



House of Commons
London SW1A 0AA

The All-Party Parliamentary Group on Primary Headache Disorders

Summer Reception 2014

6pm – 8pm, Tuesday 17th June 2014 The Macmillan Room, Portcullis House

MP's, health professionals, commissioners, academics, charities and patients came together on Tuesday 17th June for the 2014 Summer Reception of the APPG on Primary Headache Disorders (APPGPHD). The meeting was chaired by Jim Fitzpatrick, MP for Poplar and Limehouse, and launched the APPG's new report, 'Headache Services in England'.

The APPGPHD's report details the finding of the group's 2013-14 inquiry into services for headache patients in England. The inquiry panel, led by Mr Fitzpatrick MP found that the provision for headache services can be both improved and made more cost-effective, simultaneously saving capacity in overstretched neurology outpatient and A&E departments. The report makes 10 clear recommendations and urges the government and NHS England, as well as the other key stakeholders identified in the report, to take these forward.

Over 70 guests, including MPs, health professionals, academics, stakeholder groups and patients, attended the reception. Jim Fitzpatrick MP, Professor Carl Clarke, Professor Goadsby and Arlene Wilkie all addressed the reception and spoke of the importance of the new report.

Jim Fitzpatrick MP gave thanks to the individuals and organisations who had contributed to the report and to the inquiry. He thanked the other members of the inquiry panel, Mr Virendra Sharma MP, Mr Stephen O'Brien MP, Baroness Masham of Ilton and Mrs Pauline Latham MP for their time as well as the members and officers of the APPG for their ongoing support. Mr Fitzpatrick stressed the important role each attendee & supporter of the group now has in contributing to the impact that the report can have. He encouraged people to write to their MP about the report as well as share it amongst their colleagues and peers. Mr Fitzpatrick explained that the APPG were committed to the success of the report and its' recommendations and will be working to ensure it is presented to the appropriate ministers & groups.

Professor Carl Clarke from Sandwell and West Birmingham Hospitals NHS Trust spoke of the benefits of adopting a headache nurse model for CCGs. Professor Clarke, who attended with Birmingham Headache Nurse, Julie Edwards, was instrumental in setting up the diagnostic nurse specialist model which is now an integral part of the neurology service, contracted with the CCG. Professor Clarke praised the APPG report, and particularly commended the recommendation to extend the headache nurse specialist model to all primary and secondary care specialist headache services in England. He

called for more investment overall for headache services in England to improve the outlook for patients.

Professor Peter Goadsby, Director of the NIHR- Wellcome Trust Clinical Research Facility at Kings College Hospital London thanked the MPs and members of the House of Lords for the report and their commitment to primary headache disorders. Professor Goadsby said that the report 'gets it right', praising its' emphasis on the needs of the patients, the need for greater public awareness, clinical care and better headache education of health professionals. Professor Goadsby supported the report's recommendations to improve the standard of headache care through headache specific indicators in the CCG Outcomes Indicator Set and the Quality Outcomes Framework. He urged attendees to get behind this report and for NHS England and the government to implement the changes. Professor Goadsby called for those attendees and people receiving the report to engage with their MPs on the issues highlighted on the report. His call to action was supported by the MPs in the room. Professor Goadsby concluded by explaining that unfortunately, at present, this country does not invest in headache services enough. He explained that the current investment in headache research is unsatisfactory & disappointing. "Patients deserve better", he said, "and England could do better".

Arlene Wilkie, Chief Executive of The Neurological Alliance was the final speaker at the event. Arlene expressed disappointment that the APPG's findings reveal that there has been little change for headache and migraine patients despite the recommendations made by the Public Accounts Committee to improve neurology services in 2012. Arlene explained that, sadly, the issues described in the report, lack of specialist nurses, poor public awareness, lack of clearly defined pathways etc. are similar amongst almost all neurological conditions. Arlene explained that given the prevalence of primary headache disorders it was particularly disappointing that the NHS could not get this right. She drew attention to the positive progress that was being made in the field of neurology. The appointment of a National Clinical Director for Neurology, the establishment of Strategic Clinical Networks for neurology and the introduction of a national database and intelligence network for neurology were all huge achievements in the last 2 years. Arlene encouraged attendees and those with an interest in headache services to engage with the National Clinical Director and SCNs about headache services. She also encouraged those in attendance to comment on the new neurology intelligence network, launched this month by Norman Lamb MP. This provides an opportunity to influence commissioners, highlight the recommendations in the report and raise awareness of the issues for headache disorder patients.