

RDNZ Messaging Guide, 2022

	<i>Message</i>	More Detail and Action
1	<i>Rare voices matter and should be respected, given attention, and heard.</i>	<p>Despite all of our work to raise awareness of rare disorder concerns, it often feels as though we hit a wall of official indifference. It's not enough to have a seat at the table if we're routinely ignored. Rare voices matter, and should be respected, given attention, and heard.</p> <p>It's important for organisations to affirm our existence as a distinct population with unmet needs.</p>
2	<i>Rare disorders impact on as much as a third of our society and cannot (and must not) be ignored.</i>	<p>Individual rare disorders often consist of only a few individuals. Collectively, however, we are a huge slice of New Zealand society. Because of the need for support and care, these disorders affect the entire family of somebody afflicted, meaning that as many as 1.5 million people in NZ either have - or live with someone with - a rare disorder (around 30% of the population). The impact of rare disorders on society as a whole is being ignored.</p> <p>Always ask the question: Have we considered the impact of this decision on those with rare disorders?</p>
3	<i>Treatment, care, and support for rare disorders is inadequate and must be improved.</i>	<p>There is a public perception that <i>curing</i> rare disorders is too difficult and costly for our country to achieve. But this is a different goal from that expressed by those affected, who want equitable care, community support, and where possible, treatment. Those with rare disorders are not demanding miracles, just the chance to experience a better quality of life and care. These are goals our country can achieve, and has a duty to strive for.</p> <p>Ensure you're asking the right questions. Talk to people with lived experience of rare disorders about what adequate care might look like or ask Rare Disorders NZ.</p>
4	<i>Rare disorder data needs to be collected to improve our understanding of the needs of this community</i>	<p>Despite what we know of the scale of the issue many do not have access to the right care and treatment. But exactly how many? There is a distinct lack of data on the prevalence of rare disorders in NZ and their societal impact. Among other issues, this makes it difficult to resource care, education, and support. Education and workplace training about rare disorder issues can improve the chances of diagnosis, and subsequent care, for someone who is affected.</p> <p>Identify barriers to understanding of rare disorders by speaking to people with expertise and experience, and/or speak to Rare Disorders NZ</p>
5	<i>Let's work together to restore faith in our health system by respecting & including persons with rare disorders.</i>	<p>By including rare voices in discussions about health care we show respect for the challenges they face, we increase awareness of rare disorders, and we restore faith in a community that is being poorly served.</p> <p>Help us to raise awareness of rare disorders among community health practitioners. Be involved in co-producing our community-led vision of a National Framework for Rare Disorders.</p>