



Dear Friends,

Even the tiniest heart has a very big job, powering a child's health and wellbeing for life. That's why our Children's Heart Center team works to detect heart problems early and treats them with expertise, innovation, and the kind



of exceptional care that is the hallmark of a leading pediatric heart center. Whether a child needs short-term intervention or a lifetime of support, Lucile Packard Children's Hospital Stanford has built, over the last 15 years, a comprehensive system of care that adapts to the needs of each child's growth and development.

For many young patients, our team is their only hope. From our heart surgeons and advanced practice providers to anesthesiologists and nurses, our Children's Heart Center has some of the most talented, dedicated, and specialized care providers in the world.

In this issue of Lucile Packard Children's News, you'll meet little Orion who became our patient months before he was even born, as well as teenager Maya whose diagnosis came as a complete surprise to everyone, including her father, a seasoned pediatric cardiologist. You will also see exactly what makes Heart Center nurses so extraordinary and memorable for our patients, and the many ways that we are continuing to innovate so that children and adults with congenital heart disease can have an even brighter future.

When you look at our Children's Heart Center by the numbers, it is impressive by every count. Behind every statistic are children and their families relying on our center and the wonderful donors who support it.

Please join me in applauding the work of our amazing Children's Heart Center team.

Sincerely yours,

David Alexander, MD President and Chief Executive Officer

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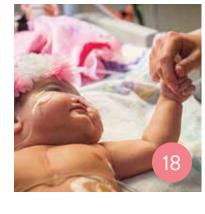
Front cover: Orion Aye. Photo by Toni Bird Photography.

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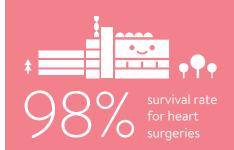
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Bringing the Best to Every Child By Frank Hanley, MD Executive Director, Children's Heart Center



A baby is born near New York City. He has a condition called pulmonary atresia with aortopulmonary collaterals, one of the most complex of all congenital heart defects. His pulmonary arteries never formed during fetal life, and his ability to take oxygen into his blood is highly compromised.

In some ways the baby is lucky. He happens to have been born close to a well-respected children's hospital. Despite the hospital's accomplished pediatric heart program, the doctors there tell the baby's parents that his condition is so complex that they have no effective treatment for him.

The parents are given two options. One is to bring their baby home, provide comfort and love, and prepare for the reality that he has a 50 percent chance of making it to his first birthday. And if he survives, he faces a very poor quality of life and almost certain death by age 10. The other option is to take their baby to another hospital that is known for performing some of the most complex heart surgeries in the world.

That hospital is not in New York, Chicago, or Boston. The baby's doctors recommend traveling across the country to Lucile Packard Children's Hospital Stanford,

where our Children's Heart Center team has developed a management program for this problem that involves highly specialized diagnostic and imaging techniques, complex innovative surgical correction, and outstanding multidisciplinary care.

With generous support from the philanthropic community and the leadership of renowned pediatric heart specialists including surgeons, cardiologists, anesthesiologists, intensivists, radiologists, and nurses, our program has evolved over the past 15 years, and babies with severe heart conditions who undergo treatment at our hospital now have a survival rate of 98 percent after surgery, and long-term survival into adulthood of over 90 percent.

Around the world, thousands of babies are born with heart defects each year. At the Children's Heart Center,

we provide cutting-edge care not only for patients like this baby, but also for those with a range of needs including heart failure and transplantation, single ventricle heart disease, fetal and premature infant heart disease, and adult congenital heart disease.

The families who find their way to our hospital do so in one of several ways.

Their babies may be born in our region and are primarily evaluated at our hospital, or they may be born at another top children's hospital where the level of knowledge is such that they are aware of our unique capabilities. Or increasingly, parents who are told that there is no hope for their child take matters into their own hands and reach us through social networks and their own research.

In spite of the breakthrough treatments delivered by our team, there remain many challenges. Management of these very complex patients is labor intensive. Despite the outcomes we have achieved, we must continue to invest in our personnel and in our center's infrastructure. We must continue to fine-tune our existing protocols in order to save more lives, improve further on our already outstanding outcomes, and advance the entire field for the benefit of children with heart disease nationwide. Our goal should be 100 percent survival.

Our success and status as a renowned pediatric cardiology program is the result of decades of donors and partners who believe in us and our patients. With your continued support, we look forward to meeting the challenges — continuing to push the boundaries of what is possible, and allowing all children with heart disease to win.



Works of Heart By Stacy Finz

Giving birth to her first child was a surreal experience for Tawny Aye — and not the way it is for most mothers.

That evening in February 2007, there were as many as 14 doctors, nurses, and other staff members from Lucile Packard Children's Hospital Stanford and the Children's Heart Center in the delivery room with her, waiting for Orion to make his first appearance. As a high-risk baby with a missing pulmonary valve, Orion had only a short time before the situation could become dire. No one was leaving his defective heart to fate. The newborn needed constant monitoring and medication until they could get him into the cardiac operating room.

Luckily, Tawny and her husband, Bo, were well prepared for this moment. When Tawny was 18 weeks pregnant, she went in for a genetic screening test followed by a high-resolution ultrasound which showed Orion had pulmonary atresia with intact ventricular septum. The rare congenital malformation is life-threatening because the valve that lets blood out of the heart to go to the baby's lungs never fully develops. Tawny's doctors in Orange County, California, said there wasn't anything they could do until the baby was born. They even seemed a little flummoxed by the grave situation.

"Our original cardiologist didn't know about these kinds of heart defects and had only seen it in a textbook," Bo recalls.

The Ayes wanted expert advice so they began researching their son's heart condition in earnest. After checking out various children's hospitals that specialized in pediatric cardiology, they chose Lucile Packard Children's Hospital Stanford. Our Children's Heart Center, led by executive director Frank Hanley, MD, a renowned cardiothoracic surgeon and luminary in the medical community, and director Stephen Roth, MD, MPH, a nationally recognized cardiac intensivist, is known for caring for some of the sickest and most complex patients anywhere. As a result, our center continuously ranks as one of the nation's top 15 pediatric heart programs by U.S. News & World Report.

The Ayes were impressed enough to travel across the state.

"We were 200 percent on board with everything the doctors there wanted to do," Bo recalls. "Whereas our doctors in Orange County said we would just have to wait until Orion was born before addressing his heart

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Lynn Peng, MD

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issues, the doctors at Stanford wanted to begin observing him immediately."

That convinced the couple to pack up and move to Mountain View, only a 15-minute drive from our hospital.

Within five days of Orion's birth, our surgeons operated to put in a shunt and patch open the pulmonary outflow so he would have adequate blood flow to his lungs. By the time

he was 18 months old, Orion had already undergone four open-heart surgeries to repair his abnormal cardiac structures. His doctors, including pediatric cardiologist David Axelrod, MD, continued to watch him closely.

For children like Orion, our Heart Center's advanced diagnostic imaging capabilities are a crucial component of their care, notes Frandics Chan, MD, associate professor of radiology. Chan leads a team of nationally recognized experts in cardiac imaging who have brought many new technologies to our hospital — including MRI, CT, radiography, and ultrasound scans — that enhance safety for patients and reveal new information about pediatric heart disease. To obtain detailed information on Orion's condition, the cardiac imaging team conducted non-invasive MRI scans that provided a three-dimensional image of his moving heart as well as the blood flowing through it.





When Orion was 5 years old, doctors decided to treat a leaky pulmonary valve conduit between his heart's right pumping chamber and his lungs with an artificial MelodyTM pulmonary valve. This valve can be implanted

> into the heart using catheters instead of open-heart surgery. Orion had certainly had enough of those.

That's where Lynn Peng, MD, an interventional cardiologist at the Children's Heart Center, came in.

"Not everything has to be fixed in an operating room," Peng notes. "Sometimes we prefer to go with a procedure that is less invasive."

Peng explained that non-surgical intervention has become a crucial part of the center's therapies. She successfully implanted Orion's new MelodyTM valve in the Pediatric Catheterization Laboratory, a procedure room with diagnostic imaging equipment used to visualize a patient's arteries and heart chambers. A catheter can be inserted into the leg, neck, or shoulder and threaded through veins or arteries to perform everything from a simple diagnosis and biopsy to stenting of blockages and closure of holes in the heart.

Importantly, the recovery process is shorter and easier for patients than it is after surgery. In total, the Children's Heart Center's interventional cardiologists now perform 1,100 catheterizations a year, Peng says.

She praises the Children's Heart Center as one of the most advanced in the nation. "We have some of the most highly trained specialists in the world. We have

people who are not only advancing the field but have also pioneered it."

The day after Orion's catheterization, Bo shared the happy news on their family's blog. "The MelodyTM valve was placed successfully and we



are ecstatic at the

outcome," he wrote. "Just five years ago, when Orion got his pulmonary valve placed, there was no option but open-heart surgery. Now, after two days in the hospital, Orion already seems back to his goofy self and is about to be sent home."

For Orion, Lucile Packard Children's Hospital Stanford has made all the difference in the world to his quality of life, the Ayes say. Since receiving his MelodyTM valve, his mother adds, "He's awesome. He's a regular 7-year-old."

"What we like the most about Packard is its coordination across the board," Bo says. "The doctors worked in unison, which helped us better understand what was going on with our son."

A Track Record of Success

ver the years, with investments from the philanthropic community, the Children's Heart Center has become an integral part of Lucile Packard Children's Hospital Stanford with more than 250 dedicated faculty and staff representing a broad range of disciplines including cardiology, cardiothoracic surgery, cardiac anesthesiology, radiology, cardiac intensive care, neonatology, nursing, respiratory therapy, and even social work. Everyone works as a team and has in-depth knowledge of each case.

Last year, the center saw 6,600 outpatient visits and performed more than 600 heart operations on-site, plus another 500 with its partner programs throughout Northern California. The team has already performed 25 pediatric heart transplants this year, out of only 500 pediatric heart transplants performed annually worldwide.

Even before the Children's Heart Center was established, Stanford was renowned for heart transplantation. In 1968, Stanford's Norman Shumway, MD, performed the nation's first successful adult heart transplant. Today, the pediatric team continues to build on that rich history of success.

The Children's Heart Center thrives on the concept of regionalization of pediatric health care, a proven method of delivering the best coordinated and comprehensive care possible to children with complex medical needs. Studies have shown that caregivers are much more specialized and successful when they treat a large volume of complex cases at regional specialty centers



Today, Orion is enjoying a full life as a healthy, loving big brother.

like ours — hence our Heart Center's 98 percent patient survival rate after cardiac surgery.

Furthermore, with partners and clinics throughout Northern California, our Heart Center's broad network enables patients to receive the same superior care and outcomes as if they came to Stanford, while staying close to home. The Children's Heart Center is responsible for about 80 percent of pediatric heart surgeries and 100 percent of pediatric heart transplants in Northern California.

As faculty members at Stanford University School of Medicine, our physicians also conduct research on pediatric heart disease which is then translated into innovative patient treatments or preventive techniques. The center is currently participating in 20 clinical research trials and submitted more than 150 papers for publication in peer-reviewed journals just in the past

The Aye family moved to the Bay Area to ensure that Orion had access to the life-saving care his ailing heart needed.

year. Located in the heart of Silicon Valley, our physicians and researchers not only benefit from Stanford

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Center means that even

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• Stephen Roth, MD, MPH

University's advances in science and biotechnology, but from technological innovations as well. And so do our patients.

The Children's Heart Center has been so successful that it is now planning an expansion that will increase capacity from 20 to 36 beds in the cardiovascular intensive care unit (CVICU), and 20 to 26 beds in the cardiology ward. There will also be six new operating suites in the hospital's 521,000-square-foot expansion when it opens in 2017, which will provide more access for life-saving heart operations

advanced imaging capabilities.

"Expanding our Heart Center means that even more children with complex heart problems, as well as growing numbers of adult survivors of congenital heart disease, will have access to one of America's most advanced programs," explains Roth, chief of pediatric cardiology. "Many of these children and adult survivors have run out of options elsewhere."

and transplants. In addition, we are creating a state-of-

the-art cardiac catheterization lab and expanding our

Roth, also a professor of pediatrics in cardiology at Stanford University School of Medicine, says there is now more demand for highly specialized treatment for congenital and acquired heart conditions than ever.

"We have a well-deserved reputation for expert teamwork, advanced tools and technology, and one of the most highly qualified and experienced physician and care teams anywhere," he says.

Chandra Ramamoorthy, MD, who leads a team of 11 cardiac anesthesiologists, seconds that.

"Pediatric heart patients are usually very complex," she says. "Many have non-cardiac medical problems in addition to their heart disease. They typically have multiple doctors, including pediatricians from wherever they live. We see patients from all over the world, which requires quite a lot of coordination and planning with all the players involved."

Ramamoorthy says there are weekly meetings where the faculty and staff discuss patient cases and as a group

they work together to devise a strategy where everyone is on the same page, including the anesthesiologists who all specialize in caring for children with heart disease. Cardiac anesthesiologists play a crucial role, using medication to safely block pain and keep a child comfortable during operations, diagnostic tests, catheterizations, and other procedures. In the operating room, the anesthesiologists work closely with all members of the team and control vital functions such

as blood pressure, temperature, heart function, and oxygen levels in the blood. Every patient is unique and anesthetic management is individualized to provide the best care.

"It's an expertise," Ramamoorthy says. "Cardiac anesthesiologists are highly trained and patient safety is our top priority. Not only are we talking about very young people with severe illnesses, but the child's emotional requirements also need to be addressed. This can include issues such as phobias of being anesthetized. You have to be flexible and have a plan 'A' and a plan 'B."

Expertise Required

aren Vargas' only plan was to find help for her 3-year-old daughter, Kate Zuno. At age 1, Kate's health wasn't right. She suffered from constipation and flu-like symptoms, including trouble breathing. Her local doctors in Ukiah thought she had a virus. But Vargas' inherent mother's sense told her it was something more. Vargas' mother agreed, pushing her to take Kate to the emergency room for additional tests.

"This time when I took her, I told the staff that I wasn't leaving until I found out what was wrong with Kate," Vargas recalls, convinced that her daughter had asthma.

As it turned out, Kate was diagnosed not with asthma, but with dilated cardiomyopathy, a disease that had caused progressive weakening of the muscle throughout Kate's heart. The condition required expertise, and doctors at UCSF Benioff Children's Hospital Oakland, where Vargas eventually took her



daughter, thought Lucile Packard Children's Hospital Stanford was Kate's best option.

The team at our Children's Heart Center wanted to get at the root of what was causing the cardiomyopathy and conducted a battery of cardiac, infectious disease, genetic, and metabolic tests. Ultimately, our doctors found that Kate suffered from a rare mitochondrial disorder which displayed most of its symptoms in her heart.

For two years, our doctors treated Kate with medication and monitored her closely. But this past March her health took a turn for the worse. What was believed to be a stomach flu was actually decompensating heart failure. As her condition quickly worsened, Kate was admitted to the CVICU and put on extracorporeal membrane oxygenation — commonly known as ECMO — which provided mechanical support to replace the function of both her heart and lungs.

Her cardiologist, Beth Kaufman, MD, said they had to make difficult decisions regarding long-term therapies.

Otherwise, Kate would die. The recommendation was that a heart transplant was her best remedy.

"Is she going to get better?" was my only question," Vargas says. Satisfied with the answer, Vargas gave the go-ahead to put Kate's name on the national heart transplant waiting list.

For a couple of months Kate lived in the hospital on a bridge-to-transplant device, called a Berlin Heart, which kept her alive until a donor heart became available. Fortunately for children like Kate, our Heart Center's Pediatric Advanced Cardiac Therapies program has seen tremendous growth in recent years, and is the only institution in Northern California that offers pediatric advanced heart failure management and cardiac transplantation. Our Heart Center was also among the first to petition the FDA for use of the Berlin Heart in the United States and holds the record for longest pediatric heart-assist in North America with this device, at 234 days.

Luckily, Kate didn't have to wait that long. Her donor heart came June 20. Kate received the transplant, performed by surgeons Katsuhide Maeda, MD, and Olaf Reinhartz, MD, and the world looks like a different place to Vargas.

"It's like my daughter is starting a whole new life," says Vargas, who is back living in Ukiah and beaming with pride as Kate gets steadier on her little feet. "I'm so excited to see her future. She'll be able to be in sports. She won't have any limitations. She'll get to be a normal child, like she deserves."

The Obvious Choice

eville Spearman, of DeKalb, Illinois, also thanks the Children's Heart Center for her son's new life. Two years ago, her son, Jordan Ervin, was diagnosed with Williams syndrome, a chromosomal disorder that affects just one in 10,000 people worldwide. The disease causes severe

"We're definitely

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• Frank Hanley, MD

heart and major blood vessel defects in addition to other maladies. For Jordan, then 5, it was pulmonary artery stenosis, multiple areas of narrowing in the branches of the pulmonary arteries, which caused pulmonary hypertension and made it difficult for the right side of his heart to pump blood into his lungs to pick up oxygen.

The typical treatment involves using a small balloon to expand the artery. But because Jordan had multiple blockages — 12 within his left lung and 14 within the right — Seville and her husband, Charles, were told that it would take several procedures and still might not work. Then she heard about pulmonary artery reconstruction surgery and Frank Hanley, who is known throughout the world for performing some of the most complicated pediatric heart surgeries. In fact, Hanley pioneered a procedure called unifocalization, a surgery in which he reconstructs the pulmonary arteries in children who either have no true pulmonary arteries or severely underdeveloped arteries. To Seville and Charles, Hanley and his expertise with pulmonary artery surgery were the obvious choice.

"We just didn't see a point in multiple ballooning procedures when we could do it all at once — and for good," Seville says.

Both graduate students, Seville and Charles spent the next couple of months raising the money to come to California and found a short-term rental house for them and their three other children. On December 10, 2014, Hanley reconstructed the main pulmonary artery and its branches in Jordan's heart in a marathon eight-hour surgery.

"They told us it was risky and we were scared," Seville recalls. "But the type of support we received from the staff was beyond helpful. It made a difficult situation easier."

During the surgery, Hanley and his team placed Jordan on life support, separated his right and left lung arteries and then spliced open the main and initial branch arteries, as well as the second- and

third-level branch arteries where the 26 blockages were located. Each blockage was either repaired or patched open with human tissues.

As a result of the procedure, Jordan's pulmonary hypertension was cured, and he headed home to Illinois — right around Christmas — with normal pulmonary artery pressure.

Jordan's surgery was one of more than 540 pulmonary artery reconstruction surgeries Hanley has performed at Lucile Packard Children's Hospital Stanford for children with complex pediatric heart defects, and with superior outcomes. Through talent, stamina, and experience, Hanley is able to use this innovative, one-stage approach to decrease overall hospital time for patients, reduce the number of times a heart must be stopped for surgical repairs, and fix problems before they worsen or become impossible to repair.

"We're definitely on the leading edge of this kind of surgery," says Hanley, who is also the Lawrence Crowley, MD, Professor in Child Health and a professor of cardiothoracic surgery at Stanford University School of Medicine. "Jordan is going to have a perfectly normal life expectancy."



"Before, I didn't know if Jordan would make it to his seventh birthday," Seville says. "It's nearly a year later, and he can run longer and faster than before the surgery and only occasionally has to use his inhaler. Everything is back to normal and that black cloud hanging over us is gone. Still, our family takes nothing for granted."

Throughout the Children's Heart Center, staff members agree that they want every child — like Orion, Kate, and Jordan — to have access to our hospital's cutting-edge treatments and the chance for a healthier life. •



What happens when a 25-year veteran pediatric cardiologist suddenly finds himself with an unexpected new patient—his own daughter?

Everything Changed in a Heartbeat By Stacy Finz

Q&A with Kavin Desai, MD, and Maya Desai

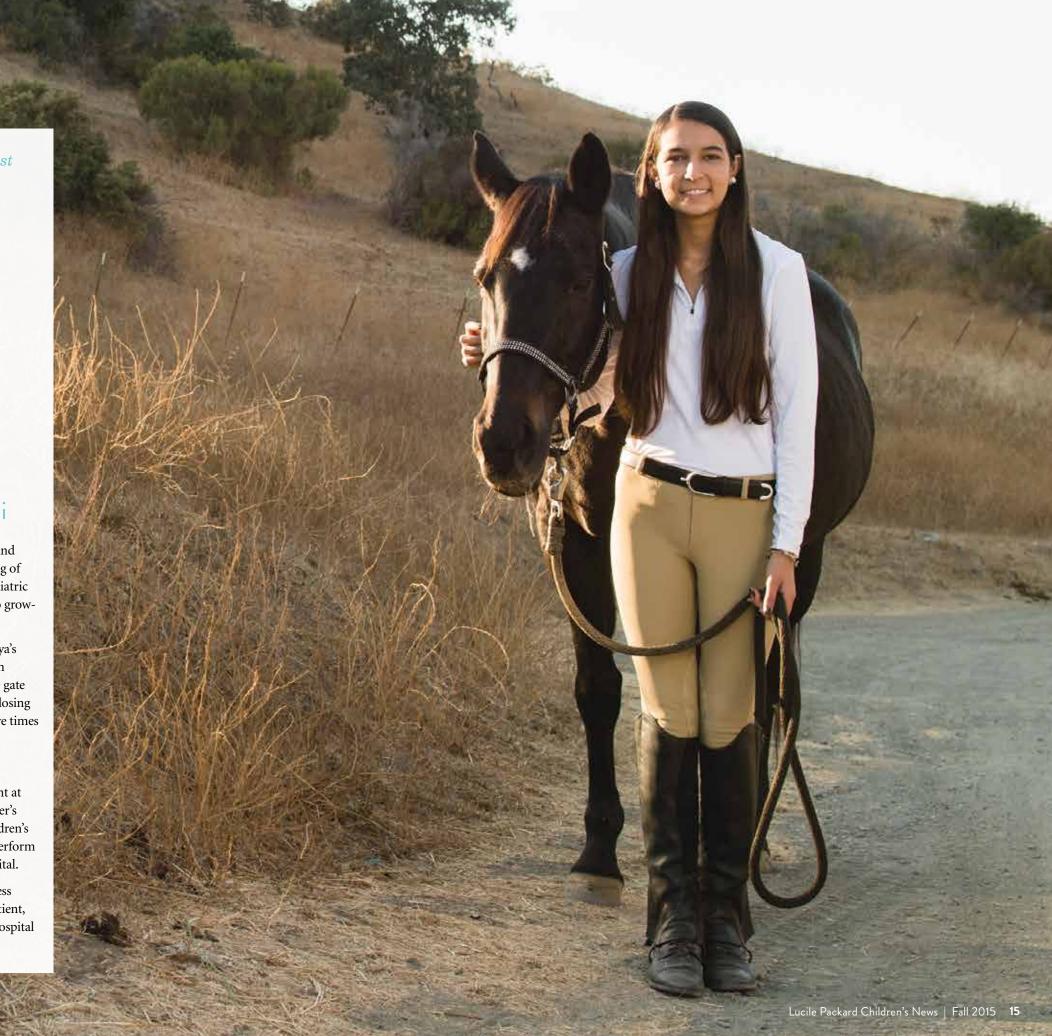
Earlier this year, 15-year-old Maya Desai, an accomplished high school student and equestrian from Los Altos, who had led a normal, healthy life, began complaining of fatigue, chest pain, and heart palpitations. Her father, Kavin Desai, MD, lead pediatric cardiologist for Kaiser Permanente Northern California, initially chalked it up to growing pains.

But one evening after work, he was worried enough to hold a stethoscope to Maya's chest. After several late-night tests at Kaiser Santa Clara, Desai diagnosed his own daughter with a congenital abnormality of her mitral valve. Her mitral valve, the gate between the left atrium and the left ventricle of the heart, was opening but not closing properly, leading to so much valve leakage that her heart had to work three to five times harder to get enough blood to Maya's body.

She needed open-heart surgery — the sooner the better.

As a Stanford-trained pediatric cardiologist who still holds a clinical appointment at Lucile Packard Children's Hospital Stanford, Desai says his choice for his daughter's operation was easy: he wanted Frank Hanley, MD, executive director of the Children's Heart Center and one of the nation's top pediatric cardiothoracic surgeons, to perform the operation. On August 7, Maya underwent the four-hour surgery at our hospital.

In a Q&A eight weeks after her surgery, Desai and Maya talk about the strangeness of suddenly having their relationship change from father-daughter to doctor-patient, and how Hanley and the Children's Heart Center at Lucile Packard Children's Hospital Stanford made all the difference in the world.



As the chair of Kaiser Permanente's pediatric cardiology group, was it unorthodox for you to have Maya's heart surgery performed at Lucile Packard Children's Hospital Stanford?

Desai: Kaiser Permanente doesn't perform pediatric heart surgeries, so we refer all of our patients who need surgeries to other institutions. It is not unusual to send our patients to Lucile Packard Children's Hospital Stanford. I have an active relationship with Stanford — I'm on the faculty and still see patients and teach medical students, residents, and fellows there.

I very quickly decided that I wanted to be Maya's father, not her doctor, so I called in a colleague from Kaiser to handle other preliminary cardiac tests. And Dr. Hanley was my choice for her surgeon, as I felt that he provided the best opportunity to salvage my daughter's heart valve. There are not a lot of pediatric heart surgeons, especially if you want to stay relatively local, and the fact that there is a person of his caliber right here was a "no brainer."

People ask me all the time whether I was in the operating room with Maya. I stayed in the waiting room like any other parent. When you have a surgeon with your daughter's heart literally in his hands, you don't want anything to distract him.





Desai: We knew we had to do something quickly, as Maya's valve was deteriorating rapidly and she was becoming more and more symptomatic. We had to decide whether to repair the valve or replace it with a mechanical one. If we replaced it, Maya would have to be on blood thinners, which would have major implications on her life. A future pregnancy would be difficult if not impossible, and her favorite pastime, horseback riding (she competes in dressage), would be off limits. So our first choice was for a repair. With Dr. Hanley's expertise, he was able to do that.

Maya: The scariest part was thinking about what could go wrong: a stroke and the possibility of not waking up. But Dr. Hanley described the surgery as being as routine as getting gas for his car. His confidence made me feel more confident.

How does this experience shape your view of Lucile Packard Children's Hospital Stanford and your colleagues there?

Desai: I've known and respected Dr. Hanley as a friend and colleague for a long time. But being in the position of the protective parent was different. I'm really happy with the care he gave my daughter.

But successful surgical outcomes also depend on outstanding contributions of the many other caregivers who are part of the care team. I will always be grateful to all the excellent physicians, nurses, and staff in the operating room, CVICU, and pediatric ward who provided such professional and attentive care to my daughter and my family.

You also helped found Camp Taylor, a series of summer camps here in California for children with heart disease and their families. In hindsight, how did your family's participation in the camp help prepare both of you for Maya's diagnosis?

Desai: Ordinarily, physicians get to spend about 30 minutes in an appointment with their patients. We don't get to know them very well that way. But spending a week with them at camp, you become

part of a giant family of heart patients. You get to see the other side and hear the patients' stories about what it's like to live with heart disease — the entire journey from diagnosis and treatment to getting married and living life.

Living 15 years with a healthy daughter and then suddenly finding out that she too has congenital heart disease — it was a very strange thing for me. Now I had skin in the game. But knowing these other children and their families and seeing how they've come through it helps.

Maya: I went to the camp with my parents when I was younger, but when I got older I stopped going because I didn't feel like I fit in. I didn't know I had heart disease at the time. Looking back on it now, knowing some of those kids made my journey less scary. A lot of them are going to college and doing normal things.

Did being a cardiologist and a cardiologist's daughter make the process easier? How does this change your perspective for the future?

Desai: It was a double-edged sword. It was terrible knowing everything that could go wrong, which I didn't share with my family. And because I'm a cardiologist, everything working up to the surgery was streamlined. Everything happened so fast we didn't have time to process it as a family.

On the other hand, after doing this for 20 years, you're able to put things in perspective. You know just what to expect and how to prepare your child for it.

Maya: It was great having parents [her mom, Julie, is a former nurse] who could explain everything to me. Any question I had, they could answer. And my dad and doctors encouraged me to be active after the surgery. I'm already back to riding horses, playing my violin, and riding my bike up a pretty steep hill to school.

Desai: As for the future, this made me part of the club. I'm no longer the cardiologist looking from the outside in. I know what it's like to walk in the shoes of a parent of a child with heart disease. Now I can tell my patients and their families that I really do know what they're going through. •



Heart and Soul By Megan

Nurses in the Heart Center deliver extraordinary care and compassion on the front lines

It's not uncommon this time of year to see refrigerators covered with holiday cards and warm wishes from friends and family. But the multitude of cards on display in our Children's Heart Center's break rooms often share sentiments much deeper than the average "Happy Holidays." They feature proud updates from parents whose children were once fighting for survival just down the hall. Many of the cards are addressed to individual nurses, whom families remember fondly even five or 10 years after their child has left our hospital.

The 150 nurses working in the Heart Center build strong bonds with patient families as they serve as the most constant and handson point of connection between patients and medical teams.

Catherine Krawczeski, MD, the James Baxter and Yvonne Craig Wood Director of the Cardiovascular Intensive Care Unit (CVICU), believes that the care provided by Heart Center nurses goes beyond what most people imagine.

"Our nurses are the front-line providers for often extremely critical patients, managing the most complex and ever-changing technologies," Krawczeski says. "And while doing so, they provide comfort



to frightened patients and families during a time of crisis, celebrate with them when things go well, and are a source of strength and support for the times they do not."

Whether they are dancing with a teenager to his favorite 1980s music or gently stroking the arm of a toddler while monitoring her connection to a life-saving machine, the depth of dedication and compassion that Heart Center nurses bring to work is almost limitless, says Juanita Hickman, PhD, MSN, RN, interim director of inpatient care in the Heart Center and Pediatric Intensive Care Unit. "To be a nurse in the Heart Center, it takes determination, empathy, and a willingness to learn something new every day."

Hickman says that throughout the Heart Center, nurses carry a sentiment of "service before self" and a commitment to excellence. Many of the Heart Center's nurses have been on staff for more than two decades, watching patients grow from tiny infants to college students. The registered nurses (RNs) in the Heart Center have various degrees and have specific skill sets. A high percentage holds a bachelor's or master's degree and some are certified in a nursing specialty.

"Studies have shown a correlation between the level of patient care and the level of education of the nurse," Hickman says, brimming with pride in her team.

The Heart Center's reputation as a nationally ranked pediatric cardiology program has attracted nurses from



In the Cardiovascular Intensive Care Unit, our specialized nurses provide advanced care for patients before and after major heart surgeries, and play a vital role in ensuring successful outcomes.

as far away as New Zealand, the Philippines, and China who were drawn to the opportunity to be involved with patient care as well as innovative research.

Hickman estimates that nearly one-third of Heart Center nurses are involved in clinical research, including pilot studies about a congenital condition called tetralogy of Fallot, pain management in cardiac surgery patients, and how to best educate parents as they prepare to bring their child home from the hospital.

"Having as many nurses involved in research as we do is unprecedented," she says. "But we are the front line and the 'doers,' so what better way to make sure something can be implemented at the bedside than to have nurses involved?"

Sometimes, it takes unconventional measures to care for children in the Heart Center. Patria Eustaquio, RN, the patient care manager for the center's step-down unit, 3 West, recalls with a laugh a memorable scenario when a 7-year-old girl refused to allow her nurses to insert a nasogastric tube. The tube, which travels from the nose to the stomach, is essential to providing food or medicine to a patient.

"Her nurse kept assuring her that it didn't hurt," Eustaquio remembers. "The little girl asked the nurse, 'Have you had it done before?' and the nurse said, 'No, but I can show you.' She then placed a similar tube into her own nose and down her throat. She removed it in front

of the patient, who then said, 'Okay. Now I can do it.'"

While far beyond the call of duty, Heart Center nurses take exceptional steps to provide extraordinary care for patients, including those in the midst of health crises.

Melanie Munsayac, MSN, RN, the CVICU patient care manager, oversees



Nurse Susanna Zeigler comforts 9-month-old Melina.

nurses who skillfully care for numerous patients with congenital heart defects. A tool that is sometimes used to support a child's recovery is extracorporeal membrane oxygenation (ECMO), a machine that circulates oxygen and blood through the body when the heart and lungs are struggling. Nurses primarily monitor these machines, and Munsayac says they balance the enormity of their responsibilities while maintaining compassionate care for the families at the child's bedside.

"Behind every procedure or high-pressure situation are scared and concerned family members," says Munsayac. "Our nurses recognize that, and their ability to think critically while maintaining strong relationships with patients and families allows them to communicate openly and provide support during incredibly stressful times."

Krawczeski agrees. "Their skill and compassion are the cornerstone of the Heart Center."

How Your Support Helps in the Children's Heart Center

Every day, the Children's Heart Center at Lucile Packard Children's Hospital Stanford delivers unsurpassed outcomes for patients with complex heart conditions. As a not-for-profit hospital, we are very grateful for the donor support that helps make this possible.

"There are hundreds of good children's hospitals in our country, and only a handful of truly great ones," says David Alexander, MD, president and CEO of the Lucile Packard Foundation for Children's Health. "The truly great ones, like Lucile Packard Children's Hospital Stanford, have outstanding leaders and clinicians, an academic research infrastructure, and one other key ingredient — community support that provides resources for innovation."

Philanthropic gifts, including major investments from the David and Lucile Packard Foundation, made it possible for our hospital to establish the Children's Heart Center and recruit top pediatric cardiac specialists such as Drs. Frank Hanley, Stephen Roth, Chandra Ramamoorthy, and many others. This team has propelled the Children's Heart Center into the ranks of the nation's best.

"Clinical revenue supports day-to-day operations," notes Christopher Dawes, president and CEO of Lucile Packard Children's Hospital Stanford. "Philanthropy supports transformational projects and programs that ensure excellence and allow us to provide world-leading care to children and families."

Donor support plays an invaluable role in:

- Advancing research toward better patient care
- Recruiting and retaining top pediatric cardiac experts
- Training the next generation of specialists
- Expanding state-of-the-art facilities so that no child is turned away due to lack of space
- Ensuring care for all children in need, regardless of their families' ability to pay
- Sustaining essential services such as child life and social work, which are not covered by insurance

While much has been achieved, we continue to strive to provide ever better care for the growing number of children and adults with complex congenital heart conditions.

To support the Children's Heart Center, please visit supportLPCH.org.

Shaping a Brighter Future By Stephen Roth, MD, MPH Director, Children's Heart Center



In medicine we often refer to the "natural history of disease"— the normal course that a disease takes in an individual if no treatment occurs. In the case of congenital heart disease, the "natural history" was often death or, at best, survival with significant limitations. Fortunately, that history has changed.

Over the past 70 years, innovations developed by physicians, clinical researchers, engineers, and basic scientists have transformed the care of children with heart disease and made life-saving interventions not only possible but routine at hospitals like ours. New surgical techniques and medical therapies, some of which were developed here at Stanford University School of Medicine and Lucile Packard Children's Hospital Stanford, have evolved and greatly improved outcomes for children with almost every type of congenital heart disease.

Today in the Children's Heart Center, our survival rates following almost all cardiac surgical procedures are at 98 percent, effectively eliminating the poor outcomes that were once the natural history of these common birth defects. With a team of over 250 highly specialized physicians, nurses, and staff, and through our close ties to the School of Medicine and its outstanding research capabilities, we are changing history and shaping a brighter future.

Beyond survival alone, the goal of our care is now to ensure an excellent overall outcome — from normal brain function for even the most fragile patients, to the ability for children to perform well in school and to exercise and enjoy an active life into adulthood. In the Children's Heart Center, our physicians, nurses, and researchers are dedicated to achieving this possibility for the children and families we treat. In partnership with our colleagues in the Johnson Center for Pregnancy and Newborn Services, we have bolstered our capabilities for diagnosing cardiac diseases using advanced imaging

techniques long before babies are born. With prenatal diagnosis, our team can provide optimal planning for care at and shortly after birth, and treat some babies even before they are delivered. Furthermore, as more children survive with congenital heart disease, we are now looking at lifespan care — bringing together the resources needed to provide state-of-the-art, comprehensive care to our patients from prenatal diagnosis all the way through adulthood (see "A Lifetime of Extraordinary Care" on page 24).

In 2017, the much-needed expansion of our hospital will open, allowing us to provide our high-quality, family-centered cardiac care and unsurpassed outcomes to more kids in the Bay Area and beyond. And along with growth in the number of patients and families we serve, we plan to expand our clinical, translational, and basic science research capabilities by recruiting more nationally recognized researchers such as Heart Center faculty members Sushma Reddy, MD, Alison Marsden, PhD, and Doff McElhinney, MD, (see "Thinking Outside the Box" on page 30) who are each making important contributions to further advance the entire field.

Donor support has been critical to the success of the Children's Heart Center since its creation in 2001.

and with continued, strong support from the philanthropic community, we aim to lead our field forward through innovations in the areas of cardiovascular bioengineering, genetics, regenerative medicine, ventricular assist device development, and bioinformatics that will further improve the lives of our patients.



Adult Congenital Heart Program

A Lifetime of By Julie Greicius Extraordinary Care

In August, George Lui, MD, gave the Stone family of Aptos news that none of them, including Lui himself, had expected.

Brooke Stone, 27, had spent the day undergoing rigorous evaluation of her heart function. Now, Lui, medical director of the Adult Congenital Heart Program at Stanford, a collaboration between Lucile Packard Children's Hospital Stanford and Stanford Health Care, joined Brooke and her parents, Barb and George, in the clinic room.

"It's always scary going in for a check-up, because in the past they always found something new," says Brooke. "So we were really nervous this time, too."

But this time was different. Lui, who is also clinical assistant professor of cardiovascular medicine and pediatric cardiology at Stanford University School of Medicine, sat down quietly. "He looked at us and said, 'Everything is really good. Your heart function is in the normal range. We're very excited about this.' My parents and I were speechless, very emotional, and I think he was, too," says Brooke. "It was amazing. I don't think my heart function has ever been normal in my life."

Three years earlier, in September 2012, Brooke had undergone a high-risk, life-saving surgery that was only being done at Lucile Packard Children's Hospital Stanford, only for a small set of carefully evaluated, medically eligible patients, and only by Frank Hanley, MD, executive director of the Children's Heart Center at Lucile Packard Children's Hospital Stanford and professor of cardiothoracic surgery at Stanford. The

surgery involved performing an arterial switch procedure in addition to undoing a previous life-saving but non-curative operation that had been done when Brooke was a newborn. It was Brooke's only hope.

Brooke was born in 1988 with transposition of the great arteries (TGA), a congenital heart defect in which the two main arteries that carry blood away from the heart — the pulmonary artery and aorta — are connected to the wrong pumping chambers of the heart, causing the blood to flow improperly. When Brooke was a newborn at the University of California, San Francisco, a team including Hanley — who was a young surgical fellow there at the time — had performed a complex operation that stabilized her and allowed her to grow and develop, but did not cure her. That surgery, called a Senning procedure, was the most trusted procedure for TGA at the time. Because it wasn't a cure, doctors made sure Brooke's parents understood that she would not have a normal life span or quality of life.

Barb Stone was a fierce advocate for her daughter, continuing her follow-up care and cardiac monitoring while searching for innovations in treatment. "I looked everywhere," says Barb, "from Denver to Germany. I would have taken Brooke anywhere."

Ultimately, there was only one place for Brooke: Lucile Packard Children's Hospital Stanford, where Hanley was, by then, the only surgeon in the U.S. still doing the arterial switch for patients like Brooke who met his strict medical criteria.

Brooke qualified for the surgery not only because of the unique details of her heart's anatomy, but also because she had been carefully monitored by a cardiologist

her entire life. These annual visits ensured that any deterioration in her heart function could be caught and medically managed before she experienced heart failure, and that she would be healthy enough for surgery when the time came. Many patients already in heart failure may be too vulnerable for the lifesaving intervention they need.

Eight months after her 2012 arterial switch and Senning takedown, Hanley performed a third successful surgery to replace Brooke's aortic valve because of residual aortic regurgitation after the arterial switch. Today, Brooke is a healthy 27-year-old with a career in veterinary care, making time for exercise and hula hooping, spending time with her boyfriend of 10 years, and, she says, "just enjoying a normal life for a change."

Yet, even now, empowered by the good news that her heart is functioning in the normal range, Brooke has already scheduled a follow-up visit to confirm the results with further testing, and will continue her annual heart check-ups.

Growing Up With Heart Disease

oday, according to the American Heart Association, 1.3 million adults and one million children are living with congenital heart disease (CHD) in the U.S. Each year about 40,000 children are born with CHD, about half of whom survive into adulthood. But surviving into adulthood doesn't happen by chance. For all people born with CHD, like Brooke, knowing that their heart is never "cured" could be, paradoxically, the very thing that saves their lives.





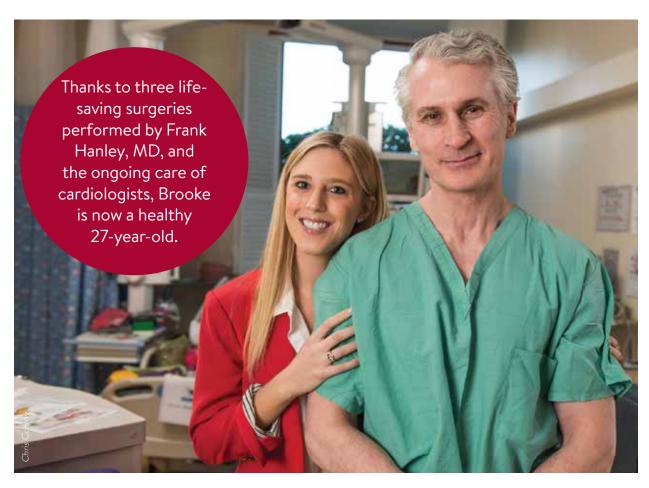
From the day Brooke was born with a complex heart condition, she needed innovative treatments and careful cardiac monitoring.

"Many parents of children with CHD don't recognize that their kids need lifelong cardiac care," says Susan Fernandes, LPD, PA-C, program director of the Adult Congenital Heart Program at Stanford, and lead author of a 2011 study on the topic. "It is estimated that more than 50 percent of adults with CHD are not receiving specialized, adult congenital cardiac care or are lost to follow-up, most falling out of appropriate care before mid-adolescence."

A cardiologist specializing in adult congenital heart disease is the best choice because a primary care doctor may not know about the potential complications of a CHD condition, and adult cardiologists are more experienced with heart diseases that are acquired later in life, which are very different than the heart conditions present at birth. The heart of a person with CHD may be weakening (heart failure) and experiencing potentially lethal, abnormal rhythms, known as arrhythmias, without any outward signs or symptoms.

This unseen risk points to the need for a lifetime of specialized monitoring, which can include annual echocardiograms, cardiac catheterizations, and advanced imaging such as MRI or cardiac CT, and perhaps additional surgeries in the future. This lifespan approach, along with bold advances in treatment, has helped more children with CHD do what was once unimaginable: thrive far into adulthood.

In the Adult Congenital Heart Program at Lucile Packard Children's Hospital Stanford, lifespan care means just that. "You're born here at our hospital with a congenital heart defect, you get your heart surgery



here; our cardiologists and nurses follow you through your adolescent years, teach you how to advocate for your health, and educate you about how to become an adult with CHD. Then we introduce you and transfer you to an adult practitioner at Stanford Health Care, and then, if you want to get pregnant, we support you through pregnancy and deliver your baby at Lucile Packard Children's Hospital Stanford. Then, when you're 40 and you need heart surgery again, we do your heart surgery," says Lui. "So, working closely together across both hospitals, we are your family that takes care of you from zero to 100."

By zero, Lui is referring to the comprehensive screening, diagnosis, and care patients get at Lucile Packard Children's Hospital Stanford before they're even born. "We encourage all of our patients to understand the impact that their CHD has on their future offspring," says Fernandes. "We offer genetic counseling and all of our pregnant patients have a fetal echocardiogram to look for CHD in the fetus during pregnancy."

Theresa Tacy, MD, director of the fetal cardiology program and echocardiography laboratory at Lucile Packard Children's Hospital Stanford and associate professor of pediatrics at Stanford, coordinates care for fetuses who are at risk for or diagnosed with a congenital heart defect — whether or not the mother has CHD.

"We diagnose fetuses with heart disease," says Tacy. "Just as important, we counsel families and develop a very close bond with them so that they fully understand all of their options and what lies ahead." Tacy's team also draws together multidisciplinary teams to plan and prepare for the baby's high-risk birth. "By the time the baby arrives, we've already prepared for everything and know exactly what the baby will need."

Pregnant women are referred to the fetal cardiology service when a routine ultrasound shows an abnormality in the fetus' heart. Others are referred for a careful screening when their preexisting health condition such as CHD in the mother or father, maternal diabetes obesity, or lupus — is associated with increased risk of fetal heart defects or dysfunction.



Some of the most complex congenital heart conditions cannot be treated before birth, which is why Tacy's team works closely with the Maternal-Fetal Medicine team at Lucile Packard Children's Hospital Stanford, ensuring counseling, coordination, and the safest possible delivery for high-risk births. Helping fragile newborns with complex heart conditions live past their first days and weeks is a job for a diverse collection of specialists, and can involve medication, surgery, and more often a combination of the two. As they grow, these children will also need a lifetime of monitoring.

Filling the Gap of Care for Adults

he careful monitoring that ensured Brooke's good health and paved the way for her second life-saving surgery is, tragically, not the norm. Christy Sillman, RN, who works as the nurse coordinator for the Adult Congenital Heart Program, was born in 1980 with tetralogy of Fallot with pulmonary atresia — a life-threatening condition that includes several defects of the heart, including the absence of the vessel that carries blood from the heart to the lungs. She survived infancy by the place-

ment of a shunt, followed by several more treatments and surgeries through her adolescence.

She had surgery for a leaky heart valve when she was 17— a surgery again performed by Hanley— and a year later her pediatric cardiologist sent her on her way with a clean bill of health and the instruction that she never needed to see a cardiologist again.

"He told me to have a nice life," Sillman recalls.

But 10 years later, when Sillman was married and in her second trimester of pregnancy, she started having arrhythmias. Though she was stabilized and able to give birth to a healthy son, she found herself in a far worse situation two months later. Sillman was found to have cardiomyopathy, a disease of the heart muscle, and was diagnosed with heart failure. Thankfully, medication and exercise were successful treatments. Sillman now gets regular monitoring of her heart.

Today, in her nursing role at Lucile Packard Children's Hospital Stanford, Sillman has turned the danger of that experience into a benefit for her patients — and

she's a favorite among them. "Many times my patients come in and say, 'Can I see Christy?" says Lui. "It just shows the connection that Christy brings to them about their experience."

Sillman sees her advantage both ways. "Not only do I help the patients, but I help the providers as well," she says. "They might ask me, 'I have to deliver some bad news

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appropriate care before

Susan Fernandes, LPD, PA-C

and I was going to say this. What do you think?' I can provide perspective from my experience as a patient. And as a provider, I can ask if they'd like me to be in the room for the discussion. I straddle both lines, patient and provider."

To Sillman, one of the unique advantages to our Adult Congenital Heart Program is the physical connection between the children's and adult hospitals. As Sillman sees it, that physical connection also represents

the deep connection and collaboration between the adult and pediatric congenital heart disease expertise. "We are truly made up of both institutions and seek consultation from both sides," says Sillman. "That's really the unique edge that our program has, that sets us apart from all others."

That connection is part of the breadth of care that the Adult Congenital Heart Program provides, with a diverse team that spans pediatric and adult care and includes surgeons, adult congenital cardiologists, fetal cardiac specialists, advanced practice providers, nurses, social workers, and psychologists.

At the other end of the lifespan spectrum, care teams in the Adult Congenital Heart Program have also studied patients with CHD for their risk of acquired heart disease — the leading cause of death worldwide, including conditions such as coronary artery disease, stroke, and peripheral vascular disease. "In the past we didn't think patients with adult congenital heart disease would live long enough to be at risk for these conditions," says Fernandes. "Our study showed that we need to start educating medical providers to start screening adult congenital heart patients for these risk factors, and taking steps to reduce their risks."

As our care teams and medical researchers successfully help more and more newborns survive infancy,

childhood, and adolescence, one additional challenge remains: will there be enough cardiologists specializing in adult congenital heart disease to care for them?

"Because this is a relatively new subspecialty, there are currently just 16 institutions in the United States who train these individuals in medical fellowship programs, including Stanford University School of Medicine,"

says Lui. There are more than 1,000 pediatric cardiologists for 1 million kids with CHD, and only a little more than 100 trained adult congenital heart disease specialists for 1.3 million adults. Most of the institutions train only one or two specialists in adult congenital heart disease each year, or in some cases, every other year.

"This means that less than 15 individuals are being trained every year," Lui notes. "That's a problem

when you have more than a million of these patients in the U.S., with an estimated 20,000 new patients with CHD graduating into adult care every year."

Thanks to the Adult Congenital Heart Association (ACHA) Actelion Fellowship Award and support from generous donors, Lucile Packard Children's Hospital Stanford has funding to provide a two-year fellowship for a single fellow every other year in adult congenital heart disease. Our first fellow, Christiane Haeffele, MD, will complete the program in spring 2016. "With more funding," says Lui, "We could increase this training to one fellow every year."

Our Adult Congenital Heart Program has also been recently chosen as one of only five pilots sites in the U.S. for adult congenital heart disease program accreditation by the Adult Congenital Heart Association, as a model to achieve consistency of care and inclusion for patients and practitioners. In May 2016, the ACHA will open the accreditation process to the entire country.

And that training is essential for every patient with CHD, like Brooke Stone and Christy Sillman, whose lives depend not only on life-saving surgeries and medical advances, but on the consistent dedication of an adult congenital cardiologist who can be a lifelong partner to these unique patients and liaison to the right care at the right time.

Thinking Outside the Box By Rina Shaikh-Lesko

With some of the nation's most innovative researchers in pediatric cardiology, the Children's Heart Center is transforming the health and well-being of children with heart disease in our community and around the world.



Doff McElhinney, MD

Director, Clinical and Translational Research Program, Children's Heart Center at Lucile Packard Children's Hospital Stanford

What if you could take all the physician notes, all the MRIs, all the x-rays and lab results that patients have accumulated at different doctors' offices and hospital visits and bring them all together? What insights and patterns might doctors and researchers learn by analyzing large-scale data?

Doff McElhinney, MD, professor of cardiothoracic surgery at Stanford University School of Medicine, is

driving progress toward finding out what patient care in that kind of connected world might look like.

As McElhinney explains, electronic patient data and data-gathering devices are becoming ubiquitous, creating an excellent opportunity to utilize high throughput analytics to glean important insights and enable more precise, personal, and effective health care. Such advances are especially crucial for the most vulnerable patients with complex, chronic conditions, such as children with single ventricle heart defects.

A year ago, McElhinney moved across the country to Stanford to take the helm as director of the Children's Heart Center's new Clinical and Translational Research Program. The novel program, one of only a few like it in the nation, provides critical infrastructure for collaborative pediatric heart research at Lucile Packard Children's Hospital Stanford and brings clinicians and researchers together to speed the process of translating basic science findings into medical advances.

Through these collaborations, McElhinney is keen to explore novel areas of research. "Although tremendous advances have been made in the management of children and adults with congenital heart disease, there are still many unsolved problems and opportunities to move the field forward," he notes.

The Clinical and Translational Research Program is pursuing investigations into the fundamental pathophysiology, evaluation, and care of patients; the development of new medical devices and technologies; and the use of big data to analyze information from patient records and further our understanding of complex clinical and pathological processes.

McElhinney aims to elucidate how personalized medicine can be applied to cardiac care. "Oncologists use

different drugs based on the type of mutations, and that allows for different care," he says. "Maybe it's the same thing in congenital heart disease. A clearer, finer understanding of that patient may allow for more fine-tuned

"Although tremendous advances have been made in the management of children and adults with congenital heart disease, there are still many unsolved problems and opportunities to move the field forward."

Doff McElhinney, MD

medication." Stem cell therapies are another arena that McElhinney is eager to investigate as a promising treatment for congenital heart defects — one that can be personalized to each patient's needs.

Fortunately, McElhinney is in the perfect place to find answers to these important

questions. The Clinical and Translational Research Program is ideally situated at Stanford University, a research-intensive institution already leading the way in using big data to tackle challenges in biomedicine and make a global impact on the way we diagnose, treat, and prevent disease.

"Stanford has a dynamic, innovative culture in terms of working with information in creative and progressive ways," McElhinney says. "We're hoping to leverage that culture to do unique things in the cardiac program. We're really hitting our stride and bringing a lot of people together."

McElhinney says that one of the draws of pediatric cardiology for him are the challenges that still need to be addressed, considering the anatomical and physiological complexities pediatric cardiologists deal with. "In so many dimensions, there's more to learn. It's not the same job it was when I started," he says. "And it won't be the same in 10 years."

Alison Marsden, PhD

Associate Professor of Pediatrics (Cardiology) and of Bioengineering

A decade ago, Alison Marsden, PhD, was designing quieter airplane wings. But when she completed her dissertation on wing optimization for her PhD in mechanical engineering at Stanford, she knew she wanted to pursue something more down-to-earth for her postdoctoral studies.

As it turns out, her background in mechanical and aerospace engineering provided the perfect foundation for her current role — designing better surgeries for children with congenital heart disease.

"I was interested in working on something that had a more human application," she says. "And I found it extremely motivating to work on medical problems in children."



Partnering with Jeffrey Feinstein, MD, MPH, a pediatric cardiologist and the Dunlevie Family Professor of Pediatrics (Cardiology) at Stanford, Marsden spent long hours learning about cardiology and shadowing Feinstein on his rounds at Lucile Packard Children's Hospital

"Computer modeling

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Alison Marsden, PhD

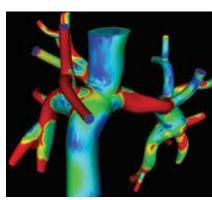
Stanford. "He would guiz me like I was a med student," Marsden recalls, laughing. Eventually, Marsden and Feinstein became major collaborators.

Marsden, who recently returned to Stanford as associate professor of pediatrics in cardiology after several years on the faculty at the University of California, San Diego, applies her knowledge of fluid mechanics to understand how blood flows through the hearts and blood

vessels of children with congenital heart defects. She started out using her computer simulations diagnostically and now also uses computer models to find ways to improve surgical procedures.

Teams building engineering solutions to medical problems are relatively common, Feinstein explains, but ensuring those theoretical designs will work in a clinical setting, as Marsden does, is a higher hurdle to jump. "It's a miniscule group of people who choose to do what she does, and who do it as well as she does," Feinstein says. "Having her as a member of our pediatric cardiology faculty is a tremendous asset as we seek to further refine care for our patients."

Marsden's work provides a way of testing new surgery designs on the computer before trying them on patients, much like engineers use computer codes to test new designs for airplanes or automobiles. Marsden and her team have simulated a refinement of a surgical procedure called a Fontan - the last step in a series of



Marsden uses computer models to develop and test novel surgical techniques for children with complex heart

operations that children with single ventricle defects must undergo in order to survive.

In the Fontan surgery, the large veins returning blood to the heart from the body are directly connected to the arteries that send deoxygenated blood to the lungs,

> forming a modified T-shaped junction. This bypasses the heart on the one side so that the resulting circulation puts the single pumping chamber to optimal use. Using models derived from MRI image data, Marsden used computer models to design and optimize a new type of connection for the Fontan procedure in the shape of a Y (called the Y-graft Fontan). Computer models can help pediatric surgeons determine whether

this procedure will benefit a patient, as well as how a patient's heart will perform during moderate exercise.

"Computer modeling makes it possible to test out high-risk, high-reward approaches," Marsden says. "It gives us a way to test out-of-the-box ideas with no risk

That Y-graft refinement was recently successfully tested in a pilot study in six patients with promising clinical outcomes. Marsden is now beginning to develop refinements and novel approaches to other pediatric heart surgeries as well.

"Alison's work enables us to look at things we can't look at in any other way," says Feinstein. "The whole concept of simulation-based medicine offers opportunities to try things with zero risk to the patients. With this type of computer modeling, you can do 100 simulations before you ever try it in a patient."

Sushma Reddy, MD

Assistant Professor of Pediatrics (Cardiology)

Can tiny strands of mouse RNA teach us how to help children with congenital heart defects live longer, healthier lives? Sushma Reddy, MD, assistant professor of pediatrics in cardiology, says yes, and is uncovering signals in mouse blood that can warn doctors about impending heart failure.

Reddy first became interested in cardiology as a medical student. Why cardiology? "It's the physiology that

makes it absolutely exciting and it makes you think on your feet," Reddy says. Since then, there have been tremendous strides in treating congenital heart defects, and patients are staying alive and doing better than they were 20 years ago.

"We are continuing to push technological boundaries to aid our patients," she says, noting that there are still many unanswered questions.

Reddy is particularly interested in children born with one functioning ventricle — a condition called single ventricle heart defect. Even after a series of complex surgeries to improve the situation, these children continue to have one pumping chamber instead of two, and they are thereby not as strong as children with normal hearts.

"At some point in time, all these children go into heart failure - all of them," explains Reddy. Doctors use echocardiograms and cardiac MRIs to keep tabs on how well the hearts of these patients are doing, but early signs of trouble may be undetectable using these imaging tech-

"The children and families I see are amazing. It's a privilege to take care of them, and their perseverance motivates me to find the best possible treatment."

Sushma Reddy, MD

niques. By the time they show clinical evidence of heart failure, the disease is advanced and most medical therapies are ineffective in reversing this process.

Reddy is tackling this problem by studying heart defects in mice that mimic the problem human congenital

heart disease patients have. Specifically, she studies the machinery that regulates the genes and proteins mediating heart failure. She found that tiny strands of RNA – microRNAs – are one marker of impending heart failure. "We've identified a group of microRNAs that we think are important," says Reddy. "They give us clues of when the heart is beginning to decompensate, much sooner than the current methods that we use. We have early data in children with heart disease showing that these biomarkers are useful predictors of disease progression."

She is currently collaborating with other centers to see if the blood biomarkers she identified in mice are also present in children on a larger scale. The best approach, she says, is to combine blood biomarker tests with current



imaging tests to give the most complete picture of how well a patient with congenital heart disease is doing.

Reddy's research recently received a major boost when she was awarded a Mentored Clinical Scientist Research Career Development Award, a K08 grant from the National Institutes of Health (NIH), which will fund her work on understanding the mechanisms of heart failure and the development of biomarkers over the next five years. In her first years at Stanford, Reddy relied on private sources such as grants from the Children's Heart Foundation and a gift to the CVICU to fund her research. Those early grants and gift funding allowed her to establish preliminary data, which she has now successfully leveraged to garner the prestigious NIH grant. "It was the private funding that helped me get where I am now," she notes.

Reddy says she admires the willingness of her patients to try new approaches. "The children and families I see are amazing," she says. "They are born with the disease and live with it for their life span. It's a privilege to take care of them, and their perseverance motivates me to find the best possible treatment."

Corporate Philanthropy

Coldwell Banker Residential Brokerage

"When we heard stories

who have received

from Lucile Packard

Children's Hospital

Stanford, Coldwell

Banker's independent

sales associates and staff

were so touched that it

• Mike James, president of Coldwell

Banker Residential Brokerage

was impossible not to

jump in and help."

outstanding care

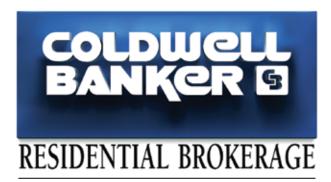
about the local families

rom Santa Rosa to the Monterey Peninsula, Coldwell Banker Residential Brokerage branches across the greater Bay Area rallied to support Lucile Packard Children's Hospital Stanford this year. On May 19, the Coldwell Banker Community Foundation, the philanthropic arm of Northern California's leading real

estate services company, kicked off its inaugural "Give Health. Give Hope." employee giving campaign, inviting more than 3,000 Coldwell Banker affiliated sales associates from 54 branches to participate.

Raising more than \$80,000, the seven-week campaign engaged employees, family, friends, and their local communities in a variety of creative ways, including a companywide raffle, parking lot sales, wine tasting, and Bocce ball events. Coldwell Banker Residential Brokerage executives say it wasn't hard to get agents and staff behind the fundraising once they learned more about the hospital.

"This wonderful organization has helped so many kids in need throughout the Bay Area who might otherwise not have received the urgent care they desperately needed," says Mike James, president of Coldwell Banker Residential Brokerage. "When we heard stories about the local families who have received outstanding care from Lucile Packard Children's Hospital Stanford, Coldwell Banker's indepen-



dent sales associates and staff were so touched that it was impossible not to jump in and help."

Coldwell Banker Residential Brokerage in Gilroy alone raised \$12,000 at "The Party in the Vineyard" held at Fortino Winery in May with great food and raffle items organized by agents and staff. The branch also collected

> and shared stories from agents and local families whose lives have been touched by the hospital.

Coldwell Banker's Burlingame offices partnered with the San Mateo office to host the "Rock and Roll for Health and Hope" fundraiser. Featuring tunes from their very own "As-Is" band, sales associates, staff, and community members gathered for a fun evening in support of health, hope, and excellence at Lucile Packard Children's Hospital Stanford.

Other events were also hosted by the Los Gatos, Menlo Park, Monterey Peninsula, Novato, Portola Valley, San

Francisco, San Jose, Santa Rosa, and Woodside offices. In addition to each branch's individual fundraising efforts, Coldwell Banker colleagues participated in the 2015 Summer Scamper 5k/10k race. The Coldwell Banker community and their families were among the more than 3,200 individuals who walked, ran, and volunteered to support patients and their families.

Proceeds from Coldwell Banker Residential Brokerage's employee giving campaign will go to the Lucile Packard Children's Fund, serving the hospital's highest priority areas. One hundred percent of each dollar raised will directly support care for thousands of children and expectant mothers by funding uncompensated care, family and community services, and child health research.

To learn more about corporate giving, please visit supportLPCH.org/corporate.

Foundation Grants

Alex's Lemonade Stand Foundation

Since 2000, Alex's

Foundation has raised

million toward fulfilling

founder Alexandra

"Alex" Scott's dream

of finding a cure, and

500 pediatric cancer

funded more than

research projects

nationally.

Lemonade Stand

more than \$100

lex's Lemonade Stand Foundation (ALSF), a

national fundraising movement launched by the creativity of one young cancer patient, has provided generous support to expand our capacity for pediatric cancer research. Recently, ALSF awarded more than \$1 million in grants to five Stanford scientists using innovative approaches to address important challenges in understanding and treating pediatric cancers. These awards are providing our Bass Center for Childhood Cancer and Blood Diseases powerful opportuni-

ties to translate groundbreaking work

in Stanford labs into life-changing

benefits for young cancer patients.

Maria Grazia Roncarolo, MD, and Sheri Spunt, MD, MBA, professors of pediatrics and co-directors of the Bass Center for Childhood Cancer and Blood Diseases, received a five-year \$625,000 Phase I-II infrastructure grant. Its purpose is to bring a portfolio of unique Stanford-driven discoveries successfully through Phase I and II pediatric clinical trials. Roncarolo is the George D. Smith Professor in Stem Cell and Regenerative Medicine and chief of the Division of Pediatric Stem Cell Transplantation and Regenerative Medicine. Spunt is Endowed Professor of Pediatric Cancer and chief of the Division of Pediatric Hematology/ Oncology.

Michael Cleary, MD, Lindhard Family Professor in Pediatric Cancer Biology and professor of pathology, received a two-year \$250,000 Innovation Grant to study and characterize individual cells, tracking how they respond when acute leukemia begins to develop. Cleary hopes to use this insight to develop novel treatments with less toxicity and fewer long-term negative effects.

Ramin Dubey, PhD, and Siu Ping Ngok, PhD, both postdoctoral research fellows, each received a two-

> year \$100,000 Young Investigator Grant. Dubey's research seeks to discover resistance mechanisms and biomarkers that will identify which cancer patients will most benefit from specific chemotherapy drugs. Ngok will investigate the causes of Ewing sarcoma, a common bone cancer in children and young adults, to create methods for preventing its development.

Since 2000, Alex's Lemonade Stand Foundation has raised more than \$100 million toward fulfilling founder Alexandra "Alex" Scott's dream of

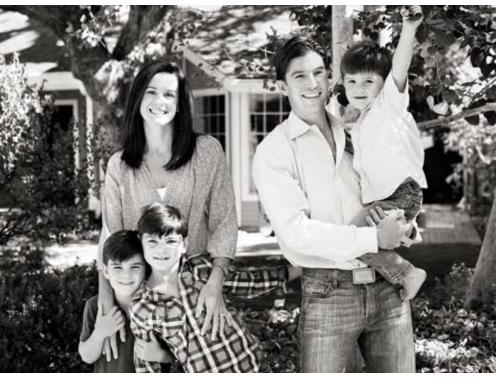
finding a cure, and funded more than 500 pediatric cancer research projects nationally.



To learn more about foundation giving, please visit supportLPCH.org/foundation.

Children's Circle of Care

The Staley Family



ocelynn Staley says her relationship with Lucile Packard Children's Hospital Stanford has evolved over time from a concerned parent to a grateful supporter.

The Staley family's first connection to the hospital came when their son, Cole, was admitted to the Neonatal Intensive Care Unit shortly after birth. After a week and a half, Cole was able to head home, and continued to return for visits with specialists over the next three years. Because of the care he received early on, Cole has grown into a healthy, thriving 8-year-old who enjoys spending time with his two younger brothers, Wyatt and Reid.

Jocelynn and her husband, Jeff, look back on those early days with Cole and feel appreciation and admiration for the care they received.

"We felt so fragile," Jocelynn remembers. "But once he made it through, we felt so grateful. It was not just the doctors, but also the nurses, the social workers, and more — the whole team — that made us feel supported as an entire family. It became important for us to give back." "As we learned more about the hospital and saw the depth of the resources and innovation available, we realized what an important part of our community it is." • Jocelynn Staley

In the years following their experience with Cole, Jocelynn and Jeff have seen many others benefit from the world-class care available at our hospital.

"We've had friends go through other medical challenges, and we've seen how other families in the community have benefited from areas of the hospital including the transplant and oncology programs," Jocelynn says. "As we learned more about the hospital and saw the depth of the resources and innovation available, we realized what an important part of our community it is."

Today the Staleys belong to the Children's Circle of Care (CCOC), supporting the *Lucile Packard Children's Fund* annually. Their gifts, and those of other donors, are directed to the hospital's highest priorities including community and social services, research, and uncompensated care.

"Forty percent of the hospital's patients need financial assistance. It's hard to think about how families deal with the financial burdens of this kind of crisis on top of everything else. It's been important to Jeff and me that our donations go into the *Children's Fund* to help these families," Jocelynn says. "And we also saw the hospital's commitment to innovative research, so we felt comfortable giving in a general way, trusting that there will be an impact from our contribution."

The Children's Circle of Care recognizes donors who give \$10,000 or more annually. To learn more, visit **supportLPCH.org**.

Gift Planning

John Kriewall and Elizabeth Haehl

ohn Kriewall and Elizabeth Haehl are loyal supporters of our hospital. In 2000, the couple was instrumental in the establishment of the Pediatric Palliative Care Program, which combines compassionate and collaborative care to provide complete physical, emotional, social, and spiritual support to children facing very serious illness. Their contribution included the establishment of the John A. Kriewall and Elizabeth A. Haehl Directorship for Palliative Care, currently held by Barbara Sourkes, PhD.

Philanthropic support, including bequests, helps ensure that Lucile Packard Children's Hospital Stanford and the child health programs at Stanford University School of Medicine have the resources to provide extraordinary care to our patients.

"It has been our privilege to give back," says John, "and that can come in many different forms."

In addition to establishing the Palliative Care Program, John and Elizabeth have also chosen to include our hospital in their estate plan. "As parents ourselves, we know how important having a world-class children's hospital is for this community," Elizabeth explains. "Our greatest gift, and our greatest responsibility, will be providing for tomorrow and the next generation."

John retired from a career at RCM Capital Management in San Francisco and currently serves on the board of the Lucile Packard Foundation for Children's Health. Elizabeth is currently on the board of Jasper Ridge Farm and previously worked helping children with special health care needs and their families. They are involved with other nonprofit organizations that focus on children's health and education, including the Children's Health Council, where they helped start Sand Hill School. As they continue to share their resources and plan ahead, they ensure that tomorrow is even better than today.

Through their bequest designation, John and Elizabeth are investing in the future of our hospital — and creating a pipeline for tomorrow's success.



Giving Through Bequest

A bequest offers great flexibility and can reduce the size of the taxable portion of your estate. It can be given through a specific amount, percentage, or remainder share. Depending on your interest and the language you specify in your will or living trust, it can be used for restricted or unrestricted purposes. You can give through cash, securities, real estate, or other options, such as including our hospital as the beneficiary to your life insurance policy or retirement fund.

Suggested Bequest Language:

"I hereby give to the Lucile Packard Foundation for Children's Health, a California not-for-profit 501(c)(3) corporation (tax ID# 77-0440090), the following: (description of the dollar amount, portion of estate, or property) to support Lucile Packard Children's Hospital Stanford."

To learn more about making a bequest or other planned gift, please visit **supportLPCH.org/ giftplanning**.

news



Yasser El-Sayed, MD

El-Sayed Appointed Associate Dean for Maternal and Child Health

aternal-fetal medicine expert Yasser El-Sayed, MD, has been appointed an associate dean for maternal and child health at Stanford University School of Medicine. El-Sayed will focus on obstetrics and related women's issues, ensuring that pre-conception and pregnancy-related care are fully integrated into the portfolio of services at Lucile Packard Children's Hospital Stanford and into the school's strategic planning.

El-Sayed is also the Charles B. and Ann L. Johnson Professor and director of the Division of Maternal-Fetal Medicine and Obstetrics at the School of Medicine, co-director of the Johnson Center for Pregnancy and Newborn Services, and obstetrician-in-chief at Lucile Packard Children's Hospital Stanford. Over the course of his career, El-Sayed has been instrumental in developing and directing the division's clinical and research programs.

Save the Date: Childx Conference

n April 21-22, 2016, leading researchers and clinicians will gather at Stanford University School of Medicine to discuss critical

challenges and share the latest advances in child and maternal health research, with the aim of transforming the landscape of patient care.

April 21-22, 2016 ♥ Stanford, California child X The top voices in child and maternal health

The second annual Childx Conference will feature thought

leaders from Stanford and across the nation addressing the most salient health topics for children and expectant mothers, ranging from innovative technologies that deliver precision in pediatric health, advancing our understanding of the integrated human system, and creating new diagnostic paradigms, to the social justice of precision health and ensuring access in developing communities worldwide.

This event is sponsored by the Stanford Child Health Research Institute, Stanford Medicine, Lucile Packard Children's Hospital Stanford, and the Lucile Packard Foundation for Children's Health. Interested community members are welcome to attend. For more information, visit childx.stanford.edu.

Silicon Valley Business Journal Recognizes Carrion for Excellence in Healthcare

In August, Victor Carrion, MD, director of the Stanford Early Life Stress and Pediatric Anxiety Research Program at Lucile Packard Children's Hospital Stanford, received the Silicon Valley Business Journal Excellence in Healthcare Award.

"Very early in life, it was clear to me that people had this great potential of being anything they wanted to be, but environmental circumstances



Victor Carrion, MD

would shape that in different ways to different people," Carrion says. "I took that as a mission to help people develop to their full potential."



Bustamante Named Chair of Biomedical **Data Science**

arlos Bustamante, PhD, professor of genetics and founding director of the Stanford Center for Computational, Evolutionary and Human Genomics, has been appointed chair of the new Department of Biomedical Data Science. The department will build on the School of Medicine's strengths in using information technology to advance precision health by analyzing biomedical data from sources including biosensors, electronic medical records, and genomic sequencing.

CIO Kopetsky Receives Lifetime Achievement Award

n June, our hospital's chief information officer, Ed Kopetsky, received the 2015 CIO of the Year Lifetime Achievement Award from the Silicon Valley Business Journal, San Francisco Business Times, and PwC. The award recognized Kopetsky's significant contributions to the field of information technology and his use of IT to advance health care.



Five Life-Saving Organ Transplants in 48 Hours

ne weekend this summer turned into a 48-hour whirlwind of multiple organ transplants at our hospital. On Friday night, July 17, surgeons Katsuhide Maeda, MD, and Olaf Reinhartz, MD, performed a heart-lung transplant, while Waldo Concepcion, MD, Carlos Esquivel, MD, PhD, and Andrew Bonham, MD, performed a liver transplant. The next day, three hours after completing the heart-lung surgery, Maeda and Reinhartz performed a heart transplant on a baby. Then on Sunday, Amy Gallo, MD, and Concepcion led, respectively, a kidney transplant in a young girl and a liver transplant in a young adult.

"Five transplants in that amount of time is unusual in a children's hospital," says Esquivel, the Arnold and Barbara Silverman Professor in Pediatric Transplantation. "But when it happens, we're prepared. This really shows the depth of the institution and our transplant programs."

glassybaby Helps Fund Packard Playcart

ancer survivor and entrepreneur Lee Rhodes founded glassybaby in 2001 with a vision for helping others. Ten percent of proceeds from every handcrafted "glassybaby" candle holder is donated to charity — including Lucile Packard Children's Hospital Stanford.

The "grateful red" glassybaby, specially designed for our hospital, helps fund the Packard Playcart, providing books games, and toys to some of our most critically ill patients. To date, sales of



glassybabu one of a kindness®

"grateful red" have raised more than \$12,000 for our hospital.

news



New Teen Health Van Hits the Road

| n October the new Teen Health Van made its debut, and medically underserved adolescents from San Francisco to San Jose will now receive care on the most technologically advanced "doctor's office on wheels" in the nation. The new unit is the result of a partnership between Stanford Children's Health, Children's Health Fund, and Samsung, as well as the generous support of the Westly Foundation, Fabian and Caroline Pease, and our seven Auxiliaries.

"Our purpose is to really be a safety net for those youths who otherwise would not have access to the kind of comprehensive primary health care services that we provide," says Seth Ammerman, MD, medical director of the Teen Health Van and a clinical professor of pediatrics in adolescent medicine at the School of Medicine.

Since the Teen Health Van program was established in 1996, it has served more than 4,500 patients during 15,000 visits. Serving seven sites in the Bay Area, the Teen Health Van is the single point of health care access for many homeless and uninsured teens and young adults. The Teen Health Van provides care free of charge and relies on philanthropy for its ongoing operations.

New Chief of Pediatric Critical Care

/ anwaljeet J. S. ("Sunny") Anand, MD, DPhil, has been appointed the new chief of the Division of Pediatric Critical Care. Anand, who comes to Stanford from the University of Tennessee Health Science Center in Memphis, has published more than 250 peer-

reviewed articles and received numerous awards for his research on neonatal pain and stress. In addition to providing clinical and academic leadership at Lucile Packard Children's Hospital Stanford, he will also lead pediatric critical care faculty located throughout Stanford Children's Health, including at John Muir Medical Center.



Kelly M. Johnson, PhD, RN, NEA-BC

Johnson Named VP for Patient Care Services and Chief **Nursing Officer**

elly M. Johnson, PhD, RN, NEA-BC, is joining Stanford Children's Health and Lucile Packard Children's Hospital Stanford in November as vice president for patient care services and chief nursing officer.

"We are incredibly fortunate to have such a strong and experienced leader step into this very important role," says Anne McCune, chief operating officer. "Kelly has proven time and again to be an innovator in providing high-quality, safe, and compassionate health care."

Johnson has more than 22 years of experience as a health care executive and chief nursing officer. She served most recently as the Dori Biester Chair in Pediatric Nursing and senior vice president and chief nursing officer at Children's Hospital of Colorado. ■

Golf Classic Supports New Mental Health Program

On September 21, 18 foursomes of donors and friends played in the second annual Golf Classic to help raise funds for the child and adolescent mental health programs at Lucile Packard Children's Hospital Stanford and Stanford University School of Medicine.

Held at the beautiful Stanford University Golf Course, the day's highlights included Mitch Juricich (host and creator of KNBR's "Hooked on Golf") serving as emcee, members of the Stanford women's golf team helping players with their swing, and a chance to drive from the fairway to the freeway in a brand new Lexus with a hole-in-one.

The event raised \$180,000 for the mental health programs at our hospital and School of Medicine. During the reception, Antonio Hardan, MD, director of the division of child and adolescent psychiatry, shared plans for the development of a new crisis team that will include a child psychologist and pediatric psychiatrist and provide individual, family, and group therapy and pharmacotherapy services. Clinicians will be available daily to provide crisis evaluation to children and adolescents who are referred by the emergency department or who are acutely ill and lack appropriate mental health services. The new service may prevent hospitalization and allow for stabilization and more optimal treatment of patients.



Honorary Committee:

Jeff Chambers and Andi Okamura Suzanne and J. Crandall Keith Fox Evan Goldberg Michèle and Steve Kirsch Lauren and Brad Koenig Anne and Ken Lawler David Lee Xin Liu Katy Orr Mindy and Jesse Rogers Sara Terheggen



Barb Fallon, Maude Scott, Laurie Bassin, and Andi Okamura



Mitch Juricich, Antonio Hardan, MD, and David Alexander, MD



Ken and Anne Lawler, Jacque and John Jarve



Marshall Koch, Paul Edwards, Cary Cole, and Oliver Evans



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