Prime Minister Jacinda Ardern
Parliament Buildings
Wellington 6160

**[Insert date]**

Dear Prime Minister,

**[Insert your organisation’s name if relevant]** is writing to you to provide an update on the Fair for Rare NZ campaign and to highlight the issues being faced by those living with rare disorders in our electorate.

As you may be aware, over 300,000 New Zealanders live with a rare disorder in New Zealand (1 in 17 people or 6% of the population) – half of whom are children. The impact of living with a rare disorder is significant, affecting not only the individual, but extending to affect families and carers, the health system and society.

**[Insert your story/experience and the issues important to you/your group]**

The collective Fair for Rare NZ campaign was launched on 28 February 2021 at Parliament by Dr Liz Craig MP. [Insert your organisation’s name] as one of the 125 support groups that constitute Rare Disorders NZ is seeking to:

1. gain widespread acknowledgement of the very existence of this group of people;
2. secure a Government commitment to addressing the challenges by establishing a New Zealand National Rare Disorder Framework;
3. secure sustainable funding for Rare Disorders NZ, the ONLY organisation representing all people living with a rare disorder.

Those living with a rare disease in New Zealand face inequitable access to diagnosis, treatment and care – particularly when compared to countries such as Australia. The initiatives we wish to brief you on would not only benefit those with a rare disease, but have much further-reaching advantages for wellbeing and contribution to society.

As Helen Clark said at the United Nations in 2016 “No country can claim to have achieved universal healthcare if it has not adequately and equitably met the needs of those with rare diseases.”

We know you value kindness and are focused on the wellbeing of all New Zealanders, so we hope you will commit to improving healthcare and wellbeing for people and their whānau living with a rare disorder in New Zealand.

Yours sincerely,

**[INSERT SIGN OFF/CONTACT DETAILS AS WELL AS LINK TO ORGANISATION’S WEBSITE]**