Adult Congenital Heart Association

LEADING THE WAY FOR THE 1 IN 100
A partnership with the Adult Congenital Heart Association (ACHA) can help your organization build relationships with congenital heart disease (CHD) patients and medical providers, as well as gain name recognition as a well-regarded provider of services and therapies.

Interested in being a partner? Contact partner@achaheart.org.
There are an estimated 1.4 million adults & 1 million children with CHD in the U.S.

THE NEED

Nearly one out of 100 babies is born with a heart defect. Many defects are life-threatening and require surgical or catheter intervention in childhood. Today, most children receive congenital heart defect treatment and live to adulthood. This has caused a new, growing population of adults with repaired heart defects. There are an estimated 1.4 million adults and 1 million children with congenital heart disease (CHD) in the United States. Heart defect surgery or catheter intervention may repair the initial defect, but it is now clear that these patients are not “cured”; they are at increased risk of an array of adverse outcomes later in life.

Little provision has been made for the long-term care of adult survivors. Patients often are not aware of the risks of new problems, such as acquired heart disease issues as they age, greatly increasing premature death and disability. Expert guidelines state that at least half of all CHD patients should receive lifelong monitoring from an adult congenital heart disease (ACHD) specialist at least once a year. ACHA's medical program survey data suggests that fewer than 10% of the 1.4 million adults are currently being seen at recommended ACHD medical programs, and ACHA's current membership only represents less than 5% of the 1.4 million adults.

The shortage of CHD specialists in the United States threatens to create a critical problem as more children with CHD grow to adulthood. Even in the largest cities, it can be difficult to access the appropriate specialty care, and finding information about specific congenital heart defects and health risks can be confusing. With the growing number of adolescents with CHD reaching adulthood, there is a need to increase patient education and public awareness of the lifelong care needs related to CHD.
ABOUT THE ADULT CONGENITAL HEART ASSOCIATION

The Adult Congenital Heart Association’s (ACHA) mission is to improve and extend the lives of the millions born with heart defects through education, advocacy and the promotion of research. Our vision is to be the leading voice in CHD education and advocacy, and raise the public awareness of CHD as a lifelong disease. As an organization we improve the standards for access to and delivery of quality care for adults with CHD, and in collaboration with our partners we drive the public policy agenda affecting adults with CHD.

As the only national nonprofit organization solely dedicated to serving adults with CHD, our mission and programs serve a large and growing underserved patient population in the United States. We have a wide and growing range of programs, services and activities, which are outlined in the following brochure.

We improve the standards for access to and delivery of quality care for adults with CHD
PATIENT AND FAMILY MEMBER PROGRAMS

ACHA Regional Conferences: These full-day in-person ACHD patient education events are hosted across the country to help adults who were born with heart defects take an active role in their cardiac care. Each event is organized in collaboration with a dynamic local partnership including ACHD healthcare providers, ACHD medical programs and affiliated institutions, and ACHA Ambassadors. Each year we host at least four ACHA Regional Conferences across the country with an average of 400+ total attendees.

ACHA Webinars: ACHA brings top ACHD experts into the comfort of our members’ homes via live webinars. Every webinar is 60 minutes long, includes an educational presentation and Q&A session, and is uploaded on our website’s free educational library. ACHA’s Medical Advisory Board members serve as faculty for each webinar. Annually, nearly 800 participants attend live webinar broadcasts and more than 7,500 participants view recorded webinars.

ACHA Clinic Directory and Travel Directory: Our ACHD Clinic Directory offers comparative information on all self-identified ACHD clinics in the United States and Canada that currently participate in the annual ACHA/ISACHD ACHD Clinic Survey Project. All data in the ACHD Clinic Directory is self-reported. Also from this data, ACHA produces an ACHD Program Travel Directory on an annual basis that provides address and contact information for all self-reported ACHD clinics in the world.

Regional Community Outreach: Through Regional Development Leaders based throughout the country we: 1) increase visibility and awareness of ACHA, CHD and ACHD medical programs within the region; 2) increase the number of active ACHA constituents and ACHA volunteers in the region; 3) increase fundraising for ACHA through corporate sponsorship and grants, ACHD medical program sponsorship, individual giving, and fundraising events; 4) drive CHD awareness and patients to appropriate ACHD care; and 5) provide opportunities for community building, networking and support through growing local ACHD communities.
ACHA Volunteer Program: As a non-profit organization, we value the contribution of time, passion, energy and enthusiasm from volunteers as a means to extend and enhance the mission of ACHA. ACHA volunteers make a significant contribution to ACHA through areas including advocacy, education, outreach and online presence/social media, Walk for 1 in 100 and other fundraising opportunities. In addition, the ACHA Heart to Heart Peer Support Program connects ACHD patients and family members with trained volunteers who provide support, guidance and resources. Opportunities range from one-time commitments to ongoing roles, and volunteers can contribute at the national office, at the regional level, in their own community and online.

ACHD FELLOWSHIP PROGRAM

National guidelines of care provision for adults with CHD recognize that the delivery of appropriate healthcare largely remains unmet due to a combination of factors, such as lack of organized systematic ACHD care and lack of trained ACHD medical providers. Recognizing this call to action to increase and sustain subspecialty ACHD training, we face the immediate challenge of the limited number of existing ACHD fellowship programs in the United States. ACHA's fellowship awards foster program start up and development of training programs that clearly demonstrate a sustainable commitment to ACHD care and fellowship training.

CONGENITAL HEART ADVOCACY

ACHA is dedicated to advocating on behalf of those born with heart defects across their lifespan. As a key player in the successful future of those living with CHD, ACHA partners with lawmakers and federal agencies to improve and prolong the lives of those with CHD. In addition to advocacy work on a national level, ACHA works with grassroots advocates in engaging and educating their legislators.

Congenital Heart Legislative Conference:
In partnership with pediatric CHD organizations, ACHA organizes a two-day event for patients, caregivers, families, and medical providers from around the country to come to Washington, D.C. to learn about current policy initiatives and to advocate on behalf of CHD patients. Advocates receive training on our key messaging and goals, and learn how to participate in an effective visit on Capitol Hill. Advocates attend pre-scheduled visits to their lawmakers to share their story and educate the lawmakers on key priorities selected from our policy agenda.
**E-Advocate:** Dedicated volunteers receive regular emails with information related to legislative CHD issues and a call-to-action, whether it is writing an email or calling their local legislator, visiting district legislative offices, or meeting with a legislative health aide. The consistent recruitment of e-advocates enhances our members who participate in the Congenital Heart Legislative Conference and increases the power of our voice, while creating an opportunity to foster and strengthen legislative relationships throughout the year.

**RESEARCH**

ACHA research grants are awarded to proposals most likely to advance the ACHA’s goal of achieving best possible outcomes for people born with heart defects. Proposals may involve basic, translational, population-based, clinical, or other forms of research.

**OUTREACH AND AWARENESS**

A priority for ACHA is to increase public awareness of CHD and ACHA by: 1) implementing an annual strategic communications plan, 2) developing and strengthening partnerships with ACHD medical programs, and 3) fostering a united voice for the CHD community. One key way we are increasing public awareness is through traditional media, social media and mobile marketing campaigns. Continuing these type of public awareness campaigns is vital to increasing awareness of CHD and ACHA to the majority who are lost to care. Public awareness campaigns can range in timeframe, reach and cost.
ACHA BENEFIT

As ACHA continues to grow, we must increase and diversify funding. The purpose of ACHA Benefits are to foster the local ACHA presence within communities and raise funds to support ACHA's work within those regions and from a national level. Each event can have a range of 150-250 attendees. Our attendees are those who care about making a difference in the number one birth defect in the United States, including CHD patients and their families and those from the corporate, medical, pharmaceutical and social communities in each area.

Our attendees are those who care about making a difference in the number one birth defect in the United States.
NATIONAL CONFERENCE

Our national conferences offer a unique opportunity for the entire ACHD community—patients, families, healthcare providers, and researchers—to come together to interact, learn and build hope for the future. Held every two to three years, our national conference offers overlapping educational tracks—the Patient/Family Conference, the Research Symposium, and the Health Professionals Conference—which meet separately and in plenary sessions throughout the event.

ACHA WALK FOR 1 IN 100

Join us as we walk for the 1 in 100 children and adults thriving with CHD across the country. ACHA is the only national nonprofit organization devoted to supporting the full lifespan of the millions of people impacted by CHD. The ACHA Walk for 1 in 100 reaches to communities across the country to raise money for outreach, education, research and more. Our events were created to empower all of those who were born with a heart defect, their loved ones, and the medical community that cares for them.

Although ACHA has made great strides in delivering valuable programs and driving critical initiatives to improve and extend the lives of everyone born with a heart defect, there is still much that can and needs to be done. Opportunities and challenges lay ahead. Thanks to tremendous medical advances there are now more adults living with CHD than children, yet there is never an age or stage physicians can point to and say their patients are past the dangers of CHD. And, each year the number of adults with CHD continues to grow.

To ensure this amazing progress continues, we need the support of those who understand the extent and impact of CHD, and who are committed to making an impact. There has never been a greater need for an organization to drive quality programming and initiatives for lifelong care. ACHA is the only organization whose sole purpose is to meet this growing demand and we need your partnership. CHD doesn’t go away and neither will we.

For more information about any of these programs and how you can become a strategic partner in the future of ACHA and help improve the lives of those born with heart defects, please email partner@achaheart.org.
Adult Congenital Heart Heart Association

280 N. Providence Road
Suite 6
Media, PA 19063
(215) 849-1260