



## 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 TUESDAY 10<sup>th</sup> DECEMBER 2002 AT THE HOUSE OF COMMONS

### PRESENT

- Tony Wright MP
  - Brian Iddon MP
  - Des Turner MP
  - Bob Blizzard MP
  - Tony Cunningham MP
  - Andrew Stunnell MP
  - Office of Stephen Hesford MP
  - Office of Huw Edwards MP
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- Mr Dick Paterson, Chair of Dorset M.E. Support Group
  - Mr Derek Vernon, Project Manager, Stockport Outreach Nurse Service

### 1. MINUTES OF THE LAST MEETING

The minutes of the last meeting were agreed

### 2. APOLOGIES

Apologies for absence were noted

### 3. PRESENTATIONS - SERVICES FOR CFS/M.E.

- 3.1 Dick Paterson gave an overview of the Dorset M.E. clinic which until a year ago was run by the Dorset M.E. support group and outlined some of the issues that had been faced by the group in getting the service established and maintained

Mr Paterson and the Dorset M.E. support group had begun lobbying the local health authority to establish a service in 1993. In 1994 and 1995 the group submitted formal bids that were unsuccessful on the grounds that there were not enough funds to support a service and that there remained controversy over the illness and the appropriate course of treatment. In 1996, however, it submitted a bid which was supported by 38 local GPs, 5 consultants and 3 MPs and, as a consequence the group was finally invited, to submit a business plan to run the service

This was accepted and in 1997 it was invited to launch a trial exercise unit by the LHA. The group itself was charged with running the service at the Wareham

Community Hospital in Dorset. Patients could access the service through referral from a Dorset registered GP and on completion of a medical protocol.

The service is staffed by a lead consultant, a clinical assistant, a clinical psychologist and two occupation therapists. Clinical sessions are held on one morning per month and follow up treatment by Occupational Therapists.

There are three levels of service which the clinic provides. The first is 1 to 1 and aimed at those who have a less acute form of the illness. The second (which is most common) and is aimed at affected fairly severely. - this consists of a six session programme held every two weeks. The third level is aimed at those most severely affected - and consists of domiciliary visits (generally by the Occupational therapists but occasionally the consultant).

Mr Paterson explained that the service was initially financed by the Dorset Health Authority and the Dorset Support Group but, following a very supportive independent report three years on was integrated fully into the local NHS and is now run and financed by the South & East Dorset PCT.

To date over 300 patients have been seen and an established treatment programme has been set up. Improvement rates are carefully evaluated and there is a significant success rate amongst patients.

The Group continues to seek to improve the service and is currently looking into options for providing support both for children and people severely affected with M.E.

### **Stockport Outreach Nurse Service**

3.2 Derek Vernon detailed how the Stockport M.E. support Group had initially received a £69,000 National Lottery Grant spread over three years in 1998 in order to establish a Nurse Outreach Service for the estimated 1300 cases in the Stockport area. This was augmented by a further grant of £156,000 spread over three years from the Community Fund in 2001.

The aims of the service are to promote the early identification and appropriate treatment of CFS/M.E.; to provide a domiciliary service within primary care; to tailor treatment to individual need; to support carers; and to offer a specialist resource to other health professionals. The service targets the newly diagnosed; those severely affected and families and children with CFS/M.E.

Mr Vernon then explained that the service is staffed by 3 part time nurses and also operates a telephone helpline. Nurses make a minimum of 5 home visits (following visits depend on severity and the ability of the patient to plan and prioritise). The nurses identify and offer relief for current symptoms, as well as identifying additional needs (which may involve a referral to social services/welfare rights). They will then try to draw up a care plan involving pacing, planning, appropriate goal setting such as a gradual increase in activity as tolerated by the individual.

Finally Mr Vernon demonstrated that the service is properly monitored for success outcomes and revealed a change questionnaire which showed the vast majority of patients had benefited from the service.

### **Questions**

- 4.1 Tony Wright asked how information about the services could be disseminated?
- 4.2 Derek Vernon replied that the Stockport group had published a report on the service in January for medical professional and this had been issued to enquirers from across the UK including NHS commissioners and M.E. groups. Wished to disseminate the report to local and regional groups but feedback from groups is that PCTs do not have the finance to support this. Dick Paterson stated that word gets around on how the Dorset service was established simply because it is one of the few with the expertise - and other groups which are not as far forward are keen to learn from their experience.
- 4.3 Tony Wright stated that he was aware of cases in Great Yarmouth where doctors had worked with patients but this was the tip of the ice-berg. PCTs needed to follow up recommendations of CMO report regarding services.

## **5 Update on Medical Research Council**

The Group was given a handout updating them on the Medical Research Council's first meeting of its Expert Group on CFS/M.E.\*

## **6 Interim Guidance following CMO's report**

The Group was given a handout informing them of the decision by the Health Minister, Jacqui Smith to refer GPs to Action for M.E.'s guidance for GPs on CFS/M.E. in the October DoH Health Bulletin. It follows correspondence between the charity, Tony Wright, Chair of the group and both the CMO, Professor Liam Donaldson and the Health Minister, Jacqui Smith on the issue of interim guidance.

## **7 RiME Petition**

Tony Wright informed the group that he had been in correspondence with the organisers of the RiME petition who were asking that they be allowed to address the group. It had previously been agreed that as there were so many ME support groups and charities and because the time of the APPG on ME was limited that it would be wrong to accept a request from one particular group to address the APPG on ME. It was agreed that this should continue as the policy of the group

## **8 AOB**

## **9 Date, time and subject of next meeting**

It was agreed that the Medical Research Council be invited to address the next meeting in order to update the Group on progress once it has published its final strategy, expected in February.

\* The meeting of the APPG on M.E. took part the week before the MRC published its draft recommendations on advancing strategy on the illness. This can be found, in full, at [www.mrc.ac.uk](http://www.mrc.ac.uk)