## 1000 INS INCIPENS CENTER MAGAZINE a Bernier Second The Draw of Pediatrics Residents and veteran How did critical care physicians share what specialist Meghan Bernier attracted them and and other staff manage the how they've evolved. pandemic, themselves and each other, the second time around? Photo Journal Kids giving back in surprising ways.

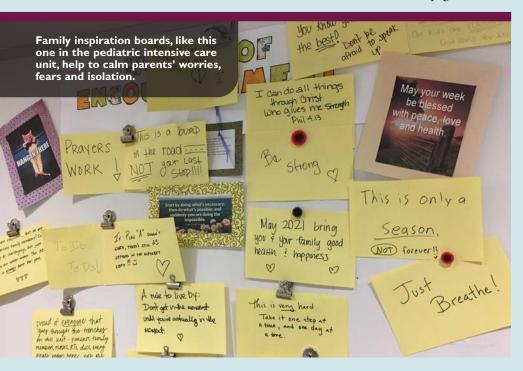
#### As Always, Supporting Families

"WHAT I WISH YOU KNEW" is a catch phrase used often over the last 11 years by parent members of the Pediatric Family Advisory Council (PFAC). We find that message even more important now, as we continue to search for effective ways to support families during the COVID-19 pandemic.

Interestingly, the realities of living during a pandemic are not unlike what our families deal with while caring for a critically ill child in the hospital: different circumstances, yet similar feelings. Each day, we receive new insights, but often, there are no concrete answers. There's worry, fear, exhaustion, added expenses and isolation. Yet, like these brave families, we keep pushing forward and gain strength as we confront this crisis.

It was only a little more than a year ago when, as we served our traditional Thursday night meal to Children's Center families, the governor held a press conference to announce the closure of schools because of the pandemic. We joked that this was likely the "Last Supper." Little did we know then! But COVID-19 didn't stop the council from continuing to assist both staff and families. We did our best to support staff with food and snacks, while volunteering at the warehouse to help make face shields, bottle hand sanitizers and fold reusable heavy

As the months wore on, we soon realized how difficult it was for only one parent to be permitted at the bedside. We tried to decrease their social isolation by introducing activities like parent bingo on Tuesdays via CCTV, hoping to provide a little entertainment and distraction — not to mention gift-card prizes. Similarly, an artist-in-residence Child Life specialist now works with parents on art projects to engage them in a medium that can help them process what they are going through and normalize their lives (see page 60).





Parent Advisor

Interestingly, the realities of living during a pandemic are not unlike what our families deal with while caring for a critically ill child in the hospital. ""

On Thursdays we continued our free meals for parents program, providing individually packaged lunches from local restaurants. We helped to orchestrate virtual town halls from every pediatric division, so that patients and families could hear directly from our physicians about COVID-19, its effects and how to protect themselves. We also launched a food pantry in the Pediatric Intensive Care Unit and in Oncology to provide grab-and-go meals and snacks, so that families don't have to leave the unit to purchase food or to feed family at home.

All Johns Hopkins Family Advisory Councils continue to meet monthly via Zoom — with better attendance than ever. We continue to advise and offer feedback about visitation, marketing and patient education surrounding COVID-19 and the vaccine. We have also created our own social media page for families to follow while they're in the hospital. That way, they can receive daily updates on special virtual activities on CCTV. In the spirit of "What I wish you knew," we continue to solicit ideas from parents to support them and their families, especially during this difficult time. Please let us know your ideas, too. Thank you. 🐠



The daughter of a bricklayer, King knew since childhood that she wanted to do something with her hands. Little did she know it would be saving the lives of children needing new kidneys and livers.

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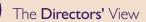
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## Aiming for Health Equity

It has been quite a year. In addition to grappling with racial injustice and increasing urban unemployment and poverty — among other stressors — we and our patients and families have faced a pandemic that has claimed half a million lives in this country. Children have not gotten as sick as adults, but, as Pediatric Hospital Medicine Division Director **Eric Biondi** noted this winter, "We can no longer say that children are not affected by COVID-19." Read "The Second Surge" feature story in this issue (pages 4-15).

Similarly, issues such as racial disparities have motivated us to work harder to ensure health equity for all of our patients. That means promoting equal access to health care and, especially during these times, providing vaccines against COVID-19. Another concern is the need for greater awareness by our staff about unconscious discrimination in working with our patients and families — as well as each other. See our interview on implicit bias with **Maria Trent**, chief of the Division of Adolescent and Young Adult Medicine, and her colleagues (pages 30-31).

Being aware of how we as pediatricians communicate with our patients and their families, colleagues and staff is one trait of a superb pediatrician. Compassion, curiosity, empathy — seeing medicine through the patient's lens — are equally vital attributes. How do we support these goals? Learn what pediatricians **Barry Solomon**, **Hoover Adger** and **Nicole Shilkofski**, among others, have to say on the subject, in "The Draw of Pediatrics" (pages 22-29).

An innovative mind is yet another characteristic we aspire to—and remains at the heart of much of what we do here. Whether through the delicate resection of a spinal cord tumor with neurosurgeon **Alan Cohen** or the building of a new congenital heart center with cardiac surgeon **Bret Mettler**, cardiologist **Shelby Kutty** and intensivist **Jamie McElrath Schwartz**, we continue to advance care for children (see "Pediatric Rounds" pages 32-45).

Thank you, and enjoy this issue.



Margaret "Maggie" Moon, M.D., M.P.H. 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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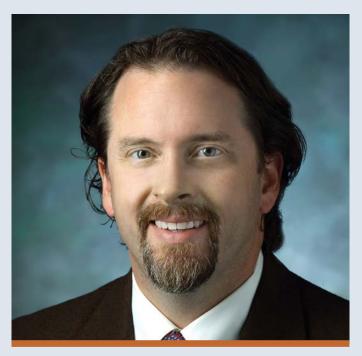
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Give us feedback Send letters to Gary Logan at the above address, or email glogan@jhmi.edu.

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## Pediatric Chaplain Matt Norvell

Following training, he sought a place where the pace was fast and the stakes higher.

by Julie Weingarden Dubin

att Norvell pulls into the hospital parking garage during the early morning and receives a page: A young patient unexpectedly went into surgery and the mother is crying, afraid that her child may not survive. Norvell sits for hours with her in the surgical waiting area, reminding himself this is why he chose to become a minister and pastoral counselor.

"In high school, people said I was a really good listener and that shaped me," he says. "A piece of my inspiration toward professional ministry was the desire to be with people and understand their relationship with themselves, with other people and with God."

Norvell was always drawn to the oneon-one counseling of ministry, but he found through his early intern work that the pace and intensity of the medical world was a better fit. "When you get a call in the hospital, there's an acute need to help someone, where in a church setting it's more sporadic," says Norvell, pediatric chaplain at Johns Hopkins Children's Center.

Why the focus on children and their families? "The stakes feel a little higher working with sick kids," he says. "Nobody ever says, 'He lived a good life' when a kid dies. It's always a bad thing."

Norvell received a Master of Divinity from Duke Divinity School and a Master of Pastoral Counseling from Loyola University. He started at Johns Hopkins in 2007 as a chaplain resident in pediatrics, and he was then hired as a pediatric palliative care support specialist. When funding came through for a Department of Pediatrics chaplain, he landed the job following a national search.

In addition to supporting patients and families, Norvell tends to the spiritual and emotional health of Children's Center staff members: "A challenge for health workers taking care of sick, vulnerable children, is there isn't a place built into their professional role to deal with emotions."

Norvell lets them know that he's available when they need to talk. If the stress they face isn't addressed, Norvell says, there may be consequences that interfere with their mental health and their ability to do their job.

44 A challenge for health workers taking care of sick, vulnerable children, is there isn't a place built into their professional role to deal with emotions.

"They tell me they haven't slept because of stress," he explains. "I say, 'Dude, this is a real thing. You should pay attention to this."

When the pandemic hit, however,

Norvell had to make such connections in new ways: Walking the halls and making eye contact above all the masks. Comforting patients by talking by phone through glass doors. Sending the entire staff weekly inspirational emails to ease anxiety.

"Most of the world was being told to stay home and health care workers were told to come to work," says Norvell. "That worry of putting their lives and their families at risk layered on top of trying to teach kids at home, see a sick parent and somehow find toilet paper, was too much."

One resource for staff is the RISE (Resilience in Stressful Events) program, co-developed by Norvell. It provides emergency psychological and emotional first aid to employees — if something goes wrong with a patient and the staff member doesn't want to talk about it with coworkers, the employee can talk to a peer responder.

"When COVID hit, RISE went from about four calls a week in January to 30 calls a week March through May," says Norvell. "RISE is now in 65 hospitals across the country."

For his own emotional stability, Norvell focuses on his family and hobbies like gardening, golf and bluegrass jam sessions. "When I'm playing the banjo," he says, "I can immerse myself in the music and not think about health care or COVID."



**BY MAT EDELSON** 



"SUDDENLY WE WERE WORKING 100-HOUR WEEKS FOR SIX STRAIGHT WEEKS IN THE COMMAND CENTER, BECAUSE IN THE FIRST WAVE PROVIDERS WERE SCARED. THERE WAS SO MUCH TO FIGURE OUT ON THE FLY—THINGS LIKE HOW TO TEST PATIENTS COMING INTO THE HOSPITAL, WHAT KIND OF PPE WORKED BEST, ANYTHING AND EVERYTHING REGARDING INFECTION SPREAD."

#### — AARON MILSTONE

#### This was definitively not a drill.

In early March 2020, the newly formed Incident Command Center at Johns Hopkins Children's Center (JHCC) convened for the first time. After nearly three months of rumors, chatter and terrifying news reports, SARS-CoV-2, the virus that causes COVID-19, had made the 7,573-mile journey from Wuhan, China, to Johns Hopkins' front door.

The mood in the Command Center was concern tinged with fear; the scene, frankly, a bit chaotic. Some in the overcrowded small room wore masks, others did not. Open platters of food were scattered about the conference table, as if this was just another catered meeting. With little official guidance yet on what to do — this was before the words "physical distancing" and "mask" became as ubiquitous as "um" — everyone was ad-libbing, and no one was pleased. Said one participant, "We were all looking at each other like 'this doesn't feel OK."

But from this initial tumult emerged a coordinated effort unprecedented in the Children's Center's history. Hundreds of faculty and staff united to solve daily crises. In a time calling for the ultimate in fluidity and flow, the can-do spirit that has so often permeated the walls of Johns Hopkins led to a "get 'er done, titles-be-damned" mentality.

And it paved the way for the Chil-

dren's Center to remain open and care for patients, staff and the community as the second surge of COVID-19 engulfs Baltimore.

OW DOES ONE DESCRIBE the unprecedented 18 months since the pandemic assaulted Charm City? For the staff — and we talked with more than 20 for this story — there's the daily dichotomy of living inside a plague of seemingly biblical proportions. They've been awed by their fellow staff members, describing them as "heroic," "brilliant," "creative" and "innovative." But individually, they admit to feeling "frustrated," "exhausted," "soul-crushed" and "helpless," from the experience.

Even as vaccines reach outstretched arms across Johns Hopkins, the finish line remains hazy. Virus variants muddy the view as death tolls climb well past the half-million mark nationally, with more than 8,000 dead in Maryland. Fortunately, childhood deaths make up a very small percentage of that number, but that doesn't mean pediatric staff have sat on the sidelines during the crisis.

Far from it. Because of its physical and institutional connection to the adult side of Johns Hopkins Medicine, the Children's Center has been pulled

into the pandemic's vortex like wind being sucked through a jet engine. This dynamic tension between sharing precious resources serving the highly impacted adult population while still carrying out the Children's Center's mission to safely treat children is the continuing through-line in this tale. It is a story of great self-sacrifice, a shelving of egos, and a marshaling of talents and skills that have so far met — and perhaps even stayed a step ahead - of the greatest medical emergency Johns Hopkins has ever faced.

On a functional level, there have been huge alterations in day-to-day operations. Part of the pediatric intensive care unit (PICU) was retrofitted to admit and care for adult patients with COVID-19. Necessary negative pressure rooms for patients with COVID-19 were built nearly overnight. Telemedicine (Zoom-like video outpatient consults with patients and families in their homes) soared. A scarce resources allocation group was convened to ensure all staff had proper PPE (personal protective equipment). Child Life expanded from the bedside to the car side, developing coping plans that nurses could use to comfort anxious children as they got tested for coronavirus in drive-up sites. Work schedules were revamped when the



governor banned elective procedures for roughly two months beginning last March. Even pediatric medical residents felt the impact, deploying into adult care across Johns Hopkins. In the Children's Center, overseeing it all was its Incident Command Center, which met daily for weeks, coordinating the crisis and pumping out a steady stream of science-solid information to an understandably uneasy staff.

And make no mistake — keeping the staff safe and healthy, both physically and psychologically, has been as daunting as maintaining premium standards of patient care. In the first surge, nearly 100 staff members tested positive for COVID-19, but that number has dropped drastically as the Children's Center successfully created a "bubble" environment. By instituting a oneparent visitor policy, and urging nonfront-line staff to work at home when possible, the Children's Center feels like an awfully quiet but far safer place these days, at least when it comes to COVID spread.

Yet those same distancing policies, and the social isolation they impose, are difficult to bear for months on end for patients, families and staff. Not surprisingly, calls from staff to Johns Hopkins RISE (Resilience in Stressful Events) teams have soared, as has outreach to pastoral care and other psychological services.

In other words, everyone's helping, and everyone's hurting.

T'S NOT AN OVERSTATEMENT to say that in the first days of the pandemic, people were desperate for information. With treatment and PPE protocols and the Centers for Disease Control and Prevention recommendations changing sometimes hourly, getting up-to-the-minute info to the front lines was critical. That task fell to the JHCC Incident Command Center. "A crisis situation requires an all-handson-deck community where everybody has a voice, and the Incident Command Center got people together

daily to make decisions," says **Maggie Moon**, co-director of Johns Hopkins Children's Center, "but a big part was informing everybody affected by those decisions to help them anticipate and feel engaged and confident about what's coming next as much as anyone else."

Between in-person and Zoom attendees, several dozen people often took part in the daily briefings, including division heads, charge nurses and top administrators. Even for those with previous disaster training, this was suddenly the real deal unpredictably unfolding in real time. As one faculty member put it, "COVID was like playing whack-a-mole, where stuff just pops up and we all had to jump on it." Each day's briefing included a COVID case and PPE count, along with robust discussions of how to put out the latest COVID-related brush fires. Recording and distilling all that conversation into easily digestible all-staff emails and texts fell to Cathy Garger and Rebecca **Trexler**. As was common with many staff during the crisis, Garger, a pedi-



"IT'S A MOMENT IN TIME WHEN A GROUP OF PEOPLE IDENTIFY A SUDDENLY EMERGING PROBLEM AND RAPIDLY COMBINE BRAINPOWER TO FREELANCE A SOLUTION. TEAMING THRIVES ON TRUSTING YOUR TEAMMATES AND IMPLEMENTING RAPID **ITERATIONS."** 

-DANIEL HINDMAN

atric nurse with disaster-coordinating experience, and Trexler, the project administrator for patient- and familycentered care, went beyond their job descriptions to take on these crucial communications duties. Trexler's daily email (it's now weekly) covered the basics for staff: negative pressure room bed availability, ICU COVID cases, the latest advice from the Hospital Epidemiology and Infection Control (HEIC) team, hospital COVID-care resources and contact info to reach the Command Center. "We were seeking consistent messaging and narrowing the info to 'here's what you need to know that's happening during the surge," says Trexler.

In time, Trexler's notes, vetted by Moon, have become a one-stop CO-VID-awareness shop cutting through the numbing amount of emails common to any staff member's inbox. By example, Trexler's Dec. 14, 2020, all-staff email contained the JHCC Incident Command Center summary, along with a PowerPoint explaining why Johns Hopkins Medicine was starting asymptomatic COVID testing for hospitalized patients every seven days of their stay, and another Power-Point featuring pediatric infectious disease specialist Anna Sick-Samuels explaining the workings and studies of the then-just-approved Pfizer vaccine.

This regular messaging is helping to keep everyone on the same page, says Moon. "The feedback I was getting from staff is that, if the rules change from yesterday to today, it's unjustifiable to ask people to work in the dark; the staff all said, 'we'll do anything we need to do to make this right, but we need to know what to do, and we need to know why.""

HERE'S AN OLD SAYING, perhaps apocryphal, that in crisis comes opportunity. The COVID crisis stripped Hopkins' bureaucracy to the core. There were simply too many problems requiring too many solutions too quickly for the process to be slowed by traditional medically conservative chain of command. What occurred is what pediatrician Daniel Hindman calls "teaming," borrowed from the book Teaming by Amy Edmonson.

"It's a moment in time when a group of people identify a suddenly emerging problem and rapidly combine brainpower to freelance a solution," says Hindman, who practices mostly at Johns Hopkins Bayview Medical Center. "Teaming thrives on trusting your teammates, and implementing rapid iterations. And when you don't have an option to wait around, you decide to do something knowing it won't be perfect, (then) figure out what doesn't work, then try it again with some modification and keep doing that."

This idea of teaming spread through pediatric staff nearly as fast as the pandemic. It's a delicate balance. Ethically, one can't improvise to the point that care is compromised. But in the absence of established protocols, sometimes a best guess is the best (and only) way to go. For Hindman, that meant handwriting a negative-pressure-care protocol for Johns Hopkins Bayview the night the governor announced the first COVID cases reached Maryland.

#### For Residents, Uncharted Waters

obody enters a residency expecting to confront a pandemic, but that's exactly what happened to Zach Claudio and Shira Ziegler. Claudio, a third-year resident, remembers the pandemic's onset as being "in unchartered waters," what with anxieties of how the disease spread, whether children would be affected, and if residents would get sick en masse. Claudio says that unease was quelled somewhat "as Hopkins had been manufacturing some of their own PPE, so we knew we had adequate supplies versus some friends I knew who worked in community hospitals."

Claudio was redeployed into an adult ICU. His last adult care experience came in medical school, and he admits, "I was nervous at first, because a lot of the co-morbidities these adults had I hadn't seen in quite some time, being a pediatric resident. But we had a really strong team where no one cared that I was a pediatrician; I always felt I had someone who could answer my questions, and I never felt like I was doing anything unsafe."

For Ziegler, a third-year pediatrics and genetics resident with an M.D./ Ph.D., COVID ground her research to a sudden halt. "They needed (clinical) hands, and though it's a little cliché, I had this very inner desire to help," says Ziegler, who volunteered to work in the part of the PICU redesigned for adult patients with COVID. "We created a biodome and had to bring in all this adult equipment; new beds, pumps, supplies, lots of logistics for dealing with patients five times larger than who we're used to taking care of," says Ziegler. "But our team rallied and just came together, focusing on giving them the best care during a novel virus and circumstances nobody could have expected."

"We created a biodome and had to bring in all this adult equipment; new beds, pumps, supplies, lots of logistics for dealing with patients five times larger than who we're used to taking care of."

- SHIRA ZIEGLER



For pediatric anesthesiologist and critical care specialists Jamie McElrath Schwartz and Rahul Koka, it meant literally taking down walls and reorganizing staff.

With the adult side of the hospital getting slammed by COVID, Schwartz, who is division chief of pediatric critical care medicine, worked with building operations and pediatric leadership to quickly create new adult ICU beds within the PICU. Koka's role, as the anesthetic director of the daily flow within the pediatric operating rooms, was to work with Schwartz's team to ensure the safety of all providers and patients who required emergency and trauma surgeries, which were still allowed after elective surgeries were temporarily banned by Maryland Gov. Larry Hogan in early March 2020.

Koka also handled redeployment of the numerous pediatric anesthesiologists who volunteered to work in other adult side departments to meet the crisis.

"We went from a complete bureaucracy and not being able to change a lightbulb without input from nine different departments, to building seven ICU beds in three days," recalls Koka. "That's amazing, and I'm proud of our ability to become agile overnight."

That ability was sorely tested in the wake of the elective surgery shutdown, as there was an immediate ripple effect on the Children's Center. Many parents canceled pediatric visits, fearing that Johns Hopkins, like many hospitals, was a COVID hot spot. From a care viewpoint, this belief had potentially dire consequences. Children with controlled chronic conditions risked becoming unstable, while other youngsters faced disrupting their scheduled routine childhood vaccines.

The situation might have become untenable, if not for the efforts of pediatrician Helen Hughes and pediatric cardiologist and Chief Informatics Officer Philip Spevak. Hughes had independently started a telemedicine pilot a few years earlier, serving a rural Maryland community (Talbot County) so they wouldn't have the long commute to Baltimore for routine care. Her small outreach, roughly 10 cases, along with a few scattered cases in pediatric cardiology and other specialties, accounted for all of the Children's Center's telemedicine cases. But when COVID hit, Hughes began mentoring other faculty to get them comfortable with providing telemedicine care.

Hughes, Spevak and Senior Business Intelligence Analyst Muhammad Ismail partnered with the institution's Office of Telemedicine to streamline the process so patients could access telemedicine video calls with just a few clicks on their MyChart account.

The results have been nothing short of astounding. "By May and June, we averaged over 4,000 telemedicine video visits per month, accounting for about 60% of our total case volume," says Hughes, who was promoted to assistant medical director for Johns Hopkins Medicine's Office of Telemedicine on July 1, 2020.

That confidence level in using video has spread to the inpatient service as well. With COVID protocols demanding the fewest people possible by the bedside, telemedicine has changed traditional patient rounds for perhaps the first time in a century. Instead of simultaneously jamming residents, fellows, attendings, students, Child Life spe-

cialists and nutritionists into a patient's room, "Now we have our team sitting in a conference room, and we have only one or two people walk around the patient with an iPad for everyone else to see and hear," says Eric Biondi, director of pediatric hospital medicine. "We're still 'rounding' with the whole team, and honestly, it's increased our efficiency quite a bit. I don't really want to go back to the old way of doing it."

There have been other innovations as well. Throughout the second surge, as care protocols for adults became standardized, the Children's Center pitched in by creating non-ICU space for recovering adult patients. They also found they were able to treat multisystem inflammatory syndrome in children (MIS-C), a rare and terrifying disease linked to COVID. Tragically, one child died from MIS-C last May, but since then, the Children's Center has successfully cared for more than 30 patients with MIS-C. And over at the

outpatient Harriet Lane Clinic, faculty have had a good response reaching out to East Baltimore residents and convincing them that it's safe to bring their children back in for well-care visits and scheduled vaccines.

If the story were to stop right here, one might assume all was humming along well at the Children's Center.

But that's not the case. Just like nearly all front-line workers, mental health issues facing Children's Center staff were palpable. "At first, it was easier to recognize the emotional toll because it was based on stress and fear," of CO-VID's communicability and lethality, says pediatric epidemiologist Aaron Milstone.

In the second surge, that fear has given way to an unrelenting funk. "The number of calls to our RISE teams has actually decreased (from the first surge) says epidemiologist and surgeon Albert Wu, who directs RISE. "I think people are just getting discour-



"WE WENT FROM A COMPLETE **BUREAUCRACY AND** NOT BEING ABLE TO **CHANGE A LIGHTBULB** WITHOUT INPUT FROM NINE DIFFERENT DEPARTMENTS, TO **BUILDING SEVEN ICU** BEDS IN THREE DAYS. THAT'S AMAZING, AND I'M PROUD OF OUR ABILITY TO BECOME AGILE OVERNIGHT."

-RAHUL KOKA

#### **Nurses: The Soldiers in the Battle**

enior Director of Pediatric Nursing **Dawn Luzetsky** understands the stress front-line workers have felt during the pandemic. Her job has been to quell that anxiety wherever she can. When nurses were asked to go to the adult side of the hospital to provide overflow care, they were torn; they wanted to help, but preferred to do it in a familiar location. So Luzetsky and other pediatric administrators lobbied hospital leadership for a new unit within the pediatric intensive care unit (PICU) that could handle adults with COVID. In essence, a new team was created: PICU nurses on their home turf working side by side with a medical intensive care unit (MICU) adult intensivist and a MICU nurse consultant to provide

top-notch care. "I was so proud of that partnership, because it was truly the voice of the pediatric front line saying, 'we want to help,' and leadership heard them," says Luzetsky.

Just staying employed was another major concern for nurses. Inpatient cases plummeted when the governor banned elective surgeries in March 2020 for two months, and outpatient visits dropped precipitously as well. But between some early retirements and creative scheduling, Luzetsky and Assistant Director of Pediatric Nursing **Lisa Fratino** have kept nurses working and their paychecks rolling, and their efforts didn't go unnoticed.

"The nurses are really the heroes of this pandemic," says former chief surgi-

"The nurses are really the heroes of this pandemic. I felt like there was no nurse not utilized, redeployed everywhere, such as our testing sites. It was a massive effort on their parts, and so I feel we can't thank our nurses enough for being the soldiers in this battle."

-FORMER CHIEF SURGICAL QUALITY OFFICER EMILY BOSS

cal quality officer and otolaryngologist **Emily Boss**. "I felt like there was no nurse not utilized, redeployed everywhere, such as our testing sites. It was a massive effort on their parts, and so I feel we can't thank our nurses enough for being the soldiers in this battle."



aged. Even when we do respond to a call, more people are silent; they're just emotionally and physically fatigued."

Still, RISE and other staff committed to offering psychological help have done their best to keep the demons at bay. **Carisa Parrish**, who co-directs pediatric medical psychology, launched an initiative for employees dealing with home-schooling challenges. She admits it's not always an easy sell. "For many people, prioritizing their mental health is the last thing they do after they have covered every other priority, regardless of the positive influence it might make for them," she says.

And yet there are breakthroughs, both big and small. Johns Hopkins, unlike many institutions, deemed Child Life and Pastoral Care staff as essential workers, which greatly benefited patients and staff. By example, Child Life has long had a closed-circuit TV channel for children. With COVID infection prevention efforts eliminating play visits with siblings and friends, Child Life has tried filling that void by rapidly expanding live programming to five days a week, broadcasting entertaining and educational shows for kids eight hours a day.

Similarly, limited parental visitation has affected the neonatal intensive care unit. Consider that one of the most stressful events for parents and staff is dealing with a terminally ill baby; in response, Reverend **Kat Kowalski** had previously created a perinatal palliative care program, helping parents from when they first receive pre-term news about their baby's condition through end-of-life care. But when COVID hit,

visiting restriction meant parents were rarely in the room together with their child until the very end.

Still, Kowalski was determined to remain that constant reassurance in these parents' lives, even if she is now often physically off-site to keep patients and their families safe. "I've been able to do a lot of teleministering this year, and I think it's actually been very effective," she says. "It was a natural segue, really, because I'm already working with a lot of outpatient pregnant moms in the perinatal program. It's always been easy for me to text a mom and say, 'I'm thinking about you,' and then I can come in and provide in-person support during really tough times, having already established a relationship (through teleministry)."

Kowalski adds that staff members



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-CARISA PARRISH

have also been reaching out to her in increased numbers throughout the pandemic. "There was a huge uptick in prayer requests. Whether it was 'My grandfather has COVID and I'm really worried about him,' or 'I'm pregnant and I'm afraid to be at work' ... various things people would send me, and it was reaching out in a different way for help."

COVID's greatest long-term institutional impact may be that the psychological resources available around Johns Hopkins are working together in new ways. "We've coordinated for the first time very closely with the other helping services at the hospital," says RISE's Albert Wu, pointing to programs available to all Children's Center staff. These include the Healthy at Hopkins initiative as well as outpatient psychiatric services, which brought back retired and semiretired staff to handle the mental health crisis. "As an institution, I think there's a new appreciation for staff resiliency and their ability to execute their mission," says Wu. "Our leadership has really embraced the services we call MESH — protecting our staff's mental, emotional and spiritual health."

O WHERE, EXACTLY, does the Schildren's Center stand as it endures this second surge? It's tempting to think that as vaccination rates rise across Johns Hopkins (the institution has been lauded for the fairness with which they've disseminated vaccines to front-line workers), the pandemic will eventually recede into memory, overtaken by whatever is the "new normal." And indeed, that may eventually happen; barring some unforeseen circumstance like the spread of a new, uncontrolled variant, leadership doesn't expect that there will be additional elective procedures or clinical shutdowns. There's also a sense that many of the initiatives (such as telemedicine) implemented throughout the pandemic will become a permanent part of clinical care.

But in the meantime, many staff members believe there's still a psychological toll to be paid, a shock that may set in when the pandemic has supposedly passed. Call it pandemic PTSD. Some have already succumbed, retiring or resigning when possible, calling in sick for days or weeks on end when that's not an option.

"There's a mental health tsunami coming at us, and it's tough to know

"WE KNOW WHAT WE'RE DOING NOW: IT'S NOT THE SAME PANIC SITUATION AS DURING THE FIRST SURGE. YES, IT'S A BURDEN, BUT WE ARE CALM NOW, WE UNDERSTAND IT, AND WE'RE CAPABLE OF A VERY NIMBLE RESPONSE."

-MAGGIE MOON

when it's going to hit," says Parrish. "It'll be when people can actually unclench and think about what they went through, the losses. There's going to be a lot of PTSD and depression. It's not surprising; people have been operating on hypervigilance 12 hours a day for so long."

As with all wars, pandemics do end, whether it's after this second surge or additional aftershocks. Either way, there's the sense that the Children's Center will come out of this a better institution, even more deft and with far greater resilience than anybody could have expected or asked for. That's already happening, says Children's Cen-

ter Surgeon-in-Chief **David Hackam**, who notes that while the Children's Center ceased elective surgeries early in the pandemic, its need to perform emergency surgery, especially in newborns, never slowed down significantly.

"Multiple teams operating in spacesuit-like, battery-powered protective gear came together and showed an incredible amount of creativity, flexibility and expertise in providing complex pediatric care," says Hackam. Comparing the second surge with a marathon, he adds, "We will get through this together, and those who are struggling, the rest of us will pick them up — and we will carry them forward." It should, at least, be a more manageable lift, thanks to what the Children's Center has learned over the past yearplus. The JHCC Incident Command Center is still convening and communicating, although virtually now, expanding the content of its Friday email summary and Wednesday Zoom update. "We know what we're doing now; it's not the same panic situation as during the first surge," says Maggie Moon. "Yes, it's a burden, but we are calm now, we understand it, and we're capable of a very nimble response."

### Infection Control: 100-Hour Weeks on the Fly

t's rare that infectious disease specialists are a hospital's most soughtout physicians, but COVID-19 has spotlighted the work of faculty such as epidemiologist **Aaron Milstone**. A member of the Children's Center Hospital Epidemiology and Infection Control (HEIC) team, Milstone, along with **Lisa Maragakis**, **Anna Sick-Samuels**, **Taylor McIlquham** and other HEIC members were the go-to consortium for keeping hospital staff and patients COVID-safe.

For Milstone, suddenly being high profile and in demand was a career first. He agrees that, in normal times, infectious disease docs are often seen as a bit of a pain in the neck, always reminding people of basic hygiene. "It's

like being a traffic cop. You're trying to protect people, but you're unpopular," says Milstone.

That all changed when COVID hit. "Suddenly we were working 100-hour weeks for six straight weeks in the Command Center, because in the first wave providers were scared," says Milstone. "There was so much to figure out on the fly—things like how to test patients coming into the hospital, what kind of PPE worked best, anything and everything regarding infection spread."

Millstone adds, "Usually, we're told we're doing too much (regarding normal infection protocols)," says Milstone. "But in the beginning of the pandemic, we ironically got criticized for not being conservative enough; people wanted more PPE, more testing."

Now with COVID care becoming more routine in the second surge, Milstone worries that, even with vaccinations, staff are letting down their guard. "We're beginning to get that resentment again," regarding their infection-protection advice. "This is not the time to be complacent. This is when it matters most."

"We're beginning to get that resentment again. This is not the time to be complacent. This is when it matters most."

- AARON MILSTONE



Levin and Katherine Hoops.

#### **Battling Multisystem Inflammatory Disease**

#### **BY GARY LOGAN**

After a year in the trenches facing the pandemic's most lethal threat to children. intensivists cite significant gains in diagnosing and treating this new disease and saving lives.

ollowing the arrival of the coronavirus in early 2020, a new mysterious and serious — and in some cases, deadly — related disease appeared. Called multisystem inflammatory syndrome in children (MIS-C), its symptoms initially confounded diagnosis and treatment by critical care intensivists like **Meghan Bernier** — but not so much today.

"Back in May and June 2020 we were struggling with how to treat these patients and what protocol to use," says Bernier. "Now, we're 12 months into MIS-C and have developed a lot of experience. Today I can hear a story from an outside hospital or our transport team about a patient with certain signs and symptoms and can say with pretty significant acumen this child has MIS-C until proven otherwise."

Many children with MIS-C, Bernier explains, typically present with abdominal pain, difficulty breathing, fevers, gastrointestinal issues, inflammation, neurologic manifestations such as seizures, and skin rashes — all signs and symptoms that can also mimic many other diseases.

"What makes MIS-C such a challenging diagnosis is that it has so much in common with other clinical syndromes that we see, like sepsis or even a Gl illness," says intensivist Katherine Hoops.

On the other hand, Hoops adds, the signs can be really subtle — a challenge for families and clinicians to see the forest through the trees.

"It looks like a lot of things but the effects can be devastating," says Hoops.

Intensivist Amanda Levin, who leads one of two PICU teams that admit MIS-C patients, agrees: "In the beginning, so many patients came in with vague symptoms, really sick and we weren't sure why, or seemed to manifest MIS-C with a predilection for one or two organs involved as the primary problem. Early on, and even now, people are not always recognizing that it might be MIS-C, even though we're getting more and more savvy. We see the whole gamut."

Further complicating diagnosis and treatment, however, is how quickly these intensivists have seen patients decline due to a tsunami of inflammation attacking multiple organ systems.

"Rapid diagnosis and rapid initiation of treatment is really important because kids can get very ill very fast," says Hoops. "They may have progressive multisystem failure with heart failure, respiratory failure needing mechanical ventilation, and kidney failure needing dialysis."

Adds Bernier, "They can go from walking into the ED to needing life support within hours."

Initially, Hoops says, there was a lot of fear among health professionals about how to respond to MIS-C. At the same time, she adds, intensivists do not like to be put on their heels, which prompted an aggressive fast-paced learning process in the PICU to work collaboratively to understand how MIS-C presented and what treatments could best tame it. They have seen enough cases to always have a high index of suspicion for MIS-C if a critically ill child comes in with symptoms consistent with sepsis.

In addition, garnering 12 months of experience encountering the signs and symptoms of MIS-C, they have built — seemingly brick by brick with each patient they've seen or case they've reviewed — a diagnostic and treatment algorithm with their pediatric subspecialist colleagues in cardiology, hematology, infectious disease and rheumatology. As cardiac and respiratory functions are the highest priority concerns in their protocol, the intensivists adhere to the ABC formula — airway, breathing, circulation — they've been trained to follow for life-threatening conditions.

"Our main role is to help stabilize the critical functions of the body, to make sure the child's blood pressure is staying stable, the heart rates and function are working appropriately, and the patient is breathing and exchanging air acceptably with whatever medicines and interventions are needed," says Bernier.

This stabilizing step relies on a team of faculty physicians, fellows, residents and nurse practitioners — a tailored MIS-C group of specialists within the PICU — working 24/7 to constantly evaluate and initiate therapies to prevent worsening of illness. Meanwhile, at times because time is of the essence, Bernier adds,

"you have to go with your gut instinct and your best idea of what is going on with the child."

To help fill in any holes in care — like an unrelenting fast heart rate that despite fluid or antipyretics cannot be brought down — they reach out to their subspecialist colleagues in cardiology and rheumatology, among other disciplines, for speedy remedies and input on workup, possible causes and treatment. Collaboration and communication, stresses Bernier, are essential.

"We're still generalists in the ICU — we can do 80% to 90% of the work, but we need the help of our specialists to refine the last 10% to think of presentations and diseases and workup we hadn't thought of," says Bernier.

Hoops agrees: "Through this process we've been grateful for a lot of collaborative work from a multidisciplinary team to better understand the disease process and also to develop diagnostic and treatment protocols so we can rapidly identify new cases and quickly intervene to give our patients the best evidence-based therapies."

One such proven targeted therapy is intravenous immune globulin (IVIG), which Bernier describes as applying white noise to the immune system: "It's amazing to watch this listless child lying in bed febrile and tachycardic, then get the infusion of IVIG to quiet the immune system, and six to 10 hours later that child has perked up and is playing in the parent's lap or walking around the room. The parents are like, 'I have my baby back.'"

That, however, has not and will not always be the case, says Hoops, noting that each child's recovery is different: "When you see a child in the PICU, it's hard to predict if they're going to return

"I was drawn to the PICU because I like caring for and thinking about the whole child and the interaction of all of the body's systems. I love our work caring for critically ill and injured children — they challenge us all to be our best."

- KATHERINE HOOPS

to their baseline level of functioning in a week, a month, a year. However, we are encouraged that kids are leaving the ICU faster and responding to those therapies."

So, the learning curve continues?

"Oh sure, we're still refining these algorithms as we learn about new therapies shown to be effective by our colleagues here at Johns Hopkins and around the world," says Hoops. "Our practice is constantly evolving with the evidence — that is how we in critical care manage anything."

Managing MIS-C, the intensivists conclude, is not by any means easy work.

The alarm-bell, all-hands-on-deck moments when everybody swoops in to quickly reverse the inflammation and potentially save a life is both exciting and rewarding. But not all patients survive, which takes an intense toll on the team members as well, as they see firsthand the struggles and distress families face — which they also face.

The rewards they cite are seeing a child turnaround following treatment, in some cases dramatically, and getting to know a patient and the family at the bedside or on twice-daily, family-centered rounds. They also cite intrinsic rewards.

"I was drawn to the PICU because I like caring for and thinking about the whole child and the interaction of all of the body's systems," says Hoops. "I love our work caring for critically ill and injured children — they challenge us all to be our best."

# KIDS GIVING BACK

#### IN SURPRISING WAYS

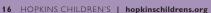
#### Most children, teens or parents never imagine

finding themselves at Johns Hopkins Children's Center. Whether for a broken bone, a cancer diagnosis or a chronic illness, patients, families and friends alike are afraid of the unknown and look to their care team for answers.

For many, the care providers become like family, and the hospital feels like a second home. This connection extends even deeper for some who decide to give back to Johns Hopkins to show their gratitude. Some people who don't visit the Children's Center firsthand, but are touched by the experience of their family and friends, feel inspired to contribute, as well.

Meet five patients and friends of the Children's Center who, through their compassion and resiliency, provide invaluable resources to help kids and teens like them.

> PHOTOGRAPHY BY KATHRYN DULNY TEXT BY AMANDA LEININGER





#### JULIA ALEXANDER, 14

#### **Grade II Ependymoma**

Diagnosed with a brain tumor at age 8, Julia has undergone three brain surgeries, five minor surgeries, eight rounds of chemotherapy and two months of radiation at the Children's Center. Julia and the Sparklettes regularly participate in Team Hopkins Kids during the Baltimore Running Festival, the Children's Center's Radiothon, and Baltimore Boogie dance marathon. The performances raise funds for Child Life services and other programs that provide fun play opportunities for kids in the hospital.

#### 66

"Johns Hopkins means so much to me and my family," Julia says. "They saved my life. Miss Mollie is my Child Life specialist, and she makes my time at the hospital as enjoyable as it can be. Because of her, I am looking into being a Child Life specialist or an art therapist."



# TEDDY MOSHER, 14 Traumatic Injury, Commotio Cordis

14-year-old Teddy, a goalie, was struck in the chest by a shot on goal during a lacrosse tournament. The impact triggered a disruption in the rhythm of his heart, causing it to stop, and Teddy collapsed on the field. After follow-up care at the Children's Center, he was playing lacrosse again within weeks. Today he is happily "back in the cage" with the Looney's Lacrosse Club, and he plans to play at Loyola Blakefield in Towson, Maryland next year as a freshman.

Teddy passionately advocates for player safety, and promotes use of new required chest protectors through social media. He also designed a wristband that reads "HeartStrong" on one side and "#Looneys2025" on the other side, and he donates all proceeds from their sale to support pediatric cardiology at the Children's Center.

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"I want to raise awareness for what happened to me and for all athletes to wear the proper equipment," Teddy says. "I just want to make sure that nothing like this happens to anyone else."

#### HANNAH VINITSKY, 14

E. Coli Poisoning, Kidney Disease

At 4-years-old, Hannah was admitted to the Children's Center with E. coli poisoning. In addition to dehydration, she suffered severe kidney damage. Hannah underwent two surgeries and three blood transfusions at the Children's Center, and she is now regularly seen there for kidney disease caused by the E. coli poisoning. While waiting for appointments in the renal clinic over the years, Hannah has always loved to read, and she wanted to help provide books to other patients. Hannah collected over 120 books to give to the clinic.



"Johns Hopkins Children's
Center means a lot to
me, and I'm happy to do
something for the other
kids like me that have to go
there," Hannah says. "I love to
read, and I wanted to help the
older kids at the Children's
Center have something to do
while waiting to see doctors."



#### **AMBER** BRISCOE, 17

#### Founder and President of **Arts-n-STEM 4 Hearts**

Amber began volunteering at local hospitals at the beginning of middle school and she recalls her interactions with pediatric patients as the most profound and meaningful. Her creative passions led her to engage young patients through drawing, painting and other crafts. Inspired by the "moments of joy" she saw when they discovered their creativity, and with her conviction to make the world a better place, she combined her passions for art and science and founded the Arts-n-STEM 4 Hearts foundation, which supports 32 organizations (including Johns Hopkins Children's Center) through volunteering and by providing art and science kits.



"To me, Johns Hopkins Children's Center means family," Amber says. "The resilience and courage of the patients and families continue to inspire me every day. I have an immense love for every child, and I am truly honored and blessed to be able to make a difference wherever I can. I hope to continue living a life of significance for my family at the Children's Center."



#### **RUBY ROSEN, 5**

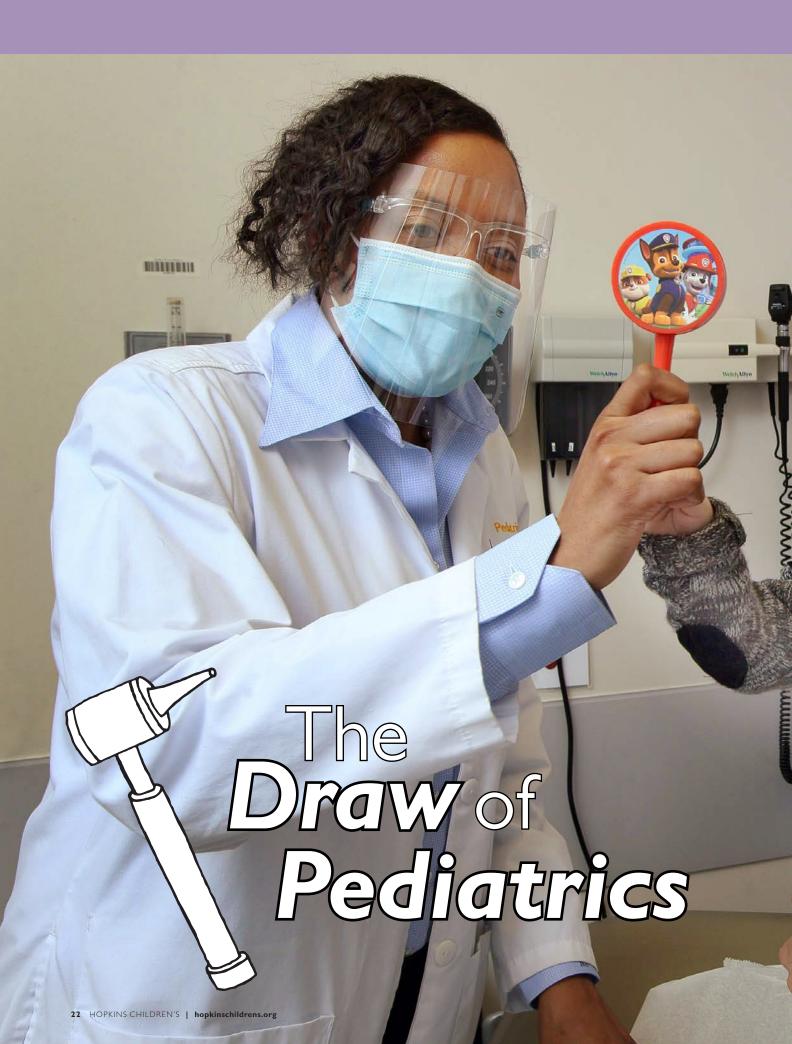
**Atrial Septal Defect** 

Diagnosed with an atrial septal defect, or hole in her heart, at 6 months old, Ruby has been closely followed by pediatric cardiologists at Johns Hopkins Children's Center ever since. Doctors carefully monitored her, hoping the hole would close on its own. Unfortunately, it was too large and needed to be closed surgically. At age 4, Ruby had open heart surgery. Just 60 days later, she ran a lemonade stand in her neighborhood to raise funds for the Children's Center's Division of Pediatric Cardiology.

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"When I stayed at the hospital to get my heart fixed, I got a Frozen nightgown and toys," Ruby says. "Now other kids can get that when their heart is fixed."









akiya Showell says she first thought about a career in pediatrics as a teenager. She was 14 when her twin brother and sister were born, and she enjoyed watching them grow and accompanying them to pediatric visits. She also was inspired by her own dedicated pediatrician, a woman in an all-female practice in Philadelphia.

"It was empowering as a young girl, seeing that model," Showell says. "I had no idea that every practice was not that way."

Now a general academic pediatrician, Showell gets to do a little bit of everything - research, teaching, administrative leadership work, and seeing her own panel of patients at Johns Hopkins Children's Center's Harriet Lane Clinic, where she is the Associate Medical Director, and at the Children's Medical Practice at Johns Hopkins Bayview Medical Center. She always knew her pediatrics career would be multifaceted, but she wasn't sure exactly how. Then, during her decade at Johns Hopkins, different doors opened. Now, her schedule varies from day to day, whether supervising residents and medical students in clinic or holding research meetings. Patient care remained central to her interests.

"I never wanted to give up being able to see kids over time, and I was always very attracted to preventive medicine, development and parenting," she says. "I just love the model of the child embedded within a family, and how that influences their health. ... I wanted to be able to play the kind of role that I saw my pediatrician play in my life."

That's a big part of the draw of general pediatrics, say Showell and others, the opportunity to partner with families to help influence children's health over the lifespan. Learning how to conduct research also advances their care, as does teaching and mentoring the next generation of pediatricians. To do so, they strive to become complete pediatricians, the best they can be. Here, residents and faculty share their experiences at Johns Hopkins Children's Center and reveal what inspired them and their journeys. But first off, how did they arrive?

Aspiring physicians come to pediatric primary care through different paths, says **Barry Solomon**, director of the Division of General Pediatrics and assistant dean for medical student affairs. In his role guiding pediatric residency applicants, Solomon reads their personal statements on what drew them to the field.

"Some of them will say things like, 'Ever since I was 5, I loved pretending to be a doctor, and I knew I wanted to be a pediatrician," he says. "For others, it's a surprise, and it comes across to them in medical school, and they had never worked with children. But it always comes down to, 'I love working with children and families, and really enjoy that role in supporting children and partner-

"I started out with no thought that I would head to pediatrics, but I scheduled it as my first rotation so that I could get it out of the way and get to the 'real' medicine. It's odd that I fell in love with it right from the beginning, but I was fortunate to be matched with pediatricians and activities that inspired me to right some of the wrongs that I saw."

-HOOVER ADGER

ing with adult caregivers.' I think that's pretty essential."

Solomon himself was one who was surprised to find pediatrics. Although he had worked with children at summer camps and supervised teen trips, he began medical school focused on geriatrics. Then, he saw the light at the opposite end of the spectrum during a third-year clerkship.

"It reminded me of why I liked working with children — their excitement and energy," he says. "I really enjoyed partnering with them, and the dynamic between the child, the caregivers and the pediatrician. By the end of my first week, I knew pediatrics was the right fit for me."

**Hoover Adger**, director of adolescent medicine with an interest in addiction medicine, says he was in the same boat.

"I started out with no thought that I would head to pediatrics, but I scheduled it as my first rotation so that I could get it

out of the way and get to the 'real' medicine," he recalls. "It's odd that I fell in love with it right from the beginning, but I was fortunate to be matched with pediatricians and activities that inspired me to right some of the wrongs that I saw."

One of his early experiences was seeing a juvenile detention center, which quickly hardened 12- and 13-year-olds who started off crying for their mothers. He saw a void he could fill.

"What I saw just suggested that the things we were doing in providing services to these children and adolescents were not what they needed," he says. "That's what drew me to the field of pediatrics."

Some pediatricians say patient encounters have helped shape their practices.

Showell, for instance, still thinks about a toddler girl she had as a primary care patient during her pediatrics residency. The parents felt challenged maintaining their daughter's weight in a healthy range





early on; she had put on excess weight between ages 1 and 2. Showell talked with the parents about behavioral and dietary changes they could make at home, which they took to heart. Even at age 2, the girl also followed along.

When the family returned six to nine months later, the girl and her family were doing better. They told her in Spanish, "She goes around and says, 'My doctor says no soda.""

"The parents were laughing with me about their daughter's sayings. Importantly, as a family, they really had made significant changes, and she was now on a more healthful growth curve," Showell says. "It was amazing that not only had they integrated the advice that I gave

them, but they could see that their child was starting to understand and adopt those same behaviors. They understood how important it was for them to be a positive role model when it came to behavior change."

It was a key clinical experience that stayed with her. If she could partner with other families and understand their barriers to healthy behavior changes, she thought, she could do more. It set her on a course for research developing and implementing programs that address childhood obesity, typically among underrepresented minority and low-income communities.

Most of Showell's research has focused on the prevention and management of obesity in children under age 5, but she has joined forces with other mentors and colleagues throughout Johns Hopkins who have allowed her to broaden her interests in childhood obesity and cardiovascular disease across the lifespan.

"That's one of the amazing things of being at a place like Johns Hopkins. There are so many different schools of thought and different researchers with different backgrounds," says Showell. "You're re-

ally able to do a lot with an idea and be very collaborative, and that's been very appealing for me."

Adger will always remember a patient he inherited during his first year at the Children's Center: an 11-year-old boy with uncontrolled type 1 diabetes. The child was well-known around the hospital for his multiple admissions. Adger first thought the family needed to know more about diabetes, and referred them to a nearby intensive diabetes education program. A few months later, when the boy had a new series of hospital admissions, Adger says he felt like a total failure. Making matters worse, the boy returned to the hospital yet again, for new-onset seizures and very low blood sugar.

When diagnostic tests revealed no new answers, Adger went back to the basics, retaking a good patient history. There, he found an answer. The boy's mother struggled with alcoholism. Depending on how intoxicated she was and how blurred her vision was, she pulled up either too much or too little insulin in the syringe. Adger helped get the mother into treatment, and over the next 10 years, this boy he cared for had zero hospital admissions. It spurred Adger's interest in learning more about addictions to help other children and families suffering in silence.

"They are some of the most amazing, resilient people I've ever met in my life. I'm thinking about medicine as not just the health of that child right there in front of me, but thinking about what medicine is in the context of the health of the whole family and community."

MEGAN TSCHUDY



Edith Dietz, at left with young patients and their mom, at the Children's Medical Practice at Johns Hopkins Bayview Medical Center.

"If you see your job as a doctor as being a problem-solver, or always fixing stuff, then probably pediatrics isn't the right field. You have to be interested in seeing more minor nuances."

#### - EDITH DIETZ

Megan Tschudy also was inspired by a family interface. She was an intern, interacting with the first patient she saw in the Harriet Lane Clinic, where she is now medical director. As she listed a litany of things she felt the parent should do, the mother bounced her two young children on her lap. Finally, she looked at Tschudy and said, "I don't mean any disrespect, but you don't really know a lot about me personally or my family." Tschudy had to stop, draw a breath, and confirm the mother was right.

After Tschudy left the room, she continued to think about the exchange and what else could be done. Part of her role now involves supervising a community health-worker program, with three staff members who work with children and families in homes and schools. Through this experience and a former program supervising in-home visits for medical residents, Tschudy has done countless home visits, gaining a greater appreciation and fuller picture of her patients. The clinic she directs takes a holistic approach to children's needs.

About 94% of patients seen at the Harriet Lane Clinic have Medicaid, and a large percentage are African American. The case mix includes children who are generally healthy and those who are some of the most medically complex in the state. Some come to clinic visits with a mother or grandmother who also have



been clinic patients. Tschudy loves it.

"They are some of the most amazing, resilient people I've ever met in my life," she says of clinic patients and families. "I'm thinking about medicine as not just the health of that child right there in front of me, but thinking about what medicine is in the context of the health of the whole family and community."

All patients are screened for social determinants of health when they come into the clinic. Taking a medical home approach, pediatricians also are trained to consider the mental and financial health of the family, and help refer families to wraparound services like help finding food benefits or housing if needed.

"With a lot of these kids and families, we form really deep bonds with them and help them in so many ways outside of the traditional health system," Tschudy says. "For well kids who live in poverty, one of the best things we can do is help get them into early Headstart. That may have a much broader, profound impact on their health throughout their entire life than anything we could have done in the clinic."

Across town at Johns Hopkins Bayview Medical Center, **Edith Dietz** splits her time between seeing patients in the emergency room and in clinic at the Children's Medical Practice, which sees largely Spanish-speaking immigrant families.

It's impossible to think Dietz wasn't swayed to the joys of pediatrics by her mother, Julia McMillan, a pediatric infectious disease specialist and longtime pediatrics residency program director at Johns Hopkins. But Dietz took her own path. Although she enjoyed the sciences, she studied anthropology in college and did a two-year stint with the Peace Corps in Gabon in Western Africa. There, she worked as a community health volunteer, conducting sex education classes with adolescents, and found herself surprised by the open conversations locals would have with her about potentially taboo subjects like pregnancy and sexually transmitted diseases.

"I really started to understand the reward of being led into these very personal stories, and looked to as someone who could offer advice and guidance," Dietz says. "That was my first taste of thinking

that maybe medicine would be interesting to me."

When she returned to the United States, she began taking premed and medical Spanish courses, followed by medical school at Johns Hopkins. Seeing the diverse careers her classmates were plan-

#### **Building Leaders** Through Autonomy

"When I was a resident on the wards, I was really the one making the decisions," says pediatrician Megan Tschudy. "There were always people to back me up, but I was teaching while I was rounding, and helping to make medical decisions. There was a sense of ownership and the feeling that when I graduated, I was ready."

That formula, Tschudy adds, is what distinguishes the Johns Hopkins pediatric residency program. Kristen Cercone agrees: "We've created this culture where as you grow from your intern year up through your third year as a senior resident, you get these graduated levels of autonomy to practice independently. To have that competence to feel like you were ready to be out there making decisions is huge."

The program also exposes trainees to potentially careerchanging mentors, says Nicole Shilkofski, pediatrics residency program director. Sometimes, finding a mentor happens serendipitously; other times, learners have to seek out one or a panel of mentors. Now, Shilkofski helps match up residents with advisers, hoping they enjoy the same inspiration she had.

"I saw my former program director, Julia McMillan, as a mentor and someone who really encapsulated what the ultimate pediatrician should look like," Shilkofski says. "I remember wanting to be her. ... It was always my dream to fill her very big shoes, and I always thought about wanting to have a career in medical education."

She still admires McMillan for her confidence and leadership skills. "As pediatricians, we're taught to be keen observers of people. ... I think we do the same thing with role models. It wasn't a single piece of advice [that inspired me] but the perception of her and others in my career as role models that I wanted to emulate their behavior and the way that they approached patient care."

What makes a complete pediatrician? A leader in general pediatrics?

Top-notch diagnostic skills and the ability to listen and observe in a nonjudgmental manner, to be a team player, and to see yourself as a partner working with families to promote the best outcomes for their children are just some of the qualities that make for an outstanding pediatric provider, Johns Hopkins pediatricians say. Also, praising families for doing a good job, and making sure families leave each visit with plans for the next steps in care.

"People who are naturally good leaders make for good pediatricians, because they're calm under pressure, and they're willing to take necessary risks to do what's right for their patients and their families," Shilkofski says. "Those are some of the things we look for in our applicants, and also things that we try to engender through education and training."



"We've created this culture where as you grow from your intern year up through your third year as a senior resident, you get these graduated levels of autonomy to practice independently. To have that competence to feel like you were ready to be out there making decisions is huge." -KRISTEN CERCONE

"Parents see us as authority figures, but we want to make sure we're on the same page, and both of us are at the same table with the same chair height," adds Showell. "Just by opening up a conversation with a statement similar to that, it allows parents to be more open and more transparent, and to feel more comfortable."

Communication skills are particularly important with adolescents, who often say adults don't understand them, Adger says. The fundamental reason that people don't understand them is they don't listen to them, he explains, citing data showing that the typical physician only listens 17–18 seconds before interrupting a patient the first time, and in between questions they only allow one to two seconds for a response.

"If you can give your patient just 90 seconds — and what physician doesn't have 90 seconds? — you'll see all the things that they're concerned about," Adger says. "There are a lot of patients, including myself, who walk away from physician visits feeling that they haven't been heard. They haven't been validated, and their doctor doesn't have any idea what they're really concerned about."

Trust also is key, says Tschudy: "It's easy to tell [patients and families] what to do, but to make a plan with someone ... and to see how that progresses over time, is an amazing experience you can have with people that really bonds you together," she says. "You celebrate the wins with the family and you mourn the losses with them, and you learn to really partner and be a team together." ...

ning with their degrees, she says, "It verified for me that kids are the best patients to have, and that pediatricians are the best colleagues to have. ... If you see your job as a doctor as being a problem-solver, or always fixing stuff, then probably pediatrics isn't the right field. You have to be interested in seeing more minor nuances."

A recent clinic day showcases the variety of patients Dietz sees, from a 12-year-old girl who had had COVID-19 experiencing a list of ailments including chest and abdominal pains, to a 22-month-old girl with potential developmental delays, to a 14-year-old girl with attention-deficit hyperactivity disorder, anxiety and a challenging home situation. The girl's brother was shot within the past year, and her mother died of an overdose. The grandmother she lived with was recently hospitalized with COVID-19, and the girl has gained over 50 pounds, putting her at risk of developing diabetes.

In each case, Dietz says, she works with the patient and family to first address the areas they feel are most concerning. Dietz asks the 12-year-old to keep a pain diary, and refers her to a pediatric cardiologist to evaluate her chest pain. She refers the toddler girl's mother to the Baltimore Infants and Toddlers Program and to a pediatric ophthalmologist for further evaluations. Although the 14-year-old had a challenging year, she expressed excitement about going back to school when it reopens, so Dietz plans to follow her more closely.

Dietz says she finds it rewarding working with this population, many of whom have social challenges. Sometimes they just need guidance about where to find certain resources, she says, or how to interact with their children's schools. She admits to doubts about how some parents can balance work and the demands of parenting.

"A lot of them have totally proven me wrong," she says. "With a lot of family support and a lot of motivation to get their kids the best resources possible, families navigate the system and kids thrive."

Pediatricians make a difference in com-

munity settings, too. Michael Crocetti found himself drawn to pediatrics hoping to help children stay healthy at young ages, to prevent adult disease. After being chief resident at Johns Hopkins Children's Center, he worked in pediatrics at Johns Hopkins Bayview for about 13 years, before becoming chief of pediatrics for Johns Hopkins Community Physicians. Now, at an office in Baltimore's Canton neighborhood, he sees the children of young urban professionals as well as some of his former patients from Hopkins Bayview, along with some young adults in their 20s with chronic medical conditions such as cerebral palsy. He's been at it so long that he's beginning to care for the children of some of his former patients.

"The families are phenomenal," Crocetti says. "I've developed tremendous relationships with them over the years, and that's one of the big things that keeps me going, and affirms why I went into pediatrics."

He starts visits with new families telling them he will be with them all the way, but likes to let them figure some things out on their own. "Parents get lots of advice about how to raise their kids," he notes, "but at the end of the day, it always comes down to what fits into their philosophy. ... I always like to say, 'If I'm worried about something or have a concern, I'm going to let you know. But other than that, we're going to go through this together."

Primary care pediatrics is much more than just 15- to 20-minute office visits, Crocetti says. It's taking care of the family. A lot of the work gets done outside those appointments, he notes: following up on laboratory test results or referrals made, or responding to issues or problems that arise between scheduled visits. "This is what continuity is all about," says Crocetti. "To be a complete and impactful pediatrician, you have to be there for your patients whenever they need you. Many times, it's at inconvenient times. Parents appreciate that so much."



Community pediatrics also appealed to **Kristen Cercone**, one of this year's chief pediatric residents. Cercone first went to art school with aspirations to become a graphic designer. Finding a tough job market upon graduation, she made a turnaround in her early 20s and went to medical school.

"I really enjoyed my time rotating through those services and found I was more fascinated by the pediatric diagnosis and the interplay of working with kids and families than I was with other aspects of medicine," she says. "So, I think pediatrics found me."

In July, Cercone will start work at a community primary care pediatrics clinic in Winchester, Virginia, run by other former chief residents. Her interest in community care was shaped by rotations at St. Agnes Hospital in Baltimore, spending time in the newborn nursery and seeing general pediatric inpatients.

"It was a place where I thrived," Cercone says. "When you work in community pediatrics, you really become embedded in the community. You get to know people who you see as patients, but also the people who you work with really well. There's so much work to be done in providing good quality education and evidence-based pediatric care in that setting. That's what I was looking for in a practice, and I was lucky enough to be able to find this practice that really embodied all of that."

Interview:

#### Addressing Racism **Head On**

Adolescent medicine specialist Maria Trent, academic pediatrics fellow Monique Jindal and education specialist Cheri Wilson discuss how pediatricians can help patients, families and themselves address the issue.

#### How do discrimination and racism affect young children early on?

Trent: Children can see the subtle differences in people around them starting in infancy, so the impact of parental and societal behavior begins early. They see what their family looks like, and as they grow and move through society, they see the variation in packaging that we all have. The problem is that they also start to observe how adults assign value to different groups of people. Racism is a socially transmitted disease because it is taught and passed down, but the impact on children, adolescents and families is significant from a health perspective.

#### How so?

**Trent:** There is this ongoing stress of living with racism that can lead to biological changes such as inflammation and hormonal dysregulation. Perceiving that they are living in a threatening world, children may exhibit behavioral characteristics such as hypervigilance and remain in a crisis mode, unable to resolve or predict the next threat.

Jindal: You hear all these negative messages that you are part of and you start



to believe and internalize them. That can really have detrimental effects regarding your identity, what you choose to pursue, what you see for yourself.

Wilson: Discrimination and racism can affect the child's perception and use of health care, too. If the child observes his or her parents disrespected in a very poor manner and treated awful by doctors, the child will say, "I'm not going there." The parents bring the child in for a well-child visit and now the child is afraid to go. When they become adults, they do not trust the health care system. This distrust affects their participation in clinical trials, too. Early experiences do spill over.

Monique Jindal, left, and Maria Trent in Johns Hopkins Children's Center.

#### What can pediatricians do?

**Trent:** An easy first start is to make sure that everyone feels welcome in the pediatrician's office. Are there images of diverse families on the clinic walls and multicultural books, videos and toys in the waiting area? Are staff diverse and able to deliver culturally and linguistically appropriate services to all families? Are you performing quality assurance assessments to determine if your patients are having similar outcomes regardless of race, and are you acting to improve quality when possible? Can you improve your own

behavior in practice, emphasizing that all children should receive the best quality of care? Doing that requires that we examine our own biases, acknowledge the role of racism in child and adolescent health, and then commit to proactive change that leads to strategies that optimize clinical care, training behavior and research to reduce the health effects of all forms of racism.

#### Training behaviors?

Trent: In adolescent medicine, we developed a program to train health professionals in cultural competency and communication using a variety of teaching techniques. One of the most effective approaches has been to use the Johns Hopkins simulation center to allow pediatric trainees to practice managing cultural communication and use of interpreters. When we engage in this work, we have to ask ourselves if we are working and living in line with the principles we embrace. How do we talk to and treat our adolescents? How do we interface with young people in public spaces? For parents and families, we focus on what kind of advice and guidance around race and racism we should be giving them.

Jindal: During residency, I looked into the scientific literature and was amazed to see a ton of literature linking racism to poor health, and how our actions as health professionals when driven by racist policies impact quality of care. Therefore, we created a racism in medicine curriculum as part of resident training. We needed to have something that does not just talk about poverty and social economics but instead addresses racism head on.

#### How do you address it?

Jindal: Self-awareness is the first step. Studies show being aware of racist beliefs and tendencies, our own implicit biases, makes a difference. Practicing empathy and perspective taking — actively putting yourself in the patient's shoes — has been

shown to be helpful. In addition, physicians can focus on a common group identity to connect with patients, to make it a humanizing encounter. We also educated medical professionals about the history of structural racism, like redlining and racial segregation, and how that impacts a child. This subject is not mandatory in medical schools.

#### How has the training been received?

Jindal: The curriculum has been well received — some people cited it as the best part of medical education up to this point in their career. However, some scientists do not like us focusing on empathy, even if our whole job is about making human connections. If you cannot understand one's life story, what it might be like to live in their skin, I do not think you get very far. I was initially surprised how difficult it was for providers to admit they might have some unconscious biases and need to work to move forward. This is a group of people who went into this profession to presumably help other people, so it might be very threatening to say you might be doing something that leads to less than ideal care for people.

#### **Unconscious biases?**

Wilson: As human beings, we operate on autopilot in a world where we have to make a conscious decision about every little thing. With everything and everyone we interact with, some preconceived notion or stereotype comes to mind driven by the lens we bring to the world through our upbringing, school and media, what we learn about a group of people. When we meet someone, we quickly size the person up even before the person opens their mouth. In a matter of seconds, we determine everything we need to know about the person, whether they are safe or not — originating from the whole concept of "friend or foe." From a health care perspective, we look at how a patient is dressed and make assumptions about

whether someone is educated, has good insurance or is going to be a compliant patient. As a result, we may do the bare minimum for this patient so we can get to the next patient, who we are more comfortable with and prefer to work with. That is how implicit bias comes into play, and it can be very harmful.

#### How do you mitigate bias?

Wilson: By realizing that none of us is perfect! Recognize that every single one of us has many biases of which we are unaware. If we are called on it, the first inclination is to get defensive, to say, "I treat all of my patients the same," or, "My intentions were good." We cannot focus on the intention — it is the impact of the bias. The answer is in seeing it, owning it, engaging in introspection. After an encounter with a patient, you may ask yourself, "Why did I react that way and come to that decision?" Get feedback from other people.

#### What are the benefits of self-awareness and empathy?

Jindal: The reward is the patient's wellbeing. It is the exact opposite of what happens if you do not have that empathy. We see that providers who have higher levels of bias are less likely to provide high-quality care, are less likely to be trusted by their patients. Research also shows that higher levels of empathy decrease the impact of racist tendencies among healthcare professionals and lead to higher quality care. If you do lean into this, you will gain stronger relationships with your patients and your patients will have reason to confide in you and come to you. You the health professional get something out of it, too. In a profession in which you are constantly interacting with people all day, every day, a warm and meaningful interaction leads to you having a better day. When you do better by your patients, you feel better as a physician, as well.

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# Addressing Obesity-Related Hypertension By Gary Logan

AT A RECENT GRAND ROUNDS, pediatric resident Adam

**DeLong** updated Johns Hopkins Children's Center faculty about the state of childhood obesity in America. Nationwide, he noted, rates of childhood obesity continue to rise, affecting 18.5% of children and adolescents, or 13.7 million young people. A child who is obese at age 12, he said, has a 75% chance of being obese as an adult, with all the related and potentially lethal risk factors such as type 2 diabetes, severe hypertension, heart disease and obstructive sleep apnea (OSA). However, there are effective resources against these threats, DeLong added, including one in the pediatric cardiology clinic just down the hall from where he spoke.

"As a resident working with children, I feel like I'm offering stage-one interventions every week, so I wonder if what we're doing works," says DeLong. "But there is a lot of potential with the ReNEW clinic, its medical home model and one provider steering the ship."

The captain of that ship — the Obesity Hypertension Clinic: Reversing the Negative Cardiovascular Effects of Weight (ReNEW) — is pediatric nephrologist **Tammy Brady**. Each week, she and a diverse team from child psychology, nutrition and physical therapy assess the progress of young patients with obesity-related hypertension, which untreated leads to multiple other organ diseases, including early onset heart disease. Up to 25% of children who are overweight/obese — eight times as many as in the general population, stresses Brady — have high blood pressure.

"We screen these kids for early signs of heart disease related to their cardiac disease risk factors — things like abnormal heart thickening or suboptimal relaxation — because we know in adults these markers lead to arrhythmias, heart attacks and death," says Brady.

To lower those risks, Brady and the team see patients every three months rather than every six months. At each 2 ½-hour visit, the pediatric dietician guides patients on nutrition and weight loss, and the physical therapist works on exercise options for patients, especially those with the obesity-related hip condition slipped capital femoral epiphysis. In addition, the behavioral psychologist consults with and refers patients with underlying mental health issues such as anxiety and depression that may be influencing their eating habits. To motivate behavior change, patients

#### **FACTS & FIGURES**

18.5%

of children nationwide are obese.

25%

of overweight children have hypertension.

**75**%

chance of children carrying on obesity into adulthood.

National Center for Health Statistics 2017

and their families collaborate with the psychologist to set meaningful goals such as exercising and eating vegetables at least once a day.

"I would say 60%–70% of our patients make some meaningful progress in goal attainment from one session to the next," says behavioral psychologist **Jeffrey Garofano**.

Another issue, OSA, is common among individuals who are obese. Pediatric pulmonologist and sleep specialist **Laura Sterni** notes that with the rise in childhood obesity she is seeing "more and more patients" with OSA, which like obesity can exasperate hypertension and contribute to cardiovascular issues.

"A lot of the complications that you get from obesity alone — heart disease, hypertension, metabolic syndrome — you also see with sleep apnea alone," says Sterni. "Put them together, and it's unfortunately a perfect storm."

Multiple clinical services, evidence-based medicine, continuing research, and community partnerships, Brady stresses, are all vital to the success of the clinic and patients' progress. However, at the heart of the clinic in Brady's eyes is its open connection and communication with patients and families.

"We're still learning, but they're putting a lot of faith in our responses," says Brady. "Working together, we're figuring out ways to motivate these kids and families."

# Expanding Expertise in Congenital Heart Disease

A new collaborative center representing disciplines of pediatric cardiology, cardiac surgery, and anesthesiology and critical care medicine offers lifelong care for patients born with CHD.

#### **By Karen Blum**

IN NOVEMBER 1944, Johns Hopkins surgeons performed the first landmark operation on an infant whose heart is unable to pump blood to the lungs to provide enough oxygen to the body. A surgical team led by **Alfred Blalock**, with his longtime technician **Vivien Thomas** guiding him, implanted a shunt to increase blood flow to the lungs. Pediatric cardiologist **Helen Taussig** worked with Blalock to develop the shunt. The procedure is credited with saving the lives of thousands of children and launching the field of modern cardiac surgery.

In 2020, Johns Hopkins Medicine brought multiple specialists in pediatric and congenital heart disease (CHD) into the new Blalock-Taussig-Thomas Pediatric and Congenital Heart Center. A collaboration among the divisions of pediatric cardiology, pediatric cardiac surgery, and pediatric anesthesiology and critical care medicine, the center offers lifelong care for patients born with CHD.

"Johns Hopkins was the birthplace for congenital heart disease interventions in surgery," says **Jamie McElrath Schwartz**, co-director of the new center and division chief of pediatric critical care medicine. "We picked the name specifically to include these three pioneers, as we are building on that past and creating



a new future."

Although experts from different disciplines who care for CHD patients collaborated in the past, Schwartz says this reorganization establishes a fully integrated, multidisciplinary approach at Johns Hopkins Medicine.

"We have the ability to create dedicated services like operative teams, pediatric perfusion teams, a cardiac intensive care unit and nursing," she says. "That's exciting, because these are people who want to narrow their practice to CHD, to work with these families long term and provide them excellent care."

Center co-director **Shelby Kutty**, who also serves as director of pediatric and congenital cardiology, says the center's structure maximizes the available expertise at Johns Hopkins Medicine, benefits patients' families and gives the institution a competitive edge for recruiting top experts and garnering research dollars. CHD patients are very complex, he adds, often requiring a spectrum of services: "It's a very outcomes-driven specialty, and the key to having good outcomes is a dedicated team and teamwork."

**Bret Mettler**, director of pediatric cardiac surgery, is also a co-director of the center. He recently came to Johns Hopkins Medicine from Vanderbilt

University Medical Center, where he was director of pediatric cardiac transplantation and mechanical support. Pediatric and congenital cardiac surgeon **Danielle Gottlieb-Sen**, with expertise in the genetics and prenatal diagnosis of CHD, will have a clinical practice while directing pediatric cardiac research for the heart center.

"Our goal is to provide a service line of care, where patients and their families can call one phone number and have access to outpatient care, surgeries, postoperative care and research studies," Mettler explains. "We do plan to develop the heart center at Johns Hopkins into an elite destination."

With Johns Hopkins experts in maternal-fetal medicine and obstetrics close at hand, the new heart center will help extend full-service care for mothers and their babies. The new center also incorporates an adult CHD program, directed by cardiologist **Ari Cedars**, to manage teens and young adults' CHD needs as well as any adult-onset heart conditions such as coronary artery disease and arrhythmias. Also, because congenital heart disease affects a relatively small patient population, Mettler hopes to form clinical and research partnerships with other CHD programs.

#### A Cardiac ICU for Children

THE SO-CALLED BLUE BABY breakthrough saved the lives of thousands of children and also had the effect of attracting world-class pediatric heart specialists to Johns Hopkins, including most recently critical care specialist **Darren Klugman**.

"Building this cardiac critical care program is an opportunity, when coupled with the systems and programs and — importantly — the people at Johns Hopkins, that will allow us to provide a level of evidence-based care and a patient-family experience that is truly unique in this region and the country," says Klugman.

While one-year survival for infants with critical congenital heart defects has been improving over time, mortality remains high. Advanced surgical approaches allowing early intervention, Klugman explains, along with specialized cardiac critical care of these children, has translated into better outcomes. Research shows PCICU care has many advantages over traditional ICU cardiac care, including shorter ventilator stays, improved continuity of care and more seamless coordinated multidisciplinary care, which is a necessity to ensure high-quality outcomes.

Developing such a model multidisciplinary pediatric cardiac ICU to achieve

All of the dedicated subspecialty care, research and education here will allow us to ask important questions, to understand the differences between our patients, and participate in research and clinical care advances to improve our outcomes.

– DARREN KLUGMAN



Darren Klugman, second from left, leading morning rounds in the PCICU.

those benefits, however, is not without its challenges. There are a limited number of trained pediatric cardiac intensivists, especially ones such as Klugman who is board certified in pediatrics, pediatric cardiology and critical care medicine. The unit he is building will be composed of cardiac critical care specialists with specialized training, nurse practitioners with training in cardiac critical care, and dedicated PCICU nurses. An internationally known researcher in congenital heart disease quality and outcomes, Klugman will be leading efforts to advance outcomes in the PCICU and optimize practice through scientific inquiry and quality improvement.

"One of the things that attracted me to Johns Hopkins was the enormous research infrastructure and resources that exist within our system," says Klugman. "All of the dedicated subspecialty care, research and education here will allow us to ask important questions, to understand the differences between our patients, and participate in research

and clinical care advances to improve our outcomes."

In addition to the evidence-based medicine research approach, Klugman notes there will be a strong focus on the family experience and parents as partners in care.

"We will engage them in a way that allows them to be part of the healing and care decisions for their child," says Klugman. "Without them, we can only do so much."

Pointing to the people, the resources and culture at Johns Hopkins, Klugman is optimistic that the PCICU will exceed his expectations.

"There are exceptional people here, a rich environment of collaboration, a thirst for knowledge and an intense desire to advance our care," says Klugman. "We are facing the opportunity now to really rethink and reinvigorate our focus to provide these patients and families with a comprehensive care program that will optimize the rest of their child's life." — GL

### A Sly Spinal Cord Tumor

THE PATIENT, AN 8-YEAR-OLD boy from Western Michigan, experienced progressive back and hip pain, constipation and urinary hesitancy for over six weeks. His father took him to the local emergency department, where a staff physician ordered an X-ray that, unfortunately, did not reveal the source of the boy's pain.

The doctor said he should be fine in a week or two but he got worse — it got to the point where he couldn't walk and could only sleep with his knees on the bed," says his father, Kesong Hu, tearfully. "Jake is an awesome son, highly empathetic and he always tries to consider others first. When he hurts he doesn't tell you."

That prompted a visit to another physician, who gave the child an examination and a massage but no answers. The father then contacted colleagues at the university where he works as a neuropsychologist. They recommended a work-up at another hospital six hours away, where imaging uncovered the culprit: a tumor embedded deep in the spinal canal, beneath the dura at the thoracolumbar junction. Jake needed to see a neurosurgeon and quickly, one with extensive experience in resecting such evasive spinal tumors. His father knew right away where to look.

**11** The tumor was filling the whole spinal canal with no room to go anywhere else. If it got any bigger, he could have lost all motor function as well as control of his bowel and bladder. "

-ALAN COHEN, PEDIATRIC SURGEON

Having grown up in College Park, Maryland, and as a former neuropsychology student at Johns Hopkins, he was well aware of The Johns Hopkins Hospital's reputation. A website search steered him to pediatric neurosurgeon **Alan Cohen**, who quickly initiated a telemedicine consult with the father and the referring hospital staff. With medical records and imaging electronically in hand — and seeing the large schwannoma tumor occupying and compressing the spinal cord and nerve roots — Cohen agreed time was of the essence.

"The tumor was filling the whole spinal canal with no room to go anywhere else," says Cohen. "If it got any bigger, he could have lost all motor function as well as control of his bowel and bladder."

Three days later, Jake was in the operating room designed for pediatric neurosurgical patients at Johns Hopkins Children's Center. Because schwannoma tumors arise from the lining of the nerve cells, Cohen knew dissecting a tumor wrapped around the nerve roots and spinal cord would be "tricky." Intraoperative neurophysiologic monitoring was needed, along with microsurgical tools to separate the highly adherent nerves and spinal cord from the tumor. How did it go? The delicate five-hour procedure, says Cohen, was successful.

"The tumor is indeed benign and now it's gone," says Cohen. "In the recovery room, Jake was moving his legs perfectly." The father's response?

"The team was very highly efficient, very professional, and provided emotional support," he says. "I feel like they gave a second life to my son." —  $GL \stackrel{\bullet}{\diamond}$ 



# A Surgical Solution for Acute Recurrent Pancreatitis

RILEY SMITH, 15, from Pekin, Illinois, was experiencing, in his own words, increasing episodes of "excruciating abdominal pain." Diagnosed with hereditary pancreatitis, he faced a potential lifetime reliance on narcotics. Then, one of his doctors told him about a new pancreas program at Johns Hopkins Children's Center. Today, after having his pancreas removed in a complex transplant procedure, Riley is free of the painful episodes and is weaning off insulin injections to a point where he may not need them at all.

Not too long ago, such an outcome would not have been conceivable, says pediatric gastroenterologist Kenneth Ng. Two factors, Ng explains, came into play. One is the formation of the International Study Group of Pediatric Pancreatitis: In Search for a Cure, a consortium that expanded understanding of pancreatic disease in children. The other is the collaboration with the nationally known Johns Hopkins Pancreatitis Center, which serves adult patients. The result was establishment of the pediatric Total Pancreatectomy with Islet Autotransplantation (TPIAT) program for children with acute recurrent pancreatitis.

"Being part of the consortium has allowed us to not only build upon the foundational knowledge we already have but also cross-talk with other centers to learn and grow our TPIAT program, which translates into even better care," says Ng. "Also, we've been very fortunate in being physically connected to The Johns Hopkins Hospital, home to renowned leaders in pancreatic medicine. We've been able to leverage their expertise to get our program up and running."

The adult TPIAT program helped staff the pediatric program with its own expert transplant coordinator, **Christi Walsh**, who plays the vital role of coordinating the multidisciplinary care required for proper evaluation and treatment. In addition, pediatric surgeon **Daniel Rhee** 



Pediatric gastroenterologist Kenneth Ng with Riley and his mom, Lindsay Smith, at a follow-up appointment following his TPIAT surgery.

worked closely with his colleagues in the adult pancreas center to learn the nuances of the TPIAT procedure. In this new approach, the source of the pain — the pancreas — is completely removed, and the islet cells that make insulin are isolated and re-implanted into the liver.

"There they can set up shop and over time reestablish their function," says Ng. "The hope is that it will remove the original environment at risk of these inflammatory events, and still allow the body to do the important job of creating insulin."

Patients with chronic or recurrent pancreatitis are first seen by Ng to determine if they are candidates for the TPIAT procedure. The patient and family then meet with Rhee to discuss surgical options. Also, **Kristin Arcara** of pediatric endocrinology counsels the family on the post-surgical course regarding insulin and blood sugar management, which is critical for survival of the islet cells and their

ability to take over the insulin production that the body needs.

How do young patients respond to TPIAT? Most families report significant relief and improvement in their child's quality of life — they typically return to school, social activities and sports. Parents are able to reduce or eliminate the child's need for narcotic pain relief, but knowing whether the patient will remain on insulin therapy takes longer — sometimes a year or more.

"Riley is doing great," says Arcara. "We've had one other patient recently, and both are doing better than I ever could have imagined with the use of the most cutting-edge diabetes management technologies." — GL

# **Pediatric** Surgeon Shaun Kunisaki

The stem cell scientist and pediatric thoracic specialist discusses his research and the newly established pediatric esophageal center.

#### What steered you toward a career in medicine?

My father, who was an African-American obstetrician, died when I was only 6 weeks old. With a promising career ahead of him, his life was cut short. I have always felt that one of my purposes in life was to pursue his unfinished business of helping others and to carry on his legacy.

#### What is your niche as a pediatric surgeon?

Although I enjoy the full breadth of the specialty, my niche as a surgeon is in the treatment of fetuses and infants with non-cardiac thoracic surgical problems, which typically affect the esophagus or lungs. Chest surgery in kids is quite interesting but a bit of a neglected field.

#### How so?

Pediatric cardiac surgeons focus on fixing the heart, and there really are very few dedicated pediatric general thoracic surgeons. Congenital anomalies of the lungs and esophagus often require highly complex operations, and there continues to be debate in our field about how to best manage them. In some babies born with esophageal atresia, do we stretch the esophagus or replace it with another organ? In babies with lung malforma-



tions, does it make sense to remove the lung mass even if it may never cause a problem? There is still work to be done to maximize outcomes in these children.

#### What are your goals here?

One of the main reasons I came here is to help establish a formal esophageal center, very few of which exist in this country. I have been fortunate to treat children from all over the country and from Europe. However, you need a truly multidisciplinary effort with pediatric surgery, gastroenterology, otolaryngology, anesthesia and speech pathology, to create a center of excellence to manage the most complex esophageal disorders. You need the collective experience of the whole group to figure out whether medicines, endoscopic techniques, minimally invasive surgery, or open surgery can fix the problem.

#### We understand you are also reaching outside Johns Hopkins to tackle these problems.

Yes, over the past decade, there has been this growing realization that no individual children's hospital can really study in a rigorous fashion many of the disorders we take care of as pediatric surgeons. Most hospitals simply do not have enough of these patients, and national

administrative databases have their limitations. Thanks to the vision of pediatric surgeon-in-chief David Hackam, I am working on forming a multi-center pediatric surgery research consortium based at Johns Hopkins.

#### Other interests?

As a pediatric surgeon who does prenatal counseling and treats newborns with birth defects, I am continually fascinated with fetal organ development and how that goes awry. About 10 years ago, I was given the opportunity to start a basic and translational science laboratory looking at perinatal stem cell reprogramming using induced pluripotent stem cell technologies. In the lab, I learned how to transform skin, placenta and amniotic fluid cells into stem cells that behave almost identically to embryonic stem cells. With this technology as well as funding from the National Institutes of Health. our lab has been studying how to better regenerate the spinal cord in spina bifida patients. We are also working with engineers to learn how to grow lung tissue for patients with congenital diaphragmatic hernia. The Holy Grail would be to use a child's own fetal stem cells to improve patient outcomes at the time of surgery.

# Lori Vanscoy Drops Anchor at Johns Hopkins

were among **Lori Vanscoy's** career choices as she entered the United States Naval Academy, although she figured her less than 20-20 vision would disqualify her for deep space travel. Nonetheless, she did travel quite a bit after her senior engineering design project — a vision aide for quadriplegics — cultivated a strong interest in medicine.

"I met with people at rehab facilities in Baltimore and realized that there was no such things as remote control for computers," says Vanscoy. "My work in that area became my bridge to medicine."

She found her way to Duke University School of Medicine and a pediatrics residency at the Naval Medical Center in San Diego, California. Her next stop—two months before 9/11—was Camp Pendleton, where she served for three years as a general pediatrician.

"Our patients' parents were being deployed — it was a crazy time," says Vanscoy.

After her fellowship in pediatric pulmonary medicine at Johns Hopkins Children's Center, Vanscoy was also deployed on a four-month long humanitarian mission aboard the USNS Comfort. With stops in Columbia, the Dominican Republic, El Savador, Haiti, Nicaragua and Panama, she was part of a team of pediatricians providing care for local children and families, which she found deeply rewarding. But her favorite pediatric experience was taking care of children with cystic fibrosis (CF) during medical school, residency and in practice as a general pediatrician, which led her to the fellowship.

"I loved the chronic care aspect of taking care of patients with CF, where you could really get to know them and their families longitudinally from infancy through college and young adult years," says Vanscoy. "I was also fascinated by the complexity of this systemic disease

and its varied manifestations."

That experience stimulated her research interests in genetic modifiers of CF lung disease and the causes of variation in response to cystic fibrosis transmembrane conductance regulator (CFTR) modulator drugs. Thanks to these therapies, survival for patients with CF is now in the late forties and beyond, which Vanscoy calls a game changer.

"With the advent of these new medications just within the last year, we are projecting that CF will now be a chronic disease you live with and not one that confers any shortened life expectancy," says Vanscoy. "From the time I started in pulmonology, it has really been a tremendous, seismic shift in what we can do for patients with CF."

Following her fellowship, Vanscoy served as the Cystic Fibrosis Center director for six years at the Naval Medical Center in Portsmouth, Virginia. There, she began to pursue another research interest related to her systems engineer-

ing background — machine learning — which she believed could also benefit young patients with CF.

"I'm interested in studying predictive machine learning algorithms to better understand disease trajectory and treatment response at the individual level to tailor our CF treatment for the individual," says Vanscoy.

What better place to pursue such investigations, she pondered? Flying and being an astronaut may have fallen further down her list, she acknowledges, but now as a pediatric pulmonologist at Johns Hopkins, she feels the sky's the limit.

"I was really drawn to the interdisciplinary collaboration, the opportunity to work with people in the CF Center and potentially the Applied Physics Lab, the school of engineering and computer science, to do what I want to do research wise," says Vanscoy. "That's what really drew me back, and I'm thrilled to be back." — GL



### **A Nursing Trifecta**

Three new nurse managers share their personal path to pediatric nursing and vision for pediatric intensive care.

#### By Christina Frank

Colleen Gordon doesn't hold back when expressing how thrilled she is to have landed the job of nurse manager of Johns Hopkins Children's Center's newly opened pediatric cardiac intensive care unit (PCICU), calling it the "holy grail" of opportunities. The PCICU opened its doors in October 2020 and is partnering with the pediatric ICU to take care of infants to young adults with congenital heart defects.

"I mean, you never get an opportunity to open a brand-new unit in an institution like Johns Hopkins, like, ever," says Gordon. "We all know about Alfred Blalock and Helen Taussig and Vivien Thomas and the work that they did for blue babies. So not only do I get to put my stamp on it — but I'm also doing the things that I love, which are patient care, designing systems and putting operations in place. So, going to the mecca, the birthplace of pediatric cardiology, and helping to design an entire unit — who says no to that?"

Gordon was a bedside nurse for 12 years, and has always worked with pediatric cardiology patients. It was the perfect match and mix, she says, for her inquisitive mind: "It just clicked with me, it's the thing that I felt made the most sense. There are so many different heart defects and variants of a defect."

In addition to her passion for pediatric cardiology, Gordon, who has a master's in health care administration, loves a good bed-management challenge. She likens the task to a huge chess game.

"You've got five patients sitting in the



New nurse managers, from left, **Christopher Reyes, Barbara Buckley** and Colleen Gordon.

ED, and you have to find a bed and a nurse for each of them somewhere in the hospital. I love trying to shift patients. I sort of thrive on adrenaline," says Gordon. "I like being in a high-chaos environment and straightening it out."

Gordon has been blown away by the commitment of her team of bedside nurses in the middle of a pandemic. It's rare, she explains, that nurses miss a shift - something that can be a problem in some hospitals, especially during the COVID-19 crisis.

"I'm attributing it to the fact that the people who are here chose to be in this unit specifically," says Gordon. "They didn't just end up here as new nursing school grads ... they [are experienced nurses] who all left other jobs to come here."

Gordon is determined to advance her team of nurses into clinical experts in pediatric cardiac care: "They are going to know just as much, if not more, than the new fellows that are coming in here, because that's how invested we are. We have specialized classes and physicians partnering with us to teach us about echo data and cath lab information."

She adds, "I love what we're trying to do here. And I think what's more important is that the [other nurses] are just as excited as me."

Christopher Reyes, prior to starting as nurse manager of the Johns Hopkins pediatric intensive care unit (PICU) in the fall of 2020, spent over a decade working as an Army nurse at military bases around the country and at Walter Reed Medical Center in Bethesda, Maryland. He was trained in adult critical care. but he found his calling when he was assigned to a pediatric intensive care unit. Working with children inspired him to pursue a doctorate in pediatric acute care nursing.

16 The nurses provided so much comfort for me as a parent, I knew that my daughter was in good hands and that things were going to be OK. The care exceeded my expectations, and that's what really pushed me back into nursing.

#### - BARBARA BUCKLEY, NICU NURSE MANAGER

"I love the resiliency children possess," says Reyes. "In spite of how sick they are ... they show an ability to find the good in everything, and they're playful and easy to work with."

Reyes' experience as the chief nurse of a task force deployed to New York City during the peak of the pandemic in the spring and summer of 2020 served him well when his team at Johns Hopkins was tasked with creating a seven-bed COVID-19 area within the 28-bed PICU.

"That was a really demanding time because we had to convert some of the rooms into negative pressure rooms, or what we call biodomes," says Reyes. "Children typically don't have many complications [from COVID-19], but those that do definitely are pretty sick, and are at increased risk of developing multi-inflammatory syndrome. It's my responsibility to make sure that my almost 150-member staff have the resources necessary to care for these COVID-19 patients while still maintaining our standard operations within the PICU."

Reyes sees parallels in his roles working at Johns Hopkins and in the military. Both jobs, he says, involve putting efficient systems and processes in place, and both have far-reaching global implications across the health care platform.

"Johns Hopkins really sets forth this tone of being a global health leader," says Reyes. "So, coming out of the Army, this opportunity allowed me to realign my new civilian aspirations with what I historically knew myself to be, which was somebody who was in tune with serving a greater good."

Reyes' vision is for the PICU nurses to be innovators and thought leaders in

pediatric critical care medicine and nursing. He gives the example of PICU Up!, an innovative multidisciplinary program developed at Johns Hopkins in 2016. Instead of keeping critically ill children in bed, and often sedated, to avoid dislodging IVs or a breathing tube — which was standard practice at the time — the team experimented with keeping these children more physically active and mobile during their PICU stay. In all cases, the kids fared better physically and emotionally and experienced no adverse effects. The PICU Up! program has since become a model for hospitals nationwide, and an inspiration for Reyes.

"I want us to be the gold standard," says Reyes. "I want people in the health care community to say that because Johns Hopkins PICU does it, they should do it as well."

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**Barbara Buckley** graduated with her nursing degree in 1983, but she didn't become a nurse right away — instead, she worked as an account executive at a Fortune 500 company. It wasn't until shortly after the birth of her third child in 1994 that she found nursing again. Born with a cleft lip, her daughter would undergo four surgeries by the time she was 2 years old.

"We were in and out of the PICU," she says. "The nurses provided so much comfort for me as a parent, I knew my daughter was in good hands and that things were going to be okay. The care exceeded my expectations, and that's what really pushed me back into nursing."

Not only did her daughter's experience reconnect Buckley with nursing, but with

the niche of neonatal nursing as well: "I love working with the families, especially when the babies are just born, and teaching parents about what's going on with their child and what to expect."

Before taking on the role of nurse manager of the neonatal intensive care unit (NICU) at Johns Hopkins in October 2020, Buckley worked at three different hospitals. While she loved being a bedside nurse, she also found herself taking on more administrative roles — a natural fit, given her business experience. "I love being able to help people figure out problems," she says.

Managing the nursing department during the pandemic has, naturally, been challenging. There have been staffing shortages, as well as a heightened level of distress among parents, who, with rare exceptions, are only able to visit their babies one at a time. "It's unfortunate and very challenging for the families because they just can't be with their baby together," says Buckley.

Still, Buckley is thrilled to be at Johns Hopkins Children's Center. One of the things that attracted her, she says, is its focus on advanced practice and designation as a Magnet hospital for nursing. "To be accredited every few years, you have to show that the members of your nursing force have autonomy and are exemplars in different areas, such as patient outcomes, community outreach, quality of care and safety."

With this in mind, one of Buckley's goals is to encourage the nurses in her unit to be actively involved in areas outside the realm of bedside care, such as working on committees and participating in making decisions about the department and the unit as a whole. She has also been serving as a mentor to the new nursing school graduates in the unit.

"I love being able to support new nursing grads as they navigate the nuances of being a new nurse, figuring out how to take care of patients, and how to balance that with their home life as well," says Buckley. "I think they're awesome. We really owe them a lot, and we should do whatever we can to keep them."



# Organ Transplant Surgeon **Betsy King**

**BETSY KING SAYS SHE** cannot pinpoint when during her childhood outside Chicago that she first wanted to be a surgeon. But for sure, she says, her parents were strong influences.

"My dad was a bricklayer, which had nothing to do with surgery, but I saw my whole life as doing something with my hands, either building something or making something or fixing something," says King, who is now helping to direct the pediatric transplant program at Johns Hopkins. "I was fascinated with anatomy at a really young age, maybe around 10," she says, "and the idea of using your hands to fix the human body was very

appealing to me. I never turned back."

Fast forward 15 years, and she found herself in medical school at the University of Chicago. There she held on to her vision of being a surgeon, perhaps a plastic surgeon, she thought, after rotating on that surgical service. Her interest in painting and sculpture seemed to complement the subspecialty.

"It seemed to be the culmination of everything I was looking for," says King.

Despite the initial pull of plastic surgery, it seemed to lack the medical complexity and patient management she had appreciated as a student during internal medicine and other rotations. She had a

moment of panic: "What am I going to do with my life now?"

The answer came during her next rotation — transplant surgery. King was blown away. "It was just this beautiful combination of elegant, complex, technically challenging operations and equally complex and challenging medical issues that the patients were going through," she says. "The management they required really appealed to me. I said to myself, 'Wow, this is what I need to do, this is my passion."

After medical school, that passion deepened during a visit with her husband to the Johns Hopkins medical campus. As a couples match, they were both applying for residencies there — she in surgery and he in pediatric anesthesiology and critical care medicine. While King's husband was familiar with Johns Hopkins because his father had trained there, she felt like she was in Oz, far removed

from her roots.

"I always thought of Hopkins as this great mecca of medicine, where surgery was really born," says King. "At the time, it was kind of overwhelming for me."

After a day of interviews and campus tours, however, she was smitten. So was her husband.

"We met back up at the airport, and it was a nice moment because we had both fallen in love with Johns Hopkins and immediately felt won over," says King.

How? King points to the people. "The single greatest thing about Hopkins is this collection of people who are so dedicated and committed to the same common goal," she says. "That was just awesome — it was everything I wanted."

It was what she got, after she and her husband were accepted into their residency programs. King also wanted research experience, so she took three years away from her surgical training to pursue a Ph.D. program in clinical investigations at the Johns Hopkins Bloomberg School of Public Health. Her focus was hospital readmissions following kidney transplants. Through that subject, she found a research track very much in sync with her surgical path and who she was at her core.

"In studying who is at risk for readmissions and how it impacts post-transplant outcomes, one important but poorly understood factor was the influence of social determinants of health," says King. "That was the beginning for me in understanding social disparity and how it can have a negative effect on our patients."

Around the same time, King was helping to run Johns Hopkins' live donor

campaign, a program in which she and colleagues train patients and family members how to identify live organ donors rather than wait for a deceased donor organ. Wait lists for donor kidneys and livers can be long, and patients can die before an organ becomes available — "a terrible outcome we want to avoid at all costs," says King.

One answer for a pediatric patient is a friend or family member willing to donate a kidney or portion of their liver. But historically, King notes, underserved and minority populations have not had great access to living related donors, partly because they may be unaware of the resource. The live donor program is designed to address that disparity.

"I was able to work with a group of wonderful patients on our wait list in the Baltimore area who otherwise wouldn't have known about live kidney donation," says King. "We educated these patients and helped them understand the details of live donation so they could be well informed about considering that as an option for their care. In a way, this sort of leveled the playing field for them, to advocate for themselves and better utilize resources."

That grass roots effort appealed to King and, more importantly, to the patients in the program. Even if they did not identify a live organ donor, they were better informed about transplantation, says King.

"It made such a profound impact on their lives to have that one-on-one interaction and engagement with the staff and faculty here at Hopkins that they otherwise wouldn't get," King says. Stimulated by the potential impact, King has been applying for National Institutes of Health funding to continue her research on social determinants of health related to kidney and liver transplant and to make transplant more accessible for underserved populations. One avenue is a group of non-directed live donors, or altruistic donors, who have offered to donate a portion of their liver to any patient — adult or child — who needs it.

"It's an option for pediatric patients, especially for those who may otherwise not be able to get a live donor transplant," says King.

King and colleagues are also exploring ways to boost post-transplant support for patients and families in disadvantaged communities. Managing the medications and frequent clinic visits for a 2-year-old liver transplant patient is no easy chore even for a family with resources, notes King. For a single mom with a full-time job, it's nearly impossible.

"Just coming to Johns Hopkins for labs can be a very big deal," says King. "This is another area where we can empower our patients and their families with varying levels of health literacy, to engage them and create accessible post-transplant care. We can help parents better utilize hospital and community resources that can help following transplant."

King sees such holistic pursuits and her social determinants research as very much part of the framework of the hands-on culture at Johns Hopkins and the career she is building. As director of the pediatric surgical abdominal program, she is leading efforts to grow the program. In her free time, she still paints and sculpts — the other thing she does with her hands.

"As surgeons, we're creative in the operating room, so for me it's important to have time to be creative in a different way," says King. "Also, my art is something I share with my children."— *GL* 

16 It was just this beautiful combination of elegant, complex, technically challenging operations and equally complex and challenging medical issues that the patients were going through. ... I said to myself, 'Wow, this is what I need to do, this is my passion.' >>>

- BETSY KING

# Bridge Builder John Campo

WHEN ASKED ABOUT EARLY influences that pushed him toward medicine, John Campo recalls the loss of his baby brother at 4 months of age. The oldest of four siblings, Campo, then only 8, remembers vividly the doctor trying to reassure his mother that her baby would be OK as he wrote her a prescription for valium. She persisted that something was wrong.

"After that, I grew into the idea of being the family watchdog," says Campo. "That was really influential."

A watchdog takes care of people, Campo figured, so in his early school years he gravitated toward science and later found his way to medical school at the University of Pennsylvania. What kind of doctor did he want to be?

"If you asked me then," he answers, "I'd say I don't know, but I do know what I'm not going to do. I'm not going to be a surgeon because I don't have that kind of hand-eye coordination, and I definitely don't want to be a pediatrician because being around sick kids really, really upsets

So, of course, after medical school he headed off to pediatrics in Philadelphia with the idea of being "an internist for kids" with a specific interest in hematology-oncology. "I guess I can be a bit counter-phobic," he says.

In ways, Campo has intuitively followed that path, immersing himself in that which presented the greatest blend of challenge and anxiety. During his pedi-

I got an introduction into how physical illness can affect emotional life and vice versa. It gave me permission to go into psychiatry. "

- JOHN CAMPO



"I got an introduction into how physical illness can affect emotional life and vice versa," says Campo. "It gave me permission to go into psychiatry."

At the University of Pittsburgh Medical Center, he was drawn to the interface between pediatrics and psychiatry, and disorders such as functional abdominal pain — recurrent pain in the gastrointestinal tract with no obvious physical cause that may be provoked by anxiety.

"It's common to see patients with illness or subjective distress but not a clearcut disease in the traditional sense, some sort of pathology you can point to in a biophysical way," says Campo. "The reality is a large number of patients don't fit neatly into the biomedical model, and end up feeling terribly misunderstood and may not get the really good care they deserve."

As a pediatrician training in psychiatry, Campo found himself a referral source for these patients and parents frustrated by the lack of a definitive physical or psychological cause. Known as someone who could, in his words "dance on both sides of the equation," colleagues believed he had viable answers.

Troubled by what he considered to be a false dichotomy between physical and mental health in our health care system, Campo integrated mental health services into general medical settings and developed a practice-based research network in

primary care for kids with anxiety and depression. His growing awareness that suicide is the second leading cause of death among 10- to 24-year-olds, encouraged him to think more seriously about the relationship between suicide and lack of access to mental health care.

"How do you rescue these children?" asks Campo. He concluded that one answer lies in primary care medical models infused with mental health services. There, clinicians can bridge the gap between pediatrics, psychiatry and traditional medicine, integrate mental health services and create sustainable models of care. Such models require a strong collaborative culture, which drew him to Johns Hopkins.

Building bridges to collaborators, including the Kennedy Krieger Institute where Campo has the additional role of vice president of psychiatric services, is another goal. There a new developmental neuropsychiatry scholars' program was recently launched to leverage KKI's world-leading expertise in neurodevelopmental disorders and disabilities, which will further enhance his division's training program.

"It's part of our blueprint to together create a division of child and adolescent psychiatry that has one unified culture of excellence across multiple sites," says Campo. "We want to make the whole greater than the sum of the parts." — GL

# Erica Hodgman Follows a Mother's Footsteps

**GROWING UP, Erica Hodgman** recalls, she heard stories from her mother about her experiences as a neonatal nurse at New York-Presbyterian Hospital in the 1970s, jumping on board medevac choppers to help rescue babies in need of emergency care. Hodgman also remembers rummaging through her mother's medical textbooks, fascinated by the world of medicine the pages revealed.

"Needless to say, from then on I always knew I wanted to be a doctor," Hodgman says. Laughing, she adds, "My mother clearly gave me the idea of becoming a pediatric surgeon."

In ways, Hodgman has wedded her own vision as a physician with her mother's experience as a savior of sorts for young patients. After medical school at Emory University, it influenced Hodgman's choice to pursue treating children, and surgery to potentially have a dramatic impact on their outcomes — in other words, to save them.

"You can have a child on the verge of dying, who is that sick, and you can do your intervention, work together as a team, and that kid can not only survive and recover but go on to live a full life," says Hodgman.

That realization came through a general surgery residency and burn/trauma research fellowship at the University of Texas, a pediatric surgery fellowship at Le Bonheur Children's Hospital in Memphis, Tennessee, and a surgical oncology fellowship at St. Jude Children's Research Hospital, also in Memphis. Underlying that technical training — and even medical school, for that matter — was a strong sense of advocacy that Hodgman gleaned from a program supporting first responders who had medical injuries from the 9/11 World Trade Center collapse.

"You have salty union plumber dudes who are suddenly finding human remains," says Hodgman. "Everyone down there was trying to save lives and not thinking about themselves and basically breathing in a pulverized building, which turns out is something you really shouldn't do."

Lobbying congress through a partnership with the New York fire department and area hospitals such as Mount Sinai, Hodgman helped lead efforts to obtain federal funding for screening and treating the first responders for issues like heartburn, reflux and asthma-like diseases.

"That for me was like an aha moment for what you can do with research and advocacy," she says. "You can actually have a good impact on people."

As a burn and trauma surgeon at Johns Hopkins Children's Center, Hodgman is

We are asking parents to trust us with what is far and away most important in their life. That's really special.

- FRICA HODGMAN

beginning to segue that advocacy spirit into other areas — such as fire safety, injury prevention, gun control and social support for disadvantaged communities. Her research goals include development of evidence-based interventions to improve burn care and reduce pain by using better dressing options and laser therapies. For Hodgman, the mental health impact for patients and their families, some of whom suffer severe guilt and post-traumatic stress disorder, is another important issue.

"Some families have a huge amount of guilt, which can be a barrier for their participation in their child's care," says Hodgman. "They may already feel like they were negligent and hurt the kid, and now they have to hurt him again when they do the dressing change. It all compounds the guilt."

Being a pediatric surgeon and all that comes with it is tough work, concludes Hodgman, but it is well worth it. "We are asking parents to trust us with what is far and away most important in their life," she says. "That's really special."—
GL



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# researchroundup



# A 'Game Changer' Grant for Managing MIS-C By Gary Logan

**MULTISYSTEM INFLAMMATORY** syndrome in children, or MIS-C, is a complex syndrome associated with SARS-CoV-2, the virus that causes COVID-19. Children have presented with diarrhea, vomiting and severe cardiovascular problems in addition to respiratory problems. Other symptoms include conjunctivitis, skin rash, swollen hands or feet, cracked lips and a red tongue — signs typically associated with classic Kawasaki disease, an inflammatory disease that can cause coronary artery aneurysms. Also confounding this clinical picture, some children experience neurologic symptoms such as headache, sleepiness and confusion. Clinicians are significantly challenged when it comes to diagnosing and managing these patients, and predicting which children need hospitalization and which will become critically ill.

"Normally the clinical management of patients with this novel syndrome is very difficult — it affects multiple systems and there is a lot of overlap with different diseases and signs and symptoms that are still evolving," says **Shelby Kutty**, director of pediatric cardiology at Johns Hopkins. "Treatment at the onset and the epidemiology of this disease are still very new, presenting the need for salient prediction models for diagnosis and figuring out which patients are likely to develop new problems."

Kutty and lead principal investigator **Cedric Manlhiot**, in partnership with the International Kawasaki Disease We'll establish an interface that can be deployed in Epic and similar electronic records with clinical data that can aid diagnosis and treatment.

- SHELBY KUTTY

Registry (IKDR), aim to produce such predictive models for a syndrome that doesn't act in a predictive way. How? Kutty is chair and Manlhiot is director of Johns Hopkins' Cardiovascular Analytic Intelligence Initiative (CV-Ai²), which uses artificial intelligence and machine learning tools to turn real-time clinical data into prediction models that can help forecast patient outcomes.

"The goal of CV-Ai<sup>2</sup> is to find better ways to utilize data and design solutions for important clinical problems, which in turn are directly evaluated at the physician and patient level," says Manlhiot.

After submitting a proposal to the National Institutes of Health (NIH), the co-investigators were awarded a four-year, \$4.8 million Rapid Acceleration of Diagnostics-Radical (RADx-rad) initiative grant, what Johns Hopkins Hospital president **Redonda Miller** calls a

"game changer" for children with SARS-CoV-2 related disease.

During the first two years, patient data collected by the IKDR, a consortium of 19 hospitals, will be used to help create algorithms employing artificial intelligence-based models for diagnosis, treatment and outcome prediction. In the third and fourth years, the performance and clinical utility of these models will be validated.

"Ultimately, by year four, we'll establish an interface that can be deployed in Epic and similar electronic medical records with clinical data that can aid diagnosis and treatment," says Kutty.

Because MIS-C has some similarities with Kawasaki disease in its presentation, the strategic partnership with the IKDR will provide an established data collection platform and make use of substantial clinical and research expertise. Pointing to interest from some 40 other hospitals in the United States as well as hospitals in South America, France, Italy, the United Kingdom, Taiwan and India, Kutty concludes that this work will grow the IKDR consortium and improve care and outcomes globally for children with MIS-C.

"Based on what we have gathered so far," says Kutty, "this should lead to a meaningful prediction model for patients all over the world." — GL

# **Reducing Readmissions** for Nephrotic Syndrome

A multicenter care bundle aims to standardize treatment to keep children out of the hospital due to recurring complications of this kidney disease.

AS A PEDIATRIC NEPHROLOGY fellow, Olga Charnaya led a quality improvement (QI) initiative designed to manage nephrotic syndrome consistently in children. She learned that nephrologists' approaches vary in treating this disease, which due to too much protein in the urine can lead to frequent fluid buildup and swelling in the abdomen, legs and feet. In addition, patients and families lack standardized educational material to help them identify early signs of nephrotic syndrome relapse. The result is repeated visits to the hospital to manage these complications and reduce the risk of acute kidney disease.

"When it comes to nephrotic syndrome, everybody treats these patients a little bit differently," says Charnaya. "There is no one right way."

Charnaya's QI project, however, showed that the need for emergency room care or hospitalization for relapses can be reduced through a standardized outpatient approach including patient education. Under the initiative, in which 75%–80% of families were provided nephrotic syndrome education, emergency department and inpatient admission counts were reduced for the first three quarters of the year, and clinic visits did not change over the period (Front Pediatr. 2019 March 29; 7:112).

When Charnaya joined the faculty at Johns Hopkins Children's Center in 2017, Alicia Neu, pediatric nephrology director, immediately leveraged her research experience. The division had just joined the glomerular disease learn-



In clinic, pediatric nephrologist Olga Charnaya follows the GLEAN care bundle follow-up schedule for patients with nephrotic syndrome.

ing network (GLEAN), a collaborative of nine pediatric nephrology programs all sharing the goal of Charnaya's research to reduce patients' need for acute care. The director thought, who better to lead the division's nephrotic syndrome efforts?

"Their work was really an extension of my fellowship project, so it made sense that Dr. Neu asked me to be the QI lead for this project," says Charnaya. "This condition can be ideally managed in the outpatient setting."

The result was the GLEAN Acute Care Change Packet, a care bundle that started rolling out in November 2020. Included are standardized steps for patients with new onset nephrotic syndrome for each clinic visit during the 90 days after diagnosis. For instance, the first visit should occur within five days after diagnosis and include a tuberculosis screening and enhanced vaccination. Pneumovax, a vaccine to prevent peritonitis, and an annual flu vaccine are

administered in the clinic at the time of diagnosis. Also, the patient education packet is introduced, which includes guidance on how parents can monitor their child's loss of protein each day.

The second follow-up visit should occur within four weeks to assess for remission of disease and to plan for alternate therapies and procedures, if needed. The algorithm includes a weekly or biweekly nursing check-in call to monitor patients' and preempt complications.

Following this GLEAN group formula, Charnaya and colleagues will assess the outcomes of this approach to help determine best practices.

"Our goal," says Charnaya, "is to start with this multiprong approach and study it in a systemic way to see the best mechanism for improving care." — GL

### Research Briefs



Smart' Tool for Diabetic Retinopathy Although the American Diabetes Association (ADA) advises regular screening for pediatric diabetic

retinopathy, it's estimated that fewer than half of all youth with diabetes follow the recommendation. Without early detection and treatment, these patients put themselves at risk for serious vision problems or blindness as they get older. In a recent study in *Diabetes Care* (Mar; 44(3): 781-787) researchers at Johns Hopkins and three other medical centers demonstrated that autonomous artificial intelligence (AI) can be used to detect pediatric diabetic retinopathy with high sensitivity, specificity and accuracy. The technique had already been approved for adults with diabetes by the U.S. Food and Drug Administration and is part of the ADA's retinopathy screening guidelines for patients age 21 or older. Because the AI screening does not require eye dilation, it takes less time to perform and is easier for pediatric patients to undergo. Therefore, the adherence of the patients in this study to getting regular retinopathy screenings, as defined by the ADA, more than doubled. "Use of autonomous AI in adults has shown extremely high levels of sensitivity, specificity and accuracy in diagnosing referable diabetic retinopathy, when the disease is most treatable," says pediatric endocrinologist and lead author Risa **Wolf**. "So, with the rising incidence of pediatric diabetes — especially type 2, which is associated with an earlier onset of retinopathy — we felt it was important to see if AI could make an improvement in adherence to screening guidelines and early diagnosis for younger patients." — Michael E. Newman 🜕



Immune
System Boost
Against NEC
Medical researchers
have long understood that a pregnant mother's diet

has a profound im-

pact on her developing fetus's immune system and that babies — especially those born prematurely — who are fed breast milk have a more robust ability to fight disease, suggesting that even after childbirth, a mother's diet matters. However, the biological mechanisms underlying these connections have remained unclear. In a study published in the journal Nature Communications (Feb. 15, 2021), a Johns Hopkins research team reports that pregnant mice fed a diet rich in a molecule found abundantly in cruciferous vegetables — such as broccoli, Brussels sprouts and cauliflower — gave birth to pups with stronger protection against necrotizing enterocolitis (NEC), an inflammatory condition that destroys a newborn's intestinal lining, making it one of the leading causes of mortality in premature infants. The team also found that breast milk from these mothers continued to confer immunity against NEC in their offspring. In earlier mouse studies, Johns Hopkins researchers showed that NEC results when the underdeveloped intestinal lining in premature infants produces higher-thannormal amounts of a protein called tolllike receptor 4 (TLR4). TLR4 in full-term babies binds with bacteria in the gut and helps keep the microbes in check. However, in premature infants, TLR4 can act like an immune system switch, with excess amounts of the protein mistakenly directing the body's defense mechanism against disease to attack the intestinal wall instead. "Based on this understanding, we designed our latest study to see if indole-3-carbinole, or I3C for short, a chemical compound common in green leafy vegetables and known to switch off the production of TLR4, could be fed to pregnant mice, get passed to their unborn children and then protect them against NEC after birth," says study senior author David Hackam, surgeon in chief at Johns Hopkins Children's Center. *— MEN* **●** 



Peanut Allergies in Infants

Approximately 2%-3% of Americans are allergic to peanuts. Previous research studies

have suggested that introduction of the peanut in the first year of life to infants highly likely to develop a peanut allergy reduces that risk by approximately 80%. However, the best method to safely do this is unclear. A Johns Hopkins Medicine research team has conducted a study that shows which babies are most at risk for peanut allergy and which tests are best for diagnosing them. The team's findings were reported in two papers in the Jan. 19, 2021, issue of the Journal of Allergy and Clinical Immunology. One paper (March 2021, pages 984-991) identifies the likelihood of babies developing a peanut allergy, finding that older infants and ones with moderate-to-severe eczema are most at risk. The other paper (March 2021, pages 977-983) compares diagnostic tests for detecting peanut allergy. "Early introduction of peanut is important to prevent peanut allergy," says pediatrician Corinne Keet. "Current recommendations are that infants with severe eczema be exposed to peanuts early in the first year of life, but also that they get testing before introducing peanuts to make sure that they are not already allergic. We wanted to know what the real risk for peanut allergy was in this group, and in other potential risk groups, and what tests would be best to use for screening." The researchers found that 18% of the infants with moderate to severe eczema were allergic before introducing peanut. They found that risk increased with the severity of eczema, and also increased with each month between 4 months and 11 months of age. This, say the researchers, suggests that introducing infants with severe eczema to peanuts before they reach the age of 6 months is necessary to effectively prevent the allergy. — Waun'Shae Blount 🧼

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# The Julie and Neil Reinhard Professorship in Pediatric Allergy and Immunology Comes to Full Fruition

Since 2007, a grateful patient family continues its support of immunologist Robert Wood and the Eudowood Division of Allergy, Immunology and Rheumatology in studying allergic diseases and helping children and families best manage them.

IMAGINE BEING A CHILD and never eating birthday cake at a friend's party because it might contain trace amounts of peanuts or tree nuts, or being a teenager who can't go to a coffee shop because of the milk in the air. Imagine needing to read every single food label before eating snacks — because your life depends on it. For children and teens with food allergies, these scenarios are all too real. Pediatric food allergies are extremely common — their prevalence has nearly tripled in the last 20 years. Food allergies can cause severe reactions and can have an enormous impact on the daily life of a child — and the child's family.

Julie and Neil Reinhard experienced the fear caused by a life-threatening food allergy reaction when their son, Seth, had an allergic reaction to peanut butter two days after his first birthday. After going to an emergency department, the Reinhards saw **Robert Wood**, director of the Eudowood Division of Allergy, Immunology and Rheu-

matology at Johns Hopkins Children's Center.

"We didn't know anything about food allergy then, and wanted the top expert in the field to care for Seth and help us navigate this new territory," Julie Reinhard says. "We soon found Dr. Wood and felt relieved as he demystified food allergies and explained how to best manage them on a day-to-day basis. Equally important was Dr. Wood's genuine concern, patience and care."

Reinhard adds, "That was just the beginning. Year in and year out, Dr. Wood has been there for us, sharing the key information and facts we needed to keep our son safe and healthy."

For more than 20 years, Wood has been at the forefront of research and treatment regarding pediatric food allergies. Therapies for food allergy have traditionally revolved around avoiding the allergen and ensuring that medication is available in case of accidental exposure, but Wood and his team have

**By Amanda Leininger** 

been leading investigations for years on approaches to not only treat the symptoms but also to reduce the risks. Currently, Wood oversees more than 20 studies at Johns Hopkins, with 200 to 300 total patient participants — many studies supported by philanthropy.

Inspired by the compassionate care Seth received from Wood, the Reinhards — along with Neil's mother, Myra, and father, Eli — supported Wood's work with the lead gift to establish an endowed professorship for him in 2007. The professorship supports the Eudowood Division in perpetuity, providing integral funds to help reach the goal of arming children and parents with the ability to best manage childhood allergies, and to find comfort and confidence — through all phases of life.

Since the initial gift in 2007, dozens of patient families like the Reinhards have recognized the need for Wood's research to continue and have made contributions to the endowment. Years

If There's nothing more important to us than investing in research for health care, and there's no one working harder than Dr. Wood to improve the lives of children with food allergies. We are so grateful to all the families whose lives he's touched immeasurably who joined us to help make this happen.

– JULIE REINHARD

#### People&Philanthropy Foundation Relations

in the making, the efforts of these grateful donors finally came to fruition in 2020, when the Julie and Neil Reinhard **Professorship in Pediatric Allergy** and Immunology was fully established. Wood was named the inaugural recipient.

"It's a true honor to be able to see the support that has come in thanks to the dedication of many families who are committed to the work that we're doing," Wood says. "Thanks to philanthropy, we have been able to really provide the world's best care for patients with severe allergic disease, and have taken it to the next level with our research program. At this stage of my career, it's very important to me to leave behind a legacy of trainees, and this will guarantee our work has no end in sight, even beyond when I'm no longer actively doing this."

The endowment provides discretionary funds that will allow investigator-initiated research to continue despite potential changes to other funding sources. Endowment funds will also support training of the next generation of pediatric allergists and immunologists, ensuring that they have the resources they need to be successful.

"I'm so incredibly grateful for the combination of the brilliant mind and the tremendous compassion and empathy that Dr. Wood gave to Seth and my entire family," Julie Reinhard says. "There's nothing more important to us than investing in research for health care, and there's no one working harder than Dr. Wood to improve the lives of children with food allergies. We are so grateful to all the families whose lives he's touched immeasurably who joined us to help make this happen."

Hear from our patients and care providers bit.ly/HopkinsFoodAllergy.



# **Gaming for Kids**

WHILE MANY EVENTS went virtual for the first time in 2020, Extra Life, a 24-hour gaming marathon, has proven its success in the virtual space for over a decade. Extra Lifers commit to playing any video, desktop or tabletop game (or combination of games) of their choice for 24 hours to be scheduled to raise funds for local children's hospitals through Children's Miracle Network Hospitals, of which Johns Hopkins Children's Center is a member hospital. Gamers can play from anywhere, connecting with other Extra Lifers through livestreams and virtual meetups forming a unique community with the mantra, "Play Games, Heal Kids."

Since 2010, more than 5,000 gamers have raised over \$900,000 for the Children's Center through Extra Life, with an impressive \$181,314 raised in 2020 alone. This year, Australian You-Tube streamer and influencer Legend of Total War joined in supporting the Children's Center, livestreaming for 24 hours to raise funds for pediatric food allergy research — he even dueled a Children's Center patient during his stream, raising more than \$32,000.

"We wanted to celebrate the milestone of reaching 300,000 subscribers on YouTube, and chose to do that by hosting a 24-hour livestream for charity. Because our audience is spread across the world, it was important to us to choose an organization that helps people worldwide," says Legend of Total

War. "Johns Hopkins Children's Center is doing some amazing research into childhood allergies, which could be life-changing for kids everywhere."

And it's not only game day gamers raise funds and collaborate year-round as part of the Extra Life Baltimore Guild, meeting throughout the year to plan recruitment events, attend conventions, hear from patients to stay connected to the cause, and meet up for fun activities like laser tag and escape rooms. Guild President Drew Nicolo has raised funds for the Children's Center through Extra Life since 2012. Each year, he sets higher goals and keeps things fun by adding different incentive levels for his fundraising goals — like letting his donors pick his new hair color.

"Extra Life is not just a fundraiser, it's a whole community. It's an event, but it's also a yearlong journey to meet new people, spreading the word and championing for kids and families who might be at the lowest points of their lives and need people like us out there fighting for them," Nicolo says. "There's really no downside to signing up or coming to a meeting; it's laid back, all about playing games, having a great time and raising money for a great cause." —AL

Save the date for this year's game day on Nov. 6, 2021. Sign up at bit.ly/JHCCExtraLife21 or email hopkinschildrens@jhmi.edu for more information on the guild.



IN SHOW BUSINESS, "the show must go on," and when a pandemic swept the globe, radio shows – and fundraising events – were no exception. Despite much uncertainty, when the time came to plan Mix 106.5's 32nd Annual Radiothon benefitting Johns Hopkins Children's Center, everyone's creativity went into overdrive with one common goal: making Radiothon as successful as possible for the patients and families who need it most.

Mix 106.5's new morning show hosts, **Kramer and Jess**, joined by veteran DJs **Priestly**, **Maria Dennis** from 101.9 WLIF and **Jeremy Conn** from 105.7 The Fan, held virtual interviews with Children's Center patients and families to gear up for the event. While broadcasting from the hospital wasn't an option this year, the DJs stayed connected during the two-day broadcast via Zoom, sharing stories on-air of the strength and resilience of the patients, families and care providers at the Children's Center asking listeners to call in and donate.

A central theme in this year's stories? There's no place like home. While many people spent more time at home than ever this past year, patients and families at the Children's Center would love nothing more than to be at home rather than in the hospital. From the teenager who had a traumatic longboarding accident to the parents whose daughter was born with her umbilical cord wrapped around her neck, all echoed the same sentiment: if they couldn't be at home, they were thankful for the care they received at the Children's Center, made possible by funds raised through events like Radiothon.

When the time came to announce how much Baltimore and

We raised more than \$1.3 million for Hopkins and restored faith and hope to a community who desperately needed it, as did I. It was pure magic! Hope in the face of adversity. #MoStrong!

- PRIESTLY, MIX 106.5 DJ

the surrounding community helped raise, patient families, care providers, and donors alike eagerly tuned into Facebook to watch the live card parade, which revealed the event's second highest total ever raised: \$1,328,335.32.

"In a time when the world was flipped upside down, life as we knew it was paused. I witnessed a city unite for a common cause – our sick kiddos and Miracle Makers at Johns Hopkins Children Center. With a new morning show and the recent passing of our beacon of light, Mo Gaba, we overcame what experts said would be impossible numbers in a virtual environment during times like this," Priestly says. "We raised more than \$1.3 million for Hopkins and restored faith and hope to a community who desperately needed it, as did I. It was pure magic! Hope in the face of adversity. #MoStrong!"—AL

Save the date for Mix 106.5's 33rd Annual Radiothon, Feb. 24 – 25, 2022.

# A GIANT Impact

ROOTED IN A LONGSTANDING belief that it's important to make a difference where you operate, The GIANT Company, based in Carlisle, Pennsylvania, has been giving back locally since the company's founding as a butcher shop in the 1920s. Now 187 stores strong, The GIANT Company has supported Johns Hopkins Children's Center through its partnership with Children's Miracle Network (CMN) Hospitals for more than 20 years. Each year, the company hosts the largest golf tournament on the East Coast, spanning 13 golf courses and more than 2,000 participants. The event supports eight CMN hospitals, including Johns Hopkins Children's Center. From June 1 through Aug. 31, the organization also holds its "Round Up" campaign, during which customers are asked to round up their total to the nearest dollar at checkout. At stores in Maryland, 100% of the donations stay local to help patients and families at the Children's Center.

In March 2020, when the COVID-19 pandemic swept America, essential workers — like those at The GIANT Company — were on the front lines. At a time when panic-buying was rampant, shelves were empty and lines were long, leadership at the company was keenly aware of how the pandemic was impacting not only themselves, but others as well.

"When we saw the work that was being done by our health care partners and the pictures of overcrowding of hospitals, ambulances, the stress and long hours, the shortage of PPE, we knew that we needed to step up," says Jessica Groves, social impact manager for The GIANT Company. "We felt it was important that they knew that we were there for them. We were in the enviable position to be able to help, and we knew we needed to act fast."

In late March, Cynthia Palacz, senior

associate director of development, received an unexpected phone call: The GIANT Company wanted to donate \$50,000 to support COVID-19 efforts at Johns Hopkins Children's Center.

"In a time when the world stopped and we were all in crisis, we weren't sure how we were going to raise money for our kids, whose needs didn't stop — and in some cases, increased — in the middle of a global pandemic. Getting that call was a ray of sunshine in the middle of a storm," Palacz says. "We are so grateful for amazing partners like The GIANT Company

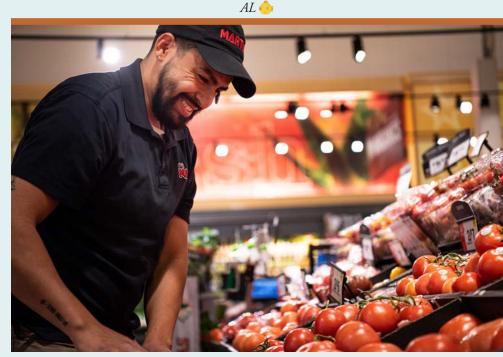
GOur team members love supporting the Children's Center. After more than 20 years, it's ingrained in who we are. "

- JESSICA GROVES, GIANT

who were thinking of our care providers, kids and families when they themselves were also on the front lines."

Pivoting in this time of crisis, The GIANT Company remained committed to its annual fundraising efforts, implementing a contactless version of its Round Up campaign in support of CMN Hospitals. Despite the challenges faced throughout 2020, The GIANT Company surpassed its fundraising goal, raising nearly \$40,000 for the Children's Center — a 19% increase from 2019.

"Our team members love supporting the Children's Center. After more than 20 years, it's ingrained in who we are. Our team knows that they're part of a company culture that isn't just selling groceries. They're connecting families for a better future," says Groves. "The GIANT Company is dedicated to changing children's lives, and we're honored to be able to raise funds and get them to organizations like Johns Hopkins who can make a difference in the lives of kids." -



# 'Kids Can't Wait' For the '30 Day Miracle Movement'

THROUGHOUT THE PAST YEAR of uncertainty, one thing remained decidedly certain: Kids can't wait. During the global pandemic, children couldn't wait for a cure or vaccine, or for the curve to flatten, and funds still needed to be raised to provide resources for our patients and families.

Johns Hopkins Children's Center merged two beloved signature, in-person events into one virtual happening: Kids Can't Wait — 30 Day Miracle Movement. Kicking off with the Team Hopkins Kids Race and ending with Baltimore Boogie, the Children's Center's annual dance marathon, participants — known as Miracle Movers — joined in various virtual events and raised funds from home over the course of 30 days.

Individuals and businesses in the community stepped up to rally behind the patients, families and care providers at the Children's Center by hosting and supporting the events, sponsoring activities, and asking friends and family members to donate via social media. Core Cycle Studios in Lutherville, for example, hosted virtual and socially distanced in person spin and barre

So many people who come into the studio or join us virtually are quietly fighting things we know nothing about, just like we have no idea what the families are going through at the Children's Center. Fundraising is important, but so is garnering awareness and education in the midst of a crisis. I'm so proud of how our team came together to be part of this. "

— HEATHER CHILCOT, FOUNDER AND OWNER OF CORE CYCLE STUDIOS

classes as part of the Miracle Movement. The fitness studio was founded on the principle of building relationships and a strong community.

"Giving back is important to us, and we want to be interwoven into the community. So when I heard about the Miracle Movement, it really pulled at my heartstrings," says **Heather** 



**Chilcot**, founder and owner of Core Cycle Studios. "So many people who come into the studio or join us virtually are quietly fighting things we know nothing about, just like we have no idea what the families are going through at the Children's Center. Fundraising is important, but so is garnering awareness and education in the midst of a crisis. I'm so proud of how our team came together to be part of this."

"It felt like in the midst of COVID, this event brought a sense of normalcy," adds **Tracy Newman**, one of Core Cycle's spin instructors. "People were smiling, clapping and singing along to the music — it was the perfect opportunity to connect our communities and do something that mattered."

Other virtual events included a wine tasting hosted by the **Kendall Burrows Foundation**, beer tasting with **Team Abby May** and **Oliver Brewing Co.**, and a **Charm City Trivia event**. Throughout the monthlong program, more than 525 Miracle Movers participated in daily activities and events from 31 states across the country, raising more than \$207,700 for the Children's Center.

"We loved participating in the Kids Can't Wait campaign to give back to the Children's Center in honor of our son, Bobby, who was a patient in 2018," says **Liz Soper**. "We love that our friends and family got to be involved in our team from wherever they are and share in Bobby's legacy. We can't wait to participate this year!" —AL

Save the dates for the second annual KIDS CAN'T WAIT — 30 Day Miracle Movement! The program will happen Oct. 8 – Nov. 6 of this year.

# **Knock Knock-**The 'Art Lady' Is Here

**By Gary Logan** 



AS A STUDENT at St. John's College in Annapolis, Linnea Payne wanted to pursue a career in art with the goal of working with emerging artists. With a master's degree in modern and contemporary art, she did just that, working at Christie's auction house with the David Rockefeller Collection and then at Sotheby's. In doing so, creative forces within her were reignited and led her back to Annapolis and her own studio where she now pursues her art fulltime — almost.

"I've always had a love for creation so, in working with these amazing works of art, I decided I should probably create art too," says Payne. "I've been absolutely loving it. I'm a people and pet portrait artist, it's kind of my bread and butter."

Payne also saves a day each week to uncover the emerging artist in parents of patients at Johns Hopkins Children's Center. As an artist in residence with the hospital's Child Life Healing Arts program, each Tuesday she travels with her art

To engage [patients and parents] with meaningful art activities that sometimes inspire them and distract them if only for a brief while, in a medium that can help them process what they are going through. My main goal is for them to have fun. "

— LINNEA PAYNE

The power of art, notes Linnea Payne at right, gives parents of patients in the hospital a sense of control in an environment where they may often feel little control.

cart room-to-room where she meets parents at their child's bedside to pique their interest in a creative project. The goal?

"To engage them with meaningful art activities that sometimes inspire them and distract them if only for a brief while, in a medium that can help them process what they are going through," says Payne. "My main goal is for them to have fun.'

Payne's translation of Mennonite folk art into large-scale works of glitter art is her passion, and often the realm in which parents find themselves. Bracelets, facemask lanyards, ornaments, inspirational picture frames and wooden tea lights are among the parents' projects. Whatever the undertaking, explains Payne, it gives parents moments of focus and control in an environment where they may often feel little control.

"Sometimes the parent is feeling kind of low," says Payne. "In the process of creating something they're excited and, after finishing the project, they're happy. The process helps redirect their focus.'

Payne, the self-described "Art Lady," can relate to these parents in recalling her own childhood when she often visited her sister in the hospital. She also spent time in Kuwait, where she worked with children with disabilities.

"I have a tender heart for families facing such circumstances," says Payne.

"Being able to come into the hospital and share my love of creating art with other people is truly a highlight of my week."

PICU 'Superheroes'

Come to Harrison's Rescue

# A lifesaving event inspires the Carter family to give back.

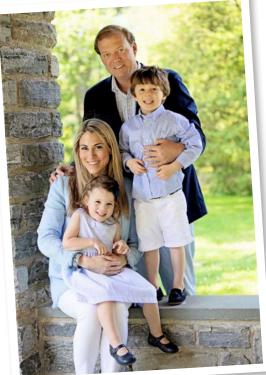
By Leslie Feldman

"SUPERHEROES LANDED on the roof and saved my son's life."

That's how **Mike Carter** describes the lifesaving event that allowed his 6-year-old son, **Harrison**, to still be alive today.

Residents of Philadelphia, Pennsylvania, the Carter family spent much of their time at their vacation home in St. Michaels, Maryland, during the onset of the COVID-19 pandemic. On the night of Sept. 4, 2020, the family was gathered around their dinner table when Harrison, according to his mom, Meredith, suddenly "shut down." She explains, "He just froze. His eyes were open, but he was unresponsive. We panicked and called 911."

Harrison was transported by ambulance to the nearest hospital



on Maryland's Eastern Shore. During the trip, he stopped breathing and his condition worsened. After Harrison was triaged at the hospital in respiratory failure, and following several attempts at intubation, emergency medicine physicians determined that he needed to be immediately airlifted to Johns Hopkins Children's Center to save his life. The Johns Hopkins Children's Center Pediatric Transport Team, including pediatric intensive care unit (PICU) fellow Jessica LaRosa and pediatric transport nurse Brittanie Coleman, arrived by helicopter and were able to reintubate Harrison, immediately increasing his

oxygen level so he was prepared to make the flight to Baltimore.

"We could not go [in the helicopter] with him, so we made the journey by car while the transport team flew with him and stabilized him," explained Meredith. "After 45 minutes, we received a call that he was stable. We were so relieved."

At Johns Hopkins Children's Center, under the care of pediatric neurologist **Christopher Latimer**, Harrison received numerous tests including CT scans, a spinal tap and extensive bloodwork, which resulted in a diagnosis of focal onset seizures. When some people experience focal seizures, they are fully awake, alert and able to recall events during the seizure. Others, however, are frozen during the seizure and un-



essic LaRosa

able to respond to others. After Harrison spent two days dependent on a breathing tube, his condition improved dramatically, and on his third day in the hospital he was able to go home. He now takes medications to control the seizures and remains under Latimer's care.

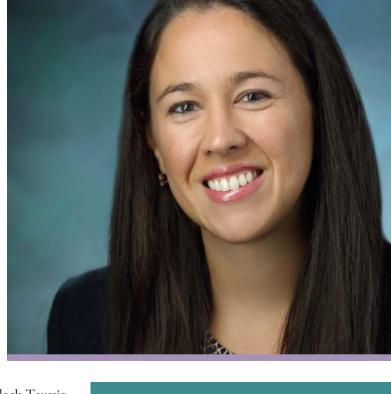
In gratitude for Harrison's lifesaving care, his family established an education fund for the pediatric critical care fellowship and pediatric transport team.

"Their contribution will support continuing education for pediatric critical care fellows and allow them to conduct research that will benefit patients like Harrison in the future," says **Corina Noje**, the PICU attending physician and medical control physician for the emergency transport.

"If the Hopkins team did not come to Harrison's rescue that night, I would not have my son here today," says Mike. "The helicopter transport is equipped to handle these pediatric emergencies and is vital to saving lives."

# Pediatric Cardiac Anesthesiologist **Natalia Diaz-**Rodriguez

By Christina Frank



AS A PEDIATRIC ANESTHESIOLOGIST at the Blalock-Taussig-Thomas Pediatric and Congenital Heart Center at Johns Hopkins, Natalia Diaz-Rodriguez has a short window of time in which to meet her patients before they undergo surgery. Understandably, children are often scared, and their parents anxious.

Diaz-Rodriguez tries to ease the tension with a little bit of levity. "We had a child coming for a big surgery last week," she says. "He was a bit hesitant to let me get close to him at first, but with the help of our Child Life specialist, we made his experience fun. She brought him a bubble blower and after playing with bubbles for a few minutes, he let me carry him to the OR, all the while laughing and smiling."

Diaz-Rodriguez received her MD from the University of Pennsylvania. In 2012, she began her residency at Johns Hopkins — which is, coincidentally, where she was born. (Her father was doing his pediatric residency at the University of Maryland at the time.) The family then moved back to Puerto Rico, where Diaz-Rodriguez grew up. After a number of years working in finance in the United States, she decided to follow in her father's footsteps and pursue pediatrics. Diaz-Rodriguez had originally considered specializing in critical care medicine, but was ultimately drawn to pediatric anesthesiology.

"It was a combination of the procedures, the physiology, and being able to take care of children in the operating room,"

Diaz-Rodriguez feels privileged to be part of the recently opened Pediatric and Congenital Heart Center. Going forward, she plans to combine a clinical career with an academic career, focusing on pulmonary hypertension research.

Diaz-Rodriguez acknowledges that it can be hard to see chil-

**66** Children are very receptive to listening and understanding that the procedure is something that they need and that we're going to try to make it as best as we can for them, so you can push forward knowing that you're doing what's right for them. At the same time, they're loving and they're funny and they make you laugh. They're perfect. That's why I chose to work with children, and I wouldn't change it for the world. ""

- NATALIA DIAS-RODRIGUEZ

dren who are very sick with congenital heart problems that may require cardiac bypass surgery or open-heart surgery. But just as she eases the fears of her young patients, she credits them with inspiring her.

"Children are very receptive to listening and understanding that the procedure is something that they need and that we're going to try to make it as best as we can for them, so you can push forward knowing that you're doing what's right for them," she says. "At the same time, they're loving and they're funny and they make you laugh. They're perfect. That's why I chose to work with children, and I wouldn't change it for the world."

### For the Chief Residents, a Year Unlike Any Other

#### By Rachel Hackam

IN YEARS PAST, chief residents at Johns Hopkins Children's Center have cited the thrill of not knowing what each day will bring. As one former chief noted, "You sort of walk into the day with your scheduled meetings, your to-do list, but you realize an email or someone at your door can completely change the way you thought your day was going to be." Fast forward to 2020–2021, the pandemic-infused year devoid of normalcy.

"In some ways, taking on a leadership and teaching role in such an unprecedented time has meant that we have tackled challenges that we never would have imagined — like conducting family-centered rounds when the whole team couldn't be at the bedside," says chief resident **Kristen Cercone**. "Through trial and error, we learned how to use new technology and find solutions that would allow us to continue to provide high-quality care and education for our patients and residents."

Such resourceful thinking is required of the job, agree Cercone's fellow chiefs **Jeanette Beaudry** and **Sam Gottlieb**. This is part of what drew them to pediatrics, they say. Other factors that pushed them on that path include an underlying appeal in working with children and families longitudinally over decades. Unlike what they perceive in many adults, they cite "an inherent joy" and optimism in children.

"Kids are resilient in facing serious illnesses," says Gottlieb, a Georgia native who plans to pursue a career in pediatric hospital medicine. "As pediatricians, we appreciate the opportunity to impact a child's health over a lifespan."

Beaudry, who grew up in Philadelphia and attended Columbia Medical School, is taking a different tack through a fellowship in infectious disease (ID), which she plans to complete following her chief residency year. That area of medicine turned out to be especially timely given the coronavirus pandemic.

If Though COVID often added an extra layer of complexity to many of the events we planned and the day-to-day life of ourselves and our residents, these opportunities to learn and grow we will remember for years to come.

— KRISTEN CERCONE



"I was in the first year of my ID fellowship when the pandemic hit. At that time, our understanding of transmission, prevention, manifestations in children, and management was changing rapidly," says Beaudry. "While it was enormously challenging to keep up with the latest information and to manage patients who had a new disease process that we were just learning about, it was also exciting to watch the process of discovery unfolding for a novel virus, and it reaffirmed my love for infectious disease."

What they may have learned about themselves in working together, the chiefs say, is their flexibility. While some chiefs decide to "divide and conquer," these three have taken an "all hands on deck" approach in supporting each other and the residents they lead. That includes adding to their weekly menu of responsibilities a cooking class, candy rounds, origami lessons and a new snack cart in the chiefs' office — what they consider special resiliency-building endeavors for pediatric residents during a pandemic.

"Though COVID often added an extra layer of complexity to many of the events we planned and the day-to-day life of ourselves and our residents," Cercone concludes, "these opportunities to learn and grow we will remember for years to come."

#### In Memoriam



#### William Howard Zinkham, M.D.

Pediatric hematologist William Howard Zinkham was a beloved mentor to many residents, fellows and faculty members, revered by residents for his diagnostic acumen and his ability to solve problems. His career

at Johns Hopkins spanned five decades, first as an undergraduate student at Johns Hopkins University and then as a student at its schools of medicine. After graduation, he rose from intern to chief resident in pediatrics, and then as a faculty member in 1954 focusing on diseases of the blood in children. He was the first recipient of the Alexander J. Schaffer Award for excellence in clinical teaching in 1970, and in 1974 he became the founding director for the Pediatric Hematology Division. His designation as the first Rainey Professor of Pediatric Hematology in 1987 recognized the importance of his work as a physician scientist. Jerry Winkelstein, former director of Pediatric Allergy and Immunology, called Zinkham "the heart and soul of the department" from the 1970s to 1980s. To honor his legacy, donations can be made to the Ernest C. Brown Pediatric Hematology Fund at www.hopkinschildrens.org/givenow.



#### Kwang Sik Kim, M.D.

Division Chief of Pediatric Infectious Diseases at Johns Hopkins Children's Center, Kwang Sik Kim's major scientific contributions were in the area of central nervous system infections. His work was amongst the

earliest to demonstrate the mechanisms used by pathogens to penetrate the blood-brain barrier and cause neurologic disease. His model has been used by investigators throughout the world to understand central nervous system infection and inflammation, and was the basis for establishing novel concepts such as the neurovascular impact of Alzheimer's disease. In addition to his scientific rigor, he was committed to mentorship and training. Since arriving at Johns Hopkins in 2000, he maintained a T32 training grant that has led to the development of many nationally recognized leaders in the field of pediatric infectious diseases. "Dr. Kim individually impacted each of our lives," says Deborah Persaud, interim director of the Division of Pediatric Infectious Diseases. "He was a gentle and warm person, a true pioneer in CNS infections, and an inspiring leader for our team who gave young faculty the autonomy to allow them to learn and develop." A lectureship fund, in collaboration with the Division of Pediatric Infectious Diseases, has been established to honor Kwang Sik Kim's legacy.



#### James C. Harris, M.D.

James Harris served for 50 years at Johns Hopkins as a distinguished clinician, educator, mentor, scholar, investigator, and advocate. He received his medical degree in 1966 from George Washington University and

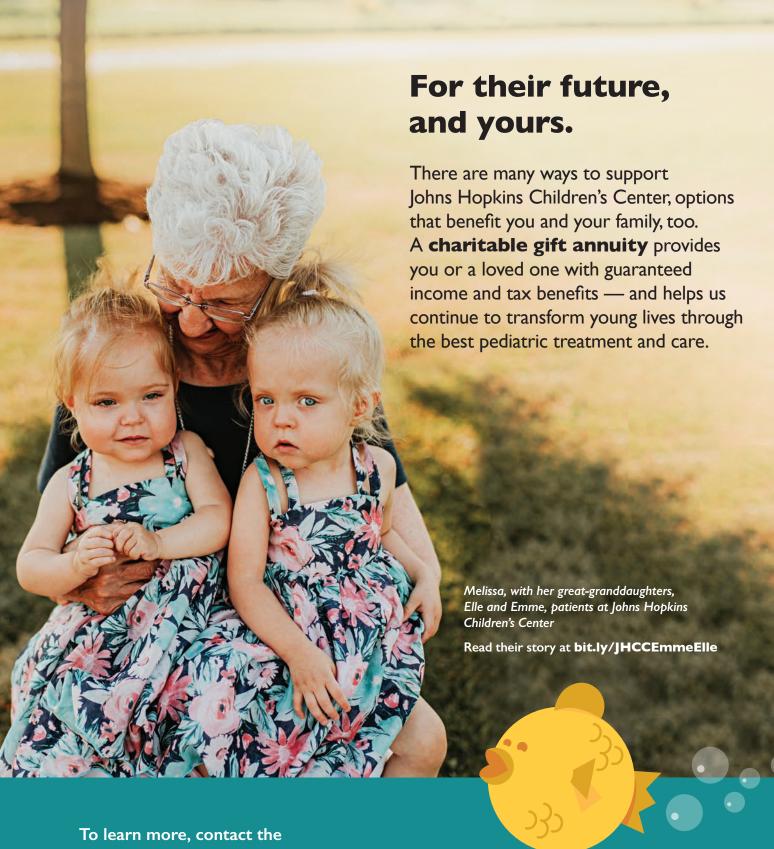
trained in pediatrics at the University of Southern California Children's Hospital and the University of Rochester before joining Johns Hopkins for his psychiatry residency and fellowship in child psychiatry from 1972-1974. His research focused on behavioral phenotypes in neurogenetic disorders and psychopharmacology in neurodevelopmental disorders. His many contributions to the field include serving as lead author of the DSM-5 criteria for intellectual disability, and serving on the President's Committee for People with Intellectual Disabilities during the Clinton administration. "Jim Harris worked doggedly to burnish the legacy of Dr. Leo Kanner, penning wonderful appreciations of his one-time Johns Hopkins professor, the discoverer of autism," said John Campo, director of Child and Adolescent Psychiatry, and James Potash, director of the Department of Psychiatry, in a joint statement. "All of us will certainly remember Dr. Harris, whose revels may have ended, though his spirit remains vital."



#### Eric Jelin, M.D.

Eric Jelin came to Johns Hopkins from the Children's National Medical Center in Washington, D.C., where he was a fellow in pediatric surgery from 2013-2015. He served as director of the Johns Hopkins Children's

Center Fetal Program, where he performed prenatal, neonatal and pediatric surgery, as well as counseled parents with pregnancies complicated by fetal anomalies. His research interests focused on improving outcomes after fetal therapy for congenital hernia, and device development for fetal therapy. He led the trailblazing Renal Anhydramnios Fetal Therapy (RAFT) study with a prestigious R01 grant. He was also awarded the Judah Folkman Prize from the American Pediatric Surgery Association. "Eric's loss leaves a huge hole in all of our hearts. He was a consummate surgeon, a brilliant scientist, and a wonderful human being," says pediatric surgeon-in-chief David Hackam. "Through his hard work in caring for patients, and the development of a major trial in fetal therapy, Eric helped to elevate the field of surgery, and to put the Johns Hopkins Children's Center on the worldwide map for fetal care." Among the condolences from patient families: "Dr. Jelin, words fail me. You are amazing and you saved my baby. You are kind, compassionate and so funny. I will forever miss you. I am so grateful for your work, but most importantly for your heart."



To learn more, contact the Office of Gift Planning:

Phone: 410-516-7954 or

800-548-1268

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

### The Charlotte R. Bloomberg Children's Center building

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

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

