



Maree Roberts
Deputy Director-General, Strategy Policy and Legislation | Te Pou
Rautaki
Manatū Hauora

11th January 2024

Dear Maree

Rare Disorders Strategy (RDS)

Thanks for your letter of 27th November 2023 in response to my letter of 13th November.

RDNZ has always understood and hoped that the final version of the RDS will be “an aspirational and actionable guide to the health system to support people living with rare disorders and their whānau to achieve” equitable health and other outcomes (our words) or “pae ora - healthy futures” (Manatū Hauora’s words).

We have also understood that it is not intended that the RDS will provide specific actions by which to achieve this. However RDNZ believes that the four recommendations that I outlined in my 13th November letter are part of what would constitute an “actionable guide” and are sufficiently high level for them to fall outside of a reasonable interpretation of a “specific action”.

Although we were unfortunately not given an opportunity to provide feedback on a completed RDS draft we nevertheless responded to the partial completed draft that we did see by reiterating our previous recommendations that the following be included in the RDS

1. Creation of a rare and undiagnosed disorders centre of expertise, modelled on Rare Disorders New Zealand’s Rare Support Centre Aotearoa proposal presented in Appendix X (attached separately to this letter)
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.

A further recommendation included in my 13th November letter that coding of rare disorders be incorporated in the roll-out of the nationwide Electronic Medical Record (EMR) and other administrative data sets seemed to be covered of sufficiently and with more specificity than we had expected.

Stacey has let me know that the RDS is now expected to be delivered to the Minister on 19th January and I’m hoping that this has created a small window of opportunity for our three above recommendations to be further considered for inclusion. Stacey also indicated that it should be possible for RDNZ to be supplied with a strictly in-confidence

copy of the RDS shortly after it has been delivered to the Minister, which we'll look forward to receiving

Kind regards

A handwritten signature in black ink, appearing to read "Chris Higgins".

Chris Higgins
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cc:

Stacey Connor, Manager, System Enablers