



Children's News

Children's Hospital Boston
The Hospital for Children

A bumpy ride to health

It's amazing how much life can change in just three short months. Just ask Vanessa and Charlie Koch, who quickly went from showing off their healthy newborn son to awaiting a call that would save his life.

Andy Koch was born healthy, but a week before his 2-month check-up, Vanessa noticed that his face was a little yellow. After weeks of different hospitals, different doctors and many tests, Andy was diagnosed with biliary atresia (the congenital absence or closure of the ducts that drain bile from the liver)—a condition only treatable with surgery. Without surgery children don't live past age 2.

The family, who is from Bangor, Maine, was referred to Barbara Bush Children's Hospital in their home state, where Andy underwent a surgical procedure to remove the atretic biliary ducts outside his liver and attach the small intestine to his liver for drainage. But the procedure didn't hold and Andy needed a second surgery a week later. That was followed by more complications, so Andy was referred to **Heung Bae Kim, MD**, surgical director of the Liver, Intestine and Multivisceral Transplantation Center at Children's Hospital Boston. After a full evaluation, Andy was placed on the transplant list to receive a new liver.

The next three months were filled with visits to doctors in different states and anxiety, as the Koches waited for a liver for Andy. The family prepared as much as possible, mentally and physically, for the transplant, and after two trial runs, they felt as prepared as they could be.

When the call finally came on January 12, 2005, that a liver was available, the Koches thought they had cleared the biggest hurdle in restoring their son's health. Little did they know that a raging New England blizzard would prove to be their biggest challenge.

"We think we have a match, but go back to sleep. We'll call you back around 6 a.m.," said a voice on the other end of the line at 1 a.m. Unable to sleep, Vanessa grabbed her suitcase and to-do lists, made phone calls to the extended family and tried to stay focused. After getting the go-ahead at 7 a.m., Vanessa called Life Flight to arrange their trip to Children's. "We don't fly in bad weather," they said, "but we will see what we can do." An ambulance was out of the question, as they had to be in Boston by 12 p.m. "My

continued on page 6)))



Vanessa and Andy Koch

Newlywed docs save life of fellow passenger

Picture this: you're flying home after your romantic honeymoon in Maui, when the man seated behind you suddenly becomes very ill. What do you do? If you happen to be doctors like Children's Hospital Boston Infectious Diseases fellow **Paul Lantos, MD**, and his new wife, Gretchen Green, MD, you help save his life.

The newlyweds were just settling into their oversized first class seats on January 25, when the 61-year-old man, who had a history of high blood pressure and recent fainting spells, suddenly took a turn for the worse. Lantos checked his vital signs using the equipment on board the plane, all of which pointed to the possibility that the man was having a heart attack.

One minute honeymooners and the next doctors, the couple sprang into action. As the plane flew over the Pacific, they gave the man oxygen and chewable baby aspirin and remained in constant communication with the flight crew. The man's symptoms remained



Gretchen Green, MD,
and Paul Lantos, MD

consistent for two hours, but the automatic defibrillator on board indicated he was experiencing heart rhythm changes consistent with a heart attack. "At that point, we told the crew that we needed to land," says Lantos. As the plane began to descend, Green, standing awkwardly in the aisle, started an IV, while Lantos hooked up fluids to support the man's blood pressure.

Paramedics arrived as the plane landed in Los Angeles, getting an update from Lantos and Green and quickly transporting the man and his wife to a nearby hospital. The couple later learned that, as they had suspected, he suffered a significant heart attack requiring an angioplasty and stenting of two coronary arteries. The newlyweds heard from the man a few days after he was discharged from the hospital and returned home to Texas. He is doing well, and they plan to stay in touch.

INSIDE: CHILDREN'S CLINICAL
BUILDING EXPANSION

Children's visitors looking for help can just...

Have you worked at Children's Hospital Boston long enough to know your way through its maze of halls and offices? Do you wish you had more contact with the hospital's patients, families and other visitors? If so, then Ask Me! is the perfect program for you.

Starting next month, Ask Me! is a new effort to station employee volunteers in the Main Lobby and at the top of the triple staircase in the Pavilion Lobby to welcome visitors and assist them with questions and directions.

Prior to beginning the program, each staff volunteer must have permission from their immediate supervisor, and must be able to commit to a minimum of six months in the program. Volunteers will also attend a two-hour orientation session and a one-hour facility tour, then serve four hours per month, from 8 to 10 a.m. on two separate days.

To sign up to be an Ask Me! volunteer, go to NetLearning on the home page of the intranet and look for Ask Me! For more information, contact one of the program coordinators below:

Karen Dias, ext. 5-5625, karen.dias@childrens.harvard.edu
 Greg Fredo, ext. 5-8713, greg.fredo@childrens.harvard.edu
 Todd Katzman, ext. 5-4022, todd.katzman@childrens.harvard.edu
 Carol Sayles, ext. 5-8929, carol.sayles@childrens.harvard.edu



Children's Hospital Boston will provide an array of clinical programs and services in an ambulatory clinic setting at the new Children's Hospital Boston at Waltham, opening this summer. They will include:

- Adolescent Medicine
- Audiology
- Cardiology
- Dermatology
- Endocrinology
- Gastroenterology
- General Surgery
- Genetics
- Neurology
- Nutrition
- Ophthalmology
- Orthopedic Surgery
- Otolaryngology
- Plastic Surgery
- Renal
- Sports Medicine
- Urology

More information on Children's Hospital Boston at Waltham and the Clinical Building Expansion will be provided at the upcoming Open Meetings to take place on Tuesday, April 12 at 12 p.m., Wednesday, April 13 at 3 p.m., and Friday, April 15 at 8:30 p.m. in the Enders Auditorium.

If you're interested in being an Ask Me! volunteer, you must attend:

One orientation session

- Wednesday, April 6, 8 to 10 a.m.
- Tuesday, April 12, 8 to 10 a.m.
- Thursday, April 28, 8 to 10 a.m.

and

One hospital tour

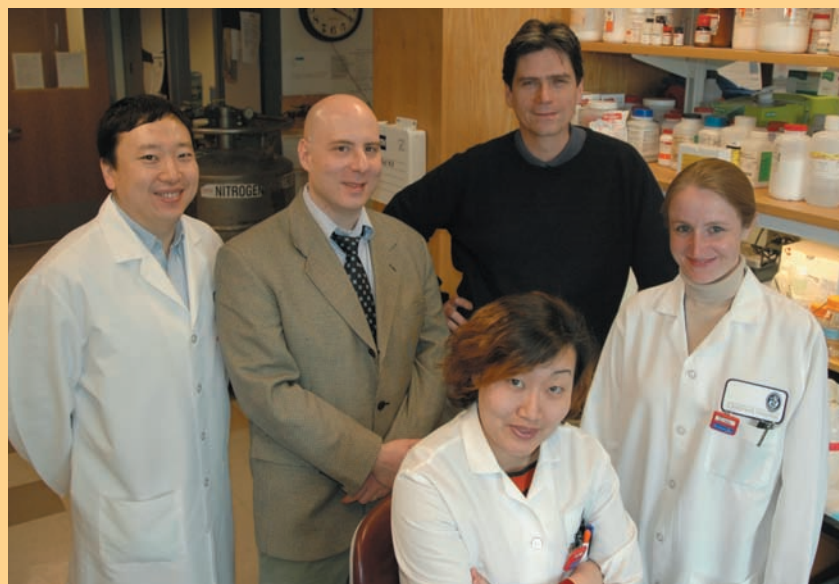
- Friday, April 8, 3 to 4 p.m.
- Thursday, April 14, 9 to 10 a.m.
- Friday, April 29, 1 to 2 p.m.

Beaker bytes

High cholesterol may accelerate prostate cancer

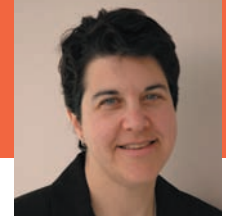
Population studies have linked prostate cancer with high cholesterol levels and Western-style, high-cholesterol diets. Now, a Children's Hospital Boston team, led by **Michael Freeman, PhD**, director of the Urological Diseases Research Center, has found that high cholesterol levels accelerate prostate tumor growth by altering chemical signaling patterns within tumor cells. Reporting in the April 1 *Journal of Clinical Investigation*, the team also presents evidence that cholesterol-lowering "statin" drugs may inhibit cancer growth.

The researchers injected human prostate cancer cells into mice and found that those whose cholesterol had been raised through diet had a more than doubled tumor incidence, and their tumors were markedly larger. The cholesterol accumulated in tumor-cell membranes in structures called lipid rafts, then activated a "cell-survival" pathway, enabling tumor cells to resist chemical instructions to commit suicide and allowing the cancer to proliferate. When tumor cells were treated with the cholesterol-lowering drug Zocor, the cell-survival pathway was inhibited and tumor cells died off.



Collaborators on the study, from left, Liyan Zhuang, MD, PhD; Keith Solomon, PhD; Jayoung Kim, PhD; Michael Freeman, PhD; and Rosalyn Adam, PhD.

Intriguingly, recent studies have found that people taking statins have a significantly lower incidence of prostate and other cancers. Freeman believes the group's findings support the idea of testing such drugs as preventive or adjunctive therapy for prostate cancer.



Talking about eating disorders

What are eating disorders?

They're psychiatric disorders with physical manifestations that occur when an individual's eating and nutrition becomes unhealthy or dysfunctional. They often start with weight loss, or the intention to lose weight, and take on a life of their own. Approximately 90 percent of eating disorders occur in women.

How many different types of eating disorders are there?

There are three classifications:

The first is *anorexia nervosa*, which is present when an individual:

- refuses to maintain weight within a normal range for height and age—more than 15 percent below ideal body weight
- has an irrational fear of weight gain or becoming fat
- has severe body image disturbance
- no longer has a menstrual cycle—in women of the appropriate age.

There are two subtypes of *anorexia nervosa*: restricting, in which patients only restrict eating to reduce their weight; and binge eating/purging, in which patients may either binge or use purging to control their weight.

The next type of eating disorder is *bulimia nervosa*, which is distinguished by binge eating with:

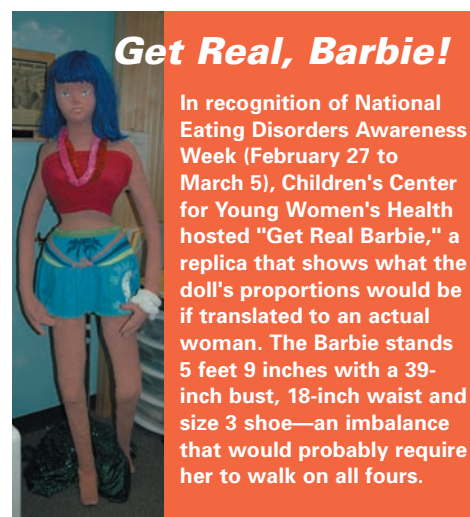
- a sense of loss of control
- behavior to offset it through purging—self-induced vomiting or laxative or diuretic abuse
- behavior to offset it through non purging—excessive exercise, fasting or strict diets
- dissatisfaction with body shape and weight

The final classification is *eating disorder not otherwise specified*, which includes patients with eating patterns and weight management habits that are clearly abnormal but don't meet the criteria for *anorexia nervosa* or *bulimia nervosa*.

What causes eating disorders?

There's really no consensus, but they're probably related to a combination of psychological, biological, family, genetic,

environmental and social factors. For example, individuals with a history of eating disorders can also have anxiety, depression or obsessive compulsive disorder. There's also a lot of societal pressure. Just look at the cover of most women's magazines—they typically highlight stories about weight management, dieting or how to tighten specific muscle groups. Also, think about the recent reality makeover TV shows like "The Swan."



What are some of the indicators for eating disorders?

It's important to note that eating disorders are illnesses of denial and secrecy; they're often very difficult to track down. So family members and friends shouldn't feel badly about not figuring out if their loved one has a problem right away. That being said, there are some signs you can look for: unexplained weight loss; dizziness; fainting; fatigue; irritability or moodiness; going to the bathroom often, especially after meals; cutting food into tiny pieces and pushing it around the plate, etc. It's really any major change in eating or exercise behavior.

How are eating disorders diagnosed?

A pediatrician or primary care physician can typically diagnose an eating disorder by obtaining a complete medical history from a patient and conducting a thorough physical exam. They will also most likely request a full lab assessment, as well nutritional and psychiatric evaluations. It's important to remember that the sooner an

eating disorder is diagnosed, the sooner the individual can get help.

How are eating disorders treated at Children's?

Children's Eating Disorders Program treats both inpatients and outpatients—about 200 new cases annually. As outpatients, individuals are seen by an Adolescent Medicine physician and a nutritionist. They also see a psychologist or social worker with whom their parents meet separately. Patients come in for follow-up visits as needed.

When they become really sick—their condition gets worse and worse, causing unstable vital signs, for example—patients are admitted to the hospital. Inpatients are placed on the hospital's "Restrictive Eating Disorders" clinical practice guideline and meet with the same group of caregivers as an outpatient would, while participating in a special meal plan with weight gain goals.

What are some of the medical complications that can occur as a result of eating disorders?

Several can occur during starvation or persistent purging, such as cardiovascular issues like an abnormally slow heart rate or arrhythmias; gastrointestinal dysfunction like constipation, severe heartburn or reflux; dermatologic problems like hair loss; or bone loss leading to osteoporosis or even growth problems. These and other medical complications put each patient at serious risk.

Is there any eating disorders research going on at Children's?

There's quite a lot actually. For example, **Dr. Catherine Gordon**, who directs the Bone Health Center, is working to identify factors that contribute to bone loss in healthy children and adolescents, as well as in those with *anorexia nervosa* and other disorders. Also, **Dr. Bryn Austin**, of Adolescent Medicine, is addressing social and physical environmental influences on physical activity, nutritional patterns and eating disorders risk in school and community settings. Other researchers at Children's are looking at cardiac function as it relates to eating disorders.

Brighter, more colorful welcomes

Reception areas will greet visitors as they come off the elevators from the Main Elevator Lobby.



Children's Clinical B

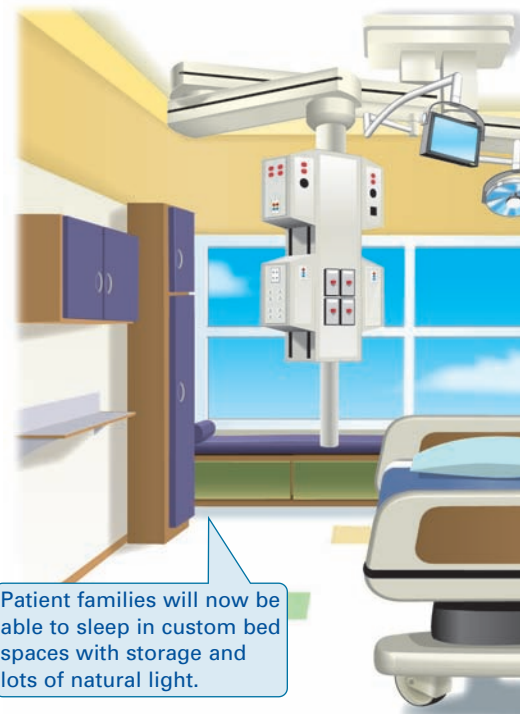
In late June 2005, Children's Hospital Boston will open the upper floors of the new 11-story Clinical Building Expansion (CBE) as part of a two-phased occupancy. An extension of the hospital's existing Main Building, the CBE will give clinicians access to some of the most cutting-edge technology while carving out more room for patients and their families.

Here are some of the highlights of the new space.



Occupancy Dates
 Phase I: Floors 6 to 10 → June 29, 2005
 Phase II: Floors 1 to 3 → August 15, 2005

Ceiling-mounted booms stocked with nearly everything needed for patient care—including surgical lights and small TVs for patients—allow the beds to be moved to the center of the room so clinicians can have 360-degree patient access.



Patient families will now be able to sleep in custom bed spaces with storage and lots of natural light.

Larger, more open ICUs

The hospital's world-class Cardiac and Medical/Surgical ICU is moving into new space in the CBE. Forty-eight beds will give critical caregivers unfettered access to patients near

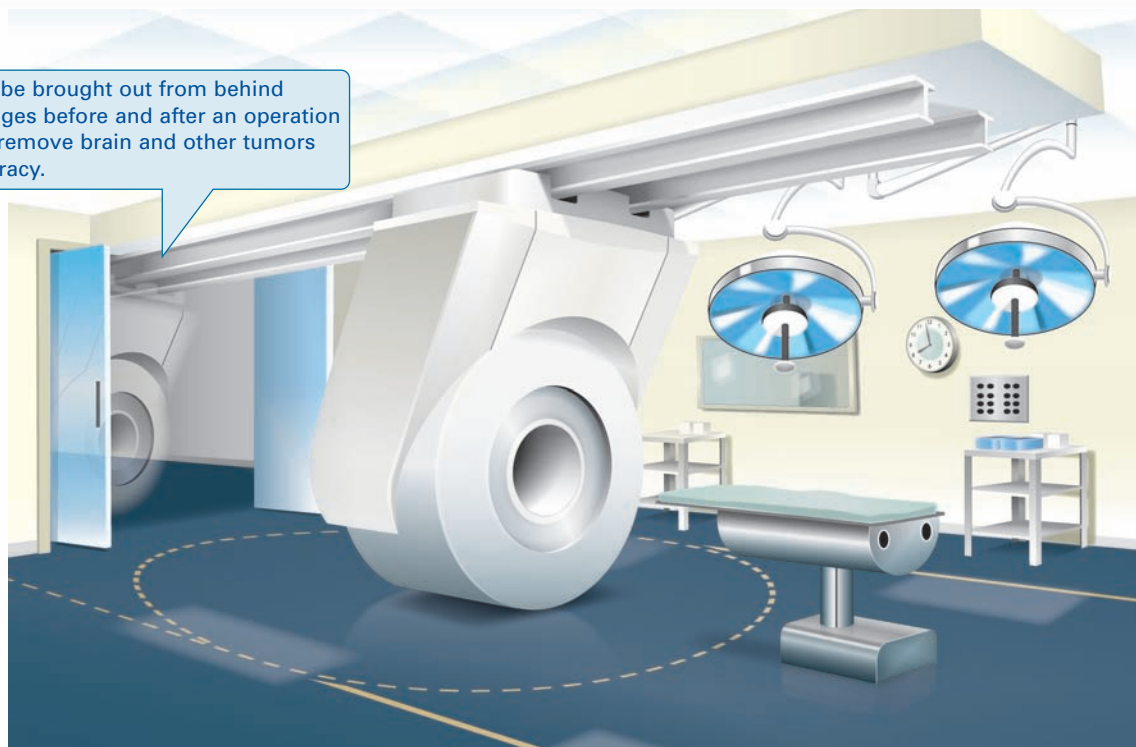
A bay for the ICU on wheels

The back side of the CBE will be home to Children's Critical Care Transport Ambulance. Special features include room for two patients, an X-ray box, IV warmer and a DVD player for children awake during transport.



Building Expansion

The magnet will be brought out from behind doors to take images before and after an operation so surgeons can remove brain and other tumors with utmost accuracy.



A mobile MRI unit for more precise surgery

A first-of-its-kind 15,000-pound mobile magnetic resonance imaging (MRI) unit suspended from a piece of structural steel similar to those holding up the building is the main feature of this space-age operating room. The mobility of the MRI unit lets surgeons use their usual metal surgical tools instead of those made of non-metallic substances developed for use in other intraoperative MRI machines. The MR/OR is one of eight new surgical suites in the CBE.

Medical intensive care units (ICUs) are spread out over two floors will give leading the highest level of care.

An entertainment center in each room features a TV, DVD player, video game console, Internet connection and a place to hang artwork or get well cards.



More room, comforts for patients and families

The 48 new inpatient rooms on floors 9 and 10 are home to amenities and comforts to make hospital stays more comfortable. Every room is a single, and there's more room for family members, as a wardrobe and bed space with a mattress have been built into the alcove next to each window.

els



Image guidance system helps newborn breathe easier

Ten fingers, 10 toes...when Maryan Shah was born on February 5, 2005, she was the picture of perfection, but her delivery team at Brigham and Women's Hospital noticed she was having difficulty breathing. It was then that a barely visible, tissue-like structure was discovered inside her left nostril.

Otolaryngologist **Reza Rahbar, DMD, MD**, was called to consult on her case, and Maryan was soon transferred to Children's Hospital Boston where a magnetic resonance image revealed that the newborn had a sizeable nasal glioma—a benign congenital tumor—filling the left side of her nose and extending up to her brain, where it was attached to the base of her skull. Since the glioma was inhibiting Maryan's breathing, Rahbar and his team determined it needed to be removed.

"A nasal glioma can generally be removed in one of two ways," says Rahbar, "by an open approach requiring an incision to the face and nose, or by debulking it—surgically removing as much of the tumor as possible—through the nostril."



According to Rahbar, there are pros and cons to both methods. While cutting open the nose typically guarantees removal of the entire tumor, recovery time is longer, and it can leave a facial scar. And debulking doesn't always ensure the tumor will be completely extracted, particularly the extension of the tumor at the base of the skull.

In Maryan's case, Rahbar's team was able to remove the entire tumor through her nostril by using a special image guidance system, the LandmarX Evolution Plus. Using the images from her CT (computed tomography) scan, the system constructed a three-dimensional model of Maryan's head that was then electronically matched to her anatomy during surgery.

"At only 3 days old, Maryan was very small when we performed the procedure," says Rahbar. "So we had to find creative ways to secure the headset portion of the system, adding sponges and towels to make the circumference of her head large enough to attach it." In fact, according to the manufacturer, Maryan is the youngest child in the country to undergo a procedure using this system.

The image guidance system allowed Rahbar to track the movement and location of his

surgical instruments in real time throughout the three-hour procedure, using cameras and infrared light to ensure he was removing the full tumor while avoiding other areas of Maryan's nose and brain.

"The surgery was a great success," says Rahbar. "The baby did very well. She was eating and drinking within a day of the procedure and was discharged after only two days."

And mom, Koldia, couldn't be more thrilled. "Dr. Rahbar treated my 3-year-old son when he needed ear tubes, so it was very comforting to see a familiar face," says Koldia, who refers to Maryan as her "inspiration." "But when you're a new mother and it's your child, it's very difficult. I'm truly amazed at this fantastic procedure. I thank God, and I thank the wonderful care team at Children's."

Rahbar and other members of the Department of Otolaryngology have used the image guidance system for 50 or so patients to date—some of whom could not have been treated without it. "This summer, we will begin performing these procedures in the hospital's new state-of-the-art pediatric MR-OR," says Rahbar. "It will allow us to take an MRI scan immediately following surgery to ensure the tumor was completely removed and decrease the need for additional surgery."

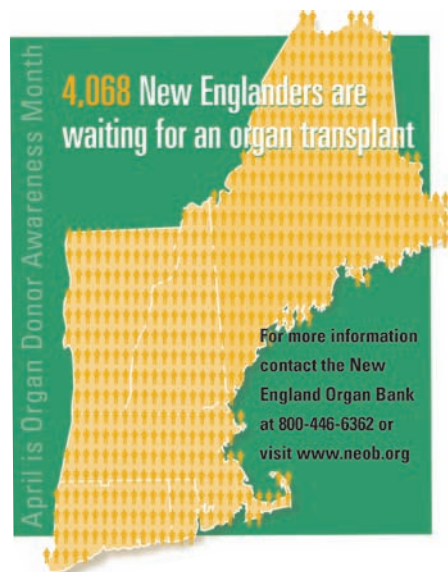
Organ transplant »» continued from page 1

whole body took a step back," Vanessa recalls. "Things were supposed to work."

Panic set in. It was creeping up to 9 a.m. when the phone rang again. "Pack a small bag with only the necessities and Andy's car seat," they said. "The Maine National Guard is going to fly you to Boston in a helicopter, and they are scheduled to leave at 9:30 a.m." After a frazzled, 20-minute car ride in the blizzard, friendly members of the National Guard greeted them as if it was part of their daily routine. "I was absolutely floored that the National Guard could do this for us," Vanessa says. "It was overwhelming to see how everyone pitched in to help out a baby they had never even met."

Vanessa laughs recalling the bumps and white-out conditions of the flight. "I am petrified of flying," she says. "I never thought I would fly in a helicopter, let alone a Black Hawk, to take my son to Boston for a liver transplant. It was quite a ride."

The National Guard got Andy to Children's safely, and for seven hours, the Koches anxiously passed the time by pacing, mindlessly reading and napping. Running on adrenaline and a lot of coffee, Vanessa and Charlie were glad to hear that the surgery went extremely well. "We were so relieved that it went smoothly," Vanessa says.



On January 21, after five days in intensive care and five more on 8 North, doctors told Vanessa and Charlie that their son could go home. Tons of questions raced through their heads about their ability to care for Andy, but after being quizzed on all of the medications, possible side effects and complications, the Koch family returned home. They made the trip in yet another winter snow storm, but this time without the help of the National Guard.

Today, Andy is 8 months old and is doing very well. With chubby cheeks and lots of hair, you'd think he was a completely healthy baby. And although nothing could prepare the Koch family

for the events of the last five months, they can say that a Black Hawk helicopter saved little Andy's life. "The six-inch scar and eight bottles of medicine are a good reminder of what we're dealing with," says Vanessa. "But we live day-to-day life normally again, with a new perspective on bumps and bruises."

Spotlight Running for Andy

Children's Hospital Boston's **Kelli Cole, RN**, has been running the Boston Marathon for the past three years. But this year the race is more than just a personal challenge—Cole is teaming up with one of her patients, Andy Treviño, to raise money for Children's.

A nurse on 6 West for the past three and a half years, Cole cares for patients whom she refers to as “the bravest, strongest kids that run their own marathons every day.”

Five-year-old Andy is one such patient. Born in Mexico, Andy arrived at Children's on April 25, 2001, where he was diagnosed with a mutated nuclear factor kappa B essential modifier (NEMO) gene, which has caused a primary immune deficiency that makes his body unable to protect itself from even common infections. NEMO has caused Andy to be in the hospital for more than one-third of his life.

Cole became Andy's primary nurse in September 2004, shortly before a stem cell transplant aimed at restoring his immune system. The two quickly became good friends. “Andy's been through a lot,” says

Cole. “So many kids like him become quiet and withdrawn, but not Andy. He's so full of energy and has a great sense of humor. He's really an amazing kid.”

When Andy's parents, Paulina and Andrés, found out Cole would be running the 2005 Boston Marathon, they asked if she would consider running for the hospital in their son's honor. “It was perfect timing,” says Cole. “There are so many days that I leave work wishing I could do more, so I thought that running for Children's and honoring Andy would be the ‘more’ that I could do.”

As a gift to Kelli, Andy designed the sneakers she will wear for the race. Using www.nikeid.com, he was able to select the colors and have them personalized with his name on the left shoe and Kelli's on the right. “He's only 5 years old, but Andy's a whiz on the computer,” says Cole. “We sat



down together in his hospital room, and he mixed and matched colors until he found a combination he liked. He even threw in some pink for me, since he knows it's my favorite color.”

Andy has been home since February and has started back to school, learning in a private room to protect him from infection. “It's unfortunate that he can't be with the other kids,” says Cole, “but at

least he has a normal routine again. He's doing great.”

Cole hopes Andy will be able to cheer for her along the race route this year, but regardless, she'll be thinking of him as she runs. “No matter how bad I might feel during the race, I have to finish for Andy,” she says. “In years past, I've never run for Children's, but the kids that I've cared for have always run with me. And this year, I'll be thinking of Andy.”

Gratitudes

The following letter was sent to Tom Sherr, benefits manager in Children's Hospital Boston's Human Resources Department.

Dear Mr. Sherr,

My husband and I would like to thank you and Children's Hospital Boston for the adoption benefit we received in November 2004. Although well worth it, the amount of money expended to bring our son home was not insignificant. Financially, the benefit is quite helpful. It is also gratifying to know that Children's supports employees opening their homes to children in need. We were also granted this benefit when we adopted our daughter, Elaine, from China in 2001. It is yet another way that Children's contributes to bettering children's (and families') lives, and why I am proud to say that I have been a nurse here for 26 years.

On a more personal note, our son Edwin is 7 years old and has been with us for over a year now. He is originally from the Philippines, is acquiring the language and acclimating to life in “the States.” He can give us a run for our money, but he is a happy, funny boy with many gifts, and we can't imagine our home without him.

Thank you again.

Sincerely,
Dawn Garrity-Woods and Edward Woods

The Woods family



Child Life Week

In celebration of Child Life Week, April 4 to 8, the following events will be available to staff, employees and/or patient families:

Puppy Pre-Op April 5, 10 a.m. to 12 p.m.

Patient Entertainment Center. All are welcome.

Nursing Child Life Exemplar April 7, 1 to 2 p.m.

A Palette of Professional Practice: Embracing Family-Centered Care and Diversity

Byers A and B. For staff and employees.

Scout update

It's almost that time—the HIPAA Security Rule goes into effect on April 20, 2005.

Visit www.childrenshospital.org/chnews/scout for some last-minute tips.



Child Abuse and Neglect Prevention Month

In recognition of Child Abuse and Neglect Prevention month in April, the following events will be available:

Babies Cry, Have a Plan Presented by Alice

Newton and Allison Scobie-Lloyd

April 13, 1:30 to 3 p.m. Enders Seminar 1

Child Development and Positive

Parenting Strategies Presented by Amy

Tishelman and Allison Scobie-Lloyd

April 26, 12 to 1:30 p.m. Binney 4

Celebrating service

Children's Hospital Boston has a longstanding tradition of recognizing employees and staff who celebrate a service anniversary. Employees who reached a service milestone in 2004 will be honored at celebrations in mid-May. Service Award recipients will receive notification of the program by mail in early April. For more information and a list of award recipients, visit the Service Awards internal Web site (<http://web2.tch.harvard.edu/hr/serviceawards.cfm>) the week of April 4.

Cooking for families



On Thursday, March 3, employees from Children's Hospital Boston's Center on Media and Child Health cooked dinner for patients and their families staying at the Devon Nicole House. Employee cooks included (from left): Michael Rich, MD, MPH; Brandy King, MLIS; Amy Branner; David Bickham; Julie Szymczak; Marie Evans Schmidt; Jessica Ochs; and Laura Hacker. Interested in hosting a meal for the Devon Nicole House? Contact Jennifer Darling at ext. 5-8457 to set up a date.

From Children's to Washington



Brian Skotko and Ben Allard

Motivated by the recent Down syndrome studies conducted by Harvard Medical student **Brian Skotko, MS**, (reported on in the February *Children's News*), Senators Edward Kennedy (D-MA) and Sam Brownback (R-KS) introduced legislation on March 16 that would provide \$25 million in federal funding so that women with positive prenatal test results for Down syndrome and other conditions receive current, science-based information and referrals to support services. The bill, S. 609, is supported by Children's Hospital Boston, and Skotko presented the results of his studies at a press conference with the senators in Washington, D.C., joined by patient Ben Allard.

Dream Research available
The Research Edition of *Dream Magazine* is out and can be found in bins throughout the hospital and at www.childrenshospital.org/dream.



Children's News

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Published monthly by the Department of Public Affairs for Children's Hospital Boston employees, staff, volunteers and visitors.

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