



All Party Parliamentary Group on M.E.

Chair: Des Turner MP
Vice-Chairs: Andrew Stunell MP
Tony Wright MP
Secretary: Countess of Mar
Treasurer: David Amess MP

DRAFT

Minutes of the meeting of the All Party Parliamentary Group on M.E.
held at 1.30-3pm, Wednesday 21 October 2009
Committee Room 20, House of Commons

Present

Parliamentarians

Dr Desmond Turner MP (Chair)
Andrew Stunell MP (Vice Chair)
Tony Wright MP (Vice Chair)
Countess of Mar
Bill Wiggin MP
Russell Brown MP
Rt Hon Yvette Cooper, Secretary of State for Work and Pensions

Parliamentary office representatives

Koyes Ahmed, office of Dr Turner MP
Christopher Hares, office of Rt Hon Yvette Cooper, Secretary of State for
Work and Pensions
Dr James Bolton, Deputy CMO, Department for Work and Pensions

Secretariat

Sir Peter Spencer (Action for ME)
Heather Walker (Action for ME)
Tristana Rodriguez (Action for ME)
Charles Shepherd (MEA)

Organisations and individuals

Natasha Posner, University of Warwick, Royal College of Nursing
Doris Jones, 25% ME Group
Janice Kent, reMEMber
Jill Cooper, Warwickshire Network for ME
Colin Barrat, Network MESH West London
Catherine Ross
Bill Kent, reMEMber
Joy Birdsey, KASAME Group
Ciaran Farrell
Paul Davis RiME
Michelle Goldberg

Christine Harrison, BRAME
Jo Dubiel, person with M.E.
Augustine Ryan
Annette Barclay, person with M.E.
Colin Barton, Sussex and Kent ME/CFS Society
David Butler, Sussex and Kent ME/CFS Society
Laurence Swift
Nicky Zussman

Apologies:

Parliamentarians:

Hugh Bayley MP, Tim Boswell MP, Peter Bottomley MP, Angela Browning MP, Nigel Evans MP, Sandra Gidley MP, Peter Luff MP, Kerry McCarthy MP, Edward O'Hara MP, Gavin Strang MP

Non-parliamentarians:

Mary Jane Willows

1. Welcome

The Chair welcomed all and confirmed that Yvette Cooper would be speaking. In view that she had not yet arrived the agenda would be rearranged to avoid wasting time.

2. Minutes of 8 July 2009

The meeting agreed to:

- a) Remove Doris Jones from the list of attendees as she had not in fact been able to attend that particular meeting.

The minutes were then adopted as a true record.

3. Matters arising

a) APPG Inquiry on NHS service provision for people with ME

The Chair advised the group that the inquiry was approaching a first working draft and that the final report could be expected in December.

Sir Peter Spencer commented that it was important that the Inquiry report be circulated in advance of the next meeting if it was to be discussed at that meeting, in order to give people opportunity to read it.

Paul Davis made the point that some people felt that matters outside the terms of reference of the Inquiry were allowed by the Chair. The Chair stated that he had been flexible.

Christine Harrison stated that she hoped that the report would have impact on replacing services which had been closed in her local area, and the Chair agreed that this was his hope also.

The Chair also identified the need to consider his replacement as Chair when the APPG is reformed after the next General Election

The meeting agreed to:

- a) Make the report the subject of the next meeting and invite a health minister to attend
- b) Schedule the next meeting for 2 December in order for the Chair to attend

b) APPG Legacy Paper

The Chair asked the group for their comments on the paper.

The meeting agreed to:

- a) Post the paper on the APPG website for consultation

Discussion then turned to issues relating to Disability Benefits, and the Chair suggested they could be raised with the Secretary of State when she arrived.

The Group discussed examples of other illnesses which received better treatment because there was a clear physical diagnosis, and the hope that the latest research on xenotropic murine retrovirus might achieve the same for ME. The group discussed the importance that this research was carried forward.

Lady Mar put on record the Group's appreciation of the work that had gone into the paper.

There followed a discussion of the work of St Bartholomew's Hospital.

4. Speaker: Rt Hon Yvette Cooper MP, Secretary of State for Work and Pensions

The Secretary of State opened with a few words about her background, that she has a strong personal interest in the Group having been an ME sufferer back in 1993, and that she is probably the only Secretary of State who has claimed sickness benefits. She went on that she was fortunate enough to have had a supportive employer, and that she is very conscious of the difficulties and challenges people face.

The Secretary of State told the group that she was happy to answer any questions raised, and that she has also been working on the new work capability assessment. Her Department had done a lot of work to try to

ensure that employment support allowance takes account of fluctuating conditions and fatigue.

The Chair then posed a series of questions to the Secretary of State, submitted by members of the public in advance. (Note-please see the transcript for the full set of questions and answers)

The Secretary of State summed up by saying that they are trying to ensure that those people who can work are given the support to work, and that they are continuing to review the position on social care more widely.

The Chair thanked the Secretary of State and she left.

5. WMMEG (West Midlands ME Groups Consortium) Statement

Jill Cooper advised the group that the statement refers to the CFS/ME Clinical and Research Network and Collaborative (CCRNC) Constitution, with supporting information provided.

A general discussion of the statement followed.

6. Date of Next Meeting

2 December 2009