Special Page 4 Feature

Adolescent and Young Adult Oncology Program
Fighting cancer with individualized care

Traumatic Brain Injury
NIH grant funds search for effective treatments

Introducing myCHP
Online medical information for patients and parents
The FALL 2013 issue of Pediatric INSIGHTS

In this issue of Pediatric INSIGHTS, learn how Children’s Hospital of Pittsburgh of UPMC’s Adolescent and Young Adult Oncology Program provides effective access to cancer care and helps teens and young adults live their lives as close to normal as possible during treatment.

In addition:

• Children’s Hospital has established a dedicated Thyroid Center where physicians and staff from many different specialties come together to diagnose and treat all types of thyroid conditions including cancer, which has risen in recent years.

• In Memoriam: We remember the life and contributions of Holly W. Davis, MD, former co-director of Children’s Child Advocacy Center and medical director of the Emergency Department, who died Sept. 6, 2013.

• UPMC is investing $30 million in pediatric research programs, including the $10 million David H. Perlmutter Research Endowment to allow Children’s to recruit and retain national leaders in pediatric research.

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 3.
Researchers Study Traumatic Brain Injury
NIH GRANT FUNDS SEARCH FOR EFFECTIVE TREATMENTS

Children’s Hospital of Pittsburgh of UPMC and University of Pittsburgh Graduate School of Public Health researchers have been selected by the National Institutes of Health (NIH) to lead a $16.5 million international study to evaluate treatments for pediatric traumatic brain injuries (TBI).

This effort is being led by Michael J. Bell, MD, director, Pediatric Neurocritical Care and Neurotrauma in the Brain Care Institute at Children’s Hospital and Stephen Wisniewski, PhD, senior associate dean and co-director of the Epidemiology Data Center at the University of Pittsburgh Graduate School of Public Health. Dr. Bell will coordinate patient enrollment and clinical activities within the project, and Dr. Wisniewski will coordinate data collection and statistical analysis.

The five-year study aims to provide compelling evidence to change clinical practices and provide recommendations for guidelines that could immediately improve outcomes for injured children.

The researchers plan to enroll 1,000 children up to 18 years old from more than 36 locations in the United States and abroad to compare the effectiveness of immediate treatments of the injury, including strategies to lower intracranial pressure, strategies to treat secondary injuries, and the delivery of nutrients in a study that is called the Approaches and Decisions for Acute Pediatric TBI (ADAPT) Trial.

“Incremental improvement in outcomes of traumatic brain injury could make enormous differences for the health of children, but such advances have remained elusive,” says Dr. Bell, also associate professor, critical care medicine and neurological surgery at the University of Pittsburgh School of Medicine. “No mitigating treatments have been translated into clinical practice, so we hope this study helps us gain a better understanding of contemporary therapies.”

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~ Michael J. Bell, MD

year from severe TBI. Any benefits that can be gained by improving clinical practice can have enormous consequences for children right now, and for clinical trials in the future.”

The study, which is expected to more than double existing evidence-based treatment recommendations for traumatic brain injuries in children, will provide volumes of data for improved TBI research protocols that would limit variability in treatments. Such variability has led to the failure of previous randomized controlled trials. The study also will evaluate the effectiveness of six therapies encompassing three specific aims — intracranial hypertension therapies, secondary insult prevention, and metabolism.

“This novel study, which includes many dedicated international physicians and scientists, has the potential to accelerate our knowledge of how to treat children who sustain severe traumatic brain injuries,” says Ramona Hicks, PhD, a program director at the NIH National Institute of Neurological Disorders and Stroke (NINDS), which is providing the grant support for the study. “NINDS looks forward to rapid results that will inform clinical practice within the next few years.”

Other key investigators on the project include an international group of TBI experts: Patrick M. Kochanek, MD, and Sue Beers, PhD, University of Pittsburgh; P. David Adelson, MD, Barrow’s Neurological Institute Phoenix Children’s Hospital; Jamie Hutchison, MD, The Hospital for Sick Children in Toronto; Robert Tasker, MD, Boston Children’s Hospital; and Monica Vavilala, MD, University of Washington. Statisticians and epidemiologists include Tony Fabio, PhD, MPH, and Sheryl Kelsey, PhD, University of Pittsburgh Graduate School of Public Health; and Joel Greenhouse, PhD, MPH, Carnegie Mellon University. Collaborators from the NIH include Deborah Hirtz, MD, and Ramona Hicks, PhD.
Thyroid problems affect nearly 60 million Americans, including children and teens, and the chance of being diagnosed with thyroid cancer has risen significantly in recent years.

In light of this troubling trend, Children’s Hospital of Pittsburgh of UPMC has established a dedicated Thyroid Center where physicians and staff from many different specialties come together to diagnose and treat all types of thyroid conditions — from nodules and conditions associated with increased and decreased hormone levels, to thyroid cancer.

The center is staffed by experts in pediatric endocrinology, oncology, ophthalmology, otolaryngology, pathology, and radiology, as well as child life specialists.

Keegan Berber, formerly of Ligonier and now living in Virginia, is grateful for that confluence of expertise in one hospital. She was diagnosed in 2011 at age 13 with thyroid cancer after discovering a lump in her throat.

Because the cancer had spread to her lymph nodes by the time it was discovered, Children’s ENT surgeons removed her thyroid and 70 lymph nodes. Fifteen now, Keegan continues to recover from the effects of her surgery but is doing very well.

Like Keegan, patients at Children’s Thyroid Center experience a multidisciplinary, integrated team approach for the evaluation and treatment of thyroid disease and related conditions.

Advanced imaging and molecular diagnostic studies are used to help clinicians develop innovative treatment plans.

A range of specialized services
For patients with any type of thyroid disorder, Children’s Thyroid Center offers a wide range of specialized services:

• State-of-the-art imaging for thyroid disease, including ultrasound and SPECT/CT interpreted by pediatric radiologists with expertise in thyroid disease
• Evaluation of all specimens by pathologists experienced in diagnosing pediatric thyroid disease with the most up-to-date molecular genetic testing, including testing pioneered at UPMC
• Initial and follow-up clinic visits, imaging studies, and treatments based upon a patient’s specific clinical situation with an individualized approach to care developed by a team of experts from Children’s Thyroid Center
• Family centered-care that includes child life specialists

**Thyroid cancer diagnosis and treatment**
For patients diagnosed with thyroid cancer, Children’s Thyroid Center provides expert surgical and diagnostic imaging services.

Highly trained pediatric radiologists perform fine-needle aspiration biopsies of thyroid nodules with a specialized pediatric cytopathologist on-site to optimize diagnostic yield.

Children’s also provides thorough preparation and appropriate treatment with radioactive iodine, based upon the latest recommendations by the American Thyroid Association for hyperthyroidism and thyroid cancer.

Children’s offers post-surgical consultation and counseling with specialized members of the team, including a dedicated pediatric oncologist.

To refer a patient, request a consultation, or schedule an appointment, please call Children’s Thyroid Center at 412-692-7618.
Children’s Hospital of Pittsburgh of UPMC is committed to helping pediatricians and family practitioners meet their goals. Our team of physician liaisons is dedicated exclusively to addressing the needs of family practitioners and community pediatricians.

This December, the Rehabilitation Institute at Children’s Hospital of Pittsburgh of UPMC will open the hospital’s newest inpatient unit — the Children’s Hospital Rehabilitation Unit (CHRU). To accommodate this new unit, Children’s Hospital partnered with The Children’s Home at 5324 Penn Ave., just nine blocks from the hospital, to lease the eight-bed unit. The addition of the CHRU brings Children’s licensed bed count from 296 to 304.

The CHRU is an extension of the care provided at Children’s Hospital and will operate under its policies and procedures. Attending coverage will be provided by board-certified pediatric rehabilitation medicine physicians, and consultation services will be provided as needed by pediatric medical and surgical subspecialists. Intense rehabilitation will be delivered by a multidisciplinary team of pediatric rehabilitation staff. Children’s nurses will provide 24/7 nursing care.

Any patient referred to the program will be screened by the rehabilitation patient liaison to determine whether he or she has the potential to participate in and benefit from comprehensive inpatient rehab. If you think your patient may benefit from comprehensive pediatric rehabilitation, or you need assistance determining the best disposition plan for your patient, email CHPRehabInstitute@upmc.edu.

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New Unit to Provide Inpatient Rehab

COMING SOON:
New Directory of Services and Medical Staff Listing

Look for Children’s Hospital of Pittsburgh of UPMC’s new Directory of Services and Medical Staff Listing, coming in November. The 2013-2015 edition is available in both print and electronic versions. The Web-based interactive PDF is searchable by physician name or department. Access the online version at www.chp.edu/directory.

To receive your copy, please contact Children’s Hospital at 412-692-5016 or send an email to webmaster@chp.edu.
For a year or so, he had an on-again, off-again pain in his right leg. Consultations with several doctors and physical therapists brought no relief. Then a biopsy revealed a tumor in his right hip. The diagnosis was Ewing sarcoma, a rare type of bone cancer that occurs in about three people per million per year in the United States — more than half of them teenagers.

Nearly 70,000 adolescents and young adults between ages 15 and 39 are diagnosed with cancer every year in the United States. As in Alex’s case, it can take weeks or longer for a person in this age group to be diagnosed accurately, says Peter Shaw, MD, medical director of the Adolescent and Young Adult (AYA) Oncology Program at Children’s Hospital of Pittsburgh of UPMC.

“Most physicians don’t think of adolescents and young adults as potentially having cancer, so it’s lower on their differential diagnosis list,” says Dr. Shaw.
Unique needs
The AYA Oncology Program, established in 2006, “addresses the unique medical and psychosocial needs of adolescents and young adults with cancer,” Dr. Shaw adds.

In international studies, adolescents and young adults with certain cancers have higher survival rates when they are treated by pediatric oncologists rather than by medical oncologists who generally treat adults. This is especially true for young people who have cancers that are more common in children and adolescents than in adults, such as Ewing sarcoma and acute lymphoblastic leukemia. In addition, international data from clinical trials shows that adolescents and young adults with leukemia fare better when treated on pediatric protocols.

Simply put, says Dr. Shaw, adolescents and young adults with cancer have better outcomes when they’re not treated like adults.

Rites of passage
Alex’s tumor proved to be localized to the pelvic bone. His life began to revolve around chemotherapy sessions at Children’s Hospital. Chemotherapy given every two weeks for 28 weeks is now the standard of care for patients younger than 50 with localized Ewing sarcoma, explains Dr. Shaw. Clinical trial results published in 2012 showed this more intense regimen was more effective and no more toxic in this patient population than the same regimen administered every three weeks. (See sidebar, Improving Outcomes Through Clinical Trials.)

The spring of senior year is a time for many rites of passage, including graduation and beach week. Alex thought his chemotherapy schedule would keep him from participating in these milestones, but Dr. Shaw and the AYA medical team worked to ensure that didn’t happen.

On graduation day, Alex was in the hospital receiving the third of five days of chemotherapy. “At 4 p.m., they unhooked me, I went home, went to my graduation at 7 p.m., and I did the remaining two days of chemo at home.” Not only did he make it to his graduation, but as senior class president he spoke at the podium to open the ceremony and welcome those attending.

So that Alex could join his classmates in Sandbridge, Va., for beach week, Dr. Shaw arranged for him to receive a scheduled dose of outpatient chemotherapy 30 miles from there at Children’s Hospital of the King’s Daughters in Norfolk.

“Individualizing care is an important aspect of what we do in the AYA Program,” says Dr. Shaw. “We try to maintain patients’ school and social calendars to the extent possible without jeopardizing their medical care. If that means rescheduling chemotherapy by a few days so a patient can go to their graduation or to the prom, it’s not usually a problem.”

In September, following a lengthy international search for bone from a matching donor, Alex had surgery to resect the tumor from his hip, followed by a bone graft. The nature of Ewing sarcoma in the pelvis, explains Dr. Shaw, makes it difficult but not impossible to completely remove a tumor surgically. The next step, if there is any microscopic residual disease, would be for Alex to receive radiation therapy along with chemotherapy — which should be completed in February 2014.

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Further investigation

Adolescents and young adults comprise about 7 percent of all cancer patients in the United States, says Dr. Shaw. Ensuring that each of them gets a prompt diagnosis and a referral to the most appropriate treatment often starts with the patient’s pediatrician or general practitioner, he adds.

“If a patient presents repeatedly with a symptom that isn’t responding to therapy, pain management, or rehabilitation, it bears further investigation,“ he says. “Of course, not every patient with hip pain will have Ewing sarcoma,” but when a persistent symptom can’t be otherwise explained, the possibility of cancer should be considered and follow-up evaluation is warranted. The most appropriate referral for a cancer evaluation in a young adult may be to a pediatric cancer center, says Dr. Shaw.

“In the AYA Program here at Children’s Hospital, we see patients up to age 25 and we offer consultations for patients up to age 50 who have tumors that are more common in the pediatric population and who may be candidates for a clinical trial.” (See sidebar, Improving Outcomes Through Clinical Trials.)

Good prognosis

“I don’t think about the future,” says Alex. His long-term prognosis, however, is good — 70 percent of patients with localized Ewing sarcoma are cured, says Dr. Shaw.

In July, Alex learned the Lola G. Duff and William H. Duff, II Scholarship Fund had awarded him a four-year scholarship. Although he has postponed entering college for a year to complete his chemotherapy, Alex says the scholarship “will open more doors for me — and I have this great essay I can write” for college admission applications.

The AYA Oncology Program staff make Children’s a special place, says Alex. “My nurse practitioner, Aimee [Costello], is awesome,” he says. “All the nurses are so nice. When I told them I was graduating, they made a big congratulations card for me. At other hospitals, the staff don’t do stuff like that for you.”

To learn more about Children’s Hospital’s Adolescent and Young Adult (AYA) Oncology Program, visit www.chp.edu/aya. To make a referral, please contact Peter H. Shaw, MD, at 412-692-7432 or peter.shaw@chp.edu.

Preserving Fertility After Cancer Treatment

One of the nation’s first comprehensive programs to help preserve fertility after cancer treatment in adults and prepubescent children has been established by Children’s Hospital of Pittsburgh of UPMC in collaboration with Magee-Womens Research Institute, Magee-Womens Hospital of UPMC, and the University of Pittsburgh School of Medicine.

The treatments that young people with cancer hope will save their lives often threaten their ability to have children of their own. Radiation therapy and many chemotherapy drugs adversely affect fertility — in males, by damaging sperm-producing stem cells in the testes, and in females, by damaging eggs or injuring the reproductive organs.

The American Society of Clinical Oncology recommends that oncoologists talk with all patients of reproductive age about the risk of treatment-related infertility and about fertility preservation options. Studies show, however, that as many as 90 percent of cancer patients are not informed about the risks cancer treatment can pose to fertility.

“Oncologists tend to be focused on curing the patient’s cancer,” says Peter Shaw, MD, medical director of the Adolescent and Young Adult (AYA) Oncology Program at Children’s Hospital. “They are not consistently good at talking about the effects of treatment on fertility. But as more cancer patients survive long-term, we have a duty to discuss all the potential long-term side effects of treatment and ensure they have options for preserving fertility.”

The only proven fertility preservation methods are sperm banking for young men, and in vitro fertilization followed by embryo freezing for young women. There are no proven options for children diagnosed with cancer before puberty.

Experimental options now available to patients through the Fertility Preservation Program in Pittsburgh include testicular tissue freezing for boys and young men; egg freezing for young women; and, for girls and young women, ovarian tissue freezing.

For more information about the Fertility Preservation Program, please visit www.mwrif.org/220.
Holly W. Davis, MD

Holly W. Davis, MD, former co-director of Children’s Hospital’s Child Advocacy Center and medical director of the Emergency Department, died Sept. 6, 2013 of brain cancer. She was 68.

Dr. Davis spent her entire medical career at Children’s after earning her bachelor’s and medical degrees from Duke University. She trained under Thomas K. Oliver Jr., MD, and was ambulatory chief resident under Jack Paradise, MD.

She served as medical director of the Emergency Department (ED) from 1978 until 1999. Her tenure in that position included an appearance on “Mister Rogers’ Neighborhood,” during which she explained to kids through Mr. Rogers how they would be cared for in the ED.

With Basil Zitelli, MD, chief of the Paul C. Gaffney Diagnostic Referral Service, Dr. Davis co-edited the Atlas of Pediatrics Physical Diagnosis, a leading pediatric textbook that now is in its sixth printing. “Holly was indefatigable,” Dr. Zitelli says. “Her energy and enthusiasm were apparent in her clinical work as well as in her contributions to the genesis of the Atlas and its subsequent editions.”

As co-director of the Children’s Child Advocacy Center (CAC) from 1999 until her retirement in 2005, Dr. Davis was dedicated to the detection and evaluation of children who may be victims of abuse or neglect. “One of the things I will remember most about Holly is the amount of time she would spend with every family,” says Rachel Berger, MD, MPH, chief, Child Advocacy Center. “She was able to establish a rapport with almost every family even when the rapport was with the person who had abused the child. She really did the job of both a physician and a social worker.”

Dr. Davis’ ashes will be scattered at Kiawah Island, S.C. Donations in her memory should be made to Habitat for Humanity, Doctors Without Borders, and public television.

Children’s Hospital of Pittsburgh of UPMC is making it easier and more convenient for patients and parents to access and manage their medical information online with myCHP – Children’s Health Portal. This secure, Web-based portal provides quick access to a patient’s medical information any time of the day or night from a computer or mobile device, for both inpatients and outpatients.

With myCHP, patients and parents can:

- Request prescription renewals
- Request an appointment with a Children’s Hospital specialist
- View test results from clinic and hospital visits
- Send a secure message to a Children’s specialist
- View and print clinical discharge summaries and instructions
- View immunization, allergy, and health history
- Receive alerts and reminders about appointments
- Access and download patient forms

myCHP accounts are available for parents, legal guardians, adoptive parents, and patients ages 13 and older. Parents and legal guardians will be granted pediatric proxy access to their child’s account from birth to age 13. Patients ages 13 and older are eligible for their own myCHP account and will determine proxy access for parents. At age 18, proxy access is automatically discontinued.

Parents, legal guardians, and patients must sign up in person during a hospital stay or a clinic visit at Children’s main campus in Lawrenceville. Sign-ups will also be available at regional locations soon, including Children’s North, South, and East; and Specialty Care Centers in Chippewa, Erie, Hermitage, and Johnstown, Pa., and Wheeling, W.Va.

The portal was developed through a partnership with Cerner Health, which also created Children’s electronic medical record system.

To learn more about myCHP, visit www.chp.edu/mychp.
Sylvia Choi, MD, FAAP, associate professor of pediatrics at the University of Pittsburgh School of Medicine, was recognized by the Allegheny County Health Department for her work promoting breastfeeding. As medical director of the Feeding and Swallowing Center and a member of The Paul C. Gaffney Diagnostic Referral Service, both based at Children’s Hospital of Pittsburgh of UPMC, Dr. Choi teaches medical students how to talk to expecting parents about the benefits of breastfeeding and the drawbacks of using formula.

Amy Houtrow, MD, PhD, MPH, chief, Division of Pediatric Rehabilitation Medicine, was awarded the international Pursuit Award for improving the lives of children with disabilities. She also recently presented her research on the changing demographics of childhood disabilities at the American Academy of Pediatrics Presidential Plenary Session and was interviewed by multiple news organizations including U.S. News and World Report.

Ashok Panigrahy, MD, chief, Department of Pediatric Radiology, was awarded a grant from the Society for Pediatric Radiology titled “Innovative Neuroimaging Biomarkers of Pediatric Brain Tumor Immunotherapy.” Dr. Panigrahy also received a grant from the American Society for Pediatric Neuroradiology titled “Neural Correlates of Math Deficiencies in Preterm Children.”

Vivek Allada, MD, interim chief of Pediatric Cardiology, founded and served as co-chair for an American Society of Echocardiography Committee on Pediatric Echocardiography Productivity. Under his direction, a national survey on Pediatric Echocardiography Laboratory Organization and Clinical Productivity was completed culminating in a publication in the October edition of the Journal of the American Society of Echocardiography. Dr. Allada and other leaders in the field of pediatric echocardiography analyzed data on annual laboratory volumes, daily sonographer workload, and echocardiography physician productivity. As the most comprehensive evaluation of academic pediatric echo labs to date, the survey will be instrumental in determining work force needs especially in the changing health care environment.

Peter Wearden, MD, PhD, cardiothoracic surgeon and director of the Pediatric Mechanical Cardiopulmonary Support Program, reports on the Heart Institute’s experience with the transport of patients while on the Berlin Heart in the paper, “First Berlin Heart EXCOR Pediatric VAD Interhospital Transports of Nonambulatory Patients with the Ikus Stationary Driver,” published in the September/October 2013 issue of ASAIO Journal, the official journal of the American Society of Artificial Internal Organs.

Pediatric gastroenterologists Sohail Husain, MD (left), and Arvind Srinath, MD (right), of the Division of Pediatric Gastroenterology, Hepatology, and Nutrition led the development of the “Pediatric Gastroenterology Research Agenda” commissioned by the North American Society for Pediatric Gastroenterology, Hepatology, and Nutrition (NASPGHAN) to help generate funding for research. Dr. Husain, who chairs NASPGHAN’s Research Committee, served as its editor while Dr. Srinath was associate editor. The eight-page document, which identifies critical issues that should be emphasized for future research, was a response to Congress’ decision to decline funding for pediatric gastroenterology research.
UPMC Invests $30 Million in Pediatric Research Programs

UPMC is investing $30 million to support research programs at Children's Hospital of Pittsburgh of UPMC, including the establishment of an endowment fund to honor David H. Perlmutter, MD, Children's Hospital's scientific director.

The $10 million David H. Perlmutter Research Endowment will allow Children's to continue to recruit and retain national leaders in pediatric research.

Dr. Perlmutter is the Vira I. Heinz Chairman of Pediatrics at the University of Pittsburgh School of Medicine and physician-in-chief at Children's.

Under his leadership, sponsored pediatric research at Children's Hospital has increased four-fold, making Children's one of the fastest-growing pediatric research programs and among the top 10 in the nation, as measured by National Institutes of Health funding.

“UPMC's substantial commitment will ensure that Children's remains a world leader in pediatric research, education, and clinical care. This is an extraordinary contribution, dedicated to existing and future research programs, and will be an engine for continued discovery long into the future,” says Christopher Gessner, Children's president. “It also is a wonderful and well-deserved tribute to Dr. Perlmutter, who has been a transformational leader at Children's.”

In addition to the David H. Perlmutter Research Endowment, UPMC has committed $20 million to existing and future research programs at Children's.

Nearly 390 active protocols are being pursued by more than 125 principal investigators in 63 separate laboratories at Children's John G. Rangos Sr. Research Center. Significant current programs include:

- Stem cell biology/regenerative medicine
- Developmental biology
- Infection and immunity research
- Inflammatory and autoimmune diseases
- Novel strategies for treating pediatric cancer
- Inherited metabolic and other rare diseases of children
- Drug discovery for childhood diseases
- Genomics of childhood diseases

"UPMC is committed to the ongoing support of Children’s Hospital’s pediatric health care and research, and we are honored to make this investment to their programs;" says Steven Shapiro, MD, chief medical and scientific officer, UPMC.

Building a Strong Foundation

RADIOTHON SETS NEW RECORD
Children's Hospital of Pittsburgh of UPMC is built on the generous spirit of the community working together with a common goal — a commitment to children.

The Sixth Annual DVE Rocks for Children’s Radiothon concluded Sept. 14, 2013, raising more than $564,000 from 3,952 generous donors over three days. The money will support the most urgent needs of the hospital to ensure Children’s continues to provide compassionate care to our patients and families.

Thank you to 102.5 WDVE, faculty, staff, volunteers, donors, and event sponsors Equitable Gas, Great Clips, Northwood Realty, Berger & Green, Express Scripts, Pizza Hut, Rohrich Toyota, Settlers Ridge, Stage AE, and Turner’s who helped make this year’s event a tremendous success with their overwhelming support.

Additional opportunities to support Children’s include:

Saturday, Nov. 16, 2013
In Style With Children’s
10:30 a.m.– 2:30 p.m.
Omni William Penn

Thursday, Dec. 19, 2013
60th annual KDKA/Children's Hospital Free Care Fund Benefit Show
7–8 p.m.
Broadcast live from Children's Hospital’s Eat’n Park Atrium

Visit givetochildrens.org or call 412-692-3900 for more information on events and ways to get involved.
We’re Your Children’s Hospital.

No matter where your patients are in the tristate region, Children’s Hospital of Pittsburgh of UPMC is their children’s hospital. From Altoona to Zelienople and all points in between, Children’s Hospital has the medical and surgical subspecialists and individualized, family-centered care your patients and their families have come to rely on. Visit www.chp.edu.