Special Page 4 Feature

Friends for Life
Doctors treat rare disease with living-donor liver transplant

Neonatal Telemedicine
Technology brings Children’s NICU to community hospitals

Andy’s INSIGHTS
Harnessing the healing power of health care data

Walk for Children’s
125th anniversary celebration ends with community event
To refer a patient to any of Children’s Hospital of Pittsburgh of UPMC’s clinical services, please call our Physician Referral Service at 412-692-PEDS (7337).

Visit the Referring Physicians section of Children’s website at www.chp.edu/physicians.
Children's Hospital Lauded for Health Information Technology

Children's Hospital of Pittsburgh of UPMC has been named a 2015 Healthcare Information and Management Systems Society (HIMSS) Enterprise Davies Award recipient. Children's representatives accepted the award at the 2016 Annual HIMSS Conference & Exhibition in March in Las Vegas.

Since 1994, the award has recognized outstanding achievement by organizations that have used health information technology to substantially improve patient outcomes while achieving return on investment. The Davies Awards program promotes electronic health record (EHR)-enabled improvement in patient outcomes through sharing of case studies and lessons learned across a wide range of efforts, including implementation strategies, workflow design, best practice development and adherence, and patient engagement that have improved outcomes for patients.

Leveraging robust reporting from a state-of-the-art data warehouse, Children's Hospital has significantly reduced hospital-acquired infections. A variety of clinical data populate a dashboard to generate a pediatric Rothman Index, a real-time, easy-to-understand composite score that evaluates the patient's condition. Using this scoring and alert interface that works through both the EHR and a number of mobile devices, providers trigger the preventive measures to significantly reduce intensive care unit admissions associated with pulmonary and cardiac events.

“This award recognizes the enhancements we have made to Children's health informatics program and the tremendous impact these technological advances have made on care provided to our patients and families,” says Srinivasan Suresh MD, MBA, FAAP, chief medical information officer.

Children's Hospital also has leveraged information technology to improve supply chain management. For instance, radio-frequency identification technology, bar-coding, patient identification, and system automation have been utilized to improve on-time delivery of medication rates while lowering medication errors by 60 percent. An improved labeling and delivery system has virtually eliminated errors in breast milk delivery.

“The Davies Committee and HIMSS congratulate the team members of Children's Hospital of Pittsburgh of UPMC on receiving the Davies Award as recognition of their utilization of information technology to improve the health outcomes of the children of western Pennsylvania,” says Jonathan French, HIMSS North America.

Telemedicine Extends Care to Newborns at Community Hospitals

Modern technology is bridging the distance between neonates and neonatology at Children's Hospital of Pittsburgh of UPMC and Magee-Womens Hospital of UPMC.

Telemedicine brings the Neonatal Intensive Care Unit (NICU) to the patient’s bedside to help newborns get the care they need in their home communities and facilitate transfer to Children's for the sickest infants.

“The UPMC Newborn Medicine Program's telemedicine initiative utilizes specialized state-of-the-art video conferencing technology to enhance access to high-quality neonatology care in the nurseries of community hospitals by providing real-time connectivity between the partner hospitals and the UPMC Newborn Medicine team,” says Abeer Azzuqa, MD, medical director, Neonatal Telemedicine at Children's and Magee. “Using two-way, secure, real-time interactive communication allows the UPMC Newborn Medicine Program physician to virtually evaluate newborns at distant sites any time of the day or night.”

The program began in 2011 as a pilot with UPMC Mercy and has expanded to partnerships with eight community hospitals.

Children's and Magee neonatologists staff the Tele-NICU round the clock, utilizing equipment on specialized telemedicine carts located in the community hospitals. In addition to consultation and pre-transport care, the neonatologists perform virtual tele-rounds at UPMC Horizon and Excela Westmoreland Hospital.

The UPMC Newborn Medicine Program also uses telemedicine to provide remote continuing education opportunities for nurses, respiratory therapists, and physicians at community hospitals as well as opportunities to enhance family centered care.

To learn more, contact the Telemedicine Center at 412-692-TMED (8633) or telemedicine@chp.edu.
Heart Institute Shines in National STS Report

The Pediatric Cardiothoracic Surgery Program at Children's Hospital of Pittsburgh of UPMC has the lowest overall four-year surgical mortality rate among all high-volume programs, according to a new report from the Society of Thoracic Surgeons (STS). For the reporting period 2011 to 2015, Children's Hospital's mortality rate is 1.5 percent — tied with one other institution — compared with a national average of 3.4 percent.

The STS National Database™ was established in 1989 as an initiative for quality improvement and patient safety among cardiothoracic surgeons. The database has since grown exponentially, both in terms of participation and stature, and has become the gold standard for clinical registries.

Expert to Direct New Valve Therapy Center

José da Silva, MD, internationally recognized as the developer of the cone technique for Ebstein's anomaly, has joined the Division of Pediatric Cardiothoracic Surgery. "Dr. da Silva has pioneered a novel way to treat Ebstein's anomaly that is now the worldwide standard, and with his recruitment to Children's Hospital, he will educate our team and offer care for patients with the most complex cardiac conditions," says Victor Morell, MD, co-director of the Heart Institute and chief of the Division of Pediatric Cardiothoracic Surgery. Dr. da Silva comes to Children's from Hospital Beneficencia Portuguesa de Sao Paulo, Brazil. He also is visiting professor of Cardiothoracic Surgery at the University of Pittsburgh School of Medicine.

Dr. da Silva will have a leadership role as surgical director of the new Center for Valve Therapy at Children's Heart Institute. The center will be dedicated to the care of children and adults with congenital heart defects that involve absent or poorly functioning heart valves. Other elements of the Center for Valve Therapy will include the use of Sapien valves and pulmonary valve rehabilitation.

Registration Opens for Summer Heart Camp

The Dr. Bill Neches Heart Camp for Kids is set for June 14 to 18, 2016. Camper registration is open now through a partnership with CampDoc.com, which offers online registration and an electronic health record system for camps. The CampDoc.com system will consolidate and integrate camper registration and health information into a centralized and secure location. Heart Camp is held at Camp Kon-O-Kwee, a YMCA camp in Fombell (near Zelienople).

To register, go to www.chp.edu/heartcamp for a link to the Children's Hospital page on CampDoc.com. Questions about Heart Camp? Contact Keith McIntire, Heart Camp coordinator, at 412-821-1906.
Specialty Care and Express Care

The services are close to home; the care is Children’s.

**Express Care** (ɪk-sprɛs’ kɑːr) n. Any of seven locations where parents can bring their child after normal business hours or on weekend days for care for injuries or illnesses that don’t rise to the level of a trip to the Emergency Department. No appointments necessary; free parking.

- **58,000 Visits in the Last 12 Months**
- **7 Locations**
  - LAWRENCEVILLE
  - ERIE
  - MONROEVILLE
  - SOUTH FAYETTE
  - WASHINGTON
  - WEST MIFFLIN
  - WEXFORD
- **Most Common Diagnoses**
  - Sore Throat
  - URI or Cold
  - Ear Infection
- **3 Counties**
  - ALLEGHENY
  - ERIE
  - WASHINGTON
- **Busiest Days**
  - Sunday and Monday
- **Busiest Time**
  - Noon Saturdays and Sundays
- **More details:** chp.edu/express

**Specialty Care** (spɛsh’ al-tɛ kɑːr) n. Any of five centers in the greater Pittsburgh region where families can see the same specialists and staff as at Children’s Hospital's main campus in the Lawrenceville section of Pittsburgh — close to home.

- **5 Locations**
  - CHIPPEWA
  - ERIE
  - HERMITAGE
  - JOHNSTOWN
  - WHEELING, W.VA.
- **5 Counties**
  - BEAVER
  - CAMBRIA
  - ERIE
  - MERCER
  - OHIO, W.VA.
- **Gastroenterology**
- **Neurology**
- **Pulmonary Medicine**
  - See patients at all 5 Specialty Care Centers
- **16 Active Divisions/Programs**
- **Physicians and Physician Extenders**
  - More than 55

More details: chp.edu/express
FEATURE STORY

S-adenosylhomocysteine hydrolase (AdoHcy) deficiency is a hereditary disorder that affects brain, muscle, and liver development. The disease results from mutations of the gene that encodes AdoHcy hydrolase. AdoHcy is an amino acid derivative that forms a critical link in a chemical cycle called the transsulfuration pathway, which is the body’s main source of methyl groups. These small carbon units are attached, like chemical “tags” to many different types of molecules, including lipids, proteins, and even DNA.

When Kennedy was 8 months old she had a seizure, which prompted Ms. McCoy to take her to the nearby Clinic for Special Children in Lancaster. The Clinic is dedicated to diagnosing and treating children with genetic disorders, and it’s where

Friends for Life
Two Families Connect to Treat a Rare Disease With a Successful Living-Donor Liver Transplant

Every mother knows that her own child is somebody special — one in a billion, and different from other people in every way. But what Donya McCoy didn’t know was that her daughter, Kennedy Stevenson, really was one in a billion. Kennedy was diagnosed at age 3 with a metabolic disease so rare that only eight other people in the world have ever been known to have it.

ABOVE: Donya McCoy (left) hugs her daughter, Kennedy Stevenson, who is thriving following a living-donor liver transplant at Children’s Hospital of Pittsburgh of UPMC. Ms. McCoy’s tattoo is a symbol of Kennedy’s transplant journey and includes a tracing of the scar that Kennedy bears on her abdomen from her liver transplant surgery.
they met Kevin Strauss, MD, the medical director of the Clinic and a leader in the diagnosis and treatment of rare diseases.

Dr. Strauss and his colleagues discovered that Kennedy was not growing typically. Her presentation included microcephaly, global developmental delay, myopathy, hepatopathy, and factor VII deficiency. The late S. Harvey Mudd, MD, a world-renowned metabolic specialist, was part of the team that pinpointed Kennedy’s condition as a disorder involving her AdoHcy hydrolase enzyme.

Solving the mystery
Kennedy’s tests showed elevated levels of plasma methionine, S-adenosylmethionine (AdoMet), and AdoHcy. She also had an abnormal concentration ratio of AdoMet to AdoHcy. The proper ratio of these two enzymes is believed to regulate methyltransferase reactions, which are vital to the functioning of a wide variety of processes. Incorrect methylation is common to many metabolic diseases, and over time it can lead to severe brain injury. In the case of AdoHcy deficiency, changes in the ability to metabolize protein lead to disordered methylation, which affects nearly every system in the body. Kennedy’s brain development was delayed; without treatment, her ability to function would decline severely. Kennedy’s congenital clotting disorder, known as factor VII deficiency, complicated matters further. Factor VII is a protein that initiates the process of coagulation; deficiency is rare.

Dr. Strauss realized that a liver transplant could correct some of the factors contributing to Kennedy’s disease by correcting AdoHcy hydrolase activity in the liver and, perhaps, returning the transsulfuration cycle into proper balance. However, AdoHcy hydrolase deficiency had never been treated with liver transplantation before, and Dr. Strauss recognized that liver transplant might not address the adverse chemical changes affecting Kennedy’s brain.

Assembling the team
The Clinic for Special Children is an independent clinic, but the experts there collaborate quite frequently with the transplant team at the Hillman Center for Pediatric Transplantation at Children’s Hospital of Pittsburgh of UPMC. Dr. Strauss got in touch with his colleague Kyle Soltys, MD, a transplant surgeon at Children’s Hospital who travels regularly to Lancaster to follow up with former patients. Children’s Hospital’s expertise with liver transplantation for a variety of metabolic diseases, particularly maple syrup urine disease, made it possible for the experts to work together on this rare case of AdoHcy deficiency. Dr. Strauss introduced Dr. Soltys to Ms. McCoy and Kennedy.

Kennedy had already demonstrated that she was a brave patient who was willing to do what needed to be done. “We never imagined something like this would touch our lives. But Kennedy has done so well — she took it all in stride,” says Ms. McCoy.

“A liver transplant is not without risks, and because Kennedy’s disease is so rare, we explained that we couldn’t be certain the surgery would correct all of the problems,” says Dr. Soltys. Ms. McCoy and the rest of Kennedy’s large family made a commitment to learn more about AdoHcy and the risks and benefits of liver transplant surgery. “Kennedy’s family was so dedicated to learning about the process and her condition that we all felt confident in proceeding with the transplant,” says Dr. Soltys. “The next step was to locate a liver donor.”

Because of the way the organ donor list prioritizes patients, Kennedy would not have had a very good chance at securing a deceased donor liver. The organ allocation system is controlled by an algorithm that doesn’t take into account extremely rare diseases like AdoHcy deficiency. According to the computer, Kennedy’s liver was healthy. A living-donor liver transplant was the best possible solution.

A procedure with promise
Living-donor liver transplantation is a major operation performed only by the most experienced transplant teams. Children’s has performed more pediatric liver transplants, including living-donor, than any other center in the United States, and its survival rates are higher than the national average. Since 1997, Children’s has
perform more than 125 living-donor liver transplants, and the hospital has also performed more transplants for patients with metabolic disease than any other hospital, including adult facilities.

In contrast to traditional deceased-donor liver transplants, a living-donor transplant enables a donor to give part of his or her healthy liver to the person who needs it. The donor’s liver then regenerates, and the donated portion grows into its new home in the recipient’s body. The procedure is complex and demanding, but outcomes are generally favorable. The challenge lies in finding a suitable donor.

A complicating factor in the situation was that any living donor would have to be unrelated to Kennedy because of the hereditary nature of the disease. Ms. McCoy knew that if she were to find an unrelated liver donor, she would have to reach out to her friends. And what better place to find a large group of friends than Facebook?

**Reaching out**

“Okay friends … here it is … the request of a lifetime,” she posted to her 800 or so friends in July 2014. “Is there anyone out there who has O+ blood and would be willing to donate 25 percent of their liver to save Kennedy’s life? Trust me, I know it’s a lot to ask, I can’t even believe I’m posting this, but as a mother, I have to exhaust every option possible.”

“This was the biggest network of people I knew, and I had to do it. When I clicked that button, I was nervous and overwhelmed,” she says. “This isn’t something you’d ever think would happen.”

But soon after her post went up, she was surprised by a message from Mike Thompson, a former classmate from Bethlehem Catholic. When Mike’s son was in the Neonatal Intensive Care Unit, Ms. McCoy had reached out to him — and now he wanted to help Kennedy.

“I’m a firefighter, so I help people every day, but to help somebody like this is just a once-in-a-lifetime opportunity,” says Mr. Thompson. “It’s just the right thing to do.”

**The spirit of giving**

After the requisite testing, everybody headed west to Pittsburgh for the transplant surgery. Abhinav Humar, MD, chief of Transplant Surgery at the Thomas E. Starzl Transplantation Institute, and Rakesh Sindhi, MD, co-director of pediatric transplantation at Children’s Hospital, worked together to remove about 25 percent of Mr. Thompson’s liver for transplantation into Kennedy’s abdomen. Dr. Soltys and George Mazariegos, MD, FACS, chief of Pediatric Transplantation at Children’s, performed Kennedy’s surgery. In all, the surgeries took about eight hours and went extremely well.

Kennedy’s condition began to improve dramatically immediately after she received her new liver tissue. Within just a few hours, her enzyme counts were normal. The physicians were astounded at the rapid change.

Mr. Thompson says he wasn’t nervous. “I knew I was in good hands the entire time. I’ve heard so many good things about UPMC,” he says. “My only real worry was that the transplant would get rejected. That was my only fear.”

Today, Mr. Thompson and Kennedy are both doing well. “Physically, she’s great,” says Ms. McCoy. “She’s eating protein and developing. She seems to be catching up, and the doctors are amazed at her brain development. She emulates her big sister, and they are so close. She’s such a happy, playful, loving child. You’d never know she’s gone through anything serious.”

“Kennedy’s prognosis is good,” says Dr. Soltys. “Living-donor liver transplant offers hope to people and an improved chance of survival. People who have to wait for a deceased donor liver may become too ill for the surgery. Living-donor transplant increases the number of organs available. It’s a real solution to a real problem.”

For an appointment, consultation, or patient referral to the Pediatric Liver Transplant Program at the Hillman Center for Pediatric Transplantation at Children’s Hospital, contact us at 412-692-6110 or livertransplant@chp.edu.
Harnessing the Healing Power of Big Data and Health Care Technology

At Children’s Hospital of Pittsburgh of UPMC, we are leading the way in the application of technology to improve patient quality, safety, and outcomes. Recently, our efforts were recognized with the prestigious HIMSS Enterprise Davies Award for health care technology innovations (see page 1).

But we’re not stopping there: Here are insights into a handful of related projects we are now developing.

Improved appointment scheduling
As a primary care physician, have you ever had a parent forget to make a recommended appointment for a subspecialty service? To enhance compliance, we are streamlining the referral process by shifting the responsibility from the parent to Children’s Hospital. Once a referral is entered into the electronic medical record (EMR), our scheduling department contacts the parent for an appointment. During a five-month pilot with Children’s Community Pediatrics, our schedulers proactively handled 2,347 appointments from 20 pediatricians, resulting in more timely and efficient care.

Supporting at-risk patients
We are pioneering the first pediatric version of the Rothman Index — a predictive warning system that evaluates a patient’s condition in real time with an easy-to-understand composite score. Software gathers data from the patient’s EMR, along with live data from continuous monitoring systems (vital signs, nursing assessments, and lab results), to ensure closer monitoring for our sickest patients.

Reducing hospital readmissions
Our innovative SHARP Project (System for Hospital Adaptive Readmission Prediction and Management) is the country’s first pediatric decision support system to help clinicians and patient care teams identify and manage patients who are at high risk for 30-day readmission. SHARP uses data to create real-time risk estimates from the moment a patient enters the hospital, allowing staff to focus on personalized patient education and prevention measures. The system will be operational by July 2016.

Standardizing best practices
We’re developing standardized protocols for the management and treatment of specific conditions. Integrated into the EMR, these clinical pathways will provide step-by-step decision algorithms to guide care from admission through discharge for all specialists. Pathways will be developed initially for the most common illnesses such as appendicitis, cellulitis, and jaundice, with 27 more pathways planned over the next three years.

Patient engagement
Through PNC’s generous support, we’ve launched Children’s Connect — an online engagement tool that is changing how we communicate with patients and families. New equipment allows children to play games, listen to music, or watch television shows or movies. It also provides parents convenient access to information about treatment, their care team, and hospital resources.

These are challenging but exciting times in health care. At Children’s, we’re proud to be at the vanguard in harnessing the power of “big data,” and we look forward to our continued partnerships with you to maximize their value and impact for your patients.

Andy Urbach, MD, is associate chief medical officer at Children’s Hospital. He welcomes your comments and questions. Please send an email to mdrelations@chp.edu.

Andy’s INSIGHTS

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At Your Call

VISIT NAVIGATION
Our outpatient visit coordinator helps manage the complexities of scheduling multiple medical appointments for patients from outside Allegheny County who need to return to Children’s Hospital of Pittsburgh of UPMC three or more times within the same month.

Erin Marlowe
Outpatient Visit Coordinator
412-692-5687
erin.marlowe@chp.edu

PHYSICIAN LIAISONS
Our team serves as liaisons between physicians in the community and our pediatric specialists. Contact them with questions, comments, and concerns.

Judi Morris-Feinberg
412-692-5428
judi.feinberg@chp.edu

Monica Reisz
412-692-5376
monica.reisz@chp.edu
Laurels

These Children’s Hospital staff members recently received the following recognition in their fields.

Craig Byersdorfer, MD, PhD, of the Division of Blood and Marrow Transplantation and Cellular Therapies, had an abstract selected for the Immuno-Oncology Young Investigators forum in Houston in March and his presentation was awarded first place. Dr. Byersdorfer also is an assistant professor of Pediatrics at the University of Pittsburgh School of Medicine.

Ingrid Libman DeGordon, MD, PhD, is co-author of a study titled, “Effect of Metformin Added to Insulin on Glycemic Control Among Overweight/Obese Adolescents With Type 1 Diabetes.” It was published in the December issue of the Journal of the American Medical Association. She is also an investigator for “Search for a Cause of Diabetes: Etiology and Epidemiology of Type 1 Diabetes.” Now entering its 37th year, this groundbreaking, long-term study explores the causes of Type 1 Diabetes, with the overall objective of prediction and prevention of the disease.

Linda McAllister-Lucas, MD, PhD, chief of the Division of Pediatric Hematology/Oncology, has been selected as a member of the prestigious Pediatric Cancer MoonShot Consortium. Dr. McAllister-Lucas is an internationally recognized expert in lymphoma whose research has provided new insights into the molecular basis of these types of cancers. The Cancer MoonShot 2020 Program is a collaborative initiative seeking to accelerate the potential of combination immunotherapy as the next-generation standard of care for cancer patients. This group aims to explore a new paradigm in cancer care by initiating randomized Phase II trials involving 20,000 patients with 20 tumor types within the next 36 months. These findings will inform Phase III trials and the aspirational “moonshot” to develop effective, vaccine-based immunotherapies to combat cancer by 2020.

Shaylyn McDaniel, RN, Division of Pediatric Endocrinology and Diabetes, received the Rising Star in Clinical Practice Award at the 2016 UPMC Nurses Week. The award is presented to a Registered Professional Nurse within two years of entry into the profession who demonstrates high performance and potential to make significant contributions to the practice of nursing, serves as an exemplary role model, and actively seeks professional growth opportunities for herself and others.

Ian Pollack, MD, chief of the Division of Pediatric Neurosurgery, will be honored by the Children’s Brain Tumor Foundation (CBTF) at its annual Dream and Promise Gala on June 1, 2016. Dr. Pollack will receive the CBTF Award for Scientific Excellence. The CBTF’s mission is to improve the treatment, quality of life, and long-term outlook for children with brain and spinal cord tumors through research, support, education, and advocacy for families and survivors.

Energy Digital magazine recently published its list of the “Top 10 Energy Efficient Hospitals in the World,” which included Children’s Hospital of Pittsburgh of UPMC. It noted that the 10 hospitals on its list have been particularly effective at protecting the environment while maintaining or improving patient outcomes.

Children’s is designed as a “green” campus, meaning that buildings use key resources such as energy, water, materials, and land more efficiently than buildings erected simply to building code. It’s been established that environmentally sustainable buildings contribute to improved health, comfort, and productivity of their residents by utilizing more natural light and promoting better air quality.

Two buildings on Children’s campus have received Leadership in Energy and Environmental Design (LEED) certification: The hospital building was designated LEED-certified, and the John G. Rangos Sr. Research Center received a silver rating. Children’s South, our ambulatory site in South Fayette, also was recently designated LEED-certified.
Walk for Children’s and Give Kids a Chance
125th Anniversary Celebration Culminates With 5K Walk and Patient Champion Parade

Children’s Hospital of Pittsburgh of UPMC began its 125th anniversary year with a kickoff celebration on June 4, 2015, that launched the “Give Kids A Chance To Be Kids” campaign — celebrating 125 years of caring and the important role of community support for the clinical and research advances at Children’s Hospital.

On Saturday, June 4, 2016, the 125th anniversary year will culminate with Walk for Children’s, a 5K walk and patient champion parade. This community-wide event will allow participants to start their own teams and fundraise together for Children’s. It will also feature music and activities so the community can join in celebrating Children’s patients and families.

Mark your calendar
Our community is part of Children’s legacy, and a part of its future. Now community members have a chance to give kids a chance to be kids by registering to walk, or to form a team to walk, at Walk for Children’s.

We all know how quickly summer weekends get booked, so make plans now to join us on June 4 at Flagstaff Hill in Schenley Park, Pittsburgh. For more information, visit the Walk for Children’s website at www.givetochildrens.org/walk where you can register yourself and your team. And please encourage your patients and families to register as well.

The campaign rolls on …
In addition to television and online advertising, the “Give Kids A Chance To Be Kids” campaign features the Giving Booth, an interactive mobile video booth that has been traveling to special events throughout the region. Take a moment to browse the videos being featured on www.givetochildrens.org/125.

Our work is not done
Children’s is in pursuit of discoveries that can help us anticipate, prevent, and ultimately avoid devastating diseases. What we care for today can be what we cure for the next generation — and that’s why we celebrate our extraordinary history and look toward the next 125 years of care and innovation.

Children’s is able to make great advances in pediatric health care because of all our donors, large and small, who are committed to helping kids in need. And as a result, our donors are giving every kid a chance to be a kid. Caring for children for 125 years has brought Children’s Hospital to the forefront of pediatric health. Together, we can continue this legacy for future generations.

You can learn more about the yearlong celebration, watch, and share stories at www.givetochildrens.org/125.
I’m walking for Children’s to give kids a chance to be kids!

June 4 Schenley Park

givetochildrens.org/walk