It is our hope that this booklet will help you to understand your preterm baby and assist you in parenting your baby in the NICU.

Any feedback about this booklet is welcome.
**Information for parents who have a premature baby in NICU**

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When your baby’s in the NICU

New parents eagerly look forward to having their baby and bringing their baby home, so it can be frightening if your newborn needs to be admitted to the Neonatal Intensive Care Unit (NICU). At first it may seem like a foreign place, but understanding the NICU and what goes on there can help reduce your fears and better help your baby.

What is the NICU?

If your baby is sent to the NICU, your first question will probably be: What is this place? With equipment designed for infants and a hospital staff who have special training in newborn care, the NICU is an intensive care unit created for sick newborns who need specialized treatment because they’re developing so rapidly.

Sometimes the NICU is also called:
• a special care nursery
• an intensive care nursery
• newborn intensive care

Babies who need to go to the unit are often admitted within the first 24 hours after birth. Babies may be sent to the NICU if:
• they’re born prematurely
• difficulties occur during their delivery
• they show signs of a problem in the first few days of life

Only very young babies (or babies with a condition linked to being born prematurely) are treated in the NICU – they’re usually infants who haven’t gone home from the hospital after being born. How long these infants remain in the unit depends on the severity of their illness.

What can I expect in the NICU?

Walking into the NICU can feel like stepping onto another planet – the environment is probably unlike anything you’ve experienced. The unit is often busy, with lots of activity, people moving around, and beeping monitors. Sometimes the lighting is intense, although the staff usually tries to control the level of brightness in the room.

Once your baby is settled in the unit, he or she will receive care tailored to your little one’s specific needs. Most NICU babies are on special feeding schedules, depending on their level of development or any problems they have. For instance, some infants are too premature or too sick to eat on their own, so they have a feeding tube that runs through the mouth and into the stomach. Others need high-calorie diets to help them grow.

Medications are another crucial part of NICU care – your child may take antibiotics, medicine to stimulate breathing, or something to help his or her blood pressure or heart rate, to mention just a few.

To ensure that your baby’s care stays on track, the doctors will also order various tests, possibly including periodic blood and urine tests, X-rays, and ultrasounds. For infants whose care is complicated and involved, the doctors or nurses will place a line into an artery or vein so they can draw blood without having to repeatedly stick the baby. NICU staff try to make the infants’ stay in the nursery as comforting as possible to the infant as well as to the families.

At the beginning or as your baby’s stay in the NICU goes on, the nurses can explain what all of the monitors, tubes, tests, and machines do, which will go a long way toward demystifying the NICU.

In the meantime, refer to Common NICU Equipment for a brief look at what some of the unfamiliar equipment does and how it may help your baby, depending on your little one’s condition and diagnosis.

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Although there will be many people helping your infant during the NICU stay, those who are the most responsible for your baby’s day-to-day care will likely be nurses, whom you may come to know very well and may rely on to give you information and reassurances about your baby. The nurses you may interact with include:

- **head nurse** (in charge of the nurses and the quality of care they provide in the NICU)
- **assistant head nurse** (in charge of day-to-day nursing activities in the NICU and assists head nurse)
- **charge nurse** (in charge of the shift and the nurses on that shift)
- **assigned nurse** (assigned to your baby and who may be one of a few nurses assigned to you and your baby, your cohort nurses)
- **clinical nurse specialist** (has additional training in neonatology care)
- **family nursing consultant** (has additional training in caring for NICU families and is a consultant to nurses for families)
- **follow-up clinic nurse** (follows premature infants developmentally after discharge)

You’ll also meet many other people who may help care for your baby:

- **a neonatologist** (a doctor specializing in newborn intensive care who heads up the medical team)
- **neonatology fellows and medical residents** (all pursuing their training at different levels. They rotate through the NICU for short intervals)
- **various medical specialists** (such as a neurologist, a cardiologist, or ophthalmologist to treat specific issues with the eyes, brain, the heart, etc.)
- **respiratory therapist** (administers treatments that help your baby with breathing and manages breathing equipment)
- **occupational therapist** (works with feeding and movement issues with the infants and consults with the parents)
- **a pharmacist** (helps manage your baby’s medications)
- **a social worker** (helps you get the services you need, lends emotional support, and connects you to other families and therapists, as needed)
- **students** (as a teaching hospital, you may meet medical, nursing, respiratory, pharmacy and social work students who are learning in their specific field and rotate through the NICU for their learning)

Some questions you might want to ask

To better help you help your baby during his/her time in intensive care, it’s a good idea to get as much information as possible about what to expect. If you have questions throughout your baby’s stay in the unit, talk to the neonatologist or the nurses.

The nurses see your baby every day, so they can give you frequent updates on your little one. Remember, though, that nurses do not make diagnoses. To discuss a diagnosis or your baby’s overall plan of medical care, speak to the neonatologist or the resident. They have this information about your baby and can talk to you about the big picture.

Some things you might want to ask the neonatologist and/or the nurses include:

- How long could my baby be in the unit?
- What, specifically, is the problem?
- What will be involved in my baby’s treatment and daily care?
- What medicines will my baby have to take?
- What types of tests will be done on my baby?
- What can my baby eat and when?
- Will I be able to nurse my baby - if so, when and how?
- Will someone help me learn how to nurse my baby?
- What can I do to help my baby?
- Will I be able to hold or touch my baby?
- Will I be able to do kangaroo (skin-to-skin) care?
- How often and for how long can I stay in the unit? Can I sleep there?
- What sort of care will my baby need when we get home?
- Is there someone who can help us through the process?

You may also want to talk to the nurses in more detail to find out more about your baby’s daily care and what to expect when you spend time with your little one. You should also learn the visiting schedule and any rules of the NICU so you’ll know which family members can see the baby and when they can visit.

You may also want to ask some of the following questions to nurses or specific questions to the social worker:

- Are there cots or recliners available if we’re allowed to stay overnight?
- If you live far away, is there nearby temporary housing available (such as through the Ronald McDonald House)? If so, how do we get a room and what is the cost?
- Are there computers, with Internet access, available for doing work or emailing friends and loved ones about our baby’s progress?
- Are there books we can borrow to learn about premature babies?
- Can we use our cell phones in the NICU? If not, can we be reached in the NICU?
Medical challenges of my baby

Premature babies, especially those born more than 4 to 6 weeks early, may develop medical complications. If your baby has one of the medical complications listed below, talk to your baby’s doctor and ask your nurse for one of the written handouts to assist you in understanding your baby’s medical challenge.

- Anemia
- Apnea and bradychardia of prematurity
- Blood pressure, low
- Bronchopulmonary dysplasia (BPD)
- Infection
- Hydrocephalus
- Intraventricular hemorrhage (IVH)
- Jaundice/hyperbilirubinemia
- Necrotizing Enterocolitis
- Patent Ductus Arteriosis
- Periventricular Leukomalacia
- Pneumothorax
- Reflux
- Respiratory Distress Syndrome
- Retinopathy of Prematurity
- Sepsis
- Transient tachypnea
The following is a list of some of the machines and equipment that are used to help premature or sick babies:

**Billights:** The bright blue fluorescent lights placed over the baby’s incubator used to treat jaundice (yellowing of the skin and eyes due to accumulation of a waste product called bilirubin in the blood). Babies with jaundice usually receive phototherapy treatment for three to seven days.

**Blood pressure monitor:** A machine connected to a small blood pressure cuff wrapped around a baby’s arm or leg.

**Cardiopulmonary monitor:** A machine that tracks a baby’s heart and breathing rates, and is connected to him by small adhesive monitoring pads placed on his chest. The monitor displays information on the screen. If a baby’s heart or breathing rate becomes too fast or too slow, an alarm will sound.

**Central line:** An intravenous line inserted into a vein, often in the arm, and threaded from there into a larger vein in the body close to the heart. It is used to deliver medicines or nutritional solutions that would be irritating to smaller veins. A PICC (peripherally inserted central catheter) line is a type of central line, which is placed in one of the major blood vessels.

**C-PAP (continuous positive airway pressure):** A constant flow of air, sometimes with added oxygen, is delivered to a baby’s lungs through either small tubes in the baby’s nose or through an endotracheal tube. This helps keep the baby’s lungs open while the baby breathes comfortably on his or her own.

**Endotracheal tube:** It is a small, flexible plastic tube which goes through a baby’s nose or mouth down into the trachea (windpipe). The endotracheal tube allows air, sometimes with added oxygen, to pass to and from the lungs. It is attached to a breathing machine (ventilator) which breathes for the baby.

**High-frequency ventilation:** is a different way the ventilator breathes for the baby. The breaths are rapid and the amount of air to the lungs is smaller than regular ventilation, which will result in the baby’s chest vibrating. This type of ventilation is used to treat specific breathing or lung problems.

**Incubator:** A clear plastic crib that keeps babies warm and helps protect them from noise.

**Intravenous line:** Most premature and sick babies cannot be fed immediately, so they must receive nutrients and fluids intravenously (through a vein). A doctor or nurse will
Common NICU tests

In the NICU, various tests are important in diagnosing problems and identifying progress in newborns. The following are some of the tests typically performed:

Blood tests: These are among the most frequent procedures done in the NICU. Blood tests provide crucial information on how a baby is doing, and alert doctors to potential problems before they become more serious.

- Blood tests can tell if a baby is anaemic or if bilirubin levels are too high. Bilirubin is formed when red blood cells break down. Jaundice occurs when the liver can’t remove bilirubin from the blood.

- They show whether a baby has low blood sugar (hypoglycemia), high blood sugar (hyperglycemia), salt or water imbalances, or nutritional needs (such as problems with protein, liver and kidney function)—all of which can cause problems if not corrected.

- Blood tests also can help determine if a baby has an infection and which antibiotic(s) should be used to treat it.

- If a baby is very sick, she may need blood tests several times an hour to measure the levels of blood gases (oxygen and carbon dioxide). This may be done on a blood sample taken from an artery, because arteries carry oxygen to all parts of the body. The sample can be taken through the umbilical catheter.

A baby may have a blood test to check blood gases soon after she is admitted to the NICU, to determine whether she needs additional oxygen or mechanical ventilation.

Electroencephalogram (EEG): A specialized form of ultrasound examination that is used to study the heart. It can detect structural problems (heart defects) and problems with how the heart works.

Electroencephalogram (EEG): a less common test used to detect abnormalities related to electrical activity of the brain. This procedure records brain wave patterns. Small metal discs with thin wires (electrodes) are placed on the scalp, and then send signals to a computer to record the results. Normal electrical activity in the brain makes a recognizable pattern. Through an EEG, doctors can look for abnormal patterns that indicate seizures and other problems.

Hearing test: Premature and other sick babies are at increased risk of hearing problems. Before a premature baby goes home, she probably will have a hearing test called a "brainstem auditory evoked response test." A tiny earphone is inserted into one of the baby's ears. The sound is triggered by a stimulus that the baby should recognize.

Respirator: See ventilator.

Umbilical catheter: A baby’s umbilical cord has two arteries and one vein, which end in his belly button. A thin tube (catheter) can be inserted into one of these vessels, most commonly one of the arteries, and threaded to the aorta, the largest artery supplying oxygen to the body. Through this catheter, doctors and nurses can painlessly draw blood (without having to repeatedly stick the baby with needles), and give him fluids, blood, nutrients and medications. A small device can be attached to the catheter to continuously monitor the baby’s blood pressure. Once an umbilical catheter is removed, the normal process of closure of these blood vessels occurs, to eventually form a normal “belly button.”

Ventilator (also known as a respirator): Premature babies have underdeveloped lungs and they may need a ventilator which is a machine that helps a baby breathe. It delivers, through an endotracheal tube, warmed and humidified air, sometimes with added oxygen, to a baby's lungs. The amount of oxygen, air pressure and number of breaths per minute are adjusted to meet the needs of each baby.
will be placed in her ear to deliver sound. Small sensors, which are taped to the baby’s head, will relay information to a machine that measures the electrical activity in her brain in response to sound. A follow-up is necessary. It is important to detect hearing problems early, in order to help prevent speech and language problems.

**Newborn screening test:** This is a test performed by pricking a baby’s heel to obtain a few drops of blood on a filter paper. It tests babies for serious hereditary disorders. New technologies have made it possible to test for even larger numbers of disorders at one time.

**Retinopathy of prematurity (ROP) examination:** This test is done on babies born 31 weeks gestation or less, and on babies whose birth weight is less than 1500 gms whether or not they have special oxygen needs. An ophthalmologist (eye doctor) will examine a premature baby’s eyes four to six weeks after birth with a special scope (ophthalmoscope). Before the examination, the doctor places drops in her eyes so the doctor can see her retina and determine whether the blood vessels are developing normally. If a baby has any signs of ROP, the doctor will repeat this examination regularly to see if the condition is clearing up on its own, or whether treatment is necessary.

**Ultrasound:** Ultrasound takes a picture of a baby’s organs using sound waves, rather than x-rays. A small hand-held device called a transducer is rubbed back and forth over the area that the doctor wants to see. An ultrasound examination is painless and done at the baby’s incubator. It often is done to determine if a baby has any bleeding in the brain. A head ultrasound is the routine test to diagnose bleeding in the brain. A heart ultrasound may be done if the doctor hears a heart murmur.

**Urine tests:** Like blood tests, urine tests can tell a great deal about a baby’s overall condition. Urine tests can help determine how well the kidneys are functioning, and whether a baby has a urine infection.

**Weighing:** Every baby is weighed soon after delivery, and then at least once a day while he is in the NICU. Don’t be alarmed if your baby loses some weight in the first days. Babies can lose up to 20% of birth weight after birth. This is normal, especially for very small babies. When a premature baby starts gaining weight at a steady rate, it is an encouraging sign that he is doing well.

**X-rays:** X-rays provide pictures of a baby’s lungs, bones and other internal organs. These pictures help the baby’s doctor plan her treatment and monitor her progress. A baby may receive several lung x-rays each day if she has serious breathing problems. She will be exposed to a little radiation from these x-rays. The amount is so low it should not affect her health now or in the future. The baby will not need to be moved to the radiology department for this test; it is done right at her incubator.

*Adapted From March of Dimes website, August 2009*
To the parents of a premature baby

Emotional responses of parents

Having a premature baby is one of the most stressful experiences a parent can have. Most parents find it very difficult to go through the experience of having their baby in a NICU (Neonatal Intensive Care Unit) without needing emotional support. It is normal for parents to feel overwhelmed by stress and confused by their feelings.

How can I get help?

The doctors, family nurse consultant, nurses, specialized nurses, and social workers on the unit can be wonderful sources of support. There are parent support groups which meet weekly in French or English.

What are some common feelings of parents of premature babies?

• I feel guilty that I did something to cause my baby to be premature. This is a common reaction of many parents. It is important to realize that many parents of premature infants feel some guilt, even if they took excellent care of themselves during pregnancy. Mothers who have had excellent prenatal care, who have watched their diet, and who have neither smoked nor drank alcohol may still have premature babies. It will be important to find out if the doctors know what caused your baby to be premature. In most cases, the cause will be something out of your control. Talking with your doctor or others will help these feelings of guilt go away.

• I worry that I don’t feel more love for my baby. When premature babies are born, almost all parents have some fear that their baby will die. Because of this fear, parents naturally have what is known as anticipatory grief. Anticipatory grief is a way of preparing yourself emotionally, in case your baby would die. Anticipatory grief both helps parents and causes them problems. Anticipatory grief helps reduce the pain already felt by premature parents. For example, some parents of premature babies delay giving their baby a name. These parents believe that their baby’s death would be easier to adjust to if their baby had no name. This fear of death creates a temporary separation of the bond between premature babies and parents. And this is the reason why many parents wonder why they don’t love their baby more. When their baby starts to get healthy, almost all parents of premature babies re-establish their bonds of love with their baby. If you find that you continue to have problems loving your baby for a few weeks, it would be helpful to talk to someone on the medical staff. They are very familiar with your worries because this worry is very common.

• I am grieving. Having a premature baby involves many losses. It is natural to grieve. During pregnancy and even before, parents create many hopes and dreams for their expected baby. You may have had hopes for a boy or girl, blue eyes or brown, dark hair or blond. You also had hopes for a healthy, full term baby, and these hopes were shattered. You are coping with shattered dreams now, and that involves grieving. Many women also feel inadequate that they did not carry their pregnancy to full term. Often mothers of premature infants feel that they are not complete women or mothers. You want to do so much for your baby, but you feel there is little you actually can do while your baby is sick. It is normal for you to grieve the loss of the pregnancy and healthy baby, just as you would feel sorry if someone you loved moved away from you or died. Support from others can help you in your grief.

• I am worried that my baby will not know that I am his/her parent. It is normal to have this worry, but it is very likely that your baby already knows that you are its parent. Babies learn to recognize their mother’s voice while they are in the womb. A premature baby can already tell the differences between its mother’s voice and the voices of nurses and doctors. It has been shown that the oxygen saturation of premature babies improves when their parents are close by. Unfortunately, the treatment of premature babies requires some painful procedures that are done by doctors and nurses. Sucrose is given to reduce pain.
When you gently touch your baby and talk softly, your baby will then learn that you have the voice that is special; the voice that gives comfort, the voice your baby will want to go home with. For some premature babies, touching is very stressful. Check with the nurse to figure out how much and what kind of contact is best.

- **I am worried that the treatment in the NICU will have long-lasting emotional effects on my baby, which will be bad.** Research indicates that there are no long-term emotional effects of the painful procedures used in the NICU. Premature babies grow up to be just as emotionally normal as babies that are born healthy at full term.

- **I am afraid to ask questions of the doctors and nurses.** There are so many medical terms and abbreviations used in the NICU that no parent (even those with PhDs) can understand them all. Many parents are afraid to ask questions because they don’t want to appear ignorant. But remember that the doctors and nurses had to go to school for years to learn these terms, so they certainly can’t expect that you will learn it all in a few weeks or days. And it is very important for you to understand what is going on with your baby. Most of the time, getting an answer to your question will help to reduce your worries. Please ask questions. There are no dumb questions. If you feel confused by what is going on, try to have someone else with you (your spouse, your own parent, or a friend) when you ask questions. This may clarify your understanding.

**Why am I afraid even though my premature baby is getting healthy?**

Unfortunately, many parents find that fearing for their baby’s life does not go away as rapidly as they would like. Even when a premature baby comes home, some (perhaps many) parents have flashbacks of fear about their baby’s birth or hospitalization. These are normal reactions to the stress of having a premature baby. Sometimes parents feel like they are not normal because they are still afraid, even though they “know in their mind” that their baby is healthy. Realizing that these flashbacks are common helps parents to cope with them. The flashbacks decrease over time and they do go away.

**Why do I feel sad and depressed and have so little energy?**

Sadness and depression are common reactions to having a premature baby. Everyone dreams of giving birth to a healthy, full-term baby. Not having this dream come true is a natural cause of sadness. No one in their right mind would want to experience the following sequence of events: mother on bed rest, an emergency C-section, fearing that mother and baby might die, visiting the NICU day after day after day, hearing bad news about the baby’s health, worrying about the rest of your family and money worries.

Even taking a healthy premature baby home is a source of stress. Parents who are sad because some of this has happened are having very normal feelings. Sadness and depression may become excessive, however. If feelings of depression become very troublesome, it would be wise to ask the health care staff for help.

**Are my fears and feelings excessive? Am I going crazy?**

The majority of parents of premature babies feel fearful and upset. Having many feelings of distress is normal for parents of high-risk babies. Here are some common fears and feelings of parents of premature babies.

- “When the telephone rings at home I panic because it might be a call from the hospital with bad news.”
- “I am afraid to walk into the NICU because something bad may have just happened.”
- “I am afraid that I won’t find my baby in the isolette.”
- “This experience has been so terrible that I sometimes wish that my baby would just die, so that the whole thing would be over. I feel like an awful person for thinking this.”

Many times parents are afraid to talk about these feelings because parents are concerned that someone will think that they are coping poorly. Experienced members of the health care team and other parents of premature babies have come to learn that feelings like these are common. It can be comforting to talk about these feelings with someone who can understand you.
Why am I angry with the nurses and doctors about my baby’s treatment?

The causes of anger are pain, suffering, and frustration. Parents of premature babies are in frustrating situations that produce pain and suffering; so, of course, many parents will feel anger. Often parents are afraid to express their worries to the NICU staff, but this should not stop parents from expressing their concerns. A recent emphasis in perinatal care and neonatal care is called “Family-Centered Care”. This means that the nurses and doctors are concerned with the well-being of families, in addition to the well-being of babies. In order for “Family-Centered Care” to work well, parents are encouraged to express their concern, even if they are angry concerns.

Stages or phases of adaptation

Some parents feel that learning about the emotional stages or phases of adaptation help them understand what they are going through and what to expect. Although these can be listed as stages, the stages are not clear cut and often a parent is in more than one stage at a time. Therefore, we have grouped them as early and later emotions. Many of these feelings are discussed in greater detail in Emotional Responses of Parents.

What are the early stages of emotional adaptation that a parent goes through in adjusting to the experience of having a sick baby?

Early reactions (stages) are:

• **Shock** – A feeling of being stunned or dazed. Your mind is completely occupied by the problems surrounding early delivery. How will this affect my life? How will it affect my baby’s life? Will my baby live? During this stage it is often difficult to think clearly or remember what has been said. You may need to hear the same information several times. Others may be able to understand and remember information better than you.

• **Denial** – Not wanting to believe that the whole event is occurring. Hoping that you will wake up from this bad dream. Hoping that it will just go away and everything will be all right. Wanting proof that what doctors and nurses say is wrong with your baby is really true. Sometimes seeing your baby, seeing the isotope with your baby’s name on it, looking at x-rays or other indicators of “proof” makes the situation more believable.

• **Grief, fear and sadness** – Grieving away the perfect baby that every parent hopes and expects to have. Grieving away the ideal birth experience, happy celebrations, bring your baby home with you. Feeling sad for yourself and everything you are going through. Feeling sad for your baby, especially about the pain and suffering that s/he might endure. Fear that your baby might die or not be normal.

• **Anger and guilt** – You are angry that your baby is sick. You wonder, why did this happen to me? What did I do wrong to make my baby sick? (Most mothers did nothing wrong and could have done nothing to prevent it). Because you can’t be angry with your baby, it is common to direct your anger toward your spouse, your friends, relatives or those caring for your baby.

Can I have more than one of these emotions at once?

Most parents experience all of these emotions, both immediately before and after the baby is born.

How long do these feelings last?

Different emotions may last for different lengths of time. Shock and denial usually resolve more quickly than the grief, sadness, anger, and guilt. Even after you think you have resolved your feelings, you may find yourself going back and experiencing these feelings again. Parents vary in the length of time it takes for resolving these emotions. Some of this relates to the degree of illness and the time course of the infant. Sicker infants take longer to stabilize and keep their parents on an emotional roller coaster for longer periods of time.

What happens later?

Later is a period of attaining equilibrium and beginning to reorganize. It includes:

• **Adjusting to the guilt of having a sick baby** – Having faced the fact that you did not have a normal labour and delivery, you can now move on to focusing on your baby.

• **Giving up anticipatory grief and fear of death** – This comes gradually as your child becomes healthier, when s/he begins to grow and develop.

• **Understanding your own baby** – Understanding your baby involves adjusting your expectations to what your baby can do. You focus more on the normal aspects of your baby, not what is wrong with your baby or the baby’s medical problems. Increasing interaction with your baby - You become involved in the normal aspects of baby care such as changing diapers, holding, and feeding your baby.

How long does it take to finally adjust?

These emotions may take months or longer to reduce. During this period, some parents become involved in support groups or parent organizations which can be helpful.
What can I do to help myself?

Some things that parents tell us are helpful:

• Learn about common emotional reactions so you understand that what you are experiencing is normal.
• Talk to someone. This may be a spouse, family, clergy, or the baby’s caregivers. Many parents become involved in parent support groups or offer to talk to new parents of babies with similar problems. Through sharing their experience, they hope that they can make the emotional transition of other parents a little easier. Most new parents find contact with other parents who “have been there” to be helpful.
• Seek information about your baby and his/her problems. Ask lots of questions. Understand as much as possible about your baby.
• Get involved in the care of your baby as early and as much as possible.
• Appreciate that having a sick baby is likely to be the biggest life stress that you have encountered. Don’t hesitate to get help or counseling if you think that you might need it.
• Take care of yourself – adequate sleep and good nutrition.
• Keep a journal.
• Learn relaxation techniques; listen to soft music, take a warm bath.
• Let yourself take a day off from the NICU. The stresses of the NICU can take an enormous emotional toll on you. These pressures can cause you to become physically run-down and ineffective in the care of your baby. It might be worthwhile for you to consider taking a break.
Your beautiful baby has arrived. But he or she was born prematurely or is sick, and needs special care. Your joy over your baby’s birth may be mixed with worry and heartache. Here is what to expect and ways to cope.

The birth of a premature or sick baby is stressful and difficult for all family members. But it can be especially rough on you. You may worry about your baby and your partner, as well as other children at home, demands from your job and financial concerns. While each father develops his own way of coping with the birth of a premature or sick infant, this information may help make this difficult time a bit easier.

Expect strong emotions

You may feel many conflicting emotions after your baby is born. These emotions can be very intense. All of the feelings listed below are normal and most men experience some of them. As your baby gets stronger, your negative feelings may lessen.

- Anxiety and fear over your baby’s medical condition and what her future holds
- Grief over the loss of the birth you had planned
- Anger and resentment over the changes in your life
- Helplessness and frustration over your inability to help your baby
- Tension from being pulled in so many different directions as you try to support your partner, deal with financial concerns and demands at home and at work, and spend time with older children as well as with your baby
- Overwhelming love and pride in your new baby
- Amazement over the progress she makes and the obstacles she overcomes
- Hope that she will have the bright future you dreamed of

Keep in mind

- The birth of a sick child can put stress on the relationship between you and your partner, as well as your relationships with other family members. It is important to share your feelings with and support your partner through your baby’s illness, and come through it a stronger team. Remember:
- Men and women sometimes cope differently. Some men tend to keep their feelings to themselves in order to spare their partner. A woman may feel that this behaviour shows a lack of caring.
- You and your partner may experience many of the same feelings, but not always at the same time. Accept that you may not always be on the “same page.”
- You, your partner and your families may react differently to the same situation. Try to discuss why you feel the way you do, and listen and empathize with your partner’s feelings.
- You, your partner and your families may differ on how much information on your baby’s condition to share with family and friends. Sometimes, a woman may prefer to share fewer medical details than her partner because she may feel responsible for her baby’s condition. It’s important to respect differences and decide what information you are both comfortable sharing.

What you can do for your baby

You play an important role in your baby’s recovery. Here are some ways you can help care for your baby:

- Spend time with your baby. Get to know the neonatal intensive care unit (NICU) staff and learn about your baby’s health care needs. The more time you spend with your baby, the more comfortable you will feel about his condition and care. Share any concerns
about your baby's care with the staff. Trust your instincts – you are the dad.

- Ask questions. Ask as many questions as you need to about your baby's care. There is no such thing as a stupid question.
- Make decisions about your baby’s medical care with your partner.
- Touch and hold your baby as soon as the nurses give you the go-ahead. Although your baby may be tiny and fragile, you can still touch and interact with him. Know that your baby recognizes your voice and touch.

### Let others help

You can’t be everywhere at once, so set your priorities and let others pick up the slack. This frees you to spend more time with those who need you most.

- If you have other children at home, try to spend some special time with them and reassure them that they are loved. They are worried about Mom and the baby, too.
- Ask for and accept help. Many family members and friends want to help, but are not sure what to do. Make a list of practical things people can do to help: cook meals, clean the house, mow the lawn, go grocery shopping, take children to school and walk the dog.
- Ask a trusted family member or friend to pass on to other family members and friends the information you and your partner have agreed to share about your baby’s medical condition and progress.
- Balance the areas of your life. When you return to work, try to limit your work hours so that you can spend time with your baby, partner and other children. Let your employer know about your baby's condition, in case you need to leave work unexpectedly or are sometimes unable to accomplish all that you would like. This can take some pressure off of you.
- Maintain your sense of humour. Whenever possible, try to joke about the little things. Humour can be healing, and can make a difficult situation better for everyone.

### Support your partner

New moms of premature or sick babies have some special concerns. Your partner may need some extra support and understanding in the early days after your baby is born. Here’s how you can help:

- In the early days, your partner may be too tired, uncomfortable or sad to spend much time in the NICU. Or your baby may have been transported to a different hospital where she can receive the best care. Show your partner pictures of your baby and share all the day-to-day details of your baby’s care.
- Be patient. Mom’s fears, pain, fatigue and hormonal changes can make her more emotional and irritable than usual.
- Reassure her. Many mothers of premature or sick babies feel responsible and guilty for their baby’s condition. Listen and empathize with her feelings, but reassure her that nothing she did caused her baby's condition.
- Help with the demands of pumping milk. If your partner chooses to pump her milk, support her in any way you can. Help get bottles ready, offer to put milk in the freezer and deliver it to the hospital, when necessary. Breast milk is the ideal food for all babies, and may have special health benefits for premature and sick babies.
- Encourage her to take care of herself. In her concern over the baby, she may not get enough rest or eat right.
- Praise her for spending time with the baby, pumping milk and everything she does. Your partner will appreciate hearing that she’s a great mom.

### Take care of yourself

Nobody expects you to be Superman. In order to remain strong and support your family, be sure to take care of yourself.

- Get enough sleep and maintain a healthy diet.
- Take a break. Though your time is limited, try to fit in activities that help you relieve stress, such as exercise, sports, hobbies, going to the movies or playing with your other children. You will be better able to cope and help your family if you give yourself a break once in a while.
- Find support. Consider attending a NICU parent support group. You may find it helpful to talk with other dads with babies in the NICU. No one understands what you are going through better than other dads who have been there.
- Though you may not know it, you are already playing an important role in your baby's life. You are a member of the NICU team that is working to make your baby stronger. You provide your baby with comfort and support, and celebrate his victories, as only his dad can do. Being a NICU dad can be difficult, especially if your baby is very sick. You should take pride in all the things you do to help your baby and your partner, and realize that you are making a difference.

*From the March of Dimes website, 2010*
Holding your baby close: Kangaroo care (skin-to-skin)

Kangaroo care is the practice of holding your diapered baby on your bare chest (if you’re the father) or between your breasts (if you’re the mother), with a blanket draped over your baby’s back. This skin-to-skin contact benefits both you and your baby. Kangaroo care is safe and beneficial, even if your baby is connected to machines. Whatever your situation, this is a precious way to be close to your baby.

Ask your neonatal intensive care unit (NICU) staff about kangaroo care. Sometimes kangaroo care is postponed until the infant is medically stable.

You may be a little nervous about trying kangaroo care. If your baby is very small or sick, you may be afraid you’ll hurt him. But you won’t. Your baby knows your scent, touch and the rhythms of your speech and breathing, and he will enjoy feeling that closeness with you. Kangaroo care can help your baby:

- Maintain his body warmth
- Regulate his heart and breathing rates
- Gain weight
- Spend more time in deep sleep
- Spend more time being quiet and alert and less time crying
- Have a better chance of successful breastfeeding (kangaroo care can improve the mother’s breastmilk production)

Kangaroo care has emotional benefits for you, too. It can build your confidence as you provide intimate care that can improve your baby’s health and well being. You are giving something special to your baby that only you can give. By holding your baby skin-to-skin, you may feel the experience of new parenthood and closeness to your baby. Kangaroo care is positive in many ways, for both you and your baby.

From the March of Dimes website
You can comfort your premature baby in the NICU by minimizing noise, providing positioning support, and reading your baby’s cues.

Although your baby needs to be in the hospital nursery, it is not always a very comfortable or restful place to be. Lights are on 24 hours a day; machinery, alarms, people, telephones, and radios can create a lot of noise and necessary medical procedures are often painful. Even routine caretaking activities can be tiring and disruptive.

In the last ten years, researchers developed ways of making nurseries and neonatal care more “baby friendly”. They have recommended changes in the ways nurseries operate to help lessen the negative effects of hospital care and minimize the baby’s stress. In addition, they recommend that the care each baby receives be adjusted to best fit that baby’s needs and coping abilities. This approach, known as individualized developmental care, is designed to provide an environment in which a preemie’s development can continue as normally as possible despite his early birth. Research into its effects has shown that babies who are cared for using the individualized developmental care approach have fewer medical complications, shorter stays in the hospital, better weight gain, and fewer days on respirators. There may be long-term effects of this approach, as well. Some of the early research has indicated that babies cared for with this approach may show better development in their first year of life.

As a result of this work, many nurseries have made modifications to the nursery environment and to the way in which they provide care. For example, medical and caregiving procedures are often grouped so that babies can sleep undisturbed for several hours at a time. In addition, during uncomfortable procedures, various comforting methods may be used to help babies stay calm. These include holding a baby in a curled position with hands or swaddling, giving the baby something to grasp, or a pacifier to suck on, giving sucrose.

As a parent, you can provide comfort and support to your growing baby in a number of ways. These may include making modifications to your baby’s surroundings to minimize stress from noise and lights, as well as learning how best to touch, hold and interact with your baby as he grows and matures.

Observe your baby’s environment and try to minimize unnecessary noise and light. There are a number of simple adjustments you can make in your baby’s surroundings to help reduce the amount of disruptive stimulation that he receives.

- Make sure your baby is shielded from light either by adjusting the amount of light shining directly on him or by putting a blanket or other covering over his incubator or bassinet. If your baby is on a warming table, see if there is some way to shield his eyes from light.
- Always close the doors to his incubator quietly instead of snapping them shut. Try not to set anything down on top of the incubator, or do it quietly.
- Keep voices low around your baby, particularly when he is sleeping, or move away from his bedside for conversations.
- If your baby’s bed is located in an area of the nursery where there is a great deal of activity or foot traffic, maybe ask if it is possible to be moved to a quieter spot.

When you hold your baby, keep him in a flexed position and place boundaries around him while he sleeps. Premies, like all newborn babies, feel more secure when they are swaddled securely in a blanket with their legs tucked up, arms bent, and hands brought together in front of them and near their mouth. When they sleep, they prefer to be touching or lying up against something, and will often move in the incubator until they are up against the wall or the bottom of the enclosure. By positioning your baby in a curled position and providing boundaries for him when he sleeps, like a nest, he will feel calm and comfortable. This encourages the development of the curled position—known as flexion—that babies naturally assume in the womb. Premies, with their lack of muscle strength, have a hard time maintaining this position by themselves, and, if not supported in a flexed position, will lie with straight arms and legs on their nursery beds.

To provide comfort to your baby and support his physical development, try the following measures:
- Swaddle your baby in a blanket with his arms and legs bent and hands brought together in front of him or to his face.
- When you hold your baby, keep him in a slightly curled position, with his legs tucked up and his hands brought forward in front of him.
- Create a nest for your baby to sleep in. Ask you nurse about this. She will roll blankets and place them around your baby to help keep his legs tucked or put them against his back and around the top of his head. Place a folded cloth blanket under your baby’s chest when he is on his stomach to help him to feel secure and be in a flexed position.

Learn to read your baby’s cues and pace your activities with him accordingly. Premature babies tend to express themselves through physical changes and behaviour. As you spend more time with your baby and as he matures, you will begin to recognize how he signals that he is getting tired or upset, and the things he does to calm himself. The following techniques may help your baby stay calm or regain his calmness if he has become upset.

- Provide one form of stimulation at a time: if you rock...
him, don’t talk; if you are feeding him, try not to look him in the eye; while you are holding him, shield his eyes from strong light. Add more types of stimulation slowly, watching your baby for signs of stress.

• When your baby signals that he is getting tired and needs some time out, give him a rest period by cutting back on some of the stimulation he is receiving. For example, if you are rocking and looking at him, look away and just hold him quietly, perhaps shading his eyes from light until he relaxes again. Or decrease the intensity of the stimulation by talking more softly, or rocking more slowly. If these approaches don’t work, your baby may simply need to be placed back in his incubator or bassinet to rest and sleep.

• Help your baby bring his hands to his face or mouth, or offer him your little finger to hold or a pacifier to suck on.

• Handle and move him slowly and gently.

• If your baby must be unwrapped from his blankets during certain procedures, use your hands to keep his arms and legs tucked up and to create boundaries around him. This will comfort him and help him feel more secure.

Apply gentle but firm pressure on your baby’s back or chest with your open hand. This helps him to block out other stimulus, and calm himself.

Why does my baby not act like a full-term baby?

To learn about what babies do, it is helpful to think about five different areas of development. These areas of development are controlled by the brain and develop in cooperation with each other.

The five areas of development are:

**Physiological** – things that happen automatically, such as breathing, heart rate, color changes, digestion, bowel-movements

**Motor** – posture, movements, muscle tone

**States of consciousness** – levels of sleep and being awake, and changes from one to the other

**Attention** – the ability to focus on a message, such as to turn to sounds and look at faces and other objects; this leads eventually to being able to respond socially – to interact with – people

**Self-regulation** – the ability to keep the other areas in balance, for example, the ability to calm down (reduce motor activity and change from a state of crying to being quietly awake) when upset, by tucking limbs close to body, bracing self against side of crib, or sucking on hands

Because the nervous systems (brains) of preemies are not as mature as those of full-term babies, development in these five areas is not as far along as in a full-term baby.

For example, you may find your preemie has:

• Immature physiologic development, as seen when:
  – the baby changes color often
  – breathing or heart rate is uneven
  – the baby gags easily

• Immature motor development, as seen when the baby:
  – twitches, is tense or stiff, trembles
  – is limp
  – can’t stay curled up

• Immature control over states of consciousness, as seen when the baby:
  – can’t become alert, or stay alert for long
  – is generally fussy

• Immature development of attention, as seen when the baby:
  – can’t focus on you
  – becomes worn out trying to respond to you

• Immature self regulation, as seen when the baby:
  – has a hard time calming down after being disturbed
  – has trouble handling several kinds of things going on at the same time, e.g. having you talk to and look him/her in the eyes at the same time, or talk while also feeding.

What can my baby do?

**Hearing – The Auditory System**

Hearing is fairly well developed by 20 weeks gestational age (GA).

By 25 to 28 weeks GA, the preemie responds in different ways to different sounds.

For example:

• Shows more interest in voices than other sounds

• Shows dislike (by frowning or startling) of loud noises, such as a machine alarm or loud voice

• Can pick out the mother’s voice (which he/she has heard in the womb) and prefers it over other voices

What sounds do preemies hear?

By 28 weeks GA, sounds of about 40 decibels (dB) loudness (between normal speech at 50 dB and whispers at 30 dB).

At full term, sounds as soft as 20 dB loudness, equal to what an adult with good hearing can hear. Sounds with low and medium pitches are better than high-pitched sounds.
Seeing – The visual system

Seeing takes longer to mature than hearing and touch, but progress occurs rapidly between 22 and 34 weeks of gestational age (GA).

- At first, preemies spend only very brief periods of time with their eyes open, and do not focus on anything.
- By 30 weeks gestational age, preemies will respond in different ways to different sights.
  - They respond to bright light by blinking or shutting their eyes, but in softer light will open their eyes and focus on objects.
  - They can scan an object with their eyes, even though they can’t yet control the movement of their heads.

Infants don’t see as well as adults.
- They are nearsighted (can only see things up close). They see best when objects are about 8 to 10 inches away from their faces.
- Preemies take longer to focus on an object than do full-term infants, and their vision is not as clear as either full-term infants or adults.

Sleeping and waking

What a baby does and how he/she reacts to what is going on depends a lot on the state of sleep or wakefulness the baby is in.

For example:
- A baby who is in a deep sleep is hard to wake up and will try hard to go back to sleep; a baby in light or dream sleep can be waked quite easily and is more likely to stay awake.
- A baby cannot focus on your face when in the drowsy wake state, no matter how hard you try to get his/her attention, but can if in an alert state.

Babies have two sleep states, an in-between sleep-wake state, and three wake states. At first, the states are hard to tell apart, but they become clearer as the baby grows. The amount of time a baby spends in each state also changes as the baby grows. Both of these patterns of change reflect the gradual maturing of the brain and nervous system.

Sleep states

Deep sleep (also called Non-REM or quiet sleep) – The baby is very still. Every now and then there is a sigh or startle. Breathing is quite even. Deep sleep is thought to be the more restful stage of sleep, and important for growth. Young preemies have very little deep sleep, and there may be more little movements and less even breathing.

Light sleep (REM or active sleep) – The baby may move quite a bit and make little noises; breathing is uneven; eyelids often flutter (Rapid Eye Movements [REM]), and eyes may open briefly or be kept slightly open for long periods of time.

Young preemies spend most of their time in light sleep. Very young preemies don’t move as much or have as much REM as older preemies.

Going from asleep to awake – It is hard to tell whether the baby is asleep or awake, as when the baby is beginning to wake up. The baby moves quite a bit, may grunt and open eyes briefly, but may go back into light sleep several times before really waking up.

Young preemies may be in this state quite a bit.

The pattern of sleep states

A full-term baby spends about 15-20 minutes at a time in deep sleep and 65-70 minutes in light sleep. A young preemie may spend only 2-5 minutes in deep sleep before going back into light sleep. All infants (preemies, too) go to sleep into light sleep, and if not disturbed, wake up from light sleep.

The pattern of more light than deep sleep changes slowly over the first year to the adult pattern of spending more time in deep than light sleep. Thus a gradual increase in the amount of deep sleep shows that the brain is growing as it should.

At term age (40 weeks), preemies still do not have as much deep sleep as the full term. However, if light levels are lower at night than during the day during their “growing” period in the NICU, they may progress faster.

During each sleep period, infants go through two or three light-deep-light sleep cycles. It is important that they be able to go through this cycling. That is a big reason for trying not to disturb infants during their sleep periods.

Wake states

Just as there are levels of sleep, babies also have several levels of being awake:

Drowsy – The baby’s eyes open and close, looking like he or she can hardly stay awake or is having trouble waking up. Sometimes the eyes are open, but the baby is “dazed out”, not looking at anything. There is usually not much movement.

Active awake – The baby is awake, but is not really looking at anything. Eyes may be open or closed, and the baby is usually quite active. This is often the state the baby is in when fussing or crying.

Alert – The baby is awake with eyes open and is looking around (scanning). Preemies often have a “not very alert” state, in which they seem to be trying to focus but don’t have the wide open, shiny eyes of a fully alert baby.

Fussing/Crying

This is a pattern we recognize in any infant. It usually happens during active wakefulness. But fussing can occur in light sleep, and as they get older, infants may be able to cry and stay alert, although this is hard for them to do. The
very young preemie may not have the strength to make any noise when fussing or crying.

The pattern of wake states

Before 26-27 weeks, it may be hard to tell whether the preemie really wakes up. There is no alert state. Between 27 and 30 weeks the preemie usually can become alert only for a very short time. When awake, the preemie is either drowsy or active awake. The time spent alert gradually goes up as the baby grows, and the amount of active awake goes down. Thus increasing alertness is another sign that the brain is growing well.

Communicating

Your baby talks to you through his/her behavior and you can learn to understand or “read” your baby’s behavior. You can learn who your baby is, what his/her behaviors mean, what he/she likes and doesn’t like. For example, there are cues, or signs, a preemie gives when stressed and others when stable:

<table>
<thead>
<tr>
<th>Example of stress</th>
<th>Example of stable</th>
</tr>
</thead>
<tbody>
<tr>
<td>color changes, gagging, hiccups, yawn, sneezing</td>
<td>stable color, sucking</td>
</tr>
<tr>
<td>tremors or twitches, arms or legs out stiff, spreading fingers wide, arching back</td>
<td>smooth movements, relaxed posture, grasping/ hand-holding, loosely curled up/flexed</td>
</tr>
<tr>
<td>weak or gaspy cry, can’t be wakened up, irritability, a lot of fussing or crying</td>
<td>rhythmic or robust cry, will slowly wake up, no irritability, not much fussing or crying</td>
</tr>
<tr>
<td>glassy-eyed stare, turning away, or abruptly going to sleep</td>
<td>focused attention</td>
</tr>
</tbody>
</table>

The baby needs to be alert to attend to (think about) what he/she sees. This is a very important form of learning. Alertness is also very important for interacting with people, and therefore is related to social development.

At full-term age (39-40 weeks), preemies still are not spending as much time alert as a full-term baby does. However, many of the things now being done in NICUs to help preemies grow well (see section on Developmental Care) may help them be more alert earlier.
Before your baby was born, you may have imagined what it would be like to hold and feed her. And you may have already decided to feed your baby breastmilk or formula. But now that your baby is in the neonatal intensive care unit (NICU), you may need to adjust your plans.

Experts agree that breastmilk provides many wonderful and vital health benefits for all newborns, especially premature or sick babies. A baby needs good nutrition to grow and become stronger. But the baby may need to be fed a different way for a while, before being ready for breast or bottle.

**Intravenous feeding.** Babies who are very small or sick are often fed through a tiny tube put in the vein in the baby’s hand, foot or scalp. She will receive sugar (glucose) and essential nutrients through the vein. As soon as she is strong enough, the baby will be fed by gavage feeding. (See below.)

**Gavage feeding.** The baby is fed breastmilk or formula through a tube placed through the nose or mouth into the stomach. The tube may be left in place or inserted at each feeding. Inserting the tube should not bother the baby too much because babies this small generally do not gag. When she can suck and swallow well, gavage feedings are stopped, and the baby can be breast- or bottle-fed.

**Breastfeeding**

Breastmilk provides many wonderful and important health benefits for all newborns, including premature babies. But many NICU babies aren’t ready to feed from the breast at first, so the mother can learn how to pump her milk so it can be given by tube to the baby’s stomach. If your baby can’t suckle, tube feeding is the best way for your baby to get your breastmilk.

Here are some ideas for meeting the challenges of breastfeeding your baby in the NICU:

- **Discuss your desire to breastfeed with your baby’s nurse.**
- **Ask to speak to a breastfeeding resource nurse** or to other NICU moms who are successfully breastfeeding their babies.
- **Start pumping as soon as you can,** and use the pump that best works for you, such as a hospital-quality electric pump in good working order.
- **Establish a relaxing habit** so that you condition your breasts to “let-down” (eject milk) when it’s time to pump or feed.
- **Establish or build your milk supply** by pumping every 2 to 2-1/2 hours around the clock for a couple of days and nights (or 8 to 12 times during the day, if sleeping at night is very important). After your milk supply is established, go no more than five hours (give or take) at night, and then pump at least eight times throughout the day.
- **Empty your breasts when you pump** as this brings the hind milk, which is highest in fat – calories your baby needs. Pump for a minute or two after milk flow stops or comes out in slow drips.
- **Keep going through the ups and downs** of your milk supply. Expect very small amounts at first. At any time, if your breasts give less milk in spite of pumping, you may be tempted to give up. Try getting more rest, drinking more water and pumping more frequently (rather than for longer sessions). Your milk supply may build up naturally in response to less in stress in your body.
- **If your baby is able to suckle, he will be more ready to feed when he is wide awake and quiet.** Ask to feed him in a quiet, darkened environment so he does not become distracted. If possible, start by doing kangaroo care: hold your diapered baby between your bare breasts. Kangaroo care may relax both of you, and the skin-to-skin contact may inspire him to suck and your milk to flow. When he starts rooting around on your skin, guide him to your nipple.
- **Recognize that every mother has to do a certain amount of figuring out what works best.** For instance, if your baby has trouble latching onto your nipple, try using your pump’s suction to draw out your nipple before putting your baby to the breast. Or if your milk spurts out at the beginning of the feed and overwhelms your baby, pump just enough to decrease the pressure or volume. That way, your baby can keep up without swallowing air or choking. Try to find solutions that work for both of you.
• **View the entire feeding relationship as meaningful for you and your baby.** If you choose to supply a small amount of milk, or if you want to put your baby to the breast even if you supplement with a bottle-feeding afterwards, do so. Give yourself time to try things out and adjust.

If you wanted to breastfeed but then decided not to or are forced to give it up, you may feel disappointed. Remember that you also can have a close and rewarding relationship with your bottle-fed baby. You can experience the closeness of breastfeeding by cuddling your baby against your warm skin and letting your baby observe your face.

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**Formula feeding**

If you cannot breastfeed, formula will be given to your baby.

You may need to wait a while before you feed your baby from the bottle. If she is very premature or ill, she may first require gavage feeding, where a thin tube is put through the baby’s nose or mouth to the stomach, and the formula is inserted into the tube (see page 20).

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As you may already know, breast is best. Your breast milk closely matches your baby's requirements for nutrition as well as for a healthy immune system; it is made specifically for the needs of your baby.

Premature babies need breast milk as much if not more than term infants as this milk has many benefits, like reducing the incidence of NEC (a bowel infection that some preemies get), respiratory diseases, diarrhea, etc.

This document is meant to support you in your decision to breastfeed your baby. If you have any questions, feel free to ask your nurse.

Get started!
While you are still in hospital:
- Hold your baby skin-to-skin as soon as you can
- Start expressing your milk within 24h of delivery; but earlier is better, ideally within the first 6 hours.
- Using your hand to get out your milk (manual expression) can be the best way to collect colostrum (the first milk). This milk can be as thick as honey and often gets lost in the bottle. Ask your nurse to show you how to manually express.
- You can use the pump after manually expressing to increase your milk production.
- Purchase 2 breast pump kit(s) from 5-West/Post-Partum Unit. Double pumping is recommended to establish and maintain a long term milk supply.
- Ask your nurse to give you plastic bottles, caps and labels. Your NICU nurse will give you 18 bottles at discharge (to get you started), then as needed when pumping in the hospital.
- Use a hospital-grade electric breast pump (available on 5-West/Post-Partum and in the NICU Mother's corner). Single pumping with a manual or non-hospital-grade electric pump will not establish or maintain a long-term milk supply.
- Do not be discouraged if you get very little the first few days. As you stimulate your breasts, your milk supply will increase. Save any and all milk you get – every little bit counts!

Equipment needed
Rent a hospital-grade electric pump:
- For long term pumping it is strongly recommended to rent a hospital-grade electric pump. Ask your nurse for a list of available rental places around the hospital or your home. You can also find out where to rent a pump by calling the pump companies or visiting their websites.
  - Medela Pumps: 1-800-435-8316
  - Ameda Pumps: 1-800-604-6225
    http://www.motherschoiceproducts.com/Where-to-Buy-or-Rent

Buy breast pump kit:
- Available for purchase in 5 West / Post-Partum (approximately $16/kit).

Buy bottles / plastic containers:
- Clear hard plastic bottles (and caps) are available for purchase in the hospital from the HERZL Breastfeeding Clinic (Pavilion H).
- Any reusable plastic bottles for milk storage are available in department stores, pharmacies or grocery stores.
- Make sure to ask for milk labels to identify each bottle.

Buy freezer gel packs / insulated bag / cooler:
- Available in department stores (Canadian Tire, Walmart, Zellers) or Dollar stores.

Cleaning the equipment
Breast pump kit:
- All pieces of the breast pump kit have to be washed with soap and hot water after each use and rinsed thoroughly.
- All pieces of the breast pump kit that come into contact with breast milk have to be sterilized once daily by either boiling for 20 minutes or putting in the dishwasher (once you’re home).
- Allow the equipment to air-dry by laying it out on a clean paper towel or a clean cloth; do not wipe the inside of the equipment with a cloth.

Expression of breast milk
- Wash hands.
- Express your milk a minimum of 7 times every 24
hours; ideally 8-12 times a day. Because your baby was born early, long-term frequent pumping is necessary to maintain your milk supply. (Pumping 5-10 minutes is better than missing a pumping session altogether.)

- With a single or double breastpump kit, pump approximately 15 minutes or 2 minutes after the milk droplets have stopped flowing.
- If no drop of milk is coming, make sure the suction is well regulated. After about 2 minutes, try the stimulation phase again (button on right). If there is still no milk flowing after 2 stimulation phases, take a break and try again in 15-30 minutes. Try not to get discouraged, it is common for women to experience moments when the milk does not flow, especially in the first few days.
- Make sure that the phlange (cup you put on breast) fits properly. Your nipple should be centered and should not rub up against the sides. Ask your nurse if you have any concerns. Different sized flanges exist.
- Massaging or compressing your breast while pumping can help increase your milk volume (if you are double-pumping, you can purchase a hands-free pumping bra or you can cut holes into a tight tank-top so that your hands are free to massage/compress your breasts). See http://newborns.stanford.edu/Breastfeeding/MaxProduction.html for a good video.
- If you express milk every 2-3 hours during the first 10-14 days, the daily milk volume should reach approximately 750-1000 mL (a minimum of 350 mL). If this is not the case, please advise your nurse.
- It is advisable to pump at least once during the night because prolactin (a hormone that helps with milk supply) is increased at night. Try not to let more than 5 hours go between pumpings more than once/day as this will decrease your milk production.
- Avoid filling the container to the top. Leave about 1 cm (1/2 inch) air space to allow milk to expand during freezing. If you have more milk, use a second container.

Handling of breast milk

- Wash hands.
- Store expressed breast milk in sterile plastic containers/bottles.
- Label the container with hospital labels stamped with your infant's addressograph; verify the label for the right name and unit number. (It is suggested to apply pieces of masking tape before putting the label on the container.)
- Add the date and time of pumping on the top line of the label.
- Refrigerate any breast milk within 1 hour of expression.
- Once a day, freeze the milk you plan to keep at home. This will avoid you opening/closing the freezer often and will keep the cold chain going.

Storage of breast milk

While you (the mother) are still in hospital:

- Your nurse will give you sterile plastic bottles (Volufeed) with caps and labels; these bottles are single use and must be discarded after each use.

When you are back home:

- Use clear hard plastic containers/bottles to bring your milk to the hospital.
- Glass container/bottle and breast milk storage plastic bags are a good choice for conservation but can only be used to store milk at home. It will not be accepted in the hospital for safety reasons.
- Use a separate container/bottle for each milk expression. Adding warm milk to cold or frozen milk is called “layering” milk and is not recommended for premature infants because it can alter the milk.
- Store milk in feeding-sized portions to prevent wastage; ask your nurse the approximate amount of milk your infant is receiving in order to meet his/her needs for the next 24 to 48 hours.
- Bring a maximum 48-hour supply of expressed milk to the hospital refrigerator and freezer, unless you are unable to visit for a longer period of time.
- Never refreeze thawed breast milk.
- In the NICU, fresh breast milk can be put in the freezer within 48 hrs of conservation.
- Keep the extra milk pumped at home, labeled and frozen.

In hospital breast milk conservation policy:

<table>
<thead>
<tr>
<th></th>
<th>Room Temperature</th>
<th>Refrigerator</th>
<th>Freezer compartment inside refrigerator</th>
<th>Separate freezer door</th>
<th>Deep freezer</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fresh breast milk</td>
<td>1 hour</td>
<td>48 hours</td>
<td>N/A in NICU</td>
<td>2 weeks</td>
<td>N/A in NICU</td>
</tr>
<tr>
<td>Defrosted breast milk</td>
<td>1 hour</td>
<td>24 hours</td>
<td>N/A</td>
<td>N/A</td>
<td>N/A</td>
</tr>
</tbody>
</table>

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1: http://newborns.stanford.edu/Breastfeeding/MaxProduction.html
**Transport of breast milk**
You are encouraged to bring fresh breast milk to your infant.

- Once you give your infant the colostrum (even frozen) initially, you can then bring fresh milk.
- Use an insulated container/bag or a cooler, and freezer gel packs to transport the breast milk to and from the hospital. Please do not use ice cubes.
- Keep the milk at the same temperature during transport. If milk was frozen, keep milk frozen during transport. If milk was refrigerated, keep milk cool during transport.

**Tips for pumping and increasing milk supply**
- As soon as you can, hold your baby skin to skin. This can help to increase your milk supply and milk let-down. Bring your kit to the hospital and use the pump in the mother’s corner or beside your baby’s crib after holding him/her.
- Like everyone, you should try to eat a balanced diet. Eat when you are hungry and drink when thirsty (http://www.hc-sc.gc.ca/fn-an/food-guide-aliment/track-suiit/table_bf-fa_female-femme_age19-50-fra.php). Have a pumping routine at home. Set up a comfortable area where you can relax in a supportive chair. Place a picture of your baby nearby or have a piece of your baby’s clothing or blanket beside you to help you think of your baby.
- When your baby is ready to start breastfeeding, set up a feeding time with your nurse. Continue to pump your breasts after each breastfeeding.
- When your baby is ready to start breastfeeding, set up a feeding time with your nurse. Continue to pump your breasts after each breastfeeding.
- If you have any concerns or questions, please feel free to ask your nurse.

**Breastfeeding advantages for you**
- Delays fertility
- Decreases incidence of breast cancer
- Protective effect from uterine cancer
- Decreases the risk of ovarian cancer
- Protective effect from endometrial cancer
- Improves emotional health
- Decreases insulin requirements
- Decreases risk for osteoporosis
- Promotes postpartum weight loss

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**At home breast milk conservation - Only when your baby is considered term:**

<table>
<thead>
<tr>
<th>Room Temperature</th>
<th>Refrigerator</th>
<th>Freezer compartment inside refrigerator</th>
<th>Separate freezer door</th>
<th>Deep freezer</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fresh breast milk</td>
<td>Ask your pediatrician/doctor</td>
<td>Ask your pediatrician/doctor</td>
<td>2 weeks</td>
<td>3 months</td>
</tr>
<tr>
<td>Defrosted breast milk</td>
<td>1 hour</td>
<td>24 hours</td>
<td>N/A</td>
<td>N/A</td>
</tr>
</tbody>
</table>

1Jones F, Tully MR. “Best Practice for expressing, storing and handling human milk in hospitals, homes and child care setting”. Human Milk Banking Association of North America. 2006

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**Breastfeeding Resource**
The Goldfarb Breastfeeding Clinic is a centre for mothers and babies who are having breastfeeding difficulties. Specially trained breastfeeding consultants and family physicians trained in breastfeeding work together with mothers and babies to manage complicated breastfeeding cases. Mothers need a referral from their healthcare professionals from Montreal and surrounding areas. The referral form can be printed from the Breastfeeding Clinic section the the jgh.ca website: http://jgh.ca/en/Breastfeeding

How to reach us: 514-340-8222, ext. 3268 · Fax: 514-340-8634
Where to find us: Herzl Family Practice Centre, JGH, Pavilion H, Room 231.1
Closest entrance: 5790 Côte-des-Neiges
Taking your premature baby home

If you have a baby who was born prematurely, you may greet the day of discharge from the hospital with a mixture of joy and anxiety. You may have waited days, weeks, or even months to take the baby home, but when the day finally arrives it can be frightening to walk away from the security of the hospital nursery.

If you’re anxious about caring for your preemie at home, try to relax—after all, health care professionals do not send preemies home from the hospital until the babies are ready. With some preparation and planning, you will be ready, too.

Health challenges of premature babies

Babies born at less than 37 weeks’ gestation are considered premature. These babies may need support as newborns for a number of medical issues, including breathing problems that require supplemental oxygen or a ventilator, temperature regulation, feeding problems, apnea (irregular breathing), or jaundice (which occurs when a baby’s immature liver initially cannot get rid of excess bilirubin, a yellow pigment in the body produced by the normal breakdown of red blood cells). Because of these needs, premature babies may have to spend weeks or even months in a neonatal intensive care unit (NICU).

Fortunately, with support and growth, the immature organs recover and eventually are able to function independently in most cases. By the time of hospital discharge, most preterm babies do not require specialized medical care, but all continue to need good supportive care. For some babies, special medical needs persist even after discharge. To meet your babies needs, the medical team sending your baby home will prepare a follow-up plan of medical care, which will coordinate care with the baby’s pediatrician and other medical specialists as needed.

Requirements for discharge

Before a premature baby can be discharged from the hospital, the baby must meet several basic requirements that will help to ensure good health and fewer medical problems following discharge. Some nurseries require a minimum weight for discharge, but more often the NICU staff will evaluate the baby on these three criteria:

- Can the baby maintain body temperature in an open crib for at least 24 – 48 hours, depending on how premature the baby was at birth?
- Can the baby take all feedings by breast or bottle without supplemental tube feedings?
- Can the baby gain weight steadily?

The average preemie meets these criteria 2 to 4 weeks before or close to the original due date. Babies who have had surgery, babies born with malformations, or newborns who spent weeks on breathing machines and oxygen are the most likely to stay beyond their original due date.

Medical needs after discharge

Although most premature infants do not require specialized medical support after they are discharged from the hospital, there are certain medical considerations for some premature infants. In addition, all infants need regular medical care and evaluation. This includes routine immunizations, usually on the same schedule as that for full-term babies.

Infections – Like other organ systems, the immune system of a premature infant does not function as well as that of older children or adults. This places preemies at risk for contracting infections (especially viral ones) after discharge. Although premature babies can become infected with many different viruses, there is one infection they are particularly vulnerable to.

Respiratory syncytial virus (RSV) is a common and highly contagious viral infection in young children, often mistaken for a cold or the flu. It is a major cause of lower respiratory infections in infants and toddlers worldwide. Although the virus causes few problems in adults and older children, in premature babies RSV can lead to severe illness, breathing problems, or even death; it is a common cause for rehospitalization among preemies.

Synagis is a medication available to help protect infants from RSV. All preemies who were born less than 32 weeks and six months prior to the start of RSV season should have the medication. Other babies with certain risk factors are also eligible to receive this medication. For premature babies who are discharged during RSV season, the first injection of medication generally is given prior to discharge, then monthly as an outpatient throughout the RSV season.

Preparing for discharge

The discharge of a preemie from the hospital isn’t a single event, but a process. That process is designed to assure the doctors, nurses and parents that the infant can survive and thrive outside the hospital, and it prepares parents to take care of the baby on their own.

Parents of preemies are encouraged to stay overnight in the parents’ room prior to discharge. This allows parents to gain some experience in taking care of all of the baby’s needs. Parents can gain confidence as solo caregivers while having the security of knowing that a nurse is available.

As your preemie progresses toward discharge day, you can get ready for the big day and the weeks that follow by making the following preparations.
Caring for your baby in the stepdown area

When your baby moves to the stepdown area, this is a big day and signals that you baby is getting ready to go home. In this area, parents take over most of the care of the baby and the nurses are available for teaching and support. Parents are encouraged to spend most of the day and evening with their baby, getting to know their baby, bathing, feeding, talking to and cuddling their baby. This will help you as parents to gain confidence in caring for your baby.

Transfer back as part of discharge plans

If your baby was transferred from another hospital at the time of admission to the NICU, there is a possibility that your baby will be transferred back to that hospital when the baby’s needs are only to grow and develop. The transfer back, which is closer to your home, would be discussed with you ahead of this happening. The baby would go home from that hospital when ready.

Babies who are born prematurely often have two ages

Chronological age is the age of the baby from the day of birth—the number of days, weeks, or years old the baby is. Adjusted age or corrected is the age of the baby based on his due date. Healthcare providers may use this age when they evaluate the baby’s growth and development. So, if a baby is 6 months old, but was born two months early, his adjusted age is 4 months.

What should you say when someone asks your baby's age?

This is up to you. You can say, “He’s 6 months old, but he was born two months early. That’s why he looks like a 4-month-old.” Or you can say, “He’s 6 months old” and leave it at that.

Remember: When people ask about your baby, they’re usually trying to be kind, not nosy.

When will your baby catch up developmentally?

Most premature babies “catch up” to their peers, developmentally, in two to three years. After that, any differences in size or development are most likely due to individual differences, rather than to premature birth. Some very small babies take longer to catch up.

Choose a Pediatrician and make an appointment

Choosing a doctor for their child is an important decision for parents and especially for parents of preemies. Do not wait until the last minute to choose a pediatrician or doctor. In addition to the usual questions, you should ask whether the doctor cares for many premature infants. Your baby’s hospital doctor will tell you when to schedule the first visit with the pediatrician—commonly it is 1 to 2 weeks after discharge from the hospital. More commonly with premature babies, we ask the pediatrician to see them within the first week of discharge.

Discuss with the NICU staff whether your baby will require visits with medical specialists other than a pediatrician. If so, ask the NICU staff for referrals and for the telephone numbers of those health care providers. In addition, prior to discharge and after going home, your child might need to undergo routine tests, including blood, hearing, and vision tests; other tests may be scheduled as well. Make sure you understand the results of any tests and the need for studies after discharge. Your baby may also be followed in the Follow-up clinic at the hospital. The follow-up nurse will give you the date for this appointment before you leave the hospital.

CLSC nurse

The CLSC nurse may have contacted you in the first few days after the birth. The NICU staff inform and send a report to your CLSC when your baby is discharged. The CLSC nurse can provide teaching and support around breastfeeding, care of the baby and development of the baby.

Learn CPR training

To be prepared for emergencies, consider taking a course in infant CPR before your child comes home from the hospital. Make sure your partner takes the course, as well as grandparents or other caregivers who will be alone with the baby. There are infant CPR courses given both in English and in French. There are pamphlets around the NICU that give the dates and times for CPR courses at the JGH. There are also courses given in many communities.

Outfit your vehicles with a car seat

Before heading home, your premature infant will need to be placed in an infant-only car safety seat with a five-point harness system. Most car seats need to be modified with padding or head supports so that a preemie’s head stays in a position that keeps the airway open. A preemie often does not have the muscle control required to keep her head upright or to move it if he or she is having trouble breathing. As a precaution, many hospitals require that parents bring in their car seat for a test. The baby is placed in the seat and attached to a cardiopulmonary monitor that evaluates the heart and breathing.

Because of potential breathing problems, it is generally recommended that parents limit the time a premature baby remains in a car seat to an hour or so. If you require more prolonged periods of travel, ask your pediatrician if it is appropriate for your baby or remove your baby from the car seat every hour or so.
Suggestions for adapting the home environment for a premature infant

The first 24 hours at home
Your baby may react differently than he did in the nursery during his first 24 hours at home. He may sleep more than usual or cry or become restless. This is probably the result of another very different environment. It may last only a day or two or for as long as a week.

The first week at home
During the first week:
• Keep a dim light on and/or a radio low where your infant sleeps.
• Limit the number of visitors.
• Expect feeding to be slow and tiring.

When your baby fusses, try the following:
• Reduce light and noise.
• Offer a pacifier.
• Hold your baby close to you.
• Place your baby in his bed with boundaries all around.
• Wrap your baby snugly, but not too tightly.
• Avoid doing several activities at once; reduce activity; be still and quiet with your baby.

Other ways to assist your baby to adapt at home:
• Attempt to establish regular routines for bathing and play, but keep in mind that your baby may not want to be scheduled.
• If your baby is alert, offer your face and/or voice slowly and gently.

Adapted from: VandenBerg K, and Hanson M. 1993. “Going home: Caregiving issues”. In Homecoming for Babies after the Neonatal Intensive Care Nursery. Austin, Texas: Pro

Discharge debriefing
A discharge debriefing can occur sometime shortly before discharge. The main purpose of this is to review medical care after discharge, confirm follow-up appointments, and allow you time for questions about your baby. All debriefings should include a thorough discussion about caring for your preemie once you’re home. Make sure you understand all the instructions and advice, and do not hesitate to ask questions.

When you leave with your baby, be sure you have the baby’s doctor’s telephone number. If you are worried about your baby’s breathing, call 911.

Adapted and reprinted by permission from Kidshealth.org, 2010
Books for NICU parents are available in the JGH Health Science library, Patient and Family Resource Centre – located at A-200. Hours 9:00 a.m. – 4:30 p.m. After registering in the library, parents can borrow books.

Books and websites for parents can be viewed at:  
http://www.jgh.ca/pfrc

Click on this site and then on “NICU”. On this page, there are websites relevant to parents with a premature baby as well as a listing of some books for parents who have a baby in the NICU. New books in English, French and Spanish will become available as they are purchased. In the library, computers are available for families to view websites.

The following books are available in the Centre. They can be read there and can also be taken out for 2 weeks at a time. Check with circulation desk for additional books.

**Your premature baby book: Everything you need to know about your premature baby from birth to age one** by William Sears, Robert Sears, James Sears, and Martha Sears, (From Sears Parenting Library). Paperback

**The breastfeeding book: Everything you need to know about breastfeeding your child from birth to weaning** by Sears, W., & Sears, M., (2000). Paperback


**Kangaroo Care: The best you can do to help your preterm baby** by Ludington-Hoe, S. & Golant, S. Paperback

**Accompagner son enfant prématuré**, Sylvie Louis, Editions Enfant Quebec.

**A petits pas - S’occuper de son enfant prématuré à la maison**

**Les enfants Prématurés et leurs parents: Histoire d’amour** par Sylvie Louis et Gaille Treboul.


**Newborn Intensive Care: What every parent needs to know** by Jeanette Zaichker.


**Early Arrival** by Rebecca Parlakian and Claire Lerner (packet of 20 booklets), in Spanish and English.

**Preemies: The Essential Guide for Parents of Premature Babies** Paperback

**Early Passage: A Journal for Parents of Preemies** by Priscilla Hernandez Hacker, PhD & Carolyn Ringo.

**Empty Cradle, Broken Heart: Surviving the Death of Your Baby** by Deborah L. Davis.

**The Next Steps - Caring for Your Preemie at Home** 2nd edition (Canadian Institute of Child Health).
# Websites for parents of preterm infants

A lot of health information is out there but it can be hard to know where to look and what you can trust. At the PFRC you can meet with a librarian who will help you find the most up-to-date and reliable health information to answer your question. The librarian will do the search with you, guide you to the best resources to meet your specific needs, and print out the information you need to take home.

Contact us: 514-340-8222 local 2438 or 5930
library.jgh@mail.mcgill.ca

<table>
<thead>
<tr>
<th>Website/Location</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>JGH Patient and Family Resource Centre</strong></td>
<td>Website (includes links to resources created for the NICU) <a href="http://www.jgh.ca/pfrc">www.jgh.ca/pfrc</a></td>
</tr>
<tr>
<td><strong>Montreal Children's Hospital Library</strong></td>
<td>In English/en français <a href="http://www.mchfamilylibrary.ca/page.asp">www.mchfamilylibrary.ca/page.asp</a> (under Medical Conditions, select &quot;Premature infants&quot;)</td>
</tr>
<tr>
<td><strong>Kids Health Website</strong></td>
<td><a href="http://www.kidshealth.org/parent/growth/growing/preemies.html">www.kidshealth.org/parent/growth/growing/preemies.html</a></td>
</tr>
<tr>
<td><strong>Mount Sinai Hospital, Toronto NICU</strong></td>
<td>(Includes several links to other sites for understanding emotions after the birth of a preemie) In English <a href="http://www.mtsinai.on.ca/NICU/Support/default.htm">www.mtsinai.on.ca/NICU/Support/default.htm</a></td>
</tr>
<tr>
<td><strong>Toronto Sick Kid's Hospital</strong></td>
<td>In English <a href="http://www.aboutkidshealth.ca/prematurebabies">www.aboutkidshealth.ca/prematurebabies</a></td>
</tr>
<tr>
<td><strong>University of Wisconsin-Milwaukee</strong></td>
<td>(Good site for general information) In English <a href="http://www.meriter.com/living/preemie/understand.htm">www.meriter.com/living/preemie/understand.htm</a> (Parent’s story of birth of premature infant) In English <a href="http://www.meriter.com/living/preemie/Adaptation">www.meriter.com/living/preemie/Adaptation</a></td>
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<tr>
<td><strong>March of Dimes Site</strong></td>
<td>In English <a href="http://www.marchofdimes.com/prematurity">www.marchofdimes.com/prematurity</a> (Go to “for NICU families”)</td>
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<td><strong>Wisconsin Association for Perinatal care</strong></td>
<td>In English <a href="http://www.perinatalweb.org">www.perinatalweb.org</a></td>
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<tr>
<td><strong>Canadian Paediatric Society</strong></td>
<td>En français <a href="http://www.soinsdenosenfants.cps.ca">www.soinsdenosenfants.cps.ca</a> In English <a href="http://www.caringforkids.cps.ca/index.htm">www.caringforkids.cps.ca/index.htm</a></td>
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<tr>
<td><strong>Hopital Ste Justine</strong></td>
<td>En français <a href="http://www.famille.chu-sainte-justine.org">www.famille.chu-sainte-justine.org</a> (Famille &gt; Documentation)</td>
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<td><strong>Préma-Québec</strong></td>
<td>– L’Association regroupe les enfants nés prématurément (avant 37 semaines de grossesse), leur famille ainsi que tous ceux qui s’intéressent à la cause des enfants prématurés En français <a href="http://www.premaquebec.ca">www.premaquebec.ca</a> Courriel: <a href="mailto:info@premaquebec.ca">info@premaquebec.ca</a></td>
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<td><strong>La Leche League</strong></td>
<td>– Breast feeding the premature infant In English <a href="http://www.llli.org//NB/NBpremature.html">www.llli.org//NB/NBpremature.html</a></td>
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<td><strong>University of Washington NICU</strong></td>
<td>In English <a href="http://depts.washington.edu/nicuweb">http://depts.washington.edu/nicuweb</a></td>
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<td><strong>Brigham and Women’s Hospital</strong></td>
<td>In English <a href="http://healthlibrary.brighamandwomens.org/HealthCenters/Pregnancy">http://healthlibrary.brighamandwomens.org/HealthCenters/Pregnancy</a></td>
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[309x36]– 29 –
Acknowledgements

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