

# Ahmanson/UCLA Adult Congenital Heart Disease Center

FOR THOSE TOUCHED BY CONGENITAL HEART DISEASE

Spring 2020



The Adult Congenital Cardiology Team

## CENTER UPDATES

### 40 year Anniversary Celebration

The Adult Congenital Heart Disease Center at UCLA was founded in 1980 by Dr. Joseph Perloff, with the collaboration of Dr. John Child and nurse specialist Mary Canobbio.

The year 2020 marks the 40th anniversary of the Center and we will commemorate this occasion with a tribute to the History of ACHD at UCLA on Sunday, September 27th. Featured speakers will include Dr. Hillel Laks, Dr. John Child, Dr. Jamil Aboulhosn, Dr. Glen Van Arsdell, Dr. Kevin Shannon, Dr. Kalyanam Shivkumar, Mary Canobbio & Pam Miner. We would like to gather together for this celebration, but with current need for social distancing during the COVID Pandemic, we will be presenting this celebration via Zoom/Webinar on Sunday, September 27th at 2pm. We hope that you will consider tuning in for this event, and commemorating this 40th anniversary tribute.

#### 40th Anniversary Celebration of the UCLA Adult Congenital Heart Disease Center

Sunday, September 27th at 2pm via Zoom/Webinar

If you are interested in attending this virtual meeting, please RSVP for this event to Yvonne Jose at [yjose@mednet.ucla.edu](mailto:yjose@mednet.ucla.edu), so we can provide the registration link to join the meeting. Further details will be available on our website at: <http://heart.ucla.edu/ACHDC>

### COVID-19 Update

The COVID-19 pandemic has inevitably affected ACHD patients and has understandably resulted in an immense amount of anxiety related to concerns around the impact of SARS-CoV-2 infection on ACHD patients. In March of 2020, the Adult Congenital Heart Association hosted a COVID-19 educational webinar lead by UCLA physicians, Dr. Jamil Aboulhosn and Dr. Aric Gregson. Much of the information presented is meant for patients and families explaining basic virology and the potential mechanisms by which COVID-19 can affect heart function. Since then, Dr. Aboulhosn at UCLA has taken a leading role along with collaborators at the Oregon Health Sciences University in developing a multi-national registry of ACHD patients with COVID-19. Thus far, over 30 ACHD centers around the globe have joined the registry and are actively contributing data. Early registry results are expected in the Fall of 2020 and will help us better understand the impact and burden of COVID-19 on ACHD patients.

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Dr. Aboulhosn and Dr. Damien Kenny

### Perloff Lectureship 2019 - Damien Kenny

In Dr. Perloff's memory, and honoring his legacy as the founding father of adult congenital heart disease, this annual lectureship carries his name, and seeks to spotlight world-class ACHD cardiologists and cardiac surgeons.

In May 2019, the Ahmanson/UCLA Adult Congenital Heart Disease Center invited Dr. Damien Kenny to UCLA as the 2019 Joseph K. Perloff visiting professor. Dr. Kenny presented "From the US to Europe – Transitioning of an ACHD Cardiologist" to an audience of cardiologists, fellows, house staff, and nurses.

Dr. Damien Kenny is an internationally renowned interventional congenital cardiologist who has brought his expertise back to his homeland of Dublin, Ireland at Our Lady's Children Hospital.

### ACHD Satellite Site Update

#### UCLA ACHD in the Community - Santa Clarita, Thousand Oaks, and Simi Valley

The Ahmanson/UCLA Adult Congenital Heart Disease Center is proud to announce monthly ACHD clinics with Dr. Aboulhosn at the UCLA Health offices in Santa Clarita, Thousand Oaks, and Simi Valley. Please contact our office at 310-794-5636 or email us at [achdc@mednet.ucla.edu](mailto:achdc@mednet.ucla.edu) if you are interested in scheduling your next appointments at one of these locations.

## Faculty and Contact Information

### Faculty

#### Ahmanson/UCLA ACHDC Faculty

**Jamil Aboulhosn, MD**, Director, Streisand Chair, Congenital Cardiology and Interventional Cardiology  
**Leigh Reardon, MD**, Congenital Cardiology  
**Jeannette Lin, MD**, Congenital Cardiology  
**Gentian Lluri, MD, PhD**, Congenital Cardiology  
**John Child, MD**, Emeritus Director  
**Daniel Levi, MD**, Interventional Cardiology  
**Kevin Shannon, MD**, Electrophysiology  
**Jeremy Moore, MD**, Electrophysiology  
**Kalyanam Shivkumar, MD, PhD**, Electrophysiology  
**John Moriarty, MD**, Interventional Radiology  
**Paul Finn, MD**, Cardiovascular Radiology  
**Pierangelo Renella, MD**, Cardiovascular Radiology  
**Ashley Prosper, MD**, Cardiovascular Radiology

#### Surgical Faculty

**Glen Van Arsdell, MD**, Chief of Congenital Cardiovascular Surgery  
**Hillel Laks, MD**, Congenital Cardiac Surgery  
**Reshma Biniwale, MD**, Congenital Cardiac Surgery  
**Richard Shemin, MD**, Chief, Division of Cardiac Surgery

#### Nursing Staff

**Mary Canobbio, RN, MN**, Transition and Pregnancy Nurse Specialist  
**Pamela Miner, RN, MN, NP**, ACHD NP  
**Katrina Whalen, RN, MSN, NP**, ACHD NP  
**Vanessa Kalis, RN, DNP**, ACHD NP  
**Caroline Moh, RN, NP**, ACHD NP  
**Jennifer Doliner, RN, BSN**, Nurse Coordinator  
**Nicole Antonville, RN, MSN**, Nurse Coordinator/Transition Educator

#### Administrative Staff

**Veronica Olmedo**, Clinical Coordinator  
**Yvonne Jose**, Administrative Manager  
**Adriana Magallanes**, Physician Support Representative  
**Andrew Yuen**, Program Manager  
**Marzetta Crawford**, Administrative Assistant  
**Tracy Hough**, Development Liaison

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#### Research Coordinators

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### Contact Us

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### 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)



## Pamela Miner retiring July 1<sup>st</sup> after 29 years of service at the Ahmanson/UCLA ACHD Center

By Jamil Aboulhosn, MD

Well it's here, that dreaded day that we all hoped would never come. Pam Miner, our senior nurse practitioner, our dearest colleague, our trusted healer, and our teacher, has decided to hang up her stethoscope after nearly 30 years of service at UCLA. Other than Mary Canobbio, Pam is the longest serving member of the ACHD medical team and has in so many ways shaped and guided the Center into what it has become today. Pam will be sorely missed by so many of us, patients and providers alike, she has touched us all with her kindness, knowledge and wisdom.

Pam joined the ACHD Center in 1991, initially as a clinical nurse specialist and thereafter as a nurse practitioner after receiving her NP certification from UCLA in 1998. She was the first NP to join the practice and helped revolutionize the care of ACHD patients by promoting and codifying the now essential role of the nurse practitioner in ACHD care. As early as 1995 and throughout the coming decades Pam worked closely with the American College of Cardiology, the American Heart Association and the International Society for ACHD (ISACD) to develop national and international programs advocating for and helping define the role of the advance practice nurse in the care of ACHD patients. She is considered foundational by the medical community and widely appreciated for her leading role in the field. She has authored 18 peer reviewed manuscripts, 4 book chapters, and was a co-author on the first ACC/AHA ACHD practice guidelines published in 2008. She has presented numerous lectures, abstracts and has planned and hosted numerous symposia, including all of the educational symposia held by the UCLA ACHD Center over the past 29 years. It is difficult to overstate just how much she has done to move this program and this field forward.

Pam is widely beloved by her patients and their families and for good reason. First, she is an excellent clinician; she is naturally very intelligent, perceptive, analytical and decisive. Pam is a keen observer and a quick learner. She soaked in the teachings of Drs. Perloff and Child, made her own observations, read deeply into the existing literature, and had the acumen and confidence to put it all into practice. Many of those reading this article will know exactly what I am talking about because they have witnessed Pam in action and benefited from her clinical acumen. Second, she has a huge heart and is one of the kindest and most giving people I have met. One cannot connect with others if they themselves are closed off and weary of the contact. Pam gives so much of herself and prioritizes the humanization of every patient and every situation, by doing so she helped maintain the moral compass of the group and always kept the focus on the human being behind the medical condition. Pam



The ACHD medical team in 1998- From right to left- Joseph Perloff MD, Pamela Miner NP, John Child MD, Mary Canobbio CNS, Samuel Kaplan MD, Robert Ross MD/PhD

developed lasting connections with her patients and their families because she took the time and put in the effort to build these strong bonds.

For those of us that work with Pam, her retirement means the end of an era. Pam



Pam Miner NP, Fabian Chen MD, Joseph Perloff MD, John Child MD, Jamil Aboulhosn MD

actually bridged 3 eras of the Ahmanson/UCLA ACHD Center, she arrived during the tenure of our founding director Dr. Joseph Perloff, facilitated the transition to the directorship of Dr. John Child in 2000 and then shepherded the program through another transition in 2013 when Dr. Child retired. For me personally, her retirement is that day that I knew was coming but I had hoped would never actually come. She

has been a teacher, a trusted adviser, and a good friend to all of us and she will be sorely missed. She is not fully replaceable; how can one possibly replace three decades of experience, wisdom, relationships, and memories? Alas, the only constant in life is change and so we must accept this change and go on with our mission to deliver the highest quality care, in the most humane



Pam Miner NP and John Child MD reviewing radiographic images in 1996

manner; that is what Pam would extol us to do. We will miss her daily presence but consider ourselves blessed to have worked with her and learned from her over the years. Be assured of one thing, the many lessons that Pam Miner taught us will continue to guide us in the years to come.



Linda Houser NP, Jamil Aboulhosn MD, and Pam Miner NP at the ACHA National Conference in 2010

## Fontan Symposium

One of the core missions of the Ahmanson/UCLA Adult Congenital Heart Disease Center is to educate our colleagues and share knowledge with the greater ACHD community. UCLA is currently one of the few centers in the country offering heart and combined heart/liver transplant for patients with complex congenital heart disease. On September 21, 2019, the Ahmanson/UCLA Adult Congenital Heart Disease Center hosted a 1-day symposium focused on this topic, "New Frontiers for the Fontan Survivor: Challenges, opportunities, and the ultimate destination of heart/liver transplantation." The course was held at the Luskin Conference center on the UCLA campus. Over 100 participants attended, including many UCLA physicians and nurses, as well as providers from adult congenital heart disease centers across the country. We discussed care of Fontan patients, challenges of the Fontan circulation, evaluation of Fontan patients for transplant, and our approach for optimizing transplant outcomes for our Fontan patients. In addition to our UCLA ACHD faculty, speakers included many of our collaborators in the areas of heart failure/transplant, anesthesia,

## Pam Miner's Farewell

I was incredibly lucky in 1991 when the door opened to my career in adult congenital heart disease (ACHD). Now, 29 years later, I can truly say the field of congenital cardiology changed the course of my professional life, and touched my personal life in ways I had not predicted.

My early career in nursing was spent in intensive care units, providing me a very small window into patients' lives, over a short period of time, maybe a day or week on average. The relationships I had with patients were problem focused and revolved around a major health crisis. ACHD was a totally different experience, in that I was essentially providing care and connection with patients over the course of their adult lives... potentially spanning decades. In 1991 we had no roadmap for long-term outcomes in ACHD to be able to predict how long we would be sharing that path with our patients. Little was known about how "mid-life" or "old-age" would look for those with complex forms of congenital heart disease. This road untraveled provided me an amazing partnership with patients and their families, many of which I have had treasured connections with since we were in our 20's, continuing through to our current "senior citizen" status! These relationships have left an unforgettable personal imprint on my life, for which I will always be grateful.

Beyond my patients, my ACHD colleagues have provided me a second family of sorts. I stood in the shadows of giants in this field, Dr. Joseph Perloff, Dr. John Child, and Dr. Hillel Laks, and marveled at how ACHD, as an under-recognized sub-sub specialty of cardiology unfolded before my eyes. My most important nurse mentor, Mary Canobbio, provided me my first glimpse of the ACHD field, and nudged me towards this career path, and I will always be indebted to her. Dr. Jamil Aboulhosn has transformed the field of ACHD in the 21st century, and his friendship and leadership have been lifelines for me as he propels our UCLA program forward, elevating and redefining the benchmark for all other ACHD programs. His energy, intellect and humor commands a loyal following from his UCLA family as well as ACHD providers around the world.

Retirement is now within my grasp, and I am relieved that my patients and the UCLA ACHD program are in the capable and caring hands of exceptional doctors, nurses, and an incredible staff that, together, will guide generations of young adults with congenital heart disease safely through the milestones of life. Their future is bright.

With heartfelt gratitude,

Pam

hepatology, radiology, cardiac surgery, and liver transplant surgery. Dr. Paul Clift, an ACHD specialist from Birmingham, England, was a special guest speaker. Dr. Glen Van Arsdell, chief of congenital cardiac surgery at UCLA, gave a keynote speech entitled "The Fontan Operation: What we have learned and where are we going," outlining new surgical strategies for children born with complex congenital heart defects.

The undisputed highlight of the conference was provided by one of our long-term UCLA Fontan patients, Tom Townsend. Throughout the day, we described his journey at UCLA. Tom had his Fontan surgery by Dr. Hillel Laks in 1984, and has been cared for by cardiologists Dr. Joseph Perloff, Dr. John Child, and Dr. Jamil Aboulhosn. He underwent successful heart and liver transplant by Dr. Van Arsdell and Dr. Fady Kaldas in December 2018. We were grateful to have Tom come to the symposium with his wife Gina and their son Logan. Tom spoke movingly about his life as a Fontan patient, and received a long standing ovation from the audience!

## Research Updates, New Publications

Right ventricular outflow tract (RVOT) defects are common in the congenital heart disease population. While initial surgical correction has been performed successfully, pulmonary insufficiency or regurgitation can result later in life. Transcatheter pulmonary valve replacement (TPVR) is a less invasive alternative to surgical reoperation of failing RVOTs. Currently, amongst various clinical trials being conducted at the ACHD Center, two FDA regulated clinical trials are open to enrollment that offer TPVR therapies for eligible patients.

Alterra: The Edwards Alterra Adaptive Presten is designed to provide a safe landing zone for the Edwards SAPIEN transcatheter heart valve in patients with native RVOTs, which are patients that have not undergone surgical pulmonary valve or conduit replacement. The objective of this study is to demonstrate the safety and effectiveness of the Alterra Presten in patients with dysfunctional RVOTs who are indicated for treatment of pulmonary regurgitation.

Harmony: Medtronic has developed a novel transcatheter device option for congenital heart disease patients without RVOT conduits who are indicated for pulmonary valve replacement, called the Harmony TPV. The two sizes available are the TPV 22 and the modified TPV 25. The purpose of this study is to evaluate the safety and effectiveness of the Harmony TPV system.

## Social Worker / Support Group Message and Updates

The monthly UCLA ACHD Patient and Family Support Group had a minor name change in mid-2019, and are now the UCLA ACHD Patient and Family Connections Meeting. We want to provide support for our ACHD patients and their support system, and to connect ACHD patients.. Through the Connections Meetings, we aspire to reach out and connect CHD patients and their support system members, with the hope of providing effective peer support to this growing population. In the spirit of the beloved Camp del Corazon, the Progressive Adult Congenital Experience (P.A.C.E.), as well as the ACHA's Ambassador program, we hope to build comfort and support by connecting patients with similar experiences. Attendees are invited to share phone and email information so you may stay connected, reach out for questions and share information. Having the opportunity to connect with other patients and their family members dealing with similar issues and having similar diagnoses can be extremely helpful. As technology continues to progress and enhance CHD treatment, the adult congenital population continues to grow and enjoy improved quality of life.

Connections Meetings are in the evening on the last Thursday of each month. Participation no longer requires that you to drive through the wonderful Los Angeles traffic to attend, as we now offer participation through video and teleconferencing.

Our ACHD social worker David Highfill is the group facilitator. David is a Licensed Clinical



David Highfill, LCSW

Social Worker and is also a CHD patient who underwent a modified Fontan procedure in 1990 and received a heart transplant in 2012, both here at UCLA.

Connections Meetings are open to all Adult Congenital Heart Disease patients and their family members. When planning to attend whether in person or remotely, we ask that you please RSVP to our office manager Yvonne Jose at (310) 825-2019 or [YJose@mednet.ucla.edu](mailto:YJose@mednet.ucla.edu) as meeting room space is limited. We look forward to seeing and/or hearing from you at our Connections Meetings very soon!

For those interested in more individual attention with any issues that may be leading you to experience changes in sleep, appetite or concentration, or if you notice you are experiencing an increase in feelings of anxiety, depression, trauma, stress, agitation and frustration, we also encourage you to contact the ACHD office to schedule an appointment for individual counseling with our clinical social worker, David Highfill, LCSW. To make an appointment or find out about counseling and therapy services, please email [ACHDScheduling@mednet.ucla.edu](mailto:ACHDScheduling@mednet.ucla.edu) or [DHighfill@mednet.ucla.edu](mailto:DHighfill@mednet.ucla.edu) or call our nurse line at 310-794-5636.

## Transition Update

Dr. Reardon and Mary Canobbio, MN, RN FANN for many years have championed transition education for patients as they transition their medical care from pediatrics to the adult setting. In the last newsletter, I was introduced in my new role to augment and support the amazing transition efforts for our patients and to provide services to even more patients who might fall through the cracks.

As a previous CCU nurse, I started this new direction in my career as a Transition Nurse Coordinator with compassion for CHD patients and their families. And, I saw firsthand how beneficial this position with increased education and tracking would serve the well-being of the patients I cared for in the hospital. There is clear evidence that structured transition programs assist patients in moving from their pediatric programs to adult congenital programs with increased trust, reduced gaps in care, fewer ER visits and better overall well-being.

My goal is to help facilitate lifelong care for our patients and prevent them from becoming lost to follow-up. I currently do this in two ways: one is via outreach and the other is via education. Over the past year, I have contacted well over 150 patients and their families via phone and email. Furthermore, I search our electronic medical records for patients who are overdue for a visit, then reach out and assess for transition and transfer issues and refer appropriate patients in conjunction with their pediatric cardiologist to Dr. Reardon and Mary Canobbio's transition clinic. Secondly, I provide education about how to become medically independent and take responsibility of their care.

During routine pediatric cardiology visits, I introduce the topic of transition and emphasize the importance of lifelong care. If time allows, I provide education to patients about their diagnosis, medications and what symptoms to report to an adult/what to do in an emergency.

We discuss ways to become medically independent such as making appointments, refilling prescriptions, and facilitating difficult or uncomfortable discussions between patients, parents and pediatric cardiologists.

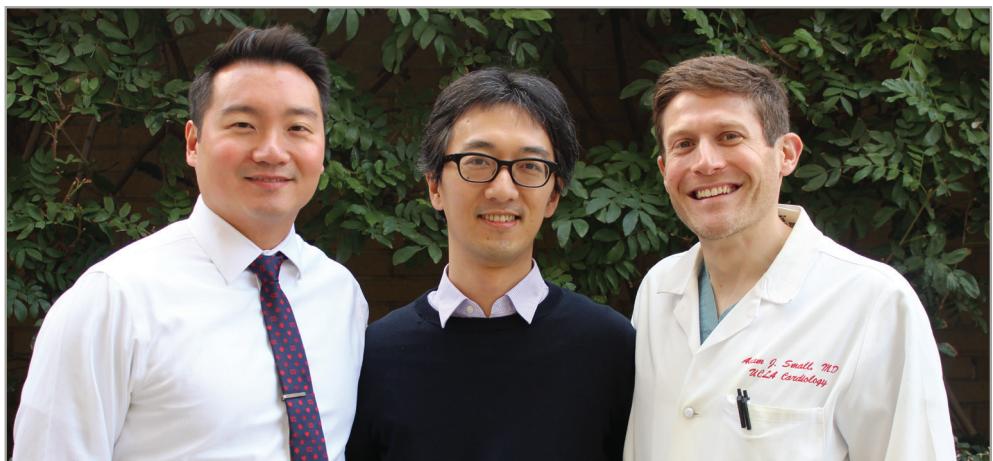
When the pediatric cardiologist has determined it is time to transfer care, we decide together if they would be best served transferring to the Ahmanson/UCLA Adult Congenital Heart Disease Center or if they should have further visits in the Transitional Cardiac Care Program under the pediatric umbrella. I am so appreciative of the collaboration between the pediatric cardiologists, Dr. Reardon, Mary Canobbio and the entire ACHD team. Our goal is to ensure that every patient gets the education and support they deserve to succeed as they transition from the pediatric to adult setting. To reach Nicole or find out more about this service, please email [ACHDScheduling@mednet.ucla.edu](mailto:ACHDScheduling@mednet.ucla.edu) and copy Nicole Antonville [NAntonville@mednet.ucla.edu](mailto:NAntonville@mednet.ucla.edu).

## Profile on Terry Fukuda MD, PhD

### Terry Fukuda:

In September 2019, the ACHD center welcomed Dr. Terunobu “Terry” Fukuda for an 18-month research fellowship. Dr. Fukuda earned his MD and PhD at Kobe University in Japan, and completed his training in internal medicine, cardiology, and pediatric cardiology in Japan.

Since 2016, he has been working as an interventional cardiologist at St Luke’s International Hospital in Tokyo. He developed a passion for adult congenital heart disease under the mentorship of Dr. Koichiro Niwa, a world leader in ACHD who himself was part of the UCLA ACHD family under Dr. Perloff and Dr. Child in the late 1980s! Dr. Fukuda has been wonderful addition to our team, providing a valuable international perspective on ACHD care, working in the catheterization lab with Dr. Aboulhosn, and publishing cutting-edge research on catheter-based ACHD interventions. When he is not working, he has been enjoying exploring California with wife Ai and daughters Chisato and Sayuri. We look forward to seeing him grow the field of ACHD in Japan and across east Asia, and to continuing a lifelong collaboration!



Dr. Weiyi Tan, Dr. Terry Fukuda, and Dr. Adam Small

## ACHD Fellowship Updates

As another academic year draws quickly to a close, it will soon be graduation time for our current Adult Congenital Heart Disease fellows, Dr. Weiyi Tan and Dr. Adam Small! Dr. Small has accepted a position with the ACHD team at New York University, and we look forward to seeing great things from him! Dr. Tan will remain at UCLA for an additional fellowship in interventional cardiology and adult congenital interventional cardiology, and will continue to work closely with Dr. Aboulhosn and the ACHD team during this year.

At the same time, we look forward to welcoming our next class of ACHD fellows in July 2020! Dr. Prashanth Venkatesh is currently a chief fellow in the adult cardiology fellowship at UCLA. Dr. Katia Bravo-Jaimes will be joining the UCLA family from the University of Texas Houston, where she is currently a fellow in adult cardiology. Dr. Venkatesh and Dr. Bravo-Jaimes have both shown tremendous grit and determination in their professional journey, and impressed us with their compassion, intelligence, and dedication to the field of ACHD. We are excited to work with them in the coming years!



## Nurse Practitioner Introduction - Caroline Moh

Caroline Moh joins our ACHD nurse practitioner team in April 2020, bringing experience from 12 years of caring for acutely ill patients in intensive care units. She has worked as a NP in the UCLA cardiac surgery intensive care unit for the past three years, often caring for our ACHD patients recovering from cardiac operations. On a personal note, Caroline enjoys world travel to experience new cultures, getaways to wineries, and winter is her favorite season, often escaping to snowy mountains.



## Faculty Profile - Jeremy Moore, MD

Dr. Jeremy Moore attended medical school at Virginia Commonwealth University School of Medicine and completed his pediatrics residency and pediatric cardiology fellowship at Mattel Children’s Hospital at UCLA. He then completed a fellowship in pediatric electrophysiology at Monroe Carell Children’s Hospital at Vanderbilt University before returning to UCLA and receiving his Masters of Science in Clinical Research. He is currently an Associate Professor of Pediatrics at UCLA and serves as the Director of Adult Congenital Electrophysiology Program, Director of the Pediatric Cardiology Fellowship, and Director of Research for Pediatric Cardiology. On a personal note, when not taking care of patients, Dr. Moore enjoys spending time with his family, surfing, and running the bleachers at Drake Stadium.

## PATIENT STORIES



### Tom, age 54

#### Single Ventricle, Fontan Heart/Liver Transplant

I was diagnosed at birth with a single ventricle, and followed at Children's Hospital of Los Angeles as a kid. Fortunately, my parents had always encouraged me to live my life as normal as possible, and allowed me to be a kid. I had some limitations, but with the support of my family and friends, I had a relatively normal childhood. I enjoyed running, playing sports, and most importantly, racing motocross. My dad bought me a Honda Trail 50 when I was just 5 years old!

Before my senior year of high school, the doctors at CHLA proposed doing a third Blalock Taussig shunt procedure. My parents decided to seek a second opinion, and I came to the newly formed Adult Congenital Heart Disease Center (ACHDC) at UCLA in 1983, shortly after graduating high school. At our first meeting, Drs. Perloff and Child proposed a relatively new procedure called the Fontan Operation. To me this seemed like a definitive cure to my condition that would allow me to be more active, and most importantly, race motocross!

In November of 1983, I underwent my first Fontan procedure at the old UCLA hospital. I looked forward to my new life, but unfortunately over the next two years I never felt well. What I thought would be a cure left me feeling worse than I did before. I had just started college and struggled in school. I wondered would I even be able to get a degree or a decent job with health insurance benefits. Eventually, it was determined that the Fontan had closed, and a redo surgery was needed. After my second major heart surgery in two years, I finally started to feel better.

I obtained an AA degree and transferred to the University of Nevada Reno to study advertising. I made new friends who were into dirt bikes. I felt better than ever, and even started working out in the gym with the UNR baseball team. Unfortunately, I then began to experience the first of several complications associated with the Fontan. One day while out riding with my friends, I experienced my first arrhythmia. Later, after a round of golf, the arrhythmias became so severe that I needed to be airlifted to UCLA. I transferred to California Lutheran

University so I could be closer to home, and got my bachelors degree in 1992. I would eventually find a job at a broadcast rental facility, and was happy to have a good full-time job with benefits. I continued to grow with the company and a short time later, purchased my first home in Westlake Village.

In 2005 I met my future wife Gina. At the time, she was studying to be a Registered Dietician, something every heart patient could use. She inspired me to continue my education and receive my Master's in Business Administration. We were married in 2008. Shortly after that, there were discussions of revising my Fontan, but the heart pressures were too high. A liver biopsy confirmed some liver damage from the heart pressures, and my creatinine levels indicated mild kidney problems as well.

In 2012, Dr. Perloff and Dr. Child had both retired. I had known them, Pam Miner, and Mary Canobbio my entire adult life. I was nervous about no longer having Dr. Child as my doctor but knew Dr. Child and Dr. Perloff would only leave the program in the best hands; with Pam staying on to work with the patients, I felt comfortable with the change. Drs. Aboulhosn and Reardon continued to encourage me to live my life. For the first time, they also started mentioning the idea of a transplant.

In February 2013, my wife and I welcomed our son Logan. I couldn't believe how fulfilled my life had become: beautiful wife, son, nice home, good job with insurance. However, the effects of the Fontan continue to take their toll, and I needed a pacemaker/defibrillator in 2013. Over the next couple of years, I continued to work full time, help raise our son, and even played golf and rode a little motocross. In 2016, Pam Miner asked me what I thought about being evaluated for a heart transplant. I talked it over with my wife and we agreed in order to have the best life together and with our son, a transplant made sense. After a long evaluation process, it was determined that I would need a heart and a liver transplant. As I was still functioning well enough and working full-time, we agreed to wait. This turned out to be a blessing, because in May of 2017 my wife was diagnosed with breast cancer. Over the next several months she would undergo a double mastectomy, chemotherapy, radiation, and reconstructive surgery.

By mid-2018, my kidney function was worsening and I had required an ablation to control a new arrhythmia. Dr. Baas recommended admission to the hospital to stabilize my kidneys and be listed for a heart and liver transplant. The timing was difficult -- my company was going through a bankruptcy and my wife was scheduled to fly to New Orleans to have her second reconstructive

surgery. There were uncertainties about our health insurance as well.

On October 19, 2018 I worked my last full day of work. On October 21, I was admitted to UCLA where I would be placed on a continuous IV medication to help my kidneys and wait for a new heart and liver. On Sunday December 9, seven weeks after I was admitted, Dr. Cruz told me they had found donor organs and I would be having surgery that evening. At 2:00 am on December 10, my mom, as she had done so many times before, went down to the operating room with me. Inside the surgical staff turned motocross videos on the O.R. monitors until we had confirmation. At 4:00 am Dr. Van Arsdell confirmed we were ready to go, and my transplant began. The transplant lasted 13 hours. During that time, my wife was on a plane returning from New Orleans, where she had undergone reconstructive surgery. I was in the hospital a total of 17 days post-surgery. The time recovering in the hospital went fast.

Life after transplant – although I hoped I would be able to run with my son, my peroneal nerve was damaged during the surgery. After several months of testing, therapy and having to use a cane, I was finally able to get an AFO brace which improved my mobility. It took about six months for me to start feeling like myself. Even though I was still very weak and had mobility issues, I could ride the exercise bike longer and faster without getting out of breath. At the end of April 2019, I went back to work full time.

Infections are a huge part of life after transplant because of the immune suppressing rejection meds. I feel fortunate to have had only a few infections this year. You quickly learn that a simple case of the sniffles can turn into pneumonia quickly. My best advice to any transplant patient: stay out of Chuck E. Cheese!

Overall, I would say my life after transplant has gone quite well. For my birthday my wife bought me a pedal-assist mountain bike. I'm looking forward to going all out on the new motocross bike I got just before the transplant. Best of all, I can enjoy spending time with my family. Nowadays, it is me trying to get my son off the couch to do something.

Looking back, last year was a difficult journey with my wife and I both facing health challenges at the same . I have had so many people in my corner my entire life, from my mom and dad, my wife and son, my aunt Robbie, the entire Ahmanson/UCLA Adult Congenital Heart Disease Center staff, especially Dr. Perloff and Dr. Child, Dr. Aboulhosn and Dr. Reardon, Mary Canobbio and Pam Miner, as well as everyone at the heart and liver transplant clinics whom I'm just getting to know. For me 2019 was a year of healing and 2020 will be a year of strengthening.



## Cindy, age 48

### Tetralogy of Fallot

My story started before I was born. It started two years prior, with the birth of my sister. Born a blue baby and diagnosed with Tetralogy of Fallot, my parents questioned if they should have another child. After consulting with doctors and much conversation with the information they were given, they felt it was safe enough to have another child. 9 months later, in May of 1971, I was born a beautiful pink baby with Tetralogy of Fallot.

This is where my story began and it was quite simple, my family knew the routine. After officially being diagnosed with TOF, I went to the Mayo Clinic in February/March of 1975. Back in 1975 the Mayo Clinic was one of two hospitals who performed the corrective surgery and if my sister went there, why wouldn't I? I can't say that I remember much, what 4 year old child would? All I remember was being upset because I could not eat some candy when I got home because I was on a salt free diet. Hard life, right? From there, I lived a completely normal life without any complications. I was snow skiing 30 plus days a season two years later. I played tennis, spent my summers in a pool playing with friends, water skiing, going to sleep away camp, traveling. You name it, I could do it. The only restrictions in my life were that I could not be an astronaut or an Olympic athlete, and on a couple of really smoggy days in Los Angeles, CA I had to sit in the office during recess. In truth, the only things that reminded me I had Tetralogy of Fallot was my annual doctors appointments, which included

stress and holter tests at times, pre-medicating prior to teeth cleanings and the antibiotics I had to take when I had fever. Not even my scar had an affect on me.

Then in 1994, during a routine appointment with my cardiologist, I was told within 1-5 years I would need my valve replaced. Which, might have made sense since there was a slight change in my annual tests and that my sister just had her first valve replacement surgery. However, 5 years past, 10 years past, 20 years past, 25 years past and nothing. No surgeries were needed. I even started playing a game, giving my doctors milestones until I was able to have surgery. The first, the building of UCLA's new hospital had to be completed, then stem cell research was all over the news, so I said that I had to wait until I could grow my own valve. I was half joking here, but it was a game and games are meant to be fun. Finally, and more realistically, I had to wait until there was a valve that could be done via catheterization instead of open chest.

The latter, valve replacements via catheterization became a reality. In the early 2000's, the development of the Melody Transcatheter Pulmonary Valve ultimately was used in the U.S. by 2010 and allowed valve replacements in this manner for some. Not so much for me. I still had my original valve with an opening too large to hold a valve like these in place. So, we continued to play the game. Additional studies were coming out for new adaptive pre-stent devices that could allow for a catheter-inserted valve to work and I was determined to wait for one.

This leads us to July 2019, a new study for the Alterra adaptive pre-stent (the hour glass as my family has named it) device was being tested and UCLA received 5 out of 500 slots nationwide, and Dr. Aboulhosn wanted me to be considered for one of them. This is when the world wind began, July 19th. I had a day to get the required MRI and Echo done so Dr. Aboulhosn could present my case to the panel on July 23rd. On July 24th I received a call from Dr. Aboulhosn telling me the panel found me to be a perfect candidate for the Alterra study and am I available on August 19th. Now, lets talk about perfect timing. After reviewing and

comparing the MRI to results of an MRI I had two years prior it showed that the leakage and size of my valve has increased and it was time for a new valve. So I had two options: enter the study or have valve replacement surgery via open chest. To me there was no option. We moved forward with the study and on August 19, 2019, I was the first patient in which Dr. Aboulhosn and his team inserted the Alterra adaptive pre-stent device into an original valve followed by the insertion of the Sapien Transcatheter Valve all in a matter of 6 hours and a hospital stay of 24 hours from check in to check out.

My recovery lasted about week and a half. And in truth, the recovery was being tired and needing to get the anesthesia and other medication out of my system. Not a physical recovery due to the surgery, or procedure as they call it. Two weeks after, I was back to my everyday life that included 1-2 mile walks.

Today, 6 months later, I am back to my normal life with no thoughts to anything heart related. My workouts include Orange Theory (a high intensity workout), spinning (indoor cycling), tennis and my walks on a weekly base. Yes, I will have a number of follow up appointments required by the study for 5 years and then it will be back to my normal annual visits. My heart is not what I worry about. I don't need to. Never have and never will.

For me, the two best things that have come about in the past year are: One, I won my game. I didn't have to have a valve replacement open chest. Two, and the most important, I am helping in the advancement of technology and opening the door to new procedures for thousands of people to come. I have sat on panels, told my story to others, but in the past it was an uneventful story. A great story of 44 years with no symptoms, surgeries or procedures and a huge example of an extremely healthy life a person with Tetralogy of Fallot can have. But to help further medical procedures that allow patients less invasive, lower risk procedures that accomplish the same thing that required major surgery in the past. I'll do it and be thankful that timing and a team of such experts allowed me this opportunity.

## Telehealth

You can now schedule a telehealth visit with your ACHD physician! Telehealth is a great option for patients to see their physician from home. All you need to sign up is an active myUCLAhealth account and the myChart application. A short video explaining the process, starring Dr. Jamil Aboulhosn and Dr. Leigh Reardon, can be found on our website <https://www.uclahealth.org/heart/achd> under Center updates- Watch Now Connected Video Visits.

For more information on Telehealth, myUCLAhealth, or myChart please contact our center's administrative staff  
[ACHDScheduling@mednet.ucla.edu](mailto:ACHDScheduling@mednet.ucla.edu)

## COVID-19 Update CONTINUED FROM PAGE 1

To access the webinar and other ACHA resources please visit:  
<https://www.achaheart.org/about-us/news/2020/covid-19-response-update/>

For latest COVID-19 updates see  
<https://www.uclahealth.org/coronavirus>

The following medical articles are co-authored by UCLA ACHD faculty and are specific to COVID-19 in CHD

<https://pubmed.ncbi.nlm.nih.gov/32441586/>  
<https://pubmed.ncbi.nlm.nih.gov/32248966/>

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## Regional ACHD Conferences for Patients and Families

The Adult Congenital Heart Association (ACHA) works with regional ACHD providers to organize and facilitate patient education regional conferences nationwide. The objectives are to help adults with congenital heart disease (CHD) and their family members better understand their disease, take an active role in their cardiac care, and connect with their peers and with ACHD medical programs around

the county. Through these regional conferences, patients and families have the chance to meet and network with others with CHD and to speak one-on-one with CHD experts and ask questions. This is a unique opportunity for CHD patients and their families, as well as CHD medical professionals. Watch the ACHA website for conferences in your area: [www.achaheart.org](http://www.achaheart.org)



### **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 help us provide care for patients like Jeff by directly supporting:

- 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 or email our Administrative Manager Yvonne Jose [YJose@mednet.ucla.edu](mailto:YJose@mednet.ucla.edu) and Development Liaison Tracy Hough [THough@support.ucla.edu](mailto:THough@support.ucla.edu)