The All-Party Parliamentary Group on Primary Headache Disorders

AGM
Tuesday 8th July, 4pm Meeting Room S, Portcullis House

Member Attendees:
Jim Fitzpatrick MP for Poplar & Limehouse
Baroness Masham of Ilton
Viscount Simon
Jeremy Lefroy MP for Stafford
Stephen O’Brien MP for Eddisbury

External Attendees:
Hannah Verghese, APPG Coordinator/The Migraine Trust
Wendy Thomas, The Migraine Trust
Peter Wynne Davies, OUCH UK
Clive Clifton, TNA UK
Simon Evans, Migraine Action

Welcome:
JF welcomed attendees to the meeting and introduced the agenda for the AGM. Papers were circulated.

Election of Officers:
JF confirmed that he would continue his post as chair of the group for a further year. This was supported by all officers in the room. S’OB was elected as a new vice-chair of the group with support from all the officers in the room. JF welcomed Virendra Sharma MP for Ealing Southall as a new qualifying member of the APPG. There were no further changes to the register. JF thanked BM, VS, JL, S’OB for their continued commitment to the group.

Summary of Activities:
JF summarised the APPG’s activities over the last year. The group’s work has focused on an inquiry into headache services in England. As part of the call to evidence the group held 2 oral evidence sessions in the House of Commons. The final report was launched at a reception in June. JF thanked the expert speakers & the APPG members & officers who supported the inquiry. BM noted that the last year’s work was excellent.
**APPGPHD Report in to Headache Services – work plan**

JF explained that in the lead up to the election next year the group would be undertaking a series of activities to raise the profile of headache disorders and the report. JF summarised the work plan including writing to appropriate minister, front bench health team, scheduling parliamentary questions, asking constituents to contact their MPs and writing to local & national NHS departments. JF invited comments from the attendees. S’OB noted that the group could widen the scope to have headache included as a public health issue given the number of people it affects. S’OB explained that this would draw wider attention and therefore raise the profile. JF agreed that this was an excellent idea due to the different budgets; he proposed explicitly mentioning this in the letters & pushing the stats in the public domain. BM noted that it was also important to raise the impact on employment and the economy.

WT suggested that parliamentary questions on headache disorders would be useful. JF agreed that parliamentary questions were a good idea to push the profile of headache disorders. He noted it is important that questions come from a wide source. S’OB noted the role that constituents can take in contacting their MP for questions. JF & HV agreed that questions would be drafted from the report. S’OB proposed that the group define a sentence on prioritising the health conditions that affect such a large group of people to be put forward for each party’s manifesto. JF noted that as the APPGPHD it would be important that headache disorders were explicitly mentioned in this since the group wants headache services to be included and prioritised. This was agreed as a good idea by the group.

**Upcoming meeting priorities:**

JF explained that alongside the report work plan the group would also be holding more meetings in the coming year. Attendees were asked for priority areas based on their knowledge and experience of current issues. PWD raised the problem of employment issues amongst cluster headache suffers as an important theme. BM noted that oxygen is a treatment for cluster headache but that there are issues around access and this could be a valuable discussion. HV suggested that, in light of the UK Strategy for Rare Diseases a meeting on Trigeminal Neuralgia in relation to the strategy could be very timely. JF agreed that this was a timely topic that would attract interest and that Professor Zakrzewska, an international expert on the condition would be the choice speaker. S’OB noted concern that this did not distract from the group’s work plan as the issue with rare conditions can move away from the focus on the report and the ‘mass’ issue of headache disorders. JF agreed but noted that this would be a separate single meeting and would not be part of the report work plan.

**Close:**

JF thanked the attendees for their time and the valuable discussion and closed the meeting. Attendees were informed that HV would circulate the papers electronically.