



Stanford  
Children's Health

Betty Irene Moore  
Children's Heart Center



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# Stanford Advantage

## Unrivaled Research Fuels Clinical Success

Lucile Packard Children's Hospital Stanford is proud to be the pediatric and obstetric teaching hospital for Stanford Medicine – one of the foremost academic medical institutions in the country, home of the West Coast's oldest medical school, and a worldwide leader in patient care, education, research and innovation.

Established in 1885, Stanford University is one of the world's leading research universities and premier academic institutions, particularly noted for its top-ranked programs in the physical and biological sciences. Our young heart patients benefit in myriad of ways from the multidisciplinary research and groundbreaking innovation that characterize Stanford research. Stanford Medicine has long been at the center of cutting-edge medical advances, including performing the first successful adult human heart transplant in the country and the first combined heart-lung transplant in the world. Every day, our Children's Heart Center team works closely with Stanford's researchers, educators and engineers to cultivate their scholarship and translate it into best-of-class pediatric care.

# Basic Science and Engineering (BASE) Research Initiative

The Betty Irene Moore Children's Heart Center launched the Basic Science and Engineering (BASE) Research Initiative in 2018, under the direction of Marlene Rabinovitch, MD, and the leadership of the Children's Heart Center under Frank Hanley, MD.

We believe the field of congenital cardiac care is currently at a critical juncture along its evolutionary path: Looking forward, the next major advances in survival, quality of life, and true cures will not be achieved using our well-established techniques. Rather, new approaches, derived from discoveries in basic science and engineering will fuel the next wave of advances in the management of children's heart disease. BASE is positioned to contribute to play a leading role in this new era.

Our overarching goal is to address the challenges we face in children with heart disease through innovation in computer science, bioinformatics, machine learning and engineering disciplines, interfacing with advances in genetics, developmental, chemical and structural biology, cell physiology and metabolism. The integration of these disciplines can be applied to reverse damage and to regenerate young and developing heart tissue, valves, blood vessels, and lungs.



Dr. Rabinovitch joined Stanford University School of Medicine Faculty in the summer of 2002 as the Dwight and Vera Dunlevie Professor of Pediatric Cardiology, and Scientist at the Vera Moulton Wall Center for Pulmonary Vascular Disease. She is also the Associate Director in Basic Research at Stanford's Cardiovascular Institute. From 2002-2013, she was appointed as Professor (by courtesy) of Developmental Biology. Dr. Rabinovitch is a graduate of McGill University Medical School and completed her pediatrics training at the University of Colorado and sub-specialty training in cardiology at Boston Children's Hospital, Harvard Medical School. She was Assistant Professor at Harvard and then moved back to Canada where she became Associate and later Professor of Pediatrics, Laboratory Medicine and Pathobiology, and of Medicine at the University of Toronto, Hospital for Sick Children. There, she was the Director of Cardiovascular Research and held the Robert M. Freedom/Heart and Stroke Foundation Chair.

“Research and care are linked. It's always been my philosophy that there are many ways to take care of patients. Finding new answers is one of them.”

*Marlene Rabinovitch, MD*

# The Heart Center

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The Betty Irene Moore Children’s Heart Center at Stanford Children’s Health is an internationally-recognized Center of Excellence that offers the most advanced diagnostic and therapeutic modalities available for addressing the entire spectrum of congenital and acquired cardiovascular disorders in babies, children and adults with congenital heart disease.

Formally established at Lucile Packard Children’s Hospital Stanford in 2006, the Betty Irene Moore Children’s Heart Center was founded on decades of historic achievements by Stanford Medicine physicians. After performing the first successful adult human heart transplant in the United States at Stanford Hospital in 1968, surgeon Norman E. Shumway, MD, PhD, and his surgical team performed the world’s first successful pediatric heart transplant on a 2-year-old patient in 1984. That same patient has received continued care at Lucile Packard Children’s Hospital Stanford, which opened in 1991, and Stanford Health Care. She is the world’s longest-surviving pediatric transplant patient and is thriving with the heart she received more than 30 years ago.

In 2004, cardiologists at Lucile Packard Children’s Hospital Stanford used the “Berlin Heart,” a miniature external heart-pump attached to the heart by tubes, to help a 5-month-old – the youngest patient ever to receive the device – survive for 55 days until a heart transplant saved his life. The Packard Children’s team also used the “Berlin Heart” to help another 5-year-old survive for a record-breaking 234 days until transplant, longer than any child in North America.

As one of the world’s premiere centers for the development of new scientific and technological innovations for the care of children with heart disease, the Moore Children’s Heart Center has pioneered groundbreaking treatments such as unifocalization, a procedure used to treat tetralogy of Fallot with pulmonary atresia and major aortopulmonary collateral arteries. These advanced procedures are reinforced by the Heart Center’s unparalleled outcomes: our overall non-risk-adjusted survival rate is greater than 97 percent, which is especially remarkable given that high-complexity and high-risk patients are referred to the Heart Center from around the world.

Today, our physician-scientists continue to lead investigations into the fundamental biology, diagnoses and care of heart disease and to develop new medical devices and technologies to improve outcomes for our patients. They’re also harnessing “big data” gathered from patients across the continuum of care to advance understanding of the pathological processes of heart disease so we can deliver personalized care. Among their many and diverse projects, investigators in the Moore Children’s Heart Center are currently leading the first-ever randomized controlled clinical trial of an anti-rejection therapy in children who have received heart transplants, in keeping with Stanford’s long history of leadership in this field.



# Pediatric Cardiothoracic Surgery

Our pediatric cardiothoracic surgeons reliably succeed at procedures considered daunting elsewhere, including surgery for premature or low-birthweight babies, complex heart transplants, ventricular assist device (VAD) implants, and highly specialized pulmonary artery reconstruction for patients with Williams syndrome or others with pulmonary atresia and major aortopulmonary collaterals.

In part, our program is successful because we do so many operations; the literature is clear that outcomes in pediatric heart surgery relate directly to the volume of procedures performed. More is distinctly better. Only five pediatric cardiac programs in the United States conducted more than 500 heart surgeries last year. We performed close to **1,000**. Our success also stems from our extraordinary teamwork. Our **10** dedicated pediatric heart surgeons, **60** pediatric cardiologists, **11** pediatric cardiac anesthesiologists and **3** pediatric heart-imaging specialists combine their expertise into one focused effort to bring the very best treatment to each unique young patient. We also exploit powerful new technologies for anesthesia, perfusion, imaging, and surgery itself and our new larger ORs afford ample space for everything and everyone needed to make

them work. For example, our surgeons have worked closely with pediatric cardiac imaging specialists to develop 3D imaging of complex heart conditions that can be displayed on large monitors just behind the operating table, so that surgeons can use a road map to explore the cardiac defect they are addressing in real time. The better surgeons can visualize the nuances of a patient's heart defect, the faster and more thoroughly they can access and correct it. We extend and amplify the impact of our expertise through partnerships with hospitals in Sacramento, Honolulu, and Madera. Our surgeons and other specialists regularly travel to and treat patients at these centers and sometimes, for particularly complex cases, patients are sent here to Packard Children's for their surgery.

“It is the entire team working so closely and in concert that allows our outcomes to be so good.”

*Frank Hanley, MD*  
*Chief, Pediatric Cardiothoracic Surgery*



# Frank Hanley MD

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**Chief, Pediatric  
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Medical Education  
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Fellowship  
University of California San Francisco  
Medical Center (1988)

Board Certification  
Thoracic Surgery, American Board  
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Frank Hanley, MD, has always been drawn to complex frontiers. When he was a junior surgeon in the 1990s, pulmonary atresia with aortopulmonary collaterals and the problems it presents constituted challenging terrain. Back then, young children with disorders such as tetralogy of Fallot with complex pulmonary artery abnormalities typically required multiple surgeries. Mortality was high, and quality of life was not good for those who survived. Dr. Hanley consolidated several procedures into one innovative marathon surgery, called unifocalization, that has transformed both the field and the lives of those who have undergone it. Decades later, Dr. Hanley has conducted more than 1,000 unifocalization procedures. With mortality rates at about 2 percent, the procedure has become almost routine for him. While Dr. Hanley has trained other top surgeons to do unifocalization, and while the procedure has spread to several international heart centers, Dr. Hanley remains the world's authority on the procedure and Stanford Children's remains the best place on earth for children to get reconstructive pulmonary artery surgery. Dr. Hanley also oversees the Pediatric Cardiac Surgery Lab, which continues to push back other frontiers, as well. His research foci include fetal heart surgery, bioengineered heart valves that will one day grow along with the babies who receive them, and blood-flow dynamics studies aimed at improving circulation to the brains of our tiny heart surgery patients.

# Pulmonary Artery Reconstruction Program

Stanford Children's Health is the world leader in pulmonary artery reconstruction (PAR) for patients with congenital cardiovascular disease. The surgical procedures that define the cutting edge of this practice were invented and perfected by our chief cardiothoracic surgeon, Frank Hanley, MD. But while PAR requires a powerful surgical effort, the needs of this patient population begin before surgery and extend beyond it.

The multidisciplinary approach of the PAR Program focuses on the entire experience of the patient and family from first contact. "The program takes a holistic approach to patient care. We help patients and families prepare not only for their surgery, but also for rejoining their communities after surgery and for the rest of their lives, as well," says PAR Program Director Doff McElhinney, MD. The program offers patients a much higher level of individualized care. "Our aim is to be responsive, personal, engaged, reassuring and informative," says Dr. McElhinney. "While health care is outstanding today, there is always room to better understand and further refine our practices so we can improve the quality of evaluation and treatment and

continue pushing the frontier," he continues. Because Lucile Packard Children's Hospital Stanford sees more pediatric PAR patients than any other medical center in the world, we are also best positioned to study them and their outcomes. How, for example, does the pulmonary vasculature of patients with different genetic conditions respond over time? Which patients are most at risk for the emergence of new complications? In addition to data analytics, Stanford-based research in areas such as less-invasive approaches to imaging the heart, vasculature and blood flow; genetic therapies; and tissue engineering are positioned to further improve the treatments we provide our patients in years to come.



“We hope not only to improve the patient experience from the time they contact our program through the time of their procedures and beyond, but also to facilitate more efficient and higher-level care.”

*Doff McElhinney, MD  
Director, Pulmonary Artery  
Reconstruction Program*

# Doff McElhinney MD

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Medical Education

University of California San Francisco (1998)

Internship and Residency

Children’s Hospital of Philadelphia,  
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Fellowships

Boston Children’s Hospital, Pediatric  
Cardiology (2005) and Pediatric  
Interventional Cardiology (2006)

Board Certification

Pediatric Cardiology, American Board  
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Adult Congenital Heart Disease, American  
Board of Internal Medicine (2015)

It was through his work at other great hospitals that Doff McElhinney, MD, became aware of “just how unique Frank Hanley’s surgical abilities are.” Specifically, he was impressed by Dr. Hanley’s pulmonary artery reconstruction (PAR) surgery. Indeed, patients and their families come to Stanford Children’s Health from around the world to be treated by Dr. Hanley, our chief of pediatric cardiothoracic surgery. However, from the moment they arrive until well after they leave, our patients’ needs extend beyond the operating room, says Dr. McElhinney, director of the new Pulmonary Artery Reconstruction Program. “These complex patients face several challenges,” he explains. “Many of them come from great distances and aren’t necessarily well prepared for the intensity of the testing, procedures and surgical preparations they find here. Many of them also have associated conditions.” Dr. McElhinney is passionate about what he can do to help these patients and their families, but he also cares deeply about what they can do for each other. By closely tracking the details and outcomes of all PAR Program patients, he and his colleagues hope to advance their understanding of these conditions in order to provide the best care for every patient. For example, can we predict which patients might avoid some invasive testing and which must be especially vigilant for the possible emergence of specific complications later in life? “Examining neurodevelopment,” he says, “and how different surgical or anesthetic techniques and other conditions may impact learning and behavior over time in this population are just a couple of important areas we are currently studying.”



## PAR Program

A rare pulmonary defect prompts parents' nationwide search for answers. After hearing that their baby was not a candidate for a life-saving surgery they scoured the internet for help that led them to Lucile Packard Children's Hospital Stanford.

When Carter Johnson came into the world on January 9, 2018, he was perfect in every way, according to his parents, Kelly and Malcolm. But their joy was short-lived and replaced with worry and fear.

Something wasn't quite right. Carter's color was off and he was turning grey, prompting the care team at the local hospital in the Baltimore–Washington Metro area of Maryland to whisk him to the neonatal intensive care unit (NICU) for tests. When that failed to provide answers, the family was sent to a regional hospital for further examination. That's where they discovered there was no blood flow into Carter's right lung. He was diagnosed with a rare condition called absent right pulmonary artery.

Time was of the essence. Typically, this condition is associated with multiple congenital heart defects, prompting additional echocardiograms, more tests and a rapid search for answers. In Carter's case, his doctors in Maryland determined that the uncommon malformation was isolated. But risks were high, as Carter's test results revealed pulmonary hypertension and other complications could be imminent. Carter needed help.

### Searching for the best treatment

Kelly and Malcolm were told by the regional hospital that the best course of treatment for Carter's condition was surgery but that he was not a candidate because, as Malcolm describes, "The small size of his artery and

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lack of a good target in the lung for connection (to the artery).” Malcolm went into research mode and delved into pages of medical journals. He also sought second and third opinions from some of the nation’s leading children’s hospitals. All the results of his research pointed to the same treatment plan of placing a shunt to initiate blood flow to the right lung. This plan would require repeat surgeries throughout Carter’s life to up-size the shunt as he grew. Malcolm wasn’t satisfied with that.

“I’m stubborn by nature,” he laughed. “I just felt there was something else for Carter.”

One night, on his laptop he came across the Pulmonary Artery Reconstruction (PAR) program at Lucile Packard Children’s Hospital Stanford. He shook Kelly awake and told her, “I think I found it.”

The next day, Kelly and Malcolm were on the phone with Jennifer Shek, a nurse practitioner in the Cardiothoracic Surgery department at Stanford Children’s Health. She told them Carter was a promising candidate for the PAR program. The team – led by Division Chief of Pediatric Cardiothoracic Surgery Frank Hanley, MD, and Director of the Pulmonary Artery Reconstruction Program Doff McElhinney, MD – is rated as a top cardiology and heart surgery program in U.S. News & World Report and has been recognized worldwide for using innovative approaches for surgical management of complex pulmonary artery procedures.

After the team at Stanford reviewed Carter’s cardiac catheterization and angiography tests, they saw that Carter did in fact have a pulmonary artery, but it was in the wrong place. The doctors diagnosed Carter with discontinuous pulmonary artery resulting from a ductal origin, the condition is also sometimes called absent pulmonary artery. A unique surgical approach to Carter’s case would restore his lung blood flow without requiring any long-term treatments.

“We could hardly believe our ears,” said Kelly.

According to McElhinney, the Stanford Children’s team’s unique experience and expertise with complex pulmonary artery reconstruction surgery and

management is the expert care that the Johnson’s needed to get the best result for Carter.

“We perform 2-3 complex pulmonary artery repair and reconstruction procedures every week on patients from all over the world,” said McElhinney. “Our techniques pioneered by Dr. Hanley and practiced by his surgical partner Dr. Michael Ma, allow thorough and complete enlargement of pulmonary artery branches not only outside of the lung but within the lung as well.”

### Exceeding all expectations

Carter underwent two surgeries in 2018 to repair his defect. His first surgery in June implanted a shunt that established blood flow to his right lung, which doctors expected would allow his pulmonary artery to grow naturally. Five months later in November 2018, Hanley and team performed the final artery reconstruction in which they removed the shunt and connected the grown pulmonary artery. During the five months between the two surgeries, Carter’s pulmonary artery grew to normal size – surpassing the doctors’ expectations.

Today, Carter is back home in Maryland and doing well. His hometown medical care team – from his pediatrician to his cardiologist – have communicated frequently with the Stanford team to ensure fully coordinated care, coast to coast.

“Dr. Hanley and his team have delivered on their promise that Carter will live a normal life,” said Kelly. “[Dr. Hanley] told us [Carter will] be repaired [and] he will run, play baseball and have no restrictions. As parents, that was our greatest hope.”

“We perform 2-3 complex pulmonary artery repair and reconstruction procedures every week on patients from all over the world.”

*Doff McElhinney, MD  
Director, Pulmonary Artery Reconstruction Program*

# Pediatric Cardiothoracic Bloodless Surgery Program

A compelling and growing body of evidence demonstrates the advantages of minimizing or eliminating the use of blood products during surgery. Patients who avoid transfusions have lower infection rates, spend less time in the intensive care unit (ICU) and on ventilators, are less likely to experience adverse immune responses, and recover more quickly, in general.

Going bloodless also eliminates any chance of the rare but potentially catastrophic event of transfusing with mismatched blood. The techniques that make bloodless surgery possible even for small children have come a long way in recent years. Key innovations such as the use of much smaller circuits in heart-lung bypass machines, the recovery and recycling of blood during surgery, and the evolution of less invasive surgical techniques have all contributed to making bloodless surgery possible for smaller and smaller patients. Led by surgeon Katsuhide Maeda, MD, the Betty Irene Moore Children's Heart Center's Pediatric Cardiothoracic

Bloodless Surgery Program is focused on advancing minimally invasive surgical techniques (which have significant advantages beyond simply reducing blood loss), using new medications to bolster red blood cell levels before surgery, quickly stopping blood loss during surgery, and researching the safety of working at lower hematocrit levels than are now standard. Dr. Maeda and Vamsi Yarlagadda, MD, a pediatric cardiologist and the program's co-director, are dedicated to bringing all the advantages of bloodless surgery to even the smallest patients at Packard Children's and, through a training program, to the field of pediatric surgery at large.

“Since high school, I’ve been fascinated by congenital heart conditions, by the complexity of the anatomy involved and by the great potential of surgical corrections to help.”

*Katsuhide Maeda, MD*

*Director, Pediatric Cardiothoracic Bloodless Surgery Program*



# Katsuhide Maeda MD

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Medical Education

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Residency

Asahi General Hospital (1998)

Fellowship

The University of Tokyo (2004)

Board Certification

Japanese Board of General Surgery (1999)

Japanese Board of Cardiothoracic  
Surgery (2005)

Japanese Board of Cardiology (2010)

When Katsuhide Maeda, MD, studied medicine in Japan, minimizing the use of donated blood had long been a priority, mainly because the donated blood supply in Japan often contains pathogens. “When I came to the United States for further study as a young surgeon,” Dr. Maeda remembers, “I was a little shocked by how much blood was used here.” As proof accumulated that avoiding transfusion has other benefits, too, Dr. Maeda began to reconsider his early training in order “to make every effort to avoid unnecessary blood transfusion. It’s just better for the patients,” he says. Dr. Maeda is also focused on perfecting minimally invasive techniques for pediatric congenital heart surgery. Such methods are more common in adult heart surgery than in pediatrics. One advantage of minimally invasive techniques such as using smaller incisions and avoiding cutting the sternum to gain access to the heart, is that these techniques help eliminate the need for transfusions. Other advantages for patients include spending less time in the ICU, quicker recovery, reduced likelihood of post-surgical complications, and smaller scars. “I want to increase my patients’ chance for life and improve the quality of their lives,” explains Dr. Maeda. “They’re not responsible for their conditions, and they deserve the very safest and best treatment we can give them. That includes minimizing the use of blood products and eliminating surgeries that are unnecessarily invasive.”

# Pediatric Cardiac Anesthesia

The Betty Irene Moore Children's Heart Center's 11 pediatric cardiac anesthesiologists are remarkably diverse in their interests and areas of expertise. They all share a dedication to minimizing the discomfort and suffering of our young patients while keeping them safe and sound, but the team has subspecialists in heart transplants, ventricular assist device (VAD) implantation, bioethics and genetics, bioinformatics, and complex case coordination.

Young patients with multiple concerns often require anesthesia for several procedures, each conducted by a different subspecialist. An anesthesia subspecialist is often in the best position to track these patients as they move from one area to the next and not only to optimize their anesthesia, but also to coordinate protocols, ensure safety and avoid potential redundancy or conflicts in treatment. The anesthesia team works closely with surgeons, of course, but it also works with intensive care physicians, interventional cardiologists and cardiologists working with adult congenital heart disease patients.

Our dedicated, world-class pediatric anesthesiologists are pushing back the boundaries of understanding about the long- and medium-term neurodevelopmental effects of anesthesia, as well as the long-term, quality-of-life impacts that different anesthesia approaches can have on single ventricle patients. Other team physicians are also studying coagulation management, which could have great significance for transplant and VAD patients, among others. Still other faculty are exploring the best anesthesia protocols for surgeries that avoid or minimize the use of blood products.



“Anesthesiology is a kind of hub for the Heart Center’s other programs.”

*Madalane Gail Boltz, MD  
Director, Pediatric Cardiac Anesthesia*

# Madalane Gail Boltz MD

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Medical Education  
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George Washington University (1984)

Residency  
George Washington University (1986)

Fellowship  
Children’s Hospital Colorado, Anesthesia (1987)

Board Certification  
Anesthesia, American Board of Anesthesiology (1988)

“Although everyone in our group is a pediatric cardiac subspecialist, we are a very diverse bunch. We each have interests that complement those of the others,” says M. Gail Boltz, MD, the Betty Irene Moore Children’s Heart Center’s director of pediatric cardiac anesthesia. Her own focus is complex care coordination, or leveraging anesthesiology’s interconnection with all the other programs in order to optimize care for the many patients who frequently cross departmental boundaries. In addition to coordinating multiple treatments for multiple conditions, Dr. Boltz and her colleagues also help patients whose families choose “bloodless” surgery. By minimizing blood draws for labs and employing techniques to recover, clean and re-infuse a patient’s own blood cells during surgery, Heart Center physicians can reduce or eliminate the need to use donor blood for transfusions. While some of these techniques have long been deployed to treat Jehovah’s Witness patients, who object to transfusions on religious grounds, they are now being applied to broader patient populations to reduce infection and occasional harmful immune responses to donor blood. “We also work with a lot of single ventricle patients,” says Dr. Boltz, “and we want to know how different approaches to anesthesia during their surgery may influence their neurodevelopment in the longer term. Understanding even subtle neurological effects, which could be amplified over decades, can make big differences to the quality of our patients’ lives.”

# Cardiovascular Intensive Care Unit

Last year, more than 700 patients (including more than 600 patients after heart surgery) were cared for in the 24-bed pediatric Cardiovascular Intensive Care Unit (CVICU) at Lucile Packard Children’s Hospital Stanford, which provides extraordinary care for critically ill heart patients in the region.

Thirteen cardiovascular intensive care physicians with advanced training, six of whom are board certified in both pediatric cardiology and pediatric critical care medicine, provide direct patient care in the CVICU. They collaborate with surgeons, imaging specialists, nurses, respiratory therapists and ten advanced practice providers, all of whom are committed to achieving the best possible outcomes for our patients. In light of a growing awareness of the long-term multisystem ramifications of heart disease, the CVICU team focuses not only on post-surgical recovery and acute illness, but also on minimizing the risks of downstream health complications. The CVICU draws complex congenital heart disease patients and end-stage heart failure patients from around the world, many of whom will eventually need transplants or mechanical circulatory

support. As a result, the CVICU’s multidisciplinary teams are developing clinical practice “pathways” to optimize care before, during and after surgeries, along with procedures for optimizing outcomes, shortening hospital stays and reducing costs. In 2015, the CVICU launched a cardiac consult service for all critically ill patients in the hospital, including those in the Pediatric and Neonatal Intensive Care Units. In the next year, the CVICU will expand to 30 beds due primarily to growth in the Heart Center’s surgical program. CVICU faculty members are leading research efforts in quality improvement, cardio-renal physiology, care of single ventricle patients, respiratory failure in patients undergoing unifocalization surgery, clinical trials of new therapies, and the basic science underlying right ventricular failure.



24

Beds



13

CVICU faculty



700+

Patients per year



# Vamsi Yarlagadda MD

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**Children's Medical Center Dallas,  
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**Residency**

**Children's Medical Center Dallas,  
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**Fellowships**

**Boston Children's Hospital, Boston,  
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**Board Certification**

**Pediatrics, American Board of Pediatrics (2003)**

**Pediatric Critical Care Medicine, American  
Board of Pediatrics (2008)**

**Pediatric Cardiology, American Board  
of Pediatrics (2006)**

Vamsi Yarlagadda, MD, director of the Cardiovascular Intensive Care Unit (CVICU), is determined to further integrate knowledge and collaboration among the dedicated specialists who help the more than 700 patients who come through the unit each year. The CVICU provides care for newborns, young children, adolescents and young adults with congenital and acquired heart disease. "Our patients are inherently unstable, so everything we do matters. We have to pay very close attention. There is no room for mistakes," he said. Dr. Yarlagadda is also director of the Heart Center's Extracorporeal Membrane Oxygenation, or ECMO, program. He has a special interest in furthering the utilization of VADs and ECMO for critically ill infants and children, who are increasingly able to use devices as a bridge to cardiac transplantation. Because of all they've been through, these patients tend to be complex cases that require clinicians with deep expertise to achieve optimal outcomes. "It is the managing of all the subtleties of making sure the heart, kidneys and liver are all happy and working well together that stretches us and makes us better doctors," Dr. Yarlagadda explained. "The magic happens when we can help patients take that first step after surgery, stabilize them so they can recover as fast as possible, and then send them off toward what may well be a long and healthy life."



## Bloodless Surgery

Physicians at Lucile Packard Children’s Hospital Stanford performed open-heart surgery without a blood transfusion for the smallest infant ever to undergo such a procedure in North America. The surgery was done in a 10-day-old baby girl born in Hemet, California with a serious congenital heart defect.

From the moment of her birth on October 21, little Lola Garcia struggled to breathe. She and her parents, Felisa and Jared Garcia of Hemet, California, were rushed to a children’s hospital near the family’s home.

Lola was diagnosed with transposition of the great arteries, a congenital heart defect in which the heart’s major arteries are not connected correctly. Normally, the blood follows a single figure-eight-shaped circuit through the heart and lungs, then back to the heart and out to the body to supply oxygen to the internal organs and the brain. In Lola’s heart, the blood made two separate

circuits – from the heart to the lungs and back, and from the heart to the body and back. The normal figure-eight was separated into two poorly connected loops. Her brain and other organs did not get enough oxygen.

“They said she would definitely need heart surgery, and most likely a blood transfusion, to correct the problem,” said Felisa. “We were happy there was a solution, but when they said ‘transfusion,’ my heart dropped.” The Garcia family are Jehovah’s Witnesses; they requested that Lola’s surgery be done without a blood transfusion because of their religious beliefs.

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Although many hospitals now offer bloodless surgery for adults, the challenges of avoiding transfusion are much greater in newborns who need open-heart procedures. Several hospitals around the country turned the family down. But the pediatric cardiothoracic surgery team at Packard Children's offered to attempt baby Lola's arterial switch procedure without transfusing blood.

During surgery, Lola needed to be connected to a heart-lung machine which would pump her blood through a circuit of tubing and membranes for re-oxygenation.

The machine's tubing is primed with saline that mixes with the patient's blood. For an adult, the volume of saline in a standard heart-lung machine does not dilute the blood enough to be dangerous, but a 7-pound newborn has much less blood to begin with. Connecting Lola to a standard heart-lung circuit would have dangerously lowered her red blood cell count.

In the past, the problem has been solved by transfusing blood. For Lola, the Packard Children's team took a different approach.

"We used a miniaturized heart-lung circuit so that we could use a much lower priming volume of saline," Hanley said. The team of surgeons, anesthesiologists, cardiologists and other experts also planned every step of Lola's care to minimize blood loss, monitoring her with as few blood draws as safely possible and picking surgical techniques and materials with

minimal blood loss in mind. Hanley and pediatric cardiothoracic surgeon Katsuhide Maeda, MD, operated together to enable them to perform the surgery as precisely as possible. "There were multiple decisions we made before, during and after surgery to minimize the likelihood of bleeding," Hanley said.

Still, the team could not guarantee in advance that Lola would not need a transfusion. California state law gives physicians authority to decide to administer blood to a

minor in emergency situations, even if the parents disagree. When they shared their plan with Felisa and Jared Garcia before surgery, the physicians explained the steps they would take to reduce blood loss, and told the parents they had set a safe lower threshold for Lola's red cell count. "If it reached the threshold, we planned that we would evaluate Lola for

negative effects, and if she was showing those, we would give blood," Hanley said.

During and after surgery, Lola's red blood cell count stayed in the safe range. As she recovered, the family and doctors soon saw the medical benefits of her bloodless procedure.

"I couldn't believe how fast she was healing," Jared said. "Dr. Yarlagadda had said she would be in the hospital for at least a month, but we went home in less than two weeks. It was great."

"Lola is doing fantastic; she looks phenomenal," Hanley said. "Our team is excited to build this program that will help many other children and families in the future."

*"There were multiple decisions we made before, during and after surgery to minimize the likelihood of bleeding."*

*Frank Hanley, MD  
Chief, Pediatric Cardiothoracic Surgery*

# Pediatric Cardiology

The Betty Irene Moore Children’s Heart Center is a “destination program” that draws some of the most complex cases of congenital and acquired pediatric heart disease from around the country, and yet our patients and families experience some of the best outcomes and survival rates in the United States.

For decades, our pediatric cardiology faculty have worked at the leading edge of pediatric heart disease research to develop and hone approaches to diagnosis and treatment for infants, children and adolescents with cardiovascular disease. We diagnose congenital heart defects through echocardiograms, cardiac MRI and CT scans, cardiac catheterizations, and electrophysiology studies. We manage critically ill cardiac patients and address the many sequelae of pediatric heart disease. As our understanding of the long-term health consequences of heart disease deepens, our need for collaboration grows, both across divisions in the Heart Center and across the Stanford research and clinical ecosystems. The Heart Center’s clinical reach extends beyond

our Palo Alto home. Within in the Packard Children’s Health Alliance, we have cardiologists based in Capitola, Emeryville, Fremont, Los Gatos, Salinas, San Francisco, San Rafael, Santa Rosa, Sunnyvale and Walnut Creek. Through our extended reach, we conduct over 16,000 cardiology outpatients visits per year. Our cardiac catheterization labs in the expanded Lucile Packard Children’s Hospital Stanford, include a hybrid surgery and interventional catheterization lab that allows for innovative approaches to procedures. The Division of Pediatric Cardiology is also committed to educating the next generation of physicians, including those in our fellowship program who are seeking exceptional advanced training in our discipline’s subspecialties.

“It is our connections to basic science departments, to the School of Engineering and to other programs on the Stanford University campus that help us to be so much more than the sum of our parts.”

*Stephen J. Roth, MD, MPH  
Chief, Division of Pediatric Cardiology*



# Stephen J. Roth MD, MPH

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**Chief, Division of Pediatric Cardiology**  
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Medical Education

**Yale University (1986)**

Internship

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Fellowship

**Boston Children's Hospital,  
Pediatric Cardiology (1992)**

Board Certification

**Pediatric Cardiology, American Board  
of Pediatrics (1994, initial)**

“At the center of all we do in the Heart Center are the patients and their families,” says Stephen Roth, MD, MPH, director of the Betty Irene Moore Children’s Heart Center and chief of the Division of Pediatric Cardiology. “Around them, we have assembled a circle of care composed of a remarkable faculty who are dedicated to doing whatever it takes to achieve the best outcomes and the best experience for patients and families,” he says. Dr. Roth came to Lucile Packard Children’s Hospital Stanford from Boston Children’s Hospital in 2003 to lead the Packard Children’s Cardiovascular Intensive Care Unit (CVICU), where he served as medical director for eight years. When he was appointed chief of Pediatric Cardiology in 2011, Dr. Roth was determined to maintain his division’s reputation for clinical excellence while also amplifying the impact of its research. He envisions a future where heart defects that are currently corrected with surgery will be approached with a set of precise biological tools allowing the repair or regeneration of defective or missing tissue. “I can imagine a day when we wouldn’t have to put in a mechanical valve or replace defective blood vessels with non-living ones. Instead we might fashion new tissue derived from a patient’s own cells,” Dr. Roth says. With advances in regenerative medicine and tissue-engineering techniques, there’s even a chance that we could develop an entire implantable heart. That approach would solve today’s tissue-rejection challenges and ease the shortage of transplantable hearts.

# Adult Congenital Heart Program

Since children born with congenital heart disease (CHD) are much more likely to live long and relatively healthy lives than they would have just 25 years ago, the community of CHD patients — once mostly children — now includes more adults than children.

These survivors require highly specialized care by adult CHD (ACHD) specialists. A collaboration between Lucile Packard Children's Hospital Stanford, Stanford Health Care and Stanford University School of Medicine, the Adult Congenital Heart Program (ACHP), provides exceptional care to the full spectrum of these patients at all stages. As CHD patients age, they often face new heart problems, organ dysfunction, adult comorbidities, psychological issues and high-risk pregnancies. "You need full collaboration between pediatric and adult hospitals to coordinate and provide the [level of] exceptional care we [offer]. It's very rare to find that," says Susan Fernandes, program director of the ACHP. The American Board of Internal Medicine (ABIM) recently recognized

the subspecialty of ACHD in acknowledgment of the specialized care these patients require, and the ACHP has one of the largest concentrations of ABIM-accredited ACHD doctors in the United States, highlighting our commitment to the lifelong treatment of these patients. In late 2016, we were designated one of the first accredited comprehensive care centers for ACHD in the United States in recognition of the patient-centered, high-quality, comprehensive care we provide for ACHD patients. "We also support doctors in the broader community in whatever ways we can, collaborating with them to achieve the best possible outcomes for their adult congenital heart disease patients," says Fernandes.



Susan Fernandes is a clinical professor of Pediatrics and Medicine in the Divisions of Pediatric Cardiology and Cardiovascular Medicine at Stanford University. She has held numerous leadership positions over her 20-year career in congenital heart disease as a clinical physician assistant, researcher, and educator, and she currently serves as the program director for the Adult Congenital Heart Program at Stanford. Dr. Fernandes is a nationally-recognized leader in clinical and health policy research in the field of congenital heart disease and has published and presented extensively on the topic. She is an advocate for improving access to specialized cardiac care for the ACHD population and serves on numerous national committees, including the Adult Congenital Pediatric Cardiology Council of the American College of Cardiology, where she is the co-chair of the council's Adult Congenital Heart Disease Working Group. She is on the medical advisory board of the Adult Congenital Heart Association and is a member of the Association's Accreditation Steering Committee. Dr. Fernandes also serves on the executive committee of the International Society for Adult Congenital Heart Disease and is a select member of the Society's Research Working Group.



“Because of my experience in pediatrics, I have some appreciation for where these adult patients with congenital heart disease are coming from. That understanding is key to charting their best course forward.”

*George K. Lui, MD  
Medical Director, Adult Congenital Heart Program*

# George K. Lui MD

**Medical Director, Adult Congenital Heart Program**  
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**Medical Education**  
**Yale University School of Medicine (2002)**

**Internship**  
**Harvard Combined Internal Medicine and Pediatrics Residency Program (2003)**

**Residency**  
**Harvard Combined Internal Medicine and Pediatrics Residency Program (2006)**

**Fellowship**  
**Columbia University Medical Center, Cardiology (2009)**

**Board Certification**  
**Internal Medicine, American Board of Internal Medicine (2006)**

**Cardiovascular Disease, American Board of Internal Medicine (2009)**

**Echocardiography, National Board of Echocardiography (2009)**

**Adult Congenital Heart Disease, American Board of Internal Medicine (2015)**

As a medical student at Yale, George Lui was interested in becoming a surgeon so he could repair the hearts of children with congenital heart disease (CHD). “At some point, though, I realized that surgeons were already doing a great job of fixing children’s hearts,” says Dr. Lui, medical director of the Adult Congenital Heart Program. “The challenge for these patients had moved downstream; it was keeping them alive and healthy after successful surgeries.” Dr. Lui shifted his sights from surgery to the treatment of pediatric congenital heart disease. After years of training in internal medicine and pediatrics, he adjusted his course once again, throwing himself into a fellowship focusing on adult cardiology and adult congenital heart disease (ACHD). To treat ACHD patients properly, he says, we need both expertise in CHD from pediatric cardiologists and expertise in adult acquired cardiovascular disease. “These patients are living long enough to develop other kinds of problems, some in their hearts and some elsewhere, including diabetes, high blood pressure, and hyperlipidemia.” Today, Dr. Lui is also the program director for Stanford’s ACHD fellowship. He is ideally suited for both of his jobs, leading doctors who are already experts at treating ACHD and training that select group of physicians who are looking to gain such extraordinary expertise. “We’re one of only seven Accreditation Council for Graduate Medical Education (ACGME)-accredited ACHD fellowship programs in the country training cardiologists to take care of these patients,” Dr. Lui says.

# Cardiovascular Connective Tissue Disorders Program

Connective tissue disorders (CTDs) pose potentially grave threats to a patient's cardiovascular system. In fact, symptoms of vascular or heart failure are often the first indicators of a CTD in young patients.

But the effects of CTDs such as Williams, Marfan, and Loeys-Dietz syndromes extend well beyond the cardiovascular system, often causing problems for the skeletal system, joints, teeth and eyes, says Thomas Collins, MD, director of the Heart Center's Cardiovascular Connective Tissue Disorders Program. Williams syndrome patients, for example, should consult not just with cardiologists, but also with geneticists, nephrologists, developmental pediatricians, neuropsychologists, gastroenterologists, orthopedists, and ophthalmologists. For our Williams syndrome patients, the program can assemble top pediatric specialists from all of these areas in a single clinic to drastically reduce wear on caregivers and families and facilitate communication between the specialists.

“When the physicians collaborate in real time, patient outcomes improve,” explains Dr. Collins. “And when patients do well, that draws more patients who fuel research into still more effective treatments.” Dr. Collins is hopeful that current research on deploying viral vectors to deliver corrections to targeted genetic defects may one day lead to cures for CTDs such as Marfan syndrome. Disorders with more complex etiologies, such as Williams syndrome, probably are not similarly curable, but new medications could help patients' bodies better cope with accumulated stresses and other pathological expressions of the disease. The program has an educational component, as well, and seeks to widen the circle of expertise among physicians treating these rare and disabling disorders.



“Our overarching goal is to build the best center in the world for treating and researching connective tissue disorders.”

*Thomas Collins, MD  
Director, Cardiovascular Connective  
Tissue Disorders Program*

# Thomas Collins MD

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Medical Education

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Internship

University of Tennessee Health  
Science Center (2003)

Residency

University of Tennessee Health  
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Fellowships

Children’s Hospital of Philadelphia,  
Pediatric Cardiology (2009) and  
Adult Congenital Heart Disease and  
Cardiac Imaging (2010)

Board Certification

Pediatric Cardiology, American  
Board of Pediatrics (2010)

Adult Congenital Heart Disease,  
American Board of Internal Medicine (2015)

Thomas Collins, MD directs the Cardiovascular Connective Tissue Disorders Program, a clinical, research and teaching program devoted to connective tissue disorders such as Williams, Marfan, and Loeys-Dietz syndromes. As a fellow at Children’s Hospital of Philadelphia, Dr. Collins planned to become an interventional cardiologist until his advisor suggested he study the outcomes of pediatric Williams syndrome patients who’d had interventions in their first month of life. Next thing he knew, Dr. Collins had become the institutional authority on Williams syndrome and eventually other major connective tissue disorders, too. Today, Dr. Collins can diagnose a case of Marfan syndrome from a fair distance. He recently identified a seventh-grade runner as an undiagnosed case as he watched her from the bleachers at an outdoor track. “I knew if she had an enlarged aorta, she shouldn’t be running. I told her parents to bring her in,” he says. Although patients seek him out for his cardiovascular expertise, he knows optimal care requires close collaboration with specialists working on other aspects of the patients’ diseases. When families are overwhelmed with appointments, prescriptions, and medical directives coming from a half dozen different specialists, their compliance often suffers. “When I started gathering all the doctors in the same clinic on the same day, families were elated. And if one specialist needs to consult with another, we can do it in real time while the patient is on hand. That can make a huge difference.”

# Wall Center

Since 1981, when Stanford doctors performed the world's first heart-lung transplant in a patient with pulmonary hypertension (PH), our experts have advanced the frontiers of PH treatment and care, including the discovery of drug treatments that function as a bridge to transplantation or as palliatives for enhancing quality of life in patients who are ineligible for transplant.

In 2000, an anonymous gift established the Wall Center, one of the only programs in the western United States that provides comprehensive diagnostic and therapeutic services to both adults and children with PH. Rarely an isolated disorder, PH is often co-morbid with rheumatic, liver, lung and congenital heart diseases. Our ability to identify, study and address those relationships is just one important benefit of the Betty Irene Moore Children's Heart Center's extraordinary emphasis on interdepartmental collaboration. Our patients have access to the latest large-scale multicenter pharmaceutical trials, and the Wall Center itself typically has between five and ten active studies. The Wall Center

bridges one program for children and another for adults, but the transition for patients is seamless. The teams work together on each patient's transition. If adult-focused physicians have questions about a patient, the pediatricians who treated the patient as a child are there to consult. We are well positioned to study differences in how PH manifests and can be best treated at different ages. That focus is leading to improved drug delivery methods and better-gauged dosages for young metabolisms. In recognition of its excellence as a world leader in the care of PH patients, the Wall Center was designated an accredited Center of Comprehensive Care by the Pulmonary Hypertension Association in 2014.

*Mission: The Wall Center seeks to enhance the lives of patients with pulmonary vascular disease by providing the highest level of clinical care, providing advanced training opportunities for physicians and other health care providers, and participating in clinical and benchtop research in pulmonary vascular disease.*



“One big advantage of having both programs in the same center is the seamless transition in care for patients passing from childhood to adulthood.”

*Jeffrey Feinstein, MD, MPH  
Director, Wall Center*

# Jeffrey Feinstein MD, MPH

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and Pediatric Cardiology**

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**Medical Education**  
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**Children’s National Medical Center (1992)**

**Residency**  
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**Fellowships**  
**Children’s National Medical Center,  
Pediatric Cardiology (1997)**

**Boston Children’s Hospital, Pediatric  
Interventional Cardiology (1998)**

**Board Certification**  
**Pediatric Cardiology, American Board  
of Pediatrics (1996)**

It is much more common for adults to have heart disease than children, so many assumptions underlying pediatric clinical practice are scaled down from the broader and deeper research on adults. But when it comes to medications, children are not simply scaled-down grown-ups. They metabolize drugs at different rates and experience different side effects. Paying close attention to those dissimilarities has had important clinical payoffs for the Children’s Heart Center patients of Jeffrey Feinstein, MD, MPH, medical director of the Wall Center. Dr. Feinstein is collaborating with researchers from three major heart centers to look into how common heart medications are metabolized in children. “The absorption curves for kids are quite different than those for adults. And while the two most common drug delivery methods – intravenous and subcutaneous – require similar dosages in adults, in kids they work differently,” he explains. Dr. Feinstein has also worked closely with fluid dynamics specialist and pediatric cardiology faculty member Alison Marsden, PhD, to develop models that help make new surgery designs possible and that help identify which patients are in urgent need of transplants. “Some of our patients are the sickest of the sick,” says Dr. Feinstein. “Knowing precisely when to actively pursue transplants has been difficult. Waiting too long to put a patient in line is a problem, but so is listing a patient too soon. Our new models help us predict the need for a transplant years before that need is urgent.”

# Single Ventricle Program

The Single Ventricle Program (SVP) at Stanford Children’s Health aims to improve survival rates and optimize functional outcomes for children and young adults with single ventricle physiology by providing comprehensive, longitudinal care for these patients. The Single Ventricle Program builds on the success of our work with infants and aims to improve outcomes in older children and young adults.

Comprehensive, coordinated care with a multidisciplinary approach has improved early survival rates in single ventricle patients locally and nationally. Building on this success, the Single Ventricle Program has been developed to enhance care coordination across multiple settings for single ventricle patients, who often have complex needs that extend beyond cardiology. In addition to a cardiologist and cardiology nurse, single ventricle “champions” who specialize in hepatology,

nephrology, neurodevelopmental psychology, nutrition, child psychiatry, and social work will see the patient and family in a coordinated visit at the same clinic. Patients continue to be managed by their primary cardiologist and will have a consultation visit with the Single Ventricle Program once every one or two years. With the Single Ventricle Program, we hope to extend our promise of “extraordinary outcomes” and “happier, healthier lives” to this unique patient population.



# Gail Wright MD

## Medical Director, Single Ventricle Program

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### Medical Education

Johns Hopkins University  
School of Medicine (1992)

### Internship

Johns Hopkins University  
School of Medicine (1993)

### Residency

Johns Hopkins University  
School of Medicine (1995)

### Fellowships

University of Michigan Medical Center,  
Pediatric Cardiology (2002) and  
Pediatric Critical Care (2004)

### Board Certification

Pediatrics, American Board of Pediatrics (1996)

Pediatric Cardiology, American Board  
of Pediatrics (2002)

Pediatric Critical Care Medicine,  
American Board of Pediatrics (2004)

Gail E. Wright, MD, developed a special interest in children with single ventricle physiology during her pediatric cardiology fellowship at the University of Michigan. Her research at that time investigated risk factors for sudden, unexpected death following the Norwood operation. In 2004, Dr. Wright was recruited to Stanford as a faculty member subspecializing in pediatric cardiovascular intensive care. Soon after her arrival at Stanford, she initiated quality improvement efforts focused on single ventricle infant survival, pediatric ventricular assist devices, and coordination of care for medically-fragile children. In 2005, she worked with a multidisciplinary team to develop the Single Ventricle Interstage Home Monitoring Program, which reduced mortality between the first and second stages of surgical palliation to less than 2 percent. This program subsequently served as a model for the National Pediatric Cardiology Quality Improvement Collaborative, a multicenter learning health network that has improved interstage survival across the nation for this population. Expanding this vision, Dr. Wright is now focused on optimizing long-term functional outcomes in older children and young adults with single ventricle physiology. As the medical director of the Single Ventricle Program, she oversees interdisciplinary longitudinal care for these patients. In addition to helping them live longer, she hopes to continue to improve their quality of life, as well.

# Pediatric Advanced Cardiac Therapy Program

In 1974, Stanford physicians conducted the first successful heart transplant in a child. More than four decades later, more than 440 pediatric heart transplants have been performed at Lucile Packard Children's Hospital Stanford – more than at any other institution in the United States.

In 2004, Packard Children's launched the first heart failure and transplant program fully dedicated to children. Known as the Pediatric Advanced Cardiac Therapy (PACT) Program, it has been so successful for our young patients that it has been imitated across the nation. Not only are we better established and larger than those other programs, we also see the broadest possible spectrum of heart failure patients, from those with a genetic predisposition for cardiomyopathy but no disease symptoms, to those in critical condition awaiting transplantation in an ICU. We care for more than 1,000 clinic patients a year, most of whom have been referred by cardiologists who collaborate with our dedicated experts to co-manage and tailor treatments to the

patients' needs. In addition to transplants, we specialize in using ventricular assist devices (VADs) not just for patients awaiting transplants, but also in selected cases as long-term therapy. We are even exploring the frontier of using VADs to help maintain patients while we heal their hearts with the cardiac medications, and we avoid some transplants altogether through a careful combination of medical treatments and the innovative use of VADs. We also use VADs to help treat heart failure patients with Marfan syndrome and others with single ventricle heart conditions. Our approach to treating antibodies against transplanted hearts gives us a remarkably low rate of organ rejection.

  
**450+**  
Heart transplants

**160+**  
Ventricular Assist Devices (VADs)

**40+**  
Years of experience



“We continuously put the patient at the center of what we do.”

*David Rosenthal, MD  
Director, Pediatric Advanced Cardiac Therapy (PACT) Program*

# David Rosenthal<sub>MD</sub>

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**Professor of Pediatrics (Cardiology)**

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Medical Education

Albert Einstein College of Medicine (1987)

Internship

Columbia Presbyterian Medical Center (1988)

Residency

Columbia Presbyterian Medical Center (1991)

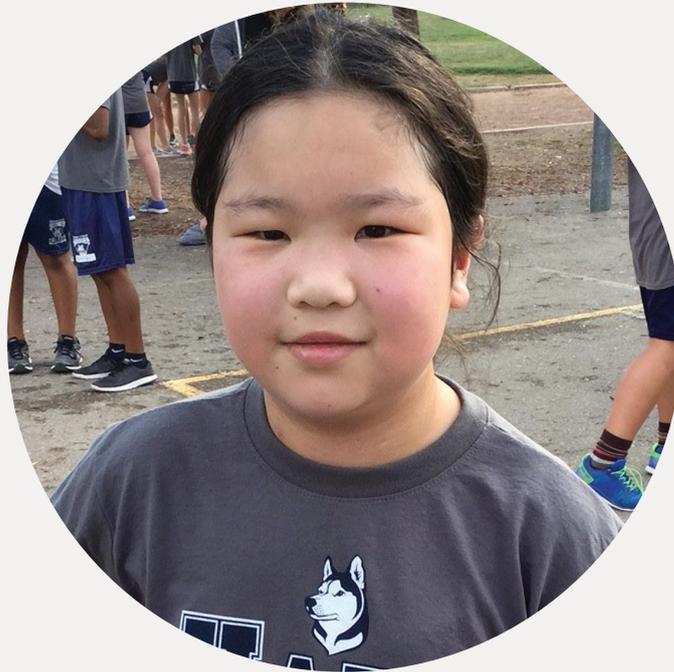
Fellowship

Yale University School of Medicine,  
Pediatric Cardiology (1995)

Board Certification

Pediatric Cardiology, American Board  
of Pediatrics (1996)

When David Rosenthal, MD, started the Packard Children’s Heart Failure and Heart Transplant Program more than a decade ago, he was responding to a disconnect between physicians in the two subspecialties. “The patient pool was largely the same,” he says, “but the children were seen by two groups of doctors who were often not in close enough communication.” He organized his new program around the patients, not around the treatments they needed. As he had hoped, both patient experience and outcomes improved significantly. The Betty Irene Moore Children’s Heart Center at Stanford Children’s Health was formed around a similar conviction. “It is our solution to the balkanization of treatment that happens at other institutions. Our antidote was to build an interdisciplinary structure that fosters close and effective working relationships between subspecialties, not only within cardiology, but also in cardiac anesthesiology, cardiothoracic surgery, physical and occupational therapy, and dietary support,” says Dr. Rosenthal, who is the director of the Pediatric Advanced Cardiac Therapy (PACT) Program. PACT attracts the most difficult cases. Even so, its patients do extremely well. Beyond the clinic, the research environment also plays a crucial role for Dr. Rosenthal: “What I find most gratifying is delivering excellent care in a setting where we have the academic depth to train the best of the next-generation providers and to conduct investigations that will make care even better 10 years from now.”



## PACT Program

Every Wednesday at Ziyan Liu’s middle school in Pleasanton, California, students run the mile as part of “Workout Wednesday.” Eleven-year-old Ziyan, who was born with a congenital heart condition, wasn’t healthy enough to join them. Soon she was even too sick to stay in school. But a rare surgery helped her survive long enough to receive a heart transplant. And, just a few months later, she lined up for the race.

Ziyan was born in China in 2006 and got very sick when she was about three months old. She was diagnosed with pulmonary hypertension and abnormal narrowing of her pulmonary vein. She was weak and had cyanosis.

Ziyan’s doctors in China found the root of her condition was a life-threatening structural abnormality in her heart. Instead of having separate mitral and tricuspid valve inlets, Ziyan’s heart had a single opening into the ventricular chambers, and mostly to one side, resulting in an unbalanced atrioventricular (AV) canal defect.

Her right ventricle was significantly larger than her left, resulting in a heart with a functional single ventricle. Surgeons in China performed pulmonary artery banding – the only procedure that could potentially help her – to reduce her pulmonary artery pressure and excess pulmonary blood flow. The procedure was palliative.

Because Ziyan’s heart condition was so dire, there was nothing else her doctors could do for her. Ziyan had traveled to the U.S. a few times to have her care managed by Rajesh Punn, MD, clinical

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associate professor of Pediatrics (Cardiology) at Lucile Packard Children's Hospital Stanford. Then, when she was five years old, her family moved from China to California. Dr. Punn recognized that Ziyang was going to need a heart transplant, and that's when she met her new care team at Packard Children's.

After about two years of waiting for a new heart, Ziyang's condition became critical in the fall of 2016. Her parents, Bin and Xuan, brought her to the pediatric emergency department at Stanford Health Care. "I thought I would just get better and go home," Ziyang says. "I did go home, but then I had to go back a second time two weeks later." It was then that her surgical care team at Packard Children's, led by Katsuhide Maeda, MD, clinical associate professor of Cardiothoracic Surgery at the Stanford University School of Medicine, decided to try something unconventional.

Many patients who are awaiting transplant rely on a surgically-implanted mechanism called a ventricular assist device, or VAD, but using this device in patients with single-ventricle hearts is very challenging — so much so that these patients are not considered candidates for the device at most hospitals. Yet Packard Children's has more experience placing VADs in single-ventricle patients than most other pediatric centers.

The structure of Ziyang's heart presented an added challenge. "Usually we attach the VAD onto the ventricle," Dr. Maeda says. "But for Ziyang, we attached

the VAD on the atrium. That is something people usually do not do. We are proposing that this method is easier and results in a better hemodynamics," which refers to the flow of blood throughout the organs of the body.

Dr. Maeda and his surgical team performed Ziyang's innovative single-ventricle HeartWare VAD placement on December 2, 2016, and added a modified Blalock-Taussig shunt to increase blood flow to Ziyang's lungs.

The surgery was a success. Just a few weeks after the procedure, Ziyang had recovered enough to leave the hospital.

Months passed, and in July 2017, Ziyang's family finally got the call that a donor heart was

available. Compared to the rare single-ventricle VAD placement Ziyang had received, "the transplant was relatively straightforward," says Dr. Maeda. Although Ziyang's heart transplant procedure lasted several hours, it went off without a hitch.

Three months after her transplant, Ziyang was able to return to school in her hometown, which also meant returning to physical education class. Two "Workout Wednesdays" passed, and then Ziyang made her move. On November 15, she lined up with her classmates and successfully ran the mile, just five months after her heart transplant. "I thought, as long as I don't come in last I'd be happy. And I didn't!" says Ziyang. "I felt proud of myself."

Yet Packard Children's has more experience placing VADs in single-ventricle patients than most other pediatric centers.

# Advanced Cardiac Imaging

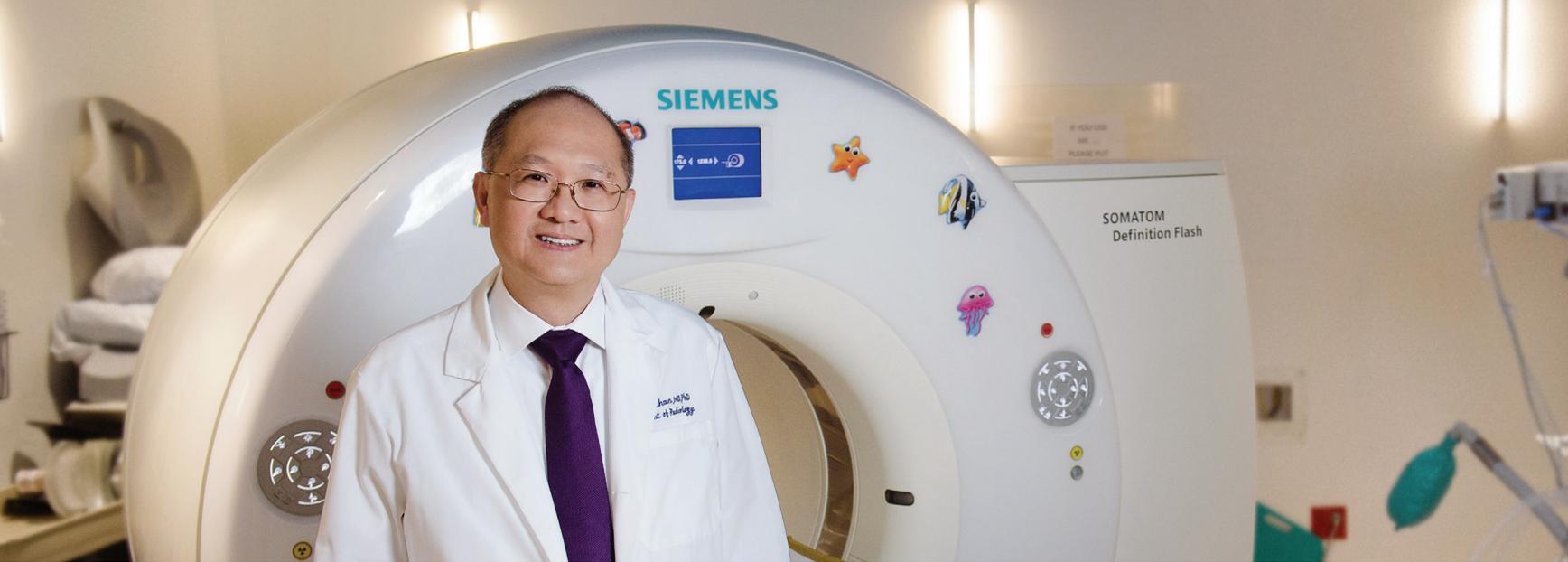
The Betty Irene Moore Children's Heart Center deploys leading-edge computed tomography (CT) and magnetic resonance (MR) imaging to see details of anatomy, measure blood flow and other physiological processes, determine if surgery is warranted or how to proceed if it is, and direct the best recovery process after surgery.

CT imaging reveals anatomical intricacies, sometimes in sufficient detail to avoid the need for additional catheterization procedures. MRI, which provides high-quality information on blood flow and physiology, may also obviate the need for invasive procedures. Our three pediatric heart-imaging specialists, who access all of Lucile Packard Children's Hospital Stanford's radiology resources, conduct about 500 studies annually. Keeping our very young patients still and comfortable during these procedures can be challenging, so the team works with anesthesiologists and other experts to help patients remain calm and immobile, sometimes employing headsets that play immersive cartoons or movies. Our faculty's engineering innovations have helped reduce the

duration of MRIs. A procedure that took one hour five years ago takes only 20 minutes today. Brevity boosts comfort and lowers cost for all, but for some patients, it also reduces risk by avoiding the need for anesthesia. Thanks to other Stanford radiology research, imaging isn't just faster; it's also safer and more accurate. In December 2016, the imaging team brought EchoPixel True3D into the operating room. This tool creates manipulable three-dimensional images of patients' anatomical features, allowing for whole new levels of visualization. True3D allows physicians to explore MR and CT images in a virtual reality space, an exercise that, until now, had only occurred inside physicians' imaginations.

“When we get a referral, we ask our colleagues, ‘What do you need to know?’ Then we find the very best way to deliver those answers.”

*Frandics Chan, MD*  
*Director, Advanced Cardiac Imaging Program*



# Frandics Chan MD

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Medical Education

University of California at San Francisco  
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Internship

Kaiser Foundation Hospital San Francisco  
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Residency

Stanford University School of Medicine  
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Fellowship

Stanford University School of Medicine,  
Radiology (2000)

Board Certification

Diagnostic Radiology, American Board  
of Radiology (1999)

“Holding our place as one of the top pediatric heart centers in the country requires excellence in surgery, anesthesia, medicine, echocardiography, CVICU and other subspecialties,” says Frandics Chan, MD, director of the Betty Irene Moore Children’s Heart Center’s Advanced Imaging Program. “We add two essential pieces: computerized tomography (CT) scanning and magnetic resonance imaging (MRI).” Dr. Chan points out that while “echocardiography is the ‘bread-and-butter’ imaging for cardiac patients, there are some essential questions an echo can’t answer. For those, we need CT and MR imaging.” Because CT scans and MRIs are more involved, sometimes requiring anesthesia, there must be a good reason to escalate from echocardiography. When it is necessary, Dr. Chan’s team is on hand to quickly answer whatever questions surgeons or cardiologists may have. “It’s a remarkable time to be a radiologist,” says Dr. Chan. “Not only are the imaging techniques safer, faster and more accurate than ever before, but they are giving us whole new ways to visualize what’s going on inside the hearts and lungs of our young patients. New virtual-reality 3D imaging allows surgeons to explore the individual anatomy of the patient’s body before entering it so that their surgical approach can be optimal.” Dr. Chan finds it gratifying to not only get the best and clearest images possible, but to do so in record time. “Whenever an urgent request comes in,” says Dr. Chan, “we can have an MRI or CT scan done in an hour. That speed saves lives.”

# Pediatric Electrophysiology & Arrhythmia Program

Deploying state-of-the-art imaging techniques, our electrophysiology (EP) and arrhythmia specialists evaluate and treat the full range of arrhythmias in children of all ages, including those still *in utero*.

Our five-member team provides a full range of procedures and coordinates care with other Heart Center physicians so that patients with complex heart problems get the most benefit from the fewest invasive procedures necessary. The program is renowned for its treatment of arrhythmias in pediatric patients with heart failure. In the program's clinic for inherited arrhythmias, pediatric and adult arrhythmia specialists – including genetic counselors and cardiologists with genetics expertise – collaborate to treat entire families. The team minimizes the risks of invasive procedures by using a gentler freezing technique (cryoablation) for performing ablations near the normal conduction system and by reducing exposure to x-rays during procedures. Always seeking ways to improve the

treatment experience of our young patients, the EP service concentrates on the whole patient, taking into consideration many of the psychosocial issues that can arise in this complicated group. Clinical psychologist Lauren Schneider, PsyD, helps patients with implantable cardioverter defibrillators (ICDs) address the psychological challenges surrounding their disease. Dr. Schneider and Anne Dubin, MD, director of the Electrophysiology and Arrhythmia Program, recently developed a virtual-reality tour that introduces new patients to the hospital and to the routines surrounding procedures they're scheduled to undergo. Patients even take periodic breaks within the virtual environment to practice relaxation techniques. "It's an effective form of stress inoculation," says Dr. Dubin.

"I believe our ability to coordinate with the other providers caring for the child sets us apart at Packard Children's and helps drive not only our clinical care but our research, as well."

*Anne Dubin, MD*

*Director, Electrophysiology and Arrhythmia Services*



# Anne Dubin<sub>MD</sub>

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**Fellowships**

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**Yale - New Haven Hospital,  
Electrophysiology (1995)**

**Board Certification**

**Pediatric Cardiology, American Board  
of Pediatrics (1998)**

**Adult Congenital Heart Disease, American  
Board of Internal Medicine (2015)**

“We consider the whole patient, not just their arrhythmia,” says Anne Dubin, MD, director of the Electrophysiology and Arrhythmia Service. “Across subspecialties, we consider how what one of us does may influence what others need to do.” For example, Dr. Dubin says, complex heart disease patients often require the services of many subspecialists. Finding the best treatment option often requires close collaboration with heart failure and adult congenital specialists. “Collaboration among doctors can make a huge difference to patients. Sometimes procedures and surgeries can even be combined to minimize risk, expense, and disruption to the patient.” Known for her innovative use of resynchronization therapy in children with heart failure, Dr. Dubin is further advancing that frontier with studies of the long-term ramifications of resynchronization. She and colleagues are studying paced single ventricle patients. They have a much higher than average likelihood of developing heart failure and needing transplants than single ventricle patients who are not paced. Dr. Dubin also focuses on adapting implantable devices for optimal use in those children. “Most implantable technologies are developed for adults,” she says. “Making them work well for kids gives them a huge advantage.”

# Pediatric Echocardiography Laboratory

Advances in transducer technology and data processing allow cardiologists in the Pediatric Echocardiography Lab to evaluate congenital heart disease in patients from when they are fetuses all the way into their adulthood.

Early diagnosis of disorders such as hypoplastic left heart syndrome may mean the difference between life and death. Some of our patients require immediate intervention at birth in order to survive, and they can now go straight to the operating room or Cath Lab after delivery if the diagnosis is made prenatally. Real-time 3-D images of the heart are another benefit of these recent technological advances. “We can now obtain a 3-D echo dataset and easily view it from multiple perspectives in order to formulate a diagnosis and treatment plan,” says Leo Lopez, MD, medical director of Echocardiography at Lucile Packard Children’s Hospital Stanford. The Lucile Packard Children’s Hospital Stanford Echo Lab plays an important role throughout the life of a child with heart disease. If a prenatal evaluation is performed, the Echo Lab’s sonographers and echo physicians are often among the first Heart Center clinicians that families

meet, and they play ongoing roles in the diagnosis, treatment, recovery and long-term surveillance of our Heart Center patients. “We work symbiotically with everyone in the Heart Center,” explains Dr. Lopez. “It is a pure and egoless collaboration. We all gather as much information about our patients as possible in order to provide the best possible care.” An important highlight of the Heart Center is the Pediatric Stress Echo Lab, which provides a rare service to our patients by tracking changes in a child’s heart when the child is exposed to stress. This can provide important information for patients with coronary problems, cardiomyopathy, and pulmonary hypertension. The Pediatric Vascular Lab is another unique service that evaluates the health of a patient’s blood vessels, particularly in patients who are at risk for vascular disease. These state-of-the-art services can give Heart Center patients life-saving advantages.



# Leo Lopez MD

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**Medical Director  
of Echocardiography**  
**Clinical Professor of Pediatrics  
(Cardiology)**

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**Medical Education**  
**Perelman School of Medicine at the  
University of Pennsylvania, Philadelphia,  
Pennsylvania (1987)**

**Internship**  
**Boston Children’s Hospital and  
Harvard Medical School (1988),  
Boston, Massachusetts**

**Residency**  
**Boston Children’s Hospital and  
Harvard Medical School (1990),  
Boston, Massachusetts**

**Fellowship in Pediatric Cardiology**  
**Boston Children’s Hospital and  
Harvard Medical School (1993),  
Boston, Massachusetts**

**Board Certification**  
**Pediatric Cardiology, American Board  
of Pediatrics**

“Physics was my first love in the sciences,” says cardiologist Leo Lopez, MD, director of the Betty Irene Moore Children’s Heart Center’s Echocardiography Laboratory. “Evaluating the heart involves the principles of physics on many levels, from the fluid dynamics of blood flow to the mechanics of heart muscle contraction to the concepts of ultrasound reflection and refraction and the Doppler effect that underlie the echocardiogram. My experience with and understanding of these principles definitely gives me an advantage,” he explains. Dr. Lopez is also motivated by the aesthetic components of echocardiography, most of which he learned during his pediatrics and cardiology training at Boston Children’s Hospital: “We must use ultrasound to create the most precise, informative and clear pictures of a patient’s heart in order to know how to treat the problem.” Whether they are two-dimensional images from transthoracic or transesophageal echocardiograms or real-time three-dimensional reconstructions of the heart, these images help cardiologists and surgeons to understand the problem and formulate a treatment plan. Dr. Lopez’s research focuses on the growth of cardiovascular structures relative to age and increasing body size as well as the factors that influence that growth. To understand how heart diseases affect the size of cardiovascular structures, we must first know the range of these measurements in the heart of a healthy growing child. Dr. Lopez and his colleagues are establishing Z scores for the different parts of the heart, creating a set of measurement values that reveal whether a structure in the heart is too big, too small or just the right size for a particular child.

# Fetal Cardiology Program

Early fetal detection has been a key to improving outcomes for our youngest patients born with heart defects.

To discover malformations of the heart as early as possible, the Fetal Cardiology Program deploys the most advanced fetal echocardiogram and MRI technology and the full attention of our extraordinary team of echocardiographers, cardiologists, and genetic counselors. They partner with each mother and her obstetrician to ensure her new baby starts life as healthy and happy as possible. When a pregnant patient is first referred to the program, she is often unaware that her fetus may have a serious heart problem. Typically, the first clinician to discuss with her the ramifications of her baby's illness—often the need for heart surgery soon after birth—is the cardiologist in the Pediatric Echocardiography Lab. That initial encounter is profoundly important, and our physicians sometimes spend hours with parents explaining the condition,

exploring the ramifications, and helping them consider the possible options. The mother and her fetus are distinct patients, but they have a deeply shared destiny; so, the Fetal Cardiology Program works hand in hand with the Center for Pregnancy and Maternal Health to ensure both patients' safety, health, and comfort. Continuity between the pre- and post-natal cardiac care is also key to our success. Heart Center surgeons, cardiovascular intensivists, and neonatologists are all well aware of the details of the patient's case long before the birth date. By then they have together charted the optimal plan A, but also are prepared for situations B, C, and D. Starting with prenatal diagnosis and extending, for some patients, all the way into adulthood, our tightly-coordinated programs provide extraordinary coordinated and continuous care.

“If a patient needs surgery, we make sure the parents know exactly what's coming. Everything is anticipatory, not reactionary”

*Theresa Tacy, MD*  
*Director, Fetal Cardiology Program*



# Theresa Tacy<sup>MD</sup>

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**Director, Fetal Cardiology Program**  
**Professor of Pediatrics (Cardiology)**

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Medical Education  
University of Texas (1987)

Residency  
University of Chicago Medical Center  
(1990)

Fellowship  
University of Michigan Medical Center,  
Pediatric Cardiology (1993)

Board Certification  
Pediatric Cardiology, American Board  
of Pediatrics (1994)

“Each heart is unique, and we treat them that way,” says Theresa Tacy, MD, director of the Fetal Cardiology Program. “We may counsel parents for hours at the time about the diagnosis, helping them chart the best way forward based on what can be an overwhelming amount of information,” she continues. “We are a resource for the family. We don’t just give them a flag and say, ‘Get out there.’ We use our echocardiograms to help families really grasp and understand the diagnosis and the options they face. Then we help them navigate the system.” Echocardiography is an excellent teaching tool, not only for the patients and their families, but also for the next generation of doctors. Medical students, residents, fellows in intensive and critical care, and fellows in pediatric anesthesia all come through the lab and study our images. “You can learn so much about the physiology and management of heart disease by looking at these images,” she explains. Hands-on experience is essential in echo, too, which leads to another reason our team is so exceptional – we have a lot of it. “The quality of an echo is exceedingly operator-dependent,” Dr. Tacy says. “All you’ve got is a probe to move around the outside of the body. Your level of skill with moving it has everything to do with the accuracy and efficacy of the resulting study.”

# Pediatric Interventional Cardiology

Some conditions that once were the exclusive domain of surgery can now be fixed quickly, effectively, and with less pain and risk of complications through catheterization procedures.

Since 2007, Lucile Packard Children's Hospital Stanford has been using cardiac catheterization to place Melody transcatheter pulmonary valves for tetralogy of Fallot patients, allowing some patients to avoid a second round of open-heart surgery. We are also exploring catheter placement of the Impella, a tiny heart pump that can help children suffering from heart failure, in the hopes that some of them may be able to avoid heart replacement surgery. The extraordinary collaboration between our surgeons and catheter specialists has opened whole new clinical areas for the future, and the hybrid surgery and interventional catheterization lab accelerates these exciting new frontiers. We treat some of the sickest pediatric heart patients in the country. When it comes

to caring for especially complex patients who have tetralogy of Fallot with pulmonary valve atresia and major aortopulmonary collateral arteries (TOF/PA/MAPCAs), we have had far more experience than anyone else, says Lynn Peng, MD, director of the Pediatric Cardiac Catheterization Laboratory. "But we treat all our cases, whether straightforward or complex, with the same attention and dedication," she says. Of course, our dedicated interventional pediatric cardiologists also perform valvuloplasty, angioplasty, stent placement and device closures for many types of congenital heart defects. The cardiac catheterization team performs more than 1,000 catheterizations each year, about 60 percent of which are interventional procedures.



“At the Moore Children’s Heart Center, we have a diverse group of cardiologists trained in a wide range of subspecialties from the top programs. It’s partly the influx of new ideas and ways of thinking these doctors bring from outside that helps us to innovate and to make so much progress.”

*Lynn Peng, MD  
Director, Cardiac Catheterization Laboratory*

# Lynn Peng MD

**Director, Cardiac  
Catheterization Laboratory  
Clinical Associate Professor,  
Pediatrics (Cardiology)**

lynpeng@stanford.edu | (650) 721-2121

Medical Education  
Johns Hopkins University School  
of Medicine (2001)

Internship  
Johns Hopkins Hospital (2002)

Residency  
Johns Hopkins Hospital (2004)

Fellowship  
Boston Children’s Hospital, Pediatric  
Cardiology (2007) and Pediatric  
Interventional Cardiology (2008)

Board Certification  
Pediatric Cardiology, American Board  
of Pediatrics (2008)

When she was still a medical student at Johns Hopkins University, Lynn Peng’s adviser, Jean Kan, MD, was a pioneer of interventional cardiology. That early introduction to cardiac catheterization made a big impression on Dr. Peng, but it wasn’t until her fellowship at Boston Children’s Hospital that she knew for sure what she wanted to do. “There was so much innovation going on in the Boston Children’s Cath Lab; it was an extraordinary place and an amazing experience,” she says. When Dr. Peng moved to Stanford in 2009, she was determined to bring that enthusiastic approach to new technologies and clinical trials with her. “Diagnosing and following heart disease is key, but I also want to be able to fix the problems we diagnose,” Dr. Peng says. “It is a big deal to see emerging technologies that allow us to do that without open-heart surgery,” she says. The first device Dr. Peng introduced to Stanford Children’s was the Melody valve, which was not widely available at that time. “As soon as I showed promising results, the faculty and surgeons here at Stanford embraced transcatheter pulmonary valve procedures. The surgeons routinely refer patients to the Cath Lab when we believe percutaneous valve placement is an option.” Dr. Peng is currently participating in two new trials of promising catheter-based devices that can repair anatomic problems in the heart. “Collaboration between the device industry and hospitals, and between colleagues at different hospitals, is extremely important. It’s how new devices get created and how things improve,” she says.

# Referrals

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We believe that the best outcomes are the result of a collaborative relationship that includes the patient, the patient's family, and the patient's providers.

## Pediatric Cardiology

(650) 721-2121

## Pediatric Cardiothoracic Surgery

(650) 724-2925

## Pediatric Advanced Cardiac Therapy (PACT)

(650) 721-2598

Referring physicians can stay in step with their patients' progress through our MD Portal. The MD Portal offers referring physicians and their staff secure web access to their patients' health records at Stanford Children's Health, including up-to-date clinical information such as appointment history, lab results, transcriptions, radiology results and inpatient medication lists, as well as the ability to submit online referrals and track appointment dates.

Please visit [mdportal.stanfordchildrens.org](https://mdportal.stanfordchildrens.org).

To learn more about the Betty Irene Moore Children's Heart Center visit [heart.stanfordchildrens.org](https://heart.stanfordchildrens.org).





## Contact Us

For more information, visit  
[heart.stanfordchildrens.org](http://heart.stanfordchildrens.org)  
or call (650) 721-2121