AHMANSON/UCLA ADULT CONGENITAL HEART DISEASE CENTER (ACHDC)

NEWSLETTER SUMMER 2025

UCLA Health | David Geffen School of Medicine

AS SUMMER ENDS, THE ACHDC SAYS A BITTERSWEET GOODBYE TO AN ERA

A heartfelt sendoff: Dr. Kevin Shannon's retirement

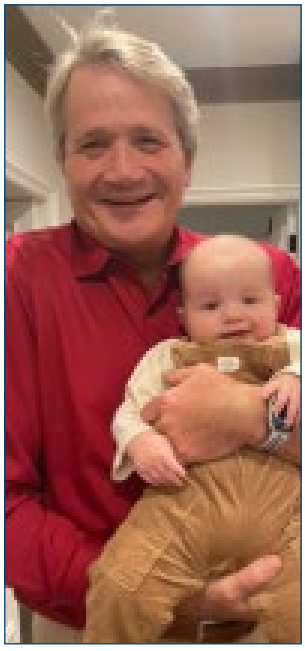
World-renowned pediatric and adult congenital heart disease (ACHD) cardiologist and electrophysiologist Kevin Shannon, MD, is set to retire from UCLA in September.

Dr. Shannon completed his pediatric cardiology internship, residency and fellowship at UCLA, where he stayed for the rest of his consequential career. Over the past 39 years, Dr. Shannon has literally touched the hearts of generations of children.

Following an early interest in engineering, Dr. Shannon pivoted to medicine upon realizing that he liked helping children and disliked working alone. His gift for understanding physics, hemodynamics and electricity steered him toward cardiology and electrophysiology (EP). Many cardiologists agree that EP is among the most intellectually strenuous specialties — fitting for a physician often regarded as the smartest person in the room. Dr. Shannon is also revered for his tact when discussing challenging cases, as well as his ability to form meaningful connections with patients founded on mutual trust and respect.

Dr. Shannon chose to study EP with the intuition that arrhythmias would likely impact more than half of people born with CHD. His mentor was ACHDC Founding Director Joseph Perloff, MD, who stressed the importance of playing the "long game" with CHD and monitoring the disease over the course of a lifetime.

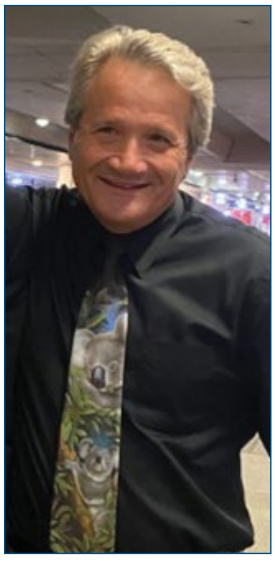
These insights set Dr. Shannon apart in a rapidly developing field focused on electrical disturbances of the heart. Because heart rhythm issues tend to progress with age, Dr. Shannon



became equally proficient in treating children and adults. The nearly four decades that Dr. Shannon spent at UCLA mirror the development and evolution of EP as a specialty, including diagnostic studies, catheter ablation, revolutionary advances in pharmacologic therapies, and life-changing progress in implantable pacemakers and defibrillators.

Dr. Shannon's influence goes beyond hospital walls. In 1995, he was moved by a 10-year-old cardiac surgery patient who was reluctant to remove his shirt. To help this child and other young CHD patients overcome scar insecurity, Dr. Shannon and Lisa Knight, RN, started Camp del Corazon.

For 30 years, this medically supervised summer camp has played an instrumental role in the psychological and social development of children with CHD. Dr. Shannon has attended every camp session and never fails to live up to his camp name "Big Kahuna." Camp del Corazon is a cherished piece of the legacy built by Dr. Shannon and his wife Heatherly Vandeweghe, M.D, a retired pediatrician who has similarly devoted her life to service.



During residency, wearing a tie became part of Dr. Shannon's professional ethos. His ties, which usually depict animals and cartoon characters, bring joy to patients and colleagues alike. Approaching the end of his UCLA tenure, most of Dr. Shannon's ties are gifts from patients and families.

UCLA wishes Dr. Shannon a well-deserved retirement and will miss his wisdom, compassion and charm.

TEAM SPOTLIGHTS

ACHDC administrative staff

Answering our phones, scheduling and coordinating patient appointments and diagnostic testing, connecting patients with their health care providers, and navigating the complicated "dance" with insurance companies are just some of the ways that the ACHDC admin team helps make the center great. Let us introduce this essential group of skilled and dedicated individuals:

- **Veronica Olmedo** has been with UCLA for 29 years and the ACHDC for 24 years. She is invaluable to both patients and medical staff. She approaches every complicated scheduling need, every anxious patient or family member, and every insurance representative with unflappable calmness and competence. Her long tenure at UCLA has enabled her to be the perfect teacher and mentor to the rest of the admin staff.
- **Miriam Silva** has been with UCLA for 20 years and the ACHDC for three years. Her expertise makes her the perfect champion for our patients when dealing with insurance companies.
- **Maggie Follmer** joined UCLA and the ACHDC team a year ago.
- **Evelyn Carpio** has been with UCLA for five years and joined the ACHDC team in February 2025 as the ACHD fellowship coordinator.

Adult congenital cardiac sonographers

Having an echocardiogram is an important part of living with ACHD, and our patients become very skilled at recognizing the expertise of sonographers performing these complex ultrasounds of the heart. We are fortunate to have two dedicated sonographers who have focused their expertise on the complexities of CHD:

Tom Cheong has been at UCLA since 2021 and a cardiac sonographer since 2017. He has been an ACHDC principal sonographer since January 2025.

Carlos Bermeo Cellan has been at UCLA since 2024 and a cardiac sonographer since 2020. He has been an ACHDC principal sonographer since February 2025.

Introducing the 2025 ACHD fellows

Julian Hirschbaum, DO

After attending the A.T. Still University School of Osteopathic Medicine in Arizona, Dr. Hirschbaum's training has been based entirely in Los Angeles — first at Los Angeles General Medical Center for a combined internal medicine and pediatrics residency and then at Children's Hospital Los Angeles for his pediatric cardiology fellowship. With strong mentors in pediatric cardiology, such as Roberta Williams, MD, his foundation in CHD is strong.

His interest in ACHD stems from a desire to care for patients throughout their lifespan. He has a special interest in improving health care systems and the transition of care from childhood to adulthood. He enjoys spending time with his family, traveling, playing tennis, hiking, running and skiing.

Marie-Christine Blais, MD

Dr. Blais is a native of Quebec, Canada, and earned a doctor of veterinary medicine degree before attending medical school at Laval University in Quebec. She remained at Laval University for her internal medicine residency and fellowship in adult cardiology. There, she helped care for ACHD patients alongside her mentor Emilie Laflamme, MD, sparking her interest in ACHD. She completed an elective rotation in ACHD with Rafael Alonso-Gonzalez, MD, at Toronto General Hospital, which houses one of the largest ACHD centers in the world. As a Quebec native, she speaks fluent French and English.

Niall Linnane, MD

A native of Ireland, Dr. Linnane attended medical school at the University College Dublin School of Medicine. He remained in Dublin for his pediatrics residency at the Royal College of Physicians and then his pediatric cardiology fellowship. He obtained a research degree investigating tissue characteristics in patients with coarctation. He went on to spend 2024-25 at Texas Children's Hospital, Baylor College of Medicine, for an interventional cardiology fellowship.

Dr. Linnane now comes to UCLA in hopes of securing a strong foundation in adult congenital cardiology to make him a well-rounded ACHD cardiologist and interventionalist. He plans to return to Ireland to serve its ACHD community after he completes training. On a personal front, Dr. Linnane is an avid tennis player and golfer. He also enjoys tag rugby and going to the gym.

RESEARCH

The 34th International Symposium on Adult Congenital Heart Disease took place in Toronto in early June 2025. UCLA played a key role in this widely attended forum, with presentations by Jamil Aboulhosn, MD; Jeannette Lin, MD; Leigh Reardon, MD; and Jeremy Moore, MD. ACHD fellow Hans Gao, MD, attended and presented a number of abstracts. He was also a member of the duo that won ACHD *Jeopardy!* In addition, UCLA's ACHD research program was spotlighted with five presented abstracts, summarized on the following page.

- **"Sotatercept in ACHD-PAH Patients: A Promising Trend"** (lead investigator Dr. Gao)
  - Sotatercept is the newest drug to be FDA approved (in March 2024) for treatment of symptomatic pulmonary arterial hypertension (PAH). As is the case with many major clinical trials, ACHD patients were not part of the study population, so UCLA sought to document the efficacy of sotatercept in ACHD patients with PAH and poor functional capacity despite triple-drug therapy with the core PAH meds (oral and intravenous). Three cases were highlighted, all with clear symptomatic improvement and two with documented hemodynamic improvement by echocardiogram.

- **"Impella-Assisted Right Ventricular Unloading and PAH Therapy: A Bridge to Transplant in Systemic Right Ventricles With Prohibitive Pulmonary Pressures"** (lead investigator Dr. Gao)
  - ACHD patients with systemic right ventricles (SRV) — such as transposition of the great arteries with atrial switch (Mustard or Senning) — are at higher risk for SRV failure, and occasionally this is complicated by PAH. This study reports two cases of SRV and PAH in which a temporary ventricular assist pump was successfully used to unload the SRV during aggressive pharmacologic management of the PAH, resulting in successful reduction in the pulmonary pressures. Since PAH precludes candidacy for a heart transplant, both of these cases demonstrated sufficient resolution of PAH to enable subsequent heart transplantation.

- **"A Single-Center Descriptive Study of Liver Fibrosis Progression Documented by Serial Liver Biopsies in Adult Fontan Patients"** (lead investigator Dr. Gao)
  - Fontan-associated liver disease (FALD) occurs in virtually all Fontan patients, and liver biopsy is valuable in assessing for FALD progression. UCLA routinely performs liver biopsies in the setting of surveillance catheterizations in Fontan adults. This study examined 21 Fontan patients with at least two serial liver biopsies/catheterizations. Thirteen of the 21 patients (61.9%) had progression of liver fibrosis from one biopsy to the next. FALD progression (more advanced liver fibrosis) was more common in those with Fontan pressures equal to or higher than 15 mmHg. This study underscores the importance of hemodynamic (catheterization) surveillance in the Fontan population, combined with liver biopsy.

- **"Characteristics of Aortopulmonary Collateral Formation and Recanalization After Embolization While Awaiting Heart or Combined Heart-Liver Transplantation in Fontan Patients"** (lead investigator Angela Li, MD)
  - Collateral blood vessels in the thoracic cavity are common in Fontan patients and pose a higher risk of operative bleeding during heart or heart-liver transplantation. This study looked at 22 Fontan patients who underwent catheterization prior to transplantation and required occlusion of collateral vessels. With long wait times for transplants, repeat catheterizations were necessary to track recurrence of collaterals,

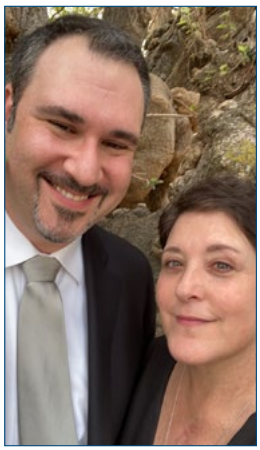
and this study revealed that 57% of patients had recurrent collaterals after three months. There was a higher rate of recurrent collateral formation in the upper chest cavity. Interval surveillance catheterizations were found to be beneficial for Fontan patients with longer-than-anticipated wait times on the transplant list (more than 90 days).

- **"Investigating Prevalence and Predictors of Thrombus Detection in Fontan Circulation With Transesophageal Echocardiography"**
  (lead investigator Neeja Patel, MD)
  - Thrombus (blood clot) formation in Fontan circulation has been reported at rates from 17% to 33%. Transesophageal echocardiography (TEE) has increasingly become the gold standard for thrombus detection. This study looked at 71 Fontan adults who were undergoing cardiac catheterization and TEE — 14 (43%) of whom were found to have thrombus in the Fontan circulation. Interestingly, there was no statistical difference in the rates of Fontan thrombus according to type of Fontan anatomy or among patients who were on aspirin versus anticoagulation, nor in those with prior arrhythmias. TEE was found to be an effective and valuable method for detecting previously undiagnosed thrombus in Fontan patients and could play a key role in influencing future management strategies for anticoagulation. TEE should be part of every Fontan cardiac catheterization.

PATIENT STORIES

SIENNA, 58

Condition: hypertrophic obstructive cardiomyopathy (HOCM)



I was diagnosed with HOCM when I was 6 weeks old. This was back in 1967 when the disease was only referred to as idiopathic hypertrophic subaortic stenosis. My father had the same heart disease, but he wasn't officially diagnosed until he was well into adulthood. His mother had it also, but she died of a sudden arrhythmia at 58. Back then, no one even knew why.

My pediatrician was the one who first discovered my heart murmur and sent me to UCLA. It was so long ago that my UCLA ID number begins with a zero. It was a blessing to be accepted, and I wouldn't be here today if it weren't for the thousands of people I have met during my lifetime there. It was suggested by my pediatric cardiologist — the wonderful Arthur Moss, MD — that I start a new medicine that had been approved. My beloved father, who was also symptomatic, offered to test it out by taking it first for an entire year before my parents agreed to let me take it.

It made a huge difference in how we both felt. But by the time I was 5, I became too ill for even the newly approved medicine to make a difference.

Dr. Moss told my parents that they couldn't be sure how long I would live without intervention. To help me, my parents could agree to let me undergo heart surgery that had never been done before on someone my age. They ultimately did, and custom surgical instruments were made small enough to fit my anatomy. They said I had only a 5% chance of living through it. I had the surgery when I was 6 and turned 7 in the hospital.

I was always very symptomatic as a child. I had all the classics: dizziness, shortness of breath, chest pain and very limited exercise tolerance. Despite my physical limitations, I was so grateful for my life. I always found a way to do things in my own way, at my own pace, until I was 13 years old, when I started realizing that I might not be able to have children. When I asked at one of my appointments, I found out that children were not in the cards for me. I was devastated, but I set out to make sure I would have a good life anyway.

Many years later and a lot of life lived, I had a second surgical septal myomectomy at 26. (I turned 27 in the hospital.) At 29, I got married, but my heart health began to suffer. I had an extensive arrhythmia history that ultimately landed me too many failed ablations to count and an implantable defibrillator (to prevent my own sudden death). Because of this, my health improved to the point that my then cardiologist — the magnificent Dr. Perloff — told me it was possible to have a baby. The only catch was that every child I should conceive would have a 50% chance of inheriting the same heart condition as mine. But as was typical for someone so full of wisdom and compassion, Dr. Perloff told me, "If the baby did get it, who better to teach it to have a full and rewarding life than you?" I couldn't believe my ears.

I had the most incredible pregnancy. I loved every minute of it — even the morning sickness in the first month. Because of my strong family history of HOCM, my baby was followed in utero the whole pregnancy, and there was no sign of the disease even upon delivery, which was a cesarean section (C-section). Everything was going smoothly until three days after delivery. My C-section scar opened up 7 inches wide by 5 inches deep on top of water in my lungs, liver failure, heart failure and postpartum depression. This was not the first, or last, time I left my team scratching their heads.

My daughter, who is 22 now, was diagnosed with HOCM when she was 4 weeks old. She has benefited from many of the advantages that were not available to me. She is literally the definition of a dream come true, and I couldn't imagine a life without her. Dr. Perloff was so right when he said there was no one better to teach her than me, but

the pregnancy definitely changed the trajectory of the two decades that followed. I ultimately required a heart transplant due to the fact that I could never quite get back to baseline and just continued to lose quality of life.

My daughter has also had a surgical septal myectomy and is doing very well, and thankfully, we share the same incredible doctors at UCLA. If it weren't for the pioneers of treating HOCM and the team that followed in their footsteps, neither of us would be here today. In fact, it was the wise Dr. Aboulhosn who gave me the single piece of advice that got me through the incredibly difficult transplant: "Give up the control, Sienna." I held onto those words like a lifeline.

The relationships I've had with my care team have always been built on the trust that they understood so well my approach to life. They have always given me the best chance at success because of it. Through their passionate guidance and fierce love, they have touched our lives and our hearts — both literally and metaphorically. We are full of gratitude that can never be adequately expressed. One of my greatest honors has been being a "student" of Dr. Perloff, one of the finest human beings to ever grace this Earth. He empowered me in ways that I will use for the rest of my life, and I hope my life has made him proud.

HEIDI, 38

Condition: transposition of the great arteries

I'm a mom of two wildly amazing boys (Huxley, 4, and Bodhi Blu, 1), entrepreneur, wellness enthusiast and beach lover living with CHD. Not many of my friends have to get an extra pat down when we walk into the Hollywood Bowl for a concert because they have a pacemaker. Sometimes I feel like I have two lives: one where having CHD greatly affects me and one where I forget I have it.

A few years ago, if someone asked me to share my heart story, it was easy. I was deep in the heart world after having an open-heart surgery in 2014 and then a pacemaker placed in 2017. But then something changed. I got pregnant in 2020. It was a high-risk pregnancy and in the height of the pandemic. Things were scary not only for a mom-to-be but also for a person living with CHD. On Sept. 2, 2020, my beautiful baby boy was born

three weeks early, and a brand-new chapter of my life opened. One where I realized that CHD was a part of me, but it was not all of me. I now had a reason to advocate for my health and really learn my story from a medical perspective.

I've had CHD my whole life, but I didn't really know what it meant. All I knew was that I had a scar down my chest, and I had way more doctor's appointments than my two older sisters. As I got older and there were more procedures that led to surgeries, I began to realize that CHD was a major part of my life — not just a scar. This scared me. I knew nothing about it. I couldn't even explain my condition if someone asked. After having my first baby, I may have stepped away from the day-to-day of the heart world, but I began truly educating myself on CHD. My heart story went from how it made me feel to what my specific CHD is and how I can live the longest, healthiest life for myself and my family.

I was born blue, like so many other heart babies. I was born with transposition of the great arteries. A few days after coming into this world, I was flown from Southern California to Boston Children's Hospital to quite literally save my life. I became the 100th baby in the world to have the switch surgery under the care of the renowned heart surgeon Aldo Castañeda, MD. I'll forever be grateful that I was born at a transitional time in medical history and that my parents took the chance to give me a better life.

Since that first open-heart surgery, I have had other issues and needed additional procedures, but it could have been so much worse. For almost a decade now, I have been under the care of UCLA, and it has been incredible. Not only do I feel safe and in the best hands, but I feel like I have a team of doctors who sees me for who I am and not just as a patient with CHD. I've also had the pleasure of meeting other patients and families on this same path through the UCLA community. It really is special to have that.

In conclusion, is it weird to say I'm thankful for CHD? Do I wish I didn't have to live with some of the fear associated with it? Of course. However, CHD has given me strength, purpose and a real love for life. I know how lucky I am to be here and will make sure to continue living life to the fullest, not only for myself but also for my adorable boys.

HOW YOU CAN HELP

There are many opportunities to help patients like Sienna and Heidi thrive.

Philanthropic contributions to the ACHD Program and Research Development fund provide essential resources to implement pilot studies, develop state-of-the-art technologies, hone programming, and enact other diagnostic and therapeutic measures for these patients.

You may also choose to designate your gift to a specific area that resonates with you, such as Fontan survivorship or pediatric patients as they transition to adult care and navigate the complexities of long-term health management.

Your generous, tax-deductible donation to the ACHDC will make a difference for our patients.

For more information about how you can support the ACHDC, please contact:

Lindsey Walton
Senior Director of Development
424-946-6102
lswalton@mednet.ucla.edu

UCLA ACHD PATIENT AND FAMILY CONNECTIONS

ACHD Patient and Family Connections Meetings unite patients and their loved ones with others affected by heart conditions. ACHDC social worker David Highfill — a CHD patient who underwent a modified Fontan procedure and received a heart transplant at UCLA — leads the support group. Connections meetings are open to all ACHD patients and their family members.

ACHD patients who are under evaluation for, are wait-listed for, have undergone or may be considering an organ transplant are also invited to attend our monthly ACHD Transplant Focused Connections Meeting. These meetings typically occur on the second Thursday of each month from 6 to 7 pm Pacific time. These too are peer support meetings for any ACHD patients who are or may become transplant recipients.

If you are interested in either or both of these meetings, please contact Office Manager Yvonne Jose at 310-825-2019 or **yjose@mednet.ucla.edu** to be added to our patient distribution list.

TEAM

Jamil Aboulhosn, MD
Streisand Chair in Cardiology
Director, ACHDC
Congenital and Interventional Cardiologist

Leigh Reardon, MD
Transition Director, ACHDC
Congenital Cardiologist

Jeannette Lin, MD
Program Director, ACHD Fellowship
Congenital Cardiologist

Gentian Lluri, MD, PhD
Associate Program Director, ACHD Fellowship
Congenital Cardiologist

Jeremy Moore, MD
Electrophysiologist

Kevin Shannon, MD
Electrophysiologist

Kalyanam Shivkumar, MD, PhD
Electrophysiologist

Daniel Levi, MD
Interventional Cardiologist

Glen Van Arsdell, MD
Chief, Congenital Cardiovascular Surgery

Ming-Sing Si, MD
Congenital Cardiac Surgeon

Reshma Biniwale, MD
Congenital Cardiac Surgeon

Richard Shemin, MD
Robert and Kelly Day Chair in Cardiothoracic Surgery
Chief, Division of Cardiac Surgery

Katrina Whalen
Nurse Practitioner

Mia Talamantes
Physician Assistant

Jennifer Doliner, RN
Nurse Coordinator

Amanda Meier, RN
Nurse Coordinator

Nicole Antonville, RN
Transition Nurse Educator

David Highfill
Social Worker

John S. Child, MD
Director Emeritus, ACHDC

ADMINISTRATIVE SUPPORT/CONTACT INFO

Yuri Argueta
Program Manager

Veronica Olmedo
Clinical Coordinator

Miriam Silva
Administrative Assistant

Maggie Follmer
Administrative Assistant

Evelyn Carpio
Fellowship Coordinator

Yvonne Jose
Office Manager
310-825-2019

Nurse line: 310-794-5636

Nurse email:
achdc@mednet.ucla.edu

Patient inquiries and scheduling: 310-825-9011

Website: uclahealth.org/medical-services/heart/achd

Fax: 424-465-6189