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Ninety percent of world's heart kids die preventable deaths

New non-profit alliance creating a stronger voice on behalf of patients and families

Philadelphia, PA – July 2018 – Worldwide each year about 1.3 million children are born with congenital heart disease (CHD), heart disease due to an abnormality in the structure of their heart. One in four will die without immediate intervention and many more will need childhood surgery to reach age 18. But 90% of the world's children have no access to cardiac care; these children will die preventable deaths.

In many disadvantaged communities, untreated infections also can cause rheumatic heart disease (RHD), the most common children's heart problem in many low-income countries. Worldwide there are an estimated 33 million people living with RHD.

The Global Alliance of Rheumatic and Congenital Hearts (Global ARCH), an alliance of organizations and individuals, is speaking out to ensure that all patients have access to the care they need to live long, healthy lives. "We are thrilled to be in the position to represent patients in countries where the pediatric cardiac needs are so great and so under-recognized. As an alliance we will be partnering with professional and humanitarian organizations from around the world to promote global awareness of both CHD and RHD, and to advocate for better services for every person affected by childhood-onset heart disease", says Global ARCH Chair Amy Verstappen.

Member organizations share ideas and resources through the Global ARCH website and action alerts, member discussion forums, training sessions, educational webinars, and the Global ARCH Leadership Summit

About Global ARCH

Global ARCH began with a visionary group of CHD and RHD leaders, each directly affected by childhood-onset heart disease. They shared a vision of transforming global CHD and RHD outcomes through empowering patient and family-led organizations.

In 2017, they convened the first International Congenital Heart Leadership Summit which brought together 30 CHD and RHD leaders representing 21 countries on six continents. Global ARCH was formed after participants unanimously agreed to create a stronger voice on behalf of CHD and RHD patients and families.

Global ARCH was incorporated in the United States in February of 2018, at which time it had 18 founding member organizations. Collectively these organizations raised over \$18 million, facilitating 6,000 surgeries, and serving over 30,000 patients and families between 2015 and 2017.

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