



All Party Parliamentary Group on M.E.

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

**Minute of the Meeting of the APPG on M.E.
held 1.30pm, Thursday 22 February 2007,
Committee Room 17, House of Commons**

PRESENT

Dr Des Turner MP (Chair)
Andrew Stunell MP (Vice Chairman)
Peter Luff MP
Tony Wright MP
Sarah Vero, office of Dr Ian Gibson MP
Andrew Falconer, office of Sir Robert Smith MP
Professor Peter Littlejohns, NICE
Dr Esther Crawley, NICE Guideline Development Group
Fiona Cairns, Action for M.E
Angela Murphy, Action for M.E
Heather Walker, Action for M.E.
Dr Charles Shepherd, ME Association
Tony Britton, ME Association
Adrian Ward, NICE
Colette Marshall, NICE
Sarita Tomber, NICE
Paul Davis, RiME
Richard Crossick, North London ME Group
Hazel Griffiths North London ME Group
Ciaran Farrell, Person with ME
Christine Harrison, BRAME
Criona Wilson, mother of the late Sophia Mirza
Doris Jones, 25% Group
Di Newman, Peterborough ME and CFS Group and Cambs Neuro Alliance
Clive Page, Father of person with ME
Augustine Ryan, Person with ME
Hubert Berger
Rebecca Anderson
Jo Dubiel, Person with ME
Jill Pigott, Worcestershire ME Group

APOLOGIES

John Baron MP, Betty Williams, MP, Kelvin Hopkins MP, Dr Julian Lewis MP, Jenny Willott MP, Bill Olnier MP, Clive Efford MP, Nadine Dorries MP, Dr Roger Berry MP, Steve McCabe MP, Jim Hood MP, Ann Widdecombe MP, John McDonnell MP, Joan Humble MP, David Lepper MP, Mark Todd MP, James Plaskitt MP, Chris Mullin MP, Tim Boswell MP, Lembit Opik MP, Ben Wallace MP, Jeremy Wright MP, Lady Sylvia Hermon MP, John Thurso MP, Peter Bottomley MP, Cheryl Gillan MP, Hywel Williams MP, Tom Brake MP, Mike Hancock MP, Fraser Kemp MP, Lord Clement-Jones, Tim Farron MP, Celia Barlow MP, Tony Wright MP, Ann McKeichin MP, Eddie O'Hara MP, Sandra Gidley MP, Sir Robert Smith MP

1. WELCOME

Dr Turner welcomed people to the meeting. He explained that as Professor Michael Rawlins, chairman of the National Institute for Health and Clinical Excellence (NICE), was unable to attend the meeting to discuss the draft clinical guideline for CFS/ME, NICE was being represented by Professor Peter Littlejohns, Clinical and Public Health Director of NICE and Dr Esther Crawley, Consultant Paediatrician and Guideline Development Group member.

Professor Peter Littlejohns thanked the Group for inviting NICE to attend. He explained that he had been responsible for clinical guidelines at NICE since their inception. All NICE guidelines were produced on the basis of best available evidence and on a process based on transparency, active consultation and review. He added that guidance however robust is not set in stone; medical advances can happen very quickly and NICE aims to make guidance as up to date as possible. A total of 118 guidelines, including 51 of clinical guidance, have been produced over the past 18 months. NICE was the biggest guideline production unit in the world. Any organization affected by a guideline should be part of the development of that guideline.

Dr Crawley explained that as well as being on the Guideline Development Group, she is a paediatrician who sees 150-200 children with CFS/M.E. every year. She said she had been very struck by the consultation, both the initial questionnaire and the feedback on the draft guideline.

Dr Turner said that the guideline on CFS/M.E. was unique compared to guidelines on other illnesses, in that M.E. is a spectrum of illnesses.

Dr Crawley said that although this had been a cause of controversy and had made the guidelines difficult to draft, the aim of the Development Group had been to encourage clinicians to consider a diagnosis of M.E. at an earlier stage.

Professor Littlejohns said each new guideline has its own challenges. The initial scoping exercise helped people to focus and identify limitations on what was possible in the timescale available.

Hugh Berger, father of a person with M.E., asked the NICE representatives if they agree with the WHO definition of M.E. as a neurological condition. Professor Littlejohns and Dr Crawley were unable to answer directly. Dr Crawley said the issue had come up in the consultation but that it wasn't part of the scope of the guideline to discuss definitions. Hugh Berger asked if they considered M.E. a psychiatric condition. Professor Littlejohns said that although NICE considered definitions, NICE was not in a position to define conditions. Dr Crawley said she believed in the biopsychosocial model of the illness, that it can be genetically inherited but that body and mind are linked. Hugh Berger said this model is offensive to people with M.E., a physical illness.

Di Newman added the draft guideline is already turning back time for those GPs who have accepted that M.E. is a physical illness and that terms like "biopsychosocial" are used by insurance companies which do not want to make payouts to people with M.E.

Dr Charles Shepherd highlighted that people with M.E. suffered financially, by losing benefits, when the psychosocial model was used. NICE had to accept the WHO classification of M.E. as a neurological illness.

Professor Littlejohns said the guidance would be listed on the neurological section of the NICE website. He said that he was not qualified and did not feel the APPG was the place for him to discuss definitions.

Paul Davis said the terminology of the draft guideline was skewed and based in misinformation. In his opinion the document was irrelevant and potentially dangerous in that it recommended graded exercise therapy (GET) and said lack of exercise prolongs the illness. This is offensive to people with M.E.

Ciaran Farrell later echoed this, saying a guideline which recommends cognitive behaviour therapy (CBT) and GET as treatments of first choice was at odds with definitions of and criteria for M.E., which indicate that exercise makes people with M.E. feel worse. He also felt that by regarding relapses as set-backs, the draft guideline implied that the illness was psychological and that people were choosing not to recover.

Professor Littlejohns said that the guide was a draft and that while he could not predict the results of the consultation process, he believed a number of concerns raised had been heard by the Guideline Development Group.

Dr Crawley said the guideline emphasised that there should be a choice of treatments and that programmes should be individually tailored. No-one would be forced into CBT or GET.

Dr Shepherd challenged this: the guideline described CBT and GET as therapies of first choice. A number of charities had signed a joint statement which drew on feedback from patients: GET can be harmful and CBT does not benefit everyone.

Dr Crawley said that the guideline could have been worded better, adding that the Group had listened to consultees and been informed by the consultation.

Professor Littlejohns confirmed that NICE was keen to listen to patients as well as clinicians and others involved.

Christine Harrison BRAME read out a statement, raising the specific problems of the severely affected and their carers and pointing out that specialist NHS services are under threat due to funding. She asked who would take responsibility if health professionals follow the NICE guidelines promoting CBT and GET and patients are mismanaged, misdiagnosed or experience a serious deterioration in their health, or even die?

Under the current system, the severely affected are sometimes taken into care against their will, and forcibly removed from their home, despite their families' protests.

Criona Wilson described the tragic circumstances of her late daughter, Sophia Mirza, who was treated as mentally ill by doctors and sectioned before her death. It took an autopsy to prove that her spinal chord was inflamed. Christine Harrison and Di Newman confirmed that Sophia was not a solitary case. Christine had been in contact with a number of parents whose children with M.E. have been sectioned or lost their children completely in their 20s or 30s.

Dr Turner said that if the NICE guidelines are going to be any use, they should give some protection to families and individuals affected by M.E.

Tony Wright MP said that the importance of the NICE guideline was clear when children and young people were being sectioned and adults were not getting benefits to which they were entitled. He said it was wrong that people may be seen either by doctors who do or do not accept the WHO classification of M.E. as a neurological illness. He believed that NICE has a duty to protect people from doctors who do not accept the evidence of families who say their loved one has a physical condition.

Professor Littlejohns said that changes to the guideline would be documented. The guideline would form part of national clinical standards and doctors would be assessed on whether they meet these standards.

Angela Murphy was disappointed that the guideline had made no recommendation for further biomedical research.

Dr Crawley said that she was passionate about biomedical research and that the guideline group had been struck by the lack of epidemiological and other evidence.

Angela pointed out the difficulties people had experienced with the consultation process, in terms of accessibility and transparency. For example, the guideline was too long, there had been problems with electronic distribution, the information needed to be tailored for specific audiences and the timeframe for responses was limited for people with severe fatigue.

Professor Littlejohns said he took these points on board.

Doris Jones echoed earlier points made about the potential dangers of CBT and GET, quoted evidence for the physicality of the illness and pointed out that suicide is the third most common cause of death among people with CFS/M.E. after cancer and heart attack. CBT/GET cannot resolve serious physical illness, she added.

Dr Shepherd asked whether the guideline would still be implemented after publication in August if it still did not have the confidence of patients.

Professor Littlejohns said that guidelines were not always carried forward if they were not seen to be useful to the NHS.

Fiona Cairns asked if the phrase about CBT/GET being the first treatment of choice would be removed.

While Professor Littlejohns and Dr Crawley could not predict what the guideline would say, Dr Crawley admitted that the phrase did not reflect the meaning intended by the guideline group and said she felt that the comments made by consultees would be taken on board.

Professor Littlejohns was asked whether NICE would consider a second phase of consultation. He replied, "We have a process which we try to keep to. Occasionally we do move away from that process."

The Chair suggested that NICE might wish to take some more time to consider how best to address some of the issues that had been raised.

Professor Littlejohns said he would report the point back to the NICE Executive Committee, as he was not empowered to make that decision.

2. MINUTES OF THE LAST MEETING / MATTERS ARISING/OTHER BUSINESS

- i. As time was short, Dr Turner suggested that the following items be carried over to the next meeting:
 - a. Mental Health Bill
 - b. APPG Code of Practice

This was agreed.

- ii. Cairan Farell asked if Mr Hutton had written to Dr Turner with details of any contractual penalties to which Atos Origin were subject. Dr Turner said he would follow up on this and report back to the next meeting.
- iii. Dr Shepherd asked if Dr Ian Gibson had made progress on the wording of an Early Day Motion (EDM). Dr Gibson's assistant, Sarah Vero, circulated a draft (attached). Dr Turner said the EDM would probably be tabled after Easter.
- v. Christine Harrison reported that on 15 February, the DWP had responded to the charities' joint statement on version 9 of DWP guidance, saying: "we are considering the final version of the ME/CFS guidance and will look at the level of detail contained therein. We expect to provide you with a fuller response by the end of April 2007."
- vi. Sarah Vero said that the Gibson Inquiry Group were interested in seeing if they could get the Standards Agency to look at conflict of interest eg. on occasions where advisers are representatives from insurance companies, psychiatrists etc. She asked people to contact her if they had already looked into this.
- vii. Paul Davis asked if Dr Turner could comment on a letter sent by the leader of the Kent Group. Dr Turner said he would follow up on this and respond in due course.
- viii. Doris Jones asked how best to ensure that representatives from the MRC, NICE etc would respond positively to invitations to meetings. Sara Vero suggested that invitations could be made through the APPG.

3. DATE OF NEXT MEETING

To be confirmed.

The meeting closed shortly after 2.45pm.

Appendix

Dr Ian Gibson's draft EDM

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/M.E. 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.