

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

3 October 2022

Margie Apa, Chief Executive, Te Whatu Ora Riana Manuel, Chief Executive, Te Aka Whai Ora Wellington

Via email: <u>Margie.Apa@health.govt.nz</u>

Riana.Manuel@health.govt.nz

Kia ora Margie and Riana,

Neurological Disorders within the new Health System

The <u>Neurological Alliance</u> (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.

We are writing today as we see there is a significant opportunity for the Alliance to collaborate with Te Whatu Ora and Te Aka Whai Ora, to support the needs of the more than 1 in 5 Kiwis living with neurological conditions. We are very keen to ensure these needs are not overlooked as the new health system is established. There are significant risks ahead linked to current gaps in services, funding, and the significant workforce issues, in particular with neurologists, specialist nurses, and other health practitioners.

The Alliance members believe 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.

As NGOs 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 free services subsidise the public health services. And we would like to work together to ensure this becomes even more effective in the future, addressing resource and chronic funding issues.

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 korero to ensure the future outcomes in the new health sector 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 Te Whatu Ora, Te Aka Whai Ora, the Ministry of Health 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 both 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 starting this vital korero with you.

Ngā mihi nui,

Catherine Hall Chair, Neurological Alliance

CEO, Alzheimers New Zealand

Low

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

Copied to:

Diana Sarfati,
Director General of Health (NZ), <u>Diana.Sarfati@health.govt.nz</u>

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	lain 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