

RARE DISORDERS NEW ZEALAND



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Māori Advisory Group Applicant Pack



About us

The New Zealand Organisation for Rare Disorders (NZORD) was established in September 2000, and changed its name to Rare Disorders NZ (RDNZ) in 2019.

RDNZ offers a central starting point for patients and families affected by rare disorders, and helps families, patients and healthcare providers find essential information and support groups.

RDNZ is the only umbrella group for rare disorders in New Zealand and provides a strong common voice to advocate for an equitable healthcare system that works for the 300,000 Kiwis with a rare condition.

RDNZ is a member of Rare Diseases International and the Asia Pacific Alliance of Rare Disease Organisations (APARDO).

Our mission

To enable and empower people with rare disorders to best benefit from services and therapies available in New Zealand, and to champion their collective voice, advocating for the provision of world-leading evidence-based health, disability, education and other services.

Our vision

Best possible health and wellbeing for people and whānau living with rare disorders in New Zealand/Aotearoa.



Values

Aroha

We will demonstrate love, compassion, empathy and respect for people living with rare disorders and we will support and encourage our stakeholders to do likewise.

Whakamana

We will advocate assertively and constructively with strength and resilience, supporting communities of people living with rare disorders to be similarly empowered.

Manawa rahi

We will steadfastly and stout-heartedly maintain an unwavering evidence-based commitment to the RDNZ cause.

Kotahitanga

We will exhibit unity, cohesion and collaboration both internally as a team of staff and volunteers, and externally in our relationships both with New Zealand's rare disorders community and supporters, and internationally.

Tiakitanga

We will do everything we can to sustain, protect and respect the viability and reputation of our organisation, our fellow team members, those living with rare disorders and the physical, cultural and spiritual environments which sustain us.

Our Strategic Plan

View our Strategic Plan 2025 – 2028 & July 2025 – June 2026 work plan [here](#).



Annual Reports

View our Annual Reports [here](#).

Role Description

Title: Member – Māori Advisory Group, Rare Disorders New Zealand

Purpose of the Role: To provide culturally grounded and strategic Māori perspectives that guide RDNZ in upholding Te Tiriti o Waitangi and advancing equity for Māori with rare disorders and their whānau.

Key Responsibilities:

- Offer Māori cultural and strategic advice on RDNZ policies, advocacy, and programmes.
- Champion whānau ora approaches that support holistic wellbeing for Māori.
- Identify and advise on inequities in diagnosis, treatment, and support for Māori with rare disorders.
- Strengthen RDNZ's relationships with iwi, hapū, Māori health providers, and whānau.
- Promote mātauranga Māori and tikanga in RDNZ's operations where appropriate.
- Participate actively in quarterly hui and contribute to decision-making by consensus.
- Provide support and guidance to RDNZ staff as they implement measures to achieve our Māori and Tiriti-aligned strategic goals.

Membership Composition:

- Māori with lived experience of rare disorders or as whānau members
- Māori working in health, policy, education, or research sectors
- Representation from across iwi, hapū, and rohe, including rangatahi and kaumātua perspectives

Term: Three years (renewable)

**Time Commitment:**

- Four hui per year (three online, one in-person).
- Preparation time between meetings.
- Time spent supporting queries from staff as and when suitable.

Reporting Line: Reports via the MAG Co-Chairs to the RDNZ Board.

Appointment Process

The appointment of a person to fill the vacancy will be decided by members of the RDNZ Board following a shortlisting and online interview process.

To apply, please complete the Expression of Interest Form together with a covering letter and a copy of your CV outlining your experience, skills and expertise which you will bring to the RDNZ Māori Advisory Group.