

April 18, 2002

Caring

HEADLINES

MassGeneral Hospital *for Children:*

Olympians of pediatric care

—by Mary Lou Kelleher, RN, MS,
pediatric clinical nurse specialist

The spirit of the Olympics was alive and well this year in Salt Lake City with tag lines like: 'Light the fire within.' This year as we reflect on the

accomplishments of the Mass-General Hospital *for Children*, we see that same spirit in our work. Courage, commitment, drive, and inner strength are words we hear a lot in connection with the Olympics. But every day at the MassGeneral Hospital *for Children* continued on page 3



When in Rome!
Pediatric staff nurse, Kim Waugh, RN, matches 4-year-old, James Zizza, funny face for funny face in the playroom on Ellison 17.

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Children are the future: *it's not just a catchy slogan*

As we prepare to celebrate Children and Healthcare Week, 2002, we have an opportunity to reflect not only on the outstanding care delivered to children and families by The MassGeneral Hospital for Children, but to think about the impact we all have on children every day. It's not an exaggeration to say that every single interaction we have with children and adolescents makes an impression. Whether in a clinical setting, in a classroom, or in our own homes, the comments we make and the stories we tell form the foundation for how children perceive health care. In many cases, we may be a child's first encounter with a healthcare professional. And today, more than ever, first impressions count!

At a time when the country is facing an unprecedented shortage in healthcare workers (especially nurses, pharmacists and radiology technicians) children really are the future. We need to make the pride and passion we feel for our professions known. We need to tell our stories.

As many of you know, I chair the Partners Chief Nurse Council. One of the initiatives we're currently working on is creating an image campaign to generate interest in nursing as a profession and to attract qualified nurses to our hospitals.

As a preliminary step in developing an effective campaign, we conducted some market research to assess what the current perception of nursing is among junior-high-school and high-

school students, first-year nursing students, parents, and adults who may be considering a shift in careers. Research was conducted using focus groups comprised of individuals identified by an independent research firm. The ideas and perceptions brought forth in these focus groups were both surprising and revealing. In many cases, inaccurate media portrayals and antiquated stereotypes have resulted in a skewed image of what nurses really do.

But despite many misconceptions about nursing as a career, there was universal agreement that nurses are caring, nurturing, compassionate, patient and sincere.

When asked what factors impact their decision in choosing a career, participants identified several common themes, including:

- being able to make a difference in their work
- enjoying what they do
- flexible scheduling to allow more time with family
- the ability to make enough money to support a family and maintain a desirable life-style
- stability
- continuous learning

It was interesting to learn that most participants had some vision of



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

themselves in a certain career by the time they were in the seventh grade. Many of the students interviewed reported that friends and family members play a pivotal role in influencing career choices. First-hand communication with professionals, exposure to the workplace, and 'career days' were also cited as strong influences.

It's clear that the Internet, television, and print media play an important part in providing information to young people about nursing.

I thought it was especially significant that individuals who had had some personal experience or interaction with nurses recognized nurses as important members of the medical team.

A lot of good feedback was generated in our discussions with focus-group participants. This information will be of great value as we move forward in creating an image campaign about nurses.

I think one of the most important lessons we can take from this research is the power that first-hand experience has in influencing a young person's career choice. And we all have the ability to exert that influence simply by talking about what we do; by letting people know that our work is important, dynamic, educational, diverse and rewarding. We need to let young people know that working in health care is a great way to make a difference.

Update

I am pleased to announce that Aileen Tubridy, RN, has accepted the position of nurse manager for the Ellison 10 Cardiac Step-Down Unit. She has served as interim nurse manager for the past 17 months. Aileen's clinical expertise, knowledge and long-standing commitment to cardiac nursing make her the ideal candidate for this position.

Welcome, Aileen.

Call for Portfolios

PCS Clinical Recognition Program

The Patient Care Services Clinical Recognition Program is now accepting portfolios for advanced clinicians and clinical scholars. Beginning May 1st, portfolios may be submitted on the first of each month, and decisions will be made within three months.

Refer to the <http://pcs.mgh.harvard.edu/> website for more details and application materials, or speak with your manager or director.

Completed portfolios should be submitted to The Center for Clinical & Professional Development on Founders 6.

For more information, call 6-3111.

Cover Story

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ren, clinicians, support staff, children, and families reach within themselves to mine new depths of strength and courage to meet the challenges of childhood illness. You might say that MassGeneral Hospital *for* Children has its own team of Olympians—Olympians of pediatric care.

Celebrating only its second anniversary on January 23, 2002, the MassGeneral Hospital *for* Children entered its toddler phase (to borrow from Erikson's theory of personality development). Those of you who have children know that the toddler phase is characterized by a strong sense of independence, will power, and self-control. In that respect, our hospital within a hospital is firmly committed to our mission to provide out-

standing, personalized, developmentally appropriate care for infants, children and adolescents within the context of their families and community.

And we are becoming more independent as our logo is being recognized more and more as a symbol of quality healthcare for children and their families; and a new understanding of pediatrics as a unique specialty has emerged. Our family-centered practice is embraced with pride and respect throughout the entire institution. And like any two-year-old, we continue to test the limits. We continue to look at our practice and assess where and how we can do better.

We applaud the wonderful work of our Family Advisory Committee. This group, made up of patients and family members, has worked diligently with staff to identify ways to improve the pa-

tient and family experience at the MassGeneral Hospital *for* Children. One extraordinary accomplishment of the Family Advisory Committee is the establishment of Project DOCC (Delivery of Chronic Care). This program, managed by Colleen Hammond (parent),

hospital *for* Children was the 20th teaching hospital in the country and the first in Massachusetts to implement this program.

Thanks to a grant from the Elizabeth White-side Foundation and matching funds from the MGH Ladies Visiting Committee, children at the



MassGeneral Hospital
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enlightens professionals about the demands and care needs of children and families living with chronic illness. The program provides opportunities for staff to dialogue with family members and take part in home visits. Project DOCC is a national initiative that began in 1994. MassGeneral Hos-

MassGeneral Hospital *for* Children are able to express their thoughts, fears and dreams through the creative arts. Joan Drescher became our artist in residence in November, 2001. With her 'Imagination Kart' at her side, Joan brings color and fantasy to the bedside under the direction of our child life specialists. Joan visits general care units twice a week and visits the Pediatric Hematology Oncology Clinic one morning a week. Feedback about this program (from children, family members and staff) has been extremely positive, supporting the idea that children experiencing illness are affected by the stress of their illness as well as by the stress of their medical environment (the hospital). In studies conducted across the country, it has been shown that art programs help children to handle this stress and

better cope with the hospital experience. (See story on page 6.)

The day-to-day work and dedication of our multidisciplinary team of pediatric caregivers has established MassGeneral Hospital *for* Children as a center of excellence within the healthcare community. Every day, relationships are formed that become the foundation of the healing process. These relationships are the essence of our practice, providing hope and strength to children and families.

MassGeneral Hospital *for* Children is not a building, it is a team of individuals, each with his or her own personality, skill set, and unique perspective. Our patient-satisfaction surveys tell us that our efforts are making a difference. Just three years ago families rated their overall satisfaction with their children's care at 59.5%. In 2001, their satisfaction climbed to 90.5%. This increase is the result of an entire team of individuals working relentlessly to provide better care and better systems in an environment that is caring, responsive and compassionate.

In the year ahead, we look forward to the phase we're calling the 'thrilling twos' for the MassGeneral Hospital *for* Children. We will continue to grow, develop, and nurture an infrastructure that drives our Olympians of pediatric care to, 'light that fire within.'



James Zizza continues to mug for the camera as Waugh, his biggest fan, looks on.

The other victims of pediatric trauma: parents and siblings

—by Mary D. O'Brien, RN, MS, CS,
pediatric trauma nurse coordinator

Traumatic injury is the leading cause of childhood death and disability. When traumatic injury strikes healthy children without warning, it can quickly overwhelm the coping skills and support systems of even the strongest family. Suddenly, the family is thrust into a crisis they had not foreseen, one that could change their lives forever. Testani-Dufour, Chappel-Aiken, and Gueldner in their article, "Traumatic Brain Injury: A Family Experience," state that, "Without a doubt, patients' families suffer as much, if not more, than the patients themselves."

The article compares traumatic injury of a child to injury of an integrated system. Theory suggests that if one part of a system is injured, then the entire system is injured. It goes on to say that injured families travel through identifiable 'recovery milestones,' and that the flow from initial reaction to re-integration are very similar to the stages of grief.

The first stage can be called the initial reaction. This stage is characterized by utter disbelief, helplessness and frustration. The telephone rings and without warning, a crisis unfolds. The immediate concern

is for the survival of the child. Often, the family just saw the child moments before, and now they're frantically trying to find the answer to the question, "Is the child alive?" If the child has left the scene of the accident or has been transferred to a trauma center, the worst case scenario is feared. During this initial phase, stress can be so acute that families experience difficulty receiving and comprehending information; there is a sense that time has been suspended, there are feelings of dissociation, as if the experience is not really happening.

Even after they learn the child is alive, the family continues on an emotional roller coaster with feelings of anger, grief and guilt. Processing medical information and understanding the decisions that have to be made can be difficult. Often a chaotic re-organization takes place as child care, work responsibilities and family routines are realigned to deal with the immediate crises. An overwhelming need to continue the parental caregiving role when their child needs them the most, may have to be given up temporarily if the child requires resuscitation, surgery, or care in an ICU. During

this time when adults are dealing with the immediate needs of the crisis, siblings are often in despair, struggling with feelings of responsibility and guilt. Frequently, a sibling has witnessed the traumatic event or was involved in the event but escaped injury. If the injury occurred while the children were not following parental rules, feelings of guilt can lead to negative behavior patterns.

Younger children may engage in magical thinking, believing they could have prevented the events that occurred. They blame themselves for the disruption in their family's life. They may become withdrawn or compete for the attention being focused on the injured child.

Older children may take on added responsibilities at home, feeling the burden of having to care for younger siblings. These kids may actually become the 'perfect child' so as not to worry their parents, but secretly worry that normalcy will never return.

During the intermediate stage of reaction, the family focuses on the injured child's physical recovery and adjustment. They ask what the child will be like a month from now, a year from now. Will she be normal, will

she be scarred, will she walk with a limp? Often these questions can't be answered by the medical team, adding to the family's frustration.

During this time, the family begins to form relationships with health-care providers and negotiate the acute care environment of the hospital. They rely on support from extended family members and friends, and continue to try to re-organize their lives and daily routines. Some of the issues they're dealing with include: finding child care and house-keeping support, making arrangements with employers, replacing a motor vehicle, modifying the home environment in anticipation of the injured child's return, and coping with medical, legal and insurance issues.

Toward the end of the intermediate stage, the family may re-experience the stages of grief as they begin to gain insight into the fact that their child may not be the same child they knew before the injury. This phenomenon is experienced most frequently by families of children who sustain traumatic brain injury. The family mourns the loss of the child they knew, especially if the child experienced changes in personality or cognition.

Finally, the family enters the rehabilitation stage where decisions have to be made about home care or care in a

rehabilitation hospital. This stage sees a decrease in professional support and the support of family and friends as they go back to their normal routines. The family begins to assume the full burden of care of the injured child and starts to re-integrate the family to a newly defined normal routine. Finances can be very difficult at this time, especially if there is no insurance, if there's a need for home modifications, medical equipment, and a loss of income due to time away from work. And the family will have to negotiate school re-entry depending on the specific needs of the child.

The major goal at this time is to re-invent normalcy. This means adapting to the changes that have taken place in such a way that each member of the family can continue to grow and have their needs met within the family system. Studies suggest that families have the greatest difficulty re-creating normalcy when dealing with changes in personality, cognition and the disinhibition that accompanies many head injuries.

Luckily, families are resilient in their ability to cope, adapt, and create new normalcy to meet the needs of their members. Staff interventions that can help families in the aftermath of traumatic injury are:

- Provide clear information about the injury
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Children and stress: coping mechanisms for our young patients

—by Elyse Levin-Russman, LICSW
clinical social worker, Pediatrics

We hear a lot about stress today. Whether discussed as a normal part of our lives, or in the context of a host of medical difficulties, everyone seems to experience it. Typically, stress has been considered an ‘adult,’ issue, but plenty of children deal with stress, too. A recent study, published in the American Psychological Association’s *Journal of Personality and Social Psychology*, concluded that normal, healthy children, 9–17 years old, are much more anxious than their counterparts of almost 50 years ago. And other studies support the belief that children today are increasingly more ‘stressed out’ than in past years.

This is understandable. Certainly since September 11th, children feel more vulnerable. Fears about safety and security

are natural. There is uncertainty about future terrorist activity. The world is suddenly perceived as a dangerous place. As adults struggle to cope with the magnitude of these events, so do children.

Even before the horrific events of September 11th, children lived in a more stressful world. The divorce rate has increased, which may limit the involvement of some parents. Difficulties in the economy contribute to family stress. Unemployment and job uncertainty impact the whole family. Many children are ‘latch-key kids,’ who don’t have the supervision children had in past years. Families are more isolated and often can’t rely on support from the extended family during difficult times. With grandpar-

ents, aunts and uncles working or living in distant communities, children are often more independent and more lonely.

Children’s exposure to violence on a daily basis has escalated as television news coverage and dramatic programming consistently show images of explicit violence. Kidnapping, murder, rape and assault come right into the home. The faces of missing children on milk cartons is another reminder of a looming threat. Children learn quickly to be less trusting. The luxury of an ‘innocent’ childhood is fast becoming obsolete.

We live at a time when expectations of our children are very high. Parents expect the best from children in the classroom, on the basketball court, or at band practice. Em-

phasis is placed on competition and winning. There can be enormous pressure for children to succeed; it can come from parents, teachers, coaches, and others.

Standardized tests, such as the MCAS and SATs become associated with success, and children feel pressure to do whatever it takes to measure up. And let’s not forget peer pressure to drink, take drugs, and wear the right clothes. Children perpetually struggle to fit in.

As parents and professionals, what can we do to help our children?

- Recognize stress. This is the first step in helping children to deal with their feelings. Some children will develop stomach aches or headaches. Others may become worried about leaving the house, or may become less interested in usual activities and friends. Others may become irritable or belligerent. Talk about these signs and symptoms with the child; help them find the language to share their feelings.
- Encourage good self care, such as healthy eating habits, hygiene, and regular exercise. This helps children feel better about themselves and establishes the importance of caring for oneself.
- Don’t underestimate the stresses in a child’s life. We can never

know how another person perceives a situation, even if we think it’s not that bad. Validating a child’s feelings can go a long way in helping them feel supported.

- Give children the tools to deal with their stress. Problem-solve with them to develop their own ways of coping. Some children might benefit from learning relaxation exercises, while others might need to cut back on activities that cause them to feel pressured or ‘over-programmed.’
- Supervise their television and computer activities. Younger children should be prohibited from seeing disturbing images and reports, while older children will need an opportunity to process what they see, hear, or read.
- Know when stress becomes so problematic that it interferes with a child’s daily life. Disturbances in sleep, problems concentrating, or withdrawing from social activities are just a few signs that professional help may be needed. Be sure to talk with the child’s pediatrician or school counselor if you have concerns.

For more information about children and stress, contact the MGH Social Services Department, at 726-2640.

Pedi Trauma

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- Allow family to feel hope
- Allow the family time to process information; be willing to repeat information as often as necessary

- Create a consistent method for the family to obtain accurate information
- Relate to injured child and family in a caring manner

Family interventions include:

- Take care of yourself
- Write down and ask all questions you may have

- Touch base with your other children frequently
- Accept help from family and friends
- Utilize individual and family counseling

For more information about caring for the siblings of pediatric trauma, call Mary O’Brien at 724-4377.

The Imagination Kart: bringing the joy of creativity to hospitalized children

—By Joan Drescher,
artist in residence, author, and illustrator

*Beauty is the awakener that brings forth hope and wholeness.
Art is the powerful regenerative tool of beauty.*

Since it was almost Valentine's Day I asked Kimberly, the sister of a young patient, if she'd like to make a special Valentine. I provided the materials; she provided the imagination. Kimberly took a very large coffee filter and cut it into the shape of a heart. Wearing a silver crown on her head, she cut little designs out of the heart,

then wrote, 'Benjamin,' her little brother's name, in the center. She made colorful rays radiating outward from his name. Between each ray, she wrote the names of all Benjamin's caregivers at the MassGeneral Hospital for Children—nurses, chaplains, child life specialists, social workers, doctors, and family members.

Kimberly's artistic expression told me she knew that her little brother was surrounded by caring people and helping hands. Her art project gave her, not only a vehicle for communication, but a way to say "Thank-you," an expression of hope and healing.

Watching Kimberly create this heart was like

coming full-circle for me. The day I arrived at MassGeneral Hospital for Children four months earlier to begin my journey as artist in residence, I had met Kimberly and her family. They helped me decorate a hospital cart and transform it into an "Imagination Kart."

The Imagination Kart is covered with little kites that spin; it has moons and stars and streamers that float in the breeze. In the Imagination Kart you'll find watercolors, crayons, tissue paper, coffee filters, colored paper, cardboard and lots of other art supplies

just waiting to inspire hospitalized children to explore their imaginations. And like young magicians, children transform the simplest things into giant butterflies, castles, rainbows, and expressions of their own personal stories.

As an artist who has created murals in hospitals across the country, and written and illustrated numerous children's books, I've always believed in the power of art to help heal. Using playful drawings of hot-air balloons to represent different feelings, I have seen first-hand how artistic symbols can help

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1) Artist, Joan Drescher and The Imagination Kart, with the Hannon family (clockwise from top left): Timothy, Joshua, Kimberly, John, and Benjamin.



2) Drescher with budding young artist, Aimee Dennler.
3) Dr. Sheikh with 7-year-old, Jake (Jacob Cabral).





Staff physical therapist, Kerri McDonald, PT, MSPT, works with 13-year-old, Patrick Mathias, doing stair training and functional-mobility exercises.

Summer programs at MGH

The City of Boston's Summer work and learning programs may be the answer to your summer scheduling problems. This year, part-time summer help is available to MGH through two Community Benefit Programs. Each program is supported by an on-site coordinator who works closely with participating departments and student interns. Programs are funded through Partners Community Benefit and Bulfinch Temporary Services, and are available at no cost to individual departments. The only requirement is a commitment to provide a meaningful work experience in a supportive environment.

SummerWorks 2002

A career exploration/summer internship program for graduating eighth-graders from the Timilty Middle School in Roxbury. Now in its fifth year, SummerWorks combines weekly interactive workshops with real work experience. Students spend 23 hours a week at the worksite. For additional information call 4-3210.

Jobs for Boston Youth (J4Y)

For more than a decade, MGH has provided part-time (25 hours per week) employment to Boston youth. The Jobs for Boston Youth Program links SummerWorks alumni and students from East Boston High School with job opportunities at MGH.

If you need additional summer help and are able to provide a meaningful job experience to a motivated young student, please call 4-3210.

The Imagination Kart

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children cope with the stress of illness and the pain of loss.

With the help of grants from the Elizabeth S. Whiteside Charitable Foundation and the MGH Ladies Visiting Committee, we have been able to bring the Artist in Residence Program to The MassGeneral Hospital for Children. The program works in conjunction with child life specialists, the pedi-

atric chaplain, nurses, social workers, and physicians under the supervision of Mary Lou Kelleher, RN, pediatric clinical nurse specialist.

Twice a week, I make bedside visits, work with children in small groups in the playroom, and visit children in the Pediatric Oncology Outpatient Clinic with hands-on art projects for patients and families. I conduct educational ses-

sions for child life specialists, the Family Advisory Committee, nurses, therapists, social workers, chaplains, administrators, physicians and residents.

Engaging in the artistic process is not just simple entertainment; sometimes it's a doorway to a child's soul. I remember one child, Jake, who couldn't speak or use his arm after a traumatic accident. He looked longingly at the watercolors on the Imagination Kart. Although his body was bruised, his eyes said he

wanted to create. Speech therapists had tried 'coaxing' him to talk, but he remained silent. After a long while he managed to say, "Blue, red, yellow," and with great effort reached for the small bottles of watercolor. It wasn't long before Jake created a beautiful mandala (artistic symbol), which he proudly displayed on his IV pole. This child's creativity was an act of courage that also served as a diversion for his pain.

When Dr. Sheikh asked Jake how he had

created the beautiful design, Jake happily demonstrated how he folded the coffee filter into "pizza slices" and added color.

Many young patients and their families have told me that creative expression has helped them feel more in control and improved their quality of life.

My dream is that these simple images of hope and beauty will help open hearts and make the world a better place for children.

Child life specialist 'humanizes process' for 8-year-old, Emma

My name is Tracie Grant and I am a child life specialist. When I began my first internship in the study of Child Life, my supervisor gave me a very valuable piece of advice. He said, "Always remember that you can't change the end result for children, but you can change the process." My work with one family in particular has taught me that the only way to change the process is by humanizing it.

The sign on the door read, "Essential medical staff only." The patient I had come to see was 8-year-old Emma. Emma was immobilized by fear

of the hospital environment and fear of all the strangers surrounding her. Emma had been recently diagnosed with a CNS relapse of acute lymphoblastic leukemia after being in remission for four and a half years. My first glimpse of Emma revealed a small child who was clearly feeling ill and on high alert. At the slightest sound, her eyes opened wide in fear, and she clung to her mother's hand. To see a child in such distress was difficult enough, but when I looked at her mother, the need for intervention was clear. Tomasen, Emma's mother, looked as distraught and sleep-

deprived as her daughter.

Over the next several days I spent time with Emma and Tomasen. It was clear the news of relapse and unexpected hospitalization was taking its toll on Emma and her family. Tomasen was unable to leave Emma's side as it would cause Emma so much distress she would become hysterical. As a child life specialist, it's my role among the interdisciplinary team to normalize the hospital environment, provide developmentally appropriate explanations of diagnoses and procedures, to help implement and support coping strategies for children, par-

ents, and siblings, and provide social and emotional support to families and staff. It was clear to me that all of these interventions would be needed to help Emma and her family through this difficult time.

Over the next several months, Emma had many scheduled admissions as well as some unscheduled ones. Each time she was admitted to the inpatient pediatric unit, I made a point of visiting her every morning and afternoon just to talk. I quickly learned that Emma had a 5-year-old brother, Zach, who was also having a difficult time with Emma's frequent hospitalizations, and who was often at home with dad while Tomasen and Emma were here at MGH. Fortunately, Emma's dad and brother were able to make frequent visits to the hospital. Nurses and child life specialists worked together to familiarize Zach with the hospital environment, which enabled him to feel comfortable when visiting Emma. Zach quickly looked forward to coming to the hospital (he really enjoyed the grilled cheese at the Eat Street Café, the "Zach Snacks" from the Gift Shop, and the many stickers that Emma's primary nurse, Sandra, always had waiting for him).

With Zach and dad visiting, Emma was among familiar faces and able to relax and be more herself. Emma began to feel more comfortable

with me and was soon able to separate from her mother to spend time with me. During our talks, Emma and I would talk a lot about school, her friends, her love of reading, and eventually about her medical treatment.

Through our talks, Emma disclosed that one of the most difficult things for her was accessing and de-accessing her port-a-cath. I engaged Emma in some role-reversal play where she was able to assume the role of 'nurse' for her doll. Through this exercise, Emma was able to gain control and some understanding of this procedure and develop coping skills that made the procedure more bearable for her. As this process of education and support was occurring, something far more important was also happening. Emma, her family, and I were becoming invested in one another and in our mission to change the process.

Over the next few weeks, Emma began to cope increasingly better with medical procedures as she became more comfortable with the hospital environment and more talkative with staff. It was then that I learned another of Emma's great fears: going to school. For Emma, having to return to school with no hair, being tired, and having sporadic attendance was a very daunting thought. So Sandra, Emma's primary nurse,

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Child life specialist, Tracie Grant (left) with 8-year-old, Emma Carey, her mom, Tomasen, and her doll, Kit.

Nurse's compassion helps family take 'baby steps' toward recovery

My name is Deborah Sullivan, and I am a staff nurse in the Pediatric Intensive Care Unit (PICU).

It was a relatively slow day in the PICU. I heard that my next patient had arrived in the Emergency Department with a possible C4-C5 fracture. He was a 16-year-old boy. I had time, so I thought I would go down and introduce myself to the family, and more importantly, speak to my patient. Due to the level of spinal cord injury, the muscles he needed to be able to breathe would inevitably be affected. I knew that his breathing would be labored, and intubation was imminent. I wanted to talk to him before the tube went in. It can be frustrating as a nurse to care for a critically ill child without ever hearing a voice or having a thread of knowledge of what the child sounds like. I also wanted to introduce myself to him, so that even if he didn't get to the PICU during my shift, he'd know who I was when I came to his room the next morning.

Down to the Emergency Department I went. What I found when I got there was a very scared, yet silent, 16-year-old boy. His name was Kyle. Kyle was lying on the

examination table with doctors and nurses all around him, talking back and forth across him, giving him a view of their chins. His parents were outside the trauma bay in summer beach garb, looking on with wet eyes, helpless. They were being told what would happen next. A halo would be placed to stabilize Kyle's spine, and then intubation; they had a minute (maybe less) to speak with him before the tube had to be placed. "Say good-bye, and you can wait in the waiting room."

I wanted to go to them and tell them to savor this moment because it could be the last time they hear his voice in a long time. I stood in the corner and watched. His parents went to him, one on each side of the table, each holding one of Kyle's hands. In the midst of the chaos, they leaned over him with dry eyes and spoke to him. I could see they were reassuring him. I only saw his eyes, staring into theirs. His head was being held in place by a doctor. He moved his eyes back and forth from his father to his mother and back again. His eyes held such trust. Still, not a tear. They had about sixty seconds before they were asked to leave.

The moment his parents walked away from the table, I wanted to go to Kyle. I wanted to tell him the chaos would soon be over, that he was going to be brought to the PICU where things wouldn't be so hectic. I wanted him to know that someone was watching out for him. For some unknown reason, I felt the need to protect him, this child whose eyes told me he was more afraid than he was letting on. This child who had been on a beautiful beach just 90 minutes before. This child who raced into the surf without a care in the world as all of us have a hundred times. This child whose world

had now changed forever. He would be paralyzed from his shoulders down. His friends had saved him from drowning, but now, here he lay in the Emergency Department, the bravest sixteen year-old I had ever seen.

They started with the halo. They told him he'd feel a few sticks of a needle as they injected Lidocaine to buffer the screws of the halo. I watched him from afar. He scrunched his eyelids tightly, but never uttered a sound. Doctors talked over him; the ED nurse took his hand. They placed the screws and started to turn them. I waited. Nothing, not a sound from him. He clenched his teeth. Finally he screamed out, "This really hurts!"

"We're done," said the doctor.

I walked over, took

his hands in mine and said, "Kyle."

His eyes opened.

"My name is Deb Sullivan, and I'll be your nurse tomorrow in the PICU."

He nodded slightly.

"When you come up to the unit, we'll help get you settled, okay?" I squeezed his hands and stepped away.

Next was the intubation, awake and fiberoptic. My heart started to ache. How much more could he bear? He resisted and fought, but was remarkably cooperative given the intensity of the situation. After intubation, he'd go to MRI, CT, and then the OR. It would be hours before he arrived in the PICU. I would see him in the morning.

After that night in the ED, I found out just how

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Deborah Sullivan, RN, cares for young patient in the PICU.

Exemplar (Deborah Sullivan)

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much Kyle would persevere, and how much he had already overcome in his life. As it turned out, I knew Kyle's father. The next morning when I was getting report from the night nurse, I saw Kyle's father again and thought he looked familiar. I hadn't noticed it the night before.

The nurse began with Kyle's social history. His biological mother had passed away shortly after he was born. I fought back tears as I realized my mother had worked with Kyle's father when I was a child. I not only knew Kyle's father, I had known Kyle as an infant through stories my mother had told me: a father who'd been left to care for a newborn without his wife. Her stories had been filled with such dedication and love. I was in high school at the time; just 16 years old. It seemed like a cruel twist of fate that I would now care for this cherished boy as a 16-year-old himself. I wasn't sure I could do it.

My mother called just before I went into Kyle's room. She had heard what happened to Kyle. She told me I was meant to be there to care for him. She asked me to introduce myself to Kyle's father and explain who I was. When I did, Kyle's father started to cry. He had worked closely with my mother for eight

years. My mother had been there for Kyle's father during some of the toughest moments of his life. Now, it seemed, it was my turn.

I cared for Kyle and his family for nine days before seeing them off to the Shepherd Center in Atlanta. I listened to their fears and hopes. I waited for Kyle's tears, which didn't come until he saw his younger siblings, days into his admission. I explained to his mother when she questioned how she would get through this, that she was climbing a mountain, and she would have to take very small steps. And each baby step would add up to part of the mountain. Those steps consisted of stabilizing Kyle, focusing on his emotional well-being, and on the emotional strength of both Kyle's parents. I explained the immense physical strength Kyle would need to be able to breath on his own again without a ventilator; the strength she and Kyle's father would need as parents helping their child through the fight of his life. I prepared them as

best I could for future disappointments. I warned them about having too much hope, and I warned them about not having enough hope. I reminded them that Kyle is young, and miracles can happen. Through all of this, I watched one of the most caring and supportive families I've ever seen at their child's bedside around the clock.

Kyle and his parents went to The Shepherd Center in Atlanta, which is where he is today. I've heard he has full movement of his arms and wrists, and they're hoping for more. I have no doubt that Kyle will persevere; I had no doubt of that since my first glimpse of him in the ED. His strength comes from a

strong and loving family. I hope to see them fulfill their promise to 'walk' back into the PICU, but I'd settle for a hug from this remarkable child who was not able to hug before he left.

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

In a very subtle way, this narrative tells us a lot about Deb's practice. She went to the ER to assess the situation and introduce herself to a patient she would not see on her unit for another 24 hours. She wanted Kyle to know that as he and his family struggled through this difficult

time, she would be waiting for them in the safe and peaceful environment of the PICU where he could begin to heal. She did this even before she knew she had a personal connection to Kyle and his family.

Deb's desire to hear Kyle's voice, to have knowledge of that special part of him, shows the depth of her compassion. Learning about the coincidence of their past relationship was both chilling and comforting. But it's clear that Deb's care for Kyle would have been no different with or without that knowledge.

This narrative is a wonderful glimpse of the fast-paced, complex care delivered in the PICU.

Thank-you, Deb.



Yes, there were a few tears for Ririko Uchida in the playroom on Ellison 17, but it wasn't anything a hug from mom and a cherry lollipop couldn't fix.

'Thank-you,' from Tim's mom

—by Kathleen Smith, parent

“Yes,” the officer said, “he is alive. He’s being flown by helicopter to Mass General Hospital. It’s the best place he could go.”

It was 6:30pm on December 30, and as I stood on the dark street near my home in Andover, I was grateful to know my critically injured 13-year-old son, Timothy, was on his way to an extraordinary medical center. I knew he would be surrounded by the most advanced medical technology in the world.

I wondered, though, if he would be enveloped in that environment that seems to intensify technology in an almost geometric way. I had come to know that environment through my work years ago at both MGH and Spaulding Rehabilitation Hospital.

Within minutes of arriving at the Emergency Department, my confidence was bolstered, and my hopes for my son’s future found a place to grow. The pas-

sion and skill of every person struggling to save Tim’s life seemed to fuel the commitment each clinician brought to the effort.

As you watch your beloved child inch back from the edge of a steep precipice, the support of those who help him rings with bell-like clarity through the fog of pain and fear. The staff of the PICU (Dawn, Jesse, Cristen and others), Dr. John Schultz, and Dr. Michael Whalen, stood

at the center of that experience for Tim and me and the rest of our family. But over and over I was reminded of the end-to-end commitment of MGH staff in advancing the precious mission of this hospital. For example:

Tim’s 73-year-old aunt rushed to the ED late that night and was greeted by a security guard. She was only able to say, “My nephew,” before the guard calmly realized she must be talking about Tim, and took her back to where the family was waiting.

I hung Tim’s school photo near his bed in the PICU as a way for all of us to focus on where we wanted his recovery to go. As I sat there days later, resting my head against the side rail, weeping, the housekeeper came over, put her arm around me, told me I had a handsome son, and said she was praying for him.

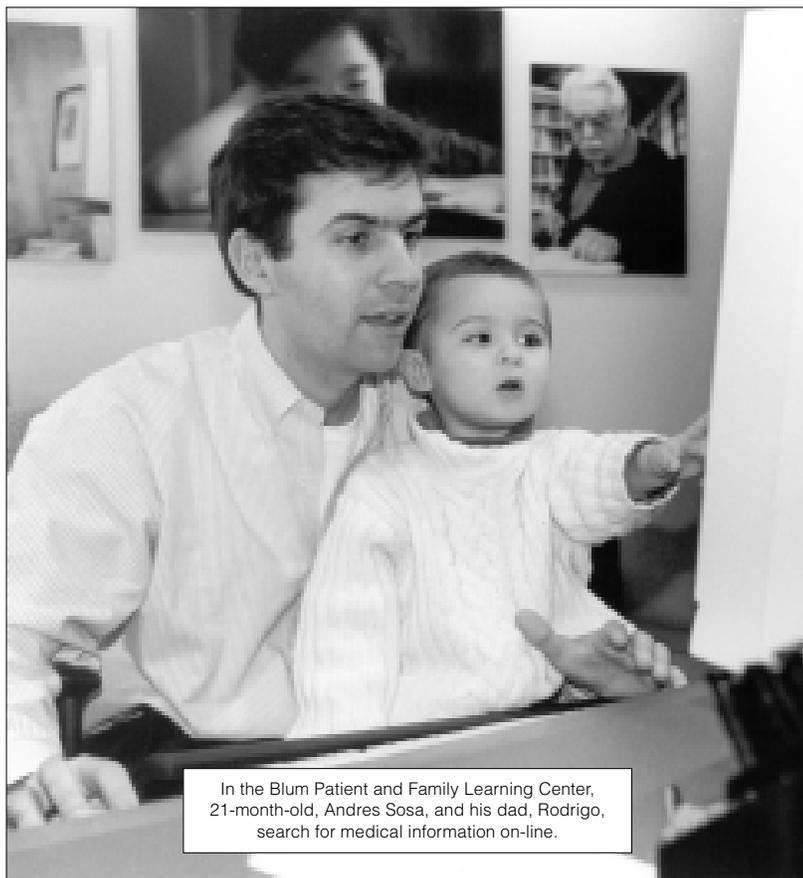
Late one Sunday evening I saw a well-dressed man quietly making rounds throughout the PICU. I had never seen him before, but clearly he was interested in each of the children. As he approached Tim’s bed, he introduced himself as Dr. Ezekowitz. I recognized his name instantly, and asked how he knew Tim’s name and condition. He assured me that he followed each child on the Pediatric Service, and then he talked with me about Tim’s progress with great concern and empathy.

One caring intervention followed another as Tim’s team worked to provide the right mix of knowledge, technology, skill, and compassion to help our whole family through a difficult time.

Over the past two decades, American business has grappled with the need to build and nurture high-performance teams as a means of ensuring quality. I’ve always been grateful that my first work experience was at MGH. Recognizing the unique contributions of every team member, fostering a spirit of collaboration across disciplines to achieve a desired outcome; these things happen as easily as falling off a log at MGH. As huge and complex as MGH is, it is simple in one profound and fundamental way. MGH is committed to fighting the good fight for people in need of medical care, and it encourages staff to engage with every gift of personal commitment they can bring to the table.

As this new year dawned, I was again reminded of how the extraordinary culture of MGH continues to thrive. Tim came home on January 25th, returned to school a week later, and continues what is truly a remarkable recovery. His life and health are a tribute to the many individuals who fulfill the mission of MGH and the Mass General Hospital for Children.

We thank you all from the bottom of our hearts.



In the Blum Patient and Family Learning Center, 21-month-old, Andres Sosa, and his dad, Rodrigo, search for medical information on-line.

The CNS: influencing patient care in the NICU

—by Patricia A. Maloney, RNC, MS,
clinical nurse specialist

As the clinical nurse specialist for newborn intensive care patients throughout MGH, my primary responsibility is advancing nursing practice to ensure a safe, caring environment for patients and their families. To ensure quality of care and optimize patient outcomes, I give nurses at the bedside the tools to remain current in practice, evaluate practice standards, seek out new ways to guide practice, provide resources to staff, and support families in crisis.

A primary concern for any patient is adequate pain management. This is especially important in pre-verbal patients. The importance of

pain management is well publicized, and parents around the world are concerned about pain management during their infant's hospital stay. At MGH, staff in the Newborn Intensive Care Unit (NICU) also recognize the need to address pain management. Premature and full-term infants are our tiniest and most vulnerable patients. Throughout their hospitalization, newborns may undergo many painful procedures. These may include blood sampling via heel sticks, veni-punctures, IV placement for fluid administration, medication administration, eye exams, lumbar punctures, simple wound care, and immunizations.

As the CNS, I reviewed the literature and discovered that sucrose was being used to control procedural pain in premature and full-term infants in a number of venues nationally.

Further research revealed that the use of sucrose for pain management was the standard of practice in many NICUs. I drafted a protocol for the use of sucrose at MGH and presented it to the Collaborative Practice Group, a multidisciplinary group in the NICU. It has now become our standard of care for premature and full-term infants. This process of identifying issues and applying evidenced-based practice



Patricia A. Maloney, RNC, MS,
clinical nurse specialist

promotes up-to-date clinical practice and provides optimal care for our patients and their families.

The education of families and staff is an important aspect of my role as CNS. In the NICU we recently had a patient who had a Kaposiform Hemangioendothelioma (a benign tumor of the vascular endothelium). This is a diagnosis not usually seen in the NICU, so treatment was unfamiliar to staff. Having had experience with patients with this diagnosis, I was able to provide information to staff, access resources outside the unit to assist with the treatment plan (chemotherapy), and develop a plan of care for this patient with the staff nurses. Providing this kind of support helped alleviate staff's concerns about caring for a patient receiving chemotherapy, and 'de-mystified' the treatment process for them.

This particular patient's family was in crisis when they arrived in the NICU. To provide

support to the family as well as staff, I introduced myself as the clinical nurse specialist and assured them I would be working closely with the nursing staff and primary team in planning the care for their daughter. I checked in with them daily and spent a great deal of time talking with them about my past experiences caring for patients with this diagnosis and the positive outcomes I had seen. The primary team and I kept the family informed, and I was able to help both the team and the family as far as what to expect during the infant's hospitalization. Though I was involved in the patient's care, the success of the infant's treatment and positive outcomes were the result of a team effort.

As a CNS, I have a unique opportunity to influence patient care and outcomes. I evaluate practice, integrate the use of evidenced-based practice, and provide support and resources to nurses at the bedside. I partner with families to support them through crisis.



Easter in the NICU

NICU staff nurse, Lindsay Davidson, RN, shares a holiday moment with 7-week-old, Cole Sparks, and his mom, Julie Swinimer.

MassGeneral Hospital for children

The Fielding the Issues section of Caring Headlines is an adjunct to Jeanette Ives Erickson's regular column. This section gives the senior vice president for Patient Care a forum in which to address questions presented by staff at meetings and venues throughout the hospital.

Question: I've heard people talk about child life specialists. What are child life specialists, and what do they do?

Jeanette: Child life specialists are professionals who are specially trained to assess and treat the developmental, psycho-emotional, and social needs of children and adolescents in the health-care setting. They're part of the interdisciplinary team; they collaborate with nurses, social workers, and physicians to determine appropriate therapeutic interventions to optimize the medical experience, decrease stress, and instill positive coping skills in children of all ages.

Question: Is there a difference in the way spiritual care is delivered to children and adults?

Jeanette: One major difference between the spiritual care of children and adults is that most children are not imbedded in religious traditions, so other, age-appropriate tools are used to support their spiritual life. Because children rely so heavily on their families for survival, often the care provided is indirect; spiritual support is given to parents, siblings, and others in an effort to strengthen a system that may be stressed by illness, injury, or death.

Question: Why does the MassGeneral Hospital for Children sponsor a health fair every year?

Jeanette: The children's health fair is just one event in a week-long celebration of National Children & Healthcare Week. It

is an opportunity to acknowledge the special work we do in providing quality care to our children and their families.

The health fair has grown dramatically since our first one six years ago, but the objectives of the event are the same:

- Provide fun and educational exposure to the healthcare setting for children and the community at large
- Increase awareness about the MassGeneral Hospital for Children and the work we do
- Bring the departments within MGH together to 'play,' enjoy children, and showcase their practice
- Instill in young people an interest in healthcare careers

Question: Has the MassGeneral Hospital for Children been a successful enterprise since its inception?

Jeanette: Over the past 5 years there has been tremendous growth, both in the number of children and families we care for, and in the services we provide. Our patient-family satisfaction surveys demonstrate a dramatic upward trend, with an overall positive rating of 91% in 2001.

This year, the MassGeneral Hospital for Children will continue to advance its mission by defining pediatric standards of practice and promoting a strategic effort to create a pain-free pediatric environment.

Memorial Service

A memorial service for Anthony Kirvilaitis, MDiv, will be held on Monday, April 29, 2002, from 11:00am–12:00pm in the MGH Chapel (teleconferenced to O'Keefe Auditorium). A reception in the Bulfinch 2 Trustees Room will follow.

Kirvilaitis worked at MGH for more than 16 years, much of that time as a training specialist in The Center for Clinical & Professional Development. Kirvilaitis trained hundreds of support staff within the department of Nursing and was a constant role model



Tony Kirvilaitis

for how to work together as a team to achieve common goals. He also served as an on-call chaplain.

Kirvilaitis's legacy will be remembered by those of us who knew him personally, and more formally with the establishment of the Anthony Kirvilaitis, Jr. Partnership in Caring Award, which will recognize support staff within the department of Nursing. Please join us as we celebrate Tony's warmth and humor, and his commitment to MGH patients, families, and employees.

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Exemplar (Tracie Grant)

continued from page 8

and I arranged a school visit. During the visit, Sandra and I were able to dispel misconceptions Emma's classmates may have had about cancer. We discussed how being different was okay; we empowered her classmates by suggesting ways they could help Emma (both when she came school and when she wasn't able to). We were able to bridge that gap between hospital and home for Emma.

During the school visit, Emma readily shared information with her peers about her illness and her feelings. She quickly learned that they cared deeply for her and were eager to help. From that day forward, Emma seemed to blossom. Now, instead of lying in bed at the hospital and clinging to her mother, Emma spent time with other children in the playground. Her days were filled with arts and crafts, talking with friends, visits from family members, and special projects. With her imaginative ideas and stories to fill the days, weeks seemed to roll by. We were planning Emma's end-of-chemo party before we knew it.

Although Emma will be in treatment for two and a half years, her inpatient stay had come to an end. The next phase was outpatient radiation. This was perhaps the biggest challenge for

Emma since learning of her diagnosis. Treatments only lasted about 20 minutes each day, but they were extremely anxiety-producing for Emma and, in turn, her family. Through extraordinary teamwork, support, and determination, Emma was able to use guided imagery, relaxation techniques, diversional activities, and artistic expression to undergo radiation without medication. This challenging time for Emma made me realize how close the bond between patient and caregiver becomes. I suddenly realized that my presence had become part of Emma's coping strategy.

As radiation concluded, we all thought the worst was behind us, that Emma would be able to go back to school and friends in no time. But that was not the case.

Emma's radiation treatment left her with severe temporary side effects that caused her to need intense physical therapy and several unexpected hospital admissions. Again, through diversional activities, artistic expression, and lots of love and support, Emma rose to the challenge, making spectacular gains in a very short amount of time. She has now returned to school and is doing well.

During the low points of Emma's treatment, Tomasen related an inci-



Who says you can't get a taxi when it rains? It might be raining outside... but in the playground on Ellison 17, 22-month-old, Benjamin Hutchinson and his mom (left); and 1-year-old, Alexis Colameta, enjoy an afternoon jaunt in a pair of taxi strollers donated by Jordan's Furniture. With a fleet of 24 of these roadsters at the disposal of children on Ellison 17, you may want to look both ways before crossing the hall!

dent to me that illustrated what a profound impact I and other team members had had on Emma during this phase of her treatment. Emma had been talking with a priest and expressing her anger with God for causing her to be sick. The priest asked Emma to look at the situation differently, suggesting that maybe God wasn't responsible for the cancer, but rather for the good things that had come of having cancer.

Emma's reply was, "Oh, you mean like my nurses, Sandra and Lisa, who take care of me, and Tracie who makes me smile? And Dr. Weinstein, and Patricia and..."

It was obvious the MGH team had made an impression on Emma. This story made me feel as though I'd made a

difference for Emma during one of the most stressful times of her young life. The depth of that impact was even more evident when Tomasen said to me, "Emma has always hated coming to the hospital. Now she says she feels like a princess when she's here. You did that for her. You changed the process."

I want to take this opportunity to thank Tomasen, Jeff, Zach, and especially Emma, because they have, in more ways than words can express, changed the process for me.

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

Tracie walked into a room filled with fear and earned the trust of this

family. She showed Emma and her mom that they were in a place where people care, where people get involved, and where Tracie Grant is 'one of the good things' that can happen to you.

Tracie's interventions allowed Emma to take control of her environment. When Tracie and Sandy visited Emma's school, they paved the way for Emma to re-enter her classroom in a welcoming and non-threatening way. She was able to talk honestly with her friends, and they were able to talk openly with her. This is a huge hurdle for a young child.

Tracie did change the process for Emma and her family. And I think she changed a lot more than that.

Thank-you, Tracie.

Educational Offerings

April 18, 2002

When/Where	Description	Contact Hours
May 2 8:00am–4:30pm	Introduction to Culturally Competent Care: Understanding Our Patients, Ourselves and Each Other Wellman Conference Room	7.2
May 2 7:30–11:30am, 12:00–4:00pm	CPR—American Heart Association BLS Re-Certification for Healthcare Providers VBK 401	---
May 2 1:30–2:30pm	Nursing Grand Rounds O’Keeffe Auditorium	1.2
May 7 9:00am–4:30pm	Management of the Burn Patient Bigelow 13 Conference Room	6.9
May 8 8:00am–2:30pm	New Graduate Nurse Development Seminar I Training Department, Charles River Plaza	6.0 (contact hours for mentors only)
May 8 1:30–2:30pm	OA/PCA/USA Connections “September 11th and Diversity: Our Journey, Our Values.” Bigelow 4 Amphitheater	---
May 8 5:30–7:00pm	Advanced Practice Nurse Millennium Series “The Role of Reflective Practice in Advanced Practice Nursing.” O’Keeffe Auditorium	1.2
May 13 8:00am–3:30pm	Continuous Renal Replacement Therapy (an offering of the ICU Consortium), St. Elizabeth’s Medical Center	TBA
May 14 7:30–11:30am, 12:00–4:00pm	CPR—American Heart Association BLS Re-Certification for Healthcare Providers VBK 401	---
May 14 8:00–12:00am	Pediatric Advanced Life Support (PALS) Re-Certification Program VBK601	TBA
May 16 1:00–2:30pm	Conflict Management for OAs and PCAs VBK601	---
May 16 1:30–2:30pm	Nursing Grand Rounds O’Keeffe Auditorium	1.2
May 16 10:00–11:30am	Social Services Grand Rounds “Basic Human Needs in Mediation and Negotiation.” For more information, call 724-9115.	CEUs for social workers only
May 20 8:00am–4:30pm	Post-Operative Care: the Challenge of the First 24 Hours Wellman Conference Room	8.7
May 20 7:30–11:30am, 12:30–4:30pm	Pediatric Cardiac Series—Part III VBK 601	---
May 22 and 23 8:00am–4:30pm	BLS Instructor Program VBK601	13.2 for completing both days
May 22 8:00am–2:30pm	New Graduate Nurse Development Seminar II Training Department, Charles River Plaza	5.4 (contact hours for mentors only)
May 22 8:00am–4:30pm	Psychological Type & Personal Style: Maximizing Your Effectiveness Training Department, Charles River Plaza	8.1
May 28, 29 and June 3, 4, 10, 11 7:30am–4:00pm	ICU Consortium Critical Care in the New Millennium: Core Program SEMC	45.1 for completing all six days

For more information about any of the above-listed educational offerings, please call 726-3111.
For information about Risk Management Foundation educational programs, please check the Internet at <http://www.hrm.harvard.edu>

The Child Protection Team: working toward a safer future for children and families

—by Alice Newton, MD, and Susan J. Lipton, LICSW,
Child Protection Consultation Team

Child abuse and neglect are an unfortunate reality in our society. MassGeneral Hospital for Children has responded to this reality by enhancing its Child Protection Team with a new consultation service available now, full time, to staff.

Every day, reports of child maltreatment are filed in Massachusetts. In 1999, more than 34,000 reports of child abuse or neglect were investigated by the Massachusetts Department of Social Services; almost 18,000 of those reports were substantiated. Children are the victims of many types of maltreatment. Although physical and sexual abuse receive the

most attention, they account for less than one third of all cases of child maltreatment. More than half of all cases of child maltreatment are due to neglect including not being given enough food, shelter, health care, and education. An additional 10-12% of maltreated children are exposed to emotional abuse, and often, children are subjected to more than one type of maltreatment.

All professionals who have contact with children are considered by Massachusetts law to be mandated reporters. This means that any nurse, social worker, medical assistant, physician, psychologist, or other professional has a duty to

report possible child abuse or neglect to the Department of Social Services. This report is made 'on behalf of the child,' and is not intended to be a punitive action.

Frequently, there are many factors that contribute to child maltreatment. In certain cases, drug and alcohol use and domestic violence may play a role. The stress of poverty, depression, or a family history of intergenerational abuse may contribute. But it is important to note that child maltreatment occurs in families of all socioeconomic backgrounds, making it impossible to identify a 'typical family' where abuse may occur.

Because these cases can be complex, hospitals across the country are establishing multidisciplinary consultation teams to address cases of possible child maltreatment. For many years, The Child Protection Team, within the MassGeneral Hospital for Children, has met monthly to discuss cases where child maltreatment may be present. The Child Protection Team is an interdisciplinary team consisting of social workers, nurses, pediatricians, legal counsel, domestic violence advocates, and a representative from the Department of Social Services.

In October, 2000, Susan Lipton, LICSW, and Alice Newton, MD, joined the team. Lipton and Newton both have specialized training in the field of child maltreatment, and together they serve as a consultation team to staff who

may encounter child maltreatment. Brenda Miller, RN, nurse manager of the PICU, serves as nurse liaison to the consultation team. This newly augmented Child Protection Consultation Team provides consultation on specific cases, as well as training to staff about the issues surrounding child abuse and neglect.

The Child Protection Consultation Team is available 24 hours a day, 7 days a week, to all staff who have cases of possible child abuse or neglect. The team provides hospital-wide multidisciplinary education about child maltreatment and serves as liaison between staff and Child Protection Services, the police, the district attorney, and other community agencies.

The consultation team can be reached by calling pager #3-2728 (3-CPCT).

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