

Ahmanson/UCLA

Adult Congenital Heart Disease Center

FOR THOSE TOUCHED BY CONGENITAL HEART DISEASE

Winter 2021



CENTER UPDATES

Renowned Cardiac Surgeon Professor Hillel Laks Announces His Retirement

By Jamil Aboulhosn, MD

After 40 years of extraordinary service to the UCLA community, a giant in the world of cardiac surgery, Professor Hillel Laks, has decided to retire from clinical practice. Dr. Laks arrived at UCLA in 1981 when he was recruited from Yale University as the Chief of the Division of Cardiac Surgery. Instrumental in his recruitment was the Founding Director of the ACHD program, Dr. Joseph Perloff.

Dr. Laks was born in South Africa and attended medical school in Johannesburg. It was during his early training years that Christian Barnard performed the first human heart transplantation in South Africa, an event that had an important impact on the young Dr. Laks and propelled him towards a career in cardiac surgery. He left South Africa for Jerusalem following his internship, determined to become a cardiac surgeon and contribute to this exciting and growing field of medicine. The 1960's were in many ways the golden age of cardiac surgery, it was during this era that many of the congenital cardiac surgeries done today were imagined and undertaken; it is no surprise that an intellectually superior and creative mind would be drawn to the field. After one year in Israel where he trained in surgery and pathology, he secured a highly competitive residency in Boston at the Brigham and Women's Hospital, one of the Harvard teaching hospitals. After a residency in General Surgery Dr. Laks did his pediatric cardiac surgery training at the Boston Children's Hospital. He trained with one of the great pediatric and congenital cardiac surgeons, Dr. Aldo Castaneda, who was renowned for advancing the field of neonatal cardiac surgery. His first attending position was at St. Louis University where he spent 3 years, performed adult cardiac surgery and took over as the principal pediatric and congenital cardiac surgeon. He then took the

Fellowship Updates

Dr. Prashanth Venkatesh

joined the UCLA ACHD team in July 2020 for a two-year adult congenital heart disease fellowship. Dr. Venkatesh received his medical degree from the Weill Cornell Medical College in Qatar, and completed a residency in internal medicine at the New York-Presbyterian/Weill Cornell Medical College in New York City. We recruited him to UCLA in 2017 for his adult cardiology fellowship, and he has remained a UCLA bruin for his ACHD fellowship. He is incredibly dedicated to the care of patients with congenital heart disease and excels in the care of even our most complex patients. He enjoys watching cricket and hiking in his spare time!



Dr. Katia Bravo-Jaimes

joined the UCLA ACHD team in July 2020 for a two-year adult congenital heart disease fellowship. Dr Bravo attended the Universidad Nacional Mayor de San Marcos Facultad de Medicina San Fernando in her native Peru, and graduated at the top of her class. While a medical student, she volunteered as an interpreter for the Hearts with Hope medical mission, which included many UCLA faculty! She came to the US to pursue internal medicine residency at the University of Rochester, and then moved to Houston where she completed her adult cardiology fellowship at University of Texas Houston. She then came to UCLA for ACHD fellowship. She has a passion for research, and improving the health of patients with CHD in her native Peru. As a fellow, she won the UCLA Global Health Seed Grant, and is overseeing a research team in Peru to develop a new algorithm for screening for congenital heart disease in neonates born at different altitudes!



Faculty and Contact Information

Faculty

Ahmanson/UCLA ACHDC Faculty

Jamil Aboulhosn, MD, Director, Streisand Chair,
Congenital Cardiology and
Interventional Cardiology

Leigh Reardon, MD, Congenital Cardiology

Jeannette Lin, MD, Congenital Cardiology

Gentian Lluri, MD, PhD, Congenital Cardiology

John Child, MD, Emeritus Director

Daniel Levi, MD, Interventional Cardiology

Kevin Shannon, MD, Electrophysiology

Jeremy Moore, MD, Electrophysiology

Kalyanam Shivkumar, MD, PhD, Electrophysiology

John Moriarty, MD, Interventional Radiology

Paul Finn, MD, Cardiovascular Radiology

Pierangelo Renella, MD, Cardiovascular Radiology

Ashley Prosper, MD, Cardiovascular Radiology

Surgical Faculty

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Cardiovascular Surgery

Ming-Sing Si, MD, Congenital Cardiac Surgery

Hillel Laks, MD, Emeritus Congenital Cardiac
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Reshma Biniwale, MD, Congenital Cardiac Surgery

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Information & Resources

Adult Congenital Heart Association (ACHA)

Website: www.achaheart.org

Call (888) 921-ACHA

Email: info@achaheart.org



New Faculty Profile: Dr. Ming-Sing Si

Please join us in welcoming Dr. Ming-Sing Si as Associate Professor-in-Residence in the Division of Cardiac Surgery. Dr. Si is a congenital cardiac surgeon who joins UCLA from the large and impactful CS Mott Children's Hospital at the University of Michigan where Dr. Si operated on a large number of children and adults with congenital heart disease. Dr. Si will care for patients across

40 Years And Looking Forward

By Leigh Reardon MD

Last September, the Ahmanson/UCLA Adult Congenital Heart Disease Center celebrated 40 years of service to patients with congenital heart disease at UCLA – one of the first centers of its kind in the world. The tribute was telecast live from UCLA and remains on YouTube for your enjoyment <https://www.youtube.com/watch?v=Lk7zByBnFJA>. The program re-visits the pioneering spirit of our founder, Dr. Joseph Perloff, and the foundational figures in our history with special interviews with Dr. Hillel Laks, Dr. John Child, Dr. Glen VanArsdell and Mary Canobbio, RN. Several patients who have been touched by our staff, nurses and physicians over the years also shared their stories. The event was hosted by the current director, Dr. Jamil Aboulhosn and Pam Miner, NP who recently retired after 29 years of service to the center.

The program highlighted the center's research efforts and achievements with Dr. Gentian Lluri; the center's training opportunities and commitment to training future generations of ACHD providers with Dr. Jeannette Lin; and the centers efforts to a smooth transition from pediatric to adult care with Dr. Leigh Reardon. The program ended with a slide show curated by our missed nurse practitioner, Linda Houser who retired from the center two years ago after 13 years of service. The slide show highlighted many patients, patient events and generous donors who have made our efforts possible.

the spectrum of ages in congenital cardiac care including transplantation in ACHD patients.

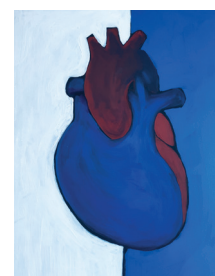
Dr. Si earned his undergraduate degree from the University of California, Irvine, and medical degree from the David Geffen School of Medicine at UCLA. Following this, he completed residency training in general surgery at UCI and UCSF and then cardiothoracic and congenital cardiac surgery at the University of Michigan. During his residency he had a postdoctoral fellowship in transplantation immunology at Stanford University.

Dr. Si's first three years of practice were at UC Davis. He was then recruited to the University of Michigan where he rapidly became an important team member and managed the congenital cardiac transplantation program. Additionally, Dr. Si is a noted expert in aortic valve repair.

Dr. Si has a successful research program with a primary focus on cardiac fibrosis and a NIH grant entitled Role of SLIT-ROBO and MT1-MMP in MSC-Mediated Neovascularization. He has mentored numerous graduate students, postdoctoral fellows, undergraduate students and visiting scholars.

Please join us in welcoming Dr. Si to the Ahmanson/UCLA ACHD family!

As we move into the next 40 years, we thank you for entrusting your care to our team. We continue to invest our time, efforts and resources in being a world leader in ACHD care. We are committed to excellence in congenital surgery and transcatheter interventions with our adult congenital interventional program having one of the highest transcatheter valve implanting volumes in the country. We have become one of the largest centers for heart transplant in patients with congenital heart disease and we are committed to develop strategies that reduce risk and increase our success in complex cases – and have become a model for programs around the world. Among many of our other programs ranging from research and transitional care to cardio-obstetrics we are committed to providing the best care for our patients and training future leaders. As we reflect on the past 40 years, we are grounded and inspired by the moments we have shared with you and your family. We thank you for the past 40 years and look forward to the years to come.



Transition Update: Reducing The Gaps In Care

Nicole Antonville

A gap in care is defined as greater than 3 years without seeing a congenital cardiologist. Gaps are common among young adults for many reasons ranging from insurance issues, moving away from a CHD center, lack of transportation, to a lack of knowledge of where to go and who to see in adulthood.

Mary Cannobio, RN, Dr. Reardon and I set about looking for individuals who maybe fell through the cracks and are having a prolonged gap in care. While Mary and Dr. Reardon provide education and structured transition to those young adults in care at the Transitional Cardiac Care Program Children's Heart Center some of the most vulnerable patients slip through the cracks. With the pandemic hitting in 2020, it was the perfect opportunity to start outreach and develop enduring systems. After creating an algorithm in our electronic medical record, I identified UCLA patients who have a gap in care both in the Children's Heart Center or the Ahmanson/UCLA Adult Congenital Heart Disease Center. Then I began to contact, connect, and help these patients and families get back into care.

Once I make contact, I assess and explore their current cardiac care and reasons for having a gap in care – did they move, change insurance, find a new provider, etc? My goal is to ensure and educate on the importance of lifelong follow-up with qualified providers. Then I assess barriers to being in care and provide resources with the help of our social workers, administrators, providers and insurance specialists. Then I provide transition education and provide resources on their condition either by phone or a zoom call.

Success Story:

Recently, I found a 20-year-old female, with congenital heart disease, who had her last visit in 2017. I reached out to get more information and see if she has had been getting follow up outside of UCLA that wasn't visible in the electronic medical records. Her mom answered and was relieved to hear from someone who might be able to point them in the right direction. The patient had not seen anyone for quite some time and felt a little helpless in knowing where to go and how to make the next appointment – but it was on her "to do" list. Our conversation was a relief to the patient and her mom as there was so much going on with the patient recently having started college. We were able to discuss her diagnosis, the importance of long-term follow-up care and learned that she was having some symptoms worthy of a visit. She also had questions about exercise and pregnancy that were best to be addressed in person.

Our office played a crucial role in helping this patient navigate the insurance system with our office staff reaching out and helping her realize that she needed to get a referral from her primary care physician.

It is understandable why patients fall through the cracks – particularly like this patient who is facing the excitement and challenges of going off to college. In order to develop a lifetime of healthy habits, sometimes patients need a little help navigating the healthcare and insurance system. And they need a little coaching on understanding the changing medical needs of adulthood.

I'm proud to be part of this program and excited to help more patients like this avoid gaps in care.

COVID Related ACHD Research:

The UCLA ACHD Center in collaboration with colleagues at the Oregon Health Sciences University have created an international registry of Adult Congenital Heart Disease COVID positive patients. So far this registry has accounted for more than two thousand subjects. The findings of the registry were initially published in the Journal of the American College of Cardiology in February 2021:

<https://www.sciencedirect.com/science/article/pii/S0735109721003971?via%3Dihub>

This one-of-a-kind registry offers a glimpse of how COVID-19 has impacted the global ACHD community. The registry is on-going and now looking at a variety of sub-studies.

In addition to looking at the global impact of COVID on ACHD patients, the Center is undertaking another study that looks to measure what impact the virus has had on the overall mental health of our Center's patients.

For more information on our research studies being conducted at the Ahmanson/UCLA Adult Congenital Heart Disease Center, please email us at ACHDC@mednet.ucla.edu or call 310-825-5950.

Telehealth/myUCLAhealth/myChart Update

Telehealth services were revolutionized throughout healthcare by the COVID-19 pandemic – and the Ahmanson/UCLA Adult Congenital Heart Disease Center was no exception. We greatly expanded our telehealth services, allowing our patients to stay connected, have consultations and follow-ups from the comfort and safety of home. While nothing can replace in-person testing and visits, our telehealth visits offer the opportunity to make our care more comprehensive and convenient. We anticipate being able to offer continued telehealth services to augment your care – but keep in mind that there may be updates to federal, state and insurance regulations that may change who can take advantage of these services. Our office is here to help you navigate the telehealth process and schedule the most convenient and appropriate visits for your health care.

Do You Take Clindamycin For Dental Visits?

Guidelines for endocarditis prophylaxis for dental visits have been updated for those who have an allergy to Amoxicillin or Penicillin. Clindamycin is no longer recommended as a prophylaxis treatment. Contact our office or discuss at your next visit the best option for you.

ACHD Advisory Board Member Tom Bliss

I have been a patient of ACHDC since the Clinic was founded by Dr. Joseph Perloff, who pioneered the very discipline of adult congenital heart disease. My son very unexpectedly became a future patient at birth – but that's a story for another time. The care I have received over four decades inspired me to serve as a member of the Advisory Board, a key source of support group for the Clinic, raising funds to support its mission and expand its reach. [I hope you too will keep the Clinic in mind when making gifts].



Tom Bliss
and son, Jonah

position as director of pediatric cardiac surgery at Yale University for five years. He was awarded an NIH grant using electron microscopy to measure the effects of myocardial preservation on cellular transportation. Dr. Laks was then recruited as the Chief of Cardiac Surgery at UCLA and served in that role from 1982 until 2006. He was awarded the Chancellor's Professorship of Surgery, and he continued doing pediatric and congenital cardiac surgery in adults, adult cardiac surgery and heart transplantation.

During his tenure at UCLA, starting in 1982, the pediatric cardiac case volume increased dramatically from about 30 cases per year to over 300. The adult cardiac surgery cases rose from about 220 to over 1,000. Included among the adults were adult with congenital heart disease. Over the years he developed one of the largest ACHD surgical programs in the world. Dr. Laks performed the first heart transplant, and the first lung and heart lung transplant in Southern California. The heart and lung transplant programs that he started both grew to be among the largest and best programs in the world. Dr. Laks inserted the first artificial heart, and started the very active cardiac assist device program.

In addition to his pioneering clinical work, Dr. Laks had a productive research laboratory and studied myocardial preservation, heart and lung

transplantation and mechanical cardiac assist devices. He also led or participated in many clinical studies and reported on outcomes of cardiac surgery and transplantation. He has over 300 publications in scientific peer reviewed journals, many book chapters and was a co-editor of two cardiac surgery textbooks

Dr. Laks' impact on the field of cardiac surgery in general, and in congenital cardiac surgery in particular, cannot be overstated. Many adult patients and patients with very complicated or advanced congenital heart disease that were turned down at other major programs were referred to UCLA for surgery. Dr. Laks has created innovative and new surgical techniques to improve surgical outcomes and to extend surgery to patients considered too high risk for surgery. In 1992, he introduced UCLA's revolutionary Alternate Recipient Heart Transplant Program, which allowed older and high-risk patients including adult with congenital heart disease who would not normally qualify for a heart transplant to receive hearts that would not otherwise have been used. In order to use more donor hearts that were in short supply he undertook the repair of hearts which would otherwise not have been used. Congenital holes in the heart were closed, and donors with less extensive coronary artery disease underwent coronary bypass operations

UCLA ACHD Center Paving The Way Forward With Groundbreaking Research

The UCLA ACHD center has been involved in groundbreaking research that is paving the way with new treatment options for adults living with congenital heart disease.

Compassion S3 Trial:

The Edwards Compassion S3 study is a multicenter study that examined the effectiveness of the Edwards SAPIEN S3 Transcatheter Heart Valve in patients with pulmonary regurgitation or right ventricular outflow tract conduit or valve obstruction.

At three-year follow-up visits, the results have been overwhelmingly positive, demonstrating excellent valve function. In addition, there was an improvement in clinical outcomes such as improved overall cardiac function, and a decreased likelihood of patients needing to undergo open heart surgery.

The SAPIEN S3 Transcatheter Heart Valve was recently granted approval by the FDA in 2020. The UCLA ACHD team played an important role in this approval. It is a source of pride, that our center was one of the top enrolling sites in the entire study. Thus continuing the commitment to bringing the most innovative and best possible care to our patients.



The Edwards SAPIEN S3 Transcatheter Heart Valve

Alterra Adaptive Pre-stent trial:

The Alterra Adaptive Pre-stent is a self-expanding partially covered nitinol platform that is deployed within the native right ventricular outflow tract in patients with pulmonary valve regurgitation. This pre-stent allows for the remodeling of the outflow tract to create an hour-glass like landing zone for the Sapien S3 valve in those who are not candidates for valve placement due to an excessively large 'landing zone'. By reshaping the 'landing zone' with the Alterra pre-stent, the Sapien S3 can now be safely implanted and patients can avoid open heart surgery.

At this time, the Alterra pivotal trial is in the continued access phase and Edwards Lifesciences is seeking FDA approval for this product. UCLA has been a contributor to the trial and will be an implanting center once FDA approval has been given.

Harmony Transcatheter Pulmonary Valve:

The Center also contributed patients to the Harmony trial from Medtronic, the Harmony valve is a covered self-expanding catheter delivered valve that is designed for the treatment of pulmonary valve regurgitation in patients with native right ventricular outflow tract. The Harmony valve was granted FDA approval in early 2021 as the first, self-expanding device to be used in the pulmonic position in native right ventricular outflow tracts. The Center is actively implanting Harmony valves currently, and both Dr's Aboulhosn & Levi are certified proctors with regards to the implantation of the Harmony valve. The Center was also a contributor to the trial that led to FDA approval of this valve.



The Alterra Adaptive Pre-stent



The Medtronic Harmony Valve

before implanting the heart in a high risk patient who would otherwise not have been accepted for transplantation. This approach was adopted by several other programs. On the congenital cardiac surgical front his creativity became the stuff of legend. He created or revolutionized numerous surgical procedures, including novel modifications to the Fontan operation, with the first use of an externally adjustable opening between the high-pressure Fontan circulation and the low pressure left atrium. This decompression of the venous pressure saved many lives and became modified and widely used. He innovated a repair for children born with the arteries to the lung arising from the aorta instead of from the right ventricle. This unifocalization technique allowed for a staged repair resulting in a near normal pulmonary circulation using the patient's own pericardium to create a tube to which the disconnected pulmonary arteries were attached. Gortex grafts were then used to connect these tubes to the right ventricle. He advanced the repair of children's obstructed aortic valves using the patient's own pericardium to repair the valve instead of replacing it. He was instrumental in the development of ACHD surgery and advancement of transplantation and mechanical support in ACHD patients. Many of the ACHD patients currently cared for at UCLA have had operations by Dr. Laks.

Dr. Laks has made an indelible impact on me, and my colleagues, both on the professional, and the personal front. On the professional front he taught us to be detail oriented and yet see the big picture. He is a voracious reader and has an encyclopedic fund of knowledge to impart, yet he is also an out of the box thinker and is constantly coming up with creative solutions for the most difficult problems. His faith serves as his bed-rock and he values the sanctity of human life above all. This faith, combined with an immensely creative and progressive scientific mind, resulted in a surgeon that went well above the standard to ensure good outcomes for his patients. We all have Hillel Laks stories from the operating room, consisting of heroic surgical endeavors that not only saved lives but also made deep marks on trainees and colleagues. On the personal front, over the past two decades, he went from a distant idol to a cherished friend. We wish Dr. Laks health and happiness in his retirement from clinical practice. We give him immense gratitude for all he has done for our patients, for us, and for the field of cardiac surgery.

PATIENT STORIES

Transposition Of The Great Arteries And My Journey To A Heart And Kidney Transplant

I was born with the transposition of a great arteries in 1977 and underwent my first open heart surgery in 1978 where my surgeons re-routed my blood flow using baffles to redirect blood coming back from my lungs and body to the best possible alternative at the time – a Mustard procedure. The surgeons told my parents that I only had a 30% chance of surviving the initial procedure. At age 12 I had my second open heart surgery because I needed a new valve – again the statistics were grim and my parents were told that I had about a 15% chance of survival and if I did make it I would likely only live to age 20.

I'm someone who beats the odds and keeps going. I had a pretty normal childhood and did most of the things I wanted to do – I would hike and be active but I was never much of an athlete. After high school, I went to college and got a degree in early childhood education and went on to be a kindergarten teacher for 6 years in Michigan. After a while I was itching for a change so I moved to Las Vegas, went back to college and got a BA in psychology with a minor in social worker and domestic violence.

I went back to teaching and social work with a school district in the suburbs of Las Vegas. My mom actually found my husband, Ty for me. She said one day "Hey I found this guy who's got a cute butt. He's really cute – you should meet him." I was pretty resistant at first but we just clicked. After we had dated for about

2 months, I said, "Look I feel like things are getting serious and I need to tell you I was born with a congenital heart defect and I may have to have a heart transplant someday. I don't know how long I'm going to live." His response was, "nobody knows how long they have Amy. I would rather have 5 minutes of something incredible with you than a lifetime of not

with the Children's Heart Center, Nevada. In March of 2021, Dr. Galindo – a pediatric cardiologist in Las Vegas – broke the news to me that it was time for a transplant. I knew I was sick and I was probably dying – my heart function had deteriorated, I was having heart rhythm issues and my kidneys were failing. I looked at him and I said, "if I don't do this I'm



knowing." It didn't matter what was wrong with me. He loved me and he said, "anybody can die even driving to work." So it was clear he was a keeper.

I had regular follow ups and even met the UCLA ACHD team when Dr. Reardon was coming out to Las Vegas on an outreach basis

going to die," he said, "yes, I'm afraid that is the case." He said, "we need to get you to UCLA as quickly as possible I'll make some calls and have you reconnect with Dr Reardon."

I remember feeling scared and lost, and I was willing to do whatever was needed – no matter how much it hurt because I was fighting for



my life. I had always said that I didn't want my heart to be the one thing that takes me out. On May 3, 2021 I was admitted to UCLA for the transplant evaluation. At times, I was being poked and prodded like a zoo animal but I didn't care because I was determined to go through the process with grace and a smile on my face. I was so blessed just being at UCLA and I was hoping for a new heart and a second chance on life. I knew time was running out. I also knew that they might not be able to save me and I made peace with that as long as they did their best. It was a tricky situation because in the work up they discovered that my kidneys were too ill to recover after a transplant, so Dr. Wilson recommended a kidney along with the heart transplant. Also, we discovered that with my heart being so unhealthy that the pressures in my lungs had increased to such a high level that a transplanted heart wouldn't be able to cope with the high pressures. I was first put on several medications to lower the pressure in my lungs and then they placed a Impella device in my heart to take over some of the pumping function. It's basically a catheter that I was hooked up to that had a propeller that pushed blood forward. I was so fortunate that all this worked and I was finally listed for a heart-kidney transplant.

It was a hard wait and I remember in the middle of June calling my husband in the evening and telling him I was too tired to keep fighting. He told me hang on just one more day. The very next day, June 16, 2021, I got my heart and kidney transplants. To me it was like dream. I remember looking at my nurse and I just started crying. On June 18, 2021, I opened my eyes and I was alive and kicking. I couldn't have been more blessed and grateful.

I thought to myself: "Ok, you got a second chance – don't take this beautiful gift for granted." I pushed myself every day to drag my butt out of bed and walk – my chest hurt and my legs felt like jello but I knew this was all part of the journey.

As a patient with congenital heart disease, I was always bargaining with myself figuring I wouldn't make it past a certain age and fortunately my doctors were always honest

that someday I would probably need a heart transplant. In the back of my mind, I always had a goal to make it to age 50 – I'm 43 now so I'm close and ready to live well beyond 50. I have been a congenital heart patient for 43 years – trust me, I have been to a lot of doctors and met a lot of nurses. I have to say the best experience of my life and the scariest part of my life was this past year this year being at UCLA. It showed me the true meaning of human kindness – these doctors and nurses had compassion and were willing to fight alongside you.

I'm so fortunate to have Dr. Galindo in Las Vegas and I have so much trust in my team at UCLA. It's been 4 months since I've had a heart transplant and a kidney transplant I'm doing great better than probably was expected and it's all because I had an amazing team behind me. I was away from my husband and my dogs for 4 months and I missed them dearly, but I look back fondly having fun with the nurses and doctors and laughing with them. It made the time fly by a little bit faster.

For 43 years I have felt like a prisoner of my own body – I was never able to walk too far or even run. I joked that I wouldn't even run if someone was chasing me – I'd just play dead. Now, I walk 6 miles a day without being out of breath and without having chest pain. I can also run and jog – not because someone's chasing me because I actually like doing it now. Most importantly, I feel like I have my life back and I feel like this was the person I was supposed to be all along. Now I don't like to be told what I can and can't do because I have all this amazing power and energy – all these things I want to experience and live without fear. So far I've been doing just that.

I want to help other people like me or if they're going through something and they need to talk or they need to vent. When I was growing up with a heart condition there wasn't a lot of resources out there. It was tough growing up with congenital heart disease and being left out. I would wonder if there was a reason I ever survived. We may not know what the plan for our life is, but I kind of feel like I know mine now. Maybe it was to be a trail blazer in the

seventies for the Mustard procedure or maybe it's so that I can go through all these things to help other people.

I'm not scared anymore and I feel like I can probably do anything I put my mind to. I've never pushed myself so much in my entire life than I did in the past 4 months. When I woke up from that heart and kidney transplant everything changed: my outlook on life changed. The little things that used to matter to me don't matter anymore, I care about helping others, being a good person and taking good care of myself. I don't think I would have made it this far without the love and support of my parents, Jerry and Deborah Miracle and my husband Ty Lee. Everything takes time, and trust me when you feel like you're running out of time it's okay to have patience because good things come to those who wait.

Amy Miracle Lee

49, Tetralogy Of Fallot

by Marty Bieti

To look at me you would never think that I've been through 5 open heart surgeries. People are always shocked when I tell them. You would think I was a normal 49-year-old, and my wife would probably disagree with you. She would say "He's definitely not normal." I just keep telling myself that she means that in a good way.

I was born with Tetralogy of Fallot. I've been told that in the first few months of my life in the Midwest my parents would have to take me to the hospital as I was turning blue. We lived in Michigan's Upper Peninsula, hours away from any major cities. In fact, even now my hometown is about an hour and a half away from a freeway. Very much unlike the city I live in now, Los Angeles. When my Dad got pulled over by the police as he was speeding from our small Upper Peninsula town to the University of Wisconsin at Madison hospital during one of these cyanotic events he told the officer "If you want to keep me pulled over you'll have to shoot me!" Fortunately, after explaining the situation, he got a police escort the rest of the way to our destination.

My first 3 surgeries were all at the UW at Madison hospital. From my earliest memories, I was a patient there. I remember echos taking over two hours in those days. Echo technology has certainly changed over the years! My first surgery was when I was 6 months old, and as you would expect, I have no memory of that one. The first surgery that I do remember was in third grade. I had another surgery while I was in high school to swap out my pulmonary valve. Over my life, I would find out that this would be a "routine" surgery as it is common

to need new valves as they are outgrown or slowly rejected.

Since I was seeing the pediatric clinic at UW at Madison, they recommended that I see the Mayo Clinic as I progressed into adulthood. During a follow-up at the Mayo Clinic, the doctors noticed that the pressure gradients were elevated and recommended they be corrected. My next surgery was while I was in college and it ended up being somewhat benign as they noticed that the pressure gradients across my valve dropped dramatically after they opened me up. I did not need a new valve at the time, but just some “clean up”, so to speak. They removed some of my pericardium to give some more room for my valve and buttoned me back up.

Growing up I had few limitations. Although, I did get winded a lot quicker than my friends when playing sports when I was at the end of my valve’s life. I remember after having surgery in high school I felt like I could just

my pulmonary valve again, something I’d been through multiple times before. While other valves had lasted about 10-12 years, Dr. Laks’ magic touch helped make this valve last much longer!

In 2004, Mary Cannobio asked me to be a member of a panel of patients at a CHD symposium at Universal Studios. The symposium was for parents of kids with CHD and was part of Camp del Corazon. My role was to be an example of someone who has had CHD and has gone on to live a normal life. There were two things I remember well from that day. One, I got an applause break for a joke. The line was “I’ve had 5 open heart surgeries so far. If I have one more, I think I’ll go pro.” The other was much more significant. At lunch, I ended up sitting next to a woman who had a son with the same problem that I had, Tetralogy of Fallot. His life, up to that point, was very similar to mine; multiple surgeries, many doctor visits, and a lot of echos. I knew exactly what he was going through. She and I began

voice when he came in during this follow-up appointment. I had a good joke locked and loaded that day, but after reading the room, decided it was not the time.

So, while Dr. Aboulhosn was slamming in a new heart valve through a catheter, Dr. Shannon was wiring up a defibrillator. After having five surgeries where they rip your chest open, I don’t even consider my last procedure a surgery. I remember my Dad would say that it was always better to push off a surgery if you could because he always believed that someday they would be putting valves in with a catheter. He was right.

Near the ski jump in my hometown in Michigan, they refurbished the steps up the side of the landing. There are 500 steps to the top. While we were visiting this fall, we walked up the stairs for some exercise. After getting my new valve earlier this year, I could definitely feel the improvement in my stamina. Now my legs just need to get in some better shape.



go and go and go. It was such a night and day difference in my endurance! I graduated high school and went on to college like any normal teenager would.

In 1996, after receiving my Bachelor of Science and Master of Science in Electrical Engineering, I joined the workforce and moved to Los Angeles. I took a job at a local aerospace company building satellites. This was quite a culture shock for a kid from the Upper Peninsula of Michigan to venture out to Los Angeles. I asked my cardiologist at Mayo Clinic who he would recommend out in Los Angeles and he pointed me toward Dr. Perloff at UCLA.

I started seeing Dr. Perloff and Dr. Child shortly thereafter. The team at UCLA has been easy to work with and I have the utmost trust in them. I was fortunate to have had Pam Miner as a part of my team for nearly her entire career!

A couple of years after arriving in Los Angeles, the time had come for me to have another surgery, my fifth one, in 1998. Dr. Laks performed the “routine” surgery of replacing

emailing, then we progressed to calling, and before I knew it we were a couple. She is now the one that doesn’t think I’m normal, which I would say is a fair assessment. She and I got married and I officially adopted her son, RJ. He is now an adult and also a patient at UCLA. He was a pediatric patient at CHLA when he had a Melody valve put in a few years ago. I like to say he was just testing out a transcatheter valve before me.

During a follow-up early in 2021, they decided that it was time ... again. In the back of my mind, I had a feeling that it was time. How long could that valve go? If you’d been paying attention to the years of my surgeries, you’d calculate that it had “only” been nearly 23 years at this point! So, I was completely prepared for a new valve. What I wasn’t prepared for was what would come next. After noticing some arrhythmias in my monitor results, my team decided that it would be best if I had a defibrillator implanted, just in case. I had always had some minor heart palpitations in my life, but I distinctly remember the level of concern in Dr. Aboulhosn’s demeanor and

I am eternally grateful for the team at UCLA! Since I’m now a patient of Dr. Shannon in addition to Dr. Aboulhosn, I have the opportunity to give even more UCLA doctors a hard time.

People can easily focus on the negative aspects in their life and question “Why did this happen to me?” I have always tended to see the positive side of things, and I think is due to what I’ve been through. I’ve always been a pretty “even keel” kind of guy. My heart condition ultimately led to the biggest positive in my life – my wife and son. So, it all has a way of working out.

Giving Back

By Pam Miner

This newsletter is our way of reaching out to our ACHD community at UCLA, and staying in touch. To the point, this publication is dedicated to “those lives touched by congenital heart disease.”

Without a doubt, my life has been touched by congenital heart disease after spending my career as a nurse practitioner caring for ACHD patients. I hope I can continue to make a meaningful difference in the ACHD program at UCLA. What better motivator than retirement, getting older, and a global pandemic, to focus on what’s important and how to give back?

One way I have chosen to give back is in a volunteer capacity on the UCLA ACHD Board of Advisors. I joined this board to get the word out about ACHD and with the hope to inspire others to invest in activities that will ultimately improve the lives of patients.

I have quite literally put my money where my mouth is by recently including the Center in my will, and becoming a member of the UCLA Legacy Society. A planned gift is a wonderful way to impact ACHDC patients long after our own lifetime.



It is through the generosity of the philanthropic community that the Center is what it is today. There is no question that the caliber of our doctors, nurses and staff is the beating heart of our program. However, the muscle behind that team depends on how we respond to the changing needs of our ACHD population.

Demand for the Center’s specialized care continues to steadily increase annually and our core priorities, listed below, rely heavily on strategic resources:

- **Research** to advance scientific discoveries that will translate to life-saving and life-extending treatments as well as therapeutics for better quality of life.
- **Education & Training** of physician-scientists, who will become the next generation of leaders in the field of congenital heart disease.

There are many ways to help advance these vital initiatives. If you have a specific question about charitable donations to the program, or have contacts or suggestions that might foster our philanthropic goals, I would be happy to talk further. You may contact me through Yvonne Jose at YJose@mednet.ucla.edu or (310) 825-2019.

If you would like to learn more about how to include the Ahmanson/UCLA Adult Congenital Heart Disease Center in your estate plans, please contact:

Devon Brown
Director, Office of Gift Planning
devonb@support.ucla.edu (310) 794-2334



CONTRIBUTIONS

How You Can Help

The Ahmanson/UCLA Adult Congenital Heart Disease Center relies on donations in order to pursue many of its goals. Online donations may be made at: giving.ucla.edu/HeartCenter