

The Invisible Child

Take Action Today to Change the Future

The Case for a World Health Assembly Resolution on
Pediatric and Congenital Heart Diseases

**10 YEARS LATER
THE WORK
CONTINUES**





Ten Years Later: Assessing Progress and the Need for Stronger Global Heart Care Policies

Ten years ago, the first [Invisible Child Policy](#) paper was published, which laid out a roadmap for addressing the profound global disparities in access to pediatric and congenital heart care. Yet global progress has been minimal, with one-third of the world's countries reporting stagnant or worsening outcomes. Despite the growing impact of these diseases on infant mortality and the high life-long disease burden, there is no evidence that countries are creating the national policies and strategies essential to addressing this growing burden. We believe that the existing gross inequalities in the health status of people with pediatric and congenital heart disease, particularly LMICs, are politically, ethically, socially, and economically unacceptable and is, therefore, of common concern to all countries.

Advocacy is always more impactful when done together. The Global Coalition for Pediatric and Congenital Hearts, a coalition of patients and families, professionals and humanitarian organizations, was started in 2024 and is now launching a campaign advocating for a 2026 World Health Assembly Resolution on Pediatric and Congenital Heart Care to be adopted by the 194 Member States of the World Health Assembly (WHA), the highest multilateral health policy-setting body.

A [WHA Resolution on Pediatric and Congenital Heart Diseases](#) will aim to scale up and integrate pediatric and congenital heart care into health systems as part of Universal Health Coverage (UHC) and compel governments to put in place effective policy responses supported by adequate financial investments to address the growing needs of all with pediatric and congenital heart diseases.



**Global Coalition for
Pediatric & Congenital Hearts**

In 2024, Children's HeartLink and the Global Alliance for Rheumatic and Congenital Hearts (Global ARCH) invited everyone who signed the [Call to Action](#) to join a movement to assure pediatric and congenital cardiac patients have access to quality lifelong care by joining the newly formed Global Coalition for Pediatric and Congenital Hearts. The 140-member advocacy coalition aims to reduce global inequities in access to quality pediatric and congenital cardiac care by improving timely diagnosis, treatment and lifelong care through enhanced global and national policies and increased investments in services for pediatric and congenital heart diseases.

WHAT IS THE PROBLEM?

An estimated 8 million babies are born with a congenital anomaly each year, and an estimated 240,000 die worldwide in their first month of life, making birth defects a leading cause of both neonatal and post-neonatal child deaths.¹ Most newborns with a birth defect are born in low- and middle-income countries (LMICs) where diagnostic, treatment and management services are limited. Crucially, as child survival improves through better control of infectious childhood diseases, congenital anomalies account for an increasing proportion of under-5 deaths, up to 30% in low-mortality settings.

Congenital heart disease (CHD) is the most common congenital anomaly and a leading cause of mortality due to birth defects. CHD affects 1 in 100 newborns, with an estimated 1.35 million babies born each year with CHD worldwide². 1 in 4 will need surgery in the first year of life to survive, but most children do not have access to timely diagnosis or treatment. The disease burden is much higher in countries with higher birth rates, which also tend to have the lowest per capita income and highest levels of poverty, making CHD an overwhelming health and social challenge to address. In high-income countries, medical advances have increased childhood survival from 10% in 1950 to roughly 97% by 2017.^{3,4} Today, 70% of the deaths globally occur in infants, and 85% of those occur in low-and middle-income countries (LMICs). Up to 90% of those born with CHD in LMICs do not have access to necessary cardiac care and continue to suffer the high levels of death and disability that high-income countries overcame more than fifty years ago. CHD is quickly becoming a leading cause of mortality in neonates and children in LMICs, and for those who survive it is often a life-limiting condition without treatment. CHD does not discriminate. Sadly, survival is largely dependent on where one is born, and the available medical and surgical resources for treatment in that area.

This gap in cardiac care is not limited to CHD. Rheumatic heart disease (RHD), a preventable non-communicable disease, is endemic in many LMICs, and is considered the most common cause of acquired heart disease in children and young adults, affecting over 38 million individuals worldwide. It is estimated that in Africa it affects 1.5–3% of school-aged children. More than 10% of affected individuals die within 12 months of diagnosis, and many will develop heart failure and arrhythmias and require cardiac surgery to survive. Few can access needed cardiac care, and RHD currently accounts for a substantial proportion of maternal mortality, with the economic burden of the disease estimated ranging from US\$ 791 million – \$2.37 billion.⁵

Other heart conditions acquired in childhood also contribute significantly to the burden of pediatric and congenital heart disease and all have less favorable prognoses in LMICs. Whether or not these children survive and grow to reach their full human potential depends largely on birth location and access to heart care treatment throughout their lifetime. There is a dire need for more comprehensive treatment facilities and programs to prevent premature death and disability in all people affected by childhood-onset heart disease, and to provide them with ongoing care as they enter adulthood.

In 2023, we saw the publishing and signing of the 2023 Washington D.C. 8th World Congress of Pediatric Cardiology and Cardiac Surgery (WCPCCS) Call to Action, where more than 1,500 leading advocates and organizations from over 90 countries issued a collective call for urgent action to address the profound global health disparities among individuals affected by pediatric and congenital heart disease.



THE LIVES IMPACTED

Shabariwaasan, a 3-year-old with Tetralogy of Fallot, was diagnosed at birth due to low oxygen levels. Born prematurely at 32 weeks and weighing just 1.8 kg, he spent 25 days in the neonatal intensive care unit and was discharged at 1.9 kg. Referred to Hospital Serdang, he received treatment for cyanosis and was placed on a waiting list for corrective surgery. He also has urinary tract issues, leading to frequent infections; his recent surgery was canceled due to another infection. Shabariwaasan's parents work in a factory and a sugar company, respectively, and manage with support from grandparents. Although he enjoys playing with Legos and is sociable, he has developmental delays and gets tired easily. His prolonged wait for surgery has caused clubbing in his fingers and toes.



The 2023 WCPCCS Call to Action on Addressing the Global Burden of Pediatric and Congenital Heart Diseases brought a common voice to increase awareness of the global burden of disease promoting the development of sustainable care systems and improving access to quality healthcare for children and adults with cardiac diseases that begin in childhood. It recommended for countries to develop strategic plans to address pediatric and congenital heart diseases burden and 2030 goals in support of the Sustainable Development Agenda.

Based on the Invisible Child framework, the call to action was developed by patient and family advocates, clinicians, and health policy experts, and calls upon governments, multilateral organizations, funders, professional societies, research and teaching institutions, civil society, and the private sector to address the glaring inequities in recognition, access to and investment in health services for congenital and pediatric heart disease patients. In 2024, the Global Coalition for Pediatric and Congenital Hearts came together to continue advocating for the goals laid out in the call to action. Co-led by Children's HeartLink and the Global Alliance for Rheumatic and Congenital Hearts (Global ARCH), an alliance of patient and family organizations, it brings together over 140 individuals, patients, professionals, and humanitarian organizations to collectively advocate for change.



The 2023 WCPCCS Call to Action serves as an impactful advocacy tool, reaching influential leaders at the United States Agency for International Development (USAID), the World Bank, the United Nations General Assembly, various Ambassadors and high-ranking government officials, and leaders in the pediatric & congenital cardiac community.

And we're just getting started!

WHAT PATIENTS & FAMILIES ARE SAYING

"When my daughter was diagnosed with endocardial cushion defect at 5 days old, it seemed our world had collapsed. Luckily, we were complete strangers to any type of congenital disease and this was all foreign and frightening information. As we educated ourselves on the issue, our doctors in New York gave us the hope for our daughter, Chloe. Through the science, equipment, experience and teams at hand- they assured us Chloe's condition was "fixable". After living in New York City for 14 years and having all the resources we needed, we moved to Honduras last year with a now healthy five year old Chloe. Even though her condition is not fully cured, should we have been living in Honduras at the time of Chloe's birth, we would have probably never have gotten a diagnosis and/or the necessary healthcare to diagnose, follow, operate and cure her condition. We are blessed that we have the option to look for help elsewhere, but every child in Honduras and in the world deserves the universal right to have life saving healthcare options accessible and available to them. Access to screening, treatment and life long care is necessary for the longevity of a child with cardiac disease. We need to work towards finding support for every child living with a congenital heart disease. There is no life without a precious heart and it is a moral responsibility to give access to basic health needs to everyone on this planet."

- Jackie, mother of child living with congenital heart disease

WHY A WHA RESOLUTION?

With the Global Coalition for Pediatric and Congenital Hearts, over 140 individuals and civil society organizations are coming together to call on United Nations member states to adopt a World Health Assembly (WHA) Resolution that urges governments to increase these investments and build this critical capacity for care.

Despite the significant and growing impact of pediatric and congenital heart disease on the global burden of disease, governments and policy makers continue to lack awareness of this issue, and global progress has been minimal. Ensuring lifelong care for pediatric and congenital heart disease patients will require leadership and investment at the local, national level, and global level.

In 2024 the WHA adopted a crucial resolution responding to slowing progress in tackling maternal and child mortality and member states committed to accelerated action. The resolution accelerate progress towards reducing maternal, newborn and child mortality in order to achieve Sustainable Development Goal targets 3.1 and 3.2, highlighted the need for a comprehensive, life-course approach to tackling these urgent issues and for the first time called out congenital anomalies as a key cause of mortality needed to be addressed.⁶ By adopting a WHA resolution on pediatric and congenital heart disease, UN Member States will bring global attention to this existing unmet need. Such global action will continue the important work from 2024 and will set in motion the development of national action plans and strategies to address this burden through health systems strengthening, policy development and assuring appropriate financing for equitable access to screening, diagnosis and care for people with pediatric and congenital heart diseases. As the most common congenital anomaly requiring specialized lifelong care and systems, CHD needs to be addressed through separate health policies or policy decisions.

Pediatric and congenital heart services should be considered a best buy. It is estimated that CHD represents 66% of the preventable deaths from scaling up sub-specialty services, which represents 58% of avertable disability adjusted life years (DALYs).⁷ By scaling up surgical services addressing pediatric and congenital heart disease with the WHA Resolution we can prevent these deaths and strengthen health systems everywhere.

Accelerating progress to address the burden of pediatric and congenital heart disease globally is in line with the 2030 Global Agenda for Sustainable Development (SDG). To achieve the childhood mortality targets of SDG 3, we must address mortality from CHD, which represents over one third of congenital anomalies burden worldwide. Long-term investment into the lifelong well-being of affected infants, children and adults also aligns with countries' commitments to UHC, health worker development and mortality and morbidity from noncommunicable diseases. This resolution would also support SDG 1, 8 and 10, as it will ensure that those affected escape poverty by avoiding catastrophic healthcare expenses, can work, support their families, and avoid disability-related stigma. Addressing the high burden of pediatric and congenital heart disease should be a guiding value for investments in health, and a key priority for all, because investments in capacity for the most vulnerable, such as pediatric cardiac care capacity, strengthens the entire health system. Finally, a WHA resolution on pediatric and congenital heart disease will also support the goals of WHO's 14th General Programme of Work⁸ to promote, provide and protect health and well-being for all people, everywhere, and specifically Strategy 4, Improve health service coverage and financial protection to address inequity and gender inequalities, where congenital anomalies are included.

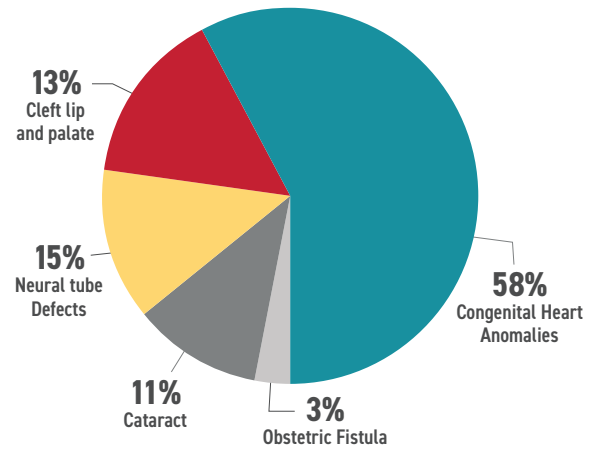


Figure 2. Distribution of Burden That Could Be Averted by Scaling Up Selected Subspecialty Surgical Care in LMICs

SUSTAINABLE DEVELOPMENT GOALS



Targets that Policies Focused on Pediatric and Congenital Heart Disease Can Help Achieve



- 3.2** By 2030, end preventable deaths of newborns and children under 5 years of age, with all countries aiming to reduce neonatal mortality to at least as low as 12 per 1,000 live births and under-5 mortality to at least as low as 25 per 1,000 live births.
- 3.4** By 2030, reduce by one third premature mortality from non-communicable diseases through prevention and treatment and promote mental health and well-being.
- 3.8** Achieve universal health coverage, including financial risk protection, access to quality essential health-care services and access to safe, effective, quality and affordable essential medicines and vaccines for all.

WHAT SHOULD A WHA RESOLUTION FOCUS ON?

A WHA Resolution on Pediatric and Congenital Heart Care will emphasize the need for a comprehensive agenda to help countries develop national pediatric and congenital heart strategy and a plan for the development of adequate workforce, infrastructure, capacity and financing of pediatric and congenital heart services.

In recognition of the 2023 WCPCCS Call to Action, a 2026 WHA resolution would include the following:



1. Increase capacity to care for people with pediatric and congenital heart diseases

2030 Goal: The timely diagnosis, treatment and lifelong care of pediatric and congenital heart disease will be integrated into all health system strengthening and surgical scale-up plans.

1. **Domestic and global investments** to increase capacity for pediatric and congenital cardiac care at secondary and tertiary hospitals. Strengthen and expand newborn screening, early detection, and diagnosis of childhood-onset heart disease followed by referral to appropriate medical and surgical treatment that is family-centered and includes early childhood development and follow-up care.
2. **Harness existing private sector capacity and innovations** to assure fast scale up of services to all who need them.
3. **Promote a multidisciplinary approach** for specialized care such as surgery, mental health, and speech and occupational therapy, among other professional services.
4. **Support of local referral networks** by ministries of health and regional academic institutions to improve early diagnosis, surveillance, and lifelong care of heart disease, and to develop diagnostic and treatment guidelines for low-resource settings.
5. Universities, NGOs (Non-Governmental Organizations) and teaching hospitals should **invest in multi-year partnerships** focusing on leadership, infrastructure development and training to increase the technical capacity and financial sustainability of local hospitals.



2. Build the pediatric and congenital cardiac workforce

2030 Goal: Health professionals will be able to recognize the basic signs and symptoms of congenital and other pediatric (or childhood-onset heart disease). Accredited pediatric cardiac training programs will be available in all countries.

Ministries of health, finance, and education, and regional professional bodies should collaborate to:

1. **Evaluate workforce needs** in pediatric and congenital cardiac care.
2. **Develop accredited pediatric and congenital cardiac training and education centers and programs** that include developing the technical and leadership capacity of multidisciplinary teams including specialist pediatric cardiac nurses, physicians, pharmacists, perfusionists, and respiratory therapists, and others.
3. **Training clinicians to practice respectful and family-centered care**
4. **Develop pediatric and congenital cardiac workforce** strengthening plans with appropriate recruitment and incentivization to minimize attrition, promote career satisfaction and skills retention in the nursing and pediatric cardiac care professions.
5. **Support the careers** of existing pediatric and congenital cardiac care professionals and build mentorship programs and viable career path options for the next generation.



WHAT PATIENTS & FAMILIES ARE SAYING

"Access to timely screening, quality treatment, and patient-centered lifelong care for childhood-onset heart diseases has been neglected by the global health community for far too long. We need a World Health Assembly resolution that calls upon governments to act urgently to ensure universal health coverage for this life-saving healthcare"

– Anu Gomanju, patient advocate as well as a person living with rheumatic heart disease (RHD) from Nepal



3. Close the data gap

2030 Goal: Data on pediatric and congenital heart diseases will be collected in national health surveys and included in burden of disease and cause of preventable deaths in childhood statistics.

1. **Support and expand information systems** to generate key data on pediatric and congenital heart disease with a particular focus on LMICs, including incidence, prevalence, risk factors and lifelong outcomes. Congenital and pediatric heart disease should be included in all national child health, surgical, burden of disease and cause of death surveys and reported to national health ministries and international organizations such as the World Health Organization and the World Bank.
2. **Update the burden of disease data** on pediatric and congenital heart disease, with a particular focus on LMICs.
3. **Research and advocacy** on ending preventable child deaths must include pediatric and congenital heart disease as a significant contributor.
4. **Publication** by pediatric and congenital cardiac care providers in LMICs of outcomes research, cost analyses, and other topics relevant to low-resource settings, especially to inform health policy.
5. **Prioritize the application** of cost-effective technologies and quality improvement strategies that can reduce costs and improve outcomes for people living with heart disease in low-resource settings.



4. Finance pediatric and congenital cardiac care

2030 Goal: Pediatric and congenital heart disease services including identification, diagnosis, surgery and lifelong care of newborns and children will be integrated in benefits packages in universal health coverage and social protection platforms, protecting patients from catastrophic expenses related to their care.

Ministries of health, finance, and education, and regional professional body collaboration to:

1. **Mobilize increased funding** at domestic and international levels in order to achieve scaling of cardiac surgical and anesthesia care in LMICs.
2. **Provide support** to individuals and families of children with heart disease who experience indirect expenses related to accessing and sustaining care, particularly those at risk of poverty.
3. **Track and report financial data** at hospitals in LMICs with functional pediatric cardiac care services using standardized metrics such that analyses can be made on the cost of scaling up care for children with heart disease.
4. **Develop and strengthen** cross cover and mutually beneficial funding relationships between public and private health providers.
5. **Mobilize funding** for LMIC-focused research and data collection.

The Global Coalition for Pediatric and Congenital Hearts is launching a campaign for a 2026 World Health Assembly Resolution on Pediatric and Congenital Heart Care. Adopting a WHA Resolution on Pediatric and Congenital Heart Diseases will urge member states to respond to the global trends of increased burden of pediatric and congenital heart diseases and shape the future but putting in place effective policy responses supported by adequate financial investments. The SDG and UHC agenda cannot be achieved without prioritizing the systems and resources needed to ensure everyone living with PCHD has access to quality lifelong care.

A WHA RESOLUTION FOR PEDIATRIC AND CONGENITAL HEART CARE WILL BE AN IMPORTANT MILESTONE ON THE PATH TO HEALTH FOR ALL.

WHAT PATIENTS & FAMILIES ARE SAYING

"Childhood heart disease knows no class, gender, race, status or nationality it is a risk for any child anywhere. Let's unite for heart action."

– Tendai Moyo, Brave Little Hearts, Zimbabwe





childrenshearlink.org

Children's HeartLink saves children's lives by transforming pediatric heart care in underserved parts of the world. The global nonprofit organization (NGO), partners medical volunteers from top teaching and research institutions with doctors, nurses and health care professionals in Bangladesh, Brazil, China, India, Malaysia and Vietnam to develop or improve paediatric cardiac care programs. Since 1969, the organization has reached more than 1.5 million children.



global-arch.org

Global ARCH is a global alliance of organizations dedicated to improving the lives of those impacted by childhood-onset heart diseases, including congenital and rheumatic heart disease. With patient and family groups at the heart of our efforts, we work together to empower local community leaders, foster global collaboration, and unite our voices, ensuring that every individual has access to the essential care, support, and services they deserve to live life unlimited by their disease.



Global Coalition for Pediatric & Congenital Hearts

The Global Coalition for Pediatric and Congenital Hearts works to reduce global inequities in access to quality pediatric and congenital cardiac care. We aim to improve timely diagnosis, treatment and lifelong care through enhanced global and national policies and increased investments in services for pediatric and congenital heart disease. The 140-member advocacy coalition, made up of patients, advocates, clinicians and patient and family organizations from 42 countries.

The coalition emerged through efforts at the 8th World Congress of Pediatric Cardiology and Cardiac Surgery in August 2023. Work is supported by a dedicated Secretariat and co-hosted by the Global Alliance for Rheumatic and Congenital Hearts (Global ARCH) and Children's HeartLink.

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²Zimmerman MS, Smith AGC, Sable CA, et al. Global, regional, and national burden of congenital heart disease, 1990–2017: a systematic analysis for the Global Burden of Disease Study 2017. *The Lancet Child & Adolescent Health*. 2020;4(3):185–200. doi:10.1016/S2352-4642(19)30402-X

³Centers for Disease Control and Prevention. Data and Statistics on Congenital Heart Defects. Centers for Disease Control and Prevention n.d. <https://www.cdc.gov/ncbddd/heartdefects/data.html>

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⁵Watkins DA, Johnson CO, Colquhoun SM, Karthikeyan G, Beaton A, Bukhman G, et al. Global, regional, and national burden of rheumatic heart disease, 1990–2015. *N Engl J Med*. 2017; 377:713–722. doi: 10.1056/NEJMoa1603693

⁶World Health Organization (WHO). 2024. Accelerate progress towards reducing maternal, newborn and child mortality in order to achieve Sustainable Development Goal targets 3.1 and 3.2 (A77/A/CONF./5). Seventy-seventh World Health Assembly, World Health Organization, Geneva. Available: https://apps.who.int/gb/ebwha/pdf_files/WHA77/A77_ACONF5-en.pdf

⁷"Global Burden of Surgical Conditions". In: *Disease Control Priorities (third edition): Volume 1, Essential Surgery*, Washington, DC: World Bank.

⁸ <https://www.who.int/about/general-programme-of-work/fourteenth>