

8 March 2021

Lisa Foster  
Chief Executive  
Rare Disorders NZ  
Email: [lisa.foster@raredisorders.org.nz](mailto:lisa.foster@raredisorders.org.nz)

Dear Lisa

### LETTER OF SUPPORT FOR RARE DISORDERS NZ

I am pleased to provide this letter as an acknowledgement of PHARMAC's support for Rare Disorders NZ (RDNZ).

RDNZ provides a valuable conduit for communication and fostering understanding between people impacted by rare disorders, and the health system. PHARMAC is aware of the challenges faced by people with rare disorders in receiving a diagnosis and accessing effective treatment and is keen to remain connected to the rare disorders community. Without RDNZ PHARMAC would find connection and communication with this community much more difficult.

Effective pharmaceutical treatments are only one aspect of the needs of people with rare disorders, and your work to improve broader understanding is important. PHARMAC recognises and supports the work RDNZ does to raise awareness about rare disorders both generally and within the health system.

The recent 50 percent reduction in funding for RDNZ makes sustainability of your organisation and work challenging. We would be disappointed to lose the connections and valuable relationship we have developed with RDNZ. If RDNZ was unable to continue the community you serve would be both less informed and more isolated from the health system. It would be much more difficult for health and other agencies to engage effectively with this community.

We consider that the 300,000 people and their whānau impacted by a rare disorder still require the unique and purposeful voice of your organisation.

We look forward to continuing to work with you

Yours sincerely



Alison Hill  
Director, Engagement and Implementation