

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 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 around Matariki).

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.