



*Count us in*

## The Neurological Alliance Australia seeks commitments for the 2025 Federal Election

The Neurological Alliance (NAA) seeks commitments from parties and candidates for the upcoming Federal Election to address the urgent unmet needs of adults and children living with neurological or neuromuscular conditions or disorders in Australia.

We want you to *count us in*



## **Make your commitment to addressing the urgent, unmet needs of the neurological community!**

**Neurological and neuromuscular conditions and disorders have a devastating impact on those diagnosed, their families, friends and loved ones.**

The World Health Organisation recently reported that globally over 1 in 3 people are affected by neurological conditions<sup>1</sup>. Neurological and neuromuscular conditions and disorders collectively represent the most significant global burden of disease, surpassing all other health conditions in terms of Disability-Adjusted Life Years (DALYs) and Years of Life Lost (YLLs). In 2021, an estimated 3.4 billion individuals—43.1% of the global population—were affected<sup>2</sup>.

In Australia, neurological conditions are one of the five leading disease groups causing burden. They account for approximately 8.3% of the total burden of disease and almost 456,000 lost years of 'healthy' life due to illness, disability, or premature death (DALYs)<sup>3</sup>.

**Neurological conditions are on the rise in Australia and worldwide, yet despite being recognised as one of the nation's top disease burdens, neurological conditions remain under-recognised and underfunded.**

These conditions are incurable, many are progressive and degenerative, resulting in significant disability, and very few have effective disease modifying treatments available.

The Neurological Alliance Australia (NAA) is a coalition of 35 not-for-profit peak or national patient organisations representing adults and children living with neurological or neuromuscular conditions or disorders in Australia, formed to pursue pressing areas of need including an increased investment in neurological research.

**We represent approximately 1 in 4<sup>4</sup> Australians living with diverse neurological or neuromuscular conditions or disorders.**

Collectively, their annual economic cost exceeds \$100 billion<sup>5</sup>, including through National Disability Insurance Scheme support.

**Our vision—a world where these conditions and disorders are preventable, detectable, manageable, and curable—is within reach. But to get there, we urgently need your willingness to address the urgent unmet needs of those living with these conditions.**

## **We are seeking your commitments to:**

- 1. Invest \$300 million to establish a Neurological Mission within the Medical Research Future Fund to provide a focus for effective and efficient neurological research and innovation.**

We need a Mission, or risk healthcare and disability support crises including rising costs, overwhelmed health systems, and growing inequities.

- 2. Strengthen the NDIS by addressing barriers to access, improving education and training of NDIA staff about neurological conditions and progressing the work of the Neurological, Palliative Care and Rare Conditions Working Group.**

The conditions we represent are generally poorly understood by the NDIA; this affects access, and the quality of assessment and care received.

- 3. Ensure harmonised and unified national Assistive Technology access is established to meet the needs of people with disability who do not qualify for the NDIS.**

Australians living with disability should have equal access to the life-changing assistive technology they need, regardless of their age, location or gender.

- 4. Address neurological conditions data gaps by progressing the work of the Australian Institute of Health & Welfare's Neuro Conditions Expert Advisory Group.**

Most NAA members experience considerable data gaps. This data is a key foundation for building a platform for planning and prioritising health policies and evaluating intervention programs and initiatives. The AIHW's Neuro Conditions Expert Advisory Group has commenced initial scoping for a neurological conditions data set; we need this work to progress so that a comprehensive data set is established and regularly updated.

- 5. End age discrimination for NDIS eligibility by reference to the person's disability, regardless of age.**

Access to, and funding for, the NDIS and the Aged Care systems are not equitable. NDIS eligibility should be assessed solely by reference to the person's disability, regardless of age. We want an end to age discrimination related to funding to support people with disability over the age of 65 years.

- 6. Improve Aged Care, Health and Disability sector integration by urgently improving the interface between these sectors to improve care.**

Current gaps in services must be identified and addressed, referral services must operate effectively and movement of people between these sectors must be person-centred, equitable and safe.

## **Members of the Neurological Alliance Australia:**

- Angelina CASK Neurological Research Foundation (ACNRF)
- Brain Foundation
- Brain Injury Australia
- Childhood Dementia Initiative
- Dementia Australia
- Dystonia Network of Australia Inc.
- Emerge Australia (ME/CFS)
- Epilepsy Action Australia
- Epilepsy Australia
- Epilepsy Foundation
- FAST Australia (Angelman Syndrome)
- Fight Parkinson's
- FND Hope
- Fragile X Association of Australia Inc
- Huntington's Australia
- Leukodystrophy Australia
- Meningitis Centre Australia
- Migraine Australia
- Mito Foundation
- MJD Foundation
- Motor Neurone Disease Australia
- Multiple Sclerosis Australia
- Muscular Dystrophy Australia
- Muscular Dystrophy Association of WA
- Muscular Dystrophy Foundation Australia (MDFA)
- Myasthenia Alliance Australia (Myasthenia Gravis)
- Neurological Council of WA
- Parkinson's Australia
- Polio Australia
- Post Polio Vic
- SCN2A Australia (rare genetic seizure disorder)
- Spinal Muscular Atrophy Australia
- Stroke Foundation
- The Australian Young Onset Dementia Special Interest Group
- Young People in Nursing Homes National Alliance



## References

1 <https://www.who.int/news/item/14-03-2024-over-1-in-3-people-affected-by-neurological-conditions--the-leading-cause-of-illness-and-disability-worldwide> .

2 GBD 2021 Nervous System Disorders Collaborators (2024). Global, regional, and national burden of disorders affecting the nervous system, 1990–2021: a systematic analysis for the Global Burden of Disease Study 2021. *The Lancet Neurology* 23(4) 344–381. DOI:[https://doi.org/10.1016/S1474-4422\(24\)00038-3](https://doi.org/10.1016/S1474-4422(24)00038-3)

3 <https://www.aihw.gov.au/reports/burden-of-disease/australian-burden-of-disease-study-2023/contents/interactive-data-on-disease-burden/burden-of-disease-in-australia> .

4 Based on an aggregation of data from organisations who have commissioned prevalence studies.

5 Based on an aggregation of data from organisations who have commissioned economic impact studies.