

2024

Annual Report



Global
ARCH



Message from the Executive Director & President

As we look back on 2024, what stands out most is how far we've come and how much potential lies ahead. This was a year of real momentum for Global ARCH. We launched new programs, embraced leadership transitions, and deepened our commitment to building a more inclusive and connected global community for those impacted by childhood-onset heart conditions.

Our inaugural Virtual Summit brought together voices from around the world to discuss care gaps, stigma, mental health, and what it takes to create lasting change. From that success, we laid the foundation for our new working groups, choosing topics based on what matters most to patients and families.

We also launched a Member Relations Council to help keep our programs grounded in the experiences of the people we serve. Our Medical Advisory Council expanded to bring in more diverse expertise, including mental health. And we began building Invisible Hearts, Collective Action—a new global initiative to raise visibility for childhood-onset heart conditions and inspire collaborative action across regions and sectors.

This year also marked a meaningful milestone. Our co-founders, whose vision and dedication built Global ARCH from the ground up, officially stepped back from day-to-day leadership. We are deeply grateful for their compassion, courage, and commitment. Their legacy lives on in everything we do.

As we look ahead, we are shaping a bold vision for the future. These collective efforts are laying the groundwork for long-term impact, and we are actively working with our board, members, and partners to define clear goals for 2030 and beyond. At the heart of it all is a shared belief: that every life impacted by a childhood-onset heart condition deserves to be seen, supported, and included in the decisions that shape their care and their lives.

To our members, partners, and supporters, thank you. Your belief in this work fuels our momentum and reminds us why we do what we do.

From our hearts to yours,



A handwritten signature in black ink that reads "Kate Doherty-Schmeck".

Kate Doherty-Schmeck,
Executive Director



A handwritten signature in black ink that reads "Amy Verstappen".

Amy Verstappen,
President, Board of Directors



What is Global ARCH

Global ARCH is the only global alliance dedicated to childhood-onset heart conditions, uniting patient and family organizations from around the world. Together, we're working toward a future where every child, youth, and adult born with or affected by a heart condition has access to lifelong care and support.

Our Mission

To improve worldwide lifelong outcomes in childhood-onset heart disease through empowering patient and family organizations.

What We Do

Global ARCH connects over 110 organizations across 47 countries, including more than 75 patient- and family-led organizations focused on childhood-onset heart conditions. We provide these organizations with the tools, knowledge, and resources they need to empower communities and take action. By fostering collaboration, we facilitate the sharing of best practices and strengthen efforts to address the needs of underserved populations. Our work centers on capacity-building, improving care, and supporting lives impacted by these conditions, including rheumatic (RHD) and congenital heart disease (CHD). Our work focuses on 4 key areas: building a global community, capacity building, advocacy, and meaningful inclusion of patients and families.

Our Global Impact



110+
organizations working
together for global change



47
countries, one global
community



50%
representation from low-
and middle-income countries



20+
impactful networking and
training events annually



88,000
patients and families
collectively reached annually



100+
patient and family
advocates worldwide

Global ARCH by the Numbers



Member Organizations

AACIC Associació de Cardiopaties Congènites and Fundació CorAvant
ADANEC
Adult Congenital Heart Association
AICCA Onlus
Amar El Club De Los Corazones Peculiares
Amigos de Corazón
Amigos do Coração Goiás
Ayuda A Corazon De Niño Ac
Bebé Cardio
Big Heart to Small Heart
Bihotzez Elkartea
Brave Heart
Brave Little Hearts Namibia
Brave Little Hearts South Africa
Brave Little Hearts Zimbabwe
Bundesverband JEMAH e.V.
Camp Odayin
Canadian Congenital Heart Alliance
CHD Malaysia
Child Heart Care Project under National Institute for Woman and Child Development
Children's Heart Association
Children's Heartbeat Trust
Children's HeartLink
Children's Heart Federation
Círculo do Coração
Congenital Heart Disease India
Connecting Hearts to End Heartbreak (CHEER Hearts)
Conquering CHD
Cuore Matto
Cure Kids Fiji
European Congenital Heart Disease Organization
Faayo Community Heart Health Initiative
Finnish Association for Heart Children and Adults
Fundación Corazones Luchadores Chile
Fundación Corazoncitos
Fundación El Cielo Para los Niños de Ecuador
Fundacion Estrellita de Belen Corp
Fundacion Live Longer Mexico
Fundación Menudos Corazones
HeartCharged
Heart Children

Heart Crusaders Venezuela
Heart Heroes Fiji
Heart Kids Ltd.
Heart Kids New Zealand
Heart Kids South Africa
Heart Warriors of the Philippines Inc.
Hearts Unite the Globe
Herznetz.Ch
Hjärtebarnsfonden
Hole in the Heart
Justice For Heart Warriors
Kardias AC
Kawasaki Disease Canada
Kehilat HaLev (The Heart Community)
Kenya Mended Hearts Patient Association
Let it Echo
Little Heart Community
Mending Hearts Nigeria
Mending Tiny Hearts
Namibia Rheumatic and Congenital Hearts
Neistinn, Children's Heart Foundation in Iceland
Ollie Hinkle Heart Foundation
Operación Corazón
Pakistan Children's Heart Foundation
Panhellenic Congenital Heart Disease Association
Patiëntenvereniging Aangeboren Hartafwijkingen (PAH)
Rare Warriors of Bengal Association
Ray of Light
RHD Support Group, Uganda Heart Institute
Rheumatic Heart Disease Philippines
Saloni Heart Foundation
Sisters by Heart
Somerville Heart Foundation
Tanzania Children Heart Support Group
The Association for the Protection of Children with Heart Disease
The Children's Cardiac Foundation (Nadácia Detského kardiocentra)
The Heart Chamber
The Mended Hearts, Inc.
Voice of a Heart/Ijwi ry'Umutima
Voksne Med Medfødt Hjertefeil
Zipper Sisters

*Red denotes new member

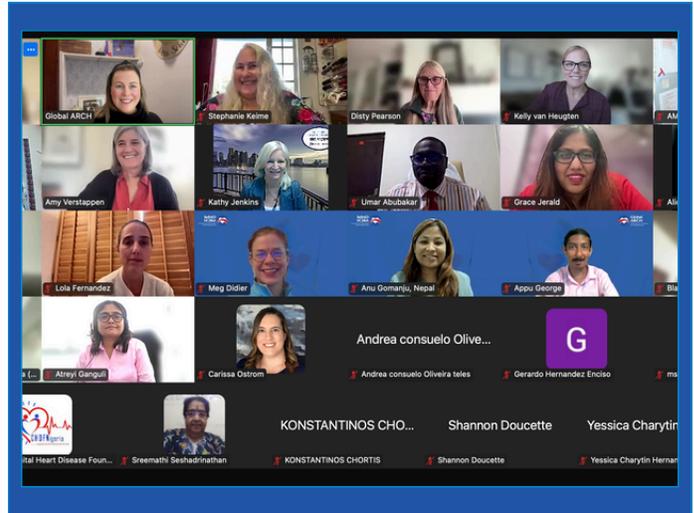
Partners

In addition to our member organizations, we collaborate with clinical, academic, and nonprofit partners working to strengthen care systems around the world.

Action for Disadvantaged People
 American Heart Association
 Children's HeartLink
 Dar Elteb Eltakhassosi Charity Hospital
 Fundación María / Hospital María
 Global Cardiac Alliance
 Global Cardiac Surgery
 Grupar BR - Grupo de Apoio ao Paciente Reumático Brasil
 Heart and Stroke Foundation
 Hearts of Joy International
 iHOPE Kids-A Ray of Hope Foundation
 iLIKA
 International Hospital
 International Society For Adult Congenital Heart Disease
 International Society For Social Pediatrics And Child Health
 Jakaya Kikwete Cardiac Institute
 JK Hope & Health Foundation
 Johns Hopkins Adult Congenital Heart Center
 Kidus Petros Hospital
 Los Cabos Children's Foundation

Mending Kids
 Mending Tiny Hearts
 MITERA
 National Institute of Cardiovascular Disease, Karachi Pakistan
 Pan African Network of Pediatric and Congenital Heart Disease
 Siut
 Sri Sathya Sai Sanjervani Hospitals Nawa Raipur
 Surgeons of Hope
 Tanzania Rheumatic Heart Disease (R.H.D) Registry
 Team Heart, Inc.
 The Children's Cardiac Foundation of Africa
 The Children's Heart Disease Research Unit
 The Congenital Heart Disease Foundation of Nigeria, CHDF Nigeria
 The Heart Foundation Of Zimbabwe
 Tiny Hearts Fetal and Pediatric Cardiac Clinic -Thanjavur
 University of Jordan Hospital
 World Pediatrics
 Ziauddin Medical University Hospital

*Red denotes new partner



DID YOU KNOW ?

Our member organizations span 6 continents and serve communities from urban centers to rural villages. Whether supporting surgical care or fighting stigma, our members are driving change at every level.

Centering the Voice of Our Members: From Connection to Collective Action

Gathering to Learn and Lead

Our members don't just participate in our programs—they shape them. Through regular gatherings like the Leaders' Forum and global events like our Virtual Summit, members shared challenges, identified solutions, and helped shape new initiatives.

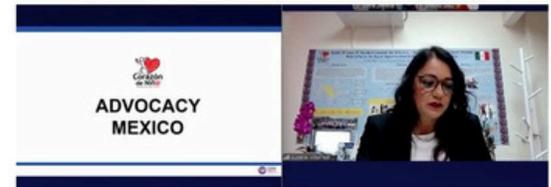
Mind the Gap: Working Together to Transform CHD and RHD Care Virtual Summit

Global ARCH hosted our inaugural Virtual Summit, bringing together 190+ participants from 45+ countries, including medical professionals, advocates, and people with lived experience, to address gaps in care for childhood-onset heart conditions. Day 1 focused on well-being and mental health. Day 2 explored data use, success stories, and advocacy strategies.

190+ registrants
45+ countries
6 sessions
4 breakout groups
1 new program launched

Breakout sessions encouraged participants to explore collaboration, with one noting:

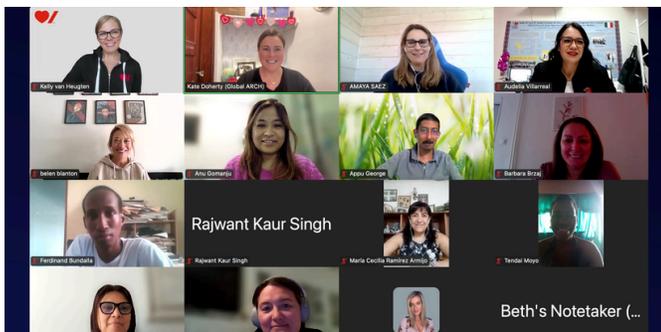
"Collaboration is key—balancing science, data, and lived experience to create impact aligned with each organization's strengths."



The Summit also served as a springboard for launching our 2025 Working Groups, directly shaped by member input and engagement. A huge thank you to all our panelists and moderators for helping to make this such a successful event.



Monthly Leaders' Forum: Connection and Learning



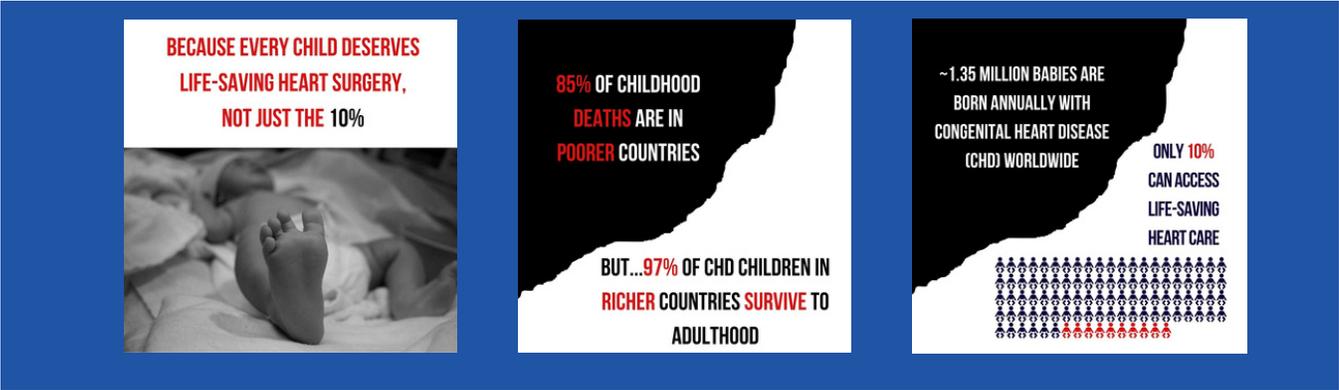
Our Leaders' Forum continues to be a cornerstone for peer learning and connection. In 2024, we hosted over 10 virtual sessions, each engaging more than 15 member leaders from around the world. These sessions provided space to share experiences, learn from experts, and strengthen community ties.

CHD Awareness Week



2024 **CHD Awareness Week** focussed on the power of the patient voice, and we profiled many of our organizations on our social media channels throughout the week to showcase their outstanding work. A big thank you to all who participated!

We also created a reel titled **The Hard Facts About Congenital Heart Disease**, had it translated into several languages, and shared it on social media. It included a call to action to join the **Global Coalition for Pediatric and Congenital Hearts**, a Global ARCH advocacy collaborative initiative.



Global Impact Stories: Voices that Lead

This year, we re-launched our Global Impact Stories to spotlight the experiences of patients and caregivers around the world—sharing journeys of resilience, interrupted care, and community leadership.

Stories from Namibia, the Philippines, and Canada highlighted the urgent need for lifelong care and the vital role families and advocates play in bridging systemic gaps. From confronting stigma to organizing support groups, patients and families are not only advocating for better care—they're driving it forward.

We also expanded the series to reflect the collaboration between patients, families, and health professionals working together to improve care systems. These stories serve as a powerful reminder that meaningful change begins with the people living it—and grows stronger through partnership.



Sharing Experience to Inspire Change

Lived experience is a source of knowledge, power, and global impact. In 2024, we lifted the voices of patients and families through storytelling, global platforms, and cross-sector collaborations.

World Birth Defects Day Webinar



To mark World Birth Defects Day, Global ARCH joined forces with the World Health Organization and the U.S. Centers for Disease Control and Prevention for a global webinar focused on congenital anomalies. This event brought together patient organizations, policymakers, and advocates to call for greater investment in lifelong care for people impacted by congenital conditions. We were honored to spotlight success stories from across our network, demonstrating how lived experience can drive more responsive, community-led systems of care. As one of the few patient/family alliances represented, Global ARCH reinforced the need for patients and families to be included wherever decisions are made.

Global Voices, Global Platforms

Members of the Global ARCH community brought the voices of patients and families to key global conversations.

Board member Ruth Ngwaro represented Kenya Mended Hearts Patient Association and Global ARCH at the second annual Symposium on Integration Science in Global Health Equity in Boston, where she shared her journey as a lifelong advocate and one of the Voices for PEN-Plus. Her participation highlighted the vital role of lived experience in shaping care for chronic conditions around the world.



Global ARCH also presented at the European Congenital Heart Disease Organisation (ECHDO) bi-annual meeting in Milan, held in conjunction with the AEPC psycho-social meeting. We were proud to share insights from our global network and contribute to discussions focused on peer support, mental health, and the power of cross-border collaboration.



These opportunities reflect our continued commitment to ensuring that patients and families are included in shaping the systems that affect their lives. When they are truly seen and heard, stronger, more responsive care can follow.

“ *It’s a privilege to be on the Medical Advisory Committee Global ARCH. I think it’s an important organization, and what encourages me is that it’s global and collaborative. It represents the real interests of the patients and fights for them. I’m inspired by the team at Global ARCH and their energy and drive, which I think is characteristic of people working for congenital heart disease. Global ARCH is doing great work.*

-Dr. Fenny Shidhika, pediatric cardiologist in Namibia



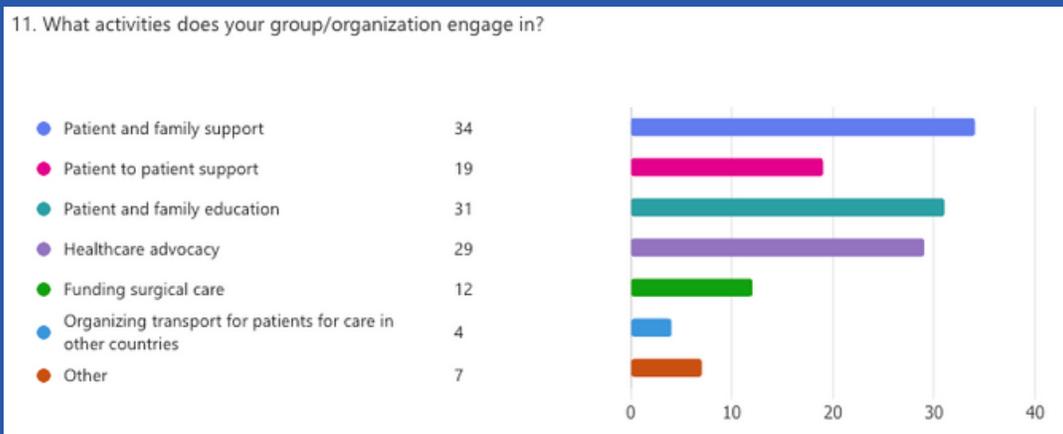
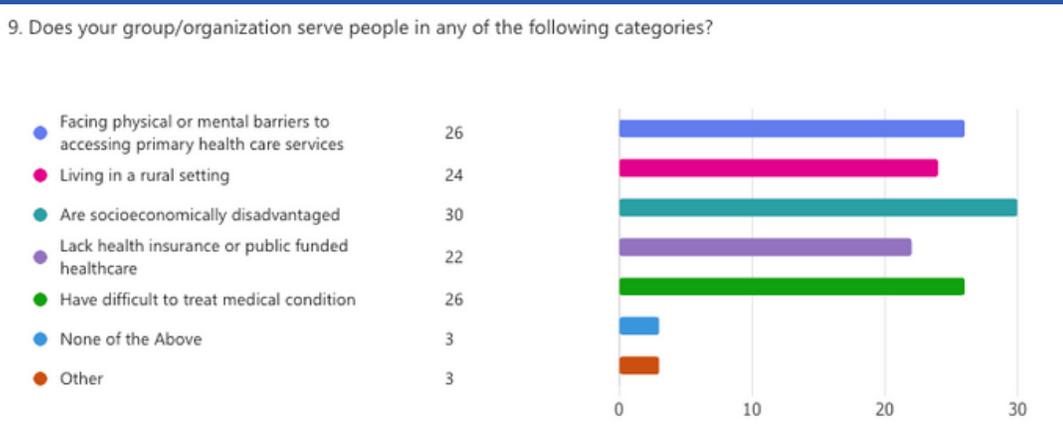
Listening, Reflecting and Improving

True leadership begins with listening. From global meetings to annual surveys, we remain committed to learning from our members and ensuring their feedback drives our next steps.

Annual Member Survey

In 2024, we once again distributed our Annual Member Survey to better understand the priorities of our network. The feedback we received helps us shape programs that reflect our members' realities and deliver resources where they are needed most.

We also collected updated data on our member organizations, helping us strengthen partnerships, identify gaps, and align future offerings with the needs of our community. Thank you to all who participated and shared your insights. Your voices help keep our work grounded and relevant.



“ Love, love, love hearing from the wonderful passionate leaders out there. Makes us feel we are not alone and invigorates us and helps us in our work. Thank you so very much.

- HeartCharged, US



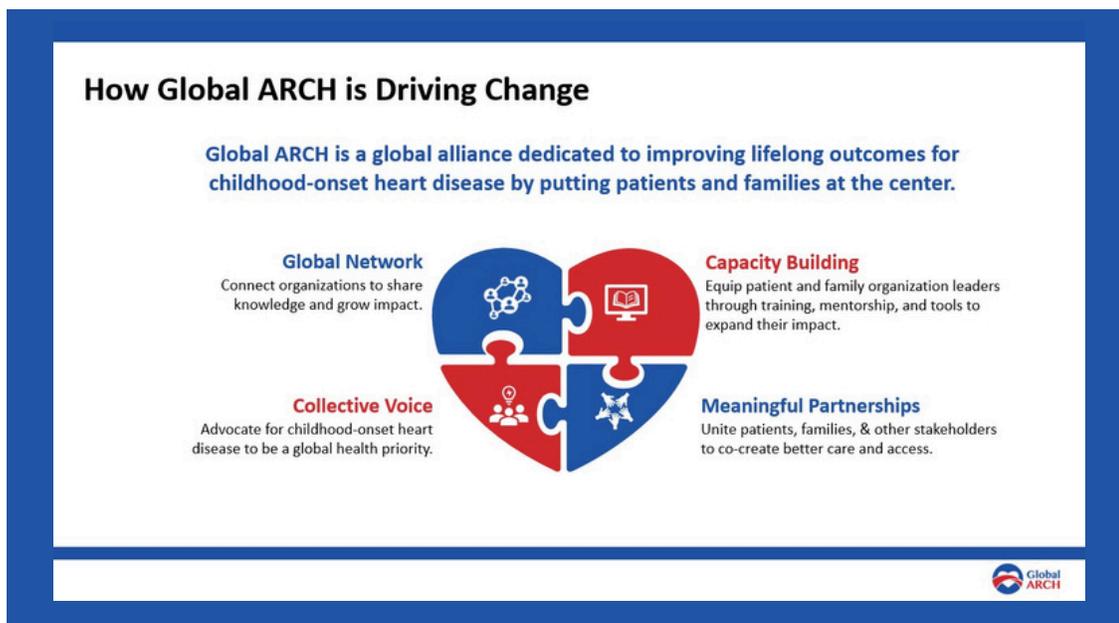
New Global ARCH Initiatives

In 2024, Global ARCH launched **Invisible Hearts, Collective Action**—a new global initiative to raise visibility and drive action for lives impacted by childhood-onset heart conditions, including congenital and rheumatic heart disease. Through Invisible Hearts, Collective Action, we are turning vision into action.

This initiative equips patient and family organizations with tools, training, and connections to lead change in their communities. It also brings together health providers, policymakers, and partners to co-create stronger systems of lifelong care.



Invisible Hearts reflects our commitment to equity and collaboration. Aligned with global goals like SDG 3 (health), SDG 10 (equity), and SDG 17 (partnership), this initiative lays the foundation for long-term, patient- and family-led impact.



Our Bold Goals for 2030 are to:

- **Impact 500,000 lives annually** by equipping patient and family organizations with the tools to deliver vital support and resources
- **Strengthen 150 patient- and family-led organizations in 75 countries**, working together to drive change and elevate their voices across care, research, policy, and innovation
- **Support advocacy that breaks barriers**, reaching local, regional, and global platforms, ensuring childhood-onset heart conditions becomes a priority on the global health agenda

For more information please visit <https://global-arch.org/invisible-hearts-collective-action>.

“

Being part of Global ARCH is the best thing that could happen to our organization internationally.

- Child's Heart, Bulgaria

”

Advocating For Change

Global ARCH continues to raise the profile of childhood-onset heart conditions through targeted advocacy at global, regional, and national levels, ensuring that the voices of patients and families are heard where decisions are made.

Global Collective Advocacy

At the World Health Assembly in Geneva, we co-hosted the side event “Congenital Anomalies and Universal Health: Leaving No One Behind” with key partners.

This event was a pivotal moment. It confirmed plans to launch **Global Action for Congenital Conditions**, a new global coalition uniting partners across sectors to drive visibility, coordination, and investment in congenital conditions worldwide.

We also participated in the **WHO Symposium on Meaningful Engagement** to help shape more inclusive systems through patient and family voice.

“Congenital anomalies are missing from the agenda. This is important because there is increasing evidence that congenital anomalies are becoming a major contributor to childhood mortality. Without addressing this, targets set for reducing childhood mortality will likely be missed.”

- Bistra Zheleva,
Global ARCH Board Member



Regional Advocacy

Global ARCH joined health ministry leaders, funders, and advocates at the first **International Conference on the PEN-Plus Regional Strategy** in Tanzania, focused on expanding care for people with severe chronic conditions. While there, our team helped support the formation of a new Tanzanian patient and family group and identified a local leader to carry that work forward. This effort reflects our commitment to ensuring regional action is grounded in local leadership.



National Advocacy

In the United States, Global ARCH leaders met with members of Congress to advocate for the **Reauthorization of the Congenital Heart Futures Act**, which plays a critical role in advancing research, awareness, and early detection for congenital heart disease. This national advocacy effort is part of our broader mission to promote recognition and support at every level of health policy.



Global Coalition for Pediatric & Congenital Hearts

Using our collective voice to make a bigger impact!

Secretariat work supported by Global Alliance for Rheumatic & Congenital Hearts and Children's HeartLink

Global ARCH co-leads the Global Coalition for Pediatric and Congenital Hearts alongside Children's HeartLink, serving on the Steering Committee and leading efforts to ensure that patient and family voices are meaningfully included throughout the coalition's work.

The coalition is advocating for a World Health Assembly resolution to formally recognize childhood-onset heart conditions as a global public health priority. This initiative builds on the urgent call to action from the 8th World Congress of Pediatric Cardiology and Cardiac Surgery in 2023 and brings together patient advocates, clinicians, policymakers, and partners worldwide.

As part of this effort, the coalition hosted the webinar "Calling Governments to Action on Childhood-Onset Heart Disease," which outlined specific steps governments and global stakeholders must take. Speakers included members of the Global ARCH Medical Advisory Council and leaders from our member organizations in Kenya, Namibia, and Pakistan.

Global ARCH remains a driving force in this coalition, ensuring that lived experience shapes not only the conversation but the global response.

OUR 4 KEY ACTIONS

GREATER ABILITY
TO CARE FOR
PATIENTS

TRAIN & HIRE ENOUGH
HEALTHCARE
PROVIDERS

FINANCE PEDIATRIC
& CONGENITAL
CARDIAC CARE

INVEST IN
RESEARCH

“

It was an incredible honor to share my personal story of living with CHD, coming from an undeveloped country that does not have these kinds of privileges, and to discuss why research matters with such a dedicated and accomplished group of survivors, parents, and clinicians who are on the front lines of CHD.

- Belen Blanton, Fundacion Estrellita de Belen

”

Building Our Sustainability

Global ARCH made key organizational investments to strengthen our ability to grow sustainably and deliver on our mission. These changes reflect a commitment to inclusive leadership, transparency, and long-term vision. With guidance from the Board and input from members, partners, and advisors, we completed a new **Strategic Plan** focused on five pillars: **Advocacy, Patient-Centered Collaboration, Alliance Empowerment, Governance, and Sustainability.**



To support this vision, we:

- Expanded and formalized councils to elevate patient and family leadership across our work
- Strengthened governance practices and clarified roles to prepare for future growth and leadership transitions
- Implemented new systems to better manage projects and volunteers
- Refined our member and partner model to reflect the evolving needs of our global network

These updates give us the structure we need to reach our 2030 goals while remaining nimble, inclusive, and mission-driven. Looking ahead, we remain focused on expanding programs, deepening partnerships, and building a strong, sustainable movement led by patients and families.



Honoring Our Founders



Global ARCH established a *Founders* designation to recognize the extraordinary contributions of five individuals whose vision and leadership gave rise to a global movement: **Amy Verstappen, Disty Pearson, Bistra Zheleva, Shelagh Ross**, and the late **Noemi de Stoutz**.

In 2017, these leaders organized and supported the first ***International Congenital Heart Leadership Summit***, bringing together 30 advocates and organizational leaders from 21 countries across six continents. It was the first time so many voices from congenital and rheumatic heart disease communities met face-to-face to share challenges, build partnerships, and define a shared vision for action. That gathering sparked the creation of Global ARCH.

The founders envisioned a world where every person born with a childhood-onset heart condition, no matter where they live, has access to the care and support they need to survive and thrive. That vision continues to guide our work today.

Board of Directors

Amy Verstappen - President
Disty Pearson - Vice-President
Shelagh Ross- Secretary
David La Fontaine - Treasurer
Belen Blanton Altuve
Flavia Kamalembo Batureine
Blanca del Valle
Anu Gomanju
Grace Jerald
Tendai Moyo
Lavinia Ndemutila Ndinangoye
Ruth Ngwaro
Amaya Saez
Bistra Zheleva

Emeritus Board Member:
Vikas Desai

Medical Advisory Board

Kathy Jenkins- Co-chair
Disty Pearson – Co-chair
Jack Colman
Sandra da Silva Mattos
Babar Hasan
Christopher Hugo-Hamman
R Krishna Kumar
Matt Oster
Alexis Palacios-Macedo
Fenny Fiindje Shidhika
Sivakumar Sivalingam
Dominique Vervoort
Liesl Zühlke

Our Donors

Global ARCH extends heartfelt thanks to the individuals, families, and partners who supported our work in 2024. Your generosity fuels our mission to improve lifelong care for those impacted by childhood-onset heart conditions around the world.

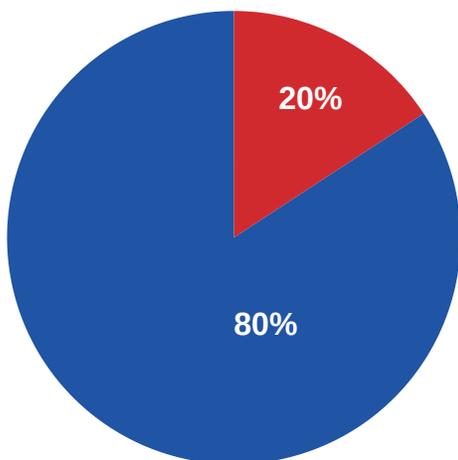
We are especially grateful to the many donors who give not only their financial support, but their time, energy, and belief in the power of community-led change.

Jackie Baillargeon	Green Street Monthly Meeting	Disty Pearson
Kira Barker	Joshua Gutoff	Shelagh Ross
Maryellen Barker Hays	Patti Harbman	Gail Rosseau, MD
Deepti Bhat	Maryellen Hays	Margaret Schafer
Belen Altuve Blanton	Susan Helliwell	Marie-Jeanne Schellen
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Dylan Goh	Nancy Owens	Bistra Zheleva
Pamela Gray	Kee Park	Liesl Zühlke
		Anonymous Donors

*Sponsorship

Our Financial Health

as of December 31, 2024 - USD



■ Program
■ Administrative

Assets \$77,693

Cash \$63,185
Accounts receivable
\$10,000
Other \$4,508

Liabilities \$2,130

Net Assets \$90,608

**Total Liabilities & Net Assets
\$77,693**

Revenue

Grants \$194,000
Contributions \$24,775

Total Revenue \$218,775

Total Expenditures \$233,821

Net Assets \$75,563



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