

Transitioning to a Community Nursery

FLOATING HOSPITAL FOR CHILDREN SPECIAL CARE NURSERY PARTNERS:

Lowell General Hospital

295 Varnum Ave.
Lowell, MA 01854
Main 978-937-6000; SCN 978-937-6032
Director – Dr. Mario Cordova

Lawrence General Hospital

One General Street
Lawrence, MA 01842
Main 978-683-4000, SCN X-2662
Director – Dr. Francheyska Silfa Mazara

Melrose-Wakefield Hospital

585 Lebanon St.
Melrose, MA 02176
Main 781-979-3000; SCN 781-979-6400
Director – Dr. Karen Harvey-Wilkes

Jordan Hospital

275 Sandwich Street
Plymouth, MA 02360
Main 508-746-2000, SCN 508-830-2215
Director – Dr. Laurie Konowitz

Brockton Hospital

680 Center St.
Brockton, MA 02302
Main 508-941-7000; SCN 508-941-7617
Director – Dr. H. Ozlem Kasaroglu

MetroWest Medical Center

115 Lincoln St.
Framingham, MA 01701
Main 508-383-1000; SCN 508-383-1474
Director – Dr. Geoff Binney

Please note the hospital you wish your baby to be transferred to is not limited to the ones listed above. As long as the community hospital is comfortable with your baby's level of care and it is approved by your insurance we can bring your baby to many hospitals in the area.

Many babies may overcome their acute medical or surgical illness but still are not quite ready to leave a hospital. These babies no longer require intensive care yet need to complete medical treatment, learn how to breast or bottle feed, or simply gain weight before going home.

If you don't live nearby, this is when your baby will be "reverse" transported to the community hospital closest to your home. Generally this is the hospital where you delivered or planned to deliver. In several area community hospitals, the same group of doctors who are caring for your infant here at the Floating Hospital for Children runs the special care nursery. If you live near Tufts Medical Center, or if this was the hospital you chose to deliver at, your baby will stay here at the Floating Hospital until they are ready to go home.

If your baby is moving back into the community this should be a positive and happy moment. Moving your baby closer to home will allow you to spend more time with your baby and much less time traveling to and from Boston. Parking is usually free, the cost of food is less and your baby is one step closer to going home. It is not uncommon for you to be concerned, worried or fearful about your baby leaving the NICU here at the Floating. You have grown to know and trust the staff here and you are used to the way our unit operates. When faced with the idea of moving to a new nursery with new nurses and new routines, it can be scary and frightening. We do understand your fears, but remember we too were strangers once.

When your baby is "reverse" transported to a community hospital, he/she will be taken by ambulance in an isolette. A nurse from the NICU will accompany your baby. You will be informed of the time when your baby should be arriving at the community hospital so you may make arrangements to meet your baby there if you would like.

Some parents like to contact the community hospital to visit the nursery prior to the transfer. You should also feel free to request to meet with a member of the medical or nursing staff of the nursery so that you can feel comfortable with your baby's next move. If you have concerns or questions about this transition, please do not hesitate to discuss it with your baby's primary nurse, nurse practitioner or doctor.

Discharge/Going Home

Most parents can expect their baby to be ready to go home, right around the baby's original due date. While this holds true in many instances, it is not a guarantee. There are several milestones, or criteria that a baby must meet before discharge. It is important for you to also remember that these guidelines for discharge are general guidelines. Each baby is different and your baby's doctor will look at him or her as an individual when deciding on the right time for going home.

- ▶ One of the biggest obstacles a baby faces before going home is good, consistent weight gain. There really is no magic number of ounces or pounds your baby has to gain, he or she needs to be showing a trend in gaining weight.
- ▶ Most babies will have made a complete transition to all bottle or breast feedings.
- ▶ Your baby must also be able to keep warm when placed in a crib or bassinette.
- ▶ If your baby has been monitored for "spells", most doctors require a baby to be spell free for at least 5–7 days before discharge.
- ▶ While not always the case, most babies will also be off oxygen.
- ▶ You must also have identified and made an appointment with your baby's private pediatrician for follow-up care. Generally this first pediatric appointment is within the first few days after discharge from the hospital.
- ▶ Finally, you as parents must feel comfortable with caring for your baby.

If your baby requires specialized equipment at home, all of this will be discussed with you in detail. Assistance in obtaining this equipment is provided to you by our discharge coordinator and your baby's nursing and medical staff. Delivery of equipment to your home and individualized teaching on how to use this equipment is coordinated with you and the home care company.

Resources

HELPFUL BOOKS

- ▷ *Preemies: The Essential Guide for Parents of Premature Babies 2nd Edition*; Linden D., Paroli E., and Doron M., Pocket Books, a division of Simon & Schuster Inc, 2010. An excellent general information book for parents and prospective parents of premature and/or multiple birth babies.
- ▷ *Your Premature Baby and Child: Helpful Answers and Advice for Parents*; Tracy A., Maroney D., Bernbaum J., Groothuis J., Berkley, 1999. Another excellent general information book for parents.
- ▷ *Your Premature Baby: Everything You Need to Know about Child Birth, Treatment, and Parenting*; Manginello F. and DiGeronimo T., Wiley, 1998. A reference for medical and practical issues of having a premature baby.
- ▷ *Kangaroo Care: The Best You Can Do to Help Your Preterm Infant*; Laudington-Hoe S. and Golant S., Bantam Books, 1993.
- ▷ *Breastfeeding Premature Babies*; La Leche League's Lactation Consultant Department, available from the Birth and Life Bookstore.
- ▷ *Baby Talk and Special Beginnings*; Johnson J., Johnson M., Hatcher D. and Lehman K., Centering Corporation, 2000. Talks about feelings that parents of babies who are hospitalized in an intensive care unit may experience and offers practical suggestions.
- ▷ *Loving and Letting Go*; Davis D. Available from Centering Corporation. For those parents who decide to turn away from aggressive medical intervention for their critically ill newborn.

BOOKS WRITTEN FOR SIBLINGS:

- ▷ *Special Care Babies*; Althea, Parkwest Publications, 1986.
- ▷ *Katie's Premature Brother*; Hawkins-Walsh E., Ryan J., Centering Corporation, 1990.
- ▷ *No Bigger Than My Teddy Bear*; Panlow V, Family Books, 2004.

BOOKS FOR FAMILIES WITH CHILDREN WITH SPECIAL NEEDS

- ▷ *A Difference in the Family*; Featherstone H., Penquin Books, 1981. The mother of a child with disabilities writes about how a child's disability affects the family. She includes information about her own experiences as well as those of other families, professionals and people with disabilities themselves.
- ▷ *After the Tears*; Simons, R., Harvest Books, 1987. Describes the impact of a child's disability on family members and offers practical coping ideas.
- ▷ *Exceptional Parent Magazine*. For information contact: Exceptional Parent, 120 State Street, Hackensack, N.J. 07601-5421; 1-800-247-8080; www.eplibrary.com. Written for parents of children with special needs. Many of the articles are written by parents.
- ▷ *Profiles of the Other Child: A Sibling Guide for Parents*; McCaffrey, F. W. and Fish, T. Available from The Nisonger Center, Publication Department, 1581 Dodd Drive, Columbus, Ohio, 43210-1205. Addresses siblings of children with special needs.
- ▷ *Living with a Brother or Sister with Special Needs*; Meyer D. and Vadasy P., University of Washington Press, 1996.

WEBSITES AND AGENCIES

- ▷ March of Dimes Share Your Story. On-line parent to parent community. www.shareyourstory.org
- ▷ Family Voices—Advocacy and information for families of persons with special needs. State and regional coordinators. Parent-to-parent support. (888) 835-5669. www.familyvoices.org
- ▷ The Association for Retinopathy of Prematurity and Related Diseases (ROPARD)—Provides information and resources regarding retinopathy of prematurity (ROP) and related conditions. www.ropard.org
- ▷ Pediatric/Adolescent Gastroesophageal Reflux Association (PAGER)—Provides information and support regarding reflux. www.reflux.org
- ▷ The Federation for Children with Special Needs. An excellent resource for information related to caring for a child with special needs. 617-236-7210. www.fcsn.org
- ▷ National Organization of Rare Disorders (NORD). 1-800-999-6673. www.raredisorders.org
- ▷ Disability Law Center. Provides legal advice and information for people with disabilities. 617-723-8455 or 1-800-872-9992. www.dlc-ma.org
- ▷ Handicapped Parking Placard: Contact local Registry of Motor Vehicles for application.
- ▷ The Department of Public Health. Provides information and referrals for children with special health care needs. 1-800-882-1435.
- ▷ Parental Stress Line: 1-800-632-8188. Trained volunteer counselors are available by phone 24 hours a day to talk with parents who are feeling stressed, lonely or angry. In Spanish, 1-617-421-1789.
- ▷ National Domestic Violence Hotline: 1-800-799-SAFE, or 1-800-799-7233.
- ▷ 24 Hour Battered Women's Hotline: 1-800-992-2600.
- ▷ WIC (Women Infants and Children) provides food and nutritional education for eligible women, infants, and children less than 5 years of age. For further information and for the office in your area, call 1-800-WIC-1007.
- ▷ La Leche League—For breastfeeding support. 617-298-2540. www.lalecheleague.org.
- ▷ Triplets, Moms & More. For families with triplets, quadruplets, or more, this local organization offers networking with other families and information about resources. 1-339-927-2365 or www.tripletsmomsandmore.org.
- ▷ March of Dimes—provided information while in the NICU and beyond. www.marchofdimes.com/inthenicu

Baby Essentials

FOR THE RIDE HOME:

- Traveling outfit from hospital to home
- Infant car seat
- Diaper Bag (see “diaper bag” for contents)

CLOTHING AT HOME:

- 6–8 pajamas (with feet)
- 6–8 t-shirts/onesies with snap at diaper area
(Mix of short and long sleeve)
- 2 sweaters
- 5 pairs pants
- 2 hats
- 4 pairs of socks or booties
- 4–6 receiving blankets
- Swaddling sleep sack (optional)
- Snowsuit for cold weather

DIAPER BAG

- 5–6 diapers
- diaper wipes
- 2 changes of clothes
- Extra pacifier
- bibs
- Pediatrician name and phone number
- Other doctors name and phone numbers
- List of baby’s medication
- Receiving blanket
- If formula feeding — enough bottles for expected length of outing
- If breastfeeding extra breast pads

BATH/CHANGING TABLE

- 3–4 dozen weight appropriate diapers
- Baby wipes (to clean diaper area)
- Diaper rash cream
- Changing table or mat
- Baby size nail clippers
- Baby size bath tub
- Mild soap for bathing
- 6 washcloth
- 2 towels with hoods
- 2–3 pacifiers

FEEDING

If you will be using bottles try to find bottles that are “phthalate free” & BPS free

- 3–4 8oz bottles
- 3–4 4oz. bottles
- 3–4 bibs
- bottle/nipple cleaning brush
- If Formula feeding: enough formula for one week
- If Breastfeeding: nursing/brat pads, Lanolin ointment
- If using a breast pump: storage bags/containers for breastmilk

NURSERY

- Crib or bassinet or co-sleeper (with no bumpers)
- 2 fitted sheets
- Light weight blanket
- Night light
- Monitor if baby will be separate room

The Neonatal Intensive Care Unit (NICU) Follow-up Program

WHAT IS THE NICU FOLLOW-UP PROGRAM?

Your child has overcome many obstacles in the NICU. Our support and care for your child does not stop once you leave our hospital. The purpose of our NICU Follow-Up Program is to provide ongoing evaluation and guidance during the first 3 years of life for children at high-risk for developmental delays. Our mission is to make sure that each child is developing to the best of his/her ability. We believe that the potential for each child has no boundaries, and we are constantly pleased at how well our NICU graduates do. National guidelines recommend that hospitals with a NICU have follow-up programs to monitor progress after a child goes home.

**NICU
FOLLOW-UP
CLINIC
TELEPHONE
LINE:
617-636-0056**

Which babies attend the NICU Follow-up Program?

We routinely see infants who were born very premature, weighing less than 1250 grams (2 pounds 12 ounces) at birth; infants with a variety of complications including bleeding in the brain, breathing problems, certain infections and birth defects; or any infant that a pediatrician has developmental concerns about.

**DIRECTOR:
ELISABETH
MCGOWAN, MD**

Who will see my child?

Our team consists of a medical director, fellows (pediatricians obtaining additional training to specialize in newborn medicine or infant development), a clinical coordinator, a physical and occupational therapist, and a NICU nurse.

What happens during a NICU Follow-Up appointment?

A neonatologist and fellow evaluate your child's health, growth, and development. An occupational or physical therapist conducts standardized testing to see how well your child thinks, moves and talks. At the end of each appointment, we summarize our results for parents, provide suggestions, answer questions and give parents educational handouts to help improve their child's development at home. A detailed report of testing results and recommendations is sent to the parents, the pediatrician and if the child receives early intervention services, an early intervention program. We also help coordinate specialist appointments, including pulmonary, neurology, neurosurgery, gastroenterology/nutrition, ophthalmology and otolaryngology.

How often does my child attend the NICU Follow-up Program?

After your child goes home, the first visit is usually at 6 months of age, corrected for prematurity (6 months after when your baby would have been born if not born early). Visits are scheduled approximately every 6 months until 3 years of age.

Is there a measure of success? If so, what is it?

Our success is making sure that children have all of the support services they need to enable the best development possible.

RESEARCH

Some patients enrolled in research studies when in the NICU and we follow their progress. We also contribute to a national research database of information about the development of babies born premature. This information is used to understand the most effective medical care for the best growth and development of premature babies. If your child is eligible to be a part of the national study, you will be invited to participate. Research is always voluntary and it is OK to decide not to participate.