



**All Party Parliamentary Group on M.E.**

**Chair:** Des Turner MP  
**Vice-Chairs:** Andrew Stunell MP  
Tony Wright MP  
**Secretary:** Ian Gibson MP  
**Treasurer:** David Amess MP

**Minutes of the meeting of the All Party Parliamentary Group on M.E.  
held at 4pm, Tuesday 22 January 2008  
Committee Room 17, House of Commons**

**PRESENT**

Dr Ian Gibson MP (acting chairman for the meeting)  
The Countess of Mar  
Kerry McCarthy MP  
Andrew Stunell MP  
Tony Wright MP

Matt Maguire (Office of Dr Des Turner MP)

Sir Peter Spencer, Action for M.E.  
Heather Walker, Action for M.E.  
Dr Charles Shepherd, ME Association  
Tony Britton, ME Association

Mary-Jane Willows, Association for Young People with ME  
Jane Colby, Young ME Sufferers Trust  
Doris Jones, 25% Group  
Christine Harrison, BRAME  
Sue Waddle, ME Research UK  
Barbara Robinson, Suffolk Youth & Parent Support Group  
Paul Davis, RIME  
Joy Birdsey, Kent and Sussex Alternative Group supporting RIME  
Bill Kent, ReMEember  
Colin Barton, Sussex and Kent ME/CFS Society  
Jill Piggott, Worcester ME Support Group  
Natasha Posner, Warwick University RCN Research Institute  
Janet Taylor, Kirklees Independent ME Support Group  
Augustine Ryan, person with M.E.  
Angela Kennedy, carer of person diagnosed with ME  
Annette Barclay, person with ME  
Nigel Waddle, carer of person with ME  
Jo Dubiel, person with ME  
Lindsey Middlemiss, West Berkshire ME and FM Group and Reading area ME Group.  
One illegible signature.

**1. Welcome**

Dr Ian Gibson took the chair in the absence of Dr Des Turner, giving Dr Turner's apologies. He said Dr Turner was hoping to be called to speak in a debate on the Energy Bill. He offered to turn the chair over to former APPG chair Tony Wright MP, but Mr Wright declined.

## **2. Apologies**

Anne Begg MP, Lord Bilston, Peter Bottomley MP, Tom Brake MP, Tony Cunningham MP, Andrew Dismore MP, David Drew MP, Andrew George MP, Linda Gilroy MP, Clive Efford MP, Mike Hancock MP, Oliver Heald MP, Charles Hendry MP, Jim Hood MP, Kelvin Hopkins MP, Dr Brian Iddon MP, Lynne Jones MP, John Leech MP, Chris Mullin MP, Mike O'Brien MP, Eddie O'Hara MP, Bill Olnner MP, Rudolf Vis MP, Betty Williams MP, Hywell Williams MP.

In answer to a question from Janet Taylor (Kirklees Independent ME Support Group), Dr Gibson said she would certainly have an opportunity to be heard later.

## **3. Minutes of the last meeting:**

Paul Davis (RIME) complained that the minutes of the last meeting failed to report, or even reflect accurately, what he said at the meeting on 12 July 2007. He had read out comments from five group leaders who each condemned the NHS services in their areas. Two of the five (Kent and Birmingham) were not mentioned at all; the other three comments were inaccurately recorded. Mr Davis said his remarks were corroborated by three other attendees and had been sent to the Chair and to the secretariat. He called for the minutes to be amended. Mr Davis said he did not recall the chairman saying he noted the views of Mr Davis and then adding that they did not reflect the views of the majority present.

Heather Walker apologised for omitting mention of two of the five leaders. Otherwise, she stood by the minutes.

The Countess of Mar pointed out that this meeting was scheduled to last for only an hour and a half. She urged people should move on.

After further discussion, Dr Gibson suggested that the meeting vote on whether the minutes should be amended. At this point, Angela Kennedy then drew attention to a petition she and Ian Mclachlan had raised about the NHS services. She proposed that it be entered into the record. This was seconded by Joy Birdsey.

Paul Davis said the last meeting had not been the first time that RIME's comments had not been accurately reported or reflected. In July 2006, for instance, RIME's comment had been reduced or diluted and important details omitted all together. Several observers believed that the minutes were being manipulated, with MPs misled on important issues such as services.

Lindsey Middlemiss (representing the Berkshire ME Support Groups) said she agreed that controversial topics should not be omitted from the minutes. Colin Barton (Sussex and Kent ME/CFS Society) objected to time being spent on the issue; there was more important business on the agenda.

Tony Wright MP said the APPG had been set up to put ME on the government's agenda. There were many issues that needed to be focused upon and the need for continued involvement of MPs; if there were criticisms, they should be made through one's own MP.

Annette Barclay said she had attended the last meeting where there had been a loss of control over the discussion. She, too, had not heard the words attributed to Dr Turner in the minutes.

At this point, Angela Kennedy moved her motion. On a show of hands, the result was 14-0 in favour of the motion being recorded in the minutes.

### **Angela Kennedy statement**

We are a group of individual people suffering from or closely connected to someone suffering from Myalgic Encephalomyelitis, also known as Chronic Fatigue Syndrome; an illness classified as neurological by the World Health Organisation's ICD-10 under code G93.3. We advise the APPG today of the following:

From the evidence available, it has become apparent that the majority of NHS 'CFS/ME' clinics do not adopt a suitably biomedical approach towards M.E. sufferers. Instead, these clinics inappropriately focus on a Cognitive Behavioural Therapy approach, some combined with Graded Exercise Therapy approaches, neither of which has been shown to be effective treatments for M.E. sufferers, and for which there is evidence of potential risk to patients from both treatments,

We advise you that, by not focusing on a biomedical approach to diagnosis and treatment/support, and by focusing on controversial psychosocial treatments, such clinics are causing M.E. sufferers to be put at risk, both physically and psychologically. We therefore feel the approaches of these clinics are inappropriate for M.E. patients,

In addition we remind the APPG of its duty to safeguard the interest of ME sufferers, and ask that it immediately clarifies its ambiguous position of supporting the setting up and continuation of the CFS/ME clinics – especially as that support is also being given on the extremely vague pretext that they are “a base to build from”, despite all evidence to the contrary. We also remind the APPG that their remit is to support only the WHO code G93.3 of ME/CFS, and therefore believe an unequivocal position of insistence on only a biomedical approach should have been taken from the outset.

We trust that the APPG will now acknowledge that there are, within the ME/CFS community, serious concerns about and objections to the approaches of the majority of the NHS 'CFS/ME' clinics, and have this formally entered in the minutes.

### ***The statement carries the names of 504 people.***

While the APPG waited for the main speaker – Ann Keen MP, Parliamentary Under Secretary of State for Health Services – Dr Gibson departed from the agenda to proceed with remaining business.

### **3. Matters Arising**

**NHS Services:** Sir Peter Spencer (Action for ME) said AfME was conducting a survey among Strategic Health Authorities to establish how plans for NHS services for ME/CFS were faring in England. There had been 13 responses so far, with nine indicating various levels of uncertainty.

Lindsey Middlemiss said there were no NHS services at all in Berkshire. Barbara Robinson mentioned the declining provision in East Anglia. Charles Shepherd (ME Association) said MEA had prepared a questionnaire to be completed by clinical leads to establish the level of provision in new services: this has been trialled in Portsmouth. Dr Shepherd also tabled a 'hot topics' briefing paper on behalf of the MEA.

Janet Taylor said Kirklees Independent ME Support Group was meeting with Kirklees PCT to establish a clinical pathway for an ME/CFS service in the area, though no conclusions had been reached. Christine Harrison (BRAME) said continuing shortfalls in provision should be brought to the minister's attention. Mary-Jane Willows (Association of Young People with ME) said the continuing lack of NHS paediatric provision in many geographic areas should also be raised.

**Adjournment debate and revised Early Day Motion:** Dr Shepherd reported that John Bercow MP had not been successful in achieving an adjournment debate in the December ballot. He would try again, when the opportunity arises. Ian Gibson suggested that it may be useful to prepare another Early Day Motion, this time concentrating on services. He would be available to table one, if necessary.

**DWP Guidance:** Tony Wright said more people with ME were being turned down for benefit than any other illness and more people were winning on appeal. This had been a constant concern of the APPG over the years. It was important to have another meeting with a DWP minister. In answer to a question from Natasha Posner who wanted the revised DWP guidance to be raised with Ann Keen because of the probability that it would reduce the number of DLA awards to people with ME, Dr Gibson suggested that a minister from the DWP would more appropriate. Dr Shepherd said that, without any DWP statistics to go by following the introduction of the guidance in July 2007, all we have are continuing anecdotal reports; more information on benefit problems was really required before asking a DWP minister to return to the APPG. It was decided to consider arranging a meeting with the DWP to discuss continuing concerns.

**Occupational Health Guideline:** Dr Shepherd reported that Dr Ira Madan, director of NHS Plus, had written back to the ME Association on January 11 to say she was considering the points made in the joint charity response submitted by the MEA. The three leaflets would be revised. Sir Peter Spencer said he hoped that the amendments would meet the concerns and objections that had been expressed.

**NHS Collaborative Conference:** Sir Peter Spencer and Mary-Jane Willows gave a positive report on this conference at Milton Keynes, about which concerns had been expressed at the last APPG. Sir Peter said the inadequate evidence base had been discussed at the conference, and the conference had completely debunked the myth that AfME was not interested in seeing more biomedical research.

#### **4. Any Other Business:**

With no sign of the Minister, **Dr Gibson** felt the meeting should move on and agree a small number of points that should be raised in the limited amount of time we would have with Ann Keen and what we should ask for at the end in order to keep the momentum going – otherwise we would miss a marvellous opportunity to contribute to government policy-making.

It was decided to concentrate on the issue of NHS services, in particular problems with existing services (ie financial difficulties and closures following the end of the Department of Health ring-fenced funding) and new services that are being introduced or proposed following the NICE guideline (ie early indications that PCTs may be opting for services that are not physician-led, offer no diagnostic service, and concentrate on CBT and GET). And, as Lord Darzi would be completing his work on the long-term neurological conditions chapter of his NHS review shortly, we should be seeking an urgent meeting with him to discuss ME services.

Dr Gibson also suggested that the time may have come for the government to appoint an 'ME Tsar' who can deal with all issues relating to ME – in the same way that high profile diseases such as cancer and heart diseases have their own government health tsars.

**Jane Colby (Young ME Sufferers Trust)** presented an unpublished paper by Dr David Sampson PhD that contained a critical evaluation of some of the research input that comes from psychiatry. She asked for the paper to be presented to the Minister and this was agreed.

**Paul Davis** moved the amendment of the Minutes of the last meeting as per item 3. This was seconded by Annette Barclay. On a show of hands, there were three votes for the motion but it was lost by a large majority. Mr Davis said that, if the Minutes were not corrected, he would complain to the Parliamentary Commissioner.

***The Minister arrived for the meeting at 5.09pm – accompanied by Dr Chris Clough, a consultant neurologist at King's College Hospital, who is also member of the External Reference Group for the National Service Framework in long-term neurological conditions.***

#### **5 . Presentation by Ann Keen MP, Parliamentary Under Secretary of State for Health Services:**

The Minister said she had worked for 25 years in nursing – much of the time spent in the community with people who had neurological and long-term conditions. She said she accepted without reservation that ME was a neurological disease, and referred to it as such several times during her address

Mrs Keen said she understood and sympathised with many of the well-known problems facing people with ME. These included: unsympathetic doctors; lack of medical education of ME; the need for early diagnosis; good quality management that covers all aspects of the illness; and research, or lack of it, including the need for better epidemiological data so that health providers know the full extent and severity of the problems.

Lord Darzi, her ministerial colleague in the Department of Health, was working on his review of NHS services, and planning to sign off the section of long-term conditions shortly. Mrs Keen said she thought it would be very useful for the APPG to feed into that review and offered to facilitate a meeting with Lord Darzi. The Minister said she could not guarantee an appointment with Lord Darzi "but as good as".

Mary-Jane Willows (putting a question on behalf of **Sir Peter Spencer**, who by this time had left the meeting to catch a train to Scotland where he was due to attend the Cross Party Group the following day) asked how the Government remained accountable for the consequences of decisions delegated through strategic health authorities to primary care trusts? Care commissioners inside PCTs were being forced to make choices because of funding restraints. In many cases, specialist ME services were not getting a look in; as a result, service provision overall was patchy.

On behalf of the Association of Young People with ME, **Mary-Jane Willows** said paediatric provision was geographically restricted. Two of the 11 specialist paediatric services in England had closed in the past year, which meant there were fewer services that could intervene quickly and effectively to prevent some of the worst child care abuses. The infrastructure to support families at times of crisis was not properly in place.

**Charles Shepherd** said the problems stemmed from 2003, when the first services had been set up with £8.5m ring-fenced funding. In July last year, for instance, Dr Terry Mitchell had told the APPG how his own service in East Anglia had come under immense financial pressure even before his own retirement from the NHS. The MEA was attempting to obtain feedback about the level of provision in any new services through a questionnaire designed to be completed by the clinical lead.

**Christine Harrison (BRAME)** said she was mother and full-time carer of a daughter who had been affected by ME for many years. ME had a multi-system effect and affected people in a myriad ways; simply assigning them to CBT/GET treatment centres was not good enough.

***At this point, Dr Gibson had to leave the meeting because of a prior commitment. He invited Kerry McCarthy MP to take the chair for the last few minutes, which she did.***

The Minister said she would be happy to stay on and take a few more questions and comments.

These included: a statement that the existing services had seen 23,000 patients so far but more services were needed to cater for demand; the lack of services in Portsmouth, where people with ME felt abandoned by the NHS; and the proposed service in Kirklees, west Yorkshire, where the impetus had come from a rise in the number of neurological referrals

**Annette Barclay** said she had suffered from ME for 20 years. Medical recognition of her ME as a neurological condition had diminished, not improved, over that time. Never had she been more consulted and felt less listened to in her life. **Sue Waddle** (ME Research UK) agreed that recognition had become much worse in that time.

**Dr Chris Clough** said he was sorry to hear Annette Barclay's story. He acknowledged that there was a problem with the training of doctors, who had not given enough consideration and respect to patients with ME, and it was time to put that right.

Annette Barclay added all the doctors with experience of ME were retiring or dying. **Barbara Robinson** said the NHS Plus and DWP guidelines were – at national policy level – just two examples of failure to acknowledge neurological causation.

**Jane Colby** pressed for the central collection of statistics for ME. Until they were available, the actual size of the problem would never be known,

The Minister said the important topic of child abuse was the subject of much work across departments nowadays – with Kevin Brennan MP in the Department for Children, Schools and Families leading on ministerial co-ordination.

She said was also time to improve the medical profession's perception of ME and other long-term neurological conditions; more work needed to be done in this area. She expected the Darzi Review to address these issues.

At this point, Kerry McCarthy drew the meeting to a close by thanking the Minister for her attendance. There was applause for Ann Keen and Dr Clough.

## **6. Date of the Next Meeting.**

To be arranged.

The meeting closed shortly after 5.30pm