Pediatric INSIGHTS

A Physician Resource From UPMC Children's Hospital of Pittsburgh | www.chp.edu



Pediatric INSIGHTS

Inside this issue

Top Honors
New Hospital President

2 New Mental Wellness App

3 UPMC Children's Milestone

4 | Feature Story Healthy Growth With a Spring Assist

7 Andy's INSIGHTS

8 Laurels for Our Staff

9 Pediatric Telegenetics

EDITOR

Lisa Clark

CONTRIBUTORS

Andrea Kunicky, Kate Lindholm, Andrew Urbach, MD

DESIGN

Jim Zahniser

PHOTOGRAPHY

Jake Carlson, Annie O'Neill, Bill Paterson, UPMC Creative Services

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To submit comments or story suggestions, email Kate Lindholm at mdrelations@chp.edu.

Learn more about UPMC Children's Hospital of Pittsburgh by visiting www.chp.edu.

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The SUMMER 2019 Issue of Pediatric INSIGHTS

Cover story: As a newborn, Fulton Kramer's craniosynostosis was barely detectable. By 2 months old, his pediatrician referred him to the **Cleft-Craniofacial Center** at UPMC Children's Hospital of Pittsburgh, where doctors offered his family a less-invasive spring-assisted alternative to traditional cranial surgery to correct his fused skull suture.

In addition:

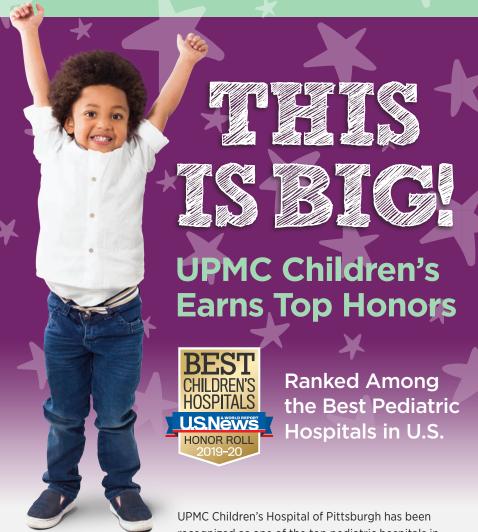
- > UPMC Children's is recognized as **among the top pediatric hospitals** in the country and receives accolades in all 10 specialty areas on the *U.S. News & World Report* Honor Roll of America's Best Children's Hospitals.
- > The Children's Hospital of Pittsburgh Foundation receives a \$500,000 grant to develop a new app to support mental wellness for teens and young adults.
- > It's been a decade since **UPMC Children's** moved to its state-of-the-art campus in Lawrenceville, and we're celebrating!

Physician Referral Service

412-692-PEDS

To refer a patient to any of UPMC Children's Hospital of Pittsburgh's clinical services, please call our Physician Referral Service at 412-692-PEDS (7337).

Visit the Referring Physicians section of UPMC Children's website at www.chp.edu/physicians.



recognized as one of the top pediatric hospitals in

the country, earning 8th position on the annual U.S. News & World Report Honor Roll of America's Best Children's Hospitals.

Nationally, UPMC Children's Hospital is ranked for excellence in all 10 specialty areas and is among the top 10 hospitals in five of the specialties: cardiology and heart surgery (No. 3); diabetes and endocrinology (No. 6); gastroenterology and gastroenterology surgery (No. 7); pulmonology (No. 6); and urology (tied for No. 10).

"It is an extraordinary achievement to be recognized as one of the best children's hospitals in the country," says Mark Sevco, president, UPMC Children's. "I am honored to work with all the outstanding and talented health care professionals who are committed to putting children first. The rankings reflect our staff's dedication to creating the ultimate patient care experience by providing compassionate and worldrenowned care for every single patient and family every single day."

"We are grateful to receive this national recognition," says Leslie Davis, senior vice president, UPMC, and executive vice president and chief operating officer, UPMC Health Services Division. "The exemplary team at UPMC Children's plays an integral role in delivering the best patient care to ensure the best outcomes not only for the children of western Pennsylvania but for children around the world."

The 2019-20 Best Children's Hospitals rankings are available online now and will be published in the "Best Hospitals 2020" guidebook, available in September.

The Best Children's Hospitals rankings were introduced in 2007 to help families of children with rare or life-threatening illnesses find the best medical care available. The rankings open the door to an array of detailed information about each hospital's performance. •

New UPMC Children's President Announced



UPMC has announced the appointment of Mark Sevco as president of UPMC Children's Hospital of Pittsburgh.

Mr. Sevco has served as interim president of UPMC Children's Hospital since January 2019. Previously, he was the chief operating officer of UPMC Pinnacle, a multihospital system in central Pennsylvania. In this role, he oversaw hospital operations for eight hospitals over a 10-county region.

"At UPMC, we are committed to providing outstanding care every day to everyone who enters our doors, and UPMC Children's Hospital is a stellar example of that," says Leslie Davis, senior vice president, UPMC, and executive vice president and chief operating officer, UPMC Health Services Division. "Mark's extensive experience with UPMC has paved the way for him to lead this world-class hospital and continue to support our extraordinary efforts to provide outstanding care for children and adolescents."

Mr. Sevco has served UPMC in various capacities for more than 25 years. Prior to his role at UPMC Pinnacle, he was president of UPMC East and UPMC McKeesport, responsible for business development, strategic planning, physician relations, and administrative operations.

"It's a privilege to now lead one of the nation's finest children's hospitals and work with so many talented clinicians and staff who passionately strive every day to provide the best patient experience for every child and family," says Mr. Sevco. •

Hospital Foundation Receives \$500,000 Gift

Grant Supports Development of Mobile App for Pediatric Mental Wellness

Children's Hospital of Pittsburgh Foundation has received a \$500,000 gift from YourMomCares to adapt and implement a mental wellness mobile app for children and adolescents.

A digital platform built by the UPMC Health Plan for the behavioral needs of adults will be used as a starting point for this initiative. With the help of this funding from YourMomCares, a digital product will be adapted and implemented for youth in a project involving UPMC Children's Hospital of Pittsburgh and UPMC Western Psychiatric Hospital. The app integrates digital behavioral health therapy with trained mental wellness coaches to provide personalized support for adolescents and young adults with behavioral health needs identified by their pediatrician.

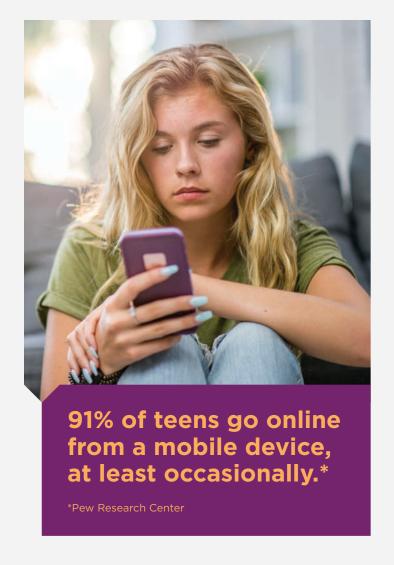
"Anxiety disorders are on the rise in this population, and **early intervention** with digital tools that are **easily accessible** and **evidence-based** are critical in helping more children and adolescents."

 Ken Nash, MD, chief of clinical services, UPMC Western Psychiatric Hospital, and vice chair for clinical affairs, Department of Psychiatry, University of Pittsburgh School of Medicine

The app is structured to be interactive, with coaches helping to motivate youth to learn and practice new coping skills that will be available right on their smartphones, and its use will be directly monitored by medical professionals. The app content, gamification, and coaching style will be adjusted to match the developmental level across kids through young adults.

"Teens and young adults use their mobile phones every day, so our goal is to capture their behavioral health needs by integrating our research into a technological solution that will appeal to this age group, which can lead to individualized clinical therapies in a timely fashion," says Eva Szigethy, MD, PhD, child and adolescent psychiatrist, UPMC Children's Hospital, and professor of psychiatry and medicine, University of Pittsburgh School of Medicine. "We hope that with this app we can help target problems most affecting the individual's life and ultimately help children and teens get the support and answers they need."

"We are proud to support the groundbreaking mental health work done at UPMC Children's and UPMC Western Psychiatric



Hospital," says Sharon Feldstein and Patsy Noah, co-founders, YourMomCares. "We are passionate about ensuring that no child suffers alone, so the development of this new tool will help youth and young adults in this pilot program, and ultimately can soon impact millions of kids nationwide."

"Our goal at YourMomCares is to expand the field of mental health and change the dialogue from mental illness to mental wellness," add Feldstein and Noah. "With this app, we will do just that. We are bringing an interactive tool that will offer the support and guidance needed for so many of these kids and teens who are fighting a mental illness."

The gift will help to pilot this new approach with 500 patients starting at ages 16 to 26 and is projected to be available by the 2019 school year, with results made available in 2020. •

Celebrating 10 Years in Lawrenceville

This year, UPMC Children's Hospital of Pittsburgh celebrates 10 years of delivering world-class pediatric care at its Lawrenceville complex, built from the ground up in 2009 with a \$665 million initial investment from UPMC. UPMC Children's staff, volunteers, patients, families, elected officials, and even Smiley, the life-size Eat'n Park Smiley Cookie, gathered in the Eat'n Park Atrium on May 2, 2019, to mark the hospital's move from Oakland to the Lawrenceville campus exactly 10 years earlier, on May 2, 2009. With additional capital expenditures of \$150 million from UPMC, the decade since the move has been a time of impressive change and growth for UPMC Children's.









UPMC CHILDREN'S — THEN AND NOW

Visits, Admissions, and Volume	2009	2019	% Increase
NICU Admissions	578	1,007	74.2%
Total Admissions and Observations	18,030	21,839	21.1%
ED Visits	64,752	80,219	23.9%
Express Care Visits	0	81,160	(New Service)
Total ED and Express Care Visits	64,752	161,379	149.2%
Total Outpatient Visits	927,733	1,413,766	52.4%
Total Surgical Volume	20,759	23,535	13.4%





Healthy Growth With a Spring Assist



At 10 months old, Fulton
Kramer is a beautiful
baby, grabbing his
chubby little toes and
giggling at his mother
while his watchful
2-year-old sister hovers
nearby. It's difficult to
notice the scar under
his sandy-blond hair
flanked by four tiny
bumps on his scalp —
the fading reminders of
a remarkable surgery
performed by specialists
at UPMC Children's
Hospital of Pittsburgh.

The hospital began offering spring-assisted cranioplasty surgery in 2014, when pediatric plastic surgeon Jesse Goldstein, MD, FAAP, FACS, joined the staff at UPMC Children's Cleft-Craniofacial Center. Since then, he's completed close to 40 of the surgeries in lieu of traditional — and more invasive — cranial vault surgery.

Humans are born with five major bones in the skull that allow the brain to expand quickly during the first several years of life. The bones are separated by six seams, or sutures, which is where most skull growth occurs. Sometimes these sutures fuse together too early, stopping those bones from growing apart and causing the brain to press the skull out into an awkward shape. If left untreated, it can cause pressure on the brain and lead to developmental delays, chronic headaches, and blindness.

"Craniosynostosis is the most common condition you've never heard of," says Dr. Goldstein. "It occurs in about one in 2,000 births." It can also occur after birth.

Fulton was born on Sept. 17, 2018, with a fused sagittal suture — the most common skull abnormality, representing about half of all craniosynostosis patients, Dr. Goldstein says.

It's characterized by a long, skinny head shape with a rounded, protruding forehead and narrow back and side of the head. Severe forms of craniosynostosis can be detected prenatally, but the condition usually is not detected until birth, because the changes can be subtle at first.

Fulton's pediatrician was the first to notice the unusual shape of Fulton's head when he was born, even though it was barely detectible to his parents, Nadia and Daniel Kramer of Steubenville, Ohio.

"The pediatrician came to see us in the hospital when Fulton was born. She noticed an irregularity with his skull and told us to keep an eye on it," says Mrs. Kramer. At Fulton's 2-month check-up, the pediatrician referred the family to the Cleft-Craniofacial Center at UPMC Children's, where doctors determined that he was a candidate for spring-assisted cranioplasty.

"We were in shock. We had never heard of this condition," she adds. Although any type of surgery — particularly surgery near the brain — can be scary for parents, spring-assisted cranioplasty is a much less invasive alternative to traditional surgery on the cranial vault to correct craniosynostosis. "Spring-assisted cranioplasty is a phenomenal leap forward in the quality of care we can provide, allowing us to offer better treatment with less risk and discomfort, which resonates with everything we try to do here at UPMC Children's," says Dr. Goldstein.

"Our craniofacial team at UPMC Children's Hospital has routinely treated patients with craniosynostosis for decades. However, Dr. Goldstein has helped bring us 'into the future' with these advanced, cutting-edge technologies, used to help treat these complicated problems. In addition, he is leading the way with innovations and applied research from the computer laboratory to the patient," says Joseph Losee, MD, chief, Division of Pediatric Plastic Surgery, and director, Cleft-Craniofacial Center, who also serves as vice president of education for the American Society of Plastic Surgeons.

The best time to perform spring-assisted cranioplasty is between 3 and 6 months of age, preferably around 4 months old. Fulton's first surgery was scheduled for Jan. 17, 2019.

"When Dr. Goldstein laid out the timeline, I was overwhelmed at the thought of my baby going in for surgery and how quickly it had to be done. But the more I heard about the spring-assisted cranioplasty, I was relieved there was an option other than the more invasive surgery," Mrs. Kramer says.

Less invasive, immediate results

Spring-assisted cranioplasty requires the collaborative skill of a pediatric neurosurgeon and pediatric plastic surgeon. During Fulton's 90-minute surgery, lan Pollack, MD, chief, Pediatric Neurosurgery, used an incision made in the scalp directly above the sagittal suture to remove a thin strip of the fused bone about the width of an adult finger. Dr. Goldstein then placed two parallel springs into the newly opened suture and secured them in place. It required one overnight stay at the hospital for recovery.

The miniature springs slowly push the narrowed skull bones apart over the next four to eight weeks. But the results are immediately visible.

by the Numbers

More than **60 years** in Pittsburgh



At UPMC Children's Hospital of Pittsburgh since 2003

3,000 patients annually







Actively following **5,800** patients



2 convenient locations:

- UPMC Children's, Lawrenceville
- Children's South, Bridgeville



Specialists from 13 clinical areas:

- Audiology
- Dentistry
- Genetic Counseling
- Neurosurgery
- Ophthalmology
- Oral and Maxillofacial Surgery
- Orthodontics
- Otolaryngology
- Pediatrics
- Plastic Surgery
- Psychology
- Social Work
- Speech Pathology

"When we put the springs in, you can see them starting to work, right there on the operating table," Dr. Goldstein says.

That first post-op glimpse of their baby reassured Fulton's parents that they made the right choice authorizing the surgery. "We were very relieved. He actually came out of surgery and hadn't started swelling yet, so we could already see his forehead going back into place," says Mr. Kramer.

Fulton's springs were removed in a second, 30-minute surgery on May 13. Since the removal surgery is less complex, it can usually be done as an outpatient procedure, and the patient can go home the same day.

"The alternative treatment is cranial vault remodeling, which is a more complex surgery that requires a blood transfusion, a five-day stay in the hospital including the

Center Offers Informed, Compassionate Care



Matthew Ford, MS, CCC-SLP, strides through clinic day at the Cleft-Craniofacial Center, doling out teddy bears and princess wands to patients and words of understanding to parents with equal skill.

Mr. Ford, clinical coordinator and a speech-language pathologist, understands because he has *been there*. His career is inspired by his own childhood experience, undergoing 10 surgeries to repair a cleft lip. His daughter was born with a cleft palate.

He has helped patients and their families at the Cleft-Craniofacial Center since 1997, when it was part of the University of Pittsburgh School of Dental Medicine. When one of the nation's oldest cleft-craniofacial specialty care centers, with roots in the 1950s, moved to UPMC Children's Hospital of Pittsburgh in 2003, he moved too.

"I think it helps some of the patients to know that I've had surgery and I've faced the same issues. I can provide insight into what it's like to go through the process. I think that's a comfort for the family," says Mr. Ford.

Informed, compassionate care is a hallmark of UPMC Children's Hospital. Mr. Ford is one of many specialists who care for the myriad issues children with cleft and craniofacial malformations may have, including difficulty with eating, hearing, vision, appearance, and psychosocial development.

"Cleft and craniofacial disorders are exceptionally common," says pediatric plastic surgeon Jesse Goldstein, MD. "More than one in 10 kids have some kind of issue, ranging from benign and insignificant to substantial and life-altering."

The team cares for children with a wide variety of craniofacial conditions, including:

- Abnormally shaped skulls
- Cleft lips and palates
- Conditions affecting the growth of the face
- Congenital birthmarks
- Craniofacial clefts
- Craniofacial tumors
- Malformed ears

For more information or to refer a patient, call 412-692-8650 or visit www.chp.edu/craniofacial. •

Intensive Care Unit, and lots of anxiety and pain and hardship for the family," says Dr. Goldstein. An incision is made across the head from ear to ear, and bones are removed and put back in new positions. "Although patients do great with this open procedure, the ability to achieve comparable results with a much smaller operation is what draws patients to springs," he adds.

Planning for a full future

Fulton's follow-up care at the Cleft-Craniofacial Center includes regular visits with Drs. Goldstein and Pollack, as well as a pediatric ophthalmologist and psychologist through age 12 when the head is finished growing. "The clinic team is awesome. They coordinate it so that we have all the appointments on the same day. It makes a huge difference, especially since home is more than an hour's drive from UPMC Children's," says Mrs. Kramer.



"Spring-assisted cranioplasty is a phenomenal leap forward in the quality of care we can provide, allowing us to offer better treatment with less risk and discomfort ..."

— Jesse Goldstein, MD, FAAP, FACS

Fulton may not be thinking beyond his favorite toy and his big sister, Sophia, but the adults are pleased with the outlook for his future.

"He did wonderful with the surgery. He had a little bit of discomfort after surgery, which is normal. Now his head shape is normal, and he's flourishing," says Dr. Goldstein. "My expectation is that he's going to grow up not having this as an issue that he thinks about. He'll have a scar on his head, but if his parents don't tell him, he probably will never know until he sees the scar."

Fulton's father, a former rugby coach, is already planning a lifetime full of sports for his son. "He's doing great. He's just a normal baby, starting to talk and trying to stand up. His head looks great. He could play rugby and football when he grows up. There's no limitations," says Mr. Kramer. "The doctors are continuing to monitor his brain function and make sure there is no pressure in his head. As long as all that stays normal, he'll be fine."



ANDY'S INSIGHTS

Physician Liaisons: A New Approach to Better Serve You

As physicians, we often talk about patient communication as a tenet of great health care. But effective communication between UPMC Children's Hospital of Pittsburgh and you — our referring pediatricians — is also vital to great health care.

Last year, we took a hard look at your ability to connect to the people and programs at UPMC Children's Hospital that are key to the care you provide your patients. This prompted us to significantly restructure our physician liaison program to improve both our communication and collaboration with you.

More direct access

Our seven new physician liaisons are senior administrators in pediatric, surgical, and ambulatory services. By virtue of their positions, they have the authority and resources to quickly resolve your concerns, implement your feedback, and link you to our specialists. This structure will connect you directly to hospital leadership to receive the support you need.

A hospital-wide commitment

Recognizing the importance of this program, our executive team is taking a hands-on role. They provide the vision and strategic direction of the program, and meet with our physician liaisons monthly to review progress and address concerns.

Dawn Edwards, our director of population health and the Pennsylvania Pediatric Health Network, will lead strategy and implementation of the enhanced program. I will continue to serve as the executive sponsor to oversee its development and growth.

More layers of support

Through personal office visits, written correspondence, and telephone calls, our physician liaisons will be your link to "everything UPMC Children's." As another result of our restructuring, you can also expect these benefits to enhance our communication:

- > Special events for referring physicians at our main hospital campus and convenient regional locations
- Practice visits from your physician liaison, including other hospital and physician leaders as needed
- Opportunities for your practice to participate in new hospital pathways
- > Monthly emails with strategic, provider, and program updates
- > Updated materials designed to make working and interacting with us on a daily basis easier and more efficient

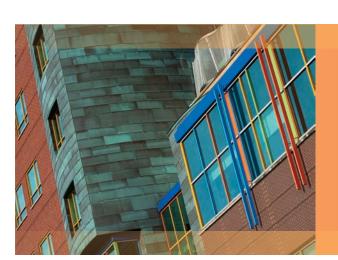
It's my hope that through this renewed partnership, we'll more fully understand and meet your clinical needs. Ultimately, this relationship will enable us both to better serve your patients and their families.

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



Learn More

You can learn more about Physician Liaisons at www.chp.edu/mdrelations or contact Dawn Edwards at EdwardsDL3@upmc.edu or 412-692-6813.



Visit Navigation 7

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

Laurels

These UPMC Children's Hospital of Pittsburgh staff members recently received recognition in their fields.



Diego Chaves-Gnecco, MD, MPH, Division of General Academic Pediatrics, was named Pediatrician of the Year by the American Academy of Pediatrics Pennsylvania Chapter. His clinical and academic interests include the diagnosis and treatment of

children with autism and attention deficit hyperactivity disorder, providing care to families and children with disabilities, providing care to children from minority and underserved populations, and addressing barriers to health care access. He is the founder of Salud Para Niños (Health for the Children) at UPMC Children's, providing culturally and linguistically competent primary care for children and families complemented with activities oriented toward prevention and community health empowerment.



Benjamin Miller, MD, was recently named chief of the Paul C. Gaffney Division of Pediatric Hospital Medicine, a role which he has filled on an interim basis since 2017. He earned his medical degree at the University

of Pittsburgh School of Medicine, where he is currently an associate professor of Pediatrics. He served as chief resident at UPMC Children's Hospital from 2007-2008. He completed his undergraduate work at Yale University in New Haven, Connecticut, and the Pennsylvania State University. Dr. Miller is a member of the American Academy of Pediatrics, Alpha Omega Alpha Honor Medical Society, and Association of Pediatric Program Directors (APPD), where he is co-chair of the APPD Associate Program Directors' Special Interest Group.



Erin Keim, OD, has joined the Division of Pediatric Ophthalmology, Strabismus, and Adult Motility. She is a graduate of Elon University in Elon, North Carolina, and earned her doctorate of optometry at Southern College of Optometry in Memphis. She is a member

of numerous professional organizations, including the American Optometric Association and American Academy of Optometry.



Hannah Scanga, MS, LCGC, Division of Pediatric Ophthalmology, Strabismus, and Adult Motility, received the Code Talker award from the National Society of Genetic Counselors. Nominations for the award came from patients who shared stories of both

the clinical and personal impact a genetic counselor had on their lives and the lives of their families. She was nominated by the father of a young boy with a rare genetic disorder that severely limited his vision in both eyes. A specialist in the field of ocular genetics, she guided the family through genetic testing that provided a diagnosis and a gateway to follow-up care that restored the child's vision and allowed him to resume the normal activities of childhood.



James Squires, MD, MS, Division of Pediatric Gastroenterology, Hepatology, and Nutrition, has received the 2019 Autoimmune Liver Diseases Pilot Research Award from the American Association for the Study of Liver Diseases Foundation. He

will utilize the tested model of a learning healthcare system to decrease variability and improve care for children with autoimmune liver diseases. Dr. Squires will work to develop a collaborative partnership with the most mature of these systems, the inflammatory bowel disease-focused ImproveCareNow.



Tune in, Learn, & Earn

Podcasts

Listen in as UPMC Children's Hospital of Pittsburgh experts explore new frontiers of pediatric and adolescent medicine on "That's Pediatrics," our new podcast series.





You can also find "That's Pediatrics" on YouTube and Libsyn.

Webinars

Earn CME or CEU credits when you participate in free "Pediatric INSIGHTS" webinars featuring UPMC Children's specialists, noon to 1 p.m. the third Wednesday of each month. Visit www.chp.edu/webinars.

Pediatric Telegenetics in Johnstown and Erie

New Grant-Funded Equipment Enhances Weekly Telemedicine Clinics

With a background in public health, Audrey Woerner, MD, MPH, is a passionate advocate for the medically underserved — especially those in rural communities. It was a logical next step for Dr. Woerner, a geneticist with the Division of Medical Genetics at UPMC Children's Hospital of Pittsburgh, to use telemedicine to help address the need for community-based care for children with known or suspected genetic disorders.

UPMC Children's is one of only three hospital systems statewide offering pediatric genetics. "For parents in western Pennsylvania who live a significant distance from Pittsburgh, scheduling regular genetic care presents major challenges," says Dr. Woerner. "Making long trips to our Lawrenceville hospital can be hard on children with disabilities, and a time and financial burden on parents."

Last year, Dr. Woerner started UPMC Children's first pediatric telegenetics service in Erie. Based on regional needs, a similar service was launched this summer in Johnstown. In addition to an online, face-to-face examination by Dr. Woerner, each appointment includes an online meeting with a genetic counselor.



ABOVE: Audrey Woerner, MD, MPH, conducts a patient visit using telemedicine.

"The program has been very well received by families," she says. "I recently spoke with a parent who would need to travel six hours roundtrip to come to our Lawrenceville campus. Telemedicine cut that time in half for the family."

Featuring weekly clinics, both the Johnstown and Erie programs use new, state-of-the-art exam cameras and electronic stethoscopes, made possible through a recent grant from the New York/Mid-Atlantic Regional Genetics Network. Funded by the Health Resources and Services Administration (HRSA), the grant promotes expanded use of telegenetics in rural areas of the state.

Partnering with pediatricians

"Our telegenetics clinics are intended to collaborate with pediatricians to support their care for children with genetic challenges," notes Dr. Woerner. "Most patients are referred to us directly by the child's pediatrician or pediatric specialist."

To participate in the telegenetics program, each patient must initially be seen by Dr. Woerner at the General Genetics Clinic at UPMC Children's main campus for an evaluation and possible testing. Subsequent visits can be conducted via telemedicine as appropriate. •

Who We Serve

We treat and manage care for children with one or more diagnosed birth defects, a potential genetic condition, or a family history that may pose health risks. These may include:

- Autism diagnosis
- Chromosomal abnormalities
- Cleft lip
- Cleft palate
- · Club foot
- Development delay
- Hearing loss
- Heart defects
- · Short stature

Additional services

- Counseling
- Education
- Laboratory tests

Locations

Children's Specialty Care Center Erie Magee-Womens, UPMC Hamot 118 East 2nd St., First Floor, W1150 Erie, PA 16507

Children's Specialty Care Center Johnstown

863 Eisenhower Blvd. Johnstown, PA 15904

To make a referral

Contact the Division of Medical Genetics at **412-692-5070** to refer a patient to Dr. Woerner.



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