

Treating The Invisible Child

Childhood Heart Disease and the Global Health Agenda

3rd in a Series
of 4 Briefs from
Children's HeartLink



Strong Health Systems are Essential for Treating Children with Heart Disease

It is inconceivable that a baby in the United States or Western Europe born with a “hole in her heart” would not receive the care she needs. Yet because pediatric cardiac care centers are rare elsewhere in the world, millions of children born with congenital heart disease are awaiting surgical care that will not likely come in their shortened lifetime.

Hear disease and children are not often considered together, but for the sake of the one million children born each year with congenital heart disease and the 300,000 school-age children who acquire rheumatic heart disease, they need to be. Rarely preventable, but mostly surgically treatable, *congenital heart disease* is an abnormality in the structure of the heart. Afflicted infants rely on early detection and intervention to grow to be strong, healthy children capable of playing, learning and maturing into healthy, productive adults. *Rheumatic heart disease* is the most common form of acquired heart disease in children and adolescents. It is easily preventable using cheap and effective penicillin regimens to treat repeated bouts of *Streptococcus A* infection, yet persists at endemic levels in too many areas with high poverty and low access to primary health care.

Despite the magnitude of disease and the potential health and productivity gains, pediatric heart disease is not often considered in strategies to reduce child deaths.

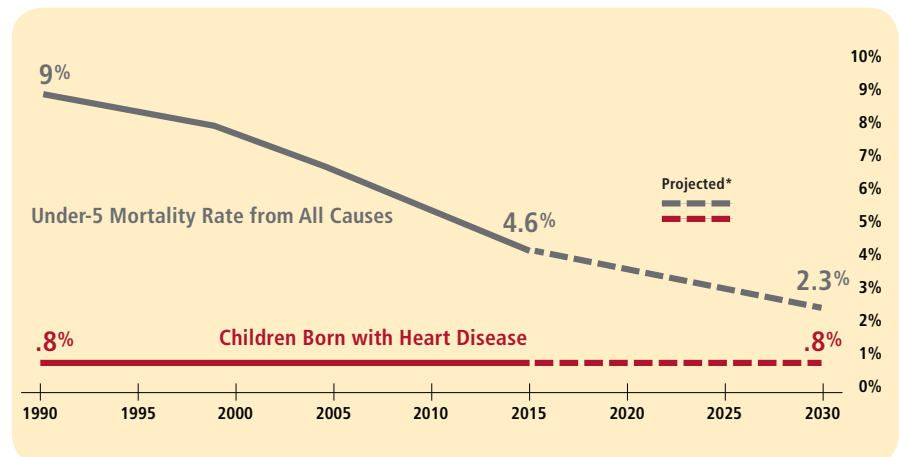
The Sustainable Development Goal (SDG) target to end preventable child deaths¹, however, cannot be achieved without due attention to children with heart disease.

Since the turn of the millennium, child deaths overall have decreased by half, and the current rate is predicted to halve again by 2030. By contrast, the rate of children born with heart disease is relatively constant at one in 120 live births. This means that as overall under-5 mortality decreases and fewer children die from diseases and conditions that thrive alongside poverty, pediatric heart disease will become a relatively greater burden on health systems.

By 2030² it is predicted that heart disease and other congenital abnormalities will for the first time be among the leading five causes of child death.³

Local health authorities in several developing countries have committed to caring for children with heart disease. Results have been remarkable for the children treated, yet the reality is that these are just a relative few of the millions in need globally. Guaranteeing access to all children awaiting care will require not only local demand and leadership, but also the commitment of the global health community to include the needs of children with heart disease within health systems strengthening efforts. The success and sustainability of pediatric cardiac care in developing countries is dependent on integrated health systems, quality training programs, surveillance and research, and financing treatment. In this paper, the third in a series on children with heart disease and the global health agenda, we will discuss how each of these elements factor into pediatric cardiac care and will provide examples of success in various developing countries. The subsequent and final paper of *The Invisible Child* series will provide specific recommendations for action in these same areas.

Decreasing U5MR Will Reveal the Constant Burden of Heart Disease



Increasing Capacity to Care for Children with Heart Disease

Congenital and rheumatic heart disease together are responsible for over 35 million DALYs* every year⁴, with 70 percent of the burden borne by developing countries⁵, yet little attention is given to pediatric heart disease in either non-communicable disease or child health strategies. When pediatric cardiac care is incorporated into the full continuum of care (from rheumatic heart disease prevention and early detection through primary health care, to treatment and case management), rheumatic heart disease can be eradicated and upwards of 85 percent of children with congenital heart disease can survive into adulthood⁶.

The opportunity for quality life years gained makes scaling up pediatric cardiac care a wise global investment in countries that are already meeting the basic surgical needs of its population. Many countries, however, are undeniably still grappling with deadly childhood diseases rooted in poverty, lack of basic sanitation and insufficient infrastructure to support even emergency surgery. Congenital heart disease still afflicts millions of children in these countries, but for these countries the imperative at this point is for policymakers to prioritize eradication of rheumatic heart disease in their immediate public health plans, and to consider the needs of all children with heart disease as they look toward the future of their health infrastructures and population needs.

The increasing chronic and complex population health needs in many areas of the world require governments, donors and the global health community to invest in health system



strengthening strategies that will build capacity in increasingly specialized and complex services, like pediatric heart surgery. It is imperative that this be done in ways that encourage health system integration and sustainability, as children with heart disease need the same continuum of care as patients with other chronic and complex diseases. They need strong primary health care to provide entry points into the health care system. They need providers that have the capacity to recognize symptoms of their disease. They need instruments and institutional knowledge to diagnose their disease and develop a treatment plan. They need referral systems and tertiary

care facilities capable of advanced surgery. And along every step they need protection from impoverishing costs associated with their care.

Safe surgery serves as an indicator of the responsiveness, strength and capacity of a health system to deliver on complex cases⁷.

Many countries are already secure in their ability to meet basic and emergency surgical needs. It is now time to invest in the surgical needs of the millions of children with heart disease.

*Disability-adjusted life years

Developing Sustainable Centers of Excellence

Children’s HeartLink is an international non-governmental organization founded in 1969 that aims to improve access to care for children with heart disease in developing countries. This is achieved by supporting multi-year partnerships between leading teaching hospitals worldwide and hospitals in developing countries. In the past decade, over 6,500 health care professionals received clinical training and more than 100,000 children underwent surgery at partner hospitals using local resources.

Children’s HeartLink supports 13 partner hospitals in six countries, four of which are Centers of Excellence in pediatric cardiac care. An organization is deemed a Center of Excellence when it delivers comprehensive, evidence-based, multidisciplinary pediatric cardiac care at a minimum volume of 250 surgical cases per year with room for growth and yields exceptional patient outcomes while demonstrating financial stability. Their staff are actively engaged in knowledge transfer and clinical research within and beyond their hospital. Children’s HeartLink’s goal is to help develop 50 Centers of Excellence and reach one million children with heart disease by 2030⁸.

Institut Jantung Negara (National Heart Institute – IJN) in Kuala Lumpur, Malaysia, is the newest Children’s HeartLink Center of Excellence. A partner hospital since 2007, IJN’s partnership goal initially focused on strengthening

their own capacity to meet the needs of children with heart disease. Leadership from the Malaysian Ministry of Health assisted IJN in exceeding this goal and ultimately becoming the leading pediatric cardiac care training institution for the region.

Strategic investments in surgical skills, critical care nursing training programs, and monitoring and quality improvement systems resulted in improvements that surpassed expect-

tations. The number of surgeries and clinical interventions nearly doubled from 760 cases in 2008 to 1,500 cases in 2014, and although the caseload included patients with increasingly complex conditions, mortality was significantly reduced in children under one year old. Today IJN serves the majority of Malaysia’s neonatal population with heart disease, regardless of insurance coverage, and is a training partner to cardiac care professionals throughout Asia and the Pacific region.

Children’s HeartLink Partner Hospitals and Centers of Excellence

Country	City/Region	Partner Hospital	Primary Medical Volunteer Partner	Partnership Established
Brazil	Fortaleza	Hospital de Messejana	Seattle Children’s Hospital	2015
	São José do Rio Preto	Hospital da Criança e Maternidade	Mayo Clinic	2009
China	Chengdu	West China Hospital	The Hospital for Sick Children, Toronto	2006
	Kunming	First Affiliated Hospital of Kunming Medical University	University of Minnesota Masonic Children’s Hospital	2014
	Lanzhou	First Hospital of Lanzhou University*	University of Minnesota Masonic Children’s Hospital	1999
India	Bangalore	Narayana Hrudayalaya Institute of Cardiac Sciences*	Lucile Packard Children’s Hospital at Stanford University	2002
	Chandigarh	Postgraduate Institute of Medical Education and Research	Boston Children’s Hospital	2012
	Kochi	Amrita Institute of Medical Sciences*	Lucile Packard Children’s Hospital at Stanford University	2000
	Kolkata	Rabindranath Tagore International Institute of Cardiac Sciences	Children’s Hospitals and Clinics of Minnesota	2015
Malaysia	Kuala Lumpur	Institut Jantung Negara*	Birmingham Children’s Hospital	2007
Ukraine	Kyiv	Ukrainian Children’s Cardiac Center	Seattle Children’s Hospital	2007
Vietnam	Ho Chi Minh City	Nhi Dong 1	Gleneagles Hospital, Singapore	2008
	Rach Gia	Kien Giang General Hospital	British Columbia Children’s Hospital	2015

*Center of Excellence

Building a Pediatric Cardiac Workforce

The people who deliver care are the heart of a health system.

A significant roadblock in the accessibility of pediatric cardiac care is the lack of a professionally trained workforce. An optimal surgical workforce* has been estimated at 40 per 100,000 population. In order to meet this need within the time-frame of the SDGs, an additional 2.3 million specialists—a doubling of the world's current surgical workforce—are required.

Specialty surgical care is no exception. Only a fifth of the world's specialist surgeons and even fewer anesthesiologists attend to the poorest half of the world's population⁷. The etiology of heart disease is different for children and adults; so must be the academic preparation and ongoing professional development. Globally, few students graduating from medical training programs have specialized training in how to diagnose, manage and treat

the child with heart disease. When they go on to work in clinics and hospitals that don't have capacity to treat pediatric heart disease, they have no opportunity to further learn about the disease, let alone practice any related skills.

The surge of investments in mobile technology and digital connectivity create tremendous opportunity for distance learning and partnerships within and between regions. The International Quality Improvement Collaborative for Congenital Heart Surgery in Developing World Countries (IQIC) is an ongoing collaborative of health care teams from around the world working to create a culture of patient safety and sustainable mortality reductions for children receiving congenital heart surgery in developing countries. Surgical teams from 44 sites in 22 countries benefit from free participation in a patient registry collecting data on clinical

outcomes, annual results analysis and monthly educational webcasts from Boston Children's Hospital that range from team-based practice to nurse empowerment to infection prevention and safe peri-operative practices. IQIC data show that participating institutions realized significantly lower rates of post-surgical infection and mortality since joining the collaborative⁹. Over 51,000 surgical procedures have been entered into the database since 2008, making it possibly the only such collection of surgical data from developing countries.

As the burden of childhood disease shifts from largely preventable diseases to chronic conditions like heart disease, the lack of qualified health care workers will become more apparent and critical.



Dedicated to Quality Improvement for all Patients

Caring for the child with heart disease does not occur solely within the confines of the operating theater. Likewise the dividends from training and quality improvement extend through the entire health system. Hospital da Criança e Maternidade, a Children's HeartLink partner hospital and IQIC participant in São José do Rio Preto, Brazil, recognized that despite the important role nurses play in the health care workforce, they were not well prepared for the breadth of knowledge and skills necessary to succeed in a large hospital setting. Their decision to create the internal position of Nurse Educator displays the leadership capacity necessary to assess and adapt to the changing demands on health systems.

Bruna Cury, RN, MSN, specializes in pediatric cardiac intensive care, but as Nurse Educator for the entire hospital, she must anticipate the broad educational needs of nurses across departments and specialties. Cury uses the data collected for IQIC to identify health system weaknesses and then adapts techniques and protocols designed for pediatric cardiac care to improve outcomes in departments across the hospital. "If you have an awesome surgeon you still can't take things for granted. I see a much improved doctor-to-nurse relationship as a result of our Children's HeartLink training visits. I see the empowerment and education of nurses and the increased use of protocols, all of which are key to quality care."

*surgeons, anesthesiologists and obstetricians

Closing the Data Gap

Among the factors limiting the scale-up of treatment options for children with heart disease are the wide gaps in data: incidence and prevalence, treatment access and costs, associated morbidity, mortality and economic impact. Extrapolations from data sets of high-income countries are helpful in stating a case for improved access to care, but nothing compares to country-level data in guiding the decisions that truly have local impact.

Surveillance of pediatric heart disease is not a simple undertaking and in most cases will require international support and coordination in the initial design and implementation phases.

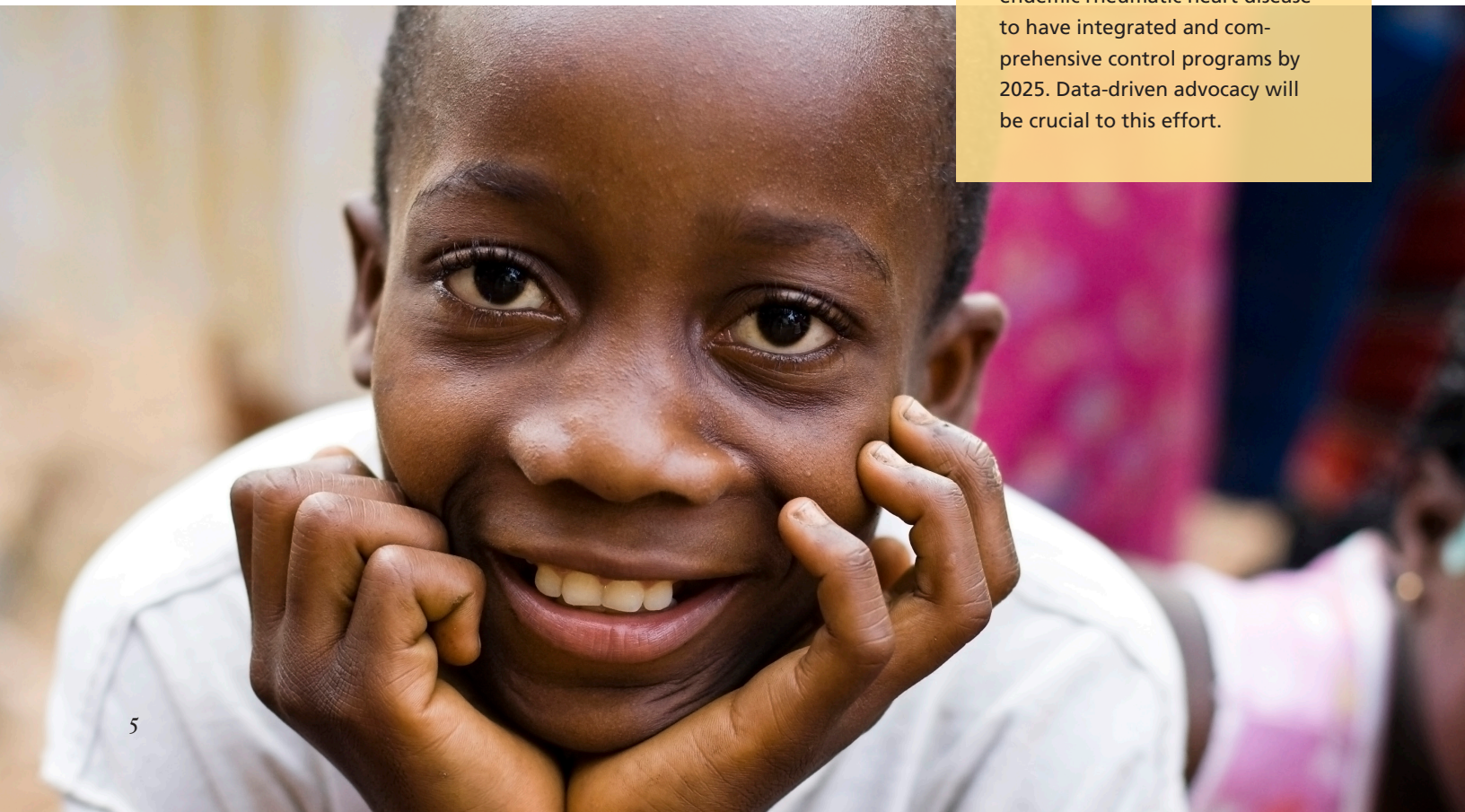
Household surveys, civil registrations and verbal autopsies are among

the common methods of collecting data on disease burden and cause of death, but such questionnaires are not typically designed to capture pediatric heart disease. Nor are health workers skilled at recognizing the signs and symptoms of heart disease as such, often attributing them to other common childhood disorders. It is important for physicians, nurses and midwives to have the knowledge and ability to diagnose heart disease in children—not only to refer for treatment where available, but to better understand true causes of child illness and death.

Investments in understanding how many children are suffering, and sharing information about ways to prevent and treat heart disease using local resources, cannot be overlooked. Efforts to quantify and accurately reflect pediatric heart disease in global and country-level disease burdens

will enable health policy decisions that better respond to emerging local needs and global targets.

Rheumatic heart disease remains the largest cardiac burden in Africa¹⁰, despite being completely preventable. The African Union recently recognized surveillance as a priority need in efforts to eradicate rheumatic heart disease. In June 2015 the African Union called on Member States to increase surveillance, and for the international community to provide open-access resources¹¹. This step will aid in the World Heart Federation's campaign to achieve a 25 percent reduction in premature deaths from rheumatic fever and rheumatic heart disease among individuals younger than 25 years by 2025. Among the targets of this ambitious goal is for 90 percent of countries with endemic rheumatic heart disease to have integrated and comprehensive control programs by 2025. Data-driven advocacy will be crucial to this effort.



Financing Pediatric Cardiac Care

Many congenital heart lesions requiring correction can be treated with relatively simple interventions that offer a high chance of complete cure. Yet, even in the few areas where care is available, the financial cost to the family is generally unattainable. These are the children for whom the disparities between those who receive care and those who die are most unfair, and the economic arguments for investing in pediatric cardiac care most compelling. Investing in the capacity to diagnose and treat pediatric heart disease will require substantial investments but will realize an enormous health dividend.

Building capacity to treat children with heart disease cannot come before a commitment to strengthen surgical capacity in a health system at large. Rather, pediatric cardiac care should be included in long-range surgical scale-up plans. The Lancet Commission on Global Surgery estimates that investments in health that support a moderately aspirational surgical scale-up rate of 8.9 percent per year (versus a historical rate of 5.1 percent), could see 59 current low- and middle-income countries (LMIC) reach the surgical capacity target of 5,000 procedures per 100,000 population by 2030. This surgical rate is associated with desirable health outcomes for a country, including high life expectancy and a low maternal mortality rate. Children's HeartLink uses these and other metrics to assess a country's readiness to support pediatric cardiac care and determine where to invest in partnerships with local hospitals.



Based on our experience, it is possible that more than 40 current LMICs will have the capacity to incorporate care for children with heart disease into their health systems by 2030.

Leadership from ministries of health, regional health officials and hospital administrators are key to the success of long-term collaborations such as those supported by Children's HeartLink. Local buy-in and own-

ership is critical to accomplishing sustainable increases in capacity building at lowered domestic costs. Such investments must also be mirrored in global health development priorities and financial support in order to ultimately achieve reliable access to quality surgical care for all children with heart disease. High-income and developing countries, non-governmental organizations and philanthropic donors must work collectively to close the access gap by 2030 and meet the SDG target of ending preventable child deaths.

All Children Have a Right to Health

The right to health includes access to timely, acceptable and affordable health care of appropriate quality. Children with heart disease should not be excluded from the right to health, nor from the financial protection offered by universal health coverage (UHC). As the burden of disease shifts globally, so must our collective sense of moral obligation to provide the full breadth of care that can relieve suffering, reduce poverty and contribute to shared prosperity.

Although causes of death are shifting away from poverty-related diseases, poverty is still a significant factor in whether a child lives or dies. The costs of accessing care can be insurmountable, driving a family into irreversible poverty simply for seeking care for their sick child. UHC serves to remove financial barriers to accessing care as well as providing financial protection against catastrophic medical expenses. As Dr. Margaret Chan, Director-General of the World Health Organization told the 2012 World Health Assembly at their annual meeting, UHC is “a powerful equalizer that abolishes distinctions between the rich and the poor ... the ultimate expression of fairness.”

Over 100 LMICs have taken active steps toward achieving UHC¹³. In these, and all countries, adapting models of UHC to fit their particular needs—current and future—will serve much better than a standard template of coverage. Countries must make coverage decisions based on epidemiological data and a true understanding of when and how children are suffering and dying. Countries still experiencing crippling levels of infant and child mortality may be best served by prioritizing a basic set of services covered by scant health system dollars. However, in many parts of the world, resources, need and demand are such that coverage for children with heart disease should be included as part of a core package for surgical and anaesthesia care⁷.

India's Plan to Screen All Children for Heart Disease

As part of India's progress toward UHC, the Ministry of Health supports Rashtriya Bal Swasthya Karyakram (RBSK)¹⁴, a child screening program focused on early identification and intervention of the “four Ds”: birth defects, deficiencies, diseases and developmental delays. Using a network of health facilities, trained home health visitors, mobile health teams and schools, 360 million children are targeted to be screened for congenital and rheumatic heart disease among other conditions that could affect their health and development. District Early Intervention Centers refer children with health concerns to existing health facilities for necessary treatment and intervention at no cost to the family. The RBSK scheme also supports regional collaborative centers to provide essential training to medical and professional staff. Standardized training modules and tracking tools enable national surveillance of childhood diseases and access gaps, which in turn strengthens the understanding of disease burden and enables informed health policy decisions.

There is still great unmet need for pediatric cardiac care in India, but recognition of congenital heart disease and rheumatic heart disease in the government's health priorities and coverage schemes means that children with heart disease will not be excluded from the benefits of future health system strengthening efforts.

Few developing countries will achieve UHC without international support. The global health community and donors, together with ministries and policymakers, must consider the trends of the future over those of the past when providing technical assistance and development aid for health. The up-front costs of increasing coverage to diagnose and treat children with heart disease will have enormous dividends in quality years of life gained for millions of children and the financial protection offered their families.

Setting the Stage for Action

The global health community has embraced the SDGs, including the target to end preventable child deaths. It must be acknowledged that the deaths of millions of children with heart disease are preventable.

Even in the poorest regions, we must assume that development will continue with forward momentum and the burden of pediatric heart disease will become more apparent as overall disease burden shifts away from communicable diseases. Treating children with heart disease is not only the ethical thing to do, but also represents large health and economic gains.

All children have a right to the care that enables them to live full and productive lives. Researchers, policymakers and funders committed to improving child health have the opportunity, and responsibility, to include the needs of children with heart disease in the global health agenda. Health systems that are capable of investing in pediatric cardiac care and coverage, but continue to choose not to are telling these children that their lives and potential do not matter.

The burden of heart disease in children exists, and so does the ability to ease it. By including pediatric cardiac care and rheumatic heart disease prevention in the strategic planning

considerations of health systems undergoing transformation, the global health community can set the stage for children with heart disease across the globe to enjoy the same quality of life as their peers in countries and regions with greater access to surgery. It is only then that it will even be possible to end preventable child deaths.

Change begins with the decision to act; the decision to act is preceded by knowledge of the problem. We have the knowledge. It is up to the global health community to act. The Call to Action to be released in Fall 2016 will provide specific recommendations to help end preventable child deaths from heart disease.

All children have a right to the care that enables them to live full and productive lives. Health systems that are capable of investing in pediatric cardiac care and coverage, but continue to choose not to are telling these children that their lives and potential do not matter.



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Series Synopsis

Children's HeartLink is issuing a series of discussion briefs over a 2-year period to engage audiences and bring attention to congenital and rheumatic heart disease within the context of the global health agenda.

Our **first brief**, issued in April 2015, 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.

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

Finally, in our **fourth brief** we will present a call to action within the global pediatric care agenda that melds with the broader global health agenda. We will discuss 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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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

(to be released Fall 2016)

