



Hon Dr Shane Reti
Minister of Health
Private Bag 18888
Parliament Buildings
Wellington 6160

PO Box 7081
Newtown
Wellington 6242
027 2500619

www.raredisorders.org.nz

27th June 2024

Dear Minister

Rare Disorders Strategy

Thank you for your letter of 29th May.

In a telephone conversation on 20th May between RDNZ's Chief Executive, Chris Higgins, and Manatū Hauora's Deputy Director-General, System Strategy and Policy, Maree Roberts, Chris was advised that:

- the Rare Disorders Strategy (RDS) is to be published before the end of July;
- its content would remain unchanged from the prepublication draft we were sent on 15th March 2024 (despite having drawn RDNZ's concerns about its content to your attention in our letter to you of 6th May 2024); and,
- a Manatū Hauora led implementation group is to be established comprising RDNZ and the three implementation agencies namely Te Whatu Ora, Whaikaha and Pharmac.

There was no indication on that call that the RDS is to be a Manatū Hauora document signed by the Director General of Health, rather than a document signed by the Minister, and yet that is what is outlined in your letter. This comes as a surprise. Throughout the consultation process we and the rest of the rare disorder community were led to believe that the RDS would have the status of a Ministerially signed document making it, in our eyes, the next best thing to a legislatively mandated Pae Ora Strategy. This apparent reduction in status will be very disappointing to all those in the rare disorder community who engaged, in good faith, in the consultation process.

Although it is not directly related to this correspondence I think you should also be aware that people with rare disorders which are treatable by medicines on Pharmac's OFI list were hopeful that the 24th June medicines funding announcement would extend to treatments for at least some of these rare disorders. Pharmac is declining to confirm or deny whether this will be the case. Along with the FAQ content on the Pharmac website (which omits any references to rare disorders when outlining what the 28 newly funded non-cancer medicines will be used for) this creates the strong impression that those with rare disorders will miss out once again.



RDNZ has been campaigning for a Rare Disorders Strategy for some twenty years and had been looking forward to celebrating its release. It is therefore a shame that both the content and status of the document fall short of expectations and that its release will come at a time of increased frustration and distress about a lack of funding for rare disorder medicines.

We appreciate your engagement on issues affecting people with rare disorders, and despite the concerns outlined here we're looking forward to engaging as a member of the implementation group. We are excited to be part of bringing about real improvement to the experiences, health, and wellbeing outcomes of people with rare disorders.

Yours sincerely

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

Chris Higgins
Chief Executive
Rare Disorders NZ

A handwritten signature in black ink that reads "James McGoram".

James McGoram
Chairperson
Rare Disorders NZ

Mobile: +64 27 292 8433
Email: chris.higgins@raredisorders.org.nz