

Declaration of Rights of Individuals with Childhood-Onset Heart Disease

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**.

- States must ensure the availability, accessibility, affordability, and safety of treatment facilities
- Relevant government authorities and service providers *must* be held accountable for maintaining the highest possible standards of care
- Accountability should be monitored through regular collection, analysis, and dissemination of data to inform laws, policies, and programs that affect health and survival
- Patients and families should have access to relevant and meaningful data to inform their health care decisions
- 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.

- Legislation to protect educational, economic, and social rights and *ensures* right to medical privacy
- Inclusion of CHD and RHD in all policies addressing needs of those with chronic disease and disability
- Monitoring *of the impact* of childhood-onset heart disease on education, employment, and social inclusion through regular collection, analysis, and dissemination of data
- Government educational campaigns to promote awareness of childhood-onset heart disease and ameliorate associated stigma
- Government, professional organizations, and civil society should promote the creation of patient and family organizations to provide support, education, and advocacy for their community