


2019

IMPACT REPORT

Adult
Congenital
Heart 
Association

Message from Leadership

As the only national patient advocacy organization dedicated solely to serving the unique needs of the nearly 2 million adults

living with congenital heart disease (CHD) in the United States, the Adult Congenital Heart Association (ACHA) proudly moved into its third decade of existence in 2019.

In many ways, the year built upon the tenets that have propelled ACHA's mission since the very beginning: a relentless drive to consistently deliver timely, accurate information; a focus on providing opportunities for patients and professionals to connect with and learn from each other; and a platform to share stories and experiences within the CHD community and beyond.

And yet, 2019 also featured many new and expanded initiatives that boldly position ACHA for the future. We launched our peer-reviewed research program by awarding

the first six grants at a total investment of \$225,000. We introduced our own Walk for 1 in 100 series that attracted thousands of new members to ACHA and raised more than \$600,000 in its inaugural year. And we experienced explosive growth in our network of ACHA ACHD Accredited Centers, thus impacting quality care and positive outcomes for patients nationwide.

ACHA's achievements are YOUR achievements. None of our successes would be possible without you—our dedicated volunteers, staff, sponsors and supporters. We thank you for the time, talent and treasure you contributed to our mission in 2019, and we hope you take great pride in the shared impact we are having on the lives of so many individuals, families and friends across the country.

Mark Roeder
President & CEO

Cindy Huie
Board of Directors Chair

Regional Conferences Expanded



This is what it's all about: Three adults with transposition of the great arteries from different states who met for the first time and connected at the Atlanta Regional Conference.

We continued offering Regional Conferences around the country—and hosted our most events in a year yet. In 2019, we hosted five events around the United States: Atlanta, GA; Denver, CO; Houston, TX; New York, NY; and Milwaukee, WI. At these full-day events, attendees learned about specialized lifelong care for adults with CHD from experts in the field, and had the opportunity to connect with the CHD community.

Here's what a participant had to say about their experience at an ACHA Regional Conference:

“Really impressed with the conference—I left feeling confident that I am being well cared for and plan on becoming more involved in ACHA.”

ACHA Benefits

ACHA hosted fundraising receptions in Los Angeles and Houston—with a total of more than 300 attendees, we raised \$110,000 for ACHA's mission. In the photo, guests of the Los Angeles Benefit enjoy their time at Firestone Walker Brewing Company.



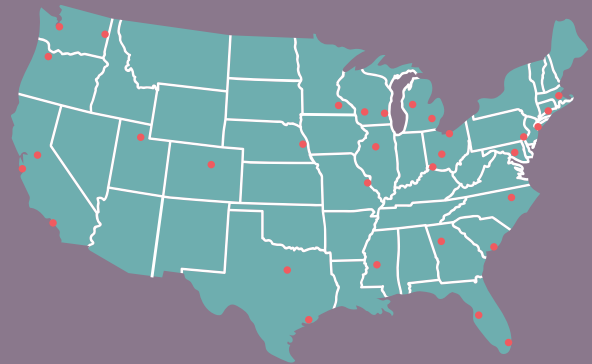
CHD Education for Adults



In addition to live educational events such as Regional Conferences, in 2019 we continued to provide excellent educational resources and expert knowledge at www.achaheart.org and in print. Some of the most accessed resources included 14 interactive educational webinars, and print and PDF resources on specific defects, ACHD care guidelines, and more— with some of the most accessed resources available in both English and Spanish.



Dozens of ACHD Centers Now Accredited



10 adult congenital heart disease (ACHD) centers became accredited in 2019, bringing the total of ACHA ACHD accredited centers at the end of the year to 34. With more centers in the pipeline, this program continues its aim to ensure that every person with CHD has access to specialized care regardless of where they live.

"The accreditation program has really elevated the standard for care delivery in the United States," said Jamil Aboulhosn, MD, ACHA Medical Advisory Board Chair. "The centers that are accredited have the staffing, processes, and procedures in place to give patients and their families the sort of comprehensive, coordinated care that they want and deserve."

Two exciting developments surrounding ACHA ACHD Accreditation took place in 2019:

- In the study, "Improved Outcomes of Heart Transplantation in Adults with Congenital Heart Disease Receiving Regionalized Care," published in the *Journal of the American College of Cardiology*, **the most powerful factor predicting the lowest pre-transplant mortality was being listed at an ACHA ACHD Accredited site.** This was more powerful than a center's overall transplant volume or high volume vs low volume heart transplant center. This result would indicate it is the comprehensive, expert ACHD care the

patient receives at an ACHA ACHD Accredited site that improves survival waiting for a heart transplant.

- U.S. News & World Report began using accreditation as a factor in their ranking and reviews. The following question is now part of the publication's questionnaire: **Does your adult congenital heart program have full accreditation as, or has it partially completed the accreditation process to become, an Adult Congenital Heart Association Comprehensive Care Center (www.achaheart.org)?**

"Going to an ACHA accredited program gives me the utmost confidence in my providers. I know I'm going to be receiving the best care possible from my cardiac team."

— Jennie F., ACHA peer mentor

For a full list of accredited centers, visit www.achaheart.org/accreditation.

Inaugural Research Grants Funded

In 2019, a watershed moment for ACHA took place, as we funded six research grants to advance the science of congenital heart disease (CHD) in adults. The research program aims to improve the lives of CHD patients and future generations in partnership with medical professionals.

The following two-year ACHD provider grants, jointly funded by ACHA and the Meil Family Foundation, were funded at \$32,500 per year:

Patient Centered Research Models to Diagnose and Treat Anxiety Disorders in Adult Congenital Heart Disease: A Pilot Pragmatic Clinical Trial, Matthew Lewis, MD, MPH, Schneeweiss Congenital Heart Program, Columbia University Medical Center, New York, NY

Peer Coaching Adaptive Self-Management Interventions for Young Adults with Congenital Heart Disease (CHASM IN ACHD), Richard A. Krasuski, MD, Adult Congenital Heart Disease Center, Duke University, Durham, N.C.

Improving Pregnancy Outcomes in Women with Tetralogy of Fallot, Valeria E. Duarte, M.D., Boston Adult Congenital Heart Disease Program, Boston Children's Hospital

“The ACHA research program will provide reliable funding for ACHD investigator and trainee-initiated studies. These studies can produce the early data needed to design future large multi-center studies and subsequently guide and improve ACHD patient care.”

– Arwa Saidi, MB, BCh, MEd, ACHA Medical Advisory Board Vice Chair



In addition, jointly funded by ACHA, Project Heart, and the Dale Amorosia Heart Fund, the following three fellows received one-year grants of \$10,000 each:

Strategies for the Successful Adaption of the PRISM (Promoting Resilience in Stress Management) Intervention to Promote Resilience for Patients with Adult Congenital Heart Disease, Jill M. Steiner, MD, MS, Division of Cardiology, University of Washington, Seattle

Cognitive Impairments in Adult CHD Patients, Carla P. Rodriguez-Monserrate, MD, Boston Adult Congenital Heart Disease Program, Boston Children's Hospital

Serial C-Reactive Protein Measurements to Predict Clinical Events in Adults with Congenital Heart Disease, Nael Aldweib, MD, Boston Adult Congenital Heart Disease Program, Boston Children's Hospital



In 2019, ACHA was thrilled to launch its brand-new fundraising campaign, Walk for 1 in 100! We walked to raise funds for the 1 in 100 children and adults impacted by CHD across the country. In our inaugural year, 3,300 supporters walked in one of our 12 walk locations across the country or virtually—and together, they raised \$600,000.

One of those walkers is ACHA member and volunteer Kelly DiMaggio, an adult living with a complex single ventricle physiology, who shared her story:

The first-ever Walk for 1 in 100 was at Wheaton Park in Maryland, and was nothing short of a rousing success! There are no adequate words to describe not only the walk itself, but everything leading up to it—there was so much pure emotion associated with it all. However, if I had to pick three words to sum it all up, it would be love, support and passion.



As part of the planning committee, my husband Mike—who was diagnosed with atrial septal defect a little over two years ago—and I instantly felt comfortable and like part of the family. With no prior exposure to event planning, fundraising and donor relations, sponsorship or the ins and outs of non-profit organizations, my

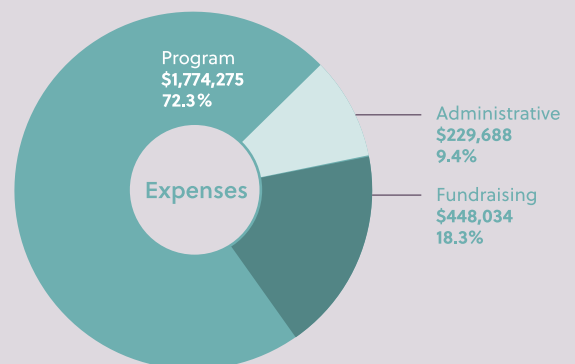
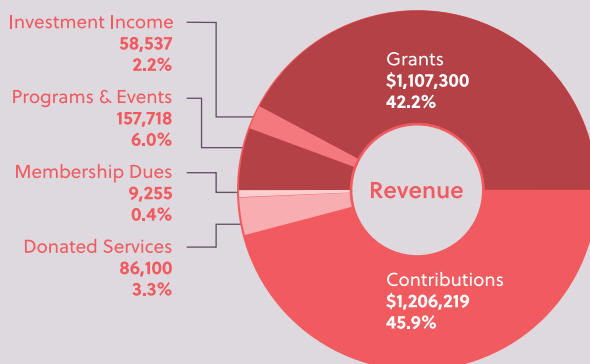
mind was blown. The behind-the-scenes efforts are incredible and fueled by some truly passionate individuals.

Everyone involved brought so much passion to the table. Mike and I were beyond honored to serve as the honorary chairs for the walk and to take a few minutes to share our story. The support, sense of community, and love was palpable in the energy of the event. There were hundreds of people in attendance and everyone there shared a genuine love and passion for the cause.

I pushed myself this year, I stepped out beyond my comfort zone to fundraise as hard as I could, and it really paid off. I think this year was one of the most emotional years for me in terms of all of those who came out to support. To share our community with our friends and family, and for them to “see us in action” was beyond cool.

ACHA and Walk for 1 in 100 raises money for research, education and continuing outreach. From working with parents to educate them on the lifelong care their child may need in the future, to supporting adults who have, or are currently, transitioning from pediatrics to adult CHD specialized care, ACHA is here for us!

2019 By the Numbers



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