March 16, 2006

Caring
HEADLINES

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'You're incredible'

celebrating our pediatric patients and caregivers

—by Pamela Wrigley, RN, pediatric team leader, Same Day Surgical Unit

Once upon a time, there was a big hospital dedicated to the care of patients, and scattered throughout this hospital were many pediatric specialty areas. Staff who worked with pediatric patients were creative and committed but had no way of connecting that spirit. Then one day, a message came: "Come join your spirit, commitment, and talents and celebrate Children and Health Care Week. Most people had never heard of Children and Healthcare Week, so they traveled to a meeting to see what it was all about. They were told that Children and Health Care Week was a special time set aside for educational acti-

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23-month-old, Dickenson, and his mom have pre-operative family meeting with pediatric surgeon, David Lawlor, MD, and pediatric OR nurse, Paula Kraus, RN

MGH Patient Care Services
Working together to shape the future

You're incredible: an appropriate theme for this year's CHW celebration

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

This issue of *Caring Headlines* is a testament to the incredible work done every day at the MassGeneral Hospital *for* Children. Many of you may not realize the long history MGH has in caring for children. In 1821, MGH was the first hospital in the country to establish a service dedicated exclusively to the care of children, and it has been providing expert pediatric care to patients and families ever since.

In March, 1997, the first issue of *Caring Headlines* exclusively dedicated to pediatric care was published at MGH. At that time, I wrote, "Every family has a unique culture, value system, and history. Values passed from generation to generation guide our work with children and families. One definition of family is: a group of people who share significant emotional bonds."

Clinical staff throughout MassGeneral Hospital *for* Children promote the principles of patient- and family-centered care through the work of collaborative governance and the Clinical Practice Management Committee (a group that explores ways to improve systems and care delivered to children and families).

In 2004, the Yvonne Munn Nursing Research Award funded a study to look at family-centered care and how MassGeneral Hospital *for* Children is doing in the eyes of families and caregivers. And research continues to drive improvement in pediatric care. Recently, parents were invited to join the Clinical Practice Management Committee to ensure that patients and families have a strong voice in decisions that affect care-delivery.

Staff of the MassGeneral Hospital *for* Children have been on the front lines delivering care and humanitarian aid around the world. After September 11th, nurses, child life specialists, social workers, pediatric chaplains, and psychiatrists developed, 'How to Talk to your Kids about Terrorism,' a set of guidelines that was distributed throughout the hospital, to the media, and to a number of local schools.

Pediatric nurses and social workers were among the first to respond when disaster struck in southeast Asia in January, 2005. Three pediatric nurses spent a month working with Project Hope aboard the US Mercy. Their skill and spirit made an extraordinary difference as they cared for children and families far from the walls of MGH.

In August of last year, when hurricane Katrina ravaged the Gulf Coast, pediatric clinicians again teamed with Project Hope to provide much-needed care and disaster relief.

It's hard to believe it's been ten years since the first Children and Health Care celebration at MGH. The stories and photographs in this issue of *Caring Headlines* showcase the amazing spirit and dedication of our pediatric patients, families, and caregivers.

'You're incredible.' What an appropriate theme for this year's Children and Health Care Week celebration.

Reading tutor, Kimberly Minnucci, uses decoding strategies with dyslexic student, Giovanni Lorquet, in the Orton Gillingham Program

Children and Health Care Week

continued from front cover

vities for children of all ages. It encouraged children to learn about hospitals and health care in a positive, non-threatening way. People were told that Children and Health Care Week was held every year during the third week of March and is sponsored by the Association of Care of Children's Health (ACCH).

Everyone at the meeting became very excited. This sounded like a wonderful idea. They soon realized they were all working toward a common goal, so they joined together and spread the news of this great plan. And that was the beginning of Children and Health Care Week at MGH and the formal integration of family-centered care into pediatric practice.

That was ten years ago, and due to the commitment of everyone involved, the tradition lives on. I have been involved in Children and Health Care Week since the very beginning, and it's still exciting to see the interdisciplinary committee come together to discuss and vote on the theme for the coming year. After we decide on a theme, members of the committee decide what tasks have to be done to make the week a success. One of our biggest tasks is planning the annual children's health fair.

In 1997, the committee was small, and so was the fair. Twelve booths were set up in the Walcott Conference Room, and 208 people attended the fair that year. It was an exciting start.

As more and more disciplines became invovled, the annual children's health fair outgrew the Walcott Conference Room. The Timilty Middle School and the Boston Fire Department joined our team, and other activities were added to our celebration of Children and Health Care Week. Grand Rounds, Family-Centered Care Awards, and unit-based activities for pediatric inpatients became part of the mix.

In 2000, the MassGeneral Hospital *for* Children was created, and Pedi the Bear, our mascot, made his first appearance at the fair. It wasn't long before the fair grew so big, we had to move into tents on the Bullfinch terrace. By 2005, there were 58 booths, and more than 2,200 people attended.

Incredible.

On the day of the fair children arrive in large groups with their schools or with their parents. Children and families learn together as they make their way through the fair, goody bags in hand, learning about the operating room, physical therapy, the Chaplaincy, pet therapy, food and nutrition, fire safety, and lots of other fun, health-related topics.

When it's all over, staff have a whole new batch of memories as they reflect on the smiles on those young faces and the challenging questions they always manage to ask. Those memories inspire us to be the best we can be as we continue to provide family-centered care at the MassGeneral Hospital *for* Children.

Pam Wrigley, RN, gives children a chance to experience the operating room up close and personal at the 2005 health fair

Food and nutrition services in the NICU

—by Martha Lynch, RD, senior manager, Clinical Nutrition Services

Jamie Sheldon is a senior clinical specialist and registered/licensed dietitian in the department of Nutrition & Food Services. She has worked at MGH for almost 18 years; the past ten specializing in neonatal nutrition. Sheldon is part of the Neonatal Intensive Care Unit (NICU) team, caring for newborn and premature patients with complex medical issues.

Proper nutrition is important to people of all ages, but it is particularly important in the NICU where you can see tangible results such as improvements in growth and development every day. Babies admitted to the NICU have significant nutritional needs. Sheldon, or another pediatric registered dietitian (RD), assesses these infants, develops an individualized plan, and follows their progress very closely. The nutrition plan is constantly fine-tuned according to the infant's responses and changing conditions.

Babies in the NICU are at risk for nutrient deficiency due to premature birth and the increased nutrients needed for rapid growth. Preterm babies have immature gastrointestinal (GI) tracts, which means that feeding by mouth or with a feeding tube (enteral feeding) can be a challenge. Babies receive most of their prenatal nutrients (such as calcium, iron, and fat) during the third trimester of pregnancy. Since premature babies miss much of the third trimester, these nutrients need to be provided after birth with a combination of intravenous and enteral nutrition. If an infant is too sick to be fed initially, catching up when he/she is able to take nutrition becomes even more difficult. And prolonged periods of intravenous and enteral feeding can impact liver function, bone development, and growth.

Reasons for admission to the NICU vary greatly, and each reason requires a special plan for nutrition. Once patients at risk are identified, a nutrition assessment is performed and a care plan is developed. The assessment involves reviewing the baby's birth history, head circumference, weight, length, lab data, social information, feeding method, and nutrient requirements. Growth, tolerance to feeding, calorie and protein intake, and vitamin and mineral intake are monitored frequently, and the plan is adapted based on the baby's progress. Every plan is individualized to the unique needs of each baby.

Sheldon works closely with NICU nurses, doctors, and nurse practitioners when implementing a plan of care. Babies can remain in the NICU for months, but discharge planning starts as soon as they're admitted. Sheldon meets with parents to review the feeding plan and make sure they understand what needs to be done at home. And she arranges follow-up care with the outpatient pediatric dietitian.

In addition to direct care, patient education is a big part of Sheldon's job. She gives lectures to incoming medical staff and to nurses as part of their core curriculum.

There have been many advances in neonatal nutrition over the past 20 years, and each new advancement is incorporated into NICU practice.

Sheldon recalls a baby who was born at 27 weeks gestation with a birth weight of 800 grams (one pound, 12 ounces). The baby required intravenous feeding for the first three weeks of his life. Skeletal X-rays at six weeks of age revealed that his bones weren't developing well, which is common in such small, premature babies. Sheldon made changes to the baby's formula, and his bone development improved. Sheldon monitored and adapted this baby's care plan throughout his 11-week stay in the NICU, and he weighed 2,400 grams (five pounds, five ounces) at discharge.

Seeing critically ill infants improve and progress to good health is a rewarding experience for all pediatric nutritionists.

Jamie Sheldon, RD, senior clinical specialist

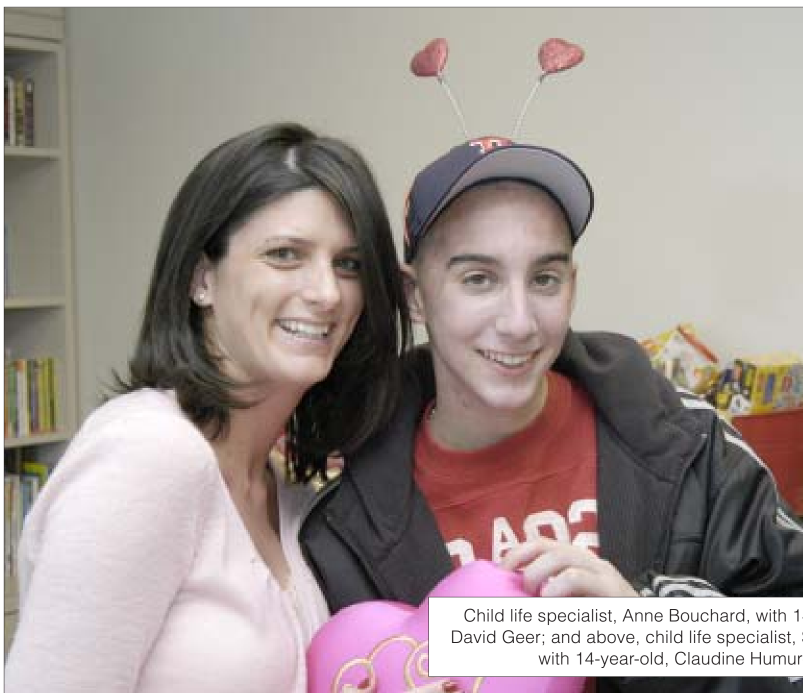
The Child Life Program at MGH*f*C

—*by Anne Bouchard, CCLS, child life specialist*

Child life specialists at the Mass-General Hospital *for* Children promote a positive hospital experience for children and families. Child life services include interventions aimed at reducing stress and anxiety. The role of a child life specialist is to ensure that every pediatric patient's physical, mental, and emotional needs are met as routinely and proficiently as their medical needs. Our main goal is to create a comfortable environment in the hospital that fosters optimal human development, decreases stress and anxiety, and helps children develop positive coping skills. Child life specialists are primarily based on the Ellison 17 and 18 pediatric units and in the Pediatric Hematology-Oncology Unit, but referral services are provided to patients in the Pediatric Intensive Care Unit, Emergency Department, Transplant Unit, Endoscopy, the operating rooms, and anywhere else pediatric patients receive care.

Play, socialization, and normalization are integral parts of the child life program and help children cope with the stress of hospitalization. During play, children learn to express their feelings associated with illness, injury, and the healthcare experience. Child life specialists design and modify play activities to meet each child's unique needs through arts and crafts, games, books, stuffed animals, and other activities.

Expressive, dramatic, medical, and vicarious play are the most common types of play. Hospitalized children have anxiety and concerns about their bodies, their physical condition, and impending procedures or events. Fostering play activities gives children an opportunity to express their feelings, become familiar with medical equipment, and practice new coping strategies.



Child life specialist, Anne Bouchard, with 14-year-old, David Geer; and above, child life specialist, Sacha Field, with 14-year-old, Claudine Humure

An important element of the child life program is preparing children for hospitalization, clinic visits, and medical procedures. Patients are supported through the use of various coping and distraction techniques. Bubbles, picture books, and sensory toys are used to distract a distraught toddler. Guided imagery and music are often used to decrease anxiety and distress in adolescents. Our pre-admission program familiarizes children and their families with the hospital environment and any procedures they may be scheduled to have. Our school re-entry program helps ease the transition of children back into the school setting after a lengthy hospitalization or serious diagnosis.

The presence of family members can have a positive effect on a child's ability to adjust to the healthcare setting. We strongly encourage family involvement in patient care. Hospitalization disrupts the whole family. By including parents and siblings in therapeutic activities, we help 'normalize' the hospital experience.

The child life program at MGH is supported by a large and committed group of volunteers, under-graduate and post-graduate students from Wheelock College, donations and involvement from community organizations such as Angels Above, and the kindness and generosity of many, many people.

Child life specialists at MGH are:

- Anne Bouchard, CCLS
- Sacha Field, CCLS
- Marilyn Gifford, CCLS
- Ashley Laliberte, CCLS
- Heather Peach, CCLS; Hematology-Oncology Outpatient Clinic

For more information about the Child Life Program at MGH*f*C, call 4-5727 or 4-5839.

One child's story

—by Sarah Conway, 13 years old

My name is Sarah Conway. I'm 13 years old, and I live in Connecticut with my family. I'm the oldest of six children.

In early 2005, I started having headaches; more headaches than children my age are supposed to have. Over the next couple of months, they got so bad, no medication would help. As time went on, I started to vomit when I got these headaches. In June, when my family and I went on vacation, the headaches were at their worst. By the end of the week, they were so bad, we cut our vacation short. The next morning, my mom called a doctor, and we went to see him immediately. The doctor looked in my eyes for about 15 seconds and said I needed to have a CT scan right away.

I had the scan, and it showed I had a tumor in the third ventricle of my brain. The next day, I had an operation to drain the fluid that was building up because of the tumor. When I woke up, my headache was gone for the first time in months. During surgery, they took a small piece of the tumor to see if they could find out what type it was. The diagnosis was a malignant brain tumor.

13-year-old, Sarah Conway, and her mom meet with pediatric radiation oncology nurse, Rachel Bolton, in the waiting area of the Proton Beam Radiation Center; and below in the exam room

About ten days later, I had another operation to try to remove the tumor, but it was unsuccessful. We decided to seek help somewhere else.

After more surgery and chemotherapy, they finally succeeded in shrinking the tumor to the point that it no longer showed up on the MRI. I was so happy and relieved; but unfortunately, that wasn't the end of my treatments.

I was referred to the Proton Beam Radiation Center at MGH to try to kill any remaining cancer cells that might be lingering. Treatments began in December and ended in February. By the time I finished proton beam radiation therapy, I had had 33 treatments in all.

The first time I saw the proton machine, I felt overwhelmed; it was a bit scary. But I quickly became accustomed to it, and pretty soon I could just climb onto the table and relax. I had to wear a special mask that they made for me at the beginning of treatments. They had to put a warm, mesh-tape material on my face (which actually felt good). The mask hardened, and they put it on my face every time I went for treatment to help keep my head still.

Treatments were quick, usually about 15 minutes, and painless. During the course of my treatments, I stayed in Boston at the Ronald McDonald House during the week and went home on weekends.

I'm very excited to be finished with my treatments and getting my life back to normal.

Pediatric physical therapy at MGH*f*C

—by Anne Chastain, PT, physical therapist

Pediatric physical therapists support children's motor development to maximize their ability to function and promote participation in all their natural environments, including: home, school, and community. The outpatient Physical Therapy Department at MGH*f*C provides children with evaluation and treatment related to:

- musculoskeletal, neurologic, and orthopaedic disorders
- balance and coordination problems
- delayed gross motor development
- infant torticollis/plagiocephaly
- posture and movement abnormalities
- equipment and seating needs
- Gait disorders
- consultation to schools and day care

The physical therapy assessment process is comprehensive and includes an examination of multiple systems, including: musculoskeletal, neuromotor, and cardiopulmonary. The examination typically includes an assessment of the child's developmental status in gross motor skills using standardized testing, clinical observations, and information gathered from the patient, the parents, and any school reports that may be available.

Outpatient visits to the physical therapist include age-appropriate developmental play so therapy sessions are fun as well as therapeutic.

The Pediatric Therapy Team (PTT) offers a day-long, comprehensive, team evaluation that consists of assessments by a physical therapist, a speech-language pathologist, and an occupational therapist. A PTT evaluation can be scheduled by calling 617-724-0767.

For more information about pediatric physical therapy, call 4-0125.

Above: physical therapist, Maria Fitzpatrick, PT, works with patient, Erica Saravia, in the physical therapy gym.

At right: pediatric physical therapists, Anne Chastain, PT (center), and Lilian Dayan-Cimadoro, PT, work with 19-month-old, Mohamed Alsakkaf, to improve balance and motor skills.

MGH Pediatric Radiology: simply i-n-c-r-e-d-i-b-l-e

—by Mary Johnson, RT(R); Heather McPherson, RT(R); Marie Oliver, RT(R); and Ladora Rose, RT(R)

One of the toughest and most rewarding aspects of a radiology technologist's job is imaging pediatric patients. Parents and children require special attention when they come to an unfamiliar environment for care.

From the moment you enter the pediatric radiology setting, you are greeted by a friendly, professional staff member who makes the experience of patients and families a pleasant one. All examinations are performed by experienced pediatric imaging technologists on state-of-the-art equipment, and interpreted by fellowship-trained pediatric radiologists.

Our goal is to provide the highest quality imaging services while respecting the goals and preferences of each child and family. The Pediatric Radiology Department strives to provide an 'incredible' experience for patients and families. Coincidentally, the incredible nature of our program makes a useful acronym to describe the services we provide.

I-N-C-R-E-D-I-B-L-E

Innovation. The innovative care we bring to each patient puts us on the cutting edge of pediatric care.

Needs. More than just a name on a requisition form, pediatric patients are little people with big and varied needs, such as comfort, compassion, confidence, and direction.

Caring. When it comes to sincere concern for patients and their families, the Care Bears have nothing on the Pediatric Radiology Team.

Radiation Protection. Children are more sensitive to low levels of radiation than adults. We strive to reduce exposure by checking previous radiological exams, positioning children properly, using the minimum exposure necessary, and using effective distance, shielding, collimation, and communication.

Enthusiasm. Enthusiasm is contagious and critical when 'connecting' with pediatric patients and families.

Donations. We appreciate the stuffed animals, prizes, books, posters and stickers that have been donated to the pediatric area. The smiles they bring to our patients are truly priceless.

Individuality. By recognizing the unique characteristics, culture, age, history, and family situation, of each patient, we deliver exceptional diagnostic care, one patient at a time.

Babies. Babies and children are our specialty.

Learning. Pediatric Radiology is a dynamic and effective team because we're constantly learning from each other and our patients.

Excellence. Excellence is not optional.

Over the years, our team has developed some useful guidelines for making the pediatric radiology experience a postive one:

- Prepare in advance
- Introduce yourself and other team members
- Use age-appropriate language
- Explain procedures
- Demonstrate the procedure using yourself or a stuffed animal
- Sing songs
- Ask questions about a child's favorites things
- Talk about school, family, or sports
- Make up a story
- Listen to music
- Be familiar with children's TV programs
- Provide services quickly and accurately
- Always smile and be gentle

The pediatric radiology team will continue to maintain the highest standards of excellence in providing *incredible* care to our youngest patients.

Pediatric Radiology staff members (l-r): Heather McPherson, RT(R); Marie Oliver, RT(R); Ladora Rose, RT(R); Colleen Iudice, RT(R); Mary Johnson, RT(R); and Deb Gorham, RN

Pediatric Occupational Therapy

—by Elizabeth O'Farrell, OTR/L

"The act of playing is an important tool that influences a child's life. The primary goals of childhood are to grow, learn, and play. It is often through play that children learn to make sense of the world around them. It is a child's 'job' or 'occupation' to play to develop physical coordination, emotional maturity, social skills to interact with other children, and self-confidence to try new experiences and explore new environments."
—American Occupational Therapy Association, 2002

Sometimes children are confronted with cognitive, physical, or mental-health challenges that impact their normal development. Occupational therapists (OTs) work with these children and their families to develop age-appropriate skills focusing on activities of daily living (ADLs), such as feeding and dressing oneself, playing, socializing, learning, and vocational pursuits.

At MassGeneral Hospital *for* Children, OTs work with children of all ages in varied settings, from the Neonatal Intensive Care Unit to general medical pediatric units. Some common medical diagnoses of children receiving OT include prematurity, traumatic brain injuries, developmental delays, pervasive developmental disorders, sensory integration and processing disorders, orthopaedic injuries, cancer, congenital and acquired neurological injuries, and gastro-intestinal disorders.

Occupational therapists may help:

- teach a third-grader in a bulky arm cast ways to comfortably manage school tasks such as handwriting
- educate a parent in how to safely and independently feed their premature baby, who requires supplemental oxygen to breathe.
- facilitate upper-body strength and coordination in an 18-month-old with low muscle tone so he can hold a toy with both hands.
- educate the parents of an 18-year-old who suffered a severe traumatic brain injury on how to aid neurological recovery by limiting excess stimulation in his hospital room

Occupational therapists work in both inpatient and outpatient settings. They are part of multi-disciplinary teams, including PRIME (the Pediatric Rehabilitation and Injury Management Evaluation team), the Feeding Team, and the CORE Team (consisting of Occupational Therapy, Physical Therapy, and Speech, Language & Swallowing Disorders). Whenever the medical team consults Occupational Therapy, an evaluation is performed highlighting the child's strengths and areas of need. At that time, either a direct OT intervention will occur, or the child may be referred to a provider in an outpatient or school setting. Integral to OT treatment is the inclusion of the child's family and care providers.

To learn more about Occupational Therapy and its role with children, visit: www.aota.org.

For more information about Occupational Therapy at MGH, contact Jane Evans, clinical director, Occupational Therapy Services, at 4-0147.

Pediatric occupational therapists, Julie Park, OTR/L (left), and Liz O'Farrell, OTR/L, work on developing play skills with 19-month-old, Mohamed Alsakkaf

A Look Back

From humble beginnings...

1997

The first children's health fair is held in the Walcott Conference Room (with 12 educational booths and 208 visitors), and the first pediatric issue of *Caring Headlines* is published—the theme, "Health Care Everywhere"

1998

The health fair moves to the Wellman Conference Room (20 booths; 426 visitors), and live music is introduced to Children and Health Care Week with a family concert featuring the Celebration Shop Singers. The first presentation of the Family-Centered Care Awards is held this year.

1999

The Boston Fire Department lends its fire-safety, Safe House on Wheels, to the children's fair (28 booths; 812 visitors). MGH receives award from the Association for the Care of Children's Health (ACCH) for its celebration of Children and Health Care Week; and this is the first year that multi-disciplinary pediatric grand rounds are held.

2000

The children's health fair outgrows MGH conference rooms and moves to the Bulfinch terrace (1 tent; 41 booths; 1,108 visitors). Students from the James P. Timilty Middle School help staff booths as part of our educational partnership with them. The year 2000 sees the creation of the MassGeneral Hospital *for* Children and the first recorded sighting of Pedi, the Bear.

2001

Playing off *2001: a Space Odyssey*, the theme of this year's health fair is, "2001: a Healthcare Odyssey." The Bulfinch terrace is transformed into a futuristic, space-age extravaganza, and attendance at the fair earns Girl Scouts an official Health Care Badge (2 tents; 54 booths; 1,209 visitors).

Celebrating ten incredible years

Continued on next page

What else would you call the children's fair in an Olympic year—"The Olympics of Good Health." And this year, the Boy Scouts earn Health Care Badges for their attendance (2 tents; 54 booths; 1,866 visitors).

2002

2003

After months of intensive planning and preparation, the Children and Health Care Week Planning Committee decides to cancel this year's fair due to a heightened national terrorist alert. Always erring on the side of safety, the fair is 'down-sized' and brought to the pediatric units for the enjoyment of inpatient children (15 booths).

Expanding on the nautical theme of the pediatric units at MassGeneral Hospital *for* Children, this year's fair is, "Jump Aboard for Good Health!" (2 tents; 56 booths; and a record 2,500 visitors). Reinforcing the spirit of health education driving the children's fair, this year's event meets the requirements for MCAS Education Day.

2004

2005

In a year when the Boston Red Sox *and* the New England Patriots win world championships, what's a children's health fair to do? "Champions of Good Health," of course (2 tents; 58 booths; 2,200 visitors).

Children's Health Fair 2006 under the Bulfinch tent "You're incredible!"

2006

Children and HealthCare Week Activities

April 24th
Hurt Alert Day

April 25th
"Moon Balloon," presented by Joan Drescher

April 26th
Family-Centered Care Awards

April 28th
Children's Health Fair

On in-patient units:

April 24th
Caricature Artist

April 25th
Angels Above Party

April 26th
Queen for a Day

April 27th
Ice Cream Party

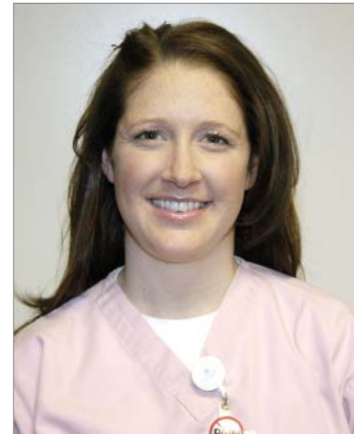
April 28th
Health Fair

(see full schedule on page 13)

of children and health care!

Young patient helps pediatric nurse realize her true calling

Meghan McDonald is an entry-level clinician



Meghan McDonald, RN
pediatric staff nurse

My name is Meghan McDonald, and I am a new nurse to the Pediatric Unit at MassGeneral Hospital *for* Children. As with any job, some days are calm and trouble-free, while others are jam-packed and can't end quickly enough. But I've found one truth: At the end of a long day, I'm always proud of the work I do and grateful I've chosen a career where I have the opportunity to serve others. I learn something new every day—from new medications to new diseases to new technology. Nothing, however, has been more powerful than the lesson I've learned about service. Already, I've realized that in giving, I also receive.

I don't think I could count how many times I hear a patient say, "Thank-you," or listen to a parent express her appreciation, or enjoy one of the many treats families bring to express their gratitude. But it wasn't until I encountered a 17-year-old girl with kidney, pancreas, and liver failure that I realized how *much* a nurse can receive.

For a lifetime, Amy had battled complications of cystic fibrosis. Like many patients, her hospitalizations were no more than two-week courses of antibiotics, physical therapy and diabetes-management. But the past year had brought a new scare. Her body had simply surrendered to the disease, and news of triple organ failure suddenly became a harsh reality. The only hope for Amy was the possibility of new kidneys, a new pancreas, and a new liver.

It seemed like a typical day. I looked forward to getting home after 7:00 and giving my feet a rest. But an hour before I was supposed to leave, Amy took a turn for the worse. I got a call from the Hematology Lab informing me that her potassium level was critically elevated. In a state of crisis, I worked hard to remain calm and explained the life-threatening situation to Amy.

Frightened, she asked, "What's going to happen to me?"

As a new nurse, I was unsure of what to say in this unnerving situation. It felt like a million years before I was able to say anything.

At last, I explained how potassium levels affect the body and the risks associated with elevated potassium levels. Amy didn't raise her head or even respond to my explanation. I sensed her fear as she remained silent. I assured her the medical team and I would work hard to keep her safe and contact her parents immediately.

"I don't know how you feel or what you're thinking," I said, "But I do know I'll be right here at your side to support you through this. If there's anything you need, please don't hesitate to ask."

I assured her I wouldn't leave until her parents arrived. I know how important a nurse's presence is, and I knew she needed support.

After beginning a calcium gluconate bolus and administering kayexalate, the only thing left to do was wait to hear what her new potassium level was. In those uncertain moments waiting to hear from the lab, I gave her a back massage in hopes of easing her anticipation. As I watched her cardiac monitor, I noticed both her heart and respiratory rate slowing. I felt her neck loosen and her hands released their tight grip. I felt her body relax and watched as she drifted off to sleep.

Seeing her respond to the massage, I realized what a gift it is to be a nurse; how with the simple touch of my hands, I had let her know I was with her, and she was able to relax.

It took 24 hours for her potassium level to come down, but I realized that much more had happened that day than pharmacology. I had helped Amy in a very real way.

Though I had been in her room many times that day, I didn't notice the elaborate decor until I began giving her a massage. Every inch of the walls were covered with quotes, flowers, balloons, even letters from strangers who had heard about her illness. From the look of her room, it seemed as if the whole world was with her, shouting, "Yes, you can!"

As I sat there, I couldn't help realizing how relentless she had been. Her daily routine was marked by medications, blood-sugar tests, and respiratory care when she should have been cheer-leading and going to homecoming dances.

Regardless of her powerless state, she never

continued on next page

Quick Hits to improve your writing!

A low-stress, high-yield class aimed at helping develop your writing style and eliminate some of the angst associated with writing

Offered by Susan Sabia, editor of *Caring Headlines*

Classes now scheduled for:

Monday, April 17, 11:00am–2:00pm
Tuesday, May 30, 11:00am–2:00pm
Monday, June 12th, 10:00-1:00pm
Wednesday, July 19, 12:00-3:00
Monday, August 14th, 10:00-1:00

All classes held in GRB-015
Conference Room A

Classes limited to 12; pre-registration is required
To register, call Theresa Rico at 4-7840

complained. She waited patiently for that phone call telling her, "We have your organs."

I looked at her and thought, "Thank-you," because never had I been so grateful for my life until that moment.

Unfortunately, Amy didn't make it to that phone call. On March 2, 2006, Amy finally let go. She told her parents she loved them and peacefully said good-bye.

A wise professor once explained how people should choose the profession that's right for them. He said, ask yourself, "Is this profession something you're interested in?" If yes, ask yourself, "Are you good at it?" If yes again, ask yourself, "Is this something that will better serve the world?" If you answer yes to all three, you've found your true profession, your vocation.

My experience with Amy has led me to answer 'Yes' to these questions. I'm more certain than ever that I've found my true vocation. I'm proud to call myself a pediatric nurse.

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

In the first year of practice, it can be overwhelming for a new graduate to absorb all the complexities and nuances of caring for a critically ill patient. This is a time when they are gaining an understanding of the patient experience. In this story, Meghan was given the opportunity to be present to Amy during one of the most difficult and intimate times in a patient's life. I'm sure this experience will be one of many memories that stays with Meghan throughout her career, guiding her to be the best nurse she can be.

Thank-you, Meghan, for sharing this story.

March is Colon Cancer Awareness Month

Take a moment to learn more about the screening, prevention, and treatment of colon cancer during Colon Cancer Awareness Day

Friday, March 24, 2006
10:00am–2:00pm in the Main Corridor

10th annual Children and Healthcare Week

Schedule of activities

April 24, 2006
Hurt Alert Day (children's activities throughout the hospital)

April 25, 2006
12:00pm, O'Keeffe Auditorium
Grand Rounds
"Moon Balloon," presented by Joan Drescher
buffet lunch, all are welcome

April 26, 2006
1:00pm (location TBA)
Family-Centered Care Awards

April 28, 2006
9:00am–3:00pm, under the Bulfinch Tent
Children's Health Fair

Activities for in-patient children:
April 24: Caricature Artist
April 25: Angels Above Party
April 26: Queen for a Day
April 27: Ice Cream Party
April 28: Health Fair

For more information, call 4-5720

Artist in residence

inspiring individual expression

Artist in residence, Joan Drescher, works with children in the Ellison 17 playroom, encouraging creativity, imagination, and the free expression of feelings

Pediatric Operations Committee invites parents to take a seat at the table

—by parents, Carole Trainor and Seta Atamian

My name is Carole Trainor. I have many different roles in my life and am many things to many people. But first and foremost, I am the mother of two beautiful boys. It was through my role as a mother that I first came to participate in the Pediatric Operations Committee as a family advisor.

My introduction to the MassGeneral Hospital *for* Children came in December, 1999, following my son, Stephen's, bone marrow transplant and frequent, subsequent hospitalizations. Nurses, of the Pediatric Hematology-Oncology Unit and the Ellison 18 Pediatric Unit cared for my son during his time here until his death in February, 2001. Stephen's illness and death brought about profound changes in the everyday activities I had once taken for granted. I had a new understanding and appreciation for the challenges faced by families with a seriously ill child.

My desire to channel what I had learned into improving the experience of other children and families led me to the MGH*f*C Family Advisory Council. In February, 2004, Seta Atamian and I were invited to participate on the Pediatric Operations Committee to provide the perspective of parents and families.

The transition to including family members on this committee seemed to occur with great ease, and I was encouraged by how clinical and administrative committee members seemed to value our contributions and opinions.

Every year, the committee identifies projects or initiatives to help improve the quality of care to children and families. Recently, family-centered care and pediatric palliative care were identified as important areas of focus. Seta has played a key role as co-chair of the Family-Centered Care Subcommittee, and I have acted as family advisor on the Pediatric

continued on next page

Parent, Seta Atamian, (pictured above) sits in on recent meeting of the Pediatric Operations Committee

Pediatric caregivers coordinate toy drive for Rwandan orphanage: send holiday cheer to friends in Africa

When 14-year-old, Claudine Humure (pictured above with staff nurse, Sandra Pugsley, RN), was brought to MGH last year, she left behind family and friends in a Rwandan orphanage. As a holiday project, staff coordinated a drive to collect toys and games to send to the orphanage. Pictured at left are (l-r): Anne Bouchard, CCLS, child life specialist; Sacha Field, CCLS, child life specialist; and Patti Scott, RN, staff nurse.

Pediatric Pharmacists

Pharmacists, Bob Young, RPh, and Fallon Vaughan, RPh

Pediatric pharmacists are part of a large team of professionals caring for children. Pediatric pharmacists have a combined understanding of physiology and pharmacology to ensure effective drug treatment for children of every age. As many parents know, if medications don't taste good, children won't take them; so ensuring that medications are palatable is a big part of the job. After years of formal pharmacological education, there is still a lot of on-the-job-training required to be fully prepared for pediatric pharmacology.

At the MGH*f*C, pharmacists are committed to ensuring that our youngest patients get the safest, most effective medication in doses appropriate for their specific needs. Every time a pharmacist receives a new medication order, he/she evaluates the patient's entire health profile including age, weight, and other medications. The goal is to always provide the safest medication to make pediatric patients feel their best.

Parents

continued from page 14

Palliative Care Subcommittee. The group has demonstrated great interest in working with parents, being flexible in the scheduling of meetings, and reaching beyond the hospital to support pediatric palliative care legislation.

I welcome the opportunity to shed light on the unique needs of families caring for children with life-limiting diagnoses. I'm hopeful that a formal Pediatric Palliative Care Program will have a positive impact on the lives of children and families at the MassGeneral Hospital *for* Children.

Seta Atamian

My name is Seta Atamian. I can't believe it's been two years since Carole Trainor and I were invited to participate on the Pediatric Operations Committee.

Since my daughter became a patient in 1999, we have accrued many experiences in a variety of healthcare situations. I joined the MassGeneral Hospital *for* Children's Family Advisory Council in 2001 to try to 'give back' to a system that had supported my child and my family through thick and thin. It has been wonderful representing the voice of families on this committee.

Becoming a patient is inherently stressful to children and families. It sets off a huge chain of events ranging from inquiries from concerned friends and loved ones, to drastically altered personal and professional lives, a roller-coaster of emotions, and the beginning of sleep-deprivation as a way of life.

Patients and families need to be encouraged to participate in their own healthcare planning and decision-making. This may represent a shift for some patients and families accustomed to being 'passive' recipients of care and for some providers accustomed to delivering care with no input from patients and families.

The Family-Centered Care Subcommittee is addressing many of these issues with projects such as:

- our campaign to promote education about the core concepts of patient- and family-centered care
- exploring the possibility of including patients and families on rounds
- encouraging partnerships by involving parents and families in program- and policy-development and representation on various other committees
- recruiting more family advisors
- creating documents that involve patients and families directly in their own care

I'm confident that these efforts will reap many rewards for the children and families of the MassGeneral Hospital *for* Children. It's a privilege to work alongside the creative, committed, and talented professionals on this committee, and I look forward to serving in this capacity that promotes the well-being of children and families in a place where children can go about the business of 'just being a kid.'

Do you believe in angels?

—by nurse managers, Brenda Miller, RN, and Judy Newell, RN

Do you believe in angels? We do. We walk among them every day. The dictionary defines angels as spiritual messengers; watchful guardians; those who manifest goodness, purity, and selflessness. Based on that definition, we think pediatric caregivers qualify for angel status. Every day, pediatric caregivers help children and families accept, cope, and live with the lives and deaths they face. Children are the future. It's daunting to think that you hold the future in your hands, caring for children physically, mentally, and emotionally. On pediatric units (both inpatient and outpatient) often the pain of sadness and loss is palpable. But staff weave their way through it, somehow separating themselves from it while at the same time diving headlong into it.

Pediatric staff nurse, Kim Waugh, RN, with 6-year-old, Maverik Riel, on the Ellison 17 Pediatric Unit.

Orchestrating the life or death of an ill child, and sculpting those experiences into memories for parents and families is the intimate and routine world of a pediatric caregiver. We paint a scene for others to remember, a keepsake that each family will have forever. These scenes are etched into the memories of the caregivers as well, some remembered as vividly as the day they happened.

If you've ever heard a symphony orchestra, you know how a conductor can seemingly invisibly create a cornucopia of sounds and music that swell to a magnificent crescendo. When done well, all within earshot are changed just a little.

On pediatric units, nurse managers are the conductors, seemlessly orchestrating the members of the team, always including family members. The team works together, single-mindedly building toward that crescendo—the future of a life.

Angels in disguise are truly what they are. Creative in practice, colorful in dress, and incredible by nature. We see them among us every day. We pray for the insight to recognize them, the clarity to remember their gentle interventions, and the strength to support the amazing work they do with children and families.

In the GCRC Research Unit, staff nurse, Kathleen Egan, RN (left), draws blood from 12-year-old, Jaquilla Edwards-Keyton as part of a protocol screening. At right, staff nurse, June McMorrow, RN, explains IV blood sparing technology to 13-year-old, Sarah Robinson, during an overnight stay.

The Neonatal Emergency Transport Team

—*by Anita Carew, RN, nursing coordinator, Neonatal Emergency Transport Team*

For more than 28 years, the MGH Neonatal Transport Team has been transporting critically ill infants from outlying locations to the Neonatal Intensive Care Unit (NICU) on Ellison 3. Some infants are transported from as far away as New York, Bermuda, Cape Cod, and New Hampshire; others come from as close as our partner hospitals, Salem and Newton Wellesley. The team transports more than 200 infants every year.

The Neonatal Transport Team is comprised of a registered nurse, a registered respiratory therapist, and a physician. Currently, more than 20 nurses in the NICU have been trained to practice as part of the transport team.

When an outlying hospital needs to transport an infant requiring more specialized care than they can provide, the physician activates the emergency transport team. Once admission is approved, the team is mobilized, and an ambulance is deployed to pick up the team (and any equipment needed to care for the infant en route to MGH) and take them to the referring hospital. The Neonatal Transport Team is a traveling intensive care unit, equipped for any emergency. We take great pride in the safe, expert care we provide during every transport.

Many of the infants we see/transport suffer from prematurity, respiratory distress, surgical emergencies, congenital anomalies, heart failure, and other serious medical conditions. It's not uncommon for extremely premature infants (weighing less than one pound) to be transported to MGH for care. Many critically ill infants are in need of extra corporeal membrane oxygenation (ECMO) therapy. Once infants are stabilized in our NICU, they're transported back to their originating hospitals to be closer to their families.

In the spring, the NICU will be moving to its new home on Blake 10. The team is very excited about this move, as the new space will offer overnight accommodations for a parent to stay with his/her infant ensuring a higher level of family-centered care.

The Neonatal Transport Team can be activated by calling 617-724-HELP, or the 1-800-MD-REFER line. For more information, contact Anita Carew, RN, at 4-4310.

Robert Insoft, MD, medical director (back left), and Anita Carew, RN, nursing coordinator (back right), with members of the Neonatal Emergency Transport Team, at recent Neonatal Emergency Transport Conference

Published by:

Caring Headlines is published twice each month by the department of Patient Care Services at Massachusetts General Hospital.

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Written contributions should be submitted directly to Susan Sabia **as far in advance as possible.** *Caring Headlines* cannot guarantee the inclusion of any article.

Articles/ideas should be submitted by e-mail: ssabia@partners.org
For more information, call: 617-724-1746.

Next Publication Date:

April 6, 2006

Please recycle

Advanced practice nursing in Pediatric Orthopaedics

—*by Erin S. Hart, RN, nurse practitioner*

The Pediatric Orthopaedic Team continually sets new goals and looks for new ways to improve the patient and family experience. As a nurse practitioner, I work collaboratively with three pediatric orthopaedic surgeons, primarily in the ambulatory clinic, but also providing inpatient care. There was a steep learning curve in developing this advanced practice role, but I feel privileged to be part of such an incredible team.

There are many components to my practice, some are common to all nurse practitioners, others are unique to my role. For surgical patients, I often perform pre-operative assessments and physical examinations during their initial visit. I provide any necessary teaching and guidance for patients and families. Working collaboratively with the orthopaedic surgeons, I obtain informed surgical consent, follow patients throughout their inpatient post-operative course, address any questions and concerns that may arise, and follow patients long-term, if necessary, in our outpatient clinic.

We recently developed a number of educational hand-outs and brochures, and we've established a new website that's easily accessible for individuals seeking information on common pediatric orthopaedic conditions.

The Pediatric Orthopaedic Team was recently awarded a Making a Difference Grant, which will be used to create a digital library with CDs and DVDs describing the diagnosis and treatment of common orthopaedic conditions and addressing many of the questions and concerns that frequently arise. The first DVDs, *Broken Bones* and *What to Expect on Your Day of Surgery*, will be available in May of this year.

I'm involved in several research projects, and with the assistance and support of the entire department, I've published several articles in various nursing and primary care journals, including: "The Newborn Foot: Common Diagnoses and Management of Common Conditions"; "Developmental Hip Dysplasia: Implications for Nurses and Anticipatory Guidance for Parents"; "Straight Talk on Scoliosis: Guidelines for Primary Care Providers"; "Slipped Capital Femoral Epiphysis: Don't Miss this Pediatric Hip Disorder"; and "Broken Bones: Common Pediatric Fractures," parts I and II.

Working as a pediatric nurse practitioner in a surgical specialty is a unique position. No two days are the same. I have the opportunity to provide comprehensive care, patient-teaching and family-education, and really make a difference in the lives of our young patients.

Advanced practice nurse practitioner, Erin Hart, RN, above with colleague, Brian Grottkau, MD, in the operating room, and below (second from left) with members of the Pediatric Orthopaedic Team

When/Where	Description	Contact Hours
March 30 12:00–3:30pm	**Basic Respiratory Nursing Care** Sweet Conference Room	- - -
April 5 8:00–11:30am	**Intermediate Arrhythmias** Haber Conference Room	3.9
April 5 12:15–4:30pm	**Pacing Concepts** Haber Conference Room	4.5
April 6 7:30–11:00am/12:00–3:30pm	**CPR—American Heart Association BLS Re-Certification** VBK401	- - -
April 7 8:00am–4:30pm	**MGH School of Nursing Alumni Program** O'Keeffe Auditorium	- - -
April 10 and 11 7:30am–4:30pm	**Intra-Aortic Balloon Pump Workshop** Day 1: NEBH; Day 2: VBK401	14.4 for completing both days
April 10 8:00am–4:30pm	**A Diabetic Odyssey** Thier Conference Room	TBA
April 10 and 17 8:00am–4:00pm	**Oncology Nursing Society Chemotherapy-Biotherapy Course** Yawkey 2220	16.8 for completing both days
April 12 8:00am–2:30pm	**New Graduate Nurse Development Seminar I** Training Department, Charles River Plaza	6.0 (for mentors only)
April 12 7:30am–12:00pm	**Congenital Heart Disease** Haber Conference Room	4.5

Music Therapy

Music therapy is a healthcare profession that utilizes the unique qualities of music to establish a connection with patients; address physical, emotional, cognitive, and social needs; and improve the quality of life for hospitalized children (and adults).

At left, music therapist, Lorrie Kubicek, and 13-year-old, Cornelius Muhammad, enjoy an impromptu jam session in the Ellison 18 rec room.

ED caregivers receive Excellence in Action Award

For some time now, MGH president, Peter Slavin, MD, has been recognizing staff, both clinical and non-clinical with his Excellence in Action Awards to acknowledge the important but often unsung contributions of staff in providing the highest quality patient care. On Friday, February 24, 2006, Slavin visited the Emergency Department to deliver an Excellence in Action Award to members of the pediatric staff.

Slavin shared a letter written by a grateful grandmother:

I just want to let you know how much I appreciate the care given to us in your Emergency Department to the six-year-old patient, to her concerned parents, and to me, the grandmother. I felt we were in very good hands and under very watchful eyes. How do you really explain numbness to a child this age before you anesthetize a laceration? Fortunately, my grand-daughter is well on her way back to good health and being the light of my life.

So often we don't hear about the positives; please let these caregivers know that we all appreciated their care—from the big things to the small things. My grand-daughter is en route home as I type this with much gratitude...

MGH president, Peter Slavin, MD, presents Excellence in Action Award to staff in the Emergency Department. Above, accepting the award on behalf of the team, are: Mindy Sherman, RN (left), and Stephanie Grimes, RN.

For more information about Excellence in Action Awards, contact Mary Cunningham at 4-1004.

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