

# hopkinschildren's

SUMMER 2017

THE JOHNS HOPKINS CHILDREN'S CENTER MAGAZINE

## Beyond the North Star

Tina Cheng  
leads innovative  
evidence-based  
approaches to  
pre-empt and  
prevent illness  
and injury in  
children.

**Photo Journal**  
The Charlotte R.  
Bloomberg Children's  
Center Building Turns 5

**Ryan's Story**  
The more aggressively  
doctors treated a child  
with epilepsy, the worse  
his seizures progressed.



# Finding MyVoice

by Grace Oakey

**After undergoing an appendectomy at another hospital, I was in severe pain.** Doctors told me that I was simply sensitive to pain and had to try harder to get up and walk around. I was only 9 years old and had difficulty taking it all in. When they eventually realized that there could be something else going on, they transferred me to Johns Hopkins Children's Center. There I underwent a long exploratory surgery in which doctors discovered that my pain resulted from a burst ulcer around my intestines.

I spent the following weeks in the hospital, undergoing two more surgeries and recovering. But that was not my last stay. As a result of my pre-existing rare muscle disease, juvenile dermatomyositis, I experienced several other hospital stays as well.

Needless to say, my time in the hospital has not been the best time of my life. While the comfort and physical layout of the hospital improved remarkably in the move to the new Charlotte R. Bloomberg Children's Center building, being in the hospital is difficult and, at times, dull and glum. Holed up in a hospital room, I felt like I was going stir-crazy and yearned to be outside. The nurses and child life specialists proposed different activities and crafts, which did not interest me. But I appreciated their efforts to take my mind off things. That's when I got the idea—I could use my hospital experience to help other patients.

I decided to join the Teen and Children's Council (TACC) in 2015, which was a big step for me. I felt very shy and unsure of myself at first, though I eventually became more vocal at TACC meetings. I had many opportunities to share my story and to be involved in activities like organizing a homecoming dance for patients and participating on a panel with pediatric residents during Patient- and Family-Centered Care Week. In the process, I've learned a great deal about the experiences of other patients, as well as about myself. And as the council continues to grow, I'm very excited about opportunities ahead to continue to share my voice. 🌟

*Grace Oakey is a sophomore at Notre Dame Preparatory School who enjoys playing music and studying, and hopes to travel the world one day.*





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# Two Minds, One Vision

**As co-directors** of Johns Hopkins Children's Center, we are of two minds but one unified purpose—to ensure that our physicians, nurses and staff provide the very best care for our patients. Achieving that goal on a consistent basis requires ongoing collaborative and innovative efforts, some of which are illuminated in this issue of *Hopkins Children's* magazine.

Providing first-rate care, for example, means creating novel services, like a surgical clinic designed for children with the most complex colorectal conditions (page 30) or services not easily accessible for patients and families, like outpatient hemodialysis (page 31). Superb care also means employing the latest technology and creating comprehensive multidisciplinary teams, like the cardiac intensivists, cardiothoracic surgeons, cardiac nurse practitioners, cardiologists and nurses who make up our new pediatric cardiac intensive care unit (page 34).

Evidence-based medicine is essential too, which means translational research that leads to better ways to treat children. Whether the issue is preventing peanut allergy (page 39) or reducing adolescent HIV risk (page 40), our investigators are pursuing new and more effective therapies for patients here and outside our walls. Education and training are also vital for maintaining best practices, which we're sharing at other hospitals through our simulation outreach program (page 35).

Also central to excellent care is a robust patient- and family-centered care philosophy. In this issue, a mother and her young daughter, both heart transplant patients here, share their unique experience in supporting each other through treatment (page 29). And in our Family Matters column, a mother shares her memorable moments in guiding care for her son born with a potentially fatal disease (page 52).

All that we do here, however, is not possible without the generous support of our donors and grateful families, who have found both fun and personal rewards in giving (page 42). In that regard, in this issue we also celebrate The Charlotte R. Bloomberg Children's Center—and the gifts this beautiful new building has brought our staff, patients and families—as it turns 5 (see page 14).

Thank you, and please enjoy this issue.

**Tina Cheng, M.D., M.P.H.**  
**David Hackam, M.D., Ph.D.**  
 Co-Directors, Johns Hopkins Children's Center



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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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# Judy Rohde, Director of Pediatric Nursing

After 46 years working fulltime as a nurse, and the past five years as director of pediatric nursing, Judy Rohde decided to retire. Before she stepped down, the native Baltimorean shared some of her thoughts about becoming a nurse and nursing at Johns Hopkins Children's Center.

## Why nursing?

I came from a big family of six kids and both of my parents, who were bacteriologists at the Department of Health and Mental Hygiene here in Baltimore, encouraged all of us to go into science. They were very encouraging of my wanting to go into nursing.

## Where did you train?

I was an undergrad at Georgetown University School of Nursing and received my master's from the University of Maryland in Baltimore. Later, as a clinical specialist in neurology/neurosurgery at the University of Maryland Medical System, I enrolled in a certification program to become a nurse practitioner.

## At some point, you found your way to Johns Hopkins.

Someone called to let me know a new building here would contain all of the mind and brain sciences, and combine neurology and neurosurgery as one functional unit. That was a big change. Come over and have a look, they said, so I did.

## And your initial impressions?

It was very conservative, very physician driven, and not very progressive in terms of how medications and medical supplies were managed. But what I saw in the 1970s is the antithesis of what Johns Hopkins is like now.

## And that is?

Much more interprofessional. I am impressed that people really work as wonderful collaborative teams. Nurses have

such confidence in their competence and really speak up as advocates for patients.

## To what do you attribute that?

To the support of our frontline nurses from nursing leadership. Nurses are so well-educated now and are able to present a patient situation in a very confident and comprehensive way.

## Did you find pediatric nursing different from adult nursing?

If you have always worked on the adult side, you can't appreciate the inner workings of the Johns Hopkins Children's Center—it feels like a distinct hospital. So many of our services—from the operating rooms to the post-anesthesia care unit and respiratory therapy—are integrated, which makes the building feel like one living organism. We are all in the family, which causes people to feel more accountable.

“ I WILL NOT FORGET SEEING HOW GIVING AND TOLERANT PARENTS ARE WHEN THEY HAVE A CHILD HERE IN A STRESSFUL SITUATION. ”

## How does that affect nursing?

I cannot say enough about how patient- and family-centered our nurses are, what a strong value that is here. I have never

seen clinical teams work harder for children who are in dire straits—they bend over backward for a child's survival.

## What draws nurses here?

Our Magnet designation, which says that we promote an environment that supports nurses and encourages them to stay. There are more and more opportunities for interprofessional education.

## What are the challenges ahead?

The lengths of stay will continue to go down, and there will be more emphasis on the outpatient side. On the other hand, there are emerging new specialty service lines, like fetal therapy, which will mean higher acuity and require us to be better educated about new conditions.

## Your most memorable moments here?

There was the excitement of coming into the new building and being a member of the Pediatric Family Advisory Council. I will not forget seeing how giving and tolerant parents are when they have a child here in a stressful situation. Working with the pediatric nursing leadership group, who built a culture of making sure our nurses are highly competent, is something I will always remember. Another memorable is working with former Director George Dover, who was very vocal that nurses should always speak up. I will always think the world of our current leadership too—Tina Cheng and David Hackam and Ted Chambers all have been wonderful to work with. 🌟

# Beyond the North Star

by Gary Logan

Via a visionary eye, Tina Cheng leads pioneering, evidence-based approaches to pre-empt and prevent illness and injury in children.







Connecting with a young patient in the Harriet Lane Clinic, Pediatrician-in-Chief Tina Cheng and pediatric resident Amanda O'Hallaron.





**At pediatric Grand Rounds on a cool September morning in 2016, Tina Cheng presented a sweeping range of challenges facing faculty and staff members of Johns Hopkins Children’s Center. She cited new and shifting epidemics, like childhood obesity and opioid addiction, increases in adverse childhood experiences and inner-city violence, a widening gap between the rich and the poor.**

The United States, she noted, ranks 26th out of 29 developed countries in child well-being. With her pediatrician’s eye on the horizon during a national election year, Cheng anticipated declining biomedical research dollars, dramatic changes in health insurance for families and potential cuts in federal support of health care spending for children. “How do we address it all?” Cheng asked the residents and faculty members packing the auditorium.

Then Cheng reiterated in multiple ways the institution’s mission and reputation as the birthplace of modern pediatric medicine and its great achievements in pediatric research that have led to increased survival and improved quality of life for children. She noted emerging new concepts of pediatric care like life course theory—treating the whole child, the whole family, the whole community to influence health across the life span—and treating children in the context of their lives. She talked about the “three-generation continuum,” in which pediatricians are urged to focus not only on the parents and

the child but the next generation to come to optimize their health and wellness. She cited terms like precision medicine, population health and “big data,” as though within them lie solutions to improving child health. By reaching out into the community and identifying social determinants of health, like education, employment, food and housing, and their impact on families, Cheng emphasized, pediatricians could actually reduce or prevent their need for health care services: “Pediatricians can do more than care for children. They have the power to change their lives—to pre-empt injury and illness.”

It seemed Cheng would take a breath, slow down or end this talk. Instead, she posed a challenge: “Some people have said our strategic plan is kind of bland, that we don’t have a North Star. I think for us our North Star is pretty clear—it is the children and the families we serve and what is in their best interest. I think our future is very bright, but it’s up to us to create that future.”

There was the slightest pause of silence in the auditorium, punctuating a growing impression that Cheng, Johns Hopkins' new pediatrician-in-chief and co-director of Johns Hopkins Children's Center, could steer its faculty members and staff to the answers, to the North Star and beyond. The ovation was impressive.

"The way she expresses her vision of the future of pediatrics is inspiring to me and, I think, to most people who hear it," says pediatrics faculty member Maggie Moon. "And she has the focus and skills to help us move in that direction."

"There are a lot of data around health disparities in Baltimore, which is a real challenge we have to face," says fellow faculty member Maria Trent. "Tina's understanding of that will allow her to not only uphold the mission and vision of the larger Johns Hopkins institution but really make a difference for the people who live here."

## From Iowa to Baltimore

In the wake of her Grand Rounds presentation, a sense of Tina Cheng emerged—she seldom stands still. As observed by others, her mode of operation is envision, assess, solicit, collaborate, implement

and—core to that formula—innovate. She constantly looks forward, then moves ahead thoughtfully, a mindset that dates back almost a half-century to a Coralville, Iowa, elementary school classroom where Cheng wrote "ENT doctor" in her school yearbook, in response to the question, "What do you want to be when you grow up?" She was 6.

"I had a lot of nose bleeds as a kid and a lot of visits to the ENT doctor," Cheng explains. "The following year, I wrote pediatricist—I meant pediatrician—after reading some books about kids who had illnesses, and one I remember had osteogenesis imperfecta. I was really taken with the fact that I wanted to help people and be a doctor."

One vision led to another, and Cheng, breaking the mold that encouraged young women in the Midwest to attend schools near home, enrolled at Brown University's combined undergrad-medical school program: "I can't say I knew very much about Brown. I just ended up there."

The child of immigrant Chinese parents—her father was a biochemist, her mother, a kindergarten teacher—and one of only three Asians in her high school class, Cheng feels she may have been searching for her own identity in selecting a diverse northeastern campus. Diversity she also found in Brown's curriculum as a biology major, which allowed her the flexibility to take electives like international relations, history and literature. Brown and a wider world stimulated her, though she would not stray far from medicine. She did, however, reconsider pediatrics.

"People said women should not go into pediatrics. I didn't want to be stereotyped, so in medical school I wasn't thinking I would be a pediatrician," says Cheng. "When my colleagues said to take the rotation you think you don't want first, I selected pediatrics. But I loved it and saw great potential to influence kids and their health behaviors early in life."

The next several years were foundational. In medical school at Brown and a pediatrics residency at the University

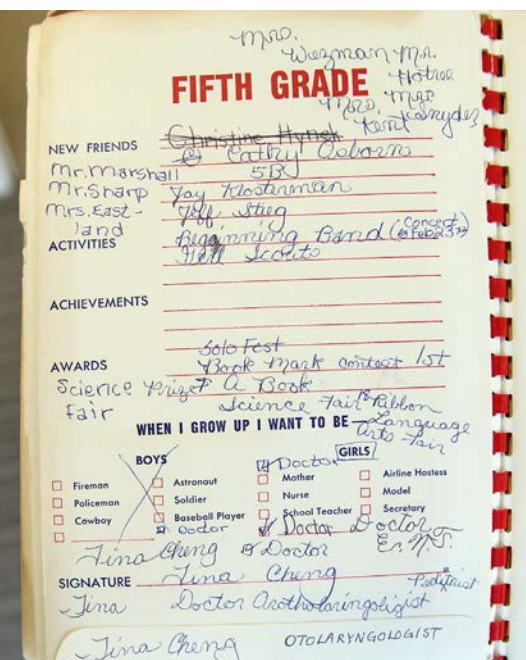
of California, San Francisco, she found taking care of patients extremely rewarding, but she wanted to make more of a difference. The public health scientist in Cheng emerged: "I loved seeing patients one on one, but I also thought about how we could make a bigger impact across populations."

That vision led her to a preventive medicine residency and a graduate degree in public health at the University of California, Berkeley, followed by a research fellowship at the University of Massachusetts. Working with underserved populations and studying injury prevention and child health disparities deeply resonated with her and became her next quest, which she found at Children's National Health System in Washington, D.C. Eight years later, she got a call from Julia McMillan, head of a search committee for a new director of the Division of General Pediatrics and Adolescent Medicine at Johns Hopkins Children's Center. Was she interested?

Initially, Cheng thought no. She considered herself too early in her academic career to be a division director. Also, while Cheng could cite worthy accomplishments at Children's National, including founding the Generations Clinic in Washington, D.C., a clinic for teen mothers and their children recognized as an evidence-based practice in reducing rapid repeat pregnancy in adolescents, she was not yet a full professor. And, as her mentor warned, "looking can be dangerous."

But Johns Hopkins had reached out to her, Cheng figured, and if the institution's goals were in sync with hers, she could take some giant steps in her calling to improve the health of children, noting the division's strong collaboration with the Johns Hopkins Bloomberg School of Public Health: "I think I had a smaller view of what was possible. Hopkins just has incredible people resources and a culture of striving for excellence."

Meanwhile, McMillan and former division Director Modena Wilson saw the same determination in Cheng. As a leader, hands-on clinician, accomplished



Tina Cheng's fifth grade yearbook





**Tina Cheng arrives early at her office before leaving with Marlene Miller, vice chair quality and safety, and colleagues for a patient safety meeting on appropriate dosing of pediatric patients and preparing patients for removal of central lines. She then stops to discuss a patient issue with pediatric social worker Beth Bounds.**

“I really learned a lot from Tina: how she leads teams, includes everyone, thinks about everyone’s perspective and partners with key stakeholders.”

—BARRY SOLOMON, M.D.

researcher and teacher, and passionate advocate for children, she certainly met the criteria for the job. While they agreed she was junior in age, her achievements were much greater than her age would suggest.

“Tina has a nice way of understating her own accomplishments, but there is a confidence about her,” says McMillan. “I had an impression that if she assessed the situation and believed she could do it, then she could do it. Also, we were looking for a strong leader vested in research, and she had this robust record of research in injury prevention and youth violence. Modena thought we’d be lucky to get her.”

Former Pediatrician-in-Chief George

Dover agreed, citing Cheng’s advocacy: “Tina emphasized that all children should be exposed to all possible medical care in pediatrics, and that should absolutely be the highest priority in this country.”

Still, not having been groomed by Johns Hopkins, Cheng felt a bit intimidated. Also, she had concerns about whether she would find Johns Hopkins “stuffy” or “supportive.” After she took the division chief post in 2002, she found the latter in abundance.

“I quickly discovered that if you had an idea and a plan,” Cheng says, “Hopkins would provide a platform to take it to the next step.”

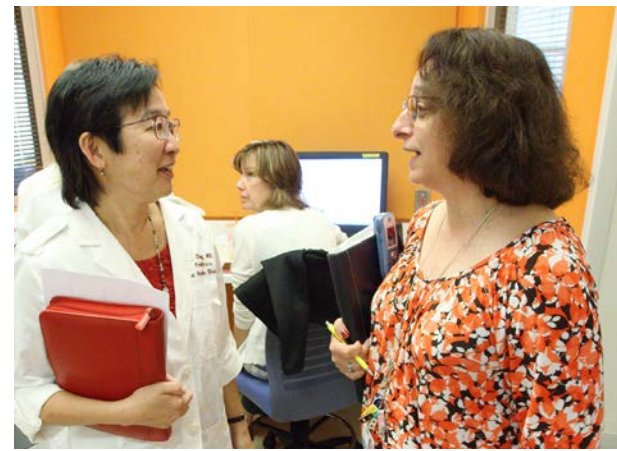
And steps she took.

## Forging an Agenda

First off as division director, Cheng saw the urgent need for Johns Hopkins’ pediatric primary care clinic—the Harriet Lane Clinic—and subspecialty clinics to be under one outpatient roof. Harriet Lane had limited space within the hospital, and pediatric subspecialists were holding their clinics across campus in an outpatient building designed primarily for adults. The \$20 million David M. Rubenstein Child Health Building did not exist when Cheng stepped into her new role, so immediately she began to work with Johns Hopkins leadership and architects to make it happen, which it did in 2007.

In concert with building the new pediatric outpatient building, Cheng focused on improving access to care. Another priority was continuing the type of violence prevention research she had conducted in Washington, D.C. Prior to her arrival at Johns Hopkins, adolescents who came into the pediatric Emergency Department (ED) with assault or fight-related injuries





were stitched up and sent home. Cheng added a case management violence prevention intervention with the patients and families to identify and address the root causes of the injuries.

“What caused the fight? How could it be prevented in the future?” she asked.

This pre-emptive approach resulted in an increase in referrals to community services, such as mentoring and afterschool programs, bullying prevention, conflict resolution and substance use programs. It also led Cheng and pediatric ED physician Leticia Ryan to a violence prevention collaboration in Baltimore and Philadelphia called Take Charge, in which ED patients are referred to a mentoring volunteer with Big Brothers Big Sisters to learn how to solve problems without violence. Cheng’s previous research, says Ryan, shows that a prior violent injury is a strong risk factor for future assault-related injuries and homicide.

“Early results of the Take Charge program have been promising, with participating youth showing improved

**“What Tina and the faculty members she recruited were able to do was emphasize this idea that the health of children was more than prevention of biological disorders and to bring the resources in the community into the clinic to address specific problems of child health.”**

—GEORGE DOVER, M.D.

self-efficacy in avoiding violence, decreased aggression and problem behavior,” says Ryan. “Before this program, we had very little to offer youth who came to the ED with fight-related injuries to help them prevent future injuries.”

In another mentoring and parenting intervention called Healthy Futures, Cheng and her colleagues leveraged the strengths of the youth and families and employed career counseling and techniques, like motivational interviewing, to prompt kids to plan for their futures to improve educational, employment and health outcomes.

“If you have more of a sense of your future and how to get there, you’re more

likely to move in that direction and not get involved in risky healthy behaviors,” says Cheng. Her work resonated with faculty members and residents. As an intern inspired by Cheng’s studies targeting families whose health was compromised by poverty, Devan Jaganath proposed an initiative called Financial Futures for Families, in which Harriet Lane Clinic case managers connect families with community resources related to their financial needs, whether that means help getting a job or opening a savings account. In the six months prior to the initiative’s launch in January, Jaganath, now a third-year resident, detected a high number of

failed connections for families due to barriers like transportation. But at the end of January, there was a significant rise in successful linkages, showing that having the service in the clinic really reduced some potential barriers.

“The ultimate goals are to see whether integrating financial services in a clinic-based practice increases patients’ and families’ access to services, and results in higher employment, higher income

and hopefully better health,” explains Jaganath.

Indeed, as effective services were identified, Cheng and Harriet Lane Clinic Director Barry Solomon incorporated them into an expanding medical home model in the clinic. To help reduce the risk of teen pregnancy and remove barriers to preconception care for low-income women, for example, the Preconception Women’s Health in Pediatrics Initiative

was added to the menu of clinic services. Today, 14 years after Cheng was named division director, the clinic features numerous wraparound services not typically found in a pediatric primary care clinic, including nutrition and lactation services, screening for family social needs and risks, services for mothers experiencing depression and intimate partner violence, injury prevention counseling, and a community help desk.

“All of these services and nontraditional programs, and our thinking now about the continuum of care, life course theory and the whole child in the family and the community have been influenced by Tina,” says Solomon. “It really comes back to social determinants—people can’t take care of themselves if they don’t have the basics.”

“Tina has broadened the definition of what a medical home should be—a program that addresses multiple needs, from housing and mental health to the health of parents,” adds Dover. “I don’t think anyone will ever create a medical home that has all of the resources Tina

“I don’t want to leave out the word mentor. The percentage of underrepresented minorities she has mentored and included in fellowship or faculty is profound. And she understands you don’t just wait for people to come but you actually seek them out to help them be the people they become. She’s a genius at that.” —JULIA McMILLAN, M.D.

Following her Grand Rounds presentation, Tina Cheng stops to discuss research proposals with Barry Solomon, medical director of the Harriet Lane Clinic, and pediatric resident Devan Jaganath, who was inspired by Cheng to propose a financial needs initiative to support patients.







In clinic, Tina Cheng enjoys some lighter moments with pediatric residents Caroline DeBoer, above, and Amanda O'Halloran, right, and their patients.



“ Tina and I share the belief that many pediatric problems are socially determined, and if you do not do work outside the clinical setting in the community, you will not reduce the overwhelming causes of morbidity and mortality in children. ”

—JONATHAN ELLEN, M.D.

has brought to bear, which has become a phenomenal multidimensional approach to optimizing the health of children.”

The clinic is an important point of contact, notes Cheng, but through her lens it cannot solve all the challenges facing families in impoverished communities. Her answer? “To appropriately address health disparities, we have to go beyond the clinic and go where the kids are—in the schools.”

In 2014, Cheng and pediatrics faculty member Sara Johnson did just that in a big way. Acting on evidence that students’ access to school-based health services improves attendance and academic performance, they founded the Ruth and Norman Rales Center for the Integration of Health and Education. By supplementing the school nurse model with a medical team that includes a pe-

diatrician and pediatric nurse practitioner who can diagnose, treat and screen schoolwide for asthma, dental and vision issues, as well as keep immunizations up to date, the center is helping to control chronic diseases like asthma, keeping students in class and out of the ED.

“Tina’s vision has helped promote the idea that by providing comprehensive health services in schools, we can reduce health and educational disparities at the same time,” says Johnson.

In another tack, Cheng looked across the street, leveraging pediatrics’ close alignment with faculty members in the Johns Hopkins Bloomberg School of Public Health to improve the health of Baltimore’s children. Cheng, Johnson and Solomon, among other pediatrics faculty members, have joint appointments in the Bloomberg School of Pub-

lic Health’s Department of Population, Family and Reproductive Health, which holds that families remain a fundamental influence on early, lifelong health.

“One of Tina’s strengths was her ability to closely align with leaders at the school of public health, find common ground and collaborate on training and community programs,” says Dover.

For Cheng, these were all pieces of the puzzle in implementing a whole child, whole family, community approach emphasizing early determinants of health. Meanwhile, through her prolific research—Cheng is the author of over 150 publications—speaking at various national conferences and serving in leadership positions with groups like the American Academy of Pediatrics, Cheng was further evolving into a nationally recognized administrator and scholar.





“What I am passionate about is focusing on where child health care is going, and how we innovate to provide the best clinical care, education and research to make sure we do the best for kids and families. We can’t just sit back and wait for things to change around us; we need to be proactive and create the future.”

—TINA CHENG, M.D.

Tina Cheng with patients, back, Anderson Jones, Jared Daniels and, front, Eli Sponseller, Zannah Simons and Lucy Jenkins.

That was a history Johns Hopkins Medicine leadership was well-familiar with when searching for a new chair of pediatrics at Johns Hopkins Bayview Medical Center, a position vacated by Jonathan Ellen after he was named president, CEO and physician-in-chief for Johns Hopkins All Children’s Hospital in St. Petersburg, Florida. Like Cheng, Ellen subscribed to a health disparities

approach in treating children: “Tina and I share the belief that many pediatric problems are socially determined, and if you do not do work outside the clinical setting in the community, you will not reduce the overwhelming causes of morbidity and mortality in children.”

But if Cheng was going to accept the post, which she did, she knew she’d have to quickly scale the learning curve

of providing care for Latino children, who comprise 75 percent of patients at Bayview Medical Center’s primary care clinic. That led to Cheng—with pediatricians Lisa DeCamp and Sarah Polk, and adult internists Kathleen Page and Adriana Andrade—founding the Center for Salud/Health and Opportunity for Latinos, or Centro SOL.

“We felt Latinos were a unique

population with unique needs, and that it was important to have a center focus on the clinical issues facing families, as well as research and advocacy,” says Cheng. “With the support of a generous donor and matching funding from the institution, it has been amazing to see the reach of that center in a relatively short time.”

The success of this program wasn’t lost among leaders of Johns Hopkins Medicine three years later in looking for a replacement for George Dover as its next pediatrician-in-chief.

## Creating the Future

As noted in her first Grand Rounds presentation as pediatrician-in-chief, there was no shortage of challenges facing Cheng, faculty and staff members when she stepped into her new leadership role. The landscape of health care was rapidly changing, with fewer small pediatric practices and more group practices and systems of care, posing the need to work even more closely with community pediatricians, subspecialists and hospitals to help them and their patients navigate the Johns Hopkins system. Continuing to build a network throughout the region was another task, as was developing new evidence-based ways to provide health care for children. Internally, adding a chief medical officer to the pediatrics leadership team (see page 36), a first for the department, was another priority, as was recruiting, training and mentoring the next generation of pediatricians to be innovators.

But in these endeavors and others, Cheng would not be flying solo. In her latest promotion, Cheng was also named co-director of Johns Hopkins Children’s Center with Pediatric Surgeon-in-Chief David Hackam, who also has a strong research record and a vision—the development of six pediatric surgical centers. Cheng and Hackam complement each other’s strengths and perspectives, and any tricky issues are usually settled over a bag of potato chips, their shared addiction.

“We both find that potato chips allow us to think more broadly,” says Hackam. “And it’s a challenge to see who can eat the fewest. I usually lose.”

Hackam smiles, then adds: “Tina is incredibly inviting and encouraging of ideas, and respectful of other opinions and thoughts. And she puts up with a surgeon, which takes tremendous amounts of patience.”

Others also cite Cheng’s calm-in-a-storm demeanor, though her mantra is more about being proactive than patient, innovative rather than complacent. For instance, writing about the seven great achievement in pediatric research over the past 40 years wasn’t enough (*Pediatric Research*, September 2016), so as this magazine was being printed, “The Next Seven Great Achievements in Pediatric Research,” with Cheng as lead author, was being published in the May 2017 issue of *Pediatrics*. Among her predictions: the development of pediatric immunizations to prevent emerging diseases, such as Zika and Ebola virus disease; advances in cancer immunotherapy; and genomic screening prenatally and in pediatrics that will greatly enhance pediatricians’ ability to diagnose and prevent diseases early.

There is no question Cheng is a forward-thinking scholar and perhaps an evidence-based prophet of sorts for pediatricians too. She sees what’s ahead because she is constantly looking around corners searching for answers for children, something she is not shy about expressing.

“What I am passionate about is focusing on where child health care is going and how we innovate to provide the best clinical care, education and research to make sure we do the best for kids and families,” says Cheng. “We can’t just sit back and wait for things to change around us; we need to be proactive and create the future.” 🍌



Watch Tina Cheng talk about seven great achievements in pediatric research: [youtube.com/watch?v=GU1HTfUmSMo](https://youtube.com/watch?v=GU1HTfUmSMo)

## Cheng Initiatives

**CENTRO SOL:** Cheng helped found the Center for Salud/Health and Opportunity for Latinos to advance clinical care, research, education and advocacy at Johns Hopkins and beyond in active partnership with the Latino community.

### D.C.-BALTIMORE RESEARCH CENTER ON CHILD HEALTH DISPARITIES:

Cheng is the principal investigator of this fifteen-year NIH-funded center in collaboration with Howard University and Children’s National Health System designed to improve minority health and overcome child health disparities.

### HEALTHY GENERATIONS

**PROGRAM:** In 1994, Cheng spearheaded this teen-tot clinical program and community coalition in Washington, D.C., to support the needs of teen parents and their children, and reduce rapid repeat pregnancy.

**MEDICAL HOME MODEL:** With medical director Barry Solomon, Cheng enhanced the Harriet Lane Clinic’s comprehensive medical home model by adding services linked to the basic needs of children and their families, including child care assistance, food and housing, education and employment, and increasing parent education and support.

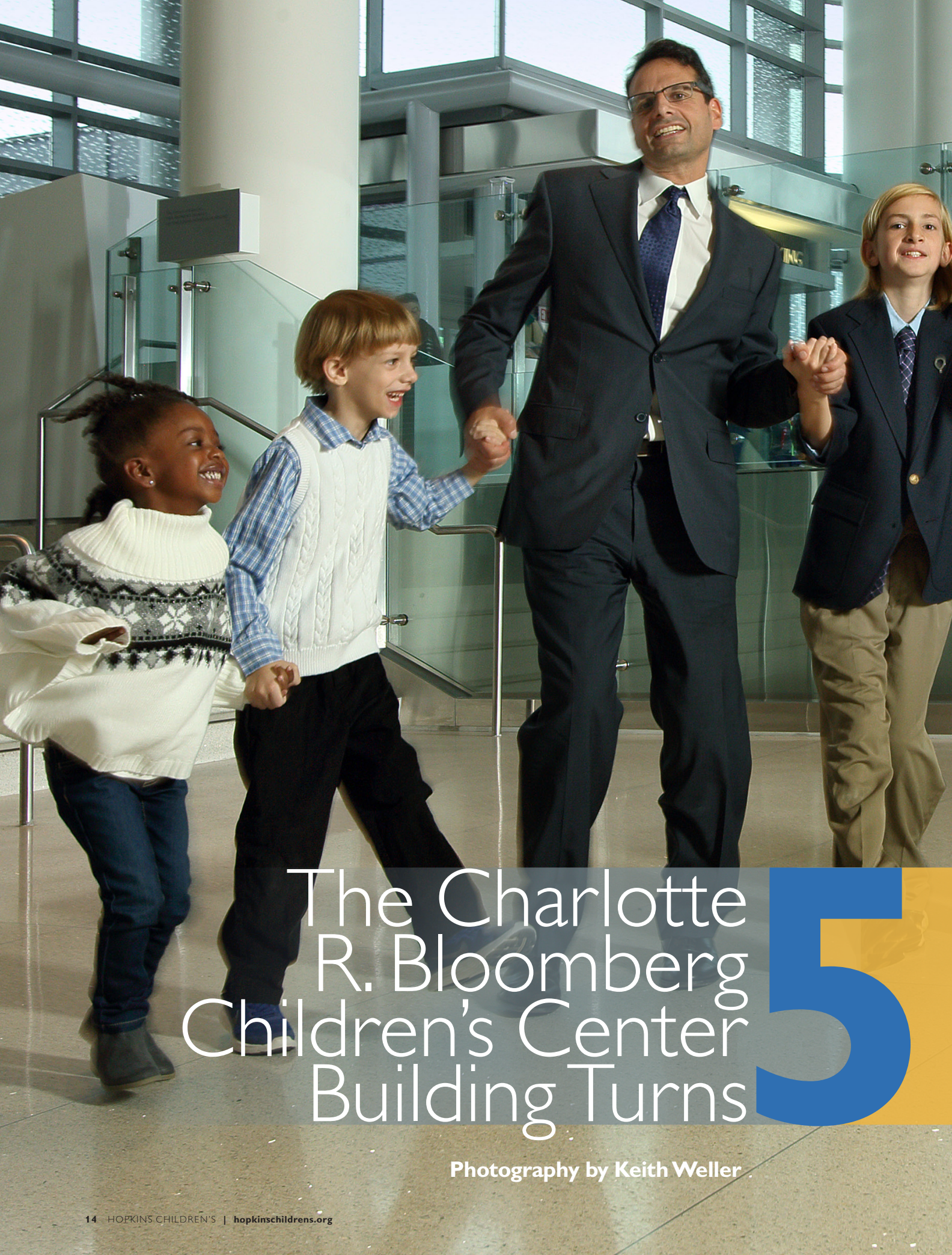
### PRECONCEPTION WOMEN’S HEALTH IN PEDIATRICS:

With faculty member Krishna Upadhyia, Cheng helped develop this multisite initiative to reduce inequities in birth, infant and maternal health outcomes by promoting women’s health in pediatric practices and removing barriers to preconception care for low-income women.

### THE RUTH AND NORMAN RALES CENTER FOR THE INTEGRATION OF HEALTH AND EDUCATION:

Acting on evidence that good health enhances learning and success in life, Cheng and Sara Johnson founded this center serving more than 1,500 students and logging more than 100 school nurse and doctor visits each day at two Baltimore charter schools.





# The Charlotte R. Bloomberg Children's Center Building Turns



Photography by Keith Weller





**It has been five years since Michael Bloomberg, the former mayor** of New York, said these words at the dedication of The Charlotte R. Bloomberg Children's Center building, named after his late mother: "If this center will bring the youngest and most vulnerable patients the kind of care and comfort that they need, if it will increase the knowledge and experience of the greatest doctors and teachers; if it will inspire other institutions to do more and do better, then we all will be happy." Recently we took our lens to members of our faculty and staff and, more importantly, patients and families for a glimpse of the building as it turns 5.

**The Charlotte R. Bloomberg Children's Center building and its airy atrium continue to bring new light and some lighter moments for patients and Co-Directors David Hackam and Tina Cheng.**





**THE NATURALLY LIT** two-story atrium of the new chemotherapy infusion unit and additional exam rooms, which have increased patient flow and decreased wait times, are among the highlights of the new oncology floor; note pediatric oncologists Ken Cohen, left, and Don Small with nurse manager Lisa Fratio.

A place to  
**HEAL**

**TWO DEDICATED TRAUMA** resuscitation rooms, along with a trauma/emergency surgery room for children, notes pediatric surgeon Dylan Stewart, have been instrumental in improving pediatric trauma care in the Children's Center; the state of Maryland's designated trauma center for children.







# A place to PLAY



“THE GREAT ROOM IS JUST THAT—GREAT! IN ADDITION TO LARGE EVENTS, THE SPACE ALLOWS FOR WORKSHOPS, WIRE SCULPTING, GAMES, AND ARTS AND CRAFTS. OUR HOLIDAY GIFT SHOP, SNOWFLAKE STATION, WOULD NOT BE POSSIBLE WITHOUT IT.”

— PATRICE BRYLSKE, CHILD LIFE DIRECTOR

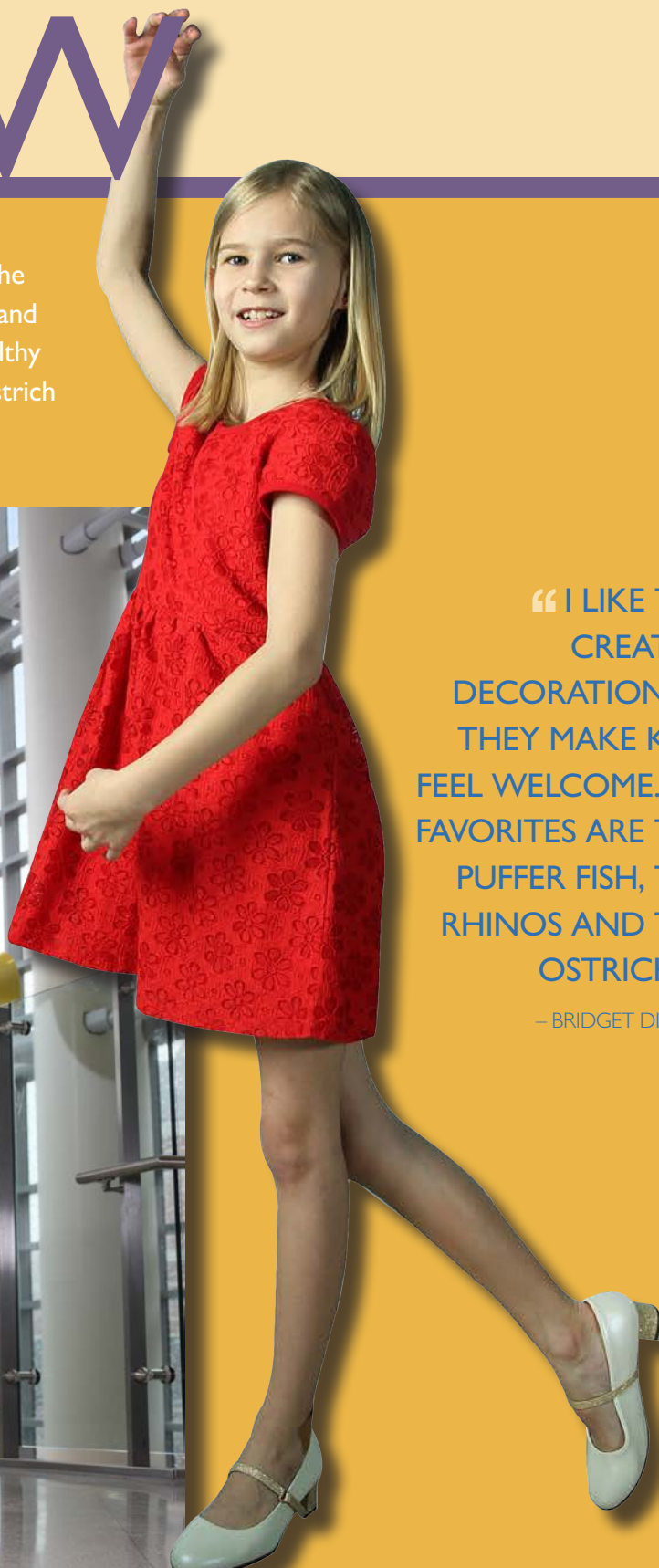
**EACH YEAR, THE** two-story Julia Clayton Baker Great Room accommodates a menagerie of artists, musicians, poets and even MLB umpires. It also offers a suitable venue for a photo shoot with Child Life Director Patrice Brylske.

**THE TANGIBLE EFFORTS** of patient- and family-centered care, whether it be in the Great Room during a homecoming dance or in a rocking chair with *Corduroy* and a young patient like Zannah Simons, are evident throughout The Charlotte R. Bloomberg Children's Center building, says librarian Phoebe Bacon.



# A place to GROW

**BRIDGET DIVELEY**, a patient in 2012 when the Bloomberg Children's Center building opened, and today, is making even bigger steps toward a healthy future. Her dancing partner is a 22-foot-long ostrich known by some as Oscar the Ostrich.



“I LIKE THE  
CREATIVE  
DECORATIONS—  
THEY MAKE KIDS  
FEEL WELCOME. MY  
FAVORITES ARE THE  
PUFFER FISH, THE  
RHINOS AND THE  
OSTRICH.”

— BRIDGET DIVELEY





**ART AND CHILDREN'S** literature in the Bloomberg Children's Center building takes patients like Elijah "Eli" Sponseller, now 7 years old, on journeys to another time and place. Over 300 works of art by some 30 artists call the building home, as does Eli. "Johns Hopkins Children's Center is our second family," he says.

“WE HAVE LEARNED SO MUCH FROM OUR EXPERIENCES HERE—  
 COMPASSION, STRENGTH AND COURAGE—AND WE'VE MADE SO  
 MANY LIFELONG FRIENDSHIPS. WHILE MOST OF ELI'S TREATMENT WAS  
 IN THE OLD HOSPITAL, WE LOVE HOW BRIGHT AND OPEN THE NEW  
 BUILDING IS, HOW COMFORTABLE AND CHEERFUL HIS ROOM FELT.”

— RACHAEL SPONSELLER, ELI'S MOM

# A place to **LEARN+** **DISCOVER**

**WITH LARGE SINGLE-**  
patient rooms, staff  
rapid response teams  
have plenty of space to  
conduct training sessions  
for emergency medical  
care at the bedside.



“THE BEAUTIFUL VIEWS FROM  
THE BUILDING DEFINITELY  
PROVIDE AN INSPIRING PLACE  
TO SIT DOWN AND THINK  
ABOUT NEW RESEARCH  
IDEAS.”

— SANJAY JAIN, M.D.





“WHAT MOST  
INSPIRES ME  
ABOUT THE  
BLOOMBERG  
CHILDREN’S  
CENTER  
BUILDING? THE  
LIGHTS THAT  
GREET ME WHEN  
I ARRIVE BEFORE  
THE SUN RISES.”

— PHOEBE BACON, LIBRARIAN

# A place to ARRIVE+ SAY GOODBYE

**FAREWELL  
AND FLY** safe,  
flight nurses on  
the helipad tell  
patients and  
families.











# Ryan's Story

The more aggressively doctors treated a child with epilepsy, the more aggressive his seizures became with no answer in sight.

by Gary Logan

**Ryan Bigelow's parents were concerned when at age 3,** his right leg began to shake a bit for a day or two. What Ryan jokingly called his “wiggly leg” showed up again a month later, a pattern that would repeat itself over Ryan's early years. Then, at age 10, Ryan's wiggly leg spread to his entire right side in a violent, minute-long seizure. The Pasadena, Maryland, family called 911.

“He was given Ativan at the emergency room to ‘break the episode,’ a term we would become very familiar with over the next five years,” says Ryan's dad, Sonny Bigelow.

Ryan was diagnosed with epilepsy—the idiopathic form, in which the cause is not known. Like many children with epilepsy, he would be managed with anti-seizure medicines that reduced the frequency and severity of his partial seizures but did not eliminate them. For Ryan's parents, life became a continuous cycle of adjusting and changing medications, giving him multiple drug cocktails. However, no matter what combination doctors tried, Ryan's seizures continued to get worse—confining him to a wheelchair because even the slightest pressure on his right foot would trigger seizures. The parents were distraught, Ryan in despair.

“I remember telling him when he was 10, as tears started rolling down his cheeks, that it's OK to cry,” says Sonny. “Then, he said, ‘I hope this is not a lifelong condition.’”

That, however, appeared to be the prognosis. Indeed, at what Sonny calls Ryan's “first and last day at high school,” he collapsed from another violent seizure that paralyzed his right leg and sent him to the Emergency Department at Johns Hopkins Children's Center. But that visit turned out to be serendipitous, as physicians noted that Ryan was not presenting as a patient would with idiopathic epilepsy. He was no longer having “episodes” of seizures but continuous seizures—60 or more a day—a condition called *epilepsia partialis continua*. The good news was Ryan's epilepsy was reclassified as refractory epilepsy, or drug-resistant epilepsy, which meant that it could be treated surgically—but only if a lesion in Ryan's brain triggering the seizures could be located. As it turned out, that would be no easy feat.

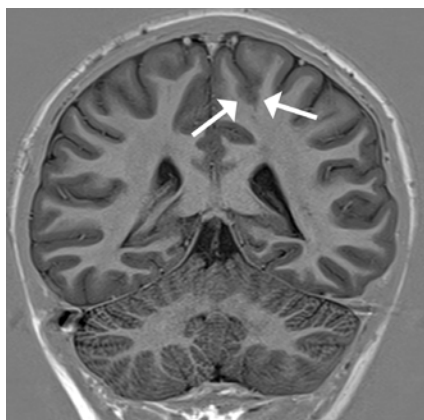
For the next six days, under the direction of pediatric neurologist Sarah Kelley, who has extensive experience treating children with refractory epilepsy, Ryan's seizures were cap-

**Ryan Bigelow, with his dad, Sonny, finds his balance after successful epilepsy surgery with pediatric neurosurgeon Shenandoah “Dody” Robinson.**





In this high-resolution MRI scan, arrows point to the subtle abnormality—what neurologist Bruno Soares, above, described as “a little bit of blurring between the junction of gray and white matter”—along the folds of the outer layer, or cortex, of the brain.



tured by EEG and video in the epilepsy monitoring unit. But while the EEG suggested a possible area of abnormality in the brain, the MRI scans did not reveal anything structurally wrong in Ryan’s brain. The culprit lesion was still in hiding, and Kelley felt it might take a needle-in-the-haystack search to find it.

Enter pediatric neuroradiologist

Bruno Soares, who was asked to review an earlier MRI scan of Ryan’s that had been interpreted as normal. Correlating Ryan’s clinical picture and EEG, he knew almost immediately where to look for the lesion on the scan.

“I went to the patient’s chart and saw that the seizures start in the right hip and leg, so it’s something in the motor area of the brain on the left side,” says Soares. “And the spikes in the EEG suggest the seizure focus is near the vertex, the top of the brain, in the primary motor cortex that controls movement.”

From there, Soares scanned the convolutions and folds in the cortex, where there should be a clear demarcation between gray and white matter. There, at the bottom of a sulci, an enfolding in the brain, was “a little bit of blurring between the junction of gray and white matter,” says Soares, what he knew was a shadowy sign of a certain type of lesion. In his mind, the search for the source of Ryan’s seizures was over.

“I said it’s very subtle, but this patient definitely has a focal cortical dysplasia,” says Soares, noting that the literature shows up to 40 percent of these very

“We received an email from the family over Christmas saying Ryan’s wheelchair was collecting dust in a corner. He’s walking everywhere, and the family is very happy we gave them their son back.”

— SARAH KELLEY, M.D.

faint lesions can be missed on conventional MRI scans. “Now, suddenly everyone in the epilepsy conference is excited and hopeful because there is a lesion, something to address.”

Doing the addressing would be pediatric neurosurgeon Shenandoah “Dody” Robinson. But first, both she and Kelley



**Ryan undergoes a neurologic examination with pediatric neurologist Sarah Kelley.**

wanted additional imaging to confirm that this lesion was indeed the culprit. To determine the extent of the lesion, they ordered a magnetoencephalography and a higher-magnification MRI scan using neighboring Kennedy Krieger Institute's 7 Tesla research MRI scanner, which produces higher-resolution images than those generated by the 3 Tesla MRI scanner used by most academic medical centers. Ryan would become the first patient under a new clinical protocol using the 7 Tesla, which depicted

the lesion in greater detail.

"It looked like a teardrop of cells at the bottom of a sulcus folding in the cortex of the brain, very close to the left motor strip, the area that controls the movement of the right side of the body," says Kennedy Krieger pediatric neurologist Michael Johnston.

Now the team, knowing that removal of a focal cortical dysplasia can result in a seizure-free outcome, was really excited. But knowing where the lesion lived did not mean removing it would be risk-free,

as the lesion was a few millimeters away from the area in the brain responsible for language and motor movement. Ryan was at risk of losing the function of his right arm and leg, as well as his speech.

Intracranial monitoring in the epilepsy monitoring unit helped reduce that risk, and subcortical motor brain mapping was used during the operation to ensure vulnerable areas were not injured. With advanced neuro navigation at her side, Robinson was able to remove the lesion last November.



The patient's outcome?

Immediately after surgery, Ryan was able to speak, and 24 hours later, he gave his family a high-five with his right arm. Two weeks later, Ryan was walking with a slight case of drop foot, which physical therapy was improving.

"I do not know how Dr. Robinson

was able to successfully perform this difficult and delicate surgery so close to these motor control areas without any noticeable impairment—it's a miracle," says Sonny. "There are no words to describe how wonderful Dr. Kelley and Dr. Robinson are, or how wonderful the epilepsy monitoring unit, the surgi-

cal team, the PICU staff, the pediatrics ward staff and the physical therapists at the Kennedy Krieger Institute are. I can only tell you that Johns Hopkins Children's Center pulled out every stop to make sure that Ryan received the best care possible."

Kelley adds: "We received an email

## Maximizing the Benefits of Spasticity Surgery

**HAVING DEEP EXPERIENCE** in performing surgery to reduce spasticity and improve motor function in children with cerebral palsy (CP), says pediatric neurosurgeon Shenandoah Robinson, does reduce the risk of complications and increase the likelihood of a good outcome.

Robinson should know—she's been doing the procedure for 15 years now. But what makes as much of a difference in achieving the goal of the child being able to walk independently, she adds, is a multidisciplinary team approach and patient selection.

"Outcomes are greatly influenced by having the resources of a team of pediatric neurosurgeons and neurologists, anesthesiologists, intensivists, orthopedic surgeons, and physiatrists, which we're fortunate to have," says Robinson. "Screening for patients and families who are committed to intensive physical therapy for up to a year following the surgery is paramount."

In the surgery, called selective dorsal rhizotomy, Robinson divides certain sensory nerve fibers entering the spinal cord from leg muscles, interrupting the abnormal circuit of nerve impulses in patients with CP that result in high muscle tone and spasticity. These patients, Robinson explains, lack inhibitory signals from the brain to dampen this feedback loop.

"We cut a fraction of the sensory nerve roots to help restore the feedback loop into a more normal range and give patients more selective control of their muscles," she says.

Before cutting these nerve roots, however, Robinson, with the aid of a microscope, separates bowel, bladder and motor nerve roots to protect them. In another innovation, Robinson also uses a minimally invasive approach to minimize the removal of lamina covering spinal vertebrae.

After the four-hour surgery, patients may report their legs feel different and, in some cases, weaker—a consequence of losing their abnormal muscle tone in the surgery. But as spasticity is reduced, patients find it easier to increase their strength with therapy and exercise.

In that regard, Robinson notes that her patients benefit from Johns Hopkins' close relationship with Mt. Washington Pediatric Hospital and the Kennedy Krieger Institute, both recognized for their pediatric physical therapy and brain injury rehabilitation programs.

"Our goal is to get these kids to be as normal as possible, and to maintain that as they enter young adulthood and go off to college," she says. —GL 🌟



Pediatric neurosurgeon Shenandoah Robinson, left, and Mt. Washington Pediatric Hospital physical therapist Sharon Selko, assess patient Justin Thompson's range of motion.



**Watch Shenandoah Robinson explain spasticity surgery:**  
[youtube.com/watch?v=HcWqCF8dsFM](https://www.youtube.com/watch?v=HcWqCF8dsFM)

from the family over Christmas saying Ryan's wheelchair is collecting dust in a corner. He's walking everywhere, and the family is very happy we gave them their son back. They said it's the best Christmas present they could ever have."

For Johns Hopkins Children's Center and the Kennedy Krieger Institute,

this case was the catalyst for the shared evaluation and treatment of patients like Ryan, as well as those with cerebral palsy and neurodevelopmental disorders.

"Historically, we've drawn more severe patients who may be eligible for a surgical approach, but because of the number of problems they have, surgery

has not always been accessible to them," says Johnston. "With Dr. Robinson, there's a real collaboration in seeing these patients."

For referrals to Johns Hopkins Children's Center, call 443-997-5437. 🌟





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# pediatricrounds



Stephanie Brown with her daughter, Maiyah, and pediatric cardiologist William Ravekes.

# Two Hearts Intertwined

**A MOTHER AND DAUGHTER** support each other through their heart transplants at Johns Hopkins.

by **Gary Logan**

**STEPHANIE BROWN REMEMBERS** her daughter Maiyah's rapid breathing at birth, her two days in the neonatal ICU, her discharge and her return to the hospital three days later where she was diagnosed with cardiomyopathy, which can lead to heart failure. Indeed, looking back seven years later, Stephanie remembers these early moments in her daughter's life like they happened yesterday.

"This was the very beginning, before I knew anything about me," says Stephanie, of Frederick, Maryland.

The first few weeks of her daughter's life, Stephanie explains, were both the beginning and foretelling of an unexpected and unique experience she shares with her daughter to this day. She knew Maiyah had a potentially life-threatening heart condition that at some point might require a heart transplant. What she didn't know was revealed at a cardiology checkup for Maiyah at 18 months—when doctors wanted to check Stephanie's heart too.

"Maiyah's doctor came back looking very serious and said, 'I'm sorry to tell you this, but your heart is failing and we need to get you admitted,'" says Stephanie. "I could not believe it—the appointment went from Maiyah to me."

Stephanie was referred to Johns Hopkins

cardiologist Daniel Judge, who prescribed Stephanie drugs similar to those Maiyah had been receiving. The good news was Maiyah's heart function had improved. Stephanie's, however, had declined to 10 percent. Two weeks after learning she had cardiomyopathy, she was rushed to the Emergency Department, where doctors told her she needed an internal cardiac defibrillator to keep her heart pumping.

"I was scared," says Stephanie. "The transplant team said my heart was barely squeezing."

One month after being admitted to the ICU, Johns Hopkins cardiac surgeon John Conte gave Stephanie a new heart. She recovered over the next month at home, and has been doing well since then. Under the management of pediatric cardiologist William Ravekes, Maiyah fared well too, until summer 2016, when she began to struggle walking up stairs.

"That's when I knew she needed a new heart. I could identify with her symptoms, having experienced them myself," says Stephanie. "She was excited about getting a new heart. It meant she could run and play again. It also meant she could eat again, especially her favorite food, a breakfast sandwich."

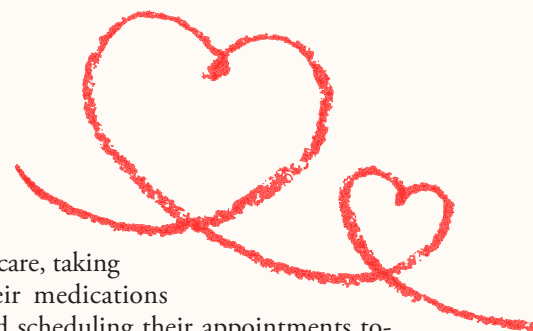
Throughout this shared experience, mother and daughter have been partners

in care, taking their medications and scheduling their appointments together, getting to know each other's cardiologists, and supporting each other beyond the typical bond between a mother and daughter.

"I hate to say this, but this is our normal," says Stephanie. "She's not alone—I know what it feels like, and I'm there for her. That helped her a lot, especially after her transplant, because I knew what to expect and what she might feel."

Such awareness among a parent and child sharing a disease can be therapeutic, adds Ravekes: "It's a huge benefit that mom also went through this because she understands the medicines and what Maiyah is feeling. That helped normalize the experience for Maiyah, so it wasn't her battle alone. She was well-prepared emotionally by her family."

The way she sees it, Stephanie says, Maiyah got her to the lifesaving transplant that allowed her to support her daughter: "The way everything unfolded, she saved my life. She is my little blessing." 💎







# For Children with Complex Colorectal Conditions

**SEAN HOOLAN WAS BORN** in China with imperforate anus, in which the anus does not fully develop in utero. Two days after birth, he had corrective surgery. The operation, in which surgeons opened the area where the anus should be, went well. But Sean did not receive sufficient follow-up care and, consequently, suffered damage to the nerves of his bowel that required another surgery when he arrived at Johns Hopkins at age 3 with his adoptive parents.

“Dr. Hackam said Sean’s surgeons in China did a wonderful job, but they didn’t continue doing dilations for the next several months, so his anus closed up and backed up his digestive system,” says his adoptive mother, Mary Eileen Aldana. “Had they done that follow-up, we wouldn’t be here.”

The here Aldana referred to is Johns Hopkins Children’s Center’s new pediatric colorectal surgical center, one of six surgical centers David Hackam planned to develop after taking the helm as

director of pediatric surgery in the fall of 2015. The other centers include fetal medicine, short gut/intestinal care, trauma/burn, oncology and vascular anomalies.

For the colorectal center, Hackam recruited pediatric surgeons Alejandro Garcia and Isam Nasr, who specialize in correcting colorectal conditions like anorectal malformations, constipation, Hirschsprung’s disease and inflammatory bowel disease. But in addition to an evidence-based center staffed by surgeon-scientists who could develop innovative, minimally invasive surgical approaches for colorectal problems, Hackam wanted a bowel management clinic fully staffed with all the pre- and post-surgical services needed by patients like Sean.

“Our goal is to work with gastroenterologists, nutritionists, nurse practitioners, psychologists, radiologists and urologists so we can not only provide a consultative surgical opinion but also

the best follow-up care,” says Garcia.

Indeed, after Nasr created a functional anus and rectum for Sean, his parents regularly attended the bowel management clinic. There they met with Nasr and pediatric nurse practitioner Margie Birdsong to learn how to use an instrument to dilate Sean’s rectum at home each day to prevent scar tissue from contracting. Birdsong coordinates the care of all patients in the clinic, and guides parents on how to perform enemas and titrate laxatives for their child at home to achieve continence. She also conducts biofeedback testing to measure patients’ level of anal rectal muscle control and then prescribes at-home exercises to strengthen the muscle. How is Sean, now almost 4, doing?

“He has no fear coming to the hospital at all,” says Aldana. “He makes it all fun, jumps on the table for his X-rays and calls all the nurses by their first name.”—GL 🍌

In the bowel management clinic, from left, pediatric surgeons Alejandro Garcia and Isam Nasr, parents Paraic Hoolan and Mary Eileen Aldana, and pediatric nurse practitioner Margie Birdsong, with young patient Sean Hoolan.





In the pediatric hemodialysis unit, from left, social worker Cristina Ibarra, psychologist Kaushal Amatya, nephrology nurse Barbara Case, pharmacist Elizabeth Goswami, nephrology director Alicia Neu, nephrology fellow Kathleen Altemose, administrator Shirl Wood, child life specialist Tiffany Potterfield, nutritionist Kirstie Ducharme-Smith, and nurse practitioner Alison Hewitt.

## Making Outpatient Hemodialysis Possible

**THE STANDARD OF CARE** for pediatric patients with end-stage renal disease (ESRD) is kidney transplant, but transplant is not immediately available for all children. Meanwhile, many patients require dialysis. Many choose peritoneal dialysis, where fluid is infused through a catheter into the abdomen to remove toxins from blood vessels lining the abdomen. Typically performed at home at night while the child sleeps, the procedure allows fewer limitations on school and social activities than hemodialysis, where the child receives treatments three to four times a week in a dialysis unit. But not all children can be treated with peritoneal dialysis, and significant training is required to perform this complex procedure at home and to avoid infection.

"It's a lot of work for patients and families, who independently set up the dialysis machine every night and disconnect it every morning," says Alicia Neu, director of pediatric nephrology. "Also,

they are making therapeutic decisions about what fluid to use. It's very labor-intensive for the families."

Peritoneal dialysis, Neu adds, may not be able to remove toxins adequately in children who have had prior abdominal surgeries or infections. In these patients, hemodialysis is required. However, in recent times in the state of Maryland there hasn't been an outpatient hemodialysis unit dedicated to pediatric patients with ESRD, which means children had to either receive this treatment at a facility that also treats adults or travel out of state three to four times a week. Last October, Johns Hopkins Children's Center relieved patients and families of that burden—and also improved continuity of care for these patients—by opening the only outpatient hemodialysis unit in the state dedicated to children.

"It means patients and families now have the best dialysis modality for them in their own backyard instead of having to go out of state," says Neu. "Also, they

**"It means patients and families now have the best dialysis modality for them in their own backyard instead of having to go out of state."**

—ALICIA NEU, M.D.

get to stay with the multidisciplinary health care team here that has cared for them, often from the time when they were infants, who will now follow them through dialysis and kidney transplant."

The pediatric hemodialysis unit is staffed by a multidisciplinary team with training in the care of children with ESRD, including pediatric nephrologists, pediatric dialysis nurses, a pediatric renal social worker, a pediatric renal dietitian, a full-time child life specialist and a behavioral psychologist. —GL 🍌





# A Single Incision for Craniosynostosis

WHEN JONAH CANTU was born, his mother immediately noticed his head was an unusual shape. “I was in shock and knew something was wrong,” says Amelia Cantu of Welcome, Maryland. “His head was long, like a banana.”

Doctors at an outside hospital diagnosed Jonah with craniosynostosis and referred him to pediatric neurosurgeon Edward Ahn, nationally known for his innovative approaches in treating the condition. In the early 2000s, Ahn was among the first neurosurgeons to use an endoscopic approach for sagittal craniosynostosis surgery, avoiding the need for an open operation and an ear-to-ear incision. Then, he made refinements to this minimally invasive procedure, including the use of an ultrasonic bone cutter to minimize blood loss—important

because even a small amount of lost blood is proportionally large for tiny patients like Jonah. That was not all. Ahn informed the Cantu family that he had developed a novel, single-incision technique for the endoscopic procedure, which offered advantages over the traditional two-incision approach. Not only would Jonah be at less risk of complications, but he would have the cosmetic advantage of only one tiny scar.

Amelia agreed with his plan and today couldn’t be more pleased: “I look at baby pictures before and after surgery, and his head has totally changed. Now he looks like a normal kid.”—GL 🍌



Watch Edward Ahn explain craniosynostosis surgery: [youtube.com/watch?v=f9MdKmQcVus](https://youtube.com/watch?v=f9MdKmQcVus)



Pediatric neurosurgeon Edward Ahn with Jonah Cantu and his mother, Amelia Cantu, at his one-year follow-up.

## Practicing Painless Medicine

PEDIATRIC CHRONIC AND interventional pain physician Irfan Suleman recalls treating an injured teen soccer player with a lumbar disc protrusion and excruciating pain in his right lower back radiating into his right leg and foot. Three weeks after administering an epidural steroid injection, his young patient reported that his pain had completely resolved, and he was back to his normal routine. Similarly, Suleman administered a sacroiliac joint injection to a high school cheerleader experiencing episodes of chronic pain in her right hip. “In the follow-up, her pain was zero,” says Suleman.

Noting that only a few children’s hospitals in the country offer such interventional pain services guided by imaging in the OR, Suleman says these cases illustrate a distinctive aspect of the pediatric pain management program at Johns Hopkins, which he directs.

“I do pediatric pain procedures with ultrasound and fluoroscopy, if conservative management fails,” says Suleman. “I always do these procedures in the operating room under sedation so that patients don’t feel any needle pain, which frightens most kids.”

The pediatric pain clinic includes a psychologist and physical therapist, along with Suleman, who meet with the patient and family as a team to arrive at the most effective treatment plan. That may include physical therapy to strengthen muscles, as well as cognitive behavior therapy (CBT) to change the way patients perceive their pain and the brain’s physiological response to pain.

“Here, we spend one hour with each patient, get a detailed history and physical examination, and discuss all the possible options,” says Suleman. “We don’t normally jump on injections—first, we do CBT and physical therapy, and, if needed, use non-narcotic pain medicine.”

He adds, “My goal is to relieve their pain and get them back to their normal activities. They deserve a healthy and happy life.”—GL 🍌



# Jumping into the Family Experience

TRADITIONALLY, MEDICAL SOCIAL workers have assisted families while their child is in the hospital or clinic. But increasingly for Johns Hopkins Children's Center social workers, the focus has been on the patient's and family's life at home and in the community to improve their access to care.

"Just as we train residents in the Harriet Lane Clinic to know the family outside of their medical status, our social workers here know that within that knowledge lie solutions to barriers

to care," says Paula Heneberry, director of social work. "It's a real value shift, bringing the social worker's interests in family life in the community in a way that everyone understands."

Following this proactive approach and employing tools like motivational empathy, Harriet Lane Clinic social worker LaToya Mobley makes as many as five contacts each month with a patient and family to build long-term rapport to identify and break down barriers related to finances, housing, insurance, transportation and the urban environment, among other issues.

"If I'm hungry and cold, if I don't have boots for winter, then I'm not worried about my asthma or anything that comes after my basic needs," says Mobley. "Our job is to jump into the family experience, to understand they have a life outside of their doctors' appointments and the Emergency Department."

She adds that she's not shy about asking families lots of questions to help move them in the direction they want to go: "You can't just hand people a bunch of resources—you have to meet your patients and families where they are to understand they have challenges outside of their health."

Dawn Warfield, social worker in the pediatric cardiology clinic, agrees with this more personalized approach. For social workers, she says, that means creating an open and honest dialogue with families, anticipating their needs, and capitalizing on their strengths.

"You have to get an understanding of the family, their values, what they perceive as their challenges, because each family is unique," says Warfield. "Don't make assumptions—people will share their experiences if they think you care."—GL 🍌

“Our job is to jump into the family experience, to understand they have a life outside of their doctors’ appointments and the Emergency Department.”

— LATOYA MOBLEY, LGSW

The key to supporting parents and patients like Brianna Howell and her daughter Rihanna, says social worker Dawn Warfield, is developing an open and honest dialogue.







The PCICU multidisciplinary team of cardiac intensivists, surgeons, cardiologists and cardiac nurses.

## A New Intensive Care Unit for Treating the Heart

AFTER GLORIA BARRETTO had the first ultrasound of her first pregnancy in May 2016, she was heartbroken: “I just could not believe my baby would have something like this.”

Barretto was referring to a ventricular septal defect, or VSD, a hole in the wall of the heart separating its two lower chambers. The Anne Arundel County mother to be was referred to Johns Hopkins Children’s Center and pediatric cardiac surgeon Luca Vricella, who walked Barretto through the course of treatment following delivery. Then she learned about a new intensive care unit—staffed with physicians and nurses trained in intensive cardiac care—for patients with heart problems, including those like her daughter who have not yet arrived in the world.

“That was very reassuring,” says Barretto. “Each of these doctors and nurses, whoever we spoke to, assured us our baby would be in good hands.”

And in a good place, adds pediatric intensivist Kristen Nelson, director of the pediatric cardiac intensive care unit (PCICU). In addition to a comprehensive multidisciplinary team of cardiac

intensivists, cardiothoracic surgeons, cardiologists and cardiac nurse practitioners, the unit offers the latest technology supporting cardiac care, including extracorporeal membrane oxygenation and ventricular assist devices.

“You have to remember that Johns Hopkins is the home of the first ‘blue baby’ open heart surgery for infants suffering oxygen deprivation after birth, which resulted in development of the Blalock-Taussig shunt in 1944,” says Nelson. “Since then, we’ve been inspired to make other advances in cardiac care, including development of the first implantable pacemaker and balloon angioplasty, and continue to look for innovative ways to treat children with heart problems.”

After her birth in October 2016, Barretto’s daughter, Sara, underwent catheterization procedures to place stents in her heart to protect it until she gained enough weight to have open-heart surgery. In February 2017, Vricella closed the VSD in Sara’s heart, and since then, follow-up echocardiograms have shown her heart is growing well. —GL 🍌

### Pediatric Cardiac Services

- A dedicated team of nine cardiac intensivists, two cardiac surgeons, 10 cardiologists and six cardiac nurse practitioners
- Comprehensive cardiac care from birth through early adulthood for patients with congenital and acquired heart disease
- Coordinated care from fetal diagnosis
- Pre- and post-operative management
- Co-management of adults with congenital heart disease
- Cardiac extracorporeal membrane oxygenation program
- Temporary and permanent ventricular assist device program
- Electrophysiology ablation and pacemaker program
- Dedicated cardiac anesthesia team
- Cardiac imaging program, including CT and MRI



# Parlaying Simulation into Practice

**AT FIRST, MARC** Callender felt uneasy. He knew everything he had learned in medical school, pediatric residency, fellowship and as a pediatric hospitalist would be tested by 10-day-old Christofer Ter Bush before him in the Emergency Department at Anne Arundel Medical Center (AAMC). The infant's blood pressure and arterial blood gas levels were dangerously low, he appeared very acidotic with poor organ perfusion, and his heart was barely beating and near arrest. While this was not the first seriously ill neonate Callender had faced, he was perhaps the sickest.

"He came in with shallow and labored breathing, and his blood gas values were quite abnormal and typically not compatible with life," says Callender. "It's hard not to be overwhelmed—these situations can be quite harrowing."

Pushing emotions aside, Callender, as the Emergency Department attending physician, focused on the task at hand and directed the team to start IV

infusions to increase his young patient's blood pressure and heart rate. Callender also ordered additional labs and X-rays to diagnose and treat the cause of his shock. Suspecting a heart-related infection as the culprit, he was mostly concerned about his young patient arresting. Facing that possibility, he flashed back to resuscitation simulation training he and his colleagues had received just three weeks earlier at AAMC from pediatric intensivists at Johns Hopkins Children's Center.

"I could hear their instructions over my shoulder as we cared for this child because we had just practiced it," says Callender.

Jamie Schwartz, medical director of the Johns Hopkins pediatric ICU, explains that the simulation outreach team conducts training sessions at community hospitals like AAMC because they tend not to see a high volume of critically ill neonates.

"If you're not a specialty children's center, it may be only once a year

**"I could hear their instructions over my shoulder as we cared for this child because we had just practiced it."**

—PEDIATRIC HOSPITALIST  
MARC CALLENDER

where you have an event like this," says Schwartz. "That's the advantage of simulation outreach—it brings our expertise out into the community and allows pediatricians to practice something that's rare and time sensitive."

Indeed, after Callender called the Johns Hopkins pediatric ICU to report his young patient needed emergency transport and extracorporeal membrane oxygenation (ECMO) support, intensivist Courtney Robertson called back to help walk Callender through the resuscitation protocol. Meanwhile, fellow intensivist Nicole Shilkofski alerted the transport and ECMO teams, which were instantly activated. With all that support and a fresh dose of confidence, Callender and his team stabilized the child and had him safely transported to the Johns Hopkins pediatric ICU and placed on ECMO.

"When the heart stops, it's hard to get it restarted, and you're then looking at end-organ damage, brain damage and kidney damage," says Schwartz. "But this child didn't suffer such damage because they aggressively managed him, prevented the arrest and got him on ECMO, which was key to his survival."

"I can't give enough credit to Anne Arundel Medical Center and Dr. Callender," adds Caitlin O'Brien, the intensivist fellow on the flight transport crew. "Being involved early on and having that communication from the outside hospital made all the difference."

—GL 🍌

**With Christofer Ter Bush and his mom, Joyce, in the pediatric ICU, critical care specialists Jamie Schwartz and Kristen Nelson**







“Actually, there’s not a ton of authority in the role, except what I call convening authority—the authority to ask people to come together, achieve consensus and solve a problem.”

—MARGARET MOON,  
CHIEF MEDICAL OFFICER

## Maggie Moon, Johns Hopkins Children’s Center’s First CMO

**MARGARET MOON**, OR “Maggie,” as she likes to be called, is out of breath as she arrives at her second-floor office in the David M. Rubenstein Child Health Building. Her teaching session on medical ethics across campus at the Johns Hopkins University School of Medicine, she explains, ran a bit late. Catching her breath, she says, “I love teaching, I really do.” Indeed, teaching, along with research and clinical practice, has filled Moon’s time at Johns Hopkins since she joined the pediatrics faculty in 2004. Now, the former Robert Wood Johnson fellow is parlaying what she has learned into a new role for both herself and Johns Hopkins Children’s Center as its first chief medical officer (CMO).

### So, you are pediatrics’ first CMO?

Yes, yes, I’m the pioneer CMO. When Tina Cheng took over as co-director, it was one of the things she really wanted to do. The Children’s Center is such a complicated place with operational activity that needs ongoing and detailed attention. Tina’s vision includes a much

broader focus, so she decided to expand her leadership group to include a CMO.

### What are the CMO’s responsibilities?

My perception of the job and what I’m interested in doing relate to the complexity of Johns Hopkins Medicine and its emphasis on research, education and the highest-quality patient care. These three parts of its mission can create obstacles for each other. The role of a chief medical officer is to minimize those obstacles.

### Obstacles?

There’s always a chance the demands we place on faculty members to teach and do research conflicts with the demands to provide high-quality patient care. The job of a chief medical officer is to make sure our patients don’t notice a potential conflict between the academic and clinical side. And part of that is managing patient and family expectations, making it clear that patients are treated by a team and not one individual physician. But it also means enhancing a culture of dedication to the patient.

### Anything else?

Also making sure that the strategies we’re implementing are consistent with our mission and our organizational ethics, not just within pediatrics but throughout the Johns Hopkins Health System. So it is current operations, strategic planning and our interactions with our member hospitals.

### Does a lot of authority come with the job?

Actually, there’s not a ton of authority in the role, except what I call convening authority—the authority to ask people to come together, achieve consensus and solve a problem. The real challenge facing the CMO is to implement that consensus through working with our department administrator Ted Chambers, nursing leadership, faculty and staff. Also, part of my job is to raise awareness of our children’s hospital to the Johns Hopkins Hospital community, to give our patients a stronger voice. Equally important, this is a communications job. I have to be able to listen and to hear. 🍌



# Nurses Making a Difference in South Africa

**LITTLE DID JOHNS** Hopkins Children's Center nurses know they would play a role in Nelson Mandela's dream to build a children's hospital in Johannesburg, South Africa. But last fall, three Johns Hopkins pediatric nurses found themselves in the new, 200-bed Nelson Mandela Children's Hospital to assess the facility and its nursing needs, and share their own experience in providing care for children.

"They wanted to learn what we're doing to determine what they may need," says Dörte Thorndike, a 20-year veteran pediatric nurse with experience working in international hospitals. "They were genuinely interested in how we practice nursing here."

In evaluating nursing at Mandela Children's Hospital, the Johns Hopkins nurses met with leaders and nurses at the hospital. They also visited other hospitals and nursing schools in South Africa to get a sense of the quality of nursing education and practice guidelines in South Africa. Among their questions: "What kind of patients do you care for? What does your work structure look like? How would you describe the role of the charge nurse and nurse educator?" recalls Dawn Luzetsky, assistant director

of pediatric nursing

"How do they educate their nurses?" adds Thorndike. "We had to figure out where they are and where they want to be."

While the Johns Hopkins pediatric nurses found a modern and spacious children's hospital with state-of-the-art medical equipment, they felt the nurses needed more training to provide first-rate care in such a tertiary care facility. Among the recommendations in their comprehensive 45-page report was implementation of a train-the-trainer model, in which Mandela Children's Hospital nurses would visit Johns Hopkins Children's Center and take what they learned back to their colleagues in South Africa. They submitted the report to Jhpiego, which funded the trip through a grant from the United States Agency for International Development. What lessons did the Johns Hopkins pediatric nurses bring home?

"They have fewer resources than we have, but because they are so dedicated and hardworking, they manage to provide great care," says Luzetsky.

"I loved it," says Dorte. "I really enjoy talking to people from other cultures and backgrounds." —GL 🍌



**Only four dedicated pediatric hospitals in Africa serve nearly 450 million children, many with life-threatening illnesses, according to the Nelson Mandela Children's Hospital Trust.**



Back home in Baltimore, pediatric nurses Dörte Thorndike and Dawn Luzetsky.



# researchroundup

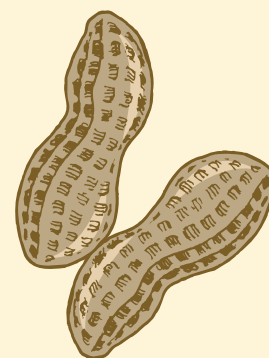


Pediatric allergist Corinne Keet with a young patient and mom in her early introduction to peanut trial.

# A Safe Approach to Preventing Peanut Allergy

by Karen Blum

FOR THE PAST SEVERAL YEARS, new parents have been told to hold off on feeding potentially allergenic foods like peanut products to their babies until they reached the ages of 1 to 3.



“What we’ve recently realized is that was exactly the wrong advice,” says pediatric allergist Corinne Keet of Johns Hopkins Children’s Center.

The landmark LEAP (Learning Early About Peanut) trial, conducted in the United Kingdom and published two years ago in *The New England Journal of Medicine*, found that early exposure to peanut protein was associated with a significantly reduced incidence of peanut allergy. By age 5, the prevalence of peanut allergy among those exposed to peanut in infancy was just 3 percent, compared with 17 percent among those not exposed to peanut. As a result, groups such as the American Academy of Pediatrics now recommend early introduction of peanut in infants at risk of developing allergy.

But questions remain, says Keet, about who needs to be screened for peanut allergy prior to introduction of peanut, how screening should be conducted and how early peanut consumption will

proceed outside of a clinical trial. In an observation study supported by the National Institute of Allergy and Infectious Diseases, Keet and colleagues have set out to find answers.

“We’ve done studies of peanut treatment, which are promising, but it would be much better to prevent peanut allergy rather than treat it.”

They’re enrolling 400 infants ages 4 to 11 months at potential risk for peanut allergy, identified by the presence of another food allergy, eczema, or a parent or sibling with peanut allergy. The investigators will use a blood test and skin prick test to check for allergies in the infants, and then introduce them

to peanut (usually a powder mixed with baby food) in a monitored setting. If the infants have no allergic reaction, parents will be asked to regularly feed their babies peanut products each week and return for a follow-up visit 18 and 30 months later. Infants who do react to peanut will be referred to allergy care.

“It’s really exciting that we have these new data that we can introduce peanut early and help prevent peanut allergy, but I’m worried that we may not implement it in a way that is practical,” says Keet. “My goal is to provide data to shape guidelines so we can do this in a way that is safe for children but also doesn’t overwhelm our medical system or lead to unnecessary testing and its consequences.” Noting that 1 to 2 percent of the population at large has peanut allergy, she adds, “We’ve done studies of peanut treatment, which are promising, but it would be much better to prevent peanut allergy rather than treat it.” 🌰





# Pushing PrEP to Reduce HIV Risk

AMID THE CHILDREN'S ARTWORK decorating Renata Arrington-Sanders' office door is a black and white poster from the Baltimore City Health Department featuring a young African-American man sporting tattoos and a fur vest. "Have balls," it reads. "Get tested."

The message is salient for Arrington-Sanders, an adolescent medicine and HIV specialist who, during pediatrics training, became interested in working with 15- to 24-year-olds, a time period she views as a "tipping point to either go in the right direction or not." During an adolescent medicine fellowship at Johns Hopkins, Arrington-Sanders saw a number of homosexual HIV-positive youth. "What struck me was the challenges that they had to deal with, particularly around their sexual identity and behavior, and how not being accepted or being marginalized really creates an environment of negativity toward oneself, resulting in adverse health outcomes."

Inspired by these patients, Arrington-Sanders has focused on helping youth have healthy romantic relationships and creating a safe space where patients can speak freely with their doctor. When early relationship experiences are bad or youth feel vulnerable, that's most often when outcomes like sexually transmitted

diseases or HIV occur, says Arrington-Sanders: "It's a privilege to have someone share some of the most intimate aspects of their life and to be able to provide them with guidance," she says. "I'm really blessed to be able to do that on a day-to-day basis."

Her work includes being a strong and early proponent of pre-exposure prophylaxis, or PrEP, a medication that, if taken daily, can reduce one's risk for HIV by up to 90 percent. Despite its efficacy, uptake for PrEP has been slow among young African-American gay men—the very population at highest risk for contracting HIV. The reasons are several, she says, including a persistent sense of medical mistrust in the community: "There's a sense of 'I need to wait a while and see how this goes to make sure it's safe.' Unfortunately for some individuals, seeing how it goes for a while may be too late. They may end up being HIV-positive because of the network they're in."

Beyond her own research about PrEP usage and attitudes, Arrington-Sanders is part of a citywide program, funded by the federal Centers for Disease Control and Prevention, to get more patients engaged in PrEP. Through the city health department-directed effort, trained community health navigators from Baltimore engage youth at risk for HIV—including young men who have sex with men and transgender women of color—to come to clinics including Johns Hopkins for PrEP counseling and prescriptions. The health department also started a program called Baltimore in Conversation, in which locals share their stories of accessing health care and HIV prevention. Arrington-Sanders participated in the first program, discussing her experience as a health provider.

"My overall goal is to create a method to really help these youth develop healthy lives," she says. "As an adolescent medicine specialist, I just want to see them succeed." —KB 🍌

“My overall goal is to create a method to really help these youth develop healthy lives. As an adolescent medicine specialist, I just want to see them succeed.”

—RENATA ARRINGTON-SANDERS, M.D.

In clinic, HIV specialist Renata Arrington-Sanders reviews the PrEP protocol with a patient.





## Asthma and the City

**CRIME, TRAFFIC,** cost of living and ... asthma? Johns Hopkins researchers just added asthma morbidity to the list of concerns often associated with city living. By analyzing national data, Corinne Keet, a pediatric allergy and immunology specialist, and her team found that living in inner cities can worsen asthma in poor children (*The Journal of Allergy and Clinical Immunology*, March 8, 2017). Children who lived in inner-city areas had an overall 40 percent higher risk of asthma-related emergency room visits and 62 percent

higher risk of asthma-related hospitalizations. She also found that African-American children had higher rates of asthma-related emergency room visits and hospitalizations. Keet's previous work had shown that living in inner cities didn't affect rates of asthma; combined, these findings, says Keet, serve as evidence that there are differences between risk factors linked to developing asthma and those linked to making asthma worse if you already have it. — Chanapa Tantibanchachai 🌟



Corinne Keet, M.D., Ph.D.

## Over-the-Counter Oral Contraceptives for Teens?

**SOMETIME IN THE NEAR FUTURE,** oral contraceptives may be available to women and adolescents over-the-counter (OTC), just like Advil, Claritin or Pepto-Bismol. A team of pediatric, adolescent and women's health specialists, led by Johns Hopkins' own Krishna Upadhy, says scientific and regulatory evidence support allowing teen females to have access to OTC contraceptives (*Journal of Adolescent Health*, March 14, 2017). For the review, the Johns Hopkins-led team looked for teen-specific data related to the safety and ef-

fectiveness of oral contraceptives, pregnancy risk associated with typical use of various forms of contraception, teen ability to use oral contraceptives correctly and consistently, the impact of OTC access on sexual behaviors, and concerns that OTC access might reduce clinician counseling opportunities with young people. Says Upadhy, "Our review emphasizes that any future over-the-counter pill has the potential to benefit teens, and there is no scientific rationale to restrict access based on age." —CT 🌟

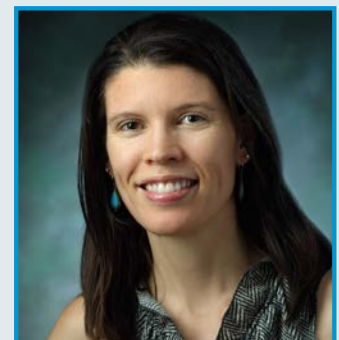


Krishna Upadhy, M.D., M.P.H.

## Mental Health Screening Tools for Latino Children

**IN A BID** to improve mental health screening of Latino children from immigrant families, researchers at Johns Hopkins Medicine have identified a culturally sensitive set of tools that is freely available to pediatricians, take less than 10 minutes to use, are in easy-to-read Spanish, and assess a wide range of emotional and behavioral problems. The four identified screening tools can be used by pediatricians who would like to screen patients for mental health symptoms, such as anxiety, depression or aggression (*Clinical Pediatrics*, Nov.

22, 2016). "The Latino population in this nation will only keep growing, and with that reality, physicians need to be aware of the population-specific barriers to health care," says pediatrics research and clinical fellow Tania Caballero, the research paper's lead author. "Latinos statistically have a poorer health status compared to whites due to lack of access to health care, fear of going to the doctor if they're undocumented and an inability to communicate health needs due to language barriers." —CT 🌟



Tania Caballero, M.D.



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# people&philanthropy



Stavros Niarchos  
Foundation Fellow  
of Pediatric  
Palliative Medicine  
Silvana Barone  
with Ryan, Debi and  
Dave Burrows.

# Championing Palliative Care

by Karen Blum



**WHEN 9-YEAR-OLD** Kendall Burrows was treated at Johns Hopkins Children's Center in 1995 for a rare autoimmune disease called Evans syndrome, in which the body produces antibodies that destroy blood cells, there was no palliative care program available to help families.

"Kendall was in the hospital for a long period of time before she died," recalls her father, Dave Burrows. "During that time, there wasn't even a place to meet except sitting in the lobby on the covers of the radiators and talking to her doctors." There was no one to talk to about Kendall's illness except their family, he says.

Fortunately, times have changed. When the Burrows family established the Kendall Burrows Foundation in Kendall's memory the following year, one of their missions was to support palliative care at Johns Hopkins. With backing from the Burrows and other families and foundations, the Harriet Lane Compassionate Care program—founded in 2000 and headed by pediatrician Nancy Hutton—now offers services, including support and bereavement groups for patients' siblings and parents, to well over 200 families a year.

Philanthropy supports several aspects of the program, Hutton notes. In clinical care, donations help fund a child life specialist with advanced counseling training. She meets with seriously ill patients and their families in the hospital or at home to help them cope with the stress of illness and improve quality of life. This specialist also offers bereavement support. It covers "what I think of as child quality of life,"

says Hutton, including making sure children understand, at an age-appropriate level, what's happening to them as well as addressing their worries and things they want known or said.

"It's not a billable service or something we can recoup reimbursement for, and yet it's clearly an absolutely essential part of care for children and families," Hutton says. Gifts also support her time as a palliative care physician, allowing her lengthy meetings with patients and families, which are not covered by insurance.

Philanthropic funds also help support teaching and research in palliative care, leveraging clinician-parent communication research by neonatologist and palliative care specialist Renee Boss. Donations from the Kahlert Family Foundation and the Stavros Niarchos Foundation have supported the first Johns Hopkins pediatric fellowships in hospice and palliative medicine. This year's Kahlert Fellow, Arun Singh, came to Johns Hopkins from a pediatric critical care medicine fellowship at Emory University, where he came to see the value of palliative medicine and what it can offer patients.

"In the middle of the night, we often have to share really bad news with patients or their families," Singh says. "As a fellow in the intensive care unit, no one really teaches you how to break that kind of news. It's kind of unnerving." One of the things Singh says he appreciated most during fellowship is learning "how to orchestrate really effective communication between the medical team and families."

Not only is the need for palliative care growing, but a palliative care elective offered to pediatric residents has become among the most popular, notes Hutton: "People are seeing the value of palliative care as a specialty area in which they want more training." 🌻

**“People are seeing the value of palliative care as a specialty area in which they want more training.”**

—NANCY HUTTON, M.D.





# Peter Rowe's Relentless Battle with Chronic Fatigue

**WHEN IT COMES** to sleuthing out the causes of chronic fatigue syndrome (CFS) and managing patients' symptoms, Peter Rowe has remained indefatigable for more than 20 years.

"He will never give up on you," says patient Emily Steffensmeier, 41, of State College, Pennsylvania. "He always has something new to try. Every time you think there can't be anything left, he's going to find it."

Rowe, director of Johns Hopkins Children's Center's chronic fatigue clinic, first encountered CFS patients in the early 1990s, when he directed a diagnostic referral clinic for patients with unusual conditions. Some had fatigue with or without fainting spells. He and cardiologist Hugh Calkins used a tilt table to study these patients' drops in blood pressure, finding that a nervous system disorder called neurally mediated hypotension can contribute to CFS symptoms. When they treated patients with medications used for fainting, a proportion improved. When their case

series was published in *The Lancet* in 1995, Rowe says, "We got 5,000 phone calls in the next week. I had never experienced a response like that before—we got a very clear indication there was a huge unmet need in the population."

As Rowe became more educated about CFS, he decided to devote his time to the condition. "These are complicated patients with a lot of dysfunctional organ systems, so it's very hard to do the treatment within the confines of the usual medical office," he says. "Philanthropy has allowed me to spend a lot more time with people, to dig in and understand problems and provide a level of care that I think would not be possible outside of a university setting."

His donations, from foundations and individuals, also permitted Rowe, the Sunshine Natural Wellbeing Foundation Professor of Chronic Fatigue Syndrome and Related Disorders, to continue CFS research and hire a part-time research assistant as well as summer students.

Steffensmeier found Rowe 13 years ago through a Johns Hopkins geneticist she saw on her quest for relief from CFS. She had become ill one month after graduating with honors from Davidson College and for six years traveled from specialist to specialist while continuing to get sicker. "I was bedridden and homebound," she says. "There were years I was completely in bed."

Rowe identified rare conditions contributing to Steffensmeier's symptoms and microdosed medications to make them work for her. Steffensmeier can now walk a mile a day and travel to the North Carolina beaches with her mother. In gratitude, she asks for donations to Rowe's research in lieu of birthday gifts.

"At times he couldn't do anything physically to make me feel better, but he would still nourish the emotional and spiritual side of me," Steffensmeier says. She adds, "I can't think of a better person to support."—KB 🍌

“Philanthropy has allowed me to spend a lot more time with people, to dig in and understand problems and provide a level of care that I think would not be possible outside of a university setting.”

— PETER ROWE, M.D.

“He will never give up on you,” says Emily Steffensmeier, in the pediatric physical therapy suite with pediatrician Peter Rowe.





## Liftoff for Johns Hopkins Children's Center Council

**THIS SPRING, THE** Johns Hopkins Children's Center Council was launched to welcome leaders who serve as supporters and advisers to Johns Hopkins Children's Center Co-Directors Tina Cheng and David Hackam. The council's role is

to enhance awareness of Johns Hopkins Children's Center, serve as ambassadors in the community, and support the mission of Johns Hopkins Children's Center by identifying resources in support of children's health. Co-chairs Ann Han-

kin and Annette Pakula are honored to bring together devoted friends who want to transform pediatric health care at Johns Hopkins Children's Center. For more information, email [hopkinschildrens@jhmi.edu](mailto:hopkinschildrens@jhmi.edu). 🌟

## Building an Arch of Hope for Children

by Amanda Leininger

**PHILANTHROPY IS ESSENTIAL** to providing care for patients and families at Johns Hopkins Children's Center, and we rely on and greatly appreciate the ongoing support of individuals and private family foundations every day. To thank our most generous supporters, Johns Hopkins Children's Center in spring 2017 launched Children's Arch of Hope.

Through this new annual giving soci-

“We are grateful for the personalized, high level of care and want to make it possible for other children to receive the same.”

—FRANCES “LOUIE” DWECK

ety, donors who make an annual commitment to the institution on an annual basis will be recognized and invited to exclusive events, such as Live the Mission, to experience the impact of their contributions. At the society's founding, more than 200 donors received letters recognizing their annual philanthropic commitment to Johns Hopkins Children's Center, including Frances “Louie” and Ralph Dweck, who have been supporters since 2001. Every donor to Johns Hopkins Children's Center has a unique reason for providing support. For the Dwecks, it is their daughter, Nora, who received treatment for growth hormone issues. In her honor and through their family foundation, the Dwecks have supported pediatric endocrinologist Leslie Plotnick and her nurse, Lisa Rasbach.

“We support patient care because we are so grateful for the personalized and attentive care that Leslie and the whole team provided to our family,” says Louie. For more information on Children's Arch of Hope or to make a donation, please email [hopkinschildrens@jhmi.edu](mailto:hopkinschildrens@jhmi.edu) or call 410-361-6493. 🌟



Ralph and Frances “Louie” Dweck

## Living the Mission

**IN MARCH, JOHNS** Hopkins Children's Center hosted its second Live the Mission event, inviting new Children's Center Council members and friends behind the scenes to witness firsthand the work of our care providers. Attendees chose from five tracks, including touring the new hemodialysis lab, participating in a Simulation Center skills lab, creating slides in Pediatric Surgeon-in-Chief David Hackam's research lab, learning about infection control, or meeting with the diabetes nursing team and a patient family.

“Dr. Hackam told us that typically the least sick child in our pediatric ICU is often the sickest child in other hospitals. I never realized that until today,” says council member and Johns Hopkins University trustee Mayo Shattuck, a longtime supporter of Johns Hopkins Children's Center.

Johns Hopkins Children's Center Council Co-Chair Annette Pakula toured the new outpatient hemodialysis center, not knowing that prior to its opening, patients were sent to Washington, D.C., or Delaware for treatment.

“I never knew there was such a need. I'm so glad I was able to see it and meet a patient to see it from their perspective,” says Pakula. “It gave me a better understanding of how different patients are able to cope with their illnesses and how the children are often the stakeholders for their own care.”

To receive future invitations to events like Live the Mission, make a donation and become a member of Children's Arch of Hope, email [hopkinschildrens@jhmi.edu](mailto:hopkinschildrens@jhmi.edu). —AL 🌟





# Ace Hardware: A Commitment to Local Kids

**ACE HARDWARE, KNOWN** as “The Helpful Place,” does more than just help with home and garden needs; the chain is committed to helping sick and injured kids in the community. All 36 Ace Hardware locations in and around Baltimore raise funds \$1 at a time for Johns Hopkins Children’s Center through national Children’s Miracle Network Hospitals (CMNH) campaigns, like the “Ace Cares for Kids” icon campaign and Blue CMNH Bucket Weekend, as well as through local events like barbecues and golf tournaments.

“Being helpful is the core value of Ace Hardware, and we believe there’s nothing more helpful than supporting local kids and families,” says Ace Foundation Manager Chris Doucet. “We are proud and honored to partner with Children’s Miracle Network Hospitals in communities across the country to help raise much-needed funds and awareness for these extraordinary hospitals.”

Since becoming a CMNH partner in 1991, Ace Hardware has raised more

than \$82 million for local CMN hospitals across the country, with more than \$227,000 directly supporting Johns Hopkins Children’s Center. As a thank-you for their commitment, local Ace Hardware employees regularly have the opportunity to visit Johns Hopkins Children’s Center to see firsthand where their money goes when they are asking customers to make a donation. Courtney Belew, marketing manager of “A Few Cool Hardware Stores” in the Baltimore/Washington, D.C., area, has joined Ace Hardware employees on these visits.

“Instead of just a faceless ask, employees really got to understand that the money does go to things that make the hospital more kid-friendly. There are toys and games that the kids wouldn’t have access to without our help,” says Belew. “You don’t think about what it would be like for a child to be in the hospital. When you get to see these things, it really is eye opening.”

In addition to receiving integral funds

from Ace Hardware, patients and families at the Children’s Center received a special visit in May 2016 thanks to Ace’s partnership with Stanley Black & Decker. Johns Hopkins Children’s Center participated in Ace’s annual Racing for Miracles Weekend, which kicked off with a visit from Carl Edwards, the STANLEY Racing Team and the #19 car—patients even witnessed a pitstop demonstration with the team’s official pit crew. The #19 car also visited Ace Hardware locations throughout the spring 2016 campaign, helping to increase the stores’ engagement and commitment, and ultimately resulting in Ace Hardware’s largest annual donation to the Children’s Center to date, a number it hopes to top in 2017.

Ace Hardware’s representatives stress they are thrilled to continue their fundraising efforts this year. Save the date for Ace Hardware’s annual Bucket Weekend Aug. 4-5, 2017. For a \$5 donation, customers will receive a bucket and 20 percent off anything that fits in it. —AL 🍌



“Being helpful is the core value of Ace Hardware, and we believe there’s nothing more helpful than supporting local kids and families.”

—CHRIS DOUCET,  
ACE FOUNDATION  
MANAGER





Patients, families, faculty and staff members, and Mix 106.5 DJs celebrate the record-breaking Radiothon 2017.

## 28th Annual Radiothon Marks Most Successful Year Yet

**THE 28TH ANNUAL** Mix 106.5 Radiothon benefiting Johns Hopkins Children's Center held in February raised \$1,117,835.28, bringing the total raised through Radiothon to more than \$20 million. Mix 106.5 talent Jon Boesche, Maria Dennis, Priestly and Kaite Rose interviewed patients, families, faculty and staff members, who shared stories of courage, hope and the excellent care received at Johns Hopkins Children's Center. Nearly 500 volunteers answered phones at the on-site phone bank throughout the event, bringing an infectious energy that helped invigorate the DJs during their long days on air.

New this year, Johns Hopkins Children's Center launched the I Give for the Kids employee giving campaign, which raised more than \$25,000, helping to make the 28th annual Radiothon the most successful year yet.

Next year's 29th annual Mix 106.5 Radiothon will be held Thursday, Feb. 22, and Friday, Feb. 23, 2018. If you are interested in sharing your story or participating in Radiothon 2018, please email [hopkinskids@jhmi.edu](mailto:hopkinskids@jhmi.edu). —AL 🍌

## Wawa: A Leader in Corporate Support

CORPORATE PHILANTHROPY IS a critical component of providing care to children at Johns Hopkins Children's Center. Among the best examples is Wawa, a steadfast supporter of Johns Hopkins Children's Center. With more than \$1.5 million in donations since 1986, Wawa is now committed to donating \$5 million over five years through three pillars of its foundation: health, hunger and everyday heroes.

In the fall of 2016, Johns Hopkins Children's Center received a \$150,000 grant from The Wawa Foundation to support the Department of Child Life and the Department of Social Work. Funds will specifically support the art therapy program and the emergency needs fund, and help make child-friendly environmental enhancements, including artwork, on the patient floors. In October, Wawa Foundation Board members presented child life Director Patrice Brylske, social work Director Paula Heneberry, and former patient Trip Black with a check for \$150,000.

"For many years, Wawa and the

**At the Wawa check presentation, from left to right: Mike Davis, Chris Casey, Jay Culotta from Wawa; Amy Osborn from Johns Hopkins Children's Center Development Office with former patient Trip Black; Stephanie Mooningham, Liz Simone, Karen Thurber and John Sharpless from Wawa.**

Wawa Foundation have been proud supporters of Johns Hopkins Children's Center, and we couldn't be more delighted to continue that partnership throughout this past year," says Jay Culotta, president of The Wawa Foundation. "We're focused on partnering with organizations committed to saving and improving lives in the communities Wawa serves, and few do that better than the Children's Center. We look forward to supporting Johns Hopkins' groundbreaking research and services in the future."

Wawa, through its local fundraising efforts and grants, has been recognized as a top business and community leader. For more information, email [hopkinschildrens@jhmi.edu](mailto:hopkinschildrens@jhmi.edu). —AL 🍌







# Patients, Families and Friends Helping Their Own

**WHEN ANDERSON JONES** accepted the invitation to go paintballing for a friend's birthday party, he never imagined that instead of ending the day eating cake, he'd find himself at Johns Hopkins Children's Center. After colliding with a fence while running downhill, he experienced what he recalls as the worst pain of his life. Hours later, pediatric surgeons removed 50 percent of Anderson's perforated pancreas. Inspired by his care, Anderson decided to help other patients like himself, donating his entire \$20 allowance to the Children's Center each month and, in doing so, becoming a monthly Radiothon Miracle Maker.

"I decided to give my allowance to Johns Hopkins so doctors can buy medical equipment and things they need or even just board games and toys in general," says Anderson. "Radiothon is a huge event, it's live and everyone can hear it. I wanted to donate my money to help kids feel better, but I also want to inspire others to donate to help kids like me."

Like Anderson, Sarah and Matt Kilaeski, who between them have undergone more than 20 surgeries at Johns Hopkins, have been inspired to give back because of their experiences. Together, they have run in the Baltimore Running Festival every year since 2010, and have raised more than \$46,000 for Johns Hopkins Children's Center by going door-to-door, mailing letters, asking businesses for support and pet sitting. Sarah wants to help kids like her, while Matt wants to thank the hospital that "helped my sister and is now helping me."



**Anderson Jones, 12**, who received a piggy bank as an inpatient, intended to save up for an Xbox like the one in his hospital room but decided to use it to save his money for donations. **Matt, 12**, and **Sarah Kilaeski, 10**, present a check for their donations over the last seven years.

Hundreds of children are treated at the hospital each day, and Children's Center Co-Director Tina Cheng is humbled by the number who later give back to help other kids just like them.

"Kids shouldn't have to be sick or be in the hospital, so their plight touches the hearts of many," says Cheng. "When a classroom decides to host a fundraiser for a classmate or when a child promises to help his nurse because he or she helped him get better, I know we are doing more than healing the body of a child. We are healing their spirit and bringing them hope, and that inspires us all."

It's not just former patients who want to help those their own age. Since 2013, the Columbia Figure Skating Club Junior Board holds an annual One Skate for Many Hearts event during National Heart Month. Since its inception, the board members have raised nearly \$25,000 to support the Division of Pediatric Cardiology. All of the junior board members are managing school, skating and community service, and planning the event is part of their service requirement. They say, "It's fun, and we love getting to meet a patient family we are helping each year."

For more information on hosting a fundraising event to benefit Johns Hopkins Children's Center, please email [hopkinschildrens@jhmi.edu](mailto:hopkinschildrens@jhmi.edu). —AL 🍀



Members of the Columbia Figure Skating Club Junior Board at the 2017 One Skate for Many Hearts event.



## The Force Is Strong at Johns Hopkins Children's Center

by Katelynn Sachs

HIGH-PITCHED ROBOTIC beeps, trills and whistles nearly matched the squeals and laughter of 5-year-old Declan Ambrose as he caught a glimpse of his all-time favorite *Star Wars* character, R2-D2. He came face to face with the life-sized droid not in a galaxy far, far away, but at Johns Hopkins Children's Center, where Declan had recently undergone surgery to remove a brain tumor.

"When he woke up this morning, he immediately asked if it was *Star Wars* day," says his mom, Stevi. "You would never know he had surgery just four days ago."

On Feb. 3, seven local *Star Wars* volunteer characters, including allies from the Rebel Alliance and villains from the dark side, spent the day at the Children's Center with one common goal: to make patients forget they were in the hospital.

"Today, we see children—who haven't gotten out of bed for days—who got

up and came down to interact with the *Star Wars* characters," says Patrice Brylske, director of child life.

Having watched a screening of *Rogue One: A Star Wars Story* the previous evening, many patients were awestruck at seeing R2-D2, Jedi Masters, storm troopers, a biker scout and an X-Wing pilot in real life. They danced with R2-D2 to *Star Wars* tunes, high-fived and fist-bumped the characters.

Pediatrician-in-Chief Tina Cheng and Pediatric Surgeon-in-Chief David Hackam joined in the fun to give R2-D2 a thorough checkup. Two Jedi Masters also taught Children's Center patients how to become Johns Hopkins Jedis with Force training and lightsaber demonstrations.

The event was made possible by Lucasfilm and its associated *Star Wars: Force for Change* platform, as well as local volunteers from the 501st Legion, Terrapin Base and droid builders. 🌟

## Upcoming Events and Campaigns

Help support Johns Hopkins Children's Center at an upcoming fundraising event or corporate campaign.\* If you would like to know more or help with any of the events below, please email [hopkinschildrens@jhmi.edu](mailto:hopkinschildrens@jhmi.edu).

### JUNE

- 2 Tower Federal Annual Golf Tournament
- 3 Colleen's BA (biliary atresia) 5K and 1-Mile Fun Run/Walk
- 5 Griffith Energy Annual Golf Outing
- 9 20th Annual Zachary Meehan Memorial Golf Tournament
- 15–16 Dunkin' Donuts Iced Coffee Days
- 25–July 8 Giant Food Stores Icon Campaign
- 26 Hayden's Heart Heroes 12th Annual Golf Tournament

### JULY

- 14 Elkridge Furnace Inn's Bastille Day Wine Tasting
- 16–17 Giant Food's Golf Tournament
- 27 Dairy Queen's Miracle Treat Day
- 28 Johns Hopkins Federal Credit Union Golf Tournament

### AUGUST

- 4–5 Ace Hardware Bucket Campaign
- 28–Oct. 1 Walmart Campaign

### SEPTEMBER

- 11 Ledo Pizza Annual Golf Tournament
- 16 Baltimore Boogie
- 28–Oct. 1 Walmart Campaign

### OCTOBER

- 20 The Kendall Burrows Foundation 4th Annual Footloose Gala
- 21 Baltimore Running Festival

### NOVEMBER

- 4 Dance Marathon at Johns Hopkins University
- 12–25 Giant Food Stores Icon Campaign
- 29 Giving Tuesday

### FEBRUARY 2018

- 22–23 29th Annual Mix 106.5 Radiothon

\*Dates are subject to change. This is not a comprehensive list of all events and fundraising campaigns benefiting Johns Hopkins Children's Center. If you'd like more information on planning a fundraising event, please email [hopkinschildrens@jhmi.edu](mailto:hopkinschildrens@jhmi.edu).





## Grief and Bereavement Seminar Goes Global

by Gary Logan

**FOR A PEDIATRICIAN**, sharing bad news, like the diagnosis of an incurable disease or the death of a patient, can be an extremely nerve-wracking experience.

“If you don’t know how to do it, or you resist the opportunity and distance yourself, it’s a very stressful experience,” says Janet Serwint, director of Johns Hopkins pediatrics residency program. “These educational sessions give physicians in training a structure and basis for sharing bad news, which is part of the journey we walk with patients and parents.”

Serwint refers to the daylong annual grief and bereavement workshop she’s been directing at Johns Hopkins Children’s Center for the past 22 years, thanks to funding from the Cameron Kravitt Foundation, founded by two parents who lost their son at birth. Over the years, the program’s popularity has attracted residency programs at other academic medical institutions, including Weill Cornell in 2007 and, this past April, the University of California, San Francisco. Now Serwint is taking that agenda across the Atlantic to Great Britain and pediatricians in training there.

“We have the same problem with bereavement communication in the United Kingdom as in the United States—it is difficult to get it right without experience, and getting it wrong can produce a lifetime of distress for bereaved parents,” says Richard Brown of the East of England School of Paediatrics.

The curriculum for the United Kingdom workshop, planned for Oct. 11 at the University of Cambridge, was co-developed by Serwint and pediatrician Lorene Rutherford. “Hundreds of residents have experienced this seminar,” says Serwint, “and now even more will be able to participate thanks to the Cameron Kravitt Foundation.” 🍌



Jason and Beverly Kravitt

“These educational sessions give physicians in training a structure and basis for sharing bad news, which is part of the journey we walk with patients and parents.”

— Janet Serwint, M.D.

## Robert Wood Leading the Way in Food Allergy Research

**A WORLD LEADER** in the quest to cure food allergies in children, pediatric immunologist Robert Wood has been among the first to study multiple novel treatments for food allergy, including oral immunotherapy, sublingual immunotherapy and several new vaccines in collaboration with the pharmaceutical industry and the National Institutes of Health. Indeed, his team conducted the world’s first double-blind, placebo-controlled study of oral immunotherapy, a treatment that has shown



Robert Wood, M.D.

great promise for children with severe allergies to eggs, milk, peanuts and wheat. In recognition of his accomplishments, Wood was recently chosen to lead food allergy research efforts over the next seven years by the Consortium for Food Allergy Research and its seven member medical centers, including Johns Hopkins. Wood is also director of the Division of Pediatric Allergy and Immunology at Johns Hopkins Children’s Center, and president-elect of the American Academy of Allergy, Asthma, and Immunology. Yet despite these achievements, he does not yet hold an endowed professorship, which would allow him to

grow his research programs and train the next generation of pediatric allergists. These efforts are critical, as the number of children with food allergy and asthma has risen dramatically in recent years. To make a gift or to learn more, please contact the Johns Hopkins Children’s Center Development Office at 410-361-6493. —GL 🍌



Watch Robert Wood discuss food allergy research.  
[youtube.com/watch?v=d2L\\_73y\\_I EU](https://youtube.com/watch?v=d2L_73y_I EU)



## Lauren Small Named Assistant Professor

For two years, **Lauren Small**, an adjunct professor of English at the University of Maryland University College, and Johns Hopkins combined medicine and pediatrics resident Ben Oldfield held a novel monthly session called AfterWards for pediatric faculty and staff members. Employing narrative devices like art and literature to prompt reflections and explore feelings about experiences with patients and families, AfterWards became a popular program for physicians, nurses, child life staff members and social workers. But when Oldfield graduated from residency last summer and began a fellowship at Yale, Small was left without a partner and her connection to Johns Hopkins Children's Center. Aware of the growing popularity of the program, pediatrics leadership asked Small to continue it. And, to support her work, they appointed her a part-time assistant professor in the department. Small chuckles



At an AfterWards session, Lauren Small with former resident Ben Oldfield.

at the notion of being the Department of Pediatrics' first "humanities professor" but considers the appointment an honor. "This speaks to the institution, that the whole hospital is based around delivering

compassionate, humanistic and family-centered care," says Small. "I would like people to know AfterWards is still here and can potentially be of use to them." 🍌



Pediatric cardiologist **Anne Murphy** received the 2016 Council on Cardiovascular Disease in the Young Meritorious Achievement Award

from the American Heart Association. The award recognizes an individual whose achievements have made a significant impact on the field of cardiovascular disease in the young.



Pediatrician **Maria Trent**, director of the Adolescent Medicine Fellowship Program, has been appointed a full professor of pediatrics. A major focus

of her research and clinical interests has been on reducing health disparities and improving adolescent and young adult reproductive health outcomes. She is currently the chair of the American Academy of Pediatrics section on adolescent health.



**Janet Serwint**, director of the Pediatric Residency Program, received the 2016 American Academy of Pediatrics Education Award, which

recognizes a member of the academy whose career reflects educational contributions that have had a broad and positive impact on the health and well-being of children.



Pediatric allergist **Elizabeth Matsui** received the 2017 Baltimore City Health Leadership Award for her tireless work to reduce health disparities.

Pediatrician **Renata Sanders** was featured in the San Francisco Department of Public Health video "Breaking the Silence through Storytelling: Confronting Medical Mistrust to Advance HIV Prevention."

[youtube.com/watch?v=serpFX3syBQ](https://www.youtube.com/watch?v=serpFX3syBQ)



Pediatric pulmonologist **Laura Sterni** and pediatric gastroenterologist **Wikrom Karnsakul** were promoted to associate professor.



Pediatric nephrologist **Barbara Fivish** received the American Academy of Pediatrics' Henry L. Barnett Award.

**Deanna Wilson**, a fellow in adolescent medicine, received the Emerging Leader in Adolescent Health Award from the American Academy of Pediatrics.

**Barbara Case, Elizabeth Russell** and **Nancy Sumpter** were among 11 Johns Hopkins nurses who received the 2017 Excellence in Nursing Award from *Baltimore* magazine.





# A Mother's Memorable Moments

by Kathy Hart

IN APRIL 2010, my son Patrick, then a 20-year-old sophomore at St. Bonaventure University in New York, came down with what appeared to be a typical case of mononucleosis. It wasn't. After weeks of fevers and a stay at our local hospital, Patrick was transferred to Johns Hopkins Children's Center, where he was diagnosed with hemophagocytic lymphohistiocytosis, a rare and potentially fatal condition. Over the next several years, Patrick was treated by pediatric oncologists with chemotherapy, a bone marrow transplant, high-dose steroids and immunosuppressants. We are hopeful the worst is behind him.

So, how did we, his parents, survive? For one thing, we always felt we were an important part of Patrick's care team. But there were also some unexpected and memorable moments that lifted us up during the hardest days. For instance, during Patrick's first week in the pediatric ICU, my husband and I were headed down a long escalator when we saw Patrick's oncologist at the bottom, certain he would head the other way. The last thing he probably wanted to do at 7 p.m. was run into the parents of one of his critically ill patients. But he waited for us and asked if we had any concerns.

Another day, doctors rounding explained to Patrick that his kidneys were having trouble doing their job. He replied that he didn't know much about kidneys but believed he could help cure himself if he could just visualize the problem. Later that day, a medical student came back with a diagram highlighting the affected area of his kidneys.

Then there was my last-ditch effort to help Patrick avoid a bone marrow transplant, asking his doctor if he would check with his colleagues around the world regarding any new alternative treatments. Two days later, this very busy pediatric oncologist took the time to come back to our room and tell us that he had reached out to his colleagues, who all agreed transplant was the only option.

Also, there was that Friday evening when we learned Patrick would need a bone marrow transplant, and his transplant doctor and fellow unexpectedly stopped in and said, "We're sure you must have a lot of questions. What would you like to ask us?" Then they sat down and listened to us for almost two hours. "Don't you two have wives waiting for you?" I asked.

"It's Friday night!" They said "yes," but they didn't want to leave until they were satisfied we had all the answers.

Finally, there was the email we recently received from the first-year fellow who cared for Patrick for more than two years: "What an absolute honor it has been to be a part of your lives. Certainly, not the circumstances that anyone would have ever expected, but getting to know you and your family, and learning from the course that his disease and therapy took, was truly formative, and I am so glad to hear of all the good things that are happening in his life." 🍀

*Kathy Hart is a member of the Pediatric Family Advisory Council at Johns Hopkins Children's Center.*



Patrick, now 27, is living in an apartment, working full time at George Washington University and pursuing his undergraduate degree part-time.



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**Questions?**

Contact the Children's Center Office of Development at  
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