



**APRIL 2009**

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### 1. NATIONAL EPILEPSY WEEK 2009



The JEC is co-ordinating a national lobby of Parliament to keep the pressure on politicians to improve services for people with epilepsy during this year's National Epilepsy Week (17<sup>th</sup> – 23<sup>rd</sup> May).

The event will take place in the Jubilee Room, just off Westminster Hall at the House of Commons on the afternoon of Wednesday, 20<sup>th</sup> May between 1.30 and 4.00 pm. All JEC member organisations are being asked

to mobilise their members, supporters and members of staff to contact their local MP to ask them to meet with them at the lobby to discuss not only their own experiences of epilepsy and how it impacts upon their lives, but also how MPs can help to improve the way epilepsy services are delivered to benefit everyone with the condition. It is hoped that as many people as possible from all areas of the UK will make the journey to lobby their MP and help raise the profile of epilepsy.

A template letter is available for people to use to contact their MP and this will be circulated to all member organisations and can also be found on the JEC website – [www.jointepilepsycouncil.org.uk](http://www.jointepilepsycouncil.org.uk). A briefing paper containing key messages and relevant statistics for all people attending is also being prepared.

After the event, each MP at Westminster will receive a letter outlining the key messages from the day together with a copy of the review of the APPG report into epilepsy services *Wasted Money Wasted Lives*. This review is currently being produced and will be circulated to all members as soon as it is finalised.

#### **Additional Parliamentary Activity**

Lobbying activities will take place in other Parliaments in the UK during National Epilepsy Week.

There will be a JEC display stand in the Scottish Parliament on the 20<sup>th</sup> and 21<sup>st</sup> May with Epilepsy Scotland manning the stand on the 20<sup>th</sup> and a photo opportunity for MSPs on the 21<sup>st</sup>. Further details can be obtained from Allana Parker at Epilepsy Scotland (AParker@epilepsyscotland.org.uk.)

At the National Assembly for Wales, the All Wales Epilepsy Forum (AWEF) will be hosting a JEC sponsored Epilepsy Aware Public Day at the Welsh Assembly on Wednesday, 20<sup>th</sup> May. Invitations have been sent to all Assembly Members and to Local Health Board Executives. In addition, clients and members of the AWEF charities have been asked to write a personal letter to their A.M.'s asking to meet them there. This will give people affected by epilepsy the opportunity to talk to their AM's about epilepsy services in Wales; will give the Local Health Board members an opportunity to find out more about the Service Level Directive direct from the Assembly; and for the AWEF to promote the services the individual charities can offer clients around Wales.

During May and June the AWEF will be staging a series of Epilepsy Aware Road shows around the new 7 local health boards in Wales – again an opportunity to promote the new Welsh Assembly Service Directive for Epilepsy to the professional ranks, and for the AWEF charities to promote the services they can offer to both the epilepsy specialists and to the people affected by epilepsy. Further details can be obtained from Lesley Morris, Epilepsy Wales (epilepsywales@aol.com).

In Northern Ireland, Epilepsy Action is staging an awareness event in the Long Gallery in Stormont from 12.00 pm to 3.00 pm on Monday, 18<sup>th</sup> May. Further details from Morina Clarke (mclarke@epilepsy.org.uk.)

In addition to this, many JEC member organisations are planning their own awareness and fund-raising activities during National Epilepsy week which include a River Clyde zip slide, an epilepsy road show at Oxford University, and sponsored walks and runs. Further details of all these can be found on the JEC website.

## **2. JEC AGM – NOMINATIONS FOR EXECUTIVE DIRECTORS REQUIRED**

2009's JEC Annual General Meeting will take place on Thursday, 2<sup>nd</sup> July, and will be hosted by Epilepsy Scotland at their Govan offices in Glasgow. Please ensure this is in your diary.

Elections for Directors to join the JEC Executive will take place and I would ask you to seriously consider standing or making a nomination to the JEC Executive Committee, the Board of Directors who work closely with me setting and delivering the organisation's strategic objectives. The JEC is a member organisation and exists to represent your interests working for the benefit of people affected by epilepsy. Joining the Executive Committee is a positive and practical way in which you can help direct the work of the organisation.

I, or any other member of the current Executive Committee, would be pleased to discuss any aspects of the role of an Executive Director, confidentially and without commitment if required. Please do not hesitate to give me a call if you are unsure about what it might entail.



*Please do consider your nomination to the JEC Executive.*

### **3. JEC LAUNCHES NEW STRATEGIC PLAN**

Work is now completed on a new JEC Strategic Plan for the period 2009-2011. Objectives, under four Key Aims, are designed to drive the work of the General Secretary, the Executive, our Lobbying provision and the JEC Working Groups to represent the united voice of epilepsy in the UK and Ireland and to present evidence based views on the need for improved epilepsy services and influence decision makers in the health, social and education arenas. Please contact me if you require further copies of the Strategic Plan.

### **4. OTHER PARLIAMENTARY ACTIVITY**

#### **Programme of Meetings with Politicians**

A programme of meetings with key parliamentarians will continue with meetings currently scheduled for discussions with Health Select Committee members Lee Scott and Greg Mulholland, and DCSF Committee members John Heppell and Andrew Pelling.

Contact continues with other key targets and it is expected that further meetings will be arranged to add to our current programme.

#### **Epilepsy in England: time for change**

In January Epilepsy Action launched the *Epilepsy in England: time for change* report at an event at the House of Commons. The launch was attended by MPs, Lords, health trusts, key organisations and people with epilepsy.

The report draws on the results of a survey of health trusts in England and a survey of people with epilepsy. As expected, following on from evidence in the *Wasted Money Wasted Lives* report, the results of the surveys revealed a concerning variation in the provision of epilepsy services and serious variations in the collection of information and the quality of care.

The key findings include:

- Despite NICE guidelines that all people with suspected epilepsy should be seen by an epilepsy specialist, half (49 per cent) of acute trusts do not employ one.
- Despite NICE guidelines stating that all people with suspected epilepsy should be seen urgently (within two weeks), most trusts (more than 90 per cent) have waiting lists of longer than this.
- Despite NICE guidelines stating epilepsy specialist nurses (ESNs) should be an integral part of the medical team providing care to people with epilepsy, well over half of acute trusts (60 per cent) and of PCTs (64 per cent) do not have one.

Epilepsy Action hopes this will provide a basis for the JEC lobby of Parliament during National Epilepsy Week, on May 20.

If you would like to read the report and have not already seen a copy, they are available from Epilepsy Action (telephone 0113 210 8877 or email [pscott@epilepsy.org.uk](mailto:pscott@epilepsy.org.uk)). Alternatively the full report and the individual data returned by each trust can be found on the Epilepsy Action website at <http://www.epilepsy.org.uk/timeforchange> .

### **Ann Keen debate**

Members of Parliament were then given the opportunity to debate the Time for Change report, and the general provision of epilepsy services, in an Adjournment Debate in Westminster Hall on the 24<sup>th</sup> February.

The debate proposed by Calder Valley MP Chris McCafferty and attended by Health Minister Ann Keen, raised many of the JEC's main concerns over epilepsy services, including trusts not implementing the current National Institute for Health and Clinical Excellence (NICE) guidelines. Access to epilepsy specialists, waiting times for an appointment after a first seizure and the new Care Quality Commission were also discussed.

The Minister indicated that she would be writing to strategic health authorities to draw their attention to Time for Change's recommendations.

### **All-Party Parliamentary Group on Epilepsy at Westminster**

The next meeting of the group will take place on Wednesday, 22<sup>nd</sup> April, 2009 in the Wilson Room at Portcullis House, Westminster between 4.00 and 5.00 pm. Sarah McCarthy-Fry MP, Parliamentary Under-Secretary Department for Children, Schools and Families will be present. 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. As usual I would ask you to encourage your local and supportive MPs to attend.

Representatives from JEC member organisations are also very welcome to attend but please advise the JEC General Secretary for security purposes.

A further APPG meeting is planned to take place during NEW when Health Minister Ann Keen has promised to attend to feed back on the identification of levers and areas of action for the Department of Health, local health communities and the third sector to support the necessary improvements to epilepsy services outlined in the *Wasted Money Wasted Lives* report. This meeting will take place on Wednesday, 20<sup>th</sup> May at 4.00 pm in Committee Room 2 of the House of Lords.

### **Cross Party Group of the Scottish Parliament**

The next meeting of the group will take place on Thursday, 30<sup>th</sup> April in Committee Room 4 of the Scottish Parliament between 1pm and 2pm. The topic is Epilepsy and Mental Health, with guest speaker Sue Copstick.

Please contact Nicole Wright at Epilepsy Scotland ([NWright@epilepsyscotland.org.uk](mailto:NWright@epilepsyscotland.org.uk)) if you are interested in attending this meeting.