



Strategic Plan 2025 - 2028 & July 2025 - June 2026 Work Plan

Strategic Plan 2025 - 2028

Vision, Mission and Values

Vision:

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

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.

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

Strategies and impact indicators:

	We will fulfill our mission by:	Impact/outcome indicators	target
1.	Campaigning for full implementation of New Zealand's Rare Disorder Strategy (RDS)	No of health agencies engaging with implementation of the RDS No of RDS implementation agencies with RDS action plans	4 4
2.	Raising awareness and understanding of rare disorders and strengthening RDNZ's presence as the collective voice for rare disorders in New Zealand	Number of recipients of RDNZ's monthly newsletter Number of usable "Voice of Rare Disorders" survey respondents	trending up trending up; 1000 minimum
3.	Making connections in the rare disorder community	Number of rare disorders support groups in the RDNZ collective	150
4.	Becoming an effective and relevant Te Tiriti partner	% of Māori who respond to RDNZ's "Voice of Rare Disorders" survey	13%
5.	Ensuring RDNZ's long term financial and reputational viability and sustainability	Annual income from all sources Net assets Income diversification index	trending up reserves>contingency TBD

RDNZ Annual Plan 2025 - 2026

#	Strategy	Actions	RDNZ lead	RDNZ support roles	Potential/actual external collaborators	Timeframes			
						Q1	Q2	Q3	Q4
1.	Campaign for full implementation of the Rare Disorder Strategy (RDS) ¹	a) Pursue a mātauranga Māori informed approach to implementing the RDS	CH	RDMAG ² MMSIL ^{3 4}		✓	✓	✓	✓
		b) Actively participate in and as necessary lead an RDS implementation group comprising RDNZ, Manatū Hauora, Te Whatu Ora, Pharmac and HQSC	CH	KM LP	PCPGRUD ⁵	✓	✓	✓	✓
		c) Work towards and advocate for a rare and undiagnosed disorders centre of expertise.	CH	KM LP CAP ⁶	PCPGRUD	✓	✓	✓	✓
		d) Advocate for health entities to ensure early and accurate diagnosis of rare disorders	LP	KM CAP	PCPGRUD	✓	✓	✓	✓
		e) Advocate for health entities to deliver co-ordinated and integrated pathways for cohesive healthcare	LP	KM CAP	PCPGRUD	✓	✓	✓	✓
		f) Advocate for health and other government entities to implement mechanisms to ensure appropriate access to disability and social supports, including support for carers	LP	KM CAP	PCPGRUD	✓	✓	✓	✓

¹ As set out in RDNZ's 7 Priorities for Rare <https://raredisorders.org.nz/about-rare-disorders/7-priorities-for-rare/>

² Rare Disorders Māori Advisory Group

³ Mātauranga Māori Strategy Implementation Lead

⁴ Dependent on new additional funding

⁵ Parliamentary cross-party group for rare and undiagnosed disorders

⁶ RDNZ's Clinical Advisory Panel

<https://nzord.sharepoint.com/Shared Documents/Strategic Planning/2025/RDNZ strategic and operating plan 2025 2026 final 100725.docx>

#	Strategy	Actions	RDNZ lead	RDNZ support roles	Potential/actual external collaborators	Timeframes			
						Q1	Q2	Q3	Q4
		g) Develop a rare disorders research strategy and advocate for health and other government entities to deliver a coordinated and funded programme of rare disorders research.	CH	RDRNLG ⁷ KM LP CAP	PCPGRUD	✓	✓	✓	✓
		h) Advocate for health entities to capture relevant data on rare disorders in New Zealand.	KM	LP RDRNLG CAP	PCPGRUD	✓	✓	✓	✓
		i) Advocate for Pharmac to provide equitable access to modern rare disorder medicines through a specific assessment pathway	KM	LP CAP	RTC ⁸ PVA ⁹ MNZ ¹⁰ PCPRUDG	✓	✓	✓	✓
		j) Develop and support the work of RDNZ's Round Table of Companies	CH	LP GJ		✓	✓	✓	✓
		k) Advocate for health and other government entities to plan and provide training on rare disorders for health and other professionals and support staff	LP	KM CAP	PCPGRUD	✓	✓	✓	✓
		l) Collaborate with the PCPGRUD to secure its support in advocating for RDS implementation	CH	KM LP		✓	✓	✓	✓
		m) Complete and commence responding to implications of an NZIER commissioned report to demonstrate the economic and health	CH	LP	NZIER		✓	✓	

⁷ Rare Disorders Research Network Leadership Group

⁸ Round Table of (therapeutic) Companies

⁹ Patient Voice Aotearoa

¹⁰ Medicines NZ

#	Strategy	Actions	RDNZ lead	RDNZ support roles	Potential/actual external collaborators	Timeframes			
						Q1	Q2	Q3	Q4
		sector benefits of investing in early diagnosis for rare disorders ¹¹							
2.	Raise awareness and understanding of rare disorders and strengthen RDNZ's presence as the collective voice for rare disorders in New Zealand	n) Run rare disorders public awareness and promotional initiatives and campaigns, including rare disorders month March 2026	AN	KM AP	Maia	✓	✓	✓	✓
		o) Support RDNZ's advocacy campaigning through awareness raising, PR and media activities	AN	KM LP		✓	✓	✓	✓
		p) Support RDNZ's income generation activities with branding and collateral support	AN	GJ		✓	✓	✓	✓
		q) Promulgate, undertake and report on the results of RDNZ's biennial Rare Voices survey of people living with a rare disorder	KM	LP	Health TV		✓	✓	
		r) Rare Disorders Month Rare Voices Survey Report launch event ¹²	KM	AN				✓	
		s) Promulgate discoveries and opportunities from the rare disorders research network	AN	KM LP RDRNLG		✓	✓	✓	✓
3.	Make connections in the rare disorders community	t) Foster opportunities for rare disorders support group leads to meet and offer support on-line, via social media and face to face	KM	LP AP		✓	✓	✓	✓
		u) Produce and disseminate regular newsletters and other sources of RDNZ provided information both to support group members	AN	ANi		✓	✓	✓	✓

¹¹ Dependent on new additional funding

¹² Dependent on new additional funding

#	Strategy	Actions	RDNZ lead	RDNZ support roles	Potential/actual external collaborators	Timeframes			
						Q1	Q2	Q3	Q4
		and the wider community of people living with a rare disorder							
		v) Provide an enquiries service for people seeking rare disorders information and support	KM	LP		✓	✓	✓	✓
		w) Offer support group leads opportunities to be consulted on RDNZ planning and policy development	KM	LP		✓	✓	✓	✓
		x) Collaborate with complementary organisations and networks which also support the rare disorders community	KM	LP CH AP		✓	✓	✓	✓
4.	Become an effective and relevant Tiriti partner	y) Implement the intentions set out in RDNZ's June 2024 "Tiriti journey" position statement ¹³	CH	RDMAG		✓	✓	✓	✓
		z) Complete and respond to implications of the Costello Medical funded report comparing whānau Māori and non-Māori experiences of living with a rare disorder	CH	RDMAG		✓	✓		
		aa) Operate RDNZ's CAP and RDRN in ways that demonstrate RDNZ's commitment to being a better Tiriti partner	CH		CAP and RDRNLG co chairs	✓	✓	✓	✓
		bb) Recruit and retain new te ao Māori experienced RDNZ Board members to demonstrate commitment to being a better Tiriti partner	RDNZ Chair	RDNZ Board RDMAG		✓	✓		

¹³ Dependent on new additional funding

#	Strategy	Actions	RDNZ lead	RDNZ support roles	Potential/actual external collaborators	Timeframes			
						Q1	Q2	Q3	Q4
		cc) Establish and be responsive to an RDNZ Māori advisory group	RDNZ Board	CH		✓	✓	✓	✓
		dd) Identify an RDNZ kaumatua	RDNZ Board	RDMAG			✓		
5.	Ensure RDNZ's long term financial and reputational viability and sustainability	ee) Appropriately value, remunerate and formally performance review RDNZ staff	CH		McClaren	✓			✓
		ff) Diversify, scale up and grow income from all sources sufficient to meet the expectations of the Annual Plan and cover operating costs	GJ	AN KM		✓	✓	✓	✓
		gg) Maintain sufficient financial reserves to enable RDNZ's long term sustainability	CH	SL		✓	✓	✓	✓
		hh) Evolve governance arrangements to ensure fitness for purpose, appropriate skill sets and connection with the rare disorders community	RDNZ Chair	RDNZ Board		✓	✓	✓	✓
		ii) Maintain a comprehensive risk identification and mitigation/policy development programme, covering financial, reputational, ICT, legal operational and other material risks ¹⁴	CH	KM LP AN SL		✓	✓	✓	✓
		jj) Be globally recognised and valued within the rare disorders community internationally ¹⁵	CH		EURORDIS ERDERA RDI HGSA NRDCE ¹⁶	✓	✓	✓	✓

¹⁴ Additional resources allocated in 2025/26 budget

¹⁵ Dependent on new additional funding

¹⁶ Newcastle Rare Diseases Centre of Excellence

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#	Strategy	Actions	RDNZ lead	RDNZ support roles	Potential/actual external collaborators	Timeframes			
						Q1	Q2	Q3	Q4
		kk) Engage with external and internal stakeholders, and supporters, in ways that are consistent with RDNZ values	CH	all		✓	✓	✓	✓