NEUROLOGICAL ALLIANCE AUSTRALIA

PATHWAYS TO PROGRESS

A Research Mission for Neurological and Neuromuscular Health

Executive summary

- A Neurological & Neuromuscular Health Research Mission of $300 million over ten years within the MRFF will revolutionise the prevention, detection, treatment, and care of neurological and neuromuscular conditions, enhancing individual health and strengthening our health system.
- One in four Australians live with neurological or neuro-muscular conditions, or neurological disorders.
- The associated annual economic cost to the Australian economy exceeds $100 billion (see Appendix 1).
- The World Health Organisation (WHO) recently reported that globally over 1 in 3 people are affected by neurological conditions.
- Neurological and neuromuscular 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 Australia, neurological conditions are one of the five leading disease groups causing burden.
- *WHO* Intersectoral global action plan on epilepsy and other neurological disorders calls for actions to advance research that improves prevention, diagnosis, treatment and care.
- Given the scale of the burden and economic impact, neurological and neuro-muscular conditions collectively have been underfunded.

Introduction

Conditions like stroke, epilepsy, Parkinson's disease, motor neurone disease, multiple sclerosis, ME/CFS and many others that affect neurological and neuromuscular health have a devasting impact. Almost 25 percent of Australians suffer from these conditions. Collectively, their annual economic cost to the Australian economy exceeds $100 billion[1], including through National Disability Insurance Scheme support.

Our vision—a world where these conditions are preventable, detectable, manageable, and curable—is within reach. But to get there, we urgently need more research investment. A dedicated research Mission is essential to fund and coordinate the innovations that will make this vision a reality.

Without a dedicated Mission the risk is a deepening crisis in our already stretched healthcare and disability support sectors, including rising costs, overwhelmed health systems, and growing inequities. The urgency cannot be overstated: failing to act today will have profound consequences for individuals, families and the entire healthcare and disability systems for generations to come. The time to act is now.

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 several common interests including an increased investment in neurological research. We represent approximately 1 in 4[2] Australians living with diverse neurological or neuromuscular conditions (see Appendix 1).

The Unmet Need

The WHO recently reported that globally over 1 in 3 people are affected by neurological conditions[3]. Neurological and neuromuscular 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 percent of the global population—were affected[4].

In Australia, neurological conditions are one of the five leading disease groups causing burden. They account for approximately 8.3 percent of the total burden of disease and almost 456,000 lost years of 'healthy' life due to illness, disability, or premature death (DALYs)[5].

A lack of reliable, up-to-date data highlights the critical need for better data collection and reporting. Gathering this data to inform better decisions and practice is at the centre of our joint call for increased research investment. Almost a quarter of Australians live with a neurological or neuromuscular condition and their voices matter.

We are calling for the establishment of a strategic, focused research model to address the profound impact of neurological conditions, both on individuals and the Australian health system.

Friends, families and colleagues living with these conditions deserve more. They deserve a bold 'moonshot' – a Mission targeting and coordinating efforts towards cures and investment to integrate evidence-based care into our health and disability systems.

Transformative impacts

A Neurological and Neuromuscular Health Research Mission will revolutionise the prevention, detection, treatment, and care of neurological and neuromuscular conditions, enhancing individual health and fortifying our health system.

Just as Missions in cancer and cardiovascular research have delivered life-saving treatments and groundbreaking therapies, this Mission will revolutionise neurological and neuromuscular health. It will impact nearly 25 percent of Australians whose voices have long been unheard, plus the voices of their families, carers and friends. By uniting and building on separate research investments in

neurological conditions, this Mission will coordinate action and accelerate progress in neurological and neuromuscular health and add value to research occurring across other diseases.

Our vision is driven by the conviction that there is a better way—that together we are stronger; that better-focused efforts and shared insights across diverse diseases will deliver the breakthroughs we need.

The long-term impacts of a Neurological and Neuromuscular Health Research Mission are clear—reduced health and disability system costs, improved quality of life for those with lived experience and a healthier, more resilient population.

A Bold and Comprehensive Mission

Neurological and neuromuscular conditions affect many Australians and account for a very significant portion of the nation's disease burden. The National Health and Medical Research Council (NHMRC) has invested just under $200 million[6] per year in neurological disorders research over the past decade and the MRFF has also made important contributions to research. While critical, this funding falls well short given the scale of the challenge. **Further investment is urgently needed** to achieve the outcomes that are crucial for improving detection, diagnosis, treatment and care, and for reducing health system costs and inequities.

Including rare neurological and neuromuscular diseases in this Mission drives impact by enabling cross-condition approaches that ensure underfunded areas receive the attention they deserve. Rare diseases can serve as models for better understanding more common conditions, demonstrating how a multi-condition strategy can drive greater innovation and impact.

Previous Missions in Genomics, Dementia, Brain Cancer, Traumatic Brain Injuries, Stem Cell Therapies and others are important. However, reviews of key Missions[7,8] call for improved coordination, translation efforts, and collaboration to maximise impact.

Disease-based approaches have yet to deliver on their potential. It's time for a paradigm shift—one that fosters coordinated efforts across neurological, neuromuscular, and other diseases, leveraging existing investments for greater impact. Current efforts for neurological disorders are scattered across 25 uncoordinated[9] activities comprising diverse disease categories, research strategies and government programs. And unlike other areas of health, the Government has no clear mechanism[10] to drive coordination in neurological and neuromuscular health.

Our Mission will provide this opportunity. It will unite and spearhead efforts across previously siloed initiatives, energising collaboration and data sharing for real, lasting change. Building on the foundations of other MRFF-funded Missions and important neurological disease research investments, this new approach will break free from narrow disease-specific investments like those for Parkinson's, Dementia, and Stroke. It's time to turbocharge coordination between experts and industry, embed critical infrastructure, and build the capacity needed to take on these conditions now and into the future. Through enhanced coordination and collaboration, **this** Mission will make a tangible, enduring impact—accelerating breakthroughs and changing lives.

Strategic Context

The time is right for a Neurological and Neuromuscular Health Research Mission. It will address the historical underfunding of key conditions and support delivery of the Australian Research Council's recently released National Research Priorities. It will 'support healthy and thriving communities' by advancing innovative diagnostic and therapeutic solutions, fostering precision medicine, and ensuring culturally appropriate care. By contributing to the development of an inclusive, preventive Australian health system, it will also provide crucial evidence to manage the growing demands on the NDIS. This Mission aligns with key government policies and priorities on addressing healthcare costs, Medicare and NDIS reforms, and the recent Health Technology Assessment review. It will build on these policies and leverage the principles of the *WHO Intersectoral global action plan on epilepsy and other neurological disorders*[11] to advance research that improves prevention, diagnosis, treatment and care.

Through research, this Mission will provide equitable access and support, opportunities, and autonomy for individuals with lived experience, while reducing stigma, impact, and burden. By improving quality of life and enhancing support for families and caregivers, it will contribute to a more sustainable, cost-efficient healthcare system –ensuring that it continues to deliver impacts beyond short-term funding cycles and into the future.

Almost 25 percent of Australians want this. All Australians need it. The time for a Neurological & Neuromuscular Health Research Mission is now.

This Mission will be a cornerstone of Australia's first whole-of-government national health and medical research strategy. It sets a new standard for best practice in the joint administration of NHMRC and MRFF investments. As a flagship initiative, it will drive the integration of medical research efforts across the nation, marking a transformative step in coordinated national healthcare strategy.

Research Strategy

Research funding through the Mission is essential, but it's not the end goal—it's the engine driving our vision to transform neurological and neuromuscular health.

With a strategic focus on enhancing prevention, advancing early detection, innovating treatment, and elevating care, the Mission will be structured around four interlinked, outcomes-driven Pillars: Prevent, Detect, Treat, and Care. Pillars will leverage the powers of basic discovery research, clinical and medical approaches, population health, and health promotion research, to achieve its objectives.

This Mission follows a traditional research framework but stands apart by building off other Missions and integrating powerful enablers like genomics and AI to drive achievements under each Pillar. By harnessing these technologies, building First Nations capacity and involvement, ensuring ethical conduct and robust governance, and maximising co-design opportunities to enrich research impact by collaborating with those with lived experience, this Mission will revolutionise healthcare.

Pillar 1: Prevent

Objective: Reduce the incidence of neurological and neuromuscular conditions through targeted prevention strategies.

- Use emerging technologies and data analytics to identify and manage risk factors and implement preventive interventions.
- Develop and promote evidence-based public health campaigns.
- Identify at-risk communities and collaborate with them to co-design and deliver educational prevention programs.
- Build an evidence base to inform policies on preventive health measures and lifestyle interventions.
- Integrate both primary (addressing risk factors early) and secondary prevention (screening and early intervention to prevent progression) in research protocols.
- Ensure 'brain health' is central to prevention efforts, and frames overall health.

Pillar 2: Detect

Objective: Identify and diagnose neurological and neuromuscular disorders at the earliest possible stage.

- Integrate advancements in key technologies, including imaging, to refine diagnostic techniques.
- Validate biomarkers for early detection.
- Enhance screening programs through partnerships with healthcare providers and industry, employing best-practice consumer involvement in their design and implementation.
- Train researchers from diverse backgrounds in diagnostic innovation.

GENE THERAPY: PIONEERING CURES FOR NEUROLOGICAL AND NEUROMUSCULAR DISORDERS

Spinal Muscular Atrophy (SMA): Breakthrough gene therapy, Zolgensma, has transformed the treatment of SMA, a leading genetic cause of infant death. Early intervention has shown life-saving potential, improving motor function and survival rates.

Why It Matters

- » Gene therapies are reshaping the future for individuals with previously untreatable neurological and neuromuscular disorders.
- » These therapies offer life-changing outcomes—longer lives, improved mobility, and enhanced quality of life for those affected.
- » Continued research and investment in gene therapies pave the way for broader applications, unlocking the potential to cure or dramatically improve many more neurological conditions.

Call to Action

Further research, through a Neurological & Neuromuscular Health Research Mission means saving lives, transforming futures and driving down health system costs.

Pillar 3: Treat

Objective: Innovate and refine therapeutic approaches to treat neurological and neuromuscular conditions.

- Integrate advanced therapeutic platforms like gene therapies and neuroprotective agents.
- Foster partnerships for drug discovery and personalised medicine.
- Build capacity in genomics, personalised medicine, and therapeutic development.
- Explore and apply precision medicine approaches.
- Test cutting-edge treatments and novel interventions.

Pillar 4: Care

Objectives: Through research:

- enhance the quality of life for individuals with neurological and neuromuscular conditions to inform care models.
- drive development of evidence-based care by learning from international best practice[12].

PATIENT MANAGEMENT AND SUPPORT

» Develop evidence-based, holistic care models encompassing medical treatment, rehabilitation, and psychosocial support.

» Explore barriers to best-practice management and care of individuals with lived experience.

SUPPORTING CAREGIVERS:

» Ensure research strengthens health literacy and underpins development and communication of best practices to enhance caregivers capacity to support patients.

» Test programs focused on improving the physical and mental well-being of both patients and caregivers.

Research Enablers

Programs of research under each Pillar will be supported by the six Enablers outlined below.

Advanced Technology, Data, and Infrastructure

- Invest in cutting-edge technologies and capabilities such as genomics and AI.
- Support enabling infrastructure including biobanks, data repositories, and clinical trials.
- Expand high-speed data networks, cloud computing, and AI capabilities and leverage national research data infrastructure capabilities.
- Promote open access to research outputs with robust and ethical data management standards.

Collaborative Partnerships

- Foster partnerships across academic, clinical, industry, community, and consumer sectors, both locally and globally.
- Facilitate and harness large-scale international and industry collaborations given their critical importance to advancing neurological research.
- Build strong international and industry ties to leverage expertise and translate research into clinical applications and policy outcomes.
- Partner with other research Missions, enabling neurological and neuromuscular research to leverage existing investments, enhance efficiency drive innovation.
- Emphasise the importance of partnerships, including with First Nations Australians and local communities, in driving economic benefits and fostering innovative solutions.

Diverse and Inclusive People & Communities

- Integrate First Nations peoples and knowledge systems into research by employing co-design principles, ensuring inclusion and respect.
- Create environments that foster talent, value diverse perspectives, and promote equitable and inclusive research environments and research outcomes.
- Uphold high ethical standards and actively promote diversity within research teams,
- Ensure lived experience is integrated through all research activities to generate patient-centred outcomes relevant to real-world needs.

Public Engagement and Communication

- Enhance public understanding through outreach, public lectures, and both social and mainstream media.
- Develop a clear strategy for co-design and engagement with people with lived experience, ensuring their voices shape research outcomes.
- Strengthen health literacy to improve understanding of neurological and neuromuscular conditions and their treatments and improve health equity.

Harmonised Efficiency

- Harmonise research processes and infrastructure across diverse conditions, and leverage advances from other Missions, fostering coordinated efforts to maximise impact.
- Promote economic efficiencies through collaboration and shared resources across research programs.
- Balance the drive for efficiency with the unique needs of each disease, providing and enabling specialised approaches, where necessary.

Robust Governance

- Ensure clear, accountable, and transparent processes in strategic planning and coordination.
- Promote effective research management and financial oversight, and drive highest-standard research ethics and integrity.
- Establish strong leadership with well-defined roles.
- Establish evidence-based key performance indicators to measure improvements in patient outcomes, enhanced health system efficiency and economic gains.

Pathways to Progress: A Research Mission for Neurological & Neuromuscular Health

Research within each Pillar is supported by six Enablers, interwoven throughout all research objectives and methodologies. A table illustrating how Enablers will support research under each Pillar is at Appendix 2.

Benefits and Legacy

The Mission's strength lies in leveraging existing investments and adopting a disease-agnostic approach to kick-start progress across all four pillars. For the first time, many rare and underfunded neurological conditions will receive dedicated research investment, enabling transformative advances in their diagnosis and treatment.

We'll measure success through tangible improvements in patient outcomes, enhanced health system efficiency, and significant economic gains. Our legacy will be a robust and coordinated national medical research capability and sustainable infrastructure, to drive ongoing breakthroughs in neurological and neuromuscular health.

This Mission will create strengthened enablers that transform the landscape of neurological and neuromuscular research while catalysing advancements in other diseases.

Funding

To tackle the complexity and scale of the research challenges across so many conditions, this Mission calls for a $300 million investment over ten years. While acknowledging the crucial investments already made in key diseases, this Mission goes further — targeting the historical underfunding of numerous neurological and neuromuscular conditions, which collectively impose a heavy disease burden in Australia.

By including rare diseases within a disease-agnostic framework, the Mission can drive breakthroughs that extend beyond neurological health. This investment will strategically build off existing Missions for maximum impact. The funding will enable substantial health, economic, and knowledge advancements, leading to improved patient outcomes and a stronger health system.

Appendix 1

Neurological Alliance Australia (NAA) membership and key condition statistics.

Organisation/disease	Number of people diagnosed	Cost to Australian economy per year ($ billion)	Disability Adjusted Life Years (DALYs)
Angelina CASK	277		
Brain Injury	338,700	10.50	
Cerebral palsy*	34,000		7,492
Childhood Dementia	2,273	0.39	
Dementia Australia	421,000	14.25	247,714
Dystonia	8,000		
Emerge Australia (ME/CFS)	250,000	14.58	
Epilepsy	252,000	12.30	45,346
FND Hope (functional neuro disorder)	2,000		
Fragile X Australia	7,000	0.18	
Freidereich's ataxia*	879		
Huntington's Australia	2,160		
Leukodystrophy Australia	2,000		
Migraine	4,900,000	35.70	48,305
Mito Foundation	4,500	1.09	
MJD Foundation	550		
MND Australia (motor neurone disease)	2,000	2.37	16,750
MS Australia (multiple sclerosis)	33,300	2.50	15,525
Muscular Dystrophy	30,000	6.00	
Myasthenia Gravis Alliance Australia	1,900		
Parkinson's Australia	150,000	12.30	42,565
Polio Australia	40,000	1.90	
Developmental and Epileptic Encephalopathies incl SC2NA	8,644		
Spinal cord injury*	20,800	3.70	
Spinal muscular atrophy	600		
Stroke Foundation	440,481	9.00	212,251
Tourette syndrome*	130,000		
Other neurological conditions (AIHW def)			48,440
Total	**7,083,064**	**126.76**	
Australian population (as at mid-2024)	**26,713,205**		
Approx. 1/4 Australians (25%)	**3.77****		

*The peak bodies for these conditions are not currently NAA members.

**Noting the presence of multimorbidity across these conditions, it is challenging to provide a clear estimate.

Blank cells indicate that data are unavailable.

Appendix 2

Illustration of Enablers supporting research under each Pillar.

	Pillar			
Enablers	**Prevent**	**Detect**	**Treat**	**Care**
Advanced Technology, Data, and Infrastructure	• Leverage tech for evidence-based risk management. • Use AI for risk prediction • Use emerging technologies and data analytics to identify and manage risk factors.	• Investigate and refine diagnostics with genomics, AI, imaging & other technologies • Invest in diagnostic innovations. • Explore and validate new biomarkers.	• Apply modern genetic techniques and neuroprotective agents. • Support precision medicine tools. • Improve and implement precision medicine. • Integrate advanced therapeutic platforms like gene therapies. • Build capacity in genomics and personalised medicine.	• Develop and demonstrate holistic care models. • Leverage tech for remote patient care. • Drive development of evidence-based care by learning from international best practice. • Develop care databases for outcome tracking.
Collaborative Partnerships	• Collaborate with other sectors on prevention education through co-design. • Engage with public health entities. • Foster partnerships across academic, clinical, industry, community, and consumer sectors.	• Partner with healthcare providers and industry to enhance screening with co-designed strategies. • Foster cross-disciplinary partnerships.	• Partner with industry on drug discovery using co-design principles. • Collaborate with patient groups and industry to jointly develop and trial new drugs. • Foster partnerships for drug discovery and personalised medicine.	• Develop and share best practices with caregivers. • Collaborate with caregivers' organisations. • Strengthen health literacy and communicate best practices to caregivers.

Diverse and Inclusive People & Communities	• Collaborate with communities on prevention education through co-design. • Address risk factors in diverse groups. • Identify at-risk communities and co-design educational prevention programs.	• Train diverse researchers, including those from First Nations, to enhance capacity. • Ensure diverse populations in studies.	• Ensure diversity in research teams and sampling protocols. • Develop personalised treatments for varied populations. • Include First Nations perspectives in developing treatment protocols.	• Foster inclusive, culturally safe research environments. • Promote equitable access to care. • Develop inclusive care models for diverse patients, with robust evidence base. • Test programs to improve the well-being of patients and caregivers.
Public Engagement & Communication	• Establish evidence-based outreach. • Collaborate with stakeholders for awareness campaigns. • Develop and promote evidence-based public health campaigns.	• Raise public understanding of research outcomes. • Engage communities in early diagnosis efforts. • Validate biomarkers for early detection.	• Foster wider understanding of genomics and personalised medicine with co-designed communication strategies. • Partner with patients and carers in trial designs.	• Encourage public involvement in research. • Involve caregivers in care model development. • Communicate patient-centred research outcomes to improve health literacy.
Harmonised Efficiency	• Streamline prevention efforts across diseases and other Missions. • Build an evidence base to inform policies on preventive health measures and lifestyle interventions.	• Coordinate diagnostic research across conditions. • Integrate both primary and secondary prevention in research protocols.	Streamline treatment development processes, leveraging disease-agnostic principles.	Integrate care strategies for systemic improvements.
Robust Governance	Uphold ethical standards in research.	Ensure transparency in research practices.	• Maintain strong governance in research development & oversight • Ensure ethical compliance.	• Uphold leadership in research. • Establish KPIs to measure success

References and citations

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

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

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6 https://www.nhmrc.gov.au/funding/outcomes-and-data-research/research-funding-statistics-and-data. Accessed 8/10/24.

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9 https://www.health.gov.au/topics/chronic-conditions/what-were-doing-about-chronic-conditions/what-were-doing-about-neurological-conditions. Accessed 28/09/24.

10 The Australian Department of Health and Ageing convenes 121 expert committees and groups, yet none focuses specifically on neurological and neuromuscular conditions—a critical gap in addressing these pressing health issues. See https://www.health.gov.au/committees-and-groups. Accessed 28/09/24.

11 https://www.who.int/publications/i/item/9789240076624. Accessed 27/09/24.

12 See, for example, the ‘Optimal clinical pathways for adults with neurological conditions’ by the UK’s National Neurosciences Advisory Group: https:/www.nnag.org.uk/optimum-clinical-pathways. Accessed 28/09/24.