The 5 × 5 Path Toward Rheumatic Heart Disease Control

Outcomes From the Third Rheumatic Heart Disease Forum

Timothy D. Johnson*, Alice Grainger Gasser†, Claire Boardman‡, Bo Remenyi§, Rosemary Wyber*, Bongani M. Mayosi‖

West Perth, Western Australia, Australia; Geneva, Switzerland; Darwin, Northern Territory, Australia; and Cape Town, South Africa

Rheumatic heart disease (RHD) and rheumatic fever are the post-infectious sequelae of group A streptococcal infection. An estimated 30 to 70 million people worldwide live with RHD, 90% of whom live in developing countries [1–3]. Acquired in childhood and symptomatic from the first decade of life, RHD is a disease of vulnerable and impoverished communities worldwide. The disappearance of RHD from high-income settings precipitated a period of neglect in research, advocacy, funding, and policy discussions. However, an accelerating community of clinicians, researchers, advocates, supporters, and people living with RHD has re-emerged in recent years with a shared vision for global RHD control [4]. This community has benefited from increasing visibility at international meetings, particularly 3 global fora on RHD control over the last 2 years.

The first forum was held in April 2012 at the World Congress of Cardiology in Dubai, United Arab Emirates. The forum provided a foundation for development of the World Heart Federation (WHF) Position Statement on the Prevention and Control of RHD [5]. The second RHD forum was held in February 2013 at the Sixth World Congress of Pediatric Cardiology and Cardiac Surgery in Cape Town, South Africa. The congress focused on issues affecting the majority of the world's children and, in particular, the diseases of the poor and marginalized [6]. With the intention of expanding on the conversation initiated at the first RHD forum and providing feedback on the strategy elaborated in the WHF position statement, 4 discussion groups were chaired by recognized experts within the RHD community at the second RHD forum. These groups consisted of: 1) advocacy, policy, public health, and government engagement; 2) science and research—priorities and translation; 3) training and capacity-building; and 4) practical issues in RHD at the country level [7].

OBJECTIVES

The third global RHD forum was intended to carry forward dialogue from previous RHD fora and to engage new stakeholders in the RHD control agenda. Holding the event in Melbourne provided a unique opportunity to integrate the large RHD community in Oceania into the broader global movement. The major objective of the event was to explore needs and opportunities to address the global goal of a 25% reduction in RHD mortality in those >25 years of age by 2025 ($25 \times 25 < 25$) [5]. This goal, articulated in the position statement on RHD, is aligned with and complements the broader goal of reducing premature mortality from noncommunicable diseases by 25% by 2025, endorsed by all World Health Organization member states as part of the Global Action Plan on noncommunicable diseases.

PARTICIPATION

The participants of the RHD forum included clinicians, researchers, public health practitioners, and private sector supporters. Two critical new stakeholder groups were represented for the first time in the third RHD forum: people living with RHD; and governments. These groups, essential to all efforts to address the disease, enriched the already diverse group of participants of previous fora, which included people with backgrounds in the private sector, philanthropy, advocacy, and filmmaking, as well as clinicians and medical practitioners. For the countries represented at the third RHD forum, see Figure 1 and Table 1.

CONTENT

The forum began with the opportunity to network and was officially opened by Professors Jonathan Carapetis, Bongani Mayosi, and Bart Currie. The opening provided an overview of the forum concept, an introduction of RHD to new stakeholders, and a brief review of the 2 previous RHD fora.

Ms. Kenya McAdam and her family members then gave a personal account about the impact of living with RHD as a young indigenous Australian woman. Ms. McAdam's address was the first time a young person with RHD had addressed the global RHD community. Marking a turning point in inclusiveness in the RHD control agenda, her talk illustrated the importance of including individuals, families, and communities living with the disease at all levels of discussion of action on RHD. The brief segment of the film *Take Heart,* which had opened the World Congress of Cardiology, was shown at the start of the evening, reinforcing the lived experience of patients with RHD and the role of RHD champions.

This was followed by an hour of breakout discussions, when 19 small groups (of up to 10 people per group) engaged in in-depth discussions on specific issues relevant to each of the 5 targets outlined in the WHF position statement on global control of RHD. Groups were asked to identify needs in the following areas:

- Definition and baseline data;
- Technical support and resourcing needs;

Dr. Mayosi reports receiving research funding from Lily and Ernst Hausmann Research Trust, South African Medical Research Council, National Research Foundation of South Africa, Wellcome Trust, and the Canadian Institutes of Health Research. All other authors report no relationships that could be construed as a conflict of interest.

The Third Global Rheumatic Heart Disease Forum was made possible by the generous support of Medtronic Philanthropy, CureKids New Zealand, and BUPA. The organizers acknowledge the support provided by the scribes and chairs of discussions.

RHDAustralia was established in 2009 as the National Coordination Unit to support control of rheumatic heart disease in Australia. It is funded under the Australian Department of Health's Rheumatic Fever Strategy. RHDAustralia is based at Menzies School of Health Research in Darwin.

From the *Telethon Kids Institute, University of Western Australia, West Perth, Western Australia, Australia; †World Heart Federation, Geneva, Switzerland; ‡RHD Australia, Menzies School of Health Research, Darwin, Northern Territory, Australia; §Menzies School of Health Research, Darwin, Northern Territory, Australia, and Northern Territory Cardiac Services, Royal Darwin Hospital, Darwin, Northern Territory, Australia; and the ‖Department of Medicine, Groote Schuur Hospital and University of Cape Town, Cape Town, South Africa. Correspondence: T. D. Johnson (timothy.johnson@telethonkids.org.au).

GLOBAL HEART

VOL. 10, NO. 1, 2015
ISSN 2211-8160/$36.00.
http://dx.doi.org/10.1016/j.gheart.2014.12.005

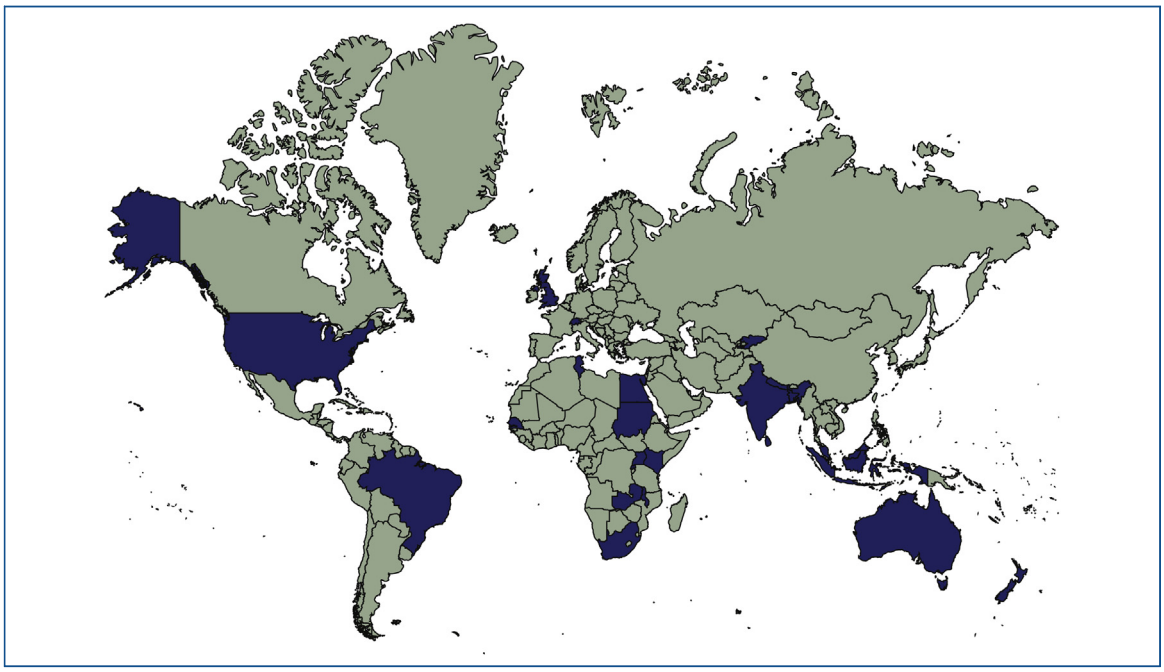

FIGURE 1. Countries represented at the third RHD forum.

- Stakeholders needed to achieve disease control targets;
- Monitoring and measuring outcomes.

Key discussion points in each domain encompassed control programs, benzathine penicillin G (BPG), champions, hubs, and vaccine development.

Control programs

Discussion focused on the need for a comprehensive RHD program to include primordial, preventative, secondary, and tertiary elements. There was a consensus reached on the necessity for control programs to be integrated into existing health systems. The group emphasized the importance of primordial and preventative aspects of comprehensive RHD programs and identified a need for technical support, resources, and high-quality epidemiological data as well as tools, skills, training, and guidelines.

Stakeholder feedback provided good examples of RHD private and public sector engagement in country-specific contexts. In discussion and feedback, there was also a focus on control program outcomes centered on the engagement of people and communities living with RHD and the need for patients, programs, and champions to advocate for RHD and hubs to coordinate regional action.

Benzathine Penicillin G

BPG is essential to both primary and secondary prophylaxis and thus is critical for RHD prevention and control. Participants reiterated concerns surrounding the availability, quality, and safety of BPG. Cost of medication to consumers and supply chains were considered barriers to access. Technical support and resources discussions were duly focused on health care strengthening at the primary and preventative levels. The importance of improving quality, safety, and supply of penicillin while a vaccine is under development was emphasized.

Champions

The experience of people living with RHD was a prominent theme of the forum, articulated by the opening speaker and the *Take Heart* film clip. There was substantial discussion within groups regarding the role that a champion of RHD may play, their role and ability to advocate for stakeholders; particularly those who are immediately affected by RHD. Some groups emphasized the importance of the recruitment of an RHD champion from a population that was affected by RHD and made some suggestions of candidates from the Australian context. However, there was consensus across the discussion groups engaged in this topic that there are different types of roles and levels of champions and that within these roles are indeed a key "spectrum of roles" ranging from clinical champions, political champions, and social champions who would appeal to a broad range of stakeholders engaged in or affected by RHD. It was noted that the key role of any champion is to raise the profile of the disease in multiple spheres.

Groups stressed the importance of a "community of patient advocates" in order to create opportunities and the possibility of forming clubs that support other patients and empower each other. This approach supports individuals while facilitating engagement with peers as part of a broader community in sharing their experiences. The role of patient

groups having champions was noted in discussions and feedback, as a person who may be able to facilitate discussion and articulate experience to other champions, be they political or clinical, and more broadly in general.

One group emphasized the important role of primary care in championing RHD control. They noted that the "delivery of secondary prophylaxis is imperative" and in this way health care workers are seen as "champions" by those affected by RHD in the delivery of these programs. It is important for primary care staff to be proactive and seek out patients and not wait for them to come into the clinic. Existing examples were given in relation to the role of primary health care workers in facilitating a champion role, such as the example of "Peer Educators Model" in Zambia in providing support and advocacy on a number of fronts. These roles include providing psychosocial support and education from a patient perspective to help patients understand the importance of treatment.

Hubs

Discussion groups articulated that an RHD hub "should be a center of excellence for RHD prevention, research, treatment, and advocacy." Participatory models were suggested for local communities that would be able to identify their specific needs and be able to best direct the roles of those involved in education (including that of culturally appropriate education), training, the development of records and registers, and the administration of BPG and other factors surrounding BPG. In many ways, hubs were seen to be closely aligned with the role of RHD champions at a community level; however, there was also considerable discussion and feedback surrounding "RHD hubs" from a clinical and political perspective.

It was articulated that each vulnerable population or country where prevalence is high should have an RHD hub. Similar models deployed by other disease communities should be explored and adapted to the RHD context. There was widespread acknowledgment of the prevalence of RHD in low- and middle-income country settings and, therefore, suggestions that developing countries would benefit in having a supporting relationship or the ability to network with a developed neighboring country. The benefits of which would relate to addressing the imbalance between burden of disease and resources in low- and middle-income countries, facilitating the collaborative nature of the transfer of knowledge and the ability to leverage technology (both basic and advanced), such as computers, mobile technology, and echocardiography machines, and also the exchange of personnel. A governing body or organizational structure was proposed and suggestions for management of the networking of hubs were explored. The establishment of at least 1 hub of training, research, and advocacy for rheumatic fever and RHD in World Health Organization—defined regions was suggested. The outcomes of hubs should be based on measurable results related directly to the 3 areas of focus: training; research; and advocacy.

TABLE 1. Countries represented at the Third RHD Forum

North America	South America	Africa	Europe	Australasia/ Oceania	Asia
United States of America	Brazil	Egypt	Switzerland	American Samoa	Bangladesh
		Kenya	United Kingdom	Australia	Cambodia
		Malawi		Fiji	India
		Rwanda		Kiribati	Indonesia
		Senegal		New Caledonia	Kyrgyz Republic
		South Africa		New Zealand	Malaysia
		Sudan		Samoa	Nepal
		Tunisia			Sri Lanka
		Uganda			Timor-Leste
		Zambia			

RHD, rheumatic heart disease.

Vaccine development

In order for a group A streptococcal vaccine to have the greatest impact, it would need to result in considerable reduction in RHD morbidity and mortality rates. Feedback on the effectiveness of this concerned the need for there to be political will at a number of levels and this in turn has an effect on the cost-effectiveness of a vaccine, the economic effects of vaccine, and the eradication of RHD.

A ROADMAP FOR REALIZING RHD CONTROL

The evening was concluded by a panel discussion highlighting perspectives from the public, private, and philanthropic sectors. Panelists included Prof. Chris Baggoley, Australian chief medical officer; Dr. Chrissie Pickin, director of the New Zealand Ministry of Health program on rheumatic fever; Dr. Steve Justus, vice president of Touch Foundation; Dr. Jacob Gayle, vice president of Medtronic Philanthropy; Dr. John Musuku, director of the BeatRHD A.S.A.P. Programme in Zambia; Ms. Vicki Lee, CureKids New Zealand; Prof. Anita Saxena, All India Institute of Medical Sciences; Ms. Johanna Ralston, chief executive officer of the World Heart Federation; Ms. Kenya McAdams, a person living with RHD; and the Honorable Neil Sharma, Minister of Health in Fiji. Panelists responded to questions from the breakout groups and synthesized some of the major challenges in RHD control. The Third Global RHD Forum concluded with consensus to develop a roadmap for defining, monitoring, and achieving the targets addressed by the breakout groups.

A roadmap for achieving global targets for RHD is urgently needed. A swathe of reviews, calls to action, and profile articles have been published in recent years [4,5,8,9]. It is time for to those calls to come to fruition. The RHD roadmap is part of a broader WHF initiative to develop roadmaps in priority areas for achieving the primary global goal, adopted by the World Health Assembly in 2013, of reducing premature noncommunicable diseases mortality by 25% by 2025. The WHF has adopted this goal

TABLE 2. Targets and threads for tackling RHD control

Targets				
Comprehensive Control Programs	**BPG**	**Champions**	**Hubs**	**Vaccine Development**
Ensure that 90% of countries with endemic RHD have integrated and comprehensive control programs by 2025.	Ensure the availability of high-quality BPG for 90% of patients with RHD in 90% of countries with a high burden of this disease within 10 years.	Foster at least 1 prominent public figure as an "RHD champion" in every country where RHD is endemic.	Establish at least 1 hub of training, research, and advocacy for RF and RHD in each WHO-defined geographic region by 2025.	Test a group A β-hemolytic streptococcal vaccine in phase III clinical trials in RHD-endemic countries within 10 years.
Threads				
Burden of Disease and Data	**Supporting Communities**	**Resources**	**Technical Support**	**Advocacy**
Monitoring progress toward targets by collecting and collating burden of disease and other data.	Fostering individuals and communities living with RHD to tell their stories and ask for change.	Development of resources to support the RHD control agenda including a core website. Practical tools for service delivery including tools for implementing RHD programs and the Stop RHD A.S.A.P. Programme.	Engagement with other disease communities. Development of briefing document for different sectors.	Ensuring that the necessity of RHD control is communicated at the highest levels of government, nongovernment, and community sectors.

BPG, benzathine penicillin G; RF, rheumatic fever; RHD, rheumatic heart disease; WHO, World Health Organization.

and recognizes that the political windows opened by governments' coordinated efforts to meet it represent a once-in-a-generation opportunity to influence policy makers to dramatically accelerate action around cardiovascular disease. In other disease communities, roadmaps for disease control and prevention have been developed in recent years, capitalizing on increased momentum and interest within specific disease communities [10]. Roadmaps are currently being developed for achieving goals of preventing heart attack and stroke through drug therapy and counseling for high-risk individuals (those with known cardiovascular disease); reducing daily tobacco use by 30%; and increasing hypertension control by 25%.

The first 2 RHD fora provided an opportunity for input from the global RHD community to the development of the position statement of the WHF and the developments of overall goals and key targets. The third forum identified the need for a coordinated approach for RHD control and the fundamental need for a roadmap to take implementation of the 5 targets and threads to an unprecedented scale. Public and private funding agencies are urged to invest in a roadmap to maximize gains in global RHD control.

In the wake of the Third Global Forum on RHD, we propose that the RHD roadmap have a 5 × 5 structure encompassing the 5 targets and 5 threads necessary to achieve those targets (Table 2). This structure will ensure that pursuit of measurable targets is paralleled by processes and service delivery needs. Preliminary consultation and discussions are underway to refine the structure, format, and outcome of the roadmap for RHD control. Extensive consultation and drafting requires financial and logistic resourcing to take the process to scale. Roadmap development should be prioritized by funding agencies to maximize gains in global RHD control.

REFERENCES

1. Carapetis JR, Steer AC, Mulholland EK, Weber M. The global burden of group A streptococcal disease. Lancet Infect Dis 2005;5:685–94.
2. Zuhlke L, Steer A. Estimates of the global burden of rheumatic heart disease. Glob Heart 2013;8:189–95.
3. Paar JA, Berrios NM, Rose JD, et al. Prevalence of rheumatic heart disease in children and young adults in Nicaragua. Am J Cardiol 2010; 105:1809–14.
4. Mayosi BM, Gamra H, Dangou JM, Kasonde J, the 2nd All-Africa Workshop on Rheumatic Fever and Rheumatic Heart Disease Participants. Rheumatic heart disease in Africa: the Mosi-o-Tunya call to action. Lancet Glob Health 2014;2:e438–9.
5. Remenyi B, Carapetis J, Wyber R, Taubert K, Mayois B. Position statement of the World Heart Federation on the prevention and control of rheumatic heart disease. Nat Rev Cardiol 2013;10:284–92.
6. Zuhlke L. Successes, failures, challenges and ground-breaking research: messages from the 6th World Congress of Paediatric Cardiology and Cardiac Surgery. Cardiovasc J Afr 2013;24:93–5.
7. Zühlke L, Engel M, Remanyi B, Wyber R, Carapetis J. The second rheumatic heart disease forum report. Glob Heart 2013;8:253–61.
8. Carapetis J, Zuhlke L. Global research priorities in rheumatic fever and rheumatic heart disease. Ann Pediatr Cardiol 2011;4:4–12.
9. Maurice J. Rheumatic heart disease back in the limelight. Lancet 2013;382:1085–6.
10. WHO. Roadmap for Childhood Tuberculosis: Towards Zero Deaths. Geneva, Switzerland: World Health Organization; 2013.