

Rare Disorders NZ Strategy Released Today!



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We are pleased to announce the release of Aotearoa New Zealand's first Rare Disorders Strategy, developed by Manatū Hauora | Ministry of Health, with input and advice from Rare Disorders NZ as part of the Reference Group representing the collective voice of rare in Aotearoa.

The Strategy marks the culmination of over 20 years of advocacy from Rare Disorders NZ and other patient advocates calling for official recognition of the inequities faced by people living with a rare disorder and the need for strategic direction to ensure improved health and well-being for this vulnerable population group.

While the Strategy does not include everything we were hoping, it is an important first step to seeing meaningful change in our health system and other services for the rare community.

This is a significant milestone for people living with a rare disorder in Aotearoa and a moment to celebrate and reflect on what we have achieved as a collective.

Thank you to everyone who has been involved in the consultation process, provided input and given feedback.

We look forward to the next steps of ensuring the Strategy is implemented to deliver meaningful change for people living with a rare disorder.

Access the Rare Disorders Strategy here.

Help us ensure the strategy leads to life changing progress for people with rare disorders and their families! Please Donate now, your gift will help us ensure rare voices are listened to in the implementation of the Rare Disorder's Strategy!

