



Advancing community health worldwide.

WEBINAR SERIES

Session 5: Tackling Cardiovascular Diseases in the Young

November 20, 2020

- Welcome
- Background: NCD Workgroup & Webinar Series
- Feature Conversation and Discussion: Tackling Cardiovascular Diseases in the Young
- Questions & Answers with Presenters & Panelists
- Wrap-Up



CORE Group convenes global community health professionals to **share knowledge, evidence, and best practices**, and then translates these into the real world with a **direct impact**.



CORE Group's NCD Interest Group works to convene those working to treat and prevent NCDs at the community level, to share resources, events, and vital information to improve their work.

Chair: Dr. Arti Varanasi, Advancing Synergy 

Staff Representative: David Imbago Jacome, CORE Group 

Today's Focus:

- Share realities impacting efforts to support children living with heart disease
- Provide advocacy, research, and frontline experiences
- Present advocacy documents and invite endorsement



Session 5: Tackling Cardiovascular Diseases in the Young

November 20 | 8:30AM – 10:00 AM EDT | Online

Hosted by the CORE Group NCD Interest Group

Session Leads: Diana Vaca McGhie, Director, Global Advocacy, American Heart Association, Jeremiah Mwangi, Executive Director, Reach, Bistra Zheleva, Vice President of Global Strategy and Advocacy, Children's Heartlink

Moderator: Bistra Zheleva



Today's Focus:

- Share realities impacting efforts to support children living with heart disease
- Provide advocacy, research, and frontline experiences
- Present advocacy documents and invite endorsement



SPEAKERS



Andrea Beaton, MD
Pediatric Cardiologist,
Cincinnati Children's
Hospital
Associate Professor,
University of Cincinnati,
Department of Pediatrics
USA



Wilson Were, MD
Senior Medical Officer,
Child Health Services,
Department of Maternal,
Newborn, Child and
Adolescent Health and
Ageing
WHO
Switzerland



Ornella Lincetto, MD
Medical Officer Newborn
Health, Department of
Maternal, Newborn,
Child and Adolescent
Health and Ageing, WHO
Switzerland



Mahesh Kappanayil, MD
Professor Pediatric
Cardiology, Lead - 3D
Printing/Innovation Lab
Amrita Institute of
Medical Sciences and
Research Centre
India

PANELISTS



Ruth Ngwaro
Advocate
Global Alliance for Rheumatic
and Congenital Hearts
USA
Co-Founder
Kenya Mended Hearts
Patient's Association
Kenya



Jeremiah Mwangi, MPP
Executive Director
Reach
Switzerland

*In collaboration
with:*



American
Heart
Association®

reach
To stop rheumatic heart disease

 **Children's HeartLink®**
HEALING HEARTS WORLDWIDE



Presenters

- Dr. Andrea Beaton, Pediatric Cardiologist, Cincinnati Children's and Associate Professor, University of Cincinnati, Department of Pediatrics, USA
- Dr. Ornella Lincetto, Medical Officer Newborn Health, Department of Maternal, Newborn, Child and Adolescent Health, WHO
- Dr. Wilson Were, Senior Medical Officer, Child Health Services, Department of Maternal, Newborn, Child and Adolescent Health, WHO

Panelists

- Dr. Mahesh Kappanayil, Professor Pediatric Cardiology, Amrita Institute of Medical Sciences, India
- Mr. Jeremiah Mwangi, Reach, Switzerland
- Ms. Ruth Ngwaro, Global Alliance for Rheumatic and Congenital Hearts, USA/Kenya



The Global Burden of Heart Disease in the Young

Dr. Andrea Beaton, Pediatric Cardiologist

Cincinnati Children's and Associate Professor

University of Cincinnati, Department of Pediatrics, USA



**A special thanks to Dr. Craig Sable
Children's National Medical Center
for sharing many of the slides in this deck**



Remembering those living with disease



CHD and RHD: How are they different

	Congenital Heart Disease	Rheumatic Heart Disease
Age of Onset	Infancy	Middle to late childhood
Preventable	No	Yes
Cause	Congenital	Acquired – GAS infection
Distribution	Similar Globally	Disproportionate LMICs

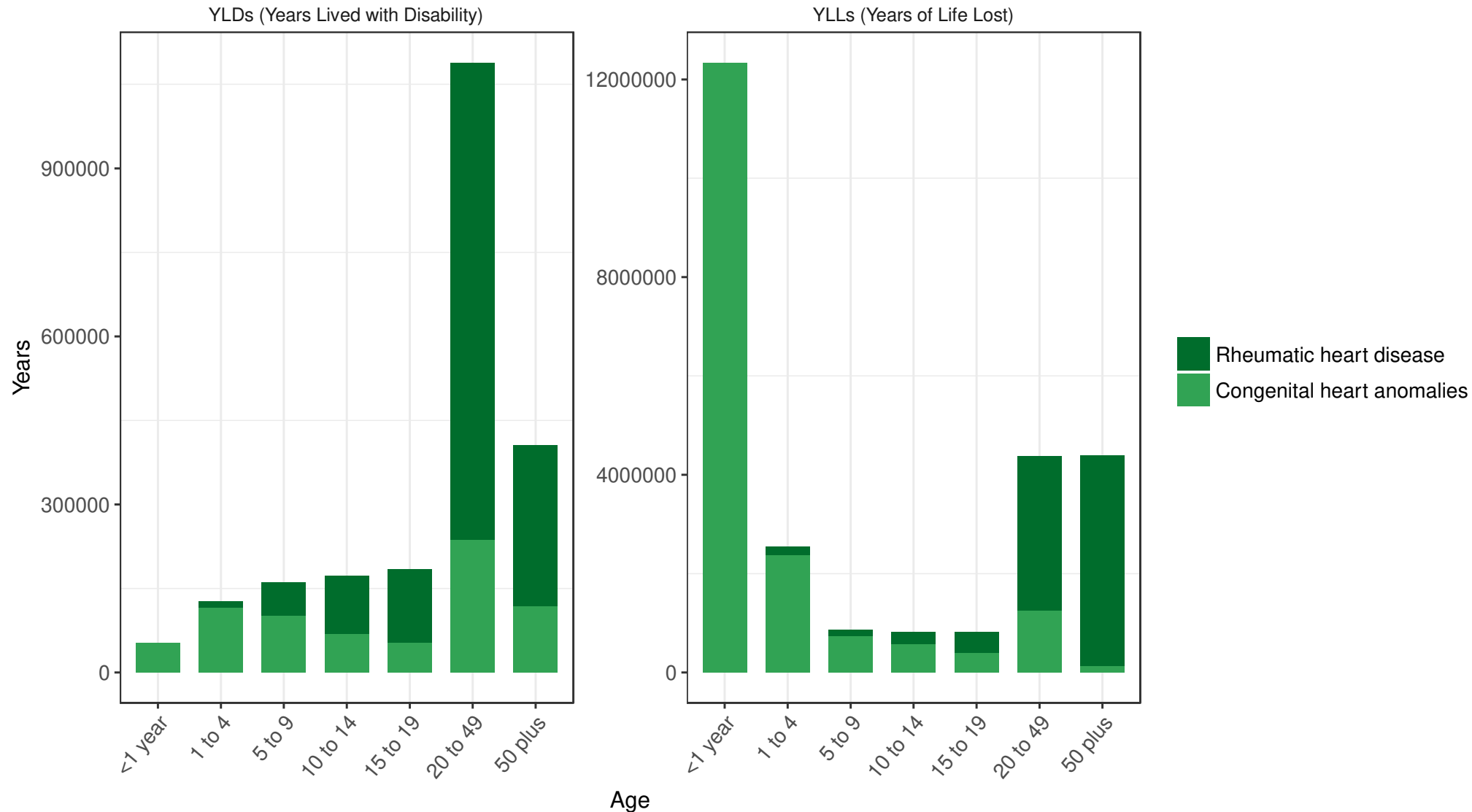


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CHD vs. RHD: Age of Onset

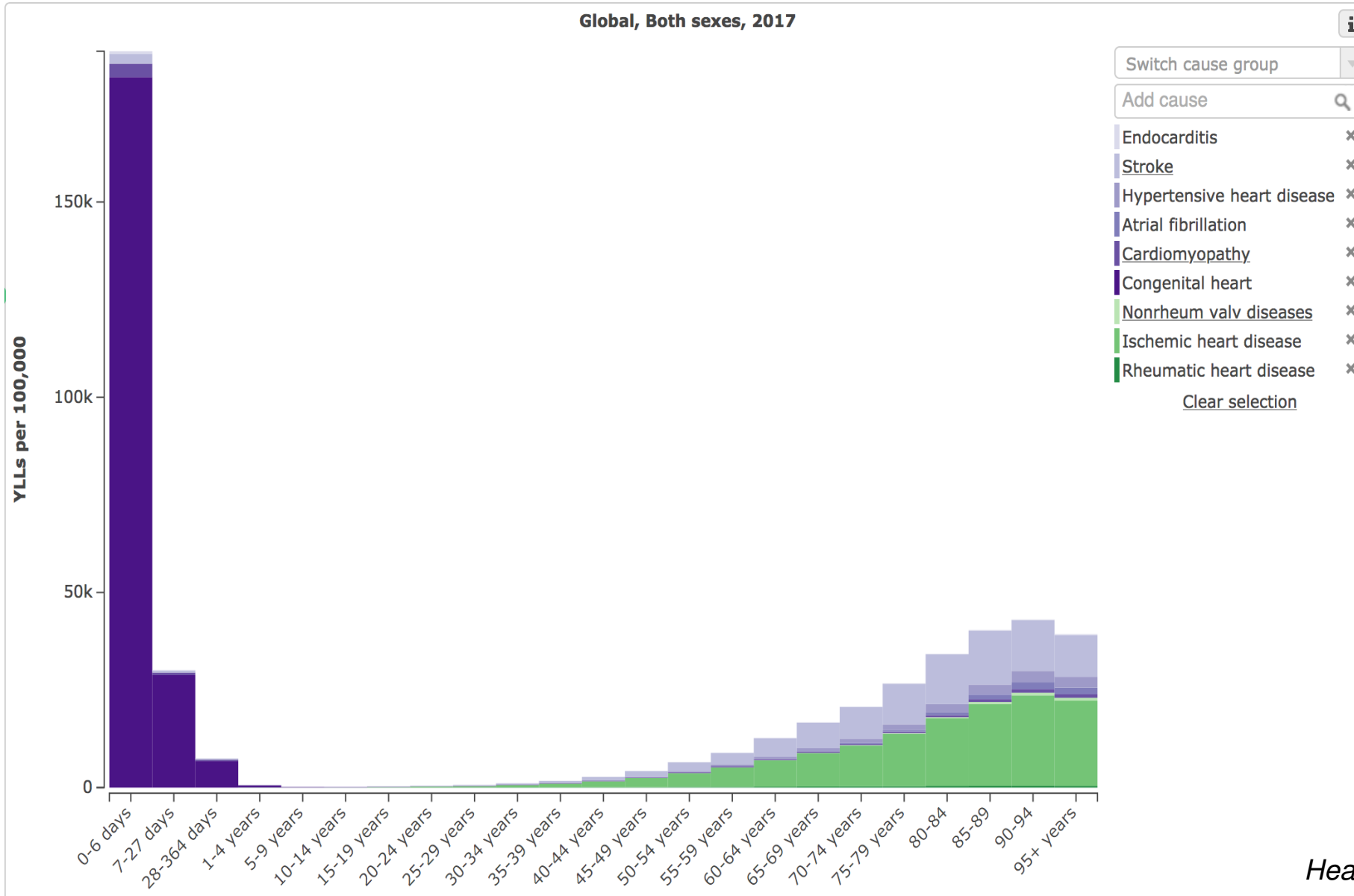


**Biggest
impact of
CHD is in the
first decade**

**RHD starts
in middle
childhood,
biggest
impact in
20s**



CHD and RHD Years of Life Lost (rate per 100,000)



**CHD deaths
highest in
first 1 year.**

**Most RHD
deaths
decades
later.**



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CHD and RHD: Etiology + Prevention



Children are born with congenital heart disease.

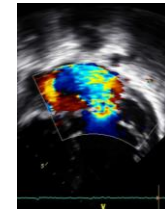
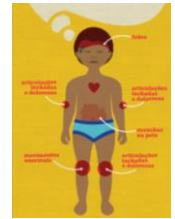
STREP A INFECTION



RHEUMATIC FEVER



RHEUMATIC HEART DISEASE



Children who are born with normal hearts acquire RHD due to untreated Group A strep infections.



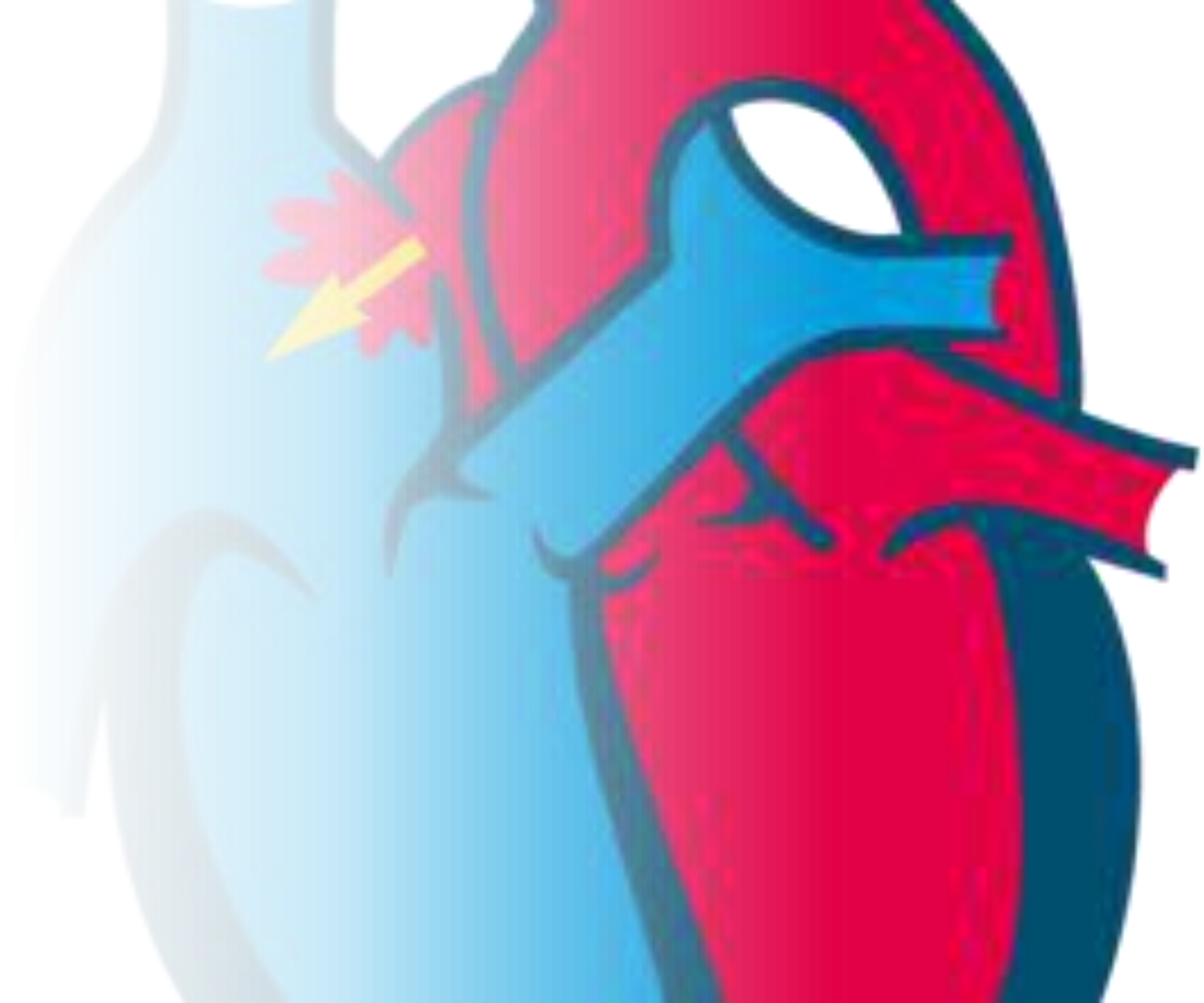
CHD and RHD: How are they different

	Congenital Heart Disease	Rheumatic Heart Disease
Age of Onset	Infancy	Middle to late childhood
Preventable	No	Yes
Cause	Congenital	Acquired – GAS infection
Rate of New Cases	Similar Globally	Disproportionate LMICs



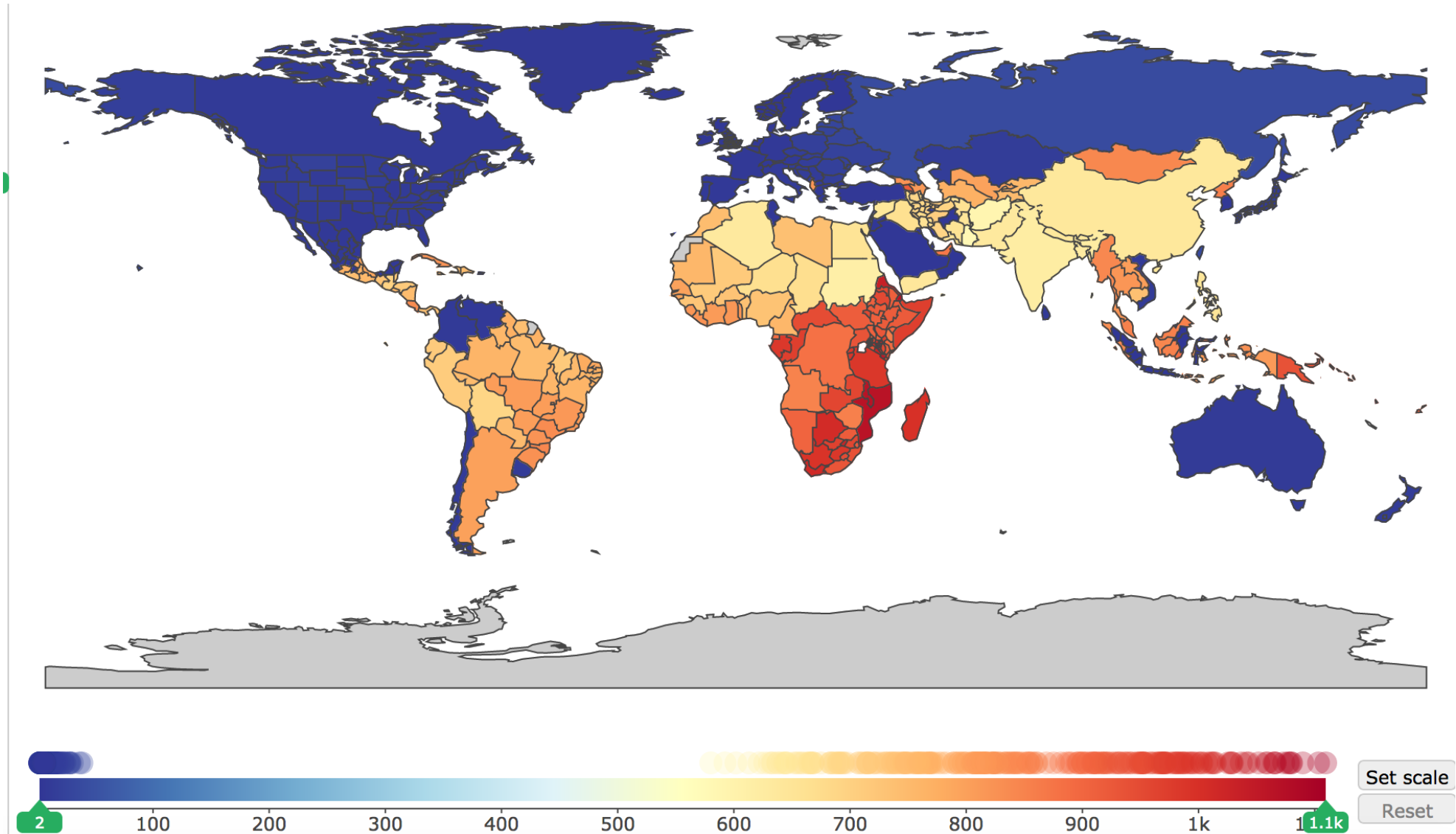
**Approximately
1.8-1.9% of
children are born
with a structural
heart defect.**

**Rates vary little
globally.**

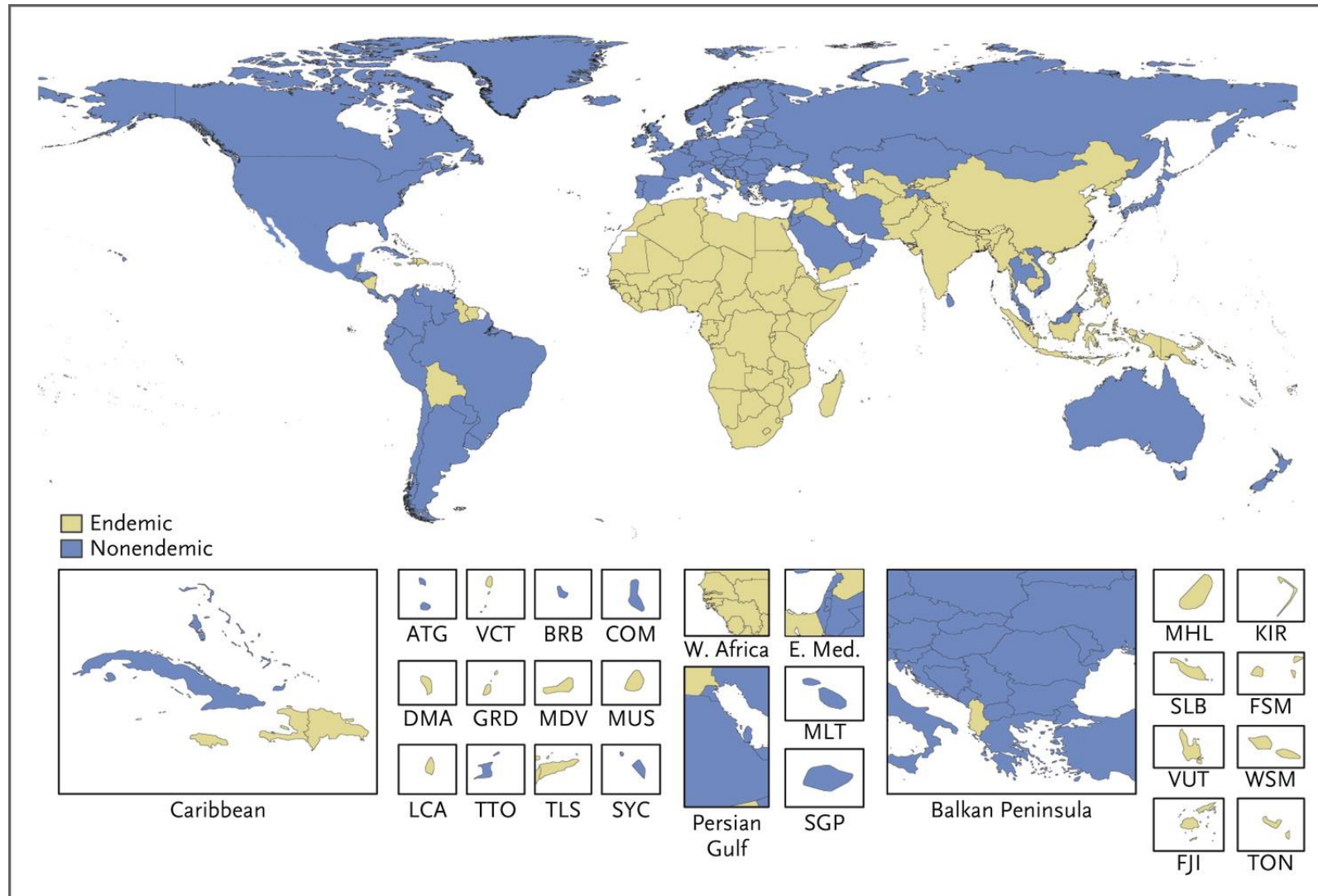


RHD Global Prevalence (2017)

**In contrast
the burden
of new RHD
is
shouldered
mainly by
LMICs**



80% of children live where RHD is endemic



CHD and RHD: How are they the same

	Congenital Heart Disease	Rheumatic Heart Disease
Lack of quality data	X	X
Disproportionate burden	X	X
Lack of Diagnostics	X	X
Need for tertiary care capacity building	X	X
Need for lifelong care	X	X
Need for increased financing for NCDs	X	X



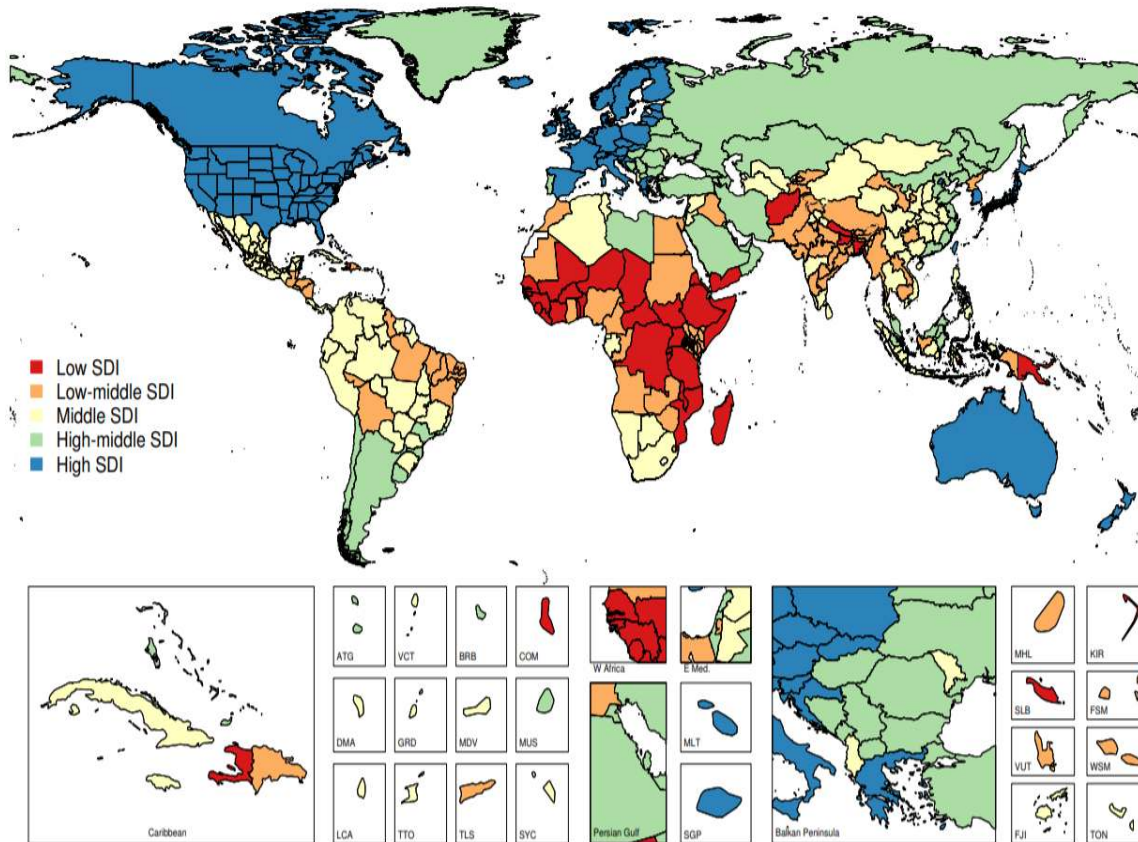
CHD and RHD: How are they the same

	Congenital Heart Disease	Rheumatic Heart Disease
Lack of quality data	X	X
Disproportionate burden	X	X
Lack of Diagnostics	X	X
Need for tertiary care capacity building	X	X
Need for increased financing for NCDs	X	X

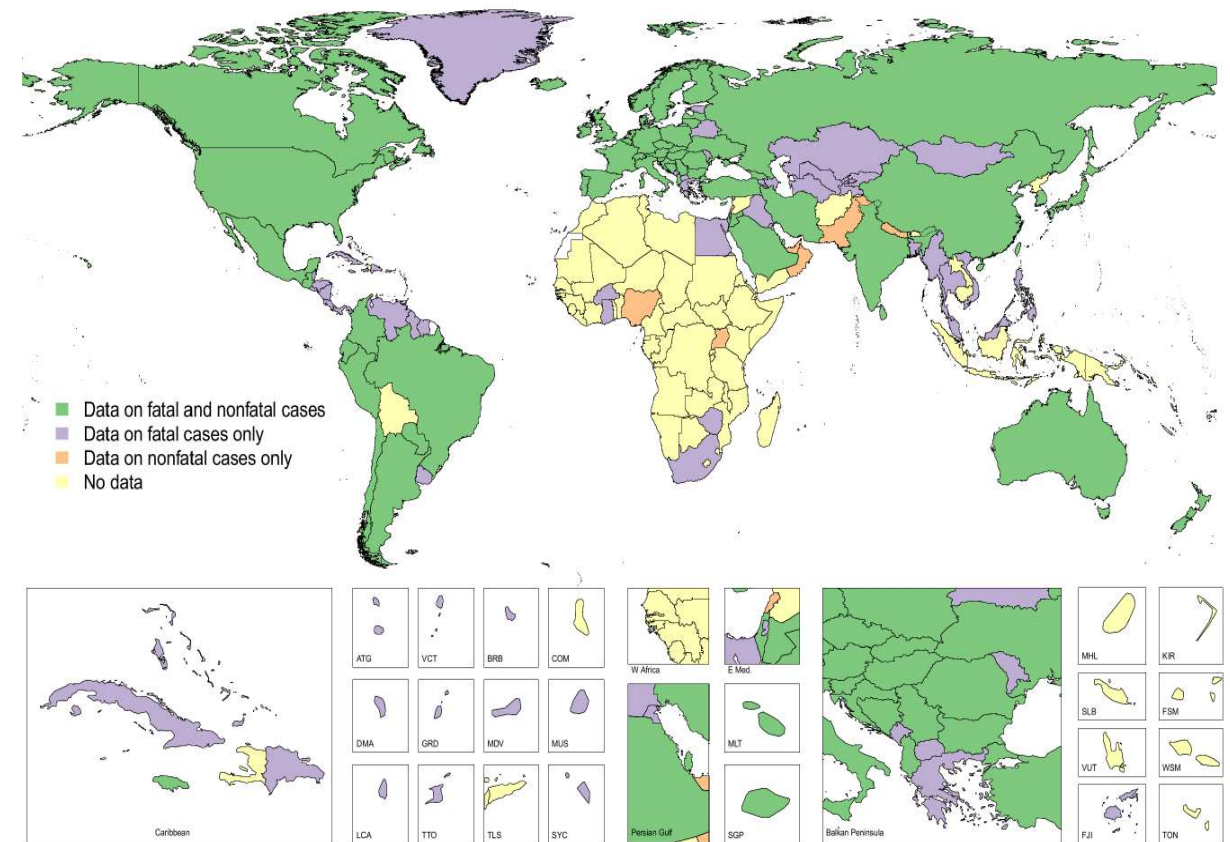


CHD and RHD: Lack of Quality Data CHD

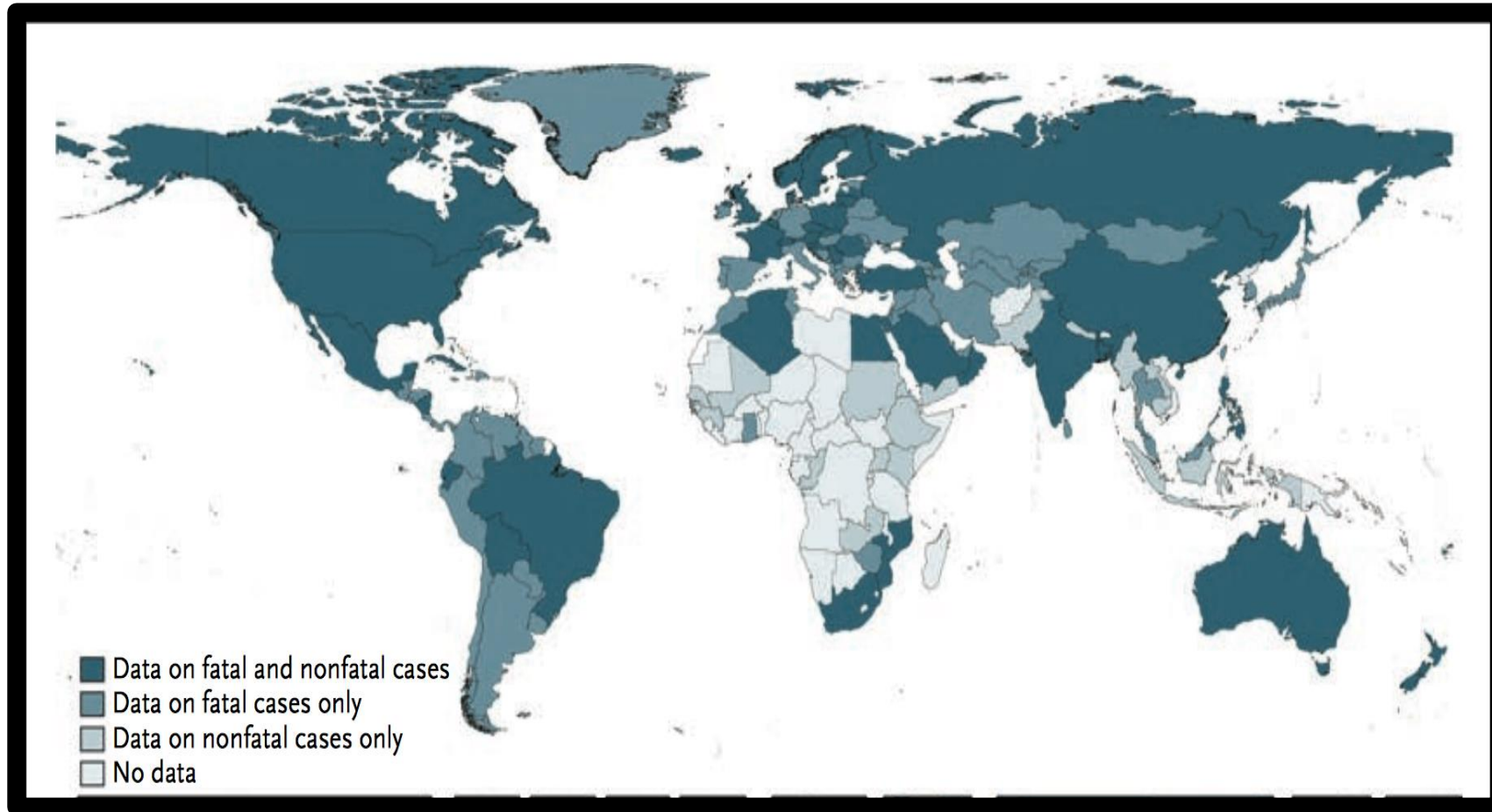
Socioeconomic Status



Data Availability



CHD and RHD: Lack of Quality Data



Only 15 of 53 countries in sub-Saharan Africa had any primary source data on fatal or non-fatal RHD

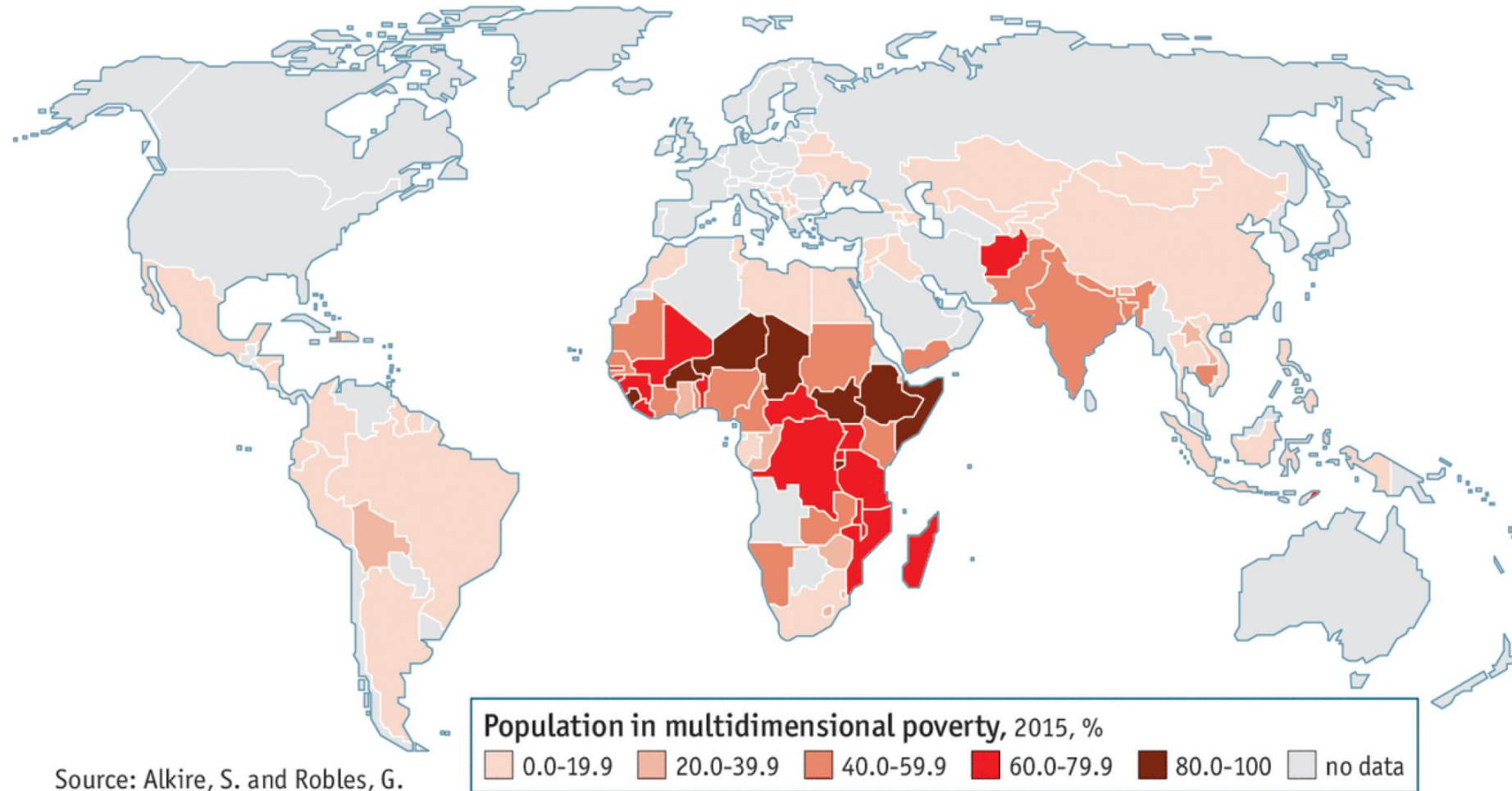


CHD and RHD: How are they the same

	Congenital Heart Disease	Rheumatic Heart Disease
Lack of quality data	X	X
Disproportionate burden in LMICs	X	X
Lack of Diagnostics	X	X
Need for tertiary care capacity building	X	X
Need for increased financing for NCDs	X	X



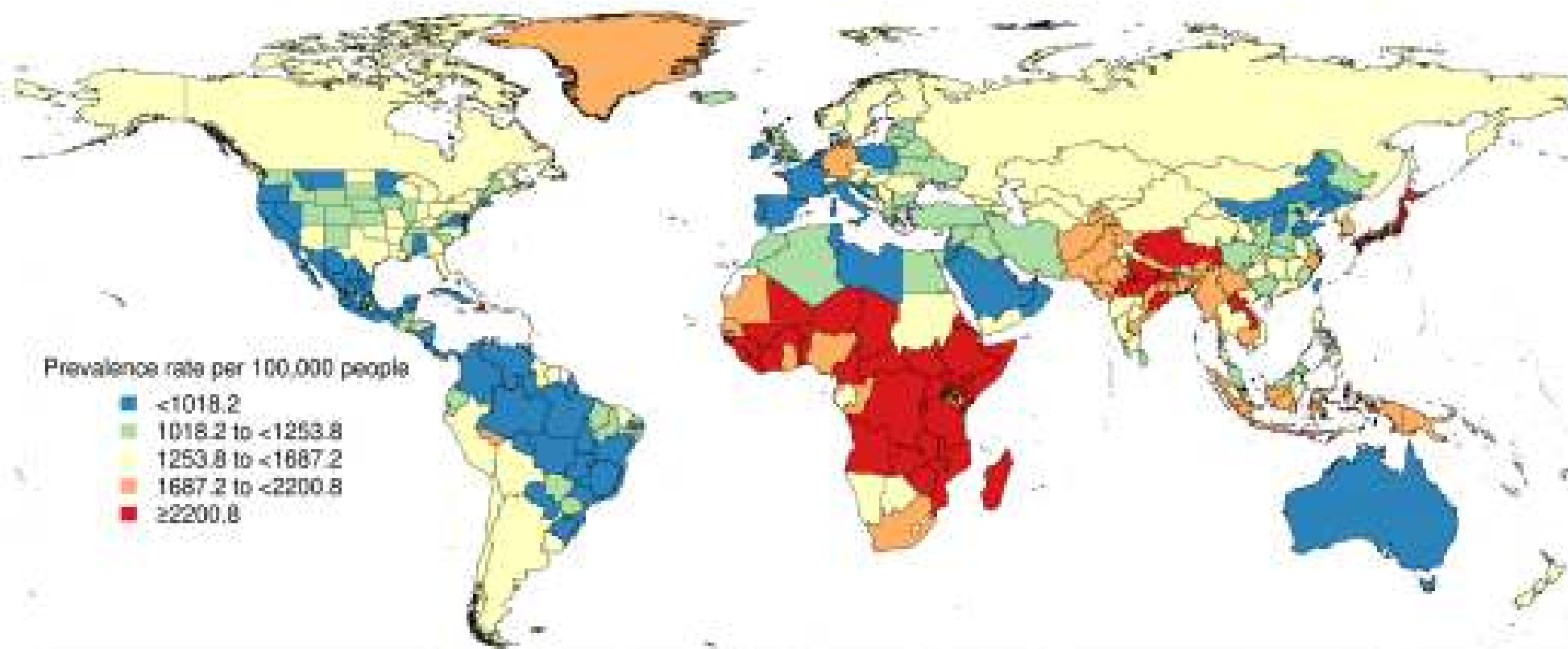
Global Population in Multidimensional Poverty (2015)



Source: Alkire, S. and Robles, G.



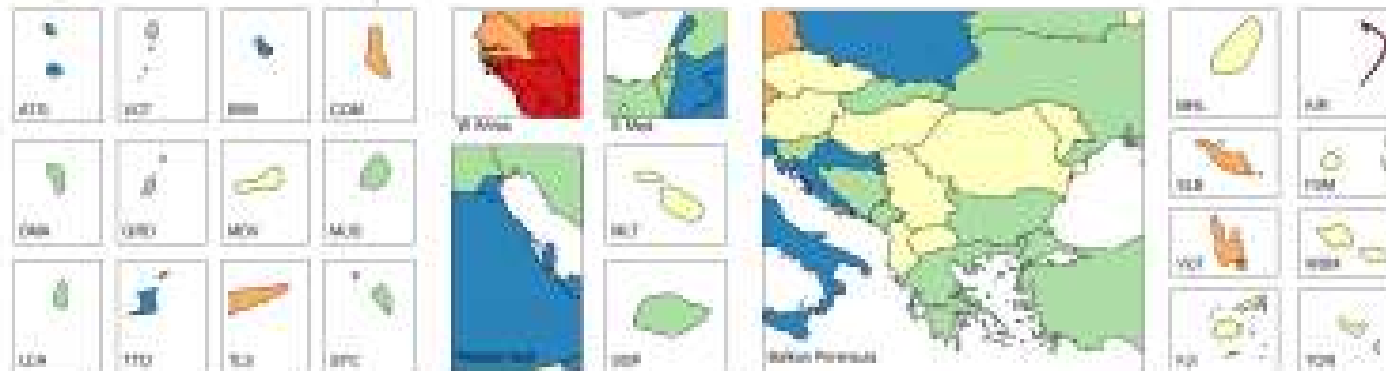
The Global Burden of Congenital Heart Disease



Prevalence
11,998,283

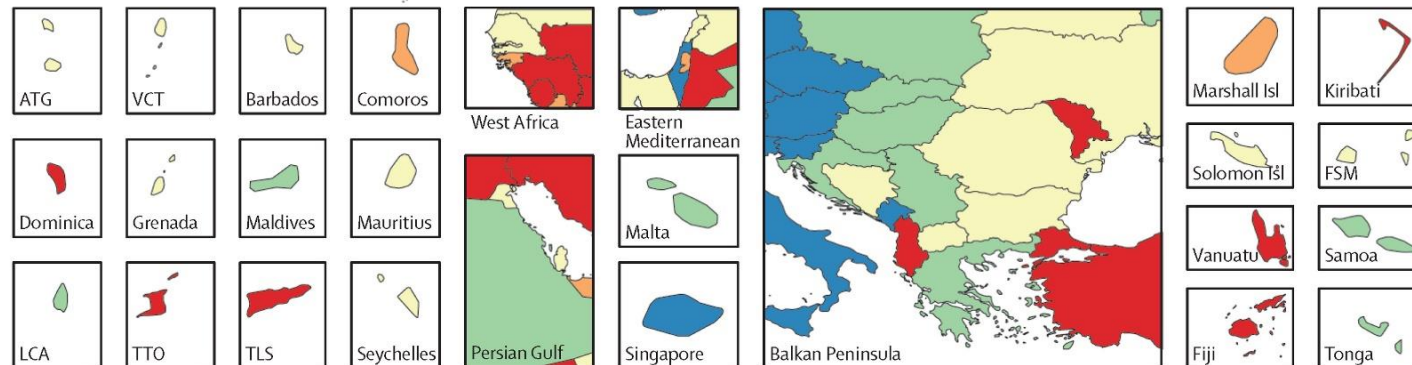
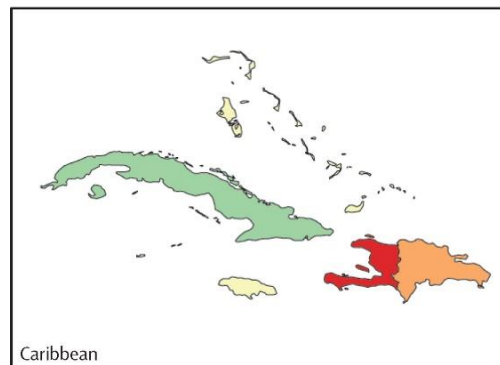
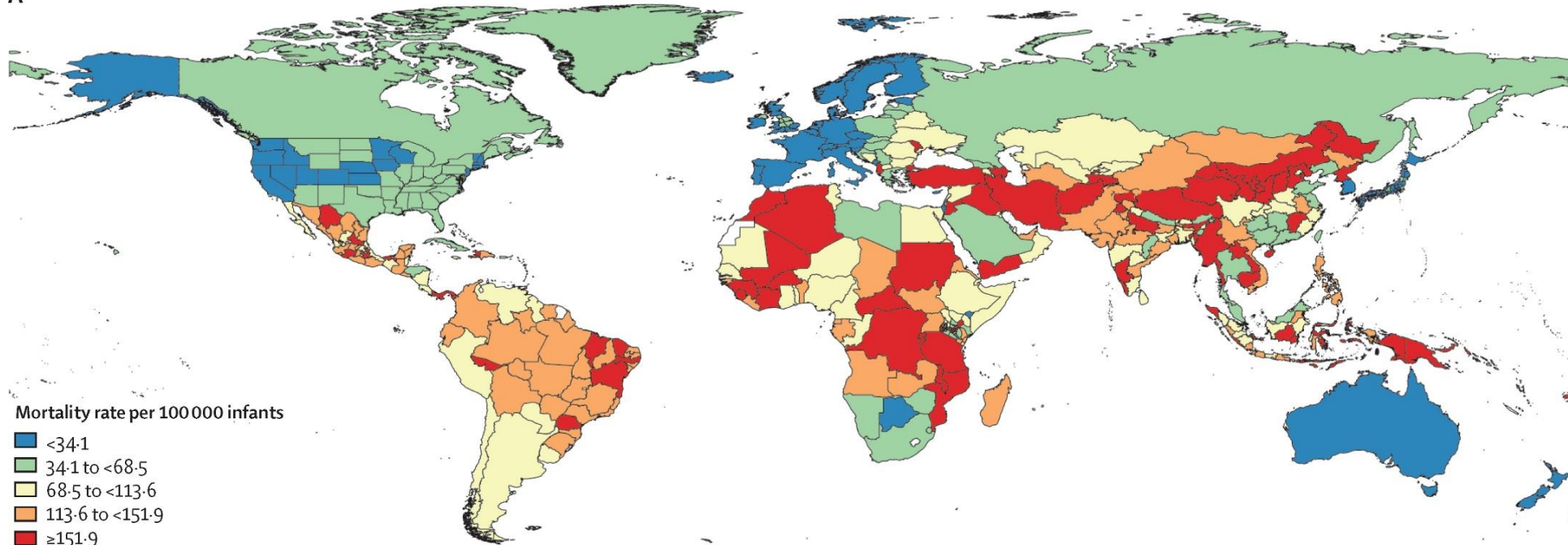
Deaths
261,247

DALYs
22,223,897

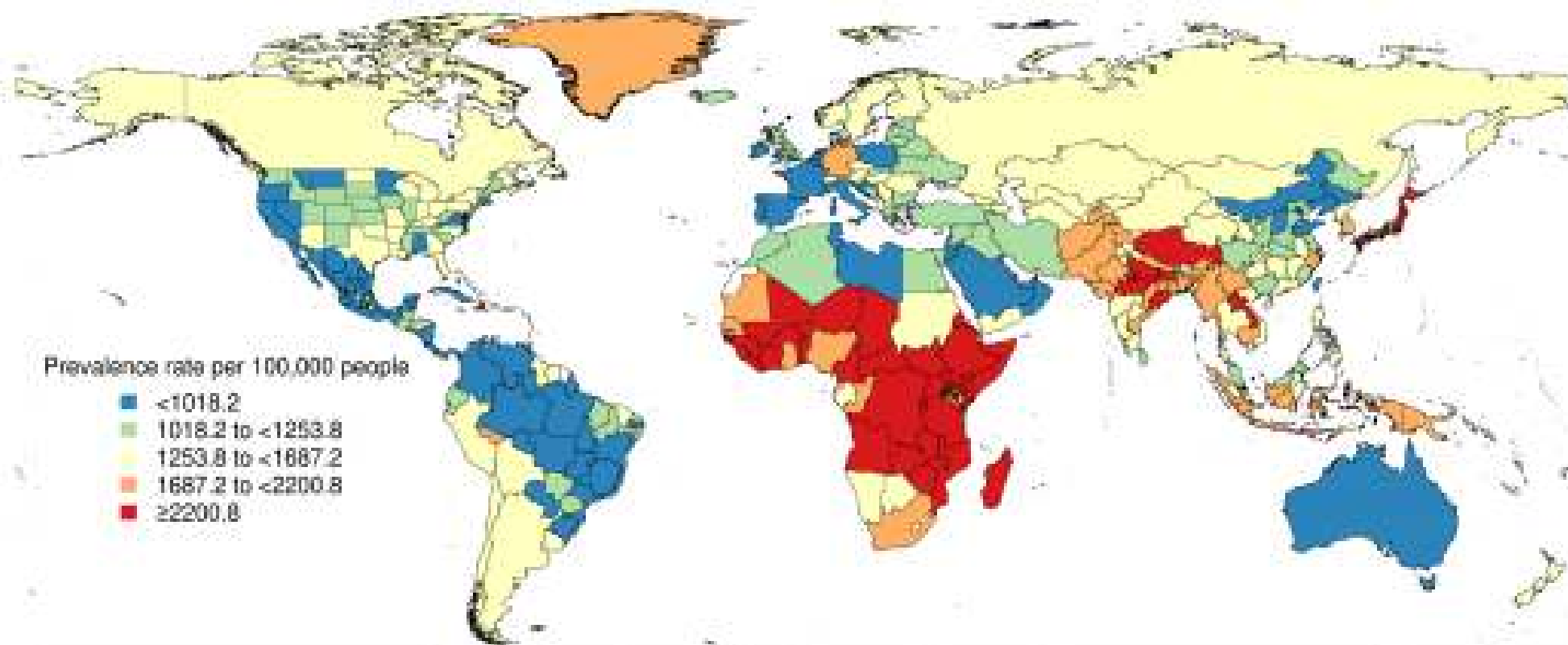


CHD Death rate per 100,000 in the first year of life

A



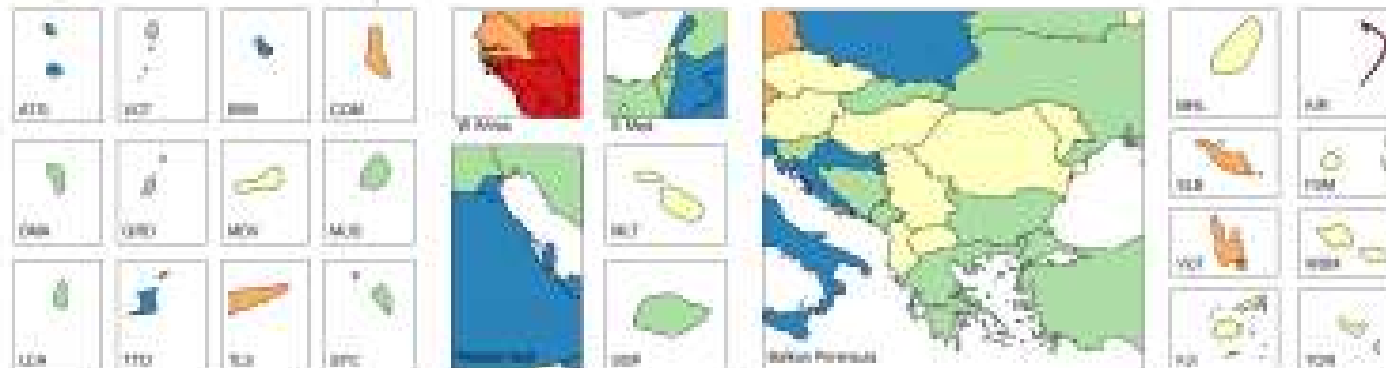
The Global Burden of Rheumatic Heart Disease



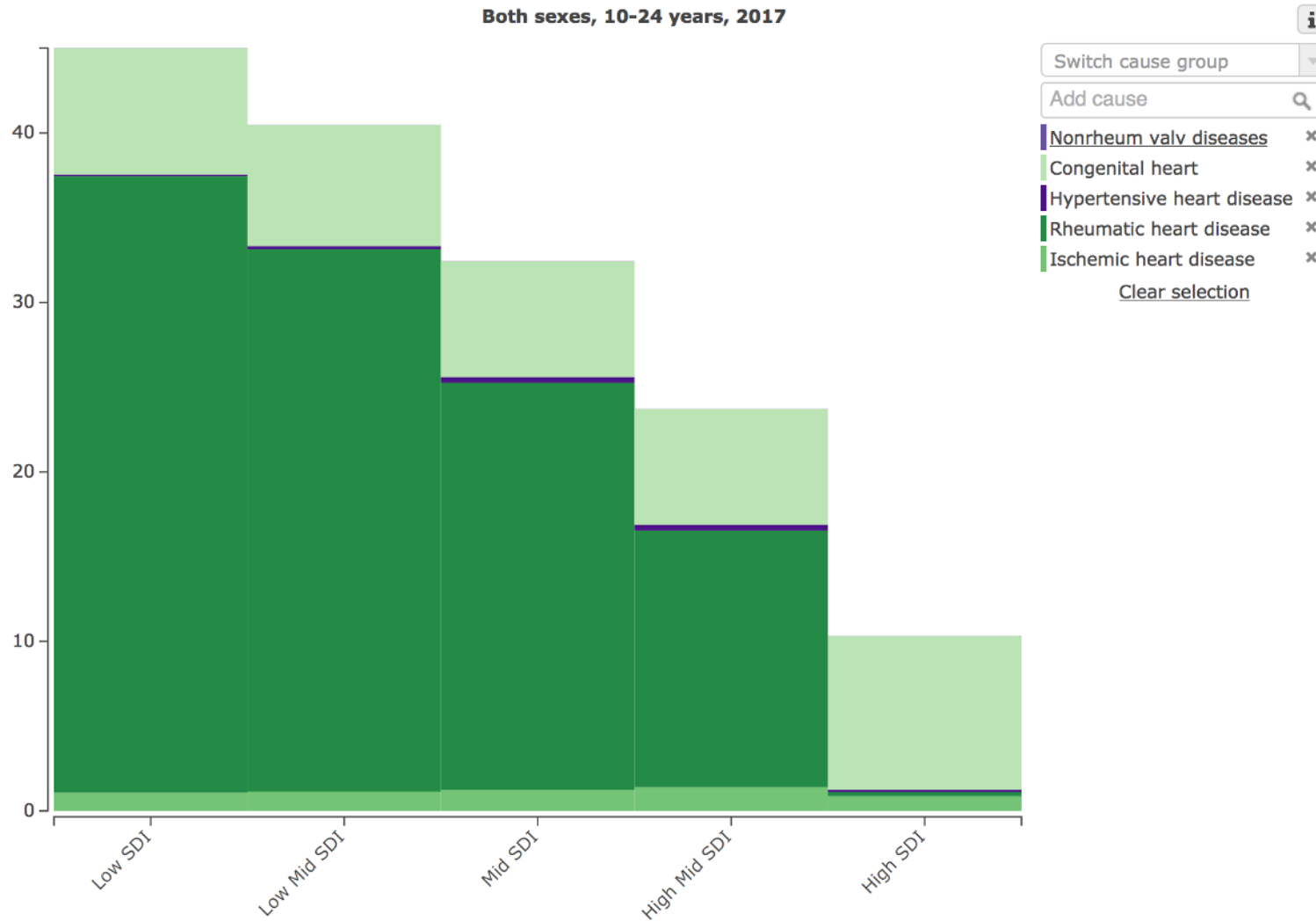
Prevalence
39,345,369

Deaths
285,517

DALYs
9,393,559



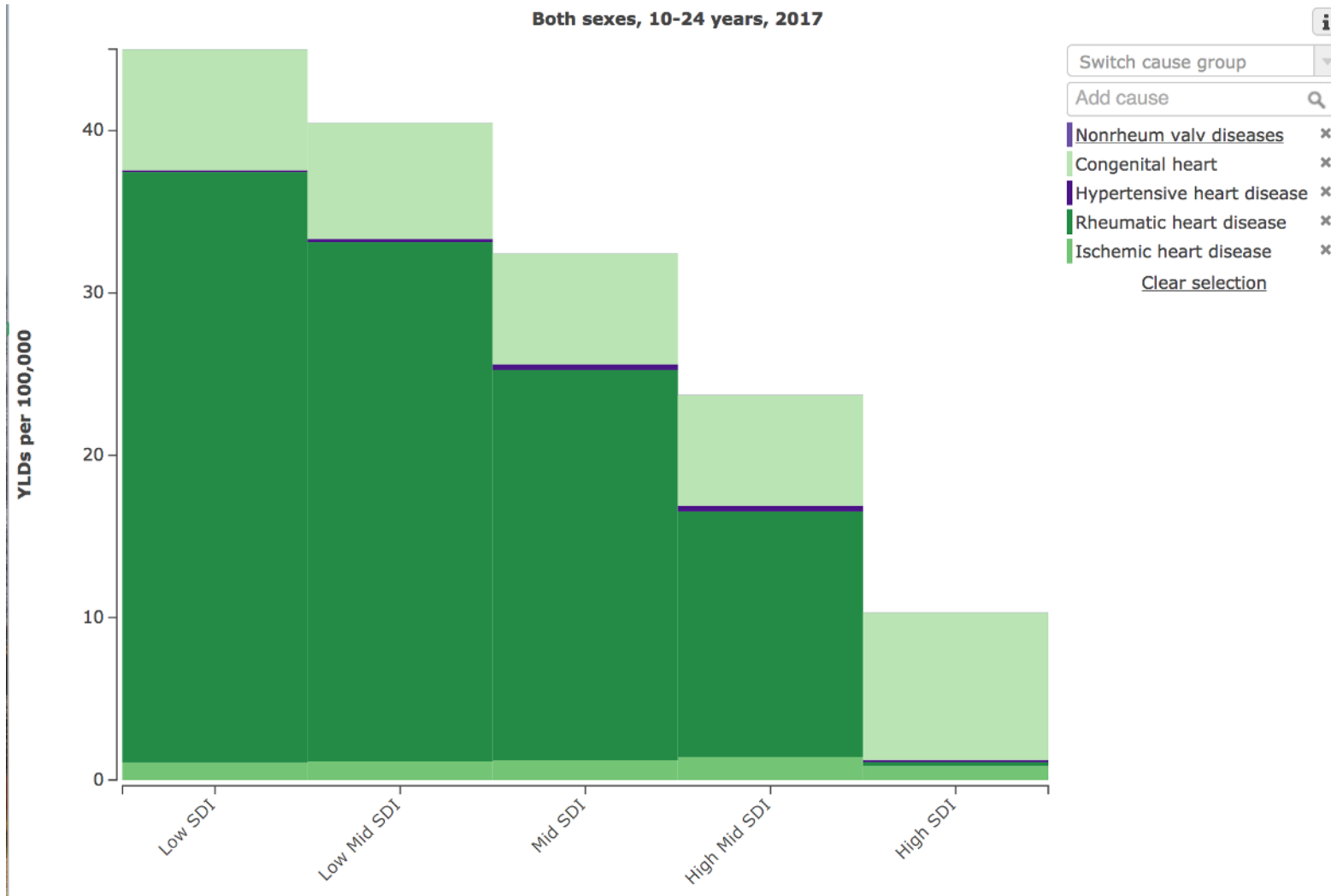
RHD Disability



- RHD leading cause of cardiovascular disability for those between 10-24 years in all but high income countries



RHD Death

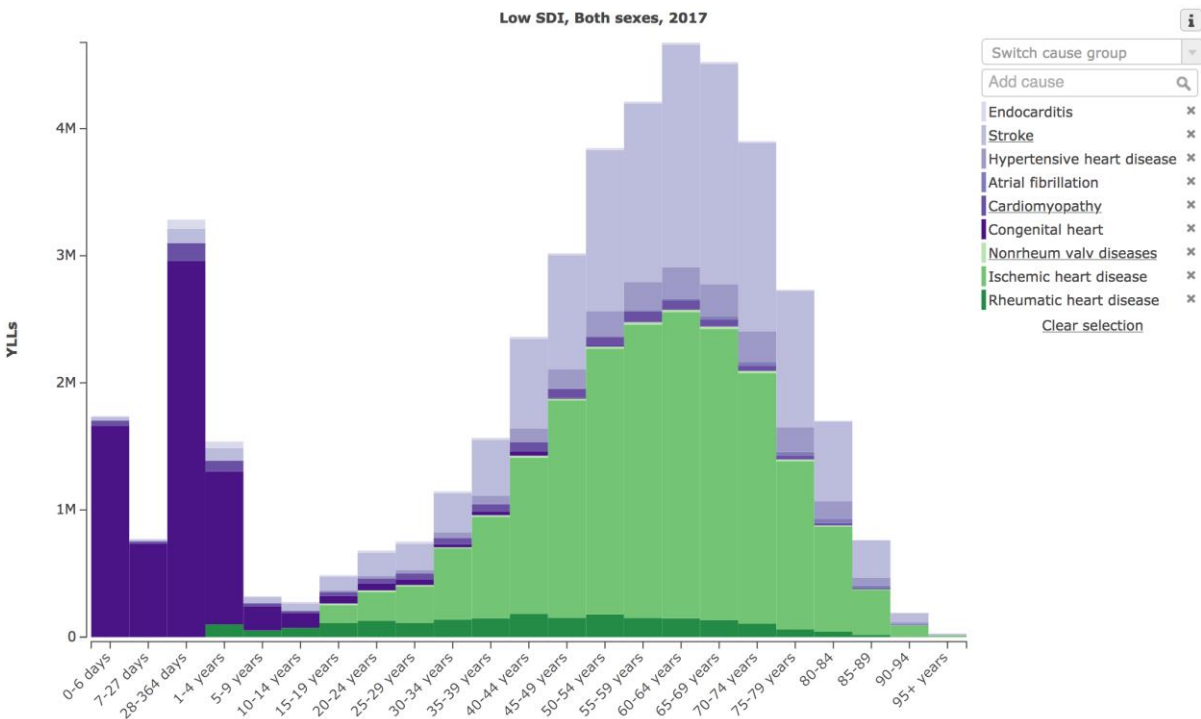


- 85% of RHD disability is driven by early loss of life

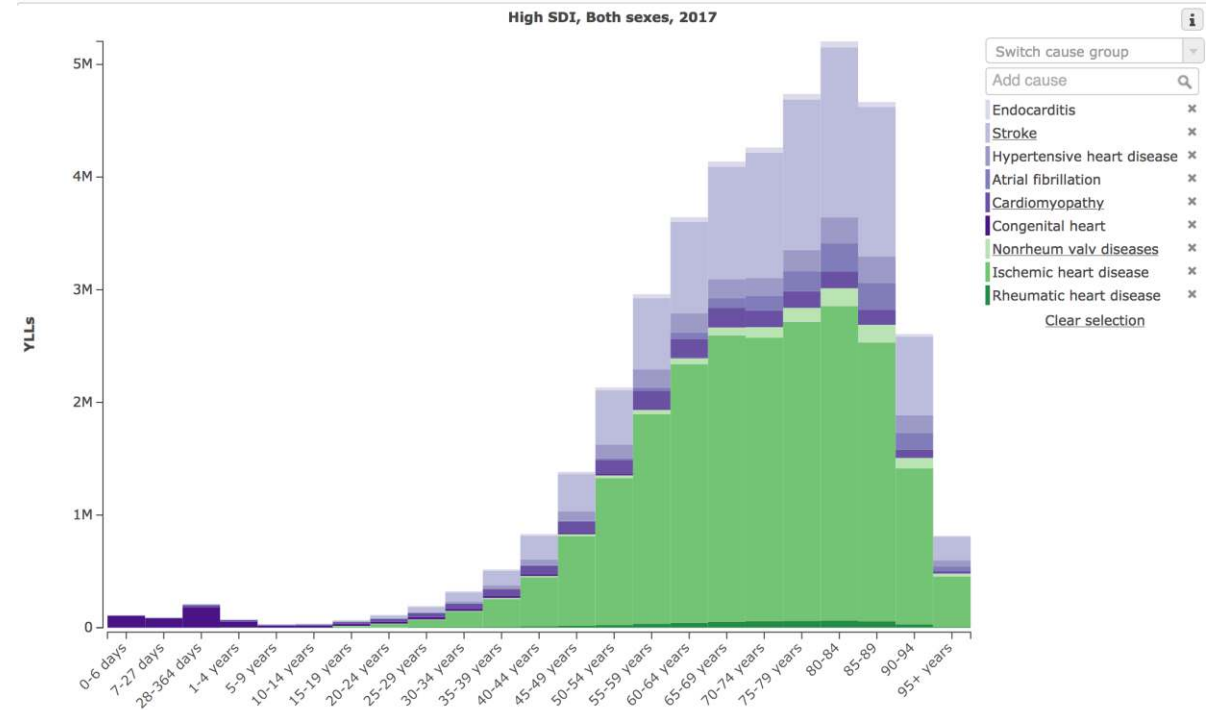


CHD and RHD Absolute Years of Life Lost

Low Income

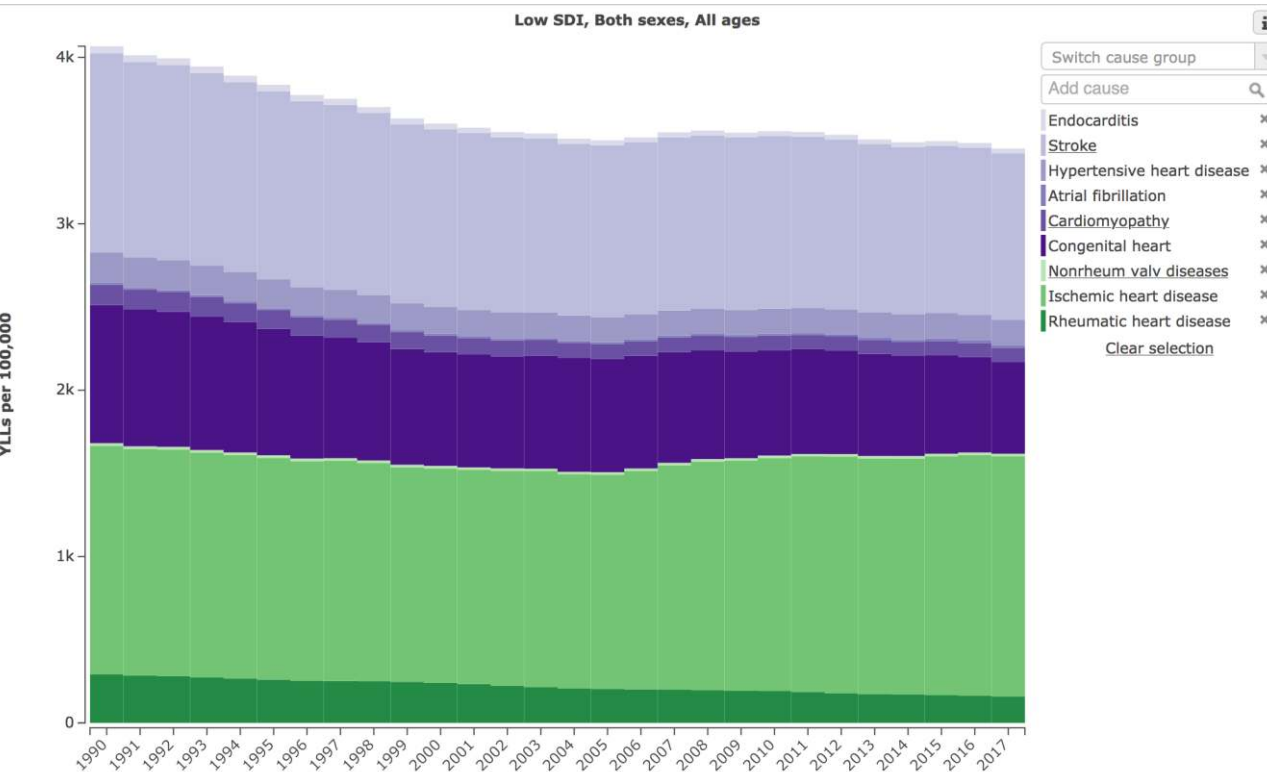


High Income

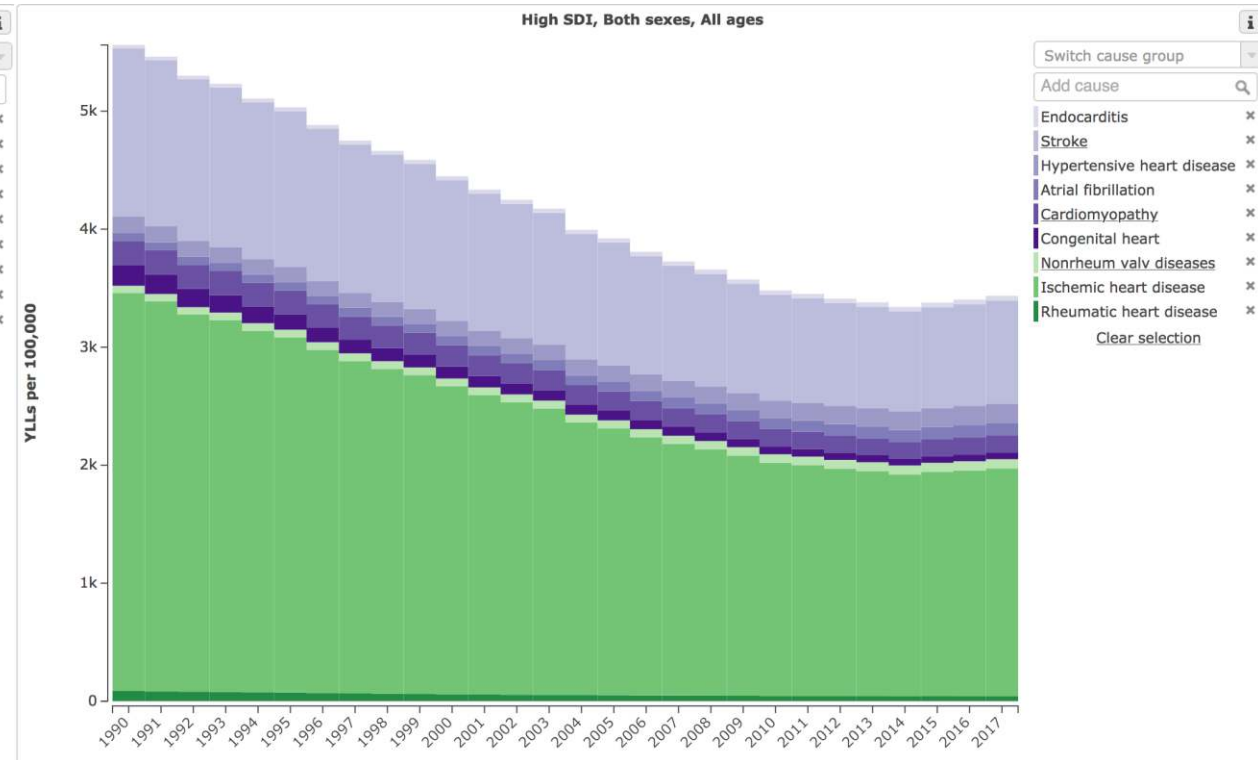


CHD and RHD Years of Life Lost – Rate per Year

Low Income



High Income



CHD and RHD: How are they the same

	Congenital Heart Disease	Rheumatic Heart Disease
Lack of quality data	X	X
Disproportionate burden	X	X
Lack of Diagnostics	X	X
Need for tertiary care capacity building	X	X
Need for increased financing for NCDs	X	X





The confirmation of CHD and RHD is reliant on echocardiography

Lack of Diagnostics



At least 1.5% of schoolchildren in sub-Saharan Africa have evidence of early RHD. <2% are diagnosed.



1.6% of women with heart disease during pregnancy, 84% of these with RHD

11% attributable risk for mortality



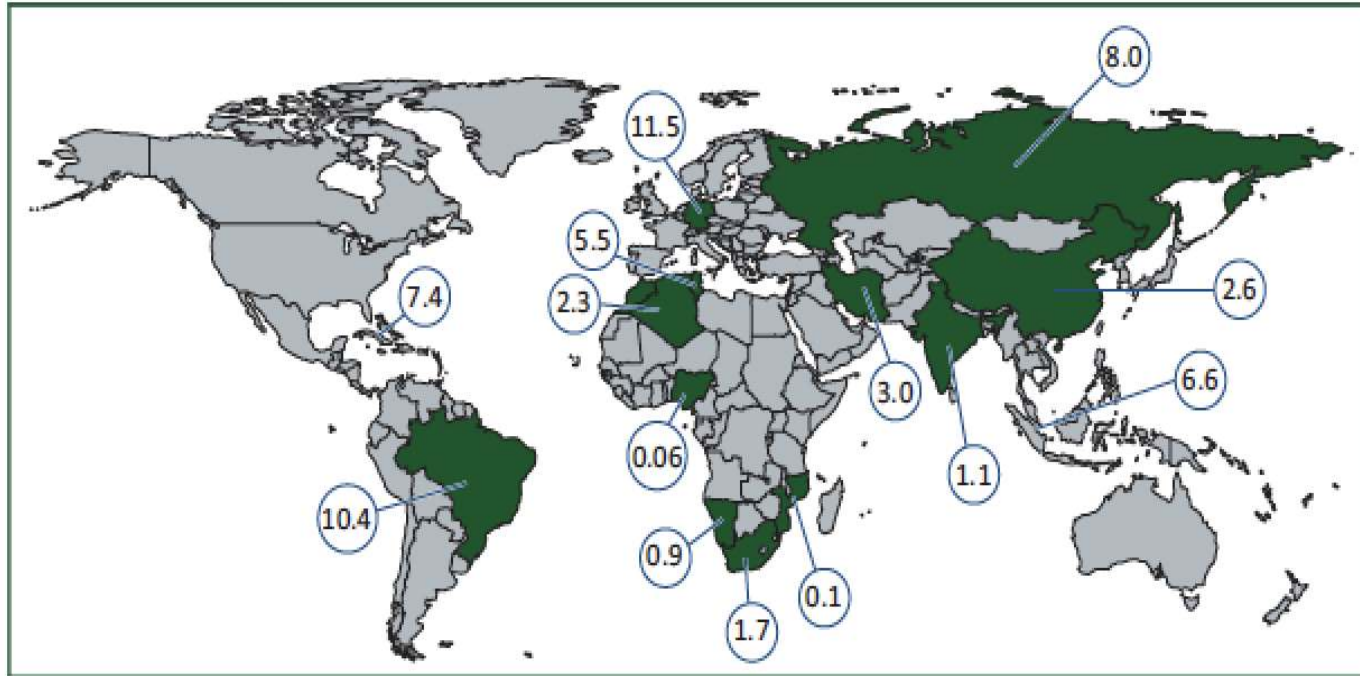


CHD and RHD: How are they the same in LMICs

	Congenital Heart Disease	Rheumatic Heart Disease
Lack of quality data	X	X
Disproportionate burden	X	X
Lack of Diagnostics	X	X
Need for tertiary care capacity building	X	X
Need for increased financing for NCDs	X	X



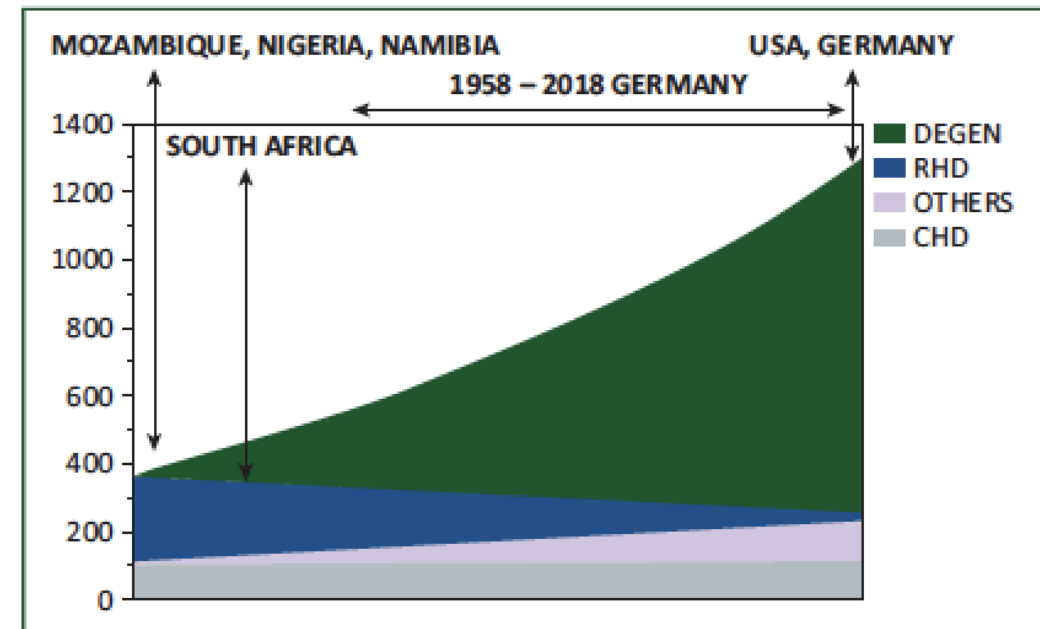
Shared need for Tertiary Cardiovascular Capacity



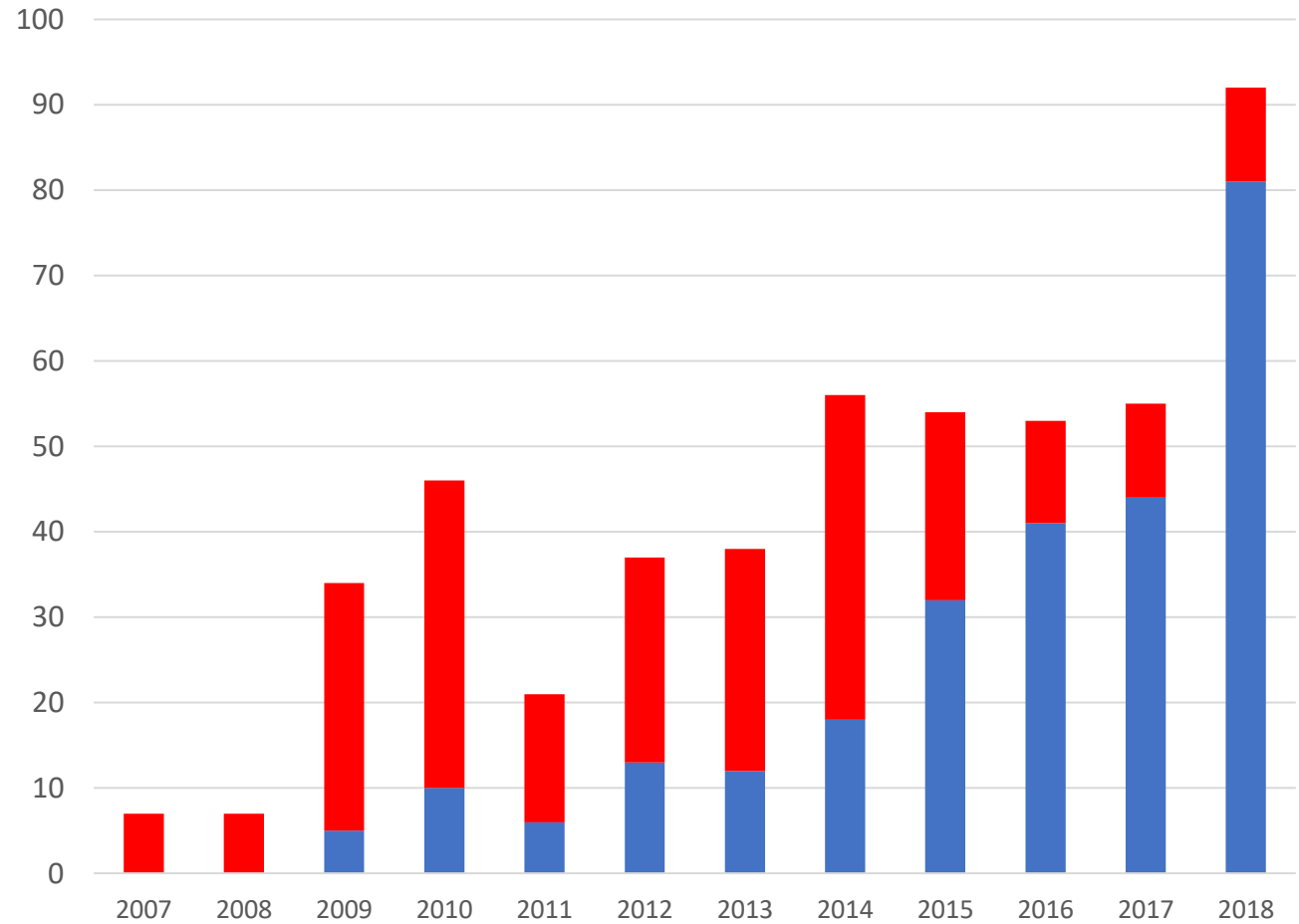
cardiac surgeons per 1M population

CHD: 100 per 1M
RHD: 250 per 1M (LMICs)

SSA alone, 350,000
surgeries needed each year,
<5% have access



Shared need for Tertiary Cardiovascular Capacity



International Quality Improvement Collaborative for Congenital Heart Disease
Improving care in low- and middle-income countries



CHD and RHD: How are they the same in LMICs

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Need for Increased Financing

	4C countries (death rate per 100 000 population)	All other low-income and middle-income countries		
		Premature deaths (thousands)	Avertable deaths (thousands)	Percentage change in deaths
Sexually transmitted infections (excluding HIV)	0.033	22	21	–96%
Diarrhoeal diseases	0.17	490	480	–96%
Lower respiratory infections	2.9	620	490	–68%
Cervical cancer	1.8	180	85	–69%
Rheumatic heart disease	2.9	120	61	–90%
Chronic liver diseases related to hepatitis B	17	380	180	–64%
Total	..	1800	1300	–75%

Avertable deaths were calculated by applying death rates specific to age, sex, and cause observed in 4C countries to population estimates in low-income and middle-income countries. Only deaths occurring between the ages of 5 and 69 years were included. Diarrhoeal diseases and lower respiratory infections in children under 5 years of age are already covered in the global health 2035¹ grand convergence package. 4C countries=Chile, China, Costa Rica, and Cuba. Data from the 2016 Global Health Estimates.⁴⁹

Table 1: Avertable deaths from an expanded set of health conditions for grand convergence, 2016

- Grand convergence package in GH2035 dealt with major adult infectious disease (HIV/TB/Malaria), NTD's, family planning, maternal mortality, and infectious disease mortality in <5
- Commission on investing in health (CIH) made the case that GH2035 should be expanded to include infectious diseases with *known available interventions* (Table)
- RHD specifically mentioned – would represent 120,000 premature deaths/year



2018 Global RHD Resolution



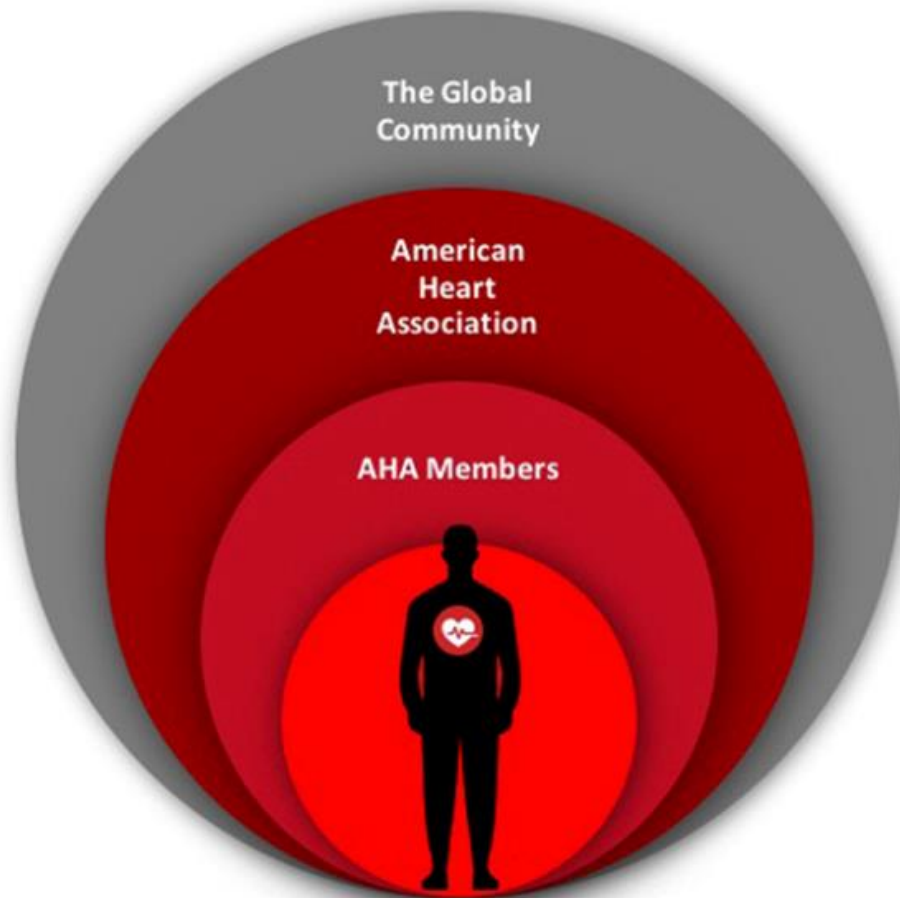
- Culmination of global efforts to reposition RF/RHD on the global agenda to accelerate control and elimination
- Led by clinicians, researchers, and people living with RHD living and working in RHD-endemic settings
- Set an agenda for member states, stakeholders, and the WHO director general
- Now need support for action: development and dissemination of best-practices, education, support for ministries of health and member states



2020 AHA Call to Action



The American Heart Association Call to Action to Reduce the Global Burden of Rheumatic Heart Disease



People living with and at risk for RHD	<ul style="list-style-type: none">• Use your stories to raise awareness• Be an RHD champion in your community• Advocate locally, nationally, and globally for RHD control
AHA Members	<ul style="list-style-type: none">• Be aware and raise awareness about RHD• Improve understanding of RHD in high-risk US populations and abroad
The American Heart Association	<ul style="list-style-type: none">• Develop and disseminate healthcare worker education and training• Provide technical assistance to member states implementing the WHO resolution• Improve access to essential medications (BPG) and technology• Support research to develop innovative strategies for RHD control• Advocate globally for RHD control
Global Health Community	<ul style="list-style-type: none">• Give RHD attention and funding proportional to the disease burden to support implementation programs, research, clinical capacity building and advocacy• Encourage and support WHO Member States to take action to implement the 2018 Global Resolution



Novel Integration Approached

PEN-Plus Toolkit

Toolkit for Outpatient Care of Severe, Chronic, Noncommunicable Diseases at First-Level Hospitals

In many low- and lower-middle income countries, clinical services for chronic noncommunicable diseases (NCDs) are only available through urban referral centers. In rural areas, services for severe chronic NCDs such as type 1 diabetes and advanced rheumatic heart disease are unavailable even at district (first-level) hospitals.

[Read More](#)



In summary: Overcoming disparity in CHD + RHD

- Better data on incidence, prevalence and costs
- Improved diagnostics, community-level care, prevention
- Improved tertiary capacity
- Prioritization for financing for NCDs in children



Remembering those living with disease



Dr. Ornella Lincetto
Medical Officer Newborn Health
Department of Maternal, Newborn, Child and Adolescent Health, WHO



Dr. Wilson Were
Senior Medical Officer, Child Health Services
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Mahesh Kappanayil, MD
Professor Pediatric
Cardiology, Lead - 3D
Printing/Innovation Lab
 Amrita Institute of
 Medical Sciences and
 Research Centre
 India

PANELISTS



Ruth Ngwaro
Advocate
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*In collaboration
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Questions & Conversation





DECLARATION OF
THE RIGHTS OF
INDIVIDUALS WITH
CHILDHOOD-ONSET
HEART DISEASE

Declaration Information and Action Toolkit

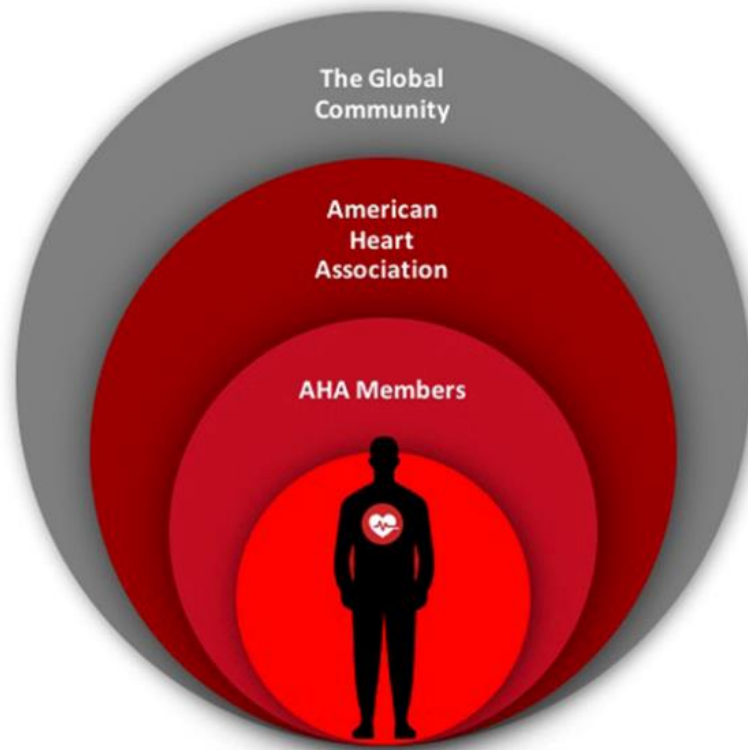
This user-friendly document explains what the Declaration of Rights is and how you can use it in your organization. It includes a summary, fact sheet, and social media toolkit to help you reach your target audiences. We hope you find it useful! **To read and sign the Declaration please click [HERE](https://www.global-arch.org/declaration-of-rights-of-individuals-affected-by-childhood-onset-heart-disease/)**

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





The American Heart Association Call to Action to Reduce the Global Burden of Rheumatic Heart Disease



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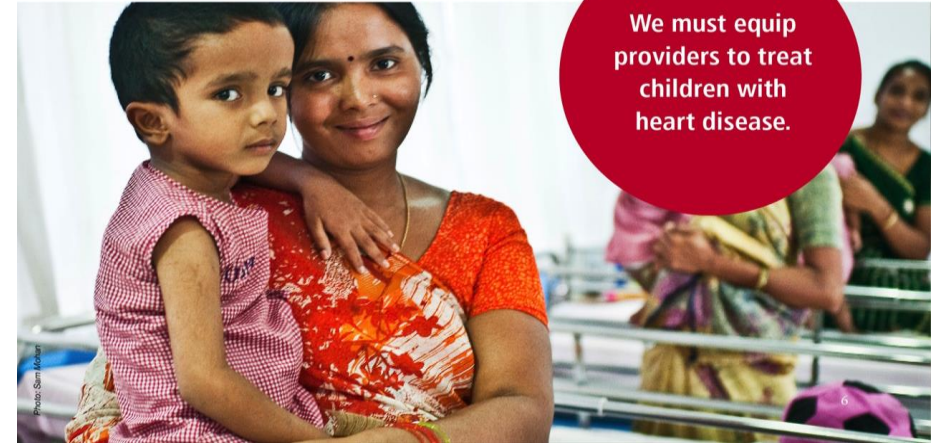
<https://childrensheartlink.org/the-invisible-child/>

Increasing Capacity to Care for Children



Children with heart disease deserve care from robust health systems.

Building a Pediatric Cardiac Workforce



We must equip providers to treat children with heart disease.

Closing the Data Gap



Care for children with heart disease will improve when their disease is counted.

Financing Pediatric Cardiac Care



Poverty should never be a side effect of treating pediatric heart disease.



THANK YOU

Complete survey: https://bit.ly/NCD_Session5

Stay tuned for future opportunities to join us and share.

Interested? Email NCD Interest Group Chair,
Arti Varanasi (avaranasi@advancingsynergy.com)