

Unconventional Medicine: The Children's Difference

Stephanie Dill wears the same necklace to work every day. Strung on a thin, black cord, there are several beads on the necklace, including the letters that spell her name. But there is one, new red-white-and-blue bead that regularly draws compliments. "Where did you get your necklace," a patient's mother might ask, and that's when Dill, Child Life Specialist, smiles and tells her story.

Dill's beads are part of a national program called "Beads of Courage" that awards beads to pediatric patients for milestones, like medical procedures or acts of bravery. Each bead has a different color or pattern, and it tracks or celebrates a patient's progress. "Strung together, the beads create a timeline. They're a simple, powerful way of marking every patient's journey," said Dill.

Although every bead has meaning, there is one that stands out to Dill as especially memorable. A gift from Children's patient, 9-year-old Olivia Harvey, the bead is called the "Olympic Spirit" bead, and it traveled a long way to get to Dill. Carried by Olympic athletes during the Summer Games in London, the Olympic Spirit Bead recognizes healthcare workers with "Olympic-sized hearts." Dill received hers after Olivia, who has earned more than 300 beads herself, nominated Dill for the special honor.

"Stephanie was the one person who helped me the most through my surgery," said Olivia. "She helps kids not to be scared, and she's just such an awesome person."

Olivia awarded the bead to Dill during a surprise party, hosted by Olivia and a few of Dill's co-workers.

"It was one of the biggest moments in my career," Dill said. "To have a child tell you what a difference you've made—it's unbelievably gratifying."

This touching moment represents thousands more stories at Children's—a steady stream of stories, in fact, linking decades past with decades to come—of patients who've been touched by the care and compassion unique to Children's.

In 2012 alone, Children's treated more than 346,000 patients. That's more than 40 times the size of our 8,200-employee careforce.

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And most of those children and their families received so much more than medical care. Many of them gained a home-away-from-home and an extension of their family. They got someone like Stephanie Dill to comfort them. They received access to passionate, dedicated healthcare professionals. They experienced the Children's difference, a level of care and support that exceeds a typical hospital stay.



Offering comfort, counseling and laughs whenever possible, Stephanie Dill, Child Life Specialist, has touched the lives of many Children's patients, including Zyshun, a 13-year-old heart transplant patient, seen above choosing a few new Beads of Courage to commemorate her recent surgery.

Today: Delivering the best care

Dill and Olivia first met at Camp Braveheart, a Children's-run overnight camp for children and teens that have had a heart transplant or are affected by heart disease. They bonded quickly, and soon, Dill would help Olivia prepare for the biggest operation of her life: open-heart surgery.

For Dill, getting Olivia ready for surgery meant sharing detailed facts and information as well as offering emotional support. "We show patients pictures of every room they'll be in, and what they'll see, hear and feel. It gives families trust in us and trust in the process," said Dill. Dill knows that helping a patient cope can significantly lower stress and pain and even reduce the need for sedation. "It's easy enough for a big hospital

with lots of patients to overlook these things, but they're vital to a patient's well-being. At Children's, we want every patient to feel safe."

For Olivia's mom, Melissa Harvey, these personal touches make all the difference. For her, Children's is the total package. "Of course, we're tremendously grateful for the clinical care. But at Children's, they didn't just push parents aside. Stephanie made the ordeal much less stressful and the bead program gave Olivia a sense of pride and motivation. The social workers, chaplains, librarians, therapists, dog therapy program, libraries, play areas, Camp Braveheart—they all come together to give kids like Olivia the best possible care."

Children's has grown to be one of the nation's preeminent pediatric hospitals, and through

the years, we've kept our eye on what's most important: what's best for our patients. And as the Harvey family points out, that all-encompassing kind of care means great things for the patients we see.

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Yesterday: Lessons from the past

The Children's difference doesn't happen by accident. It's not only what we do, it's who we've been for years. Since Children's opened its doors, our spirited "above and beyond" approach has touched the lives of the children who need us, lives like Hanna Bauer Pintozzi's.

▶ Hanna Pintozzi knows how precious life is and celebrates every moment of it with her husband and four children.



Pintozzi was born in 1978 in South America, and at the age of 10, doctors pronounced her dead of a heart attack.

"I died in an emergency room in Venezuela," said Pintozzi. "For several minutes, I had no vital signs. The doctors pulled up the sheet and broke the news to my mother. And then somehow, God brought me back."

Even though she had been revived, with multiple heart defects, Pintozzi's prognosis was grim, and her family was desperate for a solution. "My parents saw a *Reader's Digest* story about cardiology research at Emory, and they knew I had to be in Atlanta," she said. "Very quickly, we got visas and moved to Atlanta, where Emory connected us to Egleston's pediatric heart team."

Her time at Egleston wasn't always easy. Hospitalized for months at a time, Pintozzi was often scared and in pain. "My father worked and my mother couldn't always be there," Pintozzi recalled. "I could have been very lonely, but the

was normal. Their visits were the highlights of my days."

Multiple surgeries and medications failed, but her doctors wouldn't give up. And in 1992, nearly three years into Pintozzi's journey, doctors performed a procedure known as a cardiac ablation to successfully restore her heart's rhythm. The procedure works by scarring or destroying tissue in the heart that triggers an abnormal heart rhythm. "Back then, it was an experimental surgery," she explained. "Thanks to doctors like mine who pioneered it, ablation has since become routine and highly successful."

Pintozzi's time with Children's changed her life forever. Today, she lives in Atlanta with four children of her own and a career inspired by Children's. "I especially appreciated the hospital's teacher, who helped me stay on top of my education even though I was in the hospital for long stretches of time. After college, I joined my husband in the family educational publishing business producing

Tomorrow: Transforming pediatric care

Celebrated as one of the best hospitals in the country, it would be easy for Children's to rest on our laurels, but just as we were for Pintozzi in 1992, we're still keeping our eye on the future of pediatric care and making strides wherever we can.

One of the areas we hope to see even more breakthroughs in soon is cystic fibrosis (CF). Infants born with CF in the 1980s weren't expected to live much past middle school. Now, due to advancements made through exhaustive research, the life expectancy is age 40 and beyond.

And if Nael McCarty, Ph.D., Marcus Professor of Cystic Fibrosis, Department of Pediatrics at Emory University School of Medicine and Director for Cystic Fibrosis Research at the Emory+Children's Pediatric Research Center, has anything to say about it, the future for CF patients looks even brighter. Dr. McCarty has dedicated his career to studying the pathophysiology of CF, including the structure and function of CFTR, the protein that is defective in CF. Through further research, Dr. McCarty hopes to better understand the pathophysiology of this disease and/or generate new devices and treatments to increase the length and quality of life for CF patients.

And to Children's patients with CF, like 5-year-old Blake Jones, that's great news. Jones' parents have been supporting McCarty's research for two years, and, like McCarty, they are committed to doing everything they can

"I could have been very lonely, but the Children's staff treated me like their own daughter. And the volunteers made a huge impression, playing with me and treating me like I was normal. Their visits were the highlights of my days."

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study guides for standardized tests," she said. "Children's supported my education; now, I can help others with theirs."



Dr. Nael McCarty and Blake Jones formed a special bond through their interaction over the past two years.

in the name of a cure for CF. And thanks to young CF patients, like Blake, who are willing to share their experiences, and partnerships with research facilities, such as Emory, that research marches forward. Not only does Blake participate in research studies and new drug therapy, his parents have also contributed to finding a cure for CF in a unique way.

When the Joneses decided to expand their family, they used IVF to select a disease-free embryo. Then, they donated the remaining embryos—all positive for CF—to a research program in California. Through the IVF process and help from the team at Emory, the Joneses have an addition to their family: a CF-free baby girl named Lila.

“We understand the critical role we can play in the development of new treatments and the search for a cure,” said Justin Jones, Blake’s dad. “The more people involved, the faster we’ll have answers.”

And Children’s is dedicated to finding those answers. Children’s has made a commitment to invest in research, tapping a deep reservoir of preeminent scientists, physicians and engineers at Emory, Georgia Tech and other Atlanta institutions.

“With the combination of our large patient base, the tremendous intellectual potential at our constellation of academic institutions and strong financial resources, Children’s and its partners stand

to become leaders in developing new therapies and approaches that will have great impact on the lives of our patients,” said Dr. McCarty.

“Much of this research is being done in partnership with our patient families, such as the Joneses. For many of those families, research is the basis of hope for a cure or control of the condition that threatens their loved ones. Knowing this adds motivation to our researchers, driving them to leave no stone unturned, no hypothesis untested.”

A story of strategic transformation

Past, present and future, our stories represent our accomplishments and strengths, even as they point us toward the future. And it’s worth repeating: These stories don’t happen by accident.

There is a common thread: the Children’s difference, crafted carefully and nurtured over years to make sure we deliver the best care, inspire the best in our people, reach out to our community and advance scientific discoveries. Our caregivers realize how important it is to treat the entire family. That is the Children’s difference. It’s the reason our patients and their families return for treatment ranging from the flu to traumatic brain injuries. And the reason we know there will be more stories—and more happy endings—for our patients for years to come. 📍