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Walking Beside Communities: Deadly Heart Trek Returns to Big Rivers Region

4/08/2025 Katherine: Following strong community demand, the Deadly Heart Trek returns to the Big Rivers Region this August—a powerful step forward in tackling rheumatic heart disease (RHD), which continues to disproportionately affect Aboriginal children in remote Northern Territory communities.

Rheumatic Heart Disease (RHD) is a leading cause of preventable death and disability among First Nations Australians. While rare in the general population, RHD and its precursor, acute rheumatic fever (ARF), remain hyperendemic in First Nations communities—highlighting persistent structural inequities. Children, young people, and women are most at risk.

The Trek delivers education, early diagnosis and treatment through a culturally safe, community-led model. Activities include echocardiographic (echo) heart checks to detect RHD in children, skin checks to identify sores and scabies linked to the disease, and tailored education for schools, health workers, and the broader community.

Now in its fifth major journey since 2021, the Deadly Heart Trek brings together a multi-disciplinary team of paediatric cardiologists, nurses, sonographers, Aboriginal cultural guides and local health professionals to tackle RHD and its precursor, acute rheumatic fever (ARF), in partnership with schools and health services.

From **4 to 15 August**, two Trek teams will visit around nine communities, including those in very remote areas. Screening and education will be primarily delivered at schools, with support from Katherine West Health Board Aboriginal Corporation, Sunrise Health Service Aboriginal Corporation, Wurli-Wurlinjang Health Service, Jawoyn Association Aboriginal Corporation, NT Health, and NT Education.

The Trek is centred on a community-focused approach—deeply rooted in the needs and perspectives of First Nations people. At its core is a long-term commitment to empowering local Aboriginal health professionals to prevent and manage these devastating and entirely preventable conditions.

"The only way we close the gap is by walking beside, not in front. Aboriginal health workers are the backbone of our communities. They speak language, they understand the culture, and they know what our kids and families need," said Senior Noongar woman and Trek cultural leader Aunty Vicki Wade.

"In addition to scanning hearts and checking skin, a big part of this Trek is about education and empowering mob where they live—giving them tools to manage this disease and build confidence, strengthen community leadership, and drive long-term change from within."

MEDIA RELEASE



Paediatric cardiologist and Trek founder Dr Bo Reményi said Aboriginal health workers are central to the work and its long-term impact.

"These are often the only staff who stay in community year after year. They are the fabric of remote health care. By bringing training to them, where they live and work, we are not just sharing knowledge, we are reinforcing their critical role and growing the next generation of leaders in Aboriginal health," Dr Reményi said.

The Deadly Heart Trek is the flagship initiative of Deadly Hearts Ltd, co-chaired by Aunty Vicki Wade and Georgina Byron, CEO of Snow Foundation. The Snow Foundation has been committed to First Nations health for 14 years and are the founding philanthropic partner of the Trek, providing core funding, project management and logistical support.

Georgina Byron said: "The Trek was created in response to those with lived experience of RHD, and the urgent need in Aboriginal and Torres Strait Islander communities for greater access to medical services for early diagnosis and treatment, and more education and awareness on ARF and RHD.

"Over the past four years, we've visited 37 communities across the NT and QLD, screened more than 3,900 children's hearts, diagnosed and treated 107 new cases of RHD, and delivered education to around 8,000 people.

"We're looking forward to returning to Katherine and the Big Rivers region—walking alongside communities who are empowered to drive change for their own futures."

The Trek has been embraced by Indigenous communities and leaders as a model of positive action. Post-visit community surveys have confirmed the strength of this approach: 100% of communities welcomed the Trek's return and 100% would recommend it to others.

Event: An RHD and Trek awareness community event will be held on Saturday 9 August from 10am to 12pm at the Godinymayin Yijard Rivers Arts and Culture Centre in Katherine. It will feature Aboriginal leaders, cardiologists and lived experience advocates, and will showcase the new Take Heart: Songlines film - sharing powerful stories of RHD in community.

BACKGROUND

About Rheumatic Heart Disease (RHD)

- RHD begins with a **common strep A infection**—a sore throat or skin sore left untreated.
- It can lead to **lifelong complications**, invasive treatments, and premature death.

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- Aboriginal and Torres Strait Islander people are **64 times more likely** to have RHD than non-Indigenous Australians.
- Australia has one of the **highest RHD rates in the world**. Most of those affected are young, and **two-thirds are women**.
- Over 11, 000 people are living with ARF/RHD*

* Epidemiology of ARF and RHD – Australia (2023 Data)

The Blueprint to End RHD Exists

- The **2020 RHD Endgame Strategy**, developed by Aboriginal leaders and endorsed by 21 peak bodies, lays out the clear steps needed.
- We have committed to Ending RHD by 2030 under the World Health Assembly.
- We have what we need: an evidence-based plan, government commitment, and **Aboriginal-led programs that work**.

Impact from four Treks to date

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.

To assist members of the public to contribute to ending RHD, a MyCause page has been set up. To donate, go to - <https://www.mycase.com.au/p/374606/deadly-heart-trek-2025>

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