Pediatric INSIGHTS A Physician Resource from Children's Hospital of Pittsburgh of UPMC www.chp.edu

Special Page 4 Feature Beating the Odds

Experimental therapy targets kidney disease

Children's Ranks No. 1 **Best liver transplant outcomes**

Low-Dose Imaging New Spine Center opens

Remembering Dr. Starzl Transplantation pioneer





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The SPRING 2017 issue of Pediatric INSIGHTS

Cover story: What appeared to be an allergy at 18 months old was actually something much more rare and complex for **Lexi Hatfield**. Children's Hospital of Pittsburgh of UPMC is one of only eight centers in the United States to use an experimental therapy to treat **refractory kidney disease** — and it proved to be Lexi's salvation.

In addition:

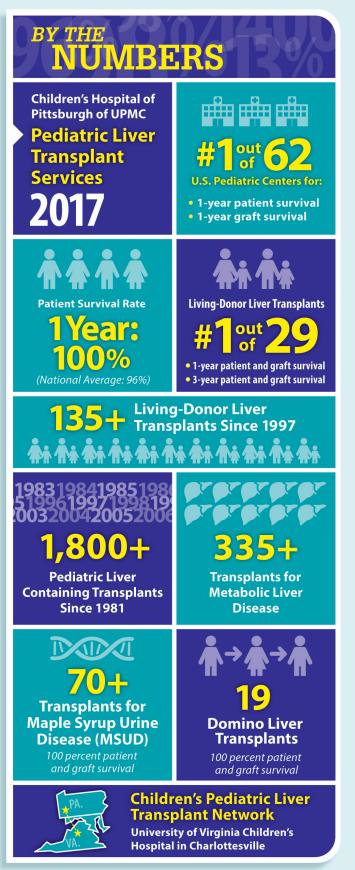
- Children's expertise is recognized with another top ranking leading the nation in pediatric liver transplant outcomes as well as several other significant achievements.
- Low-dose imaging technology is the centerpiece of Children's new Spine Center, a comprehensive clinic offering a coordinated approach to the treatment of idiopathic scoliosis.
- > Andy Urbach, MD, medical director of Patient Experience and Development, remembers the late Thomas E. Starzl, MD, PhD, and his groundbreaking work in the field of transplantation which has transformed the lives of children in Pittsburgh and around the world.

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.

Physician Referral Service 412-692-PEDS (7337)

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.



Sources: Internal data; Scientific Registry of Transplant Recipients (www.srts.org) January 2017 release

Children's Ranked No. 1 for Liver Transplant Outcomes

The Hillman Center for Pediatric Transplantation at Children's Hospital of Pittsburgh of UPMC is ranked highest in the United States for pediatric liver transplant outcomes, according to January data released from the Scientific Registry of Transplant Recipients (SRTR).

The SRTR, which manages and analyzes a wide range of transplant data as a service to the public, noted several achievements for Children's Hospital in 2017. When comparing hazard ratio estimates, Children's ranks as No. 1 out of 62 pediatric liver transplant centers in the United States in one-year overall patient survival as well as one-year overall graft survival.

Of the 29 centers performing pediatric living-donor liver transplants, Children's hazard ratio estimates also rank first in one-year patient and graft survival, as well as three-year patient and graft survival. Children's has performed over 135 living-donor liver transplants since 1997.

The hazard ratio provides an estimate on how the results at Children's compare with what was expected based on modeling the transplant outcomes from all U.S. programs. Based on the characteristics of patients transplanted at Children's from July 2013 through December 2015, SRTR hazard ratio results indicate a 59 percent estimated lower risk of patient mortality and a 76 percent estimated lower risk of graft failure when compared to other pediatric liver transplant centers.

"This new data exemplifies the extraordinary talent and skill our surgeons, hepatologists and entire transplant team bring to hopeful patients and families around the world," says George Mazariegos, MD, chief, Pediatric Transplantation at Children's. "Our decades of experience are unparalleled — we have performed more pediatric liver transplants than any other center in the United States while achieving patient survival rates that are consistently among the best."

Children's has performed more than 1,800 pediatric liver containing transplants since the program's inception in 1981 through December 2016. This includes more transplants for children and young adults with maple syrup urine disease and metabolic liver disease, and more domino liver transplants, than any other U.S. center. In the last five years of recorded data (2011 to 2016), Children's performed more living-donor liver transplants than any other pediatric liver transplant center in the country.

Children's also is the first and only pediatric transplant center in the nation to expand the geographic reach of its program through a partnership with the University of Virginia Children's Hospital in Charlottesville.

Building a Firm Foundation

Division of Pediatric Hematology/Oncology Continues Growth

The Division of Pediatric Hematology/Oncology has undergone several years of building and growth since Linda McAllister-Lucas, MD, PhD, took the helm in 2013. Now, with three new recruits set to join the division over the next several months and new programs on the horizon, the Pediatric Cancer program at Children's Hospital of Pittsburgh of UPMC is poised to continue its dominance as the most comprehensive pediatric cancer and blood disease center in the region.

New physicians

In the coming months, three new physicians will help round out the division, which also has added a number of new physician-scientists over the past year. Louis Rapkin, MD, the division's new clinical director of Oncology, comes on board this April. Dr. Rapkin, who comes from Children's Healthcare of Atlanta and Emory University, also will begin a Rare Tumor Program at Children's Hospital.

Frederico Xavier, MD, currently director of Hematology and of Thrombosis and Hemostasis at Penn State Hershey Children's Hospital, will join the division in the section of Hematology. Dr. Xavier completed a clinical fellowship in Pediatric Thrombosis/Hemostasis at The Hospital for Sick Children in Toronto and a clinical fellowship in Pediatric Hematology/Oncology at St. Jude Children's Hospital in Memphis. He joins Cheryl Hillery, MD, who came on board as the clinical director of Hematology last year. Dr. Hillery is a renowned researcher in sickle cell disease who recently received an R01 grant from the National Institutes of Health to study the mechanisms underlying pain crisis using mouse models of sickle cell disease.

Alberto Broniscer, MD, will be the director of the Section of Pediatric Neuro-Oncology when he joins the division in August. With Ian Pollack, MD, Dr. Broniscer and the rest of the Neuro-Oncology team will work to develop new insights into better diagnostic, prognostic, and treatment methodologies for refractory brain tumors.

Additional news from the division

Debra Cohen, MD, runs a telemedicine program for patients with sickle cell disease who live in the Erie, Pennsylvania, area and cannot easily travel to Pittsburgh for care. Jake Cooper, MD, is clinical director of the coagulation program. He co-directs a clinic with the Division of Adolescent and Young Adult Medicine for adolescents with menstrual issues due to bleeding disorders. Brittani Seynnaeve, MD, is building a multidisciplinary Pediatric Melanoma Center at Children's with involvement from the divisions of General and Thoracic Surgery, Plastic Surgery, and the University of Pittsburgh Cancer Institute. Dr. Seynnaeve is currently a pediatric hematology/oncology fellow.

To refer a patient or if you have questions about any Pediatric Hematology/Oncology program, call the division at 412-692-5055. •

Brain Tumor Consortium



Children's Hospital of Pittsburgh of UPMC recently was unanimously selected to remain within the Pediatric Brain Tumor Consortium (PBTC). Led by Ian Pollack, MD (*left*) Children's Hospital's group

represents one of only four institutions that has remained in the PBTC throughout its 19-year history. The PBTC is a multidisciplinary cooperative research organization devoted to the study of correlative tumor biology and new therapies for primary central nervous system tumors of childhood. Throughout its history it has carried out three recompetitions mandated by the National Cancer Institute based on member organizations' performance and designed to bring new sites in to the PBTC. In the most recent PBTC recompetition, Children's Hospital was one of the institutions that scored highest.

Ring That Bell, Jimmy!



Unless you've been out of the country — and maybe even if you have — you've likely heard of 6-year-old Jimmy Spagnolo (*left*) who recently got to ring the bell at Children's signifying the end of his yearlong treatment for brain cancer. We

shared a video of his bell ringing and belly patting on social media, where it quickly went viral: on Facebook, it reached over 991,000 people, had over 364,000 video views, and gained over 26,000 likes, comments, and shares. Jimmy's story on the local television news led to more press for him and his family, too — from the Washington Post, to "World News Tonight With David Muir," to US Weekly.

New Spine Center Features State-of-the-Art Low-Dose Imaging for Children With Scoliosis

The treatment can be arduous to bear for adolescents — the age group that most often presents with idiopathic scoliosis. There are countless appointments, diagnostic imaging every four to six months, braces that require frequent adjustment with growth, and in the most severe cases, surgery. But thanks to Children's Hospital of Pittsburgh of UPMC's new Spine Center, comprehensive specialty care is safer and more convenient than ever.

Opened in January 2017, the Spine Center brings the best of Children's Hospital's orthopaedic specialty care for children with scoliosis together in one convenient location along with innovative technology that significantly reduces patients' exposure to radiation during diagnostic testing.

Located at Children's main campus in Lawrenceville, the Spine Center offers nonoperative and operative treatment options administered by a team of physical therapists, orthotists, nurses, and orthopaedic surgeons, including Timothy Ward, MD, chief, and Stephen Mendelson, MD, vice chief, Division of Pediatric Orthopaedic Surgery, and Patrick Bosch, MD.

"This is a centralized, coordinated approach to care for children with idiopathic scoliosis, as well as those with early onset and congenital scoliosis," says Dr. Ward.

The centerpiece of the Spine Center is an EOS imaging machine (*right*) capable of full-body, three-dimensional scans that emit microdoses of radiation approximately one-eighth that of traditional x-rays.

As many as four in 100 adolescents have idiopathic scoliosis. It is the most common type of scoliosis, affecting children between ages 10 and 18, according to the Scoliosis Research Society.

Active treatment can last three to four years during the child's growth period, with the number of x-rays required to monitor



the progression of scoliosis and properly fit braces ranging from 10 to 20. Although the radiation emitted by traditional x-rays is minimal, it accumulates in the body and could contribute to radiation-induced cancer later in life. "We don't want to expose children to any more radiation than is absolutely essential for treatment," Dr. Ward says. "The EOS machine is state-of-the-art technology for taking x-rays with minimal radiation, and it allows us to analyze the spine better because we can visualize it from top to bottom."

At Children's, patients and their families have on-site access to therapists who specialize in the Schroth Method, a physical therapy regimen designed to reduce pain and arrest spinal curve progression. There also are orthotists who fit patients for a wide variety of braces that previously were not available from local suppliers. "Now we're able to offer all of that — and much more — here in Pittsburgh," Dr. Ward says.

The Spine Center also channels support groups and other valuable resources to patients and their families. "Our emphasis is on guiding and educating patients and their families through treatment. They need to understand what the spinal deformity is, and what their options are," says Joanne Londino, BSN, RN, Spine Center and clinical research coordinator, Division of Pediatric Orthopaedic Surgery.

For more information about the Spine Center or to refer a patient, call 412-692-6869. •

COMING EVENTS

Feeding and Swallowing Clinical Update 2017

Sept. 15, 2017 Children's Hospital of Pittsburgh of UPMC

This course will explore current evidence-based feeding practices for children. Anticipated topics include: the role of the modified barium swallow in evaluation of childhood dysphagia, infant-driven feeding, babyled weaning, and the examination of clinical decision making behind different feeding therapy approaches.

For more information, visit **chp.edu/fasc**.

Nephrotic Syndrome Symposium Sept. 28, 2017

Children's Hospital of Pittsburgh of UPMC

This one-day symposium covers all aspects of nephrotic syndrome, including cutting-edge basic and clinical research, topics to educate general practitioners and allied professionals, and patient and family support.

For more information, visit **chp.edu/nss**.

Three Rivers Pediatric Update 2018

Stay tuned for information about Three Rivers Pediatric Update 2018 — a CME event that's all about pediatric medicine. (We're taking a break in 2017.) We'll also be honoring Basil Zitelli, MD, for his distinguished career in pediatric medicine.

For updates, visit **chp.edu/ThreeRivers**.





Beating the Odds

Experimental Therapy Puts Refractory Kidney Disease Into Remission

ABOVE: Lexi Hatfield enjoys dancing, cheerleading, and just being a kid following specialized therapy at Children's Hospital of Pittsburgh of UPMC — one of only eight hospitals in the nation to offer the experimental treatment.

Kidney disease can sneak up on a kid. In the case of Lexi Hatfield, born in 2008, it disguised itself as stomach trouble at first, when she was about 1 year old. Then, when her cheeks and face got puffy and swollen at 18 months, along with a distended belly, it looked like an allergy.

Parents Jake and Erika Hatfield, living in rural southwestern Pennsylvania, were frustrated. "We'd gone to many doctors, urgent care, the pediatrician ..." says Ms. Hatfield. "They just kept saying it was allergies. We had her tested. We were avoiding the stuff they said she was allergic to, and nothing was working. It was frustrating."

Then one night, when she was nearly 4 years old, Lexi's stomach pain got so severe that the Emergency Room team at her community hospital diagnosed appendicitis, and referred Lexi to Children's Hospital of Pittsburgh of UPMC. After a week of tests at Children's, massive protein in the urine and a low albumen level in the blood indicated nephrotic syndrome.

FSGS and nephrotic syndrome

A biopsy confirmed a diagnosis of focal segmental glomerulosclerosis (FSGS), a relatively rare kidney disease that accounts for about onesixth of the cases of nephrotic syndrome. FSGS is usually diagnosed by the appearance of the kidney tissue on biopsy: focal (only some of the glomeruli are involved), segmental (only part of each glomerulus is involved), glomerulosclerosis (scarring of the glomerulus, part of the nephron). FSGS has a variety of origins, usually related to a primary disease or other condition that leads to nephropathy. Nephrotic syndrome associated with FSGS can progress to endstage renal disease (ESRD) requiring dialysis and kidney transplantation. In children who present at younger than 2 years of age, FSGS is often genetic and does not respond to therapy.

Lexi was treated aggressively with immunosuppressive therapy, but had no response, and her renal function steadily declined. Although genetic testing was inconclusive, "given her young age, lack of response to therapy, and rapid progression to ESRD, we suspected that Lexi had the genetic form of FSGS," says Michael Moritz, MD, clinical director, Division of Pediatric Nephrology at Children's. Her best hope for a normal life, based on this assessment, was a pre-emptive kidney transplant.

Pre-emptive kidney transplant

Timing for the transplant was critical: By late 2014, 6-year-old Lexi was facing renal failure. The Hatfield family and their community responded. More than 30 volunteers stepped forward. A donor was found and qualified, and Lexi was able to receive a pre-emptive kidney transplant in time to avoid the stress of dialysis.

The transplant went well with excellent function and no protein in the urine. After two weeks, however, Lexi's symptoms returned in the form of proteinuria. Lexi's FSGS was recurring. "This can happen in 50 percent of cases," says Dr. Moritz. "But we can't predict who will have a recurrence and who won't. The fact that it recurred was a definite sign that we weren't dealing with genetic FSGS."

Dr. Moritz and his team treated Lexi with plasmapheresis, a therapy where the plasma is removed from the body and replaced with unaffected protein. The regimen began with four treatments a week, accompanied by blood transfusion because of Lexi's small size, and gradually decreased to once a week. She responded to this therapy, going into remission after two and a half months.

"It helped that Lexi is an incredibly strong kid," says Dr. Moritz. "This was almost daily treatment at first, with a lot of needle sticks and a lot of discomfort." "Strong" may be an understatement. The way Lexi's mom tells it, life didn't slow down at all. "She'd go right from treatment to cheerleading and dance competitions. She didn't miss a beat."

But then the therapy hit a wall: When plasmapheresis was tapered to every two weeks, proteinuria recurred. Biopsies showed that FSGS was recurring, and without the weekly plasmapheresis, scarring and ultimately kidney failure would occur. For Lexi, remission from FSGS depended on weekly plasmapheresis, potentially for the rest of her life.



ABOVE: "It's an outcome like no one has seen before, especially in such a small child," says Michael Moritz, MD, clinical director, Division of Pediatric Nephrology, who treated Lexi at Children's.

Experimental in the United States

Faced with limited options, Dr. Moritz recommended LDL-apheresis, a therapy used in Japan to treat extremely high cholesterol as well as nephrotic syndrome, most commonly in adults. The therapy is recognized to control hyperlipidemia and promote remission in patients with refractory nephrotic syndrome associated with FSGS.

How this therapy works, whether it works long term, and the extent of its effectiveness, are all still under investigation. Although it is approved and covered by health insurance in Japan, LDL-apheresis is considered experimental by the U.S. Food and Drug Administration. Children's is one of only eight centers in the United States that offers this therapy to children with FSGS. "Results for this therapy are good in Japan," says Dr. Moritz. "But there is no comparable data in the U.S. It's not widely available to treat kidney disease."

In LDL-apheresis, plasma is passed through a dextran sulfate column and LDL-cholesterol is adsorbed due to an electrostatic interaction between negatively charged dextran sulfate and

Continued on page 6



ABOVE: The Hatfield family enjoys spending time together (*left to right*): Lexi, Julian, Jake, Erika, and Madison Hatfield.

positively charged apoprotein B on the surface of the lipoprotein. VLDL and LDL are adsorbed, but HDL-cholesterol (with ApoA or other plasma components including albumen) is not. This process can purify 3,000 to 4,000 ml of plasma in two to three hours.

One theory on treating refractory FSGS with LDL-apheresis is that the high levels of LDL-cholesterol produced in patients with FSGS work to defeat medications, and that rapid removal of these high levels of LDL eliminates this resistance. When this treatment was first used for FSGS in 1988 in Japan, researchers observed both the correction of hyperlipidemia and rapid resolution of nephrotic syndrome in response to immunosuppressive therapy.

Stable kidney function

"We turned to LDL-apheresis as a strategy to get Lexi off of weekly plasmapheresis," says Dr. Moritz. And that's exactly what happened. Following a nine-week course of LDL-apheresis that was completed in December 2016, Lexi is now in remission without any therapy aside from normal transplant medication. "She has good, stable kidney function without high blood pressure, and the protein in her urine is actually going down further," says Dr. Moritz. "It's an outcome like no one has seen before, especially in such a small child. Many similar cases are on lifelong plasmapheresis."

Dr. Moritz estimates that Lexi is one of probably less than 10 patients in the United States who has benefited from LDL-apheresis. As more becomes known about this novel therapy for a debilitating, life-shortening disease, more good outcomes could potentially follow.

From Jake and Erika Hatfield's point of view, it's more than an outcome. It's a journey that has brought Lexi to a place every parent wants their child to reach: a normal life. The best part? "I can eat hot dogs now!" Lexi says, without hesitation.

It doesn't get much better than that.

For a consultation or referral to the Division of Pediatric Nephrology, please call us at 412-692-5182. •

Regenerating Kidney Tissue



The search for a better cure for kidney disease has led a team of scientists under Carlton Bates, MD, (*left*) at Children's Hospital of Pittsburgh of UPMC

to explore the body's potential to regenerate its own kidney tissue. And that research is showing promise.

"What we propose to do," Dr. Bates says, "is to use the lymph node as an in vivo bioreactor to test the true potential for induced pluripotent stem cells to differentiate into structural and functional tissues that actually produce urine."

The lymph node's powerful role in processes like the spread of cancer and in inflammatory disease indicates its potential as a site for in vivo cell development, says Dr. Bates. And work at the University of Pittsburgh's McGowan Institute for Regenerative Medicine led by Eric LaGasse, PharmD, PhD, has shown that the lymph node has the capacity to allow engraftment of kidney and other cells. Working with Dr. LaGasse, Dr. Bates and his team have demonstrated for the first time that kidney progenitor cells were able to reform and make urine within the entrapped lymph node.

"More than 660,000 people suffer from end-stage kidney disease now, and we have no cure," says Dr. Bates. "This research could provide a rare, unique opportunity, whereby you can take your own tissues and grow them into tissues that will replace kidney function and truly cure end-stage kidney disease."



"The pathfinders were the children."



These words by **Thomas E. Starzl, MD, PhD**, were a reference to his work at Children's Hospital of Pittsburgh of UPMC. Those of us who worked alongside him knew that Dr. Starzl always regarded his young patients as the true heroes of his pioneering work at our hospital — and he dedicated his life to ensuring their future.

When Dr. Starzl came to Children's Hospital in 1981, among the first of four physicians to be tapped to care for his pediatric transplantation patients was pediatrician Basil Zitelli, MD, now chief of Children's Paul C. Gaffney Diagnostic Service. A couple years later, I was privileged to become part of that care team, and in 1994, surgeon George V. Mazariegos, MD, joined the Thomas E. Starzl Transplantation Institute, where he now serves as chief of Pediatric Transplantation.

As we at Children's mourn the passing of one of the world's greatest medical and scientific geniuses, we'd like to take this opportunity to share a glimpse of what it was like to work during those remarkable times with that equally remarkable man.

A time for courage

Dr. Zitelli remembers Dr. Starzl's early years as tumultuous and difficult. "There were very mixed feelings then about

transplantation — particularly for children — across the country, in Pittsburgh, and within our own hospital. It took great courage and tremendous vision on his part every day to move forward," he says.

"Beyond the technology, there were great social, ethical, and financial challenges," he adds. "Who was going to pay for this? Who would get an available organ? We were on the cusp of something new; there were few precedents to follow."

I saw firsthand the overwhelming response we received worldwide from desperate parents. As our survival rates grew, it quickly became clear that transplantation would shift from experimental to mainstream. We were in the midst of medical breakthroughs that were happening not in slow motion, but at warp speed.

Inspired by a long view

"Tom was an unbelievable man — but it was his relationships with his patients and families that were most incredible," recalls Dr. Zitelli.

"It was those relationships with the children that drove him," agrees Dr. Mazariegos. "By his example, we all became better doctors, better surgeons. He taught us to put ourselves in their shoes."

I believe he had a unique connection to children — and because of that, to our hospital and transplantation program. He was focused on the long-term impact only children could offer: He wanted to see them grow up, get married, and have children of their own.

"When Tom would see a statistic or outcome — three years, five years out — he'd say, 'George, tell me about your 25-year outcomes, and we could!" says Dr. Mazariegos. "And now, incredibly we're looking at nearly 36-year outcomes among our pediatric transplants. That's the true legacy of Tom Starzl."

Andy Urbach, MD, is medical director for Patient Experience and Development at Children's Hospital. He welcomes your comments and questions. Please send an email to MDrelations@chp.edu.

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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.



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Laurels

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

Himss Analytics

Children's Hospital of Pittsburgh of UPMC has been successfully

revalidated for Stage 7 certification on the Healthcare Information and Management Systems Society (HIMSS) Analytics Electronic Medical Record Adoption Model (EMRAM). HIMSS Analytics developed the eight-stage EMRAM as a tool to benchmark information technology maturity in health care organizations. Children's is a national leader in applying health information technology to improve pediatric care, and was the first pediatric hospital to achieve a Stage 7 award.



Erick Forno, MD, MPH, assistant professor, Department of Pediatrics, University of Pittsburgh School of Medicine, received the prestigious Klosterfrau Award from the Wilhelm Doerenkamp-Foundation. The Klosterfrau Award is a 30,000

Euro international award aimed at researchers in basic science, pulmonology, and pediatrics whose work is focused on providing a better understanding of airway diseases in children, especially asthma, congenital disorders of the airway tract, and primary diseases of the lung parenchyma. In addition, Dr. Forno authored an article on obesity and dysanapsis that was recently published in the American Journal of Respiratory and Critical Care Medicine.



The American College of Critical Care Medicine presented a Lifetime Achievement Award to **Patrick Kochanek, MD, MCCM**, Ake N. Grenvik Professor of Critical Care Medicine, University of Pittsburgh School of Medicine, at the 46th Congress of the

Society of Critical Care Medicine in January. The organization's highest award, it recognizes pioneering contributions to the field of critical care through the advancement of medical science, medical education, and medical care.



Ashok Panigrahy, MD, radiologist-in-chief, Department of Pediatric Radiology, was appointed vice chair of Clinical and Translational Imaging Research, Department of Radiology, at the University of Pittsburgh School of Medicine, where

he also serves as associate professor of radiology. As vice chair, Dr. Panigrahy will develop and implement a strategic plan for building a successful clinical and translational research program, while aligning the imaging research goals and initiatives with the department's overall mission and vision.



The University of Texas Medical Branch School of Medicine Alumni Association has selected **Robert Squires Jr., MD**, Division of Pediatric Gastroenterology, Hepatology and Nutrition, as a 2017 Ashbel Smith Distinguished Alumnus Award

recipient. The award recognizes Dr. Squires' contributions to the medical profession and his support for the high standards of excellence within the profession. He will receive the award during a reception on June 2, 2017, in Galveston, Texas.

Several physicians have received prestigious grants for research in their areas of expertise. They include:



Nitin Arora, MD, a second-year fellow in Neonatal-Perinatal Medicine, has won the 2017 Clinical Research Award from the Society for Pediatric Research.



Laura Jackson, MD, a third-year fellow in Newborn Medicine, received the 2017 David G. Nathan Research Award from the Society for Pediatric Research.



Kristin Ray, MD, MS, assistant professor, General Academic Pediatrics, University of Pittsburgh School of Medicine, received a career development grant from the National Institutes of Health to study how telemedicine is used to deliver subspecialty care to children. NEWS FROM TELEMEDICINE

Telemedicine Brings Children's Hospital's Genetics Expert to Erie

A new telemedicine service gives patients and families in Erie convenient access to Children's Hospital of Pittsburgh of UPMC's world-class pediatric specialty care in genetics.

Whether patients are hospitalized newborns with non-acute genetic conditions or children who need follow-up exams, Audrey Woerner, MD, MPH, Division of Medical Genetics, has plugged into technology to offer video-based consultations.

From her office at Children's main campus in Lawrenceville, Dr. Woerner sees patients in the Neonatal Intensive Care Unit at UPMC Hamot in Erie. These are patients who may have been diagnosed with a genetic condition prior to birth, including dysmorphic features such as cleft lip, cleft palate or club foot, heart defects, or chromosomal abnormalities.

"All are scheduled consultations, so they are for non-emergent cases," Dr. Woerner says. "This enables us to get the evaluation and treatment started as soon as possible."

Children's also launched a complementary telemedicine service for follow-up visits with Dr. Woerner at Children's Specialty Care Center Erie. Each patient must be seen in Pittsburgh by Dr. Woerner at least once, but may opt to schedule subsequent

visits via telemedicine.

A telemedicine visit is very similar to an in-person evaluation. The doctor discusses patient history and test results, and may provide a PowerPoint presentation for patients and families to follow along when explaining complex results or concepts in genetics. "I can Telegenetics is something I wanted to implement when I came to Pittsburgh. Pennsylvania is a large state with many rural areas, providing significant opportunity for telemedicine to enhance the delivery of pediatric care.

— Audrey Woerner, MD, MPH

control a camera from my end — zoom in and move it around during the examination. With the help of a medical assistant, we have a Bluetooth stethoscope that we hook up to a computer so that I can hear heart, lung and bowel sounds," Dr. Woerner says.

"With services like this, we're offering patients better and more convenient access to care," says Sarah Claassen, program coordinator, Telemedicine. "It gives patients the opportunity to see specialists without the cost and time associated with traveling to Pittsburgh."

Dr. Woerner is no stranger to telemedicine. She was director of the telegenetics program at Boston Children's Hospital prior to joining Children's Hospital of Pittsburgh of UPMC in July 2016.

For more information or to refer a patient, call the Department of Medical Genetics at 412-692-5070. •

Cardiovascular Stars

The Heart Institute at Children's Hospital of Pittsburgh of UPMC ranks among the top cardiovascular surgery programs in the United States. According to the latest data compiled by the Society of Thoracic Surgeons (2012–2016), Children's Hospital had an overall, non-risk adjusted mortality rate of 2 percent; the average for all 116 ranked centers was 3.08 percent.

Children's had the 7th lowest mortality among high-volume centers in North America. Our mortality for STAT category 5 — the highest risk cases — was 5 percent, which was the second lowest among large centers in North America.

Children's Hospital received three stars, the highest rating from STS, for the four-year reporting period of 2012 to 2016. Children's was one of only 11 centers in North America, out of 116 total centers, to receive the three-star rating.

STS' Congenital Heart Surgery Database has a three-star rating system (based on the overall observed to expected (O/E) operative mortality ratio for all patients undergoing pediatric and/or congenital cardiac surgery. For a center to receive three stars, the O/E ratio must be less than 1.0 and the upper lower limits of their confidence interval must be less than 1.0. Children's Hospital had an O/E ratio of 0.65, garnering it a three-star rating for the four-year reporting period.

New Pulmonologist



Mark Dovey, MD, joined the Division of Pulmonary Medicine, Allergy, and Immunology in March 2017 as associate director of the Antonio J. and Janet Palumbo Cystic Fibrosis

Center at Children's Hospital of Pittsburgh of UPMC. He also will be director of the Pediatric Pulmonology Fellowship Program. Dr. Dovey has had a distinguished career as a clinician, educator, administrator, and leader in pediatric pulmonary medicine, most recently serving as vice-chair of pediatric clinical services at Boston Medical Center and Boston University.



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