



VOICE OF RARE DISORDERS SURVEY 2025



Let YOUR voice be heard!

Our [2025 Voice of Rare Disorders Survey is now open](#) and this year we need YOUR participation more than ever.

[Access survey here](#)

What is the survey about?

The 2025 Voice of Rare Disorders Survey is a biennial survey facilitated by Rare Disorders NZ, with the support of Medicines New Zealand. It captures important information on what it is like living in Aotearoa New Zealand with a rare disorder.

Why is the survey so important?

We use the anonymised data to identify gaps in the services and care for people living with rare disorders, and this helps us advocate for meaningful change.

While New Zealand finally has a Rare Disorders Strategy, the Government has been dragging its feet to implement it. This is unacceptable. People living with rare disorders deserve more than intentions on paper; they deserve the intentions to be actioned.

The more people who take the survey, the stronger the data will be showing that urgent action is needed NOW.

Who can take the survey?

You are invited to participate in this survey if you are living with a rare disorder in Aotearoa New Zealand, or you are the primary carer. The questions refer to the person living with the rare disorder.

A disorder is considered rare when it affects fewer than or equal to 1 in 2,000 people.

Rare disorders include, but are not limited to, genetic disorders, cancers, infectious disorders, poisonings, immune-related disorders and idiopathic disorders.

You must have a confirmed diagnosis to participate.

Please share the survey widely with your networks so that we can get the highest and strongest response rate yet.

Access the survey [here](#).

Thank you for your time and for helping to strengthen the collective voice for rare.



Rare Disorders NZ · New Zealand

This email was sent to admin@disabilityconnect.org.nz · [Unsubscribe](#)

Created with [NationBuilder](#). Build the Future.