

# Children's News

For Children's Hospital Boston employees, staff and volunteers

April 2009 | [childrenshospital.org/chnews](http://childrenshospital.org/chnews)

## A Christmas story

This past Christmas, two children with kidney disease got gifts that even Santa couldn't have pulled off. Amanda Edme hadn't been looking forward to Christmas, even if it meant she'd get the pink Hannah Montana lunch box that was on her wish list. "It's not going to be a good Christmas because I'll have to get my shot that day," she'd told her mother, referring to the bi-monthly injection she was scheduled to receive to boost her red blood cell count.

As it turned out, she didn't need the shot. The shy 7-year-old from Brockton, Mass., had been put on the deceased donor waiting list while receiving 12 hours of dialysis each night. "The call came at 1 a.m.," says her mother, Antoinette. "The phone rang and rang and finally I answered and heard, 'Amanda has a kidney.' I was so shocked I couldn't do anything. But Amanda was jumping up and down and dancing, she was so excited."

Amanda had planned to wake up Christmas morning, unwrap presents and spend the rest of the day playing with them. Instead, she and her parents jumped in the car and headed to Children's Hospital Boston, hardly able to contain themselves while they waited for the operation to get underway.

As Amanda was operated on, Cameron Passarelli, a 10-year-old spitfire from upstate New York, was on his way to Boston. His mom had also received an early morning call letting them know that that the same deceased donor was also a good match for Cameron, and that they should drop what they were doing and drive to Children's.

"That day epitomizes teamwork," says **William Harmon, MD**, director of Children's Division of Nephrology. "From the donor hospital to the organ recovery team, flight crew and other transport teams, to surgeons and fellows, transplant coordinators, nursing and OR staff, so many people came together on a day when the hospital is traditionally empty to make this happen."

Before leaving the house, Cameron was able to open the present he'd been hoping for: a new three-piece suit to add to his collection. A dapper fourth grader, Cameron loves to dress up in suave ensembles for everyday occasions, like going to school or for a hospital visit. He even occasionally tops them off with a wide-brimmed hat.

Photo: Patrick Bibbins



THREE MONTHS AFTER GETTING A KIDNEY FOR CHRISTMAS, Amanda Edme takes a play-doh set for a spin.

Cameron is no stranger to hospitals; he's had dozens of surgeries, including some on his heart and back. "I used to go to a hospital in Albany, but they said they couldn't do kidney trans-

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Children's Hospital Boston

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## New fund to advance Children's technologies

Hoping to advance the translation of technologies into products for patient care, Children's Hospital Boston launched the Technology Development Fund last month. Through internal awards to Children's investigators and outsourcing to contract research organizations (CROs), the fund will eventually give out more than \$1 million per year. It will be administered through Children's new Technology and Innovation Development Office, or TIDO, formerly the Intellectual Property Office (IPO).

The new fund will pay for projects that traditionally aren't



ERIK HALVORSEN, PHD



MONIQUE YOAKIM-TURK, PHD

done in academic labs, but are necessary to carry discoveries into the preclinical and clinical stage, such as synthetic or medicinal chemistry, toxicity and pharmacodynamic studies and prototype construction. "Many of our technologies are in a very early stage,

sometimes not much more than an idea on a napkin," says **Monique Yoakim-Turk, PhD**, TIDO's technology development manager. "We want to get to products that impact patient care, so we need to come up with a more complete package."

A Request for Proposals was issued on March 16, and initial Letters of Intent are due April 8. An external advisory board—composed of venture capitalists and leaders of biotech, pharmaceutical and device companies—will vet the applications and make recommendations on projects to be funded. They will also act as project advisors, giving Children's research groups direct access to feedback from the business community. The first grants will be announced by this summer.

With the hospital now assuming some of the risk in the development of new drugs, devices and diagnostics, it's hoped that more discoveries bubbling out of Children's labs will be licensed by industry and enjoy commercial success. "Before, we thought this fund would help open more doors to industry," says TIDO Director **Erik Halvorsen, PhD**, "but now it's necessary to open any doors."

📄 See their new Web site at [childrensinnovation.org](http://childrensinnovation.org).

## Cultivating translational leaders

Children's Translational Research Program (TRP) has issued its first round of five-year Investigator Awards. The intent is to support and cultivate promising faculty-scientists, give them protected time to conduct translational research and, most importantly, help them bring their discoveries to clinical development.

The three awardees, **Bernhard Kuhn, MD** (Department of Cardiology), **Mustafa Sahin, MD, PhD** (Department of Neurology), and **Dario Fauza, MD** (Department of Surgery), will receive funding for half of their salaries. As junior investigators, Kuhn and Sahin will receive an additional \$40,000 a year in research support.

Kuhn, winner of the American College of Cardiology's 2007 Young Investigator Award, is working to regenerate heart tissue as a way of treating heart attacks in adults and heart failure due to congenital heart disease in children. Kuhn's prior work in rats found that a patch soaked in a growth-stimulating substance called periostin, placed over the site of cardiac injury, regenerated heart muscle and improved pumping ability; he now plans to use his TRP award to take the findings to patients.

Sahin, who received the Young Investigator Award from the Child Neurology Society in 2005, studies how nerve cells connect to one another and how this connectivity goes awry in disease. He focuses on tuberous sclerosis complex (TSC), a neuro-genetic disease that causes benign tumors in the brain (and elsewhere in the body) and has neurologic symptoms. His laboratory has produced evidence for abnormal neuronal connectivity in TSC, a finding that also has implications for epilepsy, developmental delay and autism.

Fauza, whose postdoctoral fellows have won American Academy of Pediatrics awards for four consecutive years, works with fetal stem cells—taken from amniotic fluid during pregnancy—to repair congenital diaphragmatic hernias and congenital airway obstruction in newborns. Much work has been done in animals and Fauza hopes the project, combining stem cell biology with tissue engineering, will lay the groundwork for treating a variety of congenital anomalies at birth, later in life and through Children's Advanced Fetal Care Center, where he is director of research.

The awards are part of an overall strategy to build a Translational Investigator Service, a multidisciplinary cadre of productive faculty-scientists with leadership skills and strong scientific and clinical backgrounds. "Success of this program will facilitate the rapid translation of discovery sciences into human trials and facilitate the use of human patient resources in advancing scientific discovery," says TRP Director, **David Williams, MD, PhD**, also chief of Hematology/Oncology. A second round of applications are due May 1.



MUSTAFA SAHIN, MD, PHD



DARIO FAUZA, MD



BERNARD KUHN, MD



DAVID WILLIAMS, MD, PHD

📄 Have research news you would like to share? E-mail [nancy.fliesler@childrens.harvard.edu](mailto:nancy.fliesler@childrens.harvard.edu).

## A Christmas story



CAMERON PASSARELLI

a vase as a present for his family. Dressed in one of his signature, suave suits, he happily told staff everything they'd ever want to know about professional wrestling and his favorite sports team, the Yankees. (He can also tell you which Children's employees are closet Yankee fans.)

Now, Cameron and Amanda come into Children's twice a week for tests, when they see one another and their moms catch up. Soon, they'll move to a monthly schedule to monitor their health and medication regimens. Cameron is looking forward to returning to school when his mandatory three-month wait is over. And Amanda is returning to her old self, gaining weight, bursting with energy and eating all sorts of things that had been off limits before her transplant, like bananas and popcorn. "She had been too tired to do her homework before," Antoinette says. "Now she has a different life, a better life, a normal life. She is so happy."

plants on little people so they sent me to Children's," he says.

Cameron's operation lasted into the night, and, like Amanda's, it was a success, although he's had to come back to Children's for an inpatient stay due to a bout of pneumonia. Despite the slight setback, he was upbeat and full of energy during his recent stay, and was a regular in the playroom, where he colored helicopters, made pictures of dragons and decorated

**April is Donate Life Month, when people across the country celebrate the generosity of those who have saved lives by becoming organ, tissue, marrow and blood donors, and to encourage more people to follow their example.**

**Help spread the word: By signing up to be donors, we each have the potential to save eight people's lives with our organs. Bones and tissue can go up to 15 more people. Find out how you can become a donor at [unos.org](http://unos.org).**

## ORGAN DONATION BY THE NUMBERS

**The United Network for Organ Sharing collects data about every transplant in the United States and facilitates the organ matching and placement process. According to their latest statistics:**

**108,833** people are currently on the U.S. waiting list for organs

**83,447** of these people are waiting for kidneys

**8,711** of those waiting for kidneys have been waiting for five or more years

**550** children 11 to 17 years old are waiting for kidneys

## GRATITUDES



## My sister, my daughter

To whom it may concern:

Fifteen years ago, I walked through the door of Children's Hospital Boston. I wasn't the patient, my sister was. She was diagnosed with leukemia, and at that moment I was the lost little kid sister, feeling very scared. The nurse I met, Julie, changed that for me. She promised I would grow up and be OK, and even wrote and illustrated a story about my experience.

Fast-forward to this summer, when I found myself back at Children's, this time with my 3-month-old daughter, Jordan, who had a fever. Sick to our stomachs with worry, my husband and I met with **Alyssa Abo, MD**. As soon as she walked through the door, I picked up on her amazing interpersonal skills. She used appropriate humor to calm a first-time mother, all the while staying intently focused on assessing my daughter. She took control of my anxiety and made me feel calm and trusting, a feeling that slowly started to feel familiar from many years ago when my sister was sick.

Dr. Abo was an extremely efficient educator who explained the pros and cons of every option running through her head. I smiled, as I knew I had won the lottery of emergency room doctors that night! I left feeling that we were Dr. Abo's only patient. I know there's nothing special about our family; I truly believe that Dr. Abo went into medicine because it's what she was put on this earth to do. We feel incredibly lucky to have found a hospital that treats a family twice with such exceptional care.

Sincerely,

Jodi, Jordan and Dave Pas



## The breakfast club

Each Saturday morning begins the same way for **Michelle Gordon**: She wakes early, travels to Children's Hospital Boston and dons a blue volunteer smock.

Her path to Children's fluctuates; when she first started, she took the bus from Belmont, rode the red and green lines and walked from Longwood Station. Nowadays, the 20-year volunteering veteran spends the first hours of her weekend making the scenic drive from Nashua, New Hampshire. Despite career changes, moving out of state and a new marriage, Gordon's Saturday routine remains constant, and she intends to keep it that way. With 2,972 Saturday hours under her belt, it's Gordon's goal to reach 3,000 hours by May 15.

Gordon is one of a handful of long-time Saturday morning volunteers who give up brunches and lazy weekends in bed to volunteer at the hospital. As the years have gone by, a core group of volunteers have emerged to form the backbone of the weekend crew. **Barbara Blundell, MS**, supervisor of Volunteer Services, says the Saturday morning crew is invaluable. "These are sterling people," she says. "We call on them to do a lot of the behind-the-scenes work, as well as playing with the kids."

This morning, sitting in the Volunteer Office, Gordon puts together orientation packets with **Anne Powell**, who has been spending her Saturdays at Children's for 10 years. Collating packets, the women discuss what originally brought them to volunteering. Gordon, a medical assistant in Winchester, says she was ingrained with a commitment to community service early in life. And she never liked to sleep in on weekends anyway. "I really look forward to coming in," she says.

Gordon organizes the monthly dog shows in the Patient Entertainment Center, where the dogs do obedience tricks to the delight of patients. Most valuable, says Blundell, is the way Gordon takes new volunteers under her wing. "That's her first priority," Blundell says. So what keeps Gordon coming back, year after year? She says it's the resilient attitude of the kids that never fails to lift her spirits. "No matter how sick they are, they don't let anything hold them back," she says. "Their positive outlook is inspiring."

For Powell, a research coordinator for the Massachusetts Office of the Commissioner of Probation, chance brought her back to Children's after being treated here as a child. On an evening a decade ago, Powell was flipping through TV stations and stumbled across a telethon raising money for the hospital.

As she watched it, she recalled her own experience at Children's and decided she wanted to come in and play with the children. "I remembered how difficult it was for me here, and I wanted to do something and give back," she says. Powell is now about to break the 1,000 volunteer-hour mark.

Because fewer activities are scheduled on weekends, the days can seem long and boring for children on the inpatient floors. Breaking up that monotony and entertaining the kids is what drives **Paul Kimball**, another member of the group. If it weren't for Kimball, the playroom on 10 NW would remain locked on Saturdays. Each Saturday, the investments accountant for Wellesley College retrieves the keys from the nurse's station and opens up the colorful room with big windows.

On this day, he unlocks the door, turns on the lights and the radio, and one minute later, 9-year-old Steven is hobbling in as fast as he can, heading for the Nintendo.

"He would be running if he could," says his mom. Steven, who was hospitalized for an operation a week earlier, begins intently playing Transformers as his mother rests on a kiddie chair. She says Steven was crushed when the playroom closed on Friday night. "This room is the best medicine," she says.

When Kimball started volunteering, he planned on doing it for a few years. Now, 16 years later, he calls the playroom his "little home on Saturday." Kimball says he enjoys meeting people from all around the country and the world, and that the kids help him to keep life in perspective. There's never a typical day in the playroom. "At times, people are waiting for me to open the room, other times, kids drift in and out, looking for puzzles and games," he says. It's not only the kids who appreciate the volunteers: "Sometimes the parents need someone they can just unload on, someone who doesn't necessarily know all the medical stuff but can listen," he says.

After spending so much time together, the Saturday morning group has gotten close. They celebrate each other's birthdays and know each other's families. There's also friendly competition: Kimball wants to make it to his 20-year anniversary, just like Gordon. **Arquimedes Areche**, a Volunteer Services employee who supervises on Saturdays, says he's impressed with the way the group has adapted over the years. "What makes them unique is how long they've been together and how well they work together," he says. Blundell says the crew is a powerful example for other volunteers. "As their lives have gone in different directions, they still keep coming in," she says. "They plan their lives around Saturday mornings." For Kimball, it doesn't seem that extraordinary. "I'm not doing brain surgery," he says, "I'm just playing with the kids." Coaxing a smile onto a child's face makes all the early mornings worthwhile for him. "There's no price tag for that," he says.

**National Volunteer Week is April 19 to 25. A dinner recognizing volunteers who are celebrating service milestones will be held on May 14.**



Photos: Melissa Jeltzen

# Savings suggestions

So far, more than 70 suggestions have come in from employees through the Justifiable Costs Web site with ideas for ways that individual departments and the hospital overall can save money and work more efficiently. "We've been overwhelmed and very pleased by the response," says **Sandra Fenwick**, president and chief operating officer. "People from across the organization have taken the initiative to give us thoughtful ideas on both short- and long-term ways we can work together to save money and time."

The suggestions have been reviewed by a new multidisciplinary Justifiable Costs/Cost Saving screening team that is currently determining which changes can be implemented quickly and effectively.

The screening team's executive sponsors are **Mark Marcantano**, vice president of Ambulatory and Network Services, and **Henry Tomasuolo**, vice president of Support Services. They've found that many of the ideas fall into the broad category of "resource efficiency," which includes things like saving electricity, recycling and reducing consumption of things like paper.



KARP in the middle of the night

"Ambulatory Services is a large part of the hospital, so is naturally a large consumer of resources," says Marcantano. "I'm excited to know that we can have an equally large impact on the hospital's ability to use those resources more cost-effectively."

For his part, Tomasuolo, who has responsibility for Food Services and Environmental Services and Materials Management, knows his staff are in a unique position to save the hospital money in these tough times. "My staff do the recycling, take out the trash, process the dirty laundry and turn out lights after meetings," he says. "They can really make a difference, but they can also help us understand how everyone in the hospital can get involved."

- Along those lines, one way staff throughout Children's can have an immediate impact is by simply turning off lights at the end of the day—or when meetings are over in conference rooms. Engineering points out that about 30 percent of energy costs come from lighting. Other simple steps, like shutting off computers, copiers and unneeded clinical equipment at the end of the day, and adjusting the heat or air-conditioning when a room isn't in use, could also lead to significant savings.

## T I M E TO B O L D Children's Hospital Boston's long-range strategic plan

- Another way to get involved is to maximize the Recycling Program, since recycling costs far less than the cost of disposing of garbage. In 2008, it cost the hospital significantly more money to throw a bottle or can in the garbage than to recycle it. While groups are working to get recycling bins on more floors, everyone is encouraged to collect their recyclable materials and bring them to one of the recycling collection areas, including those in the Café and main lobby. Environmental Services points out that the future savings greatly depend on compliance: If people throw trash into the recycling bins or sort recyclables incorrectly, then the cost savings go down, since people need to be paid to resort the bins.

- Reducing laundering costs is another way to save. The cost to wash scrubs, sheets, towels, blankets, washcloths and other linens is \$0.59 a pound. Collectively, if we used just 50 fewer sets of scrubs per day in the entire facility, we'd save more than \$10,000 a year. A simple way to cut down on the scrubs cost is to encourage coworkers who don't need to wear scrubs, due to position or location, to not use them.

- Many suggestions came in about reducing the amount of paper used throughout the organization. The hospital spends more than \$200,000 to purchase white copy paper each year. If one out of every 10 papers is printed out double-sided, we can save more than \$20,000.

- We could save about \$11,000 if everyone who has direct deposit (83 percent of us) opted to not have our paystubs printed. Everyone who has direct deposit has the option to suppress pay stub printing; either on the intranet under the Finance page or by filling out a form at Human Resources' Employee Service Center.

For more information about how the departments can save money and be more efficient, check out the Justifiable Costs Web site on the intranet. Here, you'll also find information on how to set your printer to print double-sided.

## NEWS BY NUMERALS

**National Volunteer Week is April 19 to 25. Whether playing with children in waiting rooms, visiting patients or answering phones, Children's Hospital Boston's volunteers play a vital role in the hospital. Last year, more than 830 volunteers provided special services for patients and families.**

60%

Percent of volunteers who have (at least) a Bachelor's degree



1,420

Postgraduate social work fellows work at Children's

16

Number of laps that a volunteer needs to walk a patient around the unit to complete one mile



73% 35

Percent of volunteers who are younger than

18,000

Approximate number of stickers volunteers give to children a year



## Crossing continents for answers

For **Hanna Gazda, MD, PhD**, associate scientist in Genetics at Children's Hospital Boston, the unpredictable trajectory of her life was triggered by a simple question to which she had no answer.

As a resident at a hospital in Warsaw, Poland, Gazda was treating a teenage boy with Diamond Blackfan Anemia (DBA), a congenital blood condition in which bone marrow can't produce red blood cells. The weak 18-year-old patient wasn't responding to any medications and required blood transfusions every month. One day, as Gazda was making her rounds with some medical students in tow, the patient confronted her. "Doctor, you're talking about my disease, and you present my case to these students, but you don't really know what's going on with me, do you?" Gazda recalls him saying. "Why am I sick? Why can't you fix me?" It was a challenge Gazda accepted, and the beginning of an odyssey that would stretch across continents.

She began collecting DNA samples of children with DBA and their families, convinced of a genetic cause of the disease. The samples would be vital to uncovering the responsible genes. But the more samples she collected, the more she yearned to devote further time to DBA research. Gazda had dabbled in clinical research before, but it was always secondary to her duties as a practicing doctor. "I was thinking I wanted to work on this disease full-time for a few years," she says.

After creating a registry of children with DBA, Gazda searched for a Polish laboratory interested in having her work on the disease, to no avail. So she expanded her search to include Western Europe, but still there were no takers. Finally, she

discovered someone who shared her drive to decipher the cause of DBA: Colin Sieff, MB, BCh, who had a laboratory at the Dana-Farber Cancer Institute. "He had DNA from one large family and needed more," she says. "I had samples and a real passion for this work."

Moving to the United States was a difficult decision for Gazda. "I had family, I had friends, my life was there," she says. But in the end, her desire to understand DBA triumphed. In 1997, she arrived in the United States carrying a suitcase full of DNA samples to add to Sieff's collection. The goal was to perform a linkage analysis study, which is a gene-tracking technique that traces patterns of heredity in large, high-risk families, in an attempt to locate a disease-causing gene mutation. "The genome is huge, so the point was to find out where the gene is located," she explains.

A few years later, she joined the laboratory of **Alan Beggs, PhD**, in Children's Division of Genetics. Eleven years since arriving in the United States with little but DNA samples and high hopes, Gazda's work has contributed to science's understanding of DBA, by identifying seven genes that are mutated in DBA patients. Her work confirmed that DBA is the first identified human disease caused by mutations in ribosomal proteins.

Gazda praises Children's for its dedication to studying rare diseases, namely its new Manton Center for Orphan



Photo: Patrick Bibbins

HANNA GAZDA, MD, PHD

Disease Research—the world's first and only such center. "It's not easy to get funding for these diseases because they are so uncommon," she says. "But even if one person is affected, it's worthwhile to perform studies to save this person."

She's still surprised by the path her life has taken. "From the moment I met that patient in Poland, I wanted to work on this disease—I just didn't think it would take so long," says Gazda. "I never thought I would be dedicating my whole life to one rare disease." The boy whose question initially challenged Gazda has died. Although she's disappointed that her research wasn't advanced enough to save his life, she's determined that others won't share his fate. "In 10 years, we'll hopefully have a better treatment and maybe even a cure," she says.

## A pizza for your thoughts



Two years ago, Patricia Branowicki, MS, RN, NEA-BC, was seeking a way to hear directly from staff in Medical Patient Services (MPS) about what's happening across the institution. As a result, the Vice President of MPS created Pizza with Patti, an employee lunch series where nurses, administrative staff and clinical assistants discuss workplace issues with Branowicki over a hot slice of pizza. More than 50 Pizza with Patti lunches have occurred since its inception. "These sessions have become integral to the work of nursing leaders throughout MPS," says Branowicki. She attempts to visit each department twice a year, with attendance ranging from small intimate groups of four or five to large group sessions.

## Ethical disagreements and dilemmas

The headline in one newspaper read, “Couple wants no surgery for son.” Another read, “Mom’s plea: Let my baby die in peace.” It was 1985. I had recently come to work at Children’s Hospital Boston and this was one of my first ethics consults. The hospital’s Ethics Advisory Committee had just begun the year before.

The newspaper clippings in our file are faded and ambering, but I remember those parents and their baby clearly. Randy (not his real name) was born early (at 34 weeks) with a short esophagus and a tracheo-esophageal fistula—something that can often be fixed. He had three major surgeries and 10 other procedures requiring anesthesia with lots of clinical problems and setbacks. He’d been in the intensive care unit (ICU) for four months; his lungs and intestines had failed and his kidneys and liver were headed for failure.

The surgeon and many of the staff thought Randy could survive, albeit with difficulty and perhaps with deficits. The neurological exam showed “no evidence strong enough to serve as the basis for withdrawing support,” although the neurologist acknowledged the stress on Randy’s developing brain. Maybe he could make it with more months of aggressive care and intensive life support. Some of the best nurses and doctors in the world work at Children’s, and if anybody could keep him alive, they could.

Randy’s parents thought he should be allowed to die. So did some of his nurses. Both parents said they would take their case to court if need be; they had already taken it to the court of public opinion by talking to journalists.

What difference, if any, should these things make? How sure should we be that a child is dying before withdrawing life support? And does a child have to be dying, or is it enough that what it would take to live is too big a burden for the child? For the family?

I talked with our new ethics committee about Randy. The committee recommended that life-sustaining treatments continue, and they were—for two more weeks. When Randy had another near-death crisis, the clinical team accepted the parents’ decision to halt any further medical treatment, and he died. I can’t remember what I thought that day as clearly as I can recall the pictures I have in my mind of Randy and his parents. To be sure, his parents felt certain that stopping further treatment was the right thing to do, and Randy’s doctors thought they should continue saving and supporting his life.

Looking back, I think this was an ethical dilemma with no single right answer. Whatever one chooses—a longer life for a very sick baby, the right of parents to decide, a doctor’s duty to fight against death and disease, or a nurse’s responsibility to advocate for a sick and suffering child—something of value is sacrificed in resolving an ethical dilemma. That year, the country went through a polarizing public debate in Congress and in the media about how to handle such cases. New regulations requiring medical treatment of handicapped infants had come out, but they didn’t seem to reflect widespread public consensus and contained ambiguous language about “inhumane” and “virtually futile” medical treatment.

It’s been nearly 25 years since Randy died, and next month, the Ethics Advisory Committee will talk about a different theme

Photo: Jeffrey Jalovec



CHRISTINE MITCHELL

that has developed over the past decade. In contrast to those years when parents like Randy’s were saying “please stop,” the majority of moral disagreements these days involve parents who want—some would say demand—everything and anything that might possibly help their child survive, even when the clinical team is telling them there’s nothing more they can do.

A decade ago, the committee developed a policy to guide staff in confronting dilemmas raised by cases titled “Resolving Conflicts over Possibly Inappropriate or Harmful Life-Sustaining Therapies.” It describes the steps that should be taken when *either* parents, like Randy’s, or clinicians (as in a few recent cases) think treatment should stop and others think it should continue.

The hardest cases are those in which hospital staff think continuing medically useless treatment on a suffering or dying child is wrong, yet they also feel it is wrong to override parents’ decisions. That’s the ethical dilemma. Staff realize that parents will live with the way their children die forever. Nevertheless, cases like these take their toll on staff, too. What weight should we give to the moral distress of staff who do things day after day that they don’t believe in their hearts are right?

Back in 1986, Randy’s mother sent us a letter after his funeral. She said she could never express how fortunate she felt that she had us as a link to Randy. Few if any of us can really know what it is to face the ethical and emotional predicaments that these parents have. But after more than 25 years and lots of ethics consults, I’ve come to appreciate how very hard it is for parents *and* for staff.

Not all of our consults deal with death. And not all of them are ethical dilemmas. But some of the hardest are. One of the reasons we have an Ethics Advisory Committee is to help parents and staff think through the moral choices they must face in a way that enables each of us to preserve our moral consciences and continue to care—even when we aren’t entirely sure what’s right and, especially, when we think we know what’s right but others disagree.

## EMPLOYEE OF THE MONTH

Congratulations to **Danuta “Donna” Grodzinska**, clinical assistant in Children’s Hospital Boston’s Plastic Surgery Department, who’s been selected as April’s Employee of the Month.

Whether she’s sprinting to the cashier’s window to break a \$20, on her hands and knees cleaning every inch of the front desk area or personally escorting families to their next appointment, Grodzinska’s coworkers are constantly wowed by her “unending generosity.” According to one of them, she’s “undoubtedly one of the most selfless people I’ve ever met.”

Grodzinska came to Children’s as an administrative associate in 2002 and was promoted to clinical assistant a few years later. Since English is her second language, she took English classes and improved her skills tremendously. She now plays a key role in keeping Plastic Surgery operations running smoothly and its families happy. She bounces in and out of patients’ rooms to make friends with the children and offers parents helpful tips, like how they can get their parking validated. If a child is upset, she’s one of the first to rush over, usually offering them a sticker to calm them down.

Always extending a helping hand, Grodzinska often walks through other departments to see if an employee or patient from her area left something there by mistake. Once, when a patient forgot a cell phone in the waiting room, she dropped what she was doing and dashed through the hospital, across the street and out into the rain (without a coat) to return it to them before they drove home. “She’s a reminder that there’s always something more that can be done,” says a colleague.


 To nominate a co-worker for employee of the month for exemplifying Exceptional Care, Exceptional Service standards, submit a form online at [web2.tch.harvard.edu/eces/recognize.cfm](http://web2.tch.harvard.edu/eces/recognize.cfm).



Photo: Ethan Bickford

## UPCOMING EVENTS

### Open Meetings

The next sessions, hosted by James Mandell, MD, chief executive officer, and Sandra Fenwick, president and chief operating officer, will be **May 8, at 8:30 a.m.** and **May 12 at noon** in Enders Auditorium. Refreshments will be provided on May 8 and lunch will be served on May 12.

### Employee Wellness Fair

This year’s Employee Wellness Fair takes place **May 21, from 10 a.m. to 2 p.m.** in the Patient Entertainment Center. Everyone is invited to stop by to talk with representatives from benefits vendors and employees about topics related to health. There will also be raffles and giveaways.

### A little cheer goes the distance

You don’t have to be a runner to participate in the Boston Marathon on **April 20**. You can hoot, holler and high-five from the sidelines, cheering on runners who’ve raised money for Children’s as part of the Miles for Miracles Team Boston.

 For more information: [childrenshospital.org/run](http://childrenshospital.org/run).

### Is your child an ambassador?

Know a special child age 6 to 16 who participates in NSTAR’s Walk for Children’s and inspires others to do the same? Does he or she know what a special place Children’s is and love to give back to the hospital? Nominate that child to be the Walk Child Ambassador. He or she will receive pre- and post-walk publicity, special recognition and fun responsibilities—like ribbon-cutting—on **June 14**.

 For more information: [childrenshospital.org/walk](http://childrenshospital.org/walk).

## THIS MONTH’S SCOOP

### Black History Month observance


Children’s Hospital Boston marked its second Black History Month Observance in February with a special keynote address by Valerie Montgomery Rice, MD, Harvard Medical School class of 1987 and senior vice president for Health Affairs and Dean at Meharry College School of Medicine in Nashville, Tennessee.

“It was an honor to have the Dean of Meharry College School of Medicine, the largest private, historically Black professional college in the United States, present at Children’s,” says **Jessica Henderson Daniel, PhD, ABPP**, Black History Month Observance committee coordinator. “Her presentation was excellent—informative and thought-provoking. It was consistent with Black History Month as a time to highlight the intellectual contributions of Black Americans.”

Rice’s address, Health Care Realities for Diverse Populations, focused on health care disparities, insufficient access to health care for people of color and the rise of breast cancer and HIV/AIDS in Black communities.

Photo: Patrick Bibbins



 More at [childrenshospital.org/chnews](http://childrenshospital.org/chnews)

### Spring issue of *Vector* and *Dream*

The Spring issue of *Vector* will soon be arriving, featuring articles on the economic downturn, research on congenital myopathies in the Beggs lab, the Gene Partnership Project and more. Also, the new issue of *Dream* hits stands throughout the hospital this month, with stories about patients helped through our Augmentative Communications and Orthopedics departments, and more.



## Children’s News

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