

# hopkinschildren's

SPRING 2015

THE JOHNS HOPKINS CHILDREN'S CENTER MAGAZINE

**Saving the  
Newborn Brain**  
Multiple specialists  
bring their insights to  
the table

**From Hopkins to  
Navajo Nation**  
Residents expand  
their clinical skills  
and their horizons

## The Surgeon Scientist

Steeped in science, David Hackam emerges in the OR with an elevated understanding of the disease afflicting the child before him.



# A Blessing to Be Here

by **Lea Armstead**

**From a very young age, I knew that nurses were angels.**

When I was in the hospital, at Hopkins Children's, they were always there, as was my mother. They saw beyond my physical pain, beyond the "crisis" of my sickle cell disease. They saw me. They asked about school, about friends, about movies I liked. I didn't know then, when I was so young, that I wanted to be a nurse when I grew up. But, I knew that I wanted to do something that would impact other people this way, that could make them feel better, too.

When I was in high school, I liked science, and was good at it. I heard, "Oh, you should be a doctor." But, by then, I knew I wanted to be a nurse.

When my parents heard the news 24 years ago that their newborn had sickle cell, they decided that the disease was not going to define me. When I was in elementary school, the pain caused by the disease—in which your blood cells are "sickle-shaped," and stick together sometimes—was so acute that I had to spend several days a year in the hospital, and more at home. There's no cure yet for sickle cell, though there are treatments to help prevent some of the serious possible consequences of sickle cell, such as clotting and stroke.

One of my hematologists here, George Dover, and a colleague first discovered that a cancer drug, hydroxyurea, decreases the pain of a sickle cell crisis. I'll stand on a mountain top and say what a difference it has made in my life. It allowed me to go to college.

My family so appreciated my care at Johns Hopkins that they started the Armstead-Barnhill Foundation for Sickle Cell Anemia to fund sickle cell research. Dr. Dover and Dr. (James) Casella and others here are using the funds to find cures. I continue to raise funds.

Today, I am a nurse in the pediatric intensive care unit at Johns Hopkins Children's Center and I help kids with sickle cell transition into college and adult care. It's just a blessing to be here, to return the favor of hope and understanding. ■



**Patient and PICU nurse Lea Armstead with her hematologist and Children's Center Pediatrician-in-Chief George Dover.**



In the Neurosciences Intensive Care Nursery, neonatal nurse Charlamaine Parkinson, left, and NICN fellow Monica Lemmon; see page 14.

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*Cover photo by Keith Weller*



# Advancing Innovation



**George J. Dover, M.D.**  
Co-Director, Johns Hopkins  
Children's Center  
Given Foundation Professor  
of Pediatrics

**As we mentioned** in the previous issue of *Hopkins Children's Magazine*, last year we turned two in our new home, The Charlotte R. Bloomberg Children's Center. As we blew out the candles we also noted that the building was designed to launch a new era in pediatric medicine—one that would redefine the hospital experience and push the boundaries of biomedical discovery and innovation in clinical care. And it would do all this in a patient- and family-centered environment. Now, this issue of our magazine provides some evidence that we are doing just that. How?

First off, we've recruited a new pediatric surgeon-in-chief, someone who will co-lead the Children's Center as well as direct Hopkins' pediatric surgical program. In conducting a national search we were amazed by the outstanding candidates interested in filling the spot. Yet the decision was still an easy one as David Hackam, from the University of Pittsburgh, rose above others in representing the dynamic mix of skills and experiences we were looking for—surgeon, scientist and executive manager (see page 4).

If ever there was a clinical service that pushes the boundaries of clinical innovation, our Neurosciences Intensive Care Nursery would have to be at or near the top of the list. In this story, we see how collaboration among specialists from multiple disciplines translates into the best possible treatment plan for newborns at risk of brain damage (see page 14).

Our ongoing quest for biomedical discovery is illustrated in the "Research Roundup" section of the magazine (see page 36), and in this issue's "Family Matters" column we see, or hear, the essence of patient- and family-centered care—the patient's voice (see page 52). We need to hear your voice, too, so please write to us with your thoughts about any of the articles in *Hopkins Children's Magazine*. And please enjoy this issue. ■

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### For more information

To read more on the clinical services and programs covered in *Hopkins Children's*, visit [hopkinschildrens.org](http://hopkinschildrens.org).

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## Child Life Turns 70

by Wendell Smith

Developmental specialists and play experts, Child Life staff continue to help Children's Center patients cope with the stress of hospitalization and illness.

**FORMER PEDIATRIC SURGEON** Alex Haller once said that part of being a good surgeon is "putting yourself in a child's shoes." At the Johns Hopkins Children's Center, Child Life specialists do it every day. Today, as members of each child's health care team, these specialists are patient advocates, child development specialists and play experts. Through activities and conversation with patients, they help children cope with the stress of hospitalization and illness, to ensure that emotional and development needs are met. Child Life specialists are now integral members of patients' medical teams. They play leading roles in their care and evaluation and help medical teams experience life from the child's perspective. Such was not always the case.

Child Life took root at Johns Hopkins more than 70 years ago. Chief of Pediat-

ric Nursing Helen Schnetzer impressed upon Edwards Park, then director of the Harriet Lane Home for Invalid Children (Hopkins Children's predecessor), that their young patients needed more nurturing and developmentally appropriate play than nurses or nursing aides had time or training to provide. Visiting hours for parents, at the time, consisted of an hour on Sunday and Wednesday.

In 1943, Schnetzer brought on board the head of child development at Hood College, Md., Onica Prall. Intent on helping Johns Hopkins as part of her volunteer "war effort," Prall, along with some of her students, set up a playroom and began training nurses in child development and age-appropriate play. One of her students, Mary Caulkins, became the Lane's first "play director" in 1944, her salary funded by the Johns Hopkins



At top, Child Life specialists with nursing staff in the 1940s and, above, celebrating in modern times in the lobby of the Charlotte R. Bloomberg Children's Center.

Women's Board. When the 1964-2012 Hopkins Children's building opened, the play program moved from nursing to the Department of Pediatrics and was renamed Child Life.

Johns Hopkins' Department of Child Life celebrated its 70th birthday last October with a reunion for specialists and a party for pediatric patients in the hospital's Julia Clayton Baker Great Room. Haller, who was Johns Hopkins's first director of pediatric surgery and a strong supporter of Child Life, joined the party, which featured a photo booth, a pie toss and plenty of snacks.

"I wouldn't have missed it," said Haller at the time, before biting into a cupcake. ■



# The Surgeon Scientist

Johns Hopkins leaders were looking for a unifying and transformative leader in their search for a new pediatric surgeon-in-chief. They found one and more in David Hackam.

by **Gary Logan**



# DAVID HACKAM begins our “interview this way: Let me tell you my story.”

Then he tells it or, swimmer that he is, dives into it, starting with the life-changing event—the premature, failing 2-week old newborn with the distended belly he cared for as a newly minted pediatric surgeon. In the OR Hackam saw pink intestine turned black, the scourge of necrotizing enterocolitis (NEC), the leading cause of death and disability in premature infants. The newborn pulled through but Hackam had to remove more intestine in another surgery, and then in another.

“He’d get better and then worse,” Hackam recalls.

Hackam had saved what he could, but it was too little to sustain a young life—at 11 months of age, the infant died. The surgeon recalls being fixed on the limp child in his father’s arms, the nurses around them: “I was looking at them out of the blue, asking myself how many diseases have this kind of hit rate? I decided then that this would be my life’s work, to understand how we can identify, prevent and treat diseases like this.”

Indeed, the experience transformed the template of his career, his life. He was a pediatric surgeon mystified by disease, a surgeon who wanted to become a scientist as well. If he could better understand the mechanisms of a disease he could better treat it. He took a sabbatical from residency training to pursue

a Ph.D. in cell biology at the University of Toronto, which changed his view as a surgeon: “From that point on I approached every patient in a ‘what causes this disease’ kind of way.”

In fact, it was a natural evolution. Growing up as the son of a scientist and nurse in Stafford, England, in what he describes as an academic environment where curiosity and inquiry were nurtured daily, didn’t hurt. Becoming a surgeon scientist was hardly an unusual path for Hackam.

But surgeon as scientist? Aren’t surgeons robotic-like technicians, decisive mechanics, rigid thinkers rather than curious and creative free thinkers? Hackam raises his eyebrows, seemingly astonished by such naïve characterizations. Yes, surgeons are mechanics, Hackam acknowledges, but surgery—prompted by research—has evolved.

“When I was in training in the ‘90s, we believed ulcers were caused by stress, acid and spicy foods, and surgeons would remove part of the stomach. Now we know ulcers are caused by bacteria, a discovery that led to the Nobel Prize in 2005, and that it’s not necessary to remove part of the stomach,” Hackam explains. “Surgery is the ultimate scientific pursuit because you’re repairing damaged tissue and that’s what scientists seek to do. Of course surgeons are scientists.”

The discovery of insulin, he adds, was made by Frederick Banting, an unknown Canadian surgeon. Also, the field of immunology was advanced through the important work of transplant surgeons. More recently, cancer immunotherapy, gene therapy, organ and cellular transplantation, trauma and critical care, were advanced, in part, by surgeon scientists. And the 2012 Lasker-DeBakey Clinical Medical Research Award winner? University of Pittsburgh surgeon Thomas Starzi, who with Roy Caine of Cambridge in the 1960s developed liver transplantation. Examples abound.

“Surgeons have always been on the

“This was a very impressive search with all stellar candidates, but David Hackam stood out as a magnificent academic clinician, scientist and leader who would draw people of the same ilk to Johns Hopkins Children’s Center.”

— PEDIATRICS ADMINISTRATOR  
TED CHAMBERS





As gently as a neonatal nurse, Pediatric Surgeon-in-Chief David Hackam cradles a newborn in the NICU.

forefront of medical research,” says Hackam. “You just don’t always hear about it.”

It’s hard not to have heard of David Hackam. His evolution as a surgeon scientist has been marked by a series of remarkable achievements and appointments. At the University of Pittsburgh

School of Medicine he was the Watson Family Professor of Surgery and Professor of Surgery, Cell Biology and Physiology, the Associate Dean for Medical Student Research, and co-director of the Fetal Diagnosis and Treatment Center of the Children’s Hospital of Pittsburgh. He’s a recipient of the prestigious Hart-

well Award for his research into NEC, and this year he is serving as president of the Society of University Surgeons, the organization dedicated to advancing the surgical sciences. Also notable, today he’s the surgeon-in-chief of the Johns Hopkins Children’s Center and the Robert Garrett Professor of Pediatric

Surgery. So what brought him to East Baltimore?

The answer is more about what Hackam brought to Baltimore, says Ted Chambers, administrator for the Department of Pediatrics. Three years earlier Hopkins had completed construction of the new Charlotte R. Bloomberg Children's Center, a state-of-the-art children's hospital featuring 10 specialty-customized pediatric operating suites, a giant leap from the few general adult ORs previously made available to pediatric surgeons. Now the Children's Center needed more pediatric surgeons to fill the new ORs and grow its surgical program. But being Hopkins, leaders didn't want strictly clinical surgeons—they wanted forward thinking academic surgeons with strong research records. And to steer their ship they wanted a known visionary who could attract, recruit and mentor like-minded souls.

"This was a very impressive search with all stellar candidates, but David Hackam stood out as a magnificent academic clinician, scientist and leader who would draw people of the same ilk to Johns Hopkins Children's Center," says Chambers. "We also knew his background and the way he looks at pediatrics would take us to new places."

"He's a national presence—people know him through his research work, through his leadership in the Society of University Surgeons," adds pediatric surgeon Dylan Stewart. "He's a known commodity and people are very drawn to him."

Hopkins leaders were, too, but they were also searching for someone who had managerial mettle, a dynamic CEO type who could co-run the Children's Center—a new function of the pediatric surgeon-in-chief role—and unite the various pediatric surgical subspecialties based in various departments. The evolution of pediatrics and pediatric surgery, Johns Hopkins Hospital President Ronald Peterson says, mandated such a melding and the elevation of the chief pediatric surgeon position to lead the way. An executive both substantive and

affable was added to the list of qualifications, all of which appeared in Hackam.

The search for this unique, multifaceted individual, as Chambers suggested, was an intensive one. Over the course of 18 months some 30 candidates, all national leaders in pediatric surgery, were seriously considered for the position. Skype interviews narrowed the list to eight prominent finalists who presented their portfolio and vision to Hopkins leaders like Peterson, Dean/CEO Paul Rothman, Department of Surgery Interim Director Jonathan Efron, former Department of Surgery Director Julie Freischlag, Children's Center Director George Dover, and Pediatrics Nursing Director Judy Rohde, in addition to Chambers. The substance of the search itself reflected the importance of the position in a new era for pediatric medicine at Johns Hopkins. In the past, the pediatric surgeon-in-chief was selected by the head of the Department of Surgery—here input was solicited from many, the final decision a collective one.

Importantly, Hackam also saw in Hopkins an authentic, top-down patient- and family-centered care institution—a model, in his mind, essential for 21st century health care facilities to be successful.

"Paul Rothman, Ron Peterson, George Dover, Ted Chambers, Judy Rohde, they live and breathe family centered care," says Hackam. "It's a pretty apparent cultural thing here—you sense it as soon as you walk into the place."

And all that attracted Hackam to Hopkins he molded into a strategic plan grounded in innovative thinking, multidisciplinary approaches to solving complex problems unique in children, and translational research, what he calls his "blueprint for excellence in pediatric surgery." Among his goals—meet unmet clinical needs, tap into new patient pools out of state, recruit top surgeons and staff, build relationships with pediatricians and pediatric subspecialists in the community, set a standard for excellence—and specialize.

“At meetings he calls on everybody because he wants to make sure he's heard every point of view—so don't be reading your iPhone because he wants your perspective.”

— PEDIATRICS NURSING DIRECTOR JUDY ROHDE

Indeed, the reviews tightened the list to two and then one, David Hackam, who eagerly stepped on board. If Hopkins had found its match, he had found his—an academic medical center with world class clinicians, national centers of excellence and, in his words, "unique footprints and exceptional resources." Hopkins' history removed any doubts.

"Being successful as a surgeon-scientist only happens in certain places—environments with a history of training generations of surgeons to understand the balance between cutting edge surgery and science," Hackam says.

"To commit yourself to be excellent, you have to focus on areas where you're going to distinguish yourself and make yourself unique and separate yourself from other institutions," says Hackam.

Contemplating what could be special morphed into a vision of six strategically selected surgical centers of excellence in fetal medicine, colorectal/bowel management, short gut/intestinal care, trauma/burn, oncology and vascular anomalies. And linked to these multidisciplinary, evidence-based centers would be a new emphasis on research excellence in pediatric surgery, which would



Along with his deep research and surgical experience, David Hackam brings executive management skills that will come in handy in co-directing the Children's Center, a new feature of the pediatric surgeon-in-chief position.

translate into more robust recruitment, mentoring, research training and grant support—all essential elements of a successful pediatric surgical program in the 21st century.

“The extent to which the pediatric surgical services are involved with research, both basic science and clinical, will have a large impact on the degree to which the Children's Center can grow and market and position itself as a world leader in pediatric surgical care,” says Hackam. “You cannot be excellent unless you commit yourself to being excellent—these centers allow us to do that.”

And attract more patients and talented clinicians, too, adds Stewart: “I think that's how you help your institution stand apart—you concentrate on great care and get really, really good at it.”

With his vision in front of him, last September Hackam walked into Hop-

kins, or, in Judy Rohde's words—“hit the ground running”—and began the work. Itching to make a difference but in a collaborative way, he dug deep and reached out to all corners of Johns Hopkins Medicine to absorb its people and culture, to learn the lay of the land.

“He's been making all the right connections,” explains administrative supervisor Reatha Holt, who manages Hackam's schedule. She points to his standing meetings with Hopkins leaders, department chairs and division directors, but also with staff typically not on the calendar of a pediatric surgeon-in-chief. “He schedules a lot of meetings with staff because he wants their input, as well. For some people, this is new, which is refreshing.”

“At meetings he calls on everybody because he wants to make sure he's heard every point of view—so don't be reading your iPhone because he wants

your perspective,” echoes Rohde. “My personal experience is that he's been very engaged and has made an effort to know all the details about what makes the Children's Center tick.”

Or over-engaged? In addition to the standing meetings and staff meetings and open door interactions there's Hackam's regular clinic to see his surgical patients, his spot on the surgeon on-call calendar to manage surgical emergencies, his Fridays in the lab. And as a national leader in pediatric surgery and newly elected president of the Society of University Surgeons, he's often in the air and on the road, too.

“His schedule is aggressive and ever changing, ever growing,” says Holt. “Do you see why I drink coffee?”

Interestingly, Hackam's outreach and open availability not only surprised but also concerned some staff. “Over the past few months everyone has been

so excited about his role and everyone wants part of his time,” says Assistant Director of Pediatric Nursing Dawn Luzetsky. “How can he possibly meet everyone’s expectations?”

Apparently he has. Rohde, Luzetsky and others point to the new pediatric

surgeon-in-chief’s participation in activities like patient safety rounds, his formation of a new and diverse pediatric OR executive committee for the pediatric subspecialties, pediatric anesthesia and pediatric nursing, to discuss OR workflow and safety, policies and procedures,

resource needs. No longer would pediatric OR issues risk getting missed in the Department of Surgery’s OR executive committee.

“There are particular issues with pediatrics that need more local management,” says John Hundt, administrator

## IN THE LAB

# The “Magnificent Seven” vs. NEC

### JOHNS HOPKINS

**PEDIATRICIAN-in-Chief** George Dover was deeply gratified that institution leaders had chosen a new pediatric surgeon-in-chief who shared his view of a fully integrated Children’s Center. Then, having learned about what David Hackam and the members of his lab in Pittsburgh had uncovered in intestinal disorders in children, he was even more gratified. His partner would be someone like himself, a physician scientist intrigued by the mysteries of disease and passionate about finding the answers.

“David and his research team are a real ‘magnificent seven,’ whose work has reshaped our understanding of intestinal inflammation and whose ongoing research is on the cusp of transforming the way we treat some of the most devastating intestinal conditions in children,” Dover says.

Those conditions include necrotizing enterocolitis, or NEC, which leads to rapid and irreversible death of intestinal tissue. Therapy is limited to surgery that

leaves patients with insufficient intestine—short bowel syndrome—and at risk of long-term complications. Unable to absorb enough nutrients, these children require feeding support for life—and many transplantation and immune-suppressive therapy that pose long-term risks. If ever a disease needed a lab, Hackam felt, NEC was it.

Through simulating NEC in mouse models and employing genetic and pharmacologic approaches to prevent its course, Hackam, and his colleagues have made some significant inroads. For NEC to develop, explains Assistant Professor of Surgery Chhinder Sodhi, three factors must come into play—premature birth, hypoxia, and a bacterial infection. In that perfect storm, Hackam’s group identified a specific molecule that attracts gram-negative bacteria in the gut—toll like receptor 4 (TLR4)—which is highly expressed in the initiation of the disease. Expression of TLR4 is necessary for the development of the intestines, Sodhi

explains, but high expression of it halts blood flow to the intestines and normal development in its tracks, resulting in NEC. The Hackam lab had its treatment target.

The group has also found that amniotic fluid, which contains the wound-healing protein epidermal growth factor or EGF, inhibits TLR4 signaling, which could lead to development of a drug inhibiting TLR4 activity and preventing NEC inflammation in premature infants. In the womb, Sodhi notes, normal birth babies bathe in and drink amniotic fluid while premature babies do not.

Lab members have also found protection against NEC in breast milk, which is not readily available to premature infants. They showed that NEC did not develop in mice fed with infant formula containing sodium nitrate, a compound known to improve blood flow and found in breast milk.

“NEC often develops within the first two weeks of life, usually after milk feeding has begun and the infant’s immature bowels are prone

to infection,” says Sodhi. “The premature infant’s difficulty with blood and oxygen circulation also increases their risk of NEC. Without the breast milk and amniotic fluid, you have high levels of TLR4.”

In another preventive strategy, the group is also searching for diagnostic markers in, among other places, the mother’s stool. Another goal is identification of mutations in the TLR4 gene that cause higher signaling and expression.

“We’re studying all of the genes in the TLR4 pathway, taking them away and putting them back, to correct the signaling,” says Sodhi.

In yet another approach, what Hackam calls his lab’s “most exciting work,” he and his team are collaborating with Cornell scientist John March to create an artificial intestine for NEC patients. They’ve mastered a way to culture intestinal stem cells but they’ve been unable to create a structure where the cells can grow—but Hackam is determined to find such a scaffold.

“Science has to be driven

for the Department of Surgery. “The pediatric ORs, PACU and PICU all interface with the Children’s Center.”

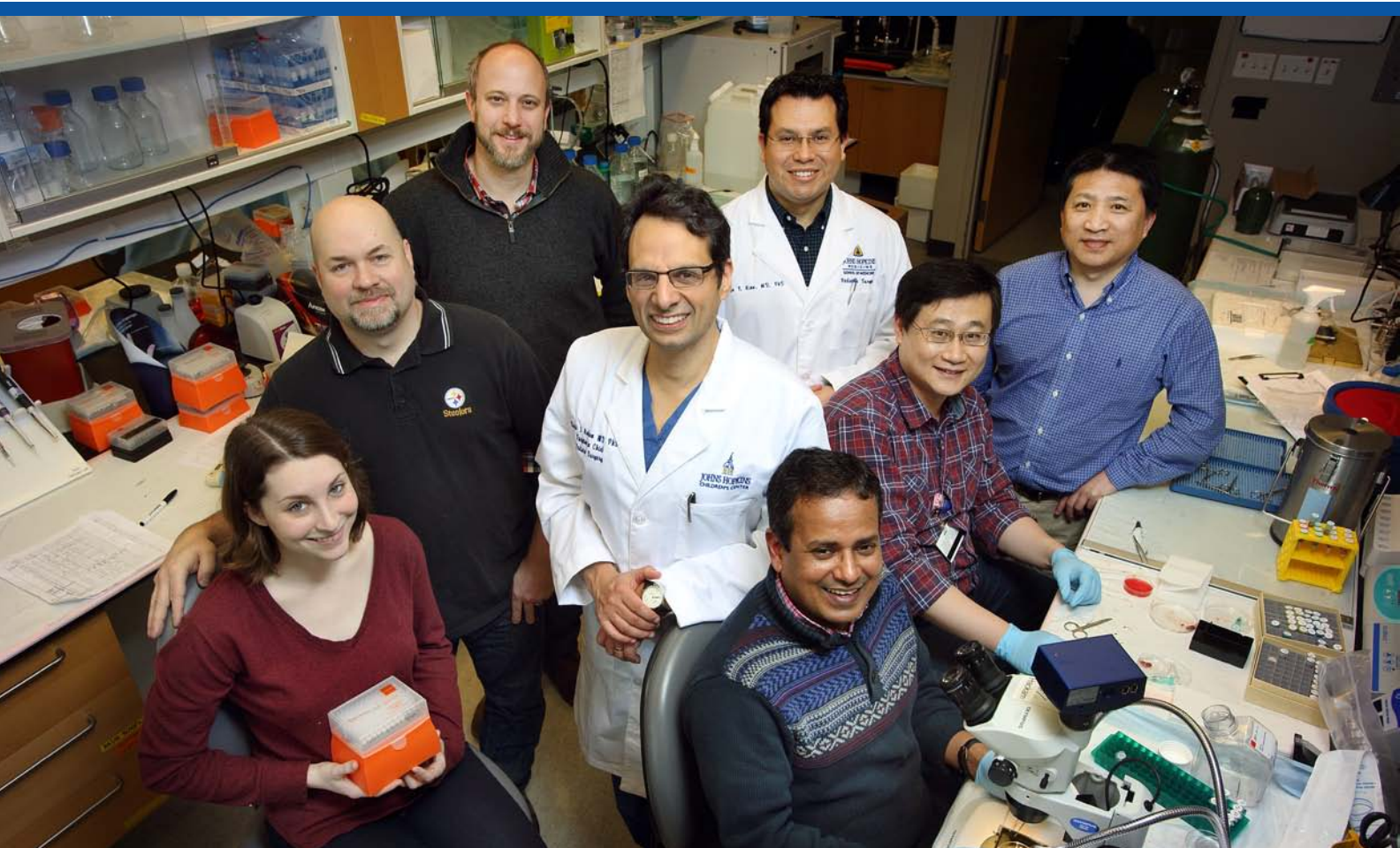
Luzetsky sees in Hackam’s vision improved communications and interactions between the pediatric surgical specialties and pediatric nursing, which

will enhance patient care. Performance improvement initiatives like family centered rounds worked well with the pediatric medical services, notes Luzetsky, but not as well with the pediatric surgical services.

Now, with a counterpart to Pediatri-

cian-in-Chief George Dover—someone who would represent all surgical services in the Children’s Center, not just general pediatric surgery—such challenges seemed less formidable and the benefits clear.

“Surgeons can’t operate in silos and



by necessity,” says Hackam. “These infants, born with intestines that don’t work, are left without a gut. They can wait for an intestinal transplant, but why not develop an artificial intestine? There’s a clear, unmet need for it.”

This research initiative, funded by a \$500,000-plus grant from The Hartwell Foundation, also dovetails

with studies by Hopkins pediatric plastic surgeon Anand Kumar in the plastics stem cell lab. There Kumar and his colleagues are investigating muscle stem cell biology for regenerative applications for bone defects of the skull and face for cleft lip and palate, and craniosynostosis patients.

“These children have too

much or too little bone and we don’t have great places to get bone grafting materials,” says Kumar. “We’re working constantly to engineer bone.”

In Hackam’s mind, that’s one more illustration of the continuing influence of science on surgery. ■

—GL

**In the Hackam lab (l to r), first row: Dorothy Hallberg, Chhinder Sodhi; 2nd row: Thomas Prindle, David Hackam, Peng Lu; 3rd row: William Fulton, Diego Nino, Hongpeng Jia.**

manage patients independently, they need to be attuned to systems of care and work with the pediatricians, hospitalists and intensivists,” says Hundt. “They need not just pop in to see their patients but do it in a multidisciplinary way and engage with all the team members in the Children’s Center to provide the best care for the patient.”

That approach is also in sync with Hackam’s surgical centers of excellence strategy, which pediatric reconstructive and plastic surgeon Anand Kumar sees

as not only a comprehensive care model but a sound business blueprint, as well. Kumar, who worked with Hackam at the Children’s Hospital of Pittsburgh, cites the experience of its Cleft-Craniofacial Center, which had its roots in one clinic supported by one department. Transforming the clinic into a hospital-based center united the surgical and medical subspecialists, Kumar explains, and incorporated team-centered and family-centered care with comprehensive services like audiology, dentistry,

orthodontics, ENT, gastroenterology, genetics, pulmonary, and neurosurgery, in addition to plastics.

“Bringing all of those services together in a hospital-based program really helped bridge pediatrics with surgery,” says Kumar. “It also allowed us to hire coordinators, schedulers, people devoted to the center without being bounded by the financial costs of having only one department support it. We know that works—today it’s a really robust center.”

Needless to say, such institution-



changing initiatives pose great challenges, too. How will David Hackam manage it all?

His daily pre-dawn swim helps immensely, he says, citing the physical benefits and the ability to think uninterrupted in an environment free of distractions: “While under water, I’ve written grants, speeches, tackled problems large and small, and had the opportunity to reflect on progress from day to day. Plus, starting the day underwater means things can only get better.”



Do Hackam’s colleagues on dry land share his aquatic perspective? What kind of leader do they see?

“In terms of leadership style, he’s very interested in supporting what others are trying to do so they can achieve greater levels of productivity and scholarship,” says Kumar. “But he also believes achieving greatness is not about what one person is doing but what everyone around that person is doing.”

“He’s very dynamic, very educationally minded, always trying to teach the residents something,” adds Stewart. “He’s one of those people who like big ideas—you can’t bring an idea to him he doesn’t like.”

“He strikes me as someone who is very positive and collaborative,” says Rohde. “Very approachable,” adds Luzetsky. “He has a very calm demeanor and does actively listen.”

Adds Chambers, “Right from the beginning there was this warmth about him that impressed everyone—that quality of listening, bringing up topics and asking others what they think, building consensus before acting.”

Holt, from her viewpoint just outside Hackam’s office, sees someone quite adept at managing multiple responsibilities—even as he helps manage the relocation of his family, his wife and four children, from Pittsburgh to Baltimore. What strikes her most about David Hackam?

“He’s a great family man,” says Holt. “To me, that’s the most impressive thing—he loves his family.”

So, David Hackam, you’re here and moving forward—any big questions that confound you?

“Am I really going to be able to get up at 5:15 a.m. so I can swim and be at work by 7,” he laughs. “Am I going to make it to work without getting lost? I think I finally figured out the best route

**Johns Hopkins Children’s Center’s deep history, its “unique footprints and exceptional resources,” sealed David Hackam’s decision to accept the position of pediatric surgeon-in-chief.**

“Someone once described the tremendous hope that exists when you’re on the threshold, and I feel like I’m on the threshold. I feel like I’m starting this big adventure and I’d like to think I’m already making an impact.”

— DAVID HACKAM, M.D., Ph.D.

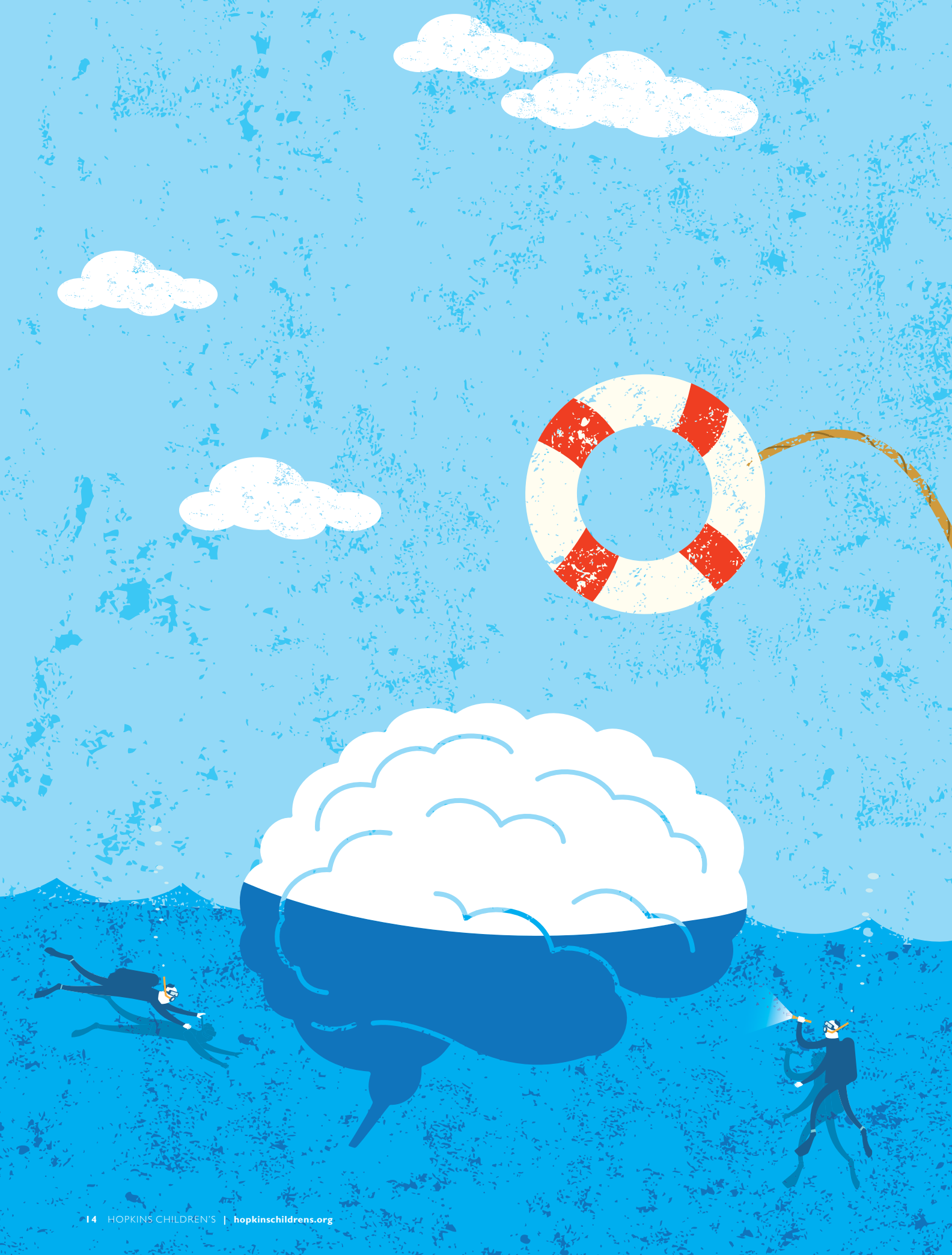
from Pikesville.”

Seriously, we ask, how are things going? He takes a breath, seemingly meditating the moment and the undertakings in front of him—a fully integrated Children’s Center with a full-service surgical enterprise, pediatric surgical centers of excellence, robust research and recruitment, and relationship building with community pediatricians.

“Is it daunting, yes, but I think I’m up to it,” he says. “Someone once described the tremendous hope that exists when you’re on the threshold, and I feel like I’m on the threshold. I feel like I’m starting this big adventure and I’d like to think I’m already making an impact. Is it easy? No. Have I made everyone happy? No, but am I going to do the right thing for patients and families and staff? Yes, 100 percent yes. That’s what gets me up every day and to the office.”

There multiple monitors, surgeon’s shoes and two long rows of framed family photographs greet him. On the wall behind his desk one can’t help but notice the Van Gogh painting entitled, appropriately, “First Steps.” On another wall hangs a framed farewell card from former colleagues in Pittsburgh. Among the best wishes, “End of an era in Pittsburgh! Beginning of another in Baltimore. Best of luck.” Another reads, “You’re not really leaving, are you? Baltimore is lucky to have you.”

Indeed! ■





# Saving the Newborn Brain



When infants come into the world with conditions like hypoxic ischemic encephalopathy, a group of specialists collaborate to provide the best possible care.

**by Karen Blum**



Soon after boxes of Girl Scout cookies are passed around the table and pleasantries are exchanged, the weekly Neurosciences Intensive Care Nursery (NICN) Friday afternoon conference gets down to business. Over the next hour, a multidisciplinary team of neonatologists, pediatric neurologists and neuroradiologists, among other specialists, review the status of babies either at high risk of neurological injury or who already have signs of brain abnormalities.

They've come to Johns Hopkins Children's Center because of a variety of circumstances—a baby diagnosed during the mother's pregnancy with hydrocephalus, a buildup of fluid inside the skull that leads to brain swelling; an infant with seizures born to a drug-addicted mother; a baby born to a teen mother unaware she was pregnant. In that case, emergency medical services arrived at the home to find the baby limp, with its umbilical cord wrapped around its neck three times. About 85 percent of patients are transferred to Johns Hopkins from elsewhere.

Over the faint whirring noises from an MRI machine next door, the group hones in on a particularly challenging case: a 21-day-old infant with signs of a possible genetic disorder. The baby has wide-spaced eyes, a poor sucking reflex, poor muscle tone and ambiguous genitalia. Its body periodically has involuntary muscle contractions. Pediatric neuroradiologist Aylin Tekes-Brady shows the group images from head ultrasound and MRI studies, which illuminates areas where the mobility of interstitial water is altered within various regions of the neonatal brain. After some debate about the next steps in testing, the group suggests the



**If it's Friday afternoon it's the weekly Neurosciences Intensive Care Nursery conference, where specialists from multiple disciplines fuse their experiences and insights in diagnosing and treating newborns at risk of brain damage.**

residents in charge consult with genetics and check OMIM, a comprehensive online catalog of genetic disorders authored by Hopkins' McKusick-Nathans Institute of Genetic Medicine.

The group shares thoughts about two other infants before closing. Then, neonatologist and NICN founder Frances Northington tells the two residents caring for the first baby that they have the most complex case, but not to worry: "Use your resources. You've got a lot of help."

These meetings are central to the mission of the NICN, which has cared for hundreds of infants since forming in May 2009. Co-directed by Northington, pediatric neurologist Adam Hartman and pediatric neuroradiologist Thierry Huisman, the unit not only provides multidisciplinary, state-of-the-art care for babies to minimize brain damage, but also serves as an ongoing learning environment for the care team and a rich source of research ideas. Faculty associated with the NICN are pursuing at least 14 research projects, such as measuring blood-based biomarkers associated with brain injury in preterm infants and babies' ability to

regulate blood flow to their brains.

Originally three of the 45 private rooms in the neonatal intensive care nursery (NICU) were designated for NICN patients, but it immediately became clear that as many as a third to a half of infants in the NICU required NICN-type consultation at one time or another during their stay. Now, the NICN is available to any infant that has a neurologic issue.

The NICN's origins date back to 2008, when Northington and colleagues had the opportunity to apply for funding for a formal neonatal neurosciences program from the Dana and Albert R. Broccoli Charitable Foundation. The organization, started by film producers known for their James Bond pictures, already had funded a heart disease center at Johns Hopkins. With Neonatology Division Director Edward Lawson, Northington pulled her colleagues across disciplines to put together a proposal.

Some other medical centers have a dedicated pediatric neurologist in the NICU, Northington says. "While that's great, that wasn't a possibility for us because of personnel demands and rather a low supply of neonatal neurologists," she

explains. "We decided to spread a wider net and try to advance the field, using our clinical cases as a core and then expand from there with educational and research missions."

With the \$170,000 grant, Northington was able to hire neonatal nurse Charmaine Parkinson as the NICN nurse coordinator and move forward. Since then, the NICN has evolved into a highly consultative group that also includes specialists from maternal fetal medicine, pediatric anesthesiology and critical care, and neonatal respiratory care.

"The cases serve as the talking points for the meetings—we present the neuroimaging and neurophysiology from those cases and there's always input from multiple other people who are not directly involved in the care, to give ideas about diagnostic workup, care management, and even some idea of what type of outcomes to expect," she says. "But mostly it's about doing things to improve the care of those infants."

The NICN mentality "cuts across the silos" seen in other institutions where experts work independently in their own areas of expertise, adds Hartman: "The

problem with the traditional model is that everyone weighs in on different points at different times in the day. You can have a situation where a radiology report can be misinterpreted or miscommunicated.

“I’m a better EEG reader because I know how it correlates with different imaging findings and clinical findings—it has made me a better bedside clinician,” he adds.

Talking about patients in a cross-disciplinary manner helps suggest potential research questions, too.

“I think that we are comfortable enough as a group that we’re OK saying, ‘I don’t know the answer to these questions,’ and either I have to look it up or it’s completely an unknown and that’s what drives some of the generation of new knowledge,” Hartman says. “In a sense I think we push each other a little bit to the limit of what is known and not known.”

Huisman adds, “It is patient care, in the most humane way of respecting each other and getting the input of all specialists into patient care, optimizing the interpretation of acute findings, evaluating treatments and giving some information on prognosis for all people involved.”

With Lawson’s support, an MRI-compatible incubator was purchased, allowing the neonate to be transported and imaged within the safe, well-controlled environment of the incubator. Neuroimaging includes both the bedside use of a dedicated brain ultrasound protocol as well as high-end, multisequence anatomical and functional MR imaging, allowing neuroradiologists to better characterize the quality and degree of brain injury. The advanced neuroimaging information has become an essential parameter in guiding and monitoring brain injury and treatment.

Central to the NICN’s care management offerings is therapeutic hypothermia, otherwise known as “brain cooling.” The treatment, which involves placing infants on a water-filled blanket to cool their core body temperature to 92.3 degrees Fahrenheit, then gradually warming them after three days, is considered the standard of care for hypoxic ischemic encephalopathy (HIE), a condition in

which oxygen supply to the brain is diminished. Cooling the baby, experts have found, interrupts the injurious metabolic processes that cause neurons to die. Johns Hopkins’ NICU has had a cooling protocol in place since 2007.

The group also incorporates biomarkers, measurable indicators of disease, in their treatment decisions. Work chaired by maternal-fetal medicine expert Ernest Graham determined that increased levels of a protein called glial fibrillary acidic

“The cases serve as the talking points for the meetings—we present the neuroimaging and neurophysiology from those cases and there’s always input from multiple other people who are not directly involved in the care, to give ideas about diagnostic workup, care management, and even some idea of what type of outcomes to expect.”

—FRANCES NORTHINGTON, M.D.

protein in the blood of premature infants with HIE could help predict injury to part of the brain’s white matter, a precursor of cerebral palsy. Parkinson now takes into account those measures when she talks to parents, to give them a realistic picture of what to expect.

“We want to make sure we’re not just saving their body, but also their brain and quality of life,” she says.

The unit constantly evaluates how to improve care for its charges. In December 2014, the neurology group began performing continuous electroencepha-

lography (EEG) on all babies undergoing therapeutic hypothermia to gain a broader perspective of brain activity than the limited sampling afforded by periodic bedside EEG monitoring or by using the simpler aEEG machines. This year nurses will be trialing a cooling head wrap to see if they can achieve better regulation of infants’ core body temperature.

After discharge, all babies are referred to Kennedy Krieger Institute for neurodevelopmental follow-up, and, if they have had a neurologic diagnosis, to Johns Hopkins’ pediatric neurology group. “If we see something that’s not looking good two years down the road, we have the potential to modify whatever it is,” Hartman says. “We don’t have to wait until they come back when they’re 10 or 12 years old, and having all kinds of school problems. We can see these things now and routinely get feedback from Kennedy Krieger. That’s something unusual.”

Recently, he says, a focus has been on what to offer the babies beyond cooling. And researchers here have been hard at work. Developing a neuroprotective bundle of interventions for premature infants has been the focus of one project, led by neonatal nurse practitioner Karen Dittman.

Due to advances in neonatal care, babies born at 25 weeks’ gestation routinely survive, and even those as young as 23 to 24 weeks’ gestation can be saved, Dittman says. But because the blood vessels in the brain are not fully developed, babies in this age group are at high risk for bleeding. Up to a quarter of infants born weighing less than 2.5 pounds experience intraventricular hemorrhage (IVH), which can lead to more serious conditions including hydrocephalus and periventricular leukomalacia—a brain injury involving the death and loss of brain tissue around the ventricles in the brain, which in turn can lead to cerebral palsy or other motor deficits, seizures, and severe developmental delays and cognitive impairments.

Dittman and colleagues are actively searching the medical literature for interventions that could decrease these fragile infants’ risk of IVH. Some ideas include keeping the baby’s head straight



**Pediatric neurologist Adam Hartman, neuroradiologist Thierry Huisman and neonatologist Frances Northington, all co-directors of the NICN, consult over the care of a newborn.**

and slightly elevated, avoiding rapid administration of IV fluids and rapid blood drawing, and minimizing pain.

“There’s a lot of pseudoscience out there,” Dittman says. “We’re trying to sort through what’s pseudoscience, what’s real science, and what may have been based on somebody’s hunch.”

One intervention already in practice, identified by NICU nurse Karen Frank, is delaying the clamping of preterm infants’ umbilical cords. Waiting just 45 seconds before clamping the cord is enough to allow the placenta to bring more blood cells to the baby so there’s less chance of anemia and a lower risk of intracranial hemorrhage, Dittman says. Doctors also give laboring mothers a shot of betamethasone, a steroid that could decrease their babies’ risk of IVH. In addition, NICU staff work to keep the babies’ temperatures stable, and avoid swings in blood pressure. Upon completion of her review, Dittman will report back to the NICN team. “We want the best possible outcome for our babies.”

Infants undergoing the cooling protocol are routinely given the pain medication morphine to prevent shivering,

but neonatologist Estelle Gauda and colleagues are investigating whether clonidine, a blood pressure medication, might better improve neurological outcomes. Beyond lowering blood pressure, the agent also has been shown to have some neuroprotective effects in newborn rats recovering from stroke. It suppresses output from the sympathetic nervous system that activates our innate “fight or flight” response, reducing agitation, excitement, and is quite effective in reducing shivering. As an added bonus, while morphine decreases respiration, which causes the need for additional interventions in some infants, clonidine does not suppress breathing, increasing the probability that the infant can breathe without ventilator support.

Gauda’s group has finished the first part of her study, testing NICN babies’ tolerance of clonidine and the optimal dose, with good success. Next, they’ll study a larger group of infants to better understand how the babies metabolize clonidine during cooling. Ultimately, she says, she’d like to conduct a double-blinded, randomized controlled trial comparing morphine and clonidine on

neurological outcomes.

Also, work directed by pediatric anesthesiologist Jennifer Lee is finding that NICN babies’ ability to regulate blood flow in the brain in the first few days of life can predict how they will do in the next two years. In conjunction with cooling, Lee has been studying cerebral autoregulation, a natural process that maintains stable blood flow to the brain. Within a normal blood pressure range, the brain controls its own blood flow and adapts to changes in blood pressure. So if blood pressure drops, the brain should regulate its own blood flow to prevent a stroke. By contrast, if blood pressure rises, the brain should compensate so it doesn’t hemorrhage.

But babies born with brain injuries may have low oxygen levels and may need medication to support proper blood pressure. Using cerebral near infrared spectroscopy (NIRS), a technology that monitors the concentration of oxygen in the brain, Lee and colleagues can estimate blood flow to the brain and determine the safest range of blood pressure for an individual baby. NIRS uses just a small sticker placed on the forehead, so “it’s an

“We want to make sure we’re not just saving their body but also their brain and quality of life.”  
— MONICA LEMMON, M.D.

ideal technology for babies,” she says.

Babies who can’t regulate their own blood flow are more likely to show signs of brain injury on an MRI scan at age two weeks, and more likely to have signs of neurocognitive injury at age two years, according to Lee’s research.

The NICN will also participate in national clinical trials like the PENUT (Preterm Epo Neuroprotection) study, funded by the National Institute for Neurological Disorders and Stroke. This study, led locally by neonatologist Maureen Gilmore, is studying whether a high dose of a medicine called erythropoietin (Epo) can help protect premature infants’ brains from injury and reduce the occurrence of later developmental problems. They are just beginning recruiting

for the study, which will give either Epo or a placebo three times a week until the baby reaches 32 weeks’ gestational age, and follow the babies until they are 2 years old.

Education also is a major focus for the NICN. Parkinson trains all new nurses and fellows in bedside technologies like brain cooling. The NICN faculty organizes regular in-service training workshops on care management for the babies, and every other year partners with Children’s National Medical Center in Washington, D.C., to teach a continuing medical education course covering updates and advances in neonatology. Hartman started a rotation through the NICN that is now required for pediatric neurology residents from Johns Hopkins and neurodevelopmental disabilities residents from Kennedy Krieger Institute. One pediatric neurology resident, Monica Lemmon, was so inspired that she has chosen neonatal neuroscience as a career. She is now the NICN’s first fellow.

“For me, there is no more exciting population to work with,” Lemmon says. “First, you’re working with families

at a critical and vulnerable time in their baby’s life. There is a lot of uncertainty. Fortunately, the newborn brain can recover in ways that the adult brain cannot. It is hugely rewarding to work with these children as they grow and develop.”

Among other duties, Lemmon organizes the weekly NICN conferences. A research project she’s undertaking will survey parents of former NICN babies to find out what worked and didn’t work in terms of communication between the families and the NICN teams; their responses may inspire additional changes to the program.

“This fellowship has set the stage for how I’d like to spend my career,” she says. “There is a big interest nationwide in setting up programs like the NICN. People want to replicate it.”

“I tell audiences when I talk about the NICN that everybody needs an NICN because every baby in the neonatal intensive care unit either has a primary neurologic problem or they are at risk for neurologic injury,” says Northington. “Every single patient. That’s how important it is to pay attention.”

In the NICU, neonatal nurse Charlamaine Parkinson with NICN fellow Monica Lemmon.



Parkinson keeps a log of patients and outcomes so she can communicate with parents. “I tell them, ‘I know it’s scary now, but let me tell you about someone in a similar situation, and how they are

doing.’” She keeps in touch with many of the NICN “graduates” and their families. Even some parents whose children have passed away come back to say hello, she says.

“I like seeing how we made a difference,” Parkinson says, “because I know how they would have turned out if we hadn’t intervened.” ■

## Savannah’s NICN Journey

**CHERYL CARR KNEW HER** second pregnancy was tougher than her first. Diagnosed with complete previa, in which the placenta supplying nutrients and oxygen to the fetus blocks the cervical opening, Carr was put on bed rest. Doctors hoped the placenta would shift before her March 2012 due date.

Then, during a routine prenatal exam that February, Carr’s obstetrician noted that the placenta had moved, and scheduled her for induction at Greater Baltimore Medical Center on February 23. But when Carr started bleeding out from the previa during labor, and the baby’s heart rate dropped, Carr underwent an emergency Caesarean section. When her baby girl Savannah was born, doctors found the child had a velamentous cord insertion—meaning her umbilical cord was not inserted correctly into the placenta—and she had suffered some blood and oxygen loss. Savannah’s Apgar scores fluctuated wildly and she wasn’t breathing properly. At one point, she needed resuscitation.

Doctors knew they had only one choice to turn Savannah’s prognosis around—immediate transfer to Johns Hopkins’ Neurosciences Intensive Care Nursery (NICN). They also arranged for Cheryl Carr to be transferred to The Johns Hopkins Hospital the next morning so she could be closer to her daughter.

Carr’s husband William reluctantly left his wife and quickly arranged child care coverage for their 11-month-old son. William dropped off the baby at home and headed to Johns Hopkins. When he and his sister arrived at the NICN, doctors there gave him several consent forms to sign. Shortly after, Savannah had a seizure. During her first 48 hours, she was almost in kidney failure.

Over the next 18 days, Savannah received a number of interventions to rescue her health, including a tube inserted into her windpipe to help her breathe; two blood transfusions and four platelet transfusions; anti-seizure medications; and therapeutic hypothermia, or brain cooling. Savannah started her NICN journey hooked up to multiple monitors but over time, says Cheryl Carr, 34, of Middle River, Md., “We would notice one less wire or one less machine, and we knew we were making progress.”



Since her NICN stay as a newborn, now 3-year-old Savannah Carr has thrived.

Since discharge, Savannah has done well. The Carrs were able to discontinue her anti-seizure medications when she was nine months old, and physical therapy services when she was 15-18 months old. Savannah, now 3, still needs to see a kidney specialist once a year but otherwise acts like any typical toddler. She enjoys dress up games and playing with her “Darbie” dolls, and she has been known to steal her 4-year-old brother’s Ninja Turtle figures. The family recently returned from a vacation to Disney World.

“Savannah proved everyone wrong,” Cheryl Carr says. “She’s my little miracle baby.”

“Savannah was critically, critically ill when she arrived at Hopkins,” says neonatologist and NICN Co-Director Frances Northington. “To see her thrive and do well is the greatest joy I have in terms of our NICN program. And to know we’re working to better the outcomes for more kids like Savannah is a real thrill.” ■

—KB







# From Johns Hopkins to Navajo Nation

Facing the health care needs of Native American children firsthand in remote Tuba City, Arizona, pediatric residents expand their clinical skills and their horizons.

**by Gary Logan**

## Facing residents and faculty filling Johns Hopkins Chevy Chase auditorium last fall, pediatric resident Amena Weston Smith discussed the health care needs of Native American children in this country.

In her talk, entitled “The New Morbidity of Native Americans,” she noted that these children face an overwhelming burden of disease with higher rates of depression and mental health disorders, drug and alcohol abuse, adolescent pregnancy and youth suicide, chronic illnesses like diabetes, and a higher incidence of obesity than their non-Native American counterparts.

She added, “One thing that stuck out was the high child mortality from injury, which is three times higher compared with other ethnicities.”

Smith’s presentation was prompted by more than an interest in researching the health status of Native American children. She had just completed a one-month rotation at Tuba City in northeast Arizona, where Johns Hopkins pediatric residents face these health disparities first-hand. Why did she go?

“I wanted to understand why *we* go there, the health care needs of Native American children in this country, and how we help meet them through our elective,” Smith said at a recent Johns Hopkins Children’s Center Grand Rounds.

That’s a commonly heard motivation, says Johns Hopkins Pediatrics Residency Director Janet Serwint, noting that the Indian Health Service Elective has been offered to residents since 1992. In total, some 240 pediatricians in training have gone through the program, caring for children from 8 a.m. to 5 p.m. each day in Tuba City’s Indian Health Service Hospital, its pediatric ambulatory clinic and emergency department, and twice monthly in the local high school clinic. Living in an apartment adjacent to the hospital and clinic, they are “deeply integrated” in the community, which, Serwint adds, helps them understand the patient in the context of their daily lives.

“They run into people in the grocery store, see them on the street, interact in

meaningful ways to better understand their environmental, lifestyle and medical issues,” Serwint says. “It’s a very powerful experience.”

Part of the elective’s allure is also practicing in an extremely rural environment and treating a homogenous patient population with chronic conditions, as well as some exotic ones.

“Scorpion bites have not been on my differential diagnoses here in Baltimore,” says Serwint, “but they were in Tuba City.”

Practicing in a different culture is another attraction, adds Serwint, noting that the experience helps the pediatrician understand the medical, social and emotional issues important to patients and their families.

“How does the culture guide you, how do customs and the family’s health care beliefs guide your negotiation with the patient?” Serwint says. “This experience helps inform their future decision making. It’s certainly good preparation for community practice.”

Pediatric resident Kristal Prather agrees, citing the community commitment and cultural sensitivity of Tuba City pediatricians she worked with.

“Families do come with a certain set of beliefs and practices, which helps you achieve the health goals for the family,” says Prather. “Practitioners in Tuba City feel it’s very important to integrate yourself into the community.”

Among the challenges, Prather adds,

Tuba City, AZ is **2,176 miles** from Johns Hopkins Medicine in Baltimore, Maryland

Some **240 Hopkins pediatricians** in training have gone through the program in Tuba City’s Indian Health Service Hospital

Navajo Nation is sparsely populated with some **150,000 people** scattered across an area about the size of West Virginia



is managing patients living in very rural areas. Navajo Nation is sparsely populated with some 150,000 people scattered across an area about the size of West Virginia. Many residents live miles from town in dilapidated trailers or small ramshackle homes on dirt roads with little or no access to electricity and running water. Consequently, the emphasis is on community outreach and ambulatory care.

“Pediatricians work hard with families to avoid an admission if possible because it’s so hard on families,” says Prather. “They do whatever they can to manage the child as an outpatient, which is a refreshing way to work with patients.”

Such remote and impoverished conditions—80 percent of children in the region live under the federal poverty line—also invite difficult-to-manage health problems like diabetes, diarrhea, influenza, obesity, pneumonia, and mental health issues like depression and alcohol/substance abuse.

“It’s a different set of illnesses in a different setting,” says Steve Holve, pediatrician-in-chief of the Tuba City Regional Health Care Corporation. “No one in Baltimore doesn’t have water and electricity and lives 80 miles from the nearest hospital.”

A significant shortage of pediatric subspecialists in the area, observes Holve, adds both another obstacle and opportunity for the pediatric residents. For specialty care, patients rely on telemedicine consults and quarterly visits from Phoenix-



based pediatric cardiologists, neurologists and orthopedists, and what the attendings and residents have picked up.

“It can be quite challenging to know a little about everything in making decisions,” Holve says. “You use all the things you learn and a lot more.”

Pediatric resident Helen Hughes concurs: “Primary care providers there, by necessity, become a little more comfortable with specialist management.”

Hughes notes that her Tuba City

**Back home at Hopkins following their Native American experience, (l to r) pediatric residents Amena Smith, Laura Scott, Kristal Prather and Helen Hughes.**

“The highlight for me was incredibly supportive pediatricians who integrate you with the community as much as they can. And there’s so much land to explore.”

— KRISTAL PRATHER, M.D.

comfort level was raised by what she was learning there as well as by her experience in Baltimore treating urban poor children with chronic conditions like diabetes. She also found Hopkins in another way in Tuba City, pointing to its public health initiative “Together on Diabetes,” in which children and families receive nutrition and physical education. The value of the Tuba City elective for her, Hughes adds, was learning how to do more with less.

“The experience makes you think more and to be open to different ways to treat patients because Tuba City doesn’t have as many resources as we have here,” says Hughes. “You have to be more thoughtful about the care you’re providing, about ordering tests and imaging, what you’re putting your patient through, which we should be thinking about anyway.”

Tuba City veteran Laura Scott agrees, citing Tuba City’s all-paper outpatient clinic: “There’s no computer charting, no EPIC.”

But what Scott liked was the intimacy

of the small clinic where, unlike the expansive Harriet Lane Clinic at Johns Hopkins, nursing and physicians work together in one place.

“They know their families really well and the patients and families see the same faces every visit,” says Scott. “It’s very much about the continuity of care. It’s a really neat dynamic.”

That dynamic has helped improve outcomes for patients, too, Smith noted in her Grand Rounds presentation. Disparities in vaccination coverage in the area have been eliminated, post-neonatal mortality has declined 90 percent between 1965 and 2009, and child mortality rates have stabilized during that time, as well. Infectious causes of death other than pneumonia are now responsible for less than 1 percent of childhood deaths, compared with 22 percent in the 1960s.

How about outcomes for the residents who rotate through Tuba City? Has the experience shaped and influenced their careers in pediatric medicine? Serwint hasn’t tracked their paths but one tell-

Pediatric resident Kristal Prather at Zion National Park, Utah.





ing outcome, she says, is the number of residents—currently 11—who end up practicing in Tuba City following their rotation.

“People are drawn to the practice and the community,” says Serwint. “The environment offers a balanced way to live, a more solitary kind of place where you can reflect on your career.”

So, how would the residents sum up their experience?

“It’s cool to be able to go somewhere and train for a month in a totally different environment. It’s such a different patient population and a different approach to treating those patients,” says Scott. “I learned a lot about primary care there.”

“The highlight for me was incredibly supportive pediatricians who integrate you with the community as much as they can,” says Prather. “And there’s so much land to explore.”

“You leave understanding so much more about Native American culture, what it’s like to live on a reservation and deliver health care in an extremely rural environment,” says Hughes. “And the most beautiful sunsets I’ve ever seen.”

“I loved being in Tuba, living in the southwest, working with the people, experiencing a whole other part of the country,” says Smith. “This is a treasure for residents. ■



At top, sprawling Tuba City enveloped by mountain ranges in Northeast Arizona. Above, resident Amena Smith, second from right, with a Native American family.



The Indian Health Service ambulatory clinic where Johns Hopkins pediatric residents spend most of their time during their one-month rotation in Tuba City, Az.

PHOTO BY LAURA SCOTT

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# pediatricrounds



Pediatric cardiologist Shetarra Walker, with pediatric nephrologist Tammy Brady, assesses a patient's echocardiogram. All children with high blood pressure are at risk of heart thickening, or left ventricular hypertrophy.

# Treating the Hypertensive-Obese Child

by Gary Logan

**IN TREATING CHILDREN** in her hypertension clinic, pediatric nephrologist Tammy Brady noticed that while most patients did not have a secondary condition like heart or kidney disease, an increasing number were overweight or obese. Indeed, looking into the literature she found that the increase in hypertension corresponded to the rise in obesity rates among children, which have tripled in the United States over the past three decades.

“In the 1970s and 1980s, about 1 percent of children were hypertensive—today that number is up to 5 percent,” Brady says.

Brady also found that successfully treating these obese-hypertensive patients was particularly challenging. Getting patients’ weight down would lower their blood pressure levels, but how do you achieve that when so many factors may underlie obesity?

“We’d say you need to work on weight loss and they’d come back for their next appointment in six months having gained weight,” Brady says. “I found that the standard-of-care tools that we had were not successful.”

What these patients needed, Brady concluded, was a multidisciplinary clinic that could effectively address both the hypertension and weight issues. Brady pieced together such a hypertension-

obesity clinic, adding a dietician, physical and occupational therapists, a behavioral psychologist and a pediatric cardiologist to her team.

“So I thought, let’s try and come up with a one-stop shop to treat all of the aspects of hypertension and obesity for these patients,” Brady says. “Also, we wanted to make it easier for families, so they don’t have to make multiple appointments or jump from provider to provider.”

In this new clinic, patients are also seen more frequently—every three months rather than every six months—to keep them on track with the treatment plan. At each visit, the dietician guides the patient on nutrition and weight loss, the physical therapist on exercise options, the occupational therapist on how to incorporate recommendations into daily life, and the behavioral psychologist on

underlying mental health issues that may be influencing the patient’s eating habits. Treatment recommendations promote a heart-healthy lifestyle—a diet that includes fruits and vegetables, limited screen time, and one or more hours of physical activity daily.

“Our dietician does a full metabolic workup and we assess patients for any physical reasons they can’t be active,” Brady says.

Also, an echocardiogram is performed as part of an assessment by the pediatric cardiologist for early signs of heart disease. All children with high blood pressure are at risk of heart thickening, or left ventricular hypertrophy, Brady notes, especially those who are overweight or obese. ■

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For more information, call 410-955-1247.



English professor Lauren Small and pediatric resident Ben Oldfield explore the underlying meaning of Mexican artist Frida Kahlo's self-portraits.

## Healers Mine Medical Narratives

**PHYSICIANS AND NURSES**, among others in health care, live in a world of stories—and they and their patients are the storytellers. Each day they reveal new narratives immersed in illness and injury, pain and suffering. What do these health professionals do with the stories? Do they disregard them and move on to the next patient, or infuse them into their daily working lives?

Such questions are at the root of “AfterWards,” a new narrative medicine program designed to illuminate stories of healing for the healers. The brainchild of Hopkins pediatric resident Ben Oldfield and University of Maryland English professor Lauren Small, AfterWards is designed to connect caregivers in more intimate ways to the human story underlying the disease. But to find the therapeutic value, Oldfield explains, caregivers must learn how to metabolize stories of illness.

“Effective medicine requires narrative

competence, or the ability to acknowledge, absorb, interpret and act on the stories and plights of others,” says Oldfield. “Recognizing the narratives important in your patients can empower you to understand the illness experience and help generate resilience in the face of adversity.”

Each AfterWards monthly session comes with a theme like “bearing witness to suffering” and an accompanying narrative. But Oldfield and Small define narrative as more than the printed word—a painting, photograph or sculpture, as well as a piece of literary fiction or a poem, will do.

At one session, for instance, the work of Mexican artist Frida Kahlo was appraised by staff physicians, residents and nurses. What they found was a brief and isolated life plagued by painful injuries from a horrific bus accident and emotional distress during her turbulent marriage to artist Diego Rivera. Perhaps unable to

express her pain in words, Kahlo played hers out in surreal self-portraits.

In reviewing such artwork, AfterWards participants are asked to write their own reflections as caregivers. One physician wrote about the difficulty in deciding how much pain medicine to administer to a terminal patient, and another about the first death she witnessed on her unit. “I can still hear the mom sobbing, see the pain on everyone’s face,” she wrote.

Such self-reflections, adds pediatric fellow Deanna Wilson, may also counter the stress that comes with caring for patients.

“Reflection allows better clarity, helps us process our experiences and emotions, which allows us to give more of ourselves to our patients,” says Wilson. “It also allows us to see that our colleagues have similar emotions, and in seeing our common threads we all might approach the care of our patients in more effective ways.” ■

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# For Nephrology Chief Barbara Fivush, a Career Move

by Mat Edelson

**THE DIVISION OF PEDIATRIC** Nephrology's loss will be the School of Medicine's gain as current chief Barbara Fivush is set to switch roles. Fivush, who over 20 years built pediatric nephrology from one faculty member into a nationally respected division, will be moving on to concentrate more fully on a lifelong passion; that of gender equity in her role as Associate Dean and Director of the Office of Women in Science and Medicine (OWISM).

Summing up a generation at the helm isn't easy, so maybe the best place to start is with the numbers. From the most modest of beginnings, the division has grown to seven faculty and a clinical associate. Research dollars have jumped ten-fold, to a half-million dollars annually. The division now operates five unique centers, including programs for end-stage renal disease and pediatric kidney transplantation. What make those numbers even more remarkable is that Fivush, way back when, took over a division that barely existed on paper.

"Other division chiefs, they come in and the program is already here and they just have to make it better," says Department of Pediatrics Director George Dover. "Barbara did it all on her own. That took a tremendous amount of academic and clinical expertise—she became a national authority publishing the standards of care for children with chronic kidney disease, developed a close alliance with her young faculty and fellows as a mentor, and she had to be a business woman at the same time. To me, she was highly successful at all those things."

Fivush, who will remain on the faculty, has always been about her staff, building connections as a way of enhancing personal reputations and the division's national prestige. Alicia Neu and Susan Furth, Fivush's first and second faculty hires, respectively, benefited tremendously

from the academic connections forged by Fivush. She impressed upon them the importance of establishing collaborative relationships outside the institution, personally introducing them to leaders in the field, and encouraging them to network.

"She's a fabulous mentor," says Neu. "The very first time Sue Furth and I attended a meeting without Barbara, we knew, when we got back, that she was going to ask us who we said 'hello' to because that was important for our careers."

Indeed, careers have blossomed under Fivush's watch. Furth, for instance, went on to become Chief of Pediatric Nephrology at The Children's Hospital of Philadelphia. Alicia Neu is currently the clinical director of the division at Johns Hopkins and the principal investigator on a national multi-center study aimed at reducing infections in pediatric peritoneal dialysis patients. Pediatric nephrologist Jeffrey Fadowski has become an expert on environmental exposures and the impact on kidney function. Meredith Atkinson is nationally renowned for her work on anemia in youngsters with chronic kidney disease, while Tammy Brady is the go-to researcher/clinician on pediatric hypertension. Cozumel Pruette's interests include pediatric hypertension and home telemonitoring to improve medication adherence. And Sangeeta Sule continues to target rheumatic diseases in children.

With all this expertise in place, Fivush can focus on her work in OWISM, which she's been involved with since its founding in 2008. As for the role she's vacating: "The division is really in a great place. It's stable, well-funded, the faculty is collaborative and successful. I'm comfortable that it will continue to do well and to be nationally recognized as one of the best pediatric nephrology divisions in the country." ■



“Other division chiefs, they come in and the program is already here and they just have to make it better. Barbara did it all on her own.”

— GEORGE DOVER, M.D.



# Advancing Pediatrics

**Renee Boynton-Jarrett, M.D., Sc.D.**

Evolving from cultural anthropologist to epidemiologist, pediatrician and community advocate, this former Johns Hopkins pediatric resident is making a difference for children in Boston.

by **Chris Iliades**



**RENEE BOYNTON-JARRETT** has always had a plan. One of her first memories is growing up in Englewood, NJ during a contentious school desegregation proceeding: “I could not understand why there was such division. It sparked my early interest in understanding human behavior and social differences.”

One of her early influences was Zora Neale Hurston’s “Their Eyes Were Watching God.” At a young age she decided to become a cultural anthropologist. But she would also become an epidemiologist and a pediatrician. It has all been part of a plan that keeps evolving.

At Princeton, Boynton-Jarrett studied anthropology and medicine: “I was interested in stories about illness, the myths that people use to explain illness, how illness changes a person’s life, and how they deal with those changes.”

In 1996, as part of a Princeton community outreach program, she spent time with 12 women who had become pregnant as teenagers. “I was astounded by the level of fear and violence that these women and their children were exposed to on a daily basis,” says Boynton-Jarrett.

Next, at Yale University School of

Medicine, Boynton-Jarrett did a four-month fellowship for an underserved community in Mattapan, Mass.: “It was then that I knew my place, my passion, was to work closely with communities to improve health.” A degree in social epidemiology would be helpful, so she

Another formative influence was Harriet Lane Clinic Director Barry Solomon: “He taught me how important it is to have and to be a great teacher. He believed in me and made me realize we can create an opportunity for healing and wellness in every clinical encounter.”

“I was interested in stories about illness, the myths that people use to explain illness, how illness changes a person’s life, and how they deal with those changes.”

– **RENEE BOYNTON-JARRETT, M.D., SC.D.**

detoured through the Harvard School of Public Health, emerging with her M.D. and Sc.D.

Boynton-Jarrett always loved children and their world. Becoming a pediatrician was the final step in her plan. “I loved my years at Johns Hopkins,” says Boynton-Jarrett, recalling her first mentor, pediatrics professor Tina Cheng: “She showed me how to combine great clinical medicine with solid research.”

Yet another mentor was Janet Serwint, now director of Hopkins’ pediatric residency program: “She taught me that when you deliver bad news to a parent, your words will live in their memory forever. Time, she taught me, is the most important thing we give to our patients.”

In 2007 Boynton-Jarrett left Hopkins, where she received the David Kamsler Award for excellent and compassionate care, and landed at Boston University



School of Medicine. The school is located in loud and busy South Boston—but Boynton-Jarrett's office is an oasis of tranquility. She is fully present and calming to be near. She gives you her time.

Her clinics keep her busy and she enjoys teaching—she received the Teacher of the Year Award for the Pediatric Clerkship—but her heart is in the community. Founder and director of the Vital Village Community Engagement Network, she focuses on the role of early life adversities as social determinants of health. She is particularly interested in psychosocial stress as a predictor of health outcomes like obesity and early puberty. But her interest is far from academic—she rolls up her sleeves and makes a difference.

“I found that the communities were awash in good social programs and smart, creative and committed people, but outcomes were not so stellar because of a lack of coordination and accountability,” says Boynton-Jarrett. “It was like we were all working in our own little silos.”

She and her colleagues have identified areas where existing programs, like preconception and preschool, can come together and coordinate care. In the past four years, Vital Village has become a network of residents and over 75 organizations committed to child, family and community. Last year, the Doris Duke Charitable Foundation awarded well over \$1 million to the Vital Village Network to promote child well-being and prevent abuse and neglect in three low-income Boston neighborhoods.

Boynton-Jarrett has always had a plan. Along the way she has nurtured it into what she is today—a teacher, researcher, pediatrician, and advocate. She is also a wife and mother of three. She has been married to her life partner, Gene Jarrett, a professor of English at Boston University, for 17 years.

In her spare time, she loves to read and would like to have a garden, but how much free time can there be when you have a plan that keeps growing. And as Boynton-Jarrett says, “the soil in Boston is not as good for gardening as it was in New Jersey.” But what she has planted in Boston will likely bear fruit for a long time to come. ■

# Taking Surgery To the Tropics

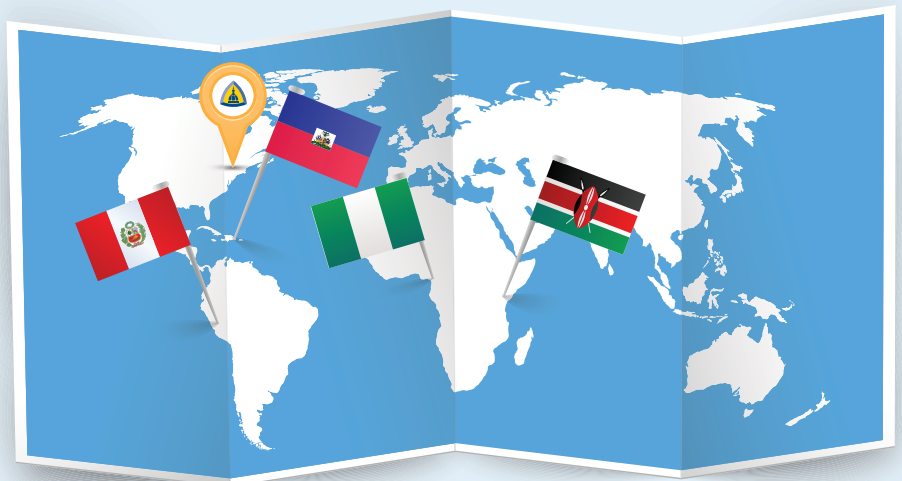
**OVER THE PAST DECADE,** pediatric emergency medicine physician Karen Schneider had already treated thousands of children in remote areas of the world through her tropical medicine elective. She and her teams of pediatric residents and nurses would set up clinics in remote places in developing countries like Peru and Guyana for weeks at a time, treating medical conditions ranging from dehydration to malnourishment. But any surgical cases that came her way she'd have to refer to urban hospital centers with a surgical service—some hundreds of miles away and difficult to access for poor families. Also, many families could not afford the fees for even the simplest operations, like hernia repair.

“I had 95 patients on the waiting list for hernia operations in Peru but they didn't have the money,” says Schneider. “Surgeons wanted \$500 per child.”

Five years ago Schneider decided she needed to take a new tack to treat these patients. She recruited a general pediatric surgeon and anesthesiologist to perform operations at the nearest local hospital. If there was no local hospital, she'd set up a surgical clinic, using a portable pressure-cooker sterilization unit she purchased in the states. The pediatric residents who accompanied her on her tropical medicine elective would screen patients for surgical as well as medical needs, take online courses in sedation and assist in the makeshift ORs.

“Anyone who has been on a trip with me knows the difference between hernia and hydrocele and which patients need a surgical consult,” says Schneider. “This is exactly what they would do as pediatricians.”

The impact of the surgical missions? To date, Schneider and her teams have completed a dozen surgical missions in Haiti, Kenya, Nigeria and Peru, among other developing countries, providing or facilitating surgical services for some 800 pediatric patients. ■





# A Matter of Trust

by Divna Wheelwright

**IN THE TRAUMA** room children offer me their trust with a gaze that cuts through the latticework of hands pressing down on their flesh. Other times trust presents itself in the delicate clasp of a hand, tightening ever so slightly as the nurse's shears cut through a bloodied "Hello Kitty" tee shirt warm with sweat. Trust can hide in plain speech, the child's voice admonishing: "Don't let me go." Recently I watched as trust flashed then expired in a ten-year-old boy who—confident in the surgeon's assurance that the rod protruding through his thigh would not be pulled without warning—thought it safe to return his head to the pillow.

A hospital breeds hierarchies. When is a Child Life specialist justified in challenging medical authority? I wondered this as the surgeon approached the bedside to assess the rod with the same serenity that one contemplates a Japanese centerpiece. From his defenseless position the boy lifted his head to ask, "What are you doing? Can you tell me if you're going to do something?" The surgeon professed his innocence: "You can relax. I'm only looking." Then, in the same moment as the boy's head fell back into the pillow, he freed the rod with one swift yank.

For days I replayed the scene in my mind: the quality of the child's scream, a piercing response not only to physical pain but emotional betrayal, and my own attempts to soothe crashing headlong into his disbelief. Walking out of the room the surgeon had turned to the attending and shrugged, "It had to be done." It was that shrug that impelled me to email him days later about the patient's regression. A boy who had been astonishingly calm became one who was later unable to cope through the routine squeeze of the blood pressure cuff. I cited the data, specifically how children who receive preparation prior to invasive procedures demonstrate greater long-term coping than those who do not.

Through a litany of statistics I tried not only to break through to the surgeon but to shame him, too.

The surgeon responded immediately: "Can you please meet me in my office in ten minutes?" Mouth dry, I took the stairwell up to his corner suite, rehearsing the psychosocial tag lines in perfect concert with the blood thumping through my ears: "Doctor there is a remarkable difference between providing care to a child and providing care in partnership with a child. Patients and families are allies for quality and safety within the health care system." Breathless, I never had the opportunity to deliver my proverbs. Instead the door

opened to reveal the surgeon with his head in his hands, grimly surveying the sprawl of Baltimore city. He rose like a sheepish schoolboy. "I am grateful for your email and deeply sorry for the pain I caused this child. When I realized the rod could easily be slid out without further trauma, I did what I would have done for my own son." Then, meeting my gaze square on, he asked: "How can I be child-centered when I know that my schedule allows me approximately three minutes to spend per patient? Shadow me for one day and *then* advise." Stupefied by his candor, I agreed.

Over the course of our shift in the operating room the next day, the shades of the surgeon's disposition and the complexities of the system that governed him revealed themselves like shifting glass in a kaleidoscope. I watched him perform

“The resolution of my question—how could this man fail to recognize the impact of falsifying a child's trust—had to be connected to moments like these.”

opened to reveal the surgeon with his head in his hands, grimly surveying the sprawl of Baltimore city. He rose like a sheepish schoolboy. "I am grateful for

five major surgeries that day, spending no more than two minutes between each to peel off gloves, roll his neck, and prepare to meet the child's family. Though



In the pediatric trauma bay, Child Life specialist Divna Wheelwright contemplates the intersection of her role as a Child Life specialist and that of a surgeon.

the procedures differed dramatically—extrication of diseased bowel from a patient with Crohn’s disease, biopsy of lung, and a skin graft from thigh to hand—the expression on every parent’s face as he approached was identical. In silent unison they would rise with pleading in their eyes. *Just tell me my child is okay.*

“What does it feel like to hold that kind of power?” I asked the surgeon as we turned the corner away from one couple still holding each other upright. “Not power, responsibility,” he corrected. Then it occurred to me: as a Child Life specialist I will never fully understand or bear the weight of that kind of respon-

sibility. How then could I condemn the decisions of those who do? My version of the story, teeming with injustice, was a half-truth. True understanding would require both sides.

Back in the OR a teenage boy lay before us, ribs sunken by a congenital chest deformity. Like a conductor holding a baton, the surgeon raised the pectus bar for implantation, cueing his symphony of chirping monitors and hissing cauterizers. “This is the part that scares me,” he announced. “A small movement of the wrist and I will impale his heart.” And then in one fluid motion, the surgeon slid the bar beneath the child’s skin and across his sternum as though gliding

through water.

Humility swept over me, my mind flashing back to when I stood at the bedside silenced by his callousness. The resolution of my question—how could this man fail to recognize the impact of falsifying a child’s trust—had to be connected to moments like these. For the surgeon both interventions had the same goal—free the child of pain. Not only was his humanity manifest in the tenderness of pectus bar skating past heart, it also motivated the swift yank he knew would carry the boy to relief.

The truth of the health care environment reveals itself when perspectives overlap and forgiveness, transparency, perspective, and accountability slip in and out of each other like shadows. The surgeon’s reality of performing five surgeries daily, every move timed and measured, was as undeniable as the boy’s right to be prepared prior to his procedure. From the corner of the operating room I thought of my own desire to be understood, how as Child Life specialists we yearn to be utilized by the medical team not just for our kindness but for the empirical sum of our training. So too must the humanity of physicians be weighed alongside the demands of their environment.

The surgeon was pulling the final suture taut when he received a page that a child was coding in the PICU. In the doorway he shook my hand and said, “I hope today has been useful to you.” He was already halfway down the hall when I answered, “Yes, more than you know.” Then, glancing over his shoulder, he shot me a grin as if to say, “We are all at each other’s mercy, always.” ■

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# researchround up



Visualizing live bacteria where they exist in the body, says infectious disease specialist Sanjay Jain, will improve diagnosis of tuberculosis and other infectious disorders.

# A Better Picker-Upper

by Marjorie Centofanti

Targeted imaging poses a sea change in diagnosis and therapy for pediatric TB and other infectious diseases.

**HARIS, A CHEERFUL** 7-year-old, wasn't himself on returning from a family trip. His bounce was missing, said his father, and he'd lost weight he'd put on the previous summer spent in Central India, sampling the home cooking of a doting grandmother.

Unable to diagnose Haris's malaise after several office visits, his pediatrician reached wider, based on the boy's stay where the TB burden was high. A tuberculin skin test came up negative. So did the sputum sample and its six weeks' culture for TB mycobacteria. The child had no fever, no markers for inflammation. His only symptoms were fatigue and weight loss. Just to be sure, a second culture was ordered.

This time, six weeks later, results were positive. By now, diagnosis had stretched more than three months, plus the nine months since Haris' exposure to TB. His CTs now showed bronchial blockage and dead lung tissue. He had a cough and early pneumonia. Once in the hospital, he was started on heavy IV antibiotics, a necessary gamble since lab work to uncover drug resistance would cost more time.

A small admission here: Haris's case happens to be hypothetical. "But our frustration is real," says Sanjay Jain, the pediatric infectious disease specialist who laid the basis for it, "because the scenario's so realistic." Recently, Jain worked with a team in Central India, where sampling is easier, to update medicine's take on pediatric TB diagnosis. "It's maddening that accurate diagnosis can be so elusive in children," he says.

What makes it difficult? Waiting to culture slow-growing bacteria is a prime reason. But Jain's work with kids five and younger highlights others. Unlike adults, children often show extrapulmonary TB, with disease heaviest in brain, lymph nodes or swaths of non-lung tissues. Yet positive sputum tests rely upon mucus from infected airways. That means children with bad TB elsewhere can test negative, as in the India study:

The gold-standard lab culture flagged only 15 percent of them.

"Even with positive tests," Jain says, "nothing convincing exists to tell us where TB has spread."

A sea change is underway. The past five years, Jain and colleagues with Hopkins' Center for Infection and Inflammation Imaging Research (CI3R), which he heads, have crossed hurdles in visualizing live bacteria wherever they exist in the body.

CI3R researchers borrowed and greatly adapted cancer-imaging techniques from oncology that rely on sensing areas of high or unusual metabolism in the body. Last fall, they published news of prototype imaging that's exquisitely sensitive to particular bacteria—benign, pathogenic, whatever—"so we can't mistake what we see for inflammation or tumors," Jain says. The technique uses mildly radioactive tracers and PET or related scanners to detect them.

Four years ago, he explains, his lab singled out molecules taken up by bacteria but not human cells. One hit was sorbitol—a favorite breathe mint sweetener. The team bonded sorbitol to a radioactive isotope tracked by PET scanners. Bacteria took to the radioprobe 1,000 times more readily than human or animal cells.

Next, as a test case, mice were injected with the fast-growing gut bacteria, *E.coli*. The rodents had earlier eaten chow laced with sorbitol radioprobes. Within hours, their PET scans glowed like homing beacons in thigh regions where infection had settled (see photo). Most exciting was the lab's trial of *E.coli* "superbugs" resistant to many antibiotics. Jain's group monitored fadeout of the PET signal over a day, as the antibiotic ceftriaxone killed bacteria.

"This proof of principle drives our parallel work for TB with other, specific tracers. Plans are underway for human trials soon," says Jain. "I remain very optimistic." ■



# Asleep, or Not, in the PICU

Sleep is a challenge in the cacophony of the pediatric intensive care unit, yet it's vital for short- and long-term health, says pediatric intensivist Sapna Kudchadkar.

by Mat Edelson



Very much awake in the PICU, pediatric intensivist Sapna Kudchadkar.

THE LAST THING ONE expects a patient to get in the cacophony of the Pediatric Intensive Care Unit (PICU) is deep, restorative sleep, but such sleep may be vital for short- and long-term health. So says Sapna Kudchadkar, a pediatric intensivist who specializes in sleep disturbances among critically ill children. While sleep issues in hospital settings have been fairly well studied in adults, the same is not true of children. That leaves Kudchadkar in the role of detective, uncovering clues as to what disrupts sleep in the PICU, and the physiological consequences.

Consider first the children themselves. “They’re scared, they’re anxious, they don’t understand what’s going on; that can lead to sleep disruption at baseline,” says Kudchadkar.

Then there’s the PICU environment. “The noise is constant, there’s talking at the bedside, the lights are on 24-7,” she notes. “There’s a balance between turning down the lights so a child can get sleep and get their circadian rhythms in order,

but there’s worry that if we turn off the lights we might miss a very subtle change in a child’s clinical status. So you’re navigating all those factors.”

Drugs and mechanical assist devices play a role as well. Sedatives and analgesics, common PICU tools that at higher doses can inhibit restorative sleep, are of particular interest to Kudchadkar. “We use the terms ‘sedation’ and ‘sleep’ interchangeably,” she says. “Just because a child’s eyes are closed we assume they’re sleeping. I wondered ‘do we *know* that they’re actually sleeping?’ Similarly, ventilators set at a constant rate are at odds with how breathing naturally changes as one moves into deeper levels of sleep, a dysynchrony that may lead to severe sleep disruption.”

The fallout from such sleep disruption can be disastrous. In the PICU, it can lead to delirium and an impending insult such as acute sepsis. Just as disturbing is the notion that sleep loss in the PICU could cause serious issues long after hospitalization. “Every single child that

comes through our PICU, their brains are actively developing; if they were healthy, natural sleep is playing a major role in brain plasticity,” says Kudchadkar. “But then you come to the PICU and a child is sleep deprived. What happens down the line? Behavior problems? Anxiety?”

Kudchadkar has begun enrollment of patients in a study that will begin to answer those questions by monitoring their sleep/wake cycles as they move from the hospital back to the home setting. Small wrist-watch sized devices called actigraphs will non-invasively measure activity indicating whether or not a patient is asleep.

Eventually a better understanding of encouraging quality sleep in the PICU could yield wholesale changes of how patients are managed during critical illnesses. Kudchadkar says that new initiatives that get patients up and moving—even when they’re attached to breathing tubes—improve sleep/wake cycles. Call them the circle of healing. ■





# Aaron Milstone, M.D.

## Transforming Treatment of Hospital-Acquired Infections

by Christen Brownlee

ON THE MEANDERING road that brought Johns Hopkins pediatric infectious disease specialist Aaron Milstone to where he is today, there have been a lot of lucky turns. After avoiding following in his physician-parents' footsteps for years—even majoring in political science in college—Milstone eventually decided on med school after all. Rather than becoming a surgeon or a sports medicine specialist, or studying hookworms—all paths he considered—he decided to take care of children and study how to reduce infectious diseases in this population. In a further tweak, during his infectious diseases fellowship at Hopkins, he decided to train in epidemiology and got his Masters in Public Health, steps that would allow him to help a multitude of patients beyond those he treated.

But these young patients have had anything but lucky turns by the time they end up in his care. Most have acquired infections common to children and adults being treated in hospitals, infections that health care providers have struggled to reduce. That's because many, including prevalent strains of the common infectious bacterium *Staphylococcus aureus*, are now resistant to first- and second-line antibiotics used to treat them. Seeing these young patients struggle to recover has motivated Milstone from the start.

"These are the things that weigh on you," Milstone says.

One of Milstone's greatest contributions to the field started when he was just a fellow—a time when financial and personal support for research is hard to come by. Though it took six years, he not only completed the research but gained significant attention for changing practice.

The project focused on a simple intervention that can significantly cut rates of bacteremia, blood borne bacterial infections that can be devastating to children in pediatric intensive care units (PICUs).

By bathing PICU patients daily with washcloths impregnated with the antibacterial agent chlorhexidine, Milstone and his colleagues reduced rates of bacteremia by a whopping 36 percent—a giant leap for infection control in this population that other medical centers quickly adopted. "You hope that as a clinical researcher, you'll contribute something that will change practice. But this really did," Milstone says.

More recently, he and his colleagues have embarked on a study that they hope can cut the rates of both methicillin-resistant *S. aureus*, a prevalent infectious agent that now plagues patients both in and out of hospitals, and resistant *S. aureus*, the related strains of bacterium that cause about three times as many

infections. Because both types of bacteria can live on unsuspecting individuals without causing infection, and be passed unknowingly, the researchers rationalized that treating parents might keep babies in the neonatal intensive care unit (NICU) free of these infections for longer. In their latest study, parents of NICU patients are screened for both resistant and susceptible *S. aureus*, and those that carry these bacteria get an antibiotic.

Gaining a better understanding of hospital-acquired infections such as these, Milstone notes, will be the key to gaining the upper hand: "The goal is still to move the needle toward zero hospital-acquired infections, but without more knowledge, today's best practices won't get us there. We still have a lot more work to do." ■



Aaron Milstone continues to move the needle toward zero hospital-acquired infections.

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# people&philanthropy



Sara Johnson, left, and Tina Cheng from Johns Hopkins Children's Center lead an innovative new child health initiative with Joshua Rales, president of the Norman and Ruth Rales Foundation.

# On the Healthy Road to Academic Success

by Wendell Smith

**WITH THE HELP OF A FAMILY FOUNDATION**, the Johns Hopkins Children's Center is launching a whole new child health enterprise, the first fully integrated school-based health clinic in the United States. Johns Hopkins faculty and staff are piloting an innovative model of education that bundles comprehensive health care into schools to help children thrive and achieve academic success.

"In short, we need to go where the kids are," says pediatrician Tina Cheng, one of the initiative's leaders and director of General Pediatrics and Adolescent Medicine at Johns Hopkins. "Children's health and school performance are intertwined."

The "kids" in this case are elementary through middle school students from families who live in Baltimore City. Cheng and fellow researchers, community and educational collaborators, are setting out to narrow the achievement gap between children from less affluent and more affluent communities in American schools by addressing the multiple health challenges in households and communities that could hinder any child.

"This enterprise is right in our sweet spot, in our wheelhouse," says Joshua Rales, President of the Norman and Ruth Rales Foundation, which expects to invest \$5 million in the \$6 million project. "Our family Foundation was created to honor our parents' legacy of championing the needs of children, living lives of integrity and leaving the world a better place than they found it. In joining forces with Johns Hopkins and the KIPP schools, we foresee tremendous potential to boost children up the academic ladder and to create a promising future that might otherwise be unimaginable to them."

The new "Ruth and Norman Rales Center for the Integration of Health and Education" at Johns Hopkins Children's Center will launch its pilot Rales Educational and Health Advancement of Youth (READY) program with KIPP Baltimore, part of a national charter school network designed to prepare students from low income / underserved communities for college and beyond. The KIPP Baltimore schools, Harmony



The Rales Center at Johns Hopkins Children's Center seeks to boost academic success by improving children's health.

Academy and Ujima Village Academy in Park Heights—an elementary and middle school respectively—will be the first to implement the READY program, which unites health care providers, teachers and parents, all to benefit children.

"The aspiration of this endeavor is transformative," says Rales. "We could change the life trajectory of these children

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## On the Healthy Road to Academic Success

and give them an opportunity to experience the success of their peers from more affluent communities.”

The schools implementing the READY program will have a full-service health and wellness program. This includes a health clinic (the Rales Clinic), staffed by a physician, nurse practitioner and school nurse. In association with teachers and parents, they will routinely assess students’ health and developmental progress; screen for behavioral problems; provide dental screenings and referrals for dental services, keep vaccinations up-to-

date; monitor and help children manage their chronic diseases such as asthma or diabetes; and provide individual and group mental health counseling. Further, wellness staff will partner with KIPP teachers to bring physical activity and health education to students during class time and after school. School wide health campaigns will focus on things like vision screening and bullying prevention. Parent and teacher conferences will include an individualized student health review, led by a school health professional who knows the student. And student families will

## Why We Support This Venture

With Joshua Rales, President and Trustee of the Norman and Ruth Rales Foundation, founding philanthropic partner of the Ruth and Norman Rales Center for the Integration of Health and Education at the Johns Hopkins Children’s Center.

### What drew you in?

R: First of all, this is our form of philanthropy: plant the seeds, as we are doing with our initial investment of monetary support and strategic analysis, then join like-minded individuals to create a potentially transformative venture—in this case, integrating children’s health care with their education—and then allowing it to take root and flourish. In this vein, our Foundation will match all gifts to the Rales Center at Johns Hopkins, until we reach its total goal of \$6 million.

Second, this venture was right up our funding alley. Johns Hopkins’ well-researched and scientific program to bolster underserved children’s academic success by boosting their health meshes beautifully

with our Foundation’s commitment to improving lives. The Foundation is a legacy of my parents Ruth and Norman. My siblings (Steven and Mitchell) and I have chosen to employ its funds to create a legacy for our parents whose lifelong values were integrity and compassion for the less fortunate, values they instilled in us. They always offered a helping hand to others, especially children. Perhaps this was in part because they had received the same growing up in this country. My father, who was raised in an orphanage, never forgot the medical care and educational foundation he received there, all through the kindness of strangers. My parents went on to live the American dream of personal and financial success as

well as to revel in the love of their children and grandchildren.

Third, my own highly satisfactory personal experience with Johns Hopkins Children’s Center, as a patient (and later friend) of immunologist Jerry Winkelstein, drew me to partner with this outstanding research institution. A belief Jerry and I share and discussed frequently is the concept, long promoted by experienced and compassionate physicians, that good children’s health requires a good education and vice versa. From my own experience, I knew the level of skill outside of the doctor’s office that managing a chronic condition required, and I could not imagine how children with fewer family resources and more stress-

ors could possibly manage. The obvious solution to Jerry and me as well as to the team at Johns Hopkins was to bring the management of the children’s health to the school and integrate it into the curriculum. Parents don’t have to take off work, and access and transportation to quality medical care would no longer be an issue.

### How did the partnership between the Rales Foundation, Johns Hopkins and KIPP evolve?

KIPP has schools in the DC Metro area where our Foundation is located. Their focus on closing academic disparities is in line with our Foundation’s mission and that of Johns Hopkins Children’s Center pediatrician Tina Cheng, an

have access to a “parent liaison” in the school that can connect them with supportive community resources, such as adult health programs.

In the community Harriet Lane Clinic at the Johns Hopkins Children’s Center, clinicians see the ill health effects of household poverty and poor living conditions on their young patients. Residing in the neighboring area of East Baltimore, patients’ substandard housing can trigger and exacerbate chronic diseases like asthma; poor diets and lack of safe areas for play

and exercise contribute to rising rates of obesity and type 2 diabetes; family stressors related to impoverished circumstances or violence amplify behavioral and mental health conditions, and make critical day-to-day management of complex chronic diseases like diabetes—which takes micro-management to control—nearly impossible.

“Infusing comprehensive health care in children’s schools will be a game-changer,” says Rales. “At present, health care and education are siloed in schools throughout the nation.”

expert on health disparities among children. Her Johns Hopkins colleague Sara Johnson also has shown, through research, the life-long consequences of early exposure—even in utero—to the kinds of social and mental stresses that some children experience in their families and communities. Tina had the vision to build full-spectrum health services into children’s schools, but she hadn’t found the right school. As a supporter of the KIPP schools, I introduced Tina and Sara to KIPP Baltimore, which has an elementary and middle school on one campus in Park Heights serving families primarily from less affluent communities. KIPP has a tremendous track record. While nearly 100 percent of its students go on to graduate from high school, with most moving on to college, KIPP Baltimore’s students nonetheless face many health challenges that stem from poverty that if addressed, could lift them even higher.



**Is the Rales Foundation’s investment strictly financial at this point?**

Not at all. We are partners and advocates. We are highly disciplined and hold people accountable for promised results, but we also are advocates for programs we support. In addition, we bring extensive financial and managerial experience to the table to support our partners. The Rales Foundation is very fortunate to have my

brothers Steven and Mitchell as trustees. As the founders of the Danaher Corporation, a highly successful Fortune 500 company, my brothers, through their business acumen, intellect and overall engagement bring a level of rigor to the Foundation’s decision-making process that is invaluable. With Johns Hopkins, KIPP and the City of Baltimore, we’ve joined the best of the best to transform children’s lives. ■

**At KIPP Baltimore, the new Rales Clinic will open in August 2015.**

Continued from page 43

## On the Healthy Road to Academic Success

“The goal of the Rales Center is to lay a foundation of good physical and mental health and to plant the seeds of lifelong healthy behaviors among disadvantaged children...to empower them to achieve more — academically and socially — as they transition from childhood to adulthood.”

— JOSH RALES, PRESIDENT OF THE NORMAN AND RUTH RALES FOUNDATION



## Please Join Us:

**ALL GIFTS** to the Rales Center for the Integration of Health and Education **WILL BE MATCHED** by the Norman and Ruth Rales Foundation, until we reach the \$6 million needed to develop and sustain the center and demonstrate the READY model.



To lend your support, contact Maureen Royer, senior director of Development, 410.361.6396 or [mroyer2@jhmi.edu](mailto:mroyer2@jhmi.edu)

KIPP Baltimore, under the leadership of Kate Mehr, is a natural collaborative partner in this effort to lessen educational and health disparities for school children from low income / underserved communities. More than 96 percent of its students outperform their local school district peers in reading, and 92 percent in math. Nearly 100 percent graduate from high school, and most go on to college. “KIPP’s track record makes it an ideal partner,” says Johns Hopkins’ Cheng. “It recognizes how crucial good health is to a child’s ability to focus and learn.”

A national expert in the field of health disparities, Cheng is a longtime proponent of merging health care into inner city schools. Cheng’s colleague, Sara Johnson, has found in her research that the stress of poverty and/or family dysfunction brings about biological changes in children that directly affect the way in which their brains and immune systems function, and how they respond to stress. “So, by addressing the whole range of factors that affect health and academic achievement in a setting where kids already spend time, we expect this program could have lasting positive impacts on students throughout their lives,” she says.

Cheng and Johnson will direct the Rales Center, and with Johns Hopkins and community colleagues, monitor its ongoing development. The two and their team will measure progress, while tailoring their approach along the way, so that this innovative program can be replicated elsewhere.

“We have a great partner in Johns Hopkins,” says Rales. “We all acknowledge that good physical and mental health bolsters children’s chances for academic achievement, something they can carry into adulthood and champion for their own children.” ■



# The Power of One, the Power of Many

**MRS. WALLACE PLAYS WITH TODDLERS,** lab technician Devin Mack teaches sculpting, and therapy pets work their magic. Behind the scenes, a small army of volunteers work to comfort patients and families, and to ensure that physicians, researchers and staff have the funds they need to pursue critical research and clinical advances. Welcome to our world of volunteers.

## Give Time and Comfort

**GENEVA WALLACE** has always loved babies. Growing up, she says, “we always had someone’s baby visiting in the house.” Today the retired Calvert County elementary school principal spends Monday mornings playing with patients on the Infant and Toddler unit. There is “just something about helping these innocent little children that keeps me coming in every week,” she says. Her daughter, Tria Tucker, the television services coordinator at The Johns Hopkins

Hospital, first suggested Wallace volunteer seven years ago upon her retirement. After training, Wallace began her volunteering years rocking babies and singing to them. Today, her loving care might include comforting the child who is lonely or giving another a stroller ride around the unit. “What I do frees the nurses tremendously,” says Wallace, “so they can take care of children’s medical needs. They are so appreciative of the volunteers.” ■



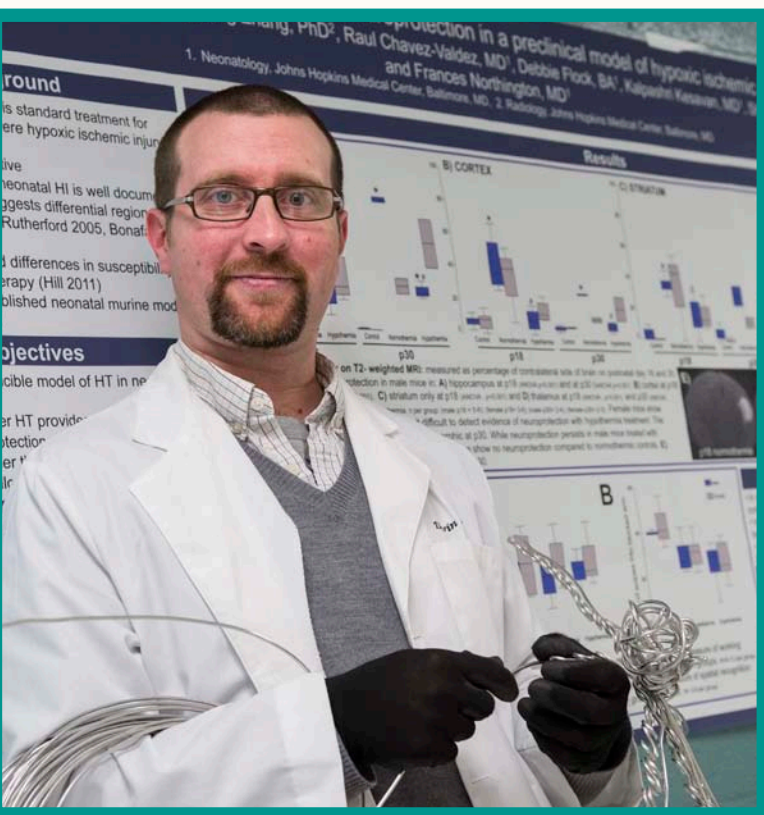
## Empower with Craft

**CAROL DAVENPORT** knows what it’s like to have a child in the hospital. Her son, now a young adult, spent weeks at the Children’s Center throughout childhood. Today, Davenport volunteers at the hospital, teaching patients and parents to crochet—a hobby she took up at her son’s bedside—to give back for the care her son and family received here. “Learning a skill like crochet helps give kids control in an environment in which they have so little. Their faces light



up when I stop by with my bag of yarns. It’s an opportunity for them to make some-

thing for their nurse, family or friends. I’ve watched kids crochet, pausing only to push their morphine pumps to ease their pain. Crocheting gave me, as a parent, some sense of control. You hope it’s a good outcome for your child, but you don’t know, so you work to keep yourself busy, focused on something else.” Davenport also co-leads with Child Life Specialist Annie Woods Beatson a monthly “Art Safari” TV show and serves on the hospital’s Pediatric Family Advisory Council. ■



Lab technician and sculptor Devin Mack.

## Sculpting Joy

**NEONATOLOGY LAB** technician Devin Mack teaches wire sculpting to patients monthly in the hospital’s Julia Clayton Baker Great Room. Hearing that Child Life wanted to expand its art program, he volunteered last year to be a visiting artist. A sculptor for more than 12 years, Mack is never far from the thin coils of metal and alloy from which he fashions steel and brass honey bee for Baltimore Honey, a collective of bee keepers in Maryland, and a six-foot-long neuron for the neuromuscular division at Johns Hopkins. “I give each a

small bundle of prepared wire, then it’s bend, twist, divide into a shape. They get really absorbed in what they’re making.”

Brought to the lab in 2004 by neonatologist Frances Northington, impressed by his attention to detail in his artwork, Mack recently followed this same methodology to create an aluminum octopus in a hospital corridor. “My sculpting career has been good to me,” says Mack, who works in the lab four days a week as part of research team working to reduce brain injury in newborns, and the other days in his Drawn Metal studio. “I was in a position to give back a little, and I love seeing the joy it brings to the kids.” ■

## Lead Pet Therapy

**AS A FORMER NURSE** in the adult cardiac care unit at Johns Hopkins, Anne Efron has experience helping to amend hearts. Today, a project administrator for the Center for AIDS Research at Johns Hopkins, Efron has enlisted a fellow volunteer, Grendel, to spread some heartfelt joy among Johns Hopkins’ youngest patients. Grendel is a 150-pound American mastiff who comes with his own tennis balls for fetch. Efron and Grendel visit pediatric oncology and psychiatry patients monthly. Grendel has the true pedigree of a hospital volunteer. His father, Diesel, is also a therapy dog. “It’s in the genes,” says Efron, of her

personable pet that aced his therapy pet tryout in 2014 “with flying colors.”

Earlier, at the 125th Anniversary Celebration for Johns Hopkins, she had met Stephanie Cooper Greenberg, who trains and evaluates the pet therapy teams that now visit. Greenberg, who says she is always looking for “recruits for our dog ministry,” encouraged Efron to put Grendel through the training paces and have him certified. “The visits by dogs like Grendel help children and their families relax, forget where they are for a while and take heart in the delight of canine visitors,” says Efron. “I’m still a nurse at heart, so our visits let



Anne Efron and Grendel make a new friend in a playroom.

me continue the bedside care I love.”

National Capital Therapy Dogs, Inc., and the Pet Partners Therapy Animal Program have been sending dog teams to Johns Hopkins since 1998.

The Pet Therapy program is expanding throughout the hospital and needs more teams. ■

For more information, contact Jan Jaskulski, [jjaskul@jhmi.edu](mailto:jjaskul@jhmi.edu).





## Play in Friendship



Peabody musicians at the Children's Center.

**WHEN THEY PERFORM** monthly in Hopkins Children's lobby, Peabody musicians can't see most of their young audience, but they know many are listening to the music streamed into hospital rooms above. It's a "very powerful experience to perform for an audience that is going through so much just out of your view," says Jessica Korotkin, a Peabody student and site coordinator for Johns Hopkins Peabody Conservatory's Creative Access program. The volunteers might perform on a viola, violin and renaissance harp one month,

and a flute and two cellos the next. Music by Bach is a favorite, says Korotkin, given that it is "both complex and beautiful, and much of it doesn't require piano."

A student outreach program, Creative Access was launched at the Peabody in 2004 to create new opportunities to perform and share music with diverse audiences. "Performing for the children at Johns Hopkins is a favorite activity," Korotkin adds. "We want to make their lives a little better and play for them out of friendship with hope for a safe return home." ■

## Make a Difference

**CHILD LIFE IS** "like oxygen" for the youngsters where Rosemary Connolly volunteers every Wednesday. "The happiness factor on the unit is palpable when the Child Life specialist is around," says Connolly. "Play and attention are two of the greatest balms for these children."

A volunteer on the Infant and Toddler Unit since 2013, Connolly describes Child Life's focus on the developmental and emotional wellbeing of patients, as "a wonderful ancillary way to help heal body and mind that brings to mind the power of integrated medicine." Child Life briefs her on the patients who need a visit or a change of scenery. The children appreciate visitors, Connolly adds, especially when their parents are away or working. Staff

are "just wonderful with the children, and care for them as though they were their own," she continues.

Noting a number of recalcitrant eaters on the unit, Connolly drew on experience in feeding her own children, and wrote letters to a manufacturer requesting little airplane-shaped spoons that make eating more fun. The spoons arrived a few weeks later. "Now, THAT," she says, "was a lesson in what anyone can do to make a difference, even a little one, in the life of a child here." ■

—WS

Interested in becoming a volunteer at the Johns Hopkins Children's Center? Visit <http://www.hopkinsmedicine.org/volunteer-services> or call 410-955-5924.



On the Infant and Toddler Unit, volunteer Rosemary Connolly.



**A**mong those fueling transformative research, clinical programs and training here are the volunteer members of our largest hospital boards: The Harriet Lane Home Foundation, The Home for the Consumptives of Maryland (Eudowood) and the Robert R. Garrett Fund for the Surgical Treatment of Children. Members describe what guides them.

## Continuing a Family Legacy

**A THIRD GENERATION** trust and estate planning attorney, Frederick Singley Koontz is the current president of the Harriet Lane Home Foundation board and past president of the Eudowood board. Volunteering time and service to the hospital continues a family legacy. His grandfather, uncle and cousin directed the board of trustees of the Hospital for the Consumptives of Maryland (Eudowood), a 19th and 20th century sanatorium for the treatment of tuberculosis. The sanatorium closed in the 1950s, as TB was brought under control with modern medicine. Proceeds of its sale were directed, by the board, to Johns Hopkins. A separate Eudowood endowment, created by the women who founded the

sanitarium, became the origins of today's Eudowood Foundation, which now supports Johns Hopkins' "Eudowood" divisions of pediatric infectious diseases, allergy-immunology, pulmonary medicine, neonatology, the adult division of pulmonary medicine and, most recently, the Division of Pediatric Quality and Safety. "As board members, we serve to steward assets and manage endowments," says Koontz. "As individuals, it's critically important in life to contribute to the wellbeing of others. Incredible, passionate people make such compelling cases for the needs of their patients and the promise of research here that you are just awestruck and want to help." ■



Frederick Koontz chats with Edie Garrett at a December 2014 board reception at Johns Hopkins.

## Leaving the World a Better Place

**LINDA MISTLER** has a history at Johns Hopkins University. A graduate and former professor, she has endowed a scholarship at the Johns Hopkins Carey School of Business. She also volunteers as a member of the Harriet Lane Foundation board, which stewards some of the original funds bequeathed at the turn of the 20th century by a Maryland family to create what became the Harriet Lane Home for Invalid Children, now the Johns Hopkins Children's Center. Foundation funds help support the Division of Pediatric Nephrology, its Camp All Stars for children with kidney disease and, since 2012, the hospital's pediatric palliative care program. "You don't need a lot of money to make a difference," says Mistler, who has contributed not only her time but a planned gift to the foundation. "There is power in one—we can each do something to help another. You just have to believe inherently that it is your responsibility in life to leave the world a better place. Like good manners, philanthropy makes each of us part of the greater good." ■



## In It for the Long Haul



Luke Marbury, far right, and his wife, Nancy, chat with Pediatric Infectious Diseases Director Kwang Sik Kim in December 2014.

**NATIVE BALTIMOREAN** Luke Marbury grew up thinking that Johns Hopkins was, if not the most important place in the world, among the most important in medicine. “It was natural for me to be interested in doing what I could to be of assistance,” says Marbury, a 17-year member and a former chairman of the Eudowood board. “Most board members have shared the view that this is an opportunity to join Johns Hopkins in serving those in its care.”

Eudowood funds have fueled development of profoundly better ways to diagnose and treat bacterial meningitis

infections and cystic fibrosis, as well as research to cure food allergies and HIV in the young. Funding or conducting research isn’t “flashy,” Marbury says, just critically important: “A lot of what our Eudowood Divisions are doing is pure research, accumulating knowledge. It can be a slow, almost invisible process, taking years. But then one day, someone pieces it all together to answer a big medical question and save a child’s life. I think people who get involved here as donors understand that this is the way that medicine and breakthroughs happen and are in it for the long haul.” ■

## A Labor of Love

**VOLUNTEERING AS** a member and, now, chairman of the board of the Robert Garrett Fund for the Surgical Treatment of Children has been a labor of love, says

Jim Garrett, both of family and Johns Hopkins. The Garrett Fund has supported Johns Hopkins Medicine since the mid 1940’s, fueling dramatic advances in pediatric surgery and related research. Its board united with the Harriet Lane Foundation and Eudowood



Edie and Jim Garrett at the 2014 board reception.

to contribute substantial funds for the second and third generation of pediatric hospital buildings at Johns Hopkins, including today’s Charlotte R. Bloomberg Children’s Center building. Generations of Garretts have supported Johns Hopkins since its founding. Established in 1936, the Garrett Fund has supported pediatric surgery and the creation of Johns Hopkins’ first chair in pediatric surgery. “Our family and the Garrett Fund stand with Johns Hopkins in its mission to protect and heal children, and advance American pediatric medicine,” says Garrett. “We are committed in seeing that children have a chance at a healthy future.” ■

## Honoring Our Volunteer Boards

**MEMBERS OF** the Harriet Lane Home Foundation Board, The Hospital for Consumptives of Maryland (Eudowood) Board and The Robert Garrett Fund for the Surgical Treatment of Children Board of Trustees gathered in December 2014 for a reception in their honor at the Johns Hopkins Children’s Center. Young singer Montria Walker (left) performed in appreciation of the care her brothers have received from pediatric endocrinologist Leslie Plotnick (right), as well as for those assembled, who help ensure that research and the advances in care it makes possible are funded. ■





# COMPASS Guides Corporate Board

A GROUP OF BOOZ ALLEN HAMILTON volunteers set out last year to help members of Hopkins Children's Corporate Advisory Board (CAB) become stellar fundraisers and ambassadors. Board chair Emile Trombetti, a Booz Allen Hamilton vice president, had proposed the hospital as a beneficiary of the strategy and marketing firm's COMPASS program, which provides pro bono consultation with Booz Allen Hamilton experts. "We were asked to evaluate the board's operating model and suggest ways to elevate overall per-

formance," says Booz Allen Hamilton's Shelley Merritt, a COMPASS volunteer.

Beginning their work in February 2014, the COMPASS group found a passionate and diverse community of CAB volunteers.

"Everyone felt inspired by the opportunity to work closely with Johns Hopkins," says Merritt. "We had a wonderful experience working with Pediatric-in-Chief George Dover and his development team."

By summer's end, COMPASS volunteers presented Johns Hopkins with

a new restructuring for the CAB, one that matched members "with the right roles and responsibilities," says Booz Allen Hamilton volunteer Rob Ruyak.

Ruyak later joined the CAB: "I had an epiphany. I am blessed beyond belief with three healthy children. Here was an opportunity to help other parents, other children in distress." ■

—WS

Corporations interested in partnering with us are invited to contact Cynthia Palacz, [cpalacz1@jhmi.edu](mailto:cpalacz1@jhmi.edu).

RADIOTHON TOPS  
\$1,053,000!



FOR OUR FIRST on-site phone bank, more than 350 volunteers turned out to take calls and generate enthusiasm for the 26th Annual MIX 106.5 Radiothon, broadcast live from Johns Hopkins Children's Center, Feb. 25-26. Deejays interviewed patients, families and staff, who told on air their stories

of hope, courage and gratitude. "The energy of our volunteers, deejays and wonderful families and kids elevated this year's fund raiser to a new level," says Johns Hopkins Children's Pediatric-in-Chief George Dover, who with Pediatric-Surgeon-in-Chief David Hackam (along with Tweety and Bugs

Bunny from Six Flags America) helped kickoff the event, which has now raised more than \$18 million. ■

—WS

To be a part of Radiothon 2016, contact our Office of Development, 410-361-6493.

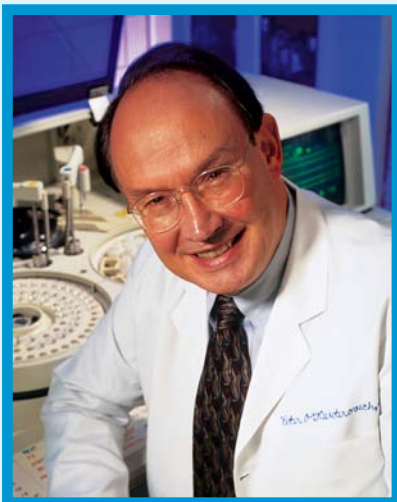


## In Memoriam: Peter Kwiterovich, a Pioneer in Pediatric Lipid Disorders

A PIONEER IN DIAGNOSING and treating lipid disorders, an early advocate of cholesterol screening in children and founder of the lipid clinic at Hopkins Children's, Peter O. Kwiterovich, Jr., died on Aug. 15, 2014, after a long battle with prostate cancer. He was 74.

In a career that spanned nearly half a century, Kwiterovich established himself as one of the pre-eminent clinicians and scientists on familial lipid disorders, a group of inherited conditions marked by abnormal fat metabolism, exceedingly high cholesterol and early-onset heart disease. In the 1980s, Kwiterovich and a colleague, Allan Sniderman, presented a report that led to a new understanding of early-onset heart disease and the role that elevated cholesterol plays in the development of this disorder. Kwiterovich's work led to new therapies to slow or halt the progression of heart disease and avert premature death among thousands of families. He launched a novel, alternative cholesterol-lowering therapy at Johns Hopkins known as LDL apheresis, a treatment reserved for a small group of patients with familial hypercholesterolemia. ■

—WS



## Postcard from Florida: Moving science towards a cure for pediatric HIV



The Pakulas, from l to r: granddaughter Jennifer Waldholtz, daughter Annette Pakula, Lawrence and Sheila Pakula in Naples, Fla.

AT A JOHNS HOPKINS Children's Center event in Naples, Fla., this past January, world-renowned pediatric HIV/AIDS specialist Deborah Persaud reminded her audience that HIV is not just "an African problem, it's world-wide and happening in your state." Indeed, most of the nation's HIV-infected babies are born there.

Persaud is at the vanguard of an ongoing effort to find a cure for children whose HIV was transmitted to them in utero, at birth or early in life. Her HIV lab at Johns Hopkins has an unrivaled depth of experience in its focus on infants, children and adolescents.

Recognized for her pioneering research by the journal *NATURE*, which in 2013 named her "One of the 10 People Who Matter Most" in the world, Persaud and her team are working to find the ground-breaking strategy that will finally end HIV's capacity to form reservoirs in the young. They have already demonstrated that very early treatment with antiretroviral therapy can transform HIV infection, and potentially transform it into a curable disease.

Aware of Persaud's revolutionary

research and the need for funding to continue, Lawrence and Sheila Pakula, longtime friends and stalwart supporters of the Children's Center, offered to host a reception for Persaud to help raise awareness. Not only have the Pakulas named the Sutland/Pakula Neonatal Intensive Care Unit, they have also endowed a professorship and a young investigator research fund in neonatology in their family's names. They know firsthand the power of private support and continue efforts to introduce more potential philanthropists to Persaud. "We want to foster an appreciation of the stunning potential of her research and present opportunities to support it," says Lawrence Pakula, an associate professor of pediatrics at Johns Hopkins.

At Johns Hopkins, fundraising is underway for a new global Center for the Cure of Pediatric HIV/AIDS, led by Persaud. Its foundation already is in place. Her lab is recognized internationally as a leader in this field. ■

To support this mission contact  
Alicia Spitznagel at 410-361-6397.



# Hearing the Patient

Teen and Children's Council amplifies the patient's voice.

by Gary Logan

**THIS WAS A DIFFERENT** residents' noon conference. Gone was the usual shuffling of papers and finger tapping of pagers, the cell phone calls and the side conversations between colleagues. The only words heard were those of the five teenage patients at the front of the room facing the residents. As the saying goes, you could have heard a pin drop.

"My biggest fear, had I not gone to Hopkins, was waking up in a boring old hospital room with nurses checking my vitals every few hours, being given the bad news about my blood clot and collapsed lung without my parents in the room, having to go into the operating room alone," said patient Stephanie Turner.

Added patient Brooke Szachnowicz, "The doctors here talked to me, which made me feel much more comfortable. It's a lot easier when they talk to you instead of talking to your parents about you."

The silence in the room may have had much to do with that point—seldom, it seems, do physicians speak one-on-one with their young patients about their care. That's what this special "Patient-and Family-Centered Care Week" noon conference in mid-March was all about—hearing the pediatric patient's voice to improve care.

"Often we think we know what will be good for them and project our ideas onto them," says pediatric nurse Nadia Lauer, "but a lot of times we're way off."

"Without input from patients it's hard for us as providers to help make the experience better, to do things that we might not think about without getting their perspective," adds medical student Matt Molloy.

The patients' insights at this noon conference also illuminated the purpose and early work of Johns Hopkins Teen and Children's Council, or TACC—of



TACC members, from left to right, Brenna Hohl, Brooke Szachnowicz, Rima Teymourlovei, Jordan Magsamen, Abbey Rhodes, Stephanie Turner in the Children's Center lobby.

which the noon conference panel are members.

"Part of the mission of the group is to continue efforts like this, to make sure the voice of teens is heard," says Tricia Willis, a pediatric nurse who helped form TACC. "They see things through a different lens and really do bring a different perspective."

"They don't filter issues, they just tell you how it is, which is awesome," adds Child Life specialist Gina Pizzano, a TACC member. "They really want to make changes."

Telling it like it is and effecting "patient-centered" change is at the core of the group, now in its second year with 13 teenage patients—up from six in year one—and three Children's Center staff members. They meet monthly, establishing goals like recruitment criteria for new members and creating opportunities to speak about their own

experiences, a hallmark of patient- and family-centered care at Johns Hopkins. Group members also participate in fundraising and other activities for patients and families. One day they're planning a homecoming dance in the hospital for adolescent patients, and the next participating in a panel discussion on transitioning to adult care.

"We have a full plate at each meeting," says Willis. "We're talking about extending the meetings to two hours because we don't have enough time to cover everything."

"They have so much energy and want to contribute in such a big way—it's amazing to see how the group has evolved," adds Pizzano. ■

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To learn more about TACC or to apply for membership, email [gpizzan1@jhmi.edu](mailto:gpizzan1@jhmi.edu) or visit the TACC webpage at [www.hopkinschildrens.org/Teen-and-Childrens-Council/](http://www.hopkinschildrens.org/Teen-and-Childrens-Council/)



# It Was Worth It to Feel Better

by Trip Black

We were camping with my cousins and one of them popped out of a dog crate and scared me. I fell back into the campfire and burned my hand, leg and my right behind cheek.

It really hurt. This was a long time ago. I was just 4. I'm 6 now. But I remember. An ambulance came to get me. My burns were so bad, they said I should go to Johns Hopkins, that they were really good at fixing burns. I stopped crying when they started up the helicopter and put me in. We flew 200 feet above the ground and over the Chesapeake Bay Bridge and landed on the roof at Johns Hopkins.

They did a lot of things to help me every day. Dr. (Dylan) Stewart took skin from my leg and put it on my hand. It's called a skin graft. My friends and family came to see me and my mom and dad stayed with me in the hospital. I was there for 12 days. Most adults stay in the hospital for two years. So this was good. My nurses were really nice and gave me toys like army men and dinosaurs. My Child Life specialist played light shows on the walls during my bandage changes. The doctors were nice, too, but didn't have time to play because they had to check on other patients.

The hardest part was getting the skin from my leg onto my hand. I was out cold for it. Also good. After this, they showed me how to work my arm and leg again. I learned more stuff at the Johns Hopkins burn camp. Because I'd been really hurt and had to be brave to get better, I got to go Disney World. The Children's Miracle Network (Hospitals) sent me. I was a champion for Delaware, where I live.

My parents say that I am now one hundred percent better. I play with my neighbors and play soccer and have a new bike. If somebody asked me about Johns Hopkins, I'd tell them not to be afraid, to just be brave and think that everything will be fine. It's really worth it to feel better. They took care of me and made me feel safe. And the food is good. ■



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futures and save lives, please contact:

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