Special Beginnings
Our unit Philosophy

We believe the parent and child relationship is essential. We believe in providing a nurturing environment where:

The child is part of the family
And the family is part of the care team
A SPECIAL BEGINNING | CONTENTS

The ICN: The Intensive Care Nursery
Welcome 8
Introduction to the ICN and Your Baby’s Care 9
Telephone Calls To and From the ICN 11
Guidelines for Family Presence & Participation 12
DHMC Services for Parents 14
Birth Certificates 14
Steps for Direct Parental Blood Donation for ICN Patients ???
Frequently Asked Questions 14
Newborn Screening - Questions and Answers 19

ICN Care Team Members & Equipment
ICN Care Team 22
Extended ICN Care Team Members 24
Equipment Commonly used in the ICN 25

Common Medical Terms
Temperature Regulation 28
Jaundice and Hyperbilirubinemia 29
Infection 30
Respiratory Distress Syndrome 31
Apnea with Bradycardia 32
Nutrition 33

Caring For Your Baby in the Intensive Care Nursery
Parenting Your Baby in the ICN 36
About Your Baby 37
How Your Premature Infant Looks 39
How Your Premature Infant Acts 40
Expectations You May Have 41
Skin to Skin Holding (Kangaroo Care) 42
Skills to be Learned Check-List 44

Parents Supporting Parents
About Your Feelings 46
Parent Involvement in the ICN 47
Families Share their Experiences 48
Hello from “The ICN Parent Council” 56

Journal: Your Baby’s Story
The Day You Were Born 58
Who Were Your Caregivers in the Nursery 60
A Journal of Baby 62
Pumping Log and Tips 66
<table>
<thead>
<tr>
<th>CONTENTS</th>
<th>A SPECIAL BEGINNING</th>
</tr>
</thead>
<tbody>
<tr>
<td>Your Special Moments in the Nursery</td>
<td>67</td>
</tr>
<tr>
<td>Breathing Progress Chart</td>
<td>69</td>
</tr>
<tr>
<td>Height/Weight Conversion Chart</td>
<td>70</td>
</tr>
<tr>
<td>Growth Tracking Charts and Graphs</td>
<td>71</td>
</tr>
<tr>
<td>Nutrition Summary</td>
<td>75</td>
</tr>
<tr>
<td>Leaving the Nursery/Going Home</td>
<td>77</td>
</tr>
<tr>
<td><strong>Development: Growth and Development of Your Baby</strong></td>
<td>75</td>
</tr>
<tr>
<td>Your Baby’s Development in the ICN</td>
<td>76</td>
</tr>
<tr>
<td>What Can I Expect and Do During My Baby’s Early Development?</td>
<td>77</td>
</tr>
<tr>
<td>Baby Talk in the Intensive Care Nursery</td>
<td>78</td>
</tr>
<tr>
<td><strong>Ready? Preparing for Discharge</strong></td>
<td>89</td>
</tr>
<tr>
<td>Preparing for Discharge</td>
<td>90</td>
</tr>
<tr>
<td>Rooming In</td>
<td>90</td>
</tr>
<tr>
<td>What to Learn Before Discharge</td>
<td>91</td>
</tr>
<tr>
<td>Checklist for Parents</td>
<td>91</td>
</tr>
<tr>
<td>Car Seat Check</td>
<td>92</td>
</tr>
<tr>
<td>Choosing Your Baby’s Pediatrician</td>
<td>93</td>
</tr>
<tr>
<td><strong>Home: Going Home</strong></td>
<td>94</td>
</tr>
<tr>
<td>Return Transport</td>
<td>95</td>
</tr>
<tr>
<td>Home at Last</td>
<td>95</td>
</tr>
<tr>
<td>Baby Talk – Taking Me Home</td>
<td>96</td>
</tr>
<tr>
<td>Getting Ready to Go Home</td>
<td>97</td>
</tr>
<tr>
<td>Follow-up Appointments &amp; Programs at DHMC</td>
<td>97</td>
</tr>
<tr>
<td>Respiratory Syncytial Virus</td>
<td>107</td>
</tr>
<tr>
<td>Commonly Asked Questions</td>
<td>108</td>
</tr>
<tr>
<td>Crying Babies</td>
<td>109</td>
</tr>
<tr>
<td>Developmental Check Ups *</td>
<td>111</td>
</tr>
<tr>
<td><strong>Resources: Available Resources</strong></td>
<td>111</td>
</tr>
<tr>
<td>Utilizing Your Resources</td>
<td>112</td>
</tr>
<tr>
<td>ICN Parent Library</td>
<td>112</td>
</tr>
<tr>
<td>Resources within DHMC</td>
<td>114</td>
</tr>
<tr>
<td>Resources within the Community</td>
<td>114</td>
</tr>
<tr>
<td>State and Federal Services (NH and VT)</td>
<td>116</td>
</tr>
<tr>
<td>Useful Websites</td>
<td>118</td>
</tr>
<tr>
<td><strong>Glossary: User Definitions</strong></td>
<td>119</td>
</tr>
<tr>
<td>ICN Medical Terms</td>
<td>120</td>
</tr>
<tr>
<td>ICN Abbreviations</td>
<td>126</td>
</tr>
<tr>
<td>Notes</td>
<td>128</td>
</tr>
</tbody>
</table>
A Special Beginning

The ICN Parent Council welcomes you and your baby to the Intensive Care Nursery (ICN). As parents who have also had babies in the ICN, we can relate to many of your experiences. To help welcome you and perhaps ease your transition into the ICN, please accept our tote bag and the items inside as gifts from the ICN Parent Council.

Your gift bag will include a variety of different gifts based on the availability of the specialty and donated items. Two gifts EVERY bag will include are:

- **A Special Beginning**
  A book written and created by the ICN Parent Council and staff. This book includes a special “baby book” section specifically designed for babies in the Intensive Care environment. The book also contains a wealth of information about Dartmouth Hitchcock Medical Center (DHMC), the care team, policies, medical information, resources and general information related to your ICN experience.

- **A Handmade Quilt**
  We have many wonderful volunteers in the community who sew quilts for families who have a baby or babies in the ICN. Feel free to use this quilt as an isolette cover and it is yours to keep when you go home. We recommend that you use the quilt for supervised tummy time or as a wall hanging but never in the crib with your baby.

Sincerely,

The ICN Parent Council
Welcome
Introduction to the ICN and Your Baby’s Care
Telephone Calls To and From the ICN
Guidelines for Family Presence & Participation
DHMC Services for Parents
Birth Certificates
Steps for Direct Parental Blood Donation for ICN Patients
Frequently Asked Questions
Newborn Screening - Questions and Answers
Welcome

The Intensive Care Nursery (ICN) staff welcomes you to the Children’s Hospital at Dartmouth. It is our goal to provide your baby with high quality care and to help you through this stressful time. We would like to prepare you for the ICN experience and make your stay as comfortable as possible.

Having a baby hospitalized in critical care is not an easy journey, but the ICN team and other hospital staff people can help. When your baby is admitted to the ICN, you will meet with the doctor or nurse practitioner and the staff nurse caring for your baby. The nurse will talk to you about your baby’s needs, and help you become familiar with the nursery and the medical center. We will give you an enormous amount of information, and it may be hard to understand and remember it all. Please talk with us about your questions and concerns. We care about you, and we want to know how we can help you and your family.

We want you to spend as much time as needed, to take part in your baby’s care.

This is your baby. He or she will know that you are here and respond to you. Your baby will know your presence, your voice, your touch and your love. Together we will provide the best possible care for your baby.

Sincerely,

The Staff of the Intensive Care Nursery
Introduction to the Intensive Care Nursery and Your Baby’s Care

The Intensive Care Nursery (more commonly referred to as the ICN) is a place in our hospital where healthcare providers give around-the-clock care to sick newborns. Other hospitals may refer to their intensive care nursery as the Neonatal Intensive Care Unit (NICU). In the ICN, babies are observed more closely than is possible in a newborn nursery. ICN staff members have special training for your baby’s special needs.

Your First Time here in the ICN

The first time you come to the ICN, it may seem like a strange place. The nursery is full of machines and various sights and sounds. Buzzers and alarms go off. Your baby seems to have tubes and wires attached everywhere. Don’t let all this technology scare you.

At the very center of all this equipment is your baby that you love. Your baby is getting the care he needs. At first you may feel overwhelmed in the ICN, but with time you will become more comfortable. The staff is here to help you while you get through this period of adjustment.

Special Equipment

Your baby will require special care to grow and develop. He may need help with breathing, maintaining body temperature, and feeding. The equipment used in the nursery is complex, but we will explain how it helps us to monitor your baby’s progress.

We want you to focus on your baby; try not to become too distracted by the equipment. Your baby will be observed and monitored continuously in the ICN. Special equipment fills the ICN. Heat is maintained at just the right level. Oxygen is supplied if needed and nourishment is delivered in ways and amounts that your baby needs.

Care Team

As parents, you are a valuable member of the ICN Care Team. We encourage you to participate in your baby’s care and continue parenting throughout your baby’s stay in the ICN. You are encouraged to ask questions. The nurses taking care of your baby will be your primary contact for questions or assistance while your baby is here. Also, please feel free to use the note pages in the back of this book to write down any questions you may have for the nurses, doctors or anyone on the ICN Care Team.
Special Care

As you become comfortable with the setting, the care team will suggest ways you can help your baby. Even if he is very sick, there is always something you can do for him. You can sit next to his bed, talking or reading to him softly which can help strengthen your bond with him.

Some babies, when they are small or very sick do not like certain kinds of touching. Talk to your nurse about ways to touch your baby that will help him feel safe and more secure. Your touch can be very comforting. As you feel comfortable you will be changing his diaper and helping with his care.

When your baby becomes more stable you will be able to hold, feed and bathe him. Your baby’s nurse will help you with all these things until you are caring for him independently.

Personal Clothes and Toys

Please feel free to bring in some of your baby’s personal clothes and toys to be arranged at the bedside. Talk to your nurse about what items may be appropriate. Please label all toys and clothes that you bring in for your baby’s personal use.

We have personal laundry bags for your use that can be left at your baby’s bedside. Make sure you clearly label each garment. We encourage you to take home your baby’s items to launder. They could be lost in the hospital’s main laundry system. The ICN does have a washer and dryer for your use upon request.

In addition, artwork from your baby’s siblings and cards of well wishes from friends are other things you might want to put by your baby’s bed. Talk to your nurse about where these items might be appropriately placed.

Suggestions of items that you could bring into the ICN

- Music box or mobile
- Photos of family members
- Tape recording of your voice or music - tape a bedtime story, your baby will be able to hear your voice when you aren’t there.
- A personal laundry bag for the bedside - the nurses will put your baby’s soiled clothes in this bag.

Remember, the most important gift you can give your baby is your presence and your love.

Bed Spaces

Occasionally, there are circumstances that require babies to be moved to a different bedspace within the nursery. We try to notify parents in advance, however, it is not always possible to do so. If you come in and your baby is not in his usual place, don’t be alarmed. Please check at the reception desk to find out which bedspace your baby has been moved to. This often happens as your baby becomes stable, or your baby may require a quieter environment and at times for nursing assignment purposes.

Your Suggestions

The ICN staff values their collaborative relationship with families. If you have any suggestions for helping us support and care for families, please share them with us. We thank you in advance for your comments and/or suggestions.
Telephone Calls To and From the ICN

Calls To the ICN

Parents are welcome to call the ICN and receive up-to-date information on their baby and talk to their baby’s nurse. Please feel free to use the following phone numbers at any time during the day or night.

We discourage calls into the ICN by friends and family members looking for you unless it is an emergency.

For local calls, please call 1-603-650-7256

For parents or legal guardians that are calling long-distance, please call our toll free number 1-866-ICN-BABY (1-866-426-2229)

Please remember this is a line only for parents or legal guardians of a baby staying in the ICN.

Calls From the ICN

Pay phones are located outside the ICN Family room towards the Birthing Pavilion.

The ICN has phones available for parents’ use for a limited amount of time. Please use the pay phones for longer conversations.

You might find it helpful to ask a family member or close friend to act as a resource to screen calls. Have them take care of questions and concerns and to share the information that you want shared. This is a stressful and busy time for you. Family and friends will naturally be concerned for both you and your baby. They may call when you are feeding, rocking, holding your baby, or even discussing your baby’s care with your ICN Care Team. Their support is helpful, however it can be overwhelming if you are interrupted too often.

Additional Communications

Cellular Phones

We recognize that during this stressful time it is important for you to stay connected to your friends and family members. There are many ways to accomplish this with the technologies available today.

While cell phones will not interfere with monitors and equipment, we know that a calm, quiet setting is important for your baby’s well-being.

We ask that you turn your cell phone to vibrate or silent mode before entering the nursery and that you refrain from phone conversations at your baby’s bedside. Text messaging and e-mailing are acceptable but not while holding your baby.

Please remember to perform hand hygiene after using your phone or other communication device.

Pager Devices

The ICN may provide a pager (Beeper) for parents who need to leave the ICN. These are provided so we may stay in contact with you. They cannot be used for long-range or home use. They will operate on the DHMC campus. Pagers must be signed out at the ICN reception desk and signed in when you return.

If you have your own pager – your baby’s nurse can record the number so that you can be reached. This should always be kept on vibrate mode when you are in the nursery.
Guidelines for Friends and Family Members

Please check-in at the reception desk each time you enter the nursery. For safety reasons we must know who is in the nursery at all times. The receptionist will check with your baby’s nurse every time you come to be with your infant. Everyone must clean their hands each time they enter the ICN. We will teach you and your guests our hand washing techniques.

Recommendations and Precautions

Your baby needs a protected environment to recover and grow. For this reason we ask you to limit the number of people you invite into the ICN to see your baby. If you need help explaining this to families and friends, please talk to your nurse. Any more than 2-3 people at your baby’s bedside at any given time can be disruptive for your baby and the unit. Please use the family room for general visiting and conversation.

Anyone with a recent exposure to chickenpox or other communicable disease will not be allowed in the ICN. During the fall and winter season we have Respiratory Syncytial Virus (RSV) precautions. Any visitors with a cold will not be allowed in the ICN. Parents with a cold may come to the ICN if they do not have a fever, but should wear a mask. Booklets that explain more about RSV are available at the reception desk.

In order to respect others’ privacy we ask that you and your guests remain at your baby’s bedside and avoid "peeking" or asking questions about other babies. In the close setting of the ICN, it may be impossible to avoid overhearing information about other babies. It is not appropriate to discuss these details with anyone in or outside the unit, (i.e. Cafeteria, David’s House). You will be asked to sign a confidentiality form.

Parents/Guardians

As a parent you are not considered a visitor but a part of the ICN Care Team. We want you to feel welcomed and included in caring for your baby and participating in decision-making for your baby.

Siblings

Brothers and sisters of the baby are always welcome if they are healthy. Younger siblings, especially toddlers, require special planning on your part. These visits need to be brief as young children have short attention spans and get restless. It is important that someone is watching them while you are with your baby. Other parents have found it helpful to bring a spouse or friend who can take children to the family room or for a walk. This helper can also keep the child quiet and away from other babies. For additional support and developmental preparation for the initial visit to the bedside or for resource in coping with a new hospitalized sibling, ask for a Child Life Specialist to be consulted.
Other Relatives and Close Friends

Other guests over the age of 12 may come see your baby. There is a Visitor Book at the reception desk where you can list special relatives or friends who may be with you at the bedside.

Please remember that your baby needs a protected environment to recover and grow. As a parent, it’s OK to tell your family and friends that you’d prefer no one else come to the ICN to see your baby.

ICN Family Waiting Room

The waiting room is located on the left after crossing the bridge and turning towards the ICN.

The family waiting room is designed to accommodate you and your guests. There are books, magazines, a computer and a television to help pass the time.

Snacks and simple meals are available in the room for you and your family. David’s House generously provides the supplies in the kitchenette. Please use this space or the cafeteria to eat your meals. Light snacks and drinks are acceptable at your baby’s bed space.

Children may also use the waiting room to play or snack. Please make sure that children are supervised while they are in the waiting room.
DHMC Services for Parents

Overnight Lodging

David’s House (Logo)
David’s House provides temporary lodging for families who need to stay close by while their child is hospitalized. There is no charge to stay, however donations of any size are greatly appreciated. Please visit their web site at davids-house.org for more information or call 603-643-2298 to make a room request.

The Rest Easy Program
This is available for outpatients, families, and friends who live far from Dartmouth-Hitchcock. Some hotels offer specially discounted room rates. Information about this program is available at the information desks at both the Main Entrance and the North Entrance of the Hospital.

Center Court (at DHMC)
Several shops are located on Level 3 of the Medical Center
- The Pink Smock Gift Shop
- Au Bon Pain Bakery
- Sbarro’s Pizza
- Cravin’s
- Bank of America

Other Shops (at DHMC)
More shops are located on Level 4, just above the main reception desk at the Rotunda.
- Wheelock Travel
- Split Ends Inc. (Beauty Salon)
- Service Federal Credit Union

The outpatient pharmacy is located on level 3 of the Doctor’s office building near the parking garage. They can fill prescriptions written here, but not those from other institutions.

Birth Certificates

If your baby is born at DHMC, you have 3-4 days to complete the green worksheet at the Birthing Pavilion.

- See the Perinatal Data Specialist (secretary) at the reception desk in the Birthing Pavilion.
- In a week to 10 days, a Parent’s notice should arrive in your mail. You will need to take this to the City Clerk at the Lebanon City Hall in Lebanon, NH to get the original birth certificate.
- There is a small fee for this that is payable to the Town of Lebanon. The City Clerk’s telephone number is (603) 448-3054.

If your baby was born at another hospital, paperwork must be completed there.
Frequently Asked Questions

What is my baby’s diagnosis and what does it mean?

What is the doctor really saying is wrong with my baby? What does it all mean? Can anyone tell me in words that I can understand?

- You can ask for medical terms to be written down. This may be like a new language for you. Ask for articles and any other material that will help you learn and understand what is going on with your baby.
- Ask people to speak simply so that you can understand and ask for clarification as needed.

Who is my baby’s doctor? What is a Neonatologist?

- A Neonatalogist is a pediatrician with additional specialization in caring for sick newborns.
- Many Neonatologists work in our nursery. Your baby may be seen by several of them over the time he is in the nursery. Ask to talk with the doctor and any specialists that care for your baby. Write their names down and ask for updates on a regular basis.

Who are the people caring for my baby?

- There are many people with different jobs caring for your baby. There are nurses, respiratory practitioners, neonatal nurse practitioners, physical therapists, pediatric interns, residents, and others who take part in the care of your baby.
- Write down the names of those who care for your child most of the time. Also write down the name of the discharge planner, social worker, chaplain, developmental therapist and any specialists working with your baby.

What are the chances my baby will live?

Have they cared for other babies with the same problems your baby has? What happened to them?

- While no one can give you a guarantee of what will happen to or how well your baby will do, the care team can provide you with their ideas based on past experience of how well your baby will progress. Some statistics can be found at patients.dartmouth-hitchcock.org/quality/quality_report/ICN.

What about the cost of care for my baby?

- Ask to meet with someone from the hospital’s business office. They can help you get information about healthcare coverage for your infant.
- The nursery Social Worker and or the Clinical Resource Coordinator can help you regarding this issue.
What tests are being done on my baby and what do they tell us?

- Ask those caring for your baby what tests are being done on your baby and why.
- Ask about the results and what the results show.

Is my baby in pain?

Does your baby's problem cause pain and is the treatment painful? Is your baby getting anything for pain and how is it working? Can things such as positioning, swaddling, and boundaries be used to make your baby comfortable?

- Your baby will be evaluated for pain upon admission, during routine care and during procedures.
- If your baby is experiencing pain or discomfort, both non-medication and medication options may be used to help decrease his pain. Non-medication options may include wrapping the infant snugly in a blanket, providing containment or boundaries with the use of blankets or other developmentally supportive devices, kangaroo care, soft music, or decreasing the environmental stimulation by decreasing the light, sound, or activity at your baby's bedside. These options may be used alone or in combination with medications to decrease your baby's pain. Please feel free to ask your baby's nurse if your baby is on any pain medication.

- We will help you learn your baby's cues that indicate pain, as well as pain relief, so you may help comfort him during those times when he is experiencing pain or discomfort. Feel free to ask your baby's nurse how you might be able to help comfort your baby.

What are the options for treatment of my baby's problem?

What treatments, medicines, or surgeries can be used to treat your baby's condition? How effective are they? Will they help your baby get better or will they help him to maintain her present condition? What are the risks involved in the treatment or procedure?

- There may be a variety of treatment options for your baby, it is best to talk with your care team about what treatment is being done and what are some other options available.

Do all our decisions have to be made now or can we take time to think them over?

What decisions must be made now and what can wait until you have talked to others and had time to think through your options?

- Some decisions need to be made right away for your baby's best interest and well-being. Your doctor will keep you informed and help guide you as to when a decision is needed right away or when to take more time to consider other options.
How can I help in the care of my baby?

- Learn all you can about your baby. Review the “Caring for your Baby” part of this book.
- Bring toys, clothing, tape recorder and tapes, or special decorations to personalize your baby’s bedspace.
- Sit with your baby. Read softly to him.
- Learn to do routine care for your baby such as taking the temperature, changing the diaper, and so on as your baby’s condition allows. Talk to your baby’s nurse about when to start these.
- If you plan to breastfeed, pump your milk and store it for future feedings. There is a Lactation Consultant to assist you with breastfeeding or pumping.

What about when my baby comes home?

When will your baby come home? Will my baby be able to go to my home hospital soon? Will I need special training and who will support us? What medicines will your baby need and what are the side effects to watch for?

- Your baby needs to be on full feedings, growing steadily, free of apnea episodes for at least seven days and able to maintain her temperature in an open crib. Each baby is different, so talk to your baby’s healthcare team about how your baby is doing.
- Return transfer to your home hospital is dependent on where it is. Talking with the discharge coordinator will give you an idea of when this might happen.
- Your ICN Care Team will work with you about what you will need to learn prior to going home. The team will help you learn to care for your baby.

What will my baby’s life be like if he lives?

Will my baby’s condition affect his ability to care for himself? Will special adjustments need to be made for him to participate in family activities? Will he need physical therapy and developmental therapy?

- It may be difficult to predict and it all depends on your baby’s medical course – the medical care team can give you some facts as to what they can predict.
- Also realize that no one knows all the answers and the experience of the medical team is a good guide for helping you understand what your baby’s outcome might be.
Why and when are head ultrasounds done?

What are the doctor’s looking for?

- A head ultrasound is done in the ICN with a portable ultrasound machine. This is a sonogram that allows us to look into a tiny baby’s head without disturbing him. It doesn’t involve radiation like an x-ray, but uses sound waves to record images on videotape. This is done by placing gel on the transducer and placing this on the fontanel (your baby’s soft spot).

- The ultrasound looks at the ventricles in the brain for any signs of bleeding that may have occurred. Since a premature baby’s brain is still at an early stage of development, it is not quite ready to withstand all of the stress of living outside of the womb. Some of the tiny vessels that are in the inner part of the brain are especially fragile and vulnerable to changes in blood flow. If any of these vessels rupture, bleeding occurs in or near the ventricles, which are fluid-filled chambers located within the brain.

- The first one is done the first week of life, then at one month of age and/or when your baby reaches full term corrected age. Repeat studies are done as needed.

When are my child’s eyes checked?

What are the doctors looking for?

- Premature infants, particularly those weighing less than three pounds, are at risk for development of retinopathy of prematurity (ROP). In this condition abnormal blood vessels grow within the eye and may lead to permanent vision loss if left untreated.

- Infants at risk will have eye examinations prior to discharge to look for the presence of ROP. The exams are scheduled at about 32-34 weeks corrected age. Often times it is necessary to coordinate follow up exams after discharge from the hospital.

When is my child’s hearing checked?

What are the doctors looking for?

- There is a test used to find out if your baby has any hearing loss.

- The hearing tests done are actually hearing “screens,” designed to be overly inclusive, so they don’t miss any babies with hearing problems.

- Repeat exams are done when the initial test is unsuccessful. Many factors may cause this, for example; a noisy environment or that your baby was crying, fussy or wiggly. The repeat exam is done again in a few days or weeks prior to discharge. Follow-up information will be shared with you about your baby’s hearing exam.

Are there parents of babies like mine that I can talk to?

- Many times staff will know of other parents who are willing to share their experiences with you.

- There is a web-based community of other families from the ICN that is found on Facebook. See the Parents Supporting Parents section of this book for more details.

- If you would like to meet with another parent, please ask your baby’s nurse if she could recommend someone.
Newborn Screening - Questions and Answers

Why is it important?

■ The test is used to find out if your baby has one of several rare but potentially serious disorders. Finding and treating a problem early can help prevent the mental and physical problems associated with these disorders.

Who needs it?

■ All newborn babies.

How is the screening done?

■ A small amount of blood is taken from a prick in the heel of your baby’s foot and a blood test is done.

When is it done?

■ The screening is usually done between 48-72 hours after birth. Additional screens may be requested by the state lab as your baby gets older.

How will I get the results?

■ Your baby’s doctor will be sent a copy of the results of the test. If the test shows that any of these disorders MAY exist, your doctor will contact you.

What if my baby has a positive test?

■ The screening test identifies only that a problem MAY exist. Further testing is indicated if the test is positive. If your baby has one of these disorders, your pediatrician and other specialists will help you learn how to meet you baby’s special needs.

Why not wait to see if my baby gets sick?

■ Babies born with these disorders look healthy at birth. By the time they begin to look sick, brain and nerve damage has already begun. It is very important that your baby is tested early.

■ Before leaving the hospital, ask your nurse if your baby’s Newborn Screen has been done. This is often referred to as the “PKU,” but it is a screening test for many metabolic diseases.
## What is your baby being tested for?

This is a partial listing of tests that will be performed.

### Phenylketonuria (PKU)
Caused when a baby can’t use a part of protein foods called phenylalanine. If not treated, PKU can lead to severe mental retardation. A special diet, low in phenylalanine, begun in the first weeks of life can prevent the side effects of this disease.

### Galactosemia
Occurs when a baby can’t digest the sugar found in milk. The condition can lead to damage of the eyes, liver and brain or even death. Starting a special milk-free diet in the first week of life allows the baby to develop normally.

### Homocystinuria
Caused when a baby can’t use an amino acid called methionine found in protein foods. This disorder can cause mental retardation, as well as eye and blood clotting problems. A special low protein diet and vitamin therapy helps avoid these problems.

### Hypothyroidism
Caused by the lack of a hormone produced by the thyroid gland. This can lead to poor body and brain growth and can result in mental retardation. If hormone treatment is started early, normal growth and development occur.

### Maple Sugar Urine Disease
Caused when a baby cannot use the amino acids (leucine, isoleucine, and valine) found in protein foods. The name comes from the maple sugar smell of the baby’s urine. The disorder leads to mental retardation, seizures, and death. A special low-protein diet started early helps avoid the severe effects of this disease.

### Toxoplasmosis
Is a condition caused by a protozoan carried by cats. The disorder can lead to impaired vision, hydrocephalus, and mental retardation. Early treatment and follow-up exams help minimize problems in the newborn and reduce or prevent later problems.

### Sickle Cell Disease
A hereditary disease in which red blood cells are deformed. African Americans are at risk for this disorder. It can lead to anemia, infections, pain, poor growth, and even death. Special medical care begun early increases a baby’s chance for avoiding these problems. Screening also identifies individuals with the genetic trait for sickle cell. If your baby is African American, ask your doctor to test him for sickle cell disease.

---

The information in this document was taken from the Bureau of Special Medical Services Newborn Screening Program, New Hampshire Division of Public Health Services and the Vermont Newborn Screening Program, Vermont Department of Health Laboratory.
ICN Care Team & Equipment

ICN Care Team 22
Extended ICN Care Team Members 24
Equipment Commonly used in the ICN 25
The ICN Care Team

Your ICN Care Team is made up of many health care professionals with special training and skills. Most of them will have continuous contact with you and your baby. Others come to the ICN only when asked to examine or treat a baby and consult with the doctors about special topics. These professionals work as a team, discussing your baby’s needs and progress.

We view you as the most important member of your baby’s ICN Care team. Our goal is to keep you informed and make you as comfortable as possible. As the parent(s), you are a valuable team member and, we would like to help you to form partnerships with the ICN care team.

The following is a description of the ICN care team members.

<table>
<thead>
<tr>
<th>Role</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Receptionist/Secretary</td>
<td>These will be the first people you meet when you stop at the nursery desk. They are a resource for you and will help you become familiar with the ICN setting. They will show you the hand washing routine and where your baby is.</td>
</tr>
<tr>
<td>Neonatologist, (also referred to as “the Attending” or MD)</td>
<td>Physicians who have additional special training in the care of premature and sick newborn babies. They coordinate the team caring for your baby.</td>
</tr>
<tr>
<td>Neonatal Nurse Practitioner (APRN, NNP)</td>
<td>Registered nurse with advanced training, education, and experience in the care of an ICN baby. Your NNP will work closely with the ICN care team to plan the care for your baby.</td>
</tr>
<tr>
<td>Resident /Interns (MD)</td>
<td>Doctors who are in their 1st, 2nd or 3rd year of being trained in pediatric specialties. They also will work closely with the ICN care team to plan the care for your baby.</td>
</tr>
<tr>
<td>Neonatal Registered Nurse (RN)</td>
<td>Registered nurses who specialize in the care of premature and sick babies in the ICN. These RNs will care for your baby 24 hours a day. All ICN nurses work 12 hour shifts.</td>
</tr>
<tr>
<td>Primary Nurse(s) (RN)</td>
<td>A registered nurse who is responsible for planning and overseeing your baby’s nursing care. They are your baby’s consistent caregivers and also support you through your ICN stay.</td>
</tr>
<tr>
<td>Resource Nurse (Charge Nurse)</td>
<td>A registered nurse who is in charge of the ICN and is responsible for scheduling the nursing assignments. This nurse also manages the fluctuating needs of the ICN on a daily basis. If you have questions or concerns you may ask to speak with the nurse in charge.</td>
</tr>
<tr>
<td>Clinical Resource Coordinator (CRC)</td>
<td>A registered nurse who collaborates with the Children’s Hospital at Dartmouth-Hitchcock (CHaD)/ICN team and maintains contact with your local hospital. The CRC becomes involved in your baby from the day of admission to facilitate the discharge planning process. This RN helps plan for your infant’s discharge or transfer from CHaD to your local community hospital as soon as your baby is stable and meets transfer criteria.</td>
</tr>
<tr>
<td>Role</td>
<td>Description</td>
</tr>
<tr>
<td>-------------------------------------------</td>
<td>-------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td><strong>Unit Director (Nurse Manager, RN)</strong></td>
<td>A registered nurse who manages and plans for the overall needs of the ICN. This nurse is the liaison with other departments in the hospital and a resource to the nurses in the ICN. You may ask to meet with the Unit Director if you have concerns or issues related to the ICN.</td>
</tr>
<tr>
<td><strong>Clinical Nurse Specialist (CNS, RN)</strong></td>
<td>The Clinical Nurse Specialist is a registered nurse who has advanced training and education in the care of infants and children.</td>
</tr>
<tr>
<td><strong>Social Worker (MSW)</strong></td>
<td>A licensed social worker that will be able to assist with counseling and support as needed. She can also assist in making referrals for in-depth counseling as well as provide information related to finances and hospital bills. She works closely with the nurses and doctors to prepare your family for discharge and to assure that you have access to the appropriate resources in your community.</td>
</tr>
<tr>
<td><strong>Lactation Consultant (LC)</strong></td>
<td>A registered nurse who is a Board Certified Lactation Consultant. She will assist you with breast milk pumping and breastfeeding your baby. She can also help you to obtain an electric breast pump to use while your baby is in the ICN.</td>
</tr>
<tr>
<td><strong>Respiratory Care Practitioner (RCP)</strong></td>
<td>Staff trained to be experts in airway management, they are often referred to as RT'S. They specialize in the use of ventilators (breathing machines) and oxygen. They are assigned to be in the ICN at all times. They work closely with the nurses and physicians on your baby’s care.</td>
</tr>
<tr>
<td><strong>Developmental Care Team</strong></td>
<td>A developmental specialist, developmental pediatrician, occupational and physical therapist who are specially trained to understand the needs of infants in the ICN. They are available to do developmental evaluations when they are needed. The therapist is available to provide developmental information about premature or developmentally at risk infant babies. She will also meet with parents to help develop a developmental care plan that is individualized for your baby. Most infants will be scheduled for developmental follow-up clinic after discharge.</td>
</tr>
<tr>
<td><strong>Neonatal Transport Team</strong></td>
<td>A specially trained group of nurses, respiratory care practitioners, neonatal nurse practitioners and doctors, and an EMT/ambulance driver. If your baby arrived by helicopter, there is usually a respiratory therapist, an ICN nurse and the pilot. They begin specialized treatment for your baby at the community hospital. They will maintain that care while transporting your baby to our ICN.</td>
</tr>
<tr>
<td><strong>Licensed Nursing Assistant</strong></td>
<td>A Licensed Nursing Assistant (LNA) who performs some nursing tasks like taking temperature and vital signs, feeding and holding infants.</td>
</tr>
<tr>
<td><strong>Unit Support Assistant</strong></td>
<td>Maintain equipment and supplies in the unit and perform secretarial duties.</td>
</tr>
</tbody>
</table>
Extended ICN Care Team Members

<table>
<thead>
<tr>
<th>Additional Care Team members that may be involved as part of your baby’s Team, depending on your baby’s needs (listed in alphabetical order)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Cardiologist (Pediatric)</strong></td>
</tr>
<tr>
<td><strong>CHaD Administrative Nursing Director</strong></td>
</tr>
<tr>
<td><strong>Chaplain</strong></td>
</tr>
<tr>
<td><strong>Family Support Specialist</strong></td>
</tr>
<tr>
<td><strong>Geneticist (Pediatric)</strong></td>
</tr>
<tr>
<td><strong>Medical Student</strong></td>
</tr>
<tr>
<td><strong>Metabolic Specialist(s)</strong></td>
</tr>
<tr>
<td><strong>Transitional Long-term Care Coordinator (TLC)</strong></td>
</tr>
<tr>
<td><strong>Neonatology Fellow</strong></td>
</tr>
<tr>
<td><strong>Nephrologist</strong></td>
</tr>
<tr>
<td><strong>Neurologist (Pediatric)</strong></td>
</tr>
<tr>
<td><strong>Ophthalmologist (Pediatric)</strong></td>
</tr>
<tr>
<td><strong>Radiologist</strong></td>
</tr>
<tr>
<td><strong>Speech-Language Pathologist</strong></td>
</tr>
<tr>
<td><strong>Surgeon (Pediatric)</strong></td>
</tr>
<tr>
<td><strong>Urologist (Pediatric)</strong></td>
</tr>
<tr>
<td><strong>Volunteers</strong></td>
</tr>
</tbody>
</table>
Equipment Commonly Used in the Intensive Care Nursery

There are many types of equipment commonly used in the Intensive Care Nursery (ICN). Most of them cause no discomfort to babies. Their purpose is to help babies breathe or keep warm or to help the doctors and nurses monitor your baby’s heart rate, breathing rate, blood pressure, amount of oxygen in the blood, and body temperature.

Cardio-respiratory monitor

This type of monitor records and shows your baby’s heart rate, breathing rate, and blood pressure. Small, adhesive patches with wires are placed on the baby’s chest or arms, and attached to the monitor.

If the heart rate, breathing rate, or blood pressure goes outside of the limits set on the monitor, it will alarm, alerting the staff so they may check on your baby. Alarms will also sound if the patches or wires become loose.

Ventilator (breathing machine)

A ventilator is a machine that helps babies breathe when they are unable to do so on their own. It helps deliver the right amount of air and oxygen to the baby’s lungs through a small soft tube (endotracheal tube) that is placed in the windpipe (trachea) through the baby’s mouth.
CPAP

Continuous Positive Airway Pressure (CPAP) is a method of helping babies breathe when they’re breathing without the help of a ventilator. When babies are placed on CPAP, air is delivered through small, soft tubes (prongs) that are placed in each nostril to help keep the air sacs (alveoli) from collapsing at the end of each breath.

Pulse oximeter

A pulse oximeter measures the amount of oxygen in the blood. A small red light that can sense the amount of oxygen in the blood is taped to the baby’s foot or hand. It will then show a number on the monitor which reflects the amount of oxygen in the blood. If the amount of oxygen is too low or too high, the monitor will alarm, alerting the staff so they may check on your baby. Alarms will also sound if the baby is wiggling his foot or hand because the monitor may have trouble sensing the amount of oxygen in the blood when this occurs.

Incubator or radiant warmer

These are special beds that provide a warm environment to help keep babies warm. The incubator may also be referred to as an isolette, and is capable of delivering a warmed humidified environment as needed. The radiant warmer is open from all sides and also maintains heat support for your infant.
Common Medical Terms

Temperature Regulation 28
Jaundice and Hyperbilirubinemia 29
Infection 30
Respiratory Distress Syndrome 31
Apnea with Bradycardia 32
Nutrition 33
Temperature Regulation

Description

When babies are born prematurely, their heat-regulating system isn’t fully developed. In addition, these babies have little body fat to help keep them warm. An ill full term baby may also have difficulty staying warm. Because temperature changes can cause serious problems in newborns, maintaining a normal body temperature is very important.

Treatment

In order to help keep babies warm, they are usually placed in an incubator or radiant warmer. These are special beds that provide a warm environment. They usually remain there until they are able to regulate their own body temperature. During this time, stable babies may be taken out of the isolettes or radiant warmers so parents can hold them.

Staying Warm

By the time babies are ready to go home, they can regulate their own body temperature, so do not need any kind of warming equipment.
Jaundice & Hyperbilirubinemia

Description

The body normally breaks down used red blood cells, and replaces them with new cells. When used red blood cells are broken down, a substance called bilirubin is released. However, before the body can dispose of the bilirubin, the liver must change it into a form than can be eliminated from the body in the stool (feces). When babies are born prematurely, their liver isn’t fully developed, so it may be difficult for them to change the bilirubin into the correct form. This occurs in full term babies also, especially if they are ill. When this occurs, bilirubin levels in the blood may rise (hyperbilirubinemia) and cause the skin and eyes to look yellow. This yellow coloring of the skin is called jaundice.

Hyperbilirubinemia occurs when the bilirubin level is higher than normal or rises faster than normal. This is a concern for two reasons. First, it may be a symptom of another problem. Second, very high levels of hyperbilirubinemia can cause serious neurological problems.

Treatment

Bilirubin levels are monitored by taking a small sample of blood from the baby and testing it to see how much bilirubin is present. If the bilirubin is higher than it should be, phototherapy may be started.

Phototherapy is a form of treatment that uses a special light to help break down the bilirubin into the form that can be eliminated from the body. When phototherapy is begun, the baby’s clothes are removed and he is placed in an isolette (incubator) or radiant warmer to help keep him warm. The phototherapy light is then positioned so that it shines on the baby. During this time, the baby’s eyes are covered with soft protective patches while the lights are on. The lights can be turned off for short periods of time while he is receiving care, or so parents can hold their baby.

While babies are receiving phototherapy, the bilirubin level in the blood will be checked every day to see if it is decreasing. Depending on the results, phototherapy may need to be continued for a few days.

Phototherapy is very effective in helping to get rid of bilirubin. Most babies recover without any problems.
Infection

Description

When babies are born prematurely, their immune (infection fighting) system is not fully developed, which can make them susceptible to infection. A full term infant who is not breathing well or is not staying warm may also have an infection.

Treatment

Most babies who are admitted to the ICN are given medications (antibiotics) shortly after birth for 2 days. A small sample of blood will usually be taken from the baby and tested for bacteria. If it shows bacteria, the baby may be given antibiotics for a longer period of time to help fight the infection. If it does not show bacteria, the antibiotics may be stopped.

The babies are started on the antibiotics before the tests are back because if they have an infection, it is important that they be treated. These medications are given intravenously (IV) through a small soft tube which is placed into a vein in the baby’s foot, hand, scalp, or belly button (umbilicus).

Predicted Outcome

The antibiotic medications are usually very effective in getting rid of the bacteria and most babies recover from the infection.
Respiratory Distress Syndrome

Description

When babies are born prematurely, their lungs haven’t fully developed, so many times they have breathing problems. The most common breathing problem is called Respiratory Distress Syndrome (RDS). RDS occurs when the lungs aren’t fully developed and have a decreased amount of a substance called surfactant in the lungs. Surfactant is a medication that coats the tiny air sacs (alveoli) in the lungs, and helps to keep them open as babies breathe. Without surfactant, the tiny air sacs have difficulty opening and closing, so babies have problems getting air in and out of their lungs. The more prematurely a baby is born, the more likely he is to have RDS.

Treatment

Many babies with RDS will need a ventilator (breathing machine) to help them breathe. If this occurs, a small, soft tube (endotracheal tube) is placed into the windpipe (trachea) through the baby’s mouth. This tube is then attached to the ventilator so it can deliver the right amount of air and oxygen to the baby’s lungs. In order to monitor how well the baby is doing, small samples of blood are usually taken throughout the day to check the amount of oxygen, carbon dioxide, and other values that are present in the blood. This blood may be taken from a very tiny soft tube (umbilical catheter) that is placed in a blood vessel in the belly button (umbilicus), or it may be taken from other blood vessels or from the baby’s heel.

A form of surfactant may also be given to babies with RDS. It is given through the endotracheal tube, so it drains into the air sacs in the lungs, coating the surface, helping to keep them open as the baby breathes in and out. It is usually given shortly after birth, and may be repeated later.

Some babies may not require a breathing tube in their trachea (wind pipe) but still need assistance to breathe from the ventilator. Small, soft prongs are placed in each nostril. The prongs are attached to tubing which is hooked up to the ventilator. This is referred to as NIPPV (Non-Invasive Positive Pressure Ventilation).

Once babies no longer need the ventilator, they may still continue to need some help keeping their air sacs open. Continuous Positive Airway Pressure (CPAP) is a way to do this. In CPAP, small, soft tubes (prongs) are placed in each nostril and pressure helps keep the air sacs from collapsing at the end of each breath, but still lets the babies breathe on their own.

When babies no longer need CPAP, they may still need extra oxygen. Oxygen may be given through small soft prongs (nasal cannula) that are placed in each nostril, or babies may be placed in an oxygen hood.

As the baby’s lungs grow and develop, they outgrow the need for the ventilator, CPAP, and oxygen. However, occasionally, some babies may need to go home with oxygen that is given through a nasal cannula.

see photos on page 30
Apnea with Bradycardia

Description

Apnea is a condition in which a baby’s breathing pauses for 20 seconds or longer, then starts again on its own or with help. Premature babies are especially prone to this because the system that controls breathing is not fully developed. Apnea may also be a sign that a baby is getting sick. When your baby has an apnea episode for greater than twenty seconds his heart rate will drop, if it goes below eighty this is called Bradycardia associated with apnea.

Treatment

Premature babies are placed on a monitor, which monitors their heart and breathing rates. Small adhesive patches with wires are placed on the baby’s chest or arms. The wires are then attached to the monitor, which shows the heart rate and breathing pattern and rate. If any of these go outside of the limits set on the monitor, the monitor will alarm, alerting the staff so they can check the baby.

When an alarm sounds, many times babies begin breathing on their own. However, sometimes the nurse may need to gently stimulate the baby to breathe by rubbing the baby’s foot or back, or he may need to give them some extra oxygen. Occasionally, the nurse may need to gently pump some air and oxygen into the baby’s lungs with an oxygen bag and face mask. Sometimes the monitor alarms even when the baby is fine, because the patches or wires have become loose.

Premature babies may also be placed on another type of monitor (pulse oximeter) that measures the amount of oxygen in the blood. A small red light, which can sense the amount of oxygen in the blood through the skin, is taped to the baby’s foot or hand and attached to the monitor. It will then show a number on the monitor, which reflects the amount of oxygen in the blood.

If the amount of oxygen in the blood is outside of the limits set on the monitor, it will alarm, alerting the staff, so they can check the baby. Many times the baby’s oxygen level increases on its own. However, sometimes the nurse may need to gently stimulate the baby by rubbing the baby’s foot or back, or he may need to give them some extra oxygen. Sometimes the monitor alarms even when the baby is fine, because the baby is wiggling his foot or hand and monitor has trouble sensing the amount of oxygen in the blood.

Caffeine may also be given to babies with apnea. This helps to control and decrease the apnea. As babies grow and develop, they outgrow the need for caffeine, so it is usually stopped before they go home.

As babies grow and develop, their central nervous and breathing systems also develop. As this occurs, their breathing becomes more regular and the apnea usually disappears. Before babies can go home, the episodes of apnea need to be absent for a certain period of time (usually 7 days in a row).
**Nutrition**

**Description**

When babies are born prematurely, their digestive systems have not fully developed, so they may have difficulty digesting food. Full term infants who are ill or stressed, may not be able to eat or may also have problems digesting food until they are feeling better. They may receive nutrition in several ways. They may receive a nutritional solution that is given through an intravenous line (IV), or they may receive breastmilk or special formulas through a feeding tube (a small soft tube that is placed into the stomach through either the mouth or nose). As they grow and develop, and show signs that they are interested in eating, they will be given the opportunity to feed by mouth, either by breastfeeding or bottle-feeding.

**Treatment**

**Intravenous Fluids**

Initially, babies may be given nutritional solutions containing sugar, vitamins, minerals, and other nutrients intravenously (IV) through a small soft tube that is placed into a vein on the hands, feet, scalp, or belly button (umbilicus). They will receive nutrition in this way until they are ready to handle breastmilk or formula.

**Nasogastric or Orogastric Feedings**

When babies' digestive systems are ready to tolerate breast milk or formula, a small, soft tube may be placed into the stomach through either the nose (nasogastric tube) or mouth (orogastric tube). Feedings are usually started very slowly in small amounts to make sure the baby’s digestive system can tolerate them. During the time that the baby’s feedings are being increased, the baby will continue to receive the IV solution. It may take a week or longer before babies are able to take all their feedings by naso or oro-gastric tube. Once this occurs, the IV solution will be stopped.

We recommend all mothers provide their breastmilk for their baby while they are in the ICN. For mothers that have breast milk supply problems pasturized donor breast milk may be offered. There are certain criteria required for babies to receive donor breast milk.

For mothers who plan to feed the baby formula, a premature infant formula will be given to their baby, until he no longer needs the extra nutrients. He will then be switched to a regular formula.

Premature babies will usually be fed in this manner until they are about 32 weeks gestation. This is done because before 32 weeks gestation, most infants have difficulty coordinating sucking, swallowing, and breathing. However, after this time, once they begin to show signs that they’re ready to eat by mouth, breast or bottle feedings may begin. Full term infants may also be be fed this way until they are able to eat.
Breast or Bottle Feedings

Once babies show signs of being ready to breast or bottle feed, they may be given the opportunity to do so. Usually, breast or bottle feedings are introduced slowly and then increased according to how well the baby can tolerate them. It may take a few days to several weeks for babies to learn how to breast or bottle feed, so during this time, they will be given the remainder of their feedings through the nasogastric tube.

Once babies are mature enough, they will exhibit behavior that indicate they may be ready to breast or bottlefeed. These are called feeding cues. They include the baby waking up around feeding time, rooting and sucking on his or her fingers or blanket. The best time to try breast or bottle feeding is when your baby shows these feeding cues. This is called infant driven feeding. The ICN has several resources available to assist parents in learning about cues their baby may give them to show they are ready to feed.

By the time babies are ready to go home, they should be able to take all of their feedings by breast, bottle, or a combination of both.
Caring For Your Baby in the Intensive Care Nursery

Parenting Your Baby in the ICN 36
About Your Baby 37
How Your Premature Infant Looks 39
How Your Premature Infant Acts 40
Expectations You May Have 41
Skin to Skin Holding (Kangaroo Care) 42
Skills to be Learned Check-List 44
Parenting Your Baby in the Intensive Care Nursery

You are an essential and important part of your baby’s life and a valuable member of your baby’s health care team. You may feel overwhelmed by some of the equipment used in the Intensive Care Nursery (ICN), as well as the amount of information you receive, but we always want you to feel comfortable to ask questions, call, or be with your baby as often as you’d like. In addition, we encourage you to be involved in your baby’s care as much as you’d like to. She will know your presence, voice, touch, and love.

When babies are admitted to the ICN, you are welcome to be with your baby as often as you’d like. However, there may be times when you may be asked to leave for short periods of time, for example during a sterile procedure. Grandparents, siblings, relatives, and friends may also spend time with your baby with your permission, but will be asked about their exposure to any infectious diseases before being allowed into the ICN. Please be sure to ask the staff of the ICN for their guidelines. If you live far from the ICN, there are places close to the hospital where you may stay including David’s House. See the “Overnight Lodging” section of “The ICN” chapter to read more about David’s House and the Rest Easy Program.

Support

Many types of support will be available to you and your baby in the ICN

- **Health Care Team** doctors, nurses, respiratory care practitioners and nurse practitioners
- **Social Worker** who can provide information on counseling services, support groups, and financial assistance. She is also available to talk to you about how having a baby in the ICN impacts you and your family.
- **Parent Council** In 1999 with the help of the ICN staff, a small group of parents of ICN "graduates", created The ICN Parent Council. The purpose of the council is to provide a forum for information sharing between families and staff in order to facilitate positive family and clinical. The Parent Council also helps to develop and facilitate activities, identify parent improvement projects, support local and community education and act as a parent resource for other ICN families.

The council also sponsors your parent welcome bag. Occasionally, Parent Council Members can be seen in the nursery saying hello to parents and families. For more information or to find out how to talk to someone who has "been there", ask your nurse.

There is a special Facebook group created just for ICN families. Some families have found this group to be helpful to connect with other families who have had the experience of having a baby or babies in the ICN – Ask your nurse or at the front desk for information about this online community.

- **Lactation Consultant** who can help mothers who wish to pump breastmilk for their babies or breastfeed.
- **Chaplain** who is available to offer spiritual support.
- **Educational materials**: books, pamphlets, and videos about a variety of topics.

Please feel free to ask any questions you’d like, and participate in your baby’s care. You are an essential part of your baby’s care as well as a member of the health care team.
About Your Baby

Gestational Age

Gestational age is the number of weeks from the last menstrual period. On average, babies are born at 40 weeks gestational age. Full term babies are considered to be 37-42 weeks gestational age. For premature babies, the earlier a baby is born the higher the risk of complications and the higher the level of care he will need.

The Premature Infant

“Premie” is short for premature, a word meaning “born before mature.” Premies are born three or more weeks early and usually weigh 5 ½ pounds or less at birth. Their bodies just aren’t ready for the outside world yet. For example, many preemies can’t breast or bottle-feed or they may need help breathing.

The reasons for early birth are known for only about half of all preemies. Twins often arrive early. Things the mother did or didn’t do rarely have anything to do with the baby’s early birth.

Premature babies will be placed in a warming unit (incubator or radiant warmer) in order to help keep them warm for the next several weeks. Small, adhesive patches with wires will be placed on their chest or arms and attached to a monitor that will record their heart rate, breathing rate, blood pressure and amount of oxygen in the blood. The following information will provide you with some general information about babies born at specific gestational ages.

24-28 Weeks Gestation

Babies born during this time usually weigh between 1 1/2 - 2 1/2 pounds. Most of the time, they will need help breathing because they are immature and may not be ready for breathing outside the womb without assistance.

They will be given nutritional solutions through an intravenous (IV) line, which is a small soft tube that is placed in a vein in the hands, feet, scalp, or belly button (umbilicus) until their digestive system has developed enough to handle breastmilk or formula.
28-32 Weeks Gestation

Babies born during this time usually weigh between 2 1/2 - 3 1/2 pounds. Some babies may need help breathing from a ventilator for a period of time. However, some babies may just need help keeping their air sacs (alveoli) open, so may be placed on NIPPV or CPAP (continuous positive airway pressure). When babies are placed on CPAP, small, soft tubes (prongs) are placed in each nostril and pressure helps keep the air sacs from collapsing at the end of each breath, but still allows the babies to breathe on their own. Other babies may just need extra oxygen that will be given through small, soft, short tubes in each nostril (nasal cannula), or by placing a small oxygen hood over their heads. Some babies will be able to breathe on their own without any help or extra oxygen.

Nutritional solutions will be given intravenously at the beginning, and depending on how your baby is doing, she may also be started on breastmilk or a special premature formula within a couple of days. When he is ready to begin breastmilk or formula feedings, they are usually given through a small soft feeding tube that is placed into the stomach through the mouth or nose.

32-36 Weeks Gestation

Babies born during this time usually weigh between 3 1/2 - 5 1/2 pounds. Occasionally, babies may need help breathing from a ventilator, CPAP, or require extra oxygen for a short period of time. However, many babies breathe on their own without this kind of help. Nutritional solutions will usually be given intravenously at the beginning, then they will be started on breastmilk or formula very shortly afterward. Depending on your baby’s gestational age and how she is doing, they may be given breastmilk or formula through a small, soft feeding tube, or may be given the opportunity to breastfeed or bottle feed.

The Full Term Infant

37-42 Weeks Gestation

Term infants usually do not have to stay in the nursery as long as pre-term infants but can be very sick and require intensive care. Term infants are also in our nursery due to a variety of complications, e.g. birth-related difficulties, heart defects, other conditions requiring surgery and other physical problems.

Term infants may not be as sensitive to touch and handling as pre-term infants but still need to be watched for “time out” signals because they can get over-stimulated. Your nurse will help you determine when and if your baby is stressed and help you use strategies to decrease the stress.

Please feel free to ask the nurses and doctors any questions that you may have about your baby. We understand that this is a very stressful time for you and want to help you in any way we can.
How Your Premature Infant Looks

Parents react differently when they see their baby for the first time. You may be shocked the first time you see your premature baby. Many parents are. Not only does the baby appear fragile and tiny, but there are machines, lights, and noises all around. As you get to know your baby and get used to the ICN, your feelings of shock and fear will decrease. You will see that in the middle of all the tubes and wires is your lovable little baby.

Size

Preemies are smaller than term babies. Babies who are very premature often weigh less than 2 pounds. They don’t have the plump look of term babies. The reason preemies are so thin is that they haven’t had the chance to add a fat layer under the skin. The fat layer is added in the last weeks of pregnancy. Lack of fat makes it harder for your baby to stay warm, so heat must be supplied by a special warmer. In time, your baby’s arms, legs and rest of her body will fill out.

Skin

Your preemie’s skin may look papery thin. You will see her blood vessels and ribs through the skin. When your baby gets a fat layer below the skin, she will have the same robust, rosy look as other babies.

Head

Your baby’s head may look too big for her body. The rest of her body will soon catch up. If your baby was born 3 or more months early, the eyes may stay closed for a few days. Also, the ears fold over easily. Later, she will develop the tough tissue that makes the ears stiffer.

Hair

Your baby may have no hair on her head and no eyebrows. But you may see a light covering of hair called lanugo on her back, arms and forehead. This hair will be shed in a few days or weeks.

Genitals

Your baby’s genital area may look big compared to the rest of the body. In a few weeks or months, these and other parts of your baby’s body will be in better proportion.
How Your Premature Infant Acts

Moving
Your baby’s movements will be jerky at first. Like other babies, she will stretch, yawn, and wave her arms and legs, but her movements won’t be smooth. She might suddenly stiffen her arms and legs. Then your baby may go limp. This is because the baby’s nervous system isn’t mature yet.

Sleeping and Waking
Premature infants, like other newborn babies, need sleep. In fact, they sleep most of the time. You can expect your baby to sleep 18 to 22 hours a day at first. We will encourage your baby to sleep without being disturbed except when she needs care.

Crying
Your baby cries for the same reasons that all babies do. She could be hungry, her diaper could need to be changed, she might want her position changed or she may just want to be held. If your baby is on a ventilator, you’ll be able to see them crying, but you’ll hear no sound because the ventilator tube temporarily blocks her vocal cords.

Seeing and Hearing
Your baby’s eyes may wander at times. One eye may go off in a different direction from the other. You may wonder if she sees anything. Most premature infants can see shapes and objects and especially like to look at faces. Objects can be seen best if around 18 inches away from the baby. Your baby’s eyesight will improve with time. Her ability to hear sounds and noises is stronger than her ability to see objects. Your baby already knows your voice and will respond to it. Talking to her in a calm, soothing voice whenever you’re with her will be comforting.
Expectations You May Have

This is why the idea of adjusted age is useful. Adjusted age is a better yardstick for judging a premature infant’s progress. It counts the baby’s age from actual due date instead of the previous noted due date. This is often stated as “corrected for gestational age.”

Example

Let’s say Heather was born on September 17th 2 months before she was due. By December 17th, Heather’s real age is 3 months, but her adjusted or corrected age is 1 month.

\[
\begin{align*}
3 \text{ months} &= \text{Real Age} \\
-2 \text{ months} &= \text{Months Premature} \\
\hline
1 \text{ month} &= \text{Adjusted/Corrected Age}
\end{align*}
\]

As you watch your baby’s progress, don’t be afraid if your baby is slow in some ways. She will take a little while to catch up. Remember too, that every baby is different. Some babies make rapid progress in one area but take longer in others. Things usually even out in the long run.
Skin to Skin Holding (Kangaroo Care)

What is Kangaroo Care?

Kangaroo Care is a way for parents to hold their baby on their chest with skin to skin contact to share warmth and natural closeness. Kangaroo Care was introduced in Bogota, Columbia and has been used successfully in South America, Europe, Canada and the United States.

What are the Benefits of Kangaroo Care for Your Baby?

Studies show there are several benefits for the babies who receive this physical care.

- Nurturance and growth
- Attachment and bonding
- Weight gain
- Deeper sleep and better rest
- Possible earlier discharge

What are the Benefits of Kangaroo Care for You?

Studies show there are several benefits for parents who do Kangaroo Care

- Generally parents feel more confident about meeting the needs of their baby
- Usually they are more comfortable taking their baby home
- Kangaroo Care may stimulate breast milk production
- Fathers who do Kangaroo Care may feel more comfortable and less anxious with their tiny baby
How and where is Kangaroo Care done?

- The parent sits in a comfortable chair next to the baby’s isolette.
- The parent should wear loose fitting clothing that opens down the front to allow for skin to skin contact (a bra should be removed).
- For privacy, a light weight blanket is placed over you and the baby. Curtains can be pulled around your bed space for privacy.

How will my Baby react?

Your baby’s reaction to Kangaroo Care will vary each time. Your baby may fall asleep or remain awake while resting on your chest. Your nurse will help you learn to understand your baby’s behavior and responses.

How often can I do Kangaroo Care with my Baby?

This depends on how well your baby responds to Kangaroo Care. The care program is individualized to your baby’s response. The length of time you first hold your baby will vary. The length of sessions will be determined by the baby’s response and by the comfort level for both of you. Kangaroo care may be provided once the ICN team feels the baby is stable enough for the activity. Typically, very tiny babies will be offered kangaroo care once daily for at least an hour. As babies grow and are more stable, intervals can increase and frequency can increase as well.

Will my Baby be monitored during Kangaroo Care?

Yes, your baby will continue to be monitored. Nurses will follow-up with you every so often to be sure your baby is warm and comfortable.

If you have further questions or want more information about Kangaroo Care, please see your baby’s nurse.
Parents Supporting Parents

About Your Feelings 46
Parent Involvement in the ICN 47
Families Share their Experiences 48
Hello from “The ICN Parent Council” 56
About Your Feelings

Having your baby cared for in the ICN is not easy. You are bound to become tired, short-tempered, and fearful. Many parents are upset that they can’t be with or hold their baby like they would if they were home. You may feel like your role as a parent has changed and that the nurses and doctors have taken over the care of your child.

Having a baby in the ICN raises many strong feelings for parents, siblings, and other family members.

At Times You May Feel

■ Anxious about how your baby is doing.
■ Concerned about how your child will grow and learn.
■ Upset about leaving your baby in the hospital.
■ Angry that your baby’s beginning has been so hard.
■ Happy to be with your baby.
■ Eager to take your baby home.

All these feelings are normal. You will likely notice your feelings changing often. Sometimes you might feel several strong opposite feelings at the same time. This is normal. Families have many ways of coping with these feelings.

Possible Ways to Cope

■ Find things you can do for your child and for other family members.
■ Talk to someone you trust.
■ Get information from the ICN staff.
■ Treat yourself to a favorite activity.
■ Spend time alone, perhaps away from the nursery.

It is just as important to give yourself permission to have a range of feelings and for you to respect that there are various coping styles that you will experience. Your family members will also have a variety of ways that they cope. You need time at home as well as at the hospital. You should take time out to eat well, and get enough rest and sleep. This will help you to cope with your baby’s stay in the hospital.

When new parents go to the nursery to see their child they are often afraid to touch their baby. If you feel this way, get involved in your baby’s care as soon as possible. The nurses will encourage you to take care of your baby in every way that is possible to help you bond with your child. Be sure to ask any questions you may have, no question is silly. The staff understands this is a new and frightening experience for you. That same question that you thought was too silly to ask may be the one that keeps you awake all night wondering. Your peace of mind is important to the staff.
It is important to create a balance between being with your child and carrying on with the rest of your life. Make sure that you take the time to eat and sleep, as your health is important as well. Also, take time to spend with your other children or spouse. The mental break may help you to function better.

Try not to be too hard on yourself. Many parents feel a great deal of guilt and are always asking themselves, "Why did this happen? Could I have done something differently?" All of these feelings are very normal and are experienced by almost all parents. Take the time to talk to other parents to see that you are not alone. If you are having a hard time dealing with these feelings, don’t be afraid to talk to our social worker or one of the ICN staff.

Parent Involvement in the ICN

The ICN staff recognizes that, while caring very deeply about all patients and empathizing with families, they cannot truly understand all the parental feelings that accompany having a baby in the ICN. For this reason, we have formed an ICN Parent Council. The mission of the council is to educate staff about how to consistently support families and provide pertinent and meaningful information that will assist families in developing their parental role early in the stay of their infant in the ICN. The goal of the ICN is to achieve the best clinical outcomes by supporting early parent-to-child bonding and by maintaining ongoing communication between families and staff. Members of this Council are parents of former ICN patients.

Families often find that the ICN has come to be the place where they first knew their infants and where they became a family. For some, this is where entire lives were lived. The Facebook Group created just for ICN families is a great way to connect to other families who have this shared experience of the ICN.

Members of the ICN Parent Council are sometimes available for parent-to-parent support. While the ICN staff is caring and supportive, there is nothing like talking to someone who has “been there”. If you would like to meet and talk with a former ICN parent please let your baby's nurse know.
Families Share their Experiences

The next pages are letters, stories, and poems that have been written or collected by some of our families. These reflect how important it is that we acknowledge and respect your feelings. Supporting parents who are coping with their feelings is an important part of our work. If you are interested in sharing your experiences, please feel welcome to write your own parent letter. For information on submitting your letter, please talk to your baby’s nurse.
Benjamin's Story

“It’s a roller coaster” is what we were told by anyone we talked to. “It” referring to both infertility and the NICU. Five years of infertility led to the birth of our son Benjamin at 33 weeks and 1 day after losing twins at 24 weeks just over 18 months prior to Ben’s birth. It was our second rodeo in the NICU and extremely overwhelming. The emotions were nothing like any that we had ever experienced. Even the years of emotions surrounding our infertility did not compare to the emotions of watching your little baby struggle in an isolette.

After going into preterm labor, Benjamin came out screaming, bringing tears to our eyes as it was proof to us of a healthy set of lungs. While Mommy’s c-section was completed, Ben and his Daddy were taken into the Panda room so that he could be evaluated. Within 5 minutes, he was on oxygen support via CPAP. That didn’t stop Mommy from getting to hold him the first time we met. The feeling of holding your child for the first time, despite all the tubes, is amazing. Daddy waited to hold Ben for a few more days, but even then, it was a miracle to be holding a baby that shouldn’t be born yet.

Two days went by and Ben was doing great. But then, after we came back from lunch one day, he had started struggling to breathe. We were sat down by his doctors and told that he needed a chest tube and to be intubated. After seeing him only on CPAP, the thought of a tube down our baby’s throat and another in his side was unnerving. Within a couple of hours, he had a tube in his side and a tube down his throat to issue surfactant. Within a day of these procedures, he was already doing better. Within two days, he was breathing over his tube and trying to pull his tube out of his mouth by himself! He was extubated and a cannula was put in, but that didn’t last long before he pulled that out as well! Our baby was breathing on his own!

The following two weeks were spent learning how to eat…suck, swallow, breathe. Those weeks were also filled with goals of gaining weight and learning to manage his body temperature outside of his isolette. Born at 5 pounds, 1 ounce, he had dropped to 4 pounds, 4 ounces and needed to start gaining weight regularly. We struggled with breast feeding and struggled with having the energy to suck on a bottle, too. Getting rid of the NG tube was our biggest struggle. But watching as the breathing tube, followed by the IV, followed by the plastic walls of the isolette, and finally the NG tube were removed were each one milestone after another and each a step closer to going home.

We were given 3 days notice that Ben might be coming home. This left the biggest hurdle on the checklist of passing his car seat test. Unfortunately, he failed the first time we tried. We were worried this would mean a longer stay, but thankfully the NICU had another car seat we could try and he passed with flying colors in that one! We FINALLY got to come home!

Benjamin is thriving at home and we are loving every minute of our little boy. Nothing could replace the journey to get here or the emotions along the road, but having a healthy, growing baby is all we could hope and dream for.
Maya is a beautiful 8 year old girl. She is fun loving and mischievous. A great lover of animals she has volunteered time at an animal shelter. She loves music and right now has fixated on Michael Jackson. She loves school and works harder to learn than almost any other kid I know. Maya has a charisma that draws people to her. I am amazed that even though she is non-verbal she can get a group together to play ball. Maya doesn’t have a shy bone in her body. I admire her strength and determination. She has an unflagging good spirit and a great attitude when it comes to overcoming challenges. We have gone together to Concord to testify during budget committee hearings. Maya is amazing!

However, it wasn’t always this way …

There were times that I thought this would never end. It was such a strange existence. Other people would come and go, but we stayed. And stayed. And stayed.

I delivered twins at 37 weeks. We knew mid way through the pregnancy that one of the twins would have challenges. Her heart was malformed and she had three markers for Down syndrome. We continued with the pregnancy when we found out because she was ours. After 6 weeks of bed rest, I delivered a 6lb 4oz boy and a 4lb 6oz girl. Maya came first and with a very brief look at her (literally seconds) she was whisked away into the ICN. Her brother was placed in my arms and we went to the birthing pavilion.

We went expecting and planning for a two-week stay. When her first surgery was completed, she had failure to thrive. Then her heart issues came into play along with a CMV infection. At 4 months we were transferred to Boston Children’s. She battled through pneumonia and feeding issues upon return to the ICN. We were in the hospital for 6 months initially.

I took relatively few pictures during our stay. Even the ones I have I can hardly bear to look at. The ICN is simultaneously a terrible, wonderful place.

It is terrible in the sense that I felt overwhelmed and not sure I was up to the task. Walking down the hall into the ICN was always a challenge—where was the roller coaster taking me today? Would we have a good day of gaining weight and more awake time? Would she do something different and would new problems develop? One of the hardest parts of the experience for me was the not knowing and the inability to plan anything. Maya was driving this bus.
It was a wonderful place as well. They gave me my daughter. I have no doubt that even 10 years prior to her birth, she would have struggled for her survival and would likely not have made it. The excellent medical care she received from caring, brilliant and committed doctors saved her life many times over. Gratitude is technically what I feel to the ICN, but it seems to weak a word to really adequately express my emotion.

They were also so supportive of our entire family! We moved up to David’s House during that time. We have met people there who have continued to this day to be supportive and caring friends. I learned a lot about myself during our stay. I learned just how strong I could be. I learned about the depth of a mother’s love for all of her children. I learned about what a rock my husband was and how much he could work to keep our entire family going. My larger family was also so supportive!

I continue to volunteer with the ICN parent council to give back to this great institution. I hope to make the experience even better for people who come after.

As you read this you, too, may be wondering if you will ever get out of this place. The answer is YES! The length of your stay will vary. The depths of the problems will change. But I am on the other side and I want you to know that the ICN does go away. Life will return to normal(ish) and will get easier. But what you learn there doesn’t go away. You will know yourself better. You will love your child more and know with even greater certainty the gift of that child in your life.
Morgan's Story

Morgan was born at 27 weeks weighing 2 pounds 5 ounces. I was shocked when the doctors said that was big for her age! She came into the world early because I had an infection of the amniotic fluid called chorioamnionitis. The only treatment for the infection was to induce me. My labor was 52 hours long. I went from being totally afraid of what was to come to being excited to meet Morgan and then back to being afraid. I was nervous about how Morgan would look when she was born. I remember wondering what a baby so tiny would look like. When she came out I thought she was the most precious thing.

She was taken right to the ICN and intubated. She did very well the first few days. She was taken off the vent, put on CPAP and then put on high flow oxygen all within 3 days. The doctors said she would stay in the hospital until her due date and since the first few days were going so smoothly I fooled myself into thinking that we would go home much faster than that. However, by day 3 Morgan started having trouble breathing and was put back onto CPAP. That is when I realized that the ICN would be a roller coaster ride of ups and downs. I started to treasure the good days and hold my breath waiting for a bad day to come.

While Morgan was in the ICN, I settled into David’s House. My son (at the time 5 years old) stayed at Davids House with me. It was a struggle having an older sibling and a baby in the ICN. Noah had a hard time sitting in the ICN and being quiet. He would only last about an hour so we were in and out visiting Morgan all day. When Morgan was two weeks old, I enrolled Noah in a daycare near the hospital so that he could have a safe and fun place to be and I could spend the time I needed with Morgan. It was heart breaking leaving him in the daycare and at the end of the day it was heartbreaking leaving Morgan. The only time I felt at peace was when I took Noah to the ICN with me and I had both my children together. We had one special nurse who allowed Noah to help dress or change Morgan’s diaper. It was wonderful that she was willing to help them form a bond even while Morgan was still so sick.

For about a month, Morgan followed a pretty “typical” premature baby path. She had a few A’s and B’s during the day, slowly increased her feeds and gained a few little grams of weight. But, even though Morgan was doing well in most areas, she was never able to reduce her oxygen use. This was the most frustrating time for me. I felt that something seemed off with her, but I wasn’t sure exactly what. It seemed odd to me that her oxygen use was slowly increasing. This is when I learned the most important lesson of being a preemie mom, one that is still important today. The lesson was to speak up if something was wrong. Ask questions, ask for different tests to be done, advocate for your child. For me rounds were intimidating. I have never been good at talking to groups of people and the ICN situation made it worse since it was so emotional. Many times during rounds, I couldn’t get the questions I wanted out because I was trying so hard not to cry in front of all the doctors. But, I had this gut feeling that something
was not right with my daughter and I got the courage to talk to the doctors about it. The ICN doctors brought in a team from infection control and a pulmonary specialist. They found out that Morgan had an virus called CMV that was targeting her lungs. It was a slow growing virus so it had been hard to catch. It caused scarring on her lung tissue which is why she as having an increased need for oxygen. The virus was treated with two weeks of antiviral medication and Morgan started to make improvements. Though it seemed like it would never come, Morgan was finally allowed to go home. This is the part of the story that I want to share the most with you. The ICN may seem like it will never end, but it does and when it does taking a special needs baby home can be very scary.  

Morgan came home on oxygen and a monitor. She was breastfeeding and taking one bottle of fortified formula per day. It was a major adjustment to take her home. The first adjustment and the most important thing was that I had to keep her away from most people. The chance of Morgan getting an infection was high and with her poor lungs she would not be able to handle any type of infection well. I put a sign on my door explaining nicely that visitors were not welcome. I placed hand sanitizer at the door way for when my son came home from school. I had to explain to my family multiple times why they couldn’t come to see her. When they got upset I would remind myself that I would be the one sitting by Morgan in the hospital if she got sick, not them. It’s impossible for someone without an special needs child to understand what it is like to see your baby in the hosiptal.

The second thing that I was not prepared for were the emotions of bringing her home. I don’t think I had time to emotionally process everytrhing that happened in the ICN until I got home. I remember getting her dressed on her first Thanksgiving and breaking down crying because I was so grateful to have her. The reality that I could be celebrating a holiday without my daughter sank in and I held her tight knowing how lucky I was.

The third thing I was not prepared for was the amount of appointments Morgan would have once she came home. She had visiting nurses, early intervention therapy, visits to multiple doctors including: developmental pediatrician, pulmonology, the eye doctor, neonatology follow up, regular appointments with her pediatrican and appointments with Keene Medical for the home oxygen. I felt like all I did was spend my days going to appointments or having people come to our hosue for appointments. While it was good to have the support and frequent check ins, I felt myself wishing for time to spend with my daughter that did not involve anything medical. My advice is to pick one day a week where no appointments are allowed to be scheduled and use that day as a family day.

Home oxygen was not the easiest thing, but it was not the worst thing either. The equipment was easy to use, but hard to lug around. I asked for extra long tubing so that I could carry Morgan around the house witouth needing to bring the tank. I learned to always bring an extra tank while going out just in case. I also had a home concentrator
so that I did not have to use a tank at home. This is a big machine that plugs into the wall and generates oxygen. It does not run out like a tank does so it never needs to be changed. One important thing with home oxygen is to make sure you order supplies well in advance because oxygen supplies are not something you want to run out of.

The first year home with Morgan when well. She made it through her first winter without getting sick or needing to be re-hospitalized. However, she was still needing oxygen even after one year old. This was worrisome as the original thought was that she would only need the oxygen for a month or two after leaving the ICN. She ended up needed surgery to have her adenoids removed and after that, at 18 months old, she was finally able to come off the oxygen!

Morgan’s second winter was harder though. When she was tiny it was easy to keep her away from germs, but keeping a toddler who puts everything in her mouth away from germs is not an easy task. She ended up being hospitalized twice that winter, once overnight and once for a week. Both times after the hospitalizations she again came home on oxygen. It was so frustrating to have those set backs and see Morgan back on oxygen when she had worked so hard to get off of it.

As far as development, Morgan was very slow even for her corrected age. When Morgan was a year old she was unable to sit up or roll over. The developmental pediatrician began to question if she had cerebral palsy and even wondered if she would ever be able to walk. Hearing those things were so hard, but I never gave up hope. Another lesson I learned about being a premie mom: Never say never because premie babies always surprise you. Though it took hard work and hours of physical therapy Morgan learned to roll over, she learned to sit up and she learned to walk! I still tear up thinking about her taking her first wobbly steps! Only a parent of a preemie can know how special it is to see your once two pound baby toddle her way across the living room.

As I write this story, we have just celebrated Morgan’s third birthday! In the past year Morgan has grown so much and she even became a big sister to a healthy full term baby! I look at Morgan with awe and wonder everyday. The greatest lesson I have learned through this experience is to appreciate, love and cherish every moment that you have with your children. Seeing Morgan fight for her life changed me in ways I am still figuring out. I know that my life could be totally different and that I could be writing a story about my baby who went to Heaven. I know that life changes in an instant and the moments we have today could be our last. Morgan has taught me to love with everything I have and hold tight to those close to me. Being a preemie parent is tough and challenging, but it also has its beautiful lessons. Find whatever beauty you can in your experiences with your preemie and allow the beauty to give you strength in the hard times.
Ayden & Konnor’s Story

Hello! My name is Amanda and here is Our Story.... My identical twin boys were born at Dartmouth Hitchcock Medical Center at 32 weeks 5/7 days- (2 months early) and spent the first month in the NICU, their names are Ayden (twin A) & Konnor (twin B). Ayden weighed 3 lbs. 11 oz and was 16 1/2 inches long, Konnor weighed 3 lbs. 14 oz and was 16 1/2 inches long-they were born all natural, 3 minutes apart!! They were born April 8th, 2009 and came home from DHMC on their 1 month Birthday- May 8th. It was so very scary, seeing my babies- so tiny, hooked up to the monitors, having NG tubes in their noses-taped to their little faces and having iv’s in their tiny little hands & feet. It was definitely an emotional roller coaster ride the whole time we were there. Some days would be great & other days not so much, we’d have set backs. But we got through it with all the help from the amazing NICU doctors, nurses and lactation consultants. We are so grateful for the care that the boys received while in the NICU at CHaD. I never really left DHMC much and we (my husband & I) stayed right at David’s House (wonderful place!!). We are so very lucky & feel extremely blessed that my boys have no medical issues! They are 100% Awesome! They are now happy, healthy, smart & loving 5 year olds who will start Kindergarten this Fall! Crazy how it seemed like our 1 little month in the NICU seemed to drag on forever, but the last 5 years have flown by. Hang in there, you’ll get through!
If I could tell you one thing to make it better I would; but I know from experience no matter how many people tell you things will get better it’s hard to believe, for I was in the exact same spot as you not that long ago. As I am Writing this story to let you all know there is a world outside of those nicu walls by precious little bundle of joy will be six months old on the 22 of this July. Our journey all started off with genetic testing which had come back extremely high for Trisomy 18 and a possibility of Down syndrome. So we had to make the heart wrenching decision if we were going to give our little baby a chance at life even though her risks even at that weren’t very high of making it, or if we wanted to terminate the pregnancy. Myself and Brooklynn’s dad decided we were going to do whatever we could possibly do to make sure we gave our baby a chance at life, she lived for a minute, a week, a month, a year, or an entire lifetime of joy we would know we did our best. We were going to love her unconditionally regardless!

So I was sent up to Dartmouth to be watched by the high risk doctors, during my pregnancy I had multiple complications such as cholestasis, detachment of the babies placenta, and an umbilical cord verix. So I was being watched very closely. I to the two hour drive from my house to Dartmouth twice a week if not more for doctor’s appointments and non-stress tests.

You may ask what Brooklynn’s journey was like? It all started a month before my due date I woke up knowing something wasn’t right, but didn’t think anything of it even though we had been told she would definitely come early. I was at home coloring with Brooklyn’s older brother at the kitchen table when I had a feeling to call my parents to come and get him because something wasn’t right with the baby. I then proceeded to start packing bags and then went into the bathroom and was bleeding but my water hadn’t broke at that time I was just leaking amniotic fluid. We ended up rushing up to the hospital and delivering my precious little miracle that next very next morning very early. Although she was premature she spent until that night she was born in the room with us, I kept telling the nurses something wasn’t right because she seemed so purple like she wasn’t getting oxygen even after they had given her oxygen right when she was born to get
her to breathe. It was that night when our nicu journey started I was holding her and she stopped breathing and started arching her body all I remember is the nurse grabbing her and running with her down the hallway. Next thing I know the double doors of the birthing pavilion are busting open and a pediatrician comes flying in he looked at me and told me your baby is going to the intensive care nursery, my heart dropped into my stomach and I couldn’t breathe. I felt like everything that was given to me was suddenly take away with in a matter of minutes.

During our Nicu stay I spent countless hours, and countless days without sleep sitting on my baby girls bedside for the first day to day and a half I was scared to touch her all the cords and wires and iv I was scared I was going to hurt her more. Well in the nicu she had emesis, bradycardia, and apnea. Doctors ran every test they could and couldn’t give us an answer on why specifically she did what she did. Although we had a short stay I still never will get over what happened. Brooklynn currently is on pulse oximetry machine at home that monitors her heart rate and oxygen levels because she still has apneic spells at home, she has been rushed from our house four times to CHAD, just the most recent one on oxygen; we are still working to figure out why she does it. She has projectile vomits up almost everything she takes in we currently have her on Elecare formula until we figure that out with the doctors. She sees pediatric gastroenterology, Pediatric neurology, and pediatric neurosurgery at CHAD; also Pediatric neurosurgery at Boston Children’s Hospital. We are hoping to get answers soon! Although we are going through a lot with our baby I am here to tell you there is a light at the end of those Doors! You aren’t alone and thing will get better, they may not seem it right now but they will. I remember the day we left the nicu I wasn’t even happy to be going home I was sad for all the babies that were still there. We had become so used to the babies and the faces of the parents, nurses, and doctors it was like I was living my safe haven and all the people who knew what I was going through behind. Remember don’t give up, Preemies are Warriors and they fight from the day they come into this world!
Nova's Story

At our 19 week ultrasound we got hit with scary news. I remember feeling so confused and emotional. So excited to be having a little girl and our son being able to have a little sister. But being terrified that they couldn’t see the stomach filling up. Did that mean she didn’t have a stomach? How would she eat? But she is growing. So this doesn’t make sense. They must be wrong. Its a mistake. It wasn’t a mistake. Our daughter was diagnosed in utero and confirmed after birth to have esophageal atresia, a rare birth defect where the esophagus and stomach doesn’t attach. We researched and prepared ourselves, our son and our family as much as possible. But nothing could prepare for the realization that we wouldn’t be taking our daughter home for a while. Some days were hard, some days were easier, some days were devastating. So began the ICN stay. Nova Leilani was a day old when she first had surgery to place a gtube to allow her to eat. At a week old she had her second surgery lasting almost nine hours to connect her esophagus and stomach together. I don’t think I would have made it through those eight hours if not for the nurses of the ICN and other support specialists all checking on me, hugging me, praying with me, and frequently calling to the OR to check on her. She made it through the surgery okay but her journey wasn’t over. She would need to go through frequent dilations to stretch our the repair site of her esophagus so that it would stay open. She had to still be fed through her gtube and when having a hard day, be placed on oxygen. There was a time I thought this would never end. It will never get better. But seeing her grow, smile, hold my finger, and the reassuring staff reminded me how wrong I was. She would grow, get better, and be stronger than anyone would ever imagine a baby to be. Nova is now four months old and in a hospital that specializes in her condition. Her fight is far from over but her smiles and strength amaze me every day. Some people offer words that don’t always help. I hear how ‘you are so strong I don’t know how you do it’. But, I know how I do it. I do it for my daughter. She makes me strong and I need to be strong for her. This too shall pass. And when she is a teenager and making my hair turn gray with her teenage ways, I will have all the pictures and memories to remind her how much she has already put me through and hey, it just made me stronger!
Aiden's Story

Aiden was born on January 28, 2011, 16 weeks early and weighing 1lb. 13 oz. Up until the day he arrived, my pregnancy was perfect. I went into labor for unknown reasons, and he was born at our home hospital in Plymouth, NH. They did not have the level of NICU that Aiden needed, so the team came from DHMC in the helicopter to take him to the CHaD ICN. He had nearly every complication that micro preemies have including: a PDA that had to be surgically closed, a Grade IV intraventricular hemorrhage, breathing issues caused by BPD, bowel perforation, renal failure, and needed several blood transfusions. He had a five day trip to Boston Children’s Hospital for emergency injections in an attempt to save his vision from ROP and fought to learn how to eat, breathe and grow.

Right after mother's day, Aiden was doing well on moderate oxygen and learning how to breastfeed. Then he stopped breathing. He had contracted RSV and once again was fighting for his life. He fought hard for ten days in an induced coma (while we questioned whether or not he would beat it) before he finally began to improve. Another two months of growing and healing and our little miracle was finally ready to come home.

After 167 days in the ICN, Aiden came home on oxygen and monitors, which he used until he was almost thirteen months old. He also came home with a G-tube for feedings and struggled to learn to eat for another eight months after discharge. He had to take kidney medications until he was 24 months.

At 3, our little miracle is astounding every person he meets. He is now 35 lbs, eats like a grown man, knows each letter by name and sound, identifies shapes, has perfect hearing, good vision, and is a busy, curious, sweet little boy who continues to thrive. We were honored to be the ambassador family for both the Upper Valley and Laconia March for Babies walks in 2013 and continue to try to give back to the hospital and people that gave us so much.
Our ICN story started 11 weeks too soon when I found out that I was in preterm labor at 29 weeks with boy/girl twins. After staying on hospital bed rest and doctors trying to stop the labor my twins were born under emergency circumstances at 32 weeks. It was devastating, instead of moments of happiness and joy, we faced medical emergencies and uncertainty. Both babies and my husband were rushed from the Operating Room to the Panda Suite where they were evaluated and the babies were stabilized.

Walking into the ICN for the first time and seeing your babies in the incubators is indescribable. Seeing such tiny babies, hooked to machines, fighting to survive took my breath away. It is exciting as you meet your baby for the first time but it is also scary and overwhelming. Nurses helped ease this transition by explaining what everything is and why it was being used. They explained how best to “care” and “interact” with our babies.

We thought for a minute that everything was going to be alright, since the babies were stable; but we quickly learned that the ICN journey is a roller coaster ride. It is filled with highs and lows, dips you didn’t see coming and an outcome that you can’t predict. Our first dip was at 14 hours old, when a resident came to find us and explained that our son was working hard to breathe on CPAP and they wanted to put him on a ventilator, give him steroids to develop his lungs further with the hope that it would allow his lungs to develop further. Deciding to ventilate our son was the first parenting decision we made.

My daughters ICN journey was different. She was born and was stable. She had an IV line and monitors but needed no breathing support. We were thrilled. She thrived in the ICN. We were on a high and had no idea what a low was coming. At 8 days old my daughter started de-stating. Then the roller coaster ride became slow motion. I remember my daughter looking paler, de-stating, nurses trying to place a new IV but not being able to since her body was shutting down and all her blood was pooling in her core, all available nurses came running; residents join them, followed by all the doctors in the ICN. I clearly remember one of the residents saying “wow, it’s not every day that you see the head of the department working on a baby”. I knew then that this was serious. The medical teams placed my 8 day old baby on life support. We watched as she silently cried around the vent. The medical team came and talked to us about what was going on. The overall the consensus was some kind of infection. The doctors informed us that they had to wait for the labs to come back to confirm and all we could
do was treat her and wait and see. Walking out of the hospital that night was surreal. The unknown of the ICN is something you can’t prepare yourself for. We prayed and waited. The labs came back and it was confirmed that she had a staph blood infection. Slowly my daughter responded to the medications.

The highs of the ICN look vastly different then when I had imagined our newborns but they do exist. Some of our favorites were: First time holding the babies, moving from the “tile side” to the “carpet side”, kangaroo time, successful pumping, successful feedings, gaining weight, good reports at rounds, first time giving them a bath, babies with no breathing support, no central lines or Iv’s, babies with clothing, changing diapers, taking temps, moving from the isolate to the open cribs, passing the car seat test and spending the night in the Koala Suite.

Our story has a happy ending. Thirty days after our twins were born; we took our first family photo. That photo is of our 36 week old perfectly healthy twins leaving the ICN. That picture represents so much to our family; heartache, triumph, wonder, family and most of all MIRACLES! Today you would never know that our families’ beginning was created in the ICN. If you saw us on the street, at the playground, or at school you would see two healthy children and a grateful family.
Hello from the ICN Parent Council

In 1999, with the help of the ICN staff, a small group of parents of ICN "graduates", created The ICN Parent Council. The Intensive Care Nursery (ICN) Parent Council is a council of staff members and, families who work in partnership with the ICN to promote and enhance patient-and family-centered care and services of the ICN. The mission of the Council is to support improving the outcomes of infants and to improve the experience of families in the ICN.

Joanna F. Celenza
March of Dimes/CHaD ICN Family Support Specialist
(603) 650-6138
Page (603) 650-5000, pager 5082
Joanna.F.Celenza@hitchcock.org

If you would like to be considered for membership on the Council, Please email your information to Joanna.F.Celenza@Hitchcock.org and someone will contact you to discuss further.

Please note:
We ask that you take some time to reflect on your personal experience in the ICN and wait a year before joining the Council.
Journal: Your Baby's Story

The Day You Were Born 58
Who Were Your Caregivers in the Nursery 60
A Journal of Baby 62
Pumping Log and Tips 66
Your Special Moments in the Nursery 67
Breathing Progress Chart 69
Height/Weight Conversion Chart 70
Growth Tracking Charts and Graphs 71
Nutrition Summary 75
Leaving the Nursery/Going Home 77
The Day You Were Born

YOUR NAME ____________________________

YOUR NICKNAME ____________________________

PLACE, DATE, AND TIME ____________________________

YOUR ACTUAL DUE DATE ____________________________

YOUR WEIGHT ____________________________ LENGTH ____________________________

HAIR COLOR ____________________________ EYE COLOR ____________________________

DELIVERED BY ____________________________

OTHER PEOPLE AT YOUR DELIVERY ____________________________

FEELINGS ABOUT YOUR DELIVERY

________________________________________________________________________________

________________________________________________________________________________

________________________________________________________________________________

________________________________________________________________________________

________________________________________________________________________________

________________________________________________________________________________

________________________________________________________________________________

________________________________________________________________________________

________________________________________________________________________________

YOUR STAY IN THE NURSERY BEGAN ON ____________________________
YOUR FIRST BED WAS ____________________________

WHAT YOU LOOKED LIKE THE FIRST TIME I SAW YOU

___________________________________________________________________________________________________
___________________________________________________________________________________________________
___________________________________________________________________________________________________

YOU WERE FIRST HELD

BY ____________________________ ON ____________________________

BY ____________________________ ON ____________________________

BY ____________________________ ON ____________________________

MY FEELINGS WHEN I FIRST HELD YOU

WHO WERE YOUR CAREGIVERS IN THE NURSERY

___________________________________________________________________________________________________
___________________________________________________________________________________________________
___________________________________________________________________________________________________

WHO WAS IN THE DELIVERY ROOM WHEN YOU WERE BORN

___________________________________________________________________________________________________
___________________________________________________________________________________________________
___________________________________________________________________________________________________
___________________________________________________________________________________________________
___________________________________________________________________________________________________
___________________________________________________________________________________________________
## Pumping Log

<table>
<thead>
<tr>
<th>DATE</th>
<th>START TIME</th>
<th>END TIME</th>
<th>AMOUNT EXPRESSED</th>
<th>TOTAL PUMP TIME</th>
<th>NOTES</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

SAFE BREASTMILK HANDLING/STORAGE TIPS
Your Special Moments in the Nursery

Your child and family will experience many transitions, small and large, during your stay in the ICN (i.e. transition from Labor and Delivery to ICN, transition from respiratory support to oxygen only, transition from the critical to the stabilization phase).

Take time to write about these transitions and record the dates. They will be important to you and your child in the future.

The following are some things you may want to note, although there may be others. Please use the space on the following pages to note other special moments and transitions while your baby is in the Nursery.

Special Moments During Your Stay

YOU FIRST OPENED YOUR EYES ON ____________________________________________

YOU FIRST RECOGNIZED MOM OR DAD ON ______________________________________

YOUR FIRST TUB BATH WAS ON ______________ AND GIVEN BY ______________________

YOU MOVED INTO A BASSINET ON _______________________________________________

YOUR FIRST __________________________________________________________________

YOUR FIRST __________________________________________________________________

YOUR FIRST __________________________________________________________________

YOUR FIRST __________________________________________________________________

YOUR FIRST __________________________________________________________________
THE FIRST FAMILY AND FRIENDS TO COME SEE YOU WERE

___________________________________________________________________________________________________
___________________________________________________________________________________________________
___________________________________________________________________________________________________
___________________________________________________________________________________________________
___________________________________________________________________________________________________
___________________________________________________________________________________________________
___________________________________________________________________________________________________

SPECIAL COMFORT AND SOOTHING TECHNIQUES YOU LIKED

___________________________________________________________________________________________________
___________________________________________________________________________________________________
___________________________________________________________________________________________________
___________________________________________________________________________________________________
___________________________________________________________________________________________________
___________________________________________________________________________________________________
___________________________________________________________________________________________________

SPECIAL GIFTS THAT YOU RECEIVED

___________________________________________________________________________________________________
___________________________________________________________________________________________________
___________________________________________________________________________________________________
___________________________________________________________________________________________________
___________________________________________________________________________________________________
___________________________________________________________________________________________________
___________________________________________________________________________________________________
## Breathing Progress Chart

<table>
<thead>
<tr>
<th>DATE</th>
<th>BREATHING PROGRESS</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Height/Weight Conversion Chart

ICN babies are weighed in grams and kilograms, not pounds and ounces. Your baby will also have their length and head size monitored. These will be measured in centimeters. This is an additional way of seeing how your baby is growing.

Charts are provided so you can convert weight to pounds and length to inches.

<table>
<thead>
<tr>
<th>CENTIMETERS TO INCHES (centimeters x .4 = inches)</th>
</tr>
</thead>
<tbody>
<tr>
<td>CM</td>
</tr>
<tr>
<td>-------</td>
</tr>
<tr>
<td>20.0</td>
</tr>
<tr>
<td>20.5</td>
</tr>
<tr>
<td>21.0</td>
</tr>
<tr>
<td>21.5</td>
</tr>
<tr>
<td>22.0</td>
</tr>
<tr>
<td>22.5</td>
</tr>
<tr>
<td>23.0</td>
</tr>
<tr>
<td>23.5</td>
</tr>
<tr>
<td>24.0</td>
</tr>
<tr>
<td>24.5</td>
</tr>
<tr>
<td>25.0</td>
</tr>
<tr>
<td>25.5</td>
</tr>
<tr>
<td>26.0</td>
</tr>
<tr>
<td>26.5</td>
</tr>
<tr>
<td>27.0</td>
</tr>
<tr>
<td>27.5</td>
</tr>
<tr>
<td>28.0</td>
</tr>
<tr>
<td>28.5</td>
</tr>
<tr>
<td>29.0</td>
</tr>
<tr>
<td>29.5</td>
</tr>
</tbody>
</table>
Growth Tracking Chart

In the first few days of life, your baby will lose a few ounces. This is normal and happens with all babies. In time, your baby may gain up to an ounce a day though her weight gain may be uneven. It usually takes premature infants longer to regain lost weight than it does full term babies. How well your baby gains weight is one measure of her progress.

<table>
<thead>
<tr>
<th>DATE</th>
<th>WEIGHT IN GRAMS</th>
<th>WEIGHT IN LBS./OZ.</th>
<th>LENGTH/HEAD CIRCUMFERENCE</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*ADDITIONAL "SPECIAL NOTES" PAGES ARE AVAILABLE AT THE FRONT DESK.
# Growth Tracking Chart

In the first few days of life, your baby will lose a few ounces. This is normal and happens with all babies. In time, your baby may gain up to an ounce a day though her weight gain may be uneven. It usually takes premature infants longer to regain lost weight than it does full term babies. How well your baby gains weight is one measure of her progress.

<table>
<thead>
<tr>
<th>DATE</th>
<th>WEIGHT IN GRAMS</th>
<th>WEIGHT IN LBS./OZ.</th>
<th>LENGTH/HEAD CIRCUMFERENCE</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*ADDITIONAL "SPECIAL NOTES" PAGES ARE AVAILABLE AT THE FRONT DESK.*
Growth Tracking Graph

First 2 Weeks

<table>
<thead>
<tr>
<th>WEIGHT IN POUNDS</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
<th>11</th>
<th>12</th>
<th>13</th>
<th>14</th>
</tr>
</thead>
<tbody>
<tr>
<td>10</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Growth Tracking Graph

Weeks 3 - 17
## Nutrition Summary

### APPROXIMATE CONVERSIONS

<table>
<thead>
<tr>
<th>5 cc</th>
<th>15 cc</th>
<th>30 cc</th>
<th>60 cc</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 TEASPOON</td>
<td>1 TABLESPOON</td>
<td>1 OUNCE</td>
<td>2 OUNCES</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>DATE</th>
<th>HOW MUCH AND WHAT YOU WERE FEEDING</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Your Prints
Leaving the Nursery and Going Home!

YOUR LOCAL COMMUNITY HOSPITAL, WHERE YOU RECEIVED CARE AFTER LEAVING THE ICN

Homecoming!

THE DAY YOU CAME HOME

YOU WERE BROUGHT HOME BY

THE TOTAL NUMBER OF DAYS YOU SPENT IN THE ICN

NUMBER OF DAYS IN YOUR LOCAL COMMUNITY HOSPITAL

A DESCRIPTION OF THE OUTFIT THAT YOU WORE HOME

SPECIAL EQUIPMENT THAT ACCOMPANIED YOU HOME
Going Home Keepsakes (Photos, Name Card, etc.)
Development Growth and Development of Your Baby

Your Baby’s Development in the ICN 76
What Can I Expect and Do During My Baby’s Early Development? 77
Baby Talk in the Intensive Care Nursery 78
Your Baby’s Development in the ICN

Infant development is a term that means “the physical and mental progress of a baby”. Babies who spend their early weeks in the ICN may need help with their development. This is why our ICN has staff members with special training in this field.

Our Developmental Team hold, touch and play with your infant in ways that help senses develop. They talk to your baby and show her pictures and objects. They let your baby hear different sounds. They also give your baby tests and exams to measure her progress.

You can begin providing your baby emotional and physical support at first by learning positioning and calming techniques, as well as your baby’s tolerance to different levels of stimulation by watching her behavioral cues. The specialists and nurses will also teach you how to provide developmental exercises.

Bonding

Some parents are concerned because they didn’t get to “bond” with their baby in the first few moments after birth. Is this important? Yes and no. Bonding with your baby in the delivery room is good, but it may not make a lot of long-term difference. Bonding is not just a matter of holding your child. It is the feelings you have as she curls her hand around your finger or when you wish you could take your baby away from all the equipment and just be home with her. You can begin the bonding process with your baby in the ICN. This is one reason the ICN staff encourages you to help in your baby’s care and decision-making.

What’s most important to your baby is how close you are in the months and years that lie ahead. Get to know your baby as a person, enjoy being with her, and help her adjust and learn about life at her own pace. The unique bond that you form with your child during this experience will provide a strong foundation for the years ahead.
What can I Expect and Do During My Baby’s Early Development

The following chart is a guideline on how your baby develops during the very early weeks of life. Please use this chart as a guideline only. All babies, full term, healthy, sick or premature develop at their own pace.

<table>
<thead>
<tr>
<th>WEEK</th>
<th>WHAT TO EXPECT</th>
<th>WHAT YOU CAN DO</th>
</tr>
</thead>
<tbody>
<tr>
<td>23</td>
<td>Eyes remain closed, little apparent responsiveness.</td>
<td>Put your hands on your baby softly and firmly when suggested by nurse.</td>
</tr>
<tr>
<td>24</td>
<td>Tiny response to voice and touch; little movements; lean body without fat.</td>
<td>Talk softly as you touch baby.</td>
</tr>
<tr>
<td>25</td>
<td>Arms and legs are limp and outstretched.</td>
<td>Help your baby to be in a position with arms and legs folded so muscles will be stronger.</td>
</tr>
<tr>
<td>26</td>
<td>Eyes begin to open; sleeps most of the time.</td>
<td>Shield your baby’s eyes from bright lights, let her sleep undisturbed as much as possible.</td>
</tr>
<tr>
<td>27</td>
<td>Startles at loud noises; arms and legs are limp and outstretched.</td>
<td>Avoid sudden movements and noises; help baby to tuck in arms and legs; swaddle to hold and move him.</td>
</tr>
<tr>
<td>28</td>
<td>Sudden, jerky movements of arms and legs are common; hand grasp and sucking reflex appears but is very weak.</td>
<td>Shield your baby from bright lights and loud sounds; let your baby hold your finger; offer a pacifier or hold her hand near their mouth so she can suck on her hand.</td>
</tr>
<tr>
<td>29</td>
<td>Sense of smell and hearing may help baby begin to recognize parents.</td>
<td>Always speak to your baby as you approach; speak very slowly and in a relaxed tone.</td>
</tr>
<tr>
<td>30</td>
<td>May see occasional broad smile; begins to wake more frequently.</td>
<td>Swaddle her when you hold her so that she can concentrate on looking at you more than controlling her movements.</td>
</tr>
<tr>
<td>31</td>
<td>Sometimes keeps eyes open wide; body begins to round.</td>
<td>Try moving your face back and forth very slowly as she looks at you to give her practice using her eyes.</td>
</tr>
<tr>
<td>32</td>
<td>May show dislike for feeding tube; enjoys pacifier during tube feedings.</td>
<td>Offer pacifier during tube feedings; hold during tube feedings if tolerated.</td>
</tr>
<tr>
<td>33</td>
<td>On the move in the isolette; sleep and awake times more clear.</td>
<td>Your baby is beginning to have more awake times now, especially before feedings, so it might be a good time to develop a routine of saying a nursery rhyme softly or singing a certain song quietly.</td>
</tr>
<tr>
<td>34</td>
<td>May be ready to start nipple feedings; enjoys sucking on pacifier and hands; breathing is coordinated with swallowing.</td>
<td>Tolerates more interaction and light and sound; will be able to learn nipping and breast feeding; let her really concentrate on feeding so don’t talk to her as she tries to eat.</td>
</tr>
<tr>
<td>35</td>
<td>Baby displays hunger and thirst; may cry to be fed or changed; eyes look at people or objects for brief periods.</td>
<td>Respond to cries quickly as baby will tire quickly so that baby learns to communicate well; spend time letting baby gaze at your face as you talk with her.</td>
</tr>
<tr>
<td>36</td>
<td>Baby has a long quiet alert period and begins to develop a more dependable sleep-wake schedule; grasping while sucking may help her stay focused on eating.</td>
<td>Your face is still the most important visual “stimulation” and your voice the most important sound; she may enjoy music or a mobile as well.</td>
</tr>
</tbody>
</table>
Baby Talk in the Intensive Care Nursery

Ways to understand and encourage my development while I am in the hospital

Dear Family

I want you to know a little bit about what I might say if I could talk. I hope this will help you to understand what my needs are. My nurses and doctors want to work closely with you to give me the best of care. They help me in many ways but you and I are family...So your love is the most important to me.

Love,

Your Baby
Stage 1. Mellow Zone Please
(Babies less than about 30 weeks, sick or just born)

What’s happening?

I am trying very hard to adjust to life outside the womb. Inside, it was quiet except for the beating of Mom’s heart and some muffled sounds. I was in a warm, constantly moving place. When I kicked, the walls of the womb would help me to stay tucked into a comfortable position. I could suck my thumb and grasp the umbilical cord. I didn’t have to breathe, cry or do very much except sleep and be awake for periods of time. (I especially liked to wake up when mom sat down or went to sleep.)

Now, I need to spend all my energy keeping my heart beating and my blood pressure stable. I may need help breathing regularly. I have some monitor wires taped onto me to help the nurses to know if my heart is beating regularly and if my breathing is regular. The oximeter wire shows them that I have enough oxygen in my blood. If I really need help to breathe, the doctors and nurses will use a ventilator, which will breathe for me so that I can rest more easily.

The nurses need to give me nourishment through a tiny tube called an intravenous (IV). When they think my stomach and intestines are mature enough, they will feed me some milk, first through a tube that goes down through my nose or mouth (nasogastric-NG; or orogastric-OG). It may take me some time to breast or bottle feed. Learning to suck, swallow and breathe in the right order is hard work!

These things help me to stay comfortable.

1. Peace and quiet.
I am used to sleeping for at least 20 hours out of every 24. It was pretty quiet inside the womb. I know the doctors and nurses have to check on me regularly, but I would like as few interruptions of my sleep as possible. So, they will try to “cluster” my care. This means that they will plan to do several things at once (if it is not too much for me) so that when they are done, I can really sleep. I really need sleep unless I look like I am ready to wake up. Much as I love you, I can’t deal with much talking, holding or looking at you. All my energy has to go into getting bigger and healthier.

When I am ready I may come out for Kangaroo care. I can be held on my mom’s or dad’s chest, bare skin to bare skin, and covered with a warm blanket. I need to stay out with you for about an hour.

2. Routine Care
It is a good idea to find out from my nurse when the next time for routine care is. You could be here then and help to hold my hand or put your hands around my feet and head so that I feel more secure when they are taking my temperature or changing my diaper. I might like a quiet, firm hand on my bottom or at my feet and head, especially when I have to be unwrapped for some care. I might really like to grasp onto your finger with my hand.
3. A comfortable position to help me relax
I am used to being in a tucked position with something touching me firmly all around. In my isolette, it is very hard to get comfortable unless you or the nurses help me.

- I like to have borders around me and to have something to push my feet against. This lets me be nested and secure as well as be all tucked in comfortably where the nurses and you can still peek in and see me.
- Sometimes, when I am first born, they place a clear plastic tent over me to help me keep in moisture and to help reduce drafts on me as people walk by.
- When I am able to be covered up a bit more, the nurses will use a blanket to swaddle me lightly or tightly, depending on what I show them I like.

4. I like low light and slow, quiet sounds
- I don’t much like sudden changes in light, like flash bulbs or when my isolette cover is taken off. You can help me by shielding my eyes with your hand or by turning down the overhead light if you need to remove the cover over my bed.
- Sudden noises seem very loud to me. I may get so upset that I forget to breathe! But, if you talk very slowly and very quietly, it will help me to stay calm when you touch me or move me.
- Because I am so little, looking at you and listening to you at the same time is confusing to me. It tires me out. Be patient... someday soon, when I am bigger, I will love it when we can chat.

5. I want to be understood
One of the things you will notice is that I don’t cry much. I may make faces that look uncomfortable. I may look more relaxed. I may move my body a lot if I am getting uncomfortable. I can’t always tell you what I need in the way that I will when I am older. Since it is hard for me to let you know what I want, one of the things to do is look at my heart rate monitor. My heart rate is usually between 120 and 160.

- If I am getting excited, my heart rate may increase. My nurses may call this “tachycardia” (fast heartbeat). If it increases a lot, it may set off an alarm. It may help you to know if something is bothering me. My heart rate may go up when my nurse or you are taking care of me. She will watch my monitor and try to slow down what she does if it seems to bother me too much.
- Sometimes, my heart rate will go down. This is called a “Brady” which stands for “bradycardia” (slow heartbeat). This is a sign that I am getting stressed, either by handling or because I am feeling sick. Sometimes I stop breathing too. This is called “Apnea” (no breathing) and when I have apnea and bradycardia together, the nurses call it “having As & Bs”. This lets them know that I need to be watched closely for any signs that I may need to rest or may not be tolerating what is being done.

Another way I can communicate is with my oximeter. The nurses attach a sensor to one of my extremities, this looks like a red light. It measures the amount of oxygen in my blood, which is, of course, very important. My nurses call this the “O2 sat”. It should be between 88 and 100 on the monitor (my nurse can tell you the desired level for me). My O2 sat may drop if I get moved suddenly, if I am in an uncomfortable position, if I hear a loud noise, if I have a bright light shine in my face, or if I need more oxygen (for example). This is a hint that I need something different to happen. My nurses can tell you by looking at all the monitors together what I might need. Soon you will get to know what I need by looking at the way I move and at the faces I make. By watching me and my reactions it will be much more helpful as you try to understand me and what I need.
**Stage 2. I'm Growing**  
(Babies between about 30 and 36 weeks)

As I get older and healthier, I will be able to stay awake longer and be a little more able to control my movements. If I get sick, I may go back to needing some of the things I needed when I was younger.

**What’s Happening?**

Once I have more control over my breathing, blood pressure and heart rate, I can start to work on staying awake longer. I still sleep a lot but my deep sleep may be deeper and my awake times will be more alert.

I still can’t take a lot of activity. I may try to go to sleep to avoid too much commotion. I may sleep all day when it is busy in the ICN and then be wide-awake at night when it is quieter. I will get more active and start moving my arms and legs. I may scoot down to the bottom of my bed, I still like to have something to push against. I call these my **boundaries**.

If I can’t find boundaries, I sometimes get frantic and may not be able to stop moving. You can help me by swaddling me with a blanket or by using your hands to help me to contain myself. Some movement is good - but too much movement wastes the calories I am trying to take in so that I can grow. I may LOVE to be held. There is something called “**kangarooing**”, which helps me to grow and get close to you. What we need to do is for you to open up your shirt and I’ll just wear my diaper so we can touch our skin together, chest to chest and covered with a blanket to keep us warm. Then I can hear your heart beat. This makes me feel secure and loved and we can sit together nice and cozy. I may not be able to handle being held for a long time, but sometimes I am most comfortable in this position for at least an hour - you and my nurse can decide when I need to get back to bed. Talk with my nurse before you want to kangaroo so you will have help getting me out of my bed. All of those wires can be a lot to handle.

It can be hard for me to be moved from one place to another. You can help by swaddling my body with a blanket. I will probably need a hat to keep my body heat in. It is important to support my neck so that I can keep my airway open.

You may find that I will look at you if you are not talking to me but that I look away if you talk. This is called **gaze aversion**.

Please don’t be insulted - it is just that I can’t do two things at one time yet. You can help by talking very slowly and softly into my ear when I am up on your shoulder and not looking at you. Or try looking at me without talking until I am used to it and then start talking very slowly. If you stop talking when I look away, I will come back to you when I am done with my time out. You will know to talk more slowly or quietly or just let me gaze at your face. Your face is really the most important thing to me and I love to look at it. I really don’t need toys and other things yet!
(Continued)

I may be learning a new trick - SUCKING! This is a really good thing for me to do. It helps me to calm myself. I find it easier to relax and to tuck my arms and legs in so that I am comfortable when I have something to suck on. Sucking helps the food to go down through my stomach better too.

It is easy to suck on a pacifier if it is the right size for my mouth. Even while I am on a ventilator, I can still suck if the pacifier is cut to fit my ventilator tube.

Sucking to eat is different than sucking to relax. When there is formula or breast milk to swallow, I have to be very coordinated. I have to be able to breathe and suck and swallow, all in order! I have to do this for quite a long time (at least 20 minutes) to get in all the food I need to take. My nurses help me by putting a tube down my throat into my stomach so that they can drip in the food I need while I am asleep. This way, I can suck a little to practice but I won’t get exhausted by trying so hard to eat. Gradually, I will learn to eat more and more as I get bigger and stronger.

A message from the caregivers

- The doctors, nurses, and development specialists are the most readily available people to answer questions you may have about this information.

- There are people in your community, besides your doctor, who can help as well. These people are family support coordinators and therapists who work in your statewide early intervention program. Please refer to the “Resources” section of this book for more information on the state and federal services available.
Stage 3. Cuddle Time
(Well babies older than about 34-36 weeks)

Now I am really growing and you will notice that I am much more alert when I am awake. I will also be awake much more of the time.

You can tell I should have something to look at since I am awake so much. Mobiles and stuffed animals are sometimes fun for me. But remember, I can’t turn my head very easily yet and so I might not be able to move my face away when I am done looking at something. I don’t really like to have too many things to look at. I also might have trouble going off to sleep if there is a big black and white (very stimulating) design in my face! Don’t forget that your voice and face are the most important things to me.

I still need my sleep. I may develop a schedule that people around me can count on. I often sleep for 2-3 hours and then am awake for almost an hour, during which time I want to eat, get cleaned up and have my position and my diaper changed. I may even have enough energy to have a “chat” with someone.

I can give pretty clear signals, now, about things that please me, things that bother me a bit and things that really stress me a lot. My nurse has a book called Understanding Your Baby’s Signals. I need to learn to take care of some of my problems myself. I might know how to suck now and will do that for a long time if you position my pacifier just right. I know how to grasp a blanket or your finger or a tube near me and that will help me to cope. If I am doing those things, I probably don’t really need help. But, if you see me giving “stress signals” like those in the book, that probably means that I really need you to do something, like feed me, change my diaper or pick me up to cuddle.

My movements are stronger and seem more coordinated. I might be starting to lift my head when you hold me up at your shoulder. I might need a bit less neck support than before, but please continue to support my head. I can’t always control my neck movements as well as I think I can and I need you to guard me carefully. You might notice that I still would like it best if you can help me to contain my movements, especially when I am moving from one place to another. A hand on my tummy might be all I need to help me settle down.

Bath time is especially exciting because I can really have a nice tub bath now. I may startle easily and that will make me cry. You can help by wrapping me in a blanket or towel to help me feel secure when I am in the water. Unwrap the parts you need to wash one at a time a time so I don’t get too cold or nervous. Then, wrap me up again as you remove me from the water. This will help me stay calm until you can get me into a nice dry and cozy towel.

(Continued)
I am getting to be a pretty good eater by now and may even wake up when it is time for me to eat. Sometimes the nurses and doctors decide that I can let them know when I would like to eat, instead of feeding me on a set schedule. They call this eating “ad lib”. They will still want to be sure that I get enough calories each day under this kind of schedule. I can show you that I want to eat by rooting (turning my open mouth toward you) or by sucking on my hand or on your shoulder or on my blanket. You may find that if I can eat when I want to, I am more likely to eat quickly and efficiently. This is one of the things they would like me to be able to do before I go home.

If I am breastfeeding, I will need you to come be with me very regularly now so that we can practice together. I certainly appreciate as much breast milk as I can get, whether it is in a bottle or from the breast directly.

If I am bottle feeding, with expressed breast milk or formula, it really helps me to use the same nipple with every feeding. I may get easily confused if the nipple changes each day.
<table>
<thead>
<tr>
<th>Topic</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Preparing for Transition Home</td>
<td>90</td>
</tr>
<tr>
<td>Rooming In</td>
<td>90</td>
</tr>
<tr>
<td>What to Learn Before Discharge</td>
<td>91</td>
</tr>
<tr>
<td>Checklist for Parents</td>
<td>91</td>
</tr>
<tr>
<td>Car Seat Check</td>
<td>92</td>
</tr>
<tr>
<td>Choosing Your Baby’s Pediatrician</td>
<td>93</td>
</tr>
</tbody>
</table>
Preparing for Transition Home

The ICN staff takes a number of factors into account to determine the time of your transition home. Here are the most important goals your baby must attain:

- Gain weight steadily.
- Awaken when hungry and breast or bottle feed for all feedings.
- Maintain body temperature in a crib.
- Be free of apnea episodes for 7 straight days.

In some cases, your baby may go home on medications, oxygen or some type of monitor.

While you are eager to have your baby home, you may be nervous about it too. It will help if you start caring for your baby in the ICN well before discharge. You will learn how to bathe him and change his diapers. You will learn how to identify signs of illness so you’ll know when to call your baby’s doctor. We’ll coach you while you breast or bottle feed. We will help you learn how to tell if your baby is getting enough to eat.

If your baby is going home on oxygen or requires a monitor, we will help you learn how to use it. We will instruct you in the use of any medicines that may be needed. The ICN also offers CPR to families. If you are interested please ask the front desk for a schedule.

Spend as much time with your baby as you can in the days before discharge. You will feel more confident with your parenting skills when you take him home. There may be an opportunity to room in with your baby before taking him home. This will allow you to care for your baby independently while having the comfort of the nursing staff close by, if needed.

You may also want to do some preparation at home to make the transition to home less stressful. A well-stocked refrigerator, having 2 weeks worth of diapers and all the equipment your baby needs bought and installed, will help you focus on establishing a new routine at home.

Rooming In

Before you and your family take your baby home, you may have the opportunity to “room in” with your baby; this is not necessary for all families. This will be in a separate room where you will be caring for your baby independently. There will be a nurse assigned to your baby for support and assistance when needed but rooming in is your time to interact with and care for him on your own as if you were at home.

Rooming in can happen within a week of your baby’s discharge and can be planned with your ICN care team. The nurses will reserve the Koala Suite when the date for discharge has been confirmed. It is best that you room in prior to the night before discharge so that you have a chance to rest the night before your baby goes home. Any family may room in, but it is a particularly good idea for first time parents. It is required for parents whose babies have special needs to room in prior to the transition home. (For example, a baby that requires oxygen, a heart monitor, tube feedings, and other equipment at home.)

There will be a bed and linen provided for two adults. Please bring your own toiletries and soap, etc. We ask that you arrange for family members or friends to care for any siblings away from the hospital when you room in with your baby. Children generally do not enjoy being confined to a small room in a hospital. This will make it easier for you to concentrate on what you need to know to care for your new baby at home.
What to Learn Before Transition Home

The nurses have a general plan for helping parents to learn the necessary transition home information. The plan is individualized for each baby. It would be helpful to keep track of what you have learned so that you can plan your teaching sessions with the nurses at times that are convenient for you.

Checklist for Parents

In preparation for your baby’s home coming, the following items are things you need to have in place and/or need to be doing before your baby is discharged.

- **Choose a physician.**
  Do this as soon after the birth as possible. Following in this section are guidelines on how to do this.

- **Obtain a car seat.**
  Talk to your nurse about getting the correct type for your baby, especially if your baby was premature, or has some respiratory problems.

- **Be familiar with developmental issues**
  (for example behavioral cues, appropriate stimulation, calming techniques that reduce stimulation, positioning, etc.)

- **Organize your supplies at home;**
  crib, clothes, diapers, feeding supplies, etc

- **Provide your baby’s care independently;**
  bathing, feeding, knowing the signs of illness, etc.

- **Learn any care specific to your infant;**
  medications, treatments, CPR, monitors, etc

- **Care plan.**
  The teaching is done with the family and documented. This must be completed prior to leaving the ICN. A care plan was started at admission and has been revised throughout your infant’s stay.

You’ll manage better at home if you are prepared. Baby care takes a lot of time at first and running to the store is an extra chore. Here are some things that you will need:

- **Clothes:**
  If your baby was born early, you may want to buy clothes made especially for preemies. All babies tend to outgrow clothes quickly, so you might want to have several sizes on hand to ensure you have clothes that will fit for a while. If you want to buy clothes specific for preemies, there are websites listed in the Resource area of this book that may be helpful.

- **Diapers:**
  Many babies are wearing regular diapers by the time that they go home, but if you want preemie diapers, there is information in the Resource area of this book.

- **Toys:**
  Keep toys simple. It will be a while before your baby can play with them. Give your baby things to look at and listen to when awake. Put a bright mobile above the crib for when he is awake and alert. Put a colorful toy in the crib. Place a music box or radio nearby. Many babies find soft music soothing. Don’t give your baby anything he can grab and get tangled up in. Don’t put stuffed animals in the bed and never use bumper pads in the crib. Remove toys when putting your baby to bed so they learn it’s quiet time.
Car Seat Check

The law requires the use of a car seat for all babies. Find a safety-approved car seat that lets your baby sit without slumping, so that he can breathe easily. Some infants who were born at 37 weeks or less or have had breathing problems may have difficulty breathing when sitting up in a car seat. Other infants are small and may not fit securely or safely in a standard car seat. All infants < 37 weeks at birth and infants with respiratory distress will require a car seat test.

The infant is placed in the car seat while attached to a pulse oximeter and a cardiac monitor. The infant is then monitored for desaturation, apnea, and bradycardia while in the car seat. For this test, please bring the car seat, the instruction manual, and clothing typical to what your child will be wearing in the car seat. We recommend that you be present for this test, so that the nurse can demonstrate how to position the baby. This will take at least 90 minutes. If you live farther then 90 minutes away, your infant’s car seat test will be the length of time it takes you to get home.

Depending on the results of the car seat check, we may require that your baby initially use a car bed to ensure safety. Please refer to the Car Seat Safety Reference Book for more useful information.

The ICN has a video that demonstrates the importance of car seats. We require you to view it before going home. In addition, there are staff members who are certified car seat technicians who can provide assistance in installing your car seat.
Choosing Your Baby’s Doctor

Now that your baby is in the ICN, it is extremely important to choose a family doctor or pediatrician in your local community to care for your baby when he transitions home. If you have other children and are satisfied with their doctor, notify him/her as soon as possible after your baby is admitted to the ICN. If you do not have a doctor, find one as soon as you can. It is important to allow your doctor to have ample time to review your baby’s history and schedule an appointment appropriately.

Your family doctor or pediatrician has special training to manage your child’s total health care needs, including:

- Growth and development
- Illnesses
- Nutrition
- Immunizations
- Injuries
- Healthy life styles
- Behavior issues
- Parenting and family issues
- Learning and school challenges

For recommendations about choosing a doctor for your baby, ask your ICN Care Team. After you have a list of names, set up meetings to get acquainted. A face-to-face interview gives you the chance to find out for yourself about this doctor’s philosophy of caring for infants and children.

The following is a sample of questions to bring with you when interviewing your potential doctor:

- What are the office hours?
- How does the office handle billing?
- Is payment due at the time of visit?
- Is my insurance contracted with your practice?
- How do I reach you after hours or during an emergency?
- To what hospital do you admit patients?
- If I cannot speak with you, who will handle my questions?
- Do you have a sub-specialty or area of pediatric interest?
- Have you taken care of other ICN patients?
- Do you have experience with children with special needs (i.e. monitor, oxygen)?

These are just sample questions. Ask other questions about things that are important to you.

It is also important to note how you felt about this first meeting with the doctor. Some important questions to consider are:

- Did the doctor listen to your concerns?
- Did the doctor answer your questions?
- Did the doctor seem interested?
- Did you feel comfortable discussing your baby with the doctor?

When someone you know suggests a doctor, it is also helpful to ask that person some questions about the doctor, such as:

- Does the doctor and the office staff answer all your questions?
- Does the doctor talk with and care about the children as well as you?
- How helpful and friendly is the office staff?
- Is the office clean?
- How well does the office staff manage your telephone calls?
- Do you have to wait long before seeing the doctor?
- Is there anything about the doctor or the office that bothers you?

After your baby leaves the ICN, he will need an appointment with his own doctor shortly after discharge. The doctor will then give you a schedule for recommended health care visits.
Home: Going Home

Return Transport 95
Home at Last 95
Baby Talk – Taking Me Home 96
Getting Ready to Go Home 97
Follow-up Appointments & Programs at DHMC ???
Respiratory Syncytial Virus 107
Commonly Asked Questions 108
Crying Babies 109
Developmental Check Ups * ???
Return Transport

In some cases your baby may be transported back to your home hospital before returning home. When this happens your baby will be going by ambulance with our ICN nurse; this is called a return transport.

Specific information about the hospital you are returning to is available through the Clinical Resource Coordinator (CRC) in the ICN. We recognize that being far from home and your usual support system is very stressful and we support your baby being transported back to your own physician and a hospital near home when your baby is more stable.

The decision to do a return transport with your baby is a joint one made by you as parents, your Neonatologist, the ICN care team, the accepting hospital and local physician.

Home at Last

It’s a happy day when you take your baby home, but being home can be stressful too. There are several things you can do to make life easier for yourself and your baby.

Keep visitors to a minimum for the first few weeks. Don’t let anyone with a cold or other contagious illness visit the baby. Also, don’t allow anyone to smoke around your baby. Your baby needs peace, quiet, and clean air.

Take care of yourself as well as your baby. It is hard for parents who are tired and upset to give loving care to their new baby. Eat well. Get enough sleep. Find a baby sitter now and then, and get away from the full-time job of being a parent. Even if it is only for a ten-minute break. Have a little fun.

Get help. Being a parent of a new baby is not a one-person job. When people offer to cook, clean and run errands for you, accept their kindness.
Baby Talk - Taking Me Home

Ways to understand and encourage my development during the first few months at home

Dear Family and Friends

I am so excited to be going home! I can’t wait to meet everyone who will be important to me. I am grateful that you were so patient in waiting for me to come home.

Even though I am big enough and well enough to come home, I will still need your understanding. It may be hard for me to adjust to a new situation. It may take several weeks before I really settle in.

I am unique. Some of the things in this booklet might not apply to me. There are lots of different things to try since I may be a challenge at times! You will soon know which things help me. You will find many other things that I like too.

Love,

Your baby
Getting Ready to Go Home

What’s happening

I will be letting people know that I am ready to go home because I will be less likely to have “As & Bs.” The doctors and nurses will talk about a “countdown” - this means they want me to have seven days without any apnea before I head for home.

They want to be sure that you are comfortable caring for me. They will offer times to “room in” in the Koala Suite. This means that you will have more chances to care for me on your own. The nurses will be close by and available to us if you have questions.

The nurses will have several aspects of my care to teach you. This may include CPR (cardiopulmonary resuscitation). There is a specific way to do this for little babies. It is an important skill to learn for everyone who will help take care of me. The nurses will also teach you how to bathe and feed me.

Car Seat

You will need to buy or rent a car seat that will fit me. The ICN staff can help with sources for these car seats. I will have to pass my “car seat test” before I head home. This means trying me in the car seat for a while to make sure that I am comfortable and can tolerate that position for as long as it will take to get home.

Please review the Car Seat video in the ICN. Also, there is updated car seat information available from the ICN for you to learn more about updates and recalls.

Walkers and Vibrating Seats

Please don’t buy a walker. Walkers are not good for babies, premature or not. They cause babies to get into things they shouldn’t. Lots of accidents happen because of walkers. Also, premature babies are especially likely to have difficulty learning to keep their balance when they have walkers. (More about this in a later section!) We don’t know the effects of the stimulation of a vibrating bouncy seat, so for this reason we don’t recommend them.
Smoking

Smoking is not allowed in the NICU and should not be introduced into the infant’s environment. Call: 1-800-QUIT-NOW or D-H Tobacco Treatment Program 603-653-9456 to choose your quit tobacco plan.

- Parents/Caregivers need to be made aware of the dangers of anyone smoking around the infant
- Bed-sharing may be more dangerous if the mother smokes and should be strongly warned against
- Parents/caregivers should be encouraged to stop smoking and create a smoke & tobacco free environment for the infant

The American Academy of Pediatrics

Third-hand smoke is the smoke left behind — the harmful toxins that remain in places that people have smoked previously. Third-hand smoke can be found in the walls of a bar, upholstery on the seats of a car, or even in a child’s hair after a caregiver smokes near them.

Bathing Me

Since I can’t go outside to play yet, I don’t need a bath every single day. You can sponge bathe my face and bottom until I am older.

I might enjoy a tub bath though, especially if you can help me to adjust to the change from warm bed to water.

When I am in the tub, you should support my head above the water. The water will support the rest of my body fairly well. You will have a hand free to wash me. Some dirt usually hides in the creases, especially around my neck and around my bottom. Just gently wipe these areas using a tiny washcloth.

It may help to undress me, wrap me in a blanket, and then place me swaddled into the tub. Receiving blankets are light and won’t soak up much water. If I am swaddled, then I don’t have to worry about holding my arms and legs in. This way I can concentrate on being moved and being in the water. I will probably startle less too. Sometimes sitting me on a folded up towel in the water makes the tub less slippery and more comfortable too. You can keep me swaddled when I’m in the water and unwrap each body part when you want to wash it. Then cover that part back up and uncover the next part.

Have a warm towel ready to wrap me in so I can feel safe and warm.
Feeding Me

I may be eating quite well by bottle or breast. I usually eat every 3 to 4 hours (maybe more often if I am breast-fed). It should only take me between 20 and 30 minutes to finish the amount that the doctors say I need to grow.

I may still need some help so I don’t eat too fast when I am really hungry. Tipping the nipple down slightly so that I don’t get quite so much with each suck can help prevent this. If I am breast-fed and mom is engorged, she may want to pump off a little of the extra milk before offering me the breast. This will keep me from getting too much milk when I first start to suck. I may feed better in a quiet, dimly lit room.

I may need help staying awake long enough to finish eating. Sometimes, unwrapping me will help me to wake up. Sometimes, swaddling me firmly before feeding me will help me not waste my energy by trying to suck and control my movements at the same time.

I may "spit up" quite easily since the valve that closes off the top of my stomach is not very strong yet. This may not seem to bother me much or I may act like I have heartburn. (I may make a face, cough or cry.) The doctors call this reflux. They may have suggestions about how to help, such as not sitting me up right away after feeding. If I vomit with force, you probably should ask the doctors about it, since it might mean that I am sick.

Playing With Me

I will really enjoy my awake times if all my needs are met. I still have trouble doing more than one thing at a time. If I am hungry or have a dirty diaper, I will probably not seem very relaxed and ready to play. I can tell you by my actions what I need help with. I might not be able to cry very loudly, so I still need you to read my cues.

Understanding My Signals

Please refer to Understanding My Signals, a pamphlet (from the Developmental department) that shows my different cues.
How to help me when you see cues that say “I am not happy and need a change.”

I might make faces or just seem wriggly and uncomfortable. This might mean I need a change of position if you already know I am clean and not hungry. When you do change my position, try to help me “contain” my arms and legs by folding them to my body with your hands. Roll me to my side or onto my tummy. Try not to “flip” me over, because this quick action is hard for me to handle.

If I am trying to look at you but keep looking away, it might mean that I am trying to do too much at a time. Maybe you are talking too loud and fast or you are jiggling me and talking at the same time. You can help me by holding me still, perhaps up at your shoulder or under your chin to give me a break. I call this my Time out. It means that I am working too hard to pay attention and I need a minute to calm down. If you stop moving or talking for a minute, you will find that I will bring my eyes back to your face. Then you can let me look at your smile. You can talk very slowly and quietly and watch my face. If I can stay focused on you, I will. If not, I need you to let me just look at you without talking. Or, you can talk to me as I am lying on your chest so that I don’t need to look at you too.

If I am stiffening out my arms or legs, you can help give me boundaries by using your hands or by swaddling me. Help me to tuck my arms and legs back in and keep them there for a little while until I relax. Bringing my hands to my mouth might mean different things. I may be saying “I’m hungry” or it might mean, “I’m trying to calm myself.” You can tell the difference by watching me for a little while.

■ If I start to fuss and “root,” and it is close to time for eating, you might offer me a bottle or breast.
■ If my hands move away from my mouth, you could help me to keep them where I can suck on them.
■ If I seem content with my hands in my mouth, you might just keep looking at me and/or talking very slowly and quietly with me. That can be my way of helping to concentrate on your face.
■ Sometimes, things might get to be too much for me. Then I might cry a lot. If you know that I should not be hungry because I just ate, I might just be tense and tired from having a busy day.

Things to do to help me.

■ Some gentle pressure from your hand on my tummy might help me to tuck my body.
■ Decreasing the number of things to look at may help. (Remember that I can’t shut things out like you can.)
■ Sometimes I just want to be put back to bed. You can put your hand firmly on my back or hip or shoulder and pat firmly, with a regular rhythm (like a heart beat).
■ Jiggling is not good for me since it over-stimulates me. I may be soothed by slow rocking with a steady rhythm.
Home at last!

I will be very excited by the ride home. It is a big change for me. Please try to shield my eyes from bright lights (like the sun). If it is cold or windy, you can shield my face with your hand or a very light blanket to keep the cold air and wind from bothering my breathing.

Please plan to have things very QUIET at home.

**Keep Colds Away.** I would love to meet people but I won’t have the energy for at least a week or two (maybe longer). Even then, since I have some trouble fighting off colds, please don’t let anyone near me who has a cold. You should ask anyone who wants to hold me to wash his or her hands first.

**No Smoking** Please be sure no one smokes in the house - my lungs are very delicate still and smoke gets in very easily.

**Introduce Activities Slowly.** I am still easily overwhelmed by lots of action. There are some new things at home which I have never had to deal with before. I will learn to live with these things as I get older. You could help me a lot by making me only deal with a few of them at a time.

Some of these things might include

**siblings or other small children.** There may be little children around who are very excited about my coming home. This is a good time to reinforce the importance of washing hands before touching me. Please help them to learn to whisper when they are near me. In a few weeks, I will learn to love all their noise but it is a little hard for me when so many other new things are happening! If they have runny noses, have them stay away. If they want to touch me, it would be better to help them touch my leg or blanket instead of my hands or face.

**Our family pet.** We may have a pet that makes a lot of noise. Maybe I could be in a room away from our pet to make it easier for me. Please don’t leave me unattended with a pet.

**Music.** You may enjoy music. Rock and roll or heavy metal will "hype" me up and may make me irritable (or make me sleep all the time to avoid it). Classical or mellow music is better for me right now since it is usually slower and quieter. Your voice is really the best music for me. I will be happy with no music except your quiet singing!

**Television.** The TV may be on a lot in our house. It makes bright flickering light that is very hard on my eyes. It has loud, jazzy music and talk. Commercials are much louder than the shows. Maybe you could be sure that it is on quietly and you place me where I don’t have to look at it? I will learn much more from looking at you, while you talk with me than from being near a TV set.
Sleeping

Sometimes babies who have been in the NICU have difficulty settling down when it's "too quiet". Playing quiet music or having a fan on in the room may help me. I will still sleep most of the time. This will probably go on for months. You can count on getting up with me every three or four hours during the night as well as during the day. Try to play with me a little during my awake times to lengthen how long I can stay awake. Try not to disturb me when I am asleep unless I have been sleeping a long time (5-6 hours) and you feel that I should eat.

You may need to have me sleep near you or use a baby intercom to hear me since my cries might not be that loud at first.

When I wake at night...

When you get me up at night, try not to play with me. I need to learn that night is for sleeping and day is for playing.

- Keep the lights low, change me and feed me but don’t talk much to me or make it interesting for me to be awake.
- Put me back to bed as soon as possible after I finish eating.
- Try to get me into the habit of going to sleep without being held. If I get in the habit of being rocked to sleep, I may find it hard to get myself to sleep in a few months when you really want me to do that.

Eating

Usually I will wake up when I need to eat. You will want to change my diaper and be sure that I am awake before you try to feed me. Otherwise, I might just snack a little and go back to sleep. If this keeps up, I might be eating 24 hours a day! If I am hungry and awake, I will take the amount that I am supposed to before falling asleep again. Then I can sleep soundly until my next feeding, instead of waking up every hour or two to eat.

If I usually seem to fall asleep before finishing, look at what else is happening around the house to see why I am doing so.

- If it is very loud, I may fall asleep to avoid lots of noise and activity. You might try turning off TVs and radios.
- You might try feeding me in a room that is dim instead of bright.
Playing with me

You are my best “toy” for the first few months after I have reached term. I love to look at your face and listen to your voice.

- Talk to me about what you do with me or about what you think I might be looking at. You can even talk about your day - I will listen. This is how I begin to learn language even though I am very young. Sing to me - I won’t mind if you are a bad singer. The rhythm of your singing and the different sounds help me to learn.

- I usually like the voice of my Mom and Dad better than voices of other people. I might seem afraid of people with voices that are quite different from my parent’s voices especially if they are loud. Have patience. I will get used to a new voice after a little while, especially if the person stays relaxed and is nice to me.

- Watch how I use my eyes. I can see. My best vision is probably at about 10 to 12 inches away from my face. Soon you will notice that I can see you across the room also.

Try moving your face and see if I can follow your face with my eyes. See if I can follow better if you talk to me as you move your face. If it is too hard for me, I will probably look away. You can slow down how fast you move or try it without talking.

Watch how I scan your face when you talk to me - I am learning what you look like. Soon I will notice the difference between your face and that of someone new. I might even cry when someone with a very different face comes near me. For example, if I have never seen a beard or glasses on a face, those things might startle me and make me cry.

When I am learning to focus on something close up, my eyes will probably cross. You can move your face away a little to help me to uncross my eyes. This eye crossing should get better as I get older.
Positions for play.

- **Lying on my back** is most comfortable if you can place a rolled up blanket around me to help me tuck my arms and legs up like when I was in the hospital. This is true whether I am in an infant seat or lying flat in bed.

- **Lying on my side** is also a good position for me. I can have my hands together and bring them to my mouth more easily than when I am lying on my back. Put my back against something so that I will not roll onto my back. If you place a toy at the level of my tummy, I will be able to look at it and maybe try to reach out and touch it.

- **Lying on my tummy or side** is not suggested for sleeping. It is a good position for learning to do “push-ups” which are the first step to learning to crawl. It is really hard for me to like lying flat on my tummy since there is nothing to see or do in that position. But, if you hold me on your chest, I might try to lift my head so that I can look at your face. If you put my arms underneath my shoulders, I will be more able to push up and support my head and shoulders.

- **An infant front-pack** might be a comfortable way for me to be near you while you work around the house. Be sure that my head control is good enough and keep a close eye on me. Front packs are usually good when I weigh about 7-9 pounds. My head needs to be supported well by the front pack so that it doesn’t slump forward too much.

- **A baby swing** is great but I can’t really sit up safely in one until my head control improves. If my neck is still floppy, you should probably use a rocking infant seat or a swing with a bed instead of a seat.

- It will be quite a while until I am really using my hands to reach out for a toy. You can help me notice my hands by helping me stroke your hair or your face. I don’t usually seem to see my hands until I am between 3 and 4 months old (after term).

How Old Am I?

This would be a good time to discuss “corrected age.” My friends in child development want you to know that they don’t expect me to “catch up.” I was born early and there is no reason for me to speed up my development just because I was born. They will talk about my age “corrected for prematurity.” This means, take my actual age and subtract the number of months that I was early. I was supposed to be in the womb for 40 weeks. If I was born at 28 weeks, that is 12 weeks or 3 months early. So take 3 months away from my actual age. When I am 6 months old, my development will be that of a 3-month-old child if all is going well. If I was born at 32 weeks, that is 8 weeks or 2 months early. If I am 6 months old, my development will be like that of a 4-month-old child.

- This difference is most obvious in the first year. The older I get, the less difference those months make. By the time I am 5 years old, you will have a hard time telling the difference between me and someone who is 2 or 3 months younger than I am! But right now, I need for you to have patience. I seem like a little baby a lot longer than my friends who were full-term.
Respiratory Syncytial Virus (RSV)

Respiratory Syncytial Virus (RSV) is a common cold virus found in the community every winter. It usually causes only cold-like symptoms in older children and adults. However, it can make premature babies and those with chronic lung disease very sick.

Is RSV contagious?

Yes. It is mainly spread when the virus gets on the hands of caregivers through the infant’s saliva or nasal mucus. Coughing may also spread it, but not directly. Sharing bottles or eating utensils also spreads the virus. It spreads easily in day care settings. During an outbreak many people are infected, including adult and other children in the house.

What makes it worse?

Infants with lung trouble or who were born very prematurely are more susceptible to RSV disease. However, all newborn babies should be protected from crowds, other children with colds and day care settings as much as practical. Exposure to tobacco or wood smoke at home is especially irritating to the lungs. Babies exposed to passive smoke have an increased number of viral infections.

Can children get RSV more than once?

Yes. Every child gets RSV several times before the age of five. The first infection is usually the most severe, particularly if the child is less than six months old.

How can I prevent it?

- Avoid crowds (including daycare if possible, especially during cold season).
- Avoid exposure to cigarettes or other smoke.
- Keep away from people with colds. A mild cold in an adult or older child might cause a serious infection in your baby.
- Don’t let anyone put the baby’s pacifier or bottle in their mouth. Don’t kiss the baby on the mouth.
- Wash your hands before feeding or handling the baby, especially if you have a cold. Most cold viruses are spread by touching, not from the air.
- Keep yourself well. Don’t share cups or utensils.
Commonly Asked Questions

When can I take my baby out in public?

It is best not to take your baby out in public for the first three months after bringing her home from the hospital.

When you do take her out, try to avoid crowds of people who might have colds and other illnesses. Some of these places to avoid may be:
- Church
- Older children’s school/group day care
- Malls or grocery stores
- Buses

Your baby’s doctor’s office

You may ask for an early appointment or when arriving for your appointment, you could ask if you could be put in an examining room to wait.

Should I allow visitors when my baby gets home?

When your baby comes home there will be many well-meaning people who want to come and visit. Some things to keep in mind are:
- People with colds or the flu will have to visit at a later date.
- Your premature baby will be more sensitive to stimulation and may do better if not held or only held for a limited time by one person.
- You can limit the number of people who visit at one time and limit the amount of time they visit.
- Don’t let people drink hot liquids or smoke when near the baby.
- Remember you are your baby’s best advocate. It is okay to say that your doctor said it is not good to have visitors until your baby is a little older.

How do I deal with people’s reactions to my premature infant?

People may respond with surprise or concern about your premature baby’s size.

They may be afraid to hold her for fear of “breaking” your little one. This is a common response and they will need your reassurance that they will not harm your baby.
How can grandparents and other relatives help?

Grandparents can help with the care of siblings once you are home. Maybe an outing or an overnight at their house will help you and give the siblings special time with their grandparents. Often there is very little energy left to handle regular living with other children. If possible, having a grandparent come to stay for a short time can be a big help.

Grandparents can also watch older children so that you and your spouse can take a break together. Going for a walk or for a cup of coffee can help you keep in touch with each other.

Making meals for the freezer or grocery shopping are other ways for friends and family to help.

While most relatives are well-meaning, there are those who give advice you do not want to hear or advice that is incorrect for your baby. Parents need to decide what is best for their family and whether visits or phone calls from others will help or hinder. You have come home equipped with the best knowledge to care for your baby and, as the parent; you know what is best for your little one.

It is a stressful time for everyone. If you find just one person who will be there to listen and be your advocate, they can help you explain your needs to the others in your family.

How do I interact with my baby?

By helping to care for your baby in the hospital you have been getting to know your baby and your baby has been getting to know you. Things that parents can do once you are home:

- Talk, read a book, or sing to your baby in a soft voice.
- Draw a picture with a black marker on a white piece of paper. Place it near your baby’s crib or infant seat while your baby is awake. Babies like to look at the contrasting colors.
- Touch and hold your baby closely to you.
- Carry your baby in a sling or pack in front of you.
- Lay on your side on the bed and place your baby down next to you so she can see your face. Babies love to look at faces and eyes.

Signals your baby may be getting tired

Premature babies are much more sensitive to stimulation.

- Turning away from you, or squirming
- Grimaces, yawning, sneezing or sticking her tongue out
- Faster breathing
- Crying or becoming irritable, maybe spitting up
- Skin color changes
- Straining as if to have a bowel movement.
- Arching of the neck and back

Remember that your baby needs to have short times of stimulation because she tires quickly. Refer to the “Timeout Signals” in the Growth and Development section.
How will I know if my baby needs something?

Premature babies may not always cry when they need something. Ways to tell if your baby may need something are:

- Squirming or moving their arms or legs, becoming more active in their crib
- Facial grimaces
- Crying

Crying Babies

Never, Never, Never Shake a Baby

There is probably nothing that gets to parents more than the sound of their baby crying. Continued crying can make parents feel frustrated, overwhelmed and angry. Out of that anger they may shake their baby.

Did You Know?

- Shaken Baby Syndrome is a medical term describing what can happen to an infant or small child when it is shaken violently or even when it's tossed playfully.
- Babies have heavy heads and weak neck muscles. Shaking makes their head flop back and forth causing their fragile brain to slam against the hard shell of their skull.
- Shaking a baby can cause brain damage, blindness, mental retardation, seizures or even death.

What can a Parent do?

- Check to see if the baby is wet, hungry or has a problem like a rash or if their clothes might be pinching.
- A pacifier may calm the baby.
- Try holding the baby in different positions and gently rocking her/him.
- Walk with the baby held close to you or in a stroller or take the baby for a ride in a car.
- Talk softly or sing to the baby.
- If you can’t quiet the baby and are feeling frustrated and angry, make sure the baby is safe and go into another room. Take a break, listen to soft music or call a friend.
- Talk to your health care provider if continued crying is a problem.
- Let your baby sitter and other caretakers know that they should not use physical punishment or shake your baby. Share these tips and what works for you.

For information or help (all calls are confidential)
In NH call Helpline, PAL at 800-852-3388 (1-800-727-3687) | In VT call 1-800-Parents
## Resources: Available Resources

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Utilizing Your Resources</td>
<td>112</td>
</tr>
<tr>
<td>ICN Parent Library</td>
<td>112</td>
</tr>
<tr>
<td>Resources within DHMC</td>
<td>112</td>
</tr>
<tr>
<td>Resources within the Community</td>
<td>114</td>
</tr>
<tr>
<td>State and Federal Services (NH and VT)</td>
<td>116</td>
</tr>
<tr>
<td>Useful Websites</td>
<td>118</td>
</tr>
</tbody>
</table>
Utilizing Your Resources

Many resources are available to help you deal with what is certainly a stressful time. Your whole life has been changed and you are sure to face many challenges in the weeks and months ahead. Do not be afraid to ask for help. There are many people who are willing to help you in many different ways. The only way they can be of assistance to you is if you ask.

The following pages are resources to help you discover the many private and public sources of support available to families. Please feel free to contact any of these agencies or groups, or speak to a social worker if you need further assistance.

ICN Parent Library

The ICN has a variety of information available to parents that include videos and books on prematurity, immunizations, cardiopulmonary Resuscitation (CPR), breast-feeding and many other subjects.

Please ask your baby’s nurse for information.

Resources within DHMC

Social Worker (603) 650-5789

The social worker is here Monday through Friday, from 8:30 am to 5:00 pm, with an office around the corner from the ICN Parent Waiting Room. On-call social work services are available evenings and weekends. The social worker tries to meet all of the parents whose babies are in the ICN. If you have not met her/him and wish to talk, ask the ICN receptionist or your baby’s nurse to help you make contact. You are also invited to stop by the social worker’s office.

The social worker will be able to assist with:

- **Counseling, support, and help in coping.** Many families are under stress when their babies are in the ICN. It can be helpful to talk about your feelings and how your baby’s hospitalization is affecting you and your family. The social worker can also assist in making referrals for in-depth counseling.

- **Finances/hospital bills.** These are often a major worry for parents. Any family from New Hampshire or Vermont can request a financial aid application called “Needed Services.” In addition, many families become eligible for New Hampshire or Vermont Medicaid once they have high medical bills, even if they have a stable income. Families can apply for Medicaid to supplement their commercial insurance. Both Vermont and New Hampshire have Medicaid programs for children needing special medical care at home. These programs are available regardless of family income. Also, many babies in the ICN qualify for SSI under Social Security (at least for a short while). The social worker will provide you with details about these programs.

- **Resource information and referrals.** Sometimes families are unemployed, and have landlord/housing difficulties, transportation that is not dependable, and family-parenting worries. The social worker can work with you to find solutions or refer you to someone in your own community who can help.
Chaplaincy (603) 650-7939

When a newborn is in the Intensive Care Nursery, parents and loved ones often desire and can benefit from the support services available on our ICN team. Our chaplains are a part of the ICN team that can assist you.

DHMC chaplains welcome the opportunity to visit and provide support to patients, parents, and families of all faiths and spiritual traditions, as well as those who do not affirm any particular religious or spiritual affiliation. If you would like a visit from a Chaplain, please inform your nurse or the ICN secretary who will then notify the Chaplaincy Department. You may also arrange a visit by calling the Chaplaincy office directly at 603-650-7939. You are welcome to stop by the Chaplaincy Office (Level 3 on the mall, next to the gift shop) as well.

A chaplain is a trained spiritual care professional who can:

- Provide emotional support to parents and families
- Help manage the stress of uncertainty and waiting
- Listen carefully and attentively to the concerns and worries of parents and loved ones
- Help parents and families find inner strength and courage
- Assist parents and families in thinking through problems
- Help parents and families find realistic sources of hope
- Pray with patients and families
- Provide spiritual guidance
- Help parents and families connect with leaders/members of their own religious group
- Help parents and families identify sources of distress and ways to address them
- Counsel parents and loved ones on questions of faith and life decisions
- Help manage feelings of fear and anxiety
- Provide supportive care in times of grief and crisis

Some parents wish to have their baby baptized. The hospital chaplain can provide this sacrament, or arrange for your own pastor to provide this service.

The chaplains offer an interfaith ministry with a goal to support you and your family, respecting your personal beliefs. A Roman Catholic priest and an Interfaith Chaplain are on-call at all times. If you need the services of a religious group not on our own staff, the Chaplaincy Office can help connect you with someone from our local community.

The Hospital Chapel is located on Level 3 of the Patient Towers, just off the main elevators. It is always open for quiet retreat, meditation, and prayer. Sacred books of many religious traditions are available in the chapel or by contacting the Chaplaincy office at 603-650-7939. Catholic Mass is held at noon on Tuesdays, Thursdays, and Holy Days, and at 11:00 am on Sundays. Mass is also televised on hospital channel 15.

Breast Feeding and Breast Pumps

If you would like to breastfeed your baby, or need assistance with pumping because your child is too small or too ill to breastfeed, please talk to your nurse and/or the Lactation Consultant. They can help you and your baby learn to breastfeed. They can also assist you with pumping until your baby grows and is feeling better, and can assist you in the rental of a breast pump.

There are videos and pamphlets about breast feeding and pumping that are available on the unit. Your nurse can help you with these.
Resources within the Community

Women’s Health Resource Center
On the Mall, 9 Hanover Street, Lebanon, NH
Monday – Friday | 9:00 am – 5:00 pm
(603) 650-2600

Since 1991, the Women’s Health Resource Center has welcomed many women seeking information and education about their health and the health of their loved ones. As a community service of Dartmouth-Hitchcock Medical Center, we are committed to promoting preventive care and respecting women’s wisdom in making informed health care decisions.

Their educators are available to answer your questions about childbirth preparation, postpartum care, and breastfeeding issues. They can help you find resources in the lending library, their classes and support groups, in the on-site boutique and the community.

CHaD Family Center/Molly’s Place
Level 6, DHMC
Monday – Friday | 9:00 am – 5:00 pm
Phone: (603) 653-9899
chadfamilycenter@hitchcock.org

The CHaD Family Center was created by families, for families.

We understand that caring for children who need medical care can be challenging for every member of the family. A child may see a pediatrician once a week for care, but families are home the rest of the time continuing that care.

It is essential for families to have resources to help them:

- Learn about the health care system
- Support siblings
- Teach their families about a chronic condition

March of Dimes
share.marchofdimes.org

A moderated online bulletin board for NICU families across the country. There are also links to other sites and resources within the March of Dimes community.
## ICN Medical Terms

<table>
<thead>
<tr>
<th>Term</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>AGA</td>
<td>(Appropriate for gestational age) A newborn is considered appropriate for gestational age if her birth weight is between the tenth and ninetieth percentiles on the standard growth curve for her age.</td>
</tr>
<tr>
<td>Alveoli</td>
<td>Tiny sacs in the lungs where oxygen and carbon dioxide are exchanged in the bloodstream.</td>
</tr>
<tr>
<td>Anemia</td>
<td>A low number of red blood cells.</td>
</tr>
<tr>
<td>Apnea</td>
<td>No breathing for longer than 20 seconds.</td>
</tr>
<tr>
<td>Arterial Blood Gas</td>
<td>Samples of blood from an artery to check the amount of oxygen, carbon dioxide and acid. This helps us to know how much help your baby needs with his breathing.</td>
</tr>
<tr>
<td>Atelectasis</td>
<td>This is a condition when some of the alveoli in the lungs are collapsed and can’t work efficiently.</td>
</tr>
<tr>
<td>Billi Lights (Phototherapy)</td>
<td>Bright lights used to treat jaundice.</td>
</tr>
<tr>
<td>Bilirubin</td>
<td>A yellowish substance produced in the blood when red blood cells break down. This is a normal process. In some infants this may cause jaundice, a yellowing of the skin.</td>
</tr>
<tr>
<td>Blood Gas</td>
<td>A sample of blood to check the level of oxygen, carbon dioxide, and acid in the blood.</td>
</tr>
<tr>
<td>Bradycardia (Brady)</td>
<td>A slower than normal heart rate in an infant. This is usually below 80 beats per minute.</td>
</tr>
<tr>
<td>Bronchopulmonary Dysplasia (Bpd)</td>
<td>Damage to the lungs that may occur in infants whose lungs are very immature and/or have to remain on a ventilator for several weeks or more.</td>
</tr>
<tr>
<td>Bronchospasm</td>
<td>Sudden constriction of the airways, resulting in difficulty breathing. May require treatment with albuterol, bagging, and may cause desaturation and bradycardia until episode resolves. Most common in infants who have been on a ventilator for sometime, or who have Chronic Lung Disease (CLD).</td>
</tr>
<tr>
<td>Central Line</td>
<td>An IV line that is threaded through a vein until it reaches a position as close to the heart as possible. Some medicines can only be given through a central line. A central line can sometimes stay in for several weeks or months. The medical team may suggest placing a central line if your baby is going to need an IV for a long time.</td>
</tr>
<tr>
<td>CBC (Complete Blood Count)</td>
<td>A blood test that counts the number and types of cells in the blood.</td>
</tr>
<tr>
<td>Chest Tube</td>
<td>A tube inserted into the chest to remove fluid or air that has collected and is interfering with your baby's ability to breathe.</td>
</tr>
</tbody>
</table>
**Chronic Lung Disease (CLD)**  
Same as Brochopulmonary Dysplasia (BPD).

**CPAP (Continuous Positive Airway Pressure)**  
Some babies can breathe on their own, but need a little help. The CPAP set-up helps to keep the small lung air sacs from closing when the baby breathes out. This means that he doesn’t have to work extra hard when he’s breathing. The CPAP is delivered through prongs that fit into the baby’s nose.

**Cyanosis**  
A blue or “dusky” color of the skin caused by a low amount of oxygen in the blood.

**Desaturation (Desat)**  
When the amount of oxygen in your baby’s blood is decreased. The oxygen saturation monitor measures this.

**Dextrostix (D-Stick)**  
A blood test to check the sugar in your baby’s blood.

**Diuretic**  
A medicine that increases the amount of urine. This medication is used at times to get rid of extra fluid that can cause swelling; a condition known as edema.

**Echocardiogram (Echo)**  
A picture of the heart using an ultrasound machine. This is a painless procedure.

**Edema**  
Fluid retention in the body tissues that causes puffiness or swelling.

**EEG (Electroencephalogram)**  
A recording of the electrical impulses of the brain.

**EKG (Electrocardiogram)**  
A recording of the heart’s electrical activity.

**Electrodes**  
Adhesive patch placed on the body connected to a wire to a monitor. It’s used to detect heart rate, respirations, or oxygen levels.

**Electrolytes (“Lytes”)**  
Minerals dissolved in the blood. Electrolytes are analyzed routinely by blood tests include sodium, potassium, chloride, and bicarbonate.

**Endotracheal Tube (ET Tube)**  
A thin plastic tube inserted through your baby’s mouth or nose and into his lungs, which is connected to a ventilator. This is used when babies are too small or sick to breathe without help.

**Extubation**  
The removal of the endotracheal tube.

**Feeding Tube**  
This is a small slender tube that is passed through your baby’s nose or mouth and into his stomach. It is used to give your baby breast milk or formula until he is old enough to suck and swallow his food. It may also be called a nasogastric (NG) or orogastric (OG) tube.

**Gavage Feedings**  
Feedings given through a tube passed through the nose or mouth into the stomach. Also called TUBE FEEDINGS.
<table>
<thead>
<tr>
<th>Term</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Heart Monitor</strong></td>
<td>This machine monitors your baby’s heart rate and breathing. Small patches are placed on your baby’s skin. These patches are called electrodes. These are attached to wires, which are then connected to the monitor. The monitor shows the how fast the baby’s heart is beating; the heart beat pattern, how fast the baby is breathing and the breathing pattern.</td>
</tr>
<tr>
<td><strong>Heelstick</strong></td>
<td>The procedure of pricking the baby’s heel to obtain a small amount of blood for testing.</td>
</tr>
<tr>
<td><strong>Hematocrit (HCT or CRIT)</strong></td>
<td>The percentage of red blood cells in the blood. This is used to check for blood loss or anemia.</td>
</tr>
<tr>
<td><strong>Lumbar Puncture (Spinal Tap, LP)</strong></td>
<td>Placing a hollow needle in between the bones of the spine. This may be done to remove some spinal fluid for testing.</td>
</tr>
<tr>
<td><strong>Magnetic Resonance Imaging (MRI)</strong></td>
<td>A patient is placed in a scanner which uses magnetic fields to generate cross-sectional images of the head or body.</td>
</tr>
<tr>
<td><strong>Metabolic</strong></td>
<td>There are processes that occur in the body that help with the breakdown of food and its transformation into energy. Your body produces different components that do this. If your baby is missing one of these components, he could become very ill. This is called a metabolic disorder. The state requires that we test all infants for some of the more common metabolic disorders. This is a blood test and it will be done before your baby is discharged from the ICN. If the results are abnormal, you and your home doctor will be notified.</td>
</tr>
<tr>
<td><strong>Nasal Cannula</strong></td>
<td>Small plastic tubing that brings oxygen to your baby when he needs it. There are small prongs on one end that fit into the baby’s nose. The oxygen is delivered through a cool water bubbling system. Sometimes babies need more support and may require high flow nasal cannula with warmed, humidified oxygen.</td>
</tr>
<tr>
<td><strong>Non-Invasive Positive Pressure Ventilation (NIPPV)</strong></td>
<td>Some babies may not require a breathing tube in their trachea (wind pipe) but still need assistance to breathe from the ventilator. Small, soft prongs are placed in each nostril. The prongs are attached to tubing which is hooked up to the ventilator. This is referred to as NIPPV (Non-Invasive Positive Pressure Ventilation).</td>
</tr>
<tr>
<td><strong>Necrotizing Enterocolitis (NEC)</strong></td>
<td>An inflammation in the intestines (usually the colon) that can be life-threatening if not treated right away. NEC may affect only the lining of the intestine or its entire thickness. The damage caused by NEC to the intestinal tissues can cause a hole in the intestines that allows the bacteria normally present only in the intestinal tract to leak out into the abdomen and cause infection. Once this occurs, the infection can progress very quickly and is considered a medical emergency.</td>
</tr>
<tr>
<td><strong>Neonatology</strong></td>
<td>The art and science of caring medically for the newborn.</td>
</tr>
<tr>
<td><strong>Patent Ductus Arteriosus (PDA)</strong></td>
<td>A condition, common in premature infants, in which the ductus (the fetal blood vessel that connects the pulmonary artery to the aorta) fails to close after birth.</td>
</tr>
</tbody>
</table>
Percutaneous Central Venous Catheter (PCVL)

Also sometimes called PICC line or percutaneously inserted central catheter. This line is like an IV and is often placed by one of our nurse practitioners. It is usually inserted into a vein in the antecubital space, which is the inside of the elbow area. It can stay in longer than a regular IV.

Persistent Pulmonary Hypertension Of The Newborn (PPHN)

The persistence, after birth, of a pattern of circulation typical of the fetus in which the blood bypasses the lungs through the PDA and/or foramen ovale (PFO). This shunting causes lower amounts of blood to reach the tissues.

Phototherapy (Bili Lights)

These are special lights that help your baby recover from jaundice. The baby's clothes are removed so he will get the most light. The lights are most effective when kept on most of the time. His eyes are covered with patches for protection.

Platelets

Elements in the blood that are needed for proper clotting.

Pneumothorax (Pneumo)

A collection of air in the chest caused by air leaking from the alveoli. If this occurs, your baby may need a chest tube to remove the air.

Panda Room

Most babies who come into the ICN from the Birthing Pavilion are first examined in the PANDA Room. This stands for Premature And Newborn Diagnostic Area. The ICN Care Team evaluates and examines your baby there. The team ensures that your baby is stable before she is moved into the ICN.

Pulse Oximeter (Pulse Ox)

This machine helps to monitor how well your baby is using the oxygen that he is breathing. There is a long cord that has a sensor and a small light at the end. It is taped to your baby, usually on his finger, toe, or foot.

Respiratory Distress Syndrome (RDS)

Respiratory distress that affects premature babies. It is caused by a lack of surfactant, which make it difficult for the aveoli to open and close.

Red Blood Cell (RBC)

The type of blood cell that carries oxygen to and carbon dioxide from the tissues.

Reflux

The movement of stomach contents up into the esophagus. It is nearly universal among infants. If excessive, reflux can cause apnea, bradycardia, and pneumonia. It may be treated with medications.

Residuals

The amount of undigested milk left in the stomach. This may be checked when the next feeding is due to be given by pulling back on the feeding tube with a syringe. It is one way to check if the baby is tolerating the feeds.

Room Air

We can adjust the level of oxygen that we give your baby from 21% to 100%. The amount of oxygen in the air that we usually breathe is 21%. This is called room air.

Rounds

Conducted each morning in the ICN, all aspects of care for all of the ICN patients are discussed in detail between the attending neonatologist, the nurse practitioners, residents, and nurses. This is when plans of care are decided upon.
<table>
<thead>
<tr>
<th>Term</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Saturation (O2 Sats)</td>
<td>An indication of the amount of oxygen in your baby’s blood.</td>
</tr>
<tr>
<td>Sepsis</td>
<td>The presence of bacteria in your baby’s blood that is causing him to become sick.</td>
</tr>
<tr>
<td>Sepsis Work-Up</td>
<td>A series of tests to check for the presence of an infection.</td>
</tr>
<tr>
<td>SGA (Small For Gestational Age)</td>
<td>A newborn is considered small for gestational age if her birth weight is below the tenth percentiles on the standard growth curve for her age.</td>
</tr>
<tr>
<td>Suction Catheter</td>
<td>A small tube is used to remove mucus from your baby’s nose, mouth, throat or endotracheal tube. The use of suction helps keep your baby’s breathing passages clear and makes him more comfortable.</td>
</tr>
<tr>
<td>Surfactant</td>
<td>A substance formed in the lungs that helps to keep the small air sacs or alveoli, from collapsing and sticking together. If a baby is not able to produce his own surfactant, we can give him some surfactant.</td>
</tr>
<tr>
<td>Tachycardia</td>
<td>An abnormally fast heart rate. In an infant this is usually above 180 beats per minute.</td>
</tr>
<tr>
<td>Tachypnea</td>
<td>An abnormally fast breathing rate. In an infant this is usually above 60 breaths per minute.</td>
</tr>
<tr>
<td>Transport Team</td>
<td>If your baby is brought to the ICN from another hospital, a transport team was sent to pick her up. If she came to the ICN by ambulance, the team is usually made up of a team leader, a nurse, a respiratory therapist, and an EMT/ambulance driver. If she arrives by helicopter, there is usually a respiratory therapist, an ICN nurse and the pilot.</td>
</tr>
<tr>
<td>Total Parenteral Nutrition (TPN)</td>
<td>If your baby is not yet ready for food, or unable to eat, it is still important that he get the nutrients and calories he needs to grow. TPN refers to IV nutrition. The calories, protein, vitamins and minerals that your baby needs are given through the IV. (see intralipids)</td>
</tr>
<tr>
<td>Transcutaneous Monitor (TCM)</td>
<td>This machine has sensors that can help monitor the oxygen and carbon dioxide level in your baby’s blood. A small circular piece attaches to the skin with a special adhesive.</td>
</tr>
<tr>
<td>Ultrasound</td>
<td>Inaudible sound waves that have a different velocity that vary with tissue density and shape. By using ultrasound it can outline the shape of various tissues and organs in the body. It is often used for on babies through the fontanel.</td>
</tr>
<tr>
<td>Umbilical Catheter</td>
<td>A small plastic tube may be inserted into a vein or artery in your baby’s belly button. This tube can be used to give your baby fluids or to remove blood samples. It can also be used to measure your baby’s blood pressure. Abbreviations used to describe this are UAC (umbilical artery catheter) and UVC (umbilical venous catheter).</td>
</tr>
<tr>
<td><strong>Ventilator</strong></td>
<td>Some babies need more help to breathe when they are premature or sick. This is a machine that helps them. A tube called an endotracheal, or ET tube is placed through your baby's mouth or nose and into his lungs. The machine sends the air in and out of his lungs at the rate and pressure that he needs. As your baby changes, the rate and pressure set on the ventilator will also change. There are different types of ventilators and your baby will be using the one that works best for him.</td>
</tr>
<tr>
<td><strong>Vitamin K</strong></td>
<td>Vitamin K helps the liver produce substances that are important in blood clotting. Generally, the bacteria in the intestine produce enough Vitamin K for our use. However, newborns lack the intestinal bacteria. We give Vitamin K shortly after birth to prevent complications from a deficiency such as prolonged bleeding.</td>
</tr>
<tr>
<td><strong>Warmer</strong></td>
<td>These are special beds that help keep your baby warm until he is bigger and can stay warm without a lot of help. A warmer is open with heaters above the baby. (See Isolette)</td>
</tr>
<tr>
<td><strong>White Blood Cells (WBC)</strong></td>
<td>Blood cells that fight infections.</td>
</tr>
</tbody>
</table>
Medical Abbreviations

The world of neonatal intensive care has a language all its own. Many diseases and therapies are abbreviated. Common abbreviations are listed below. If your baby’s nurse or doctor uses a word you do not understand, please ask.

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>A&amp;B</td>
<td>Apnea and Bradycardia</td>
</tr>
<tr>
<td>Ad Lib</td>
<td>As desired or as needed</td>
</tr>
<tr>
<td>Bagging</td>
<td>The use of a rubber bag connected to an oxygen supply (ambu bag) which is squeezed by hand to deliver oxygen into the lungs via a face mask or endotracheal tube.</td>
</tr>
<tr>
<td>BP</td>
<td>Birthing Pavilion or Blood Pressure</td>
</tr>
<tr>
<td>BPD</td>
<td>Bronchopulmonary dysplasia</td>
</tr>
<tr>
<td>CDL</td>
<td>Chronic Lung Disease</td>
</tr>
<tr>
<td>CNS</td>
<td>Clinical Nurse Specialist or Central Nervous System</td>
</tr>
<tr>
<td>CPAP</td>
<td>Continuous Positive Airway Pressure</td>
</tr>
<tr>
<td>CPR</td>
<td>Cardio-Pulmonary Resuscitation</td>
</tr>
<tr>
<td>CPT/CHEST PT</td>
<td>Chest Physical Therapy</td>
</tr>
<tr>
<td>CT (CAT)</td>
<td>&quot;Cat Scan&quot;, computed Tomography</td>
</tr>
<tr>
<td>ECG</td>
<td>Electrocardiogram</td>
</tr>
<tr>
<td>ECHO</td>
<td>Echocardiogram</td>
</tr>
<tr>
<td>EEG</td>
<td>Electroencephalogram</td>
</tr>
<tr>
<td>ET</td>
<td>Endotracheal</td>
</tr>
<tr>
<td>ICN</td>
<td>Intensive Care Nursery</td>
</tr>
<tr>
<td>ID</td>
<td>Infectious Disease or identification</td>
</tr>
<tr>
<td>IV</td>
<td>Intravenous</td>
</tr>
<tr>
<td>IVH</td>
<td>Intraventricular Hemorrhage</td>
</tr>
<tr>
<td>Abbreviation</td>
<td>Definition</td>
</tr>
<tr>
<td>--------------</td>
<td>------------</td>
</tr>
<tr>
<td>LP</td>
<td>Lumbar Puncture</td>
</tr>
<tr>
<td>MRI</td>
<td>Magnetic Resonance Imaging</td>
</tr>
<tr>
<td>NEC</td>
<td>Necrotizing Enterocolitis</td>
</tr>
<tr>
<td>NG</td>
<td>Nasogastric</td>
</tr>
<tr>
<td>NPO</td>
<td>nothing by mouth</td>
</tr>
<tr>
<td>OG</td>
<td>Orogastric</td>
</tr>
<tr>
<td>OT</td>
<td>Occupational Therapy</td>
</tr>
<tr>
<td>PCVL</td>
<td>Percutaneous central venous catheter</td>
</tr>
<tr>
<td>PDA</td>
<td>Patent Ductus Arteriosus</td>
</tr>
<tr>
<td>PICC</td>
<td>Percutaneously Inserted Central Catheter</td>
</tr>
<tr>
<td>PO</td>
<td>Taken by mouth</td>
</tr>
<tr>
<td>PT</td>
<td>Physical Therapist</td>
</tr>
<tr>
<td>RN</td>
<td>Registered Nurse</td>
</tr>
<tr>
<td>ROP</td>
<td>Retinopathy Of Prematurity</td>
</tr>
<tr>
<td>RDS</td>
<td>Respiratory Distress Syndrome</td>
</tr>
<tr>
<td>RT</td>
<td>Respiratory Therapist</td>
</tr>
<tr>
<td>TPN</td>
<td>Total Parenteral Nutrition</td>
</tr>
<tr>
<td>TTNB</td>
<td>Transient Tachypnea of the Newborn</td>
</tr>
<tr>
<td>UAC</td>
<td>Umbilical Artery Catheter</td>
</tr>
<tr>
<td>UTI</td>
<td>Urinary Tract Infection.</td>
</tr>
<tr>
<td>UVC</td>
<td>Umbilical Venous Catheter</td>
</tr>
<tr>
<td>VS</td>
<td>Vital Signs</td>
</tr>
</tbody>
</table>
Notes/Questions for Team
Notes/Questions for Team
Notes/Questions for Team
Notes/Questions for Team


