge from the hospital. Car seat evaluation is usually done with infants born less than 37 weeks of age. Ideally the car seat is brought to the hospital approximately 48 hours prior to anticipated discharge. Parents of preterm infants should be educated to choose an “infant only” seat. The infant’s nurse encourages the parents to bring the car safety seat preassembled. Remind parents to bring the base as well as the car seat for the evaluation. Parents are encouraged to refer to their car owner’s manual and car safety seat instructions for information about how to secure the seat in the car prior to performing the car seat evaluation. The parents and NICU staff should confirm that the car seat is not subject to manufacturer recall and verify that it meets Federal Motor Vehicle Safety Standard (FMVSS) 213 and is not simply an infant carrier. Nurses or parents can verify a car seat’s compliance with FMVSS 213 at www.safercar.gov.

The infant is positioned in the car safety seat in the riding position and monitored for 90 minutes or for the duration of travel, if longer than 90 minutes, with a cardiorespiratory monitor and pulse oximeter. Studies are usually performed within an hour after a feeding. The nurse documents any episodes of apnea, bradycardia, and desaturations as well as any stimulation or intervention required. Typically, to pass the car seat evaluation, the infant should have no instances of apnea, bradycardia, or oxygen desaturation during the observation period. Any episode of apnea, bradycardia, or oxygen desaturation during the observation period usually indicates a failed car seat evaluation. The nurse should notify the appropriate medical team member for a full evaluation of results.

The American Academy of Pediatrics advises parents to keep their toddlers in rear-facing car seats until age 2 years or until the child reaches the maximum height and weight for their seat. A rear-facing child safety seat does a better job supporting the head, neck, and spine of infants and toddlers in a crash, because it distributes the force of the collision over the entire body. They also advise that most children will need to ride in a belt-positioning booster seat until they have reached 4-ft 9-in. tall and are between 8 and 12 years of age. Some hospitals will recommend parents have a car seat inspection prior to infants being discharged home. Local law enforcement officials usually can do this and some hospitals also provide this service. Make sure parents get this information early so they can get this done as soon as the car seat is purchased.

Bibliography
Car Seat Testing and Safety: Information for Parents

If your baby was born before 37 weeks, they may undergo a car seat challenge test before being discharged from the hospital. This test will last about 1–2 hours (the time will be about equal to the duration of the car ride home), and during the test your baby’s heart rate and breathing will be monitored. This test will determine if your child can tolerate being in a car seat for a car ride.

A child who is younger than 1 year of age and weighs less than 20 pounds must be in a rear-facing car seat. Your child’s car seat should never be placed in the front seat of a vehicle. Place your baby’s car seat in the center of the back seat facing the rear, because this is the safest position. Make sure to read any instructions that come with your baby’s car seat as well as your vehicle’s instruction manual to learn how to install your car seat properly. Many fire departments, law enforcement agencies, and hospitals may have fitting stations with certified child passenger safety technicians to help parents and families determine if their car seat is installed properly.

When you reach your destination, remember to take your baby out of the seat and out of the car. Every year, between 30 and 50 infants die after being left in their car seats when their parents got distracted. Many people find it helpful to store items they will need (e.g., brief case, purse) on the floor by the baby so they must go into the back seat before leaving the car. Never use a baby carrier instead of a car safety seat. Make sure the straps in the car seat are properly positioned, secured, and fit snugly against your baby’s chest. You should only be able to fit two fingers in between your baby and the straps. Loose straps do not provide maximum safety. Every car seat has an expiration date. Contact the manufacturer of your specific seat to find out what the expiration date is if you do not know this information.

Resources and Tips for Keeping Kids Safe in Cars

- Use car seats and seat belts on every single trip you take, even if it’s just down the street.
- Model good behavior. If you buckle up, your child will be more likely to do so.
- Make sure your kids understand that unless everyone is buckled up, the car doesn’t move. No exceptions.
- Never use a car seat that has been in a serious crash. A seat that has been in a minor crash might be okay to use. To find out more, visit www.nhtsa.gov.
- Safety advocates do not recommend buying a used car seat from a garage sale, flea market, or thrift store. These seats may be expired, have missing parts, be damaged, or have been recalled. There is no way of knowing if these seats have been in a crash or if they had received damage that can’t be seen with the naked eye. Used car seats can still be used, but if you were not the original owner of the seat or do not
know the history of everyone who used the seat, you should not use it.

- Never use padding or other products that did not come with your car seat.
- Never use a car seat that has been recalled. For information on recalls, contact the manufacturer or the Vehicle Safety Hotline toll free at 888.327.4236. Be sure to fill out the registration form when you purchase your car seat. This will ensure that you are informed of any recalls of that seat.

Find out about the child passenger safety laws in your state online at www.safekids.org.
Cardiopulmonary Training (CPR)

Healthcare professionals caring for high-risk infants and their families are responsible for preparing parents and families for safe discharge and transition to home. Discharge education for these patients should cover safety at home, including cardiopulmonary resuscitation (CPR) training. This education can decrease parents’ and families’ worry about discharge to home. Families must be evaluated to determine what form of education is appropriate to meet their needs. Learning disabilities or language barriers among family members must be recognized and taken into consideration. Education should be tailored to these family members. There are several potential educational styles for infant CPR, including in-person, written, and video instruction. The following publications offer comparisons of methods used to provide CPR training:

The American Academy of Pediatrics suggests all parents learn infant cardiopulmonary resuscitation (CPR) before their babies leave the hospital. For some families, CPR training is required before their baby can be discharged. CPR training for infants and children may be offered through the Red Cross, American Heart Association, local libraries, and your local hospital. You will learn basic CPR skills to help your baby until emergency responders arrive. If an emergency happens, CPR can save your baby's life by reestablishing blood flow to the heart, brain, and other organs and restoring breathing. CPR may be necessary in many different emergencies, including suffocation, accidents, near drowning, and suspected sudden infant death syndrome (SIDS). CPR works best when started as soon as possible, but you must first decide if it's needed. CPR should only be done if your baby is not breathing, has no heartbeat, or is not responding.

Although you may feel very anxious as your baby is being prepared for discharge from the hospital, becoming familiar with emergency procedures will help decrease your fear and increase your confidence when taking your baby home. Partner with the neonatal intensive care unit team early in your baby's hospitalization to help prepare you for your baby's safe transition to home. If your family is having trouble understanding the steps in infant CPR, stop your instructor and ask questions. After learning infant CPR, review the steps often. It is common for parents to be concerned that they will not remember the steps to CPR in an emergency. When calling 911, explain the issue you are having. They will try to walk you through it by phone until the team arrives. Remember, this class is provided so you can give lifesaving care and increase your child's chance for survival in case of emergency until emergency responders can take over.
Sudden infant death syndrome (SIDS) is defined as the sudden, unexpected death of an infant in the first year of life. Since the beginning of the campaign against SIDS, there has been a 50% reduction in incidence. However, there has been no further improvement in the past several years. It is now clear that just changing the sleep position of an infant is not enough to prevent sleep-related deaths. Many other factors in the sleeping environment impact the risk of SIDS for an infant. Therefore, the campaign against SIDS is no longer just “back to sleep” but is now “safe sleep,” addressing all the known factors that may result in a sleep-related infant death.

The healthcare team is responsible for modeling safe sleep while infants are in the hospital. Evidence has shown that parents copy what they see done in the hospital:

People learn best through observation, and research shows that parents are more likely to follow safe sleep practices—particularly placing infants in the back sleep position—when they see nursery staff consistently model this behavior in the hospital. A 2002 study in New Haven, Connecticut, found that nurses who placed infants in the back sleep position during the postpartum hospital stay changed parents’ behaviors significantly (Colson & Joslin, 2002).

In the full-term nursery, safe sleep practices need to be modeled right from delivery. For preterm and sick infants, boundaries and positioning that are appropriate in the early phase of hospitalization need to be eliminated well before discharge. These babies need to be transitioned from ill status to healthy status first, followed by changing from prone positioning to supine positioning and then from supported to unsupported positioning.

Key principles for protecting infants against sleep-related death include:
- eliminating secondhand smoke
- preventing infants from becoming overheated
- teaching the importance of breastfeeding
- keeping immunizations up to date
- using a dry pacifier
- putting the baby to sleep alone (never co-sleeping)
- eliminating soft and loose bedding and toys in the bed
- always placing the infant on his or her back for every nap and at nighttime.

These practices not only need to be thoroughly discussed with the parents of every baby before discharge but also should be modeled while the infant is hospitalized.

Reference

Bibliography
Safe Sleep: Information for Parents

SIDS
The term SIDS, or sudden infant death syndrome, is used to describe when babies die in their sleep without any warning before their first birthday. In the early 1990s, parents were told to stop putting babies on their tummies to sleep. They were told to put them on their backs or sides only. Later, experts said the side position wasn’t safe either, so parents were told to put their babies only on their backs.

Today, we know that just putting babies on their backs to sleep is not enough to keep some of them from dying in their sleep. There are many other easy things parents can do to keep their babies safe when they sleep.

Safe Sleep
“ABC” is an easy way to remember how to make babies safe when they sleep. ABC stands for “alone, back, crib.”

Alone
Babies should always sleep alone. That means they should never sleep in the same bed as an adult, another child, or a pet. They should not sleep with anything in their cribs like stuffed toys, pillows, bumper pads, loose blankets, quilts, hats, headbands, bibs, or pacifier holders. The only thing that should be in the bed is the baby.

However, experts say sleeping in the same room with a parent, as long as the parent and baby are in their own separate beds, is safer than the baby sleeping in a room alone. Parents can bring their babies into their beds to feed or comfort, but when parents feel themselves getting sleepy, they need to put their babies back in their own beds.

Back
Babies should sleep on their backs for every sleep, for all naps and at nighttime. They should be put on their backs to sleep at home, at day care, at church, or in any friend or family member’s home.

Crib
A crib can be a crib, bassinet, Pack-N-Play, play-yard, or playpen, but it should have a firm mattress and be covered with a well-fitted sheet only. It is very dangerous for babies to sleep on a sofa or armchair, because they can wiggle as they sleep and get trapped and be smothered. It is also not safe for them to sleep in a car seat, bouncy seat, swing, baby carrier, or sling, because their neck can bend in ways that makes it hard for them to breathe.

There are some other very important things that can help babies sleep safely:
• Smoking—Keep babies away from people who smoke. We know that babies who are around people who smoke or babies born to mothers who smoke have a higher risk of SIDS.
• Breastfeeding—Babies who are breastfed are less likely to have SIDS.
• Immunizations—Making sure babies get their shots may cut their chances of SIDS by almost half.
• Pacifiers—We’re not exactly sure why, but giving your baby a pacifier when he or she is put to sleep helps, too. You shouldn’t force your baby to use a pacifier, and if it falls out after your baby is asleep, it’s OK. It doesn’t have to be put back in. It’s important to not start using a pacifier until your baby has learned to breastfeed well.
• Temperature—Keeping your baby from getting too hot can help. Dress your baby in no more than one extra layer than you would be comfortable wearing. Using warm sleepers, known as blanket sleepers, instead of a blanket is a good idea. Blankets can get loose, cover a baby’s head, and make it hard to breathe. If you do use a blanket, use it “feet to foot.”

First, put the baby in the bed with his or her feet at the bottom of the bed. Then, with the top of the blanket no higher than the baby’s chest, tuck it in at the sides and at the bottom of the mattress. This way,
when the baby moves around during sleep, the blanket will stay below the baby’s face.

- Worries—Parents sometimes worry that babies will choke if sleeping on their backs. Actually, research shows that they are more likely to choke sleeping on their stomachs. Parents also worry their babies won’t sleep as well on their backs, and this is probably true. Babies do seem to sleep more deeply on their stomachs, but experts think that because some babies sleep too deeply, they are more likely to die from SIDS. These babies don’t wake up in time when they can’t breathe. Another thing many parents worry about is the flat or bald spots some babies get on their heads from sleeping on their backs. These almost always go away after babies learn to roll over and sit up by themselves. You should think of these as signs of a healthy baby who has been put to sleep safely.

ABC (alone, back, crib), no smoking, breastfeeding, keeping immunizations up to date, using a pacifier, and not letting a baby get too hot are all things you can do to keep your baby safe while sleeping.
Step 7
Respiratory Syncytial Virus

*Respiratory syncytial* (RES-pri-tor-ee sin-SISH-shul VYE-ris) *virus,* or RSV, is a common illness of the lungs and breathing passages affecting high-risk populations, especially babies born prematurely who are less than 2 years of age.

- By age 2, most children have had or been exposed to RSV.
- In healthy children, RSV is like a cold. It can be more serious for those in high-risk groups, such as
  - children more than 4 weeks premature at birth
  - twins or other multiple births
  - children younger than 2 years born with lung or heart disease
  - children who weighed less than 5.5 pounds at birth
  - school-aged brothers and sisters
  - children who live in a crowded home environment
  - children with a family history of asthma
  - children who are exposed to tobacco smoke and other air pollutants.

RSV can be dangerous for premature babies because premature babies, even those who did not require oxygen or positive pressure ventilation in the neonatal intensive care unit, do not have fully developed airways. In addition, they may not have received antibodies to help fight off RSV and other viruses because they were born early.

It is important that parents understand prior to discharge that it is essential during this first year of life to take specific precautions to decrease their baby’s exposure to RSV. Precautions include continued proper hand washing and limiting their baby’s exposure to crowds and school-aged students.

children. Healthcare professionals should discuss day care arrangements with parents and other intended caregivers. For infants with severe chronic lung disease or heart defects, traditional day care may not be the best alternative. The healthcare professional can help parents explore other options (e.g., private day care).

RSV infections usually begin in the fall and end late in the spring. Unfortunately, there also are several strains of RSV, so even if a baby has had it once during RSV season, there is still a chance he or she can get it again. We each will have RSV several times in our lifetime.

RSV is very contagious. It can be spread through the air when a person coughs or sneezes. RSV also can spread by touching an object that has the virus on it. In fact, the virus can live on countertops, doorknobs, hands, and clothing for up to 7 hours. Hand washing and proper cleaning are the best ways to help prevent the spread of RSV. Synagis (palivizumab) is an immunoglobulin injection that helps prevent RSV. Synagis is not a vaccine, but it helps to prevent or lessen the symptoms should the infant contract RSV. The National Perinatal Association and the American Academy of Pediatrics each offer dosing guidelines (see links in bibliography below). Follow the dosing guidelines of your institution.

Bibliography
Respiratory Syncytial Virus: Information for Parents

Respiratory syncytial (RES-pri-tor-ee sin-SISH-shul VYE-ri-sis) virus, or RSV, is a virus that can make your baby sick. There are times of the year when your baby has more chance of being around people with the virus. This is usually from fall through spring (October through March). RSV can cause a mild cold, but it can also lead to a more serious sickness and a stay in the hospital. Babies born early and children younger than age 2 have the greatest risk for RSV. This is because babies born early, even those who did not need any help breathing while they were in the neonatal intensive care unit, do not have fully formed lungs. Also, their bodies may not be able to fight RSV and other viruses.

Symptoms of RSV
RSV usually causes a mild cold with a runny nose and fever. However, RSV also can make your baby very sick. Call your baby’s provider right away if your baby has any of these symptoms:

- cough that does not go away, gets worse, or produces yellow, green, or grey mucus
- wheezing (a high-pitched whistling sound when breathing)
- trouble breathing or breathing faster than usual
- blue color on the lips or around the mouth
- high fever
- thick nasal discharge that is yellow, green, or grey.

There are ways to protect your baby. RSV is very easy to spread through coughing and sneezing. The virus can live on countertops, doorknobs, hands, and clothing for up to 7 hours. During RSV season, wash your hands well and avoid crowded places (likes malls and churches) and school-age children. Speak with your baby’s provider about your day care plans. You might have to tell other people what RSV is and how dangerous it can be for your baby. Your baby’s provider can help with this by giving you some handouts to help you discuss RSV with friends and family.

Hand washing and keeping your baby away from sick people is a good way to protect your baby. There is also a medication that can help lower your baby’s risk of getting an infection.
Preventing Infections

NICU graduates have a higher rate of rehospitalization than the average newborn population. Common reasons for unexpected readmission are poor weight gain, feeding problems, dehydration, and upper respiratory infections. Healthcare providers should encourage parents to discuss with extended family and friends the precautions they should take to ensure the continued good health of their premature infant. Parents will need to ask for respect of their boundaries and support during preparation for discharge.

The best preventive measure is good hand washing. Everyone who interacts with the baby at home should learn about and practice good hand washing. Placing soap by all sinks and cleansers or hand gel in any rooms in which the baby may be cared for will help ensure good hand hygiene.

Cleaning
The baby’s room needs to be cleaned thoroughly. It is important to remove dust and dirt but avoid the use of harsh smelling cleaning products. Harsh cleaning solutions and insecticidal sprays can leave residual odors that may irritate or even harm the baby.

Sleeping
The baby should always be placed on his or her back for sleep. The National Institutes of Health (NIH) confirmed that studies demonstrate the benefits of infants sleeping on their backs. “Placing infants to sleep on their backs not only reduces their risk of Sudden Infant Death Syndrome, but also appears to reduce the risk for fever, stuffy nose, and ear infections” (NIH, 2013). See Safe Sleep for additional information on safe sleeping precautions.

Contact with Others
The American Academy of Pediatrics (AAP) Committee on Environmental Health has identified these problems associated with secondhand smoke exposure: decreased lung growth, decreased lung function, and increased frequency of lower respiratory tract infections and respiratory symptoms. Research also clearly shows that exposure to smoke can cause ear infections and related hearing problems, increased incidence of hospitalization related to bronchitis or pneumonia, and increased risk for sudden infant death syndrome.

The following precautions will reduce the possibility of exposure to illnesses, especially during the cold season:

- not allowing smoking in the home
- asking anyone who is ill or feels that they may become ill to postpone their visit
- teaching everyone to do proper hand washing prior to touching the baby
- limiting the frequency—and duration—of times guests visit (outside family included)
- limiting initial contact with small children (other than those who already live in the house).

RSV Prevention
Respiratory syncytial virus (RSV) is a very contagious virus spread easily through the air when a person coughs, sneezes, or touches an object that has the virus on it. In fact, the virus can live on countertops, doorknobs, hands, and clothing for up to 7 hours. Hand washing and proper cleaning is the best way to help prevent the spread of RSV. Synagis is a medication that can be administered to help prevent RSV. Depending on the severity of certain underlying illnesses and the presence of risk factors, the baby may benefit from a series of monthly injections during RSV season.

Feeding
The AAP recommends exclusive breastfeeding for the first 6 months, followed by continued breastfeeding as complementary foods are introduced, with continuation of breastfeeding for 1 year or longer, as determined by mother and infant. According to the AAP, “The risk of hospitalization for lower respiratory tract infections in the first year is reduced 72% if infants are breastfed exclusively for more than 4 months” (AAP, 2012). The severity of RSV infections and gastrointestinal infections are also greatly reduced in breastfed babies. See Breastfeeding Overview and Breastfeeding at Home for more information.
The AAP guidelines for storing breast milk are as follows:

- Wash hands before expressing or handling milk.
- Use only clean containers to store expressed milk. Use collection containers specific for the purpose of storing human milk. Do not use ordinary plastic bags or formula bottle bags for storing milk.
- Freshly expressed milk can remain at room temperature for up to 4 hours.
- Use refrigerated and not previously frozen milk within 48 hours.

Instruct the mother to label, date, and time the bottle of breast milk when it is expressed. Preferably, human milk should be refrigerated or chilled right after it is expressed. Acceptable guidelines for storing human milk are as follows:

- At room temperature for 4 hours (ideal) and up to 6 hours (acceptable)
- In a refrigerator for 72 hours (ideal)
- In a freezer for 6 months (ideal) and up to 12 months (acceptable).

Seal and chill breast milk for 4 hours, if possible, and discard breast milk that has been refrigerated for more than 72 hours. Milk can be kept in a freezer attached to a refrigerator for 1 month and for 3–6 months if kept in a zero-degree deep freezer. Milk can be thawed in the refrigerator or by swirling in a bowl of warm water (not shaken). Once thawed, milk must be used within 24 hours. Thawed milk should not be refrozen.

Be sure that the mother understands that heating milk in microwave ovens is not safe. Excess heat can destroy the important proteins and vitamins in the milk. If parents heat the milk in the storage container, they should avoid rigid plastic bottles that have recycling plastic identification code 7 in the triangle to prevent exposure to bisphenol A (BPA), a potential hormone disrupter. For more information, visit www.niehs.nih.gov/health/topics/agents/sya-bpa.

If the mother will be using formula or supplementing, safe preparation is essential. Water used for mixing infant formula must be from a safe source. The local health department can help parents determine if tap water is safe to use for their baby’s bottles.

According to the U.S. Food and Drug Administration, “In most cases, it’s safe to mix formula using ordinary cold tap water that’s brought to a boil and then boiled for one minute and cooled.” Prior to discharge, teach parents how to follow mixing directions exactly, preparing the smallest quantity needed for a day. Allow parents to perform this skill and observe their technique well in advance of discharge. This is an important safety requirement, because underdiluted formula can lead to digestive problems, including dehydration. Overdiluted formula will not provide adequate nutrition or calories.

As with all food preparation, the area must be clean. Feedings should not be prepared near where parents change the baby’s diaper. Instruct parents to wash their hands before and after preparing milk or formula. There are several methods for cleaning nipples and bottles. Home sterilization kits are available or parents can wash bottles in the dishwasher.

The AAP recommends that once formula has been prepared and mixed, it must be consumed or stored in the refrigerator within 1 hour to prevent the growth of bacteria. Formula that has not been given to an infant can be stored in the refrigerator for up to 24 hours.

**Prevention of Diaper Rash**

The first sign of diaper rash is usually redness or small bumps on the lower abdomen, buttocks, genitals, and thigh folds—surfaces that have been in direct contact with the wet or soiled diaper. This type of diaper rash is rarely serious and usually clears up in 3 or 4 days with appropriate care. Diaper rash can be prevented by changing wet diapers, especially stool-soiled diapers, every 2–3 hours. The stool-soiled diaper can irritate the skin. The baby’s bottom can be cleansed with plain water and a soft cloth. Allow the area to air dry before applying an ointment barrier and a clean diaper. Because yeast thrives in wet places, yeast infections are common. If the baby is not responding to routine diaper care or the parent...
suspects he or she has a yeast infection, they should contact the baby’s provider for advice on over-the-counter or prescription medications that may help.

**References**


**Bibliography**


Preventing Infections: Information for Parents

Babies born early have more risk of needing to return to the hospital due to problems with feeding, weight gain, or respiratory infections. There are things you can do to lower these risks. The most important thing to remember is to wash your hands. Teach everyone who touches your baby about good hand washing. Be sure to have soap or hand gel by all bathroom sinks. It’s a good idea to have hand gel in any room in which you will take the baby. Keep hand gel in purses and diaper bags, too.

Cleaning
Give the baby’s room a good cleaning. Remove dust and dirt, but avoid the use of strong-smelling cleaners. Preterm babies don’t like strong smells and because their lungs are still growing, those smells may be irritating. This is especially true for secondhand smoke.

Sleeping
Your baby should always be placed on his or her back for sleep. Sleeping on the back lowers the risk of sudden infant death syndrome (SIDS) as well as fever, stuffy nose, and ear infection.

Friends and Family
Do not let anyone who is sick or smokes near your baby. Ask anyone who is “coming down with something” to wait to visit. Limit the number of visitors and the length of time that guests stay. Secondhand smoke can harm your baby’s lungs and increase your baby’s chances of having respiratory infection, ear infection, and hearing problems. Don’t take your baby to crowded areas (malls or church) until they have been home for several weeks. This is especially important during the winter months of respiratory syncytial virus (RSV) season (October through March).

RSV Prevention
There are ways to protect your baby. RSV is a respiratory virus that spreads easily from coughing and sneezing. The virus can live on countertops, doorknobs, hands, and clothing for up to 7 hours. During RSV season (October through March in most parts of the United States), wash your hands frequently and avoid crowded places and school-age children. Speak with your pediatric provider about your day care plans, too.

There is also a medicine (Synagis) that can help lower your baby’s risk of getting sick with RSV. Follow the appointment schedule given by your baby’s provider.

Other Notes
Breast milk is the best food for your baby for the first 6 months of life. Breast milk helps your baby’s immune system fight respiratory and stomach infections.

You may see redness or small bumps on the parts of your baby’s bottom that have been near the wet or dirty part of the diaper. A poopy diaper can bother the skin. Diaper rash isn’t serious and usually heals in 3 or 4 days with care. You can prevent diaper rash by changing wet and dirty diapers every 2–3 hours.

Clean your baby’s bottom with plain water and a soft cloth. Let the area air dry before putting on an ointment and a clean diaper. If the diaper rash doesn’t get better in 3–4 days, call your baby’s provider. Ask about diaper care ointments you can buy at the store. They may want to give your baby medications that can help clear up diaper rash.
Step 8
Preparing to Take Your Baby Home

The American Academy of Pediatrics (AAP) has published discharge guidelines for high-risk newborn babies. Generally, babies may be ready for discharge when they

- are steadily gaining weight
- have a stable temperature in a regular crib
- can feed from a bottle or the breast without difficulty breathing or other problems
- have mature and stable heart and breathing ability.

The baby will undergo some or all of the following before discharge: hearing test, eye exam for retinopathy of prematurity, metabolic screening blood test, a car seat study, immunizations/respiratory syncytial virus prevention, and assessment for special home equipment and home care.

Preparing for discharge begins the day the baby is admitted to the NICU. It is important to encourage parents to actively participate in direct care activities with the baby as soon as possible during the baby’s hospital stay. Before discharge, parents and other primary caregivers will need instruction on

- feeding (feeding plan for moms who plan to breastfeed)
- basic infant care (baths, skin care, taking temperature)
- infant cardiopulmonary resuscitation (recommended if available in your hospital)
- symptoms of illness
- sleep positioning and safe sleeping
- car seat safety
- use and care of special medical devices and equipment
- giving medications
- performing special procedures or care, such as suctioning or special dressings
- basic home safety.

Preparing the Home, Friends, and Family for Baby’s Homecoming

The AAP Committee on Environmental Health has identified these problems with secondhand smoke exposure:

- decreased lung growth
- decreased lung function
- increased frequency of lower respiratory tract infections and respiratory symptoms.

Research also clearly shows that exposure to smoke can cause ear infections and related hearing problems, increased incidence of hospitalization related to bronchitis or pneumonia, and increased risk for sudden infant death syndrome (SIDS).

Anyone who may be caring for the baby needs to know about the safe sleep campaign that recommends placing babies on their backs for sleeping (see Safe Sleep). Studies demonstrate that this position significantly reduces the incidence of SIDS. Caregivers should allow the baby to have tummy time when the baby is awake and a caregiver is there to observe him or her.

If the family has a family pet, they should be encouraged to bring home clothing or a blanket with the baby’s scent on it before the baby is discharged so the pet can become familiar with the baby’s scent. The baby’s direct contact with pets should be limited until the baby is older and the pet has become comfortable with this newest family member.

As the family prepares their home for their new baby, they should look for sturdy furnishings and equipment. Be sure that all products meet current safety standards. This is especially important when borrowing or buying second-hand items.

Preparing for When the Baby Cries

Caregivers should have a plan in place for times when the baby is crying or fretful. They can enlist the help of trusted family members or friends who can help when they are tired or need a break. The baby’s crying episodes may increase in frequency and severity at times, especially at 8–12 weeks of life. This crying is not related to sickness or ability of the caregiver.
Shaken Baby Syndrome

*Shaken baby syndrome* (SBS) is a form of abusive head trauma and is the term used to describe the constellation of signs and symptoms resulting from violent shaking or impacting of the head of an infant or small child. Although shaking an infant can cause neurologic injury, blunt impact or a combination of shaking and blunt impact can also cause injury. In recognition of the need for broad medical terminology that includes all mechanisms of injury, the American Academy of Pediatrics (AAP) 2009 policy statement, “Abusive Head Trauma in Infants and Children,” recommends use of the term *abusive head trauma (AHT)* by medical professionals to describe an inflicted injury to the head and its contents. The AAP supports prevention efforts that reduce the frequency of AHT and recognizes the utility of maintaining the use of the term shaken baby syndrome for prevention efforts.

Because there is no central reporting registry for cases and a lack of standardized data, statistics on SBS/AHT are not available on a national level. However, it is recognized as the most common cause of mortality and accounts for the most long-term disability in infants and young children. Based on a North Carolina research project published in the *Journal of the American Medical Association* in 2003, approximately 1,300 U.S. children experience severe or fatal head trauma from child abuse every year (Keenan et al., 2003). The same study revealed that approximately 30 per 100,000 children under age 1 suffered inflicted traumatic brain injuries.

What Can Happen to a Shaken Baby?

Shaking an infant can cause bleeding within the brain or the eyes. The degree of brain damage depends on the amount and duration of the shaking and the forces involved in impact of the head.

There are various signs and symptoms of SBS/AHT that range on a spectrum of neurological alterations from minor (irritability, lethargy, tremors, vomiting) to major (seizures, coma, stupor, death). These neurological changes are due to destruction of brain cells secondary to trauma, lack of oxygen to the brain cells, and swelling of the brain. Extensive retinal hemorrhages in one or both eyes are found in the vast majority of these cases. Subdural hematoma, brain swelling, and retinal hemorrhages are accompanied in some, but not all, cases by bruising of the part of the body used as a “handle” for shaking. Fractures of the long bones and ribs may also be seen in some cases. In many cases, however, there is no external evidence of trauma either to the head or the body.

The consequences of less severe cases may not be brought to the attention of medical professionals and may never be diagnosed. In most severe cases, which usually result in death or severe neurological consequences, the child usually becomes immediately unconscious and suffers rapidly escalating, life-threatening central nervous system dysfunction.

Any of these injuries can lead to severe disability or death. If you suspect a child has been shaken, seek medical attention immediately. This could be the difference between life and death.

Common symptoms of SBS include lethargy, extreme irritability, decreased appetite, vomiting for no apparent reason, grab-type bruises on arms or chest (rare), no smiling or vocalization, poor sucking or swallowing, rigidity or posturing, difficulty breathing, seizures, head or forehead appears larger than usual, inability to lift head, and inability of eyes to focus or track movement or unequal size of pupils.

A significant proportion of cases of SBS/AHT (about 25%) die during the initial phase of hospitalization. The survivors do very poorly as shown in a number of studies. In a study done in Canada, only 7% of the survivors were reported as “normal,” 12% were in a coma or vegetative state in the hospital, 60% had a moderate or greater degree of disability, 55% had lasting neurologic deficits, 65% had visual impairments, and 85% would require ongoing multidisciplinary care for the rest of their lives. The negative effects following hospital discharge are likely to be underestimated, because it often takes several months or even years before neurologic and developmental difficulties become apparent.
Activities involving an infant or a child such as tossing in the air, bouncing on the knee, placing a child in an infant swing or jogging with them in a back pack, do not cause the brain, bone, and eye injuries characteristic of shaken baby syndrome.

**What Population Is at Highest Risk?**
Babies less than 1 year of age (with the highest risk period at 2–4 months) are at greatest risk for SBS/AHT, because they cry longer and more frequently and are easier to shake than older and larger children. Male infants are at a slightly greater risk than females.

**How Can SBS/AHT Be Prevented?**
It is important to note that SBS/AHT is preventable. Parents should share the message of the dangers of shaking with all who care for their infant or child, including spouses, their own parents, siblings, day care providers, and others. Parents need to let those caring for the infant know that it is okay to call for help when needed.

Most cases involving shaking injuries occur when a frustrated care giver loses control with an inconsolable crying baby. It is important to realize just saying “don’t shake a baby” is not enough; a plan of action or suggestions to deal with the situation need to be offered. Parents and other care providers need assurance that allowing a baby to cry is okay if all of their needs have been met.

There is evidence that infant crying is the most important stimulus for SBS/AHT. The Period of PURPLE Crying program approaches SBS prevention by educating parents about normal infant development and, specifically, about crying patterns to be expected in normal infants based on scientific evidence about infant crying. Information about the Period of PURPLE Crying is available at http://PURPLEcrying.info/nann.


**Bibliography**


Preparing to Take Your Baby Home: Information for Parents

Babies are ready to go home when they
• are gaining weight regularly
• keep a normal temperature in a regular crib
• can feed from a bottle or the breast without breathing or other problems
• have regular heart beat and breathing (no periods of stopped breathing [known as apnea] or slow heart rate [known as bradycardia])

To get ready for your baby to come home, help care for your baby as soon as possible during your baby’s hospital stay. Before going home, you and others who will take care of the baby will need to learn about
• feeding
• voiding and stooling patterns
• basic care (baths, skin care, taking temperature)
• safety at home
• infant cardiopulmonary resuscitation (CPR)
• signs of illness and protecting your baby from infection
• sleep positioning
• car seat safety
• use and care of special equipment
• giving medicine
• other special care that your baby might need.

Before leaving the hospital, your baby may have some or all of the following
• eye exam
• hearing test
• car seat study
• critical congenital heart disease and jaundice screening and eye examinations
• immunizations and respiratory syncytial virus prevention
• assessment for special home equipment and home care.

Your Home
To prepare for your baby to come home, give your baby’s room a thorough cleaning. Remove dust and dirt, but avoid the use of strong-smelling cleaning products. Premature babies don’t like strong smells, and their lungs are still growing. Don’t let anyone who is sick or smoking around your baby. If you have a pet, keep the pet away from the baby until the baby is older and the pet has become used to this newest family member.

The room should be comfortable—not too hot or stuffy. Look for sturdy furniture and baby care items. Be sure that they meet today’s safety rules. This is especially important if you are borrowing or buying used items.

The baby should always be placed on his or her back for sleep. This position is safest and decreases the chance of sudden infant death syndrome (SIDS). When you are with the baby and he or she is awake, you can place your baby on his or her tummy to help make his back and neck muscles strong.

Have a plan for times when the baby is crying or fretful. Your baby may cry more at times, such as at 8–12 weeks. This kind of crying is not because the baby is sick or you are not a good parent. It is easy to become angry when the baby won’t calm down when you try to comfort him or her. Reach out to trusted family and friends who can help when you are tired or need a break.

About Shaken Baby Syndrome

What is shaken baby syndrome?
Shaken baby syndrome happens from violent shaking of the head of an infant or small child.

What can happen to a baby that is shaken?
Shaking an infant can cause bleeding in the brain or the eyes. The degree of brain damage varies. Any of these injuries can lead to severe disability or death. If you suspect a child has been shaken, get medical help right away. This could be the difference between life and death.

What are the symptoms of Shaken Baby Syndrome?
• Decreased muscle tone
• Crying all of the time
• Poor feeding or vomiting for no reason
• No smiling or baby talk
• Poor sucking or swallowing
• Stiffness or posturing
• Difficulty breathing
• Seizures
• Head or forehead appears larger than usual or soft spot on head appears to be bulging
• Not able to lift head

What population is at the highest risk?
Babies who are less than 1 year of age (with the highest risk period at 2 to 4 months) are at greatest risk. Babies can cry longer and more often at this age. Male infants are at a slightly greater risk than females.

How can shaken baby syndrome be prevented?
It is important to know this is preventable. Parents should share the message of the dangers of shaking with all who care for their infant or child. This includes husbands, grandparents, older children, day care providers, and others who care for your baby. Parents need to let those caring for the infant know that it is okay to call for help when needed.

Most cases involving shaking injuries occur when a frustrated caregiver loses control with a crying baby. It is important to realize that just saying “don’t shake a baby” is not enough; a plan of action or suggestions to deal with the situation need to be offered. Parents and other care providers need assurance that allowing a baby to cry is okay if all of their needs have been met.

Breastfeeding at Home

Prior to discharge from the NICU, a feeding plan should be discussed and written out for the family. The infant’s gestational age, feeding endurance of the infant, and the mother’s milk supply should be considered. Many preterm infants will be discharged with the plan to breastfeed every other feed with supplementation offered after feeding at the breast if pre- and postweights indicate that the infant is unable to transfer adequate volumes at the breast. The healthcare team and family should discuss options for providing supplementation, such as use of a supplemental nursing system (SNS), a feeding tube at the breast, or bottle feeding. Outpatient lactation follow up should be encouraged for feeding evaluation.

If supplementation is provided by bottle, the nurse, lactation consultant, or feeding specialist may discuss options for bottle-feeding systems. Wide-based nipples, which are often recommended for the breastfed full-term infant, may not be appropriate for the premature infant in the early days after discharge. In general, if it takes longer than 30 minutes to complete the bottle feeding, the infant may need a different bottle system. A standard or narrow-based nipple may be needed during the first week or two for the infant to extract milk. The mother may want to transition to a wide-based nipple at a later date. Alternative options, such as SNS for supplemental feeding, should be considered on an individual basis with close outpatient follow up to monitor weight gain.

Bibliography
Breastfeeding at Home: Information for Parents

Most mothers of premature and special care infants are a little nervous about how they will manage breastfeeding once their infants are home. For this reason, health professionals encourage parents to spend as much time as possible in the neonatal intensive care unit (NICU) during the last week of their infant’s hospital stay. During this period, the goal is to prepare you for the first few weeks at home. The healthcare team will help you create a feeding plan and determine whether you need to add any supplements to your milk to help your baby grow. The team will also discuss ways to tell if your infant is taking enough milk while feeding at the breast. We encourage you to ask your NICU nurse to schedule an appointment with the lactation consultant when the infant starts breastfeeding and again several days prior to his or her discharge.

Breastfeeding begins with skin-to-skin time and some nuzzling (suckling without swallowing much milk). Over time, your baby will learn to move milk out of the breast and begin to suck and swallow in a rhythmic pattern. As your baby gets closer to his or her due date, your baby will have more endurance and coordination to take a full feeding at the breast.

The journey toward full-time breastfeeding takes time. Be patient with yourself and your baby. Most babies who are born premature are not ready to fully breastfeed until they are 1–2 weeks past their due date. Term babies who have been very ill or have had surgery may need extra help to learn to breastfeed. This means your baby may be 41–42 weeks gestation before he or she is breastfeeding without additional supplements.

In general, you should continue to pump your breasts after nursing, while the baby is learning to breastfeed. Before you drop the number of times you pump each day, make sure your baby is getting enough milk and gaining weight. During the first week at home you may be pumping six to seven times per day after breastfeeding. If your baby gains weight that first week, you can drop to four to five pump sessions after breastfeeding. Continue to gradually drop pumping sessions every 3–4 days if your baby is gaining weight and no longer needs to take a supplemental bottle after breastfeeding. Be sure to talk to your baby’s provider or lactation consultant about any concerns you have with breastfeeding.

Your nurse will provide you with outpatient resources and support groups to help you after discharge. Remember to ask for the name and contact information of a board-certified lactation consultant you can call to answer questions or to provide one-on-one assistance.

How to Tell If Your Baby Is Getting Enough Milk

The following signs indicate that your baby is getting enough milk when breastfeeding:

- Your baby wakes up on his or her own every 2–3 hours.
- Your baby latches and stays on the breast sucking and swallowing for more than 10 minutes before falling asleep.
- Your baby sucks and swallows in a nice rhythmic pattern, taking 8–10 bursts of sucking and swallowing before pausing for 5–10 seconds.
- You can hear swallowing.
- Your breast softens during and after the feeding is over.
- When you pump after breastfeeding you remove less milk than you do if you did not breastfeed.
- Your baby is having 6–8 wet diapers and several dirty diapers every day.
- Your baby is gaining weight—6–8 oz/week—and growing well.

If your baby does not wake up on his or her own to feed, has a weak suck, and falls asleep after only 5 minutes at the breast, it is likely that he or she is not drinking enough milk. Be sure to contact your baby’s healthcare provider if your baby is not feeding well.
Step 9
Home Medical Equipment: Apnea Monitor (Cardiorespiratory Monitor)

The neonatal intensive care unit (NICU) team celebrates with you as your baby goes home! After graduation from the NICU, your baby will need special home medical equipment (also called durable medical equipment) to help keep him or her well.

Why does my baby need this equipment?
Your baby is at risk to stop breathing, take too long to take the next breath, or have a heartbeat that is too fast or too slow. You will hear an alarm if your baby's breathing or heartbeat is not safe.

Vendor Information
A company, also called a vendor, will bring the equipment to your home and teach you how to use and manage any problems with the equipment that may arise.

Name: ____________________________________________________________________________________________

Phone Number: _____________________________________________________________________________________

Address: __________________________________________________________________________________________

Other Emergency Numbers: ____________________________________________________________________________

Important Things to Remember
• Apnea monitors do not prevent sudden infant death syndrome (SIDS). Always use safe sleep practices (Put your baby on his or her back to sleep and keep your baby alone on a firm crib mattress with his or her face uncovered; do not overdress your baby for sleep and keep toys and stuffed animals out of the crib).
• Always use the apnea monitor when your baby is asleep, takes a nap, while he or she is riding in the car, or when you are busy. Don’t leave the monitor at home.
• Always check on your baby when you hear the monitor alarm. Tap your baby’s foot or rub your baby’s chest to help remind your baby to breathe or help to raise the heartbeat. If your baby is not breathing, shout for help, start cardiopulmonary resuscitation (CPR), and call emergency medical services (EMS) or 911 right away.
• False alarms may sound if the monitor belt around your baby’s chest is too loose.
• Call your EMS, telephone, and electric companies to let them know that your baby uses an apnea monitor. This is important so if there is a power outage or emergency, you will be on a priority list for help.
• The equipment company may visit your home to get (download) information from the apnea monitor about your baby’s breathing and heartbeat.
• Do not stop using the apnea monitor until your baby’s provider tells you it is safe to do so.
• You may be nervous at first, but with practice, you will become more comfortable using the equipment. It’s always OK to ask for help! Make sure you ask your baby’s healthcare provider who you can call for help, questions, and concerns.

The above information is to help you better understand your baby’s care. Always follow the instructions given by your baby’s healthcare provider and ask questions if you have concerns about your baby.

Online Resources
American Academy of Pediatrics
www.aap.org

Kids Health
www.kidshealth.org
Home Medical Equipment: Feeding Pump

The neonatal intensive care unit (NICU) team celebrates with you as your baby goes home! After graduation from the NICU, your baby will need special home medical equipment (also called durable medical equipment) to help keep him or her well.

**Why does my baby need this equipment?**

- Some babies who need extra nutrition or cannot swallow require special feeding tubes. A nasogastric tube (NG tube) is inserted into the nose and goes directly down into the stomach. A gastrostomy tube (G-tube) goes directly into the stomach. A jejunostomy tube (J-tube) goes past the stomach and directly into the top part of the small intestine (called the *jejenum*). Proper nutrition helps your baby to have the best health and healing abilities.

- *A feeding pump* is a small electric or battery-powered machine that sends formula or breast milk (liquid food) through a tube that connects to your baby's feeding tube.

- The feeding pump controls how much of the food is given, how fast, and for how long.

**Vendor Information**

A company, also called a vendor, will bring the equipment to your home and teach you how to use and manage any problems with the equipment that may arise.

Name: ____________________________________________________________________________

Phone Number: ____________________________________________________________________

Address: __________________________________________________________________________

Other Emergency Numbers: __________________________________________________________________

**Important Things to Remember**

- Always follow the directions for mixing your baby's formula or breast milk.

- Always follow the directions given by the vendor of the feeding pump.

- Always follow the schedule for your baby's feedings. A *bolus feeding* is a large amount of feeding given at regular meal times over a set amount of time (usually 20–30 minutes). A *continuous feeding* is given slowly (usually overnight); small amounts of food go through the feeding pump each hour.

- Some babies who need a feeding pump are also able to eat by mouth. Be sure to talk with your baby's provider to check if it is safe for your baby to take any food or liquid by mouth.

- Do not stop using the special formula or feeding pump until your baby's provider says it is safe to do so.

- Check with your insurance company to see if they can arrange to have the formula sent directly to your house. Make sure you have extra supplies and formula on hand so you don’t run out.

- Call your emergency medical services, telephone, and electric companies to let them know that your baby uses a feeding pump. This is important because if there is a power outage or emergency, you will be on a priority list for help.

- You may be nervous at first, but with practice, you will become more comfortable using the equipment. It’s always OK to ask for help! Make sure you ask your baby's healthcare provider who you can call for help, questions, and concerns.

*The above information is to help you better understand your baby’s care. Always follow the instructions given by your baby’s provider and ask questions if you have concerns about your baby.*

**Online Resources**

American Academy of Pediatrics  
www.aap.org

Kids Health  
www.kidshealth.org
Home Medical Equipment: Nebulizer (Aerosol or Inhalation Treatment)

The neonatal intensive care unit (NICU) team celebrates with you as your baby goes home! After graduation from the NICU, your baby will need special home medical equipment (also called durable medical equipment) to help keep him or her well.

Why does my baby need this equipment?
- Nebulizer treatments help prevent or treat breathing problems.
- A nebulizer is a small electric or battery-powered machine that turns liquid medicine into a mist that will help your baby breathe more easily.
- A face mask or mouthpiece sends the misted medicine to your baby so he or she can breathe the medicine right into the lungs.

Vendor Information
A company, also called a vendor, will bring the equipment to your home and teach you how to use and manage any problems with the equipment that may arise.

Name: ____________________________________________

Phone Number: ______________________________________

Address: ___________________________________________

Other Emergency Numbers: ____________________________

Important Things to Remember
- Wash your hands before giving your baby a nebulizer treatment.
- Get together all needed supplies (a face mask works best for children younger than 3 years old).
- Always follow the directions given by the vendor of the nebulizer.
- Hold your baby upright and support his or her head and neck, or place your baby in an infant seat.
- Always give your baby his or her breathing medicine(s) using the directions on the bottle or container given to you by the pharmacy. Never mix medicines unless specifically told to do so by your baby's providers.
- Stay with your baby during the nebulizer treatment and try to keep your baby calm so that he or she can breathe in most of the medicine.
- When the treatment is finished, take off your baby's face mask and turn off the nebulizer. Your baby's breathing should be easier. Call your baby’s provider if you’re worried.
- Wash your hands and clean the equipment following the vendor’s instructions.
- Do not stop using the nebulizer or change the times when you give the treatments unless your baby's provider tells you it is safe to do so.
- Call your emergency medical services, telephone, and electric companies to let them know that your baby uses a nebulizer. This is important so that if there is a power outage or emergency, you will be on a priority list for help.
- You may be nervous at first, but with practice, you will become more comfortable using the equipment. It’s always OK to ask for help! Make sure you ask your baby’s healthcare provider who you can call for help, questions, and concerns.

The above information is to help you better understand your baby’s care. Always follow the instructions given by your baby’s healthcare provider and ask questions if you have concerns about your baby.

Online Resources
American Academy of Pediatrics www.aap.org
Healthy Children www.healthychildren.org

Kids Health www.kidshealth.org
Home Medical Equipment: Ostomy Supplies

The neonatal intensive care unit (NICU) team celebrates with you as your baby goes home! After graduation from the NICU, your baby will need special home medical equipment (also called durable medical equipment) to help keep him or her well.

Why does my baby need this equipment?
- Your baby has a stoma (also called ileostomy or colostomy opening) on his or her belly that lets fecal waste (poop/stool) leave the intestine.
- An ostomy bag (also called a pouch) covers the stoma and collects the waste.

Vendor Information
A company, also called a vendor, will bring the equipment to your home and teach you how to use and manage any problems with the equipment that may arise.

Name: ____________________________________________________________________________________________

Phone Number: _____________________________________________________________________________________

Address: __________________________________________________________________________________________

Other Emergency Numbers: _________________________________________________________________________

Important Things to Remember
- Get together all needed supplies before starting ostomy care (emptying or changing pouch).
- Wash your hands.
- Follow the package directions to ready the pouch and skin barrier to put on your baby.
- Wear gloves during ostomy care.
- Place your baby on his or her back.
- Warm the skin barrier by placing it under your baby while you prepare his or her skin.
- Gently take off the old ostomy bag. (If needed, use a warm, damp cloth to loosen stickiness.)
- Clean the skin around the stoma with warm water only. Your baby’s skin is delicate, so avoid use of products that contain powder or alcohol.
- Dry skin well with a clean, soft towel.
- Check your baby’s skin for color, breakdown, and signs of infection. (Is it swollen, firm, or tender to touch? Is there any redness or a rash?) Check the stoma to see if it is getting larger or smaller. Call your baby’s care provider if you’re worried.
- Follow the package directions to put on the new stoma bag and close the clamp.
- Empty the old bag into the toilet or diaper pail.
- Take off gloves and wash your hands.
- You may be nervous at first, but with practice, you will become more comfortable using the equipment. It’s always OK to ask for help! Make sure you ask your baby’s healthcare provider who you can call for help, questions, and concerns.

The above information is to help you better understand your baby’s care. Always follow the instructions given by your baby’s healthcare provider and ask questions if you have concerns about your baby.

Online Resources
American Academy of Pediatrics
www.aap.org

Healthy Children
www.healthychildren.org

Kids Health
www.kidshealth.org
Home Medical Equipment: Oxygen

The neonatal intensive care unit (NICU) team celebrates with you as your baby goes home! After graduation from the NICU, your baby will need special home medical equipment (also called durable medical equipment) to help keep him or her well.

Why does my baby need this equipment?

- Oxygen is a gas that provides energy for every organ in the body. Room air is 21% oxygen.
- Oxygen is also a drug and must be ordered by a doctor or nurse practitioner.
- Extra oxygen from the nasal cannula will help your baby breathe easier, feed better, and grow.
- You will be going home with a pulse oximeter (pulse or oxygen saturation monitor).

Vendor Information

A company, also called a vendor, will bring the equipment to your home and teach you how to use and manage any problems with the equipment that may arise.

Name: ____________________________________________________________

Phone Number: __________________________________________________________________________

Address: ____________________________________________________________________________________

Other Emergency Numbers: __________________________________________________________________________

Important Things to Remember

- Complete cardiopulmonary resuscitation (CPR) teaching, as well as monitor and equipment training.
- Stay overnight with your baby—use the equipment you will be going home with and care for your baby for at least 24 to 48 hours before going home.
- Prepare for a smoke-free home, so that your baby can breathe easy.
- Do not let anyone smoke in the house, the car, or anywhere around your baby or the oxygen tanks.
- Oxygen burns easily. It cannot be around an open flame. Keep the oxygen tanks and tubing at least 6 to 10 feet away from candles, fire or burners, radiators, fireplaces, or heaters.
- Do not use grease, oil, rubbing alcohol, powders, petroleum jelly, or spray cans near your baby on oxygen or the equipment.
- Keep the door to the baby’s room open.
- Use stands to keep the oxygen tanks on a flat surface. Be careful that the tanks don’t tip over on anyone.
- Call your emergency medical services, telephone, and electric companies to let them know that your baby uses a pulse oximeter (pulse ox or oxygen saturation monitor). This is important so that if there is a power outage or emergency, you will be on a priority list for help.
- Always check your baby when you hear the pulse monitor alarm. If your baby is blue or having breathing problems, be sure the oxygen tank is on, that oxygen is flowing out of the cannula, and that prongs are in your baby’s nose. If your baby is not breathing, shout for help, start CPR, and call emergency medical services (EMS) or 911 right away.

The above information is to help you better understand your baby's care. Always follow the instructions given by your baby's health-care provider and ask questions if you have concerns about your baby.

Online Resources

American Academy of Pediatrics

www.aap.org
Home Medical Equipment: Pulse Oximeter (Pulse Ox, Oxygen Saturation Monitor)

The neonatal intensive care unit (NICU) team celebrates with you as your baby goes home! After graduation from the NICU, your baby will need special home medical equipment (also called durable medical equipment) to help keep him or her well.

Why does my baby need this equipment?
- Your baby needs a pulse oximeter to monitor the amount of oxygen in his or her blood (oxygen saturation).
- A small, lighted probe attached to your baby’s foot or hand will measure the amount of oxygen in his or her blood.
- You will hear an alarm if the amount of oxygen in your baby’s blood becomes too low.

Vendor Information
A company, also called a vendor, will bring the equipment to your home and teach you how to use and manage any problems with the equipment that may arise.

Name: _______________________________________________________________________________________

Phone Number: _________________________________________________________________________________

Address: ______________________________________________________________________________________

Other Emergency Numbers: _______________________________________________________________________

Important Things to Remember
- Always use safe sleep practices. (Put your baby on his or her back to sleep in crib and keep him or her alone in the crib on a firm mattress with his or her face uncovered; do not overdress your baby for sleep, and keep toys and stuffed animals out of the crib.)
- Always use the pulse oximeter when your baby is asleep, takes a nap, while he or she is riding in the car, or when you are busy. Don’t leave the monitor at home.
- False alarms may sound if your baby is moving or the lighted probe becomes loose. Make sure the monitor is hooked up the right way to decrease false alarms.
- Always check on your baby when you hear the pulse oximeter alarm. If needed, tap your baby’s foot or rub your baby’s chest to help remind your baby to breathe or help raise the heartbeat. Check to make sure their nasal cannula oxygen is still in their nose if the alarm goes off. If your baby is not breathing, shout for help, start cardiopulmonary resuscitation (CPR), and call emergency medical services (EMS) or 911 right away.
- Call your EMS, telephone, and electric companies if your baby also uses oxygen. This is important so that if there is a power outage or emergency, you will be on a priority list for help.
- Do not stop using the pulse oximeter until your baby’s provider tells you it is safe to do so.
- You may be nervous at first, but with practice, you will become more comfortable using the equipment. It’s always OK to ask for help! Make sure you ask your baby’s healthcare provider who you can call for help, questions, and concerns.

The above information is to help you better understand your baby’s care. Always follow the instructions given by your baby’s healthcare provider and ask questions if you have concerns about your baby.

Online Resources
American Academy of Pediatrics  Kids Health
www.aap.org  www.kidshealth.org
Home Medical Equipment: Tracheostomy

The neonatal intensive care unit (NICU) team celebrates with you as your baby goes home! After graduation from the NICU, your baby will need special home medical equipment (also called durable medical equipment) to help keep him or her well.

What is a tracheostomy?

- A tracheostomy is surgically created so air enters the windpipe and lungs directly through the neck instead of going through the nose and mouth. This causes some changes in how the body works.

Vendor Information

A company, also called a vendor, will bring the equipment to your home and teach you how to use and manage any problems with the equipment that may arise.

Name: __________________________________________________________________________________________

Phone Number: _________________________________________________________________________________

Address: _______________________________________________________________________________________

Other Emergency Numbers: _______________________________________________________________________

Important Things to Remember

- Air now bypasses the voice box, or vocal cords, so your baby may or may not be able to make voice noises.
- Breathing through the mouth and nose filters, warms, and moistens air. Your baby will need extra moisture to keep the airway from drying out and to keep mucus thin.
- You can give moisture through a “trach collar.” This is a humidifier with flexible tubing and a mask that fits loosely over the tracheostomy.
- You can also use an “artificial nose” that collects the moisture and heat that your baby breathes out. The “nose” puts the heat and moisture back in with every breath.

Stoma Care

The stoma is the opening in the neck. It is very important to keep the skin around the tracheostomy clean and dry.

- Look at the skin for any red or irritated areas.
- Clean this area at least twice a day; more frequent cleaning may be needed.
- Wash hands with soap and water before performing any cares.
- Use cotton-tip applicators or lint-free gauze to clean around the stoma.
- Use a mild, fragrance-free soap and water.
- Use a rolling motion, starting at the stoma and working outward. This will prevent you from pushing dried secretions or soap into the tracheostomy.
- Rinse with water and then dry the area completely.

Suctioning

Suctioning is a way to keep the airway clear. Suction the tracheostomy if you notice that your baby is

- breathing faster or harder
- tugging or pulling the skin around and under the ribs with each breath
- pale, gray, or blue color especially around the mouth or has a decreased oxygen saturation
- frightened or anxious looking
- bubbling mucus out of the tracheostomy tube
- making rattling or whistling sounds
- refusing to eat or drink.
In children with no evidence of secretions, a minimum of suctioning, at morning and bedtime, to check for patency of the tube is recommended.

**Suction Technique**
To suction your baby you need to
1. Wash hands with soap and water before performing any cares.
2. Remove the catheter from the package, taking care not to touch the tip of the catheter.
3. Turn on the suction machine and attach the catheter to the tubing.
4. Insert the catheter into the trach tube to the premeasured depth.
5. Place your thumb over the suction port.
6. Withdraw the catheter using a rotating motion.
7. Limit suction time to less than 5 seconds.
8. Suction catheter size.
9. Suction catheter insertion depth.

**Changing the Tracheostomy Tube**
If the tube is plugged it may need to be changed. Your team recommends a routine change every day. Have all of your supplies ready before you begin to change the tube.
1. Wash hands with soap and water before performing any care.
2. Put the obturator into the clean tube.
3. Attach a tracheostomy tie to one side of the neck plate.
4. Lightly coat the tip of the tube with a water-soluble lubricant.
5. Use a roll under your baby's shoulders to extend the neck.
6. Keep the head straight.
7. Hold the old tube in place while the trach tie is loosened.
8. Remove the old tube.
9. Put the clean tube in using a downward curving motion.
10. Remove the obturator and secure the trach tie to the other side of the tube.

**Cleaning the Reusable Supplies**
- Use warm, soapy water to clean supplies. Rinse well and air dry thoroughly.

**Keeping Your Baby Safe and Healthy**
- Make sure all who come in contact with your baby washes their hands and do not have any symptoms of illness.
- Your baby should not be around anyone who smokes. Smoke will irritate the airway and lungs and make it hard to breathe.
- Keep your home free from lint, dust, and fine pet hair.
- Do not use powders, strong cleaning products, or aerosol sprays in the same room with your baby.
- Choose clothes that do not block the tracheostomy. Avoid high necklines and clothes that shed fibers or lint.
- Do not have toys with small parts that could fit inside the tracheostomy.
- Bath water must be shallow to avoid splashing. Water will go directly to the lungs if it gets in the tracheostomy. When your baby is sitting up, make sure the tracheostomy isn’t blocked.

**Signs of Illness**
Call your health care provider if your baby has
- a fever above 101 °F
- mucus that is yellow or green or smells bad
• blood in secretions
• breathing problems that do not improve after suctioning.

**Signs of an Emergency**

• Make sure all local emergency responders (e.g., fire, police, ambulance), and electric, gas, water, phone companies know of your baby’s condition.
• Keep a list of emergency phone numbers including the local emergency room and your pediatrician.
• Ensure any family members or friends that take care of your baby know who to call and what to do in an emergency.
• An emergency can happen at any time. If the tracheostomy is not working your baby will not be able to get enough air in and out of the lungs. In an emergency call out for help, begin CPR, and call 911. Some common emergencies are:
  – inability to clear the tube with suctioning (it is probably plugged)
  – inability to replace the tracheostomy tube

Keep the following equipment with you at all times, including leaving your home:
• suctioning equipment (suction machine, catheters, saline)
• tube change supplies (extra trach tubes with obturators) (same size and one size smaller), lubricant, tracheostomy ties
• self-inflating resuscitation bag and mask.

_The above information is to help you better understand your baby’s care. Always follow the instructions given by your baby’s healthcare provider and ask questions if you have concerns about your baby._
Medications at Home: Albuterol (Proventil, Ventolin)

The neonatal intensive care unit (NICU) team celebrates with you as your baby goes home! After graduation from the NICU, your baby will need medication to stay well.

Why does my baby need this medication?

• Albuterol is used to prevent and treat shortness of breath, wheezing, and chest tightening caused by obstructive lung disease (chronic lung disease).
• This fast-acting, emergency drug (rescue medicine) acts to relax and open the airways of the lungs.

How, how much, and when is this medication given to my baby?

• Albuterol is given with a special machine called a nebulizer that turns liquid medication into a mist. Your baby will breathe in the mist from a face mask. Be careful not to get the mist in your baby’s eyes. Nebulizer treatments take about 10–20 minutes to complete. The NICU team will teach you how to use the nebulizer.
• Some babies may use an inhaler. Always follow the directions given to you by your baby’s team about how to administer the medication, including the use of a spacer if it is provided.
• The amount of medicine to give has been carefully calculated based on your baby’s weight and needed response from the medicine. Do not change the dosage without talking to your baby’s provider.
• Dose Instructions: ______________________________________________________________________________

What are the possible side effects?

• Increase in heart beat
• Tremor
• Restlessness (fussiness)
• Dry nose and throat
• Nosebleed

Call your baby’s provider right away if your baby has

• fast, pounding, irregular heartbeat
• rash or hives
• problems swallowing
• swelling of face, throat, tongue, lips, eyes, hands, feet, ankles, or lower legs
• hoarse voice
• increased shortness of breath, wheezing, and increased work of breathing.

What if my baby misses a dose?

• Give the missed dose as soon as you remember it. If it is almost time for the next dose, skip the missed dose and stick to the regular medication schedule.
• Never give a double dose.
• Call your baby’s provider if your baby misses two or more doses.

Important Medication Safety Tips

• Only give your baby medicine prescribed by your baby’s provider. Do not share prescription medicines with other children or adults.
• Check with your baby’s provider before giving your baby any over-the-counter medicines.
• Keep all medicines out of reach of children, closed tightly in the bottles or containers they came in, and with the labels of directions given by the pharmacy.
• Give albuterol exactly as directed by your baby’s provider.
Never stop albuterol or give too much, too little, or more or less often without first talking with your baby’s provider. Too little may not be enough to help, and too much may cause harm. In the case of an overdose, immediately call the Poison Control Center at 800.222.1222. If you cannot wake your baby or he or she has stopped breathing, start cardiopulmonary resuscitation (CPR) and call your local emergency medical services (EMS) or 911 right away.

Store albuterol in the refrigerator.

• If your baby also uses an inhaled steroid, such as budesonide (Pulmicort), give albuterol first to open the airways.
  • If your baby is receiving more than one inhaled medication, do not mix them together for the nebulizer unless specifically instructed to do so by your baby’s provider.

• If your baby has severe difficulty breathing or stops breathing, start CPR and call your local EMS or 911 right away.

• Always use the five rights when giving medicines to your baby:
  • Right baby (if other children are in the home)
  • Right medication
  • Right amount (always measure the dose with the syringe or dropper provided by the pharmacy, not a common household teaspoon)
  • Right time
  • Right way (exactly as prescribed and directed by your baby’s provider).

The above information is to help you better understand your baby’s care. Always follow the instructions given by your baby’s provider and pharmacist. It’s always OK to ask questions if you have concerns about your baby.

Online Resources
American Academy of Pediatrics
www.aap.org

HealthFinder.gov
www.healthfinder.gov

Institute for Safe Medication Practices
www.ismp.org/consumers

Kids Health
www.kidshealth.org

Medline Plus: Drug Information
www.nlm.nih.gov/medlineplus/druginfo/meds

U.S. Food and Drug Administration
www.fda.gov
Medications at Home: Budesonide (Pulmicort)

The neonatal intensive care unit (NICU) team celebrates with you as your baby goes home! After graduation from the NICU, your baby will need medication to stay well.

**Why does my baby need this medication?**
- Budesonide is used to prevent or control wheezing and shortness of breath caused by lung disease.
- This medication is a corticosteroid used to prevent or treat inflammation (swelling) in the airways.
- Budesonide does not give fast relief of wheezing and shortness of breath.

**How, how much, and when is this medication given to my baby?**
- This medicine is given with a special machine called a nebulizer that turns liquid medication into a mist. Your baby will breathe in the mist from a face mask. Be careful not to get the mist in your baby’s eyes. Nebulizer treatments take about 10–20 minutes to complete. The NICU team will teach you how to use the nebulizer.
- Some babies may use an inhaler. Always follow the directions given to you by your baby’s team about how to administer the medication, including the use of a spacer if it is provided.
- The amount of medicine to give has been carefully calculated based on your baby’s weight and needed response from the medicine. Do not change the dosage without talking to your baby’s provider.
- Dose Instructions: ______________________________________________________________________________

**What are possible side effects?**
- Dry mouth or throat
- Cough
- Dizziness
- Problems sleeping
- Neck or stomach pain

**Call your baby’s provider right away if your baby has**
- white spots or sores in the mouth
- swollen face, lower legs, or ankles
- common cold or other infection
- weakness
- increased difficulty with breathing
- skin rash
- bleeding or bruising
- fever
- pain with urination.

**What if my baby misses a dose?**
- Give the missed dose as soon as you remember it. If it is almost time for the next dose, skip the missed dose and stick to the regular medication schedule.
- Never give a double dose.
- Call your baby’s provider if your baby misses two or more doses.

**Important Medication Safety Tips**
- Only give your baby medicines prescribed by your baby’s provider. Do not share prescription medications with other children or adults.
- Check with your baby’s provider before giving your baby any over-the-counter medicines.
• Keep all medicines out of reach of children, closed tightly in the bottles or containers they came in, and with the labels of directions given by the pharmacy.

• Give budesonide exactly as directed by your baby’s provider.
  – Never stop giving the budesonide or give too much, too little, or more or less often without first talking with your baby’s provider. Too little may not be enough to help, and too much may cause harm. In the case of an overdose, immediately call the Poison Control Center at 800.222.1222. If you cannot wake your baby or he or she has stopped breathing, start cardiopulmonary resuscitation (CPR) and call your local emergency medical services or 911 right away.
  – If your baby is taking more than one inhaled medication, do not mix them together for the nebulizer unless specifically instructed to do so by your baby’s provider.
  – Store budesonide at room temperature and away from excess heat and damp areas like the bathroom.
  – Clean your baby’s mouth with a soft cloth moistened with water after treatment is finished.

• Always use the five rights when giving medication to your baby:
  – Right baby (if other children are in the home)
  – Right medication
  – Right amount (always measure the dose with the syringe or dropper provided by the pharmacy, not a common household teaspoon)
  – Right time
  – Right way (exactly as prescribed and directed by your baby’s provider.

The above information is to help you better understand your baby’s care. Always follow the instructions given by your baby’s provider and pharmacist. It’s always OK to ask questions if you have concerns about your baby.

Online Resources
American Academy of Pediatrics www.aap.org
HealthFinder.gov www.healthfinder.gov
Institute for Safe Medication Practices www.ismp.org/consumers

Kids Health www.kidshealth.org

U.S. Food and and Drug Administration www.fda.gov
Medications at Home: Caffeine Citrate

The neonatal intensive care unit (NICU) team celebrates with you as your baby goes home! After graduation from the NICU, your baby will need medication to stay well.

Why does my baby need this medication?
- Caffeine citrate is used to prevent and treat apnea (long pauses between breaths or irregular breathing during sleep).
- This medication stimulates the brain to “remind” your baby to breathe.

How, how much, and when is this medication given to my baby?
- Caffeine citrate is given by mouth.
- The amount of medicine to give has been carefully calculated based on your baby’s weight and needed response from the medicine. Do not change the dosage without talking to your baby’s provider.
- Dose Instructions: __________________________________________________________________________

What are possible side effects?
- Restlessness (fussiness)
- Vomiting
- Fast heartbeat

What if my baby misses a dose or spits up the medication?
- Give the missed dose as soon as you remember it. If it is almost time for the next dose, skip the missed dose and stick to the regular medication schedule.
- Never give a double dose.
- Call your baby’s healthcare provider if your baby misses two or more doses or spits up the medication.

Important Medication Safety Tips
- Only give your baby medicines prescribed by your baby’s provider. Do not share prescription medications with other children or adults.
- Check with your baby’s provider before giving your baby any over-the-counter medicines.
- Keep all medicines out of reach of children, closed tightly in the bottles or containers they came in, and with the labels of directions given by the pharmacy.
- Give caffeine citrate exactly as directed by your baby’s provider.
  - Never stop caffeine citrate or give more or less than prescribed without first talking with your baby’s provider. Too little may not be enough to help, and too much may cause harm. In the case of an overdose, immediately call the Poison Control Center at 800.222.1222.
  - If you cannot wake your baby or he or she has stopped breathing, start cardiopulmonary resuscitation (CPR) and call your local emergency medical services or 911 right away.
  - Store caffeine citrate at room temperature and away from light, heat, and damp areas like the bathroom.
  - If your baby begins to have more monitor alarms, contact your baby’s provider.
  - If your baby’s heart rate is higher than 180 beats per minute, talk to your baby’s provider before giving caffeine citrate.
  - Do not give your baby food or drinks that contain caffeine (e.g., soda, energy drinks, coffee, tea, chocolate).
  - Your baby may need blood tests while on this medication.
- Always use the five rights when giving medication to your baby:
  - Right baby (if other children are in the home)
  - Right medication
  - Right amount (always measure the dose with the syringe or dropper provided by the pharmacy, not a common household teaspoon)
– Right time
– Right way (exactly as prescribed and directed by your baby’s provider).

The above information is to help you better understand your baby’s care. Always follow the instructions given by your baby’s provider and pharmacist. It’s always OK to ask questions if you have concerns about your baby.

**Online Resources**
- American Academy of Pediatrics
  www.aap.org
- HealthFinder.gov
  www.healthfinder.gov
- Institute for Safe Medication Practices
  www.ismp.org/consumers
- Kids Health
  www.kidshealth.org
- Medline Plus: Drug Information
  www.nlm.nih.gov/medlineplus/druginfo/meds
- U.S. Food and Drug Administration
  www.fda.gov
Medications at Home: Chlorothiazide (Diuril)

The neonatal intensive care unit (NICU) team celebrates with you as your baby goes home! After graduation from the NICU, your baby will need medication to stay well.

Why does my baby need this medication?
- Chlorothiazide helps babies with chronic lung disease breathe easier by decreasing extra fluid in the lungs.
- It is also used to treat high blood pressure and diabetes insipidus.
- Commonly called a water pill (diuretic), this medication helps the kidneys get rid of extra water and salt that the body does not need.
- You may have to give other medicines with this one, such as other electrolytes (potassium).

How, how much, and when is this medication given to my baby?
- This medication is given by mouth.
- The amount of medicine to give has been carefully calculated based on your baby’s weight and needed response from the medicine. Do not change the dosage without talking to your baby’s provider.
- Dose Instructions: ______________________________________________________________________________

What are possible side effects?
- Muscle weakness
- Decreased appetite
- Thirst
- Cramps
- Stomach pain
- Upset stomach
- Vomiting
- Diarrhea (watery stools) or constipation
- Hair loss
- High blood sugar
- Restlessness

Call your baby’s provider right away if your baby has
- fever
- bleeding or bruising
- skin rash with peeling skin
- problems breathing or swallowing.

What if my baby misses a dose or spits up the medication?
- Give the missed dose as soon as you remember it. If it is almost time for the next dose, skip the missed dose and stick to the regular medication schedule.
- Never give a double dose.
- Call your baby’s healthcare provider if your baby misses two or more doses or spits up the medication.

Important Medication Safety Tips
- Only give your baby medicines prescribed by your baby’s provider. Do not share prescription medications with other children or adults.
- Check with your baby’s provider before giving your baby any over-the-counter medicines.
- Keep all medicines out of reach of children, closed tightly in the bottle or container it came in, and with the label of directions given by the pharmacy.
• Give chlorothiazide exactly as directed by your baby’s provider.
  – Never stop chlorothiazide or give more or less than prescribed without first talking with your baby’s provider. Too little may not be enough to help and too much may cause harm. In case of overdose, immediately call the Poison Control Center at 800.222.1222. If you cannot wake your baby or if he or she has stopped breathing, start cardiopulmonary resuscitation (CPR) and call your local emergency medical services or 911 right away.
  – Store chlorothiazide at room temperature away from extreme heat or cold.
• Always use the five rights when giving medication to your baby:
  – Right baby (if other children are in the home)
  – Right medication
  – Right amount (always measure the dose with the syringe or dropper provided by the pharmacy, not a common household teaspoon)
  – Right time
  – Right way (exactly as prescribed and directed by your baby’s provider).

The above information is to help you better understand your baby’s care. Always follow the instructions given by your baby’s health-care provider and pharmacist. It’s always OK to ask questions if you have concerns about your baby.

Online Resources
American Academy of Pediatrics
www.aap.org

HealthFinder.gov
www.healthfinder.gov

Institute for Safe Medication Practices
www.ismp.org/consumers

Kids Health
www.kidshealth.org

Medline Plus: Drug Information
www.nlm.nih.gov/medlineplus/druginfo/meds

U.S. Food and Drug Administration
www.fda.gov
Medication at Home: Compounding Pharmacy

The neonatal intensive care unit (NICU) team celebrates with you as your baby goes home! After graduation from the NICU, your baby will need medication to stay well.

Some prescription medications must be made using a special process called *compounding*. Your baby is taking the drug, ________________________________, which is made by compounding. For help finding a compounding pharmacy in your neighborhood, please call the hospital pharmacy at ________________________________. Another resource for locating a compounding pharmacy is the *Professional Compounding Centers of America* (www.pccarx.com).

**Compounding Pharmacy**

Name: ________________________________________________________________

Address:  _____________________________________________________________

Phone Number: _______________________________________________________

_________________________________________________________
Medications at Home: Digoxin (Lanoxin)

The neonatal intensive care unit (NICU) team celebrates with you as your baby goes home! After graduation from the NICU, your baby will need medication to stay well.

Why does my baby need this medication?
• Digoxin is used to treat heart failure and heart arrhythmias (supraventricular tachycardia, atrial fibrillation, and atrial flutter).
• This medication controls the heartbeat so that the heart works better.

How, how much, and when is this medication given to my baby?
• Digoxin is given by mouth.
• The amount of medicine to give has been carefully calculated based on your baby’s weight and needed response from the medicine. Do not change the dosage without talking to your baby’s provider.
• Dose Instructions: ______________________________________________________________________________

What are possible side effects?
• Rash
• Irregular heartbeat

Call your baby’s provider right away if your baby has
• upset stomach or vomiting
• diarrhea (watery stools)
• loss of appetite
• swelling of feet or hands
• fast weight gain
• problems breathing.

What if my baby misses a dose or spits up the medication?
• Give the missed dose as soon as you remember it. If it is almost time for the next dose, skip the missed dose and stick to the regular medication schedule.
• Never give a double dose.
• Call your baby’s provider if your baby misses two or more doses or spits up the medication.

Important Medication Safety Tips
• Only give your baby medication prescribed by your baby’s provider. Do not share prescription medications with other children or adults.
• Check with your baby’s provider before giving your baby any over-the-counter medicines.
• Keep all medicines out of reach of children, closed tightly in the bottle or container it came in, and with the label of directions given by the pharmacy.
• Give digoxin exactly as directed by your baby’s provider.
  – Count your baby’s heart rate before giving this medicine. Do not give your baby digoxin if his or her heart rate is less than ________________.
  – Never stop digoxin or give more or less than prescribed without first talking with your baby’s provider. Too little may not be enough to help and too much may cause harm. In case of overdose, immediately call the Poison Control Center at 800.222.1222.
  – If you cannot wake your baby or he or she has stopped breathing, start cardiopulmonary resuscitation (CPR) and call your local emergency medical services or 911 right away.
  – Call your baby’s provider right away if there is a sudden increase or decrease in your baby’s heart rate.
  – Store digoxin at room temperature and away from light, heat, and damp areas like the bathroom.
  – Your baby may need to have blood tests and heart monitoring while on this medication.
• Always use the five rights when giving medication to your baby:
  – Right baby (if other children are in the home)
  – Right medication
  – Right amount (always measure the dose with the syringe or dropper provided by the pharmacy, not a common household teaspoon)
  – Right time
  – Right way (exactly as prescribed and directed by your baby’s provider).

_The above information is to help you better understand your baby’s care. Always follow the instructions given by your baby’s health-care provider and pharmacist. It’s always OK to ask questions if you have concerns about your baby._

**Online Resources**

American Academy of Pediatrics  
www.aap.org

Kids Health  
www.kidshealth.org

HealthFinder.gov  
www.healthfinder.gov

Medline Plus: Drug Information  
www.nlm.nih.gov/medlineplus/druginfo/meds

Institute for Safe Medication Practices  
www.ismp.org/consumers

U.S. Food and Drug Administration  
www.fda.gov
Medications at Home: Ferrous Sulfate (Elemental Iron)

The neonatal intensive care unit (NICU) team celebrates with you as your baby goes home! After graduation from the NICU, your baby will need medication to stay well.

**Why does my baby need this medication?**
- Ferrous sulfate is used to prevent and treat anemia (also called low blood count).
- This medication helps your baby’s body make red blood cells and carry oxygen to his or her important organs like the brain and heart.

**How, how much, and when is this medication given to my baby?**
- Ferrous sulfate is given by mouth.
- The amount of medicine to give has been carefully calculated based on your baby’s weight and needed response from the medicine. Do not change the dosage without talking to your baby’s provider.
- Dose Instructions: ____________________________

**What are possible side effects?**
- Upset stomach
- Stomach pain
- Constipation
- Black stools (causes no harm to baby)
- Weakness
- Decreased appetite

**What if my baby misses a dose or spits up the medication?**
- Give the missed dose as soon as you remember it. If it is almost time for the next dose, skip the missed dose and stick to the regular medication schedule.
- Never give a double dose.
- Call your baby’s healthcare provider if your baby misses two or more doses or spits up the medication.

**Important Medication Safety Tips**
- Only give your baby medicines prescribed by your baby’s provider. Do not share prescription medicines with other children or adults.
- Check with your baby’s provider before giving your baby any over-the-counter medicines.
- Keep all medicines out of reach of children, closed tightly in the bottle or container it came in, and with the label of directions given by the pharmacy.
- Give ferrous sulfate exactly as directed by your baby’s provider.
  - Never stop ferrous sulfate or give more or less than prescribed without first talking with your baby’s provider. Too little may not be enough to help and too much may cause harm. In case of overdose, immediately call the Poison Control Center at 800.222.1222. If you cannot wake your baby or he or she has stopped breathing, start cardiopulmonary resuscitation (CPR) and call your local emergency medical services or 911 right away.
  - Store ferrous sulfate at room temperature and away from excess light, heat, and damp areas like the bathroom.
  - Mix ferrous sulfate with a small amount of breast milk or water to help make it easier on your baby’s stomach.
  - Your baby may need to have blood tests while on this medication.
- Always use the five “rights” when giving medication to your baby:
  - Right baby (if other children are in the home)
  - Right medication
- Right amount (always measure the dose with the syringe or dropper provided by the pharmacy, not a common household teaspoon)
- Right time
- Right way (exactly as prescribed and directed by your baby's provider).

The above information is to help you better understand your baby's care. Always follow the instructions given by your baby's healthcare provider and pharmacist. It's always OK to ask questions if you have concerns about your baby.

**Online Resources**

American Academy of Pediatrics  
www.aap.org

HealthFinder.gov  
www.healthfinder.gov

Institute for Safe Medication Practices  
www.ismp.org/consumers

Kids Health  
www.kidshealth.org

Medline Plus: Drug Information  
www.nlm.nih.gov/medlineplus/druginfo/meds

U.S. Food and Drug Administration  
www.fda.gov
Medications at Home: Fluticasone (Flovent)

The neonatal intensive care unit (NICU) team celebrates with you as your baby goes home! After graduation from the NICU, your baby will need medication to stay well.

**Why does my baby need this medication?**
- Fluticasone is used to prevent or control wheezing or reactive airway episodes caused by lung disease. Fluticasone is a corticosteroid used to prevent or treat inflammation (swelling) in the airways. It does not give fast relief of wheezing and shortness of breath.

**How, how much, and when is this medication given to my baby?**
- Fluticasone is given in “puffs” with an inhaler and a spacer. You will have to fit a mask over your baby’s nose and mouth to give this medicine. Be careful not to get the mist in your baby’s eyes.
- Always follow the directions given to you by your baby’s team about how to administer the medication.
- The amount of medicine to give has been carefully calculated based on your baby’s weight and needed response from the medicine. Do not change the dose without talking to your baby’s provider.
- Dose Instructions: _______________________________________________________________________

**What are possible side effects?**
- Nausea (upset stomach)
- Eye irritation (redness, watery eyes)
- Dry mouth or throat irritation when swallowing
- Shortness of breath

**Call your baby’s provider right away if your baby has**
- white spots or sores in the mouth
- swollen face, lower legs, or ankles
- common cold or other infection
- weakness
- increased difficulty with breathing
- skin rash
- bleeding or bruising
- fever.

**What if my baby misses a dose or spits up the medication?**
- Give the missed dose as soon as you remember it. If it is almost time for the next dose, skip the missed dose and stick to the regular medication schedule.
- Never give a double dose.
- Call your baby’s provider if your baby misses two or more doses.

**Important Medication Safety Tips**
- Only give your baby medicines prescribed by your baby’s provider. Do not share prescription medicines with other children or adults.
- Check with your baby’s provider before giving your baby any over-the-counter medicines.
- Keep all medicines out of reach of children, closed tightly in the bottles or containers they came in, and with the labels of directions given by the pharmacy.
- Give fluticasone exactly as directed by your baby’s provider.
  - Never stop fluticasone or give more or less than prescribed without first talking with your baby’s provider. Too little may not be enough to help, and too much may cause harm. In case of overdose, immediately call the Poison Control Center at
800.222.1222. If you cannot wake your baby or he or she has stopped breathing, start cardiopulmonary resuscitation (CPR) and call your local emergency medical services or 911 right away.

- Store fluticasone at room temperature and away from excess heat and damp areas like the bathroom.
- Clean your baby’s mouth with a soft cloth moistened with water after treatment is finished.

• Always use the five “rights” when giving medication to your baby:
  - Right baby (if other children are in the home)
  - Right medication
  - Right amount (always measure the dose with the syringe or dropper provided by the pharmacy, not a common household teaspoon)
  - Right time
  - Right way (exactly as prescribed and directed by your baby’s provider).

The above information is to help you better understand your baby’s care. Always follow the instructions given by your baby’s healthcare provider and pharmacist. It’s always OK to ask questions if you have concerns about your baby.

**Online Resources**

American Academy of Pediatrics
www.aap.org

HealthFinder.gov
www.healthfinder.gov

Institute for Safe Medication Practices
www.ismp.org/consumers

Kids Health
www.kidshealth.org

Medline Plus: Drug Information
www.nlm.nih.gov/medlineplus/druginfo/meds

U.S. Food and Drug Administration
www.fda.gov
Medications at Home: Lansoprazole (Prevacid)

The neonatal intensive care unit (NICU) team celebrates with you as your baby goes home! After graduation from the NICU, your baby will need medication to stay well.

Medication Name: Lansoprazole (Prevacid)

Why does my baby need this medication?
Lansoprazole is used to treat gastroesophageal reflux disease (GERD), sometimes called acid reflux. In GERD, stomach acid flows upward into the throat and may cause pain and harm to the throat. Lansoprazole decreases the amount of stomach acid.

How, how much, and when is this medication given to my baby?
- Lansoprazole is given by mouth. It can also be given through a feeding tube.
- The amount of medicine to give has been carefully calculated based on your baby's weight and needed response from the medicine. Do not change the dose without talking to your baby's provider.
- Dose Instructions: ______________________________________________________________________________

What are possible side effects?
- Nausea (upset stomach)
- Abdominal distention (enlarged tummy)
- Headache
- Diarrhea (watery stool)

Call your baby’s provider right away if your baby has
- rash
- blisters or peeling skin
- hives (raised, red, itchy patches of skin)
- swelling of eyes, face, lips, mouth, tongue, or throat
- hoarse voice
- fast, pounding, or irregular heartbeat
- unusual tiredness
- uncontrollable shaking of a body part or seizures
- stomach pain
- fever.

What if my baby misses a dose or spits up the medication?
- Give the missed dose as soon as you remember it. If it is almost time for the next dose, skip the missed dose and stick to the regular medication schedule.
- Never give a double dose.
- Call your baby’s provider if your baby misses two or more doses or spits up the medication.

Important Medication Safety Tips
- Only give your baby medicines prescribed by your baby’s provider. Do not share prescription medicines with other children or adults.
- Check with your baby’s provider before giving your baby any over-the-counter medicines.
- Keep all medicines out of reach of children, closed tightly in the bottles or containers they came in, and with the labels of directions given by the pharmacy.
- Give lansoprazole exactly as directed by your baby’s provider.
Never stop lansoprazole or give more or less than prescribed without first talking with your baby’s healthcare provider. Too little may not be enough to help, and too much may cause harm. In case of overdose, immediately call the Poison Control Center at 800.222.1222. If you cannot wake your baby or he or she has stopped breathing, start cardiopulmonary resuscitation (CPR) and call your local emergency medical services or 911 right away.

Store lansoprazole at room temperature and away from excess heat and damp areas like the bathroom.

For best results, give your baby lansoprazole no more than 30 minutes before meals.

Your baby may need to have blood tests while on this medicine.

Always use the five “rights” when giving medication to your baby:

- Right baby (if other children are in the home)
- Right medication
- Right amount (always measure the dose with the syringe or dropper provided by the pharmacy, not a common household teaspoon)
- Right time
- Right way (exactly as prescribed and directed by your baby’s provider).

The above information is to help you better understand your baby’s care. Always follow the instructions given by your baby’s healthcare provider and pharmacist. It’s always OK to ask questions if you have concerns about your baby.

**Online Resources**

American Academy of Pediatrics  
www.aap.org

Kids Health  
www.kidshealth.org

HealthFinder.gov  
www.healthfinder.gov

Medline Plus: Drug Information  
www.nlm.nih.gov/medlineplus/druginfo/meds

Institute for Safe Medication Practices  
www.ismp.org/consumers

U.S. Food and Drug Administration  
www.fda.gov
Medications at Home: Multivitamins

The neonatal intensive care unit (NICU) team celebrates with you as your baby goes home! After graduation from the NICU, your baby will need medication to stay well.

**Why does my baby need this medication?**
Multivitamins are a nutritional supplement that promote healthy growth and development.

**How, how much, and when is this medication given to my baby?**
- Multivitamins are given by mouth.
- Dose Instructions: _____________________________________________________________

**What are possible side effects?**
- Upset stomach

**What if my baby misses a dose or spits up the medication?**
- Give the missed dose as soon as you remember it. If it is almost time for the next dose, skip the missed dose and stick to the regular medication schedule. Never give a double dose.
- Call your baby’s provider if your baby misses two or more doses or spits up the medication.

**Important Medication Safety Tips**
- Only give your baby medicines prescribed by your baby’s provider. Do not share prescription medicines with other children or adults.
- Check with your baby’s provider before giving your baby any over-the-counter medicines.
- Keep all medicines out of reach of children, closed tightly in the bottles or containers they came in, and with the labels of directions given by the pharmacy.
- Give multivitamins exactly as directed by your baby’s provider.
  - Never stop multivitamins or give more or less than prescribed without first talking with your baby’s provider. Too little may not be enough to help, and too much may cause harm. In case of overdose, immediately call the Poison Control Center at 800.222.1222. If you cannot wake your baby or he or she has stopped breathing, start cardiopulmonary resuscitation (CPR) and call your local emergency medical services or 911 right away.
  - Store multivitamins at room temperature and away from excess heat and damp areas like the bathroom.
  - Be aware that multivitamins that contain iron may stain clothing if spilled or if the infant spits up.
- Always use the five “rights” when giving medication to your baby:
  - Right baby (if other children are in the home)
  - Right medication
  - Right amount (always measure the dose with the syringe or dropper provided by the pharmacy, not a common household teaspoon)
  - Right time
  - Right way (exactly as prescribed and directed by your baby’s provider).

The above information is to help you better understand your baby’s care. Always follow the instructions given by your baby’s healthcare provider and pharmacist. It’s always OK to ask questions if you have concerns about your baby.

**Online Resources**
- American Academy of Pediatrics
  www.aap.org
- HealthFinder.gov
  www.healthfinder.gov
- Institute for Safe Medication Practices
  www.ismp.org/consumers
- Kids Health
  www.kidshealth.org
- Medline Plus: Drug Information
  www.nlm.nih.gov/medlineplus/druginfo/meds
- U.S. Food and Drug Administration
  www.fda.gov
Medications at Home: Omeprazole (Prilosec)

The neonatal intensive care unit (NICU) team celebrates with you as your baby goes home! After graduation from the NICU, your baby will need medication to stay well.

**Why does my baby need this medication?**

Omeprazole is used to treat *gastroesophageal reflux disease* (GERD), sometimes called *acid reflux*. In GERD, stomach acid flows upward into the throat and may cause pain and harm to the throat. Omeprazole decreases the amount of stomach acid.

**How, how much, and when is this medication given to my baby?**

- Omeprazole is given by mouth.
- The amount of medicine to give has been carefully calculated based on your baby's weight and needed response from the medicine. Do not change the dosage without talking to your baby's provider.

  **Dose Instructions:**

**What are possible side effects?**

- Nausea (upset stomach)
- Vomiting
- Stomach pain
- Constipation
- Gas
- Rash

**What if my baby misses a dose or spits up the medication?**

- Give the missed dose as soon as you remember it. If it is almost time for the next dose, skip the missed dose and stick to the regular medication schedule.
- Never give a double dose.
- Call your baby's provider if your baby misses two or more doses or spits up the medication.

**Important Medication Safety Tips**

- Only give your baby medicines prescribed by your baby's provider. Do not share prescription medicines with other children or adults.
- Check with your baby's provider before giving your baby any over-the-counter medicines.
- Keep all medicines out of reach of children, closed tightly in the bottles or containers they came in, and with the labels of directions given by the pharmacy.
- Give omeprazole exactly as directed by your baby's provider.
  - Never stop omeprazole or give more or less than prescribed without first talking with your baby's provider. Too little may not be enough to help, and too much may cause harm. In case of overdose, immediately call the Poison Control Center at 800.222.1222. If you cannot wake your baby or he or she has stopped breathing, start cardiopulmonary resuscitation (CPR) and call your local emergency medical services or 911 right away.
  - Store omeprazole at room temperature, away from excess heat and damp areas like the bathroom.
- Always use the five *rights* when giving medication to your baby:
  - Right baby (if other children are in the home)
  - Right medication
  - Right amount (always measure the dose with the syringe or dropper provided by the pharmacy, not a common household teaspoon)
  - Right time
  - Right way (exactly as prescribed and directed by your baby's provider).
The above information is to help you better understand your baby's care. Always follow the instructions given by your baby's provider and pharmacist. It's always OK to ask questions if you have concerns about your baby.

**Online Resources**

American Academy of Pediatrics
www.aap.org

HealthFinder.gov
www.healthfinder.gov

Institute for Safe Medication Practices
www.ismp.org/consumers

Kids Health
www.kidshealth.org

Medline Plus: Drug Information
www.nlm.nih.gov/medlineplus/druginfo/meds

U.S. Food and Drug Administration
www.fda.gov
Medications at Home: Phenobarbital

The neonatal intensive care unit (NICU) team celebrates with you as your baby goes home! After graduation from the NICU, your baby will need medication to stay well.

Why does my baby need this medication?

• Phenobarbital is used to prevent or treat seizures (convulsions).
• This medication is also used to treat sluggish gallbladder.

How, how much, and when is this medication given to my baby?

• Phenobarbital is given by mouth.
• The amount of medicine to give has been carefully calculated based on your baby’s weight and needed response from the medicine. Do not change the dosage without talking to your baby’s provider.
• Dose Instructions: ______________________________________________________________________________

What are possible side effects?

• Eye sensitivity to light
• Dry mouth
• Sleepiness
• Constipation
• Nervousness
• Skin flushing (redness)
• Excessive sleepiness

Call your baby’s healthcare provider right away if your baby has

• rapid heartbeat
• eye pain
• skin rash
• problems urinating
• lack of sweating in older child.

What if my baby misses a dose or spits up the medication?

• Give the missed dose as soon as you remember it. If it is almost time for the next dose, skip the missed dose and stick to the regular medication schedule.
• Never give a double dose.
• Call your baby’s provider if your baby misses two or more doses or spits up the medication.

Important medication safety tips

• Only give your baby medicines prescribed by your baby’s healthcare provider. Do not share prescription medicines with other children or adults.
• Check with your baby’s provider before giving your baby any over-the-counter medicines.
• Keep all medicines out of reach of children, closed tightly in the bottle or container it came in, and with the label of directions given by the pharmacy.
• Give phenobarbital exactly as directed by your baby’s provider.
  – Never stop phenobarbital or give more or less than prescribed without first talking with your baby’s provider. Too little may not be enough to help, and too much may cause harm. In case of overdose, immediately call the Poison Control Center at 800.222.1222. If you cannot wake your baby or he or she has stopped breathing, start cardiopulmonary resuscitation (CPR) and call your local emergency medical services or 911 right away.
– Store phenobarbital at room temperature and away from excess heat and damp areas like the bathroom.
– Your baby may need to have blood tests while on this medicine.

• Always use the five rights when giving medication to your baby:
  – Right baby (if other children are in the home)
  – Right medication
  – Right amount (always measure the dose with the syringe or dropper provided by the pharmacy, not a common household teaspoon)
  – Right time
  – Right way (exactly as prescribed and directed by your baby’s provider).

The above information is to help you better understand your baby’s care. Always follow the instructions given by your baby’s healthcare provider and pharmacist. It’s always OK to ask questions if you have concerns about your baby.

Online Resources
American Academy of Pediatrics
www.aap.org

HealthFinder.gov
www.healthfinder.gov

Institute for Safe Medication Practices
www.ismp.org/consumers

Kids Health
www.kidshealth.org

Medline Plus: Drug Information
www.nlm.nih.gov/medlineplus/druginfo/meds

U.S. Food and Drug Administration
www.fda.gov
Medications at Home: Ranitidine (Zantac)

The neonatal intensive care unit (NICU) team celebrates with you as your baby goes home! After graduation from the NICU, your baby will need medication to stay well.

**Why does my baby need this medication?**
- Ranitidine is used to prevent and treat stress ulcers.
- This medication prevents and treats gastrointestinal bleeding caused by stomach acid.
- Ranitidine also treats gastroesophageal reflux disease (GERD), sometimes called acid reflux, by decreasing the amount of stomach acid. In GERD, stomach acid flows upward into the throat and may cause pain and harm to the throat.

**How, how much, and when is this medication given to my baby?**
- Ranitidine is given by mouth.
- The amount of medicine to give has been carefully calculated based on your baby's weight and needed response from the medicine. Do not change the dosage without talking to your baby's provider.
- Dose Instructions: ______________________________________________________________________________

**What are possible side effects?**
- Irritability (due to headache)
- Constipation
- Diarrhea (watery stool)
- Nausea and vomiting
- Stomach pain
- Enlarged stomach
- Irregular heartbeat

**What if my baby misses a dose or spits up the medication?**
- Give the missed dose as soon as you remember it. If it is almost time for the next dose, skip the missed dose and stick to the regular medication schedule.
- Never give a double dose.
- Call your baby's provider if your baby misses two or more doses or spits up the medication.

**Important Medication Safety Tips**
- Only give your baby medicines prescribed by your baby's healthcare provider. Do not share prescription medicines with other children or adults.
- Check with your baby's provider before giving your baby any over-the-counter medicines.
- Keep all medicines out of reach of children, closed tightly in the bottles or containers they came in, and with the labels of directions given by the pharmacy.
- Give ranitidine exactly as directed by your baby's healthcare provider.
  - Never stop the ranitidine or give too much or too little without first talking with your baby's healthcare provider. Too little may not be enough to help, and too much may cause harm. In the case of an overdose, immediately call the Poison Control Center at 800.222.1222. If you cannot wake your baby or he or she has stopped breathing, start cardiopulmonary resuscitation (CPR) and call your local emergency medical services or 911 right away.
  - Store ranitidine at room temperature and away from excess heat and damp areas like the bathroom.

Always use the five rights when giving medication to your baby:
- Right baby (if other children are in the home)
- Right medication
- Right amount (always measure the dose with the syringe or dropper provided by the pharmacy, not a common household teaspoon)
- Right time
- Right way (exactly as prescribed and directed by your baby’s provider).

The above information is to help you better understand your baby’s care. Always follow the instructions given by your baby’s healthcare provider and pharmacist. It’s always OK to ask questions if you have concerns about your baby.

**Online Resources**

American Academy of Pediatrics  
www.aap.org

HealthFinder.gov  
www.healthfinder.gov

Institute for Safe Medication Practices  
www.ismp.org/consumers

Kids Health  
www.kidshealth.org

Medline Plus: Drug Information  
www.nlm.nih.gov/medlineplus/druginfo/meds

U.S. Food and Drug Administration  
www.fda.gov
Medications at Home: Vitamin D (Ergocalciferol, Cholecalciferol)

The neonatal intensive care unit (NICU) team celebrates with you as your baby goes home! After graduation from the NICU, your baby will need medication to stay well.

Why does my baby need this medication?
• Vitamin D helps to prevent and treat low levels of vitamin D in the blood.
• This medication prevents and treats bone diseases like rickets (bone softening).
• This medication helps the body absorb calcium and phosphorus so that bones grow strong.
• This medication helps keep your baby’s nerves, muscles, and immune system healthy.

How, how much, and when is this medication given to my baby?
• Vitamin D is given by mouth.
• The amount of medicine to give has been carefully calculated based on your baby’s weight and needed response from the medicine. Do not change the dosage without talking to your baby’s provider.
• Dose Instructions: ______________________________________________________________________________

What are possible side effects?
• None (at the proper dose)

What if my baby misses a dose or spits up the medication?
• Give the missed dose as soon as you remember it. If it is almost time for the next dose, skip the missed dose and stick to the regular medication schedule.
• Never give a double dose.
• Call your baby’s provider if your baby misses two or more doses or spits up the medication.
• Do not give with a multivitamin unless specifically recommended by your baby’s provider. Many multivitamins also have vitamin D in them. In some instances, giving both is needed, but always ask before giving both.

Important Medication Safety Tips
• Only give your baby medicines prescribed by your baby’s provider. Do not share prescription medicines with other children or adults.
• Check with your baby’s provider before giving your baby any over-the-counter medicines.
• Keep all medicines out of reach of children, closed tightly in the bottles or containers they came in, and with the labels of directions given by the pharmacy.
• Give vitamin D exactly as directed by your baby’s provider.
  – Never stop vitamin D or give more or less than prescribed without first talking with your baby’s provider. Too little may not be enough to help, and too much may cause harm. In case of overdose, immediately call the Poison Control Center at 800.222.1222. If you cannot wake your baby or he/she has stopped breathing, start cardiopulmonary resuscitation (CPR) and call your local emergency medical services or 911 right away.
  – Store vitamin D at room temperature, away from excess heat and damp areas like the bathroom.
• Always use the five rights when giving medication to your baby:
  – Right baby (if other children are in the home)
  – Right medication
  – Right amount (always measure the dose with the syringe or dropper provided by the pharmacy, not a common household teaspoon)
  – Right time
  – Right way (exactly as prescribed and directed by your baby’s provider).
The above information is to help you better understand your baby's care. Always follow the instructions given by your baby's provider and pharmacist. It's always OK to ask questions if you have concerns about your baby.

**Online Resources**

- American Academy of Pediatrics
  - [www.aap.org](http://www.aap.org)

- HealthFinder.gov
  - [www.healthfinder.gov](http://www.healthfinder.gov)

- Institute for Safe Medication Practices
  - [www.ismp.org/consumers](http://www.ismp.org/consumers)

- Kids Health
  - [www.kidshealth.org](http://www.kidshealth.org)

- Medline Plus: Drug Information

- U.S. Food and Drug Administration
  - [www.fda.gov](http://www.fda.gov)
Follow-Up Appointment: Cardiology

The neonatal intensive care unit (NICU) team celebrates with you as your baby goes home! Because your baby is a NICU graduate, he or she is at higher risk for certain problems after discharge. That’s why your baby needs important follow-up appointments to ensure his or her best health.

Why does my baby need this appointment?
A pediatric cardiologist is a children’s doctor who is also an expert in the diagnosis and treatment of nonsurgical heart problems.

Where is the appointment?
Name: ____________________________________________________________

Street Address: ___________________________________________________________________________________________________

Phone Number: _____________________________________________________________________________________________________

When is the appointment?
☐ Date: ____________________________________________ Time: ______________________________

☐ You will need to call the pediatric cardiology office to schedule your baby’s appointment.

☐ The pediatric cardiology office will call you to schedule your baby’s appointment.

Important Things to Remember
• Each follow-up appointment with pediatric cardiology is important and is in addition to well-child check-ups with your baby's primary care provider.
• If you are unable to keep this important follow-up appointment, please call to reschedule.
• Always take your baby for future heart examinations as directed by the pediatric cardiologist.
• Bring a list of your baby's current medicines, dose, and time you gave the last dose with you to the appointment. Make sure you tell the staff if you need refills.
• If your baby takes special medications to help the heart pump better, always follow the directions on the bottle or container that came from the pharmacy.

The above information is provided to help you better understand your baby's care. Always follow the instructions given by your baby's provider and ask questions if you have concerns about your baby.

Online Resources
American Academy of Pediatrics
www.aap.org

Kids Health
www.kidshealth.org
Follow-Up Appointment: Cardiothoracic Surgery

The neonatal intensive care unit (NICU) team celebrates with you as your baby goes home! Because your baby is a NICU graduate, he or she is at higher risk for certain problems after discharge. That’s why your baby needs important follow-up appointments to ensure his or her best health.

**Why does my baby need this appointment?**

A pediatric cardiothoracic surgeon is a children's doctor who also is an expert in the diagnosis and surgical treatment of heart problems.

**Where is the appointment?**

Name: __________________________________________________________________________________________

Street Address: __________________________________________________________________________________

Phone Number: ____________________________________________________________________________________

**When is the appointment?**

- Date: __________________________________________________________________ Time: ___________________________

- You will need to call the pediatric cardiothoracic surgery office to schedule your baby’s appointment.

- The pediatric cardiothoracic surgery office will call you to schedule your baby’s appointment.

**Important Things to Remember**

- Each follow-up appointment with pediatric cardiothoracic surgery is important and is in addition to well-child check-ups with your baby’s primary care provider.

- If you are unable to keep this important follow-up appointment, please call to reschedule.

- Always take your baby for future surgical examinations as directed by the pediatric cardiothoracic surgeon.

- Bring a list of your baby’s current medicines with you to the appointment. Make sure you tell the staff if you need refills.

*The above information is provided to help you better understand your baby’s care. Always follow the instructions given by your baby’s provider and ask questions if you have concerns about your baby.*

**Online Resources**

American Academy of Pediatrics  
www.aap.org

Kids Health  
www.kidshealth.org
Follow-Up Appointment: Dermatology

The neonatal intensive care unit (NICU) team celebrates with you as your baby goes home! Because your baby is a NICU graduate, he or she is at higher risk for certain problems after discharge. That's why your baby needs important follow-up appointments to ensure his or her best health.

**Why does my baby need this appointment?**

A **pediatric dermatologist** is a children's doctor who is also an expert in the diagnosis and treatment of skin problems.

**Where is the appointment?**

Name: ____________________________________________________________

Street Address: _______________________________________________________

Phone Number: _______________________________________________________

**When is the appointment?**

- Date: ___________________________  Time: ______________________________
- You need to call the pediatric dermatology office to schedule your baby’s appointment.
- The pediatric dermatology office will call you to schedule your baby’s appointment.

**Important Things to Remember**

- Each follow-up appointment with pediatric dermatology is important and is in addition to well-child check-ups with your baby's primary care provider.
- If you are unable to keep this important follow-up appointment, please call to reschedule.
- Always take your baby for future skin examinations as directed by the pediatric dermatologist.
- Bring a list of your baby's current medicines, dose, and time you gave the last dose or any ointments for their skin with you to the appointment. Make sure you tell the staff if you need refills.

The above information is provided to help you better understand your baby's care. Always follow the instructions given by your baby's healthcare provider and ask questions if you have concerns about your baby.

**Online Resources**

- American Academy of Pediatrics  
  www.aap.org
- Kids Health  
  www.kidshealth.org
Follow-Up Appointment: Early Intervention or Early Childhood Intervention

The neonatal intensive care unit (NICU) team celebrates with you as your baby goes home! Because your baby is a NICU graduate, he or she is at higher risk for certain problems after discharge. That’s why your baby needs important follow-up appointments to ensure his or her best health.

Why does my baby need this appointment?

- Babies born premature, with low birth weight, or with other complications around birth are at higher risk for delays in development or problems with movement and speech.
- Early intervention/early childhood intervention (EI/ECI) is a program to promote your baby’s best development by helping you be your baby’s first and most important teacher.
- EI/ECI experts include teachers and rehabilitation therapists such as occupational therapists, physical therapists, and speech language pathologists.
- EI/ECI experts help prevent and also diagnosis and treat problems with movement, feeding, and language.
- Because a baby’s job is to play, EI/ECI experts use play activities to help your baby learn how best to move, feed, talk, and play.

Where is the appointment?

(Many EI programs make home visits to teach you how to help your baby’s development.)

Name: _________________________________________________________________

Street Address: ____________________________________________________________________________

Phone Number: ________________________________________________________________________________

When is the appointment?

- Date: ____________________________________________________________________________ Time: __________________________
- You need to call the EI/ECI office to schedule your baby’s appointment.
- The EI/ECI office will call you to schedule your baby’s appointment.

Important Things to Remember

- Each follow-up appointment with EI/ECI is important and is in addition to well-child check-ups with your baby’s primary care provider and any high-risk infant follow-up appointments.
- If you are unable to keep this important follow-up appointment, please call to reschedule.

The above information is provided to help you better understand your baby’s care. Always follow the instructions given by your baby’s provider and ask questions if you have concerns about your baby.

Online Resources

American Academy of Pediatrics  High-Risk Infant Follow-Up Quality of Care Initiative
www.aap.org  www.ccshrif.org

American Occupational Therapy Association, Inc.  Kids Health
www.aota.org  www.kidshealth.org
Follow-Up Appointment: Endocrinology

The neonatal intensive care unit (NICU) team celebrates with you as your baby goes home! Because your baby is a NICU graduate, he or she is at higher risk for certain problems after discharge. That’s why your baby needs important follow-up appointments to ensure his or her best health.

Why does my baby need this appointment?

- A pediatric endocrinologist is a children's doctor who is also an expert in the diagnosis and treatment of problems of the endocrine system.
- The endocrine system is also called the hormone and gland system and affects almost every cell and organ in your baby's body.
- Growth disorders and diabetes are just a few types of endocrine problems.

Where is the appointment?

Name: __________________________________________________________________________________________

Street Address: __________________________________________________________________________________________

Phone Number: ______________________________________________________________________________________

When is the appointment?

- Date: ___________________________ Time: ________________
- You will need to call the pediatric endocrinology office to schedule your baby’s appointment.
- The pediatric endocrinology office will call you to schedule your baby’s appointment.

Important Things to Remember

- Each follow-up appointment with pediatric endocrinology is important and is in addition to well-child check-ups with your baby’s primary care provider.
- If you are unable to keep this important follow-up appointment, please call to reschedule.
- Always take your baby for future endocrinology examinations as directed by the pediatric endocrinologist.
- Bring a list of your baby's current medicines with you to the appointment. Make sure you tell the staff if you need refills.

The above information is provided to help you better understand your baby’s care. Always follow the instructions given by your baby’s provider and ask questions if you have concerns about your baby.

Online Resources

American Academy of Pediatrics
www.aap.org

Kids Health
www.kidshealth.org
Follow-Up Appointment: Gastroenterology

The neonatal intensive care unit (NICU) team celebrates with you as your baby goes home! Because your baby is a NICU graduate, he or she is at higher risk for certain problems after discharge. That’s why your baby needs important follow-up appointments to ensure his or her best health.

**Why does my baby need this appointment?**

A pediatric gastroenterologist is a children’s doctor who is also an expert in the diagnosis and treatment of stomach and intestinal problems.

**Where is the appointment?**

Name: __________________________________________________________________________________________

Street Address: __________________________________________________________________________________

Phone Number: ___________________________________________________________________________________

**When is the appointment?**

- Date: ____________________________ Time: __________

- You need to call the pediatric gastroenterology office to schedule your baby’s appointment.

- The pediatric gastroenterology office will call you to schedule your baby’s appointment.

**Important Things to Remember**

- Each follow-up appointment with pediatric gastroenterology is important and is in addition to well-child check-ups with your baby’s primary care provider.

- If you are unable to keep this important follow-up appointment, please call to reschedule.

- Always take your baby for future follow-up examinations as directed by the pediatric gastroenterologist.

- Bring a list of your baby’s current medicines with you to the appointment. Make sure you tell the staff if you need refills.

This information is provided to help you better understand your baby’s care. Always follow the directions given by your baby’s provider. Always share your questions or concerns about your baby with the healthcare provider.

**Online Resources**

American Academy of Pediatrics  
www.aap.org

Kids Health  
www.kidshealth.org
Follow-Up Appointment: Genetics

The neonatal intensive care unit (NICU) team celebrates with you as your baby goes home! Because your baby is a NICU graduate, he or she is at higher risk for certain problems after discharge. That’s why your baby needs important follow-up appointments to ensure his or her best health.

Why does my baby need this appointment?
A pediatric geneticist is a children’s doctor who is also an expert in the diagnosis and cause(s) of birth defects and genetics problems.

Where is the appointment?
Name: ________________________________________________________________
Street Address: __________________________________________________________
Phone Number: __________________________________________________________

When is the appointment?
☐ Date: _____________________________ Time: _____________________________
☐ You need to call the pediatrics genetics office to schedule your baby’s appointment.
☐ The pediatrics genetics office will call you to schedule your baby’s appointment.

Important Things to Remember
• Each follow-up appointment with pediatric genetics is important and is in addition to well-child check-ups with your baby’s primary care provider.
• If you are unable to keep this important follow-up appointment, please call to reschedule.
• Always take your baby for future genetics examinations as directed by the pediatric geneticist.
• Bring a list of your baby’s current medicines with you to the appointment. Make sure you tell the staff if you need refills.

The above information is provided to help you better understand your baby’s care. Always follow the instructions given by your baby’s provider and ask questions if you have concerns about your baby.

Online Resources
American Academy of Pediatrics www.aap.org
Kids Health www.kidshealth.org

American Academy of Pediatrics
www.aap.org
Follow-Up Appointment: Hematology

The neonatal intensive care unit (NICU) team celebrates with you as your baby goes home! Because your baby is a NICU graduate, he or she is at higher risk for certain problems after discharge. That’s why your baby needs important follow-up appointments to ensure his or her best health.

Why does my baby need this appointment?  
A pediatric hematologist is a children’s doctor who is also an expert in the diagnosis and treatment of blood problems.

Where is the appointment?  
Name: ______________________________________________________________________________________
Street Address _____________________________________________________________________________________
Phone Number: _____________________________________________________________________________________

When is the appointment?  
☐ Date: __________________________________________________________________ Time: __________________________________________________________________
☐ You will need to call the pediatric hematology office to schedule your baby’s appointment.
☐ The pediatric hematology office will call you to schedule your baby’s appointment.

Important Things to Remember  
• Each follow-up appointment with pediatric hematology is important and is in addition to well-child check-ups with your baby’s primary care provider.
• If you are unable to keep this important follow-up appointment, please call to reschedule.
• Always take your baby for future hematology examinations as directed by the pediatric hematologist.
• Bring a list of your baby’s current medicines with you to the appointment. Make sure you tell the staff if you need refills.

The above information is provided to help you better understand your baby’s care. Always follow the instructions given by your baby’s provider and ask questions if you have concerns about your baby.

Online Resources
American Academy of Pediatrics  
www.aap.org  

Kids Health  
www.kidshealth.org
Follow-Up Appointment: High-Risk Infant Follow-Up (Neuro Brain Developmental Follow-Up)

The neonatal intensive care unit (NICU) team celebrates with you as your baby goes home! Because your baby is a NICU graduate, he or she is at higher risk for certain problems after discharge. That’s why your baby needs important follow-up appointments to ensure his or her best health.

Why does my baby need this appointment?
• Babies born premature, with low birth weight, or with other complications around birth are at higher risk for problems or delays in growth and development.
• During your child’s first 3 years of life, he or she will have several in-depth neurodevelopmental examinations at high-risk infant follow-up (HRIF).
• The HRIF team uses play to check on the quality of your child’s
  – thinking and learning (cognitive skills)
  – movement (gross motor or large muscle and fine motor or small muscle skills, strength, and coordination)
  – play with toys (adaptive skills)
  – smiling and eye contact (social skills)
  – talking and gestures (communication skills).

Where is the appointment?
Name: _______________________________________________________________________________________
Street Address: ________________________________________________________________________________
Phone Number: _________________________________________________________________________________

When is the appointment?
☐ Date: ________________________________ Time: ________________________________
☐ You will need to call the HRIF office to schedule your baby’s appointment.
☐ The HRIF office will call you to schedule your baby’s appointment.

Important Things to Remember
• Each HRIF appointment is important and is in addition to well-child check-ups with your baby’s primary care provider and any early intervention.
• When problems are identified early, children receive help from experts and community services so they can reach their best growth and development.
• If you are unable to keep this important follow-up appointment, please call to reschedule.

This information is provided to help you better understand your baby’s care. Always follow the directions given by your baby’s provider and ask questions if you have concerns about your baby.

Online Resources
American Academy of Pediatrics
www.aap.org

High-Risk Infant Follow-Up Quality of Care Initiative
www.ccshrif.org
Kids Health
www.kidshealth.org
The neonatal intensive care unit (NICU) team celebrates with you as your baby goes home! Because your baby is a NICU graduate, he or she is at higher risk for certain problems after discharge. That’s why your baby needs important follow-up appointments to ensure his or her best health.

Why does my baby need this appointment?
A pediatric nephrologist is a children’s doctor who is also an expert in the diagnosis and treatment of kidney problems.

Where is the appointment?
Name: __________________________________________
Street Address __________________________________________
Phone Number __________________________________________

When is the appointment?
☐ Date: __________________________  Time: __________________________
☐ You need to call the pediatric nephrology office to schedule your baby’s appointment.
☐ The pediatric nephrology office will call you to schedule your baby’s appointment.

Important Things to Remember
- Each follow-up appointment with pediatric nephrology is important and is in addition to well-child check-ups with your baby’s primary care provider.
- If you are unable to keep this important follow-up appointment, please call to reschedule.
- Always take your baby for future nephrology examinations as directed by the pediatric nephrologist.
- Bring a list of your baby’s current medicines with you to the appointment. Make sure you tell the staff if you need refills.

The above information is provided to help you better understand your baby’s care. Always follow the instructions given by your baby’s provider and ask questions if you have concerns about your baby.

Online Resources
American Academy of Pediatrics  Kids Health
www.aap.org  www.kidshealth.org
Follow-Up Appointment: Neurology

The neonatal intensive care unit (NICU) team celebrates with you as your baby goes home! Because your baby is a NICU graduate, he or she is at higher risk for certain problems after discharge. That’s why your baby needs important follow-up appointments to ensure his or her best health.

Why does my baby need this appointment?

A pediatric neurologist is a children’s doctor who is also an expert in the diagnosis and treatment of nonsurgical nervous system (brain and spinal cord) problems.

Where is the appointment?

Name: ____________________________________________________________

Street Address: _______________________________________________________

Phone Number: _______________________________________________________

When is the appointment?

☐ Date: _____________________________ Time: _____________________________

☐ You will need to call the pediatric neurology office to schedule your baby's appointment.

☐ The pediatric neurology office will call you to schedule your baby's appointment.

Important Things to Remember

• Each follow-up appointment with pediatric neurology is important and is in addition to well-child check-ups with your baby’s primary care provider.

• If you are unable to keep this important follow-up appointment, please call to reschedule.

• Always take your baby for future neurology examinations as directed by the pediatric neurologist.

• Bring a list of your baby’s current medicines with you to the appointment. Make sure you tell the staff if you need refills.

The above information is provided to help you better understand your baby’s care. Always follow the instructions given by your baby’s provider and ask questions if you have concerns about your baby.

Online Resources

American Academy of Pediatrics

www.aap.org

Kids Health

www.kidshealth.org
Follow-Up Appointment: Neurosurgery

The neonatal intensive care unit (NICU) team celebrates with you as your baby goes home! Because your baby is a NICU graduate, he or she is at higher risk for certain problems after discharge. That’s why your baby needs important follow-up appointments to ensure his or her best health.

Why does my baby need this appointment?
A pediatric neurosurgeon is a children’s doctor who is also an expert in the diagnosis and surgical treatment of nervous system (brain and spinal cord) problems.

Where is the appointment?
Name: __________________________________________________________________________________________
Street Address: _____________________________________________________________________________________
Phone Number: _____________________________________________________________________________________

When is the appointment?
✓ Date: ___________________________________________ Time: __________________________
✓ You will need to call the pediatric neurosurgery office to schedule your baby’s appointment.
✓ The pediatric neurosurgery office will call you to schedule your baby’s appointment.

Important Things to Remember
• Each follow-up appointment with pediatric neurosurgery is important and is in addition to well-child check-ups with your baby’s primary care provider.
• If you are unable to keep this important follow-up appointment, please call to reschedule.
• Always take your baby for future neurosurgery examinations as directed by the pediatric neurosurgeon.
• Bring a list of your baby’s current medicines with you to the appointment. Make sure you tell the staff if you need refills.

The above information is provided to help you better understand your baby’s care. Always follow the instructions given by your baby’s provider and ask questions if you have concerns about your baby.

Online Resources
American Academy of Pediatrics  
www.aap.org  
Kids Health  
www.kidshealth.org
Follow-Up Appointment: Nutrition Clinic

The neonatal intensive care unit (NICU) team celebrates with you as your baby goes home! Because your baby is a NICU graduate, he or she is at higher risk for certain problems after discharge. That’s why your baby needs important follow-up appointments to ensure his or her best health.

Why does my baby need this appointment?

• Babies born premature who have low birth weight or other complications around birth are at higher risk for poor growth.
• A registered dietitian, a nutrition expert in infants and children, will teach you how to safely help your baby eat healthy and grow.

Where is the appointment?

Name: __________________________________________________________

Street Address: __________________________________________________

Phone Number: __________________________________________________

When is the appointment?

☐ Date: ____________________________________________ Time: ________________________

☐ You will need to call the pediatric nutrition clinic to schedule your baby’s appointment.

☐ The pediatric nutrition clinic will call you to schedule your baby’s appointment.

Important Things to Remember

• Each follow-up appointment with the pediatric nutrition clinic is important and is in addition to well-child check-ups with your baby’s primary care provider.
• If you are unable to keep this important follow-up appointment, please call to reschedule.
• Always take your baby for future nutrition or dietitian examinations as directed by the pediatric nutrition clinic.
• Bring a list of your baby’s current medicines with you to the appointment.

The above information is provided to help you better understand your baby’s care. Always follow the instructions given by your baby’s provider and ask questions if you have concerns about your baby.

Online Resources

American Academy of Pediatrics  Kids Health
www.aap.org  www.kidshealth.org

California Department of Health Care Services
www.dhcs.ca.gov/services
Follow-Up Appointment: Ophthalmology

The neonatal intensive care unit (NICU) team celebrates with you as your baby goes home! Because your baby is a NICU graduate, he or she is at higher risk for certain problems after discharge. That’s why your baby needs important follow-up appointments to ensure his or her best health.

Why does my baby need this appointment?

- A pediatric ophthalmologist is a children’s doctor who is also an expert in the diagnosis and treatment of eye problems.
- Babies born premature or with certain complications around birth are at higher risk for eye and vision problems.
- If your baby has retinopathy of prematurity, he or she is at even higher risk for vision problems that may lead to severe loss of sight if not treated by a pediatric ophthalmologist.

Where is the appointment?

Name: ________________________________________________________________

Street Address: __________________________________________________________________________

Phone Number: __________________________________________________________________________

When is the appointment?

☐ Date: ____________________ Time: ____________________

☐ You need to call the pediatric ophthalmology office to schedule your baby’s appointment.

☐ The pediatric ophthalmology office will call you to schedule your baby’s appointment.

Important Things to Remember

- Each follow-up appointment with pediatric ophthalmology is very important and is in addition to well-child check-ups with your baby’s primary care provider.
- If you are unable to keep this important follow-up appointment, please call to reschedule.
- Always take your baby for future eye examinations as directed by the pediatric ophthalmologist.
- Bring a list of your baby’s current medicines with you to the appointment.

The above information is provided to help you better understand your baby’s care. Always follow the instructions given by your baby’s provider and ask questions if you have concerns about your baby.

Online Resources

American Academy of Pediatrics
www.aap.org

Kids Health
www.kidshealth.org
Follow-Up Appointment: Otolaryngology

The neonatal intensive care unit (NICU) team celebrates with you as your baby goes home! Because your baby is a NICU graduate, he or she is at higher risk for certain problems after discharge. That’s why your baby needs important follow-up appointments to ensure his or her best health.

Why does my baby need this appointment?
A pediatric otolaryngologist is a children’s doctor who is also an expert in the diagnosis and treatment of ear, nose, and throat problems.

Where is the appointment?
Name: ____________________________________________

Street Address: ____________________________________________

Phone Number: ____________________________________________

When is the appointment?
- Date: ___________________________________________________ Time: ________________________________
- You will need to call the pediatric otolaryngology office to schedule your baby’s appointment.
- The pediatric otolaryngology office will call you to schedule your baby’s appointment.

Important Things to Remember
- Each follow-up appointment with pediatric otolaryngology is important and is in addition to well-child check-ups with your baby’s primary care provider.
- If you are unable to keep this important follow-up appointment, please call to reschedule.
- Always take your baby for future ear, nose, and throat examinations as directed by the pediatric otolaryngologist.
- Bring a list of your baby’s current medicines with you to the appointment. Make sure you tell the staff if you need refills.

The above information is provided to help you better understand your baby’s care. Always follow the instructions given by your baby’s provider and ask questions if you have concerns about your baby.

Online Resources
American Academy of Pediatrics
www.aap.org

Kids Health
www.kidshealth.org
Follow-Up Appointment: Primary Care Provider

The neonatal intensive care unit (NICU) team celebrates with you as your baby goes home! Because your baby is a NICU graduate, he or she is at higher risk for certain problems after discharge. That’s why your baby needs important follow-up appointments to ensure his or her best health.

Why does my baby need this appointment?
A pediatric primary care provider (PCP) is a physician or nurse practitioner who is an expert in caring for babies, infants, and children as they grow and develop.

Where is the appointment?
Name: _____________________________________________________________
Street Address: _____________________________________________________
Phone Number: _____________________________________________________

When is the appointment?
☐ Date: ___________________________________________ Time: _______________________
☐ You will need to call your pediatric PCP office to schedule your baby’s appointment.
☐ The pediatric PCP office will call you to schedule your baby’s appointment.

Important Things to Remember
• Each follow-up appointment with pediatric PCP is important and is part of your baby’s well-child check-ups.
• If you are unable to keep this important follow-up appointment, please call to reschedule.
• Always take your baby for future examinations as directed by the pediatric PCP.
• Bring a list of your baby’s current medicines with you to the appointment. Make sure you tell the staff if you need refills.

The above information is provided to help you better understand your baby’s care. Always follow the instructions given by your baby’s provider and ask questions if you have concerns about your baby.

Online Resources
American Academy of Pediatrics  Kids Health
www.aap.org  www.kidshealth.org
Follow-Up Appointment: Pulmonology

The neonatal intensive care unit (NICU) team celebrates with you as your baby goes home! Because your baby is a NICU graduate, he or she is at higher risk for certain problems after discharge. That’s why your baby needs important follow-up appointments to ensure his or her best health.

Why does my baby need this appointment?
- A pediatric pulmonologist is a children’s doctor who is also an expert in the diagnosis and treatment of lung problems.
- Babies born premature, with chronic lung disease (also known as bronchopulmonary dysplasia, or BPD), or with other complications are at higher risk for ongoing lung problems.

Where is the appointment?
Name: __________________________________________________________________________________________
Street Address: ______________________________________________________________________________________
Phone Number: ______________________________________________________________________________________

When is the appointment?
- Date: ___________________________________________ Time: ____________________________________________
- You will need to call the pediatric pulmonology office to schedule your baby’s appointment.
- The pediatric pulmonology office will call you to schedule your baby’s appointment.

Important Things to Remember
- Each follow-up appointment with pediatric pulmonology is important and is in addition to well-child check-ups with your baby’s primary care provider.
- If you are unable to keep this important follow-up appointment, please call to reschedule.
- Always take your baby for future lung examinations as directed by the pediatric pulmonologist
- Bring a list of your baby’s current medicines, dose, and the time you gave the last dose with you to the appointment. Make sure you tell the staff if you need refills.
- If your baby takes special medicines to help breathe easier, always follow the directions on the bottle or container that came from the pharmacy.

The above information is provided to help you better understand your baby’s care. Always follow the instructions given by your baby’s provider and ask questions if you have concerns about your baby.

Online Resources
American Academy of Pediatrics  Kids Health
www.aap.org  www.kidshealth.org
Follow-Up Appointment: Surgery

The neonatal intensive care unit (NICU) team celebrates with you as your baby goes home! Because your baby is a NICU graduate, he or she is at higher risk for certain problems after discharge. That’s why your baby needs important follow-up appointments to ensure his or her best health.

**Why does my baby need this appointment?**

* A pediatric surgeon is a children’s doctor who is also an expert in the diagnosis and surgical treatment of a variety of problems.

**Where is the appointment?**

Name: ________________________________________________________________

Street Address: ________________________________________________________

Phone Number: ________________________________________________________

**When is the appointment?**

- Date: __________________ Time: __________________
- You need to call the pediatric surgery office to schedule your baby’s appointment.
- The pediatric surgery office will call you to schedule your baby’s appointment.

**Important Things to Remember**

- Each follow-up appointment with pediatric surgery is important and is in addition to well-child check-ups with your baby’s primary care provider.
- If you are unable to keep this important follow-up appointment, please call to reschedule.
- Always take your baby for future surgery examinations as directed by the pediatric surgeon.
- Bring a list of your baby’s current medicines, dose, and the time you gave the last dose with you to the appointment.

*The above information is provided to help you better understand your baby’s care. Always follow the instructions given by your baby’s provider and ask questions if you have concerns about your baby.*

**Online Resources**

- American Academy of Pediatrics  
  www.aap.org
- Kids Health  
  www.kidshealth.org
Follow-Up Appointment: Urology

The neonatal intensive care unit (NICU) team celebrates with you as your baby goes home! Because your baby is a NICU graduate, he or she is at higher risk for certain problems after discharge. That’s why your baby needs important follow-up appointments to ensure his or her best health.

**Why does my baby need this appointment?**
A pediatric urologist is a children’s doctor who is also an expert in the diagnosis and treatment of urinary problems.

**Where is the appointment?**
Name: ____________________________________________________________________________________
Street Address: ____________________________________________________________________________
Phone Number: ____________________________________________________________________________

**When is the appointment?**
- Date: ________________________________________________________________________________
- Time: __________________________________________
- You need to call the pediatric urology office to schedule your baby’s appointment.
- The pediatric urology office will call you to schedule your baby’s appointment.

**Important Things to Remember**
- Each follow-up appointment with pediatric urology is important and is in addition to well-child check-ups with your baby’s primary care provider.
- If you are unable to keep this important follow-up appointment, please call to reschedule.
- Always take your baby for future urinary examinations as directed by the pediatric urologist.
- Bring a list of your baby’s current medicines, dose, and the time you gave the last dose with you to the appointment. Make sure you tell the staff if you need refills.

*The above information is provided to help you better understand your baby’s care. Always follow the instructions given by your baby’s provider and ask questions if you have concerns about your baby.*

**Online Resources**
- American Academy of Pediatrics
  - www.aap.org
- Kids Health
  - www.kidshealth.org
Step 10
Rooming-In

For many infants, the NICU experience is lengthy and complex. As families prepare for their infants to come home, they may exhibit varying degrees of anxiety and stress. A thorough assessment of the family’s needs, environmental issues, and knowledge of their infant’s care before discharge is an important part of the transition to home. Providing an opportunity to care for their infant with professional caregivers nearby for assistance has been shown to increase parental competence and provide confirmation of their readiness to provide independent care at home.

Rooming-in is a practice where parents and other caregivers provide total care for their baby in a home-like environment while in the hospital. This process provides the caregiver with the opportunity to care for their infant with the availability of assistance from healthcare professionals. Studies indicate that mothers found rooming-in experiences to be beneficial in preparing them for the discharge of their infant. Other mothers stated that it was an extremely positive experience, aided them in breastfeeding, increased their confidence, and helped them feel like a family. Rooming-in facilitates the transition of the patient from hospital to home prior to discharge.

While rooming-in, the parents or caregivers provide all of the physical care and supervision for their infant, including giving medications, changing diapers, and feeding. Any additional equipment, such as monitors, oxygen therapy, or feeding pumps, is also used during the rooming-in period. All discharge education, including equipment training from the identified home health agency or durable medical equipment company, is completed prior to rooming-in.

The rooming-in period is usually 12–48 hours. Ideally, both the mother and father—or other adult family members who may be involved in the infant’s care—are involved with rooming-in. A family member or other caregiver remains with their infant during the entire rooming-in period. Be aware of state laws regarding minor parents (those under age 18). Some states will require parental consent for minors to room-in with their baby.

Once the rooming-in period has been completed successfully and all discharge goals for the infant, family, and staff have been achieved, it is time for discharge and transition to home.

Bibliography
Rooming-In: Information for Parents

Shortly before your baby is discharged from the NICU, you may have the opportunity to room-in with him or her for a certain amount of time. Rooming-in usually takes place for 24–48 hours in a private room with a home-like atmosphere. This experience is like a practice session for taking care of your baby on your own before you go home. It gives you a chance to try all you have learned with a nurse close by for help and advice. Rooming-in can make the change from hospital to home much smoother for you and your baby. Some hospitals may not have a private room for you to room-in, but you can go to your baby’s room for 12–16 hours and spend time caring for him or her.

Before Rooming-In

- Hospital staff will give you instructions, and you will be able to demonstrate all care for your baby.
- You will receive training on equipment to be used at home.
- Your baby’s nurse will review the rooming-in process and make suggestions about what to bring for rooming-in, such as comfortable clothing, a toothbrush, and personal grooming items.
- You may bring clothes you want your baby to wear during the rooming-in time.
- All the supplies you need to care for your baby (for examples, diapers, bottles/nipples, and blankets) will be in the room with you. Make sure you bring items you will need when you take your baby home (for example, blankets, outfits, etc.).

During Rooming-in

- You provide all care for your baby, including giving medications, changing diapers, and feedings.
- You use any monitoring or other equipment you will need to use at home.
- Take notes on what your baby is doing, what you did and when you did it, and how your baby responded. Things you should note include the time of feedings, number of wet or dirty diapers, times when your baby is fussy, or other things you may have questions about.
- Nurses are available by phone to answer questions and offer assistance.
- One parent or caregiver is expected to stay with the baby at all times.
- Rooming-in is a time for you and your baby; visitation by family and friends who are not primary caregivers is not recommended.

You are almost home. Rooming-in helps you learn more about your baby’s habits, behaviors, and routines before going home. It gives you time to ask questions and gain confidence in caring for your baby.
The goal of the discharge plan is to ensure a successful transition to home. Essential discharge criteria are a physiologically stable infant, a family who can provide the necessary care with appropriate support services in the community, and a primary care provider who is prepared to assume the responsibility with appropriate backup from specialists and other professionals as needed. The American Academy of Pediatrics (AAP) has provided recommendations for the discharge of the high-risk neonate to guide us (AAP, 2008).

Infant Readiness for Hospital Discharge
The infant is considered ready for discharge if, in the judgment of the responsible provider, the following have been accomplished:

- a sustained pattern of weight gain of sufficient duration has been demonstrated
- the infant has demonstrated adequate maintenance of normal body temperature while fully clothed in an open bed with normal ambient temperature (20 °C–25 °C)
- the infant has established competent feeding by breast or bottle without cardiorespiratory compromise
- physiologically mature and stable cardiorespiratory function has been documented for a sufficient duration
- appropriate immunizations have been administered
- appropriate metabolic screening has been performed
- hematologic status has been assessed and appropriate therapy has been instituted, if indicated
- nutritional risks have been assessed and therapy and dietary modification has been instituted, if indicated
- hearing evaluation has been completed
- critical congenital heart disease screening has been completed, as indicated
- eye (retina of prematurity) examinations have been completed, as indicated
- neurodevelopmental and neurobehavioral status has been assessed and demonstrated to the parents
- car seat evaluation has been completed
- review of the hospital course has been completed, unresolved medical problems have been identified, and plans for follow-up monitoring and treatment have been instituted
- an individualized home-care plan has been developed with input from all appropriate disciplines and family.

Assessment of the family’s caregiving capabilities, resource availability, and home physical facilities is essential prior to discharge. This includes identification of at least two family caregivers and assessment of their ability, availability, and commitment to caring for the infant. The case manager or care coordinator can assist in review of financial resources and support.

In preparation for home care of the technology-dependent infant, parents should complete an assessment documenting availability of 24-hour telephone access, electricity, safe in-house water supply, and adequate heating/cooling. Parents and caregivers should have demonstrated the necessary capabilities to provide all components of care, including completing cardiopulmonary resuscitation (CPR) training. A rooming-in period of 24–48 hours is recommended so parents and caregivers have time to care independently for their baby while still having the support of NICU staff.

Nurses are instrumental in bridging the gap between the hospital and home. You have partnered with the family in caring for the infant and now are ready to reinforce education and preparation for discharge to home. You assess discharge readiness, completion of fundamental and specialized education, and transition points in care from hospital to primary care. Parental education includes basic infant care and safety, car seat safety, medication administration, nutrition support, reinforcing instructions for any home equipment or special care procedures, reinforcing importance of follow-up appointments, home safety, and CPR. Nurses also assist in connecting parents with community resources and follow-up agencies. Communicating the importance of timely follow-up regarding unresolved
medical conditions such as retinopathy of prematurity, hearing screening referrals, and other individualized care is essential. Additional follow-up of the infant's neuro-developmental progress is also recommended to identify and promote optimal development through infancy and childhood.

Reference

Bibliography
Going Home: Information for Parents

Congratulations, you are going home!

Going home with your baby is an exciting time. You and your healthcare team have worked together throughout your time in the neonatal intensive care unit (NICU) to prepare you for this wonderful moment. It is normal to feel anxious about bringing your baby home. Your baby’s healthcare team will help you learn about your baby’s condition, medications, and care so that you are confident in taking your baby home. Your baby needs to meet three milestones before going home:

• maintain normal body temperature in an open crib
• take all feedings by breast or bottle
• have steady weight gain.

There are a few important things to review and complete before you go home:

• **Selecting a Primary Care Provider (PCP).** It is important to choose your pediatric PCP before it is time for your baby to be discharged. Let your baby’s nurse know your provider’s name and phone number. The NICU will send important information about your baby to your baby’s provider.

• **Infant CPR Classes.** Preparing for emergencies at home is very important. Classes are held in the hospital and at community sites. Ask your baby’s nurse about times and places for classes.

• **Car Seat.** Every baby must have a car seat in place at time of discharge. If you have a premature or very small baby, your baby will have a car seat test before going home.

• **Hearing Screening.** All infants are given a hearing screen prior to discharge. A baby who does not pass the screening does not necessarily have hearing loss. A retest to confirm the results should be done within the first 3 months of life. You will receive any needed information prior to discharge of your infant.

• **Circumcision.** If your baby is a boy, you will need to decide whether to have him circumcised. Full-term baby boys usually can be circumcised before they leave the hospital. Usually the same applies to a healthy premature baby.

• **Medications.** Your baby’s provider may prescribe medications to give to your baby at home. Before your infant is discharged, your baby’s healthcare team will ask you to get the prescriptions filled and bring them to the hospital. They will teach you what the medicine is, why your baby needs the medicine, and how to give it to your infant. They will also help you with a home schedule for the medicines.

• **Special Equipment.** Some babies require home oxygen, a home apnea monitor, or other special equipment. The healthcare team will arrange for all the needed equipment for discharge. The company that supplies the equipment will train you to use it.

**Discharge Follow-Up**

• **Developmental Follow-Up.** Babies who were very small at birth or who had other difficulties that may affect their development are referred to follow-up clinics or early intervention services. Providers, occupational therapists, and physical therapists who specialize in infant development examine the babies. If any problems are found, early treatment is recommended to improve your baby’s development.

• **Other Specialists.** At discharge, your baby may need to be seen by other specialists such as a pulmonary (lung), urology (urinary tract), cardiology (heart), or ophthalmology (eye) specialist. It is very important for the health of your baby to get follow-up care. Please be sure to follow the recommended appointments as scheduled.

**When to Call Your Baby’s Provider**

If you are concerned about your baby and wonder whether you should call your primary care provider’s office, call them. If you see something unexpected or different that concerns you, call them. Here are some important reasons for calling your pediatric provider:

• temperature 100.4 °F (38 °C) or higher (in babies younger than 3 months) or when fever rises above 104 °F (40 °C) repeatedly for a child of any age
• symptoms of dehydration (crying without tears, sunken eyes, a depression in the soft spot on baby's head, no wet diapers in 6–8 hours)
• a soft spot that bulges when your baby is quiet and upright
• a baby who is difficult to wake up
• rapid or labored breathing (Call 911 if your baby has breathing difficulty and begins turning bluish around the lips or mouth.)
• repeated forceful vomiting and an inability to keep fluids down
• bloody vomit or stool
• more than eight diarrhea stools in 8 hours.

If your concern is urgent, call your provider or take your baby to the emergency room.

Visits from Family and Friends
Don’t be afraid to tell friends and family not to visit right away so you can spend precious time with your baby and settle into home life together.

Once friends and family do start to visit, remember that premature infants and babies who have had a long NICU stay are more likely to catch an infection, so if someone is even a little sick, they should not visit. Visitors should be limited and should always wash their hands before touching the baby. Visitors should not be around the baby if they are smoking or have been smoking. Trips outside the home should be limited to appointments for the first several weeks. This is especially important if your baby is discharged during the winter months. Try scheduling follow-up appointments as the first of the day or request to wait in an examining room instead of the main waiting area.
Diagnoses
Respiratory Distress Syndrome

Respiratory distress syndrome (RDS), also known as hyaline membrane disease (HMD), is the dominant clinical problem and a major cause of morbidity and mortality in the premature neonate. Surfactant deficiency or dysfunction along with structurally and functionally immature lungs contribute to RDS.

Risk Factors
Premature and low-birth-weight infants are at the highest risk for developing RDS, and risk increases with younger gestational age and lower weight. Approximately 15%—30% of infants born prior to 37 weeks gestation will develop RDS, but 60%—80% of infants born at 26–28 weeks gestation will develop the disorder. Incidence is higher in infants born prior to 26 weeks gestation and less common in infants born at or near term (more than 38 weeks gestation). Other risk factors include
• male gender
• Caucasian race
• previous infant with RDS
• perinatal asphyxia
• cesarean section without labor
• maternal diabetes
• antenatal infection such as chorioamnionitis (Newborns who develop RDS after exposure to chorioamnionitis tend to have a more severe course of RDS and more frequently develop bronchopulmonary dysplasia [BPD].)
• absence of antenatal steroid administration to the mother.

Factors Associated with Decreased Risk
The risk of neonatal RDS may be reduced in the presence of
• maternal chronic or pregnancy-induced hypertension
• maternal cocaine use
• maternal stress, placental insufficiency (Stress in the fetus may have the secondary effect of inducing accelerated lung maturation.).

Normal Fetal and Neonatal Lung Development
A basic understanding of lung development and maturation will facilitate an understanding of how RDS occurs. Normal lung development can be divided into five stages:
• embryonic stage
• pseudoglandular stage
• canalicular stage
• saccular stage
• alveolar stage.

The Embryonic Stage (Embryonic Weeks 4–7)
The fetal lung bud—consisting of epithelium and surrounding mesenchyme, an endoderm-lined out-pouching of the primitive foregut—is first evident around embryonic day 24–26. During the next 3–5 weeks, the lung bud divides and branches dichotomously, giving rise to the conducting airways (trachea, right and left main bronchi, and segmental bronchi) and five primordial lung lobes (two left and three right). During the initial phase of development, the primitive airways are surrounded by loose mesenchyme supplied by primitive systemic arteries. Near the end of the embryonic period, the primitive systemic vessels are replaced by the pulmonary arteries.

The Pseudoglandular Stage (Embryonic Weeks 6–16)
During this stage, the airways grow to the level of the terminal bronchioles and primitive acini are formed. By the end of the pseudoglandular stage, branching of the large conducting airways is complete.

The Canalicular Stage (Embryonic Weeks 17–27)
During this stage, the blood-gas barrier begins to thin and an immature surfactant-producing system starts to develop, transforming the previable lung into a potentially viable lung. Distal airways develop into definitive primary acini, and the alveolar capillary barrier is formed. True acinus, the gas exchange unit of the lung encompassing a respiratory bronchiole and its associated alveolar ducts and alveoli, do not develop until around 36 weeks gestation. By 20–22 weeks gestation, epithelial differentiation into immature type I and II pneumocytes begins. Type I
pneumocytes are flat cells lining the alveoli and are necessary for gas exchange. Type II pneumocytes are cuboidal cells responsible for producing surfactant. At this stage, the surfactant components produced by type II cells are detectable in the form of lamellar inclusion bodies. Vascularization of the dense mesenchyme surrounding the airways begins.

The Saccular Stage (Embryonic Weeks 25–38)
During this stage of development, evolution of the relationships between the airspaces, capillaries, and mesenchyme acquire greater significance, and airway walls become increasingly thin, increasing the gas-exchanging surface area. Lamellar bodies containing surfactant and phospholipid in type II pneumocytes increase and mature, and further maturation of type II into type I cells continues. Alveolar ducts, mature cup-shaped alveoli, line the elongated saccules by around 34 weeks gestation.

The Alveolar Stage (Embryonic Week 36–3 Years of Age)
Alveolar formation and maturation continues through this phase of development. At the beginning of the alveolar stage, the walls of the alveoli are thicker than adult alveoli. The double capillary supply persists, as does mesenchymal tissue between the epithelial layers. Apoptosis enables development of a single capillary loop, and the number of type I and II pneumocytes lining alveolar walls increases. There is an overall increase in gas-exchanging surface area. The majority of alveolarization is believed to occur within the first 5–6 months of age, but it continues at a slower rate up to at least 2–3 years of age. Some evidence suggest this stage lasts through 7–8 years of age; others suggest it lasts even later into early adulthood.

Timing of the stages is not definitive, and the stages overlap.

Normal Anatomical and Physiological Features of Newborn Respiratory System
The respiratory system of the healthy term neonate is anatomically and physiologically different from the adult respiratory system. These differences are more profound with younger gestational age. Some of the differences are outlined below.

The head of the neonate is larger in proportion to the body than the adult’s head is to the body. The large head size predisposes the neonate to malposition and mechanical occlusion of the airway. Further, neuromuscular development is immature, which limits ability to correct by repositioning. The large head size is also the largest body surface area in the neonate and where heat loss is most abundant. Hypothermia may induce and exacerbate respiratory compromise.

The tongue is also proportionately larger in the neonate, and combined with the large amount of lymphoid tissue in the pharynx, can contribute to airway obstruction.

Neonates prefer to breathe through the nose, but the diameter of the nares is smaller. The small nares can be easily occluded by secretions, inflammation, and devices, which may compromise the newborn respiratory status.
The ribs and sternum are primarily cartilage, the ribs are horizontally oriented, and the muscles are immature and shorter. These differences decrease the ability to lift the ribs during inspiration to increase intrathoracic volume. The diaphragms are inserted horizontally and are flatter than the adult, resulting in an inward movement of the lower ribs during inspiration. Muscle endurance is determined by muscle mass and oxidative capacity of the muscle fibers. Premature infants with respiratory compromise have both decreased muscle mass and are subjected to frequent periods of hypoxemia, which increases the risk of muscle fatigue and respiratory failure.

The airways are smaller both in length and diameter, and they have less smooth muscle than the adult. These features predispose the infant to having “floppy,” or more compliant, airways.

The upper airway is significantly different in the infant. The epiglottis is proportionately larger than in the adult, less flexible, and Omega shaped. These differences increase the risk of trauma and obstruction. The larynx lies higher in the neck in relation to the cervical spine. The cricoid ring is the most narrow point in the trachea, forming the distinct funnel shape of the neonatal trachea. This natural narrowing allows the use of uncuffed endotracheal tubes in neonates.

The alveoli are the gas-exchange units in the lung and comprise the largest surface area of the lungs. The healthy full-term neonate is born with approximately 50 million alveoli with a well-developed microvasculature, whereas an adult has around 300 million alveoli. Premature infants born prior to 24 weeks gestation have just matured beyond the canalicular stage to the beginning of the saccular stage of development. This lung has undifferentiated distal air saccules and a poorly developed microvasculature. The potential gas-exchange surface area increases significantly after 29 weeks gestation.

**Surfactant**

Surfactant is produced and stored by type II pneumocytes in the distal airway epithelium. The first evidence of cellular differentiation occurs around 22 weeks gestation. Primitive type I and type II pneumocytes are evident at this stage, and primitive lamellar bodies are present. The 22-week fetal lung contains primitive structures and functions to survive outside of the womb, though this capability is limited and most often requires assisted ventilation.

Surfactant is a complex mixture of phospholipids, neutral lipids, and proteins and is a major determinant of alveolar wall surface tension. A thin film is spread at the air-liquid interface of the alveolar surface, thereby lowering the surface tension and preventing alveolar collapse, especially at low alveolar volumes reached at end-expiration. Surfactant produced by the 22- to 24-week fetal lung is functionally immature, and the volume is inadequate. It is not until around 30 weeks gestation that an adequate volume is produced and around 34 weeks before the produced surfactant shows functional maturity.

Surfactant synthesis is a dynamic process that depends on normal pH, temperature, and perfusion, and may be compromised by cold stress, hypovolemia, hypoxia, and acidosis. Exposure to high inspired-oxygen concentrations and the effects of barotrauma and volutrauma from assisted ventilation can trigger the release of proinflammatory cytokines and chemokines and further damage the alveolar epithelial lining, resulting in...
impaired surfactant synthesis and function. Furthermore, leakage of proteins such as fibrin into the intra-alveolar space aggravates surfactant deficiency by promoting surfactant inactivation.

Pathophysiology
RDS is a state of pulmonary insufficiency that manifests at or shortly after birth. Premature infants are born with underdeveloped, small alveoli that are difficult to inflate and larger, though still immature, alveoli that can easily become overdistended. The alveoli that are available for gas exchange do not have the amount of surfactant necessary to maintain alveolar distention at end-expiration, resulting in atelectasis, and inspired air preferentially flows to the larger alveoli, resulting in further overdistention. The premature infant is unable to achieve the significant negative inspiratory pressure required to open the atelectatic regions, and the result is significantly increased work of breathing and hypoxemia.

Shear stress caused by repetitive reopening of collapsed alveoli results in significant damage to the lung epithelium. Increased work of breathing, hypoxia, and atelectasis leads to decreased tidal volumes causing alveolar hypoventilation and hypercapnia. Hypoxia and hypercapnia cause pulmonary vasoconstriction, which increases intrapulmonary resistance and intrapulmonary shunting. Intrapulmonary shunting results in the collapse of arterioles receiving decreased blood flow, resulting in pulmonary hypertension. Prolonged hypoxemia activates anaerobic glycolysis, which produces lactic acid, resulting in lactic acidosis. Alveolar hypoventilation causes a worsening hypercapnia, which results in combined metabolic and respiratory acidosis. The acidosis causes further vasoconstriction, leading to more severe hypoventilation of the lung, intrapulmonary shunting, pulmonary hypertension, and intracardiac shunting through the foramen ovale and ductus arteriosus. Inadequate pulmonary perfusion causes worsening hypoxemia, acidosis, and decreased ability to produce surfactant. Capillary permeability increases, resulting in leakage of plasma proteins. Fibrin deposits accumulate in the air spaces, creating the appearance of hyaline membranes and further interfering with the function of available surfactant.

Clinical Manifestations
Signs and symptoms usually are apparent within minutes of birth, though manifestation may occur over the first few hours of life. Infants presenting with severe respiratory distress or asphyxia require immediate resuscitation. The most striking clinical manifestations include tachypnea or apnea, expiratory grunting, intercostal and subcostal retractions, nasal flaring, poor color, decreased perfusion, and bradycardia. Progressive hypoxemia and dyspnea characterize the natural course. Within the first 6 hours of life, the chest X ray will reveal air-filled bronchi (air bronchograms) silhouetted against lung fields that have a “ground glass” appearance. Without intervention, RDS can progress to death. Uncomplicated or appropriately managed RDS usually peaks within the first 3 days followed by a gradual improvement.

Management
Management optimally begins prenatally, with prevention of preterm birth being the most effective method to prevent RDS. Mothers presenting in preterm labor between 24 and 34 weeks gestation, when labor can be stopped or is not imminent, should receive antenatal glucocorticoids. Glucocorticoids are optimally administered in two doses over 48 hours; however, one dose administered at least 12 hours prior to delivery has been effective in reducing the severity of RDS. Multiple dosing has been associated with adverse effects, though the evidence is unclear, and dosing prior to 24 weeks gestation has not been well studied. Glucocorticoids induce significant and rapid acceleration of lung maturation and stimulation of surfactant production in the fetus. Some evidence shows that glucocorticoids not only reduce the severity of RDS but also may be valuable in reducing the incidence of central nervous system hemorrhage and neonatal mortality. Some research has suggested that although glucocorticoids are effective in accelerating early lung maturation, they may also be associated with abnormal lung development later in neonatal life.

Exogenous surfactant is another major advancement in the care and treatment of infants with RDS. Exogenous surfactant is available in synthetic or purified forms from animal sources, and it is instilled down the endotracheal
tube. It is administered either prophylactically or as a rescue measure. Prophylactic surfactant is ideally administered to the infant in the delivery room or within the first 15–30 minutes of life. The criteria for prophylactic administration varies among institutions and is most often determined by weight or gestational age for the smallest and most premature infants included in the selection criteria. Otherwise, for larger premature infants, prophylactic surfactant is administered based on clinical presentation. Repeat dosing is determined via manufacturer guidelines and depends on the form of surfactant given. Immediate improvement in oxygenation and ventilation is common and requires immediate intervention, such as decreasing inspired oxygen concentration, the peak inspiratory pressure (PIP; tidal volume, mean airway pressure), and possibly the positive-end expiratory pressure (PEEP) to avoid overdistention and oxidative damage to the fragile lung tissue. Rescue surfactant is administered to infants who exhibit progressively worsening clinical symptoms, increasing oxygen requirements, or worsening blood gases. Current research investigating aerosolized surfactant administration is still under investigation.

Current evidence promotes treatment methods directed at protecting the fragile lung. Oxidative damage has been well researched, and studies show that administering high concentrations of oxygen in the delivery room induces oxidative lung damage that may be irreversible. Further, resuscitation provided via a T-piece device that allows control of PIP and delivering a constant PEEP improves lung volumes, facilitates functional residual capacity, and reduces the incidence of volutrauma and barotrauma. Stable premature infants who do not meet criteria for prophylactic surfactant administration may be placed on continuous positive airway pressure (CPAP) and monitored closely. Some infants who require surfactant (prophylaxis or rescue) are intubated, given surfactant, and immediately extubated to CPAP. Volume ventilation provides a more physiologic method of ventilation and high-frequency ventilation provides a gentler method of ventilation.

**Complications**

Significant complications found in survivors of RDS include
- intracranial hemorrhage
- patent ductus arteriosus
- pulmonary hemorrhage
- sepsis
- necrotizing enterocolitis
- bronchopulmonary dysplasia.

It is unknown if the complications are the result of the underlying pathophysiology of RDS, administered treatments, or underlying prematurity.

**Bibliography**

Respiratory Distress Syndrome: Information for Parents

Respiratory distress syndrome, or RDS, is also known as *hyaline membrane disease* (HMD). This condition makes it difficult for the baby to breathe on his or her own.

RDS happens in babies whose lungs have not yet fully developed. It is caused when the baby does not have a slippery, protective substance called *surfactant* in the lungs. Surfactant helps the lungs inflate with air and then keeps them from collapsing when the baby exhales. Surfactant is a normal substance found in fully developed lungs.

The earlier a baby is born, the less developed the lungs are and the higher the chance of developing RDS. RDS is most commonly seen in premature infants born before 30 weeks gestation. It is very rare in full-term babies.

Other things can increase the risk of the baby developing respiratory distress syndrome:
- a brother or sister who had RDS
- when the mother has diabetes (high blood sugar levels) or an infection (chorioamnionitis)
- cesarean section, especially when mother has not experienced labor
- complications that decrease blood flow to the baby before he or she is born:
  - problems with the placenta
  - problems with the umbilical cord
  - a mother who smokes
- multiples in pregnancy (twins/triplets, etc.); the second and third babies are at higher risk
- quick labor (less than 3 hours).

The symptoms usually appear within minutes of birth, but sometimes they do not appear for several hours. Some of the symptoms include
- bluish color of the skin and mucus membranes (cyanosis)
- brief or prolonged periods where the baby stops breathing (apnea)
- a whining or grunting sound when the baby exhales
- nose “spreads out” when the baby inhales (nasal flaring)
- agitated or very weak and limp baby
- shallow and/or rapid breathing
- difficult breathing
- chest that appears to “sink in” with breathing (retractions).

Babies with the worst symptoms appearing in the delivery room will have a breathing tube placed; your baby may receive a form of surfactant (the slippery substance his or her lungs did not produce) down the breathing tube into the lungs to help him or her breathe more easily. Your baby may require more of the surfactant later. Some babies need only one dose, and other babies need as many as four doses. The breathing machine allows the baby to rest while the lungs have a chance to grow and recover. Babies with less severe symptoms receive help breathing from nasal continuous positive airway pressure (CPAP). This type of support gives pressurized air through the nose and helps the baby take a deep breath and keep the lungs inflated.
The neonatal intensive care unit (NICU) staff will watch closely to make sure your baby rests and continues to breathe easily. If your baby needs more help breathing, he or she may need to have a breathing tube placed. Your baby may get a dose (or more) of surfactant.

Your baby’s healthcare team usually knows within a few hours if more help to breathe is necessary. The signs and symptoms they look for are

- low blood oxygen levels (desaturations or blood gases)
  - requires more oxygen
- difficulty breathing (retractions, grunting, nasal flaring)
  - requires more pressure from the nasal CPAP or ventilator
- worsening apnea (more episodes, longer episodes, or more effort to stimulate the baby to breathe again).

Some other treatments that may be used include

- high-frequency ventilation
  - a breathing machine that breathes very fast but may be less harmful to the fragile lungs
- medications to help the baby breathe easier
  - caffeine or theophylline stimulates the baby to breathe
  - lasix (furosemide) or other diuretics to help get rid of extra fluid
  - blood pressure support medications.

Babies with RDS have to be monitored very closely. Your baby may need X rays and small amounts of blood drawn to test his or her oxygen levels.

It is very important that all babies with RDS receive excellent supportive care. The following will help to decrease how much oxygen your baby needs:

- dim lighting, quiet room, and few disturbances
- gentle handling
- maintaining ideal body temperature.

Babies with RDS are too sick to eat from a bottle and receive nutrition through the IV fluids we give. We may try to feed your baby through a tube inserted into the nose or mouth that goes down into the stomach. At first the amount of food will be very small. Breast milk has the best nutrients and antibodies for your baby. Breast milk will help your baby recover better.

When RDS is the only problem and your baby responds well to the treatments, he or she will start to recover within about 3 days. The full recovery usually takes about 7–10 days, but sometimes a little longer.

Some of the complications associated with RDS, prematurity, or the treatments are

- chronic lung disease, also called bronchopulmonary dysplasia
- bleeding in the
  - lungs
  - head or brain
- higher risk of developing an infection
- pneumothorax or other air leaks
  - Pneumothorax is when air is found in the chest but outside of the lung.
- necrotizing enterocolitis
  - an infection in the bowel
- patent ductus arteriosus
  - A blood vessel in the heart that is normally open before the baby is born but closes after birth either stays open or reopens after birth.
Bronchopulmonary Dysplasia

Introduction
Bronchopulmonary dysplasia (BPD) is a form of chronic lung disease (CLD) that is seen in preterm infants who had respiratory distress syndrome (RDS) and required respiratory support in the first few days of life. In addition to premature birth, risk factors include the need for supplemental oxygen and ventilator support. Factors such as intrauterine growth restriction, infection (acquired either in utero or postnatally), patent ductus arteriosus (PDA), and genetic predisposition may contribute to the pathogenesis of this disorder. For nurses who work in the NICU as well as those who are involved in the delivery, resuscitation, and stabilization of preterm infants, understanding the disease process, treatment, and outcomes will allow patient care to be based on a strong scientific foundation.

Definition
The definition of BPD has evolved over the years as viability thresholds for preterm infants have decreased; thus, it is often described as “old BPD” versus “new BPD.” This is a reflection on the distinct embryologic differences in pulmonary development at different gestational ages. It is also influenced by changes in treatment strategies and by technological and pharmacological options that exist today.

Old BPD
This form of chronic lung disease was first described in the 1960s by Northway and colleagues, who observed radiographic changes in late preterm infants who had been exposed to aggressive mechanical ventilation and high concentrations of oxygen (Northway, 1990). This damage occurred in the late saccular stage of lung development with X-ray findings consistent with extensive inflammation and fibrotic and cystic changes in the lung parenchyma and airways. The diagnosis of BPD was assigned to the infant if he or she was oxygen dependent at 28 days of age.

As the practice of neonatology evolved and new technological and treatment modalities were developed, the gestational age at which infants were surviving became lower and lower. Exogenous surfactants improved lung compliance and reduced oxygen requirements. Ventilators designed for use in this patient population became increasingly more sophisticated. These innovations and others allowed for gentler methods of ventilation and, in some cases, reduced damage to airways and resultant fibrosis. However, as survival improved in extremely preterm infants, there was an inverse relationship seen in the severity of BPD with gestational age. Today, approximately two-thirds of infants who develop BPD are extremely low birth weight (< 1,000 g) and less than 28 weeks at the time of their birth.

New BPD or CLD
As our knowledge of factors that contribute to the development of BPD grew, neonatal centers worked to refine their management of respiratory diseases in preterm infants. Many centers have seen a reduction of the clinical presentation in the older preterm infant, but they have now noticed a different form of CLD that may not be associated solely with the absence of surfactant, high oxygen exposure, or lung damage related to ventilation. Although providers thought that reduction of volutrauma and surfactant replacement would significantly decrease BPD, chronic changes in respiratory function in full-term or near full-term infants experiencing antenatal infection, pulmonary hypoplasia, and meconium aspiration have instead been noted. This new BPD results in impaired organogenesis of the lung (what historically was called pulmonary insufficiency), impaired distal lung growth, decreased microvascular development, and impaired pulmonary function in the first years of the infant’s life. Rather than being able to assign the diagnosis of BPD solely based on the presence of oxygen at a specific gestational or chronological age or on X-ray findings, the newer form of BPD is related more to the pulmonary outcomes of infants that are severely affected by respiratory disease. This is why some centers use the term CLD to describe this new form of respiratory disease.
A consensus conference in 2000 at the National Institutes of Health (NIH) suggested that the diagnosis of BPD/CLD be defined by a more clinical severity-based definition related to the level of respiratory support needed near term gestation. The new definition uses oxygen dependency at 36 weeks postconceptual age (PCA), total duration of oxygen supplementation (> 28 days), positive pressure requirements, and gestational age of infant (< 32 weeks) to delineate the three degrees of severity: mild, moderate, and severe. Infants stratified by these diagnostic criteria rarely progress to severe BPD/CLD. Of those with the severest BPD, approximately 75% will be discharged on home oxygen therapy or require a tracheostomy for long-term ventilation.

**Definitions**

*Mild BPD/CLD* is assigned if there is a need for supplemental oxygen for more than 28 days but not by 36 weeks PCA.

*Moderate BPD* is defined as a need for supplemental oxygen for more than 28 days but the fraction of inspired oxygen (FiO₂) was less than 30% at 36 weeks PCA.

*Severe BPD* is defined as an oxygen requirement for more than 28 days and more than 30% FiO₂ and/or positive pressure ventilation (CPAP or ventilation) at 36 weeks PCA.

**Etiology of BPD/CLD**

Pulmonary disease of the newborn is multifactorial. Infants develop respiratory distress and possibly BPD/CLD in part because there is an interruption in the development of the lungs and inability to manufacture surfactant necessary to prevent alveolar collapse. Other factors that contribute to the pathogenesis of BPD include inflammation, genetic predisposition, clinical management techniques of respiratory failure, and response to infection or oxygen toxicity. These factors may increase the likelihood of chronic lung changes and support the need for continued support.

**Genetics**

As our knowledge of genetic expression and the ability to identify specific markers in the DNA of individuals have expanded, so too has the understanding of which of these markers may predispose or increase the likelihood of an individual developing different diseases, including BPD. For example, twin studies have shown that lacking the portion of the arm that expresses surfactant protein B (SP-B) may increase the risk of BPD. In addition, other gene pathways that regulate things such as DNA repair, mitochondrial energy metabolism, and control cell growth may be altered in the developing premature infant, resulting in their response to factors such as infection, exposure to oxygen, and growth. The continued study of the genome may lead to future opportunities to intervene earlier in the disease process by altering ventilation strategies or by tailoring therapies for those infants at highest risk.

**Inflammation**

Inflammation is a major factor in the development of BPD. The initiation of inflammation appears to cause impairment of the growth of alveoli and of the microvasculature. The ability of the infant to block inflammation by their own anti-inflammatory mediators is limited and may be easily overwhelmed. There is growing evidence that the persistent imbalance on the side of pro-inflammatory mediators and inadequate anti-inflammatory mediators is important in the pathogenesis of BPD.

Maternal chorioamnionitis is the single most important cause of preterm delivery, with severe chorioamnionitis seen frequently in infants who are born at less than 30 weeks gestation. Infants born in the presence of chorioamnionitis have a higher rate of BPD/CLD. The infant may present with mild to moderate RDS at the time of birth, rapidly improve with exogenous surfactant and ventilation, and wean to low ventilator support or continuous positive airway pressure (CPAP). Chest X-ray findings at that time may have been consistent with mild RDS. Sometime after the first week of life, the infant will exhibit symptoms of respiratory distress and increased oxygen requirements without associated infection. Chest X rays may show progressive development of atelectasis, scarring, and hyperinflation—all consistent with BPD.

The development of this atypical CLD is thought to be a systemic response by the infant following exposure to
intrauterine infection. The fetus responds to this environment by increasing its inflammatory biomarkers, such as chemokine, pro- and anti-inflammatory cytokines, proteases and their inactivated inhibitors, and growth factors. Infants who were exposed to intrauterine infection and had histologic confirmation of chorioamnionitis were found with elevated interleukin 6 present in the cord blood and went on to develop BPD. The presence of these inflammatory biomarkers creates a complex interaction that alters subsequent lung maturation.

**Disruption of Vasculogenesis**

Inflammation in utero results in a cascade of events following delivery; one of these, decreased vascular endothelial growth factor (VEGF), has a major impact on the development of new pulmonary vessels, pulmonary capillary beds, and ultimately, alveoli. In the presence of inflammation, VEGF regulation is altered. Pathways that lead to VEGF production are inhibited, which leads to reduced production of growth factors. These are required for new healthy lung tissue to grow. Infants born at the threshold of viability are at highest risk because they have very few vessels and alveoli developed at birth. In addition, exposure to the higher levels of oxygen in extrauterine life will also contribute to the abnormal development of pulmonary circulation. Infants with severe BPD often will have comorbidities such as cor pulmonale or pulmonary hypertension caused in part by the interruption of pulmonary vascular growth.

**Oxygen Toxicity**

In the developing fetus, weeks 23–30 are a period of active development of the pulmonary system. Fetuses move from simple bronchial “tubes” to saccules, which are the precursors to alveoli. This growth occurs in utero in what would be considered hypoxic by extraterine factors. Preterm birth interrupts this development and events such as chorioamnionitis or hyperoxia can result in changes to the growth and further branching of the lung, specifically alveolar development. Although it was thought that high levels of oxygen (>40%) were toxic to the neonatal lung, there is strong evidence indicating that even room air (21%) may result in lung injury.

**Ventilator-Induced Injury**

Initiation of positive pressure ventilation during resuscitation often triggers a cascade of damage and changes to the airways and alveoli of the preterm infant. Volutrauma, the overdistension of the airway, causes stretching of the air sac on inspiration. At the end of the expiratory phase of the respiratory cycle, partial or total collapse potentially can alter the stretch responsive mediators in the preterm infant’s lung. Overventilation may induce an inflammatory response of the lungs, with large numbers of neutrophils being released. This can lead to scarring and alteration in existing lung tissue. The use of CPAP immediately after delivery and continued use in the NICU versus intubation after delivery was thought to reduce some of the mechanical injuries by mechanical ventilation. However, in a large randomized controlled study that evaluated CPAP versus mechanical ventilation, there was no difference found in BPD at 36 weeks.

**Treatment**

Despite increasing knowledge about factors that contribute directly to BPD/CLD, there is still uncertainty as to which treatment modalities are most successful in reducing the incidence of and treating the infant with BPD. Awareness of the importance of ventilation and nutritional and pharmacologic management will allow the team to apply best practices to improve both short- and long-term outcomes.

**Ventilation/Oxygen**

Reduction of volume and distending airway pressure will help reduce volutrauma and minimize alterations in the architecture of the developing airway. The use of positive pressure, even CPAP, has an impact on the ability of the neonate to continue to grow new saccules and alveoli, even after birth. Maintaining functional residual capacity and avoiding repeated bouts of atelectasis is an increasingly common strategy. Oxygen, though essential to avoid tissue damage and allow for anabolic growth, can also be damaging in concentrations that are higher than necessary. Studies have evaluated what is considered a “safe range” for oxygen saturations and have recommended the range of 90%–95%. However, it is more important to avoid frequent swings in oxygen saturations from hypoxic
to hyperoxic states, because this affects overall growth and neurodevelopmental outcomes.

**Nutrition**
Infants born prematurely miss an important window of intrauterine growth. Care providers are limited in their ability to deliver calories and nutrients, yet these infants have very high energy requirements to meet basic metabolic functions, even without their need to grow. Delay in establishing positive nitrogen balance with early introduction of protein and lipids is known to decrease alveolar number and delay extrauterine growth. Establishment of enteral feeds as early as possible with maternal breast milk provides the infant with growth factors found in maternal milk such as inositol, which has a role in cell membrane maintenance and maturation of pulmonary surfactant. Infants with BPD/CLD may need up to 130 kCal/kg/day to achieve positive growth. Some of these infants are fluid sensitive, and meeting high caloric needs with a restricted fluid intake can be a clinical challenge.

**Medication Management**
Although there is no “magic bullet” for BPD, the use of certain medications during the course of the disease may help to reduce severity and manage symptoms associated with long-term ventilation. Controversy remains surrounding the use of these medications. Antenatal steroids have been found to reduce mortality, RDS, and intraventricular hemorrhage (IVH) in preterm infants. Although antenatal steroids reduce risk factors for the development of BPD, they do not reduce the incidence of BPD. Antenatal steroids may reduce the severity of BPD, but there is conflicting evidence in this area.

**Surfactant**
The introduction of surfactant into the NICU has significantly changed outcomes of neonatal patients. Previously, infants as mature as 36 weeks gestation had prolonged and difficult RDS courses, with many ending with the cystic BPD described in early neonatal literature. The widespread use of surfactant has, in part, reduced the threshold of survival so that NICUs are routinely resuscitating and later discharging preterm infants born at 24 weeks gestation. The debate of early versus late surfactant delivery after birth recognizes that surfactant should be given early in the clinical presentation of respiratory symptoms to reduce complications associated with RDS (e.g., pneumothorax, pulmonary interstitial emphysema, chronic lung disease, or death). Early use of surfactant also has been shown to reduce the risk for BPD or death at 28 days, even though surfactant use has not reduced the overall incidence of BPD.

**Caffeine**
Although caffeine is commonly used in infants to treat apnea of prematurity, it also has an impact on ventilation and has been shown to prevent BPD. Infants who received caffeine in the first week of life were shown to have a reduction in duration of positive pressure ventilation by 1 week versus when compared with the placebo group. Caffeine may possess the ability to prevent respiratory failure in infants following extubation and may be related to adenosine receptors in the brain that affect capillary permeability, inflammation, and lung remodeling.

**Vitamin A**
Vitamin A is essential for immunity, growth, and the integrity of the epithelial cells that line the respiratory tract. Most preterm infants have low levels of vitamin A because of decreased intrauterine growth, which then increases the risk for BPD/CLD. In a large, multicenter, randomized, controlled study that compared giving 5000 IU of vitamin A intramuscularly three times a week for the first month of life versus placebo, results showed a significant decrease in either death or CLD in the treatment group. Analysis of the both groups at 18–24 months showed no change in mortality or neurodevelopmental outcomes, but the number of infants who required oxygen at 1 month or 36 weeks PCA was statistically significant. Vitamin A has not been available since 2010 because of manufacturing issues, and it is unclear when it will be available again. The current status of this drug can be found on the U.S. Food and Drug Administration (FDA) website in the Current Drug Shortages Index.

**Corticosteroids**
The extremely preterm infant often has a reduced cortisol response that may increase the response to inflammation seen in the lungs. This can affect the preterm infant’s lung that has been exposed to inflammation from maternal
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chorioamnionitis as well as mechanical ventilation and exposure to oxygen. Systemic corticosteroids have strong anti-inflammatory properties. Systemic steroid use in infants with RDS allows for rapid weaning from both mechanical ventilation and high levels of oxygen. During the 1980s, steroid use was thought to have a major impact on the reduction of BPD and the improvement of neonatal outcomes. Dosing strategies were widely divergent in terms of initiation and duration of treatment and dosage. However, in the 1990s, as these infants were followed in high-risk clinics, there was a concerning increase in poor neurodevelopmental outcomes, reduced head circumference, and some potentially worse outcomes once the child reached school age with poor cognitive and motor skills. The American Academy of Pediatrics (AAP) released a policy statement regarding the use of postnatal corticosteroids for prevention or treatment of CLD in preterm infants in 2002. They called for limiting steroid use to exceptional clinical circumstances and counseling families about the risk of adverse neurodevelopmental outcomes. In 2010, following an update of a systematic review of studies, the AAP released a revised policy statement on the use of postnatal corticosteroids to prevent or treat BPD. They continue to stress concerns about long-term neurodevelopmental outcomes in infants exposed early to steroids. However, following the review of the literature, the AAP now recommends judicious use of dexamethasone at a later time (after day 7) if the infant is unable to be weaned from the ventilator. The rationale is that, at this point, the risk of cerebral palsy from exposure to dexamethasone compared with the higher rate of mortality if not treated is equal. The small studies that have been reported since then do not show an increase in adverse neurodevelopmental outcomes when steroids are used after the first 7 days of life. There also was no difference in the response to high-versus low-dose dexamethasone, resulting in the conclusion that low doses and shorter duration of treatment can achieve the same effect as high dose or prolonged therapy.

In 2012, a large Cochrane review concluded that inhaled corticosteroids given to infants age 7 days or older who were at high risk for developing BPD/CLD did not reduce death or BPD rates and did not decrease ventilator days or oxygen requirement. The authors did not recommend inhaled corticosteroid use at that time.

Bronchodilators

Increased airway reactivity and decreased lung compliance are hallmarks of BPD/CLD. The use of beta-agonists such as albuterol to improve these clinical complications was a method to improve airway compliance and reduce incidence of bronchospasm. However, in a randomized, controlled study to evaluate use in the infant with BPD, there was no difference in mortality, incidence of BPD, duration of ventilation, or oxygen requirement when the treatment and control groups were compared. Although there may be a short-term response to bronchodilators, it does not appear that chronic use of this medication group improves outcomes.

Diuretics

Neonates with BPD/CLD have high caloric requirements, often resulting in high daily fluid intake. Alveolar edema, capillary leak from inflammation or lung injury, and volume overload because of left to right shunting across the PDA can result in pulmonary edema. This excess fluid can alter lung compliance and function.

The most common diuretic used is furosemide (Lasix), a loop diuretic. Furosemide works to increase interstitial fluid reabsorption and increase urine output. There is a transient improvement in both oxygen requirement and lung compliance, which is seen clinically but not always reflected by blood gases. A Cochrane meta-analysis reviewed the use of furosemide to treat infants with BPD/CLD and showed no benefit to duration of oxygen requirement, ventilator support, CLD/BPD, or death. There are several risks involved with the use of furosemide. It may delay the closing of the ductus arteriosus, because furosemide stimulates renal production of prostaglandin. Ototoxicity, electrolyte disturbances, nephrocalcinosis (kidney stones), or bone demineralization also are potential complications of this therapy.

Another class of diuretics, thiazides, has less of an effect on diuresis but also less of an impact on the infant's electrolyte homeostasis. Thiazides have a short-term effect on pulmonary function but do nothing to improve or
alter the outcomes or severity of BPD. Use of thiazides is thought to reduce the use of furosemide, thereby reducing the side effects.

**Oxygen**

Oxygen remains the most commonly used drug in the NICU. Tissue oxygenation is essential for life. Chronic hypoxia can contribute to the development of pulmonary hypertension, necrotizing enterocolitis, IVH, and adverse neurodevelopmental outcomes. In infants with BPD/CLD, episodes of acute hypoxia may also increase airway resistance. Oxygen toxicity has been associated with alterations in pulmonary development. Excessive oxygen levels may increase production of free oxygen radicals and cytokines that increase inflammation, which then inhibits the development of alveoli and the microvascular growth. These alterations affect critical organ blood vessel development in the lung and eyes, leading to increased rates of BPD and severe retinopathy of prematurity (ROP).

There is not a clear range of oxygen saturations that avoids both short- and long-term complications. Studies have examined preterm infants beyond the first 28 days of life. The STOP-ROP and Benefits of Oxygen Saturation Targeting (BOOST) trials evaluated using target saturation ranges in two groups, low (saturations 89%–94%) and high (saturations 95-98%) and the impact on growth, development, and changes in pre-threshold ROP. In the BOOST study, there was no significant difference in the outcome measures (growth or development) between the two groups. In the high saturation group, a longer duration of oxygen therapy, greater need for home oxygen, and increased rate of BPD/CLD was found. In the STOP-ROP study, there was no change in the progression of the ROP between the groups; however, they also reported that the group with lower saturations had fewer incidences of pneumonia or BPD exacerbations. There is concern that targeted saturations (less than 90%) may be associated with increased risk of death based on the recent BOOST II trial. Several multicenter, randomized, controlled studies are underway to determine the most appropriate target saturations for preterm infants.

Once the diagnosis of BPD/CLD has been made and the infant is on oxygen (nasal cannula or positive pressure device), it is important to maintain saturations in the 90%–95% range. This promotes growth and avoids using more energy to breathe because of lower oxygen saturations. It also reduces the risk of developing pulmonary hypertension and vasoconstriction. Some infants with BPD will require oxygen for up to 2 years of life, either by cannula or by ventilator with a tracheostomy in the most severe of cases.

**Nitric Oxide**

The use of inhaled nitric oxide (iNO) is part of the NICU toolbox to manage full-term infants with persistent pulmonary hypertension of the newborn (PPHN). iNO decreases pulmonary vascular resistance, improves ventilation/perfusion mismatch, and provides bronchodilation. In addition, iNO has been found to have an anti-inflammatory effect and may assist in remodeling of the pulmonary vasculature following chronic hypoxic failure. Several randomized trials evaluating the use of iNO in low-birthweight infants have produced inconsistent results, with a limited number of patients experiencing a reduction in the incidence of BPD. In 2010, the NIH issued a consensus statement on the use of iNO in preterm infants. The recommendation was that iNO should not be used routinely in the care of infants younger than 34 weeks to prevent BPD or alter neurodevelopmental outcomes. However, they did not rule out the use of this treatment in extreme cases as a lifesaving measure. Studies are underway to evaluate timing, dose, and duration of iNO use and potential respiratory and long-term outcomes in the preterm infant. Currently, it does not have widespread acceptance as a useful therapy for preventing BPD.

**Other Possible Therapies**

Attempts to target specific issues that surround BPD, such as inflammation and tissue growth, have led to small studies examining other interventions that may lead to a reduction of the incidence or the severity. One such intervention is the administration of stem cells to the neonate with the goal of targeting damaged lung tissue and providing healthy cells to generate new growth. Systemic treatment with erythromycin is given to reduce ureaplasma colonization, which may play a role in developing BPD/CLD, although the role ureaplasma plays in
developing CLD remains controversial. Heliox, a mixture of helium and oxygen, has been found to aid ventilation in infants with BPD/CLD and to decrease work of breathing, improve gas exchange, and decrease respiratory support requirements. These findings have been noted anecdotally and require more rigorous study before efficacy can be determined.

**Treatment of Severe BPD**

Many infants who have severe BPD remain ventilator dependent despite maximal medical management; they can remain in the NICU for as long as 1 year. These infants have unique challenges and additional management strategies may need to be employed.

**Ventilation**

As with the infant who has RDS in the first days and weeks of life, the goal for older, more chronically affected infants remains the same: minimize oxygen requirements and mechanical ventilation support. However, in infants with severe BPD/CLD, these goals are more difficult to achieve. Infants with severe BPD/CLD need to maintain oxygen saturation levels in a range allowing for adequate oxygenation, yet avoiding extreme swings. Chronic hypoxia has been shown to diminish neurodevelopmental outcomes and can cause vascular remodeling in the pulmonary and cardiac vessels. This results in pulmonary hypertension (PH) or cor pulmonale. Infants with severe BPD may have reduced lung compliance and increased airway reactivity, much like that of a child with asthma. In some but not all cases, use of bronchodilators for acute symptom management may improve bronchospasm. In addition, long-term endotracheal intubation or tracheotomy may result in tracheobronchomalacia, which presents as airway obstruction unresponsive to bronchodilators. These infants may require a higher amount of positive end expiratory pressure to reduce collapsing of the central airway on exhalation. To minimize these episodes, sedation, and in some cases, temporary pharmacologic paralysis may be required.

Weaning infants with severe BPD must include attempting to “normalize” blood gases that have previously been allowed to reflect a higher degree of carbon dioxide retention and compensatory metabolic alkalosis. The carbon dioxide set point of some chronic infants has been allowed to go as high as the mid 60s in an effort to wean the infant off of the ventilator. There is usually an accompanying metabolic alkalosis as the infant attempts to normalize his or her acid base balance. If the infant’s electrolytes are within normal limits, additional medications to reduce the alkalosis, such as Diamox, a carbonic anhydrase inhibitor, or arginine hydrochloride, may need to be added.

If multiple attempts to extubate the infant with severe BPD have not been successful, performing a tracheotomy should be considered. Placement of a tracheostomy (trach) in an older NICU patient may have some direct benefits. First, it may allow for easier ventilator weaning due to less dead space and decreased airway resistance. The trach allows for better clearance of secretions and is usually more comfortable for the infant, thus reducing the need for sedation. The risk associated with placement of a trach needs to be considered. Most infants who progress to requiring tracheostomies will require long-term ventilator support that may extend into the home setting. Trachs offer a more stable airway and may allow the older infant more freedom of movement. This permits more normal play and feeding options and promotes better neurodevelopmental outcomes.

**Pulmonary Hypertension**

Some infants with severe BPD will go on to develop PH, resulting in increased morbidity and mortality. The mechanism of action is not known, but it has been suggested that this is a result of changes in the pulmonary vasculature related to hypoxia and exposure to inflammation and ventilator-induced injury. Alterations of growth factors and vascular tone may lead to thickening of the ventricles and septum and abnormal growth of capillaries throughout the cardiac structure. Infants also may have elevated pulmonary vascular resistance, precipitated by the presence of chronic hypoxia, hypercapnea, and acidosis.

Diagnosis of pulmonary hypertension can be difficult. Echocardiograms, which evaluate the velocity of regurgitation through the tricuspid valve, with pulmonary pressures being compared to systemic pressures, are more
commonly used. The echocardiogram can also be helpful to assess the heart’s response to initiation of a particular therapy.

Treatment of PH in the infant with BPD/CLD is determined by the severity. Often, in milder forms of PH, avoidance of hypoxia and optimizing overall growth is all that is required. In more severe forms of PH, additional support may include ventilation and medications such as iNO, sildenafil, and bosentan. There is a higher incidence of mortality in infants with this severity of BPD/CLD.

Although it has proven effective in acute PPHN, in this subgroup of NICU patients, iNO is not an ideal therapy due to its expense and unwieldy long-term use. Sildenafil has been used in long-term treatment of PH. Animal studies have been conducted to determine the efficacy of sildenafil’s use earlier in the life of preterm infants to decrease the incidence or severity of BPD. There is little known about the long-term effects of sildenafil’s use in this patient population. There is concern about the safety of this drug, and the FDA has issued an advisory about the use of sildenafil in children between the ages of 1 and 17 with PH. Bosentan is also being evaluated for use in treating BPD/CLD infants with PH. Bosentan, an antagonist of ET-1, which is a neurohormone released from the vascular endothelium and a potent vasoconstrictor, has been shown to reduce endothelial smooth muscle constriction, hypertrophy, and hyperplasia in adult populations. It has a direct antifibrotic effect that makes it appealing for treating BPD. Much like sildenafil, bosentan is used with extreme caution in the NICU population, because there is no data on patients younger than 9 months in currently published studies.

Complications and Long-Term Outcomes

Long-term morbidities in infants with BPD/CLD have included ROP, cerebral palsy, cognitive and behavioral difficulties, speech and feeding disorders, and long-term pulmonary disease. They often require physical, speech, and occupational therapy—to address issues such as feeding aversion, developmental milestone delays, speech delays, and dental problems related to long-term intubation with oral endotracheal tubes—as well as diligent monitoring of growth. These infants may require frequent rehospitalization during the first 2 years of life due to their lung disease.

Nursing Implications

The nurse at the bedside is the first line of defense for these vulnerable infants. It is through diligent assessment and monitoring that subtle changes are noted. Consistent and aggressive titration of oxygen delivery is very important. Prevention of oxygen toxicity is equally important for issues discussed earlier in this section. Assessment of comfort and pain with provisions of both nonpharmacologic as well as pharmacologic therapies will assist in maintaining a stable oxygen saturation range.

The hospital course of extremely preterm infants is defined by periods of ups and downs followed by long periods of feeling as though things will never change or get better. Many families are far away from their own social support network and experience isolation and loneliness due to the extended length of hospital stays. It is essential that the NICU staff refer parents to support venues in the hospital and nearby while their baby is hospitalized.

Maintaining breast milk supply over a long period of time is a difficult endeavor for the mother, but it is critical to the well-being of the infant. Ongoing support and management of this process is an integral part of the nurse’s role. Provision of skin-to-skin care is a major incentive for moms, who observe a noticeable increase in milk production after or during time with the baby. Later, as the infant is extubated and beginning to take oral feeds, close work with lactation specialists will help mom and baby transition successfully to breastfeeding if the baby is physiologically stable.

Parental inclusion in the daily care of their infant increases confidence in caring for their child as well as encourages engagement through the long days when things seem to be at a standstill. Inclusion of families as members of the multidisciplinary team conveys the message that they are very much a part of their baby’s care. As the infant progresses to discharge, early teaching reduces the amount of overwhelming information provided at the
last minute. Offering information and care activities early decreases anxiety and fear of not being able to care for their baby outside the hospital setting. Many parents will room-in with their child for a period of time as a transition to home. Follow up by home healthcare providers offers reassurance and resources following discharge from the NICU.

Post-discharge follow-up may be challenging due to the number of subspecialty services involved. Coordinating visits as much as possible is recommended. Infants with BPD/CLD are at high risk for developing upper respiratory infections, such as respiratory syncytial virus (RSV) in the first 2 years. It is important to provide education about limiting exposure to visitors and practicing good hand hygiene at home. Immunizations for care providers and siblings, including flu shots and a pertussis (whooping cough) vaccine booster shot, should be up to date. RSV immunoprophylaxis and appropriately timed immunizations should decrease the incidence of potentially lethal infections. Transfer of care to the community provider is accomplished through both verbal communication and by comprehensive discharge summaries. Providing the families with a copy of the discharge summary will help them convey vital information concerning their baby's hospital course should they need to seek emergency services for any reason.

**Bibliography**


Bronchopulmonary Dysplasia: Information for Parents

What is bronchopulmonary dysplasia?
- Bronchopulmonary dysplasia, also called BPD or chronic lung disease (CLD), is a lung disease that can develop in babies who are born early and have breathing problems.
- Broncho means “airways or air tubes in the lungs.”
- Pulmonary means “air sacs in the lungs.”
- Dysplasia means “unusual changes in cells.”
- Chronic means “long term.”
- The lung tissue and airways of a premature baby are very soft and fragile. They are easily damaged and can become inflamed (swollen) and scarred.
- Once damaged, the growth of lung tissue and airways is abnormal and breathing becomes difficult.
- BPD is one of the most common lung diseases in children.

What causes BPD?
The exact cause of BPD is not known. The following are some things that make a baby more likely to develop BPD:
- BPD is most common in babies who have immature lungs. Babies born more than 10 weeks premature or weighing less than 2 pounds have the highest risk for developing BPD.
- Sometimes the very things that are needed to save the lives of preemie babies with respiratory distress syndrome (RDS) can also damage their lungs. Important treatments like oxygen and a breathing machine (ventilator) are very helpful. Sometimes if large amounts or high pressures are needed to help breathing, they can be harmful to fragile lung tissue.
- Lung infections like pneumonia can cause swelling in the airways and tissue of the lungs.

What are the signs of BPD?
BPD is usually suspected when a baby is between 1 and 2 months of age and has one or more of the following:
- baby needs extra oxygen at 1 month before the baby’s due date or at 1 month of age
- a chest X ray shows lung damage
- ongoing breathing problems (breathes too fast or uses extra chest muscles to breathe) are present
- blood tests show low blood oxygen levels or infection.

How do babies with BPD act?
Babies with BPD may have some or all of the following:
- fast, shallow, or noisy (grunting) breathing
- frequent coughing, wheezing, shortness of breath, and flaring of nostrils
- pulling of chest muscles inward between the rib spaces (retractions)
- sometimes look blue or dusky in color because of low blood oxygen levels
- need extra oxygen to grow and develop
- tire easily or breathe fast with feedings, which may slow growth and weight gain
- breathing sounds may sound crackly or wet when listening with a stethoscope.

Is there a cure or treatment for BPD?
There is no quick cure for BPD, but there are many treatments that help babies breathe easier.
Oxygen is used to make breathing easier and more comfortable. Some babies need to use oxygen at home. Oxygen may be needed for many weeks or months.

Medications are sometimes used to help babies with BPD breathe easier. Surfactant and caffeine therapy in premature babies helps prevent BPD. Bronchodilators open the airways in the lungs. Corticosteroids help reduce inflammation in the lungs. Diuretics decrease fluid build-up in the lungs. Antibiotics treat bacterial lung infections, which are common in babies with BPD.

High-calorie breast milk or formula gives your baby extra calories and nutrients to help growth and healing. Because some babies use so much energy just to breathe, they may need to be fed by a tube in the nose or stomach to make sure they take in enough calories to grow.

Growth is the best treatment for BPD. With time, your baby will grow new, healthy lung tissue.

In rare cases, some babies will have severe lung damage and need the help of a breathing machine (ventilator) for many months or more. If so, a tracheostomy is often used to help with breathing. A tracheostomy is a small hole in the neck so a special breathing tube can be put into the windpipe with a ventilator to support breathing.

**Good News About BPD**

- New devices (machines) make oxygen therapy and breathing machines more gentle to the baby’s lungs.
- Medications help make breathing easier and decrease breathing problems.
- Most babies will outgrow BPD, because they rapidly grow new lung tissue during the first 2 years of life.
- Babies with BPD can usually be cared for at home in close partnership with the baby’s provider and pediatric pulmonologist. A pediatric pulmonologist is a doctor who specializes in the treatment of lung disease in children.

**Going Home**

**Call your baby’s provider right away if your baby has**

- breathing problems that become worse or signs of respiratory infection:
  - fever
  - breathes faster than usual
  - works harder to breathe than usual
  - coughs, wheezes, or breathes more noisy than usual
  - pale, dusky, or blue color of lips or fingernails
  - more irritable or fussy than usual
  - tires more easily with breathing or feeding
  - spits up more than usual.

**If your baby stops breathing,** start cardiopulmonary resuscitation (CPR) and call 911 or the local emergency medical services right away.

**Important Things to Remember**

- Babies with CLD or other complications are at greater risk for ongoing lung problems. It will be important for you to know how your baby breathes “normally” and how his or her chest muscles may look if he or she is having trouble breathing.
- Prevent lung infections. Always wash your hands before touching your baby or preparing your baby’s food. Only allow people to visit your home when they are not sick. Keep young children away from your baby. Avoid crowds and day care centers.
- No smoking should happen around your baby. Limit exposure to pollution and other lung irritants.
- Encourage all people who care for your baby to get a flu shot before the start of cold and flu season and a pertussis (whooping cough) vaccine booster shot.
- Take your baby for all regular well-child check-ups and follow the recommended schedule for immunizations.
- Talk to your baby’s provider about palivizumab (Synagis), a medication used to prevent respiratory syncytial virus infection in young children.
- Each follow-up appointment with the pediatric pulmonologist is important and is in addition to well-child check-ups with your baby’s provider.
• If your baby needs to take special medications to help breathe easier, always follow the directions on the bottle or container that came from the pharmacy.
• Your baby may need to be on oxygen to help him or her breathe better, feed better, and grow.
• Your baby may need extra oxygen for several weeks or months until he or she grows new lung tissue.
• You may be nervous at first, but with practice, you will become more comfortable caring for your baby with BPD. Remember, it’s always OK to ask for help!
Necrotizing enterocolitis (NEC) is an inflammatory disease, or necrosis, of the bowel. NEC is a serious, life-threatening gastrointestinal emergency that primarily affects premature neonates; the more preterm a neonate is, the higher the incidence of NEC. Up to 10% of NICU admissions will develop NEC (incidence varies regionally and within individual units). Full-term infants can also develop NEC. It is estimated that 20%–40% of neonates with NEC will require surgical intervention. Surgical NEC fatality rates are as high as 50%. The onset of NEC most commonly appears within the first 6 weeks of life; in more premature infants, the age of inflammatory disease onset is earlier (days 3–30). The most common areas of intestinal damage are the distal ileum and proximal colon. Spontaneous intestinal perforation (SIP), or isolated intestinal perforation, generally occurs within the first week of life. Although infants with SIP will present similarly to those with NEC, SIP is distinctly different from NEC. SIP is a focal perforation without an inflammatory component.

The exact etiology of NEC is unknown, although it is characterized by intestinal injury, inflammation, and necrosis. Prematurity is the most common risk factor. Other factors that have been found to play a role in NEC include enteral feeding, decreased bowel motility, and an immature immune system allowing for bacterial invasion. The premature neonate has an immature intestinal tract and therefore has decreased intestinal motility. The intestinal barrier isn’t “tight” (or strong). As the intestinal wall’s mucosal barrier breaks down from the invasion of abnormal bacteria (i.e., gas-producing bacteria), intestinal injury can become severe. Other risk factors include the following:

**Feeding Practices.** Feeding does provide a necessary medium for the multiplying of bacteria. Feeding hyperosmolar formula or medications can damage the intestinal mucosa. Some examples of osmolarity for different feeding types include

- breast milk: 257 mOsm/L
- preterm breast milk with fortifier: approximately 300 mOsm/L

- premature infant formulas (20 cal/oz): approximately 210 mOsm/L
- premature infant formulas (24 cal/oz): approximately 250 mOsm/L
- elemental formulas (20 cal/oz): approximately 250 mOsm/L–310 mOsm/L
- some examples of medication osmolality include
  - Polyvisol: > 11,000 mOsm/L
  - NaCl: > 7,000 mOsm/L
  - Phenobarbital: > 7,000 mOsm/L (Jew, Owen, Kaufman, & Balmer, 1997).

Breast milk has been identified to be protective against NEC, mostly due to immunologic factors. Mothers should be encouraged to provide their own milk. If the mother is unable to provide her own milk, use of donor milk should be considered, especially for the very-low-birthweight (< 1,000 g) population. Recent randomized, controlled trials comparing donor milk and formula demonstrated twice the incidence of NEC in the formula-fed groups (Ramani & Ambalavanan, 2013).

Gastric residuals do not necessarily indicate the presence of NEC. Gastric motility is slower in the preterm neonate. Because the motor complexes of the intestines are immature (thus slower motility), it can be normal to have light green-tinged or milky residuals in the absence of other clinical signs and symptoms. One must note the color of the residual, the amount of the residual in comparison with the amount of the feeding, and if there are any signs or symptoms.

Adopting a standardized feeding guideline may decrease the risk of NEC. There is some evidence to suggest this practice may decrease incidence of NEC, however, other studies do not show a significant difference. Some centers have noted a consistent decline in the incidence and severity of NEC following the institution of feeding guidelines.

**Hypoxic/ischemic events.** After a hypoxic event, intestinal ischemia may follow as blood is shunted away from the intestines. With reperfusion of the bowel, damage to the intestine may occur. Some examples of events that
may impact gut perfusion include patent ductus arteriosis (diastolic steal), hypotension, hypovolemia, umbilical line(s) placement, exchange transfusion, packed red blood cell transfusion, and polycythemia. In addition, neonates with congenital heart disease have compromised bowel perfusion, which may make them susceptible to ischemic injury of the bowel.

**Abnormal bacterial colonization.** Abnormal bacterial colonization of the immature intestinal tract is a significant risk factor identified with NEC. Some studies have shown that neonates who were born via cesarean section, fed formula, or exposed to antibiotics have a decrease in diversity of intestinal microbiota and abnormal patterns of bacterial colonization.

**H2 blockers.** These medications (e.g., Pepcid, Zantac) alter the pH of the stomach. Histamine-2 blockers have been shown to increase the risk of sepsis and meningitis for neonates (Torraza & Neu, 2013).

**Presentation**

Nonspecific symptoms of NEC may include apnea, bradycardia, temperature instability, lethargy, and hypotension. More specific symptoms may include discolored abdominal wall, visualization or palpation of bowel loops, abdominal distention, feeding residuals, bloody stools, and decreased or absent bowel sounds. Laboratory findings can also be nonspecific. These may include thrombocytopenia, neutropenia, and metabolic acidosis.

The Modified Bell’s Staging Criteria chart is used to categorize NEC presentation using clinical symptoms and radiologic findings. There are three stages, and each stage is divided into two presentations, shown in the table below.

### Modified Bell’s Staging Criteria for Necrotizing Enterocolitis (NEC)

<table>
<thead>
<tr>
<th>Stage</th>
<th>Systemic signs</th>
<th>Abdominal signs</th>
<th>Radiographic signs</th>
</tr>
</thead>
<tbody>
<tr>
<td>IA suspected</td>
<td>Temperature instability, apnea, bradycardia, lethargy</td>
<td>Gastric retention, abdominal distention, emesis, hemepositive stool</td>
<td>Normal or intestinal dilation, mild ileus</td>
</tr>
<tr>
<td>IB suspected</td>
<td>Same as above</td>
<td>Grossly bloody stool</td>
<td>Same as above</td>
</tr>
<tr>
<td>IIA definite, mildly ill</td>
<td>Same as above</td>
<td>Same as above, plus absent bowel sounds with or without abdominal tenderness</td>
<td>Intestinal dilation, ileus, pneumatosis, intestinalis</td>
</tr>
<tr>
<td>IIB definite, moderately ill</td>
<td>Same as IA, plus mild metabolic acidosis and thrombocytopenia</td>
<td>Same as above, plus absent bowel sounds, definite tenderness, with or without abdominal cellulitis, or right lower quadrant mass</td>
<td>Same as IIA, plus ascites</td>
</tr>
<tr>
<td>IIIA advanced, severely ill, intact bowel</td>
<td>Same as IIB, plus hypotension, bradycardia, severe apnea, combined respiratory and metabolic acidosis, disseminated intravascular coagulation, and neutropenia</td>
<td>Same as above, plus signs of peritonitis, marked tenderness, and abdominal distention</td>
<td>Same as IIA, plus ascites</td>
</tr>
<tr>
<td>IIIB advanced, severely ill, perforated bowel</td>
<td>Same as IIIA</td>
<td>Same as IIIA</td>
<td>Same as IIIA, plus pneumoperitoneum</td>
</tr>
</tbody>
</table>

Interventions
Lab work such as complete blood counts, blood cultures, inflammatory markers (e.g., C-reactive protein), blood gases, electrolytes, and glucose and coagulation studies should be evaluated and repeated as indicated. Frequent abdominal X rays may be taken in one or two views and may include left lateral decubitus or cross-table lateral views.

Nonsurgical interventions include gastric decompression to low intermittent suction, intravenous fluids or parenteral nutrition, monitoring of vital signs, antibiotics, pain management, ventilator support as needed, circulatory support as needed (e.g., for hypotension), strict intake and output, and laboratory studies (as mentioned above), including serum glucose, and frequent X rays. The pediatric surgeon should be called if Bell's Stage II or greater NEC is noted or if medical management is not successful.

Surgical intervention is necessitated if pneumoperitoneum is noted on the X ray. Other indications for surgery can include portal venous gas; fixed, dilated intestinal loops noted on the X ray; an abdominal mass; or clinical deterioration. Options for surgery include an exploratory laparotomy or placement of a peritoneal drain. The type of surgery performed will depend on the condition of the neonate as well as the progression of bowel necrosis. Peritoneal drain placement can be performed at the bedside and is a temporary measure for an unstable neonate. With an exploratory laparotomy, the bowel is examined and the necrotic segments removed. Most times, an ostomy is created with a mucus fistula. After the neonate has grown and is stable, with feedings re-established, a reanastomosis is performed, assuming there is enough viable bowel length to do so. Timing of reanastomosis may be weeks to months after the laparotomy.

Complications from NEC may include intestinal strictures, malabsorption with or without short bowel, cholestatic liver disease, recurrent NEC episode, and neurodevelopmental delay. Intestinal strictures are more often found in NEC patients managed medically, not requiring surgical intervention. Malabsorption is seen in infants having significant bowel length resected or those who lose their ileo-cecal valve. A general rule of thumb is that more than 30 cm of bowel with intact ileocecal valve or more than 50 cm of bowel without the ileocecal valve is required for an infant to survive on enteral nutrition (Kastenberg & Sylvester, 2013). Recurrent NEC occurs in about 5% of cases. Cholestatic liver disease may occur due to prolonged use of total parenteral nutrition and intralipids. Neurodevelopmental delay is related to the severity of NEC as well as the presence of circulating inflammatory mediators, which may contribute to a less than favorable neurodevelopmental outcome.

References

Bibliography


Necrotizing enterocolitis (NEC) is a disease that affects the intestines of sick babies. NEC occurs more often in premature babies—the earlier the baby is born, the greater the risk of NEC. Up to 10% of all babies admitted to the NICU can have NEC.

NEC is an inflammatory disease of the intestine (also known as the bowel). First, the intestinal wall lining becomes damaged. Then, bacteria attack the intestine to cause swelling and infection. This can lead to a rupture, or perforation, of the intestine. If the intestine ruptures, bacteria can get into the abdomen, which can be life threatening. The exact cause of NEC is unknown, but the most consistent risk factor is related to feeding. Babies who are fed formula are more likely to have NEC than those who are fed breast milk (human breast milk has a protective effect against NEC).

It can be difficult to identify NEC, because the premature infant may have other issues that appear similar to NEC. Symptoms of NEC may include feeding intolerance, a round stomach or belly with “loops of bowel” noticeable, vomiting, bloody stools, not being active (lethargy), and times of not breathing and slowing of the heartbeat (apnea and bradycardia). Your baby may need assistance with breathing, such as the use of a ventilator. The best way to diagnose NEC is with an X ray of the stomach.

NEC treatment includes allowing the bowel to rest, so feedings will be stopped. This may be for as little as 3 days but may last for several days to weeks. A tube from your baby’s mouth to the stomach will be placed to remove fluid and air from the stomach. Blood sampling will be done. Intravenous fluids will be started for nutrition as well as antibiotics. Abdominal X rays will be frequent. Many infants who have NEC do not need surgery, but there are some infants who will. If surgery is needed, a pediatric surgeon will be involved. During surgery, the sick part of the intestine will be removed. Sometimes, the healthy ends of the intestine can be sewn back together. Other times, the two ends of the intestine are brought to an opening in the skin called an ostomy. Your baby will stool through the ostomy into a bag. The ostomy may last a few weeks to months before the ends of the intestines are healed enough to be reconnected. After your baby has recovered from surgery and the antibiotics are done, he or she will be able to start feedings again.

Some babies experience narrowing of the intestines and poor digestion of feedings after having had NEC. When narrowing (also called strictures) happens, it can cause a blockage in the intestine. Poor digestion of feedings (called malabsorption) may also occur. If this happens, the use of human milk or another easy-to-digest formula may help.

During the initial diagnosis of NEC, you may not be able to hold your baby because he or she is so sick. Please ask questions of the NICU staff. The staff is here to support you together as a family.
Cardiac Defects: Aortic Stenosis

When the heart squeezes, the left ventricle (the lower left chamber) contracts, pushing blood out into the aorta, the main artery that takes blood to the body. The aortic valve is located on the way out of the heart, to prevent blood from leaking back into the heart between beats. A normal aortic valve is made up of three thin leaflets.

In aortic stenosis, the leaflets are fused or are too thick, or there are fewer than three. As a result, the valve is too narrow, and the heart has to work harder to pump enough blood to the body. Aortic stenosis, or obstruction at the aortic valve, can be trivial, mild, moderate, severe, or critical.

Sometimes the stenosis is below the valve, caused by a fibrous membrane or a muscular ridge; this is called sub-aortic stenosis. The stenosis also can occur above the valve, in the aorta itself; this is called supravalvar aortic stenosis.

Symptoms
Aortic stenosis usually won’t cause symptoms in infants or small children. As the child gets older, signs and symptoms of aortic stenosis may appear, including fatigue; a heart murmur (an extra heart sound when a doctor listens with a stethoscope); or rarely, chest pain, fainting, or arrhythmias (abnormal heart rhythm).

How is aortic stenosis in children diagnosed?
In rare cases, newborns have critical aortic stenosis, which requires immediate medical attention. Sometimes these severe cases are diagnosed before birth through a fetal heart program.

In most cases, cardiologists diagnose aortic stenosis after a primary care doctor detects a heart murmur and refers the child to a cardiologist.

Diagnosis may require some or all of these tests:
- pulse oximetry—a painless way to monitor the oxygen content of the blood
- chest X ray
- echocardiogram (also called echo or cardiac ultrasound)—sound waves create an image of the heart
- electrocardiogram (ECG)—a record of the electrical activity of the heart
- cardiac MRI—a three-dimensional image shows the heart’s abnormalities
- cardiac catheterization—a thin tube (catheter) is inserted into the heart through a vein or artery in either the leg or through the umbilicus (“belly button”).

Aortic stenosis can run in families, so be sure to tell your cardiologist if there is a history of a heart murmur in other close family members.

What are the treatment options for aortic stenosis?
The exact treatment required for aortic stenosis depends on each child’s heart anatomy. Trivial and mild aortic stenosis typically require no treatment. However, moderate, severe, and critical aortic stenosis require treatment.

Cardiac Catheterization
In most cases, aortic stenosis is treated with balloon valvuloplasty, which requires cardiac catheterization. Doctors advance a thin tube (catheter) to the heart through a vein in the leg. The catheter has a balloon on the end of it. To open up the narrow valve, the balloon is briefly inflated, deflated, and withdrawn. Sometimes, two catheters and balloons are used. Sometimes, in newborns, the blood vessels in the umbilical cord are used as the site where the catheters are inserted and advanced toward the heart.

Older children will spend one night in the hospital after this procedure. They will need to rest the next day but then can resume normal activity. Newborns with critical aortic stenosis will usually stay in an intensive care unit before and after the procedure and will require some time to recover.
Valvuloplasty Surgery
Surgery to repair or to replace the valve is often necessary in severe cases. Depending on the age, gender, and particular needs of your child, as well as the valve anatomy, surgeons may attempt to repair the valve, or at least improve its function, with a surgery called a valvuloplasty.

Artificial Valves
Another option to treat aortic stenosis includes the use of mechanical (artificial) valves as replacement valves. If this is the case, your child may need to stay on blood-thinning medicines for the rest of his or her life.

Ross Procedure
Yet another option to treat aortic stenosis is the Ross Procedure. In this operation, the aortic valve is replaced with the patient’s pulmonary valve. The pulmonary valve is then replaced with one from a donated organ. This procedure allows the patient’s own pulmonary valve (now in the aortic position) to grow with the child.

Subaortic and Supravalvar Stenosis Treatment
Subaortic and supravalvar stenosis do not get better with balloon dilation and will require surgery if the amount of obstruction is moderate or severe or, with subaortic stenosis, the aortic valve begins to leak significantly. Surgery for subaortic stenosis involves cutting out the ridge. Surgery for supravalvar aortic stenosis involves enlarging the aorta with a patch.

Follow-Up Care
Through Age 18
Children with aortic stenosis require regular check-ups with a pediatric cardiologist. Some children must remain on medicine and limit physical activity.

As the child with aortic stenosis grows, blood may begin to leak through the abnormal valve. This is called aortic regurgitation or aortic insufficiency. In other children, the stenosis can reoccur. When this happens, balloon valvuloplasty can be repeated, as long as there isn’t significant aortic regurgitation. In severe cases, additional surgery may be necessary.

Pediatric cardiologists follow patients until they are young adults, coordinating care with the primary care providers.

Into Adulthood
Adults with aortic stenosis must continue to see a cardiologist regularly. Your child’s pediatric cardiologist will help with the transition to an adult cardiologist. All patients with aortic valve disease need some form of lifelong follow-up with a cardiologist. Because of enormous strides in medicine and technology, today most children with heart conditions go on to lead healthy, productive lives as adults.

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An atrioventricular canal defect is a problem in the part of the heart that connects the upper chambers (atria) to the lower chambers (ventricles). There are two types of atrioventricular canal defects: complete and partial.

**Complete Atrioventricular Canal (CAVC)**
Complete atrioventricular canal (CAVC) defect is a severe defect in which there is a large hole in the tissue (the septum) that separates the left and right sides of the heart. The hole is in the center of the heart, where the upper chambers (the atria) and the lower chambers (the ventricles) meet.

As the heart formed abnormally, with this large hole, the valves that separate the upper and lower chambers also developed abnormally. In a normal heart, two valves separate the upper and lower chambers of the heart: the tricuspid valve separates the right chambers and the mitral valve the left. In a child with CAVC defect, there is one large valve that may not close correctly.

As a result of the abnormal passageway between the two sides of the heart, blood from both sides mix and too much blood circulates back to the lungs before it travels through the body. This means the heart works harder than it should have to, and it will become enlarged and damaged if the problems aren’t repaired.

**Partial Atrioventricular Canal Defects**
A partial atrioventricular canal defect is the less severe form of this heart defect. The hole does not extend between the lower chambers of the heart and the valves are better formed. Usually it is necessary only to close the hole between the upper chambers (this hole is called an atrial septal defect, or ASD) and to do a minor repair of the mitral valve. Partial atrioventricular canal is also called atrioventricular septal defect, or AVSD.

**What are the symptoms of atrioventricular canal defects?**
In CAVC defect, the following symptoms may be present within several days or weeks of birth:
- blue or purple tint to lips, skin, and nails (cyanosis)
- difficulty breathing
- poor weight gain and growth
- heart murmur—the heart sounds abnormal when a doctor listens with a stethoscope.

Partial atrioventricular canal defects cause fewer symptoms and sometimes aren’t diagnosed until the child reaches his or her 20s or 30s and begins to experience irregular heartbeat (arrhythmia), leaky valves, or other effects.

**How are atrioventricular canal defects diagnosed?**
The healthcare provider who evaluates the newborn in the hospital might make the diagnosis, or a primary care provider might notice a murmur and other symptoms and refer the baby to a cardiologist.
Diagnosis of atrioventricular canal defects may require some or all of these tests:

- **echocardiogram**—sound waves create an image of the heart
- **electrocardiogram (ECG)**—a record of the electrical activity of the heart
- **chest X ray**
- **pulse oximetry**—a noninvasive way to monitor the oxygen content of the blood
- **cardiac catheterization**—a thin tube is inserted into the heart through a vein and/or artery in either the leg or through the umbilicus ("belly button")
- **cardiac MRI**—a three-dimensional image shows the heart’s abnormalities.

Sometimes a complete atrioventricular canal defect is diagnosed on a fetal ultrasound or echocardiogram. Your baby’s providers can prepare a plan for delivery and care immediately after birth.

Complete atrioventricular canal defects often occur in children with Down syndrome.

**What are the treatment options for atrioventricular canal defects?**

**Through Age 18**

A child who has had surgical repair of an atrioventricular canal defect will require lifelong care by a cardiologist. Most children recover completely and won’t need additional surgery or catheterization procedures.

Pediatric cardiologists follow patients until they are young adults, coordinating care with the primary care provider. Patients will need to carefully follow providers’ advice, including staying on any medications prescribed and, in some cases, limiting exercise.

Sometimes children with an atrioventricular canal defect experience heart problems later in life, including irregular heartbeat (arrhythmia) and leaky or narrowing valves. Medicine, additional surgery, or cardiac catheterization may be required.

**Into Adulthood**

Pediatric cardiologists will help patients transition care to an adult congenital heart disease specialist. Because of enormous strides in medicine and technology, today most children born with atrioventricular canal defects go on to lead productive lives as adults.

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Cardiac Defects: Coarctation of the Aorta

The aorta is the main artery that carries oxygenated blood out of the heart to the body. It starts at the left ventricle of the heart as one large vessel and branches out into the smaller vessels in the body. From the heart, the aorta arches up and then curves around. Arteries that deliver blood to the head, arms, and other parts of the upper body branch off at the top of the arch. Arteries that deliver blood to the abdomen, legs, and other parts of the lower body branch off from the descending aorta.

With coarctation of the aorta in children, the aorta is too narrow at the portion just after the upper-body arteries branch off—this obstructs blood flow. Because of this narrowing, the left ventricle of the heart must pump much harder than normal to move blood through the aorta to the lower body. This can lead to damage to the heart, or heart failure, and high blood pressure in the heart and brain as well as damage to organs in the lower body that don’t get enough blood.

Sometimes children with coarctation of the aorta can also have a ventricular septal defect, a hole between the lower chambers of the heart, or a bicuspid aortic valve, which means the valve has two flaps instead of three.

What are the symptoms of coarctation of the aorta?
In severe cases, coarctation of the aorta symptoms will appear within the first few days of life. The more the aorta is narrowed, the more severe the symptoms will be.

In infants where the coarctation of the aorta is severe or moderate, symptoms can include

- labored or rapid breathing
- weak femoral artery pulse (taken in the groin area)
- heavy sweating
- poor growth
- pale or gray appearance
- heart murmur—extra heart sound heard when the doctor listens with a stethoscope.

If the narrowing is mild, coarctation of the aorta symptoms may go unnoticed until the child is older or even an adult. In those cases, symptoms can include

- high blood pressure
- cold feet or legs
- difficulty exercising (gets out of breath quickly)
- dizziness
- fainting
- nosebleeds
- headaches
- leg cramps
- heart murmur.

How is coarctation of the aorta diagnosed in children?
When an infant has severe coarctation of the aorta, in most cases a doctor in the birth hospital will notice symptoms.
Milder cases of coarctation of the aorta sometimes aren’t diagnosed until the child is older. Healthcare providers refer children to cardiologists for evaluation after parents notice symptoms or if the child has high blood pressure.

Diagnosis of coarctation of the aorta may require some or all of these tests:

- echocardiogram—sound waves create an image of the heart
- electrocardiogram (ECG)—a record of the electrical activity of the heart
- chest X ray
- pulse oximetry—a noninvasive way to monitor the oxygen content of the blood
- cardiac catheterization—a thin tube is inserted into the heart through a vein and/or artery in either the leg or through the umbilicus (“belly button”)
- cardiac MRI—a three-dimensional image shows the heart’s abnormalities.

What are the treatment options for coarctation of the aorta?

Coarctation of the aorta requires either cardiac catheterization or open-heart surgery, depending on the severity of the narrowing and on other factors, such as the child’s age and overall health.

Surgeons can remove the narrowed section of the aorta and then sew the ends of the aorta back together, or they can enlarge the aorta with a patch.

In catheterization, a cardiologist will thread a thin tube (catheter) with a balloon on the end of it through an artery in the leg up to the heart. Then, using the catheter, the cardiologist can inflate the balloon in the narrowed section of the aorta to open it, and might also place a stent, or a stiff metal cage, to keep it open.

Your child will recover from these procedures in the intensive care unit.

What is the follow-up care for coarctation of the aorta?

Through Age 18

Most children who have repair of coarctation of the aorta recover completely and won’t require additional procedures. Rarely, the aorta becomes narrow again and balloon catheterization or surgery will be required.

Pediatric cardiologists follow patients until they are young adults, coordinating care with the primary care provider. Patients will need to carefully follow healthcare providers’ advice. Sometimes, these children can have persistently elevated blood pressure, despite removal of the obstruction. These children will need to take medicines to lower their blood pressure and may need to avoid certain isometric activities, like football, weight-training, and wrestling.

Into Adulthood

It is important that children born with coarctation of the aorta continue to see a cardiologist. We will help patients transition care to an adult cardiologist.

Because of enormous strides in medicine and technology, today most children born with coarctation of the aorta go on to lead productive lives as adults.

Adapted with permission. © The Children’s Hospital of Philadelphia.
Hypoplastic left heart syndrome (HLHS) is a severe congenital heart defect in which the left side of the heart is underdeveloped.

The heart’s left side has the job of pumping oxygenated blood into the aorta, the large artery that carries blood to the body. In a child with HLHS,

- The mitral valve, which separates the two left chambers of the heart, is too small or completely closed (atretic).
- The left ventricle (the lower, pumping chamber) is very small.
- The aortic valve, which separates the left ventricle and the aorta, is too small or completely closed (atretic).

In addition to the most common form of HLHS, there are a number of complex cardiac conditions with variations in the structures as described. In these children, where one ventricle is also small (sometimes called “HLHS variants”), the treatment strategy is similar to those with the more typical HLHS.

**What are the symptoms of HLHS?**
The following symptoms of HLHS may be present at birth or several days later:

- blue or purple tint to lips, skin, and nails (cyanosis)
- difficulty breathing
- difficulty feeding
- lethargy (sleepy or unresponsive).

**How is HLHS diagnosed?**
Often, HLHS is diagnosed before birth, with fetal echocardiogram (ultrasound). Your baby’s provider will prepare a plan for delivery and care immediately after birth.

Sometimes HLHS is diagnosed hours or days after birth and the baby will need immediate therapy. Diagnosis of HLHS may require some or all of these tests:

- echocardiogram (also called “echo” or ultrasound)—sound waves create an image of the heart
- electrocardiogram (ECG)—a record of the electrical activity of the heart
- chest X ray
- pulse oximetry—a noninvasive way to monitor the oxygen content of the blood
- cardiac catheterization—a thin tube is inserted into the heart through a vein and/or artery in either the leg or through the umbilicus (“belly button”)
- cardiac MRI—a three-dimensional image shows the heart’s abnormalities

Your baby will need intravenous medicines, and possibly a ventilator for help with breathing. Cardiologists and cardiac nurses will immediately begin procedures to help stabilize your baby.

**What are the treatment options?**
HLHS is most often fatal without early intervention. It will typically require open heart surgery to redirect the oxygen-rich (“red”) blood and oxygen-poor (“blue”) blood
in a series of three reconstructive operations known as “staged reconstruction.”

**Stage I—Norwood procedure**
Stage I, known as the Norwood procedure, occurs within a few days of birth. In Stage 1 of reconstruction of a heart with HLHS, the shunt used is called a “Blalock-Taussig” shunt. Alternative types of shunts may be used based upon a child’s individual anatomy.

For a small number of children, alternative approaches to the Stage I Norwood procedure may be recommended, such as heart transplantation or a combination of surgery and catheter-based treatment called a “hybrid procedure.” Compared with 25 years ago, there are now many different options for treatment of this complex heart condition; an individualized approach is taken for each and every child. Your baby’s provider will explain each individual option, and why one particular approach might be recommended for your child.

**Stage II—Glenn Procedure**
Stage II, known as the bidirectional Glenn or the hemi-Fontan, typically occurs within 4 to 6 months of birth.

**Stage III—Fontan Procedure**
Stage III, known as the Fontan procedure, typically occurs between 1 1/2 to 4 years of age. In Stage 3 of reconstruction of a heart with HLHS, a technique called an “extracardiac Fontan” is used. The small hole intentionally placed to connect the conduit to the right atrium is called a fenestration. In some children, a different modification, termed a lateral tunnel fenestrated Fontan is used. Your baby’s provider will explain the differences and why one might be recommended for your child.

Frequent surveillance in infancy and early childhood is important to minimize risk factors for the eventual Fontan operation. Your child will also need a customized series of diagnostic tests between the planned stages of surgery, and throughout childhood. Additional surgical or catheter therapies, or in rare cases heart transplantation, may also be recommended.

After these operations,
• The right side of the heart will do what is usually the job of the left side—pumping oxygenated blood to the body.
• The deoxygenated blood will flow from the veins to the lungs without passing through the heart.

**What is the follow-up care for HLHS?**

**Between the Norwood and Glenn Operations**
Though early outcomes for patients with single ventricle heart defects after staged reconstruction have improved dramatically, the period between the Norwood procedure and the Glenn operation remains a very vulnerable time for infants. Your baby’s provider will focus on the care and monitoring of your baby between the first and second reconstructive surgeries.

**Through Age 18**
Children who have had surgical reconstruction for HLHS require lifelong care by a cardiologist experienced in congenital heart disease. Sometimes they experience serious health problems. Many remain on medication, and additional surgeries may be required.

Patients with Fontan circulation are referred to as single ventricle patients. As these patients get older, doctors are recognizing that, although some do fine, many experience complications, including lung, liver, and gastrointestinal diseases.

In addition, as a group, children with complex congenital heart defects who have had open heart surgery as infants are at a higher risk for neurodevelopmental issues when compared with children without congenital heart defects.

Your baby’s cardiologist will follow your baby until he or she is a young adult, coordinating care with the primary care providers.

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Blood flow is different in the fetus, and most blood bypasses the lungs. An extra blood vessel (passageway) called the *ductus arteriosus* (DA) allows blood from the right side of the heart to flow to the aorta, one of the largest arteries, and back out into the body without going through the lungs.

After the baby is born and begins to breathe, the flow of blood changes to include the lungs. The pulmonary artery opens to carry blood from the right side of the heart to the lungs, and the DA is supposed to close.

*Patent ductus arteriosus* (PDA) is a condition in which the ductus arteriosus doesn’t close. *Patent* means “open.” Sometimes the open passageway is wide (a large PDA) and sometimes it is narrow (a small PDA). A large PDA is dangerous, because blood flow to the lungs isn’t as controlled as it should be, leading to problems with the lungs and heart.

PDA is most common in premature infants.

**What are the symptoms of PDA?**
Symptoms vary depending on the size of the PDA, and include
- breathing difficulties soon after birth (especially in premature babies)
- heart murmur—the heart sounds abnormal when a doctor listens with a stethoscope
- rapid breathing
- difficulty feeding, poor growth
- lung infections (pneumonia).

**How is PDA diagnosed?**
Neonatologists, doctors who care for premature babies, work with the cardiac doctors to diagnose and treat PDA in newborns. Older infants and children with PDAs are most often sent to cardiac doctors after their primary care providers notice a heart murmur.

Diagnosis of patent ductus arteriosus may require
- echocardiogram (also called “echo” or ultrasound)—sound waves create an image of the heart
- electrocardiogram (ECG)—a record of the electrical activity of the heart
- chest X ray.

Some babies with PDA have other heart defects and will require other tests, including cardiac catheterization and cardiac MRI.

**What are the treatment options for PDA?**
If the PDA is not life threatening, doctors might wait until the child is 1 or 2 years old before recommending treatment. Small PDAs often close on their own.

In premature babies in whom the condition may be dangerous, doctors immediately give medicines to help close the PDA.
If the PDA does not close or narrow significantly in response to medicine, an interventional procedure may be necessary. In most cases, the PDA can be closed through cardiac catheterization. Healthcare providers insert a thin tube (catheter) through a vein or artery in the leg, guide it to the heart, and insert a tiny device to block the PDA. In more complex cases, surgery may be required. Cardiothoracic surgeons use stitches or clips to close the PDA.

**What kind of follow-up care is required for PDA?**

Once a PDA is closed, no long-term follow-up care is necessary unless there are other cardiac concerns.

Adapted with permission. © The Children’s Hospital of Philadelphia.
Cardiac Defects: Pulmonary Stenosis

When the heart squeezes, the right ventricle (the lower right chamber) contracts and pushes blood out into the pulmonary artery (the artery that takes blood to the lungs). The pulmonary, or pulmonic, valve sits on the way out of the heart between the right ventricle and the main pulmonary artery to prevent blood from leaking back into the heart between beats. A normal pulmonary valve is made up of three thin leaflets.

In pulmonary stenosis, the leaflets are fused or are too thick, or there are fewer than three. As a result, the pulmonary valve is too narrow, and the heart has to work harder to pump enough blood to the body. Pulmonary stenosis, or obstruction at the pulmonary valve, can be trivial, mild, moderate, severe, or critical. This condition is also called pulmonic stenosis or pulmonary valve stenosis.

Sometimes the stenosis is below the pulmonary valve, caused by muscular bundles. This is called subpulmonary stenosis. Also, the stenosis can occur above the pulmonary valve, in the pulmonary artery itself. This is called supravalvar pulmonic stenosis.

What are the symptoms of pulmonary stenosis in children?
Pulmonary stenosis usually does not cause symptoms in infants or small children. As the child gets older, abnormal signs and symptoms may appear, including fatigue, a heart murmur (an extra heart sound when a healthcare provider listens with a stethoscope) and, rarely, chest pain or fainting.

How is pulmonary stenosis diagnosed?
In rare cases, newborns have critical pulmonary stenosis, which requires immediate medical attention. Sometimes severe cases of pulmonary stenosis are diagnosed before birth.

Cardiac specialists usually diagnose pulmonary stenosis after a primary care provider detects a heart murmur and refers the child to them.

Diagnosis of pulmonary stenosis may require some or all of these tests:
- pulse oximetry—a painless way to monitor the oxygen content of the blood
- chest X ray
- echocardiogram (also called “echo” or ultrasound)—sound waves create an image of the heart
- electrocardiogram (ECG)—a record of the electrical activity of the heart
- cardiac MRI—a three-dimensional image shows the heart’s abnormalities
- cardiac catheterization—a thin tube is inserted into the heart through a vein or artery in either the leg or through the umbilicus (“belly button”).

Pulmonary stenosis can run in families, so be sure to tell your cardiologist if there is a history of a murmur in other close family members.

What are the treatment options for pulmonary stenosis in children?
The exact treatment required for pulmonary stenosis depends on each child’s heart anatomy. Trivial or mild pulmonary stenosis typically require no treatment. However, moderate, severe, and critical pulmonary stenosis require treatment.

Cardiac Catheterization
In most cases, pulmonary stenosis is treated with balloon valvuloplasty, which requires cardiac catheterization. Healthcare providers advance a thin tube (catheter) to the heart through a vein in the leg. The catheter has a balloon on the end of it. To open up the narrow valve, the balloon is briefly inflated, deflated, and withdrawn. Sometimes, two catheters and balloons are used. Sometimes, in newborns, the blood vessels in the umbilical cord are used as the site where the catheters are inserted and advanced toward the heart.

Older children may spend one night in the hospital after this procedure and will need to rest the next day but then can resume normal activity. Newborns with critical
pulmonary stenosis will stay in an intensive care unit before and after the procedure and will require some time to recover.

**Surgery**
In rare cases, surgery will be required. Surgeons use a procedure called *valvotomy* to separate fused leaflets in the pulmonary valve. Another option includes the surgical placement of a valve called a *pulmonary homograft*, which is a donated pulmonary valve and artery. This valve may grow with the child, and blood-thinners are not required.

**New Valve**
An exciting future option is a tissue-engineered valve that is grown with the patient’s own cells on a biodegradable mesh. This may be the future of all valve replacement but is still in the research and development phase.

**Surgery for Subpulmonic and Supravalvar**
Subpulmonic and supravalvar pulmonic stenosis do not get better with balloon dilation and will require surgery if the amount of obstruction is moderate or severe. Surgery for subpulmonic stenosis involves cutting out the muscle bundles. Surgery for supravalvar pulmonic stenosis involves enlarging the pulmonary artery with a patch.

**Follow-Up Care**
**Through Age 18**
Children with pulmonary stenosis require regular check-ups with a pediatric cardiologist. Some children must remain on medicine and limit physical activity.

As the child grows, blood may begin to leak through the abnormal valve. This is called pulmonary regurgitation or pulmonic insufficiency. In other children, the stenosis can reoccur. When this happens, balloon valvuloplasty can be repeated, as long as there isn’t significant regurgitation. In severe cases, additional surgery may be necessary.

Pediatric cardiologists follow patients with pulmonary stenosis until they are young adults, coordinating care with the primary care providers.

**Into Adulthood**
Adults who were born with pulmonary stenosis must continue to see a cardiologist. Pediatric cardiologists will help with the transition to an adult cardiologist. All patients with pulmonary valve disease need some form of lifelong follow-up with a cardiologist. Because of enormous strides in medicine and technology, today most children with heart conditions go on to lead healthy, productive lives as adults.

*Adapted with permission. © The Children’s Hospital of Philadelphia.*
Cardiac Defects: Tetralogy of Fallot

Symptoms
The symptoms of tetralogy of Fallot include:
- blue or purple tint to lips, skin, and nails (cyanosis)
- heart murmur—the heart sounds abnormal when a doctor listens with a stethoscope
- in older children, abnormal shape of the fingertips ("clubbing")
- spells in which oxygen levels drop—lips and skin will become bluer, and the child will become fussy or irritable and then sleepy or unresponsive.

How is tetralogy of Fallot diagnosed?
Tetralogy of Fallot may be diagnosed with fetal echocardiogram (ultrasound). Your baby’s provider will prepare a plan for delivery and care immediately after birth.

Your baby’s providers might make the tetralogy of Fallot diagnosis before your baby leaves the hospital if they hear a murmur or see a blue tint to the skin. A primary care provider might detect the same symptoms during a checkup, or you might notice the symptoms and bring your baby to a doctor or hospital.

Diagnosis of tetralogy of Fallot may require some or all of these tests:
- pulse oximetry—a painless way to monitor the oxygen content of the blood
- electrocardiogram (ECG)—a record of the electrical activity of the heart
- echocardiogram (also called “echo” or ultrasound)—sound waves create an image of the heart
- chest X ray
- cardiac MRI—a three-dimensional image shows the heart’s abnormalities
- cardiac catheterization—a thin tube (catheter) is inserted into the heart through a large vein in the leg.

A number of children with tetralogy of Fallot also have genetic syndromes such as DiGeorge syndrome, Trisomy 21 (Down syndrome), Alagille syndrome, or 22q11...
deletion syndrome. Genetic testing (a blood test) may be part of the evaluation.

**What are the treatment options for tetralogy of Fallot?**

Surgery is required to repair tetralogy of Fallot.

Typically, in the first few months of life, surgeons will perform open-heart surgery to patch the hole and widen the pulmonary valve or artery. In some cases, depending on the unique needs of the patient, they will perform a temporary repair until a complete repair can be done. The temporary repair involves connecting the pulmonary arteries (which carry blood from heart to lungs) with one of the large arteries that carry blood away from the heart to the body. This increases the amount of blood that reaches the lungs, and so increases the amount of oxygen in the blood.

**What is the follow-up care for tetralogy of Fallot?**

**Through Age 18**

A child who has had surgical repair of tetralogy of Fallot will require lifelong care by a cardiologist.

Pediatric cardiologists follow patients until they are young adults, coordinating care with the primary care provider. Parents will need to carefully follow the advice of their baby’s provider, including staying on any medications prescribed and, in some cases, limiting exercise.

Sometimes children with tetralogy of Fallot experience heart problems later in life, including a leaky heart valve and irregular heartbeat (arrhythmia). Medicine or repeat surgery may be required.

**Into Adulthood**

Because of enormous strides in medicine and technology, today most children born with heart conditions like tetralogy of Fallot go on to lead healthy, productive lives as adults.

Adapted with permission. © The Children’s Hospital of Philadelphia.
Cardiac Defects: Total Anomalous Pulmonary Venous Return

Arteries carry blood away from the heart; veins carry it toward the heart. The pulmonary veins are very important. They carry the “red” blood that has picked up oxygen in the lungs back to the heart to be pumped out to the body.

There are typically four pulmonary veins, two from each lung. Normally they all connect directly into the heart’s left atrium (left upper chamber). From the left atrium, blood travels into the left ventricle (left lower chamber), which pumps it out to the aorta and to the body.

Anomalous means abnormal. In a child born with total anomalous pulmonary venous return (TAPVR), the pulmonary veins connect to other veins and ultimately drain their blood into the right atrium. You may also hear the term total anomalous pulmonary venous connection (TAPVC). Ordinarily, the right atrium only receives “blue” blood coming back from the body without oxygen, which then passes into the right ventricle and is pumped to the lungs. In TAPVR, the right atrium receives both “blue” blood from the body and “red” blood from the lungs.

As a result, the right side of the heart is overworked, pumping the extra blood it receives. Frequently, there is obstruction (blockage) to the veins that receive blood from the pulmonary veins, which causes a backup of blood in the lungs. This disrupts the normal flow of blood between the lungs and the body. In addition, the blood leaving the heart for the body doesn’t have as high a level of oxygen as it should.

Children with TAPVR also have other heart defects. They have a hole in the wall separating the two upper chambers of the heart (atrial septal defect) and may have a patent ductus arteriosus, an extra blood vessel between the pulmonary arteries and the aorta. These heart defects can actually help the child with TAPVR survive by allowing more blood to get from the right side of the heart to the left side and out to the body.

Your baby’s cardiologist will explain your baby’s heart anatomy in detail. Generally, there are four types of TAPVR:

- **Supracardiac TAPVR**: The pulmonary veins drain into the right atrium through the superior vena cava. (Normally this large vein carries only deoxygenated, or “blue,” blood into the right atrium.)
- **Infracardiac TAPVR**: The pulmonary veins drain into the right atrium through the liver (hepatic) veins and the inferior vena cava (another of the large veins that normally carries only deoxygenated blood).
- **Cardiac TAPVR**: In one type, the pulmonary veins can directly enter into the right side of the heart, into the right atrium. In the second type, the pulmonary veins can drain into the coronary sinus, a vein which usually only carries blood coming out of the heart muscle. This vein is usually very small but becomes quite large with this abnormal amount of blood.
- **Mixed TAPVR**: The pulmonary veins split up and drain partially to more than one of these options.

**Symptoms**

TAPVR symptoms include:
- blue or purple tint to lips, skin, and nails (cyanosis)
- rapid breathing or working harder while breathing, especially while eating
- heart murmur
  - an extra heart sound when a doctor listens with a stethoscope.

The severity of TAPVR symptoms varies.

**How is TAPVR diagnosed?**

In some cases, newborns with TAPVR have difficulty breathing and quickly become very ill. This occurs when the pulmonary veins are too narrow or are obstructed at some point, and blood can’t flow from the lungs as quickly as it should. This is called TAPVR with pulmonary obstruction.
In other cases, TAPVR is diagnosed in the first few months of life after a child demonstrates milder symptoms such as a heart murmur or cyanosis (blue tint to skin).

Diagnosis of TAPVR may require some or all of these tests:
- echocardiogram—sound waves create an image of the heart
- electrocardiogram (ECG)—a record of the electrical activity of the heart
- chest X ray
- pulse oximetry—a noninvasive way to monitor the oxygen content of the blood
- cardiac catheterization—a thin tube is inserted into the heart through a vein or artery in either the leg or through the umbilicus (“belly button”)
- cardiac MRI—a three-dimensional image shows the heart’s abnormalities.

What are the treatment options for TAPVR?
TAPVR requires open-heart surgery in all cases.

Critically ill newborns will have surgery immediately. If the child is not critically ill, surgeons may wait up to 2 months to perform surgery, depending on the strength of the child and on the heart anatomy.

To understand the surgery, one important thing to know about TAPVR is that the pulmonary veins, despite their abnormal connections to other veins, all end in a collection (called a “confluence”) at the back of the left atrium. The surgeon opens the confluence so that the veins can drain into the left atrium. Then he or she ties off all the abnormal connections between the pulmonary veins and other veins, so that blood can follow only the path to the left atrium. The surgeon also closes septal defects (the abnormal holes) with tiny patches or stitches and closes the patent ductus arteriosus. As the child ages, the lining of the heart grows over the stitches.

What is the follow-up care for TAPVR? Through Age 18
Children who were born with TAPVR and had it repaired must continue to see a pediatric cardiologist regularly. Children who were critically ill as newborns may have a longer road to recovery. In most cases, however, children won’t experience long-term effects—they won’t have to remain on any medicines or limit physical activity.

Rarely, the pulmonary veins become obstructed later in life and additional surgery or a catheterization procedure is required. Also rarely, children experience arrhythmia (abnormal heart rhythm), which may be treated with medicines, radiofrequency ablation, or a pacemaker.

Into Adulthood
It is important that children who were born with total anomalous pulmonary venous return continue to see a cardiologist. Because of enormous strides in medicine and technology, today most children born with total anomalous pulmonary venous return go on to lead productive lives as adults.

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Cardiac Defects: Transposition of the Great Arteries

Transposition of the great arteries (TGA) is a complex congenital heart defect in which the two large arteries that carry blood out of the heart are connected to the heart abnormally:

- The aorta is attached to the right-sided pumping chamber (ventricle), instead of the left.
- The pulmonary artery is attached to the left-sided pumping chamber (ventricle), instead of the right.

Normally, blood flows in this pattern: body to right side of heart to lungs to left side of heart and back to body. The pulmonary artery carries blood from the right side of the heart to the lungs, and the aorta carries blood from the left side of the heart to the body. In children with TGA, the normal pattern of flow does not exist, and the body doesn’t get enough oxygenated blood.

**What are the symptoms of TGA?**

The symptoms of TGA include

- blue or purple tint to lips, skin, and nails (cyanosis)
- rapid breathing
- difficulty feeding, poor appetite, and poor weight gain.

**How is TGA diagnosed?**

TGA may be diagnosed before birth with a fetal echocardiogram (ultrasound). Your baby’s provider will prepare a plan for delivery and care immediately after birth.

Sometimes TGA is diagnosed when an infant is a few hours or days old, and in some cases, infants may not have visible symptoms for weeks or months. Pediatricians refer newborns to a cardiologist when they notice symptoms or abnormal values on laboratory testing such as pulse oximetry.

Diagnosis of TGA may require some or all of these tests:

- echocardiogram (also called “echo” or ultrasound)—sound waves create an image of the heart
- electrocardiogram (ECG)—a record of the electrical activity of the heart
- chest X ray
- pulse oximetry—a noninvasive way to monitor the oxygen content of the blood
- cardiac catheterization—a thin tube is inserted into the heart through a vein or artery in either the leg or through the umbilicus (“belly button”)
- cardiac MRI—a three-dimensional image shows the heart’s abnormalities.

**What are the treatment options for TGA?**

TGA is unpredictable. Approximately one-third of newborns with the condition will require an urgent
intervention called a *balloon atrial septostomy* (BAS) within hours after birth. This procedure creates or enlarges a hole between the upper chambers of the heart to allow blood to mix.

For babies requiring a BAS procedure, access to immediate expert care is essential.

All children with TGA will require open heart surgery to treat the defect. Without surgical repair, the overwhelming majority of patients with TGA will not survive their first year. The surgery, known as the *arterial switch operation*, is typically performed within a few days of birth. Surgeons reconstruct the heart so that the aorta is attached to the left ventricle and the pulmonary artery is attached to the right ventricle.

After surgery your child will recover in an intensive care unit.

**What is the follow-up care for TGA?**

**Through Age 18**
Children who have had surgical repair of TGA require lifelong care by a cardiologist. Ongoing medication use is uncommon. More surgery may be required as the child grows.

Pediatric cardiologists follow patients until they are young adults, coordinating care with the primary care physicians.

**Into Adulthood**
Your baby’s pediatric cardiologist will help your baby transition to an adult cardiologist.

Until approximately 25 years ago, infants with TGA were managed by alternative surgical procedures, sometimes referred to as the *Senning* or *Mustard* operations. As a result, we don’t yet know the truly long-term effects of the arterial switch operation beyond young adulthood. It is anticipated that the overwhelming majority of children born with TGA will go on to lead healthy, productive lives. Limitations to day-to-day activities, including sports, are rare.

*Adapted with permission. © The Children’s Hospital of Philadelphia.*
Cardiac Defects: Tricuspid Atresia

The right side of the normal heart receives oxygen-poor blood (blue blood) from the body's veins and pumps it to the lungs to receive oxygen. The oxygen-rich blood (red blood) returns from the lungs to the left side of the heart, which pumps the blood to the body. The tricuspid valve is the opening between the right atrium (the upper chamber) and the right ventricle (the lower chamber). A heart with tricuspid atresia is characterized by poorly developed right heart structures and

- no tricuspid valve
- a smaller-than-normal, or hypoplastic, right ventricle
- a hole between the right atrium and left atrium, so that oxygen-poor and oxygen-rich blood mix inside of the heart
- a hole between the right ventricle and left ventricle.

Tricuspid atresia in children is often associated with pulmonary stenosis or narrowing of the pulmonary valve, or pulmonary atresia, where the pulmonary valve is completely closed. Tricuspid atresia can also be associated with transposition of the great arteries, where the aorta, the large artery that carries blood to the body, is connected to the small right ventricle.

Tricuspid atresia is a single-ventricle lesion, because the heart has only one functioning ventricle (the left ventricle).

Symptoms

Tricuspid atresia symptoms in children include

- blue or purple tint to lips, skin, and nails (cyanosis)
- heart murmur—the heart sounds abnormal when a doctor listens with a stethoscope
- shortness of breath
- difficulty feeding
- poor weight gain
- fatigue
- abnormal shape of the fingertips (“clubbing”) in older children.

How is tricuspid atresia diagnosed?

Tricuspid atresia in children may be diagnosed before birth with a fetal echocardiogram. Your baby's providers can prepare a plan for delivery and care immediately after birth.

Tricuspid atresia is usually diagnosed a few hours or days after birth. Pediatricians refer newborns to pediatric cardiologists when they notice symptoms and signs such as a “blue baby with a heart murmur.” Pulse oximetry is a painless way to monitor the oxygen level of the blood.

Some or all of these tests may be required for diagnosis of tricuspid atresia in children:

- chest X ray
- blood tests
- electrocardiogram (EKG)—this test shows the electrical activity of the heart
- echocardiogram (also called “echo” or ultrasound)—sound waves create an image of the heart. This test usually confirms the diagnosis.
- cardiac catheterization—a thin tube is inserted into the heart through a vein or artery in either the leg or through the umbilicus (“belly button”).

What are the treatment options for tricuspid atresia?

Your baby will be admitted to the cardiac intensive care unit. The baby may require oxygen and a medication called prostaglandin to maintain adequate oxygen levels in the blood. Prostaglandin is an intravenous medication that keeps open the connection between the pulmonary artery (the artery that normally carries blue blood to the lungs to receive oxygen) and the aorta (the artery that carries red blood to the body). This connection, called patent ductus arteriosus (PDA), is open in the fetus and closes soon after birth. When the PDA closes, some babies with tricuspid atresia turn quite blue (cyanosed). An infusion of prostaglandin can reopen the PDA and is a lifesaving intervention. Not all babies with tricuspid atresia require prostaglandin.

If the baby has labored breathing or poor effort, he or she may need help with a breathing machine or ventilator. It
is not uncommon for babies to have poor respiratory effort or apnea while on prostaglandin infusion.

At least two and possibly three surgeries will be required:

**Blalock-Taussig Shunt**
Babies who require prostaglandin to maintain adequate oxygen levels will require surgery soon after birth. The surgery involves the creation of a “shunt,” which is a tube that connects one of the branches of the aorta and the pulmonary artery, and thus replaces the PDA. This operation is called the Blalock-Taussig (BT) shunt. Many babies with tricuspid atresia are well enough to be discharged home soon after birth. However, some of these babies may require the shunt operation at a few weeks of life if the level of oxygen in their blood is decreasing.

Some babies with tricuspid atresia are too “pink” or have too much blood-flow to the lungs and will require an operation called pulmonary artery banding to narrow the pulmonary artery and regulate blood flow to the lungs. Babies with tricuspid atresia and transposition of great arteries may require the Norwood operation if the aorta is too small (see hypoplastic left heart syndrome).

**Hemi-Fontan/Glenn**
The second operation, called the hemi-Fontan/Glenn operation, usually occurs within 6 months of birth. During this surgery, the superior vena cava, one of the two large veins attached to the heart to return deoxygenated or blue blood from the upper half of the body, is disconnected from the heart and attached to the pulmonary artery. During this operation, the surgeon also removes the BT shunt. After this operation, deoxygenated or blue blood from the upper body goes to the lungs without passing through the heart.

**Fontan**
The third operation, called the Fontan, occurs at approximately 18 months to 3 years of age. During this surgery, the inferior vena cava, the other large vein that returns deoxygenated blood to the heart from the lower half of the body, is disconnected from the heart and attached to the pulmonary artery. This means that deoxygenated or blue blood from the whole body goes to the lungs without passing through the heart.

After these operations, deoxygenated blood flows to the lungs without passing through the right side of the heart. The cardiac team will explain the surgical procedures to you in more detail, based on your child’s heart anatomy.

What is the follow-up care for tricuspid atresia?

**Between the Norwood and Glenn Operations**
Although early outcomes for patients with single ventricle heart defects after staged reconstruction have improved dramatically, the period between the Norwood procedure and the Glenn operation remains a very vulnerable time for infants.

**Through Age 18**
Children with tricuspid atresia require lifelong care by a cardiologist. Many remain on medications for life. Additional surgeries may be required.

As single ventricle survivors get older, doctors are recognizing that, although some do fine, many experience complications, including lung, liver, and gastrointestinal diseases.

In addition, as a group, children with complex congenital heart defects who have had open heart surgery as infants are at a higher risk for neurodevelopmental issues when compared with children without congenital heart defects. Pediatric cardiologists follow patients until they are young adults, coordinating care with the primary care physicians.

**Into Adulthood**
It’s important that your child continue to see a cardiologist as an adult. Your baby's pediatric cardiologist will help with the transition to an adult cardiologist. Because of enormous strides in medicine and technology, today many children born with tricuspid atresia go on to lead healthy, productive lives as adults.

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Cardiac Defects: Truncus Arteriosus

When the fetus develops during pregnancy, the heart has a single large blood vessel coming from the heart called the \textit{truncus arteriosus}. If fetal development progresses normally, the truncus divides into two arteries that carry blood out of the heart:

- The pulmonary artery, which is attached to the right bottom chamber (ventricle) of the heart, divides into two arteries carrying oxygen-poor (“blue”) blood to each side of the lungs.
- The aorta, which is attached to the left bottom chamber (ventricle) of the heart, carries oxygen-rich (“red”) blood to the body.

Sometimes the single large blood vessel fails to divide during fetal development, and the baby is born with a heart that has one artery carrying blood out of it. This condition is known as \textit{truncus arteriosus} or \textit{persistent truncus arteriosus} (the trunk “persists”).

The undivided trunk is attached to the heart as one artery straddling the bottom chambers and then divides into arteries taking blood to the lungs and body. The oxygen-poor blood from the right ventricle (bottom chamber) and the oxygen-rich blood from the left ventricle (bottom chamber) mix when ejected out into the trunk, and more blood than normal goes back to the lungs, making it harder for the infant to breathe.

In almost all cases, children with the congenital heart defect truncus arteriosus also have a large hole between the bottom chambers of the heart. This is called a \textit{ventricular septal defect} (VSD).

As a result of these abnormalities, the baby’s blood isn’t as oxygenated as it should be when it circulates through the body.

**Signs and Symptoms**

Signs and symptoms of truncus arteriosus include

- blue or purple tint to lips, skin, and nails (cyanosis)
- poor eating and poor weight gain
- rapid breathing or shortness of breath
- profuse sweating, especially with feeding
- more sleepiness than normal
- unresponsiveness (the baby seems “out of it”)
- heart murmur—the heart sounds abnormal when a doctor listens with a stethoscope.

**How is truncus arteriosus diagnosed?**

Truncus arteriosus is a life-threatening congenital heart defect; most babies won’t live for more than a few months without treatment.

Usually truncus arteriosus is diagnosed before the baby leaves the hospital if the doctor hears a murmur or sees a blue tint to the lips or skin. In some cases, a primary care pediatrician might detect the symptoms of truncus arteriosus during a check-up, or a parent might notice symptoms and bring the baby to a doctor or hospital.

Diagnosis of truncus arteriosus may require some or all of these tests:

- pulse oximetry—a painless way to monitor the oxygen content of the blood
- electrocardiogram (ECG)—a record of the electrical activity of the heart
- echocardiogram (also called “echo” or ultrasound)—sound waves create an image of the heart
- chest X ray
- cardiac MRI—a three-dimensional image shows the heart’s abnormalities
- cardiac catheterization—a thin tube is inserted into the heart through a vein or artery in either the leg or through the umbilicus (“belly button”).

Sometimes truncus arteriosus is diagnosed on a fetal ultrasound or echocardiogram. Your baby’s providers can prepare a plan for delivery and care immediately after birth.

A number of children with truncus arteriosus also have a genetic syndrome called 22q11 deletion syndrome (also known as DiGeorge, velocardiofacial, or conotruncal...
anomaly face syndromes). Genetic testing (a blood test) for this syndrome may be part of the evaluation.

**Truncus Arteriosus Treatment**

Open-heart surgery is required to treat truncus arteriosus, usually before the baby is 2 months old. More than one operation may be required.

Cardiothoracic surgeons place a patch to close the hole (the ventricular septal defect). They separate the pulmonary arteries from the trunk and then connect the pulmonary arteries to the right bottom chamber (ventricle) of the heart using different kinds of conduits (tubes). They repair the trunk so that it becomes a complete, functioning aorta. Other repairs may be needed, based on each child’s unique needs.

**What is the follow-up care for truncus arteriosus?**

**Through Age 18**

A child who has had surgical repair of truncus arteriosus will require life-long care by a cardiologist.

Pediatric cardiologists follow patients with truncus arteriosus until they are young adults, coordinating care with the primary care provider. Patients will need to carefully follow providers’ advice, including staying on any medications prescribed and, in some cases, limiting certain types of exercise.

Sometimes children with truncus arteriosus experience heart problems later in life, including irregular heartbeat (arrhythmia), a restricted conduit or pulmonary artery, or a leaky aortic valve. Medicine, surgery, or cardiac catheterization may be required.

**Into Adulthood**

Your baby’s pediatric cardiologist will help patients who have had truncus arteriosus treatment transition to an adult cardiologist.

Because of enormous strides in medicine and technology, today most children with heart defects go on to lead productive lives as adults.

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Cardiac Defects: Ventricular Septal Defect

A ventricular septal defect (VSD) is an opening in the tissue (the septum) between the heart’s lower chambers (the ventricles). A VSD is one of the defects referred to as “a hole in the heart.”

When the VSD is large, the heart may have to pump harder to deliver enough oxygen to the body. Patients with a small VSD usually do not have any symptoms.

Sometimes children with a VSD also have other heart abnormalities.

What are the symptoms of a VSD?
If the hole is large, a child might exhibit symptoms including
• rapid heartbeat
• difficulty feeding
• heart murmur—the heart sounds abnormal when a doctor listens with a stethoscope.

How is a VSD diagnosed?
VSD might be diagnosed before birth with a fetal echocardiogram. In this case, your baby’s providers will prepare a plan for care after birth.

In some cases, a VSD might be diagnosed soon after birth if the newborn exhibits symptoms or a doctor notices a heart murmur. Sometimes a VSD isn’t diagnosed until the child is older.

Diagnosis of a ventricular septal defect may require some or all of these tests:
• echocardiogram (also called “echo” or ultrasound)—sound waves create an image of the heart
• electrocardiogram (ECG)—a record of the electrical activity of the heart
• chest X ray
• cardiac catheterization—a thin tube (catheter) is inserted into the heart through a large vein in the leg
• cardiac MRI—a three-dimensional image that shows the heart’s abnormalities.

It is important that a VSD be diagnosed and treated, as needed, or the heart and the arteries between the heart and lungs might be damaged.

What are the treatment options for a VSD?
Treatment will depend on your child’s health and on the size of the VSD. Doctors may wait to see if the VSD will close on its own. Many small VSDs will do so before the child is 2 years old.

If the VSD requires surgery, doctors might wait until your baby is older and stronger. During that time, your baby may have to take medicines as well as have higher calorie intake to help with the symptoms. If surgery is needed, surgeons will place a patch or stitches to close the hole during open-heart surgery.

What kind of follow-up care is required for a VSD?
Through Age 18
After VSD repair, many children recover quickly and don’t experience additional cardiac problems. They must see a pediatric cardiologist for check-ups, and some remain on medicine. Rarely, additional surgery is required.

If the child has other heart abnormalities, more follow-up care will be required.

Pediatric cardiologists follow patients until they are young adults, coordinating care with primary care providers.

Into Adulthood
It’s important that adults who were born with a VSD continue to see a cardiologist. Your baby’s pediatric cardiologist will help your baby transition to adult cardiologists.

Because of enormous strides in medicine and technology, today most children with heart conditions go on to lead healthy, productive lives.

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Intraventricular Hemorrhage and Periventricular Leukomalacia

_Intraventricular hemorrhage (IVH)_ is bleeding inside the lateral ventricles. Bleeding frequently occurs in areas of high arterial and capillary blood flow, which most commonly occurs in the subependymal germinal matrix of the brain in preterm infants. Bleeding occurs in the first 72 hours of life for about 90% of affected infants, with at least half of affected infants experiencing bleeding in the first 24 hours (Gardner, Carter, Enzman-Hines, & Hernandez, 2011). IVH is the most common type of intracranial hemorrhage present in infants.

Risk factors for IVH are prematurity and hypoxic events. Any event that results in hypoxia, alteration of cerebral blood flow, or intravascular pressure increases the risk of an infant developing IVH (Kenner & Wright Lott, 2007). IVH is also associated with perinatal asphyxia, low Apgar scores, low birth weight, respiratory distress requiring mechanical ventilation, rapid volume expansion, and pneumothorax. Depending on the degree of bleeding, infants with IVH may present with a range of symptoms. Some infants will not have a noticeable change in clinical condition; others will present with sudden deterioration or shock-like symptoms.

The extent of the bleed in the ventricles and brain will predict what future complications may occur. Bleeding may be confined to just the germinal matrix or may enter the ventricular system. When blood enters the ventricular system, it can cause the ventricles to dilate due to increased pressure.

There are different grades assigned to IVH based on their severity. These include:
- grade I (slight)—isolated germinal matrix hemorrhage
- grade II (small)—IVH with normal ventricular size
- grade III (moderate)—IVH with acute ventricular dilation
- grade IV (severe)—both intraventricular and brain parenchyma hemorrhage.

The diagnosis of IVH is determined via cranial ultrasound. For monitoring of an extensive bleed, serial ultrasounds may be used.

_Periventricular leukomalacia (PVL)_ refers to necrosis of white matter in the brain that occurs in a characteristic pattern. PVL is believed to be the long-term outcome of ischemia and injury to the fragile cerebral white matter in the premature infant. PVL can be caused by systemic hypotension, cerebral infarction and ischemia, and episodes of apnea and bradycardia.

Additional complications that may arise from PVL depend on the size of the initial lesion and how much time has passed since the injury first occurred. Clinically, at about 6–10 weeks of age, an infant with PVL will present with irritability, hypertonicity, frequent tremors, and may have an abnormal Moro reflex. Diagnosis is made via cranial ultrasound, computed tomography (CT) scan, or magnetic resonance imaging (MRI).

Neonates who are born at younger than 30 weeks should be screened with cranial ultrasound at 7–14 days of age. Many units will rescreen again at 36–40 weeks of age to determine if PVL is present. To help prevent IVH and PVL in the premature infant, care must be taken to avoid events that create swings in arterial and venous pressures. The immature neonatal brain does not have mature autoregulation of cerebral circulation in place to compensate for changes in blood pressure. Limiting handling, preventing changes in blood pressure or carbon dioxide levels, preventing breathing against the ventilator, and making sure blood coagulopathies are normal may help decrease the chances of developing IVH or PVL. These interventions will also help prevent extension of an initial hemorrhage. Treatment for IVH and PVL is supportive in nature.
Hemorrhage alone will not account for all neurological deficits in the neonate with IVH. Ironically, half of premature infants with IVH will be free of neurologic symptoms. Outcome will depend on the severity of the hemorrhage. For a small hemorrhage, neurodevelopment disability is similar to that in premature infants without hemorrhage. For a moderate hemorrhage, major neurodevelopmental disability occurs in 40% of infants; for severe hemorrhage, major neurodevelopmental disability occurs in 80% of infants.

The long-term outcome of an infant with PVL may include spastic diplegia, motor deficits, intellectual deficits, visual impairments, upper arm involvement, and lower limb weakness.

References

Bibliography
Intraventricular Hemorrhage and Periventricular Leukomalacia: Information for Parents

Your baby is very fragile, including the way that his or her brain is forming. Right now, your baby’s body is not able to control blood pressure changes in the same way that an older infant or adult body can. Sometimes, when your baby’s brain receives too much blood, it can cause the vessels that carry the blood to break. When these vessels burst, blood can build up inside your baby’s brain and can cause what is known as an intraventricular hemorrhage (IVH). The term intraventricular refers to the inside of the brain. The term hemorrhage refers to bleeding (see image below). Both terms together mean there is bleeding inside the brain.

There are different levels of bleeding in the brain with IVH. These levels are also called grades. Grade I means that there is a small bleed in the brain. Grade II means that there is a little more bleeding in the brain than Grade I, but it has not affected the inner part of the brain. Grade III means that there is bleeding that has also affected the inner parts of the brain. This includes the way that blood moves out of the brain. Grade IV means that there is more bleeding than in Grade III, and that there is so much bleeding that the brain is being pushed against the bones of the head (see image below).

Periventricular leukomalacia (PVL) is a different disorder than IVH; they do not mean the same thing. Periventricular refers to the brain; leukomalacia describes the way the baby’s brain looks. PVL means that sections of your baby’s brain have been hurt. These areas that have been hurt have died and left little holes in the brain tissue.

Your baby’s provider will tell you if your baby has any bleeding in his or her brain (IVH) or if your baby has PVL. To test for IVH or PVL, your baby will have a special procedure done called an ultrasound. An ultrasound is a painless test that uses a special wand with a jelly-like substance to take a video of your baby’s brain (see photo below). These videos can be broken down into pictures that a doctor will look at. Your baby’s provider will then let you know the results of the test. Expect that an ultrasound be done on your baby after about a week of being in the hospital. Not all babies will have an ultrasound done. This is only done if your baby was born before 32–34 weeks. The ultrasound may be done again when your baby is 36–40 weeks gestation (considered full term).

Your baby is at risk for bleeding in the brain because he or she was born early. Some other risks are if your baby had a low amount of oxygen during birth, had a low birth weight, or needs a machine to help with breathing.
If your baby is diagnosed with IVH or PVL, the outcome will be different depending on how much of your baby’s brain is affected. Talk to your baby’s provider to find out what the future effects will be for your baby. If your baby has a small bleed, there is a slight chance he or she will have future disabilities. If your baby has a severe bleed, there is a greater chance of having problems in the future. It is hard for your baby’s providers to predict what will happen in the future for your baby, but it is important that you ask questions about any concerns that you have.
Persistent Pulmonary Hypertension in the Neonate

Persistent pulmonary hypertension in the neonate (PPHN) is a serious respiratory disorder—potentially deadly—that primarily affects infants who are term or near term. PPHN is frequently associated with respiratory disease or failure from other causes such as meconium aspiration, sepsis, or congenital diaphragmatic hernia. Occasionally, PPHN occurs without any other conditions that we can identify.

During pregnancy, the infant’s mother and the placenta provide the infant with oxygen, and very little of the infant’s blood goes to the lungs. The blood vessels in the lung constrict (high pulmonary vascular pressure) to decrease blood flow to the lungs during this time. As a fetus, blood can bypass the lungs using the patent ductus arteriosis (PDA) and the foramen ovale. When an infant is born and takes his or her first breaths, the blood vessels in the lungs expand and allow blood to travel to the lungs to pick up oxygen and eliminate carbon dioxide. When these blood vessels fail to fully relax or fail to allow adequate blood to reach the lungs, it is called persistent pulmonary hypertension. The failure of these vessels to dilate may be related to underdevelopment of the vessels, hypertrophy of the muscle layer in the blood vessels, or abnormalities in the transition to extrauterine life. Because newborns still have the PDA and a foramen ovale, blood can bypass the lungs. This process is called shunting and can cause cyanosis. Oxygen is one of the molecules that helps vasodilate the newborn’s pulmonary blood vessels. When an infant develops hypoxia or cyanosis, it acts as a pulmonary vasoconstrictor and tends to worsen the pulmonary hypertension. This cycle can be difficult to break.

The incidence of PPHN may be increased if the mother took certain medications during the last months of pregnancy, including nonsteroidal anti-inflammatory agents and serotonin reuptake inhibitors.

The diagnosis of PPHN should be considered in any infant with severe cyanosis or high oxygen requirements. PPHN may be suspected due to an infant’s clinical picture, but diagnosis should be confirmed with echocardiography (showing increased right atrial pressures, increased right ventricular pressures, or tricuspid insufficiency).

Treatment of PPHN includes support of oxygenation and ventilation, fluids and medications to maintain good cardiac output, and sedation. Surfactant may be given to improve lung function. Infants may require inhaled nitric oxide, a clear, odorless gas that when inhaled acts as a pulmonary vasodilator. In extreme cases, the infant may require extracorporeal membrane oxygenation, which is a form of heart lung bypass to avoid lung injury and allow the PPHN to resolve.

Persistent pulmonary hypertension puts the infant at risk for low blood oxygen levels, increased requirements for support, and long-term neurodevelopmental impairment such as developmental delays, motor delays, and hearing loss.
Bibliography
Persistent Pulmonary Hypertension in the Neonate: Information for Parents

Persistent pulmonary hypertension in the neonate (PPHN) is high blood pressure in the lungs and is a serious respiratory disorder that primarily affects infants who are born full term or near term (usually 34 weeks or more). PPHN is frequently associated with other respiratory problems. During pregnancy, the baby’s mother and the placenta provide the baby with oxygen, and very little of the baby’s blood goes to the lungs. The blood vessels in the lungs are mostly closed, because the lungs are not being used. When an infant is born and takes his or her first breaths, these blood vessels expand and allow blood to go to the lungs to pick up oxygen. When these blood vessels do not fully relax or do not allow enough blood to reach the lungs, it is called PPHN. PPHN is very dangerous because it can limit how much oxygen the baby can deliver to his or her brain and organs.

The treatment of PPHN may include the use of oxygen, special ventilators that breathe for the baby at a very fast rate, a gas called nitric oxide, or even temporary heart lung bypass.

After treatment for pulmonary hypertension, your baby’s lungs will take weeks or even months to recover fully. It will be important to help protect your baby from catching colds or flu bugs. Good hand washing and keeping your baby away from sick people and large crowds will help. It will also be especially important for your baby to see his or her pediatric provider and other specialists regularly to be screened for normal developmental milestones.
Pneumothorax and Air Leaks

An air leak occurs when the infant’s lung sacs, or alveoli, become overinflated and rupture, allowing air to escape. This can occasionally occur with an infant’s first breath, but it happens most frequently in infants who have lung disease, such as respiratory distress syndrome or meconium aspiration syndrome. The incidence of air leaks also increase when the infant is receiving some form of positive pressure ventilation, such as continuous positive airway pressure, high-flow nasal cannula, or mechanical ventilation. The many different types of air leaks are identified by the location of the free air that escapes from the lungs (see table below). Pneumothorax occurs most frequently.

Air leaks are more likely to occur in the newborn period than at any other time of life. In the

<table>
<thead>
<tr>
<th>Air Leak Types</th>
<th>Location of Free Air</th>
<th>Clinical Signs and Symptoms</th>
<th>Possible Treatments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pneumothorax (most frequently occurring air leak)</td>
<td>Between the lung and the chest wall</td>
<td>If small, may be asymptomatic</td>
<td>None (if asymptomatic in the absence of positive pressure ventilation)</td>
</tr>
<tr>
<td>Tension pneumothorax (can be life-threatening if there is a large enough pocket of air collected to increase pressure in the chest and decrease cardiac output)</td>
<td>Between the lung and the chest wall</td>
<td>Respiratory distress, decreased oxygen saturation, decreased breath sounds on affected side, movement of heart sounds away from affected side</td>
<td>Increase oxygen high-frequency ventilation</td>
</tr>
<tr>
<td>Pneumomediastium</td>
<td>In the mediastinal space</td>
<td>Most are asymptomatic. A large pneumomediastium may cause respiratory distress and cyanosis, distant heart sounds</td>
<td>Needle aspiration for emergent evacuation, often followed by the placement of a chest tube</td>
</tr>
<tr>
<td>Pulmonary interstitial emphysema</td>
<td>Air is trapped in the tissues that surround the air sacs and blood vessels in the lungs</td>
<td>Increasing oxygen and ventilation needs (may occur before and with other air leaks)</td>
<td>Supportive treatment, minimizing pressure to the lung (some use high-frequency ventilation)</td>
</tr>
<tr>
<td>Pneumopericardium</td>
<td>Area around the heart and inside the pericardial sac</td>
<td>Rapid development of tachycardia, hypotension, and narrowed pulse pressure. Heart sounds are distant.</td>
<td>Emergent needle aspiration, may require indwelling pericardial tube</td>
</tr>
<tr>
<td>Pneumoperitoneum (rare)</td>
<td>Peritoneal space</td>
<td>Abdominal distension</td>
<td>May require aspiration</td>
</tr>
<tr>
<td>Subcutaneous emphysema (rare)</td>
<td>Subcutaneous tissue</td>
<td>Crepitus (crackles) on palpation, usually in face, neck, or upper chest</td>
<td>Supportive treatment</td>
</tr>
</tbody>
</table>
extremely-low-birth-weight infant, air leaks are associated with an increased risk of intraventricular hemorrhage. Transillumination with a high-intensity light source may demonstrate a halo or glow in the area of free air and give an initial clue to the diagnosis and location of the free air. A definitive diagnosis of all types of air leaks is made by X ray.

Bibliography
A newborn’s lungs are very fragile. Occasionally, some of the air sacs in the lungs will burst, allowing air to escape outside of the normal airways. This “free air” can collect outside of the normal airways and make it difficult for the lungs to properly inflate and for the infant to breathe. Air outside of the normal airways is called an *air leak*, and air leaks are named by where the free air is located. The most frequent air leak, called a *pneumothorax*, is when the air collects between the lung and the chest wall. Air can also become trapped in the mid chest, in the tissue of the lung, around the heart, and in other spaces.

Rarely, an air leak can occur with baby’s first big breath, but these are usually small and sometimes resolve without help.

Air leaks can range from minor to life threatening. Ask your medical team to discuss the severity of your baby’s air leak. Babies with large, sudden air leaks are at risk for low oxygen and changes in blood pressure. In very premature babies, these sudden changes may put them at risk for bleeding in the brain. Babies who develop air leaks due to severe lung illness may be at risk for long-term breathing problems.
Chest Tubes

A chest tube may be placed to aid in the drainage of air, in the case of a pneumothorax, or to drain fluid, such as with a pleural effusion, hemothorax, or chylothorax. A chest tube is placed between the lung and the chest wall (see figure below). The chest tube will be placed anterior (above the lung) for removal of air or posterior (below the lung) for the removal of fluid.

Immediately after the chest tube is placed, it should be connected to a collection device that prevents air or fluid from being pulled back into the chest. This can be accomplished temporarily with a Heimlich device, or a chest tube drainage system can be used (see figure below). A chest tube drainage system will have a water seal to prevent air from entering the chest, a chamber to collect any drainage, and a method for applying suction. This device must be positioned below the infant and remain upright at all times.

There are many different types and brands of chest tubes. The type of chest tube will depend on the type of drainage needed. Chest tubes may be placed using a needle introducer or by making a small incision in the chest wall. All chest tubes have potential complications, including pain, infections, hemorrhage, lung trauma or perforation, scarring, damage to breast tissue, nerve damage, and injury to the diaphragm. A chest X ray should be obtained after chest tube placement to ensure that the chest tube is appropriately positioned and achieving the desired drainage. The infant may require special positioning to help this tube drain properly. Generally, infants must remain on their back or tipped slightly to one side; infants should not be placed on their abdomen with a chest tube in place.

An infant receiving a chest tube will be given medication to control pain and should have routine monitoring for pain and the adequacy of pain medication.

Bibliography
Chest Tubes: Information for Parents

Your baby has developed a collection of air or fluid in his or her chest that will require a chest tube to allow for drainage. This is a sterile procedure, and you may be asked to step away from the bedside so that a germ-free area can be maintained. Your baby will be given medication to control any pain during this procedure and will be monitored at all times. A tube will be placed between the lung and the chest wall. The chest tube may be introduced using a needle or by making a very small incision in the chest (see figure below).

After the chest tube is in place, an X ray will be taken to make sure that the tube is in the right place and working well. A bandage will be placed over the chest tube site to protect it and keep the tube securely in place. A drainage system will be attached to the chest tube to allow the medical team to monitor drainage and function of the tube. The attached tubing will be secured to the bed so that no pressure is placed on the tube. Please do not try to pick up or move your baby without assistance to stabilize this chest tube. Your baby will benefit from your touch, comfort, and presence at the bedside while this tube is in place.

Some problems associated with chest tube placement are bleeding and infection. Occasionally, the tube will need to be replaced due to plugging by fluid or blood. Other problems, including injury to the lung, breast tissue, and other structures in the chest, are very rare.

The length of time the chest tube will be in place is determined by how long it is needed for drainage. Once drainage appears to be decreasing, the medical team will make a plan for when they can safely remove this tube.

While the tube is in place, your baby will be given pain medication as needed to ensure that he or she is comfortable. Your baby might need to be positioned in a certain way to assist with proper drainage. Most babies heal quickly after the tube is removed, but they may have a small scar where it was placed.
Gastroesophageal Reflux (GER) is the involuntary passage of gastric contents into the esophagus. Physiologic GER occurs on a regular basis in both healthy infants and adults and is characterized by passive spitting up without other associated complications. It usually resolves by 12 months of age. Less frequently, pathologic GER occurs when regurgitation of gastric contents is accompanied by other symptoms or complications and may be particularly problematic for the NICU population. Severity may be related to the pH and volume of fluid that is refluxed into the esophagus, larynx, or mouth. Symptomatic GER may be referred to as gastroesophageal reflux disease (GERD) and is characterized by forceful vomiting (rather than the more passive spitting up of GER) and often poor weight gain or weight loss, irritability, and dysphagia. Other complications include esophagitis, neurobehavioral changes, hematemesis, growth failure, and respiratory problems such as apnea (controversial).

Diagnosis is based on patient history and physical exam, with full exploration of the differential diagnosis to rule out other disorders that may present with vomiting. A thorough feeding history, growth patterns, and relevant medical and familial history are requisite to the diagnosis of GERD. Diagnostic tests such as upper gastrointestinal series, gastric emptying study, video swallow study, esophagogastroduodenoscopy with biopsy, and esophageal pH probe monitoring may be considered to aid with diagnosis, although each has its own limitations.

Management of GERD aims to prevent and alleviate symptoms while promoting normal growth and the resolution of inflammation in the esophagus. A stepwise approach starting with the least invasive and inexpensive therapies is recommended, because reflux may improve with maturity without unnecessary and unproven therapies. Nonpharmacologic treatment may include

- left lateral positioning after feedings (right side down)
- slowing bolus feeding times or changing to continuous feedings
- removing the naso- or oral gastric tube in between feedings
- smaller, more frequent feedings (which may require higher calorie formulas to meet nutritional needs)
- placement of nasojejunal tube for continuous feedings if there are airway concerns
- thickening feeds (Please note that, although common, this treatment is controversial. Use of Simply Thick® in the NICU population is against the recommendations of the U.S. Food and Drug Administration.).

Pharmacologic management is only used in an infant who continues to have pathologic GERD despite nonpharmacologic intervention. Benefits versus adverse effects of the medications should be carefully considered. One goal is acid suppression or neutralization, which may be achieved by using histamine antagonists (ranitidine, famotidine) or proton-pump inhibitors (omeprazole, lansoprazole). Prokinetic agents (metoclopramide, erythromycin) may be used to improve motility of the esophagus and stomach. Surgical intervention is considered only when medical management fails, leading to failure to thrive, reflux-induced aspiration and pneumonia, esophagitis, Barrett’s esophagus, and acute life-threatening events. A Nissen fundoplication is the most common surgical procedure performed to treat GERD.

**Bibliography**


Gastroesophageal Reflux: Information for Parents

You may have been told that your baby has reflux, which is short for *gastroesophageal reflux* (GER). Reflux happens when food from the stomach moves back into the esophagus or mouth. This can happen in healthy babies and adults. A baby with “normal” reflux may spit up often but does not have any other problems. This usually goes away before your baby is 1 year of age.

A more serious form of reflux, called *gastroesophageal reflux disease* (GERD), can cause problems, especially for babies in the neonatal intensive care unit. This kind of reflux is defined by stronger vomiting and other symptoms. Your baby may have trouble gaining weight or may lose weight. He or she may cry a lot or act like he or she has trouble swallowing. Your baby may have blood-tinged vomit and problems with breathing and may need some tests to be sure that there was nothing else causing the vomiting. To help your baby with reflux, your baby’s provider may try positioning your baby a certain way after feedings, giving smaller feedings more often, or increasing the time of a feeding. If these things do not work, medicine may be used. Ask your baby’s provider if you have any questions about what you can do to help your baby have less reflux.

Surgery is only considered when medicine does not help. Surgery will be discussed if your baby cannot gain enough weight or if the vomiting causes a lot of problems with breathing (sometimes this is due to aspiration).

When you take your baby to see your pediatric provider after you have gone home, let him or her know how much and how often your baby is spitting up or vomiting. If your baby is going home on medication, please make sure to give the right amount at the right times. It is important not to change your baby’s diet or medicines without talking to your pediatric provider. Talk about how well you think the feedings are going so that the medicines can be changed or stopped as needed.
Apnea of Prematurity

Apnea of prematurity (AOP) is the most common and recurring problem of respiratory control in the premature infant. AOP occurs in more than 85% of all infants born prior to 34 weeks gestational age. The incidence of AOP is inversely proportionate to gestational age at birth—as gestational age decreases, apnea becomes more prevalent.

In premature infants without respiratory distress syndrome (RDS), AOP may occur on the first day of life, but it may not present for several days in infants with RDS. Many perinatal and postnatal complications increase the infant’s risk of developing AOP, including central nervous system insult or injury, respiratory insult or injury, metabolic disease, sepsis, congenital defects, inborn errors of metabolism, birth trauma, and maternal substance use (including smoking and alcohol consumption). Some evidence supports heredity as a risk factor.

**Definition**
AOP is most commonly defined as the cessation of breathing for more than 20 seconds, or 5–10 seconds in the presence of bradycardia (heart rate < 80 bpm or 30 bpm below baseline) or desaturations (SaO₂ < 80%–85%). Brief respiratory pauses that are less than 10 seconds in duration and not associated with bradycardia or desaturations can occur in conjunction with startles, movement, defecation, or with asynchrony during feedings and are usually self-limiting.

In the premature infant, apnea may be the presenting symptom accompanying altered homeostasis of nearly all organ systems. Temperature instability, asphyxia or hypoxemic events, sepsis, metabolic disturbances, respiratory compromise, patent ductus arteriosus or other heart defects, intracranial hemorrhage, feeding disruptions, hematologic disturbances, pain, and agitation are some examples. AOP is considered a diagnosis of exclusion because it is often the presenting symptom of other pathologic conditions and should be thoroughly investigated before being assigned this diagnosis.

**Classification**
AOP is distinguished by duration and hemodynamic dysfunction and is further classified into three categories based on the presence or absence of obstruction. **Central apnea** involves total cessation of respirations or the absence of respiratory muscle activity accompanied by the absence of air flow. **Obstructive apnea** is characterized by the presence of respiratory muscle activity in the absence of air flow that continues throughout the entire apnea episode. **Mixed apnea** consists of a combination of obstructed apnea and central apnea and is believed to represent the most common type of apnea in the newborn. Obstructive apnea may occur in the pharynx, the larynx, or in both areas of the upper airway. **Idiopathic apnea** is most commonly associated with prematurity.

Hypoxemic events resembling apnea have been detected in intubated, mechanically ventilated preterm infants. These episodes of hypoxemia are preceded by increased pulmonary resistance and decreased compliance similar to events occurring before apnea in unintubated infants. Subtle, spontaneous movements precede these episodes, and they are characterized by central respiratory depression and obstructed airflow. The events are a consequence of hypoventilation and are frequently associated with arousal.

**Periodic Breathing**
AOP should be distinguished from periodic breathing, in which the infant exhibits regular short cycles (10–20 seconds in length) of respiration that are interrupted by respiratory pauses of at least 3 seconds. The pattern recurs for at least 2 minutes followed by a stronger respiratory drive to restore normal ventilation and often is accompanied by mild hypoxemia. Periodic breathing is considered a benign developmental phenomenon, and medical treatment is not indicated. However, when preceded by significant hypoxemia or when associated with bradycardia or prolonged apnea with alveolar hypoventilation, it is abnormal and may be a precursor to pathologic apnea.
AOP and periodic breathing are disorders that tend to decline in frequency with advancing postconceptual age and are treated with administration of methylxanthines.

**Pathophysiology**

AOP is a common disorder of respiratory control in premature infants. Apnea presenting independent of other pathology is most likely a maturational feature representing a physiologic rather than pathologic immaturity of respiratory control. However, a clear mechanism responsible for apnea in premature infants has not been identified.

Normal rhythmic breathing requirements include a patent airway; a central respiratory drive originating from respiratory centers in the brainstem (modulated by input from peripheral neural and chemical receptors); and coordinated, effective functioning muscles of respiration. Changes in arterial PCO₂, PO₂, and pH act on neural and chemical receptors from these centers and are integrated by the respiratory center in the brainstem, which sends signals to the respiratory muscles responsible for maintaining airway patency and regulating the level of ventilation. The immature brainstem respiratory centers in preterm infants have an attenuated response to carbon dioxide and a paradoxical response to hypoxia, which results in apnea rather than the normal hyperventilation response. Anatomical characteristics such as decreased number of synaptic connections, decreased dendritic arborization, and poor myelination result in functional immaturity of the brainstem, which improves after treatment with methylxanthines.

Obstructive apnea can be the result of poor pharyngeal tone, which can cause the pharynx to collapse with negative airway pressures generated during inspiration. Structurally, the airways are more compliant and smaller, both in diameter and length, and are at increased risk for blockage by malpositioning, edema, and excess mucus.

Genetic factors associated with a higher risk of occurrence in premature infants include being born to first-degree consanguineous parents, being monozygotic twins, and having a sibling who presents with complications of apnea. Significant ventilatory and cardiovascular consequences are associated with AOP. Prolonged apnea results in hypoxemia and hypercarbia, which is directly related to the frequency, duration, and intensity of the episode.

**Apnea and Gastroesophageal Reflux**

Gastroesophageal reflux (GER) is a common problem in premature infants and is often suggested as a component of apnea of prematurity. Reflux of gastric contents into the larynx may induce apnea as a result of stimulation of the laryngeal nerve or other afferent pathways; however, this mechanism is not proven to either cause or prolong apnea. The frequency with which the two conditions coexist is debated, and the cause-effect relationship is multifactorial. The majority of apnea occurring before GER is central in origin, but when apnea occurs during or after a GER episode, it is more frequently mixed apnea. In some instances, apnea occurs prior to reflux, decreasing lower esophageal tone and lower esophageal sphincter pressure resulting in reflux. In the overall premature infant population, GER does not induce apnea, prolong the duration of apnea, or exacerbate apnea-related bradycardia or desaturations. Further, there is no clear evidence that pharmacologic agents that decrease gastric acidity or enhance gastrointestinal motility impact the frequency or duration of apnea.

**Management**

Management begins by eliminating factors associated with increasing risk of apnea, by taking measures such as a stable thermal environment, maintaining airway patency, and proper positioning. Ensuring proper placement of nasal- and oral gastric tubes is important, as misplacement of these tubes has been implicated in association with apnea. Cue-feeding, pacing with feedings, and chin support are good measures for parents to facilitate better feeding patterns, which may reduce the incidence of choking and apnea. Prone positioning of the preterm infant assists to “splint” the chest wall and facilitate slight neck extension positioning and stabilization of the head; this positioning has been shown to improve breathing. Prone positioning in the preterm infant is also associated with improved gastric emptying time. Prone positioning is indicated only with the use of cardiorespiratory...
Admitting continuous airway pressure is associated with decreased apnea. Evidence suggests it may serve as a “splint” for upper airways and the chest wall, increase oxygenation, and help maintain functional residual capacity. Many times, the flow is enough to support the infant with apnea, but sometimes administration of oxygen along with flow is necessary. Continuous positive airway pressure reduces the frequency of only mixed and obstructive apnea, with little or no effect on central apnea in infants. Infants unresponsive to these therapies or methylxanthines will require intubation and ventilatory support.

Methylxanthines are the mainstay of treatment for apnea. These agents have multiple pharmacologic and physiologic mechanisms of action, including increased minute ventilation, improved CO₂ sensitivity, decreased hypoxic depression, enhanced diaphragmatic activity, and decreased periodic breathing episodes. Treatment is usually initiated with a loading dose followed by maintenance therapy in either oral or intravenous preparation. Common side effects include tachycardia, feeding intolerance, emesis, jitteriness, restlessness, and irritability. Toxic levels may produce cardiac dysrhythmias and seizures. Methylxanthines increase metabolic rate and oxygen consumption, have a mild diuretic effect, increase cerebral metabolic rate, and decrease cerebral blood flow.

Theophylline, aminophylline, and caffeine citrate have demonstrated effectiveness in the treatment of apnea of prematurity. Caffeine citrate is considered preferable, because it is better tolerated and has fewer side effects, a larger margin of safety, a higher therapeutic index, and a longer half-life. The long half-life allows once-per-day dosing, and the larger margin of safety means monitoring levels at the recommended dosing is seldom necessary. Caffeine has been shown to reduce the rate of bronchopulmonary dysplasia and may have neuroprotective benefits as well.

Doxapram, another respiratory stimulant, has been used in infants with idiopathic apnea of prematurity refractory to methylxanthines. It acts through stimulation of a peripheral chemoreceptor and has shown to increase minute ventilation, tidal volume, inspiratory flow, and airway pressure. Side effects include hypertension, irritability, hypoglycemia, gastric irritability, and in a small number of preterm infants, heart block. Doxapram is available as an oral drug, but it is poorly absorbed. Because of this, it is typically used as a continuous IV infusion. Benzyl alcohol is the preservative used in doxapram, although the concentration is considered low (0.9%/mL) and at recommended dosing, toxicity in the neonate is unlikely. Toxicity is associated with a potentially fatal side effect known as the gasping syndrome in neonates. Due to the benzyl alcohol preservative and its potential side effects, use of doxapram is limited in the United States.

Anemia can lead to apnea of prematurity, desaturations, and bradycardia. The symptoms of anemia appear to be worse in more premature infants, and in infants with underlying disease processes. Red blood cell transfusion is a proposed mechanism to increase oxygen carrying capacity; however, blood transfusions are also associated with worsening bronchopulmonary dysplasia and necrotizing enterocolitis. Red blood cell transfusions should be reserved for infants with significant clinical signs and symptoms of anemia.

AOP often resolves and then resurges in response to other pathology. Retinopathy of prematurity exams, immunizations, and surgery are associated with recurrence of apnea.

Resolution
Apnea of prematurity resolves by around 36–40 weeks gestational age. However, in more premature infants it may last beyond 43–44 weeks gestational age and is a problem that frequently delays discharge.

Consequences
In premature infants, desaturations and bradycardia frequently occur along with apnea. Bradycardia most often occurs after the onset of hypoxemia and may be
accompanied by increased stroke volume. Prolonged apnea, bradycardia, and desaturations lead to decreased systemic blood pressure and cerebral hypoperfusion, which can contribute to hypoxic-ischemic injury of the immature brain. Untreated significant apnea often progresses and can lead to complications of the respiratory system, cardiac system, gastrointestinal system, central nervous system, and renal system.

Identifying the long-term consequences of apnea is difficult because of the numerous secondary causes of apnea. Neurodevelopmental outcome is less favorable in infants when apnea persists, when mechanical ventilation is required for longer periods of time, and when frequent apnea persists after discharge. Former premature infants with apnea of prematurity may be at a higher risk to develop sleep-disordered breathing later in life.

Consistent and reliable evidence continues to support no relationship between persistent AOP and an increased risk of sudden infant death syndrome (SIDS). The use of home monitoring for prevention of SIDS in infants with AOP is not indicated by the American Academy of Pediatrics. However, when apnea persists, the use of home monitoring may be an alternative to delayed hospital discharge. Because the monitors are subject to false alarms and “missing” some apnea and bradycardia, this practice remains controversial.

**Bibliography**


Apnea of Prematurity: Information for Parents

Apnea of prematurity is when your baby’s breathing pauses. It is a very common for this to happen in premature babies. The more premature the baby is, the more common apnea is. The pauses in breathing may happen alone, but more commonly they happen with drops in heart rate (bradycardia) or oxygen saturations (desaturations).

Apnea can happen just because the baby is premature, or it can be a symptom of some other illness or problem. When the apnea happens alone and only once in a while, we will watch your baby very closely. When the apnea happens with bradycardia or desaturations, we will run blood tests and possibly do other tests such as X rays, head ultrasounds, and heart sonograms (known as echocardiogram or a cardiac echo) to make sure nothing else is causing the apnea.

Many times, premature babies need medications to help their bodies remember to breathe, and sometimes they need more help from a nasal cannula, continuous positive airway pressure, or a breathing machine. Apnea is often the first symptom we see when a baby has an infection, so we may start antibiotics even before we get test results back.

We often place premature babies on their tummies, which helps support the chest (so they breathe easier) and helps with digesting feedings. We can safely do this in the neonatal intensive care unit, because your baby is on monitors that will sound an alarm if the baby stops breathing or has a drop in heart rate or oxygen saturations. As your baby grows and the apnea (and other conditions) improve, we will start placing your baby on his or her back, because this is the safest way for your baby to sleep and rest as he or she gets closer to going home.

Apnea usually improves as your baby gets older, but it takes longer for it to improve in more premature babies. Sometimes even after the apnea seems to have stopped, it starts again. This can happen because the baby is still immature or because of necessary tests like an eye examination. Apnea may start again (briefly) after we give immunizations. The apnea that happens after immunizations is usually very mild. It is important that your baby has eye examinations and receives immunizations to protect him or her from serious problems later on.

Sometimes apnea continues as your baby is getting closer to going home. It is important to continue watching and caring for your baby in the hospital until it is safe for your baby to go home. Babies are sometimes sent home on the medications that help them remember to breathe.

Apnea of prematurity does not mean your baby is more at risk for sudden infant death syndrome (SIDS). Things that increase the baby’s risk for SIDS are cigarette smoke; sleeping on their tummies; a lot of soft fluffy bedding (e.g., blankets, pillows, stuffed animals); keeping the room too warm; and sleeping with others.

It is important that you keep all of your follow-up appointments and that your baby receives immunizations at the scheduled times.
Retinopathy of Prematurity

Retinopathy of prematurity (ROP) is a potentially blinding eye disorder that primarily affects premature infants, with risk and incidence increasing as gestational age and birth weight decrease. Infants at highest risk are those born before 31 weeks gestation and weighing less than 1,250 g, those who experience intrauterine growth restriction, males, and those who experience prolonged exposure to supplemental oxygen.

Several complex factors impact the development of ROP. The eye starts to develop at about 16 weeks of pregnancy, when the blood vessels of the retina begin to form the macula at the optic nerve in the back of the eye. The blood vessels grow gradually toward the edges of the developing retina, supplying oxygen and nutrients. During the last 12 weeks of a pregnancy, the eye develops rapidly. At term gestation, the retinal vessel growth is near complete (The retina is usually fully vascularized within a few months after birth.). When an infant is born prematurely, the normal pattern of vascularization is disrupted and may be halted. The peripheral edges of the retina are at risk for oxygen deprivation.

For premature infants, titrating oxygen saturations within acceptable targets can be challenging at best. There have been differing opinions as to maintaining saturations lower (85%–89%) or higher (91%–95%). In the SUPPORT trial, the rates of severe retinopathy or death did not differ significantly between the groups. Death before discharge was higher in the lower-oxygen-saturation group even though this lower saturation group had a lower occurrence of severe retinopathy.

ROP is the result of abnormal blood vessel growth throughout the retina. As these abnormal blood vessels grow, they become fragile and can leak, scarring the retina and pulling it away from its position on the back of the orbit, causing retinal detachment. Retinal detachment is the main cause of visual impairment and blindness in ROP. Infants with ROP are considered to be at a higher risk for developing certain eye problems later in life, such
as retinal detachment, myopia (nearsightedness), strabismus (crossed eyes), amblyopia (lazy eye), and glaucoma.

ROP disease is diagnosed based on the zone of the eye where it is identified and assigned a stage based on severity of the disease (see figure at top right on previous page).

**Treatment**

The most common and effective treatments for ROP are laser therapy or cryotherapy. Laser therapy burns away the periphery of the retina, which has no normal blood vessels. With cryotherapy, the surface of the eye that overlie the periphery of the retina is “frozen” to stop the abnormal growth of blood vessels. Both laser treatment and cryotherapy destroy the peripheral areas of the retina, slowing or reversing the abnormal growth of blood vessels. The side effect of these therapies is that the peripheral vision is lost in an effort to preserve the most important part of vision near the macula. Both therapies are performed on infants with advanced ROP, usually Stage III with “plus disease.” An experimental, off-label treatment using Avastin (bevacizumab) has also shown promise. Avastin is an angiogenesis inhibitor, slowing the growth of new blood vessels. First used in cancer patients, this antivascular endothelial growth factor drug is injected into the posterior chamber of the eye into the vitreous. In the BEAT-ROP clinical trial, Avastin was found to be superior to laser treatment in Zone 1, Stage III plus disease, but not in Zone 2. The role of anti-VEGF medications is still unclear but initial research is promising.

**Bibliography**


Retinopathy of Prematurity: Information for Parents

*Retinopathy of prematurity* (ROP) is an eye disease found in some premature babies. When a baby is born early, the blood vessels in the retina (the inner lining of the back of the eye) may not be fully developed. After birth, the blood vessels begin to grow abnormally. This is called ROP. Researchers do not know all the reasons why ROP happens, but premature birth and exposure to high amounts of oxygen are two risk factors. Many times, this a balancing act, because sick babies may die without oxygen. It is very difficult to tightly control oxygen levels in sick babies.

Although most babies with ROP will heal over time, in some babies, the blood vessels continue to grow abnormally. This can cause the retina to separate from the back of the eye. Severe ROP can lead to loss of vision and even blindness.

ROP can be treated with a laser or medicine injected into the eye. Both treatments can slow down or even reverse the abnormal growth of the blood vessels in the eye.

While in the hospital, an eye doctor will check your baby’s eyes on a regular basis until the retina is fully developed. When your baby goes home, you will have an appointment with an outside eye doctor for your baby. Please be sure you know the time and location of this appointment.

Because ROP is a serious disease that can get worse very quickly, you should not change or reschedule this appointment unless it is absolutely necessary. Waiting too long for ROP check-ups and treatment can lead to blindness for your baby. An eye doctor (called an ophthalmologist) must do the exam, because ROP can only be seen using special equipment. Your baby’s eyes may look normal to you even when there is severe ROP.
The two most common congenital abdominal wall defects are gastroschisis and omphalocele. They are similar in some ways and distinctly different in others. Both involve incomplete closure of the abdominal wall during fetal development, and for both, their cause is unknown. A gastroschisis is usually an isolated congenital defect, whereas a baby with an omphalocele often has chromosome anomalies and other major birth defects as well. A *gastroschisis* is a herniation of abdominal contents through a defect in the abdominal wall, usually just to the right of the umbilicus. An *omphalocele* is a herniation of abdominal contents into the umbilical cord itself. The contents of a gastroschisis are directly exposed to amniotic fluid, whereas the contents of an omphalocele are usually covered with a protective membranous sac.

At delivery, the ABC (airway, breathing, circulation) rules should be followed for babies with gastroschisis or omphalocele. Immediately afterward, protection of the herniated contents and management of evaporative loss should be accomplished. Abdominal contents should be wrapped in warm, saline-soaked gauze and covered with plastic wrap. Alternatively, the babies should be placed in a sterile bowel bag up to their nipple line. Preventing evaporative fluid loss is particularly important for the baby with gastroschisis because of the lack of the protective membranous covering in babies with that defect. Diligent observation of the color and perfusion of the abdominal contents of a baby with gastroschisis is imperative. This baby should be placed on his or her right side with abdominal contents supported with additional gauze or blankets to prevent kinking of the mesentery blood vessels. Babies will need IV fluids started; the baby with a gastroschisis will need a higher than normal intravenous fluid rate to prevent dehydration. Both will need placement of a replogle tube to intermittent wall suction to prevent gastrointestinal distention. Both will need to have broad spectrum antibiotics started.

These babies will require surgical intervention after birth, but the timing of surgery in each case may differ. If the defects for both are small, surgery may be done shortly after birth with a primary closure. Closure for a gastroschisis must be done on a more urgent basis than that of an omphalocele to prevent continued damage to the exposed abdominal contents. If the defects are large, the size of the abdominal cavity may not be spacious enough to safely replace all of the herniated contents. If the contents are replaced under pressure this could compromise respiratory function and vascular perfusion and result in the loss of bowel tissue. If this is the case, with a large gastroschisis, a silo will be placed surrounding the contents so they can be gradually reduced into the abdomen over a period of days to weeks. The contents of an omphalocele may also be reduced in this manner.
Multiple alternative staged methods of closing omphaloceles have also been described. Some use the baby’s own tissue; others use grafts from other sources. A nonsurgical way of initially closing a particularly large omphalocele, a so-called giant omphalocele in which multiple organs have herniated, has been to harden the membranous sac covering the contents with various topical chemicals. This method provides long-term protection, allowing skin to eventually grow over the sac. Once skin has covered the sac, closure is then surgically performed.

Outcome for the baby with a gastroschisis depends on how much viable intestine is available, whether or not there were associated atresias, and how long it takes for gastrointestinal function to take place. Outcome for the baby with an omphalocele largely depends on the extent of complications with the other associated congenital defects. For both babies, it can be a long road to achieve full feeds; gastroschisis babies usually take longer to accomplish this. It is common for both to have many episodes of feeding intolerance. Both are also subject to short- and long-term dependence on parenteral nutrition with all their associated potential problems of infection, poor growth, and liver failure. Parents of these babies need substantial encouragement and support.

It may take a long time for babies with gastroschisis and omphaloceles to be able to eat normally and have normal intestinal function, especially those with gastroschisis. In many cases, it is “two steps forward and one step back” for feedings. There can also be complications with the IV and special IV fluids these babies need to grow until they are able to digest their food well. However, almost all of these babies are eventually able to eat on their own.

Bibliography
Gastrochisis and Omphalocele: Information for Parents

Gastrochisis and omphalocele are the two most common abdominal wall birth defects. We don’t know what causes them. They are not due to anything a mother did or didn’t do during pregnancy.

Babies with gastrochisis and omphaloceles are the same in some ways and different in other ways. Both are types of hernias where the parts of the body that should be inside the abdomen are on the outside instead. With a gastrochisis, the hernia is through a hole in the muscle wall of the abdomen. With an omphalocele, the hernia is through the area of the belly button.

When babies are born with these hernias, they will have several extra things done in the delivery room. The parts that are on the outside will be carefully protected. The abdomen may be covered with warm, wet sterile gauze and plastic wrap or the baby’s whole body may be put in a big clear plastic bag up to the chest. This is done to keep the babies from losing fluid from the parts that shouldn’t be exposed to the air. These babies will also have a tube hooked up to a suction machine and put through their mouth or nose to their stomachs. This will keep air from getting in and swelling their intestines. An intravenous (IV) line and IV fluids will be started. Antibiotics will be started, too. Surgery will be needed to put the herniated parts back into the abdomen. If there is enough space in the abdomen, it may be possible to do this in one step. But sometimes the space is not big enough; in that case, it may take a few days to weeks to put everything back in comfortably.

It can take a long time for babies with gastrochisis or omphaloceles to be able to be held and eat normally and have normal intestinal function, especially babies with gastrochisis. Once the baby recovers from surgery and the abdomen is closed, they can be held. Starting feedings is a slow process. Your baby may have an IV for a long time until he or she can digest food well. However, almost all of these babies are eventually able to eat on their own.
Malrotation and Volvulus

Due to the risk for loss of bowel, any infant with bilious emesis must be evaluated for malrotation and volvulus. Malrotation is in itself harmless, and an infant can have malrotation without a volvulus. However, because having malrotation places the infant at an increased risk for a midgut volvulus, surgical correction will be needed at some point.

Embryology

Normal Intestinal Rotation

The duodenum makes a C-loop to the infant’s left, and the third portion of the duodenum—at the ligament of Treitz—is to the left of the spine. The superior mesenteric artery (SMA) then runs in front of the third portion of the duodenum, and the mesentery attaches posteriorly from the left upper quadrant by the ligament of Treitz to the right lower quadrant by the cecum. This prevents the mesentery from twisting on itself. In the fourth week of gestation, the intestinal tract rapidly elongates, leaves the abdominal cavity, and undergoes rotational changes. The duodenum and colon both have to rotate 270 degrees counterclockwise, and the midgut needs to return to the abdominal cavity by the 12th week of gestation. If these events do not occur, malrotation or an incomplete rotation will result.

Abnormal Intestinal Rotation

When normal intestinal rotation fails to happen, the third portion of the duodenum lies to the right of the spine and the SMA never crosses it. There is a narrow mesenteric base that then connects the duodenojejunal junction with the cecum. The bands between the duodenum and cecum place the mesentery at risk for complete volvulus, because it cuts off the vascular supply to the SMA. This results in ischemic necrosis of the entire midgut from the duodenum to the proximal transverse colon.

Diagnosis

An upper gastrointestinal (GI) series is the gold standard for the diagnosis of malrotation and volvulus. Upon evaluation, contrast will leave the stomach and enter the duodenum. The duodenum will be to the right of the spine, the small intestine will be on the right side of the abdomen, and the colon will be on the left side of the abdomen. In an infant with a volvulus you will see a “corkscrew” or “beaking” appearance of the duodenum and proximal jejunum.
Diagnoses

220 Baby Steps to Home

Malrotation with Volvulus

“Corkscrew” appearance of duodenum to right of the spine

Other diagnostic tools that can be used are plain abdominal X rays and ultrasound. With abdominal X ray, when Ladd’s bands are present a “double bubble” may be seen, or if a midgut volvulus is present, radiographic signs and symptoms similar to necrotizing enterocolitis may be visualized. Ultrasound has been used to visualize a swirl or whirlpool pattern on Doppler of the SMA, as well as free peritoneal fluid, portal venous gas, pneumatosis, and intestinal wall edema.

Treatment
Infants with suspected malrotation or volvulus will be given nothing by mouth (NPO) and have a replogle tube placed to low intermittent wall suction. A peripheral intravenous (PIV) line will be placed and intravenous fluids will be started. Laboratory studies will be collected, especially a Type and Screen so the patient can go to the operating room, followed by complete blood count with differential and electrolytes. Additional fluids will be given to correct any fluid deficits. Prophylactic antibiotics will also be administered.

As initially stated, an infant presenting with bilious emesis must have a volvulus ruled out. If the patient is stable, an upper GI series should be performed immediately. If a volvulus is revealed, the patient is either immediately taken to the operating room for emergency surgery or bedside surgery is performed. As a bedside nurse, expect hypovolemia due to vomiting and third spacing of fluid.

Once in the operating room, the volvulus is addressed first by untwisting the intestine in a counterclockwise fashion that allows blood flow to be restored to the intestines. One must then assess the viability of the intestine. Only intestine that is necrotic should be resected; over resection will lead to short bowel syndrome. If necessary, the surgeon will re-explore the abdomen at 24–48 hours to check the viability of the remaining intestine. Depending on the remaining bowel, an ostomy may need to be created.

After the volvulus has been corrected, the malrotation must be addressed to prevent reoccurrence. A Ladd’s procedure is performed by widening the mesenteric base; any bands that cross anteriorly to the duodenojejunal junction are divided. The duodenum is then placed on the right side of the abdomen, and the cecum and ascending colon are placed on the left side of the abdomen. An appendectomy completes the Ladd’s procedure.

Postoperative Care
In the immediate postoperative period, routine postoperative nursing care is provided. A salem sump or replogle is inserted and placed to low intermittent wall suction to maintain abdominal decompression. Pain is assessed at least every 4 hours using the appropriate pain assessment tool; appropriate analgesic therapy is then administered.

Many patients have a prolonged ileus, especially if a volvulus or bowel ischemia was present. Some will even have symptoms of duodenal dysmotility or a pseudo-obstruction. A central line will be needed to provide adequate nutrition via parenteral nutrition and intralipids. Those who lost a significant portion of bowel and are considered to have short bowel syndrome are faced with malabsorption and failure to thrive.
Once the return of bowel function has been achieved, enteral feedings will be initiated. The extent of the injury will determine how quickly feedings will be advanced. During this time, the bedside nurse will observe signs and symptoms of feeding intolerance. As the patient advances on enteral feedings, parenteral nutrition is titrated to meet total fluid needs and is eventually discontinued.

**Bibliography**


Malrotation and Volvulus: Information for Parents

- What is malrotation?
  - It is when the intestines do not sit in the belly the right way.

- What is volvulus?
  - When the intestines do not sit in the belly the right way (malrotation), the intestines can twist around one of the big arteries that supplies blood to the intestine and cut off the blood supply to part of the intestines. The twist is known as the volvulus.

- What causes malrotation and volvulus?
  - Both malrotation and volvulus are problems that happened when your baby was developing. They are not caused by anything you did or did not do. The intestines did not rotate and move around inside the amniotic sac like they should have.

- What is the treatment for malrotation?
  - Malrotation by itself is harmless and your baby can have malrotation without a volvulus. However, having malrotation places your baby at an increased risk for a volvulus; therefore, surgery will be needed at some point to correct this.

- What is the treatment for a volvulus?
  - Immediate surgery is needed for any baby who has a volvulus, because the blood supply to the intestines is being cut off.

- Some babies with a volvulus may have a lot of intestine that has to be removed because there was not enough blood flow to it for a long period of time. If this is the case for your baby, the surgeon will have to create an ostomy (an intestine loop that sits on the outside of the abdomen, as pictured below). This is not usually permanent, but your baby may go home with an ostomy.

- Babies with a volvulus will need to receive intravenous (IV) nutrition through a special IV called a peripheral inserted central catheter line. This will allow your baby to grow while the intestines heal.

- Your baby’s providers will be waiting for your baby to have a bowel movement before feedings are restarted. Breast milk feedings are preferred and will be given in small amounts in the beginning.
Neonatal Sepsis

Neonatal sepsis is a clinical syndrome of systemic illness or infection. Other definitions one may associate with sepsis include:

- bacteremia—presence of bacteria in the blood
- septicemia—systemic illness due to bacteria in the blood stream
- meningitis—inflammation of the meninges of the brain and the spinal cord, most often caused by a bacterial or viral infection
- pneumonia—inflammation of the lungs caused by viruses, bacteria, or other microorganisms and sometimes by physical and chemical irritants
- early onset sepsis—sepsis occurring at 3 days of age or earlier; some references define early onset sepsis as occurring within first 5 days of life
- late onset sepsis—sepsis occurring after 3 days of age; some consider late onset sepsis to occur later than 5 days of age.

The incidence of sepsis is 1–5 per 1,000 live births. According to the National Institute of Child Health & Human Development (NICHD) Neonatal Research Network, the incidence of early onset sepsis in very-low-birth-weight infants is 15–19 per 1,000 live births and 21% for late onset sepsis.

Early-Onset Sepsis

The more common organisms that can cause early-onset sepsis are Group B streptococci (GBS), Escheria coli (E. coli), Listeria monocytogenes, Haemophilus influenza, Staphylococcus aureus, Enterococci, and Streptococcus pneumonia.

In early-onset sepsis, the infant will present quite suddenly with systemic symptoms and illness that can progress rapidly to shock and death.

There are risk factors for early-onset sepsis. These include preterm birth, maternal vaginal colonization with GBS, premature or prolonged rupture of membranes, and maternal fever, which can be an indicator of chorioamnionitis. Early-onset sepsis is usually associated with vertical transmission, which is from mother to baby. In 2010, the NICHD Neonatal Research Network noted sepsis was diagnosed more frequently at lower gestational ages. Early-onset sepsis rates were 6% at 22 weeks gestational age and 1% at 28 weeks gestational age. Late-onset sepsis rates were 58% at 22 weeks and 20% at 28 weeks.

Late-Onset Sepsis

The more common organisms that can cause late-onset sepsis include coagulase-negative Staphylococcus, Staphylococcus epidermis, Staphylococcus aureus, Pseudomonas, GBS, and Candida. Late-onset sepsis is more often associated with horizontal transmission, which is from family, hospital personnel, and contaminated or inadequately disinfected equipment. It can also be known as nosocomial, or hospital-acquired, infection.

In late-onset sepsis, the infant can present with systemic symptoms and illness that occurred suddenly or with subtle symptoms. Risk factors for late-onset sepsis can include prematurity, low birth weight, and invasive lines or procedures. The infant can present with a wide spectrum of signs and symptoms for both early-onset and late-onset sepsis, which can range from subtle to life-threatening.

Signs and symptoms of sepsis can include:

- temperature instability
- lethargy or irritability
- seizures
- grunting, flaring, retracting, tachypnea, and apnea
- cyanosis, pallor, mottling, apnea and bradycardia, hypotension, tachycardia, and poor perfusion
- hypoglycemia, hyperglycemia, and metabolic acidosis
- jaundice and petechiae
- decreased urine output.

These signs and symptoms can be seen in a multitude of disease states such as meconium aspiration, necrotizing enterocolitis (NEC), respiratory distress syndrome, intraventricular hemorrhage, and drug withdrawal. Therefore, it can be difficult to diagnose sepsis based only on these signs and symptoms.
Laboratory studies may include:
- Blood tests, which may include a complete blood cell count with differential, acute phase reactants (i.e., C-reactive protein, procalcitonin, nonspecific inflammatory markers).
- Blood culture, with 1 mL of blood volume placed in the single bottle.
- Urine culture, although not recommended for early-onset sepsis.
- Lumbar puncture (LP), also known as a spinal tap. Not all sepsis work-ups include an LP.
- X rays may also be considered, especially for symptoms of respiratory distress or abdominal distention.

The management recommendation for early-onset sepsis is to perform the LP when (a) there is a positive blood culture, (b) the infant’s clinical course has worsened, (c) lab data strongly suggest bacterial sepsis, or (d) infants worsen even after starting antibiotic therapy. In late-onset sepsis work-ups, LPs, and urine cultures should be considered.

Treatment for sepsis is started before culture results are back from the lab, especially when there is a high suspicion of infection in a symptomatic infant. Providing supportive treatment for any of the symptoms the infant has is essential. For early-onset sepsis, a combination of ampicillin and an aminoglycoside (usually gentamicin) is used for synergy. For late-onset sepsis, determining which antibiotics are selected may be based on the epidemiology data from that particular NICU or hospital. Vancomycin and either gentamicin or tobramycin are the antibiotic combinations most commonly initiated for late-onset sepsis. Length of treatment for early- and late-onset sepsis will vary. Antimicrobial therapy should be discontinued at 48 hours in clinical situations in which the probability of sepsis is low (improved clinical course, negative blood culture). Confirmed bacteremia is generally treated for 10 days. Uncomplicated meningitis is generally treated for a minimum of 14 days. Gram negative meningitis is generally treated for 21 days or 14 days after the first negative culture. Other focal infections (e.g., osteomyelitis) are treated for longer durations.

Controversy surrounds the duration of treatment for the infant with a negative blood culture. Consideration should be given to how the infant’s clinical course is progressing and the risks and benefits of a longer course of antibiotics. Cotton and colleagues (2009) demonstrated a possible association between a prolonged duration of antibiotics (longer than 5 days) and NEC. Kuppala and colleagues found that a prolonged administration of empirical antibiotic therapy to preterm infants with sterile cultures in early-onset sepsis is associated with subsequent severe outcomes.

Sepsis prevention starts with early intervention. Intrapartum antibiotics are used in maternal treatment for possible infection. Penicillin, ampicillin, or cefazolin are considered first-line treatment options. Clindamycin or possibly vancomycin may be provided to the mother who has a penicillin allergy. Good handwashing is of the utmost importance. Encouraging mothers to provide breast milk is another way to decrease the risk of infection.

References

Bibliography
Neonatal Sepsis: Information for Parents

*Neonatal sepsis* (you may hear it referred to simply as “sepsis”) is an infection of your baby’s bloodstream. The infection can spread throughout the body and can be very serious.

Sepsis can be caused from an infection by bacteria, viruses, and funguses. Your baby could have been infected during the pregnancy, delivery, or after the birth from being in contact with others.

During pregnancy or delivery, an infection from the mother may pass to the baby by way of the placenta or through the birth canal. If the sac around the baby starts to leak, the baby is no longer protected from infection. Once born, the baby also can get an infection from being around people who are sick or objects in the environment. Even normal “good” bacteria that live on the baby’s skin may make the baby sick. Remember that your baby is in the neonatal intensive care unit (NICU). Frequently, more procedures are required for NICU babies, so there can be more opportunities for an infection to happen, even while trying to prevent infection. In addition, if the baby is premature, his or her immune system that fights bacteria is immature. The baby’s immune system sometimes is not strong enough to fight off the bacteria, virus, or fungus. When the immune system is not strong enough to fight the infection, the baby can become quite sick.

There are many different ways a baby may show that he or she does not feel well, and each baby is different. Some signs that your baby is not feeling well may include:

- feeling sluggish or more sleepy than usual (also known as lethargy)
- decreased breathing or breathing too fast (apnea or tachypnea) or slowing of their heart rate (bradycardia)
- not feeding well (tolerating their tube feedings or not breast/bottle feeding well)
- pale, cool, clammy skin
- not being able to keep their temperature regulated.

The NICU team is observing your baby all of the time. If you notice your baby acting differently, please let any one of the team members know (e.g., nurse, provider, respiratory therapist). Don’t be afraid to talk with the team if you are concerned.

To determine whether your baby has sepsis, the NICU team may do many different tests: blood tests, urine tests, a spinal tap (also called a lumbar puncture), or X rays. Your baby may stop eating and need an IV and fluids. Your baby may need some help to breathe (such as oxygen or a ventilator). Antibiotics, which are medication given to fight the infection, may be started. The medical team will watch your baby closely and follow the test results closely. Your baby may need to have some of the tests repeated to make sure the infection is going away.

Here are some ways to help your baby fight against getting an infection:

- Wash your hands every time you are with your baby and especially after changing his or her diaper.
- Stay home if you do not feel well. You can call the NICU staff to check in on your baby until you are feeling better.
- Breastfeeding may help prevent infections. If you are able to supply breast milk for your baby, that is great!
Meconium aspiration syndrome (MAS) happens when fetal stress occurs and the fetus/newborn gasps then aspirates meconium stained amniotic fluid into his or her lungs before, during, or immediately after birth. MAS can be caused by placental insufficiency, maternal hypertension, preeclampsia, tobacco use, maternal infections, and fetal hypoxia, and most commonly postdates pregnancy. MAS can be a serious respiratory condition causing respiratory failure, acute inflammatory response, and air leaks. One-third of infants with MAS will develop persistent pulmonary hypertension. MAS can range from mild to severe.

A team trained in neonatal resuscitation should attend all births with meconium-stained fluid. Not all infants delivered with meconium-stained fluid will develop MAS. Initial resuscitation steps are critical to prevent MAS. Please refer to current Neonatal Resuscitation Program guidelines to manage newborn during delivery, which are available at www2.aap.org/nrp.

Newborns with mild to moderate MAS may present with meconium-stained skin, fingernails, or umbilical cord; tachypnea; rales; cyanosis; nasal flaring; grunting; and retractions. In severe cases of MAS, gasping respirations, pallor, and an increase in the anteroposterior diameter of the chest may be noted. Babies experiencing severe MAS may require oxygen, intubation, and ventilator support; inhaled nitric oxide; hypothermia treatment; and even extracorporeal membrane oxygenation. Newborns will usually require placement of central lines and frequent arterial blood gases to observe for hypoxia and hypercarbia. If your unit does not have these capabilities, a transfer to a higher level of care NICU should be initiated as soon as possible.

Severe complications of MAS may include persistent pulmonary hypertension, pneumomediastinum, pneumothorax, and pulmonary hemorrhage. The infant may require a chest tube if a pneumothorax needs to be evacuated. Although surfactant therapy is not routinely recommended, it may be helpful in certain circumstances, because meconium inactivates surfactant in the baby's lungs.
Newborns with MAS require a multidisciplinary team approach to manage their many medical challenges, and parents will need support and education throughout their baby’s NICU stay to ensure the family’s needs are met during this difficult time.

**Bibliography**


Meconium Aspiration Syndrome: Information for Parents

A baby’s first stool is called meconium. It is green and black in color and thick in consistency. Meconium is an early stool passed by a newborn soon after birth. In some cases, a baby passes stool inside the womb before he or she is born. This can happen when the baby is under stress during labor. If the baby breathes in the stool before or during delivery, the baby can develop meconium aspiration syndrome (MAS). Not all babies who have a bowel movement before birth will develop MAS.

MAS happens when the baby breathes this thick fluid into his or her lungs before, during, or right after birth. MAS babies may develop trouble breathing and will need help to breathe. A skilled team will attend your delivery if you have meconium-stained fluid noted during labor.

If your baby is crying and active, no treatment may be needed. If the baby is not crying or active right after delivery, a tube is placed in the infant’s windpipe and suction is applied as the tube is pulled out. This might be repeated until the meconium is no longer seen in the suction tube. If the baby is not breathing or has a low heart rate, he or she may require help to start breathing. At delivery, oxygen and breaths given by face mask will help inflate the baby’s lungs.

Your baby may be placed in a special care nursery or newborn intensive care unit (NICU) for close observation. Other treatments may include:
- antibiotics to treat possible infections
- breathing machine (ventilator) to keep infant’s lungs open
- oxygen
- surfactant
- medicines to help keep their blood pressure stable (vasopressors)
- medicine to help bring the pressure in their lungs down (nitric oxide)
- a chest tube to reinflate a collapsed lung.

This can be a scary time for parents. The special care nursery or NICU team will be there to support you and answer your questions. It may take a few weeks for your baby’s lungs to heal so that they can begin to eat, grow, and go home. After you are able to go home, your baby may need frequent follow up with specialized healthcare providers.
Hypoxic ischemic encephalopathy (HIE) is defined as an acute brain injury diagnosed by clinical and laboratory findings. HIE affects 6 in 1,000 live births in the United States. There are several causes for HIE in newborns, including interrupted circulation in the umbilical cord, abruption of the placenta or other insufficiencies of the placenta, maternal hypotension, and maternal hypoxia or difficulties during an infant’s resuscitation. HIE results in death for about 50% of infants impacted. Survivors may develop devastating complications that include mental retardation, epilepsy, and cerebral palsy.

There are several pathophysiologic mechanisms that cause the brain injury associated with HIE. The sympathetic nervous system is stimulated by asphyxia, which results in a redistribution of blood flow. Cardiac output is redistributed to the vital organs including the brain, heart, and lungs. Initially, systemic blood pressure increases to maintain cerebral blood flow, but with continued hypoxic insult, the neonate is unable to maintain adequate cardiac output and cerebral perfusion is compromised. With continued hypoxic insult, the brain converts to anaerobic metabolism resulting in an increase in lactic acid formation in the brain. The combination of energy failure, acidosis, free-radical formation, calcium accumulation, lipid peroxidation, and neurotoxicity from glutamate and nitric oxide disrupt the structure of the cell and ultimately result in cell death.

Approximately 6–15 hours after the initial event, a secondary reperfusion injury occurs. In this phase, there is a brief period of restored cellular function, followed by decreased cerebral blood flow and clinical deterioration due to increased calcium influx into the cell and continued cell injury. This phase involves irreversible cell death, either by necrosis or apoptosis.

**Table 1** shows clinical findings associated with moderate and severe HIE.

There is no treatment available for HIE; however, induced hypothermia is thought to provide neuroprotection to the brain by reducing cellular metabolism and improving oxygen delivery.

<table>
<thead>
<tr>
<th>Category</th>
<th>Signs of HIE</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Level of consciousness</td>
<td>Lethargy</td>
</tr>
<tr>
<td>2. Spontaneous activity</td>
<td>Decreased activity</td>
</tr>
<tr>
<td>3. Posture</td>
<td>Distal flexion, complete extension</td>
</tr>
<tr>
<td>4. Tone</td>
<td>Hypotonia (focal or general)</td>
</tr>
<tr>
<td>5. Reflexes</td>
<td>Weak</td>
</tr>
<tr>
<td>–Suck</td>
<td>Incomplete</td>
</tr>
<tr>
<td>–Moro</td>
<td></td>
</tr>
<tr>
<td>6. Autonomic System</td>
<td>Constricted</td>
</tr>
<tr>
<td>–Pupils</td>
<td>Deviation/dilated/non-reactive to light</td>
</tr>
<tr>
<td>–Heart rate</td>
<td>Variable</td>
</tr>
<tr>
<td>–Respiration</td>
<td>Apnea</td>
</tr>
</tbody>
</table>

brain and may also reduce the severity of the secondary reperfusion injury. The cerebral metabolic rate decreases by 6%–7% for every 1 °C decrease in body temperature. Induced hypothermia can be done via two interventions: head cooling or body cooling. Research has not yet shown which method is most effective. Currently, research has shown induced hypothermia should be used only on neonates older than 37 weeks gestational age at birth who have at least one of the following:

• a history of an acute perinatal event and are exhibiting signs of moderate to severe HIE
• a cord or neonatal pH less than 7.0
• base deficit greater than 16 on a cord gas or postnatal gas
• Apgar score less than 5 at 10 minutes.

In addition, treatment should begin within 6 hours of the injury to prevent a secondary reperfusion injury from occurring.

When caring for an infant with HIE, the most critical element of resuscitation is maintaining a stable airway and ensuring adequate circulation to prevent additional injury. These infants may exhibit seizures shortly after birth; therefore, an electroencephalogram to determine the presence of seizures and anticonvulsants are often required. Prior to induced hypothermia, infants often require mechanical ventilation and inotropic support to increase cardiac contractility. To initiate hypothermia treatment, the infant is placed on a precooled blanket per the manufacturer’s instructions. Ensure that all heat sources, such as the radiant warmer, are shut off. The infant’s core temperature is monitored by an esophageal probe that is secured to the nose with tape; placement is verified with an X ray. The infant’s body temperature is lowered to an acceptable range of 32.5 °C–34.5 °C. To prevent increased metabolic activity, sedatives and paralytics may be administered. Frequent evaluation of blood gases and electrolytes are critical for the management of these infants due to the many different complications of asphyxia. Nursing interventions when caring for the infant with induced hypothermia include clustering care to avoid excessive stimulation, decreasing light and noise in the immediate area, frequent skin assessments, and pain assessment and management.

Induced hypothermia continues for 72 hours after treatment begins, even if the infant’s condition seems to improve. After 72 hours, the infant is rewarmed over a period of 6 hours by increasing the blanket temperature 0.5 °C every hour until 36.5 °C is reached. It is important for vital signs to be closely monitored because hypotension (secondary to vasodilation) may occur during rewarming. Once the infant is rewarmed, neurologic function will be assessed (physical exam, EEG, weaning of anticonvulsants) to evaluate the effectiveness of the treatment. Parents should be educated on the possible long-term outcomes associated with HIE, including cerebral palsy, delayed neurodevelopment, and possible learning disorders.

**Bibliography**


Hypoxic Ischemic Encephalopathy: Information for Parents

What is hypoxic ischemic encephalopathy (HIE)?
HIE refers to a brain injury resulting from too little blood flow or oxygen delivery to the brain. It affects nearly 6 in 1,000 births per year in the United States.

What causes HIE?
There are many causes, but sometimes the exact cause can be unknown. Possible causes are too little oxygen supplied by the placenta during labor, a blockage in the baby’s umbilical cord, a clot in the baby’s brain, shock or sudden blood loss, or infection.

What are the symptoms of HIE?
Symptoms can include lethargy, weak to absent muscle activity, flaccid or “floppy” arms and legs, a weak or absent suck reflex, weak to absent breathing, seizures, and coma.

What is the treatment for HIE?
Treatment is meant to prevent any further damage due to low oxygen levels. Infants who are older than 36 weeks gestational age may qualify for treatment. Some babies may benefit from hypothermia, which is cooling of the head or the entire body, and is done by using a cooling blanket or cooling cap. Cooling limits the amount of damage to the brain after a low-oxygen event. The hypothermia treatment will usually last for 72 hours, and the infant will be cooled to a temperature of 33.5 °C, or 92.3 °F, then the baby will slowly be rewarmed to a normal temperature.

Your baby may need to be sedated with medication. He or she is monitored for pain on a regular basis, and medication is given as needed. Due to the cooling and lack of movement by your baby, skin assessments will frequently be performed by your baby’s provider. Optimal nutrition is also important, because of decreased blood flow to your baby’s bowels. Total parenteral nutrition therapy may be started through an intravenous (IV) line, so your baby can receive the nutrients he or she cannot get through eating.

How is HIE diagnosed?
Some of the symptoms for HIE include
- history of an acute perinatal event
- an Apgar score of 5 or less at 10 minutes (Apgar scores are a simple way for your baby’s provider to assess your baby’s health right after being born.)
- continued need for ventilation initiated at birth and continued for at least 10 minutes
- low pH on blood in the umbilical cord
- level of alertness, ranging from being sluggish to in a coma
- decreased or no spontaneous activity
- inappropriate posture, such as arching of back or neck; rotation of arms or legs
- weak or absent reflexes
- seizures
- constricted to nonreactive pupils
- decreased to absent breaths.

Not all babies with HIE will survive. Depending on the severity of the injury, some babies may have long-term problems.

Electroencephalograms (EEG) are often performed after the infant has been rewarmed to evaluate the treatment and to look for seizures.

Babies with moderate to severe HIE often have serious long-term problems such as learning disorders, delayed development, or cerebral palsy. Follow up with a developmental specialist after discharge will be important to assess your baby’s progress.
Resources
Resources

Retinopathy of Prematurity

InfantSEE
www.infantsee.org
InfantSEE is a public health program, managed by Optometry’s Charity. The American Optometric Association (AOA) Foundation is designed to ensure that eye and vision care becomes an integral part of infant wellness care to improve a child’s quality of life. Under this program, AOA optometrists provide comprehensive eye and vision assessments for infants within the first year of life regardless of a family’s income or access to insurance coverage. Their website has helpful information for families on babies’ developing eyes. It also explains vision screenings and what they detect. To find an optometrist who participates in the InfantSEE program call 1.888.396.EYES(3937).

The Association for Retinopathy of Prematurity and Related Diseases (ROPARD)
www.ropard.org
Founded in 1990 by a concerned group of physicians and volunteers, ROPARD is the first organization in the country dedicated to eliminating the problems of low vision and blindness in children caused by premature birth and retinal disease. They offer practical information for parents and physicians about understanding ROP and caring for children who have it. To contact them, e-mail ropard@yahoo.com, call 800.788.2020, or visit their website at www.ropard.org.

Parenting

NICU Journal: A Parent’s Journey

Bonding with Your Medically Fragile Baby in the Neonatal Intensive Care Unit
Written by Dawn K. Gibson, LCSW, this printable PDF discusses bonding with your baby during the NICU stay and beyond.

Immunizations

Centers for Disease Control and Prevention

Bronchopulmonary Dysplasia (Electronic)
American Lung Association
www.lung.org/lung-disease/bronchopulmonary-dysplasia

National Heart, Lung, and Blood Institute, National Institutes of Health
www.nhlbi.nih.gov/health/health-topics/topics/bpd

National Library of Medicine, National Institutes of Health

Books


Hearing Screening

Centers for Disease Control and Prevention
www.cdc.gov/ncbddd/hearingloss/ehdi-contacts.html
Visit the CDC website for contact information for hearing specialists organized by state and territory.

National Institute on Deafness and Other Communication Disorders
If your baby’s screening reveals a possible hearing problem, visit this website for information about next steps.

**General Information**

**Eli’s Hope**
www.elishope.org

**Graham’s Foundation**
www.grahamsfoundation.org

**Hand to Hold**
www.handtohold.org

**KidsHealth**
www.kidshealth.org

**Parent Preemie Alliance**
www.preemieparentalliance.org

**Preemie World, LLC**
www.preemieworld.com/blog