



21 Nov 2025

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Chris Higgins
Chief Executive
Rare Disorders NZ
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Subject: Response to Rare Disorders NZ – Outcomes and Next Steps from the 11 November Roundtable

Dear Chris,

The Minister of Health has asked me to respond to you following the Rare Disorders Roundtable meeting on 11 November and your letter to Minister dated 30 October 2025. The Roundtable provided a valuable opportunity for open discussion between Rare Disorders NZ, the Ministry of Health, Health New Zealand, Pharmac, and HQSC. I appreciate your constructive engagement and leadership in advancing the rare disorders community's priorities.

I am writing to confirm, on behalf of the agencies, the commitment to the four outcomes you outlined, and to set out the next steps agreed at the Roundtable:

1. Leadership and Oversight

Each agency will appoint a senior lead to oversee the implementation of the Rare Disorders Strategy:

- Ministry of Health: Dr Joe Bourne
- Health New Zealand: Professor Dame Helen Stokes-Lampard, National Chief Medical Officer
- Pharmac: Dr David Hughes
- HQSC: Carlton Irving, Director of Māori Health and Consumer

2. Implementation Planning

Agencies will develop an implementation plan to support the delivery of the Strategy, the Ministry of Health will both convene and coordinate the development. These plans will outline key actions, timelines, and responsibilities. A draft consolidated implementation plan will be provided to the Minister early 2026.

3. Ongoing Coordination

On behalf of the Ministry of Health, I will chair a cross-agency forum to oversee delivery of Rare Disorders Strategy. The group will include Rare Disorders NZ, Health New Zealand, Pharmac, and HQSC, and is intended to meet every six months. The first meeting will be scheduled for May 2026.

4. Accountability and Reporting

Health New Zealand, the Ministry of Health, and Pharmac will report on progress through their existing performance and accountability mechanisms. My expectations are that they provide further detail on accountability and reporting arrangements as the implementation plans are finalised.

Thank you again for your partnership and advocacy. I look forward to ensuring the Rare Disorders Strategy delivers meaningful outcomes for people living with rare disorders and their whānau.

Yours sincerely



Dr Joe Bourne
FRNZCGP | MPH | MBChB
Chief Medical Officer
Ministry of Health | Manatū Hauora

