**Blog post/EdM template**

*[You don’t need to copy this template verbatim, but it’s a good place to start. Reduce the length if needed]*

Today is International Rare Disease Day, and we’re calling on our community to fight for fair through the power of storytelling.

Our friends at Rare Disorders NZ have released their Voice of Rare Disorders survey 2021. The survey results emphasise the need for urgent action for the 300,000 Kiwis living with a rare disorder like [insert respective disorder].

As part of their Collective, [insert organisation name] is standing with Rare Disorders NZ in calling for action from Government to commit to a National Health Strategy for Rare Disorders.

[Quote from organisation spokesperson about supporting RDNZ]

Unlike other countries in the OECD, New Zealand has no strategy or national action plan for rare disorders.

Rare Disorders NZ Chief Executive Lisa Foster says the findings are unacceptable in the current pandemic climate and when we look overseas.

“Other OECD countries have implemented clear frameworks to reduce the time to diagnosis, and in turn, reduce the impact on the health system. With COVID-19 spreading fast, we are at a crisis point. It is a very worrying time for those with underlying rare medical conditions and compromised immune systems.”

The government is currently undertaking a once-in-a-generation health reform. This is our opportunity to make sure the [insert disorder] community and other rare disorder communities are heard.

This will ensure people with [X disorder] and other rare disorders in Aotearoa receive improved healthcare and wellbeing through access to diagnosis, medicines and services.

**How can you help?**

To make our voices heard, we’re calling on our community to use the empower of storytelling. Share your story on social media to advocate for more #FairForRare.

Share some of the challenges you’ve faced as a Kiwi affected by a rare disorder. Whether it’s a wrong or delayed diagnosis, inaccessible medicine or care, or impacted physical or mental wellbeing – every story helps build our case for more government support.

Tweet, post, film, or photograph your story today. Together, let’s make our voices heard. Visit raredisorders.org.nz for more info.