



**Strategic Plan 2024 - 2027**  
**&**  
**July 2024 - June 2025 Work Plan**

# Strategic Plan 2024 - 2027

## 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)	% of “Voice of Rare Disorders” survey respondents who say that: <ul style="list-style-type: none"> <li>• It took less than six months to get an accurate diagnosis for the rare disorder</li> <li>• The rare disorder was misdiagnosed before getting the final diagnosis</li> <li>• They were provided with care coordination support which meets their needs</li> </ul>	trending up  trending down  trending up
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 “Voice of Rare Disorders” survey respondents	trending up  trending up
3.	Connecting all those in the rare disorder community to achieve improved health and wellbeing outcomes	% of “Voice of Rare Disorders” survey respondents who say that the person with the rare disorder and/or their family/whānau are fairly or very well connected with others with their condition	trending up

	We will fulfill our mission by:	Impact/outcome indicators	target
4.	Becoming an effective and relevant Te Tiriti partner	Number of Māori who respond to RDNZ’s “Voice of Rare Disorders” survey	trending up
5.	Ensuring RDNZ’s long term financial and reputational viability and sustainability	Annual income from all sources Net assets	trending up reserves>contingency

## RDNZ Annual Plan 2024 - 2025

#	Strategy	Actions	RDNZ lead	RDNZ support roles	Possible external collaborators	Timeframes			
						Q1	Q2	Q3	Q4
1.	Campaign for full implementation of the Rare Disorder Strategy (RDS)	a) Pursue a mātauranga Māori led approach to implementing the RDS	CH	SIL <sup>1 2</sup>		✓	✓	✓	✓
		b) Actively participate as a member of the Manatū Hauora led RDS implementation group comprising RDNZ, Te Whatu Ora, Whaikaha and Pharmac	CH	SIL KM LP		✓	✓	✓	✓
		c) Establish a parliamentary cross-party rare disorders MPs group	CH	KM LP		✓	✓	✓	✓
		d) Advocate for a rare and undiagnosed disorders centre of expertise.	CH	SIL KM LP AN CAP <sup>3</sup>		✓	✓	✓	✓
		e) Recommend enhancements to current arrangements for neonatal screening and diagnosis	CH	SIL KM LP CAP			✓	✓	✓
		f) Press for adoption of regimes which code for rare disorders across all Te Whatu Ora data sets	CH	KM LP SIL		✓	✓	✓	✓

<sup>1</sup> RDNZ Strategy Implementation Lead

<sup>2</sup> Dependent on new additional funding

<sup>3</sup> RDNZ's Clinical Advisory Panel

#	Strategy	Actions	RDNZ lead	RDNZ support roles	Possible external collaborators	Timeframes			
						Q1	Q2	Q3	Q4
				CAP					
		g) Press Whaikaha to implement relevant RDS requirements	CH	SIL KM		✓	✓	✓	✓
		h) Contribute to the development of a new medicines strategy; and advocate for improvements in Pharmac’s culture and operating practices.	CH	KM LP CAP	RTC <sup>4</sup> PVA <sup>5</sup> MNZ <sup>6</sup>	✓	✓	✓	✓
2.	Raise awareness and understanding of rare disorders and strengthen RDNZ’s presence as the collective voice for rare disorders in New Zealand	i) Run rare disorders public awareness initiatives and campaigns, including rare disorders month March 2025	AN	KM LB	Maia		✓	✓	
		j) Commission NZIER to estimate the size of the expected demand for and value of the opportunity presented by new cell and gene therapies for rare disorders <sup>7</sup>	CH	CH	NZIER		✓	✓	
		k) Develop and maintain, and promulgate discoveries and opportunities from, a rare disorders research network (RDRN)	CH	KM AN		✓	✓	✓	✓
		l) Redevelop the RDNZ website	AN	JM		✓	✓	✓	
		m) Establish a rare disorders photograph library <sup>8</sup>	AN	KM LP			✓	✓	

<sup>4</sup> Round Table of (Pharmaceutical) Companies

<sup>5</sup> Patient Voice Aotearoa

<sup>6</sup> Medicines NZ

<sup>7</sup> Dependent on new additional funding

<sup>8</sup> Dependent on new additional funding

#	Strategy	Actions	RDNZ lead	RDNZ support roles	Possible external collaborators	Timeframes			
						Q1	Q2	Q3	Q4
		n) Develop and implement recommendations for RDNZ re-branding	CH	AN SIL					✓
3.	Connect all those in the rare disorder community to achieve improved health and wellbeing outcomes	o) 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		✓	✓	✓	✓
		p) 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	KM	AN		✓	✓	✓	✓
		q) Provide an enquiries service for people seeking rare disorders information and support	KM	LP		✓	✓	✓	✓
		r) Scope a mental health support resource for people living with rare disorder <sup>9</sup>	KM	LP SIL				✓	✓
		s) Collaborate with complementary organisations and networks which also support the rare disorders community	KM	LP CH		✓	✓	✓	✓
4.	Become an effective and relevant Tiriti partner	t) Implement the intentions set out in RDNZ's June 2024 "Tiriti journey" position statement <sup>10</sup>	CH	SIL		✓	✓	✓	✓
		u) Communicate externally through a te ao Māori lens	AN	SIL		✓	✓	✓	✓

<sup>9</sup> Dependent on new additional funding

<sup>10</sup> Dependent on new additional funding

#	Strategy	Actions	RDNZ lead	RDNZ support roles	Possible external collaborators	Timeframes			
						Q1	Q2	Q3	Q4
		v) Operate RDNZ’s CAP and RDRN in ways that demonstrate RDNZ’s commitment to being a better Tiriti partner	CH	SIL		✓	✓	✓	✓
		w) Run externally facilitated RDNZ values and other workshops to promote mutual understanding and expectations for operating as a better Tiriti partner	CH	SIL			✓		
		x) Develop RDNZ branding options which reflect Te Aka Whai Ora’s Whanua Voice recommendations	SIL	AN				✓	✓
		y) Recruit and retain new te ao Māori experienced RDNZ Board members to demonstrate commitment to being a better Tiriti partner	RDNZ Chair	RDNZ Board		✓	✓	✓	✓
		z) Consider establishment of a Māori advisory group and kaumatua appointment	RDNZ Chair	RDNZ Board				✓	✓
5.	Ensure RDNZ’s long term financial and reputational viability and sustainability	aa) Appropriately value, remunerate and formally performance review RDNZ staff	CH			✓	✓	✓	✓
		bb) Establish and operate a regular giving programme	RGS <sup>11</sup>	AN KM MR		✓	✓	✓	✓
		cc) Grow Round Table of Companies support and financial contributions	CH	MR		✓	✓	✓	✓
		dd) Secure and increase the value of the Te Whatu Ora (ex MoH) contract for 2024/25 and beyond	CH	MR KM		✓			✓

<sup>11</sup> Regular giving specialist



#	Strategy	Actions	RDNZ lead	RDNZ support roles	Possible external collaborators	Timeframes			
						Q1	Q2	Q3	Q4
		ee) Maintain and increase the value of grants income	MR			✓	✓	✓	✓
		ff) Identify avenues for further diversification and growth of RDNZ revenue	MR	CH		✓	✓	✓	✓
		gg) Maintain sufficient financial reserves to enable RDNZ's long term sustainability	SL	MR		✓	✓	✓	✓
		hh) Evolve governance arrangements to ensure fitness for purpose, appropriate skill sets and connection with the rare disorders community				✓	✓	✓	✓
		ii) Operate in ways which are legislatively compliant and consistent with financial and organisational risk management and other best practice	CH	SL		✓	✓	✓	✓
		jj) Be globally recognised and valued within the rare disorders community internationally <sup>12</sup>			<ul style="list-style-type: none"> <li>• Eurordis</li> <li>• Global Genes</li> <li>• Apardo</li> <li>• RDI</li> <li>• WARCC</li> </ul>	✓	✓	✓	✓
		kk) Engage with external and internal stakeholders in ways that are consistent with RDNZ values	CH	all		✓	✓	✓	✓

<sup>12</sup> Dependent on new additional funding