

ME in Parliament



Brief Report on APPG on ME Meetings

Doris Jones was unable to attend the July 2009 meeting, but prepared a submission to the APPG's Inquiry into NHS Services in England on behalf of the 25% ME Group, which was presented at the first Oral Evidence Session on 9.7.2009 (details are on the 25% ME Group's website).

The 8th July APPG meeting was attended by the Chair, Dr Des Turner MP, the Countess of Mar and 4 other MPs, representatives of the Secretariat, plus 9 other patient group representatives and persons with ME. No special speaker was present at this meeting, which incorporated the re-election of officers of the group as part of the AGM's agenda. All were re-elected, apart from Dr Ian Gibson who had resigned as an MP – the Countess of Mar had replaced him. Dr Turner announced he would not stand at the next General Election. Some details of the forthcoming Oral Evidence sessions for the APPG's Inquiry into NHS Services were discussed – the first would hear from patients and patient organisations; it was hoped that the second session would include a Minister, the CMO and service providers. Many patients had submitted evidence. The Countess of Mar outlined some problems they encountered in collating information for the Inquiry. The WMMEG Statement submitted at the last meeting was discussed, as was the future work of the APPG and the Group's Legacy Paper.

The next APPG meeting took place on 21.10.2009 and was attended by Dr Des Turner (Chair), the Countess of Mar, 4 MPs and the Rt Hon Yvette Cooper with Parliamentary Office representatives from the DWP and Dr James Bolton, Deputy CMO, DWP. Also present were the Secretariat, numerous representatives of patient groups and patients. This meeting was well attended. The APPG Inquiry into NHS Services in England as well as the Group's Legacy Paper were discussed before Yvette Cooper and her staff addressed the meeting. She gave a few details of her background and personal interest in the group, as she had ME in 1993. She then tried to answer many questions – some prepared and submitted in advance to the Chair, some directly from attendants. She said the DWP had been working on the new work capability assessment and they had tried to ensure that employment support allowance (ESA) took account of fluctuating conditions like ME. She summed up saying they will try to ensure that those people who can work are given adequate support and they will continue to review the position on social care more widely.

The 2nd December 2009 meeting was attended by the Chair, Dr Des Turner MP, the Countess of Mar, 5 other MPs, the Minister of State for Health Mike O'Brien MP, plus DoH staff, as well as the Secretariat and patient group representatives and patients.

This was an important meeting because the Minister had been invited to give his response to the Interim Report on NHS Service provision for people with ME in England. Copies of this report were provided to all attendants at the meeting and the Chair explained that the group had not yet

been able to prepare the full report due to limited resources, but this would be available in due course. He summarized briefly the 11 recommendations in this Interim Report, stating these would remain unchanged in the final report. The Minister then gave his response to the report (see separate coverage) and answered questions from the group. The remaining time of the meeting was devoted to discussing the APPG Legacy Paper, some comments on the XMRV virus and related research, access to APPG meeting venues, a welfare reform bill update – with particular thanks to Lady Mar who had worked hard on these issues at various stages. ME patients are still experiencing great problems in the welfare benefits system. Queries raised under AOB concerned the Lightning Process, the CCRNC metamorphosing into the British Association of CFS/ME (BACME), details on adult as well as child protection to be incorporated in the Legacy Paper, and confirmation that the APPG Inquiry Report would be available on the group's website.

The most recent meeting of the group took place on 10th March 2010. Dr Charles Shepherd has released a brief personal summary of this last meeting of the current APPG on ME before the General Election on Co-Cure (Digest 12-13.3. #2010-70). He described this as a 'friendly and harmonious occasion', which finished with a vote of thanks to the Chair who is retiring from Parliament, and all parliamentarians involved in this APPG. A new APPG on ME will need to be formed after the election provided enough parliamentarians are willing to take on the tasks. This meeting was attended by Dr Des Turner MP (Chair), the Countess of Mar, Nick Osborne (who had collated the APPG Inquiry Report), the Secretarial and patient group representatives and some patients. Vanessa Stanislas, CEO of the Disability Alliance, gave a presentation on issues surrounding disability poverty, distributing copies of a relevant booklet produced to bring these issues to the attention of all political parties before the General Election. This can be accessed on <http://www.disabilityalliance.org/damanifesto.htm> . Vanessa highlighted some important facts on disability poverty – disabled people are twice as likely to live in poverty as other citizens. – Copies of the full APPG Report on the Inquiry into NHS Services for ME were distributed; this is also available on the MEA's website. Copies will be circulated to the CMO, DWP, PCTs + SHAs, Medical Royal Colleges and other professional bodies (e.g. Royal College of Nursing etc). Copies of the final version of the APPG Legacy Paper were distributed to those present.

Thanks to Doris Jones for this Report