

Joint Epilepsy Council of Australia

Australian Chapter of the International Bureau for Epilepsy

Media Release

Inquiry into the impact of Epilepsy in Australia A National Call for Submissions

A first-ever Inquiry into Epilepsy, which will examine the issues and needs of people living with epilepsy in Australia, will be held in Canberra on 30 October.

Called by the Parliamentary Friends of Epilepsy, convenors Jill Hall MP, Sen Gary Humphries, Mark Coulton MP and Sen Clare Moore, the inquiry will shed light on epilepsy and ways public policy can improve the lives of people with epilepsy.

Mr Graeme Shears, Chair of JECA, said “The Inquiry will, for the first time, analyse key factors impacting on the quality of life of the more than 650,000 people estimated to be living with epilepsy in Australia. This figure does not take into account their families and carers, who are indirectly affected, which is estimated to be approximately 2.6 million Australians. This is a health condition that is a growing problem for the community and for many individuals and families, which can have a devastating impact.”

Submissions are required to be lodged by 2 October 2009, and are being sought from any interested person who has epilepsy, their families or carers, or any organisation involved in the treatment, care, management or support of those with epilepsy, on any issues they face.

The Joint Epilepsy Council of Australia (JECA), representing the state epilepsy association service-providers has lobbied for the Inquiry through the Parliamentary Friends of Epilepsy, a group of parliamentarians and interested people who are concerned about the quality of life of those with epilepsy and their families.

The Inquiry will examine the incidence and prevalence of epilepsy in Australia, including morbidity and mortality, and the incidence in relation to diverse cultural groups and the Aboriginal and Torres Strait Islander community. It will review issues that impact on quality of life including education, employment, transport, community supports such as funding and policies, medical services and, importantly, community attitudes towards those with epilepsy and the social stigma that still exists.

It is estimated up to 3 percent of Australians will have epilepsy during their lifetime. Alarming, the number of people who will experience epilepsy over the age of 65 is increasing in line with our ageing population.

“This Inquiry is critical to address the future needs of people with epilepsy, particularly giving our ageing population and the growing incidence of older people having first-time seizures. The Inquiry will guide funding needs, future research and services, from medical through to support services, over the next 10 years and beyond,” Mr Shears said.

The Inquiry will be undertaken in all states of Australia and will begin with a mini-hearing in Darwin on the 23 September 2009, and will examine reports and information available on the key issues that impact on a person's life at various stages, and will supplement this material by additional inquiry and research where necessary, as well as analysing best practice globally.

Mr Shears said it is well known, through Australian research, that people with epilepsy, their families and carers are socially excluded and this impacts on their quality of life.

The terms of reference for the Inquiry recognise that stigma and discrimination associated with epilepsy are a significant barrier to full participation in life and the community. The unique and continually changing episodic nature of the many and varied epilepsies make managing epilepsy both challenging and complex.

Mr Shears said the lack of data relating to incidence, prevalence and impact of epilepsy is a barrier to developing policies and services to improve the lives of people with epilepsy.

"JECA strongly urges any person or organisation with an interest in epilepsy to put forward their submission and take advantage of this opportunity to influence future policy," he said.

The terms of reference are available at www.epilepsyaustralia.net
Submissions can be made to:

Jill Hall MP
Federal Member for Shortland
PO Box 499
BELMONT NSW 2280

Or by email to Mark.Raper@aph.gov.au

Closing date for submission: **2 October 2009.**

Ends

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