



Pānui

August 2024



Message from the Chief Executive

Greetings and kia ora koutou,

It has been a significant time for Rare Disorders NZ since our last newsletter with the long-awaited publication of the Rare Disorders Strategy and the release of the Pharmac Minister's Letter-of-Expectations to new Chairperson Paula Bennet, which represents

the best prospects for decades of improved access to life-saving rare disorders medicines.

The RDNZ team is gearing up to best respond to these two new opportunities, as reflected in our refreshed Strategic Plan and 2024/25 Annual Plan, both of which were approved by the Board at its June 27th meeting. Both plans can be seen [here](#) on our website.

It was a real pleasure meeting with so many support group leads at our recent Support Group Lead Hui in Te Whanganui-a-Tara. Listening to everybody's stories and understanding the different journeys that we're all on is an important part of ensuring that I stay in touch with the things that really matter for people who live with rare disorders every day.

Coming so soon after the release of the long-awaited Rare Disorders Strategy, the hui was a real watershed and set the scene for the Strategy's next phase – its implementation. While we wait for Manatū Hauora to formally establish its implementation group, which will also include Te Whatu Ora, Pharmac and RDNZ, we're getting on with progressing things where we can, include meeting with Whaikaha, increasing our reach into the primary healthcare sector, and continuing engagement with Pharmac.

Ngā mihi,

Chris Higgins

Chief Executive



Reflections on the Rare Disorders Strategy

The release on 25 July of Aotearoa New Zealand's first Rare Disorders Strategy was a huge moment for the rare disorder community. We now finally have recognition of our unique challenges and needs and official recognition that improvements in health system responsiveness are needed.

During the development of the Strategy, we were in close contact with Manatū Hauora's Strategy development team and provided feedback and input as work progressed. We were successful in getting many important elements included, but we were disappointed other elements didn't make it across the line.

You can read about our reflections on the Strategy and get an insight into communications along the way [here](#).

Access the Rare Disorders Strategy [here](#).



Implementing the Strategy

We look forward to the next steps of ensuring the Strategy is implemented to deliver meaningful change for people living with a rare disorder. We will continue to use the agreed seven priorities that we developed collectively with patient groups for our Fair for Rare campaign to guide the focus of the Strategy's implementation.

On our website you can find a breakdown of these seven priorities and how points within the strategy align with the priorities [here](#).



Biennial support group lead hui

On 2 August Rare Disorders NZ hosted our biennial Support Group Lead hui in Wellington. It was an opportunity for support group leads from around the country to get together, share learnings and come away with new tools to help support their roles.

Read more [here](#)



Rare Disorders NZ at GPCME South

Rare Disorders NZ were at GP CME South in Christchurch from 16 – 18 August, raising awareness among GPs, nurses, practice managers and health professionals about rare disorders and our work as a collective.



Rare Disorders NZ at Cell & Gene Therapy meeting

Our CE Chris Higgins presented to the International Society for Cell & Gene Therapy regional meeting in August about the Rare Disorders Strategy and the need for better support for people living with rare disorders in Aotearoa New Zealand.

Rare Disorders NZ at GP24

In late July our CE Chris presented at GP24 - the Conference for General Practice. This was another opportunity to get rare disorders on the radar of GPs, and Chris spoke about New Zealand's first Rare Disorders Strategy and the system improvements we would like to see implemented as a result.



Patient advocates discuss medicine access with Labour

RDNZ alongside Patient Voice Aotearoa and other patient organisations met with Labour MP and health spokesperson Dr. Ayesha Verrall and her colleagues Rt Hon Adrian Rurawhe and Camilla Belich on 16 July at a meeting organised by Patient Voice Aotearoa.

Read more [here](#).



RDNZ attends release of Letter of Expectation to Pharmac

Patient advocacy organisations, including Rare Disorders NZ, were invited to attend the release of Associate Health Minister David Seymour's letter of expectation to Pharmac's new Chair Paula Bennett.

The letter sets out the Minister's expectations of what he would like to see Pharmac focus its efforts on for the remainder of 2023/24 and for 2024/25.

Read more [here](#).

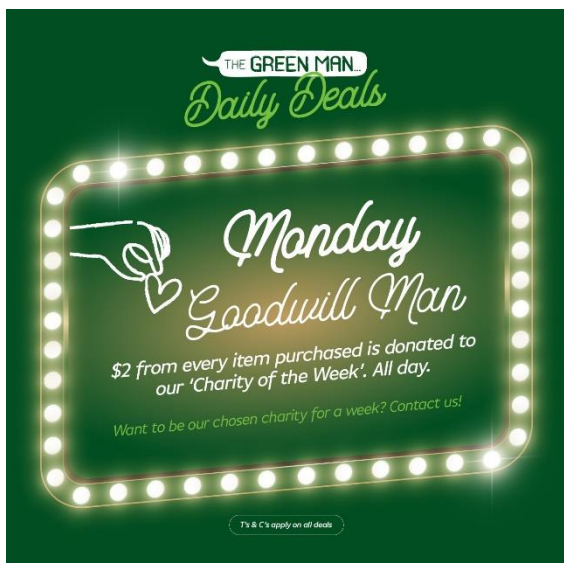
Recent submissions

[Submission for the Health and Disability Commissioner Act and Code review consultation](#)

[Submission to the Therapeutics Product Act repeal bill](#)

[Review of Disability Support Services Joint Submission](#)

[Submission on proposal to fund supplements for phenylketonuria and other inherited metabolic disease](#)



Support Rare Disorders NZ at Green Man Pub on 16 September

We are stoked that Rare Disorders NZ has been chosen for [Green Man Pub's](#) 'charity of the week', where \$2 of every item purchased all day on Monday 16th September will be donated to Rare Disorders NZ.

So if you're in Wellington on 16th September, come down to Green Man Pub on 5 Victoria Street for some delicious food and drink and support Rare Disorders NZ!

THANK YOU!!



Thank you!

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

- Pub Charity
- One Percent Collective
- COGS Committees – Waitakere, Kahungunu Ki Heretaunga, Manukau, Tauranga, Waikato West, Hamilton City, Rodney/North Shore and Papakura/Franklin.

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.

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