Pānui
August 2025

Message from the Chief Executive

It's been another busy couple of months between newsletters, with one important milestone being the RDNZ Board's approval of our annual plan. This document affirms our continuing commitment to:

- campaigning for full implementation of New Zealand's Rare Disorder Strategy (RDS);
- raising awareness and understanding of rare disorders, and strengthening RDNZ's presence as the collective voice for rare disorders in New Zealand;
- making connections in the rare disorder community;
- becoming an effective and relevant Te Tiriti partner;
- ensuring RDNZ's long term financial and reputational viability and sustainability.

Although the latter objective is becoming increasingly challenging as financial support becomes more and more constrained, I do want to thank the many organisations and individuals who have supported us to date – and who have pledged continuing support this year. It's your support that enables us to support and advocate for the some 300,000 New Zealanders with a rare disorder.
In the meantime, we continue to press ahead with our advocacy for implementation of the RDS. Following a meeting on 15th May with Minister of Health, Hon. Simeon Brown, when he pledged to ensure that Te Whatu Ora and Manatū Hauora would formally engage with implementing the RDS, we have written to him three times, most recently on 18th August when we noted that, "*since its publication in July 2024, we've been attempting to progress the coordinated implementation of the RDS in a way that's consistent with what's set out in the Strategy itself, and we're becoming perplexed as to why achieving this should be so elusive*".

Senior officials in both Te Whatu Ora and Manatū Hauora seem more amenable than previously to engaging with the Strategy's implementation, but it's the Minister's leadership which will make it happen. In the meantime, we'll be breathing new life into our petition to get some action, and if you haven't already done so we ask you to sign it here.

Despite all of this we're not sitting on our hands and we continue to progress the implementation of the RDS in other ways including: making a submission on Te Whatu Ora's Draft Genomics Strategy; engaging in Te Whatu Ora's preliminary work on establishing a rare disorders clinical reference group; exploring how we might progress a leadership and coordination mechanism for rare disorders; and making a submission on the Pae Ora Amendment Bill where among other things we've called for the RDS to be recognised in the legislation as a formal Pae Ora strategy. We're also pleased to note that Pharmac Minister, Hon. David Seymour, has once again included implementation of the RDS in his Letter of Expectations to Pharmac Board Chair Hon. Paula Bennett.

Ngā mihi,
Chris Higgins
Chief Executive

RDNZ CE appointed to new Pharmac Consumer and Patient Working Group
Rare Disorders NZ CE Chris Higgins attended the first meeting of Pharmac's new Consumer and Patient Working Group on 21st July as one of ten appointees representing the patient and consumer community.

The group has been established for a 12-month period to support Pharmac's reset programme, which aims to improve Pharmac's transparency and relationship with consumers.
Read more here.

RDNZ urges Government to include Rare Disorders Strategy in Pae Ora legislation

With the Government set to make a number of amendments to the Healthy Futures (Pae Ora) Act, Rare Disorders NZ is calling for the Government to incorporate the Rare Disorders Strategy as one of the official health strategies in the Healthy Futures (Pae Ora) legislation.
Read our media release here.
Read our submission on the Healthy Futures (Pae Ora) Amendment Bill here.

Keep an eye out for our survey in September

We are working hard behind the scenes to launch our biennial Voice of Rare Disorders Survey in September. Keep an eye out for it and please make sure you complete it if you live with a rare disorder, or if you are a primary caregiver of a person living with a rare disorder.
With the Government dragging its feet on implementing the Rare Disorders Strategy it is more important than ever that we get a strong response rate to strengthen our call for urgent action.

Rare Disorders Research Network newsletter

Our first newsletter of the Rare Disorders Research Network is out, keeping New Zealand's community of rare disorders researchers up to date up to date about what's

happening in our sector, and offering opportunities to contribute to how we grow and ultimately offer hope and solutions to New Zealanders living with rare disorders.
Read the newsletter here.
Anybody who is interested in rare disorders research is warmly encouraged to sign up to receive our newsletter. Email RDNZadmin@raredisorders.org.nz to subscribe.

Working with Te Whatu Ora on a Rare Disorder Reference Network

Rare Disorders NZ met with the National Clinical Networks team at Te Whatu Ora to discuss how a Rare Disorder Reference Group at Te Whatu Ora could be progressed. We will continue to engage on this further and advocate for committed resourcing to further advance this initiative moving forward.

Rare Disorders Strategy mentioned in Letter of Expectations to Pharmac

Chris attended the release of the Minister responsible for Pharmac’s Letter of Expectations to Pharmac Chairperson Paula Bennett. We were pleased to see that the implementation of the Rare Disorders Strategy was explicitly mentioned.
Rare Disorders NZ wrote to the Minister in June requesting that he include a directive to action priorities outlined in the Rare Disorders Strategy, similar to his previous Letter of Expectations.
Rare Disorders NZ will continue to strengthen our engagement with Pharmac to improve access to rare disorders medicines.

Petition still open

As progress towards implementing the Rare Disorders Strategy remains slow, we will continue to push our petition demanding Te Whatu Ora | Health NZ urgently engage with Rare Disorders NZ and develop an implementation plan for the Rare Disorders Strategy.
Please sign the petition and share with your networks. Collectively our voice is stronger!

Submissions

Healthy Futures (Pae Ora) Amendment submission

[Submission on Proposal to change Pharmac’s policy principles for funding rare disorder medicines]

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

- COGS – (Papakura / Franklin, Rodney / Northshore, Kirikiriroa / Hamilton City, Waikato West, Waitakere City, Manukau, Kahungunu Ki Heretaunga, Tauranga / Moana, Manawatu, South Waikato, Wairarapa)
- One Percent Collective
- Jack Jeffs Charitable Trust
- Kiwi Gaming Foundation
- Takeda

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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