




# 2020

## IMPACT REPORT

**Adult  
Congenital  
Heart   
Association**

# MESSAGE

## *from* LEADERSHIP

We hope this letter finds you and your family well as we continue to navigate around COVID-19.

2020 certainly presented a unique set of challenges for all of us. At ACHA we were faced with the unfortunate decision to cancel all in-person activities across the country, including our Walk for 1 in 100 events, regional conferences, and social gatherings. With little notice, we had to quickly rethink how to deliver our critical programming in a new virtual reality.

We are proud of the agility and flexibility our staff and volunteers displayed as we shifted to answer the challenges of the moment. Building on the confidence that our community has in us as the leading organization for adult congenital heart disease (ACHD) information, this year we became a trusted source for COVID-19 resources as well. Our webinars and online resources related to the pandemic reached tens of thousands of viewers, and our COVID-19 online resource page quickly emerged as the most viewed of our website all year.

In total, we reached more than 2 million people through our website, social media content and 19 educational webinars in 2020. We rallied ACHA members in all 50

states to raise their voices in support of telehealth expansion and federal CHD research funding through our Virtual CHD Advocacy Event. And, while impacted by limited travel guidelines, we completed 9 ACHA ACHD Accreditation site visits this year, which is a vital step in accrediting new centers and advancing access to quality ACHD care throughout the country.

As we continue through uncharted territory, we want you—our dedicated volunteers and donors—to know how much we appreciate your support. You make it possible for ACHA to continue to provide educational resources, advocate for quality ACHD care, and create opportunities for adults living with CHD and medical providers to come together to learn and connect. You make it possible for ACHA to be a leader in the congenital heart disease community. In short, you enable us to have great impact, and we sincerely thank you, especially during these challenging times.



**Mark Roeder**  
President & CEO



**Cindy Huie**  
Board of Directors Chair

## ACHA'S COMMITMENT TO DIVERSITY, EQUITY AND INCLUSION



ACHA is committed to improving outcomes and access to care for the entire CHD community—regardless of age, race, ethnicity, gender, sexual orientation, socioeconomic background and geographic location. In 2020, the CEO Task Force on ACHD Health Disparities and Diversity was created, which resulted in the forming of a standing Diversity, Equity and Inclusion (DEI) Committee that reports directly to ACHA's Board of Directors. This diverse group of patients, providers, staff and Board Members will recommend initiatives that ensure ACHA's research, outreach and advocacy work are supportive and representative of all impacted by CHD.

# ACHA YOUR WAY

Last year, all Walk for 1 in 100 events were canceled due to the COVID-19 pandemic. Despite this setback, we were heartened to see that our volunteer fundraisers so successfully pivoted and raised more than \$130,000 for our vital mission through the ACHA Your Way campaign. This campaign gave ACHA supporters an opportunity to get creative in the way they spread awareness and fundraise for ACHA.

Scott Langbein is one of those supporters.



*“Awareness, awareness, awareness. That’s why I’m part of ACHA, and that’s why I did a daily walk/hike to raise money and awareness for congenital heart defects and disease. There is a two-mile loop—mostly a dirt trail—up a steep hill near our neighborhood in Northern California. Before I knew I had a congenital heart defect, I would run the hill and challenge my niece to see who could run it the fastest. Then, my day of CHD awareness struck on April 1, 2016 (not the kind of fool’s day joke I wanted). The cardiologist told me I needed to talk to a surgeon for an aorta and aortic valve replacement. Now, feeling good again, ‘The Hill’ is a measuring stick for me—where I can measure my physical health, stamina, and commitment to taking care of myself. So why not take the ACHA Your Way challenge and hike every day in June! I Facebook promoted my challenge with daily updates and got a bunch of friends, neighbors, and family to donate more than \$1,500. In 2021, I plan to do it again, My Way, and include some night hikes.”*





# ADVANCING ACCREDITATION DURING COVID-19

Throughout 2020—and with safety during the pandemic of significant importance—continuing to move the ACHA ACHD Accreditation Program forward was a priority. Accreditation improves and increases access to specialized care by setting standards for ACHD program staffing, policies and services. There are 20 categories with more than 100 individual criteria that programs must meet prior to becoming an accredited comprehensive care center. Every program undergoes a thorough application review followed by an in-person, all-day site visit with an ACHA staff member and Medical Advisory board member.

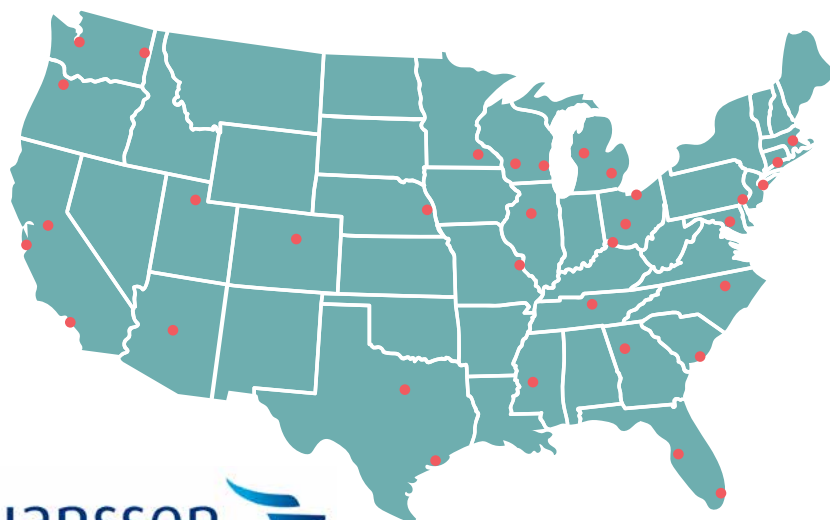
There are two meetings a year, one in the spring and one in the fall, where programs that have completed an application and site visit are discussed, along with other topics related to the Accreditation Program. The spring meeting in March, which is typically conducted in-person, was transitioned to a virtual meeting using the Zoom platform. With the rise in COVID-19 cases, travel restrictions for providers, and uncertainty surrounding when it would be safe to conduct in-person site visits again, ACHA began to explore options to conduct site visits virtually.

Beginning in June and for the rest of the year into 2021, ACHA conducted completely virtual site visits using Zoom.

The ACHA ACHD Accreditation team developed guidelines for these site visits and worked with programs in preparing for these site visits in much the same way as if they were in-person. We are happy to report that this transition was very successful. Additional features, such as the waiting room, have been very helpful with ensuring interviews run smoothly throughout the day. The virtual platform has also allowed certain providers, who otherwise may not have been able to participate in an in-person site visit, to do so.

**In total, ACHA continued to move 10 total programs through the accreditation process in 2020, resulting in 38 total accredited centers by year's end.** The four comprehensive care centers that became accredited during the year were:

- The Schneeweiss Adult Congenital Heart Center at NewYork-Presbyterian/Columbia University Irving Medical Center (New York, NY)
- Mount Sinai Adult Congenital Heart Disease Center (New York, NY)
- Vanderbilt University Medical Center Adult Congenital Heart Disease Program (Nashville, TN)
- Phoenix Children's Hospital Adult Congenital Heart Disease Program (Phoenix, AZ)



*“The Vanderbilt Adult Congenital Heart Program has already benefited from our accreditation effort. During this process, our program formalized preexisting policies, which are complicated and exist among different departments at Vanderbilt University Medical Center and between the pediatric and adult enterprises. Importantly, the ACHA ACHD Accreditation process revealed the need for additional nursing resources dedicated to the ACHD program. Our institution responded to this need by doubling our nursing support.”*

— Dr. Benjamin Frischhertz, Director





# HEART TO HEART PEER SUPPORT PROGRAM

The ACHA Heart to Heart Peer Support Program connects ACHD patient and family members with trained peers who provide support, guidance, and resources. Learn more about one of these relationships from Katie and Monisha.

I've had cardiac symptoms since I was a teenager, but my diagnosis of intramural interarterial anomalous right coronary artery was not made until 2019. That year, I completed my first 5k and in the days after, I thought I was having a heart attack. Many doctors and tests later, and thanks to support and guidance from ACHA, I was finally appropriately diagnosed.



MONISHA



KATIE

In 2016, I was stunned to be diagnosed with anomalous right coronary artery during an unexpected trip to the ER. During my recovery from needed open heart surgery, I was in search of an outlet to "give back" by providing support and resources to others like me, especially patients diagnosed with a CHD as an adult. I am thankful to have found that outlet through ACHA and becoming a Peer Mentor.

The one good thing that came out of that terrifying time in my life was ACHA. It is an organization whose sole focus is people like me. My particular defect is extremely rare, yet somehow ACHA was able to link me with someone who also has an anomalous right coronary artery. I remember exactly where I was when I first spoke to Katie. I was driving and crying. I was not alone.



MONISHA



KATIE

Monisha is a bright light even when the news isn't great. She is a genuine, caring, and inspirational individual and I feel honored to have been paired with her through the Peer Mentor Program.

Katie is my heart sister! She's the first person I ever spoke to with my condition. We immediately connected through our shared bond of faith. So in the beginning she was a lifeline because I didn't think people lived with my condition; now of course I know they do!



MONISHA



KATIE

One of the things I remember reiterating to Monisha (and that I reiterate to all of my matches) is the importance of the right type of care, and making sure the individual is seeking medical advice from an adult congenital heart team. I often refer my matches to the ACHA Clinic Directory as well as searching for specific heart-related Facebook groups. There is such power in finding others who have walked or are walking in the same shoes.

Katie is so empathetic and informative. She really helped me know I could live, and gave me concrete guidance and language around something 100% foreign to me.



MONISHA



KATIE

Monisha and I became fast friends. While she will tell you that I was a lifeline to her in the beginning, she too, has been a lifeline to me. Not only have we bonded over our unique heart condition, but we share a common faith that has gotten both of us through tough times.

To learn more about the Heart to Heart Peer Support Program, visit [www.achaheart.org/H2H](http://www.achaheart.org/H2H).



# RECOGNIZING OUTSTANDING ACHA SUPPORTERS

During our first-ever Annual Stakeholders Meeting (held virtually in November), we hosted an awards ceremony and honored four recipients for their dedication to ACHA.



INFLUENCER  
OF THE YEAR  
AWARD

**Dr. Fred Wu**



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

**Medtronic**

**Medtronic**  
Further, Together

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.



ROOKIE  
OF THE YEAR  
AWARD

**The Stenzel Family/  
Jerry's Jamboree**



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



FUNDRAISER  
OF THE YEAR  
AWARD

**Susan Timmins**



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

**Thank you to all our ACHA volunteers and partners—we couldn't do it without you!**  
To read more, visit [www.achaheart.org/2020Awards](http://www.achaheart.org/2020Awards).

# 2020 BY THE NUMBERS

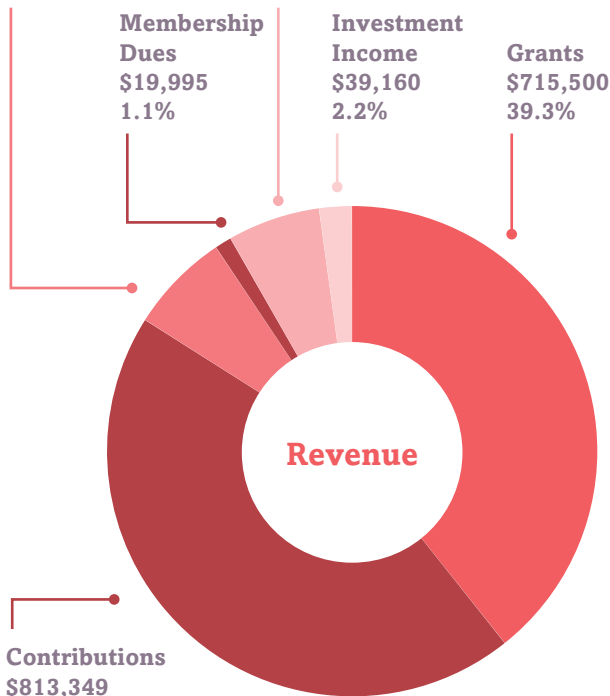
**Donated Services**  
\$120,900  
6.6%

**Program and Events**  
\$111,155  
6.1%

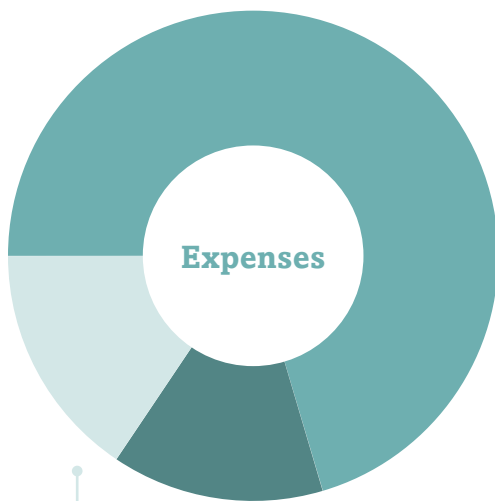
**Membership Dues**  
\$19,995  
1.1%

**Investment Income**  
\$39,160  
2.2%

**Grants**  
\$715,500  
39.3%



**Contributions**  
\$813,349  
44.7%



**Program**  
\$1,321,631  
70.4%

**Fundraising**  
\$292,339  
15.6%

**Administrative**  
\$262,584  
14%

## EDUCATIONAL RESOURCES REACH RECORD NUMBERS

Our first COVID-19 webinar, presented on March 16, had nearly

**5,000 registrants,**

a first for ACHA.

Overall, our webinars presented in 2020 reached

**26,000+**

either live or through archived views.

ACHA's COVID-19 resource webpage, available at [www.achaheart.org/COVID19](http://www.achaheart.org/COVID19), ended the year as the most accessed page on our website with

**35,000 pageviews**

All told, all health information pages (which includes defect-specific resources and more) accounted for well over a third of our total website traffic for 2020.

# OUR SUPPORTERS

## JANUARY 1, 2020–DECEMBER 31, 2020

### Medical Professional Membership

ACHA Medical Professional Members not only support the work ACHA does to improve health for adults with CHD, but also demonstrate that as medical professionals, they have a vital stake in ACHA's mission. The list below includes all paid professional members of ACHA for 2020.

#### MD/DO Membership

Abraham Abernethy, MD  
Jamil A. Aboulhosn, MD  
Faris Al-Mousily, MD  
Laith Alshawabkeh, MD, MScI  
Gerald Angoff, MD  
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Jordan Awerbach, MD  
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Joanna Ghobrial, MD  
Salil Ginde, MD  
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Pooja Gupta, MD  
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Lopa P. Hartke, MD  
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Pei-Hsiu Huang, MD  
Seiji Ito, MD  
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Maan Jokhadar, MD  
Michael Joynt, MD  
Pooja Kashyap, MD  
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Danyal Khan, MD  
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R. Allen Ligon, Jr., MD  
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Jannine Deckard, RN  
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 Logan Eberly  
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 Angel Whitlow

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#### Staff Membership

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 Tara Haskell  
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 Maria Pernetz, RDCS, RVT, FASE  
 Margaret M. Powers, BA  
 Mallorece Rice  
 Michele Slane, BSN  
 Karen Sneed, RN, BSN  
 Kendra Vartia

*We make every effort to present complete and accurate member information. Please advise us of any errors or omissions.*

## Corporations, Medical Centers and Foundations

**Below is a list of our funders who gave \$250 or more.**

### Platinum (\$100,000 and more)

Janssen, Inc. Pharmaceutical  
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### Gold (\$50,000-\$99,999)

Browne Family Fund  
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**Below is a list of our donors who gave \$250 or more.**

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*We make every effort to present complete and accurate donor information. Please advise us of any errors or omissions.*

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