RDNZ
MĀORI ADVISORY GROUP
TERMS OF REFERENCE

Date of Establishment: 9 July 2026

Date of Review: Biennially

Preamble (He Kupu Whakataki)

Rare Disorders New Zealand (RDNZ) recognises the profound impact of rare disorders on individuals and whānau across Aotearoa. RDNZ is committed to a relationship with Māori that supports equitable health outcomes for Māori living with rare disorders, acknowledging Te Tiriti o Waitangi as a foundational document for this relationship.

This Māori Advisory Committee is established to provide strategic guidance and a strong Māori voice to RDNZ, ensuring that its advocacy, support services, and policy positions are culturally relevant and responsive. The committee also aims to contribute to Pae Ora (healthy futures) for Māori with rare disorders and their whānau, in alignment with the enduring commitments of Te Tiriti o Waitangi and the overarching mission, vision, and values of Rare Disorders New Zealand.

RDNZ Mission, Vision & Values (Te Aronga, Te Kitenga, me Ngā Uara o RDNZ)

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 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.

Our 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.

Ingoa / Name of the Rōpū

Māori Advisory Group for RDNZ
Kōtuku?
To be appointed by the rōpū at first hui?

Te Kaupapa / Purpose

What is the core purpose of this group?

To guide RDNZ in honouring Te Tiriti o Waitangi and advancing equity for Māori living with rare conditions by providing culturally grounded, strategic, and relational advice.

The group serves as a voice for whānau Māori, helping to shape the organisation's policy, advocacy, partnerships, and services through a kaupapa Māori lens.

Ngā Uaratanga / Values and Principles

What values will guide the group's way of being? RDNZ values?

The rōpū will be guided by the following kaupapa Māori principles:

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.

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Te Ara Tūhono: Te Tiriti o Waitangi - Guiding Framework: Te Tiriti o Waitangi

The Committee's work will be underpinned by the recognition of Te Tiriti o Waitangi as a foundational document for Aotearoa New Zealand, with particular reference to the understanding of its Articles from a Māori perspective:

Te Kupu Whakataki (The Preamble): RDNZ acknowledges the aspirations for peace, good order, and the protection of Māori rights and taonga.

Wāhanga Tuatahi (Article One): Kawanatanga (Governance) RDNZ recognises the right of the Crown to govern, while understanding that for Māori, this meant a sharing of authority rather than a complete cession of sovereignty. The Committee will advise on how RDNZ can best navigate its role within the governing structures while supporting Māori self-determination.

Wāhanga Tuarua (Article Two): Tino Rangatiratanga (Absolute Authority/Chieftainship) RDNZ acknowledges and commits to the unqualified exercise of Māori tino rangatiratanga over their lands, resources (taonga), and cultural practices. The Committee will guide RDNZ in actively protecting and promoting Māori control over their health, cultural identity, and wellbeing in the context of rare disorders, including their collective and individual possessions and values. This includes the right for Māori to determine how their taonga (which encompasses intangible aspects like language, knowledge, and health systems) are managed and developed.

Wāhanga Tuatoru (Article Three): Ōritetanga (Equity/Equality) RDNZ acknowledges the commitment to Māori receiving the same rights and duties of citizenship as all people of New Zealand. The Committee will advise on ensuring equitable access, outcomes, and opportunities for Māori affected by rare disorders, addressing systemic barriers to achieve true equity.

Ngā Whāinga / Objectives

Scope of Work (Te Arahanga Mahi)

The Committee will advise on, but not be limited to, the following areas:

- Development and implementation of RDNZ's strategic plan and annual work programmes, ensuring alignment with Māori health aspirations and the Articles of Te Tiriti o Waitangi, and supporting RDNZ's overall mission and vision.
- Policy submissions and advocacy positions on rare disorders from a Māori perspective, reflecting RDNZ's commitment to championing the collective voice.
- Culturally appropriate service models, information resources, and support programmes for Māori with rare disorders and their whānau, in pursuit of best possible health and wellbeing.
- Strategies for engaging with Māori communities, iwi, and hapū, fostering Kotahitanga.
- Opportunities for capacity building and workforce development to enhance Māori cultural competency within the rare disorders sector, demonstrating Aroha and Whakamana.
- Response to government health reforms and the Aotearoa New Zealand Rare Disorders Strategy, ensuring Māori equity remains central and upholding Manawa rahi.
- Identification of research priorities and ethical considerations related to Māori and rare disorders, ensuring Tiakitanga for the community.

The Committee will:

- Provide Māori Cultural and Strategic Advice: Offer expertise and a Te Ao Māori perspective on RDNZ's strategies, policies, programmes, and communications to ensure cultural appropriateness and effectiveness for Māori, aligning with RDNZ's mission to enable and empower.
- Champion Whānau Ora: Advise on approaches that support whānau ora (holistic family wellbeing) for Māori living with rare disorders, recognising the centrality of whānau in Māori health and decision-making, in line with RDNZ's vision for best possible health and wellbeing.
- Identify and Address Māori Health Inequities: Identify systemic barriers, unmet needs, and disparities in diagnosis, treatment, care, and support for Māori with rare disorders, and recommend strategies to address these inequities, upholding the value of Aroha and contributing to Whakamana.
- Inform Policy and Advocacy: Guide RDNZ's advocacy efforts to government, health agencies (e.g., Manatū Hauora, Te Whatu Ora, Pharmac), and other stakeholders, ensuring Māori perspectives and priorities are strongly represented in rare disorders policy development and implementation, demonstrating Manawa rahi and Whakamana.
- Promote Mātauranga Māori: Advise on the integration of Mātauranga Māori (Māori knowledge systems), tikanga (customs), and reo (language) into RDNZ's operations and service delivery where appropriate and beneficial, respecting cultural environments as per Tiakitanga.
- Facilitate Engagement and Partnerships: Support RDNZ in fostering genuine and reciprocal relationships with Māori communities, iwi, hapū, and Māori health providers to improve outreach and support for Māori with rare disorders, exemplifying Kotahitanga.
- Review and Advise on Research: Provide input and guidance on rare disorder research initiatives, support research involving Māori that is culturally safe, ethical, and benefits Māori communities, demonstrating Tiakitanga for the community.

Te Tūranga me te Pūrongo / Status and Reporting

The rōpū is an independent advisory body to the RDNZ Board and CEO

The group does not hold governance authority, but will influence strategic direction. The Committee will not be involved in the day-to-day operational management of RDNZ.

The MAG and the CEO will meet to discuss relevant matters. A summary of insights/recommendations will be reported to the Board quarterly via a liaison (likely Board of Trustee MAG representation).

Te Hāpori o te Rōpū / Membership

Membership should reflect a balance of:

- Iwi, hapū, and rohe diversity
- Whānau with lived experience of rare disorders
- Health, research, or Māori policy expertise
- Māori Board of Trustees
- Rangatahi and kaumātua representation where possible
- Taha wāhine taha tāne
- Minimum of 4 plus 1 Board of Trustees
- Chair, co-chair, Secretary

Appointment Process: Members will be appointed by the RDNZ Board following an open expression of interest process or direct invitation, aiming for diverse representation from across Iwi, hapū, and regional areas, reflecting Kotahitanga.

Ngā Haepapa a Ngā Mema / Responsibilities of Members

Members are expected to:

- Act in the best interests of Māori with rare disorders and RDNZ.
- Actively participate in Committee meetings and discussions.
- Prepare adequately for meetings by reviewing provided materials.
- Maintain confidentiality of sensitive information.
- Declare any real or perceived conflicts of interest and recuse themselves from discussions where a conflict exists.

- Contribute to a respectful and collaborative environment, upholding Aroha and Kotahitanga.

Membership details:

Name	Region	Expertise/Lived Experience	Contact Details	Notes

Membership term: 3 years - renewable

Te Huihuinga / Meetings

Hui will be held quarterly or as agreed
At least one hui ā-tinana (in-person) annually – e.g. around Matariki?
Hui will be conducted in alignment with tikanga and reo Māori where possible

Ngā Tikanga / Ways of Working

Whakawhanaungatanga will underpin all engagements
Consensus decision-making will be preferred
Cultural safety and manaakitanga will be upheld
Confidentiality will be respected
Members will be provided support with travel/accommodation

Pūtea / Resourcing

RDNZ will allocate an annual budget to support the mahi of the rōpū.

This includes:

- Hui expenses (venue, kai, travel, accommodation)
- External facilitation or kaumātua support if needed

Te Arotake / Review and Feedback

These ToR are a living document.
A formal review will be conducted after the first year of operation.
Reviews and amendments will be made in consultation with all members of the MAG and the wider Board.