



**RHD Action**

United to End  
Rheumatic Heart Disease

# PEOPLE POLICY PROGRAMMES PROGRESS



**RHD GLOBAL STATUS  
REPORT 2015-17**

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## People, Policy, Programmes and Progress

### FOREWORD



**When I was a little kid, around five years old, I came down with a series of raging fevers. Mum, a nurse during the war, was worried sick. But we lived 100 miles from the nearest city hospital. And rural medicine back in 1960s Australia was not the best.**

By the age of 12, I was struggling to keep up in cross-country running and was exhausted when playing school-boy rugby. Only then did the doctors – by this time Mum had taken me to specialists in the city – realize that my

earlier fevers had been more than your average childhood bug. I had caught **rheumatic fever**, which if left untreated with effective penicillin, can damage the valves of the heart. In my case, it resulted in an impaired aortic valve.

Around the world today, this is known as **rheumatic heart disease** (RHD). Currently, there are 32 million sufferers, primarily in ‘developing’ countries, resulting in 275,000 premature deaths each year.

Thanks to the support of my family and the Australian health system, my rheumatic heart disease has never held me back. I served as Prime Minister of Australia twice, sporting a heart valve replacement from a generous donor family, which has since been upgraded to a ‘newer model’ valve (all replacement heart valves wear out over time). With close monitoring, regular penicillin, and clinical interventions every 15 years or so, people with this condition can lead long, normal, healthy lives.

Of course, RHD is entirely preventable. If we had clocked my rheumatic fever when I was a kid, I could have been given penicillin to prevent that fever from damaging my heart in the first place.

#### So how to prevent this disease for others?

We’ve had the science behind RHD control for over 50 years, and managed to eradicate it completely in many of the world’s ‘developed’ countries. Yet in the countries and

communities worst affected by RHD, our progress is limited and uneven. To close these gaps, we need to focus on the Three Ps that together have the best chance of eradicating RHD once and for all: **People, Policy and Programmes**.

**People** are the defining part of RHD prevention and control. From patients, to community nurses, to researchers in the lab, there is a heap of work being done around the world to help people struggling with this disease. While attending the launch of the RHD Action movement at the United Nations General Assembly in 2015, I was struck by the diversity, energy and commitment of so many individuals working on RHD. We need to work together, strategize how best to use our talents, and reach out to bring more exceptional people into the RHD family.

**Policy**, while sometimes opaque and hard to pin down, has huge potential to instigate change across the RHD community. As a politician myself, I can see the impact of major policies at the global, regional and national levels that trickle down into good action and opportunities locally. But this is not always obvious for people engaged in crucial, lifesaving work on the ground. For RHD, it is not only important that good policy is set, but that it is carried out in a practical way. Only then will people living with and working with RHD see progress being made.

**Programmes** for RHD are where progress can be seen and measured. Every endemic country experiences RHD differently, therefore every endemic country should have tailored and nationally-relevant RHD programmes. For example, in my country, the vast majority of people living with RHD are young Indigenous Australians – shockingly, Aboriginal and Torres Strait Islander people are more than 20 times more likely to die of RHD than non-Indigenous Australians. This is why, when I established the RHD Australia programme as Prime Minister, we first rolled out the programme in areas with a high Indigenous population, including my home state of Queensland.

I’m very pleased that RHD Action is leading the global movement to consign RHD to the history books and am proud to be its Global Ambassador. We know how to prevent, control and end this disease. Now is the time for action: let’s get cracking.

**The Honourable Mr Kevin Rudd**, Former Prime Minister of Australia and Global Ambassador for RHD Action

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Substantial contributions were gratefully received from:

Jeremiah Mwangi (World Heart Federation)  
Alastair White (World Heart Federation)  
R. Krishna Kumar (Co-Chair, World Heart Federation RHD Working Group)  
Ana Olga Mocumbi (Co-Chair, World Heart Federation RHD Working Group)  
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# INTRODUCTION

## What is RHD?

**Rheumatic heart disease (RHD) is a preventable disease that affects children and young people living in conditions of poverty and overcrowding.**

Practically eliminated in wealthy countries, RHD is still common in Africa, Asia, and the Latin American and Pacific regions.<sup>1</sup> Thirty two million people around the world suffer from the condition, which kills 275,000 people a year and is the most common acquired heart disease among children and young people in developing countries.<sup>1</sup>

RHD is preventable, but continues to cause significant levels of mortality and morbidity in countries with health systems too fragile to control it. Starting with an untreated or inadequately treated strep throat, the disease progresses over time to inflict serious heart damage and can lead to death for some of the world's most vulnerable people.

Prevention of RHD in some developing countries, such as Cuba, demonstrates that disease control is possible.<sup>2</sup> It is urgent that well-resourced, operational and sustainable RHD programmes are available in the countries that need them. Only then can we take steps to eliminate this preventable disease from the world's poorest communities.

## About this Status Report

Rheumatic heart disease (RHD) is a truly global problem, causing premature death and disability in almost every region of the world.<sup>3</sup> However, even RHD experts have several unanswered questions and RHD remains completely unknown by many people, despite it being a major cause of premature death in children, young people and pregnant women.<sup>4</sup> Lack of resources and political will have hindered the RHD community from bringing together its expertise to find global solutions to tackle RHD at the local level.

But this is changing. Since the dawn of the Sustainable Development Goals in 2015 and the simultaneous formation of the RHD Action movement, the RHD community has continued to work hard to pool knowledge and resources.

Tools such as the online **RHD Atlas** are now mapping RHD programmes from around the world (including those featured as case studies in this report).<sup>5</sup> The **RHD Resource Hub** is now providing the world's first 'one-stop-shop' repository of multi-lingual RHD materials, which can be accessed freely online.<sup>6</sup>

This Status Report builds on existing progress by giving global insights on the **people, policies** and **programmes** that work together to end RHD:

- **By exploring the PEOPLE living with RHD, and those who support them, RHD is lifted out of the abstract and grounded in real-life experience.**
- **By understanding the complex POLICY environment, we can identify opportunities to push RHD forward on national, regional and global agendas.**
- **By comparing and contrasting RHD PROGRAMMES from around the world, we get a clear picture of what is working and how much progress is being made on the ground.**

RHD prevention and control is improving day by day. The RHD Action movement exists to drive this momentum on behalf of the **32 million people currently living with RHD around the world.**<sup>1</sup> We hope you enjoy this Status Report – thank you for supporting our work.

[www.rhdaction.org](http://www.rhdaction.org)

# KEY ACRONYMS

## 25x25<25 – The '25 by 25' Goal

The World Heart Federation goal to achieve a 25% reduction in premature deaths from rheumatic fever and rheumatic heart disease among individuals aged <25 years by 2025.

## AU – African Union

A union of 54 African countries established to promote solidarity and integration over issues such as economic growth, cooperation and health.

## BPG – Benzathine Penicillin G

The most effective antibiotic drug available for prevention and control of rheumatic fever and rheumatic heart disease.

## CVD – Cardiovascular Disease

Diseases of the heart and vascular system, including heart attack and stroke.

## MSF – Médecins Sans Frontières

An international, independent, medical humanitarian organization currently conducting RHD screening among migrant populations in Europe.

## NCD – Non-Communicable Disease

Chronic diseases which are non-infectious, including cardiovascular disease, diabetes, cancers and lung disease.

## NGO – Non-Governmental Organization

A non-profit entity, whose work is often organized around a specific development issue, e.g. rheumatic heart disease.

## PASCAR – Pan-African Society of Cardiology

An organization of physicians from across Africa involved in prevention and treatment of cardiovascular disease.

## RF – Rheumatic Fever

A consequence of untreated sore throat, this recurrent fever can cause damage to the valves of the heart, leading to rheumatic heart disease.

## RHD – Rheumatic Heart Disease

A preventable disease that starts with untreated strep throat and progresses into rheumatic fever which, when left untreated, can inflict serious heart damage.

## RhEACH – Rheumatic heart disease: Evidence. Advocacy. Communication. Hope.

A technical support and policy translation initiative to amplify rheumatic heart disease control efforts worldwide.

## SDGs – Sustainable Development Goals

17 goals adopted in 2015 by the 193 UN Member States (countries) to end poverty and ensure sustainable development and prosperity for all.

## UHC – Universal Health Coverage

A way of structuring a health system to ensure that all people can use the health services they need without being exposed to financial hardship.

## UN – United Nations

An intergovernmental organization that convenes its 193 Member States (countries) to achieve consensus on pressing global issues.

## WHF – World Heart Federation

A founding member of RHD Action, WHF is an NGO that advocates for the prevention, control and reduction of cardiovascular disease.

## WHO – World Health Organization

An intergovernmental organization which is the public health arm of the UN, responsible for directing and coordinating all of the UN's work on health.

## WHO PEN – Package of Essential NCD Interventions for Primary Health Care

Guidelines produced by the WHO in 2010 for cost-effective ways to provide NCD care in low-resource settings.



## KEY TERMS

**Primary prevention** – Also known as ‘primary prophylaxis’. For RHD, this involves preventing a first attack of rheumatic fever developing in a patient with a sore throat. This is done by prescribing penicillin, either through a series of oral pills or a single injection.

**Secondary prevention** – Also known as ‘secondary prophylaxis’. For RHD, this involves preventing a further episode of RF in patients who have already had rheumatic fever. This is important, as recurrent RF can lead to RHD.

**Tertiary prevention** – Advanced medical or surgical interventions for people with severe RHD, e.g. heart valve replacement or repair.

**Adherence** – The ability of a patient to stick to their treatment plan. This can be affected by many factors, including distance to health facilities, education levels, and ability to pay for medicines.

**Echocardiography** – Also known as ‘echo’, this is the ‘gold standard’ method used to diagnose RHD, which involves capturing an image of the heart using specialized medical equipment.

**Health systems strengthening** – The process of designing and implementing policies, initiatives and strategies to improve a country’s health system, which should lead to improved health outcomes for the population.

**Primary care** – Health care provided in the community, e.g. local clinics or health centres.

**Registers** – Databases that contain the information of people who have been diagnosed with RHD. They can be either electronic or paper-based.

**Risk factor** – An element or activity that can contribute to a person’s risk of disease. Examples of risk factors for RHD include poverty, poor sanitation and overcrowding.

**Screening** – The activity of seeking out, testing and diagnosing people for rheumatic fever or RHD, ideally using echocardiography.

**Stakeholder** – Any individual or organization that is engaged with RHD prevention and control.

**Surveillance** – An epidemiological activity, involving ongoing systematic collection, recording, and analysis of data reflecting the current health status of a population.

# PEOPLE

“The biggest concepts in health, such as sustainability and universal health coverage (UHC) have a big focus on inclusivity. So it’s very important that for RHD, as for every health topic, we don’t leave those excluded, and those poor, behind.”

– Simon Wright, Head of Child Survival, Save the Children.

# PEOPLE

**People are at the heart of the RHD community: both those living with the disease and the health workers who care for them. An estimated 32 million people are currently living with RHD across the world. This little-known disease kills 275,000 individuals each year, causing untold debilitation, pain, and lack of opportunity for millions more.<sup>1</sup> Yet people living with RHD, who are often young and marginalized by socio-economic disadvantage, continue to fight for their lives with dignity and determination.**

This section profiles individuals who share their personal stories of living with RHD. Their experiences are complemented by the insights of health workers from around the world. These professionals, many of whom have dedicated their entire careers to preventing and controlling RHD, are another integral part of the RHD community. All stakeholders interested in ending RHD, from policy-makers to cardiac surgeons, can learn a great deal from these two courageous groups of people.

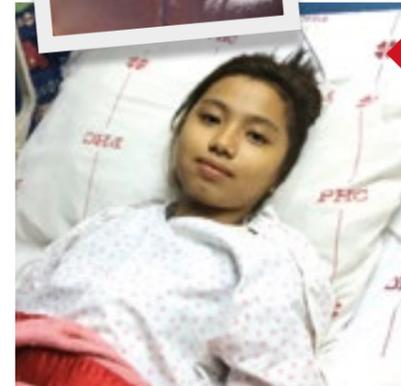
## People Living with RHD



◀ Trenton is from the Tiwi Islands in Northern Australia. He lives in a traditional Tiwi Indigenous community and is a passionate hunter. When he was 6 years old, Trenton was diagnosed with rheumatic fever and then RHD which required surgery in Melbourne, almost 4,000 kilometres (2,500 miles) from his home. Since his surgery he has been 100% adherent to his penicillin shots, largely thanks to his supportive mum Andrea.



Aarti is a six year old girl from Banka, Bihar, India. Earlier this year she went to hospital finding it hard to breathe. Doctors found that she had heart failure caused by rheumatic heart disease. Aarti was admitted to the All India Institute of Medical Sciences for treatment. Despite medication, she will need a heart valve operation to survive. Aarti lives in a simple mud house: her operation and ongoing care have a significant impact on her whole family.



Anne Cristobel discovered that she had rheumatic heart disease two years ago when she had palpitations and difficulty breathing. Her family struggled to pay for the regular BPG penicillin she needed to control her condition, as this medicine is not covered by the national health system in the Philippines. Consequently, Anne took the penicillin, but not regularly enough to provide effective protection. Now she will need expensive heart surgery and afterwards, lifelong follow-up. Pregnancy may be risky and Anne will still need to take penicillin for many years to protect her heart from further valve damage.

▶ Acayo Patricia is a 7-year-old girl from Gulu, Uganda. She was diagnosed with RHD in March 2015, after she was referred to the Gulu Cardiac clinic with body swelling, fatigue, chest pain and difficulty breathing. In addition to monthly penicillin injections, she is also prescribed multiple cardiac drugs to help manage her condition. Patricia's family lived in Atiak, 25km from the hospital, when she was diagnosed but has recently relocated to Gulu town to be closer to care. Her parents were finding it difficult to raise enough money for transportation to the hospital causing her to miss multiple monthly injections. Finding money for her other medications has also become increasingly difficult and has caused a large financial strain on her family. Her father is currently disabled following a tragic accident last year, which prevents him from working. Despite these hardships, Patricia is in good spirits and enjoys going to school. She is currently in Form 1 and says, "school days are my favourite". She wishes she could play with her friends longer but often finds herself out of breath and needs to sit down



# JEAN-PAUL IYAMUREMYE

**Q: Tell us about yourself, Jean Paul**

My name is Jean Paul Iyamuremye, I come from Rwanda. In 2007, with support from an organization called Team Heart, I had the first valve replacement in Rwanda to treat my rheumatic heart disease.

**Q: How did you feel before you were diagnosed?**

Before my surgery, I was dying, I kept trying to tell my wife how sorry I was...I thought I would have to stay in the house for the rest of my life because of my disease.

**Q: What happened after you were finally diagnosed with RHD?**

I was immediately scheduled for surgery to replace my leaky heart valve. I was then prescribed regular doses of BPG (benzathine penicillin G) to prevent any more damage to my heart. Penicillin is very, very important for people with rheumatic heart disease. It can be difficult to remember to take every dose, but it is important to our life and to our health.

**Q: Since accessing surgery and medical treatment for RHD, how do you feel?**

Just six months after surgery and starting medical treatment with BPG penicillin, I could notice a difference. I was looking better and feeling much stronger. Now I know that I have the power to achieve anything I want to. I try to do everything I can to get outside, to support other patients and talk about their problems.

**Q: Now that your RHD is properly managed, what are you doing with your life?**

After my recovery, I began my job as a taxi driver. I also volunteer for Team Heart, and help to support and educate other people with RHD in Rwanda. I started the Rwanda Patient Care Network, offering my time and experience to inform people about their condition, and also use my taxi business to help transport them to their medical appointments.

**Q: What is your message for people living with RHD in Rwanda?**

My message is for all people – young and old, men and women. If you are diagnosed with RHD and need to take BPG penicillin, make this your first priority. Whenever possible, make sure that you get this medication to save your life. We need more RHD programmes to make sure BPG is accessible for everyone.

But finally, I want to share a message of hope. Look at my face – I'm a strong guy! **I have a future.** And I plan to do everything to maximize that future.





## TA'AFULI ANDREW FIU

### Q: Tell us about yourself, Ta'afuli

My name is Ta'afuli Andrew Fiu. I'm a Random House author, educator and motivator for New Zealand schools. I am Samoan, and currently divide my time between New Zealand and Australia. I have undergone six full open-heart surgeries, died twice, and spent four and a half years in hospital.

### Q: When did you develop rheumatic heart disease?

I was misdiagnosed with the flu at the age of 14, ten years after my family immigrated into New Zealand. I had actually contracted rheumatic fever. If I had been correctly diagnosed, I could have accessed penicillin to prevent the rheumatic fever from progressing into RHD. As it was, I needed a heart operation at the age of 15 to treat my rheumatic heart disease. This was the first of six entirely preventable open-heart surgeries.

### Q: How was your own childhood affected by RHD?

When I first got sick, I spent six months of every year in bed rest. I watched winters come full circle in my hospital room instead of progressing with my education. It really does affect a child's confidence and it drags families through an emotional, harrowing experience. I was an immigrant child and my parents spoke no English, so at the hospital I was actually the translator. I really feel for my parents; they felt guilty that they let this happen to me. But I also felt guilty, as I was supposed to be the one to lift my family out of poverty, but got sick instead.

### Q: What would have made things easier for your parents, and other immigrant families coping with RHD?

Awareness programmes would have made things much easier for us, especially if written in different languages. Information at point of arrival would help, so that immigrants coming through the airports can access information sheets about which diseases to watch out for. Even once I was diagnosed, there was no written information in hospitals for immigrants about rheumatic fever in New Zealand.

### Q: As a writer and educator, what steps are you taking to raise awareness of RHD?

About ten years ago, I decided that it was time for me to tell my story. I wrote a book, *Purple Heart*, about my journey living with RHD. This was released in 2006 and was very well-received by the critics. The education system soon picked it up, and it became a 'must-read' text in New Zealand schools, which has been a great awareness-raising platform. I visit colleges and schools to talk to students about my journey and what I've experienced. That's how I use my drive, my energy, and my experience to get that message out.

### Q: What does the future hold for you, Ta'afuli?

The best thing I can do is get out there, and use this time that I've got left. I owe it to the doctors, the nurses, the care managers, and my parents, brothers and sisters, for all the angst they went through. Now that I'm alive, now that I'm able-bodied, I will continue to travel and put the RHD message across. I love to show other people living with RHD that if you access good treatment, you can live a full and productive life. I have just completed my MBA, even though I didn't finish high school because I was so sick. My next big project is climbing Mount Kilimanjaro, and next year I am planning Mount Everest. My RHD is not stopping me from leading a decent life and contributing to society.

## KAT WALKER



### Q: Tell us a little about yourself

I'm Katrice Walker, most people call me Kat, I was born in the United States and I have been living with RHD since the age of 11 or 12.

### Q: What was your experience of living with RHD in the United States?

My experience living in the United States with RHD has actually been pretty good. I've lived a normal lifestyle and have not had any major surgeries, as they caught the disease pretty early for me. As a child, I went and saw a cardiologist; throughout my life I have had access to the healthcare and the resources that I needed to live comfortably with this disease.

### Q: What is your strongest memory of being diagnosed with RHD as a child?

One time that stands out for me is overhearing the doctors telling my mum that I may need heart valve replacement surgery. Hearing that at 11 or 12 years old was mortifying. When I got home later, I went to my mum and asked her if I was going to die. I can't imagine how my mum felt at that time, but she told me no, I wouldn't die. It's very emotional for me to think about that moment because I'm thinking about myself as a scared child, but also about myself as an adult mother today. I sometimes wonder if I would have the same strength as my mum if my own children fell ill. I think about mothers in other countries that don't have access to the same resources that I had – would they be able to tell their daughter that she wasn't going to die with the same certainty?

### Q: How do you treat and manage your RHD?

I was on penicillin to manage my RHD for nearly 15 years – I was able to stop this treatment six years ago, as my cardiologist said there was no longer a need for me to take the penicillin on a monthly basis. I still have my regular cardiology visits and I have an echocardiogram once a year. As a child, the main barrier to getting the treatment via penicillin injections was the pain. When I first started getting the penicillin I had to get two injections – one in each leg – and it was horrifying. As a child I was paper thin, so having to bear that intense treatment and then going to school and pretending to be as healthy as possible with my friends was very difficult.

### Q: You are proof that people living with RHD can have good health outcomes if they are able to access healthcare and catch the disease in time. How does that make you feel?

Knowing that I am some sort of "success story" as a woman living with RHD is two-fold. I feel very fortunate and very grateful to have the life I do, but at the same time I feel very sad for several women around the world living with RHD in developing countries who don't have the access to those resources I did. Those women are so much more likely to have problems giving birth and mothering a child – that really, really saddens me.

### Q: What do people really need to know about RHD?

My message to the world about rheumatic heart disease, is **know it**. Teach the community and the people around you about the symptoms and signs. Encourage families to take their children to the doctor, if those services are available. And if the resources are not there – we certainly need to do something about that!

## RHD HEALTH WORKERS

*'Nurses play a key role in the early screening for and detection of rheumatic heart disease, which is a huge issue in areas of deprivation, particularly amongst Indigenous populations. Nurses' frontline role in combating this disease requires adequate training and educational resources as well as increased social support for families. RHD is a disease of poverty which can be prevented with the proper investment in nursing services.'*

– Dr Frances Hughes, CEO, International Council of Nurses

## Emele



**Q: Emele, tell us about yourself and your RHD work in Fiji.**

My name is Emele Naiceru; I work for the Ministry of Health in Fiji as a nurse practitioner. For the last 28 years, most of my work has been in primary healthcare settings, such as nursing stations and health centres outside the hospital. I was asked to join the Rheumatic Heart Disease Control

Programme in Fiji six years ago, which has been a blessing and a challenge!

I coordinate activities around rheumatic heart disease (RHD) control in Fiji at a national level: liaising with all collaborators and stakeholders, providing training for health staff, and supporting them to deliver care, monitor and reporting on people with rheumatic fever and RHD at the primary care level.

**Q: What are the greatest challenges you face in your work?**

One great challenge is to have a good management plan for all our patients, as we look after a lot of people. We do our best to understand where each person comes from, tracking their socio-economic status and their education or career aspirations, as well as their emotional journey so that we can work with patients for their care. We also work hard to understand the broader health system, which is a test of our flexibility to meet patients' needs for regular BPG penicillin treatment.

**Q: How do you help people access RHD services in Fiji?**

Access is a big issue in RHD control for island nations, as people need to be able to receive regular penicillin injections. Nurses and doctors in Fiji are currently planning outreach services, giving people flexible hours to come in for their appointments, and taking into account when people need to navigate a particular bus or boat service. These things all need to be taken into consideration if we want patients to have their penicillin injections on time and not drop off the programme's radar. Increasing public awareness through outreach programmes, school visits and conducting screenings are other avenues to improving access to services in Fiji.

**Q: What is the role of nurses in prevention and control of RHD in Fiji?**

Nurses contribute a lot in caring for rheumatic heart disease patients in Fiji. Nurses play a very important role in educating patients about RHD and the importance of adherence to penicillin. Nurses also play an important role in early recognition of the symptoms of rheumatic fever, whether sore throats, painful joints, muscle spasms or shortness of breath.

Nurses are in charge of the RHD registry in Fiji – we monitor people's attendance for injections at hospitals or clinics and make sure they receive their penicillin injections on time. This is a big task as we have a very mobile population in Fiji; people move from one place to another and can be hard to track down.

Networking with our public health nurses to follow up patients who have missed their appointments is another way nurses contribute a lot to control of RHD. Nurses also create community awareness around rheumatic fever and RHD prevention.

**Q: How engaged is the Fijian Ministry of Health in RHD? Is the Minister of Health very involved?**

The Ministry of Health programme is very much involved in supporting the care of patients with rheumatic fever and rheumatic heart disease. Together, we have created strategic plans to prevent rheumatic fever from progressing into RHD. The Ministry has recognised that we need to have access to official management guidelines, clinical pathways and referral systems to help us diagnose and treat people.

It is very important that Ministers of Health have policies that recognize the needs of programmes such as ours – they create a good foundation for the programme to build on, and help us care for our patients as a whole. Now Fiji has a rheumatic fever and RHD policy in place at the Ministry of Health.



## Isaac

**Q: Isaac, tell us about yourself and your work with RHD?**

Isaac Ssinabulya is my name, I'm from Uganda, I work with Makerere University and I practise cardiology in the Uganda Heart Institute.

**Q: How much RHD do you see in your work as a cardiologist?**

Rheumatic heart disease contributes to the bulk of the patients that I see back home in Uganda. Around 20% of people who show up with heart failure have rheumatic heart disease. In terms of the disease burden in the country, it's a prevalence of about 2%.

**Q: What drives you to keep working in rheumatic heart disease?**

Seeing young people affected with rheumatic heart disease. I connect with them and I want to save their lives. I want them to live longer, which gives me the drive to do a lot for them so I can keep them healthy. Because these people have dreams, they have hopes, some of them have kids, wives and husbands. They want to live longer, so it gives me the drive to do more to keep them healthy.

**Q: Describe a typical RHD patient in Uganda?**

Typical patients that present to us with RHD are teenagers or young people from socio-economically limited communities. They often live in crowded areas that are a little hard to reach, but eventually because of their longstanding ailment they show up to us and present with shortness of breath, lower limb swelling and palpitations – then our suspicion of rheumatic heart disease comes in. Sometimes, if people come to us early, they present with sore throats, fevers and joint pains, which gives us a better opportunity for screening. This is important because malaria is also a big problem in Uganda, so most joint aches and fevers are treated as malaria, yet actually this is rheumatic fever. An opportunity that is always missed...

**Q: What are the particular problems with RHD in pregnant women?**

Diagnosing RHD in people who are pregnant is quite a challenge. Symptoms of RHD can mimic pregnancy, such as shortness of breath or swelling. But these are signs of heart failure, which we often pick up too late, and sadly lose many women to advanced disease.

**Q: What are the implications for families and communities in this case?**

The challenges can be huge, especially if pregnancy is involved, because if the mother doesn't die, sometimes the child dies. Or if the child dies and the mother lives, she will live to mourn her child. In Uganda, mothers are a strong bridge for our survival. People who have lost a mother to RHD miss that part of life, because the person who would motivate them to do more and achieve more has passed away.

**Q: What do people need to know about RHD?**

**RHD is common.** It's robbing us of a productive age group, because it affects the young, and it's robbing us of our mothers. Every health worker in Uganda needs to know that RHD exists and they need to think about it whenever somebody presents with symptoms that mimic heart disease. Our governments are poor, so we cannot invest in advanced rheumatic heart disease management, but we can do a lot in terms of early prevention. So awareness is the key.



## Rosemary

### Q: Tell us a bit about yourself

My name is Rosemary Wyber. I'm the Deputy Director of RhEACH – an organization that provides technical, clinical scientific support for RHD control. RhEACH is one of the founding partners of the RHD Action movement – and I'm currently a clinician working in Australia.

### Q: When did you first encounter rheumatic heart disease?

I'm a New Zealand-trained doctor – after I completed medical school I went to work in the Pacific Island of Samoa. I was in my early twenties and while in Samoa I cared for a number of young women my own age who died of rheumatic heart disease. It's a disease we have in New Zealand, but not a disease I'd seen people die of before.

### Q: What most struck you about rheumatic heart disease?

What really struck me was not just the age of the women who were dying, but the fact that many of them had already been medically evacuated for heart surgery. So they had already had an enormous amount of time, money and energy invested by the government and the community to get them well again. But because they didn't have access to the penicillin or blood-thinning medications they needed to stay well, many of those women suffered catastrophic cardiovascular collapse. Many of them died during pregnancy or after delivery. It was a devastating outcome.

### Q: What are your biggest frustrations about rheumatic heart disease?

When I saw women die of rheumatic heart disease, I was frustrated by the basic need for more support and primary care resources to be able to care for them properly. Without these, all the investments that had been made were in vain. Their deaths really struck a chord for me, not just on a personal level, but on a resource allocation level. We had already spent money on curing these people, but we lacked the follow through. I realized that if we could reallocate some of these resources into prevention rather than cure, we could really change the trajectory of the disease.

### Q: What do people need to know about rheumatic heart disease in the Pacific?

In our part of the world, the real challenge is making sure that we have comprehensive, register-based control programmes, which can deliver timely diagnosis, ongoing management and treatment of rheumatic heart disease. We also need to build health systems to be robust enough for people to escalate up a level of care when they need it, and back down when they have received that care and their health has improved. I think is the way forward for us in Australia, New Zealand, and indeed the rest of the world.

### Q: What are your hopes for rheumatic heart disease prevention and control?

I hope that, in the near future, being diagnosed with rheumatic heart disease is no longer a death sentence, but an opportunity for a conversation about treatment, prevention and management – and a chance for us all to work together, to tackle RHD on a global scale.



# POLICY

// We pledge that no one will be left behind ... we will endeavour to reach the furthest behind first"

– The 2030 Agenda for Sustainable Development, United Nations, 2015



# POLICY

According to the World Health Organization, 'health policy' refers to:

## 'DECISIONS, PLANS, AND ACTIONS THAT ARE UNDERTAKEN TO ACHIEVE SPECIFIC HEALTH CARE GOALS WITHIN A SOCIETY'.<sup>7</sup>

Health policy is set by decision-makers at the global, regional and national levels. Different organizations and groups influence different levels of health policy. For example, **global** health policy is largely in the domain of vast, intergovernmental organizations, such as the United Nations and the World Health Organization. On the other end of the scale, **national** health policy is usually decided by each country's Ministry of Health and carried out by a range of actors, including the national health system, private healthcare providers, and NGOs.

Even positive health policy decisions will fail unless they are implemented properly at the local level. At its best, good health policy at the global, regional and national levels creates an enabling environment for good local health outcomes in communities. But all too often, high-level policy

does not have the desired 'trickle-down' effect. This can lead to a disconnect between what decision-makers agree upon, and any actual benefit felt by people accessing the health system.

There is a distinct lack of RHD-specific health policy at all levels, whether global, regional or national. However, the RHD Action movement is calling for an official Resolution on RHD to be agreed on by all Member States of the World Health Organization. When passed, it is hoped that this Resolution will mandate the WHO and its participant countries – known as 'Member States' – to further prioritize RHD as a major global health issue. This will better enable all people in the RHD community to establish well-resourced, sustainable programmes to eliminate this preventable disease for good.

The United Nations (UN) is an international organization that was founded in 1945 with the aim of solving international problems, especially those related to peace, security, sustainable development and humanitarian affairs.<sup>8</sup> The UN is currently made up of 193 countries, which are referred to as 'Member States' – today, nearly every nation in the world is a Member State of the UN and takes an active role in developing and voting on global policy issues.<sup>9</sup>

Since 2015, the work of the United Nations has been guided by **Agenda 2030**, an ambitious global plan to promote sustainable development in all countries of the world. The work

is focused around **17 Sustainable Development Goals**, which address topics as wide as health, education, climate change, poverty and economic growth.<sup>10</sup>

Rheumatic heart disease is not mentioned specifically in the 17 Sustainable Development Goals – this is no surprise, as the health goal (Goal 3) is carefully worded to encompass all challenges to global health without naming every disease individually. However, there are several parts of Agenda 2030 which are particularly relevant to RHD, and progress in these areas is likely to have 'knock-on' positive effects on RHD prevention and control.

# GLOBAL RHD POLICY

## United Nations

*'Rheumatic heart disease is entirely preventable and treatable, but has been a terribly neglected issue. Since the UN passed the Sustainable Development Goals (SDGs) in 2015, we have committed to end preventable maternal, newborn and child deaths by 2030. This means that we need to tackle all causes of death for women and children. This includes RHD, which is, for the first time, coming front and centre of the global health agenda.'*

– Leith Greenslade, Vice Chair, MDG Health Alliance



Agenda 2030	Commitment by 193 Member States	Relevance to RHD
Preamble	'We pledge that no one will be left behind [...] we will endeavour to reach the furthest behind first'	People at the highest risk of RHD are typically the most poor, vulnerable and marginalized in society. Agenda 2030's preamble recognizes this, and tasks Member States to take special measures to 'fast-track' these populations in sustainable development plans.
Declaration	'We commit to accelerating the progress made in reducing newborn, child and maternal mortality by ending all such preventable deaths before 2030'	RHD significantly impacts child and maternal mortality, as the disease often begins in childhood and can make pregnancy dangerous for women. It will be impossible to end all preventable deaths in newborns, children and mothers without first eliminating RHD.
Goal 1	End poverty in all its forms, everywhere	Poverty is a significant risk factor for RHD. <sup>11</sup> The effects of poverty, such as inadequate sanitation or poor housing, create an enabling environment for the disease. <sup>12</sup> Simultaneously, people living in poverty who develop RHD are less likely to access the medical treatment they need. By curbing global poverty, fewer people will be at risk of RHD.
Goal 3	Ensure healthy lives and promote well-being for all at all ages	This goal, which is the umbrella aim of Agenda 2030's pledge on health, commits Member States to address diseases such as RHD in a holistic way – ensuring that health is understood as a state of physical, mental and social wellbeing, rather than just the absence of disease (as per the WHO Constitution). <sup>13</sup> This is important for RHD because the disease is chronic, so interventions should focus on maximizing the individual's quality of life and sustaining the wellbeing of the person, not just the health of the heart.
Target 3.4	By 2030, reduce by one third premature mortality from non-communicable diseases	RHD is a 'non-communicable disease' (NCD), as once a person has RHD, the disease is both chronic and non-transmissible. The RHD community seeks to partner with the broader NCD agenda to achieve this target.
Target 3.8	Achieve universal health coverage	The ethos of universal health coverage (UHC) is to ensure that all people in a country can access their national health system and receive good-quality essential care, without being exposed to financial hardship. <sup>14</sup> In practice, this involves a lot of work at the national level, as health ministers must adapt their health systems and make difficult decisions over what is considered 'essential'. There is a rich opportunity to advocate for RHD interventions to be included within these essential care packages. RHD Action has published a full <b>Policy Brief on RHD and UHC</b> , which contains further information and guidance on this topic. <sup>15</sup>
Goal 4	Ensure inclusive and equitable quality education [...] for all	Comprehensive and inclusive health education about RHD, including who is at risk, how to avoid the disease, and how to treat and manage it, is crucial at the community level. <sup>16</sup> Longstanding research shows that when knowledge of the disease increases, the number of reported cases increases and thus the number of patients treated increases. <sup>17</sup> It is important that Ministers of Education are encouraged to invest in health literacy as part of formal and informal learning.
Goal 11	Make cities and human settlements inclusive, safe, resilient and sustainable	One of the biggest reasons that RHD was eliminated in wealthy countries in the 20th Century was improved living conditions. <sup>11</sup> By managing urbanization, reducing overcrowding, and providing access to nutrition and medical services in settlements, countries will be able to better control RHD risk factors.

The comprehensive, people-centred approach of the United Nations' Agenda 2030 is useful to RHD advocates and the wider RHD community, as it reflects the disease in three ways:

- 1. THE HEALTH ISSUES** around RHD: such as child and maternal mortality, tackling non-communicable diseases, universal health coverage and access to care
- 2. THE PRIMORDIAL FACTORS** that cause RHD: such as poverty, lack of education and inadequate living conditions
- 3. THE PEOPLE AND COMMUNITIES** affected by RHD: such as the poor, vulnerable and marginalized, especially women and children

As all 193 Member States of the UN have committed to this plan of action for the next 15 years, the RHD community is now able to hold governments accountable for progress related to RHD outcomes in their countries.

## World Health Organization



The World Health Organization HQ in Geneva, Switzerland

The World Health Organization (WHO) is the public health arm of the United Nations (UN). Its global headquarters are based in Geneva, Switzerland, but the organization also has offices at the regional and national levels. Like the UN, the WHO is also made up of Member States, which convene regularly to decide on health policy and strategize how to make these policies impactful on the ground. The work of the WHO is directed by its constitution, which is based on the principle of health as a human right.<sup>13</sup>

As RHD is an entirely preventable disease, its continued prevalence in endemic countries contravenes the WHO's principles of health as a human right. Rheumatic heart disease is briefly referenced in a few key WHO resources, such as the Global NCD Action Plan and the Pocket Book of Hospital Care for Children.<sup>18,19</sup> But little currently exists beyond this; the World Health Organization has not undertaken a contemporary, well-strategized, well-resourced and sustainable programme of work to eliminate RHD. Indeed, the historic commitments that WHO have previously made on RHD often fell by the wayside, due to lack of resources, lack of data, lack of coordination and lack of ownership of the issue.

**'We hear you. We hear you loud and clear that there is a need for concentrated progress on RHD.'**

– NCD Technical Officer, World Health Organization

### WHO RHD Programme (1984-2002)

Historically, RHD used to be considered a much higher priority issue by the World Health Organization than it is today. The WHO first began to tackle the disease in 1954, through technical meetings and convening activities about rheumatic fever (RF) and RHD. But it was not until 1984 that a concerted programme of work was launched. This programme, which operated from 1984-2002, focused its work on many levels, including improving living standards, improving access to care and medications, and planning and implementing registry-based control programmes.

The WHO RHD Programme did have some successes: 1.5 million school children were screened with stethoscopes, while 125,000 healthcare workers were trained in RHD management. However, despite these achievements, the programme was shut down at the turn of the millennium, and many of the registries were abandoned.<sup>20</sup>

Reasons for the premature closure of this programme are unclear, and remain under internal evaluation at the WHO. Possible reasons include:

- **The difficulties in quantifying the burden of RHD before the introduction of echocardiography meant that RHD dropped down the list of WHO priority areas**
- **The structure of the WHO RHD programme as a 'vertical' (separate and non-integrated) plan of work made it less sustainable across the health system**
- **Lack of sufficient advocacy from WHO Member States, who task the WHO with all aspects of its workplan**
- **A 'declining sense of international camaraderie', as identified by a former advisor to the WHO on RHD<sup>21</sup>**
- **Lack of resources and competing global health priorities, including efforts to tackle HIV/AIDS, tuberculosis, malaria and the rising tide of non-communicable diseases**

Now, as the World Health Organization is reawakening to the reality of RHD, it is important that all stakeholders learn from the successes and challenges of this programme. We cannot afford for future efforts to be abandoned prematurely. As one spokesperson from the WHO has said: 'We pressed the pause button on this programme when the work was not done'. It is likely that many lives were lost as a result – so it is crucial that RHD is resurrected as a policy priority of the WHO.

### WHO Expert Consultation on RF and RHD (2001)



The most recent WHO Expert Consultation on Rheumatic Fever and Rheumatic Heart Disease, took place in Geneva in 2001, just as official WHO RHD programmatic work on RHD was fading.

The purpose of the meeting was to convene experts to update the WHO Technical Report on Rheumatic Fever and Rheumatic Heart Disease, which had first been published in 1988.<sup>22</sup> This updated Technical Report would then stand

as official WHO policy and guidance on RHD. The focus and outputs of the meetings were heavily epidemiological and scientific, yet key statements were included on the scale and importance of addressing RF and RHD as significant global public health issues.

Across the Expert Consultation, the WHO acknowledged that:

- **Control of RHD through primary and secondary interventions is 'both cost-effective and inexpensive'**
- **RF and RHD are 'still major public health problems among children and young adults in developing countries'**
- **Prevention programmes can result in a 'marked decrease in the mortality, incidence, prevalence, morbidity and severity' of RF and RHD**
- **The criteria used to diagnose RHD (the Jones Criteria) should be adapted and adopted by the WHO in forming their own diagnostic criteria. The consequent WHO criteria for the diagnoses of rheumatic fever and rheumatic heart disease were developed from 2002-2003**
- **There are 'significant advantages' to using echocardiography (heart scans using ultrasound waves) rather than auscultation (listening to the heart using a stethoscope) or chest X-ray in the diagnosis of RHD**
- **All countries require laboratories to handle routine diagnostic tests for RF and RHD, as well as laboratories equipped to conduct research and training on RHD**
- **Pregnant women with RHD are at high risk of poor health outcomes, therefore it is 'mandatory' that they are specially evaluated and followed-up by healthcare workers and given 'special attention'**
- **The 'most effective strategy' for avoiding RHD once a person has contracted rheumatic fever (i.e. for secondary prevention) is an injection of benzathine penicillin G (BPG) every three to four weeks**



The Expert Consultation ended with some policy recommendations and conclusions, three of which are especially relevant to people working on programmes:<sup>22</sup>

- 1. Integrate sore throat diagnosis into existing healthcare facilities, as untreated sore throats can lead to rheumatic fever and rheumatic heart disease**
- 2. Establish registries of known RHD patients, as this is an 'effective' and 'proven' way to reduce morbidity and mortality**
- 3. Establish a national prevention programme for RF and RHD, as this is 'essential' in endemic countries**

The results from this Expert Consultation – the last meaningful policy and guidance on RHD to come of the WHO – are already 15 years old. This is unacceptable, given that 15 years is over half the lifetime of many Ethiopians with RHD, 70% of whom die before their 26th birthday.<sup>23</sup>

The RHD community has joined forces to urge WHO Member States to seek the reopening of RHD as a priority on the organization's global health agenda. The most impactful way to ensure this is for Member States to request an official World Health Organization Resolution on RHD (see below) and to request a technical update of the 2001 Expert Consultation.

### World Health Assembly Resolution

Member States submit proposed resolution to WHO Executive Board (August)

WHO Executive Board submits proposed resolution to World Health Assembly (January)

World Health Assembly debates resolution and passes it (May)

For RHD to regain its place on the WHO's official workplan and list of priorities, Member States will have to pass a Resolution on the disease. A WHO Resolution is a written-out motion that is submitted by Member States to the Executive Board of the WHO, which acts as an advisory committee to the World Health Assembly. If passed by the Executive Board, the Resolution is then submitted directly to the World Health Assembly, which meets in Geneva each May. The Resolution is then debated by the health ministers of all Member States and, if successful, passed at the end of the Assembly meeting.

The World Health Organization Executive Boardroom, Geneva

The effect of a WHO Resolution is that the health issue in question is officially recognized by all Member States as a priority, and all must commit to honouring and fulfilling the text of the Resolution.

Proposals for WHO Resolutions must come from Member States themselves – it is not possible for the RHD community to suggest a Resolution directly. However, non-state actors can work with key decision-makers, as well as provide the data and costing studies that will make the content of an RHD Resolution compelling and impactful once it is adopted.

## WHO Essential Medicines List

The World Health Organization's Essential Medicines List was established in 1977, and has been updated every two years since then. The list aims to draw together the medicines 'that satisfy the priority health care needs of the population', which must be available within the health system at all times, in adequate amounts, as good-quality and affordable products.<sup>24</sup>

The WHO's Essential Medicines list is often referred to as a 'Model List', as it is not designed as a global standard, but rather as a guide for the development of national or sub-national essential medicines lists. Encouraged by the WHO, almost every country has drawn up their own national Essential Medicines List tailored to their populations' specific health needs, and many of these can be accessed online.<sup>25</sup>

Benzathine Penicillin G (BPG), the life-saving drug to prevent and control RHD, has been on the WHO 'Model List' since its first iteration in 1977.<sup>26</sup> Almost all countries include BPG on their national list (whether for rheumatic heart disease or other health issues such as syphilis), including settings as diverse as Afghanistan,<sup>27</sup> Maldives,<sup>28</sup> and Zambia.<sup>29</sup>

Although BPG is a stalwart of national essential medicines lists, many countries experience difficulty in accessing the drug. Manufacturing shortages and distribution instability have created widespread stockouts, meaning that people living with RHD cannot access their disease-altering medication.

The continued challenge of BPG stockouts is an example of policy on paper not translating into improvements in reality. Beyond emulating the example of the Model List and including BPG in their national list, countries would benefit from guidance and technical advice from the WHO regarding how to maintain sufficient and sustainable access to good quality, affordable drugs for RHD.

## World Heart Federation



The **World Heart Federation** (WHF) is a Geneva-based NGO that unites a community of over 200 national members who are dedicated to leading the global fight against cardiovascular disease (CVD), including heart disease and stroke. In line with WHO strategies and targets, the WHF strives towards a world where there are at least 25% fewer deaths from cardiovascular disease by 2025 – this is known as the '25 by 25' strategy.<sup>31</sup>

## WHO PEN

In 2010, the World Health Organization's NCD department produced a resource for improving primary health care for NCDs in low-resource settings: the Package of Essential NCD Interventions for Primary Health Care (WHO PEN).<sup>30</sup> This resource provides information and guidance on the core medicines, technologies and interventions needed to achieve holistic, impactful NCD care in some of the world's poorest settings.

All the interventions recommended in WHO PEN have been selected due to their feasibility 'even in low-resource settings with a modest increase in investment'.<sup>30</sup> They are also able to be delivered by both primary care physicians and – importantly – non-physician health workers, which makes them appropriate for implementation or integration within a local RHD programme.

Secondary prevention of RHD is included as one of PEN's cost-effective, feasible interventions, with WHO advising investment in: 'Regular administration of antibiotics to prevent streptococcal pharyngitis (sore throat) and recurrent acute rheumatic fever'.<sup>30</sup> While entire programmes can be, and have been, devoted to administering BPG to existing RHD cases, it is also desirable to integrate this cost-effective intervention as a contributory part of wider health programmes (see 'Integrated RHD Programmes', below).

As with all global strategies on RHD, it is important to be sensitive to the potential gaps between WHO policy and local practice. For example, RHD interventions have not been included in the accompanying protocols that guide users on how to implement the PEN package, so pilot programmes have tended to overlook these. While it is an advantage that secondary prevention of RHD is included in the WHO PEN package, this should not be seen as an end in itself. Instead, the RHD community should view this piece of policy as an encouragement and stimulus to guide secondary prevention activities on the ground.

The WHF has focused on rheumatic heart disease as a priority area for many years, as the disease is a sentinel condition of inequality and its prevalence directly contravenes the human right to health.<sup>15</sup> In order to guide its work on RHD, the WHF developed the following goal, based on the '25 by 25' strategy: **Achieve a 25% reduction in premature deaths from RF and RHD among individuals aged <25 years by 2025 (25x25<25).**

This goal draws on the existing '25 by 25' framework to emphasize that RHD is part of the wider CVD epidemic that the world currently faces. It also emphasizes the young demographic of people who are at risk of RHD: throughout Africa, the average age of people with severe RHD is 28 years (66% of whom are women).<sup>32</sup>

Work towards the 25x25<25 strategy comes in many forms. From its strategic location near the UN and WHO secretariats, the World Heart Federation works to enter the international diplomatic policy space and advocate for RHD to be included more centrally in the global agenda. Key actions include convening experts, integrating RHD into wider global health activities and discussions, creating

educational materials, and advocating passionately about RHD, to give a voice to this silent killer.

WHF's most demonstrative recent commitments to the 25x25<25 goal have been through its contributions to the RHD Action movement, which was established in 2015. You can read more about the RHD Action movement **online**.<sup>33</sup>

# REGIONAL RHD POLICY – THE AFRICAN EXAMPLE

**Each region of the world has an approach to health policy that is as unique and varied as the region itself. The African region has been chosen here as historically it has had the greatest prevalence of clinically detected RHD,<sup>34</sup> and also because it has made the most progressive and cohesive policy outputs in this area.**

## African Union

The African Union (AU) was formalized in 2002 in order to unify the countries of the African continent and intensify their solidarity, cooperation and harmony.<sup>35</sup> As of 2016, all countries on the African continent are considered Member States of the AU, with the exception of Morocco.<sup>36</sup> Much like the European Union, the AU has the power to enact policy to accelerate the political and socio-economic integration and growth of the continent.



*The African Union headquarters in Addis Ababa, Ethiopia*

## Abuja Declaration (2001)

In April 2001, the African Union countries met to draft and sign the Abuja Declaration, in which they recognized that health crises, including HIV/AIDS, tuberculosis and other diseases, constituted an 'exceptional threat' to the development and security of the continent.<sup>37</sup>

As part of the Abuja Declaration, African heads of state pledged to set a target of allocating at least 15% of their respective annual budgets to improving the health sector.<sup>37</sup> Had this policy been enacted fully, without the impediments of political upheaval, changes in government, and conflicting development priorities, the African region would have been in a position to make great strides towards achieving the health goals of the UN's Millennium Development Goal agenda (2000-2015).

However, when the World Health Organization came to review progress on this ambitious commitment a decade later, it found that by 2011, only one country had reached the 15% target: Tanzania.<sup>38</sup> (Unfortunately Tanzania's success was not sustained: the latest figures range between 8.9% in 2014 and 11.3% for the 2015-2016 budget.)<sup>39</sup>

Meanwhile, the WHO found that eleven countries had actually reduced their relative contributions of government expenditures to health since the Abuja Declaration, while others had stagnated their progress.<sup>38</sup> The MDG health goals have been, correspondingly, underachieved by the majority of African countries, with UNDP and other organizations categorizing the MDG goals on child and maternal mortality as 'off-track' in 2015.<sup>40</sup>

The Abuja Declaration remains: African countries are still mandated to try to allocate 15% of their annual budgets to health. Yet the missed opportunity and unfulfilled potential of the Abuja Declaration indicate that, while African countries are aware of the health problems facing the continent, many struggle to implement targets and actions to remedy them. Fortunately, in the case of RHD, the African Union is making progress to close this gap through the AU Communiqué.

## AU Communiqué on RHD (2015)

In 2015, experts and leaders in RHD from the African region were convened by the Pan-African Society of Cardiology (PASCAR) to deliver a written statement expressing their concern about the prevalence of RHD on the continent and presenting recommendations for action to all African governments. This document, known as the AU Communiqué, identifies the barriers to RHD prevention and control in Africa and calls upon international stakeholders such as the World Health Organization, the World Heart Federation and UNICEF to join governments in eradicating this disease.<sup>41</sup>

Based on evidence and experience from the region, the AU Communiqué provides seven recommendations to African heads of state for RHD. These reflect the need to establish:<sup>41</sup>

- 1. RHD REGISTERS** at sentinel sites to monitor RHD-related health outcomes
- 2. Adequate supplies of BPG** for primary and secondary prevention of RHD
- 3. Universal and integrated access to REPRODUCTIVE HEALTH SERVICES** for women with RHD
- 4. DECENTRALIZED TECHNICAL EXPERTISE** to the primary and district levels
- 5. CENTRES OF EXCELLENCE** for cardiac surgery
- 6. NATIONAL RHD CONTROL PROGRAMMES** for implementation of national RHD action plans
- 7. A FRAMEWORK FOR PARTNERSHIPS** between the African Union, Ministries of Health, international agencies and other stakeholders

Over the course of 2015, the AU Communiqué was adopted unanimously by African Member States and enshrined as an official African Union declaration endorsed by all African heads of state. Now that this ground-breaking regional policy is in place, it is incumbent on ministries of health to develop and carry out implementation plans at the national level.

To enable and complement this work, RHD stakeholders in Africa, including the Pan-African Society of Cardiology, are currently developing a roadmap of action, so that the region can deliver on its promises to 'end [...] RHD in Africa within our lifetime.'<sup>41</sup>

## WHO AFRO

WHO AFRO is the regional body of the World Health Organization for Africa. It is located in Brazzaville, Republic of Congo, and has a mandate of working to attain the highest standards of health and wellbeing for all people within the region.

Of the six WHO Regional Offices, WHO AFRO is probably the most active and engaged on the issue of RHD. In collaboration with the African Union (AU) and PASCAR, it endorsed two important policy documents: the Drakensberg Declaration (2005)<sup>42</sup> and the Mosi-o-Tunya Call to Action (2014),<sup>43</sup> which both aimed to place RHD more centrally on Africa's regional agenda.

The Regional Director of WHO AFRO, Dr Matshidiso Moeti, has also spoken out about RHD on the global stage. During the 2015 World Health Assembly in Geneva, Dr Moeti underscored the importance of strengthening African health

services to tackle RHD, and promised to retain RHD and other NCDs as a prominent priority.<sup>44</sup> Making reference to WHO PEN (see above), Dr Moeti acknowledged the potential for RHD services to be integrated into primary healthcare delivery at the national level.

It is vital that WHO AFRO remains friendly to the idea of RHD as a global health priority and that its policies continue to reflect this. The Regional Office is strategically placed to make sure that WHO, African Union and civil society policies and actions are aligned. It also has regional oversight over the national progress of African countries, so provides a useful perspective over whether global and regional policy translates into progress at the national level.

## NATIONAL RHD POLICY

### 'GOVERNMENTS MUST DO MORE TO INTEGRATE RHEUMATIC HEART DISEASE SERVICES INTO EXISTING NATIONAL HEALTH SYSTEMS, PARTICULARLY AROUND PRIMARY CARE AND MATERNAL AND CHILD HEALTHCARE.'

– Johanna Ralston, CEO, World Heart Federation

In 2011, the United Nations required all Member States to create and implement a national NCD (non-communicable disease) policy or plan as part of their broader national health strategy.<sup>45</sup> The World Health Organization's *Non-Communicable Diseases Progress Monitor* was released in 2015 to track each country's progress on this, before the countries report back on their work to the United Nations at a High-Level Review scheduled for 2018.<sup>46</sup>

The *Progress Monitor* makes for disheartening reading: out of 173 countries featured in the report, only 64 had created a national policy or plan. Twenty-three countries had 'partially met' this deliverable, while the majority – 86 countries – were operating without a policy or plan on NCDs.<sup>46</sup>

Of the approximately 64 national NCD plans that do exist, not all of them reference cardiovascular disease (CVD) specifically, so heart disease is easily lost within the broader 'NCD' category. Even fewer of these NCD plans refer to rheumatic heart disease (RHD), which means that many endemic countries are lacking essential guidance and strategies for tackling this public health priority.

There are a few countries, however, which have taken positive steps to create national health policy that address RHD and its related health issues. The three examples below can act as an inspiration and a guide to Ministries of Health which seek to improve their progress on RHD prevention and control.

## Pakistan



The Ministry of Health of Pakistan has developed a very complex and comprehensive national NCD policy based around a **National Action Plan**, in collaboration with other Government ministries, the World

Health Organization and Heartfile, a non-profit health NGO.<sup>47</sup>

Pakistan's National Action Plan goes further than most national NCD policies in its inclusion of RHD: it describes what the disease is and its implications for the national health system, as well as providing action points related to prevention and control. In the National Action Plan, RHD is characterized as an important and preventable CVD, albeit one which requires a different strategic approach to more common heart diseases such as hypertension.<sup>47</sup> Its links to poor housing, overcrowding and poverty are made clear to non-RHD specialists, so that national policy-makers from other areas can identify the relevance to their sector.<sup>47</sup>

The Pakistani National Action Plan on NCDs issues four strong policy measures for RHD prevention and control, including:<sup>47</sup>

- 1. INTEGRATION** of rheumatic fever and RHD prevention with national work to improve living conditions and reduce poverty
- 2. Provision of HEALTH CARE EDUCATION** on RHD, targeted at parents
- 3. Locally TAILORED GUIDELINES** for clinicians working with RHD
- 4. PENICILLIN** to be made available at all healthcare levels

Overall, Pakistan's National Action Plan offers a suitably in-depth, sophisticated roadmap to preventing and controlling NCDs (including RHD) for a country that holds the sixth highest population in the world<sup>48</sup> and struggles with a 'double burden' of disease: both communicable and non-communicable.<sup>47</sup> However, its contemporary usefulness is limited by its lack of recent updates. National burdens of NCDs, including RHD, can change rapidly, so national policies require regular additions and amendments to keep them 'on track' to serve the current needs of a population.

## Samoa



The Government of Samoa issued a **National Non-Communicable Disease Policy 2010-2015**,<sup>49</sup> in response to global policies, such as the Alma-Ata Declaration on Primary Health Care (1978)<sup>50</sup> and regional policies, such as the Yanuca Islands Declaration on Health in the Pacific in the 21st Century (2005).<sup>51</sup>

Samoa is a country with a small population, but a high burden of RHD: historically, nearly 10% of its total annual health budget has been used on heart surgery for RHD.<sup>52</sup> Recognizing that this level of expenditure is unsustainable, Samoa's health system has become more strategic in its approach to RHD prevention and control, as shown in its National NCD Policy.

The first strategic approach on RHD in Samoa's plan of action is to gain a greater understanding of Samoa's burden of disease. The policy calls for **RHD registries** to be established in the country, to help with informed decision-making and the gathering of timely information.<sup>49</sup>

The second strategic approach on RHD is to implement a national **RHD prevention programme**, based on an evaluation of outcomes from a 2009 pilot programme.<sup>49</sup> This is an encouraging step, as the plan specifically

mentions that the programme should be evidence-based and guided by past experience.

As well as focusing on RHD and CVD in particular, the Samoan National NCD Policy takes an impressively holistic view of NCDs as a society-wide problem. As the Minister of Health says in the foreword: 'This is everybody's business'.<sup>49</sup> The policy therefore mentions sectors outside of health, such as education, industry, agriculture, trade and environment. It also emphasizes that all members of society have a role to play in enacting national policy: from the Governments that set the plans, to the individuals in society who are at risk of NCDs.

Overall, Samoa's National NCD Policy 2010-2015 is a strong document that benefits from a clear strategy, some good attempts at costing interventions, and detailed reference to particular NCDs that threaten the population, including RHD. Although now concluded, the policy can still be used as a blueprint for other Small Island Developing States that seek to concretize a strategy on RHD prevention and control.

## Kenya



Like Pakistan, Kenya's Ministry of Health has created a full and detailed national policy on NCDs, called the **Kenya National Strategy for the Prevention and Control of Non-Communicable Diseases (2015-2020)**.<sup>53</sup> While the

policy focuses primarily on the four major NCDs (CVD, cancers, chronic respiratory diseases and diabetes), the strategy's scope remains broad and makes special reference to rheumatic heart disease as a 'significant challenge in the region'.<sup>53</sup>

The National Strategy acknowledges that RHD has an uneven distribution across the Kenyan population, and that prevention and control of RHD 'require[s] a strong systematic approach and response'.<sup>53</sup> It also provides some contextual analysis of RHD in Kenya, stating that 'around half of patients admitted to hospital with Heart Failure is due to RHD'.<sup>53</sup>

However, despite outlining the problem of RHD in Kenya, the National Strategy offers few tailored solutions on how to prevent and control the disease. The Kenya National

Monitoring Framework for NCDs, found at the end of the document, does not contain an indicator to track progress on RHD interventions, which may compromise action due to lack of accountability.

One of the overriding strengths of Kenya's National Strategy is that it directs all actions towards achieving the global target of '25 by 25': i.e. achieving a 25% relative reduction in premature mortality from NCDs (including CVD) by the year 2025.<sup>53</sup> This goal, which has been adopted and adapted by the World Health Organization and the World Heart Federation, among others, is a strong unifying force, which will help unite countries as they work to prevent and control NCDs.

Countries who are still developing their national NCD strategies could adopt Kenya's '25 by 25' focused approach, as this would ensure that their national policy was coherent with regional and global ambitions.

**Overall, it is clear that national policies on RHD are diverse, with each containing strengths and weaknesses. The best national RHD policies are set against clear accountability mechanisms, and include tailored solutions to specific targets or indicators.**

They are also closely influenced by regional and global health policies, as this promotes coherence and firmly contextualizes RHD within the wider global health landscape. When put into practice in-country, national policies on RHD can have a positive enabling effect on local programmes, as we will see in the following section.

# PROGRAMMES

// **The establishment of a national prevention programme is essential in countries where rheumatic fever (RF) and rheumatic heart disease (RHD) remain significant health problems."**

- World Health Organization<sup>22</sup>



## OVERVIEW

**'The establishment of a national prevention programme is essential in countries where rheumatic fever (RF) and rheumatic heart disease (RHD) remain significant health problems. Both primary and secondary prevention of RF and RHD have been proven to be safe, feasible and effective.'**

– World Health Organization<sup>22</sup>

In 2011, RHD researchers described a 'new surge in activity' to prevent and control RHD, including public health programmes, research and political advocacy.<sup>54</sup> The experts noted an important difference in the type of activity being generated: public health programmes (along with research and advocacy) were largely driven from parts of the world where rheumatic fever and RHD mostly occur, rather than traditional 'donor countries' or global organizations such as the WHO.

The case studies below illustrate that the surge of RHD activity continues. RHD programmes are increasingly rooted in the countries and communities that carry the biggest burden of RHD, much to the benefit of national prevention and control efforts which gain local knowledge, community engagement, and a strong sense of national ownership.

**So what is an RHD programme?** Simply put, RHD programmes provide a way to translate what we know into practical RHD prevention and control efforts to help people at risk.<sup>54</sup> They have existed since the 1950s, where concerted efforts in Baltimore and New York helped to gather information, document trends, and set the scene for future RHD control activities.<sup>55</sup> RHD was largely eliminated in the United States during the 20th century, so most RHD programmes now operate in resource-poor countries, or in vulnerable communities within richer countries.

RHD programmes are extremely varied – there is no 'one-size-fits-all' solution, though many programmes contain similar elements. The core components of RHD control programmes are outlined in a conceptual framework (see below, following the case studies) and range from basic surveillance to advanced cardiac surgeries. The case studies profiled below illustrate how different settings have prioritized different elements of RHD control. These programmes also vary in scope and geography, from **Egypt's** whole-of-country programme to **Canada's** fledgling work in one district. The programmes featured are also at various states of progress: **Cuba's** seminal RHD programme ran for 16 years before concluding, while in-country work in **Timor-Leste** is just beginning.

Small-scale, experimental projects limited to a particular area or timeframe are called 'pilot programmes'. Some 'pilots' focus on one RHD intervention only, but many take a more 'comprehensive' approach (i.e. implementing several interventions at once to maximize positive health outcomes). 'Pilots' are used to determine the feasibility of a certain methodology or set of interventions in a particular geography, which may, if successful expand their reach and scope: this is called 'scaling up'. There is a concerning lack of 'scaled up' national programmes on RHD, as most work to date has been limited by geography and resource.

The case studies also testify to the various approaches that can be taken for RHD prevention and control. Countries such as **Sudan** have adopted and adapted existing models, such as the comprehensive ASAP (Awareness, Surveillance, Advocacy, Prevention) programme model, developed in 2005.<sup>56</sup> Others, including **Tonga**, prefer to develop their own clinical guidelines and strategies, taking into account their own particular circumstances and needs.

There is no definitive 'right' way to design and implement an RHD programme. Indeed, the case studies from **Nepal**, **Yemen** and **Fiji** show that even the best laid plans require flexibility and resilience under humanitarian and natural disasters.

We hope you enjoy reading these shared experiences and that they help inform your own work in the field, or inspire you to support RHD programmes in your own settings. You can find more case studies on the **RHD Atlas** or submit information about your own work to: [info@rhdaction.org](mailto:info@rhdaction.org)

## MIDDLE EAST

### Egypt

*Dr Alaa ElGhamrawy, Director, RF/RHD Prevention and Control Programme, Cairo*

#### Introduction

Egypt's *Rheumatic Fever/Rheumatic Heart Disease Prevention and Control Programme*, established in 2002, is one of the most longstanding RHD programmes operational today. Egypt has a notoriously high burden of RHD, which is unequally distributed across its 27 governorates (administrative regions).<sup>57</sup>

#### About the programme

The programme is securely integrated into the Ministry of Health's workplan, having been approved for work within the government's NCD programme in September 2014. It provides a comprehensive programme of primary, secondary and tertiary care, with services impressively decentralized across the country.

The programme operates out of 30 regional centres, evenly distributed across the nation's governorates. Between them, the centres are equipped with 60 echocardiograms. Most of these centres have their own registries, which are based on the registries developed in partnership with WHO in 2005. The scale-up of this work has been rapid: back in 2013, there were only five regional centres consistently pooling their data through registry systems.

For people with advanced RHD, the programme provides surgical interventions. These procedures take place in the surgical facilities of the 30 RHD centres and are coordinated via a referral system embedded within the programme.

The Egyptian programme is working to integrate with other health areas related to RHD, e.g. maternal and child health. Reproductive health in Egypt is accessed through its family planning system. The RHD programme has ensured that echo screening is integrated into this system, so that every woman receives a heart scan during the first trimester to identify any undiagnosed RHD that may become problematic during the later stages of pregnancy and labour.

#### Challenges

Though the programme's attempts to decentralize its work is admirable, the process has not been completely smooth. In practice, there is no consistent network linking up regional registers and centres, although a referral process between primary health care centres and the RHD centres is now in place.

Integration efforts into the maternal and child health sectors have been hampered by uneven coverage of ante-natal care for pregnant women. Moreover, the programme is facing a limited availability of good-quality penicillin, which is a common problem across most RHD-endemic regions.

#### Achievements

In 2015, Egypt's RHD programme trained 300 cardiologists and 1,500 primary health care physicians in RHD management, and established a referral system between primary care centres and RHD centres.

The programme has also signed a protocol with the League of Arab States to ensure cooperation over research into a vaccine that has the potential to prevent rheumatic fever and RHD.

The work of Dr Alaa ElGhamrawy, coordinator of the programme, has been officially recognised by WHO, who awarded him the prestigious State of Kuwait prize in 2015 for his efforts to prevent and control RHD in Egypt.<sup>58</sup>

Overall, the Egyptian RHD programme is endorsed by several long-standing international partners. It has enjoyed support from the WHO since 2005, the WHF since 2010, and also the Pan-African Society of Cardiology and the African Union. It also has strong links with local partners, including universities, NGOs and the Egyptian Society of Cardiology. But the programme's special relationship with the Egyptian Ministry of Health has been its greatest enabler and it is essential that this support remains ongoing.

#### Moving forward

Egypt has a population of almost 90 million, so the programme hopes to scale up interventions and establish more centres to cope with the correspondingly high burden of RHD. If resources permit, the programme hopes to explore increased use of rapid antigen tests to give an 'on the spot' diagnosis of the throat infection that can lead to RHD. Establishing a good quality supply of BPG will remain a priority; in some cases, the medications currently available only stay in the blood for two weeks instead of the four weeks required for adequate protection against RHD.



An Egyptian boy undergoes echocardiography at one of Egypt's 30 RHD centres

## Sudan

*Prof. Sulafa Ali, Secretary General of Sudanese Children's Hearts Society and Paediatric Cardiologist at Sudan Heart Institute, Khartoum*

### Introduction

The Sudan Heart Society established a new RHD control programme in 2012, aiming to increase awareness about the disease and strengthen primary and secondary prevention.<sup>59</sup> The programme has adopted the World Heart Federation's '25x25<25' goal and is based on the pillars of awareness, surveillance, advocacy and prevention – championed by many successful RHD programmes. The program is self-funded with some support from WHO's Sudan country office, as well as NGOs such as the Sudanese Children's Heart Society and Sudanese American Medical Association.

### About the programme

Sudan's RHD programme was inspired by the Pan-African Society of Cardiology's call for RHD Control in 2005 which has been a model for many countries in the African region.<sup>55</sup> The programme is well supported by the Sudan Ministry of Health and has been successfully integrated into its Non-Communicable Disease and School Health Programmes.

### Public Awareness

Sudan celebrates National RHD Awareness Day on 17 August each year. In 2015, educational materials (posters, pamphlets, video clips) were distributed in Khartoum and other RHD target zones. A school awareness campaign was run in the peripheries of Khartoum. The media were receptive to this campaign, and most newspapers featured it as headline news.

### Surveillance

Screening projects have been undertaken using donated hand-held echo devices. In 2016, the programme implemented a screening project in South Darfur, where preliminary results showed that RHD prevalence is 22 per 1,000 compared with 3 per 1,000 in Khartoum. In 2017 a similar program is planned in Kurdufan, the second most affected area of the country.

Sudan Heart Society initiated a National Registry for RHD to help in program implementation and evaluation. Data is presented to regional government officials as part of the programme's advocacy efforts to decentralize and expand RHD interventions beyond the capital city

### Advocacy

One characteristic of the Sudanese RHD programme is the quality and quantity of written and visual materials that it produces. These include multilingual brochures, awareness materials and educational websites for the public, many of which can be found on the **RHD Action Resource Hub**.<sup>6</sup> A dramatic film that details the tragic suffering of a child who dies from RHD is published and **available to watch online**.<sup>60</sup>

### Training of Health Workers

In 2015, Professor Sulafa Ali and her colleagues launched 'Sudan's Guidelines for Diagnosis, Management and Control of RHD, which now serves as a standardized reference booklet for all physicians and health care providers working with RHD.<sup>61</sup> The launch event was attended by 65 physicians, 25 of whom were from Sudan's four RHD target areas.

### Challenges

Sustainable funding is needed to complete the integration of RHD into Ministry of Health programmes including NCDs, IMCI (childhood illness programmes) and school health programmes. This has to be consolidated in the country's RHD target zones which are far away from the capital Khartoum, imposing additional logistical difficulties.

### Moving forward

A future goal for Sudan's programme is to develop the national registry for RHD to ensure a better system for surveillance and research. The project has already mapped RHD hotspots, but is unable to move ahead without funding. The programme also hopes to train physicians in echocardiography and is seeking fundraising to support poor families who need cardiac interventions.



*School children celebrating National RHD Awareness Day on 17 August 2015*



*Training workshop for RHD physicians*

## Yemen

*Dr Mohammed Al-Kebisi, National Coordinator for Cardiovascular NCDs, Ministry of Health, Yemen*

### Introduction

At the time of writing, Yemen is in a state of conflict and political upheaval. Despite this, Dr Mohammed Al-Kebisi and his team at the Ministry of Health are continuing to implement a national rheumatic heart disease programme in the country, with some support from the World Health Organization (WHO).

### About the programme

The programme's main focus is to provide RHD workshops across different cities in Yemen. Dr Al-Kebisi's original vision before conflict broke out was to undertake ambitious levels of RHD screening among school children, but this has been postponed due to lack of resources.

The workshops focus on secondary prevention of RHD, as information from the hospital-based registry at Al-Thawrah (the principal referral hospital in Yemen) showed that all the patients that entered the healthcare system at that point had established RHD, with the most advanced cases requiring heart surgery.

Surveillance is an essential component of Yemen's RHD programme. Registry-based work at Al-Thawrah is part of a global rheumatic heart disease registry called REMEDY. REMEDY has two phases: the first phase involved a baseline registry of 3,000 patients (in total 3,343 patients were enrolled); in the second phase these patients were followed-up for 24 months to document disease progression, adherence to penicillin, adverse cardiovascular events such as heart failure or stroke, and any causes of death.

REMEDY was designed to provide comprehensive and contemporary data on patients with RHD, which will help in the development of strategies to prevent and manage RHD and its complications.<sup>62,32</sup> Yemen contributed 300 cases to REMEDY.

As the crisis in Yemen has worsened, many non-registry elements of the programme have been postponed, as the RHD health facilities have been mostly destroyed. WHO support has been redirected towards the country's state of emergency and the provision of essential drugs.

### Challenges

Beyond challenges posed by the national conflict, Dr Al-Kebisi highlighted several critical needs for Yemen. The first is a need for national data about the burden of disease. The second is the need for a roadmap to indicate key actions and investments that are needed to eradicate RHD in Yemen. As part of its CVD Roadmaps series, the World Heart Federation is developing a global RHD Roadmap on behalf of RHD Action – this resource is due for release in June 2016.<sup>63</sup>

*Yemeni children raising awareness of rheumatic heart disease*



A third challenge, which Yemen shares with many national RHD programmes, is access to and use of BPG. Yemen is experiencing problems with supply of the drug, as well as training appropriate health workers to administer it safely. Task shifting and sharing among health workers is particularly difficult in Yemen, as the primary healthcare sector can be quite dysfunctional.

Financing for RHD interventions – including programmes, patient support, portable echo machines and staff training – is hard to come by due to so many conflicting national priorities. It remains very difficult for RHD specialists to leave the country and to travel to international conferences and meetings on RHD.

### Achievements

Impressively, Yemen was one of the quickest countries in the REMEDY study to enrol the requisite 300 patients, making a substantial contribution to the 3,343 patients who were included in the registry overall. The registry design is sustainable and forward-looking, involving 12 and 24 month follow-up questionnaires.

The register has already yielded some fascinating results. Most Yemeni people enrolled in the registry are between 21-30 years of age, which indicates that people are presenting with RHD at a late stage. A disproportionate burden of advanced disease suggests problems in primary health care delivery.

According to the register, a large number of Yemeni patients have already had a valve replacement in comparison to the wider REMEDY study. This points towards the need for sustained anticoagulation medicines to keep the blood flowing through mechanical heart valves and prevent fatal blood clots.

### Moving forward

Dr Al-Kebisi is certain that a national RHD prevention programme is essential in Yemen, where rheumatic fever and RHD remain significant health problems. He notes that these programmes need strong commitments at the policy levels, especially from the Ministries of Health and Education. Looking to the future, Dr Al-Kebisi hopes for Yemen to have a strong and comprehensive RHD programme to treat its high burden of disease. It will require both financial support and an enabling socio-political environment for this dream to become a reality.

# AFRICA

## Uganda

*Dr Chris Longenecker, Programme Director of Bridging the Treatment Gap and Assistant Professor of Medicine at Case Western Reserve University School of Medicine, Ohio, USA*

### Introduction

Uganda is a landlocked country in East Africa, on the northern shores of Lake Victoria. The country's health system is spread thinly across its population of 37.8 million people,<sup>64</sup> with only one physician for every 8,300 people.<sup>65</sup> An estimated 1.5 million Ugandans are currently living with HIV (7.3% of the total population),<sup>66</sup> and the current life expectancy is one of the lowest in the world, at 57 for men and 61 for women.<sup>67</sup> Among these compelling health priorities, RHD remains endemic in the country.

Like the Tanzanian programme (see below), Uganda's *Bridging the Treatment Gap* programme is supported by RHD Action, so has a special focus on integrating RHD services into other health areas. The programme goal is to develop a community-based model for RHD care leveraging existing HIV/AIDS infrastructure, in order to make efficient use of resources already in Uganda.

### About the programme

*Bridging the Treatment Gap* is an RHD Action partnership with Case Western Reserve University, Makerere University and the Uganda Heart Institute, which links RHD into an existing national network of HIV/AIDS clinics and primary healthcare facilities. This existing network, known as the Joint Clinical Research Centre (JCRC), is well-established and recognised in the country, with space available to house RHD and other cardiology interventions in its clinics.

*Bridging the Treatment Gap* has been leveraging the JCRC's infrastructure and resources since 2012. There are several components to the programme.

#### 1. Education

The programme is currently training existing local health workers at the JCRC to expand their skill-sets and perform echocardiography. With the expertise of the Uganda Heart Institute, it has also trained approximately 60 health workers (mainly nurses) to deliver penicillin injections appropriately, so that discomfort to the patient is minimised. While making use of international education models and resources, such as those provided by Case Western Reserve University in Ohio, USA, the programme promotes the principle of training and retaining Ugandan health workers: this is important to make staffing of the programme sustainable and keep much-needed knowledge on RHD in the country.

#### 2. Establishing a register and optimizing penicillin delivery

One of the first tasks completed by the programme was establishing a national registry. Currently, over 1,300 people are enrolled, nearly 80% of whom reported greater than 80% adherence to penicillin in a 2014 assessment. These high adherence rates may partly be due to the programme's

new system which was designed to help decentralize BPG delivery. People with RHD who live close to the Ugandan Heart Institute in Kampala, or any of the JCRC's regional centres, receive monthly penicillin injections at these sites. Those who reside in more rural areas, however, receive a three-month supply which is then administered by health workers at their local health centres, removing the need for expensive monthly travel.

#### 3. Leveraging and enhancing JCRC facilities to establish RHD regional centres

The main integration thrust of the programme involves creating a physical RHD clinic within existing JCRC HIV/AIDS centres. This involves hiring new staff, training existing staff, and re-allocating and sharing existing resources, from specific medical equipment (e.g. echo machines) to staff time and transport vehicles. A good example of this is the Gulu Regional Centre of Excellence, which was established in 2015. Patients were transferred into new care infrastructure which is overseen by specially-hired staff, including one physician and three nurses. At present, nearly 200 people living with RHD are enrolled into Gulu's regional registry, which is synced with the national registry.

#### 4. Outreach activities

The *Bridging the Treatment Gap* programme aims to keep people living with RHD at the centre of its operations and decision-making. It therefore established an RHD Community Advisory Board within the JCRC governance structure, in order to help with outreach. The RHD Community Advisory board runs two pilot patient support networks: one in the capital city Kampala for adults, and one in Gulu for the region's children. The programme hopes to 'scale up' both of these support groups in the near future. In the meantime, outreach in the form of awareness-raising and prevention training is being undertaken, especially for influential members of local communities, such as teachers. In March 2016, 26 teachers from 15 schools in the Mbarara region were trained in prevention and awareness of RHD.

### Challenges

In the initial phases of the programme, some new cardiac patients were anxious about seeking care at JCRC clinics, due to fear and stigma about seeking care at centres associated with HIV/AIDS. Programme staff are working to minimize this challenge by conducting local focus groups with over 50 people living with RHD, to understand their needs and desires and make sure that JCRC facilities are patient-friendly and welcoming to those accessing them for RHD services.

Some local health facilities ask patients receiving BPG to pay a small administrative fee (USD 1-2) per visit to help bear the costs of procuring and delivering the penicillin. However, the programme has found that this cost can be prohibitive for some people living with RHD and deterred them from returning for their monthly injections. Other patients struggled to pay for transportation costs to their local health clinics,

and fell behind with their life-saving injections for this reason. The programme is actively finding solutions for this challenge, such as dedicating a portion of health clinic funds to reimburse people for transportation fees where needed. In individual cases, this has been shown to increase adherence to BPG to 100%.

### Achievements

In general, the complex process of integrating HIV/AIDS and RHD services has gone smoothly. There is a good system in place to refer patients to relevant specialist institutions once diagnosed within the JCRC RHD regional centres. For example, one patient arrived at a JCRC regional centre experiencing severe respiratory difficulties. She was initially treated for pneumonia (which is common among people living with weakened immune systems due to HIV). However, thanks to the integration of RHD services and knowledge into the centre, she was given an echo scan that revealed evidence of RHD. The patient was then referred to the Uganda Heart Institute in Kampala, to receive appropriate treatment there

### Moving forward

Now in its fourth year, the *Bridging the Treatment Gap* programme has many projects planned for the future. It is conducting a needs assessment of primary prevention capacity in schools and primary health centres. This year, the programme will also be creating a maternal cardiovascular health clinic to integrate obstetrics and heart failure care for mothers with RHD and will test BPG samples for quality control. Another RHD Regional Centre of Excellence is planned in Lira for 2016, also to be integrated with the region's existing JCRC HIV/AIDS facilities.

As a good example of using policy to support programmatic work, the programme aims to reintroduce sore throat management into Uganda's training and guidelines for health workers. For example, the WHO's current guidelines for the management of child illnesses currently make no reference to rheumatic fever or RHD,<sup>68</sup> but have the potential to be tailored to include more robust guidelines for sore throat in Uganda.

Long-term, the hope is to transition the *Bridging the Treatment Gap* programme over to the Ugandan Ministry of Health, so that the programme will be fully integrated into the national health system and be securely and sustainably funded by the government. It is important that support is maintained. As HIV/AIDS rates among Ugandan children fall, due to effective policies and programmes that reduce mother-to-child transmission, RHD is set to become more visible and in need of national attention.



*A group of school boys wait for the results of their echocardiograms in Uganda*

## Tanzania

Dr Renae Stafford, Programme Director (Academic and Clinical Services) of Rheumatic Heart Disease Control in Tanzania: A Health System Strengthening Approach

### Introduction

Tanzania is an East African country, bordered by Malawi, Burundi, Rwanda, Uganda, Zambia, Kenya, Mozambique and the Indian Ocean. According to the National Bureau of Statistics, its estimated population in 2014 was 47,421,786.<sup>69</sup> Thanks in part to the focus of the Millennium Development Goals (MDGs), Tanzania has recently experienced improvements in child health and is now on the brink of integrating RHD interventions into existing reproductive and child health programmes in Sengerema district, through a programme supported by RHD Action.

### About the programme

The RHD programme in Tanzania – *Rheumatic Heart Disease in Tanzania: A Health System Strengthening Approach* – is a very new initiative, which is designed to integrate with local reproductive and child health services to provide a holistic response to RHD, using a data-informed approach. The programme is taking place between April 2015 and April 2020 in the Sengerema district, and has recently completed its planning phase.

*A typical home in the Sengerema District, Mwanza Region, Western Tanzania*



Sengerema district, which is on the shores of Lake Victoria in the Mwanza region of western Tanzania, has a catchment population of approximately 663,034.<sup>70</sup> The district is rural and primarily agricultural, with the majority of the population engaged in small-scale farming and fishing. Common health concerns in the district include malaria, diarrhoea, infections, pneumonia, anaemia, dysentery and typhoid.

Since 2013, Sengerema district has been the primary site of the *Mobilizing Maternal Health* campaign, implemented by the Touch Foundation, based in Mwanza, Tanzania. The site was chosen in part due to its population's high fertility and maternal mortality rates. *Mobilizing Maternal Health* is the programme that has been selected to integrate with RHD services.

### There are five planned components of this integrative progress:

#### 1. Securing a coalition of national and local partners

As a key theme of this programme is integration, the list of Tanzanian RHD partners is long and diverse, including PRINMAT: the Private Nurse and Midwives Association of Tanzania. The inclusion of the Midwives Association ensures that integration is a two-way process, with engagement from multiple fields and levels of healthcare provider.

This partner coalition has been active in the planning process and is updated on progress through dissemination meetings and ad hoc informal meetings with programme staff. Representatives plan to convene in Sengerema during an official site visit in August 2016.

#### 2. Leveraging existing local health system strengthening programmes

Touch Foundation's *Mobilizing Maternal Health* campaign has a number of practical resources that can be modified and leveraged for RHD control. For example, it has set up a toll-free number which can be used to summon a medical ambulance or taxi for pregnant women and newborns experiencing medical emergencies. This could be used by the RHD programme to provide transport in the case of a medical emergency for people (including pregnant women) with RHD. It also lays the groundwork for a triage procedure for patients with RHD, to ensure appropriate referral to a health care facility.

Sengerema already has an advanced system of connectivity and triage between the district's medical centres for maternal health, so that women at high risk of medical complications (e.g. mothers with RHD) deliver in the district hospital, while others deliver in a local health facility. This system could be used by the RHD programme to ensure that local RHD interventions are suitably decentralized, and that people at high risk from advanced disease can access the services they need.

Touch Foundation has educational resources for reproductive and child health in Sengerema which will be integrated into RHD services. The NGO currently provides training for 'pre-service' health care students such as medical students and 'in-service' students such as assistant medical officers, as well as for currently employed health care workers. Educational modules on RHD can be integrated into these existing courses.

#### 3. Undertaking a comprehensive, local Needs Assessment

This process, currently in its final stages, will provide insight into the health-seeking behaviours and needs of Sengerema's population. Gaps and barriers to accessing care and delivery of health care services will be identified. This knowledge will then inform the overall design of the programme, to ensure that these needs are met. The Needs Assessment involves a desk review of existing data and guidelines, as well as a mixed-methods approach that uses quantitative and qualitative data to gather information from community members, health workers and patients. From conception to completion, the exercise is estimated to take five to six months.

#### 4. Training of nurse midwives to prevent and control RHD

The up-skilling of frontline health workers is planned in order to strengthen the health system and decentralize RHD prevention and control into more rural areas. The programme will train nurse midwives in RHD screening, so that they can integrate echocardiography into routine maternal health check-ups and identify mothers at risk.

#### 5. Geographic Information System (GIS) mapping

GIS mapping involves using geographical coordinates to digitally map a site for health facilities and other enabling infrastructure, roads and service availability. This has already been completed in Sengerema District for the *Mobilizing Maternal Health Programme*, and has identified 71 active health facilities in the district, including one designated district hospital, nine health centres and 61 dispensaries. The RHD programme plans to map information gathered from the RHD Needs Assessment and future registries onto the map as a new 'layer' on the GIS to show health care services and RHD cases within the district. The identification of 'RHD hotspots' will enable targeted interventions in specific geographic areas. All information gathered by GIS mapping is shared with the local community and the local council, so that they can put this knowledge to use in other projects.

### Challenges

The programme faces challenges on two levels: national and local. A major national barrier is the minimal existing data on RHD incidence and prevalence, which challenges the programme's desired data-informed approach. RHD is not notifiable in Tanzania (i.e. officially recorded and reported whenever diagnosed at a health centre), nor is it one of the indicators tracked on death certificates. Even less is known about the incidence of RHD in pregnant women, as the cause of cardiac deaths in these cases is particularly difficult to determine.

There has been limited epidemiological surveillance, and no large-scale formalized prevention and control programmes in Tanzania to date. However, small screening programmes have been done by other NGOs and data reviews have been carried out by Tanzanian postgraduate students. The so-called 'grey literature' produced by these students is encouraging: other countries struggling from a lack of local knowledge are encouraged to use their students to carry out similar research.

Although still in its preliminary stages, Sengerema's RHD programme has already met and overcome local challenges. Prior to collecting local data as part of the programme's Needs Assessment, staff anticipated language barriers: many members of the Sengerema community speak a local tribal language with only varying use of KiSwahili and English. Therefore, the programme ensured that one data collector on each team was able to speak the local language in addition to KiSwahili and English. RHD programmes operating in similarly diverse linguistic settings should also anticipate the extra resources needed for translation obstacles.

A second, unavoidable local challenge was collecting data during planting season. The population of Sengerema is agricultural; during planting time, people typically work on their family's plot of land, which can be a day's walk away from the family home. This made finding subjects for interview difficult for data collectors, who often had to make repeat visits to a single home. Future RHD programmes in agricultural sites would benefit from taking seasonal practices into account during the planning process.

### Achievements

Though only in its first year, the programme has built a strong coalition of local and national partners to ensure engagement and enhance the sustainability of the integration process. The Needs Assessment is almost complete, which will give insight into health-seeking behaviour among Sengerema's population among other data. The findings of this assessment will be shared with all stakeholders, including the communities who participated in the assessment. This inclusive approach seeks to foster community engagement and ownership for future RHD interventions.

*A ward in Sengerema District Hospital*



### Moving forward

The next steps of the programme are to conclude and disseminate the findings of the Needs Assessment exercise to all stakeholders (including the communities who contributed to the exercise) in order to share knowledge and gain input into the design of the programme. Then, after the programme design has been modified according to the Assessment's results, Dr Stafford and her team will be able to undertake the first steps of implementation in mid-2016.

## South Africa

*Dr Liesl Zühlke, Paediatric Cardiologist, Red Cross Children's Hospital and Groote Schuur Hospital and University of Cape Town; Co-Director, RhEACH*

### Introduction

South Africa has a high burden of rheumatic heart disease, with a study from Soweto determining new cases of RHD to be 23.5 cases per 100,000 people in that region,<sup>71</sup> but also one of the highest concentrations of pioneers in the RHD field. South Africa has been the seat of many recent advances in RHD, from the Drakensberg Declaration (2005) to the launching of the REMEDY study (2015). Work to prevent and control RHD in South Africa falls under its ASAP programme, which contains many specialized streams, including work on surveillance, research and advocacy.

The ethos that drives South Africa's ASAP programme is one of collaboration, especially South-South cooperation and capacity building. Shared methods of work ('joint protocols') have been developed in South Africa and implemented in Ethiopia and Zambia, with hands-on support from the South African team given through site visits and training activities. Likewise, the ASAP programme model and the REMEDY study were developed in South Africa with an eye to implementation and adoption across the continent, with active support from the programme's hub in Cape Town.

### About the programme

The ASAP programme model was developed in South Africa following the Drakensberg Declaration (2005), which was initiated by the Pan-African Society of Cardiology (PASCAR). The ASAP programme has four pillars, all of which are key to comprehensive RHD prevention and control: Awareness, Surveillance, Advocacy and Prevention. South Africa has been a key national implementer of the programme since its inception, and has incorporated several streams of work within it, including:

#### 1. Vanguard Population Demonstration Project

This project centres around a surveillance study, which was launched in 2008 following the donation of a mobile clinic. The site that was chosen for surveillance is located approximately 10km outside of Cape Town city centre and has a population of approximately 100,000 people, most of whom fit into two diverse socio-economic strata. From 2008-2014, a team consisting of two echo technologists and a field site coordinator screened 2,720 schoolchildren for RHD, using a mutual methodology that was shared between Cape Town and Jimma, Ethiopia.<sup>72</sup>

Another instance of South-South cooperation within this project is the focused hand-held echocardiography study, which tested a shortened method adapted from existing screening criteria. This new, concise method – which takes 1-2 minutes to carry out – has been validated by the project and has been shared with practitioners in Zambia, who are now using it to carry out larger-scale screening.<sup>73</sup>

The project is committed to meaningful follow-up of the children screened in this surveillance study. Many 'long-term' follow-ups of similar studies track the outcomes of patients for up to two years, but this only gives limited information as the children are not tracked into young adulthood, which is typically when symptoms and complications of RHD arise.

To avoid this, the Vanguard Population Demonstration Project tracked children for five years, following the progress of many into adulthood. These findings have provided insight into screening practices and suggest that those diagnosed via echo should be followed up for at least 5 years. They will also help inform whether surveillance projects are cost-effective and have changed the long-term health outcomes for those with valve problems detected during screening echos.<sup>74</sup>

#### 2. The Global Rheumatic Heart Disease Registry (REMEDY)

South Africa developed and coordinated the multicentre REMEDY study, which involved 25 centres and 14 low- and middle-income countries.<sup>32</sup> REMEDY has led to two other major collaborations: RHDGen an African consortium involved in understanding the importance of genetics to RHD, and INVICTUS, a registry platform that is running trials which aim to include over 30,000 patients across all continents.

#### 3. Rheumatic Fever Week

South Africa's Ministry of Health has allocated the first week of every August as Rheumatic Fever Week, which puts a spotlight on rheumatic fever and RHD across the country. Advocacy efforts around Rheumatic Fever Week are largely led by people living with RHD themselves. Across the year, the South African programme will also consult a newly formed Community Advisory Group, which was initiated by individuals living with RHD and also includes members of the scientific RHD community. The aim of the Community Advisory Group is to provide a platform for liaison and support, both patient-to-patient and between patients and scientists.

The Community Advisory Group, along with Rheumatic Fever Week, empowers people living with RHD to engage with the ASAP programme actively, rather than in the more passive role of survey subject. These give people living with RHD a meaningful voice and platform to take ownership over their disease and encourages them to participate in decision-making that will impact their quality of life.

### Challenges

Rheumatic heart disease remains hugely expensive for South Africa's health system. A prosthetic heart valve can cost around 50,000 Rand (approximately USD 3,300) with costs of the replacement procedure as much as 500 000 Rand (approximately USD 33,000). The need for such complex and expensive surgery remains high: newly presented cases of established RHD comprised almost 10% of the burden of new admissions at a tertiary centre in Soweto.<sup>75</sup>

These high costs are being borne by a country which continues to struggle with high levels of economic inequality.<sup>76</sup> The programme is facing this challenge head on, for example by choosing demonstration and surveillance sites that cover diverse socio-economic populations.

### Achievements

Thanks to advocacy and input from those involved in its ASAP programme, South Africa has a national guideline for RHD prevention – the first on the African continent.<sup>34</sup> Rheumatic fever has also been made a notifiable condition across the country, which means that health workers must alert the government's health authorities about the prevalence of the disease.

South Africa has also published the first cost-effectiveness information regarding primary prevention using real data from local clinics, which indicates that the amount of money saved per rheumatic fever episode prevented in South Africa is USD 46.<sup>34</sup>

### Moving forward

The ASAP programme continues apace in South Africa, with each of the four pillars served by a programmatic area. The programme's strong record of surveillance projects continues with INVICTUS, which is the most ambitious RHD registry project launched to date. South Africa is also moving ahead in terms of research through the RHDGen project, which is studying the genetic makeup of people living with RHD, in order to identify people at high risk of developing RHD so that they may be prioritised for preventive treatment.

Advocacy for people living with RHD is another priority for the future. The South African programme has a good track record of including and empowering these communities: for example, the findings of the REMEDY study and RHDGen are being communicated to participants living with RHD before being released to the wider scientific community.

Patient advocacy will be a central theme during 2016's annual congress of the South African Heart Association in Cape Town. A consortium of RHD organizations, including RHD Action, will invite 150 people living with RHD to join the congress for a morning of mobilization and advocacy, providing a venue for people living with RHD to better understand and manage their disease, network with their peers, and strengthen their relationships with the RHD research community.

*Members of South Africa's ASAP programme enjoy a lunch with participants in REMEDY after presenting scientific findings to the group at a European Society of Cardiology meeting in August 2014*



# THE AMERICAS

## Cuba

*Dr Porfirio Nordet, Cuban Institute of Cardiology, Havana City*

### Introduction

Cuba's pioneering RHD programme formally concluded in 2002, but it is included in this report as a seminal example of a successful programme and a model for other countries. More recently, Dr Porfirio Nordet, who spearheaded the programme, contributed to a cost-effectiveness analysis which was released in 2015.<sup>77</sup> This emerging evidence helps us to make a strong case for investment in and support of RHD programmes elsewhere in the world.

### About the programme

Between 1986 and 1996, Dr Porfirio Nordet and his team carried out a comprehensive 10-year prevention programme in the Cuban province of Pinar del Rio. The programme then underwent five years of follow-up and review, before a thorough evaluation in 2002 was carried out to determine how effective the programme had been.

Pinar del Rio was chosen as the programme site as the province had one of the highest rates of rheumatic fever in Cuba, and the prevalence and severity of RHD cases often led to hospitalization and heart surgery.

The objective of the programme was clear: to reduce death and disability from RHD and its complications. To achieve this objective, the team developed and implemented a practical RHD strategy, and later evaluated the cost-effectiveness and benefits of the methods used.

The programme included all five- to 25-year olds with permanent residence in Pinar del Rio from 1986-1996. To start with, a permanent provincial rheumatic fever/RHD register was established, which captured data on diagnosis, registration, follow-up, and secondary prevention using penicillin.

A large part of the programme revolved around the training of healthcare and educational personnel. A group of trained doctors and RHD programme leaders conducted seminars and further education courses in local hospitals and primary health care units. Supported by educational brochures and posters, the training activity topics included:

- Early detection and correct treatment of sore throats
- The importance of early detection and effective treatment,
- Follow-up and secondary prevention of rheumatic fever and RHD
- Encouraging people to adhere to penicillin, and
- The prevention of adverse reactions and infectious endocarditis (inflammation of the heart).

These training activities were supported by educational brochures and posters.

More general education was provided to the population through schools, the local media, and face-to-face interviews with people living with RHD. These activities raised awareness of:

- Aspects of rheumatic fever and RHD prevention
- Correct diagnosis and treatment of sore throats and strep throats, and
- Adherence to secondary prevention for people living with rheumatic fever and RHD.

During the 10-year period of 1986-1996, the programme maintained permanent surveillance of rheumatic fever and RHD morbidity and mortality, the work of the register centres, the activities of healthcare and educational units, and compliance with the operational plan.<sup>2</sup>

The project was designed as a service-oriented plan to be implemented through the primary healthcare structure and facilities of the national health system, in collaboration with the education system. The project was supported by the Pinar del Rio Province Direction of Health, the Pinar del Rio teaching hospital and also involved local hospitals of the province, with direct participation of primary healthcare units and family doctors. The Cuban Institute of Cardiology and the World Health Organization provided technical support.<sup>78</sup>

### Challenges

While the programme was supported by dedicated RHD officers, local representatives and medical professionals, it was felt that family physicians (general practitioners) could have played a greater role in the programme.

### Achievements

Overall, there was a progressive decline in both the number and severity of RHD cases in Cuba. While in 1986, there was a prevalence of 2.27 out of 1,000 children with RHD, by 1996 the chance of a school child developing RHD was only 0.24 out of 1,000 – more than ten times lower.<sup>2</sup>

Moreover, over the course of the decade, fewer cases of severe RHD were reported and fewer cases involved complications such as carditis (inflammation of the heart). The number of patients requiring surgery for advanced RHD fell, in part due to rates of adherence to penicillin nearly doubling.<sup>2</sup>

Perhaps the biggest achievement of Dr Nordet's RHD programme was its sustainability. Five years after the programme closed, most of the measures that it had initiated were still in place, and Pinar del Rio's burden of RHD remains low.

### Moving forward

The Pinar del Rio programme was the first ever population-based strategy for RHD to have its cost-effectiveness comprehensively analysed. The findings of this analysis should help to guide RHD programmatic work going forward and acts as proof that RHD programmes can save money, as well as lives.

The study looked at the outcomes of the children aged 15-25 who participated in the programme, and estimated their cost on the health system if the programme had not been established. In terms of human cost, the Cuban programme was shown to have preserved 5,051 years that would otherwise have been lost to disability and death from among the 5-25-year-olds.<sup>77</sup>

In terms of financial cost, the programme prevented people living with RHD from needing advanced medical and surgical care, so was deemed 100% cost effective. Indeed, due to the expense of advanced RHD treatment, the programme also had an 85% chance of being cost-saving.<sup>77</sup>

The positive findings of the cost-effectiveness study should motivate current RHD work going forward, as well as stimulating investment in resources and political will from those with the power to support these programmes. Dr Nordet is available for further information on the Pinar del Rio project implementation and outcomes, as well as more general procedures on how to action an RHD project or programme protocol. Please contact [info@rhdaction.org](mailto:info@rhdaction.org) to pursue this opportunity.



## Canada

*Janet Gordon, Chief Operating Officer of the Sioux Lookout First Nations Health Authority, Ontario*

### Introduction

Rheumatic heart disease was largely eliminated from Canada over the course of the 20th century. However, the disease still remains a lethal problem for Canada's First Nations peoples. For First Nations people living in Sioux Lookout area, the likelihood of contracting rheumatic fever (which can develop into RHD) is 75 times greater than the non-Indigenous Canadian population.<sup>79</sup>

Sioux Lookout area is home to approximately 25,000 First Nations people living in 31 rural and remote communities dispersed over a geographic area the size of France. From the time of the first treaty negotiations between First Nations and the settlers of Canada, provision of health care for designated First Nations has been the responsibility of the government of Canada. In contrast, health care provision for all other Canadian residents falls to respective provincial governments. Jurisdictional wrangling between federal and provincial governments has led to a fragmented health care system for First Nations communities resulting in inadequate primary care services and limited public health infrastructure. This is further compounded by the fact that 26 of the Sioux Lookout area First Nations are only accessible by aeroplane for 10 months of the year.

Frontline health care in Sioux Lookout area is provided primarily by nursing stations staffed 24/7 by community health nurses. Physicians visit communities for five to 20 days a month depending on community size. Some communities have infrastructure to support x-ray equipment however all lab specimens must be flown to the local referral hospital and patients must leave the community for any other diagnostic imaging. In general, the communities experience a disproportionately high burden of health issues.

In 2015, an ad-hoc Acute Rheumatic Fever Working Group was established to examine emerging cases of RF and RHD, given the lack of a formal RHD programme in the area. Janet Gordon, who is the Chief Operating Officer of the Sioux Lookout First Nations Health Authority, is looking at ways to establish an effective control programme for the people in her communities.

*Part of an English-language version of a poster used to educate people about the progression of RHD in Cuba during implementation of the programme*

## About the programme

Following reports of the deaths of two children from rheumatic fever in two of the Sioux Lookout area First Nations communities, one of the first tasks of the Working Group was to understand the epidemiology of rheumatic fever in the region. Due to limited infrastructure for public health surveillance, case finding was largely by word of mouth. Each case was assessed to determine whether it met the Jones criteria (guidelines used to diagnose rheumatic fever and RHD) and other risk factor information was collected.

Subsequently, the Working Group sought to ensure that cases received appropriate follow-up investigations and secondary prevention to stop the patients' health from worsening. Access to penicillin had to be negotiated with the federally-run benefits programme for First Nations people in Canada. Referral to specialists at tertiary centres (e.g. hospitals) for assessment for RHD was ensured.

A large initial focus of the Working Group was education on rheumatic fever for health care providers and communities. Given the general absence of newly presenting cases of rheumatic fever in Canada, most health care providers were unaware of the clinical presentation and diagnostic information required. Education sessions were held with both physicians and community health nurses. A new practice guideline was established for the frontline community health nurses for the assessment and management of sore throats. In addition, a referral pathway for newly identified cases was established to ensure that cases were also assessed by clinicians more familiar with rheumatic fever.

## Challenges

Surveillance for rheumatic fever and rheumatic heart disease remains a significant challenge in Sioux Lookout area. Rheumatic fever is not 'reportable' in the province of Ontario and identification of cases remains reliant on clinician diagnosis. This means that cases might easily go unrecognized, and the country's burden of disease is likely to be underestimated.

In addition, treatment and secondary prophylaxis is provided by the Canadian government through the Non-Insured Health Benefits programme, available to eligible registered First Nations and Inuit people in Canada.<sup>80</sup> Eligibility is determined by Canada's controversial Indian Act and registration is not always possible for people at risk of RHD, due to administrative and cultural hurdles.

Furthermore, there is high turnover of health care providers in the region, which poses a challenge to ongoing education efforts.

## Achievements

Local advocates, including local and regional Chiefs of First Nations communities, are using social media and online platforms to spread awareness of RF and RHD among First Nations people.

The ad-hoc Acute Rheumatic Fever Working Group has been successful in expediting the lengthy administrative process for people with rheumatic fever and RHD to access their rightful health insurance benefits.

Local physicians have also successfully advocated for penicillin to be re-established on the basic medicines list for the Non-Insured Health Benefits programme.

## Moving forward

Janet Gordon recognises that there is an immediate need to establish surveillance systems, such as registries, to detect and diagnose RHD in the Sioux Lookout region and monitor trends. She is also calling for Ontario to add rheumatic fever to its list of regionally reportable diseases. Meanwhile, she and her colleagues are also advocating for consistent education protocols, so that health workers and communities can be aware of RHD and how best to prevent it.

Janet knows that simply monitoring RF and RHD in the region will not decrease the burden of disease. For the people of First Nations communities in the Sioux Lookout area, the primordial causes of RHD need to be addressed, in particular poor housing. First Nations people living on a reserve have the highest rates of overcrowding in Canada and are four times more likely to live in homes that require major repairs.<sup>79</sup> These issues, which lie outside the health system, will need to be tackled via housing improvement strategies.

Sioux Lookout area, Ontario, Canada  
(Photo credit: J Hazard/Wikimedia Commons)



## Brazil

*Dr Bruno R. Nascimento, Director, PROVAR (Programa de Rastreamento da VALvopatia Reumática), Rheumatic Heart Disease Screening Programme*

*Dr Antonio L. P. Ribeiro, Senior Advisor, Hospital das Clínicas, Telehealth Center, Universidade Federal de Minas Gerais, Belo Horizonte, Minas Gerais*

## Introduction

RHD has been shown to exert a substantial burden on the health system of Brazil, despite it being an upper-middle income country. Notwithstanding recent economic growth, Brazil still suffers from socio-economic conditions that are known to be risk factors of RHD, such as overcrowding, poverty, poor sanitation, limited access to medical care and high levels of income disparity.

A retrospective review of the Public Health System Database showed that RHD was responsible for over 60% of adult heart valve surgery in Salvador, Brazil.<sup>81</sup> In 2013 the Brazilian Public Health System reported 5,169 hospitalizations related to rheumatic fever, and 8,841 related to chronic RHD, at a cost of USD 33 million, mostly related to cardiovascular surgeries.<sup>82</sup>

However there are limited data on the prevalence of latent RHD in Brazil and other Latin American countries. Lower socio-economic regions in Brazil meet criteria for echocardiography screening of RHD, given the high burden of advanced RHD and ready access to penicillin prevention methods. To tackle this challenge, a multinational team with a strong track record in implementing echocardiography screening formed the PROVAR programme to: determine the burden of RHD in the Brazilian state of Minas Gerais, provide follow-up for positive RHD cases, educate children about RHD, and validate innovative approaches (including task-shifting and telemedicine) to make echocardiography screening more practical.

## About the programme

The PROVAR (*Programa de Rastreamento da VALvopatia Reumática*) programme is a collaboration between the Universidade Federal de Minas Gerais, the Telehealth Network of Minas Gerais<sup>83</sup> and Children's National Health System, Washington DC, USA. The Verizon Foundation funded the first three years of the programme. Joint development of the programme started in 2013, with the creation of action plans, timelines, regulatory steps and grant submission.

From 2013-2016 the programme has focused on echocardiographic ('echo') screening of schoolchildren, which is performed by non-physicians supported remotely by experts in Brazil and the US who participate via telecommunications technology (this is known as 'telemedicine').

PROVAR field activities have been conducted in Brazilian primary and secondary schoolchildren since October 2014 at various locations in Minas Gerais, the second most populous Brazilian state, located in the southeast of the country. Schools in the low-income areas of metropolitan Belo Horizonte (capital of Minas Gerais) and Montes Claros and Bocaiúva (poorer areas in the north of the state) were

School children from Minas Gerais who have received RHD education and echo screening through the PROVAR programme



consecutively selected based on socio-economic data (e.g. the Human Development Index and local indicators of health vulnerability) under the advice of local regulatory authorities.

Non-physicians (two nurse research coordinators, one biomedical technician, and one imaging technician) were trained to acquire and interpret echocardiographic images. Training consisted of a combination of an online RHD educational course provided by WiRED International and translated into Portuguese, as well as 4-12 weeks of hands-on training supervised by cardiologists in the University's Echocardiography Lab.

After initial meetings between the research team and school authorities, school-wide RHD education was provided to all students, teachers, and staff prior to echo screening. An educational curriculum that includes age-targeted slides and tablet-based modules was delivered to the children. Education was reinforced by posters and printed brochures with information about RHD: causes, consequences, diagnosis, importance of identifying and treating sore throats and secondary prevention. These were directed to children, school workers and families.

A simplified echo screening protocol (using World Heart Federation's 2012 diagnostic criteria) is being performed on children that have participated in the educational curriculum. Acquired images are uploaded to cloud computing solutions with image viewing, measurement, and reporting capabilities. The non-physician scanners flag abnormal cases, which are prioritized for reading. Images are uploaded on a weekly basis and analyzed via telemedicine by cardiologists in Brazil and the United States. Positive cases (as defined by criteria set by the World Heart Federation) are referred to the Hospital das Clínicas for follow-up echo performed by expert paediatric cardiologists with experience in RHD imaging and clinical appointments. When recommended (for all definite and selected borderline cases) secondary prevention with penicillin is initiated.

Whenever necessary, the Hospital das Clínicas – a public educational institution linked to the biggest Federal university of Brazil – provides tertiary clinical care including, if needed, surgical interventions for management of advanced RHD. The hospital, which has more than 450 beds, has marked experience in cardiology, paediatric cardiology, cardiovascular imaging and interventional cardiology. There are also anticoagulation hubs to serve patients requiring long-term use of blood-thinning medication for their heart condition. The integration of RHD services with specialized care is a key feature of the PROVAR programme.

## Challenges

To achieve its goals, the programme had to overcome several barriers, from regulatory to operational aspects. Several meetings were held with educational and health authorities from different levels of the government to explain the importance and potential benefit of the project, and gather support.

Training non-physicians was another challenge, since it is unusual to have non-medical personnel acquiring ultrasound images in Brazil. In an ancillary study, we showed that non-medical personnel could accurately detect subclinical RHD by the echocardiogram, showing that the training used was effective.<sup>84</sup> Finally, we had to deal with several telemedicine issues, from the absence of adequate Internet bandwidth in schools to connect to the cloud server, the need for several steps to make images available for remote analysis, and diligent attention to record-keeping while not violating confidential patient health information.

## Achievements

Since 2014, 29 schools have been included in the *PROVAR* programme (23 in Belo Horizonte and 6 in Montes Claros/Bocaiúva), and the educational curriculum was delivered to more than 19,000 children. More than 7,000 screening echos were performed by non-experts and interpreted through telemedicine. Two cloud computing systems (Lifelimage™ and ViTel Net™) have been developed in the USA and implemented for remote interpretation of images, and are fully operative. Computer-based educational modules were successfully applied for training of scanners and more recently for the education of children using tablet devices.

In their most recent interim analysis of 5,996 children performed in January 2016, the overall RHD prevalence was 3.7% for borderline cases and 0.5% for definite cases. Additionally, congenital heart disease was found in 0.7% of the individuals. All positive cases were systematically referred for long-term clinical and echocardiographic follow-up, and secondary prevention with penicillin was prescribed for all definite cases.

The programme now has full support from the State Board of Education and Health, and the City Boards of Education, and is part of the Telehealth network in Minas Gerais. Primary care centres (two on each site) have been pre-selected for participation in the current phase of the programme – education and screening in primary care.

*A panoramic view of Belo Horizonte, Minas Gerais, South-Eastern Brazil (Photo credit: LucioFlavio/Wikimedia Commons)*

## Moving forward

From year three of the *PROVAR* programme, we have been integrating RHD screening into primary care, in addition to our continuing school-based strategy. We are piloting a project that incorporates health worker and community education, primary prevention awareness and echocardiographic screening into the existing Family Practice programme in Brazil.

The programme will be based in primary care centers located in socially vulnerable neighbourhoods. Healthcare workers will receive continuing education on RHD, and local health agents will be trained to educate the surrounding population and spread public awareness on the disease, using online and conventional modules.

Age-targeted echo screening will be performed, and health workers will perform active case search and referral. The existing infrastructure of the Federal University will provide follow-up and specialized care for children with RHD, including family counselling. The goal is to establish a sustainable ‘diagonal’ approach to be evaluated for future integration into public health policies. Additional regulatory and operational procedures are being designed for the implementation of this strategy.

Drs Nascimento and Ribeiro would like to acknowledge Dr Craig Sable and Dr Andrea Beaton from the Children’s National Health System for their outstanding support and collaboration in all phases of the *PROVAR* programme. This case study was written on behalf of all *PROVAR* investigators in Brazil and in the US.

# ASIA

## Nepal

*Dr Prakash R. Regmi, Executive Director of the National RHD Prevention and Control Programme; Programme Director and Past President of Nepal Heart Foundation*

### Introduction

Dr Prakash Regmi of the Nepal Heart Foundation, has been collaborating with the Nepalese government to prevent RHD since 2008. Nepal’s *National RHD Prevention and Control Programme* is a useful model of widespread efforts taking place across an entire country. It offers an example of good integration and sustainability as the programme fits disease-specific RHD interventions within broader efforts to strengthen Nepal’s health system using a ‘diagonal’ approach.

### About the programme

The main focus of the programme is secondary prevention, i.e. making sure that the health of people with existing rheumatic fever or RHD is well managed and does not deteriorate. This involves seeking out people with undiagnosed RHD. In Nepal, Dr Prakash Regmi and his team screen 10,000 school children per year. Those who are given a confirmed diagnosis of RHD are entered into a registry.

Thirty-eight participating hospitals throughout the country keep paper records of rheumatic fever and RHD patients, while a central computerised database is maintained in Kathmandu to compile regional data. Nepal’s central registry contains the data of some 11,000 RHD patients from across the whole country.

Patients receiving penicillin as part of their secondary prevention programme are given a ‘penicillin card’ to chart their injection histories. BPG is procured by the Nepal Heart Foundation for the whole country; there is a six-month emergency supply stockpiled to prevent shortages.

The *National RHD Prevention and Control Programme* is entirely integrated with the health system of the government. This means that staff working in hospitals are also trained to work for the programme, for example in administering BPG injections. This ‘diagonal’ approach means that resources that already exist within the health system are maximised, reducing the need to create more jobs or train health workers from scratch.

The programme’s awareness campaign aims to emphasize the fact that sore throats can lead to rheumatic fever, and later RHD. To get the message across, the programme has:

- Developed a formal class for teachers and an annual training scheme for community health workers, structured around four presentations over half a day
- Integrated RHD into the national school curriculum in partnership with the Ministry of Education
- Placed large billboards in public places, showing the link between sore throat and RHD (inspired by a previous survey that indicated 97% of a recently surveyed Nepalese community were unaware of this link)

- Scheduled daily advertisements on morning radio, and
- Released a professional documentary, which has been aired more than 50 times on national television.

Monitoring and evaluation of the programme is carried out by volunteers of Nepal Heart Foundation, who are active across the 75 districts of Nepal. These volunteers monitor BPG supply and the state of the registry. Volunteers and experts are also used to conduct training of community health workers, which often involves extensive travel to provide training on-site.

### Challenges

The Nepal earthquake of 2015 left the country and its health system in extreme distress. Many hospitals and health centres were destroyed by the earthquake and many people living with RHD were unable to access penicillin for a month. The National RHD Prevention and Control Programme quickly adapted its model to address this challenge. It visited children living in temporary shelters to screen them for sore throats, as the cold temperature, inadequate living conditions and poor nutrition posed a high risk of rheumatic fever and rheumatic heart disease.

Three thousand children were screened across seven affected districts, and it was found that 10-15% of these children had signs of a bacterial throat infection that might lead to RHD. The programme treated these children with antibiotics, potentially saving many lives.

Political challenges have also threatened the progress of Nepal’s programme. Although Nepal has a strong six-month emergency stock of BPG, it does not manufacture the drug within the country but instead imports it from India. In 2015, disturbances at the Nepal-India border resulted in significant problems accessing penicillin from across the border.

For four months, Nepal was unable to procure BPG from its usual suppliers and had to resort to oral penicillin manufactured domestically to control RHD, despite this being less effective. Oral penicillin was used for two to three months; during this time, several RHD patients were reported to have a dangerous recurrence of rheumatic fever.

Nepal’s situation has since stabilized. But though the programme is operational and active across the country, it has not yet been able to go beneath the district level. This means that people often have to make long journeys across their districts to seek BPG injections and medical appointments on a regular basis – some have to walk a whole day to seek basic care. Dr Prakash Regmi and his team have hopes of decentralizing the programme further, to the community health workforce level, but the government is currently unable to fund this.

## Achievements

Nepal Heart Foundation's RHD registry maintains the data of 11,000 people living with RHD. Survey was done in central Nepal to evaluate the impact of National RF/RHD control programme. It was observed that the prevalence of RHD has declined dramatically, from 1.35 to 0.8 cases per 1,000 children aged 5-16 years. Hospital admissions for RHD have also decreased, as has the need for advanced surgery to repair damaged heart valves.

The educational aspect of the programme is very strong: the half-day community health worker training package designed by the Nepal Heart Foundation is now included in the national NCD training curriculum, which is conducted through a national health training centre and endorsed by the government. To date, around 1,000 community health workers have received this training, as have around 150 newly qualified medical officers.

With funding from the Australian government's Direct Aid Programme, Dr Prakash Regmi and his team conducted screening of 15,000 school children across seven districts in March 2016, seeking out children with sore throats, rheumatic fever and RHD. Thanks to Nepal's commitment to universal health coverage (UHC), the children diagnosed with rheumatic fever or RHD will not see their disease impoverish their families.

Medicines for primary prevention of RHD are free of charge to citizens living in the villages, and BPG for secondary prevention is also freely available from all 38 hospitals that participate in the programme. Even tertiary interventions such as surgery are free of cost to most users, due to the advocacy of the Nepal Heart Foundation and financial support of the Ministry of Health.

The Nepal Heart Network, a consortium of 19 heart NGOs, helps to advocate for resources and attention to be given to the national RHD programme. This unified approach is a good model for programmes working in countries where the civil society voice is strong and governments are receptive to lobbying.

There is also an official Implementing Committee for the national programme, which includes members from many sectors and professions. This has enabled the 'diagonal' approach to integrating a programme into the existing health system, rather than remaining separate and disease-focused, which is an example of good practice for all well-established RHD programmes.



RHD awareness billboards have been established in public places to show the links between sore throats, rheumatic fever and rheumatic heart disease

## Moving forward

According to Dr Prakash Regmi, RHD will continue to be Nepal Heart Foundation's first priority over the coming years. The organization's network has recently expanded from 65 districts to include all 75 districts of Nepal.

Now that scale-up of secondary prevention for RHD has been achieved, the programme is taking a more comprehensive approach and turning its attention to primary prevention, i.e. making sure people never develop RHD in the first place. Nepal is mid-way through a 3-year project (supported by Rotary International and the District Public Health Office) to screen children age 5-15 for sore throats and place symptomatic individuals into a sore throat registry.

These children will then be treated with one of two oral antibiotics (Amoxicillin and Azithromycin), to test their efficacy, as the WHO recommendations of BPG via injection are not always possible in Nepal, especially for sore throats only. Paramedics, who are responsible for delivering most of Nepal's health care needs, have historically been very reluctant to administer penicillin injections for primary and secondary prevention. This is because of the small risk of adverse health consequences such as anaphylaxis, which occur in very few people receiving BPG to control their disease.

The Nepal Heart Foundation has surmounted this challenge by providing bespoke paramedic training on this issue. The training was so effective that, after completion of the course, more than 90% of previously unwilling paramedics agreed to administer BPG injections.<sup>85</sup> It is now trialling these oral antibiotic drugs as part of a primary prevention pilot, combining practical RHD interventions with research.

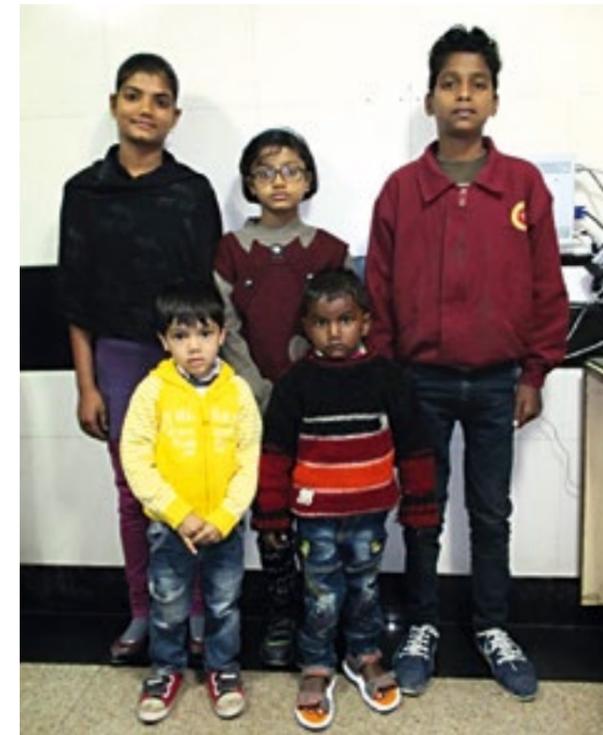


A health worker managing a busy caseload as part of the decentralized national RHD programme

## India

*Professor Anita Saxena, Professor of Cardiology, All India Institute of Medical Sciences, New Delhi, India*

*Dr R. Krishna Kumar, Professor and Head of Paediatric Cardiology, Amrita Institute of Medical Sciences*



Children and youth with RHD being treated at the All India Institute of Medical Sciences, New Delhi

### Introduction

India is the second most populous country in the world, according to the World Bank, with a population of around 1.3 billion.<sup>48</sup> Some researchers estimate that there are 2-2.5 million people living with RHD in India: more than any other country in the world.<sup>86</sup> Although India is a regional centre of cardiovascular expertise in Asia, it continues to struggle with RHD prevention and control. The country's health workers are increasingly overwhelmed by other heart diseases, including congenital heart disease and also coronary artery disease, which has acquired the status of an epidemic.

Consequently, RHD has been deprioritized to the point of neglect, especially as communities with high RHD burdens are often far from the urban centres in which many cardiologists and health workers practice. The *National Rheumatic Heart Consortium* was founded in 2012 to meet the need for a concerted effort towards RHD prevention and control in India.

### About the programme

The *National Rheumatic Heart Consortium* convenes a diverse group of professionals who are committed to the RHD cause in India. Members include caregivers, public health experts, cardiologists, and represent different regions of the vast country. Anita Saxena is President and R. Krishna Kumar is Vice President of the *Consortium*.

The *National Rheumatic Heart Consortium's* work is carried out over and between a succession of meetings. The first meetings in 2012 and 2013 commissioned and reviewed various screening studies, which were carried out among school children from various sites across the country. The meetings also concluded that for people in India with advanced RHD requiring surgery, valve repairs should be encouraged over valve replacements. This is because people who have been fitted with mechanical heart valves need to take follow-up medication for the rest of their life to prevent strokes or other cardiac events – and this proves difficult in India.

The third meeting of the *Consortium*, held in late 2014, set an ambitious agenda for work that is continuing today. It has identified the Indian states that rank lowest on the Human Development Index as RHD 'hot spots' requiring special and immediate attention; these include: Bihar, Uttar Pradesh, Chhattisgarh and Jharkhand.

The agreed programme of work also included awareness-raising among teachers, parents, health workers and the general public, especially around the connection between sore throats and RHD. This was due to be carried out in collaboration with village health workers and NGOs, with support from professional organizations such as the Indian Academy of Paediatrics and the Indian Medical Association.

For Indian health workers treating RHD on the frontline, the *Consortium* acknowledged the potential for allergic reactions to injectable penicillin and decided to prepare a handbook containing guidelines for safe delivery of injectable BPG. It also decided to formulate guidelines for monitoring the health of post-operative patients who have been fitted with mechanical heart valves following advanced RHD.

### Challenges

RHD prevention and control in India suffers from misconceptions shared by the general public (and even some health professionals) that RHD is declining, so should no longer be treated as a public health priority.<sup>87</sup> Moreover, there is a lack of data on the burden of RHD in India's poorly served rural populations, urban slums and tribal communities, which means that it is difficult to see the 'whole picture' of RHD prevalence in the country.<sup>88</sup>

There is a concerning lack of national RHD policy in India: neither rheumatic fever nor RHD are notifiable diseases, so the government's Ministry of Health is not presented with timely data about new cases affecting the population. Perhaps because there is little concrete policy to engage around, stakeholders in India (including civil society and government representatives, NGOs and professional groups) have previously struggled to convene and participate in RHD work as a unified entity.<sup>87</sup> The *National Rheumatic Heart Consortium* is working to overcome these challenges by presenting a united advocacy, policy and technical force that is representative of the whole country.

## Achievements

The *National Rheumatic Heart Consortium* has had some success in convening a coherent and comprehensive platform for people to discuss and tackle RHD in India. Meetings of the *Consortium* have been inclusive and regionally representative. The landmark third meeting in 2014 was almost certainly the first time participants from diverse disciplines across India gathered for a full 2-day brainstorming session to develop an action plan for the future. The meeting organizers also reached out to colleagues from organizations outside of India, including the World Heart Federation and the Nepal Heart Foundation, so that India's strategy could learn from and inform international work on RHD.

Currently, the *Consortium* is working closely with the government's Ministry of Health and Family Welfare to develop training manuals on RHD. Separate training manuals are being prepared for medical officers, alternative/traditional medicine practitioners, and other front line health workers, both at the district and village level.

## Timor-Leste

*Dr Josh Francis, Paediatric Infectious Diseases Specialist, Royal Darwin Hospital, Menzies School of Health Research, Bairo Pite Clinic*

### Introduction

Timor-Leste is listed by the UN as the poorest country in Asia, with approximately 40% of the population currently living below the poverty line.<sup>89</sup> The burden of RHD in Timor-Leste has not yet been measured, but this is clearly a disease that the island's fragile health system is struggling to control. Local clinicians, as well as visiting specialists, medical students and aid organizations, all report large numbers of people with severe RHD, with significant associated morbidity and mortality, including a high demand for expensive surgery and medical evacuation.<sup>90</sup>

Although Timor-Leste lacks a formalized national RHD programme, work is underway to improve prevention and control of the disease. Much of the current work is being actively supported by organizations and institutions in Australia, working collaboratively to increase awareness of the RHD burden in Timor-Leste and provide the necessary tools for delivery of effective prevention. There is a need for greater programmatic coordination, which would ideally be delivered through the Timor-Leste Ministry of Health.

### About the programme

Despite modelling data that suggests that RHD is one of the top 25 causes of years of life lost in Timor-Leste, RHD control has not been prioritised by the Ministry of Health and a formal national programme does not currently exist.<sup>91</sup> Stakeholders working on RHD in Timor-Leste – many of whom are based in Australia and include NGOs, academic institutions and professional societies – all coordinate to some extent with health providers and institutions in the country, but no single body has taken on an overarching programmatic coordination role.

The government of India is also planning to initiate interventions for rheumatic fever and RHD through existing channels of the health system, namely NCD and child health initiatives. The *National Rheumatic Heart Consortium* will provide technical input throughout this integrative work.

### Moving forward

Future plans for the *National Rheumatic Heart Consortium* include the development of evidence based guidelines for safe administration of BPG. The *Consortium* is already working with the government and industry to ensure availability of BPG injections. Oral penicillin availability is still problematic; plans are being made to address this.

The *National Rheumatic Heart Consortium* will continue to engage with *Rashtriya Bal Swasthya Karyakram*, an existing government health scheme for children up to the age of 18 years. RHD is one of the 30 diseases covered under this scheme, which provides a good opportunity for large-scale work in the future.

People may be diagnosed with RHD at one of five hospitals in the country, or at Ministry of Health-and NGO-run health clinics. Anecdotally, many people first present with advanced disease, often associated with heart failure and death. Mild cases of RHD are less frequently seen, and presentations with rheumatic fever in the absence of significant heart disease are surprisingly uncommon.

Timor-Leste's community health centres and village-level health posts are staffed with healthcare workers with variable levels of education and training. As such, knowledge regarding the diagnosis and management of rheumatic fever and RHD is limited in many parts of the country.

In Dili, the country's capital, physicians and paediatricians at the Hospital Nacional Guido Valadares frequently diagnose cases of severe RHD. BPG is usually available within the hospital, but stockouts have occurred. On discharge, children with RHD are advised to attend their local community health centre to receive monthly BPG injections, but there is currently no follow-up mechanism for ensuring that this occurs. Stockouts of BPG are more common in smaller clinics, and in some cases secondary prevention measures are not provided even if patients and their families seek them out.

One prominent NGO healthcare institution in Timor-Leste is Bairo Pite Clinic, based in Dili. The clinic has a small registry of people living with RHD, who attend the clinic regularly for BPG injections for secondary prevention, though national stockouts of BPG have compromised the programme at times. Local clinic staff receive regular training and education relevant to the diagnosis of rheumatic fever, as well as primary and secondary prevention strategies for halting the progress of RHD. Bairo Pite Clinic works cooperatively with the Timor-Leste Ministry of Health and also has close relationships with international stakeholders working on RHD in Timor-Leste, including East Timor Hearts Fund and the Menzies School of Health Research.

The East Timor Hearts Fund is an Australian NGO, which seeks to address both the lack of surveillance and lack of surgical capacity in Timor-Leste. Using its existing relationships with Bairo Pite Clinic and the National Hospital, the charity aims to bring more than ten people living with RHD into Australia each year for life-saving heart surgery.

As well as evacuating patients to Australia for heart surgery, stakeholders are flying Timorese health professionals to Australia's Northern Territory for further training. Timorese paediatric trainees have been hosted by Royal Darwin Hospital for six-month rotations, where they gain first-hand experience of how successful RHD prevention and control can operate. The stark contrast between RHD services in Darwin, which operate within an established and consolidated programme, and the limited services available in Timor-Leste, motivates these physicians to implement more effective prevention and control when they return to Timor-Leste. Work has also been carried out to translate RHD Australia's English-language RHD resources into the Tetum language to help train local health workers.



*Dr Noel Bayley of the East Timor Hearts Fund performing echocardiography on a Timorese man (Photo credit: Basil Rolandsen/East Timor Hearts Fund)*

### Challenges

The impact of RHD in Timor-Leste in terms of morbidity, mortality and cost to the economy has been grossly underappreciated. In terms of development, the country is still fragile and health policy and priorities are heavily influenced by WHO (which has not historically prioritized RHD). Clinicians who are faced with the reality of the RHD burden on a daily basis are convinced of the need to act on RHD, but it has been difficult to engage key decision-makers within the Ministry of Health without verifiable national data.

Beyond RHD, there are challenges posed by Timor-Leste's fragile health system, which is stretched across many competing priorities. Rates of tuberculosis and malnutrition, for example, are among the highest in the world. According to WHO in 2013, just 1.3% of Timor-Leste's modest GDP (gross domestic product) is spent on health per year.<sup>92</sup> Limited resources may partially explain the difficulty in establishing coordinated RHD control, and even in ensuring steady supply of essential medicines like BPG.

Health-seeking behaviour also poses challenges. Rates of access are low across the country, despite the government-provided free health care.<sup>93</sup> In many cases, low access is due to geographical remoteness: some Timorese are at least a four-hour walk from their local health clinic. For RHD, these low access rates are compounded by lack of awareness about the disease's progression from a basic sore throat. There are very few people who know to make the connection between sore throats or joints and RHD and it is rare for Timorese people to seek health care for these 'minor' childhood health issues.

### Achievements

Advanced heart surgery and medical evacuation are both expensive undertakings that have the potential to decimate the Timorese national health budget. But research into the East Timor Hearts Fund has found that its working model is actually cost-effective: for every 1 dollar invested in the programme, 9 dollars are generated in benefits by adding an average of 32 years to each patient's life expectancy.<sup>94</sup> The cost-effectiveness study that informed this model will hopefully pave the way for more rigorous research on the economic as well as personal impacts of RHD in Timor-Leste.

Though the actors, national and international, working on RHD in Timor-Leste are not yet linked through a formalised national programme, they have formed several successful bilateral and multilateral partnerships. For example, RHD Action global partner RhEACH is active in Timor-Leste, working in partnership with the Menzies School of Health Research and the Telethon Kids Institute. Such partnerships are precious achievements when working to strengthen a country with a fractured and under-resourced health system, and provide proof that RHD control in Timor-Leste has the potential for greater cohesion and impact.

### Moving forward

Timor-Leste is not alone among south-east Asian countries struggling with a high burden of RHD and an inadequate national capacity for response. With the support of willing partners, significant progress is not only possible, but anticipated. For example, East Timor Hearts Fund plans to move towards provision of cardiosurgical services in Timor-Leste, using visiting missions to provide life-saving surgery to more people and to facilitate training and capacity-building of local staff.

Improved understanding of the burden of disease is desperately needed, to help the country identify public health priorities and allocate resources proportionally. In 2016 it is hoped that a collaborative team of existing stakeholders will undertake echo-based prevalence screening in Timorese schools and describe the impact of RHD within hospitals. This prevalence study would also provide a platform for a more extensive registry of people living with RHD, as a new cohort of children requiring secondary prophylaxis with BPG will be identified.

Progress towards a comprehensive RHD programme in Timor-Leste may rely on adaptation of existing resources, tools and knowledge from neighbouring programmes in Asia and the Pacific region. Whichever method is taken, Timor-Leste provides an example of a country with all the ingredients for a national RHD programme – though the end result is still a long way off.

# THE PACIFIC

## Tonga

*Dr Toakase 'Toa' Fakakovikaetau, Paediatrician, Kingdom of Tonga 'Mafu Sai' Programme*

### Introduction

'Mafu Sai' translates as 'Good Heart', (or Heart Screening And Intervention) which is what Dr Toa and her team are trying to achieve for each of the 100,000 people living on the islands of Tonga. The *Mafu Sai* programme was established in 2008, following results from a large-scale screening exercise in 2003 which unveiled that Tonga had the highest prevalence of rheumatic heart disease confirmed by echocardiography yet recorded: a shocking 33.2 cases per 1,000 children.

### About the programme

The *Mafu Sai* programme is formally recognized as part of Tongan National NCD Prevention Programme. Funding for *Mafu Sai* is secured through the Ministry of Health and it also receives some technical support from the WHO and Australia and New Zealand.

The main focus of the programme is screening and secondary prevention for the country's school children. This is a biannual project that takes place over two weeks and aims to screen 4,000-5,000 children per year. Dr Toa is supported by a team of primary health workers, and joined by experienced sonographers from New Zealand and Australia who carry out 100-150 echos per day over this period. Each of the seven primary health centres on Tonga's main island helps with this intensive process and ensures good, decentralized follow-up after screening.

Thanks to strong advocacy to the Tongan government, it is compulsory for children in their final year of primary school to be screened for RHD using echocardiography. Those children who are diagnosed with RHD are then entered into a centralised database, which currently holds 1,385 cases of RHD.

Back in 2013, 90% of all registered RHD cases were classified as 'mild'. Every child on the register, even those with mild or asymptomatic RHD, is started on monthly BPG, administered at his or her local health centre. Adherence rates are high, thanks in part to the positive social pressure and awareness-raising that comes from living in a small island community.

Historically, Tonga has spent an enormous proportion of its total healthcare budget on flying children abroad to receive surgery for RHD. Dr Toa estimates that the cost of sending one child abroad for surgery equated with the cost of the entire annual budget for RHD screening and secondary prevention. Therefore, it is more common for overseas surgeons to visit the islands.

Many resources to support the RHD programme come from outside the country. Australia is the biggest source of international support, through the bilateral aid programme that supports the overseas echo technicians to come to Tonga and participate in the biannual screening projects. WHO is the second most significant international donor, followed by New Zealand, which supports a paediatric cardiologist to undertake 10-day visits to Tonga for clinical cardiology work.

### Challenges

As with many Pacific Islands, Tonga is facing a critical shortage of healthcare workers. Dr Toa spent 8 years of her career as the country's only paediatrician, even though almost 40% of Tongan population are under 14 years old. Many Tongans who acquire health-related skills and qualifications choose to emigrate to Australia or New Zealand to seek a different life there.

While Tonga's health workforce does include an adult cardiologist, who is very supportive of the RHD programme and is able to carry out diagnostic echo screening for people living with RHD, there is no resident paediatric cardiologist in the country. This is a large challenge, as this is critical not just for treating and managing RHD, but also congenital heart disease, which can be diagnosed through screening.

### Achievements

Dr Toa's RHD programme is operating at a much larger scale than many national RHD programmes, and therefore covers a large proportion of the small country's population. There is also high-level political support for the programme from Tonga's royal family. In 2015, Her Majesty Queen Nanasipau'u made a special visit to the children's ward of Vaiola Hospital to donate equipment, furniture, and funding support to the *Mafu Sai* programme.<sup>95</sup>

Tonga has a very sustainable supply and procurement strategy for BPG, the penicillin used to prevent and control RHD. Apart from a period during 2007-8 in which some problems were reported blockages in syringes used to administer BPG, there have been no further quality issues or procurement difficulties. This translates into high levels of adherence recorded among the children in the national RHD registry.

Work so far has significantly reduced the number of children under 20 years old who are admitted to hospital with acute rheumatic fever, bacterial endocarditis, or needing valvular heart surgery.

There is positive work being done to integrate RHD interventions into other Tonga's health services. Tonga's high-quality maternal and child health services typically end when the child reaches 5 years old, then resumes during adolescence under the banner of reproductive health. Therefore, Dr Toa sees RHD interventions as an expansion of the good maternal and child health, and reproductive health services available in the country.

### Moving forward

Tonga is in great need of local trained health workers who are formally qualified to undertake echo screening. However, this training consists of a Master's degree qualification in Radiology, which is most feasibly undertaken in Australia. This means that the two local staff in Tonga who currently participate in the echo screening project need to complete both BSc degree (bachelor's degree), and then the further MSc (Master's degree) before being able to lead the project themselves. One member of staff has already completed the BSc degree in Australia and plans to continue with the MSc before returning to Tonga with the formal, recognized qualification that will allow them to conduct screening independently.

Dr Toa has hopes for a rheumatic fever vaccine in the future, but until this dream is realised her plan for the future is to continue echo screening and diagnosis. She also hopes that the young adults currently taking preventative penicillin as part of the *Mafu Sai* programme will one day help to set up a heart foundation in Tonga, to help the generations that come after them.



*Health workers conducting echocardiograms on children as part of the Mafu Sai biannual screening project*

## Australia

*Claire Boardman, Deputy Director and responsible for day to day operations of RHDAustralia*

### Introduction

Established in 2009, RHDAustralia works to support jurisdictions that currently have an RHD control programme or are working towards creating one. RHDAustralia is based at Menzies School of Health Research in Darwin, Northern Territory and aims to reduce death and disability from rheumatic fever and RHD in Australian Aboriginal and Torres Strait Islander people.

Despite Australia's national high-income status, the Northern Territory's Indigenous people have one of the highest rates of RHD in the world: at least 1-2% of Indigenous Australians living there are thought to have RHD,<sup>96</sup> and Indigenous children are 26 times more likely to develop the disease than non-Indigenous children.<sup>97</sup> Jurisdictional registers contain information about more than 6,000 people living with RHD, with 40% of them under 24 years of age.

### About the programme

RHDAustralia is the National Coordination Unit supporting the control of rheumatic heart disease in Australia. It supports and liaises between the four jurisdictional RHD programmes that are funded under the Australian government's Rheumatic Fever Strategy: in Queensland, Northern Territory, Western Australia, and South Australia.

Each jurisdictional programme has its own priorities and unique characteristics in terms of burden of disease, geography and service provision. But they are united by common goals, which include: surveillance, secondary prevention, awareness and education, and preventing new cases of disease. RHDAustralia supports these programmes by providing technical assistance, educational assistance and data assistance.

### Technical assistance

Most of RHDAustralia's technical resources are available online, so are accessible by national and international health workers and practitioners. They include e-learning resources, online health worker training modules and BPG administering guidelines. There are more than 800 registered users who have completed more than 2,600 hours of online education, the majority of whom reside in Australia.

RHDAustralia works in partnership with Australia's national heart foundation and cardiac society to develop, review and disseminate evidence-based, national RHD guidelines. **The Australian guideline for the prevention, diagnosis and management of acute rheumatic fever and RHD (2nd edition)** was published in 2012,<sup>98</sup> there is currently a review of these guidelines with a 3rd edition expected for release in 2017.

Key information from the guidelines is available as a free app for iPhone and Android devices. The app includes a rheumatic fever diagnosis calculator, which provides a text and visual reference for each technical stage of diagnosing rheumatic fever. The calculator aims to minimize diagnostic error and inconsistency, as rheumatic fever can present in very complex ways. The app has been downloaded by 3,800 users, both Australian and international.

In 2016, RHD Australia will launch an innovative, Self-Management App for Secondary Prophylaxis. Using Facebook as a platform, the project creates an interactive reminder for young Indigenous people (aged 13 to 25) to receive penicillin to prevent RHD from developing or worsening and will hopefully increase uptake among this target group.

In addition to these technical resources, RHD Australia provides an online discussion forum for RHD health workers. This ensures that the decentralized RHD programme units have a platform to share experience, advice and information, and come together as a community.

### Educational assistance

RHD Australia continues to produce a suite of excellent educational materials, making strong use of digital communications and its website, which was updated in 2016. The programme's online newsletter, Murmur, now in its sixth year, continues to collect and disseminate RHD-related news, stories and clinical updates from across Australia to more than 1,200 registered subscribers.

RHD Australia is on social media, and recently launched the **RHD Australia Facebook page** which encourages sharing of information by Australian patients and health care professionals alike. Recently RHD Australia supported the launch of the Western Australian 'Heart on Your Sleeve' online campaign, which involves individuals drawing or pinning a heart onto their sleeve and sharing this image via social media to raise awareness of RHD and direct participants to educational key messages.

RHD Australia also provides more formal educational assistance, for example the New South Wales and Queensland RHD Symposium and Education Workshops of 2015 and 2016. These workshops include objective-driven information sessions, and consolidate knowledge with a series of targeted clinical and practical case studies. Supported through local Health Departments and other key partners, scholarships have been provided for Aboriginal and Torres Strait Islander participants, to ensure that the healthcare workers from communities most affected by RHD can attend.

The RHD Australia website is the most valuable tool available for people to access information on rheumatic fever and RHD in Australia. Each year the website attracts more than 100,000 Australian and international visitors. There is a dedicated webpage for people and communities living with RHD, which 'translates' technical jargon and guidelines into practical information, delivered through the perspective of 'Aunty Mary', a fictional member of an Indigenous community. By reading Aunty Mary's advice and stories, people living with RHD can access a relatable, jargon-free narrative of the disease, which remains accurate and helpful.

### Data assistance

RHD Australia manages a Data Collection System, which is Australia's central repository for rheumatic fever and RHD data. The system was established in 2015 to ensure consistency and quality in data collection and reporting across the jurisdictional programmes. Information generated by the system is mapped against a recommended clinical data set and key performance indicators to track Australia's progress on RHD prevention and control. Findings are included in reports back to the government's Department of Health, and stimulate analysis to support the work of the territorial RHD control programmes. Work is currently under way to establish a register in New South Wales.

This area of the programme is well-staffed, with a Data Liaison Officer who oversees collection and validation processes, and an Epidemiologist who analyses and reports on the data. People with RHD must give their consent before being included in the Data Collection System, and all information is secure and de-identified.

### Challenges

The majority of patients in Australia are Aboriginal and Torres Strait Islander people living in remote and rural areas. Remoteness, transient populations, poor living and education standards, high health worker turnover, and limited knowledge of the disease all contribute to delays and deficiencies in health service delivery and, ultimately, to the burden of disease.

Different jurisdictions are progressing at different rates. The state of New South Wales has the greatest population of both Indigenous and non-Indigenous people, yet does not currently have a RHD register in place. There are no registers operating in Victoria, Tasmania or the Australian Capital Territory, which limits the scope of these regions' work to prevent and control the disease.

### Achievements

RHD Australia's work is strongly guided by Australia's national policy context on RHD. The programme tracks which regions have made RHD a 'notifiable disease' (i.e. officially recorded and reported whenever diagnosed at a health centre) and is advocating powerfully for RHD to become notifiable across the country. In February 2016, South Australia became the latest Australian territory to make rheumatic fever and rheumatic heart disease notifiable, thanks in part to advocacy by RHD Australia.

RHD Australia's guidelines and advice support national medical guidelines and policy, which ensures consistency in practice across the country. In 2014, work began on a Series of National Guidelines, which aims to provide consistent guidance to national public health units in responding to a notifiable or significant disease event. RHD Australia acts as the secretariat for this work, which is expected for release in July 2016 and will complement the **Framework for nurse practitioners working in RHD**, which was launched by RHD Australia in May 2015.<sup>99</sup>

### Moving forward

Australia's first National RHD Colloquium was convened by RHD Australia in May 2015. The forum built relationships between key stakeholders, identified current issues and gaps in service delivery, and prioritised future action required to address these gaps. Work is now beginning to implement the recommendations that emerged from the Colloquium, which seek to improve prevention and control of RHD in Australia.

RHD Australia will continue to contribute to the END RHD Centre for Research Excellence, which is based in Perth. It plans to undertake several projects under the theme of 'Implementation and Translation', one of which includes updating Australia's national RHD guidelines.

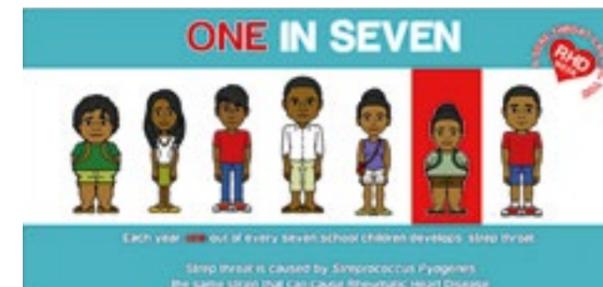
RHD Australia aims to work with people living with RHD and wherever possible aims to ensure these people have a voice. RHD Australia sincerely thanks the champions who live with this disease and the clinicians, researchers and carers who are working to end RHD in Australia.



Some members of the RHD Australia team, pictured with RHD champions Eddie and Marita Masina (centre)

## Fiji

*Dr Joseph Kado, Chair of the Fiji Rheumatic Heart Disease Technical Advisory Committee; Consultant Paediatrician, College of Medicine, Nursing and Health Sciences, Fiji National University*



Public information about RHD can be found on Fiji's Ministry of Health Website (2016)

### Introduction

The Republic of Fiji is an archipelago of more than 330 islands and 500 islets, located in the Western Pacific. According to its most recent census, the Fijian population is estimated to be 837,271 people.<sup>100</sup> RHD is thought to be the second highest cause of death among young Fijians aged 5-29 years, with only drowning claiming more lives among this age group.<sup>101</sup>

### About the programme

The *Fiji RHD Prevention and Control Programme* operates within the Non-Communicable Disease and Wellness Unit of the Fiji Ministry of Health and Medical Services. RHD activities are covered by a National RHD Policy (2015) which is operationalized by a core team led by the national coordinator and three divisional coordinators who are senior nurses.

Programme oversight is provided by a Technical Advisory Committee made up of senior Ministry of Health staff, clinicians, public health staff, an education representative and a patient representative. The programme currently receives funding and technical support from Cure Kids (a New Zealand NGO) and the NZ Ministry of Foreign Affairs and Trade.

RHD prevention and control in Fiji operates within a relatively well-organized health system infrastructure. Since 2001, each Fiji Islander who seeks healthcare at hospital facilities is issued a nine-digit national health number and is entered into a national hospital patient information system.

Fiji has demonstrated the feasibility of nurse-led community screening for RHD. Since 2009, some 13,000 primary school-aged children from over 100 schools have been screened using portable echo. But a review into the follow-up of children diagnosed with RHD has questioned the advisability of screening, as secondary prevention adherence has been poor. Currently, echo screening is carried out opportunistically and is not yet part of a systematic programme.

The use of BPG for primary and secondary prevention of RHD is widespread across the country's primary healthcare services. In 2009, 24 hospitals and 84 health centres were known to have the capacity to administer BPG injections. The Ministry of Health has endorsed a national Benzathine Penicillin Guideline document, which has been made available to all centres that have the capacity to deliver the medication.

National and community outreach and awareness is a strong component of the programme. In mid-2014, in partnership with the Rotary Club of Suva, the programme launched an RHD awareness campaign which included the Ministry of Education and all schools. This included RHD stats teasers, such as 'One in Seven' which highlights that, each year, one out of every seven Fijian school children develops strep throat, which can lead to RHD if left untreated.

The Ministry of Health website has a **dedicated area for RHD**, which contains simple and clear information about RHD targeting the general public, especially parents.<sup>102</sup> The website issues **online reminders** for people with rheumatic fever and RHD to visit their nearest health clinic to receive BPG injections, providing a telephone number and email address for ease of access.<sup>103</sup> Conscious of the potential for self-stigmatization among those who have missed months or even years of BPG prevention, the language used in these reminders is deliberately inclusive and non-judgmental.

The Ministry of Health also organizes awareness-raising events, such as RHD Week and an annual **'Move for Health Walk'**, which aims to combat NCDs such as diabetes and cardiovascular disease (CVD), as well as raise awareness of RHD.<sup>104</sup> Fiji's RHD programme and the Ministry of Health has also celebrated **World Heart Day** since 2000 with an organized health walk and awareness-raising activities which highlight the burden of RHD and other cardiovascular diseases in Fiji.

The latest phase of Fiji's *RHD Prevention and Control Programme* was launched in the summer of 2015. The launch event saw the Ministry of Health formalize its relationship with the Cure Kids, academic institutions in New Zealand, Australia and Fiji, and other expert organizations as part of a co-funded programme with a budget of 5 million Fijian dollars (around USD 2.4 million). Among several new projects, a new web-based rheumatic fever register is being developed which is linked to the Ministry of Health Patient Information System and will be accessible to clinicians and clinic staff for patient management in real-time. The ultimate aim of this partnership is to improve secondary prevention and health outcomes for people living with RHD and to strengthen systems within the Ministry of Health.

## Challenges

Fiji continues to experience challenges with BPG delivery, as primary care staff who administer BPG injections are not always trained or supported to monitor, follow-up and report on their patients. A 2009 review showed that only 38% of people who required secondary prevention via BPG injections had received 'adequate treatment', leaving the remaining 62% at high risk of recurrent rheumatic fever and rheumatic heart disease.

Given the above results, the Fiji programme has embarked on a multi-pronged approach to improve secondary prevention. This includes developing closer working relationships between clinic staff to improve patient lists, up-skilling staff where needed, and (most excitingly) developing 'pilot sites' within the central, western and northern divisions. These pilot sites have liaison clinic nurses who are the focal points for all RHD activities and are in the process of developing patient support advocacy groups. Early indications appear positive; formal assessment of these activities will be undertaken as part of the programme later in 2016.

Like many Pacific island nations, Fiji is vulnerable to natural disasters. Cyclone Winston, the worst storm recorded in the southern hemisphere, tore across the country in February 2016, leaving 44 people dead, 125 injured, and many thousands without shelter, food or water. While the Ministry of Health received support from WHO, UNICEF and other organizations, health challenges remain. At least 88 of 214 health facilities were damaged, seven so badly that patients

needed to be relocated to access the health services they needed.<sup>105</sup> At the time of writing, severely affected areas remain in an official State of Emergency, and WHO reports on the disaster note 'reports of acute fever and rash' among the consequent health outbreaks, which may point towards an increase in rheumatic fever cases.

## Achievements

The Ministry of Health in Fiji is highly sensitised to the issue of NCDs, including RHD. It currently funds one of the RHD programme's four core nursing positions, with talks underway to have the remaining positions formalized within the Ministry too. There is good communication between those working on RHD and those working on NCDs more broadly, including the Ministry of Health's first Non-Communicable Diseases Officer, who was appointed in 2009. Fiji now has a dedicated RHD Policy (2015) which states the Fiji government's commitment to the prevention and control of rheumatic fever and RHD. The Fiji Rheumatic Fever Information System is currently in development with a launch date proposed for July 2016. This register will link with the Ministry's existing patient information system.

Fiji's national programme benefits from investment into understanding the national burden of disease. A 2015 paper concluded approximately twice as many patients were dying from RHD than had been previously suggested and most of these deaths were occurring earlier than originally thought, with significant knock-on economic effects for Fiji.<sup>101</sup> This research, which provides the first national population-based, age-standardised RHD mortality estimates in a developing country, both validates and informs Fiji's RHD programme, as will recent KAP (Knowledge, Attitudes and Practices) surveys which are being conducted among people living with RHD, their families, communities and health workers.

## Moving forward

The beginning of 2016 saw some exciting developments in RHD, which are set to improve RHD prevention and control at the community level. In January, the Minister of Health and Medical Services launched Fiji's first RHD Mobile Clinic. Funding for the Mobile Clinic was the direct result of a fundraising partnership between Cure Kids (an NGO) and AccorHotels (a private sector hotel operator). The Mobile Clinic has been custom-built to go out into Fijian communities and undertake echocardiograms for RHD detection and follow-up. According to the current strategy, the Mobile Clinic will screen close to 400 children from local communities for RHD in the near future.



Fiji's RHD Support Group meeting with the western divisional RHD coordinator as part of the package of interventions at 'pilot sites' to improve secondary prevention

# RHD PROGRAMMES AND THE HEALTH SYSTEM

## Integrated RHD Programmes

As shown by the case studies above, effective RHD prevention and control does not happen independently, but occurs in connection with the wider health system of a country. RHD is a multi-faceted disease, which has many overlaps and linkages with other disease areas found within a health system, including, among others:

- Maternal and child health
- Adolescent health
- Non-communicable diseases (NCDs)
- Neglected tropical diseases, and
- Infectious diseases such as HIV/AIDS.

RHD also has many synergies with factors that traditionally lie outside the health system, such as:

- Education
- Housing
- Sanitation
- Poverty, and
- Transport.

Due to these complexities and overlaps, it is useful for RHD programmes to integrate the diagnosis, treatment and control of RHD with other sectors. This allows for mutual benefits for people living with RHD, and also renders the programmes more sustainable and likely to receive funding. A good example of this are the two programmes supported by RHD Action – **Tanzania** and **Uganda** – which show how countries can integrate RHD interventions with maternal and child health, or services for people living with HIV/AIDS.

**Nepal** offers another model of integration: instead of employing and training newly recruited specialist staff to carry out the work of the programme, the model ensures that existing health workers are trained to prevent and control RHD. This so-called 'diagonal' approach is cost-effective and makes best use of the people already engaged in primary care on the ground.



## Universal Health Coverage and Health Systems

With the advent of the universal health coverage (UHC) movement, donors and decision-makers are working to ensure that work on any particular disease area will benefit the wider health system. RHD Action has produced a **policy paper on RHD and UHC**, which is accessible online, and provides six key messages and six key actions to ensure that RHD can benefit UHC, and vice versa.<sup>15</sup>

The World Heart Federation and RhEACH have also produced a manual for programmatic RHD work with a health systems focus: the **TIPS Handbook**.<sup>21</sup> By following the TIPS Handbook, RHD practitioners can take steps to turn their pilot programmes into comprehensive programmes. The resource, which is also available online, provides a ‘menu of options’ for comprehensive disease programmes, and gives guidance on each potential constituent part of a programme.

Comprehensive programmes, whether in the early ‘pilot’ phase, or fully ‘scaled-up’, are complex, as they usually involve coordinating several levels of RHD intervention (from primary, to secondary, to tertiary) and can have a wide geographical and population scope once operating at scale. By spanning the health system, comprehensive programmes allow RHD to be easily integrated with broader work in non-communicable diseases (NCDs) or other, less ‘vertical’ disease groupings.

You can see from the TIPS conceptual framework table below that there are several ways to prevent and control RHD. The idea of a ‘comprehensive programme’ is actually a misnomer: no programme will be able to tackle all of them at once, but should instead select the most effective and feasible interventions for their setting, taking into account local needs, community consultation, existing infrastructure and economic and human resources.<sup>21</sup>

	Research				
Tertiary Prevention	Medical management of RHD and AHD	Anticoagulation	Triage and preoperative planning	Postoperative planning	Provision of interventional services
Secondary Prevention	RHD Register	RHD and other antibiotic supply	Provision of secondary prophylaxis	Priority based follow up (clinical review)	Active case finding (echocardiography screening)
Primary Prevention	Community education	Low-throat diagnosis & treatment guidelines	Provision of primary prophylaxis	Active case finding (low throat clinic)	Vaccine development
Health and Health Systems	Government engagement	Disease notification	Human resources	Health worker training	Programme evaluation
	Burden of disease data	Governance & the RHD/RHD Advisory Committee	Funding	Laboratory services	Integration with primary care and health systems
	Poverty	Overcrowding	Malnutrition	Access to healthcare	

A conceptual framework for comprehensive RHD control programmes with a health systems approach: the TIPS framework

Despite the promise of comprehensive RHD control, there are relatively few comprehensive programmes for RHD operating at scale within national health systems.<sup>54</sup> The **TIPS Handbook**,<sup>21</sup> **RHD Action website**,<sup>33</sup> and other technical support services have been developed to help countries move towards comprehensive RHD control activities. Scale-up of programmes remains an ongoing challenge, often because local burden of disease data are not available, or there is little understanding of local priorities. Without a clear understanding of cost-effectiveness, practicality and sustainability, comprehensive programmes pose a larger health investment risk than pilots. The development of RHD Action’s **Needs Assessment Tool** to help countries define their baseline RHD control strategies will tackle some of these issues when it is released in 2016.

## INVESTING IN RHD PROGRAMMES

**The success of an RHD programme is primarily based on the people who run it and the policies that support it. But resources also play a critical role in how programmes can develop and how many lives they are able to save.**

It is a myth that RHD programmes are prohibitively expensive, even for endemic countries with very low resources. **Cuba’s** case study points towards research that shows that its RHD programme had a 100% chance of being cost-effective, and an 85% chance of being cost-saving.<sup>77</sup>

This national evidence is backed up by global policy-makers. In 2011, the World Health Organization noted that ‘secondary prevention programmes are the most cost-effective’ way to prevent and control RHD, ‘with the potential for considerable cost savings’ in terms of financial resources and – most importantly – human life.<sup>22</sup>

However, donors and philanthropists should be aware that not all investments in RHD will generate these cost-saving returns. Funnelling money into programmes that focus

on tertiary interventions (such as advanced surgical and medical care), rather than prevention programmes, is an expensive enterprise. Though this trend is changing, some Pacific Islands have historically spent up to 10% of their annual health budget on evacuation for RHD surgery, despite these amounts being equal to the cost of establishing a comprehensive RHD prevention programme for the whole country.<sup>52</sup>

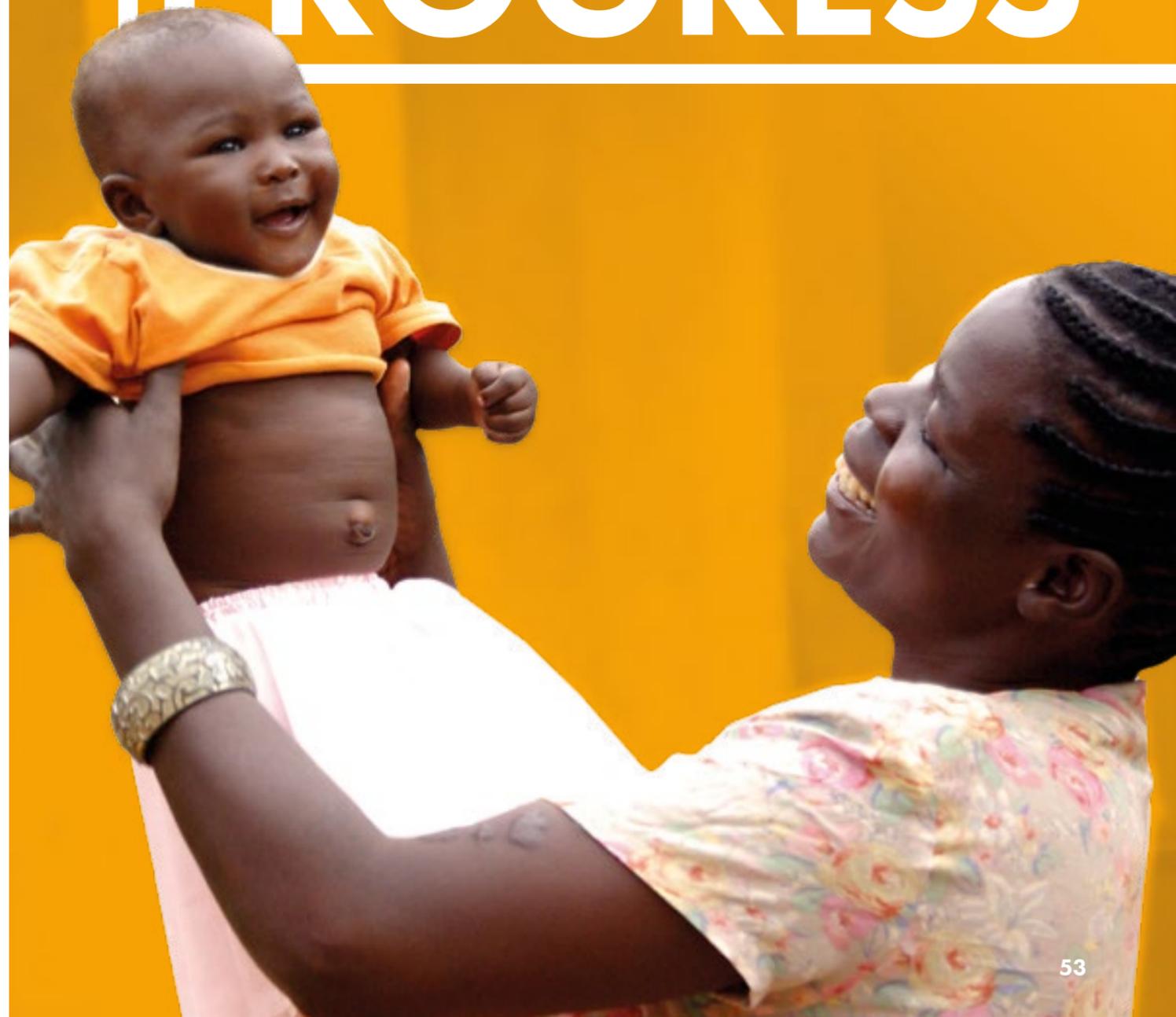
This points to a critical need for more up-front, carefully considered funding for RHD programmes across the world. National governments, the WHO, NGOs, the private sector, donor organizations and philanthropic individuals all have a role to play in this area – investing in RHD is a matter of social justice and health systems strengthening that cannot be ignored.

For RHD, prevention is not only better than the cure – it is much cheaper too. Investing in primary and secondary prevention programmes, as well as socio-economic causes of RHD (including poverty, poor housing, low education levels and overcrowding) is the most sustainable way for us to consign RHD to the history books.

“ Together, we believe it is possible to reduce premature mortality from this preventable disease and to consign RHD to the history books”

– Excerpt from the Declaration of the RHD Action movement, signed in New York City on 29 September 2015

# PROGRESS



## KEY FINDINGS: IDENTIFYING TRENDS AND SOLUTIONS

**This Global Status Report 2015-2017 provides a snapshot of RHD prevention and control around the world, focusing on the people, policies and programmes that make progress possible. While generalizing about the current state of RHD would be over-simplistic and unhelpful, it is possible to identify some trends and solutions across these areas:**

### People

One of the defining characteristics of the RHD community is diversity. The people living with RHD and the health workers profiled in this report span a range of backgrounds, genders, ages and ethnicities. Through sharing their stories, they also bring to light their diverse experiences of living with the disease and show the power of the patient voice.

Looking ahead, it will be important to keep people living with RHD and those who care for them at the forefront of future work at the local, national, regional and global levels. This includes amplifying the voice of health workers, especially those whose roles have been historically overlooked: such as nurses, carers and community health workers.

### Policy

At present, the biggest policy 'wins' for the RHD community have been at the regional level. Thanks to commitment from the African Union, WHO AFRO and PASCAR, the African continent is ahead of other RHD-endemic regions in the policy sphere. Other endemic regions, which often have a strong track record in programmatic work, are moving ahead with policy progress and it is hoped that this trend continues.

On a global level, major opportunities are emerging – such as the UN Sustainable Development Goals – which the RHD community needs to seize and act upon. This requires comprehensive understanding of what the current policy environment is, as well as recognizing the value that policy can give to on-the-ground RHD prevention and control.

To maximize this potential, RHD Action is producing resources and engaging with the WHO and UN on behalf of the RHD community so that, through policy, all RHD stakeholders can receive the commitment and resources needed to eradicate the disease.

### Programmes

Just as we recognize the diversity of people connected to RHD, we can also recognize the diversity of programmes being implemented on the ground. As shown in the case studies above, no two RHD programmes are the same, though many are linked by mutual frameworks, such as the ASAP programme model. This is important, as the burden of RHD is unique to each setting and can vary widely in terms of demographic (who is affected) and weight (how many are affected).

A key trend across RHD programmes is an appetite for cooperation and collaboration, not just with traditional stakeholders such as the WHO, Ministries of Health and academic institutions, but also with other international RHD programmes. This is borne out in the example of South Africa, Zambia and Ethiopia, which have shared protocols around screening methods for RHD surveillance. This is a strong example of a programme that brings together people within an enabling policy environment, which all together translates into progress.

## LOOKING TO THE FUTURE

**“RHD IS A GLOBAL HEALTH ISSUE WHICH SHOULDN'T EVEN EXIST IN THE 21<sup>ST</sup> CENTURY, YET IT CONTINUES TO LIMIT THE LIVES AND OPPORTUNITIES OF INDIVIDUALS ACROSS THE WORLD. WE MUST SEIZE EVERY OPPORTUNITY WE CAN TO ELIMINATE THIS PREVENTABLE DISEASE.”**

– Dr Salim Yusuf, President, World Heart Federation

We live in a constantly changing world. The persisting Ebola and Zika virus crises remind us that health issues are rarely confined within countries: national and geographical boundaries are permeable and cannot limit the spread of disease. Therefore, RHD must be seen as 'everybody's business', even by countries that are not currently endemic.

This is especially true given the many refugee and migrant populations across the world, who are at high risk of RHD even while lacking access to consistent and high-quality health care. In this case, programmes that are constricted by national borders are inadequate; new models are needed that can respond to health emergencies.

Over 1 million migrants crossed into Europe during 2015, many of which come from RHD-endemic countries and are desperately seeking healthcare.<sup>106</sup> In February 2016, international NGO Médecins Sans Frontières (MSF) decided to start an echocardiographic screening programme in Rome, targeted at migrant populations living in informal sites.<sup>107</sup> The MSF project is being carried out in partnership with several institutions in Italy, including the Cardiology department of Tor Vergata University Hospital in Rome.

The partners are currently leveraging MSF's own facilities for the rehabilitation of victims of torture to screen unaccompanied young people (age 10-25) for RHD, the majority of whom are young Egyptians. Over the course of 2016, MSF expects to screen about 1,000 young people, with the aim of putting those with RHD on secondary prevention.

The screening project will give insights into the epidemiological status of RHD among migrants, indicate whether screening programs are feasible in these settings, and forge relationships between RHD and other humanitarian issues. The initiative provides an insight into what the nature of RHD prevention and control might be in the future: sensitive, responsive and unfettered by national borders.

**The RHD community is better equipped than ever before to reduce the global RHD burden. It is armed with knowledge gained from the people and programmes currently tackling RHD around the world. The policy environment is undergoing positive changes and people wishing to join the movement have access to several resources including the RHD Action Resource Hub,<sup>6</sup> RHD Atlas,<sup>5</sup> TIPS Framework<sup>21</sup> and many more.**

**However, there is still much hard work to be done and more support is needed from many sectors, including donor and philanthropic organizations, to help achieve this. The global RHD community will not rest on its laurels as it moves forward to consign RHD to the history books.**



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