AHMANSON/UCLA ADULT CONGENITAL HEART DISEASE CENTER

NEWSLETTER FALL 2023

UCLA Health | David Geffen School of Medicine

THE AHMANSON/UCLA ADULT CONGENITAL HEART DISEASE (ACHD) CENTER WELCOMES NEW FELLOWS TO THE TEAM

From left: ACHD Center Fellows Drs. Angela Li, Jenica Thangathurai, and Eihab Ghantous who joined the team on July 1, 2023.

Angela Li, M.D., has spent much of her life on the East Coast, but now looks forward to spending the next two years in Southern California developing her expertise in adult congenital heart disease. She attended Johns Hopkins University for her undergraduate work where she double majored in molecular and cellular biology and East Asian Studies. Dr. Li completed her medical degree at The Pennsylvania State University in 2015, her residency in internal medicine and pediatrics at Rush University in Chicago in 2019, and her cardiology fellowship in New York at the Donald and Barbara Zucker School of Medicine at Hofstra/Northwell in 2019. During the COVID-19 pandemic, Dr. Li authored multiple articles published in peer-reviewed journals, many focused on the cardiac complications from COVID-19. After finishing her cardiology fellowship in 2022, she remained at Hofstra/Northwell and completed an additional year of training in interventional cardiology. Dr. Li's interest in ACHD stemmed from her background in caring for both pediatric and adult patients during her residency, and her goal is to focus on interventional ACHD cardiology at UCLA. Dr. Li is fluent in English and Chinese and her hobbies include photography, running, travel, and learning new languages.

Jenica Thangathurai, M.D., grew up in the San Francisco Bay Area, and has remained in California for all her medical training. She attended the University of California, Davis for her undergraduate work, majoring in neurobiology, physiology, and behavioral biology, with a minor in Spanish. Her medical degree and internal medicine residency were at the Keck School of Medicine of the University of Southern California, where she served as chief resident from 2019-2020. Dr. Thangathurai completed her cardiology fellowship at Harbor-UCLA Medical Center in June 2023, serving as chief fellow in her final year. Her interest in ACHD was cultivated by her mentor Priya Pillutla, M.D., who is a past UCLA ACHD fellow. Dr. Thangathurai is engaged to be married next summer and is fluent in English and Spanish. Her hobbies include cooking, strength training, and yoga.

Eihab Ghantous, M.D., a native of Israel, completed his bachelor's in medical sciences and his master's in public health at Tel Aviv University. He received his medical degree from Sackler School of Medicine through the American Medical Program at Tel Aviv University in 2015, and completed his internal medicine residency and cardiology fellowship at Tel Aviv Medical Center. During his cardiology fellowship from 2020 to 2023, he authored several articles published in peer-reviewed journals, many focusing on the cardiac manifestations and recovery from COVID-19. Beginning in 2021, Dr. Ghantous volunteered for Physicians for Human Rights, providing primary care to Palestinian villages in the occupied Palestinian territory, as well as performing echocardiograms on immigrants who lack civil status in Israel and therefore, have no access to universal health care. He came to Los Angeles to pursue his interest in ACHD, hoping to bring his expertise back to the ACHD population in Israel. Dr. Ghantous recently married Aseel, who is a neurosurgery resident doing research at Cedars-Sinai Medical Center during her time in Los Angeles. Dr. Ghantous is fluent in English, Arabic, and Hebrew and has a passion for soccer. He stays active with weightlifting, jogging, and swimming, and enjoys reading and staying up to date on technology news.

UCLA LEADING THE NATION IN TRANSCATHETER CONGENITAL CARDIAC INTERVENTIONS

Jamil Aboulhosn, M.D., Director, ACHD Center, Streisand Chair in Cardiology.

The historical significance of congenital heart disease in the 21st century has been dominated by non-surgical options to replace or repair valves, open arteries, and close holes. The drive to reduce mortality and improve quality of life logically means less surgery, less time in hospitals, and less pain and trauma. UCLA's dedication toward lifelong congenital cardiac care has translated into significant advances in interventional cardiology. The ACHD Center's interventional catheterization program continues to be one of the busiest in the nation, with excellent outcomes and novel techniques being developed and applied.
In addition to structural interventions, UCLA has one of the busiest ACHD electrophysiology

programs whose surgeons perform some of the most challenging and complex electrical procedures in the world. The ACHD team's creativity and ability to respond to these anatomical challenges in the interventional and electrophysiology laboratory has resulted in international recognition. Technological advances and multicenter clinical trials the ACHD Center has participated in have resulted in the FDA approval of multiple valves and devices that impact the lives of patients with congenital heart disease. Many UCLA patients bravely volunteered to be part of these clinical trials in the hope of making a difference not only in their own lives, but also in those of the wider community of congenital heart disease survivors. Currently, the following valves and devices that were evaluated at UCLA are now FDA approved:

- NuMed G-Armor Covered Stent for coarctation of the aorta (May 2022)
- ŌNŌCOR endovascular retrieval system for clots/embolized devices (May 2022)
- Edwards SAPIEN 3 transcatheter pulmonary valve with Alterra adaptive prestent (December 2021)
- Amplatzer Talisman PFO occlusion system (September 2021)
- Medtronic Harmony transcatheter pulmonary valve (March 2021)
- Edwards SAPIEN 3 transcatheter pulmonary valve (August 2020)
- GORE Cardioform ASD occluder (June 2019)
- NuMed Cheatham-Platinum covered stent for coarctation of the aorta (June 2016)
- Edwards SAPIEN XT transcatheter pulmonary valve (August 2016)
- Medtronic Melody transcatheter pulmonary valve (January 2010)
- Amplatzer muscular VSD occluder (September 2007)
- Amplatzer septal occluder device for atrial septal defects/patent foramen ovales (2001)

MONTHLY GIVING PROGRAM

The 21st century has proven to be transformative in the field of ACHD. From raising the bar in ACHD fellowship training, to national certification of ACHD cardiologists and accreditation of comprehensive ACHD centers, UCLA has earned the reputation as the gold standard for all other ACHD centers. Clinically, UCLA Health has become a world leader in transcatheter interventions and complex congenital cardiac transplantation. If you would like to join a monthly giving program to express your dedication to the future of the Ahmanson/UCLA Adult Congenital Heart Disease Center, please consider a $25 monthly tax-deductible donation. You will join a community of grateful patients/donors who have made a commitment to the center in a very meaningful way. All contributions directly benefit UCLA ACHD research and programs and help propel advancements in congenital heart disease treatments. Please contact Lindsey Walton, Director of Development, UCLA Health Sciences Development at LSWalton@mednet.ucla.edu or visit <www.uclahealth.org/medical-services/heart/achd/about-us/ways-give> to learn more.

UCLA ACHD SYMPOSIUM IN FEBRUARY 2024

For some patients with congenital heart disease, the last step is an organ transplantation. Combining the long legacy of the transplant programs at UCLA and the ACHD Center, UCLA Health has emerged as having one of the largest programs in the world offering transplantation to congenital heart disease patients. In the past few years, numerous patients have undergone heart transplantation, heart-liver transplantation, and heart-kidney transplantation. UCLA contributed the largest statistics to the Fontan Outcomes Study to Improve Transplant Experience and Results (FOSTER), which examined heart and heart-liver transplants in congenital heart disease patients. The study was recently published in the *Journal of the American College of Cardiology* this past summer.

In conjunction with the UCLA liver transplant program, the Ahmanson/UCLA Adult Congenital Heart Disease Center is proud to present “Beyond Palliation: Exploring Transplantation Options for Fontan Patients” on February 24, 2024. This one-day symposium will bring together esteemed experts in the field to share the UCLA experience as a leading center for complex congenital heart and heart-liver transplants, and also to explore the challenges, innovations, and future directions for those with a failing Fontan. Physicians, allied health professionals, and physicians-in-training from across the country are expected to attend.

One of the highlights of the symposium will be Skylar Collins, one of the center’s recent Fontan heart-liver transplant patients, who will share the story of his remarkable transplant journey. Matthew Lewis, M.D., M.P.H., who led the data collection and analysis of the FOSTER study will serve as the keynote speaker.

UCLA CONGENITAL CARDIAC SURGERY ANNOUNCES OFFICIAL COLLABORATION WITH CHILDREN’S HOSPITAL OF ORANGE COUNTY

Glen Van Arsdell, M.D., Chief, UCLA Congenital Cardiovascular Surgery, and UCLA congenital cardiac surgeon Ming-Sing Si, M.D.

UCLA Health has formalized a partnership with the Children's Hospital of Orange County (CHOC) to provide world-class congenital cardiac surgery in Orange County. Drs. Glen Van Arsdell and Ming-Sing Si currently perform congenital cardiac surgery at CHOC two days per week. This allows children and their families to remain near their homes during their surgical recovery, while also benefiting from the surgical expertise of UCLA Health congenital cardiac surgeons. UCLA's dedication to lifelong congenital cardiac care provides these pediatric families with a bridge to access care as they transition to adulthood.

PROGRESSIVE ADULT CARDIAC EXPERIENCE (PACE) MEMORIAL DAY WEEKEND RETREAT

PACE is a community of young adults with cardiac disease, and an important part of Camp del Corazon. Established nearly three decades ago as a nonprofit camp for children with heart disease, Camp del Corazon has played an important role in nurturing future adults who have congenital heart disease (CHD). UCLA ACHD Center cardiologist Leigh Reardon, M.D., and ACHD nurse practitioner Katrina Whalen participate as mentors/educators in the PACE program. The group gathered over the Memorial Day weekend for an educational and social retreat in Glendale at Camp Bob Waldorf.

This year, 45 ACHD patients attended (ages 18-25), traveling from as far away as New York and North Carolina, and participated in workshops on adult cardiac transitions and health insurance, healthy cooking, traveling with CHD, critical thinking, and maintaining adult friendships. Many of the workshops are led by "camp graduates" and adults with CHD. The three-day retreat also included many social opportunities and informal workshops on basic life skills, such as car and home repairs, finances, and cardiopulmonary resuscitation training.

Dr. Leigh Reardon and Katrina Whalen at the PACE retreat.

GROWING UP WITH A COMPLEX CONGENITAL HEART DEFECT: SARA'S STORY

Sara, Max, and Matt.

Reflecting on the past 46 years, every major life decision was either consciously or subconsciously influenced by my heart condition or my perceived limitations. In 1977, I was diagnosed with complete transposition of the great arteries, which was repaired with an atrial switch operation. Growing up with a complex congenital heart defect has not only defined who I am, but it has also shaped the trajectory of my life. As a teenager, I had participated in numerous research studies at the University of California, San Francisco, the hospital where I had my original surgery. The findings of one particular heart defect study revealed that my life expectancy would be sometime in my third decade; making it to my forties seemed improbable. I know so many of us older adult congenital patients are beholden to those arbitrary expiration dates. Thirty or so years ago, so many of us were casually told these statistics by our well-intentioned pediatric cardiologists. The "ticking time bomb" metaphor lingers in the recesses of our minds. This fear and the constant anticipation and bargaining of when that imaginary "shoe was going to drop," left me depleted and mentally exhausted.

That all changed when I had a stroke shortly after I turned 40 years old. Subsequently, I was in the cardiac catheterization lab having an angioplasty and getting an implanted device to close a baffle leak. Figuratively, the "shoe had dropped," but in spite of it all, here I am, not only still standing, but thriving. I added a few more medications to my daily routine, and yes, the emotional recovery hasn't been linear, but I now feel calm and productive. I am choosing to no longer allow anxiety to be the driving force in my life. The experience of "leaning in" to my heart defect actually brought on positive changes. I self-published a children's book about living with invisible differences; I fell in love with light jogging and ran a 5k; and I joined a weekly dance class, which makes me smile. I also co-founded a company called HeartSnug (www.HeartSnug.com and Instagram @HeartSnug) that makes disposable medical bras that support patient privacy and enhance the patient experience. The company was created out of a lifetime of countless medical exams and procedures.

The UCLA Adult Congenital Heart team is so wonderful. Notably, Dr. Aboulhosn and social worker David Highfill are the anchors in my medical journey. There are no words to *adequately express my gratitude for and trust in Dr. Aboulhosn. David's monthly Zoom heart support group provides a sense of community with other survivors. Their combined expertise in balancing the medical realities of aging with a complex heart defect, while also providing perspective, hope, and a little comic relief, has proved to be an ideal fit for me. With their support, I will begin to start thinking about what my fifth decade may look like … in a few years.*

Life has been full of many experiences that I never thought possible. The pride I have felt watching my 16-year-old son, Max, live such a beautifully unencumbered childhood has satisfied all of my curiosity of what feeling invincible looks like. The unconditional love and support from my parents Wayne and Judy, husband Matt, sister Lisa and lifelong friends (affectionately nicknamed) Laur, Kras, and Howie have not only been the foundation, but also the sunshine in my life.

I am proud of my journey and how I have come to accept what is. May we all have, as the Serenity Prayer says, the serenity to accept the things we cannot change, courage to change those we can, and the wisdom to know the difference.

Thank you UCLA.

SPOTLIGHT ON THE ADVISORY BOARD

Jackie Sereboff.

Participating on the UCLA ACHD Center's Advisory Board has been a great way to help the center and its patients. I have a long history with the center, and I am a big fan of the doctors and staff. They're amazing. Through the board, I have been able to help the center find new sources of funding, and also give a patient's perspective on the center's priorities. For example, having a social worker part time on the staff has been terrific, but my goal is to raise funds to increase this vital role to full time, and ideally increase the number of social workers at the center. I've also guided the doctors toward more patient education, especially with respect to the center's accomplishments in research, training, and technical advances.

I was born with Tetralogy of Fallot about 56 years ago. In 1972, I had my first open-heart surgery at UCLA. Back then, there was no care for adult congenital heart disease patients because so few of us survived childhood. At that time, UCLA was in the vanguard of caring for children, and as the patients have survived and thrived, UCLA created the ACHD Center.

After that first open-heart surgery so many years ago, I fell out of care. Around 1990 I learned about the UCLA ACHD Center and reestablished care. Like most people with CHD, I have faced *many additional lifelong health challenges. I fought Hodgkin's lymphoma in 1980, had a heart arrythmia in 2014 (solved with a pacemaker), and breast cancer in 2017. These are not isolatable issues, and my doctors at UCLA from the ACHD Center have coordinated care and worked together with the physicians in other departments on treatment plans for me.*

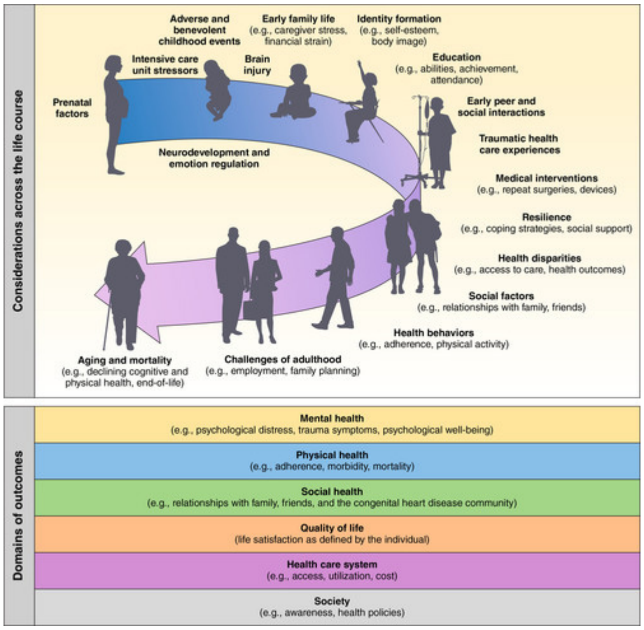
Supporting the UCLA ACHD Center means better research and education in this field. My "aha" moment with the ACHD Center came in 2020 when I went in for my second open-heart surgery in the midst of the COVID-19 pandemic. In the surgery, the doctors replaced my pulmonary valve and corrected other issues with my heart's anatomy, some of which were either caused by or left suboptimal from my first surgery in 1972. The care I received was phenomenal. This care started the moment the surgery was scheduled. I could see the coordination among my entire care team to make sure the surgery was successful. The care in the hospital was beyond expectation and the follow-up care I received from the moment I got home helped me achieve a successful recovery. At that moment, I knew I wanted to do more to support the UCLA ACHD Center. I reached out to my friends and family who were following my heart surgery journey and asked them to help support this fantastic center. Shortly after that, I joined the UCLA ACHD Center Advisory Board. My hope is to continue to donate and make sure the UCLA ACHD Center can expand its mission and research and stay number one so others can receive the same great care I received.

To learn more and become involved with the ACHDC Advisory Board, please contact Lindsey Walton at LSWalton@mednet.ucla.edu or (424) 956-6102.

UCLA ACHD PATIENT AND FAMILY CONNECTIONS SUPPORT GROUP

Through the UCLA ACHD Patient and Family Connections meetings, the center aspires to reach out and connect CHD patients and their support system members with other patients to provide effective peer support to this growing population. Connections meetings take place virtually via Zoom on the last Thursday of each month. The ACHD social worker David Highfill, LCSW, facilitates the group. He is also a CHD patient who underwent a modified Fontan procedure in 1990, and received a heart transplant in 2012, both at UCLA. Connections meetings are open to all ACHD patients and their family members. To obtain the Zoom link for the monthly Connections meeting, those interested can RSVP to the office manager, Yvonne Jose at (310) 825-2019 or YJose@mednet.ucla.edu

IMPORTANT PUBLICATION IN THE WORLD OF CONGENITAL HEART DISEASE



"Psychological Outcomes and Interventions for Individuals with Congenital Heart Disease: A Scientific Statement from the American Heart Association (AHA)" was published in August 2022. Those who have had their lives touched by CHD understand that lifelong cardiac issues can take a psychological toll. While resiliency is an impressive hallmark of CHD survivors, there is now more than five decades of literature documenting higher rates of anxiety, depression, learning disabilities, and social challenges stemming from multiple childhood hospitalizations, surgeries, procedures, and disruptions in normal developmental milestones. There is emerging evidence suggesting that sustained, elevated psychological stress and distress may affect CHD morbidity and mortality.

Adrienne Kovacs, Ph.D., a widely respected psychologist who has dedicated her career to treating adolescents and adults with CHD, and her co-authors have compiled the most important findings related to psychological outcomes in those born with CHD, and set forth a foundation for recognizing and managing mental health in this population. The authors strongly advocate for a culture shift in which mental health professionals are deemed essential members of CHD teams. Dr. Kovacs makes a convincing argument, summarizing that within CHD, depression and anxiety are costly to the health care system and are associated with greater risk of death. She also suggests that although the field of congenital cardiology is not in a position to improve access to mental health care around the world, it is definitely within reach to improve psychological outcomes within the CHD community, and there is urgency to do so.

This scientific statement stands as a catalyst for health care systems caring for CHD patients to implement a care model that offers these patients the best possible quality of life. The AHA found that this important goal to urge hospital systems to include dedicated mental health professionals within pediatric cardiology and ACHD interdisciplinary teams can provide a roadmap and "call to action" for patients, families, health care providers, mental health professionals, and, most important, to the health care systems that commit to lifelong treatment of CHD survivors.
Access the full text of this scientific statement at: https://www.ahajournals.org/doi/epub/10.1161/HCQ.0000000000000110

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Wishing our entire ACHD community Happy Holidays.

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