



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

3 October 2022

Hon Andrew Little MP
Minister of Health,
New Zealand Government,
Wellington

Via email – A.Little@ministers.govt.nz

Kia ora Minister Little,

Neurological Disorders have no home in the Health System

The [Neurological Alliance](#) (the Alliance) acknowledges and supports the work you have underway to build a health system able to deliver nationally consistent, equitable, and accessible services for everyone, plus the Ministry of Health's recent efforts to address the health workforce issues.

We are writing today because we are concerned that the needs of the more than 1 in 5 Kiwis living with neurological conditions are being overlooked as the new health system is being established because of gaps in services, and the significant workforce issues, in particular with neurologists, specialist nurses, and other health practitioners.

It is vital that Aotearoa's health system is setup to successfully support our communities, as their challenges grow bigger every day. As reported in the [2018 Global Burden of Disease Report](#), neurological disorders are the leading cause of disability and the second cause of death, representing a huge global health problem. In the past 15 years, the proportion of people affected by neurological conditions has increased from 20 percent to more than 30 percent globally.

The impacts of neurological conditions are often hidden, and many of the Alliances members have experienced significant social stigma associated with their condition. 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.

Given this impact, and the intention that the new system delivers equitably to everyone, wherever they live, and whatever their health condition, it has been disappointing to find that our efforts to engage with the new system have been unsuccessful. This has been because there appears to be confusion about engagement pathways to those developing the new frameworks and the lack of clarity about whether some conditions, such as long term neurological conditions, sit in health or disability. Engagement is difficult because some neurological conditions do not have a 'home' or 'owner' as yet in the system.

As NGO's we have a longstanding commitment to our clients, delivering professional health services as part of networks of providers within our communities. We bring a wealth of knowledge, expertise, and lived experience, and our services subsidise the public health services. And yet the Alliance's members struggle with

chronic underfunding, if they are fortunate to receive any funding from the Government. Some of our members never have their work recognised through a contract, and yet fulfil essential services for their consumers not covered elsewhere in the health system.

We believe strongly that getting these changes right will have significant benefits for Aotearoa through effective, equitable service delivery and a collaborative focus on achieving the greatest impact within the resources available. We are keen to help, and we want to play an active role in the process.

We are seeking a meeting with you to start the kōrero to ensure the future outcomes in the new health system deliver for those impacted by a neurological condition, including their supporting whānau. The members of the Alliance are optimistic about the opportunities ahead and are ready to engage in this vital work. We believe that this can be best achieved together, through close collaboration between Ministers, Te Whatu Ora, Te Aka Whai Ora and the Alliance's 16 members, who represent more than 1 in 5 Kiwi's. And in taking this approach we believe this will greatly help the Ministry of Health, Te Whatu Ora, and Te Aka Whai Ora by reducing the individual contact points and having direct access to expertise in the provision of neurological health support.

We look forward to the opportunity to start this vital kōrero with you.

Ngā mihi nui,



Catherine Hall
Chair, Neurological Alliance
CEO, Alzheimers New Zealand



Rich Easton
Secretary, Neurological Alliance
CEO, Neurological Foundation of New Zealand

Copied to:

Hon Dr Ayesha Verrall, MP
Minister for Research, Science and Innovation of New Zealand, A.Verrall@ministers.govt.nz

Margie Apa,
Chief Executive Te Whatu Ora, Margie.Apa@health.govt.nz

Riana Manuel,
Chief Executive, Te Aka Whai Ora, Riana.Manuel@health.govt.nz

Diana Sarfati,
Director General of Health (NZ), Diana.Sarfati@health.govt.nz

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, along with their current representatives:

- Alzheimers New Zealand Catherine Hall
- Associated NZ Myalgic Encephalomyelitis Society Inc Fiona Charlton
- Brain Injury New Zealand Iain Watkins
- Cerebral Palsy Society Clare Williams
- Dementia New Zealand Darral Campbell
- Dyspraxia Support Group Jacqui Scott
- Epilepsy New Zealand Ross Smith
- Huntington's Disease Association New Zealand Jo Dysart
- Motor Neuron Disease New Zealand Scott Arrol
- Multiple Sclerosis New Zealand Amanda Rose
- Muscular Dystrophy Association of New Zealand Denise Ganley
- Neurological Foundation of New Zealand Rich Easton
- Parkinson's New Zealand Andrew Bell
- Rare Disorders New Zealand Michelle Arrowsmith
- Stroke Foundation of New Zealand Jo Lambert
- Tuberous Sclerosis Complex New Zealand Helen Willacy