

# reach .

To stop rheumatic heart disease

## Strategic Plan 2019 - 2020



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UN Photo / Kibae Park

# Executive Summary

**Founded in 2013, Reach has evolved in response to a rapidly growing body of evidence, local, often individuals, and global campaigning aimed at lifting the profile and ultimately bringing much needed resources and attention to this neglected disease.**

Since inception Reach aimed to meet a global demand for technical advice, epidemiological and operational research, and support for people and organisations working to prevent and treat rheumatic fever (RF) and rheumatic heart disease (RHD). Through its work Reach has produced several comprehensive resources that now help guide efforts to tackle RHD around the world, supporting emerging RHD control programs and a significantly expanded global awareness of RHD.

However, global progress in RF/RHD prevention and control programme implementation has continued to be slow or even non-existent beyond tertiary level care, often end of life or life prolonging care, in many countries. A lack of sustained in-country funding to support programme implementation, a lack of prioritisation of RF/RHD among decision-makers, and in many countries insufficient capacity and tools to advocate and respond to local needs led to an internal review and re-focus amongst Reach stakeholders and partners in late 2017.

A widely recognised need, within a rapidly growing RHD community, for knowledge transfer, practical technical support and guidance to countries with high prevalence of RF/RHD led Reach to evolve its strategic framework and in May 2018 registered as a not for profit association (NPA) in Geveva, Switzerland. With a refreshed brand and a new set of aims and objectives, the aim of Reach is to be the global technical lead in RHD prevention and control.

Since 2017, Reach has been more intentional about building strategic relationships at the regional and national level, advising and supporting decision-makers and programme implementers. These efforts are aimed at effecting sustained and integrated change across health systems for improved health outcomes for people at risk of, or living with, RF and RHD.

Reach's mission is to promote the health of vulnerable populations through technical support to local, regional and global efforts to prevent and control rheumatic fever and rheumatic heart disease.

This Strategic Plan outlines the vision and mission of Reach recognising current capacities while setting forth a bold ambition to expand and realise the potential for growth that exists in the context of greater political attention to RHD and diseases of poverty.







# Global Health Landscape

**At least 33 million people globally live with RHD and 319,000 die annually of the disease. While many of the people with or at risk of RF/RHD live in low- and middle-income countries, a significant number of indigenous and vulnerable communities in high resource settings are also affected.**

The incidence of rheumatic fever, which can lead to RHD, peaks between 5 and 15 years of age. This is a disease that overwhelmingly affects children, teenagers and young adults. Most people who die of RHD are under 40 years of age.

Despite this bleak picture we believe global control of RF/RHD is eminently achievable. Comprehensive register-based programmes have already effectively reduced the burden of RF and RHD in different geographic settings. The drugs and technology needed for successful control programmes date from the 1950s. Freeing young people from RHD and its consequences (heart failure, arrhythmias, stroke, endocarditis and maternal death) could be achieved with existing knowledge.

Clinicians, researchers, governments, civil society groups and funding agencies have attempted to tackle specific aspects of RF/RHD control. However, current efforts are often fragmented, not implemented at scale, not embedded within government structures and lack sustainable funding.

Several organisations have sought to address these gaps, but a greater and more focused effort is needed.

In 2018, the World Health Organization (WHO) adopted a resolution on RF and RHD. It calls on governments, the WHO and civil society to take actions that will accelerate RHD prevention and control efforts. The resolution was prompted by demand from countries for greater support in their own quests to address an issue affecting their most vulnerable communities. Reach is primed to scale up these efforts and provide the technical support to make an RHD free world a reality.

**This is a disease that overwhelmingly affects children, teenagers and young adults. Most people who die of RHD are under 40 years of age**

## Our Vision

Every child free from  
Rheumatic Heart Disease

## Our Mission

To promote the health of vulnerable populations through technical support to local, regional and global efforts to prevent and control RF and RHD

## Objectives

Create an RHD free generation by 2030

Ensure access to quality care for everyone living with RHD by 2030

**By December 2020, Reach aims to:**

Support 4 countries in RHD endemic regions to have a funded national control programme

Support 6 patient support groups

Establish regional offices in WHO AFR and WHO WPR

Support 15 initiatives through small grants or capacity building programmes



# Strategic Focus Areas

UN Photo / Albert Gonzalez Farran

## 1 People

**Realising our vision to end RHD requires supporting the people who have the power to change things. This starts with those at risk of, or living with, RF/RHD. We work to support their access to care, and to ensure that the experience and perspective of patients is heard in the development and planning of prevention and control activities.**

In addition, we work to provide those who care for patients – their families, health providers and communities – with the tools needed to understand and manage the condition, and to prevent further disease. Last, but not least, are the policy-makers and officials who shape the environment we work in. We will ensure they have accurate data on which to base their planning and allocation of resources.

**We provide tools, training and one to one support to programme staff in endemic countries**

### Under this focus area, we will:

- Provide tools, training and one to one support to programme staff in endemic countries to implement RF/RHD control activities
- Through our Community Advisory Network (CAN) involve people living with RHD in the development of Reach's tools and resources
- Support communities of people living with RHD through engagement with RHD peer support groups
- Facilitate knowledge and experience sharing among the RHD community
- Create a network of clinicians, researchers, governments, civil society groups and funding agencies



### People

Ms Buli Wainiqolo has been a vocal advocate for rheumatic heart disease prevention and control efforts and has used her own experience as someone living with rheumatic heart disease to raise awareness within her community and more broadly.

She was first diagnosed with rheumatic fever at the age of 11, and her treatment is now entering its ninth year. In her home country of Fiji, Buli has highlighted the importance of prevention, emphasising the need for early diagnosis and treatment.

**Buli has used her advocacy to explain the importance of adherence to ongoing treatment with regular penicillin injection and of following the advice of medical professionals.**

**In 2017 she successfully used her platform as a contestant of the Fiji Hibiscus Queen Festival to spread her message of prevention and to elevate the stories of others living with the condition throughout the country. As well as being an advocate in Fiji and throughout the Pacific region she has also represented others living with rheumatic fever and rheumatic heart disease at important global health forums amplifying the patient perspective in Australia, Switzerland and the United Arab Emirates.**

**In addition to working full time, Buli has been an active member of the Reach Community Advisory Network (CAN) alongside others living with RHD and frontline health-workers who guide our activities and priority-setting.**



## 2 Policy and Programmes

**Appropriate and effective policies are needed to ensure that resources and efforts are directed to the activities that will quickly and efficiently bring RHD under control.**

In addition to policies that facilitate and support efforts to tackle RHD, effective programmes are also required. These programmes need to be based on best-practice, supported by the best evidence available and integrated with other programmes and health initiatives. They require access to diagnostic tools, medication and treatment.

### Under this focus area, we will:

- Provide governments with technical assistance and guidance on the implementation of RF/RHD prevention and management activities. This includes sharing best practice clinical care and service delivery for people living with RHD
- Support efforts to ensure RF/RHD is a national health priority in endemic countries
- Support efforts for a secure, reliable, quality-assured supply of benzathine penicillin G (BPG)
- Contribute to the development of global monitoring systems
- Guide research, advocacy and policy priorities for the global RHD community
- Support the estimation of disease burden at different levels (global, regional, country, sub-national) and identification of populations at greatest risk
- Work with the World Health Organization and other global bodies to support global efforts to prevent and manage RHD



### Policy

Reach has been supporting the World Health Organization Eastern Mediterranean Office (WHO EMRO) to provide assistance to countries in the region interested in establishing or strengthening their activities on rheumatic fever (RF) and rheumatic heart disease (RHD). We led the development of a Regional Framework for Action on RF/RHD, which can be used to guide individual country action plans, and support national and regional monitoring of progress.

Taking the WHO Resolution on RF and RHD as a starting point, we reviewed existing efforts to address the burden of RF/RHD in countries where RHD is endemic throughout the region. In partnership with Ministries of Health and other key stakeholders, we identified where the needs are greatest and suggested potential areas to prioritise. In response to countries' requests for support we have been able to highlight tools and examples of policies in other countries and regions that could be implemented to achieve their goals.



### Programmes

The Philippines Heart Centre (PHC) is working to strengthen the capacity of the health workforce to detect and manage RF/RHD. They have placed a focus on ensuring that these activities are embedded and integrated within existing government health structures and facilities, and are conducted in partnership with, and supported by, the Department of Health.

Reach is providing assistance and technical consultation on priority-identification, programme planning, implementation, and monitoring and evaluation. This includes supporting the implementation of an RHD registry and providing advice and tools to support primary and community health workforce training.

## 3 Governance and Sustainability

**Our activities will only succeed if they are supported by a robust organisation with strong governance and sustainable resources.**

Our growth will be based on engaging the RHD community in our work, including a diverse range of expertise on our board and taking a long-term approach to the sustainability of our programmes.

### Under this focus area, we will:

- Develop a partnership model to engage the RHD community
- Implement a sustainable fundraising programme
- Implement a scalable model to deliver technical support to countries
- Include a member of the Community Advisory Network (CAN) on the Board
- Grow the Board to include a diverse set of experience and expertise
- Establish Reach as the lead technical agency for the provision of support to governments in their efforts to prevent and control RHD





## Our Values

### Inclusivity:

First and foremost our activities are driven by the needs of people living with RHD and the people who care for them

### Quality:

What we do, we do well

### A global outlook:

Our work is shaped by the RHD community

### Evidence-based decision making:

We respect the facts

### Innovation:

We are driven to find ways to help more people more effectively

## Partnerships and Collaboration

**In order to truly be a home for the different actors working on or affected by RHD, it is important to have a mechanism to formally engage the community.**

Reach wishes to strengthen existing relationships while embracing a wider range of organisations who have a role to play in RHD prevention and control. Only through collaboration can the outstanding needs in RHD prevention and control – and the ambitious proposed programme of activities – be achieved. We are working with private sector entities, philanthropies, foundations, governments and UN agencies. We invite others who share our vision to get in touch and discuss how we can work together.

### Through our partnerships, we aim to:

- Harness expertise around our core mission to provide technical support to regional, local and global efforts to prevent and control RHD
- Facilitate dialogue between people and organisations working to support Reach's mission
- Amplify the voice of the RHD community
- Provide a platform to engage patient support groups and ensure they have a stake in our work
- Realise economies of scale across a shared agenda
- Speed up the dissemination of information, and ensure clear and consistent messages across the network
- Ensure rapid access to the repository of experience and guidance across the network
- Unify global efforts to tackle RHD across sectors and geographies

**Each year, more than 300,000 people die from rheumatic heart disease (RHD)**



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