Immigrant Family Health **p. 8** // Cardiac Long Haulers **p. 22**

hopkinschildren's

SPRING 2024

The Johns Hopkins Children's Center Magazine

5 traits that make our pediatric emergency medicine doctors so good at what they do.

Stamina, Empathy and More …STAT!

SPRING PALETTE
Through the Arts in Health program at Johns Hopkins Children's Center, 14-year-old Kirsten painted a vase of flowers to brighten up her hospital room. She explored different watercolor techniques — some she knew and some she created herself.

SPRING 2024

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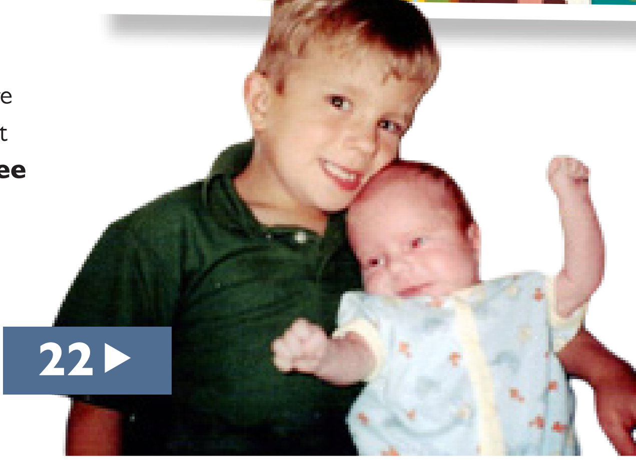

Cover photo by Jennifer Bishop
Pictured (l to r): Kate Deanehan, Leticia Ryan, Raquel Millet

DIRECTORS' LETTER


ILLUSTRATION BY MATTHEW COOK

This issue's cover story (p. 16) aptly describes the traits that make our pediatric emergency doctors so effective. Arguably, those very same traits are crucial for clinicians in every other pediatric specialty, from adolescent medicine to pulmonology.

That said, we believe that one of the skills highlighted in "… STAT!" is particularly crucial for pediatric clinicians serving young patients and their families: That skill, which is admittedly in short supply these days throughout much of our society, is empathy.

As doctors who have devoted our careers to pediatrics, we've experienced firsthand the power of empathy — of being finely tuned in to the feelings and emotions of our young patients and their caregivers as they grapple with difficult diagnoses, potentially painful treatments and sometimes uncertain outcomes. Fear, disbelief, anxiety, sadness — as well as optimism, determination and hope — are all part of the palette of emotions that greet us each day as we make our rounds.

In response, all of us at Johns Hopkins Children's Center aim to model the skills that exemplify empathy. We listen actively and we do all that we can to understand and experience the emotions and perspectives of those we are caring for, both patients and their families. Not only is demonstrating empathy the right thing to do as human beings; we know that it results in better outcomes for our patients. Studies have found that patients who rate their doctors as having higher empathy are able to connect with them better — and thus are more apt to adhere to their treatments and to experience greater control of their symptoms.

Simply put, empathetic clinicians are the cornerstones of good medicine.

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Co-Director and Pediatrician-in-Chief, Johns Hopkins Children's Center

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JOHNS HOPKINS
CHILDREN'S CENTER

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Improving Heart Surgery with 3D Printing

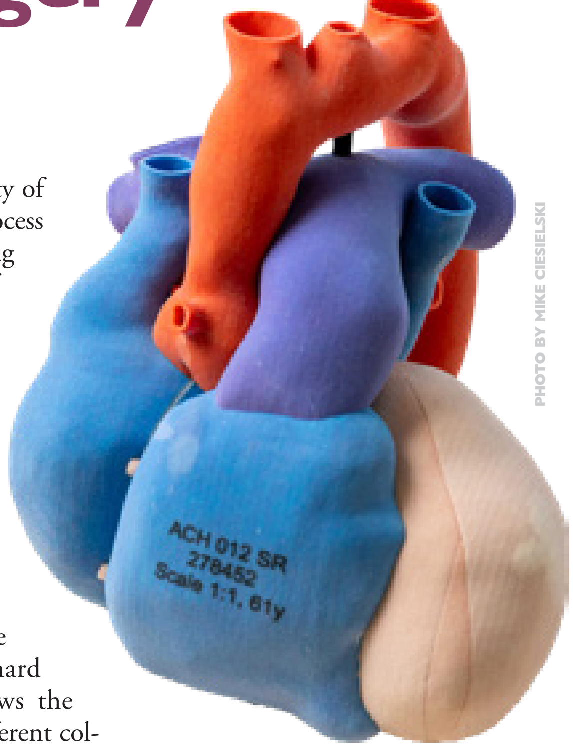

PHOTO BY MIKE CIESIELSKI

When pediatric interventional cardiologist JOHN THOMSON was planning a recent procedure for a patient with congenital heart disease, he made use of a 3D-printed plastic model of that patient's heart. By holding and turning this replica of the patient's complex anatomy, Thomson was able to study the heart's blood vessels up close and determine what type of stent would be needed to fix the problem — where blood was being diverted from the heart into a lung artery.

"It allowed me to almost re-create the intervention and fit a stent in there to work out how we could do things — and if it was doable," Thomson says. "Indeed it was, and we managed to get him successfully treated with a good result."

It's just one example of how Thomson and others at the Johns Hopkins Children's Center have been employing the heart models for some patients.

The surgeons says the models help ensure that they have all needed materials before starting an operation and make them more confident of what they can achieve through surgery when they counsel families during preoperative visits.

Just as people use GPS navigation systems to direct where they're going, the 3D models provide an added depth perspective helpful to devising procedures for patients with particularly unique or complicated anatomy, explains pediatric cardiologist **SRUTI RAO**, who oversees MRI and CT imaging that is used to construct the models. "In reality, we see everything in 3D, but most of our imaging techniques are usually 2D," she says. "We have to reconstruct that 3D part in our head."

Rao is part of a multidisciplinary team involved in the printing efforts, with engineers and colleagues including **STACY FISHER**, director of the Adult Congenital Heart Disease Center; **JUAN GARCIA**, from the Department of Art as Applied to Medicine; and radiologist Jeff Hirsch from the University of Maryland. The process involves translating cross-sections of images into precise dimensions for the 3D printer. That part can take as many as 15 hours; the printing itself adds another 10–15 hours.

Models can be printed from a hard resin, which allows the team to assign different colors to different parts of the heart or use silicone to make a pliable, clear model through which cardiac specialists can practice routing a patch or inserting a catheter. In some cases, Thomson and Fisher say, it allows experts to plan procedures using a catheter that previously could only be done in the operating room. Because newborn babies' hearts are so tiny, the team can create models scaled 1.5 to two times larger for study.

The models also go far in helping families better understand their children's heart conditions to make educated choices about their care, Fisher says. "We are hoping in the future to be able to offer that experience in the virtual reality environment, where we could take somebody inside a model of their own heart and actually experience their anatomy and understand what would need to be done to make it whole or to improve it." ***KAREN BLUM***

A Radiothon to Remember

Thanks to generous donations from listeners and others, the 35th annual Mix 106.5 radiothon raised $1,453,157.35 for Johns Hopkins Children's Center. The final total from the event was announced on the radio on Monday, March 4. During the event, DJs from the station broadcast live from the Children's Center for 26 hours over two days.

Funds raised during the annual two-day event help the Children's Center purchase vital tools and technology, fund important research and develop innovative equipment and programs, as well as provide patients with books, toys, games, art supplies and more.

For a Baby Born with Brain Cancer, Everything Had to Go Right

When 3-week-old Julian Letchworth arrived at Johns Hopkins Children's Center's emergency department on a Saturday in August, his prognosis was beyond dire. Emergency brain surgery might save his life — temporarily — if he survived the procedure.

"I remember having a discussion with his mother, telling her that it was a bad situation and we would do our best," says neurosurgeon **ERIC JACKSON**, who operated on the tiny baby that day.

Julian had been diagnosed with bleeding in his brain, likely caused by a tumor. The goal of the surgery was to remove blood clots, control the bleeding and stabilize him.

Brain surgery on a 3-week-old baby is uncommon and incredibly risky, partly because immature brains bleed more than adult ones, and such a small person can't afford to lose much blood, explains Jackson, who primarily operates on children but rarely ones that young.

Julian survived the four-hour surgery, but a biopsy confirmed the newborn had brain cancer, specifically an aggressive cancer: high grade glioma. His condition was rare. Johns Hopkins pediatric oncologist **ERIC RAABE** says he may see 40 to 50 patients each year with pediatric tumors, but maybe just one with a cancer that developed in utero.

Eric Jackson, Sarah Watt, Eric Raabe

He and fellow Johns Hopkins pediatric oncologist **SARAH WATT** solemnly broke the news to Julian's parents, Emily and Jordan, who live in Elkridge, Maryland. The doctors explained that the tumor was aggressive and would re-grow after the surgery. They suggested palliative and hospice care to help manage the symptoms caused by the tumor and potential treatment.

A few days later, after reviewing the tumor's appearance with pathologists, the oncology team proposed a chemotherapy regimen.

Emily and Jordan's emotions were almost beyond comprehension. "We had to make the decision to go into treatment knowing there was a possibility he wasn't going to make it," says Emily.

That was more than three years ago. Today, Julian is a sturdy, impish toddler who greets new friends with an enthusiastic, "Hi," punctuated by a grin that lights up his face. The cancer is gone.

He is receiving help to overcome some speech delays, but "he's somebody who

> “[Julian] got a clear scan and it started to sink in that **we had turned a corner.**”
>
> —EMILY LETCHWORTH

has the capacity to have an almost complete recovery,” says Raabe. He is the rare child who enters and leaves hospice care.

Julian started chemotherapy when he was 7 weeks old, and continued it for a year. Based on regimens that were known to work for children with aggressive brain tumors who are less than a year old, Raabe and Watt devised a custom regimen for Julian that alternated between cycles of cyclophosphamide/vincristine and carboplatin/temozolomide/vincristine. Switching between regimens would keep the cancer off balance, Raabe explains.

The medications were administered through a central line once per month. Each time, Julian stayed in the hospital for five days or so to monitor for infections while his white blood cell count dropped. During his first 13 months of life, Julian spent 97 nights in the hospital, says Emily.

And, though he had every reason not to, Julian smiled a lot. “He tolerated chemo really well and tolerated the central line really well,” says Watt, a research and clinical fellow in pediatric oncology.

When Julian was 7 months old, Jackson again operated, this time to remove the remains of the chemo-shrunken tumor. When pathologists looked under the microscope, they saw a tumor that was mostly dead, Raabe says, noting, “This was very encouraging and led us to continue with the therapy to make sure we kept the pressure on any surviving tumor cells.”

Julian finished chemo when he was 13 months old, and in March 2022, “they got a clear scan and it started to sink in that we had turned a corner,” says Emily.

These days, Julian gets checked every six months. He will eventually have surgery to replace a missing piece of his skull. He still takes anti-seizure medication because of the risks posed by the tumor location and surgery, but he hasn’t had a seizure in years and is being weaned off the medicine.

“If you saw him at the playground, you might say he doesn’t have as many words as some his age, but he’s talking and he’s going to catch up,” says Raabe. **KAREN NITKIN**

A ‘Greener’ Approach to Anesthesiology

NICK DALESIO, director of pediatric anesthesia clinical operations, is on a mission “to significantly reduce the environmental impact of waste that’s coming from the operating rooms at Johns Hopkins Children’s Center,” he says, noting that waste generated by ORs constitutes 20–33% of hospital refuse.

He has undertaken several initiatives, including recycling foam pads used to position pediatric patients for surgery. In a one-month pilot, his group collected 50 pounds of foam — enough to fill two giant tipster bins. The waste is being sent to a company that turns the foam into carpet padding.

He’s also leading efforts to embrace more reusable products, including reusable gel-filled rings to position patients’ heads during surgery, which can be sanitized and better maintain their shape than foam. And he’s launched a one-year trial to recycle the handles and blades of laryngoscopes, used to insert breathing tubes. So far, his team has shipped out seven full bins of the parts. “Each bin weighs about 50 pounds,” Dalesio says. “It’s a lot of weight of metal and batteries that are getting diverted from our regular waste into recycling.”

In the anesthesia realm, Dalesio joined an international consortium of pediatric hospitals, Project SPRUCE, that aims to achieve a 50% or greater reduction in emissions from anesthetic gases while ensuring, he says, “that patient safety is not sacrificed.”

As part of that effort, he removed the general anesthetic desflurane (which has a significantly higher — 2,450 times — global warming potential than carbon dioxide) from the pediatric ORs at the Children’s Center, the Johns Hopkins Outpatient Center and the Ambulatory Surgery Center at Green Spring Station.

He also is promoting more judicious use of nitrous oxide, which remains in the atmosphere for more than 100 years. By altering settings in anesthesia vaporizers to lower fresh gas flow and instituting an alert 15 minutes after starting anesthesia to remind clinicians to continue that practice, he’s found anesthesiologists are reducing the use and waste of these agents.

To achieve further environmental impact, Dalesio is aiming to abandon central pipes supplying the gas in favor of self-contained tanks that avoid pressure release into the atmosphere. **KAREN BLUM**

How the Hall Sisters Found Their Swing

When Hope Hall was 4 and her sister Alana was 2, therapists at the Kennedy Krieger Institute suggested they find ways to improve their eye-hand coordination and grip strength. So, their father, Marvin Hall, bought a toy golf set that changed their lives.

Both girls were born prematurely, with Hope weighing just 1.4 pounds and Alana 2.1, and they spent their first months in the neonatal intensive care unit (NICU) at The Johns Hopkins Hospital. After each baby left the NICU, the Owings Mills family continued care at Johns Hopkins through a clinic at the Kennedy Krieger Institute.

Now, Hope is a sophomore at Dartmouth College and the only Black woman currently playing golf for an Ivy League team. Alana, a similarly accomplished golfer and student, is committed to play on the women's golf team at Lehigh University in the fall.

"Once we knew we were going to have high-risk pregnancies, we immediately thought of Johns Hopkins," says their mother, Pamela Hall, who developed gestational hypertension and preeclampsia during both pregnancies.

While carrying Hope, Pamela's ankles became noticeably swollen at 27 weeks — a sign that her blood pressure was spiking. She went to The Johns Hopkins Hospital, where Hope was born a week later, on Dec. 5, 2004. "Everyone there was calm and clear on a plan, which made it that much better, because it was a scary time for us," Pamela says.

Healthy survival of babies who are premature isn't unusual, but the Hall sisters stand out for their journey from tiny preemies to athletic and academic superstars.

Like many newborns who are premature, Hope faced one challenge after another in her first days. "Each week we had to battle something," Pamela says. "We did so in the great care of that team. First, it was all about her lungs and jaundice. Then it was about her intestines."

Every concern was confronted and surmounted, and after

three months, Hope, weighing just 4 pounds, went home. The family returned to the Johns Hopkins NICU when Alana was born nearly two years later, on Oct. 16, 2006, weighing a relatively robust 2.1 pounds and requiring a month in the NICU.

Pediatricians such as neonatologists **LAWRENCE NOGEE** and **FRANCES NORTHINGTON**, who both joined the Johns Hopkins Children's Center faculty in 1992, say they are thrilled that the sisters are doing so well, and that Marvin and Pamela Hall deserve much of the credit.

When the Hall babies were born in the early 2000s, the NICU was treating babies born as much as 24 weeks early and weighing as little as 1 pound, says Nogee. The smallest ones had about a 60% chance of survival, and of those who lived, about 40% might have had neurological challenges, he says.

Since then, the NICU at Johns Hopkins Children's Center has grown, from 24 acute care beds in 1992 to 45 today, and treatments have advanced too, with better incubators, a gentler approach to ventilation, and more reliance on parental skin-to-skin contact and maternal or donated breast milk. The survival rate has ticked up, to about 80%, and the NICU team now treats babies as young as 22 or 23 weeks, Nogee says.

Just as the NICU has grown and flourished, so too have the Hall sisters. Hope and Alana both predict that golf will always be part of their lives. Alana, who plans to major in civil engineering and architecture at Lehigh, hopes to play in the Ladies Professional Golf Association (LPGA) one day. Her long-term goal is to design golf courses.

Hope, with a more than respectable drive of 265 yards, is majoring in engineering and government at Dartmouth. She hopes to get an M.B.A. and someday work with the LPGA to increase access for women of color.

Being the only Black woman playing golf in the Ivy Leagues brings pressure, Hope says, but she can handle it. "My dad says pressure is a privilege," Hope says. "I'm honored, and I think it's a good step toward making sure golf widens its range and shows that everybody can play." **KAREN NITKIN**

Alana, left, and Hope Hall

MEET THE EXPERT

Erin Honcharuk, Pediatric Orthopaedic Surgeon

How did you become interested in orthopaedic surgery?

I grew up with a single mom who was a pediatric nurse practitioner. I went to work with her during summer breaks. I spent a lot of time in a primary care office seeing kids come in and out, so I knew pretty early on that I wanted to do something within medicine, and I likely was going to do something within pediatrics.

Then, in medical school, when we had our anatomy lectures and classes, I was really fascinated by the muscular skeletal system and the idea that you could look at someone from the outside and understand what's going on inside. For example, with hand tendons, you can move your hand a certain way, and that tells you something about how the hand inside is working. That's how I made the switch to orthopaedics. Pediatric orthopaedics fit what I was looking for really well — the idea of being able to follow a child from almost near birth through adulthood, and to have a prolonged impact on them.

I treat a large variety of conditions and see lots of different patients now, from an adolescent having pain from sports to a child born with a congenital difference. I particularly specialize in limb deformity reconstruction and lengthening — where one leg might have a bowing to it or might be shorter than the other. I'm doing procedures to either reconstruct the joints or lengthen a limb and get the leg straight so we can get them back to being active. Children are so resilient. All they want to do is get back to playing.

My goals are to make sure that everyone in the room understands what's going on, what our treatment options are and what our ultimate plan will be. You don't want a kid to feel like we're doing something to them or at them, or that they're not involved in the process.

AS TOLD TO KAREN BLUM

‘Give Me Your Tired…’

Many immigrant families who seek refuge in Baltimore’s communities have experienced deep trauma and face daunting obstacles in obtaining essential health services. Pediatric specialists at Johns Hopkins are leading efforts to make sure these families get the help they need.

BY LACEY JOHNSON
ILLUSTRATION BY SONIA PULIDO

Under the watchful eye of a volunteer, a toddler and her 6-year-old sister giggle in a hallway, delighted to be playing with a donated Barbie and baby doll. In a nearby room, their mother sits with a group of seven Latina teenagers and young women, crafting valentines out of pink paper and heart-shaped doilies. Across the hallway, nine teenage boys prep ingredients for arepas in a communal kitchen while a community chef gives instructions in Spanish.

The night's activities are designed for 15- to 25-year-old survivors of human trafficking who traveled from their home countries in Latin America to seek refuge in the United States. It's not uncommon for human smugglers, who are hired to help immigrants get across the southern border, to exploit vulnerable young people by forcing them into sex work or physical labor during their journey. Some of these survivors end up in Maryland and don't know where to turn for health care, psychological support, employment and other essential services.

Asylee Women Enterprise (AWE), a nonprofit in northeast Baltimore, has partnered with HEAL Refugee Health & Asylum Collaborative, a Johns Hopkins-based partnership that assists people forcibly displaced from their home countries, to help trafficking survivors get the support they need. Together, they offer free individual therapy, host peer support groups, and connect youth to social, academic, employment and skill-building opportunities. The program, called Steps to Success, is one of many ways that Johns Hopkins and its pediatric faculty members are supporting immigrants and their children, who too often fall through the cracks of health care systems.

"The peer support groups were the first time that I could unravel what I had been through and talk to other people who had experienced the same things," shares Juan (not his real name), an 18-year-old high school student and trafficking survivor from Honduras, speaking through an interpreter, who participates in Steps to Success.

In 2022, he made a perilous two-month journey to the United States with his 8-year-old brother. He's still waiting to start the asylum process to see whether he will be allowed to remain in the country.

Meeting the needs of Juan and others like him is critical, says pediatrician **KEITH MARTIN**, an expert on immigrant child trauma and resilience. "The goal of the Children's Center and Hopkins is to achieve health equity among the kids of Baltimore City and surrounding areas. Immigrant kids are an integral part of that and cannot be ignored," says Martin. He notes that low rates of health insurance coverage, language barriers, lack of transportation and prohibitive work schedules are common obstacles that can prevent immigrants and their children from accessing health care and social services.

Martin's research is focused on how these and other barriers contribute to health disparities for Latinx children — an area for which limited data exists — and what can be done to level the playing field. The bulk of existing research pertains to U.S.-born children whose

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>
> —KEITH MARTIN

PHOTO BY MIKE CIESIELSKI

parents immigrated from Latin America, who are more likely than their peers to have mental health issues, utilize mental health services less than white children and more likely to be obese as compared to white children.

One of Martin's goals is to identify a set of best practices when treating Latinx children in immigrant families, especially when it comes to addressing trauma. His research has found that racial bullying, discrimination from teachers and deportation of family members are common stressors for Latinx children, yet these factors aren't currently measured during screenings for adverse childhood experiences — potentially traumatic events found to have negative, lasting effects on health and well-being.

"Oftentimes, we see patients whose parents have been deported multiple times," says Martin. "It is common enough that in our clinic at Yard 56, we have template letters that we send to immigration. In these letters, we try to articulate the medical problems of these kids and the harm that will come to them if you forcibly take away their parent."

When Johns Hopkins pediatricians recommend specialized mental health services for their patients, they often hit roadblocks trying to connect children in immigrant families to care. Despite federal law requiring that children have access to free language services for mental health care, some providers still refuse to accept Spanish-speaking families. In one documented case, a 16-year-old Johns Hopkins patient was referred for a special type of behavioral therapy to treat anorexia, only to be turned away because her primary language was Spanish. In another case, a 15-year-old Johns Hopkins patient diagnosed with depression was denied treatment by a mental health agency because her mother could not speak English.

"We have many situations where a child has a complicated medical need, and figuring out a way to get them access to the resource they need is very challenging," says Martin. Even when language is not an issue, parents' inability to take time off work or find transportation to appointments can delay necessary medical treatment. "One of my teenage patients, for example, had a painful, benign tumor around his kneecap that needed to be removed, but he had multiple challenges in accessing care — like needing to work and care for his family — that kept preventing him from going to see an orthopaedic surgeon," Martin says.

By determining the right questions to ask during pediatric appointments, Martin's research could one day help clinicians to better identify and treat the unique needs of children in immigrant families, as well as guide them to bilingual, trauma-informed resources within their communities. "If we can deliver more

equitable care to Baltimore's growing Latinx population, we can generalize it to deliver equitable care to everyone — that is really the goal," he says.

'If I Made It Here, They Can Make It Too'

When **MONICA GUERRERO VAZQUEZ** was 10 years old, her parents left her in Ecuador. They were building a new life for the family in Spain, but it would be at least a year until they were ready for their three children to join them.

Before he left, her father sat her on his lap and taught her how to write her signature. "You are going to be in charge, so you have to learn how to sign," he told her.

"I didn't know what was going on," remembers Guerrero Vazquez, whose youngest sibling was still in diapers at the time. "I didn't know what life would be like for us or if I would even see my parents again. Many of my friends' parents left, and they never came back."

Without a responsible adult to help care for her brother and sister, she was forced to drop out of school and become a full-time caregiver. She looks back on that year as one of the darkest periods of her life.

Three decades later, Guerrero Vazquez has two master's degrees — one in computer science and one in public health — and is working toward a doctorate in public health at Johns Hopkins. She also serves as executive director of Center for Salud/Health and Opportunities for Latinos (Centro SOL), an academic-community partnership at the Johns Hopkins University School of Medicine based at Johns Hopkins Bayview Medical Center that is working to improve health and opportunity for the Latinx community in the Baltimore area.

Centro SOL, which is celebrating its 10-year anniversary this spring, connects people to medical resources and social services, offers online and in-person support groups, and hosts workshops on topics like teen

> "**We sit at the crossroads of research and community outreach,**" says Guerrero Vazquez, whose research focuses on suicide prevention among non-English-speaking youth.

suicide prevention and mindfulness. The center's faculty members, most of whom have appointments in the Johns Hopkins University School of Medicine, also conduct research on the unique health issues affecting Latinx children and adults in Baltimore.

"We sit at the crossroads of research and community outreach," says Guerrero Vazquez, whose research focuses on suicide prevention among non-English-speaking youth. According to 2019 data from the Centers for Disease Control and Prevention (CDC), Hispanic adolescents are more likely to die by suicide than their non-Hispanic white counterparts, and suicide attempts were 30% higher for Hispanic high school girls.

Guerrero Vazquez says many of the girls she works with through Centro SOL have no time for extracurricular activities or socializing with friends because they are consumed with responsibilities at home. "They are going through very hard situations sometimes," explains Guerrero Vazquez. "If you're the oldest daughter, you're going to be in charge because your parents are going to be working. You have to be taking care of everything."

Last year, Guerrero Vazquez launched a mental health pilot project for Spanish-speaking students at Benjamin Franklin High School, in southern Baltimore, which has since received funding from the Bloomberg American Health Initiative. As part of the pilot, 25 immigrant teenagers attended group meetings, where they were encouraged to open up to Guerrero Vazquez and their peers.

"It's important because these young people don't have access to mental health care, and they don't have a safe space where they can go and talk about their thoughts and feelings," says Guerrero Vazquez. Most of the students she works with are still going through the resettlement process and facing challenges related to their immigration status, which can affect their ability to get a part-time job or receive financial aid for college. Many are also struggling to reconnect with formerly estranged parents, complete coursework in a new language and manage the stress of household responsibilities.

"I took my siblings to school. I picked them up. I helped them with homework. And I see the high schoolers in our youth program doing the same thing because their parents are working," says Guerrero Vazquez. "To help build their self-confidence, I tell them that, if I made it here, they can make it too."

Online Extra

Read about the work of **NICOLE WARREN**, HEAL's associate director of women's health, who is leading a trauma-informed team of experts to address gaps in care experienced by women and girls impacted by female genital mutilation/cutting (FGM/C).
Bit.ly/JHCCMagSPR24

A Lifeline for Asylum Seekers

While Centro SOL focuses exclusively on the well-being of Baltimore's Latinx community, HEAL serves asylum seekers and refugees from around world, many of whom have experienced severe trauma. HEAL co-founder and medical director **C. NICHOLAS CUNEO**, who began working with refugees in Baltimore more than a decade ago while a student at the school of medicine, has heard stories of kidnapping, rape, government-sponsored torture and people being dragged through the streets solely because of their sexual or gender identity.

"Thankfully, the United States still has a reputation as a country of hope, of safety, of opportunity — and that's attracting people to our doorstep," says Cuneo, a pediatrician at the Johns Hopkins Children's Center, whose research explores patterns of trauma and violence among asylum seekers, as well as the political determinants of health, such as immigration enforcement policies.

According to the latest census data, the number of immigrants to the U.S. grew to the highest level in two decades last year. Today, immigrants make up nearly 16% of Maryland's population, compared to less than 10% in 2000.

HEAL is a partnership between Johns Hopkins, the Esperanza Center, AWE and Loyola University Maryland. The Esperanza Center, a Catholic Charities of Baltimore program, is a nonprofit that connects immigrants to job training, employment, English classes, housing and free health care should they not qualify for government assistance due to their immigration status.

HEAL has grown significantly over the past two years. Initially home to Maryland's first and only comprehensive asylum clinic, HEAL has since expanded to provide comprehensive primary care services to immigrant survivors of torture at the Esperanza Center, as well as

PHOTO BY MIKE CIESIELSKI

> “**Thankfully, the United States still has a reputation as a country of hope, of safety, of opportunity** — and that’s attracting people to our doorstep.”
>
> —C. NICHOLAS CUNEO

a range of mental health services to asylum seekers and youth survivors of trafficking, including Juan. He participates in the Steps to Success trafficking survivors program run by HEAL and AWE, which has been funded by grants from the U.S. Department of Justice as well as Baltimore’s Promise and the Annie E. Casey Foundation.

“Steps to Success helped me process my past and deepen the way I can talk about what I’ve been through. I have more empathy,” says Juan, who comes in regularly for music therapy, stress reduction workshops and cooking classes. He recently decided to join Steps to Success’ Youth Advisory Board. “Because of the life experience that I’ve had, I find that I’m more mature, and I want to support and help other young people like me.”

Creating a partnership to help asylum seekers like Juan was at the top of Cuneo’s to-do list when he joined Johns Hopkins’ pediatrics and medicine faculty in 2020. He launched HEAL in November 2021 with co-founder Nouf Bazaz, a clinical assistant professor of counseling at Loyola University Maryland and expert on refugee mental health.

Last year, HEAL provided services to 207 unique clients from 36 countries of origin, and about one-third were children or young adults. The children referred to HEAL commonly struggle with trauma-related mental health conditions, such as anxiety, depression or PTSD, as well as delayed or misdiagnosed developmental disabilities, like autism.

“There is such a dearth of resources for quality counseling that’s accessible to kids. If we can help to fill that niche, that would just be huge,” says Bazaz, who serves as HEAL’s mental health director. Sixty-seven immigrants received mental health services through HEAL in 2023, including 12 who received individual therapy from Bazaz.

She often meets with her youngest clients in a therapy playroom at AWE, which is stocked with art supplies, puppets and stuffed toys with sewn-on faces representing different emotions — objects that make it easier for children to reenact experiences and communicate their feelings. Bazaz’s favorite tool in the playroom is a sand tray, where kids use figurines to create scenes in the sand.

“Kids are able to create these worlds that can be quite symbolic of their own,” she says. “One kid is obsessed with creating disaster scenes in the sand, and together we have to save all the people in often elaborate ways. So, it does get a lot out.”

Building a Case for Asylum

One of the most important services that HEAL offers is free forensic evaluations — an hourslong process that can include a physical exam and psychological assessment to document any abuses that a client may have experienced in their home country — and they can make or break an immigrant's case for receiving asylum in the U.S.

"Applicants' chances of being awarded some sort of humanitarian protection, including asylum, can approximately double if they submit a detailed medicolegal evaluation," says Cuneo. "In one recent study, 81.6% of cases where a forensic medical evaluation was submitted were granted protection in comparison to the national rate of 42.4%."

Over the last two years, HEAL has grown into one of the highest-volume forensic evaluation clinics in the country, and it's one of the only clinics in the region to offer the service at no cost. Such evaluations can be more than $2,000 on the private market, and HEAL's patients often travel from surrounding states for the service.

HEAL's work is made possible with the help of over 100 volunteers, including many Johns Hopkins students and residents, along with a patchwork of government and philanthropic funds. HEAL has received grants from the U.S. Office of Refugee Resettlement Services for Survivors of Torture Program, the U.S. Department of Justice Office for Victims of Crime, the Aaron Straus and Lillie Straus Foundation, the Abell Foundation, the Goldseker Foundation, the Leonard & Helen R. Stulman Chartiable Foundation, and the Center for the Study of Democratic Institutions. Johns Hopkins provides in-person interpretation for HEAL and funding for transportation assistance for clients facing significant barriers. Johns Hopkins' Urban Health Institute has also funded HEAL's student arm at the school of medicine, the Refugee Health Partnership.

"To do this work is very hard. It's so difficult to assemble these coalitions," explains Cuneo. "But once you have the right mix, it's beautiful."

Meeting the health care needs of immigrants comes with challenges, but Johns Hopkins doctors and staff members say the resilience of their clients never fails to inspire them. Guerrero Vazquez has seen students blossom during their time at Centro SOL, with some going on to receive full scholarships at Loyola University, Goucher College and Johns Hopkins.

"Being undocumented and being able to get into Johns Hopkins is a huge deal," says Guerrero Vazquez. "One girl who attended our mentoring and summer programs was very lost and didn't know what she wanted to do. She later told me, 'Thanks to your help, I went to nursing school.' She graduated last December."

When given the opportunity to fulfill their potential, immigrants can successfully rebuild their lives, even after suffering unspeakable things, says Cuneo.

"I've seen folks who start with very serious challenges because of the traumas they've experienced blossom over the course of months into completely different versions of themselves. They just needed the chance to thrive and the security to establish their lives," he says. "That's what makes the work worth it." ■

TAPPING Into Health Care

When immigrants in Baltimore have pressing medical needs, clinicians can connect them to free specialty services through The Access Partnership (TAP), Johns Hopkins Medicine's program for uninsured and underinsured patients who live in the communities surrounding The Johns Hopkins Hospital and Johns Hopkins Bayview Medical Center. Through TAP, immigrant children and their parents have been able to receive cardiac surgeries, dental work, diagnostic tests, physical therapy and other services that would otherwise be financially out of reach.

When it launched in 2009, most TAP patients were African American. Because of the additional insurance coverage now available through the Affordable Care Act and expansion of Medicaid, TAP now primarily assists uninsured immigrants. Today, about 95% of patients are Latinx. The program is the first of its kind in Baltimore.

Stamina, Empathy and More …STA

5 traits that make our pediatric emergency medicine doctors so good at what they do.

BY KAREN NITKIN

PHOTOS BY
JENNIFER BISHOP

Nobody becomes a pediatric emergency medicine doctor because they think it will be a relaxing or an easy way to make a living.

About 35,000 patients a year seek treatment in the Pediatric Emergency Department at Johns Hopkins Children's Center — between 60 and 160 a day. They arrive around the clock, a cross-section of young people, from newborns to 21-year-olds, in just about every state of duress it's possible to imagine.

Caring for these patients is difficult, important work. It requires an almost supernatural ability to radiate warmth and calm in even the direst moments.

> **"I can't imagine doing anything else."**
>
> **—RAQUEL MILLET**

"I think many of us like the fast-paced environment," says Pediatric Emergency Medicine Director **LETICIA RYAN**.

With each patient, these doctors must quickly gather information and decide next steps. That could mean ordering more tests, consulting with specialists, finding an inpatient bed for continued care, comforting grieving parents or simply affixing a splint to a child's broken finger.

"I can't imagine doing anything else," says **RAQUEL MILLET**, a second-year pediatric emergency medicine fellow.

Here are some of the qualities that make Johns Hopkins pediatric emergency medicine physicians so good at what they do.

1 Empathy

JULIA KATHLEEN “KATE” DEANEHAN has a way of walking into a room and putting patients and families at ease. “I heard you hurt yourself yesterday,” she says to a child with a minor injury. To a sicker patient, describing her pain, she says “Oh, I’m so sorry,” almost under her breath.

“No one wakes up and thinks they're going to end up in the Emergency Department that day,” says Deanehan, who has been comforting and treating patients and families in the Children’s Center since 2013, the last two as director of pediatric emergency medicine clinical operations.

“You’re meeting people who are often in very stressful situations,” she says. “Sometimes we’re treating a minor cold, but sometimes we’re giving a life-changing diagnosis. It’s important to really try to connect with someone you don't have a background with or a history with, and in a very short time frame.”

Millet always attaches a small, colorful toy to her stethoscope, a Baby Yoda doll or Mickey Mouse ears, whatever she finds at Target. They distract her young patients, she says, and shows that she likes toys too. “It’s important to be approachable,” she says.

2 Communication Skills

As Deanehan and Millet make their rounds, they focus on the patients and their families, not on their computer monitors. Only after the visit do they circle back to their workstations to update electronic medical records.

Communication skills are essential in a job that requires constant gathering and sharing of information. Pediatric emergency medicine doctors listen carefully to patients, parents and grandparents who may be having the worst day of their lives or are experts in their little one’s chronic disease that has brought them once again through the Emergency Department doors.

It’s not enough to ask a patient with cystic fibrosis if she’s having trouble breathing. Deanehan wants to know when the problem started, where it hurts most and if the IV in her arm is uncomfortable.

Communication skills are also essential for interacting with a changing roster of nurses, specialists, residents, fellows and others, all with the same goals but different levels of experience and expertise. With each shift change, the doctors who are leaving give detailed updates on the pediatric patients who are staying.

“A huge part of what we do is talk with other clinicians,” says Millet.

> **“It's important to really try to connect with someone you don't have a background with or a history with, and in a very short time frame."**
>
> **—JULIA KATHLEEN "KATE" DEANEHAN**

> **Every other shift, I see something I haven't seen before.”**
>
> —RAQUEL MILLET

3 *Knowledge — and Humility*

Pediatric emergency care doctors at Johns Hopkins know a lot — including how much they don’t know. “Every other shift, I see something I haven’t seen before,” says Millet.

They treat everything, from common colds to rare genetic disorders, from happened-in-a-flash traumas to long-simmering chronic illnesses.

“We touch probably every specialty in the hospital and know concentrated bits about each one,” says Deanehan. “We might not know the details of a rare hematology diagnosis, but we know how to take care of an oncology patient who comes in with a fever.”

As the only accredited pediatric trauma and burn center in the state, the department draws severely injured patients from hundreds of miles away. And as Millet notes, treating kids from birth to age 21 means she has to know what’s normal and what’s not for every age group.

“If I see a heart rate of 130 or 140 in a newborn, I’m not worried at all,” says Millet. “If I see that in a 16-year-old, they could be very ill.”

That’s why it’s so important, she says, “to recognize what I don’t know.”

The emergency doctors consult frequently with specialists and use point-of-care medical information resources like UpToDate to fill in knowledge gaps on the fly.

4 *Sustained Energy for Multitasking*

Shifts are so busy that doctors rarely find time to eat or even use the bathroom. “I keep PowerBars in my pockets so that I can eat one quickly,” says Deanehan.

New demands pop up constantly.

Emergency medical technicians call to say they’re on their way and to share what they know about the patients they’re transporting. Officials with Child Protective Services bring children in for evaluations. Pediatricians and specialists call with questions or to say they’re referring a patient.

“There’s a lot of juggling, and you’re constantly being pulled away from what you’re doing,” says Deanehan.

More than the physical exertion, though, is the stress of constant, high-stakes decision-making. “You’re making decisions for eight hours straight, and you have to make them quickly,” she says. “I’ll come home, and my husband will ask what I want for dinner, and I’ll say I just can’t make another decision. The decision fatigue is real.”

5

A Sense of Humor

This may be the most important quality of all, the physicians agree. Laughter and jokes forge connections, put serious situations in perspective and help everyone get through difficult days.

Recently, Millet checked on a patient with a seizure disorder. The child, who wasn't particularly verbal, suddenly announced, enthusiastically, that he wanted a certain fast-food treat.

Tension in the room disappeared as Millet and the child's parents burst into laughter. The patient, clearly pleased with the reaction, said it again, even louder.

For a moment, the swirl of activity and the relentless push for information and decisions stilled, as the adults in the room simply delighted in a child's happiness.

> **"Our lens gives us a unique opportunity to reach families at what we call a teachable moment."**
>
> **—LETICIA RYAN**

Helping Kids Stay Out of the Emergency Department

In addition to treating patients, pediatric emergency medicine doctors often provide education and resources that can protect people from needing their services in the future.

"We have an opportunity to do a lot of work in prevention, including injury prevention, suicide prevention and violence prevention," says Pediatric Emergency Medicine Director **LETICIA RYAN**. "Our lens gives us a unique opportunity to reach families at what we call a teachable moment."

For example, she says, before discharging patients, doctors might discuss safe storage of guns or refer families to the Baltimore City Fire Department for free smoke alarm installations.

When nervous first-time parents come in with newborns who aren't really sick, "those are my favorites," says second-year fellow **RAQUEL MILLET**. "We get to cuddle babies and also educate parents that babies do weird things, and to go to the pediatrician, not the Emergency Department, if it's not life threatening."

Long Haulers

Infants born with congenital heart defects, like Tyler and Jeremy Harshman, often require lifelong follow-up as they grow. Through relationships they've built over the years with their care team at Johns Hopkins, the brothers have found 'a second home.'

BY CHRISTEN BROWNLEE

Jeanine Harshman's pregnancy with her first son, Tyler, "could not have been more normal," she remembers. But when Tyler was born on a Tuesday in 1992 at a hospital in Hagerstown, Maryland, he was quickly whisked away by ambulance to The Johns Hopkins Hospital. Doctors there found that his heart had just a single ventricle, compared to two of these pumping chambers in a normal heart. His brother, Jeremy, born at Johns Hopkins eight years later, was diagnosed during one of Jeanine's prenatal visits with a different congenital heart defect (CHD) called transposition of the great arteries.

Brothers Tyler, left, and Jeremy Harshman, have been "regulars" at Johns Hopkins since they were born.

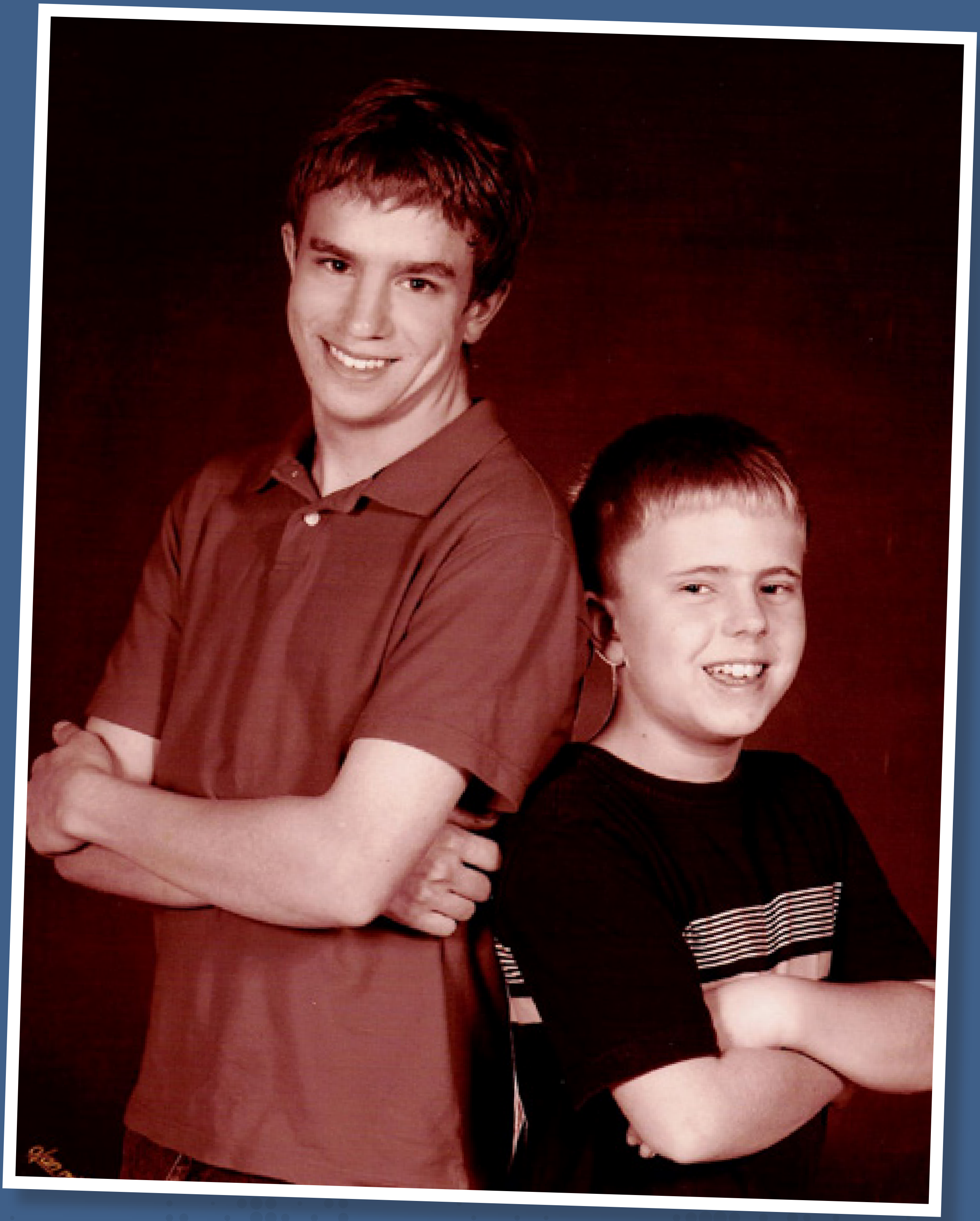


PHOTO COURTESY JEANINE HARSHMAN

Now ages 31 and 23, and with six open-heart surgeries between the two of them, Tyler and Jeremy have received care over their entire lives at Johns Hopkins' Blalock-Taussig-Thomas Pediatric and Congenital Heart Center — one of relatively few places of its kind that treat patients with CHDs across the life spectrum.

"There's a significant advantage to having pediatric and adult care all in one place — to having experts who can provide care for both congenital heart disease and adult-related problems, and who know the ways in which those two worlds will interact in the same patient," says pediatric interventional cardiologist **JOHN THOMSON**.

For example, general adult cardiologists typically have great depth of experience in treating coronary vascular disease and other heart problems that occur with aging but very limited training in congenital heart defects that exist since birth — and they are generally unfamiliar with the ways that early repairs deteriorate over time.

Thomson loves the extended relationships that come with his role. "We join families in their medical journey very early on, usually when patients are infants or even in utero. Then we get to know patients and their families so well, and they get to know us, as we care for them throughout the whole of their lives," he says. "It's extremely satisfying."

A 'SECOND HOME'

Tyler's first memories of his heart condition start at his second surgery, at nearly 6 years old, and his awareness intensified when Jeremy was born with a congenital heart defect two years later. These conditions didn't stop their parents from letting them be typical kids — after Tyler turned 13 and Jeremy turned 8, they began racing go-karts with "the very best safety equipment we could get," Tyler recalls.

Their childhood was marked with races and learning how to build engines and make parts, a passion they have spun into a family business doing the same for sprint racecars with their father, Randy Harshman. It was also punctuated by frequent trips to Johns Hopkins Children's Center — their medical home for their congenital heart defects since birth.

About 40,000 babies are born with congenital heart de-

> “**We get to know patients and their families so well,** and they get to know us, as we care for them throughout the whole of their lives.”
>
> **—JOHN THOMSON**

fects in the U.S. every year, affecting about 1% of all births in this country, according to the U.S. Centers for Disease Control and Prevention. These defects span a wide range of types, explains Johns Hopkins' **ARI CEDARS**, adult congenital cardiologist for the Harshman brothers.

Tyler Harshman, left, with baby brother Jeremy.

While Jeremy's transposition of the great arteries is relatively common among patients with CHD, affecting about one in every 3,413 live births, Tyler's single-ventricle defect is relatively rare, affecting only one in 20,000 live births.

Like many patients with CHDs, both brothers required urgent surgery early in life — Tyler had his first operation at about 6 months of age, and Jeremy's first operation was at just 5 days old. A common misconception is that these initial surgeries are curative, but many congenital heart defects require multistage surgeries at different points in life, and these surgical fixes tend to deteriorate in predictable ways that require revisions over time, Cedars explains. For this reason, nearly all patients with congenital heart defects require lifelong follow-up, with most patients in the Blalock-Taussig-Thomas Center seen at least once a year.

"These frequent visits allow us to screen for and anticipate problems, and to prevent more severe problems [that could arise] if not attended to in a timely fashion," Cedars says.

Coming to the same medical team over the long haul has a multitude of benefits for patients and their care team, Cedars adds: Clinicians forge strong relationships with young patients as they grow, gathering information on life circumstances and events that could ultimately affect heart health but might not make it onto a medical chart. For patients and families, it is reassuring to receive care in the same familiar environment by clinicians who become more like family as the years go by.

Until recently, Tyler and Jeremy usually attended their annual appointments together, accompanied by Jeanine — first with cardiologist **JOEL BRENNER**, and then with Cedars after Brenner's retirement in 2022. The family developed its own routine over the years, visiting the Christus Consolator statue in the lobby of the Billings Administration Building before each appointment at the Blalock-Taussig-Thomas Center, now located in The Charlotte R. Bloomberg Children's Center building.

"Johns Hopkins feels more like a second home to me than a hospital. I have always felt comfortable there," says Jeremy.

'WARM' HANDOFFS

These annual visits, with more interspersed as needed for check-ins and procedures, allowed the care team for Tyler and Jeremy to decide when to schedule each of them for surgery over the years to keep their hearts working well. Tyler's first two surgeries rerouted his blood vessels in order to access oxygen-rich blood from the lungs to allow his single ventricle to pump it throughout his body. A necessary revision at age 16 replaced an artificial vein integrated during those earlier surgeries with a larger one to accommodate his growing blood vessels. Jeremy's surgery in his first days of life switched the position of the two largest arteries leaving the heart.

Each of these surgeries, performed by longtime Johns Hopkins cardiothoracic surgeon **DUKE CAMERON**, took place before the boys turned 18. As Tyler approached this critical milestone into adulthood, Jeanine says she became nervous about the upcoming transition from pediatric to adult care — after all, Tyler, who also has type 1 diabetes, had to leave his pediatric endocrinologist behind once he became a legal adult.

But the story was different in the Blalock-Taussig-Thomas Center, she says. "The team told us that these boys were theirs


PHOTO BY MIKE CIESIELSKI

> “**These frequent visits allow us to screen for and anticipate problems,** and to prevent more severe problems [that could arise] if not attended to in a timely fashion.”
>
> **—ARI CEDARS**

forever, that they would stay with a team at the same center. It was a huge relief,” Jeanine remembers.

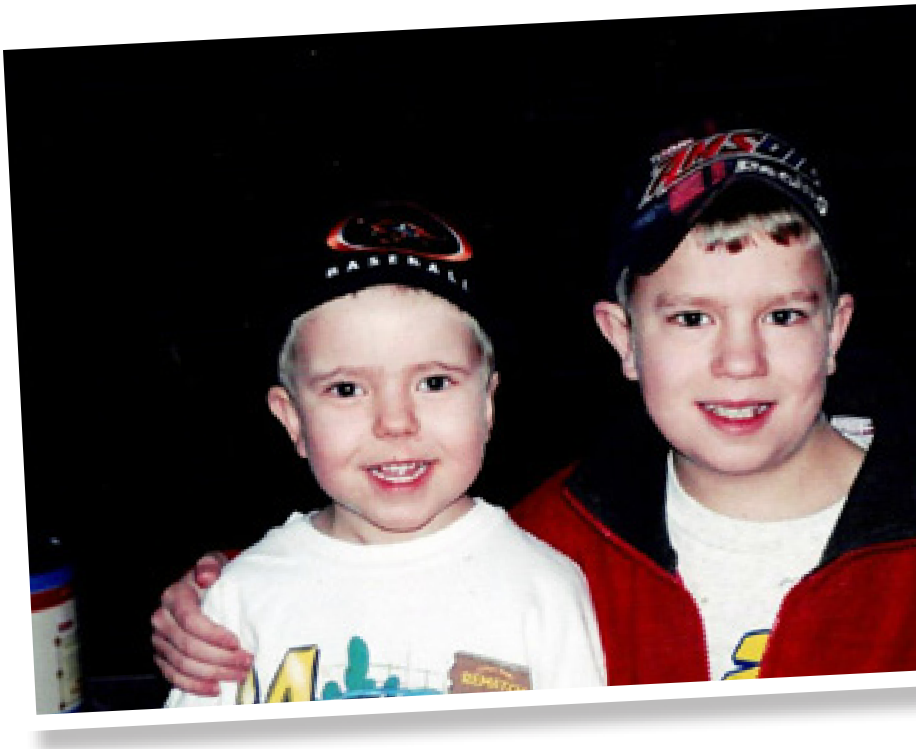
Indeed, says Cedars, although he is an adult cardiologist, his office sits within the Children’s Center. He says that physical location facilitates “warm handoffs” when patients with congenital heart disease age out of pediatric care, allowing pediatric colleagues to stop by to brief him on patients new to him and their often-complex histories.

The same CHD surgeons at the Blalock-Taussig-Thomas Center operate on babies and adults alike, says **DANIELLE GOTTLIEB SEN**, who performed Tyler’s most recent surgery in October 2023 — an operation to implant a pacemaker, since an evaluation by Cedars showed that Tyler’s heart was no longer responding to increased demand, stubbornly stuck at a heart rate of 51 beats per minute regardless of Tyler’s activity level. There are only a few hundred cardiac surgeons trained to perform surgeries for CHD over the lifespan in the U.S., with Gottlieb Sen one of just 22 women surgeons. The training for this field is the longest in all of medicine, she explains, taking on average 17 to 18 years, with more time for surgeons who pursue research concurrently, as she did.

“Congenital heart defects are more of a calling for me than a job,” she says.

Gottlieb Sen says that the training she and her colleagues received, as well as the care they provide, is vastly different from that of general cardiac surgeons who operate on patients with acquired heart disease, such as the coronary artery dis-

Growing up, Jeremy, left, and Tyler stayed active playing sports and riding go-karts.



ease so prevalent in adults in the United States. Rather than treating conditions that arise in a structurally normal heart, she and her colleagues have the daunting task of trying to correct abnormal anatomy, often developing creative solutions customized to patients' individual needs.

"Patients with acquired heart disease have had some time when their cardiac anatomy and function was normal. But patients with CHD have never had a normal heart. Our job is to help them live as normally as possible," she says.

TAKING LIFE IN STRIDE

To accomplish this goal, members of the congenital heart disease care team — including cardiologists, cardiac surgeons, cardiac catheterization specialists, electrophysiologists, social workers, psychologists and nurses, among others — meet every Thursday at 7 a.m. to discuss the most complex patients currently on the roster. Together, Gottlieb Sen explains, the team uses their diverse expertise to decide on the care plan for each one.

For young adults like Tyler and Jeremy, the team also helps patients transition from having their care managed by their parents and pediatric clinicians to managing their own care independently.

Today, rather than Tyler and Jeremy attending appointments jointly as they typically did in the past, Tyler — who is recently married — now often attends with his wife, Kara, while Jeremy often continues to attend with Jeanine.

With the support of their care team, both brothers have made tremendous strides both medically and personally over the years. Today, their business building racecar engines and parts is thriving. Both are active in their churches, families and communities, which they expect to continue for decades to come.

"You learn to take it in stride and go to into each appointment saying that you don't know what will happen, but it will be OK," says Jeanine. "We are so grateful to have had Johns Hopkins with us the whole way." ■

> "Congenital heart defects are **more of a calling for me than a job**."
>
> **—DANIELLE GOTTLIEB SEN**

New Insights in Pediatric Stroke

Through the course of her research and clinical work on pediatric strokes, Johns Hopkins neurologist **LISA SUN** has found herself building expertise on a disease that's rarely seen — and that is little understood — in the United States.

Sun is at the forefront of research and treatment regarding moyamoya disease, a blood vessel disorder characterized by progressive narrowing and blockage of internal carotid arteries. The condition can lead to reduced blood flow to the brain, increasing risk of strokes and other neurological impairments.

Frequently found in East Asia, where it is the most common cause of stroke in children, moyamoya appears more rarely in the United States, affecting approximately 0.9 per 1 million people. The term "moyamoya" is Japanese for "puff of smoke," referring to the way the fragile, abnormal blood vessels appear in angiograms.

> "Moyamoya can be very impairing, and there is no cure, **but we have treatments that, if instituted early enough, can significantly reduce the risk of stroke** and bleeding in the brain."
>
> **—LISA SUN**

Johns Hopkins, one of the few medical institutions in the U.S. that specializes in treating moyamoya, saw only about 70 cases of pediatric moyamoya from 2003 to 2019, according to data from Sun, who is at the Johns Hopkins Pediatric Stroke and Neurovascular Center.

Moyamoya is typically diagnosed with imaging studies such as MRI and cerebral angiogram. But Sun is particularly interested in the potential of transcranial doppler (TCD) — an ultrasound-based technology that uses sound waves to measure blood flow in the brain — to catch moyamoya early for high-risk pediatric patients, which include children with sickle cell anemia, trisomy 21 and neurofibromatosis.

"TCD is an established technology that's routinely used in children with sickle cell disease, but we haven't utilized it much as a screening tool for moyamoya," Sun says. "It's an appealing option to investigate, because the main method we use now, MRI, comes with risks associated with anesthesia for children with moyamoya."

Treatments for moyamoya include medications to prevent blood clots, treatment of anemia and other stroke risk factors, and optimizing blood pressure and hydration. But in many cases, revascularization surgery — a delicate procedure to build a new blood supply to the brain — is the best option.

"Moyamoya can be very impairing, and there is no cure, but we have treatments that, if instituted early enough, can significantly reduce the risk of stroke and bleeding in the brain," Sun says.

Though revascularization surgery decreases long-term risks of stroke, it comes with the cost of increasing risk of stroke during the perioperative period. Sun recently led a study on this phenomenon, aiming to find areas of consensus among 30 neurologists and other specialists in North America with expertise in moyamoya. It found many areas of agreement, such as the importance of good hydration and pain control around the time of surgery. It also identified a few major research priorities for the future, including understanding the ideal postoperative blood pressure and hemoglobin levels, and studying the importance of supplemental oxygen and continuous electroencephalography immediately after surgery.

Another recent study Sun led, aiming to understand modifiable risks for perioperative stroke among pediatric patients with moyamoya, identified anemia as a major risk factor.

KATIE PEARCE

Proven to Prevent Injuries in Young Children

Unintentional injuries are a leading cause of pain and death among young children. While injuries can range in severity — from cuts and burns to drownings and poisonings — clinicians agree that many are preventable.

Now, a study led by Johns Hopkins Children's Center researcher **ELIANA PERRIN** and colleagues shows that an intervention program developed by the American Academy of Pediatrics (AAP) dramatically reduces injuries in young children. The findings provide evidence for implementing The Injury Prevention Program (TIPP) in routine well-child care, the researchers conclude.

"From this large study, we learned that a relatively simple intervention in pediatric offices really helps parents keep their children safe. TIPP uses what we know about how children develop to tailor the advice we give to parents at each stage, and it works," says Perrin, Bloomberg Distinguished Professor of Primary Care and first author of the study, which included four academic medical centers in the U.S. and was published in *Pediatrics*.

At two of the centers, pediatrics residents were trained on TIPP and used the TIPP screening and counseling materials at all well-child checkups for patients from 2 to 24 months old. The two other centers did not use TIPP and instead implemented a separate, unrelated intervention program.

The findings show that sites using TIPP reported significantly fewer injuries in young children — with an estimated risk of reporting injuries across each of the well-child checkups of only 14% as opposed to more than double that (30%) in the control group. The team says their findings show that TIPP was able to significantly prevent injuries in young children, and that the benefits of TIPP improved as children got older.

A total of 781 parent and infant pairs were enrolled in the study. The majority of parents were Hispanic (51%) or Black (28%), and most were insured by Medicaid (87%). **KAITLYN ROMAN**

> "The day-to-day life of patients with food allergy is consumed by fear of accidental exposure to food allergens. **Our findings have the potential to be very meaningful, and potentially even life changing, for people with food allergies.**"

—**ROBERT WOOD**, director of the Eudowood Division of Allergy, Immunology and Rheumatology at Johns Hopkins Children's Center, speaking about a study he led that found that omalizumab (an injectable, FDA-approved medication for treating asthma and other allergic conditions) substantially reduced potentially life-threatening reactions in patients with an allergy to peanut and other common food allergies.

In the study, investigators compared the effects of 16–20 weeks of omalizumab injections with placebo injections in 180 participants ranging from age 1 to 55 with a history of peanut allergy and at least two other food allergies. The subjects were randomly assigned to receive omalizumab or placebo. All but three of the participants were age 17 or younger.

Researchers found that after 16 weeks, 66.9% of patients treated with omalizumab were able to tolerate 600 milligrams or more of peanut protein (equal to about 2.5 peanuts) compared with 6.8% of participants who received placebo injections. The team also found that omalizumab injections increased participants' threshold reactivity to other common food allergens — milk, eggs, wheat, cashews, walnuts and hazelnuts — to levels that would protect most patients from reactions after accidental exposure.

A report on the first stage of the three-stage study, was published in *The New England Journal of Medicine*. The FDA recently approved omalizumab for treatment of multiple food allergies following an interim analysis based on this study. **KAITLYN ROMAN**

100%

The percentage of young patients at the Johns Hopkins Pediatric Diabetes Center who opted to complete an autonomous artificial intelligence (AI) diabetic eye exam during a visit to their endocrinologists. During the exam, pictures are taken of the backs of the eyes without the need to dilate them and AI is used to provide an immediate result. Nearly one-third (31%) had a result indicating a diabetic eye disease.

In contrast, just 22% of young patients in the same study who received the current standard of care — referral to an optometrist or ophthalmologist to complete annual screening — followed through within six months to complete an exam.

"With AI technology, more people can get screened, which could then help identify more people who need follow-up evaluation. If we can offer this more conveniently at the point of care with their diabetes doctor, then we can also potentially improve health equity, and prevent the progression of diabetic eye disease," says Johns Hopkins pediatric endocrinologist **RISA WOLF**, who led the study, which was published in *Nature Communications*.

Diabetic eye disease (DED) primarily refers to diabetic retinopathy, a potentially blinding complication of diabetes that occurs when poorly controlled sugar levels cause the overgrowth of, or damage to, blood vessels and nerve tissues in the light-sensitive retina at the back of the eye. Frequent screenings for DED facilitate early detection and treatment, and can help prevent its progression.

Previous studies by Wolf and her team have found autonomous AI screening that uses cameras produce results that enable accurate DED diagnosis. **KAITLYN ROMAN**

Holes in the Safety Net

Across the United States, a growing number of families with low income are being displaced from their homes due to an inability to afford rising housing costs — which disrupts their access to three key federal assistance programs: Medicaid, the Special Supplemental Nutrition Program for Women, Infants and Children (WIC), and the Supplemental Nutrition Assistance Program (SNAP).

That's according to the results of a recent study by researchers from Johns Hopkins Children's Center and UCLA.

"These types of social safety net programs are designed to protect children's health and well-being during times of hardship, but our study findings show that their access may be disrupted precisely when they need them most," says **KATHRYN LEIFHEIT**, who trained at Johns Hopkins before joining UCLA, and co-led the study, which appeared in *Pediatrics*, with **JACKY JENNINGS**, a professor of pediatrics at Johns Hopkins Children's Center.

Researchers found that of the 9,344 study participants (all children), 1,938 (21%) experienced a coverage gap in at least one of the social safety net programs. Among those, access to WIC was disrupted for 75%, access to SNAP was disrupted for 20% and Medicaid access was disrupted for 16%.

Compared to children who hadn't moved, those who had a cost-driven move in the past year had 44% higher odds of disrupted access to WIC, SNAP or Medicaid. Researchers also found that moves not driven by cost were associated with a smaller, 14% increase in odds of disrupted access to the programs.

"Given the high levels of financial strain and housing insecurity among low-income families during this period of record inflation, we are at a critical moment right now," says Jennings. "There is an urgent need to take action to ensure access to these programs."
KAITLYN ROMAN


Jacky Jennings

Toward a Blood Test for Postpartum Depression

By using genetic material from human blood and lab-grown brain cells, a team led by Johns Hopkins' **SARVEN SABUNCIYAN** has made progress in developing a blood test to identify disease-associated changes in the brain specifically linked to postpartum depression and other psychiatric and neurological disorders.

"This is very exciting, because right now, there isn't a blood marker for disorders affecting the brain. Essentially, these conditions are diagnosed by clinical interviews between patients and providers," says **LENA SMIRNOVA**, an assistant professor at the Johns Hopkins Bloomberg School of Public Health and co-author of the research findings, which were published in *Molecular Psychiatry*.

The researchers focused on identifying the "footprints" of brain cell-derived mRNAs in blood circulating outside the brain. These blood extracellular vesicles carry brain-specific pieces of genetic material that potentially allow researchers to detect disease-associated changes in gene activity inside the brain. Extracellular vesicles (EVs), fatty sacs of genetic material essential to communication among cells, carry messenger RNA (mRNA) and are released by every tissue in the body, including the brain.

The new research was inspired by results of an earlier study led by Sabunciyan, an assistant professor of pediatrics, which discovered EV communication is altered in pregnant women who go on to develop postpartum depression after giving birth.

The goal, Sabunciyan says, is to develop a simple blood test to detect changes such as higher or lower levels of blood EV mRNAs directly linked to changes in the brain associated with mental disorders without having access to the brain itself. Eventually, he adds, the availability of such blood tests could enable detection of early signs of mental health emergencies, such as suicidal behavior, in time to intervene and possibly prevent negative outcomes.

In future studies, the researchers plan to use lab-grown brain samples to identify similar biomarkers to develop tests for autism spectrum disorder. **KAITLYN ROMAN**

Vanquishing HIV in Infants

Research co-led by **DEBORAH PERSAUD**, professor of pediatrics at Johns Hopkins Children's Center, shows that four children born with HIV who were safely removed from antiretroviral therapy (ART) continued to have undetectable levels of the virus for about a year or more without treatment. The children were among 54 newborns who were given very early treatment within the first 48 hours of life — rather than within weeks or months, as is typical.

The study was conducted by the International Maternal Pediatric AIDS Clinical Trials Network at 30 clinical research sites in 11 countries. It was designed to replicate the case of the "Mississippi baby," who is believed to be the first documented case of HIV remission in a child who was born with the virus and received very early HIV treatment at 30 hours of age.

Persaud, who was part of the research team to report on the case in 2013 and is director of the Eudowood Division of Pediatric Infectious Diseases, says the study findings confirm the notion that ART-free remission is possible with very early effective antiretroviral treatment of newborns. She adds that standard treatment of babies with HIV typically starts weeks after birth, often due to delays in testing and getting results — particularly in countries outside of the U.S. where the burden of HIV is highest and ART drugs are less available.

"These results are an important first step to understanding how to curtail HIV reservoirs in children toward ART-free remission and cure for more children living with HIV," says Persaud.

KIM POLYNIAK

Keeping Malcolm's Memory Alive

BY JENNIFER WALKER

After a medical emergency at their local hospital, Lauren and Joe Grossman had their just-born son, Malcolm, transferred to the neonatal intensive care unit (NICU) at the Johns Hopkins Children's Center. Following Malcolm's birth, his brain had been deprived of oxygen for 15 minutes, and he needed cooling therapy, an intervention used to allow a baby's body to use less energy and heal. At the Children's Center, Lauren and Joe, who have two older sons, ages 6 and 4, say their family received compassionate care from Malcolm's team of providers for eight hours until Malcolm was taken off of medical support.

"The doctors and nurses sat with him, they held him, they sang him lullabies," says Lauren, a pediatric neuropsychologist. "His doctor made sure to say that it was an honor for her to be able to care for Malcolm. I think that's a wonderful thing to say. And they gave us as much time as we needed with him."

"Even after Malcolm passed, they were sitting with him and singing," adds Joe, an attorney with the Social Security Administration.

In the next several weeks, Lauren and Joe decided they wanted to raise funds for the Children's Center's NICU in honor of Malcolm. With the help of the Children Center's development team, Lauren set up a donation page, which she and Joe circulated on social media. They raised around $20,000, a portion of which is being used to introduce a new program to the NICU: Supporting and Enhancing NICU Sensory Experiences (SENSE). Created by Bonnie Pineda, a neonatal therapist and an assistant professor at the University of Southern California, the SENSE program provides actionable steps that parents and caregivers can take to help their premature babies, ages 23 to 40 weeks, have positive experiences with their five senses.

"The NICU is a stressful and scary place for babies and their families," says **KATHLEEN MARTIN**, lead clinical nurse, who has practiced in the

The Grossman family, flanked by Miles for Malcolm supporters.

Lauren Grossman with Malcolm

Children's Center's NICU for 37 years. "This program is going to help parents to have more individualized opportunities to engage with their babies. This will help build the parents' confidence and abilities to care for their babies, especially as they get closer to going home."

Martin says the funding raised by Lauren and Joe has supported a two-hour introductory training for 25 providers, including nurses, occupational therapists and physical therapists. She also purchased a SENSE program license and accompanying materials. After the initiative launches in May, Martin plans to schedule a two-hour online meeting with Pineda to answer questions and address any challenges. Parents and caregivers can access the training on their devices, but informational sheets describing the recommended positive sensory experiences for each baby's age will also be placed in the room for each family's reference.

If babies are 28 weeks old, for example, the program instructs parents/caregivers to expose them to one hour of positive touch, such as hand holding or skin-to-skin contact, and three hours of parent scent. Reading, talking or singing to them for at least 20 minutes a day will develop their auditory sense, and shielding them from bright light will protect their visual sense. To promote positive oral experiences, parents can put some breast milk on a swab and gently rub it on their lips.

For Lauren and Joe, supporting the Children's Center in this way is keeping Malcolm's memory alive. "I haven't had a grief like this before, and I needed to do something with that and for him," says Lauren.

"We say this gives him a voice," Joe says.

Backpack Buddies

Young children who land in the Emergency Department at Johns Hopkins Children's Center sometimes arrive with only the clothes on their back.

Thanks to generous support from **MERRITT PROPERTIES**, a "backpack buddy" can help ease their transition when they are discharged to foster care. Each backpack is stuffed with age appropriate items — clothing, toiletries, and a special toy or book — all aimed at providing comfort during a troubling time. Support from Merritt Properties has made it possible for approximately 150 children to benefit.

SAVE THE DATE

Little Steps for a Big Cause

September 21, 2024
Maryland Zoo in Baltimore

Miracles in Motion 5K run/1 mile walk to support the work of Johns Hopkins Children's Center.

To register:
HopkinsChildrens5k.org

Tackling Obesity in Latinx Children

BY SUE DE PASQUALE

Obesity rates among America's children have increased at an alarming rate. Latinx kids living in low-income households are particularly hard hit, putting them at dangerous risk of type 2 diabetes and cardiovascular disease.

In East Baltimore, a family-based Spanish-language weight management program is making a difference, notes **SARAH POLK**, an associate professor of pediatrics at Johns Hopkins Children's Center who works closely with Centro SOL: the Johns Hopkins Center for Salud/Health and Opportunity for Latinos.

Through the Active and Healthy Families program, caregivers and children (ages 5–12) with obesity meet biweekly at Our Lady of Pompei Church over 16 weeks to learn about healthy eating habits (such as how to read nutrition labels to purchase the healthiest breakfast cereal), talk candidly about daily stressors associated with immigration, and get moving with some easy exercises that can be done with no equipment and very little space.

"Our community health worker, **YESSICA MARROQUIN**, is really the most critical piece — the linchpin. Families find her to be their strongest connection to the program," says Polk, the principal investigator for the program. "Their phone conversations with Yessy in between sessions are really helpful for motivation and getting over bumps in the road," says Polk, who notes that funding for Marroquin's position has come through the **RITE AID FOUNDATION**.

"The Rite Aid Foundation funding has been essential in allowing us to sustain this important program. We are now on our 15th cohort of participating families," Polk says.

Marroquin, who conducts sessions in Spanish, provides opportunities for adults to meet and talk together while their children take part in fun, instructive activities. She's found during these sessions and in her biweekly follow-up phone calls that there are many hurdles to implementing healthy habits.

"The most frequent thing parents ask for is help with access to basic resources, such as electricity or rent. In addition, they ask me about how to renew health insurance for their children or how to apply for food stamps (SNAP)," says Marroquin. Other common challenges: limited space in their homes (many share with family or nonfamily members), limited time (parents often must work during after school and evening hours), the high price of healthy foods and unsafe neighborhoods, which limits opportunities for kids to play safely outside.

"In general, during my weekly follow-up calls, parents say that some bad habits change when they started sharing more as a family and started doing activities together. Those are things we learn in the program together — to share," notes Marroquin. She adds, "It's not a hierarchical relationship. They feel that we are working as a team, and they have the confidence to share what is going on with their children."

Follow-up evaluations have found the Active and Healthy Families program has a positive impact on children with obesity, Polk says. "Their weight gain slows, relative to kids who don't participate." And importantly, the insights gained benefit other family members.

"Parents in the program talk a lot about how it is motivating them to improve their own personal health habits. To positively influence an adult who is at risk of type 2 diabetes — that is very meaningful," says Polk. Younger siblings also absorb healthier habits. "If we can catch a 5-year-old before they start gaining weight, then they may avoid ending up in the same situation as their brother or sister."

In addition to funding Marroquin's position, the Rite Aid Foundation's $200,000 gift supports other crucial elements of the program, including providing transportation to meetings for families who need it and supplies — from jump ropes to measuring cups — to help families integrate healthy new habits into their daily routines.

"We are incredibly grateful for the Rite Aid Foundation's generosity," Polk says.

Read more about Johns Hopkins-led efforts in immigrant family health: p. 8.

Healthier Habits Take Hold

A two-year outcomes study by Johns Hopkins researchers, currently in press, included these comments from participating caregivers:

"We have made, thank God, many changes. What we say is: 'We are no longer going to get this. The sodas are no longer going to be in the house because they are harmful.' And it is understood that [these things] will not be brought in."

"Before, we were not consuming so many vegetables, but now since I began with the program, I set a goal to include more vegetables in each meal. Before it was just the children and me, and little by little, my husband was integrated […] and the littlest one also. He did not like to eat many vegetables, but now he also eats them."

"I bring [my son] to the park, and we take a walk, we run with a ball or things like that. And the other times here in the house, we do Zumba or kids' yoga, a very good program. We also have a stationary bike, and they also get on the bike."

A Reunion with Heart

BY SUE DE PASQUALE

For families of infants born with a congenital heart defect (CHD), the first days and months at Johns Hopkins Children's Center often pass in a blur — marked by surgeries, periods of recovery, follow-up visits and high anxiety.

Amid the emotional intensity, families meet and bond with each other and with the dedicated care team — physicians, nurses, child life specialists and others — who provide crucial 24/7 treatment and support.

"The only people who understand what it's like to have a child with CHD are people who have one," says **KATIE SWAN**, clinical operations manager for the Blalock-Taussig-Thomas Pediatric and Congenital Heart Center.

Which is what inspired Swan and others to organize the first annual **HEART CENTER FAMILY REUNION** last October — a joy-filled day at the Prigel Family Creamery in Glen Arm, Maryland, which drew dozens of families and Heart Center clinicians and staffers together to connect through fun, games and carnival food.

"This was an opportunity for parents, patients and their siblings to get together and just play and have fun — there was no agenda for the day. And it was wonderful for our team as well," says Swan. "We rarely get to see our patients outside of the medical setting, living their best lives."

The reunion was made possible through the generosity of families, nonprofit organizations and vendors, who raised $7,500 for the event. There were even T-shirts donated for the day (blue "Heart Saver" shirts for the care team and red "Heart Warrior" shirts for young patients).

Thanks to such support, and because the first Heart Center Family Reunion was such a hit, it has now become an annual event: The second gathering took place in late April at the Robinson Nature Center in Columbia, Maryland.

Read more about how patients with congenital heart defects and their families find a "second home" at Johns Hopkins: "Long Haulers," p. 22.

Make a gift to the Blalock-Taussig-Thomas Pediatric and Congenital Heart Center: **Bit.ly/JHCCHeart**.

Ensuring Universal Dignity

ILLUSTRATION BY MATTHEW COOK

The Johns Hopkins Children's Center strives to provide both exceptional health care and an exceptional patient and family experience in partnership with patients, families and communities in a diverse and inclusive environment. When we think of "diverse and inclusive," our minds often go to socioeconomic status, race or religion. But we are also called to build an equitable world for individuals with disabilities. No patient is the exact same as another, and neither are their needs. Recognizing patients as individuals is an essential part of quality care. At the Children's Center, we need to provide access to care and basic necessities to all who come through our doors — regardless of their diagnosis or abilities.

Recently, our Pediatric Family Advisory Council (PFAC) identified the need for a universal bathroom on campus, so that children over 40 pounds who need to be changed are accommodated. What is a universal bathroom, and why is it important? A universal bathroom accommodates the needs of many without the need for a special designation. It can have grab bars to help one sit and lift, space for a turning radius for those who use a wheelchair or walker, and a changing table that fits an infant or an adult. It can be used by any gender and will accommodate a bathroom helper for those who need assistance. Universal changing tables are essential for inclusion and transform the lives of those with disabilities and complex medical conditions, providing a safe, hygienic space for their needs.

> "**Universal changing tables are essential for inclusion** and transform the lives of those with disabilities and complex medical conditions, providing a safe, hygienic space for their needs."
>
> **—SUE MEAD**

One of our physical therapists, Holly Loosen, who is also a longtime, dedicated PFAC member, has worked with numerous patients and families who have struggled to find an appropriate, accessible place to be changed when they came to the hospital for a clinic visit or therapy. Some families had to take their child back to the car to change them. Some, out of urgency, had to lay their child across the bathroom floor to change them, as it was the only space big enough to accommodate them. Listening to their challenges and empathizing with the situation, Holly rallied the PFAC, which worked with the hospital's Quality and Safety Leadership and Operations teams to identify a space for a universal bathroom with a changing table to accommodate someone heavier than 40 pounds. After much planning, in fall 2023, the hospital opened its first universal bathroom in The Charlotte R. Bloomberg Children's Center on the third floor, just outside the Family Library. We continue to work with the hospital to identify additional spaces to create more universal bathrooms to ensure a more inclusive Children's Center.

Diversity and inclusion. Dignity and respect. These are important principles in health care and expand well beyond the bedside. Even to the bathroom!

Sue Mead is a parent adviser on the staff of Johns Hopkins Children's Center and co-chair of the Pediatric Family Advisory Council. Her daughter was successfully treated for a brain tumor at Johns Hopkins in 2006.

Johns Hopkins Children's Center

Miracles in MOTION 5K

Little Steps for a Big Cause

little steps *for a* big cause.

Join us, Saturday, Sept. 21, 2024, 8:00am

for the inaugural *"Miracles in Motion"* 5K, to benefit Johns Hopkins Children's Center.

This event is a 5K run or 1 mile walk, followed by a "Critter Crawl" Kids Dash, all to benefit **Johns Hopkins Children's Center!**

Pricing:

5K or 1 mile	**$25/person**
Critter Crawl	**$15/person**
Virtual 5K	**$20/person**

Your registration fee includes:

Admission to the Maryland Zoo in Baltimore on race day *and a cotton t-shirt!*

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INAUGURAL RACE *at the* **MARYLAND ZOO**

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