



MEDIA RELEASE

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Campaign to tackle RHD, a preventable yet deadly disease, builds momentum

Three Aboriginal brothers – the youngest only three - who are living with deadly rheumatic heart disease (RHD) will today join community representatives, health workers and medical experts at Parliament House, asking for a commitment to end the disease in Australia.

Virtually eliminated from the rest of Australia and most wealthy countries decades ago, rheumatic heart disease remains a scourge in developing countries and remote Aboriginal and Torres Strait Islander Communities, where rates are among the highest in the world. RHD starts with a sore throat or skin sores but can end with permanent heart damage, open-heart surgery and death at a very young age.

Ms Pat Turner AM, Co-Chair of END RHD and CEO of the National Aboriginal Community Controlled Health Organisation (NACCHO), says comprehensive and collaborative action to tackle the disease is needed to ensure Aboriginal and Torres Strait Islander children are given the chance to reach their full potential.

“Aboriginal and Torres Strait Islander children are 55 times more likely to die of rheumatic heart disease than other Australian children. We’re here today seeking a commitment from all political parties to stop this preventable disease from ever taking the life of another child in Australia.”

“Aboriginal leaders are here to let politicians know that we are ready to partner with them, and that with their support, ending the disease is achievable,” Ms Turner said.

Also speaking at the event is one of the world’s leading rheumatic heart disease researchers, Professor Jonathan Carapetis AM, Co-Chair of END RHD and Director of the Telethon Kids Institute, who says a nonpartisan commitment is the next step needed to tackle the disease in Australia.

“I’ve spent 25 years researching rheumatic heart disease, and I truly believe that we’ve never been in a stronger position to eliminate the disease in this country.”

“Aboriginal and Torres Strait Islander organisations are taking the lead and working hand in hand with communities. We researchers are bringing the evidence to support them. If there is one country in the world that should be able to eliminate RHD, it is Australia,” Professor Carapetis said.

The Snow Foundation CEO, Georgina Byron, said event participants are pleased that RHD has become a priority for the Australian Government.

“The Government’s commitment to developing a roadmap to eliminate RHD is a great start, but we need an urgent allocation in the 2019 Federal Budget to commit to immediate action, fund

comprehensive primary health care and appropriate educational activities in communities at high risk of RHD. We need to continue to ensure Aboriginal and Torres Strait Islander leadership, and set stretch targets to end RHD," Ms Byron said.

Aboriginal Communities are taking local action to stop the devastating effects of the disease through community-led solutions. A unique program highlighted today engages Aboriginal Health Practitioners to use traditional languages and new technology, to create a comprehensive local effort to identify and stop RHD.

"With the engagement and participation of traditional owners in Maningrida, the local school, the health clinic, and Malabam Health Board, 13 new cases of RHD were discovered among 450 children, and two children – aged 8 and 12 – needed emergency heart surgery," says Dr Bo Reményi, paediatric cardiologist and NT Australian of the Year. "At the same time, teachers and health workers were educating children and families about prevention in traditional language and through local metaphors. As one traditional owner recently remarked, *'it's been the greatest community collaboration I've ever experienced.'*"

A comprehensive, community strategy, led by Aboriginal and Torres Strait Islander people, is critical to ending RHD. With strong leadership and political support, we will meet Australia's commitment earlier this year at the World Health Assembly to prevent, control and eliminate rheumatic heart disease, but we need to take action now so that no child born in Australia from this day forward will develop rheumatic heart disease.

For more information, please contact Kathleen Sweetapple, Communications and Media Officer at the Snow Foundation at 0455 22 77 11 and K.Sweetapple@snowfoundation.org.au or Kate Harford, END RHD Communications and Advocacy Specialist at 0402 558 465 and Kate.Harford@telethonkids.org.au.

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About The Snow Foundation

The Snow Foundation is the creation of brothers Terry and George Snow who have a straightforward view—if you see someone struggling, give them a helping hand.

Since it was established in 1991, the foundation has helped more than 250 groups, more than 240 individuals and provided more than \$27 million in funds. Every dollar donated was given with the aim to enable individuals and organisations introduce positive improvement in their lives and their communities.

The foundation has helped with projects big and small, in a broad range of areas such as education, belonging, social change and health. Projects include purchasing vital equipment for people with disabilities, developing microloans to help women escape domestic violence, funding scholarships, providing a home for the homeless, advocating for marriage equality, broadening the impact of excellent palliative care and partnering with community organisations, philanthropy, businesses and governments to improve and save lives whenever possible.

About END RHD

END RHD is an alliance of health, research and community organisations seeking to amplify efforts to end rheumatic heart disease in Australia through advocacy and engagement. END RHD is the first time such a broad-based alliance has come together to pool their collective expertise. END RHD is:

- Working with the communities most at risk of rheumatic heart disease in Australia. Only through Indigenous-owned, community-led strategies will we be able to successfully tackle the disease.
- Securing funding and the political will to turn the world class research conducted by the End Rheumatic Heart Disease Centre of Research Excellence (END RHD CRE) into action.
- Educating and empowering Australians about the role they can play in ending rheumatic heart disease

The founding members of END RHD are **the Australian Medical Association, Heart Foundation, National Aboriginal Community Controlled Health Organisation (NACCHO)**, RHD Australia based at **Menzies School of Health Research, Aboriginal Medical Services Alliance Northern Territory (AMSANT), Aboriginal Health Council of Western Australia (AHCWA)**, the END RHD Centre of Research Excellence based at **Telethon Kids Institute, The Aboriginal Health Council of South Australia (AHCSA)**, the **Queensland Aboriginal and Islander Health Council (QAIHC)** and the **Aboriginal Health and Medical Research Council (AH&MRC)**.