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Active case finding in community with highest Rheumatic Heart Disease rates in the world saves several lives

All kids who needed urgent heart surgery in Maningrida are recovering

Two of Australia's leading remote community doctors have completed a ground-breaking, active-case finding blitz targeted at Maningrida, West Arnhem Land, where rates of Rheumatic Heart disease are highest in the world. Their work identified several children in need of immediate care.

"Finding cases of rheumatic heart disease as early as possible can prevent children from having to undergo life-saving heart surgery and stay on medication for the rest of their lives, all because of a preventable disease," says Dr Boglarka Remenyi, the only paediatric cardiologist in the Northern Territory and co-lead of the active case finding project.

The project team trained four, local, Aboriginal, healthcare workers from Maningrida, along with other healthcare workers from the Northern Territory and Timor-Leste, to do heart scans using portable hand-held devices which can detect rheumatic heart disease.

In March 2018, the team of Aboriginal health workers, nurses and doctors checked the hearts of more than 450 children in Maningrida. Twenty of those screened had rheumatic heart disease, and two of children with severe cases needed open-heart surgery to repair damage from the disease.

"The community was very pleased we were able to perform heart scans on their children and detect these serious cases so treatment can begin immediately," says Dr Remenyi. "However, there were also immediate concerns for the children who live outside of Maningrida and on homelands, who hadn't had a scan yet. Community members urged us to hold a second screening that would reach more children."

The second screening happened in November 2018, at the local pool and in remote homelands outside of Maningrida. Another 170 children were scanned, picking up a further 12 cases of rheumatic heart disease, including one child who needed emergency, open-heart surgery.

Both screenings were accompanied by rheumatic heart disease prevention education in traditional languages at local schools.

"This is a disease of poverty. It should be educated in schools, to the families, to everybody," says Mayor Matthew Ryan of West Arnhem Regional Council. "It should be a community-led program so we can eliminate rheumatic heart disease once and for all in our communities."

Today all children who were treated for rheumatic heart disease are doing well; they are taking all necessary injections and keeping healthy. All three children who needed surgery have returned home from hospital after successful surgeries.

“This effort had a tremendously positive impact in Maningrida. What we found is at least 5% of children in Maningrida have rheumatic heart disease, and nearly two-thirds have not been diagnosed before,” says Dr Josh Francis. “It’s also unique in that it has inspired other surrounding communities to request active case finding medical visits and more traditional-language education at school so children can learn how to help prevent rheumatic heart disease from a very early age.”

“We are so thrilled that all of the children that we found to have rheumatic heart disease are under treatment and on track with their medications and injections. The last hospitalised child just returned home after two months in hospital,” says Dr Remenyi. “He loves cameras, ham and pineapple pizza and can’t wait to go to the zoo. Stories like his are the success of this program. Now he and others can get back to everything childhood is about and with more traditional language education at schools, we’ll see more prevention, so fewer children get this preventable illness.”

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