

RARE DISORDERS NZ

PĀNUI

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CE Update

Kia ora koutou,

You are all probably aware by now, but in case not, I have now left my role as CE of Rare Disorders NZ, and I'm moving on to new adventures.

It is a good time to reflect over the last 9 months since July 2022; a lot has been achieved. Whilst it has been a relatively short time, we have been able to raise the voice of those living with a rare disorder. We had an extremely successful #GlowUpShowUp and #DoRightByRare campaign for the month of March, our media and social media coverage has been off the scale, and our tattoos have been everywhere!

We have provided strong advocacy to government agencies, and in particular the health agencies. We have responded to an enormous number of submissions to ensure your voice is heard in a number of very important matters. We are now working jointly with the Ministry of Health and are set up well to partner on the national strategy for rare disorders, exemplified through two great sessions recently to gain the voice of the rare disorder community into the Pae Ora Strategies, as well as a roundtable discussion for the Long-Term Insights Briefing on Precision Health.

Te Whatu Ora have secured our contract for at least another year too, and we look to have further dialogue. We have launched our new parent guide, which you can download from our website. We have also seen a number of medicines funded, however, there is much work to do here and we need to work hard to drive the change required from Pharmac and the funding of medicines.

We are also growing as a team, with a new team member who started just before Easter in our new Navigator role. So, all in all much achieved and in a better place than 9 months ago. It has been a privilege and I hand the baton on.

The board are well underway with recruiting to the role and will be supporting the team and overseeing any matters that need direct attention until a new CE is in place. Please be reassured the business of Rare Disorders NZ will continue without disruption.

I trust that you will support the team at RDNZ during this time of transition and if you have any questions prior to a new CE being appointed please use the enquiries line.

I have thoroughly enjoyed my time working with the team, the board, many agencies and most importantly the rare disorder community. I have learnt a lot more about rare disorders, advocacy, the lived experience voice and of course fundraising! Thanks for all your support during my time at RDNZ and your hard work especially during our very successful #GlowUpShowUp #DoRightByRare campaign.

I wish you all well for the future and I am sure that RDNZ will go on providing great support and advocacy over the next years, and can count on your continued support.

Go well team RDNZ and the rare disorders community of New Zealand.

Ngā mihi

Michelle Arrowsmith



Inaugural Rare Disorders Month a success!



Aotearoa – you heard our call to Glow Up and Show Up for Rare during the month of March, and we can't thank you enough for your efforts! The Glow up and Show up for Rare campaign provided an opportunity for the 300,000 strong community of rare patients, as well as friends and whānau to rally together and call for urgency in the health reform that has been promised. From Invercargill to Warkworth, events were held in local communities all around the motu and the sustained media campaign also enabled the rare disorder community to be heard far and wide, with coverage across major broadcast, print, and online news media - reaching hundreds of thousands of New Zealanders.

[Read more here.](#)

Raising a child with a rare disorder: A guide for parents and caregivers living in Aotearoa New Zealand.



The highlight of Rare Disorders Month for us was the launch of our new parent and caregiver guide. The guide was developed to help parents and caregivers navigate the path in caring for a child with a rare disorder in Aotearoa New Zealand. *Raising a child with a rare disorder: A guide for parents and caregivers living in Aotearoa New Zealand*, was launched at Government House with Rare Disorders NZ's patron Her Excellency, The Right Honourable Dame Cindy Kiro. Invited guests included families of children with rare disorders, patient group representatives and other key stakeholders. It was a very special and warm occasion for those attending.

[Download the guide from our website here.](#)

Celebrating rarity at the Rare Beer Challenge



This year's Rare Beer Challenge, hosted as always by our friends at Fortune Favours, was another resounding success with the Fortune Favours HQ in Wellington packed on 10th March, and a record \$17,385 raised for Rare Disorders NZ. Aucklanders were this year also treated to a taste of rare with 16 TUN pouring Rare Beers over the same weekend.

The Rare Beer Challenge is an annual event to raise awareness and funds for Rare Disorders NZ. Craft breweries from around the motu were invited to come up with their version of a rare beer using rare ingredients and unusual brewing techniques. An esteemed panel of judges voted for the best 'rare' beers with top marks going to innovative breweries who were able to make the connection to rare disorders through their beer and marketing efforts.

[Read more and find out who took out the top prize here.](#)

Global nursing network on rare diseases



On the 9th and 10th March 2023, Rare Disorders NZ sent New Zealand nurses, Sharron Meadows and Rebecca Nicol, to Singapore to an international

roundtable, *Connecting Nurses Globally – A Roundtable in Rare and Undiagnosed Diseases*, to work with 33 nurses from 25 countries across the globe on the establishment of a global nursing network on rare diseases.

The nursing network will inform and influence the development of nursing education resources to upskill and raise awareness of rare diseases across the workforce. The event was hosted by Curtin University Singapore, Singhealth Duke-NUS Genomic Medicine Centre and Rare Care Centre, Perth Children's Hospital.

You can read more about their experience [here](#).

Sharron and Rebecca will be sharing their learnings from the roundtable and how to get involved in the global nursing network in a webinar hosted by Rare Disorders NZ for registered and trainee nurses working in New Zealand and interested in rare disorders.

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

Embedding the rare voice in our future health system



Rare Disorders NZ is working with Manatū Hauora to facilitate engagement with the rare disorder community to ensure the voice of those affected by a rare disorder is included in the development of the Pae Ora health strategies.

Manatū Hauora/the Ministry of Health – in partnership with Te Aka Whai Ora/the Māori Health Authority and Te Whatu Ora/Health New Zealand – is developing the health strategies to help guide health entities in improving health outcomes for specific population groups:

- Hauora Māori Strategy
- Pacific Health Strategy
- Health of Disabled People Strategy
- Women's Health Strategy
- Rural Health Strategy

Rare Disorders NZ and Manatū Hauora jointly hosted two webinars in March 2023 to enable anyone in the rare community to engage with Manatū Hauora and share their thoughts on how the health system can best meet the needs of those impacted by a rare disorder.

You can read a summary of the responses shared, and answers to the questions posted during the webinars [here](#).

This information will be used to inform the Pae Ora strategies and to help with early work towards a rare disorder strategy.

Update from Manatū Hauora on collaboration and strategy progress



We continue to have ongoing discussions with Manatū Hauora - the Ministry of Health, on the development of the National Rare Disorder Strategy.

Update from Manatū Hauora on collaboration and strategy progress:

This Rare Disorders NZ X Manatū Hauora colab has been fruitful and rated well by participants. More joint events are being planned over the coming months – this will be particularly valuable as the work on a rare disorders strategy for New Zealand proceeds.

The Government announced the development of a rare disorders strategy in its response to the independent review of Pharmac. The first focus for Manatū Hauora was on the Pae Ora strategies as the changes being brought in through the Pae Ora Act were well aligned with the independent review panel's recommendations for rare disorders.

As the Pae Ora Strategies are completed, Manatū Hauora is increasing its focus on a rare disorders strategy.

The Government intends the strategy to make it easier for people, practitioners and organisations to get the information and support that would help - and lead to better, more timely services and more equitable support and outcomes for people and whānau with rare disorders. The strategy will seek to seize opportunities created through a more unified and consistent health system, advances in science and progress being made internationally. It will set a direction for work over coming years. There will be many more joint events and activities over the coming year. We had positive feedback about webinars and surveys. We'd appreciate if you could answer a very quick, one minute survey to let us know the best ways for you to provide input: <https://www.surveymonkey.com/r/383X2SH>

[You can read more on our website](#)

You can also keep updated on the progress of our engagement and the development of the strategy [here](#).

Rare Disorders NZ's statement on Pharmac's response to the Pharmac review



Rare Disorders NZ is extremely disappointed to learn from Pharmac's final response to the independent Pharmac Review that the drug-buying agency is waiting for Manatū Hauora to develop its National Rare Disorder Strategy rather

than take immediate action to improve assessment pathways for modern rare disorder medicines to save lives.

You can read [our statement on Pharmac's response to the Independent Pharmac Review here.](#)

Submissions by Rare Disorders NZ in first quarter of 2023



Submissions by Rare Disorders NZ in first quarter of 2023

We may be a small organisation, but as the collective voice of rare disorders in NZ we advocate on a wide range of issues that affect people living with a rare disorder.

In the first three months of 2023 alone, we responded to eight calls for submissions/feedback:

- Feedback on the proposal to fund Trikafta for people with cystic fibrosis
- Submission on precision health consultation
- Submission on rule 8.1b
- Submission on Proposal to fund Risdiplam (Evrysdi) for Spinal Muscular Atrophy
- Submission on the Therapeutic Products Bill
- Submission to the Pae Ora Women's Health Strategy
- Submission to Pae Ora Health of Disabled People Strategy
- Submission to Pharmac's review proposal to phase out funding of food thickeners.

[View the submissions here.](#)

Welcome to Lewanna, RDNZ Navigator



We are thrilled to welcome a new team member at Rare Disorders NZ in the role of Navigator.

Lewanna has a background in the health sector and more recently in the social sector. She is passionate about health equity and reducing the barriers faced by people trying to access social and health support. Lewanna is returning to the working world after four years at home with her two young daughters. When not working, Lewanna is busy enjoying the outdoors with her family and dog.

Lewanna will be working to provide education, information and connection for people and their whanau with rare disorders to ensure people with rare disorders feel well supported and informed and that they are aware of services and support that they are entitled to.

You can [contact Lew](#) if you have any questions regarding navigating support systems in New Zealand.

In the media



Across rare disorders month, we had 60 pieces of coverage across major broadcast, print, and online news media - reaching hundreds of thousands of New Zealanders. Highlights include:

- Breakfast interview,
- 10 articles in the NZHerald
- 8 Stuff community articles full of key messages
- 9 major national radio interviews
- triple page exclusive feature in Woman's Day magazine

You can read and watch some of the media coverage highlights over rare disorders month [on our website](#).

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:

Deane Endowment Fund

Aotearoa Gaming Trust

Grassroots Trust Central

One Percent Collective

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.](#)

Become a regular donor to Rare Disorders NZ through [One Percent Collective](#)

Join us on social media.

Please connect with us on social media and help us to reach more New Zealanders by sharing our posts!

- [LinkedIn](#)
 - [Facebook](#)
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 - [Twitter](#)
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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



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