Ahmanson/UCLA
Adult Congenital Heart Disease Center

FOR THOSE TOUCHED BY CONGENITAL HEART DISEASE

Winter 2018

CENTER UPDATES

UCLA welcomes
Dr. Glen Van Arsdell
as Chief of Congenital Cardiac Surgery

We are pleased to welcome Dr. Glen Van Arsdell, one of the world’s leading congenital cardiac surgeons, as the Chief of Congenital Cardiac Surgery at UCLA. Dr. Van Arsdell previously served as the Chief of Cardiac Surgery at the Hospital for Sick Children in Toronto, one of the largest congenital cardiac surgery programs in North America. His career began at Loma Linda University Medical Center, where he received his medical degree and completed his surgery residency and cardiothoracic surgery fellowship. He then moved to Toronto, completed additional training in congenital cardiac surgery before joining their surgical faculty in 1996. He quickly developed a reputation as an outstanding congenital cardiac surgeon, equally as adept at the complexities of cardiac surgery in newborns as he was in operating on the sickest adults with congenital heart disease. By 2001, he was Division Head of congenital heart surgery at the Hospital for Sick Children, later becoming University Division Chair. He has routinely been invited to speak at international meetings on ACHD and is recognized by his peers for his expertise in congenital cardiac surgery across the lifespan.

Dr. Van Arsdell’s academic work is currently focused on developing patient specific precision surgery for Tetralogy of Fallot. Towards this end, he currently has two PhD candidates conducting research studies in Tetralogy including a global enrollment study. Dr. Van Arsdell has received several grants for his research endeavors and has co-authored over 200 peer-reviewed manuscripts on various aspects of congenital heart surgery. Dr. Van Arsdell is a master teacher, and he has spearheaded the use of 3D printing as a means of improving surgical training. He also has an interest in the development of event based databases for program management, and as a tool for determination of best clinical practices.

We are fortunate that Dr. Van Arsdell has returned to California as a Bruin! Please join us in welcoming Dr. Van Arsdell to UCLA; we look forward to working with him closely to continue to provide world class care to our ACHD patients.

New ACHD Guidelines Published!

The 2018 ACC/AHA Guidelines for Management of Adults with Congenital Heart Disease were published in August. This is a valuable resource for all healthcare providers caring for adults with CHD, and serves as the standard for ACHD care. Dr. Jamil Aboulhosn was a member of the writing committee for the 2018 guidelines.

Jamil Aboulhosn awarded Sherman Mellinkoff Faculty Award in June 2018.

Dr. Jamil Aboulhosn was presented the Sherman Mellinkoff Faculty Award at the David Geffen UCLA School of Medicine annual commencement ceremony on June 1, 2018. The award, (established in 1979) recognizes the finest in doctor-patient relationships, medical education and is the highest honor bestowed on a physician by the medical school at UCLA. One of its past esteemed recipients was Dr. Joseph Perloff, our founding director, who received the award in 2000. We congratulate Dr. Aboulhosn on this accomplishment, recognizing the importance of a caring patient relationship, while teaching our next generation of medical providers and transforming the field of adult congenital heart disease through innovation and research.

UCLA ACHD in the Community

Porter Ranch, Santa Clarita and Thousand Oaks

The Ahmanson/UCLA Adult Congenital Heart Disease Center is proud to announce monthly ACHD clinics with Dr. Aboulhosn at the UCLA Health offices in Porter Ranch, Santa Clarita, and soon Thousand Oaks. Please contact our office at 310-794-5636 or email us at achdc@mednet.ucla.edu if you are interested in scheduling your next appointment at one of these locations.
In July, we bade farewell to retiring nurse practitioner Linda Houser, as she left UCLA after devoting 15 years to the ACHD Center. Linda’s compassion and singular dedication to the wellbeing of her patients will be the trademark of her impressive career. She will most definitely be missed and expresses her own heartfelt farewell in a personal message below.

Dear Friends,

It was with mixed emotions that I retired from UCLA on July 1st, drawing the curtain on a 31 year career—half of which was spent as a nurse practitioner with the UCLA Adult Congenital Heart Disease Center. When I started my job with the Center, I had no idea that it would be one of the most rewarding and meaningful jobs of my life. Since then, I have served as a regular staff member at the Ahmanson/UCLA ACHD Center, where I have come to know many of the patients! He received his B.S. degree in psychology and M.D. degree from Duke University, and received an MPH from University of North Carolina Chapel Hill. He then completed a combined medicine and pediatrics residency at UCLA, and has remained a UCLA Bruin for his cardioiology and now ACHD fellowships. His dedication to the care of individuals with congenital heart disease is second to none, and he shares this enthusiasm volunteering as a counselor at Camp Del Corazon (summer camp for children with heart disease), where he is known by his camp name, “Junior Mint.” He also enjoys playing soccer and golf, and skiing.

Congratulations to Linda Houser on her Retirement!

Linda Houser, RN, MSN, NP

Weiyi Tan, MD, MPH

Dr. Weiyi Tan also joined the ACHD team in July 2018 for a two-year adult congenital heart disease fellowship. He received his B.S. degree in Biology and M.D. degree from Duke University, and received an MPH from University of North Carolina Chapel Hill. He then completed a combined medicine and pediatrics residency at UCLA, and has remained a UCLA Bruin for his cardioiology and now ACHD fellowships. His dedication to the care of individuals with congenital heart disease is second to none, and he shares this enthusiasm volunteering as a counselor at Camp Del Corazon (summer camp for children with heart disease), where he is known by his camp name, “Junior Mint.” He also enjoys playing soccer and golf, and skiing.

Dr. Weiyi Tan

Dr. Weiyi Tan also joined the ACHD team in July 2018 for a two-year adult congenital heart disease fellowship. He received his B.S. degree in Biology and M.D. degree from Duke University, and received an MPH from University of North Carolina Chapel Hill. He then completed a combined medicine and pediatrics residency at UCLA, and has remained a UCLA Bruin for his cardioiology and now ACHD fellowships. His dedication to the care of individuals with congenital heart disease is second to none, and he shares this enthusiasm volunteering as a counselor at Camp Del Corazon (summer camp for children with heart disease), where he is known by his camp name, “Junior Mint.” He also enjoys playing soccer and golf, and skiing.
Dr. Marelli presented mechanical valves in children was very new, daily for the rest of my life. At the time, placing take an anticoagulant medication, Coumadin, a mechanical valve meant that I would have to weighing the options, my parents chose to my second open heart surgery to replace my failure due to a leaking heart valve. Three days my childhood without any medical problems. On my second open heart surgery, I am managing my own health, and feel like an active member of my healthcare team. Taking responsibility of my own health has allowed me to live the life I chose. I began traveling internationally, hiking alone up mountains, and spreading CHD awareness. I know that ultimately my heart, defect and all, is leading me on my journey through life.

In July 1983, one day after I was born, a doctor heard a murmur when performing my newborn check. I was diagnosed with partial atrioventricular septal defect. Doctors were hopeful that the hole in my heart would close on its own, so I went home after a few days with my very worried parents. They took me to annual cardiology appointments, yet at the age of 10 years old, I determined that I would have to home. Six months later, I had gained several years of knowledge in the Pediatric ICU, I decided to travel nursing, and have worked in over a dozen children’s hospitals across the US. With the flexibility of travel nursing, I explored the option of joining medical mission trips in need of nurses with my expertise.

In 2012, I found my true passion, in life and in my career - I began volunteering with a nonprofit organization that travels to developing countries to provide cardiac care and surgery to children in need, and educate local teams. Upon witnessing the lack of medical care, specifically pediatric cardiac care in the developing world, I realized I might not have survived childhood had I been born elsewhere. Feeling compelled to continue to help more children with CHD in developing countries, I have held the role of PCNP, PCNP Educator and Coordinator with the William Novick Global Cardiac Alliance. The true mission of our medical mission trips is to educate local teams and build sustainable pediatric cardiac programs, so that children with CHD worldwide can have healthcare solutions and can thrive.

For the past six years, I have volunteered with Camp Del Corazon as a Medical Volunteer and Nurse Coordinator. I administer the medications to the campers and ensure their safety. I have thoroughly enjoyed the activities offered at camp. The magic of camp is inspiring, witnessing these children doing activities that they’ve been told “can’t.” It is through Camp Del Corazon that I met my future husband, whose unique heart story brought us both together in life. In July 2018, I became employed by the UCLA Adult Congenital Heart Disease Center seeing patients at the Adult Congenital Heart Disease Center at the UCLA Health System. One of the main reasons I accepted the opportunity to join the UCLA ACHD team was because I was passionate about patient care.

Marcy, 53 yrs old

Living Life

In Memorium Written by Marcy’s husband Ron

Marcy was born in June of 1964 with Transposition Arteriosus Type 1, severe pulmonary hypertension with Eisenmenger Syndrome and was given three or four months to live. But don’t let that description of her heart condition make you think that Marcy ever let that stand in her way. In her own words, “I was just a child that needed to be coddled. I heard more than once that as a child growing up, Marcy had to be told to slow down and rest. This is not to say that her parents and her...”
Counseling & Therapy Services for ACHD patients & families:

Our ACHD Social worker David Highfill, LCSW is available for supportive counseling and therapy sessions in our ACHD clinic, 100 Medical Plaza, Suite 630 East, the same clinic where you see your cardiologist. David’s clinic hours on Mondays and Thursdays from 9:00 am to 4:00 pm. A few common reasons why ACHD patients benefit from counseling services include:

- Coping mechanisms and behavioral therapy to address anxiety
- Management of depression and identifying need for pharmacologic treatment
- Facilitating successful transition to autonomous adult health maintenance

To schedule an appointment with David or find out more about this service, please email ACHDScheduling@mednet.ucla.edu and copy DavidHighfill@mednet.ucla.edu or call our nurse line at (310) 825-5636.

ACHD Support Group

We are proud to maintain the UCLA ACHD Monthly Patient and Family Support Group, now entering its third year. The group meets in the evening of the last Thursday each month. With the continuing technological developments of CHD treatment, the adult congenital population continues to grow. As CHD patients are living longer, we continue to face the challenges of managing chronic illness in addition to the regular changes we face through the aging process. Managing your changing individual, family, social, economic, and health issues in today’s uncertain climate can be frustrating and at times overwhelming. Having the opportunity to meet with other patients and their family members dealing with similar issues and having similar diagnoses can be extremely helpful. Some beneficial effects of participating in a support group include:

- Learning and sharing with other CHD patients and their loved ones can be reassuring
- Group connection provides a unique sense of camaraderie.
- Meeting others with similar diagnoses and issues can help build confidence and self-esteem while simultaneously adding to your overall support system.
- Participants share real-life situations that many CHD patients face (surgeries, procedures, etc)
- Lifestyle coping is a focus of discussions, such as preparing for and adjusting to school or work, how to discuss your CHD, medications, and scars with others, preparing for major stepping stones such as dating, marriage, and whether or not to start a family.
- Group discussions can focus on navigating insurance options, understanding your hospital bills, even when to consider disability benefits.
- Group members often share articles, websites, and other resources offering additional information.

Our ACHD social worker David Highfill is the group facilitator. David is not just another medical social worker but is also a CHD patient who underwent a modified Fontan procedure in 1990 and received a heart transplant in 2012, both here at UCLA. David may have direct personal experience that relates to your situation in addition to his training as a licensed clinical social worker.

The group is open to all Adult Congenital Heart Disease patients and their family members. When planning to attend, we ask that you please RSVP to our office manager Yvonne Jose at (310) 825-2019 or Yvonne@mednet.ucla.edu as space is limited. To increase group participation, we recently added phone and video conferencing to the support group allowing us to include patients who are not easily able to come to UCLA in person. We are also planning to feature information sessions from the ACHD cardiologists at future meetings. Stay tuned for these announcements.

If you would like to be added to the ACHD Support Group mailing list or have questions about the group, please send your contact/email information to Yvonne Jose.

The 2018 Greater Los Angeles Congenital Heart Walk

On Sunday, May 6th 2018, the 6th annual Greater Los Angeles Congenital Heart Walk was held in beautiful Griffith Park.

In all, over 1.1 million 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.

Regional ACHD Conferences for Patients & 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

UCLA Fontan Survivorship Program

The effects of congenital heart disease on other organs can be profound. This is especially true in patients with severe chronic right heart failure or those with single ventricle Fontan physiology. There is an increasing awareness of the impact of chronic heart problems on liver function and the potentially irreversible liver damage related to congestion and decreased perfusion of the liver. Patients who have undergone the Fontan operation universally develop liver congestion and scarring that worsens over time and eventually may lead to liver failure in some patients. This has spurred UCLA clinicians to develop mechanisms for better understanding, diagnosing and managing combined cardiac and liver disease. Through the generous donation of Ms. Delphine Lee and Mr. Ron Ainsworth, we have developed a multi-specialty program at UCLA to coordinate and promote the diagnosis, management and research into combined heart and liver disease. If you would like to learn more about this important clinical initiative, please visit our website at http://heart.ucla.edu/ACHDC.
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. Jeff Wong (pictured with his brother) is one beneficiary of the highly advanced care we provide at UCLA. He shares his journey to becoming a patient at UCLA:

“Your VSD has enlarged. You are going to need surgery as soon as possible -- open-heart surgery.” It all happened so fast. Before I could process it, I found myself a week away from scheduled open-heart surgery at my local hospital. Thankfully, I eventually came out of shock and remembered I had a college friend who had become a cardiologist. He recommended I seek a second opinion at The Ahmanson/UCLA Adult Congenital Heart Disease Center. From the get-go, the nurses and doctors at the ACHDC seemed as concerned with putting my mind at ease as they were with treating my heart. They performed the necessary tests and quickly determined I was a candidate for a catheter-based approach to correct my defect. I had been having nightmares about bone-saws and rib-spreaders; instead, I was offered an alternative that seemed nothing short of miraculous. Thanks to the entire ACHDC team, I was out at the movies the second night after my procedure. Just a month after my procedure, I was able to fly across the country to be the Best Man at my brother’s wedding.”

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 and clicking on “ways to give.” To discuss specific gift options, or for more information, please call (310) 825-2019.