



JULY 2009

1. NATIONAL EPILEPSY WEEK 2009 – ROUND-UP OF EVENTS



A series of lobbying events took place during this year's National Epilepsy Week, sponsored by the JEC. An excellent turnout of people from across the UK met with politicians to raise awareness of the condition and to demand better epilepsy services in their respective countries.

At Westminster, over 100 people attended a lobby event to meet with their MPs. Some had pre-arranged meetings and others used the green card system in Central Lobby to ask to see their parliamentary representative. As a result, over 35 MPs or

their researchers met with constituents. The event was opened by Sharon Hodgson MP, who sponsored the room, and who spoke about the need for improved epilepsy services.

In Northern Ireland 30 members of the legislative assembly (MLAs) attended an event in Stormont to highlight the need for improved epilepsy services. The event was sponsored by George Robinson, MLA, who in his opening speech, expressed surprise at the lack of services and praised the event in highlighting this to MLAs.

Around 150 people attended the Epilepsy Awareness event at the Welsh National Assembly, meeting with 30 Assembly members (AMs) or their representatives. Many AMs attended, even without a meeting with a constituent arranged, to show their support for improved services.

In the Scottish Parliament, a JEC display stand was manned by staff from Epilepsy Scotland, with a photo opportunity for visiting MSPs.

Thanks to staff from all JEC member organisations who helped in the facilitation of these very successful events.

2. JEC ANNUAL GENERAL MEETING 2009

The 2009 JEC Annual General Meeting took place on Thursday, 2nd July, kindly hosted by Epilepsy Scotland at their Govan offices in Glasgow. Turnout by JEC members was disappointing, with only 12 of the 26 JEC member organisations represented.

Elections for Directors to join the JEC Executive took place and I am pleased to advise the election of Alan Cruikshank (NCYPE), Sally Gomersall (NSE & individual member), Matthew Walker (ILAE) and Lesslie Young (Epilepsy Scotland) to the JEC Executive Committee, the Board of Directors who work closely with me setting and delivering the organisation's strategic objectives.

Sincere thanks go to Alice Hanscomb and John Hirst, retiring Executive Directors, for their past work and involvement on the JEC Executive.

Despite a low turnout, a lively discussion took place at the Council Meeting following on from the AGM when issues such as financial planning and the JEC Strategic Plan were discussed.

The next Council Meeting will take place at the joint ILAE/JEC Annual Conference at Sheffield United Football Ground on the afternoon of Thursday, 8th October, 2009.

3. Downing Street ePetition

From January 2010 new dispensing regulations will be in place throughout the UK. Pharmacists will be expected to change the brand of drug named on a prescription and replace it with a different, generic brand. This is as part of the Department of Health's 2009 Pharmaceutical Price Regulation Scheme agreement.

This agreement will make 'generic substitution' legal. This means a pharmacist can (and will) replace more expensive branded versions of drugs for cheaper generic versions. They will not have to consult with either the patient or the doctor who wrote the prescription. The National Health Service estimates this will save £40 million a year.

The JEC is concerned about this. Unless epilepsy is excluded from this legislation it could lead to thousands of people with epilepsy having their medication switched, for purely financial reasons. There will be no consideration of how this will affect them, or their epilepsy. We are campaigning to make anti-epileptic drugs (AEDs) exempt from the rules of generic substitution.

As part of this, an ePetition has been tabled on the Downing Street website. This is an online



petition to the Prime Minister asking him to take action in this area. We need as many people as possible to sign, to show how important this is for people with epilepsy. With enough signatures the government is committed to respond to everyone who signs about the issues raised.

You can sign by going to <http://petitions.number10.gov.uk/epilepsygenerics>

If you are able, please show your support and sign; please also ask your members, colleagues and friends to sign as well.

The full text of the petition is below.

“We the undersigned petition the Prime Minister to ensure an exemption for epilepsy from the new generic prescribing proposals, on the grounds that the active ingredients in different brands of anti-epileptic medication can legally vary by up to 45% and that unnecessarily switching between versions can have a profound negative effect on a person’s health and quality of life, can cause breakthrough seizures, worsening of seizures or increased side effects, leading to loss of employment, driving licence, educational opportunity, serious injury and, in the most severe cases, death, and that consistent effective treatment should not be altered on questionable cost grounds.”

4. OTHER PARLIAMENTARY ACTIVITY

All-Party Parliamentary Group on Epilepsy at Westminster

The last meeting of the APPG took place during NEW when Health Minister Ann Keen attended to fulfil her promise to announce the Department of Health’s identification of levers and areas of action to support the necessary improvements to epilepsy services outlined in the *Wasted Money Wasted Lives* report.

In accepting the need for her to lead improvements she announced some immediate actions:

- A ministerial letter to all Strategic Health Authorities highlighting the findings of “Time for Change” and the serious shortfalls in epilepsy services in many parts of the country. The letter will urge them to examine their epilepsy services and how well they meet the NICE epilepsy guidelines and encourage them to make improvements. The letter has been drafted and will be sent out in the next week or so (although at the time of going to press and despite repeated requests, no evidence of this has yet been received by the JEC).
- The minister is arranging for the Joint Epilepsy Council to meet with the Director of Commissioning for the NHS, Mark Britnell, within the next four weeks. He is responsible for the department’s World Class Commissioning programme and she is asking him to work with the JEC to identify how World Class epilepsy services should be designed and commissioned. Unfortunately Mark Britnell has since left the NHS

and we are endeavouring to arrange a meeting with his colleague, currently caretaking the post of Director of Commissioning, Gary Belfield.

The next meeting of the APPG is the AGM and is scheduled for Tuesday, 13th October, 2009 in Committee Room 2 of the House of Lords. It is hoped Diana Johnson MP, Parliamentary Under-Secretary to the Department of Children, Schools and Families as will be guest speaker. The meeting will provide an important opportunity to discuss with the Minister responsible for special educational needs the current poor outcomes for children with epilepsy in mainstream education.

Cross Party Group of the Scottish Parliament

The next meeting of the group will take place on Thursday, 24th September at the Scottish Parliament between 1pm and 2pm. Topic and guest speaker to be confirmed.

Please contact Allana Parker at Epilepsy Scotland (AParker@epilepsyscotland.org.uk) if you are interested in attending this meeting.

Programme of Meetings with Politicians and Policymakers

Our programme of meetings with key parliamentarians and policy makers will continue during the parliamentary recess as far as is practicable. Recent meetings have included a teleconference with Ian Salt, Long-term Conditions Manager at the DH, Andrew Pelling MP (CSF Select Committee) and Howard Stoate MP (member of the Health Select Committee).

Contact continues with other key targets and it is expected that further meetings will be arranged to add to our current programme following the return of Parliament in October.

