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New Zealand Rare Disorders Research Network (RDRN)/ERDERA National Mirror Group (NMG)

Action Plan

July 2026 – June 2029

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PURPOSE

The purpose of having an entity for rare disorders research in New Zealand, and therefore this plan, is to bring about significant improvements in the lives of and outcomes for New Zealanders living with rare disorders.

Research can address the many knowledge gaps that exist when optimally responding to rare disorders, but for it to be effective the knowledge needs to be communicated to professionals and others providing care and support (including people and whānau living with rare disorders), health and other systems should support and require the translation of the results of rare disorders into evidence based best policy and practice, and advocacy should be applied where they don't. This plan sets out what needs to happen over the next three years to provide a platform for these issues to be addressed in the short, medium and longer terms.

An RDRN Leadership Group member has suggested an overarching aspiration of enabling people living with rare disorders and their whānau in Aotearoa New Zealand to live well and participate fully, with research helping to remove the health, social and educational barriers that currently prevent this.

ERDERA's vision is: better prevention, better diagnosis, better treatment, with a core pledge to make Europe a global leader in rare disease research and innovation; and "leaving no one behind: the alliance aims to build an integrated, multi-stakeholder ecosystem that connects patients, researchers, clinicians, industry, and regulators"

The vision of the International Rare Diseases Research Consortium (IRDiRC) is to enable all people living with a rare disease to receive an accurate diagnosis, care, and available therapy within one year of coming to medical attention, with three goals for the next decade:

1. All patients coming to medical attention with a suspected rare disease will be diagnosed within one year if their disorder is known in the medical literature; all currently undiagnosable individuals will enter a globally coordinated diagnostic and research pipeline
2. 1000 new therapies for rare diseases will be approved, the majority of which will focus on diseases without approved options

3. Methodologies will be developed to assess the impact of diagnoses and therapies on rare disease patients[1]

Feedback on this section will be appreciated.

SECTION 1: Optimising Composition and Governance

#	Action	Tasks	Who	Y1[2] Q1	Y1 Q2	Y1 Q3	Y1 Q4	Y2	Y3
1.	Harmonise NZ RDRN and NZ ERDERA NMG governance structures	a) NZ Board approved terms of reference	RDNZ						
		b) Entity and governing entity names	MAG[3]						
			RDRNLG+[4]						
		c) Clarify governing entity Māori and consumer representation	RDRNLG+		✓				
		d) Clarify RDS[5] implementation agencies representation	RDRNLG+						
		e) Appointment of governing entity members	RDNZ Board						
		f) Confirm meeting rhythm and support	RDRNLG+						

[1] https://irdirc.org/vision-goals/
[2] Y1 = July 2026 – June 2027
[3] RDNZ Māori Advisory Group
[4] New Zealand Rare Disorders Research Network/ERDERA National Mirror Group combined governance/oversight group
[5] Aotearoa New Zealand Rare Disorders Strategy 2024 - 2034

#	Action	Tasks	Who	Y1[2] Q1	Y1 Q2	Y1 Q3	Y1 Q4	Y2	Y3
2.	Grow and develop the NZ rare disorders research network	g) Secure funding to resource ✓ tasks[6]	RDRNLG+		✓	✓	✓	✓	✓
		h) Clarify network eligibility criteria	RDRNLG+		✓				
		i) Active inclusion of Māori rare disorders researchers and research networks	RDRNLG+ MAG			✓	✓	✓	✓
		j) Biennial rare disorders research network events	RDNZ	✓		✓		✓	✓
		k) Regular bi-monthly newsletter to network members and stakeholders	RDNZ		✓	✓	✓	✓	✓
		l) Identify specific RDRN membership vs stakeholders' benefits	RDRNLG+		✓				
3.	Ensure continuity of the RD research network over time	m) Refresh the 3 year plan annually	RDRNLG+				✓	✓	✓

SECTION 2: Understanding the national status quo and existing knowledge gaps.

[6] Tasks that won't be able to be implemented in the absence of external funding and resources

#	Action	Tasks	Who	Y1 Q1	Y1 Q2	Y1 Q3	Y1 Q4	Y2	Y3
4.	Identify specific areas for future rare disorders research development	n) Develop a template of the knowledge gaps that should be address by rare disorders research over the next three years organised under the following headings[7]: a. Early diagnosis b. Access to treatment and therapies c. Care delivery d. Support and well-being e. ecosystem	RDRNLG+			✓	✓		
		o) Undertake a documented stocktake of immediate past, current and known future rare disorders research	RDNZ					✓	
		p) Undertake a gap analysis and identify and advocate for specific areas for future rare disorders research development	RDNZ					✓	
5.		q) Present the gap analysis to the RDS implementation agencies	RDNZ					✓	

[7] Clinical Centre of Expertise for Rare and Undiagnosed Diseases (CCERUD). Perth. WA

#	Action	Tasks	Who	Y1 Q1	Y1 Q2	Y1 Q3	Y1 Q4	Y2	Y3
	Build an awareness of what is happening at national level for rare disorders research	r) Present the gap analysis to MBIE[8], tertiary and other rare disorders research funders	RDRNLG+					✓	

SECTION 3: Shaping and influencing national-level activity.

(The ERDERA template asks for the steps and concrete actions your NMG will take to improve the situation at national level for rare disease including:
a) Influencing National Plans & Strategies for RD:
b) In which topics/areas will your NMG exert influence, and how?)

The Aotearoa New Zealand Rare Disorders Strategy 2024–2034 implementation plan for 2026/27 states that RDNZ will contribute to the rare disorders research aspects of the Rare Disorders Strategy through its leadership of the rare disorders research network leadership group and the European Rare Diseases Research Alliance (ERDERA) affiliated New Zealand National Mirror Group. Through RDNZ these two entities will seek to both integrate rare disorders research with the Te Whatu Ora | Health NZ Clinical Reference Group over time and contribute to the implementation of the RDS.

[8] Ministry of Business, Innovation and Employment

#	Action	Tasks	Who	Y1 Q1	Y1 Q2	Y1 Q3	Y1 Q4	Y2	Y3
6.	Lead prioritisation of rare disorders research in annual RDS implementation action plans	s) Contribute to "an expanded health research infrastructure that will support rare disorders research and evaluation"	RDNZ			✓	✓		
		t) Contribute to "people living with rare disorders participating in rare disorders research"	RDNZ					✓	
		u) Contribute to "supporting clinical trials infrastructure to support participation by people with rare disorders from all parts of the country"	RDNZ						✓
		v) Initiate development of a national rare disorders research registry based on the SNOMED CT[9] coding regime	RDSIG						✓
7.		w) Engage with New Zealand's rare disorders clinical community including the Te Whatu Ora | Health NZ rare disorders clinical reference	RDRNLG+ RDNZ	✓	✓	✓	✓	✓	✓

[9] Systematized Nomenclature of Medicine — Clinical Terms . https://www.healthnz.govt.nz/health-professionals/guidance-standards/topic/data-and-standards/health-information-standards/snomed-ct-national-release-centre/snomed-ct-new-zealand-edition

#	Action	Tasks	Who	Y1 Q1	Y1 Q2	Y1 Q3	Y1 Q4	Y2	Y3
		group and RDNZ's clinical advisory panel							
8.	Press for prioritisation of rare disorders research within MBIE's "health and thriving societies" investment pillar	x) Leverage the RDS to advocate for specific rare disorders research allocations in the health and thriving societies and other investment pillars	RDNZ		✓	✓	✓	✓	✓
		y) Leverage NZ's ERDERA membership to achieve access Horizon's Europe funding	RDRNLG+					✓	✓
9.	Pitch for rare disorders research to be recognised as a tertiary education sector CORE (Centre of Research Excellence)	z) Identify a host institution and mechanisms for inter-institution collaboration	RDRNLG+					✓	✓

SECTION 4: Optimising national engagement with international rare disorders research alliances and networks

#	Action	Tasks	Who	Y1 Q1	Y1 Q2	Y1 Q3	Y1 Q4	Y2	Y3
10.	Engagement with ERDERA meetings and activities	aa) Participation in ERDERA National Alignment Board meetings	LB		✓			✓	✓

#	Action	Tasks	Who	Y1 Q1	Y1 Q2	Y1 Q3	Y1 Q4	Y2	Y3
		bb) Participation in other relevant ERDERA meetings and conferences	CH PW LB				✓	✓	✓
		cc) Participation in on-line ERDERA engagement opportunities	RDRNLG+			✓	✓	✓	✓
11.	Align with other international rare diseases research alliances and networks	dd) IRDiRC[10] membership as a Patient Advocates Constituent Committee (PACC) member	RDNZ			✓	✓	✓	✓

SECTION 5: Collaboration with other NMGs which share common issues

#	Action	Tasks	Who	Y1 Q1	Y1 Q2	Y1 Q3	Y1 Q4	Y2	Y3
12.	Participate as a member of the emerging commonwealth NMG network	ee) Stay connected and share ideas and experiences with UK, Canadian and Australian NMG representatives	RDRNLG+		✓	✓	✓	✓	✓
13.	Share progress and experiences of RDRNLG+'s Tiriti journey with other NMGs where responsiveness to indigeneity is an imperative	ff) Stay connected and share progress and experiences with Canadian, Australian and other NMG representatives	MAG RDRNLG+				✓	✓	✓

[10] International Rare Diseases Research Consortium

#	Action	Tasks	Who	Y1 Q1	Y1 Q2	Y1 Q3	Y1 Q4	Y2	Y3
14.	Collaborate with the emerging Australian NMG to provide mutual solidarity as the only two southern hemisphere ERDERA members	gg) Ensure consistency between and complementarity of respective ERDERA NMG three year plans	RDRNLG CCERUD		✓	✓	✓		