

Medicine Access for Rare Disorders in NZ

At a glance

There are estimated to be around 300,000 New Zealanders living with a rare disorder.

While less than 5% of rare disorders have a specific treatment, the treatments that do exist tend to be life-changing.


Key stats

Medicines NZ's 'New Zealand Medicine's Landscape 2022-23' outlines New Zealand's alarmingly poor medicine landscape:

 **only 11%** of the modern rare disorder medicines launched in the OECD between 2011 - 2020 are publicly funded in NZ.

 **20th** NZ's ranking out of 20 comparable OECD countries for access to modern medicines.



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 www.raredisorders.org.nz

CHALLENGES

The current one-size-fits-all model within which rare disorder medicines are assessed at Pharmac does not work for low volume, high-cost medicines, and contributes to inequitable health outcomes for people living with a rare disorder. The only other avenue to access rare medicines - the exceptional circumstances framework - is too inconsistent in its application.

SOLUTIONS

A separate assessment pathway for rare medicines with criteria separate to common conditions (as is implemented in Europe, Australia and Japan) is essential to ensure equitable access to medicines for where cost per person is not a constant barrier.



Implement a rapid access scheme for proven medicines



Include assessment of wider societal benefits of access to medicine



Adopt a fair definition of what is considered a rare disorder

BENEFITS

Benefits One

1

More equitable access to modern medicines for rare disorder patients to improve their health and wellbeing.

Benefits Two

2

Rare disorder patients with access to treatment will no longer be high-need, high-cost patients, reducing the demand on health and social services.

Benefits Three

3

New Zealand will be better placed to meet the expected exponential demand for precision medicines and individualised healthcare.