Special Page 4 Feature

Dream Team

Children’s pediatric cancer specialists get aspiring soccer star back in the game

Liver Transplantation
Program expands to Florida

Andy’s INSIGHTS
Transitioning care for young adult patients

Studying Telemedicine
Exploring new uses for technology
The WINTER 2018 issue of Pediatric INSIGHTS

Cover story: The Adolescent and Young Adult Oncology Program at Children’s Hospital of Pittsburgh of UPMC brings together all of the specialists and services young people need to battle common and rare diseases. For Reese Aquilio, Children’s physicians teamed up with an adult-focused surgeon to remove a carcinoid lung tumor more common in adults and help get her back to playing the sport she loves. Read about it on page 4.

In addition:

> Children’s Hospital has created the new Division of Health Informatics, that will leverage technology to enhance innovation and patient safety and outcomes. Learn more on page 3.

> On page 7, Andy Urbach, MD, medical director for Patient Experience and Development, highlights the ways Children’s Hospital is working to improve the transition for young adults who are shifting from pediatric- to adult-focused care.

> On page 9, learn about a recent study that explores new ways to enhance Children’s Telemmedicine service, which currently offers outpatient care at seven convenient locations in western Pennsylvania.

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.

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.
In order to make lifesaving liver transplants available throughout central and north Florida, Florida Hospital for Children is partnering with Children’s Hospital of Pittsburgh of UPMC to develop a comprehensive pediatric liver transplant program. The program, which started to accept patients in January, is the first of its kind in Orlando and the second in Florida.

Florida Hospital is one of the largest not-for-profit hospitals in the country. The organization’s range of nationally and internationally recognized services includes transplant, pediatrics, cardiology, and advanced surgical programs. Florida Hospital for Children’s flagship hospital in Orlando is the heart of a children’s network that includes primary care pediatricians, specialty clinics, emergency departments, and Kids Urgent Care.

“There is a critical need for children across our state to have access to a liver transplant program that is close to home;” says Regino Gonzalez-Peralta, MD, director of Pediatric Gastroenterology, Hepatology, and Liver Transplantation with Florida Hospital for Children. “This partnership brings the experience of one the nation’s best pediatric liver transplant programs to central Florida. The Florida Hospital and Children’s Hospital partnership is not only a win for our patients, but all of Florida.”

The teams will work in partnership with Florida Hospital’s Transplant Institute, which offers kidney, liver, kidney/pancreas, lung, and heart transplants.

“Florida Hospital has been committed to saving lives through our transplant programs for more than 40 years, and it is our goal to provide the same level of advanced and compassionate care to infants and children in our community in need of liver transplants;” says Thomas Chin, MD, director of the Florida Hospital Transplant Institute’s liver transplant program. “We are honored to partner with Children’s Hospital and bring our world-class programs together.”

In order to offer these transplants to families in the Florida area, the hospital will work with the Hillman Center for Pediatric Transplantation at Children’s Hospital, which has performed more than 1,800 pediatric liver transplants — more than any other center in the United States, according to the United Network for Organ Sharing, with patient survival rates consistently higher than national averages.

“We are grateful for this opportunity to now expand our services and expertise in pediatric liver transplantation to families in the Florida area,” says George V. Mazariegos, MD, chief of Pediatric Transplantation at Children’s. “Our extension of expertise will provide the best possible care and make transplant a life-saving treatment for local families and help them to achieve a better quality of life.”

In 1981, Children’s Hospital opened the country’s first comprehensive pediatric transplant center under the guidance of transplant pioneer Thomas E. Starzl, MD, PhD. According to the 2017 data released by the Scientific Registry of Transplant Recipients, the pediatric liver transplant program at Children’s ranks number 1 out of 62 pediatric liver transplant centers in the United States for one-year overall patient and graft survival when comparing hazard ratio estimates. The program remains at the leading edge of expertise, innovation, and patient- and family-centered care for transplant patients from all over the world.

Members of the transplant team from Children’s Hospital will participate in the management of patients in Florida. Transplant surgeons, medical specialists, and nurses from Florida and Children’s Hospital will perform pediatric liver transplant surgeries together at Florida Hospital for Children.

The pediatric liver transplant partnership with Florida Hospital is the second program of its kind for Children’s Hospital. In 2016, Children’s Hospital became the first and only pediatric liver transplant program to expand the geographic reach of its expertise through a partnership with the University of Virginia Children’s Hospital in Charlottesville. Today, Children’s pediatric liver transplant network extends from Pittsburgh to Virginia, and now Florida.
NEW CHILDREN’S HOSPITAL OF PITTSBURGH OF UPMC

NEWS YOU NEED

New Children’s Webinar Series
Free CME Credit Available

Children’s Hospital of Pittsburgh of UPMC offers a lunchtime webinar series for pediatric providers. The Pediatric Insights Webinar Series features Children’s Hospital specialists presenting on challenging topics that pediatricians, family practitioners, and other pediatric providers may face in their practices.

Currently the webinars are held monthly. This frequency may increase in 2018. Continuing medical education (CME) credit is available for viewers who participate in the live broadcast. Past webinars are available to view, however, credit is unavailable.

Each webinar is worth 1 CME credit (0.1 CEU for other health care professionals). In order to receive credit, participants must provide their full name, credentials, and the last five digits of their Social Security number when requested. Credit is granted through the University of Pittsburgh Center for Continuing Education in the Health Sciences.

Visit www.chp.edu/webinars to view and register for upcoming webinars. Have a topic you’d like to see covered? Email us at mdrelations@chp.edu with your suggestions.

New Division Chief Appointed

A leading expert in evaluating and treating children with cholestatic liver disease, Andrew Feranchak, MD, recently joined Children’s Hospital of Pittsburgh of UPMC as chief of the Division of Pediatric Gastroenterology, Hepatology, and Nutrition and professor of Pediatrics at the University of Pittsburgh School of Medicine.

Previously, Dr. Feranchak served as chief of the Division of Pediatric Gastroenterology and professor in the Department of Pediatrics at the University of Texas Southwestern Medical Center in Dallas, where he also held the Willis C. Maddrey, MD Chair in Liver Disease. A native of Pittsburgh, Dr. Feranchak received his medical degree from the University of Pittsburgh School of Medicine, and he completed his pediatric residency at Children’s Hospital, followed by fellowship training in gastroenterology and hepatobiliary transport at the University of Colorado Health Sciences Center.

Dr. Feranchak’s clinical and research expertise involves cholestatic liver diseases, bile formation, hepatobiliary transport mechanisms, and membrane ion channels. Dr. Feranchak’s NIH-funded research focuses on understanding the basic mechanisms of bile formation, which may serve as the basis for therapeutic strategies for the treatment of cholestatic liver disorders.

To make a referral or for more information, contact the Division of Pediatric Gastroenterology, Hepatology, and Nutrition at Children’s Hospital of Pittsburgh of UPMC at 412-692-5180.

What an impact we have made together.
With the help of many, we’ve changed lives for the better.

The 2017 Children’s Hospital of Pittsburgh of UPMC and Children’s Hospital of Pittsburgh Foundation Community Report takes a look back at a year of innovation and impact in all aspects of the work that we do here, from excellence in clinical care, to breakthroughs in the research setting, to creative ways of healing.

Visit www.chp.edu/communityreport and you can:

> Meet some of the big thinkers at Children’s Hospital, who are developing new and improved vaccines, helping kids get healthier, and doing important work in the community

> Look back at some of the heroes who make this work possible, by donating their time and treasure

> Make a secure online donation to support the life-changing work we do every day

If you’d like a hard copy of the 2017 Community Report, email Kate Lindholm at kathleen.lindholm@chp.edu.
Since the implementation of its electronic medical record in 2002, Children's Hospital of Pittsburgh of UPMC has been recognized as a leader in digital technologies for pediatric medicine. More than a decade later, Children's Hospital continues to lead the way in health information technology and patient safety with the creation of a new Division of Health Informatics.

"I'm excited to announce the development of a new division in the Department of Pediatrics, the groundbreaking Division of Health Informatics," says Terence Dermody, MD, chair of the Department of Pediatrics at the University of Pittsburgh School of Medicine, and physician-in-chief and scientific director at Children's. “Our goal is to harness the power of technology and join forces with leaders in information science — from industry to academia and medicine — to substantially improve safety and outcomes for all patients while lowering health care costs from emergency care to the operating room, starting with primary care services.”

The Division of Health Informatics is a collaborative effort between the Department of Pediatrics, the University of Pittsburgh School of Medicine, and Children's. Its mission is to drive the delivery of pediatric health care into a new era of high-value care and data-driven outcomes through innovation and new partnerships.

The division is led by Srinivasan Suresh, MD, MBA. Dr. Suresh will continue to serve as the hospital's chief medical information officer, a position he's held since 2014. As a board-certified physician in the new specialty of clinical informatics, Dr. Suresh is passionate about the application of business intelligence tools and advanced data analytics in improving child health and patient and provider satisfaction.

Dr. Suresh is also board-certified in pediatric emergency medicine and will continue to provide clinical care in Children's Emergency Department. Additionally, he is a professor of Pediatrics at the University of Pittsburgh School of Medicine.

Key goals of the Division of Health Informatics are to integrate clinical, operational, and financial data; to create a comprehensive pediatric predictive analytics platform; and to apply information-enabled tools to transform health care delivery in pediatrics.

Over the next year, Dr. Suresh and his team will develop and refine clinical pathways (to standardize care, improve quality outcomes, and lower costs), build newer clinical decision support tools, and enable dashboards for measurement. The division will also focus on population analysis and risk-stratification models of Children's patient population.

Key Partnerships:
- Department of Biomedical Informatics, University of Pittsburgh
- Department of Industrial Engineering, University of Pittsburgh
- Heinz College of Information Systems and Public Policy, Carnegie Mellon University
- Center for Machine Learning and Health, Carnegie Mellon University
- UPMC Enterprises

Current Collaborations:
- Children's Hospital Association
- Solutions for Patient Safety Network
- Improving Pediatric Sepsis Outcomes

By 2019, Dr. Suresh anticipates that the division will be staffed with up to seven faculty members including physicians with expertise in clinical informatics, a biomedical scientist from the University's Biomedical Informatics department, and a tenure stream researcher who will lead Children's bioinformatics core. Positions that currently make up the division include a data scientist, clinical pathway coordinator, systems analysts, and nurse education specialists.

Current clinical projects include an early warning sign for clinical deterioration of acute care patients; the System for Hospital Adaptive Readmission Prediction and Management (SHARP) that calculates readmission risk; and the cardiac warning index (C-WIN) that predicts the need for invasive procedures in CICU patients. Projects on the horizon include the Personalized Medicine Initiative (PMI), which is a national study on precision medicine, and Dr. Dermody’s Pittsburgh study, which will investigate correlates of health in Allegheny County children.

The division has received funding through several grants totaling nearly $4 million, including a Beckwith Foundation Grant for the dissemination of an electronic health record-based child abuse clinical decision support system toolkit, a grant for the SHARP project, and support from the Children's Hospital of Pittsburgh Foundation to create the Starzl Network for Excellence in Pediatric Transplantation.

For more information about the Division of Health Informatics, please contact Dr. Suresh at 412-692-6303 or suresh@chp.edu.
The pain was overwhelming. It had come and gone in Reese Aquilio’s chest and back for several months when she played soccer, but during this big match it was much more intense. Later that night, the pain became unbearable. “She couldn’t breathe and her chest was really tight. She was up all night in pain,” her mother Lesley Aquilio says through tears, recalling that night. “I knew something was wrong.”

At 13, there was little reason to suspect a dangerous carcinoid cancer more commonly found in adults was slowly growing in Reese’s lungs, choking the life out of her. Once it was discovered, pediatric specialists at Children’s Hospital of Pittsburgh of UPMC employed first-ever technology and a comprehensive team approach to remove the tumor and help Reese return to the sport she loves.

As an avid athlete and year-round soccer player, the Norwin Middle School student was accustomed to pushing her body to the limit. So, when an initial x-ray in November 2016 showed a diagnosis of pneumonia, she took it in stride — using antibiotics prescribed by her primary care physician and resting until she felt better. When she returned to her soccer workouts, the pain came back, too.

Following that night of unbearable pain in March 2017, Reese’s grandmother took her back to the primary care physician, who suggested a second x-ray. “As soon as I got home from work I took her for the x-ray. I just felt like something was not right. Call it mother’s intuition,” says Mrs. Aquilio.

Reese Aquilio (top and above center) has worked hard to overcome carcinoid cancer with specialized treatment at Children’s Hospital of Pittsburgh of UPMC and support from her parents, Tony and Lesley Aquilio. (Top photo submitted.)
“The next day her pediatrician called and said, ‘This is not pneumonia. I don’t know what it is, but I’m calling Children’s Hospital to get her in for an appointment as soon as possible,’” she says.

At Children’s she underwent a computed tomography scan of the chest on April 18, and there it was: a mass in the lung, on the right main bronchus, a major airway.

Age-appropriate care
Carcinoid tumors, made up of neuroendocrine cells, rarely occur in the lungs of children, but are more often found in adults with lung cancer. “If caught early enough it is very survivable, but late-stage disease is incurable,” says Louis Rapkin, MD, clinical director of Oncology at Children’s. “If the tumor blocks the bronchial tube, the mass can cause pneumonia and other damage to the lung. If it spreads, there is little chemotherapy or other treatments can do to cure it.”

The Adolescent and Young Adult Oncology Program in Children’s Division of Hematology/Oncology offers specialized oncology and support services to meet the needs of children in their teens through young adults up to age 26. The program features a comprehensive approach to care that enables patients to be treated by pediatric oncologists in collaboration with adult-focused oncologists, when appropriate. Rather than simply requesting a consultation via telephone or computer, additional experts can be brought to Children’s Hospital in Lawrenceville.

“We are better geared to treat adolescents and young adults because we also take into account their developmental stage to make the experience more manageable for the patient. Even young adults are still developing in terms of their ability to cope with trauma. We account for their physical and psychological needs,” says Dr. Rapkin.

Reese’s team of physicians included Dr. Rapkin and Stefan Scholz, MD, PhD, a general and thoracic pediatric surgeon and Director of Minimally Invasive Surgery at Children’s. To give her the best chance possible, they collaborated with Inderpal Sarkaria.
MD, a thoracic surgeon at UPMC Hillman Cancer Center who has experience treating adult patients with carcinoid lung cancer. “It was a very tricky mass requiring high-end thoracic surgery,” says Dr. Scholz. “The ability to bring in someone who has a lot of experience with carcinoid lung cancer was a great asset.”

Pioneering radiology
On April 27, Reese’s rare diagnosis was confirmed by something even rarer: positron emission tomography (PET) imaging using a Gallium 68 dotatate injection. The radioactive diagnostic agent is a less-invasive alternative than biopsy to help pinpoint carcinoid tumors. Although it has been used in other parts of the world for many years, it wasn’t approved by the U.S. Food and Drug Administration until June 2016. Reese became the first patient at Children’s Hospital — and the first pediatric patient in the nation — to undergo a dotatate PET scan.

“We were nervous about Reese being the first child to have the dotatate PET scan, certainly as anyone would be scared, but we knew we needed to have the right diagnosis and we wanted to avoid an invasive biopsy. We needed the team of doctors to have the most up-to-date and accurate information possible. So we were willing to do whatever it takes to make sure everything went well for Reese,” says Mrs. Aquilio.

“After the test, the technician handed Reese a stuffed animal and said to her, ‘Not only are you helping yourself, you are helping many other children.’ I think that made her feel powerful to know she was helping others by being the first child to undergo the scan,” Mrs. Aquilio adds.

Bilobectomy
While doctors carefully planned Reese’s surgery, she fought through the pain in order to try to find a sense of normalcy. She continued to play soccer, participated in a chorus concert, and attended her school picnic at Kennywood amusement park. On June 2, everything was ready.

Doctors had hoped to remove only one of the three lobes of the right lung. “The mass was located at the root of the right lung at and within the division of the main bronchus to the middle and the lower lobes,” says Dr. Scholz. During the four-hour surgery, doctors made the decision to remove the two lobes — a bilobectomy — in order to assure complete removal of the tumor with a “negative margin” of healthy surrounding tissue, the key factor for a good long-term prognosis.

Reese did very well following the procedure and was discharged from the hospital six days after surgery, determined to get back on track with soccer. Within a month, she started speed and strength conditioning. After two months, she began one-on-one footwork training with her coach. She joined her soccer team for its first practice of the season in August. “She’s still working to get back to the skill level she had prior to the diagnosis. She is determined not to let this hold her back,” says her mother.

“If you take out the lower and middle lobes of the lung, initially you feel it,” says Dr. Scholz. “But in the eight weeks after surgery, Reese trained herself to approach the level of activity that she had before.” In Reese’s case, chemotherapy and radiation treatments were not necessary. Doctors will monitor her progress over the next five years with visits every four to six months that include physical examinations, chest x-rays, and pulmonary function tests.

Lesley Aquilio and her husband, Tony Aquilio, who live in North Huntingdon with Reese and her two younger sisters, Alyssa and Natalie, credit the medical professionals at Children’s Hospital for the high level of care and attention the whole family received during Reese’s treatment. “We felt like we were living a true nightmare, and everyone at Children’s made this process much easier,” says Mrs. Aquilio. “Our only option was to put our trust and faith in the professionals working with Reese. Everyone we encountered in the hospital and at all of the appointments has been nothing short of spectacular.”

**To make a referral for the Adolescent and Young Adult Oncology Program at Children’s Hospital, call 412-692-5055.**
Andy’s INSIGHTS

The transition from pediatric to adult subspecialty care can be a medical, logistical, and emotional rollercoaster for young adults with complex health conditions. How can we give them the skills, knowledge, and confidence to make this critical move?

Pediatric patients with complex or chronic medical conditions often grow up at Children’s Hospital of Pittsburgh of UPMC, spending years in our care. Many are medical pioneers, too, living longer and healthier lives than ever before.

The successful transition from pediatric care is a highly personalized process that can take months or even years, based on the needs of both patients and parents. Conversely, the successful transfer to adult-oriented providers requires a well-planned and orchestrated “passing of the baton” that gives new caregivers the succinct and meaningful documentation they need.

Here are a few of the ways Children’s is working to make transition and transfer seamless processes for patients and their families — and their new subspecialists.

Task Force 13
The mission of Task Force 13, an interdisciplinary workgroup, is to help adolescents and young adults (AYA) become more self-sufficient and improve their long-term outcomes. Many of our departments have extensive measures in place for pediatric-to-adult care transition. Task Force 13 aims to learn from these best practices while also developing resources to support transition needs hospital-wide.

Loreta Matheo, MD, a specialist in adolescent medicine, recently took over leadership of Task Force 13, which includes physicians, nurses, social workers, administrators, and community stakeholders.

Bridges Transition Pediatric to Adult Clinic
Dr. Matheo also leads our weekly Bridges Transition Pediatric to Adult Clinic in Lawrenceville. This multidisciplinary clinic of physicians, social workers, and psychologists augments the work of existing transition efforts at Children’s through its programs on reproductive and behavioral health. It also supports the development of new and emerging transition programs.

The clinic evaluates individual readiness while slowly preparing AYAs to assume a greater role in their health care. They learn to understand their illness more deeply, how to advocate for their health and talk with adult specialists, and even schedule their own appointments and reorder prescriptions. Patients can discuss sensitive topics such as sexuality, peer pressure, and drug use with trusted professionals. The clinic coordinates with adult providers to ensure the smooth transfer of care.

Other notable Initiatives
Sometimes, there are no adult subspecialists qualified to care for survivors of certain pediatric-onset illnesses. Each year, my office receives nearly 100 requests for Children’s to provide continued care for these patients. All requests are considered and approved on an individual basis.

We’re also fortunate to have Reed van Deusen, MD, and Alda Gonzaga, MD, of UPMC General Internal Medicine. Their transitional care clinic, the Progressive Evaluation and Referral Center, offers longitudinal primary care and care coordination, particularly for patients with cognitive or developmental issues.

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.

VISIT NAVIGATION
Our outpatient visit coordinator helps manage the complexities of scheduling multiple medical appointments for patients who need to return to Children’s Hospital of Pittsburgh of UPMC three or more times within the same month. For more information, contact Visit Navigation at visitnavigation@chp.edu or 412-692-5687. Erinn Kasubinski, RN, BSN, is the Visit Navigation manager.

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
Children’s Hospital of Pittsburgh of UPMC has been recognized with titanium status in the 2017 Hospital and Healthsystem Association of Pennsylvania (HAP) Donate Life Hospital Challenge that encourages Pennsylvania hospitals to increase organ donation awareness and designations within their hospital and community. To reach the titanium level, hospitals engaged in unprecedented levels of clinical and community activities, aimed at encouraging new donor signups.

Rachel Berger, MD, MPH, chief, Division of Child Advocacy, and president, Children’s Hospital medical staff, has received a grant from the Patient-Centered Outcomes Research Institute for her project titled, “Disseminating Child Abuse Clinical Decision Support to Improve Detection, Evaluation, and Reporting.”

Juan Celedon, MD, DrPH, chief, Pulmonology, Allergy, and Immunology, has received a grant from the National Institutes of Health to support social epigenomics research in health disparities. He will lead research on “Exposure to Violence, Epigenetic Variation, and Asthma in Puerto Rican Children.”

Two Children’s Hospital physicians in Pulmonary Medicine, Allergy, and Immunology were honored recently with teaching awards from the University of Pittsburgh School of Medicine. Jonathan Finder, MD (left), professor, Pediatrics, received the 2017 Sheldon Adler Innovation in Medical Education Award. Daniel Weiner, MD (right), associate professor, Pediatrics, received the 2017 Award for Outstanding Mini-Elective.

Elizabeth Hartigan, MPH, RN, CRM, clinical research manager, Pulmonary Medicine, Allergy, and Immunology, was selected to receive the 2017 University of Pittsburgh Chancellor’s Staff Award in the Research Support category.

Amy Houtrow, MD, MPH, PhD, chief, Pediatric Medicine and Rehabilitation, was recently elected to the Board of Governors of the American Academy of Physical Medicine and Rehabilitation.

Patient Satisfaction Awards
Congratulations to the 27 Children’s Hospital physicians who recently received the Patient Satisfaction Award for Outstanding Achievements in Patient Care. Physicians were rated based on Press Ganey survey questions, which focus on areas like being a good listener, showing dignity and respect, and providing understandable information in a friendly manner.

Sonika Bhatnagar, MD, MPH
Aimee Biller, MD
James Cooper, MD
Alexander Davit, MD
Stacey Drant, MD
Jason Edinger, DO
Erika Friehling, MD
Angela Garcia, MD
Kristin Hannibal, MD
Tyler Harris, MD
Alicia Haupt, MD
Daniel Kietz, MD, PhD
Ingrid Libman, MD
Scott Maurer, MD
Susan Miller, MD
Radhika Muzumdar, MD
Christina Rae Nguyen, MD
Andrew Nowalk, MD, PhD
Evelyn Reis, MD
Arthur Ritchey, MD
Timothy Shope, MD, MPH
Arvind Srinath, MD
Kishore Vellody, MD
Katherine Watson, DO
Jacqueline Weinberg, MD
Randy Windreich, MD
Matthew Zinn, DO

These Children’s Hospital staff won Poster Presentation Awards during Children’s Hospital of Pittsburgh of UPMC’s observance of HealthCare Quality and International Infection Prevention Week in October:

> **FIRST PLACE** – “The Impact of Pre-Transplant Psychosocial Risk Factors and Post-Transplant Correlations” by Christina Nguyen, MD, Beth Ann Logan, PhD, and Jada Epps.

> **SECOND PLACE** – “Emergency Department Triage: Changing the Culture” by Jeff Beveridge, Dave Rausch, and Zachary Clayton.

> **THIRD PLACE** – “A Feeding Protocol at the Children’s Hospital Rehabilitation Unit” by Unoma Akamagwuna, MD, and Elizabeth Guzek, PA-C.

Study Focuses on Pediatric Telemedicine
Technology Enhances Access to Subspecialty Care

Patients and their families have embraced the Telemedicine Program at Children's Hospital of Pittsburgh of UPMC. Now a new study shows how innovations in telemedicine could further enhance the patient experience and accessibility of pediatric subspecialty care.

The study, published in the October 2017 issue of Telemedicine and e-Health, is titled “Family Perspectives on Telemedicine for Pediatric Subspecialty Care.” The team of researchers from Children's Hospital of Pittsburgh of UPMC, the University of Pittsburgh School of Medicine, University of Pittsburgh Graduate School of Public Health, and Harvard Medical School interviewed patient families from six counties in western Pennsylvania.

“We know there are lots of barriers to specialty care. There's a limited number of specialists, long wait times, and often long distances to travel to see them,” says lead researcher Kristin Ray, MD, MS, General Academic Pediatrics, Children’s Hospital. “Telemedicine has grown to assist with those issues, but we wanted to see how else patients thought telemedicine could improve their access to care.”

Children’s Hospital’s Telemedicine Program facilitates subspecialty care with two-way audio/video and specialized equipment that allows doctors to hear a patient’s heartbeat, view x-rays, and share information with patient families in real time. In addition to consultation for pediatric inpatients at hospitals throughout the world, the Telemedicine Program bridges the distance for outpatient care at seven convenient locations in western Pennsylvania.

“It’s important to look at telemedicine as a tool to deliver care more effectively for families, and it is important to listen to families so we can find the best ways to meet their needs,” says Dr. Ray, director of Health Systems Improvements, Children’s Community Pediatrics.

The study found that “families love the idea of reducing travel time with telemedicine visits, but there are definitely more ways to benefit from it beyond replacement of traditional in-person visits,” Dr. Ray says. Suggestions from patient families included the use of telemedicine for pre-visit triage to schedule the patient with the correct subspecialist and with the appropriate level of urgency; and communication with subspecialists after in-person visits for follow-up questions, care coordination, and to discuss changes in health status. Same-day scheduling options, continuity of care with trusted providers, and clear guidelines on when to use telemedicine were also important to participants, according to the study.

“Based on this study, we are exploring ways to develop telemedicine services that are even more responsive to patient’s interests and needs,” Dr. Ray says.

To learn more about the Telemedicine Program at Children’s Hospital of Pittsburgh of UPMC, call 412-692-8633 (TMED) or visit CHP.edu/telemedicine.

Heart Institute Named Accredited Center of Care

The Heart Institute at Children’s Hospital of Pittsburgh of UPMC has been named an accredited center of care by the Children’s Cardiomyopathy Foundation (CCF), a national nonprofit organization committed to improving the health outcomes and quality of life for children with cardiomyopathy, a chronic heart disease that affects how the heart pumps blood through the body.

Children’s Hospital received this recognition for consistently providing high-quality cardiac care and specialized disease management to children with the disease.

“Cardiomyopathies are a variety of serious conditions that can lead to heart failure and death,” says Brian Feingold, MD, MS, medical director, Heart Failure and Transplantation Programs, Children’s Hospital. “At Children’s, we have a strong tradition of excellence in care for all forms of this complex disease. Accreditation by the CCF is welcome recognition of our world-class pediatric cardiomyopathy program, including our success in caring for infants, children, and adolescents across the entire spectrum of cardiomyopathies.”

As a leader in treating children with heart failure, the Heart Institute’s heart failure and recovery program and its dedicated cardiomyopathy clinic helps pediatric patients and their families on both an inpatient and outpatient basis.

Centers meeting specific criteria are designated as a CCF-accredited center of care for a two-year period.

Above: Children’s is exploring new ways to improve access to health care with telemedicine. Pictured during a telemedicine visit are patient Joseph LaRocca (left) and Stacy Gibson, MSN, RN, CPN.
Parents and families can feel secure knowing how close they are to the world-class pediatric care of Children’s Hospital of Pittsburgh of UPMC. Because the care and some of the same great doctors who treat kids in Pittsburgh are available in locations all around the region. So there is often no need to take a trip to Pittsburgh to see Children’s Hospital’s experts in specialties like cardiology, pulmonology, and more. And one less long car trip makes everyone feel better. So whether you live in the north, south, east, or west, you’ll get access to the nationally ranked pediatric expertise you trust. To learn more, visit chp.edu/everywhere.