

15 May 2026

Senator Penny Allman-Payne
Chair
Senate Community Affairs References Committee
PO Box 6100
Parliament House
Canberra ACT 2600

Dear Committee Chair and Members

We welcome the opportunity for Neurological Alliance Australia to make a submission to the Senate Community Affairs References Committee's Inquiry on Epilepsy in Australia.

Recommendations

Neurological Alliance Australia recommends that the Committee include in its final report:

1. **IGAP** – that the Australian, State and Territory governments prioritise implementation of their responsibilities under the WHO *Intersectoral Global Action Plan on Epilepsy and Other Neurological Disorders 2022–2031* as the foundation for a funded national strategy for epilepsy, and for other neurological conditions
2. **National Action Plan** – funding for the implementation of NAA's *Blueprint for a National Action Plan for Neurological Conditions*, consistent with Australia's obligations under IGAP which requires evidence of an operational national plan or framework to address neurological conditions
3. **Workforce** – expansion of neurological workforce capacity and capability, including the development of a national Neurological Nursing Workforce Strategy
4. **Data** – strengthened national data systems with additional funding to the Australian Institute of Health and Welfare to develop a national neurological dataset, including epilepsy, and reporting on neurological conditions
5. **Research** – dedicated and sustained investment in epilepsy and other neurological conditions research through the establishment of a Neurological Research Mission under the Medical Research Future Fund
6. **Rights** – consider legislative reforms to protect the rights of individuals with epilepsy and other neurological conditions, which would fulfill IGAP's human rights objectives.

About the Neurological Alliance Australia

Neurological Alliance Australia (NAA) is a national alliance of around 50 not-for-profit organisations representing the needs of approximately seven million Australians living with neurological and neuromuscular conditions. Of relevance, our members include Epilepsy Action Australia, Epilepsy Australia and The Epilepsy Foundation. NAA also maintains strong partnerships with several alliances including the Epilepsy and other Neurological Disorders Alliance (ENDA).

NAA General Comments

We wish to inform the Committee that NAA supports ENDA's submission of 13 May 2026. In particular, NAA endorses ENDA's view that this Inquiry "provides an important opportunity to address longstanding structural gaps and align Australia with the World Health Organization's [Intersectoral Global Action Plan on Epilepsy and Other Neurological Disorders \(IGAP\) 2022–2031](#)."

NAA strongly supports the IGAP which calls on Member States including Australia to:

- develop or update national neurological policies and frameworks
- improve access to care and services
- integrate neurological health into broader public health systems
- engage people with lived experience in design and implementation
- collect and report data to measure national progress.

In keeping with its support for the IGAP, NAA presented to the Australian Government in September 2025 its [Blueprint for a National Action Plan for Neurological Conditions](#). The Blueprint provides a structured approach to aligning condition-specific initiatives with government responsibilities, including Australia's obligations under the IGAP which requires evidence of an operational national plan or framework to address neurological conditions.

NAA strongly consider that the Committee's recommendations should strategically align with the IGAP objectives to:

- **elevate policy prioritisation** including national recognition that epilepsy (and other neurological conditions) must be a public health priority with appropriate funding support
- enhance **access** to earlier and accurate diagnosis, earlier access to affordable treatment and integrated care pathways
- address **workforce gaps** through funding the co-designed development and implementation of a neurological nursing workforce strategy. NAA is currently undertaking sector consultation on draft Priority Action Plan on Strengthening Australia's Neurological Nursing Workforce, which is a practical reform to improve outcomes for people with neurological conditions including epilepsy, and to reduce pressure on the health system
- fund **workforce development** through investing in epilepsy-specific and other training for healthcare professionals
- **promote brain health**, address modifiable risk factors and focus on prevention (where possible) and early intervention of neurological conditions, supporting IGAP's preventive strategies
- strengthen the **public health approach** to epilepsy through service coverage. Expanding epilepsy services would align with IGAP's target of increasing service coverage by 50 per cent by 2031
- **foster research** on epilepsy and other neurological conditions and **strengthen data** on epilepsy and other neurological conditions (*further detail below*).

NAA Comments regarding Terms of Reference 5

Specifically responding to the term of reference 5 – the adequacy of Commonwealth funding for research into epilepsy – NAA makes the following comments:

There is a need to strengthen research investment in epilepsy and other neurological conditions. Research is essential to improving diagnosis, treatment, models of care, prevention where possible, quality of life, and long-term outcomes for people living with epilepsy.

NAA has been advocating for a Neurological Research Mission under the Medical Research Future Fund to unite and build on separate research investments in neurological conditions. NAA's [Pathways to Progress](#) highlights four pillars being:

1. **Prevent** – Reduce the incidence of neurological and neuromuscular conditions through targeted prevention strategies
2. **Detect** – Identify and diagnose neurological and neuromuscular disorders at the earliest possible stage
3. **Treat** – Innovate and refine therapeutic approaches to treat neurological and neuromuscular conditions
4. **Care** –
 - Through research –
 - enhance the quality of life for individuals with neurological and neuromuscular conditions to inform care models, and
 - drive development of evidence-based care by learning from international best practice
 - Patient Management and Support
 - Supporting Caregivers.

Such a mission would support innovation in treatments, diagnostics, and neuro-prevention, gene therapy, models of care, digital health, data systems and emerging technologies including AI-enabled tools.

NAA welcomes the announcement in the 2026-2027 Budget that Medical Research Future Fund disbursements will increase from around \$650 million to \$1 billion annually from 2030-2031. However long-term and dedicated investment remains essential to prevent, halt and reverse the progression and impact of epilepsy and other neurological conditions.

Related to research is the need to strengthen national data on epilepsy and other neurological conditions. Data is essential for evidence-based approaches to diagnosis, treatment, care service planning and delivery and program evaluation. NAA's epilepsy organisational members, together with other condition-specific members, have advocated for the development of a national neurological dataset.

NAA notes that the Australian Institute of Health and Welfare (AIHW) has commenced work on data relating to the prevalence, health service use, disease burden and health

system expenditure associated with neurological conditions, with epilepsy included as one of 11 specific neurological conditions considered.

However, significant further work remains to be funded and undertaken. In the meantime, data gaps continue to limit effective planning, policy development, equitable resource distribution and program evaluation.

Further information

If you have any questions or require any further information, please contact NAA Executive Officer at david.ali@NeurologicalAlliance.org.au.

Yours sincerely



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