

Caring

April 19, 2001

HEADLINES

Children and health care:

making MassGeneral Hospital *for* Children a safe and welcoming place

—by Mary Lou Kelleher, RN, clinical nurse specialist

enjoyed a great deal of success since its conceptual inception five years ago.

Our Pediatric Service has always had a quiet presence, doing wonderful work for child-

ren and their families, but even as recently as five years ago, relatively few people knew about our pediatric services. So it became our vision and goal to make MGH Pediatrics a driving force in pediatric health care.

Patient Care Services took a leading *continued on page 3*

“I think I can, I think I can...” said The Little Engine that Could, from the children’s book of the same name by Watty Piper. And sure enough, it did! Much like that little engine, the MassGeneral Hospital *for* Children has



Four-year-old, Mary Rufo, plays nurse to two-year-old, Robert Valeri

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MGH Patient Care Services
Working together to shape the future

Responding to the need for specialized care for children

Think of all the important events we look forward to in our children's lives—their first word, their first step, their first baseball game or school play, their first date, the prom, learning to drive—the list is endless. Now think of how many toddlers, young children, and adolescents are in the

hospital when those milestone events occur (...or when they *would* have occurred). Every time that happens a memory is made that lasts a lifetime. This is just one way of illustrating how vital our pediatric services are, and how integral our pediatric healthcare team is to the lives of

our youngest patients.

It is only with the most profound understanding of children's needs, their physical and emotional development, and respect for their individuality, that excellent care can be delivered to our pediatric patients and their families. Families are at the root of our care for all patients, but they



Jeanette Ives Erickson, RN, MS
senior vice president for Patient
Care and chief nurse



Enjoying some lap time are 2-year-old, Robert Valeri, and his mom, Annie

play an especially important role in our care of children. Not only are families the social, spiritual, and cultural centers to which children turn for comfort and security... but they know their children better than anyone, which makes them invaluable members of the healthcare team.

In many ways, clinicians become part of the family unit when they enter a family's life during illness. It is a special privilege to share that trust, pain, intimacy, and often joy with a family. And the more we learn about each family's beliefs, relationships, and dynamics, the better prepared we are to provide meaningful care.

At MassGeneral Hospital *for* Children, we are fortunate to have some of the most highly skilled, knowledgeable and compassionate ped-

iatric caregivers in the world. Our team of nurses, therapists, social workers, child life specialists, physicians and others, provides seamless, multi-disciplinary care that is on the leading edge of pediatric practice. The stories and articles in this special issue of *Caring Headlines* will give you a glimpse into the very special world of caring for children.

I hope you will all have an opportunity to attend some of the many events planned for next week as we celebrate *Children and Health Care*. We owe a debt of gratitude to pediatric clinical nurse specialist, Mary Lou Kelleher, and the entire planning committee for the extraordinary effort they put forth to coordinate this annual celebration. So release that child inside you, and enjoy!

Children and health care

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role in this endeavor. The multi-disciplinary Pediatric Operations Improvement Committee determined that a new mission statement was needed, one that reflected our practice in the 21st century. Through much self-exploration and energized discussions, an understanding emerged of the theory that our practice is built on—and that theory is family-centered care. (See shaded box below.)

From this mission statement and the guiding principles of the department of Patient

Care Services, guiding principles were developed for the Pediatric Service. These principles reflect our commitment to family-centered care, drive our day-to-day work, and guide our decision-making practices around the care of children. Since being established, the mission statement and guiding principles have been included in all written materials given to our pediatric patients, families and staff.

In October of 1998, the Family Advisory Committee, comprised of patients (as young as

ten years old), their parents and siblings, had its first meeting. Today the Family Advisory Committee has more than 30 active members who provide valuable input to the hospital on countless matters affecting our care of children.

In January of 2000, following more than a year of research and public polling, MGH Pediatrics was renamed MassGeneral Hospital *for* Children. A new logo was created that reflects our image of a warm, approachable care-delivery system for children. We even introduced a new pediatric mascot, *Pedi the Bear*, a life-sized, walking, talking, New England Black Bear. One year later, follow-up studies show that our efforts have been resoundingly successful.

As MGH Pediatrics, now the MassGeneral Hospital *for* Children, has grown and evolved, much of our work has been showcased during our annual celebrations of Children and Health-Care Week. This is a week set aside each year, nationally, to applaud the children, families and dedicated staff who care for and about children and children's issues. We have celebrated Children and Health Care Week for the past five years with

Guiding Principles

- We recognize the importance of the family in the child's life. We respect the family with its strengths, individual cultures and different methods of coping. We allow the child/family to define 'family'.
- We accept accountability for the care we deliver and the system where we deliver that care. We are always attempting to improve health care for children and families, with systems improvement, medical research and in the physical environment.
- We provide a family-centered approach to care. We impart service, which is respectful, caring and personalized.
- We recognize the importance of family/professional collaboration and foster this collaboration at all levels of the health care system. We respect the family's right to have complete and unbiased information about their child, shared in a supportive manner. We encourage the family (and child) to participate in the decision-making process of the health care plan.
- We understand and incorporate the developmental and psycho-social needs of the infant, child, adolescent and family into our care.
- We acknowledge that we are most effective as a team and we regard the child and the family as valuable members of that team.
- We enhance patient care and the systems supporting children's services as we work with others, eagerly entering into new partnerships with individuals, groups and systems within and outside of Massachusetts General Hospital.
- We view learning as a lifelong process essential to the growth and development of clinicians. We accept our responsibility to educate our new professionals and expand the knowledge of our entire staff who care for children and their families.
- We acknowledge that maintaining the highest standards of family-centered care is a priority. We will make decisions based on the most effective use of internal and external resources, realizing this is a never-ending process that involves all members of the institution, our patients and families, as well as the community at large.

a growing number of activities including a Children's Art Fair, Hurt Alert Day, educational offerings, Family

Centered Care Awards, and the very popular Children's Health Fair. Each year during *continued on next page*

Mission Statement

The MassGeneral Hospital *for* Children is dedicated to providing outstanding personalized, developmentally appropriate care for infants, children and adolescents within the context of their family and community. As part of Massachusetts General Hospital, we are dedicated to serving the pediatric community and realize that excellence in patient care is the result of an interdisciplinary effort requiring collaboration from all members of the health care team. Recognizing that pediatric care is the beginning of the health care journey, we are committed to providing the best possible care for life. We honor diversity, we encourage open discussion, and respect the parent's and child's right to participate in the planning of the child's care. We are advanced in our understanding of illness by innovative medical research and education, empowered by skill and technology, and motivated by a commitment to excellence in pediatric practice that is sincere and compassionate.

Children and health care

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Children and HealthCare Week, Grand Rounds invites a speaker of interest to all disciplines to speak about topics such as law, ethics, complimentary medicine, and family-centered practice. This year's Grand Rounds will feature members of our

Family Advisory Committee discussing, "Caring for Children with Chronic Medical Challenges at Home." Grand Rounds will be held on Tuesday, May 1, 2001, in O'Keeffe Auditorium at 12:00 noon.

Children and Health Care Week culminates

with the Children's Health Fair. The fair itself has grown dramatically over the years (the first fair in 1996 was held in the Wallcott Conference Room with 12 booths and was attended by approximately 200 children. Last year the fair was held on the Bulfinch Terrace with more than 1,200 children, 800 adults, and 54 booths).



Being in the hospital doesn't mean you can't play 'dress up!' Just ask, 4-year-old, Elizabeth Rufo, seen here modeling the latest in MGH chic!

Educational booklets published by the MassGeneral Hospital for Children

- ABCs of Hospitalization
- Helping Your Child Cope With Pain
- Operation Day
- Pediatric Trauma
- Taking a Medically Complex Child Home
- Navigating the Chapter 766 Maze

Information sheets

- Care of your Child with a Central Line
- Care of your Child with a Tracheotomy
- Care of your Child with a Gastrostomy/Jejunostomy
- Care of you Child with a Colostomy

This year we are proud to have the partnership of FleetBoston Financial Foundation. MassGeneral Hospital for Children was awarded a generous \$15,000 Community Service Grant from FleetBoston to sponsor the fair, which will be held Thursday, April 26, 2001, on the Bulfinch Terrace. The theme of this year's fair is, "2001: a Healthcare Odyssey."

As MassGeneral Hospital for Children continues to move forward and expand beyond our 'walls,' we know that partnerships will be key to our success—partnerships with our patients and families, partnerships with our community, health centers, visiting nurses associations, extended care facilities, primary care physicians and schools. We continue to be active in our participation with the MGH-Timilty Partnership. We respect our

position in the community to advance the concepts of excellent family-centered pediatric practice.

We will once again host a National Pediatric Conference this year entitled, "Humanizing Health Care for Children and Families: Mentoring for our Future." The conference will be held May 27-30, at the Westin Hotel at Copley Place.

As you read this special 'Children and Health Care' issue of *Caring Headlines*, I hope you will experience some of the depth and spirit of the people who make up MassGeneral Hospital for Children. It may sound corny, but it all began with a shared attitude of: "We think we can, we think we can..." And with the perpetually renewed commitment and dedication of this team, "We know we can!"

Pediatric chaplaincy: a thread in the tapestry of care

Sometimes a thunderbolt will shoot from a clear sky; and sometimes, into the midst of a peaceful family – without warning of gathered storm above or slightest tremble of earthquake beneath – will fall a terrible fact, and from that moment everything is changed. The air is thick with cloud, and cannot weep itself clear. There may come a gorgeous sunset, though.

—george macdonald

—by Patricia Byrne,
pediatric chaplain

once made sense now comes into question. The unanswerable ‘why’ questions reverberate through the family’s broken heart. Views of self and God destabilize and often deconstruct. At this critical time, when faith is desperately needed, spiritual life is often elusive; God seems to ‘check out.’ These marker events often precipitate a move from one stage of spiritual development to another. The chaplain, acting as spiritual midwife, facilitates the pas-

sage of being into the next phase of an individual’s experience with God. Conversation, discernment, listening, more listening, prayer and rituals are useful tools for companionship and ‘compassioning.’

Just as a health crisis can precipitate spiritual upheaval in adults, it can do potentially the same thing to children. Obviously, the symptoms of spiritual distress look different in a child. Likewise, the tools of assessment and spiritual companionship are different. I recently did an initial spiritual assessment on a 12-year-old boy while teaching him a card trick. Toys, games, songs, dance, and fantasy are vehicles into the experi-

ence of the divine. Spiritual developmentalists assert that a child’s experience with primary caretakers helps form the child’s foundational image of God. This is a daunting concept considering the number of sick infants who spend much of their early lives in a hospital setting. We, as caregivers, are providing the scaffolding for a faith that could sustain a person over the course of a lifetime. As Charles Dickens said, “*It is no small thing that those who are so fresh from God love us.*”

Honoring the cultural and religious practices of each patient, chaplains use stories from their respective

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In my brief time at MassGeneral Hospital for Children, I already see the spiritual components that are present in the care that is administered. It seems that all attempts to heal and comfort have roots in major religious traditions. How then does a chaplain complement rather than duplicate services?

Although the tools of ministry differ when working with adults and children, the ultimate goal is the same. The chaplain’s intention is to provide a means, and facilitate processes, by which people can experience the unconditional love of God. Because spiritual life is experienced at the place of intersection of all other dimensions of being, the chaplain views and assesses individuals from a multi-layered lens. In

prayerful partnership with God, she and the patient and family journey together through the tumultuous territory of illness.

The serious illness of a child can push a family’s familiar world view to the limits. What



Pediatric chaplain, Patricia Byrne (left), prays at bedside with (l-r) Kimberly, Lisa, Patrick, and Steve Cote on the occasion of Patrick’s first birthday and baptism.

(Photo provided by Cote family)

Providing pediatric social services at MGH

—by Susan Eastham, LICSW
Robin Fisher, LICSW
Elyse Levin-Ruffman, LICSW
Kenneth Scheublin, LICSW
Alexandra (Andra) Sobran, LICSW

Pediatric social workers are licensed mental health professionals who are specially trained to help children and their families find solutions to the many social and emotional issues that can arise when a child is ill. This is accomplished through a unique combination of psychotherapy, active problem-solving and a direct connection with a network of community resources.

Children who become ill often experience common anxieties: fear of pain, separation from family and friends, and frustration at the unwanted change in their usual routine. Many children regress under the stress of illness or hospitalization.

Illness is usually accompanied by a variety of stressors that vary depending upon the age of the child. Younger children may be especially frightened by medical staff and procedures. They likely have limited understanding of what is happening and why, and will have an increased need for reassurance from parents and caregivers.

School-aged children may have a better un-

derstanding of their illness, but share some of the same fears as younger children. Because this age group is 'concrete' in their thinking, they may need simple explanations to dispel possible misperceptions about their illness and treatment. Being sick or hospitalized is difficult for school-aged children because it interferes with their age-appropriate focus on school, friends and play.

Adolescents typically have a more sophisticated ability to understand the implications of their illness and treatment. This can cause a number of anxieties for adolescent patients. Issues for this age group usually include a loss of independence and control, feeling different from their peers, and altered self-esteem.

A sick child impacts the entire family unit. In addition to dealing with their own and their child's emotional distress, families can be faced with a host of other challenges. Family life is disrupted as parents feel a pressure to

balance work, home responsibilities, and the demands involved with caring for a sick child. This can be overwhelming. Siblings may feel left out as the attention shifts to the child who is ill. Feelings of anger, fear, sadness, and guilt may surface during this time.

Pediatric social workers respond to the numerous emotional and

practical issues that families experience when a child becomes ill. They are skilled at identifying family strengths and individuality while maintaining respect for each individual's way of coping. They are committed to providing culturally competent psycho-social care.

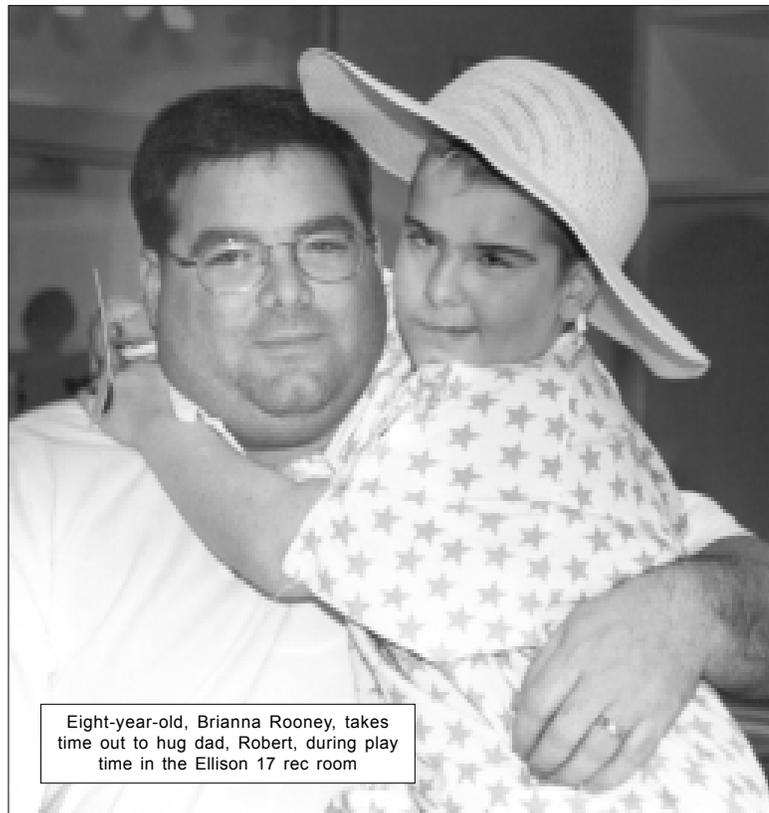
Some of the services pediatric social workers provide include:

- counseling with patients and families
- crisis-intervention
- guidance and support in coping with chronic illness
- addressing family concerns or conflicts
- identifying needed hospital or community resources

- clarifying ethical dilemmas
- Support groups

Pediatric social workers are available on inpatient and outpatient units throughout the hospital. Family members and others may request a social worker at any time. Frequently, other members of the healthcare team request the assistance of a pediatric social worker as we work collaboratively with the whole team to provide expert, comprehensive care.

For more information about pediatric social workers, call 6-2643.



Eight-year-old, Brianna Rooney, takes time out to hug dad, Robert, during play time in the Ellison 17 rec room

Project DOCC: families as partners and teachers

—by Colleen Hammond, parent

For many parents of children with chronic illnesses and disabilities, their lives are a 24-hour, non-stop process of caring for their children. Days and nights are filled with physical and occupational therapy, changing feeding tubes, giving medications, advocating for their child's support services, and working to maintain a good quality of life for their family. Many parents of chronically ill children credit the nurses, doctors, therapists, and many others in the medical community for getting their families through crisis after crisis.

The Pediatric Family Advisory Committee and the MassGeneral Hospital for Children's Pediatric Residency Training Program have partnered together to implement Project DOCC (Delivery of Chronic Care). Project DOCC is a program that helps educate pediatric residents and other health professionals about chronic illness and its impact on families and communities. The program addresses all issues involved with the care and education of children with chronic illness. Project DOCC

was collaboratively developed by parents and health professionals to be a family-centered, community-based, pediatric training program.

Project DOCC was originally created by parents of children with chronic illnesses and disabilities at North Shore University Hospital in Manhasset, NY, in 1994, based on their own experiences. The program focuses on the impact of chronic illness and disabilities on children and their families in the hospital setting, at home, and in the community. To date, Project DOCC has been implemented in 19 teaching hospitals across the country as well as two in Australia (MassGeneral Hospital for Children will be number 20 and the first in Massachusetts).

Says founding member Donna Appell. "We believe that if we can reach doctors during their training years, family-centered care will become automatic in their practice."

The song, "Colors of the Wind," from the Disney movie, *Pocahontas*, beautifully describe Project DOCC's intent. "If you walk the footsteps of a stranger,

you'll learn the things you never knew, you never knew."

"This song so aptly describes the benefits of immersing doctors into the world of chronically ill children and their families," says Appell. "Our dream is for every pediatric resident to walk the footsteps of the family of a chronically ill child."

Parents involved with Project DOCC are committed to promoting quality care and quality of life for their children. The underlying belief is that professionals are vital contributors to a child's health, education, and well-being.

The primary goal of Project DOCC is to provide pediatricians and all healthcare professionals with a holistic understanding of life with a chronically ill child, widening their perspective from the hospital to the home setting. Through interviews with family members and home visits, pediatric residents learn first-hand about the impact of chronic illness on families. They gain insight into the importance of working in partnership with families:

- to understand the impact of a sick child on family dynamics
- to appreciate the value of, and encourage referral to, support services
- to promote empathy for, and understanding of, the chronic process
- to advocate for families and encourage parent-health professional relationships

The program consists of a home visit, a parent interview, and parent-led panel discussions. Participants are given a manual that describes the goals of Project DOCC and includes references and materials to be used during each experience.

Panel members are parents of children with special healthcare needs. The experiences of each family are discussed, with a moderator directing questions to panel members. The families' personal experiences are shared in hopes that residents will gain a deeper understanding of

what life is like with a chronically ill child.

Participants visit the home of a child with a chronic illness. The program provides pediatricians-in-training with first-hand knowledge of the emotional and practical aspects of living with a child with a chronic illness and/or disability.

During the parent interview, pediatric residents gain insight into how to administer a questionnaire to parents, asking not just about the child's disease, but about family life, brothers and sisters, social services, and any catastrophic problems they may face. Project DOCC will officially begin at MassGeneral Hospital for Children on July 1, 2001. The Family Advisory Committee hopes to expand the program beyond pediatric residents to include nurses, therapists, and other pediatric healthcare professionals.

Pediatric Grand Rounds

"Caring for Children with Chronic Medical Challenges at Home."

The MassGeneral Hospital for Children's Family Advisory Committee presents a panel discussion on lessons to be learned from their experiences caring for children with chronic illnesses and disabilities. The seminar is an effort to inform nurses, doctors, therapists, and others about the important role they play in the lives of families of chronically ill children

**Tuesday, May 1, 2001
12:00pm
O'Keeffe Auditorium**

For more information, call 724-1746

It's all in a day's work for NICU respiratory therapist



Steven C. Mason, RRT,
respiratory therapist

My name is Steven Mason and I have been a registered respiratory therapist (RRT) for more than 20 years, the past 18 here at MGH. Since I started in 1982, the respiratory care profession has evolved dramatically with the influence of advancing technology. Today at MGH, the majority of our efforts are concentrated in critical care units. These patients are acutely ill and often require the support of mechanical ventilators and other types of

equipment in order to survive. Because we care for a diverse patient population that ranges from neonates to adults, we are constantly challenged to adapt our skills accordingly. We spend a great deal of time managing and adjusting life-support systems to facilitate the best possible outcomes for our patients. By collaborating with the nurses and physicians responsible for the care of these patients, we form an efficient, effective healthcare team.

It is not uncommon

for RRTs to be called by physicians requesting our assistance in the evaluation of patients with respiratory difficulties. To say that I have been involved in a myriad of life-threatening and life-saving situations would be an understatement.

In recent years, the focus of my clinical practice has been the care of patients in the Neonatal Intensive Care Unit (NICU). The NICU is a world unto itself in which very few clinicians feel comfortable. The sight of an unwell

infant can be frightening and emotionally upsetting to some. This is where my story begins.

I was going about my duties on a typically busy night in the NICU. A few hours into my shift I received

a call that I was needed in the delivery room to assist with a high-risk delivery. I quickly responded. The mother was in active labor and about to deliver a 28-week (gestational age) baby three months prematurely! After the baby boy was delivered, he required resuscitation and was stabilized in a very short time. Unfortunately, he continued to be in severe respiratory distress and we needed to move him to the NICU for definitive therapy. It was at this time that someone whispered in my ear, "She's an ICU nurse here at MGH." I took a closer look at the mother and realized that this distraught and groggy mother was a nursing colleague and friend of mine. We knew one another well, as our paths had crossed often while

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Respiratory therapist, Steven Mason, RRT,
works with premature infant in the
Neonatal Intensive Care Unit.



Sue Riley, PT,
physical therapist

The fastest way to a child's heart is through her brother... and maybe a nice game of catch!

My ability to gain the trust of a child with whom I cannot directly communicate is far more limited than with a child who speaks and understands English; particularly if that child has had multiple painful procedures prior to coming to me.

Another challenge I encounter when working with families, is finding a way to include siblings who may come to sessions with the patient. For siblings, it is often difficult and frustrating to leave their friends at home and accompany a brother or sister to America, and then sit by and watch

while he or she 'plays' in physical therapy.

This past summer, a wonderful family came to MGH from the United Arab Emirates, seeking care for 7-year-old Nadia. Nadia has severe congenital heart disease and, as a result of an intra-operative stroke many years ago, a left hemiparesis. Both of her parents and her 5-year-old, very energetic brother accompanied

her to Boston. Nadia's heart disease left her with baseline cyanosis and a poor exercise tolerance.

When I first met Nadia, she was very fearful. On our first meeting, despite my best effort to communicate through the interpreter, she began to cry, quietly at first, and then she began sobbing. As she cried harder, her

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My name is Sue Riley and I have been a pediatric physical therapist for 23 years, the last six and a half here at MGH. I have always loved working with children and their families. The ability to improve a child's function and to interact with their friends and siblings whether on the playground or athletic fields is extremely gratifying. One of the most rewarding, yet challenging aspects of working with young children is allaying their fears and gaining their confidence in order to develop a positive relationship where children will work hard to achieve their goals. Starting off slowly, talking with the children, not just their parents, and being very clear about what I am going to do, are all key strategies. Recently this

has become even more challenging as the number of international patients at MGH has grown tremendously. Many international patients speak exclusively in their native language. Recently, I worked with four wonderful children, one who spoke English, one Spanish, one Latvian, and one Arabic.



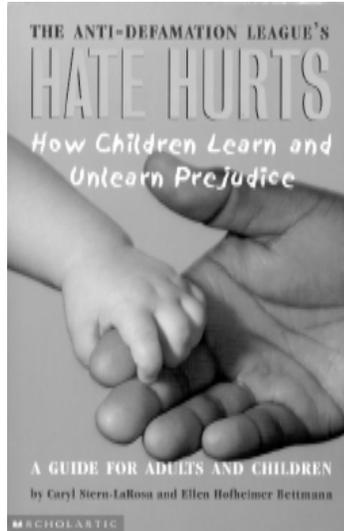
Pediatric clinical specialist, Sue Riley, PT, works with 2-year-old, Mara Cazare, to overcome neurological deficits by facilitating voluntary movement, head control, and helping her to develop a link between her movements and responses.

A Guide for Families of Children with Cancer

The second edition of *A Guide for Families of Children with Cancer* is now available in the Pediatric Hematology-Oncology Unit on Blake 255. The booklet was written by MGH staff members involved in the care of children with cancer as an introduction to newly diagnosed oncology patients and their families.

The booklet provides information to assist parents in understanding childhood cancer and what is happening to their child and their family. It is hoped that the guide will help families navigate through this difficult experience. Specific topics include: identifying a treatment team; addressing anticipated changes in the family; and identifying important aspects of growth and development for the child diagnosed with cancer and his or her siblings. The booklet provides information on diagnostic tests and radiologic scans in addition to identifying potential side-effects of chemotherapy, radiation, and surgery. There is a special section on commonly asked questions and suggestions about how you know when it's time to call the clinic. A glossary of associated medical terms is provided. *A Guide for Families of Children with Cancer* is given to all parents at the time their child is diagnosed with cancer.

The printing of this second edition was funded by a grant from the Friends of the MGH Cancer Center. For more information about *A Guide for Families of Children with Cancer*, please contact Heidi Jupp, RN, or Sherry Pleau, RN, in the Pediatric Hematology-Oncology Unit at 726-2737.



Certified Pediatric Oncology Nurses

All registered nurses in Massachusetts must pass a mandatory state licensing exam and meet renewal qualifications every two years. Nurses can also obtain optional certification in specialty nursing areas. This certification recognizes a nurse's expert knowledge in a specific area of nursing. Certified Pediatric Oncology Nurse (CPON) is one such certification, offered through the Oncology Nursing Certification Corporation, which is accredited by the American Board of Nursing Specialties. Many nurses on the Ellison 17 and 18 pediatric units have taken the initiative to become certified pediatric oncology nurses, adding to the knowledge base and resources available to staff on those units. Congratulations to Julliette Hardiman, RN; Celine Mani, RN; Roseann McCory, RN; Susan O'Brien, RN; Kathryn Pazola, RN; Sandra Pugsley, RN; and Patricia Kent, RN, who have attained CPON status.

Pediatric Brain Tumor Clinic

Due to the recent increase in the number of pediatric brain tumor patients, a pediatric brain tumor clinic has been created at Mass-
General Hospital for Children. The multi-disciplinary clinic is comprised of a coordinated group of clinicians including: nurses, clinical nurse specialists, pediatric hematology-oncologists, radiation oncologists, neurosurgeons, neurologists, child psychiatrists, radiologists and pathologists. This group meets on a weekly basis to review active brain tumor cases and discuss referrals from other medical centers. They meet patients diagnosed with brain tumors and their families on designated afternoons. A thorough evaluation is performed in which the child's functional status and current needs are identified. A multi-disciplinary plan is presented to parents with recommendations for treatment, which may include surgery, radiation therapy, and/or chemotherapy. State-of-the-art protocols and procedures such as conformal three-dimensional radiation therapy and, more recently, proton beam therapy are available and have great application in children with brain tumors. For more information about the Mass-
General Hospital for Children's Brain Tumor Clinic, contact Beverly LaVally, RN, at 726-2737.

Diversity Reading List

In our increasingly multi-ethnic, multi-cultural society, it is more and more important to teach our children that everyone is not alike. We must hold ourselves accountable for managing that our children learn about 'differences' outside the home. Deborah Washington, RN, Patient Care Services' director of Diversity, offers the following recommendations for books that may be helpful in guiding our children toward a better future and a more inclusive society.

We Can All Get Along, by Clyde W. Ford, talks about steps adults can take to understand what their children are learning outside the home as well as how to create a family vision to eliminate racism.

The Values Book, by Pam Schiller and Tamera Bryant, uses definitions, songs, and games to help adults explore values like fairness, respect, tolerance and loyalty with children.

Hate Hurts, by Caryl Stern-LaRosa and Ellen Hofheimer Bettmann, explores factors that make individuals different from one another (like gender, race and religion). It provides pointers on how to talk to children about hate.

The First R: How Children Learn Race and Racism, by Debra Van Ausdale and Joe R. Feagin, reveals the authors' observations of preschoolers and how they make use of their understanding of race and ethnicity in their everyday lives. The book explores how children use these factors to define themselves and others.

Pediatric Chaplaincy

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traditions to engender faith in a supreme being of love. Values such as, gentleness, generosity, hope, joy and forgiveness, which are common to all faiths, are modeled and shared. Feelings, such as, anger, rage, or ambivalence, are upheld as appropriate and normal human responses. Chaplains attempt to find the child's learning style and then use this as a means of connection to the self, others, and God. In this way, experience with God seems easy and natural.

Several months ago I cared for a child with severe ADHD. For her to sit and listen to a story or use verbal prayer to talk to God would have been very frustrating, perhaps impossible. She would have lost interest quickly and received the indirect message that communicating with God was difficult. But this little girl loved to dance. So, dance we did. Using music and dance to express our prayer, she was always delighted with herself at the end of our sessions. A young boy with limited verbal capacity had an artistic capability. Together we created his own personal coat of arms. This provided a

lens for me to see areas of importance to him, constructs of his young and tender soul about which he had not spoken. He learned that drawing pictures was his way of saying hello to God.

Consistently, it has been my experience that once children feel safe, loved, and accepted they will try to structure or restructure their view of God. One little girl who had been adopted and afterward relinquished back to DSS asked with wide eyes one day, "Where does God go when I am bad?" Consistent presence and loving acceptance over months helped to assure her that God is always with her and never sees any child as bad. The memory of her calling my name, running down the hall and jumping into my arms will always warm my heart.

Of particular concern to me is the ongoing feeling of disenfranchisement our children feel. Sometimes the unattended prom, the unshot baskets, the Friday nights spent alone get lost in the greater battle between life and death. Yet, these events penetrate deeply into a child's sense of self,

especially during childhood and adolescence. Sometimes despair can thrust a child into advanced stages of spiritual development. That the good suffer and the evil go unpunished is a difficult concept for us grown-ups. Some adults fall into the 'life-isn't-fair' syndrome and end up feeling a deep sense of betrayal. Children may tend to confront doubts about God's existence. This advanced state of spiritual passage can cause increased anxiety when it is out of sync with a child's

psychological development. Chaplains bring reinforcement while these dissonant realities are held and hopefully synthesized.

In terminal illness chaplains assist children in the exploration of an afterlife ("Can I see mommy from heaven?" "Will I fly or walk?" "Will God know who I am?" "What does God look like?") During the final stages of illness when difficult decisions are being considered, chaplains provide education to staff as families consider options

based on their own personal religious beliefs and traditions. When death comes, chaplains assist families and staff to create rituals and memorials that affirm and celebrate the child's life while acknowledging the pain and soutrage of such a tragic loss.

As I become one more thread in the great tapestry of care at MGH, my hope is to strengthen the fabric as I continue to learn from my colleagues, and from our greatest teachers, the children.

Job

The MGH-Timilty Partnership
presents

Shadow Day

May 22, 2001



The MGH-Timilty Partnership is currently seeking employees to act as hosts for seventh-graders participating in this year's city-wide Job Shadow Day. Volunteers are asked to spend a half day sharing their work environment with a student, imparting insight into what it's like to work in an adult work setting. If you would like to host a student, please call Wanda Velazquez at 724-3210, or send e-mail to timilty@partners.org.

Exemplar (Mason)

continued from page 8

working in adult ICUs. I calmly told her, as her newborn son was being placed into an isolette, that we were transporting him to the NICU. I assured her that we would take good care of her baby.

While in the elevator I couldn't help thinking how worrisome this turn of events must be for a parent. Knowing the usual course for a baby born at 28 weeks gestation, I knew that she and her family were in for a long and arduous ordeal.

Upon arrival in the NICU, we quickly assessed the newborn. Due to his profound respiratory distress we decided to intubate him to support his breathing. The primary problem with premature infants is respiratory distress syndrome (RDS). The lungs of infants younger than 35 weeks gestation are markedly

deficient of surfactant, a vital protein normally present in mature lungs. Because of this, the baby's lungs collapse. The only proven treatment for this syndrome is surfactant administration, and this baby was in dire need of it.

I prepared the surfactant solution and administered it with the help of a nurse. This was done by instilling a small amount of liquid directly into the lung through the endotracheal tube. The baby was then positioned to effectively distribute the surfactant to each lung. Although this procedure was tolerated well, the most critical time was yet to come. Every newborn's response to surfactant is different. A respiratory therapist must be ready for an abrupt change in lung function which necessitates rapid adjustments of the ventilator set-

tings. If these changes are not properly implemented, unwanted side effects may result. This baby's response was dramatic, and I spent the remainder of my shift fine-tuning his ventilator settings.

Halfway through the night, the baby's mother wanted to come to the NICU to see her new son. She was wheeled to the NICU in her hospital bed to see him for the very first time. She was still somewhat groggy from medication and partially unaware of her surroundings. I met her at her son's bedside. Though she appeared to recognize me, I wasn't sure she really did. I said 'hello' and proceeded to tell her that her son was doing quite well and had a positive response to the surfactant. I explained that we were weaning the ventilator support and that he was on the right course for a baby of his gestational age. She nodded her head in agreement and I went about my other duties.

The baby continued to do exceptionally well and his mother and I became closer friends during his recovery in the NICU. He had won his battle with respiratory failure, and his recovery was nothing short of remarkable. His mother's daily visits to the NICU were always

punctuated with a big 'Hello' and a smile for me.

I cannot help but think back to that night and the circumstances surrounding the events which took place in just those few hours. I've often thought about what it would be like to be 'on the other side' as a healthcare provider placed in a position of total dependence on others for my care. Add to that a premature infant, totally dependant on you for his recovery, and it might be the ultimate responsibility.

I've treated many babies in similar situations before but for some reason this was different. When you've done this work for as long as I have, you start to take it a bit for granted. But not in this case, which has left a lasting impression. The boy's mother has told me on many occasions that she feels a certain 'bond' with me for the role I played in her son's recovery.

I see her occasionally during my visits in the adult ICUs. I asked her once how her son was doing. She told me to wait a minute; she got her purse and returned with a picture of him. "Looks good to me," I said.

"Perfect," she replied. "You'd never know he was a premie, thanks to you."

"No need to thank me," I said. "I do this all the time." All the time in the little, unknown world of the NICU.

**Comments by
Jeanette Ives
Erickson, RN, MS,
senior vice president
for Patient Care and
chief nurse**

Being able to provide tangible, technology-based care to acutely ill patients is an important aspect of practice for clinicians who work in critical care settings. But providing emotional support can be just as essential. Steve's narrative gives us a wonderful example of both. The knowledge and skill that allowed him to maintain the delicate balance of lung function may well have saved the life of this premature infant. The compassion and sensitivity he showed the mother forged a bond that continues to this day. Steve didn't assume that because she was a nurse she wouldn't need the explanations and reassurance that every mother needs. Steve put himself 'on the other side' and provided the kind of care he would want for himself or his loved ones in a similar situation. What a wonderful story.

Thank-you, Steve.

MassGeneral Hospital *for* Children
presents:

Humanizing Healthcare for Children and
Families: Mentoring for our Future

A national conference to enhance collaborative
practice, enrich personal and professional growth, and
serve as a springboard for skill and knowledge around
caring for children

May 27-30, 2001
The Westin Hotel, Copley Place

For more information, log on to:
www.massgeneral.org/children

Exemplar (Riley)

continued from page 9

cyanosis increased and she began coughing, ultimately becoming sick to her stomach. This happened two more times during our initial session. I met with Nadia (and the interpreter) three times that week with essentially the same results.

The following week, I tried a new approach. I began my session by inviting Nadia's brother to 'play' with me, selecting the same activities I ultimately wanted Nadia to engage in. After a few minutes, Nadia was smiling and laughing as she watched us. I extended the ball we were playing with to Nadia, and she eagerly joined our game. As the week progressed I was able to complete my examination and implement a program that was fun but would achieve the goals we had established (with the help of the interpreter).

Nadia (and her brother) came to physical therapy three times a week for approximately 5 weeks while they were in the United States. After the first four sessions, we no longer utilized the services of the interpreter, as we had developed our own method of communication, which was quite effective and enabled us to complete our therapy sessions in a more personal way. During that time our relationship grew into a real friendship. By the final few weeks, both children would greet me with big smiles and hugs in the waiting room, and if I was late, they would leave their parents and come look for me in my office!

Nadia's brother had the opportunity to feel as though he had participated in Nadia's care, and so didn't feel like an observer. He seemed to genuinely like physical therapy and would often come up with games to play. I learned from his family that this was his main form of diversion while they were here, and both Nadia and I welcomed his participation.

Nadia returned home stronger, and walking better and farther than when she had arrived. She was also excited about continuing her exercises at home and brought her family's video camera on the final day to videotape her exercise program. She also persuaded her parents to go to a local sporting goods store to buy her some weights to help her get stronger.

I'm sure that in the next several years as the patient population here becomes more global, I will continue to use the strategies I learned from Nadia and her brother to make other young children and their families feel comfortable enough to trust me with their care. Perhaps, too, I'll learn a little more Arabic.

Comments by Jeanette Ives Erickson, RN, MS, senior vice president for Patient Care and chief nurse

It sounds to me like Sue may have a bit of Tom Sawyer in her genes! The idea of engaging Nadia's brother as a way of making physical therapy more appealing to Nadia reminds me of Tom's whitewashing of the picket fence! It was a great idea then, and it's a great idea now. Using this ploy, Sue is able to integrate play into Nadia's treatment plan. Soon Nadia is fully engaged in her own therapy, even to the extent that she wants to videotape her exercise session and take it back home with her.

The fact that Nadia's brother is equally interested and involved in Nadia's sessions is a bonus! Not only is he helping his sister and feeling a part of her recovery... he's having fun at the same time! This is a wonderful win-win situation. It's amazing the magic that can happen when you combine skill, experience and insight with the child that lives inside you!

Thank-you, Sue.

Community Health Day!

Sponsored by the MGH Revere HealthCare Center

The MGH Revere HealthCare Center will celebrate Community Health Day with staff, officials, and program leaders from the health center and from the community. Guest speaker: Ursula Kelly, RN, MSN, will talk about "Cross-Cultural Domestic Violence Issues."

**Thursday, April 26, 2001
8:00-10:30am**

For more information, contact
Bernice MacIntyre at 485-6062

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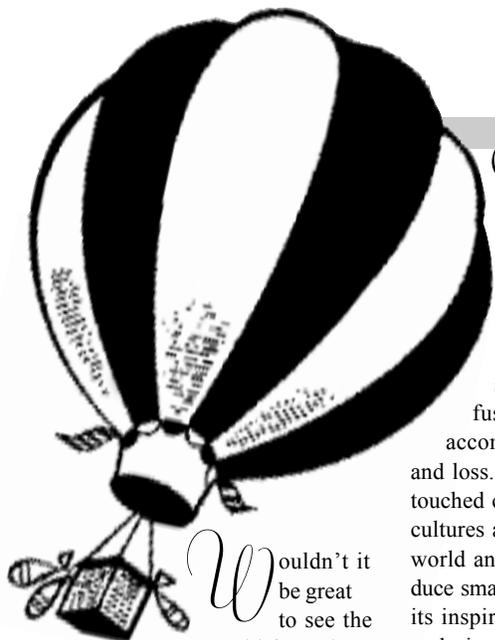
Educational

When/Where	Description	Contact Hours
April 30 8:00am–4:30pm O’Keeffe Auditorium	Care of the Respiratory-Compromised Patient This respiratory program is geared for clinicians on general units who care for mechanically ventilated and tracheostomized patients. It is also appropriate for clinicians who would like an update or review. Topics will include mechanical ventilation, tracheotomy and other airways, weaning strategies, nutritional needs, discharge planning, therapy needs and nursing care. For more information or to register, call The Center for Clinical & Professional Development at 726-3111.	7.8 (for RNs) .6 (for SLPs) Certificate of attendance for RRTs, OTs and PTs
April 30, May 1, 2, 7, 8, 9 7:30am–4:00pm St. Elizabeth’s Medical Center	Critical Care in the New Millennium: Core Program For ICU nurses only. This program provides a foundation for practice in the care of critically ill patients. Pick up curriculum books and location directions from the Center for Clinical & Professional Development on Founders 6 before attending program. For more information, call The Center for Clinical & Professional Development at 726-3111.	45.1 for completing all six days
May 1 8:00am–4:30pm VBK 601	Obstetrics Update This workshop will expand nurses’ knowledge of normal pregnancy in areas of physiological changes, breast-feeding, fetal heart monitoring, and assessment, patho-physiology, and nursing care of patients experiencing complications. For information, or to register, call The Center for Clinical & Professional Development at 726-3111.	TBA
May 3 7:45am, 1:00pm, 4:00pm VBK 401	CPR—American Heart Association BLS Re-Training Registration is required by 12:00 noon of the day <i>prior</i> to class. For information, or to register, call The Center for Clinical & Professional Development at 726-3111.	---
May 3 7:00–11:00pm VBK 601	Congenital Heart Disease: a Review of Defects, Repairs, and Management This four-hour session is designed for nurses who work with neonatal and pediatric patients diagnosed with CHD, or for nurses interested in learning more about heart disease in children. Topics will include anatomy and physiology of the heart, cyanotic and acyanotic heart defects, open and closed heart surgical repairs, temporary pacing, and post-operative management. For more information, call The Center for Clinical & Professional Development at 726-3111.	4.5
May 3 1:30–2:30pm O’Keeffe Auditorium	Nursing Grand Rounds Nursing Grand Rounds are held on the first and third Thursdays of each month. For more information about this session call The Center for Clinical & Professional Development at 726-3111.	1.2
May 4 8:00–11:00am 12:00–3:00pm O’Keeffe Auditorium	A Different Kind of Care Part of a four-part program sponsored by the Ethics in Clinical Practice Committee, the Palliative Care Department, and The Center for Clinical & Professional Development. This session introduces the evolution of palliative care in the American healthcare system and emphasizes the holistic approach to care. A discussion of all aspects of care (including spiritual) will be presented. Program will include both lecture and discussion, as well as a video of the highly acclaimed Bill Moyers PBS series. For more information, call The Center for Clinical & Professional Development at 726-3111.	3.6
May 9 8:00–12:00pm VBK 601	Pediatric Advanced Life Support (PALS) Re-Certification Program Open to all participants whose 2-year PALS certification will expire before October, 2001. Limited to 25 people; registration is on a first-come, first-served basis. Fee: \$80 for Partners nurses, therapists, residents; \$110 for all others. For more information, call 726-8287. To register, call The Center for Clinical & Professional Development at 726-3111.	---
May 9 8:00am–5:00pm Wellman Conference Room May 17 8:00am–5:00pm Wellman Conference Room	Advanced Cardiac Life Support (ACLS)—Provider Course Provider course sponsored by MGH Department of Emergency Services. \$120 for MGH/HMS-affiliated employees; \$170 for all others. Registration information and applications are available in Founders 135, or by calling 726-3905. For course information, call Inez McGillivray at 724-4100.	16.8 for completing both days
May 9 1:30–2:30pm Bigelow 4 Amphitheater	OA/PCA/USA Connections Continuing education session offered for patient care associates, operations associates, and unit service associates. This session is entitled, “Restraints Q&A Made Simple.” Pre-registration is not required. For more information, call The Center for Clinical & Professional Development at 726-3111.	---

Offerings —

April 19, 2001

When/Where	Description	Contact Hours
May 9 5:30–7:00pm O’Keefe Auditorium	Advanced Practice Nurse Millennium Series This new series provides an opportunity for advanced practice nurses from throughout MGH to network and attend clinical, management and professional development presentations for continuing education. For more information, call The Center for Clinical & Professional Development at 726-3111.	1.2
May 14 8:00am–4:30pm O’Keefe Auditorium	Coronary Syndromes This program will focus on the patho-physiology of myocardial infarction, non-invasive and interventional therapies. For more information about this session call The Center for Clinical & Professional Development at 726-3111.	TBA
May 15 7:30–8:30am Patient Family Learning Center	Internet Basics: Using the World Wide Web to Enhance Your Practice This program is targeted toward clinicians who want to learn basic skills in accessing, searching and navigating the Internet. The goal is to teach clinicians to access quality on-line healthcare information to enhance clinical practice. For more information, call The Center for Clinical & Professional Development at 726-3111.	1.2
May 15 7:45am, 1:00pm, 4:00pm VBK 401	CPR—American Heart Association BLS Re-Training Registration is required by 12:00 noon of the day <i>prior</i> to class. For information, or to register, call The Center for Clinical & Professional Development at 726-3111.	---
May 16 8:00am–4:30pm Training Department Charles River Plaza	Culturally Competent Care: Understanding Our Patients, Ourselves and Each Other Program will provide a forum for staff to learn about the impact of culture in our lives and interactions with patients, families and co-workers. Topics include understanding and defining the importance of culture; the principles of cultural competency; understanding the dynamics of difference; the culture of Western bio-medicine; and the appropriate use of language services. A variety of interactive exercises will help to illustrate the concepts presented. For more information, call The Center for Clinical & Professional Development at 726-3111.	7.2
May 17 8:00am–4:30pm Training Department Charles River Plaza	Psychological Type & Personal Style: Maximizing Your Effectiveness In this dynamic workshop, participants will engage in a journey of self-discovery using the Myers-Briggs Type Indicator (MBTI). Participants will learn about their: psychological type and leadership style; preferred methods of communication; preferred work environment; effectiveness as a team member. Following, participants will learn about: the impact of ‘psychological type’ in problem-solving and decision-making; how to work with opposite types; the implications of type in managing conflict. Registered nurses at all levels of experience are welcome. For more information or to register, call The Center for Clinical & Professional Development at 726-3111.	8.1
May 17 1:30–2:30pm O’Keefe Auditorium	Nursing Grand Rounds Nursing Grand Rounds are held on the first and third Thursdays of each month. This presentation will focus on, “Gender Roles in the Muslim Culture,” presented by Imam Talal Eid, Muslim chaplain. For more information, call The Center for Clinical & Professional Development at 726-3111.	1.2
May 17 10:00–11:30am O’Keefe Auditorium	Social Services Grand Rounds “Raising Relational Boys,” presented by Kate Dooley, MS, faculty at Jean Baker Miller Training Institute, Stone Center, Wellesley College; co-director of the Mother-Son Project, JBM TI, Wellesley College. All staff are welcome. For more information, call 724-9115.	CEUs for social workers only
May 21 8:00am–3:30pm Bigelow 13 Conference Room	Management of the Burn Patient This conference will assist nurses and therapist with the development of their practice related to the care of thermally injured patients. Topics will include the epidemiology and patho-physiology of burn injury; wound management; surgical treatment strategies; rehabilitation; psycho-social issues; and burn prevention. Registration is limited to 15. For more information, call The Center for Clinical & Professional Development at 726-3111.	6.9
May 22 8:00am–4:30pm Haber Conference Room	Advanced Arrhythmia Interpretation Program This program is designed for nurses who are competent in all aspects of arrhythmia interpretation, but wish to expand their knowledge in the areas of bundle branch blocks, and wide complex tachycardias among other topics. Pick up pre-reading packets from The Center for Clinical & Professional Development, FND645. Registration is required; call 726-3111.	7.8



Take a ride on the Friendship Balloon!

Wouldn't it be great to see the world from the vantage point of a hot air balloon as it drifts dreamily high above the earth? Joan Drescher, author-illustrator of *The Moon Balloon: a Journey of Hope and Discovery*, has always believed in the power of art to help heal. In her book, she uses playful drawings of hot air balloons to represent different feelings to help children cope with the

stress and confusion that often accompany illness and loss. The book has touched children from cultures all around the world and helped produce small miracles with its inspirational words and pictures.

Mary Lou Kelleher, RN, pediatric clinical nurse specialist, contacted Drescher to discuss the possibility of a partnership between the Moon Balloon and MassGeneral Hospital for Children. The partnership will be called, "The Friendship Balloon," and it will involve an information exchange program with the Gaslini Hospital for Children in Genoa, Italy.

The Friendship Balloon will be powered by the warmth and good will generated when patients at the MassGeneral Hospital for Children share stories and drawings about their hospital experiences with patients of the Gaslini Hospital; and children at the Gaslini Hospital share pictures and stories of their experiences with children here.

The Friendship Balloon will also be an opportunity for clinicians and caregivers to share and exchange information between the two institutions. Information on child life specialists, family-centered

care, and The Residency Training Program will be shared via (interpreted) videos. E-mail addresses will be exchanged. It is our hope that the Friendship Balloon will help forge a lasting, mutually beneficial relationship between patients and professionals of both countries.

In the coming weeks, watch for sightings of the Friendship Balloon on your unit!

To kick off the partnership between MassGeneral Hospital for Children and the Moon Balloon, the MassGeneral Hospital for Children will be conducting a three-month pilot program, funded by a grant from the Mind Body

Institute of Massachusetts. Acting as artist in residence, Drescher, working in conjunction with child life specialists, will offer a series of arts and crafts programs to help provide an artistic outlet for young patients and their families. The program will include a mentoring component with a group of graduate students from Lesley University.

We look forward to this partnership and a journey full of hope and discovery for our children, families and staff.

If you would like to share any of your best practices with staff of the Gaslini Hospital for Children in Genoa, Italy, please contact Mary Lou Kelleher at 4-5720.

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