

**MINUTES OF THE ALL-PARTY PARLIAMENTARY GROUP ON M.E.  
HELD ON WEDNESDAY 27<sup>TH</sup> FEBRUARY 2002  
AT THE HOUSE OF COMMONS**

PRESENT

- Tony Wright MP
- Liz Blackman MP
- Tom Clarke MP
- Betty Williams MP
- Phyllis Starkey MP
- Andy Love MP
- Graham Brady MP
- Brian Iddon MP
- Jim Cousins MP
- Russell Brown MP
- Rosemary McKenna MP
- Countess of Mar

Professor Allen Hutchinson, Chair of the CMO's Working Group  
Professor Anthony Pinching, Vice Chair of the CMO's Working Group

**1. MINUTES OF THE LAST MEETING**

The minutes of the last meeting were agreed

**2. APOLOGIES**

Apologies for absence were noted

**3. PRESENTATION**

- 3.1 Professor Allen Hutchison presented a brief overview of the reason for setting up the Chief Medical Officer's Working Group report on CFS/M.E. what the process involved was and what the main findings of the report were
- 3.2 Professor Anthony Pinching detailed his opinion on the outcomes of the report and what action should now be taken. He highlighted the following areas in particular
- Need to find out what the MRC timetable and terms of reference are - given that they had to be agreed by end of Feb 02
  - Short, simple guidance for GPs and other health professionals needed now pending/before the longer term plans via NICE/NSFs
  - The importance of commissioning - there were serious gaps in service provision - some areas in fact have no provision. It was not a level playing field with other similar illnesses
  - Concern that there was a lack of money allocated for the changes as recommended in the report

#### 4.0 INFORMAL QUESTIONS AND ANSWERS

- 4.1 Dr Brian Iddon said he had made contact with a local group, which felt that GPs were uneducated but also didn't know to whom to refer patients. He asked whether information on availability of services would be disseminated
- 4.2 Professor Pinching said this had been done by the Task Force report in 1996. Priority should be for PCTs to identify referral centres. Some services were at present unwilling to be identified because in doing so they would be swamped and then penalised when a long waiting list subsequently emerged. He added that there were nowhere near enough centres
- 4.3 Tom Clarke said that GPs were either very supportive or not at all. He asked whether the Government response went far enough?
- 4.4 Professor Pinching said the CMO's response was very good in that it set the agenda for the future. However, there was a significant gap between what is happening now and what may eventually be on offer.. It is the bit in the middle that is the concern which is why an interim guide for doctors would be of help.
- 4.5 Professor Hutchinson said that GPs are getting showered with information and agreed that there was an urgent need for a 4 sided document laying out the basics of the illness - i.e. what it is and what you can do for it.
- 4.6 Tom Clarke asked if this should be issued by the Department of Health?
- 4.7.1 Professor Hutchinson said he did not see the necessity in referring the matter on to NICE in order to issue guidance. NICE would produce no more than what has already been established through the Group
- 4.7.2 Professor Pinching also pointed out that the MRC had been given a tight deadline by when it should report to the CMO, however to the best of his knowledge nothing yet had been heard.
- 4.8 Countess of Marr said that she was pleased with the report. She felt that M.E. had similarities with fibromyalgia and Gulf War Syndrome. Could there be shared clinics established for these three in common – this is a territory worth campaigning on.
- 4.9 Professor Pinching said that this might evolve naturally as clinicians interested in one field could find that their skills were transferable.
- 4.10 The Countess of Mar said that these were illnesses with ill-defined terminology, and this was creating a huge waste of resources. There was a need to deal with these overlaps
- 4.11 Professor Pinching said there were implications for clinical research
- 4.12 Andrew Love said that his local group had raised the issue of having a network of tertiary services. He supported idea of a short crib sheet for doctors
- 4.13 Professor Hutchinson said NICE guidance could help and would be a good basis to provide a care pathway. However, the evidence will not change

between now and the guidance being issued and he therefore felt that a referral to NICE would be unproductive.

- 4.14 Professor Pinching said that individuals who do not have access to services or support in turn become more disadvantaged. There was a need for an epidemiological study to enable action. At present services are developing organically
- 4.15 Liz Blackman agreed that in the short term a cribsheet is necessary. She proposed that Group write to Secretary of State for Health and CMO urging this to happen. Also need to look at consultants skills mix so that we can treat people locally
- 4.16 It was agreed that the Group would to write to Secretary of State from APPG
- 4.17 The Countess of Mar asked about postgraduate training.
- 4.18 Professor Pinching said that the CMO identified a need for postgraduate education and that GPs definitely need more formal training. Such education can be provided locally, built around a patient's experience but supplemented by specialist support
- 4.19 Professor Hutchinson pointed out that some GPs have had negative experiences of referring people to secondary care
- 4.20 Tony Wright concluded by saying that this should be regarded as the beginning rather than end. The report must not gather dust and we need to continue with the momentum. Interim guidance is clearly an area of importance
- 5.0 **AOB**
- 5.1 It was suggested that George Radda, Chair of Medical Research Council or Jacqui Smith, Minister of State should be invited to address next meeting
- 5.2 Date of next meeting was made provisionally for the end of April 2002