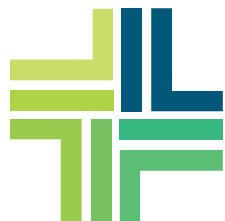




PATIENT & FAMILY  
NICU HANDBOOK





### A PATIENT CENTERED ORGANIZATION

The University of Illinois Hospital and Clinics is a patient centered organization. Providing safe, high-quality and cost-effective care for our patients is our foremost responsibility. The care of our patients and their families will always be at the heart of our mission.

### OUR MISSION

In collaboration with our academic partners our mission is to advance healthcare to improve the health of our patients and communities, promote health equity and develop the next generations of healthcare leaders.





WELCOME TO

# NEONATAL INTENSIVE CARE UNIT/INTERMEDIATE CARE NURSERY (NICU/ICN)

AT THE UNIVERSITY OF ILLINOIS HOSPITAL  
AND HEALTH SCIENCES SYSTEM

All of the staff work as a team to help provide your infant with the best possible care while being hospitalized. We understand that being hospitalized can be very stressful for both the patients and their families, so we will do our best to help make sure that your hospital stay is manageable. UI Health provides the highest level of care available. As a Level III NICU, recognized by the state of Illinois, we offer 24 hour coverage of neonatologists and subspecialties to ensure you are receiving the best care possible. If you have any questions or concerns during your stay please ask to speak to a staff member any time.

## LOCATION

Neonatal Intensive Care Unit/  
Intermediate Care Nursery

1740 W Taylor Street, 4th floor  
Chicago, IL 60612



## NICU 4TH FLOOR TELEPHONE NUMBER

312.996.4150

\*Please try to call every day to check on your baby.

## NICU / ICN STAFF WHO CAN ANSWER YOUR SPECIFIC QUESTIONS

### **Nurse Manager**

312.996.0080

### **Neonatologist**

312.996.4150

Updates you on your child's condition and the plan of care

### **Social Worker**

312.996.4141

Helps with various social issues and social security

### **Discharge Care Coordinator**

312.996.3442

Helps with insurance, Medicaid issues, and nursing care for those that have left the NICU

### **Lactation Consultants**

312.413.0233

Helps with breastfeeding and all things related to breast milk

### **Clinical Nurse Specialist**

312.355.1975

### **Developmental Specialist**

312.996.1747

Helps develop a plan of care to help premature infants develop optimally

### **Family Support Specialist**










312.996.8299

Organizes PAGes for families and helps with family issues and questions

A MEMBER OF THE PHYSICIAN TEAM IS IN THE NURSERY 24 HOURS A DAY TO ANSWER ANY QUESTIONS



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# FIRST GLANCE OF THE NICU / ICN

## FIRST DAYS

As soon as your baby arrives in the NICU / ICN we will begin to care for him/her. Tests and treatments will depend on your baby's condition. Every day your baby will be examined by his/her doctors and nurses, and plans for treatment will be updated. Depending on your baby's condition, we may need to do X-rays, blood tests, give medications, and give fluid or medications through an IV. Certain procedures carry a risk of complications, so you may be asked for permission and to sign a consent form. The nursery staff will recommend such tests only when they are necessary for your baby's care.

## MONITORS

Your baby will be put on monitors the moment she/he arrives on the unit. The monitors keep track of your baby's heartbeat, breathing, temperature, blood pressure and other bodily functions. The baby will be monitored continuously 24 hours a day. The wires you see on your baby's chest area are stuck on the skin with tape or adhesive. Alarms will sound if there is a problem with the machine, or if we need to make sure that your baby is okay.

## MEDICATIONS & IV FLUIDS

If your baby cannot eat right away, your baby will have an IV (intravenous) line. Your baby will get vitamins, fats and other essential nutrients through the IV lines until he or she is ready to receive breastmilk or formula feedings. Sometimes, medications like antibiotics are also given through the IV lines. A central line may be placed through the vein or artery of the umbilical cord, or in a vein of the arm or leg. Peripheral IVs are placed in the arm or leg but sometimes it is necessary to use the baby's scalp for IV access. If your baby needs long-term IV fluids and medications, we may ask for your consent to place a Broviac Central Line or a Peripherally Inserted Central Catheter (PICC). These types of lines can stay in place for weeks and this means your baby would be poked with a needle less often for new IVs.

## KEEPING YOUR BABY WARM

If your baby is inside an incubator, or on a warming table, you may wonder why he or she is not dressed in clothes. Your baby has a sensor that is taped on the skin to monitor her/his temperature. As the baby gets cold, it tells the warmer bed or incubator to give more heat.

As the baby warms up, the sensor also tells the warmer bed or incubator to stop making heat. Once your baby is big enough to control his own temperature, we will move your baby to a crib or bassinet.

## SUPPORTING YOUR BABY'S BREATHING

Sometimes, infants in the NICU require help with breathing. This is due to a variety of reason ranging from prematurity to illness. Depending on the condition, you may see different ways that we help your baby breathe more effectively. He or she may have a breathing tube that travels to the windpipe. This tube is connected to the ventilator and pushes air directing into the lungs (SIMV). If your baby is able to do some breathing on their own, there may be small prongs in the nose where pressure is pushed in (NIMV). As they grow stronger, you may only pressure (CPAP) or air flow (nasal cannula). Your baby's nurse, respiratory therapists and doctors discuss the amount of breathing support your baby needs multiple times a day. Changes are made based on your baby's condition.

## YOUR BABY & BLOOD TESTS

Because your baby may be very sick, we will need to test your baby's blood often at times. The doctor may place a UAC (Umbilical Arterial Catheter) in the belly button to allow the nurses to draw blood easier especially if the baby is very small or very sick. Most of the time, we stick the baby in the heel of their foot to get the blood.

Because multiple blood work may be needed and the baby may be very small and/or very sick, it may become necessary to give blood transfusions to replace the blood taken. Please let us know if you have any concern with this. You may choose to have a friend or a family member donate blood in our Blood Bank specifically for your baby. Be aware, however, that it takes several days for this blood to be processed before it can be used, and it has to be donated from someone with a compatible blood type.

This is called Donor-Directed Blood. To donate blood, you may call or walk into the Blood Donor Room and Hemotherapy Center located in room 1611. Donor hours are Monday through Friday, 8 am to 6:30 pm, Saturday, 10 am to 6 pm The Blood Bank can also be reached at **312.996.6970**. As your baby's condition improves, she/he will require less blood work.



## YOUR BABY & PAIN

We take pain control very seriously in the nursery. One thing we do is to check for pain every time we handle an infant. There are scores that use a baby's behavior to judge the level of pain they have, and this has been tested with thousands of babies to make sure it is accurate. What do we do if the scores suggest that the baby is in pain?

- If it is mild or moderate, we first try comfort measures such as changing a baby's position, offering them a pacifier, or swaddling them.
- Giving them a little bit of breast milk or concentrated sugar water, either on a pacifier, or a swab in the cheek, has been proven to help with pain.
- If the pain is more severe, we will use pain killing medications.
- There are situations that we know are painful, and so we don't wait until the pain scores are high, such as during and after a surgery.

If you are present while your baby is having a procedure, or even during the regular nursing care, you can actively help lessen your baby's stress and pain. Using your hands to gently contain your baby's body is reassuring to him/her as it makes him feel as if back in the womb. For bigger babies, being skin to skin or breastfeeding while having blood taken from their heel also helps them manage the pain.

It is our goal to keep your baby comfortable, and any concerns you might have about your infant's pain control, please ask your baby's doctor.

## ICN VERSUS NICU

Depending on the condition of your baby, he/she will require different levels of care throughout hospitalization by the same group of nurses. We will let you know of these changes. Below are the differences in the two levels of care.

**Intensive Care (NICU):** for babies who need constant medical and nursing attention. The babies are sicker or more fragile and require more complex care.

**Intermediate Care (ICN):** for babies who are more stable and getting ready to go home. This is a "graduation" and brings your baby another step closer to going home. Also there are babies who never require intensive care but need close monitoring. They may spend their entire hospital stay here.

Infants who require ICU care and ICN care may be physically placed next to each other, or separately clustered. Occasionally your baby might change their location in the nursery to balance out the care required in those rooms. However, be assured that the same doctors and nurses care for all infants, and even if your baby's status changes, you will continue to see familiar faces. The same nurses work in NICU and ICN and switch between the two areas regularly.

If your baby was transferred from another hospital to CHUI for specialized care, your baby may be transferred back to the other hospital once your baby can be cared for adequately by the hospital from which you came.





## NURSERY ROUTINES

### Who cares for your baby?

Your baby is cared for by a nurse 24 hours a day. Each nurse is assigned several babies to care for; each nurse typically works either 8 hour or 12 hour shifts. The nurse is responsible for providing the hands on care of the baby. This might be routine care that they provide when you are not here (diaper changing, feeding, calming), or it might be specialty care (giving medicines, giving IV fluids, checking vital signs). Each baby has a primary resident physician, who is directing the medical care of several infants at a time. They examine the infant every day, and evaluate how the baby is responding to treatment.

Each weekday at the beginning of the day, the residents evaluate their babies progress over the last 24 hours, and then mid-morning at “medical rounds” with the attending physician all the physicians discuss the patients and make plans for the next day or several days. You are encouraged to actively participate in these rounds if you are in the NICU. This will help you understand the medical plan, and your observations are invaluable to our understanding of the baby. If you cannot be here in the morning, it is best to call in the afternoon to find out what the plan is for your child and how you can best be involved in the care of your baby. You are a vital part of your infant’s care team.

### Caregiving and Feeding

Typically, the babies are cared for on schedules based on feedings, which are usually every 3 or 4 hours. Babies are then encouraged to rest in between times, if that is what is appropriate for their age and condition. Very fragile babies may be handled less frequently; older babies may be encouraged to have “play” times if that is appropriate for them. If your baby is on a schedule, **you can plan with the nurse how you would like to be involved with care.** Please note that we try to be flexible with care times, so if a baby wakes up early and is fussy, or if a baby is sound asleep at this time for care, we will try to adjust our routines so we can care for them when they need it.

### Baths, weights, blood tests

Baths are given as needed, not routinely. Tub baths are not necessary for small infants, and in fact can dry out the skin unnecessarily. However, tub baths on stable infants can be a very relaxing, enjoyable thing for them, **so ask the nurse to save the baths for you to do, and plan on doing them a couple times a week.** Weighing babies typically happens during the night, between 9pm and 3am. Regular blood tests (not urgent) are usually done in the early morning (5am - 7am).



# VISITATION POLICY

Parents may come at any time. At the time of birth, the mother is given two ID bands that are identical to the ID band her baby has. She wears one, and the other is to be worn by the father, or another significant other that she wishes to be able to see the baby at any time.

Only two adults can be at an infant's bedside at the same time, and one adult of the two **must** be banded for the baby.

- Other family members may wait in our patient education room. We ask that you have an adult supervise young children that may be waiting in the **patient education room**.

A parent or significant other who is wearing a band may see the baby at any time, 24 hours a day. Other family members may visit, but only if they are accompanied by the banded parent or significant other. This means that you make the decision as to who you want to come in and see your baby.

The baby's brothers or sisters may visit **if**:

- They are over 3 years of age.
- Are up to date with their immunizations (we will ask you to bring a copy of their shot record).
- Have not been exposed to chicken pox or other infectious diseases.
- The number of siblings and the duration of the visit are at the nurse's discretion.
- Siblings under 16 years **must** be accompanied by an adult at all times when they are anywhere on the unit or in the hospital.
- Siblings who are 18 years and older are considered an adult.

Premature and sick babies have underdeveloped immune systems and cannot fight off infections as well as an adult. To protect the babies, we ask that anyone with the following conditions avoid coming into the nursery.

Visitors must **not** have any of the following signs of illness:

- Fever within the last 3 -4 days
- Diarrhea
- Drainage from the eye or "pink eye"
- Skin sores or open wounds
- Colds or respiratory illnesses
- Flu-like symptoms
- Siblings who have been in contact with another child who had a rash within the last 3 weeks
- Siblings with incomplete or outdated immunization records

Parents may visit 24 hours per day. If you arrive after 8:30 pm you will need to show security a valid government identification, such as a driver's license, to come to the NICU.

Nurses hand-off care to one another at 7am, 3pm, 7pm and 11pm. You are encouraged to take part of the nursing hand-off communication at those times. Please keep in mind that when calling during those times, nurses may not be able to come to the phone immediately





# GUIDELINES COMING INTO THE NICU / ICN

For your baby's safety and security, we ask that you respect the following:

## SIGNING IN

When you first arrive in the nursery, please tell the clerk/nurse whom you are visiting. They will show you a locker so that you can put your coat, any bags and purse in a safe place. You will need to wash your hands carefully at the reception desk; you will be guided as to how to do so. When you arrive at the bedside, let your baby's nurse know that you are there and she will sign you in on the log in the nurse's chart.

## KEEP GERMS AWAY

Premature and sick babies can develop infections from germs. These germs are found on our skin and everywhere we live. To protect the babies, we have set up guidelines to keep the nursery as germ free as possible.

The staff of the neonatal intensive care unit knows that the health of your baby is very important to you.

While there may be many times you feel helpless, there are some things that you can do to help to protect your baby:

### Scrubbing in

The staff at the reception desk in the unit will show you how to properly wash your hands when you visit.

While spending time with your baby, **clean your hands after touching any personal items** (like your cell phone) by using the alcohol gel sanitizer at the bedside. **Before and after you feed your baby or change the baby's diaper**, you will want to wash your hands again.

When you are at your baby's bedside, there are sinks nearby, and also a waterless gel that you can use to cleanse your hands without leaving your baby's bedside. Please ask your nurse to point these out to you, and wash or gel your hands before and after you have been touching your baby and other surfaces (such as your cell phone).

Long Natural / Artificial Fingernails - Long natural or artificial fingernails, wraps and nail tips trap germs that could be transferred to the baby. These germs are nearly impossible to remove by hand washing. You may want

to consider trimming your nails short and remove any artificial nails.

Eating and drinking at the bedside - While we want you to keep up your nourishment, eating or drinking at your baby's bedside is not allowed. This is because it may transfer germs from your mouth to the areas around the baby's bed, which can be transferred to the baby.

## WHEN YOU MAY BE ASKED TO STEP OUT OF THE NURSERY

You are encouraged to be actively involved in your infant's care and we will not ask you to step away from the bedside unless absolutely necessary. This may happen if there is an emergency with another baby or during certain treatments or procedures that take place with your baby or others nearby. If asked to leave the nursery, please know that it is due to the safety and privacy of all infants and families in the unit.

## PRIVACY

We will at all times respect your privacy and that of your baby. Because of this, our nurses will not be able to discuss other babies in the nursery with you. We ask that when you visit the nursery that you stay at your baby's bedside and do not touch, visit, or inquire about other babies. This will help to reduce the congestion in the nursery, reduce the chances of spreading infections, allow staff to provide better care, and maintain privacy for all patients.

## VOLUNTEERS

The nursery is fortunate to have a wonderful group of volunteers who help out in many ways. They have been trained to help the nurses and to "cuddle" babies, holding them to prevent crying, aid digestion and to help them fall asleep. The nurses often rely on these volunteers to spend time helping the babies remain calm and conserve their energy for growing. All of these volunteers have passed an extensive screening and have been trained by our staff to handle the infants appropriately. They are part of our routine care; however, if you have any questions or concerns about the use of our volunteers, please contact volunteer coordinator at 312.996.1747.





## FACILITIES FOR FAMILIES

We have some limited space for families.

### Parent Education/Waiting Room

Near the ICN reception desk, we have a room that is available as a waiting area for visitors who are taking turns to see the baby. This is also used as our education room where families can watch videos that will help them get ready for their baby to come home. Children are welcome to wait here but must be supervised by an adult. Since this is a common area for all families, please keep the lights on and sleeping in the lounge is not allowed.

### Family Kitchen

Back by the family education room is a small room where you are welcome to eat. There is a refrigerator for you to store your lunch. Please help us keep it inviting by cleaning your area once you are done eating.

### Breast pumping room

We have rooms that are available to pump milk while you are on the unit.

### Lockers

Due to lack of space, and infection control issues, we ask that you not bring coats and large personal items to the baby's bedside. Please store large items in the lockers near the desk. You may bring a small bag into the patient care area, but please keep it under your control at all times. **We must be insistent that you leave no valuables in the lockers or personal belongings unattended. The hospital cannot be responsible for items that are lost or stolen.**

## FREQUENTLY ASKED QUESTIONS

### Who can call?

Information will be released to parents **only**. Your ID band bracelet has a number on it that you will be asked for when you call, so that we are sure we are talking to a parent.

### How can I get information about my baby?

Minute to minute information ask to speak to the nurse or resident (M.D.)

Medical information and test results ask for the doctor (M.D.)

Overall management plans - You can ask to schedule a meeting with your baby's primary nurse, doctor and other members of the care team.

### What if I am not able to get to the hospital regularly to care for my baby?

Temporary arrangements for an alternate visitor may be made with approval from our unit's nurse manager.

### Can I be involved in my baby's care?

Your baby belongs to you. We are only helping to care for your baby for a while by providing the specialized care that your baby needs. We wish you to take a lead part in planning and caring for your baby.

### How will I learn to care for my baby?

The nurses will give you many opportunities to practice the skills you need to know. We also will leave written information in this book, and we have videos available for you to watch.

### Can I still breastfeed?

Breastfeeding is encouraged and supported in our unit. We can give you instruction and support in pumping your milk and nursing your baby.

### Are there things I can bring or do for my baby?

We encourage you to make your baby's bed space "yours" as much as possible.

### Mementos

Some parents bring in photographs of the family to put in their baby's bed; drawings from younger children can be taped by the bed. Religious medallions or cards are fine to have on the bed. We ask that you not bring balloons since they obstruct the view of the monitors.

### Toys

It is best to bring in small toys so they do not take up too much space or block the view of the baby. We suggest that the toys be made of plastic or rubber since this makes them easier to clean. If your baby is in a crib, a mobile would be additional stimulation for your baby. You may also bring a family photograph to lend a personal touch to the incubator.



### Tape recorders or musical toys

Music or tapes of your voice can be played for your baby. This can have a comforting effect when played to your baby in your absence. The developmental specialists or music therapists may have recommendations for you on how much to use music for your baby, as some music can be over stimulating for your baby.

### Cameras and camcorders

You may videotape or take as many pictures of your baby as you desire. Please be aware that pictures should ONLY be of your baby. Including other babies, families or staff in pictures or video without their permission is NOT allowed for ANY reason. You may use your phone to take pictures or video, but please remember you are not allowed to speak on your phone while in the patient care area. Always wash your hands with soap and water or hand gel between handling phones, cameras or camcorders and your baby.

### Clothing and linens

We do have a supply of hospital linen, and also special blankets and outfits that volunteers have made for the use of our babies. But if you wish to bring clothing and blankets from home, they must be laundered first. Clothing should be made of fire retardant fabric. You are welcome to bring special blankets or premature size clothing; however, we will ask you to label them with your name. We also ask that if there is anything that you don't want lost, it is better that it be left at home. As hard as we try, articles may get lost since we do have to move your baby to different incubators, cribs, or bed spaces as necessary.

### Where can I park?

#### Paulina at Taylor

(attendant on duty 24 hours a day)

#### Wood between Roosevelt and Taylor

Hours: 7 am to 5 pm

Monday-Friday

(attendant on duty)

Discount parking is available. Please contact Guest Relations at 312.996.3610.

For further information about these parking garages, please contact the Parking Office at 312.413.5850.

### Where can I eat?

#### Garden Cafe

(on the first floor)

Open daily: 6:30 am - 10 am (Breakfast)

11 am - 2 pm (Lunch)

4 pm - 7 pm (Dinner)

Holidays: 6:30 am - 2 pm

Chicago Illini Union Dining Services. (Including fast food restaurants such as Subway®, Wendy's®, etc.) Call 312.413.5200 for information.

### Can I stay overnight?

Unfortunately we do not have space for parents who wish to stay overnight routinely. We do have a Parent's Room near our nursery used by parents for overnight stays for babies who are about to be sent home, or for unusual circumstances. Please speak with your nurse regarding specific information.





# WHO'S WHO IN THE NICU / ICN

There are many highly skilled personnel that are part of your baby's care team. Below we describe some of the people you may encounter.

An important part of providing your baby with exceptional care and service is Hourly Rounding by your caregivers.

Your baby will be checked on at least every hour.

## DURING THESE VISITS, YOUR BABY'S CAREGIVERS WILL:

- Check to see if your infant is comfortable and relaxed.
- Comfort your baby if needed.
- If you are present, check to see that you have all the supplies you need to care for your baby, and that you are comfortable.

We wish to anticipate you and your baby's needs and monitor your family's well-being so that you can focus on your baby.

### Attending Neonatologist

The leader of the NICU team. These are pediatricians who have special training in the care of premature and sick newborn babies. They supervise and are responsible for the medical care of the babies.

### Fellow

A doctor who has completed residency training in pediatrics and is taking advanced training to become a neonatologist. They are responsible for overseeing the training of the residents.

### Residents

Doctors who are training in pediatric care. They are responsible for your baby's day-to-day care.

### Neonatal Nurse

A nurse who has special preparation to care for premature and sick newborn babies. They are in charge of providing bedside care to your baby.

### Patient Care/Discharge/Family Coordinators

Healthcare professionals who will help coordinate your baby's care and prepare you for going home.

### Social Worker

A healthcare professional who is trained to counsel and support families and who can assist you with healthcare arrangements, financial matters and involvement with other agencies.

### Respiratory Therapist

A healthcare professional who is responsible for the equipment and care that helps a baby breathe.

### Developmental Specialists/Therapists

Healthcare professionals who are monitoring your child's growth and development and will make recommendations on caring for your infant to promote development.

### Lactation Consultants

A person which special training in breastfeeding to assist families in meeting their breastfeeding goals.

### Other Professionals

Many other specialists may be interacting with you and your baby, for instance:

- hearing specialists
- doctors in different specialties (cardiology or heart doctor, neurology or brain doctor, ophthalmology or eye doctor)
- technicians who perform tests (ultrasounds, x-rays)

On any given day, your baby's nurse or resident can provide **minute-to-minute** information. The doctor can give you medical information and tests results. To discuss **overall** management plans, it is best to schedule a meeting with the primary nurse and attending neonatologist.





# JUST FOR PARENTS - WHAT YOU MAY BE FEELING

You may have expected a healthy baby and probably had things set up at home. Having a baby in the NICU is a scary experience. You may also fear what will happen to your baby. Everything is unfamiliar --- people, equipment, and routines. Visiting your baby for the first time can be difficult. We recommend that you bring someone on your first visit who can share this experience with you.

No two people react to a stressful situation in exactly the same way. We want to help you understand that your reactions are normal and can affect other aspects of your life. What follows is a description of some of these feelings and some suggestions for how to cope with them.

## SHOCK AND DISBELIEF

It is an enormous shock to hear that your baby has a problem which requires special care. Your baby may look nothing like you expected. You may not be able to eat or sleep well at first. You may have trouble understanding what you are told about your baby. You may have a hard time concentrating on everyday things and even have trouble taking care of your family. You may feel helpless and confused and hope that the whole situation is a big mistake.

Because of this confusing time, it is a good idea to postpone making important decisions that can wait a few days. It is also helpful to talk about your feelings.

## QUESTIONS, ANGER, AND GUILT

You may ask yourself “Why is this happening to me?” You may be searching for blame within yourself. Often, there is no explanation or identifiable cause for your baby’s problem. You may feel guilty and think that you may have caused your baby’s problem. You may ask yourself, “What did I do to cause this?”

Instead of blaming yourself, concentrate on getting your questions answered and recognize these feelings as normal reactions that will lessen with time. Discussing your feelings with objective people (such as health care professionals, trusted friends, spiritual adviser) can help you better understand your own reactions.

You may also have mood swings and get angry easily. You may overreact to small incidents. It is important that you are patient with yourself, but also find activities and people who help comfort you.

## HELPLESSNESS AND DEPRESSION

Not knowing how your baby will progress is very difficult. You may cry a great deal during this time. Depression is a very common reaction and you may be unable to sleep, lose your appetite, feel tired or weak or be short of breath.

Calling or receiving phone calls from the nursery can also be stressful. You may feel physically sick or depressed each time you dial the nursery number or each time your phone rings. It may help to call at the same time each day or have a friend or family member with you to help you cope with this.

You can’t avoid all your sad or painful feelings. But you can deal with them. Seeing your baby improve may help relieve your depression. Visit your baby often. Keep in close touch with the nurses and doctors. Ask how you can help in your baby’s care. It is also important that you take care of yourself by eating and sleeping as regularly as possible.

Our nursery staff wants to help you cope with these normal reactions. Talk with them about your feelings. Be honest in sharing your troubled feelings with others. Coping becomes more difficult if feelings are ignored — if they aren’t expressed openly. Usually these fears and concerns subside eventually. **If they remain a problem,** please talk with your nurse and arrange a time that she can call you each day to share your baby’s progress. She can also refer you to someone to talk to share your feelings.





## POSTPARTUM DEPRESSION

Depression can be caused by the hormonal changes that occur after a mother gives birth, and is not unusual when the stress of a sick or premature baby is added. This can be a very serious illness, but fortunately it is treatable. If you or your family members think that your feelings of sadness are not improving as time goes on, please talk to the social worker and to your doctor. It is very important both for you and your child that you get needed help.

## WHAT TO SAY TO FRIENDS AND CHILDREN?

This is a very individual and personal decision and will depend upon your baby's diagnosis as well as your own wishes. You may not be ready to answer the questions that your well-meaning friends or relatives will have. We encourage you to think of your own needs at this time. We recommend that you tell these people that although you appreciate their calling, you do not feel like talking at this time and will call them back when you do. You may be surprised how your friends will be relieved by your honesty.

If you have children, explanations should be based on how comfortable you are and your child's ability to understand the new baby's problem. Be honest and keep your explanation as simple as possible. It is better to explain that you are worried about the baby than to try to conceal your concern from older children.

Your child may also get upset just as you do, and become "babyish" in their behavior. Try to help your child by being sensitive to his/her emotions and keeping the household routine as normal as possible.

## WHEN YOU LEAVE THE HOSPITAL

You may feel depressed and vulnerable. It may be very difficult to leave the hospital with empty arms. Nothing will make this an easy experience, but having somebody with you when you leave may make it easier. Try to visit your baby the day you are being sent home from the hospital.

## SUPPORT PERSONNEL

Though family and friends may be helpful at this time, many people gain additional support by talking with a professional. The hospital social worker or chaplain can also provide information and resources which may be of help to you. Of course you are also welcome to call on your own spiritual adviser. If there are any special requests you would like for your baby, like a baptism or a special prayer, please let your baby's nurse know. You may request to speak to a social worker by telling your nurse or calling 312.996.4141. The hospital chaplain can be reached at 312.996.0296.



# MY UI HEALTH

We have a free and secure online tool for you to communicate with your healthcare providers.

With MY UI HEALTH, you can:

- Email your healthcare team directly
- Review some of your medical records
- Request an appointment
- View your lab results
- Renew prescriptions and view prescription information
- Pay your medical bills and view your balances

Visit [hospital.uillinois.edu/MyUIHealth](http://hospital.uillinois.edu/MyUIHealth) for more information.

## PARTNERS IN CARE

You and your baby have rights that you should be aware of concerning how you are treated as a hospital patient. These are spelled out in the brochure “Your rights as a Hospital Patient” (in the information for Patients envelope). You have the right to being treated fairly and to having your privacy maintained.

As we work together to give your baby the best possible start in life, we ask that you help us by doing the following:

1. Please make sure that we have the right information to contact you. Please provide us with all possible numbers if case we need to contact you in an emergency.
2. Be actively involved in the care of your child! No matter your child’s age and medical condition, you will be able to help care for your baby, and your child is reassured by your loving touch. By being involved, you will learn more quickly about your child’s care which will make it easier when you go home together after leaving the NICU.
3. We have a number of guidelines in place to ensure the safety and security of all the babies who are cared for in the NICU. These are spelled out in our “parent agreement” document which you will be asked to review and sign shortly after your baby’s admission. Please understand that there are important reasons for these guidelines and we expect you to follow them.

Please do not hesitate to raise questions or concerns about your baby’s diagnosis, care and going home plans. We want to ensure that you are knowledgeable and comfortable with your baby’s care. And let us know if you don’t remember or understand what was told to you; it is common to be forgetful when you are stressed, and we will be happy to repeat any needed information.



# CARING FOR YOUR BABY IN THE NICU/ICN

## KEEPING TRACK OF YOUR BABY'S CARE

We realize that this time can be very confusing for you. Although we try hard to help you understand your baby's condition, you may not know what questions to ask about your baby. Below are some questions that you may want to ask your baby's doctor on a weekly basis.

### How is my baby growing?

The nurse can let you know the daily weight of your baby but the doctor can better explain to you if your baby is growing appropriately. It is typical for all babies to lose weight in the first weeks of life, and to fluctuate up and down day to day. It is better to focus on the week to week trends.

### Is my baby's condition progressing as expected, or are there any unexpected changes?

Almost all infants have "setbacks" just when you think they are getting better. We tell parents to expect "two steps forward, one step back", and to prepare yourself for some disappointments.

### What tests/procedures have been done for my baby? What are the results? What do they mean?

As your baby grows, there will be different tests that we do to screen your baby for particular conditions — eye exams, hearing exams, etc. Some are routinely done on all infants, and some are specific for your baby's condition. The nurse can let you know what tests have been or are scheduled to be done, but the doctor will explain the results.

### What do I need to learn to take my baby home?

We want to make sure that you are comfortable with your baby's care. The more you get involved with your baby's care, the faster you will be prepared to go home. In some cases, if you are willing to learn specialized care (taking a baby home on oxygen and a home monitor), you will be able to go home sooner. It is important that you are able to be honest with yourself as to how much special care you can handle at home.

If you think of questions at home, write them down so you will remember to ask the doctor on the phone or when you come to visit. Keeping a journal may also help you keep track of not only your feelings and concerns but also how your baby is progressing.

It is important to keep in touch with the doctor to see what's new and what the long/short term plan of your baby. It is best to call your baby's doctor between the hours of 11 am - 4:30 pm.

## BREAST MILK & BREAST PUMPING

**Breast milk is the best milk for your baby.** It is like custom made medicine for your baby. Please consider providing your breast milk for your baby. Keep in mind that no matter how much or how long you provide your breast milk for your baby...any breast milk is better than no breast milk.

**We offer** the following services to support your efforts to provide breast milk for your baby.

- Face to face assistance in learning how to breastpump and breastfeed from Lactation Consultants, Registered Nurses and Physicians as you need.
- Assistance in getting a breastpump from your insurance.
- A pumping room with a hospital grade breast pump.
- Information about pump rental programs.
- Containers for milk storage.
- Freezers and refrigerators for milk storage.
- A pumping/breastfeeding mothers' support group called TLC (The Lactation Club).
- Screens for privacy during skin-to-skin, pumping, or breastfeeding at the bedside.
- Videos and written information concerning the benefits and how-to's of breast pumping and breastfeeding.
- Pre-Natal breastfeeding class.
- Pasteurized donor milk for babies who are high-risk





#### We ask that you...

- Begin pumping for your baby within 6 hours of delivery.
- Use the best pump available to you.
- Make it your goal to pump 8-12 times a day or every 2-3 hours.
- Bring fresh or frozen milk to the nursery as needed.
- Hold your baby skin-to-skin on a regular (almost daily) basis.
- Initiate suckling at the breast for fun and then nutrition, as soon as possible, especially if actual breastfeeding is your goal.
- Contact our Lactation Consultants if you notice a decrease in your breast milk supply or as any questions or problems related to pumping or breastfeeding arise!!

#### We are here to support you!!

Please feel free to talk to your baby's nurse or doctor or to call Lactation Services if you have any interest in providing breast milk for your baby. We will do all we can to ensure that your needs are met and that your baby receives the best you have to offer.

#### Pumping breast milk

Whatever the reason your baby is in the NICU, we strongly encourage you to consider pumping to feed your baby. Even for those mothers who have already decided to feed formula at home, we encourage you to pump your milk for your premature baby while in the hospital. It has been proven that breast milk helps premature babies to fight off infections, and to digest their first feedings better. We have electric pumps and a pumping room on the unit, and we can help you figure out how to get a pump for use at home.

There are very few women that can't breast feed, at least partially. However, there are certain medications, use of street drugs, or diseases that are incompatible with breast feeding. This you can discuss with your nurse, or your baby's nurse. Pasteurized donor milk is available for fragile or at risk babies in certain situations. Staff will approach you if your baby qualifies for donor milk support.

#### Pumping of milk:

- You should begin to pump as soon as possible (within hours, if feasible) after delivery, and pump 8-12 times daily for up to 15 minutes each session.
- Wash your hands thoroughly before touching your breasts or equipment.
- Wash your nipples only with warm water (no soap necessary).
- Set up the equipment to the pump as the nurse instructs you; the double pump method is the most effective, as well as being the fastest.
- When you are done pumping, pour the milk into the sterile containers the hospital provides you; remember not to touch the inside of the container or the lid. Put only a small amount (1/2 ounce) in each container, as your baby will use only a little milk in the beginning.
- Put a label on each container with your baby's name preprinted on it. Write the date and time of the pumping.



- After pumping, you need to wash the pumping equipment in hot soapy water, rinse well, and let air dry to make sure all bacteria are killed.
- It is very important that you keep the milk as clean as possible by using the sterile containers and by cleaning the equipment as suggested.

**Storage of breast milk:**

For use in the nursery, freshly pumped milk in the refrigerator is good for 4 days from the time it was pumped. If left at room temperature, it should be used within one hour. Milk placed in the freezer is good for 24 hours after thawing, and good for at least 3 months in the freezer. You can thaw frozen milk in a container dish of warm water, but be sure you are using a tightly closed milk container so the water cannot get into the milk where it could contaminate it. Do not microwave breast milk! This destroys the protective antibodies in the milk, and it is much harder to keep the milk from getting too hot.

**Transitioning your baby to the breast:**

As your baby becomes more stable, you will be able to nurse your baby. At first, we may suggest “practice” feedings. This can be done by putting your baby to your breast after you pump your milk. This will give the very small preemie a chance to learn the feel of your breast, the smell of your milk, and a chance to exercise his sucking muscles without having to learn how to swallow a lot of milk.

Later, as he becomes more capable of sucking and swallowing, we will encourage you to put the baby to the breast at every visit. We may weigh the baby before and after feeding to get an estimate of how much milk he has taken, but normally that is not necessary.

If you have some difficulty with breastfeeding or have questions, ask to speak to one of our lactation consultants.

**Important Information:**

- UI Health does not provide formula when your baby leaves the NICU.
- If you are eligible for WIC, your baby must be in the WIC system for 24 hours before you can get an appointment to receive formula.
- Call WIC soon after your baby is born to get the registration process started and get some formula.

\*\*WIC only provides some of the formula a baby needs... families will need to buy more formula than WIC provides to feed their baby\*\*

# TLC

## The Lactation Club

Board Certified Lactation Consultants  
Peer Counselors  
Developmental Experts

Held every Tuesday!

- Meet other new moms
- Get breastfeeding help
- Weigh your baby
- Explore more infant development

Location:  
1801 W. Taylor St.  
2E OCC  
Pediatric Clinic Waiting Room

*(Sign says Pediatric Sickle Cell Center; enter through the main 2E door)*

For information, assistance or to confirm meeting call **312.413.0233**



# HOW TO HOLD YOUR BABY SKIN-TO-SKIN

## A GREAT WAY TO BEGIN

Skin-to-skin holding happens when a baby is unclothed or only in a diaper and placed on the bare skin of the mother, father, grandparent or caregiver. Skin-to-skin can happen in the hospital (with full-term babies right away or when preterm/special care babies are ready for this contact). You can hold your baby skin-to-skin at home, too. There are many benefits of skin-to-skin holding. All babies need skin-to-skin holding.

### In the First Hours: Newborn Babies in the Hospital

- When you are pregnant, be sure to tell your doctor or midwife that you would like to hold your baby skin-to-skin right after the baby is born. Tell your family/friends who plan to be present after the birth.
- Immediately after birth, the baby will be dried off and put on your bare chest. (The baby's hands are not usually dried off.)
- You and your baby are covered with a blanket. The baby's head stays out. The baby is naked and not wrapped. You and your baby will rest skin-to-skin for an hour or two after birth. This is a special time for you and your baby. Necessary procedures and checks are done with the mother and baby skin-to-skin.
- If there are medical reasons that keep you and your baby from skin-to-skin holding right after birth, start as soon as possible.

### At Home

Hold your baby skin-to-skin at home. Do it when you are awake and able to hold your baby safely. Skin-to-skin can be really helpful when:

- You want to cuddle and be close to your baby.
- The baby is having periods of fussiness or having trouble moving between infant states (such as going from sound asleep to crying without being in a quiet alert state in between).
- You are having difficulty latching on your breastfeeding baby or are having difficulty keeping up your milk supply. When your baby searches for the breast, move your baby to breast.

### Why Skin-to-Skin?

- Babies are warmer.
- Babies are calmer.
- Babies move more easily from one state (awake, asleep, crying, etc.) to another.
- Babies hear their mother's heartbeat.
- Milk supply is improved.
- Babies warm up better.
- Babies "self attach" to the breast better — gets breastfeeding off to a great start.

*If you are on medications or anything that might impair your strength or ability to stay awake when holding the baby, be sure someone else can help you care for the baby and hold the baby skin-to-skin.*





### What to Wear for Skin-to-Skin

Choose a shirt that opens in the front, or put on a bathrobe or take off your shirt. Remove your bra. Make yourself comfortable. Put your baby, dressed only in a diaper, onto your chest. Put a blanket over you and the baby, with the baby's head uncovered.

### In the Special Care Nursery

There are special benefits of holding the baby skin-to-skin in the special care nursery. Skin-to-skin contact for babies in the Special Care Nursery is called Kangaroo Mother Care. Your baby's skin and your skin are touching. You are always in a sitting position, leaning back a little. This special contact is beneficial for your baby, especially babies who need special care while they are in the nursery and later at home.

### Here's how to hold your baby skin-to-skin

- Ask your baby's nurse when it might be time for you to start holding your baby skin-to-skin.
- Ask the staff to help you transfer your baby to your chest. It may take extra care when a baby has tubes and wires attached.
- The baby will be naked (or only in a diaper) on your chest with your shirt open/removed and bra removed. (Some units have blouses that you close over your baby. These are especially nice after you are home.)
- Cover your body and the baby with a blanket, with the baby's head exposed. Stay in a sitting position, leaning back comfortably.

- You are an important part of your baby's care. After your baby comes home, keep holding your baby skin-to-skin in a sitting position.

Your baby may start moving toward your breast during skin-to-skin time. Ask your baby's health care provider if it is okay to nurse. The baby may nuzzle or "hang out" the first few times at the breast. Active suckling and swallowing come with practice.

### Benefits for Preterm and Special Care Babies

Regardless of how you are feeding your baby, your baby can benefit from skin-to-skin contact.

- Babies are warmer.
- Babies are calmer.
- Babies can hear their mother's heartbeat.
- Heart and breathing rates are normalized.
- Milk supply is improved.
- Other family members can hold and bond with babies through skin-to-skin holding too!

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Visit us on the web at [www.healthed.cc](http://www.healthed.cc)



## DEVELOPMENTAL CARE IN THE NICU

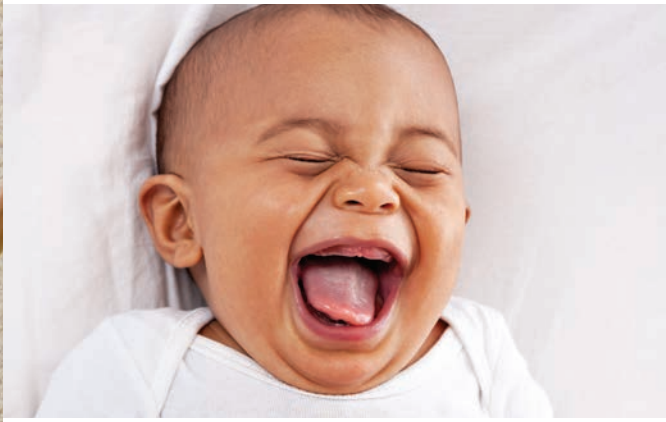
If your baby was born early, our medical care will focus on those parts of the body that are not developed enough to work on their own. We help the lungs breathe better effectively, we give nutrition that the gut can use, etc. But the organ that oversees everything, the brain, is also quite immature and needs some support to grow.

Your baby's brain is growing at a very fast rate, and does so while getting intensive medical care. We need to give that care in a way that supports best brain growth. We need to be aware of all the stimulation your baby is getting and make sure it is appropriate for best growth.

A priority is to lower your infant's experience of stress. Infants react strongly to pain and stress changes the way the brain develops. Stress can result from unpleasant procedures, but even things that we might not think of as stressful, such as the bright lights and loud sounds of the NICU, and even simple care such as a diaper change, can be stressful to a preterm infant.

The NICU at UI Health is a NIDCAP Training Center; NIDCAP is the leading method of developmental care to infants. We watch how your baby responds to NICU care so we can see what he/she finds stressful and what he/she finds comforting. Then we can make specific suggestions on how you and the nurses can handle your baby to keep him/her calm, relaxed and eager to interact with you. These might include caring for your baby very slowly so he/she stays relaxed during care, and how to gently contain your baby to help him/her stay calm.

If your baby is born early, or at higher risk for concerns, a developmental therapist will be working with your baby. They will work with you to understand what your baby's behavior is telling you and how to support your baby's overall development. If your baby would benefit from ongoing therapy work, they will refer you to services for after your baby goes home.



# WHAT DOES A SAFE SLEEP ENVIRONMENT LOOK LIKE?

## To Prevent Suffocation:

- Use a firm sleep surface, such as a mattress in a safety-approved crib, covered by a fitted sheet. Do not use a blanket.
- Do not use pillows, blankets, sheepskins, or crib bumpers anywhere in your baby's sleep area.
- Keep soft objects, toys, and loose bedding out of your baby's sleep area.
- Make sure nothing covers the baby's head.
- Always place your baby on his or her back to sleep, for naps and at night.

## More Ways to Protect Your Baby:

- Do not smoke or let anyone smoke around your baby.
- Dress your baby in sleep clothing, such as a snug one-piece sleeper, to regulate body temperature.
- Baby's sleep area is next to where parents sleep.
- Baby should not sleep in an adult bed, on a couch, or on a chair alone, with you, or with anyone else.





# ROUTINE SCREENING EXAMS IN THE NICU

## Why does my baby need newborn screening?

- Newborn screening tests are required by Illinois law for early detection of diseases that cause retardation, physical handicaps, or death, if undetected.
- The conditions are rare, and damage can be avoided with early detection.
- The tests are done from a few drops of your baby's heel blood, after the baby is at least 24 hours old.
- You will be informed by the state of abnormal results that would require another blood test. Result reports can take 6 weeks from the time the blood is drawn. *You will not be informed if the results are normal.*

## What are some type of exams that are given?

### Hearing Screen

- This is a test done on all newborns that checks for hearing loss that could cause speech problems in later life.
- Premature babies and babies who have had infections or other problems have a greater chance of hearing problems than healthy newborns.
- Before your baby's sent home, you will be informed of the screening results and any need for follow up.

### Head Ultrasound

Babies born prematurely, or who are high risk may have one or more ultrasounds of their heads. This looks at the brain tissue to identify any possible problems. This is usually done in the first couple of days for high risk babies and will be repeated as medically indicated.

### Eye Exams

The first eye exam takes place when your baby is 4-7 weeks old. The schedule is based on your baby's corrected age. Subsequent appointments will be made based on the results of the previous appointment.

## What disorders are included with newborn screening?

The Illinois newborn screening panel currently includes specific endocrine and metabolic disorders, as well as certain blood disorders. The disorders included in the panel are:

- Amino Acid/Urea Cycle Disorders
- Biotinidase Deficiency
- Congenital Adrenal Hyperplasia
- Congenital Heart Disease
- Congenital Hypothyroidism
- Cystic Fibrosis
- Fatty Acid Oxidation Disorders
- Galactosemia
- Hearing Loss
- Lysosomal Storage Disorders
- Organic Acid Disorders
- Phenylketonuria
- Severe Combined Immune Deficiency
- Sickle Cell Disease

More information about each of the diseases or disorders included in the screening panel can be found on the fact sheets provided on the website.

## Where do I get my baby's screening results?

Results of the screening are sent to the hospital or clinic where the sample was collected. Ask your doctor any questions you may have concerning the results or the newborn screening process.

## What if my baby needs a retest?

If your child's initial screening was unclear or abnormal the newborn screening may need to be repeated. If necessary, it is important to make sure that this test is repeated as soon as possible. Your baby's doctor will talk with you about what steps need to be taken.







# MEDICAL CARE AFTER THE NICU

## *Important information for parents whose babies have Medicaid*

After leaving the NICU, many parents wish to have their babies receive follow up care at the University of Illinois Hospital and Health Sciences System (“UI Health”) and see a pediatrician for primary health care at UI Health’s Outpatient Care Center (“OCC”) located at 1801 W. Taylor Street.

The UI Health system also includes Mile Square Health Center which has clinics located throughout Chicago (including the main site at 1220 S. Wood Street near the hospital) and in Cicero. Some parents wish to bring their babies to Mile Square for primary care.

**There are many different Medicaid managed care plans, some of which will allow you to come back to UI Health or Miles Square clinics for care.**

If you are asked to select a Medicaid managed care plan for your baby: You may already have a Medicaid managed care plan for your baby because your baby was added to your own Medicaid case and/or a case for your older children. During your baby’s NICU stay, however, you may receive a letter from the Illinois Department of Healthcare and Family Services (“DHFS”) asking you to pick a Medicaid plan and offering you several choices. Do not ignore this letter!

In choosing a Medicaid plan, you may wish to consider which hospitals and doctors accept the plan. You also may wish to consider the benefits available under each plan.

For example, some plans do not require co-payments, and some plans offer extra benefits, such as rides to the WIC office. To help you decide, you can compare the plans at the Illinois Client Enrollment Services website [enrollhfs.illinois.gov](http://enrollhfs.illinois.gov).

You also can get more information from a plan’s own website. If you prefer to speak with someone, or don’t have access to the internet, you may call the DHFS Client Enrollment Services at 877.912.8880.

You must choose a plan by the deadline stated in your letter. If you do not choose by that date, then the state will assign a plan and primary care provider to your baby. The assigned plan may not be the one you want, so it is important for you to pick the plan that works best for your baby by the deadline.

**Please inform the NICU staff immediately if your baby’s Medicaid coverage or plan changes.**

*Call nurse discharge planner or social worker, or ask to speak with one of them during your NICU visit.*

*If you are required to select a Medicaid plan, please let us know which plan you have chosen and the date when the new plan coverage will take effect. This will allow us to help you plan for the follow-up care your baby will need after leaving the NICU.*

# MY JOURNEY HOME

Welcome  
to the  
NICU

## NICU Orientation

- \_ Family information packet
- \_ Hand washing & Infection prevention
- \_ Parent agreement
- \_ Cell phone restrictions
- \_ Hourly rounding
- \_ Monitors, alarms, equipment
- \_ Infant security
- \_ Tour of unit
- \_ Physician Rounds
- \_ PAGes Group

## Breastfeeding

- \_ Pumping
- \_ Breastfeeding
- \_ Milk storage
- \_ Transition from bottle to breast
- \_ Supplementing
- \_ Pump for home

## Taking Care of My Baby

- \_ Infant Pain control
- \_ Diaper change
- \_ Taking temperature
- \_ Skin care & bathing
- \_ Cord care
- \_ Bottle & nipple care
- \_ Pacifier use
- \_ Clothing my baby
- \_ Bulb syringe

## Development Care

- \_ Skin-to-Skin care
- \_ Handling my tiny baby
- \_ Feeding cues
- \_ Developmental care plans/  
therapy involvement

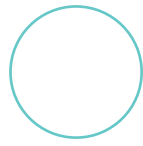
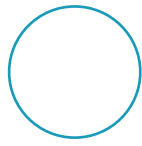
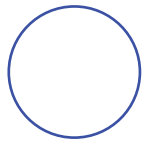
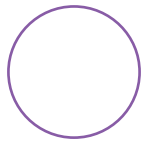
## Milestones to Going Home

- \_ Demand feedings, gaining weight
- \_ Transition to open crib
- \_ No apnea/bradycardia episodes
- \_ Going home education, screenings and videos complete

## Home Safety Education

- \_ Crib safety and safe sleep
- \_ Preventing falls at home
- \_ Preventing drowning
- \_ Clothing
- \_ Preventing shaken baby syndrome
- \_ Preventing Sudden Infant Death (SIDS)
- \_ Smoking and second hand smoke
- \_ Preventing burns
- \_ Going outdoors
- \_ Family & friends
- \_ Safe transportation
- \_ Choking
- \_ Signs of illness

# FROM THE NICU



## ○ Going Home Videos

- \_ Care seat
- \_ SIDS
- \_ CPR

## ○ Home Medications

- \_ Medication education
- \_ Prescriptions obtained
- \_ Talked with pharmacist
- \_ Practiced giving medication

## ○ To-Do to Go Home

- \_ Newborn screening
- \_ CCHD screening
- \_ Hearing screening
- \_ Eye exam, if needed
- \_ Car seat screen, if needed
- \_ Vaccines/immunizations
- \_ APORS
- \_ Update contact information

## ○ Week of Going Home

- \_ Arrange a ride/transportation for day of going home
- \_ Make a WIC appointment
- \_ Obtain home meds
- \_ Special equipment education
- \_ Special equipment education
- \_ Obtain additional formula
- \_ Take belongings home
- \_ Make follow-up appointments
- \_ Bring in car seat
- \_ Discuss patient survey with nurse

## ○ Day of Going Home Needs

- \_ Arrive at 9 am
- \_ Car seat
- \_ Going home outfit
- \_ ID Band/ID card
- \_ Special equipment
- \_ Going home summary
- \_ Camera for pictures
- \_ Gather belongings

Baby's name: \_\_\_\_\_

Reason for admission: \_\_\_\_\_

Birth date: \_\_\_\_\_

Departure date: \_\_\_\_\_

Birth weight: \_\_\_\_\_

Departure weight: \_\_\_\_\_

Gestational age: \_\_\_\_\_

Corrected gestational age: \_\_\_\_\_



