



## The Invisible Child

### Call to Action in the COVID-19 Pandemic

---

The COVID-19 pandemic has shined a harsh light on gaps in public health preparedness for infectious diseases globally and has demonstrated how connected the world is. It has also revealed the weaknesses in health systems and has amplified existing health inequities around the world. We now know that people with noncommunicable conditions like cardiovascular disease and diabetes have a higher risk of suffering and dying from COVID-19. In addition, the public health lockdowns have resulted in delays for elective surgical procedures, screening and diagnosis, a lack of essential medicines and technologies, and limited access to health workers and support services that have been reassigned to care for COVID-19 patients. These conditions have exacerbated limited access to health services that were already underprioritized and underfunded. **Sadly, this includes services for children with heart disease, care that is never truly elective for a population that doesn't have a voice and does not "choose" to get sick.**

Caring for children is a universal goal and no matter the region or culture, children must be at the center of development. During these unprecedented times, we want to reiterate the needs of children with heart disease and make sure they do not lose the gains in access to quality care that we have all fought hard to achieve. We have a responsibility to continue to call attention to inequities in pediatric cardiac care and

demand changes in health policies that increase quality and access, like we did with our four-part series *The Invisible Child*.

Just as the novel coronavirus does not discriminate in who gets infected, neither does heart disease in children. And just as the COVID-19 disease is harder on the most vulnerable and poorest populations, so does heart disease exact a higher toll on children in low- and middle-income countries (LMICs).

Today, more than ever, we want to renew *The Invisible Child Call to Action* and ask leaders in health and development to acknowledge pediatric heart disease within child health goals. We call for leadership, investment, better capacity, community engagement and accountability. Epidemic preparedness and care for children with heart disease depend on strong health systems, a resilient, qualified, well-resourced health workforce and continued health investments. Pediatric cardiac care is not luxury treatment. It is lifesaving care deserved by all children in need.

As countries continue to refine their pandemic response and preparedness, we want to make sure children with heart disease are not again forgotten. Here are our **four asks from global health leaders during the COVID-19 pandemic:**

## Continue to increase capacity to care for children with heart disease

---

- ① Assure there are no new disruptions to the delivery of routine care for children with heart disease by evaluating current capacity and wait times for surgical and other lifesaving procedures and through provision of digital health services, wherever possible.
- ② Harness private sector capacity and innovations in areas of digital, primary care and diagnostics, task shifting if available.
- ③ 2030 Goal: The prevention of rheumatic heart disease and the treatment of heart disease in children will be integrated into all health system strengthening and surgical scale-up plans.

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

**Maintain the investments to increase capacity** for pediatric cardiac care at secondary and tertiary hospitals, especially in regions where 1<sup>st</sup> 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 training to increase the technical capacity and financial sustainability of local hospitals.

## Continue to build the pediatric cardiac workforce

---

- ① Evaluate workforce needs and assure pediatric cardiac specialists remain a committed resource to pediatric cardiac care.
- ② Assure that training of pediatric cardiac professionals continues through remote education.
- ③ 2030 Goal: 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 and other technical personnel.

## Close the data gap

---

① Track and collect data on the effects of the COVID-19 pandemic on children with heart disease to inform clinical practice and burden of disease, and to inform public health officials on the relative risk of delaying care.

② 2030 Goal: 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 relevant to low-resource settings.

## Finance pediatric cardiac care

---

① As financial resources are constrained by the pandemic, assure long-term investment in the well-being of children continues to be a guiding value of health investments and a key priority.

② Support families of children with heart disease for additional expenses related to getting their children care during the pandemic, especially families in immediate need of financial protection to avoid further falling into poverty.

③ 2030 Goal: 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.