Winter 2018

Guardians for Physicians

Stories of Discovery, Innovation and Care from St. Louis Children's Hospital

pages 4 & 12

Pediatric orthopedics

Innovation for complex care

Children's HOSPITAL • ST. LOUIS
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Washington University in St. Louis
Physicians

Guardians

Stories of Discovery, Innovation and Care
from St. Louis Children's Hospital

St. Louis Children's Hospital
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StLouisChildrens.org

MAGNET RECOGNIZED AMERICAN NURSES CREDENTIALING CENTER

BEST CHILDREN'S HOSPITALS U.S.News RANKED IN 10 SPECIALTIES 2017-18

To our physician partners:

As pediatric specialists, each making complex contributions toward innovation, discovery, technology and compassionate bedside care, our collective mission is quite simple: **protect children from the things that threaten to interrupt their childhood.**

Together, we push the boundaries of what's possible because what's at stake is the very heart of our world: our children.

This is a personal mission. Who among us is not driven by the love of a child, grandchild, niece, nephew or beloved family friend?

To them, we are accountable. And inspired by them, we push ourselves and each other for better medicine, higher standards, and most importantly, the ability to provide every child and their family with the **uninterrupted** childhood they deserve. A childhood free of fear.

At St. Louis Children's Hospital and Washington University School of Medicine, we celebrated the birth of baby Jackson—twice; first at 25 weeks gestation for an in utero surgical correction of spina bifida, and then three months later when he arrived to meet his mom for the first time.

In addition to a 12-story expansion spanning all of our hospital services, our Women & Infants program opened a new bed tower in January, designed to care for the most complex prenatal and newborn challenges in our region.

Chimeric antigen receptor T cell (CAR-T) immunotherapy is now available at select centers across the U.S., including St. Louis Children's Hospital, providing hope to families with devastating cancer diagnoses, where at one time the chances of survival were extremely low. By the end of 2018, we will also be offering metaiodobenzylguanidine (MIBG) therapy for cancers like neuroblastoma.

Together, we will dig deeper, we will aim higher, and we will find cures that return children to the playground, to school and to the everyday magic of childhood. Better still, we will challenge ourselves through personalized medicine to prevent and eradicate cancer, heart disease and all of the most catastrophic illnesses that threaten our children.

Together, we are Guardians of Childhood™ and we will prevail.

There is no other option.

With gratitude,

Joan Magruder
President
St. Louis Children's Hospital

Gary Silverman, MD
Pediatrician-in-Chief
Washington University
School of Medicine

St. Louis Children's Hospital—
Washington University
Department of Orthopedics

Spotlight on Pediatric Orthopedics by the numbers

for year ending 2017

711
Ponsetti treatments for clubfoot
(age 1 and younger)

28,804
Pediatric orthopedic outpatient visits

159
Pediatric spine procedures

<1%
Pediatric spine procedure readmission rate within 30 days

<1%
Pediatric spinal fusion infection rate

400+
Active research studies focusing on advancing orthopedic care
(pediatric & adult)

13
Board-certified pediatric orthopedic specialists
(includes candidates)

59
Board-certified orthopedic specialists
(pediatric & adult; includes candidates)

8
Orthopedic residents per year

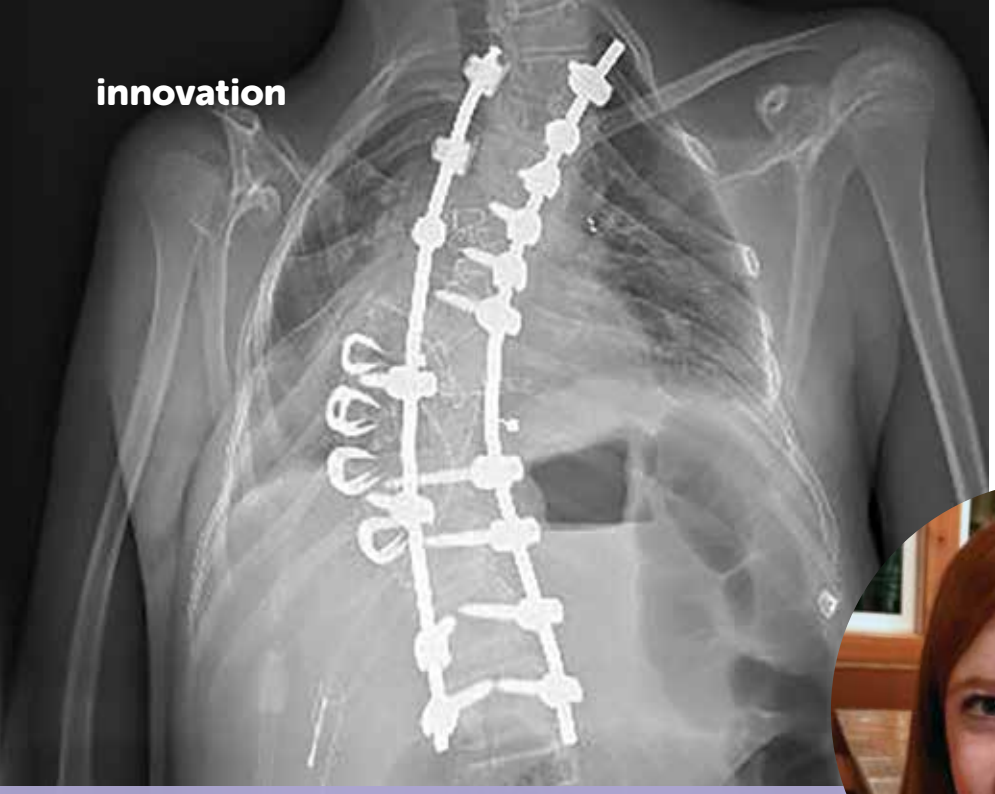
35
Total orthopedic residents

20
Orthopedic fellows

916
Pediatric orthopedic inpatient admissions

2,390
Pediatric orthopedic surgeries

$7.5 million
National Institutes of Health funding for orthopedics
(within the Department of Orthopedic Surgery)



Julia Wynne

A first at Children's Hospital

Patient with Fontan fenestration undergoes spinal fusion

Julia Wynne has dealt with a wide variety of medical issues with fortitude and grace since the day she came into the world. The 16-year-old from Montana was born with a complex medical condition called VACTERL.

An acronym for a series of congenital defects, VACTERL includes vertebral, anal, cardiovascular, tracheal, esophageal, renal and limb deformities. Children diagnosed with the disorder have at least three of the seven defects. Julia had five, including a significant heart defect in which the valve that regulates blood flow from the heart to the lungs failed to develop. While still an infant, Julia underwent a delicate procedure called Fontan fenestration, during which cardiac surgeons created a tunnel from her heart to the lungs to restore oxygenated blood flow to her body.

"Julia had numerous surgeries on her heart, esophagus, trachea and hand," says Julia's mother, Renee. "She also was diagnosed with scoliosis, but it paled in comparison to the heart and other issues we faced when she was younger."

Although the family moved from St. Louis to Montana when Julia was 6 months old, they continued to return for ongoing care. Over the years, Julia underwent abdominal and open-heart procedures at St. Louis Children's Hospital.

Then, in 2010, doctors in St. Louis and in Montana started closely monitoring Julia's scoliosis. As she grew older, her spine began

to curve significantly. If the spinal curvature continued to progress, Julia's cardiologist in Montana felt that the scoliosis would be more disabling to her lifestyle than even her heart problems.

Julia was referred to Washington University orthopedic surgeon Scott Luhmann, MD, who specializes in pediatric and adolescent spine surgery at Children's Hospital. He initially recommended vertebral stapling, a procedure that involves stapling the growth plates of the vertebrae to minimize the growth rate. By 2015, however, Julia's scoliosis had progressed from 40-degrees to 70-degrees out of alignment. Dr. Luhmann then recommended spinal fusion. In May 2016, Julia and her family returned to Children's Hospital for the spinal fusion.

It was a brave decision since Julia's heart condition added to the surgery's risk. "The surgery is performed while patients are in a prone position, which is taxing on anyone's cardiovascular system. Over an extended length of time, the heart begins having problems beating and pumping blood," says Dr. Luhmann. "With her congenitally malformed heart, that meant Julia had even greater risk of developing cardiac problems."

The solution was to perform the surgery as quickly and efficiently as possible. In preparation, Dr. Luhmann worked with multiple care teams, including cardiology, anesthesia, pediatric intensivists and surgical staff to develop Julia's surgical plan. He also contacted Julia's pediatric cardiologist in Montana. Beyond this careful preparation, Dr. Luhmann cites several reasons why he and his colleagues were up to the task.

"We have particular skill in putting pedicle screws into the spine freehand rather than using imaging to place them, which slows surgery considerably," he says. "In addition, a quick and efficient dissection with diligence to cauterizing all bleeders and giving the drug tranexamic acid—shown in studies to decrease intraoperative blood loss—minimized the need for Julia's heart to pump harder due to reduced blood volume. During the surgery, Julia lost only 200 CCs of blood; most units of blood are about 250 CCs. Basically, throughout the surgery we were careful but didn't waste time."

"The solution was to perform the surgery as quickly and efficiently as possible."

The efficiency paid off. A surgery that normally would take four or more hours took only three "skin to skin," a 25-percent decrease in the amount of time Julia needed to be in a prone position.

And the surgery was a success. Julia's 70-degree curvature was reduced to 45 degrees.

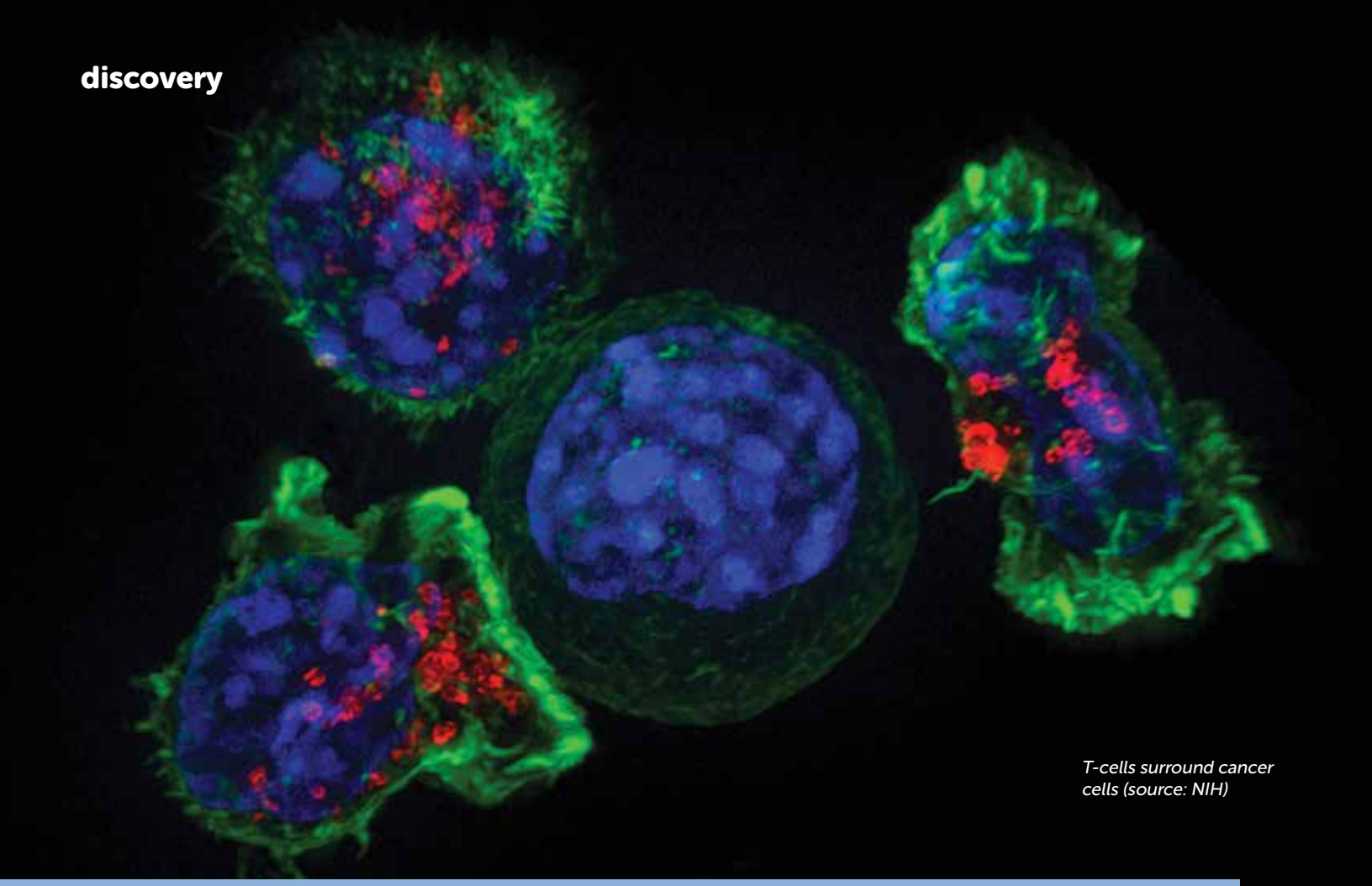
"I liked that Dr. Luhmann talked to me, and I knew exactly what would happen at all times," says Julia. "Even after surgery, he and his colleagues kept checking on me. A lot of kindness was shown throughout my time in the hospital."

Adds Renee, "Every person treated my daughter with honesty and respect. It was an incredibly difficult surgery, but the team was realistic about it from the start, and Julia knew what to expect."

Two months after surgery, Julia went biking in the countryside for 12 miles with her family. Now in high school, she is pursuing her interests in speech and debate, reading and writing, and theater.

"Words cannot express the gratitude we feel to St. Louis Children's Hospital and to all who have continually cared for my daughter with such competence and kindness. Dr. Luhmann and all of the physicians and care teams throughout the years have been an incredible blessing in my daughter's life," says Renee.

Dr. Luhmann meets with Sydney King, a scoliosis patient who received a spinal fusion in 2017. (photo: Steve Dolan)



T-cells surround cancer cells (source: NIH)

Siteman Kids at St. Louis Children's Hospital among first U.S. pediatric centers to offer

CAR-T immunotherapy

Siteman Kids at St. Louis Children's Hospital is now one of only 19 pediatric centers in the U.S.—and the only pediatric center in the region—offering this breakthrough cancer treatment. CAR-T immunotherapy harnesses a child's own immune system to fight off cancer. The Federal Drug and Administration (FDA) approved the therapy in August 2017 as a defense against an aggressive form of acute lymphoblastic leukemia (ALL) in children who have not responded to standard therapies or whose cancer has relapsed.

In cancer patients, specialized immune cells called T-cells lose the ability to recognize and attack cancer cells. With CAR-T therapy, a patient's own T-cells are isolated from the blood. Those cells then are genetically altered—or supercharged—enabling them to home in on cancer cells and destroy them. During this process, specialized receptors called chimeric antigen receptors are put onto patients' T-cells, thus the name CAR-T cells. When the immune cells are infused back into patients, these receptors allow the cells to recognize and attack tumor cells, turning the T-cells into cancer-fighting machines. These supercharged cells also stay alive and circulate in the patient's body for years.

Washington University pediatric stem cell transplant physicians with extensive experience in treating leukemia and using cellular therapy will administer the CAR-T immunotherapy at Siteman Kids at St. Louis Children's Hospital.

"If it looks like the leukemia is not responding to treatment or relapsing, the CAR-T cells can attack it effectively using a different mechanism than chemotherapy," explains Washington University pediatric hematologist/oncologist Shalini Shenoy, MD, interim director of Siteman Kids and the stem cell transplant program at St. Louis Children's Hospital. "We think this is just the first step for this kind of therapy. If we can make a patient's own cells smart enough to attack more cancers—and we think we can—we believe we'll be able to tackle many more types of cancer with immunotherapies in the future."

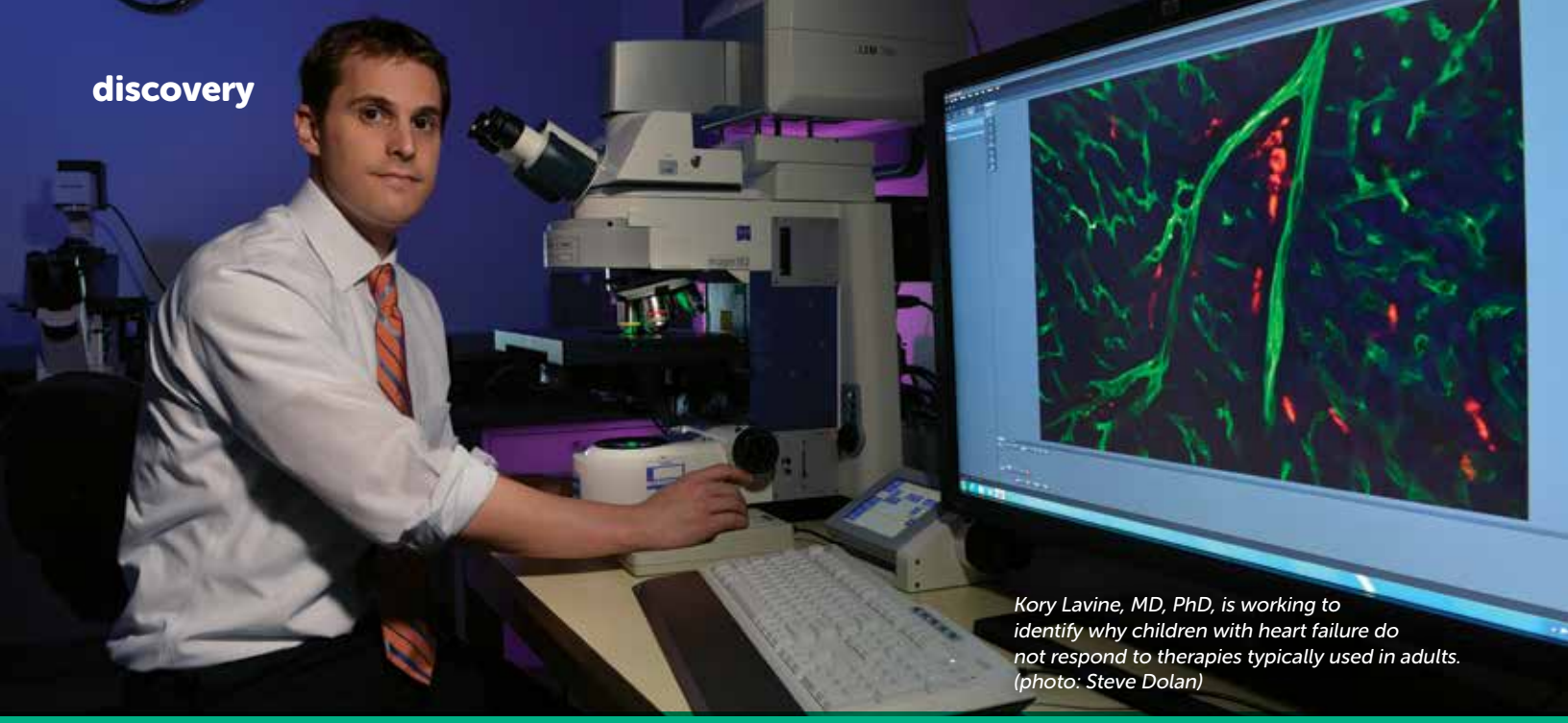
Clinical trials have shown that in children with aggressive B-cell acute lymphoblastic leukemia who have not responded to standard therapies or have relapsed, CAR-T therapy has achieved more than an 80 percent remission rate. Some patients have remained in remission for more than five years. While the treatment is considered a major advance in cancer treatment, CAR-T therapy induces a heightened immune response that can lead to a range of side effects, some of which can be severe.

> "Siteman Kids at St. Louis Children's Hospital is equipped to manage the therapy, which is why our center is among the first to offer it."

"Because of the wide range of potential side effects, it's important that patients undergoing CAR-T therapy are watched closely by physicians and care teams with extensive experience in blood cancer therapy and stem cell transplantation," says Dr. Shenoy. "Siteman Kids at St. Louis Children's Hospital is equipped to manage the therapy, which is why our center is among the first to offer it."

The future of CAR-T therapy at St. Louis Children's Hospital

Research into the potential of CAR-T therapy continues. The Children's Discovery Institute (CDI)—a research partnership between St. Louis Children's Hospital and Washington University School of Medicine—has awarded $360,000 for further investigation into these life-saving therapies. Dr. Shenoy has joined John DiPersio, MD, PhD, the Virginia E. and Sam J. Golman Professor of Medicine in Oncology and deputy director of the Alvin J. Siteman Cancer Center at Barnes-Jewish Hospital and Washington University School of Medicine; Matthew Cooper, PhD, an instructor in medicine; and Robert Fulton, an assistant professor of genetics and a scientist at the Elizabeth H. and James S. McDonnell III Genome Institute, all at the School of Medicine, in this effort. The medical team will use the CDI funding to develop an "off-the-shelf" CAR-T therapy that prevents CAR-T cells from attacking each other or non-cancer cells in the patient; strategies to overcome a life-threatening side effect of CAR-T therapy called cytokine release syndrome (CRS); and a novel "suicide gene" that will track CAR-T cells in the body using a unique form of positron emission tomography (PET) scanning and eliminate them in the case of severe toxicity cells, if needed.



Kory Lavine, MD, PhD, is working to identify why children with heart failure do not respond to therapies typically used in adults. (photo: Steve Dolan)

Discovery advances understanding

of pediatric cardiomyopathy

In 2010, just two days before Christmas, Colleen and Mike Miller learned their 6-month-old daughter, Layla, suffered from dilated cardiomyopathy. As a registered nurse with cardiac care experience, Colleen Miller knew her family's life would never be the same.

"When the diagnosis was cardiomyopathy, we felt like we were given a death sentence," she says. "More than half of all children diagnosed don't live past age 5. If they do survive, it is a fluke or due to a heart transplant, and that is not a cure, since the life span of a new heart is only around 10 to 15 years."

Layla spent her first Christmas in the cardiac intensive care unit (ICU) at St. Louis Children's Hospital, and had many more hospitalizations, tests, medical and surgical procedures after that. The Millers' lives became filled with doctors' appointments, medication schedules and worry, knowing the whole time that a transplant loomed in their future. That time came in August 2014.

Unfortunately, Layla passed away after going into cardiac arrest during a cardiac catheterization meant to determine the readiness of her lungs to handle a new heart.

A recent discovery by Washington University cardiologist Kory Lavine, MD, PhD, and his collaborators, may be a step toward better understanding cardiomyopathy in children and eventually developing effective therapies. Their research, published in the *Journal of Clinical Investigation*, identified the underlying reason why children with heart failure do not respond to therapies typically used in adult patients.

Heart failure medications currently used in adults target a process called adverse remodeling, a common mechanism by which the adult heart responds to injury. Typical drugs such as beta blockers and ACE inhibitors function to halt or slow down the remodeling process, reducing scar deposition and maladaptive remodeling of cardiac tissue. Dr. Lavine's lab proved that adverse remodeling does not happen in children with heart failure. These findings provide a framework to understand why current treatments for heart failure do not work for children and signal that new approaches are needed.

Through a grant funded by the Children's Discovery Institute, a research partnership between St. Louis Children's Hospital and Washington University School of Medicine, Dr. Lavine's lab is beginning to develop new strategies for pediatric heart failure. The researchers are inserting genetic mutations identified in children with heart failure into translucent zebrafish. They then employ advanced imaging techniques to understand why each pediatric heart failure mutation results in cardiac dysfunction and screen for drugs that may serve as precision therapies to treat an individual child's mutation.

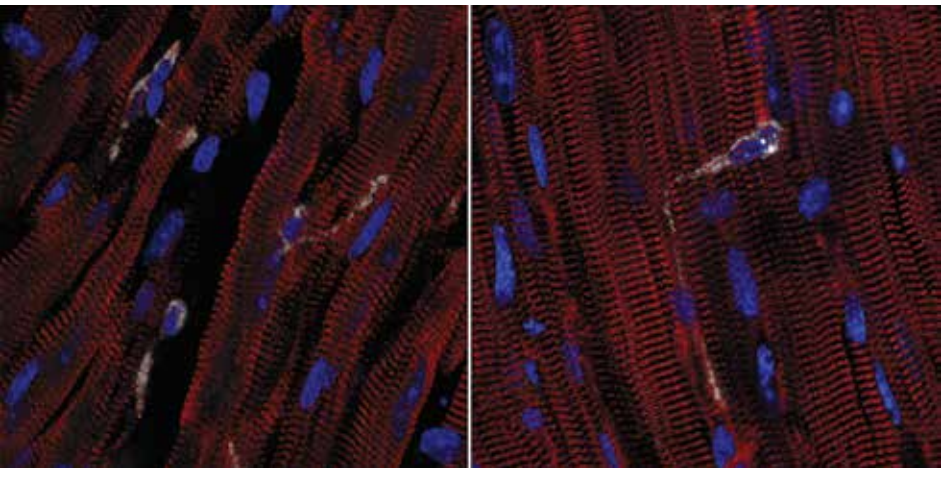
"We hope to get to the day when a patient gets diagnosed with heart failure and undergoes routine genetic screening. For children who carry a heart failure mutation, we hope to either have identified drugs that target their mutation or engineer a zebrafish line to better understand their disease and identify drugs with the potential to reverse the course of their illness," Dr. Lavine says.

"We were happy to assist Dr. Lavine in this study. His findings are intriguing as there are concerns that pediatric heart failure may not respond as well to medications used to treat adult heart failure," says Washington University pediatric cardiologist Charles Canter, MD, medical director of the cardiac transplant program at St. Louis Children's Hospital. "Dr. Kathleen Simpson and I plan to extend this work through the National Institutes of Health-funded Pediatric Cardiomyopathy Registry via an additional grant she recently received from the Children's Cardiomyopathy Foundation."

Since losing Layla, the Millers have worked to raise awareness of a condition that has no cure, limited treatment, and high mortality and needs more funding to find a cure. They also have channeled their grief into acts of kindness, such as purchasing a rocking chair for the cardiac ICU where they spent so much time. The chair has a plaque with Layla's name and a quote that has sustained the Millers through it all. It reads: "There is no foot too small that it can't leave an imprint on this world."

Layla's memory lives on through her parents, Mike and Colleen, who are working to raise awareness of pediatric cardiomyopathy. (photo: courtesy of family)

> "There is no foot too small that it can't leave an imprint on this world."



Heart macrophages and cardiomyocytes (source: Kory Lavine, MD, PhD)

Collaborative medical team performs

In utero surgery for spina bifida

A team of 35 medical professionals performs prenatal closure of a myelomeningocele. (photo: Tim Mudrovic)

In October, Washington University surgeons and physicians from St. Louis Children's Hospital and Barnes-Jewish Hospital collaborated to perform a prenatal closure of a myelomeningocele in a 25-week gestational-age fetus. In total, 35 medical professionals took part in the surgery that was the first of its kind at the Washington University Medical Campus.

"This was a significant event that has the potential for benefiting families throughout the Midwest," says Michael Bebbington, MD, MHSc, director of the Fetal Care Center of Barnes-Jewish Hospital, St. Louis Children's Hospital and Washington University. "Rather than traveling long distances, this advanced care now is available closer to home."

In years past, the standard of care for treating myelomeningocele was to perform neurosurgery, usually within 24 to 48 hours after birth. "The procedure involved separating the neural placode from the surrounding skin and placing it back into the spinal canal, then covering it with dura, fascia and skin," says Washington University pediatric neurosurgeon Jennifer Strahle, MD. "In recent years, however, evidence has shown that in some cases fetal surgery for myelomeningocele may improve neurological outcomes."

That was the finding of the Management of Myelomeningocele Study (MOMS), a randomized,

multicenter clinical trial sponsored by the National Institutes of Health comparing the outcomes of prenatal surgery with postnatal surgery. The results of the trial were published in the *New England Journal of Medicine* in February 2011.

"The MOMS trial showed that for a select group of fetuses, in utero surgery can result in three major benefits," says Dr. Bebbington, who participated in the clinical trial when he was at the Children's Hospital of Philadelphia. "One is that the high-brain herniation occurring as a result of the lesion is reversed, meaning the cerebellum migrates back up into a more normal position. Second, the need for shunting because of hydrocephalus is decreased by 50 percent compared to postnatal surgery. Finally, neurologic function may improve by up to two levels, which for some children means the difference between walking and not walking."

The surgery

Dr. Bebbington describes the October in utero surgery as a kind of ballet, with those present knowing their role and maneuvering through the operating room. In addition to the surgeons, those present during the three-hour surgery included a pediatric cardiologist, adult and pediatric anesthesiologists, a neonatologist, clinical pharmacist and a skilled team of operating room support staff.

At 25 weeks gestation, surgeons performed a prenatal closure on Jackson.

The first step in the surgery was Dr. Bebbington and Washington University pediatric surgeons Jesse Vrecenak, MD, and Brad Warner, MD, opening the maternal abdomen and positioning the fetus inside the uterus so that the small section of the spine where the lesion was located was visible.

"Once the fetus's back is in view, we identify the neural placode and separate it from the surrounding tissue and skin," says Dr. Strahle. "We position it back into the spinal canal and close the dura that normally covers the nerve roots. We then close a layer of muscle and skin to finish the surgery."

The final steps are to reconstitute the amniotic fluid and close the maternal abdomen.

"The success rates for this surgery are very impressive. Ongoing success and sustained good outcomes for each mother and child requires ready access to care, a team that can respond to questions and changes as they arise,

Pediatric neurosurgeons and surgeons begin the complex surgery on the 25-week fetus. (photo: Tim Mudrovic)

and guidance for families to help them anticipate milestones," says Dr. Strahle. "Our team at Washington University is as well-prepared to do this as any institution I have seen."

Immediately following surgery, there is a four-day protocol of post-operative care because of the risks of these surgeries, in particular fetal well-being and the possibility of contractions or infection. Furthermore, because of the nature of the surgery, the remainder of the mothers' pregnancy care changes. The mothers are on bed rest and need to live in close proximity to a large-enough medical center that has a specialist available to continue caring for them.

According to Washington University neonatologist Barbara Warner, MD, co-director of the Fetal Care Center, those involved in the in-depth screening process act as stewards of careful evaluation of benefit. "As with all surgeries, in utero myelomeningocele spina bifida surgery carries certain risks to the mother and the fetus, and we are careful to make sure the parents understand these before they make a decision," she says. "Parents can be easily swayed to want to do 'everything' for their baby, especially when new, life-changing procedures become available. In the vast majority of cases, myelomeningocele spina bifida is not a lethal congenital defect, but it can result in serious impairment and sequelae. All factors are weighed carefully before moving forward."

Approximately one out of every five families evaluated is identified as good candidates for the surgery. Regardless of the treatment option chosen, the highly integrated multispecialty program at Washington University is able to customize the best care for each individual family.

"The ability of St. Louis Children's and Barnes-Jewish hospitals to offer in utero myelomeningocele closure represents a tremendous leap forward for us in changing the lives of many children born with spina bifida," says Dr. Strahle.

A surgeon finds his calling

in the intricacy of hand anatomy

Growing up in Birmingham, Ala., Charles Goldfarb, MD, was the youngest son of a head and neck surgeon. His older brother and sister became lawyers, but Dr. Goldfarb initially thought he might follow his father's path. Then he was exposed to orthopedics, and he knew he'd found his calling.

"What had attracted me to head and neck surgery was the intricacy of the anatomy," says Dr. Goldfarb, chief of orthopedic surgery at St. Louis Children's Hospital and co-chief of the hand and wrist service at Washington University School of Medicine in St. Louis. "But the area around the hand also is very intricate, and from my perspective, those are the two most interesting anatomical areas of the body."

Another attraction was the link between orthopedics and sports. Dr. Goldfarb was a history major and a soccer player at Williams College in Massachusetts, proudly representing the school that gave the world Stephen Sondheim, John Sayles and perhaps the best mascot name in all of athletics: Ephelia the Purple Cow.

Sports have remained part of his professional life. When athletes need hand surgery, his phone rings.

"I like to say my practice has three parts, and it's an unusual combination," explains Dr. Goldfarb, who treats patients through Washington University Orthopedics as well as Children's Hospital. "One part involves taking care of kids, particularly kids with birth differences, which is where my love and my research lie. The next part is sports—athletes at all levels. It started because the St. Louis Rams football team needed a hand surgeon, and I have since been fortunate enough to take care of players from the St. Louis Blues hockey team, the St. Louis Cardinals baseball team, and other places, too."

Sydney Kendall sports a bright prosthetic arm, developed by Washington University engineering students in collaboration with Dr. Goldfarb. (photo: Robert Boston)

The third part of his practice involves treating more common hand problems, including carpal tunnel syndrome, broken fingers and lacerations.

"Dr. Goldfarb is a superb surgeon with an extraordinary range of talents," says Regis O'Keefe, MD, PhD, the Fred C. Reynolds Professor and head of the Department of Orthopaedic Surgery. "Children with the most complex hand deformities and elite athletes from all over the country come to St. Louis for his care. His commitment and personal qualities make him a role model for our residents and a trusted colleague and leader in our department."

Right place, right time

After Williams College, Dr. Goldfarb returned to Birmingham for medical school at the University of Alabama at Birmingham, where he fell in love with orthopedic surgery. In 1995, his residency brought him to the Washington University Medical Campus, just as Richard Gelberman, MD, became the inaugural head of the Department of Orthopedic Surgery. Dr. Gelberman had begun assembling a faculty of experts in several orthopedic specialties.

The late Paul Manske, MD, also a hand specialist, had directed the university's Division of Orthopedic Surgery before it became a department.

"His practice focused on kids with birth differences," Dr. Goldfarb says. "When I did my residency, I really liked almost every one of my rotations, but I had a special affinity for working with kids. And I've really been able to marry the hand work and the kids part. For a long time, my practice was mainly hand surgery, and I did some work with kids. Now it really leans strongly toward pediatric orthopedics and congenital hand surgery, though I still do treat some adults."

Dr. Goldfarb also treats patients at Shriners Hospitals for Children–St. Louis. It was at Shriners that he and Dr. Manske treated the child who still ranks as his most unusual case.

"He was from Central America, and he was born with three arms," Dr. Goldfarb recalls. "We were able to surgically combine two minimally functional arms and make them into a pretty good functional arm. It was an operation that never had been done before for a condition that never had been reported before. That young man still comes back and forth from Central America for follow-up appointments, and it's been really neat to watch him grow."

Dr. Goldfarb examines Layne Robinson's hand at a recent appointment. Layne returned to baseball after losing three fingers on his pitching hand in an ATV accident on his 15th birthday. (photo: Gara Elizabeth)

Using 3-D printers

With that child from Central America, Dr. Goldfarb was able to help build a functioning, biological arm. But that's not always possible. Birth differences and traumatic injuries mean a number of his patients need prostheses instead.

"Prostheses are heavy, and they're expensive," he says. "It used to be that we would force kids, at 6 months of age, to wear them, and the reality was that we could require that for a few minutes, but they would abandon them pretty quickly."

Then, a few years ago, a team of undergraduates at Washington University began working on a senior project in biomedical engineering. They contacted Dr. Goldfarb about building a prosthesis with a 3-D printer. They worked together to make a lightweight, powered prosthesis with fingers that move. Such devices also can be printed in bright colors.

"The concept that a prosthesis should look as natural as possible has been flipped on its head," he says. "Instead of trying to hide the birth difference a kid may have, these new 3-D printed prostheses almost say 'Look at me!' Although it's not quite ready for prime time, using these 3-D printers to make prostheses is advancing at a rapid speed."

Dr. Goldfarb and his wife, Talia, have three children ranging in age from 12 to 18. Whether one or more of them will follow their father and grandfather into medicine isn't yet clear. He'd be happy if any of them decide to pursue medicine, as long as they are happy in the choice—just as his father was happy one of his kids decided to go into medicine.

Pioneer in neurosurgical procedure honored at symposium

In September, the Department of Neurosurgery at Washington University School of Medicine held a symposium honoring Tae Sung Park, MD, the Shi Hui Huang Professor of Neurological Surgery and vice chairman of the department. More than 200 university and hospital executives, local political leaders and neurosurgeons from across the country attended the event, which recognized Dr. Park's long career helping children and the impact he has had on the field of pediatric neurosurgery.

As a result of his pioneering improvements to a neurosurgical procedure called selective dorsal rhizotomy (SDR), Dr. Park is *the* global expert in managing cerebral palsy spasticity. To date, he has performed more than 3,600 SDR procedures for patients from the U.S. and 73 other countries—by far the largest experience in the world.

Program one of 11 in nation to earn ACHD accreditation

The Washington University Adult Congenital Heart Disease Program at Barnes-Jewish and St. Louis Children's Hospitals has received accreditation from the Adult Congenital Heart Association (ACHA). The ACHA is a nationwide organization focused on connecting patients, family members and health care providers to form a community of support and network of experts with knowledge of congenital heart disease (CHD).

The Adult Congenital Heart Disease Program is the result of a collaborative effort between St. Louis Children's Hospital, Barnes-Jewish Hospital and Washington University School of Medicine to provide compassionate and comprehensive care to patients with CHD from birth through adulthood. This program has treated more than 2,000 adult CHD patients, making it one of the largest CHD programs in the country.

Individuals with CHD, the most common birth defect diagnosed in one in 100 births, are living longer. There are now 1.4 million adults in the U.S. living with one of the many different types of congenital heart defects that range among simple, moderate and complex.

"There are now more adults than children in the U.S. with CHD," said Mark Roeder, president and CEO of ACHA. "Accreditation will elevate the standard of care and have a positive impact on the futures of those living with this disease. Coordination of care is key, and this accreditation program will make care more streamlined for ACHD patients, improving their quality of life."

The collaborative program at St. Louis Children's Hospital, Barnes-Jewish Hospital and Washington University School of Medicine is one of 11 CHD programs in the country to earn ACHA accreditation.

Boy meets doctor who named his rare condition

Matthew Carothers, 13, a patient with Johanson-Blizzard syndrome, recently met the doctor who discovered the extremely rare congenital condition.

Short and thin for his age, Carothers first came to St. Louis Children's Hospital at age 5 for thyroid problems. Kathy Grange, MD, Washington University geneticist at St. Louis Children's Hospital, division chief of genetics and genomic medicine, recognized the syndrome, which causes pancreatic insufficiency. With diagnosis and treatment, his quality of life has greatly improved. Over the years, Dr. Grange said she wished she could discuss Carothers' medical issues with Ann Johanson, MD, who co-named the syndrome with mentor Robert Blizzard, MD, in 1972.

Unbeknownst to Dr. Grange, Dr. Johanson was living in the St. Louis area. Upon realizing this through Facebook connections, nurse practitioner Susan Davis invited Johanson to the medical campus.

Medical 3-D printing center opens

In January, St. Louis Children's Hospital opened a specialized 3-D printing center on the Washington University Medical Campus. The center has three printers and specializes in medical and pre-surgical modeling for adult and pediatric patient care via direct CT image remodeling, as well as custom parts for research and prosthetics. In addition, custom surgical guides, templates and other tools also may be produced for use in the operating room. Engineers design models based on surgical and research needs or print directly from a client's 3-D file model.

Symposium celebrates 50 years of pediatric neurosciences

In October, The Philip R. Dodge Symposium celebrated the leadership role St. Louis Children's Hospital and Washington University School of Medicine have held in pediatric neurosciences for the past 50 years. Experts in pediatric neuroscience from the United States and beyond attended the symposium, many of whom trained at Children's Hospital during the Philip R. Dodge era. Those attending learned a broad array of up-to-date basic, translational and clinical pediatric neurosciences information that served as a foundation for ongoing self-learning. Washington University neurologist Bradley Schlaggar, MD, PhD, neurologist-in-chief at Children's Hospital, served as the planning committee chair.

The symposium honored the advancements in pediatric neurosciences initiated by Philip R. Dodge, MD, and his ongoing legacy impacting the field. Dr. Dodge is considered one of the modern founders of pediatric neurology.

Elward earns national leadership award for patient safety

Alexis Elward, MD, St. Louis Children's Hospital associate chief medical officer and Washington University infectious diseases physician, received the Top-Performing Senior Leader Recognition from Children's Hospitals' Solutions for Patient Safety. St. Louis Children's Hospital is a member of this non-competitive national collaborative of children's hospitals. Member hospitals work to transform pediatric patient safety in pursuit of an urgent mission: to eliminate all serious harm across all children's hospitals in the United States.

Dr. Elward earned the award for being a catalyst for change, thoughtful about setting up teams for success, and relentless in the quest to reduce harm.

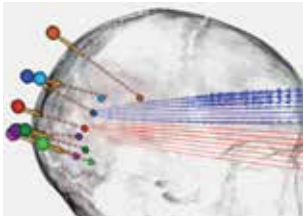
Transgender Center only center in region to offer multidisciplinary services

The newly established Washington University Transgender Center at St. Louis Children's Hospital provides care to children and adolescents who identify as a gender different from the sex they were assigned at birth.

The Center provides a safe, supportive and welcoming environment in which transgender people may receive the education, medical assistance and mental-health counseling they need to make informed decisions that will impact their well-being throughout their lives.

Services include puberty blockers, cross-sex (gender-affirming) hormone therapy, speech therapy, surgical referrals, legal services referrals, support letters for gender marker and name change, and connections to support groups and community resources.

Course offers comprehensive overview of SEEG



In August, Washington University pediatric neurosurgeon Matthew Smyth, MD, and neurologist John Zempel, MD, PhD, served as course co-chairs of a Washington University and St. Louis Children's Hospital Comprehensive Stereoelectroencephalography (SEEG) Course. The three-day course was designed to improve understanding of patient selection for SEEG, SEEG technique, and interpretation of SEEG data to improve the care and outcomes of children with medically refractory epilepsy.

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