



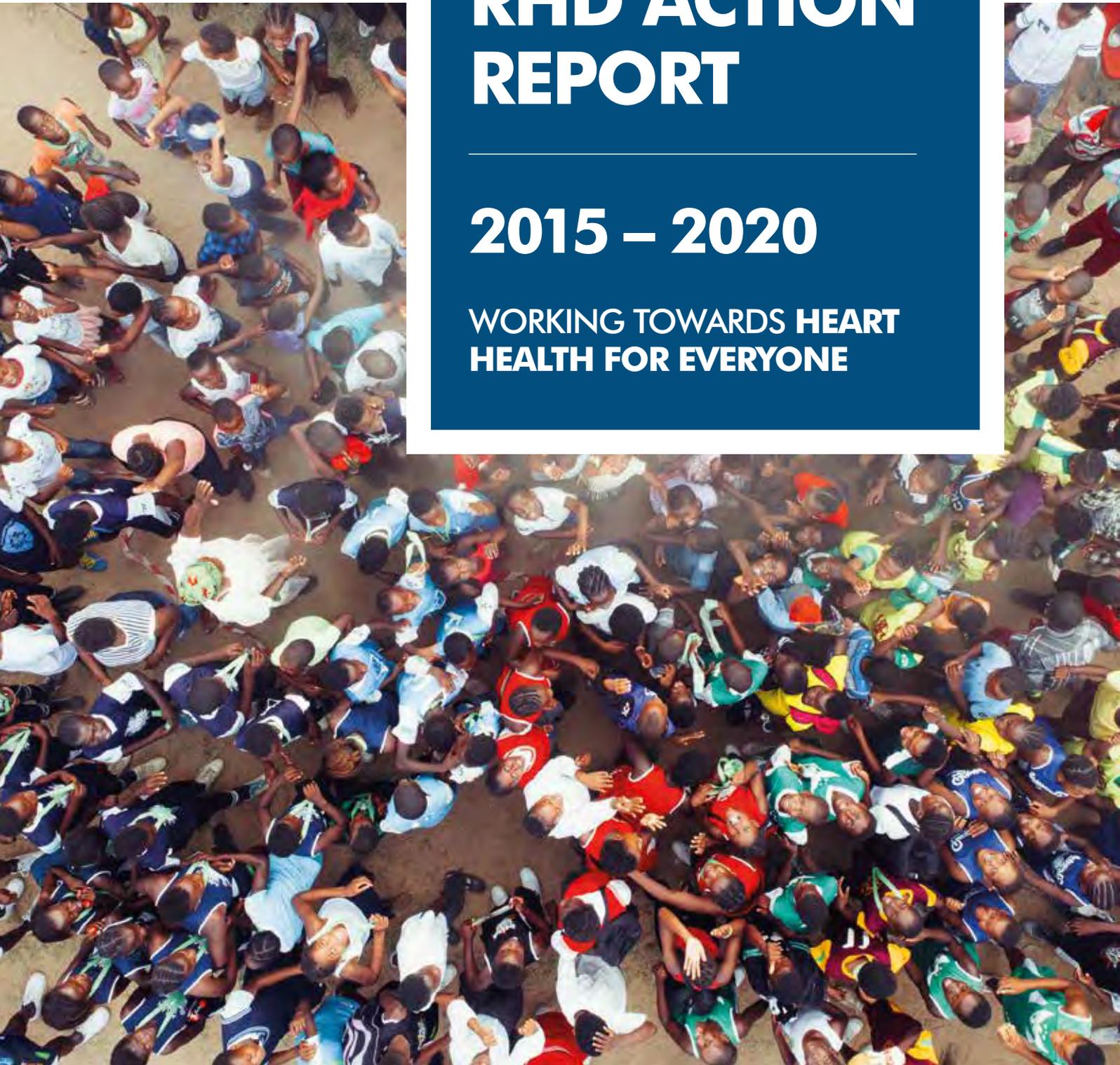
**RHD Action**

United to End  
Rheumatic Heart Disease

# RHD ACTION REPORT

## 2015 – 2020

WORKING TOWARDS HEART  
HEALTH FOR EVERYONE





## ACRONYMS

<b>ARF</b>	Acute Rheumatic Fever
<b>API</b>	Active Pharmaceutical Ingredient
<b>BPG</b>	Benzathine Penicillin G
<b>GAS</b>	Group A Streptococcus
<b>NAT</b>	Needs Assessment Tool
<b>PLWRHD</b>	People Living with RHD
<b>RF</b>	Rheumatic Fever
<b>RHD</b>	Rheumatic Heart Disease
<b>RHDA</b>	Rheumatic Heart Disease Action
<b>TIPs</b>	Tools for Implementing Rheumatic Heart Disease Control Programmes
<b>WHA</b>	World Health Assembly
<b>WHF</b>	World Heart Federation
<b>WHO</b>	World Health Organization
<b>UHC</b>	Universal Health Care

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## ACKNOWLEDGEMENTS

We would first like to acknowledge the people who live with RHD and their carers. Their strength and commitment to help others continues to serve as an inspiration to us all. We would also like to thank the frontline health workers who work tirelessly for their patients and give their time to speak about Rheumatic fever/heart disease (RF/RHD) with different audiences around the world.

We would also like to acknowledge the following people and organizations for their contributions to RHD Action (RHDA): Children's National, TKI, UCT, PASCAR, Governments of New Zealand, Australia, Uganda, Tanzania, Namibia, Sudan, Kenya, Egypt, and Fiji, The Honorable Kevin Rudd AC, Small Grant Review Committee, #timetoendrhd supporters, contributors to the RHD Action Resource Hub, WHO, WHO EMRO, UNICEF, Save The Children, and the NCD Alliance. In loving memory and following the profound examples of Professors Bongani Mayosi and Dinny Lennon whose tireless efforts contributed so much to our success.



## EXECUTIVE SUMMARY

Rheumatic heart disease (RHD) is a global problem affecting over 40 million people in 2019.<sup>1</sup> It exacts a heavy toll on the lives of the world's poorest and most vulnerable communities leading to more than 300,000 deaths each year. Despite this fact and that a small band of health workers and researchers support, improve, and change the lives of people living with RHD (PLWRHD), it has not received the investment and recognition from the wider health community and funders that is desperately needed.

In September 2015, the Medtronic Foundation, the World Heart Federation (WHF), RhEACH (later rebranded as *Reach*), and several other partners joined together to launch RHD Action (RHDA), under the auspices of Every Woman Every Child. Bringing together partners from across the world with a history and commitment to improving the lives of PLWRHD and supporting the health workers joined in those efforts, RHDA set out to make a significant impact on the prevention and management of rheumatic fever (RF) and RHD.

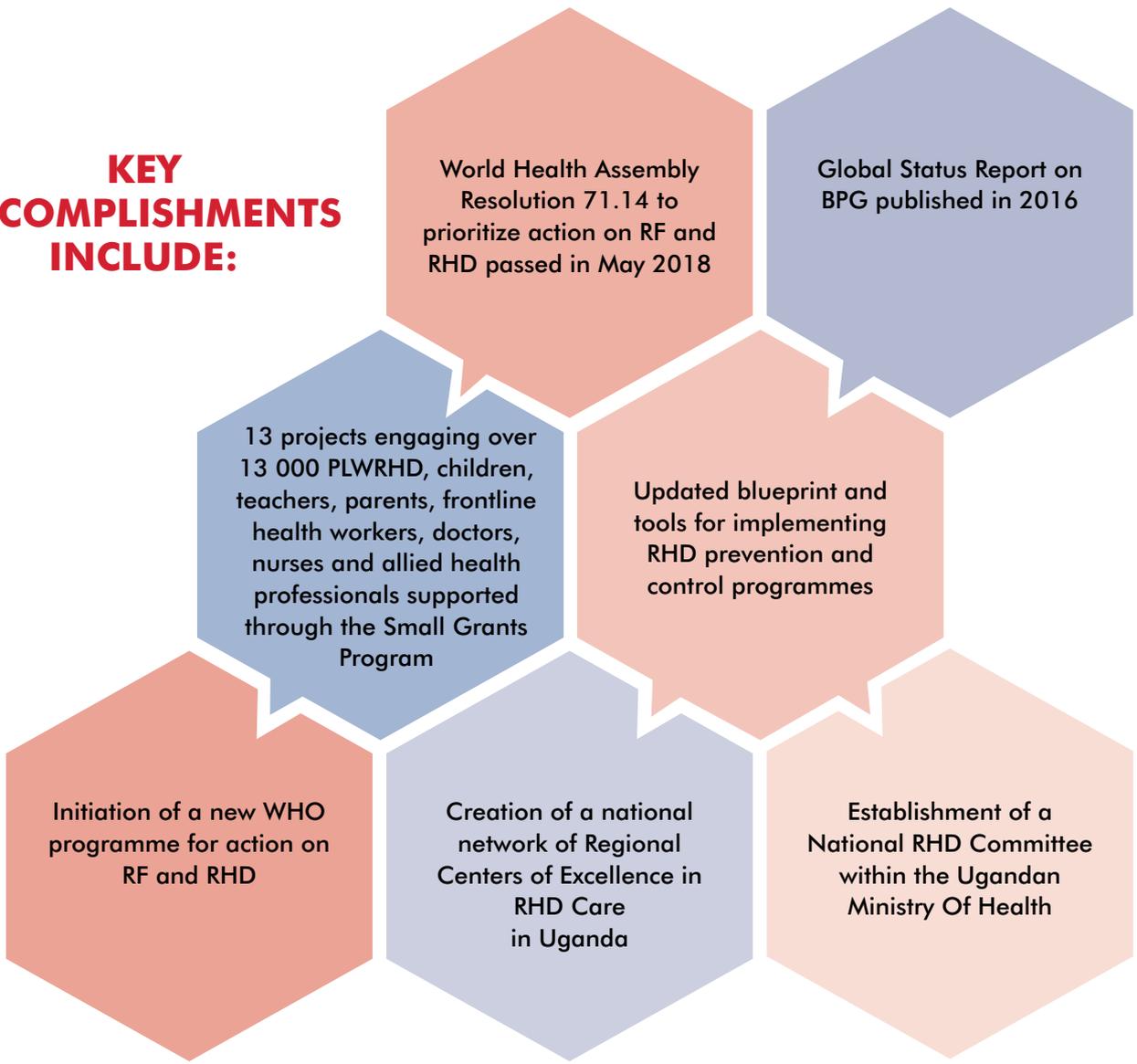
This report highlights the achievements of RHDA partners and those they serve over the last five years, 2015-2020. It demonstrates that effective prevention and management can be strengthened in the most resource-limited settings, and that RF/RHD interventions can sit alongside or be a core component of the management of childhood illnesses, non-communicable disease, infectious diseases, and reproductive and maternal health. It demonstrates the power and value of involving PLWRHD as leaders and the importance of thinking big, beyond individual disease areas, to an integrated health system built for the double burden of communicable and chronic diseases in low-resource settings. In 2018, RHDA achieved a significant milestone.

As a result of our collective advocacy efforts and partnership with governments greatly affected by RHD, the World Health Assembly (WHA) adopted a World Health Organization (WHO) Resolution on rheumatic fever and rheumatic heart disease. This moment signified global recognition of a devastating disease and the need for global coordinated action. The WHO Resolution 71.14 emphasizes the need for implementation of RF/RHD prevention and management activities around the world. Since the Resolution passed the WHO has begun development of guidelines for RHD prevention, established a team to work towards a safe and secure supply of benzathine penicillin G (BPG) and coordinated regional offices to share approaches to implementing the Resolution.

The work of RHDA over the last five years means that there is a blueprint for all stakeholders to follow, to make this happen. This report is split into six sections: Understanding the Burden of Rheumatic Fever and Rheumatic Heart Disease; Supporting Frontline Health Workers and PLWRHD; Supporting Governments and International Agencies; Addressing Access to Care: Ensuring a Steady Safe Supply of BPG for Those Who Need It; Integrating RHD into Health Systems and Lessons Learned from Our Demonstration Projects in Uganda and Tanzania. Finally, we share our recommendations for the future.

**SINCE THE LAUNCH OF RHD ACTION IN 2015, SIGNIFICANT GAINS IN RHEUMATIC FEVER AND RHEUMATIC HEART DISEASE PREVENTION AND CONTROL HAVE BEEN MADE WORLDWIDE**

**KEY ACCOMPLISHMENTS INCLUDE:**



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# INTRODUCTION

RHDA is a global initiative that unites and empowers the RHD community. Led by a coalition of core heart health and disease organizations, RHDA shares technical advice, advocacy support, and policy insights with partners and allies across the world. Together, we work to create positive change and better health outcomes for PLWRHD and their communities. Formed in 2015 as a partnership between the Medtronic Foundation, Reach, and the WHF, with inaugural demonstration projects in Uganda led by the Ugandan Heart Institute and Case Western Reserve University and Tanzania led by the Touch Foundation, RHDA is a global initiative that unites and empowers the RHD community.

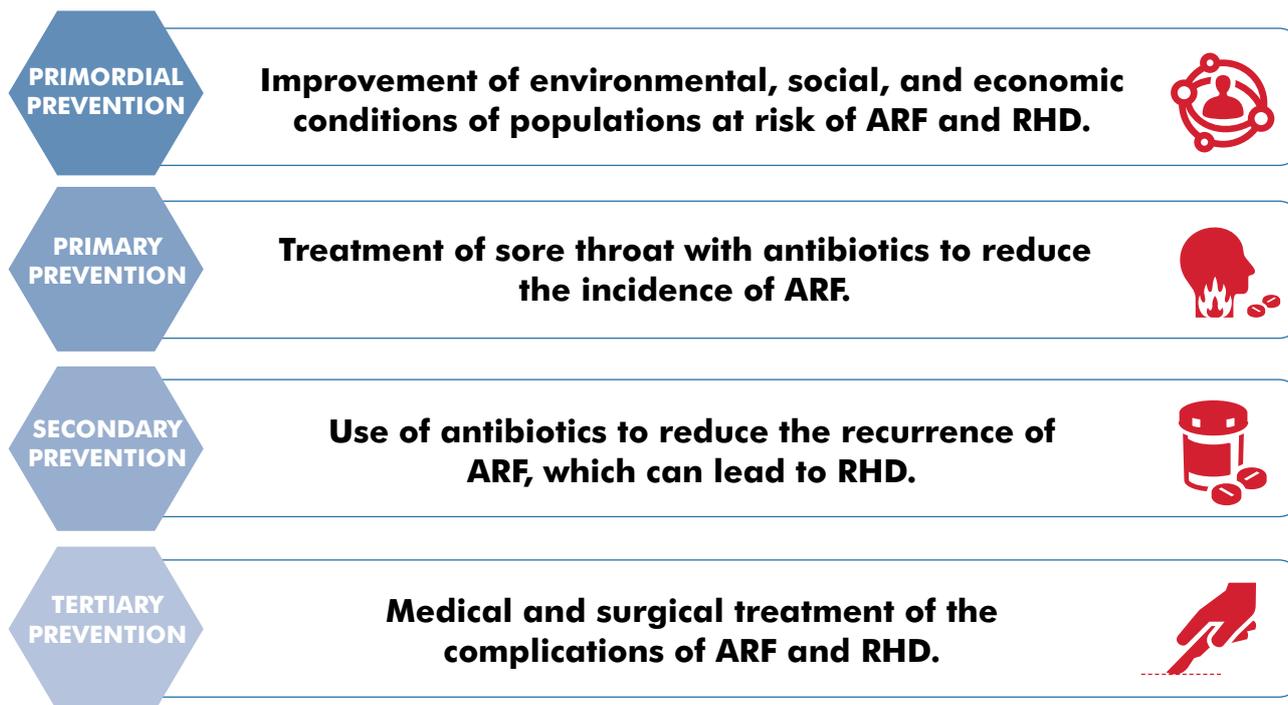
**THE PROBLEM**

RHD is a disease of the world’s poorest and most vulnerable communities. RHD primarily affects women, children, and young people in Africa, Asia, the Middle East, Latin America, and the Western Pacific. Although virtually eliminated in Europe and North America, it continues to affect underserved communities worldwide.

RHD is a preventable and treatable form of cardiovascular disease, but when left unchecked, it can cause devastating consequences. **RHD is the most commonly acquired heart disease in young people under the age of 25.** It most often begins in childhood as strep throat, caused by a Group A streptococcus (GAS) infection. If GAS is left untreated, it can lead to acute rheumatic fever (ARF), an abnormal immune reaction to the GAS bacterial infection. Repeated episodes of ARF cause inflammation of the heart valves and muscle and may progress to serious heart damage that kills or debilitates adolescents and adults.

**RHD affects over 40 million people around the world and kills more than 300,000 each year,** imposing heavy costs on the health systems of those who can least afford it.<sup>1</sup> If left untreated, RHD can lead to heart valve damage (requiring costly heart valve surgery), stroke, heart failure, and death. Women with RHD have an increased risk of cardiac failure, death, and loss of an unborn child during pregnancy. In endemic countries, prevalence of this preventable disease is a stark measure of health system failure and inequality.

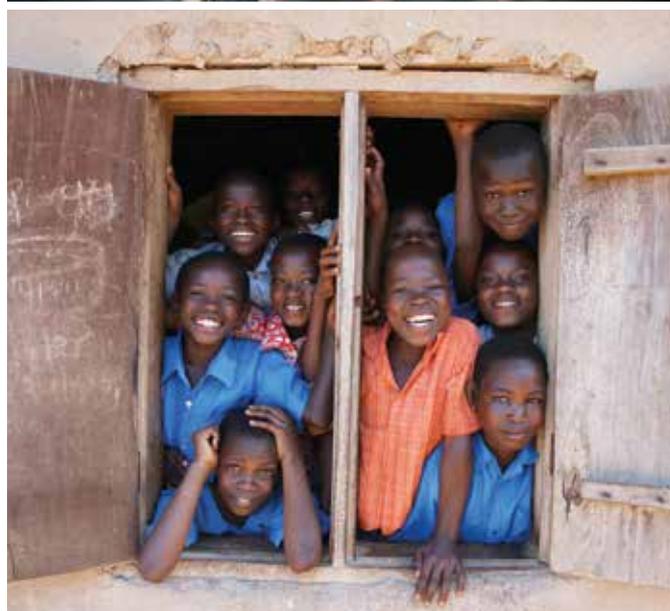
## RHD CAN BE PREVENTED AND CONTROLLED. SEVERAL POINTS OF INTERVENTION HAVE BEEN SHOWN TO BE EFFECTIVE:



### OUR GOALS (OBJECTIVES)

- Raise the profile of RHD globally and bring attention to key barriers to eradication of the disease
- Support countries in need of RF/RHD prevention and control through health systems strengthening activities, resource development and distribution, and assistance with national guideline development
- Create a supportive environment for people living with RHD

To support these efforts, we created a powerful platform for existing work in RHD prevention and control, while providing innovative new tools, guidance, and opportunities for the RHD community.





## OUR WORK

### 6 UNDERSTANDING THE BURDEN OF RHEUMATIC FEVER AND RHEUMATIC HEART DISEASE

*“One key challenge in addressing RHD lies in the lack of reliable data capturing the true burden of disease – i.e., precise geographical, age and gender distribution and health systems measurements such as where and when care is being sought, by whom and at what cost. Health authorities in many countries rely on regional estimates of the burden of RHD given the absence of national disease registries and underreporting or misdiagnosing of acute and chronic cases of RHD.”*

**DR. AGNES BINAGWAHO,**  
FORMER MINISTER OF HEALTH, RWANDA, 2013

#### **Global Status Report on RHD – Launched at the WHA, May 2016**

The **RHD Global Status Report 2015-2017** brought to the forefront the individuals and countries living with and tackling RHD.

The report explored the lives of PLWRHD, and those who support them, to help ensure action is lifted out of the abstract and grounded in real-life experience. It also summarized the policy environment to help identify opportunities to push RHD forward on national, regional, and global agendas. Finally, the report analyzed current and historical RHD programs from around the world to provide a clear picture of what is working and how much progress is being made on the ground.

The Status Report was instrumental in making the case for a Global Resolution on addressing RF/RHD. It highlighted the successes of the earlier WHO RHD programme, the gap in action since the programme was ended and profiled political efforts at the regional level in Africa, Asia and the Pacific calling for urgent global support.

In addition to the Global Status Report, RHD Action has supported development of Global Burden of Disease estimates of RHD prevalence and mortality that were featured in a landmark paper (NEJM, 2017) and in annual revisions of the GBD study.



## SUPPORTING PEOPLE LIVING WITH RHD (PLWRHD)



PLWRHD are often among the poorest and most marginalized communities in the world. RHDA has worked to empower and support PLWRHD, their families, and communities by aiding them in finding their voice to speak on RHD issues.

To date, the experience of living with RHD has been relatively hidden. In most of the world, PLWRHD remain isolated from each other and from the global conversation about ending this disease.

We are connecting PLWRHD, amplifying their voices, and learning from their experiences. In this way, we reliably address the needs and priorities of the people who matter most.

The experience, perspective, and priorities of PLWRHD have been cornerstones of our work. Throughout the program, we have ensured that PLWRHD had an active role at high-level global health events in New York and Geneva as well as developed a “[Living with RHD](#)” section of the RHDA website to center RHD issues around the affected.

### Listen to My Heart Events for PLWRHD and Their Carers

**Listen to My Heart** is the name of events designed with and for PLWRHD to learn more about RHD and the services health care workers provide. Most importantly, these events offer the chance for PLWRHD to meet and network with one another.

The events typically feature six demonstration tables, which provide a wide range of information that encompasses the different aspects of RHD care and prevention. Patients are able to use a microscope to examine GAS bacteria, view demonstrations of the use of stethoscopes and handheld echocardiography and obtain information on adhering to BPG prophylaxis. Highlights include Listen to My Heart events in [Uganda](#) and [South Africa](#).



### Profiling the Stories of PLWRHD

We collected the stories of women with RHD to represent the reality of our patients' lived experiences.

The stories of [Livini](#), [Zafira](#), and [Ruby](#) scratch the surface of the daily and practical challenges faced by women with RHD in managing their pregnancies.



# 12,159



children, teachers and parents have been reached through school-based activities

# 320



Frontline care workers have received training

# 414



Doctors & Nurses have received up-to-date information on strengthening health services

## RHDA Small Grants Programme

The RHDA Small Grants Program was designed to support activities around the world that would lead to improvements in care for, or would empower, PLWRHD. Launched in year three of RHDA, offering up to 2500 USD per activity, the grants have supported numerous activities such as the establishment of RHD clinics, the training of frontline health workers, awareness raising of RHD in refugee settlements, and the empowerment of adolescents through leadership and skills building.

With a modest investment, the grants have had a significant impact on local communities around the world.

Of the 13 projects supported to date worldwide, a total of 591 PLWRHD have been directly engaged; 12,159 children, teachers, and parents have been reached through school-based activities; 320 frontline health workers have received training; and 414 doctors, nurses, and allied health professionals have received up-to-date information on strengthening health services. Feedback from beneficiaries of the project activities included an increase in confidence recognizing RF and RHD among healthcare workers, increased comfort levels among nurses when giving BPG injections, better understanding among family members about how to support someone living with RHD, and greater outreach to affected communities.

*Throughout this report, we are happy to share the stories of our small grant recipients so that the successes can be replicated while learning how to overcome the challenges they face. These stories can be found in the boxes accompanying each section.*

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## RHDA SMALL GRANT –FIJI

### EMPOWERING AND SUPPORTING YOUNG PEOPLE LIVING WITH RHD

PROJECT COORDINATOR: DR. SAI BOLADUADUA

The “Empowering and Supporting Young People Living with RHD (PLWRHD) Activity” was led by members of the Fiji RHD Program Team, including representatives of the PLWRHD and care community. The program was aimed at adolescents, who make up nearly 60% of the national RHD register in Fiji.

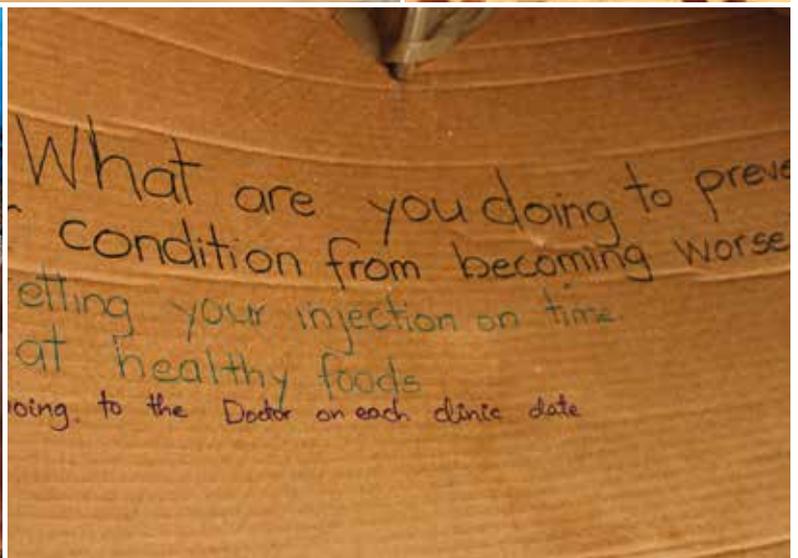
Through the activity, the Fiji Team aimed to:

- Enable more informed decision-making around adherence to secondary prophylaxis treatment among a group of 50 young PLWRHD in the Central Division of Fiji
- Promote discussion around challenges in living with RHD
- Identify 15-20 young people that are willing and able to attend one day peer support worker training with the aim of becoming “RHD Champions” in September 2017.

In preparation for the activity, a group of six young PLWRHD, between 15 and 25 years of age, met to form an informal committee of RHD Champions (Champs). The group was tasked with organizing what came to be known as the “Mosquito Island” Activity. 38 adolescent PLWRHD came together to participate in various activities designed to promote teamwork, effective communication, and leadership skills.

The feedback and enthusiasm generated from the program illustrate the need for ongoing investment in activities that are aimed at educating and empowering young people living with ARF and RHD. It is a time when young people are taking more control over their health, and strategies that help address knowledge gaps and reduce isolation, for example, will help improve health outcomes in the medium and long term. The overwhelming positive feedback and comments received from the activities highlight the importance of supporting peer support groups that lend and cultivate a spirit of sharing and support, as well as celebrating lives lived with ARF/RHD.





## Demonstration projects partner with national and local government in Tanzania and Uganda

At the national level, both demonstration partners worked closely with the national government and health authorities to advocate for recognition of RHD as a serious problem and for screening and treatment.

In addition, they worked closely with local and regional health committees to ensure that programming was relevant, culturally acceptable, and appropriate.





## Assessment of Barriers and Facilitators to RHD Care in Tanzania and Uganda

Demonstration project partners in Tanzania and Uganda, along with partners from Reach, conducted a systematic review of the epidemiology of RHD in these countries. They also outlined the health systems barriers to and facilitators of care and treatment for strep throat, ARF/RF, and RHD. The review found that more investigation needs to be done because there are critical gaps in the data.

Challenges such as lack of knowledge in the community about strep throat and its relation to RHD, lack of financial resources to seek treatment, lack of knowledge of health care workers about strep throat and ARF/RHD, as well as distrust of health care providers and lack of resources for treatment, were significant barriers to seeking care. Facilitators included increased health literacy, community/family support, and educational level.

## RHDA SMALL GRANT – CAMEROON

### INITIATING A RHEUMATIC HEART DISEASE CLINIC IN YAOUNDÉ, CAMEROON

PROJECT COORDINATOR: **DR. YANWOU NATHAN**

Very little has been published about RHD and ARF in Cameroon, so the true prevalence of these conditions on a country-wide basis is unknown. A group of junior doctors in the capital city of Yaoundé knew they were seeing numerous cases of RHD in their pediatric clinics and felt that something must be done for these children and young people. Dr. Yanwou Nathan, a resident in cardiology at the Faculty of Medicine and Biomedical Sciences, University of Yaoundé was motivated to address this challenge. He commented: *“There is no registry, no national control program, no awareness campaign. Against this backdrop most people are first diagnosed with advanced disease, requiring expensive surgery; many patients do not survive the wait for surgery.”*

Dr. Yanwou organized a group of four doctors and a nurse with a plan to mobilize care for their young RHD patients. Starting with an echocardiography register, they identified young patients who had been diagnosed with RHD over the prior five years. The team then contacted the carers of these children to attend a specially designated RHD event and clinic at the Chantal Biya Foundation Mother and Child Health Center in Yaoundé. A social media campaign was conducted prior to the launch of the clinic, targeting health care providers as well as the general population.

**FOLLOWING THIS LAUNCH, 23 PATIENTS ARE NOW SUCCESSFULLY REGISTERED IN THEIR NEW RHD CLINIC PROGRAMME. THE PATIENTS ARE MAINLY FEMALE (70%) WITH A MEAN AGE OF 12 YEARS, ALTHOUGH THE AGES RANGE FROM 4 TO 22 YEARS, WITH THE MAJORITY OF THE PATIENTS LIVING IN URBAN YAOUNDÉ.**





## LESSONS LEARNT FROM DEMONSTRATION PROJECTS IN UGANDA AND TANZANIA

### UGANDA – Bridging the Treatment Gap for RHD in Sub-Saharan Africa

The overarching goal of this project was to create a national RHD care infrastructure by leveraging existing HIV/AIDS resources.

#### Key objectives included:

- Establishment of a regional center of excellence model.
- Increases in screening and referral by making echocardiography available outside of Kampala.
- Removal of barriers to BPG adherence, and to improve upon a nascent National RHD Registry.



#### Highlights of our accomplishments include:

- Establishment of a National RHD Committee within the MOH.
- Commitment from the health information department of the MOH to capture RHD data as part of the greater CVD data.
- Creation of a national network of Regional Centers of Excellence in RHD Care.
- Robust infrastructure for patient support and empowerment, including patient support groups and training for PLWRHD.
- One of the largest registries of PLWRHD in the world.
- Strengthened clinical registries have resulted in lower mortality. 8% pa compared with 17% pa at project inception.
- High-impact qualitative research with PLWRHD to identify priorities and barriers to care for penicillin prophylaxis, primary prevention of RF, and maternal health.
- Echo screening of over 13,000 children for latent RHD.
- Point of care diagnostics in the community improving management of patients and a reduction in morbidity.
- Decrease in BPG stockouts and increased rates of BPG adherence.
- Advanced training in interventional cardiology for Uganda Heart Institute physicians who now independently perform percutaneous valvuloplasty for rheumatic mitral stenosis.
- A Uganda RHD Stakeholders Meeting in November 2017 which featured over 100 guests, international invitees from over 10 countries, and a day-long event for PLWRHD.

## TANZANIA

The overarching goal of this project was to bring RHD knowledge, diagnosis, treatment, and prevention to the local level by leveraging existing NCD and maternal health programs.

### Key objectives included:

- Conducting a school health and community needs assessment to identify facilitators and barriers to seeking care for sore throat in the community.
- Education and training of lower-level health care workers at the district hospital and health center level about strep throat, ARF/RF, and RHD, and to screen for RHD via ultrasound.
- Education of school children and teachers about sore throat, need to seek treatment, and its relationship to ARF/RF and RHD.
- Screening and referral for treatment of school aged children for strep throat and RHD.
- Testing a clinical scoring system for strep throat against gold standard rapid test.
- Embedding RHD screening in an existing maternal health program.
- Training of biomedical technicians on maintenance and repair of ultrasound machines.

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### Highlights of our accomplishments include:

- In partnership with National Institute of Medical Research and Bugando Medical Centre teaching hospital Department of Community Health, a school health assessment was conducted in Sengerema District.
- An RHD school screening program in Sengerema district, designed to address gaps identified in the needs assessment and collect valuable data that was missing about strep throat and RHD prevalence and associated risk factors was conducted.
- 3,000 school aged children were screened for latent RHD using portable ultrasound.
- 3,000 school aged children and 1,000 pregnant women were screened for strep throat using both a clinical scoring system and a rapid test kit to allow for comparison of results between the screening modalities for strep throat.
- Teachers and children at schools in Sengerema district received education about strep throat and ARF/RF and RHD.
- The screening in pregnant women for RHD was expanded to Shinyanga region.
- 2,600 pregnant women received RHD echo screening in the program.
- In addition to the RHD screening echo, 2,600 pregnant women received a routine obstetric ultrasound which is not a standard of care at the district level.
- The referral network between lower-level health facilities and the zonal referral hospital was strengthened.
- Health care workers from district hospitals and health centers were trained to do RHD screening echocardiography using portable and then handheld ultrasound machines, and results were compared to an expert's results to measure agreement.
- 10 biomedical and electrical engineers were trained in maintenance and repair of portable ultrasound machines.
- Qualitative and quantitative research have been performed.



## SUPPORTIVE RESOURCES FOR GOVERNMENTS



### Tools for Implementing Rheumatic Heart Disease Control Programs (TIPs)

Responding to a request from health professionals and policymakers for guidance on how to prevent and manage RF/RHD, RHDA produced an updated version of the “Tools for Implementing Rheumatic Heart Disease Control Programmes” for 2018.

The TIPs Handbook is a resource for people and places developing RHD control programs around the world. TIPs provides an overview of RHD and opportunities to reduce the burden of disease. The resource is intended to help describe, design, implement, and evaluate comprehensive RHD control programs.



### Needs Assessment Tool (NAT)

To provide guidance and structure to the development of interventions to prevent and control RF/RHD, RHDA developed a NAT. The NAT brings together a series of data collection instruments and processes recommended for conducting a comprehensive needs assessment in local communities in RF/RHD endemic countries.

The NAT makes use of scientifically validated methods and is designed as a collection of tools for public health practice.

It provides technical guidance based on the experience of ARF/RHD programs in resource-limited settings and focuses on the key data required for developing and monitoring interventions. The NAT is built on elements of the Tools for Implementing Rheumatic Heart Disease Control Programmes (TIPs) Handbook and the Medtronic Foundation Continuum of Care Framework for Health Systems (CoC). The CoC framework helps identify the barriers and challenges within a health system while keeping the individual seeking care at the center of the process. It also helps provide support for RF/RHD endemic countries.

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## RHDA SMALL GRANT – NEPAL

### KNOWLEDGE, ATTITUDE, AND PRACTICE (KAP) OF RHEUMATIC HEART DISEASE AMONG HEALTH CARE PROVIDERS IN EASTERN NEPAL: MEASURING THE IMPACT OF AN EDUCATIONAL INTERVENTION

Dr. Swatantra was awarded an RHDA Small Grant in 2018 to support a project aimed at educating and raising awareness about RHD among primary health workers at the district teaching hospitals in his region.

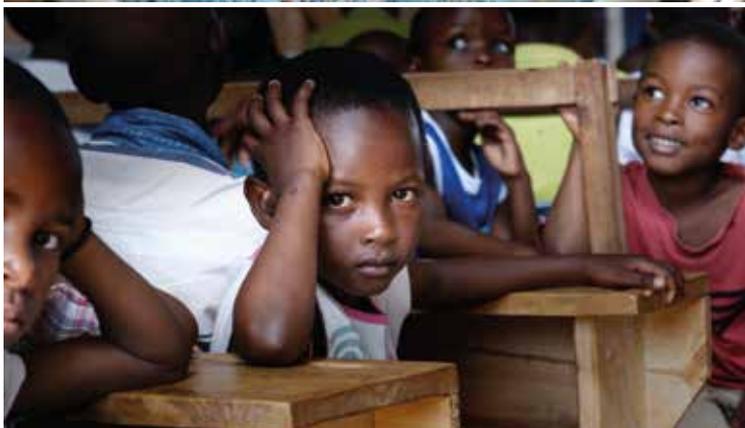
Over the course of this project, Dr. Swatantra organized and conducted three RHD training sessions for health workers.

Measuring the domains of knowledge, attitude, and practice (KAPs) about RHD, Dr. Swatantra had proposed reaching 50 providers in his project proposal but ended up recruiting 123 – the majority of whom were junior doctors, nurses, and auxiliary health workers. Just three participants had attended any recent training on caring for patients with sore throat, ARF, and RHD.

One of the most important accomplishments of this work is fostering a strong and renewed commitment to secondary prevention among the participants. The majority of them were found to be very concerned about their potential liability in cases of BPG-related anaphylaxis. Participants were grateful for the new knowledge and skills they gained from attending the workshops.

Participants from each workshop site agreed to create an RHD patient registry to monitor and support regular BPG injections to prevent recurrence of ARF – the cause of heart valve damage in RHD patients. Having this registry will support better availability of BPG by providing current and accurate evidence of need to health officials.





## ADDRESSING ACCESS TO CARE: ENSURING A STEADY SAFE SUPPLY OF BPG FOR THOSE WHO NEED IT



BPG supplies have long been subject to stockouts and shortages, critically impacting the continuation of care for those with RF and RHD. Shortages have largely been attributed to difficulty securing the quality-assured active pharmaceutical ingredient (API) for the manufacture of formulated product.

Shortages of API reflect the vulnerabilities of the global BPG market: procurement is fragmented by clinical indication; the number of manufacturers is small; and the total price of the drug is low. Improving access to this essential medication has been an important part of addressing access to care issues for PLWRHD and those at-risk populations. In 2016, at the World Congress of Cardiology in Mexico, RHDA published a [Global Status Report on BPG](#).

The report took a detailed look at the complex issues involved in improving access to BPG and included an action plan at global, regional, national, and community levels.

In recent years, WHF has continued to advocate for improved access to a secure quality supply of BPG, particularly at the global level. WHF continues to work closely with Reach as well as other stakeholders such as the Concept Foundation, Clinton Health Access Initiative, and the WHO Essential Medicines team to make progress on this issue. In depth investigations into API manufacturers based in China are currently under way. WHF, along with other stakeholders, is developing a plan of action to help drug manufacturers achieve the WHO's globally recognized safety and quality standard.

### RHDA SMALL GRANT – PHILIPPINES

#### BPG IN UNIVERSAL HEALTH CARE (UHC) IN THE PHILIPPINES

In 2019, a UHC bill was signed into law in the Philippines. This bill includes an "Outpatient Benefit Package for the Secondary Prevention of Rheumatic Fever/Rheumatic Heart Disease" to mandate treatment protocols and benefits for RF and RHD patients. Facilities accredited to deliver the new benefit package will provide BPG injections every 21 days and an annual echocardiogram free-of-charge for registered RHD patients, removing significant financial barriers to care.



The groundwork for this remarkable achievement is largely due to the dedicated efforts of the Philippine Heart Association - Council of RF-RHD, Philippine Society of Pediatric Cardiology, and the Philippine Foundation for the Prevention and Control of RF RHD. Following the bill becoming law, they were awarded an RHDA Small Grant for their project entitled, "Creation of Standardized RHD Educational Materials to Support and Promote the National Implementation of Free Secondary Prophylaxis in the Republic of the Philippines" to support their continued advocacy for the implementation of Outpatient Benefits Package for RHD Patients.

The team created educational materials to cover important topics for facilities to meet the nationally required certification standards to become an approved RHD provider under PhilHealth. They formally launched their program at the Children's Heart Foundation Grand Auditorium Philippine Heart Center in Quezon City in November 2018. From October 2018 through May 2019, using in-person and video conferencing, the team was able to reach over 700 doctors, nurses, and other allied health professionals affiliated with school health programs (not counting all those who attended via video link) with five presentations of their Symposium for Hospitals Accredited for the Outpatient Benefit Package for RHD Patients.

Dr. "Jing" (Ballelos) expressed her enthusiasm and excitement: "This has never happened in Philippine history. After this approval, we wish to eradicate RF in the country within the next 10 to 20 years."

## SUPPORTING NATIONAL AND INTERNATIONAL AGENCIES

### WHF Roadmap for Reducing CV Morbidity and Mortality Through Prevention and Control of Rheumatic Heart Disease

In 2017, WHF convened a group of diverse global experts from the RHD global health community to publish the “WHF Roadmap for Reducing CV Morbidity and Mortality Through Prevention and Control of Rheumatic Heart Disease.”

Part of WHF’s Roadmap series, the document provided a concise summary of the current status quo for RF/RHD globally and provided a comprehensive look at barriers in access to care with proposed solutions. Keeping PLWRHD at the center of this document, barriers were identified along the patient health care journey, and the proposed solutions were tailored to different levels of the health system. As such, the Roadmap provides an overarching framework for integrating RHD interventions into every level of health care.



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### WHA Resolution on Rheumatic Fever and Rheumatic Heart Disease

RHDA led a sustained campaign – **#TimeToTackleRHD** – from 2016 to 2018, bringing together governments, health professional associations, health NGOs, PLWRHD, and the private sector, from around the world to advocate for a Global Resolution on RF and RHD.

As part of advocacy efforts, the WHF conducted a survey of the global RHD Community. In response to the question: *“What would be your one big ask to the WHO Director General?”*, stakeholders highlighted the need for:

1. A concerted drive to raise awareness and allocate resources (human and financial) to RHD, including allocating human and financial resources to RHD staff in the WHO Secretariat.
2. Investment and technical support in direct epidemiological measurement of global and national RHD burdens, as currently we rely on modelling estimates.
3. A synchronized global RHD prevention and control program, supported by a global funding source that is replenished by a coalition of global health funders and Ministries of Health.
4. Integration of RHD prevention and control into WHO’s existing child and adolescent health packages, including provision of nurses for schools.
5. Technical and financial support to improve quality, supply, access, and efficacy of BPG.

Following several years of high-level events, national and global advocacy initiatives, Member States of the WHO, led by the Governments of New Zealand, Australia, Namibia, Egypt, and Kenya, unanimously adopted a Global Resolution on RF and RHD at the 71st WHA in Geneva, Switzerland. This historic decision marked the first time that RF and RHD were recognized as global health priorities on the world stage. The Resolution was co-sponsored by countries from all six WHO regions, demonstrating the urgent need for a global response.

Following the adoption of the World Health Assembly Resolution, RHDA Partners have entered partnerships with several Ministries of Health to provide support to their RF/RHD prevention and management activities.

Using the tools developed through the RHDA Program, Reach is working with the governments of Kenya, Uganda, and Vanuatu to undertake a rapid situation assessment in endemic areas and develop strategies for improving the detection and management of sore throats, RF, and RHD.



## WHO Eastern Mediterranean Regional Office Technical Consultation

RHDA, in partnership with the WHO Regional Office for the Eastern Mediterranean, co-organized a technical consultation on RF/RHD in the Eastern Mediterranean Region (EMR).

The meeting, held in January 2019, was attended by Ministry of Health representatives from eight countries: Egypt, Afghanistan, Sudan, Somalia, Pakistan, Morocco, Tunisia, and Jordan, as well as a number of expert advisors from the region. The meeting included a presentation on the preliminary findings of a top-level situation analysis of RF/RHD activities in each of the participating countries and review of the draft Regional Framework for Action to address RF/RHD in the region. Participating countries agreed to form a Regional Expert Network (REN) to provide peer support and further guide country activities. The REN is supported by Reach through the RHDA program.



### Framework for Action on Rheumatic Fever and Rheumatic Heart Disease in the WHO Eastern Mediterranean Region (EMRO)

In October 2019, the Regional Framework for Action (RFA) was endorsed by Member States during the 66th Regional Committee Meeting. The development of the Framework was led by Reach, and outlines the key steps to be taken by countries in operationalizing WHA Resolution 71.14.

The Framework builds on the health system elements and care pathway identified in TIPs, highlighting opportunities to intervene along the pathway from Strep A infection to the further complications caused by RHD.

RHDA will continue to support engagement with the WHO EMRO and implementation of the Framework through the WHO EMRO REN.



## INAUGURAL MEETING OF THE REGIONAL EXPERT NETWORK

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Members of the REN for RHD convened in December 2019 to discuss the current situation in the region as well as develop and finalize a 2-year work plan. The REN is expected to carry forward the regional agenda and support implementation of the RFA by providing technical input to WHO EMRO-led country support in the field of RHD prevention and control.

*“Our Region continues to suffer greatly from RF/RHD. The creation of the RF/RHD Expert Network is an important step forward for RHD prevention and control in our Region. We are working to implement the Regional Framework for Action on RF/RHD that was developed by WHO EMRO and Reach, to identify regional solutions and support countries to address challenges”*

**DR HABIB GAMRA,**  
**WHO EMRO RHD REGIONAL EXPERT NETWORK**



## Recommendations in the Resolution on Rheumatic Fever and Rheumatic Heart Disease

### The Resolution calls on Member States to take action in five areas:



- Improve access to primary health care.
- Strengthen data collection and knowledge of RHD prevalence in endemic countries.
- Ensure affordable and reliable access to technologies and medicine.
- Strengthen national and international cooperation.
- Tackle the root determinants of RF & RHD.

### Secondly, the Resolution invites all stakeholders to collaborate with WHO and Member States in order to:

- Put PLWRHD at the center of the prevention and control agenda.
- Raise the profile of PLWRHD and other NCDs of children and adolescents on the global health agenda.
- Support and facilitate timely, affordable, and reliable access to existing and new cost-effective medicines and technologies for the prevention and control of RHD.

### Finally, the Resolution makes 5 requests to the Director-General of WHO:

- Lead and coordinate global efforts to prevent and control RHD.
- Support Member States to measure their RHD burdens and implement programs.
- Foster international partnerships.
- Monitor efforts for the prevention and control of RHD.
- Report on implementation of this Resolution to the 74th WHA, which will be held in 2021.



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## Towards 2021 and Completion of the First Reporting Period (2018-2021) at the WHA in 2021



Since the adoption of the Resolution in 2018, WHF has continued to spearhead advocacy for RHD globally. In 2021, the WHO Director-General, WHO, and Member states will report on implementation of this resolution to the Seventy-fourth World Health Assembly.

Given the significant burden of RHD in Sub-Saharan Africa, WHF has been taking advantage of the unique window of opportunity to support the African Union to develop a Call of Action requesting support and funds from the Chinese International Development Cooperation Agency (CIDCA). China – being both the world's only source of the active pharmaceutical ingredient (API) product – has a unique role to play in the production of BPG

and has demonstrated a significant interest in global health and development, particularly in the African region where RHD is a hugely important problem.

CIDCA funding will allow for the implementation of the RHD Resolution especially (but not exclusively) regarding action on BPG and the possible eradication of RHD in all endemic countries.

The production of quality-assured BPG is the only intervention that requires global or bi-lateral cooperation between countries (as well as with the WHO), an area that WHF is uniquely positioned to champion from a global advocacy perspective.



## RHDA SMALL GRANT – RWANDA

### IMPROVING HEALTH EDUCATION AMONG POST-OPERATIVE RHD PATIENTS

The Team Heart organization conducted four day-long health education workshops for post-operative RHD patients and NCD nurses at selected district hospitals throughout Rwanda. Their objective was to improve frontline health workers' and patients' knowledge about medication adherence, family planning, nutrition, and lifestyle/behavior changes to better inform and enable patients to improve their health and well-being.

For this project, Team Heart collaborated with the NCD Division within Rwanda Biomedical Center to coordinate the workshops. Posters and pamphlets with information about symptoms, prevention, and treatment of RHD were developed and produced for participants to take home. These materials, as well as workshop presentation materials with case studies, were jointly developed by Team Heart and the RBC team with input from the Rwanda Heart Foundation.

A symposium was held by Team Heart at Marasa Umubano Hotel in April 2019 to disseminate the results from the workshops, discuss the challenges identified by post-operative patients regarding family planning, and establish recommendations for standardized prevention and treatment of these patients. A range of cardiac stakeholders attended that included specialist physicians, nurses, and representation from the RBC. Patient feedback expressing a lack of resources, support, and knowledge about family planning was presented. A plan was made to establish a technical working group that would meet regularly to produce recommendations to address this issue.

As a result, Team Heart has developed a plan to improve health worker knowledge and skills for treating post-surgical cardiac patients by working more closely with NCD nurses at the district hospitals. Their plan also targets the home-based care practitioners and other community-level health workers who provide care for these patients. "We learned from patients during the workshops that effective and appropriate care is difficult to access at the community level. By training health practitioners, we aim to bolster the continuum of care for patients from the district hospitals down to the health posts in the communities."

# CONCLUSION AND RECOMMENDATIONS

The past five years have seen an increase in interest in RF/RHD, but there is still much more to do to support the predominantly young people living with the disease who require regular treatment and potentially surgery as well as to prevent future generations from experiencing heart valve damage from RF.

**As the work of the RHDA partners and community continues, we ask for your assistance to:**

## 1. Support Frontline Health Workers and People Living with RHD (PLWRHD):

- a. Strengthen the capacity of frontline health workers to recognize, treat, and manage strep throat (GAS), RF/RHD
- b. Support PLWRHD to manage their condition by investing in support groups and communities of PLWRHD

## 2. Understand the Burden of Rheumatic Fever and Rheumatic Heart Disease:

- a. Invest in efforts to capture the burden of RF/RHD in endemic countries

## 3. Support Governments and International Agencies:

- a. Invest in governments' efforts to implement strep throat, RF/RHD interventions
- b. Support the roll out of UHC
- c. Support the implementation of the WHO Resolution on the Prevention and Management of RF/RHD

## 4. Address Access to Care:

- a. Support efforts to ensure a secure supply of quality BPG
- b. Invest in primary health care interventions that support early diagnosis and management of strep throat, RF/RHD

## 5. Integrate RHD into the Primary Health Care System:

- a. Include strep throat, RF/RHD interventions in relevant disease programs e.g., integrated management of childhood illness, non-communicable disease, and ante-natal care.

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**ENSURING FUTURE GENERATIONS ARE FREE FROM RHD IS EMINENTLY ACHIEVABLE. JOIN US IN UNITING TO END RHD.**

**A huge thank you to everyone who contributed to the success of this project, on behalf of the RHD Action partners.**



## REFERENCES

1. Roth, G. A. et al. Global Burden of Cardiovascular Diseases and Risk Factors, 1990–2019: Update From the GBD 2019 Study. J. Am. Coll. Cardiol. 76, 2982–3021 (2020).



**RHD Action**

*United to End Rheumatic Heart Disease*