



Hon Dr Shane Reti
Minister of Health

PO Box 7081
Newtown
Wellington 6242

28th February 2024

Dear Minister

Rare Disorders Strategy (RDS)

Thank you for your letter emailed to me on 21st February 2024, and I'm pleased to learn that you expect to see a draft of the RDS by the end of this month.

I haven't yet had an opportunity to see the final draft that you will be receiving, and the drafts that we did see towards the end of the year were incomplete. I note your suggestion that I continue to engage with the Ministry team as you and they progress through the next steps, but I have found that the quality of their most recent engagement has been unhelpful. While I will try again I will also ask that you be aware of Rare Disorders New Zealand (RDNZ)'s concerns as you consider your response to the Ministry's draft RDS.

Our expectations for the final RDS, which we have not seen reflected in any of the Ministry's drafts up until the end of last year are:

1. Sufficiently strong messaging to mandate creation of a rare and undiagnosed disorders centre of expertise
2. Full recognition of RDNZ as a key enabler for the Strategy's implementation
3. Establishment of a single barrier-free pathway to enable people with rare disorders to access the medicines they need. Access will be consistent with or exceed best practice international norms.

In the event that you are unable to join us for any part of today's launch of RDNZ's White Papers, please find attached electronic copies for your information.

Kind regards

A handwritten signature in black ink that reads "Chris Higgins".

Chris Higgins
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