**[INSERT RESPECTIVE TO/FROM ADDRESS DETAILS (NOTING WE ARE TARGETING THE MP’S ELECTORATE ADDRESS) AND DATE – USE ORGANISATIONAL LETTERHEAD IF ONE EXISTS]**

Dear [insert their title/name]

[Insert your organisation’s name if relevant] would like to request a meeting with you as our local MP to express our concern over the lack of inclusion of the needs of the rare disorder community in the Pae Ora legislation.

We would appreciate being able to meet as soon as convenient at your electorate office (or via a virtual meeting) and propose that in attendance from our organisation would be [list name/s] as well as local constituent [insert name]. [Insert sentence briefly outlining the rare disorder details of that local constituent].

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.

Results from a recent survey conducted by Rare Disorders NZ to understand the economic and social impacts of living with a rare disorder, paint an alarming picture of isolation, lack of timely diagnosis, poor treatment access, lack of coordinated care, significant carer impact and for many, being lost in the system.

While we were delighted to hear Minister Little recently announce his commitment to the development of a strategy for rare disorders, we are concerned that the rare disorder community was not included as a priority population group in the Pae Ora legislation alongside Māori, Pacific people, the disabled and rural communities, despite repeated calls from the rare disorder community to be identified as a priority group in the legislation.

With no legislative inclusion, we are concerned the health of the rare community will not be given equal priority to the population groups included under Pae Ora, and there will be no accountability for ensuring improved health outcomes from a strategy for rare disorders.

We are hoping that this worthy cause is one you wish to learn more about and may indeed see potential for supporting. You could make a transformational difference to the lives of 300.000 New Zealanders by championing this cause – a legacy to be truly proud of.

We appreciate that your time is valuable, so we will ensure to keep our meeting brief.

We would look forward to your response.

Yours sincerely,

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