Special Page 4 Feature

**Brain Care Institute**
Boy rebounds from skull-based bone tumor

Children’s to Expand
Hospital receives $2.5M state grant

Newborn Testing
Hannah’s Law targets genetic diseases

Andy’s INSIGHTS
Fostering physician communication
The WINTER 2015 issue of Pediatric INSIGHTS

In this issue of Pediatric INSIGHTS, discover how physicians at Children’s Hospital of Pittsburgh of UPMC’s Brain Care Institute use novel neurosurgical methods and a collaborative approach to treat rare disorders. Following treatment for a bone tumor at the base of his skull, patient Coy Shue is now a happy, playful 6-year-old.

In addition:

- Children’s Hospital announces a $6 million expansion partially funded by a $2.5 million state Economic Growth Initiative grant. The project will accommodate growth in a variety of service areas, including the Emergency Department, inpatient cardiac unit, blood and marrow transplantation and cellular therapy program, Neonatal Intensive Care Unit, and Telemedicine Center.

- Hear from Christopher Gessner, president of Children’s Hospital. His message is simple: Nothing has changed. Children’s Hospital and all of our physicians are considered “in-network providers” for every health insurance carrier in this region.

- Krabbe disease and five other lysosomal storage disorders will be added to newborn screening in 2015, thanks to Hannah’s Law. The state law is named after a child from Bucks County, Pennsylvania, with Krabbe disease.

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.
Children's Receives $2.5M for Expansion
State grant supports growing health care services

Children’s Hospital of Pittsburgh of UPMC is building an observation unit and expanding beds in other crucial areas thanks in part to an Economic Growth Initiative grant from the state.

On Oct. 22, 2014, then-Governor Tom Corbett (left) visited Children’s Hospital to announce a $2.5 million Economic Growth Initiative grant to assist in needed expansions at Children’s Hospital. Children’s will cover the balance of the project cost, estimated at $6 million. All of the areas targeted for expansion are experiencing significant growth. The Division of Blood and Marrow Transplantation and Cellular Therapies, for example, needs additional isolation rooms for expanded treatment of non-malignant diseases — not just cancers.

Originally, the new Children’s Hospital, open since mid-2009, had 31 beds in its Neonatal Intensive Care Unit, rated a Level IV (highest level) NICU by the American Academy of Pediatrics. Frequently there are more neonates at Children’s than there are beds for, necessitating some neonatal beds in other units. This expansion will eliminate that issue and consolidate the additional neonatal beds on one unit.

“We greatly appreciate the Corbett Administration’s commitment to excellence in pediatric health care,” says Christopher Gessner, president of Children’s Hospital. “This project will help us continue to provide world-class care to some of the region’s most vulnerable patients.”

Expanding at main hospital and elsewhere
While the grant from the Commonwealth will go toward updates to the physical plant at Children’s main campus in the Lawrenceville section of Pittsburgh, the hospital continues its growth in areas farther afield from Pittsburgh. In the past six months, the following facilities have opened:

• Children’s South relocated from Bethel Park to South Fayette
• Children’s Express Care Centers opened at Washington Hospital, West Mifflin, Natrona Heights, and Erie
• Children’s Hospital Specialty Care Center opened in Mt. Morris

And in 2015, Children’s Specialty Care Center in Erie, which moved to a temporary space in 2014, will relocate to its new permanent space currently under construction on the campus of UPMC Hamot Women’s Hospital.

Stay tuned for updates about Children’s Hospital’s continued growth both in and out of Pittsburgh.

Among the ongoing improvements are:

• Creation of a new 10-bed observation unit adjacent to the hospital’s Emergency Department
• Expansion and relocation of the inpatient cardiac unit
• Expansion of the blood and marrow transplantation and cellular therapy program
• Conversion of current acute care beds to 24 Neonatal Intensive Care Unit beds
• Expansion of the Telemedicine Center, which advises physicians abroad in Mexico, Italy, and Colombia
Screening Newborns for Genetic Disorders

New law targets rare neurodegenerative diseases

In October, former Pennsylvania Governor Tom Corbett signed “Hannah’s Law,” which amends the Newborn Child Testing Act of 1965 by adding Krabbe disease and five other lysosomal storage disorders into the state’s newborn screening process. The other disorders covered by Hannah’s Law are Fabry disease, Pompe disease, Gaucher disease, Hurler syndrome, and Niemann-Pick disease.

The law, which becomes effective in 2015, is named for Hannah Ginion of Bucks County, Pennsylvania, who was diagnosed with Krabbe when she was 5 months old.

Sometimes fatal within a few months to a few years, these inherited, neurodegenerative diseases frequently result in blindness, deafness, paralysis, and cognitive decline in a once asymptomatic child.

“Probably the hardest thing as a parent that you can hear is that your child is slowly going to die and that there’s nothing you can do,” says Dr. Maria Escolar, MD, MS, director of the Program for the Study of Neurodevelopment in Rare Disorders, part of the Center for Rare Disease Therapy (CRDT) at Children’s Hospital of Pittsburgh of UPMC. “Especially when treatments are available, but you found out about them too late.”

The CRDT offers help and hope to families with children diagnosed with rare genetic diseases, including those covered by Hannah’s Law, by arranging visits with Medical Genetics and specialists from the appropriate departments, which can also provide access to social workers, psychologists, nutritionists, and other caregivers. The CRDT can help newly diagnosed families connect with one another, too.

“Many challenges exist in implementing the new screening and in treating these disorders,” notes Jerry Vockley, MD, PhD, chair of Medical Genetics at Children’s Hospital and chair of Pennsylvania’s Newborn Screening and Follow-Up Technical Advisory Board. Although a cure for these disorders has yet to be discovered, the CRDT’s experts are leading the way to new treatments and in quickly and accurately assessing a child’s needs and planning the right approach. In the case of lysosomal storage disorders, this often includes enzyme replacement therapy and palliative care when needed. The primary goals of treatment are to improve quality of life for these children and to help them develop to their full potential.

For a consultation or patient referral to the Center for Rare Disease Therapy at Children’s Hospital, please contact Amy Lukanski, MSN, RN, CPN, coordinator, at 412-692-RARE (7273) or RareCare@chp.edu.

Treating Krabbe Disease

“Sometimes doctors get a lab report that says ‘Yes, there is a mutation in the Krabbe genes, but we have never seen this mutation, so we do not know whether the baby has Krabbe,’” says Maria Escolar, MD, MS, director of the Program for the Study of Neurodevelopment in Rare Disorders (NDRD). “That’s when we can help.”

Once a patient with a suspicion of Krabbe arrives at Children’s Hospital, Dr. Escolar and her team conduct further testing — including a special MRI test that was developed by Dr. Escolar and is only available at Children’s Hospital. The MRI test confirms a Krabbe diagnosis and also shows how far the disease has progressed. Although there is no cure for Krabbe, in some cases a child’s condition may be treatable to lessen the long-term detrimental effects of the disease.

At Children’s, neurodevelopmental disability pediatricians and cord blood and bone marrow transplant specialists work closely to quickly evaluate if the child is suitable for an umbilical cord blood transplant. Time is crucial, since Krabbe moves so quickly, and “we are one of the fastest in the country at doing this,” says Dr. Escolar. “We have done so many. About 80 percent of the nation’s Krabbe referrals come here.”

The prognosis of a child with Krabbe is never easy to determine. Krabbe is usually fatal by age 2. Because Dr. Escolar follows approximately 150 children (the oldest is 18), she has been able to compile an enormous neurobehavioral database that allows her to make strong predictions.

For a consultation or patient referral to the NDRD at Children’s Hospital, please call 412-692-9955 or send an email to NDRD@chp.edu.
Suresh Tapped for Chief Medical Information Officer

Srinivasan Suresh, MD, MBA, FAAP, has been named the new chief medical information officer (CMIO) at Children’s Hospital of Pittsburgh of UPMC, where he plans to improve the effectiveness of the hospital’s health informatics program by applying business intelligence tools to collect, analyze, and report quality and safety data in various patient care settings.

Dr. Suresh will continue to make the electronic medical record (EMR) system more user-friendly and improve outcomes for patients by incorporating clinical decision support tools at the point of care in the EMR. This system, which was implemented at Children’s Hospital in 2002, electronically stores each patient’s full medical history and care details, and has significantly reduced potential medical errors and streamlined processes, making Children’s one of the nation’s most technologically advanced children’s hospitals.

Prior to joining Children’s, Dr. Suresh (left) was at Children’s Hospital of Michigan, where he worked for 21 years. During his time there, he served as the CMIO, in addition to being the associate director of the pediatric residency program, the medical director of the Emergency Department, and vice chief of finance and strategy for the pediatric practice plan. He has been a pediatric emergency medicine physician since 1996 and will continue to practice in the Emergency Department at Children’s in addition to his CMIO duties.

“At Children’s, I am looking to use business intelligence tools and advanced data analytics to enhance provider and patient experience at the point of care,” says Dr. Suresh, also medical officer, Quality and Patient Safety at Children’s. “I plan to explore growth opportunities for our telemedicine capabilities regionally and internationally and evaluate additional ways to collaborate with industry and academia.”

“Children’s has been a national leader in safety, quality, and efficiency,” says Steven Docimo, MD, chief medical officer, Children’s. “By recruiting a physician with Dr. Suresh’s experience and abilities, Children’s will be able to advance pediatric health care through enhancements to the hospital’s health informatics program, and safety and quality infrastructure. These enhancements will benefit our families directly every day and, indirectly, the care of children around the world.”

Dr. Suresh obtained his medical degree from the University of Madras in India. He completed his pediatric residency and pediatric emergency medicine fellowship at Children’s Hospital of Michigan and obtained a business degree from the University of Michigan.

Dr. Suresh is a member of numerous professional organizations, including the American Academy of Pediatrics, Academic Pediatric Association, American Medical Informatics Association and Association of Medical Directors of Information Systems.

For more information on Dr. Suresh, visit www.chp.edu.

For 125 years, Children’s Hospital of Pittsburgh of UPMC has provided high-quality health care to all of the region’s infants, children, teenagers, and young adults regardless of their health insurance coverage or ability to pay.

Recently, some families have told us they have received confusing phone calls and letters from insurance companies, including Highmark, implying that they will not be able to bring their children to Children’s to receive health care this year or after they turn 18 years of age.

That is simply not true, and we would like to set the record straight.

• Children’s Hospital and all of our physicians are considered “in-network providers” for every health insurance carrier that operates in this region, including Highmark.

• Our agreements with the health insurance carriers cover all of our services from primary care visits (including Children’s Community Pediatrics) to hospitalization, and everything in between.

• We continue to provide care for many of our patients well into their 20s.

For more information, please go to www.chp.edu/NothingHasChanged.
Instead, the Shues enrolled Coy in a transitional kindergarten class. A few weeks into the school year, Coy’s teacher told his parents she was concerned about the boy’s speech development. The Shues’ pediatrician referred them to an ear, nose, and throat (ENT) specialist, who recommended an adenoidectomy for Coy.

The adenoidectomy, performed a couple of weeks before Thanksgiving, revealed a cyst that the ENT specialist biopsied. “It came back with a diagnosis of chordoma,” says Jenni.

**Slow-growing tumor**
A chordoma is a slow-growing bone tumor that can form anywhere along the spine. Coy’s was at the base of his skull. Chordomas are so rare that only about 300 are diagnosed each year in the United States, most of them in adults.
For the Shues, who live outside Charlotte, North Carolina, the next two months were a blur as they sought advice on the best treatment options for Coy. They got in touch with the Chordoma Foundation, a support and advocacy organization for chordoma patients. In late January, they received a phone call from a contact there. “She recommended that we go to Children’s Hospital of Pittsburgh of UPMC,” says Jenni.

‘One-stop shop’ for brain care
The Brain Care Institute (BCI) at Children’s Hospital brings together specialists from subspecialties ranging from behavioral health to neurosurgery, who are dedicated to developing and applying innovative treatments for infants, children, and adolescents with conditions affecting the brain, spinal cord, muscles, and nerves. Every year the BCI sees nearly 21,000 patients, who come to Children’s not only from across the country, but also from around the world.

‘We are unique in our ability to apply this approach in children as young as 2.’

Elizabeth Tyler-Kabara, MD, PhD, Division of Pediatric Neurosurgery and associate professor of Neurological Surgery at the University of Pittsburgh School of Medicine

Think of it as a “one-stop shop” for children with brain disorders, says Elizabeth Tyler-Kabara, MD, PhD, Division of Pediatric Neurosurgery and associate professor of Neurological Surgery at the University of Pittsburgh School of Medicine. “The Brain Care Institute provides comprehensive care by uniting all of the disciplines that treat children with neurological disorders, whether it’s trauma, a brain tumor, or a metabolic disease,” she explains.

Minimally invasive approach
Dr. Tyler-Kabara and her colleagues, UPMC neurosurgeons Paul Gardner, MD, and Carl Snyderman, MD, have pioneered the pediatric application of the endoscopic endonasal approach (EEA), a novel minimally invasive type of brain surgery that UPMC surgeons originally developed for adults.

“The EEA is a way of reaching tumors of the skull base using the natural pathway through the nose and sinuses,” says Dr. Tyler-Kabara. “We are unique in our ability to apply this approach in children as young as 2.”

Benefits of EEA surgery include a shorter time under anesthesia, a reduced risk of injury to critical nerves and blood vessels in the brain, a faster recovery time, and an improved cosmetic outcome with minimal external scarring.

An extensive tumor
The Shues arrived in Pittsburgh two days after Easter, having already spoken with Dr. Tyler-Kabara at length by phone. “She had answers to all of the questions I hadn’t been able to get answered elsewhere,” says Jenni.

Dr. Tyler-Kabara says her approach is to have a dialogue with the family. “I try to enlist them as allies in the process and make sure they understand what the expectations are and where the twists and turns can be.”

Coy’s magnetic resonance imaging (MRI) scan had clearly shown “a very, very extensive tumor,” she says. “It appeared to go through the dura into the anatomic space that contains the cerebrospinal fluid (CSF).”

The goal of surgery was to remove as much of the tumor as possible. “We believed we could get most of it out using a minimally invasive approach,” says Dr. Tyler-Kabara. “But we knew we would have to consider doing open surgery if there were areas of tumor that extended out laterally. We went through all of these possibilities with the family.”

Above: “By the time he left, he was well enough to start getting into mischief, which is perfectly age-appropriate for a young boy, so that’s success from our standpoint,” says Amit Sinha, MD, assistant medical director, Children’s Hospital Rehabilitation Unit.

Continued on page 6
Two-stage procedure
The surgical team prepared to perform a two-stage operation. Part one, on Friday, April 25, took eight hours; part two, the following Monday, took six hours.

Coy’s tumor was “about the size of a walnut, but it had fingers that traveled both side-to-side and down between the C1 and C2 vertebrae,” recalls Dr. Tyler-Kabara. “Removing these meant excising a sizable amount of dura.”

The surgical team used fat from Coy’s abdomen to fill the gap in the dura. They successfully performed the entire procedure using the EEA approach, avoiding the need for open surgery or cervical spinal fusion.

Because of the size of the wound in his dura, the biggest postoperative risk Coy faced was a CSF leak. And when the team took him back to the operating room to remove his surgical packing, they found that his wound was indeed leaking CSF.

“We had to do an ear-to-ear incision to make a flap big enough to cover the wound,” says Dr. Tyler-Kabara. “So Coy has a scar on the back of his head, behind his ears. But once his hair grows out it will be barely visible.”

‘The greatest gift’
Five weeks after his surgery, Coy was well enough to be transferred to the Children’s Hospital Rehabilitation Unit. He did so well there that he was discharged after a week, and the family drove home to Charlotte to be reunited with Coy’s older brother, Mason, who was being cared for by his grandmother.

Postsurgical proton-beam radiation therapy (PBRT) to the tumor bed is often recommended for patients like Coy with large pediatric chordomas. PBRT is a highly specialized type of radiation therapy that is offered at a limited number of centers around the country. In mid-August the Shues traveled to Boston, where Coy received eight weeks of PBRT.

“The team in Boston has many years’ experience treating pediatric chordomas with PBRT, and we have excellent rapport with them,” says Dr. Tyler-Kabara. “We refer most of our chordoma patients there when PBRT is indicated.”

Coy “has got about as good a prognosis as we can hope for at this point,” she adds. He will need to have follow-up MRI scans twice a year for at least 10 years to check for tumor recurrence.

For now, Coy, who turned 6 in August, is doing well and is enrolled in kindergarten, reports Jenni. “His appetite is back and he has tons of energy,” she says. “We will always be grateful to Dr. Tyler-Kabara and all of the staff at Children’s. They have given us the greatest gift we could ever receive — our son’s life.”

For more information about the Brain Care Institute at Children’s Hospital, please call 412-692-6921 or visit us online at www.chp.edu/bci.

Rehabilitation Unit Helps Kids Bounce Back
After five weeks in the hospital, Coy was recovering from his multiple surgeries but was “exceedingly debilitated,” says Dr. Tyler-Kabara. “He was ready for rehabilitation, but we weren’t ready to let him go home to North Carolina. We wanted to continue to monitor him.”

In early June, Coy was transferred to the Children’s Hospital Rehabilitation Unit (CHRU) for comprehensive rehabilitation that focuses on improving function so that children can go home as healthy and capable as possible.

Opened in November 2013 through a lease agreement with The Children’s Home of Pittsburgh & Lemieux Family Center, the CHRU is an off-site, eight-bed inpatient unit that offers comprehensive rehabilitation care for children recovering from brain or spinal cord injury, severe trauma, and other medically or surgically complex conditions.

“Our goal is to help kids bounce back from significant functional deficits,” says Amit Sinha, MD, assistant CHRU medical director, who was Coy’s attending physician during his stay in the unit.

In addition to physicians and nurses, the multidisciplinary CHRU staff includes audiologists, speech-language pathologists, child life specialists, behavioral and neuropsychologists, occupational and physical therapists, respiratory therapists, and social workers.

Patients receive intensive therapy with the goal of preparing both them and their families for a safe return to home and school, says Dr. Sinha.

Although Coy could barely walk when he arrived at CHRU, he made such rapid progress that he was discharged a week ahead of schedule.

“By the time he left, we were confident that he was healing well and that his cerebrospinal fluid leak would not recur,” says Dr. Tyler-Kabara.

For more information about Children’s Hospital’s Rehabilitation Institute, please call at 412-692-9800.
Fostering physician communication to support continuity of care

At Children’s Hospital of Pittsburgh of UPMC, we’re constantly challenged to improve how we communicate with referring physicians to build stronger relationships that support continuity of care and improved outcomes for patients with complex conditions.

To foster physician-to-physician communications, we offer a variety of channels, ranging from electronic communications designed to streamline the process, to direct personal contact that builds confidence and trust. These channels consist of the following activities:

- **Pediatric INSIGHTS** is a quarterly magazine designed to inform physicians about new programs and services offered at Children’s, to discuss trends in health care, and to recognize the achievements of our faculty.

- **Physicians’ Flash** is an electronic newsletter that’s emailed monthly, but we’re considering a weekly format. It offers the latest information about clinical activities that impact patient care.

- **Physician websites** have been developed to access key information any time of the day or night. Forms, such as the Outpatient Easy Referral, are available online at [chp.edu/physicians](http://chp.edu/physicians). Free online CME courses are available at [UPMCPHysicianResources.com/Pediatrics](http://UPMCPHysicianResources.com/Pediatrics).

- **Physician liaisons** offer direct, personal contact with Children’s Hospital. Our liaisons, Judi Feinberg and Monica Reisz, are available to meet with you and your staff on a regular basis to discuss new services or challenges that you may be experiencing with Children’s.

- **Announcement cards** are designed to inform you of new additions to our medical staff, so you know who they are and what services they provide.

- **A Directory of Services** offers a comprehensive guide to all divisions, faculty, and phone numbers. It’s offered online as well as in print and is one of the best tools for contacting Children’s Hospital. Access the directory online at [chp.edu/directory](http://chp.edu/directory).

- **Our Visit Navigation Service** offers direct scheduling support for patients with three or more appointments in a month.

Periodically, we’ll also correspond by traditional mail, such as our recent “Nothing Has Changed” letter (see story on page 3), to communicate messages that are highly important.

We’re also working to improve how we communicate about patient care. Our automated admission notification is sent by fax or email to referring physicians on a daily basis. Additionally, we send approximately 9,000 messages a month by fax, email, and through Clinical Connect Health Information Exchange to update referring physicians about inpatients and outpatients in the care of specialists at Children’s. If you’re interested in learning more about any of these services, please contact our physician liaisons.

Please know that we’re working every day to keep you informed when you send your patients to us.

**Andy Urbach, MD, associate chief medical officer at Children’s Hospital, welcomes your comments and questions.** Please send an email to chpphysicianliaisons@chp.edu.
These Children’s Hospital staff members recently received the following recognition in their fields.

**Children’s Hospital of Pittsburgh of UPMC** recently received the Silver Award for “Creating a Culture of Excellence in Central Line Care” as part of the 2014 Fine Awards for Teamwork Excellence in Health Care. The Children’s Hospital team partnered with 16 other NICUs across the country to develop a quality improvement collaborative aimed at decreasing central-line associated blood stream infections (CLABSI). Best practices were developed — including hand hygiene, central line insertion, central line care and maintenance, and more — and they implemented a “full immersion” approach to staff, patient, and family education. As a result of this initiative, CLABSI in the NICU have been significantly decreased (about 0.5 per 1,000 line days) for almost three consecutive years. Children’s has also rolled the program out to the cardiac ICU and pediatric ICU, both of which have also been able to decrease and sustain low levels of CLABSI. The Fine Awards are given annually by The Jewish Healthcare Foundation in partnership with The Fine Foundation.

**Brian Feingold, MD, MS**, medical director of the Pediatric Heart and Heart-Lung Transplant Program at Children’s and associate professor of Pediatrics at the University of Pittsburgh School of Medicine, presented a study at the American Heart Association’s 2014 Scientific Sessions revealing that children who receive a heart transplant as soon as a suitable donor is available are predicted to have better quality-adjusted survival — even if they have antibodies that may attack the new heart — than children who wait for a donor to which they do not have antibodies.

**Jacqueline Kreutzer, MD, FACC, FScai**, director of the Cardiac Catheterization Lab at Children’s and Professor of Pediatrics at the University of Pittsburgh School of Medicine, recently published “One-Year Follow-Up of the Melody Transcatheter Pulmonary Valve Multicenter Post-Approval Study” in the *JACC Journals*.

**Linda M. McAllister-Lucas, MD, PhD**, is the recipient of the 2015 Norman J. Siegel New Member Outstanding Science Award from the American Pediatric Society (APS). This award is bestowed on a newly elected APS Member to acknowledge outstanding contributions to science. Dr. McAllister-Lucas, who is chief of the Division of Pediatric Hematology/Oncology, will give a presentation at the APS Plenary Session in spring 2015. She is the director of the Mario Lemieux Lymphoma Center for Children and Young Adults at Children’s Hospital, which was established in mid-2014 with a $2.5 million gift from the Mario Lemieux Foundation.

**Michael Moritz, MD**, clinical director of the Division of Pediatric Nephrology and medical director of Pediatric Dialysis at Children’s and professor of Pediatrics at the University of Pittsburgh School of Medicine, recently published “Treatment of Hyponatremic Encephalopathy With a 3% Sodium Chloride Protocol: A Case Series” in the *American Journal of Kidney Disease*. Dr. Moritz and colleagues are the first to demonstrate that uniform protocol with hypertonic saline can be used safely and effectively to treat hyponatremic encephalopathy, a medical emergency that can result in brain stem herniation and death if untreated.

**Agnes Swiatecka-Urban, MD**, Division of Pediatric Nephrology at Children’s and assistant professor of Cell Biology and Physiology at the University of Pittsburgh School of Medicine, recently published “The Cell-Based L-Glutathione Protection Assays to Study Endocytosis and Recycling of Plasma Membrane Proteins” in the *Journal of Visualized Experiments (JoVE)*.

**Selma Witchel, MD**, director of the Pediatric Endocrinology Fellowship Training Program at Children’s, and associate professor of Pediatrics at the University of Pittsburgh School of Medicine, was appointed program director of the Androgen Excess-Polycystic Ovary Syndrome Society’s 2015 and 2016 annual meetings. She also served as past president of the international organization, which is dedicated to promoting knowledge and original clinical and basic research in every aspect of androgen excess disorders. The 2015 meeting will take place in Palermo, Italy on Oct. 4-6.
Teenagers Learn Lifelong Diabetes Management

If being a teenager is no picnic, being a teenager with diabetes can be downright challenging.

Teens with diabetes experience significant physical, psychological, and situational demands. They typically seek independence from parents who have been managing their diabetes at the time that hormonal changes result in unstable glucose levels. These upheavals can be compounded by variables such as driving, drinking, sexual issues, and learning to navigate the complicated health care system.

The Diabetes Transition Program at Children’s Hospital of Pittsburgh of UPMC equips teenage patients with confidence, knowledge, and support that can foster successful lifelong disease management. Supported by the David Paul Diabetes Transition Care Research Initiative Fund, the program has four physicians, three nurse practitioners, three diabetes educators, four outside consultants, and a psychologist.

Clinic visits are followed by a one-hour group session facilitated by a diabetes educator and a psychologist. Program leader Ingrid Libman, MD, PhD, of the Division of Pediatric Endocrinology, says “We want to provide information to the teens, and we also want to hear what they want to learn about. This will help us develop tools to effectively transition these children to the adult world.” Plans are under way to run a parallel session for parents to learn about transition from a teenager’s perspective.

In the future, Dr. Libman and Radhika Muzumdar, MD, chief of Pediatric Endocrinology, envision a protocol that involves a colleague from the adult diabetes program meeting with the teen at Children’s Hospital prior to transition to their clinic. “Research will help us understand and address the gaps in the current system of transition. We hope that this clinic will serve as a model for other clinics across the country,” says Dorothy Becker, MBCh, professor of Pediatric Endocrinology.

“In addition to medical management, the impact of diabetes on teen issues such as relationships, recreational drug use, alcohol, driving, etc., will be discussed in a group setting. The young adults will meet the same group of peers every three months and serve as their own support group. This will help transition to independent care and better long-term control,” says Dr. Muzumdar.

To learn more about the Diabetes Transition Program at Children’s Hospital, call 412-692-8724.
Children’s Express Care
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Weekends: Noon – 8 p.m.

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www.chp.edu/express