



**Strategic Plan 2026 - 2029
&
July 2026 - June 2027 Operating Plan**

Strategic Plan 2026 - 2029

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 for each other, 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.	Pressing for full implementation of New Zealand's Rare Disorder Strategy (RDS)	No of government health agencies engaging with implementation of the RDS No of government RDS implementation agencies with RDS action plans or equivalent	4 3
2.	Raising awareness and understanding of rare disorders and RDNZ, and strengthening RDNZ's reputation 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 No. of MPs on the cross party parliamentary group on rare and undiagnosed disorders No. of clinicians affiliated with the Te Whatu Ora Rare Disorders Clinical Reference Group	trending up trending up; 1000 minimum >6 >30
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	No of people on RDNZ's Māori Advisory Group No. of MAG recommendation reports	>5 1
5.	Strengthening New Zealand's rare disorders research sector	No. of researchers on the RDNZ rare disorders research network	>40
6.	Ensuring RDNZ's long term financial and reputational viability and sustainability	Annual income from all sources	trending up

	We will fulfill our mission by:	Impact/outcome indicators	target
		Income growth from all sources	= or > expenditure increases
		Net assets	reserves>contingency
		Income diversification index	4.1 ¹

¹ Based on inverted HHI score. The higher the score the greater the diversification. https://en.m.wikipedia.org/wiki/Herfindahl%E2%80%93Hirschman_index

RDNZ Annual Operating Plan 2026 - 2027

The extent to which the actions in this plan will be implemented will depend on the RDNZ team's capacity to deliver, and, where specifically indicated (>\$) availability of additional funding over and above budgeted income.

#	Strategy	Actions	RDNZ lead ²	RDNZ support roles	Potential/actual external collaborators	Timeframes				> \$
						Q1	Q2	Q3	Q4	
1.	Collaboratively advocate for full implementation of the Rare Disorder Strategy (RDS) ³	a) Actively participate in an RDS implementation group comprising RDNZ, Manatū Hauora, Te Whatu Ora, Pharmac and HQSC	CE	RM N	PCPGRUD ⁴	✓	✓	✓	✓	
		b) Work towards and advocate for a rare disorders leadership and coordination mechanism.	CE	RM N CAP ⁵ RDCRG ⁶	PCPGRUD	✓	✓	✓	✓	
		c) Advocate for health entities to ensure early and accurate diagnosis of rare disorders	N	RM CAP		✓	✓	✓	✓	
		d) Advocate for health entities to deliver co-ordinated and integrated pathways for cohesive healthcare	N	RM CAP	PCPGRUD	✓	✓	✓	✓	
		e) Advocate for health and other government entities to implement mechanisms to ensure appropriate access to disability and social supports, including support for carers within capacity as opportunities arise	N	RM CAP		✓	✓	✓	✓	

² CE=Chief Executive; RM=Relationship Manager; N = Navigator; CM = Communications Manager; IPM = Income and Partnerships manager; SIC = South Island Co-ordinator; KMT = Kaupapa Māori Trustee

³ As set out in RDNZ's 7 Priorities for Rare <https://raredisorders.org.nz/about-rare-disorders/7-priorities-for-rare/>

⁴ Parliamentary cross-party group for rare and undiagnosed disorders

⁵ RDNZ's Clinical Advisory Panel

⁶ TWO | HNZ Rare Disorders Clinical Reference Group

<https://nzord.sharepoint.com/Shared Documents/Strategic and Annual Plans/2026/RDNZ strategic and operating plan 2026 2027 final.docx>

#	Strategy	Actions	RDNZ lead ²	RDNZ support roles	Potential/actual external collaborators	Timeframes				> \$
						Q1	Q2	Q3	Q4	
		f) Promote implementation of the RDS related research imperatives	CE	RDRNLG ⁷ NZNMG ⁸ CAP		✓	✓	✓	✓	
		g) Advocate for health entities to capture relevant data on rare disorders in New Zealand.	RM	N RDRNLG CAP		✓	✓	✓	✓	
		h) Advocate for Pharmac to provide equitable access to modern rare disorder medicines through a specific assessment pathway	RM	N CAP	RTC ⁹ PVA ¹⁰ MNZ ¹¹	✓	✓	✓	✓	
		i) Advocate for health and other government entities to plan and provide training on rare disorders for health and other professionals and support staff	N	RM CAP		✓	✓	✓	✓	
		j) Complete and commence responding to implications of an NZIER commissioned report to demonstrate the economic and health sector benefits of investing in early diagnosis for rare disorders	CE		NZIER	✓	✓			✓
2.	Raise awareness and understanding of rare disorders and strengthen RDNZ's presence	k) Run rare disorders public awareness and promotional initiatives and campaigns, including rare disorders month March 2027	CM	RM SIC		✓	✓	✓	✓	✓

⁷ Rare Disorders Research Network Leadership Group

⁸ NZ ERDERA National Mirror Group

⁹ Round Table of (therapeutic) Companies

¹⁰ Patient Voice Aotearoa

¹¹ Medicines NZ

#	Strategy	Actions	RDNZ lead ²	RDNZ support roles	Potential/actual external collaborators	Timeframes				> \$
						Q1	Q2	Q3	Q4	
	as the collective voice for rare disorders in New Zealand	l) Support RDNZ's advocacy campaigning through awareness raising, PR and media activities	CM	RM N		✓	✓	✓	✓	✓
		m) Support RDNZ's income generation activities with branding and collateral support	CM	IPM		✓	✓	✓	✓	
		n) Plan for a revamped, donor database integrated, RDNZ operable website	CM	IPM		✓	✓	✓	✓	
		o) Advocate for a rare and undiagnosed disorders network of expertise	CE	N CAP		✓	✓	✓	✓	
3.	Make connections in the rare disorders community	p) Foster opportunities for rare disorders support group leads to meet and offer support on-line, via social media and face to face, including a biennial in person one day support group leads hui	RM	N SIC		✓	✓	✓	✓	
		q) Produce and disseminate regular newsletters and other sources of RDNZ provided information both to support group members and the wider community of people living with a rare disorder	CM	LT		✓	✓	✓	✓	
		r) Provide an enquiries service for people seeking rare disorders information and support	RM	N		✓	✓	✓	✓	
		s) Offer support group leads opportunities to be consulted on RDNZ planning and policy development	RM	N		✓	✓	✓	✓	

#	Strategy	Actions	RDNZ lead ²	RDNZ support roles	Potential/actual external collaborators	Timeframes				> \$
						Q1	Q2	Q3	Q4	
		t) Collaborate with complementary organisations and networks which also support the rare disorders community	RM	N CE SIC		✓	✓	✓	✓	
		u) Develop and maintain engagement with RDNZ's Round Table of Companies	CE	N IPM RM		✓	✓	✓	✓	
4.	Become an effective and relevant Tiriti partner	v) Implement the intentions set out in RDNZ's June 2024 "Tiriti journey" position statement ¹²	CE	RDMAG		✓	✓	✓	✓	✓
		w) Pursue a mātauranga Māori informed approach to implementing the RDS	CE	RDMAG ¹³ MMSIL ¹⁴		✓	✓	✓	✓	✓
		x) Complete and respond to implications of the Costello Medical funded report comparing whānau Māori and non-Māori experiences of living with a rare disorder	CE	KMTs RDMAG		✓	✓			
		y) Operate RDNZ's CAP and RDRN in ways that demonstrate RDNZ's commitment to being a better Tiriti partner	CE		CAP and RDRNLG co chairs	✓	✓	✓	✓	
		z) Recruit and retain tangata whenua RDNZ Board members	RDNZ Chair	RDNZ Board RDMAG		✓	✓	✓	✓	
		aa) Establish and be responsive to an RDNZ Māori advisory group	RDNZ Board	CE		✓	✓	✓	✓	✓

¹² Dependent on new additional funding

¹³ Rare Disorders Māori Advisory Group

¹⁴ Mātauranga Māori Strategy Implementation Lead

#	Strategy	Actions	RDNZ lead ²	RDNZ support roles	Potential/actual external collaborators	Timeframes				> \$
						Q1	Q2	Q3	Q4	
		bb) Consider options for RDNZ kupu and imagery	CE	RDMAG					✓	
		cc) Identify an RDNZ kaumatua	RDNZ Board	RDMAG			✓			
5.	Strengthen New Zealand's rare disorders research sector	dd) Develop and strengthen New Zealand's rare disorders research networks, and the NZ NMG, in line with ERDERA best practice principles	CE	RDRNLG	ERDERA IRDiRC	✓	✓	✓	✓	✓
		ee) Promulgate discoveries and opportunities from the rare disorders research network	CM	RM N RDRNLG		✓	✓	✓	✓	
6.	Ensure RDNZ's long term financial and reputational viability and sustainability	ff) Appropriately value, remunerate and formally performance review RDNZ staff	CE			✓			✓	✓
		gg) Promote a positive organisational culture consistent with RDNZ values	CE	RDNZ team Trustees		✓	✓	✓	✓	
		hh) Diversify, scale up and grow income from all sources sufficient to meet the expectations of the Annual Plan and cover operating costs	CE	IPM CM RM Trustees		✓	✓	✓	✓	
		ii) Maintain sufficient financial reserves to enable RDNZ's long term sustainability	CE			✓	✓	✓	✓	
		jj) Evolve governance arrangements to ensure fitness for purpose, appropriate skill sets and connection with the rare disorders community	RDNZ Chair	RDNZ Board		✓	✓	✓	✓	

#	Strategy	Actions	RDNZ lead ²	RDNZ support roles	Potential/actual external collaborators	Timeframes				> \$
						Q1	Q2	Q3	Q4	
		kk) Maintain a comprehensive risk identification and mitigation/policy development programme, covering financial, reputational, ICT, legal operational and other material risks	CE	RDNZ team Board		✓	✓	✓	✓	✓
		ll) Be globally recognised and valued within the rare disorders community internationally ¹⁵	CE		EURORDIS RDI HGSA NRDCE ¹⁶	✓	✓	✓	✓	✓
		mm) Engage with external and internal stakeholders, supporters, and each other, in ways that are consistent with RDNZ values	CE	all		✓	✓	✓	✓	

¹⁵ As new additional funding allows

¹⁶ Newcastle Rare Diseases Centre of Excellence

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