Fun at Camp **p. 14** / In the Flow **p. 16**

hopkinschildren's

FALL/WINTER 2025

The Johns Hopkins Children's Center Magazine

Untangling the Mysteries of MOGAD

After a baffling condition left Camden Pack-Witmer bedbound, he and his family turned to experts at Johns Hopkins to find answers.

AXEL'S ARTIST STATEMENT

"'Nostalgia' was a painting I made one day during one of my dialysis treatments. I chose the name simply because every time I see a sunset, memories flood in of seeing a sunset as a care-free child before dialysis became a part of my life. So as I wait for a donor, I'll keep brightening people's days with my awesome artwork."

FALL/WINTER 2025

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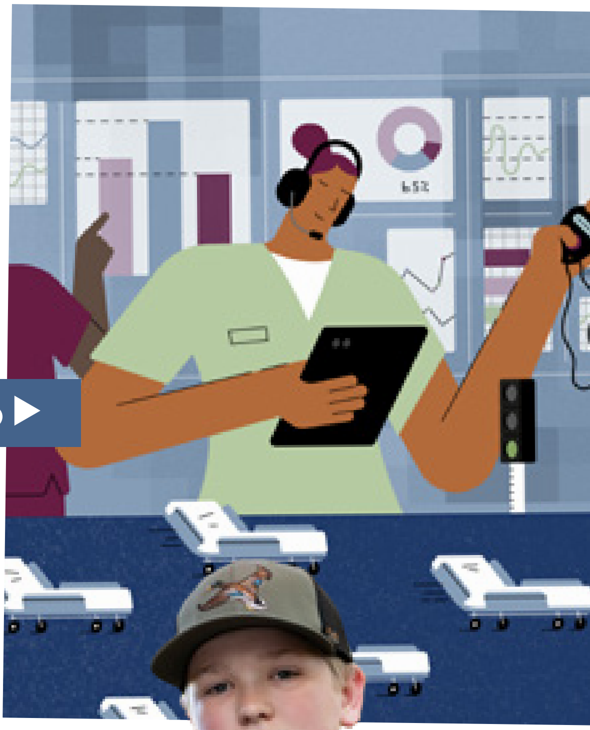

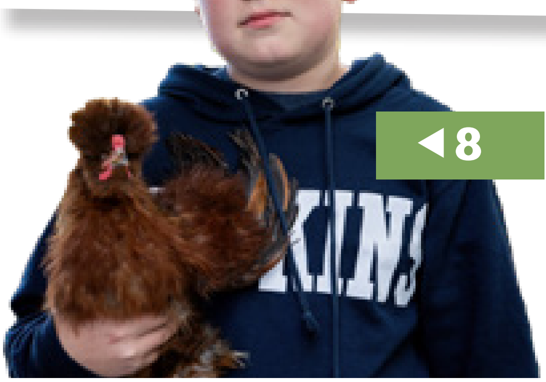

Cover photo by Howard Korn

DIRECTORS' LETTER

ILLUSTRATION BY MATTHEW COOK

Feelings of renewal and hope are typically associated with the months of spring. This year, however, as we watch the brilliantly-hued leaves here in Baltimore flutter to the ground, we find ourselves experiencing a sense of rejuvenation in autumn.

Our optimism is borne out on so many fronts. It comes from witnessing the tremendous energy exhibited by the 1,300-plus people who turned out to run, walk and dash at the Miracles in Motion event in late September at the Maryland Zoo. Together our generous supporters raised more than $225,000 for essential services at the Children's Center.

It comes from working alongside the talented batch of new medical and surgical residents who began work here this summer. Amid a healthcare landscape beset by seemingly daunting challenges, these young pediatric physicians are undeterred in their determination to improve the lives of children and their families. We are inspired by their brilliance and commitment to the advancement of pediatric health.

And our hope springs from the outpouring of support for Johns Hopkins' newly launched Research Saves Children fundraising campaign (p. 26), which comes at a time when federal cuts have created a clear need for new support. Here at the Children's Center, we save lives every day not just because of our clinical skill and cutting-edge technologies, but because of evidence-based breakthroughs made possible through research. It's been energizing to see so many people mobilizing around the rallying slogan that "Research Saves Children!" by purchasing shirts and launching new funding sources to keep our life-saving research alive.

By reading the stories in this issue of *Hopkins Children's*, we hope you will share in our sense of autumnal rejuvenation, as we set our sights on a future guided by innovation, discovery and excellence.

Brenda Banwell, M.D.
Co-Director and Pediatrician-in-Chief, Johns Hopkins Children's Center

David Hackam, M.D., Ph.D.
Co-Director and Surgeon-in-Chief, Johns Hopkins Children's Center

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CHILDREN'S CENTER

Hopkins Children's is published
by the Johns Hopkins
Children's Center Office of
Communications & Public Affairs
hopkinschildrens.org

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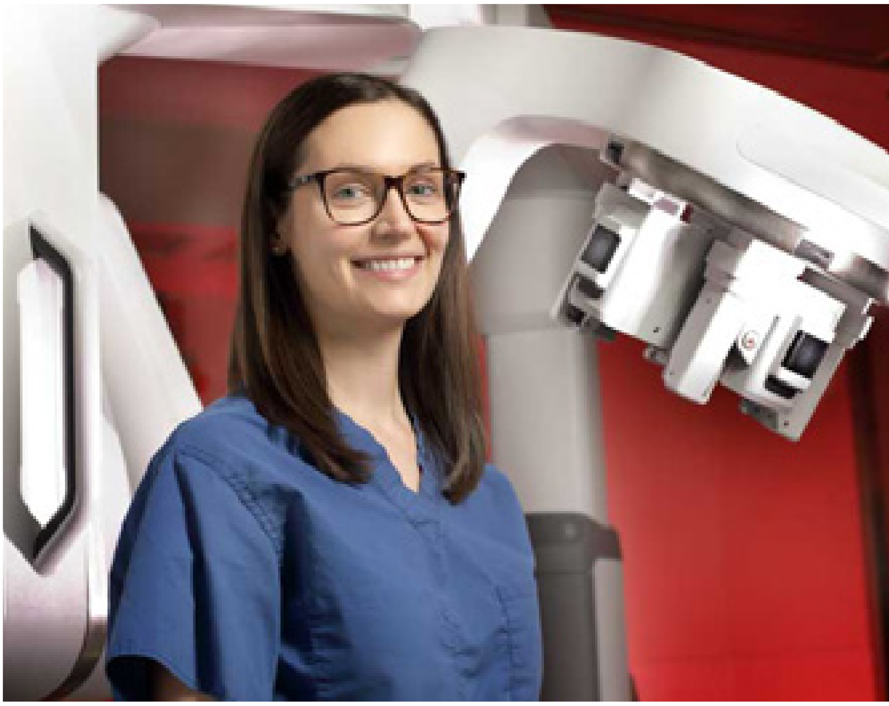
Cutting-Edge Technology for Head and Neck Surgery

Transoral robotic surgery (TORS) revolutionized head and neck surgeries when it was approved for adults by the U.S. Food and Drug Administration in 2009. Mostly used for cancer therapy, TORS allow surgeons to avoid significantly more invasive operations that require splitting the mandible and approaching tumors through the jaw and neck.



TORS also holds significant advantages for pediatric head and neck surgery. However, only a handful of centers across the country offer pediatric TORS, says Johns Hopkins pediatric otolaryngology surgeon **CAROLYN JENKS**. When she joined Johns Hopkins Children's Center in 2021, Jenks introduced this type of surgery to the hospital's repertoire and began treating children using the technique.

"I was lucky enough to train at the right places at the right times," says Jenks, who began training in TORS during her residency at the University of Pennsylvania, the birthplace of this surgery. She learned how to use it to treat children during her fellowship at Lurie Children's Hospital of Chicago, under the mentorship of Douglas Johnston, a trailblazer for pediatric TORS.

Besides lingual tonsillectomies — a treatment for refractory sleep apnea that's the most common indication for this approach — TORS can be used to treat vascular malformations in the mouth and throat, benign and malignant cysts and masses, and various laryngeal pathologies.

During these operations, Jenks serves as the primary surgeon, sitting behind the robot's controls. A second surgeon is stationed at the patient's head, observing at the bedside for safety and performing additional duties including suctioning and tissue retraction. Jenks says that she feels fortunate to partner with experienced TORS surgeons such as **LEILA MADY**.

During TORS surgery, three surgical tools of Jenks' choice and a 3D, high-definition camera emerge from the robot through a single 2½-centimeter port, allowing her significantly greater visualization and maneuverability than other minimally invasive approaches provide. Although the risks are similar compared with conventional endoscopic surgery, TORS can help avoid the increased risk of complications, prolonged recovery and scars that can result from open procedures.

"The patients for whom I've been able to offer this cutting-edge technology have been referred to me with refractory problems that many well-trained pediatric otolaryngologists can't help them with," Jenks says. "It's really fulfilling to see these children have great outcomes with TORS." **CHRISTEN BROWNLEE**

A Happy Ending for a Complex Heart Transplant

Surgeons at The Johns Hopkins Hospital have performed a technically challenging heart transplant on a 19-year-old patient with congenital heart disease who presented in shock, restoring health to the young adult.

During a 12-hour procedure in April, a surgical team led by cardiothoracic surgeon **CHETAN PASRIJA** and pediatric cardiothoracic surgeon **MARCELO CARDARELLI**, removed the patient's diseased heart and replaced it with a healthy donor heart.

The patient had been born with double outlet right ventricle, a rare disease in which his left ventricle — the part of the heart responsible for pumping blood to the body — wasn't fully formed. "It falls in the spectrum of a larger disease process known as hypoplastic left heart syndrome," explains Pasrija.

That required the patient to undergo a series of four palliative surgeries at Johns Hopkins in his infancy and as a young child, including a Fontan procedure, an operation done so the single ventricle only pumps oxygenated blood to the body.

"A transplant after a Fontan palliation is considered one of the most advanced and complicated procedures," notes cardiologist **ARI CEDARS**, director of the Johns Hopkins adult congenital heart disease program. "There are not that many institutions in the United States that do it, and there are even fewer who do it well."

During the transplant, the Johns Hopkins surgeons first disconnected the inferior and superior vena cavae from the pulmonary artery, closed the holes in the pulmonary artery and created a new hole to connect the donor heart pulmonary artery to the recipient. In this case, the patient had two superior vena cavae, a right and a left. The surgical team did an additional reconstruction to take the left-side superior vena cava, bring it to the right side, and create a new superior vena cava structure. Both heart donor tissue and bovine pericardium were used during these parts of the procedure.

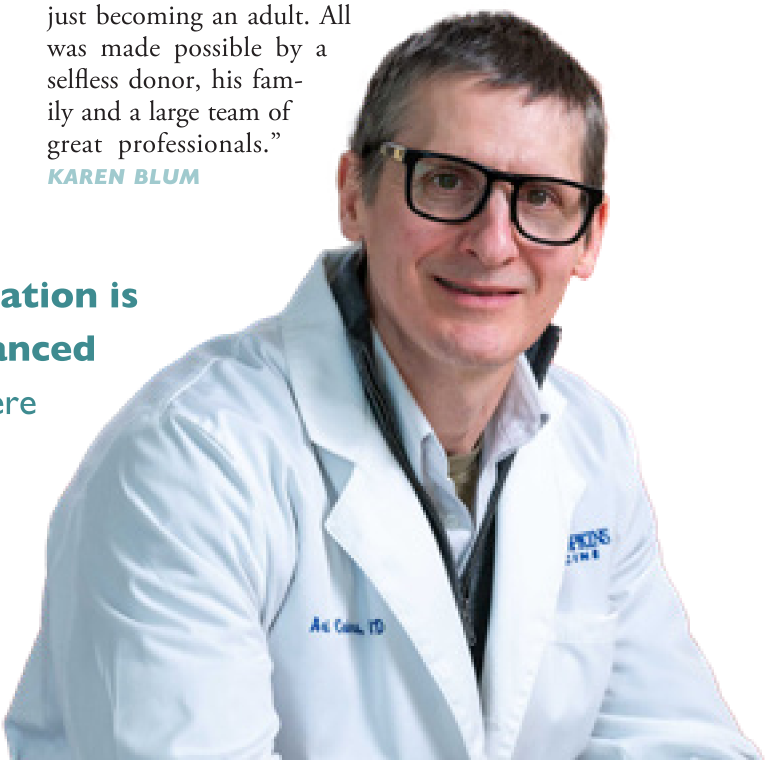
"That's one reason why a lot of institutions don't offer this surgery, because it is quite complex and is known to have significantly increased likelihood of perioperative morbidity and mortality," says Pasrija.

The patient did extremely well with the transplant, Pasrija says. After about a month, he was discharged home, where he continues to recover.

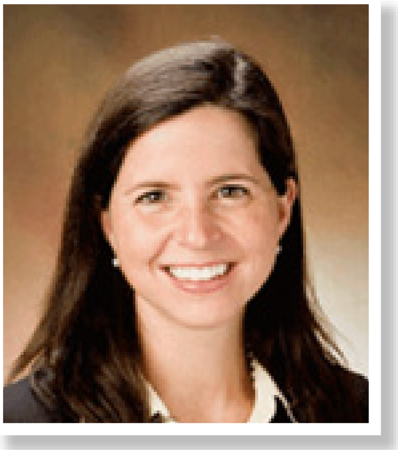
Noting the very positive outcome, Cardarelli observes, "It must be an incredible feeling transitioning from being bed ridden and connected to an assist device pumping the blood your heart can't pump anymore, to suddenly — out of nowhere — the gift of a normal heart and a pretty normal life when you are just becoming an adult. All was made possible by a selfless donor, his family and a large team of great professionals."

KAREN BLUM

> **"A transplant after a Fontan palliation is considered one of the most advanced and complicated procedures.** There are not that many institutions in the United States that do it, and there are even fewer who do it well."
>
> **—ARI CEDARS**



A New Leader in Cardiothoracic Surgery



On Dec. 1, the Children's Center will welcome STEPHANIE FULLER as chief of Pediatric Cardiothoracic Surgery and co-director of Blalock-Taussig-Thomas Pediatric Heart center.

Fuller most recently served as program director of Congenital Cardiothoracic Surgery at The Children's Hospital of Philadelphia (CHOP), and surgical director of the Philadelphia Adult Congenital Heart Center. Prior to joining CHOP, she rose from the rank of assistant to full professor in clinical surgery at University of Pennsylvania's Perelman School of Medicine. She completed her general surgery residency at Albert Einstein Medical Center, a cardiothoracic surgery residency at George Washington University and Thomas Jefferson University Hospital, and a fellowship in congenital cardiothoracic surgery at CHOP.

Noting that she was honored to join the pediatric heart center at Johns Hopkins, Fuller said, "I am so grateful for the opportunity to work alongside such a talented team to elevate cardiac care throughout the lifespan."

Read more about Fuller, the Vincent L. Gott Professor in the Department of Surgery, in the spring issue of *Hopkins Children's*.

Ranked Among the Best

U.S. News & World Report recently released its annual list of Best Children's Hospitals for 2025–26, and pediatric specialties at both Johns Hopkins Children's Center and Johns Hopkins All Children's Hospital continue to be ranked among the best in the United States.

The Children's Center is nationally ranked in 10 specialties surveyed, with seven of those specialties among the top 25 in the nation. The Children's Center also remains the #1 pediatric hospital in Maryland.

In Florida, Johns Hopkins All Children's Hospital has also been named the state's top children's hospital and is ranked nationally in eight specialties.

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Untangling the Mysteries of MOGAD

Read *Hopkins Children's* online

When Home Is Everything


JENNIFER BISHOP

Johns Hopkins pediatrician REBECCA SELTZER executive-produced a short documentary, *"Feels Like Home": Lived Experiences of Children with Medical Complexity and Their Families*, which brings viewers into the lives of three families caring for children with medical complexity.

What led to this film?

Our research shows the challenges children with medical complexity and their families face in homes that do not meet their needs. So often, people who are making decisions about kids with complex medical needs, whether they be policymakers or pediatricians, never get a glimpse into what life is like at home for them.

For these kids, home is everything. It's family. It's socialization. For many, it's also schooling. And it's health care — they have these mini-hospitals in their homes. Our goal was to use storytelling and audiovisual tools to show the challenges of navigating all of that, but also that these are just kids who deserve to thrive in their homes.

How did it come together?

I partnered with Lauren Arora Hutchinson, director of the iDeas Lab at the Berman Institute of Bioethics, for a 2024 Johns Hopkins Discovery Award. We recruited families through various listservs and chose three that captured a diversity of experiences.

At first, we were going to send film crews into the homes. As we talked more, we thought it would be more immersive and respectful for the families to film on their cellphones.

Turning all that footage into a 14-minute film was a team effort. We also relied on guidance from parent partners with lived experience, along with consultation from Bonnielin Swenor, director of the Johns Hopkins Disability Health Research Center.

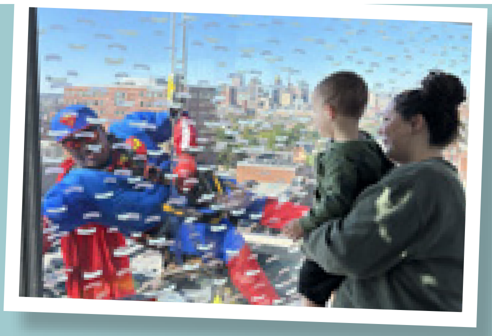
When we pre-screened it last April at a home accessibility event at Johns Hopkins University School of Nursing, it was so rewarding hearing from families, including one of the featured families, that we got it right. We hope the film can be used to educate and advocate for improved access to home modifications and supports for these children and families.

INTERVIEW BY KAREN NITKIN

Learn more: feelslikehomefilm.org

Superheroes Make Special Visit

Superheroes took on a special mission at the Children's Center in October, when window washers from Skyclean, Inc., dressed up as superheroes — including Batman, Mr. Incredible, Spider-Man, Super Man and The Hulk — and rappelled down The Charlotte R. Bloomberg Children's Center building, bringing smiles to young patients and family members through the windows.



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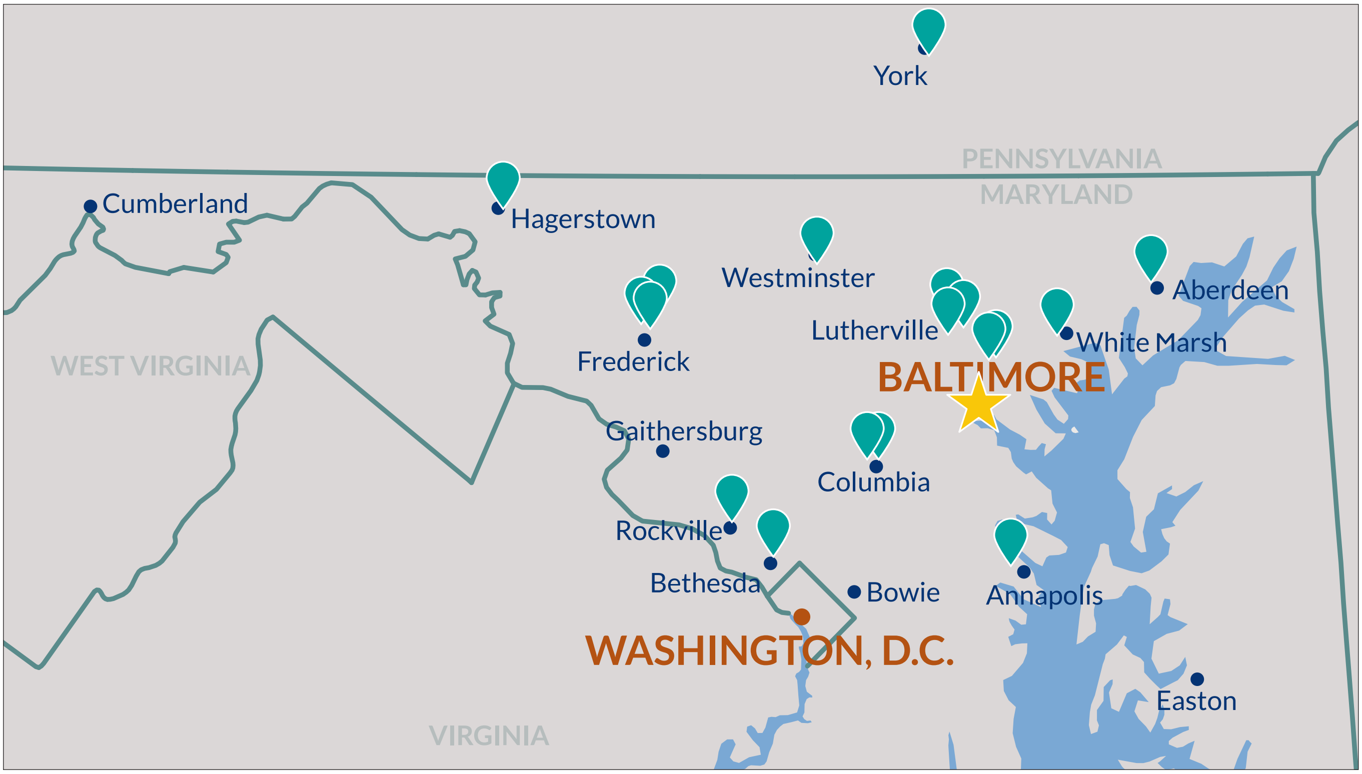

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Camden Pack-Witmer (with best friend Clover) is back to enjoying outdoor time with his family at their Carroll County home.

Untangling the Mysteries of MOGAD

After a baffling illness suddenly left Camden Pack-Witmer bedbound and then robbed him of his sight, his family turned to neuroimmunologists at Johns Hopkins Children's Center for answers.

BY KAREN NITKIN
PHOTOS BY HOWARD KORN

At first, Samantha Pack-Witmer thought her son's headache was no big deal.

Camden was just a few days into second grade, and prone to various ailments — colds, earaches, that sort of thing. Pack-Witmer has two other kids (an older son and younger daughter), and she knew the drill.

"We thought, 'This is normal. They bring home all kinds of stuff,'" says Pack-Witmer.

It wasn't normal, though. Over the next three weeks, he became lethargic. The once energetic and happy-go-lucky kid, who loved to be outdoors, especially if he was hunting and fishing with his dad, was now inside, sleeping most of the day and waking up miserable.

"Prior to this, Cam was full of life and very active," says Pack-Witmer. "He was the pitcher on his baseball team. He was so excited, and he loved doing it. This just took the spark out of him. He was upset. He was frustrated. He was like, 'Why me?' He didn't understand. We didn't understand. And all we could say is, 'We're here for you.'"

His parents, long past their original skepticism, took him to doctors near their home in Carroll County, Maryland, and even to an emergency room, where he was diagnosed with inflammatory encephalopathy and given treatments that seemed to help.

A few days after he was discharged, however, Cam took a dramatic turn for the worse. He began slurring his words, his left foot turned inward, he was wetting himself and — most alarming — one day he woke up and announced he could not see.

"My husband and I looked at each other, and we were like, 'This isn't good.' We were at the point where we were afraid we were going to lose our child."

Pack-Witmer had an idea. She asked her aunt to watch her other children and the family dogs. She put her son in her car, and she and her husband, Ryan, drove Cam 45 minutes from their home to Johns Hopkins.

"We didn't have an appointment," she says. "We just showed up, and I explained what we had been going through for the past few months."

Finally, Answers

Within 24 hours, the family had answers.

A simple blood test, combined with information about his symptoms, revealed that Cam has MOGAD, or myelin oligodendrocyte glycoprotein antibody-associated disease, a rare condition in which the central nervous system attacks the brain, spinal cord and optic nerves. Specifically, he had been experiencing ADEM (acute disseminated encephalomyelitis), an autoimmune attack of the brain and spinal cord, combined with myelitis and bilateral optic neuritis.

The diagnosis was good news, because he was in the right place, one of the few pediatric hospitals in the country with expertise in diagnosing and treating the condition, which generally responds well to early intervention.

"Finally, we can have peace of mind," Pack-Witmer recalls feeling. "We have the support that we need. We're getting answers. We took a deep breath because we knew he was safe. We knew he was getting the care that he needed."

Leading the Way

Johns Hopkins Children's Center is co-led by pediatric neurologist **BRENDA BANWELL**, one of the world's leading experts on MOGAD.

She has been studying neuroimmune disorders since 1999, starting with her first faculty job at the University of Toronto, The Hospital for Sick Children. At the time, it was clear that MOGAD was different from multiple sclerosis, though it wouldn't even have a name until 2018.

Now, she's chair of an international group of about 150 MOGAD researchers who meet every month to discuss research, clinical observations and best practices. In that role and others, she's leading efforts to increase awareness, testing and information about a disease that is still shrouded in mystery.

After Banwell joined Johns Hopkins in September 2024 as chair of the Department of Pediatrics and pe-


MIKE CIESIELSKI

“She is the master of saving kids who are in these situations,” Lefelar says of Brenda Banwell (above). “One of the things that really sets kids who have MOGAD apart is that once they do get help — **they could have a recurrence, but we know that healing is possible, especially when people get in early**.”

diatrician-in-chief for Johns Hopkins Children’s Center, one of the first things she did was join **HAIWEN CHEN** in the Pediatric Multiple Sclerosis, MOGAD and Neuroimmune Disorders Program that Chen had established.

The program is laser focused on understanding and treating these conditions, which all involve a breakdown of the coating that normally shields nerves from inflammation.

Banwell and Chen, an assistant professor who became Cam’s doctor, work closely with adult neurologists at The Johns Hopkins Hospital, as well as with pediatric physical therapists, speech therapists, psychologists and others. Chen was a fellow at Johns Hopkins when she first met Cam, who was initially treated by neurologist **ELIAS SOTIRCHOS**, whose patients are mostly adults.

MOGAD is caused by an antibody called myelin oligodendrocyte glycoprotein immunoglobulin G (MOG-IgG), which attacks the healthy MOG proteins that protect nerve cells. The antibody can be detected by an assay that was developed in 2014.

However, inflammation and attack on myelinated

> **“We have the support that we need. We’re getting answers.** We took a deep breath because we knew he was safe. We knew he was getting the care that he needed.”
>
> **—SAMANTHA PACK-WITMER**

pathways in the optic nerves, brain and spinal cord also occur in multiple sclerosis and other neuroimmune disorders treated in the Children’s Center program.

Differentiating among the conditions is crucial because they have different disease trajectories and treatments. Diagnostic criteria exist for each disorder, but telling them apart requires expertise.

Banwell is lead author of the March 2023 *Lancet Neurology* article that created definitive guidelines for a diagnosis of MOGAD, which include the antibody test, MRI confirmation and symptoms that characterize the disease. Sudden loss of vision caused by optic neuritis is the most common onset feature, particularly among adults, while ADEM attacks like the one Cam experienced are more common in children under the age of 11.

Other symptoms include headaches, weakness and incontinence (due to spinal cord involvement). In some people, MOGAD presents as a single attack, while others experience recurrences. In extreme cases, children can lapse into comas and even die due to acute brain swelling. Treatments to save children with life-threatening MOGAD have been described by Banwell and others.

When Cam was admitted to Johns Hopkins Children’s Center three years ago, he received infusions of high-dose corticosteroids for five days in order to reduce the inflammation that was causing his headaches, vision loss, incontinence and weakness.

Other treatments include plasma exchange, a process that removes MOG antibodies from the bloodstream, and medications like tocilizumab. To prevent attacks in children who experience relapsing MOGAD, monthly intravenous immunoglobulin therapies (IVIG), which provide immune-supporting antibodies from healthy donors, are often prescribed.

Cam’s symptoms abated, and after a week he went home. He could see again, he was walking much better with help from a physical therapist, and his energy was returning.

Two months later, though, his headaches worsened. They got so bad that he’d wake up, crying, from the pain. An MRI revealed new lesions in his brain, indicating that further treatment was required.

“We ended up back in the hospital for a week with the same regimen of steroids, and this time they said we are going to be more aggressive to prevent this,” says Pack-Witmer.

To reduce the risk of another flare, the now 12-year-old started getting IVIG infusions at home every two weeks. It’s now every month. The process takes several hours, so he distracts himself with visits from friends and television shows like SpongeBob SquarePants, his favorite.

MOGAD Knowns and Unknowns

Much is still unknown about MOGAD.

“Is there an infection or an exposure that leads to this condition? Are there any genetic risks? So far, we have not found any specific infection nor any genetic cause, although most patients report a minor illness in the weeks prior to their first MOGAD attack,” Banwell says.

While MS is more common in adults than in children, it’s not yet known if MOGAD favors any particular age or demographic. Many patients are diagnosed in their 20s and 30s, and it appears that about 30% of patients with MOGAD are children, though that proportion could change as more providers learn to recognize and diagnose the disease, says Banwell.

More recognition from clinicians also means more early intervention, which can make an enormous difference.

Sixteen-year-old Rose, for example, began having headaches and blurred vision that got worse over the course of a couple of weeks. “I took her to the ER, and they sent her to a specialist to check her eyes and then she got admitted to Bayview, and from there she went to Johns Hopkins Children’s Center,” says her mother, Rosa.

Rose was diagnosed with optic neuritis due to MOGAD, and treated with steroids and plasma exchange therapy. A recent MRI shows no additional damage. Now, says the Dundalk High School 11th-grader, “My vision is back to normal, maybe even a tiny bit better,” and she’s taking a full roster of challenging classes.

"It was really scary because no one was able to tell me what was going on," says Rosa. "But when we got to the Children's Center, they did their job and they told me."

Spreading the Word

Banwell is passionate about sharing her MOGAD knowledge. She regularly leads seminars and consults with neurologists who may be treating a patient with MOGAD for the first time. She's one of 15 U.S. medical advisers (along with Sotirchos) for The MOG Project, started in 2018 by Julia Lefelar, a Gaithersburg, Maryland, resident and one of Sotirchos' patients with MOGAD.

"She is the master of saving kids who are in these situations," Lefelar says of Banwell. "One of the things that really sets apart kids who have MOGAD is that once they do get help, they could have a recurrence, but we know that healing is possible, especially when people get in early."

Lefelar, 62, wasn't as lucky, although she's doing well now. She began having MOGAD symptoms in 1999, well before any doctor could recognize that her fatigue and racing heart were caused by MOGAD.

At the time, she was raising two young children, working full time at the Johns Hopkins University Applied Physics Laboratory, and swimming regularly for fitness. "I felt like I couldn't breathe unless I made myself breathe." Her vision darkened, and four separate times it disappeared altogether.

"I was going to doctor after doctor, and they were shaking their heads," she says. Some gave her antibiotics. One referred her to a psychiatrist, who hinted the problem was in her mind. Finally, in 2014, she got to Johns Hopkins, where **MICHAEL LEVY**, then director of the Neuromyelitis Optica Clinic, administered a then-new antibody test and began targeted treatment.

Today, her vision is pixilated — "like a 1970s television," she says — and she continues once-a-week immunoglobulin infusions.

Back when she began treatment, Lefelar couldn't find information online, so she teamed with family members to create The MOG Project in 2018. The nonprofit advocates for research dollars, connects patients and families with support groups, and hosts events like an annual patient summit, slated for Baltimore in 2026.

Peace of Mind

In August, Cam started middle school with a full load of honors classes. He still hunts and fishes with his dad, but he's not playing baseball anymore. "He tried, but he couldn't pitch like he used to, couldn't hit like he used to," says his mom.

He loves his dogs and his hamster, his funny shoes that are shaped like fish, and his favorite drink, AriZona green tea. He can be shy, but he also loves to joke.

So far, there have been no relapses and no signs of new brain lesions. But he feels like he's ready if another attack occurs.

"I already know what would happen, so it doesn't really bother me," he says. "I know there's a solution, so that gives me peace of mind." ■

Camden, with one of his family's 22 chickens.

Where Kids Can Be Kids

Nothing makes memories like time spent at camp. Just ask the young patients at Johns Hopkins Children's Center, who don't let challenging health conditions get in the way of making friends and having fun.

Finding Community at Camp All-Stars

For young people living with kidney conditions, daily demands of medications and procedures can lead to feelings of isolation. Each spring, Camp All Stars offers these patients a welcome reprieve: an opportunity for connection.

The two-day overnight camp at the YMCA's Camp Letts near Annapolis is free for Children's Center nephrology patients ages 10 to 21 (see p. 24), with activities such as archery, horseback riding and scavenger hunts. Volunteer nurses, doctors and staff from Johns Hopkins are on site all weekend to ensure the campers receive their medications and any other medical treatments as needed. Many kids have so much fun they return years later to serve as counselors.

Out of This World!

Camp Sunrise at Johns Hopkins Hospital brings summer camp excitement to patients, their families, and staff members at the Pediatric Oncology and Hematology department of the Johns Hopkins Children's Center.

During last summer's week-long day camp, held in the Great Room of the Children's Center, campers enjoyed an "Interstellar" theme, with space-themed crafts and games like UFO frisbee toss.

Patients and their families also had fun getting personalized caricature drawings and taking photos in a space-themed photo booth. There was even a galaxy light space tent and a pop-up rocket ship.

A Charmed Experience

Each summer, Camp Charm City gives kids living with type 1 diabetes a fun, safe and supportive summer camp experience. The five-day camp, held on the Johns Hopkins University campus, was launched in 2019 and is aimed at serving young patients in the local community.

A full medical staff from the Children's Center is on-site, led by medical directors Kristin Arcara and Risa Wolfe, as campers participate in sports, rock climbing, arts and crafts, games and other activities that help them learn to thrive while managing their diabetes.

Learn more: Bit.ly/JHCampCharm

Their Heart's in the Right Place

When parents have a child with a heart condition, the thought of sleepaway summer camp can be nerve-wracking. Enter the Brainy Ridge Heart Camp in St. George, Va., which is staffed by medical experts — including Children's Center physicians, nurses and staffers, who volunteer their time.

During the seven-day camp, kids enjoy outdoor fun, creative arts and educational sessions aimed at enhancing their knowledge and understanding of their cardiac conditions — all in a safe, supervised environment.

To help send a child to camp, contact Allie Boge:
hopkinschildrens@jhmi.edu


65%

IN THE FLOW

Inside the pediatric command center, a clinician team working 24/7 provides 'air traffic control' for maximizing beds and improving access for young patients.

BY **MARC SHAPIRO**
ILLUSTRATION BY **ERRATA CARMONA**

When a pediatric patient from outside Johns Hopkins Children's Center needs specialty care, their medical team calls the Johns Hopkins Access Line (HAL). A nurse takes a case history, evaluates the case with other nurses, consults with a physician, checks bed capacity and arranges to receive and admit the patient — all in one phone call.

That's thanks to the Johns Hopkins Pediatric Satellite Capacity Command Center, a small but crucially important room on the eighth floor of The Charlotte R. Bloomberg Children's Center Building. There, a team of four nurses works around the clock, seven days a week, to monitor the center's 189 beds (not including psychiatry), patients in the pediatric emergency department (ED), discharges, operating room statuses and more. An on-call physician also consults on cases and solves roadblocks as they come up.

"It's air traffic control for patient flow," says **DAVID STOCKWELL**, chief medical officer at the Children's Center.

The impetus for such a center came in winter 2022, when the "tripledemic" — the surge in COVID-19, flu and respiratory syncytial virus (RSV) — overwhelmed hospitals all over the country.

"Everything, from a bed management perspective, was being done with pen and paper, and there was no broad way for anyone in the Children's Center other than nurse shift coordinators to really know what was going on from a bed capacity standpoint," says **CHRISSY FLETCHER**, manager of operations for the command center and a nursing coordinator. "We needed something that was transparent and organized that we were able to monitor closely."

SAYING 'YES'

Nestled among offices at the Children's Center, the pediatric command center has four large, wall-mounted monitors displaying Epic dashboards, and five workstations — one of which is for the on-call physician, who is not always in the room. The four roles for nurses, who have someone at the command center at all times, are multifaceted to ensure that communication flows smoothly and all relevant care teams are in the loop (see sidebar).

"It really does allow us to say 'yes' more because we know exactly what's going on," Fletcher says. "It's all there. We have discharge numbers, we have the number of open beds, how many kids are in the ED … that used to involve flipping through different screens in Epic and writing it down."

A system such as this allows the Children's Center to expediently accept patients not just from within the Johns Hopkins system, but from around the state and region. During the tripledemic, calls to send patients to Baltimore

Eric Biondi, left, with Chrissy Fletcher

came in from as far away as Ohio.

With centralized communication and decision-making, clinical teams are able to spring into action, ready to address patient needs before patients even arrive at the hospital. The process has also allowed a higher number of patients to skip the ED and go straight to an inpatient bed if appropriate. Stockwell says that about 8%–10% of patients go straight into inpatient rooms; the number used to be only 2%.

By putting the shift coordinator and transport teams together in one room, the command center streamlined a process that often would entail a series of back-and-forth phone calls to providers and clinicians working throughout the Children's Center. Previously, it could have taken up to an hour or more to let outside teams know if the center would take their patient.

"It would be about six or seven phone calls, and we rarely said yes at the end of the call," says **PHILOMENA COSTABILE**, assistant nurse manager of the pediatric transport team. "Now, we're able to say yes at the end of the initial phone call. That is so imperatively important to the outside hospital because they're struggling with critical children, and they don't want to hear, 'We'll call you back.'"

To get an accurate bed count of the entire Children's Center under the old system, nurse coordinators would have to go to each unit, from the 12th floor to the emergency department on the ground floor.

"Nurse coordinators would literally work off of paper and go from unit to unit. It just wasn't efficient," says **DAWN LUZETSKY**, who oversees the command center and is the associate chief nursing officer at the Children's Center. "By the time they got down to the ED, it was old news from the 12th, 11th and 10th floors."

While not a perfect system, working off pen and paper and Epic worked, at least until the tripledemic, when it became hard to keep track of patient movement and coordinate certain services, says **ERIC BIONDI**, director of the Johns Hopkins Division of Pediatric Hospital Medicine and an on-call physician for the command center.

NURSES AT THE READY

In the Pediatric Satellite Capacity Command Center, nurses fill four crucial roles to ensure good communications among all relevant care teams.

A **transport intake nurse** takes calls from the HAL line and gets patient case information, coordinates with the appropriate clinicians and checks bed availability, then dispatches the transport team.

The **transport nurse** is positioned in the command center when not out on dispatch. The team brings the patient from the referring facility to the Children's Center, while the transport intake nurse coordinates the admission and prepares the units for patient arrivals.

A **nursing bed coordinator**, the "air traffic controller," works with the transport team to accommodate incoming patients and admit patients from the ED, outside hospitals and surgery.

A **nursing shift coordinator** rounds on the units to ascertain which units are busy or dealing with high levels of acuity, monitors discharges and determines if there are delays nursing can help with.

The [new] process has also allowed a higher number of patients to skip the ED and go straight to an inpatient bed if appropriate.

"That's when we were constantly at 100% and over 100% capacity, and it really became important to use all of our beds the best we could," Biondi says. "We realized we needed to add some coordination to this."

(The Children's Center is typically at 85%–90% capacity October–May, and 75%-85% capacity May–September, Fletcher says).

Biondi, Fletcher and nursing shift coordinator **SHANNON WUNDER** met with the leaders of the Judy Reitz Capacity Command Center, Johns Hopkins' adult command center, which was one of the first of its kind when it launched in 2016. In the 5,500-square-foot space, staff members facilitate transfers to Johns Hopkins, manage bed capacity and monitor 22 digital screens with real-time, actionable information.

For the Children's Center, the group was looking at creating a scaled-down version of the adult center, with similar dashboards.

Enter Ray Lewis. The former Baltimore Ravens linebacker and Super Bowl XXXV MVP raised $134,166 for the Children's Center by spending 15 days in the Panamanian jungle, competing on CBS reality show Beyond the Edge. (He came in second place). A portion of the money raised was used to pay for the pediatric command center's equipment.

More than two years in, the center is now overseen by a steering committee, which is led by Luzetsky and Stockwell and also includes Fletcher; pediatric surgeon **MARK SLIDELL**, who was recently named the Children's Center's associate chief medical officer; and **LETICIA RYAN**, director of pediatric emergency medicine.

The efficiencies have also resulted in better communication with member hospitals Johns Hopkins Howard County Medical Center and Johns Hopkins Bayview Medical Center, as well as Ascension Saint Agnes Hospital in Baltimore (where Johns Hopkins residents and hospitalists work). Howard County and Bayview send patients to the Children's Center, and the Children's Center sends patients to Bayview and Saint Agnes if they don't require the center's specialty care.

By working in conjunction with the nursing resource office, the command center has also been able to deploy staff members where they are most needed, based on the center's real-time data. What's more, by having detailed discharge information — including which patients are expected to be discharged, the status of their discharge and whether the order or discharge is being delayed — command center staff can deploy nurses and/or physicians to move discharges along.

EXPANDING POSSIBILITIES

The command center dashboards allow the team to drill down beyond basic statistics — they can see the number of unavailable beds; how many beds are in each unit; the day's expected admissions, transfers in and out, and discharges; as well as the number of expected open beds at the end of the day. On their desktop computers, nurses can pull up more information, including cases in which discharge orders have been placed, but patients haven't yet been discharged.

Command center staff can also send alerts throughout the Children's Center — one for high bed occupancy awareness and an elevated alert for very low bed capacity, which gets teams including social work and case management involved to help figure out how to safely open up some beds.

The pediatric and adult command centers recently relaunched their systems so that both facilities have the same Epic dashboards, and the teams can see each other's capacities. At the pediatric center, other newly launched dashboards allow even more insight into bed capacity, and further the team's ability to troubleshoot delays in real time. Dashboards with predictive analytics based on historic data were also launched, and are being tested for accuracy.

A new systemwide capacity dashboard includes bed capacity and other information from Bayview Medical Center, Howard County Medical Center and Sibley Memorial Hospital in Washington, D.C.

For Costabile, getting a system like this in place was essential for the Children's Center.

"We are the referral center for the state of Maryland," she says, "and we had a moral obligation to really address the issue of where we put patients to be appropriately cared for." ■

A New Culprit in Psychiatric Diseases

A new study led by Johns Hopkins Children's Center investigators points to liver-damaging hepatitis C infection (HCV) as a possible cause for psychiatric diseases such as schizophrenia, bipolar disorder and major depression.

Observational studies of some psychiatric diseases have long tied viral infections with behavioral symptoms in these disorders, but scientists have been unable to find direct evidence of suspected viruses in the brain. Experts say that's possibly because viruses may not get directly inside the brain, but may target the brain lining instead.

A team led by **SARVEN SABUNCIYAN**, a neuroscientist at the Children's Center, set out to test that idea using postmortem human brain samples and the electronic medical records of 285 million patients.

The team analyzed samples from postmortem brains of individuals with schizophrenia, bipolar disorder or major depression, as well as unaffected controls. The samples were obtained from the Stanley Medical Research Institute collection, a widely used postmortem repository of brain tissue from people with mental health disorders.

They indeed found evidence of HCV in the choroid plexus, a collection of cells that make up the lining of the fluid-filled cavities, or ventricles, and — notably — produce the cerebrospinal fluid that protects the brain and spinal cord.

While Sabunciyan cautions that the team's study does not suggest that everyone with schizophrenia or bipolar disorder has an HCV infection, they believe their findings provide compelling support for the existence of the virus in the choroid plexus.

"Our findings show that it's possible that some people may be having psychiatric symptoms because they have an infection, and since the hepatitis C infection is treatable, it might be possible for this patient subset to be treated with antiviral drugs and not have to deal with psychiatric symptoms," says Sabunciyan, whose team's report appeared in *Translational Psychiatry*.

Looking ahead, he hopes to collaborate with mental health professionals to screen for HCV in people with bipolar disorder and schizophrenia to learn whether treating the infection will ease or stop symptoms. **KIM POLYNIAK**

> **"Our findings show that it's possible that some people may be having psychiatric symptoms because they have an infection,** and since the hepatitis C infection is treatable, it might be possible for this patient subset to be treated with antiviral drugs and not have to deal with psychiatric symptoms."
>
> **—SARVEN SABUNCIYAN**

A Life RAFT for Levi

At 20 weeks pregnant, Sarah Smith of Hanover, Pennsylvania, was given two options: abort her pregnancy or continue carrying her child while knowing he likely wouldn't survive. During what was supposed to be the most exciting time of their lives, Sarah and her husband, Zack, instead were hoping for a miracle.

They decided to look for a third option, and found it at Johns Hopkins Medicine.

Sarah was diagnosed with early pregnancy renal anhydramnios (EPRA), a condition in which a pregnant woman does not have amniotic fluid around her baby. By 16 weeks of pregnancy, 90% of amniotic fluid is made from the baby's urine. EPRA occurs when the baby's kidneys, ureters, bladder or urethra fail to develop properly, interfering with the baby's ability to make or pass urine. This prevents the lungs from developing, leading to death after birth due to respiratory failure.

Then the Smiths heard about the Renal Anhydramnios Fetal Therapy (RAFT) clinical trial. In the trial, mothers got repeated injections of fluid (amnioinfusions) with the goal of reversing the effects of ERPA long enough for their babies to be delivered with functioning lungs.

Sarah and Zack made multiple trips from Pennsylvania to Maryland for these injections. They eventually moved to Baltimore to be closer to The Johns Hopkins Hospital for care. The treatment was successful, and Levi was born in August 2024 with lungs that worked.

"It was an overwhelming feeling of relief but also worry because I knew there was still a long road ahead of us," says Sarah. "But I know he wouldn't be here without the trial."

"Levi is alive today because of the amnioinfusions," says pediatric nephrologist **MEREDITH ATKINSON**, co-lead of the RAFT study. She met the Smiths when Sarah was around 24 weeks pregnant and continued working with the family for the four months that Levi was in the neonatal intensive care unit after he was born.

Levi is now a year old, and Sarah describes him as fun, happy and calm. He still has challenges — he needs dialysis every night, and will eventually require a kidney transplant. Levi has routine visits with his pediatric nephrologist, **ALICIA NEU**, among other physicians at Johns Hopkins Children's Center.

"It's all worth it to have him here with us," says Sarah.

PAIGE ACEVEDO

Watch a video: Bit.ly/RAFTVideo

TIME-ly Recognition

Johns Hopkins pediatric allergist **ROBERT WOOD** has been named to *Time* magazine's "TIME 100 Health 2025" list of the most influential individuals in health.

Wood, who is director of the Eudowood Division of Allergy, Immunology and Rheumatology at the Children's Center, was honored for his groundbreaking research that led to U.S. Food and Drug Administration approval of omalizumab to treat food allergies.

Read more: Bit.ly/JHWood100

New Promise in Spinal Muscular Atrophy

Two recent studies led by Children's Center researchers offer new hope for children with spinal muscular atrophy (SMA), one of the most common genetic neuromuscular disorders. Though SMA affects individuals of all ages, most are weak from infancy or early childhood.

The first study found that children with SMA could regain muscle with the help of a new monoclonal antibody treatment. The second showed that gene therapy treatments delivered in utero via amniotic fluid injection could improve treatment outcomes for patients with SMA.

The new antibody treatment builds upon findings from Johns Hopkins researchers led by **SE-JIN LED** in 1997 that discovered myostatin, a hormone that regulates muscle mass. In the recent work, a team led by pediatric neurologist **THOMAS CRAWFORD** investigated whether apitegromab — a monoclonal antibody shown in a proof-of-concept study to alter myostatin — could safely improve muscle function in a large study of patients with SMA.

At 12 months, the research team says participants receiving apitegromab showed statistically significant and potentially clinically meaningful improvements in motor function compared with participants receiving the placebo.

"Based on our findings, apitegromab has the potential to positively impact people with SMA, particularly those with weakened muscles who are unable to walk, allowing them to build muscle again and improve quality of life," says Crawford, whose team published their findings in *Lancet Neurology*.

The gene therapy study, co-authored by **CHARLOTTE SUMNER**, professor of neurology, neuroscience and genetic medicine at the Johns Hopkins University School of Medicine, finds that prenatal amniotic injections of gene therapies known as antisense oligonucleotides (ASOs) improve outcomes in two mouse models of severe SMA.

Furthermore, ASOs delivered in this manner showed broad distribution to the brain and spinal cord of fetal lambs, which are similar to humans in their fetal physiol-

> **"There is significant interest in determining how we might utilize emerging genetic therapies in utero** because there are many very severe diseases that start very, very early. This work really opens up the idea that you can use ASOs for SMA, but also for lots of other disease indications with in utero onset."
>
> **—CHARLOTTE SUMNER**

ogy. ASOs are a class of gene therapies that bind to and change messenger RNAs to alter their processing.

The implications are vast, says Sumner, both for treatment of SMA and for other neurologic diseases with onset before or at birth.

"There is significant interest in determining how we might utilize emerging genetic therapies in utero because there are many very severe diseases that start very, very early," she says. "This work really opens up the idea that you can use ASOs for SMA, but also for lots of other disease indications with in utero onset." The findings appear in *Science Translational Medicine*.

The next step, Sumner says, is finding the right ASO for a clinical trial. The ASO currently used for patients with SMA was approved nearly 10 years ago. "We would envision that a new-generation ASO would be more appropriate for testing in utero," she says. **KIM POLYNIAK**

Toward Safer Radiation Therapy

In an effort to make radiation therapy safer and more effective for children with brain tumors, Johns Hopkins is establishing the Johns Hopkins Pediatric Radiation Oncology Research Center and launching the first dedicated pediatric radiation oncology data platform in the United States.

The initiative includes collaboration between leading children's hospitals, including Children's National Hospital, Massachusetts General Hospital, Children's Hospital of Philadelphia, and the Kennedy Krieger Institute. It also includes the creation of a shared pediatric brain tumor database spanning 60 institutions.

The new center is funded by a transformational investment by an anonymous donor and includes the Johns Hopkins Proton Therapy Center at Sibley Memorial Hospital and the East Baltimore Campus of Johns Hopkins Medicine.

Look for more about the new initiative in the spring issue of *Hopkins Children's* Magazine.

Historic Support from the Harriet Lane Home Foundation

This summer's meeting of the Harriet Lane Home Foundation Board of Trustees had an exciting conclusion, as its members traveled to The Johns Hopkins University's Homewood campus to see the foundation's name inscribed on the Founders Wall. The wall celebrates benefactors who have donated at least $7 million — the amount of the gift made by benefactor Johns Hopkins to establish the university and hospital.

"We're delighted about it," says **FREDERICK KOONTZ**, chair of the foundation's board and senior counsel at Whiteford, Taylor and Preston. "The Harriet Lane Home has been an integral part of The Johns Hopkins Hospital and particularly, the Children's Center, for many, many years. So to have this history recognized on the Founders Wall is great."

Since the 1990s, the foundation has directed the majority of its gifts toward the Division of Pediatric Nephrology and the Harriet Lane Kidney Center, with annual six-figure contributions (now totaling over $8.5 million), says Division Chief **ALICIA NEU**. "It has allowed us to continue to provide state-of-the-art care to some of the sickest children in the hospital," she says.

The relationship between the board and the division began at a time when developments for treatment of end-stage kidney disease, dialysis and transplant in pediatric patients "were really advancing," Neu says, including better therapies to provide dialysis to acutely ill children. Then-Division Chief **BARBARA FIVUSH** seized upon that, developed the first home peritoneal dialysis program in the state and built up clinical programs for children with end-stage and chronic kidney disease who needed transplants and dialysis. The division also provides lifesaving dialysis for young patients with complex congenital heart disease, and those who are undergoing heart or liver transplants, who have kidney failure, Neu says.

"The foundation really has supported every aspect of the division, including comprehensive, multidisciplinary outpatient care from social workers, dietitians, behavioral psychologists, child life specialists and specialized nurses, in addition to physicians," says Neu.

Additionally, the foundation's gifts have supported Camp All Stars (see p. 14), an annual two-day overnight camp for children and young adults who have chronic kidney disease, are on dialysis or have had kidney transplants, as well as pilot research studies and advocacy projects.

Foundation funds have also provided support to the palliative care program at the Children's Center; clinical programs for children with diabetes, pancreatic disease and gastrointestinal diseases; and the development of a complex care team to coordinate care for children with multiple medical/surgical issues.

"They're absolutely dedicated to funding things that benefit the children who receive their care at the hospital, and the children of Baltimore," Neu says. "We simply could not do the work that we're doing without their support." ***KAREN BLUM***

To support the Division of Pediatric Nephrology, contact Allie Boge at hopkinschildrens@jhmi.edu

Golfing with Heart

In September, an annual golf tournament started by businessman Doug Miller Sr. in 1985, which has raised a cumulative $2 million for the Children's Center, celebrated its 40th anniversary.

Most recently, the funds raised have supported critical activities not covered by families' health insurance, including the work of social workers and Child Life specialists, through the Doug Miller Family Fund. After Miller, who owned several local fuel service stations, died in 2016, Carroll Motor Fuels, a local independent oil and gas distributor since 1907, proudly continued the event and his legacy.

"Doug Miller inspired us," says Rick Phelps, executive vice president of Carroll Motor Fuels. "We wanted to laser in more toward the community that we serve and that supported us. The Children's Center is such a great cause, and it's a local charity that we have all embraced."

Four decades ago, Miller and his wife, Joyce, started the tournament after their daughter, Jeannette, received care as an infant at the Children's Center in the 1970s. Miller had also been a longstanding business partner with Carroll Motor Fuels since the 1980s. When the company acquired the property and branding rights to 70 BP service stations in 2006, including Miller's stations, the relationship deepened. That same year, Miller and Carroll Motor Fuels launched the tournament together, united in their shared commitment to community and care. Since 2016, Carroll has kept the tradition alive by hosting the tournament in partnership with Joyce Miller and Doug Miller Jr.

This year's event was the 19th Annual Doug Miller Sr. Memorial Golf Tournament. At the Country Club of Maryland in Towson, the day began with breakfast before the golfers teed off for 18 holes. Afterward, there was a dinner and reception at the club. About 150 people attended, including Jeannette Miller, now executive director of the Fellowships & Writing Center at Harvard University, and her family.

Each year, Carroll Motor Fuels partners with the Children's Center to invite a family to share their story during the reception. This year, Patrick Campbell spoke about his daughter, Analisa, who began limping as a baby and even refused to walk. After months of confusion and unanswered questions, Analisa was diagnosed with juvenile rheumatoid arthritis by Children's Center doctors when she was 18 months old. With proper treatment and relentless care and support, she has been able to adapt and even thrive while living with this lifelong condition. Now four years old, Analisa attended the event, a bright reminder of the lives touched by the hospital's care.

> "Doug Miller inspired us. **The Children's Center is such a great cause, and it's a local charity that we have embraced."**
>
> —RICK PHELPS

"To see his daughter today at the golf tournament, she was full of energy and bopping all around, just as happy as can be," says Linda Brannan, vice president of human resources at Carroll Motor Fuels. "Stories like theirs really capture the heart of what this tournament is all about."

GEORGE DOVER, the longtime director of the Children's Center who retired in 2016, spoke about the enduring impact of this event. "All of the participants should go home much taller knowing that they had been instrumental in raising the hopes of children and families at the Children's Center," he says. "Doug Miller and his family have benefited thousands of families through their efforts." ***JENNIFER WALKER***

To support the Doug Miller Family Fund, contact Jen Doyle at hopkinschildrens@jhmi.edu

Research: 'The Fabric That Unites Us All'

WILL KIRK

Inspired by Johns Hopkins University's systemwide Research Saves Lives campaign, which is calling attention to the critical role of research in advancing patient care, clinicians and researchers at the Children's Center have started a Research Saves Children campaign.

"I think a lot of families don't really understand that the things we do every day that bring their child back to health are evidence-based clinical practices — that research indeed saves children," says **BRENDA BANWELL**, co-director and pediatrician-in-chief of the Children's Center.

Beyond building awareness, the campaign is designed to function as a mechanism for people to donate to lifesaving pediatric research, she says. "We have lots of needs for research support and a lot of programs that are right at the cutting edge of being ready to launch the next step of their work," Banwell says.

The campaign kicked off Sept. 15 with a State of the Children's Center Grand Rounds talk by Banwell and **DAVID HACKAM**, JHCC co-director and pediatric surgeon-in-chief. The gathering was well-attended by faculty and staff, many wearing T-shirts emblazoned with the new "Research Saves Children" slogan (more than 700 were sold, with proceeds going to support the campaign). A science fair-type show-and-tell event where researchers can discuss their research also is being planned, says Banwell. In addition, a campaign website features stories of children successfully treated at Johns Hopkins thanks to research advances.

At a time when there is a clear need for research funding, the idea is to build awareness of how Children's Center experts bring health

VITAL SUPPORT

In the wake of federal research cuts, **BRENDA BANWELL** and colleagues are actively pursuing philanthropic support to continue vital research efforts at the Children's Center. Newly funded initiatives include:

- Among its many philanthropic efforts (see p. 24), the Harriet Lane Foundation is supporting two additional studies. One is following 12- and 24-month-olds who had been treated in utero with amniotic fluid because they didn't have kidney function and structure, and who received kidney transplants after birth, to determine how they are doing developmentally. The other is evaluating how best to counsel, diagnose and treat adolescents with sexually transmitted infections.
- The Hospital for Consumptives of Maryland (Eudowood), a nonprofit foundation, is providing support to eight faculty members who lost federal funding by providing them with grants to support early stages of enterprising research. The foundation also created an accelerant team to move research into clinical trials, replacing a clinical trial network for adolescents that had been defunded. That team is led by pediatric infectious diseases specialist **ALLISON AGWU**.
- A member of the Children's Center's Advisory Board is supporting a research project that had lost funding, which focuses on suicide prevention in teenagers.

and recovery to children in need, Banwell says.

"Research is discovery," Banwell says. "It's clinical excellence, it's best practice, it's safety and quality. It's a lot of things that families may not see."

LAUREN JANTZIE, a neuroscientist at the Children's Center, says she was eager to join the campaign. Her lab studies babies and very young children in the Children's Center's neonatal and pediatric intensive care units, typically ones who have had severe brain injuries. The majority of the research is on preterm infants or young children with hydrocephalus, a neurological condition characterized by an accumulation of cerebrospinal fluid in the brain. The scientists' goal is to find new therapies to treat these injuries and restore neurodevelopment.

"We're dedicated to kids who have had a stroke, are at high risk for cerebral palsy, and/or have been exposed to toxins, opioids, alcohol or cannabis," she says. "When you come to the hospital, you're never going to see me or any members of my team. We're in the lab and we're working really, really hard with our friends and colleagues who are physicians, and we're all dedicated to a very common mission. Research is really the fabric that unites us all.

"It doesn't matter whether you're a scientist or physician or a grad student or lab tech," Jantzie adds. "The campaign is about recognizing that we're all here for the patients."

KAREN BLUM

For more information or to support the Research Saves Children campaign, visit: researchsaveschildren.org

Little Steps, Big Cause

On September 27, more than 1,300 people gathered at the Maryland Zoo for the second annual Miracles in Motion race. The event featured a 5K run, a 1-mile walk and a 50-meter Critter Crawl kids dash. The event raised more than $225,000 for essential programs and services at Johns Hopkins Children's Center. Thank you to the sponsors, donors, participants and volunteers who made this remarkable event possible! Save the date for next year: September 26, 2026 at the Maryland Zoo.

Scan the QR code for early bird registration savings!

SAVE THE DATE

for the Mix 106.5 Radiothon, the Children's Center's largest single fundraiser: February 26 and 27, 2026

FEB

26–27

Ensuring Emotionally Safe Care

BY SUE MEAD AND PATRICE BRYLSKE

Children and their families often feel scared, overwhelmed and confused by a medical experience. When a child is first admitted to the hospital or diagnosed with an illness, parents are initially focused on doing whatever it takes to get their child physically better, which is understandable. It can be easy to overlook how to keep young patients emotionally safe in the process. The National Child Traumatic Stress Network reports that up to 80% of children and their families experience at least some traumatic stress reactions following medical treatment for life-threatening illnesses or injuries. When these reactions persist, they can impair a child's day-to-day functioning, affect adherence to medical treatment and impede optimal recovery.

In our roles at Johns Hopkins Children's Center, we know how important it is to provide emotionally safe care to young patients and their families. The Association of Child Life Professionals defines emotional safety as "an intentional, interdisciplinary practice to promote resiliency, healing, and trust for pediatric patients and their families during medical experiences."

Emotionally safe care is built around four pillars: proactive screening, individualized coping plans, environmental enhancements, and staff communication and education. In practice, our strategies to emotionally support children and families run the gamut, from explaining each step of a procedure in advance to reduce fear and helplessness, to teaching coping skills such as deep breathing or holding a comfort item. We believe that by centering the emotional needs of children and families in every aspect of care — from their environment to staff communication — we will help to eliminate the experience of stress and medical trauma that that can have a lifelong impact on health.

> **"In our roles at Johns Hopkins Children's Center, we know how important it is to provide emotionally safe care to young patients and their families."**

To highlight emotional safety at The Johns Hopkins Hospital, the Department of Child Life hosted an all-day Emotional Safety Summit last fall, organized around the 80th anniversary of the Child Life Department at Johns Hopkins. Leaders from across the Children's Center came together to create a shared vision of how to implement emotionally safe care for all our patients and families. Additionally, "emotional safety taskforces"— including both inpatient and ambulatory care — were formed as part of a five-year strategic planning process for the Children's Center. These groups were tasked with mapping strategies and concrete deliverables to achieve emotionally safe care for every patient, in every instance.

Furthermore, members of our Pediatric Patient and Family Advisory Council provided in-person feedback on what makes them feel emotionally safe when they seek care for their child: in the emergency room, during a procedure, at bedside rounds or during discharge. From these discussions emerged several well-established patient- and family-centered themes, including the importance of information-sharing; building trust and rapport; participation; and providing a caring environment.

We look forward to continuing this work to ensure that the practice of emotionally safe care becomes as much a part of our safety and quality culture as the practices we have in place to provide physical safety. Creating an emotionally safe environment helps to reduce patients' medical trauma and distress, and it fosters trust, paving the way for positive health care encounters in the future and improving health care-related quality of life for young patients and their families. Physical safety and emotional safety go hand in hand.

Sue Mead is a parent adviser on the staff of Johns Hopkins Children's Center and co-chair of the Pediatric Family Advisory Council. Patrice Brylske is director of the Child Life Department.

I was proud to serve as team captain for the Miracles in Motion 5K, where my employees and some of our clients joined me in supporting an incredible cause. Participating in this event was a meaningful way for us to continue our commitment to serving the Baltimore community. It also turned out to be a fun and inspiring team-building experience that strengthened our connection and shared purpose of supporting worthy causes.

Beverly Winstead, Esq.
Principal, Law Offices of Beverly Winstead, LLC
Member, Johns Hopkins Children's Center Advisory Board

Why I Give

For the last 21 years, staff at the Children's Center have been caring for our son, Hayden. His life has been saved more times than we can count and for that reason we are forever grateful. The only way we know to show that immense gratitude is to give back by fundraising and volunteering. Our hope is to help other patients and families as well as to support further research for single ventricle patients, like Hayden.

Rob and Ali Lazorchak

Our twin daughters began their story as micro-preemies and spent their first few months surrounded by the incredible Johns Hopkins Children's Center Neonatal Intensive Care Unit team. The nurses and doctors became our lifeline, giving our girls the care and faith they needed to grow. We're forever grateful that through our business, Three Wildflower Designs, we can give back and help other families feel that same hope, love and unwavering support we were blessed to receive.

Brittany Paulshock Trocher
Owner, Three Wildflower Designs

Support the Johns Hopkins Children's Center with a charitable gift. Visit **secure.jhu.edu/form/children** or call **410-361-6493**.

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