



**Interests:**

Member, Pharmac Consumer and Patient Working Group  
Chair, RDNZ Round Table of Companies  
Brand Ambassador, New Zealanders for Health Research  
Principal, CHA Enterprises Ltd



# New Zealand's ERDERA National Mirror Group Journey

Chris Higgins  
Chief Executive  
Rare Disorders New Zealand

COMPASS Research Centre Community Session 2026: Working together for Rare Disorders



COMPASS  
Research  
Centre

23 March 2026



RARE DISORDERS  
RESEARCH NETWORK

## PRESENTATION OUTLINE

- ▶ Rare Disorders Research Network
- ▶ New Zealand European Rare Diseases Alliance National Mirror Group
- ▶ Aotearoa New Zealand Rare Disorders Strategy and rare disorders research
- ▶ RDNZ research initiatives
- ▶ Next steps

## THE JOURNEY SO FAR: PART 1

- ▶ Mid-2023 small HRC activation grant awarded to Karen McBride Henry and her team at Victoria University's School of Nursing, Midwifery, and Health Practice - Te Kura Tapuhi Hauora to:
- ▶ Activate, in collaboration with RDNZ, a rare disorders research strategy network and develop a research strategy for rare disorders
- ▶ RDNZ team was being approached at this time by people seeking RDNZ's support for rare disorders research funding applications
- ▶ Well respected and known internationally, or within their own clinical specialty, or to RDNZ, but not known to each other
- ▶ Culminated in our first rare disorders research network event in Rare Disorders Month, March 2024

## THE JOURNEY SO FAR: PART 2



## THE JOURNEY SO FAR: PART 2



## THE JOURNEY SO FAR: PART 2

- ▶ About 60 invitations and 40 participants
- ▶ About joining the dots so that rare disorders researchers could learn from and get to know each other
- ▶ About 12 one minute elevator presentations
- ▶ The meeting agreed that there should be a formal rare disorders research network established
- ▶ Subsequently agreed that the development of both the network and a rare disorders research strategic plan should be overseen by a rare disorders research network (RDRN) leadership group

## THE JOURNEY SO FAR: PART 3

- ▶ Following invitations for expressions of interest and in consultation with Karen McBride Henry and her team a leadership group was appointed by the RDNZ Board comprising:
  - ▶ Co-chairs Chris Higgins (RDNZ CEO) and Professor Phillip Wilcox (kaupapa Māori expert; quantitative geneticist and bioethicist, University of Otago)
  - ▶ Miriam Rodrigues
  - ▶ Sara Filoche
  - ▶ Farah Lamiable-Oulaidi
  - ▶ Stephanie Hughs
  - ▶ Justin O’Sullivan
  - ▶ Louise Bicknell
  - ▶ Tara Officer
  - ▶ Samuel Wojcik
  - ▶ Michael Roguski
  - ▶ Gareth Baynham

## THE JOURNEY SO FAR: PART 3

- ▶ RDRN Terms of Reference developed by the Leadership Group and signed off by the RDNZ Board in June 2024:
  - ▶ Connect rare disorders researchers with each other and raise mutual awareness of research.
  - ▶ Facilitate rare disorders research forums and meetings
  - ▶ Identify opportunities for interdisciplinary research and funding collaborations
  - ▶ Promote sharing of research with people living with rare disorders, media etc
  - ▶ Promote translation of research results into policy and practice
  - ▶ Promote career opportunities for aspiring and new rare disorders researchers

## THE JOURNEY SO FAR: PART 4

- ▶ March 2025: second rare disorders research network meeting and the first meeting of the RDRN leadership group



## THE JOURNEY SO FAR: PART 4



## THE JOURNEY SO FAR: PART 4



## THE JOURNEY SO FAR: PART 4

- ▶ RDRN Leadership Group:
  - ▶ Formally affirmed its terms of reference
  - ▶ Adopted the symbolism of te kōtuku which is now used in RDRN's branding
  - ▶ Endorsed the establishment of a New Zealand ERDERA National Mirror group
  - ▶ Noted the intention to develop a New Zealand rare disorders research strategy
  - ▶ considered benefits of RDRN membership:
    - ▶ Invitations to member only rare disorders research networking events and forums
    - ▶ Opportunities for your research to be promoted to the rare disorders community through RDNZ communications channels
    - ▶ Enhanced prospects for your research to be embedded into practice in New Zealand as a result of RDNZ and Support Group advocacy
    - ▶ Sharing of knowledge and ideas among colleagues in the rare disorders research community
    - ▶ Being kept up to date about international rare disorders sector collaborations and developments
    - ▶ Opportunities to contribute to the growth of New Zealand's rare disorders research capacity, including the development of a rare disorders research strategy
    - ▶ Opportunities to contribute to the growth of New Zealand's rare disorders research capacity, including the development of a rare disorders research strategy
    - ▶ Receipt of and an open invitation to contribute to the Rare Disorders Research Network newsletter

# THE ERDERA TRIBUTARY

## European Rare Diseases Research Alliance

- ▶ ERDERA launched in September 2024 with an estimated budget of 380 million euros and the goal of improving the lives of 30 million rare disease patients in Europe and beyond.
- ▶ builds on the advancements made by former EU-funded projects such as SOLVE-RD, ERICA and the European Joint Programme for Rare Diseases (EJP RD)
- ▶ championed by the European Union under [Horizon Europe](#) and Members States, is led by the National Institute of Health and Medical Research - [INSERM](#) (France).
- ▶ European Union to contribute around 150 million euros to this co-funded partnership via Horizon Europe, while the rest of the funding will come from members states, countries associated to Horizon Europe and in cash and in-kind contributions from public and private partners.
- ▶ Professor Louise Bicknell was an unofficial ambassador to this evolving initiative, representing NZ at ERDERA meetings as a prospective National Mirror Group member

## THE ERDERA TRIBUTARY

- ▶ Louise and I represented New Zealand as a prospective National Mirror Group member at ERDERA's early June 2025 meeting in Riga, Latvia
- ▶ Theme: national rare disorders plans and rare disorders research
- ▶ I presented on New Zealand's then experience of having a national plan (aka the Aotearoa New Zealand Rare Disorders Strategy, or RDS) which:
  - ▶ Included aspirations for rare disorders research
  - ▶ Wasn't being implemented, with active health agency resistance to doing so
- ▶ Cemented RDNZ's participation as an ERDERA participant

## THE ERDERA TRIBUTARY



## THE ERDERA TRIBUTARY



## THE JOURNEY SO FAR: PART 5

- ▶ Louise had applied for Catalyst funding for to “advance rare disorder research in Aotearoa New Zealand through international partnerships” in collaboration with Australian colleagues
- ▶ Project group comprising Chris Higgins, Professors Phillip Wilcox, Louise Bicknell, and Stephanie Hughes, Dr Kylie Drake, and Professors Gareth Baynam and Hugh Dawkins from WA (Australian ERDERA ambassadors)
- ▶ The funding application proposed Chris Higgins, RDNZ Chief Executive be the National Mirror Group Chair, supported by Co-Deputy Chairs Phillip Wilcox (Ngāti Rakaipaaka, Rongomaiwahine, Ngāti Kahungunu ki te Wairoa) and Louise Bicknell
- ▶ October 2025 RDNZ was subcontracted to host an initial meeting on 16 December
- ▶ ERDERA’s Clément Moreau and Victoria Hedley presented an on-line opening address and declared that we’d done enough to be conferred with National Mirror Group status

## WHY SHOULD NZ HAVE A NATIONAL MIRROR GROUP?

- ▶ Connects New Zealand rare disorders researchers and research networks with the international rare diseases research community including Europe, British Commonwealth countries, and internationally through IRDiRC (International Rare Diseases Research Consortium)
- ▶ Supports New Zealand rare disorders research to adopt a best practice approach to capacity building
- ▶ Support implementation of New Zealand's Rare Disorders Strategy
- ▶ implement strategies and goals for undertaking impactful research and improving rare disorder healthcare
- ▶ support momentum on rare disease research and healthcare opportunities within New Zealand, acting as a conduit and accelerator for knowledge sharing, collaboration, and driver of activities.
- ▶ Facilitate bringing people together for funding opportunities eg HRC, MBIE and successors
- ▶ Gateway for rare disorders research in New Zealand to the European Horizons programme

## WHAT WILL A NZ NMG NEED TO DO?

- ▶ a structured governance model that:
  - ▶ facilitates bidirectional communication between the NZNMG and ERDERA
  - ▶ brings together the national representatives of all relevant rare disorders stakeholders, eg:
    - ▶ research institutes,
    - ▶ national alliances for rare disorders that federate patient organisations from a wide range of diseases
    - ▶ national and local authorities, industry representatives, funding agencies, hospitals, and healthcare
    - ▶ partners and members of the ERDERA Governing Board
    - ▶ RDS co-implementation agencies (Manatū Hauora, Te Whatu Ora, Pharmac, HQSC and RDNZ)

## WHAT WILL A NZ NMG NEED TO DO?

- ▶ foster coordination among key national stakeholders
- ▶ Integrate NZ's RD Clinical Reference Group (the closest thing in NZ to a European Reference Network) into national healthcare systems
- ▶ ensure alignment of national and European rare diseases research strategies
- ▶ serve as a platform for knowledge exchange
- ▶ regular national meetings to consolidate research priorities
- ▶ collaborative workshops to enhance stakeholder engagement
- ▶ collection of comprehensive data on national RD research initiatives
- ▶ develop a three-year plan outlining planned activities, focusing on national advocacy, policy influence, and international engagement.

# THE NMG JOURNEY: NEXT STEPS



## THE NMG JOURNEY: NEXT STEPS

- ▶ Engage with Commonwealth NMGs (Canada, Australia, UK and NZ), Sofia, 16 March
- ▶ Participate in ERDERA National Alignment Board meeting, Sofia, 17-18 March 2026, with IRDiRC
- ▶ Become a member of the IRDiRC Patient Advocacy Constituent Committee (PACC)
- ▶ Harmonise the RDRN Leadership Group and the Catalyst funded NMG project group with updated membership and terms of reference, under the RDNZ umbrella
- ▶ development of a name for the combined group, selecting a Māori kupu (word) supported by an extended name that reflects its purpose and identity (PW and RDNZ MAG)

## THE NMG JOURNEY: NEXT STEPS

- ▶ On-line April meeting of the RDRN Leadership Group, the NMG project group, RDS implementation and other stakeholders to review progress, and feature presentations on improving rare disorders data and coding, working towards an internationally compatible rare disorders registry, and using the IDI
- ▶ Louise to return to Riga in June to discuss rare diseases data and registries
- ▶ Meet with Australian NMG stakeholders to support their NMG journey
- ▶ in-person two-day hui in Christchurch following the Human Genetics Society of Australasia (HGSA) meeting in early August
- ▶ Develop the required NMG three-year plan
- ▶ Include the RDRN/NMG Project Group progress in the Manatū Hauora led RDS implementation planning (May 2026)
- ▶ Identify how RDNZ can be resourced to provide the required momentum and bandwidth

# THE NMG JOURNEY: NEXT STEPS



# AOTEAROA NEW ZEALAND RARE DISORDERS STRATEGY



# AOTEAROA NEW ZEALAND RARE DISORDERS STRATEGY



# AOTEAROA NEW ZEALAND RARE DISORDERS STRATEGY

- An expanded health research infrastructure will support rare disorders research and evaluation
- People living with rare disorders will participate in rare disorders research
- Research and evaluation of services and systems will include measuring outcomes, effectiveness and value for money
- Clinical trials infrastructure will include participation by people with rare disorders from all parts of the country
- The RDRN leadership group/NMG will drive the implementation of the RD Strategy, rather than the other way round

# RDNZ RESEARCH INITIATIVES

## IMPACT FOR WHĀNAU MĀORI OF LIVING WITH A RARE DISORDER IN AOTEAROA NEW ZEALAND

Delivering improved outcomes for Māori living with rare disorders and their whānau

2024

HealthiNZ  
Advancing life-changing solutions

## IMPACT OF LIVING WITH A RARE DISORDER IN AOTEAROA NEW ZEALAND

Key priorities to deliver improved outcomes for people living with rare disorders, their family and whānau

2024

HealthiNZ  
Advancing life-changing solutions

## IMPACT OF LIVING WITH A RARE DISORDER IN AOTEAROA NEW ZEALAND IN 2025

Key priorities to deliver improved outcomes for people living with rare disorders, their family and whānau

February 2026

HealthiNZ  
Advancing life-changing solutions

## RDNZ RESEARCH INITIATIVES



# RDNZ RESEARCH INITIATIVES



**i**llumina



New Zealanders for  
**HEALTH RESEARCH**

*Ngā Tāngata o Aotearoa mō  
te Rangahau Hauora*

