
2021 ANNUAL REPORT



**Global
ARCH**

Global Alliance for Rheumatic
and Congenital Hearts

MESSAGE FROM THE PRESIDENT



Despite the on-going pandemic, 2021 brought many new opportunities for Global ARCH to improve the health and well-being of individuals living with childhood-onset heart disease. In response to the global rollout of vaccines, we provided accurate, timely, and accessible educational materials to our alliance members. We worked hard to

combat widespread misinformation regarding vaccine safety for children and adults with childhood-onset heart disease. We continued to disseminate information on opportunities for alliance members to participate in research, policy initiatives, guideline development, and other areas where patient and family voices are essential. Perhaps most importantly, our monthly Leaders' Forum offered an essential tool for organizational leaders to get the support they needed to get through this challenging global crisis.

Throughout 2021, Global ARCH was invited to partner with professional organizations to ensure that patient-centered perspectives were included in a variety of projects. For example, we participated in the development and publication of the first-ever ACHD transition guidelines, to explicitly address the unique needs of patients in low resource settings. Our board members presented at professional conferences in person and via Zoom, held by organizations such as the European Society of Cardiology, the American College of Cardiology, and Aga Khan University. We assisted emerging leaders as they developed the first patient and family organizations in Pakistan, Malaysia, and India. Endorsements of the Declaration of Rights for Childhood-onset Heart Disease continued to grow, and our alliance membership grew from 39 to 46 patient and family member organizations.

All of this growth could not have happened without you, our supporters and volunteers, who are both the engine and inspiration for everything we do. Thank you so much for your investment of time, energy, and faith in our organization. We look forward to all we can achieve in 2022 and beyond.

Sincerely,
Amy Verstappen



What is Global ARCH

Global ARCH is an alliance of congenital (CHD) and rheumatic heart (RHD) patient and family organizations from around the world. We have over 40 member organizations, representing 30 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.



EMPOWERING OUR MEMBERS

Connecting and **strengthening** our member organizations is one of our main goals. To this end, we were delighted to host three **Global ARCH LIVE** webinars: the first, **CHD and RHD: Planning for Long-term Health**, was led by Global ARCH president **Amy Verstappen**, and addressed important questions like, *Will my child have a normal life?* and *Can I have a baby?* She presented key resources, information, and published guidelines to help community members plan for long-term health. **Dr. Dominique Vervoort**, John's Hopkins Bloomberg School of Public Health, presented on **How to Use Global Burden of Disease Study Data to Empower Your Advocacy**. He demonstrated how to access and use this data to strengthen Global ARCH member awareness and advocacy efforts. Finally, **Bistra Zheleva**, VP of Global Strategy and Advocacy at Children's HeartLink, and Ruth Ngwaro, co-founder of Kenya Mended Hearts Patients Association, spoke on **Advocacy in Action: Advocating for Childhood-onset Heart Diseases at the National Level**. Topics included *Mended Hearts Kenya* success in getting the government to pay for CHD surgery, and Children's HeartLink's role in the expansion of screening and surgery in Kerala, India.



GLOBAL ARCH LEADERS' FORUM

On the first Friday of each month, Global ARCH hosts the Leaders' Forum, a much-anticipated event where member organization leaders gather online to share information and resources, and provide support for each other's activities. The beginning of the year centred on

the COVID vaccines situation in various parts of the world, and we then focussed on some of our new members, including Belen Blanton and her Venezuelan organization **Fundacion Estrellita de Belen**, Tendai Moyo, founder of **Brave Little Hearts Zimbabwe**, Amaya from **Menudos Corazones** in Spain, Grace Jerald and her mom Theresa, founders of **CHD Malaysia**, and in December, Lucianna Moreno Perez, who runs **Amigos de Corazon** in Peru. All are doing incredible work in their communities advocating and supporting patients and families with CHD and RHD.

Resources

We have collected a wide variety of resources for our website, including a comprehensive **Advocacy Toolkit**; **COVID-19 handouts for CHD and RHD patients**, available in 11 languages; general **COVID-19 information**; **Facts about CHD and RHD**; **social media tools**, including a CHD transition of care tip sheet, and **What you/your child should know about CHD** handout and video (English and French).

COVID-19: Information for Congenital & Rheumatic Heart Disease Patients

What is COVID-19?
COVID-19 is a new illness caused by a virus. People around the world have been affected. Each area has been affected differently by Covid-19. **Your local health experts have the most up-to-date information on COVID-19 in your area.**

What are the symptoms of COVID-19?
Common signs are fever, cough, tiredness, body pain, problems breathing, and loss of taste or smell. Many people with COVID-19 do not have symptoms. **You can pass COVID-19 to others even if you have no symptoms.**

What can I do to protect myself and others from COVID-19?
If COVID-19 is common in your area stay home as much as you can. Frequently wash your hands with soap. Keep at least two meters (6 feet) from other people. Wear a mask over your nose and mouth when you are in public.

Is COVID-19 more dangerous for people with congenital or rheumatic heart disease (CHD or RHD)?
If you have CHD or RHD you may be at higher risk than people with healthy hearts. You may have heart problems that make you more likely to get very sick or die from COVID-19. These include:

- Heart valve problems
- Heart rhythm problems
- Problems with heart strength or heart failure
- Having a heart attack
- Previous stroke
- Having low oxygen or being "blue"
- Having one heart ventricle or Fontan
- Having a heart transplant

You may have other health problems that raise your risk. These include:

- High lung pressure or pulmonary hypertension
- Diabetes
- High blood pressure
- Kidney problems
- Being very overweight or obese
- Smoking
- Down Syndrome or DiGeorge Syndrome
- Pregnancy
- Age over 60

What you should know about your Congenital Heart Disease:

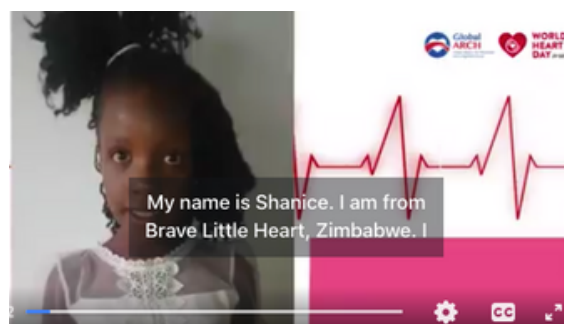
- Know the name of your heart defect
- Know your medication(s)
- Know your CHD medical history
- Know how to contact your CHD team

→ Carry your medical info with you: on a wallet card, on your phone, or wear a medical ID

Brought to you by the partnership of:

Global ARCH, en cœur, Heart & Stroke, I♥CHANGE

BUILDING AWARENESS



September 29 is **World Heart Day**, and Global ARCH celebrated by creating tributes to our heart heroes around the world. Our member organizations and board members came out in force to record and share heartfelt songs, poetry and tributes, which were posted on our social media channels.

“ Being part of Global ARCH is a great opportunity to consolidate our support for people with CHD, enhance networking with organizations around the world, promote our advocacy, and strengthen our mission. Thank you very much!

-Amaya Sáez, CEO,
Fundación Menudos Corazones





February 7-14 is recognized in parts of the world as **CHD Awareness Week**, and we focussed our activities on promoting our **Declaration of Rights**. We used Twitter, Facebook, and Instagram to share photos and videos to promote our *"I have a heart defect and have the right to live"* campaign. We also partnered with several Canadian heart organizations to create a video and resources to help patients and their families better understand CHD and how to stay as healthy as possible.

Congratulations to member organization **Brave Little Hearts Zimbabwe (BLHZ)** for officially establishing a cardiac ward at Mpilo Central Hospital in Bulawayo, as part of the commemorations for World Heart Day. The new unit was established to improve access to specialist services and corrective care to children with heart conditions.



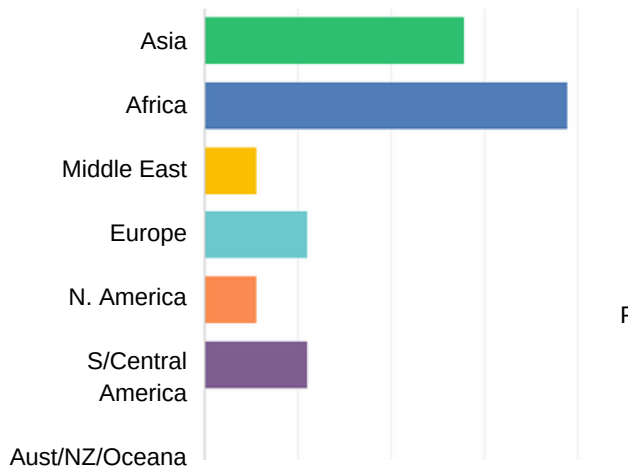
“Coming from a LMIC, Global ARCH was the missing link, the driving force that kept me going. I joined for the support, guidance, and resources to help me achieve my vision, and although we still struggle financially, we are in a much better mindset. We know that our goals are achievable through the testimony from other Global ARCH leaders.
-Tendai Moyo, Brave Little Hearts Zimbabwe

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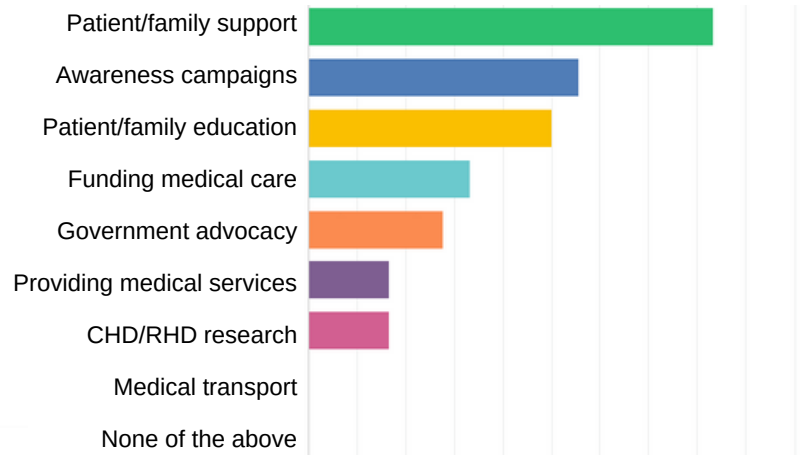
SURVEYING OUR MEMBERS

In the spring we launched a member survey, with the goal of learning how we can best serve our members going forward. Here are some more of the results.

Area served



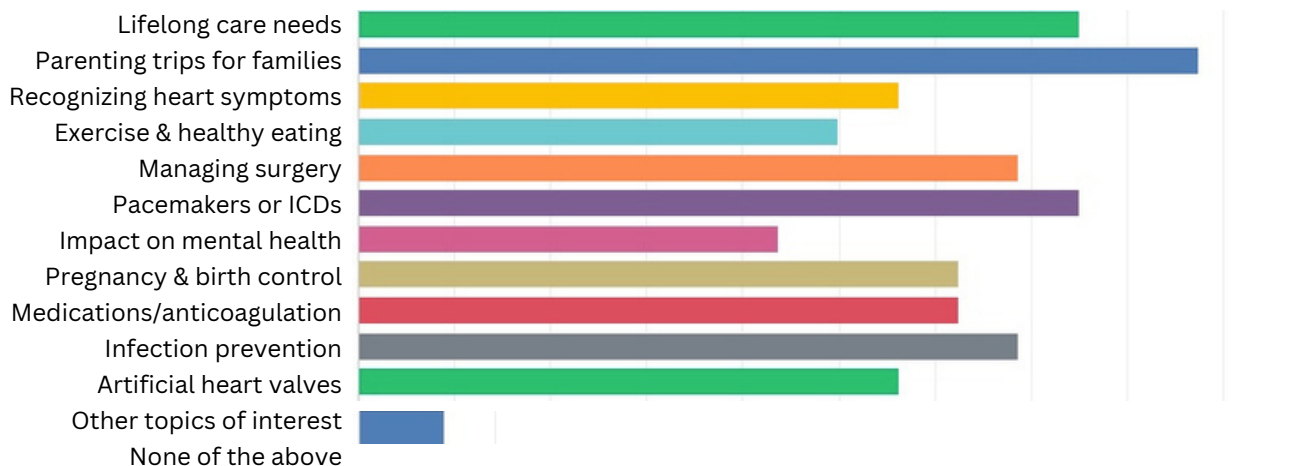
Current group activities



Participation in Global ARCH activities



Indicate which patient and family topics are of most interest to your organization



SHARING OUR PERSPECTIVE

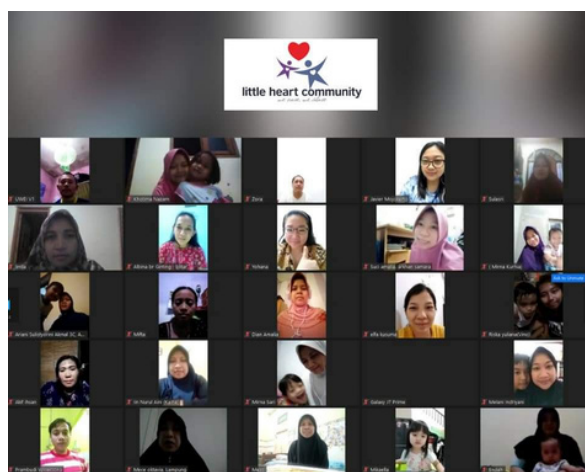
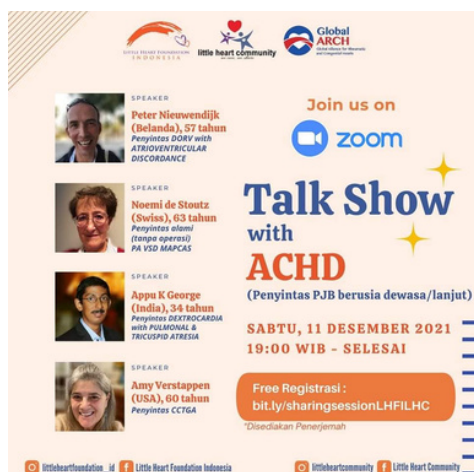
Our membership and board were busy this year, as ever, and these are just a few of the presentations given. **Disty Pearson** co-chaired, along with Dr. Liesl Zuhlke, a session at the **American College of Cardiology** on *Global health: Working together to improve pediatric and congenital heart disease care around the world*. Speakers included Dr. Anita Saxena, Dr. Masood Sadiq, Dr. Laila Ladak, Dr. Shabnam Peyvandi, and Dr. KK Kumar.

Shelagh Ross presented at the **Toronto International Adult CHD Symposium** on *The ACHD Voice: Building a Stronger Healthier Community*. Her focus was on raising awareness of adult CHD, and creating education among healthcare providers about CHD and the lifelong needs of patients. She also co-founded **#FindACHD**, a collaborative group to improve lifelong care for adults with CHD.



Amy Verstappen participated in a **Pakistan Children's Heart Foundation (PCHF)** webinar, *An anecdotal review of CHD advocacy, Global ARCH and addressing lifelong outcomes*, which was part of the PCHF's CHD awareness and advocacy webinar series. **Bistra Zheleva** also participated, speaking on *Supporting the development of pediatric cardiac programs in low resource settings: NGO perspective*.

Heru Kustiawan, founder of **Indonesia's Little Heart Community**, hosted **Talk Show with CHD**, featuring **Amy Verstappen**, **Noemi de Stoutz**, as well as Global ARCH members **Apu K George** from India and **Peter Nieuwendijk** from Amsterdam. Another webinar, on the **Psychosocial impact of COVID-19 pandemic on CHD patients and families**, featured **Amy Verstappen** and clinical psychologist **Edward Callus**.



Grace Jerald, board member, founded **CHD Malaysia** as a CHD family and patient support group, and got to work promoting the organization with articles in a Malaysian national newspaper and an Indian magazine, social media posts, and moderated two webinars: ***Life after CHD – what to expect***, and ***Managing life with pacemakers and other implantable devices***.

WORLD HEART DAY 2021
+ Life After Congenital Heart Surgery: What To Expect?

NORLIZA ALI
 Paediatric Cardiologists
 Hospital Serdang

LEONG MING CHERN
 Paediatric Cardiologists
 National Heart Institute (IJN)

GRACE JERALD
 Moderator
 Malaysian Congenital Heart Foundation

WEDNESDAY, 29th SEPT 2021
6PM - 7.15PM
Zoom Link: 837 3450 9150
 Hosted By: Children's HeartLink, Global ARCH, Malaysian Paediatric Cardiac Society

Managing life with pacemakers and other implantable devices
Live Webinar
 scan to register:

SPEAKERS:

Moderator:
Grace Jerald
 Malaysian Congenital Heart Foundation (MCHF)

Dr. Hasri Samion
 Chief Clinical Officer
 Senior Consultant
 Paediatric Cardiologist,
 National Heart Institute (IJN)

Dr. Marhisham Che Mood
 Senior Consultant
 Paediatric Cardiologist,
 National Heart Institute (IJN)

Sunday, 14 November 2021 5 PM
876 0062 7625 (Zoom ID)
 Hosted By: Children's HeartLink, Global ARCH, Malaysian Paediatric Cardiac Society

Noemi de Stoutz, patient and Global ARCH board member and co-founder, was featured in the **European Society of Cardiology World Heart Day** awareness campaign on ***Heart and Women***, which was used on the Welcome slide show of the ESC Congress. She also wrote about Global ARCH for **Cuore Matto**, the Swiss ACHD organization.

Your patient's story can change the lives of millions

"There are hundreds of thousands of young women out there with congenital heart disease. The only gene services at these hospitals require support from specialized cardiologists and geneticists working closely together. Unfortunately, that kind of care is accessible only in a few centres in some high-income countries. Everywhere, women and their babies will go on living in pregnancy or childbirth."

NOEMI DE STOUTZ

"113 million is not a statistic. That's 113 million individual lives and stories."

KARENA DUNHAM

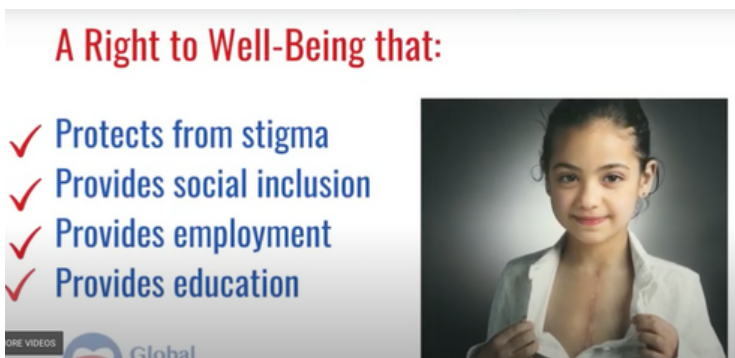


Global ARCH expresses profound sadness for the death of **Fareed Matthews**, an incredible and much-loved colleague, Global ARCH co-founder, and founder of Brave Little Hearts Africa. His wisdom, friendship, and commitment to congenital heart disease advocacy will always be remembered.

ADVOCATING FOR CHANGE

Declaration

A main focus of Global ARCH is our **Declaration of Rights** campaign, with the aim to collect enough signatures to present to the **World Health Organization** so that CHD and RHD can be recognized as significant health problems with a global impact. To add your voice to our campaign, you can visit www.global-arch.org/advocacy.



“Joining Global ARCH has been a great experience; not only am I advocating for CHD, I am learning so much, and I have realized that CHD is worldwide and there is a big information gap. I'm so proud to represent Venezuela - my country - and our organization, to keep fighting for CHD patients. Thank you Global ARCH for the opportunity.

-Belen Altuve Blanton, Fundacion Estrellita de Belen Corp

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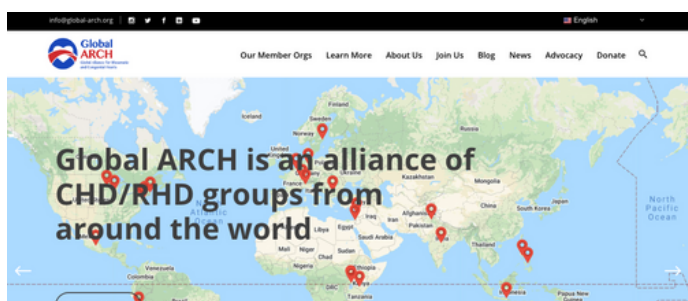
Building Our Sustainability

New website

We created a new **look**, as well as **new features**, to make our website more **versatile** and **functional** for our global audience. Now all pages can be **translated into a wide variety of languages** using the translate tool at the top of the page (on a computer) or at the footer (using a mobile device).

We also added a **blog**, and posted some initial articles, including ***Stigma: choosing words wisely can make life easier***, by Mehwish Mukhtar, and ***You're never too old to need your mother: my CHD journey***, by Shelagh Ross.

To help us keep track of our membership and donations we invested in **Little Green Light**, a software program, which has simplified some aspects of our administration.



About Us

Our Mission

The mission of the Global Alliance for Rheumatic and Congenital Hearts (Global ARCH) is to improve worldwide life-long outcomes in childhood-onset heart disease through empowering patient and family organizations. Membership is free and open to any group that serves congenital and/or rheumatic heart patients and their families. Our alliance brings together organizations from around the world to learn, collaborate, and speak out together about the unmet needs of those living with childhood-onset heart conditions.



“ I joined Global ARCH because I believe that great things can be done with a worldwide community, especially in order to connect, as in Peru we have so much to develop. As a mother of a CHD child and an advocate for a Peruvian support group, I hope that we can share best practices and keep learning together.

-Lucianna Moreno, Asociación Amigos de Corazón

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Global ARCH co-authored and endorsed an important **consensus paper**, published in the **European Society of Cardiology's European Heart Journal**. The article describes issues and practices of transition and transfer of adolescents with CHD. Global ARCH played an important role in recruiting groups and soliciting regular feedback from centres in high-, middle-, and low-income countries.

Global ARCH Members



| | |
|-----------------------------------------------------------------------------------|----------------------------------------------------------|
| Adult Congenital Heart Association | Herznetz.Ch |
| Adultos con cardiopatías congénitas de Argentina | Hjärtebarnsfonden |
| Action for Disadvantaged People | International Society for Adult Congenital Heart Disease |
| AICCA Onlus | Jemah Ev |
| Amar El Club De Los Corazones Peculiares | JK HOPE & HEALTH FOUNDATION |
| Amigos de Corazón | Justice For Heart Warriors |
| Brave Heart | Kardias AC |
| Brave Little Hearts Namibia | Kehilat HaLev (The Heart Community) |
| Brave Little Hearts South Africa | Kenya Mended Hearts Patient Association |
| Brave Little Hearts Zimbabwe | Let it Echo |
| Bundesverband Jemah E.V. | Little Heart Community |
| Camp Odayin | Mending Tiny Hearts |
| CHD Malaysia | Pakistan Children's Heart Foundation |
| Child Heart Care Project under National Institute for Woman and Child Development | Pan African Network of Pediatric and Congenital Hearts |
| Children's Heart Association | PANHELLENIC CONGENITAL HEART DISEASE ASSOCIATION |
| Children's HeartLink | RHD support Group, Uganda Heart Institute |
| Children's Heart Federation | Surgeons of Hope |
| Congenital Heart Disease India | Sydänlapset Ja -Aikuiset Ry - Finnish Association |
| Connecting Hearts to End Heartbreak (CHEER Hearts) | Team Heart Inc |
| Conquering CHD | The Mended Hearts, Inc. |
| Cuore Matto | The Children's Cardiac Foundation of Africa |
| Cure Kids Fiji | Voice of a Heart/Ijwi ry'Umutima |
| European Congenital Heart Disease Organization | William Novick Global Cardiac Alliance |
| Finnish Association for Heart Children and Adults | |
| Fundacion Estrellita de Belen Corp | |
| Fundación Menudos Corazones | |
| Global Cardiac Surgery | |
| God-Reign Gospel Productions | |
| Heart and Stroke Foundation | |
| Heart Kids Ltd. | |
| Heart Kids New Zealand | |
| Heart Kids South Africa | |
| Heart Warriors of the Philippines Inc. | |
| Hearts Unite the Globe | |

Global ARCH would like to thank the many individual and organizations who donated time and effort to help us reach out goals. We couldn't have done it without you!

Our Financial Health

as of December 31, 2021



 Administrative Expenses
 Program Expenses

Assets

Cash \$51,842

Donations receivable \$8,100

Total Assets \$59,942

Liabilities \$0

Equity

Retained earnings \$35,793

Net revenue \$31,149

Total Liabilities & Equity \$66,942

Revenue

Grants \$5,000

Board support \$28,350

Individual contributions \$3,339

Total Revenue \$36,689

Total Administrative \$286

Total Program \$5,254

Total Expenditures \$5450

Net Revenue \$31,149

Our Donors

Sarah Braun
Children's HeartLink
Noemi de Stoutz
Susan Gebelein
Valerie Gold
Green Street Monthly Meeting
Mira Gutoff
David La Fontaine
Ruth Ngwaro

Amy and Kevin Olson
Disty Pearson
Shelagh Ross
Dina Scalone
Margaret Sovec
The Nararo Foundation
Graham Turner
Amy Verstappen

Board of Directors

Amy Verstappen - President
Disty Pearson - Vice-President
Shelagh Ross - Secretary
David La Fontaine - Treasurer
Farhan Ahmad
Flavia Kamalembo Baturine
Vikas Desai
Noemi de Stoutz
Grace Jerald
Mehwish Mukhtar
Lavinia Ndemutila Ndinangoye
Ruth Ngwaro
Dominique Vervoort
Bistra Zheleva

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RK Kumar, MD
Sivakumar Sivalingam, MD
Liesl Zühlke, MBChB, DCH, FCPaeds, Cert Card, MPH, FESC, FACC, PhD

