

MINUTES OF MEETING OF ALL-PARTY PARLIAMENTARY GROUP ON EPILEPSY

12th October, 2011 – Services for People with Intractable Epilepsy

4.00pm Meeting Room T, Portcullis House

Attendees

Laura Sandys MP

Russell Brown MP

Paul Maynard MP

Teresa Pearce MP

Valerie Vaz MP

Matthew Lennon (Diana Johnson MP's office)

Susan Whitaker

Sharon Wood, JEC

Phil Royal, JEC

Marie Baker, Dravet Syndrome UK

Simon Wigglesworth, Epilepsy Action

Monica Kendall, Epilepsy HERE

Roger Kendall, Epilepsy HERE

Graham Faulkner, Epilepsy Society

Emma Williams, Matthew's Friends

Josh Coleman, National Centre for Young People with Epilepsy (NCYPE)

Alan Cruikshank, NCYPE

Karen Deacon, NCYPE

Sophie Bryant, Volunteer

Apologies

Stuart Andrew MP

Caroline Lucas MP

1. Annual General meeting

Laura Sandys (LS) welcomed participants to the meeting and group officers were elected as follows:

Laura Sandys MP (Chair)

Valerie Vaz MP (Vice Chair)

Teresa Pearce (Vice Chair)

Paul Maynard (Secretary)

Baroness Ford (Treasurer)

2. Valerie Vaz (VV), Sharon Wood (SJW), Karen Deacon (DC) and Simon Wigglesworth (SW) fed back on the meeting earlier that day with the Prime Minister, David Cameron, to discuss issues around VV's 10MRB, including his offer to assist in raising awareness of epilepsy and to endorse the forthcoming Education Seminar, sponsored by VV and Sam Gyimah MP and supported by the JEC. A letter will be sent to David Cameron confirming the issues he offered to investigate and it was agreed that very careful consideration should be given to the unique opportunity to raise awareness with the Prime Minister's help.

LS advised that James Duddridge MP and Conservative Whip, has also offered his help in raising awareness of epilepsy. Additionally, Mike Penning MP and Transport Minister has recently been involved in a review for people with diabetes. LS suggested lobbying for a review of people with epilepsy and would like the APPG to write to him to confirm that the group hopes he will be looking at epilepsy, setting out the relevant issues. SW suggested that the reviews were part of the current European driving requirement reviews.

The recent withdrawal of restrictions on people with epilepsy climbing the tower of Big Ben due to health and safety reasons were welcomed by the group and LS confirmed her interest in climbing the tower as an awareness raising media opportunity. Paul Maynard (PM) agreed to join her. SJW agreed to discuss this further with LS/PM, together with the JEC Marketing and Communications Group in order to make arrangements for an event as soon as possible.

3. Marie Baker (MB) of DRAVET Syndrome UK and Emma Williams (EW) of Matthew's Friend's, two voluntary organisations working for children and adults with intractable epilepsy, were welcomed by LS to give their presentation on Intractable Epilepsy – what happens when the medication does not work? A report of their presentation is attached.

LS thanked MB and EW on an informative and moving presentation and opened the floor to questions.

Graham Faulkner (GF) advised the group that whilst some charities, such as Matthew's Friends and Daisy Garland fund dieticians, persuading local authorities to retain the posts following cessation of charity funding is often problematic. EW confirmed that Matthew's Friends have opened a Ketogenic Dietary Therapies Clinic based in Lingfield, Surrey, as a response to the lack of facilities, taking referrals for both children and adults.

PM asked whether dietary treatments were endorsed by NICE and whether there was any financial evidence available as to how adoption of a Ketogenic diet might save money.

EW responded that efforts are currently underway to finance a health economic study in order to make a stronger case for the treatments, but at the moment there is no definitive case, improvements for people with intractable epilepsy adopting the diets and showing substantial reductions in seizure activity are purely anecdotal.

SW advised that the revised NICE guideline for epilepsy, due for publication in early 2012, does recommend the Ketogenic diet for children for the first time.

LS asked how many families Matthew's Friends has on their books and EW responded that they helped approximately 1,000 families by way of supplying information, but were regularly in touch with 100's of families.

GF advised that the Epilepsy Society are currently researching genetic links and the Ketogenic diet and results should be available next year which it is hoped will influence commissioning under the new structures. The National Centre for Young People with Epilepsy (NCYPE) is working on similar initiatives.

EW advised that in general, one third of patients will not respond to a Ketogenic diet, one third will respond with limited improvement in their condition and one third will respond extremely well with a dramatic reduction in their seizures.

SW raised the situation regarding a further alternative therapy for epileptic seizures – Vagal Nerve Stimulators (VNS). Whilst not as effective as the Ketogenic diet, for some people with intractable epilepsy, this small device that is implanted under the skin and sends electrical impulses to the brain via the vagus nerve, is able to reduce seizures. About 3,500 people in the UK use this device at the moment, but information has recently been received that East Midlands Commissioning Group have imposed a ban on such implants in their area and are looking to influence a ban nationwide. The epilepsy world is concerned about this development and will be making representation against its implementation.

MPs present agreed that this device should be available as a treatment for seizures and asked for a letter outlining inconsistencies of availability and concerns that VNS are going to be removed from the commissioning roster, together with how this device offers savings in terms of A&E admissions etc.

The meeting closed at approximately 5.00pm.