The staff of the Neonatal Intensive Care Unit has a strong commitment to providing the highest quality of care for infants and their families. We believe that the most essential part in the long term outcome of the infant is the parent-child relationship. Our goal is to support the infant and family within the NICU until the family can assume the independent role as primary care giver. We show our commitment to family-centered care by implementing services with the following goals in mind:

- Establish and maintain an adaptive fit within the family and between the family and the professional team; promote a partnership of parents and professionals.

- Recognize that families are complex, dynamic and ever-changing systems; the family is constant in the infant’s life.

- Respect each family’s values, culture and resources, while recognizing their diverse strengths and needs.

- Create a healing, nurturing environment that provides developmental, educational, and emotional support to meet the diverse needs of families.

- Welcome participation of families in the development of their infant’s care plan and in the planning and evaluation of new and existing programs.

- Strive to provide a continuum of care and communication between the hospital and community services.

- Provide outstanding medical care to infants through enhancing clinical skills, undertaking educational and research activities and serving as a clinical resource for the community.
dear parent

Congratulations on the birth of your child! If you’re like most expectant parents, you looked forward to taking your baby home with you from the hospital. Due to his or her medical condition, this is not possible right now. Your baby needs special medical and nursing attention that will be provided in the Neonatal Intensive Care Unit (NICU) at Tampa General Hospital.

We know that having your baby in the NICU can be a frightening and overwhelming experience. You may be asking yourself, “will my baby be alright?” “What can I do to help?” “When can I take him home?” These are all natural and valid questions. We hope that this booklet will help you with many of the concerns shared by parents of sick and premature infants.

We are here twenty-four hours a day to help both you and your baby. Please visit or call as often as you like. The NICU currently has beds in two locations: fourth floor, West Pavilion, 4B4, and fifth floor, East Pavilion, 5G1. To call the unit located on 4B4, you may dial extension 7224 from within the hospital, or (813) 844-7224 from outside the hospital. To call the unit located on 5G1, you may dial extension 3101 from within the hospital, or (813) 844-3101 from outside the hospital. We encourage you to talk with the medical and nursing staff. Please don’t ever feel that your calls, visits, or questions are an inconvenience. Remember that working together, we can give your baby the love and care to help in his or her recovery.

Sincerely,
The Staff of the NICU

Throughout the booklet, He/She is used interchangeably.

Special thanks to Elaine DeBrigard, RN, BSN, Denise Casey, RN, BSN, and Alba Cogdill, RN, BSN for their careful attention to the preparation of this booklet.
The NICU is a special nursery for babies who are born too early, are sick, or who may need surgery. The NICU is a very busy place. As you enter the unit, it may seem like you’ve entered another world. There are a number of people moving about the room, alarms and buzzers may be sounding, and there are machines everywhere you look. It is hard to imagine that your baby is in the middle of all of this. Don’t let the technology frighten you. It is here to ensure that your baby receives the best possible medical care.

Before you go to your baby’s bedside, we ask that you wash your hands and arms with the provided scrub package. There is also a gown for you to wear while you are in the unit. These are located near the scrub sinks. These steps protect your baby from outside germs and infections. Personal belongings should be placed in a personal belonging bag provided for your convenience.

In support of a family-centered atmosphere we encourage frequent visitations. However, we do ask that you not visit between 6:30 a.m. – 8:00 a.m. and 6:30 p.m. – 8:00 p.m. We ask that mothers choose five additional visitors who will be allowed to visit their baby. The baby’s father and grandparents are included on this list. These approved visitor names are placed on a card at the front desk in the NICU. Due to infection control concerns, these names cannot be changed during the baby’s stay in the NICU. All visitors, other than parents, must be 12 years of age or older. Visitors must show photo ID at first visit. ID will be copied and placed in the visitor log to expedite future visits.

This unit is filled with different sounds and noises. Each piece of equipment, including the bed, ventilator, monitor, and IV pump has a different alarm. The purpose of each alarm is to tell the staff to look at your baby. There may or may not be something wrong. Don’t let these alarms frighten you.

When you visit your baby for the first time, our staff will explain what the equipment surrounding your baby is and what it is needed for. If you have any questions, don’t hesitate to ask.
INTRODUCING OUR TEAM:

There are many people involved in the care of your baby. Our team, comprised of the following professionals, is committed to providing the highest level of care to your child and to meeting your needs to the best of our ability.

- House Officers (Residents): Physicians who have graduated from medical school and who are now pursuing additional education in specialized areas of medicine. The majority of house officers who rotate through the NICU are specializing in Pediatrics.

- Medical Students: Senior medical students in the last year of their education towards receiving their degree as a physician. They occasionally rotate through the NICU as part of their educational experience.

- Neonatal Fellows: Individuals who have completed their training in pediatrics and generally their certification process as well. They are doing 3 years of specialized training in neonatal medicine.

- Neonatologists (Attendings): Physicians who have been initially trained as pediatricians, and have then received additional training in the care of ill newborns. Our neonatologists have completed their training, obtained board certification in the specialty of neonatal medicine and are ultimately responsible for the care of your infant. Our neonatologists are faculty of the University of South Florida College of Medicine and staff physicians at Tampa General Hospital.

- NNP: Master's prepared registered nurses who have received additional training in the care of ill newborns.

- Registered Nurse (RN): Nurses who have experience in caring for critically ill infants, who provide nursing care and assist in the planning and coordinating of your infant’s care plan.

- Respiratory Therapist: A professional staff member trained and experienced in the procedures and equipment needed to help babies with breathing problems.

The members of our team will make every effort to meet with you on a regular basis. If, at any time, you would like to talk to the attending, please feel free to ask the nurse to arrange a meeting.
OTHER PEOPLE WHO MAY BE INVOLVED IN YOUR BABY’S CARE:

NEONATAL NURSE MANAGER: A registered nurse who has training and experience in the care of sick infants. Coordinates unit functions and supervises staff nurses.

NEONATAL CLINICIAN: A registered nurse who has training and experience in the care of sick and premature infants. Assists nurse manager in coordination of unit functions.

CHARGE NURSE: A registered nurse experienced in care of sick infants. Responsibilities include coordination of daily unit functions including: patient flow assignments, problem solving, and staffing utilization. Charge nurse works under the directions of neonatal clinician and nurse manager.

PHARMACIST: A professional who specializes in supplying medications needed for babies in the NICU.

LACTATION CONSULTANT: A registered nurse who is available to talk to mothers and help them learn how to breast-feed their sick or premature baby. Your baby’s nurse can arrange an appointment with the lactation consultant for you.

DIAGNOSTIC TECHNICIAN: A professional staff member trained to perform a variety of diagnostic tests on babies in the NICU; including EEG, EKG, X-ray and ultrasound.

PHYSICAL THERAPIST/OCUPATIONAL THERAPIST/SPEECH THERAPIST (PT/OT/ST): A specialist who helps babies develop properly.

PATIENT CARE TECHNICIAN: A skilled staff member who may take vital signs, give bottle feedings, and draw blood under the direction of an RN.

SOCIAL WORKER: A specialist who helps families cope with emotional stress and makes practical arrangement for care.

QUALITY SPECIALIST: An RN who works with the medical and nursing teams to achieve the highest level of care. Assists the Care Coordinator with discharge planning for complicated cases.

UNIT COORDINATOR: A staff member who answers the phone and helps coordinate all of the babies’ records. The unit coordinator is the person to check in with when you come to the NICU.

CARE COORDINATOR: An RN who coordinates discharge planning and ensures the appropriate utilization of resources.
You have just been told that your newborn baby needs intensive care and you are now forced into the world of the Neonatal Intensive Care Unit. All the expectations you had are now replaced with questions and worries. Your baby may look different from how you expected and you may wonder if you should even touch him. He will possibly need the support of special equipment such as a warmer, incubator, ventilator (breathing machine) and IVs (intravenous catheters). He may not be interested in interactions or alert enough to focus on you, but he does sense your presence when you are near.

Although every baby in the NICU is unique, they do share some common problems. When you first enter the NICU, you will find your baby on a radiant warmer bed or in an incubator. These special beds have the technology to monitor your baby’s temperature via a small probe taped to your baby’s skin. They also provide a heat source to keep the baby warm. Your baby will also be attached to a monitor that records heart rate and breathing, as well as a pulse oximeter that monitors the amount of oxygen in the blood.

Your baby may need the help of a breathing machine called a ventilator. Your baby may have a small tube securely taped to his mouth which goes down the windpipe. Because of this tube, you won’t be able to hear the baby cry, but the baby will use other signs to show you that he is upset, such as grimacing. A ventilator may also be used to provide continuous positive airway pressure (CPAP) to help make breathing easier. CPAP babies will have small prongs in their nose but you can still hear them cry.

Most NICU babies require intravenous catheters (IVs) for fluids or medications. These are usually placed in the arms or legs, and sometimes it is necessary to place one in the baby’s scalp. You may find the IV site changes frequently. If your baby needs long term IV access, or has difficulty maintaining IVs, a PICC line may be needed.

During one of your visits, you may find your baby under a special blue light. You’ll then hear the doctors and nurses talk about jaundice or bilirubin. Jaundice is a condition where the skin becomes yellow in color due to an increase of a substance called bilirubin. Bilirubin is a normal product of red blood cell breakdown. The liver usually changes bilirubin so the body can get rid of it. A premature baby’s liver may not be ready to handle this process adequately. This special blue light helps break down the bilirubin so the body can get rid of it more easily.
RESPONDING AND INTERACTING WITH YOUR SPECIAL BABY

When your baby was born, his energy was concentrated on regulating his heartbeat, breathing and other functions. He may not be awake enough or alert enough to focus on you, but your touch and voice will be important. Babies usually respond better to a gentle but firm touch. At first, frequent touch may be over stimulating. To calm him, you could place your hand over his trunk using firm, gentle pressure. Or contain his arms and legs by tucking them towards his body. Speak to him softly repeating his name often. He needs to hear your voice.

Positioning is important and you will see the nurses change your baby’s position often. He needs to feel snug and secure as if back in the womb. He can be placed on his tummy, back, or sides nested in a snuggly. Keeping your baby’s hands and legs tucked in close to his body will help to soothe and calm him. Being able to get his hands up to his face and mouth is especially soothing. You can also help keep his eyes covered to protect against bright lights.

When your baby is stable enough to hold, the nurses will be there to transfer the baby with whatever tubes and wires he may have. They will also stay close by in case you or the baby need help. You may be a little nervous at first and it may even be a little stressful for the baby. You can help by cuddling him towards you with a gentle, firm hold, talk to him and keep him swaddled in the blanket. There is another special way to hold your baby, called skin-to-skin or kangaroo holding. This is when the nurse places the baby upright on your chest (mom or dad) while wearing only a diaper. Then he is wrapped in your clothing and a blanket is placed on top. Your baby will be soothed by your warmth, smell, heartbeat and breathing.

At first, any kind of holding or interaction may be tiring or stressful for the baby. He will, however, give you clues that let you know when he is calm, happy and able to handle interaction. He will also let you know when he is tired and over stimulated. Behaviors which let you know he feels good are: hands on face or ears or clasping each other, relaxed arms and legs, sucking or attempting to suck, cooing, looking and listening to you, or dozing off to sleep. Behaviors which say “I need a rest” are: hiccups and spitting up, grimacing, arching, stiff arms and legs, splaying fingers and toes and avoiding eye contact. The latter behaviors do not always mean that your baby wants to be left alone. Sometimes brief rest or a position change is all they need to calm down. By learning your baby’s signals, you will be able to determine what he needs, likes and dislikes. This will be something you will continue to work on even after discharge.
WHAT PARENTS NEED TO KNOW

All new parents have strong natural urges to be close to their baby and to take care of them. When your baby requires special care and is separated from you, it is entirely normal to feel anxious, sad, angry, guilty, or even numb. You understand why your baby needs intensive medical care, however, this may be a frustrating time.

When you saw your baby for the first time, you may have been shocked. He probably looked nothing like you expected. Perhaps you imagined an average sized and healthy baby. You weren’t prepared to find out that your baby was sick and would have to stay in an intensive care nursery. Maybe you felt confused and even angry. It is common for parents to feel like “this can’t be happening to us.”

Disappointment and sadness are also common. You looked forward to going home with your new baby, and instead you may have to leave the hospital without him. Mothers often say that they feel helpless and useless leaving the baby behind.

If you go home before your baby does, your separation anxiety will probably grow more intense. Leaving the hospital without your baby may be one of the hardest parts of his nursery stay. Visiting the baby and frequent phone calls help ease the frustration. A picture of your baby can help you feel closer when you are not with him, but your feelings of separation and loneliness will be not resolved completely until your baby is home. Until that time, our staff wants to do everything we can to support you. We encourage you to talk with us about your feelings and your needs.

In addition to helping you with your emotions, we can be your resource for working out family problems, making arrangements that will help you visit your baby more often, and preparing for your baby’s homecoming. We also can direct you to any community resources that might be of use to you and your baby.

You can’t avoid all of your sad or painful feelings, but there are some things that may help. One way is to visit your baby. Please visit your baby as often and as long as you wish. Touching and talking to him is a healing experience for both of you, and it will become easier as you grow used to the environment of the NICU. Ask how you can help in your baby’s care. At first, you may be limited to touching your baby, as he is in need of lots of rest at this time. This can be especially hard for parents, as they have a powerful need to hold and cuddle their baby. The NICU staff will help you through this hard time and will be glad to have you participate in your baby’s care as soon as he is well enough.
Many parents feel guilty. They ask themselves, “what did I do to cause this?” Don’t let feelings of guilt discourage you. It only makes things harder for you and drains your energy. More than likely, the low birth weight or sickness of your baby was not caused by anything you did or didn’t do.

It is common to have trouble sleeping when you are at home without your infant. Both your conscious and subconscious minds are focused on him; thoughts about him are natural. If you wake up in the middle of the night and think of your baby, please don’t hesitate to call the unit, no matter what the hour. Your baby’s nurse will be happy to talk to you and tell you how your baby is doing. You, like other parents, may find that fear, anger and other painful feelings start to go away when the baby begins to grow and get better.

Even when you know your baby is going to be okay, you are bound to feel stressed sometimes. There are a number of things you can do to relax:

**Talk about your feelings as much as you can with your partner, family and friends.**

Keep in close contact with the doctors and nurses and share your feelings with them. Don’t try to be brave and carry your sadness or frustration alone. It may prolong your unhappy feelings.

**Join a support group for parents of babies in the NICU.**

The parents of sick or premature babies often share many of the same feelings. Our Parent Support Group was formed to help you and other parents handle this unexpected stress together. You may find, as others have, that it really helps to talk to someone who has been through a similar experience. This group meets for 30-60 minutes at various times. Check the parents’ bulletin board in the NICU for this and other parent educational opportunities.

**Take some time for yourself.**

There may be days when you do not have the emotional strength to visit, or you are busy with your family or getting prepared to take your infant home. We understand that sometimes you need a break from the constant stress of the unit.

We encourage you to get books or videotapes to help you learn to take care of your infant. The NICU nurses may be able to suggest some.
Good nutrition is a must for the growth and development of babies born too early or those who are sick at birth. At first however, most of them are too weak to nurse or suck from a bottle. The NICU staff uses special methods to feed them until they’re able to breast or bottle feed.

**IV FEEDINGS**

Your baby’s first feedings will probably be through a small catheter placed in a vein. The catheter is connected to tubing that goes up to a bag of fluid containing the nutrients your baby needs. Medicines may be given by this route, too.

**“TUBE” FEEDINGS**

After a while your baby will progress to tube feedings. Tube fed babies have a small tube passed through the nose or mouth and down into the stomach so that a special infant formula or breast milk that you have pumped may be given to the baby. You may hear the doctors or nurses refer to these feedings as “NG feedings” or “OG feedings.” Soon your baby will graduate to nursing at your breast or taking formula from a bottle.

**PO FEEDINGS**

When your baby is ready, he can begin to try to take a bottle. For the growing preemie this may be introduced slowly as one or two bottle feeding attempts a day and advanced as tolerated. Each baby is unique and will let us know how fast to progress.

**BREAST-FEEDING**

If you planned to breast-feed your baby, you don’t need to give up the idea; let the NICU staff know that you plan to breast-feed. While your baby is in the hospital, you can maintain a supply of breast milk by emptying your breasts every 2-3 hours, or 7-8 times a day. This can be done with an electric or manual breast pump. A nurse or lactation consultant will show you how to get started. This is important so you will have a good milk supply when your baby is ready to nurse. Your baby’s nurse or lactation consultant will be able to answer your questions on how to pump your breasts, how to store breast milk and how to produce enough breast milk for your baby.
**Bottle-feeding**

There are a number of infant formulas available. Whatever formula is prescribed for your baby, you can be sure that your baby’s doctor is doing everything possible to meet your baby’s special needs and that your baby is getting what he requires for energy and growth.

**Waking to Feed**

If your baby is asleep when feeding time arrives, wake him gently. Don’t hurry him. It may take him up to five minutes to become alert enough to feed. As he opens his eyes, roll him over gently and loosen his blankets. If he is still sleepy, you might change his diaper or wash his face. When he is wide awake, pick him up and cuddle him. Hold him close so he can see your face.

**Pacing the Feeding**

Let your baby suck at his own pace. Don’t rush him by moving the nipple around in his mouth. Make sure his tongue is down so he can suck. He will set his own pace of sucking and swallowing, breathing, and resting. Coughing, choking, or spitting are his ways of telling you that too much is going on; he needs to stop feeding for a moment. Let him start sucking again when he has calmed down.
Taking your baby home can be a happy time for your family, but if your baby has been in the NICU, it may also be a scary time. Frequently parents want to know when their baby can go home. Some of the ways to tell if your baby is getting ready to go home are: he is able to breathe on his own; he is able to stay warm all by himself without the incubator or warmer; he is breast-feeding well or taking all of his feedings from a bottle; he is gaining weight on a regular basis; and he is medically stable.

Many parents want to know how they can get ready to take their baby home. Some of the ways you can get ready for the baby are:

- Become more involved with your baby’s care. Learn how to feed him, change his diaper and give him a bath. If he is going home on medications, learn what they are, what they do and how to give them.

- Get items you will need, like a car seat, diapers, clothing, blankets and formula.

- Choose a pediatrician to care for your baby once he is out of the hospital. Let your baby’s nurse know who you have chosen so information about your baby can be shared.

- Learn CPR. It is required for all parents whose baby is going home on a monitor. It is highly recommended for all parents and is taught in the NICU. Ask your baby’s nurse about CPR training.

- If you smoke, stop. Babies who are around cigarette smoke are more likely to get respiratory infections during their first year.

Once you and your baby are home, there are a few things to keep in mind.

- Limit visitors during your first days at home. Ask those friends and family with colds to visit later when they are feeling better. When you and your baby do have visitors, ask them to wash their hands before handling your baby.

- Some babies have trouble getting used to sleeping in their new home. They may have gotten used to sleeping with a light on and some sounds in the background. You may find that your baby sleeps better with a light on and some soft music playing in the background.

- Take your baby to all the follow-up appointments. Some babies need to be followed by an ophthalmologist to watch their vision; some babies will need to be followed by the developmental team to watch their growth and development; while others may need to see a pulmonologist because they are on a monitor or oxygen.
COMMON MEDICAL TERMS

BLOOD TRANSFUSION: giving blood to the infant to correct anemia.

CONGENITAL: present at birth.

CORRECTED GESTATIONAL AGE: the gestational age in weeks that a premature baby would be if he/she were born on the current date.

CPT OR CHEST PHYSIOTHERAPY: tapping the chest of a baby with lung problems to help loosen mucus. It is not painful, in fact, most babies enjoy it.

GESTATIONAL AGE: the length of time from conception to birth. A full term infant has a gestational age of 38-42 weeks.
   Premature infant – one born before 38 weeks gestation.
   Postmature infant – one born after 42 weeks gestation.

GRAM: a unit of weight measure. One gram is 1/28 of an ounce. 454 grams equals one pound. One kilogram equals 1,000 grams or 2 pounds, 2 ounces.

ISOLATION: restriction of a baby to a room or an area of the nursery when a certain infection is suspected.

IV FLUIDS: method of giving babies liquids and medications through a vein in an arm, leg or scalp.
   Hyperalimentation fluid (TPN) – a yellow IV fluid that contains proteins, sugar, vitamins and minerals.
   Intralipids– a white IV fluid containing fat.

MECONIUM: a dark green material that is the baby’s first bowel movement.

NPO: an abbreviation meaning “nothing by mouth.”

ROOM AIR: the air we normally breathe that contains 21% oxygen.

SUCTION: a procedure to remove mucus and secretions from a baby’s mouth, nose or lungs.
COMMON MEDICAL PROBLEMS

ANEMIA: occurs when there are not enough red blood cells in the blood. Red blood cells carry oxygen to body tissues. This is very common in premature babies. If severe, this is treated with a blood transfusion.

APNEA OF PREMATURITY: a pause in breathing. This is common in premature babies whose brains are not yet fully developed. Monitors allow the doctors and nurses to know when this occurs. It can be treated with medication and/or ventilators.

CLD OR CHRONIC LUNG DISEASE (SOMETIMES CALLED BPD (BRONCHOPULMONARY DYSPLASIA)): a lung problem of some preemies. It requires treatment with oxygen and/or ventilators, usually for a number of weeks. When the lungs heal, special equipment is no longer needed.

BRADYCARDIA: slow heart rate. Usually it is accompanied by apnea. Treated the same way as apnea.

IVH OR INTRAVENTRICULAR HEMORRHAGE: bleeding in the brain. Affects mostly those premature babies born very early and very small. Tests are done to determine the severity and location.

JAUNDICE: a yellowing of the skin due to buildup of ‘bilirubin’ in blood. Bilirubin is the result of the normal breakdown of red blood cells. It is treated with special lights that help the baby’s body get rid of excess bilirubin.

NEC OR NECROTIZING ENTEROCOLITIS: a severe problem in the intestines. This is often accompanied by infection, so the baby receives antibiotics. The baby may not receive fluids by mouth until the intestines heal, so IVs are necessary. Surgery may be required.

PDA OR PATENT DUCTUS ARTERIOSUS: condition occurs when a major blood vessel (Ductus Arteriosus) which normally closes at birth, reopens or fails to close. This may lead to heart failure. It is usually treated with drugs and/or surgery.

PNEUMONIA: an infection in the baby’s lungs. The baby may require oxygen or be put on a ventilator to assist breathing. An antibiotic may be given.

RDS OR RESPIRATORY DISTRESS SYNDROME: difficulty breathing caused by the lack of a lung product called surfactant. Also called HMD or Hyaline Membrane Disease.

ROP OR RETINOPTHALMY OF PREMATURITY: babies born very early may get this eye problem caused by interruption of the normal eye development. The back of the eye may be damaged and need special treatment. Whether the baby’s sight will be affected depends on the severity.

SEPSIS: an infection in the baby’s blood that affects the whole body. Sepsis is treated with antibiotics and other drugs until the body heals.
**Broviac:** a large IV catheter placed by a surgeon, with the tip in a large vessel close to the heart. Can be used if the infant has or is expected to run out of other IV sites. Can also be used to give higher amounts of sugar or for long-term IV therapy.

**Crib/Bassinet:** an open bed for a baby when he/she is able to maintain his/her own temperature.

**ECMO:** extra corporeal membrane oxygenation. Similar to a heart/lung bypass. This machine is used for some infants with severe lung/cardiovascular problems.

**Electrodes:** sticky patches and wires that attach the baby to machines to monitor respiratory and heart rates.

**Endotracheal Tube:** a plastic tube inserted into the baby’s windpipe to help with breathing. You cannot hear the baby cry as long as this is present.

**Extubation:** the procedure in which the endotracheal tube is removed from the airway.

**Incubator:** a temperature-controlled, enclosed bed.

**Intubation:** the procedure in which the endotracheal tube is placed into the airway.

**Monitor:** a machine with alarms that monitors the baby’s heart rate, breathing rate and sometimes blood pressure.

**Nasal CPAP:** large prongs placed in the nose that deliver oxygen and a small amount of pressure to help keep the lungs expanded. The baby still does all the breathing.

**Oxygen Cannula:** small prongs that fit in the baby’s nose and allow delivery of oxygen while the baby breathes on its own.

**Oxyhood:** a clear plastic “box” that fits over the baby’s head and delivers oxygen while the baby breathes on its own.

**PICC:** a long catheter used to deliver IV fluids. It is placed in the arm or leg, while the tip lies near the heart.

**Respirator/Ventilator:** a machine that breathes for the baby. The baby is connected to the machine by the endotracheal tube.

**Saturation Monitor:** a special type of monitor that tells the baby’s caregivers how much oxygen is in the blood.

**Umbilical Catheter:** a soft, plastic tube inserted into an artery or vein in the umbilical cord to administer fluids, draw blood or measure blood pressure.

**Warmer:** an open bed with overhead heating allowing easy access to the baby.