As we flipped our calendars from 2021 to 2022—and despite our “new normal” we shared about last year—we finally felt optimistic that while the COVID-19 pandemic rolled on, the Adult Congenital Heart Association could finally be positive that this was the year we could offer more in-person opportunities for the congenital heart disease (CHD) community.

And that we did! In 2022, we were so grateful to add more in-person events back into our busy schedule of educational, social, and other opportunities. With the important consideration of higher risk factors for many of our supporters and with inclusivity as an important element, we thoughtfully offered a mix of both in-person and virtual activities for constituents to convene and converse.

So many of you participated, and for that we were incredibly appreciative. Opportunities to engage with other adults with CHD, along with the providers caring for them, included conferences (two regional and one national), Advocacy Day, Walk for 1 in 100, weekly webinars and regional conversations.

On the following pages, we will dig more into some of these efforts for you to learn more about:

• ACHA’s 9th National Conference, which remained virtual in order for ACHA to have the widest impact. After years of planning and multiple rescheduled dates, it was heartening to see others learn from the experts and each other in this online space.

• Our first-ever Leadership Retreat, which was an in-person meeting of our most passionate volunteer leaders and staff team to review recent efforts and plan for the future. It was thrilling to both connect and meet others for the first time after so long apart.

• …and more!

From the bottom of our hearts, thank you for the continued dedication and support through the years, and for being an instrumental part of ACHA thriving as leaders in the CHD community.

Mark Roeder
President & CEO

Jeff Ishida
Board of Directors Chair

ACHA LEGACY CIRCLE

A planned gift is one way of assuring that your legacy helps improve the lives of people with CHD. ACHA is appreciative of the generosity and vision of those listed below who chose to include ACHA in their estate plan.

Anonymous
Jerald Boegler and Brian Altman
William F. Causey
Mary Ann Dickoff*
The Fernie Family
Jessica and Joshua Freely
Tony and Denise Garvy
Kevin Gordon and Michelle Traeger
Danielle and Charles Hile
Richard and Cindy Huie
Georgia and Bill Krehbiel

Eric Mann
Wendy and Barry Meil
The Meil Family Foundation
Paula Millen Miller
Michael Pernick
Anne Stapleton-Reilly and Brian Reilly
Mark and Kris Roeder
Susan Timmins
Thomas Wix
Tom and Margaret Wuggazer

For more information on ACHA’s Legacy Circle and enrollment form, visit www.achaheart.org/legacy.

*An asterisk notes the gift has been realized.

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For the first time ever, ACHA was pleased to have the opportunity to assemble members of the Board of Directors (BOD), Emeritus Board, Medical Advisory Board (MAB), Patient and Family Advisory Board (PFAB), and staff. The group met October 28-29 in Bloomington, MN, for a Leadership Retreat to review ACHA’s accomplishments over the last few years, and plan for the next three years through Vision 2025.

“It was so inspiring to be in person with 50 of our most passionate volunteer leaders and staff team after nearly three years of Zoom calls,” said ACHA President & CEO Mark Roeder. “We shared many important opportunities and aspirations that will surely shape our next three-year plan under Vision 2025.”

Through a variety of analysis and brainstorming sessions, attendees provided valuable input and direction for each of ACHA’s core concepts. The results of the Strategic Planning Survey taken by ACHA membership in September helped bring the opinions of our community members to the discussion. The BOD approved the Strategic Plan in December and we look forward to implementing our plans over the next three years.

ACHA’s 9th National Conference took place virtually on June 23-25! We are so thankful to the more than 470 ACHD patients, providers, and family members who participated in the event—as both presenters and attendees—after multiple postponements. The conference was an incredible three days of reuniting with longtime members and meeting new ones.

Throughout the conference, attendees learned about a wide-ranging array of topics through many presentations, from psychological and neurocognitive issues in ACHD to why ACHA-funded research is critical for the ACHD community. Plus, Jon Dorenbos—a two-time NFL Pro Bowl player, Walter Payton Man of the Year Award nominee, a finalist on America’s Got Talent, and a member of the congenital heart disease community—delivered an inspiring keynote speech during the conference’s opening session.

Finally, during the joint closing session of the ACHA conference, we were honored to present awards to longtime members of the CHD and ACHA communities:

• Barry and Wendy Meil were the joint recipients of the Karen Klein McNulty Leadership Award, which is presented to a patient-family member who exemplifies unparalleled commitment to connecting, empowering and advocating for the CHD community within their local community and/or across the nation.

• Jamil Aboulhosn, MD, FACC, FSCAI, received the Amy Verstappen Leadership Award, which is presented to a medical provider who exemplifies unparalleled commitment in the fight to achieve ACHA’s vision that every adult with CHD receives specialized cardiac care.

Barry, Wendy and Dr. Aboulhosn—thank you for your decades of dedication to ACHA, and congratulations!
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 2022. As we returned to in-person events, nearly 1,775 people across the country participated—and raised $459,030.25! We shared many wonderful moments with members of these communities, and the reach of our efforts to spread awareness for CHD was only amplified as we walked together in-person for the first time in nearly two years!
ACHA and The Mended Hearts, Inc. teamed up to host a Virtual Advocacy Day in May. Passionate volunteers including patients, family members, and medical providers representing both organizations met with legislators from states across the country to urge their support for the Cardiovascular Advances in Research and Opportunities Legacy (CAROL) Act, the Newborn Screening Saves Lives Reauthorization Act, and to encourage lawmakers to make critical investments in the ACHD workforce, CHD surveillance and awareness initiatives.

In total, the event had more than 260 registrants. Upon completion, 185 meetings took place, which included meetings with legislative staff members and 10 Members of Congress from 32 states.

In late December, advocates saw their hard work pay off when the CAROL Act was signed into law! In addition, funding for the Congenital Heart Futures Reauthorization Act (CHRFA) was increased for the fifth straight year, bringing the FY2023 total to $8.25 million. Overall, many elected officials and legislative aides expressed genuine interest and concern in understanding the complex ACHD workforce challenges during the event in May, which is why advocating and advocacy overall is so important.

ACHA was proud to announce its third round of research grants to fund four new projects across the United States.

As the only national patient advocacy organization specifically funding adult CHD research, ACHA emphasizes the importance of partnership between patients, their families and the medical field.

In addition to the three traditional research grants, this year ACHA was excited to introduce the inaugural Meil Family Foundation Research Award for Neurocognitive Studies.

The following one-year ACHD early investigator grants, which began October 1, 2022, are jointly funded by ACHA, the Meil Family Foundation, the Dale Amorosia Heart Fund, and the Brad’s Heart of a Jayhawk Research Fund:

- Impact of a Home-Based Healthy Lifestyle Program on Body Composition and Exercise Capacity in Adult Congenital Heart Disease Patients with Heart Failure, Tracey Thompson, MD, Salil Ginde, MD, Medical College of Wisconsin
- REHAB Fontan Failure: RCT of the Effects of cardiac rehabilitation versus Tadalafil Among Patients with Fontan Failure, Jonathan Menachem, MD, Daniel Clark, MD, MPH, Vanderbilt University
- Validating a Patient-Reported Outcomes Tool in Adults with Congenital Heart Disease, R. Thomas Collins II, MD, Alexander Sandhu, MD, Jennifer Woo, MD, Stanford University
- Exploring Mind Body Resilience and Coping/Cognitive Exercises-(EMBRACE): A Psychoeducational Intervention for Adult Congenital Heart Disease, a Randomized Control Trial, Vicki Freedenberg, PhD, RN, Children’s National Hospital

ACHA has invested $400,000 to 14 grants in our emerging research program since it launched in 2019.

“We are becoming increasingly more aware of neurocognitive issues, and that living with CHD often leads to related challenges for many individuals,” said ACHA President and CEO Mark Roeder. “The field is just starting to do organized research around this, and ACHA wants to take a leadership role by funding research in areas such as cognition, anxiety, stress, and more—as we have begun funding in prior rounds. Now, with designated funding, we will be able to ensure we continue to focus on these studies for many years to come.”

ACHA CONTINUES COMMITMENT TO RESEARCH, INCLUDING ADDITIONAL FOCUS ON NEUROCOGNITIVE STUDIES

“Each meeting was very productive and I feel that each representative was very attentive to the legislative priorities and personal stories being presented. I look forward to participating in future advocacy events and continuing to use our CHD community voices to raise awareness, support, funds, and further promising medical research!”

From a passionate participant:
Despite the ongoing restrictions due to the COVID-19 pandemic, the ACHA ACHD Accreditation Program has continued to move ACHD programs forward through the process of enhancing patient care virtually. At year’s end, there were 48 programs in 26 states that have met the criteria for ACHA ACHD Accreditation and are accredited—and providing care for more than 84,000 patients and counting.

ACHA is actively working on the first round of reaccreditation for the ACHD programs that were the first accredited in 2017 as ACHA ACHD Comprehensive Care Centers. To obtain reaccreditation, programs must complete an application and will undergo a modified site visit based on the changes to the ACHD Program since their initial accreditation.

“ACHA’s Accreditation Program continues to set the standards for providing the highest level of care for ACHD patients while maintaining the fluidity of the required criteria. As ACHA moves into reaccreditation of the initial accredited programs, the ACHA team and the medical providers as a part of the Steering Committee look to update necessary criteria to accommodate the changes in healthcare and patient needs as we emerge from the COVID-19 pandemic.”

—ACHA Medical Advisory Board Chair Arwa Saidi, MB, BCh, MEd, FACC

In 2022, ACHA continued to move programs through the accreditation process, with 48 total accredited centers by year’s end. The four comprehensive care centers that became accredited during the year were:

- Adult Congenital Heart Disease Program at UC San Diego Health (San Diego, CA)
- Indiana University Health Adult Congenital Heart Disease Program (Indianapolis, IN)
- Weill Cornell Center for Adult Congenital Heart Disease (New York, NY)
- Program for Adult Congenital Heart Disease at Penn State Health Hershey Medical Center (Hershey, PA)

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

The Congenital Heart Initiative marked its second year in December with more than 3,300 adults with CHD who have enrolled in this first-of-its-kind patient-powered registry. Enrollees are from all 50 states and more than 30 countries.

“We developed this registry together with numerous patients and providers so it could become a platform for increasing our knowledge and improving care,” said Anitha John, MD, PhD, ACHA Medical Advisory Board member and medical director of the Washington Adult Congenital Heart Program at Children’s National Hospital, who helped drive the registry’s creation. ACHA has been a key partner with the collaboration, which has given the registry participants an opportunity to interact with others, which has been a key request from participants.

Looking ahead to more research, the Congenital Heart Initiative now has enough participants to allow researchers to complete some important studies about pregnancy, mental health, and long-term healthcare follow-ups.
As part of our diversity, equality and inclusion activities, and in order to increase the accessibility of ACHD resources to diverse patient populations, ACHA created a new webpage for Spanish-speaking members of the CHD community. While ACHA has offered Spanish educational materials for years, we have now added more defect-specific resources and housed all materials in one spot.

The new webpage includes a variety of translations of our most popular Q&As (with more to come!) as well as go-to pieces like the ACHD Fact Sheet and Personal Health Passport.

We couldn’t fulfill our mission without the support of our amazing ACHA volunteers and partners — thank you!

To learn more about the winners, visit www.achaheart.org/2022Awards

DEDICATED SPANISH WEBPAGE DEBUTS

ACHA again awarded four worthy recipients with our ACHA Volunteer Awards to recognize their dedication to our organization and mission.

ROOKIE OF THE YEAR AWARD
JENNIFER CORTES

FUNDRAISER OF THE YEAR AWARD
KAT ARMSTRONG

INFLUENCER OF THE YEAR AWARD
DUBRA KARNES-PADILLA

ORGANIZATIONAL PARTNER OF THE YEAR AWARD
PHOENIX CHILDREN’S HOSPITAL

We couldn’t fulfill our mission without the support of our amazing ACHA volunteers and partners — thank you!

To learn more about the winners, visit www.achaheart.org/2022Awards

The new hub for ACHA’s educational resources in Spanish is www.achaheart.org/informacion.

¡Atención hispanohablantes de la comunidad CHD! Achaheart.org/informacion es el nuevo centro de recursos educativos de ACHA en español. ¡Darle un vistazo!
**2022 BY THE NUMBERS**

**Revenue**
- Grants $546,570
- Contributions $981,891
- Donated Services $158,186
- Fundraising $266,261
- Program $1,621,836
- Administrative $277,578

**Expenses**
- Program and Events $179,621
- Membership Dues $33,910
- Grants $546,570
- Program and Events $179,621
- Administrative $277,578

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**OUR SUPPORTERS**
**JANUARY 1, 2022–DECEMBER 31, 2022**

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**Corporations, Medical Centers and Foundations**
Below is a list of our funders who gave $250 or more.

**Platinum ($100,000 and more)**
- Janssen Pharmaceutical Companies of Johnson & Johnson

**Gold ($50,000–$99,999)**
- Browne Family Fund
- Medtronic Incorporated
- Meil Family Foundation

**Silver ($10,000–$49,999)**
- Anonymous
- Absolute Group
- AmazonSmile Foundation
- Andrew W. Byrd & Co LLC DBA TVV Capital
- Arizona Cardiology Group
- Banner Health
- Broadcom Friends of Donna Turransky
- Cedars-Sinai Medical Center
- Children's Hospital and Medical Center and Nebraska Medicine
- Children's Hospital of Illinois
- Children's Hospital of Philadelphia
- Children's Hospital of Wisconsin

**Bronze ($1,000–$9,999)**
- Anonymous
- Coakley Williams Construction
- Connecticut Children's Medical Center
- Dodge and Cox
- Ellen Weiss Family Philanthropic Fund
- Google
- GreenState Credit Union
- Hartford Healthcare
- Haynes Charitable Foundation
- Haynes Charitable Foundation
- Hercules Industries
- Insperity Inc.
- Janus Henderson Investors
- Keith M. Jordan and Kathryn L. Moseley Family Foundation
- Landzberg Family Fund
- Cincinnati Children's Hospital Medical Center
- Children’s Hospital of Philadelphia
- Children’s Hospital of Wisconsin
- Cincinnati Children’s Hospital
- Medical Center
- Coakley Williams Construction
- Connecticut Children’s Medical Center
- Dodge and Cox
- Ellen Weiss Family Philanthropic Fund
- Google
- GreenState Credit Union
- Hartford Healthcare
- Haynes Charitable Foundation
- Haynes Charitable Foundation
- Hercules Industries
- Insperity Inc.
- Janus Henderson Investors
- Keith M. Jordan and Kathryn L. Moseley Family Foundation
- Landzberg Family Fund
Below is a list of our donors who gave $250 or more.

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- Jeff and Heather Ishida
- James Ruppel, MD
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Ronald B. Zerkel

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

A heartfelt thank you to all our 2022 volunteer fundraisers; each one contributes to supporting ACHA’s mission and programs in awareness, education, advocacy, and research. Below is a list of our top five volunteer fundraisers from 2022.

<table>
<thead>
<tr>
<th>Rank</th>
<th>Event Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>7th Annual Shamrock 5K Run/Walk to benefit Kayden’s Bravehearts presented by Coal Road Crossfit</td>
</tr>
<tr>
<td>2</td>
<td>Heart of Illinois CHD Walk 2021 presented by The Organization for Understanding Congenital Hearts (T.O.U.C.H.)</td>
</tr>
<tr>
<td>3</td>
<td>Emily’s 1000 Cookies for 1 in 100</td>
</tr>
<tr>
<td>4</td>
<td>Team Juice by Travis Allen</td>
</tr>
<tr>
<td>5</td>
<td>Jerry’s Jamboree presented by the Stenzel Family</td>
</tr>
</tbody>
</table>