



To all of our **Australian Epilepsy Research Register Members and Readers,**

We are delighted to bring you this issue of the newsletter, which brings together all the exciting activities that have occurred in the Research Unit this year. We are looking forward to updating you with more inspiring research news in 2017 so please look for regular updates through our website, in your inbox or in the mail.

Thank you very much for your continued support and contribution on the Australian Epilepsy Research Register. Without your assistance we would not be able to understand how epilepsy impacts on your life.

We wish you, your family and friends a safe and peaceful holiday break and best wishes for the New Year.

*Thank you*

*All of the research team at the Epilepsy Foundation*



## Research team update

### *Our newest team member*

We would like to welcome a new member to our research team – **Dr Loretta Piccenna**. Loretta started at the Epilepsy Foundation at the beginning of August in the role of Research Lead.

She brings to the team many research skills. She conducted her PhD at the Howard Florey Institute (at the University of Melbourne) and has worked at The National Trauma Research Institute (at The Alfred Hospital). Whilst at the National Trauma Research Institute she gained an important understanding of rigorous methodology and evidence synthesis as a tool for improving best practice.

Welcome!

### *Best of luck Pat Douglas!*

Some of you will have had contact with Pat Douglas who managed the Research Register for some 7 years! Pat looked after the Register with an eagle eye. She knew many of you personally and always understood when someone's circumstances had changed and a family no longer wanted to be involved with the Register. Pat has moved on to a new position in another organisation and is greatly missed but we wish her well for the future and know that others are now benefiting from that eagle eye of hers. Those now caring for the Research Register will ensure that it continues to uphold the standards she delivered and ensure that your membership of this important register is valued and respected.



### Contact the Epilepsy Foundation

587 Canterbury Road,  
Surrey Hills, VIC, 3127

**Phone:** (03) 8809 0600

**Email:** [epilepsy@epilepsyfoundation.org.au](mailto:epilepsy@epilepsyfoundation.org.au)

**Visit our website:** [www.epilepsyfoundation.org.au](http://www.epilepsyfoundation.org.au)

## Australian Epilepsy Research Register

Currently we have a total of **1416 people** who are registered on the Australian Epilepsy Research Register (AERR). We have had an additional 128 people join this year which is terrific!

Our target goal is to have 2000 people join the register as a representative sample of people living with epilepsy in Australia so we are getting closer. Please visit our website to check out some of our great infographics -

[http://www.epilepsyfoundation.org.au/articles/research/australian\\_epilepsy\\_research\\_register](http://www.epilepsyfoundation.org.au/articles/research/australian_epilepsy_research_register)

We are truly grateful for those of you who have registered and take part in our Longitudinal Survey. Your participation assists us in being able to show governing bodies the social and psychological impacts that living with epilepsy can have on people.

We have also included a graph here of how many people are registered from each state, which shows the growth over the last year.

We look forward to this growing again during 2017 Australia-wide.

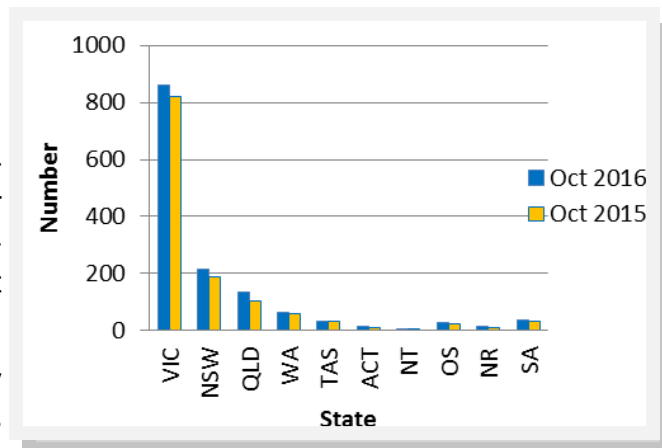
**Have you changed your contact details? Let us know, email the register at—[research@epilepsyfoundation.org.au](mailto:research@epilepsyfoundation.org.au) or phone (03) 8809 0600**

### *New research reported from Wave 3*

A research paper on the Wave 3 survey results of the Australian Epilepsy Longitudinal Study (2013) has been accepted for publication in the International Journal of Epilepsy. In the study called 'does being 'well off' help people with epilepsy cope better? The social impact of epilepsy' Drs Christine Walker and Chris Peterson used the survey results to look at the experiences of 324 people from the Australian Epilepsy Research Register.

The study focussed on to what extent does being well off help people with epilepsy develop a stronger sense of personal control in dealing with the condition , and therefore make dealing with the consequences of epilepsy easier. They found that up to a point being better off did help but after that being wealthy made no difference. This was because of the effects of having a number of other conditions, rate of seizures and other things happening in life such as stigma and influence of epilepsy on relationships.

Walker, C and Peterson, C. Does being 'well off' help people with epilepsy cope better? The social impact of epilepsy. International Journal of Epilepsy, 2016 (*accepted*)



### **Keep an eye out for our invitation to Wave 4!**

We are currently finalising the survey for Wave 4 . This survey will be asking all of you about how you access and enable services to manage your epilepsy.

