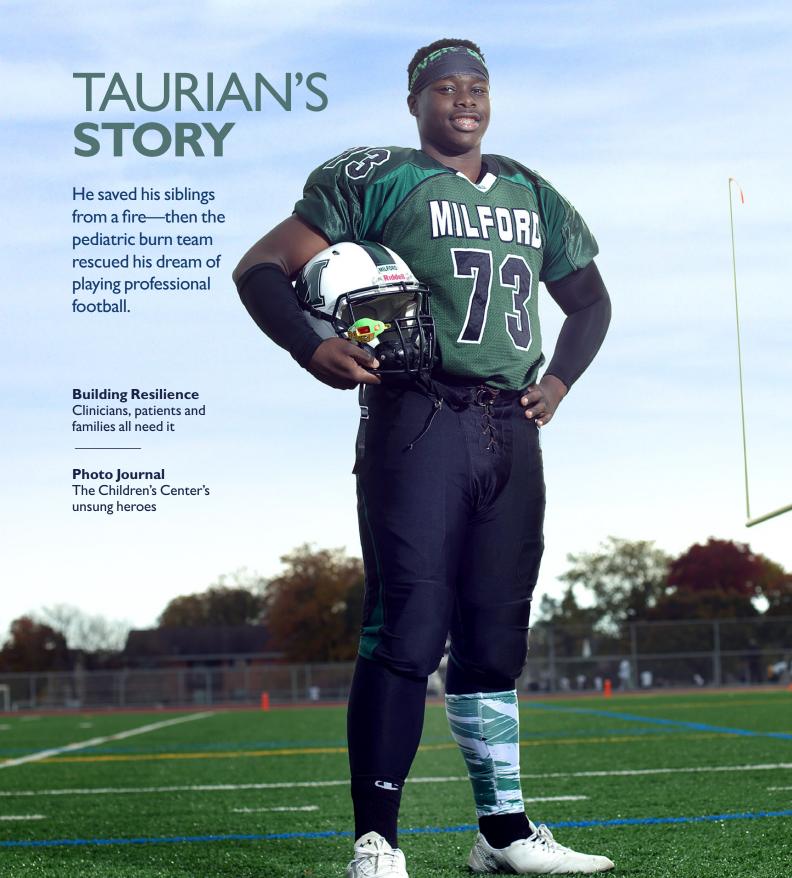
hopkins children's center magazine



Trying New Things

By Zachary Harriss

When I was 9 days old, I was diagnosed with branchio-oto-renal syndrome, which causes abnormalities in the neck, ears, and kidneys.

Over the following years, because of my condition, I had to see many specialists, including nephrologists, ophthalmologists, cardiologists and otolaryngologists, along with my pediatrician. I trusted each of them to make the best medical decisions to help me maintain a sense of normalcy in my life.

Over time, these physicians became my extended family. While it is important for doctors to treat a patient's medical condition, I believe doctors should also connect with the patient in other areas of his or her life. One doctor who exceeded my expectations is pediatric nephrologist Cozumel Pruette, who has been by my side advising me on what steps to take to ensure the well-being of my kidneys. She is always offering me new opportunities to get involved with the transplant community and share my story.

As I was transitioning into my adult years, I needed to learn how to function



Doctor and patient, Cozumel Pruette and Zachary Harriss

One doctor who exceeded my expectations is pediatric nephrologist Cozumel Pruette, who has been by my side advising me on what steps to take to ensure the wellbeing of my kidneys.

- ZACHARY HARRISS

independently. I could not thank my wonderful mother enough, who along the way helped me transition and manage my appointments and medications. Also, my doctors educated me on how best to take care of my medical needs.

During my senior year in high school, I decided to work on a capstone project for my Bio-Medical and Allied Health program. At first, I did not know what I was going to focus on—then it occurred to me to do something related to my kid-

ney transplant. Since then I have been developing an app to help connect kidney transplant patients to help improve their non-adherence rates. Today, as a student at McDaniel College in Westminster, Md., this endeavor continues.

My other goal is to pursue a career in forensic science as a crime scene technician. Some days are harder than others, but I try not to let my condition define me. To live my life fully, I feel I should reach outside the box and try new things.



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A patient's experience illuminates the diverse services the Johns Hopkins pediatric burn team brings in caring for children with severe burns.

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Managing a medical crisis well requires inner strength—how does the Children's Center help clinicians, patients and families find it?

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Giving parents doses of resiliency



Much to Celebrate, Much to Do

Last fall, in our annual address on the state of Johns Hopkins Children's Center and the Department of Pediatrics, we cited some amazing achievements—among them, our return last year and this year to the Honor Roll in U.S. News & World Report's Best Children's Hospitals ranking, placing us among the top 10 children's hospitals nationwide. Our burn center earned verification from the American Burn Association, joining only a dozen pediatric burn centers nationwide to do so. We also achieved nursing Magnet status for the fourth consecutive time since 2003



(a feat less than 1 percent of hospitals have achieved), we created a new division called hospital medicine, led by Eric Biondi, and we recruited new division directors in pediatric cardiology (Shelby Kutty), neonatology (Akhil Maheshwari) and endocrinology (Sheela Magge). After a national search, Peter Mogayzel was appointed our new division director for pulmonary medicine, Maggie Moon our first-ever chief medical officer, and Phil Spevak our first chief informatics officer. We do have much to celebrate but also much to do.

While federal funding for biomedical research has fallen over the past decade, we continue to work on maintaining our robust research activity. New initiatives include the creation of a research pipeline committee and our innovations program, which administered over \$600,000 in grants to support novel quality and safety projects such as our pediatric nephrology initiative, led by Jeffrey Fadrowski, that identifies children in the hospital who are at risk for acute kidney injury. We are expanding our clinical programs, including maternal fetal medicine, and strengthening our infrastructure by adding beds in our neonatal intensive care unit. We are also looking to grow our ambulatory medicine footprint, and develop new clinical collaborations in the Washington-Baltimore region—to bring our pediatric subspecialists closer to patients' homes.

So, where are we going? This issue of *Hopkins Children's* magazine offers some signposts ahead. Enjoy.

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



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Sallyann Koontz Director, Marketing and Communications

Gary Logan *Editor*

Amanda Leininger
Assistant Editor

Julia McMillan, M.D. Peter Mogayzel, M.D. Cozumel Pruette, M.D. *Medical Editors*

Karen Blum Christy Brownlee Jim Duffy Mat Edelson Lindsey Edwards Andrew Myers Sarah Richards Contributing Writers

Kristen Caudill

Graphic Designer

Kathryn Dulny Keith Weller *Photography*

Monique Redd Distribution

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Give us feedback Send letters to Gary Logan at the above address, or email glogan@jhmi.edu.

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Dawn Luzetsky Senior Director, Pediatric Nursing

Interview by Sarah Richards

Demands on nurses are changing, and Dawn Luzetsky wants to ensure her pediatric colleagues have the support they need at a time of transformation. Johns Hopkins Children's Center's new senior director of nursing leads nearly 1,100 nurses, nurse practitioners, clinical technicians and front-desk personnel in caring for sick children. Luzetsky, raised by a single mother who was also a Johns Hopkins nurse, took some time out to share her thoughts on nursing and leadership.

What is still one of the most misunderstood aspects of nursing?

The direct clinical care — the nurturing, caregiver-at-the-bedside aspect. Nursing goes beyond that. We are heavily involved in research, right back to the days of Florence Nightingale and the sterile field. I feel like we are still evolving the profession in the public eye. Nursing is still female dominant, but it does not need to be. We are slowly seeing an increase in male nurses, and it is great to see that increase in diversity.

What are the biggest challenges facing pediatric nurses today?

The increased complexity of the work, especially in academic medicine. Nurses coming out of nursing school are dealing with very sick, medically-complex patients. Plus, we're entering into a nursing shortage because of a mass retirement of baby boomers. We need to start thinking about how we can use technology to support bedside nurses and not necessarily think it is about more personnel.

Vision I have to put our nurses on the map for excellence in care and research. I want nurses to really feel their work is always evidence-based.

Can you give us an example?

My doctorate project was on the pediatric intensive care unit; it has 40 beds covering over 2.5 city blocks, with an extremely limited line of site. Almost 60 percent of the nurses had less than three years of experience, while experienced nurses felt huge stress as to whether they could give the latter adequate bedside support. We created a virtual mentor — a nurse who sits in a telemedicine room and monitors all bedsides through streaming video and audio. She focuses on novice nurses; they can call with questions or be guided through procedures. We have found the newer nurses find that

so helpful. I would have to hire 15 nurses to do what that one nurse does virtually.

Burn-out is a familiar refrain in health care today—how do you address it?

My goal is to continue building a pediatric flex-pool of experienced nurses who can work anywhere. For instance, if the emergency department is over capacity and stretching what it has, wouldn't it be great to send over a nurse to help them? This is part of a larger vision I have to put our nurses on the map for excellence in care and research. I want nurses to really feel their work is always evidence-based. Also, I think happy nurses are ones who can come in and hassles are out of their way for delivering care. When I do leadership rounds, I ask: what's your hassle factor today that we can help alleviate? When our nurses finish every day feeling they were recognized as professionals, their opinions counted and they were valuable team members that helped make the best experience possible for their patients and families—then I will know I have succeeded.





TAURIAZ TA

In the face of burning flames and fear-filled screams, 14-year-old
Taurian Jones-Duke had no time to think—he had to save his sister and brother. Then the burn care team at Johns Hopkins Children's Center worked on rescuing him and his dream of playing professional football.

By Gar Lindsey

By Gary Logan and Lindsey Edwards

With his mom and dad at work and schools closed due to snow and ice, Taurian Jones-Duke knew it was his job to keep an eye on his sister and little brother—he did not have to be told. He knew they were upstairs in the kitchen, joking and cooking something for lunch. Then he heard some popping sounds and smelled some smoke.

Leading nurse-driven initiatives in the burn center, from left to right, Lisa Puett, Susan Ziegfeld, Sara Fore, Amiee Turner, and Stephanie Morgenstern.



SECONDS LATER HE

heard his sister scream and the smoke detector go off. Like the linebacker he is, Taurian sprinted up the stairs to a smoke filled kitchen and flames shooting out of a pan. He pushed his sister and brother aside and told them to

get out of the house right away. Taurian then grabbed a potholder, pulled the splattering grease-filled pan off the stovetop and turned toward the door. He never made it. A January wind rushed through the open door, splashing the boiling grease onto him and the floor.

"The grease blew up on my arm," Taurian says. He slipped and fell on the now slick floor and the remaining grease emptied onto his legs, inflicting deep third degree burns from his hips to his toes. As he crawled out to the deck, he looked back into the kitchen to make sure the fire was out.

When Taurian's mother and father got home, they found him sitting in a neighbor's car. "Mom, I'm OK," he said. When the paramedics arrived, he dismissed any pain and consoled his sister. "Accidents happen," he told her. "It's not your fault." Then, at the Johns Hopkins pediatric emergency department (ED), he sat up and talked to nurses and physi-

cians as though what had just happened had not. He said his pain level was a 4 on a scale of 1 to 10. They responded, "Really—you have deep burns!"

One of the ED doctors, shaking her head, said in the 10 years she worked there, she had never seen someone handle what he went through as well as he did. That, said those who know Taurian, was just like him.

"Taurian is a great kid with a big heart, very quiet and loving. He gives his last," says Tammy Jones-Duke, his mom.

Indeed, Taurian had recently played both offense and defense in his first season on his high school's junior varsity football team, helping the team win regional and county championships. His coaches moved the freshman up to the varsity squad, which also went on to the state finals. When that game was lost by 1 point, Taurian did not despair. He told his team, "'We didn't lose, we learned," says Jones-Duke. "That's the type of child he's always been. He's very motivated, supportive and inspirational."

Taurian's story after the fire did not only illustrate who he is—it also illuminated a pediatric burn center, led by pediatric trauma surgeon Dylan Stewart, that had evolved and matured over the previous five years into one of the country's top ranked pediatric burn programs. Indeed, in May 2018,



the center achieved accreditation from the American Burn Association (ABA), joining the ranks of only a dozen other pediatric burn centers nationwide. How? Through new nursedriven protocols to assess burns in the ED and to manage fluid resuscitation for patients in the pediatric intensive care unit, by expanding psychological services for patients and parents, and by developing a late effects clinic to follow patients after discharge—in some cases long after discharge. Having a pediatric plastic surgeon such as Richard Redett who is proficient in the latest state-of-the-art techniques to treat severely burned patients, including using patients' own cells to grow new skin, also helped the burn center earn the ABA accreditation. Leveraging the latest technology, like laser therapy for patients such as Taurian who have deep burns that cause hypertrophic scarring, and building a regional consortium of pediatric burn centers to share best practices, were factors too.

"My vision for us is to bring together like-minded and similarly sized centers to share quality improvement data, to do multi-institutional trials together—to not only treat these children but also prove what the best treatment is," says Stewart. "I want us to be a national leader in pediatric burn care, and that you cannot do without collaboration and data."



FIRST STOP, THE ED

PEDIATRIC EMERGENCY MEDICINE nurse Amiee Turner had the paramedics' assessment of Taurian's burns in hand when he arrived at the pediatric ED. His burns, at 16 percent,

were on the high end of the total body surface area (TBSA) scale, so she knew he would likely need surgery sooner rather than later to treat his wounds. In such cases, the patient's trauma is treated first, following a check of the ABCs—airway, breathing and circulation—and then the child's burn injury.

Turner notified Stewart, who was already on his way to the hospital, and she alerted the pediatric ED's team of burntrained nurses, triggering their burn wound care protocol another initiative cited by the ABA. Why the protocol?

"Burn injuries are not easy to manage," Turner says. "They are distracting to providers and come with a significant amount of pain."

The protocol's standardized algorithm, she explains, supports the consistent focus critical for appropriate care and the best possible outcome. Education and training incorporated

into the algorithm encourage competency and confidence among the nurses in managing children with burns.

Pre-protocol, care was at risk of being random, Stewart says. Residents rotating in the ED, and nurses responding to the call, might not have had burn training. Now residents receive that training, and a burn resource nurse is scheduled for each pediatric ED shift. Also, whereas wound dressings varied in the past, the team standardized dressings and their application to achieve quality consistency. Patients being discharged are prescribed silver-impregnated dressing that may remain in place for up to seven days, reducing the anxiety and pain associated with dressing changes. Pediatric ED nurses now follow strict guidelines regarding whether to call in a surgeon.

The impact of the protocol? For patients with burn injuries, the time from arrival at the pediatric ED to treatment and discharge decreased from four to two hours. The protocol has also reduced the number of surgery consults in the pediatric ED and unnecessary hospital admissions.

"This is best for patients and families, and for the flow in the pediatric ED," says pediatric nurse Lisa Puett.

"Before, 10 different patients could have had 10 different experiences," adds Stewart. "The new protocol is seamless, and has helped us minimize unnecessary hospital admissions and transition a lot of kids from inpatient to outpatient care."

Stewart assessed Taurian's burns and told him and his parents that he needed surgery immediately to debride, or remove, burned tissue from the deep burn wounds on his legs. Taurian's mom was alarmed by the painful procedures her son might face, but comforted by Stewart's words: "He explained all the details and walked us through every step."

The surgery, the first of five for Taurian, went well, but he initially found it difficult to look at himself after coming out of the operating room, as a seeming endless number of staples covered his now unrecognizable skin. Then he began to face the daily dressing changes. For him, however, the bigger concern was whether his wounds would prevent him from ever being reunited with the love of his life: football. The nurses tried to console Taurian, who still insisted he was fine.

But he wasn't. How bad were his burns? "His legs were on fire," says Stewart, who was awed by Taurian's courage and grace. Where did the boy find the strength? Jones-Duke points to Taurian's mantra, "Trust the process"—the slogan on the back of his high school football shirt, which he was wearing the day of the kitchen fire.

"Whenever he felt down or doubted himself, he would remind himself to trust the process, and then things will eventually get better," says Jones-Duke.

After his surgery, Taurian was admitted to the pediatric intensive care unit (ICU), which cares for the most critically burned patients—and where another revolution in burn care was taking place. One change was the selection of an intensiv-



The laser is a heat source that creates small channels down into the scar, resulting in remodeling around that thermal dose, and tends to reorganize the hypertrophic scar into tissue more pliable that feels more like natural skin.

DYLAN STEWART



In the OR, pediatric trauma/burn surgeon Dylan Stewart treats deep hypertrophic scars on Taurian's legs and arms with laser therapy designed to enhance wound healing and function.



ist to attend ABA conferences and keep colleagues up to date on the latest intensive care approaches to burn care. And a nurse-driven protocol, led by Stephanie Morgenstern, would impact Taurian's care in the ICU.

Morgenstern, who previously worked in the inpatient unit for children with burns—10 South—focused on one of the greatest problems following major burns: fluid loss. Severe fluid loss is potentially fatal and requires fluid resuscitation within the first 24 hours after injury to support the patient's cardiovascular system and to restore and maintain tissue perfusion. Generally, fluid therapy should be tailored to individual needs based on factors such as the size of the burn, the patient's age and inhalation injury. Guidelines exist for infusions, but they are based on formulas developed 30 years ago.

For a more contemporary approach, Morgenstern led development of a new fluid resuscitation formula, using the gold standard metric of urine output to minimize under or over resuscitation and complications. Hourly titrations of fluid based on the urine output were implemented for Taurian.

"Our goal was to reduce the risk of complications and encourage quick and timely responses and interventions when they do occur, rather than wait for physician orders," says Morgenstern, who collaborated on the initiative with pediatric nurses Susan Ziegfeld and Puett. "We saw a significant downtrend in the amount of fluid given and no measurable increase in complications."

Taurian also benefited from the burn center's pain management approach aimed at minimizing narcotic medications. Child life specialists distract patients during dressing changes, and psychological services help patients deal with the emotional trauma of burn injuries (see sidebar, page 10). Following discharge, Taurian would be seen in the center's late effects clinic regarding, among other issues, the scars from the deep burns on his legs. Burns often heal with less than desirable cosmetic and functional results when they traverse joints and lead to contractures, Stewart explains. The burn center's use of a CO2 laser, he says, has been shown to enhance wound healing and functionality.

"The laser is a heat source that creates small channels down into the scar, resulting in remodeling around that thermal dose, and tends to reorganize the hypertrophic scar into tissue more pliable that feels more like natural skin," says Stewart. "It's more functional and has a lasting effect on burn pruritus, or severe itching, which can be a debilitating problem."

The investment in the technology was an expensive one, but hospital leadership was committed to improving burn care, Stewart notes. Similarly, expending after-hours energy among staff to conceive and develop new initiatives and protocols to enhance care was a major undertaking. Like Stewart, staff members were inspired to do just that. What motivated the initiatives that led to ABA verification?

As an experienced trauma surgeon, Stewart had observed

Taurian enjoys a lighter moment during treatment with his mom, Tammy Jones-Duke and pediatric surgeon Dylan Stewart.

a random, and even complacent, approach nationally to burn care for children, even at academic medical centers. The burden of treating children with burns is not nearly the burden of treating adults, he explains, so hospitals generally have not invested as many resources on the pediatric side. Another factor: Adults and children heal differently.

"If you look around the country, people do things very differently, and often in children it works because children tend to have good wound healing," says Stewart. "But that doesn't mean there couldn't be one way that works better. Our aim is to figure out what is the best treatment."



REHAB AND HOME

TAURIAN RESPONDED WELL to the nurse driven protocols in the pediatric ED, ICU and inpatient burn unit, and to the surgeries and laser treatments with Stewart in the operating room, all of which helped

minimize his hospital stay. While burn center staff initially anticipated that he would have to remain in the hospital for months, he was released after 37 days.

Nonetheless, Taurian's injuries had taken a toll. Learning how to walk again and gaining back a significant amount of leg muscle would be a daunting task in reaching his ultimate goal: getting back on the football field. Physical rehabilitation at the Children's Center got him closer, but not without daily, and at times painful, stretching and rangeof-motion exercises to reduce the risk of contractures as his deep burns healed and his scarred skin tightened. Taurian's determination, notes physical therapist Briel Gradinger, got him through the regimens with flying colors.

"Taurian is one of those patients you are excited to come to work for because he was so motivated to do everything he could to get up and moving," says Gradinger. "His success here was his motivation."

Following his discharge, Taurian continued physical rehab at nearby Mt. Washington Pediatric Hospital in the spring. Last summer, he began to participate in football workouts and practices, and in the fall he was back on the field in uniform.

Today, when people ask him how he's doing, Taurian replies, "I'm living and grateful to still be alive. My goal is to get better every day, to win every day and not let this defeat me."



Helping the Parents Help the Patient

BEING BURNED RAISES all sorts of psychological issues for pediatric patients, including distress from vivid memories of the event, anxiety and depression regarding a long intensivecare stay marked by pain, potential physical disability, lifelong scarring and self-image problems. Parents suffer psychological consequences, too, and how they react to their child's burn injury, notes psychologist Carisa Parrish, influences how well the child recovers.

"From looking at the literature and my own observations, a lot of the impact falls on the parents more so than the child with the burn injury," says Parrish, who is conducting research in this area. "The impact on the child flows through how the parents or caregivers respond."

Parrish explains that children naturally look up to their parents—the experienced narrators and social reinforcers in their lives—for emotional signs of physical safety and shelter from harm. Sometimes, Parrish has found, those signs are not supportive of the child's recovery from burns.

"Most of the children who come here with burns are around 4 or 5 years old and very resilient—they generally are not traumatized by their burn injury," says Parrish. "On the other hand, parents have many more ways to worry about the burn injury,



Reaching Out to Improve Care

SUSAN ZIEGFELD, THE Pediatric Trauma and Burn Program's lead nurse practitioner, reaches out regularly to referring hospitals and the emergency medical services (EMS) community to make sure all providers are on the same page in initially assessing burn injuries. That way, children en route to the Johns Hopkins pediatric ED are correctly coded before they arrive. Initial incorrect assessments, Ziegfeld stresses, can hinder care. "If inaccurate, they could potentially get too much or too little fluid in the outside hospital, or we could over-utilize our resources here in the ED," says Ziegfeld. To ensure accurate real time patient assessments, Ziegfeld visits emergency medical staff at regional hospitals monthly to review referred cases and burn assessment tools. In some cases, she notes, an outside hospital may use an adult rather than pediatric scale to assess the total surface body area of a burn injury. Ziegfeld also lectures at EMS conferences to address patient assessments and share the latest research and clinical developments in pediatric burn care at Johns Hopkins Children's Center.

including guilt feelings about not preventing the injury: 'If I had done this differently they wouldn't have suffered—I should have prevented this. I should've, should've, should've."'

In recognizing this phenomenon and testing it empirically, Parrish decided to change her practice. In addition to using quality of life assessment tools to gauge how children treated in the pediatric burn center respond over time, she developed screening tools to track parents' stress reactions to the injury and whether they influenced their child's recovery. Her conclusion?

"Burn injury characteristics, such as severity of the wound, appear to affect the kids' quality of life through how parents respond to that injury," says Parrish. "My clinical efforts with parents address elevated levels of stress related to guilt and self-blame, which the literature has identified as a mediator for post-traumatic stress."

In one study of predictors of family distress, for example, Parrish found that 20 percent of parents—or one in five—scored in the clinically elevated range for being at risk of post-traumatic

stress symptoms. Parents from ethnic minority groups experienced even higher levels of distress. African-American parents, in particular, were concerned about the wound's visibility and whether the child's natural skin pigment would return.

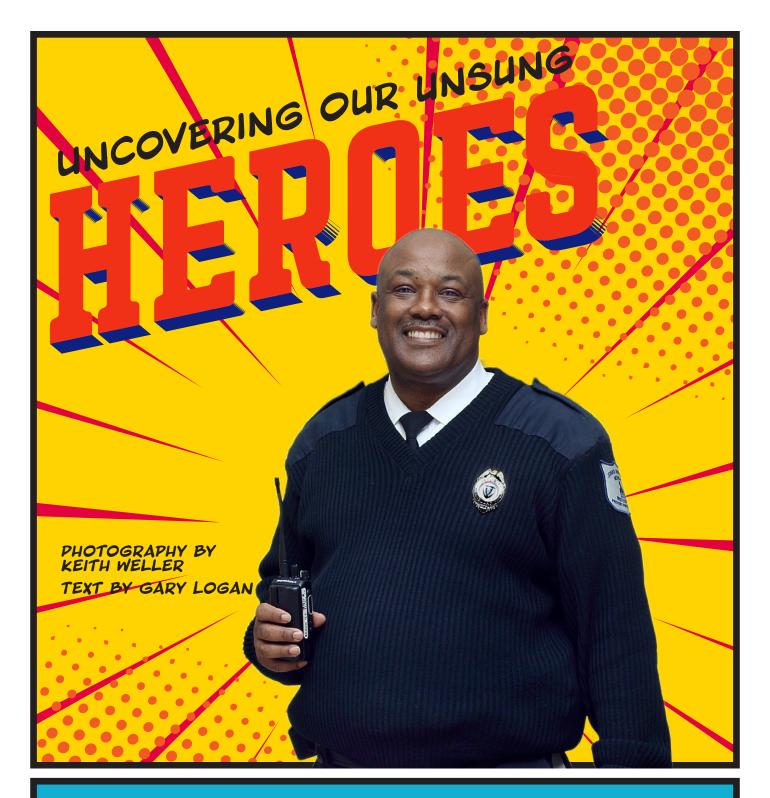
By screening and educating parents about the healing process for burn wounds, Parish aims to modify and reduce those stress reactions for the parent and, as a result, the child. This effort is helping to break new ground—only 20 percent of pediatric burn centers across the country screen parents' stress reaction to their child's injury, according to surveys by the American Burn Association.

"That we screen parents here is pretty distinctive and unique," says Parrish. "A lot of people approach kids like they're little adults and work directly with the child, but that's not how we expect kids to learn or grow—you have to work with the family. If you ignore the parents' distress and focus solely on the kids, you've given up a huge source we can use to promote their healing and development."



A lot of my clinical efforts with parents address elevated levels of stress related to guilt and self-blame, which the literature has identified as a mediator for post-traumatic stress.

— CARISA PARRISH



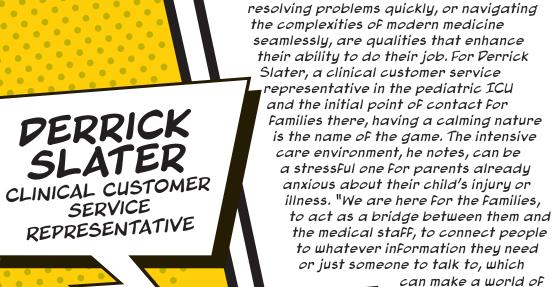
TEP CHAMBERS IS NOT CRAZY ABOUT THE TERM "UNSUNG HEROES." THE PEPIATRICS APMINISTRATOR STRESSES THAT THE EFFORTS OF ALL 3,000 STAFF MEMBERS IN THE PEPARTMENT OF PEPIATRICS AND JOHNS HOPKINS CHILDREN'S CENTER SHOULD BE IN THE SPOTLIGHT AND THEIR PRAISES SHOULD BE SUNG LOUDLY: "UNLIKE THE HIGH-FLYING SURGEON OR GROUNDBREAKING RESEARCHER, THEIR JOBS AREN'T GLAMOROUS. BUT THESE ARE THE PEOPLE HERE WHO KNOW EVERYTHING AND EVERYBODY, WHO IN SEAMLESS WAYS MANY PO NOT REALIZE GET THINGS PONE. THEY ARE COMPETENT AND COMMITTER, EFFICIENT AND EXPERIENCER, AND THEIR WORK IS CRITICAL TO OUR SUCCESS."

HERBERT ROYSTER SECURITY OFFICER

There's a warm glow on Bloomberg 12 South called Herbert. Just ask any patient or staff member who sees him in the corridors of the child and adolescent psychiatry inpatient unit. They'll tell you they are pulled magnetically to his smile and good nature. As a seasoned veteran security officer, Herbert Royster is all about his business keeping kids in the unit safe and he does it in an engaging and supportive way. "I'm always friendly when I approach a child. I do not want them to think I'm the great monster coming to see them because they did something wrong. So I try to ease that tension for them. I always greet them with a big smile, tell them how good their hair looks, and just pick out the things I know will make them smile." What motivates him? "Helping another human being get through a rough time makes my heart feel great joy," he says.







Some "unsung heroes" say assessing and



difference," Slater says. Adds his colleague, materials management specialist Halie Green, "The Families that come here are usually under such tremendous stress, it's comforting to have someone here you know is coming from a genuine and sincere place and really cares about the patient's outcome. After people leave here and come back for follow up, they ask for Perrick. That's the lasting impression he has on

Growing up, LeAnn McNamara knew she wanted to work with children someday but doing what she did not know. Then, in high school, she had an opportunity to shadow research pharmacists in a Johns Hopkins Hospital lab. There she learned "how powerful medicine can be" when she saw a mouse brought back to life with a simple injection. After graduating from pharmacy school, she worked in retail pharmacy but yearned For more of a clinical connection with patients. Since 2005, she has been working with intensivists, residents and fellows in the pediatric ICU at Johns Hopkins, while training other pharmacists how to respond to emergencies. When an infant suffers a cardiac arrest, she notes, you have to know how to quickly dilute and formulate epinephrine for that small patient to resuscitate the heart. "It's humbling to be part of this unit. I'm amazed at what they do here," says McNamara. "The fact that I can help them is so rewarding."





Thanks in part to family influences, Laura Jager knew coming out of high school in Baltimore County that she wanted to pursue a career in children's health care. In the simplest terms, she explains, children are "more appreciative. They smile. I get a feeling from the kids that makes me feel good." When asked what she most enjoys about her work in radiology in the pediatric emergency department, pediatric intensive care and neonatal intensive care units, the 13-year veteran says the answer is watching the kids she first saw as inpatients become outpatients. The hardest part of the job? Long 12-hour shifts imaging 50 or more children, but most of all knowing there are some children who do not get better. Being selected for this photo journal? "We are unsung heroes," she says. "Without imaging, how would doctors see what's wrong inside the body? What we do provides a huge piece of the puzzle."

Her parents' philosophy of helping others without being asked, says Kimberly Smith, infused an interest in health care as a high school student in the Washington, P.C., area. For the last 18 years, she has been a registered respiratory therapist at Johns Hopkins Children's Center, where she focuses on the needs of newborns and children in intensive care settings. Some of the patients are on life support and mechanical ventilation. "Patients in the pediatric and neonatal ICUs present another level of complexity in their conditions and care, so we have to be prepared to make quick decisions," Smith says. "We also have to be sensitive and empathetic with parents and families in stressful situations with a very sick loved one." About being an unsung hero? "We're not necessarily in the limelight, we might not be noticed, but we are doing good work and promoting our field. I am so happy to be part of this and my mother will be so proud."



Overweight as a teenager, AAliyah Payne began to eat healthy foods and exercise more in high school, losing 65 pounds by her senior year. Inspired by this experience, she majored in nutrition at Framingham State University in Massachusetts, and then found her way to Johns Hopkins Children's Center, where she is one of nine nutrition techs. Working alongside pediatric dietitians, they take physicians' orders for formulas, prepare them based on calorie concentrations and feeding regimens, and stock and deliver the formulas to infants at the Children's Center. Attention to details and communication with colleagues is essential to patient safety, Payne notes, especially when preparing tailored formulas for patients with complex metabolic conditions: "If we make one mistake, like putting on a label that has a different calorie concentration for a formula that's fed to a patient, that could potentially harm the patient. We are the ones who are always double checking to make sure everything we make and send out is correct."





For Tommy Washington, the hardest adjustment he had to make after obtaining his job with Environmental Care Operations at Johns Hopkins Children's Center may have been confronting the uneasy stares at his Pittsburgh Steelers lanyard. "I have had parents ask me to take it off when I come into their child's room," he laughs. Lack of loyalty to the hometown football team, however, has not influenced his relationship with the patients, Families and colleagues he has worked with over the past 17 years. Puring his daily 7 a.m. to 3:30 p.m. shift and while working every other weekend, Washington appreciates being able to support staff members whose goal is to provide the best possible care for children: "I try to go above and beyond, to make it easy on the nurses, to keep their patients' room clean as possible and supply them what they need." Shymaine Johnson, environmental operations manager, agrees: "Tommy is special. I wish I could clone him."



Building Resilience

Patients, families—and the clinicians who care for them—all need inner strength during recovery from a serious illness or injury.

Where and how do they find it?

By Mat Edelson

Photography by Kathryn Dulny

She died.

It was as if it never happened."

JANET SERWINT

hadn't been so pithy, or maybe if he were just a tad more empathetic, he might have added a few words of wisdom and solace to physicians beyond his stern admonishment to "do no harm." Maybe something like, "Remember: You're only human." Or, "Do no harm—and that includes to yourself."

Janet Serwint could have used such solace. The gut-wrenching and ultimately life-altering mistake she made while an intern some 37 years ago at a California hospital led her on a career-long quest to educate and to protect the mental health of pediatric care providers. All these years later, her error still likely happens frequently in the nonstop reality of every academic children's hospital. It began with a common request handed off between providers: Make a routine X-ray order, and read the X-ray when a break in the action occurs, or certainly by day's end.

It's a routine request unless, of course, it's just one of those days. Like when a desperate community physician calls for a consult. Or yet another code is called. Or a critical drug order needs to be signed. Etc. Etc.

When the attending physician turned to Serwint that morning during rounds, his suggestion about an X-ray of the little girl in the bed, Amy (not her real name)—the one who was so cute, so curious—seemed at first glance precautionary. Serwint, as was her custom and training, put the X-ray order in immediately.

Then something happened. Or rather, didn't.

To this day, Serwint does not know why she completely forgot to read the X-ray that day. It was not until the next morning, when she again saw Amy on rounds, that she suddenly remembered what had slipped through the cracks. Hundreds of tossed bedcovers have come and gone since then, yet Serwint, who went on to serve as the Johns Hopkins vice chair of pediatric education and the pediatric residency program director, still grasps for a reason. She has written extensively about it, an unfathomable moment so out-of-character for someone who prides herself on attention to detail.

Amy had a serious issue: She was a patient with leukemia, newly re-

Sharing bad news is hard, but there are skills that you can enhance to make it better. That compassion, that caring, that comfort with silence, with being present and sitting with them, the tone of your voice, the word choice, all make an important difference."

JANET SERWINT

lapsed and housed on the pediatric oncology floor. But all things considered, and to Serwint's then relatively inexperienced eyes, the 3-year-old looked well. There was no obvious pressing need for the chest X-ray, save for the single cough Serwint witnessed during rounds.

Yet within three days, Amy lay dead, cradled in her mother's arms. The cause was pneumonia. The same pneumonia that clearly showed up on the X-ray. The same X-ray that caused the attending and Serwint to immediately begin an antibiotic infusion—but 18 hours after the treatment would have started had Serwint read the X-ray in her normal, timely manner.

Amy's death—and, in Serwint's mind, the role her delayed action might have played—left the young intern stunned and confused. The swirl of emotions—feeling guilt-racked and ashamed—was so unnerving in the moment that Serwint could not even bring herself to console the girl's mother, even though Serwint was the oncology floor on-call doctor.

There were other patients, other very sick children for Serwint to see through the night, but her mind struggled to focus. Instead, she was stuck in an endless loop of incomprehensibility: How, how, how could this have happened?

And how, how, how was she supposed to answer?

As her shift agonizingly dragged toward dawn, Serwint paradoxically discovered herself dreading and desiring her team's morning arrival. She had an aching need to express herself to someone, somehow, to validate the moment, to try to make some sense of it. Contact, comfort—hell, even conflict ("You did what??!!")—would have been welcome. Indeed, Serwint fully expected to be rebuked, and perhaps worse. By the girl's mother. By those she worked with elbowto-elbow every day. With staff members, colleagues, administrators, superiors, all wondering....

But in the end, everyone she knew in the hospital asked but one question:

"Where's Amy?"

"She died," said Serwint.

And that was it. Not another word.

No debriefing. No support. No review. No counseling. Just next patient up.

"It was as if it never happened," says Serwint.

But it did.

And six months later, Serwint, with her bottled-up emotions that no one else seemed to feel, witnessed another child's death. It was the same diagnosis, but not her patient. The similarity, and end result, caused the dam to burst. Within seconds, she fled the room. By the time her colleagues caught up to her, she was in the corner of a closet, crying, crying, crying as if the tears would never end.

Physician, heal thyself

When it comes to pediatric providers taking care of themselves, the FAA is light years ahead of the AMA. The flight attendant's mantra—"In the case of an emergency, place your own oxygen mask on before placing one on your child"—is an idea that is foreign to pediatric medicine. In an atmosphere where a child's care always comes first, the selfcare of providers naturally comes last. Pediatrician or parent, nurse or sibling, there's an imperative: A child's survival matters above all else. It is an understandable mindset, a mandate modeled directly on Alfred, Lord Tennyson's hyperbolic Charge of the Light Brigade—"Theirs not to reason why, Theirs but to do and die!"

And dying many are—psychologically, spiritually and, in extreme cases, physically. Burnout among physicians and, particularly, academic physicians and pediatricians, was a rather poorly studied field until the 21st century. That is astonishing considering what we've since

learned: Peer-reviewed surveys uncovered that, despite generally high job satisfaction, at least 35 percent of all pediatricians suffer burnout. Pediatric residents may have even higher risk. According to a *British Medical Journal* article, 74 percent of 123 residents surveyed experienced burnout symptoms, with 20 percent meeting the criteria for depression.

On the extreme end, that high burnout rate could contribute to physician suicide (physicians are considered more susceptible to suicide than the general population). A meta-analysis of the topic's few high-quality studies found the suicide risk to be roughly 40 percent higher for male physicians and 215 percent higher for female physicians—this is of particular concern in pediatrics, where women make up 58.1 percent of pediatricians and 70.2 percent of pediatric residents.

Of course, academic medical institutions have their own unique provider stressors. It's a 24/7/365 environment where a dizzying array of technologies and tests, and reams of patient data accumulated by cadres of specialists, nurses and support staff members, come to bear on a single child and family. Walk into any emergency department and the average physician there will click a computer mouse nearly 4,000 times in a 10-hour shift to document cases. Intensive care units are provider fatigue cauldrons, with staff exposed to 7,000 "pop-up" alerts on electronic patient charts daily.

Just when the situation seemed hopeless—medicine is only destined to get more complex—a movement is afoot that might restore some emotional health to care providers. It's called "building resilience," an umbrella term for numerous health and wellness initiatives aimed at providers and patients alike. It's a movement that flies in the face of what a pediatrics professor bluntly describes as a bedrock principle: Suck it up.

Building resilience is all about not having to suck it up, of softening that

Most people I work with, they'll say, 'I need to be able to step back and hand off my patient load for a half-hour when a patient dies so that I can go cry.' We don't have that built-in flexibility yet, but we can talk. We can give people resilience tools to help themselves. Giving them the time to use those tools...that's the real challenge for our institution."

MAGGIE MOON

permanent game face, and expressing through myriad ways the multitude of emotions that, left unexpressed, steadily erode a provider's ability to practice and a patient's ability to heal. Building resilience is not about surviving stress, but actually thriving in the face of adversity. Once dismissed as "soft" or touchy-feely medicine, research now shows resilience-building initiatives are rock-solid institutional investments. Replacing a burned out academic pediatrician costs nearly \$500,000. And those depressed pediatric residents? One study showed they're more than six times more likely to make a monthly medication error, potentially costing an institution millions. As for patients, evidence suggests a cohort of resilience building programs even something as simple as providing in-room meals for parents so they can remain at their child's bedside—increase patient safety, shorten hospital stays and lessen readmissions, all huge money savers. Pediatric researchers are now diving deep into chronic ACE's—adverse childhood experiences (traumas such as abuse, domestic violence, or parental separation)—to measure and identify children and families most in need of resilience-building services.

After 30 years of fits and starts, the building-resilience movement is taking hold at Johns Hopkins Children's Center. There, programs that increase resilience among residents, staff members and nurses are being advocated for by a younger generation less inhibited about expressing emotions related to their workplace environment. These newer providers expect (nay, demand) that employers provide mental health support and a balanced work-life.

The result is numerous efforts, large and small, focusing on expressing feelings as much as uncovering the facts surrounding tragic patient cases. We're talking everything from literature workshops to safe space debriefings to meditation gardens, all designed to help deal with the internal trauma created by repeatedly witnessing external upheavals. Call it all a new launch point for practicing medicine that's compassionate to all the players, giving them tools to construct a protective armor for enduring an environment where resilience is often needed just to walk through the door.

In this light, Janet Serwint's distraught sobs were not surprising. Witnessing children repeatedly suffer and/ or succumb, even when everything is done properly and by the book, can be devastating. Yet whether it's delivering tragic news to parents or dealing with self-doubts about a course of care, these things aren't typically taught or talked about in medical school or pediatric residencies. The result? No one is prepared. Enter the resilience movement.

Serwint cites several key moments, including Johns Hopkins epidemiologist Albert Wu's ground-breaking 2000 British Medical Journal paper entitled "Medical Error: The Second Victim. The Doctor Who Makes the Mistake Needs Help Too." This "second victim" concept slowly caught fire—as Wu noted in his paper, "virtually every practitioner knows the sickening realization of making a bad mistake. ..." Yet medicine's perceived culture of perfection refused to console those who were merely human.

Over her career, Serwint learned to embrace her empathy as a strength, teaching pediatricians how to be true first responders in emotionally challenging situations. In the mid-'90s, she created a workshop for second-year residents on how to deliver bad news to parents in ways that strengthen rather than break the bonds between the family and

providers. The workshop includes standardized patients—actors playing the roles of parents and other family members—for residents to experience different scenarios. "Sharing bad news is hard, but there are skills that you can enhance to make it better," says Serwint. "That compassion, that caring, that comfort with silence, with being present and sitting with them, the tone of your voice, the word choice, all make an important difference."

Serwint's workshop curriculum, funded by the Cameron Kravitt Foundation and adopted by Cornell University; the University of California, San Francisco; and the University of Cambridge, anecdotally lessens provider anxiety. Serwint points to an e-mail from a Johns Hopkins pediatric resident describing how, before a fellow resident informed a family of their child's cancer diagnosis, both residents reflected on what the seminar taught them. "She went in and I was told she did an amazing job with the family," wrote the resident, "and she felt the seminar helped her to (communicate such news) in a more effective way." Serwint notes the curriculum also addresses the impact of these experiences on physicians, while offering resilience-building strategies. It complements Albert Wu's RISE (Resilience in Stressful Events) team, a multidisciplinary peer responder group mobilized to any unit that experiences traumatic patient events and needs emotional support.

Several other Children's Center programs allow providers to express difficult emotions as they arise. Pediatric oncology, because it cares for many seriously ill and dying children, is known for its high burnout rate, notably among nurses. Fourteen years ago, then unit nurse manager Lisa Fratino and nurse Laurie Rome watched nurses fleeing in



droves after only a few years, their psyches shattered. "Our unit was falling apart," recalls Rome. "There were brand new nurses, nurses who had been there for 15 years, and no one in the middle. It was a really pitiful longevity curve."

In response, Fratino and Rome introduced retreats for nurses to blow off steam and create camaraderie. Then came annual celebrations—recognition of a job well done. What was truly needed, however, was something more therapeutic. Three years ago, Rome introduced monthly Processing & Resiliency sessions.

"These are not M&M (morbidity and mortality) debriefings where teams get together and examine every aspect of the systems, policies and procedures that lead up to a bad event," Rome says emphatically. "In these sessions, we bring a beautiful, sumptuous array of snacks and always have a springboard topic to start



Sometimes an attending physician will come, tell a story about a particular tragic case, and the (nonphysicians) will be like, 'My God, he felt that too!' It helps to really find a commonality, where anybody's coping mechanism might help someone else."

LAURIE ROME

the conversation. We invite everyone who takes care of patients, from the people at the front desk to the head of the pediatric bone marrow transplant service."

Rome says the sessions defang hierarchies that inhibit communication and stress out staff. "Sometimes an attending physician will share their feelings about a tragic outcome, and the others will be like, 'My God, he felt that too!' It helps to really find a commonality, where anybody's coping mechanism might help someone else. So whether it's nurses, physicians, social workers, therapists or chaplains ... it's by virtue of your humanity that you have something to contribute to this forum."

Lauren Small has accomplished a similar goal using her unique skill set. Along with a Ph.D. in comparative literature, Small holds an assistant professorship appointment in pediatrics and teaches narrative medicine, an emerging field that uses storytelling to improve care. By showing doctors how to elicit their patients' stories (while perhaps sharing their own), provider empathy increases along with patient confidence and effectiveness of care. It piggybacks on studies showing that physicians who feel more closely connected to patients rarely suffer career burnout.

Small's monthly AfterWards program was an experiment designed to see if storytelling among care providers could amplify that salutary effect. Co-created with then pediatric resident Ben Oldfield, the duo first wrote a paper looking at the concept of "emotional labor"—the effort it takes to manage on-the-job emotions—which has been very well studied in nurses, but was just starting to translate a little bit with regards to physicians, says Small. "That emerged after we started talking to the physicians who came to those initial AfterWards sessions."

Small's attendees—often 25 or more—listen, discuss and then write quietly about a presented piece of literature or art. She has used 19th century Alaskan shaman masks to launch a discussion into how masks and other medical garb impact a provider's emotional and physical health...and how patients can interpret these accoutrements as symbols of competency or intimidation. Then there's the recent AfterWards session at which nursing student Juliet Garlow presented University of Wisconsin associate professor Jenell Johnson's graphic-comic, which depicted her roller coaster journey of infertility and unsuccessful in vitro fertilization procedure. The 17-page volume had the room of attendees buzzing about how the comic reframed the issue in their heads.

"Graphic (comic) medicine helps to humanize what we're doing on a regular basis, to deeply understand patients' deeply intimate experience," Garlow told the crowd. "It gives voice to patient, providers and caretakers alike, to spark conversations that are sometimes





I think everyone here is the walking wounded. Nobody notices how this hurts, how this is a loss for us (when a patient dies). So let's first start our program by not only focusing on the bereavement of the families, but also realizing we're all bereaved."

NANCY HUTTON

I'm always asking, what would emotional strength look like to you? At that point, I help them problem solve using skills they already have, because in many ways resilience building is an inside-out process."

MATT NORVELL

uncomfortable, or not often talked about."

Small is gratified that AfterWards attendees such as Garlow regularly step up to determine each session's agenda, moving the program forward as part of a larger humanistic movement at Johns Hopkins "In the 20th century, we became more technologically adept, thank goodness, because it's saving lives," Small says, "But eventually the needle swung too far—we are realizing the needle needs to swing back. Yes, we want the doctor to have all that technological expertise, but we can't ignore the human side."

Margaret "Maggie" Moon, appointed the Children's Center's first chief medical officer in 2017, embraces the inclusive work of Serwint, Rome and Small, as well as mindfulness workshops and the department's important research on "trauma-informed care." Such care has providers adjust their approach to children and adolescents who have undergone traumas such as domestic violence or sexual abuse. The goal is to create a safe clinical environment and better understand the swirling emotions these patients and their families may display.

"What happens with our providers is that when our patients are aggressive or angry, or are confusing our people, our providers take it very personally. It adds to their own stress and distress," says Moon. "This research, understanding our patients' experience, helps us to be more thoughtful and helps us not overreact."

Moon sees time as one of her biggest resilience-building challenges. Not just hers, but everyone's. "We had a resilience session a few weeks ago, where we were asking how to regain your sensibility in five minutes when what you really need is five days," Moon says.

Though the line is funny, the reality is not, as Moon, who spends most of her clinical time in the pediatric emergency department, can attest. "Most people I work with, they'll say, 'I need to be able to step back and hand off my patient load for a half-hour when a patient dies so that I can go cry.' We don't have that built-in flexibility yet, but we can talk. We can give people resilience tools to help themselves. Giving them the time to use those tools ... that's the real challenge for our institution."



Patient-Family Resiliency

At its core, building resilience is about creating a working environment with fewer communication barriers. To listen is to learn, and the Children's Center is creating an ears-wide open culture, responding to the resiliency needs of patients and families.

The nurturing relationship between Trey Price's family and pediatrician Nancy Hutton's palliative and compassionate care team is a wonderful example. Price, 19, was born with Loeys-Dietz syndrome, a serious connective tissue disorder. Loeys-Dietz puts patients at high risk for aortic enlargement and other vascular, bone, palate and spine issues.

After years of driving from Colorado to Baltimore to be treated by Hopkins' Harry "Hal" Dietz, co-discoverer of the syndrome, Price's family permanently moved to Baltimore County in 2013. By then, the family had experienced numerous short- and long-term stays in both the old and new Children's Center. The burden for managing and coordinating the many specialists (surgical, ortho, cardio, pulmonary, etc.) who rifled through Price's room often fell on Trey, his fiercely loyal sister, Tori, 17, and his parents, Veronica and Tony.

At times, it was like herding cats. Take the most recent hospitalization, last December. As a child, adjustable titanium rods were surgically implanted in Trey to stabilize his spine. Late last year, a bump appeared along his spine: The rods had broken near his neck, while an infection affected his pelvis. The replacement surgery was successful, and the infection cleaned out. A few days later, a specialist came in Trey's room, looked at his chart, and said, "You're good to go home."

But Trey was far from it. He was still in excruciating pain.

"I realized he was speaking from his own standpoint. Yeah, his job was done, but I wasn't ready to go home, and all the other specialists I was dealing with knew that. But he didn't. He thought I would be better at home even though I was still on IV medicine."

TREY PRICE WITH HIS SISTER, TORI

"I realized he was speaking from his own standpoint," Price says. "I wasn't ready to go home, and all the other specialists I was dealing with knew that. But he didn't. He thought I would be better at home even though I was still on IV medicine."

Enter Nancy Hutton's palliative care team. Palliative care originated as part of hospice care—it was only available to dying patients. That has long since evolved to include patients at any point in treatment, but the myth that it is still only for the dying persists.

"Oh yeah, my mom was concerned about that at first," recalls Price. But he explained to her the situation. "What (palliative care does) is coordinate your care, help with pain. They're the ones who come into your room and ask, 'What do you need?"

Hutton's work with palliative care goes back to 1985, a time when HIV exploded worldwide. Initially, there were no treatments—just a huge amount of fear and confusion about how to care for patients. In her role as the Children's Center's director of the Pediatric and Adolescent HIV/AIDS program, Hutton handled many end-of-life cases. The comfort palliative care brought these patients led other units with high mortality rates across the Children's Center to also desire such services. But Hutton recalls discovering, early on, just how distressed the staff were as well: "Finally, I said, 'I think everyone here is the walking wounded. Nobody notices how this hurts, how this is a loss for us (when a patient dies). So let's first start our program by not only focusing on the bereavement of the families, but also realizing we're all bereaved."

Hutton's team includes child-life specialist Cora Welsh and Matt Norvell, a chaplain. Norvell's experience and background—he also is a long-time RISE team member—give him a unique take on resilience. Whether it's a patient, family or provider, self-motivation is the key. To Norvell, it's not a matter of giving someone a resilience-building pill, if there were such a thing.

"I'm always asking, 'What would emotional strength look like to you?"

When someone takes a moment to reflect on that question, their answer cues Norvell into action: "At that point, I help them problem solve using skills they already have, because resilience building is an inside out process."

That daily back and forth has also been Patrice Brylske's lifework. As the Children's Center's director of child life services, she has preached resilience building since long before that phrase became a buzzword. "That's the perspective that drives us to learn from the child and family. We ask them, 'What is the biggest stressor for you?' Then we help break that down into more manageable parts to find a way to collaborate with the child and parent to develop a coping strategy," says Brylske.

Some of these strategies are as simple as finding out what part of a medical procedure scares a kid. Others are rather extraordinary. During then 8-year-old Reese Burdette's incredible 662-day stay in the pediatric intensive care unit for trauma related to severe burns, she was asked what she missed most from home. Reese immediately said, "Pantene."

Pantene is a cow. A big cow who lived on her family's dairy farm in South Central Pennsylvania. No matter. Staff allowed a visit by Pantene. Reese's mom and dad shined up the cow's coat just so, hooked up her trailer and delivered her to an area cordoned off behind the Children's Center. When Reese came around a corner, there was 1,600 pounds of bovine love. Despite having lost a leg and disliking physical therapy, Reese wanted to stand once again by Pantene's side—just as she had done when presenting the cow in ribbon competitions at dairy shows. Using a walker, that's what she did. "Once we saw that," says her mother, Claire, "we knew she was really on her way back."

This is just one example of the constant personal response Reese would receive, especially from her pediatric intensivist, Kristen Nelson. "Dr. Kris is important to me because she helped me get through hard times," Reese says. "She's done a lot of things for me." Like FaceTiming from a beach vacation when Reese was scared of getting extracorporeal mem-

"I remember thinking that we have to figure out how to help patients engage in mental health treatment within the primary care setting, because there's still a lot of stigma surrounding mental health care in the community. To me, bringing those services within the primary care setting was one strategy for overcoming stigma and making treatment more accessible for families."

BARRY SOLOMON



brane oxygenation (ECMO) blood ports changed. Nelson walked Reese through the process, assisted by child life specialist Caroline Potter, who was in Reese's hospital room.

This growing awareness of seeing medicine through the patient's lens, and helping patients build resilience based on their life stories, began in the early 2000s. Barry Solomon had just begun his 14-year-tenure as medical director for the Children's Center's Harriet Lane Clinic. An East Baltimore family came in for "routine" well child care, but there was nothing routine about what he learned next-something he learned only because he asked. Six months prior, a fire destroyed the family's home, killing one of the children.

"The mother and two older children who survived were all distraught, struggling with an acute major life event while dealing with the daily stressors of living in a high crime neighborhood. Yet this was the first time they were encountering a health professional since the fire," recalls Solomon. He intuitively sensed it would be difficult for the family members if he took the traditional route and referred them to outside grief counseling or a mental health provider.

"I remember thinking that we have to figure out how to help patients engage in mental health treatment within the primary care setting, because there's still a lot of stigma surrounding mental health care in the community," Solomon says. "To me, bringing those services within the primary care setting was one strategy for overcoming stigma and making treament more accessible for families.'

Improving patient-provider communication accelerated department-wide in 2007, when parents were invited to join the Children's Center's first Patient and Family Advisory Council. It proved so popular and helpful that numerous departments have since created similar councils. Often, it was parents who spoke on behalf of their children at these council meetings—effective, but perhaps not as powerful as hearing from the kids themselves.

Enter the Teen and Children's Council (TACC). Geared for patients ages 12 to 21, it serves several functions. Staff members ranging from food service directors to department chairs use TACC meetings as focus groups to improve service. More than once, Trey Price recalls, he and his sister, both TACC members, have been asked to test-run products aimed at lessening a child's discomfort during medical procedures.

TACC has other functions, such as organizing a hospital prom for teens who can't attend their own, but the council members' real power is telling and retelling their personal stories. At first, 21-year-old Stephanie Turner, a longtime patient and survivor of several pulmonary embolisms, was intimidated by the idea "of diving into the depths of my near-death experience and sharing some of the scariest moments of my life in a roomful of strangers."

One day, she realized just who some of these strangers were and how sincerely they wanted to learn from her tale. At one event, she was invited to sit up on the dais. "Everyone had a name tag. I'm

"We ask them, 'What is the biggest stressor for you?' Then we help break that down into more manageable parts to find a way to collaborate with the child and parent to develop a coping strategy."



in between the Hopkins CFO and CEO, and when it came my turn to talk, I felt everyone was listening. We then had a real conversation based upon what I had said," recalls Turner. She adds that in learning how to tell her story, what impressed her most was that TACC's director, pediatric nurse Tricia Willis, insisted it not be a sanitized version of the hospital experience, but rather "the good, the bad and the ugly."

A similar mindset guides resident Jessie Calihan and several colleagues. They introduced a trauma and resilience curriculum based upon the aforementioned "trauma-informed care." The idea is

that all residents formally learn how to elicit their patients' stories. Getting a comprehensive picture of a patient and caregiver's lives, establishing the traumas they face—that's the first step.

The next is encouraging resilience building skills, especially those that are already a part of the patient's life. So-called identity projects can be fantastic bonding and starting points for working around constant life stressors. "Say I find out a patient of mine in middle school likes to hang at the corner park and play soccer with his friends," says Calihan. "I might encourage them, work with them to try out for the middle-school soccer

team. Because soccer is something they already enjoy, it fits with resilience building skills they're already developing."

Across the Children's Center, the institution's growing financial support of such efforts encourages resilience advocates. The support includes an increase in child life and palliative care staff and the creation of a full-time parent adviser position. New family friendly initiatives include an art night and yoga.

Is there work still to be done?

Yes, of course there is still work to be done. Resilience-building initiatives vary greatly across divisions and there remains a shortage of social workers and child life specialists. Still, there is optimism that the resilience movement is not a fad but a tool destined to be just as much a part of medicine as the stethoscope. Perhaps by listening to those they care for, practitioners will finally stumble upon the secret whispered in their ears for centuries. To help others, it's wise to first heal thyself.



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pediatricrounds



Utilizing a 3D model, surgeon Jordan Steinberg points to the aggressive tumor that had eroded his young patient's jaw. After resecting it, he replaced the jawbone with one of the patient's ribs as a graft, seen on his computer screen above.

A 'Giant' Giant Cell Granuloma

By Gary Logan

AFTER AARTI AND ASHISH Sarin took their daughter to urgent care because of a low grade fever, a nurse there noticed some swelling along 3-year-old Shivaya's right jaw. Perhaps a swollen lymph node? But when she touched her child's jaw, she felt a hard mass. Differential diagnoses from ear and staph infections followed until Aarti met with a radiologist for the results of a scan of her daughter's right mandible, which had grown dramatically.

"The radiologist said, 'What the hell is this? I've never seen anything like this—go get her admitted,'" Aarti says, describing a watershed moment. "The world stopped."

What it turned out to be, after workups at hospitals in Virginia and Washington, D.C., was a central giant cell granuloma, an aggressive tumor that was eating away her right jawbone and inflicting substantial pain. Searching for a treatment for this rare tumor, Aarti and her husband consulted with and visited children's hospitals up and down the East Coast. Then they found pediatric plastic and reconstructive surgeon Jordan Steinberg at Johns Hopkins, who recommended surgery but also supported a less aggressive treatment with corticosteroid injections to shrink the tumor.

The family chose the simpler steroid therapy at a hospital closer to home. Unfortunately, the treatment showed limited effects and the parents revisited Steinberg, who recommended an extensive resection and reconstruction of her jawbone. Also, he would repurpose one of the girl's ribs as a graft to

replace the jawbone, a technique Steinberg has used in surgery for congenital deformities.

"What I proposed seemed a little radical as the first path, but I figured, given the extent of this tumor, nothing short of that was really going to work," says Steinberg. "We knew that part of her jaw was no longer functional."

The major challenge would be separating the tumor from the normal structures, including the facial nerve branches, which was no simple matter in that the lesion had grown in a very amorphous fashion. Steinberg chose as a collaborator pediatric otolaryngologist Jonathan Walsh, a specialist in operating on facial nerves. The two surgeons also relied on a 3D model of the tumor in planning the surgery.

In the 13-hour operation, using facial nerve monitoring, Steinberg and Walsh meticulously peeled the tumor off the normal structures of the jaw, leaving the nerve branches unharmed. Steinberg and Walsh also had to take a tissue flap from the neck to plug an internal portion of the mouth damaged by the tumor. The outcome?

Noting that Shivaya's parents report she is eating and behaving like a normal child and "back to herself again" following physical therapy, Steinberg says, "Things went very well with her, she's doing great. We chose the rib graft, which unlike an artificial graft will grow with the growing child, but she will likely still have some asymmetry issues and may require additional surgery in the future."

A Magnetic Approach for Scoliosis

66 This new painless, noninvasive way allows you to elongate the patient's rods in the office or clinic with the parents watching. It really is magic and life changing. 55

-PAUL SPONSELLER

TODAY THERE IS no shortage of effective treatments for scoliosis, from bracing and casting to surgery, said pediatric orthopedic surgeon Paul Sponseller at Johns Hopkins' annual Mastering Children's Orthopaedics conference last fall. Among the most innovative treatments, he added, is an externally controlled growing rods approach for severe curves that eliminates the need for repeated expansion surgeries to keep pace with the growing child. How does it work?

In the procedure, two rods are inserted—one on each side of the spine—and attached above and below the curve to brace the spine as the child grows. Each rod contains a pair of magnets that, via an external device, facilitate a millimeter-by-millimeter telescoping and lengthening of the rod every three to

six months. In the traditional growing rods approach, patients undergo a surgical procedure and hospitalization every six months to lengthen the rods

"This new painless, noninvasive way allows you to elongate the patient's rods in the office or clinic with the parents watching," Sponseller reported to general pediatricians. "It really is magic and life changing."

Noting that ultrasound is used to monitor the spine's growth, Sponseller adds, "You can program how much growth you want to have without taking a lot of X-rays."

Both Sponseller and orthopedic surgeon John Tis use the new growing rods approach. Criteria for patients include significant progressive scoliosis, immature skeleton, and early-onset or idiopathic scoliosis.

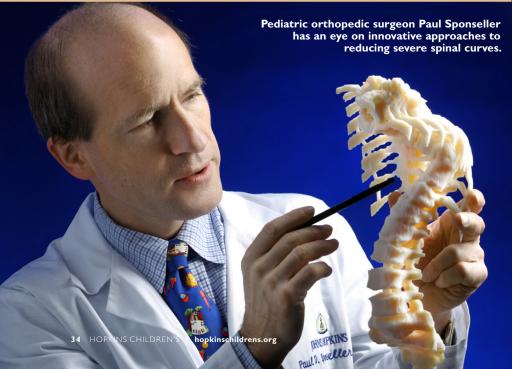
Sponseller also offers innovative bracing and casting treatments at Johns Hopkins Children's Center. While bracing usually will not straighten a severe curve, Sponseller notes, it may hold the curve and prevent it from worsening, especially for patients who have normal connective tissue. Bracing, he adds, is less effective for patients with neuronuscular disorders such as cerebral palsy, spinal muscular atrophy and genetic disorders like neurofibromatosis.

In those cases, Sponseller recommends a Mehta cast for nine months. Placed on the patient under anesthesia, the cast is designed to de-rotate the spine, stretching it out in the right places and opening spaces the body needs to fill. Families, Sponseller stresses, need to understand that their child will be in a cast 24/7

"But that's why it works so well—it never lets up," Sponseller says. "As you apply force, it stretches out the concavity and allows the spine to open up in the right direction where their muscles can eventually take over."

Sponseller cited one outcome for a young patient with a 45-degree curve whose spine worsened with bracing. After nine months in the cast, Sponseller explains, "His spine was permanently straightened and never had to undergo surgery. Six years later, it hasn't gotten worse."

Reflecting the philosophy of the Johns Hopkins pediatric orthopedic service, Sponseller concludes, "Our goal is to make the course smoother and outcomes better by intervening early through both operative and non-operative means, and to avoid a risky large surgery at the end of growth."— *GL*



Precision Targeting Pain Management

AN ADOLESCENT DANCER with radiating lower back and hip pain, a teen soccer player suffering severe concussion related headaches, a 9-year-old Little League pitcher with nerve impingement in his right shoulder, neck and back—what do they all have in common? Where orthopedic treatments fell short, they found complete relief from their chronic pain through precisely targeted steroid injection therapy with pediatric pain specialist Irfan Suleman.

The dancer, 14-year-old Grace Megargel of Forest Hill, Maryland, was born with a lowest lumbar vertebra abnormally joined to both the right sacrum and ilium, which resulted in chronic pain exacerbated by standing, sitting or leaning forward, and especially by dancing. Her congenital abnormality was missed until Johns Hopkins pediatric orthopedic surgeon Paul Sponseller detected it on a scan. While fusing the left side would ease the girl's pain, Sponseller noted, it would also limit her mobility. As a first step, he suggested steroid injection therapy with Suleman.

"I reviewed the MRI with the radiologist and developed a plan to see if a right sacroiliac (SI) joint injection would help," says Suleman. "Her injection was a bit more challenging because of a small lumbar cyst, but we delivered the injection and the pain is completely gone."

The injection is also diagnostic regarding how the patient responds, notes Suleman: "If the pain goes away, it was coming from the SI and not somewhere else."

He adds, however, that because of the nature of her competitive dancing activ-



Using real-time ultrasound and fluoroscopy imaging, pediatric interventional pain specialist Irfan Suleman targets treatments precisely to the patient's problem area.

ity, the pain may return and require another injection. "But we know where the pain if coming from, the source of the pain, and we know how to manage it."

The soccer player suffered a concussion after an opposing player's elbow hit her head. After evaluation for intermittent pain on the back and right side of her head, the patient was referred to Suleman. He injected a right occipital ultrasound guided nerve block, resulting in complete resolution of her pain.

Similarly, Suleman found an answer for the young pitcher whose pain was so intense, and the top of his right shoulder was so sensitive, that he would jump at the slightest touch. Another provider prescribed a topical lidocaine patch, which failed to relieve the pain. Suleman, who identified the culprit as a suprascapular nerve impingement, took a different tack.

"After targeting the nerve with an in-

jection, there is no more hypersensitivity," says Suleman. "He's back on the mound, pitching again and everything is back to normal."

Suleman administers the injection treatments to young patients under deep IV sedation to reduce their risk of moving, which can cause complications. Steroid injections do not come without risks, he notes, including suppression of the immune system with too many injections. To reduce risks, Suleman minimizes injections and, with the aid of ultrasound and fluoroscopy imaging, targets treatments precisely to the problem area. He also adamantly promotes collaborative holistic pain management without the use of narcotics. – GL

When Distance Is a Barrier to Specialized Care

By Jim Duffy

AS A LITTLE boy, Colin Russell was always running behind. Crawling, talking and walking: He hit each new developmental milestone at the point when his parents, Christy and Kell, were starting to worry that their son might have a problem.

Colin, however, was never far enough behind to set off alarm bells. He was 2 ½ when Christy asked a pediatrician to check his hearing in case that might explain Colin's iffy sense of balance. The pediatrician came back with a diagnosis of autism.

"It was a total shock," Christy says. "We had no idea what this was going to mean for Colin's future."

The family's journey into the world of specialized pediatric care got off to a rocky start. The Russells live on Maryland's rural Eastern Shore, while the multiple specialists Colin needed to see were all in and around the big cities of the Western Shore.

"There were weeks when Colin and I would cross the Chesapeake Bay bridge five times for five different appointments," Christy recalls. She had to cut back on work hours during a year when the family was racking up \$30,000 in out-of-pocket medical expenses.

This situation can be even more daunting when young patients suffer from rarer conditions that require highly specialized care that tends to be completely unavailable in rural areas. In a new telemedicine initiative to tackle that priority, Johns Hopkins Children's Center partnered with the Talbot County Health Department to facilitate appointments-by-video to allow Eastern Shore patients to see doctors without

crossing the bridge.

"We were inspired by the Russells and other Eastern Shore families to facilitate access to our physicians without the burden of traveling long distances," says pediatrician Helen Hughes, who with pediatrician Margaret Moon is leading the initiative funded by a JHCC innova-

of health care is headed.
Video technologies can allow us to do so many things for our patients without having to see them in person every time.

- PEDIATRICIAN HELEN HUGHES

tion grant. "This is where the future of health care is headed. Video technologies can allow us to do so many things for our patients without having to see them in person every time."

Still, Hughes and Moon plan to take a cautious approach to these appointments. One area of concern is the doctor-patient relationship: Will physicians be able to build the same rapport with patients on video as they do in person? Another concern involves rare cases where a patient shows up for a routine follow-up video visit looking sicker than anticipated, perhaps even in need of immediate attention.

"That's something everyone will be a little scared of," Hughes says.

At the outset, the new service will be limited to routine follow-up sessions with pediatric subspecialists, including nephrologist Alicia Neu, endocrinologist Risa Wolf, and pulmonologist Laura Sterni. If the program passes that test, the Children's Center will likely set up comparable programs in other rural areas.

Pediatric endocrinologist Risa Wolf at Johns Hopkins Children's Center in Baltimore, connecting via video with a young patient and parent on Maryland's Eastern Shore.



Sheela Magge, Seeing Endocrinology Patients as a Whole

By Christy Brownlee



SHEELA MAGGE, THE new director of the Johns Hopkins Division of Pediatric Endocrinology, recently met with a fellow to discuss one of their type 2 diabetes patients. After the fellow went over the patient's doses of insulin, her other medications and her glucose numbers, Magge urged him to dig deeper to better understand why this patient was having poor outcomes.

"I asked him, 'Is she depressed? Does she have food security issues? Does she have reliable transportation, a safe place to exercise?" Magge says. "How this patient ultimately does may have little to do with her diabetes and much more to do with a multitude of other underlying concerns."

Looking at patients as a whole has long been part of her care philosophy, Magge says, even before she was officially a doctor. After completing her undergraduate degree from Harvard University, Magge spent a year before medical school on a community service project. Working in a domestic violence shelter in rural Appalachia, she started a tutoring program for abused children. Then, one weekend while taking a day trip, she suffered a traumatic accident that almost took her life and required months of intense recovery.

"I already knew that I wanted to be a pediatrician and that I would always try to see situations from my patient's point of view, but it's hard to do that until you're a patient yourself," she says. "That experience gave me a completely different outlook on how vulnerable and powerless you can feel and all the many factors that go into how well patients do."

Magge went on to attend medical school at Yale University and a residency at Boston Children's Hospital, where she ultimately decided to specialize in endocrinology—a field that touches all organ systems and many intriguing biological pathways, and allows her to work with children of all ages and maintain strong relationships as they grow.

After a fellowship at Children's Hospital of Philadelphia, Magge stayed there for 13 years, developing an expansive clinical research program along with her practice. In 2014, she took a position at Children's National Health System in Washington, D.C., where she served as the director of participant and

66 By addressing all their needs, not just those that endocrinologists typically focus on, we're hoping to make a positive impact for the rest of their lives.

– SHEELA MAGGE

clinical interactions at the Clinical and Translational Science Institute.

Now at Johns Hopkins Children's Center, Magge has continued a strong focus on research, with current projects focusing on areas including how body proportions of people with Down syndrome might affect cardio-metabolic risk, and racial differences in diabetes risk and cardiovascular disease. Many of her studies focus on type 2 diabetes, a disease that's occurring at progressively younger ages due to an increasing incidence of obesity in children.

"A 60- or 70-year-old diabetic might develop complications toward the end of life, but what happens when a 10-year-old develops type 2 diabetes? We need to help protect this vulnerable population," she says.

That's why Magge and her colleagues are expanding their division's diabetes footprint, offering a multidisciplinary clinic where nutritionists, psychologists, social workers, physical therapists and a multitude of other specialists improve patients' health as a whole. The team shares Magge's approach of looking at all the factors that might affect patients' well-being, rather than just their medical history and lab values.

"By addressing all their needs, not just those that endocrinologists typically focus on," she says, "we're hoping to make a positive impact for the rest of their lives."



Shelby Kutty, Director, Helen B. Taussig Heart Center

Incorporating the teaching of diverse mentors into his own practice, Shelby Kutty searches within and reaches out.

AFTER INTERVIEWING SHELBY Kutty, the words, "Slow down, you move too fast, you got to make the morning last," from the Simon and Garfunkel song come to mind. However, there is no slowing down this mind. An ever-accelerating oomph drives the new director of the Helen B. Taussig Congenital Heart Center and chief of pediatric cardiology—there is much to do.

"It's clear he has a lot of energy—he's constantly on the go with one task after another after another," says Greg Martin, administrator for pediatric cardiology. "He doesn't look back—he looks to the future."

The past, however, does have a lot to do with who he is and his approach and vision for the heart center's future—as well as his passion for taking care of children and young adults. He grew up in Kerala, India, a popular tourist area known

for its palm-lined beaches and beautiful backwaters. Indeed, *National Geographic Traveler* named it one of the world's top 10 paradises. Kutty, in his youth, knew there was also a dark cloud over Kerala and southern India: a high incidence of rheumatic heart disease, a leading cause of cardiovascular disease among children and young adults in India at that time. Untreated, it can result in disability and even death, unfortunately the outcome for his maternal grandmother. Seeing his first cousins, age 12 and 14, succumb to obscure childhood illnesses was also traumatizing.

"Those deaths in my family affected me deeply and inspired me to go into cardiology and help people," says Kutty. "Children with heart disease in southern India at that time were totally helpless, with limited resources."

Searching for solutions, he studied pediatrics, cardiology and cardiac imaging at premier institutions in India, Australia, Canada and the United States. He underwent cardiology training at the Medical College of Wisconsin and the Cleveland Clinic, earned a master's degree in health care management from Harvard University, and became a Wharton School scholar and vice chair for pediatrics and assistant dean for research at the University of Nebraska. Along this global path, Kutty emphasizes, he found not just "great" mentors but ones who, through their varied experiences, shaped the collaborative practice he employs today.

"In training I had excellent mentors from the four corners of the world who allowed me to understand the diverse and innovative ways medicine is practiced in the care of children," says Kutty.

Incorporating this foundation early in his career, Kutty found himself cultivating young minds in many places. He discovered a love of tutoring students and mentoring fellows who worked with him on the clinical side.

"I really get stimulated by working with young people and helping their careers grow," Kutty says. "Working 44 Here tradition meets innovation. This is a place of extreme collaboration, a place where you can really forge ahead and change the world.

- SHELBY KUTTY

with young people really refreshes both parties."

Pediatric cardiologist Melanie Nies agrees. "He's bringing fresh eyes to everything we do, bringing people together, and he's been wonderful about stepping in and being a team player, working on mentoring young faculty and finding opportunities for us," says Nies, who recently joined Johns Hopkins' Emerging Women's Leadership program.

Indeed, Kutty's energy for collaboration and mentorship may be contagious. He developed an ability to give and take, he says, and to be completely open and assist others—to share the pie: "The rewards are much greater than what you put in."

This explains why, to this day, he carries a collaborative consortium of some two dozen clinical investigators in the United States, Europe and Asia in his back pocket. He teleconferences twice weekly with people like adult cardiologist Thomas Porter, head of cardiac imaging at Nebraska, and Stephen Archer, chair of internal medicine at Queens University in Canada. Then there are his collaborative resources in radiology, biomedical engineering, public health—relationships with multiple specialists and their work that he capitalizes on to adapt new methodologies and technology in caring for children and young adults.

"When you look at it from only a pediatric cardiology or congenital heart perspective, you are narrow in many ways," says Kutty. "A lot of the exciting things we have tried to do came with working with different specialties."

Consequently, Kutty's crowning achievements are many. He is one of the

foremost authorities in multimodality cardiovascular imaging. His academic interests have focused on minimally invasive nonradiation diagnostics, myocardial function assessment, therapeutic ultrasound and cardiovascular outcomes. He has published extensively in reputed journals, and has made major contributions to understanding right heart function and developing the field of theranostic ultrasound, in which ultrasound is used for therapeutic as well as diagnostic purposes.

"We're using ultrasound energy and contrast microbubbles to deliver local treatments to repair injured cardiac vessels," explains Kutty.

In his vision for the Helen B. Taussig Congenital Heart Center, he and colleagues are focusing on expanding cardiology in areas beyond cardiac imaging, including adult congenital heart disease and cardiac care in the context of genetics, maternal fetal health and oncology. Labs and programs dedicated to preventive cardiology, the right heart, data intelligence and theranostics are being developed, too. Also, once on board at the heart center, he immediately reached out to community physicians and cardiologists in the region to increase the center's collaborative relationships.

To pull all this off and lead an entire heart center in a changing health care landscape, Kutty says, "one needs the right resources in an environment with a strong history of collaboration." He has found that at Johns Hopkins.

"Here tradition meets innovation," he says. "This is a place of extreme collaboration, a place where you can really forge ahead and change the world." – *GL*

Akhil Maheshwari, Neonatology Director

Academic intensity and the density of investigators attracted the renowned neonatologist to Johns Hopkins Children's Center

AT PEDIATRIC GRAND Rounds last October, Tina Cheng, co-director of Johns Hopkins Children's Center, introduced Akhil Maheshwari, the hospital's new director of neonatal medicine. "We're very excited about being able to recruit him here," she said, noting that Maheshwari increased the patient census in the neonatal intensive care unit (NICU) at his previous hospital by 30 percent. "He's an incredible program builder, mentor and leader."

After Cheng's introduction, Maheshwari moved on to his Grand Rounds presentation on the pathology of necrotizing enterocolitis (NEC), his major focus as a physician scientist. Only later would he note his excitement about coming to Baltimore. Why? In the past, he said, institutions sought him. "This," he said, "is the one job I actually sought."

Johns Hopkins, he explained, is known for its collaborative culture and clarity of mission—the development of groundbreaking treatments. He pointed to renowned experts in neonatology and pediatrics at Johns Hopkins Children's Center.

"Almost everything I do in research is based on concepts that emerged from this place, including the strides in pediatric hematology, inflammation and neonatal intestinal injury," says Maheshwari. "It was the academic intensity and density of investigators that brought me here."

His path to Johns Hopkins began in a suburb of Delhi, India, where Maheshwari grew up with three siblings, his mother—a homemaker—and his father, a university physics professor. As a child, the physicians he saw in the community, and their focus on continuity of care, left an impression and spurred an interest in medicine. He knew that medical school admission in India was extremely competitive, with only 35 students accepted each year out of some 165,000 applicants. He was one of them.

"I was fortunate enough to get into one of the top schools," he says. "The good news is you literally have a free ride once you get in."

Going through his clinical rotations, he immediately connected with pediatrics, where most patients got better. "With children," he says, "the beauty was there was a greater possibility of a cure."

He was hooked. Maheshwari pursued a newborn residency and fellowship in India after learning that neonates with very complex conditions could be cured. The programs did not offer a research track, however, which shifted his eyes to the United States and Robert Christensen, a world leader in neonatal hematology at the University of Florida. Maheshwari found his mentor and a physician scientist track, which led to his first faculty appointment at the University of Alabama, where he established I think having profound thinkers who think about education, clinical care models and science in the same place is not something you find everywhere.

-AKHII MAHESHWARI

his own lab and a challenging future direction: "Increasingly I felt we had a progressively better handle on lung disease of prematurity, but the loss of infants due to intestinal injury was something that struck me."

From there he went to the University of Illinois at Chicago, where he rebuilt and grew the neonatology program and its fellowship by a third. "That is where I learned about program building," says Maheshwari.

Generous benefactors lured him south again to a new NICU at the University of South Florida. There he kick-started neonatal research efforts and a dual track for neonatologists who wanted to train in another specialty.

His accumulated experience and growing expertise groomed Maheshwari for the neonatal and perinatal medicine leadership position at Johns Hopkins. Here, in collaboration with division faculty, he crafted a blueprint focusing on five areas of improvement: data science, genomics, imaging, immune programming and maternal-fetal medicine.

Advances in these areas, Maheshwari stresses, will require large data searches and collaboration among immunologists, microbiologists, computational biologists, radiologists and others, all of whom, he notes, Johns Hopkins has a deep bench. The development of new genomic tools and techniques—and

education and training to use them—is especially important, Maheshwari says. Neonatologists must also keep a constant eye on the horizon, he adds, to track patients' changing needs.

"It is very likely that how we treat patients and think about their disease conditions and meet their needs will change in the next 10 years," says Maheshwari. "I believe we will have access to more diagnostic information, which will allow treatment to become less intrusive, perhaps more tailored and more effective. That is the high-energy barrier we need to cross."— GL



Chief Informatics Officer Philip Spevak

By Sarah Richards

ASK DOCTORS HOW they feel about electronic medical records (EMRs), and chances are a number will tell you they are time-consuming and cumbersome to use, especially when it comes to tapping their vast data for research.

As a physician and the director of noninvasive cardiac imaging at Johns Hopkins Children's Center, Philip Spevak is well aware of those challenges.

"We're at a point where we have tons of data, yet sometimes we feel we still don't know what's going on or that we can't find the information we want," he

Now, as the first chief informatics officer at the Children's Center, Spevak hopes he can help ease some of the information overload that so many physicians, patients and families experience. He has two goals: bring value to patients, and make the electronic record more beneficial and easier to use for providers, patients and parents.

Spevak focuses on helping doctors make better treatment decisions with support from EMRs. For instance, he has launched a project for children with asthma—one of several illnesses targeted because it lacks a consistent treatment routine for doctors to follow.

"I'm particularly interested in areas where there's a variability in care that might result in children staying in the hospital too long, or where we're all paying too much for the cost of that care," he explains.



I'm particularly interested in areas where there's a variability in care that might result in children staying in the hospital too long, or where we're all paying too much for the cost of that care.

- PHILIP SPEVAK

Spevak is collaborating with a team of doctors, nurses, respiratory care therapists and pharmacists to develop a standardized approach to asthma care, with help from data from Johns Hopkins' Epic electronic health records system. He is also considering working with other care teams and Epic data to improve treatments for appendicitis, babies born with opioid dependence and children with ketoacidosis, a potentially deadly complication of diabetes.

"The problems that I get to work on in this job, are things I get excited about," says Spevak.

Tina Cheng, director of the Department of Pediatrics, says the new informatics position highlights how important it has become for hospitals to use data from EMRs and other sources to improve care.

"It's a critical role not just for ensuring quality of care for children, but also for innovating health care delivery and enhancing research using big data," says Cheng.

For Spevak, the new responsibilities have been gratifying. He recently helped address delays confirming patients' weight in Epic. Nurses complained that these weight omissions hampered their ability to calculate medication doses promptly.

They were able to make some tweaks to Epic, and it is now much easier to obtain a patient's weight.

"In one day, our compliance with entering weight went from roughly 40 percent to 80 percent," says Spevak, noting the potential of informatics. "We helped a lot of kids with a few hours of programming." 🤒

Neonatologist Christopher Golden

The son of two teachers, Chris Golden talks about his passion for education and the creative clerkship program in pediatrics that he leads.



Fresh out of undergraduate studies at Duke, my Hopkins story began as a medical student in 1991. Here, at the school of medicine, I fell in love with the rotation in pediatrics, and have stayed ever since.

And neonatology as well?

Yes. Interestingly, many people think of neonatologists as only caring for premature and critically ill babies but many of us perform routine newborn care also. As medical director of the newborn nursery, for instance, I see healthy babies all the time with minimal stays in the hospital and uncomplicated lives afterwards. Both areas have excited and intrigued me.

When did you get the teaching bug?

My interest in teaching and how people learn goes back to my childhood watching both of my parents, who were schoolteachers. That interest was rejuvenated when I became the director of the Resident Lecture Series in the neonatal intensive care unit in 2007. In that series, the residents and teachers deal with a range of medical, social and ethical issues in newborns.

Now you are working with medical students as the pediatrics clerkship director.



Listening and empathy are among the qualities found in a good clinician, notes Christopher Golden, with medical school students Sophie Lin, center, and Michelle Juarez.

Yes, and in a format different from my pediatrics clerkship here. The advent of the new Hopkins School of Medicine curriculum in 2010 introduced PRE-CEDE, or Pre-Clerkship Education Exercises, for the medical students. The faculty teaching team in our department employs multiplatform learning in these exercises, some didactic and experiential learning, and a lot of simulation—how to do lumbar punctures or draw blood on simulated models, for example. Using standardized patients, we also help the students learn how to give bad news in a nursery setting or diagnose abdominal pain in an adolescent. In addition, all students still complete inpatient and outpatient rotations at Johns Hopkins and our community partners.

How has the clerkship been received by the students?

Overall, very well. It is not uncommon for them to say, "I learned a lot about the management of children with chronic neurologic disabilities," or, "In my inpatient experience I saw a patient with a condition I had never heard of before and learned a lot about it." Those statements energize me because they indicate that I am meeting my mission as a pediatric educator. Many students say this clerkship is a unique experience, and over the last

six years, graduating students have rated our clerkship No. 1 or 2 among school of medicine clinical rotations on the Association of American Medical Colleges Graduation Questionnaire.

What is it about education that inspires you?

I have a passion for teaching all learners, including those who may not have an initial interest in pediatrics. There is great joy in seeing medical students take ownership and engage in taking care of children along the continuum. For example, we have a session where we teach them how to do the neonatal exammany students may have played with a baby but have never had the experience of actually examining a newborn. I love the opportunity to expose them to that experience.

You sound like a recruiter for future neonatologists and pediatricians.

True, but I also remind all students that at some point during their careers, they may be caring for children. We also focus on certain qualities emphasized in our clerkship (listening, empathy, compassion and clinical reasoning), which are all key features in being a good clinician.

– GL 🐽

Improving Neonatal and Maternal Mortality in Southeast Asia

By Karen Blum

NICOLE SHILKOFSKI, DIRECTOR of the pediatric residency program, is no stranger to Southeast Asia. Since 2007, Shilkofski has volunteered for over 30 surgical missions to the Philippines, among other countries, through Operation Smile, and she lived in Malaysia for four years helping Johns Hopkins establish a medical campus in Kuala Lumpur.

More recently, through her connections in the Philippines, she has been using education as a means to improve neonatal and maternal mortality rates in the country's southern Mindanao region—where they are among the highest in Southeast Asia. Working with obstetric and pediatric partners, including Johns Hopkins gynecologist/obstetrician Jill Edwardson, Shilkofski has been training groups of midwives and community-level providers in the Helping Babies Breathe and Helping Mothers Survive programs. These global initiatives—supported by the American Academy of Pediatrics, the American College of Obstetricians and Gynecologists, and Jhpiego, a nonprofit health organization affiliated with The Johns Hopkins University—use hands-on simulation exercises with mannequins to demonstrate to health care workers how to prevent birth asphyxia and postpartum hemorrhage in newborns and delivering mothers.

"These programs have been taught in many other countries, but this is the first time they have been part of an integrated platform for these health workers," says



Pediatric resident Kelsey Stayer uses a mannequin to teach a Filipino midwife in Mati, Davao Oriental, how to ventilate a newborn infant.

The idea that you are starting a cascade of education that is going to continue far beyond your time in country is really exciting.

- SAM GOTTLIEB, PEDIATRIC RESIDENT

Shilkofski. "The goal is to regionalize some of this training, and disseminate it through a train-the-trainer cascade model." Program materials are left with students so they can teach colleagues.

With support from a Fulbright grant from the U.S. Department of Education, Shilkofski brought six residents and two medical students on a training trip in the Mindanao region last summer as part of a global health elective. Residents spent two weeks leading training courses for workers, then observing the trainees repeat the information back and mentoring them as they taught the lessons to other health care workers. Residents also spent a week in Manila shadowing residents and intensive care unit fellows at Philippine Children's Medical Center.

"It was a fantastic experience," says pediatric and anesthesiology resident Keri Koszela—especially the days when she and her colleagues watched the trainees train their colleagues. "It was so exciting to see them take this knowledge and teach it on to others, adding their knowledge of local systems."

Pediatric resident Sam Gottlieb notes that the program appealed to him because of its sustainability: "Instead of doing a clinic, bringing medications and leaving the next week, we were essentially teaching the basics of neonatal resuscitation and management of postpartum hemorrhage to midwives, birth attendants and people on the front lines taking care of women and newborns at birth. The idea that you are starting a cascade of education that is going to continue far beyond your time in country is really exciting."

From Baltimore to Brazil, Child Life Shares Practices

CAROLINA FONSECA, A volunteer at the Cancer Hospital of Londrina in Brazil, had been supporting children undergoing treatment there by purchasing art supplies and toys. Then, her cousin, Beatriz Kohler—a senior research nurse at Johns Hopkins for 25 years—suggested she talk to Patrice Brylske, director of child life at Johns Hopkins Children's Center, to learn more about what could be done to improve children's hospital experiences.

Fonseca visited and shadowed the Child Life department in 2017. Then she worked with the Londrina hospital to raise funds to bring Brylske and two child life specialists, Caroline Potter and Nilu Rahman, to the hospital the next year to provide training for staff. Brylske and Potter tag-teamed to teach a weeklong course—translated to Portuguese—for physicians, nurses, social workers and psychologists from the Londrina hospital and two others from Sao Paolo. Brylske and Potter provided skills-based education and a comprehensive approach to child-friendly health care practices. Meanwhile, Rah-

man conducted a series of two-hour workshops from the curriculum for more health care workers and students. Topics included procedural preparation and play; communication and patient-family-centered care; pain management; and death, dying and grief. Rahman also spent a day at the Londrina hospital rounding with a medical team and interacting with patients and their families.

One Londrina nurse said she and her colleagues had been struggling to support children while not being overwhelmed by stress. "She saw the information we were giving them as a way for nurses to feel inspired again, and it gave her ideas on how to help nurses feel happy about their work," says Potter.

The experience built upon earlier international trainings Brylske and colleagues conducted, in Serbia in 2010 and Malaysia in 2016. Brylske says she has noticed similarities among health care workers regardless of their home country.

"They're professionals, they are doing their best to care for patients and families, and they do not intend for treatments or procedures to frighten their patients," she says. "It's really transformational for them to learn there is a different way to provide patient- and child-centered health care."

Brylske's team has remained in contact with some of the Brazilian trainees, who have instituted changes like using treatment rooms instead of patient beds for potentially painful tasks such as blood draws, and having nurses wear colorful shirts rather than traditional white coats to help build rapport with patients.

The training provided "an incredible experience for me to see how lucky we are in our country to be able to provide child life services to patients and families, because it's so needed," adds Rahman. "I wish every country could have child life, because it meets psychosocial needs that other disciplines just don't have the time, education or training to provide." – KB



At the Cancer Hospital of Londrina, from left, Patrice Brylske, director of child life at Johns Hopkins, with child life specialists Nilu Rahman and Caroline Potter.

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Members of Jenny Lee-Summers' lab are studying ways to minimize brain injury in infants. From left to right, Ewa Kulikowicz, May Chen, Jenny Lee-Summers, Polan Santos, Raymond Koehler, Melisa Carrasco and Caitlin O-Brien.

Searching for Solutions for Hypoxic Injury

By Gary Logan

STUDYING NEONATAL BRAIN injury is personal for Jennifer Lee-Summers. Facing placental problems during her own pregnancy, she knew her baby would be at risk of hypoxia, or low oxygen flow to the brain.

"Fortunately, my baby did fine but I was very close to having a newborn with birth asphyxia," says Lee-Summers. "That really made me pay attention to just how few treatments are available for babies that have injury at birth, and how quickly it can happen to anybody."

The experience propelled Lee-Summers, a pediatric anesthesiologist at Johns Hopkins Children's Center, into the world of neonatal brain injury. The interest she already had in brain trauma research segued into the study of neonatal brain hypoxia, a major cause of lifetime disability that afflicts three to five children per 1,000 births.

Lee-Summers' goal? To develop more treatment options on top of the only current treatment: therapeutic hypothermia, in which cooling is used to reduce the brain's oxygen demand. While the therapy is effective, Lee-Summers notes, up to half of the babies who receive it suffer permanent neurologic disabilities. New treatments, she notes, may be found in the study of cell death mechanisms and cerebral autoregulation, the physiologic mechanism that maintains constant blood flow across the brain as blood pressure changes.

"If the brain is really injured, that mechanism is impaired," explains Lee-Summers.

In such circumstances, she notes, intensivists do have the capability to con-

66 I'm looking at therapeutic drugs to improve the way cells handle these stressors, reduce the risk that cells in the brain will die, and ultimately reduce the risk of stroke. 55

- JENNIFER LEE-SUMMERS

manipulating sedation and medicines to support the blood pressure. They can pick a goal blood pressure number, she says, but they do not know for certain what number will best support blood flow in a newborn baby's brain after a birth injury.

"In our lab," Lee-Summers says, "we are beginning to develop technology to do that."

Similarly, in a collaborative observational study, Lee-Summers and intensivists at Children's National in Washington, D.C., are correlating changes in cerebral blood pressure with changes in blood volume to determine how well the baby's autoregulation is performing and what blood pressure best supports it. The findings, Lee-Summers says, could lead to an interventional trial in which babies are randomized to that targeted ideal blood pressure or regular care.

Yet another aim is to determine when and how hypoxia injury occurs during pregnancy, and then model treatments to minimize that injury. "We know some of these babies can be injured during the pregnancy but we don't know exactly when," says Lee-Summers. "We're studying whether targeting blood pres-

after birth will reduce injury."

Another area of interest for Lee-Summers is how cells in the brain die and proteostasis, or how damaged proteins are regulated. After brain hypoxia, Lee-Summers explains, reperfusion brings back blood flow with oxygen radicals that can inflame and stress proteins in the endoplasmic reticulum.

"The function of the proteins depends upon their appropriate three dimensional configuration, but if they're damaged they do not fold properly. If the misfolded proteins are not cleared, this can cause a cell to die," says Lee-Summers. "I'm looking at therapeutic drugs to improve the way cells handle these stressors, reduce the risk that cells in the brain will die, and ultimately reduce the risk of stroke."

Lee-Summers believes multiple strategies are needed to address hypoxic brain injury in children.

"There's no single treatment that can fix this disease," she says. "Many, many approaches are needed to come together for these babies."



Finding Smarter Ways to Fight Antibiotic Resistance

By Christy Brownlee

PRANITA TAMMA WAS drawn into the field of infectious diseases when she was a medical student at the State University of New York at Brooklyn College of Medicine in the early 2000s. There, she imagined herself like Dr. Gregory House in the fictional television show, solving medical mysteries that puzzled even the most expert physicians. But during her residency in pediatrics at the Johns Hopkins University School of Medicine, she became intrigued by a different type of medical mystery: how to solve the growing problem of antibiotic resistance.

Tamma noticed child after child who had infections that nothing in the antibiotic arsenal could treat. These patients, many of whom had been perfectly well before, suddenly weren't and grew sicker as their doctors tried drug after drug. Many eventually succumbed to their illnesses. Even though new antibiotics are continually in development, many of those target organisms that current antibiotics can effectively treat.

"I became fascinated with this idea that there must be something new we could try with the antibiotics we already have available," she says. "Maybe we could administer them in different combinations, or administer them differently, giving them for longer periods of time of different doses. Or maybe we could be smarter about when to use antibiotics at all."

When Tamma became a fellow at Johns Hopkins, she started working to improve the hospital's antibiotic stewardship, practices that improve the appropriate use of antibiotics. She and her colleagues in the Division of Infectious Diseases worked to develop guidelines for physicians across Johns Hopkins Medicine about antibiotic use for a range of infectious processes, such as pneumonia or urinary tract infections. Which antibiotics to use, and when, can vary from patient to patient depending on their personal circumstances, Tamma explains. For example, it might be more appropriate to prescribe a broad-spectrum antibiotic for a child with cancer who gets a urinary tract infection than for an otherwise healthy child with the same condition.

Tamma joined the Johns Hopkins faculty in 2012. That same year, she launched Johns Hopkins' Pediatric Antimicrobial Stewardship Program, a broader effort that not only provides guidelines for physicians but also serves to educate trainees, providers, patients and patients' families on appropriate antibiotic use and periodically reviews charts of patients who are frequently prescribed these drugs—such as those with cystic fibrosis—to make sure they're receiving care that will reduce the chances of antibiotic resistance developing.

Their efforts are paying off, she says. "We've noticed that the durations of therapies have decreased and the use of very broad spectrum antibiotics has decreased," she says. "Resistance itself is trickier to measure, but we've seen signs that that's decreasing at our hospital

Tamma and her colleagues are also helping doctors use antibiotics more effectively through research to faster identify patients who have antibiotic resistant organisms. Right now, she explains, most hospital labs use a standard protocol that takes about 24 hours to identify which bacteria are causing an infection, and then another 24 hours to test the identified organism for antibiotic susceptibility using a standard panel of common drugs. When those fail, it takes additional time to find the right drug, if it even exists—a process that, Tamma says, many patients don't

In a study recently published in JAMA, she and her colleagues found that using whole genome sequencing could identify organisms and whether they harbor genes for antibiotic resistance more than 24 hours sooner than standard methodology—a timeframe that could save a significant number of patients.

"By finding new and different ways to attack infectious bacteria," Tamma says, "we're developing smarter and more effective ways to solve this problem of antibiotic resistance."

Just like Dr. House.



66 By finding new and different ways to attack infectious bacteria, we're developing smarter and more effective ways to solve this problem of antibiotic resistance. ""

- PRANITA TAMMA



PET Scans to Optimize Tuberculosis Meningitis Treatments

ALTHOUGH RELATIVELY RARE in the United States, and accounting for fewer than 5 percent of tuberculosis cases worldwide, TB of the brain—or tuberculosis meningitis (TBM)—is often deadly, always hard to treat, and a particular threat to young children. It may leave survivors with lifelong brain damage. Now, researchers report they have used PET scans, a rabbit model and a specially tagged version of the TB drug rifampin to advance physicians' understanding of this disease by showing precisely how little rifampin ever reaches the sites of TB infection in the brain (Science Translational Medicine, Dec. 5, 2018). "Really precise information has never been easy to come by for how much rifampin gets to any given patient where it's needed," says pediatric infectious disease specialist Sanjay "We've been able to use technology to find that long-needed information about this very troubling disease. "



information has never been easy to come by for how much rifampin gets to any given patient where it's needed.

- SANJAY JAIN

Distinguishing Child PolioLike Illness

RESEARCHERS HAVE ANALYZED patient data from 45 cases of what they thought was acute flaccid myelitis (AFM), the polio-like outbreak occurring in U.S. children, and realized that only 75 percent of diagnosed cases were AFM. The researchers say they hope that clearer diagnostic criteria identified in their study, published Nov. 30, 2018, in *JAMA Pediatrics*, will help patients receive the right treatment for their diagnosis.

Medication Management for Children with Asthma

JOHNS HOPKINS RESEARCHERS found that fewer than half of interviewed caregivers for Baltimore preschool children with asthma were prepared to administer medication for routine management or emergency response to a child's chronic condition (Pediatrics, Aug. 7, 2018). Noting that only 60 percent of the children had a rescue medication, researchers Kristin Riekert, Elizabeth Ruvalcaba, Cynthia Rand and Michelle Eakin suggest that assessment of medication availability be incorporated into the care of children with chronic conditions, and that there be interventions to improve medication management. 🜕

Liver Transplants Could Safely Help Sickest Children

Which of these variables could impact the outcomes from transplanting a split liver versus a whole liver could help guide the increased use of split livers and identify which patients will do best. "

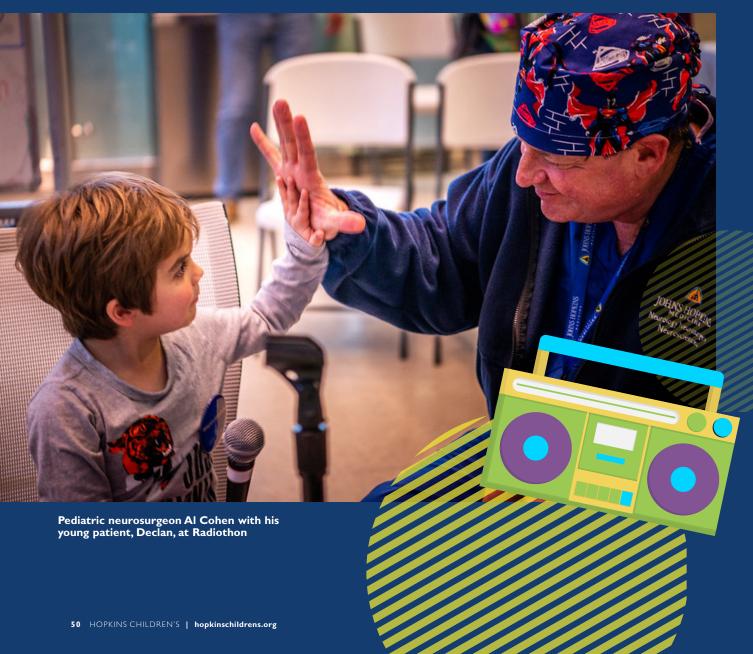
—DOUGLAS MOGUL

IN A REVIEW of registry data for more than 5,300 liver transplants performed in children nationwide, researchers identify the type of patient who is most likely to survive a split liver transplant receiving only part of a donor's liver with no additional long-term health risks, which could allow for an increase in the availability of organs (Liver Transplantation, December 2018). "We already knew from previous studies that variables including the donor's age and cause of death along with the health of the recipient can influence outcomes," says Douglas Mogul, medical director of the Pediatric Liver Transplant Program at Johns Hopkins Children Center. "But understanding which of these variables could impact the outcomes from transplanting a split liver versus a whole liver could help guide the increased use of split livers and identify which patients will do best after split or whole liver transplants, thereby being more strategic about matching donor organs with recipients."

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A Record-Breaker

Three Decades in the Making

By Amanda Leininger

MIX 106.5'S ANNUAL RADIOTHON HITS A \$1.3 MILLION HIGH FOR JOHNS HOPKINS CHILDREN'S CENTER PATIENTS AND THEIR FAMILIES

"What's it going to be? What's it going to be?" This question rang through everyone's minds as Johns Hopkins Children's Center patients one by one raised a poster with a single number over their heads. DJs from radio station Mix 106.5 read each number aloud and over the airwaves, accompanied by a chorus of volunteers, kids, donors and staff members in the hospital lobby. Everyone was on edge waiting for the final number that would reveal the dollar amount raised for Johns Hopkins Children's Center.

The undeniable energy, the laughter, the tears and the anticipation could only mean one thing: Another year of Mix 106.5's annual Radiothon was almost in the books. And this wasn't just any Radiothon—2019 marked the 30th year of the event.

As in years past, Mix 106.5 broadcast live from the Children's Center lobby for 27 hours over the two-day event. Children's Center patients, families and staff members shared their heartfelt stories on air with DJs Reagan Warfield, Bethany Linderman, Maria Dennis and Priestly. The DJs helped expertly convey the stories of hope and courage to listeners in Baltimore and beyond, urging them to call and donate.

Hundreds of volunteers joined Mix 106.5 over the two days to answer the phones—some decked out in

legwarmers, tutus and hair bows, a nod to the fashion that might have been seen at the first Radiothon.

Generous corporate sponsors matched donations during "power hours" and "triple matches," while some helped keep both the volunteers and radio station teams energized by donating meals (and caffeine!). Many of the donors and volunteers have personal connections to the Children's Center that inspire them to support Radiothon year after year.

"Radiothon is a chance for all of Maryland and beyond to come together and celebrate our kids and all of their potential. It's humbling and breathtaking to think about how many people have rallied together over the last 30 years," Warfield says. "From businesses and volunteers to the on-air staff and listeners, Radiothon truly brings out the best in Baltimore, and it's an honor to be a small part of it."

The feeling was echoed by Linderman—this was her first Radiothon, and it was the biggest yet, raising a record-breaking \$1,304,074 for the Children's Center, a Children's Miracle Network (CMN) hospital.

"As a newcomer, I am overwhelmed and thrilled by how generous our listeners' support is for Johns Hopkins Children's Center," Linderman says. "The audience really gets behind the kids and realizes what



As Radiothon 2019 closes, patients and family members reveal record-breaking donations for the annual event, which would later be updated to \$1,304,074.

a world-class institution we have in our own backyard."

The first ever—and longest running—CMN Hospitals Radiothon in the country, the event has raised more than \$23 million for the Children's Center to date. Over the past 30 years, these funds have helped support the areas of greatest need at the hospital and fund innovative faculty and staff driven initiatives that improve patient and family care.

"I cannot begin to calculate the true impact of Radiothon," says Redonda Miller, president of The Johns Hopkins Hospital. "Certainly, it has raised a significant amount of much needed money for the care of our youngest patients. But perhaps just as importantly, it has inspired our community to come together to support our patients and families, and it has highlighted the important role Johns Hopkins Children's Center plays in the care of children and teens in Baltimore. We are thankful to Mix 106.5 for its three decades of unwavering support and to all who have helped make Radiothon a success."



Save the date for Mix 106.5's 31st annual Radiothon, Feb. 20–21, 2020.

Mix 106.5 DJ Priestly with Radiothon ambassador Mo

We are thankful to Mix 106.5 for its three decades of unwavering support and to all who have helped make Radiothon a success.

- REDONDA MILLER PRESIDENT, THE JOHNS HOPKINS HOSPITAL



Reaching Out, Building Community Ties

By Andrew Myers

The greater Baltimore area is home to tens of thousands of children in low-income communities. Too often, many families do not get adequate medical care or information that could help these children lead healthier, happier lives. While the reasons for this gap are myriad, ranging from language barriers to simple lack of opportunities or access, the consequences are clear. Poverty has been associated with poorer health, greater school absenteeism and lower educational attainment.

Against that backdrop, Johns Hopkins Children's Center has joined forces with private donors to launch outreach programs designed to build ties to these underserved communities.

"Addressing socioeconomic or racial/ ethnic health disparities in our community is one of the most important missions of the Children's Center," says Tina Cheng, pediatrician-in-chief and co-director of the Children's Center.

In 2014, Cheng helped launch The Rales Center for the Integration of Health and Education, which works to reimagine school health programs to improve the health and educational outcomes of students in low-income communities. Funded by philanthropy—largely by The Norman R. Rales and Ruth Rales Foundation—its vision is that good health leads to academic achievement



KIPPster Chloe Spencer with Rales Center Medical Director Kate Connor

and lifelong successes.

The Rales Center established a school-based health clinic at KIPP Baltimore—which boasts more than 1,500 students at two schools—staffed by a doctor, a nurse practitioner, nurses, a medical assistant and a family advocate, explains Sara Johnson, a population health expert who helps design programs at KIPP, which stands for Knowledge Is Power Program. But it's more than a clinic. The program partners with KIPP Baltimore to provide everything from health education, vision screening and optometry, and social and emotional learning programs in classrooms.

"We hope that the program at KIPP can be a model for other programs in Baltimore and beyond," Johnson says. "We're trying lots of things to see what works best."

One particular focus has been on asthma, which is a leading cause of absenteeism. The Rales team does checkups, administers medicine and offers guidance on managing the disease. The results? Reduced absenteeism and emergency room visits.

"It's really a wellness program," Johnson says. "We treat the whole child, so they can do their best in school."

Meanwhile, in another part of town, Sarah Polk, assistant professor of pediatrics, runs the Center for Salud/Health (Centro SOL), a multidisciplinary health center specifically for the Latino community.

Like the KIPP program, Centro SOL is more than a medical clinic, offering programs like a summer camp and free workout classes every Saturday to improve physical fitness. There's even a summer internship program for bilingual high school students to introduce them to career opportunities in the medical profession.

Clinical care is important, but clinicians are limited in how much they can accomplish from the exam room alone, Polk says. It is this multifaceted approach of Centro SOL's programs that sets it apart and has helped make inroads in an otherwise underserved community—programs that would not be possible without integral support from donors like the Aaron and Lillie Straus Foundation and Leonard and Helen R. Stulman Charitable Foundation.

"We are grateful for the support of these foundations that allows us to address the needs of underserved children, adolescents and families in our community," Cheng says. "I am proud of the Rales Center and Centro SOL, which develop and evaluate innovative models of care to make sure that children thrive."



For more information on how you can support community outreach efforts, please email hopkinschildrens@jhmi.edu.

A Serendipitous Collaboration in Care

By Karen Blum

CALL IT SERENDIPITY that brought Johns Hopkins physicians Shameema Sikder and Priya Sekar together a few years ago at a leadership forum for junior faculty. They not only became friends, but last year, they worked together to save Sikder's son.

Sikder's then 3-year-old son, Yusef, had what seemed like a routine cold with a high fever; at one point, his eyes looked red. Yusef seemed to get better, but the following week he developed a rash and his hands and feet started peeling.

At that point Sikder, director of the Center of Excellence for Ophthalmic Surgical Education and Training (OphSET) at the Wilmer Eye Institute at Johns Hopkins, reached back out to her pediatrician. "I told her it's probably nothing, but I did remember seeing a

rare case of Kawasaki syndrome when I was a resident at Johns Hopkins 10 years ago. One of the hallmarks is high fevers, and you also can have red eyes, which is why I was consulted on that case."

The disease, in which blood vessels throughout the body can become inflamed, can affect the coronary arteries supplying the heart, causing irreversible damage. She also called Sekar, a pediatric cardiologist, for advice. The pediatrician referred them to a local cardiologist for an echocardiogram (an idea supported by Sekar), which revealed Yusef had four aneurysms, one of them giant, around his heart.

Sikder again called Sekar, who recommended bringing Yusef to Johns Hopkins Children's Center immediately. Late on a Friday afternoon before a long weekend, Sekar pulled together her oncall team to form a plan and consulted cardiology treatment guidelines, as Yusef was outside the standard window for treatment within 10 days of fever.

"I was quite worried when I met them," Sekar says. "Having Kawasaki syndrome and coronary artery aneurysms puts you in a very small percentage of children with the condition and poses greater challenges in treatment." In these patients, Sekar noted, lesions may persist and require ongoing management and, in some cases, cardiac interventions after the acute illness has resolved.

Sekar admitted Yusef to the hospital and recommended treatment with intravenous immunoglobulin, a mixture of antibodies used to fight infection. Five days later, he went home.

"I can confidently say that treatment basically changed the course of Yusef's disease for the better," says Sikder, "because over the coming months, his aneurysms continued to improve." Yusef now has just one aneurysm, significantly smaller in size. He is back to playing with his twin sister, toy cars and planes, but still needs periodic monitoring for his heart.

As a Johns Hopkins faculty member, Sikder well understands the power of philanthropy. So, in appreciation for Yusef's care, Sikder and her husband made a gift to support Sekar's faculty development and help promote her research.

"We are just so grateful to Johns Hopkins, to the Children's Center, to the entire team that took care of Yusef when he was in the hospital, and particularly to Dr. Sekar, who went above and beyond and really altered our family's history by allowing Yusef to now have a healthy life," Sikder says.

"I feel like it's a win-win," adds Sekar. "I feel so grateful to be acknowledged by Shameema, but it's also a privilege to be able to help a friend and colleague when I could."

At left, pediatric cardiologist Priya Sekar with her young patient, Yusef, and his mother, ophthalmologist Shameema Sikder.



A Family's Heartfelt Appreciation

Upon landing at Dulles Airport in Northern Virginia in 2007, Phil and Meri Gibbs of Annapolis were deeply concerned. With them was their newly-adopted 11-monthold baby Mathilde ("Tilly"), who was born with a form of congenital heart disease called tricuspid atresia. The next day they called Johns Hopkins pediatric cardiologist Joel Brenner, who quickly fit them into his clinic for an evaluation and began to manage Tilly's care over a decade.

With tricuspid atresia, Brenner explained, the blood flow from the heart to the body is low in oxygen, resulting in the bluish skin discoloration called cyanosis. Tilly had two heart operations in Korea designed to improve her coronary blood flow. At Johns Hopkins at age 3, Tilly had a third operation that allowed near normal oxygen levels to be achieved.

During Tilly's postoperative visit, Phil Gibbs approached Brenner about making a gift to help other patients like her. After further discussion, the Gibbs family decided to establish the Mathilde Lilly Chae-rin Gibbs Endowment Fund, which helps support nurse practitioner Kathleen Byrne, who manages young adults with congenital heart disease.

"There's a lot of work that goes into caring for kids with complex heart disease who thankfully are living longer into adulthood," says Brenner, Emeritus Director of the Helen B. Taussig Congenital Heart Center at Johns Hopkins. This includes tasks not reimbursed by insurance like coordinating care with child life specialists, helping patients cope with difficult medical issues and finding family resources for them. "The Gibbs' support is the type that's really critical to carry out our mission—to take optimal care of patients."

"The way that Dr. Brenner, and everybody at Johns Hopkins, took care of us inspired us to do something that would have an impact," says Phil, president and co-founder of Hamel Builders, Inc. Observing other families in the pediatric intensive care unit after Tilly's operation, he says, "You just felt like if you could do something to make their stay or their care



The family of Tilly Gibbs, here with pediatric cardiologist Joel Brenner, established an endowment fund in her name to support patients with congenital heart disease.

easier, or more manageable, it would be impactful. I wanted to contribute toward sustaining services and people."

Today, Tilly is a happy and healthy 12 year old, who sees Brenner every September for a routine check-up. She enjoys fishing, arts and crafts, and playing with her dogs Stella, Olive and Milkdud. She also loves being part of a large family with four siblings JoAnna, Eli, Joshua and John. "Dr. Brenner is really nice," Tilly says, "and I appreciate that he helped fix my heart." Her parents appreciate that Brenner makes his exam and questions child-centered, empowering Tilly.

The Gibbs have a passion for helping others and a growing interest in supporting essential services for patient care which is not reimbursed by insurance. The Gibbs also hope to someday establish a fund to support Brenner's legacy in pediatric cardiology. Aware that he stepped down as division director in 2018, the family wishes to acknowledge his commitment to excellence in research, education and compassionate patient care, hoping the example will always be remembered. —*KB*

The way that Dr. Brenner and everybody at Hopkins took care of us inspired us to do something that would have an impact. ??

- PHIL GIBBS

Camp All Stars Lets Kids be Kids

HAVING KIDNEY DISEASE can be a lonely existence for a kid. The continuous demands of medications and procedures make things hard, but the Harriet Lane Kidney Center, part of the Division of Pediatric Nephrology at the Johns Hopkins Children's Center, has devised a clever and fun way to help those kids feel not-so on their own for at least a little while. It's called Camp All Stars.

First started in 2003, Camp All Stars is a two-day overnight camp specifically designed for children and young adults ages 10 to 21 who have chronic kidney disease, are on dialysis, or have had kidney transplants. The older campers, ages 18-21, serve as leaders and mentors to the younger campers. Activities at the camp, held at the YMCA's Camp Letts near Annapolis, include archery, arts and crafts, canoeing, horseback riding and scavenger hunts. The real purpose behind Camp All Stars, however, is to just let kids be kids and get their minds off their worries and commune with friends.

"We want the kids to have fun and meet others like themselves," says Shirl Wood, camp director. "It's about coming together to be together and not thinking about their disease."

The camp is funded in large part by the board of the Harriett Lane Home Foundation, whose support over the years has been extraordinary, Woods says. The camp is also supported by the Joy in Childhood Foundation.

"Without the philanthropic support of donors, such as the Harriet Lane Home Foundation and the Joy in Childhood Foundation, we simply would not be able to provide this meaningful program to our patients," says Wood. "We are extremely grateful."

The Harriet Lane Home Foundation also supports the Children's Center's palliative care program and other initiatives in

It's about coming together to be together and not thinking about their disease. "

- SHIRLWOOD

the Division of Pediatric Nephrology, including a transplant reunion, the RENEW Clinic for patients with obesity related hypertension, and research by pediatric nephrologists Cozumel Pruette, Olga Charnaya and Meredith Atkinson, among others.

The camp is staffed by a fully trained medical team to help the kids with anything they might need medically speaking, from hooking up dialysis to dispensing medications. "Nurse Barbara" is a favorite to thirteen-year-old Kaylee Townsley, who just completed her third (or fourth, she can't remember) camp last summer. She brags of all the fun times she has had at Camp All Stars.

"I just really, really love it," Kaylee says in a happy, rapid-fire voice only a teen could muster. "There's all these fun things to do and the food delicious and healthy. And then, at the end, you get a medal and a t-shirt!"

Camp All Stars has proven so successful that many campers return after they are too old to attend to serve as counselors to new generations of All Stars. —AM







Celebrating Chicken Palooza at Johns Hopkins Children's Center, from left to right, Cynthia Palacz, Sue Mead, Patrice Brylske, John Kemp, Shelby Kemp and Breahna Brown.

Royal Farms Chicken Palooza:

Cluck for a Buck

FYOU HAVE MADE a purchase at a Royal Farms location in the last 26 years, chances are you've seen a coin canister sitting on the check-out counter. Even if not, it was probably there. That's because for more than a quarter century, Royal Farms has fundraised—pennies at a time—for Johns Hopkins Children's Center through year-round coin canisters in their approximately 200 locations.

While Royal Farms supports other charities, Johns Hopkins Childrens Children's Center is its largest beneficiary—receiving nearly \$2 million in donations to date. Royal Farms leadership felt the Children's Center was the "perfect fit," because like Royal Farms it is rooted in Baltimore but serves a broader community.

A long-time Radiothon sponsor, in 2018 Royal Farms wanted to do more. The chain launched its first-ever

Chicken Palooza, a celebration of its world-famous chicken where customers also had a chance to win chicken for a year. Royal Farms also wanted to use this opportunity to give back to the communitary by donating ten cents from every \$5 chicken box sold during the twomonth event to the Children's Center. That idea excited both customers and employees alike.

"It feels good to be part of a company that gives back to our community and allows our customers the opportunity to do the same," says Stephanie Johns, a district leader for Royal Farms who oversees numerous locations in the Baltimore area.

A few months later, Royal Farms CEO John Kemp, project manager Shelby Kemp and public relations and marketing associate Breahna Brown presented a check for the total amount raised through Chicken Palooza 2018 at

the hospital: an impressive \$100,000. If that wasn't enough, they also brought lunch for the patients and families at the Children's Center that day—a huge hit!

"When Shelby called to tell me how much they raised, I think I cried," says Cynthia Palacz, senior associate director of development. "The fact that that our community has the power to raise that amount pennies at a time in just two months is inspiring. We're so thankful to Royal Farms for its unwavering support of our hospital."

John Kemp adds, "We are very proud to partner with Johns Hopkins Children's Center. Their excellent national reputation continues to impress us year after year. Our customers and employees rallied together during Chicken Palooza 2018 for the Children's Center. We're looking forward to see what Chicken Palooza 2019 has in store!" – AL



Save the dates for Royal Farms Second Annual Chicken Palooza: July 1 – Aug. 30, 2019.

Honors & Awards



Former Johns Hopkins Pediatric **Resident Named Baltimore Health Commissioner**

Former Harriet Lane resident Letitia Dzirasa will serve as Baltimore's next health commissioner. "Dr. Dzirasa, who distinguished herself as a superb pediatrician and critical thinker here at Johns Hopkins Children's Center, embodies all that we hope for in a Harriet Lane alum," says former pediatric residency director Janet Serwint. "She is a compassionate, holistic-minded pediatrician who engages the entire family in caring for patients, and she will bring all of these attributes to her position as Baltimore Health Commissioner."

Peter J. Mogayzel, Jr., has been appointed the Director of the Eudowood Division of Respiratory Sciences after serving as the Interim Director for the past 2 years. His clinical expertise is the treatment of cystic fibrosis; research interests include the regulatory properties of the CFTR gene, mucociliary clearance and development of new therapeutics for cystic fibrosis. He has served as the Director of the Johns Hopkins Cystic Fibrosis Center since 2002.



Aaron Milstone received the Society for Healthcare Epidemiology of America Mentor Scholar Award, which recognizes individuals

for their dedication and excellence in mentoring trainees in infection prevention and control.



Pediatric emergency medicine physician Karen Schneider received the JHM Martin Luther King Jr Award for Community Service. Since 2003, she has taken

pediatric residents on over 64 mission trips to multiple international locations serving thousands of children.

John Gearhart, Jeffs Professor and Chief of Pediatric Urology at Johns Hopkins, has been awarded the Stortz Distinguished lectureship by the British Association of Paedaitric Surgery.



Emily Boss, an associate professor of otolaryngology head and neck surgery, is among 32 early-career faculty members who were selected to

receive 2018 Johns Hopkins Catalyst Awards, an honor that is accompanied by a \$75,000 grant, mentoring opportunities, and institutional recognition.



Tina Cheng, pediatrician in chief and co-director of Johns Hopkins Children's Center, has been named one of the Maryland Daily Record's

Most Influential Marylanders for her dedication and commitment to children's health.



Lauren Jansson, associate professor of pediatrics, has been awarded \$3 million over a five-year period from the National Institutes of

Health and the National Institute on Drug Abuse for research titled "Maternal buprenorphine-naloxone treatment in the perinatal period: Fetal and infant effects." The goal of the study is to explore the effects of buprenorphine-naloxone, a medication used to treat opioid dependency during pregnancy, by evaluating maternal and fetal physiology in the second half of pregnancy.



Paul Sponseller, chief of the Division of Pediatric Orthopaedics at Johns Hopkins, has been named vice president of the Scoliosis Research So-

ciety, an international organization committed to research and education in the field of spinal deformities. Membership includes more than 1,000 of the world's leading spine surgeons, researchers, physician assistants and orthotists who are involved in research and treatment of spinal deformities.



David Hackam, surgeon-in-chief and co-director of Johns Hopkins Children's Center, has been named chair of the Research Committee of

the American Pediatric Surgical Association. Hackam says his goal is to increase the pipeline of surgeon-scientists performing research to benefit children, with a focus on attracting under-represented minorities and women to the field.



Allison Baker,

New Senior Director of Development

IN JANUARY, JOHNS Hopkins Children's Center welcomed Allison Baker as its new Senior Director of Development. While new to the Children's Center, Baker is no stranger to Johns Hopkins. She first joined Johns Hopkins Development and Alumni Relations (DAR) in 2005 as part of the Whiting School of Engineering team.

As the Senior Director of Development, Baker leads the development team's overall vision and strategy and works directly with Children's Center Co-Directors Tina Cheng and David Hackam to determine fundraising priorities and secure philanthropic support on major and principal gift levels.

Baker will also lead efforts to steward donors who supported the Children's Center's successful \$110 million campaign, which concluded in June 2018. As plans for the next campaign begin, she will play a vital role in determining funding needs, goals and objectives for the Children's Center.

During Baker's 13 years with the Whiting School, she was responsible for many of their fundraising successes. Between Baker's roles as a gift officer and director, she was integral in creating a foundation relations program for the school and increasing support for faculty. In her most recent position, Baker managed and led the Whiting's School's major gifts, stew-

ardship, operations, and annual giving pro-

grams. Personally raising \$35 million of the Whiting School's \$275 million dollar goal, Baker has been instrumental in the execution and success of Johns Hopkins' Rising to the Challenge campaign.

Before coming to Johns Hopkins, Baker served in fundraising roles for the American Foundation for Urologic Disease, the Baltimore International College and Bon Secours of Maryland Health System. -*AL*

Upcoming Fundraising Events and Campaigns

Please support Johns Hopkins Children's Center at upcoming events or corporate campaigns, where retail locations raise funds on the Children's Center's behalf. If you would like to know more or help with any of the events below, please email hopkinschildrens@jhmi.edu.*

MAY

- 1-31 Costco Campaign
- 6-12 Dunkin' Donuts Iced Coffee Days
- 6-26 Wawa Campaign

JUNE

- 1-July 25 Dairy Queen Campaign
- 1 Colleen's Biliary Atresia 5K and I-Mile Fun Run/Walk
- 3 Griffith Energy Services, Inc. 24th Annual Golf Tournament
- 7 TowerCares Foundation 37th Annual Tower Classic Golf Tournament
- 10-July 7 Walmart Campaign
- 14 22nd Annual Zachary Meehan Memorial Golf Tournament
- 23-July 6 Giant Food Stores Campaign
- 24 Courtney Quinn Memorial Rock and Roll Swim Meet
- 24 Hayden's Heart Heroes 14th Annual Golf Tournament

JULY

- June 10-July 7 Walmart Campaign
- June 23-July 6 Giant Food Stores Campaign
- 1-July 25 Dairy Queen Campaign
- 1-Aug. 30 Royal Farms Chicken Palooza
- 12 Elkridge Furnace Inn's Bastille Day Wine Tasting
- 22 Cameron Diamond Memorial Swim Meet
- 25 Dairy Queen Miracle Treat Day

AUGUST

- July 1-Aug. 30 Royal Farms Chicken Palooza
- 2-4 Ace Hardware Bucket Campaign
- 27-Sept. 23 Walmart Campaign

SEPTEMBER

- 9 26th Annual Ledo Pizza Golf Classic
- 9 Doug Miller Sr. Memorial Golf Invitational Hosted by Carroll Independent Fuel

OCTOBER

- 1-31 Edwards Landing Light Show, Halloween Edition
- 7 Xavier Francis Byrd Golf Tournament
- 11 The Kendall Burrows Foundation 6th Annual Footloose Gala
- 19 Baltimore Running Festival

NOVEMBER

- 2 Extra Life Gaming Marathon
- 16 Baltimore Boogie Dance Marathon
- 10-23 Giant Food Stores Campaign
- 29-Dec. 25 Ace Hardware Round Up Campaign

DECEMBER

- Nov. 29-Dec. 25 Ace Hardware Round Up Campaign
- 1-25 Edwards Landing Light Show, Holiday Edition
- 3 Giving Tuesday

JANUARY 2020

28 Motility Gala

FEBRUARY 2020

- 17 One Skate for Many Hearts
- 20-21 31st 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.





Artist in residence Sarah Wright, left, helps parents brush away the anxieties that come with a child's hospitalization.

Giving Parents Doses of Resiliency

AS PARENTS, WE always put our children's needs before our own, especially when they are sick and in the hospital. We do it without thinking. However, we forget about the basics for ourselves—like sleep, food and self-care. An instructive analogy comes to mind: On an airplane, the flight attendant stresses that in an emergency we need to put on our oxygen masks first before tending to the child next to us. It is hard for parents to care for their children if they are not doing so for themselves.

Thanks to a Radiothon grant, Johns Hopkins Children's Center is helping parents do just that through a pilot program at the Grace Rea Garrett Children's Library and Mr. & Mrs. G. Lloyd Bunting Sr. Family Resource Center. Families are offered free self-care through yoga, art projects, chair massages, guided meditation and a hot meal—simple things we take for granted, yet a much-needed respite from a hospital bedside.

The program offers a place or activity to help unwind—even if only for a few minutes—and to let go of the emotional stress of caring for a critically ill child. A dose of resiliency and compassion during the hardest times, according to parents' responses, goes a long way.

"We were able to enjoy a lasagna dinner after spending long hours in our daughter's hospital room. These pick-me-ups keep us going," says one parent. Another says, "In the middle of my darkest days, a child life specialist sought me out and extended an invitation for a massage. Being touched, feeling and connecting with my own body, gave me such strength."

There will always be a need for such valuable resources, and we greatly appreciate any support. To learn more, or to suggest ideas for how we can help parents and families ease their stress and build resilience, please e-mail us at familysupport@jhmi.edu.

Thank you. 🤨



by Sue Mead, Parent Advisor

Help Hopkins Kids

Like to run?

Team Hopkins Kids

Run for Johns Hopkins Children's Center at the Baltimore Running Festival

October 19, 2019

Keep the fun going at the best post-race tent on Rash Field

Register: support.hopkinschildrens.org/run





Like to dance?

Baltimore BOOGLE

Boogie on down to the Johns Hopkins Children's Center dance marathon

November 16, 2019

Break out your favorite dance moves while enjoying music, games and more

Register: support.hopkinschildrens.org/baltimoreboogie

For more information or to start your own event, please contact the Development Office at 410-361-6493 or email hopkinschildrens@jhmi.edu.





Hopkins Children's
Office of Communications & Public Affairs
901 S. Bond Street / Suite 550
Baltimore, MD 21231

The Charlotte R. Bloomberg Children's Center

- Opened in 2012
- 205 private rooms with sleeping accommodations for parents
- Acoustical ceiling tiles and rubber flooring help create a quiet healing environment
- Supersized sculptures and literary themed art distract from the hospital experience
- Family amenities like on-demand meals, family lounges and multiple play rooms
- Expanded, easy-to-access
 Pediatric Emergency
 Department

- Dedicated pediatric trauma bays
- 40-bed Pediatric ICU
- 45-bed Neonatal ICU
- 10 state-of-the-art pediatric surgical suites

