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Dear Hon Dr Reti

### **Rare Disorders Strategy**

Thank you again for attending our White Paper launch at Parliament that commenced Rare Disorders Month.

We understand that you have now reviewed the draft Rare Disorders Strategy (the Strategy) and advised the Ministry of Health team to progress with work towards publication.

Rare Disorders New Zealand, as the only umbrella organisation supporting all New Zealanders who live with a rare disorder, has been involved in the development of the Strategy. This has been both as a member of the Rare Disorder Strategy reference group and as a co-designing partner.

We are pleased to that there will finally be a Strategy and this in of itself is a cause for celebration for the rare disorder community in New Zealand. We are also particularly pleased to see New Zealand's first definition of a rare disorder and affirmation that the needs of people with rare disorders should be routinely considered when new policies or services are being designed, commissioned, or provided.

However, there are areas of the Strategy that we found superficial and require further attention.

There is a lack of acknowledgment of the value that could be added by establishing a centre of expertise. Such a centre would play a pivotal role in addressing many of the leadership, service, and capability needs outlined in the Strategy. While various coordinating mechanisms are mentioned, the proposal for a centre of expertise, supported by Rare Disorders NZ and the clinical community, seems to have been overlooked.

Throughout the development of the Strategy Rare Disorders NZ asked for stronger content relating to the access to medicines, devices and other treatments. Given the Strategy came out of the 2022 Pharmac Review, it is astounding how it glosses over this issue. We are however pleased to see reference to a Medicines Strategy that supports timely and affordable access to medicines and ask that you emphasise to the Ministry the importance of improving medicine access for those with rare disorders as a part of this work.

The current one-size-fits-all model under Pharmac's pharmaceutical schedule does not work for low volume, high-cost medicines for rare disorders, and there are too many inconsistencies under the only other avenue - the exceptional circumstances framework. A

separate assessment pathway for rare medicines with criteria separate to common conditions (as is implemented in Europe, Australia and Japan) would ensure equitable access to medicines for those with rare disorders.

The Strategy is a very health-centric document and does not reflect that rare disorders touch every aspect of people and their families lives from health, to employment and recreation, as well as their access to education, disability, housing and financial support services. Government agencies work in silos, people do not live in them and we will continue to advocate for a more coordinated and whole person approach to rare disorder care.

The Strategy deals with responsiveness to Whānau Māori living with rare disorders tokenistically and superficially. It does not appear to have sufficiently honoured the contribution of the voices of Whānau Māori as articulated in the Te Aka Whai Ora report (available here: [www.teakawhaiora.nz/assets/Uploads/Whanau-Voice-Summary-Rare-Disorders-FIN.pdf](http://www.teakawhaiora.nz/assets/Uploads/Whanau-Voice-Summary-Rare-Disorders-FIN.pdf)).

It was disappointing to see little acknowledgment of the role of Rare Disorders NZ as a contributor to the Rare Disorders Strategy implementation. None the less, we are already actively engaging with Health NZ on the next steps and, in consultation with domestic and international experts, Rare Disorders NZ have identified four essential implementable actions to prioritise beyond the completion of the strategy. These are outlined below.



**Action # 1**

Establishment of a Rare and Undiagnosed Disorders Centre of Expertise



**Action # 2**

Establishment of a single barrier-free pathway to rare disorder medicines



**Action # 3**

Incorporation of coding of rare disorders in the roll-out of the nationwide Electronic Medical Record



**Action # 4**

Recognition of RDNZ as a key enabler for the Strategy's implementation

Rare Disorders NZ sees a lot of potential in the Strategy, and we are committed to continuing our constructive engagement to ensure that the needs of those affected by rare disorders are met through its effective implementation.

Kind regards



Chris Higgins  
 Chief Executive  
 Rare Disorders NZ