



## **ALL-PARTY PARLIAMENTARY GROUP ON M.E.**

<b>Chair:</b>	Tony Wright MP
<b>Vice Chairs:</b>	Andrew Stunell MP Rev Martin Smyth MP
<b>Secretary:</b>	Steve McCabe MP
<b>Treasurer:</b>	David Amess MP

### **MINUTES OF ANNUAL GENERAL MEETING OF THE ALL-PARTY PARLIAMENTARY GROUP ON M.E. AND REFORMATION OF THE GROUP**

**WEDNESDAY, 6th JULY 2005  
Committee Room W1, Westminster Hall**

#### **PRESENT**

- Tony Wright MP (Chair)
- David Amess MP
- Janet Dean MP
- Brian Iddon MP
- David Lepper MP
- Peter Luff MP
- Chris Mole MP
- Julie Morgan MP
- Gavin Strong MP
- Andrew Stunell MP
- Des Turner MP
- Lord Watson of Invergowrie
- Betty Williams MP
  
- Ian Woodcroft, Office of Tony Wright MP
- Chris Clarke, Action for M.E.
- Charles Shepherd, M.E. Association
- Tony Britton, M.E. Association

#### **RECONSTITUTION**

##### **1. Replies to the invitation to join the Group**

Tony Wright welcomed members, saying this was the best attended meeting of the group in seven years. A number of new MPs had joined since the General Election, and membership now totalled over 100 MPs and Peers.

##### **2. Election of Chair**

Tony Wright said that, after seven years in the chair, he now wished to stand down, though he would remain a member. He understood that Des Turner, MP for Brighton Kemptown, was prepared to take the chair and moved his appointment. Des Turner was elected Chair of the APPG.

### **3. Election of Vice-Chairs and Officer**

Tony Wright moved the re-election of Andrew Stunell as Vice-Chair. Mr Stunell was so elected.

David Amess moved Mr Wright's appointment as additional Vice-Chair., saying the group would welcome his continuing expertise and enthusiasm. Tony Wright was elected as additional Vice-Chair.

Andrew Stunell moved the re-election of Steve McCabe as Secretary. Mr McCabe was so elected.

Des Turner moved the re-election of David Amess as Treasurer. Mr Amess was so elected

## **BUSINESS MEETING**

### **1. Minutes of the last meeting**

The minutes of the last meeting held on Wednesday 2nd February 2005 were accepted as an accurate record and were accepted. There were no matters arising.

### **2. Apologies for absence**

There were a number of apologies for absence.

### **3. Matters arising from previous meetings**

None were raised.

### **4. Research update and agenda – report on discussions of the M.E. Alliance**

Chris Clarke (Action for M.E.) gave a presentation about gaps in research into M.E.

He said systematic reviews carried out in the UK and USA had found only one research study a year worldwide that met the quality criteria for inclusion since M.E. was first defined in 1955.

*The Medical Research Council Strategy:*

This was published in May 2003. It recognised the gaps and urgency and the need to encourage researchers:

“...CFS/M.E. is a real, serious and debilitating condition, and that research into all aspects of CFS/M.E. is needed.”

“The MRC CFS/ME Research Advisory Group recognises the urgent need for research into CFS/M.E. and that there are certain groups of patients who may not have been adequately included in research.”

“...the research community should be encouraged to develop high quality research proposals for funding that address key issues for CFS/M.E. research...”

Case definition and epidemiology were identified as key building blocks.

“Accuracy and consistency of case definition and diagnosis is a crucial issue... fundamental for the assessment, frequency, causes, outcomes and management of any disease or illness.”

“Epidemiology has a central role in addressing questions about prevalence, incidence and their relation to time, place and person within populations. It is key in formal testing of causal hypotheses, specifically in working out the contributions of environment and genetic influences. Such a framework is also necessary for research on case definition, co-morbidity, natural history and outcome.”

“The fact that CFS/M.E. affects a broad age-range, including children, means that such population-based studies will need to have considered the adequacy of case ascertainment across the whole age spectrum.”

*Actions taken by the MRC to implement the strategy:*

- Award of a Highlight Notice
- Epidemiology Workshop, September 2003

*Studies funded since May 2003:*

None

***Issues to address:***

### **1. Availability of funds in a fiercely competitive environment**

CFS/M.E is considered by one of five Boards – Neurosciences and Mental Health.

The total annual budget available to the Board for all applications is around £27m a year. 80 to 100 applications get to the stage of being considered by the Board, but only 10 to 15 are successful in any one year.

Independent research funded by Action for M.E. shows that it may cost the nation as much as £3.5bn a year to support people with M.E. who are excluded from productive life in the community.

### **2. Need to be proactive**

Action is being by the charities to promote M.E. as an attractive subject for scientific research, for instance through the PRIME project funded by the GUS Charitable Trust. But the perception of many people close to the subject is that the MRC is being overly reactive. Strategic action is needed.

### **3. Need to commission an epidemiological study**

Two years since the MRC epidemiological workshop, nothing has happened. A potential study that could be funded, ‘ALSPAC’ – while welcome, if extended to cover M.E. – will not address adults.

#### **4. Does the ethos of the MRC meet the needs of the public?**

The MRC is fiercely independent and its processes are designed to protect its Boards from political pressure.

Their processes are often stated as “funding the best science”. Its Highlight Notices only apply when applications are judged to be of equal merit.

Whilst laudable, are the 85 to 90 applications that fail to get funding “second class science”?

#### ***Do current processes meet the public need?***

Further support, and evidence of a lack of urgency by the MRC:

Extract from a letter written by the Chief Medical Officer to the M.E. Alliance, 16 June 2005: “...In April of this year, I wrote to Professor Colin Blakemore, Chief Executive of the MRC, asking him to consider funding research into the causes and treatment of CFS/M.E. He indicated that the MRC would welcome good quality research proposals in this field, and that they had recently held a CFS/M.E. research workshop to explore the potential for undertaking epidemiological research on CFS/M.E. in the UK.”

Mr Clark closed his presentation by inviting the APPG to take the political lead in seeking an urgent expansion into the funding of research into M.E. This might possibly involve exploring whether funds were available from NHS research and development funds.

Des Turner opened a discussion on the tactics which the group might adopt to pursue a research agenda and close the gaps identified by Chris Clark. He said he recognised the fiercely competitive environment and that academic researchers found other areas of work more attractive.

He said he knew of the potential epidemiological study mentioned by Mr Clark – the ‘ALSPAC’ study – but it had its limitations. It would not properly address the needs of adults with M.E.

#### **5. Draft medical and disability guidelines prepared by the Department for Work and Pensions:**

Charles Shepherd, from The M.E. Association, introduced this item. He said he had been invited to attend a meeting at the Department for Work and Pensions on 10th June at which changes to the way on which various benefits would be administered in the future were explained.

Many of the proposals presented to the meeting seemed to be genuine attempts to try and solve some of the problems involved in benefit-claiming, assessment and decision-making – one of which was illustrated by the very high number of awards made at the appeal stage after rejection of the first claim.

But the DWP proposals also included the preparations of new guidelines on the medical and disability aspects of M.E./CFS for use in the decision-making process on individual

Disability Living Allowance claims. This new guidance was intended replace that contained in the current version of the Disability Handbook.

The ME charities had not been invited to take part in this consultation beforehand. Neither had they been given any opportunity to take part in the process of revising the medical and disability guidance. It was not until the close of the meeting that the latest draft of the guidance was circulated; consequently there was no time available to either read or discuss the content, and no further meetings between charity representatives and the DWP were currently planned.

Dr Shepherd regretted that, because the document was restricted to those attending, he was not in a position to circulate it himself. But, in his initial response to the DWP on behalf of The ME Association, he had said that the draft guidance was completely unacceptable because it indicated that the group which drew it up had no practical understanding of ME, the guidance was muddled and that information on cause, aetiology, symptoms and disability was strongly biased towards the psychosomatic model of chronic illness.

He urged APPG members to obtain copies of the draft guidance and make representations. When the copies of the draft were made available for circulation, he was sure the issue would result in many complaints to MPs from constituents with ME,

Tony Wright said he had already been approached by his constituents, Tanya and Christine Harrison, of Blue Ribbon Awareness of ME (BRAME), who had expressed their extreme concern about the contents of the draft guidance, and would raise the the subject as a matter of urgency with the Department for Work and Pensions.

## **6. Programme of Work**

Members agreed that a meeting on M.E, research issues would be valuable. Des Turner agreed to explore issuing invitations to Professor Colin Blakemore, Chief Executive of The Medical Research Council, and the Chief Medical Officer to a meeting early in the New Year, possibly in January.

Chris Clarke said the NHS Service Implementation Programme was now in its second year, and would shortly be coming to an end of its £8.5million ring-fenced funding. The future development of the initiative was the subject of immense interest in the M.E. community. He suggested that Professor Tony Pinching, chair of the NHS M.E./CFS investment steering group, be invited to the next meeting to discuss progress.

Betty Williams said she had been in correspondence with Jane Hutt, Minister for Health in the National Assembly for Wales, about provision of services to people with M.E./CFS in Wales, and on research issues, and would continue to progress these matters in Wales.

Lord Watson, who is also an MSP, said he had agreed to be a point of contact between the Cross Party Group on ME in the Scottish Parliament and the APPG, and would be pleased to continue to receive invitations to the APPG.

## **DATE OF NEXT MEETING**

Members agreed to hold the next meeting in October or November, and would invite Professor Pinching to speak on service developments.