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 1.30pm, Thursday 16th November 2006
Committee Room 17, House of Commons

PRESENT

Dr Des Turner MP
Dr Ian Gibson MP
Steve McCabe MP
Tony Wright MP
Betty Williams MP
Andrew Stunell MP

Koyes Ahmed, Office of Dr Des Turner MP
Louise Leighton, Office of Tony Wright MP
Adrian Ward, NICE
Dr Charles Shepherd, The ME Association
Fiona Cairns, Action for M.E.
Tony Britton, The ME Association
Heather Walker, Action for M.E.
Doris Jones, 25% Group
Barbara Robinson, Suffolk Youth Parent Support Group, East Anglia Patient Partnership (EAME)
Paul Davis, RiME
Annette Barclay, person with M.E.
Jo Dubiel, person with M.E.
Rosemary de Hussy, Youth and Carers for M.E., member of World M.E. Committee
Augustine Ryan, person with M.E.
Clive Page, father of person with M.E.

APOLOGIES

David Borrow MP, Peter Bottomley, Russell Brown MP, Janet Dean MP, David Drew MP, Andrew George MP, Mike Hancock MP, Dr Evan Harris MP, Kelvin Hopkins MP, Dr Brian Iddon MP, Peter Luff MP, Dr Richard Taylor MP, Mark Todd MP, Rudi Vis MP, Hywel Williams MP

1. WELCOME

Dr Turner welcomed everyone to the meeting, especially guest speaker, the Rt Hon John Hutton MP, Secretary of State for Work and Pensions.

2. GUEST SPEAKER

The Secretary of State thanked Dr Turner for inviting him to join the Group to discuss welfare reform, guidance and benefits, including the draft medical guidance on M.E. / CFS for DWP decision-makers adjudicating claims for Disability Living Allowance (DLA) and Carer's Allowance.

He said that the Welfare Reform Bill which is going through Parliament will replace Incapacity Benefit (IB) with a new benefit, Employment and Support Allowance (ESA). The Department for Work and Pensions (DWP) had consulted widely on the Bill, which marks the next stage in the Government's plans to modernise the welfare system. He said the Bill was not about trying to force people to do work they were not able to do, as that would be wrong on medical and ethical grounds. Incapacity Benefit had failed: people were becoming more socially isolated and less well off. Government needed to provide help and support in getting people back into work.

Mr Hutton said that conditions like M.E. are problematic because of the fluctuating nature of the illness. Disagreement amongst the medical profession made the work of decision makers more difficult. Government recognised that too many people had to go to appeal before they received the benefits to which they were entitled. The Government aimed to cut down the number of appeals by improving decision making.

Mr Hutton said that, however much consultation took place, where medical opinion differed, it would be impossible to achieve consensus and there would be 'hot spots' of disagreement. Under these circumstances, the DWP's job was to ensure a fair and transparent process.

With regards to Disability Living Allowance, the DWP would not be in a position to issue guidance until 2007. There was still the opportunity for people to be involved in the process. The next draft would be available soon.

Dr Turner noted that the Secretary of State rightly wanted to achieve high standards of professionalism amongst DWP staff and commented that high standards were also required in terms of medical input.

Mr Hutton replied by saying that the process of assessing people is done through Atos Origin. The DWP is working with Atos Origin to make sure they fulfill their contractual obligations.

Andrew Stunell made the point that there was a risk of 'payment by inverse results' ie. the fewer the people who were paid state benefits, the more successful the assessors and the medical guidance on M.E. might be seen to be.

Mr Hutton rejected this saying that it is a myth that there is a conspiracy to stop people getting benefits. The Government has given vulnerable people a statutory right to benefits and it is the DWP's job to give benefits to those who are entitled to them. Consulting on the guidance is a way to improve the decision making process.

Charles Shepherd said that the drafting of guidance for DLA decision makers had taken 18 months so far and consultation had reached an impasse at version 8. There was a fundamental problem in that those drafting the guidance were receiving advice from a neurologist who did not believe in the biological nature of the illness.

Mr Hutton said that Ministers make decisions based on medical advice given, which is difficult when there is dispute among the medical profession. He had not realised that there had been so many drafts of the guidance.

Dr Turner asked Mr Hutton if the DWP had taken account of the Chief Medical Officer's Report. Mr Hutton said 'we're trying.'

Barbara Robinson made a number of points, citing examples of good practice in guidance, asking how people who may be too ill too express themselves can be properly assessed, saying assessors are not adequately trained to assess people with M.E and pointing out that local GPs should get more interested and involved in M.E. cases, make more home visits and be asked to provide more evidence for the assessment process.

Mr Hutton did not dispute that better medical assessments were required and said that the DWP would listen to any sensible suggestion which helps to achieve that. He agreed that there should be more home visits for the severely affected if people wanted them.

Annette Barclay asked if Atos Origin were subject to any contractual penalties. Mr Hutton said he would write to Dr Turner, as Chair of the APPG, with details.

Mr Hutton said that it was right and proper for the DWP to assess a person's ability to work even if they have a disability and wrong to leave a person with benefits but without adequate help and support. He invited anyone with specific concerns about DWP assessments to raise them in writing through Dr Turner as Chair of the APPG and that he as Secretary of State would respond.

Doris Jones voiced concerns that the psychiatric bias towards M.E. / CFS was already apparent in Occupational guidance recently published by NHS Plus and in the draft NICE guideline.

Mr Hutton was unable to comment on guidelines not drafted by his Department but presumed the Department of Health, like the DWP, had acted on expert advice received. He said he would raise the issue with the Secretary of State for Health.

Dr Turner thanked Mr Hutton for his attendance.

The Secretary of State left the meeting at 2.10pm

3. Group business

a. Minutes of last meeting

Doris Jones had submitted a written request for a change under 3.iii.e., as, in her experience and contrary to what was stated, DSS/DWP assessment was better 16 years ago than it is today. Clive Page asked that the minute also be changed as it implied that he and Doris Jones were both parents of the son and daughter noted, rather than members of separate families.

b. Election of Office Bearers

A question had been raised about the quoracy of the Annual General Meeting on 20 July 2006. Accordingly, the business of the Annual General Meeting was revisited and the following Office Bearers were elected:

Dr Des Turner MP (Chair), Anthony Wright MP (Vice-Chair), Andrew Stunell (Vice-Chair), David Amess (Treasurer), Dr Ian Gibson (Secretary).

The Chair took the opportunity to ask Ian Gibson for an update on the Inquiry into the progress of scientific research into M.E. since the Chief Medical Officer's report. Dr Gibson said that the Inquiry's report would be published very shortly, and would be submitted to NICE in time to meet its deadline for the close of the close of their consultation on ME/CFS Guidelines. He said that members of the Inquiry Group were as frustrated as many people with M.E. were by the lack of research and that the research undertaken in the UK to date was very one-sided. The Chair welcomed his comments and looked forward to the publication of the report.

c. APPG definition of M.E. and Code of Conduct

The Chair circulated a draft code of practice for the APPG (attached), which stated that: "The APPG and the Secretariat (Action for M.E. and the M.E. Association) accept the WHO Classification of M.E. as a neurological condition and welcome the recognition by the Department of Health of M.E. as a long term neurological condition. The APPG strives to support the improvement of health, social care, education and employment opportunities for people affected by M.E. The meetings of the APPG are held in public and it is expected that attendees will adhere to the principles of best practice in meetings" (which were listed).

Comments were invited.

4. Draft NICE guideline

The Chair asked for views on the draft guideline on the diagnosis and management of M.E. / CFS, produced by the National Institute for Health and Clinical Excellence (NICE). He felt the documents were extremely problematical, and ran to so many pages that they probably would not be read by the medical profession any way.

Dr Gibson agreed, saying few people would have the patience to read the guidance. He said they would be taken back to be rewritten.

Paul Davis said that the NICE guidelines ignore the WHO classification of M.E., and that that there were problems with terminology which made the guideline skewed towards vague chronic fatigue conditions and irrelevant to the assessment, diagnosis and treatment of people with M.E.

Charles Shepherd complained that NICE had paid lip-service only to the consultation process. Strongly expressed views from experienced clinicians had been airbrushed out. NICE proposed Cognitive Behaviour Therapy and Graded Exercise Therapy as treatments of first choice without taking the economics into account: where were the CBT therapists who could treat an estimated 180,000-200,000 patients who might benefit from it? The cost of each course of CBT had been estimated at £1,000. If the recommendation was pursued that could result in the NHS being burdened with additional expenditure of £200m a year.

Dr Turner said there was one safety valve – the guideline would not be mandatory. He suggested that, as people felt so strongly on the issue, NICE should be invited to address the next meeting.

Adrian Ward, from NICE, said he was attending only in the capacity of an observer but he would make sure the views of the APPG were passed on to colleagues. He said that NICE were planning to publish the guideline in April.

Paul Davis said the APPG and the ME charities, ever since the Chief Medical Officer's Report in 2002, had been sidetracked by issues around the treatment of ME. What RIME's supporters wanted was for the focus to be entirely on research issues.

5. Any Other Business

The Chair said he had received a request from Di Newman, from Peterborough, who was not at the meeting, that discussion be held on the Mental Health Bill now in Parliament. It was agreed to put the item on agenda for the next meeting.

6. Next Meeting

At the Chair's suggestion, members agreed that Sir Michael Rawlins, Chairman of the National Institute for Health and Clinical Excellence, be invited to address the next meeting about our concerns about the proposed NICE clinical guideline for CFS/ME. He hoped a convenient date could be found early to mid-February.

The meeting closed at 2.41pm

Appendix attached…

APPENDIX

DRAFT

CODE OF PRACTICE FOR THE ALL PARTY PARLIAMENTARY GROUP ON M.E.

1. The APPG and the Secretariat (Action for M.E. and the M.E. Association) accepts the WHO Classification of M.E. as a neurological condition and welcomes the recognition by the Department of Health of M.E. as a long term neurological condition.

2. The APPG strives to support the improvement of health, social care, education and employment opportunities for people affected by M.E.

3. The meetings of the APPG are held in public and it is expected that attendees will adhere to the principles of best practice in meetings:

   - **Attendees will abide by the APPG Governance Procedures and Practices**

     This means that the attendees will honour the policies set up by the APPG to govern its own activities, including meeting protocols, committee rules etc. It is anticipated that attendees will follow basic rules of personal courtesy, attendance and being prepared. The APPG and the Secretariat recognise the connection between the behaviour of individuals in meetings and the ability of the APPG to address their business effectively. Attendees will be expected to participate so that APPG business progresses smoothly and efficiently
   - Participants will give apologies ahead of time to the Chair if unable to attend meetings
   - The Secretariat will ensure that information is distributed prior to meetings, allowing participants time to read and digest important information ahead of a discussion
   - Attendees will honour the authority of the Chair and respect his/her role as the meeting leader. When problems arise with meetings they should be dealt with as procedural issues rather than a personal criticism of the Chair and other officers.
   - Participants will engage in debate according to procedures, maintaining a respectful attitude towards the opinions of others whilst making their own point.
   - Attendees must express their views clearly when it is their turn to speak and then allow others to express their opinions in turn.

- Attendees must listen respectively to other meeting participants, to the Chair and to other speakers. They must not attempt to silence minority opinions, nor should they talk over others.
- Attendees must not use their mobile phones in meetings or adopt any other bullying tactics.
- Attendees are invited to offer suggestions to the Secretariat or the Chair on how best to enhance the role and function of the APPG.

These guidelines are produced as a method of efficiency. If an individual attendee does not comply with the code the Chair may institute a warning system. The APPG anticipates that debate should be lively but controlled and every effort will be made to hear a wide range of different opinions and elicit the opinions of those who may be inclined to be silent.