

Heroes

THE MAGAZINE OF CHILDREN'S MEMORIAL HOSPITAL

SPRING 2010

Caring for Teens — Now and
into the Future


Children's
Memorial
Hospital
Where kids come first.™

CONTENTS

On the cover: Will Kelley, 17, was diagnosed with acute lymphoblastic leukemia just before the start of his junior year of high school. He is currently undergoing a three-year regimen of chemotherapy at Children's Memorial Hospital.



IN THIS ISSUE

Adolescents tend to respond to their illnesses and hospitalizations differently than younger children, both physically and emotionally. Here we explore some of the unique challenges in caring for teens with serious medical conditions at Children's Memorial Hospital.



FEATURES

- 2** Specialized care for teens with cancer: Will's story
- 6** My life as a hospital frequent flyer
- 7** Clinical trial provides new hope: Connor's story
- 8** Transitional care: Easing graduation blues
- 10** New hospital milestone
- 12** Griffins' gift will enhance emergency care in new hospital
- 14** Mazza Foundation's gift enables key leadership recruitment
- 16** Warnock family leads initiative to elevate orthopaedic care
- 17** First Chicago Dance Marathon exceeds expectations
- 18** Founders' Board celebrates 50 years of Pro Am philanthropy

IN EVERY ISSUE

- 20** News Briefs
- 21** Round Up

Children's Memorial Medical Center J. Christopher Reyes (Chairman, Board of Directors), Patrick M. Magoon (President and CEO)
Children's Memorial Foundation Daniel J. Hennessy (Chairman, Board of Directors), Thomas J. Sullivan (President) **Heroes** is published by Children's Memorial Foundation
Editor Alison DeShaw **Contributors** Dan Kening, Maureen King, Aileen Tormon **Principal Photography** Andrew Campbell **Additional Photography** Jan Terry
Design Words&Pictures, Inc.

© 2010 **Children's Memorial Hospital**. Written requests for permission to reproduce some or all of this publication are welcomed.
Contact Alison DeShaw at adeshaw@childrensmemorial.org or 773.880.6948.

We respect your right to privacy and will make every effort to remove your name from our mailing list, if requested. To do so, please forward a written notice to Children's Memorial Foundation, 2300 Children's Plaza, Box 4, Chicago, IL 60614-6636 or send an e-mail to foundation@childrensmemorial.org.

“Our teen patients face a number of challenges in keeping up with their schoolwork and social lives, all while dealing with serious medical conditions. These young people need and deserve our dedicated support.”

— Pat Ebervein, MEd, School Services Coordinator, Children’s Memorial Hospital



Will visits with oncologist Dr. Jennifer Reichel, a former adolescent psychotherapist who directs the Adolescent Oncology Program.

Will power:

Focusing on unique needs of teens with cancer

“Teens who are diagnosed with cancer have unique emotional and social needs, because their diagnoses can have a huge impact on their plans for the future.”

—Jennifer Reichel, MD, MSW

When Will Kelley was diagnosed at 16 with acute lymphoblastic leukemia, his reaction was very different from that of his parents, Joan and John. “When the doctor gave us the news, we were just trying to keep it together,” says Joan. “Will’s immediate reaction was that it was just a huge inconvenience.”

Will, who is undergoing a three-year regimen of chemotherapy at Children’s Memorial Hospital, has responded well to his treatments, although they often leave him feeling tired and sick to his stomach. While he maintains a positive attitude, the easygoing northwest suburban Chicago high school student, now 17, has found that his illness has affected virtually every aspect of his life.

An excellent student who excels at math and science and plans to become an aerospace engineer, Will has missed weeks of school, and has had to drop out of the soccer and lacrosse teams. It’s difficult for him to make plans with friends because he never knows how he’ll be feeling on any given day. Will has grown closer with some friends and made some new ones, but others have shied away.

WILL'S STORY

“When kids hear the word ‘cancer,’ they immediately think that you’re dying and they get scared,” says Will. “They don’t realize that you’re going to recover over time, but that it will be rough for a while. At school I don’t want to be known as ‘that kid with cancer.’ I just want to be known as Will.”

Looking to the Future: Enhancing cancer care and research at Lurie Children’s

When Ann & Robert H. Lurie Children’s Hospital of Chicago opens in 2012, a number of enhancements will ensure that the Center for Cancer and Blood Disorders remains the region’s top program for pediatric cancer care. These include:



All private patient rooms

Larger outpatient clinical research center

Respite lounge for teens with cancer

Playroom for kids receiving outpatient care

Private family consultation room

Enhanced research collaboration with Northwestern campus partners

Each year, Children’s Memorial’s oncology program, ranked 14th in the nation by *U.S. News & World Report*, cares for more than 250 adolescents and teens with cancer. Nationally, despite the prevalence of cancer in those between the ages of 13 and 18, programs and research focused specifically on teens has lagged behind those for children and adults with cancer.

In recent years, Children’s Memorial’s Center for Cancer and Blood Disorders has partnered with organizations like the Lance Armstrong Young Adult Alliance and the National Cancer Institute’s Adolescent and Young Adult Coalition to find ways to address this disparity. These efforts resulted in the creation of Children’s Memorial’s Adolescent Oncology Program — the only program of its kind in the Midwest. The program is designed specifically for kids like Will who are undergoing treatment for cancer while navigating their teen years, a difficult time of life even under the best circumstances.

“Teens have needs that are very different from those of the younger kids we treat,” says oncologist Jennifer Reichek, MD, MSW, the program’s director. “Teens who are diagnosed with cancer have unique emotional and social needs, because their diagnoses can have a huge impact on their plans for the future.”

The program is still in its early stages and needs additional philanthropic support to achieve its ambitious goals. Dr. Reichek hopes to be able to provide teens with a multidisciplinary team of oncologists, nurse practitioners, school liaisons, and dietitians, along with social workers and psychologists, because teens often feel uncomfortable sharing their innermost feelings with their parents and doctors. She says teens with cancer face similar challenges, including an uncertainty about the future, loss of independence, changes in appearance and their ability to have children.

When Ann & Robert H. Lurie Children’s Hospital of Chicago opens in 2012 on the campus of Northwestern University Feinberg School of Medicine, young people with cancer will benefit from a number of facility enhancements as well (see left).

Story continued on page 4

WILL'S STORY

“The smooth transition from pediatric to adult care is essential for the well-being of young adults with cancer.”

—Steven T. Rosen, MD
Director of the Robert H. Lurie
Comprehensive Cancer Center of
Northwestern University



Will plays his guitar atop a special bed covering signed by friends with messages of support.

Major benefactors of the Center for Cancer and Blood Disorders and the STAR Program include Alberto Culver, Chicago Baseball Cancer Charities, Coleman Foundation, Howard B. and Lisa Naparstek Green, the Rory David Deutsch Foundation, the Richard A. Perritt Charitable Foundation and Young Associates Board, among many other generous friends.

Research also will be an essential component of the program, as there have been far fewer studies on adolescent cancer compared with childhood cancer. Physician-scientists like Dr. Reichek hope to find answers to explain why teens are nearly three times more likely to develop cancer than children, and why adolescent cancers tend to be more resistant to chemotherapy. Most troubling of all, the survival rate for teens and young adults with cancer is 10 percent lower than for children.

“It’s much lower than it should be, and we need to find out why,” says Dr. Reichek, who regularly collaborates with colleagues at the Robert H. Lurie Comprehensive Cancer Center of Northwestern University, an adult facility near the site of the new hospital. “Studies show that adolescents respond better when they’re treated at pediatric hospitals, but even with the same treatment protocols we use for younger kids they don’t do as well.”

Another issue faced by many childhood cancer survivors who are in their late teens is the transition to continued care at an adult hospital

(see pg 8). It can be a difficult adjustment, especially for those who have had the same pediatric caregivers since their initial diagnosis.

To help with this process, Children’s Memorial and the Lurie Cancer Center have partnered in the STAR Program (Survivors Taking Action and Responsibility). The Adolescent Oncology Program will strengthen this relationship by addressing the chronic health problems caused by either the cancer itself or the treatments childhood cancer survivors received. The STAR Program follows survivors through adulthood, providing follow-up care that addresses both their medical and psychological needs. Services are provided in a clinical setting with an emphasis on patient care, education and research.

“The smooth transition from pediatric to adult care is essential for the well-being of young adults with cancer,” says Steven T. Rosen, MD, Director of the Lurie Cancer Center. “Many patients with childhood cancer who are initially treated at Children’s Memorial are later cared for as adults at our facility, so it’s important to



Will with his parents, John and Joan, and siblings Megan, 14; Drew, 11; and Mitchell, 8. He says that since he was diagnosed with leukemia his already close family has grown even closer.

A MOTHER'S PERSPECTIVE

Seeing cancer through your teenager's eyes

By Joan Kelley

Most of Will's fellow patients are younger than he is. All the kids at the hospital break my heart, but the little ones just melt me. I'm discovering that while some of their challenges are the same, there are many things that are quite different for a teen. The older kids have to deal with the emotional side of their disease in a different way. They have reached some independence in their lives (driving, dating, curfews, etc.) and then it is stripped away. They know and remember what life was like before. They yearn for normal in a deep way. One of the hardest things for me as a parent is realizing that my child has to think about his own mortality. I appreciate this quote from a young person with cancer: "Everyone is going to die someday. Once you face this real and weighty reality, you will be able to sit beside your friends who have cancer with less fear, less discomfort, less nervousness. You will erase the 'invisible' boundary that divides us and them, the sick and the well, the fortunate and the less fortunate. From this place, you can provide the very simple comfort of compassion that people living with cancer desperately want." A pretty blunt, but real way to think about how we can better love those in our lives who are dealing with any challenge by eliminating some of the mental barriers we place between "us" and "them" – no matter if it's cancer or something else.

Read more of Joan Kelley's online journal at www.caringbridge.org/visit/willkelley.

strengthen collaborative programs and research between the two institutions to best serve this population."

Will takes life one day at a time, and, according to his mom, has a level of maturity well beyond his years. As he patiently undergoes his weekly chemo treatment at Children's Memorial's Chicago White Sox Day Hospital, wearing one of the orange "Will Power!" bracelets sported by many family members and friends, Will agrees.

"I know I'm stronger than I ever thought I could be," he says. "I believe that no matter what life deals us, we can get through it if we choose to."

My life as a hospital frequent flyer

By Danisha Moore

I am affectionately known as a “frequent flyer,” a term of endearment for longtime patients like me.



“We are proud, hopeful, full of life and happy because we are still here. Through it all, we shine.”

—Danisha Moore

As a high school student, juggling a social life, school and friends is hard enough without my Crohn’s disease and diabetes adding to the load. But I and my fellow patients do not worry with self pity; instead we hope to be treated like any other teen. After all, there is much more to us than doctors’ appointments and blood work.

You know you are a frequent flyer when the hospital feels more like a home, and you see familiar faces wherever you go. Life as a frequent flyer has its ups and downs. On the bright side, you feel emotionally stronger than most, and have the pleasure of meeting so many wonderful people, who you share a deep connection with. You feel like you’re a part of an extended family.

Of course, there is a darker side too. Many times you miss out on things at school or spending time with your friends because of treatments and tests. There are times when you feel as though you can’t make it through the day. But hope, compassion and love make it easier. The people at Children’s Memorial Hospital provide all of this from the moment you walk in. It’s like no other hospital. Having been a patient at other hospitals before, I can tell you that this place is amazing. From the nurses and doctors, to the volunteers and janitors, Children’s Memorial is full of people who care about kids and try their very best to make us feel as comfortable as possible.

Our outlook on life is different than what you might expect. Our lives are not over, nor are they in the dumps because of our illnesses. We try to live like any other teen, but we hope more, laugh more, and OK, maybe cry more, but who’s counting? We are specialists in dealing with hard times and pain, but we don’t surround ourselves in it; we overcome it. We are proud, hopeful, full of life, and whether you believe it or not, we are happy because we are still here. Through it all, we still shine. We tell our illnesses: “You will not break us or control us. We will overcome because we have faith, hope and spirit.”

Danisha Moore, 16, is a high school sophomore and a member of the hospital’s Kids Advisory Board.

Clinical trial brings relief, normalcy to Connor's life

Connor McLean says the worst year of his life was seventh grade. After weeks-long episodes of almost constant vomiting, solid foods were eliminated from his diet. He could only eat soup from a thermos, missed 45 days of school and was twice rushed from school to his local hospital emergency department in the western suburbs by ambulance. This wreaked havoc on his academic and social life. "The whole throwing-up thing was kind of limiting," Connor, now age 15, says dryly.

From birth, Connor had had serious allergies, along with eczema, sinusitis, frequent ear infections and asthma. "He was allergic to everything, both food and environmental. It took very little to make him sick — a small bite of food, a whiff of perfume," says his mother, Amy.

Connor began to take allergy medications at 12 months of age. It wasn't until the fall of his fifth grade year that the vomiting problem started, and by Christmas he had lost six pounds from his already thin frame. Amy brought him to Children's Memorial Hospital, where he began treatment with the specialists in the Division of Gastroenterology, Hepatology and Nutrition, and was eventually diagnosed with eosinophilic esophagitis, or EE.

EE is an allergic inflammatory disease in which the wall of the esophagus becomes filled with large numbers of white blood cells, called eosinophils, that promote inflammation and damage the tissues of the esophagus. Standard treatments include anti-inflammatory medications or a food elimination diet. Unfortunately for Connor, nothing helped for long.

When Ameesh Shah, MD, co-director of the EE program at Children's Memorial, suggested that Connor participate in a clinical trial for a new drug therapy, mom and son began to have new hope. "Though many EE patients respond to the usual treatments, there's a subset of kids that don't," says Dr. Shah. "It's important to be able to offer patients the opportunity to participate in trials of new medications being



studied. This treatment worked well for Connor, and he's now symptom-free."

In fall 2008, when he was 13, Connor became the first patient to be enrolled in the study. Prior to starting the trial, he had an EKG, blood draws, an endoscopy and other tests before the first of many monthly brief infusions of the new drug. Within three months, Connor was feeling better, and vomiting much less, which "really helped my disposition," he admits.

Eighteen months later, Connor says his esophagus is now "clean" following two normal endoscopies. While he continues to experience some minor health challenges, his EE and eczema have now resolved, his asthma is greatly improved and he can eat most foods. Connor can now participate in extracurricular activities, like his high school gymnastics team, since his condition no longer precludes him from attending daily practices. He's also pursuing burgeoning interests in film-making and music. Connor can stay in the study and continue to receive monthly infusions until the age of 19 or when the FDA approves it, whichever comes first.

"This clinical trial has been life-changing," Amy says. "It's opened up the possibility of a normal life for Connor."


"This clinical trial has been life-changing. It's opened up the possibility of a normal life for Connor."

—Amy McLean, Connor's mother

The eosinophilic esophagitis research program is generously supported by the Buckeye Foundation and Denise and Dave Bunning.

Easing Graduation Blues

Transitioning teens to adult care



Katie Kelly, 20, recently transitioned from Children's Memorial Hospital, her lifelong hospital home, to Northwestern Memorial Hospital, which is just steps from where Ann & Robert H. Lurie Children's Hospital of Chicago will be located.

Katie Kelly, 20, has been coming to Children's Memorial Hospital since the day she was born and diagnosed with cystic fibrosis. Kelly, like many lifelong patients, says she considers the hospital her second home. She's always greeted by name and often a hug, and is deeply attached to her doctors and nurses, who feel like family.

But eventually, as they grow older, teenaged patients like Kelly must begin the process of "graduating" from the warm, kid-focused atmosphere of Children's Memorial to the sometimes daunting world of adult medicine. Imagine having to say goodbye to the only caregivers you've ever known to move to an adult hospital, where everything is unfamiliar and you're expected to manage your own appointments, medications and health insurance.

"Understandably, for many teens who have grown up at Children's Memorial, the prospect of transitioning to an adult hospital can be overwhelming and emotional," says Parag Shah, MD, newly-appointed medical director of the chronic illness transition team.

Dr. Shah is working with Rebecca Boudos, LCSW, transition program specialist on the chronic illness transition team, to establish hospital-wide programs and guidelines to help improve transitional care, which they emphasize is a process, not a singular event, and one that includes preparing patients, finding adult providers and effectively transferring care.

"Ideally the process should start years before the actual transfer of care because there are so many aspects to it," Boudos says. For example, finding adult providers who treat certain congenital conditions or childhood diseases isn't always easy. Another major barrier to care has been the loss of health insurance coverage once patients reach a certain age.

The cystic fibrosis program is generously supported by Liv for a Cure, Stephanie and John Harris and the Harris Foundation, and Maggie's Miracle Makers.



Dr. Parag Shah (right) and social worker Rebecca Boudos are teaming up to create hospital-wide guidelines that help young people stay on track while transitioning to adult care.

“Understandably, for many teens who have grown up at Children’s Memorial, the prospect of transitioning to an adult hospital can be overwhelming and emotional.”

—Parag Shah, MD

Perhaps most importantly, patients must strive to become as knowledgeable about their medical conditions, treatments and prescriptions as their parents are, while parents must practice letting go, trusting their children to manage their own health and the myriad of responsibilities it entails.

As more children with serious medical conditions, like cystic fibrosis, are surviving into adulthood, the need for comprehensive and compassionate transitional care is greater than ever. Without it, these young people are at a much higher risk of major complications, increased hospitalizations, even death, if medication adherence and follow-up visits wane.

At Children’s Memorial, there is no set age for transitioning kids to adult care; it varies by medical condition and hospital division, some of which have joint programs with Northwestern Memorial Hospital. Because of this partnership, cystic fibrosis patients like Kelly have the opportunity to meet with their new adult care team at Children’s Memorial until their care is officially transferred. When it opens in 2012,

Ann & Robert H. Lurie Children’s Hospital of Chicago will offer even more opportunities to ease the process for those who can transfer their care to nearby Northwestern Memorial Hospital or the Rehabilitation Institute of Chicago.

Kelly recently met with her friends on the hospital’s Kids Advisory Board to share her experience and to encourage them to initiate transition discussions with their caregivers and parents as early as possible. “I also wanted to dispel some of the myths about adult hospitals to let them know there are some upsides — like better TVs!” she laughs.

“While we can’t change the inherent cultural differences between children’s hospitals and adult hospitals, we can better prepare our patients for this major change in their lives, and assist their parents and caregivers through the process as well,” says Boudos. Dr. Shah adds: “Ultimately our goal is to empower young people to fully manage their own health so that they can thrive as adults and pursue their goals and dreams.”

“Topping Off” marks new hospital milestone

More than \$140 million in philanthropy still needed

Last December, hospital friends and supporters gathered to celebrate the installation of the highest steel beam on top of Ann & Robert H. Lurie Children’s Hospital of Chicago.

Known in the construction industry as the “topping off,” a brief ceremony paid tribute to the more than 1,300 construction workers involved in the project.

Praising the progress to date, leaders from the hospital and Northwestern University, along with Illinois Governor Pat Quinn, Chicago Mayor Richard M. Daley and first lady Maggie Daley, and philanthropist Ann Lurie addressed those gathered on the plaza of the Museum of Contemporary Art before they viewed the lifting of the steel beam.

When it opens in 2012, Lurie Children’s will be a catalyst for transformational medicine and science for children.

You can play a vital role by making a campaign commitment and by asking others to join in this essential campaign for the children of Chicago. There is still a long way to go to make this important project a reality. More than \$140 million in philanthropic funding is still needed for the construction of the new building. With every beam installed and every ton of concrete poured, we are one step closer to creating a brighter future for today’s children and future generations. Please help us exceed our goal.



SNAPSHOT

CONSTRUCTION

921 windows installed in the building

More than 600 workers onsite each day

60,000 square feet of concrete slabs poured each week

10,000 tons of building steel



(from right) Patient Jamarielle "Jam" Ransom-Marks, her mother, Jessica, and Kids Advisory Board members Ellen Gordon and Kendall Ciesemier watch as the building was illuminated with projected snowflakes.



The last steel beam makes its journey to the top.



Construction workers carry the steel beam, complete with signatures from children, families, hospital staff, donors, construction workers and others.



Founders' Board member Joan Angulo and Dr. Barbara Deal, Head of the Division of Cardiology, were among the 700 supporters in attendance at Topping Off.



Speakers included Chicago's First Lady Maggie Daley and Mayor Richard Daley.

To support our efforts, please call 773.880.4237 or visit heroesforlife.org.



Griffins' gift will enhance emergency care in new hospital

Grace was recently reunited with some of the paramedics and emergency department nurses who helped save her life. Pictured with Grace are (from left to right) Karyn Levine-Harper, RN; Chicago Fire Department paramedics John Pearson and Jason Kasper; and Melinda Pipik, RN.

Susan and Sean Bracken were enjoying a quiet evening after tucking their children, Grace and Sean Jr., into bed, when suddenly they heard a moan from the kids' bedroom. Seconds later they found Grace unresponsive, lying in a twisted position, and knew they needed to call for help. Their 8-year-old daughter had suffered a stroke in her brain — a life-threatening condition that required immediate care.

Within minutes, a Chicago Fire Department ambulance was rushing Grace to Children's Memorial Hospital's Emergency Department, where a team of doctors and nurses was waiting for them. When the ambulance arrived, they sprang into action. "I watched more than a dozen people working on my daughter at the same time," says Susan. "It was like something you'd see on a TV show."

Grace is one of the 65,000 children seen each year in the hospital's Emergency Department, which is sometimes referred to as its "front door," because half of all admitted children receive their initial care there. With a staff that includes over 25 physicians and nearly 80 nurses, the hospital is a recognized national leader in pediatric emergency medicine, and has the only training program for the subspecialty in Illinois. It's also the only pediatric emergency department in the Chicago area with highly trained pediatric specialists available 24 hours a day.

Thanks to a \$16 million gift from The Kenneth and Anne Griffin Foundation, sick and injured children will benefit from the most advanced care and facilities available in The Kenneth and Anne Griffin Emergency Care Center when Ann & Robert H. Lurie Children's Hospital of Chicago opens in 2012.

"A state-of-the-art emergency care center can be the difference between life and death for critically ill children," says Anne Dias Griffin, who co-heads The Kenneth and Anne Griffin Foundation with her husband, Kenneth Griffin, and is on the board of directors of both Children's Memorial and Children's Memorial Foundation. "This center will be vital for protecting the health and well-being of the children in our community and we are excited to be part of this important initiative."

"Although we have always endeavored to provide state-of-the-art care, our new emergency care center at Lurie Children's will enable us to take our emergency medicine program to the next level," says Steven Krug, MD, head of the Division of Emergency Medicine at Children's Memorial. "The new facility offers us a tremendous opportunity for continued growth in all areas of our mission, including patient care, educating tomorrow's pediatric and emergency care physicians and nurses, and our commitments to research and child advocacy."



Kenneth and Anne Griffin

The Kenneth and Anne Griffin Emergency Care Center will encompass almost an entire floor in the 23-story Lurie Children's. The demand for emergency care at Children's Memorial has steadily risen over the years, and the Emergency Department at the new hospital will provide a substantial increase in emergency care capacity, accommodating an estimated 75,000 children in its first year of operation. The center will more than double the current number of examination rooms and major trauma/resuscitation beds. It will expand the triage area to allow for expanded capacity in the rapid assessment of arriving patients, minimizing waiting times. The new facility will include the latest technology, including dedicated diagnostic radiology suites and a CT scanner.

"The new facility and its patient and examination rooms will be more comfortable for patients and their families and allow us to be more supportive of their needs," says Dr. Krug. "Children rarely come to the Emergency Department by themselves; they're accompanied by parents and family members, and these enhancements will help us in our commitment to providing family-centered care."

Grace was fortunate. Although a neurosurgery team stood by to remove the aneurysm that had burst in her brain, a neurointerventional radiologist was able to stop the bleeding using

GIFT IMPACT



Dr. Steven Krug heads the Division of Emergency Medicine at Children's Memorial.

a minimally invasive procedure. She spent two and a half weeks recovering at Children's Memorial, followed by intensive physical therapy to regain the movement she had lost on the left side of her body.

"After something like this happens, you have a special appreciation for all the things the staff at the hospital do every day and how quickly they do it — especially the paramedics and the Emergency Department nurses and doctors," says Susan. "Timeliness is so crucial in these life or death situations, and bringing Grace to Children's Memorial that night saved her life."

"A state-of-the-art emergency care center can be the difference between life and death for critically ill children."

—Anne Dias Griffin



A rendering of a nurses' station in The Kenneth and Anne Griffin Emergency Care Center at Lurie Children's.

National expert joins Children's Memorial, establishes first pediatric neuromuscular program in Chicago

Nancy Kuntz, MD, recently joined Children's Memorial Hospital as Medical Director of the Mazza Foundation Neuromuscular Program. In this role, she will spearhead the development of the first pediatric neuromuscular program in Chicago. She was most recently on the neurology faculty at the Mayo Clinic College of Medicine and served as a consultant at Mayo Clinic in Rochester.



Dr. Nancy Kuntz visits with Christopher Pacheco, age 10, who was recently placed on the waiting list for a new heart. The newly formed Mazza Foundation Neuromuscular Program will collaborate with the hospital's heart transplant program, among others, to advance care for children.

“This evolving field requires very modern and sophisticated equipment in order to be effective and creative about identifying and clarifying the types of disorders that we’ve never understood before.”

—Nancy Kuntz, MD

Neuromuscular disorders affect the muscles or nerves that control voluntary muscles, such as those in the arms and legs. These disorders can have an effect on the child’s walking, crawling, breathing, swallowing and head and neck control. They are often chronic conditions that start in childhood and persist into the patient’s adult life.

Before Dr. Kuntz’s arrival at Children’s Memorial, families of children with the most medically-challenging neuromuscular conditions had to seek care at institutions outside the state of Illinois. “The greater Chicago area has urgently needed a pediatric neuromuscular disorders program that offers specialized care for children with these disorders and advances research to find new therapies,” says Leon Epstein, MD, head of the Division of Neurology, and the Derry A. and Donald L. Shoemaker Professor of Pediatric Neurology.

Gift from Mazza Foundation enables recruitment

The Mazza Foundation’s generous gift of \$1.25 million to the *Heroes for Life* campaign helped facilitate the recruitment of Dr. Kuntz, a national expert, as well as the purchase of state-of-the-art technology. “This evolving field requires very modern and sophisticated equipment in order to be effective and creative about identifying and clarifying the types of disorders that we’ve never understood before,” she says.

The new program will employ the clinical strengths of the Division of Neurology to offer an advanced level of care for children suffering from muscular dystrophy, spinal muscular atrophy and other neuromuscular disorders. Under Dr. Kuntz’s leadership, the program will also train future specialists, provide state-of-the-art diagnostic and treatment resources and advance cutting-edge research in this emerging field.

“I’m so incredibly grateful for and humbled by the Mazza Foundation’s generosity. Their

investment will help establish a base of care and research in Chicago that will make all the difference in the world for these children,” Dr. Kuntz says.

Ann & Robert H. Lurie Children’s Hospital of Chicago’s proximity to Northwestern University Feinberg School of Medicine, Northwestern Memorial Hospital, Prentice Women’s Hospital and the Rehabilitation Institute of Chicago will bring together an unprecedented level of expertise, offering new opportunities for collaboration not only in clinical care, but also in research and education.

“These partnerships with adult specialists will help ensure these children have excellent care throughout childhood and adolescence, and a seamless transition into adult care.” She adds, “Children’s commitment to its patients and the opportunity to push the envelope and really challenge where we stand will help establish the hospital as a national leader in this field.” Dr. Kuntz is also an associate professor of pediatrics at the Feinberg School.

The hospital was recently designated as a clinical trial research site of the Cooperative International Research Group, which is a multi-center research consortium with 21 sites in 10 countries. This distinction will offer patients access to the most innovative therapies being tested nationally.

The Mazza Foundation has been committed to improving the lives of Chicagoans for more than 50 years. It provides vital funding for programs in healthcare, social services and education, as well as for cultural and religious organizations. “We are excited to partner with Children’s Memorial to develop and grow this important program,” says Nick Lavezzorio, a director of the Mazza Foundation. “We hope our gift grows into something that will provide hope for a lot of children and families.”



Grateful family leads initiative to elevate orthopaedic care

Liz and Todd Warnock understand firsthand the importance of having a world-class children's hospital in Chicago. Last year, while enjoying a day at the beach with their teenaged children, Janie and Marshall "Motts," they saw an unnatural curve in Motts's spine when he took off his shirt.

They immediately turned to John Sarwark, MD, head of the Division of Orthopaedic Surgery at Children's Memorial Hospital, who previously treated Janie for a less severe case of scoliosis.

After carefully examining Motts's x-rays, Dr. Sarwark advised spine surgery as the best treatment option. While surgery did not have to happen immediately, Motts would have to stop playing sports for a full season.

"Through it all, Dr. Sarwark really put us at ease and answered all of our questions," Liz says.

Motts underwent spine surgery in the summer of 2009. A nurse kept the family informed hourly during the procedure. After more than six hours of anxiously waiting, they were relieved to see Dr. Sarwark emerge with a successful report. Todd smiles as he recalls his son's first words after waking up: "Do you think I'm any taller?"

The family was impressed by the level of dedication of Motts's entire treatment team. "Every doctor, nurse, technician and physical therapist was totally committed to Motts's treatment every moment we were there. That was pretty incredible. The nurses, especially Teresa T. Philipp, RN, were truly exceptional," Liz says.

Thankful for the care their children received, the Warnocks are co-chairing a new initiative to form a consortium of other grateful families with the goal of raising \$2.5 million to help create Ann & Robert H. Lurie Children's Hospital of Chicago, scheduled to open in 2012, and to support Dr. Sarwark's vision of creating a top 10 nationally-ranked program. They recently made a leadership gift towards this effort. "When someone like Dr. Sarwark comes into your life and helps your child, you want to make a difference. We're extremely grateful," says Todd.

Nearly a year after his diagnosis, Motts is a thriving teen on the road to a full recovery. "I feel good," he says. "I'm ready to play contact sports again."

The need for a new state-of-the-art facility became very obvious during Motts's stay at Children's Memorial. Liz and Todd say they feel blessed to have the opportunity to enhance care for children and their families, and to provide the physicians, nurses and staff with the right tools and environment in which to do their jobs. They hope others will join them in creating a brighter future for children.

"We try to remember that each day is a gift. If you can contribute to Children's and help make it the best, you're not only helping your family, but other families as well," Liz says.

The Warnock family: Motts (left), Todd, Liz and Janie. Nearly a year after his surgery, Motts is on the road to a full recovery.

"We try to remember that each day is a gift. If you can contribute to Children's and help make it the best, you're not only helping your family, but other families as well."

—Liz Warnock

CHILDREN'S MIRACLE NETWORK

Dancers kept the positive energy going for 13 hours straight to raise more than \$240,000 to benefit kids and families at the hospital.



First Chicago Dance Marathon exceeds expectations



Seven-year-old cancer survivor Aidan Stotz thanks the dancers for "helping kids like me get better."

Hundreds of energetic and caring individuals came together on March 6 at the Hyatt Regency McCormick Place, which generously donated the event space, to stand and dance for 13.1 hours in support of all the brave children at Children's Memorial Hospital. The first-ever Chicago Dance Marathon, presented by KPMG, was a phenomenal success, raising more than \$240,000 for the hospital, thanks to nearly 300 dancers and teams, along with many dedicated volunteers and sponsors. Dozens of patients and their families shared their inspiring stories and enjoyed an array of entertainment and festivities. Excitement is already building for Chicago Dance Marathon 2011. Visit chicagodancemarathon.org for more info.



Members of the event's executive council celebrate the fundraising success of the inaugural Chicago Dance Marathon.

GOLDEN CELEBRATION

Pro Am Golf Championship celebrates 50 years of philanthropy

It's been said that good ideas are common; what's uncommon are people who will work hard enough to bring them about. Decades ago, members of the Founders' Board and their friends had both the vision and the resolve to create a new channel of ongoing support for the hospital's patients and families.



Volunteers at the inaugural Pro Am in 1961, which raised \$65,000 for the hospital.



Members of the Stepan family count 119 cumulative years of Pro Am participation.

The Children's Memorial Hospital Pro Amateur Golf Championship — the second oldest event of its kind in the country — will mark its 50th year with a spectacular Golden Celebration in June 2010. The event has a notable history that dates back to 1960 when Sissy Wheeler presented the idea of a pro-amateur golf fundraiser to her fellow Founders' Board members. Little did she know

her idea would inspire the support and involvement of thousands and create a tradition of giving that continues to thrive today — half a century later.

"I certainly never dreamed that I would be a part of the 50th Annual Pro Am! It's marvelous to see how far the event has come and what it has made possible for children and families," says Wheeler, who began volunteering for Children's Memorial Hospital in 1947.

Organized by the Founders' Board each year, the Pro Am is the most successful annual fundraising event in the hospital's history. Cumulative proceeds total more than \$12 million, which has enabled Children's Memorial to enhance patient care and to recruit renowned leaders in pediatric medicine and science.

"The longevity of the Pro Am is a testament to the many caring and devoted individuals in our community," says Jennifer Grumhaus, co-chair of this year's event.

"From the loyal golfers and Founders' Board members, to the generous sponsors and volunteers — all play an important role in making the Pro Am successful year after year," adds co-chair Marcy Brown.

In planning the inaugural Pro Am, Wheeler and her fellow Founders' Board members wisely enlisted their friend John Ames, past president of the U.S. Golf Association, to help recruit professional golfers to take part. Originally the tournament was held on the Monday following the Western Open to attract PGA tour professionals to stay and compete for the \$10,000 purse, a relatively large sum at the time. The tournament model was so well-conceived, it remains largely

1961:

First Pro Am held on July 31

1970:

First corporate sponsor added

1984:

United Airlines partnership established

FOUNDERS' BOARD



PGA professional Lee Trevino at the 11th annual Pro Am in 1971.



unchanged today. Ames also formed a men's committee, which has been instrumental in growing the event's support base.

The first Pro Am was held on Monday, July 31, 1961, at the Onwentsia Club in Lake Forest, Illinois. It raised \$65,000 for the hospital's "Free Care Fund," designated for families who could not afford to pay for their children's lifesaving treatments.

From its early years, the Pro Am attracted a number of golf legends, including Arnold Palmer, Chi Chi Rodriguez, Jack Nicklaus, Homero Blancas, Gene Sarazen, Julius Boros and Lee Trevino, in addition to entertainer Bob Hope. Today, golf professionals from the top-rated, most prestigious country clubs in the nation are invited to play with the amateurs.

The Pro Am is fortunate to have earned the loyalty of many amateur golfers who play year after year. Some local families' participation spans multiple generations. The Stepan family of Winnetka, for example, counts 119 cumulative years of participation, and the Meers family of Lake Forest counts 96 cumulative years.

In 1970, the Pro Am added its first corporate sponsor: Marcor, Inc., the parent company of Montgomery Ward. Northern Trust was another early partner. In 1984, United Airlines joined as a sponsor and has supported the Pro Am every year since. United is the presenting sponsor of the 50th annual event and festivities. Corporate support has substantially increased the Pro Am's proceeds to around \$1 million each year.

Children's Memorial program and services directly benefiting from Pro Am proceeds



Longtime volunteers Corky Cathcart (left), Harry and Sissy Wheeler, and Lulu Runnells at the 2007 Pro Am, which surpassed the million dollar mark for a single year's proceeds for the first time.

include the Center for Pediatric Cancer and Blood Diseases; Epilepsy Center; Division of Neurology; Division of Neonatology; Division of Endocrinology; Section of Pediatric, Adolescent and Maternal HIV Infection; and Department of Family Services.

This year's proceeds will benefit the hospital's Department of Family Services. The Founders' Board's has committed to raising \$10 million for Family Services over the next several years as part of *Heroes for Life: Campaign for Ann & Robert H. Lurie Children's Hospital of Chicago*.

"As we celebrate this incredible 50-year milestone, we are mindful that our work is just beginning," says Sarah Baine, president of the Founders' Board. "The hospital's needs are great and ongoing so we must continue to do all that we can to ensure the best care possible for the next generation of children."

PRO AM SCORECARD	
CUMULATIVE AMOUNT RAISED FOR CHILDREN'S MEMORIAL	Approx. \$12 million
TOTAL ROUNDS OF GOLF PLAYED	9,900
NUMBER OF HOLES-IN-ONE	4
NUMBER OF U.S. PRESIDENTS SINCE THE EVENT'S FOUNDING	10
NUMBER OF FOUNDERS' BOARD PRESIDENTS SINCE THE EVENT'S FOUNDING	18
NUMBER OF RAINOUTS	3
RECORD SCORE	63 (set in 1987 by professional Dick Mast)

1992:

Female amateurs compete in the Pro Am for the first time

2008:

Surpasses the \$1 million mark for net proceeds in a single year

2010:

Community convenes for the 50th Annual Pro Am & Golden Celebration



NEWS BRIEFS



Peter F. Whittington

Peter F. Whittington, MD, received the 2010 Sass-Kortsak Award from the Canadian Liver Foundation and Canadian Association for the Study of the Liver for sustained excellence in pediatric liver-related research. He is director of the Siragusa Transplantation Center at Children's Memorial and the Sally Burnett Searle Professor of Pediatrics and Transplantation.



Sarah Baine

Sarah Baine, a member of the Founders' Board of Children's Memorial Hospital for 18 years, recently assumed the position of president of the Board. She is known for her tireless advocacy on behalf of the hospital. The Founders' Board is made up of 93 active members and 64 associate members, who provide support through fundraising, volunteerism, governance and advocacy.



Steven Krug

Steven Krug, MD, head of Pediatric Emergency Medicine, is the recipient of the Jim Seidel Emergency Medicine Distinguished Service Award from the American Academy of Pediatrics Section on Emergency Medicine. Children's Memorial is the only institution with two physicians who have received this honor. Susan Fuchs, MD, associate head of Pediatric Emergency Medicine, received the award in 2008.



Marleta Reynolds

Surgeon-in-Chief **Marleta Reynolds, MD**, completed a two-week intensive Program for Chiefs of Clinical Services at the Harvard School of Public Health. The course included lectures from leaders in the fields of health information technology, quality infrastructure and healthcare delivery systems. Dr. Reynolds is also head of the Division of Pediatric Surgery and is the Lydia J. Fredrickson Professor of Pediatric Surgery.



Mary Clyde Pierce

Mary Clyde Pierce, MD, was named to the newly created position of Director of Faculty Research Development for the Division of Emergency Medicine. Dr. Pierce will serve as the primary leader of the Grainger Research Initiative in Pediatric Emergency Medical Services, and will implement a five-year research plan and budget for the Division. Thanks to a generous gift from the Grainger Foundation, the Grainger Research Initiative will offer

academic career development and mentorship for junior faculty and trainees aligning with their research and academic goals.

John Crispino, PhD, a researcher in the Cancer Biology and Epigenomics Program at Children's Memorial Research Center, was awarded a \$1 million, two-year National Institutes of Health Challenge Grant for his work in identifying the molecular elements that predispose children with Down syndrome to leukemia.

The American Academy of Pediatrics has granted its Special Achievement Award to **Ram Yogev, MD**, for his advocacy efforts in making Illinois a leading state in prenatal and newborn HIV testing. Dr. Yogev, the Susan B. DePree Founders' Board Professor of Pediatric, Adolescent and Maternal HIV Infection, is medical director of the Section of Pediatric, Adolescent and Maternal HIV Infection and director of the Clinical and Translational Research Program at Children's Memorial Research Center.

Ann Lurie, hospital board member and *Heroes for Life* campaign honorary co-chair, received Research!America's 2010 *Raymond and Beverly Sackler Award for Sustained National Leadership*. The award recognizes Ms. Lurie's contributions as one of the nation's foremost advocates and philanthropists for health and medical research.

MRIC Children's Ball

Magical Moments: Hope, Dream, Believe was the theme of the 2009 Children's Ball, hosted by the Medical Research Institute Council (MRIC). More than 1,100 guests gathered at the Hilton Chicago in December for a spectacular evening. The ball, co-chaired by **Donna Drescher** (second from right) and **Debra Marcus** (second from left), celebrated the culmination of the MRIC's 2009 campaign, which raised more than \$2.1 million for pediatric medical research. The 2010 co-chairs were also announced: **Elizabeth Appelbaum** (left) and **Tina Wolf** (right).



Step Up for Kids

On January 31, almost 2,400 steppers climbed the 1,643 steps to the top of the Aon Building in the 13th Annual Kohl's Step Up for Kids. The event raised more than \$500,000 for the Department of Family Services at Children's Memorial, which provides developmental, social and emotional support for young patients and their families. The climb was kicked off by patient champions **Mackenzie** (left) and **Anika Bradley** (right), sisters who are treated for cystic fibrosis at the hospital, shown with their mother Teri and Rob Feldgreber of K.I.D.S.S. *for* Kids, which has supported Family Services at Children's Memorial since 1991.

Coming up in June: Race for the Kids 5k

Spend a summer morning on Chicago's beautiful lakefront while helping sick kids! Head down to Soldier Field on **Saturday, June 19, at 8 a.m.** for Race for the Kids, a lakefront run/walk that benefits Children's Memorial patients and their families. Now in its sixth year, the race has raised nearly \$600,000 since its inception. Why not make this the year you join us?

To register or learn more, visit childrensmemorial.org/raceforthekids



Shop for the Kids

Children's Expressions is a unique line of merchandise featuring one-of-a-kind designs created by patients and their siblings at Children's Memorial. This year's collection features bright and colorful t-shirts, stationery, mugs and more. Every purchase helps fund the hospital's Family Services programs. Shop online at childrensmemorial.org/store.

CHILDREN'S MEMORIAL HOSPITAL
2300 Children's Plaza, Box 4
Chicago, Illinois 60614-6636
Address Service Requested

Non-Profit Org.
U.S. Postage
PAID
Chicago, IL
Permit No. 3470



childrensmemorial.org
heroesforlife.org

Also visit us on:



Yaneli, 15 months, with her mother.

How will you be remembered?

Create your legacy today

Did you know that by making a gift through your estate plan, you can continue to help save and improve children's lives for generations to come?

Children's Memorial Hospital gratefully welcomes bequests through wills and living trusts. If you are interested in giving a specific dollar amount or a percentage of your estate to support the mission of Children's Memorial, please use the following wording for an unrestricted gift:

I give [dollar amount, desired percentage or rest, residue and remainder of my estate] to Children's Memorial Foundation, an Illinois not-for-profit corporation, located at 2300 Children's Plaza, Box 4, Chicago, Illinois, to be used to support its mission.

In addition to bequests, there are a number of other ways to help children and families through your estate plan. Our staff can help you find the option that is right for you and your family. Please call 773.880.4237, send an e-mail to plannedgiving@childrensmemorial.org, or explore online decision-making tools at childrensmemorial.org/plannedgiving.