RHD Action | *United to End Rheumatic Heart Disease*

UNITED TO END RHEUMATIC HEART DISEASE

RHD ACTION PROSPECTUS
2017

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INTRODUCTION

Who are we?

RHD Action is a global initiative that unites and empowers the rheumatic heart disease community. Led by a coalition of core organizations, RHD Action 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 people living with rheumatic heart disease (RHD) and their communities.

We formed in 2014 as a partnership between the World Heart Federation, RhEACH and Medtronic Philanthropy, alongside inaugural demonstration projects in Uganda and Tanzania and the wider RHD community.

Our goal is to achieve a 25% reduction in mortality from rheumatic heart disease (RHD) by the year 2025 in under-25-year-olds.

We are working towards this goal by giving a powerful platform to existing work in RHD prevention and control, while providing new innovative tools, guidance, and opportunities to the RHD community.

Our priorities synthesize ten key areas of RHD control, and were developed with the participation of regional bodies, RHD research groups, and global policy advocates. These ten priorities form the core focus areas of RHD Action, and are structured in a 'priorities pyramid' with three main categories:

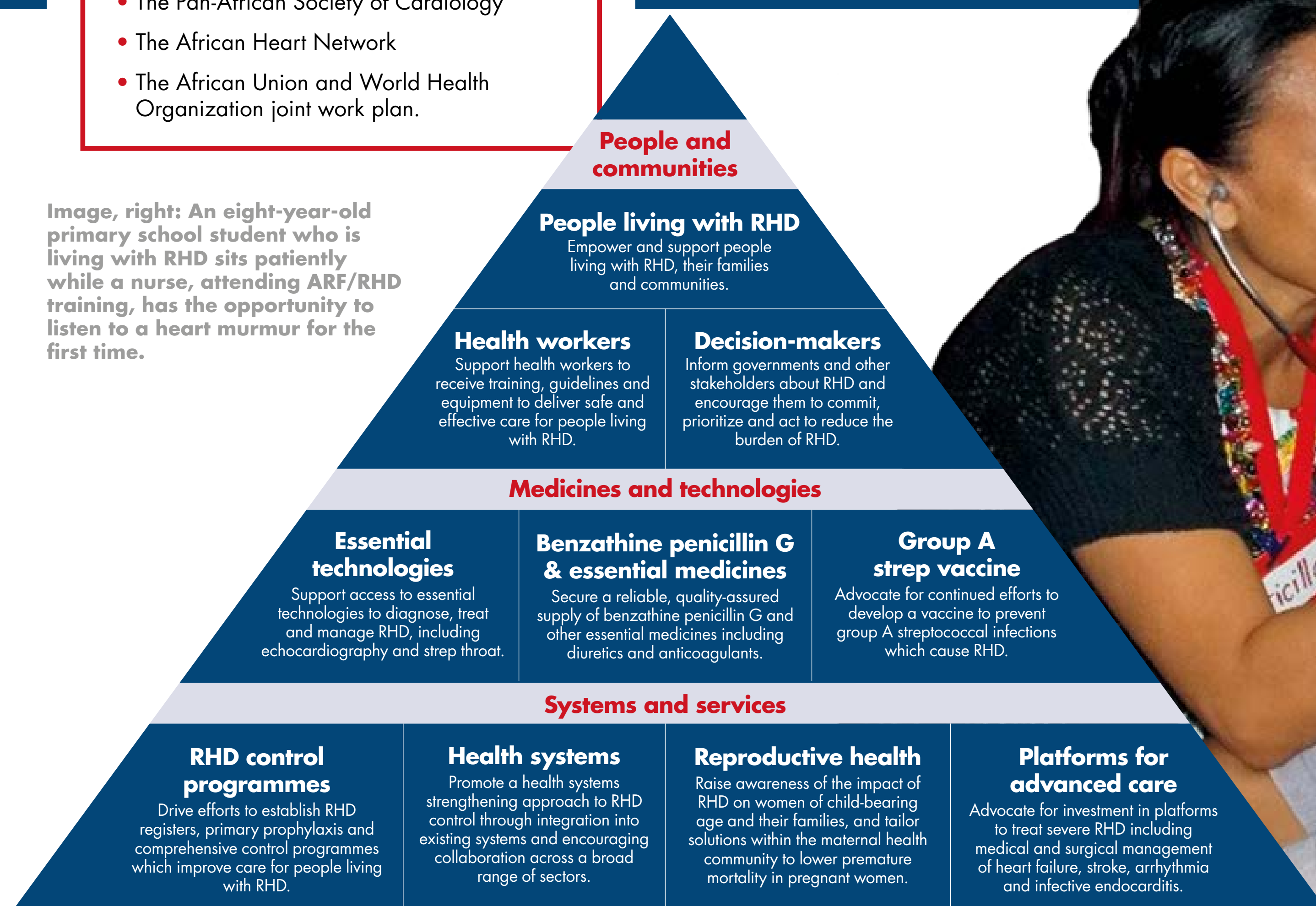
- People and communities
- Medicines and technologies
- Systems and services

The pyramid guides the programmatic work of RHD Action and informs our decision making. It reflects the primacy of people living with RHD in our activities, the essential bedrock of strong health systems, and necessary prerequisites for disease control.

This global target has been endorsed by:

- The World Heart Federation
- RhEACH
- The Pan-African Society of Cardiology
- The African Heart Network
- The African Union and World Health Organization joint work plan.

Image, right: An eight-year-old primary school student who is living with RHD sits patiently while a nurse, attending ARF/RHD training, has the opportunity to listen to a heart murmur for the first time.



Why RHD?

RHD is a disease of the world's poorest and most vulnerable communities. RHD primarily afflicts women, children, and young people in Africa, Asia, the Middle East, Latin America, and the Western Pacific, and in under-served communities worldwide. RHD is preventable, but when left unchecked it can cause devastating loss of life, potential, and resources. RHD Action unites and supports organizations to put this preventable disease in the history books.

Why now?

RHD has long been neglected by global and national efforts. But recent policy and research advances have led to increasing recognition of RHD as a health priority on the world stage. In June 2017, the Executive Board of the World Health Organization recommended a Resolution on 'Rheumatic Fever and Rheumatic Heart Disease' for adoption at the 2018 World Health Assembly. Once approved, it will be a high-level global policy that demands national and international decision-makers take action to prioritize RHD prevention and control in all endemic settings.

It is essential that we build on this momentum to integrate RHD into the mainstream global health agenda. As we progress into the era of the Sustainable Development Goals, we call on our partners to join us in serving the RHD community, so that they are no longer left behind.

What is RHD?

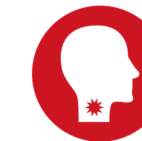
RHD is a preventable, treatable form of cardiovascular disease that affects over 33 million people around the world and kills 320,000 of them each year. It affects the world's poorest, most vulnerable populations and imposes heavy costs on the health systems that can least afford it. If left untreated, 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 and death during pregnancy. In endemic countries, prevalence of this preventable disease is a stark measure of health system failure and inequality.

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 streptococcal (GAS) infection. If left untreated, this can lead to acute rheumatic fever (ARF), which is an abnormal immune reaction to this 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.

At RHD Action, we believe that a 25% reduction in deaths from RHD among under-25-year-olds can be achieved by focusing on our ten priorities. Our approach is unique within the RHD community, as it connects national RHD experts with newly developed global tools in order to achieve this ambitious goal.

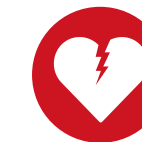
How to prevent and control rheumatic heart disease

Primordial prevention: Improvement of environmental, social, and economic conditions of populations at risk of ARF and RHD.



Primary prevention: Treatment of sore throat with antibiotics to reduce the incidence of ARF.

Secondary prevention: Use of antibiotics to reduce the recurrence of ARF, which can lead to RHD.



Tertiary prevention: Medical and surgical treatment of the complications of ARF and RHD.

KEY ACHIEVEMENTS TO DATE

People living with RHD

Empower and support people living with RHD, their families, and communities.

People living with RHD (PLW RHD) are the primary stakeholders of RHD Action: indeed, RHD Action is ultimately accountable to these individuals and their families. To date, the experience of living with RHD has been relatively hidden. In most of the world, PLW RHD remain isolated from each other and from the global conversation about ending this disease. Learning from the experiences of successful patient advocacy in HIV control, we are connecting PLW RHD, amplifying their voices, and learning from their experiences. In this way, we reliably address the needs and priorities of the people who matter most.

We aim to:

- Support PLW RHD to tell their own story, publicly and privately, through a variety of media.
- Engage PLW RHD in priority-setting and governance for RHD control activities.
- Provide empowering information and education about RHD to people living with the disease.

To achieve this we have:

- Developed a **'Living with RHD'** section on the RHD Action website, alongside an **active Twitter feed** sharing additional news and information.
- Supported three PLW RHD to attend the **Global Launch of RHD Action in New York**, alongside the United Nations General Assembly in 2015.
- Supported one PLW RHD to speak at an **RHD Action co-sponsored side event in Geneva** alongside the World Health Assembly in 2017.
- Profiled seven PLW RHD in the **RHD Global Status Report 2015 – 2017.**
- Developed style guidelines and a **consent form for images, recordings, and documents** used by RHD Action to ensure PLW RHD are represented with their knowledge, approval, and dignity.
- Supported a **Patient Conference in Cape Town**, September 2016.
- Included interviews with PLW RHD in the baseline assessment of services in Tanzania, informing preliminary plans for 'RHD Clubs' in priority areas.

Health workers

Support health workers to deliver safe and effective care for people living with RHD.

Human resources for health are critical for RHD control at every level of care. The RHD community includes health workers, midwives, nurses, sonographers, physicians, dentists, medical specialists, and support staff, who must collaborate to provide outstanding care to PLW RHD. Globally, the health workforce is stretched – particularly in low income countries where RHD is endemic. RHD Action supports the vision of the World Health Organization (WHO) to 'accelerate progress towards universal health coverage and the UN Sustainable Development Goals by ensuring equitable access to health workers within strengthened health systems'.[1]

We aim to:

- Support the development of training resources and guidelines which promote excellence in the care of PLW RHD.
- Endorse training which is applicable beyond RHD and increases the capacity of health workers to address a variety of clinical and systems requirements.
- Provide a platform to share the experiences of health workers to ensure these are reflected in the design of RHD prevention and control programmes.
- Minimize the time spent away from clinical care to deliver and receive training by embedding and delivering training in real world environments.
- Acknowledge the 'brain drain' of health professionals from least developed countries to more developed settings and seek to minimize the impact of this trend.

To achieve this we have:

- Endorsed the **WHO Global Code of Practice on the International Recruitment of Health Personnel.**
- Ensured that two frontline health workers addressed the **RHD Action launch in New York** in 2015 to share their experiences of caring for people living with RHD.
- Acknowledged the essential role of frontline health workers in three interviews featured in RHD Action's **Global Status Report 2015 – 2017.**
- Established relations with the International Council of Nurses, whose CEO endorsed the key role of nursing in the **Global Status Report 2015 – 2017.**
- Commenced training nurses, sonographers, clinical officers, and medical officers to use hand-held portable ultrasound to diagnose latent and clinically symptomatic RHD and to differentiate it from other causes of heart failure in Gulu and Lira, Uganda, Case Western University and the Ugandan Heart Institute.
- Trained Ugandan healthcare workers in basic care of RHD, including how to properly give an injection of benzathine penicillin G (BPG), the mainstay of ARF and RHD treatment.
- Commenced planning in Tanzania to integrate RHD training in pre-service and in-service non-communicable disease training, thereby avoiding an RHD training silo.

We aim to support the development of training resources and guidelines which promote excellence in the care of people living with RHD.

Decision-makers

Inform and support governments and other stakeholders to reduce the burden of RHD.

RHD is ultimately a disease of poverty and economic inequality, which are determined by the decisions of governments and multinational stakeholders. The **considerable economic cost and social burden** of RHD is borne by the most vulnerable communities and countries. Undiscounted financial costs from excessive RHD deaths in 2010 have been estimated at 2.2 trillion US dollars.[2] Supporting governments to understand and address RHD contributes to economic development and improvements in the lives of PLW RHD. We are deeply committed to helping decision-makers understand these challenges.

We aim to:

- Use the best possible data to inform governments about the burden and impact of RHD. Where data are insufficient, we seek partnerships with local researchers and agencies to generate national and subnational information resources.
- Support governments to collect their own data on the burden and impact of RHD.
- Analyze, interpret, and present data in ways that are meaningful to policy makers.
- Use routinely collected data wherever possible.
- Provide decision-makers with evidence-based resources for disease control.
- Support PLW RHD, clinicians, and other stakeholders to engage their governments in RHD through excellent resources and briefing notes.
- Provide tools for governments and other agencies to act on RHD control.
- Celebrate the contributions of governments to RHD control activities.

To achieve this we have:

- Supported and prepared for a **World Health Assembly Resolution on 'Rheumatic fever and rheumatic heart disease'** in 2018, co-sponsored by the governments of Australia, Brazil, Burundi, Canada, Colombia, Cook Islands, Ecuador, Fiji, Japan, Kenya, Namibia, New Zealand, Pakistan, Samoa, South Africa, Thailand, Tonga, Tuvalu, Uganda, and Zambia.
- Developed resources for governments and other stakeholders, including:
  - A Roadmap for RHD control, intended for national level adaptation.
  - A report outlining the rationale for including **RHD in Universal Health Coverage** initiatives, which supports the cost-effective role of primary health care for early diagnosis and management of strep throat, rheumatic fever, RHD, and heart failure.
  - Customized briefing notes for the **Pacific Islands** and Eastern Mediterranean Region of the World Health Organization.
- Profiled the work of governments in our **RHD Global Status Report 2015 – 2017** and recruited the former Prime Minister of Australia, Mr. Kevin Rudd, as a **Global Ambassador for RHD Action.**
- Developed the **Global Atlas of RHD** to display relevant information from the Global Burden of Disease Study at a national level and to augment this with additional echocardiographic screening data.
- Endorsed the African Union Communiqué commitment to tackle RHD on the African continent.
- Published a **systematic review protocol** allowing countries to use a standardized methodology for describing what is known about the domestic burden of RHD.

RHD Action members and event speakers present the declaration and celebrate the launch of RHD Action, 2015.

MEDICINES AND TECHNOLOGIES

Essential technologies

Support access to essential technologies to diagnose, treat, and manage RHD.

A range of medical equipment and technology is needed to provide care for PLW RHD. In primary care clinics this equipment is simple, including scales (to calculate drug doses and monitor weight gain in heart failure), stethoscopes (to listen for heart murmurs), and access to electrocardiography (to monitor heart rhythm disturbances). There is evidence that the use of Rapid Antigen Detection Tests for group A strep can help inform the use of antibiotics in primary prophylaxis in regions of the world where this is common practice, such as New Zealand and the United States of America.

In secondary care, ultrasound machines capable of high quality echocardiography are essential for definitive diagnosis and for surgical planning in advanced disease. The role of portable and handheld echocardiography for screening of asymptomatic young people remains unclear and we are keen to address this important knowledge gap.

We aim to:

- Ensure that appropriate training for the use and interpretation of medical technologies is provided to end users.
- Encourage the decentralization of the deployment of medical technologies wherever possible, by empowering community health workers with the greatest possible skill set.
- Ensure that medical equipment and technologies needed for RHD care are applicable to conditions beyond RHD whenever possible.
- Ensure that equipment is able to be locally maintained.

To achieve this we have:

- Endorsed the list of equipment outlined in the **WHO Package of Essential Non Communicable Disease Interventions for Primary Health Care (PEN)** including scales, blood pressure machines, syringes, and electrocardiography.
- Endorsed and abided by the **WHO Guidelines for Health Care Equipment Donations.**
- Convened an Expert Panel to develop global guidelines for the indications, ethics, and delivery of echocardiography screening projects.
- Commenced evaluating the use of hand-held ultrasound by non-expert frontline providers in Lira, Uganda, to more accurately diagnose different kinds of heart failure among patients presenting with signs and/or symptoms of cardiovascular disease.

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Benzathine penicillin G & other essential medicines

Secure a reliable, quality assured supply of benzathine penicillin G.

The antibiotic benzathine penicillin G (BPG) is the mainstay of management for ARF and RHD. BPG is used to treat sore throats caused by GAS infections (strep throat). A single intramuscular injection given within 9 days of sore throat symptoms can reduce the risk of developing ARF by 80%.[3] Use of BPG for sore throat is called primary prevention and has been a component of strategies to reduce the incidence of ARF.[4] BPG is also used in secondary prevention to prevent recurrences of ARF in people who have had a first episode of ARF or known RHD. Administration of a BPG injection every 2 – 4 weeks for 10 years or more following the last episode of ARF can prevent the progression of heart valve damage.[5] BPG has been on the list of WHO Essential Medicines since the list was first formulated in 1977, however, global shortages of BPG continue to occur and threaten the continuity of RHD treatment.

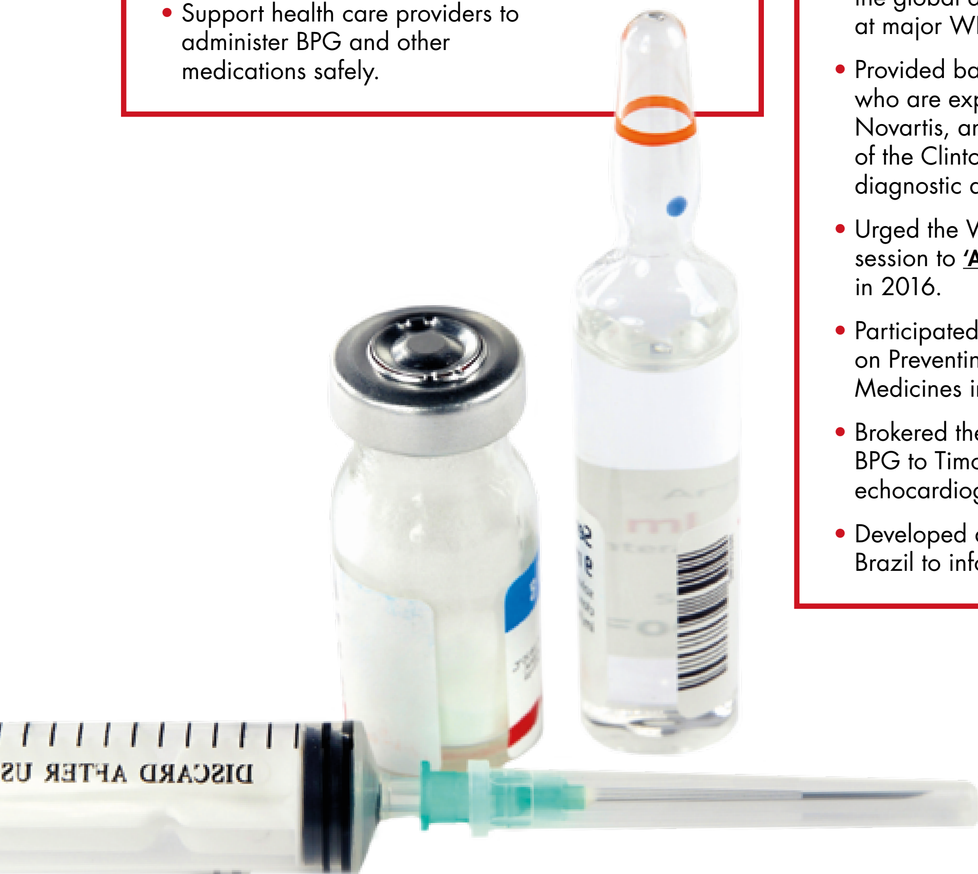
Other medications are needed to manage rheumatic fever and RHD, including aspirin (for management of joint pain), diuretics (for management of heart failure), anticoagulants (to prevent blood clotting on abnormal heart valves), contraception, and advanced heart drugs for rhythm abnormalities and infections.

We aim to:

- Support all people with a clinical indication for BPG injections to receive safe, high quality medication when it is needed.
- Work with manufacturers, purchasers, and other BPG stakeholders to understand and optimize the global supply of the drug.
- Support health care providers to administer BPG and other medications safely.

To achieve this we have:

- Published the **Global Status of BPG Report** providing a comprehensive global overview of BPG issues for all clinical indications, including the major use for treatment of syphilis.
- Contributed to work with the World Health Organization Essential Medicines team to estimate the global demand for BPG and inform case studies at major WHO meetings on essential medicines.
- Provided background and data to stakeholders who are exploring BPG shortages including Pfizer, Novartis, and UNICEF, and contributed to the work of the Clinton Health Access Initiative's market diagnostic analysis.
- Urged the World Health Assembly during the session to **'Address the global shortages of medicines'** in 2016.
- Participated in the WHO Technical Consultation on Preventing and Managing Global Stock Outs of Medicines in December 2016.
- Brokered the donation of 300 doses of BPG to Timor-Leste in conjunction with an echocardiography screening programme.
- Developed a custom briefing note on BPG supply in Brazil to inform local discussions about stock-outs.



Group A strep vaccine

Advocate for continued efforts toward a vaccine to prevent group A streptococcal (GAS) infections which cause RHD.

Rheumatic fever is caused by an abnormal response to group A streptococcal (GAS) infection of the throat, and possibly the skin. GAS infections can also become severe, invasive, life threatening infections and occur in both high and low resource settings. WHO Product Development for Vaccines Advisory Committee (PDVAC) identified a GAS vaccine as a priority in 2014 and recommended the development of a business case. Development of this vaccine could prevent the strep throat which precipitates RHD as well as controlling other GAS diseases. Pre-clinical and clinical trials of **a number of GAS vaccine candidates** are underway.

Senior researchers in RHD Action have been involved in several major GAS vaccine initiatives, including the landmark Australia-New Zealand collaboration for the Coalition to Advance New Vaccines Against Group A Streptococcus (CANVAS) project. However, we are yet to take collective action under the RHD Action banner. Although scientific development of a vaccine is beyond the scope of RHD Action, we believe we have an important goal-setting and advocacy voice in vaccine development.

We aim to:

- Support vaccine market readiness by collecting contemporary data about the burden of strep and RHD at national levels to inform purchasing decisions when a vaccine is developed.
- Advocate in the scientific community to ensure that any GAS vaccine brought to market is protective against rheumatic fever, not solely against pharyngeal or invasive isolates of GAS species. This mitigates the risk of developing a vaccine which is valuable in high resource settings but neglecting the needs of less developed communities where RHD is endemic.
- Ensure that a GAS vaccine remains on the RHD prevention agenda, alongside treatment for people already living with RHD, and that the prolonged effects of RHD are well understood by decision-makers. Even if a market-ready vaccine were invented tomorrow, it would take decades to be delivered to the populations at risk and longer still to reduce the incident cases of disease. In the event of a suitable vaccine, the costs of development and delivery are potentially enormous and necessitate ongoing review of cost-effectiveness. It is imperative that we do not 'wait' for a vaccine to tackle this disease.

To achieve this we have:

- Supported and attended the World Health Organization and International Vaccine Institute Global Consultation on Group A Streptococcal Vaccine Development.
- Amplified key messages from vaccine collaboration initiatives, including the Coalition to Advance Vaccines Against Group A Streptococcus (CANVAS).
- Raised awareness of vaccine milestones, including the endorsement of a GAS vaccine by the WHO PDVAC.

SYSTEMS AND SERVICES

RHD control programmes

Drive efforts to establish comprehensive control programmes for people living with RHD.

The implementation of comprehensive RHD control programmes is the only intervention with evidence for reducing the burden of RHD. Comprehensive programmes including primary and secondary prophylaxis can be cost-effective. We are committed to helping all interested parties design, implement, and evaluate RHD control programmes in conjunction with health system strengthening initiatives.

We aim to:

- Identify, promote, and adapt best practices in RHD control activities to local contexts, supporting stakeholders and monitoring outcomes.
- Use the platforms of RHD Action to share research outcomes and findings from RHD control programmes and to celebrate their successes.
- Maximize the national ownership and sustainability of programmes by integrating them within national Ministries of Health and/or health services.
- Champion the scale-up of successful pilot programmes to increase programmatic impact across larger populations.
- Promote the potential of RHD prevention and control programmes to integrate across disease areas and development sectors, by including co-benefit solutions with related areas such as maternal and child health.

To achieve this we have:

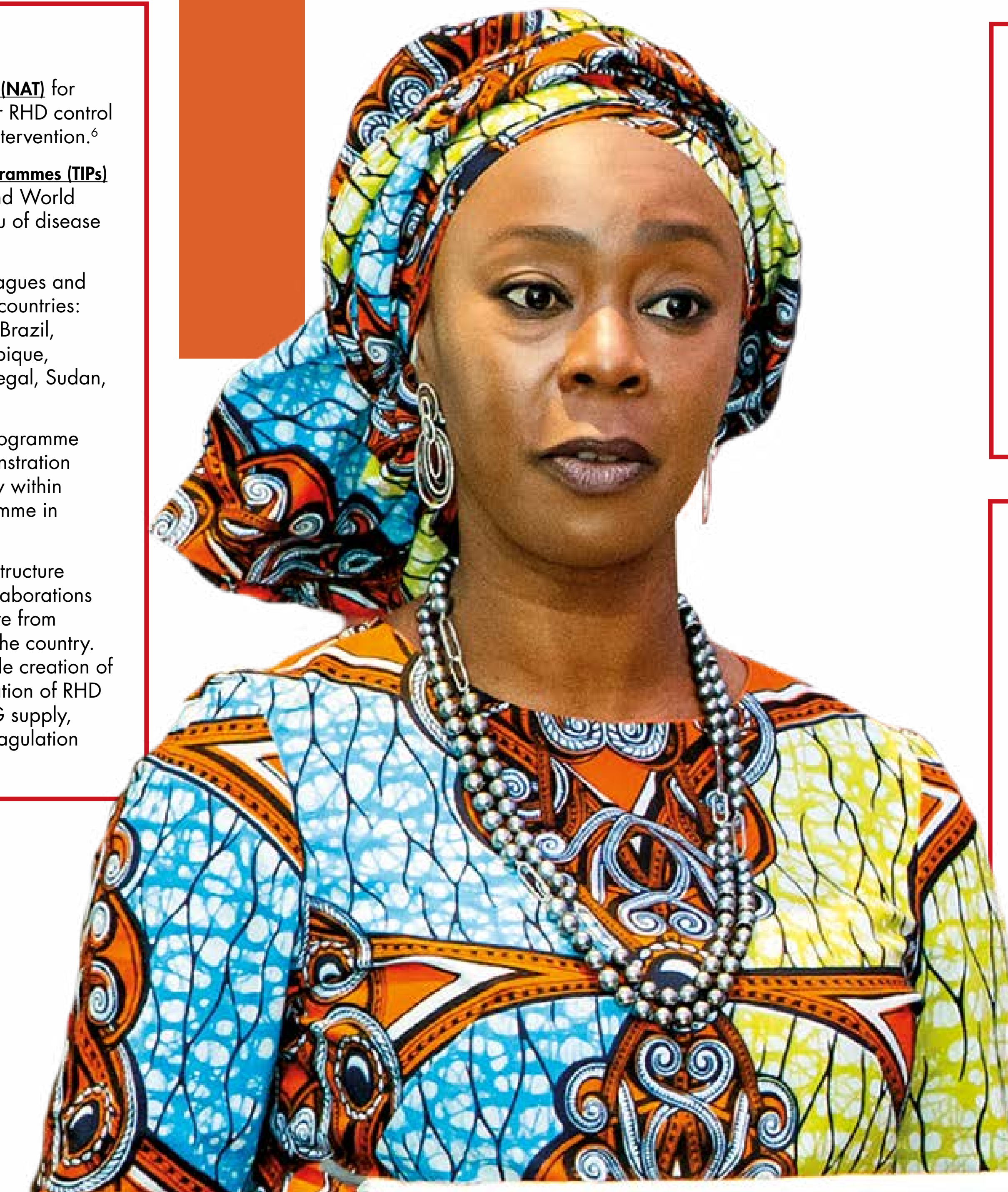
- Developed a **Needs Assessment Tool (NAT)** for evaluating existing infrastructure for RHD control and identifying priority areas for intervention.[6]
- Used the **Tools for Implementing Programmes (TIPs)** resource developed by RhEACH and World Heart Federation to provide a menu of disease control options for policy makers.
- Provided technical support to colleagues and collaborators in a diverse array of countries: Angola, Australia, Bhutan, Bolivia, Brazil, Ethiopia, India, Indonesia, Mozambique, Myanmar, Nauru, Nicaragua, Senegal, Sudan, and Timor-Leste.
- Developed novel approaches to programme development and delivery in demonstration countries, including service delivery within an existing maternal health programme in Tanzania.
- Leveraged existing HIV/AIDS infrastructure and long-standing North-South collaborations in Uganda to decentralize RHD care from Kampala to more remote areas of the country. Highlights of this programme include creation of a national RHD registry, harmonization of RHD research activities, regularized BPG supply, education and training, and anticoagulation monitoring.

We are committed to helping all interested parties design, implement, and evaluate RHD control programmes in conjunction with health system strengthening initiatives.

Health systems

Promote a health systems approach and encourage collaboration across a broad range of sectors.

RHD intersects with a wide range of health sectors, including: infectious disease, non-communicable disease, paediatrics, adolescent medicine, cardiology, family medicine, maternal health, school and dental health. Therefore, 'horizontal' health systems strengthening – supporting primary care, health records, procurement processes, and health worker training – is most sustainable and useful, especially in low-resource settings. In practice, the development of RHD control programmes is often 'diagonal': combining some disease-specific requirements (often registers for secondary prophylaxis) with 'horizontal' initiatives which strengthen care delivery for all diseases.



We aim to:

- Use advocacy, interventions and investments for RHD control as levers to support health system strengthening.
- Facilitate integration of RHD prevention and control programmes with as many sectors and stakeholders as possible.
- Advocate for the integration of programmatic RHD prevention and control efforts within the national health system.
- Identify and avoid siloed, vertical, and isolated models of care delivery which are not sustainable or detract from broader efforts of the health service.

To achieve this we have:

- Published a report on including **RHD in Universal Health Coverage (UHC)**, articulating opportunities for including cost-effective RHD interventions into basic packages of care, and offering a case study from the Philippines.
- Tracked UHC discourse from a number of key international actors, including IHP+, UHC 2030 and the G7, and encouraged emerging UHC efforts in endemic countries to include RHD interventions in UHC packages (including Nigeria, Philippines and Egypt).
- Supported integration of RHD services into existing infrastructure for HIV care in Uganda and into maternal health care in Tanzania.

RHD Champion Madame Toyin Ojora-Saraki, founder and President of the Wellbeing Foundation Africa at the launch of RHD Action, 2015.

Reproductive maternal newborn and child health

Raise awareness and tailor solutions with the maternal health community to prevent RHD mortality in pregnant women.

Pregnancy is a time of intense physiological demand – blood volume increases significantly and the heart must pump harder to supply the growing baby. For women with RHD who have damaged heart valves, these changes may be dangerous or fatal. Young women in resource-limited communities have the greatest risk of RHD and the least access to high quality maternity care. Equally, few of the most vulnerable women with RHD have access to family planning and reproductive services. In a large survey of 3343 people in fourteen countries living with advanced RHD, only 3.6% of women were using contraception.[7]

We aim to:

- Raise awareness of the impact of RHD on women, babies and communities.
- Endorse the right of women living with RHD to have planned, healthy pregnancies.
- Support efforts to embed RHD services within routine antenatal care in endemic countries, potentially including strategies for diagnosis during pregnancy.
- Endorse access to high-quality medical care during pregnancy and delivery for all pregnancies affected by RHD.

To achieve this we have:

- Invited Madame Toyin Ojora Saraki, Founder of the Wellbeing Foundation Africa, to be our Keynote Speaker at the **launch of RHD Action**. Our collaboration with the Wellbeing Foundation has included a focus on RHD during 'Maternal Health Mondays' on Twitter.
- **Addressed the World Health Assembly** on the Global Strategy for Women's, Children's and Adolescents' Health and called for the inclusion of RHD in the reproductive health agenda.
- Submitted and delivered statements advocating for RHD to be incorporated into maternal and child care at the WHO Regional Meetings for **South-East Asia** and **Africa**, and into the Regional Action Plan for Healthy Newborn Infants in the **Western Pacific.**
- Established a maternal cardiovascular health clinic in Uganda to counsel RHD patients about family planning, use of anticoagulation during pregnancy, and peripartum heart failure management.

Platforms for advanced care

Advocate for platforms to treat severe RHD, including medical and surgical management.

There is no 'cure' for RHD. In advanced cases of RHD, only surgery can prolong life. People living with RHD prioritize access to surgery and we respect the urgency of this issue for those who are critically unwell. Although delivering surgical services is outside the scope of RHD Action, we have an important role in advocating for advanced care – including anticoagulation medication – and ensuring it is delivered appropriately, ethically, and equitably.

We aim to:

- Support excellence in cardiac surgery and percutaneous interventions, ensuring that it is delivered safely.
- Advocate for surgical services to support domestic health capacity by incorporating local staff training and upskilling.
- Support access to anticoagulation and other essential preoperative care.
- Advocate for high quality palliative care for people at the end stage of their disease without further options for life-prolonging treatment.

To achieve this we have:

- Trained two Ugandan interventional cardiologists in Cleveland, Ohio, USA, who have acquired the requisite skillset to begin offering percutaneous balloon mitral valvuloplasty for patients with rheumatic mitral stenosis. Additional training is being provided through collaborators in Brazil and through ongoing training camps from visiting US teams.
- Both Uganda and Tanzania are signatories to the Addis Ababa African Union Communiqué, highlighting the need for advanced medical and surgical care. RHD Action formed part of the team developing this Communiqué and an RHD Action team member currently leads the RHD task force surgery team.

OUR FUTURE PLANS

Despite our best efforts, RHD remains a significant health burden in almost every region of the world. RHD Action is committed to our goal of reducing deaths from RHD by 25% in under-25-year-olds by the year 2025.

In line with our ten priority points, we have identified approaches to meet this target. These approaches are ambitious, yet realistic. To achieve them will require support from the entire RHD community, plus external stakeholders including funders and philanthropists. Read on to learn more about our exciting plans for the future of RHD prevention and control:

People living with RHD

- Identify PLW RHD beyond the existing heart disease community, including women affected by RHD in pregnancy, young people with stroke from RHD, and community leaders affected by the disease.
- Involve PLW RHD in RHD Action priority setting and the development of future projects and programmes.
- Support PLW RHD to tell their stories for the greatest impact through written and multimedia platforms.
- Map existing 'RHD Clubs' based on successful examples in Kerala, India, and in Kenya and Fiji and, where possible, assist in evaluating their impact.
- Work with advocacy organizations who support the needs of patients globally, potentially spearheaded by a partnership with the International Alliance of Patients' Organizations.
- Develop speaking corps of PLW RHD who can share their story at public events, in media campaigns, and in other forums.
- Develop more customised resources and support capacity for translation into most useful languages for PLW RHD.
- Explore scope for a 'Charter of Rights' for PLW RHD.
- Advocate for progressively greater involvement of PLW RHD in international RHD scientific meetings, including in programme development as well as participation in the meetings themselves.
- Explore and support emerging social media platforms in developing countries where PLW RHD are most likely to access and form online communities.

Health workers

- Share the RHD story with international bodies of health professionals, such as the International Council of Nurses and the Global Midwifery Council, and invite them to endorse RHD control priorities.
- Work with educational groups to develop RHD modular training resources, or adapt or disseminate resources already developed about RHD, which can be incorporated into existing training programmes and curriculums. Technology partners may provide opportunities to develop and scale training resources.

Decision-makers

- Develop online briefing notes about the burden of RHD in each country, populated by the most up-to-date information available.
- Continue to lead the charge for a World Health Assembly Resolution on RHD as key civil society representatives.
- Continue to support the African Union Communiqué on RHD.
- Conduct RHD Roadmap implementation at the policy levels in national settings.

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Essential technologies

- Develop global guidelines for the use, utility, and cost-effectiveness of Rapid Antigen Detection Tests for strep throat in endemic RHD settings.
- Develop a 'purchasers guide' for echocardiography machines, addressing issues to consider when procuring for different indications.
- Work with manufacturers of echocardiography machines to develop the most robust and appropriate technology to support RHD control programmes, potentially including handheld echocardiography machines with Doppler capacity.
- Develop models and cost estimates for the regular maintenance and repair of portable ultrasound in environmentally challenging conditions.
- Explore scope for group purchasing of echocardiography machines using contracting tools to ensure sustainable maintenance and training arrangements.

BPG

- Continue to build coalitions with other disease group initiatives using BPG, including the reproductive health and syphilis communities, by exploring intersecting meetings, opportunities for networking, and developing aligned work plans.
- Support the safe rational use of BPG by disseminating training resources and best practice task aids.
- Support research efforts to explore reformulation of BPG into a longer-acting, less painful product which is more acceptable to people living with RHD.

Vaccine

- Participate as an active partner in the emerging global RHD vaccine community, preparing and advocating for progression of GAS vaccine development, including learning from the Malaria Vaccine Decision-Making Framework to gain from global experience in national vaccine readiness.
- Within this partnership, offer country-level datasets about the burden of RHD and model the potential impact of GAS vaccine introduction with leading vaccine economists.

RHD Action is committed to our goal of reducing deaths from RHD by 25% in under-25-year-olds by the year 2025.

Control programmes

- Develop and publish case studies of specific integration activities and examples of health system strengthening activities.
- Embed sore throat, rheumatic fever, and RHD modules in existing clinical service protocols, including Integrated Management of Childhood Disease (IMCI), Integrated Management of Pregnancy and Childbirth (IMPAC) and CommCare platform.
- Highlight RHD intersects at meetings outside of the siloed RHD or cardiology meetings and develop an intersects document with clear examples of how RHD affects other arenas e.g. maternal health, school health, or stroke.
- Provide resources to South-South collaborations between countries facing similar challenges. Leadership on RHD control has grown from countries with the greatest disease burden. We believe that supporting low income countries to develop and disseminate solutions is the most successful and sustainable way forward.
- Support regional organizations including Pan-African Society of Cardiology (PASCAR) and projects in the Pacific Islands to collate learning outcomes and share tangible examples of programmatic excellence.

Reproductive health

- Expand existing resources on the RHD Action website for women with RHD into stand-alone fact sheets in different languages to provide information about fertility, antenatal care, and pregnancy.
- Work with the Maternal and Child Health community to integrate RHD into family planning practices and to support access to family planning for women with known disease.
- Explore scope for antenatal detection of RHD through echocardiographic screening of pregnant women at the time of their pregnancy ultrasounds.

Advanced care

- Document the current breadth of humanitarian cardiac surgery groups addressing RHD.
- Provide scientific and technical assistance to regional and local initiatives around advanced surgical and medical care. This will include using elements of the Needs Assessment Tool to define areas of need at primary, secondary, and tertiary levels.
- Help to develop guidelines on how to manage and triage PLW RHD on cardiac surgical waiting lists, given the lengthy lists and prolonged wait times globally. For example, in Haiti 14% of young people awaiting all-cause heart surgery died over a two year period.[8]
- Explore formal alliances with congenital heart disease (CHD) initiatives given that adult survivors of CHD have similar medical needs to PLW RHD.

FIND OUT MORE

About RhEACH

RhEACH is a technical support and policy translation initiative to amplify RHD control efforts locally, regionally, and globally. We aim to identify, describe, and disseminate solutions for this neglected disease and to reduce the burden on vulnerable populations around the world. As a collaborative organization, we partner with a broad range of stakeholders – including clinicians, other disease communities, academics, funders, governments, industry, and people living with RHD – to achieve our common goals.

RhEACH's core business is identifying, collating, and disseminating information, and providing support to those working in-country, to provide clear and consistent messages for RHD control. RhEACH seeks to magnify the efforts of clinicians, funders, governments, and policy-makers as they tackle this disease. Critically, RhEACH works to support individuals, families, and communities living with RHD to share their experience and to become advocates and leaders for disease control.

About the World Heart Federation

The World Heart Federation is dedicated to leading the global fight against cardiovascular disease (CVD), including rheumatic heart disease. We are the only global advocacy and leadership organization that brings together the CVD community, working with more than 200 member organizations in over 100 countries.

We share a joint workplan with the WHO, giving us huge reach and credibility at every level, from national governments to local CVD organizations. Using our strategic position in Geneva, we strive to make RHD a global health priority by helping countries to integrate RHD into their national plans, empowering people living with RHD to advocate to key decision-makers, and supporting global policy on rheumatic fever and RHD.

Why RHD Action?

RHD is a disease that cuts across many areas of global health. Though it begins as a communicable disease, it becomes a chronic, non-communicable condition. It spans the lifecourse, causing morbidity and mortality from childhood through to adolescence and adulthood. It impacts women during pregnancy, and its treatment depends on reliable access to medicines. It is a disease of inequity, affecting the world's poorest and most vulnerable communities.

Though easily preventable through a course of antibiotics, RHD can lead to costly surgery if left untreated. Effective management of RHD requires engagement and action across the health system as a whole. For this reason, no single disease programme or population focus is sufficient to address RHD. Meeting the challenge posed by this disease requires collaboration, cooperation, and an integrated response.

The RHD Action initiative embodies this approach. Our global partnership brings together a unique coalition of organizations with the technical, policy, and advocacy expertise to tackle RHD. Collectively we draw on our institutional strengths:

- A unique network of clinicians, leading researchers, advocates, and people living with RHD working together to prevent and control RHD through a broad range of approaches.
- Strong relationships with frontline health workers at the national and subnational levels.
- Global advocacy experience with connections to individual and institutional decision-makers in public health, both nationally and internationally.
- Unparalleled technical expertise through convening a critical mass of the world's leading clinician researchers in RHD control. Collectively this represents decades of experience addressing this disease in a diversity of settings.

Connect with RHD Action

Should you have any queries please get in touch with us via email at **info@rhdaction.org.** You can also stay up-to-date with our work on **Twitter** or via our newsletter **RHD Beat.**

info@rhdaction.org **@RHDAction** **www.rhdaction.org**

REFERENCES

1. WHO. Global strategy on human resources for health: Workforce 2030. Draft for the 69th World Health Assembly: World Health Organization, 2016.
2. Watkins D, Daskalakis A. The economic impact of rheumatic heart disease in developing countries. *Lancet Global Health 2015:* **http://www.thelancet.com/pdfs/journals/langlo/PIIS2214-109X(15)70156-7.pdf.**
3. Robertson K, Volmink J, Mayosi B. Antibiotics for the primary prevention of acute rheumatic fever: a meta-analysis. *BMC Cardiovascular Disorders* 2005; 5(11): **http://doi.org/10.1186/1471-2261-5-11.**
4. Karthikeyan G, Mayosi B. Is primary prevention of rheumatic fever the missing link in the control of rheumatic heart disease in Africa? *Circulation* 2009; 120(8): **https://doi.org/10.1161/CIRCULATIONAHA.108.836510.**
5. Mota C, Meira Z, Graciano R, Graciano F, Araujo F. Rheumatic fever prevention program: long-term evolution and outcomes. *Frontiers in Paediatrics* 2015: **http://dx.doi.org/10.3389/fped.2014.00141.**
6. Zühlke LJ, Watkins DA, Perkins S, Wyber R, Mwangi J, Markbreiter J, Moloi HS, Engel ME, Shato T, Hermanus T, DeVries J, Read C. A Comprehensive Needs Assessment Tool for Planning RHD Control Programs in Limited Resource Settings. *Global Heart* 2017: **http://dx.doi.org/10.1016/j.gheart.2016.10.028.**
7. Zühlke L, Engel M, Karthikeyan G, et al. Characteristics, complications and gaps in evidence-based interventions in rheumatic heart disease: the Global Rheumatic Heart Disease Registry (the REMEDY study). *European Heart Journal* 2015; 36(18): **https://doi.org/10.1093/eurheartj/ehu449.**
8. Robinson O, Kwang G, Romain J, Crapanzo M, Wilentz J. A national coordinated cardiac surgery registry in Haiti: the Haiti cardiac alliance experience. *Lancet Global Health* 2016: **http://www.thelancet.com/pdfs/journals/langlo/PIIS2214-109X(16)30036-5.pdf.**

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