



All Party Parliamentary Group on M.E.

Chair:	Des Turner MP
Vice-Chairs:	Andrew Stunell MP Tony Wright MP
Secretary:	Ian Gibson MP
Treasurer:	David Amess MP

Minutes of the meeting of the All Party Parliamentary Group on M.E.
held at 1.30-3pm, Wednesday 1 April 2009
Committee Room 20, House of Commons

Present

Parliamentarians

Dr Desmond Turner MP (Chair)
Andrew Stunell MP (Vice Chair)
Peter Luff MP

Parliamentary office representatives

Koyes Ahmed, office of Dr Turner MP
Ceri Finnayson, office of Edward Davey MP

Secretariat

Sir Peter Spencer (Action for ME)
Heather Walker (Action for ME)
Tony Britton (MEA)

Organisations and individuals

Dr Derek Pheby (ME Research Observatory)
Kirsty Haywood (Royal College of Nursing)
Sue Waddle (MERUK)
Paul Davis (RiME)
Jane Colby (Tymes Trust)
Doris Jones (25% Group)
Joy Birdsey (K&SAME)
Jill Cooper, Warks
Stephen Jones
Augustin Ryan
Alan Gold
Annette Barclay
Joan Duvey
Michelle Goldberg
Jill Cooper
Samantha Brown with Max Cotton (BBC Politics Show)

Apologies:

Parliamentarians: Anne Begg MP, Angela Browning MP, Andrew Dismore MP, William Etherington MP, Kelvin Hopkins MP, Dr Brian Iddon MP, Ann Keen MP, Kerry McCarthy MP, Iris Robinson MP, Rudi Vis MP, Countess of Mar, Lord Puttnam

Non-parliamentarians: Dr Charles Shepherd, MEA, Christine and Tanya Harrison, BRAME, Janice and Bill Kent, Member, Janet Taylor (Kirklees Independent ME Support Group), Ciaran Farrell.

1. Welcome

The Chairman welcomed those present and explained that the meeting was joined by Max Cotton, BBC Politics Show, who was filming for a future programme featuring a person with M.E., plus a transcriber from Hansard, who would produce a verbatim note of the meeting. The verbatim note would be made available in addition to more concise business minutes produced by the Secretariat.

2. Minutes of the last meeting

The meeting agreed to:

- i. Delete from item iii.f: "He also asked if the services inquiry would cover research", as this was not said by Paul Davis.
- ii. State that the Strategic Framework Document that Nicky Zussman referred to at the APPG of 8th July 2008 was:
"Children and Young People's Emotional and Mental Health in East Sussex 2005 – 08. The Strategic Framework for Commissioning and Planning Services. Appendix 4: Mental health of children and young people – classifications and definition."

3. Matters arising

The meeting agreed to:

- i. note that the Welfare Reform Bill was proceeding through the House of Lords

4. APPG Inquiry on NHS service provision for people with ME

- i. Committee: The Chair announced that the Parliamentarians who will be considering evidence would be: Dr Ian Gibson MP, Tony Wright MP, Andrew Stunell MP, the Countess of Mar, Baroness Finlay and the Chair, Dr Des Turner.

Later in the meeting (under Terms of Reference), Peter Luff MP said he would like to be party to the process of obtaining information from health authorities, at which point the Chair invited him to join the inquiry group.

- ii. Terms of Reference: The Terms of Reference (ToR), amended following feedback after the last meeting, were circulated.

The amended ToR were discussed in detail. It was decided that: while the APPG accepted the WHO definition of ME, the inquiry recognised but could not be delayed by debates about terminology and would look at services on offer to people classified as having either ME or CFS (but see below). There would be no further consultation on the amended terms of reference.

- iii. Inquiry questionnaires and submissions of written evidence:

- a. There would be two questionnaires: one for people with M.E./carers, one for PCTs.
- b. Questionnaires to PCTs would ask questions about the criteria for diagnosis and ask about the basis of estimates of people with M.E.
- c. There would also be a patient survey.
- d. People who were not at the APPG meeting would have a chance to give evidence.
- e. Anonymity would be granted to people who are prepared to give evidence. No individual would be named in the inquiry report without their express consent.
- f. The way in which patient outcomes are measured will include adverse reactions to treatment and people dropping out of treatments.
- g. To capture current USFDA guidance on how the inquiry measures and understands patient outcomes, it should refer to the term “patient-reported outcome.”
- h. Kirsty Haywood would provide the Chair with an advance copy of her paper on patient reported outcomes, as submitted to the journal of the Royal Society of Medicine.
- i. ME sufferers, carers or professionals were all welcome to submit suggestions for specific questions that could be asked in the survey. The deadline for receiving ideas was 5 May.

- j. It was recognised that the timetable was demanding and the scope of the inquiry was limited by lack of time and resources but the parliamentarians present agreed that such a timetable was necessary if the inquiry was to complete the evidence-taking process before the summer recess and publish a report before the run-up to the next general election.
 - k. A press release about the launch of the inquiry would be issued straight away.
- iv. Inquiry website: it was hoped that a website, with full timetable details of the inquiry, would be up and running shortly.

5. Any Other Business

Two documents were tabled by the Secretariat on behalf of organisations who were not able to attend the meeting.

- i. The first document tabled should have been a statement by the West Midlands ME Groups Consortium (WMMEG), entitled ME/CFS - *Education and training in the NHS* / NHS CCRNC conference (link: <http://www.afme.org.uk/res/img/resources/NHS%20%20ME-CFS%20-%20Education-Training%20 Statement%20-%20WMMEG%20200903 .pdf>).

However, a supplementary WMMEG statement from 2007 was tabled instead, in error. The correct statement was circulated electronically, with apologies, the following day.

- ii. The second document tabled related to Care Quality Commission proposals to make NICE recommendations (for all conditions) mandatory (link: <http://www.pulsetoday.co.uk/story.asp?storycode=4121395>) . This matter was brought to the attention of the APPG by BRAME.

It was suggested that a representative from the Care Quality Commission should be invited to address the next meeting.

6. Date of Next Meeting

24 June 2009 (*subject to speaker availability*)