



Pānui

December 2024



### Message from the Chief Executive

Greetings and kia ora koutou,

2024 seems to have raced by especially quickly! For rare disorders the year was dominated by the Government's Rare Disorders Strategy - punctuated with impatience as its release was delayed, with celebration when it was finally published in July, and frustration that Manatū Hauora has been unable to convene a meeting of the co-implementation group because of Te Whatu Ora's increasingly entrenched decision not to engage. To make things even more challenging it has now emerged through their just released three-year workforce plan that Te Whatu Ora apparently believes that no workforce planning is required to improve services for people living with rare disorders, even though the Rare Disorders Strategy says there is.

The RDNZ team have throughout been fighting for the health system to urgently prioritise implementation of the Strategy and will continue to do so for as long as it takes next year.

We couldn't have done this and the many other initiatives we've undertaken this year without the backing of our network of friends, colleagues and supporters. – so thank you for standing with us as we've worked to achieve our vision of “best possible health and wellbeing for people and whānau living with rare disorders in New Zealand/Aotearoa”.

As the year draws to a close, on behalf of the RDNZ team I wish everybody Meri Kirihimete, and very best wishes for the summer break.

Ngā mihi,

Chris Higgins

Chief Executive



# 2024 SNAPSHOT

Key highlights in 2024



**RELEASE OF NEW ZEALAND'S FIRST RARE DISORDERS STRATEGY**



**2024 WHITE PAPERS ON LIVING WITH A RARE DISORDER IN NZ LAUNCHED**



**BIENNIAL SUPPORT GROUP LEAD HUI HELD IN WELLINGTON**

**635**

ENQUIRIES ANSWERED



**3**

HEALTH MINISTERS AT WHITE PAPER LAUNCH



**11**

SUBMISSIONS ON POLICY PROPOSALS



**45**

BUILDINGS & MONUMENTS LIT UP FOR RARE ON RARE DISEASE DAY



**58**

MEDIA PIECES ON RARE DISORDERS LEADING UP TO & DURING RARE DISORDERS MONTH



**150K+**

REACHED THROUGH WEBSITE & SOCIAL MEDIA





### **Glow Up and Show Up for Rare in March**

March is Rare Disorders Month, and we are gearing up for a great month of raising awareness and celebrating the rare community in 2025.

Ways you can start getting involved:

You can now purchase your own Glow Up Show Up t-shirt through our [new online shop](#).

Make your participation in Round the Bays matter by registering to fundraise for Rare Disorders NZ. Find links to register in Auckland, Wellington or Christchurch on our website [here](#).

Nominate who you think has made a difference to the wellbeing of New Zealanders living with a rare disorder for our 25<sup>th</sup> anniversary awards celebration on Rare Disease Day. Nominations close 20<sup>th</sup> December so get yours in quick [here](#)!

#ShowUp for rare on social media by sharing a photo of yourself with one of our temporary tattoos! To order your free tattoos contact [RDNZadmin@raredisorders.org.nz](mailto:RDNZadmin@raredisorders.org.nz)

And remember to include the hashtag #GlowUpShowUp and tag @RareDisordersNZ on Facebook or @RareDisorders\_NZ on Instagram.

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## **Our petition is still open – please sign today!**

Stand with the rare disorder community in demanding Te Whatu Ora | Health NZ urgently engage with Rare Disorders NZ and develop an implementation plan for the Rare Disorders Strategy.

Sign the petition [here](#) to make our collective voice louder.

We had MPs question Te Whatu's Ora's leadership about the lack of action to implement the Strategy during Parliament's Scrutiny Week. See the exchange [here](#).

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# 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:

- Frimley Foundation
  - One Foundation
  - Trust House Foundation
  - The Lion Foundation
  - TG Macarthy Trust
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## Make a difference for people living with a rare disorder



We are committed to achieve our vision of the best possible health and wellbeing for people and whānau living with rare disorders in Aotearoa New Zealand, but we need your help to continue our work.

Your kindness makes a huge difference. It supports our work to get the rare voice heard at the highest decision-making levels. We must not let that voice fade.

Please donate to Rare Disorders NZ this Christmas. Every donation, no matter how small makes a difference.

Thank you for your support.

[Donate](#)

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The Rare Disorders NZ office will be closed from Friday 20<sup>th</sup> December until Monday 6<sup>th</sup> January.



Rare Disorders NZ · New Zealand

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