



2020 ANNUAL REPORT

MESSAGE FROM THE PRESIDENT

Dear Friends,



Thanks to the dedication and hard work of our board and volunteers, 2020 was a milestone year for Global ARCH. When Global ARCH's founding leaders gathered in 2017, their vision was to create a common voice for congenital and rheumatic heart groups around the world. Since our incorporation in 2018, we have steadily built our membership and expanded our activities. We have 30 member organizations, representing 25 countries, with one-half from

low- to middle-income countries. We entered 2020 poised to execute in-person regional meetings in Milan, Uganda, India, and the United States.

COVID-19 demanded that we immediately pivot our efforts to helping our alliance members meet the needs of those now struggling with the double burden of childhood-onset heart disease and a global pandemic. We created new educational resources, including a CHD and COVID fact sheet that, translated into 9 languages, was used by hospitals and patient/family organizations around the world. Our monthly Leader Forums brought together group leaders to share struggles and strategies. Multiple webinars were offered on topics ranging from the global impact of Covid 19 on RHD and CHD patients to fundraising during a pandemic. These activities expanded to cover a broad range of topics important to our community.

Perhaps Global ARCH's most important achievement was our February announcement of the first-ever Declaration of Rights of Individuals Affected by Childhood-onset Heart Disease. This document highlights the health rights promised to congenital and rheumatic heart survivors in existing global health rights statements, and clearly outlines the actions every government must take to ensure our right to health. One year later, this Declaration has been endorsed by 45 humanitarian, professional, and patient/family organizations around the world.

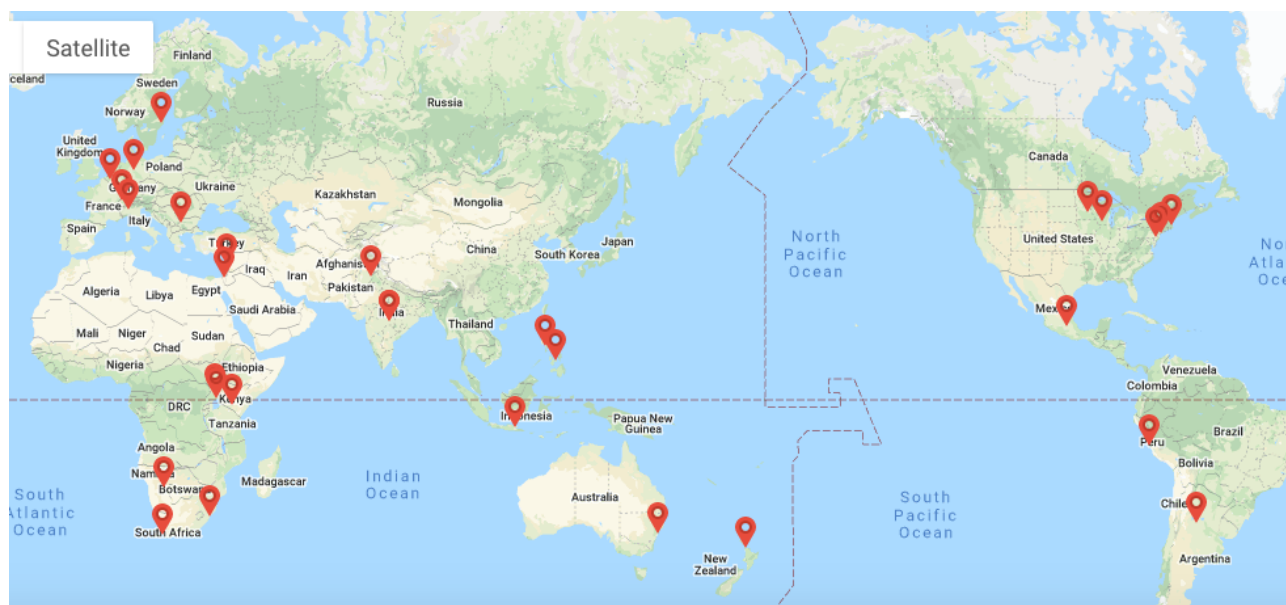
Finally, the granting of our long-awaited 501c3 charitable status meant that we could initiate our first official fundraising efforts, and we ended 2020 having raised our assets from under \$6,000 to over \$37,000. This sets the stage for Global ARCH to reach a key sustainability goal in 2021 – to begin the transition from an all-volunteer to a professionally run organization. This will allow us to partner with even more organizations around the world to educate, support, and advocate for those living with childhood-onset heart disease.

Thank you for helping us empower patient and family organizations around the world to help congenital and rheumatic heart patients thrive throughout their lives.

With gratitude,

A handwritten signature in blue ink that reads "Amy Verstappen". The signature is fluid and cursive, with the first name "Amy" and last name "Verstappen" clearly legible.

Amy Verstappen, Global ARCH President



What is Global ARCH?

Global ARCH is an alliance of congenital (CHD) and rheumatic heart (RHD) patient and family organizations from around the world. As of January 2021 we have **30 member organizations, representing 25 countries**, with one-half from low- to middle-income countries.

Our Mission

Our mission is to improve worldwide life-long outcomes in childhood-onset heart disease. We do this by empowering patient and family organizations from around the world to learn, collaborate, and speak out together about the unmet needs of those living with childhood-onset heart conditions.

What We Do

We connect and strengthen global CHD and RHD organizations through peer mentorship, leadership development, educational resources, and regional and global conferences.

We speak out for the rights of CHD and RHD patients through our Rights Campaign and by promoting and supporting patient and family-led advocacy.

We educate patients, professionals, and humanitarian organizations on the global needs of CHD and RHD patients and the issues that matter most to our communities.

We collaborate with professional and humanitarian organizations to advocate for better services for every person affected by childhood-onset heart disease.



RESPONDING TO COVID-19

In early March, the growing pandemic demanded that Global ARCH rapidly and radically shift focus. Four in-person regional conferences were cancelled and planning for future in-person events was put on hold as we responded to the extraordinary challenges facing the congenital and rheumatic heart community.

Global ARCH member organizations expressed their need for accurate, easy to read and understand information on COVID 19 written in a variety of languages. Working in partnership with **Children's HeartLink** and **Amrita Medical Center**, by April we released a **CHD and COVID 19 Fact Sheet in 9 different languages** (English, French, Arabic, German, Hindi, Malay, Portuguese, Urdu, and Japanese), which has been used by patient/family organizations and medical providers around the world.

We also offered our members a regularly-updated list of reputable **COVID information sources**, and shared the information at our website and in our **WorldBeat newsletter**.

In response to the severe stresses our member groups were undergoing, we began online **Leader Forum** meetings for organizational leaders to share COVID 19-related challenges and to receive peer support. We also initiated our **Global ARCH LIVE webinar series**, which expanded beyond COVID topics to address a broad range of topics of importance to patient and family group leaders. Both these programs are described more fully below.

Global ARCH will continue to respond to our members' need for information and support as the pandemic continues. In early 2021, we will be releasing three COVID resources: an **updated CHD & COVID Fact Sheet**, an **RHD & COVID Fact Sheet**, and a **combined Fact Sheet** offering information on both conditions.

COVID-19 AND CONGENITAL HEART DEFECTS

What is COVID-19?

COVID-19 is a new illness caused by a coronavirus. We are just starting to learn how COVID-19 will impact people. Your local health experts will have the most up-to-date information on how COVID-19 may affect you.

What are the symptoms of COVID-19?

Common signs are a fever, dry cough, tiredness and body pain. Some people also have a wet cough, chest pain or difficulty breathing. A small number of people have diarrhea, vomiting, or dizziness. However, many adults and children with COVID-19 do not have any symptoms. **You can pass COVID-19 to others even if you have no symptoms.**

How dangerous is COVID-19?

Most children get mild symptoms. Many get better in a few days. Very few children with COVID-19 have died. But this does not mean children are completely safe. COVID-19 is also a mild illness for most adults. But about one in five adults who get it need to go to the hospital. Most adults of all ages recover. Your chance of being hospitalized or dying goes up with age and other illnesses. This information may change as we learn more.

Are there special risks for children and adults with heart defects?

We do not know how this virus will affect children and adults with heart defects. Most heart centers have not yet seen any CHD patients with COVID-19. People with other kinds of heart problems are at higher risk. Many people with heart problems already have heart or lung weakness. This weakness may make it more dangerous to get the virus. We do not expect all people with heart defects to be at high risk.

COVID-19 と先天性心疾患

COVID-19 とは何ですか？

COVID-19 はコロナウイルス によって起こる新しい病気です。COVID-19 が人類に与える影響はまだ調査され始めたばかりです。COVID-19 があなたにどんな影響を与えるかは、地域の医療者が最新情報を持っています。

COVID-19 による症状は？

一般的な症状は熱、乾いた咳、疲労感、身体の痛みです。湿った咳や、胸の痛み、息苦しさが症状として現れる人もいます。少数ですが、下痢や嘔吐、めまいを訴える人もいます。しかし、COVID-19 にかかった大人や子どもの多くには症状がありません。症状がなくても、あなたが他の人に COVID-19 をうつしてしまうことがあるのです。

COVID-19 はどのくらい危険なの？

ほとんどの子どもには軽度の症状がありますが、多くは数日でよくなります。COVID-19 によって亡くなった子どもはほとんどいませんが、子どもが完全に安全というわけではありません。ほとんどの大人にとっても COVID-19 は軽い病気ですが、5人に1人は病院に行く必要があります。全ての年代の大人のほとんどが回復します。入院したり、亡くなった可能性は年齢や他の病気の有無によって異なります。どんな人が入院や死亡のリスクがあるかは今後の調査によって変わる可能性があります。

***"Global ARCH gives us a voice that can be heard by people around the world."
- Flavia Baturine, Uganda Heart Institute***

EMPOWERING OUR MEMBERS

This year Global ARCH launched **Global ARCH LIVE**, a monthly webinar series designed to offer CHD and RHD leaders the tools they need to strengthen their organizations. Interactive presentations were offered on topics such as **leveraging social media**, **accessing free/low-cost technology**, and **fundraising in the context of the pandemic**. We educated our groups on the essential health rights for those with childhood-onset heart disease, and successful advocacy strategies for expanding these rights. **Dr. Edward Callus** led a session on managing pandemic-related stress, and **Dr. Liesl Zuhlke** offered a global perspective on RHD, CHD, and COVID-19. All of our webinars were recorded and can be accessed at our website.

"It is heartwarming to be part of a CHD community and platform that can help spread awareness and give us a voice to share our mission. Thank you again for your support!"
- Shaila Afzal Abou Khali, Brave Heart Lebanon

Congenital heart disease transition of care tip sheet

Congenital heart disease (CHD) is any defects in the heart valves, great vessels, heart walls or chambers of the heart that are present at birth.

Do you know...

 CHD is the most common birth defect among newborns!

 Many people with CHD require lifelong expert medical care, and struggle with daily physical and mental health challenges.¹

 There are now more adults with CHD than children, thanks to medical and surgical advancements.²

Making the transition to adult congenital heart disease care

Transition is a process that begins in the early teenager years and continues through early adulthood. The transfer from a pediatric care provider to an adult congenital cardiologist will likely happen at around age 18. As part of the transition, you will learn to be more responsible for your own health and health decisions.

Where will I be transferred to?

Degree	Examples	Who should you see about your heart?
Simple	• Mild pulmonary stenosis • Repaired ventricular or atrial septal defect	Even simple CHD can have complications. The adult cardiologist will decide who should be following your care. They might refer you to a general cardiologist or community cardiologist who are doctors who work outside of hospitals.
Moderate	• Coarctation of the aorta • Bicuspid aortic valve • Milder forms of tetralogy of Fallot	You must be seen by an adult CHD specialist at one of the 15 adult CHD centres.
Complex	• Any of the single ventricular disorders • Transposition of the great arteries with a Mustard type of repair • Any type of congenital heart disease that causes cyanosis (blue lips or fingertips because not enough oxygen getting to the body's tissues) • Complex tetralogy of Fallot	

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We also initiated the **Global ARCH Leaders Forum** as a way to help group leaders connect in a more informal context. These meetings, held monthly on Zoom, offer an open forum for group leaders to discuss topics of interest and identify areas of collaboration. They are also a venue to provide mentoring and advice to emerging leaders and organizations, and the small group size allows attendees to share challenges and offer peer support. Over 30 leaders have participated, representing every continent.

Finally, Global ARCH partnered with **5 Canadian organizations** to develop **Covid-19 and CHD**, and **CHD Transition Tips** infographics.

SHARING OUR PERSPECTIVE

In 2020 Global ARCH ensured the inclusion of patient and family perspectives in a number of important venues. We worked with Cincinnati Children's Hospital to organize the first session on **ACHA in Lower Resource Settings** at the **30th International Symposium on Adult Congenital Heart Disease**, which featured presentations from Amy Verstappen and Disty Pearson, as well as Medical Advisory Board members Kathy Jenkins and Babar Hasan. Global ARCH's board member Bistra Zheleva moderated a session on **Tackling Cardiovascular Diseases in the Young**, hosted by the Core Group, at which Board member Ruth Ngwaro spoke about her experiences as a CHD patient in a low- and middle-income country. As well, Global ARCH president Amy Verstappen was invited to a **Pakistan Children's Heart Foundation** webinar to present **An anecdotal review of CHD advocacy, Global ARCH, and addressing life-long outcomes**. We continued to serve on the steering committee of the **International Consortium of Health Outcomes Metrics (ICHOM)**, as they defined **clinical outcomes most important to patients and families**, which were released in April, 2020. We also were invited to represent the patient and family perspective on the writing committee of the first-ever International Transition Guidelines in Congenital Heart Disease, to be published soon.

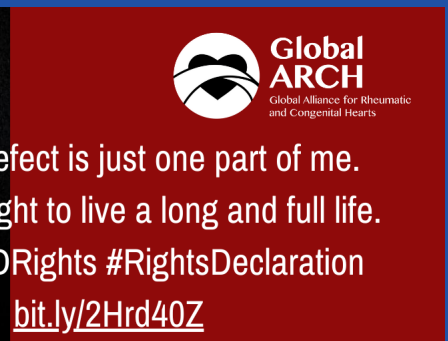
ADVOCATING FOR CHANGE

In May, we launched the first-ever **Declaration of CHD/RHD Patient Rights** ever written. We believe that every person affected by childhood-onset heart disease has the right to receive all needed services to reach their full potential. It states:

Every person with childhood-onset heart disease should receive the health care they need that is timely, affordable, accessible, safe, patient-centered, and life-long.
and

Every person with childhood-onset heart disease should live free of discrimination and have full access to the education, employment, and social benefits and services necessary to ensure their life-long well-being and full participation.

We are asking our members and the CHD/RHD community to please sign our **Declaration**, and as of February 2021 we have received **45 endorsements from professional patient and family groups** and many more from individuals. Our Declaration is accompanied by an **Advocacy Toolkit** as well as **webinars** to help organizations use it in their countries.



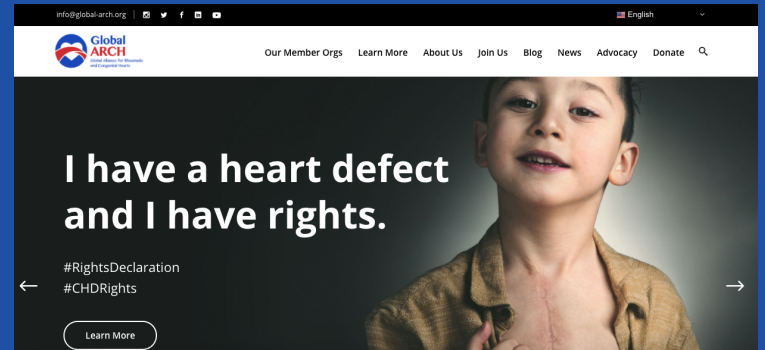
"With Global ARCH, PCHF feels a reinforced drive, dedication and support for achieving its goals for the CHD community in Pakistan. Through Global-ARCH, we feel connected to the global CHD community, which helps spur our passion to face challenges together."

- Farhan Ahmad, CEO Pakistan, Children's Heart Foundation

Our awareness campaigns have generated significant impact, reaching a wide audience via Twitter, Facebook, Instagram, and LinkedIn. We will continue to build these channels and relationships with other organizations. To support the Declaration for both World Heart Day and CHD Awareness Week we collected photos from our member organizations to support the Declaration, and shared on social media and our website. Messages included "I have the right to affordable care for my heart condition", "Every heart deserves a long and full life. CHD/RHD rights now!", and "I have a heart defect and I have the right to live"

BUILDING OUR SUSTAINABILITY

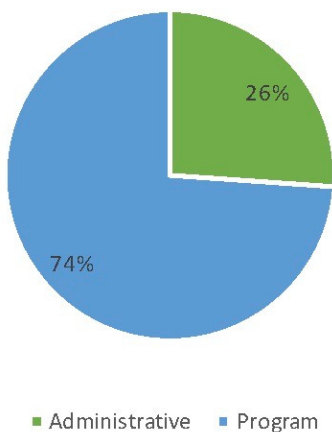
2020 saw Global ARCH take essential steps towards long-term growth and sustainability. Eighteen months after submission our application for **501c3 charitable status** was finally approved, and by year's end we had **raised over \$30,000 in individual donations**. We invested in better technology and a **major website re-design** that will go live in early 2021. It will include a global member directory, and text translation feature that will make it more accessible for our global members. We ended the year having raised our total assets from **under \$6,000 to over \$35,000**. This will allow to begin the transition from an all-volunteer to a professionally run organization that can execute our ambitious plans for 2021.



OUR FINANCIAL HEALTH

as of December 31, 2020

Global ARCH 2020 Spending



Assets

Cash	\$25,166
Donations receivable	\$12,015

Total Assets \$37,181

Liabilities

Accounts payable	\$1,809
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Total Liabilities \$1,809

Equity

Founding Donations	\$5,657
Net Revenue	\$29,714

Total Equity \$35,371

Total Liability & Equity \$35,371

Statement of Activities as of December 31, 2020

Revenue

Individual Donations	\$35,660
Total Revenue	\$35,660

Expenses

Administrative Expenses

Bank Fees	\$45
Professional Fees	\$1,541
Total Administrative	\$1,586

Program Expenses

Software	\$271
Web Service Fees	\$1,258
Website Costs	\$2,831
Total Program	\$4,360

Total Expenses \$5,946

Net Revenue \$29,714

"Action for Disadvantaged People now knows how to approach our government and demand for support to save lives of children with CHD.

This is all from Advocacy presentations organized by Global ARCH."

- George Ntambi, Director, ACDIPE, Uganda

THANK YOU!

Our Donors

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Margaret Sovek
Amy Verstappen
Lena Verstappen
Dominique Vervoort
Martha Wolf
Bistra Zheleva

Global ARCH would like to thank the many individuals and organizations who donated time and effort to help us reach our goals, including:

Action for Disadvantage People, Amrita Institute for Medical Science, Braveheart Support Society, Brave Heart Lebanon, Brave Little Hearts Namibia, Brave Little Hearts South Africa, Canadian Congenital Heart Alliance, Children's HeartLink, Children's Heart Federation, Cincinnati Children's Hospital, Let it Echo, Fondation En Coeur, Green Street Friends Meeting, HEART University, Heart Warrior, Heart & Stroke Foundation, IHeartChange, International Quality Improvement Collaborative for Congenital Heart Disease, Kardias, Kenya Mended Hearts Patients Association, Namibian Correctional Service, Pakistan Children's Heart Foundation, REACH

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"It's been privilege to be part of the formation of Global ARCH. What I've learned about how to navigate awareness and activism is phenomenal. Thank you Global ARCH, you sure do make difference in the world!"

- Monique Kemp, Heart of Hope, South Africa