

New Zealand unveils first health strategy for people with rare disorders

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To guide health entities over the next 10 years



The Ministry of Health has published New Zealand's first dedicated, health system-led strategy for people with rare disorders.

Globally, there are over 7,000 known rare disorders, with more being identified each year. Many are ultra-rare and may affect only one or a handful of New Zealanders. Yet, in total, some 300,000 may live with a rare disorder.

Dr Diana Sarfati, Director-General, Ministry of Health, says that the New Zealand Rare Disorders Strategy will enable the health system to be more responsive and supportive for both the rare disorders community and service providers.

"New Zealand needs a rare disorders strategy to improve how the health system responds and supports to those living with rare disorders, as well as the providers trying to meet patient needs. To develop the strategy, the Ministry worked in collaboration with Rare Disorders New Zealand to provide input and hear from members of the rare disorders community and their whānau as well as researchers, clinicians, and other sector experts", said Dr Diana.

The New Zealand Rare Disorders Strategy will set the direction and long-term priorities that will guide health entities over the next 10 years.

The Ministry of Health, Health New Zealand, Pharmac, and the Health Quality and Safety Commission will all play a key part in implementing and monitoring the strategy. The Ministry will support entities to make plans for actioning the New Zealand Rare Disorders Strategy priorities.