ENDA
Epilepsy and other Neurological Disorders Alliance
AUSTRALIA

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13 May 2026

Committee Secretary
Senate Standing Committee on Community Affairs
PO Box 6100, Parliament House
Canberra ACT 2600
E-mail: community.affairs.sen@aph.gov.au

Dear Committee Secretary and Members,

I write as Chair of the Epilepsy and other Neurological Disorders Alliance (ENDA) in support of the Senate Inquiry into Epilepsy in Australia. ENDA is a national alliance of clinical experts, researchers, epilepsy organisations, and individuals with lived experience, established to advance a coherent, strategic, system-level response to epilepsy and related neurological conditions.

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*—the international benchmark for coordinated neurological care.

The Global Imperative

Endorsed in 2022, IGAP reflects a clear global consensus: neurological disorders are a substantial and under-recognised component of the burden of disease, requiring coordinated, system-wide action.

Its objective is equitable access to timely, integrated, person-centred care, enabling the highest attainable quality of life.

IGAP's priorities include: Strengthening accessible, high-quality health systems; Implementing prevention strategies; Delivering integrated, cross-sector care; Advancing inclusion, stigma reduction, and human rights; Expanding and upskilling the workforce; Strengthening research and data systems, and embedding monitoring and accountability.

Critically, IGAP is intersectoral, recognising that effective epilepsy care extends beyond healthcare into education, employment, and social participation.

ENDA: A Coordinated National Response

ENDA was established in alignment with IGAP to support its implementation within Australia.

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It brings together the Epilepsy Society of Australia, Epilepsy Action Australia, Epilepsy Australia, Epilepsy Western Australia and consumer representatives within a collaborative governance model designed to address persistent fragmentation.

ENDA is also engaged in ongoing discussions with the Neurological Alliance of Australia, strengthening alignment across the broader neurological sector and supporting a more integrated national approach.

ENDA is underpinned by principles of equity, inclusion, and accountability, with lived experience embedded as the very core driver of priorities, service design, and evaluation.

Its work spans four domains:

- **Policy Advocacy and System Leadership**: advancing epilepsy as a national priority and promoting policy coherence across jurisdictions and sectors.
- **Optimal Care Pathways:** evidence-based, sustainable, person-centred care pathways that improve timeliness of diagnosis, continuity of care, and long-term health outcomes.
- **Healthcare Workforce:** strengthening capacity and capability of the specialist and multidisciplinary workforce through training and role expansion
- **Research, Data, and Knowledge Translation:** coordinated research efforts, data collection, and translation of knowledge into practice

Persistent System Challenges

Significant gaps in epilepsy care remain fragmented service delivery and inconsistent outcomes; geographic inequities across rural, regional, and remote communities; workforce limitations, including restricted access to specialist expertise and diagnostics; ongoing stigma impacting education, employment, and mental health; limited national data infrastructure to support planning and evaluation. These systemic issues reflect the absence of a coordinated national strategy and constrain equitable care and outcomes.

An Opportunity for Strategic Alignment

This Inquiry provides a timely opportunity to strengthen Australia's response through alignment with IGAP, supporting a more consistent, integrated, and accountable national approach.

ENDA offers a practical mechanism to:

- Translate global policy into national implementation

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- Support coordination across sectors and jurisdictions
- Promote consistency in care delivery
- Anchor reform in evidence and lived experience

Recommendations

ENDA respectfully recommends that the Committee:

1. **Adopt IGAP as the foundation for a funded national strategy**
2. **Recognise and support ENDA as the national coordinating mechanism**
3. **Invest in integrated models of care, workforce capacity, and sustainable care pathways**
4. **Strengthen data systems, research capacity and intersectoral action**

Conclusion

Epilepsy is a highly prevalent, lifelong condition with significant clinical, social, and economic impacts. Effective management requires coordinated, system-wide responses grounded in evidence, lived experience, and sustained national leadership.

IGAP provides the framework; ENDA provides the mechanism.

This Inquiry represents a critical opportunity to strengthen national coordination and improve outcomes. With alignment and targeted investment, Australia can deliver a more integrated and equitable system of neurological care.

Yours sincerely,

Professor Piero Perucca, MD, PhD, FRACP, FAES
Chair ENDA Executive
President Epilepsy Society of Australia