



Pānui
June 2024



Message from the Chief Executive

Kia ora koutou and greetings,

This month we mark and celebrate Matariki, noting its significance as a time for setting intentions for the future, with a focus on growth and wellbeing. I am excited therefore to be highlighting a couple of things that are “firsts” for Rare Disorders New Zealand, both of which will grow our ability to support people living with a rare disorder and be the voice for change to bring about better health and wellbeing outcomes.

First, I’m very pleased to announce the formation of RDNZ’s inaugural clinical advisory panel. We want to ensure that all aspects of our work are informed by contemporary evidence-based best clinical practice and

whakaaro Māori, and we are therefore about to invite expressions of interest from New Zealand rare disorder clinicians (including nurses, allied health professionals, and general and specialist medical practitioners) who would like to be part of the panel to provide expert advice to RDNZ's Board and staff. Click [here](#) for more information and the terms of reference.

Second, I am delighted to say that we are now poised to formalise our new Aotearoa New Zealand rare disorders research network. In collaboration with the Victoria University School of Nursing, Midwifery and Health Practice, we're creating a Development Group to support the network. We'll very soon be inviting expressions of interest in being a member of the Development Group, which will comprise internationally-respected and networked Aotearoa New Zealand rare disorders researchers including both tangata whenua and tangata tiriti (ie Māori and non-Māori). Terms of reference for the Development Group and more information is available [here](#).

Top of mind this week has been trying to understand the impact that the new funding for medicines will have for people with rare disorders. Unfortunately, despite knowing that 28 specific non-cancer medicines will be funded, Pharmac is refusing to let us know whether any of those will be for rare disorders. Their entrenched "neither confirm nor deny" position, and the lack of clear information in the FAQ section on their website which sets out what the 28 medicines are for, is hugely disappointing for people with rare disorders who are waiting for their medicines to be funded. This lack of certainty can give rise to notions of false hope and is unhelpful for those with life-shortening conditions who just want to make the most of the limited time that they have left. Pharmac is telling us that it could take months before people will be allowed to know one way or the other. We think that this is unnecessarily unfair, and we'll continue to seek answers. Please click [here](#) to read our media release.

Ngā mihi,

Chris Higgins

Chief Executive



Key stakeholders brought together for inaugural Medicines Access Summit

On 29 and 30 April, Rare Disorders NZ attended the inaugural [Valuing Life Summit](#) at parliament, organised by Patient Voice Aotearoa and Medicines New Zealand and hosted by the Honourable David Seymour, Associate Minister of Health (Pharmac).

[Read more.](#)

Rare Disorders Strategy to be launched in July

Manatū Hauora | Ministry of Health have informed us that the final Rare Disorders Strategy will be launched in July 2024.

Ahead of the Strategy being released, we have been meeting with Te Whatu Ora – Health NZ to encourage them to start thinking about how the Strategy can be implemented and what could be done quickly to start making progress for people living with rare disorders now, while the longer-term plans are worked on.

Read [more](#).



Rare Disorders NZ at North Island GP conference

In June our CE Chris attended the [General Practitioner Conference & Medical Exhibition](#) in Rotorua to help raise awareness of rare disorders and our rare disorder support groups among GPs in the North Island.

We look forward to also attending GPCME South in August.

RDNZ backs call for the full reversal of disability support restrictions

Rare Disorders NZ has, along with 51 other organisations, signed an open letter organised by the Disabled Persons Assembly NZ calling on Ministers Upston and Willis to fully reverse the 18 March disability support restrictions and ensure disabled people have the resources and the flexibility needed to thrive.

Read the open letter [here](#).

RDNZ supports submission calling for protection against genomic discrimination

RDNZ supported the submission by AGenDA (Against Genomic Discrimination in Aotearoa) to the Finance and Expenditure Select Committee on the Contracts of Insurance Bill to address the lack of protection against genomic discrimination in New Zealand's Insurance Law framework.

Read more about the submission's call for protection against genomic discrimination [here](#).

New information on website

[Transition to independent living](#)

[Advocating for Yourself](#)

THANK YOU!!



We would like to acknowledge and thank the following sponsors for funding key projects for us over the past two months:

- JR McKenzie Trust
- Kiwi Gaming Foundation
- Aotearoa Gaming Trust
- South Canterbury Trusts

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 continue improving information for patients, their whānau and professionals, and to advocate for systemic changes to benefit the entire rare disorder community.

[Donate](#)

