



ALL-PARTY PARLIAMENTARY GROUP ON ME

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

Minute of the meeting of the All Party Parliamentary Group on ME held 2.30pm, Thursday 20th July 2006 Committee Room 19, House of Commons

PRESENT

Dr Des Turner MP (Chair)
Celia Barlow MP
Simon Alcock (Office of Ed Miliband MP)
Colin Barton (Chairman, Sussex and Kent ME/CFS Society)
Paul Davis (RiME)
Neil Devlin (North London ME Group)
Ciaran Farrell (Person with ME)
Douglas Fraser (Person with ME)
Christine Harrison (BRAME)
Tanya Harrison (BRAME)
Aidan Hocking (Office of Ed Miliband MP)
Doris Jones (25% Group)
Dera Kow (Patient)
Ruth Manning
Di Newman (Peterborough ME and CFS Group and Cambs Neuro Alliance)
Clive Page (Father of person with ME)
Augustine Ryan (Person with ME)
Dr Charles Shepherd (ME Association)
Trish Taylor (Action for ME)
Stephen Vaughn (Sussex and Kent ME/CFS Society)
Heather Walker (Action for M.E.)
Adrian Ward (NICE)

APOLOGIES

Secretary of State for Work and Pensions, the Rt Hon John Hutton MP, Lord Bilston, Paul Burstow MP, Peter Bottomley MP, Graham Brady MP, Russell Brown MP, Tom Clarke MP, Tony Cunningham MP, Nadine Dorries MP, David Drew MP, Bill Etherington MP, Dr Evan Harris MP, Lady Hermon MP, Stephen Hesford MP, Jim Hood MP, Kelvin Hopkins MP, Dr Brian Iddon, Eleanor Laing MP, Julian Lewis MP, Ian Liddell-Grainger, Elfyn Llwyd MP, Peter Luff MP, Ann McKeichin MP, Chris Mullin MP, Eddie O'Hara MP, Andrew Stunell MP, Mark

Tami MP, Mark Todd MP, Ed Vaizey MP, Ben Wallace MP, Betty Williams MP, Hywel Williams AS/MP, Roger Williams MP, Mike Wood MP, Jeremy Wright MP, Tony Wright MP.

1. WELCOME

Dr Turner welcomed people to the meeting. He passed on the apologies of the Secretary of State for Work and Pensions, John Hutton MP, who had been called to a meeting of the Cabinet.

2. MINUTES OF THE LAST MEETING / MATTERS ARISING

Ciaran Farrell said the minutes did not include a full account of the meeting held 26 April 2006 in the Boothroyd Room, Portcullis House. He circulated proposed amendments, which gave a more detailed note of his comments at that meeting, together with a briefing paper on the issues surrounding the drawing up of a new Disability Handbook entry for CFS/ME, asking if the minutes could be amended to include his additions and/or circulated to MPs not present. The Chair declined, explaining that the minutes were not intended to be a verbatim account and that circulating Mr Farrell's papers at the meeting was sufficient. His ruling was supported by Colin Barton and others round the table.

3. MEDICAL GUIDANCE ON ME/CFS FOR DISABILITY LIVING ALLOWANCE AND CARER'S ALLOWANCE DECISION-MAKERS

- i. The Chair asked Dr Charles Shepherd to provide an update on the latest draft of the guidance being prepared by the DWP on ME/CFS for Disability Living Allowance (DLA) and Carer's Allowance decision-makers.
- ii. Dr Shepherd described the meeting which had taken place that morning at the DWP, when a Principle Medical Adviser and a member of the Customer and External Relations Directorate at the DWP had met representatives from Action for ME, AYME, BRAME, the ME Association, 25% Group, two physicians and a representative for Professor Puri, to discuss the latest draft (version 8) of the proposed new guidance on DLA and Carer's Allowance.

Disappointingly, the Chair, Kim Archer, was ill and unable to attend the meeting and none of the team of doctors who were involved in the drafting process, nor the neurologist who is advising the DWP, were present.

All the charities present at the DWP agreed that the latest draft:

- a. failed to explain at the onset that the term ME/CFS relates to a variety of clinical presentations, with a range of possible triggers, pathologies, degrees of severity and responses to treatment
- b. contained factual errors, inconsistencies and dogmatic statements which were inappropriate
- c. showed a significant bias towards the psychosocial model of causation and management along with a failure to properly refer to research that supports an organic basis, neurological research in particular
- d. included inappropriate discussion as to whether ME/CFS is a physical or psychological illness (which does not happen in DWP guidance for other conditions)
- e. provided inappropriately detailed information on the management of the illness
- f. did not include early specialist reports or take into account the views of the person's GP or consultant.
- g. failed to reflect that the views of people with ME/CFS, and their physicians, are often very different to the generally positive outcomes for CBT and GET found in clinical trials
- h. was completely inadequate in its description of the disability and state of health experienced by people who are severely affected by ME and the way in which this impacts on care and mobility, as evidenced by BRAME.
- i. The ME organisations who attended were united in their belief that the guidance should note the neurological nature of ME as recognised by the World Health Organisation, the UK's Chief Medical Officer and, most recently, by Ivan Lewis MP, Parliamentary Under-Secretary of State, Department of Health. The DWP did not feel that this was relevant to decision makers but to qualify for the higher rate mobility component of DLA a person has to have a physical problem.
- j. Trish Taylor, Action for ME pointed out that, under the current situation, an unacceptable number of applicants have to go to appeal in order to get the benefits to which they are entitled. She quoted the case of Jo-anne, aged 39, who wrote, "When I became severely affected I applied for DLA and was turned down. I didn't know the system and was too ill to appeal. I tried again 2 years

later and was turned down again despite being hospitalised at the time. I employed a welfare rights solicitor and won 14 months later at appeal. I still get DLA but have been turned down 3 times following a medical exam – all 3 times being successful at tribunal.”

The DWP acknowledged that far too many people were having to go to appeal and said the system was under review.

- k. The outcome of the meeting was that the DWP agreed to take comments back to the doctors who are drafting the guidance. The Acting Chair acknowledged that the current draft was a consensus document and that the doctors who had written it were unlikely to make major changes. However, she agreed that there were inaccuracies, inconsistencies and inappropriately dogmatic statements which needed to be changed. The possibility of a further meeting to discuss version 9 was raised but not confirmed.
- iii. Dr Turner thanked Dr Shepherd for his update and invited comment.
 - a. Tanya Harrison, BRAME, said that Dr Nigel Speight, the Consultant Paediatrician who had attended the DWP meeting, believed that consultants were better placed than visiting doctors to decide a functioning scale for people with ME
 - b. Christine Harrison, BRAME, expressed her appreciation of the DWP for holding meetings about the guidance. BRAME looked forward to the next draft and would continue to fight for better guidance and caution when making reference to potentially harmful and outdated treatments.
 - c. Di Newman made the point that hard-won diagnoses were often ignored by decision-makers and asked what legal redress there might be for individuals who might suffer if the issues raised about the guidance were not addressed by the final draft.
 - d. Trish Taylor, Action for M.E., endorsed everything that had been said and highlighted the agreement shared by voluntary organisations about the guidance.
 - e. Doris Jones and Clive Page said that little seemed to have changed since their son and daughter had first become ill several years ago.
- iv. Dr Turner concluded that resolution on sensible guidance for decision makers had not yet been achieved. The guidance needed to reflect the comments of voluntary organisations, medical consultants and

clinicians. It should also state that ME is a physical illness with serious effects.

Dr Turner would ask the Secretary of State for Work and Pensions to attend the next APPG to discuss these issues.

Sir Liam Donaldson would be invited to a future APPG to discuss what had changed since 2002, when as Chief Medical Officer he published the report which highlighted the lack of understanding about ME amongst health professionals and the general public, saying ME had been a 'disease in the wilderness' and calling for more research.

4. UPDATE ON THE DEVELOPMENT OF NHS SERVICES FOR ME / CFS

- i. Trish Taylor, Action for M.E., reported that Action for M.E. had drafted a briefing report on the situation regarding the new NHS services in England, as requested at the last meeting. Some of the services were under serious threat of closure as funding for them did not appear to be included in the baseline budget controlled by Primary Care Trusts (PCTs). The paper included quotes of support and concern from a number of patient representatives.

After sending the briefing paper to all members of the APPG and constituency MPs, Action for M.E. had written to the Rt Hon Patricia Hewitt, Secretary of State, about the perilous situation facing some of the new services.

- ii. Paul Davis was forcefully critical of the new NHS services, insisting that he had letters of complaint which said their approach was too biased towards the psychological school and that their definition of ME was too broad. He was concerned that financing ME services could distract the government from investing in research and asked if the research and development fund at the Department of Health could be called upon to fund more research.
- iii. Tanya Harrison, BRAME, who has severe ME, argued that her NHS ME service had been very beneficial for her.
- iv. Trish Taylor said that the centres were still new and developing and that contact with their patient representatives had produced an overwhelmingly positive response. Although some difficulties had been reported, over 80% had adopted multi-disciplinary approaches. Some had been excellent. Overall, the services provided a foundation for future development from inside the NHS.
- v. Colin Barton said the services had got off to a good start.

- v. The Chair thanked Trish Taylor for her work and noted that questions had been raised in the House about future funding for ME services. He thought there was scope for the services to contribute to research.

5. AGM

The following MPs are members of the APPG: Dr Des Turner, Anthony Wright, Dr Ian Gibson, Bob Blizzard, Janet Anderson, Liz Blackman, Dr Rudi Vis, Steve McCabe, Chris Mole, Julie Morgan, Peter Luff, Damian Green, Oliver Heald, Henry Bellingham, Laurence Robertson, Andrew Stunell, Bob Russell, Mike Weir, Paul Holmes.

The Office Bearers are: Dr Des Turner MP (Chair), Anthony Wright MP (Vice-Chair), Andrew Stunell (Vice-Chair), David Amess (Treasurer), Steve McCabe (Secretary).

The Chair noted that Mr Stunell had agreed to continue in post only because no-one else had agreed to be put forward.

6. DATE OF NEXT MEETING

To be confirmed, subject to the availability of the Secretary of State for Work and Pensions.

The meeting closed shortly after 3.30pm.