

All-Party Parliamentary Group on Epilepsy

Chair: Baroness Gould of Potternewton

PRESS RELEASE – 2 March 2007

PEOPLE WITH EPILEPSY TO HAVE THEIR SAY

People with epilepsy are being invited to comment on the standard of epilepsy services in England in a move to improve levels of care.

The All Party Parliamentary Group (APPG) on Epilepsy is undertaking an inquiry into the human and economic cost of the underfunding of epilepsy services in England, and has asked patients, health professionals and voluntary organisations to send their views in writing by Friday, April 13.

The APPG is looking for evidence from the last two years to provide a realistic picture of epilepsy services, which also highlights issues caused by poor service provision. The evidence base could include examples of the impact of recurrent seizures and possible drug side effects on a person's life, plus the influence of epilepsy on employment opportunities and education, as well as the social stigma.

Following the inquiry, a report will be published in June which will make recommendations for improving services and the quality of life for the 382,000 people who have epilepsy in England.

Baroness Gould of Potternewton, chair of the APPG on Epilepsy, said: "We hope this inquiry will be a significant turning point for people with epilepsy. Epilepsy is the most common serious neurological condition in the UK but service provision has been chronically underfunded and is under further pressure now in this time of cuts. The report will recommend ways in which services can be improved to help those with epilepsy better manage their condition and to live independently in the community".

The inquiry will take oral evidence in three sessions with patients, health professionals and voluntary organisations. Interested parties are invited to submit written evidence to phil.royal@whitehouseconsulting.co.uk no later than Friday, April 13. This should consist of a self-contained memorandum accompanied by a covering letter.

ENDS

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NOTES TO EDITORS

- The Joint Epilepsy Council of the UK and Ireland (JEC) provides the secretariat to the APPG on epilepsy. JEC is an umbrella organisation of 22 epilepsy organisations, operating in England, Wales, Scotland, Northern Ireland and the Republic of Ireland, to facilitate the sharing of information, expertise and skills, promoting good practice, maximising resources and identifying unmet needs.
- JEC campaigns to reduce stigma, challenge discrimination and disadvantage, and improve the quality of life for people with epilepsy.
- More information on JEC can be found at <http://www.jointepilepsycouncil.org.uk/>
- Statistics on epilepsy:
 - Epilepsy is the most common serious neurological disease, affecting 382,000 people in England, or one in every 131 people.
 - There are approximately 150 Epilepsy Specialist Nurses (ESNs) in the England. Clinical opinion estimates 600 are needed in a consensus statement produced by expert clinical epileptologists and representatives of the epilepsy voluntary sector.
 - ESN posts across the UK are at risk at present. Nurses are threatened with redundancy, working reduced hours or spending part of their time on non-specialist duties.
 - Misdiagnosis rates in the UK currently stand between 20 – 31 per cent. Using a rate of 23 per cent this equates to 87,860 people with a diagnosis of epilepsy and receiving medication who do not have the condition.
 - The medical cost of misdiagnosis in England is estimated to be around £23 million per annum. This does not include the economic cost or the cost in opportunities for people who could be in work but are not due to misdiagnosis or mistreatment.
 - Seventy per cent of the population with epilepsy in England could be seizure free with optimal treatment. This means that 2 out of 5 people experiencing seizures could be seizure free.

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- One thousand people every year die of epilepsy related causes. Three hundred and seventy of those deaths are young adults and children. Four hundred of the deaths per year are considered avoidable.

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