

# Declaration of the Rights of Individuals Affected by Childhood-Onset Heart Disease

As set forth in the World Health Organization's founding constitution, the highest attainable standard of health is a fundamental right of every human being. We, the undersigned organizations, believe that *every* person affected by childhood-onset heart disease has the right to receive all needed services to reach their full potential. This universal right is shared by all affected people worldwide regardless of age, gender, ethnicity, race, nationality, religion, or socioeconomic status. The following are the key principles:

**Principle 1:** Every person with childhood-onset heart disease should receive the *health care they need* that is *timely, affordable, accessible, safe, patient-centered, and life-long*.

1. In support of the right to protection from preventable causes of child mortality and morbidity set forth in the United Nations (UN) Convention of the Rights of the Child, every child born with a heart defect has the right to timely diagnosis and treatment. Children and teens with rheumatic fever should receive timely treatment to prevent or minimize heart damage, and those who have developed rheumatic heart disease have the right to timely disease detection and care.
2. All adults and children living with congenital heart disease, rheumatic heart disease, or other childhood-onset heart conditions must have life-long access to cardiac care that is safe, timely, affordable, and patient-centered.
3. Patients and their families should receive the information they need to fully understand their health status and health-related quality of life and participate meaningfully in health-related decision-making. This information should be provided in a format that responds to their individual developmental, cultural, and educational needs to ensure optimal understanding.

**To facilitate these rights the following actions must be taken:**

1. States must ensure the availability, accessibility, affordability, and safety of treatment facilities for childhood-onset heart disease.
2. Relevant government authorities and service providers must be held accountable for maintaining the highest possible standards of care for people with congenital heart disease, rheumatic heart disease, and other forms of childhood-onset heart disease.
3. Accountability should be monitored through regular collection, analysis, and dissemination of data to inform national and subnational laws, policies, and programs that affect health and survival.
4. Patients and families should have access to relevant and meaningful data to inform their health care decisions.
5. Government efforts should ensure that even the most marginalized populations have access to the highest-quality level of care.

**Principle 2:** Every person with childhood-onset heart disease should live *free of discrimination* and have full access to the *education, employment, and social benefits and services* necessary to ensure their life-long well-being and full participation in society.

1. As defined in the UN Convention on the Rights of Persons with Disabilities, individuals with childhood-onset heart disease have the right to full participation and inclusion in society.
2. Affected people should be protected from educational, employment, and social barriers resulting from physical impairment and health-related stigma and discrimination.

3. Appropriate training and accommodations must be provided to ensure that every person with childhood-onset heart disease can reach their full potential.
4. Financial assistance should be available to prevent poverty among patients and families impacted by economic hardship due to medical and surgical care.
5. Social support and mental health services must be provided to address the isolation and psychological challenges that can affect patients and families living with childhood-onset heart disease.

**To facilitate these rights the following actions must be taken:**

1. States must enact legislation that protects the educational, economic, and social rights of individuals with childhood-onset heart disease and ensures their right to medical privacy.
2. Congenital heart disease, rheumatic heart disease, and other forms of childhood-onset heart disease should be included in laws and policies addressing the needs of those affected by chronic disease and disability.
3. Effectiveness should be monitored through the regular collection, analysis, and dissemination of data addressing the impact of childhood-onset heart disease on education, employment, and social inclusion.
4. States should report on the burden of childhood-onset heart disease to the International Covenant on Economic, Social and Cultural Rights, who in turn should encourage States to report through pre-existing reporting mechanisms.
5. Governments should execute educational campaigns to promote awareness of childhood-onset heart disease and ameliorate associated stigma.
6. Government, professional organizations, and civil society should promote the development of patient and family organizations able to provide social support, education, and advocacy on behalf of their community.

**We declare our commitment to actively pursue the demands of this declaration to ensure its impact.**