

Two UCLA Heart Patients Share Their Stories



David, Age 45

Finding his career path, and feeling lucky

For the most part, I had been pretty lucky for someone born with the variety of CHD that I have. This luck helped me to live a long and mostly “normal” life well into adulthood. My first stroke of luck made itself evident after I was initially diagnosed at 4 months old when my parents were told that I had tricuspid atresia, pulmonary stenosis, atrial septal defect, ventricular septal defect, and transposition of the great vessels (now called the great arteries). The doctors followed this overwhelmingly stunning statement by saying that I was actually very lucky because if any one of these defects were not present, I would have died at birth. Luck struck the second time when at age 8 months, the doctors, who initially told my parents that I would need surgery to open the valve from heart to my lungs due to my lungs not receiving adequate blood flow, discovered just a few weeks later following repeat heart catheterization, that my pulmonary valve had actually widened on its own. My third stroke of luck came following a horrific auto accident at age 17 in which I nearly died after falling asleep at the wheel while driving home one night. I was pinned in the car, broke multiple bones from head to toe and had to be removed from the car by the Jaws of Life. While in the ER, the doctors there had never seen anyone with the cardiac configuration I had and actually became agitated with my mother demanding to know why I had not had corrective surgery to fix my “murmur”. With a great deal of restraint, my mother was

able to inform them that there was in fact no corrective surgery for my heart at that time and directed them to contact my pediatric cardiologist, the late Dr. Saul Robinson at UCSF. My records were faxed as I lay unconscious in the ER and with them, I was able to undergo the 19 hours of emergency surgery required to fix the broken bones, repair my spleen and stop the bleeding. Luck was with me through this 6 month long rehabilitation as I recovered fully and was able to return to my senior year of high school and graduate with my class.

Throughout this lengthy recovery, it became evident to me that there should be someone in the hospital who could act as a liaison between the doctors who, for all their knowledge and expertise, do not sadly, always have the best bedside manner or general comforting disposition when speaking with their patients or families. Combining this idea with my already blossoming interest in psychology, led me to the career of medical/clinical social worker. Of course, the words medical “social worker” initially repulsed me as like many people, I associated social workers with angry people who deny your government benefits or take your kids away and disappear. My luck appeared again when a very good friend of mine, then a university graduate advisor, informed me that pursuing a Master’s Degree in Social Welfare (MSW) would allow me to focus on providing direct counseling services to patients and families both in the hospital and beyond. This fit my ideal counseling pursuit even better than my original goal of seeking a PhD in clinical Psychology, not only for this ability to provide direct bedside counseling but also because the MSW degree took 3 years less than the PhD! Little did I know, it would take an additional 3 years anyway to become a Licensed Clinical Social Worker, which I am happy to say, is the career I still enjoy.

Of course, my graduate work would likely not have unfolded the way it did had I not had the tremendous fortune of being advised by Dr. Roberta Williams, then the Chief of Pediatric Cardiology at UCLA, to strongly consider the Fontan operation. I received a second opinion and elected to undergo the procedure. I was most fortunate to have received the Modified Fontan Repair by Dr. Hillel Laks at UCLA in 1991 and to be subsequently followed by Doctors Joseph Perloff, John Child (both retired) and most recently, Jamil Aboulhosn at the Ahmanson UCLA ACHD Center.

Luck has been with me throughout my life with CHD as I feel I have had the unique experience of providing counseling for CHD and other patients and family members dealing with a variety of chronic and terminal diagnoses while being able to manage the changing medications and symptoms of my own diagnosis and integrating these experiences into my personal and professional relationships.

My most recent stroke of luck came just last year when I unfortunately succumbed to symptoms of heart failure and collapsed in my living room. Obviously, that event was not lucky but the lucky part came when my wife was able to keep an amazingly level head, perform CPR and call the paramedics. I battled a lengthy hospitalization with a few unexpected complications but was able to receive a heart transplant and am happy to say that I just celebrated my one year transplant anniversary. I have been back to work since February 2013 and have returned to working with patients both in a clinic setting and in a therapeutic context. My luck is that I am able to return to this kind of work and have even greater experience with which to draw from and utilize with my patients and clients. I continue to be a CHD patient and now have the opportunity to say that I am also a transplant recipient. I continue to look forward to a life filled with new experiences and am very happy that I get to pursue these and have my amazing wife, family and friends along for the ride.



Jerry, Age 70

A Los Angeles Marathon Legacy runner continues his journey

In 1977, at the age of 34 years I was diagnosed with a congenital valve abnormality known as a bicuspid aortic valve. At the time, I was feeling well but was told that sometime down the road I would definitely need the valve replaced. I had been exercising pretty regularly since 1973, but after the diagnosis and on the recommendation of my trainer, I began to switch from weight lifting to incorporate more aerobic activities, including running, into my regimen. I became

hooked on running. By 1984 I had completed several 10K's and 2 Half Marathons and was feeling great.

In 1986 the City of Los Angeles presented the first running of the LA Marathon. I got caught up in the hype and decided to run the race. I was not trained, and ended up hitting the wall at mile 20, but still finished in a time of 3 hours, 59 minutes, 5 seconds, though radically dehydrated and needing medical attention! After I recovered, I continued to advance and improve my training, running the LA Marathon every year and also participating in other marathons including New York, San Francisco, Palos Verdes and Long Beach.

In 1996, while on a training run I suddenly experienced the first overt symptoms of my aortic valve problem. I was severely short of breath, lightheaded and sweating. I tried to rest, but every time I started to run again, the symptoms came back. I thought that I might not make it home. I visited several cardiologists and obtained many "second opinions", all of which pointed to the fact that my valve was leaking badly and needed to be replaced. However, I was scared to death about going through surgery at that time. I finally underwent an angiogram by a great cardiologist, Dr. Nakano, and he referred me to Dr. John Child at UCLA. Dr. Child sensed that I was not ready to undergo valve replacement surgery, and continued to manage me with medicines, keeping me on a training program that was not overly aggressive yet still allowed me to run the LA Marathon in March 1997, taking things very easy. A few months after the 1997 race, Dr. Hillel Laks replaced my valve with a homograft tissue valve. Once I recovered, I continued my marathon training and was able to maintain my Legacy status (a total of 28 consecutive Los Angeles Marathons) through March 2013.

In July of 2013, I began to experience symptoms that caused me to suspect my homograft aortic valve was failing. Keep in mind that tissue type valves only last for an average of 10-15 years. Mine had lasted 16, so I considered that a one year bonus! Tests confirmed the need for valve replacement, and on August 14th I had my second valve surgery. Repeat surgeries are much more difficult, and mine was no exception, but once again Dr. Laks did a great job, placing a Bovine tissue valve. I started my marathon training the next day, getting out of bed and walking for several laps around the unit! I went home 3 days later and returned to work on August 26th, my 70th birthday. At my first follow up visit with Dr. Laks and Dr. Aboulhosn, my valve was working great and I was given the go ahead to increase my exercise. I resumed training with the LA Leggers Running Club, preparing for the 29th running of the Marathon on 3/9/14.

Because of knee problems I'll be speed walking rather than running, but I'll be there!