

The Declaration of the Rights of Individuals Affected by Childhood-onset Heart Disease **Information and Action Toolkit**



**Global
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Global Alliance for Rheumatic
and Congenital Hearts

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What is the Declaration of Rights for Individuals with Childhood-onset Heart Disease?

The Declaration of Rights for Individuals with Childhood-Onset Heart Disease is a formal document stating the basic health rights for every person affected by congenital or rheumatic heart disease (CHD and RHD). It also lists actions that governments should take to meet these rights. The full text and summary of this document are included in this packet.

Why do CHD and RHD patients need their own health rights declaration?

In 1948 over 190 countries signed a declaration stating that every person has the right to the highest level of health. Additional declarations listing the health rights of children and the disabled have been signed by over 150 countries. CHD and RHD children and adults have the same right to health as every other citizen. But many governments do not provide the services needed for them to achieve these rights. The goal of this declaration is to raise awareness of the ways in which CHD and RHD patients are being denied their right to health. It can be used to educate patients, families, health professionals, policy makers, and the general public about the needs of people with CHD and RHD. It can also be used as a tool to promote needed actions by governments and other policy makers.

Why should individuals and organizations sign the rights declaration?

When you or your organization signs the declaration, you are making public your support of the basic health rights for CHD and RHD patients. All over the world, hundreds of medical providers, humanitarian groups, and patient organizations are working to improve and prolong the lives of CHD and RHD patients. Patient and families are striving to achieve the right to health they know they deserve. Signing the declaration will bring together this community and demonstrate our collective power and voice.



What else can I do to support the campaign for CHD and RHD health rights?

Raise awareness of CHD and RHD rights through social media.

The attached social media toolkit lists hashtags, handles, and sample tweets that you can use to get out the message. We hope you will follow Global ARCH on twitter and Instagram and re-tweet the RHD and CHD rights campaign messages.

Help grow the list of signers

If you are a member organization, let your members know about the CHD/RHD rights campaign and encourage them to sign via the link. If you work with other organizations that serve RHD and CHD patients, let them know that their endorsement will make a difference. If you are a CHD/RHD patient or family member, encourage friends and family to sign via Facebook and other social media.

Use the CHD/RHD Rights Declaration to support your advocacy efforts

Many CHD and RHD organizations meet with health professionals, government officials, and other policy makers in their community to educate them about the needs of their community and push for needed change. Including the declaration in these conversations will highlight the fact that CHD and RHD services are part of every citizen's right to health. You can also use the specific list of government services listed to guide conversation about what your community needs most. If you visit the Global ARCH website you will find additional information and materials to use for advocacy.

Join the Global ARCH Alliance

We encourage all organizations serving CHD and RHD patients and families to become a member of Global ARCH. These include patient and family organizations as well as humanitarian and professional organizations. Member organizations are listed in our global directory of CHD and RHD organizations and are offered opportunities to connect, learn from, and collaborate with colleagues around the world. Membership is free and an application form can be found at: www.global-arch.org/alliance-membership

We also encourage all individuals that share our commitment to improving and prolonging the lives of CHD and RHD patients to become a Global ARCH supporter. Signing up is free and you will receive regular updates and invitations to participate in Global ARCH activities. You can become a supporter at. www.global-arch.org/alliance-membership



Social Media Toolkit

Hashtags: #RightsDeclaration
#CHD
#RHD

Handles: Twitter: @GlobalARCH18
Facebook: GlobalARCH18
Instagram: global_arch18
LinkedIn: Global ARCH

English Sample Tweets – feel free to create your own!

- Everyone with childhood-onset heart disease should receive health care that is affordable and safe. Sign on the #RightsDeclaration here: bit.ly/3he2g2x. #CHD #RHD
- Everyone with childhood-onset heart disease should live free of discrimination and stigma
- Everyone with childhood-onset heart disease should have access to the education, a job, and social support. #RightsDeclaration #CHD #RHD
- Only 10% of the population has access to the care they need. Let's change that! #RightsDeclaration #CHD #RHD
- Everyone with rheumatic heart disease deserves surgery when they need it. #RightsDeclaration #CHD #RHD



Every person with childhood-onset heart disease has the right to health.

They have the right to heart care that is:

- Affordable
- Accessible
- Safe
- High-quality
- Patient-centered
- Life-long

They have the right to well-being including:

- Protection from stigma
- Social inclusion
- Education
- Employment
- Medical privacy
- Social benefits

To achieve these rights governments must:

- Fully fund CHD/RHD healthcare including detection, surgery, and long-term care
- Collect and report information on CHD/RHD health and social well-being
- Create and enforce quality standards for CHD/RHD care
- Share health information with patients and include them in decision-making
- Include CHD/RHD in existing disease and disability services, benefits, and protection
- Legally protect CHD/RHD patients from health-related discrimination
- Provide CHD/RHD patients needed educational, employment, and social services
- Run CHD/RHD awareness campaigns to combat stigma
- Promote and support CHD/RHD patient and family organizations

The Declaration of Rights for Individuals Affected by Childhood-Onset Heart Disease
To read the full text and to learn more visit www.global-arch.org



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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.

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.

About the Global Alliance for Rheumatic and Congenital Hearts

The Global Alliance for Rheumatic and Congenital Hearts (Global ARCH) is an alliance of organizations and individuals that speak out for congenital and rheumatic heart patients. Working together we can help every heart stay healthy – all life-long. In 2018 Global ARCH became incorporated in the United States.

Global ARCH began with a group of congenital heart disease (CHD) and rheumatic heart disease (RHD) group leaders, each directly affected by childhood-onset heart disease. They shared a vision of transforming global CHD and RHD outcomes through empowering patient and family-led organizations.

Global ARCH helps RHD and CHD organizations connect and collaborate on activities to promote the life-long well-being of people with childhood-onset heart disease. We also partner with health professionals and humanitarian organizations to advocate for better services for every person affected by childhood-onset heart disease.

Member organizations share ideas and resources through:

- The Global ARCH website and social media pages
- Member discussion forums
- Training sessions
- Educational webinars
- In-person meetings
- Global ARCH-led education, advocacy, and educational activities.

Now, with your help, we can do *even more*.

If you haven't already, we encourage you and your organization to join Global ARCH as a member organization or as a Global ARCH supporter. By joining, you will join the global fight for the health rights for every person affected by childhood-onset heart disease.

Join Global ARCH: www.global-arch.org/alliance-membership

Website: <http://www.global-arch.org>

Email: info@global-arch.org

WorldBeat Newsletter: www.global-arch.org/worldbeat-newsletter/

Read more about our history: www.global-arch.org/our-history

