

# DEADLY HEART TREK



## Medical & Educational Report

### Executive Summary

Rheumatic heart disease (RHD) is a preventable disease that continues to disproportionately affect Aboriginal and Torres Strait Islander communities. Invited by community, the Deadly Heart Trek works On Country in partnership with First Nations communities to address this national public health issue.

In collaboration with Aboriginal Community Controlled Health Services, schools, medical clinics and local leaders, the Deadly Heart Trek complements and strengthens existing services by providing access to a multi-disciplinary team. This team undertakes skin and heart screening for early diagnosis and treatment, delivers culturally safe education, and supports local capability.

Since 2021, five Treks have been delivered across the Northern Territory, Queensland and South Australia, partnering with 49 communities and screening more than 4,700 children and young people. Of those screened, 4.4% were diagnosed with RHD, highlighting the scale of undetected disease and the importance of early identification.

By working in partnership with communities and bringing an expert team led by First Nations leaders, the Deadly Heart Trek improves participation, identifies previously undiagnosed cases earlier, and supports local services to respond. The model demonstrates that community-led, culturally safe approaches are critical to prevention and early detection. The increasing rates of RHD underscores the need for sustained investment in local services, workforce and prevention efforts to reduce the burden of this preventable disease.

### Who is Involved?

The Deadly Heart Trek is led by Deadly Hearts Limited and delivered in partnership with communities who invite the Trek team to visit. On the ground, multidisciplinary teams are led by First Nations cultural guides and doctors, with health professionals working closely with community leaders, building on long-standing relationships and experience in RHD.

The Trek is governed by the Deadly Hearts Board with expertise across paediatric cardiology, Aboriginal health, cultural leadership, social justice and philanthropy. Working alongside First Nations community leaders and partners, Snow Foundation has funded and coordinated the five Deadly Heart Treks, overseeing logistics, community engagement and governance.



A big thank you to the many generous volunteers especially the Board, health professionals, Snow Foundation and key collaborators and sponsors including RHD Control programs, Community leaders, Heart Foundation Australia, Take Heart Project, Champions4Change, HeartKids, AMSANT, Tangentyere Council, NT Cardiac, Orange Sky Australia, QLD Children's Hospital, Far North QLD Hospital Foundation, Humpty Dumpty Foundation, GE Healthcare, Deadly Science, Goods. By A Curious Tractor, Rotary Club of North Balwyn and ACCHOs including Central Australian Aboriginal Congress, Katherine West Health Board, Sunrise, Wurli-Wurlinjang Health Service, Nganampa Health Council, Education Departments and the 50+ schools we visited.

### Principles of the Deadly Heart Trek

- Aboriginal and Torres Strait Islander leadership and community invitation underpin all Treks
- Delivered in a culturally safe way, in accordance with local protocols and supported by team cultural preparation
- Work respectfully within communities and existing services, guided by a 'do no harm' approach
- Respond to each community's needs through education, screening, treatment support and workforce development
- Align with national best practice, including the Endgame Strategy, and local public health guidance



## Treks to date

Five Treks have taken place across Northern Territory, Queensland, Central Australia/APY Lands and Alice Springs.

- 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
- Northern Territory - Big Rivers & Katherine 2025 – 12 communities and 21 sites (including 7 schools in Katherine)

## Pre-visit planning



The Deadly Hearts Board and team undertake extensive preparation and risk management including checklists for pre, during and post the visits and a comprehensive risk matrix. First Nations cultural guides and the support team engage early with communities and government to ensure visits are community-invited.

The team works closely with communities to coordinate logistics and tailor activities. A 'Register your Interest' form enables communities to identify priorities. Engagement with local health services and Aboriginal Community-Controlled Organisations is established, providing vital support for the visits.

All team members, including the Deadly Hearts Limited Board attend cultural authority sessions specific to each region, led by our Cultural lead and First Nations guides prior to visits.

## What happens in community?

Upon arrival, the teams are welcomed by community members, including Traditional Owners and Elders where possible, and work with local organisations to ensure understanding and community-led delivery. The Trek focuses on education, heart screenings and skin checks to support early understanding, diagnosis and treatment of RHD.

Activities are primarily delivered in schools as well as youth and community settings. Children are assessed for healthy heart health, skin health and general well-being.

Local communities play a key role in sharing information and supporting consent processes, helping maximise participation in screenings. Daily team briefings support reflection, shared learning and continuous improvement throughout the visit.

## Education and awareness

Education sessions are delivered to students, teachers, and community members tailored to each location. Community-led activities may include BBQs, film screenings of *Take Heart* documentary and sporting activities to build awareness.

School sessions focus on 'healthy heart' and 'healthy skin', alongside explaining the screening process. Community-created songs such as 'boom boom' and 'my heart keeps beating' support engagement and small gifts are provided to children.

## Early diagnosis and treatment

With consent children have an echocardiogram screening and skin check. Those diagnosed with RHD are supported through parental education, and consent processes, registered with the RHD control program and linked to ongoing care.

Skin infections are treated on the day (where possible) or referred to the local clinic. Where other health conditions are identified, children are supported and connected to approximate services for ongoing care.



## Heart and Skin Health Results

Measure	NT	QLD	Central & APY	Alice Springs	Katherine and Big Rivers	Total
Communities / sites visited	9	5	22	22	12	49*
Children's hearts screened	873	978	851	1205	801	4708
Normal hearts	811	922	795	1157	740	4425
New RHD cases diagnosed and treated	26	29	33	19	27	134
Existing RHD cases	14	19	14	12	15	74
Total RHD cases	40	48	47	31	42	208
% of children with RHD	4.6%	4.9%	5.5%	2.6%	5.1%	4.4%

Measure	NT	QLD	Central & APY	Alice Springs	Katherine and Big Rivers	Total
Children's skin screened	n/a	n/a	841	1017	738	3469
Normal skin	n/a	n/a	486	847	500	1833
Total skin infections**	n/a	n/a	355	170	238	763
% skin infections	n/a	n/a	42%	17%	29%	22%

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%.

\*To date 49 communities have had the trek visit including 22 sites in Alice Springs and 21 sites across Katherine and Big Rivers.

\*\* 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 9000.

### Follow-up and feedback

Following each visit, standard medical follow-ups are undertaken, with all new cases referred to a local services, recorded on the RHD register, and linked to ongoing care.

Communities are invited to provide feedback across engagement, education, clinical care and cultural safety. Feedback has been consistently positive:

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

Individual data is returned to communities and with aggregated insights shared with government and stakeholders in line with data sovereignty principles.

### What we are learning

Each Trek builds on previous experience, strengthening delivery and impact. Key learnings include:

- **Community leadership is critical** — early engagement and local champions drive participation and trust
- **First Nations cultural guidance is essential** — ensuring culturally safe, flexible and responsive delivery
- **Continuity of care matters** — strong follow-up with local services supports ongoing treatment and long-term outcomes



## Work underway and the opportunity ahead

The Deadly Heart Trek strengthens Aboriginal leadership and calls for sustained political commitment to end RHD. It highlights what is achievable when communities and partners walk together to protect children's hearts and health.



- National commitment is strong. Australia co-sponsored the 2018 World Health Assembly resolution to eliminate RHD, and the 2020 Endgame Strategy provides a clear, evidence-based roadmap
- Progress is being driven by Aboriginal and Torres Strait Islander leadership, communities and partnerships. 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 lived experience advocacy through RHD Champions4Change
- Community-led design is improving living conditions, with Wilya Janta delivering culturally appropriate housing, and Goods on Country co-designing essential goods such as washable beds and robust washing machines
- 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 with organisations including Kids Research Institute and CSIRO leading this work
- 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, Snow Foundation, who is engaged and willing to contribute to greater commitment
- Future Deadly Heart Treks are under consideration
- At the same time, the burden of disease remains high. Sustained investment in prevention, workforce and community-led approaches is required to reduce the burden of RHD and achieve long-term change.

### Delivery Team Leads

#### First Nations Leads

**NT** - Noeletta McKenzie, Vicki Wade, Henrique Thomas, Cleavon Davis

**QLD** - Geoffrey 'Jacko' Angeles, Carl Francia

**Central/APY Lands & Alice Springs** - Vicki Wade, Kellie Kerin, Greg McAdam, Rose Nean, Karen Iles, La-Toniya Norris

#### Medical Leads

**NT** - Dr Bo Remenyi, Dr Gavin Wheaton

**QLD** - Dr Rob Justo, Dr Ben Reeves

**Central/APY Lands & Alice Springs** - Dr Gavin Wheaton, Dr Bo Remenyi

### Deadly Hearts 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 Snow Foundation

#### Dr Bo Remenyi

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