

Research Participant Register An invitation from the Epilepsy Foundation of Victoria

The Epilepsy Foundation of Victoria invites you to become a participant in the Epilepsy Foundation's ongoing research program, the Research Participant Register (RPR) into the social effects of living with epilepsy and caring for those with epilepsy. We need people to tell us about their experiences and views of living with epilepsy.

What is the Epilepsy Foundation RPR?

The Epilepsy Foundation's Research Participant Register is an ongoing initiative created in 2006 to establish a unique research source from which we can learn much valuable information about epilepsy that can be used to improve the lives of people affected by this condition. This is the only register of its kind in Australia and we have not, so far, learned of another anywhere else in the world.

Why is it important to join in this register?

The World Health Organisation has stated that "the social consequences of epilepsy are often more difficult to overcome than the seizures themselves". They are talking about issues like finding and keeping a job, transport and driving, and the attitudes of other people towards epilepsy. Yet in Australia, there is hardly any reliable research into these social consequences. If the Epilepsy Foundation gathers detailed factual evidence of this kind, we will be even more successful in lobbying governments for a better deal and a fairer go for all those living with epilepsy.

Who is eligible to join in RPR?

The following individuals are eligible to join the register.

- Individuals who have epilepsy/seizure disorder
- Carers who look after someone with epilepsy/seizure disorder.

Are there risks to me as a research register participant?

This is not a medical or clinical research register. From time to time, we might contact you and ask if you would be prepared to answer some questions over the phone or fill in a mailed questionnaire. Sometimes there will be small group meetings of participants at the Epilepsy Foundation's office in Camberwell or a regional centre, to which you might be invited.

Does putting my name in the RPR obligate to participate in future research projects?

Putting your name in the RPR does not obligate you in any way. You may be too busy or just not feel like participating at that time, and that's fine. If you do participate, any information you provide will be confidential, anonymous, safeguarded and only used for specified research purposes.

How would I benefit by joining the register?

There may be opportunities to talk with other people living with epilepsy and those who work with them. Most importantly, this is an opportunity to be part of a longitudinal study of living with epilepsy - the first of its kind.

How do I find out more information about the applied social research program into epilepsy?

Contact:
Dr Jaya Pinikahana MSc PhD, Principal Social Researcher
Epilepsy Foundation of Victoria
818 Burke Road
Camberwell VIC 3124
Phone: 003 9805 9125 Fax: 03 9882 7159
jpinikahana@epilepsy.asn.au

Application to join Research Participant Register
The Epilepsy Foundation's research program into the social effects of living with epilepsy and caring for those living with epilepsy

YES, I would like to join the list of participants in the social research program of the Epilepsy Foundation of Victoria. I understand that:

- Putting my name on the list does not obligate me in any way
- I am always free to decline any request from the Epilepsy Foundation in regard to this and can ask the Epilepsy Foundation to take me off the list at any time without explanation
- The request is only for the purpose of social research and the results of projects will only be used to further the Epilepsy Foundation's efforts to improve the lives of those living with epilepsy
- My privacy will be respected and my name will not appear on any published materials. Any information I provide will be safeguarded and only used for specified research purposes
- My participation will in no way alter any services I may receive from the Epilepsy Foundation.

Name:

Address:

.....Postcode:.....

Contact Telephone No.

The following questions are optional but your answers will help us invite you to participate in the most appropriate project/s. Please tick a box:

 Female Male

 Age = under 18 years 18-30 years
 31 to 45 years 46 to 60 years
 Over 60 years

Please tick one or both boxes: (Feel free to copy this form for additional people to register.)

I am a person with epilepsy
 I am a carer, friend or relative of someone with epilepsy

To return this form:
Please fax to: 03 9882 7159
Or hand in to the Epilepsy Foundation
Or post to:
Attention Dr Jaya Pinikahana
Epilepsy Foundation of Victoria
818 Burke Road
Camberwell VIC 3124