



Spinal Muscular Atrophy
AUSTRALIA INC.

Neurological Alliance Australia

Seeks
commitments
for the
2022
Federal
Election

These are the important ways
our politicians can help us...

Neurological Alliance Australia*

BRAIN INJURY AUSTRALIA

DEMENTIA AUSTRALIA

EMERGE AUSTRALIA

HUNTINGTON'S AUSTRALIA

LEUKODYSTROPHY AUSTRALIA

MJD FOUNDATION

MOTOR NEURONE DISEASE AUSTRALIA

MS AUSTRALIA

MUSCULAR DYSTROPHY AUSTRALIA

MUSCULAR DYSTROPHY FOUNDATION AUSTRALIA

PARKINSON'S AUSTRALIA

POLIO AUSTRALIA

SPINAL MUSCULAR ATROPHY AUSTRALIA

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 progressive neurological or neuromuscular diseases in Australia.

What do we need?

People with progressive neurological or neuromuscular diseases have two basic needs:

1. A cure – through an increased investment in research
2. Improved support for their treatment, care and management to help them live better for longer

How many are affected?

The members of the NAA have estimated the number of people diagnosed with the conditions represented by the Alliance and also the annual cost to the Australian economy through economic impact studies.

Overall, it is estimated that nearly 1.6 million Australians live with a progressive neurological or neuromuscular disease in Australia with an annual cost to the Australian economy of over \$36 billion.

We understand that around 15% of NDIS Participants have a progressive neurological or neuromuscular condition.

Every Australian knows or has a loved one with one of these debilitating diseases.

*The Neurological Alliance Australia is an alliance of not-for-profit peak organisations representing adults and children living with progressive neurological or neuromuscular diseases in Australia. The Alliance was established to promote improved quality of life for people living with these conditions and increased funding to support research. Members of the Alliance are: Dementia Australia, Brain Injury Australia, Emerge Australia, Huntington's Australia, Motor Neurone Disease (MND) Australia, MJD Foundation, MS Australia, Muscular Dystrophy Australia, Muscular Dystrophy Foundation Australia, Parkinson's Australia, Spinal Muscular Atrophy Australia, Leukodystrophy Australia and Polio Australia.

What are the issues and what needs to be done?

1. Invest in funding for medical research

Issue:

The NAA represents people affected by a group of progressive, degenerative neurological and neuromuscular diseases which are lifelong and for which cures are yet to be found.

Research scientists are working hard to find discoveries about the treatment and management of these diseases, yet significant additional research investment is needed to progress this work and give hope to the more than 1.6 million people affected in Australia together with their families, friends and carers.

What needs to be done?

- A significant additional investment in medical research to treat, prevent and ultimately to cure these diseases.
- A focus on Australia to become the world leader in neurological and neuromuscular research into these diseases and translate research into better health care outcomes.
- Fast-track access to effective new drugs and novel medical technologies and in doing so implement the [New Frontier – Delivering better health for all Australians](#) report recommendations.

2. End age discrimination for NDIS eligibility

Issue:

In 2013, the Federal Government amended the Age Discrimination Act allowing the NDIS to legally exclude people over the age of 65 from the NDIS.

More than [4.4 million Australians – one in five – live with a disability. Almost half \(44.5%\) are over the age of 65.](#)

Access to, and funding for, the NDIS and the Aged Care systems are not equitable.

We need to end age discrimination related to funding to support people with disability over the age of 65 years. NDIS eligibility should be assessed solely by reference to the person's disability, regardless of age.

What needs to be done?

- [Implement recommendation 72 of the Report of the Royal Commission into Aged Care Quality and Safety](#) regarding equity for people with disability receiving aged care
- Amend relevant legislation (Age Discrimination Act, NDIS Act) to remove this inequity.
- [Implement recommendations 35 and 36 of the Report of the Royal Commission into Aged Care Quality and Safety](#) to ensure entitlement to care at home is appropriate to each person's needs.

What are the issues and what needs to be done?

3. Strengthen the NDIS

Issue:

The communities served by the NAA are increasingly alarmed by cuts to NDIS packages, media reports that the NDIS is not sustainable, the increase in cases, complaints and disputes being taken to the Administrative Appeals Tribunal and a lack of integration between the aged care, health care and disability care systems.

What needs to be done?

- Provide full and ongoing funding of the NDIS and amend legislation to formalise this undertaking
- Ensure the NDIS is not weakened ([as per proposed legislative changes](#)) and maintain its person-centred focus so that participant choice and control continues if not improved
- Ensure decision-making processes are clear and transparent
- Ensure people have their needs met, regardless of which system they access
- Modify the NDIS Act to incorporate the needs of people with progressive neurological disease (who are less employable, less able to engage with community, and less independent)

4. Ensure equal access to assistive technology

Issue:

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

What needs to be done?

- [Establish a national assistive technology program](#) to meet the needs of people with disability who cannot access the NDIS.

For more information on these 2022 Federal Election Commitments and the work of the Neurological Alliance Australia:

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