

ME in Parliament



Brief Report on the APPG Meeting on ME

8th October 2008

Venue: House of Commons, Room 18, 3-5pm

Present were: Dr Des Turner MP (Chairman), Andrew Stunell MP, Tony Wright MP (Vice Chairmen), five other MPs, The Countess of Mar, Dr Charles Shepherd and Tony Britton (MEA), Sir Peter Spencer and Heather Walker (AfME), twelve representatives from ME/CFS charities and other organisations, plus other ME/CFS patients.

Key focus of this meeting was a presentation by the **Rt Hon James Purnell MP**, Secretary of State, DWP, about the Welfare Reform Green Paper, changes to Incapacity Benefit (ICB) and the introduction of the Employment Support Allowance (ESA). He was accompanied by **Dr James Bolton**, Deputy Chief Medical Adviser at the DWP.

Reform of this arm of the benefit system was necessary to concentrate on what people could do rather than what they could not do. This would be achieved by implementing new schemes (Pathways to Work and Access to Work) and providing additional financial help to enable disabled people to resume work. Particular problems of ME/CFS patients were not mentioned by the Minister - his presence was limited to 30 minutes during which time many questions were raised on a range of aspects, including problems faced in assessing patients with ME/CFS, the Appeals procedure, still existing scepticisms about the reality of ME/CFS, the need for assessors to take note of patients' GP notes, hostility by employers towards ill or disabled people returning to work and reviews of DWP medical guidance for adjudicators and medical examiners.

The Minister gave relatively reassuring answers to most questions. The more disabled would receive increased benefits. It was made clear that patients are worried about losing benefits as a result of these changes to the ICB.

Matters discussed after the Minister's departure concerned child protection issues – an update on matters discussed at the July 2008 APPG meeting, a brief report by The Countess of Mar on an earlier meeting with charity representatives on the establishment of a new group, a proposed APPG Inquiry into NHS Service Provision for people with ME/CFS, and 2 presentations by Diane Newman entitled 'ME Services – A Template for a UK-wide Module' and 'Mental Health Act and Mental Capacity Bill – Implications for people with ME'. Diane will provide a summary of these presentations for the full Minutes of this meeting.

Following further queries on the Minutes of the July 2008 APPG meeting, The Countess of Mar proposed that in future amendments to minutes must be received by the Secretariat no later than a week before the next meeting takes place.

The next APPG meeting was provisionally scheduled for early December 2008.

More detailed comments on this APPG meeting were prepared by Dr Charles Shepherd and can be accessed at: www.meassociation.org.uk/content/view/673/70/

Many thanks to Doris Jones for attending these meetings on our behalf.

25% ME Group Response to the draft Terms of Reference for the APPG Inquiry on NHS Service Provision For People with ME

14th November 2008

The 25% ME Group believe there should be a delay to this process to facilitate wider consultation amongst the ME community. We feel that :-

There has not been proper scrutiny of the Terms of Reference to this Inquiry.

More time should be allowed for this process to take place in a more realistic and generous timeframe.

Consultation should be much wider in order to make sure other ME charities are fully involved in the process.

The NICE Judicial Review is an important element to be considered, and we call for the process of the APPG Inquiry into NHS Services to be delayed until the case has been heard.