



## **Vision 2030 Strategic Plan**

For the 40,000 babies born with heart defects each year, their story begins with unique and difficult challenges. However, thanks to advances in medical care over the past several decades, more people living with congenital heart disease (CHD) are surviving and thriving well into adulthood. Today, nearly 2 million American adults are living with CHD, and that number continues to grow by about 5% each year.

Despite this progress, fewer than 10% of adults with CHD receive the specialized, lifelong care they need to maintain their health and quality of life. The Adult Congenital Heart Association (ACHA) remains dedicated to changing this reality as we empower the CHD community by advancing access to resources and specialized care that improve patient-centered outcomes. As we look to the next five years, we continue to embrace our ongoing and vital mission with fresh energy, urgency, and clarity through this Vision 2030 Strategic Plan.

ACHA is the voice, advocate, and trusted resource for patients, families, healthcare professionals, policymakers, and the media. We recognize that every individual's story is different, and we are committed to improving health outcomes and quality of life for all adults living with CHD.

As the only national patient advocacy organization solely dedicated to the adult congenital heart disease (ACHD) population, we embrace our unique and critical role. For nearly 30 years, we have delivered timely, accurate, and credible information and programming to our stakeholders in a variety of ways. Our trusted voice allows us to connect, educate, and empower the ACHD community like no other organization can, ensuring that critical knowledge and resources reach those who need them most.

Vision 2030 charts our path forward. We will advance access to expert care, strengthen our community, and ensure that every person with CHD can live a full and healthy life, today and in the future.

## **Our Origin and Core Values**

In 1997, a group of adults living with CHD connected through online forums about their own experiences and recognized that adults with CHD were underserved as existing CHD organizations focused on children and their families. This group established ACHA. Through newsletters, a website, and in-person activities, a young ACHA offered a way for people to connect with others facing similar physical, mental, and emotional challenges.

From our roots as a patient and family centered organization, ACHA has grown to play a significant role in advancing specialty care and health policy for the ACHD population. We accomplish this by collaborating with medical providers, policymakers and other like-minded organizations, while always keeping the needs of adults with CHD as our priority. Through it all, we have embraced five core values: encouraging collaboration, empowering each other, embracing change, committing to excellence, and acting with integrity. These core values guide our daily actions as an organization and they stood as the fabric for the development of Vision 2030.

## **Our Process for Developing Vision 2030**

To ensure that Vision 2030 is grounded in the lived experiences and perspectives of our community, we employed a robust, multi-phase research process that combined both quantitative and qualitative methods. Each phase—surveys, focus groups, and key informant interviews—was intentionally designed to deepen our understanding of the CHD community and its stakeholders. Together, these approaches provide both breadth and depth of insight, ensuring that the final plan reflects the voices and priorities of those we serve.

### **Phase I: Quantitative Research - Patient-Family and Provider Surveys**

We began with large-scale surveys of the patient, family and medical provider communities. Survey participants included the Board of Directors, Medical Advisory Board, Patient & Family Advisory Board, and Peer Mentors, as well as nationwide external stakeholders, including individuals with CHD, their families, and their medical providers.

The response was robust: 969 completed surveys, representing a balanced distribution across geographic regions, age groups, and levels of CHD complexity. The survey completion rate was well above industry norms, and responses demonstrated thoughtful, engaged participation. Statistically, the findings were highly reliable, with a margin of error of  $\pm 4\%$ , thus providing a strong foundation for decision-making.

### **Phase II: Qualitative Research - Focus Groups**

Building on the survey results, we conducted five focus groups to better understand the “why” behind participants’ priorities that allowed us to more deeply explore key insights from the

surveys and to capture the nuances of lived experience that quantitative data alone cannot reveal.

These focus groups included 12 to 14 participants representing patients, family members, or medical providers. Four focus groups were with patients and families, and one with providers. To ensure diverse representation, patient and family groups were organized by geographic region—East, Central, South, and West—that included participants of varying ages and genders, as well as levels of familiarity with ACHA.

The medical providers' focus group was also diverse with representation across regions in various primary practice fields. These sessions generated rich discussion and useful qualitative data that reflected recurring themes and important differences across multiple perspectives within the medical community. Each group built on insights from earlier ones and allowed us to explore emerging topics in greater depth.

### **Phase III: Qualitative Research - Key Informant Interviews**

The final research phase involved a series of 10 Key Informant Interviews designed to capture deeper, more personal insights. Unlike focus groups, these one-on-one, hour-long conversations encouraged open storytelling, reflection, and exploration of themes as they arose naturally. This conversational approach leads to discoveries that often do not surface in a group setting.

The resulting narratives were longer and more detailed than those captured in focus groups, offering a deeper understanding of both individual journeys and collective priorities. These insights complemented earlier research phases and provide a critical lens for shaping strategies that strengthen ACHA's relationships with its community.

### **Insights that Shaped Vision 2030**

Across every phase of the research—both quantitative and qualitative—the findings were remarkably consistent and deeply meaningful. This strong alignment shows that the feedback gathered through this process reliably reflects the voices, experiences, and priorities of those we serve.

The clearest and most consistent insights focus on which ACHA programs the CHD community values most. Participants were asked to rate the importance of ACHA's current initiatives, and their responses paint a very clear picture. The top priorities are investing in medical research (78%), ACHA's ACHD Accreditation Program (71%), and legislative advocacy activities (62%). The next most valued programs include webinars and educational materials (40%) and peer-to-peer support (38%).

These results provide a confident, data-driven view of what matters most to the CHD community and offer a reliable guide for shaping ACHA's future direction.

## Turning Insights into Action

The methodology we employed provides the background to ensure that Vision 2030 aligns with stakeholder needs, provides a clear roadmap for the Board of Directors, and serves as a practical operational guide for leadership and staff. Equally important is that Vision 2030 offers the public a transparent view of ACHA's priorities and practices.

To accomplish this, a Strategic Planning Committee composed of 18 individuals was established, representing a broad cross-section of ACHA stakeholders, including Board of Director members, Emeritus Board members, the Medical Advisory Board, the Patient & Family Advisory Board, Peer Mentors, and ACHA leadership. The Committee formed three subcommittees: Revenue and Infrastructure, Macro/Environmental Factors, and Direct Engagement. These subcommittees developed and refined goals and strategies based on both the research and their own insights and experiences. A Writing Committee then crafted these strategies into a cohesive plan, and a Review Team looked at the draft for clarity and consistency. The draft received a final review by the Strategic Planning Committee for alignment with goals and priorities.

This inclusive, rigorous process of quantitative breadth, qualitative depth, and extensive stakeholder input ensures that Vision 2030 is authentically grounded in the CHD community and poised to effectively guide ACHA for the next five years.

## Our Vision 2030 Strategic Goals

The goals and strategies that follow will guide ACHA's work under Vision 2030 and reflect our commitment to advancing care, strengthening community, and improving the lives of adults with CHD.

- 1. We will lead the way by championing progress and improving patient wellbeing through innovative research, setting high care standards, and supporting year-round advocacy.**
  - We will work with partners inside and outside our organization to conduct research that helps the ACHD community, supports both mental and physical health, and clearly demonstrates how our work improves people's lives
  - We will improve care by increasing the value of program accreditation, improving ACHD expertise across the healthcare community, and staying flexible and responsive as the healthcare environment evolves.
  - We will inspire and train volunteers to work with healthcare and government groups at all levels, leading strong advocacy efforts that create real and lasting change.
  - We will grow our impact by building strong partnerships within and beyond the CHD

community and work with key lawmakers to champion and support policies that will improve the lives of all people living with chronic conditions.

**2. We will engage and empower the CHD community by expanding peer support and delivering enhanced educational tools.**

- We will enrich the Peer Support experience by expanding beyond one-on-one connections to include group-based opportunities that nurture strong relationships and build lasting bonds with ACHA.
- We will foster meaningful peer connections across ACHA and the CHD community that inspire engagement, celebrate strengths, encourage volunteerism, spark fundraising, and build a united, supportive community.
- We will modernize and expand ACHA’s digital tools and resources, using appropriate platforms and methodologies to engage diverse audiences and empower the CHD community.
- We will collaborate with medical providers, patients, and families to create credible, timely educational resources—delivered in ways that are easy to find, use, and share.

**3. We will deepen our impact and expand our reach by creating local communities of strength across the country.**

- We will create local communities of strength in key regions across the country by identifying high-impact opportunities and investing in the conditions that foster success—inspiring engagement, spurring sustained financial support, and fueling growth nationwide.
- We will enhance these communities by empowering volunteer ambassadors, recognizing success, identifying and sharing best practices, and leveraging each community’s unique qualities to grow engagement, advocacy, and fundraising.
- We will forge mission-aligned partnerships with hospitals, businesses, and nonprofits to expand our reach and impact in these communities.
- We will invest in infrastructure to unite local communities of strength through shared systems, unified branding, and clear data tracking—embracing local uniqueness while keeping every community aligned to ACHA’s national mission.

**4. We will build a culture of continuous improvement that enhances ACHA’s effectiveness, adaptability, and impact across all aspects of the organization.**

- We will expand ACHA’s capacity by strategically engaging outside experts for prioritizing and implementing high-value initiatives, while preserving our volunteer and staff-driven foundation.

- We will intentionally and purposefully use technology that will strengthen internal operations and efficiency, increase engagement and fundraising, and provide insights that lead to informed decisions.
- We will develop a robust HR framework that supports ongoing recruitment, training, and acknowledgement of the best people to lead and grow ACHA, cultivating a community of caring individuals who reflect the emerging priorities of those we serve.

**5. We will create a culture of urgency to all we do, encouraging donors and partners to invest in a stronger future for everyone living with CHD.**

- We will inspire action that encourages commitment and fundraising and shows that ACHA is an essential resource for the CHD community by widely sharing authentic stories that highlight how ACHA improves care and quality of life.
- We will amplify ACHA’s impact and visibility by ensuring that every message—across all stakeholders—reflects a clear and cohesive vision of ACHA’s value.
- We will drive urgent action by mobilizing volunteers and partners through impactful opportunities to advocate, fundraise, and lead.
- We will build confidence and inspire engagement among CHD stakeholders by openly sharing how we steward resources and by highlighting ACHA’s real, lasting impact.

## **Shaping the Future, Together**

ACHA is proud of the progress achieved through our prior strategic plan, Vision 2025, and we embrace the opportunity to continue to build upon the foundational beliefs of that plan as we transition to Vision 2030.

We move into our Vision 2030 Strategic Plan with urgency and purpose. The goals in this plan are more than organizational priorities—they are a commitment to nearly 2 million adults living with CHD and to their families, loved ones, and the providers who care for them. Together, we see a future where care is accessible, connection is constant, and every adult with CHD has the knowledge, resources, and community they need to thrive throughout the lifespan.

Through strengthened networks of support, a focus on championing progress, and a dedication to excellence in all we do, we will continue to shape the future of the ACHD population. As we implement Vision 2030, we invite our supporters, partners, and donors to join us in advancing this vision—a future where every adult living with CHD has access to care, community support and lifelong wellbeing.

## **With Gratitude to the Strategic Plan Committees**

Vision 2030 was made possible by a dedicated team of volunteers and leaders who guided this process with insight, care, and commitment. Through countless hours of reviewing research, sharing perspectives, and shaping a vision for ACHA's future, these individuals demonstrated extraordinary dedication to advancing the lives of adults with CHD. We extend our deepest gratitude for their leadership, collaboration, and unwavering belief in ACHA's mission.

### **Vision 2030 Strategic Plan Committee Members**

- Binta Baudy\*
- Web Browne
- William F. Causey\*
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- Emily Earhart
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- Susie Jannusch, RN, MSN, FNP-BC
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- Jill M. Steiner, MD, MS
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\*Also served on the Review Committee.

### **Vision 2030 Strategic Plan Writing Committee Members**

- Jennie Fox
- McLain Miller
- Conor Russo
- Christina Sillman, AGACNP-BC