

[Insert organisation logo]

**Media Release template**

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**[insert organisation] stands with Rare Disorders NZ in demanding Fair for Rare**

On International Rare Disease Day, [insert organisation] stands with Rare Disorders NZ calling for action from Government to commit to a National Health Strategy for Rare Disorders.

Today, Rare Disorders NZ released their Voice of Rare Disorders survey 2021, the largest-ever survey on New Zealanders living with rare disorders. Results reveal an alarmingly ill-equipped health system, underlining the need for urgent action for the 300,000 Kiwis living with a rare disorder.

Rare Disorders NZ Chief Executive Lisa Foster says the findings are unacceptable in the current pandemic climate and when we look overseas.

“Other OECD countries have implemented clear frameworks to reduce the time to diagnosis, and in turn, reduce the impact on the health system. With COVID-19 spreading fast, we are at a crisis point. It is a very worrying time for those with underlying rare medical conditions and compromised immune systems,” says Ms Foster.

[Insert quote + information from organisation spokesperson about the current climate for respective disorder]

Unlike other countries in the OECD, New Zealand has no strategy or national action plan for rare disorders.

“To add insult to injury, we – as the only national charity representing all persons with rare disorders - had our funding cut by half, due to end in 2023. The message the Government is sending to the rare disorder community is that they have no concern for improving their quality of life,” says Ms Foster.

With a once-in-a-generation health reform underway, the obstacles in the system could be addressed and lead to both economic and societal benefits, reducing the pressure on an already overloaded health system.

“Aotearoa New Zealand needs a health system that is Fair for Rare. Now is the time for change.

“The end of 2021 saw the UN formally recognise the challenges facing people living with rare conditions, and 2022 will see New Zealand map out a complete restructure of our health system,” says Ms Foster.

[X spokesperson] says that [X organisation] stands with Rare Disorders NZ in asking for people living with rare disorders to be officially recognised as a population group, and for a specific strategy for rare disorders like [insert disorder] to be included in the health reform.

Rare Disorders NZ, supported by [insert organisation] and other affiliated organisations, are offering to co-design a stronger healthcare system together with Government using findings from the survey.

The 2021 Voice of Rare Disorders White Paper can be viewed at www.raredisorders.org.nz.

ENDS

For interviews, or more information contact:

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[Insert your organisation contact]

**View key findings from The Voice of Rare Disorders 2021 Survey here:** <https://docs.google.com/document/d/16df_x_kk68SLKR2xTDanqjTRh5rERrdz/edit>

**About Rare Disorders NZ:**

RDNZ is the only national organisation supporting all New Zealanders who live with a rare condition, and the people who care for them. RDNZ offers a central starting point for patients and families affected by rare disorders, and helps families, patients and healthcare providers find essential information and support groups.

[Insert your organisation boilerplate here]