



Pānui

October 2024



THE HEALTH OF PEOPLE LIVING WITH A RARE DISORDER CANNOT BE PUT ON HOLD WHILE THE HEALTH SYSTEM UNDERGOES A RESET

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**SIGN THE PETITION  
CALLING FOR AN  
ACTION PLAN  
TO IMPLEMENT  
THE RARE DISORDERS  
STRATEGY**

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STAND WITH THE RARE COMMUNITY  
[rdnz.nationbuilder.com/petition](https://rdnz.nationbuilder.com/petition)

## Message from the Chief Executive

Kia ora koutou and greetings from the Chief Executive

I was hoping that this newsletter would have been an opportunity to provide an update on the Manatū Hauora | Ministry of Health led Rare Disorders Strategy (RDS) implementation group. However, citing the current reset, Te Whatu Ora | Health New Zealand have declined to engage for at least the remainder of the year. The rare disorders community has made it clear to us that this is unacceptable and RDNZ is responding with a petition requiring Te Whatu Ora to develop an RDS action plan. More on this below.

In the meantime we're directly engaging with the RDS implementation agencies ourselves (Pharmac, Health Quality and Safety Commission, and indeed some Te Whatu Ora staff who have been willing to talk to us).

One of the actions included in the draft RDS but which did not appear in the final published version was the development of a medicines strategy. RDNZ is nevertheless pushing for this important piece of work to go ahead, and were pleased to see it strongly featured in the just released White Paper from the Valuing Life New Zealand Medicines Summit 2024. Find it [here](#).

Ngā mihi,

Chris Higgins

Chief Executive



## Sign our petition calling for an action plan to implement the Rare Disorders Strategy

We are today launching an important petition, and we need your support!

We are deeply concerned about Te Whatu Ora's refusal to engage with Rare Disorders NZ to develop an action plan to implement the Rare Disorders Strategy.

The rare disorder community has been calling for action for over 20 years to improve services for people living with a rare disorder. The Government has finally delivered a Rare Disorders Strategy, but unless it is implemented it will not be worth the paper it's written on.

The health system is under a reset yes, but the health of people living with a rare disorder cannot be put on hold any longer.

[Sign the petition now.](#)

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### Strategy implementation update

We have been making every effort to encourage the coordination of a cross-agency meeting to begin discussions on implementing the Rare Disorders Strategy before the end of the year. This meeting was to be organised by Manatū Hauora | The Ministry of Health as the lead implementation agency, however they most recently confirmed that such a meeting will not be taking place this year due to challenges securing Te Whatu Ora's engagement.

You can read our correspondence with Manatū Hauora | The Ministry of Health and Te Whatu Ora | Health New Zealand [here](#).

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## Get ready to Glow Up and Show Up for Rare in March 2025!

We can't wait to again call on Aotearoa to Glow Up and Show Up for Rare during the month of March to show support for the 300,000 Kiwis living with a rare disorder.

The campaign will be kicking off on International Rare Disease Day on Friday 28 February and we hope to beat our record of 45 buildings and monuments around Aotearoa Glowing Up in orange. We will also be encouraging schools, workplaces and community groups to Show Up for Rare by raising awareness and funds for rare disorders through events such as gold-coin days, morning teas and through community events. If you would like to get involved contact [enquiries@raredisorders.org.nz/](mailto:enquiries@raredisorders.org.nz/)

Keep an eye on our website for updates about planned events for the month [here](#).





## **RDNZ seeks clarification on new attendance rules**

We wrote to Associate Education Minister David Seymour to seek clarity on the recently announced 'Stepped Attendance Response' (STAR) system and how it will apply to children with rare disorders.

You can read the letter [here](#).

We promptly received clarity from Hon David Seymour in response to our letter, which you can read [here](#).

If you have any comments or concerns regarding the contents of the letter, let us know by email [enquiries@raredisorders.org.nz](mailto:enquiries@raredisorders.org.nz).

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## **RDNZ at Human Genetics Society of Australasia branch meeting**

Our CE Chris attended the Human Genetics Society of Australasia branch meeting in Auckland in October centred on the theme *Treatment focused genomics and practical application of genomic technologies*. With 80% of rare disorders being genetic in origin and with the rapid advancements in genomics and precision medicine this is an exciting and important field for us to keep informed on.

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## **Survey for carers**

Carers NZ and the Carers Alliance, of which RDNZ is a member, are undertaking the second State of Caring survey – a comprehensive look at how carers are doing, and what help they need to do well and keep going.

If you're a family carer, please complete and share the survey – add your voice to those of hundreds of other carers! You'll be in to win a retail voucher, and help to raise awareness about carers, their role, and how they can be recognised and supported.

Access survey [here](#).

Thanks for helping.

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## In the Media

[RNZ Morning Report, Rare Disorders.org on Pharmac call for drug applications](#)

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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:

- Hugo Charitable Trust
- One Percent Collective
- Bluesky Community Trust

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## 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](#)

