



# A Case for The Invisible Child

Childhood Heart Disease and the Global Health Agenda

1st in a Series  
of 4 Briefs from  
Children's HeartLink



## Real Children with an Invisible Disease

Each year, an estimated one million children are born with a congenital heart defect<sup>1</sup>—heart disease due to an abnormality in the structure of their heart. In the regions of the world with the greatest burden of heart disease, the vast majority of them will never receive care for their often treatable condition. Ninety percent of children with heart disease are without access to the care<sup>2</sup> they need to live happy, playful and productive lives. Since 1969 Children’s HeartLink has worked to change that. Evolving from a direct care to a train-the-trainer model, over 5,000 medical professionals are now more equipped to care for children with heart disease. In the last decade alone, over 90,000 children have received treatment through Children’s HeartLink partner sites.

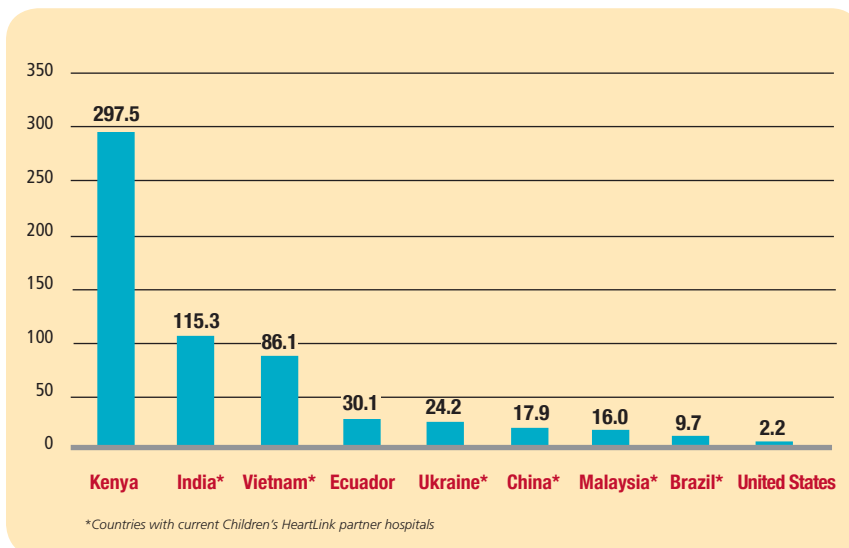
Congenital heart defects are the most common of all birth defects, occurring in approximately one out of 120 births<sup>3</sup>. Common examples include leaky valves, a hole in an interior wall of the heart, or malformed

blood vessels or heart chambers. The cause of most cases of congenital heart disease is unknown and unpreventable, and the rate of disease is relatively stable across countries and demographics. The impact of the disease, however, is heaviest on those countries with both high number of annual births and greatest levels of poverty. Children’s HeartLink has partnered with hospitals in developing countries around the world. While they all experience the same rate of congenital heart disease (1:120), the burden these cases have on their respective health system varies by the annual number of births in the country and its level of poverty (e.g., annual Gross Domestic Product (GDP)). When all measures are taken into account, the burden of congenital heart disease ranges from Brazil’s 9.7 cases per GDP (million) to 297.5 in Kenya<sup>4</sup>. By comparison, the United States, despite a large number of cases of congenital heart disease, has a CHD:GDP ratio of only 2.2, due to the high GDP.

The true incidence of congenital heart defects is difficult to measure. Surveillance systems are scant in developing countries<sup>5</sup>. Where they do exist, it is still difficult to capture the true magnitude of the disease. Globally, nearly half of all newborns don’t receive any medical attention during or immediately after birth<sup>6</sup>. Yet, to be accounted for in national statistics a child with heart disease needs a diagnosis. The process typically begins when a health provider recognizes symptoms like cyanosis, poor growth or shortness of breath, listens to the heart through a stethoscope, hears a murmur and refers a child to a cardiologist for diagnosis. Some critical cases are detected through pulse oximetry during routine newborn screening, but only when such diagnostic tools are available.

When a child has limited or no access to primary health care, or a supporting infrastructure of advanced care, they remain undiagnosed and untreated. They also remain uncaptured in morbidity and mortality statistics. Many children with heart disease sadly die soon after birth or during infancy. Some survive but don’t thrive, and as they grow they can’t keep up with their peers on the playground or in school. Without diagnosis, these deaths and limitations can be misattributed to other conditions that are compounded by the child’s weak heart.

### Congenital Heart Disease per Million GDP, 2011



**While the disease burden falls most heavily on the poorest regions, so does the inequity of access. Approximately 25 percent of children born with congenital heart defects will require surgery<sup>7</sup>. The chance of survival of a child born with heart disease depends not just on the severity of the defect, but disproportionately on where they were born.**

Pediatric cardiac surgeons in North America are available on average at a rate of 1 per 3 million people; in Sub-Saharan Africa, it's 1:38 million<sup>8</sup>. Globally, only a handful of countries have the capacity to diagnose—let alone address—heart disease in children. Their cardiac health needs are invisible to the health system and when another illness arises it can be worsened by their underlying heart disease. Without training in detection of congenital heart disease, even after treatment for pneumonia, diarrhea or other common childhood disease, their underlying heart disease can remain undetected, undocumented and therefore untreated.

Children who survive congenital heart disease become adults with congenital heart disease—adults who suffer the same physical limitations they experienced in childhood. The World Health Organization reported the annual years of healthy life lost (2011) due to the disability of congenital heart disease at 19.8 million DALYs (disability-adjusted life years)<sup>9</sup>. By comparison, childhood cluster diseases (whooping cough, diphtheria, measles and tetanus) accounted for 23.5 million DALYs. From 2000 to 2012, the burden of childhood cluster diseases decreased by 70 percent, whereas the DALYs from congenital heart disease remained constant. An estimated half of these could be averted if surgical practices of high-income countries were brought to scale in low- and middle-income countries<sup>10</sup>. This is an ambitious statement, but one worth considering as the global health community anticipates the forthcoming Sustainable Development Goals and strives to “ensure healthy lives and promote well-being for all at all ages<sup>11</sup>.”

## Countries need to be prepared to meet the full range of post-MDG health needs.

In the past decade and a half, under the auspices of the Millennium Development Goals (MDG), the global health community strove to reduce childhood mortality by half. Impressive reductions have been seen in every region of the world, and it's been predicted that the current rate will be halved again by 2030<sup>12</sup>. The great majority of these lives will be saved through improved vaccination coverage, sanitation, nutritional programs and needed public health measures of the same vein. But unless the burden of congenital heart disease is recognized, the child with heart disease will remain the health system's invisible child.

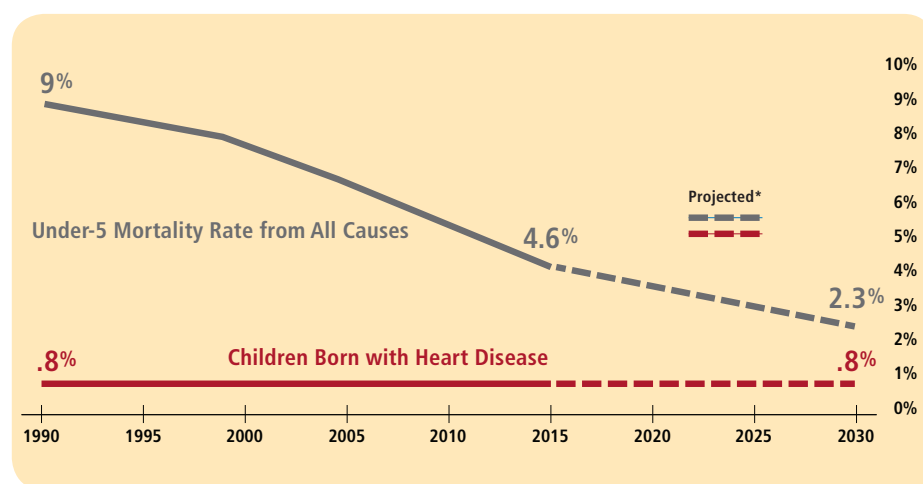
Once child mortality targets are reached, will the world stop trying to further reduce the number of children who don't reach their first or fifth or 20th birthday? Of course not. But the efforts of the global health community must be framed in the post-MDG reality of improving health systems and the advancements of many countries from low- to middle-income status.

Planning frameworks and projections need to be designed to reduce pediatric morbidity and ensure healthy development, while still increasing basic child survival in areas with high mortality rates. As countries develop economically, more communities urbanize, and families move into relative middle class, the burden of poverty-related diseases will diminish.

**Conditions like congenital heart disease will become more apparent as fewer children suffer from communicable diseases.**

From 2000-2013, congenital abnormality—of which heart disease is the leading condition—was the only cause-specific case of under-5 mortality rate (U5MR) that failed to decrease more than 20 percent; it is projected that by 2030, congenital abnormalities will be the fifth leading cause of neonate death<sup>13</sup>.

### Decreasing U5MR Will Reveal the Constant Burden of Heart Disease



## Congenital Heart Disease and its Place in the Global Health Agenda

Congenital heart disease is admittedly difficult to categorize within current global health frameworks. It is a childhood disease, yet it is not preventable by vaccination<sup>14</sup> or improved nutrition. It is a noncommunicable disease (NCD), yet it is not lifestyle related and doesn't factor into broader NCD reduction goals. It is the birth defect that causes the most infant deaths<sup>15</sup>, but it is not a visible one that commands immediate attention.

The similarity between children with heart disease and those with health conditions more readily diagnosed and treated is their need for representation in vital statistics and a robust health system that guarantees access, quality and affordability. A lack of data limits the global health community's knowledge of the true burden of congenital heart disease and our efforts to address it.

Recognizing and caring for children with heart disease is not a dilemma of investing in tertiary versus primary

health care. It is instead the responsibility of the global health community to provide all children the care they need through a network of local, regional and centralized clinics and hospitals, supported by highly trained health care workers at all levels.

Not all health systems in all countries will have the capacity to meet the surgical needs of children with heart disease in the foreseeable future. That is the reality of development. However, health systems around the world are modernizing and becoming more efficient and sustainable. Given the sheer number of children and adults suffering from congenital heart disease, it would be irrespon-

sible not to share knowledge and build on the strengths that exist. Pediatric cardiac success is possible in low-resource settings. Children's HeartLink supports health systems that have strong indicators of success to become self-sustaining centers of excellence in pediatric and congenital cardiac care.



## Amrita Institute of Medical Sciences: A Children's HeartLink Partner in Kochi, India

Dr. R. Krishna Kumar and his team built their pediatric cardiology practice at Amrita Institute of Medical Sciences (AIMS) with the mission of treating children with heart disease regardless of their families' economic situation. Removing the financial barrier to care was only one obstacle. Having a qualified team of doctors, nurses and hospital staff was another. Children's HeartLink used a phased approach to support on-site training, resource procurement, quality improvement monitoring, infrastructure development, and regional and community capacity building. Since the initiation of their partnership, surgical outcomes have improved steadily in spite of the growing complexity of case profiles<sup>16</sup>. Their success earned AIMS the 2014 British Medical Journal in India award for Quality Improvement in Healthcare<sup>17</sup>.

Robust training programs for health care providers have helped establish pediatric heart programs that serve large populations in this region of India and in neighboring

countries. Programs specifically aimed at early detection of congenital heart disease at primary care levels have reached 1,000 pediatricians through teaching initiatives supported by Children's HeartLink. Additionally, nurses teach parents how to provide at-home care, including instruction on medication, wound care, physical activity and diet for their children through the Parent Education Discharge Instructions<sup>[a]</sup> (PEDI) program; and Blissful Little Hearts is a first of its kind parent advocacy and support group in India that advocates for support for their children and families.

In 2011 AIMS was named Children's HeartLink's first Global Partner in Pediatric Cardiac Care and Training. In a model of South-South collaboration to promote capacity building, self-reliance and sustainable development, AIMS serves as a regional center of excellence in treatment and training, and as a thought leader in challenges and opportunities unique to the management and improvement of pediatric cardiac care in the developing world.



**“Despite the challenges typically encountered in a limited resource environment, targeted quality improvement measures helped our unit to produce outcomes similar to those from developed nations. I cannot stress enough what it means to me and the fellow members of my team to be able to care for the sick children in our country. Parents in India want the same thing parents everywhere want for their children: relief from suffering and the promise of a long and healthy life.”**

**Dr. R. Krishna Kumar, clinical professor and head of AIMS department of pediatric cardiology**

## Making the Case for Pediatric Cardiac Care

Over the next 18 months, Children's HeartLink will make the case for including pediatric cardiac care in the global health agenda. We will initiate discussion through a series of briefs that present issues within the scope of need for children with heart disease.

This first brief has brought attention to the dearth of accurate data on the incidence and prevalence of congenital heart disease, creating generations of children and adults invisible to the global health community. Families are rising out of poverty, communicable childhood diseases are diminishing, and health systems are modernizing. Children's HeartLink is committed to ensuring that health systems and governments are prepared to identify and care for children with heart disease.

**Our second brief will address the issue of access.**

One million children are born every year with heart disease. Only 25 percent of them live in areas with reliable access to quality care<sup>8</sup>. Even this number hides the skew toward urban centers in developed countries. Access to care overall is paramount in the global health agenda, and improved awareness of the needs of children with heart disease in the primary health care setting will improve the lives of many.

One in four children with heart disease require surgical correction for their condition. The others need less invasive support to grow and thrive. Governments and health care administrators must make choices in allocating resources throughout their health systems.


**In our third brief, we will discuss investing in pediatric cardiac care.**

It is not an either-or choice, but rather improves the quality, capacity and efficiency of health systems well beyond the operating theatre.

**Finally, we will present a call to action within the global pediatric cardiac care agenda that melds with the broader global health agenda.**

We will discuss unique opportunities for engagement by governments, health systems, international organizations, funders and civil society.

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## A Children's HeartLink Series

### Childhood Heart Disease and the Global Health Agenda

#### 1. A Case for the Invisible Child

(released Spring 2015)

#### 2. Finding the Invisible Child

(to be released Fall 2015)

#### 3. Treating the Invisible Child

(to be released Spring 2016)

#### 4. A Voice for the Invisible Child

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## About Children's HeartLink

Children's HeartLink trains health workers in underserved parts of the world to diagnose and treat children with heart disease. Our training model is helping transform health systems in the countries where we work. Founded in 1969, Children's HeartLink currently supports 10 hospital partner sites in Brazil, China, India, Malaysia, Ukraine and Vietnam. Our dedicated teams of medical volunteers come from some of the finest institutions in the world. They provide clinical and organizational expertise, training and mentoring to meet the specific needs of our partner sites around the globe.

[www.childrensheartlink.org](http://www.childrensheartlink.org)



[a] PEDI (Parent Education Discharge Instructions) is a training course and materials developed and distributed by Children's HeartLink. The PEDI package is currently available in nine languages with plans for additional languages in the future. The package contains several items, including two booklets for families with higher literacy: one on preparing for an operation and hospital stay, and a second with guidance on post-hospital care at home. The low-literacy audience instructions include documents with illustrations and minimal text.

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13 Liu, L., Oza, S., Hogan, D., Perin, J., Rudan, I., et al. (2015) Global, regional, and national causes of child mortality in 2000-13, with projections to inform post-2015 priorities: an updated systematic analysis. *The Lancet*, 385(9966), 430-440.

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