



Strategic Plan 2023 - 2026
&
July 2023 - June 2024 Work Plan

Final

30th September 2023

Strategic Plan 2023 - 2026

Vision, Mission and Values

Vision:

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

Mission:

To champion and amplify the collective voice of New Zealanders with rare disorders, advocating for access to world class and world leading health, disability, education and other services.

Values¹:

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

¹ Adapted from the outcome of an RDNZ September 2022 values setting exercise

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)	<p>% of “Voice of Rare Disorders” survey respondents who say that:</p> <ul style="list-style-type: none"> • It took less than six months to get an accurate diagnosis for the rare disorder • The rare disorder was misdiagnosed before getting the final diagnosis • They were provided with care coordination support which meets their needs 	<p>trending up</p> <p>trending down</p> <p>trending up</p>
2.	Campaigning for implementation of policies for optimising the wellbeing of people living with rare disorders which are not addressed by the RDS	To be identified post-RDS	
3.	Raising awareness and understanding of rare disorders and strengthening RDNZ’s presence as the collective voice for rare disorders in New Zealand	<p>Number of recipients of RDNZ’s monthly newsletter</p> <p>Number of “Voice of Rare Disorders” survey respondents</p>	<p>trending up</p> <p>trending up</p>
4.	Connecting all those in the rare disorder community to achieve improved health and wellbeing outcomes	<p>Number of people who are members of an RDNZ supported rare disorders support group</p> <p>% of “Voice of Rare Disorders” survey respondents who say that the person with the rare disorder and/or their family/whānau are</p>	<p>trending up</p> <p>trending up</p>

	We will fulfill our mission by:	Impact/outcome indicators	target
		fairly or very well connected with others with their condition	
5.	Becoming an effective and relevant Te Tiriti partner and internationally networked universal human rights organisation	Number of Māori who are members of NZHR’s Tiriti partner group Number of Māori who respond to RDNZ’s “Voice of Rare Disorders” survey	trending up trending up
6.	Ensuring RDNZ’s long term financial and reputational viability and sustainability	Annual income from all sources Net assets	trending up >reserves

RDNZ Work Plan 2023 - 2024

Q1: July - September 2023; Q2: October - December 2023; Q3: January - March 2024; Q4: April - June 2024								
#	Strategy	Actions	RDNZ lead	RDNZ key support	Timeframes			
					Q1	Q2	Q3	Q4
1.	Campaigning for full implementation of New Zealand's Rare Disorder Strategy (RDS)	a) Ensure that people living with rare disorders have been given genuine opportunities by Manatū Hauora to be directly consulted and validated in the development of the RDS	KM	LP	✓	✓		
		b) Submit to Manatū Hauora a compelling case for the RDS to require the provision of world class and world leading: evidence based diagnostic, support and coordination services; access to pharmaceuticals; rare disorders health service utilisation, incidence and prevalence data; and investment in rare disorders research.	CH	KM LP	✓	✓		
		c) Advocate for Health New Zealand/Te Whatu Ora, Pharmac and other health and non-health entities to develop, resource and implement plans to fully realise RDS requirements and expectations	CH	KM LP		✓	✓	✓
		d) Advocate and achieve political and government support for the establishment of a rare and undiagnosed disorders centre of expertise.	CH	KM LP AN	✓	✓	✓	✓
		e) Leverage advocacy opportunities occasioned by the 2023 General Election, including supporting complementary advocacy campaigns being run by other entities	CH	KM AN	✓	✓		
		f) Participate in complementary campaigns and activities advocating for RDS consistent change	CH	KM	✓	✓	✓	✓

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					Q1	Q2	Q3	Q4
2.	Campaigning for implementation of policies for optimising the wellbeing of people living with rare disorders which are not addressed by the RDS	g) Identify non-RDS RDNZ priorities, and develop and commence implementation of action plans to address	CH	KM LP			✓	✓
3.	Raising awareness and understanding of rare disorders and strengthening RDNZ’s presence as the collective voice for rare disorders in New Zealand	h) Run a rare disorders public awareness campaign to leverage off international rare diseases day, 29 th February 2024	AN	KM LB		✓	✓	
		i) Conduct, publish, launch, disseminate and deploy in advocacy campaigns the results of the biennial “Voice of Rare Disorders” survey, with a target of >1000 useable responses	KM	CH	✓	✓	✓	✓
		j) Identify, communicate, and participate in rare disorders research programmes	CH	KM AN	✓	✓	✓	✓
		k) Redevelop the RDNZ website	AN	JM		✓	✓	
		l) Review and implement recommendations for RDNZ re-branding	CH	AN JL			✓	✓
4.	Connecting all those in the rare disorder community to achieve improved health and wellbeing outcomes	m) Foster opportunities for rare disorders support group members to meet and offer support on-line, via social media and face to face	KM	LP	✓	✓	✓	✓
		n) 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	✓	✓	✓	✓
		o) Provide an enquiries service for people seeking rare disorders information and support	KM	LP	✓	✓	✓	✓

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		p) Collaborate with complementary organisations and networks which also support the rare disorders community	KM	LP CH	✓	✓	✓	✓
5.	Becoming an effective and relevant Tiriti partner and internationally networked universal human rights organisation	q) Establish an RDNZ Māori led Tiriti partner group to advise on and participate in initiatives for improving health and well-being outcomes for Māori and whanau living with a rare disorder	CH	JL		✓	✓	✓
		r) In addition to the existing Kaiāwhina Māori role, establish new Māori advisory and kaumatua roles to support the RDNZ Board, CE, the RDNZ team and the wider rare disorders community to genuinely engage with the RDNZ Tiriti partner group	CH	JL			✓	✓
		s) Support engagement by Māori and whanau living with rare disorders in the Te Aka Whai Ora led RDS consultation exercise	JL	CH	✓	✓		
		t) Implement strategies for achieving Māori participation in the “Voice of Rare Disorders” survey consistent with their representation in the general population, with a target of >100 useable responses	JL	KM CH	✓	✓		
		u) Produce a Māori specific “Voice of Rare Disorders” report to inform the work of the Tiriti partner group	CH	JL		✓	✓	✓
		v) Run an externally facilitated RDNZ values based team workshop to promote mutual understanding of the individual and team expectations for operating as a Tiriti	CH	AHE			✓	
		w) Reflect Tiriti partner group advice in RDNZ rebranding, communications, publications and promotional collateral	CH	JL KM AN		✓	✓	✓

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6.	Ensuring RDNZ's long term financial and reputational viability and sustainability	x) Establish and operate a regular giving programme, to be initiated in the context of the planned rare disorders awareness campaign	MR	AN KM		✓	✓	✓
		y) Initiate a bequests programme	MR	AN			✓	✓
		z) Grow Round Table of Companies support and financial contributions	CH	MR	✓	✓	✓	✓
		aa) Secure and increase the value of the Te Whatu Ora (ex MoH) contract for 2024/25 and beyond	CH	MR KM		✓	✓	✓
		bb) Maintain and increase the value of grants income	MR		✓	✓	✓	✓
		cc) Identify avenues for further diversification of RDNZ revenue	MR	CH		✓	✓	✓
		dd) Maintain sufficient financial reserves to enable RDNZ's long term sustainability	SL	MR	✓	✓	✓	✓
		ee) Operate in ways which are legislatively compliant and consistent with financial and organisational best practice	CH	SL	✓	✓	✓	✓
		ff) Engage with external and internal stakeholders in ways that are consistent with RDNZ values	CH	all	✓	✓	✓	✓