**[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 to-date.

We would appreciate being able to meet as soon as convenient at your electoral 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.

Rare Disorders NZ recently completed the largest ever survey of the rare disorder community in New Zealand, and the results unsurprisingly showed major failings in the health system to meet the needs of people living with a rare disorder.

In 2021, [Insert your organisation’s name] along with the 124 other support groups that constitute Rare Disorders NZ launched The Fair for Rare NZ campaign, calling for a National Rare Disorder Framework to address the needs of this community. Since then, Rare Disorders NZ and numerous support groups and Patient Organisations have tirelessly repeated this call through meetings with health officials, the Minister and through various submissions to the Health Select Committee, yet we continue to be met with indifference.

We are devastated to see that, despite all our efforts, there is little in the Pae Ora legislation that would make a difference to those living with rare disorders, and we are deeply concerned that our needs will once again be overlooked.

We are hoping that this worthy cause is one you wish to learn more about and may indeed see potential for supporting. Particularly as [insert any personal background/info on the MP that provides a connection to rare disorders].

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

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]**