

Count Us In: National Summit to demand action for millions of 'forgotten' Australians living with neurological conditions

Tuesday 25 June 2024: 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.

A National Summit in Canberra hopes to change that today, with calls for the establishment of a Taskforce for Neurological Conditions, to urgently address the needs of millions of forgotten Australians.

A recent [study](#) released by The Lancet Neurology revealed that there are now more than three billion (1 in 3) people worldwide living with a neurological condition, making them the leading cause of ill health and disability in the world.

The Australian Institute of Health and Welfare (AIHW) has [identified neurological conditions as one of the nation's top five disease burdens](#), with an estimated annual impact of more than \$100 billion on the Australian economy.

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

Chair of the Neurological Alliance Australia (NAA) and MS Australia Chief Executive, Rohan Greenland says neurological conditions are not adequately addressed as a group of diseases, as is the case for other disease groups such as cancer or cardiovascular disease. Alarming neurological conditions are on the rise in Australia and worldwide.

"Without effective strategies in place to mitigate their impact, they are a ticking time bomb on our health system and economy," Mr Greenland said.

The NAA's National Summit on Neurological Conditions at Parliament House, Canberra, plans to address that neglect and will bring together key decision-makers, representatives from political parties and, most importantly, people with the lived experience of neurological conditions.

NAA Deputy Chair and Emerge Australia CEO, Anne Wilson says a Government Taskforce could address the unique challenges faced by people living with these conditions, set priorities and advance investment in research, facilitate timely diagnosis and enhance access to treatments, support and services to mitigate disease progression and future healthcare and disability care costs.

"Every Australian knows someone living with a neurological condition, and witnesses the lifelong impact on that person, together with their family, friends and carers.

"What we urgently need today is for all the major Parties to acknowledge the impact of neurological conditions and work with the Neurological Alliance Australia to give hope and certainty to Australia's neurological community," Ms Wilson said.

Launching at the summit is the *Count Us In* campaign, which aims to drive meaningful change by raising awareness, advocating for policy reforms, and empowering people affected by neurological conditions.

Comedian, screenwriter and advocate Tim Ferguson lives with multiple sclerosis and has lent his support and involvement to the *Count Us In* campaign video.

"There are millions of people, millions living in Australia with neurological conditions. We need more thought, more organisation and more energy put into this particular sector of people.

"We have to get all of our politicians, all of our decision-makers, to start talking about neurological conditions as if they are the next wave of disability advancement," Mr Ferguson said.

The *Count Us In* campaign video highlights six pressing areas of need to be comprehensively progressed by a Taskforce for Neurological Conditions.

1. Greater investment in medical research
2. A stronger NDIS (National Disability Insurance Scheme)
3. Equal access to assistive technology
4. Establishment of a national neurological dataset
5. An end to NDIS age discrimination
6. Improved Aged Care, Health and Disability sector integration

Mr Greenland acknowledged the progress made in recent months with the establishment of an NDIA (National Disability Insurance Agency) Neurodegenerative Disorders and Palliative Care Working Group, which has significant representation from the NAA.

"This announcement is an important first step, with the promise our community will receive a better understanding of their conditions from within the NDIA but much urgent work remains to be done," Mr Greenland said.

Ms Wilson echoed that sentiment while also highlighting the need for a national neurological data set to better provide support for people with neurological conditions together with dedicated neurological research funding.

"We know there are world-leading researchers working hard to discover better treatments and, ultimately, cures for the range of neurological conditions.

"But progress cannot be made without significant investment, which is why we are calling for a Neurological Mission within the Australian Government's Medical Research Future Fund," Ms Wilson said.

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About the NAA

The [Neurological Alliance Australia \(NAA\)](#) was established in 2010 to give a strong, collective voice to promote and advocate for improved quality of life for people living with these conditions and increased funding to support research. Since that time, the NAA has grown to include 27 not-for-profit peak or national patient organisations representing millions of adults and children living with progressive neurological or neuromuscular conditions or neurological disorders in Australia, their families and carers.