



Neurological Alliance
c/o Rich Easton
Neurological Foundation of NZ
PO Box 110022
Auckland Hospital
Auckland 1148

11th December 2020

Hon Andrew Little
Minister of Health
Parliament Buildings
Wellington

Via email – a.little@minister.govt.nz

Dear Minister,

Neurological Alliance – Briefing for Incoming Minister

On behalf of the [Neurological Alliance](#) (the Alliance) and all the New Zealanders living daily with a neurological disease or disorder, we would like to welcome you to your new Ministerial role and add our voice to the chorus of congratulations on your appointment to arguably the most significant portfolio in the government.

As reported in the [2018 Global Burden of Disease Report](#), neurological disorders are the leading cause of disability and second cause of death, representing a huge global health problem. One-in-three people now suffer from a neurological disorder worldwide. In the past 15 years, the proportion of people affected has increased from 20 percent to more than 30 percent.

We are writing on behalf of the Alliance to brief you on our collective priorities for neurological support, care and research for the 1 in 5 New Zealanders impacted by a neurological disease or disorder. The Alliance would also like to highlight the additional challenges faced by Kiwi's and their whānau when living with a rare neurological condition, where access to care and support can become even more challenging.

We have summarised the key issues for the Alliance members below, with more details for each of them in the supporting document. The members of the Alliance welcome an opportunity to meet with you to discuss the topics we have raised in more detail and to discuss how the Alliance and its members can support you, and collaborate with the government in providing the best outcomes for Kiwi's living with neurological conditions.

Summary of key issues

The key changes the Alliance would like to see for those living with neurological conditions in New Zealand, in order for them to live their best possible lives, are:

NZ burden from neurological conditions

The Alliance would like to work with the Government to:

- Address the significant gap in the number of neurologists available to New Zealanders, providing ready access to specialist knowledge as the country forecasts a significant growth in the burden from neurological diseases
- Establish equitable access programmes to specialist neurological care throughout the country, to address the growing inequity for those living in rural areas that are unable to get the care needed
- Setup a national framework for managing rare disorders (including rare neurological disorders)
- Foster the growth of collaborative networks and platforms with countries around the globe, giving New Zealander's access to specialist knowledge and skills not physically available in the country

Review of Pharmac

The Alliance would like to work with the Government to:

- Lead a review of Pharmac and its processes and explore alternative funding options for those requiring specific medication for neurological conditions, including cost-sharing models
- Provide access to precision medicines and diagnostic tools available internationally for those living with neurological conditions

Support and care funding

The Alliance would like to work with the Government to:

- Introduce and fund support programmes for all New Zealander's diagnosed with a neurological condition, supporting them and their whānau during the many phases of living with a neurological condition
- Commit funding to providing specialist nurses, physiotherapists, occupational therapists and psychotherapists to provide community based primary health care for those living with a neurological condition, along with specialised neuro-physiotherapy programmes
- Partner with the Government on the best ways to deliver support and care services nationally
- Develop strategies and action plans for outreach to the Māori & Pasifika communities in developing culturally specific clinical and support services for those impacted by neurological conditions
- Adequately fund those providing 'in home care' supporting those living with neurological conditions throughout the sector, so that the Alliance members can deliver meaningful and consistent services
- Implement the Mahi Aroha action plan as part of the Carers Strategy for all New Zealanders

Neurological research

The Alliance would like to work with the Government to:

- Consider the development of a framework and plan for addressing the burden of neurological disease in New Zealand, which would include increasing the number of neurologists and research active clinicians working in a neurological discipline, and prioritising research funding according to the burden of neurological conditions

Conclusion

The impacts of neurological conditions are often hidden, and many have additional social stigma associated with them, though they affect a large number of New Zealanders. The 700 plus neurological conditions have a significant and growing impact on the health and wellbeing of New Zealanders, with social and economic impacts that touch all aspects of our health service and the fabric of our society.

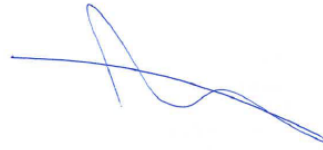
The Alliance trusts that the summary above gives you an insight to the challenges and opportunities ahead for those living with neurological conditions in New Zealand. Each of the issues are expanded in a little more detail in the supporting document.

The members of the Neurological Alliance look forward to meeting you and discussing the opportunities and risks ahead for the 1 in 5 New Zealanders impacted by a neurological condition. We look forward to hearing about the plans that you and the Government will lead in changing the future for everyone living with neurological conditions. And we look forward to collaborating with you and the government on these topics over the coming months and years.

Yours sincerely,



Catherine Hall
Chair, Neurological Alliance



Rich Easton
Secretary, Neurological Alliance

Copy to:

- Hon Carmel Sepuloni, Minister for Disability Issues
- Hon Peeni Henare, Associate Minister for Health (Māori Health)
- Hon Ayesha Verrall, Minister for Seniors, Associate Minister of Health
- Hon Aupito William Sio, Minister for Pacific Peoples, Associate Minister of Health (Pacific Peoples)

About the Neurological Alliance

The Neurological Alliance was established in 1999 to provide a forum for organisations representing a neurological disease to work together and make representations on matters of common interest. All members have a common desire to promote community awareness of neurological diseases and to see that the needs of people with neurological conditions are met. More information and the Terms of Reference can be found at the Alliance's website:

<http://www.neurologicalalliance.org.nz/>

The Neurological Alliance is made up of the following organisations & their current representative:

Catherine Hall Alzheimers NZ	Clare Williams Cerebral Palsy Society	Scott Arrol Dementia NZ
Ross Smith Epilepsy NZ	Jo Dysart Huntington's Disease Association NZ	Carl Sunderland Motor Neuron Disease NZ
Amanda Rose Multiple Sclerosis NZ	Dr Tristram Ingham Muscular Dystrophy NZ	Rich Easton Neurological Foundation NZ
Andrew Bell Parkinson's NZ	Lisa Foster Rare Disorders NZ	Dave Mitchell NZ Dystonia Patient Network
Mark Vivian Stroke Foundation NZ	Helen Willacy Tuberous Sclerosis Complex NZ	