



OCTOBER 2009

1. JEC AT ILAE ANNUAL SCIENTIFIC MEETING AND VIEWS ON FUTURE PROVISION

The JEC took part in the ILAE Annual Scientific Meeting at Sheffield United Football Club in October, as an alternative to the usual JEC Annual Conference. During this time Executive and Council meetings were held and the JEC had a stand, attracting a number of visitors wanting to learn more about the JEC and its members.

Karen Deacon and I also joined colleagues Rona Eade and Richard Brown, from the NSE and Epilepsy Action respectively, to present a session entitled “How Voluntary Organisations Supplement and Support Epilepsy Services – what has the voluntary sector ever done for you?” The session was reasonably well attended (despite its timing of 8.00 am on Friday morning!) and feedback is currently being processed.



Overall, the JEC Executive feel the link with ILAE this year was a success and are keen to build on communication and involvement with clinicians in future years. We believe an early decision on whether to join in with the ILAE Annual meeting next year could offer a better opportunity for us to ensure joint badging of the event and better presentations to attract JEC members but we also recognise that attendance by JEC members was very low and members have been consulted on their preferences – a joint event at the ILAE meeting or return to the usual stand-alone JEC members conference?

Your responses are very important – please do respond to my email consultation and let me have your views to enable us to make a decision based on your preferences.

2. “BETTER VALUE, BETTER CARE – COMMISSIONING EPILEPSY SERVICES”

Plans continue between the JEC and the Department of Health for an event to be held at the Holiday Inn, Kensington London Forum on Tuesday, 23rd February, 2010.

The conference is aimed at those responsible for commissioning epilepsy services, both adult and paediatric, within the PCTs and SHAs and will include speakers Professors John Duncan, Helen Cross, Mike Kerr and Fiona Irvine. Health Minister,

Ann Keen MP, has been invited to open the event and Earl Howe, Chair of the APPG on Epilepsy at Westminster will chair the conference.

Invitations and flyers will go out shortly. Stand space will be made available to all JEC member organisations. Please confirm with me as soon as possible if your organisation would like to attend in this way.

We are very grateful to UCB Pharma for their sponsorship of this event.

3. PARLIAMENTARY ACTIVITY

All-Party Parliamentary Group on Epilepsy at Westminster

The recent meeting, held on the 13th October, was the AGM of the group, and officers were elected as follows:

Chair: Earl Howe
Vice-Chairs: Cheryl Gillan MP (Cons)
Edward Timpson MP (Cons)
Christine McCafferty MP (Lab)
Paul Truswell MP (Lab)
Norman Lamb MP (LibDem)
Treasurer: John Battle MP (Lab)
Secretary: David Cameron MP (Cons)



We were delighted that the majority of the officers offered to restand; the one change is Edward Timpson who has replaced Sharon Hodgson MP (Lab) who stood down because she has been appointed as Labour Whip.

We were also pleased to welcome Diana Johnson MP, Parliamentary Under-Secretary to the Department of Children, Schools and Families (DCSF) and Professor Helen Cross as guest speakers. Diana listened to group members and Professor Cross voicing their concerns about the effect of epilepsy on a child's education and the serious lack of consideration of the condition in DCSF policy. The Minister promised to take many of the issues back to the department and is meeting further with JEC representatives in November.

The next meeting of the APPG will take place on Tuesday, 9th February, 2010 in CR3 of the House of Lords. Topic to be confirmed.

Cross Party Group of the Scottish Parliament

The Cross Party Group on Epilepsy at the Scottish Parliament also held a meeting next meeting in October. Professor Ian Bone was guest speaker and he gave a very interesting presentation on epilepsy and the law, prompting many questions and a full discussion by MSPs and group members.

The next meeting will take place on Thursday, 26th November at the Scottish Parliament between 1pm and 2pm. The topic will be Epilepsy in the Workplace. Please contact Allana Parker at Epilepsy Scotland - AParker@epilepsyscotland.org.uk if you are interested in attending this meeting.

Cross Party Group at the National Assembly for Wales

There will be a meeting of the Cross Party Group at the Welsh National Assembly on Tuesday, 3rd November, 2010 between 6.00 and 8.00 pm. Please contact Lesley Morris – epilepsywales@aol.com – for further details.

Programme of Meetings with Politicians and Policymakers

Our programme of meetings with key parliamentarians and policy makers will continue with the previously mentioned meeting with Health Minister Diana Johnson and educational targets Paul Holmes MP and Lynda Waltho MP. Also arranged is a meeting with Lord Walton, a member of the APPG and a retired neurologist.

4. Purple Day and National Epilepsy Week 2010

Recommendations to support Purple Day, an epilepsy awareness day originating in Canada and taking place on Friday, 26th March 2010, and a move of date for NEW 2010 to week 13th – 19th June because of the likelihood of a general election at Westminster in May next year were approved by the JEC Executive.

The support for Purple Day will simply be an acknowledgement of the day and the fact that some of our members may wish to consider their own activities in connection with this.

The topic for NEW 2010 was agreed as “Epilepsy and the Under-25s. Some member will continue with the traditional third week in May for their NEW activities where deemed appropriate.