DATE

Dear [insert their title/name]

[Insert your organisation’s name if relevant] is respectfully seeking a meeting with you as our local MP and member of the Health Select Committee to discuss the issues being faced by those living with rare disorders in our electorate, highlighted by Sue Haldane’s petition to Parliament calling for a National Rare Disorder Framework which was delivered on 24 March.

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, which impacts on other areas such as employment and education.

The Fair for Rare NZ campaign was launched on 28 February 2020 at Parliament by Dr Liz Craig MP. [Insert your organisation’s name] as one of the 100 support groups that constitute Rare Disorders NZ is seeking to:

1. gain acknowledgement of people living with a rare disorder as a vulnerable population;
2. establish specific data and measures of people with rare disorders, which evidence the reality and scale of the issues;
3. increase funding for Rare Disorders NZ, the ONLY organisation representing all people living with a rare disorder.

Those living with a rare disorder 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 health condition, but have much further-reaching advantages for wellbeing and contribution to society.

We are hoping that this worthy cause is one you wish to learn more about and may indeed see potential for supporting, particularly as a member of the Health Select Committee.

Together, we can improve healthcare and wellbeing for people and their whanau living with a rare disorder in New Zealand.

We look forward to your response.

Yours sincerely,

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