

The AEP is changing lives.

Amanda's Story

I began having seizures at the age of 23. Over time, they worsened—occurring almost daily. One seizure while cooking left me with third-degree burns. By the age of 30, I was caring for a toddler, unable to drive, and felt completely isolated from the world around me.

For eight years, I lived with the uncertainty and frustration of medication that didn't work. It's time I'll never get back.

Everything changed when I underwent advanced MRI testing—similar to what is offered through the AEP. The scans revealed scar tissue on my right temporal lobe, the result of encephalitis I had as a baby. With a clear and accurate diagnosis at last, I could finally seek the right treatment.

In 2010, at the age of 31, I underwent successful neurosurgery. It gave me my life back.

Since then, I've had another child and completed a Bachelor of Psychology. I'm one of the lucky ones who has gained seizure control. That experience inspired me to help others living with epilepsy.

Since 2019, I've proudly worked with the Australian Epilepsy Project (AEP) as a Lived Experience Ambassador and Participant Lead—supporting others on their path to understanding, treatment, and hope.



Amanda Anderson
Lived Experience Ambassador



Professor Graeme Jackson

Chief Investigator, AEP
Deputy Director, The Florey

"I want every Australian living with epilepsy to be free from seizures. This is my life's work. The AEP team will make this a reality for many."



You could be a control group volunteer for the Australian Epilepsy Project.

JOIN THE AUSTRALIAN EPILEPSY PROJECT

Scan the QR code to join
the study.



Acknowledgement of Country

The Australian Epilepsy Project (AEP) acknowledges the Traditional Owners of the land on which we work, the Wurundjeri people of the Kulin Nation. We pay our respects to their Elders past, present and emerging.

The Australian Epilepsy Project (AEP) receives funding from the Australian Government under the Medical Research Future Fund (MRFF).



The Florey
Advancing Brain Research



What is the Australian Epilepsy Project?

Close to a quarter of a million people in Australia live with epilepsy. That is 1 in 100 people. The associated costs are estimated to be approximately \$12.3* billion a year.

Current care is characterised by uncertainty, with few patients having access to Australia's world leading expertise and solutions, which at present are locked in research and a small number of specialist centres.

The **Australian Epilepsy Project (AEP)** is a multi-year research study creating a paradigm shift in the treatment and management of epilepsy, where patients can access specialist knowledge and the latest technology to fast-track their treatment pathway.

A national network of specialist hubs provides access to world leading testing, and together with integrated and predictive analysis across advanced imaging, genetics, and cognition, the AEP is helping transform the diagnosis and treatment of epilepsy for thousands of Australians.

*Deloitte, The economic burden of epilepsy in Australia 2019-20

We are recruiting volunteers for our study's control group.

Your participation will help drive new discoveries and future applications of data for epilepsy and other brain health conditions.

What is a study control group?

A study control group consists of a group of volunteers doing the same testing as the study's general participants. They play a fundamental role in clinical trials by providing comparative data as a baseline for determining the effectiveness of the study's treatments.



Can I join the study control group?

We need people who don't have epilepsy to form our study's control group.

Participation involves at-home neuropsychology testing as well as undergoing an MRI scan at one of our Hubs.

Your participation will help change the future landscape of epilepsy diagnosis and treatment for the 250,000 people living with epilepsy in Australia.

Control Group Volunteer Eligibility

Participation in the AEP requires meeting the following criteria:

- ✓ Aged 18 - 70 years
- ✓ Capacity to consent
- ✓ Have no history of epilepsy
- ✓ Have a current Medicare number
- ✓ Be willing to share your de-identified data to facilitate further research into epilepsy
- ✓ Be able to safely undergo an MRI scan (e.g. not pregnant, have no metal implants from surgery, metal braces, or non-removable piercings)

Cost commitment for control group volunteers:

There are no costs associated with participating in the AEP Study, nor will participants be paid. Reimbursement is available for costs incurred including: reasonable travel costs, and parking (if not provided).

Time commitment for control group volunteers:



~ 20 mins

Medical History Interview



~ 30 mins

Online Surveys



~ 120 mins

Telehealth Cognitive Testing



~ 90 mins

Advanced MRI Scan

Thank you for considering volunteering for the **AEP's study control group**.

Your participation in this critical study is helping to change the lives of people living with epilepsy.

Find out more by visiting our website.



AEP epilepsyproject.org.au