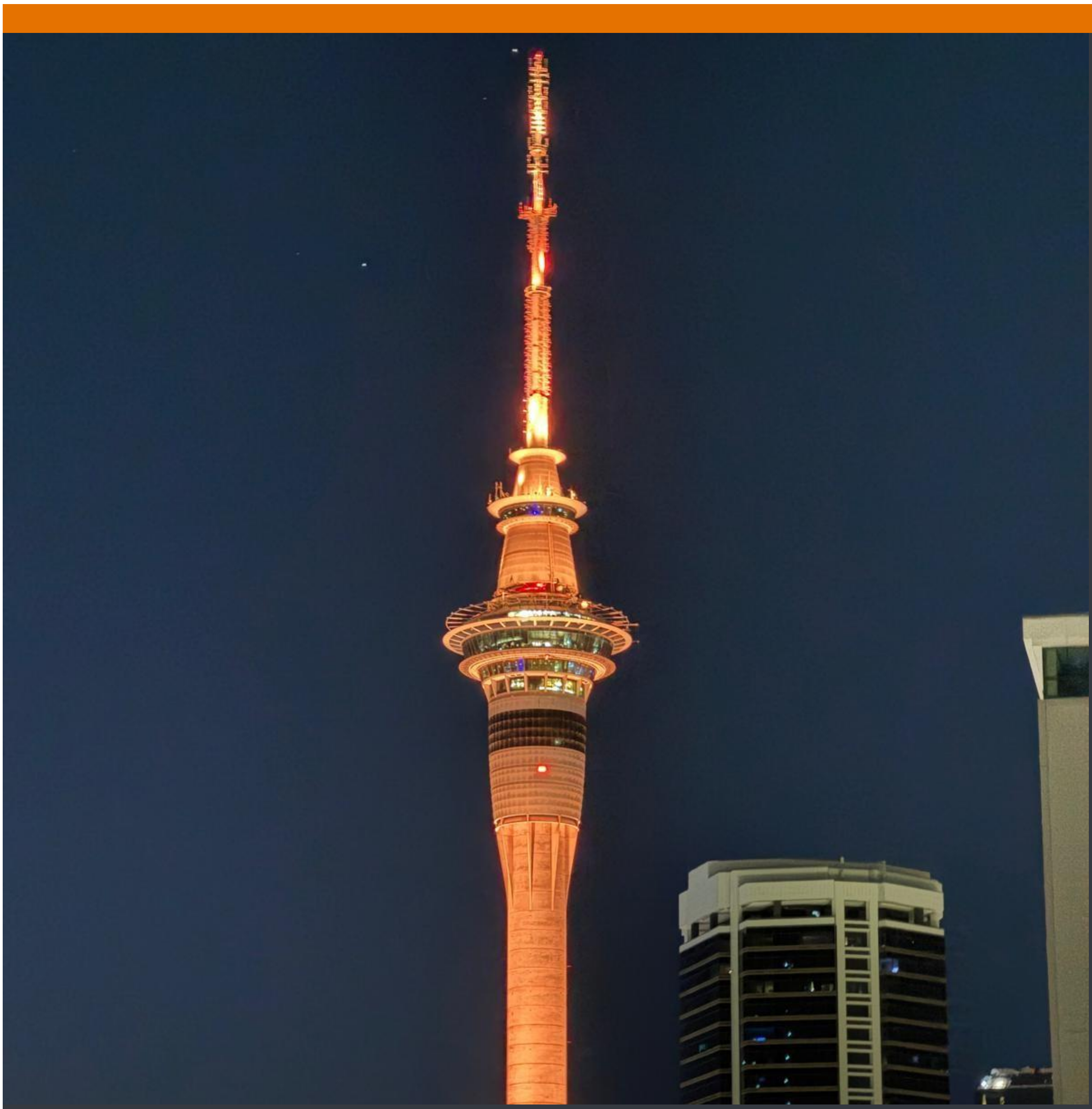
Pānui

April 2025



Message from the Chief Executive

My message in our last newsletter spoke to what we would be doing for Rare Disorders Day and Month and I’m pleased to say that we did everything we set out to do and more!

We celebrated our 25th birthday with an awards event at Government House on international rare diseases day, held the inaugural meeting of the newly established rare disorders cross party parliamentary group; and convened a meeting of members of the Rare Disorders Research Network to initiate work on the development of a Rare Disorders Research Strategy. And the rare disorders community united in glowing up and showing up throughout the motu.

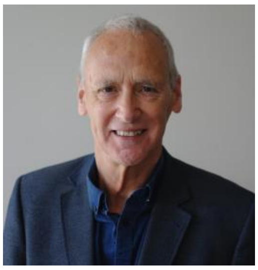
In the meantime we've been continuing our quest to re-activate the implementation of the Rare Disorders Strategy (RDS) by emailing, talking to, and building relationships with health sector representatives from Manatū Hauora, Te Whatu Ora, Pharmac and Health Quality and Safety Commission. Some of this work will come to a head on 14th May when RDNZ will be hosting a parliamentary forum to further progress implementation of the RDS in respect of early and accurate diagnosis and better access to medicines. There'll be about 30 invited stakeholders with highlights comprising presentations from selected rare disorders consumers and clinical experts, and Ministers Hon Simeon Brown and Hon David Seymour participating together for the final 30 minutes. Thanks to Alexion and potentially two other RTC members for sponsoring the event, and we'll keep everybody posted re outcomes.

Finally, this is a good opportunity to welcome our two newest Trustees to the RDNZ Board – Samantha La Hood and Nivedita Sharma Vij.

Ngā mihi,

Chris Higgins

Chief Executive



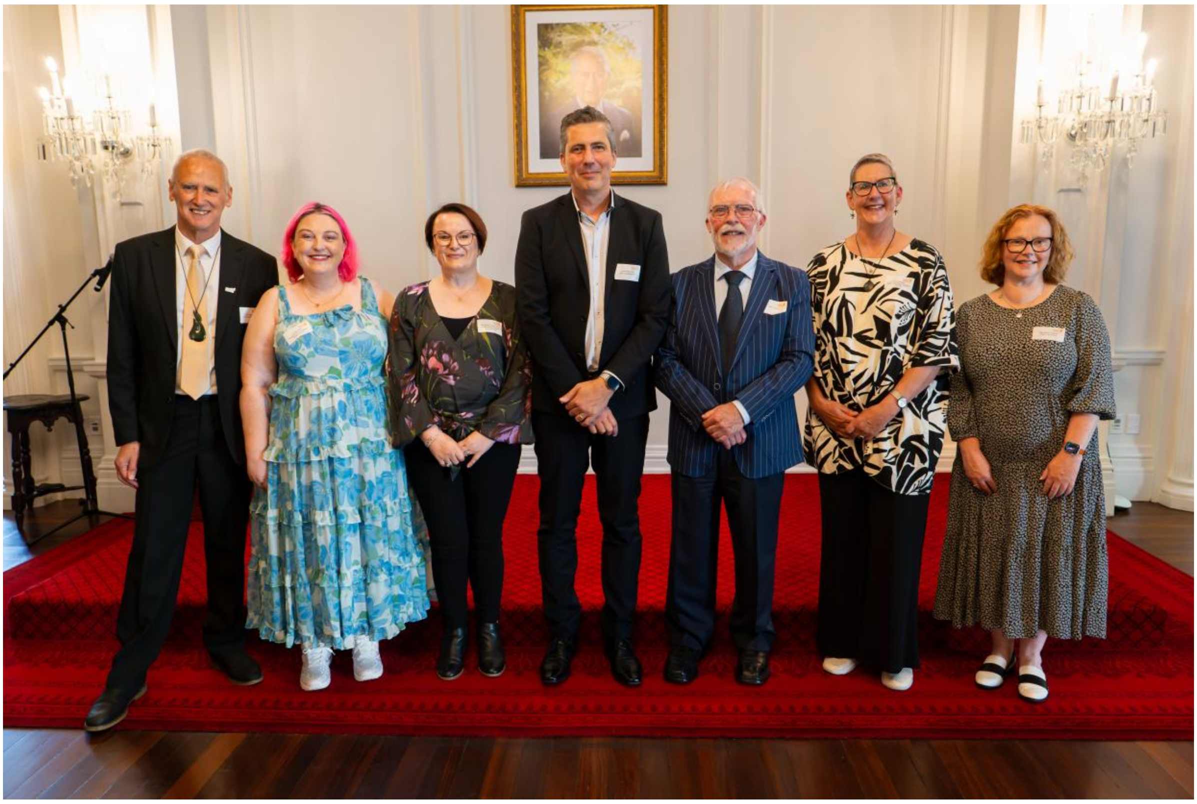
Rare Disorder Month wrap-up

Once again Aotearoa got behind Rare Disorders Month, glowing up and showing up from every corner of the motu. Over 20 schools and preschools held Glow Up days, 8 workplaces organised fundraisers, 7 community get togethers were held around the motu and 51 buildings lit up for rare during the month, including for the first time for rare disorders – the Sky Tower in Auckland.

There were 44 pieces in the media on rare disorders and 71 billboards around the country. We also held a number of significant events, which you can find further details on below.

You can view an image gallery showing ways the community got involved here.

Thank you Aotearoa for all your support – you sure know how to #GlowUpShowUp for rare.



Celebrating outstanding achievements on Rare Disease Day

Rare Disorders NZ marked Rare Disease Day and celebrated our 25th anniversary at Government House on 28th February with an awards ceremony to recognise select individuals who have spearheaded significant initiatives for rare disorders.

The awards were presented to the recipients by Rare Disorders NZ's patron, Her Excellency, The Rt Hon Dame Cindy Kiro, GNZM, QSO, Governor-General of New Zealand.

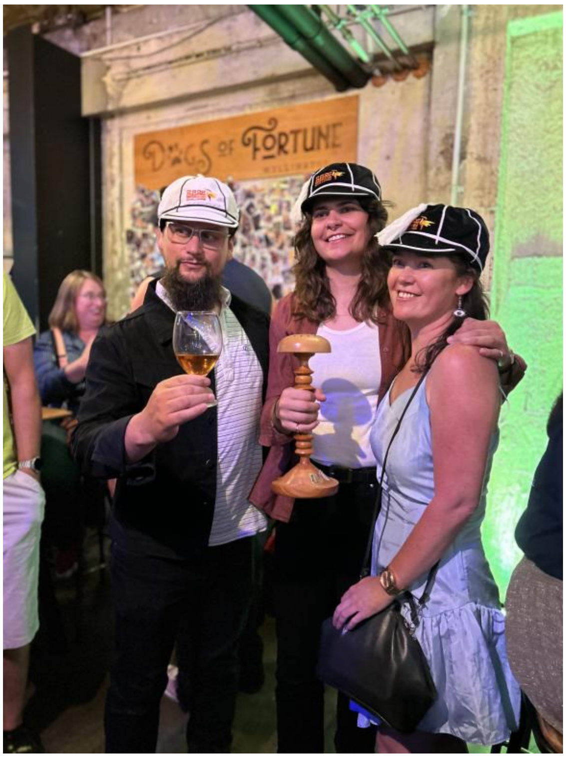
Lifetime Achievement Award – John Forman

Outstanding Advocacy Award – Sue Haldane

The Collaborative Leadership Award - Denise Astill and Jacki Morris from Foetal Anti-Convulsant Syndrome New Zealand

Rare Disorders Research Award - Professor Stephanie Hughes of Otago University

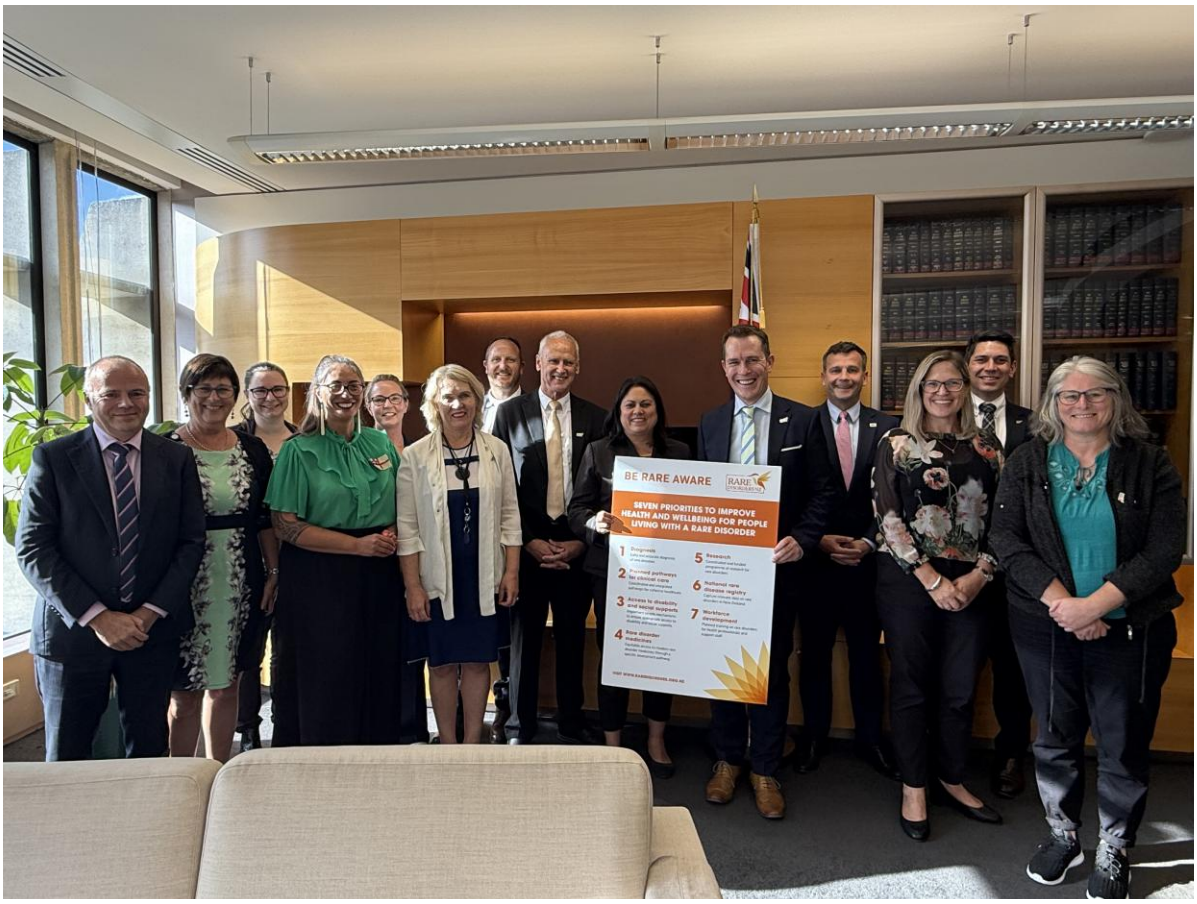
Learn more about the award recipients here.



Rare Beer Challenge

Once again the Rare Beer Challenge was a resounding success and Rare Disorders NZ was blown away by the effort and creativity that each of the 14 particiating breweries put into their 'rare brew', as well as into their social media promotions. Hosts Fortune Favours centered this year's design theme around our 25th year and did an amazing job bringing the event together as always. Satelite events were held in Auckland at 16 Tun, and for the first time in the South Island at Smoke Ashburton, with a great turn out at each venue and a lot of fun had. Over $8,000 was raised for Rare Disorders NZ, as well as lots of awareness!

To find out which brewery took home the top prize for their 'absolutely bangin'' entry click here.



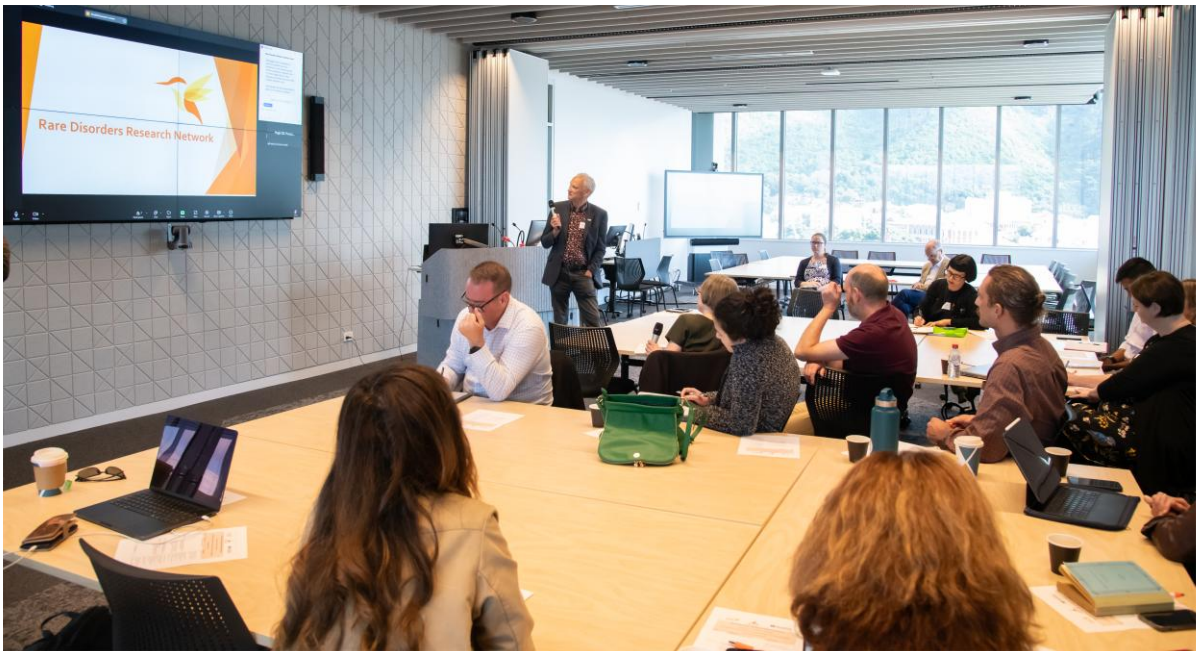
New cross-party parliamentary group for rare disorders

A huge achievement during Rare Disorders Month was the formation of the first Cross-Party Parliamentary Group on Rare and Undiagnosed Disorders in New Zealand.

Rare Disorders NZ initiated the establishment of the group, which was supported by Hon. David Seymour, Associate Minister of Health, with the inaugural meeting hosted in the Minister's office and attended by Members of Parliament from across the political spectrum.

National MP Hamish Campbell was elected Chair of the group, and Labour MP Hon. Dr. Ayesha Verrall MP was elected Deputy Chair.

Learn more here.



Rare Disorders Research Network event

During Rare Disorders Month, Rare Disorders NZ, alongside Victoria University of Wellington, brought together members of the newly established Rare Disorders Research Network to lay the foundations for developing an Aotearoa New Zealand rare disorders research strategy.

Learn more here.

Essay competition for health professional students

Rare Disorders NZ ran an essay competition for health professional students during Rare Disorders Month to encourage students to engage with and learn about rare disorders.

We asked them to look 25 years into the future and consider how they see themselves contributing to one or more of Rare Disorder NZ's seven strategic priorities to improve the health and wellbeing of people living with a rare disorder. They also needed to reflect on what their biggest challenge might be, and how they would overcome it.

Read the winning entries here.

Benefits of gene therapy presented to Health Select Committee

With the Gene Technology Bill before the Health Select Committee during March, Rare Disorders NZ was pleased to arrange for the Committee to hear about the successful clinical trial of CRISPR/Cas9 therapy gene editing technology for the rare disorder Hereditary Angioedema. Lead New Zealand investigator Dr. Hilary Longhurst and clinical trial patient Olivia Worthington both spoke powerfully of the potential of gene editing technology.

View here.

Support and Share our Petition

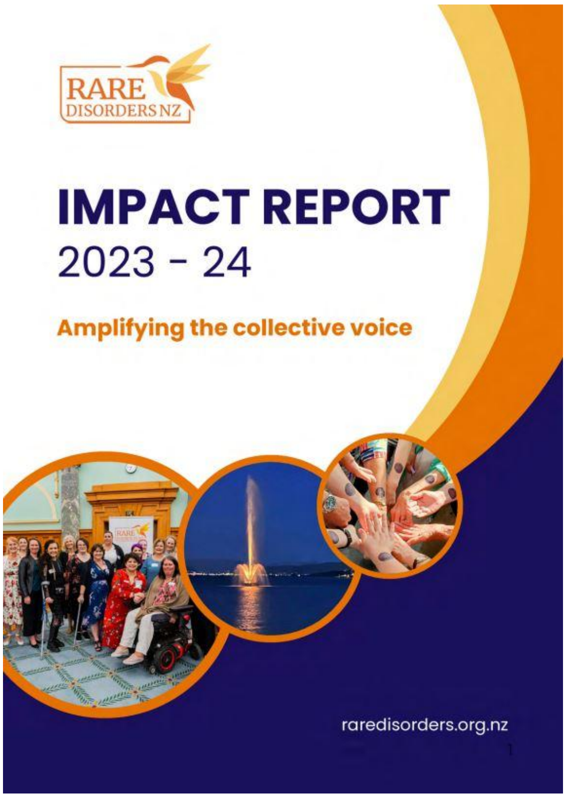
Our petition demanding Te Whatu Ora | Health NZ urgently engage with Rare Disorders NZ and develop an implementation plan for the Rare Disorders Strategy is still open, so please sign and share widely with your networks!

Sign here.

Submissions

Submission on Gene Technology Bill.

Submission on the future of Disability Support Services.



RARE DISORDERS NZ

IMPACT REPORT
2023 - 24

Amplifying the collective voice

raredisorders.org.nz

Impact Report 23/24

You can now view our Impact Report from our 23/24 financial year here.

Thank you!

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

- Alexion
- BioMarin
- Takeda
- Vertex
- GoMedia
- One Percent Collective
- Aotearoa Gaming Trust

- Four Winds Foundation
- Kiwi Gaming Foundation

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
