CHD/RHD Needs are Human Rights:

What do we need? How do we get there?

Amy Verstappen, MGH

President, Global Alliance for Rheumatic and Congenital Hearts

Global ARCH
Global Alliance for Rheumatic and Congenital Hearts

U.S-based Nonprofit
Alliance of Organizations

Global ARCH
Global Alliance for Rheumatic and Congenital Hearts

Mission: Improve worldwide life-long outcomes in childhood-onset heart disease through empowering patient and family organizations

Global ARCH
Global Alliance for Rheumatic and Congenital Hearts

Rheumatic Heart Disease

- Starts in Childhood
- Untreated Strep
- Disease of Poverty

Congenital Heart Disease

- Inborn
- Unknown cause
- Affects all

CHD and RHD need

- Life-long Cardiac care
- Surgery - 90% no access
- Cardiac medications
- Cardiac testing
- Support and information

RHD more common than CHD in countries with poor CHD survival

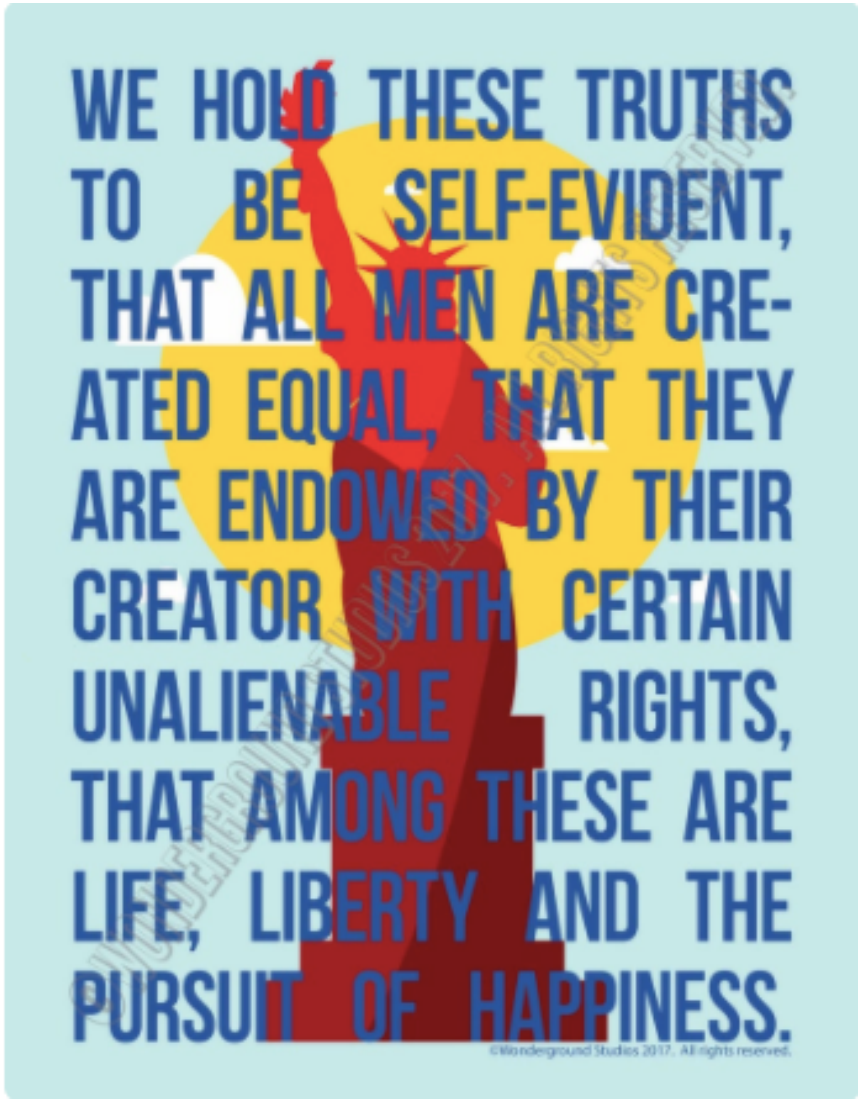
Global ARCH
Global Alliance for Rheumatic and Congenital Hearts

27 groups
24 countries
First CHD/RHD Rights Declaration

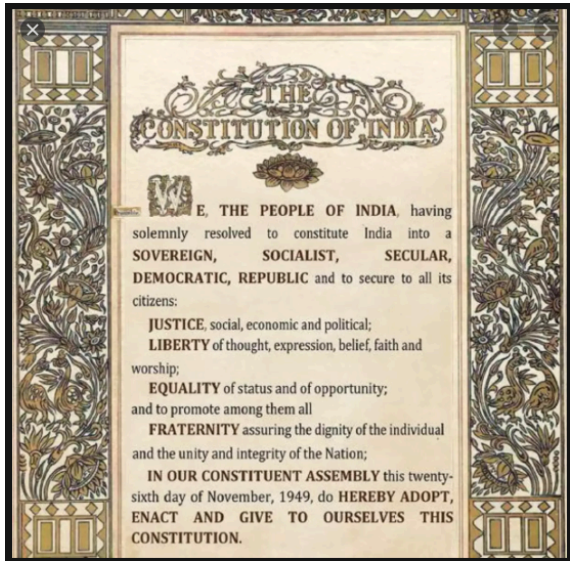
INTERNATIONAL CONGENITAL HEART LEADERSHIP SUMMIT

Global ARCH
Global Alliance for Rheumatic and Congenital Hearts

What is a Rights Declaration?



- Address injustice
- Collective statement of self-worth
- Aspirational
- Call to action



THE CONSTITUTION OF INDIA

WE, THE PEOPLE OF INDIA, having solemnly resolved to constitute India into a SOVEREIGN, SOCIALIST, SECULAR, DEMOCRATIC, REPUBLIC and to secure to all its citizens:

JUSTICE, social, economic and political;

LIBERTY of thought, expression, belief, faith and worship;

EQUALITY of status and of opportunity;

and to promote among them all

FRATERNITY assuring the dignity of the individual and the unity and integrity of the Nation;

IN OUR CONSTITUENT ASSEMBLY this twenty-sixth day of November, 1949, do HEREBY ADOPT, ENACT AND GIVE TO OURSELVES THIS CONSTITUTION.

"A formal declaration enumerating the rights of the citizen"

Global ARCH
Global Alliance for Rheumatic and Congenital Hearts

"The enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being"

Founding Constitution, World Health Organization, 1948

- 194 Countries

Global ARCH
Global Alliance for Rheumatic and Congenital Hearts

Getting CHD/RHD on the Government Agenda

- Policies
- Laws
- Regulations
- Standards
- Funding

Global ARCH
Global Alliance for Rheumatic and Congenital Hearts

"Declaration of the Rights for Individuals Affected by Childhood-onset Heart Disease"

http://www.global-arch.org/declaration-of-rights-of-individuals-affected-by-childhood-onset-heart-disease/

Global ARCH
Global Alliance for Rheumatic and Congenital Hearts

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.

Declaration of the Rights for Individuals Affected by Childhood-onset Heart Disease"

released January, 2020

Global ARCH
Global Alliance for Rheumatic and Congenital Hearts

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***

- Protection from childhood mortality
- High-quality care
- Health education
- Involvement in our own care

Global ARCH
Global Alliance for Rheumatic and Congenital Hearts

Needed Government Actions

- **Government job**: ensure accessible, affordable, safe, high-quality care
  - **Set highest possible standards of care**
  - **Accountability**
  - **Measure – collect data**
  - Use data to **create laws**, **policies**, and **programs to improve health**
- **Transparency** – Patients and families get data to inform decisions.
- **Equity -** marginalized populations get highest-quality care.

Global ARCH
Global Alliance for Rheumatic and Congenital Hearts

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.

CRPD 10
Convention on the Rights of Persons with Disabilities
2006 - 2016

- Protection from stigma
- Training and accommodation
- Disability/family leave benefits
- Social support and mental health services

Global ARCH
Global Alliance for Rheumatic and Congenital Hearts

Needed Government Actions

- **Laws** to protect educational, economic, and social rights
- **Include CHD and RHD** in disability programs and policies
- **Measure impact of CHD/RHD on** economic, social, mental well-being
- **Educate public** on CHD/RHD and combat stigma
- Promote **patient and family organizations**

Global ARCH
Global Alliance for Rheumatic and Congenital Hearts

Next Steps: CHD/RHD Rights Campaign

Use the Declaration to:

- Bring together Global CHD/RHD Community
- Raise awareness of unmet needs
- Promote rights-based CHD/RHD advocacy
- Achieve needed change – better outcomes

NOT

Global ARCH
Global Alliance for Rheumatic and Congenital Hearts

"We, the undersigned organizations"

- Endorsements
- Demonstrates strength of support
  - How many supporters
  - Who they are
    - Respected organizations
    - Professional, humanitarian, and patient/family organizations
    - Global representation

Goal: 150 organizations, 1,000 individuals by December 31st

Global ARCH
Global Alliance for Rheumatic and Congenital Hearts

Getting the Word Out

- Social Media
- On-line events
- Conferences/professional meetings
- Professional journals
- Direct “meetings” with lawmakers/policymakers
  - Ex United National General Assembly

Global ARCH
Global Alliance for Rheumatic and Congenital Hearts

Audience

- P/F Organizations
- Humanitarian Organizations
- Professional Societies
- Medical organization
- Individuals
- Government

Global ARCH
Global Alliance for Rheumatic and Congenital Hearts

How can you help?

- Endorse
- Social media campaigns
  - We will provide tools – messaging, images
  - You provide collective voice

Global ARCH
Global Alliance for Rheumatic and Congenital Hearts

Global ARCH Activities

- Global ARCH Regional Networks – India, Africa, Europe
  - Define common advocacy agenda
- Opportunities to “meet” with government, WHO
- Materials – soon to come!
  - Translate from “declaration-speak” to “human-speak”
  - Infographics
  - Data

Global ARCH
Global Alliance for Rheumatic and Congenital Hearts

Patient/Family Organizations

- Use to educate members on their rights
- Use in existing campaigns and activities
  - Education
  - Awareness
  - Advocacy – use with your government
- Identify unmet needs, set priorities, define action

Global ARCH
Global Alliance for Rheumatic and Congenital Hearts

Humanitarian and Professional Organizations

- Join in Global ARCH-led activities
- Include in existing activities/education
- Advocacy –partner with P/F organizations
- Educate members about patient needs

Global ARCH
Global Alliance for Rheumatic and Congenital Hearts

Our Vision

Every person with childhood-onset heart disease lives a long and full life

Global ARCH
Global Alliance for Rheumatic and Congenital Hearts