

RARE DISORDERS NZ

PĀNUI

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Kia ora koutou and greetings

Since the last newsletter our focus has been on responding to the Ministry of Health/Manatū Hauora draft Rare Disorders Strategy document. I would like to convey our huge thanks to the support group leads who have told us – and therefore also told Manatū Hauora – what they think about the document, and what they have said about what health and other services should look like to support people living with rare disorders to live their best possible lives. We have prominently featured the support group feedback in the body of our submission, which can be read on the [RDNZ website here](#).

To further ensure that Manatū Hauora will be very clear about the rare disorders community's expectations we have also organised for them to run two webinars at the end of this month, and I invite you to register for the one that suits you via the link below. Although this will now be the best way of having a further voice, both RDNZ and Manatū Hauora will continue to welcome feedback at any time as the strategy is developed. The RDNZ team is now meeting fortnightly with the Manatū Hauora team, so there are ongoing opportunities to influence what the strategy will look like.

Our submission recommends in detail what should be included in the strategy, focussing on the seven priority areas which have been identified through previous support group consultation, including diagnosis, planned pathways for clinical care, access to disability and social supports, rare disorders medicines, research, a rare disorders registry/data collection, and workforce development. We have also reviewed Manatū Hauora's pae ora strategies and recommended that parts of the Health of Disabled Peoples Strategy and the Women's Health Strategy be transcribed into the Rare Disorders Strategy.

While all of that has been happening, we have also been working with Te Aka Whai Ora/Māori Health Authority supporting their consultation with Māori and whānau living with a rare disorder, actively supported by Te Whānau Kōtuku – Rare Disorders NZ Māori support group. While the aim of this process is, importantly, to identify Māori specific perspectives on what the strategy should include, the feedback is also welcomed as an opportunity to inform development of a strategy which will be of universal benefit for everybody.

Ngā mihi,



Chris Higgins

Chief Executive

Rare Disorders NZ

Have your say on New Zealand's first Rare Disorders Strategy!



Manatū Hauora - the Ministry of Health is working on the development of New Zealand's first Rare Disorders Strategy and is keen for input from the rare disorder community. Join one of two webinars hosted by the Ministry of Health - Manatū Hauora and Rare Disorders NZ to share what improvements you want to see in the health system and what would make the biggest difference to your life and whānau. The webinars will follow the same format as the Pae Ora Strategies feedback webinars, where you will be able to participate anonymously.

Lunchtime session - Tuesday 29th August

Evening session - Thursday 31st August

Both webinars will follow the same format, so you only need to attend one. We strongly encourage everyone in the rare disorder community – whether directly affected by a rare disorder, or caring for someone with a rare disorder, to participate. This is your chance to have input into the development of the Ministry of Health’s Rare Disorders Strategy.

[Find out more and register here.](#)

Working with Te Aka Whai Ora to ensure the voice of Māori included in strategy development



As part of the development of New Zealand’s first Rare Disorders Strategy, Rare Disorders NZ have been having regular, weekly hui with Te Aka Whai Ora to plan how we will engage with whānau Māori to ensure that the voices of Māori living with a rare disorder are reflected in the Rare Disorders Strategy plan. From these meetings we have a joint goal to identify at least 50 whānau Māori who live with a rare disorder before the team at Te Aka Whai Ora go out into the communities in September to listen to the expert lived experiences.

This partnership with Te Aka Whai Ora has been exemplary for the way in which engagement has been prioritised and we have confidence that these kōrero will be ongoing.

If this is a kaupapa which you want to be involved in, don’t hesitate to email Julian, our kaiāwhina Māori, enquiries@raredisorders.org.nz.

Mā pango, mā whero ka oti te mahi

Response to the Ministry of Health's initial Rare Disorders Strategy document



Manatū Hauora - Ministry of Health sought feedback from Rare Disorders NZ, along with other members of the Ministry's strategy reference group, on the consultation draft of the Rare Disorders Strategy document. We welcomed Manatū Hauora's initial Rare Disorders Strategy (RDS) document, and appreciated the opportunity to contribute both as a member of the RDS reference group and as a co-designing partner. In preparing our response we elicited feedback from rare disorder support groups, from the RDNZ Board, and collectively from RDNZ staff.

[View the body of Rare Disorders NZ's response here](#)

Meeting with the Minister of Health



Rare Disorders NZ Chief Executive Chris Higgins and Board Chair James McGoram had a constructive meeting with Minister of Health Hon. Dr Ayesha Verrall in June; the first between Rare Disorders NZ and the new health minister. The meeting provided an important opportunity to discuss the progress of the Rare Disorders Strategy currently being developed by Manatū Hauora

and to seek the Minister's assurance that funding would be allocated in the 2024/25 budget for its implementation.

[Read more here](#)

Rare Disorder Centre of Excellence - a solution to improve health equity?



As we look ahead to the implementation of the Rare Disorder Strategy and how resources available across the health sector can be used in efforts to improve health system responsiveness for people and whānau with rare disorders as soon as possible, Rare Disorders NZ has identified a key opportunity for maximum leverage and progress for rare disorders through the establishment of a Rare Disorder Centre of Excellence in New Zealand. We see the establishment of a Rare Disorder Centre of Excellence in New Zealand as a solution to bridging many of the gaps in the delivery of health care to people living with a rare disorder.

[Read more here](#)

Accessibility for New Zealanders Bill

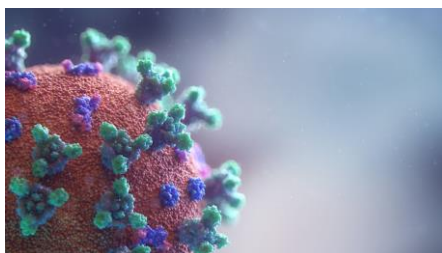


The final report on the Accessibility for New Zealanders Bill is out and makes for disappointing reading.

Rare Disorders NZ is deeply frustrated that only minor amendments have been put forward by the Social Services and Community Committee, ignoring the many concerns raised about the bill by the disabled community, including Rare Disorders NZ, during the select committee process.

[You can read our statement here](#)

Submission on Pharmac's proposal to widen access to COVID-19 antivirals



Rare Disorders NZ made a submission on Pharmac's proposal to make changes to the access criteria for COVID-19 antiviral treatments. Rare Disorders NZ has been advocating for widening of access to COVID-19 antiviral treatment for some time. The access criteria for COVID-19 antivirals as they currently stand have excluded many groups of people who would be vulnerable to severe illness from COVID-19, including many in the rare disorder community. Rare Disorders NZ wrote to Pharmac in February requesting for a review to widen the access criteria.

[Read the full submission here](#)

COVID-19 restrictions lifted too soon, says Rare Disorders NZ



Rare Disorders NZ is extremely frustrated that the Government is scrapping all remaining COVID-19 restrictions while Pharmac is still in the process of deciding whether to widen the access criteria for COVID-19 antivirals.

Currently the access criteria for COVID-19 antivirals exclude many groups of people who would be vulnerable to severe illness from COVID-19, including many in the rare disorder community.

[Read our full statement here](#)

Where do the political parties stand in 2023?



Solutions to the challenges of living with a rare disorder in Aotearoa abound, but meaningful change can only be driven with political will behind it.

We sent questions on the following priority issues to all the political parties leading up to the 2023 general election so that the rare disorder community can see where the parties stand with regards to improving the health and wellbeing of those impacted by a rare disorder.

- Complete National Rare Disorders Strategy
- Diagnosis
- Planned Pathways for clinical care
- Access to disability and social supports

- Rare disorder medicines
- Research
- Workforce development

[You can read the responses on our website here](#)

Enlighten your local MP on the challenges of living with a rare disorder



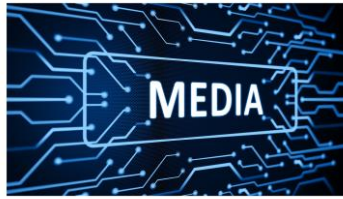
Rare Disorders NZ is gearing up for the 2023 election.

We have drafted template letters for people in the rare community to request a meeting with their local MP. This is an opportune year to get MPs backing issues important to the rare disorder community and get some political traction. We have drafted three separate letter templates respectively focusing on the following issues:

- The need for better data collection on rare disorders
- Improved medicine access for rare disorder medicines
- The need for a Rare Disorder Centre of Excellence in New Zealand

[Download the letters and supporting documents here](#)

In the media



[Rare Disorders NZ was highlighted in Metropol](#)

RNZ Nights rare disorder feature: [Living with Ramsay Hunt Syndrome](#)

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:

One Percent Collective

Foundation North

COGS Committees:

- Waikato West
- Hamilton City
- Manukau
- Rodney/North Shore
- Wairarapa
- Auckland City
- Central Otago
- Waitakere
- Papakura/Franklin

- Tauranga

How you can help us help those with rare disorders across New Zealand



Donate

We're a small organisation with a big heart. We rely on grants and donations to continue improving information and support for patients, their whānau and professionals, as well as to advocate for systemic changes to benefit the entire rare disorder community.

By donating to RDNZ, you're helping us to provide connection, guidance, advice and resources to those impacted by a rare disorder and for 150+ support groups, and enabling us to represent the rare community's voice at the highest levels to improve healthcare and wellbeing for people and their whānau living with a rare disorder.

To make a one-off donation to Rare Disorders NZ [visit our Givealittle page.](#)

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Please get in touch if you have any questions relating to any articles in this newsletter or if you have anything you wish to discuss.

Kind regards,

The team at Rare Disorders NZ

