

MEDIA RELEASE

Action to address rising RHD rates – Parliamentary event

Members from remote communities gathered at Parliament House to discuss the stark reality of First Nations people living with rheumatic heart disease and the community-led and research initiatives in place.

09/08/2023: Rheumatic heart disease (RHD) is a preventable yet devastating condition that, if left untreated, can lead to heart failure, disability, and even death. It starts with a sore throat or skin sore caused by Strep A bacteria which can eventually lead to permanent heart damage.

“RHD is a serious health justice issue causing devastation across Aboriginal and Torres Strait Islander communities. It’s destroying lives through ongoing and painful injections, surgeries for children as young as five, unnecessary deaths and the huge impact all this is having on our communities,” Vicki Wade - Senior Noongar woman - from The Heart Foundation said.

The burden of RHD continues to grow, and disproportionately affect Aboriginal and Torres Strait Islander communities, particularly in remote Northern Australia. Currently, approximately 10,000 people live with RHD or its precursor, acute rheumatic fever (ARF), with more than 80% being Aboriginal and Torres Strait Islander people. Without urgent action, this number is expected to almost double within the next decade, resulting in over 650 deaths and over 1300 individuals requiring open-heart surgery.

First Nation communities are experiencing a number of significant social and economic circumstances that lead to the exposure and spread of Strep A, including:

- Limited access to adequate healthy housing, with chronic over-crowding
- Limited access to safe and hygienic spaces and regular washing facilities
- Other systemic issues, including poverty, and low-quality food, and
- A limited knowledge of Strep A and its causes

“It’s time for action, we’ve had enough talk. We need to start to look for real practical solutions to dealing with RHD. Practical solutions that will make a real difference on the ground, in our homes, they must be healthy and maintained. We must find ways to improve our living conditions, and ways for people in our community to purchase the things they need on a weekly basis that will make a difference. White goods, quality food and cleaning products, access to a laundromat, those sorts of things, and a way to overcome the prohibitive costs that we face, simply because we are living remotely,” Alec Doomadgee – Doomadgee community - said.

Currently two Aboriginal and Torres Strait Islander people die each week from RHD, and the burden of this disease is carried predominantly by 5 – 14-year-olds.

“Coen was seven when he was diagnosed. It could have been avoided if Coen had just been screened properly,” Coen’s mother, Kara Rudken – Taribelang Bunda and Wiradjuri woman said.

“My mum had questioned if I had rheumatic fever when I was eight because I had a lot of sore throats. In a way it wasn’t detected because of my social situation. No one followed up,” Kenya McAdams – Jaru and Kira woman from Halls Creek, WA said.

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However, a large number of organisations and individuals have committed to working to end RHD, and there are several community-based and national actions well underway.

The leadership shown by the National Aboriginal Community Controlled Health Organisation (NACCHO), which has been at the forefront of national efforts to address RHD is commendable and vital. Their establishment of governance partnerships, including their Joint Advisory Committee, has been instrumental in driving progress.

Community action has also been a driving force in tackling RHD in partnership with initiatives such as the Deadly Heart Trek, laundries program by both Orange Sky and the Aboriginal Investment Group, and the transformative impact of peer support through Champions4Change.

The Deadly Heart Trek, for example, has been invited into 36 communities since 2021, empowering First Nation people by working together to enable access to health and medical specialists to conduct skin checks and heart screenings for school students in NT, SA, Central Australia and Queensland. They also provide education and engage the whole community.

“During the three major Treks, we screened over 2,700 young hearts and thankfully, we found plenty of healthy hearts,” Paediatric Cardiologist and Deadly Heart Trek leader Dr Rob Justo said. “Unfortunately, we also diagnosed and treated 88 new RHD cases. This work demonstrates the importance of prevention and early detection and of course community engagement and empowerment, in the efforts to end RHD. Without rapid treatment, these young people will need, at best, a lifetime of care, and at worst, open heart surgery.”

These actions are examples of the community-based initiatives needed in the 2020 RHD Endgame Strategy. This Strategy provides an evidence-based roadmap, to guide the path toward ending RHD in Australia. Implementing this Strategy with a focus on Aboriginal and Torres Strait Islander leadership, community-based programs, healthy environments, early prevention, and comprehensive care and support will be crucial in curbing this preventable disease.

“Together, we can put an end to the suffering caused by rheumatic heart disease. There is a strong momentum - Aboriginal leadership, community demand, collective goodwill and an evidence base in the *‘RHD Endgame Strategy’* that shows us that we can eliminate this disease. If we accelerate comprehensive community action now and empower my people and accelerate investment, we can end this preventable disease,” Vicki Wade said.

In 2018, the World Health Assembly passed an international resolution to prevent RHD. Australia was a co-sponsor of this resolution, amplifying national commitments to eliminate RHD.

The recent commitment from the Federal Government to more than double the funding for the elimination of RHD is welcome, increasing it from \$6 million to \$12 million annually plus \$1.5 million for portable echo screening equipment. This increased funding will play a vital role in helping to end this preventable disease and is a great foundation, but more is needed.

In addition to federal and state government funding commitments, significant philanthropic funding has been committed to ending RHD, by organisations like The Snow Foundation.

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