

The NICU - A perental guide to the
Neonatal Intensive Care Unit



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Congratulations on the birth of your baby!

The birth of a child - whether you're seasoned parents or first timers - is a wondrous experience. It also is a difficult one, filled with many worries and even more questions. For the parents of premature babies everything is amplified, from the moment of birth, to the moment your child gets to come home. Premature babies, neonates, are classified as such when born 37 weeks or sooner in a 39 - week cycle. The neonate arrives in this world at a disadvantage to term babies. Certain functions are not yet fully developed, which means the babies must be provided with extra care and attention. Their primary objective during their stay in the NICU is to grow. While the care for neonates is a delicate balancing act, rest assured that your hospital's nurses, doctors and the rest of the Neonatal Intensive Care Unit staff are well-trained in the care of your baby until he or she is allowed to go home. Consider the medical equipment in the Neonatal Intensive Care Unit, also known as the NICU- from the incubator to the phototherapy lights- as another set of eyes, ears, and gentle hands, guiding your baby in its most delicate, early stage of life.

As a parent, we know you want to be informed and involved in the care process of your baby. Knowledge is power. To that end, we want to provide you with this booklet to explain the life-nurturing tools that support your well-trained, experienced staff of NICU nurses, doctors and other professionals. This will allow you to be as knowledgeable about what this hospital is utilizing to keep your baby in the most optimal, nurturing environment during their stay here.

Childbirth is not easy. When a child is born premature, the situation is even more difficult. Parents must be prepared for all possibilities. We hope that, with the information in this booklet, some of your questions will be answered and some of your fears eased during this miraculous time. As always, if you have any concerns, do not hesitate to speak with your child's healthcare provider. Congratulations on the birth of your baby!

What is prematurity?

Prematurity is when your baby is less than 37 weeks old at the time of birth from the time of conception. A term baby is born at 38 to 42 weeks following the mother's last menstrual period.

A premature baby is usually not fully developed, meaning some vital organs might not be functioning at optimal levels. Some may not be ready to operate at all, which is why these babies are placed in the Neonatal Intensive Care Unit (NICU) and cared for by specialists. It is perfectly normal to be concerned about this delicate situation; you are not alone.

Globally, 12.9 million babies -10 percent of the world birth population - are born prematurely each year. In the United States, preterm births have risen 36 percent in the past 25 years.

Africa has the highest rate at 11.9 percent, followed by North America with 10.6 percent, and then Asia with 9.1%. The premature birth rates in Latin America and the Caribbean are at 8.1 percent, Australia and New Zealand are at 6.4 percent, and Europe is at 6.2 percent.

What can I expect?

Like with full-term births, one thing is certain: expect anything. This is a new experience, one that all the reading and research in the world cannot fully prepare new parents for. It is something you must experience to understand. That said, you must understand that as the parents of a premature baby, you will be faced with greater potential for complications than if your baby had been born full-term. You will spend a lot of time with your baby in the NICU and the journey will be long and hard, demanding immense courage and patience. But it will give your baby the best chances for clinical care, a positive outcome and the support of professionals and specialists.

In some cases, your baby may be sick and require around-the-clock care. He / she might be experiencing breathing problems such as Apnoea, which is temporary cessation of breathing. He / she could also face some infection problems of the lungs called Pneumonia, or psychological defects such as heart valve abnormalities. Your baby will reside in the NICU when the doctor deems it necessary to monitor the health of your child. He / she will be sleeping most of the time, as all of the baby's energy will be directed toward bringing the primary functions up to normal and ridding the body of harmful microorganisms. In short, you can expect things to be harder than if your baby had been born full-term, but also expect that in the NICU, everything is being done to ensure that your baby's growth is made as efficient as possible through the aid and care of a dedicated, highly-trained staff and the most technologically advanced equipment.



The Neonatal Intensive Care Unit

The Neonatal Intensive Care Unit (NICU) is where your newborn will stay for days, weeks, or possibly longer, depending on the his / her degree of prematurity. This department or area in the hospital is where hospital staff care for newborns having medical complications, or babies who have been born prematurely.

**HERE YOUR BABY WILL BE PROVIDED
THE OPTIMAL ENVIRONMENT FOR GROWTH**

And you can be right there the whole time. Though the environment in the NICU can be intimidating, health care professionals will familiarize you with it so you can participate in the care process.

Advances in neonatal care - from the amount of oxygen administered to how a neonate's temperature is monitored - have helped take some of the questions and worry out of the NICU. These innovations have made the process of caring for a premature baby more safe and comprehensive than ever.

With this booklet, you will also have the opportunity to be more informed about the process, from the moment of birth to the day

The Incubator

The incubator provides your baby with the optimal growing environment, balances his / her need for just the right amount of heat, humidity, and, in some cases, oxygen. Your baby will spend a lot of time maturing here. An incubator's goal is to mimic, as much as possible, the environmental conditions your baby enjoyed while in his / her mother's womb. Research is constant into finding ways to improve technology to create positive outcomes. When your baby is born premature, they will often be delicately placed inside an incubator by medical staff. Much of their treatment will be administered directly from the incubator, further reducing the risk of complications from outside elements such as changes in room temperature and viral or bacterial infection. It is a tightly controlled environment that allows the baby's nutritional intake to go as much toward growth as possible.

While your baby needs to spend as much time as possible growing in the incubator, newer incubators are designed to allow both you and medical staff greater interaction with your baby. Kangaroo Care, the skin-to-skin contact between you and your newborn can also be performed during the baby's stay in the incubator. It has been proved time and again to be extremely important in many ways, not least of all the development of that lifelong bond between you and your child.

THE INCUBATOR PROVIDES YOUR BABY THE OPTIMAL GROWING ENVIRONMENT

The incubator will display the baby's temperature and sometimes both, his / her central (in the tummy) and peripheral (in the foot) temperatures. By monitoring both temperatures, medical staff will determine whether a trend is developing that will result in heat loss and quickly remedy the situation. Since outside air changes can drop your baby's foot temperature (peripheral) quicker than her tummy (central) temperature, they can determine whether the temperature should be adjusted accordingly. Likewise, a larger increase in her central temperature can give the staff a head start in determining whether or not your baby is developing fever. The temperature inside the incubator can be set to air mode or skin mode. "Air mode" would allow you to regulate the air temperature inside the incubator at a specific value. Set to "skin mode", the incubator will add additional heat if it detects baby's temperature is dropping or decrease the amount of heat if it detects the baby is getting warmer.

It is very important to maintain a stable environment in the incubator and avoid, as much as possible, unless it is critically necessary, letting in cold air or letting out humidity. All of the baby's energy should be utilized for growth and development - not trying to stay warm.



Infant Warmer

An optimal temperature for your baby, sometimes called a "neutral-thermal environment," is perhaps the most important aspect of the time spent in the NICU. Newborns, especially premature babies, have a far narrower window of optimal environmental conditions, which is why they are placed in the NICU. The most fragile of neonates spend much of their time in closed-care incubators, though some clinicians prefer to put them in infant warmers.

THE INFANT WARMER PROVIDES THE OPTIMAL TEMPERATURE FOR YOUR BABY

As babies grow stronger, as organs fully develop and become less susceptible to outside elements, your newborn may spend time developing in an open-care warmer. Here, parents and staff can have unrestricted access to the little patients in an open environment while still being provided the warmth necessary for their maturity. The temperature of the infant warmer can be adjusted to optimize the condition of the infant versus the temperature of the room, again bringing that temperature in the highly desired neutral-thermal environment. Many infant warmers are now calibrated to do this automatically and maintain that optimal temperature, even while the baby is not resting in the infant warmer.



The Ventilator

Ventilation technology has rapidly changed the way neonatal patients are treated. Once, the same ventilation practices utilized on adults were used with premature babies. Through newer technology, neonatologists have further perfected neonatal-specific ventilation, taking into account your child's fragile body and developing lungs. Like most functions in the NICU, proper oxygen flow for babies is of critical importance. It is just another advance in neonatal care that has caused survival rates for premature babies to rise dramatically in recent years.

Proper oxygen flow for growing babies is of critical importance

Small puffs of oxygen will be administered to your baby using the ventilator. The doctor will determine the length and span between the breaths and your baby's natural rhythm. These "baby breaths" are so small because your baby is still growing, but are enough to support his / her underdeveloped lungs and ensure their overall continued growth.

As a baby's lungs mature to the point where he / she can breathe independently, the NICU staff will begin to wean him / her off the ventilator, a process that can be slow, like many elements of care here in the NICU. In some cases where lung disease is worse, your baby may be placed in a high-frequency oscillator, which can send between 600-900 very gentle breaths per minute into his / her lungs. Often, babies will then be placed on a C-PAP ventilator, a less invasive breathing assistance that allows your baby to further control the flow of oxygen into their lungs.



Photo Therapy

If someone says, "Your baby has jaundice," it means that the colour of your baby's skin has a yellow tint. But where does this yellow colour come from? Newborn infants are constantly making new red blood cells, and breaking down the old ones. One of the waste products of old blood cells is a yellow substance called bilirubin. Bilirubin is processed by the liver into an easily disposable form and then eliminated from the body in the bowel movements. Some babies make bilirubin faster than they can get rid of it, causing the bilirubin to build up in the body and make the skin appear yellow.

The yellow colour is most visible in natural daylight (near a window) or under the fluorescent lights like those in the hospital nursery. Sunlight typically breaks down any excess bilirubin. Given the fragile nature of premature babies, however, is where technology steps in.

The photo therapy unit helps battle jaundice

Photo therapy systems shine a warm blue light over your child and help break down extra bilirubin, which babies then pass harmlessly through their bowels. Photo therapy lights have proven to be an extremely capable way of helping to process excess bilirubin. Usually, jaundice is not a concern in newborns. But as with everything, extra care is taken with our youngest patients.

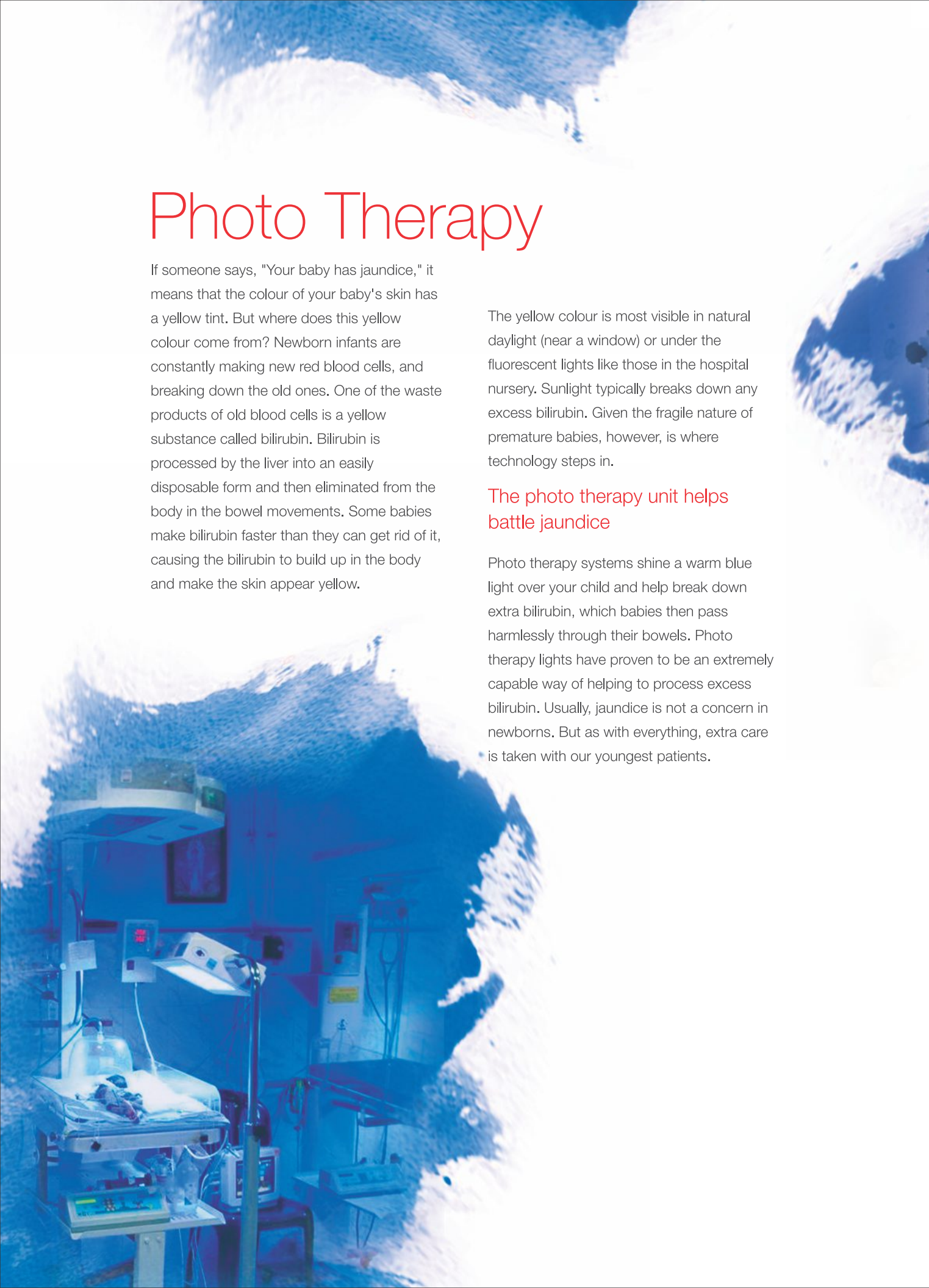


Infusion Pump

The infusion pump handles any medications, nutrients and other fluids your baby needs while in the NICU. These fluids and medications are administered to your baby through an intravenous (IV) catheter.

The infusion pump provides optimal amounts of what is needed for your baby, the dosages of which are so incredibly small that even a slight error could cause complications. For this reason, the pumps are often fitted with additional safety measures that carefully monitor how much medication is needed based on prescribed amounts, and matches that prescription to what is automatically being administered via the infusion pump. A specially trained pharmacist is on staff to handle the micro-dosing your baby may need during his / her time in the NICU.

The infusion pump provides optimal amounts of what is needed for your baby



Monitors

A lot of internal and external factors are considered when caring for a neonatal patient. Monitors in the NICU display your baby's heart rate, breathing rate, blood pressure, and oxygen levels in the blood. Other parameters can be displayed as well, depending on the baby's condition and what clinicians might need to monitor.

Monitors help us keep track of how your baby is doing

Many functions of monitors in the NICU are accompanied by the occasional warning sound, set to a very specific level. These signals are intended not to alarm parents, but to keep everyone as informed and aware as possible in the conditions of your baby's growing environment. In recent years, technology has advanced and helped reduce - and in some cases eliminate - the need for these sometimes jarring warnings in the vicinity of your growing baby. Many of these warnings are sounded at a central station. Newer monitoring technologies allow for data integration across the hospital and will allow you to see the baby's X-rays, laboratory results, and other information at the bedside that might help clinicians speed up the decision making process. Rest assured, any warning sound is a far greater benefit than a disturbing bother, and every step is taken to avoid disturbing your baby.



ECMO, X-RAY & Ultrasound

ECMO (Extracorporeal Membrane Oxygenation) ECMO is commonly used in the NICU if the baby is in pulmonary distress. It is a treatment that provides oxygenation until the baby's lung function has sufficiently recovered to maintain appropriate oxygen levels. The ECMO machine continuously pumps blood from the baby through a membrane system that imitates the gas exchange process of the lungs, by removing carbon dioxide and adding oxygen. The oxygenated blood is then returned to the baby.

X-RAY To better monitor the progress and development of your baby's internal organs, nurses and doctors look at X-rays. It helps them determine the best course of action to treat your baby's condition, especially if he is having some lung issues. Technologies today allow for X-rays to be done in incubators without having to disturb your baby. You will notice a small tray under the bed that will hold the X-ray film.

ULTRASOUND Ultrasound imaging is a common diagnostic procedure used in the NICU, which simply gives you a clear picture inside the body. It is performed by radiology or ultrasound technicians to check on the baby's developing organs, blood flow in the brain and inside the body. The procedure involves using a transducer, which is a small hand held device that sends waves into the body and detects their echoes as they bounce off internal structures. Ultrasound could be performed while the baby is resting in the incubator.

Kangaroo Care

NICUs may be technological marvels - but when it comes to tender loving care, nothing beats the real thing.

It has been well established that Kangaroo Care is one of the most important, nurturing gifts you can give your baby - from both mom and dad. Kangaroo Care is the process of initiating skin-to-skin contact between you and your newborn. Fathers, with a blanket draped over your baby's back, place him upon your bare chest; mothers, between your breasts. This has several benefits, including establishing an everlasting bond between child and parent through touch and smell. The process can help regulate your baby's heart and breathing rates and help them gain weight. It can also help calm him, serve as the catalyst for deeper sleep, and regulate baby's temperature.

For some new parents, the thought of handling such a small baby may seem frighteningly impossible. Will I be too rough with him? You won't. Starting with gentle contact through the Kangaroo Care method will allow parents to become increasingly comfortable with handling their newborn before it's time to leave the hospital, and the real journey begins.

Some NICU facilities place certain restrictions on when in your baby's growing process and for how long it is deemed safe for mother and father to participate in unrestricted Kangaroo Care. Your doctor should let you know if your child has matured to the point where Kangaroo Care is allowed. If you're not sure, ask.

When it comes to tender loving care,
nothing is like the real thing



Caregiver's Assistance

The care of your baby is something shared by everyone in the NICU, and that includes doctors, nurses, and not the least of all, the parents. Mother and nurse, especially share a special bond as together they go through the difficult journey of caring for the little one. Mother's instinct, nurse's training and the NICU's technology intertwine to create an environment optimal for the productive growth of a prematurely born child. The nurses in the NICU will spend the most hands-on time with your baby, so it is of critical importance that mother and nurse work in close, mutual understanding amongst each other.

The care of your baby is something shared by everyone in the NICU

Nurses in the NICU are not like the nurses in other hospital departments, they have been extensively trained to work within the specific requirements of tending to a premature baby. This includes newborn resuscitation. Neonatal nurses, specifically, are trained to operate the same equipments as those operated by neonatal pediatricians. This ensures that your child is receiving the same high level of knowledgeable care at all times, regardless of staff, whether it is a respiratory therapist, clinical practitioner or bedside nurse. There is a complete, excellently coordinated and a well defined system of work in the NICU.

As your premature baby matures into a full grown infant, the torch of responsibility will be passed from the nurse to the mother, and true parenting will begin. For now, however, stay assured that the nurses in the NICU are your partners in taking care of your delicate baby, with only one clear goal in mind – helping your baby grow strong enough so that he / she can go home.



The NICU family, friends and you

WHAT IS MY ROLE IN THE NICU?

While much of what is needed for your baby to mature in the NICU will be handled by the NICU staff, your role as parents will be no less important. While baby's suck / swallow / breath system will be too immature to feed directly, mother's pumped breast milk fed to the baby through a tube provides excellent nutrition to the premature child which is growing at a faster rate than term babies. This will also be a great time to try Kangaroo Care with your child. You can also read books to them or sing when they are awake so that they can hear your voice. This is the time for parents to develop the bond with their child and to get them in confidence about their love and care. If you feel unsure about yourself and your role in the NICU, it is fine to ask the NICU nurses and other staff as to what you can do to be of benefit to your child. Just being there is your main role. Some parents just have the ability to visit their child for brief periods, while others will be there for longer periods of time. It is important for you to find the correct balance, based on other factors in your life, including other children, work, or family needs.

FAMILY AND FRIENDS

Just as the NICU staff is working hard towards the goal of getting your baby's strength up to the point when he / she is fit to go home, you could, depending on the NICU you are in, ask family and friends for assistance should the need arise. And it probably will – this is a very emotional and an intense period in your life. Some of you would have gone through pregnancies before. For some, this may be the first time. You may be a veteran parent, but this may be the first time you have had a premature baby. No matter the circumstance, one thing is certain – it's never easy and it's never the same experience each time. Family and friends understand this and want to support you in any way they can. Whether it is figuring out if someone can be at the hospital if you are unable to be there or if it is simply having a hug of support or a shoulder to cry on, family and friends are essential in the process. They are a part of all this. Your premature son or daughter is also their premature son or nephew, grandchild, the child of their good friend. They too are emotionally invested in your baby's well-being.

LIFE AFTER THE NICU

Depending on how premature your baby was at the time of birth, the difficulties caring for them after leaving the NICU may be little or a lot greater than if your baby were born full term. Often, a big difficulty is going from a 24-hour guidance and care provided by the NICU to the 24-hour guidance and care required at home from you, the parents. It can be overwhelming, so never feel ashamed should you feel the need for extra help, whether from family, friends, or your baby's healthcare providers. Everybody is there to help you and your newborn grow and thrive now that they are finally out of the NICU.

While you might feel overwhelmed by this situation and perhaps frustrated that your child and you as parents, were placed in a difficult situation right at the start of your child's life, this can have a very positive effect on you as parents once you have gone home. If you have worked with your baby's healthcare providers during your time in the NICU, you have already participated in a high level of care for your child that other new parents are only starting to learn. This is not to say childcare will be easy – it won't. But it is definitely worth because your time in the NICU has brought you patience and experience. It also has brought you and your baby the beginnings of an ever-lasting bond.

Glossary of NICU terms

A - Abduction The movement of an arm or leg away from the midline of the body. Abduction of both legs spreads the legs. The opposite of abduction is adduction; adduction of the legs brings them together.

Acidosis A condition caused by the accumulation of waste acids in the body. These acid products may result from breathing problems - respiratory acidosis; or poor function in other systems – metabolic acidosis.

Adjusted Age Also known as “corrected age.” This is your child's chronological age minus the number of weeks he or she was born early. For example, if your 9-month-old was born 2 months early, you can expect him or her to look and act like a 7-month old. Usually you can stop age-adjusting by the age of 2 or 3.

Aminophylline A medication used to stimulate an infant's central nervous system. It is prescribed to reduce the incidence of apnoeic episodes. This is the intravenous form; the oral form is known as Theophylline.

Anaemia A condition in which the red blood cells in the blood-measured by a haematocrit, or “crit”- are lower than normal. Red blood cells carry oxygen and carbon dioxide to and from tissue

Apgar score A numerical summary of a newborn's condition at birth based on five different scores, measured at 1 minute and 5 minutes. (Additional measurements are made every five minutes thereafter if the score is less than 7 at five minutes, until the score reaches 7 or greater.) Premature infants generally have lower scores than full-term infants, but the Apgar score does not accurately predict future development.

Apnoea Cessation of breathing lasting 20 seconds or longer. Also known as an apnoeic episodes or apnoeic spells. It is common for premature infants to stop breathing for a few seconds. They almost always restart on their own, but occasionally they need stimulation or drug therapy to maintain regular breathing. The heart rate often slows with apnoea; this is called bradycardia. The combination of apnoea and bradycardia is often called an A&B spell. Apnoea gradually becomes less frequent as premature infants mature and grow. There is no relationship between apnoea and sudden infant death syndrome (SIDS).

Appropriate for Gestational Age (AGA) A baby whose birth weight falls within the normal range for his or her gestational age.

Aspiration 1. The accidental sucking in of food particles or fluids into the lungs.

2. Removal of a sample of fluid and cells through a needle.

B - Bethamethasone A steroid medication given to the mother before birth to help the baby's lungs mature more quickly. It is most effective if it is given more than 24 hours before delivery. Betamethasone also helps intestines, kidneys and other systems to mature.

Bilirubin Yellow chemical that is a normal waste product from the breakdown of haemoglobin and other similar body components. The placenta clears bilirubin from the foetus's blood, but after delivery this task belongs to the infant. It usually takes a week or more for the newborn's liver to adjust to its new workload. When bilirubin accumulates, it makes the skin and eyes look yellow, a condition called jaundice.

Blood Urea Nitrogen (BUN) A blood test that measures how well the kidneys are functioning.

Blood Gas A blood test used to evaluate an infant's level of oxygen, carbon dioxide and acid. This test is significant because it helps to evaluate an infant's respiratory status.

Bradycardia (“Brady”) An abnormally low heart rate. Bradys are usually associated with apnoea in premature infants. During these spells the infant will stop breathing for at least 15 seconds and the heart rate will start to slow, also referred to as an “A&B spell.” Gentle touching or other stimulation almost always restarts the breathing and increases the heart rate. Medications (theophylline or caffeine) are often used to treat these spells in newborn babies.

Brainstem Auditory Evoked Response Test A hearing test where a tiny earphone is placed in the baby's ear to deliver sound. Small sensors, taped to the baby's head, send information to a machine that measures the electrical activity in her brain in response to the sound. Premature babies are at increased risk of hearing problems, but early detection can prevent speech and language problems.

Bronchopulmonary Dysplasia (BPD)

A chronic lung disease of babies, when the lungs do not work properly and the babies have trouble breathing. It is often diagnosed when a premature baby with respiratory problems continues to need additional oxygen after reaching 36 weeks gestational age. Also referred to as Chronic Lung Disease (CLD), it is most common in babies who are born before 34 weeks gestation. Doctors think babies get BPD because their lungs are sensitive to something damaging in the environment, such as oxygen, a breathing machine, or an infection.

Catheter Type of intravenous tube used to fluids and medications to infants or children. The catheter is placed in a major vein of the body during surgery.

C - Case Manager A patient advocate who coordinates health services and home care with the insurance company during hospitalization.

Central Venous Line (CVL) The central venous line (CVL), also called the central venous catheter (CVD), is a type of intravenous tube used to give fluids and medications. The catheter is placed in a major vein of the body during surgery or by insertion through a vein in the arm, leg or head.

Cerebral Palsy (CP) Cerebral palsy is a term used to describe a group of chronic conditions affecting body movement and muscle coordination. It is caused by damage to one or more specific areas of the brain, usually occurring during foetal development; before, during, or shortly after birth; or during infancy. Thus, these disorders are not caused by problems in the muscles or nerves. Instead, faulty development or damage to motor areas in the brain disrupts the brain's ability to adequately control movement and posture.

“Cerebral” refers to the brain and “palsy” to muscle weakness/poor control. Cerebral palsy itself is not progressive (i.e., it does not get worse); however, secondary conditions, such as muscle spasticity, can develop which may get better over time, get worse, or remain the same. CP is not communicable. It is not a disease and should not be referred to as such. Although cerebral palsy is not “curable” in the accepted sense, training and therapy can help improve function.

Cerebrospinal Fluid (CSF) Fluid (produced by the ventricles of the brain) that circulates around the spinal column and brain.

Charge Nurse The registered nurse who has general responsibility for coordinating the nursing care of all babies in a unit for a particular shift. Nursing shifts may be either 8 or 12 hours.

Continuous Positive Airway Pressure (CPAP) Supplemental oxygen or room air delivered under pressure through either an endotracheal tube (tube that goes directly into the infant's lungs) or small tubes or prongs that sit in the nostrils. Delivering oxygen under pressure helps keep air sacs in the lungs open and also helps maintain a clear airway to the lungs. Nasal CPAP (NCPAP) is commonly used immediately after removing the endotracheal tube to treat apnoea and/or prevent the need for an endotracheal tube and ventilator.

Crit Slang for hematocrit, this is a test used to determine the percentage of red blood cells compared to total blood volume. It is commonly used to test for anaemia. It is significant in that it helps show a baby's ability to supply oxygen to his or her organs and tissues.

D - Developmentally Delayed / Disabled

A term used to describe infants and toddlers who have not achieved skills and abilities which are expected to be mastered by children of the same age. Delays can be in any of the following areas: physical, social, emotional, intellectual, speech and language and/or adaptive development, sometimes called self-help skills, which include dressing, toileting, and feeding. Many developmental delays can be overcome with early intervention programs.

Developmental Milestones Major and minor social, emotional, physical, and cognitive skills acquired by children as they grow up.

E - Early Intervention Program Planned use of physical therapy and other interventions in the first few years of a child's life to enhance the child's development.

Echocardiogram (“Echo”) Ultrasound picture of the heart. This is a painless, non-invasive procedure that takes accurate pictures of almost all parts of the heart. Many preemies have a cardiac ultrasound if the doctor is looking for evidence of a patent ductus arteriosus.

Edema Puffiness or swelling, usually because of fluid retention in the body tissues.

Electrocardiogram (ECG or EKG) A test that records the electrical activity of the heart. It can show abnormal rhythms (arrhythmias or dysrhythmias) or detect heart muscle damage.

Endotracheal Tube (ETT or ET Tube) Tube placed through the mouth or nose into the throat and the child's trachea (windpipe). This tube provides a secure pathway through which air can be circulated to the lungs.

Extracorporeal Membrane Oxygenation (ECMO) This long name means “oxygenation outside the body.” It's used for babies whose lungs are not working properly (i.e., transferring oxygen into the blood and removing carbon dioxide) despite other treatments. The ECMO takes over the work of the lungs so they can rest and heal. It's similar to the heart-lung bypass used during some types of surgeries.

Extremely Low Birth Weight (ELBW) A baby born weighing less than 2 pounds, 3 ounces (1,000 grams). Also known as a “micro preemie.” See also Very Low Birth Weight and Low Birth Weight.

Extubation Removing the Endotracheal Tube (ET Tube) from the baby's windpipe.

F - Fontanelle The soft spot on the top of the head. At birth the skull is made up of several plates of bone; it is not a single, solid bone. The spaces between the bone plates allow the skull to expand as the brain grows. Where four of these bony skull plates come together it forms a soft spot in the skull called a fontanelle. There is no bone in these soft spots, making these areas softer than the surrounding areas. There are usually two soft spots in the skull of a newborn, the anterior and the posterior fontanelle; both usually close by about 18 months of age.

G - Gastroesophageal Reflex (GER)

Contents on the stomach coming back up into the oesophagus, which occurs when the junction between the oesophagus and the stomach is not completely developed or is abnormal. GER is very common among preemies. In some babies, reflux can irritate the lining of the oesophagus and cause a form of “heartburn” which causes them to become irritable and uncomfortable. Mild forms of GER are common, require no treatment, and go away on their own over a period of months. However, it is necessary to evaluate how severe the GER is and whether or not it requires treatment.

Treatment of GER may include keeping the baby upright, thickening of the feedings, giving medication to reduce stomach acid, and sometimes giving medication to increase the ability of the stomach to contract.

Gavage Feeding Feeding a baby through a nasogastric (NG) tube. Also called tube feeding.

Gestation The period of development from the time of fertilization of the egg, until birth. Normal gestation is 40 weeks; a premature baby is one born at or before the 37th week of pregnancy.

Gram (GM, gm, G) The basic unit of weight in the metric system (28 grams = one ounce).

Grasping Reflex A newborn's reflexive grab at an object, such as a finger, when it touches her hand. This grasp may be strong enough to support the infant's own weight, but doesn't last very long. This reflex lasts until a baby is 3 or 4 months old. Newborns have many naturally occurring reflexes.

H - Hearing Screen Test to examine the hearing of a newborn infant.

Heart Murmur A noise heard between beats of the heart. Innocent, functional heart murmurs are common and often heard in infants and toddlers.

Heel Stick Pricking the baby's heel to obtain small amounts of blood for testing.

Haemoglobin A material in red blood cells that carries oxygen and contains iron.

High Frequency Ventilation A special form of mechanical ventilation, designed to help reduce complications to preemies' delicate lungs.

High Frequency Jet Ventilator A special ventilator capable of breathing for a baby at rates exceeding those of a normal ventilator (420 BPM, or Breaths per Minute).

High Frequency Oscillatory Ventilator A special ventilator capable of breathing for a baby at rates exceeding those of a normal ventilator (for example, 120 - 1,320 BPM, or Breaths per Minute).

Hyaline Membrane Disease (HMD) Another name for respiratory distress syndrome (RDS).

Hydrocephalus Abnormal accumulation of cerebrospinal fluid within the ventricles of the brain. It is sometimes known as "water on the brain." Within the center of our brains each of us has two fluid-filled areas called cerebral ventricles. Cerebrospinal fluid is made within these ventricles and distributed over the surface of the brain and spinal cord. When the normal circulation of cerebrospinal fluid is interrupted, fluid can accumulate within the ventricles. This fluid puts pressure on the brain, forcing it against the skull and enlarging the ventricles. In infants, this fluid accumulation often results in bulging of the fontanelle (soft spot) and abnormally rapid head growth. The head enlarges because the bony plates making up the skull have not yet fused together. In preemies the most common cause of hydrocephalus is intraventricular haemorrhage.

Hyperbilirubinemia Another name for jaundice.

I - IDEA An acronym for the Individuals with Disabilities Education Act, which provides grants to states to support services, including evaluation and assessment, for young children who have or are at risk of developmental delays/disabilities.

Idiopathic Something which happens spontaneously or from an unknown cause.

Individualized Family Service Plan (IFSP)

A written statement for an infant or toddler developed by a team of people who have worked with the child and the family. The IFSP describes the child's development levels, family information, major outcomes expected to be achieved for the child and family, the services the child will be receiving, when and where the child will receive these services, and the steps to be taken to support the transition of the child to another program.

Indomethacin A drug sometimes given to close a patent ductus arteriosus.

I & O (Input & Output) Refers to the amount of fluids given by oral feedings and/ or by IV, and the amount of fluid excreted in the urine or stools.

Ileal Perforation Puncture or hole in the last part of the small bowel (ileum). This usually occurs spontaneously in extremely premature babies. Its cause is unknown. Often an ileal perforation requires surgery to form an ileostomy and to repair the hole in the bowel. Some NICUs have reported success simply by putting a piece of drainage tubing into the abdomen to drain out the infection and let the perforation seal on its own.

Incubator Another name for an isolette.

Intracranial Haemorrhage Bleeding within the skull. Bleeding most often occurs within the ventricles of premature infants, but it can occur anywhere within or on the outside of the brain.

Intrauterine Growth Restriction (IUGR)

A condition in which the foetus doesn't grow as big as it should while in the uterus. These babies are small for their gestational age, and their birth weight is below the 10th percentile. IUGR can be caused by decreased blood flow to the placenta, maternal hypertension, drug use, smoking, poor weight gain, dieting during pregnancy, pre-eclampsia, alcoholism, multiple foetuses, abnormalities of the cord or placenta, prolonged pregnancy, chromosomal abnormalities, or a small placenta.

Intravenous (IV) A catheter (small tube) placed directly through the skin into the vein in a baby's hand, arm, foot, leg or scalp. Nutrients, fluids and medications can flow through this tube. Using an IV is a common route for delivering fluids to newborns and other patients. Babies' veins are very fragile, so the location of the IV may need to be changed frequently.

Intraventricular Haemorrhage (IVH)

Bleeding into the ventricles (fluid-filled spaces) within the brain. All of us have two small, fluid filled ventricles in the center of our brains.

These ventricles manufacture cerebrospinal fluid. The fluid-filled space within those ventricles is called the intraventricular space.

The areas just outside of those ventricles are the periventricular areas. Adjacent to the outer wall of the ventricle is the germinal matrix, an area of immature nerve cells and tender blood vessels. As the preterm baby matures, the germinal matrix tissues migrate out into the substance of the brain, and the germinal matrix gradually disappears.

The tender blood vessels within the germinal matrix can rupture and bleed; this is called a germinal matrix haemorrhage or grade I intraventricular haemorrhage (IVH). The bleeding, if severe, can lead to bleeding within the ventricle itself, a grade II IVH. If there is a lot of bleeding, the ventricles can become enlarged and swollen by the blood, which is a grade III IVH. If the bleeding either involves or secondarily injures the periventricular brain tissue, it is a grade IV IVH or IVH with extension of the haemorrhage outside of the ventricular system into the brain substance.

Intubation Inserting a tube into the trachea (windpipe) through the nose or mouth to allow air to reach the lungs.

Isolette Also known as an incubator, an isolette is a clear plastic, enclosed bassinet used to keep prematurely born infants warm. Preemies often lose heat very quickly unless they are put in a protected thermal environment. The temperature of the isolette can be adjusted to keep the infant warm regardless of the infant's size or room temperature.

J - Jaundice Also known as Hyperbilirubinemia. Jaundice comes from the accumulation of a natural waste product, bilirubin. As red blood cells and other tissues are replaced in the body, the waste products of their breakdown are normally eliminated by the liver. Bilirubin has a yellow colour, and when the levels are high it stains the skin and other tissues. A little jaundice can be expected in all newborns. If the jaundice is higher than usual, it can usually be treated with phototherapy (special lights). Phototherapy is so effective in helping the liver excrete bilirubin that elevated levels are rarely a problem. Prematurely born infants may have elevated bilirubin levels for several weeks.

K - Kangaroo Care Skin-to-skin contact between parent and baby. During kangaroo care, the baby is placed on the parent's chest, dressed only in a diaper and sometimes a hat. The baby's head is turned to the side so the baby can hear the parent's heartbeat and feel the parent's warmth. Kangaroo care is effective, but it's limited to babies whose condition is not critical.

L - Lanugo The fine, downy hair that often covers the shoulders, back, forehead, and cheeks of a prematurely born newborn. Lanugo is replaced by more normal appearing hair toward the end of gestation.

Large for Gestational Age (LGA) A baby whose birth weight exceeds the normal range for the gestational age.

Lead Wires Wires connecting the sensors on the baby's chest to the vital signs monitor.

Level A marker of the level of infant care a NICU can provide, usually expressed as I, IIa/IIb, or IIIa/IIIb/IIIc. [Click here for an explanation of the different levels.](#)

Low Birth Weight (LBW) A baby born weighing less than 5 1/2 pounds (2,500 grams) and more than 3 pounds, 5 ounces (1,500 grams). See Very Low Birth Weight.

Lumbar Puncture (LP) Also known as a "spinal tap," this test involves inserting a hollow needle in between the vertebrae of the lower back to collect a sample of cerebrospinal fluid.

M - Magnetic Resonance Imaging (MRI) Imaging technique that uses powerful magnets and computers to produce a detailed picture of tissue.

Meconium A dark green, sticky mucus, a mixture of amniotic fluid and secretions from the intestinal glands, normally found in infants' intestines. It is the first stool passed by the newborn. Passage of meconium within the uterus before birth can be a sign of foetal distress. The meconium is very irritating to the lungs.

Meconium Aspiration Syndrome (MAS) Respiratory disease caused when babies inhale meconium or meconium-stained amniotic fluid into their lungs; characterized by mild to severe respiratory distress.

Monitor Machine that displays and often records the heart rate, respiratory rate, blood pressure and blood oxygen saturation of the baby. An alarm may sound if one or a number of these vital signs are abnormal. For example, in a normal infant the heart rate is usually between 120 and 180 beats per minute and oxygen saturation should be above 90%. False alarms are common, as abrupt movements can cause the monitor to register inaccurate readings - a good general rule of thumb is "Look at the baby, not the monitor."

Moro Reflex A newborn reflex. The automatic response to loud noises or sudden movements in which a newborn will extend his arms and legs, arch his back, and sometimes cry out. Newborns can have this reaction even during sleep, but lose it after a few months.

Motor Skills Gross motor skills are the movements that use the large muscles in the arms, legs, and torso, such as running and jumping. Fine motor skills are the small muscle movements used to grasp and manipulate objects, like picking up a Cheerio or using a crayon.

Multidisciplinary Many different areas of expertise or specialization coming together to provide comprehensive care. Examples include medicine, nursing, pharmacy, social work, physical therapy and respiratory therapy.

Nasogastric Tube (NG Tube) Narrow, flexible tube inserted through the nostril, down the oesophagus, and into the stomach. It is used to give food or to remove air or fluid from the stomach.

Nebulizer Treatment A nebulizer humidifies air and/or oxygen that is passed to the infant. At home, a nebulizer is a way of delivering medication - it transforms medicine into droplet form for inhalation. Used for a variety of lung problems.

Necrotizing Enterocolitis (NEC) Swelling, tenderness and redness of the intestine caused by an infection or decreased blood supply to the intestine. The seriousness of NEC varies: it may injure or destroy parts of the bowel, or it may affect only the innermost lining or the entire thickness of the bowel.

Neonatal Intensive Care Unit (NICU) A special care nursery for preemies and newborn infants with severe medical complications. They are cared for by neonatologists and nurses with specialty training.

Neonate A term used to describe an infant during the first 30 days of life.

Neonatologist A paediatrician who has received 4-6 years of training after medical school in preparation for treating premature or sick newborns. This is the person who usually directs your baby's care if hospitalization in an NICU is required.

NPO An abbreviation for a Latin term that means "nothing by mouth" - i.e., no food or water.

O - Omphalocele A birth defect in which the intestines (and sometimes other abdominal organs such as the liver) come through an opening in the navel.

Osteopenia of Prematurity (OOP) A decrease in the amount of calcium and phosphorus in the bones. This can cause bones to be weak and brittle, and increases the risk for broken bones. Most preemies born before 30 weeks have some degree of OOP, but won't have any physical symptoms.

Causes: during the last trimester, calcium and phosphorus are transferred from the mother to the baby so that the baby's bones will grow, so preemies may not receive enough to form strong bones. Also, the baby's activity increases in those last 3 months, and that activity is thought to help bone development. OOP is usually diagnosed with ultrasound, x-rays, and blood tests to check the levels of calcium, phosphorus, and a protein called alkaline phosphatase. It is most commonly treated with calcium and phosphorus supplements added to breast milk or IV fluids, special premature formulas when breast milk is not available, and Vitamin D supplements.

Oximeter (Pulse Oximeter) Machine monitoring the amount of oxygen in the blood. A tape-like cuff is wrapped around the baby's toe, foot, hand or finger. This machine allows the NICU staff to monitor the amount of oxygen in the baby's blood without having to obtain blood for laboratory testing.

Oxygen Hood A clear plastic box that fits over a baby's head and supplies him or her with oxygen. This is used for babies who can breathe on their own, but still need some extra oxygen.

P - Parenteral Nutrition (Hyperalimentation) Solution put directly into the bloodstream, giving necessary nutrients, such as protein, carbohydrates, vitamins, minerals, salts, and fat. Other names for this are hyperal, total parenteral nutrition (TPN) and intravenous feedings.

Patent Ductus Arteriosus (PDA) The ductus arteriosus is a blood vessel connecting the pulmonary artery and the aorta. Before birth, this vessel allows the baby's blood to bypass the lungs because oxygen is supplied by the mother through the placenta. The ductus arteriosus should close soon after birth. If it does not, it is called a patent (open) ductus arteriosus, or PDA. A PDA may be treated either with medication or surgery.

Periodic Breathing Irregular breathing pattern marked by pauses for as long as 10 to 20 seconds. This is common in both premature and full-term babies and does not usually mean there is a problem. **Periventricular Leukomalacia (PVL)** Within our brains are two small fluid-filled areas called ventricles. Cerebrospinal fluid is made within these ventricles. Periventricular tissue is just to the right and left sides of the ventricles. The tissue gets its blood supply from the arteries just before the arteries narrow down into capillaries. If the periventricular tissue does not receive an adequate blood supply, the tissue may die. When the tissue dies, it leaves fluid in its place, which appears as a cyst. The cysts themselves are not a problem, but they represent brain tissue that has died and been replaced by fluid. PVL is the appearance of these cysts on an ultrasound, CT, or MRI scan of the head. The brain tissue that has been lost is important to the control of muscle movements in the legs and sometimes in the arms. PVL is often associated with cerebral

Persistent Pulmonary Hypertension of the Newborn (PPHN) High blood pressure in the lungs, which causes the small blood vessels in the lungs to become progressively narrower. It can lead to breathing problems and reduced levels of oxygen in the blood. Sometimes treated with nitric oxide, a gas naturally produced by the body that can help expand blood vessels.

Phototherapy Light therapy to treat jaundice. Bright blue fluorescent lights, called billights, are placed over the baby's incubator. Treatment usually lasts between 3-7 days.

PICC Line A special IV line used to provide fluids into a vein. A PICC line is usually very stable and lasts longer than a typical IV.

Pneumogram A sleep study, monitoring the baby's breathing and heart rate during sleep to detect any abnormal breathing patterns.

Pneumothorax When air from the baby's lungs leaks out into the space between the baby's lungs and chest wall. While small leaks may cause no problems and require no treatment, larger leaks may cause serious complications such as lung collapse and may need to be repaired with surgery.

Premature baby A baby born three or more weeks before the due date.

Pulmonary Interstitial Emphysema (PIE) A condition occurring in infants on ventilators that results in the formation of "bubbles" around the tiny air sacs (the alveoli) of the lungs. These "bubbles" may interfere with normal lung function.

R - Respiratory Distress Syndrome (RDS) Respiratory problems due to lung immaturity. Respiratory distress is a much more inclusive term meaning simply that the child is having problems breathing. Respiratory distress syndrome is a specific condition that causes respiratory distress in newborn babies due to the absence of surfactant in the lungs. Without surfactant, the alveoli (air sacs) collapse when the baby breathes out. These collapsed air sacs can only be reopened with increased work at breathing. Most newborn babies do not have a normal amount of surfactant in their air sacs until 34 to 36 weeks' gestation. However, some very premature infants (27 to 30 weeks' gestation) will have adequate surfactant production and function and some full-term infants (37 to 40 weeks' gestation) will not. **Respiratory Syncytial Virus (RSV)** The most common cause of bronchiolitis in young children. Bronchiolitis is an infection of the bronchial tubes that causes rapid breathing, coughing, wheezing and sometimes, even respiratory failure, especially in the first two years of life. RSV infection and bronchiolitis is a particular risk for infants with chronic lung problems and those born prematurely. The RSV season is usually from October to March.

Retinopathy of Prematurity (ROP) Scars and abnormal growth of the blood vessels in the retina, the layer of cells in the back of the eye. The retina does not mature until close to term (40 weeks gestation), so when babies are born very prematurely, the normal growth of blood vessels into the retina is altered. These abnormally growing vessels can eventually lead to disruption of the retina and the loss of eye function. Fortunately, severe ROP is unusual and mostly found in extremely premature infants. Routine exams for ROP will be given to premature infants at risk starting at about the 5th or 6th week after birth. If severe ROP develops, there are treatments that can reduce or prevent the loss of vision. For more information and a detailed explanation of ROP, you can visit the site of The Association for Retinopathy of Prematurity and Related Diseases (ROPARD).

Retraction An abnormal sucking in of the chest during breathing, indicating that the baby is working too hard to breathe.

Retrolental Fibroplasia (RLF) An old name for retinopathy of prematurity.

Room Air The air we normally breathe, which contains 21% oxygen. When supplemental oxygen is given for respiratory problems, it is in concentrations higher than 21%.

Rooting Reflex An instinctive reflex in newborn infants that causes them to turn their head to the side when their cheek is stroked. This reflex helps infants learn how to eat. By gently stroking the cheek, your baby will turn his or her head toward you with an open mouth ready to feed.

S - Sats Term for blood oxygen saturation.

Seizure A “short-circuiting” of electrical impulses in the brain, resulting from a variety of causes. Seizures can generally be classified as either “simple” (no change in level of consciousness) or “complex” (when there is a change in consciousness). Seizures may also be classified as “generalized” (the baby's whole body is affected) or “focal” (only one part or side of the body is affected).

Sepsis A potentially dangerous infection of the bloodstream which occurs when the body's normal reaction to inflammation or a bacterial infection goes into overdrive. Certain lab tests, cultures, and x-rays can help diagnose this condition, which is treated with antibiotics. Also known as Systemic Inflammatory Response Syndrome (SIRS). Septicaemia is sepsis of the bloodstream caused by bacteraemia, which is the presence of bacteria in the bloodstream, but this term is also sometimes used to refer to sepsis in general.

Small for Gestational Age (SGA) A baby whose birth weight is less than the normal range for the gestational age.

Social Worker Trained professional who helps coordinate social services available to families and also helps families understand and use their insurance coverage. They can help families access services available through governmental and private agencies. Some social workers also act as counsellors for parents undergoing personal or family stress while their baby is in a NICU.

Sonogram Another name for an ultrasound.

Step-down Unit Babies can be transferred from the NICU to this unit to continue their recovery after they are no longer acutely ill.

Surfactant Surfactant is a soapy material inside the lungs of adults and mature infants that helps the lung to function. Without surfactant, the air sacs tend to collapse on exhalation. Lung surfactant production is one of the last systems to mature in an infant, which can cause the breathing problems found in preemies. Fortunately, surfactant obtained from cows has been shown to be safe and effective in treating respiratory distress due to surfactant deficiency. The use of surfactant to treat respiratory problems in preemies is one of the most important recent medical advances in paediatrics.

Swaddling Securely wrapping a baby in a tight blanket to soothe and/ or restrain him or her. The NICU nurses can teach you how to swaddle your baby.

Synchronized Intermittent Mandatory Ventilation (SIMV) The ventilator mode where the mechanical breaths given by the ventilator are synchronized with the baby's spontaneous (regular) breaths.

Synchronizer Small, soft sensor attached to the infant's abdomen and certain types of ventilators that tell the ventilator when the infant is taking a breath. It helps to match ventilator support with the infant's own breathing efforts. When the baby starts to take a breath, the synchronizer triggers the ventilator to provide a ventilator breath to the infant. Other types of ventilators use sensors near the breathing tube to sense when the child is breathing in.

T - Tachycardia A faster than normal heart rate.

Tachypnea A faster than normal respiratory rate.

Theophylline A medication used to stimulate an infant's central nervous system. It is prescribed to reduce the incidence of apnoeic episodes. This is the “oral” form that can be ingested by an infant through a nipple or feeding tube. The intravenous form is known as Aminophylline.

Tone Passive resistance to movement of the extremities is called tone. Normally infants give only a moderate amount of resistance to you when you move their extremities. The amount of tone present is one way of assessing the condition of the nervous and muscular system in an infant. Infants with too much tone, too much resistance to passive movement, are called hypertonic and an extreme example of this is spasticity. Infants with too little tone (too little resistance to passive movement) are called hypotonic. In many cases, hypotonia can mean simply low muscle tone and increased flexibility or laxity of ligaments; in one who is severely ill it can mean an inability to sit up, crawl, walk, or eat correctly.

Tonic Neck Reflex A newborn reflex that resembles a fencing position. When your infant's head is turned to the side, one arm will straighten, the opposite arm will bend, and often one knee will significantly bend. You won't see this if your baby is crying and this reaction usually disappears between 5 to 7 months of age. Infants vary in the degree to which this reflex is obvious.

Transient Tachypnea of the Newborn (TTNB) Fast breathing that slowly becomes normal. It is thought to be caused by slow or delayed reabsorption of foetal lung fluid, and is more common in babies delivered by cesarean delivery and in those who are slightly preterm.

U - Ultrasound Imaging of body parts using sound waves. The reflected sound waves are then analyzed by computer and turned into pictures.

Umbilical Arterial Catheter (UAC) Catheter (small tube) placed in a belly button artery. It is used to check blood pressure, draw blood samples and give fluids.

Umbilical Venous Catheter (UVC) Catheter (small tube) placed in the belly button vein. It is used to give the baby fluids and medications.

V - Ventilator ("Vent") A machine that assists adults or children to breathe. Lung immaturity in prematurely born infants is the most common reason for a newborn to require a ventilator.

Ventriculoperitoneal Shunt A plastic catheter (shunt) surgically placed in the ventricle of the brain to drain spinal fluid from the brain into the abdominal cavity. Used to treat hydrocephalus.

Vital Signs Monitor A machine measuring and displaying heart rate, breathing rate, and blood pressure on a computer screen. If these vital signs

W - Warmer Also known as a Radiant Warmer, this bed allows maximum access to a sick baby. Radiant heaters above the bed keep the baby warm. Generally, a baby progresses from a warmer to an isolette to an open crib before leaving the NICU.



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