



Children's News

Keeping pace

The arrival of a new baby can bring both joy and concern to parents. Just ask Anna Castaneda and Luis Morales, whose two sons were born with heart conditions that required pacemakers be placed in their tiny bodies when they were just days old.

Anna, 28, suffers from lupus, a disease in which the body's immune system attacks its tissues and organs. Unfortunately, it also attacked both of her unborn babies, first Alex, then Angel, causing a condition known as "heart block."

According to Children's Hospital Boston cardiologist **Mark Alexander, MD**, "Heart block occurs when the top of the heart is not talking to the bottom of the heart. The missed signal causes a very slow heart rate." The average heart rate for a newborn is 120 to 125 beats per minute; Angel's was only 40 beats per minute. His older brother Alex, now 1 and a half, had a heart rate of 50 beats per minute at birth.

"It was very stressful for the both of us," says Luis. "There was a different story every day."

Anna and Luis's first son, Alex, received a pacemaker to correct the problem at Children's when he weighed just 4 pounds. So when Angel was born with the same problem, Anna knew there was nowhere else she would go. "I wanted to have Dr. Alexander work with Angel because I felt so comfortable with the the work he had done for Alex," says Anna.

She was monitored extensively prior to delivering Angel at Brigham and Women's Hospital on June 11, two weeks prematurely. Weighing only 2.2 pounds, Angel became a world first just four hours after birth when Children's cardiac surgeon **Emile Bacha, MD**, implanted a quarter-sized pacemaker,

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Angel Morales only days after he became the smallest patient to have a pacemaker implanted.

Sliding in at the two spot

Children's Hospital Boston was again listed as one of the top pediatric hospitals in the country, according to *U.S. News & World Report*. The July 18 "America's Best Hospitals" issue relied on surveys of physicians nationwide to determine the rankings. Since the magazine began ranking hospitals 16 years ago, Children's has either been the first or second best pediatric hospital in the survey. This year, Children's is ranked second nationally and

remains the number one pediatric hospital in New England. The hospital's reputational score was 47.2 percent.

"The results of this survey are a testament to the incredible dedication and work done by the caregivers, employees and volunteers at Children's," says **James Mandell, MD**, president and CEO. "This ranking is more good news in a summer that has already seen us successfully move into the first phase of the new clinical building expansion and open our new satellite location, Children's Hospital Boston at Waltham."

The annual issue of the magazine ranked 176 top medical centers based on a survey of 200 randomly selected pediatricians who were asked to name the five hospitals they considered best in their specialty.

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Top 10 pediatric hospitals

1	Children's Hospital of Philadelphia	53.9
2	Children's Hospital Boston	47.2
3	Johns Hopkins Hospital	33.0
4	Texas Children's Hospital	17.2
5	New York-Presbyterian Univ. Hosp. of Columbia and Cornell	14.8
6	Rainbow Babies and Children's Hospital, Cleveland	14.2
7	Children's Hospital, Denver	12.6
8	Children's Hospital Medical Center, Cincinnati	11.9
9	Children's National Medical Center	10.8
10	Lucile Packard Children's Hospital at Stanford	10.0

Inside:
Moving day



Summer fun, Trust-style

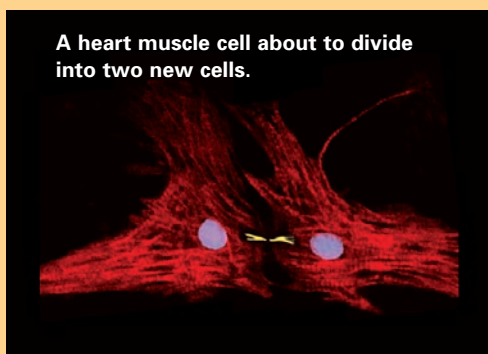
Thanks to the efforts of more than 2,300 walkers, the third annual Miles for Miracles walk raised \$620,000 for Children's Hospital Boston on Saturday, June 18. Participants, including many patient families and hospital employees, took either the two- or seven-mile path along the Charles River as part of a record 158 walk teams, including 24 employee teams. The event was supported by many generous sponsors, including Kohl's, Aquafina, Stride Rite, WBZ Newsradio 1030, Mix 98-5, CambridgeSide Galleria, Credit Unions of Massachusetts, Dunkin' Donuts, *The Improper Bostonian* and The Allied Group.

Also in its third year, the Mix 98-5 Cares for Kids Radiothon raised more than \$1 million for Children's. The event, held July 14 and 15 in the Patient Entertainment Center, featured Mix on-air talent including, John Lander, Kelly Malone, Wendy Filosi, Erin O'Malley, Gregg Daniels and Sue Brady. Funds raised through the Radiothon benefit the Children's Fund, supporting the hospital's areas of greatest need. Thank you to employees who volunteered, patients who shared their stories and all who made pledges.



Getting hearts to heal themselves

The cells that make up heart muscle in mammals have been thought incapable of replicating after birth. That's why heart attacks are such a problem: once killed, heart tissue can't grow back and is instead replaced by scar tissue. Now, in the best-documented effort to-date, **Felix Engel, PhD**, in Children's Hospital Boston's Department of Cardiology, has successfully gotten heart-muscle cells to divide and multiply—the first step in regenerating heart tissue. Engel's work, one of three prize-winning entries on Children's Research Day on June 1, could lead to new strategies for treating cardiac patients.



A heart muscle cell about to divide into two new cells.

Reporting in the May 15 issue of *Genes & Development*, Engel and colleagues showed that an enzyme called p38 MAP kinase suppresses heart-cell replication in rodents, and that inhibiting this enzyme enables cell replication to proceed. p38 proved to have a role in every major step of replication—DNA synthesis, division of the cell nucleus (mitosis) and splitting of the whole cell into two new cells (cytokinesis). Engel is now investigating whether compounds that inhibit p38 can improve heart function after cardiac injury. Preliminary results in rodents are encouraging, he reports.

Dialogue

Kathy Jenkins, MD, MPH, director of the Program for Patient Safety and Quality



Ensuring the safety of our patients

What is Children's doing regarding patient safety and quality?

The biggest thing is that we're currently formalizing and integrating our efforts across the hospital under the new "Program for Patient Safety and Quality."

Program PSQ, as we call it, encompasses the traditional areas related to risk management, quality improvement and compliance, but we've also added a faculty component; a large measurement infrastructure made up of physicians, nurses and other scientists; and an administrative staff that includes biostatisticians and programmers.

We've also created two key committees: the PSQ Measurement Committee and the PSQ Implementation Committee.

rates all the parts of the organization that we thought might be helpful in rolling out initiatives—Public Affairs, ISD, Pharmacy, and others.

What are the committees focusing their efforts on currently?

The PSQ Measurement Committee is creating a "Hospital Quality Dashboard," the highest level hospital scorecard for patient care. It is based on the six Institute of Medicine steps toward quality, which maintain that quality care should be safe, effective, efficient, timely, patient-centered and equitable. It is also based on Children's core mission to provide excellent patient care, research, teaching and service to the community. We're looking for excellent

Consult Policy. The PSQ Implementation Committee will be rolling them out over the next year.

What can patient families do to ensure their children are receiving the safest possible care?

I believe that one of the best resources we have at Children's that's different than adult hospitals is that we have parents at the bedside who are naturally highly motivated to protect their children. And as of yet, we haven't completely tapped into that resource. Parents should ask questions of their child's caregivers if they notice anything that concerns them.

Are we mounting any formal efforts to hear directly from patient families about safety?

Yes. **Lisa Horowitz**, one of our faculty members, is designing a patient family version of Executive Walk Rounds. Implemented in 2003, Walk Rounds are a forum where hospital leaders hear about issues of safety and quality directly from frontline staff. They've been very successful, and now we'd like to extend them to parents and families to hear their safety and quality concerns. Lisa has already facilitated a focus group with some parents, and not only did they love the idea, they came out with patient safety concerns that perhaps staff might not have otherwise considered.

Also, as I mentioned before, one of the Institute of Medicine's steps toward quality is that care be patient-centered. At Children's, we define it as "family-centered." We feel it's important to track how we're doing in this regard, so we're going to be looking at satisfaction surveys in our inpatient and outpatient areas and in our ED. Some of these surveys already exist, but we're working to modify them to be more reflective of the overall hospital experience.

If all of these efforts come to pass the way we hope, we would achieve a pretty aggressive goal—to provide the safest possible care to all of our patients.

"Parents should ask questions of their child's caregivers if they notice anything that concerns them."

What's the role of these new committees?

The PSQ Measure Committee is a reworking of the Data Collection and Auditing Committee, but it's bigger now, with more people. It helps the hospital do the measuring we need, and want, to do at a very high level. The committee also ensures that the measures are good, valid, important and that we compare ourselves to other groups we believe we should be equivalent to or better than, whenever possible.

In terms of the PSQ Implementation Committee, one of the things we recognized was that, in the past, we were putting in a lot of effort to create really nice policies and procedures, but we were actually doing a poor job of rolling them out across the entire institution. So the PSQ Implementation Committee, co-chaired by otolaryngologist **David Roberson** and Vice President of Cardiovascular/Critical Care Services **Patty Hickey**, will develop an integrated strategy to prioritize and implement initiatives throughout the institution. It incorpo-

measurements in each of these areas that reflect how we're doing overall as an organization. And unlike a lot of quality efforts, which are really focused on measuring the process, we're looking at actual outcomes data wherever possible.

The PSQ Implementation Committee is focused on the hospital's overall success at meeting the National Patient Safety Goals. Achieving some of them is actually very simple; they just involve changing a few processes. But others involve changing behaviors, or practices like using abbreviations, or hand washing—practices that, despite their importance and their obvious link to safety, we just are not in full compliance with yet.

The PSQ Implementation Committee is also working on three major policies that were highlighted two years ago in the institutional response to the Department of Public Health investigation. The policies are all related to communication within our organization: the Associate/Attending Policy, the Change of Service Policy and the

Moving day

On June 29, five years of planning, preparation and construction all came down to a single number: 8. As in 8 a.m., the hour at which the long-awaited, much-anticipated move into Main South, the hospital's clinical building expansion, would begin. But there was no need for concern as move day went off without a hitch, and the Cardiac ICU, Medical/Surgical ICU, Medicine Patient Services, and the Transplant and Surgical Services easily transitioned into their new homes. Take a look at some of the sights, sounds and stories from move day.

"This is very nostalgic. I've spent many long hours and seen thousands of patients on this unit over the years. It's very strange to say goodbye to P6," said Peter Laussen, MBBS, (below, center) director of the Cardiac Intensive Care Unit, as 11-week-old Gavin Bell (below) was the final patient to roll off P6 and onto 8 South.



Biomedical Engineering's Juliana Araujo, who began working at Children's just one week prior to move day, helped mount computer monitors in the new ICU rooms. Biomed moved and installed a total of 48 monitors on two floors.



Twenty-five members of the Pharmacy team moved approximately 4,000 doses of medications, six refrigerators and eight code carts on move day. By law, a pharmacist has to chaperone patients and their medications whenever they're moved.



Director of Clinical Technologies John Thompson, RRT, FAARC, transports biomedical equipment during the Main South move.



Children's PC Staging team (including Tom Read, above) was responsible for the building, deployment and repair of all Main South's standard computers, as well as the naming, deployment and service of all printers, including the 20 or so that had to be reconfigured on the fly during move day.



It was a busy first day back to work for Clinical Nurse Specialist Nancy Braudis, RN, MS, CPNP (above, right). One of her first patients was 8-day-old Christian Kelly. Diagnosed in utero with hypoplastic left heart syndrome, his parents, Tricia (above, left) and Brian, came to Boston for delivery and treatment. Even though he had already undergone two surgeries—and was scheduled for a third on move day—the Kellys knew Christian was being well taken care of. "We're confident when we leave for a bit that Christian is in good hands," said Tricia.



Just off the elevators, Yat "Cookie" Lee (left) and Martine Janvier (right) from Food Services delivered lunches to the newly moved patients. In addition to maintaining the room service food delivery option for all patients involved in the move, Food Services also served over 500 boxed breakfasts and lunches to staff and patient families and provided "welcome home" treat bags for the evening shift.



Children's Hospital Boston

The look and feel of the new ICUs is due in no small part to Bev Small and Carolyn Millett, charge nurses from P6 and P5, respectively, who helped plan the new units. They asked patient families who had spent time on the units what they liked and didn't like about the ICUs and what should be added to make staying there more comfortable and convenient. As a result, there are significantly more basic comforts (beds built into the window alcoves, storage space, etc.) for families staying with their children in an ICU.

Two wins for the Web

Children's Hospital Boston recently garnered two information technology-related awards: the 2005 Health & Hospital Networks' Most Wired award and the 9th Annual Webby award.

Each year, *Hospitals & Health Networks* magazine surveys the nation's hospitals to assess how they use information technology to develop better, safer and more efficient health care. The survey looks at five areas: customer service, safety and quality, workforce, public health, and safety and business processes. More than 1,000 hospitals and health care organizations participate in the survey annually. Of those, only 100 win the Most Wired Award; Children's was the only pediatric facility recognized in 2005.

"Achieving the Most Wired designation is a reflection of the hard work that ISD and the entire organization has put into enhancing our information systems and services," says **Daniel Nigrin, MD, MS**, Children's chief information officer. "We are deeply committed to providing state-of-the-art technologies for our staff and patients."

Children's received another exciting honor when our newly redesigned research Web site (www.childrenshospital.org/research) was deemed "Webby Worthy" at the annual



Children's Web site Development team (from l to r): Jeff Testa, Christine Carlson, Peggy Recinos and Ellen Kaspern.

Webby Awards, which are considered the top, worldwide awards for excellence in Web site design. The International Academy of Digital Arts and Sciences, whose members include those in the business world, celebrities, musicians, Web experts and more, present the honors.

Children's research Web site was judged against sites created by professional Web development firms, as well as many other technology-based sites, and out of 4,000 Webby Award entries, only 20 percent were ranked "Webby Worthy."

"The Webby Awards are the Oscars for Web sites," says **Danny Shaw**, director of Knowledge Management at Children's. "The competition involves organizations for whom Web design is their sole business, so just to be considered is quite an honor. For an organization like ours to actually receive any level of award is pretty astounding."

Pacemaker continued from page 1

making him the smallest baby ever to undergo such an operation. Routinely, pacemakers—battery-operated device that regulate the heart's rhythm—are placed directly on the abdominal wall. However, Angel's was too small to hold the pacemaker, so Bacha resorted to an old-fashioned procedure.

"The only option was to implant the device on Angel's diaphragm, where it would fit properly and offer enough support," says Bacha. But this wasn't an easy task given that Angel weighed a mere 2 pounds, and the pacemaker's wires needed to be sewn into the heart muscle. "This is an everyday procedure," says Bacha, "but with Angel, his heart muscle was really soft, so we had to be extra careful."

The procedure was a success, and Angel has since done well, putting on nearly 3 pounds and being transferred to a hospital closer to his home in Providence, R.I. His Children's doctors expect the tiny pacemaker they implanted will last two-to-three years and will need to be replaced regularly. But right now, Angel's parents are focusing on the fact that both of their sons are doing so well.

Alex offers hope that Angel will thrive. He is a typical toddler who loves to play outside, climb on boxes and splash around in the bathtub. "Alex is the best thing going for me right now," says Luis. "He makes me laugh."



And when the family visits Angel, Luis enjoys holding his two little boys and studying their faces. "Angel is a little Alex," says Luis. "I look at him and can tell that he is mapping and planning in his head how much running he and his brother will be doing and how much chasing I will be doing; I have a lot of work ahead of me!"

Spotlight An advocate always makes a connection

When Will Morales arrived at Children's Hospital Boston for the Community Leaders Shadowing Program—which provides a firsthand look at the clinical care, programs and people that make Children's so unique—he didn't realize that the day would spark new partnerships. As Assistant Director of the Roxbury YMCA, Morales was invited to "walk in the shoes of a hospital clinician" and soon found himself doing rounds with **Judith Palfrey, MD**, chief of General Pediatrics.

Palfrey was eager to show Morales around the hospital, and the two began the experience by visiting one of Palfrey's young patients. As they approached the patient's room, the child got excited and greeted Palfrey with open arms. "It was touching to see how happy the child was with Dr. Palfrey and the clear level of trust between them," says Morales. "It was a wonderful moment that got me excited about the rest of my morning."

Palfrey, a lifelong advocate for children, also wanted to make sure Morales had a chance to meet with her colleague, **Emily Davidson, MD**, director of Inpatient Services for Coordinated Care Services (CCS). "It's always exciting to educate a community advocate like Will about the programs the hospital offers," says Davidson, who talked with Morales about the center and its patients. "The children who receive care in the CCS are often the sickest of the sick. They require around the clock care, and their parents often become experts in their child's condition."

As Morales listened to Davidson, the advocate in him emerged. "Where do the parents go for a break and support? When is someone healing them?" wondered Morales, who works closely with children and families, and promotes healthy living with programs for children with asthma and support groups for adults. Morales understands the many challenges parents face when they have children with special needs, and he and Davidson quickly realized the connection they had with one another. Both are now talking about ways



the YMCA and Children's can collaborate to provide recreational opportunities for children and respite for parents.

While the goal of the Community Leaders Shadowing Program is to educate community leaders about Children's, the program accomplishes much more by linking community and hospital advocates. "When you bring community leaders together with medical experts, the fusion can lead to the health of families, as well as some great connections and innovative ideas to improve access to opportunities," says Palfrey.

To learn more about the Community Leaders Shadowing Program, contact **Christine Locke** at christine.locke@childrens.harvard.edu.

This article was reprinted from the Summer 2005 issue of the *Office of Child Advocacy's* *kidvocate*.

Gratitudes

The following is an excerpt of a letter sent to **Jeffrey Burns, MD, MPH**, chief of Critical Care Medicine.

Dear Dr. Burns and all of the Children's staff who cared for Will Guggenberger, With extremely heartfelt thanks, we want to let you know how grateful we are to you for saving Will's life. When he was diagnosed with RSV at our local hospital on December 10, 2004, we had no idea what the next 23 days of our lives would be like. Not a day goes by that we are not overcome with emotion, as we think about all we have been through and how we could not have gotten through it all without the wonderful people on P5 and at Children's. Our son was in the best possible place he could be when he needed it most.

Thank you also for caring for and about the rest of our family while your primary focus was on our littlest member. The care and compassion that we all sensed during this incredibly stressful time is so much appreciated. You should all be very, very proud of the work you do and the way that you do it!

We're thrilled to report that Will is thriving at home! He has been healthy, happy, and every day more and more his old self. He has been through an experience that he will never remember and one that we will never forget. We can hear him 20 years from now, rolling his eyes and saying, "Not the story about how I almost died again!"

Thanks again, to all of you, for all that you have done for us.

Sincerely,
Annie Marie, Kurt, Joseph, Maggie, Amy, and of course Will Guggenberger



Boston and Beyond

Ever consider running a marathon? Let Children's Hospital Boston help you meet your goal. Sign up for a marathon in any number of cities while agreeing to raise money for Children's, and we'll make your dream a reality with training sessions, transportation and lodging in the marathon city and more. All money raised benefits Children's Optimal Weight for Life program. Visit www.childrenshospital.org/giving for more information.

The great Cape escape

More than 40 hospital friends and employees have registered for the August 14 SBLI Falmouth Road Race while agreeing to raise funds for Children's Hospital Boston. Visit <http://giving.childrenshospital.org/events/runFalmouth/> to make a donation.

Endless Summer 2005

Children's Hospital Boston's employee appreciation ice cream event will be held on Wednesday, September 14. The day event will take place in the Main Lobby and the Patient Entertainment Center from 12:30 to 2:30 p.m. The night event will take place in the Main Lobby from 10:30 to 12 p.m.

Ice cream events will also be held at Children's at Lexington, Peabody and Weymouth, and at the Martha Eliot Health Center on the same date. Stay tuned for more on the Waltham event.



Tired of the rising cost of gas?

Employee platelet donors who donate twice in August will receive a \$50 gas card and two free 333 Longwood parking vouchers. Employee blood and platelet donors are also automatically entered to win a pair of Red Sox tickets for a September game. For more information, call the Blood Donor Center at (617) 355-6677.

Crimson Summer Academy

On Wednesday, July 20, eight high students from the Crimson Summer Academy (CSA) came to Children's Hospital Boston to explore careers in health care. The students met with staff and employees from Nutrition, Nursing, Social Work and more. CSA helps high school students from financially disadvantaged backgrounds in Boston and Cambridge who have a passion for learning and a desire to excel, but don't have access to all of the resources necessary for success.



Families advocate on Capitol Hill

On June 22 and 23, Children's Hospital Boston took part in the National Association of Children's Hospitals Family Advocacy Day on Capitol Hill. Over 50 children and their families from across the U.S. met with their elected officials, as they prepare to make key decisions about Medicaid—the nation's single largest health insurer for children. Beth Dworetzky (second from left) and her son Zach Friedland (far left) met with Congressman Jim Langevin (D-RI) (center) to remind him how much they depend on the specialized care and services at Children's and to thank him for his continued support of Medicaid. Josh Greenberg (second from right) and Lisa Mannix (far right), of Children's Office of Child Advocacy, also attended.



Biotech and beyond

David Altman (far right), of Children's Hospital Boston's Intellectual Property Office and John Counts (second from right), of the Office of Corporate Sponsored Research, recently attended the BIO 2005 convention, the world's largest annual biotechnology gathering. The two offices provided a joint exhibit of Children's work, networking with other companies, institutions and people, including Tom Finneran (far left), president of the Massachusetts Biotechnology Council, and Massachusetts Governor Mitt Romney (second from left).



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