Children's HeartLink®
HEALING HEARTS WORLDWIDE

A Voice for
The Invisible Child

Childhood Heart Disease and the Global Health Agenda

4th in a Series of 4 Briefs from Children's HeartLink

A Call to Action

Children with heart disease are dying preventable deaths.

In many regions of the world, infant and child deaths are no longer defined primarily by diseases preventable by vaccines and improved nutrition and sanitation. This can largely be attributed to the success of primary health care efforts and a rising middle class. This doesn't mean, however, that the work of preventing infant and child mortality is near complete. Ending preventable child deaths is rightly among the ambitions of the UN Sustainable Development Goals. Complex chronic and congenital pediatric diseases are among the conditions that require increased and sustained attention from the global health and development communities.

For every 120 children born around the world, one will have a malformation of the heart, or congenital heart disease. Whether or not this child survives and grows to be a playful child and productive adult depends largely on where they were born and whether they had access to screening and treatment.

In high-income countries there is one pediatric cardiac surgeon per three million people. In the poorest areas of the world, however, there is only one pediatric cardiac surgeon per 38 million people, leaving millions of children awaiting lifesaving care. These children will die preventable deaths.

Pediatric cardiac care is not luxury treatment. It is lifesaving care deserved by all children in need. Increasing access to pediatric cardiac care is a lofty but not insurmountable goal. It is an achievable goal, grounded in health system sustainability and equity. It will save children's lives.

Children's HeartLink has been working to meet the needs of children with heart disease for over 40 years. Their systems-based model empowers local providers in six countries to serve over 84,000 infants and children each year by partnering with local governments, renowned teaching and research institutions, the private sector and civil society. While this meets only a fraction of the need, it demonstrates the power of humanitarianism with a sustainable development focus.

In its four-part series *The Invisible Child*, Children's HeartLink has brought to light the tremendous inequity in access to pediatric cardiac care, the absolute need for such care, and their unique sustainable approach to the problem of childhood heart disease. Children's HeartLink is now calling on leaders in health and development to acknowledge pediatric heart disease within child health goals.

Caring for children is a universal goal. No matter the region or culture, children must be at the center of development. It is our decision, collectively, whether children with heart disease will be among the child deaths we failed to prevent, or if these children are allowed their right to health.

I encourage all who are engaged in global health and development to read the four briefs in *The Invisible Child* series and to respond to this Call to Action by considering the implications of millions of children suffering without care. I urge you to leverage the unique strengths of your respective organizations to increase sustainable and equitable access to pediatric cardiac care across the world.

Respectfully yours,

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Treating Children with Heart Disease is Critical to Achieving the Sustainable Development Goals

Heart disease is a significant cause of child suffering and death around the world. For every 120 children born, one will have congenital heart disease. If that child is born in an area with access to pediatric cardiac care and surgery, they will likely survive and go on to live as a playful child and productive adult. Children with heart disease born in low- and middle-income countries (LMICs), however, will most likely die or live a shortened life of disability. Their care, if available at all, may drive their family into irreversible poverty.

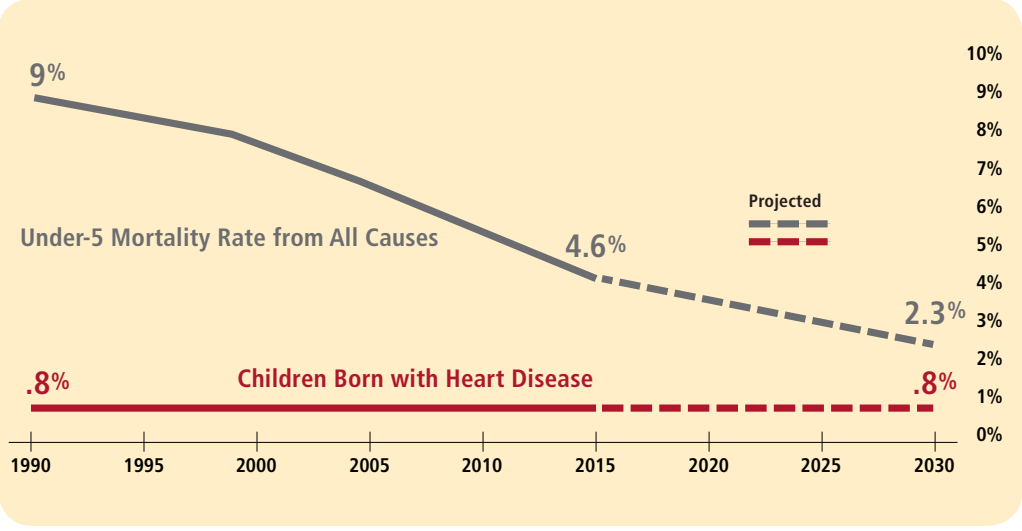
Rheumatic heart disease unnecessarily afflicts another 300,000 children every year. Rheumatic heart disease has been eradicated in most high-income countries, yet it is endemic in areas of poverty, poor sanitation and limited access to primary health care.

Coordinated efforts by the global health community to increase access to clean water and sanitation, to ensure women receive prenatal care and deliver with skilled attendants, and to improve child vaccination rates have halved the under-five mortality rate (U5MR) in the last 15 years. As a result, the major killers of children in many parts of the world are no longer diseases of poverty. Rather, by 2030, heart disease and other congenital anomalies, as a group, will be among the top five causes of child death.

National and local governments, international organizations, and donors are mobilizing efforts to "end preventable child deaths by 2030". This simply cannot be achieved without the inclusion of pediatric heart disease in the agenda. One million children, every year, are robbed of their opportunity to play, learn and grow—to reach their potential alongside their peers. Children's HeartLink is committed to leading a global effort to improve access to pediatric cardiac care in developing countries.

Our series, *The Invisible Child,* describes the burden of heart disease in children, outlines the barriers to improving access to quality care, and provides examples of locally driven success. This Call to Action culminates the series and directs recommendations in the areas of health systems, workforce development, surveillance and financing to actors with particular ability to impact change and improve the lives of children with heart disease around the world.

Decreasing U5MR Will Reveal the Constant Burden of Heart Disease



Working Together for Children with Heart Disease

Millions of children await care that will not be available unless the global health community considers pediatric heart disease within the global health agenda. Children's HeartLink's partner hospitals in Brazil, China, India, Malaysia, Ukraine and Vietnam have strengthened their capacity and now serve over 84,000 children every year. These long-standing partnerships demonstrate what is possible when governments, hospitals, universities, NGOs and industry work together to make the daunting, yet possible, task of caring for children with heart disease a reality.

As countries develop and poverty targets are met, chronic and complex diseases like heart disease will continue to increase in terms of relative burden, and parents of children with heart disease will justly demand local treatment options. Children's HeartLink aims to expand access in developing countries by establishing 50 Centers of Excellence in pediatric cardiac care by 2030. The success of this goal—the survivability of children with heart disease—depends on the willingness of actors to work together on this emerging and critical health need.

The healthy development of children born with heart disease and the eradication of rheumatic heart disease are of interest to all sectors. Likewise, we all have unique roles to play in improving access to pediatric cardiac care.

Multilateral and Financing Agencies

- Include congenital and rheumatic heart disease in global indicators of child health.
- Ensure that development aid for health reflects burden of disease trends for child health, and support the inclusion of care for children with heart disease in universal health coverage.

World Health Organization

- Integrate rheumatic heart disease prevention into all maternal and child health, noncommunicable disease and essential medicine strategies; and include pediatric cardiac care in all surgical scale-up long-range plans.
- Encourage pediatric cardiac care practitioners to remain in-country by supporting the development of country/regional pediatric cardiac centers of excellence.
- Include congenital and rheumatic heart disease in global indicators of child health.
- Ensure that development aid for health reflects burden of disease trends for child health, and support the inclusion of care for children with heart disease in universal health coverage.

National and Local Governments

- Integrate rheumatic heart disease prevention into all maternal and child health, noncommunicable disease and essential medicine strategies; and include pediatric cardiac care in all surgical scale-up long-range plans.
- Encourage pediatric cardiac care practitioners to remain in-country by supporting the development of country/regional pediatric cardiac centers of excellence.
- Include congenital and rheumatic heart disease in national indicators of child health.
- Support the inclusion of care for children with heart disease in universal health coverage.

Research and Teaching Institutions

- Ensure all students and health professionals are proficient at recognizing the basic signs and symptoms of heart disease in children.
- Develop surveillance methodologies that capture the burden of pediatric heart disease.
- Work with existing centers of excellence to develop economic models of the cost of scaling up pediatric cardiac care.

Civil Society

- Advocate for care for children with heart disease and the prevention of rheumatic heart disease.
- Advocate for specific preparation in the needs of pediatric cardiac care in local training programs.
- Advocate for the inclusion of congenital heart disease in child health surveys and cause of death reporting.
- Advocate for coverage of treatment for children with heart disease in social protection platforms, including universal health coverage.

Private Sector

- Support the development of training programs specific to the treatment of children with heart disease.
- Invest in long-term partnerships with local health systems to develop pediatric cardiac centers of excellence.

Caring for children is a universal goal. No matter the region or culture, children must be at the center of development.

Open the center spread to learn about our vision.

Photo: Susan Bordson

Increasing Capacity to Care for Children

By 2030, the prevention of rheumatic heart disease and the treatment of pediatric heart disease will be integrated into all health system strengthening and surgical scale-up plans.

Local health networks should be supported by ministries of health and regional academic institutions to improve early diagnosis, surveillance and lifelong care of congenital and rheumatic heart disease, and develop diagnostic and treatment guidelines for low-resource settings.

Rheumatic heart disease prevention should be included in all national and global (e.g. WHO, World Bank) NCD, maternal and child health, and essential medicines strategies.

Domestic and global investments to increase capacity for pediatric cardiac care at secondary and tertiary hospitals should be directed to regions where 1st level hospitals are competent at Bellwether surgical procedures.*

Universities, NGOs and teaching hospitals should invest in multi-year partnerships focusing on leadership, infrastructure development and on-location training to increase technical capacity and financial sustainability of local hospitals.

Leadership needed by:

- World Health Organization
- National/local governments and health networks
- Civil society and patient advocates
- Private sector

*laparotomy, caesarean delivery, and treatment of open fracture

Children with heart disease deserve care from robust health systems.

Building a Pediatric Cardiac Workforce

By 2030, all health professionals will be able to recognize the basic signs and symptoms of congenital and rheumatic heart disease; accredited pediatric cardiac training programs will be available in all regions globally.

Ministries of health, finance, and education, and regional professional bodies should collaborate to support regional pediatric cardiac training and education opportunities.

Ministries of health should develop surgical workforce strengthening plans that include the needs of children with heart disease, and incentivize providers to remain and practice in-country.

Surgical scale-up and training programs should include developing the technical and leadership capacity of nurses.

Leadership needed by:

- World Health Organization
- National/local governments and local health networks
- Research and teaching institutions
- Civil society and patient advocates
- Private sector

We must equip providers to treat children with heart disease.

Photo: Sam Mohan

Closing the Data Gap

By 2030, data on pediatric heart disease will be collected in national health surveys and included in burden of disease and cause of child death statistics.

Congenital 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.

Research and advocacy on ending preventable child deaths must include pediatric heart disease as a significant, yet overlooked contributor.

Pediatric cardiac care providers in developing countries should publish case studies, research findings and cost analyses to help build a literature base particularly relevant to low-resource settings.

Leadership needed by:

- Multilateral and financing agencies
- World Health Organization
- National/local governments and local health networks
- Research and teaching institutions
- Civil society and patient advocates

Care for children with heart disease will improve when their disease is counted.

Financing Pediatric Cardiac Care

By 2030, pediatric cardiac care will be included in benefits packages in universal health coverage and social protection platforms, and patients will be protected from catastrophic expenses related to their care.

Innovation toward the application of technologies that can reduce costs and improve outcomes for children with heart disease in low-resource settings should be prioritized.

Increased financing must be mobilized at domestic and international levels to meet the need of scaling up surgical and anesthesia care in LMICs.

Hospitals in LMICs with functional pediatric cardiac care services should track and report financial data using standardized metrics such that analyses can be made on the cost of scaling up care for children with heart disease.

Leadership needed by:

- Multilateral and financing agencies
- World Health Organization
- National/local governments and local health networks
- Research and teaching institutions
- Civil society and patient advocates
- Private sector

Poverty should never be a side effect of treating pediatric heart disease.

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Series Synopsis

Children's HeartLink is issuing a series of discussion briefs to engage audiences and bring attention to congenital and rheumatic heart disease within the context of the global health agenda.

Our **first brief** presented the latest available data on the incidence of congenital heart disease and highlighted how frequently the needs of children with heart disease are overlooked.

Our **second brief** highlighted how omitting the needs of children with heart disease from discussions about the global health agenda, primary health care and essential surgery maintains the barriers that children with heart disease face when seeking care.

Our **third brief** discussed the need for sustained investment in health systems, exemplified by Children's HeartLink's success of partnering with local hospitals to meet pediatric cardiac needs within their own health system, with local control and local resources.

Finally, our **fourth brief** serves as a call to action within the global pediatric care agenda that melds with the broader global heath agenda. We present unique opportunities for engagement by governments, health systems, international organizations, donors and civil society.

Children's HeartLink

Established in 1969, Children's HeartLink is a Minnesota, USA-based nonprofit humanitarian organization currently working in Brazil, China, India, Malaysia, Ukraine and Vietnam. We partner with local institutions to strengthen health systems in order to develop pediatric cardiac centers of excellence. Evolving from a direct care to a train-the-trainer model, over 6,500 medical professionals are now more equipped to care for children with heart disease. In the last decade alone, over 100,000 children received treatment locally through Children's HeartLink's 13 partner hospitals, including four self-sustaining Centers of Excellence in pediatric cardiac care. Children's HeartLink's strategic vision includes developing 50 Centers of Excellence and reaching one million children with heart disease by 2030.

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This Brief is 4th in a Series of 4 from Children's HeartLink:

1. **A Case for the Invisible Child** *(released Spring 2015)*
2. **Finding the Invisible Child** *(released Fall 2015)*
3. **Treating the Invisible Child** *(released Spring 2016)*
4. **A Voice for the Invisible Child** *(released Fall 2016)*

Photo: Bistra Zheleva