

hopkinschildren's

SPRING 2018

THE JOHNS HOPKINS CHILDREN'S CENTER MAGAZINE

LJ's Journey

A pediatric nurse searches for clues
to her son's puzzling symptoms.



Photo Journal

On the road
with the neonatal
transport team

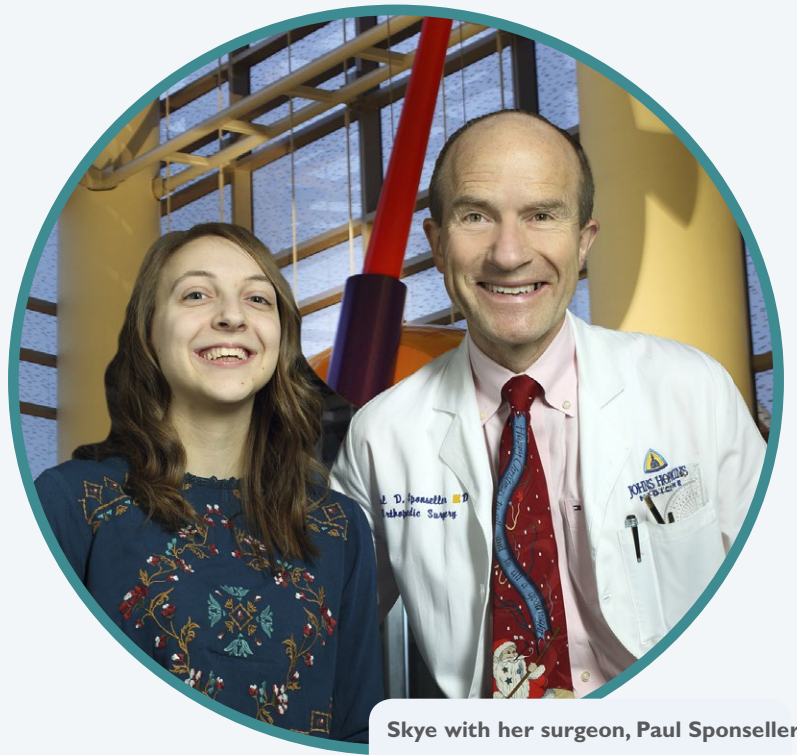
Pediatric Rounds

A neurocritical care
team faces a lethal
malformation



Treated As an Individual

by Skye Haghverdi



Skye with her surgeon, Paul Sponseller

I have been paralyzed from the compression of a vascular malformation on my spinal cord since 2002.

My condition is called an incomplete spinal cord injury, which means I have some nerve function and some related complex diagnoses.

At the time, there were not many options for treating a child with my condition, so I was admitted to a spina bifida clinic. There I received routine treatments for children with spina bifida, including orthopaedic surgeries, physical and occupational therapy, bracing and wheelchairs. Not having spinal bifida, these therapies could not fully treat me.

Fortunately, in 2009 I became a patient at the Kennedy Krieger Spinal Cord Injury Clinic, which effectively treated my level of paralysis and helped me learn independence and how to navigate life's daily challenges. Doctors there also introduced me to some of the best pediatric specialists at neighboring Johns Hopkins Children's Center—doctors who did not shy away from my complex diagnoses. Currently, I am a

patient in 11 Children's Center clinical divisions.

The Johns Hopkins pediatric orthopaedic surgery team has helped me tremendously. Paul Sponseller, my orthopaedic surgeon, treated me as an individual rather than simply a diagnosis. In all, he operated on me three times—hip surgeries in 2013 and 2014, and scoliosis surgery in 2015. In preparing for my scoliosis surgery, Dr. Sponseller considered my concerns about how I would like my back to function with my new spinal rods. He also considered my past complex medical history and sent me to other pediatric specialists for a safer, more-effective surgery.

After a complicated surgery, he allowed me to go home on Christmas Day. He also arranged for my inpatient rehab to begin on New Year's Day at Kennedy Krieger. Going home early made me happier and, I believe, aided my recovery by allowing me to recuper-

ate in familiar surroundings and giving my body time to heal before inpatient rehab.

Child Life staff members at Johns Hopkins Children's Center, who offered me activities in and outside of my hospital room, also aided in my recovery. Thanks to Child Life specialist Peyton, I got to create some crafts, see Santa fly in a helicopter, and meet a Santa dog. Also, I was excited to find out there's a Teen and Children's Council, and that Peyton was a coordinator.

Earlier, I had struggled discussing my diagnoses because I wanted to fit in among my able bodied friends. Being accepted into the Teen and Children's Council, however, gave me the confidence to open up more about my medical diagnosis. And through my experience I discovered I was able to help other children express their health needs, too. 🍀

“Being accepted into the Teen and Children's Council gave me the confidence to open up more about my medical diagnosis.”

—SKYE HAGHVERDI



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How does a neonatal transport team transport over 800 fragile infants each year—safely?

Photography by Keith Weller

Transporting fragile babies from hospitals in Maryland, Virginia and Washington, D.C., the Maryland Regional Neonatal Transport Program is among the busiest infant transport services in the country.

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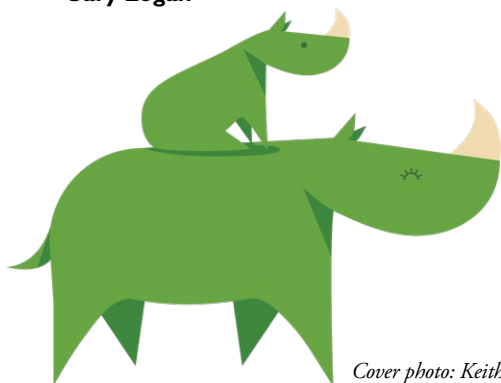
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He becomes the smallest child to receive an adult ventricular assist device—and then a heart nobody wanted.

Gary Logan



Cover photo: Keith Weller

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We Are Family, Too

The cover of this issue of *Hopkins Children's* is graced with a poignant portrait—a seasoned pediatric nurse holding a young patient who also happens to be her son, Loudon Jack. Confident and competent in her role as a nurse, Alena Fuhrman helped navigate LJ's path to specialists here and solve the cause of his mysterious symptoms. As a mother, she was naturally deeply concerned about his health, which also armed her as an advocate for his care. In our cover story, "LJ's Journey," we see the path a "medical parent" walks when facing a medical crisis—an experience that also illuminates a culture here that encourages families to participate in the care of their child.



As this issue of the magazine shows us, transparent patient- and family-centered care is not the only hallmark of Johns Hopkins Children's Center. Our deep experience in multispecialty collaborative care continues in our new neurocritical intensive care unit (Page 27) and cranial center (Page 28). An ongoing focus on innovations in medicine is reflected in our recent stem cell heart surgery (Page 29), our Digital Wings conference to support solid organ transplant patients (Page 30) and our pediatric cardiology telemedicine initiative to improve diagnosis of congenital heart disorders (Page 31). We also see our constant quest to improve inpatient care through the lens of our pediatric hospitalists (Page 32). The research enterprise here still thrives with novel therapies targeting leukemia and spinal muscular atrophy (pages 38–41). Finally, these activities continue to be possible through the philanthropic support of long-time charitable donors such as the Sutland/Pakula family (Page 43).

Through all these efforts, as the saying around here goes, we aim to treat your child as if he or she were our own. As we have learned, in some cases they are.

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



Hopkins Children's is published by the Johns Hopkins Children's Center Office of Communications & Public Affairs
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 Baltimore, MD 21231
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Printed in the U.S.A.
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 To read more on the clinical services and programs covered in *Hopkins Children's*, visit hopkinschildrens.org.

How you can help
 Call 410-361-6493



Nicole Shilkofski, Pediatric Residency Program Director

Through residency and fellowships in pediatrics, critical care medicine, simulation and educational research here and abroad, Nicole Shilkofski thrived on rich training experiences. Now she is focusing on ways to offer young physicians in training similar stimulating experiences.

What pushed you toward teaching?

One of my mentors, both in education and critical care, was David Nichols, an attending pediatrician in the pediatric intensive care unit and vice dean of education for the school of medicine. When he approached me in 2011 about establishing a new medical school curriculum in Kuala Lumpur, Malaysia, I was very interested. The marriage of global health and medical education seemed like the perfect opportunity.

What came next?

When I returned to Baltimore after three years in Malaysia, I quickly realized that I missed having a group of young learners and soon-to-be physicians whose careers I could influence. When Tina Cheng, our department of pediatrics director, asked if I would be interested in taking over the position of residency program director, it seemed a natural fit and an opportunity to come back to my roots as a pediatrician.

It sounds like your mentors brought out the mentor in you.

Having grown up under the tutelage of

people like David Nichols and [former residency director] Julia McMillan, I had great role models for fulfilling dual roles as a pediatrician and as an educator.

Now you are inspiring careers.

Well, I hope so, but this generation of learners is different and has very different needs than my generation. We have to adapt to keep things fresh. One way, thanks to an Innovation Grant from the Department of Pediatrics, is through building specific mentorship pathways within the residency program.

Mentorship pathways?

Yes, in areas like global health, health care disparities, quality improvement and patient safety, and research and scholarship. By infusing more-scholarly activities into the program and creating more academic opportunities for residents, they will benefit and grow.

How will you expose residents to global health?

One way will be through an elective to create educational programs aimed at reducing neonatal mortality and postpartum hemorrhage for mothers

in developing countries. In August, we will be taking a group of residents to the Philippines to establish a telesimulation resuscitation training program with some of the community providers there.

Any new thoughts about what we are looking for in applicants?

We are putting more emphasis on candidates' extra dimension and not just on their academic performance and test scores. We want to underscore those special things about candidates that contribute to the diversity of the program.

What are you finding?

Prospective residents are doing many amazing things, from years working for the Peace Corps to Teach for America to mission work in developing countries. We have current applicants who have spent some time in the world of finance who are now interested in health care economics. It is amazing to see the diversification of what people have done outside of medicine, which really adds to their appeal as candidates. 🍀





LJ's Journey

Alena Fuhrman relies on her experience and instincts as both a pediatric nurse and a parent in pursuing a diagnosis and treatment for her newborn son's inexplicable periods of rapid breathing. Her quest leads her to a pediatric pulmonologist, a dermatologist and an oncologist, who connect a red spot on LJ's chest to his respiratory symptoms and uncover a rare, complex disorder.

By Gary Logan



Alena Fuhrman's second pregnancy and delivery were uneventful. Loudon Jack, or LJ, came into the world appearing pink and healthy with normal reflexes and heart and respiration rates. He aced his Apgar scores. The only thing remarkable about her pregnancy, Alena says, was LJ's 3-year-old brother, Harvey, coming down with a stomach virus and being rushed to the emergency department (ED) to be rehydrated.



At home, Wes, LJ and Alena Fuhrman.

“I said this is not a sick baby—he’s bright-eyed, sleeping and waking appropriately, he’s not overly fussy or sleepy and his temp is good. I know what a sick baby looks like, and he’s not sick.”

—ALENA FUHRMAN

Still, as a seasoned nurse with experience in obstetrics, oncology and pediatrics, Alena knew well the ailments that could invade a newborn, a young child or adolescent. So, it was through a blended lens of both parent and nurse that Alena carried LJ for nine months and held him in her arms for the first time.

Then, two weeks after LJ’s birth, Alena heard something troubling while holding him—he started breathing fast, really fast. The nurse in her started counting his breaths and calculated a respiration rate of over 60 breaths per minute, abnormally high for a newborn. Weird, she thought—he was not sick, he was eating well and thriving, he had no fever. Her parents, visiting at the time, thought Alena was monitoring LJ way too much.

“Don’t be a nurse for him, just be his mom,” Alena’s mother said.

The vigilant mom was about to call LJ’s pediatrician when, just as quickly, his breathing resumed a normal rate. Then, the next day, his breathing accelerated again, and again it self-resolved.

Alena knew some babies experience periodic rapid breathing associated with an immature respiratory system, but these episodes, which lasted 10 minutes, seemed uncharacteristic of periodic breathing. She continued to watch him closely but held off on calling the pediatrician—until the next day when he started breathing at an even faster rate. The pediatrician asked about other signs. “How does he look?”

“I said this is not a sick baby—he’s bright-eyed, sleeping and waking appropriately, he’s not overly fussy or sleepy and his temp is good. I know what a sick baby looks like, and he’s not sick,” says Alena. Still, she agreed with the pediatrician to bring him in.

Baltimore pediatrician Eric Rubin, who has been diagnosing and treating children for over 20 years, was also baffled. High on his list was a pulmonary issue, possibly prompted by a heart problem and difficulty carrying oxygen to LJ’s lungs. However, he was not blue, or cyanotic, and showed no signs of a heart murmur.

“There was no evidence of a heart problem, he looked well,” says Rubin of Johns Hopkins Community Physicians at Remington. “He had a very reassuring examination but he was breathing a mile a minute.”

Indeed. Measuring LJ’s respiration rate at 94 breaths per minute,



Rubin became alarmed. Fearing the unlikely presentation of an overwhelming hidden infection, he started to call Johns Hopkins' pediatric emergency department. Picking LJ up, Alena said she could get him to the hospital quicker.

While driving to the ED, Alena says she "wasn't scared because he looked so good." The mom in her, however, was worried about what would happen to LJ in the ED. She knew how things worked there—doctors would probe and poke him, maybe stick him, possibly do a sepsis workup and aggressively search through subtle symptoms for something more serious, something systemic. Knowing right away they

would put him on a monitor, she recalled countless parents glued to their child's monitor and telling them as a nurse to focus on their child instead: "I spend a lot of time reassuring parents and refocusing them on how their kid really looks and to not worry about the numbers."

Sure enough, doctors placed LJ on a monitor first off. Before any numbers could be recorded, however, his breathing had resumed a normal range. After watching him for three hours, emergency medicine physicians noted that LJ looked well and showed no signs of fever. They had no answers for the episodic rapid breathing. Then their attention shifted to Alena.

"They focused on me a lot, that I was a worried new mom. 'Yeah, I'm post-

“The hardest moment for me was hearing the words ‘innumerable lesions,’ that there were too many tumors to bother counting.”

—WES FUHRMAN

partum and I've got some hormones going on, but I'm not your typical worried new mom," says Alena. "I've been a pediatric nurse for a long time, and I know a lot about babies and children, and I have another little one at home."

If this happens again, the ED docs said, take him back to his pediatrician.

Driving home, she was even more preoccupied with what could be going on with LJ. At the time, her husband and LJ's big brother both had chest colds; maybe a virus was the culprit? This was June. Maybe the summer heat had something to do with LJ's rapid breathing.

"I hated to open a can of worms, so we went home and he started looking better," says Alena. "Then it happened again."

And again and again with no expla-

nation, prompting two more ED visits and an overnight admission, echocardiography and electrocardiogram to rule out a cardiac cause, among other tests. Modern medicine was working hard, but LJ's journey was quickly evolving into an unresolved medical mystery.

"They wanted to do a head ultrasound," says Alena. "I saw them grasping at tests, opening up Pandora's box to every test known to man. All I wanted to do was go home with my baby."

The conclusion of the assessments seemed to be this episodic rapid breathing was indeed something weird that would eventually leave this otherwise healthy baby. LJ's only other remarkable symptom was a small red spot on his chest, suspected in the ED to be associated with a hemangioma, an abnormal growth of blood vessels that tend to recede over time. The red spot mystified Alena; maybe there was more to it than a hemangioma? Determined to find an answer, Alena called the Division of Pediatric Pulmonary Medicine at Johns Hopkins Children's Center.

NARROWING THE SEARCH

Initially, pediatric pulmonologist Jessica Rice was equally puzzled, though she thought interstitial lung disease—due to inflammation or edema from extra fluid—a possible perpetrator. A CT scan, Rice said, could rule it out. Meanwhile, the diagnostician detective in Rice could not stop thinking about the small red rash above LJ's sternum, which Alena said had become more pronounced. To Rice, who confesses she's "horrible" at reading rashes, it did not look like a hemangioma. Could it be a sign of something going on beneath the skin, she wondered, an arterial venous malformation (AVM), for instance, in LJ's lung?

"If you have a vascular-looking lesion over a location in the body, it could be a sign of an AVM," says Rice. "I started thinking some sort of vascular lesion rather than interstitial lung disease."

For answers, Rice recommended a CT

scan of LJ's lungs and a referral to pediatric dermatologist Bernard Cohen for an assessment and, if necessary, a biopsy of the lesion. Regarding the CT, Alena was concerned about radiation exposure to her newborn. More than that, suddenly, for the first time, she felt more than anxious and troubled—she was scared.

"When Dr. Rice suggested the CT scan, that made me really upset—up until that point I was worried and sad but not scared," says Alena. "When I found out

"We know what this is," Cohen said. "If people are uncomfortable with our clinical diagnosis, we can do a skin biopsy and confirm it, but I'm 99 percent sure that this is a xanthogranuloma."

—BERNARD COHEN

he needed a CT, then I thought maybe there really was something wrong, something serious."

Initially, Dr. Cohen, or "Buddy" as he is known by faculty and staff at Johns Hopkins Children's Center, alleviated Alena's fears. Noting that the inflamed spot on LJ's chest was now a firm dome-shaped nodule, Cohen strongly suspected it to be a xanthogranuloma lesion associated with a rare type of hematological disorder called histiocytosis. One form of this disease most often seen in children—Langerhans cell histiocytosis—has a one in 200,000 incidence each year. In Cohen's 30 years of experience as a pediatric dermatologist, he told Alena, these skin lesions commonly flatten and disappear in a month or two, leaving a little dimple scar behind and little or no serious consequences for the patient.

"We know what this is," Cohen said. "If people are uncomfortable with our clinical diagnosis, we can do a skin biopsy and confirm it, but I'm 99 percent sure

that this is a xanthogranuloma."

Cohen also knew that if the patient is experiencing other unexplained symptoms, such as rapid breathing, this skin lesion could signal a more serious systemic form of histiocytosis presenting throughout the body.

"My concern was there might be a connection between this skin lesion and the pulmonary symptoms, the rapid breathing, the tachypnea," says Cohen. "You have to pay attention to these lesions and any systemic symptoms and identify the connection between the two."

Pulmonologist Rice was on the same wavelength, recalling a recent Grand Rounds presentation by Johns Hopkins pediatric oncologist Elias Zambidis on histiocytosis. Indeed, she learned, a patient could have pulmonary symptoms associated with a lesion on the skin. Cohen's diagnosis of xanthogranuloma and the CT scan, which showed innumerable nodules in LJ's lungs, were illuminating—and alarming.

"Dr. Cohen's diagnosis of dermal histiocytoma was important," says Rice. "The CT scan a day later revealed innumerable diffuse nodules in his lungs, which is extremely abnormal."

The news was devastating for Wes Fuhrman, Alena's husband. Grounded in science as a physics Ph.D. student at The Johns Hopkins University, he had been a resourceful aid to Alena in researching possible causes of their son's symptoms and finding a path at Johns Hopkins to a diagnosis and treatment. While searching for clues had kept their spirits up, now the reality of what was inside LJ's body and seeing it crushed Wes.

"The hardest moment for me was hearing the words 'innumerable lesions,' that there were too many tumors to bother counting. It struck me then that this might not be so easily addressed," says Wes. "The room where we saw scans of the multiple lesions is a scene I don't think will ever go away."

Navigating these troubled waters as both a mom and nurse, Alena was anxious as well, though she also felt a bit at peace with getting closer to the cause of her son's condition. She asked herself,

“Could this in fact be a case of juvenile xanthogranuloma?”

For the answer, Rice reached out to Zambidis, one of only a handful of experts in the country on histiocytosis, a disorder that sometimes behaves like a cancer. He explained that juvenile xanthogranuloma (JXG) is a rare histiocytosis that is usually benign and limited to the skin of the head, neck and chest. Though less common, JXG may also involve the lung, liver, adrenal gland, appendix, central nervous system, kidney, heart, intestines and spleen. Biopsies of the lesion on LJ's chest and those in his lungs could confirm his particular type of histiocytosis or rule out the condition altogether. There was a chance a lethal metastatic tumor was the culprit. For the biopsies, Zambidis reached out to general pediatric surgeon Alejandro Garcia.

As LJ was only 2 months old at the time—the last thing Garcia wanted to do was make a large incision in his chest. Searching for the least invasive way to perform the lung biopsy, he chose a thoracoscopy, in which he would insert a tube with a tiny camera through a small incision in LJ's chest, and with another surgical tube obtain tissue from one of the larger nodules in LJ's lung. Recovery from a big open operation, Garcia explains, would have delayed any treatment. The minimally invasive approach worked. For Garcia, the findings were surprising.

“When we saw the images in the weekly tumor board conference before the biopsy, it presented very aggressively as something pretty bad oncologically,



A day at the oncology clinic at Johns Hopkins Children's Center

like a lymphoma or neuroblastoma,” says Garcia. “I was shocked it ended up being histiocytosis.”

LJ's pediatrician, Eric Rubin, was surprised as well: “I've seen zillions of babies in respiratory distress, but what this turned out to be was what we call a fascinoma, a very unusual presentation of an unusual disorder.”

For the benefit of both LJ and other patients like him, Zambidis ordered more tests, including a full body scan that revealed lesions in the usual suspects—LJ's lymph nodes and lungs, along with the lesion on his chest. Then the other shoe dropped and Zambidis pointed to a big tumor in LJ's growing spine and something questionable on his brain.

The good news was that in most

cases of JXG these lesions are benign and self-resolve over time. To be certain the lesions did not contain more-aggressive mutations and an even rarer form of histiocytosis, Zambidis also recommended a personalized genetic analysis of LJ's lung nodules. His instincts were right, as genetic sequencing results revealed the ALK mutation found in lung cancers. LJ had an even rarer form of histiocytosis—one very much in the wheelhouse of Zambidis and his research on the disorder.

“We don't know how aggressive this ALK form of histiocytosis is, but it's very rare, with only three documented cases,” says Zambidis. “Understanding the genetics of these tumors may teach us not only about this rare form of JXG, but help us understand other

“We don't know how aggressive this ALK form of histiocytosis is, but it's very rare, with only three documented cases. Understanding the genetics of these tumors may teach us not only about this rare form of JXG, but help us understand other types of cancers as well.”

—ELIAS ZAMBIDIS





types of cancers, as well.”

While the tumor on LJ’s spinal cord could subside without any treatment, Zambidis was concerned and referred the case to pediatric neurosurgery. Could it be resected?

“Some people say watch and leave these tumors alone,” says Zambidis. “The reason I did not in this case was because it was clearly impinging on the central nervous system, the lumbar spinal cord. Even benign tumors can cause damage.”

Because LJ did not appear to be experiencing any neurologic deficit, however, pediatric neurosurgeons held off on resecting the spinal tumor. Why risk causing a deficit that did not exist? Instead, Zambidis recommended six to eight cycles of the chemotherapy treatment Cladribine, or 2-CDA, a leukemia drug found to have potency against the dendritic white blood cells that cause JXG. The initial 2-CDA course, which could take up to six months of infusions, would be followed up by two years of a gentler, lower-dose oral maintenance chemotherapy. MRI scans every three months would monitor his progress.

Alena was relieved to have a treatment plan, though she knew the following months would be arduous. One of her most difficult experiences as a pediatric nurse was caring for children with cancer and managing central lines in their chests to administer medications and draw blood. Now her own son would have to go through that.

“He went from a perfectly healthy baby to one that breathes fast to maybe some kind of lung disease to this very rare blood disorder condition with all these tumors and he needs chemo,” says Alena. “It was just surreal.”

It was also a stark reminder of how she as a pediatric nurse viewed her relationship with parents of seriously ill children at a vulnerable time in their lives.

“When you come to work as a nurse or a physician there’s a pretty good chance some of the people you’re interacting with are having the worst day of their life,” she says, “and you are just kind of inserted into that worst day for them. Even if we can’t fix it we have a responsibility to bear witness, to be present with them and respectful of their experience.”

In LJ, however, she saw a “rambunctious and spirited” child who could be a feisty fighter in facing potentially toxic treatments against this disease. It did not surprise Alena that LJ watched the Disney animated movie *Moana* repeatedly in the hospital following surgery for his chemo port placement by Garcia, or that LJ chose the same movie during chemotherapy infusions in the outpatient oncology center. LJ’s favorite character was Maui, a fearless adventurer and protector of the people on their tropical island. Alena believed Zambidis and the other doctors who cared for LJ would continue to protect him. He would be fine.

Indeed, after three cycles of 2-CDA, 50 percent of the tumors in LJ’s body had disappeared. After another three cycles as LJ moved into his toddler years, “his tumors have shrunk to almost nothing,” says an elated Alena. “Today his immune system is not great, but his appetite is good and his growth and development are on track.”

“There’s no prognosis with this, of what’s expected, so the best metric of how he’s doing is actually how he is doing, and he’s great, he’s a lot of fun,”



Pediatric surgeon Alejandro Garcia with Maui

“It did not surprise Alena that LJ watched the Disney animated movie *Moana* repeatedly in the hospital following surgery for his chemo port placement by Garcia, or that LJ chose the same movie during chemotherapy infusions in the outpatient oncology center. LJ’s favorite character was Maui, a fearless adventurer and protector of the people on their tropical island. Alena believed Zambidis and the other doctors who cared for LJ would continue to protect him. He would be fine.”

says Wes. “The tumor in his spine was scary, and had we not had the ability to address that early on it could have led to paralysis. Now he runs faster than his older brother.”

Zambidis agrees, noting that LJ has had an excellent response to therapy with 99 percent resolution of his tumors. The future course of his condition remains uncertain, however, as the nature of this super-rare disease leaves unresolved issues.

“Because there are so few patients, we don’t really know how long we should treat LJ and whether it’s enough,” says Zambidis. “We don’t know if he has this in the rest of his body. What if he has a recurrence?”

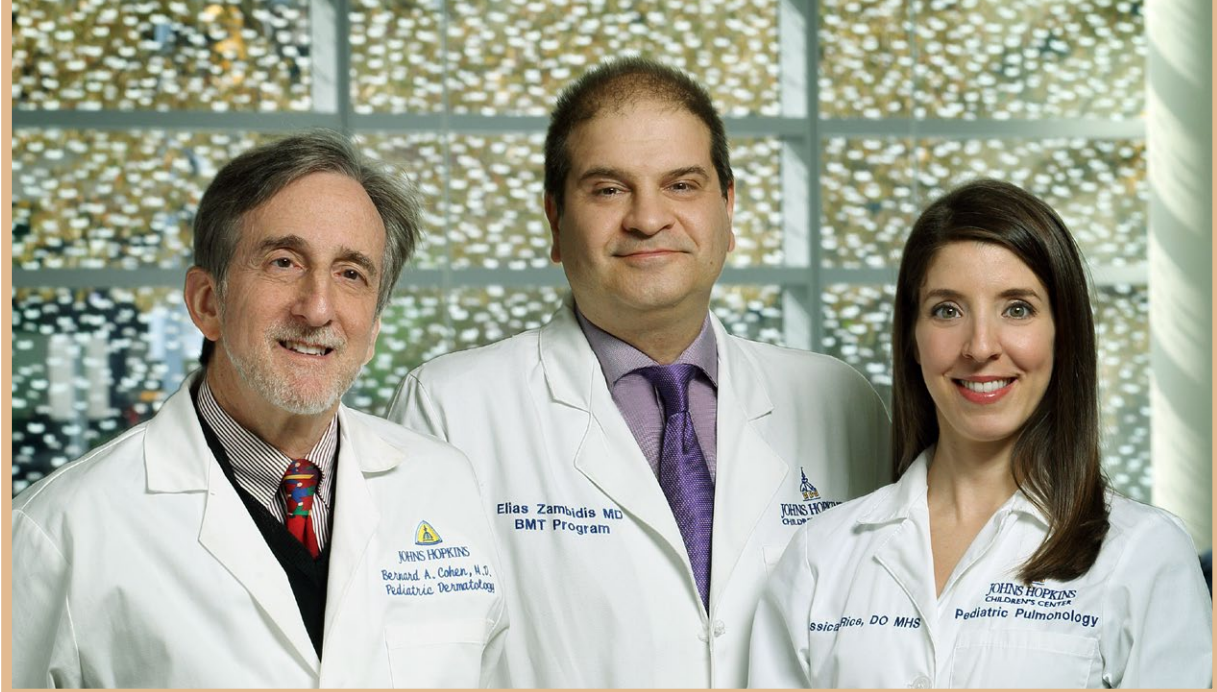
The plan now is watch and wait, monitor LJ with imaging, and continue to study the disease and potential new therapies, including drugs that target the ALK mutation, so-called ALK inhibitors. Improved screening and diagnosis, adds Zambidis, will spur research that will lead to novel and more effective therapies: “If there are other patients out there,

we want them to come here to get worked up so we can learn about them, sequence their DNA and figure out what its natural history will be. If we can catch it early, we can treat it more effectively.”

TAKEAWAYS AND TEACHING MOMENTS

LJ’s journey continues but there is no shortage of reflections from Alena and her family, as well as from the clinicians who cared for him. For Alena, the experience challenged her as both a mom and a nurse to steer LJ’s care. Being a medical parent, she learned, has its pros and cons.

“It’s hard when LJ had a setback because you don’t want to get emotional in front of people you work with,” says Alena. “On the other hand, bumping into the people who



Following up on each other's findings and instincts, pediatric dermatologist Bernard Cohen, at left, pediatric oncologist Elias Zambidis and pediatric pulmonologist Jessica Rice successfully diagnosed and treated LJ.

care for LJ keeps us connected. I feel like the more they are reminded of LJ, the more brain space his rare case can occupy, then the more people will think about it and chew on solutions.”

Alena was grateful as a mom, as well. Growing up in the Midwest, she says she was taught to show appreciation for the good acts of others. Like so many other parents of children cared for at Johns Hopkins Children's Center, she gave LJ's caregivers gifts—movie tickets for Zambidis, a film buff, and for Garcia a figurine of Maui, LJ's hero in *Moana*. On the accompanying note, Alena wrote that Garcia reminded her how to make the best of a bad situation.

Similarly, Garcia and the other clinicians who cared for LJ were deeply impressed by Alena's advocacy, her determination and knowledge base, and her attention to subtle symptoms. They considered her a leading member of the care team.

“She reported actual respiration rates, which I took right away as I would from a nurse on the floor,” says Rice. “It was real tachypnea, but no one was telling her what was causing it, so she persisted.”

“I have a great deal of admiration for Alena,” says Rubin. “She recognized something wasn't right and followed through with it.”

“I want to raise awareness of histiocytosis for other parents so they don't feel alone or bad about being an advocate for their child with this rare disorder. I don't know what would have happened if LJ was not here and if I was not a strong advocate.”

—ALENA FUHRMAN

“She was one step ahead of everybody the entire time,” adds Wes. “The charts read like a mystery novel in which you can see Alena sorting things out. It was amazing.”

There were teaching moments for the clinicians, too.

“This case makes you think about other patients who are well-appearing,” says Rice. “If the mom tells you her child has been breathing fast intermittently, even if he's not breathing fast

when you see him, you have to use that as part of your workup. You have to have a high index of suspicion for something else going on.”

“I teach medical students to pay attention to what parents tell you, to listen to them,” says Rubin. “A smart, observant parent is worth his or her weight in gold.”

Both the nurse and mom in Alena agree. She's grateful for LJ's care at Johns Hopkins Children's Center and knows that her advocacy made a difference, too. Having heard stories of other histiocytosis patients, their mysterious symptoms and struggles with diagnosis and treatment, she wants to make a difference for them, too. She started a blog to raise awareness of histiocytosis, connected families with resources and support, and began raising funds for the Histiocytosis Association.

“I want to raise awareness of histiocytosis for other parents so they don't feel alone or bad about being an advocate for their child with this rare disorder,” says Alena. “I don't know what would have happened if LJ was not here and if I was not a strong advocate.” 🌟



Alena Fuhrman's blog is accessible at histioshmistio.wordpress.com.

On the Road Again ...And Again And Again

Photography by Keith Weller

Transporting fragile infants from hospitals in Maryland, Virginia and Washington, D.C., to high-level neonatal ICUs at Johns Hopkins Children's Center and the University of Maryland Medical Center, the Maryland Regional Neonatal Transport Program (MRNTP) is among the busiest transport services for seriously ill newborns in the country. Indeed, the team of neonatal nurses and emergency medical technicians conducts up to eight transports a day, around 40 per month and over 800 each year, saving countless young lives.

Neonatal nurse Andrea Chavis, left, and neonatal transport nurse practitioner Beth Diehl arrive at the University of Maryland Medical Center to pick up a young patient for transport to the Mt. Washington Pediatric Hospital for rehabilitation and recovery. Each transport is fueled by both nervous energy and an intense focus on keeping the infant as safe as possible.



“ We roll 24/7, take whoever we need to take and do whatever we have to do. ”

—WEBRA PRICE-DOUGLAS, COORDINATOR,
MARYLAND REGIONAL NEONATAL
TRANSPORT PROGRAM



GETTING THE BALL ROLLING

First thing at 7:30 a.m. each day, neonatal nurse practitioners JoAnn Bernard, left, and Beth Diehl receive transport requests that have come into the communications centers at The Johns Hopkins Hospital and the University of Maryland Medical Center. The calls vary, from a premature infant on Maryland's Eastern Shore needing transport to the NICU at Johns Hopkins Children's Center to a baby there ready for discharge and rehabilitation at Mt. Washington Pediatric Hospital. Coordinating with patients' attending physicians, Bernard and Diehl then triage the calls for transport by medical priority and efficiency. On this day, their first patient will be an infant ready for discharge and transport from the neonatal ICU at Johns Hopkins Bayview Medical Center to Peninsula Regional Medical Center in Salisbury, Maryland, the referring hospital near the patient's home, in what the team terms a "back transport." The transport also opens up a much-needed intensive care bed in the region for another seriously ill newborn.



JoAnn Bernard alerts neonatal ICU staff at Bayview Medical Center that the mobile infant isolette and transport team, including emergency medical technician Mike McKeldin, are on their way.



PREPARING FOR TRANSPORT

Upon arrival at Bayview Medical Center at 8:30 a.m., Bernard consults with neonatal ICU medical director Sue Aucott and neonatal nurse Robin Marshall—and checks herself—on the status of their young passenger. The team then ensures that all systems are go in the ambulance for the long journey to Peninsula Regional Medical Center. Whether a back transport, elective primary or emergency transport, the team's mission is to transport infants in the safest and most effective and efficient manner possible.

“Safety is our biggest concern. We make sure the isolette is locked in and plugged in, and we scan everything on a regular basis to minimize any issues. We have an excellent safety record because we have plans in place to address risks early.”

— JOANN BERNARD



BATTEN DOWN THE HATCHES

In route to Maryland's Eastern Shore, Bernard takes responsibility in the ambulance—what team members call an ICU on wheels—for stabilizing the baby during transport, constantly monitoring the infant's vital signs, temperature and ventilator settings in the isolette to ensure the infant's respiratory, fluids and medication needs are being met. Meanwhile, EMT Guy Williams, above right, and neonatal transport nurses head to the neonatal ICU at the University of Maryland Medical Center to pick up a neonate in need of rehabilitation and recovery at Mt. Washington Pediatric Hospital. The transport team's dashboard hula dancer, Williams says, gives “good karma” for the team and its fragile patients.

“ This is not a swoop and scoop—we assess and stabilize and then transport. Once the baby is in the ambo, we are 100 percent focused on maintaining clinical stability. No transport is benign. ”

—JOANN BERNARD





TRANSPORT NOTE

For each infant, the state of Maryland requires two licensed care providers (physicians, nurse practitioners, nurses, respiratory therapists, paramedics) and one emergency medicine technician to operate the vehicle. The program relies on four dedicated custom-designed ambulances.





TRANSPORT NOTE

Taking care of fragile neonates on the road, sometimes during the most unstable stage of their illness, transport nurses are expected to be extremely adaptable, good at critical thinking and able to react quickly to changes in the patient's condition.

“ I love high-energy situations—going into a hospital and applying my critical thinking skills and sorting it out, determining clinical priorities, how I need to focus my care, who I need to obtain information from. I enjoy that process very much. ”

— BETH DIEHL



HANDLE WITH CARE

At noon, back where the team began their day at Johns Hopkins Children's Center, Beth Diehl and the team prepare another infant and isolette for transport to Mt. Washington Pediatric Hospital. The patient, a baby born at 24 weeks gestation weighing 450 grams, or just over 1 pound, now at 126 days of age, needs convalescent care, or what the team members refer to as “feed and grow.” When not on the road, the team goes through rigorous ongoing education, training and simulation exercises—and recertification every two years—to refresh their skills and ensure they are best prepared for whatever situation may arise.





ALL HANDS ON DECK

It does not take a village to pull off some 800 successful neonatal transports each year, just a well-trained and deeply experienced and proficient team committed to saving the lives of fragile infants. In the Maryland Regional Neonatal Transport Program, that includes, from left, neonatal nurse Laura Selway, nurse practitioner JoAnn Bernard, emergency medical technicians Mike McKeldin and Maurice Dacosta, and nurse practitioner Beth Diehl. Enduring 12- and 24-hour shifts is no easy chore, team members say, but well worth it. The rewards? Diehl recalls a waitress on the Eastern Shore who recognized the neonatal transport patch on Diehl's jacket and thanked her for the work she does. Ten years earlier, the waitress said, her own newborn had to be transported emergently by the team. Says Diehl, "Things like that are totally random, out of the blue, but I'm very thankful when it happens."



“They are the unsung heroes who create miracles.”

—JOHNS HOPKINS
NEONATOLOGIST FRANCES
NORTHINGTON, WHO
ALONG WITH UNIVERSITY OF
MARYLAND NEONATOLOGIST
SARA MOLA IS
CO-DIRECTOR OF
THE MRNTP



Neonatal ICU nurse Laura Levy, right, with the grateful mother of a neonatal transport patient



Pediatric intensivist Kristen Nelson at a home visit with Kamari and his mom.



Kamari's Quest for a Heart

Against all odds, pediatric cardiac specialists implant an adult ventricular assist device in the smallest child ever to receive one, and then offer him a new heart rejected by 24 other transplant programs.

By Gary Logan

FROM THE BEGINNING, note pediatric cardiologist William Ravekes, intensivist Kristen Nelson and cardiac surgeon Luca Vricella, the signs were troubling. Their 3-year-old patient, Kamari Ibn-Said, born with hypoplastic right heart syndrome, was unable to adequately pump blood to his lungs and oxygenated blood throughout his body. He successfully underwent the first two of three surgeries to rearrange his cardiac blood flow and allow the left ventricle to do the work of the right. Then, at age 3, he began to experience feeding issues and facial swelling, indications that his remaining left ventricle was struggling. Indeed, cardiac catheterization findings revealed severe heart failure.

The specialists agreed that Kamari needed a heart transplant and, to get there, the support of a ventricular assist device (VAD) as soon as possible. They felt an internal VAD would be best for Kamari because studies showed it posed less risk of stroke and better prospects of recovery than an external drive VAD.

"The beauty of this device is that the only thing sticking out of the patient is the drive line, which connects with a computer," says Nelson, director of the VAD program at Johns Hopkins Children's Center. "It allows patients to be much more mobile, improving their ability to rehabilitate while they wait for a heart transplant."

Kamari, however, was little, with a body surface area of only 0.6 square me-



“We already knew the donor heart was sick and turned down by 24 other centers—and now this?”

—PEDIATRIC CARDIAC SURGEON LUCA VRICELLA REFERRING TO THE EMERGENCY LANDING OF THE PLANE EN ROUTE TO RETRIEVE KAMARI'S DONOR HEART

ters (weight 14.2 kilograms/height 38 inches). Implanting an internal VAD, designed for adults only, posed nearly insurmountable challenges. Indeed, if Vricella was successful, Kamari would go on the record as the smallest patient with the device.

“As I knew from the literature,” says Nelson, “he would be the smallest patient to have this type of VAD.”

To overcome the challenge and ensure that the VAD fit—and functioned—appropriately, Vricella had to deploy some creative surgical manipulations, including removal of part of the VAD apparatus and Kamari’s mitral valve. It worked.

“Luca said we’ll try the internal device, and if it doesn’t fit, we can always do the external VAD,” says Ravekes. “To his credit, he tried the harder surgery because it was better for the patient, and we didn’t need to go to our backup plan because he was able to do it.”

That was in October 2016. Then the wait began for a new heart as Kamari recovered with his VAD in the Johns Hopkins pediatric cardiac intensive care unit. It ended up being a six-month wait as no compatible donors came Kamari’s way until April 2017. In addition, while the size of the donor heart was a match, due to resuscitation efforts it was a very sick heart that had been turned down by 24 other cardiac transplant centers. Worried about Kamari’s increasing risk of complications on the VAD, Nelson came up with a plan to accept the heart. She would co-manage treatment of the heart by the outside hospital and

help wean it off resuscitation support over the next 12 hours to make it more amenable for transplant. Ravekes and Vricella agreed and the three specialists accepted the heart for transplant.

“I knew the heart was sick and would take a lot of work, but I also knew it would be way better at the end of the 12 hours than it was at the beginning,” says Nelson. “The three of us decided we should take this chance and manage him postoperatively.”

“It wasn’t everybody’s favorite heart, but Kamari was so sick we felt this heart was better than what he had,” adds Ravekes.

Vricella dispatched pediatric cardiac surgeon Narutoshi Hibino to retrieve the donor heart. However, one hour after departing Baltimore/Washington International (BWI) Thurgood Marshall Airport, Hibino called Vricella to tell him the plane had to return to BWI and make an emergency landing due to fuel leakage. In a way, Vricella was not surprised: “We already knew the donor heart was sick and turned down by 24 other centers, and now this? Maybe this was another sign that we should not accept this heart.”

The team persisted, however, and later that day Hibino walked into the customized cardiac operating room at Johns Hopkins Children’s Center where Vricella waited to implant Kamari’s new heart. Already the team had to resuscitate Kamari’s failing heart and now, Vricella realized, removing his sick heart would be no easy chore given the amount of inflammation and scar tissue

from three prior operations. “It was as close to an impossible dissection I had ever done,” says Vricella.

Next, as he prepared the graft for transplant, Vricella noted the “tiny” size of the donor heart. Then, after implantation, it did not start beating right away, which Vricella attributed to the prolonged downtime of an “exhausted” donor heart.

“This was like the fourth time someone is trying to tell me something,” says Vricella.

The team immediately placed Kamari on extracorporeal membrane oxygenation, or ECMO, a heart and lung bypass system for pediatric patients that





Kamari's team, from left, pediatric cardiac surgeon Narutoshi Hibino, pediatric cardiac intensivist Kristen Nelson and pediatric cardiologist William Ravekes

Follow-Up

Intensivists House Calls?

FOLLOWING KAMARI'S DISCHARGE from the pediatric intensive care unit, Kristen Nelson was hardly done with him. As a pediatric intensivist at Johns Hopkins Children's Center, she believes patients like Kamari need some follow-up by an intensivist after they return home and, she emphasizes, at their home.

"I'm a big proponent of something called continuity of care by ICU attending physicians for children who have been patients in an ICU for an extended period of time," says Nelson.

Postdischarge intensive care is complex care, she explains, so who better than an intensivist to periodically check in on patients and ensure that their needs are being met? Among the concerns: care coordination with a pediatrician and subspecialists, management of multiple medications and medical supplies, vital-sign readings from remote monitors and pulmonary issues.

"Patients like Kamari need time to wean off of long-term ventilation," says Nelson. "We also try to answer all of the parents' questions about restrictions, mobility and quality of life."

Nelson notes that she has not formalized this personalized intensive care approach and for now has limited it to long-stay ICU patients such as Kamari. The benefits, she adds, include less risk of readmission to an emergency department or ICU. Nevertheless, intensivists do not traditionally make house calls, do they?

"Why can't we be the first," Nelson says. "I love the concept—it is patient- and family-centered care."

Parents of Nelson's patients agree, noting that her supportive outreach instills a confidence in their ability to care for a child with complex needs. For Nelson, her home visits resume a longitudinal caring relationship with her most fragile patients.

"I feel very honored to be able to take care of these kids, and taking care of Kamari since he was born has been a unique opportunity, a privilege," says Nelson. "Because of that you cannot help but get attached to them." —GL 🌟



“His heart graft function looks great and he’s had no episodes of rejection. His heart is beating strong.”

—PEDIATRIC CARDIOLOGIST
WILLIAM RAVEKES

would give Kamari's new heart time to rest. Two days later, his new heart started beating steadily on its own.

"It was the most gratifying thing to see the function of the heart return to normal," says Vricella. "Maybe the Lord was telling me to have faith."

Kamari appeared to have plenty of faith, as not long after his transplant he was zipping around the pediatric cardiac ICU in his Spider Man car, notes Ravekes: "He's great, he's interactive, he waves to you, he draws and he plays games. Neurologically he's been wonderful with no problems."

And his heart?

"After three catheterizations, his heart graft function looks great and he's had no episodes of rejection," says Ravekes. "His heart is beating strong."

Nelson attributes Kamari's successful outcome to the multidisciplinary collaborative nature of intensivists in the pediatric cardiac ICU and its dedicated VAD service, pre- and posttransplant management by Ravekes, and the surgical experience and skills of Vricella and Hibino. Kamari's mom, Miesha McMillan, made a difference, too, says Nelson: "She has been absolutely committed to understanding his cardiac disease from the second I met her. Now she is so over the moon to be going home soon, and for her son to have the opportunity to live a more normal life."

In mid-July, Kamari was discharged from Johns Hopkins Children's Center. 🌟

“I feel very honored to be able to take care of these kids, and taking care of Kamari since he was born has been a unique opportunity, a privilege.”

—PEDIATRIC INTENSIVIST KRISTEN NELSON

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pediatricrounds



When Vein of Galen Attacks

Facing a lethal neurovascular malformation,
a multidisciplinary team collaborates to achieve the best
course of care for a newborn.

by Gary Logan

WHEN ELLIOT CORREA was diagnosed in utero with the rare neurovascular malformation vein of Galen at an outside hospital, his parents Michael and Jennifer Correa started calling around for specialists who could treat the condition. The name of Johns Hopkins interventional neuroradiologist Philippe Gailloud kept popping up. “Thankfully,” says Michael, “he was available and we quickly transferred Elliot’s care to Johns Hopkins Children’s Center.”

There, the Correas learned that vein of Galen is a life-threatening congenital condition inside the brain in which malformed arteries and veins trigger a rush of high-pressure blood flow that can tax the heart and lead to pulmonary hypertension and heart failure. They also learned that not only could Gailloud effectively treat the condition by embolizing, or plugging, the malformation, but that Elliot would also be cared for by a team of neurocritical care specialists in the pediatric ICU.

“A lot of parents, local pediatricians and ER referring physicians know that we have a strong pediatric neurology and neurosurgery program, but they are not as well aware of our integrated neurocritical care program,” says pediatric intensivist Courtney Robertson. “Elliot’s case illustrates how that program works to achieve best possible

outcomes for patients.”

Upon Elliot’s delivery, however, that outcome was questionable. Already he was suffering from pulmonary insufficiency and an enlarged heart. The neurocritical care team, after reviewing Elliot’s labs and imaging at their weekly case conference, had decided that giving him medications to relax his pulmonary vessels and staging embolizations to lessen the strain on his heart were critical.

Pediatric intensivist Sujatha Kannan explains why embolizations to reduce blood flow from the malformation have to be staged: “With vein of Galen malformation, you can have as much as a third or half of all cardiac output going to the brain, so you don’t want to change that flow completely at one time and put the patient at risk of stroke and bleeds in other parts of the brain.”

Quietly and quickly, Michael says, Elliot’s heart did recover. On the 53rd day of his life he was removed from his ventilator and placed on nasal noninvasive ventilation. He got off the rollercoaster, says Michael: “Elliot remained vigilant and continued to improve. Technically, he still has pulmonary hypertension, but his lungs are clear and his heart is good.” 🍀

Elliot Correa, at the center of attention with, from left, pediatric intensivist Sujatha Kannan, Elliot’s mother Jennifer Correa, pediatric intensivist Courtney Robertson, and Elliot’s father Michael Correa



A New Center for Kids with Complex Cranial Conditions

TANYA MEWMAW RECALLS her son Tobin's head injury in February 2015 like it was yesterday. From the living room of their poorly constructed rental home near the American University of Iraq, where Tanya's husband worked, she could see then 1-1/2-year-old Tobin crawling along a railing upstairs. The railing would keep him safe, she figured, but somehow he slipped through it.

"We watched him fall 15 feet to a tile and concrete floor where he landed head first," says Tanya. "Today, I still see him falling."

Tobin let out a cry, clenched his eyes shut, and groaned. "We didn't know if he was going to be alive," says Tanya. "It was that kind of fall."

In a mad rush, the couple drove Tobin to the nearest hospital, where X-rays showed a skull fracture. Doctors there did not know how to treat traumatic head injury, so Tanya and her husband took Tobin to a hospital in Turkey. Neurosurgeons there performed a craniotomy to relieve the pressure on his brain, and a few days later the swelling had subsided. Doctors said he would be fine.

A year later, Tanya and her family moved back to Annapolis, Maryland, where a pediatrician recommended Tobin be evaluated by specialists at Johns Hopkins Pediatric Cranial Reconstruction Center. "With the language barrier, we had no idea what kind of care Tobin received in Turkey, but the Johns Hopkins name instilled confidence," says Tanya.

In reviewing Tobin's care and imaging his skull, the specialists determined that Tobin had suffered a subdural hematoma and two skull fractures from his fall. The craniotomy that surgeons in Turkey performed was the same approach surgeons at Johns Hopkins would have taken—encouraging news for the parents. But Tobin had a small defect at the site of the fracture on his forehead. Pediatric neurosurgeon Eric Jackson recommended waiting until Tobin was of school age before considering surgery to give the boy a chance to grow and fill the defect in with bone.

Several months later, Tanya noticed some swelling on Tobin's forehead, which Jackson suspected was a cyst associated with a "growing" skull fracture. Jackson and pediatric plastic reconstructive surgeon Richard Redett decided to move forward with correcting the bone defect, repairing the cyst and performing the cranial reconstruction. In the OR, however, Jackson uncovered an infection that had compromised the bone. Jackson removed the diseased bone and brought in an infectious disease specialist, delaying the planned reconstruction.

After treatment with intravenous anti-

biotics, the patient returned six months later for repair of the bone defect. In the OR, Jackson performed a craniotomy farther back on the skull to obtain a bone graft, which Redett used to make a split cranial bone graft to fill the defect. Using a very precise saw, Redett explains, he divided the two layers of a piece of skull bone for the graft.

"We can split it like a sandwich and put the undersurface back where it came from and place the outer surface as the bone graft with microplates and screws," says Redett. "It just fills in as osteoblasts come in and lay down more bone."

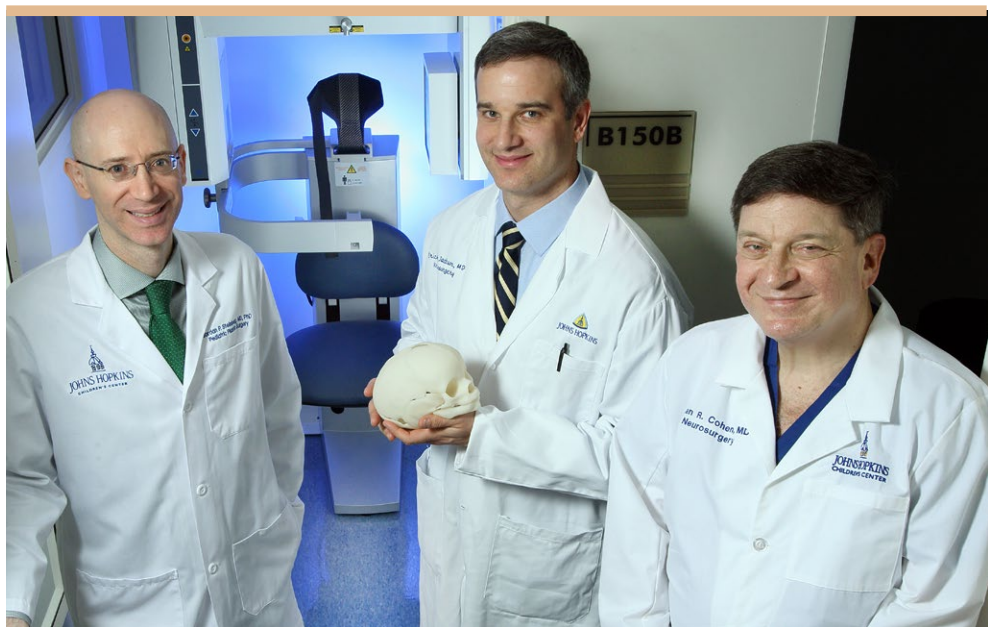
This case, Jackson adds, illuminates the benefit of a multispecialty center in treating cranial deformities in children: "Each of us has our own skill set that is synergistic in benefiting the patient."

How did Tobin turn out?

"He's doing really amazing," says Tanya, explaining that Tobin completed physical therapy at neighboring Kennedy Krieger Institute. "Doctors there reported no deficits or residual damage. It's a pretty crazy miracle—not only is he alive, but he's fully functioning."

— GL 🧡

In the Cranial Reconstruction Center, pediatric plastic and reconstructive surgeon Jordan Steinberg and pediatric neurosurgeons Erik Jackson and Alan Cohen.





A Radiation-Free Way to Treat Arrhythmias

ARRHYTHMIA TAKES MANY forms, from frequent heartbeats to sustained life-threatening tachycardia. Catheter ablation techniques effectively reduce the risk of recurrent arrhythmias and, in some cases, of sudden cardiac arrest. But ablation, in which pediatric cardiologists thread a series of catheters intravenously to the patient's heart to block the sources of the abnormal heartbeats, historically has required fluoroscopy imaging to visually guide them. Moreover, fluoroscopy, notes interventional pediatric electrophysiologist Jane Crosson, exposes the pediatric patient to radiation—not an insignificant risk over a patient's lifetime.

“National data shows that only about 12 percent of X-ray exams are for interventional cardiology or electrophysiology procedures but nearly 50 percent of a patient's lifetime radiation exposure comes from the cardiovascular labs,” says Crosson.

To reduce that risk for pediatric patients, who are more radiosensitive than adults, Crosson has employed technol-

ogy that minimizes or, in some cases, eliminates the need for fluoroscopy in placing the catheters. By superimposing a few fixed or static fluoroscopic images onto a 3-D anatomical map to visualize the catheters in the patient's heart, Crosson has been able to confirm their location without the need for real-time fluoroscopy and its associated radiation exposure. Using this approach, researchers such as Crosson have found a 64 percent reduction in fluoroscopy times and 60 percent in dosages for EP ablation procedures.

“Instead of using fluoroscopy, we use a GPS type of positioning system that allows us to see precisely where the catheters are in the heart,” says Crosson. “When you know where the catheters are and the shape of the heart, you don't need fluoroscopy. This system has enabled us in many cases to reduce X-ray time to almost zero.”

While fluoroscopy allows the operator to see more of the catheter and its course through the heart, this new system, called electro-anatomic mapping, allows



Employing a GPS positioning system and a 3-D anatomical map, pediatric electrophysiologist Jane Crosson directs a radiation-free catheter ablation procedure.

precise localization of important structures in the heart, including the native conduction system and extra electrical pathways that cause the arrhythmias. By reducing fluoroscopy and ionizing radiation, electro-magnetic mapping also improves the safety of these procedures. — GL 🍌

Stem Cell Heart Therapy

HYPOPLASTIC LEFT HEART syndrome (HLHS), in which the heart's main pumping chamber—the left ventricle—does not completely develop prior to birth, is one of the most devastating congenital cardiac conditions, with an average five-year survival of only 50-60 percent. The standard of care is a three-stage surgery that enables the remaining right ventricle to pump blood to the entire body and eventual heart transplantation. To delay that need for a new heart and improve survival, pediatric cardiac surgeons at Johns Hopkins Children's Center are employing a novel stem cell treatment to strengthen the right ventricle in patients with HLHS.

“With existing treatments we can close a hole and fix a valve, change the blood flow and the anatomy, but not the heart muscle,” says pediatric cardiac surgeon Luca Vricella. “We can fix the plumbing but not the sink.”

In this new approach, first performed at Johns Hopkins

in September 2017, a team led by pediatric cardiac surgeon Narutoshi Hibino injected allogeneic mesenchymal stem cells (MSC) directly into the heart of a 4 ½-month old girl. A follow-up MRI every six months will help determine the patient's cardiac function and response to the therapy. In adult patients, MSCs have been shown to reduce scar tissue and inflammation, and trigger the growth of new small vessels and muscle cells in the heart.

“We don't understand the exact mechanism, but stem cells contain proteins that stimulate the heart to recover and regenerate,” says Hibino.

The stem cell heart procedure at Johns Hopkins Children's Center was part of a phase I safety and efficacy trial of 10 patients, and a collaboration with the University of Maryland Medical Center, the University of Miami and Emory University. — GL 🍌



Giving Transplant Patients Digital Wings

THE GOOD NEWS? Thanks to pediatric solid organ transplantation, up to 80 percent of children receiving transplants are surviving for more than 10 years, studies show. For many of these young transitioning patients, however, nonadherence to medications and medical recommendations has become a significant and, in some cases, life-threatening issue.

“We know that teenage and young adult transplant recipients have significant medication compliance challenges as they become increasingly independent,” says Johns Hopkins pediatric gastroenterologist Douglas Mogul. “With that there are much higher rates of graft failure across all organs.”

To reduce these rates, Mogul has been

“Why did we call it Digital Wings? It ties into the notion of learning to fly and leaving the roost, an issue for adolescents transitioning to young adulthood and independently managing their lives as organ transplant recipients.” ”

—Douglas Mogul

looking to technology for solutions. A savvy tech geek as well as a pediatric liver specialist, Mogul has already advanced parents’ detection of biliary atresia—the leading cause of liver failure in children—through a digital color stool guide accessible through an app. Now, in an initiative he calls “Digital Wings,” he has a new tech target—a digital tool to help teenage solid organ transplant recipients better manage their transplant and transition to adult care.

“There’s evidence that if you can prepare adolescents and young adults early on, they’ll be much less likely to have complications,” says Mogul.

In kicking off the initiative at Johns Hopkins Children’s Center in February, Mogul sent a message that this would hardly be a solo crusade. In addition to families, patients and transplant advocacy groups, he invited seasoned leaders from various fields—including medicine, behavioral psychology, technology, gaming and augmented reality—to a multi-stakeholder symposium to strategize development of the best possible digital tool.

“This is a collaboration of people, each with unique skills, but together likely have the best chance of creating a useful digital tool,” says Mogul. “Creating a digital tool is the easy part—the real challenge is creating a tool that people download, continue to use appropriately and that changes their behavior so they can independently manage their organ transplant.”

While Mogul characterizes the conference as a conversation starter, he cites innovative concepts that surfaced from this diverse group.

“Among the biggest ideas was the digital buddy,” says Mogul of a digital strategy proposed by patient advocate Natalie Williams. “She showed us the value of teenage transplant recipients being paired with each other.”

Others agreed the cross-section of viewpoints made the discussions that much more informative and valuable in addressing adherence issues.

“In bringing together outstanding representatives from the medical, patient and advocacy communities, this conference was the ideal prototype and forum for collaboration with these important groups,” says Thomas Nealon, chief executive officer of the American Liver Foundation.

Next steps, says Mogul, include incorporating insights from the data into a survey for teenagers to help determine what types of digital tools they are most likely to use. Mogul plans to hold a follow-up conference in the fall to discuss ethical issues related to the use of digital tools by transplant recipients, potential pilot studies and new data on leveraging technology to promote adherence. Mogul says, “We’ll also present a menu of ideas for teenagers and young adults, to see which ones they see as most impactful.” —GL 🍌



Representatives from health technology companies at the Digital Wings conference included Michael Fergusson, CEO of Ayogo, which has employed game psychology and social networks to help patients manage their treatments.



Pediatric cardiologists Philip Spevak and Joanne Chiu assess blood flow in a fetal heart via real-time echocardiography imaging from Sibley Memorial Hospital in Washington, D.C.

Catching Heart Problems Early

SIBLEY MEMORIAL HOSPITAL obstetrician Rita Driggers was growing increasingly frustrated about delays in getting a follow-up echocardiogram by a pediatric cardiologist for expectant mothers whose sonogram indicated a possible cardiac problem. Visits from a pediatric cardiologist from an outside hospital 2 ½ days each month helped, but not enough. Driggers knew time was of the essence in having a detailed fetal echocardiogram performed by a physician trained in fetal cardiac evaluation.

“We do know the earlier the diagnosis is made the better the plan of care and the outcome,” says Driggers, medical director of maternal fetal medicine at Sibley.

The solution came in the form of a pilot telemedicine project initiated at Johns Hopkins Children’s Center, in which pediatric cardiologists Philip Spevak and Joanne Chiu direct and interpret echocardiograms from Baltimore with obstetric sonographers at Sibley, a Johns Hopkins Medicine affiliated hospital in

Washington, D.C.

“We’re going to test this and see whether lack of physical presence is offset by the fact that we’re more able to support the program and be accessible,” says Spevak.

How does the project work? From a reading room in the pediatric cardiology suite at the Children’s Center, Spevak and Chiu, digitally and visually connected to a fetal echocardiogram machine and a sonographer at Sibley, join the exam. In real time, Spevak and Chiu see what the Sibley sonographer sees, allowing them to provide hands-on assistance.

“Dr. Spevak can ask her to tweak the scan a little bit to the left so he can get exactly the images he wants,” says Driggers. “It’s like he’s doing the scan himself.”

If the study is abnormal, Spevak or Chiu review the results face-to-face via video with the parents at Sibley.

While being fully informed about a possible cardiac complication can be

agonizing for parents, it is beneficial for parents in a variety of cases. Spevak explains that a mother with a prior pregnancy revealing hypoplastic left heart syndrome, for instance, wouldn’t have to wait 22 weeks to see whether her second child’s heart would be normal. In addition, an echocardiogram might expose a condition such as diaphragmatic hernia, where prenatal intervention with the Children’s Center’s fetal therapy program is clearly beneficial. In almost all cases, Spevak stresses, parents are better prepared.

“If there’s structural heart disease, we can start the conversations with parents and connect them to the resources they need,” says Spevak. “They can meet with the cardiac surgeon and the neonatologist ahead of time and get a tour of the neonatal ICU. We can offer them the opportunity to talk to a family that’s been through what they’re going through.” — GL 🍌



Raising the Profile of Hospital Medicine

By Karen Blum

JOHNS HOPKINS CHILDREN'S CENTER was one of the first hospitals in the country to create a hospitalist program in pediatrics, mainly to provide medical consultations to surgical services about their patients. Starting last July, however, pediatric hospital medicine became a stand-alone division at Johns Hopkins, with seven hospitalists and one nurse practitioner.

“As inpatient and outpatient health care has changed, hospital medicine has become the fastest growing medical specialty and is now an accredited subspecialty,” says Children’s Center co-director Tina Cheng. “It was time to recognize and build hospital medicine as a separate division in the Children’s Center and to continue to lead in clinical care, education and research in this growing field.”

“This raises the profile of hospital medicine at the children’s hospital,” adds Eric Biondi, division director. “And it allows us to really take the lead on standardizing care for children with general medical illnesses and ensuring high-quality, inpatient general medical treatment.”

Hospitalists care for children hospitalized with general medical illnesses, including conditions “that are so complex that one subspecialty really can’t manage them,” Biondi says. He adds that hospitalists continue to be available for medical consultation for surgical patients, serve as medical directors on the floors and participate in hospital committees: “Hospitalists are kind of like water on pavement—they fill every crack that is

needed in a hospital.”

Biondi came to Johns Hopkins last fall from the University of Rochester, where he completed a pediatrics residency, became a hospitalist at the university’s medical center, and earned a master of business administration degree with a focus on health care management. From there, he built a complex care service staffed by nurse practitioners for the management of children with extremely complicated medical illnesses, and became director of performance improvement for the university’s children’s hospital.

Pediatric hospital medicine, which just became a board-certified subspecialty, “is a young, vibrant, energetic field nationally and I really enjoy being part of that,” Biondi says. “It’s a group of people who are really fun to be around, and everybody has that same vision of trying to make things better for kids but in a very collaborative way.”

Biondi has a number of ideas for the division, such as working closely with nurses, social workers and Child Life

“Hospitalists are kind of like water on pavement—they fill every crack that is needed in a hospital.”

—ERIC BIONDI

specialists, building relationships with specialties, and teaching residents and medical students, as well as developing a fellowship program. Noting that he would also like to integrate with other pediatric inpatient units affiliated with Johns Hopkins, he concludes, “Our group should be seen as the quarterback for children hospitalized with medical illnesses.” 🍌

Johns Hopkins pediatric hospitalists, from left to right, Rachna Kapoor, Marquita Cecelia Genies, Christopher Kazimieras Grybauskas, Alia Irshad, Abby Nerlinger, Susan Rebecca McFarland and Eric Biondi





Hoover Adger Jr., M.D., M.P.H.

Addiction Specialist Hoover Adger

Pediatrician Hoover Adger Jr., a member of the American Board of Addiction Medicine and The Addiction Medicine Foundation, and former deputy director of the White House Office of National Drug Control Policy, has dedicated much of his 33-year career to adolescent substance abuse. Here he addresses steps at Johns Hopkins Children's Center to improve physician training and the care of patients with substance abuse issues.

Is medicine today equipped to manage addiction?

If you have a heart problem, you will have no problem finding a cardiologist, or a nephrologist for a kidney problem. Go to any community hospital in this country, however, and you will find that 30 to 50 percent of the patients there have a primary or secondary issue related to alcohol or substance abuse, but there is no addiction medicine service in that hospital to treat it.

Do you see substance abuse as primarily a pediatric issue?

Yes, the majority of individuals who develop a substance abuse problem get their start as an adolescent. If we wait until we see people who are significantly involved with substance abuse when they are older, it is going to be a harder mission. Why not start upstream, get ahead of the curve, and intervene at times when we know we can do best? As pediatricians, we can build on our existing relationship and trust with families.

How do we work with patients and families facing substance abuse?

We try to emphasize a family-centered approach with a focus on prevention and early intervention. I have been unable to provide quality pediatric care for many

“Notably, pediatricians who have trained here in addiction medicine have been highly recruited to practice addiction medicine in other children's hospitals around the country and to lead their efforts against the opioid crisis.”

of my patients because either a parent or caretaker also has substance abuse issues. We need to help parents and patients understand what being at risk means. We have to reach out to parents to help them get into a healthy relationship with their child affected by substance use.

Are our pediatricians educated and equipped to do that?

We have a wonderful corps of people in our Harriet Lane primary care clinic who want to assist in addiction training, but we need to breathe some life into this enterprise. Thanks in part to a \$25,000 grant from the American Board of Addiction Medicine, we have developed an addiction medicine track for our adolescent medicine fellows that gives them in excess of 2,000 hours devoted to addiction medicine. That has allowed them to sit for certification as addiction medicine specialists by the American Board of Addiction Medicine. Notably,

pediatricians who have trained here in addiction medicine have been highly recruited to practice addiction medicine in other children's hospitals around the country and to lead their efforts against the opioid crisis.

Next steps?

Currently there are some 46 addiction-medicine fellowship programs across the country, but only two focus on pediatrics or children related issues. Our response has been to create a center to take advantage of all the things we have available to us, including access to resources in the Johns Hopkins Bloomberg School of Public Health. Then the task will be to arm our medical community with credentialed state-of-the-art addiction medicine programs and consultation services. 🍌



A Clinic for Latinos



Pediatrician Sarah Polk, with a young patient and her mother in the Centro SOL clinic at Johns Hopkins Bayview Medical Center.

WHEN A CENTER OF EXCELLENCE for Latino Health was established at Johns Hopkins Bayview Medical Center in 2013, faculty involved with the growing number of Latinos in Southeast Baltimore knew a bilingual, multidisciplinary approach to health care was warranted. But the summer of 2014 kicked things up a notch, says pediatrician Sarah Polk.

There was a significant influx of youth emigrating from Central America, largely prompted by heightened violence in the region, says Polk, medical director of the Children's Medical Practice, an outpatient pediatrics practice at Johns Hopkins Bayview. About 75 percent of its patients are Latinos from immigrant families. Adolescents as young as 12 were coming alone or with similar-aged peers or cousins. Polk and her colleagues heard about this through patient families, who asked where their newly arrived relatives could get medical care.

"We became aware of how stressful this was for families, and how harrowing the journey had been for many of these kids," Polk says. "Even in the most successful examples, these were kids reuniting with parents with whom they had only telephone contact potentially for up to a decade." On the flip side, some parents were newly responsible for teens they hadn't parented for several years.

Additionally, Polk and colleagues began receiving calls from school em-

ployees or community members concerned that some of the new arrivals had post-traumatic stress disorder and asking where they could find mental health services. With no access to insurance and a scarcity of Spanish-speaking mental health professionals, the answer was nowhere.

"It's been a very busy four years so far and successful in coalition-building and in providing direct service to the community."

— SARAH POLK

With help from a social worker in the Baltimore City public schools and Johns Hopkins child psychiatrist Rheanna Platt, Polk and colleagues created Teen Testimonios, bilingual school-based stress reduction groups for recently immigrated adolescents. The program, piloted in the 2014-2015 school year and funded by Johns Hopkins' Urban Health Institute, was so well-received that it has continued and expanded.

It's just one offering from Centro SOL (Center for Salud/Health and Opportunity for Latinos), sponsored through a five-year grant from the Aaron and Lillie

Straus Foundation and matching funds from Johns Hopkins Medicine. The center has five core areas: clinical care, education, research, advocacy, and global health. All work is done in partnership with the community.

Centro SOL pediatricians also realized that summers are difficult for adolescent immigrants, many of whom can't afford summer camps and are not eligible for work programs. Thanks to local philanthropists, Polk and colleagues added a free summer program for middle and high schoolers that includes English classes and activities such as field trips to The Walters Art Museum or Patterson Park swimming pool to enable youth to better know their new community. Upon completion of the program, students receive back-to-school supplies as well as a nominal stipend based on their attendance. Polk hopes to expand the program with scholarships to other local camps.

"We're just starting our last year of seed funding and trying to determine what will come next," Polk says of Centro SOL. "It's been a very busy four years so far and successful in coalition-building and in providing direct service to the community."

For more information, see jhcentrosol.org. —KB 🌟



Safe, Comprehensive Transgender Health Care

FOR SEVERAL YEARS, adolescent medicine specialists Renata Sanders and Errol Fields had been seeing a handful of teenage and young adult patients who questioned or felt disconnected from their gender identity. After last spring's opening of the Johns Hopkins Center for Transgender Health, however, the physicians dedicated time in the adolescent medicine clinic once a month for these patients, and inquiries have jumped.

"I'm getting anywhere from three to seven referrals a week," says Kathy Tomaszewski, adolescent nurse coordinator for the Emerge Gender & Sexuality Clinic for Children, Adolescents and Young Adults, which manages about 50 patients. At the clinic, patients as young as 6—most of whom come with parents or siblings—can find a safe space to discuss their concerns and health needs with Sanders, Fields and Tomaszewski. The multidisciplinary team includes social worker Tisha James and psychologist Kathryn Van Eck.

Depending on a patient's stage of development and desires, Sanders and Fields can prescribe pubertal blocker medications or cross-hormone therapies, such as providing testosterone to a patient born female to deepen the voice and cause hair growth. The team also provides primary care services, family support and advice negotiating any special arrangements with schools or teachers. Gender affirming surgery for those 18 and older is available through the Center for Transgender Health's plastic surgery associates.

"It's been a very rewarding experience because families have been searching for resources and support, sometimes for a

“It’s really a vulnerable time for these youth. You can’t just say they’re little adults because you miss key opportunities for intervention and support.”

– RENATA SANDERS

long period of time,” Tomaszewski says.

Many of these patients have not had supportive experiences in a health care setting, adds Fields. Even if other physicians have been open-minded, he says, they often “have no idea” how to help them because there is little training on how to work with transgender patients.

“I’ve had patients getting hormones for the first time who are in tears of joy because they are finally getting something that affirms who they are and experiencing some relief from their gender dysphoria,” says Fields.

Fields and Sanders see the clinic as part of a larger initiative they call SPACES—Supporting Pediatric Adolescent and young adult sexual and gender minorities through Advocacy, Clinical care, Education and training, and Scientific inquiry. In addition to conducting health disparities research on issues affecting lesbian, gay, bisexual, transgender and queer/questioning (LGBTQ) youth, they have conducted joint train-

ings for Johns Hopkins medical and nursing students—as well as frontline clinical staff—on how to work with these patients. Topics include counseling adolescents who are questioning their sexual orientation, encouraging parents to support their youth and identifying issues affecting the patient, such as depression or mental health needs, substance abuse or risky sexual behaviors. With clinic staff, they review using preferred names and pronouns, as well as other strategies to make transgender patients and their families feel welcome and comfortable in the clinic environment.

Adolescence is a critical time for development in terms of emotional, cognitive, neural, hormonal and physical changes, Sanders says, and those questioning their identity may feel isolated. “It’s really a vulnerable time for these youth,” she says. “You can’t just say they’re little adults, because you will miss key opportunities for intervention and support.” —KB 🌈





Eitan Kerem

An Israeli Collaboration Against CF

FOR THE PAST SEVERAL YEARS, researchers with the Johns Hopkins Cystic Fibrosis (CF) Center have enjoyed a unique overseas collaboration with CF experts at Hadassah Medical Center in Jerusalem.

The arrangement began almost a decade ago when Peter Mogayzel, director of the Johns Hopkins CF Center, invited Eitan Kerem, head of pediatrics at Hadassah, to come to Baltimore to discuss his research and clinical programs and address patient families. “Israel has a large population affected by cystic fibrosis,” a hereditary disorder causing the production of thick mucus that can block airways and impact other organs of the body, Mogayzel says. It occurs more frequently among Jewish families of Ashkenazi (Eastern European) descent. “Hadassah has several leading physicians there that both care for patients and also have developed extensive research programs.”

The discussions went so well that, ever since, Mogayzel and other Johns Hopkins CF experts have taken turns traveling to Hadassah to lecture, discuss cases, help educate families and speak at the annual Israeli CF Society Conference. Hadassah experts also have contributed genetic data about their patients to the CFTR2 website (www.cftr2.org), a worldwide collection of information on over 80,000 patients with CF maintained by Johns Hopkins molecular

“The synergy generated by the collaboration of Johns Hopkins and Hadassah on research projects, joint meetings, exchange programs and shared clinical databases will contribute to enhanced quality of life of families coping with CF.”

— EITAN KEREM

geneticist Garry Cutting. Certain mutations in the cystic fibrosis transmembrane conductance regulator (CFTR) gene are more prevalent in Israel than in the United States.

“It really has been an opportunity for both programs to learn from each other and for us to contribute to the overall education of families and to other CF caregivers through the Israeli conference,” notes Mogayzel. “Patients with CF have chronic pulmonary infections, and over time they develop infections with very resistant bacteria, which are a challenge for treatment. We have adapted some practices used at the Hadassah Medical Center to try to combat those infections,” such as altering the use of inhaled antibiotics.

The two centers are now exploring ways to conduct research projects that

can leverage the patient populations and research expertise in both locations, Mogayzel says.

“The synergy generated by the collaboration of Johns Hopkins and Hadassah on research projects, joint meetings, exchange programs and shared clinical databases,” Kerem says, “will contribute to enhanced quality of life for families coping with CF.”

The collaboration has been sponsored by the Herbert Bearman Foundation, a longtime supporter of the CF Center. Other philanthropy from the foundation has provided for creating and maintaining the center website (hopkinscf.org), sending trainees to national CF conferences, hosting family education programs and purchasing equipment that can measure lung function in very young children—allowing participation in several clinical trials investigating early lung disease and CF. — KB 🍌

Hadassah Medical Center





Bringing Calm After the Storm

AS PART OF THE Johns Hopkins Go Team in St. John to provide patient care in the aftermath of hurricanes Irma and Maria, pediatrician Robert Greenberg and pediatric nurse Marybeth Pule found a devastated island and dazed residents. They also found an extremely diverse and dedicated medical team confident and calm in caring for patients in the wake of the two storms.

“The people in St. John were solemn, wearing facial expressions still in disbelief,” says Greenberg, who also trained in anesthesia and critical care medicine. “Even though the situation was intimidating, our strength was being pretty good at whatever we needed to do.”

“Our team had synchronicity in a situation where you don’t have the availability of all the stuff we have here,” says Pule, who as a nurse assisted victims of Hurricane Katrina in 2005. Greenberg, no stranger to disaster relief, volunteered with a medical team in Haiti following its 2010 earthquake.

Their first task was helping the six-member Johns Hopkins Go Team relocate equipment from a collapsing clinic in the hills to a community health center near Cruz Bay. There they treated pa-



Marybeth Pule and Robert Greenberg, back from St. John and in the Johns Hopkins Children’s Center pre-op unit, where they often work together.

tients with an array of abrasions, cuts, infected wounds and abdominal pain, some of whom they sent to St. Thomas for surgical evaluation. They also cared for patients who were traumatized by the storms and the uncertain futures they brought.

“Our presence alone was helpful,” says Greenberg. “We were there and we kept coming back, which was reassuring to

“Our presence alone was helpful. We were there and we kept coming back, which was reassuring to the residents.”

— ROBERT GREENBERG


the residents.”

Unexpectedly, Greenberg also found himself performing physicals for students transferred to the one school that survived the storm: “The only school that was not decimated would take the kids, but they needed to know their immunizations were up to date. Being the only pediatrician on the island, I did school physicals. That was cool.”

The Johns Hopkins Go Team, organized by the Johns Hopkins Office of Critical Event Preparedness and Response (CEPAR), rapidly deploys to areas impacted by natural or man-made disasters to assist with urgent medical needs. The humanitarian mission in St. John, which continues to bring much-needed supplies, medicines and medical personnel to the island, is a collaboration with Bloomberg Philanthropies. — GL 🍌



researchroundup



In the lab, oncology researcher Pat Brown studies new agents that may be more potent than current therapies against leukemia cells.

P. Brown, M.D.

Targeting Leukemia

By Elizabeth Heubeck

PEDIATRIC LEUKEMIA PROGRAM DIRECTOR Pat Brown discusses his path to pediatric oncology, the nature of leukemia and the need to develop molecularly targeted therapies.

Patrick Brown recalls precisely the moment that he knew he wanted to make pediatric oncology a career. He was in his third year of medical school, and had just been assigned to a pediatric oncology rotation. After meeting with the first few patients, he was hooked.

“I was blown away by the maturity of these kids—and their parents were so finely attuned to what was going on with them,” says Brown. “It struck me then that it would be very easy to be motivated to go to work every day.”

A decade later, Brown applies an almost child-like enthusiasm and energy to his role as director of the Sidney Kimmel Comprehensive Cancer Center’s Pediatric Leukemia Program.

“The way our body makes blood, and how that process gets disturbed to create leukemia, is something I’ve always found fascinating,” says Brown. “One of the things that’s so neat about the study of leukemia is that we know so much about

it on a genetic and molecular level, and that knowledge is increasing faster and faster as new technology is developed.”

Brown explains that because leukemia often invades the blood stream, researchers often need only to draw blood, rather than surgically remove part of a tumor, to study it. That is not to say leukemia is easy to fight. On the contrary, he adds, it is extraordinarily complicated as it results from not one, but several gene mutations occurring together in the same cells. Subsequently, combinations of drugs must be used against it.

Brown’s lab identified such a combination—composed of standard chemotherapy drugs and FLT3 inhibitors (agents that prevent activity from FLT3, a gene mutation linked to certain forms of leukemia)—that may work more effectively than current therapies to kill leukemia cells. Through the Children’s Oncology Group, an international network of researchers, Brown led the first

clinical trials to test this combination of agents on children with leukemia.

“These were the first of many clinical trials now being done to test these new targeted strategies,” says Brown. “In the case of the FLT3 inhibitors, this combination has now become the standard treatment.”

While he is excited about the prospect of developing molecularly targeted and immune-based therapies to improve cure rates while minimizing side effects, Brown is also keenly aware of the grave responsibility that comes with the territory. The trust that patients and their families show, he says, is something I take seriously: “While I know we need new approaches to treatment, it is important that we do our homework to protect patients—to expose them only to things that we think will help, and do so in the safest way possible.” 🍌

“The infrastructure of clinical research that has been built with the help of families is really unparalleled.”



For a video of Pat Brown discussing his research, go to hopkinsmedicine.org/profiles/results/directory/profile/0011816/patrick-brown



Tom Crawford

REFLECTIONS ON A 30-YEAR CAREER treating patients with spinal muscular atrophy and helping to develop novel new therapies that dramatically alter the course of the disease.

By Gary Logan

Researching neuromuscular disorders and treating children afflicted by them was not the path intended by Tom Crawford. After studying psychology and religion at Yale College, he considered pursuing a career in science. He felt conflicted, however, because in the 1970s science seemed dedicated solely to supporting the military-industrial complex—not his cup of tea. After exposure to the hospice movement, he connected with the challenges hospice physicians faced and got onboard by going to medical school at the University of Southern California.

“At the time, you would never let anyone with a fatal disease know they were dying,” says Crawford. “The hospice movement advocated for folks in that awful position, saying they have as much right as anybody else. So, I said, ‘OK, I’ll be a hospice doc.’”

That prompted medical school and a rotation in internal medicine that, he says, did not resonate. His next rotation, in pediatrics, was far from his ambition: “I told my to-be wife and others that pediatrics was the one specialty I know I’m not going to do.”

Then, after admitting a patient with spinal muscular atrophy (SMA), the sun broke through the clouds. Characterized by the loss of motor neurons in the spinal cord and lower brain stem, the disease results in progressive muscular atrophy and weakness. In the most severe cases, patients may become paralyzed and have difficulty performing basic functions of life, such as breathing and swallowing. Many do not survive.

“It changed my life,” Crawford says. “This may have been the first baby I ever

held, and yet he was admitted to the hospital to die. That did something to me.”

During rounds the next morning, Crawford explains, the attending physician described SMA as a hopeless disease, and suggested they not disturb the grief-stricken mother. Crawford felt differently: “I felt we were isolating her—it was exactly the wrong reaction.”

The experience segued into a calling to care for kids seen as unattractive or off-putting in ways—kids with neurologic problems. Like the mom of the baby with SMA, parents felt ostracized because their children were different.

“Nobody felt comfortable being around them, they didn’t know what to say,” says Crawford. “But that’s where being a normal human being has thera-

peutic impact. I found my niche.”

That niche led to training in pediatric neurology and a fellowship in neuromuscular disorders at Johns Hopkins. With no cure for SMA, Crawford initially focused as much on the lives of patients and parents as on the disease itself. At the heart of his work, he promoted ways to further patients’ development—no easy challenge for patients with neuromuscular disease and parents who perceive their world as perilous.

“It’s a very weird process to ask parents to push a kid out the door, to take chances, and kids with profound muscle weakness are less inclined to press the issue because they also need help with so many routine things,” says Crawford. “Yet it’s essential for their self-identifica-

Recent breakthrough therapies, notes pediatric neurologist Tom Crawford, mean patients like Brynne Willis, a 25-year-old he diagnosed with SMA at age 10, may not decline as they age. Says Crawford, “I want to keep Brynne walking like this for decades.”





tion, to do something on their own, to get in trouble—that is part of growth, part of normal.”

That normal leads to confidence and success for patients, says Crawford, pointing to higher college graduation rates and postgraduate degrees among kids with SMA than their peers in the general population. He points to Brynne Willis, a patient he diagnosed at age 10 who now at 25 is pursuing a master’s degree in mental health at The Johns Hopkins University to help patients and families manage disabilities the way Crawford has managed her.

“I’m learning from my own experience in treating children and families with disability and chronic disease,” says Willis.

For the parents, Crawford says, the struggle is taking on so many unnatural roles: “They become the medical manager, the coordinator of therapy services, drugs and doctors, and at the same time they feel a sense of bewilderment, guilt and grief all at once. Parents need someone to say they’re OK, that the tensions they are feeling are normal.”

Addressing such quality of life issues became Crawford’s mission, but along the way he also found science again in studying SMA and other neuromuscular disorders. On the one hand, he could help patients become more independent and parents lighten their reins as disease managers. On the other hand, he could explore innovative new therapies through developing and participating in clinical trials.

Research gains against SMA were modest over the first part of his career, but this has changed dramatically during the last decade, culminating last summer when SMA researchers celebrated Food and Drug Administration approval of the first drug, called Spinraza, to treat SMA. Injected into the fluid surrounding the spinal cord, the drug demonstrated startling effects in clinical trials. Most patients treated with Spinraza reached measurable motor milestones



“I presently remain very bullish on making these kids’ lives work despite profound muscle weakness. We’re much better at managing this disease—we’re doing better pulmonary, orthopedic, nutritional and supportive therapies than we ever did before.”

— TOM CRAWFORD

such as head control, sitting, standing or crawling—an unprecedented outcome.

Recalling cellular studies of Spinraza that began in 2006, animal studies in 2009 and human trials in 2013, Crawford says, “Every step was, ‘Oh my God, it works.’”

Another recent breakthrough came in the form of a gene transfer therapy developed by a company named AveXis. This approach involves administration of a normal human SMA gene packaged in a clinically benign viral coat called AAV9. In a phase 1 trial of 12 infants with SMA1—the worst form of SMA (patients are expected to die or require full-time ventilation before their first birthday)—researchers at Nationwide Children’s Hospital in Columbus, Ohio, demonstrated improvement in motor function for all patients, with nine out of 12 sitting independently.

“These babies are doing spectacularly,” says Crawford. “We’re seeing lots of walkers and sitters,” he adds, noting that Johns Hopkins is one of the sites for a new multicenter trial with the therapy.

These treatments have galvanized motor neuron research, Crawford explains, but they are coming with a high price tag. Spinraza costs \$750,000 per patient in the first year alone. Crawford has developed a newfound appreciation for people such as Redonda Miller, The Johns Hopkins Hospital president, and Ted Chambers, administrator for the Department of Pediatrics, who have been striving to make these treatments accessible to patients.

“The development of a research program is no longer just scientists and clinicians trying to cobble something together that can pass FDA muster,” says Crawford. “Programs will require the entire administration to make it work. We have new barriers to getting meaningful therapy to those who can benefit from it, so they are now part of the research team.”

For his part, Crawford takes no ownership of the SMA breakthrough: “I know that I helped at lots of phases of the research, but it feels really awkward to make it about me. I’d like to think I’ve played a role in keeping the focus on what matters.”

For him the reward is the longitudinal relationships he has built with patients and parents over the years, and observing their towering achievements against the odds: “I presently remain very bullish on making these kids’ lives work despite profound muscle weakness. We’re much better at managing this disease—we’re doing better pulmonary, orthopedic, nutritional and supportive therapies than we ever did before.”

Crawford concludes, “All of this SMA success is fantastic, but it wasn’t close to my original plan.” 🍀

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people&philanthropy



The Sutland/Pakula Family's Long History of Giving Back

By Karen Blum

PEDIATRICIAN LAWRENCE “LARRY” PAKULA says philanthropy was in the genes for his late wife, Sheila Sutland Pakula—as it is for him. Indeed, for nearly 30 years, members of the Sutland/Pakula family have been generous supporters of Johns Hopkins Children's Center and, specifically, its neonatology program.

“We were both raised with the idea of being charitable and giving,” says Larry, an associate professor emeritus of pediatrics at Johns Hopkins and co-founder of Pavilion Pediatrics in Lutherville.

His most recent gifts carry on a long legacy of supporting the care of children, particularly newborns, by establishing the Sheila Sutland Pakula Professorship for Maternal and Newborn Health in memory of his wife, who died in November 2016, and providing research dollars through the Lawrence C. Pakula, M.D. Innovation Award Fund. Additional monies will fund expansion of the Sutland/Pakula Family Newborn Critical Care Center, named for the family in 2012.

Sheila grew up as an only child, but her mother, Josephine Sutland, had at least five other pregnancies that resulted in miscarriage, Larry says. Josephine and her husband, Frank, a dentist in Troy, New York, who established a chain of clinics that treated children and the disabled, would talk to Larry and his father (also a pediatrician) about work in neonatology. Along the way, the Sutlands befriended Frank Oski, former chair of pediatrics at Johns Hopkins, and began donating to the Children's Center.

The Pakula family's ties to Johns Hopkins began in the 1950s when Larry did his internship and residency in pediatrics here, and his first two children were born at The Johns Hopkins Hospital. Now 85, Larry con-

tinues to take part in The Hospital for Consumptives of Maryland (Eudowood) Foundation Board, the Johns Hopkins Children's Center Council and the board of the Robert Garrett Fund for the Surgical Treatment of Children.

Larry and Sheila later established a professorship in pediatric genetics in memory of her father and one in newborn medicine in memory of her mother. They also created an endowment for neonatal research and a fund for pediatric critical care medicine, among making other donations. Sheila was an active member of the Women's Board at Johns Hopkins and she also served on the Johns Hopkins Children's Center Council.

“The Pakula family has truly transformed children's lives,” says Tina Cheng, co-director of the Children's Center. “Every day I walk past the neonatal intensive care unit and I know our families are being cared for in the best possible place by the best experts. I'm honored I was able to know Sheila and understand her passion for, and commitment to, infant health.”

Adds Children's Center co-director David Hackam, “Larry means so much to us here at the Children's Center and to me personally. The legacy of his family is deeply meaningful here, and their philanthropy has touched generations of families and clinicians. I can't thank him and his entire family enough for their generosity and partnership.” 🌟



Through His Experience, a Donor Empowers Nurses

By Helen Grafton



At the pediatric nursing history display in the Children's Center, from left, pediatric nurses Ashley Lippert and Margo Mancl, Roger Leventer, Interim Director of Pediatric Nursing Dawn Luzetsky, and pediatric nurse Elaina Zito. Lippert, Mancl and Zito all attended the crisis prevention training funded by Leventer.

"I THINK THE NURSES play a crucial and often unacknowledged role in the patient experience," says Roger Leventer. "They are with the patients 24/7, and their level of engagement and real time understanding is remarkable."

Leventer, a longtime member of the Johns Hopkins family, lost his wife to an almost seven-year battle with colorectal cancer in 2014. His two sons struggled with the loss. After witnessing the expert care and compassion his wife received during her time at the Sidney Kimmel Comprehensive Cancer Center at Johns Hopkins, Leventer knew he needed to bring his son to Johns Hopkins when, less than a year later, he required surgery on his legs due to a birth defect.

During his son's stay, Leventer became familiar with the nurses' routines and procedures. Although he was incredibly thankful for the care his son received, it became evident that the boy was struggling to hit milestones in his recovery due to his mental health. It was an issue, Leventer felt, that demanded greater attention.

"There's a mental health component whenever anyone goes to the hospital," Leventer says. "Anxiety plays a role in everyone's experience and needs to be managed by the entire care team."

Recognizing that training care providers on how to address mental health in patients' care and recovery is essential, Leventer donated \$10,000 to the

Johns Hopkins Pediatric Nursing Department. Thanks to the donation, earmarked specifically for crisis-prevention trainings, 10 nurses became certified in crisis prevention by the international training organization Crisis Prevention Institute, allowing them to create workshops to train staff members how to address or defuse a challenging incident before it escalates to a crisis situation.

"I feel empowered and honored to educate fellow staff on how to implement these skills properly," says nurse Ashley Lippert. "I hope this will inspire change in organizational culture and foster better relationships between hospital staff and the patients and families we serve."

During a follow-up roundtable discussion among Leventer, nurse managers, educators and nursing leadership, the nurses expressed their gratitude for the funding of the program while honestly sharing their daily struggles. The conversation inspired Leventer to increase his donation to \$20,000 each year for the next five years, making it the largest gift pediatric nursing has ever received. Leventer left the use of these funds up to the discretion of nursing leadership, "putting more control into the hands of the nurses," he says.

Although nurses play a vital role in the hospital, their impact often goes unnoticed. Leventer's gift has already boosted their morale.

"It's a powerful message that our

nurses were recognized for the great work they do and that there's someone out there who is committed to their growth," says Dawn Luzetsky, interim director of pediatric nursing. "The mere fact that we can say to nurses that someone recognized them and wanted to support them is amazing."

Although there are no restrictions on how the money will be used, Luzetsky says Nurses Week, Nurses Scholars Day, professional development, education and conferences are on the list of possible purposes.

Leventer has remained vocal about his experiences at Johns Hopkins Children's Center. Serving on multiple boards across the Kimmel Cancer Center and the Children's Center, including the Pediatric Family Advisory Council, he continues to be an advocate for patients throughout the hospital. He also hopes his donations will promote the idea that any donation, no matter the size, can make a difference.

"If it's meaningful to you, it's remarkably meaningful to them," Leventer says. "You don't have to give \$160 million to be a rock star to a nurse or doctor who is trying to help sick kids." 🍌



For more information on how you can support pediatric nursing, email hopkinschildrens@jhmi.edu.



Chaplain Kat

Walks with Parents in the NICU



WHEN PARENTS UNEXPECTEDLY find themselves with a child in the hospital, religion is often the first place they look for guidance. For others, however, it's the last resort.

Regardless of religious beliefs, parents and families find an advocate and place of solace in Reverend Kat Kowalski, the first full-time pediatric chaplain in the neonatal intensive care unit (NICU) at Johns Hopkins Children's Center.

"My religion is love and kindness," says Chaplain Kat, as she is called by families in the NICU.

What started as a part-time position in 2013 has since turned into a 24/7 position thanks to recognition of the great need for her services by both staff members and leadership in the division of neonatology.

"This is wonderful news for all of our patients and their families, and all of us who help care for them," says pediatrician Nancy Hutton, medical director of the Harriet Lane Compassionate Care program. "Also, this is Johns Hopkins innovation at its best—identifying a critical need, creating an individualized response, piloting its effectiveness and implementing action for sustained impact."

In her role, Kat provides spiritual and emotional guidance to families during their stay in the NICU. During traumatic and stressful experiences, she stays with families through every step of their journeys. One of the central aspects of her job is assisting families in creating a birth plan. When families face unfore-

"The impact that one little spirit can have on a family, doctor or staff member is remarkable."

— REVEREND KAT KOWALSKI

seen circumstances before or during the birth of their child, they are often forced to make a hasty decision.

"Planning is so important because families often need to make decisions swiftly, and discussing their options beforehand eases the decision-making," says Kat, who is helping to spearhead a perinatal palliative care program at Johns Hopkins Children's Center.

Although she is not a clinician, in her role Chaplain Kat is able to translate medical information to families in a way they can understand. Her unique understanding of situations allows her to speak to previous experiences and ask questions the family may not know to ask.

Chaplain Kat's goal is simple: to help families know that their child's life was meaningful. The validation that their child was here, even if only for a brief amount of time, is something that brings comfort to many parents. She remembers well a final wish by parents to take their child to the beach, so she brought the beach to them—complete with shells and the sound of ocean waves right in their hospital room.

"The impact that one little spirit can have on a family, doctor or staff member is remarkable," she says.

Her support does not end when the

family leaves the hospital. She often communicates with them on their journeys through grief. Whether it be officiating funerals or being an open ear, Chaplain Kat's role extends far beyond the walls of the hospital.

Although the experiences that Kat goes through may be stressful, she says it is the "resiliency of the human spirit" that inspires her.

"Helping to make horrible situations better is what keeps me going," she says.

Interestingly, Kat's connection to Johns Hopkins started long before she was employed here. As a child herself, she underwent the renowned "blue baby" operation, which was pioneered at Johns Hopkins Children's Center.

Although the impact Chaplain Kat has on families is astounding, the position depends on philanthropy, and thus it is not permanent. Funding is needed to maintain her role in the hospital. For more information on how you can support our pediatric palliative care program, please email hopkinschildrens@jhmi.edu. —HG 🍌



Watch Chaplain Kat, families and faculty and staff members share the importance of palliative care in the NICU: bit.ly/HoldingSpaceJHCC



Coffee for a Cause: Dunkin' Donuts Gives Back

By Amanda Leininger

DUNKIN' DONUTS HAS a long history of local philanthropy, but after supporting multiple organizations in the community for six years, the franchisees decided they wanted to make a bigger impact on the Baltimore community as a whole. Additional conversations with their marketing agency, Alliance Marketing Partners, led Baltimore-area Dunkin' Donuts locations to Johns Hopkins Children's Center—a children's hospital they previously supported with food and coffee donations at the annual Mix 106.5 Radiothon.

Wanting to involve the community in their efforts, Dunkin' Donuts approached the Children's Center with the idea of an annual iced coffee day—where \$1 from every large iced coffee purchased on a certain day would be donated to support the hospital. A first local event of its kind for both Dunkin' Donuts and the Children's Center, Iced Coffee Day 2016 successfully raised \$11,000 to support patient care.

Excited by the positive response from the community in their first year and hoping to increase their impact, Dunkin' Donuts extended Iced Coffee Day to two days in 2017—raising \$30,000 in its second year, nearly tripling the first year's total.

"We've received a lot of positive feedback from our franchisees and crew members who really felt they were making a big difference," says Colleen Krygiel, field marketing manager, Dunkin' Brands. "I think getting to see the check presentation from the first year and seeing where the money goes

and the impact it has really inspired our crew."

The inspiration extended to faculty and staff members at Johns Hopkins Children's Center, too.

"As one of the countless faculty and staff who care for kids at Hopkins each day, I can't tell you how good it feels to walk into my neighborhood Dunkin' Donuts on Iced Coffee Day and witness firsthand this incredible giving spirit and support from our community," says pediatric intensivist Sapna Kudchadkar.

In addition to their annual Iced Coffee Day, Dunkin' Donuts has provided integral grant funding through their Joy in Childhood Foundation for child-friendly environmental enhancements, equipment for the Division of Nephrology and Camp All Stars—a therapeutic camping program

for patients with kidney disease. Their total donations to the Children's Center exceeded \$80,000 in the first two years.

"We are extremely honored to have the opportunity to work with Johns Hopkins Children's Center year after year for a cause we are all so passionate about," says Parag Patel, Dunkin' Donuts franchisee and head of the Dunkin' Donuts Baltimore Advertising Committee. "We believe it's important to give back to the communities we serve in a meaningful way, and we look forward to continuing our relationship with Johns Hopkins to help make a difference in all patients' lives." 🍌



Save the date for Dunkin' Donuts' third annual Iced Coffee Days: May 10 and 11, 2018.

Local Dunkin' Donuts representatives present a \$30,000 check for funds raised through their second annual Iced Coffee Day.





At Johns Hopkins Children's Center, Every Therapy Dog Has Its Day



Kodi, with former Children's Center nurse Donna Buscemi at left, brings a smile to a young patient and mom.

YOU MAY NOT expect to see a dog in the halls of a hospital, but for patients and staff at Johns Hopkins Children's Center this is a regular occurrence. Donna Buscemi and her Weimaraner, Kodi, are among 16 pet therapy teams that lift the spirits of patients and families—and staff—during their visits to the hospital.

Buscemi worked in pediatric nursing at the Children's Center for 40 years before retiring in January 2018. What started as visits on her days off with her dog Talie have since turned into regular appearances with Kodi.

Whether it be snuggling in bed with kids watching TV or taking walks around the hospital, Kodi is ready for anything. Kodi visits with different patients for two hours before returning home to take a long nap—her favorite activity.

Although Kodi does not visit every day, patients eagerly await the time they get to spend with her. Buscemi credits

the sense of normalcy that Kodi brings to the hospital setting.

"Most kids have dogs at home that they miss but can't come to the hospital," she says. "It makes them feel better and more like regular kids."

Even five to ten minutes make a world of difference. For Kodi, this is no dog and pony show. She often stays with patients while they are going through some of the most difficult parts of their hospital stay.

"I remember Kodi laid in bed with one little girl while she got an IV," says Buscemi. "She had one arm around Kodi while the nurse inserted her IV into the other arm."

And other staff members note the impact dogs like Kodi can have on patients. "If I could have a pet therapy dog here every day, I would," says Child Life Specialist Lindsay Sutter. "The distraction that allows our kids to forget

"I love this place. I couldn't not be involved after retirement."

— DONNA BUSCEMI

what they're going through, even if it's for a brief moment, is invaluable."

Although Buscemi is now retired, she expects to keep bringing Kodi back for visits.

"I love this place, I couldn't not be involved after retirement," she says.

Buscemi and Kodi received special training from Pet Partners, a nonprofit organization that trains and registers therapy dogs. Kodi has been visiting patients for over two years now. —HG 🐾



For more information on our pet therapy program, email Jan Jaskulski at jjaskul@jhmi.edu or visit petpartners.org.



Boogie-ing for the Kids at Johns Hopkins



WALKING INTO JOHNS Hopkins Children's Center on a Saturday, you may not expect tutus, dancing, life-sized Jenga and lip-sync battles in the lobby, but on Nov. 11 that's exactly what you would have seen. At the first-ever Miracle Network Dance Marathon in the country to take place in a children's hospital, 97 registered dancers stayed on their feet for six hours at Baltimore Boogie.

Members of the Teen and Children's Council (TACC) started Baltimore Boogie, the Children's Center's inaugural community dance marathon event, as a way to fundraise for the hospital.

"After two successful proms, we decided to try something new. One of our advisers suggested a dance marathon and we were all happy to come together to start planning," says TACC member Brenna Hohl.

Setting a goal of \$5,000, they spent a year working with their staff advisers to solicit sponsorships, plan activities and recruit members of the Johns Hopkins and greater Baltimore communities to attend their first dance marathon.

On the morning of the event, TACC members and staff advisers learned the line dance they would teach to other dancers throughout the event and helped set the stage for hours of activities, including Oreo races, Zumba and face painting.

Even Tina Cheng, Johns Hopkins Children's Center co-director, and Patrice Brylske, director of Child Life Services, joined in the fun playing life-sized Hungry Hungry Hippos.

"When they invited me to Baltimore Boogie I didn't know what to expect. I'd been to our collegiate dance marathons but was excited to see the innovative way we'd incorporate a dance marathon into our hospital," says Cheng. "It was incredible. Seeing our inpatients with their IV poles smiling while interacting with members of the community was extremely touching. It's truly humbling to see our former patients so passionate about giving back."

After six hours on their feet, TACC members and patient ambassadors lined up to reveal whether or not they'd hit their goal. From cents to dollars, one by one they raised their posters to show their numbers. Cheers, applause and even some tears filled the room at the number that far exceeded their \$5,000 goal: \$18,395.01—the penny symbolic of the year of the event.

"At that moment, I felt proud to be a part of something bigger than myself, supporting kids and families who are going through a hard time in their lives," says Hohl. "I feel very lucky to be a part of a council that is making a difference for kids in situations similar to ones we all were in at one point in our lives."

And that difference was demonstrated by more than just an impressive dollar amount.

"The best part of the night? The patients—some of them inpatients—and parents who came up to thank us. You could really tell how much the event meant to them. I think that's what it's all about," says TACC member Stephanie Turner. —AL 🍌



Save the date for the second annual Baltimore Boogie on Nov. 10, 2018.



Teens participate in the hourly line dance at the inaugural Baltimore Boogie event.



Team Hopkins Kids celebrates at the race tent on the morning of the Baltimore Running Festival.

CREDIT: KATHRYN DULNY

Team Hopkins Kids Runs in the Baltimore Running Festival

AFTER 10 YEARS of running in the Baltimore Running Festival and raising nearly \$1 million to support Johns Hopkins Children's Center, Team Sadie, named in memory of a former Children's Center patient, officially "passed the baton" to the Children's Center—which created its own charity race team last year. On Oct. 21, more than 275 runners joined the first-ever Team Hopkins Kids to run (or walk!) all the races in the Baltimore Running Festival.

“We were grateful to have an opportunity to give back in our own small way through the race.”

— PARENT DAN D'ORAZIO

Months of training and fundraising culminated in a bustling team tent early Saturday morning, when patients, families, physicians, nurses and staff members arrived to run and celebrate together with the common goal of supporting the Children's Center.

The event provided a meaningful opportunity for physicians, nurses and other clinicians to interact with patients and families, boosting morale for Children's Center staff

members. This sentiment was echoed by many of the patient families in attendance, including Dan and Brandie D'Orazio. The D'Orazios ran on race day—which happened to be their 11th wedding anniversary—in honor of their son Leo, who was born with a rare genetic disorder.

“For years, we have heard so many wonderful stories about the Children's Center. Last year, with the birth of our fourth child, Johns Hopkins became a deep part of our community. While Leo has faced many challenges, we could not imagine care without the Children's Center,” says Dan. “We were grateful to have an opportunity to give back in our own small way through the race. It was especially gratifying to be able to earmark the donations to the Child Life team who has meant so much to our family.”

The inaugural Team Hopkins Kids raised more than \$178,000 for 20 divisions and programs at the Children's Center. Funds raised can be designated to any area of the Children's Center that runners like, allowing patient families to raise money for the division that took care of their child, or for care teams to raise funds for their own programs and research. —AL 🍌

29th Annual RADIOTHON Breaks Records

ON FEB. 22 and 23, the lobby of The Charlotte R. Bloomberg Children's Center building transformed into a buzzing event space for Mix 106.5's 29th Annual Radiothon. For two days, Mix 106.5 DJs Reagan Warfield, Jon Boesche, Kaite Rose, Maria Dennis and Priestly shared stories of Johns Hopkins Children's Center patients, families and staff on the air, inspiring Baltimore community members to donate. More than 500 volunteers answered calls, contributing to the most successful two-day event to date. Raising more than \$1.1 million to benefit patient care, research and programs at the Children's Center, this year's success brings the total amount raised through the Mix 106.5 Radiothon to more than \$21 million.

As the longest running Children's Miracle Network Hospitals radiothon in the country, the 30th annual radiothon on Feb. 21 and 22, 2019, promises to be the biggest yet. —AL 🍌



Join Team Hopkins Kids at the 2018 Baltimore Running Festival on Saturday, Oct. 20. Register today at support.hopkinschildrens.org/run or email hopkinschildrens@jhmi.edu for more information.



For more information on getting involved through corporate sponsorships, sharing your story or volunteering, please email hopkinskids@jhmi.edu.



Basking in the glow of the Children's Center, from left, chief residents Jennifer Miller, Suzanne Rossi and Olivia Widger.

CONNECT WITH THE JOHNS HOPKINS PEDIATRIC RESIDENCY PROGRAM VIA –

Facebook: [/JHPedsResidency](#)
Twitter: [@JHPedsResidency](#)
Instagram: [@JHPedsResidency](#)

Three Chiefs Make a First

THERE IS LITTLE if anything in the literature on the benefits of having three co-chief residents in charge of an academic residency program. For Johns Hopkins Department of Pediatrics' first chief resident trio in its long storied history, however, the combination surely fuels a significant amount of energy and activity. Mock interviews for fellowship and job opportunities, simulation curriculums for lumbar punctures and airway skills, resident wellness events, and expanding the residency program's social media presence are among the initiatives led by chief residents Olivia Widger, Suzanne Rossi and Jennifer Miller. And that's not all.

"We are working with program leadership to increase residents' access to mentorship opportunities in the fields of research, quality improvement and safety, global and local advocacy, and medical education," says Widger. "In addition, we have expanded our role as educators and mentors for medical students rotating through pediatrics."

Following their chief year, Miller will return to her neonatology fellowship at Johns Hopkins, and Rossi to her allergy and immunology fellowship at Johns Hopkins. Widger, who plans to stay in general pediatrics, will return to the pediatric emergency department at Howard County General Hospital.—GL 🍌

Upcoming Events and Campaigns

Help support Johns Hopkins Children's Center at an upcoming fundraising event or corporate campaign.

* If you would like to know more or help with any of the events below, please email hopkinschildrens@jhmi.edu.

MAY

- 1–31 Costco Campaign
- 7–27 Wawa Campaign
- 10–11 Dunkin' Donuts Iced Coffee Days

JUNE

- 1–Aug. 2 Dairy Queen Campaign
- 2 Colleen's Biliary Atresia 5K and 1-Mile Fun Run/Walk
- 4 Griffith Energy Services, Inc. 23rd Annual Golf Tournament
- 8 TowerCares Foundation 36th Annual Tower Classic Golf Tournament
- 8 21st Annual Zachary Meehan Memorial Golf Tournament
- 24–July 7 Giant Food Stores Campaign
- 25 Courtney Quinn Memorial Rock and Roll Swim Meet
- 25 Hayden's Heart Heroes 13th Annual Golf Tournament

JULY

- June 1–Aug. 2 Dairy Queen Campaign
- June 24–July 7 Giant Food Stores Campaign
- 13 Elkridge Furnace Inn's Bastille Day Wine Tasting
- 23 Cameron Diamond Memorial Swim Meet

AUGUST

- June 1–Aug. 2 Dairy Queen Campaign
- 2 Dairy Queen Miracle Treat Day
- 3–5 Ace Hardware Bucket Campaign
- 27–Sept. 23 Walmart Campaign

SEPTEMBER

- Aug. 27–Sept. 23 Walmart Campaign
- 10 25th Annual Ledo Pizza Golf Classic
- 17 Doug Miller Sr. Memorial Golf Invitational Hosted by Carroll Independent Fuel

OCTOBER

- 19 The Kendall Burrows Foundation 5th Annual Footloose Gala
- 20 Baltimore Running Festival

NOVEMBER

- 10 Baltimore Boogie
- 11–24 Giant Food Stores Campaign
- 24–Dec. 24 Ace Hardware Round Up Campaign
- 28 Giving Tuesday

DECEMBER

- Nov. 24–Dec. 24 Ace Hardware Round Up Campaign
- 1–25 Edwards Landing Light Show

FEBRUARY 2019

- 19 One Skate for Many Hearts
- 21–22 30th Annual Mix 106.5 Radiothon

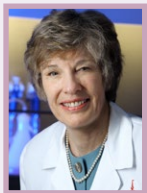
*Dates are subject to change. This is not a comprehensive list of all events and fundraising campaigns benefiting Johns Hopkins Children's Center. If you'd like more information on planning a fundraising event, please email hopkinschildrens@jhmi.edu.



Honors & Awards



Pranita Tamma received the 2017 Pediatric Scholarship Award from the Society of Healthcare Epidemiology of America (SHEA) for her contributions to the study of antimicrobial resistance. Presenting the award to Tamma, right, is Sara Cosgrove, SHEA president.



Kathleen Schwarz has been selected by the North American Society for Pediatric Gastroenterology, Hepatology and Nutrition for its 2017 Shwachman

Award for her lifelong scientific and educational contribution to the field of pediatric gastroenterology.



Tina Cheng, Given Foundation Professor of Pediatrics and director of the Department of Pediatrics at The Johns Hopkins University School of Medicine, has

been elected to the National Academy of Medicine, one of the highest honors in health and medicine. Through its domestic and global initiatives, the National Academy of Medicine works to address critical issues in health, medicine and related policy.



Maria Trent has been selected president-elect of the Society for Adolescent Health and Medicine (SAHM) for 2018. Founded in 1968, SAHM is a mul-

tidisciplinary organization committed to improving the physical and psychosocial health and well-being of all adolescents through advocacy, clinical care, health promotion, health service delivery, professional development and research.



Janet Serwint was named the Academic Pediatric Association's (APA) Miller-Sarkin Mentoring Award recipient for 2018. The award recognizes the

contributions of an APA member who has provided outstanding mentorship to learners or colleagues, both locally and nationally, and serves as a model to others who aspire to mentor others as they mature.

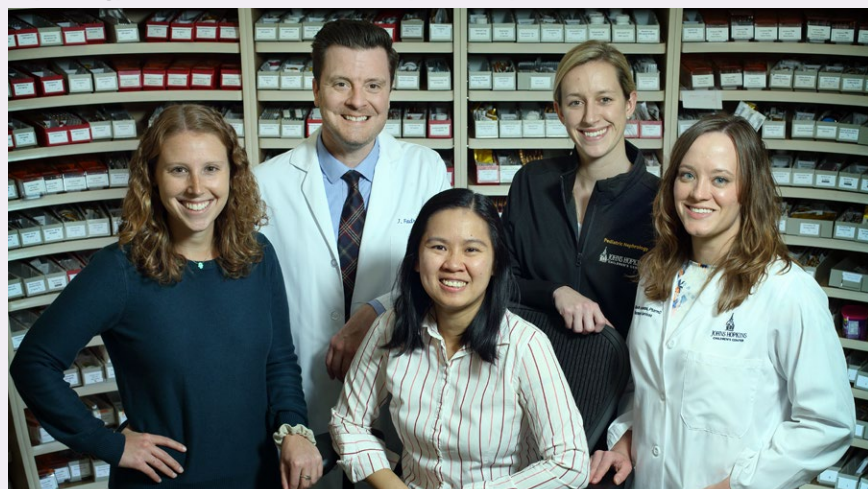


Robert Wood was installed as the new president of The American Academy of Allergy, Asthma & Immunology (AAAAI) for 2018. The AAAAI is the largest

professional membership organization for allergist/immunologists, other medical specialists and health care professionals with a special interest in the research and treatment of allergic and immunologic diseases.

Pediatric nephrologist **Jeffrey Fadrowski** and pharmacist **Elizabeth Goswami** were selected as the Minogue Award Circle of Honor winners by the Maryland Patient Safety Center for their submission "Hopkins NINJA: Nephrotoxic Injury Negated by Just-in-Time Action." For the last 12 years, health care providers and organizations from throughout the Mid-Atlantic region have been submitting solutions that improve quality and patient safety to the Maryland Patient Safety Center.

The Johns Hopkins NINJA team, from left, data analyst Erica Lander, pediatric nephrologist Jeffrey Fadrowski, clinical analytics specialist Elys Bhatia, pediatric nephrology nurse Emma Sexton, and pediatric pharmacist Elizabeth Goswami.





A Decade in Review

by Sue Mead, Parent Advisor

THE PEDIATRIC FAMILY Advisory Council (PFAC) just celebrated its 10th anniversary so it seems a natural time to reflect on how far we have come and where we are heading.

Since 2007, we have grown from a small council of 10-15 committed parents and staff to a robust council of over 60 members, most of whom are parents. We meet monthly to advance the core tenants of patient- and family-centered care: respect and dignity, information sharing, participation and collaboration. Today we have 21 parent advisors on 39 hospital committees ranging from Infection Control to the Division Directors Meeting.

The PFAC is now focusing on its new two-year goals. The first involves meeting the needs of our long-term patients and families. Did you know that over 30 percent of our patients in the pediatric ICU have been there for more than six months? We need to do a better job of meeting our patients and families' physical and emotional needs, so they can better support themselves and each other during this long experience. Some initiatives underway include expanding more accessible and affordable food and beverage options for our families, continually looking at parking costs and creating a safer environment.

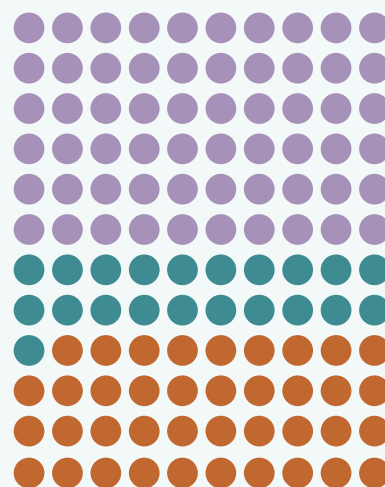
Transition of care has become a hot topic for us. We recognize transitioning from pediatrics to adult services can

be stressful and challenging. How do we as an institution promote smooth transitions, and what can we do to make this a positive experience for all? We started the conversation with a provider-parent panel pediatric Grand Rounds during Patient- and Family-Centered Care Week in March.

Finally, how can we improve communication around here? We produced a new pediatric patient and family handbook, audited admission packet information and created a "Top Tips" video that airs during Wednesday Bingo, which encourages families to use their room communication boards and to participate in Family-Centered Rounds. We have also consulted on a new communication tool called Communication CPR for our providers.

Many of us have been on this journey since the beginning and are so proud of the work our council has contributed. We are a living testimony that every voice matters. 🌟

The Pediatric Family Advisory Council



60 members
21 parent advisors
39 hospital committees

Members of the Pediatric Family Advisory Council



Help Hopkins Kids

Like to run?

TEAM HOPKINS KIDS



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

October 20, 2018

Keep the fun going
at the best postrace tent
on Rash Field

Register:
support.hopkinschildrens.org/run



Like to dance?

Baltimore BOOGIE

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

November 10, 2018

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

Register:
[events.dancemarathon.com/
event/JHCC2018](http://events.dancemarathon.com/event/JHCC2018)



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



JOHNS HOPKINS
CHILDREN'S CENTER

Hopkins Children's

Office of Communications & Public Affairs

901 S. Bond Street / Suite 550

Baltimore, MD 21231

The Charlotte R. Bloomberg Children's Center

- Opened in 2012
- 205 private rooms with sleeping accommodations for parents
- Acoustical ceiling tiles and rubber flooring help create a quiet healing environment
- Supersized sculptures and literary themed art distract from the hospital experience
- Family amenities like on-demand meals, family lounges and multiple play rooms
- Expanded, easy-to-access Pediatric Emergency Department
- Dedicated pediatric trauma bays
- 40-bed Pediatric ICU
- 45-bed Neonatal ICU
- 10 state-of-the-art pediatric surgical suites

