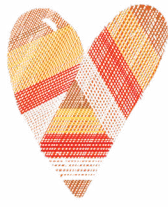


DEADLY HEART TREK



Report on Medical and Educational visits to Aboriginal and Torres Strait Islander communities

In 2020, the Deadly Heart Trek was developed in response to children being affected by rheumatic heart disease (RHD) and Aboriginal and Torres Strait Islander communities being underserved, lacking services, and needing access to medical specialists.

The Trek is an opportunity to listen and learn from Aboriginal and Torres Strait Islander communities and to offer education, diagnoses and treatment to those affected by RHD. The Trek is the major undertaking from the registered for-purpose organisation Deadly Hearts Limited.

Who is involved?

Communities take the lead, by inviting the Trek teams to visit.

The teams on the ground are led by First Nations cultural guides, doctors, health workers and nurses, working closely with the community leaders. Many team members are known to the communities as they have worked for decades on RHD.

The Trek is governed by a Board consisting of leading paediatric cardiologists, an Aboriginal health and cultural engagement lead, a social justice Aboriginal lawyer, and an independent philanthropist committed to progressing the prevention of RHD.

Key collaborators and sponsors: The Snow Foundation, Heart Foundation Australia, RHD Control Programs, Take Heart Project, Champions4Change, HeartKids, Congress, AMSANT, Tangentyere 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, Central Australia/APY Lands and Alice Springs. Two teams go for approximately two weeks for each Trek. They are jointly led by First Nation cultural guides and community members with doctors leading the medical side.

- Northern Territory 2021 - nine communities: five in the Big River Region and four in the Barkly region
- Queensland 2022 - five communities across the Cape, Torres Strait and Northwest Queensland
- Central/APY Lands 2023 - 22 communities
- Alice Springs 2024 - 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, engagement, and endorsement
- Maintain a culturally safe program: abiding by cultural protocols, adhering to cultural safety, and always listening and acting with respect. All team members participate in a cultural session before going to community
- Adhere to community protocols, do no harm and work within ethical boundaries for Aboriginal and Torres Strait Islander communities
- Listen to the needs of each State/ Territory/community and deliver to their needs, with respect to RHD echo screenings, education, advocacy and treatment, and potentially upskilling local health workers
- Only work with communities that request support
- Monitor the COVID situation, ensure COVID safety 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 conduct extensive and rigorous preparation including community checklists for pre, during and post the visits and a comprehensive risk matrix. First Nations cultural guides and support team engage and consult with communities and government departments well in advance, seeking permission to ensure the Trek teams were invited to visit.

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

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



Education and Awareness

Education sessions and activities are provided to students and teachers at the schools. Complementary community sessions vary 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 enjoy these, enabling them the opportunity to increase awareness of RHD in the community.

During school sessions, Trek team members present informative and fun sessions on 'healthy heart' and 'healthy skin' and outline the Echo screening process. Songs produced by communities called 'boom boom' and 'my heart keeps beating', are a real hit in educating students. Gift packs with socks and bracelets are a welcome treat at the end of the sessions.

? What happens in community?

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

Most of the activities occur in schools and some at youth and community centres or local organisations. Children are reviewed for healthy hearts and healthy skin, and general well-being. The local communities assist 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 hold briefing sessions, and discuss learnings of the day and prepare for the next day.



🔍 Early Diagnosis and Treatment

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

| Heart Health results | 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 |
| Existing RHD | 14 | 19 | 14 | 12 | 59 |
| Total RHD cases (new + existing) | 40 | 48 | 47 | 31 | 166 |
| New congenital heart disease | 14 | 8 | 6 | 12 | 40 |
| Existing congenital heart disease | 8 | 0 | 3 | 5 | 16 |
| % of children with RHD | 4.6% | 4.9% | 5.5% | 2.6% | 4.2% |

| Skin Health results | NT | QLD | Central & APY | Alice Springs | TOTAL |
|---------------------------|------------|------------|---------------|---------------|------------|
| Children's skin screened | n/a | n/a | 841 | 1017 | 2,731 |
| # normal skin | n/a | n/a | 486 | 847 | 1,333 |
| # total skin infections** | n/a | n/a | 355 | 170 | 525 |
| % skin infections | n/a | n/a | 42% | 17% | 19% |

NB. Heart screening predominantly consisted of Aboriginal and Torres Strait Islander children, noting that in Trek 1 to NT, non Aboriginal/ Torres Strait Islander children made up approx. 20% and in Trek 4 to Alice Springs 29%.

*37 communities have been visited, including 22 sites in Alice Springs.

**Some children had more than one skin infection but only the primary condition has been counted.

Global Burden %

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

Education

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

DEADLY HEART TREK



Follow-up and Feedback

Following the visits, standard medical follow-up is carried out and all new cases are referred to and followed up with the local health clinic, and identified on the RHD register.

An online survey is 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 has been very positive, responding that they greatly benefited from the visits;

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

Individual data is 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 shared, for data sovereignty.

Learnings

Each Trek we increase our learnings, which are 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 reaffirm our principles and our community checklists:

Prior to visiting – ensure community engagement and identification of the key community champions and leaders along with Stakeholder engagement of health and the education department.

During the visit – the First Nations Guides are essential, ensuring we develop trust, adhere to cultural protocols, listen, remain flexible, and ensure 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 cosponsor 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 and 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 advocate for First Nations' leadership and empowerment, to ensure communities are enabled to determine, drive and own their RHD story**
- **We have a philanthropic partner, The Snow Foundation, who is engaged and willing to contribute to greater commitment**

Future of the Deadly Heart Trek

Treks to further communities are under consideration for 2025.

Delivery Team Leads

| | Northern Territory | Queensland | Central/APY Lands + Alice Springs |
|----------------------------|--------------------|--|--|
| First Nations Leads | Noeletta McKenzie | Geoffrey 'Jacko' 'Angeles', Carl Francia | Vicki Wade, Kellie Kerin, Greg McAdam, Rose Nean, Karen Iles, La-Toniya Norris |
| Medical Leads | 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 and 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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RHD CONTROL PROGRAMS
QLD, NT, SA, WA

