

# DEADLY HEART TREK



## Medical & Educational Report 2021-2024

### What is the Deadly Heart Trek?

The Deadly Heart Trek was developed as an opportunity to listen to and learn from Aboriginal and Torres Strait Islander communities and to provide education, diagnoses and treatment to those affected by rheumatic heart disease (RHD).

### Who is involved?

**Governance:** The Trek is governed by the Deadly Hearts Limited Board consisting of an Aboriginal health and cultural engagement lead, expert paediatric cardiologists, an Aboriginal social justice lawyer, and an independent philanthropist committed to progressing the prevention of RHD.

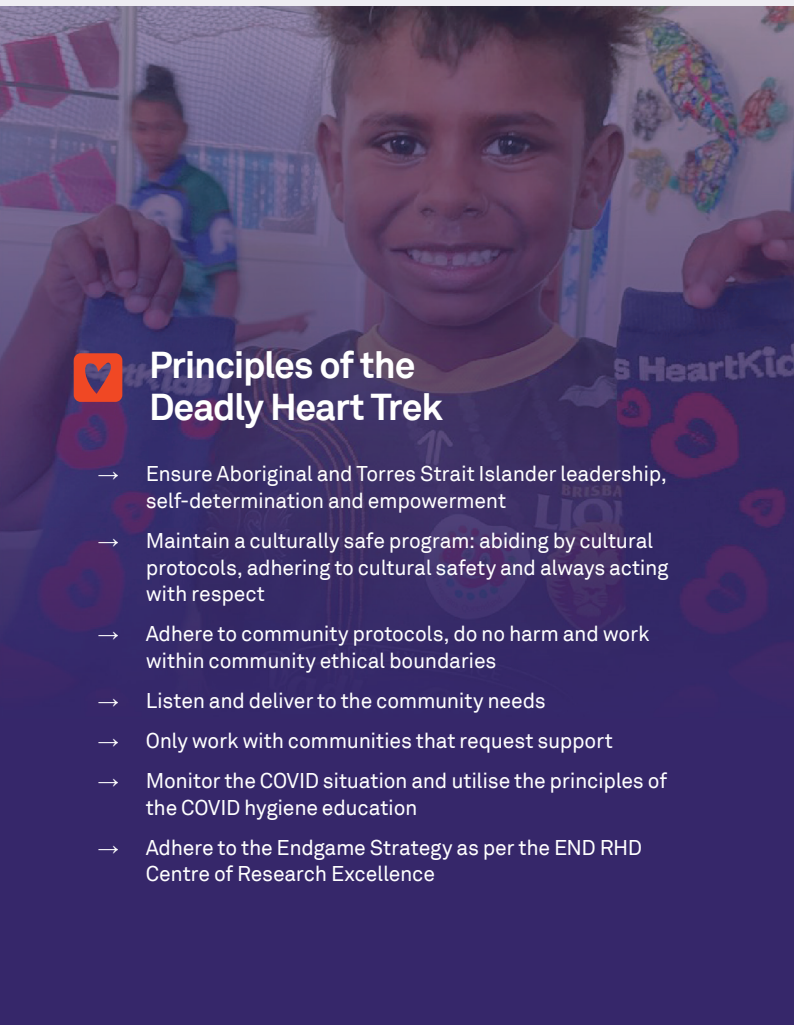
**The delivery team:** First Nations cultural guides, doctors, health workers and nurses. Many of the team have worked in communities for decades on RHD so they are well known.

**Key collaborators and sponsors:** The Snow Foundation, Heart Foundation Australia, RHD Control Programs, Take Heart Project, Champions4Change, HeartKids, Congress, AMSANT, Tangenteyre Council, NT Cardiac, Orange Sky, QLD Children's Hospital, Far North QLD Hospital Foundation, Humpty Dumpty Foundation, GE Healthcare and Rotary Club of North Balwyn.

### Treks to date

Four Treks have taken place across Northern Territory, Queensland and Central Australia/APY Lands and Alice Springs, each Trek going for approximately two weeks. They have been jointly led by First Nation guides and community members with doctors leading the medical side.

- Northern Territory 2021 - visited nine communities: five in the Big River Region and four in the Barkly region
- Queensland 2022 - visited five communities across the Cape, Torres Strait and Northwest Queensland
- Central/APY Lands 2023 - visited 22 communities
- Alice Springs 2024 - visited 13 schools, 7 town camps, 2 youth centres and 6 Congress clinics.



### Principles of the Deadly Heart Trek

- Ensure Aboriginal and Torres Strait Islander leadership, self-determination and empowerment
- Maintain a culturally safe program: abiding by cultural protocols, adhering to cultural safety and always acting with respect
- Adhere to community protocols, do no harm and work within community ethical boundaries
- Listen and deliver to the community needs
- Only work with communities that request support
- Monitor the COVID situation and utilise the principles of the COVID hygiene education
- Adhere to the Endgame Strategy as per the END RHD Centre of Research Excellence

### Pre-visit planning

The Deadly Hearts Board and team conducted extensive and rigorous project preparation including checklists for pre, during and post the visits and a comprehensive risk matrix. The First Nations Cultural Guides and support team engaged and consulted with communities well in advance, seeking permission to ensure the Trek teams were invited to visit.

They worked with communities to organise the logistics and prepare the activities. An informative 'Register your Interest' form was shared within communities, which prompted their selection of activities. Engagement with local health centres/clinics and Aboriginal Community-Controlled Organisations was established which provided vital support and leadership for the visits.

All members of the delivery team and the Deadly Hearts Board attended mandatory cultural authority sessions about the specific regions and communities, led by our Cultural lead and the Trek First Nations cultural guides prior to the visits.







## Education and awareness

Education sessions and activities were provided to students and teachers at the schools. Complementary community sessions varied across communities, with some holding specific educational and awareness events such as BBQs, movie screenings of the Take Heart documentary and some fun sporting activities. Many youth service providers enjoyed these, enabling them the opportunity to collaborate and support the Trek.

During school sessions, Trek team members presented an engaging session on 'healthy heart' and 'healthy skin' and outlined the Echo screening process. Songs produced by communities called 'boom boom' and 'my heart keeps beating', were a real hit in educating students on prevention of RHD. Gift packs with sponsor-donated items such as socks and bracelets were a welcome treat at the end of the sessions.



## ? What happened in community?

Upon arrival, the teams were warmly welcomed by community members, including Traditional Owners and Elders where possible, and further discussions were held with local organisations to ensure community self-determination and empowerment. The major focus of the Trek was education, heart screenings and skin checks so that RHD is better understood, and any new cases could be diagnosed and treated early.

Most of the activities occurred 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 information about the Trek and the coordination of consents, to maximise the number of kids' echo screenings.

Each evening and morning, the Trek team held briefing sessions, discussed learnings and prepared for the next day.



## 🔍 Early diagnosis and treatment

A screening echocardiogram and skin check were performed on all children with consent from carers. Children who were diagnosed with RHD were treated, following parental education, support and consent. The new patients were formally registered on the RHD control program and linked to standard treatment and cardiology care. Various skin diseases were treated on the day where possible or referred to the local health clinic for treatment. Children with other health conditions were treated on the same day where feasible and also linked to health services for long-term management.

## 📊 Health results from Northern Territory, Queensland, Central Australia/APY Lands & Alice Springs

	NT	QLD	Central & APY	Alice Springs	TOTAL
Communities/Sites visited	9	5	22	22	37*
Children's hearts screened	873	978	851	1205	3907
Normal hearts	811	922	795	1157	3685
New RHD cases diagnosed & treated	26	29	33	19	107
<b>Total RHD cases</b>	<b>40</b>	<b>48</b>	<b>47</b>	<b>31</b>	<b>166</b>
New congenital heart disease	14	8	6	12	40
Existing congenital heart disease	8	0	3	5	16
<b>% of children with RHD</b>	<b>4.6%</b>	<b>4.9%</b>	<b>5.5%</b>	<b>2.6%</b>	<b>4.2%</b>



The World Heart Federation considers a community where more than 0.1% of children have RHD, to be a high burden.

Across the four Treks, the estimated number of children, families and other community members that received education is 8000.

NB. Screening predominantly consisted of Aboriginal and Torres Strait Islander children/youth, noting that in NT, non Aboriginal/Torres Strait children/youth made up approx. 20% and for Alice Springs 29%. \*To date, 37 communities have had the Trek to visit. In Alice Springs, 22 sites were visited, including 13 schools, 7 town camps and 2 youth centres.

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### Post-visit follow-up and feedback

Following the visits, standard medical follow-up was carried out and all new cases identified on the RHD register.

An online survey was sent to the communities to gain feedback across all aspects; community engagement, education/awareness, medical treatment and diagnosis, culturally appropriate and safe delivery. Feedback from all communities was very positive, responding that they greatly benefited from the visits;

- 100% of respondents said they would welcome the team back
- 100% of respondents recommended the Trek team to other communities

Individual data has been provided to each community and to health boards. Summary data and learnings have been provided to Government members and stakeholders, noting that only aggregate data by region is being shared, for data sovereignty.

### Learnings

Each Trek we increased our learnings, which were then integrated into the planning and delivery for the next Trek. Below is a high-level insight into some of the essential learnings and ingredients into a successful Trek, many of these reaffirmed our principles and our community checklists:

**Prior to visiting** – ensuring community engagement and identification of the key community champions and leaders along with stakeholder engagement of the health and education department

**During the visit** – the First Nations Guides were essential, ensuring the team adhered to cultural protocols, listening, being flexible, adapting and ensuring community self-determination and empowerment

**Post visit** - follow-through with health clinics of new cases, reporting to communities and ensuring data sovereignty

## Testimonials

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

*It was amazing to have so many medical professionals visit our remote school in a coordinated activity that benefits and supports the health of so many students and community members. Thank you from the bottom of our happy, healthy pumping hearts!*

*Deadly Heart Trek changed the lives of a number of students for the better. As a result of their diagnosis, they can now receive medical treatment that will either improve their health, extend their life or clear up the condition completely.*





## Work is underway but more is needed

- In 2018, the World Health Assembly passed an international resolution to prevent and eliminate RHD. Australia was a co-sponsor of this resolution, amplifying national commitments to eliminate RHD. Yet the burden continues to grow
- Significantly since 2021, the National Aboriginal Community Controlled Health Organisation (NACCHO) has led national efforts to address RHD and established governance partnerships, including the landmark joint Advisory Committee
- Federal Government funding has increased along with philanthropic investment but more is needed
- Action is being taken by communities, in partnership with initiatives such as the Deadly Heart Trek, laundry facilities through Orange Sky, Remote Laundries Project by Aboriginal Investment Group and the transformative impact of peer support through Champions4Change

- New research offers promising new approaches for more acceptable treatment and diagnosis of Strep A infection and RHD, alongside accelerating work towards a Strep A vaccine
- The blueprint to end RHD exists - the 2020 RHD Endgame Strategy provides an evidence-based roadmap to ending RHD in Australia
- **We recommend this 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**
- **We have a philanthropic partner, The Snow Foundation, who is engaged and willing to contribute to a greater commitment**

## Future of the Deadly Heart Trek

Treks across the country are under consideration for 2025.

### Delivery Team Leads

	Northern Territory	Queensland	Central & APY Lands + Alice Springs
<b>First Nations Leads</b>	Noeletta McKenzie	Geoffrey 'Jacko' Angeles, Carl Francia	Vicki Wade, Kellie Kerin, Greg McAdam, Rose Nean, Karen Iles, La-Toniya Norris
<b>Medical Leads</b>	Dr Bo Remenyi	Dr Rob Justo, Dr Ben Reeves	Dr Gavin Wheaton, Dr Bo Remenyi

### Board

**Vicki Wade**  
Co-Chair Aboriginal Cultural Advisor

**Karen Iles**  
Aboriginal Social Justice Lawyer & Advisor

**Dr Rob Justo**  
Paediatric Cardiologist

**Georgina Byron AM**  
Co-Chair CEO The Snow Foundation

**Dr Bo Remenyi**  
Paediatric Cardiologist

**Dr Gavin Wheaton**  
Paediatric Cardiologist

### For specific data questions

Northern Territory	Queensland		Central & APY Lands + Alice Springs
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