The Second Rheumatic Heart Disease Forum Report

Liesl J. Zühlke*,†, Mark E. Engel†, Bo Remenyi‡, Rosemary Wyber§, Jonathan Carapetis§, for the RHD Forum Meeting Report Writing Committee

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

ABSTRACT

The second rheumatic heart disease (RHD) forum was held on February 18, 2013, at the Sixth World Congress of Pediatric Cardiology and Cardiac Surgery in Cape Town, South Africa, to focus attention on key areas in global RHD control, management, and prevention. Building on the foundation of the first RHD forum, over 150 interested participants met to discuss critical issues on the RHD landscape. Unique to this meeting was a mixture of diverse backgrounds and disciplines, all crucially important to the conversation around RHD control and prevention. Some clear priorities have emerged for RHD activities in the next era: the necessity for political intervention and policy change; increasing the health workforce by incorporating teaching, training, and task-shifting; revitalizing the research agenda by merging basic, clinical, and translational research; and obtaining universal access to high-quality penicillin. There was also an urgent request for new resources; for existing resources to be further developed, improved, and shared across platforms; and for resources to be supported in the nonmedical arena. Finally, the necessity of involving the patient community in the ongoing discussion was highlighted. The participants of both the first and second RHD forum represent a new, thriving, and growing community of RHD activists who should usher in a new era of significant improvements in RHD control and prevention.

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The first rheumatic heart disease (RHD) forum was held in April 2012 at the World Congress of Cardiology in Dubai, United Arab Emirates, and assembled for the first time many of those involved in acute rheumatic fever (ARF)/RHD control, prevention, and management activities across the globe. This meeting provided 33 participants the opportunity to meet, share successes, and network mutual challenges. The World Congress of Pediatric Cardiology and Cardiac Surgery held in Cape Town from February 17 to 22, 2013, was the natural venue for the second RHD forum as RHD remains the most common cause of acquired heart disease in children, adolescents, and young adults [1]. In addition, this conference had as a central tenet a deliberate focus on issues affecting the majority of the world's children with particular references to diseases of the poor and marginalized people [2]. For this forum, 4 discussion groups were chaired by experts in the RHD community: 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.

PARTICIPANTS

It was expected that 50 to 60 participants would attend; yet overwhelming interest resulted in over 150 delegates attending from 38 countries and all major continents, only 20% of whom had been at the previous RHD forum (Fig. 1, Table 1). Interestingly, the delegates represented a diverse group with interests and backgrounds outside of medicine including law, advocacy, fundraising, and filmmaking.

OBJECTIVES

The major objective of the forum was to discuss critical needs around RHD and to share common goals, visions, and strategies. Another objective was to encourage the

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From the *Department of Paediatrics, Red Cross War Memorial Children's Hospital and University of Cape Town, Cape Town, South Africa; †Department of Medicine, Groote Schuur Hospital, Cape Town, South Africa; ‡Menzies School of Health Research, Darwin, Northern Territory, Australia; §Telethon Institute for Child Health Research, University of Western Australia, Perth, Western Australia, Australia. Correspondence: L. Zühlke (liesl.zuhlke@uct.ac.za).

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FIGURE 1. Countries represented at the second RHD forum. RHD, rheumatic heart disease.

development of collaborative platforms and programs, and stress key areas of research, intervention, and emerging priorities. As the cardiovascular community tackles the vision of "a 25% reduction in premature deaths from RHD in the under 25 years olds by the year 2025" [3], it is critical for all interested groups working in the RHD space to contribute to this important conversation and build a new, vibrant, growing RHD community, allowing for new networks and friendships to develop (and strengthening of more established ones) and to highlight major common areas of need.

The major discussion points follow (Table 2).

Advocacy, policy, public health, and government engagement

RHD activities have suffered in the recent past by dwindling public health and government interest, due to decreasing

TABLE 1. Countries represented at the second RHD forum

North America	South America	Africa	Europe	Australasia/Oceania	Asia
Canada	Brazil	Angola	Austria	Australia	Bangladesh
United States of America		Cameroon	Poland	Fiji	India
		Cote D'Ivore	Switzerland	New Zealand	Indonesia
		Egypt	United Kingdom	Republic of Tuvalu	Malaysia
		Ghana			Pakistan
		Kenya			Philippines
		Mozambique			Saudi Arabia
		Namibia			
		Nigeria			
		Rwanda			
		South Africa			
		Sudan			
		Uganda			
		Zambia			
		Zimbabwe			

RHD, rheumatic heart disease.

TABLE 2. Advocacy, policy, public health, and government engagement

National level advocacy	• Importance of data • Mobilizing and engaging governments • Community involvement • RHD champions • Multimodal media messages
Advocacy to action	• Very specific asks • Need for equipped medical workforce • Health system support
Expansion of RHD control on a global level	• Mutual support of countries with variable development of RHD programs • Extension of the role of international organizations

RHD, rheumatic heart disease.

prevalence in high-income countries and competing health interests in lower-income countries [4]. Yet, engagement with government is critical to effect policy and public health interventions, whereas community awareness is vital to encourage activism around RHD. This group focused on 3 key questions in this area:

1. What helps with national level advocacy?
2. How to translate advocacy to action?
3. How to expand RHD control at a global level?

National level advocacy There is an urgent need for surveillance to detail the ARF/RHD burden of disease, particularly in low-income countries and rural settings. This is fundamental to comprehensively inform governments concerned about "endemic" disease conditions and morbidity and mortality figures. Strategies for translating burden of disease data to government engagement and action were explored. Approaches included: politicizing the issue (with the elevation of RHD in the national policy agenda of New Zealand as an example); leveraging the millennium development goals; and aligning RHD with issues of child health, maternal morbidity/mortality, and the noncommunicable disease agenda currently of interest to many governments.

An essential element to activism and advocacy was to put a "face" to RHD and escalate active community participation. Approaches should involve parent, community, and patient groups such as the patient clubs that have been successful in Kerala, India [5]. These occasions can provide important opportunities for education and can draw much-needed media attention (e.g., the work in Vietnam around nephrotic syndrome [6]). Educated, adherent patients can be powerful advocates, and a health minister with a personal connection to RHD can present a wonderful opportunity. The suggestion of teaching children at school and having them educate families at home was also raised.

Leading clinicians with a national profile are needed to act as clinical champions for RHD and to encourage nonclinical champions to develop from other arenas. Advocates and prominent clinicians from within heart foundations have already been successful in mobilizing governmental support. Film stars and sporting heroes can be very powerful role models and lessons could be learned from other disease intervention strategies such as the polio eradication campaign in India.

The importance of multimodal media outputs was stressed. Brochures can help people living with ARF/RHD understand the condition; however, literacy can be a significant challenge. Increasing public messages can build media interest, creating a global chorus for action. Documentaries, short films, and interviews can be powerful advocacy tools and can mobilize people otherwise disconnected from ARF/RHD, particularly from high-resource settings. Finally, using social media platforms such as Facebook and Twitter was proposed, acknowledging that these could be difficult to access in very low-resource settings (Table 3).

Advocacy into action—knowledge translation, translational research The greatest challenge in RHD is implementing the knowledge and evidence that already exists. ARF/RHD can be controlled with sufficient awareness, advocacy, and mobilization of political will.

Some specific "asks" may be the first step in this regard. ARF/RHD is a disease of poverty and poor social infrastructure; advocacy efforts should always emphasize primordial prevention. The next major "ask" relates to the health workforce. Translating our current evidence into practicable programs requires a trained medical workforce able to implement RHD programs. Countries reported variable compliance with clinical guidelines and inadequate education regarding the importance of secondary prevention. Even within the medical profession, inadequate understanding of the disease may exist and result in suboptimal promotion of secondary prophylaxis. In addition, the informal medical sector may be difficult to access or regulate in many areas.

RHD control at a global level One of the main objectives of the first RHD forum was to support those working in countries with less-developed RHD programs. This can take various guises: sharing of protocols and scientific data visits; joint projects; introductions to funding opportunities and establishing local and regional priorities; advocating to government; and forming groups of disease champions.

The World Heart Federation (WHF) position statement is expected to be helpful for countries to adapt to local settings or recommendations, although more technical support may be needed to help with local-level implementation (Table 3).

International organizations and industry have an important role exerting a top-down influence on policy makers at international and government levels. The importance of the World Health Assembly (held in May 2013) was

TABLE 3. Selected resources for RHD community (cited in this document)

Curricula/resources	• WHO technical report: http://whqlibdoc.who.int/trs/WHO_TRS_923.pdf • WHF curriculum: http://www.world-heart-federation.org • Position statement of the WHF on the prevention and control of rheumatic heart disease: http://www.nature.com/nrcardio/journal/v10/n5/full/nrcardio.2013.34.html • UNICEF's *Facts for Life:* http://www.unicef.org/publications/index_53254.html • WHF criteria for echocardiographic diagnosis of rheumatic heart disease—an evidence-based guideline: http://www.nature.com/nrcardio/journal/v9/n5/full/nrcardio.2012.7.html • WHO pocket book: http://www.who.int/maternal_child_adolescent/documents/9241546700/en/
Websites	• www.worldheart.org/rhd ◦ Includes resources, training manuals, guidelines, and articles • www.RHDaustralia ◦ Includes resources, training manuals, guidelines, and monthly newsletter • http://www.ncdalliance.org/ • http://www.clanchildhealth.org/ • http://www.ncdchild.org/ • http://www.curekids.org.nz/
Training	• http://www.pih.org/library/the-pih-guide-to-chronic-care-integration-for-endemic-non-communicable-dise • Global research priorities in rheumatic fever and rheumatic heart disease: http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3104531/ • Simplified Echocardiographic Strategy for Heart Failure Diagnosis and Management Within an Integrated Non-Communicable Disease Clinic at District Hospital Level for Sub-Saharan Africa: http://www.ghdonline.org/ncd/discussion/simplified-echocardiographic-strategy-for-heart-fa/?id=308828&format=html&type=digest • African pediatric fellowship program: http://www.scah.uct.ac.za/apfp/APFP
Basic sciences research	• Vaccine development: http://ip.bio-med.ch/cms/cms
Videos, interviews, YouTube links	• http://www.youtube.com/watch?v=tWMGNG61SRA • http://www.youtube.com/watch?v=MoWJiupOBo4 • http://www.youtube.com/watch?v=eUFpNK2ljgw • http://www.youtube.com/watch?v=dB7eXTh6zdg • http://www.youtube.com/watch?v=0J6Tf3cv8sg • http://www.rheumaticheartclub.org/
Apps for iPhone, iPad, or Android	• www.rhdaustralia.au
Guidelines	• Australia and New Zealand: http://www.rhdaustralia.org.au/sites/default/files/guideline_0.pdf • India: http://www.ncbi.nlm.nih.gov/pubmed/1869527

UNICEF, United Nations Children's Fund; WHF, World Health Federation; WHO, World Health Organization.

highlighted as an opportunity to inform ministers of health about RHD. The United Nations Children's Fund has produced a document titled *Facts for Life*, with a series of chapters on raising healthy children, that provides practical tips for policy makers and health professionals. Other useful tools exist: WHF's dedicated RHD website, RHDNet, provides resources, although all these resources should be more dynamic and high profile in order to generate as much interest as possible (Table 3).

One suggestion was for an A4 factsheet of hard data to distribute that would provide consistent, powerful messages required for global advocacy. Finally, all participants supported ongoing advocacy efforts directed at the pharmaceutical and biomedical industry to improve the global benzathine penicillin G supply and to consider low-cost tertiary interventions. Industry partners also have skills and experience relevant to broader disease control efforts.

Science and research—priorities and translation

The following areas were identified as research priorities (Table 4).

Interdisciplinary interaction to direct research priorities More collaboration among members at all levels (including scientists, healthcare workers, clinicians, echo technologists, nurses, health educators, etc.) within the RHD community will foster the exchange of ideas for topics for research from basic research to knowledge

TABLE 4. Science and research—priorities and translation

Coordination of research	• Interdisciplinary interaction to direct research priorities • Registries as a research tool, especially in resource-poor countries • Global collaboration
Applied science	• Screening interventions • Treatment interventions • Vaccine development
Basic sciences research	• GAS pharyngitis • Strep registries • M protein gene typing • Genetic studies

GAS, group A streptococcus.

translation. In particular, more contact between basic and clinical sciences will steer efforts in providing answers to questions arising from within the clinical environment. A clear need exists for registries as a research tool, especially in resource-poor countries, which will also facilitate the development of country-specific priorities for prevention. Furthermore, if similar protocols are used, combining data across registries will allow for the evaluation of the natural course of disease at a global level. The research can also be extended to trials involving multicenter institutions on the notification of ARF. In addition, there is a need to have research targeting the strengthening of health systems to ensure adequate management of cases. There was a call for assistance in setting up RHD programs where they currently do not exist.

Global collaboration Participants strongly suggested that investigators of programs emanating from more affluent settings consider including units from less-developed countries when planning research and applying for grants, especially in screening for RHD. Sharing training opportunities, for example, in echocardiography, will serve to strengthen the global network in RHD research.

Development of effective screening and treatment interventions There is a need to research and develop screening interventions that will be effective in diagnosing RHD in its early stages, especially in those resource-poor settings where surgery is not an option. Screening-related research should focus on: 1) identifying indicators of higher risk in children characterized as "borderline RHD" by the WHF criteria to answer the question of when to start prophylaxis; 2) identifying more cost-effective interventions (e.g., hand-held echo or nurse-led screening); 3) identifying community-based approaches to improve the accuracy of epidemiologic findings; and 4) performing cost-effectiveness analyses.

Given the concerns regarding adherence to secondary prophylaxis, treatment-related research should focus on effective and innovative means of delivery while encouraging adherence. There is also a need for an evidence base for current treatment strategies to be developed. This should include further research on penicillin as a prophylactic drug, drugs being used for patients with heart failure, and alternatives to the more expensive drugs currently used. There was consensus that concerted efforts should be directed at developing a vaccine for group A streptococcus (GAS).

Basic sciences research More studies are needed on ways of accurately identifying GAS in the absence of laboratory facilities, in other words, developing clinical prediction rules, given that many cases occur in rural areas devoid of clinic facilities. The development of registries to record streptococcal infection, especially in resource-poor settings, will serve as a useful tool to document the epidemiology of GAS-related infections. Studies on M protein gene typing are also needed to inform the development of potential M protein–based vaccines. Genetic studies may serve to identify indicators of RHD disease before the onset of symptoms and the individuals most likely to benefit from a potential vaccine, thus reducing the overall cost of vaccination.

Training and capacity building

A serious concern in combating RHD is the lack of sufficient training and health worker capacity in high prevalence areas. This was expressed by all participants in each group. However, sensitizing all levels of healthcare workers to RHD was the important initial step to raise awareness, then to generate interest in training, and then finally to offer appropriate training (Table 5).

Training requirements are complex, multilevel, and should include definitions for each role (e.g., teachers, nurses, community workers, general practitioners,

TABLE 5. Training and capacity-building priorities

Training	• Sensitizing healthcare workers • Training at all levels with a wide range of outputs • Targets including heathcare workers, communities, schools teachers, patients, and families. • Integration of ARF and RHD training in existing health worker education programs • Collaboration and networking • Exchange programs
Capacity-building	• National algorithms and referral systems • Sustainable models for low-cost technology • Sustainable models for cardiology and surgical services

ARF, acute rheumatic fever; RHD, rheumatic heart disease.

specialists) regarding expectations and desired outcomes. In South Africa, a pilot workshop trained school nurses to educate other nurses, teachers, and pupils using a locally produced DVD. It was strongly recommended that a national committee be nominated to lead training and integrate ARF/RHD training into existing health workers' education programs. Practically, anaphylaxis training must be a pre-requisite for all those involved in penicillin delivery and is critical to building confidence in the program among those instituting the delivery.

The need for human resources was well illustrated by the example of Rwanda with a desperate shortage of skilled workforce. Currently, there are only 2 pediatric cardiologists for a population of 10 million; also, there is a dire shortage of pediatricians. Existing options to address these realities include task-shifting and integrated management models. General practitioners are trained in RHD management and have become the first line of contact. A 1-year diploma in cardiology is also being offered in Rwanda, and noncommunicable disease nurses are currently undergoing echocardiography training. Other centers have trained radiographers or radiology technicians in echocardiography. Another thought was to offer the WHF curriculum in a 1-year diploma that could also be offered as distance learning. Currently, RHD Australia has training modules online. There is also a U.S. guideline for emergency echo.

Colleagues from Egypt highlighted that they were not short of training nor doctors, but they urgently needed individuals with experience in data management, statistics, and ethics. Research infrastructure was also generally insufficient, resulting in decreased research capacity. All participants were concerned that managing available resources was a priority, but it was challenging without administrative staff and financial support.

One proposition was the expansion of exchange programs to up-skill clinicians and make available local and overseas opportunities. These need not be the typical north-south collaborative model; they could be south-south coordinated training, intracontinental, or regional (Table 3). It was clear that all the specialties needed to be trained and informed (pediatrics, adult medicine, cardiology, infectious disease) using strategies appropriate for different cadres of health workers. Surgeons in the groups felt that many of their colleagues found ischemic heart disease surgery more appealing than RHD work, but others were keen to tackle the challenges of valve surgery. Surgeons generally found the interface with the rest of the health system challenging.

Finally, some practical concerns were debated. It was felt that referral systems needed to be developed with national or regional algorithms promulgated. Sustainable models for international normalized ratio (INR) monitoring and the high costs of cardiovascular technology remain concerning in low-income countries. For surgical services to succeed, local interest must be generated to sustain surgical programs and medico-surgical centers need to be accountable to local and regional needs.

Practical issues in RHD control at a country level

Many of the points raised in the first 3 groups were echoed in this group discussion, which grappled with practical issues on a country level (Table 6).

Penicillin

- Availability: The majority of the participants expressed serious concerns regarding the availability, quality, and safety of penicillin. In view of the evidence of efficacy of benzathine penicillin, the realities of intermittent supplies and the inadequate response of pharmaceutical companies and governments to ensure regular, high-quality penicillin is alarming. All countries report an even poorer supply of oral penicillin, used when benzathine was unavailable or not permitted, as in certain areas of India. Indian delegates remarked on the suboptimal compliance with oral penicillin and an observed increased recurrence rate once benzathine penicillin was discontinued in their states (because of concerns around anaphylaxis). All countries represented had different dosage intervals and thus were variably affected by poor supply.

Penicillin thus remains a critical issue for any comprehensive RHD program and a major focus area to be tackled over the next 5 years.

TABLE 6. Practical issues at a country level

Penicillin	• Benzathine penicillin remains the most effective primary and secondary preventive agent for ARF/RHD. • Serious concerns remain regarding the availability, quality, delivery, and safety of penicillin from many areas of the world.
Treatment of sore throat	• Sore throats are still under-recognized and undertreated. • Need for local clinical prediction rules. • Streptococcal sore throat programs needed.
Warfarin	• Point-of care INR is a critical need in order to monitor warfarin use.
National policy of notifiable diseases	• Governments should be encouraged to make ARF/RHD notifiable and to support local registries.
Surgical capacity	• Surgical capacity remains a concern for those caring for patients with advanced disease.

INR, international normalized ratio; other abbreviations as in Tables 1 and 5.

- Anaphylaxis: Deaths due to anaphylaxis, although rare, have been followed by cessation of secondary prevention programs using benzathine penicillin G in some settings. There were a variety of approaches to preventing anaphylactic deaths. One method was increasing the availability of and training in the use of anaphylaxis kits, whereas another was introducing regular skin testing. In 1 Indian center, RHD patients have skin tests prior to each injection. In Nepal, these were performed with the first injection, each batch change, and each brand change. New brand and constant batch changes were challenges both in India and Pakistan and have resulted in either skin tests or test doses with each injection. Two other strategies were presented: 1) In Brazil, a family history is taken prior to delivery of benzathine penicillin; adrenaline is always pre-loaded; and the patient is observed for 40 min after administration. In New Zealand, the first injections are done in a hospital with the rest delivered entirely by nurses in community settings. In South Africa, primary healthcare nurses are routinely involved in other benzathine penicillin delivery programs (such as treatment of syphilis). These units are largely not equipped with anaphylaxis kits, although nurses are taught anaphylaxis management.

Generally, it was felt that further research was needed into the causes and mechanism of anaphylaxis and prevention of anaphylaxis events. Many feel that anaphylactic events are often due to reactions to reagents or impurities rather than to the penicillin itself, yet anaphylaxis has the potential to entirely derail a functioning secondary prophylaxis program. This should be a keen priority research area.

- Delivery: All participants agreed that the evidence indicated that 2-weekly penicillin doses were highly effective. However, such regular administration was problematic in many areas of the world, and thus the standard regimen in most groups was 4-weekly doses. Compliance and adherence remain a major concern and different strategies were outlined. One approach included the situation in Perth, Australia, where nurses visit schools and homes to administer penicillin. The consensus was in favor of employing several strategies depending on the environment and target population. New models were reviewed with comparisons of successes and failures. Studies determining the barriers to adherence are critically needed as is structured evaluation of successful programs. For those on oral prophylaxis, another suggestion was using the directly observed therapy strategy used in tuberculosis management.

The role of the healthcare worker involved in benzathine penicillin delivery was also strongly debated. Skilled health workers are scarce in all regions with high RHD prevalence and increased adherence will place extra demands on already stressed health systems. Integration with coexisting benzathine programs, such as for syphilis treatment, may result in shared costs and possibly improved adherence. Each region should look at their adherence and recurrence rates and the current staff providing penicillin delivery in order to adopt the most successful model. The value of experienced, highly skilled nurses cannot be overemphasized. Reducing the pain of the benzathine injection is an important aspect of increasing adherence; skills in this area should be taught to all community and primary healthcare workers. Adjuncts such as lignocaine, the use of separate needles, normal saline, and slow injections should be practiced.

Simple, cheap, and innovative models are required to support existing health systems to improve compliance. These include delegating prescription authority from doctors to nurses for benzathine penicillin G and text message reminders for benzathine penicillin G doses. A suggestion was to provide small incentives for families to bring children for prophylaxis (e.g., offering a sibling an examination). The use of Internet and electronic records can improve standardization, making the program delivery safer and easier to monitor.

Treatment of sore throat The treatment of sore throat is pivotal to reducing the burden of ARF and eventually RHD in our communities. However, all participants agreed that sore throats were untreated and under-recognized as the primer to RHD. The Nepalese slogan of "a sore throat can break your heart" accompanied by a stern picture of Dr. Prakash Regmi, from the Nepalese Heart Foundation, has been widely distributed throughout Nepal, with good effect. A variety of similar strategies was deliberated, including the use of community health workers or health posts to diagnose and treat sore throats in Rwanda, Zambia, or Nigeria. Although it was agreed that every sore throat should be treated, the consensus was that at least 40% were being missed.

Most regions were treating sore throats with benzathine penicillin, which once again raised many previously mentioned concerns. The evidence for clinical prediction rules was discussed, and the need for further research in this area was mentioned. In addition, research on rapid streptococcal test kits in developing countries is needed to delineate its role, if any, to improve diagnostic yield and treat strep throat.

Different strep throat programs were reviewed. Brazil has a good national strep throat program with reasonable awareness of streptococcal sore throat. This is a result of a local university initiative with evidence-based guidelines tailored to the region. The importance of awareness among children and in schools was stressed and the importance and previous success stories (Cuba) of mass education cited [7]. Work continues in the Philippines, India, and Pakistan focusing on awareness and education in smaller group sessions.

Warfarin Another strongly expressed lack was for warfarin and monitoring of warfarin use for those with atrial fibrillation and/or mechanical prosthesis. Although

most countries had warfarin available in the tertiary centers, this was not often the case in regional hospitals or health posts. Access to INR monitoring was far less likely to be available in remote or rural areas. Many participants expressed a dire need for point-of-care INR testing, as they all perceived this as a real problem. As a result, many patients were commenced on aspirin only.

National policy of notifiable diseases ARF is only notifiable in New Zealand, parts of Australia, and South Africa. However, this was not without problems, despite the obvious advantages [8]. The importance of burden of disease estimates, recurrence monitoring, and case finding was explored and reinforced. Many participants expressed their frustration at the lack of data and the sense of "not knowing what is going on." It was clear, however, that great strides have been made in terms of hospital registries. In addition, registries compiled by organizations such as the Nepalese Heart Foundation have been incorporated into national control and prevention programs with input from governments and departments of health. In Rwanda, electronic integration of all chronic diseases has resulted in a national chronic disease program (Table 3). The importance of integrated programs in resource-poor settings was emphasized while stressing the specific uses of a local RHD registry.

Surgical capacity Finally, the focus turned to surgical capacity in countries with overwhelming burden of disease. The group represented different levels of capacity from mixed public and private surgical services with no real limits (Australia, New Zealand, and Unites States) to centers with no surgery (Nigeria and Zambia) and those with only visiting surgical teams (Rwanda). The difficulties of balancing adult versus pediatric surgical programs, building new surgical capacity within affected countries, and needing to have surgery performed outside of the countries (from Africa to India or Israel) were examined in detail. Many participants bemoaned the fact that the major crisis lay in healthcare manpower, whereas others discussed the realities of the brain drain and the attraction of other climes on recently skilled physicians or surgeons. Of those involved in visiting surgical teams, the frustration of being able to do only a limited amount of surgery was expressed. On the other hand, a major concern was that in these situations, valve replacements were performed in preference to valve repairs. The need exists for better business models for effective low-cost technology without affecting the patient's care. In Brazil, prosthetic valves are cheaper than mitral rings, which has increased the amount of valve replacements rather than the preferred valve repair. The inherent difficulties in patient selection, especially for surgery in other countries, were also discussed.

In general, the reality was long waiting lists for valve surgery with patients dying on these lists. Some emerging country centers such as Nepal, Brazil, and South Africa do have surgical capacity (some even free of charge or heavily subsidized), but they also have extensive waiting lists that include patients from other countries. Advocacy efforts and increased awareness in India, the Philippines, and Nepal have resulted in increased case ascertainment and, subsequently, increasing demand for surgery.

CONCLUSIONS

The second RHD forum was a remarkable event. Building on the foundation of the first RHD forum, over 150 interested participants were able to meet and discuss critical issues on the RHD landscape. Unique to this meeting was a mixture of diverse backgrounds and disciplines, all crucially important to the conversation of RHD control and prevention. It is clear that new leadership is emerging in the RHD space, as well as new focus points beyond medical management to political and policy decisions and interventions. The networking that occurred should encourage new research collaborations and sharing of resources and expertise. Some priorities have emerged: the necessity for political intervention and policy change; the need to increase the health force by incorporating teaching, training, and task-shifting; the need to revitalize the research agenda by merging basic, clinical, and translational research; and, finally, the desperate need for universal access to high-quality penicillin. There were also requests for new resources; for those that already exist to be further developed, improved, and shared across platforms; and for resources to be supported in nonmedical arenas. Finally, the need to involve the patient community in the ongoing discussion was highlighted.

The RHD forum has thus far convened at cardiology congresses that focused attention on medical participants. In the future, consideration should be given to include patient and parent groups, as well as the nonclinical disciplines needed for comprehensive disease activism. It is time to effect concrete change in RHD activities across the world, and we hope that the RHD forum will be part of the solution, rather than a reflection of current problems. Several important initiatives and champions, we envisage, will be born out of these forums and continue to invigorate RHD activities over the next years. The participants of both the first and second RHD forums represent a new, thriving, growing community of RHD activists who should usher in a new era of significant improvements in RHD control and prevention expanding beyond the borders of high-income nations.

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