

Meeting with Neurological Alliance of New Zealand

Due to MO:	7 October 2025	Reference	HNZ00098723
To:	Hon Simeon Brown, Minister of Health		
From:	Mark Powell, Acting Director, Ageing Well, Planning, Funding and Outcomes		
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Proactive Release:	This title is proposed by Health NZ for proactive release		

Contact for further discussion

Name	Position	Phone	1st contact
Mark Powell	Acting Director, Ageing Well, Planning, Funding and Outcomes		x
Joe Bourne	Chief Medical Officer, Clinical, Community and Mental Health		

Attachments

Appendix 1:	Talking Points
Appendix 2:	Biographies of attendees
Appendix 3:	January 2025 Alliance letter to Minister Brown
Appendix 4:	DREP response to the Alliance
Appendix 5:	Neurological Alliance February 2024 Infographic and Summary of Priorities
Appendix 6:	Neurological Alliance BIM
Appendix 7:	19 August 2025 PNZCT Letter to Minister of Health

About the meeting

Appendices 1 and 3 - 7 have been withheld in full.

Purpose	You are meeting with the Neurological Alliance (the Alliance) to discuss their priorities and how the Alliance can support you and collaborate with the Government in providing the best outcomes for New Zealanders living with neurological conditions
Date	Thursday, 9 October 2025
Time	10:50am – 11:10am
Venue	The meeting will be held in your office
Attendees	<p>Attendees meeting in person:</p> <ul style="list-style-type: none"> • Rich Easton, Chair, Neurological Alliance and CEO Neurological Foundation • Jo Lambert, Deputy Chair, Neurological Alliance and CEO Stroke Aotearoa NZ • Chris Higgins, CEO, Rare Disorders NZ • Fiona Imlach, Co-Founder, Migraine Foundation Aotearoa NZ • Catherine Hall, Executive Director, Alzheimers NZ • Chris Tse, Board Chair, Brain Tumour Support NZ • Anne Kelly, Advocacy Lead, Neurological Alliance <p>Attendees meeting online:</p> <ul style="list-style-type: none"> • Cathy Cooney, CEO, Dementia NZ • Emma Henderson, GM, Tourette's Association of NZ • Fiona Charlton, President, Associated NZ Myalgic Encephalomyelitis Society • Andrew Bell, Chief Executive, Parkinson's NZ <p>Note, biographies are attached as Appendix 2.</p>
Health New Zealand Te Whatu Ora officials	<p>Mark Powell, Acting Director Ageing Well, Planning, Funding and Outcomes (online)</p> <p>Dr Joe Bourne, Chief Medical Officer, Clinical, Community and Mental Health (online)</p>
Media	No media are expected
Talking points	Please refer to Appendix 1 .

Background and context

The Neurological Alliance

1. The Alliance represent the estimated one in three New Zealanders who will be impacted by neurological diseases or disorders. It was established in 1999 to provide a forum for organisations representing a neurological condition to work together on matters of common interest. This builds on a similar model in Great Britain and in Australia, where their Alliances work closely with Government and the health sector.

2. The membership of the Alliance has grown over the last two decades, and represents people with various neurological conditions, including: stroke, alzheimers and other forms of dementia, epilepsy, Parkinsons, multiple sclerosis, motor neurone disease, Huntington's Disease, migraine, brain tumour and others, including a large group of rare disorders.
3. The Alliance's 20 member organisations represent neurological conditions across the life-course. This includes neurological conditions developed in-utero or at birth, during childhood and adolescence, conditions that can occur at any age and neuro-degenerative conditions commonly associated with ageing. The causes of neurological conditions are often unknown and many have no cure.
4. The Alliance also note that they provide an external advisory role to the Government and health service providers, supporting their development of strategic priorities, health policies, white papers, research programmes and funding models to address the needs of those living with neurological conditions.
5. In 2025, the Alliance wrote to Hon Matt Doocey asking to meet to discuss their priorities. The Health New Zealand I Te Whatu Ora (Health NZ) response to this is attached (see Appendix 4). Minister Costello met with the Alliance on the 27 August 2025.

This Meeting

6. The Alliance have previously written to the then Minister of Health, Hon Shane Reti and in January 2025, to you, introducing themselves and asking to meet to discuss the below four priorities (see Appendix 3), which are:
 - a) address health workforce shortages to speed up diagnosis and treatment
 - b) increase funding for pharmaceutical treatment to improve quality of life
 - c) increase funding for community-based care and support services
 - d) improve data collection on neurological conditions.
7. They provided two documents for your information:
 - a) Neurological Alliance February 2024 Infographic and Summary of Priorities (see Appendix 5)
 - b) Neurological Alliance BIM – Health – February 2024 (see Appendix 6).

Parkinsons New Zealand (PNZ)

8. PNZ met with the then Minister of Health, Hon Shane Reti, in November 2024 to discuss the service they wanted to develop. The former Minister of Health subsequently asked them to submit a Business Case (BC) for the service.
9. PNZ met with you in April 2025, and presented the BC, which requested \$1,000,000 per annum to develop a new service. The BC proposed expanding the PNZ capacity and introducing a new model of care; 'ParkinsonNet'.
10. Health NZ has advised PNZ that it does not have funding available for the initiative and provided preliminary feedback on its content. Health NZ offered to meet to discuss exploring how PNZ can continue evolving its service model to better meet the needs of people living with Parkinsons, strengthen sustainability, and align more closely with the Health NZ primary and community care system.

PNZ wrote to you (Appendix 7), requesting that you advocate for a review of the decision. A response to this letter was prepared advising PNZ that Health NZ officials would be in touch to meet with them.

Health Committee inquiry into aged care

12. The Health Committee is undertaking an inquiry into the provision of aged care, focused on the aged care sector's current and future capacity to provide support services for people experiencing neurological cognitive disorders. This was a commitment as part of the Government's coalition agreement. The Committee's inquiry is ongoing.

Matters for discussion

13. The Alliance note that some conditions such as stroke and Alzheimers have known modifiable risk factors, lending themselves to preventive strategies. However, modifiable risk factors are unknown for most conditions. In their absence, the Alliance urge the Government to focus on improving early diagnosis and optimising treatment and rehabilitation.

14. The Alliance have asked to discuss their four priorities. These, and Health NZ's position on them are as follows.

Address health workforce shortages to speed up diagnosis and treatment

15. Just as with all other developed countries' health systems, there will always be services where we need more workforce and more capacity. Health systems around the world are facing pressure on health workforce – people in the developed world are aging, and demand for health workers is rising. In spite of that, New Zealand's health workforce has kept growing year-on-year. Health NZ is continually recruiting to fill these roles, and to tackle gaps, and we are implementing our workforce plan.

16. The Health Workforce Plan is a national plan. It's about getting the capacity we need across New Zealand and is focused on national growth. It is focused on a series of priorities as laid out in the NZ Health Plan, in particular delivering on the national health targets and mental health and addiction targets. Areas that aren't specifically focussed on in the workforce plan will benefit from the increase in the training pool and boosts in overall numbers.

Increase funding for pharmaceutical treatment to improve quality of life

17. Budget 25 significantly increased the allocation for pharmaceutical research and development by \$604 million. The enhanced funding is to support developing new and more effective treatments with a focus on improving the quality of life for patients with chronic and severe conditions through:

- a) investment in innovative technologies and methodologies for drug development, and
- b) collaboration with international pharmaceutical companies to leverage global expertise.

18. Expected outcomes include better patient care, reduced healthcare costs, and improved overall health metrics.

Increase funding for community-based care and support services

19. Health NZ is committed to making primary care more accessible and responsive to the unique needs of communities. This will directly help all people, including those with neurological conditions, to get timely, quality community-based care and support when and where they need it.
20. The Government's commitment has resulted in significantly increased investment in primary care. For example:
 - The Minister of Health recently announced a \$285 million uplift in funding for general practice over three years, on top of the capitation uplift general practice receives annually.
 - In March, the Minister announced a further \$95 million for a performance-based uplift for general practice per annum. This is also in addition to the annual capitation uplift.
 - Health NZ has agreed a 13.89% GP funding uplift through the Primary Health Organisation Services Agreement (PHOSA).
 - The government has also announced that capitation, the funding method for GPs, will be updated for the first time in more than 20 years. This will take effect from 1 July 2026.
 - Investment has also been made in a new 24/7 digital healthcare service that will give people more choice by accessing video consultations with GPs and nurse practitioners.
 - The Government has also announced a \$164 million dollar investment to expand and strengthen urgent and after-hours healthcare across the country.
21. The Aged Care Funding and Service Model Review is a significant part of Health NZ's response to challenges across the Aged Care Sector and for those with neurological conditions associated with ageing such as dementia.

Improving data collection for neurological conditions

22. Health NZ work is in the initial planning stages for a stocktake of clinical registers, many of which are hosted and funded outside Health NZ. These often have their own purpose and data collection processes which will vary for each register.
23. As this work is currently in the planning/approval stage, a start date is yet to be confirmed.
24. While Health NZ does have diagnosis information on admitted patients, that data currently does not provide a reliable indication of prevalence of neurological conditions because not all people with dementia, Parkinsons, epilepsy, etc are admitted to a public hospital. However, because all – or almost all – patients who survive a stroke will be admitted to hospital, we are able to report the incidence of stroke with a high degree of confidence.
25. We expect in the future it will become possible for Health NZ to create clinical registers through our growing national health data platform, providing conditions can be identified via routinely collected information, such as tests, images and encounters.

Appendix 2: Biographies of attendees

In person



Rich Easton is Chair of the Neurological Alliance and the CEO of the Neurological Foundation of NZ since 2017. Richard has over 30 years of experience in telecommunications and corporate leadership, having worked with British Telecom, Spark, and IAG. He transitioned into the charity sector through governance roles with organizations such as Volunteering Auckland and Make-A-Wish Foundation.



Jo Lambert is the CEO of the Stroke Aotearoa, bringing her leadership experience from both the non-profit and private sectors, including Barnardos and consulting firm Marven. She joined the organisation's board in 2018 and her commitment to stroke advocacy is shaped by personal family experience. Jo holds a Bachelor of Arts degree in Business Studies (Hons), majoring in marketing and market research and has lived in New Zealand in 1995.



Chris Higgins is CEO of Rare Disorders NZ. He began his career as a health services researcher and his background since then includes senior management roles with various district health boards, and leadership roles in community, not for profit and advocacy organisations. The latter include Presbyterian Support (Northern), Spectrum Care, Brain Injury Auckland, Muscular Dystrophy NZ and New Zealanders for Health Research. Chris has also served as a RDNZ Trustee. He has a Masters degree in politics and a post graduate diploma in health services management.



Fiona Imlach is the Co-founder of Migrane Foundation Aotearoa NZ. Fiona is a public health physician with a PhD in epidemiology. She completed her medical degree at Auckland University and worked for several years as a hospital doctor and general practitioner before training in public health. She has worked as a researcher in various settings and on a range of topics, including primary health care, inequalities, child poverty, mental well-being, alcohol and cancer.



Catherine Hall is the CEO of Alzheimers New Zealand, an organisation dedicated to supporting individuals living with dementia and their families. Her work focuses on raising awareness and improving dementia care across New Zealand.



Chris TSO is the Board Chair for Brain Tumour Support NZ since 2021. Founding Trustee of the charity, Chris is a Senior Advisor to the International Brain Tumour Alliance (IBTA), a Patient Expert in CNS Tumours for the European Medicines Agency (EMA) and the European Organisation for Research and Treatment of Cancer (EORTC), a member of the Co-operative Trials Group for Neuro-Oncology (COGNO, Australia), and a member of the executive committee of the NZ Aotearoa Neuro-Oncology Society (NANOS).



Anne Kelly is the Advocacy Lead for the Neurological Alliances since 2023. Anne previously held a similar role with the Stroke Foundation of New Zealand. Anne holds a Master's degree in Philosophy and has substantial policy experience, having worked with the Porirua City Council and served as an NGO Policy Navigator at FreeForAll.

Online



Cathy Cooney is the Chief Executive of Dementia NZ and is passionate about the equitable provision of accessible services and information that support people to have a sense of purpose, to be socially connected and to live their best possible lives. Cathy is a Registered Nurse with a background in governance, health sector and nursing leadership, and public health. In 2021 Cathy received an MNZM Award for services to health and community.



Emma Henderson is the General Manager of Tourette's Association of NZ. Emma started on the board of TANZ, and was appointed General Manager in 2023. As the General Manager of TANZ Emma has a focus on awareness and advocacy and uses her experience in running associations to strengthen the TS relationships and community within NZ and internationally. Emma comes from a management background that spans roles within many industries, from Technology through to Retail and Hospitality and running Associations.



Fiona Charlton is the President of ANZMES (Associated New Zealand Myalgic Encephalomyelitis Society) and is dedicated to advocacy, education, and support for people living with chronic and complex health conditions. Fiona holds a BSc in Psychology, a BA in Education, and a Postgraduate Certificate in Health Science (Nutrition). Fiona is currently studying Science Communication at the University of Otago.



Andrew Bell is the Chief Executive for Parkinson's NZ. The early part of his career was as a church minister where he honed his skills in community development both internationally and locally. During this time, Andrew developed his skills further by completing a Master's degree at the University of Otago. In the years since, he has gained qualifications from a number of international universities and been Executive Director of The Fred Hollows Foundation.