

Rare Disorders NZ Collective Key Messages February 2020

FAIR FOR RARE NZ CAMPAIGN

- The Fair for Rare NZ campaign was launched at Parliament on 28 February by Dr Liz Craig MP
- An estimated 300,000 New Zealanders (1 in 17 people or 6% of the population) have a rare disorder – half of whom are children, which impacts on other areas such as employment and education
- People living with a rare disorder in New Zealand face barriers to access diagnosis, treatment and care – particularly when compared to most OECD countries including Australia
- Rare Disorders NZ and its collective 140 support groups are calling on the Government to acknowledge the common challenges faced by people living with a rare disease
- We are calling for development of a National Rare Disorder Framework to enable responsive healthcare for all people living with a rare disorder
- These initiatives would not only benefit those with a rare disorder, but have much further-reaching advantages – for example, reducing the burden on the health system and lessening both the time away from work and mental stress for those living with a rare disorder and their carers
- New Zealand must honour its commitments to the Treaty of Waitangi, Maori/Pacific Action Plans as well as respective United Nations and Asia-Pacific Economic Co-operation agreements
- Rare Disorders NZ needs sustainable funding to continue its important work on behalf of those living with a rare disease

For more information: <https://raredisorders.org.nz/fair-for-rare-nz/>

Hashtags for social media use: #FairforRareNZ #RareisEverywhere