



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

MINUTES OF THE ALL-PARTY PARLIAMENTARY GROUP ON M.E. HELD ON WEDNESDAY 26TH APRIL 2006 IN THE BOOTHROYD ROOM, PORTCULLIS HOUSE

PRESENT

Andrew Stunell MP (in the Chair)
Liz Blackman MP
Russell Brown MP
Dr Julian Lewis MP
Peter Luff MP
Anthony G Wright MP

Professor Colin Blakemore (Chief Executive, Medical Research Council)
Sarah Perkins (Programme Manager, MRC)
Dawn Duncan (Public Involvement and Consultations Officer, MRC)
Adrian Ward (National Institute for Health and Clinical Excellence)
Jane Allen (Office of Andrew Stunell MP)
Trish Taylor (Chair, Action for ME)
Heather Walker (Communication Manager, Action for ME)
Dr Charles Shepherd (Medical Adviser, The ME Association)
Tony Britton (PR and Communications Adviser, The ME Association)

Paul Davis (RiME)
Ciaran Farrell (Person with ME)
Kate Tompkins (Person with ME, from Reading)
Augustine Ryan (Person with ME)
Louise Ellis (Group Leader, Manchester ME Society)
Colin Barton (Chairman, Sussex and Kent ME/CFS Society)
Annette Barclay (Person with ME)
Jo Dubiel
Martin Sayer (Member, Guildford ME Group)
Rosemary Underhill (Member, The ME Association)
Di Newman (Peterborough ME and CFS Self-Help Group)

APOLOGIES

David Amess MP
Charlotte Atkins MP
Rt Hon John Battle MP
Michael Connarty MP
Roger Williams MP

Mike Hancock MP
Jimmy Hood MP
Lindsay Hoyle MP
Mark Tami MP
Dr Richard Taylor MP

The meeting started at 10.35am

1. WELCOME

Andrew Stunell welcomed people to the meeting, the first public hearing of the APPG on ME. He passed on the apologies of Des Turner, who was attending a meeting of the Select Committee on Science and Technology. He said members of the public would be welcome to ask questions but should remember that the meeting had to be completed within an hour.

2. MINUTES OF THE MEETING ON 16TH NOVEMBER 2005

These were agreed as a correct record.

3. MATTERS ARISING

(i) Department for Work and Pensions Medical Guidelines – update

Charles Shepherd (The ME Association) said that the new medical guidelines used to inform DWP decision-makers when considering Disability Living Allowance claims had now been through eight revisions, and the situation had descended into farce. The latest version still demonstrated that the DWP working group gave more weight to the psychological construct of ME than its rapidly emerging neurological causes. The ME charities were united in continuing to find the draft guidelines unacceptable.

Tony Wright said the APPG should ask the Minister to attend to listen to the objections. Mr Stunell suggested the Minister be invited to the next meeting. This was agreed.

Paul Davis (RiME), Kate Tompkins and Ciaran Farrell all raised issues relating to the terminology and definitions of the illness, which they said were fundamental to diagnosis and management of the illness, and on the outcome of any research trials. Mr Davis said patient admittance to the clinics was too broad. Ms Tompkins said the definition of ME had got vaguer and vaguer, and that ME had become associated with people who felt a bit tired. Mr Farrell said ME had been reduced to 'a dustbin diagnosis'.

In addition, Mr Farrell said clarity on the subject and removal of the psychiatric paradigm in ME in the negotiations over the DWP medical guidelines would assist and inform decision-makers higher up in the chain – at Tribunal and Commissioner level. Dr Shepherd said that these points had been raised with great robustness in the discussions with the DWP.

Mr Wright said the APPG had in the past few years received huge amounts of correspondence from people with ME about their difficulties in obtaining Disability Living Allowance. At heart, they wanted to know why their applications could not be treated like those from people suffering from any other more visible disabilities. This must be recognised in the final guidelines from the DWP.

(ii) The new NHS clinical services for ME/CFS – update

Trish Taylor (Action for ME) said the ME charities remained very concerned about the future of the new Local Multi-Disciplinary Teams now the £8.5m ring-fenced funding had ended, and given that it is a time of acute financial uncertainty in the NHS. In some areas, vacant posts in the LMDTs were not being filled. Potentially, 21,000 patients could be seen by the existing services in a full year; she was concerned that the actual numbers of patients seen might be much less.

Mr Wright urged discussion on the subject with the Health Minister. Mr Stunell reminded members that in his constituency the Lottery-funded Stockport ME/CFS service, regarded as a model of excellence, had ended and been replaced with an inferior NHS service. Dr Shepherd pointed to Oxford where not only had the new ME/CFS service not received assurances about its long-term future but the older service at the John Radcliffe Infirmary was also under threat.

Mr Stunell asked to be supplied with a list detailing services under threat, which could be forwarded to relevant constituency MPs.

4. PRESENTATION BY PROFESSOR COLIN BLAKEMORE, CHIEF EXECUTIVE, MEDICAL RESEARCH COUNCIL – THE MRC'S RESEARCH STRATEGY FOR ME/CFS

Professor Blakemore thanked the APPG for their invitation to attend the meeting – the MRC's third appearance before the group.

He reminded members that the MRC, like all other UK research councils, operated at arms-length from government with funding by an annual Grant in aid from Parliament via the Office of Science and Innovation, part of the Department of Trade and Industry. It operated according to the Haldane principle that detailed decisions on scientific strategy and research should be taken by the research

councils rather than by government. Scientific excellence was the prerequisite for funding.

The MRC spends around £500m a year, and had already spent, in total, £3.5m in the area of CFS/ME, including the PACE and FINE trials – 0.8% of its annual budget. This compared with £2m on addiction, another major health issue causing concern and the subject under discussion at the Select and Technology Committee earlier in the morning, and £10m being spent on research into avian flu – which has the potential to cause a global health disaster if the virus mutates to allow human to human transmission

Professor Blakemore traced the involvement of the MRC with research into CFS/ME to the 2002 Chief Medical Officer's Report, when the CMO asked the MRC to develop a broad strategy for advancing biomedical and health services research on CFS/ME. Following a consultation exercise in July and August 2002 and the establishment of a dedicated Research Advisory Group, the MRC strategy was published in May 2003. This defined a number of important areas for research, as follows: case-definition, understanding symptomatology and new approaches to management.

He acknowledged that there was a shortage of good research in the area and said an illness could often be treated and managed successfully without knowing the cause.

Professor Blakemore said he was aware of the concern expressed in some parts of the ME community that the MRC has not paid sufficient attention to physical causes, but said the concern was misplaced.

MRC issued a Highlight Notice to encourage high-quality applications in the area. So far 24 proposals of relevance to CFS/ME had been received, five of which had been funded. Two of those – PACE and FINE – were clinical trials, which had attracted a great deal of comment by the patient groups. PACE and FINE, both very high quality studies, were at present recruiting participants; the results were expected to be published in 2008. Six of the 24 applications were resubmissions, which are not normally allowed for a year. To aid the CFS/ME field MRC allowed the resubmissions straight away after discussion and further peer review, of which one was funded.

In association with Action for ME, the MRC will be holding a research workshop later this year. Every effort was being made to attract the brightest researchers to the meeting and, in particular, those in related fields who have so far not shown an interest in ME.

In addition, the MRC was supporting the PRIME project funded by the GUS Charitable Trust. This identifying the experiences of people affected by ME/CFS,

studying them using qualitative research methods and facilitating communication between clinicians and researchers.

Mr Stunell then opened the subject for discussion.

Tony Wright said that, despite the money spent so far on the PACE and FINE trials, no priority appeared to be given to research into physical causes. He asked where was the recognition that ME was a real clinical identity with extremely disabling and debilitating effects?

Dr Julian Lewis said there was great cause for concern that people with full-blown versions of the illness could not be certain they were obtaining accurate diagnosis and appropriate tests while there was still widespread debate about whether they were suffering from a physical syndrome or something that was psychological. He asked when the MRC would research an accurate diagnostic test.

Professor Blakemore said the main criterion was always whether the proposed project was of high enough scientific quality. But budgets were finite: sometimes even top-quality projects could not be funded. He pointed to the developments in the diagnosis of schizophrenia which have taken place in recent years: once it was regarded as one illness, now it is widely considered to be a constellation of different conditions. He also commented that it was by finding ways to treat the illness that lead to greater understanding of the underlying causes.

Paul Davis (RiME) said the PACE and FINE trials were using the Oxford and Fukuda research criteria, which failed to separate out people with full-blown, neurological ME. Professor Blakemore said that it could not invent research proposals – the proposals submitted for consideration used these criteria. Dr Shepherd said that, as was made clear in the CMO Report, there remained an urgent need for research into aetiology and pathogenesis. He urged the MRC to consider a program of commissioned research in these areas.

Professor Blakemore said that using commissioned research as a tool to push forward strategy had not been particularly successful when used by the research councils in the past. There were no guarantees that research of the highest quality would be funded by this method. He hoped the research workshop later this year would produce brain-storming of the highest order and bring in bright, young researchers who would be prepared to submit applications.

Annette Barclay commented that people with ME were having to raise money themselves for biomedical research. Di Newman made a comment about the need for biomarkers.

Andrew Stunell thanked Professor Blakemore and everyone else for attending.

DATE OF THE NEXT MEETING

Mr Stunell said the Secretary of State for Work and Pensions would be invited to talk to the next meeting on the subject of the draft medical guidelines, at a convenient date.