Special Page 4 Feature

All Heart
Learn how a pediatric cardiac patient is paying it forward

Surgical Telemedicine
Technology cuts the distance between patients and surgeons

A Leap Ahead
Children's honored as one of the nation’s Top Hospitals

New Website Debuts
Children's enhances online experience
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The WINTER 2016 issue of Pediatric INSIGHTS

Cover story: From the moment Luke Ziegler was born, his heart was special. Now a young man, he reflects on the lifetime of care he’s received from specialists at Children’s Hospital of Pittsburgh of UPMC, and looks ahead to what he can do to help other children who share his cardiac condition.

In addition:

> A new telemedicine program cuts the distance between surgical patients at Children’s Hospital Specialty Care Center Johnstown and surgeons based at Children’s Hospital in Pittsburgh.

> The Leapfrog Group honors Children’s as a Top Hospital of 2015 — one of only 12 pediatric hospitals in the nation and the only pediatric hospital in Pennsylvania to be recognized.

> Terence S. Dermody, MD, has been named the new chair of the Department of Pediatrics at the University of Pittsburgh School of Medicine and physician-in-chief and scientific director at Children’s Hospital.

We welcome your feedback, thoughts, and story suggestions. Please share them with one of our physician liaisons, whose contact information you can find on page 7.
Telemedicine Creates Flexible Care Options
Technology Connects Johnstown Patients to Surgeons Working at Children's Hospital in Pittsburgh

When Stefan Scholz, MD, Division of Pediatric General and Thoracic Surgery, Children's Hospital of Pittsburgh of UPMC, sees a patient in Johnstown, he evaluates vital signs, prescribes medication, and discusses health concerns with patients and their family members. And it's all done from Pittsburgh.

From hernias to abdominal pain, virtual technology is bringing Pediatric Surgery patients together with physicians at Children's Hospital in extraordinary ways. Children's introduced its telemedicine service for new, returning and postoperative patients in November at Children's Hospital Specialty Care Center Johnstown, where appointments are scheduled on the first Tuesday of every month.

"Advanced technology permits reliable evaluation of a broad spectrum of surgical conditions using telemedicine," says Dr. Scholz, director of Minimally Invasive Surgery at Children's Hospital. Telemedicine consultations are available for all types of surgical health concerns, including inguinal hernias, umbilical hernias, gastrostomy tube checks, pectus excavatum, pectus carinatum, abdominal pain (such as gallbladder), enlarged lymph nodes, and cysts or lumps.

Stacy Gibson, MSN, RN, CPN, nurse manager for Pediatric Surgery, travels to Johnstown to facilitate telemedicine appointments on site for up to 10 patients per day. "She's there to guide the patients and improve the quality of telemedicine by adding clinical details and conducting the physical exam using the knowledge she has gained from working with the surgeons in Lawrenceville," says Dr. Scholz.

Although the telemedicine program for Pediatric Surgery just began, it has already received positive feedback. "The kids really seem to love it," says Ms. Gibson. Recently a patient with Down syndrome had some jitters about seeing the doctor for an examination following abdominal surgery. "As soon as the child realized the doctor was on the other side of the camera, he was fine with letting us see his incision," she says. "He stood right up and lifted his shirt! He loved the interaction over the camera."

During each visit, Ms. Gibson takes vital signs and conducts the patient's physical exam directed by a surgeon on the other side of the camera. The camera can be zoomed in to provide the surgeon with a close-up view of areas of concern. If a patient brings digital radiology images to the appointment, Ms. Gibson can upload them to a computer, providing immediate access for the surgeon to review during the appointment.

Administrators are already looking toward future expansion of Pediatric Surgery consultations to additional UPMC locations that offer telemedicine.

“The Pediatric Surgery telemedicine program in Johnstown is a prototype. We’ll evaluate how well it works and what kinds of health concerns are best suited to telemedicine technology," says Michelle Peters, division administrator. "This is something we’d like to do more of so patients don’t have to travel so far to get our care."

To refer a patient or schedule a telemedicine appointment at Children's Specialty Care Center Johnstown, please call the Division of Pediatric General and Thoracic Surgery at 412-692-7280.

Above: Nurse Manager Stacy Gibson, MSN, RN, CPN, coordinates a pediatric surgery telemedicine visit in Johnstown for patient Joseph LaRocca (left).
CHILDREN'S DEBUTS NEW WEBSITE WITH ENHANCED MOBILE INTERFACE

The Internet is changing and Children's Hospital of Pittsburgh of UPMC is keeping pace with the launch of a new website. The new site was developed to provide a better web experience for referring physicians, patients, families, and customers.

To accommodate the explosive growth of mobile devices, Children's Hospital has developed a fully mobile site for convenient access by a smartphone or tablet. Every page of the website is now mobile-friendly making it easier than ever to dial a department phone number or to find a location with instant access to driving directions.

Children's Hospital is the first of all UPMC web properties to be converted to the new technology platform, which has been designed to create a more unified web presence throughout UPMC, including Children's Community Pediatrics. To view the new site, visit www.chp.edu.

OTHER FEATURES OF THE NEW SITE INCLUDE:

- A modern design with a warm, rich color palette that mimics the hospital decor
- The latest in web technology for stability and speed
- Enhanced navigation, including a widget for conveniently accessing key information such as locations, doctors, bill pay, and more
- Integration with the most popular social media platforms for easier sharing of information
- A faceted location finder that's easily accessible throughout the site
- Physician profiles that include ratings and comments by patients and parents
- The ability to personalize content and get local, national, and international users to their desired content in fewer clicks
- A scrolling alert for breaking news

LEAPFROG GROUP NAMES CHILDREN'S TO 2015 CLASS OF TOP U.S. HOSPITALS

Recently it was announced that Children's Hospital of Pittsburgh of UPMC is one of only 12 pediatric hospitals in the nation and the only pediatric hospital in Pennsylvania named to The Leapfrog Group's 2015 class of Top Hospitals.

The selection is based on the results of The Leapfrog Group's annual hospital survey, which measures hospitals' performance on patient safety and quality, focusing on three critical areas of hospital care: how patients fare, resource use, and management structures established to prevent errors.

Performance across many areas of hospital care is considered in establishing the qualifications for the award, including survival rates for high-risk procedures and a hospital's ability to prevent medication errors.

Overall, Top Hospitals tend to have lower infection rates, higher survival rates for high-risk procedures, decreased length of stay, and fewer readmissions.

The Leapfrog Hospital Survey compares hospitals' performance on national standards of patient safety, quality, efficiency, and management structures that prevent errors, and publicly reports the results for use by consumers and purchasers.

The survey provides the most comprehensive picture of how patients fare at individual institutions. The data collected also enables hospitals to benchmark their progress and measure the care they deliver.

To see the full list of institutions honored as 2015 Top Hospitals, please visit www.leapfroggroup.org/tophospitals.
Updates in Pediatric Rehabilitation Medicine
From Cerebral Palsy to Post-Concussion, Division Provides Treatment for Patients Up to Age 26

The Division of Pediatric Rehabilitation Medicine continues to expand its services, as well as its reach, in order to provide needed rehabilitative services to pediatric patients up to age 26.

The physicians and nurse practitioners in Pediatric Rehabilitation Medicine provide care for children with functional deficits at the Children’s Hospital Rehabilitation Unit and multiple outpatient settings. They provide consultative services for inpatients who may benefit from comprehensive rehabilitation or who have ongoing rehabilitation needs. The faculty are involved in multidisciplinary clinics including Cerebral Palsy and Related Disorders, Spina Bifida and Related Disorders, Muscular Dystrophy, Chronic Pain, Spasticity Management, Brain Injury, and community outreach clinics. They also have general rehabilitation clinics and see patients with a variety of conditions from concussion to rare genetic conditions to debility after transplant.

Physician news
Jason Edinger, DO, outpatient clinical director of Pediatric Rehabilitation Medicine, now sees patients at Children’s South. Dr. Edinger is the only board-certified pediatric electromyography practitioner in the region. He also co-founded Camp Inspire, an overnight camp for children with complex respiratory needs including tracheostomies, ventilators, and BiPAP machines. Camp Inspire celebrates its fourth year in 2016.

Unoma Akamagwuna, MD, is the newest division member. She trained in Pediatrics and PM&R at Children’s Hospital of Colorado/University of Colorado. She sees patients at main campus, Children’s Pine Center, and at Easter Seals of West Virginia.

Brain Injury Clinic
The Brain Injury Clinic, which sees patients at Children’s Hospital’s main campus in Lawrenceville, welcomes Maryanne Henderson, MD, who will help patients who need to transition to adult care. The multidisciplinary team includes Dr. Henderson; Dr. Edinger; physical, occupational, and speech therapy; behavioral health; neuropsychology; and social work.

The Brain Injury Clinic sees children and youth with recent or remote, moderate to severe acquired brain injuries from traumas, tumors, strokes, or encephalopathies.

Concussion care
Children with persistent symptoms after concussion should be seen in the Pediatric Rehabilitation Medicine clinic at Children’s Pine Center in collaboration with the UPMC Sports Medicine neuropsychology team. UPMC Sports Medicine and Pediatric Rehabilitation Medicine co-treat children with concussion who:

> Are under age 10
> Have a previous history of concussion
> Were hospitalized for a concussion
> Have a history of disability
> Had other injuries with their concussion

To make a referral or for more information, call the Division of Pediatric Rehabilitation Medicine at 412-692-5097.

Paralympian Helps Celebrate Milestone
A visit from a Paralympian sled hockey champion was the highlight of the second birthday celebration of the Children’s Hospital Rehabilitation Unit in November. Dan McCoy of Fox Chapel, Pennsylvania, member of the U.S. National Sled Hockey Team, has played in three International Paralympic Committee Ice Sled Hockey World Championships. He was part of the team that won the gold at the 2014 Paralympic Winter Games in Sochi, Russia. Born with spina bifida and hydrocephalus, Mr. McCoy now is a member of the Pittsburgh Penguins club sled hockey team, the Mighty Penguins, and a student at the University of Pittsburgh.
Growing up, Luke Ziegler was always aware that he was different from other children. “I’d be playing with my friends for 20 minutes and I’d be completely exhausted and have to stop,” he recalls. “All the kids played basketball outside of school, but I wasn’t medically allowed to do that.”

Mr. Ziegler was born with aortic stenosis caused by a bicuspid aortic valve that prevented his heart from pumping normally. Within hours of his birth in October 1993, he was flown to Children’s Hospital of Pittsburgh of UPMC to undergo a balloon valvuloplasty, a catheterization procedure in which a balloon is placed across the stenotic aortic valve and inflated to open the valve.

Approximately one in 100 children are born with congenital heart disease in the United States every year. About 5 percent of these children have aortic stenosis.

Although the valvuloplasty Mr. Ziegler underwent at less than 1 day old saved his life, it could not completely resolve his heart problem. He continued to have valve insufficiency — his aortic valve didn’t close properly, allowing some blood to flow back into his heart.
I

Inevitable surgery

“As far back as I can remember, I understood that I was going to need open heart surgery, but I didn’t know when,” says Mr. Ziegler, now 22. “They wanted to wait as long as possible because a small child will outgrow the procedure in a few years and need a re-operation. When I was 10, they put me on medication to buy time so my heart would be physically bigger when I eventually had the surgery.”

Treatment with the angiotensin-converting enzyme inhibitor lisinopril postponed the need for surgery for three years. At age 13, Mr. Ziegler was scheduled for open-heart surgery at Children’s Hospital.

The operation he underwent, known as the Ross procedure, involves removing the damaged aortic valve, moving the pulmonary valve to the aortic position, and replacing the pulmonary valve with one from a human cadaver. Because the pulmonary valve is the patient’s own tissue, it continues to grow normally in the aortic position and can handle the high pressure and volume of blood that flows from the left ventricle to the body. The replacement valve in the pulmonary position assumes the less stressful task of pushing blood to the lungs.

Reassuring care

Victor Morell, MD, chief of the Division of Pediatric Cardiothoracic Surgery at Children’s, performs the procedure, or variations of it, on an average of five children annually. The Cardiothoracic Surgery program has the lowest surgical mortality among high-volume programs in the country, based on a 2015 national survey of programs performing congenital heart disease surgery by the Society for Thoracic Surgery.

“I remember meeting Dr. Morell on the morning of my surgery,” Mr. Ziegler says. “His handshake was really reassuring. He was just so confident as he explained what they were going to do. The way he carried himself and his nonverbal communication made me feel very comfortable.”

Two days after surgery Mr. Ziegler was out of bed and on his feet. “Walking around perfectly normal two days after having my chest cut open was just amazing,” he recalls. “The nursing staff and doctors were so caring and confident, and I had my family around me the whole time — all of that made it not as bad as you would think.”

Service to others

Nine years later, as he graduates from the University of Pittsburgh and prepares to apply to medical school, Mr. Ziegler reflects on how his experience with congenital heart disease set him on his chosen career path: “I was forced to grapple with mortality at a young age. I knew I owed my life to these compassionate people who had dedicated their lives to medicine. And I learned that the only way to have enduring happiness and fulfillment in life is through service to others.”

Since 2013 Mr. Ziegler has been a volunteer in the Cardiac Intensive Care Unit at Children’s, sharing his experiences with young patients who have undergone heart procedures similar to his own. Having been both a participant and a counselor at the Dr. Bill Neches Heart Camp for Kids, an annual summer event organized by the hospital (see sidebar), Mr. Ziegler knows firsthand
that youngsters who have had heart surgery may feel self-conscious and lack social confidence.

“It meant a lot to me to have role models who had been through what I was going through and see that they were now leading normal lives,” he says. “I would like to be that kind of role model for these kids.”

Before entering medical school, Mr. Ziegler will spend a year working in the artificial heart program at Children’s and UPMC Presbyterian. “Right now I’m an artificial heart technician, taking care of patients on intra-aortic balloon pumps. I am simultaneously doing research on mechanical blood trauma and receiving training as a biomedical engineer, and in a few months will begin providing engineering support for patients on ventricular assist devices.”

Already he has had the opportunity to work with a 12-year-old cardiac patient from Japan who was receiving treatment at Children’s. “I majored in Japanese and speak the language passably, so I did some interpreting for him,” Mr. Ziegler explains. “I could relate to him because he was around the same age I was when I had my surgery. When he arrived he was really sick, barely able to move due to heart failure. I saw him through his transplant and recovery, and now he has more energy than I do.”

Mr. Ziegler faces the prospect of another heart procedure at some point to repair or replace his donor pulmonary valve, which is slowly becoming stenotic. “It might not happen for another 10 years, or at my next checkup they could tell me I need surgery right away. But honestly, I don’t spend time thinking about it.”

A bright future

His long-term aspiration is to be a heart specialist. “While I’m trying to keep an open mind, I can see myself doing pediatric cardiology, pediatric interventional cardiology, or possibly cardiothoracic surgery — definitely something involving hearts and ideally involving kids. And I want research to be part of my career. Practicing medicine is amazing, but without research the procedure that saved my life wouldn’t have been developed. I’d like to be part of developing the new technology that 20 years from now could save a kid’s life.”

Vivek Allada, MD, chief of Pediatric Cardiology and co-director of the Heart Institute, says: “Luke represents exactly what we strive to achieve in the Heart Institute. Our goal is that each child will not only survive their heart condition, but thrive and be a productive member of our community. Luke has benefited from many of our subspecialist programs in the Heart Institute including echocardiography, interventional cardiology, and cardiothoracic surgical programs.

“Because of his successful outcome, he will soon see our specialized adult congenital heart disease team;” Dr. Allada says. “Luke is a very special person, he is blessed to have two amazing parents, and I really expect great things from him in the future.”
Meeting the Challenges of Change

New Strategic Plan Preserves the Best of Our Mission While Anticipating the “What Ifs” Ahead for Children’s

The late, great Yogi Berra is credited with this cautionary observation: “If you don’t know where you’re going, you’re certain to end up somewhere else.”

For an organization like Children’s Hospital of Pittsburgh of UPMC, one that is dedicated to ensuring excellence and innovation in pediatric care, the best way to avert that pitfall is having a strategic plan to guide us.

Over the past year, under the leadership of our president, Chris Gessner, we’ve been engaged in a far-reaching, ambitious, and even courageous analysis and planning process that was laser focused on this question:

How can Children’s Hospital grow and evolve successfully over the next 10 years in a constantly changing, fiscally challenging, and increasingly competitive health care environment?

For direction, we sought the insights and ideas of hundreds of individuals — from members of the community, UPMC system leadership, and Foundation and hospital board members, to Children’s Hospital’s own staff and administration.

A 10-year plan with big impact

Early on, it was determined that “big ideas” are key to Children’s future: ideas that will demand greater strategies, investment of resources, and time to achieve the desired dramatic changes.

Five expert teams were formed to first identify those big ideas and then explore “what if” scenarios that could impact their success. They weighed them against critical external uncertainties, such as potential changes in delivery of care, technology and medical advances, reimbursement and funding, population health, consumer behavior, competition, and regional economics.

What emerged is an ambitious and inspiring 10-year plan that will be executed through a series of three-year tactical initiatives, with built-in measures to monitor progress. Among its many priorities are creating responsive solutions to changing delivery demands in pediatric care; achieving greater heights of innovation and medical education, supported by increased giving and funding efforts; advancing Children’s presence and influence in expanded regional, national and global markets; and securing Children’s already established leadership in pediatric transplantation and rare disease treatment.

Our goal: to ensure that Children’s will always be a highly accessible and reliable, cost-effective system of pediatric health care that has a profound global impact in the areas of science, quality of care, and population health.

Sharing common goals

It won’t surprise you that the number one principle guiding our new strategic plan is to put patients and families first — a value that both honors and reflects our daily partnership with you on every level. Our mission directly supports the care you deliver to your patients every day. Many of the external challenges identified and targeted in our plan are the same ones that you will face. And perhaps most importantly, the results we achieve will have lasting implications on the future excellence of pediatric health care.

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.
The Intestinal Rehabilitation and Transplantation Association (IRTA) elected two transplant surgeons from Children’s Hospital of Pittsburgh of UPMC to leadership roles: George Mazariegos, MD, FACS (left), chief of Pediatric Transplantation Services, was named president-elect of the IRTA, and Geoff Bond, MD (right) was elected councilor. Dr. Mazariegos is continuing as Chair, Studies in Pediatric Liver Transplantation, in 2016.

Brian Feingold, MD, MS (left), medical director of the Heart Failure and Heart Transplant programs at Children’s, was elected vice chair of the International Society for Heart and Lung Transplantation (ISHLT) Scientific Council on Pediatric Thoracic Transplantation and Heart Failure. Dr. Feingold and Children’s pediatric cardiologist Matthew Zinn, DO (right) co-authored an article in the August issue of the ISHLT Links newsletter titled “Management of Allosensitization in the Pediatric Heart Transplant Candidate.”

Amy Houtrow, MD, PhD, MPH, chief of Pediatric Rehabilitation Medicine at Children’s, was selected to serve on the National Quality Forum’s Pediatric Standing Committee for the Pediatric Measurement Endorsement Project. The committee evaluates measures related to child health and health care.

Elizabeth Miller, MD, PhD, chief of the Division of Adolescent and Young Adult Medicine at Children’s, has received the Linda A. Dickerson Award for her support of at-risk children in Allegheny County. It is given in honor of Linda A. Dickerson, a community advocate who helped start the Homeless Children’s Education Fund. Dr. Miller will be presented with the award at the annual Champions for Children Gala.

Michael Moritz, MD, clinical director of Pediatric Nephrology, and medical director of Pediatric Dialysis at Children’s, co-authored an article titled “Maintenance Intravenous Fluids in the Acutely Ill Patient” in the October issue of the New England Journal of Medicine.

Kyle Soltys, MD, Pediatric Transplantation Services at Children’s, was elected to the United Network of Sharing Region 2 Pediatric Transplantation Committee. The American Board of Pediatrics and the National Society of Pediatric Gastroenterology, Hepatology, and Nutrition selected Robert Squires, MD, as its recipient of the Murray Davidson Award. The award recognizes an outstanding clinician, educator, and scientist who has made significant contributions to the field of pediatric gastroenterology and nutrition.

Kathryn Torok, MD, has been elected to the Society for Pediatric Research, a leading pediatric scientific society that fosters the research and career development of investigators engaged in creating new knowledge that advances the health and well-being of children and youth.

In November, Medicaid Health Plans of America and the Institute for Medicaid Innovation awarded the 2015 Children’s Health Award and Medicaid Managed Care Innovation Award to High Value Care for Kids, a program by UPMC for You that improves the value of care for children with medically complex conditions through provider flexibility and accountability, information sharing and transparency, and consumer engagement.

Jerry Vockley, MD, PhD, was named to the newly established Cleveland Family Endowed Chair in Pediatric Research at an installation ceremony held on Nov. 2.
New Chair of Pediatrics Appointed at University
Dermody Joins Hospital as Scientific Director

Terence S. Dermody, MD, has been named the new chair of the Department of Pediatrics at the University of Pittsburgh School of Medicine and physician-in-chief and scientific director at Children’s Hospital of Pittsburgh of UPMC. Dr. Dermody replaces David Perlmutter, MD, who recently left Children’s to become executive vice chancellor for medical affairs and dean of medicine at Washington University in St. Louis.

Dr. Dermody joins Children’s from Vanderbilt University, where he is the Dorothy Overall Wells Professor of Pediatrics, director of the Division of Pediatric Infectious Diseases, and director of the Medical Scientist Training Program at Vanderbilt University School of Medicine. He also is professor of Pathology, Microbiology, and Immunology at Vanderbilt.

Dr. Dermody is a virologist with interests in viral pathogenesis and vaccine development. He has focused mainly on reovirus, an important experimental model for studies of viral encephalitis, and on chikungunya virus, an arthropod-borne virus that causes epidemics of febrile arthritis. Reovirus is an enteric, neurotropic virus that infects many mammalian species including humans, although disease is restricted to the very young. Currently, his lab is developing viral vectors for oncolytic and vaccine applications.

Dr. Dermody’s work is supported by grants from the National Institutes of Health (NIH) and the Lamb Foundation; he currently holds five NIH grants, and his research has been continually funded by the NIH since 1987. He has been recognized for his research accomplishments with the Ernest W. Goodpasture Faculty Research Award, the Grant W. Liddle Award for Leadership in the Promotion of Scientific Research, and an NIH MERIT Award.

“It is apparent that Terry’s influence on our medical and scientific communities, while focused at Children’s Hospital, will have a transcendent impact on our institution as a whole,” says Arthur S. Levine, MD, senior vice chancellor for the Health Sciences and the John and Gertrude Petersen Dean of Medicine, University of Pittsburgh.

Dr. Dermody will be in Pittsburgh several times over the next few months, but he will formally assume his responsibilities on June 1, 2016.
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