You may recall our 2020 Impact Report focused heavily on the COVID-19 pandemic and the unique challenges it presented for the congenital heart disease (CHD) community. As we moved into 2021 armed with increased knowledge and new vaccines, there was optimism for a return to normalcy for our community and the world at large. Of course, as the year progressed, spikes caused by variants of the virus created new and renewed uncertainties for all of us.

As we continue to navigate through challenges related to the pandemic, we hope you and your loved ones have stayed safe and healthy. ACHA remains proud of the work of our staff and volunteers through another unprecedented year, perhaps more accurately depicted as our “new normal.” Throughout 2021, we pivoted as necessary to transition our programming and worked tirelessly to minimize financial impacts. The CHD community is strong, and because of the support and dedication to our cause by so many, we are pleased to say that ACHA ended the year strong as well.

We’re eager for you to read through this extensive report to learn more about ACHA’s substantial impact in 2021, through both traditional programs and new endeavors, reaching millions of people in the process. You’ll learn more about activities such as:

- the crucial work guided by our Diversity, Equity and Inclusion Committee, as well as the formation of the Patient & Family Advisory Board—both essential groups of volunteers ensuring ACHA speaks to, and hears from, diverse CHD voices from all parts of the country.
- the exciting launch of our new, lifelong care-focused brand, which accompanied a new mission statement, vision statement, and website.
- the ways we continued to expand virtual delivery of our mission, such as through educational conferences, accreditation site visits and Walk for 1 in 100.

We could not be more appreciative for the continued dedication of our volunteers and donors during this time. Thank you wholeheartedly for standing by ACHA and continuing to support us as leaders in the CHD community. Our impact has continued to grow because of you.

Mark Roeder
President & CEO

Jeff Ishida
Board of Directors Chair

A FRESH LOOK AND PURPOSE

ACHA Board of Directors, Medical Advisory Board, and staff came together in 2021 to review our current mission and where ACHA’s work has taken us since we last updated this important, fundamental purpose of our organization. We were excited to debut ACHA’s vision, as well as an updated mission, that incorporates our value of lifelong care for CHD and our more than 20 years of work in the CHD field and support to patients, family members, and medical providers.

OUR VISION:
Every adult with congenital heart disease receives specialized cardiac care.

OUR MISSION:
To empower the congenital heart disease community by advancing access to resources and specialized care that improve patient-centered outcomes.

Alongside the new mission and vision, we also debuted a new ACHA logo. Combined with our Walk for 1 in 100 logo, this completed our overall refreshed look. Since ACHA is an organization about connecting people, we are proud to be represented by an identifier for our organization that encompasses this notion, as well as CHD care across the lifespan.
ACHA is committed to creating a culture where patients and families across the country are empowered to communicate with the ACHA Board of Directors and staff leadership in a collaborative effort to promote understanding and outcomes. Thus, we were thrilled to announce the formation of our Patient & Family Advisory Board (PFAB) in 2021. We introduced our inaugural class in August after a tremendous response to our call for applications—and subsequent rigorous interviewing period.

The PFAB has many benefits for both ACHA and for patients and families. For ACHA, the PFAB will help ensure that planned programs and services really meet patient/family needs and priorities. The PFAB will also promote participation and input from diverse and underrepresented populations and cultivate a team of passionate volunteer advocates who champion ACHA initiatives within their respective communities.

For patients and families, the PFAB represents an opportunity to gain a better understanding of ACHA and its decision-making processes, share opinions in a formal structure that can bring about change, and work as part of a team that will motivate and mobilize others in their community around key priorities.

The PFAB has been formed in a way that ensures that voices from all around the country are heard. ACHA’s 18 new PFAB members come from each of the nine regions of the United States as determined by the U.S. Census Bureau, are elected to serve a three-year term, and will meet no less than four times per year. The PFAB functions as a standing advisory body to the ACHA Board of Directors.
We are so grateful to everyone who supported our mission by raising funds and awareness for CHD within their local communities through Walk for 1 in 100 in 2021. Despite all events going virtual for a second year due to the pandemic, nearly 1,000 people across the country participated—and raised $280,808.88! Through virtual opening ceremonies and social hours at each location, we shared many wonderful moments with members of these communities, and the reach of our efforts to spread awareness for CHD was only amplified.
Despite the second year of the COVID-19 pandemic, we are proud to report that the ACHA ACHD Accreditation Program has continued to move programs forward in the process through virtual site visits and providing valuable feedback to further enhance patient care. The 44 ACHA ACHD accredited programs in 27 states are caring for more than 77,000 patients and counting.

ACHA ACHD Accreditation—which has risen to meet unforeseen challenges in its effort to improve the quality of access to ACHD care—has also led the way in setting standards of care for adults with CHD through identification of critical staffing needs, development of policies for all levels of care and encouraging collaboration among health professionals. This was and is made possible by the efforts of and participation by both patients and providers in developing the accreditation criteria and the process.

Nearly five years into the program, ACHA has reached a milestone as we prepare for the first round of Comprehensive Care Centers seeking reaccreditation. To obtain reaccreditation, programs must complete an application and will undergo a full or modified site visit based on changes to the program since their initial accreditation.

“ACHA staff and the Accreditation Program Steering Committee have prepared for reaccreditation [in 2021] by developing a roadmap for the process and a separate reaccreditation application,” said Arwa Saidi, MB, BCh, MEd, Chair of ACHA’s Medical Advisory Board. “We know that ACHD programs are regularly increasing staff and expertise, so this process provides them with the opportunity to showcase program growth and how they’ve improved patient-centered care over the last five years.”

In 2021, ACHA continued to move 14 total programs through the accreditation process in 2021, with 44 total accredited centers by year’s end. The seven comprehensive care centers that became accredited during the year were:

- Le Bonheur Mid-South Adolescent—Adult Congenital Heart Disease Program (Memphis, TN)
- Sanger Heart and Vascular Institute Adult Congenital Heart Disease Program (Charlotte, NC)
- Houston Methodist Adult Congenital Heart Program (Houston, TX)
- University of Iowa Adult Congenital Heart Disease Program (Iowa City, IA)
- Norton Children’s Heart Institute ACHD Program (Louisville, KY)
- Loma Linda University Medical Center Adult Congenital Heart Disease Program (Loma Linda, CA)
- Children’s Hospital of New Orleans ACHD Program (New Orleans, LA)

For an up-to-date list of accredited centers and more about the ACHA ACHD Accreditation Program, visit www.achaheart.org/accreditation.

“The University of Iowa Adult Congenital Heart Disease program gained ACHA ACHD Accreditation status in July 2021. Recalling our journey through the application process evokes a sense of pride regarding the team building and program development we have cultivated. In creating the necessary policies required for ACHA ACHD Accreditation, we built strong relationships with other multidisciplinary services that will elevate our standards of care to better serve our adults with congenital heart disease patient population. The criteria ACHA has put forward for accredited centers, most importantly, helped guide us to empower our ACHD community through education and encouraging patient and family engagement concerning their own care.”

— Colleen Lancial, BSN, RN-BC
ACHD Nurse Coordinator, University of Iowa ACHD program
ACHA announced our second round of research grants in 2021 to fund four new projects taking place across the country. This brought the total commitment for ACHA’s emerging research program to 10 grants totaling $300,000 since the program launched in 2019.

The goal of this second round of research grants was to inspire fellow and young investigators, and to provide them seed money to delve into their first research projects surrounding adults with CHD. As the ACHA research program grows, it remains an integral part of the organization’s five pillars, along with awareness, accreditation, advocacy, and education. To learn more about ACHA research, visit www.achaheart.org/research.

The following one-year ACHD early investigator grants, which began July 1, 2021, are jointly funded by ACHA, the Meil Family Foundation, Project Heart, the Dale Amorosia Heart Fund, and the Brad’s Heart of a Jayhawk Research Fund:

- Intrahepatic Transcriptomics Discriminate Advanced Fibrosis in Patients with the Fontan Circulation, Katia Bravo-Jaimes, MD, Ahmanson/UCLA Adult Congenital Heart Disease Center, Los Angeles, CA
- Renal Functional Reserve in Adults with a Fontan Circulation, Adam Lubert, MD, Adult Congenital Heart Disease Program at Cincinnati Children’s Hospital Medical Center, Cincinnati, OH
- Novel Remotely-Monitored Home-Based Cardiac Physical Activity Program Using Real-Time Data for Patients with Fontan Circulation, Prashob Porayette, MBBS, MS, University of Iowa Adult Congenital Heart Disease Program, Iowa City, IA
- Our Care Wishes – Adults with Congenital Heart Disease (OCW-ACHD), Lynda Tobin, CRNP, and Yuli Kim, MD, Philadelphia Adult Congenital Heart Center, Penn Medicine, Philadelphia, PA

“Research drives innovation. This is critical to augment health care provider’s medicines, equipment and techniques to improve the outcomes and quality of life of the rapidly increasing ACHD population.”

– 2021 ACHA Research Grantee
Prashob Porayette, MBBS, MS

“ACHA was thrilled to launch a new website in 2021, which was updated with usability and simplicity in mind for our supporters and the greater CHD community. We know that people across the country are accessing our website for a wealth of information, but especially in some key areas—such as defect-specific educational resources and the ACHD Clinic Directory. With that in mind, we made these areas and other priority program content the core of our homepage, and easily accessible with fewer clicks.

We heard your feedback on our educational webinars, and made this area of our website searchable (by keyword, category, or date) so presentations are easily found in our library. The website also was refreshed with a new, clean look and is much simpler to use on a mobile device or tablet than ever before.

“One of the pillars that ACHA was founded on was being a source of easy to access, credible information for all people living with CHD,” said President and CEO Mark Roeder. “With enhanced navigation and resources on our website, we’ve now made it easier than ever for patients and medical providers to locate the information they need.”
After a second postponement of the ACHA 9th National Conference due to the safety concerns surrounding COVID-19, we created “Together From a Distance: ACHA Virtual Empowerment Symposium,” which took place on July 10 via Zoom. During this virtual half-day opportunity, patients, family members and medical providers came together to learn about CHD from the experts and from each other. The day included information sessions as well as breakout rooms and opportunities to engage with members of the CHD community.

Overall, we brought together more than 64 faculty members including doctors, NPs, PAs, nurses, psychologists, patients, family members, and ACHA staff to present a wide range of topics. Close to 150 people registered for the event, and 25 of those registrants were new to ACHA.

ACHA was thrilled to partner with the Centers for Disease Control and Prevention (CDC) in November for “Understanding & Addressing the Needs of the ACHD Population,” a virtual advocacy briefing on the 10+ years of CHD progress underway at the CDC. During the past decade, funding through the Congenital Heart Futures Act in 2010 and reauthorization in 2018 have expanded CHD research, data collection, and CHD awareness efforts at the CDC.

The key reasons for this congressional briefing were to advocate for continued flexibilities and expanded availability of telehealth, as well as appropriations of the authorized funding to continue crucial CHD research and surveillance projects through the CDC. We also are setting the stage to continue to support legislation that will address the lifelong needs of CHD patients, ensuring there is an adequate workforce to meet the demands of the growing population of adult CHD survivors.

Along with ACHA representatives, the audience of nearly 1,000 people (via Zoom and Facebook) heard from a variety of speakers including:

- Congressman Gus Bilirakis (R-FL), CHD Champion in the House of Representatives
- Kaitlyn Kelly, Senior Legislative Assistant to Congressman Adam Schiff (D-CA), another CHD Champion in the House
- CDC representatives Karen Remley, MD, MBA, MPH, FAAP, Director of the National Center on Birth Defects and Developmental Disabilities, and Jennita Reefhuis, MD, Chief of the Birth Defects Monitoring and Research Branch

“I like including both patients and medical experts in on the panel discussions. This helped provide more depth and helped my understanding of the complexities involved. Thanks so much for putting it on virtually!”

“As a provider, it is so helpful for me to hear about patient experiences about their interactions with ACHD physicians and lifelong care. This continues to help me improve our practice and approach to ACHD care and patients in the inpatient and outpatient setting.”
For the second year, we awarded four worthy recipients with our ACHA Volunteer Awards to recognize their dedication to our organization and mission.

2021’S OUTSTANDING ACHA Volunteers

**FUNDRAISER OF THE YEAR AWARD**

ANNE REILLY

Awarded to a member of the CHD community who has demonstrated exceptional commitment and success in generating revenue for ACHA.

**ROOKIE OF THE YEAR AWARD**

TRACYE SHAW

Awarded to a member of the CHD community who has demonstrated exceptional enthusiasm and commitment to ACHA for their first time on the local, regional or national level in the past calendar year.

**INFLUENCER OF THE YEAR AWARD**

CHRISTY SILLMAN, NP

Awarded to a member of the CHD community who has gone above and beyond to spread the word about CHD and the need for lifelong care—an outreach aficionado.

**ORGANIZATIONAL PARTNER OF THE YEAR AWARD**

CAMP DEL CORAZON

Awarded to a business, corporation, institution or fellow non-profit entity that has joined forces with ACHA and fully embraced our mission of improving and extending the lives of those born with CHD.

Thank you to all our ACHA volunteers and partners—we couldn’t do it without you! To learn more about the winners, visit www.achaheart.org/2021Awards.
2021 BY THE Numbers

Donated Services $90,600
Membership Dues $26,685
Government $495,815
Contributions $1,213,951
Grants $117,970
Program and Events $157,342
Investment Income $43,213
Program $1,199,158
Fundraising $292,784
Administrative $246,918

Revenue

Expenses

Our Supporters
JANUARY 1, 2021–DECEMBER 31, 2021

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