Rare Disorders NZ: Where does your party stand on issues important to the rare disorder community?

People living with a rare disorder are estimated to make up 6% of New Zealand's population. With over 7,000 known rare disorders, individually these disorders occur in very small numbers in the population, but collectively, rare disorders are estimated to affect 300,000 people in New Zealand.

Regardless of their specific disorder, those affected share the same challenges and systemic barriers - lack of timely diagnosis, poor treatment access, lack of access to modern medicines, lack of coordinated care, isolation, significant carer impact and for many, being lost in the system.

While solutions to these challenges abound, meaningful change can only be driven with political will. The rare disorder community is looking to see which political parties will recognise their value and right to equitable access to healthcare.

The health system is under pressure, and without action, rare patients will continue - often unnecessarily - to be high-need, high-cost patients. Addressing these challenges will substantially improve the quality of life for people living with rare disorders and significantly reduce their dependence on high demand services.

Advances in genetic technologies and precision medicines means diagnosis and treatment of rare disorders are at the heart of cutting edge, innovative therapies that could benefit all New Zealanders who become unwell. This is the future of healthcare, and New Zealand, currently lagging far behind other OECD countries in delivering appropriate therapies for rare disorder patients, is at risk of being ill-equipped to meet the growing demand for novel therapies.

We cannot afford to ignore the needs of those affected by rare disorders. By addressing the current challenges and systemic barriers for rare disorder patients, New Zealand will be better placed for a future health system that can deliver individualised healthcare and therapies.

Issue 1 – Implement the Rare Disorders Strategy

On 25 July 2024 Aotearoa New Zealand's first Rare Disorders Strategy was released. The Rare Disorders Strategy outlines the Government's intentions to improve health outcomes for people living with rare disorders. While the Strategy guides the long-term priorities for health entities over the next 10 years, the need for action remains urgent.

On 11 November 2025 the Minister of Health directed the four agencies responsible for implementing the Strategy to:

- Develop an implementation plan to support the delivery of the Strategy;
- Meet every 6 months (Ministry of Health to convene cross-agency meetings and oversee delivery of Strategy);
- Report on progress through their existing performance and accountability mechanisms.

Policy Question
Will your party uphold the Minister's directives above to ensure work progresses on the implementation of the Rare Disorders Strategy?

The National Clinical Networks team at Te Whatu Ora | Health NZ have been directed to establish a rare disorders clinical reference group, similar to National Clinical Networks, but without additional funding or resources. Rare disorders is a clinical subset of the population similar in size to the diabetes patient subset, and as such warrants a National Clinical Network with the same status and funding as other clinical networks, to ensure adequate clinical oversight.

Policy Question

Would your party commit funding towards a National Clinical Network for Rare Disorders as part of phase one of the implementation of the Rare Disorders Strategy?

Issue 2 – Diagnosis

Early and accurate diagnosis of a rare disorder is not only important in order to access a range of treatments and healthcare services, but also for family planning purposes and for giving people certainty about what is causing their health issues, even if a treatment is not available. Yet for many people living with rare disorders in New Zealand their journey to diagnosis is often long and distressing. It can also be costly – not only to the health system, but to their own health.

While New Zealand does screen for a number of conditions and has a publicly funded network of genetic clinics, there are a several barriers preventing timely access to diagnosis:

- Genetic Health Services NZ has a dire shortage of qualified geneticists and genetics counsellors, unable to meet demand for genetic testing. There are currently no training programmes available in New Zealand for genetic counsellors.
- New Zealand continues to lag behind other OECD countries in adopting technologies in the fast-growing field of genomics. Health NZ | Te Whatu Ora has developed a Genomics Strategy with a vision that *by 2030, Health New Zealand | Te Whatu Ora has the infrastructure, mechanisms and workforce required to capitalise on advances in genomic medicine to improve the lives of all New Zealanders*, but this is still waiting final sign-off.
- Currently, New Zealand insurers can factor genetic test results into considerations when underwriting insurance policies, potentially leading to higher premiums or policy denials. As a result, many people are hesitant to seek genetic testing. The United States, Canada, United Kingdom, Germany, Finland, Norway, Switzerland, South Korea, Australia and some Asian countries have laws restricting or prohibiting this kind of genetic discrimination

Policy Question
Will your party commit to an increase in funding for Genetic Health Services?
Policy Question
Will your party prioritise finalising Health NZ | Te Whatu Ora's Genomics Strategy and commit funding towards its implementation?
Policy Question
Will your party support a total legislative ban on genetic discrimination in insurance policies?
Policy Question
What is your party's view on the adoption of new technologies, including AI, to improve diagnostics and health care services?

Issue 3 – PLANNED PATHWAYS FOR CLINICAL CARE

People often report being lost in the health system, with their healthcare providers unsure of how best to support their patient or provide the correct long-term care. Our 2023 survey of the rare disorder population found that over half felt that communication and information exchange between different service providers was poor and that professionals are poorly prepared to support them.

The Rare Disorders Strategy identifies care standards, guidelines and pathways as part of creating a coordinated and responsive system for people living with rare disorders. The Strategy states a programme or process will be established to identify, adapt, authorise and publish guidelines, standards and pathways for rare disorders in Aotearoa New Zealand. One existing mechanism for this already embedded in the health system is Health Pathways which can be hugely beneficial, offering clear guidance for GPs, specialists and patients alike. The development of Health Pathways is however too slow due to under resourcing.

Policy Question
Would your party expect, as part of the implementation of the Rare Disorders Strategy, that Health NZ allocates funding towards a programme or process to identify, adapt, authorise and publish guidelines, standards and pathways for rare disorders in Aotearoa New Zealand?

Issue 4 – ACCESS TO DISABILITY AND SOCIAL SUPPORTS

There are systemic barriers to access disability and social supports for many with rare disorders as they often do not meet criteria to access disability support services and funding despite having equivalent need to those that do.

The rare disorder population often falls through the gaps in our support systems. People with undiagnosed and rare disorders who have disabilities are often not recognised nor receive disability support services, because the criteria are not designed with this population in mind.

Policy Question
How would your party ensure the systemic inequities in disability and social supports with respect to rare disorders, are addressed?

Issue 5 – RARE DISORDER MEDICINES/DRUG ACCESS PROGRAMME

The independent review of Pharmac found the current model within which rare disorder medicines are assessed at Pharmac contributes to inequitable health outcomes for people living with rare disorders. The current one-size-fits-all model under the pharmaceutical schedule does not work for low volume, high-cost medicines for rare disorders, and there are too many inconsistencies under the only other avenue – the exceptional circumstances framework.

Neither of these pathways provide reasonable assessment conditions for rare medicines to be approved. A separate assessment pathway for rare medicines with criteria separate to common conditions is essential to ensure equitable access to medicines for those with rare disorders and where cost per person is not a constant barrier. This could require amending the statutory objectives for Pharmac's factors for consideration to widen the costs and benefits to the individual, the whānau and society considered when funding a medicine.

Furthermore, Pharmac's Combined Pharmaceutical Budget (CPB) is inadequate to meet the growing demand for medicines. NZIER's report from October 2025 to Medicines New Zealand on New Zealand's public health and disability expenditure against selected OECD countries found *New Zealand devotes only 4.9 percent of its overall health and disability expenditure to pharmaceuticals compared with an average of 13.3 percent across the sample* and New Zealand's *health expenditure allocated to the delivery of health services significantly exceeds the sample average.* Considerable attention needs to be given to where New Zealand's health dollars should be prioritised, and how savings can be made in service delivery by giving the CPB a bigger slice of the health budget.

Policy Question
Would your party instruct Pharmac to establish a separate assessment pathway for rare disorder medicines?
Policy Question
Would your party change the statutory objectives for Pharmac's factors for consideration?

Policy Question
What is your party's view on the need to increase the Combined Pharmaceutical Budget's proportion of health and disability expenditure?

Issue 6 – RESEARCH

Awareness of rare disorders among health professionals, health system leadership and government agencies is poor, with inadequate research funding a major cause. A funded national coordinated programme of research on rare disorders that included active participation by patients, carers and patient advocacy groups, would enable greater international collaboration and information sharing, and vastly improve how New Zealand manages rare disorders.

Policy Question
Would your party commit to ring-fencing funding specifically for rare disorder research?

Issue 7 – CAPTURING RARE DISORDERS DATA

New Zealand currently has no nationwide process for collecting data on rare disorders. As a result, people living with rare disorders are currently invisible in health system data. This high-need, high-cost population group is not being factored into budget and resource allocation decisions. This could be remedied, by prioritising the following:

- It should be a requirement that all Patient Management Systems (PMS) adopted by primary care providers can integrate coding systems with a significant number of rare disorder codes, such as SNOMED – CT, to begin routinely collecting rare disorder data. (Some PMS already have this capability, such as Indici, and others are in the process of incorporation.)
- Due to the complexity of care for many rare disorders the data needs to be accessible beyond primary care. This requires that the right frameworks are in place to require PMS to transfer patient records to the Shared Digital Health Record. This would enable specialists and other health professionals to access their patients' medical history, including medications, allergies, previous diagnostic assessments etc. when permitted and required, to recommend the best and safest health care plan. Patients could choose to opt in or opt out of having their records shared.

Policy Question
What is your party's position on requiring Patient Management Systems to be capable of integrating SNOMED – CT or other key coding systems?
Policy Question
Would your party commit to seeing through the roll out of the Shared Digital Health Record?
Policy Question
Would your party prioritise establishing a regulatory framework for Patient Management Systems to transfer patient data to the Shared Digital Health Record?

Issue 8 – WORKFORCE DEVELOPMENT

Awareness and training of health professionals is essential to improving the lives of those living with rare disorders. From diagnosis to treatment, the level of awareness of rare disorders a health professional has is crucial to desired health outcomes. A lack of awareness of rare disorders often contributes to people feeling isolated and misunderstood, as well as to delays in diagnosis and treatment, potentially missing opportunities for early intervention and improved outcomes.

Priority 3 of the Rare Disorders Strategy highlights the need to equip the health workforce to provide quality care for rare disorder patients, noting the need to develop curricula for health practitioner education at all levels, as well as offer learning modules on rare disorders for the health workforce.

Policy Question
Would your party commit resources to upskill the health workforce on rare disorders through learning modules?
Policy Question
Will you develop a workforce plan to increase the number of geneticists and genetics counsellors?