

TAKE HEART

DEADLY HEART TREK

Medical and educational visit to Indigenous communities in Queensland 2022

What is the Deadly Heart Trek?

The Deadly Heart Trek was developed as an opportunity to listen, learn, educate, diagnose and treat Aboriginal and Torres Strait Islander communities affected by rheumatic heart disease (RHD).

The project is led by a dedicated group of experienced doctors, local health workers and Indigenous leaders who are committed to progressing the prevention of rheumatic heart disease.

Results from Five Communities

978 Children's hearts screened + skin checked*

922 Healthy hearts

29 New RHD cases diagnosed and treated (10 definite + 19 borderline)

19 Known RHD cases treated

8 New congenital cases diagnosed and treated

1% Had a new definite diagnosis of RHD, all mild early disease

4.9% Had definite RHD (new + known)

These results tell us these regions have a high burden of disease - the World Heart Federation considers a community where more than 0.1% of children have RHD, to be a high burden of RHD.

Approximately 1500 children and families experienced education and increasing awareness activities on RHD, healthy hearts, and healthy skin.

*Low numbers of skin infection were detected, treatment was given where needed, with a few referred to the health clinic.

The Trek to QLD Communities

Several communities in Queensland were highly enthusiastic to invite the Trek team for a visit. This leg of the Trek could finally go ahead in August/September 2022 after the previous year's COVID situation. Dr Robert Justo and Dr Ben Reeves co-lead the two trek delivery teams starting in Thursday Island and visited five communities across the Cape and Torres Strait regions.

Community consultation, engagement and understanding

The Trek team included Aboriginal and Torres Strait Community Engagement Leads who worked with the communities in advance. They sought permission and ensured the teams were invited to visit and organised the logistics to prepare the communities. During this period, engagement with local health centres/clinics and Aboriginal Community-Controlled Organisations was established which provided vital support for the visit.

All members of the delivery team and the Steering Committee attended a mandatory cultural authority session with the Lead cultural advisor, Vicki Wade prior to the visits.

What happened on the ground

Upon arrival, the teams were warmly welcomed by community members, including Traditional Owners where possible, and further discussions were held with local organisations to ensure community understanding and empowerment. The major focus of the Trek was education, and heart screenings so that RHD could be diagnosed and treated early.

A large part of the work was done in schools and some at youth and community centres or local organisations. Children were reviewed for healthy hearts and healthy skin, and general well-being. The local communities were extremely helpful, assisting with the coordination of consents, to maximise the number of kids' echo screenings.

Education sessions and activities were provided to students and teachers at the schools. Many youth service providers enjoyed these enabling them the opportunity to collaborate and support the Trek.

During school sessions, Trek team members presented an entertaining session on 'healthy heart' and 'healthy skin' and outlined the Echo screening process.

Songs produced by other communities called 'boom boom' and 'my heart keeps beating', were a real hit with the students in teaching them how to prevent RHD. Gift packs with sponsor-donated items such as socks and bracelets were a welcomed treat at the end of the sessions.



Treatment and follow-through

All children who were diagnosed with borderline or definite RHD were treated on the same day, following parental consent. The new RHD patients were formally registered on the Queensland control program and linked to standard treatment and cardiology care. A solid number had various skin diseases and were treated immediately. Children with other health conditions were also treated on the same day and linked to health services for long-term management.

Post visit follow-up

Following the visits, an online survey was sent directly to the communities to gain feedback. Each of the communities responded that they greatly benefited from the visits and would welcome them again. They also reported they would recommend the Deadly Heart Trek team to other communities.

We are in the process of writing to and meeting relevant Government members and stakeholders with the data findings and learnings.

"We were hugely grateful to the whole team for their friendly warmth with our students as well as their quick and professional screening of each child."

"There was great preliminary communication in the lead up to the day which allowed us to share the information with our parent and wider community. Follow up communication with parents/carers of students was excellent."

Recommendation

Extra efforts need to be made to address RHD and scabies in these communities both Federally and by State and Territory. We understand there has been a commitment from the Albanese Government to more than double the funding for the elimination of RHD in Australia, increasing from \$6 million to \$13.5 million nationally. We also urge each State and Territory to commit additional funds. By taking greater action and providing more funding, we can make a difference in the lives of the thousands of Aboriginal and Torres Strait Islander people living with RHD and meet our obligation to prevent and eliminate RHD by 2030 under the World Health Organisation's 2018 international resolution, to which Australia is a signatory.

We have a philanthropic partner, The Snow Foundation who is engaged and willing to contribute to a greater commitment.

The RHD Endgame Strategy Report clearly outlines what needs to happen to both prevent people from developing ARF and improve the quality of life of those living with RHD. The Report called for an initial investment of \$40 million over 3 years for Phase 1 implementation to establish the national implementation unit, invest in community-level action and support jurisdictional action plans. This investment is needed now as a minimum to meet its 2030 target.

We recommend this community listening and action work, by the Trek team, be business as usual for communities with a high burden of RHD and who don't have easy access to health workers. The Trek team is developing an overview of what this could look like, and it will include recommendations to include a First Nations health worker and/or community engagement lead as part of the team.

Future of the Deadly Heart Trek

A Trek to communities in Central Australia is being planned for March 2023, and further Treks to communities across the country are under consideration.

Torres Strait Region QLD

Heart Screenings

672 Total children's hearts screened + skin checked*

644 Normal results

11 New definite RHD cases

6 New borderline cases

2 Known definite RHD cases

4 Known borderline cases

1 Known case of ARF

23 Total with RHD

24 Total with RHD/ARF

5 Congenital cases and no known congenital

* Low numbers of skin infection were detected, treatment was given where identified

Far North West Region QLD

Heart Screenings

306 Total children's hearts screened + skin checked*

278 Normal results

4 New definite RHD cases

8 New borderline cases

13 Known definite RHD cases

0 Known borderline cases

0 Known cases of ARF

25 Total with RHD

25 Total with RHD/ARF

3 Congenital cases and no known congenital

* Low numbers of skin infection were detected, treatment was given where identified

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Data

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