



ALL-PARTY PARLIAMENTARY GROUP ON M.E.

Chair: Tony Wright MP
Vice Chairs: Paul Burstow MP
Rev Martin Smyth MP
Secretary: Steve McCabe MP
Treasurer: David Amess MP

MINUTES OF THE ALL-PARTY PARLIAMENTARY GROUP ON M.E. HELD ON WEDNESDAY 23 MAY 2003 AT THE HOUSE OF COMMONS

PRESENT

- Tony Wright MP
- Liz Blackman MP
- Ivan Henderson MP
- Steve McCabe MP
- Bill Etherington MP

- Prof Nancy Rothwell, Chair CFS/ME Research Advisory Group
- Dr Diana Dunstan, Director Research Management Group, Medical Research Council
- Chris Clark, Chief Executive, Action for M.E.

1. MINUTES OF THE LAST MEETING

The minutes of the last meeting were agreed

2. APOLOGIES

Apologies for absence were noted

3. PRESENTATIONS – CFS/ME Research Strategy and the Medical Research Council

Following introductions Dr Diana Dunstan gave an overview of the MRC's involvement in CFS/ME research. The CMO's Independent Working Group Report on CFS/ME in January 2002 had recommended research into all aspects of the illness. As a result, the Department of Health in England asked the MRC to develop a broad strategy for advancing biomedical and health services research on CFS/ME.

Nancy Rothwell then explained the process the MRC had followed to develop a strategy. A CFS/ME Research Advisory Group (RAG), chaired by Professor Rothwell, was formed to include scientific members representing all relevant scientific areas and who had not previously worked specifically on ME and two non-scientists (lay members) drawn from the MRC's Consumer Liaison Group. A paediatric neurologist was added to the RAG shortly afterwards in response to comments the MRC had received over scientific coverage of the Group.

The aims of the group were to make recommendations, set out a framework for research and identify key areas. At the start of the process, there was a large consultation exercise in July and August 2002 to ensure patient and lay perspectives, including patients, carers and M.E. charities were both sought and understood. The MRC had also received a petition from RiME with 16,002 signatures requesting “a research programme be up and running by the end of 2002”. The publication of a draft strategy for consultation in December 2002 was widely publicised by the BBC.

The CFS/ME RAG had followed the lead of the CMO’s Independent Working Group and taken an inclusive approach on views about terminology and on whether the umbrella term “CFS/ME” referred to several differing conditions. Even in well established and researched conditions new and different subgroups are identified as knowledge and understanding increases.

Nancy Rothwell acknowledged that some respondents to the consultation on the draft strategy felt that the RAG should undertake a full systematic review of existing published information. However, such an undertaking would have taken many years, and the Group’s job was to look forward, rather than back at existing work. The approach taken by the RAG was multidisciplinary and inclusive (e.g. immunology, psychiatry, virology).

Finding a cause was cited as important by many patients who feel they are not believed to be really ill. Although cause and treatment can go hand-in-hand, Nancy Rothwell pointed out that it was possible to study potentially effective interventions without knowing the underlying cause or causes. Such studies could be considered a greater priority, in order to reduce suffering of patients as quickly as possible. This conclusion is based on medical precedent, e.g. types of cancer can be treated although the exact cause remains unknown. In addition, multiple causes are possible. Clearer definition of outcome measures in treatment research was also noted as being important. In some areas, Nancy Rothwell pointed out preliminary work may be needed before any substantive research can be undertaken. It was recommended that research should be as inclusive as possible so that patient groups that may have been largely excluded from research to date such as the severely affected and children were able to participate. A potentially fruitful area of research was understanding patterns of recovery. The RAG identified research priorities, including case definition, symptomatology and management.

Nancy Rothwell concluded by pointing out that the research strategy for CFS/ME that had been produced should be seen as being available to all interested in CFS/ME research, whether they were in the UK or abroad.

Diana Dunstan then described the response of the MRC to the research strategy. The full research strategy had been published on the Internet at the MRC website on 1 May 2003. A lay summary of the final strategy will

be available at the MRC website by the end of June to make it easier to understand for those less familiar with scientific terminology.

In response to the CFS/ME research strategy the MRC has issued a highlight notice to the scientific community on CFS/ME research. This is a mechanism by which the MRC signals to the scientific community that it welcomes proposals in an area where research is considered to be difficult, and any applications are given additional weighting when being considered for funding. A meeting to discuss the feasibility of undertaking epidemiological research in the UK using existing research infrastructures is being planned for September, being chaired by Professor Philip Hunnaford (Professor of Primary Care Research, University of Aberdeen). Diana Dunstan concluded by briefly describing two studies, namely PACE and FINE, for which the MRC had recently announced funding. Results from these studies can be expected in about 4 - 5 years time.

It was also noted that the Government had announced the award of £8.5m to develop new services for CFS/ME.

Questions

In response to a question from Liz Blackman, Diana Dunstan stated that the MRC had been in contact with international colleagues, and would maintain contact. A senior representative of the Centre for Disease Control in the USA has been invited to the September meeting on epidemiology, and it was hoped that the MRC could work with them, maximising the respective strengths of the two organisations and the opportunities for research partnerships.

Tony Wright asked the MRC to identify how high CFS/ME stood, were there to be a league table of priorities. In response it was stated that it had a high strategic priority, but the level of research was starting from a relatively low base.

Bill Etherington emphasised the feeling of helplessness experienced by people with CFS/ME and went on to state his approval for the decision not to prioritise finding the cause over finding an effective treatment. Much fruitless investment could be made in causation, at the expense of improving people's lives.

Chris Clark stated his organisation's welcome for the strategy, but drew attention to the concerns that its success would be dependent on funding and the involvement of scientists.

Nancy Rothwell and Diana Dunstan accepted the comments and hoped that the strategy and large measure of consensus would attract the interest of scientists. Diana Dunstan also confirmed the possibility that further scientific meetings or conferences might be arranged in the future.

Chris Clark also asked to place on record his organisation's pleasure that a study into pacing had now been funded. This was the approach consistently reported to be beneficial by people with CFS/ME.

Tony Wright thanked the MRC representatives for their presentation.

4. Benefits

Tony Wright referred to a letter received from BRAME and correspondence with the Secretary of State at the Department of Work and Pensions in which it had been confirmed that 25% of claims from people with CFS/ME were rejected at the first attempt. This compared with 16% from other illnesses and remained a matter of concern that he would continue to pursue on behalf of the APPG.

5. Date of next meeting

To be announced