Pānui
June 2025

Message from the Chief Executive

Kia ora koutou and greetings,

Those who've been following us on our LinkedIn and Facebook pages will be aware that for much of the last month I've been overseas raising awareness of RDNZ in the global rare disorders community, so that we can not only better learn and benefit from what's happening internationally but also contribute our unique knowledge and experiences.

Highlights included participating in: a Rare Diseases International (RDI) event in Geneva as part of the leadup to the World Health Association's passing a resolution calling for WHO member states (including New Zealand) to recognise rare diseases as a "global health priority for equity and inclusion"; the biennial EURORDIS membership meeting for rare disorder support organisations across Europe and beyond; and a European Rare Diseases Research Alliance (ERDERA) event aimed at

maximising “the power of national plans for rare diseases and strengthening their capacity to foster rare-disease research”.
I also held talks with the team at Newcastle University’s Rare Disorders Centre of Excellence in the UK, and rounded out the trip with a series of meetings and a tour of the whole genomic sequencing laboratories at Illumina’s UK headquarters in Cambridge.
In the middle of all of this I stood for election as an RDI Council Member and while my candidacy was unsuccessful it did give RDNZ exposure across the international rare diseases community. The many senior level personal contacts I was able to make will offer us opportunities for future collaborations and development, with the ERDERA meeting in particular setting the scene for RDNZ to host New Zealand’s ERDERA best practice National Mirror Group for rare disorders research. I’m very grateful to both ERDERA and HGSA for the financial support which has helped to make this trip possible.
Meanwhile back in New Zealand, during the week before I left for overseas we hosted the very successful parliamentary event focussing on access to rare disorders diagnoses and medicines, and the next day secured a commitment from the Minister of Health Simeon Brown to kick start the formal implementation of the Rare Disorders Strategy. Subsequently we’ve commented on a Te Whatu Ora | Health New Zealand draft genomics strategy and have been invited to meet with the Te Whatu Ora National Clinical Networks team to discuss next steps for a National Rare Disorders Reference Group. As always we’ll keep everybody posted.
Ngā mihi,
Chris Higgins
Chief Executive

RDNZ-led high level roundtable on diagnosis and medicine access
On 14 May, Rare Disorders NZ hosted a roundtable at parliament in an effort to get work underway on the Implementation of the Rare Disorders Strategy, due to an absence of any government action. The two focus areas of the day’s discussions were on diagnosis and access to rare disorder medicines.
In attendance were executives from the Ministry of Health, Health NZ, Pharmac, specialists, industry, parliamentarians and consumer representatives. Both the Minister of Health Hon Simeon Brown and the Minister responsible for Pharmac Hon David Seymour spoke at the event.
Thank you to Alexion, Biogen and Vertex for sponsoring this event.
Learn more here.

Minister of Health supports action for Strategy implementation

Rare Disorders NZ had a positive meeting with Minister of Health Hon Simeon Brown and we were encouraged by his support to get work underway on the implementation of the Rare Disorders Strategy. The Minister undertook to get back to us with next steps.

Rare resolution adopted by World Health Assembly

It was a historic moment for the global rare disorder community on 24th May when the 78th World Health Assembly adopted the first-ever resolution on rare diseases. The resolution declares rare diseases a global health priority and urges member states to take action within their own countries to improve their health systems for people living with rare diseases. Rare Disorders NZ CE Chris Higgins was with the team from Rare Disease International during this historic week in Geneva, Switzerland.

Learn more here.

Leaving no-one behind: a RDNZ - Costello Medical collaboration
En route to Europe, Chris caught up with the Costello Medical project team in Singapore who will be undertaking a Rare Disorders NZ-commissioned detailed comparison of the Māori vs non-Māori survey results from our 2023 Voice of Rare Disorders Survey. The purpose of the project is to ensure that Māori and whānau living with rare disorders are not left behind as things start to improve for people living with rare disorders generally with the Implementation of the Rare Disorders Strategy. Costello Medical has generously agreed to undertake the project pro bono. Learn more here.

Advancing rare disorders research connections

Chris attended a European Rare Diseases Research Alliance (ERDERA) workshop in Riga, Latvia, along with University of Otago Associate Professor and researcher Louise Bicknell and was asked to deliver a plenary case study presentation about how New Zealand has been developing its rare disorders research capacity despite the implementation of the New Zealand Aotearoa Rare Disorders Strategy stalling.
Chris and Louise, along with Philip Wilcox of University of Otago are working towards RDNZ becoming the host of a New Zealand ERDERA national mirror group, which will open up many opportunities for international collaboration for New Zealand rare disorders researchers.
Learn more here.

GPCME
Rare Disorders NZ once again had a stand at the annual Rotorua GPCME (General Practice Continuing Medical Education conference) on 6-7 June in Rotorua, to connect with GPs and practice nurses and keep rare disorders on their radar. We displayed brochures and flyers from a range of the support groups in our collective and had a lot of interest in our stand.

Cross-party parliamentary group quarterly meeting
Last night we had our second meeting with the recently established Cross-Party Parliamentary Group on Rare and Undiagnosed Disorders (CPGRD). The group had requested a more detailed briefing about the Rare Disorders Strategy to understand what role they could play in helping to accelerate its implementation. From RDNZ's briefing, the CPGRD members were interested to learn more about the potential of a centre of expertise, and the RDNZ team will arrange for experts to speak more to this at the next quarterly meeting.

Submissions
RDNZ Submission on the Medicines Amendment Bill
Submission on the Plain Language Act Repeal Bill
Submission on Putting Patients First: Modernising Health Workforce Regulation consultation
Submission on Health NZ's Paediatric, Adolescent and Young Adult Model of Care proposal

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Thank you!
We would like to acknowledge and thank the following sponsors for supporting key projects over the past two months:

- Foundation North
- Grassroots Trust Central
- FH Muter Trust
- EM Pharazyn Trust
- South Canterbury Trusts
- Alexion
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Make a difference for people living with a rare disorder
We're a small organisation with a big heart. We rely on grants and donations to carry out our work. Please consider donating to help us continue to improve information for rare disorder patients, their whānau and professionals and to keep advocating for systemic changes to benefit the entire rare disorder community. Your support is greatly appreciated.

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