

# Ahmanson/UCLA

## Adult Congenital Heart Disease Center

FOR THOSE TOUCHED BY CONGENITAL HEART DISEASE

Fall 2017



*Dr. Hillel Laks, Dr. John Child, with Dr. Perloff pictured in the slide*

### CENTER UPDATES

## Recap: UCLA ACHD Symposium 2017

### Quality Care in the Era of Certification and Accreditation-A Practical Approach

Over 100 cardiologists and health care providers joined us at UCLA on February 10th and 11th for a state-of-the-art adult congenital heart disease (CHD) symposium which covered topics spanning from management of complex Fontan patients and the future of heart transplant and mechanical support devices, to management of high risk pregnancies. We also provided a half day “hands on” session so doctors, nurses, and trainees could see this advanced technology up close and personal, including transcatheter valves and stents, and even pathologic specimen of hearts impacted by complex CHD. Highlights from the symposium included a keynote lecture by Dr. Hillel Laks, (pictured above) on the history of congenital cardiac surgery, which earned a well-deserved standing ovation.

## Jamil Aboulhosen appointed Chair of ACHA Medical Advisory Board

The Adult Congenital Heart Association (ACHA) plays an integral role in providing patient and provider advocacy on a personal, community, and legislative level. The Medical Advisory Board of the ACHA guided national efforts towards ACHD center accreditation, providing key components necessary for ACHD specialty care. Dr. Jamil Aboulhosen has played a prominent role on the ACHA Medical Advisory Board for many years, and assumes the leadership role of Chair in November. Dr. Aboulhosen will serve as Chair for the next 3 years and does so at a crucial time in the development of ACHA and the field as a whole.



*Dr. Leigh Reardon*

## Teaching Humanistic Care at the Bedside Award Recipient

### Teaching Award for Dr. Leigh Reardon

In March 2017, Dr. Leigh Reardon received the 2017 UCLA Teaching Humanistic Care at the Bedside Award. He was one of 8 recipients in the David Geffen School of Medicine at UCLA, after being nominated by his peers for recognition of outstanding humanistic care of patients. He was the only cardiologist among this year’s recipients. We are grateful to have Dr. Reardon represent the Adult Congenital Heart Disease Center, and congratulate him on this well-deserved honor.

## Accreditation Update

We are pleased to announce that the Adult Congenital Heart Association (ACHA) has awarded the Ahmanson/UCLA Adult Congenital Heart Disease Center the status of an ACHA ACHD Accredited Comprehensive Care Center. This is the highest level of accreditation and was awarded to UCLA after a comprehensive review and vetting process. Programs with this designation are deemed to have all of the necessary procedures, processes, and staffing requirements to provide the highest quality ACHD care. UCLA is the first program in Southern California to receive this designation. Many thanks to the hard work of our team members, for the support of UCLA Health and the collaboration of our colleagues which has made this achievement possible.



## Faculty and Contact Information

### Faculty

#### Ahmanson/UCLA ACHDC Faculty

**Jamil Aboulhosn, MD**, Director, Streisand Chair  
**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, M.D.**, Interventional Radiology  
**Paul Finn, M.D.**, Diagnostic Radiology  
**Pierangelo Renella, M.D.**, Diagnostic Radiology  
**Mary Canobbio, RN, MN**  
**Linda Houser, RN, MSN, NP**  
**Pamela Miner, RN, MN, NP**  
**Katrina Whalen, RN, MSN, NP**

#### Surgical Faculty

**Hillel Laks, MD**  
**Reshma Biniwale, MD**  
**Richard Shemin, MD**

#### ACHDC Staff

**Jennifer Doliner, RN, BSN**, Nurse Coordinator  
**Yvonne Jose**, Administrative Manager  
**Veronica Olmedo**, Clinical Coordinator  
**Adriana Magallanes**, Physician Support Representative  
**Evelyn Garcia**, Program Manager

#### Social Work

**David Highfill, LCSW**

#### Research Coordinators

**Rachel Bolanos, MPH**  
**Jana Tarabay, MD**  
**Soraya Sadeghi**

### Contact Us

Patient Scheduling (310) 825-9011  
Nurse Coordinator (310) 794-5636  
Fax Numbers (310) 825-6346 or (310) 825-9012  
E-mail: [achdc@mednet.ucla.edu](mailto:achdc@mednet.ucla.edu)  
Website: <http://heart.ucla.edu/ACHDC>

### Information & Resources

#### Adult Congenital Heart Association (ACHA)

Website: [www.achaheart.org](http://www.achaheart.org)  
Call (888) 921-ACHA  
Email: [info@achaheart.org](mailto:info@achaheart.org)

#### International Society for Adult Congenital Heart Disease (ISACHD)

Website: [www.isachd.org](http://www.isachd.org)

## CENTER UPDATES (continued)

### ACHD in the Community – Porter Ranch

The Ahmanson/UCLA Adult Congenital Heart Disease Center is proud to announce the expansion to the San Fernando Valley Community. Starting in July 2017, Dr. Aboulhosn has been seeing patients at the UCLA Porter Ranch location, one Friday of the month. Please contact our office at 310 825 9011 if you are interested in attending this clinic.

### ACHD Support Group

The UCLA Adult Congenital Heart Disease Center is pleased to announce that we now feature social work services as part of the comprehensive care provided by our program. In April 2016, we welcomed David Highfill, LCSW to our team. David has over 20 years of experience working as a social worker with a variety of medical populations. David is uniquely familiar with many of these issues as he is also a CHD patient who underwent heart transplantation here at UCLA in 2012.

Since David has joined us, we have been able to offer comprehensive clinical social work services including supportive counseling, referrals, resources, coping education, and individual therapy services for patients experiencing urgent issues such as anxiety, panic attacks, post traumatic and acute stress, depression, and adjustment-related difficulties.

David also facilitates a monthly support group for all ACHD patients and their family members. The ACHD support group meets the last Wednesday of each month usually in the evenings to help minimize traffic. We welcome and encourage all ACHD patients and their family members to attend. This is an open group that focuses on a variety of topics as presented by the group members. Through shared personal experiences with others who may have gone through procedures or issues you may be currently facing, we hope to increase your comfort and ability to manage your own unique CHD diagnosis. Together with mediation by David, group participation can be greatly supportive, providing you with information and tips that will help you cope, prepare, and more easily live with the issues you may be facing. Please visit our website at [www.heart.ucla.edu/ACHDC](http://www.heart.ucla.edu/ACHDC), watch your email, or look for support group flyers in the 100 Med Plaza 6th floor ACHD clinic!

Talk to your doctor, nurse practitioner, or ask for David if you would like more information about the counseling services and support group. Feel Free to email our center for more information at [ACHDC@mednet.ucla.edu](mailto:ACHDC@mednet.ucla.edu).

## STAFF INTRODUCTIONS

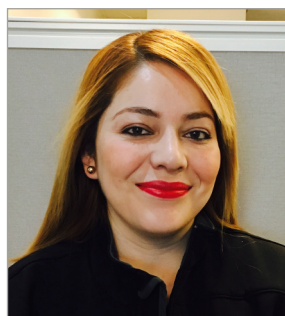
### Introducing our ACHD Nurse Practitioner



*Katrina Whalen*

We are delighted to introduce the newest member of our staff, nurse practitioner **Katrina Whalen**. Katrina is already familiar to many of our patients, as she started working at UCLA in 2004. She initially worked a registered nurse and then as a nurse practitioner in the cardiothoracic intensive care unit, and most recently as a nurse practitioner with the heart failure/transplant team at UCLA. Katrina is a natural fit for the Ahmanson/UCLA Adult Congenital Heart Disease Center, as she has always had a passion for caring for individuals with congenital heart disease. Since 2007, she has served as the nursing director at Camp del Corazon, a sleepaway camp on Catalina Island for kids and teenagers with congenital heart disease. In her free time, she enjoys exercising, and spending time with friends and family.

### Introducing our ACHD Physician Support Analyst



*Adriana Magallanes*

**Adriana Magallanes** has been with UCLA Health System for 13 years. She transitioned from UCLA dermatology and joined the Ahmanson/UCLA Adult Congenital Heart Disease Center September 2016. She has been a fruitful addition to the team. Her keen attention to detail combined with her kind demeanor made her a perfect fit for the center. She is also bilingual, speaking Spanish fluently. In her free time, she appreciates arts and crafts with her kids and planning adventures with her family.

## Faculty Profile: Mary Canobbio, RN, MN



Mary Canobbio

**Mary Canobbio** worked as a Clinical Nurse Specialist (CNS) with both Dr. Perloff and Dr. John Child in the UCLA ACHD Center until 1987, caring for our growing patient population. After 1987, she maintained close ties with the program and patients, by providing counseling to both patients and their families. Her passion for the new subspecialty of “adult congenital heart disease” (ACHD) led to a dedicated program of research, and many publications in the field of ACHD, from defining the role of the ACHD nurse, to the reproductive challenges confronted by women with ACHD. Mary’s legacy as an ACHD researcher will always be linked to her work in examining the reproductive outcomes of females with congenital heart disease. Her initial work examined the menstrual patterns of females with congenital heart disease (CHD). Subsequent work has focused

on the pregnancy outcomes of females with complex CHD. From these early studies she has established pregnancy databases collaborating with multi-center ACHD programs in the U.S which have resulted in publications on pregnancy outcomes in women with transposition of the great arteries after atrial switch repair (Mustard or Senning ) and women with single ventricles following Fontan operation. Two decades have passed since her early reports, and experience with high risk pregnancies has continued, leading to updated reports of pregnancy outcomes, particularly in Fontan population but with focus on long-term survival after pregnancy. Mary’s research and clinical work has also led to the development of a practice protocol for managing high risk pregnancies in labor and delivery here at UCLA. As a result of her work Mary has had multiple invitations for lectureships on this topic around the world, and most recently, chaired the publication of the American Heart Association’s Scientific Statement on “Management of Pregnancy in Patients with Complex Congenital Heart Disease”, published in February 2017.

Besides Mary’s work as a researcher and clinician, she has been a lecturer and program coordinator in the UCLA School of Nursing Adult/Gero Acute Care Advance Practice Nursing program. It was through this role as preceptor and teacher, that she planted the seed about ACHD to all three current NP’s for the UCLA ACHD program, Pam Miner, Linda Houser, and Katrina Whalen. Mary re-established a coordination role with the UCLA ACHD center in 2001, assisting with fund raising, working as a liaison between high risk obstetrics and cardiology, and worked to establish a transitional care program for adolescents with congenital heart disease to prepare them for transfer to adult congenital cardiology for lifelong care.

Mary has enjoyed a long and impressive career at UCLA, balancing her love of teaching with her love of the evolving field of adult congenital heart disease. She has received numerous national awards including Fellowship in the American Academy of Nursing (FAAN), and the American Heart Association’s Council of Cardiovascular Nursing’s 2012 award for Clinical Excellence in Nursing. Most recently (this past fall) she was awarded Honorary Membership to the Academy of Medical Sciences of Cordoba, Argentina, the first nurse so honored.

On a personal note, Mary has enjoyed over 3 decades of marriage to Dr. John Colias, an orthopedic surgeon in San Gabriel. Although they have no children, they are prolific dog lovers and have cared for many generations of Labrador retrievers as their canine family members.

## Palliative Care benefits with Adult Congenital Heart Disease

UCLA offers excellent Palliative Care Services , but many health care providers and patients have a misconception about what palliative care is. There is a long held belief that “palliative care” is synonymous with “end of life” care or “hospice”. This does not encompass the full spectrum of services provided, and in fact, palliative care provides services that can improve “quality of life” in patients with chronic illness. Palliative Care is specialized interdisciplinary care focused on relieving the pain, symptoms, and stress that often accompany serious illness. The palliative care team offers a consultation service providing co-management with the patient’s primary care team or provider. In other words, when palliative care services are recommended, the palliative care team will partner with your ACHD providers to coordinate your ongoing care and can provide a stabilizing force for both patients and their families. The palliative care team are skilled providers and coordinators of care, and are adept at the challenges that surround serious illness as well as the difficult decisions regarding “care planning” if we are unable to speak for ourselves. If you would like to consider a palliative care consultation, or discuss whether this would be of benefit to you, please contact our office at (310)794-5636 or email us at [achdc@mednet.ucla.edu](mailto:achdc@mednet.ucla.edu). Our ACHD social worker, David Highfill, is a valuable resource for guidance with regard to palliative care.



## CONTRIBUTIONS

### How You Can Help

The Ahmanson/UCLA Adult Congenital Heart Disease Center relies on donations in order to pursue many of its goals. This support is vital to the ACHDC’s ability to continue providing high-quality care for adult patients with CHD. Your tax-deductible contributions directly support:

- Patient programs focused on enhancing quality of life, including newsletters, educational websites, support groups, and psychological counseling
- Research programs aimed at extending life expectancy
- Training programs integral to preparing future providers to offer the highest level of care

You can learn more about how to support the ACHDC by visiting [heart.ucla.edu/ACHDC](http://heart.ucla.edu/ACHDC) and clicking on “ways to give.”

To discuss specific gift options, or for more information, please call (310) 825-2019.



# Two UCLA Congenital Heart Disease Patients Share Their Stories



## Steve, 57 yrs old

### VSD, Eisenmenger Syndrome

The hope of a gold medal or college scholarship can inspire an elite athlete to rise hours before sunrise. Sometimes knowing that the competition is working hard can motivate an athlete. At about 4am on any given day, without need of an alarm clock, I am wide-awake, lacing up my shoes, and ready to exercise over a familiar course. I see an occasional man or woman, but mostly my company is the coyote. They look well fed and I fear that some smaller critter did not make it home last night. A family of raccoons rummaging through a trashcan is common. These masked bandits avoided cars, coyotes, a trap set by a homeowner tired of his trash being strewn across his yard. It makes me smile. Can a raccoon be thankful for another day? Life has not always been easy for me either, but I am grateful for every new day.

New babies were still booming in 1960. When other new moms and dads were taking their bundles of joy home, my father, a career Army officer, and my mother were preparing for a medical-evacuation from Rhein Main Air Base in Germany destined for Walter Reed Hospital in Bethesda, MD. Today many congenital heart defects like mine can be surgically repaired at very low risk; but in 1960 infant open-heart surgery carried extremely high risk but was the best hope for a normal life. Pulmonary hypertension was a complication that would preclude surgery and mine was severe. Hospitals would be a familiar part of my life, and there was no promise for a long one. In 1965, my dad traded his Army green for a suit and tie; we would eventually settle in the farming community of Salinas, California. Making life seem normal for me was a challenge for my mom. Eisenmenger Syndrome, named after Viennese physician Victor Eisenmenger (1864 - 1932) who first

described my condition, meant that while the other kids were running around the track, I would be on the sidelines. While others hoped and dreamed about gold medals, scholarships, and careers in professional sports or the military, my family prayed for a medical breakthrough.

My own faith in Jesus Christ was the first breakthrough for my heart. Every indication was that my life would be short; I wanted it to matter that I lived. I felt a calling to full time Christian ministry, which guided me through college, seminary, and finally to my doctoral degree. In a story about my heart, it would be impossible to overlook a life-changing event that happened in college. When I first laid eyes on Joyce Phelps in the cafeteria, my heart skipped a beat. We fell in love; but before I could pop the question, she deserved full disclosure. In his office, my cardiologist described to Joyce in sobering terms my condition and the prognosis for the future. I feared that he had completely destroyed any chance that she would take a chance on me. There were many strong and healthy suitors for such a smart and attractive woman. I am so thankful that she said "yes."

After completing seminary, Joyce and I moved to Ventura county with our new baby in 1987. Not only were we fulfilling our dream of full time Christian ministry, I was about to be referred to the world renowned Adult Congenital Heart Clinic at UCLA. About an hour away on most days, I was blessed to be a patient at such a prestigious clinic. From my first appointment with Dr. Perloff and our first interaction with Pam Miner, it was clear that I was not just a patient; I was a member of the team. Gifted cardiologists and nurses were studying, learning, and implementing the best treatments and care possible for my condition. The breakthrough that an Army doctor discussed decades before and for which we prayed, was actually happening, and I was on the team that could help others with my condition.

I'm not going to hold any gridiron records at UCLA or shoot any game winning three-pointers at Pauley Pavilion, but every morning when I wake up, I am reminded that my choices matter to my UCLA team. So when it's cold or windy and staying indoors is enticing, I lace up my shoes and walk. When sugary treats are offered, I think of my team and politely decline. Maybe it's uncommon self-discipline, but it's my normal. The benefits are too many to list. Even the encounters with a coyote or raccoon give me an opportunity to tell others about my faith in Jesus Christ, my role on the UCLA team, my increased mobility and strength, and how my life has already exceeded my expectations.

This year Joyce and I will celebrate our 35th anniversary. Our adult daughters and two granddaughters are all thriving. I am blessed to have been the senior pastor of a wonderful church in Simi Valley for 25 years and counting. In our spare time, Joyce and I love the excitement and adventure of a two-wheeled Harley Davidson road trip (see photo). I am grateful to God for all the blessings I've received, and especially for the team of doctors and nurses at the UCLA ACHD.



## Cherie, 47 yrs old

### Tetralogy of Fallot

I was born in Los Angeles in 1969. I was blue. The diagnosis was tetralogy of Fallot. Although my sister was born pink less than two years later, she had the same diagnosis. The fact that we have led full, active and healthy lives, with little interruption or restriction is the result of lifelong relationships with UCLA's pioneering doctors and nurses, continuity of care, and well-timed medical advances.

Due to cyanotic events in infancy, I had a Waterston shunt at about eighteen months. Repair at the time wasn't an option. A few years later, in 1973, things had changed and two teams in the United States were performing "repairs." The Mayo Clinic was our first choice. They had an opening and we went. Somehow my surgery made a medical textbook.

My surgical results were "excellent" and from a cardiac perspective, my childhood was uneventful. I skied. I played on my high school tennis team. I answered questions about the scars I made no effort to hide. I took antibiotics when I got a fever and I visited my cardiologist every year. I should note I was very grateful when echocardiography became a standard diagnostic tool.

When I started college, my UCLA pediatric cardiologist, told me that I should start seeing an adult congenital cardiologist and referred me to Dr. Perloff.

Twenty years after my "repair," I was attending graduate school and living in a third-floor walk-up in Michigan. I was asymptomatic and

## Patients Stories (continued)

clueless about my diminished heart function. At my annual follow-up during winter break, Dr. Perloff was visibly concerned by what he heard. I was surprised to learn my pulmonary valve needed replacement, because in 1993 it wasn't yet clear this would be the norm for so many TOF patients. It also wasn't clear how long the new valve would last.

Unwilling to let a major operation get in my way, I finished my academic year and scheduled "elective" surgery between my summer internship and my best friend's wedding two weeks later! Dr. Laks did a fantastic job and after the initial recovery, I felt great.

Again, my cardiac life became unnoteworthy.

After genetic testing, and under the care of a UCLA high-risk obstetrics specialist, I had two uneventful pregnancies, followed by the births of two healthy baby boys in 2002 and 2005.

For me, by 2015, aging with TOF, meant future valve replacement and also the possibility of arrhythmias caused by scar tissue from previous surgeries (and probably other sources). I had three open-heart surgeries by age twenty-five and my valve was nearly twenty-one years old and starting to show signs of decline.

That spring I was tired, a lot. I was also leading a very busy life. What was forty-something supposed to feel like? I was still asymptomatic and the optimum point for replacement was still unclear.

When I started getting dizzy while exercising I knew it wasn't age and I knew I couldn't ignore it. A Holter monitor verified some serious arrhythmias and within a week, Dr. Shannon performed an ablation and an electrophysiology study. The procedure was a success and I felt great again.

A year later my heart rhythms were still great, but my valve function with exercise was significantly diminished. It was time for a new valve and without surgery! Over a year later, I'm still completely awestruck by the transcatheter procedure and Dr. Aboulhoss's expertise, as well as his efforts to make valves available to ACHD patients. Because of the type of valve and its non-standard (according to the FDA) pulmonary position, this was technically an experimental procedure. Amazingly, I walked in and out of the hospital in less than 24 hours. There were no stitches or soreness. It was truly unbelievable.

There's a lot of longevity among the women in my family. My great-grandmother died at ninety-five, my grandmother at 101. Although I will have more heart issues and interventions, with continued medical advancements and world-class care, at forty-seven, I hope I'm only reaching the half-way mark.

## Genetic Research



Jessica Rahman

**The Inherited Cardiovascular Disease Registry (ICDR)**, conducted by Dr. Jessica Wang in collaboration with the Adult Congenital Heart Disease service, aims to better understand the environmental and genetic factors behind cardiovascular disease. The ICDR is actively recruiting patients and families with a heart condition that is generally believed to be inherited or familial (even if they do not have a first or second degree relative with a similar condition). Should you and/or your family be interested, you and your family members will be invited for a detailed family history analysis and a one-time blood or saliva sample collection, followed by a lifestyle survey. Whenever possible, we will collect additional medical records and samples for comparison. Genetic analysis may be performed at the discretion of the research team. You will have the option of being contacted about cardiology-related genetic testing results. No payment will be made as a result of participation, although participants may receive psychological benefits from knowing that participation may further scientific and medical knowledge. The research will be conducted at the UCLA Cardiovascular Center or at the Ronald Reagan UCLA Medical Center. Interested participants should contact study coordinator Jessica Rahman, available by email ([jsrahman@mednet.ucla.edu](mailto:jsrahman@mednet.ucla.edu)), phone (858) 335-6594, or in clinic.

## Cardiac Genetics Clinic



Judy Fan

**Ms. Judy Fan, MS, CGC**, our new genetic counselor with 4 years of experience from Children's Medical Center in Dallas, joined UCLA in October 2016. She received her master's degree in genetic counseling from the University of Minnesota in 2012 and her American Board of Genetic Counselors certification in 2012. She works alongside Dr. Jessica Wang, MD, PhD, who heads the new UCLA Cardiovascular Genetics (CVG) Clinic. The CVG Clinic offers genetic evaluation and counseling to patients with cardiovascular diseases and clinical surveillance for at risk or sub-clinical family members, to promote multidisciplinary care and advance medical knowledge through collaborative research. For genetic consultation call 310-825-8816.

## New Hepatitis C Treatment Update



Did you have a blood transfusion prior to 1993? Hepatitis C (HCV) was first recognized in 1989 and reliable testing of our donor blood supply began in 1992. Many of our patients have had a blood transfusion prior to 1993 and should be tested for HCV, which is associated with morbidity and mortality related to liver damage and cancer. In the past several years, vast improvements have been made with the development of oral HCV treatments, without the side effects of interferon, that provide a sustained response in more than 90% of treated patients. These treatments are an all-oral regimen that, for most patients, have a short duration (12 weeks) and a low pill burden. The treatments include Harvoni and Sovaldi, and new medications in the process of being approved. If you had a blood transfusion prior to 1993 or think you could be at risk for having been exposed to HCV, ask your doctor for HCV testing. The Pflieger Liver Institute at UCLA has successfully treated a large number patients with HCV using one of the new oral medications, and is one of the leaders in HCV treatment in the country.



# Laker for a Day: Walter Sanchez



Walter Sanchez with daughters

[www.nba.com/lakers/laker-for-a-day](http://www.nba.com/lakers/laker-for-a-day)

In many ways, **Walter Sanchez** looked like any other father chasing his two young daughters around the court before a recent Lakers game. Except Walter's life started out anything but normal. Walter was born with only one ventricle in his heart, so instead of two ventricles pumping blood – one to the lungs, another to the body – he has just one to the body. Thanks to doctors at UCLA Health, however, Walter was able to undergo a procedure that allows him to lead a relatively normal life. “The surgery essentially linked his veins up with his pulmonary arteries,” says Dr. Jamil Aboulhosn, director of the Program. The name of the operation was a “Fontan”. Walter enjoys spending time with his two charismatic daughters, 7-year-old Samantha and 8-year-old Danielle, who infuse energy and enthusiasm into his daily activities. That was especially evident during their behind-the-scenes tour of Staples Center, where they were treated to dinner in the Chairman's Lounge and had an opportunity to meet and mingle with Lakers co-owner Jeanie Buss before the Valentine's Day game against Sacramento. “What keeps me going is I have my two daughters,” Walter says. “I take care of myself so I can provide for them. As of right now my heart is repaired and, God willing, I won't need a heart transplant.” Dr. Leigh Reardon, director of Transitional Cardiac Care at UCLA, says medical advances developed at UCLA and other research centers now allow people like Walter to recover and enjoy everything that life has to offer – including taking in a Lakers game. “UCLA was one of the first places in the world to treat adults with congenital heart disease, and we're one of the premier places for adults with congenital heart diseases in the world,” Dr. Reardon says. “And because of advances in medicine, we've been able to let people live full and productive lives, have families, exercise and live their dreams.”

For more information about UCLA Health, visit [uclahealth.org](http://uclahealth.org)

# Paul's Inspiring Legacy



Paul Duchow and Dr. Hillel Laks

Earlier this summer, we lost one of our beloved patients at the age of 78 – Paul Duchow. He truly embraced the legacy and profound accomplishments of the first half century of surgical management for congenital heart disease (CHD). Paul was born a blue baby in 1938, when there was little hope for survival for children with complex CHD. He underwent his first surgery for tetralogy of Fallot in 1949, soon after Dr. Alfred Blalock and Dr. Helen Taussig successfully created the “Blalock-Taussig” shunt procedure to bring blood flow to the lungs in children born with tetralogy of Fallot. Paul's Blalock Taussig shunt served him well until 1966, when he was 28, at which time he underwent a “Glenn” shunt to further augment blood flow to his lungs. For his final surgery, Paul sought out Dr. Hillel Laks, who in 1980 was a young cardiac surgeon at Yale. Dr. Laks performed surgery

to close Paul's ventricular septal defect, allowing Paul to have normal oxygenation for the first time in his 42 years. After this surgery, both Paul and Dr. Laks moved west to California, but their paths didn't cross again until 37 years later when they had the opportunity to shake hands in our ACHD clinic this year (see picture). Paul had spent much of the past 30 years as an ACHD patient under the care of Dr. Joseph Perloff, Dr. John Child, and more recently under Dr. Leigh Reardon. Dr. Laks arrived at UCLA in 1981, and spent the past 36 years saving the lives of many babies, children and adults with his surgical expertise. From both the perspective of the innovative surgeon and the pioneering patient, Dr. Laks and Paul Duchow embodied the remarkable advances made in treatment of blue babies, and the survival of generations of future adults with congenital heart disease.

We are grateful for patients like Paul, who always understood the value of an academic medical center, and the role that he could play as a patient in teaching future cardiologists about congenital heart disease. His openness to having medical students and residents ask him endless questions and then allowing them to put their stethoscopes on his chest was just part of the price he paid for being one of those “pioneers”. However, Paul took that obligation to teach to a higher level when he made the decision many years ago that after his death, he wanted his body donated to the UCLA School of Medicine so future generations of medical students could continue to learn from him. We are certain his legacy continues to inspire many future physicians and innovators who will be able to solve the many challenges facing our unique patients.

# The 2017 Greater Los Angeles Congenital Heart Walk



Team UCLA, 2017 ACHA Heart Walk

On Sunday, May 7th, the 5th annual Greater Los Angeles Congenital Heart Walk was held in beautiful Griffith Park. Once again, event director Barbara DeMaria and her well organized, enthusiastic crew of volunteers and vendors staged a spectacular event on a cool and very weather-friendly Sunday morning. In all, over 80 thousand dollars was raised to benefit the Adult Congenital Heart Association and the Children's Heart Foundation. The event brought together citywide organizations, including UCLA, USC, Cedars Sinai, Children's Hospital of Los Angeles, and Camp del Corazon as well as professionals, patients and their families to share experiences, honor loved ones, listen to music and inspirational speeches, and participate in the 3K or the 5K course. A wonderful time was had by all! Team UCLA was proud to be recognized as the top fund raising sponsor team, but we were even more proud to be a part of this very special Los Angeles community that has helped ensure the continued success of an event with a very worthy cause--the fight against congenital heart disease. Keep your calendars open! We'll see you all in 2018!

## Gala



Actors Tom Arnold, Sylvester Stallone with honorees Jamil Aboulhosen, Janine Hogan, and Kevin Shannon and Lisa Knight

### Camp del Corazon Honors and Celebrates Dr. Aboulhosen

Gala del Sol – the annual fundraising celebration of Camp del Corazon – honored Dr. Aboulhosen as a leader in congenital heart disease this past April. Not only is Dr. Aboulhosen at the forefront of providing the best cardiac care to congenital heart disease patients but he is a leader in treating every patient as a unique individual. At the Gala, the audience learned of Dr. Aboulhosen's resilience having grown up in war torn Lebanon to coming to the United States as a teenager and going on to becoming a physician. As Ken and Laurie Boyko said when interviewed for the Gala: "Jamil is one of the most amazing, talented guys and I wouldn't be here without him."

Dr. Aboulhosen's longtime hero, Jürgen Klopp – the coach of the Liverpool Football team – sent a personal video message to him to honor his commitment to patients and medicine. "Jamil, you are my hero" said Klopp. It was a heartfelt evening honoring Dr. Aboulhosen but also celebrating the 23 year history of Camp

del Corazon that provides an opportunity for children ages 7-17 with cardiac disease to experience camp, bonding with other children and being "normal" in a medical supervised setting. Additionally, Camp del Corazon supports young adults with cardiac diseases age 18-26 in the PACE (Progressive Adult Cardiac Experience) community.

Dr. Aboulhosen closed the evening with a quote from Khalil Gibran: "You give but little when you give of your possessions. It is when you give of yourself that you truly give."

## Insurance Update

UCLA accepts a wide variety of health insurance plans – Covered California, private, group, Medi-Cal, and Medicare. This year, we are happy to be collaborating with Gold Coast Health Plan to provide care for our Medicaid patients in Ventura County.

### Important updates for Covered California beneficiaries:

On August 1, 2017, Covered California, California's health insurance exchange, announced that Anthem Blue Cross of California will withdraw its Covered California plan offerings from many regions of California, including all regions in Southern California, effective January 1, 2018.

**IMPORTANT: This announcement relates ONLY to patients with Anthem Blue Cross Individual and Family Plans available on the Covered California health insurance exchange or patients who purchased comparable Anthem Blue Cross plans "off" the exchange. UCLA patients with other types of Anthem Blue Cross insurance plans (PPO and HMO) – such as those offered by employers – are NOT affected.**

UCLA patients currently insured by Anthem Blue Cross via the Covered California health

insurance exchange will have an opportunity to select a new Covered California plan during the 2018 open enrollment period. The 2018 open enrollment period for Covered California begins on November 1, 2017 and extends through January 31, 2018.

**Blue Shield of California PPO:** UCLA Health providers are included in the Blue Shield PPO plan network offered through Covered California in 2018. To continue their care at UCLA, patients will have the option to choose Blue Shield's PPO plan. Blue Shield has indicated it will continue to offer in-network coverage in all regions of California through Covered California during 2018.

**Oscar Health Plan of California EPO:** UCLA Health providers are included in the Oscar EPO plan network offered through Covered California in 2018. Oscar Health Plan has indicated it will continue to offer coverage in a few regions of California through Covered California during 2018. Therefore, depending on where they live, some UCLA patients will have the option to continue their care at UCLA by choosing Oscar's EPO plan.

**Off-Exchange Plans:** California requires insurers who offer Individual and Family Plans via Covered California to offer comparable plans to individuals "off" the exchange. Anthem will not offer these off-exchange plans in 2018. Therefore, UCLA patients with Anthem Blue Cross off-exchange plans will need to select a new plan that is best for them.

Go to [coveredca.com](http://coveredca.com) or call 1-800-300-1506 to get more information on the Covered California plans.

For the full list of health plans accepted, please contact UCLA Physician Referral 1-800-UCLA-MD1 (1-800-825-2631) or visit <https://www.uclahealth.org/health-plans>



## ADVANCES IN ACHD CARE: TECHNOLOGY UPDATES

### UCLA Performs First in the Western USA and a First in California Cardiac Interventions

On Wednesday, June 28th, 2017, two unique procedures were performed by Drs. Jamil Aboulhosen and Daniel Levi of the Ahmanson/UCLA ACHD Center. Dr. Aboulhosen and Dr. Levi are co-PIs on both studies and completed the procedures with Dr. Morris Salem from Kaiser Permanente, who has been an integral part of a region wide collaborative effort to deliver quality care to congenital heart disease patients. The first procedure involved a new device for closure of atrial septal defects (ASD). The Cardioform-ASD closure device (pictured below) is the latest generation of closure device from GORE Corp and is currently in the clinical trial phase as part of the ASSURED clinical trial. This device differs from the existing devices utilized for this application in that it contains very little nickel and is mostly made of polytetrafluoroethylene which is a thin impermeable and biocompatible cloth. This represented the first implant of such a device in California.

The second procedure was the implantation of a novel self-expanding pulmonary valve as part of the Harmony trans-catheter valve trial from Medtronic Inc (pictured below). This implant is part of an FDA mandated clinical trial being performed at UCLA and represents the first implant of such a valve in the western United States. This valve is designed for treatment of pulmonary valve regurgitation in those that have undergone prior surgical repairs but who do not have an existing surgical valve or conduit.

Both procedures went smoothly and the patients are doing well. The ACHD team will continue to enroll patients in both of these trials in the months to come.

