has played a large part in making PURE successful. The concept is that we bring together data globally, we publish globally but soon after we do that we give the data to each country for them to analyse and publish the data from their own country or from a region'.

However, rather than a radical re-think on the evidence and diet, he believes PURE has 'brought together a more consistent level of overview' than before.

> 'I would say by having the same standardized approach to enrolling people from the community, measuring their diet in a standardized way across the world, using validated tools and collecting what we call co-variants in a standardized way we are able to inform the discussion around diet at a global level far better than any other study has done before'.

Future of PURE

As for the future, he hopes PURE can continue following the participants for another 10, possibly 20 years with steps in place to collaborate with two other cohorts that add another 100 000 people from different countries.

> 'If we can follow these 300 000 people for at least another decade and even more, we will inform not only CVD but conditions of ageing including dementia, disability, frailty and cancers, lung disease, and kidney disease'.

Sub studies of PURE will look at what aspects of health systems and healthcare delivery at a societal level are important, issues of the environment, pollution, and medication costs.

PURE is a multi-level, and multidimensional, collecting information on societal factors, the environment, individual health behaviours, measures of risk factors and using genetics and omics.

> 'I do not know of another study that has this entire cascade and diversity of information', he said. 'But PURE has only been possible because of the selfless collaboration of hundreds of investigators around the world and the creativity that fresh thinking brings'.

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Momentum builds for a global response to rheumatic heart disease

Introduction and RHD Resolution

The World Heart Federation (WHF) serves as a representative body for the cardiovascular community (including national and continental cardiology societies and foundations) at the global level and works with scientific, medical, and professional communities, as well as patients and charitable organizations. The WHF works at the international and national levels through its own activities and those of its member organizations. The WHF is at the heart of driving the CVD agenda and advocating for better heart health globally, with a particular focus on health issues of developing countries among them rheumatic heart disease (RHD).

In recent years, WHF has led and co-ordinated civil society advocacy efforts to push for global action on RHD. On Friday 25 May 2018, Member States of the World Health Organization unanimously adopted a *Resolution on Rheumatic Fever and Rheumatic Heart Disease* at the 71st World Health Assembly in Geneva, Switzerland. (*see Box: WHO Resolution on Rheumatic Heart Disease, following this article*)

The historic adoption of the resolution marks the first time that rheumatic fever (RF) and RHD have been recognized as global health priorities on the world stage and represents the culmination of a growing number of events, declarations, and regional action plans that have sought to highlight the urgent need for a global response.

March 2016	The Pan-African Society of Cardiology (PASCAR) and the African Union Commission (AUC) convene to adopt the Addis Ababa Communiqué, which outlines seven key actions to eradicate RHD in Africa and was endorsed by African Union Heads of State.[1]
January 2017	The conference *RHD: From Molecules to the Global Community* resulted in the Cairo Accord,[2] which highlights the importance of strengthening health systems and refining clinical and policy research.
October 2017	The *WHF African Summit on Best Practices in Policy and Access to Care* (Sudan, 2017), concludes with the Khartoum Action Plan, which recommends actions on surveillance, diagnosis, availability of penicillin, and improved access to reproductive health.[3]
December 2017	On the occasion of the 50th Anniversary of the World's 1st Heart Transplant *the Cape Town Declaration on Access to Cardiac Surgery in the Developing World* is adopted to urge all relevant stakeholders to commit to develop and implement an effective strategy to address the scourge of RHD in the developing world.[4]
May 2018	Member States adopt a Global Resolution on Rheumatic Fever and Rheumatic Heart Disease at the 71st World Health Assembly in Geneva, Switzerland.

The Resolution on Rheumatic Fever and Rheumatic Heart Disease was written by a group of governments—led by New Zealand—and demands national and international decision-makers to prioritize and fund RHD prevention and control in all endemic locations.

The Resolution contains 5 recommendations for governments, 5 recommendations for WHO, and 3 action points for civil society (included at the end of the article) and was co-sponsored by 23 countries from all six WHO regions.

The Resolution also asks WHO to lead and co-ordinate global efforts to prevent and control RHD, with RHD to be considered broadly across relevant WHO work areas; WHO has announced that RHD will be the responsibility of the cluster for Family, Women's, Children's, and Adolescents' Health, reflecting the cross-cutting nature of this disease.

United to End RHD Side Event

Highlighting the impact of the resolution on patients and frontline health workers

On 23 May, WHF co-organized a side event to the World Health Assembly—entitled *United to End RHD*—which focused on the impact of a Resolution on RF and RHD on people living with RHD and frontline health workers delivering essential RHD services.

This event was organized alongside the Medtronic Foundation and Reach as part of the RHD Action partnership and was also co-sponsored by five governments: Australia, Colombia, Fiji, Namibia, and New Zealand.

After an introduction from moderator Natalie Africa (United Nations Foundation), Professor Karen Sliwa (President-Elect, WHF) and Associate Professor Liesl Zühlke (President, Reach) opened the event, praising the bold actions set out by the Resolution. They acknowledged New Zealand's leadership in pushing for the Resolution and highlighted the participation of people living with RHD and frontline health workers, whose 'voices are too often absent from discussions'.

This was followed by a moment of remembrance for Tom Okello, a committed and inspirational advocate and former chair of the RHD Patient Support Group at the Uganda Heart Institute (UHI) who sadly passed away this year. Moderator Natalie Africa then interviewed two young women living with RHD, who gave heartfelt accounts of their experiences.

Christine Katusiime (Vice-Chair of the RHD Patient Support Group, UHI) described the challenged by stigma, with many employers perceiving people living with rheumatic heart disease (PLWRHD) to be weak and vulnerable, and the financial constraints and distance travelled to accessing care. She stressed the need for services at the district level and expanded the provision of family planning services for women living with RHD. Buli Wainiqolo (Volunteer, Patient Support Group, Fiji RHD Prevention and Control Programme) issued a rallying call to policy makers to place people living with RHD at 'the forefront and not at the periphery of RHD agenda', stating 'we have a right as young people to have a chance at the table, as it is our future that we are discussing today'.

Following these powerful accounts, the Honourable Dr David Clark, Minister of Health for New Zealand, delivered a keynote speech. He began by paying tribute to Diana Lennon, a leading paediatrician and researcher who died in May 2018. Drawing on the experiences of New Zealand's national RHD programme, Dr Clark provided an overview of the Resolution and how it could contribute to tackling this disease 'from primordial to tertiary prevention'. In implementing the Resolution, he challenged the audience to 'think big, be innovative, be action-oriented [. . .] It's now time to put these thoughts into action'.

Shifting from the global policy level, Natalie Africa then discussed the impact of a Resolution on frontline health workers, interviewing Dr Bhagawan Koirala (Chief of Cardiovascular & Thoracic Surgery, Tribhuvan University, Nepal) and Elizabeth Machila (Coordinator for the Beat RHD Programme, Zambia). Dr Koirala summarized progress achieved in tackling RHD in Nepal and hopes for a comprehensive national programme after the adoption of the Resolution. Elizabeth Machila echoed this call, stating 'we can, and we should eliminate RHD in our lifetime', and emphasized the importance of increasing awareness and education among children, parents, and health workers.

The event concluded with a multisectoral panel discussion, 'a Path to End RHD', comprised of academics, government and Ministry of Health officials, and representatives of the private sector. Bernard Haufiku, Minister of Health and Social Services for Namibia, emphasized the global prevalence of RHD, noting the similar numbers of people living with RHD as HIV. Professor Brendan Murphy, Chief Medical Officer at the Australia

World Health Assembly

Living with RHD as a Young Person, Christine Katusiime, Uganda (L), Buli Wainiqolo, Fiji (R)

Panel discussion, (L) to (R) Karen Sliwa, Brendan Murphy, Bernard Haufiku, H.E. Nazhat Shameem Khan, Liesl Zühlke, Jonathan Spector

Department of Health, stated that RHD was 'almost entirely confined to our Indigenous population'. Calling this situation 'unacceptable', he outlined national plans to eliminate RHD by 2031.

Fijian Ambassador to the UN in Geneva Nazhat Shameem Khan noted the importance of collaboration with other sectors and training health workers. This message was echoed by Dr Jonathan Spector (Head, Global Health, Novartis Institutes for BioMedical Research), who called on the RHD community to draw on private sector expertise in areas such as supply chains and research.

Prof. Sliwa and Associate Prof. Zühlke described the roles played by WHF and Reach in RHD prevention and control, with Prof. Sliwa noting WHF's work to 'facilitate, promote and create awareness of RHD activities in different countries', while Associate Prof. Zühlke highlighted the technical assistance and tools produced by reach to support governments.

Liesel Zühlke Karen Sliwa

Following an interactive discussion with the audience, Natalia Africa concluded the event, saying, 'in preventing, controlling and eventually eliminating RHD, we have an opportunity to tackle one of the true diseases of poverty'.

First Meeting of the WHF RHD Taskforce in Maputo, Mozambique

In 2017, the WHF contacted our global membership to ask for their input and comments on the role of WHF in the prevention, control, and elimination of RF and RHD following the adoption of the Resolution.

Based on this feedback, three priority areas (and Working Groups to focus on these areas) were identified:

- Policy & Advocacy
- Prevention, Control, and Medical Management
- Access to Cardiac Surgery for RHD

To co-ordinate these activities—and to build on the growing momentum created by the Resolution—the WHF RHD Taskforce was established, to be chaired by the WHF's President-Elect Prof. Karen Sliwa, and with the aim of taking a small number of targeted actions on areas within RHD prevention and control to contribute to the implementation of the Resolution.

To kickstart the Taskforce's activities, the first meeting of the Working Group Leaders was held in Maputo, Mozambique on 13 June 2018.

The meeting was structured around three presentations on the three focus areas; the Policy & Advocacy Working Group (led by Prof. Krishna Kumar, Amrita Institute of Medical Sciences, Prof. Anita Saxena, All India Institute of Medical Sciences, and Prof. Cleonice de Mota, Federal University of Minas Gerais) focused on the global shortfall of benzathine penicillin G (BPG) the essential antibiotic for primary and secondary prophylaxis for RF and RHD.

WHF RHD Taskforce

Outlining the numerous challenges in the supply chain—such as the small number of manufacturers, varying formulations, price controls, and the disconnect between supply and demand—Prof. Kumar emphasized that it was essential to engage a diverse range of stakeholders to secure a reliable BPG supply. Discussions also focused on the reluctance of many patients to receive injections and health workers to administer BPG, due to both the pain of injections and occasional risk of sudden deaths among patients, particularly those with severe RHD. Participants agreed that two initiatives should be prioritized:

- Convene relevant stakeholders from different sectors to improve the global supply on BPG
- Engage with researchers and other partners to explore improved formulations of BPG

Maputo Railway Station Maputo vegetable market Maputo fish market

The presentation for the Working Group for Prevention, Control, and Medical Management (led by Prof. Sulafa Ali, Sudan Heart Institute and Prof. Ana Mocumbi, National Health Institute and Eduardo Mondlane University, Mozambique) focused on the need to implement demonstration sites showing feasibility of RHD control programmes, and to increase the capacity of health workers to diagnose and treat patients.

In the context of the emphasis of the RHD Resolution on engaging the maternal & child health community and allied health workers, participants agreed that this Working Group should focus on two areas:

- Support a demonstration site for RHD detection among pregnant women in primary health care centres
- Support the development of training programmes with clear RHD treatment algorithms for non-physician health workers

Prof. Peter Zilla (University of Cape Town) delivered a presentation on Global Access to Cardiac Surgery in which he emphasized that there is limited access to heart valve surgery for the majority of people around the world. He indicated the low numbers of cardiac surgeons per million of population in many countries such as Mozambique and Nigeria and stressed the importance of training cardiac surgeons and other specialized caregivers at centres in low- and middle-income countries to build capacity.

He noted that there was scarce data on the global need for surgery, but that estimates suggested a significant unmet need in countries such as China and India. He also highlighted *The Cape Town Declaration on Access to Cardiac Surgery in the Developing World*, which urges 'all relevant entities within the international cardiac surgery, industry, and government sectors to commit to develop and implement an effective strategy to address the scourge of RHD in the developing world through increased access to life-saving cardiac surgery'. Participants agreed to prioritize a number of actions in support of this Declaration:

- Highlight and disseminate the forthcoming publication of the Declaration
- Publish estimates indicating the Global Unmet Needs in Cardiac Surgery

The next meeting of the WHF RHD Taskforce was alongside the European Society of Cardiology Congress in Munich in August; we look forward to working with our Member organizations and others in the RHD community to develop our projects further and begin to translate the Resolution's policies into action.

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References

References are available as supplementary material at *European Heart Journal* online.