

Rare Disorders NZ: 2020 Election Manifesto

Will your party commit to a National Rare Disorder Framework?

Issue 1 – Call for National Rare Disorder Framework

Rare disorders: Policy makers often fail to realise that while infrequent or ‘rare’ disorders (diseases that affect 1 in 2,000 people or less) have relatively few patients individually, collectively have a substantial population with 300,000 New Zealanders affected. They are chronic, progressive, degenerative, and disabling. People living with rare diseases face many common challenges, such as delayed or inaccurate diagnosis, difficulty accessing care and lack of knowledge or access to expertise. For the individual sufferer this is a disaster, and for an economy it represents a significant direct and indirect cost. Therefore, most developed countries make this group a public health and social funding priority as this makes economic, social, and moral sense. New Zealand also has current international commitments to include people with rare disorders within Universal Health Coverage and aligned expectations and actions are expressed within the current APEC Rare Disease Action Plan pillars. Therefore, now is the time to afford this group higher priority within New Zealand.

Solution – Rare Disorders NZ and the support groups we represent are calling for acknowledgement and awareness of the common challenges faced by people living with a rare disease, along with a commitment to address these challenges through the development of a **New Zealand National Rare Disorder Framework**. Fairness means having the vision and leadership to develop public policy and actions to improve access to information, diagnosis, care pathways, access to disability, social supports, and medicines as well as to promote research in this field.

Greens	Labour	National
<p>Everyone has a right to the healthcare services they need; and the Green Party believes in a holistic approach to health and well-being that is focused on ensuring a healthy environment to live in, promoting positive health, lifestyles and nutrition, preventing or reducing the risk and costs of illness, respecting personal autonomy, and improving quality of life for everyone. The Green Party supports everyone having a right to the healthcare services they need so that there are equitable health outcomes for all</p>	<p>Labour stands for supporting all New Zealanders who face health challenges, whether their challenges are commonplace or rare. That’s why Labour is committed to implement the recommendations from the Simpson review of New Zealand’s health and disability system. This will make our health system more responsive to the needs of all communities in New Zealand, including the community of people who have rare disorders. It’s a large programme of change for our health providers, which presents opportunities for groups including Rare Disorders NZ to press for changes such as a Rare Disorder Framework</p>	<p>National’s full election manifesto will be released closer to the election however National believes that everyone deserves the opportunity to live well and access high quality care, regardless of their condition or where they live. National has already committed to establishing a \$20million rare disorders fund to ensure that those affected by rare disorders have better access to key drugs</p>

Will your party commit to an early diagnosis for all with a rare disorder?

Issue 1 – DIAGNOSIS

Solution – Early and accurate diagnosis of rare disorders to avoid the diagnostic odyssey and prevent unnecessary interventions.

Having a diagnosis often means having choices and the avoidance of lost opportunities.

- Connection to Global Commission to end the Diagnostic Odyssey for Children with a Rare Disease <https://www.globalrareiseasecommission.com/>
- Expanding best practice in ante-natal and newborn screening to ensure early intervention
- Genomic access for more complex and undefined cases

Greens	Labour	National
<p>Undiagnosed disease is not only a significant burden on patients and their families, but is a significant cost to New Zealand’s health and social welfare system. Early diagnoses help reduce ongoing costs to the health and welfare systems, as well as in many cases improving the lives of patients and their families. The Green Party supports early identification and intervention</p>	<p>Labour is committed to funding our health professionals properly so they can provide early, accurate diagnosis of all health challenges, whether commonplace or rare</p>	<p>National strongly believes in early intervention and has spoken about our desire to invest further in the first 1,000 days of a child’s life from pregnancy to age 2. Our full plan for improving the healthcare support during early years is yet to be released but increased support from Maternity Carers and post-natal experts will aim to improve screening and identification of conditions and further support needed</p>

Will your party commit to a planned pathway for clinical care?

Issue 2 – PLANNED PATHWAYS FOR CLINICAL CARE

Solution – Recognition of and removal of structural barriers that prevent cohesive healthcare.

Due to high uncertainty for many with rare disorders the importance of being given a coordinated “holistic” approach to care is essential. This would enable inter-disciplinary services and effective collaboration between all health professionals, community service providers, Ministry of Social Development and Ministry of Health.

- Navigator for rare and complex cases
- Access to the right treatment
- Access to appropriate specialists with effective cooperation across disciplines
- Access to centres of excellence for specific “grouped” disorders (metabolic, skeletal, neurological, etc) which link to International sites (WHO Collaborative Global Network for Rare Diseases (WHO CGN4RD))
- Care across the DHB boundaries removing postcode lottery
- Transition to adult services - clear plans and processes

Greens	Labour	National
<p>The Green Party believes in a holistic approach to health and well-being. The approach needs to be effective for all members in society, and publicly-funded health services must be flexible and diverse to meet the different needs of people of different ages, cultures, financial and social resources, and stages of physical and mental health</p>	<p>The Simpson review notes that health services need to be planned with the particular needs of communities in mind, and also notes that government should provide more active support to NGOs that can help to plan care for the people they know best. Labour agrees, and is looking forward to further improving this aspect of health care in New Zealand as we implement the findings</p>	<p>National is yet to release our full Health policy but have already committed to eliminating access inequities to surgery through our Health Discussion Document. National’s health policies will always be focused on ensuring that individuals can receive healthcare that is easy to access and personalised to them. To enable this, National has committed to encouraging Health Workforce New Zealand to consider new health workforce roles to meet the needs of 21st century health service delivery, such as navigators and coaches</p>

Will your party commit to people with rare disorders having access to disability and social support when required?

Issue 3 – ACCESS TO DISABILITY AND SOCIAL SUPPORTS

Solution – Implement simple mechanisms to ensure appropriate access to disability and social supports.

Access based on clinical need assessment not by diagnosis. Establishment of a simplified process to enable access to disability support services that includes the less common, more complex conditions so that no one is left behind because they do not tick a box.

- Implement specific mechanisms and service design that ensure **integrated care provision** and connection across ministries and organisations
- Assessment processes which include people with rare disorders – holistic assessment framework (factors for consideration)
- Inclusion of income support in the coordinated care model (exclusion often occurs with undiagnosed or poorly understood conditions)
- Adequate respite care and carer support payments

Greens	Labour	National
The Green Party believes that disability funding should be based on need not the cause of impairment. People who need intermittent support or care should be able to access services when they need them without going through screening every time. There should be no financial barriers to anyone accessing the healthcare services they need or support when they need it	Yes, Labour is committed to providing access to appropriate disability and social support for all New Zealanders with health challenges, including rare disorders	National is yet to release our detailed policy manifesto but we fundamentally believe that access should be improved and is willing to explore all ways to ensure that everyone gets better care, sooner.

Will your party commit to a review of PHARMAC to ensure equitable access to medicines for rare disorders?

Issue 4 – RARE DISORDERS MEDICINES/DRUG ACCESS PROGRAMME

Solution – Equitable access with an appropriate assessment pathway and criteria for rare disorders which takes into consideration their small patient populations, progressive disease, and limited data.

- A dedicated, adequate and ringfenced budget
- Assessment criteria separate to common conditions (as is implemented in Europe, Australia and Japan)
- Separate management processes
- Equity as the central principle to ensure balanced assessment and that cost per person is not a constant barrier

Greens	Labour	National
<p>The Green Party believes that everyone has a right to the healthcare services they need and that there should be no financial barriers to anyone accessing the healthcare services they need. The Green Party supports the independence of PHARMAC and will work to ensure that it can prioritise benefit over any restrictive trade obligations. We have a system that buys the most drugs at the best price to provide to the largest number of New Zealanders that is reasonably free of political interference, and it needs to stay that way. However the Green Party supports any increase to PHARMAC’s funding so that they have the money to acquire new medicines that will offer benefits to the people that need it</p>	<p>Decisions about specific drugs are best made by the experts at PHARMAC rather than by politicians. Labour has made it easier for PHARMAC by increasing their funding by 20 percent in our first term. That gives PHARMAC the resources to provide better access for New Zealanders to the medicines they need</p>	<p>National has committed to a \$20m ring fenced rare disorders fund which we will implement on forming Government to ensure that rare disorders are not excluded from funding based on the current funding formula.</p>

Will your party commit to a funded national coordinated programme of research on rare disorders?

Issue 5 – RESEARCH

Solution – A funded national coordinated programme of research on rare diseases that includes active participation by patients, carers and patient advocacy groups. Improved government commitment and associated funding for rare disease research.

- Includes research into diagnosis, prevention, treatment, service delivery, disability support
- Provision of opportunities for collaboration and connection between researchers

Greens	Labour	National
<p>The Green Party supports research initiatives that helps with the health of New Zealanders. Research is central to our present and future wellbeing and the Green Party believes its role is to improve the quality of our lives. The Green Party would significantly increase the total investment into research and science and would reduce the organisational complexity, transaction costs and overheads associated with funding decisions and research delivery</p>	<p>The government funds substantial health research through the Health Research Council, and in our first term we've been proud to increase the funding available for that important work. Decisions about funding individual research projects are best made by experts at the HRC rather than by politicians.</p>	<p>National will release our full science, innovation and research policy closer to the election but National are committed to ensuring adequate funding for scientific research in New Zealand.</p>

Will your party commit to a national rare disorder database?

Issue 6 – NATIONAL RARE DISEASE DATABASE

Solution – Improved data to ensure accurate awareness of the demographics of rare disorders and to allow responsive access to each other, to research participation and to clinical trials that may be available. Medical research on rare diseases is fast becoming an important source of advances in medical technology and genomics, which could hold the key to future treatments for all diseases.

- Use of clear coding for rare disorders
- Alignment with Orphanet descriptions of 6172 clinically unique RDs excluding groups of disorders and disorders subtypes

Greens	Labour	National
<p>The Green Party will develop comprehensive, nationally-integrated electronic health records that allow people to access their own health records and all health professionals to access the same information, to improve efficiency, communication and continuity of care. This would be balanced with ensuring suitable protection for sensitive health information. We believe it is important we have a strong understanding of issues in health sector and we would support having online resources, detailed information on rare diseases or databases that could help people</p>	<p>Labour is committed to improving our use of data throughout the health and disability system, because we agree that having early access to the right information helps us to provide the health services that people need. This includes safely and appropriately sharing data so government has a richer picture of the health challenges New Zealanders face, while protecting individuals' privacy rights. There's an entire section of the Simpson review which makes recommendations about improving the use of data, and we are committed to implement the review's recommendations</p>	<p>National commits to exploring the feasibility of this when in Government</p>

Will your party commit to workforce development?

Issue 7 – WORKFORCE DEVELOPMENT

Solution – Clear planning for sustainable training to ensure workforce are ready and available – including genetic counsellors, biostatisticians, trained specialists, allied health professionals and lab workers.

Greens	Labour	National
<p>The Green Party believes that all New Zealanders should be able to actively contribute their talents, skills and abilities to their communities through employment or voluntary work. We support any affirmative action to enable people participate in the workforce.</p>	<p>Yes, Labour is committed to continued development of all parts of the health workforce.</p>	<p>National believes that the health workforce needs to be looked at and has committed to an immediate stocktake of the sector as well as to encourage Health Workforce New Zealand to consider new health workforce roles to meet the needs of 21st century health service delivery, such as navigators and coaches.</p>

NOTE: RARE DISORDERS NZ CONTACTED THE MANA, NZ FIRST, ACT AND MAORI PARTIES AND RECEIVED NO RESPONSE TO THESE QUESTIONS