



The Paediatric Society of New Zealand
Te Kāhui Mātai Arotamariki o Aotearoa

25 March 2022

Lisa Foster
Chief Executive Rare Disorders NZ
Email: lisa.foster@raredisorders.org.nz

Dear Lisa

LETTER OF SUPPORT FOR RARE DISORDERS NZ

Thank you for contacting The Paediatric Society of New Zealand/Te Kāhui Mātai Arotamariki o Aotearoa regarding our support for Rare Disorders NZ.

The Society is pleased to be able to provide formal endorsement of the call for the development of a national rare disorder framework in New Zealand, which will support the over 300,000 New Zealanders living with a rare disorder, half of whom are children.

The recent 50 percent funding cut presents a number of challenges to the sustainability of your services. The Society believes that continuing education, awareness and support for the people living with a rare disorder and their whānau is needed. This would not be possible without the services of Rare Disorders NZ and this cut in funding represents a significant inequity in our health system.

New Zealand needs to provide high-quality health care that delivers equitable health outcomes for all and that includes those living with a rare disorder. As the healthcare system moves through significant changes over the next few years it is important that those living with a rare disorder and their whānau have improved healthcare and wellbeing through access to diagnosis, medicines and services.

The Society believes that the 300,000 people and their whānau impacted by a rare disorder benefit from the strong, unified voice of Rare Disorders NZ and these services must continue. We look forward to continuing to work with your organisation.

Yours sincerely



Michael Shepherd

President
Paediatric Society of New Zealand/Te Kāhui Mātai Arotamariki o Aotearoa



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