Special Page 4 Feature

Intestinal Care and Rehabilitation Center
Giving hope to children with complex intestinal disorders

Top 10 Again
Children’s Hospital named one of U.S. News & World Report’s best

Division of Pediatric Nephrology
Accurately Diagnosing Pediatric Hypertension
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The SUMMER 2013 issue of Pediatric INSIGHTS

In this issue of Pediatric INSIGHTS read an inspiring story about the life-changing medical care provided by the Intestinal Care and Rehabilitation Center at Children's Hospital of Pittsburgh of UPMC.

In addition:

- Children's Hospital's Division of Pediatric Nephrology provides accurate diagnosis of hypertension with the region's only 24-hour ambulatory blood pressure monitoring for adolescents and children.
- Rachel Berger, MD, MPH — a national leader in research on abusive head trauma and other aspects of child abuse — has been named chief of the Division of Child Advocacy at Children's Hospital.
- The Telephone Triage & Advice Center at Children's Hospital provides evening, night, and weekend call coverage for more than 175 pediatric primary care physicians and covers about 1.5 million pediatric and adult patients.

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.

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 Hospital of Pittsburgh of UPMC again has been named to *U.S. News & World Report’s* 2013–14 Honor Roll of Best Children’s Hospitals. Children’s Hospital ranked 10th in the nation overall and was ranked in each of the 10 pediatric specialties.

The Best Children’s Hospitals rankings highlight the top 50 U.S. pediatric hospitals in each of 10 specialties: cancer, cardiology and heart surgery, diabetes and endocrinology, gastroenterology and GI surgery, neonatology, nephrology, neurology and neurosurgery, orthopaedics, pulmonology, and urology. Children’s ranked third in diabetes and endocrinology, sixth in gastroenterology and GI surgery, and sixth in pulmonology.

According to *U.S. News*, the rankings are intended to be a starting point for families who need to make critical decisions about where to seek care for children who need specialized pediatric health care.

“We are honored to receive national recognition such as this and be considered one of the best children’s hospitals in the country,” said Christopher Gessner, Children’s president. “The fact that we are ranked in all 10 specialties is indicative of the high level of expertise our physicians and staff have across a wide array of programs. Ultimately, this recognition is a testament to their dedication to the patients we serve and to our position as a global leader in pediatric health care.”

For the 2013–14 rankings, *U.S. News* surveyed 179 pediatric centers to obtain clinical data in 10 specialties. The organization also asked 150 pediatric specialists in each specialty where they would send the sickest children. A total of 87 hospitals ranked in at least one specialty, and the 10 hospitals that had high scores in at least three specialties were named to the Honor Roll. The rankings are online and also will be published in the *U.S. News Best Hospitals 2014* guidebook, which will be available in August.

In addition to Children’s Hospital of Pittsburgh of UPMC, the nine hospitals named to *U.S. News*’ Honor Roll of Best Children’s Hospitals for 2013–14 are:

- Children’s Hospital of Philadelphia
- Boston Children’s Hospital
- Cincinnati Children’s Hospital Medical Center
- Texas Children’s Hospital, Houston
- Children’s Hospital Los Angeles
- St. Louis Children’s Hospital-Washington University
- Children’s Hospital Colorado, Aurora
- Ann and Robert H. Lurie Children’s Hospital of Chicago
- Johns Hopkins Children’s Center, Baltimore
Children and teens with suspected hypertension can now be referred to a dedicated pediatric hypertension program at Children’s Hospital of Pittsburgh of UPMC.

More children and adolescents are being diagnosed with hypertension as a consequence of the childhood obesity epidemic, says pediatric nephrologist Yosuke Miyashita, MD, MPH, medical director of the program.

Yet obtaining an accurate diagnosis of hypertension in a child or teen “is not as straightforward as one might think,” says Dr. Miyashita. He estimates that up to 40 percent of children and adolescents with elevated blood pressure measurements in medical settings may be due to “white coat” hypertension, a high blood pressure reading due to the anxiety of patients in a medical environment.

To address the problem of uncertain diagnosis, Dr. Miyashita’s program offers the region’s only 24-hour ambulatory blood pressure monitoring (ABPM) for adolescents and children as young as 5. A blood pressure cuff is connected to a monitor that is small enough to carry in a pocket. The monitor records blood pressure at 20- to 30-minute intervals over 24 hours. After 24 hours, the patient or a family member removes the device and mails it back to the hospital for evaluation.

“ABPM has significantly improved our ability to diagnose hypertension accurately,” says Dr. Miyashita. “Within about a week, we know whether a patient has true hypertension or not.”

If patients are determined to have hypertension by ABPM, doctors then determine whether evaluation, including blood work and imaging studies, to rule out secondary hypertension (hypertension caused by an identifiable underlying cause) is needed. They may also order an echocardiogram to look for complications of hypertension to the heart such as thickened left ventricular wall.

If primary hypertension (hypertension without an identifiable underlying cause) is associated with obesity or poor dietary habits, lifestyle changes are the first line of therapy, says Dr. Miyashita. Patients and families work with the clinic’s full-time renal dietitian, Jessica Lieb, RD, LDN, to put in place a plan for healthy eating and increased physical activity.

Patients return to the clinic at a later date for a follow-up visit, which may include a repeat ABPM and another visit with the renal dietitian. For patients whose blood pressure does not improve with lifestyle modification, antihypertensive medication may be the next step, says Dr. Miyashita.

Patients can be seen at Children’s East in Monroeville and Children’s North in Wexford, although they must come to the Lawrenceville campus to initiate ABPM. Dr. Miyashita and his colleagues also conduct outreach clinics, including ABPM, in Chippewa, Erie, Hermitage, and Johnstown.

“Our goal is to see every child in western Pennsylvania with elevated blood pressure measurements and have them appropriately evaluated and managed,” says Dr. Miyashita.

When to refer

Use the guidelines below to refer patients to Children’s hypertension program. Appointments are available within 72 business hours.

<table>
<thead>
<tr>
<th>CATEGORY</th>
<th>CATEGORY DEFINITION</th>
<th>RECOMMENDATIONS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pre-hypertension</td>
<td>BP within 90th–95th percentile for age, gender, and height or BP higher than 120/80 mmHg</td>
<td>Immediate referral not necessary. Recheck patient’s BP in 6 months.</td>
</tr>
<tr>
<td>Stage 1 Hypertension</td>
<td>BP within 95th–99th percentile for age, gender, and height plus 5 mmHg</td>
<td>Refer if patient’s average BP is within Stage 1 range on 3 successive visits or when one BP measurement is within Stage 1 range and patient has symptoms of hypertension (e.g., headache, blurred vision, dizziness, chest pain).</td>
</tr>
<tr>
<td>Stage 2 Hypertension</td>
<td>BP greater than 99th percentile for age, gender, and height plus 5 mmHg</td>
<td>Refer immediately.</td>
</tr>
</tbody>
</table>


For patient appointments and consultations, please contact the Division of Pediatric Nephrology, at 412-692-5182, Monday through Friday, 8 a.m. to 4:30 p.m. For an urgent consultation, call our 24-hour service at 412-692-5325 and ask for the nephrologist on call. •
Physician Liaisons at Your Call

Judi Morris-Feinberg
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judi.feinberg@chp.edu

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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.

Berger Named New Child Advocacy Chief

Rachel Berger, MD, MPH, has been named chief of the Division of Child Advocacy at Children’s Hospital of Pittsburgh of UPMC, succeeding Janet Squires, MD. Dr. Berger is an associate professor of Pediatrics and Clinical and Translational Science at the University of Pittsburgh School of Medicine. With work that she began during her fellowship at Children's Hospital on the biomarkers of traumatic brain injury in children, Dr. Berger has established herself as a national leader in research on abusive head trauma and other aspects of child abuse. The National Institutes of Health have funded her work continuously, including her current R01 grant, “Novel approaches to screening for inflicted childhood neurotrauma.” Dr. Berger is a member of the Society for Pediatric Research, serves on the editorial board of Pediatrics, and recently served on the Pennsylvania Task Force on Child Protection commissioned by the Governor of Pennsylvania in 2012.

Continuing Education Resources

Remember to visit UPMCPhysicianResources.com/Pediatrics when you need continuing medical education credits. You can sign up to receive occasional updates, and follow @UPMCPhysicianEd on Twitter for the latest offerings.

NEW PHYSICIANS

The following practitioners recently joined the medical staff at Children's Hospital of Pittsburgh of UPMC.

Cardiology
Jennifer Johnson, MD
Ashwin Lal, MD
Leif Lovig, MD

Child Advocacy
Adelaide Eichman, MD

Diagnostic Referral Service
Leigh Anne DiCicco, MD
Katharyn Lupo, MD
Tony Tarchichi, MD

Emergency Medicine
Sabrina Guse, MD
Melissa Tavarez, MD

General and Thoracic Surgery
Jan Goedeke, MD
Marcus Malek, MD (January 2014)

Hematology/Oncology
Erika Frehling, MD

Infectious Diseases
Anna Huppler, MD

Neurology
Deepa Rajan, MD

Newborn Medicine (UPMC Hamot)
Stacey Slagle, MD

Otolaryngology
Noel Jabbour, MD (September 2013)

Rehabilitation Medicine
Amit Sinja, MD (September 2013)
Melissa Stern, PhD (September 2013)

Urology
Heidi Stephany, MD
Giving Hope

INTESTINAL CARE AND REHABILITATION CENTER CARES FOR CHILDREN WITH COMPLEX INTESTINAL DISORDERS

Fourteen months old and weighing in at about 16 pounds, Benjamin Conrad has an engaging smile, a cheerful laugh, and, according to his mother, “a fiery little personality.” No one looking at him would suspect that this little boy had beaten the odds just by surviving.

Born three months prematurely weighing just 1 pound 4 ounces in May 2012, Benjamin was diagnosed with necrotizing enterocolitis (NEC) at age 4 weeks and underwent several surgeries that ultimately removed most of his small intestine. After surgery, unable to tolerate feeding by mouth or gastrostomy tube, he was sustained by total parenteral nutrition (TPN), nutrition injected directly into a vein.

When he arrived at Children’s Hospital of Pittsburgh of UPMC in September 2012, Benjamin was 4 months old, weighed about 6 pounds, and needed 4 to 6 liters of supplemental oxygen a day to support his breathing. In addition to having a series of central intravenous line infections, he had developed TPN-induced liver disease, the most common and serious complication affecting patients who use TPN for extended periods.

“His bilirubin was trending upward and if he stayed on TPN indefinitely he was likely to develop complications from liver disease,” says Jeffrey Rudolph, MD, medical

ABOVE: “I can’t say enough good things about Children’s Hospital. They gave us hope, and they have given Benjamin a future,” says his mother, Theresa Conrad.
director of the Intestinal Care and Rehabilitation Center (ICARE) at Children’s Hospital, who evaluated Benjamin upon his arrival to the hospital.

“After several unsuccessful feeding trials, we decided that his best chance for coming off of TPN would include an exploratory laparotomy surgery to re-establish functionality of his bowel.” The success of this procedure enabled Benjamin to begin a long journey of recovery.

Dedicated to intestinal care

ICARE is one of the first and among the nation’s largest multidisciplinary centers dedicated to intestinal care and rehabilitation for pediatric patients with complex intestinal disorders. Collectively, ICARE medical, surgical, nursing, and nutrition staff offer more than 100 years’ experience in the care and rehabilitation of children with gastrointestinal dysfunction. Patients come to ICARE from across the United States and around the world for both intestinal rehabilitation and pre-transplantation care.

“Children generally are referred to us after the diagnosis of a congenital bowel abnormality or after surgery for an abdominal catastrophe,” explains Dr. Rudolph. “We get involved when intestinal failure has occurred — that is, when there has been a reduction in functional gut mass to the extent that the patient cannot maintain fluid and electrolyte levels or consume sufficient calories to meet his or her growth needs.”

As a result of advances in surgery, neonatal care, and infection control, more children than ever before are surviving with complex intestinal disorders such as NEC, gastroschisis, intestinal malrotation, and complex Hirschsprung’s disease, says Dr. Rudolph. In addition to managing these patients’ care during hospital stays, ICARE physicians and nurses follow them long-term and provide ongoing support for patients and their families. The center also maintains a registry of more than 500 patients to monitor the effectiveness of treatment.

The ICARE staff work in partnership with the Children’s intestinal transplantation program, one of the leading pediatric intestinal transplantation programs in the world. “When a patient becomes a candidate for intestinal transplantation, we provide their care until the point at which they get transplanted,” explains Dr. Rudolph. Transplantation is a last resort, however, that some patients may be able to avoid with intestinal rehabilitation.

“The turnaround was amazing”

ICARE Transplant Surgery Director Geoffrey Bond, MD, performed Benjamin Conrad’s exploratory laparotomy — an operation that took about 8 hours — in October 2012.

Immediately post-surgery, Benjamin was so ill that he remained intubated for a month. To treat his TPN-induced liver disease, he was enrolled in Children’s compassionate-use trial of the omega-3 fatty acid supplement Omegaven (see sidebar).

Slowly but surely, Benjamin’s condition began to improve. His liver disease reversed. He began to tolerate feeding by a gastrostomy tube. In December he was discharged from Children’s in time to spend his first Christmas with his parents, Theresa and Jamie Conrad, at home in Allentown, Pa. In April 2013 he stopped TPN altogether and his central line was removed. In June, his lung function improved to the point where he no longer needs supplemental oxygen.

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“Once he began to get better, the turnaround was amazing,” says Theresa Conrad. “He just defied the statistics in all the textbooks. As one doctor said to us, ‘Benjamin doesn’t read those textbooks.’”

Although Benjamin is still small for his age, his doctors are satisfied with his growth and with the rate of increase in his height and weight, according to his mother. He is now learning to eat by mouth.

“Because he was born so early, he missed the third trimester, which is when a baby learns to swallow,” says his mother. “So he has to learn what to do with food when you put it in his mouth.

“It’s a challenge teaching him to eat, but we are progressing in small increments,” she continues. “He has started eating some solids and is learning to take a bottle. Eventually he should not have any trouble eating like a typical kid.

“I can’t say enough good things about Children’s Hospital. They gave us hope, and they have given Benjamin a future.”

To refer a patient or request a consultation, contact Children’s ICARE Center at 412-692-6906. Learn more about Children’s ICARE Center at www.chp.edu/icare.

2014 Pediatric Intestinal Failure and Rehabilitation Symposium

Plans are well under way for the 8th International Pediatric Intestinal Failure and Rehabilitation Symposium, sponsored by the Intestinal Care and Rehabilitation Center and Hillman Center for Pediatric Transplantation at Children’s Hospital of Pittsburgh of UPMC along with the Thomas E. Starzl Transplantation Institute. The symposium is set for September 2014 in Atlanta, Ga.

This bi-annual international symposium is the premier event for the specialties of intestinal failure, rehabilitation, and transplantation. It will feature a distinguished list of international speakers who are leaders in their fields of expertise. The three-day symposium offers pre-conference seminars, educational sessions, networking opportunities, continuing education, and exhibits for health care professionals, families, and caregivers.

The 2012 symposium, held in Pittsburgh, was the largest ever, with 300 attendees representing 17 countries. It featured 49 speakers, including nine international experts from multiple disciplines.

More details about the 2014 symposium will be available soon at www.chp.edu/intestine2014.
The Telephone Triage & Advice Center at Children's Hospital of Pittsburgh of UPMC serves as a registered nurse telephone triage advice line for patients of any age. It originated in 1996 as an extension of pediatricians’ practices and is based administratively at Children’s Hospital, but handles calls for adult patients as well as pediatric. Joe Suyama, MD (top left), is the adult medical director of the Telephone Triage & Advice Center. William Varley, MD (bottom left), is the pediatric medical director.

The center uses TriageLogic software, and Schmitt-Thompson evidence-based nurse triage protocols are built into the program. Basic information provided by the answering service initiates an algorithm prioritization level for the registered nurse. Practice- and patient-specific information interfaces with the system, and an electronic summary report is sent to the referring practice and health plan.

All callers are surveyed electronically, and the center has maintained a satisfaction rating of better than 98 percent.

The Telephone Triage & Advice Center’s registered nurses use clinical protocols that enable them to triage patients into one of the following five triage dispositions:

- **911 EMS** – Callers are advised to contact 911 EMS dispatch immediately.
- **See Immediately** – Callers are directed to a local emergency department or urgent care center for evaluation.
- **See Within 4 Hours** – Callers are referred to an emergency department or urgent care center or reassessed in a 2-hour time frame.
- **See Within 24-48 Hours** – The caller is given instruction for a home remedy and is instructed to contact his or her primary care physician’s office in the morning.
- **Home Advice** – The registered nurse provides home advice in accordance with the protocol.

In all cases, the triage nurse advises callers to call back if the patient’s condition worsens, or if their concerns are not alleviated. The center also has a number of mental health resources that can be activated for the caller and their family when the issue is social or behavioral in nature.

**By the Numbers**

- 17 registered nurses provide evening, night, and weekend call coverage for more than 175 pediatric primary care physicians
- 24/7 service for the UPMC Health Plan My Health Advice Line
- Average call-back time of 20 minutes
- Call volume growth of 136 percent since the program originated
- Covers about 1.5 million pediatric and adult patients

**Pediatric Practice Services**

- Full Service
  - Monday through Thursday 8 p.m. to 6 a.m.
  - Friday 5 p.m. to 6 a.m.
  - Weekend call coverage from noon Saturday to 6 a.m. Monday

- Limited Service
  - 7 days a week from 8 p.m. to 6 a.m.

**Adult Practice Services**

24/7 service for the UPMC Health Plan My Health Advice Line.

To learn more about the Telephone Triage & Advice Center, contact Mark O’Hern, executive director, Ambulatory Services and Business Development, at 412-692-6487 or ohernma@upmc.edu.
These Children’s Hospital staff members recently received the following recognition in their fields.

Lakshmanan Krishnamurti, MD, clinical director of Hematology, received a research award from the Patient-Centered Outcomes Research Institute (PCORI). Dr. Krishnamurti is the lead investigator on a research project to create an online tool for people with sickle cell disease, an inherited disorder that affects 100,000 individuals in the United States, largely of minority origin.

Ian Pollack, MD, chief of Children’s Hospital’s Division of Pediatric Neurosurgery, was named the next chairman of the Editorial Board of the Journal of Neurosurgery: Pediatrics. He joined the Editorial Board in 2003. In May 2013, the New England Journal of Medicine published his Clinical Implications of Basic Research article, “Tumor-Stromal Interactions in Medulloblastoma.” Dr. Pollack is the Walter Dandy Professor of Neurological Surgery at the University of Pittsburgh School of Medicine and co-director of the Brain Tumor Center of the University of Pittsburgh Cancer Institute.

Elizabeth Miller, MD, PhD, chief, Division of Adolescent Medicine, was interviewed about reproductive coercion by New York magazine. Her 2010 study on the topic showed that 15 percent of 1,300 women who visited federal- and state-subsidized California family planning clinics had their birth control sabotaged.

Several senior professional staff nurses from Children’s Cardiac Intensive Care Unit gave presentations that highlighted the expert work of Children’s Heart Institute at UPMC Nurses Week in May 2013. Ashleah Martinez, RN, BSN, CCRN, presented “Peer Review Beads,” Donald Reinheimer, RN, CCRN, presented “Hands-off,” and Jennifer Roundtree, RN, BSN, CPN, presented “Caring for the Caregivers.”

Lee Beerman, MD, was awarded the Howard A. Mermelstein, MD, Memorial Award for Excellence in Pediatrics for long-standing contributions to pediatrics and pediatric cardiology in western Pennsylvania. It was presented in May during the 2013 Three Rivers Pediatric Update at the John G. Rangos Sr. Conference Center.

Peter Wearden, MD, PhD, is the deputy program director for the American Society for Artificial Internal Organs for the current year and will be the program director next year. He was also the pediatric session chair for the Gordon Research Conference for Assisted Circulation held June 23-28, 2013, in Lucca, Italy.

Diana Shellmer, PhD, an expert in behavioral pediatrics for transplant surgery, was selected to receive a Travel Award for Allied Health for the 7th Congress of the International Pediatric Transplant Association, held July 13-16, 2013, in Warsaw, Poland. This award recognizes the excellence of Dr. Shellmer’s abstract, “Development and Field Testing of a Mobile Health Application to Improve Adherence in Adolescent Solid Organ Recipients: Teen Pocket Path.”

Results of a study led by Rakesh Sindhi, MD, director of Pediatric Transplantation Research, titled, “Surgical Outcome Research – Analysis of National and Single-Center Incidence and Survival After Liver Transplantation for Hepatoblastoma: New Trends and Future Opportunities,” were published in the February 2013 issue of Surgery.
Get Involved to Help Us Help Children

Events Support Children’s Hospital of Pittsburgh Foundation

Children’s Hospital is built on the generous spirit of the community working together with a common goal — a commitment to children. You can support Children’s by enjoying one of our upcoming events:

**Tuesday, Aug. 6, 2013**
**unWINED, A Toast to Hope for a Cure**
6–10 p.m.
La Casa Narcisi Winery

**Thursday, Sept. 12–Saturday, Sept. 14, 2013**
**DVE Rocks for Children’s Radiothon**
Broadcast live from Children’s

**Friday, Sept. 20, 2013**
**Wear a Hat for Cancer**
Schools across the region

**Tuesday, Sept. 24, 2013**
**Sixth Annual Children’s Hospital Golf Classic**
Laurel Valley Golf Club

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

Visit [givetochildrens.org](http://givetochildrens.org) or call 877-247-4483 for more information about events and ways to get involved.

Meet the Children’s Hospital of Pittsburgh Foundation Auxiliaries

The Children’s Hospital of Pittsburgh Foundation Auxiliaries provide philanthropic support to Children’s in five key areas — cancer and blood disorders, the Heart Institute, the Hearing Center, transplantation surgery, and family life. These groups support funding priorities through personal philanthropy and fundraising activities. Members also have the opportunity to attend exclusive presentations led by our renowned pediatric experts.

Joining any of these auxiliaries is a meaningful way to help children in our region. From volunteer opportunities to leadership roles, there are many ways you can make a difference. Contact [foundationauxiliary@chp.edu](mailto:foundationauxiliary@chp.edu) for more information on how you can get involved.

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Vascular Anomalies Center Offers Multidisciplinary Approach to Care

When a patient is born with a vascular anomaly or birthmark, the specialists at Children’s Hospital of Pittsburgh of UPMC’s Vascular Anomalies Center can provide a coordinated team approach to care. Experts from Plastic Surgery, ENT, Interventional Radiology, Radiology, Pathology, Dermatology, Pediatric Surgery, Hematology, Diagnostic Referral Group, and Neurosurgery care for children with a wide variety of vascular anomalies.

The team specializes in tumors such as hemangiomas as well as their associated potential complications. Patients with hemangiomas are screened by the nurse coordinator and then evaluated by a pediatric plastic surgeon as well as a physician from the diagnostic referral service. If medical therapy is needed, the patient is guided through the treatment process.

The Vascular Anomalies Center also specializes in vascular malformations such as lymphatic malformations, venous malformations, arterial-venous malformations, capillary malformations and combined lesions such as CLOVES, Klippel-Trenaunay, and Sturge-Weber. Prior to the patient’s initial visit, the coordinator determines which specialists need to see the patient. Multidisciplinary providers develop a care plan. Most patients undergo an ultrasound to help with diagnosis. Sometimes additional tests such as an MRI, blood work, or biopsy are required.

Complicated cases are reviewed at a monthly Multidisciplinary Vascular Anomalies Conference.

To refer patients to the Vascular Anomalies Center, call 412-692-8942.
A National Top 10
Children’s Hospital.

The hands have it. Children’s Hospital of Pittsburgh of UPMC has once again been named a Top 10 Pediatric Hospital by U.S. News & Report. This is no small feat considering that U.S. News ranks approximately 5,000 pediatric hospitals across the nation. In fact, we were ranked one of the best in all 10 specialty areas. But the best part of all is that the nation’s best care is close to the patients you treat. To learn more, visit www.chp.edu.