

# **Brief Reports on Two APPG Meetings on ME/CFS**

## **Meeting Held On 22.2.2007**

This meeting was attended by 30 people, including Dr Charles Shepherd and Tony Britton from the ME Association, Angela Murphy and Heather Walker of AfME, Christine Harrison from BRAME, Doris Jones for the 25% ME Group, Di Newman of the Peterborough ME & CFS Group and Cambs Neuro Alliance, and many others. Chairman was Dr Des Turner and 4 other MPs were present at some point. Guest speakers were Professor Peter Littlejohns and Dr Esther Crawley from NICE (there also were three other representatives from NICE).

Everyone present at this meeting was given a copy of the joint statement by ME/CFS Charities on the NICE draft guideline. Professor Littlejohns explained that he, Dr Crawley and the other NICE representatives had come in place of Professor Michael Rawlins. He spoke in general about the NICE guideline development process – he had been involved in this since its inception; many guidelines (118) had been produced. Dr Crawley said she had been on the Guideline Development Group, but as a paediatrician she also saw between 150 and 200 children with CFS/ME every year. She said this had been a very difficult guideline to develop and she was struck by both the consultation and the feedback to the draft guideline.

A very lively Q+A session followed and all patient group representatives as well as individuals made it very clear that they were extremely unhappy about the NICE draft guideline issued in September 2006. Whilst Professor Littlejohns made every effort to 'stand his ground', Dr Crawley when confronted with specific questions (e.g. was NICE accepting the WHO classification of ME/CFS as a neurological disease, as did the DoH?) was clearly 'floundering' and could not give a clear answer. These two NICE representatives were left in no doubt about the great concerns which the NICE draft guideline was causing patients and their representatives, especially with regard an apparent 'blanket recommendation' of CBT and GET as the principal management/treatment approaches for all patients.

During these discussions Professor Littlejohns conceded that they may have to rethink their strategy of considering RCTs as the principal source of evidence, and he also indicated that patient evidence might have to be given greater weighting. However, on the question of a second consultation with patient group representatives, he stated that this was not now generally done and when pressed he said that the final guideline would be published, even if this was rejected by all ME/CFS Charities (now scheduled to be published in late August 2007).

Both Professor Littlejohns and Dr Crawley admitted that the feedback from stakeholders and other parties during the consultation had been huge – perhaps the largest they had ever had to deal with.

'The meeting ran over time; Sarah Vero, Dr Gibson's Assistant, distributed copies of a draft EDM based on key findings of his report (see below for the wording of this EDM). Other items on the Agenda for this meeting (e.g. the 'Mental Health Act and Mental Incapacity Bill') were deferred to the next APPG meeting'.

## **Wording of the Draft Early Day Motion (EDM)**

*Prepared by Dr Ian Gibson MP*

'This House recognises Myalgic Encephalomyelitis (ME) as a serious, long term debilitating illness, that affects more people in the UK than HIV/AIDS; welcomes the Group on Scientific Research into ME's Report 'Inquiry into the status of CFS/ME and research into causes and treatment'; notes the Department of Health classification of ME as a neurological condition; calls on all government departments to accept this definition; calls for the implementation of nationally recognised clinical and research criteria which reflect the Dept of Health classification, similar to the guidelines used in Canada; calls for the collation of national epidemiological data of ME Patients based on this criteria; calls for an independent panel of medical experts to review the existing international and UK biomedical evidence relating to ME to identify areas for further research; calls for massive further research into potential aetiology and treatments of ME.'

## Meeting Held On 17.5.2007

This meeting was attended by an estimated 16-18 people, including Dr Charles Shepherd and Tony Britton from the ME Association, Sir Peter Spencer (the new CEO of AfME), Trish Taylor and Heather Walker from AfME, Doris Jones representing the 25% ME Group and Christine Harrison from BRAME. It was chaired by Dr Des Turner, but no other MPs were present.

The guest speaker was Dr Ira Madan, Director of the NHS Plus project, which published the recent guideline 'Occupational Aspects of the Management of CFS: evidence based guidance', with accompanying leaflets for employers, employees and healthcare professionals in October 2006. She explained the background of NHS Plus and how this particular guideline was initiated (by Dr Karen Pratt, Specialist Registrar in Occupational Medicine at BUPA Wellness, London), and how it had been produced (in consultations with stakeholders, the DWP, NICE and the DoH). She explained that the main purpose was to establish which treatments were effective in helping patients to return to or remain in work, but also to identify predictive factors for a successful return to work in those who are absent as well as identifying risk factors for relapses with regard to non-attendance or poor functioning at work.

The MEA had distributed copies of the Statement signed by 23 ME/CFS Charities and support organisations, which rejected the guidance and asked for its withdrawal (see page 15). During a lively session which followed Dr Madan went through all the points raised in this statement. She repeatedly mentioned how helpful Chris Clark (the previous CEO of AfME, who left the charity in March 2006) had been in the preparation (and writing) of this guideline. At the end she agreed to a meeting with some charity representatives to discuss the raised criticisms in more detail and consider some amendments to the leaflets. Information sent by AfME prior to finalising the guidance in 2006 had gone missing and would now be sent again.

After Dr Madan departed, other issues were discussed. Sarah Vero reported that Dr Gibson's group who had prepared the report on CFS/ME would be disbanded – an official announcement would be made soon; she also said the proposed EDM was suspended, but would remain on the parliamentary agenda. Dr Gibson was looking to the APPG to take these issues forward.

Dr Shepherd reported briefly on the morning's meeting of the Health Select Committee for their inquiry into NICE (see page 14 for some details), he said that Professor Richard Baker (Chairman of the ME/CFS Guideline Development Group at NICE) and other NICE representatives would be available at an MEA public meeting scheduled for 15th September to discuss the published NICE Guideline.

Christine Harrison reported that the DWP may be willing to make further amendments to Version 9 of their draft guideline. She and Barbara Robinson raised concerns over continued funding for the East Anglian new NHS clinics. This issue will be on the Agenda for the next APPG meeting, provisionally scheduled for 12.7.2007.

*Edit. Comments:* Attending these APPG meetings since last year has been a unique experience for me (DJ), and representing the 25% ME Group a particular challenge.

During both the above meetings specific problems for the severely affected were stressed and evidence from the January 2007 Fort Lauderdale International Conference on CFS/ME were made available to Professor Littlejohns and Dr Esther Crawley as well as to Dr Des Turner.

What is becoming clear now is that ME/CFS is being discussed more regularly within the confines of the UK parliament (if not on the floor of the House!) as well as in other institutions, but unfortunately the all-prevailing influence of certain UK psychiatrists has manifested itself in official documents produced by two major and influential UK institutions: the National Institute for Health and Clinical Excellence (NICE) and NHS Plus, an arm of the NHS.

Similarly, Dr Gibson's well-intended report appears not to be making the impact which so many patients had hoped for (see separate coverage on page 18). It is also far from certain whether NICE will make any significant amendments to the draft guideline on CFS/ME, and all the indications are that NHS Plus will only make 'minor amendments' to details in the leaflets.

Everyone awaits the new DWP guidelines with trepidation. Dr Shepherd has prepared notes on these meetings which were circulated on Co-Cure (23.-24.2. #2207-54 + 18-19.5. #2007-139).