

Date: 16 March 2026

RE: Epilepsy in Australia

Committee Secretary
Senate Standing Committees on Community Affairs
PO Box 6100
Parliament House
Canberra ACT 2600

Dear Community Affairs References Committee,

I am writing to you with hope to raise awareness of the significant challenges faced by children living with epilepsy, specifically **Benign Rolandic Epilepsy**, also known as **self-limited Epilepsy with Centrotemporal Spikes (SeLECTS)**.

Approximately eighteen months ago, my nine-year-old son experienced a severe tonic-clonic seizure while asleep. During the two-minute seizure, his breathing was impaired, and he was transported by ambulance to Monash Children's Hospital. While basic blood tests and cardiac checks were performed, and it was determined that he had recovered from the immediate effects of the seizure, we were discharged within a few hours without any explanation as to the cause. We were advised that childhood seizures are relatively common in Australia, with approximately one in twenty children (5%) experiencing a seizure at some point during childhood.

Although the paediatrician reassured us that our son had made a full neurological recovery, our family was left with ongoing fear and anxiety that there may be an underlying issue affecting our son's brain.

Three months later, while on a family holiday, our son experienced a milder focal seizure following a very active day. The following night, he suffered another tonic-clonic seizure and was once again taken to hospital. As before, blood tests and cardiac checks were conducted, and he was monitored for several hours before being discharged. At this time, we were finally given a referral for an EEG; however, we were informed that the waiting period could be up to six months.

Concerned about the delay and seeking clarity regarding our son's condition, we consulted our GP shortly thereafter and requested further investigation. Our GP referred our son for a brain MRI. By this time he

had recently turned ten and we were able to locate a radiology clinic in Melbourne that provided MRI services free of charge for children aged ten and over. It was only after receiving these results that our fears surrounding possible brain lesions were alleviated. As parents we try to avoid worst-case thinking, however prolonged uncertainty inevitably fuels significant distress.

Had we relied solely on the public hospital pathway and specialist referrals through that system, it is unclear how long our son may have waited for a diagnosis and appropriate treatment.

Without advocating strongly for an earlier MRI and accessing a private paediatric neurologist—at a personal cost of approximately \$200 per appointment—our son may have continued to experience further **catastrophic tonic-clonic seizures**. These seizures carry an associated risk of **Sudden Unexpected Death in Epilepsy (SUDEP)**, estimated at approximately 1 in 1,000. SUDEP is a rare but devastating condition in which a person can die suddenly as a result of a seizure.

Prior to my son's diagnosis, I had never heard of SUDEP. It is not discussed widely enough. Since his first seizure, I have not slept soundly, and the fear of SUDEP is a constant fear of our family's.

There remains a significant lack of awareness in the broader community about what epilepsy truly entails. Many people believe epilepsy is simply the occurrence of seizures. In reality, epilepsy is far more complex. It involves chronic fatigue, frequent headaches, body aches, disrupted sleep, anxiety, and depression. In addition, anti-epileptic medications often carry substantial side effects, including drowsiness, dizziness, weight changes, nausea, gastrointestinal upset, and behavioural changes, all of which can significantly impact a child's quality of life.

I respectfully request that Parliament consider the following actions:

1. **Increasing awareness of childhood epilepsy**, including:
 - Regular (annual or monthly) epilepsy awareness campaigns
 - Strong social media campaigns targeting parents, educators, and young people
 - Engagement of celebrity advocates
 - Partnerships with sporting organisation's
2. **Mandatory epilepsy education for all child educators**, including training on the condition and the side effects of epilepsy medications. Where a child with epilepsy is enrolled, appropriately funded epilepsy organisation's could provide targeted training to staff directly involved in that child's care, fostering greater understanding and compassion.
3. **Increased funding for epilepsy research**, with a focus on finding a cure and developing safer treatment options with fewer side effects.
4. **A faster diagnostic pathway for children**, reducing delays in access to EEGs, imaging, and specialist care.
5. **Further subsidies for paediatric neurology appointments, medications, and night-time seizure monitoring devices**, particularly for children who experience seizures during sleep. The ongoing anxiety experienced by parents and carers is profound and often overwhelming.

Your support in bringing attention to childhood epilepsy would help ensure that affected children and their families receive the understanding, support, and resources necessary to manage this condition safely and with dignity.

Thank you for taking the time to consider this important issue. I would welcome the opportunity to discuss this matter further.

Yours sincerely,