RESEARCH in REAL LIFE
Concussion, Teen Vaping, Predicting Prematurity

Called to Serve | Racing to Find a Cure | 2018 Report on Giving
Tackling the biggest problems in maternal and child health

Last fall, in my first week on the job, I was exposed to a new word: ‘JUULing.’ What a shock to learn that while cigarette smoking in the United States is at an all-time low, an enticing and addictive new vaping device called JUUL is on the rise, especially among teenagers. I wasted no time alerting all my friends with tweens and teens!

In this issue of Packard Children’s News, we share some of the latest research on vaping, as well as on concussions and prenatatal testing. These are areas where Stanford physicians and scientists are making a huge impact for families everywhere.

Philanthropic funding is often the first step toward new discoveries. Donors like you help the best and brightest minds come together, take risks, and tackle the biggest problems in maternal and child health. Even small gifts applied at important leverage points can make a big difference, enabling innovative ideas to take root and grow.

Speaking of making a difference, we also celebrate our Auxiliaries! Their members have devoted their time, talent, and treasure to children’s health since the 1919 founding of the Stanford Home for Convalescent Children, the predecessor to the children’s hospital. Today the Auxiliaries are nearly 1,000 members strong and as active as ever. You might consider joining them!

Lastly, please join me in welcoming Paul King, the new president and CEO of Packard Children’s Hospital. I am thrilled to be working with him toward a brighter future for children and families.

If you come out to the Summer Scamper 5k, 10k, and kids’ fun run on June 23, please look for me and say hello! I would love to thank you in person for your support.

With gratitude,

Cynthia J. Brandt, PhD
President and Chief Executive Officer
Lucile Packard Foundation for Children’s Health
Called to Serve

New CEO of Packard Children’s feels right at home

BY JODI MOURATIS

WHEN PAUL KING STEPPED INTO THE ROLE of president and CEO of Lucile Packard Children’s Hospital Stanford and Stanford Children’s Health earlier this year, he knew he’d found his dream job.

“How do you not get excited and motivated to improve the lives of children?” he says with a grin. Having devoted his career of over 35 years to health care, King enjoys the mission of healing and discovering ways to better fight and treat disease, especially for children.

After graduating with a bachelor’s degree in business administration and economics from the University of Nebraska and a master’s degree in health care administration from the University of Iowa, King spent his early years as an executive in adult health care with the Mayo Clinic Scottsdale and the Samaritan Physicians Center in Phoenix.

“I started my career in health care because I was attracted to an industry filled with individuals who answer its call, who share a common characteristic, and that is an unrelenting pursuit of excellence,” King says. “In health care, good is not good enough. Even the best in the industry continue to try to find ways to do it better, safer, and more efficiently.”

King homed in on pediatrics when he was recruited to be president and CEO of the Pediatric Management Group, a 550-physician academic pediatric subspecialty group practice affiliated with Children’s Hospital Los Angeles.

“When you get in the hospital, you’re immediately hit with the mission,” King says. “When you see all these kids running around and what’s going on with them, it struck me at that moment that it was really the calling for me.”

He went on to serve as executive director of the University of Michigan C.S. Mott Children’s Hospital and Von Voigtlander Women’s Hospital in Ann Arbor. His management efforts helped the organization achieve the highest patient satisfaction and employee engagement levels in the entire University of Michigan health system.

In January, King was pleased to succeed Dennis Lund, MD, who served as our hospital’s interim president and CEO, and before that Christopher Dawes, who retired in 2018.

King sits at the helm of a hospital that is nationally recognized for clinical excellence in every pediatric specialty and a national leader for pediatric organ transplant and pediatric cardiology. It also has strong ties to Stanford University, providing access to some of the most innovative minds in medicine, science, and research.

Another advantage is that our hospital is one of the few in the country to offer obstetric, labor and delivery, newborn, and pediatric services all in one place.

King will use his strong leadership skills to guide the continued growth of Packard Children’s. He plans to focus on furthering advances in patient care and research and raising the bar on patient satisfaction.

“Childhood hospitalization is a lifelong memory. It’s a very powerful and impactful experience that we’re imprinting on a child and their family for the rest of their lives.... How can we make that a good story?”

© JIM CLARK/STANFORD UNIVERSITY
THEY HAVE QUITE THE FAN CLUB back home, and it’s not hard to see how they’ve inspired so many strangers to come together for a common cause.

The siblings are two of just five children in the United States who have Schimke immuno-osseous dysplasia (SIOD), an extremely rare form of dwarfism with a life expectancy of nine to 11 years. It can cause kidney failure, a weak immune system, and hip dysplasia.

“There was a one in 80 million chance both Kruz and Paizlee would have SIOD,” says their mother, Jessica. She and her husband, Kyle, have moved their family temporarily from Muscle Shoals, Alabama, to Palo Alto so their children have access to the best care and a chance for a brighter future.

Because SIOD leads to kidney failure, Kruz, 5, and Paizlee, 4, will undergo a kidney transplant at Lucile Packard Children’s Hospital Stanford. Today, Kruz is already on dialysis and Paizlee is being monitored and treated by our nephrology team. Another way SIOD expresses itself is T-cell deficiency, leading to a weak immune system. Kruz was recently the first SIOD patient to receive a donor’s stem cells. Paizlee is undergoing evaluation for her stem cell transplant soon. Down the road, the siblings will also need hip reconstruction surgery to combat dysplasia.

“Stanford and Dr. David Lewis graciously took on SIOD research in 2017, which led to meeting Dr. Alice Bertaina and the amazing doctors who are now our stem cell transplant and kidney transplant teams,” says Jessica. “We feel blessed to have Kruz and Paizlee in the best care facility in the world.”

As the first siblings with SIOD in the country, they have become ambassadors for the condition and share their experiences through their family’s foundation, Kruzn for a Kure. Jessica recently presented Lewis with a check for $150,000, bringing their total funds donated to more than $1.3 million.

“Kruzn for a Kure Foundation is providing life-saving research funding to allow these children to have a treatment plan and a chance at a longer life,” says Jessica. “For the first time, SIOD research at Stanford has a promising chance to actually cure this incurable disease. We are so grateful for the donors who support Kruz, Paizlee, and other children with SIOD.”

On June 23, Kruz and Paizlee will be Patient Heroes at the 9th annual Summer Scamper, helping to raise money and awareness for Packard Children’s and Stanford University School of Medicine.

We are honored to have so many supporters from near and far Scampering to support patients like Kruz and Paizlee! •

Do you hear that? That’s the sound of thousands of people cheering on Kruz and Paizlee Davenport all the way from Alabama.

Support Kruz and Paizlee on their Summer Scamper page at my.supportLPCH.org/Kure.
Celebrating Our Auxiliaries

A Century of Service

BY RUTHANN RICHTER

FOR 100 YEARS, the Auxiliaries have devoted their energy, talent, and passion to ensure that our community’s children receive the medical care they need. An integral part of Lucile Packard Children’s Hospital Stanford’s mission and history, Auxiliary members have raised millions of dollars and devoted countless hours of service to support the care of children.

The first Auxiliary, now known as the Charter Auxiliary, was created in 1919 to support the Stanford Home for Convalescent Children, where children could recuperate in the sunshine on the site of the Stanford family home in Palo Alto. Over the decades as the “Con Home” and then the children’s hospital expanded, so did the Auxiliaries.

Today nearly 1,000 members spanning seven Auxiliaries from San Francisco to San Jose support the hospital through a range of activities, including a regal annual gala, a thriving thrift shop, a restaurant and retail complex, fashion shows and teas, rummage sales, and the hospital Gift Shop. Many more volunteers provide direct service to patients and families through a variety of Affiliates.

“In my role as chief of staff, I never had to turn away a child because of a family’s inability to pay, and that is because of the Auxiliaries,” says Harvey Cohen, MD, PhD, the Deborah E. Addicott – John A. Kriewall and Betsy A. Haehl Family Professor in Pediatrics, who served as chief of staff at Packard Children’s from 1993 to 2006. “They have been steadfastly loyal, giving not just their money and their time, but their heart and their true support for children’s health.”

Last year alone, the Auxiliaries raised nearly $3.5 million to support patient care and vital family and community resources. In addition, the Auxiliaries Endowment, made up of generous gifts from individual members, has grown to $22 million and provides invaluable funding to launch and sustain resources such as the Teen Health Van and the Family Guidance and Bereavement program.

In April, Auxiliary members gathered at Sharon Heights Golf and Country Club to celebrate all they have accomplished and look ahead to the future. Here’s to another 100 years!
Palo Alto Auxiliary

The Palo Alto Auxiliary launched in 1931 during the Great Depression. Over the years, the Auxiliary hosted American Girl doll fashion shows, operated the restaurant at Allied Arts Guild, and published Tastes and Traditions, a cookbook that became a local classic. The Auxiliary currently organizes Restaurants with Heart (a monthly benefit at Peninsula restaurants), The Nutcracker Tea, and an annual Garden Party.

2018 Performance of The Nutcracker

San Jose Auxiliary

Named for Mildred Hayes Roth, who devoted 50 years to supporting sick children, the Roth Auxiliary formed to manage the Gift Shop when Lucile Packard Children’s Hospital opened in 1991. Last year, Roth Auxiliary members cut the ribbon on an expanded Gift Shop in the hospital’s new Main building. Four times larger than the original space, the current shop offers newborn items, toys and balloons, hospital logo wear, jewelry, scarves, snacks, and much more. All proceeds are donated to the hospital.

San Mateo-Burlingame Auxiliary

The San Mateo-Burlingame Auxiliary hosted its first fundraising gala in 1947, a lavish affair in Hillsborough that was featured in LIFE magazine. Several years later, the Auxiliary opened the Garden Café, a restaurant and tea room. Members served as waitresses and models for the restaurant’s fashion shows. The café remained a thriving enterprise for 47 years. The Auxiliary now sponsors a popular annual Game Day.

Auxiliary Highlights

1919 First Auxiliary founded
978 Current members
7 Auxiliaries and 6 Affiliates
100,000+ volunteer hours / year
$22M Auxiliaries Endowment value

Thank you, Auxiliaries, for your decades of devotion and generosity!

To join the Auxiliaries or learn more, visit supportLPCH.org/auxiliaries.
“Ro-Ro, don’t forget your helmet!” calls David Camarillo, PhD, as his 4-year-old daughter, Rosie, jumps on her little turquoise bike. The training wheels wobble as she pedals away.

Parents give this same reminder to their children every day, but coming from Camarillo it has even greater significance. For the past seven years, he has studied concussions, an issue that affects approximately 2 million children each year in the United States.

“When I talk to people about concussions, they almost always think it’s a football problem,” says Camarillo, assistant professor of bioengineering at Stanford University. “But the most common cause of sports-related concussion in children? It’s bicycling.”

Notoriously hard to diagnose, many concussions go unreported. Clearance to resume activity following a concussion is often a judgment call made by a health care provider who has scant data on the injury and little expertise in brain trauma.

Overall, the science of concussions remains foggy. What causes them exactly? What happens in the brain during and after? And most importantly, how can we prevent them?

Camarillo, along with his colleague Gerald Grant, MD, FACS, Endowed Professor in Pediatric Neurosurgery at Stanford University School of Medicine, aims to find answers. They are among the nation’s foremost concussion experts.

Camarillo explores the biomechanics of concussion, while Grant uses the data to make the best possible clinical decisions for his patients at Packard Children’s Hospital.

The Camarillo Lab at Stanford uses mouthguard technology it developed to figure out what happens to the brain during a concussion; the lab began by supplying the Stanford football team with the devices. Because teeth are hard and connected to the skull, they are good surfaces for measuring how the skull moves. Equipped with an accelerometer and gyroscope (the same technology that’s in your smartphone but at a higher rate), the mouthguard measures g-forces that a cornerback, for instance, may experience when he’s tackled.

A video from the Centers for Disease Control and Prevention shows a rendering of the brain sloshing around within the skull after a hit, causing injury to the outer edges of the brain.

Protecting Precious Heads

Concussion experts team up to turn science into safer helmets

By Jennifer Yuan & Laura Hedli
mouthguard data, however, shows that concussion actually produces strain deep within the brain. Injury has less to do with impact and more to do with head rotation, which may stretch or twist the brain. Images from Camarillo’s lab show that brain tissue may be stretched up to 50 percent around the corpus callosum, which connects the right and left side of the brain; this may cause concussion symptoms such as dizziness.

“You don’t even have to hit your head to have a concussion,” says Grant. Concussions can also occur from a blow to the body or a fall. “The whiplash alone, without hitting your head, can cause the same symptoms.”

Reaching Youth

Last year, Camarillo and Grant expanded their research to a younger set, outfitting over 100 football players from three Bay Area high schools with the mouthguards. “There’s a lot of brain development going on between ages 13 and 18,” Grant says. “This age group has the highest risk for health issues that may accompany a concussion, such as depression, PTSD, and anxiety. It’s really important to extend the work to this particularly vulnerable age group.”

Combining video footage of practices and games with data from the mouthguards, Camarillo and Grant hope to illuminate which types of collisions lead to concussions, which tackling methods put players at greater risk, and how to play using the safest possible technique.

In addition, anyone can now access free concussion education online through CrashCourse, a video-based interactive learning experience developed by TeachAids, a Palo Alto nonprofit. The film puts the viewer on the field during a high school football game. With Stanford football players like Bryce Love serving as role models, CrashCourse provides a high-tech approach to concussion education, backed by rigorous testing and research.

Concussion Q&A with Gerald Grant, MD, FACS

Q. For children playing soccer, baseball, football, and other high-impact sports, what precautions can parents and coaches take to safeguard their brains?

A. Encourage kids to speak up. Kids need to be educated about concussion symptoms and tell someone if they have symptoms so that they can be evaluated to see if it’s safe to continue playing. The long-term risks are much greater if an athlete has a second brain injury before the first has healed. When in doubt, we should pull players out of the game.

The most common concussion symptom is headache. Others to watch out for include dizziness, vertigo, difficulty concentrating, fatigue, neck pain, and high anxiety. An athlete might have one of these symptoms or several.

Q. After a child is diagnosed with a concussion, what should parents do to help with recovery?

A. Don’t let your child go back to contact activities until they’re cleared by a health care provider to play. That’s the law in California. While they’re recovering from a concussion, the child or teen should slowly start doing something aerobic but with no contact risk. Parents also need to communicate with their child’s teachers if the recovery is prolonged. We want kids to be at school but in small doses. Taking time to recover from a concussion is especially hard for students who have super-high expectations for themselves. Parents can reassure their kids that they will get better and appropriate recovery time will allow them to heal.

For more tips, visit supportLPCH.org/Concussion.
Researchers respond to alarming rise in teen vaping

AT 17, KARIN FEL Sher noticed a risky new trend among her high school classmates. Hiding under tables in science class or exhaling into their backpacks, students were widely using a new e-cigarette called JUUL—and educators and parents were none the wiser.

Karin’s mom, Bonnie Halpern-Felsher, PhD, was a Stanford researcher studying tobacco use in teens. Karin tipped her off to the alarming new phenomenon.

Since then, e-cigarettes have grown into an epidemic among adolescents and a multi-billion-dollar industry for manufacturers like JUUL.

“With at least 20 percent of high school students reporting some use of e-cigarettes in the last year and not understanding the harms and nicotine in it, was important for me to do something about it,” explains Halpern-Felsher, professor of pediatrics at the Stanford University School of Medicine.

Halpern-Felsher immediately incorporated the topic into the Tobacco Prevention Toolkit, a free set of online materials that informs teens of the dangers of tobacco and nicotine, as well as explains adolescent brain development and nicotine addiction. Halpern-Felsher launched the toolkit in October 2016 for young people and their teachers. Today, the toolkit is being used by educators in every state (and five countries) and has reached at least 300,000 youth across the country in just the past year.

“A few years into creating the toolkit, cigarette use among teens was below 10 percent,” says Halpern-Felsher. “But a group of researchers at Stanford University School of Medicine. Stanford Research Into the Impact of Tobacco Advertising, led by Robert Jackler, MD, has intensely studied the JUUL phenomenon and archived 1,400 JUUL advertisements online. Many show attractive young models gazing flirtatiously at the camera or dancing exuberantly. Early on, JUUL also heavily marketed on youth-oriented sites such as Instagram. Halpern-Felsher, it’s no wonder they’re getting addicted. “In youth with their developing brains—and that brain is a fabulous thing—it makes them so much more at risk around addiction,” she says.

Research shows that the nicotine in e-cigarettes also primes the adolescent brain for other addictive behaviors like cigarettes and cocaine.

This is all good for the manufacturers who benefit from a new generation of users who will get addicted and become lifelong consumers, Halpern-Felsher says. Veteran tobacco companies like Altria, the maker of Marlboro, and Reynolds American also win, since their hold is growing on the e-cigarette market. Recently, Altria purchased a third of JUUL.

How JUUL Became Cool
What changed? JUUL, the most popular brand of e-cigarettes, went on sale in 2015 and now accounts for 75 percent of U.S. e-cigarette sales. JUUL is a pod-based system that appeals to youth with a variety of sweet flavors such as mint, mango, and fruit medley. The pods snap into sleek devices that resemble USB flash drives and can be charged in a laptop, making them convenient for teens to hide in Plain sight.

They’re also accessible. Karin says JUUL was easy to get in her high school, and it’s even easier on her college campus. “You can Venmo $2 to someone for two puffs from their JUUL,” she says.

JUUL is marketed as a safer, trendy alternative to cigarettes. However, the long-term effects of vaping, or JUULing, are still unknown. Made up of a cocktail of chemicals that researchers haven’t yet studied, JUUL delivers nearly as much nicotine as two packs of cigarettes in one pod.

“There’s a culture around JUUL,” Karin says. “It’s a total rebellion.”

JUUL denies that its products are marketed to teens. But a group of researchers at Stanford University cries foul. Stanford Research Into the Impact of Tobacco Advertising, led by Robert Jackler, MD, has intensely studied the JUUL phenomenon and archived 1,400 JUUL advertisements online. Many show attractive young models gazing flirtatiously at the camera or dancing exuberantly. Early on, JUUL also heavily marketed on youth-oriented sites such as Instagram.

Taking Action
Lawmakers responded by launching an investigation into JUUL’s advertising practices and the deal with Altria.

Halpern-Felsher has taken matters into her own hands. She co-authored several studies on teens’ JUUL use and found that teens believe JUUL is less harmful and addictive than other nicotine products. She also testifies before state and federal agencies about the need to regulate tobacco products including e-cigarettes to prevent them from getting into the hands of youth.

CVS Health Foundation has been a generous supporter of the Tobacco Prevention Toolkit. They made it possible to include modules on hookah and smokeless tobacco; increase content throughout the toolkit, especially additives like cigarettes and JUUL; and disseminate and train educators to use the toolkit. Additional funding is needed to share the toolkit more broadly in the United States and abroad.

“Our approach is to educate youth about the manipulation of tobacco marketing,” says Halpern-Felsher. “When I say to them that there are 400,000 smokers dying each year and the tobacco industry is looking to you to replace the next smoker who dies, it really wakes them up.”

In addition to the CVS Health Foundation, this work has received support from the Maternal and Child Health Research Institute and other generous donors.
Prenatal Testing

Making Breakthroughs

Doctors will soon be able to predict prematurity with a simple blood test

BY RUTHANN RICHTER

WHEN HIS WIFE WAS PREGNANT with their first child, physicist Stephen Quake, PhD, had an unsettling experience that would change the course of his work. His wife was undergoing amniocentesis, in which the doctor inserted a needle into her abdomen to obtain fluid to identify possible genetic abnormalities like Down syndrome. The test can put both the life of the mother and the baby at risk.

“It was the kind of experience that shook us a bit, as it does many people,” says Quake, the Lee Ottesen Professor of Bioengineering and Applied Physics. “So I began to appreciate that there were important problems in prenatal health that needed to be solved.”

The issue was on his mind when he came to Stanford in 2005. He felt intrigued by an old observation that the free-floating DNA of a fetus can be found in the mother’s bloodstream. He wondered whether the phenomenon could be put to practical use in a clinical test. It so happened that Yair Blumenfeld, MD, then a fellow in maternal-fetal medicine at Stanford, was interested in the same question.

Blumenfeld helped recruit a group of pregnant women at Packard Children’s who agreed to donate their blood for study. Using advanced gene-sequencing methods developed in Quake’s lab, the researchers accurately detected nine cases of Down syndrome among the women in the 14th week of pregnancy.

The results were published in 2008, opening the floodgates to a new non-invasive blood test, which has now been used by millions of pregnant women worldwide. It has virtually replaced amniocentesis, says David Stevenson, MD, Harold K. Faber Professor of Pediatrics, senior associate dean of maternal and child health, and professor, by courtesy, of obstetrics and gynecology.

“It has led to a complete transformation of the way obstetricians practice in this country—and around the world,” Stevenson says. “And it all started here at Stanford.”

A New Way to Predict Prematurity

Quake began collaborating with Stevenson on another intractable problem in pregnancy—prematurity—which is the leading cause of death worldwide among children under age 5. Quake’s own daughter had been born a month premature, a fragile infant in the 5th percentile of weight. Though she is now a thriving 17-year-old, he knew there had to be a way to predict which mothers might deliver early and prevent needless infant deaths and complications.

Fortunately, one of his Stanford colleagues, visiting professor Mads Melbye, MD, had assembled a group of 31 pregnant Danish women willing to have their blood taken every week. Using these samples, researchers were able to monitor the RNA in the women’s blood, eavesdropping on the molecular messages being generated over the course of the pregnancy by the mother, baby, and placenta.

“We could watch the whole program of human development happening,” Quake says. “It was amazing.”

From this data, they identified nine genes produced by the placenta that can predict the age of the fetus in the third trimester. These estimates were comparable to those based on ultrasound; however, the new technology has several advantages, Quake says.

“Ultrasound only works early in pregnancy,” he says. “If you happen to miss that window, there are not a lot of other choices. Now we can offer another choice, and we can do it in a way that we think will be cheaper and easier to use in the developing world because it doesn’t involve expensive equipment.”

He and his collaborators also worked with two groups of pregnant women at the University of Pennsylvania and the University of Alabama who were at risk of having preterm deliveries because of their past histories. The researchers twice sampled the women’s blood and identified seven genes from the mother and the placenta that could predict which pregnancies were likely to end early.

The results, published in 2018, could lead to the first prematurity test. It would give women the chance to prepare, say, by getting care from a high-risk obstetrician and being near a hospital when their delivery time comes, Quake says.

He and Melbye and Stanford Genetics Chair Michael Snyder, PhD, have since formed a startup that is planning a large trial of the prematurity test, which could reach the market in two to three years. He says collaboration was key to the success of the seven-year project.

“Those who have done it by themselves, and by working together, were able to accomplish something significant,” Quake says.

Much of the funding for this work came from philanthropy, including the March of Dimes Prematurity Research Center at Stanford; the Bill and Melinda Gates Foundation; and the Chan Zuckerberg Biohub, of which Quake is co-president.

“[Non-invasive blood testing] has led to a complete transformation of the way obstetricians practice in this country—and around the world. And it all started here at Stanford.”

DAVID STEVENSON, MD

Watch Stephen Quake’s Childx keynote here: supportLPCH.org/Quake.
In 2018, you and 15,870 other donors gave $136 million to Lucile Packard Children’s Hospital Stanford and the child and maternal health programs at Stanford University School of Medicine. Your generous support made all this and much more possible for patients and families. Thank you!
The Dinner Benefits Our Community’s Tiniest Members

ON MAY 3, we celebrated our biennial gala, The Dinner. Held at the Stanford Red Barn Equestrian Center, the dinner and live auction featured special guests Rob Lowe and James Corden, and raised over $3.2 million in commitments for the compassionate care and innovative technology that families need in our hospital’s neonatal intensive care unit.

Special thanks to our co-chairs Gioia Arrillaga, Suzanne Crandall, Susan Ford Dorsey, and Stacey Siebel who championed the event, and the event’s steering and honorary committees for their tireless efforts. Thank you to everyone who made The Dinner a success! Your generosity will save the lives of our tiniest and most vulnerable patients, and put families on track for brighter, healthier futures.

8-Year-Old Bakes Cookies to Find Cures

WHEN HER FRIEND WAS DIAGNOSED with Pediatric Acute-onset Neuropsychiatric Syndrome (PANS), 8-year-old Dana Perella wanted to help. So, she put on her own mitts and got to work! Dana, her brother, Carson, and their friends have baked 10,660 cookies to sell to raise money for child health causes, including PANS research. Her second-grade class in Boulder, Colorado, even contributed 100 pounds of baking ingredients.

In total, Dana’s campaign, called Cookies4PANS, has donated an incredible $30,000 to the scientists at the Stanford PANS Clinic, “so they can do lots of research and discover better treatments for PANS,” says Dana. “Then kids like my friend might not get so sick, and maybe the kids who are already sick can get better.”

Thank you, Dana, for being such a wonderful friend and baker!

Lightspeed Venture Partners Supports the Center for Definitive and Curative Medicine

WE THANK LIGHTSPEED Venture Partners for its generous $150,000 gift to support the Center for Definitive and Curative Medicine. This vital funding will enable Maria Grazia Roncarolo, MD, chief of pediatric stem cell transplantation and regenerative medicine and co-director of the Institute for Stem Cell Biology and Regenerative Medicine, and her team to continue their efforts to bring novel stem cell and gene therapies from the laboratory to the bedside. We could not be more grateful for your belief in the promise of these therapies! It will lead to life-changing treatments for the patients who come to our hospital to receive the best possible care.

Monthly Donors Make a Special Difference

EACH YEAR, THOUSANDS OF CHILDREN with long-term and complex health care issues turn to Lucile Packard Children’s Hospital Stanford. We appreciate our Monthly Giving Partners, whose dependable gifts add up quickly to bring novel stem cell and gene therapies from the laboratory to the bedside. We could not be more grateful for your belief in the promise of these therapies! It will lead to life-changing treatments for the patients who come to our hospital to receive the best possible care.

Jazz Pharmaceuticals Supports the Child Life Team

JAZZ PHARMACEUTICALS made a generous gift of $50,000 to support the Child Life and Creative Arts Department at Lucile Packard Children’s Hospital Stanford. This gift will allow the Child Life team to use developmentally appropriate education, support, and therapeutic play to help children receiving care on the fifth floor of our new Main building, where we will provide gene and immunotherapy treatments. Thank you for making our patients feel better during their hospital stay!

Sit Family Renews Their Commitment to Heart Research

ANDREW SIT was diagnosed with a complex congenital heart defect soon after he was born. In 2006, he needed open-heart surgery, and his cardiologist referred Andrew to cardiothoracic surgeon Frank Hanley, MD, at Lucile Packard Children’s Hospital Stanford. After Andrew’s surgery, the Sit family wanted to support the surgical techniques Hanley and his research team pioneered. They established the Sit Family Endowed Research Fund for pediatric cardiac surgery. The Sit family continues to stay involved in the innovative work happening at Packard Children’s, and, last fall, made a new commitment toward their endowment.

“Thank you, Sit family, for helping make healthy futures possible for more children!”
Louise Scott Finds a New Way to Give

LOUISE SCOTT is a longtime supporter of our hospital and has kindly given her time, talent, and gifts. She is a member of the Allied Arts Guild Auxiliary, a former president of the Association of Auxiliaries, and a previous member of our hospital and Foundation boards. Louise enjoys knitting blankets and other gifts that our patients and families cherish.

Most recently, Louise directed a gift from her Individual Retirement Account (IRA) to the Lucile Packard Children’s Fund, which provides crucial funds to support care for all, innovative research, and family and community services. Known as the “IRA rollover,” donors who are 70½ or older can make gifts of up to $100,000 per calendar year directly from their IRA to qualified charities such as the Lucile Packard Foundation for Children’s Health and do not pay income taxes on the distribution.

In 2018, 68 donors gave over $445,000 from their IRAs to our hospital and the child and maternal health programs at Stanford University School of Medicine. Thank you, Louise, and all donors who give through their IRAs.

Tad and Dianne Taube Commit $6 Million to Pediatric Cancer Research

SILICON VALLEY PHILANTHROPISTS

Tad and Dianne Taube have committed $6 million to Stanford University School of Medicine to establish the Taube Initiative in Pediatric Cancer Research, which will further the development of innovative therapies to improve the cure rates for childhood cancer.

“It is essential that we help society’s most vulnerable, our children, to beat cancer,” says Tad Taube, chairman of Taube Philanthropies. “Researchers at Stanford, one of the world’s preeminent research institutions, are leading the way in the search for better treatments for this dreadful disease. We are proud to support them in their effort to save countless children’s lives.”

The gift will accelerate the work of researchers at the School of Medicine and Lucile Packard Children’s Hospital Stanford who are exploring promising areas of discovery such as cancer genomics and immunotherapy. The new Taube Initiative in Pediatric Cancer Research will support two faculty members performing cutting-edge cancer research in key areas and establish a fund for future innovation.

“Through their generous contribution, Tad and Dianne Taube are accelerating the development of childhood cancer therapies that are more personalized, more precise, and more effective,” says Lloyd Minor, MD, the Carl and Elizabeth Neumann Dean of Stanford University School of Medicine. “I am immensely grateful for their support of Stanford Medicine’s researchers and their dedication to improving the lives of children around the world.”

The Taube Distinguished Scholar in Pediatric Immunotherapy will focus on developing and advancing immunotherapy treatments for childhood cancers. This type of therapy is associated with fewer long-term toxicities than chemotherapy and radiation, which kill cancer cells but also destroy healthy cells and weaken the immune system. Immunotherapy equips the patient’s own immune cells to specifically attack cancer cells.

“The Taube Distinguished Scholar for Pediatric Oncology will focus on developing customized therapies to treat childhood cancers utilizing knowledge of the genetic differences found in cancer cells,” Minor adds.

Secondly, the Taube Innovation Fund in Pediatric Cancer will support innovative research and clinical projects within the Division of Hematology/Oncology in the Department of Pediatrics at the School of Medicine.

Louise Scott Finds a New Way to Give

Local Merchants Give Back Through Shop for Packard

IN MARCH, several local retailers and restaurants hosted in-store shopping events that benefited kids and families at Packard Children’s. Special thanks to our Shop for Packard partners Shreve & Co., Amour Vert, California Pizza Kitchen, J. Crew, J. McLaughlin, Jenni Kayne, Madewell, SliderBar, CH Premier Jewelers, See’s Candies, Vince, and Vitality Bowls who donated a portion of sales to Packard Children’s. We are grateful to the wonderful retailers, restaurants, and shoppers who support Packard Children’s.

IN MARCH, THE AMBASSADORS for Lucile Packard Children’s Hospital celebrated 12 years of service to our hospital at their annual Lunch and Learn at Sharon Heights Country Club in Menlo Park. Guests heard from acclaimed actress, mother, and health advocate Selma Blair. She spoke with Sue McCreddie, MD, about how she coped with postpartum depression and her recent multiple sclerosis diagnosis, as well as how she balances her roles as a mother and caregiver.

This year’s Lunch and Learn benefited the Ambassadors’ 2018–2019 Fund-A-Need, supporting a dedicated clinical psychologist in our hospital’s volunteerism, and education. Thank you, Ambassadors, for your support!
Teen Health Van provides free, comprehensive primary health care services to adolescents with high-quality health care. Seth Ammerman, MD, Founder of the Teen Health Van, Retires

In the NEWS

Seth Ammerman, MD, Founder of the Teen Health Van, Retires

SETH AMMERMAN, MD, clinical associate professor of pediatrics (adolescent medicine), has retired after 28 years of service to Lucile Packard Children’s Hospital Stanford.

Ammerman’s celebrated accomplishments include founding one of the nation’s first adolescent-focused mobile health clinics in 1996. The hospital’s Teen Health Van provides free, comprehensive primary health care services to uninsured and homeless youth ages 10 to 25 at 10 sites in Santa Clara, San Mateo, and San Francisco counties.

Under Ammerman’s leadership, the Teen Van provided over 15,000 visits to more than 4,500 patients. Its multidisciplinary staff—made up of a physician, nurse practitioner, social worker, and registered dietician—provides care for those who rely exclusively on the Teen Van as their link to a network of health care services. All services are provided free of charge, including acute illness and injury care, physical exams, family planning services, pregnancy testing, HIV and STD counseling and testing, blood tests, immunizations, mental health services, substance use counseling, and nutrition and fitness counseling.

The Teen Van is nationally recognized as a successful strategy to provide adolescents with high-quality health care.

“My career has been guided by the approach that we all need to take care of each other if we are to ultimately succeed, and to provide our young people with the care and support they need and deserve,” says Ammerman.

Bone Marrow Transplants Without Chemotherapy or Radiation

AN ANTIBODY-BASED TREATMENT can gently and effectively eliminate diseased blood-forming stem cells in the bone marrow to prepare for the transplantation of healthy stem cells, according to a study in mice by researchers at Stanford University School of Medicine.

The researchers believe the treatment could circumvent the need to use harsh, potentially life-threatening chemotherapy or radiation to prepare people for transplant, vastly expanding the number of people who could benefit from the procedure.

“There are many blood and immune disorders that could be cured by a transplant of healthy cells,” says Judith Shizuru, MD, PhD, senior author of the study and professor of medicine and of pediatrics. “But the pre-treatments necessary to get the healthy cells to transplant effectively are so toxic that we can’t offer this option to many patients. A treatment that specifically targets only blood-forming stem cells would allow us to potentially cure people with diseases as varied as sickle cell disease, thalassemia, autoimmune disorders, and other blood disorders.”

Causes and a Potential Cure Discovered for ‘Chemo Brain’

MORE THAN HALF of cancer survivors suffer from cognitive impairment from chemotherapy that lingers for months or years after the cancer is gone. In a study explaining the cellular mechanisms behind this condition, Stanford scientists demonstrated that a widely used chemotherapy drug, methotrexate, causes a complex set of problems in three major cell types within the brain’s white matter.

The study also identified a potential remedy. A drug now in clinical trials for other indications reversed symptoms of “chemo brain,” as the condition is known, in a mouse model.

“Cognitive dysfunction after cancer therapy is a real and recognized syndrome,” says Michelle Monje, MD, PhD, associate professor of neurology and neurological sciences and the study’s senior author. “In addition to existing symptomatic therapies—which many patients don’t know about—we are now homing in on potential interventions to promote normalization of the disorders induced by cancer drugs. There’s real hope that we can intervene, induce regeneration, and prevent damage in the brain.”

Chemo brain is especially severe in childhood cancer patients, Monje adds, and children have the most to gain from better remedies.

FDA Appeal Saves Patient From Heart Failure

LIZNEYD SERRATOS became the youngest and smallest person in the country to receive the type of heart pump now keeping her alive. The 12-year-old was saved by her doctors and nurses at Packard Children’s, who petitioned the U.S. Food and Drug Administration for permission to use a medical device that was not yet approved for children. They got a compassionate-use exemption in roughly 24 hours.

“When Lizneyd came to us, she was very, very sick,” says pediatric cardiologist and heart transplant surgeon Katsuhide Maeda, MD, who performed her surgery. Lizneyd had dilated cardiomyopathy, a leading cause of heart transplants in children.

Lizneyd needed a surgically implanted pump that would help her failing heart move blood through her body. The Packard Children’s cardiology team wanted to give Lizneyd a pump called the HeartMate 3, which is small enough to implant in the chest. To implant it, Maeda needed to create a hole in Lizneyd’s left ventricle and suture a washer-like device called a sewing ring onto the heart to anchor the pump. But the sewing ring that was approved by the FDA was too big for Lizneyd. At the time, a smaller ring was approved only in Europe.

The problem with the larger sewing ring was that Maeda would have had to sew across one of Lizneyd’s most important coronary arteries. In rare cases, heart pumps allow children’s hearts to regain enough function to avoid a transplant. Closing the artery would have permanently severed the blood supply to part of her heart muscle, cutting off this possibility.

People in several locations across the country—including FDA staff—worked to secure a compassionate-use exemption. Approval was complete, and Lizneyd received the small sewing ring in the nick of time. The pump made an enormous difference. Lizneyd’s breathing tube was removed the next day, and she soon began eating again.

“Having her just talking and laughing and asking for things was great,” says her mom, Maricela Alvarado-Lazarit. “When she started being able to get up, it felt like she’s going back to normal.”
Brain Response to Mom’s Voice Differs in Kids with Autism

FOR MOST CHILDREN, the sound of their mother’s voice triggers brain activity patterns distinct from those triggered by an unfamiliar voice. But the unique brain response to mom’s voice is greatly diminished in children with autism, according to a study from Stanford University School of Medicine.

The diminished response was seen on brain scans in face-processing regions and learning-memory centers within the brain, as well as the areas that process rewards and prioritize different stimuli as important.

“Kids with autism often tune out the voices around them, and we haven’t known why,” says the study’s lead author, Dan Abrams, PhD, clinical assistant professor of psychiatry and behavioral sciences. “It’s still an open question how this contributes to their overall difficulties with social interaction.”

The study also found that the degree of social communication impairment in individual children with autism was correlated with the degree of abnormality in their brain responses to their mother’s voice.

Positive Mindset Helps with Treatment’s Side Effects

RESEARCHERS AT STANFORD UNIVERSITY wanted to find out whether a simple mindset shift could help patients tolerate an uncomfortable treatment. They learned that when physicians make the effort to reframe potentially unpleasant symptoms in a positive light, it helped patients stay calm and persevere.

The researchers studied this approach with a group of families who signed their children up for a study testing oral immunotherapy and its ability to build tolerance to their food allergy triggers. The procedure is safe if done with medical supervision, but many people experience unpleasant—and very occasionally life-threatening—allergic symptoms. As a result, participation can cause considerable stress.

In the study, the research team split the children in two groups. Half of the children and their parents received standard information about handling mild side effects, such as how to treat them with antihistamine medications. The other group also got the standard information but was encouraged to view mild side effects as signs that the treatment was working. At the end of the trial, patients and families in the positive-mindset group reported significantly less worry during the treatment process.

Alia Crum, PhD, principal investigator at Stanford’s Mind & Body Lab, thinks the food allergy study provides a model for studying how mindsets could help people cope with other medical procedures. “Once we understand mindsets that are more useful, hopefully we can inform clinical practice so they’re using the more useful mindsets,” she says.

Lax State Gun Laws Linked to More Youth Gun Deaths

A STANFORD STUDY found that compared with U.S. states with the strictest gun control legislation, gun deaths among children and teenagers are twice as common in states with the most lax gun laws.

In addition, states with laws that restrict children’s access to guns have lower rates of firearm-related suicides among youth, even after controlling for other factors, the study found.

Senior author Stephanie Chao, MD, assistant professor of surgery, hopes the work will inform state control legislation, gun deaths among children and teenagers are twice as common in states with the most lax gun laws.

Promising Treatment for Pediatric Tumors

WHEN THE FDA ANNOUNCED in 2017 that it was approving an immunotherapy treatment for children with certain relapsed blood cancers, doctors and patients were excited. The treatment engineers the patient’s own immune cells to make biological chimeras, called CAR-T cells, to recognize and attack cancer.

Now, with findings reported in Clinical Cancer Research, Stanford scientists have made a big step closer to using CAR-T cells for solid tumors—including tumors of the brain, nerve cells, bones, and muscle—in children who need better treatments.

In studies using mice, “the tumor just goes away,” says Robbie Majzner, MD, the lead author of the new study and an instructor in pediatrics at Stanford. “It’s very consistent. It happened in all the mice, and that’s exciting.” The next research step is human clinical trials.

Nurse Gifts Guitar Signed by Ed Sheeran to Patient Awaiting Transplant

WHEN NURSE COLIN JAMES, RN, won a guitar inscribed by musician Ed Sheeran in the Mix 106 Toy Drive drawing, he immediately knew he wanted to give the guitar to Lucile Packard Children’s Hospital Stanford’s biggest Ed Sheeran fan, Kayano Lizardo-Bristow. Kayano, a 15-year-old from Yuba City, California, was undergoing dialysis while awaiting a kidney transplant.

Packard Children’s music therapist, Rebekah Martin, MT-BC, told James about Kayano’s passion for music and how it helps him cope with being in the hospital.

“I knew I had to give this guitar to him. He is going through a difficult time in his life, and my hope is that it brings him a little joy,” says James.

“I was sitting in dialysis with Mom, Dad, and Rebekah, playing the [Ed Sheeran] song ‘Thinking Out Loud,’” says Kayano. “Rebekah said, ‘I think we need a new guitar for this part.’ Then a few people walked in; Colin was carrying a guitar case. I was in shock. I was about to have a heart attack! I had a very emotional reaction. Everyone was tearing up. I played a song on the new guitar; I finished while I was crying.”

The guitar is inscribed with the words “Play, don’t display! Ed Sheeran.”

“He has wanted his own guitar for a long time, but we couldn’t afford it,” says Kayano’s mom, April Bristow. “This is a great boost of inspiration and energy that we could both use right now!”

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“I just feel so special, having this guitar. This is my first guitar, and it will be played.”

KAYANO, 15
kidney transplant recipient

Mix 106 radio recently hosted a toy drive for our patients and gave away a guitar to their donors. But it was not just any guitar—it was signed by musician Ed Sheeran with a note to “Play, don’t display.” Colin James, RN, won the guitar and presented it to Kayano, our hospital’s biggest Ed Sheeran fan. Now he fills our hospital with sweet melodies during music therapy. Play on, Kayano!