What is the Australian Epilepsy Research Register?

The Australian Epilepsy Research Register (AERR) is a database of people who have epilepsy and their carers who have given us permission to communicate with them on an ongoing basis for the purpose of social and psychological research.

The primary objective of the register, and research over a period of time, is to learn valuable information about epilepsy, and its social and psychological effects, that can be used to improve the lives of people affected by this condition.

The Research Register was created in 2006 and is an initiative of the Epilepsy Foundation. Any person in Australia who has epilepsy or is a carer of a person with epilepsy, can join the register.

Why is it important to join the register?

The World Health Organization has stated that, ‘the social consequences of epilepsy are often more difficult to overcome than the seizures themselves’. Consequences can include difficulties with finding and keeping a job, transport and driving, gaining an education and coping with the attitudes of others towards epilepsy.

Yet in Australia, there is little reliable research being conducted into these social effects. By gathering detailed evidence of the day-to-day effects of epilepsy on people living with the condition, the Epilepsy Foundation, Epilepsy Australia, and the other state-based epilepsy community service organisations, will be better equipped to meet the service needs of people with epilepsy and to lobby government for a better deal for them.

Who can join the register?

People who are eligible include:

- Individuals over the age of 18 years of age who have epilepsy
- Parents and guardians of children with epilepsy
- Family members, friends or paid carers who look after someone with epilepsy.

We encourage people to join the register, to provide their views and contribute to the gathering of valuable information.

Joining the register does not put you under any obligation. If at any time you decide you no longer want to continue on the register you are free to request to have your name removed from it.
How will I be asked to participate?

From time to time researchers at the Epilepsy Foundation, as the custodians of the Research Register, will contact you to ask if you would be prepared to answer some questions. This may be done by posting or emailing you a survey, asking you to complete a survey on-line or inviting you to discuss a question in an interview or a group discussion.

Researchers are conducting a longitudinal survey, which collects information on how epilepsy impacts on people’s lives over a number of years. Your participation in this survey will provide evidence to improve programs and policies for all people with epilepsy in Australia.

Am I obligated to participate in future research projects?

You are free to decline to participate at any time.

Putting your name on the register does not mean you have to take part in any research in any way. You may be too busy or you may not feel like participating when we contact you – that’s fine. But if you do participate, any information you provide will be confidential, anonymous, safeguarded and only used for specified research purposes.

How do I benefit by joining the Research Register?

By registering as a participant in this ongoing research program you will assist us to construct a clearer picture of the social and psychological effects of living with epilepsy and the supports and services you and others living with epilepsy need to improve your quality of life.

We will also provide regular updates on research findings and, if interested, we can keep you informed of any upcoming events or activities.

From time to time, there may be opportunities for you to meet with other people living with epilepsy who are involved in the Research Register. Importantly, this is an opportunity to be part of a longitudinal study of people living with epilepsy.

Your privacy and confidentiality are important to us

Protecting privacy and maintaining confidentiality of personal information are important to us. The Epilepsy Foundation is subject to all state and federal legislation regarding the protection of privacy and confidentiality.

Your details will not be provided to anyone who is not part of the research team. If external researchers are used in future research projects, they will be approved by the Epilepsy Foundation’s Research Committee according to strict criteria. Only research approved by a Human Research Ethics Committee will be allowed. Your details will not be provided to any external researchers and we will de-identify all records so that no personal details are made available to any third party.

Findings from research may be published using de-identified information and no person’s details will be released.

If you would like a copy of the Epilepsy Foundation’s Privacy Policy, call (03) 8809 0600 or visit www.epinet.org.au.

Feedback and complaints

Feedback and complaints regarding the Research Register are welcomed as part of our ongoing improvement.

We believe any concerns should be dealt with in a fair, accountable and transparent manner as part of our complaints and feedback policy and procedures. For information on the Epilepsy Foundation’s complaints procedure, or to make a complaint, call the Research Coordinator on (03) 8809 0600 or visit www.epinet.org.au.
Application to join the Australian Epilepsy Research Register

Please complete this form on-line at www.epinet.org.au/research if you would like to join the Australian Epilepsy Research Register (AERR). By joining the register, you give us permission to contact you from time to time to conduct research into your experiences of living with epilepsy or caring for someone living with epilepsy.

☐ YES, I would like to join the Australian Epilepsy Research Register.

I understand that:

• Putting my name on the Research Register does not mean I have to take part in any way
• I am free to decline any request to participate in any survey/s being conducted through the AERR and can ask the Epilepsy Foundation to remove my name from the Research Register at any time without explanation
• The request to join the AERR is only for the purpose of social and psychological research and the results of projects will only be used to further the efforts of the Epilepsy Foundation and/or Epilepsy Australia to improve the lives of those living with epilepsy
• Any information I provide will be safeguarded and only used to invite me to participate in specific research projects
• My participation will in no way alter any services I may receive from the Epilepsy Foundation or any other state-based epilepsy service provider that is a member of Epilepsy Australia
• I can, if I choose, receive regular updates of research findings, newsletters etc.

Who is registering? (Please tick)

☐ I am a person with epilepsy
☐ I am a parent/guardian of a child with epilepsy
☐ I am completing the registration on behalf of a person with epilepsy
☐ I have obtained consent from the person with epilepsy to be part of the Research Register where the person is an adult over the age 18 years
☐ I am a family member (relationship)
☐ I am a friend
☐ I am a paid carer
☐ Other (please specify)

Title and first name:

Surname:

Address:

State: Postcode:

Telephone (home):

Mobile:

Email:

I prefer to be contacted by:

☐ Post ☐ Email ☐ Telephone

The following questions will help us invite you to participate in the most appropriate project/s:

☐ Female ☐ Male

Date of birth:

Date of birth of person with epilepsy:

☐ Please send me regular updates on research findings, newsletters etc. from time to time.

Please mail, fax or email to:

Australian Epilepsy Research Register
Epilepsy Foundation
587 Canterbury Road
Surrey Hills Vic 3127
Fax: 03 9836 2124
Email: research@epilepsy.asn.au
If you are interested in learning more about the Australian Epilepsy Research Register, please contact the Epilepsy Foundation:

- **Address:** 587 Canterbury Road, Surrey Hills VIC 3127
- **Telephone:** +61 (0)3 8809 0600
- **Fax:** +61 (0)3 9836 2124
- **Email:** research@epilepsy.asn.au
- **Website:** [www.epinet.org.au](http://www.epinet.org.au)
- **Helpline:** 1300 852 853

If you have a hearing or speech impairment, call 1800 555 660 for information about our services (for the cost of a local call).