



Pānui

January 2025



HOW WILL YOU

GLOW UP

— AND —

SHOW UP

FOR RARE DISORDERS



THIS MARCH?

@RareDisorders_NZ #GlowUpShowUp #RareDisordersMonth

Message from the Chief Executive

Kia ora koutou and greetings

As we rapidly approach international Rare Disease Day on 28 February and Rare Disorders Month in March here in New Zealand, we want to take this opportunity to thank everybody who has committed to supporting us over this period. Your commitment to “glowing up and showing up” continues to raise awareness of the need for people living with rare disorders to be given a fair go.

In addition to the many local events that are being organised (including for the first time ever lighting up Auckland’s Sky Tower), at a national level our petition calling for an action plan to support implementation of the Rare Disorders Strategy will run throughout rare disorders month; we will celebrate our 25th birthday with an awards event at Government House on 28th February; hold the inaugural meeting of the newly established rare disorders cross party parliamentary group; and convene a meeting of members of the Rare Disorders Research Network to celebrate achievements and initiate work on the development of a Rare Disorders Research Strategy.

Meanwhile we continue our advocacy mahi by engaging with disability sector consultation processes, and through submissions opposing a proposal to halve the size of the perinatal screening team [here](#), calling for the 2025/26 budget to provide for the needs of people living with rare disorders [here](#), and supporting with caveats the Gene Technology Bill which should remove some of the barriers to accessing gene technology based rare disorders therapies [here](#).

Ngā mihi,

Chris Higgins

Chief Executive



Glow Up and Show Up this March

March is [Rare Disorders Month](#) and we're asking Aotearoa to Glow Up and Show Up for Rare.

There are lots of ways you can get involved and show your support for the rare disorder community:

- Attend one of the [local events](#) being held around the country
- Snap a selfie next to [one of the buildings/monuments](#) lighting up for rare and share on social media with #GlowUpShowUp
- Sign [our petition](#) calling for improved services for people with rare disorders
- Organise a [local fundraiser](#) for RDNZ in your community
- Follow us and share our posts on [social media](#)
- Purchase some [#GlowUp merch](#)
- Order some free [temporary tattoos](#)
- [Donate](#) to Rare Disorders NZ



25th Anniversary Awards Celebration at Government House

2025 marks our 25th year as an organisation and we will be celebrating with an awards ceremony on Rare Disease Day hosted by our patron Her Excellency The Rt Hon Dame Cindy Kiro at Government House in Wellington. We will be recognising select individuals who have spearheaded initiatives that have made a significant difference to the health and wellbeing of people living with a rare disorder in Aotearoa New Zealand.



Rare Beer Challenge

It's round five of the [Rare Beer Challenge](#) hosted as always by our awesome friends and great supporters, Fortune Favours. 14 craft breweries have this year taken up the challenge of coming up with the best rare beer using rare ingredients and unusual brewing techniques, and we're super excited that South Islanders get to join the fun at Smoke Ashburton, who will be hosting a satellite Rare Beer event, along with 16 Tun in Auckland.

Who will be crowned Rare Beer Champion of 2025? Come along and find out for yourself!

7 March, from 5pm to late.

Wellington – Fortune Favours, 7 Leeds St

Auckland – 16 Tun, 10/26 Jellicoe Street

Ashburton – Smoke, 231 Cameron Street (book a table at Smoke [here](#))

Essay competition for health professional students

As part of Rare Disorders Month, RDNZ will be running an essay competition for health professional students to encourage students to engage with and learn about rare disorders.

The competition will be open to all individuals who are currently enrolled as students in a recognised New Zealand health professional program, or who are actively pursuing education or training in a health-related field.

The essay prompt will be released on our [website](#) on 1 March 2025.

In the meantime, you can read last year's winning entries [here](#).



Support and Share our Petition

Our petition urging Te Whatu Ora to begin implementing the Rare Disorders Strategy without further delay is still open, so PLEASE sign [here](#) if you have not already and share widely with your networks. We will be pushing this petition hard during Rare Disorders Month and we need your help to get as many signatures as we can.

Thank you for standing with the rare disorder community.

Newborn screening for Spinal Muscular Atrophy finally available

We were thrilled to learn that screening for Spinal Muscular Atrophy (SMA) was added to the Newborn Metabolic Screening Programme from 12th February after pressure from the patient community, including Rare Disorders NZ. Find out more [here](#).

SMA is a rare and severe inherited neuromuscular condition that leads to progressive muscle wasting.

Treatment for SMA has been available in NZ for the past two years, but up until now SMA has only been diagnosed once symptoms have begun. The treatment yields much better results if administered to infants before symptoms appear, so the addition of SMA in the newborn screening programme will be life-changing.



Rare Disorders Briefing to new Health Minister

Rare Disorders NZ sent a briefing about the current situation of rare disorders in New Zealand to newly appointed Minister of Health, Hon. Simeon Brown.

We look forward to working constructively with the Minister to see progress on the implementation of the Rare Disorders Strategy.

Read our Briefing to the Incoming Minister [here](#).

Submissions

[Budget Policy Statement 2025 to the Finance and Expenditure Committee](#)

[Submission on the National Public Health Service Consultation Proposal](#)

[Submission on proposal to fund Inotuzumab ozogamicin for the treatment of relapsed or refractory acute lymphoblastic leukaemia/lymphoma](#)

Disability Support Services want to hear from you!

Disability Support Services especially want to hear from people who receive essential disability support after an assessment from a Needs Assessment and Service Co-ordination (NASC) organisation, or an Enabling Good Lives (EGL) site.

In this round of consultation, they are seeking feedback on:

- clearer assessment and allocation processes
- options for changes to flexible funding.

The consultation is open until Monday the 24th of March 2025. There are a number of different ways you can provide feedback. Click [here](#) to learn more.

Rare Disorders NZ will be putting in a submission highlighting the need for flexibility as people living with rare disorders often don't fit tick boxes and have unique needs. If

you have any comments you would like included anonymously you can email them to enquiries@raredisorders.org.nz.

Whaikaha seeking expressions of interest for working groups

The Ministry of Disabled People – Whaikaha is calling for expressions of interest from people with lived experience of disability, to join the Working Groups they plan to set up to help refresh the New Zealand Disability Strategy.

The Working Groups will meet between March and November 2025, to establish and prioritise actions to progress within the outcome areas of Health; Education; Employment; Housing; Justice, and to support public engagement. Payment for meeting preparation, attendance and community engagement will be based on \$60 per hour.

Expressions of interest are due by 3 March 2025. To find out more and how to apply click [here](#).

Thank you!

We would like to acknowledge and thank the following sponsors for supporting our Rare Disorders Month campaign:

- Alexion
- BioMarin
- Takeda
- Vertex
- Maia Studio
- Go Media
- Victoria University of Wellington
- Fortune Favours
- 16 Tun
- Smoke Ashburton

THANK YOU!!



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](#)



Rare Disorders NZ · New Zealand
Created with [NationBuilder](#). Build the Future.