

Childhood-Onset Heart Disease Fact Sheet

The Global Burden of Childhood-Onset Heart Disease

- 🌐 Congenital heart disease (CHD) occurs in 1 in 100 births and makes up 1/3 of all birth defects
- 🌐 1.35 million children are born with CHD worldwide every year
- 🌐 CHD is a top cause of infant mortality globally
- 🌐 1 in 4 children with CHD need infant surgery to survive; most need surgery during childhood
- 🌐 Rheumatic heart disease (RHD) is caused by untreated infection and can be prevented with antibiotics
- 🌐 RHD affects 39 million people worldwide and kills 319,000 people each year
- 🌐 RHD is the most common heart problem that develops during childhood
- 🌐 RHD is rare in rich countries and common in many poor countries and communities

CHD and RHD are chronic diseases and need life-long care

Lifelong Impact of Childhood-Onset Heart Disease

- 🌐 High risk of heart rhythm problems, heart failure, valve failure, stroke, and heart infections
- 🌐 Need for one or more open heart surgery
- 🌐 High rates of pregnancy-related health problems and death
- 🌐 Need for long-term use of blood thinners and/or antibiotics
- 🌐 Need for life-long access to regular heart checkups including echo and EKG

Global Barriers to the Right to Health in Childhood-Onset Heart Disease

- 🌐 90% of the world's children have no access to heart care including life-saving heart surgery
- 🌐 Less than 20% of the world's population can access needed heart diagnosis and on-going treatment
- 🌐 Patients and families face a high financial burden due to the cost of care
- 🌐 The majority of RHD and CHD adults worldwide do not get needed long-term care
- 🌐 Most women with CHD and RHD do not get needed pregnancy management
- 🌐 Significant global and in-country outcomes disparities exist based on income, race, and ethnicity
- 🌐 The cost of treatment commonly results in catastrophic health costs
- 🌐 Patients often face social stigma and discrimination in employment and education

Selected Sources:

The invisible child: childhood heart disease in global health. Lancet. 2017; Global, regional, and national burden of congenital heart disease, 1990–2015 Lancet, 2020; Global, Regional, and National Burden of Rheumatic Heart Disease, 1990–2015; Structural Heart Diseases. The World Bank:2017; Medical management of rheumatic heart disease: a systematic review of the evidence. Cardiology in review, 2018; Guidelines for the Management of Adults with Congenital Heart Disease, Journal of American College of Cardiology, 2018.