

Rheumatic Heart Disease Endgame Strategy: A community resource What it means for you



END RHD is a group of ten organisations from the Aboriginal Community Controlled Health, research and advocacy sectors, leading work to end rheumatic heart disease in Australia.

We are committed to Aboriginal and Torres Strait Islander-led solutions to end RHD in Australia; at the heart of all our work is the people and communities living with, and affected by, rheumatic heart disease.

The five key recommendations that we are calling for are based on the wisdom of communities, researchers, doctors and health workers, which form the RHD Endgame Strategy: The blueprint to eliminate rheumatic heart disease in Australia by 2031.

To read the Strategy in full, head to telethonkids.org.au/rhd-endgame.

What is Rheumatic Heart Disease?

Rheumatic Heart Disease (RHD) is a permanent form of heart damage

- RHD starts with a sore throat or skin infection caused by the germ Strep A.
- When not treated with antibiotics, a sore throat or skin sore can lead to rheumatic fever (ARF).
- 3 ARF can cause sore joints, high fevers, and inflammation of the heart.
- Other symptoms of ARF go away, but the heart damage remains, this is RHD.
- People living with RHD need careful management to keep their heart strong, including regular antibiotic injections and sometimes, heart surgery.



Who has RHD?

§5,000

Aboriginal and Torres Strait Islander peoples have RHD or ARF.

2 in 3 people with RHD are women The most at-risk age group of developing ARF or RHD is

5-15 years old

Why are Aboriginal and Torres Strait Islander peoples most at risk?

- Our people get this because of history and colonisation
- + RHD is not hereditary
- + While there is no cure for RHD, it is completely preventable.



What do we need to do?



Aboriginal and Torres Strait Islander leadership

We need two-way Aboriginal and Torres Strait Islander leadership. This means listening to the voices of people in communities.

It also means having Aboriginal and Torres Strait Islander peoples in positions of power to talk to government, work with researchers and make sure communities receive the funding they need.

At the end of the day, it is Aboriginal and Torres Strait Islander peoples with lived experience of ARF & RHD who are the experts.







Community-based programs

Within our communities we have the knowledge and wisdom to be able to prevent RHD and make sure those already living with RHD have the best quality of life.

But we need the resources to fund new programs. Each community has different ideas – they should be able to choose what they want to do.



Healthy environments

We know that healthy houses and environments will stop RHD.

This means having enough houses so that our people can live comfortably and healthily. It means making sure our showers, hot water and washing machines work.

Ensuring healthy environments will stop the spread of the Strep A germ that leads to RHD.



Early prevention

We need to stop sore throats and skin sores leading to rheumatic heart disease.

This means making sure we have access to good quality care on Country. And that our clinics have a strong and well-resourced workforce.





Care and support

Everyone deserves to live their lives to the fullest. For people living with ARF or RHD this means making sure they recieve culturally appropriate care and support, with zero racism. It means making the health system easy to navigate and giving people the option to receive treatment on country if they prefer. Pregnant women especially need the support and care to ensure they have a healthy pregnancy. And teenagers need support to make sure they get their treatment on time.

No one should go through this alone. We need the funding to build networks in communities and across the country so that we can support each other. If we can work together and implement these priority actions, no one else needs to go through this.

What can you do now?

People and communities living with acute rheumatic fever and RHD are already taking action.

YOU CAN TOO.

You can talk to your friends and family and community leaders about what needs to happen to end RHD. You can join the RHD Champions4Change, who support each other, advocate to end RHD, educate and raise awareness. We can all help end RHD, you are not alone and we are stronger together.

Together, we can

This booklet was designed in consultation with the Champions4Change.

The RHD Champions4Change is a support program for people living with acute rheumatic fever and RHD.

It is designed and led by Aboriginal and Torres Strait Islander peoples and communities, with support from RHDAustralia.



The Champions4Change support each other, advocate to end RHD and design education and awareness programs for their communities.

To learn more about this program, head to rhdaustralia.org.au

Join the movement to end RHD endrhd.org.au/take-action/

