



About NICU Journeys

Welcome to the first issue of "JOURNEYS". "Journeys" was created to bring you updates and news from the Klarman Family Newborn Intensive Care Unit (NICU) at Beth Israel Deaconess Medical Center (NICU), its staff, and its families – past, present and future! We hope to publish Journeys at least twice a year, with each issue highlighting new programs and initiatives that are supporting families during their NICU journeys, celebrating the many milestones of those who have journeyed beyond the NICU, and sharing ideas on how you can get involved as a NICU Graduate Family.

We welcome your feedback to make Journeys a resourceful, inspirational and motivational tool, and look forward to your many contributions to the newsletter in the form of letters, photos, stories, and suggestions.

Inside this Issue

- Chief's Corner, Reflections from Dr. DeWayne Pursley, Chief of Neonatology
- NICU Happenings:
NICU C.A.R.E.S. for Families
- NICU Staff Spotlight
- NICU Family Spotlight
- What's New in the NICU?
- Volunteer Opportunities
- Giving Opportunities

Klarman Family NICU 15th Anniversary Reunion

This past November the Klarman Family NICU celebrated its 15th Anniversary with a very special NICU Family Reunion. Former NICU families and their children, ranging from a few months old to 15 years old, reunited with BIDMC NICU doctors, nurses, respiratory therapists, social workers, occupational therapists and many other NICU staff. Attendees were treated to a multitude of festivities including clowns, music performances, stilt-walkers, arts and crafts, games, and of course, birthday cake! Many elements of the NICU were brought "to life" at the reunion, including a video featuring staff unable to attend (they were working!), the NICU Hall of Hope, a photo gallery featuring photos and stories of former BIDMC NICU children, and a display of the recently launched NICU C.A.R.E.S. for Families programs and initiatives. The Reunion also included a fundraising silent auction and raffle, which brought in nearly \$6,000.

Most memorable, however, were the smiles on the faces of parents, children and NICU staffers alike, as they exchanged stories, hugs, thanks and appreciation for how far they've come since their time in the NICU. The NICU staff still talks of this special day, sharing with those unable to come the stories and memories of such unforgettable families and children.



A special thanks
to Beth Klarman and
Elyse Rubin, who were
co-chairs for the NICU's
15th Anniversary
Celebration event.

Klarman Family
NICU 15th
Anniversary
Reunion



Photos by Justin Knight
and Mark Whalen



Chief's Corner

by DeWayne Pursley, MD, Chief of Neonatology



It's hard to believe that the BIDMC NICU, as we know it, has just celebrated its 15th Birthday. Over the past 15 years, the field of newborn medicine has seen great strides with new technologies, that have improved outcomes for the tiniest and sickest babies. What hasn't changed, however, is the compassionate care that our staff continues to give not only the babies, but the families who journey through our Unit. For those of you who joined us at last November's 15th Anniversary Reunion celebration, the smiles, hugs and animated conversations were testament to the impact of that compassionate care. In the past three years, the BIDMC NICU has taken its commitment to families to a new level, with the creation of NICU C.A.R.E.S. for Families, a multi-faceted program that provides emotional and social support for parents, siblings, grandparents and extended family before, during and after their baby's

hospitalization. This program has far-reaching goals, and thanks to a generous endowment gift from Josh and Anita Bekenstein, NICU C.A.R.E.S. for Families will serve our families for many years to come. As we embark on the next 15 years of advances – in medicine, technology, and compassionate care – we hope that you'll continue to support the NICU financially, and share with us your talents, your photos, your stories. Often, nothing is more inspirational to a current NICU family than a graduate NICU family... seeing and hearing that you made it through this journey gives them hope that they too will make it, and have stories of their own to share, reunions to attend, and future NICU families to help.

Best wishes, best of health,
DeWayne Pursley

Who Cares? NICU C.A.R.E.S. for Families!

BIDMC's NICU C.A.R.E.S. for Families is a comprehensive program with a mission to humanize and normalize the NICU experience for families before, during, and after their NICU experience by offering them a wide variety of programs designed to support their emotional, social, and educational needs.

The program was developed three years ago in direct response to family satisfaction surveys and ongoing feedback from NICU families.

Some examples of how NICU C.A.R.E.S. for Families fosters a sense of hope and community for NICU families include:

- **Parent-to-Parent Mentors**— trained volunteer mentors who have “been there” are available to lend an empathetic ear to current NICU families and help them navigate the NICU journey.
- **NICU Binders/Information Packets** — Addressing the informational needs of NICU families, special binders/folders have been developed, and can be customized by the families and staff to address specific issues encountered during the NICU journey. The packet also incorporates information to help the family emotionally, and offers perspectives from NICU graduate families.
- **Scrapbooking Workshops** that enable parents to create meaningful tributes to their baby's time in the NICU.
- **Coffee Connection events**, communal coffee hours (and in the summer, Ice Cream socials!) for families to informally meet a graduate parent, each other, and share experiences.
- **Welcome Packages** — Thanks to the generosity of a former NICU family who donated hundreds of disposable cameras, NICU C.A.R.E.S. has been able to provide welcome packages with the cameras and photo albums, reminding families that despite the gravity of the situation, the baby's arrival is something to celebrate. We are presently offering insulated bags and water bottles as part of our welcome package.
- **Special Photo Days** are held throughout the year to commemorate special occasions such as Halloween (when the babies get to “dress up”!), Winter Holidays, and Valentines Day. A very popular event for families and staff alike!
- **Hall of Hope** — In October 2006, the NICU opened its first art exhibit which lines the hallways outside of the NICU. The Hall of Hope features the stories and photos (NICU and current) of 11 former BIDMC patients, detailing their NICU experience and beyond, offering hope to current NICU families with their inspirational journeys.
- **NICU Parent Connection** (Coming Soon!) — Although most families dream about bringing their babies home from

the NICU, they are also anxious and fearful about leaving the safety net of clinical care, equipment, and expertise. To soften anxieties and ease the transition- to-home, NICU C.A.R.E.S. matches newly discharged NICU families with graduate families who maintain a weekly phone support relationship through the parent-to-parent mentoring program. Connecting parents with local playgroups designed especially for families that have experienced newborn intensive care services is another way that NICU C.A.R.E.S. helps families develop community after they leave the security of the NICU.

- **The Newborn Cuddling Program** comprises a specially trained group of volunteers who hold and rock babies at times when parents are unable to be in the hospital.
- **NICU Memorial Service** — In March 2007, the BIDMC NICU held its first Memorial Service, honoring and celebrating the short lives of babies who died and offering their families community, comfort, and peace. We plan to hold a NICU Memorial Service bi-annually.

NICU C.A.R.E.S. for Families is a program created specifically for the Klarman Family Newborn Intensive Care Unit at Beth Israel Deaconess Medical Center. Our mission is to sustain and expand this comprehensive, compassionate and family centered program in order to build confidence and empower more families to be involved in their baby's care, which translates into better outcomes for the babies both in the NICU and beyond. It is our belief that a parent who feels confident and empowered, understands how to advocate for their child, and knows where to find resources or a sounding board for frustrations, is in a much better position to care for baby than one without these skills and capabilities both in the NICU and when they return home.

NICU C.A.R.E.S. for Families relies heavily on volunteers to share their time and talents – if you are interested in helping out with any of the programs above, please contact Kelly Fitzsimmons at 617-667-3247 or kfitzsim@bidmc.harvard.edu. We are also always in need of monetary donations for Welcome Packages, Scrapbooking Workshops and other items not covered by the hospital's operating budget.

NICU Staff Spotlight – Respiratory Therapists

If your child spent any time on a ventilator, CPAP, or oxygen while in the NICU, chances are you got to know the BIDMC NICU Respiratory Therapists (RTs) pretty well. This exceptional group is comprised of 9 clinicians, most of whom have worked in the BIDMC NICU since it opened in 1992: Nina Koyama, Glen Housefield, Steve Hamilton, Brenda Lurie, Eileen Malala, Denise McGarry, Jessica Metzger, Annemarie Spada, Kyle Spear and Candy Buckley.

Respiratory Therapists clearly play a crucial role in the Delivery Room and NICU alike. They attend all preterm and high-risk deliveries, where they assess breathing and related therapies to assist breathing. Once a baby is in the NICU, Respiratory Therapists help manage the babies' care as it relates to breathing, including ventilator support (Hi-Fi, conventional ventilator), CPAP (continuous positive airway pressure) and oxygen via nasal canula. As part of the care team, RTs assist with decisions on weaning and extubation as well. Equally important, the RT's are an critical liaison for families – helping to educate them on their babies' respiratory needs and progress, answering questions, explaining the complicated equipment and supporting them through an often difficult and uncertain time. The BIDMC NICU RT's receive advance training, are board certified, and are up-to-date on the latest respiratory advances, including new technologies such as blended oxygen and bubble CPAP, which are both used in the NICU.



NICU Respiratory Therapists Nina Koyama and Candy Buckley

We want to hear from you!

Send us your photos, stories, poetry, drawings to be published in a future issue of NICU Journeys! Please email or mail them to:

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330 Brookline Drive
NICU, Reisman 9
Boston, MA 02215

*Please note that photos and artwork cannot be returned, and that by submitting them, you give full permission to Beth Israel Deaconess Medical Center to use them in the NICU Journeys Newsletter.

NICU Volunteer Opportunities

There are many ways to get involved with the BIDMC NICU, and as you can see by reading this newsletter, many of the programs that we have, we rely heavily on volunteers to keep things going, and keep things fresh.

As a graduate family, your NICU experience goes a long way, you've been in the trenches, and many of you are still on journeys you never imagined. If the time is right – and it may not be – consider volunteering to be a mentor, join us at a scrapbooking workshop or coffee connection, meet up with other NICU families and staff at the March of Dimes Walk in April. Perhaps you have some connections through your business that could help with printing this newsletter? Or perhaps you have a talent that you could share, or resources that can help the NICU and its families.

For many families, the connection with the NICU is strong – and for many NICU doctors, nurses, respiratory therapists and others, that connection is equally strong. We love to hear from you – keep those photos and letters coming (see the back page for more info.) ... and if you can, think about volunteering for something and make a difference for someone a family who's just starting their NICU journey.

Giving Opportunities

Families often ask us how they can make a financial gift to directly benefit the NICU. The Newborn Services Fund is used at the discretion of the Chief of Neonatology. Unrestricted donations to the Newborn Services Fund allow the Department of Neonatology to address clinical, training, and family-related needs that may otherwise not be addressed. The Newborn Services Fund is used to

- promote existing programs that provide educational and emotional support to families of high-risk newborns;
 - provide for the ongoing training and development of specialized clinical staff by supporting their attendance at professional conferences; and
 - purchase equipment and supplies that are not clinically essential (and therefore not routinely purchased through existing hospital operating accounts) but nevertheless add to the education and comfort of BIDMC families.
- If you would like to make a donation to the Newborn Services Fund, please call or email Kelly Fitzsimmons or David Hyman (contact information below) for a form.

For questions on other ways to make a gift to the BIDMC NICU, please contact:

David Hyman
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330 Brookline Avenue (BR)
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Tel: 617-667-4552
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For information on BIDMC NICU volunteer opportunities, please contact:

Kelly Fitzsimmons
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Family Spotlight: The Swanson Family



After struggling with infertility, Jon and Jennifer Swanson were thrilled to learn that they were pregnant with twin boys through in vitro fertilization. Their excitement quickly turned to worry, however, when Jen developed placenta previa 12 weeks into the pregnancy – a condition where the placenta covers part of the cervix, and can be dangerous for both the mother and the baby. Jen was put on bed rest at home, but by 20 weeks, her cervix was starting to dilate, so she was taken by ambulance from Beverly hospital to Beth Israel Deaconess Medical Center, where she was put on strict bed rest and given medications – including magnesium and beta methasone – to delay labor as long as possible. Her hospitalization bought valuable time, but her twin boys decided to ring in the New Year, and were delivered at 24 weeks, 5 days via c-section, on January 1, 2003.

Nathaniel weighed in at 1 lb. 9 oz. and Avery weighed 1 lb. 8 oz.

Nathaniel's first 48 hours were particularly precarious. "The Nurse Practitioner kept telling us that they weren't sure he was going to make it," recalls Jen. "The respiratory therapists kept vigil at his side, helping him breathe by manually 'bagging' him every time he failed on the ventilator." Nathaniel fought courageously through those first days and weeks, battling numerous set-backs, including pneumonias, a pneumothorax, a grade 3 bi-lateral brain hemorrhage, and daily lumbar punctures to relieve swelling in his brain.

Avery, on the other hand, seemed to sail through his first two weeks. But on day 15, he developed necrotizing enterocolitis (NEC), a gastrointestinal disease that caused his intestine to rupture. He was rushed over to Children's Hospital for surgery, and required a colostomy.

"It was an absolute roller coaster," says Jen. "One minute I'd be crying hysterically, the next, I'd be so happy. Never in my life did I cry so much – I don't think I ever will."

Nathaniel and Avery spent more than five months in the NICU, and came home one week before Father's Day – a great gift for Jon.

Jen and Jon survived those long months with the help of their friends and family – and distractions such as their pets. They also focused on the positives, and found themselves greatly appreciative of the NICU staff.

"The NICU is not where you'd ever expect or want to be – but I wouldn't want to be anywhere else than Beth Israel," said Jon. "It was an experience filled with tears and joys."

Like many micro-preemies, Nathaniel and Avery's first weeks, months and years home were filled with doctors appointments, Early Intervention, Infant Follow-Up clinics, ELGAN studies, not to mention special care with regards to Nathaniel (who ended up needing a feeding tube) and Avery's colostomy.

Yet as the years went on, the appointments became fewer and further between, and are now replaced with soccer and t-ball games, quiet time drawing, and getting ready for kindergarten in the Fall.

"Nathaniel is quite the artist," say Jen and Jon, "and Avery is all boy, he loves anything to do with a ball. We couldn't be prouder of both of these amazing boys."

This summer, at his suggestion, Jon's company, Verosity Technology Partners, will be donating proceeds from its annual charity golf tournament to the Klarman Family NICU at Beth Israel Deaconess Medical Center. The funds raised will enable the NICU to continue and expand its efforts to support families through the NICU C.A.R.E.S. for Families initiatives.



What's New in the NICU?

GIRAFFES

This January, thanks to a generous gift from Josh and Anita Bekenstein, the NICU welcomed some new Giraffes into the Unit. No, we didn't hang new zoo-inspired wall-paper (though we are in the process of planning a NICU facelift), but rather we purchased a half a dozen Giraffe Omnibeds, state-of-the-art beds that act as both a warming table and a full-featured Isolette. The Giraffe Omnibeds create a more developmentally-ideal environment for the baby, and eliminate the stress of moving a tiny or critically-ill baby multiple times. The Giraffes get their name from the long neck that raises and closes the "lid" – creating a radiant-heat warming table when open, and an incubator when closed.



According to Susan Young, the NICU's Clinical Resource Nurse and Nurse Educator, the new Giraffe Omnibeds provide the optimal environment for our smallest NICU infants. The Omnibed has some very special features designed to support the needs of premature babies. The bed can change from an incubator to a warming table with the push of a button; and it has a built-in scale. It's designed to be very quiet so that babies can

sleep better. The mattress is of made a special memory foam that provides gentle support for our baby's fragile skin. The bed has other features, such as a mattress that swivels and sophisticated temperature control. Says Young, "babies using a Giraffe bed have the perfect environment for growing and maturing without having to be moved, unless it's to come out to be held!"

The NICU eventually hopes to replace all of its warmers and isolettes with these innovative Giraffe Omnibeds.

In February, the NICU staff embarked on a new way of entering clinical information into the computer systems that is designed to improve the care and safety of all NICU patients.

METAVISION: CLINICAL REPORTING SOFTWARE

Since the mid 1990's a computerized medical record has been used in the NICU to keep track of vital signs and other nursing and medical activities that happen during the course of a baby's hospital stay. Recently, the NICU upgraded this electronic medical documentation to *MetaVision*, designed by the company iMDsoft. The advantages of this new electronic medical record is that it is a computer program that allows information put into the medical record by one care provider to be shared between other nurses, doctors and other care providers. Information is pulled into notes and reports, and even generates an electronic growth chart.



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