AHMANSON/UCLA ADULT CONGENITAL HEART DISEASE CENTER

NEWSLETTER SUMMER 2024

UCLA Health | David Geffen School of Medicine

RONALD REAGAN UCLA MEDICAL CENTER

The Ahmanson/UCLA Adult Congenital Heart Disease (ACHD) Center was originally accredited in 2016 by the Adult Congenital Heart Association (ACHA) as an ACHD Comprehensive Care Center. In 2023, the center was reaccredited by the ACHA. See link on ACHA's website: www.achaheart.org/your-heart/resources/clinic-directory/a-e/ahmansonucla-adult-congenital-heart-disease-center/

GRAND OPENING: UCLA ACHD WESTWOOD OUTPATIENT CLINIC

We are happy to announce that the UCLA ACHD outpatient clinic in Westwood now has its own dedicated clinic space, separate from the UCLA Health Cardiovascular Center. Located on the seventh floor of the Vatche and Tamar Manoukian Medical Building, 100 UCLA Medical Plaza in Suite 700-84, the clinic officially welcomed patients on January 16, 2024. We have our own dedicated licensed vocational nurse, Xiomara Miranda, and medical assistant, Patricia Mendoza, who will become very familiar with our ACHD patient population.

Beyond our Westwood ACHD outpatient clinic, the UCLA ACHD Center continues to offer three

monthly satellite outpatient clinics to ACHD patients, served by Jamil Aboulhosn, M.D.:

- UCLA Health Santa Clarita
- UCLA Health Simi Valley
- UCLA Health Thousand Oaks

Follow-up appointments and diagnostic scheduling for all of our ACHD clinics is done via telephone by our ACHD administrative team at (310) 267-6627, rather than on-site, in order to maintain seamless continuity. You can also communicate directly with our team via UCLA My Chart at my.uclahealth.org/MyChart/Authentication/Login or by emailing achdc@mednet.ucla.edu

STAFF INTRODUCTIONS

Amanda Meier, B.S.N., R.N., joined the UCLA ACHD team in 2023 as our second full-time nurse coordinator. She comes to UCLA with 24 years of R.N. experience, notably working as the lead R.N. for six years in the ACHD program at the University of Washington. She also has advanced training in heart failure management, adding to her strong clinical background in pediatric and adult congenital cardiology. Amanda has already proven herself as a valuable asset to the ACHD team and our patients, and is working closely with our nurse coordinator Jennifer Doliner, B.S.N., R.N., to shore up all of our patients' clinical needs. On a personal note, she is happy to return to California, after starting her nursing career caring for neonatal and

pediatric cardiac patients at Children's Hospital of Orange County. She has settled into SoCal life with her two "wiener dogs" ages 2 and 14 years. One of Amanda's passions is doing cold plunges in the frigid 43-degree lakes and ocean near Seattle, and she has procured a "Cold Tub" to meet her needs in Southern California, which she can cool to 38 degrees. Brrrr! She also enjoys bike riding and loves gardening.

Yuri Argueta joined our UCLA ACHD team in 2023 as our new program manager. She has worked for UCLA since 2004, initially in an administrative front office role, but after completing her bachelor's in 2016, she has proven to be a strong manager in various roles with UCLA Health, including float manager and training coordinator and facilitator. Her talents will be an asset to UCLA ACHD, as she coordinates and directs our administrative and nursing teams, and works to optimize our patient/provider interface. On a personal note, Yuri takes pride in being the "favorite aunt" to her two nieces and loves to explore new culinary experiences in the local restaurant scene.

Miriam Silva joined our UCLA ACHD team in August 2022 as an administrative assistant and works closely with Veronica Olmedo to address all of our patient scheduling and insurance-authorization related issues. On a personal level, she enjoys hiking and spending time with her children and her fur babies, a German Shepherd and a Belgium Malinois.

UCLA ACHD PATIENT AND FAMILY CONNECTIONS SUPPORT GROUP

Through the UCLA ACHD Patient and Family Connections meetings, the center aspires to reach out and connect ACHD patients and their support system members with other patients to provide effective peer support to this growing population. Connections meetings take place virtually via Zoom on the last Thursday of each month. The ACHD social worker David Highfill, LCSW, facilitates the group. He is also a congenital heart disease (CHD) patient who underwent a modified Fontan procedure in 1990, and received a heart transplant in 2012, both at UCLA. Connections meetings are open to all ACHD patients and their family members. To obtain the Zoom link for the monthly Connections meeting, those interested can RSVP to the office manager, Yvonne Jose at (310) 825-2019 or YJose@mednet.ucla.edu

PATIENT STORIES

JEANIE, 74 years young, Congenitally Corrected Transposition of the Great Arteries

I was born in 1949 and diagnosed with a slight heart murmur, which doctors told my parents I would probably outgrow. As I had no symptoms, it was irrelevant until the early 1990s when my primary care physician referred me to a cardiologist. I was 42 years old, had given birth to five children, and was living my life with no restrictions. My local cardiologist, whom I still see today, diagnosed me with congenitally corrected transposition of the great arteries. Within three years I started experiencing shortness of breath and I underwent my first valve replacement — a mechanical tricuspid valve.

I recovered, returned to work, continued to raise my children, and lived my life. There were a few adjustments, in that I was now on maintenance medications, including coumadin, to protect my valve from blood clots. This required monthly trips to the lab for blood draws to monitor my INR (international normalized ratio that measures the amount of time it takes for a clot to form in a blood sample), which I complied with for almost 20 years. Around 2014, I was given a home monitor kit to test my INR with a finger stick. What a miracle!! All those trips downtown and the pokes were now a thing of the past. After my first heart surgery, my local cardiologist referred me to UCLA, since my congenital heart problem was unique and he felt collaboration with UCLA would be in my best interest. From my first surgery in 1995 until 2021, I underwent the placement of five pacemakers, an ablation, and numerous cardiac procedures. I still lived an active life with no restrictions.

In 2022, it was time to replace my aortic valve. My thought process was: OK, everything turned out okay the first time, right? Wrong, I had complications, a repeat surgery, and was in the hospital for a month. I guess there is a difference between having open heart surgery at age 45 and age 73. I am so fortunate to have been at UCLA and under the care of Dr. Jeannette Lin of the ACHD Center and Dr. Kevin Shannon of the ACHD Pacemaker/ICD Clinic. In addition, I had the miracle worker surgeon, Dr. Glen VanArsdell. I believe UCLA is one of the finest centers for acute and congenital cardiac care. In my experience, the entire staff at UCLA, from the doctors to the office personnel to the cafeteria workers are always helpful, knowledgeable, kind, and resourceful. My recovery was a little slower this time. I went to cardiac rehab for three months with the hope I would be able to join the Mississippi River boat cruise my family had planned for September 2022. I did make the cruise and we began planning our next adventures.

In December 2023, my family went to Costa Rica and I went ziplining and river rafting. We are planning a trip in June 2024 to Alaska, where I have already signed up for dog sledding on a glacier. In addition, we are going on a European cruise in August 2024.

I feel the trajectory of my life has changed periodically. I will be 75 years old, but I have decided this year, I am going to reverse my age to 57 for another trajectory change. I feel good, I feel healthy, and I have many things yet to do. I still live my life with no restrictions. I have a wonderful supportive family who is always there for me. I also have a fantastic medical team at UCLA.

CINDI, age 56, Dextrocardia, Double Outlet Right Ventricle

I am a Lotus. I often amaze myself I am even still alive. I have been through so much, both healthwise and emotionally. Far more than most people. Even after all I have been through, I feel I have a good disposition, I have tried my best not to dwell on the tragic life, but just on the positives.

I have always made goals for myself in the healing process and life in general. Some are as small as getting up out of bed in the hospital and walking to the front door. To build a thriving business.

I was born with a rare heart condition. Doctors told my parents to just take me home and be with me until I pass away. I was not supposed to survive. Boy, did I prove them wrong! One doctor named Henry Heins said to my parents, "do not listen to them, she is strong." I was transferred to Children's Hospital Los Angeles, where I had my first heart surgery at just three days old. I was a little fighter and dad says I always had a smile on my face even after the operation. I was a good baby and grew healthy and strong. As a little girl, I took up dance at 3 years old. I loved dancing, being so free.

At 5 years old I had my second heart surgery. Again, came out a trooper, continued to dance,

and lived a normal childhood. My parents did not treat me like I was ill and let me do whatever I wanted.

At 13 years old I needed my third heart surgery. This time the doctors at UCLA replaced my aortic valve with a pig valve. Again, I came out a trooper, continued dancing, hanging out at the Sherman Oaks Galleria, and discovering boys. My teenage life was a normal one. I had a boyfriend, continued dancing, and went to parties every weekend.

At 36, I was happily living in Pacific Grove. Then tragedy hit. I was not feeling well. Coughing, tired ... was this from stress? I took a week off of work and just hung out at the beach. I still did not feel the best, but continued working. I went to a doctor in Monterey and he said I had allergies. So, I started allergy medication. In my weak state, I flew to Los Angeles and stayed at the Bonaventure Hotel downtown. I went shopping at the L.A. Mart Design Center. I could barely function. I took a taxi back to the hotel and ordered room service. I just did not feel right, so I called my parents. They came from La Quinta and took one look at me. I was pale and had lost a lot of weight.

I was never hungry and I constantly coughed. They drove me to UCLA, where I was diagnosed with hemolytic anemia. My white blood cells were eating the red cells. I was just a week or so away from my deathbed. I stayed at the hospital for a week to recover. I was told I needed small doses of chemotherapy, for eight weeks via intravenous (IV) treatments. Since my husband was in no condition to take care of me, my parents took me in. Once a week, one would drive me to the doctor's office at UCLA to sit there for six hours with an IV in my arm. Sometimes we would spend the night at my aunt's home in Sherman Oaks or in a hotel. I was so weak I could hardly remember anything.

The IV treatment did not work and ultimately, I had to get my spleen removed. During this time, my husband left me at my parents in La Quinta. He never came back. I healed and decided to stay with my parents until I was back on my feet.

Later that year, I was not feeling the best again, I started coughing and just feeling weak. I'll never forget I was with my dad at a restaurant having lunch. I started to get very cold, my insides were cold, but I was sweating. Drips of sweat, but shivering. Dad took me to emergency at Eisenhower in Rancho Mirage. They did an echocardiogram and saw a little piece of something had landed on my pig valve, which led to be being diagnosed with endocarditis — an extremely rare form called Bartonella. Apparently, this rare infection could be caused by something as benign as a scratch from an infected cat. My body had gone into shock. It was decided I needed open heart surgery to replace the valve and remove the infected valve. But first, I had to get strong enough to make the trip to UCLA and have the surgery. A team of physicians at Eisenhower worked together to get me strong enough. I had a beautiful private room overlooking the gardens and after a week of antibiotics I was finally strong enough. The ambulance transported me from Eisenhower to UCLA. I remember the paramedic drivers were in their 20s and very attractive. We listened to rock music and chatted the whole way there.

Once at UCLA I was wheeled down a corridor. I cried and went into a depression. All I wanted to do was get back home to my parent's house. I shared a small, cramped room with another woman. I laid in bed and thought of my Aunt Manya. She had gone through hell and back as a Holocaust survivor. This thought is how I got through this hellish time. I had my heart surgery and it was a success. I spent another week in intensive care, in and out of consciousness. I was so confused and disoriented by the pain meds that I saw little devils and bugs climbing on the walls. A baby was crying next door, which in my mind, was a dog barking. When I finally started coming to, I opened my eyes and saw my dad sitting by my side.

My dad was the one man who stood by my side, through it all.

After six weeks of struggle in the hospital I was finally able to go back to my parent's home. With the help of my parents, I continued to grow strong. This time it took me three years to gain enough strength to move out of my parent's home.

It's been almost 20 years since my last heart surgery. During that time I have been living in Palm Desert, California. I live a healthy life. I own a successful interior design business and a home. I make it a priority to do some type of workout for one hour six times a week — Dr. Reardon is proud! Yoga and hiking are my favorites. I never let my past health issues stand in my way. I am like a lotus rising from the murky mud into a beautiful flower.

SKYLAR, age 30, Hypoplastic Right Heart Syndrome, Fontan, Heart/Liver Transplant

Skylar and his wife Alex.

A few facts about me: I am 30 years old, I am from Eastern Washington, and I have been married to my beautiful wife, Alex, for almost 10 years. I was born with a congenital heart defect: hypoplastic right heart syndrome. The first 28 years of my life, I had nine open heart surgeries, including a Fontan operation so that blood could flow through my heart smoothly. These surgeries have been lifesaving, but there are always side effects, one of those being that I had developed cirrhosis of the liver. Growing up, I had many restrictions, but never let this disease hold me back from living my life the best I could.

It wasn't until about February of 2017 that my congenital heart doctor in Spokane, Washington, Dr. Jeremy Nicolarsen, suggested we start the process of receiving a heart and liver transplant.

The second he spoke those words, my heart sank to my stomach. Every worry, doubt, and fear flooded my mind. Of course, no one wants to go through this, but if it means that I can live a happier, healthier, and longer life, let's roll the dice. From then on, there were many tests, phone calls, check-ups, and even a trip down to Los Angeles to Ronald Reagan UCLA Medical Center for transplant evaluation. On December 13, 2019, I was accepted as a patient for the heart and liver transplant. This meant moving down to Los Angeles.

In March of 2020, Alex and I made the trek to L.A., but were quickly asked to turn around. Why you ask? Enter COVID-19. Like many things COVID put on pause, so did admitting patients for transplants at UCLA. It wasn't until July 2020, that I was finally admitted, but with a twist. UCLA was only allowing visitors for a short period of time and it meant that I had to be in L.A. in the hospital alone, while my wife stayed back in Washington. It was the only time in our lives we were separated for a long period of time, but if it meant a better life, it was worth it. Shortly after being admitted, I was listed for transplant!

October 2020, an unfortunate event occurred; I was delisted and discharged from the hospital due to unforeseen circumstances. Since there was an unknown timeline of when I would be able to be readmitted and put back on the list, I traveled back home to Washington to wait.

During this time, my wife and I worked hard to raise money so she could be in L.A. with me. We saved every dollar we earned and ran multiple fundraisers to accomplish this.

Fast forward to August 2021, Alex and I moved to L.A., as it was time to be readmitted and put back on the transplant list. We found an apartment close to the hospital and settled in. I was finally readmitted in September 2021.

In October 2021, I was delisted and discharged for the second time for unforeseen circumstances. Instead of going back to Washington, I stayed and waited at our apartment in L.A. While it was a discouraging time in the journey, Alex and I used that time to explore and do things that made us happy. Thanksgiving came around and we decided to go home for about a week because we were both homesick.

During this trip, I experienced something that I've never experienced before. I experienced immense fatigue, extreme tiredness, and intense shortness of breath. My oxygen levels were usually in the 80s, but at this time, they were dipping down to the 60s. I was asleep for about 20-22 hours of the day and could not fight the urge to stay awake. Any sight of light would give me headaches. It felt like I was literally on my deathbed. I got transferred to the hospital in Spokane and found that there was fluid around my lungs. I got it drained and was pumped with iron. I was also put on oxygen and was told to go to L.A. to go back to UCLA.

In December 2021, with much support from the team in Spokane and my team at UCLA, I was readmitted and put back on the list for the final time. While I was feeling better, I still wasn't feeling my best, but then January 25, 2022, I received a phone call that would change my life forever. I got the call saying they found organs that were a match for me. My number had been called and it

was game time. Emotions flooded and every battle and fight flooded. Soon this would all be over and I would feel like a normal human being.

I was in surgery that night. Obviously, I don't know exactly what happened, but the important thing is that everything went the way it needed to. I woke up two days later and the sense of accomplishment flooded my brain. Over the next month, I rehabilitated to being able to walk and talk again. I was given training on my meds and new life, physical rehabilitation, and a new chance to live my life. Nothing could be sweeter.

People ask me all the time if I feel different and the short answer is I do. My body is able to be more physically active than ever, I can breathe better as my oxygen is now in the 90s, and when I look in the mirror, I love that I see pink lips and fingernails as opposed to purple or blue.

Since then, I've moved back home to Eastern Washington, I work an amazing job in social work, we bought a house, and I'm on my way to earn my master's degree.

For anyone who is skeptical about doing a transplant, I won't lie to you, it is scary. The flip side of that is that the risk is worth it if it means a healthier life with your loved ones. I tried my best to maintain a positive attitude, but it wasn't perfect. My wife, my family, and my medical team can attest to that. I'm thankful for everything that happened and I'm most thankful for my CHD. Without it, I wouldn't be the man I am today.

JASPER, 52 years old, Marfan Syndrome

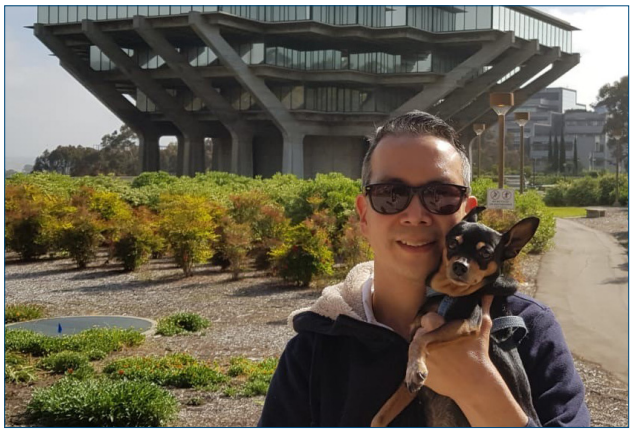
Life is transformation. For many ACHD patients who are waiting to undergo cardiovascular procedures, the fear of the unknown is tangible and understandable. Patients invariably face unknown challenges. But know this: the other side of the unknown is where fear meets the opportunity for a new and transformed life. Fear and bravery are two sides of the same coin. This is how I spring boarded my own memento mori moment (remembrance that everyone must die) into a transformed bright-sized life of carpe diem (seize the day).

I was fortunate to be made aware of my memento mori moment early in my youth during a seemingly routine eye exam. My ophthalmologist at the time, Dr. Robert Wing, mentioned briefly but seriously that he remembered reading a short

passage in one of his medical student textbooks of a condition known as Marfan syndrome, caused by an extra elasticity of the body's connective tissue. As an unknowing teenager who rarely pondered death, he explained that this could be the reason for my congenital eye conditions, and that a related concern was my cardiovascular health. After all, connective tissue plays a pivotal role in the proper functioning of heart valves. This was my "Memento Mori Moment." He told me to see a specialist soon.

A rational person would have gone to a cardiovascular specialist right away. But for some reason, it was a bit later before I started to see a cardiologist and get regular MRI exams for my heart. This could have been my psyche trying to avoid the unavoidable. With every yearly checkup, I felt a proverbial clock ticking inside my head. Deep down, I knew I couldn't outrun the inevitable need for surgical intervention. This was my worst fear come true. As context, I am (still) the type of person who nearly faints during a simple blood draw, so you can imagine how I felt about open-heart surgery.

For some reason, a voice inside my head also told me I should seek the best medical team possible. If I had to face heart surgery, I was going to do it with the best medical team I could find to maximize my chance of surgical success. From a medical perspective, I needed a championship-caliber team filled with all-stars at every position. After weeks of online searching during the early days of the internet, there was one small forum for patients with a quick blurb that read, "Thanks to Dr. Perloff and his amazing team at UCLA for saving my son's life." Just from this one sentence, my gut instinct told me that UCLA was the place I



needed to be — it would be my championship team of medical experts. I came to find out that Dr. Perloff was indeed a medical legend in his field. I told myself, I won't go down without a fight. And besides, if I have to have heart surgery with the best medical team around, why not do it at a place with perfect weather, bright blue skies, and palm trees?

The question then was whether Dr. Perloff would accept me as a new patient. This was in the nascent days of ACHD, so I took nothing for granted. I eventually made contact with Pam Miner, an absolutely amazing cardiovascular nurse practitioner at ACHD, who told me to send her a summary of my case. I frantically hand wrote a three-page note, which I faxed to ACHD. By a small (or large) miracle, Pam let me know the life-changing news: I would be accepted as a new patient at ACHD with her and Dr. Perloff as my cardiologist. My prayers were answered. Medical dreams come true. The military strategist, Sun Tzu, is widely attributed to the quote, "The battle is won before it's ever fought." You want to stack the decks in your favor by getting the best people to focus on one thing — in my case, my cardiovascular procedure. I felt that by being under Dr. Perloff's legendary care, I was best positioned to accomplish this great feat. Success is never a guarantee. But

with ACHD's medical dream team on my side, I knew I was tilting the scales of winning the medical battle before it was ever fought.

I remember the surgery morning like it was yesterday, even though it was nearly 25 years ago. My family and I stayed at Tiverton House, located just next to UCLA, and walked in the darkness of the early morning hours to the surgery check-in area. I remember thinking how calm the entire process appeared despite the stakes at play. This is it — surgical showdown, I told myself. I knew this moment was coming for many years. So in a way, I was just glad that the inevitable was finally before me. When the anesthesiologist came to prep me for surgery, he asked me, "So what's the most beautiful place you've been to?" I said, "Hawaii." He replied, "Well, think of being in Hawaii now — and just countdown from ten to one." I can't remember anything past the number eight.

Eight is a lucky number for many cultures, and it turned out it was a lucky number for me. When I woke up in the ICU, I was alert and fully aware of everything going on around me. I felt thirsty, but amazingly, I hardly felt any physical pain. Not long after, Dr. Hillel Laks, my cardiothoracic surgeon, whom I literally owe my life, came to check on me with his team. He asked if I could understand what he was saying (since I had a breathing tube and just came out of surgery). I nodded vigorously and, believe it or not, had the wherewithal to accompany this with a thumbs up! He then proceeded to tell me that my surgery relating to my heart valves was successful. I was elated! I then proceeded to stretch out my hand — I wanted to shake the hand of the person who "transformed" my life. I felt a sense of surprise by Dr. Laks and his team at that moment. Maybe this was unusual — even unprecedented? Ultimately, we did shake hands — right there in the ICU.

My procedure was a week before Christmas, so I chose a music compilation CD with some classic Christmas songs with a soft jazzy twist to put everyone at ease — namely myself in the surgery room. It turns out Dr. Laks and the surgical team liked the holiday vibe enough to have played it in its entirety during my procedure. I was told this is not always the case. I suppose great minds think alike. And I also have a theory that great music creates a sense of e pluribus unum — out of many, one — in my case, many medical experts from many backgrounds, cultures, and religions united under UCLA Health's singular mission for surgical success.

Patients may well know that the recovery process has moments of both physical and mental triumphs and setbacks. Looking back, the physical pain was much less than I anticipated. It was the internal psychological challenges that I may have underestimated. Here, mindset is eminently important. The key is to focus on small areas of improvement made every day. One thing I'll always remember is how amazingly positive, literally, everyone was at the UCLA medical center — at every level and with every task — during the next few critical days of my post-surgical recovery period. The person who delivered food to my room was super positive every day, saying "Wow, you look amazing!" The custodial staff were also always upbeat about my recovery each time we met. The nurses, the physical therapist, and the list goes on — all so amazingly positive and talented. That mindset alone could tilt a 50-50 scale to the side of recovery success. Everyone there deserves a gold medal. They are lifesavers and saviors. They are absolute heroes.

Among the top of such medical heroes is Pam Miner, nurse practitioner at ACHD, who recently retired. I truly see her as my medical guardian angel. She guided me through every step of the process in a way that was logical, but also highly caring and empathetic. She offered compassion and caring balanced with extreme expertise in a way that few if any can match in her role. Pam is priceless. Pam is my MVP.

After Dr. Perloff's retirement, I had the privilege of being treated by Dr. John Child (whose humor and care cannot be matched), and now, Dr. Jamil Aboulhosn (whom I view not just as my cardiologist, but also as a doctoral brother-in-arms). I was also connected to the care of Dr. Hidemi Dodo during my time as a trading floor banker in Tokyo. Dr. Hillel Laks, my surgeon, also recently retired. I will always remember his razor-sharp intellect and his total dedication to saving the lives of his patients. To this day, I am in awe of each of their individual sacrifices for the profound benefit of all their patients. This is the highest calling, in my opinion. My life and health are due to each of their relentless dedication and tireless efforts. I won the life lotto by being a patient of UCLA's medical care and team. Because of their profound dedication, I could travel and work around the world in places like Seoul, Tokyo, Hong Kong, Melbourne, London, and Los Angeles, as well as learn and teach at places such as Oxford, Harvard, Berkeley, and Stanford.

I'm lucky to be alive. I've learned that life can be beautiful and transformational, but you must seek such truisms. They exist, if you just look for them. Life happens for you, not to you. Countering life's challenges and darkness is hope and light. If I can survive, and prosper, from cardiovascular surgery, so can you. Just remember: memento mori is a life journey to carpe diem.

HOW YOU CAN HELP

To fulfill the mission of longer life expectancy and optimal health and wellness in the ever-growing population of adults with congenital heart disease, it takes more than exceptional health care providers and facilities.

Philanthropy plays a vital role in the continued growth of the Ahmanson/UCLA ACHD Center, providing crucial funds to develop research and training programs. Your donation will support the following key initiatives:

- **ACHD research and patient care**
- **ACHD fellowship and training opportunities**
- **Psychosocial support for our patients/families**
- **Health care provider ACHD symposiums to improve regional/national ACHD care**

All donations are tax deductible. Donate online at https://giving.ucla.edu/Campaign/Donate.aspx?SiteNum=58 or contact Lindsey Walton, Director of Development, UCLA Health Sciences Development at (424) 946-6102 or by email at LSWalton@mednet.ucla.edu

UCLA TEAM SUPPORTS THE ACHA "WALK FOR 1 IN 100"

Since 1998, the Adult Congenital Heart Association (ACHA) has empowered the national CHD community by advancing access to resources and specialized care that improve patient-centered outcomes. Their advocacy touches every region of the United States with walks for the "1 in 100" children and adults living with CHD. These walks form the foundation of fundraising for the ACHA, and bolster community spirit for CHD awareness and collaboration among major ACHD providers in each region. The UCLA team plays a key role in sponsoring and participating in the L.A. Walk for 1 in 100, and showed up on October 14, 2023 at Griffith Park to "walk the walk."

PERLOFF LECTURESHIP 2024: ZIYAD HIJAZI, M.D., M.P.H.

Drs. Aboulhosn and Hijazi.

The Joseph K. Perloff Lectureship has served to spotlight the extraordinary talent in the world of ACHD. The named lectureship is a fitting tribute to the legacy of Joseph Perloff, M.D., who is widely credited for being one of founding pioneers of the field of ACHD.

The 2024 invited speaker was Dr. Ziyad Hijazi, an internationally recognized leader in the development of techniques and catheters/devices to help treat or cure congenital and structural cardiac disease without the need for open heart surgery. His interventional cardiology acclaim has left an indelible mark on what we now view as the standard of care in children and adults, dating back to 1994 when he published his experience in using coils to close patent ductus arteriosus, to the initial trials of the Amplatzer septal occluder in 1997, which went on to achieve FDA approval in 2001.

In 2005, he was the first in the U.S. to implant a pulmonary valve via catheter in a 16-year-old boy.

Dr. Hijazi is undoubtedly a pioneer in the field of interventional congenital cardiology, so it is befitting that he served as this year's Perloff Lecturer, from one pioneer to another.

On February 8, 2024, Dr. Hijazi's lecture "Transcatheter Therapies in Adults with Congenital Heart Disease" was presented in the Dr. S. Jerome and Judith D. Tamkin Auditorium at Ronald Reagan UCLA Medical Center, and was also viewed virtually.

WITH GRATITUDE AND RESPECT: A TRIBUTE TO MARJORIE PERLOFF (1931-2024)

Many of you may remember Dr. Joseph Perloff, who passed away in 2014. He founded the UCLA Adult Congenital Heart Disease Center more than 40 years ago. He was a true visionary who is widely credited for predicting the avalanche of CHD survivors entering adulthood in the 1970s, a decade after the cardiac surgery era began. Dr. Perloff recognized the need for a new specialty of cardiology equipped to respond to what was previously relegated to pediatricians. Beyond his unparalleled contribution to the science and practice of ACHD, Dr. Perloff also had the wisdom and good fortune to marry Marjorie Mintz in 1953. Marjorie Perloff was as gifted in the literary arts as Dr. Perloff was in the science of congenital heart disease. She passed away on March 24, 2024, at the age of 92, and deserves to be remembered by our ACHD family.

Marjorie was born in Vienna, Austria, in 1931. Being Jewish in Austria in 1938, in the face of the Nazi annexation, was a perilous time. The Mintz family fled their home and emigrated to New York, among the great wave of European Jewish intellectual refugees. Marjorie was destined for academia, attaining her English degree, then her master's and a doctorate with academic appointments in English and Comparative Literature. Her prestige as a poetry scholar brought the Perloffs to California in 1976, initially for a professorship at the University of Southern California, and then as an endowed chair at Stanford in 1986. Her retirement years since 2001 have been as active and prolific in her literary community as her husband's were in the ACHD community — two legends leaving their indelible mark.

We remember Marjorie not only for her contribution to the enrichment of American culture, but for her unwavering commitment to her husband's legacy at UCLA. In the decade since Dr. Perloff's passing, Marjorie has been one of our most generous benefactors, donating in her husband's name each year. The impact of such meaningful philanthropy cannot be understated. Marjorie was invested in securing the future of ACHD at UCLA, for which she will always have our utmost gratitude and respect.

UCLA SYMPOSIUM: BEYOND PALLIATION: EXPLORING TRANSPLANTATION OPTIONS FOR FONTAN PATIENTS

Over 100 physicians, nurses, and allied health professionals attended the UCLA symposium on February 24, 2024 at the UCLA Meyer and Renee Luskin Conference Center, along with another 90 who attended virtually.

For health care providers caring for patients with congenital heart disease, the Fontan operation remains one of the most complex, mainly related to the physiologic toll it takes on more than just the cardiovascular system. After the original Fontan operations four decades ago, there was new hope for adult survival of babies born with only one functional ventricle, but by 1990 it was clear that this hope for survival came with a cost. With every decade since then, the congenital cardiology community has waged a valiant battle to recognize and combat the complications associated with Fontan physiology, with the ultimate hope of normalizing life expectancy and optimizing quality of life. In 2024, we understand that for many Fontan patients, survival may depend on heart transplantation, and for some, heart and liver transplantation.

In an effort to educate our growing referral community about the need for focused, multisystem, tertiary surveillance of all Fontan survivors, this one-day symposium centered on all aspects of Fontan care, from routine surveillance and interval exercise evaluations, to detailed liver screening, and ultimately decision-making regarding if and when to refer for transplantation evaluation.

Matthew J. Lewis, M.D., M.P.H., Director, Adult Single Ventricle Clinic, Columbia University Medical Center, served as the keynote speaker for the symposium. Dr. Lewis is the principal investigator for the Fontan Outcomes Study to Improve Transplant Experience and Results (FOSTER), a multicenter Fontan study. Dr. Lewis and his collaborators (including the UCLA ACHD team) published their Phase I data in 2023 (see link below), which included 304 Fontan patients from 14 ACHD centers across the U.S. and Canada who were referred for heart or heart-liver transplantation. The aim of this initial phase was to determine the predictors for survival in adult patients with Fontan who underwent heart transplant or heart-liver transplant, and to look at survival predictors after referral, particularly for those that were ultimately denied transplant.

The goal is to determine the optimal time to refer for transplant, to minimize morbidity and mortality and to maximize time with the Fontan. Of the 304 subjects, the average age at the time of transplant referral was 27, and the average time from Fontan completion to transplant referral was 22 years. Dr. Foster and his collaborators described key factors contributing to Fontan failure, of which supraventricular arrhythmia,

ventricular pacing, and evidence of liver cirrhosis on imaging factored prominently in over half of the patients. The next phase of the FOSTER study will seek to define optimal timing of heart or heart-liver transplantation and validate the predictors for mortality after transplant.
Dr. Lewis cited a recent publication by the UCLA team (see link), which is the first to reveal upregulation of multiple genes that correlate with advanced liver fibrosis and may help play a role in the complex liver screening of Fontan patients. See the following publication links for more details:

Morbidity and mortality in adult Fontan patients after heart or combined heart-liver transplantation:
https://pubmed.ncbi.nlm.nih.gov/37257951/

Intrahepatic transcriptomics differentiate advanced fibrosis and clinical outcomes in adults with Fontan circulation:
https://pubmed.ncbi.nlm.nih.gov/38355242/

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