

# Parliamentary News



## REPORT ON THE MEETING OF THE APPG ON ME

12<sup>th</sup> July, 2007, House of Commons, Room 17, 1.30pm

This was a well-attended meeting, with 5 MPs present (including the Chair Dr Des Turner) and about 30 patient group representatives, patients, carers and **Dr Terry Mitchell** as the invited key speaker. The meeting combined the Annual General Meeting of the APPG on ME and Dr Turner advised all present that the existing officers had agreed to stand for re-election: Dr Turner MP was re-elected as Chair, Mr Andrew Stunell MP and Mr Tony Wright MP as Vice-Chairs, Dr Ian Gibson as Secretary and David Amess MP as Treasurer.

Dr Turner explained that due to recent ministerial changes at the DoH, the attendance at the meeting of the Secretary of State for Health (Alan Johnson) or the junior minister now dealing with ME/CFS issues had not been possible. He also had not been successful in getting a response to concerns about funding from a civil servant at the DoH.

**Dr Terry Mitchell**, regional clinical champion for ME/CFS in East Anglia, had been invited to speak about NHS services, especially in his area. He started by describing how his clinical involvement with ME/CFS went back to 1984/5 whilst working as a haematologist at James Paget Hospital. He fitted ME/CFS patients into his work when possible and observed symptoms in these patients which he could not explain by any other diagnosis. Soon a waiting list was necessary, as patients came from Norfolk and Suffolk and so the ME/CFS service provision developed, which was transferred to Waveney PCT.

In 2003 the DoH announced the provision of £8.5m in ring-fenced funding (over two years) for the development of clinical services in England. Dr Mitchell was involved in three local bids for funding: 1) Extra funding for the Norfolk and Suffolk service (a multi-disciplinary team); 2) New funding for a paediatric service in Cambridgeshire led by Dr David Vickers, plus an adult service for Cambridgeshire and Greater Peterborough, i.e. two local multidisciplinary teams (LMDTs); 3) Establishment of Waveney as a clinical network co-ordinating centre (CNCC). All three bids were successful; the total amounts for 2005-2006 came to £456,000. This money was used for additional therapists, extra medical time being made available, reducing the waiting lists in Norfolk and Suffolk and setting up a new service for Cambridgeshire and Greater Peterborough. The total population of these areas was 2.1million and covered an estimated 8,000 ME/CFS patients.

During 2005-2006 these services comprised 7 full time staff who saw 8717 patients, including 581 new patients, which meant this was the busiest ME/CFS service group in England. The service provided consisted of a comprehensive package of care, including diagnosis and ongoing management delivered by a therapy team. This was based on a biomedical model with a flexible approach to activity management and appropriate symptomatic management. As in other

chronic illnesses, depression could occur, he said, and this was acknowledged. The service collaborated with local patient groups who formed the East Anglian ME Patient Partnership Network. Their own audit and feedback from patients were very positive.

Nationally, of the original £8.5m only £6.5m was allocated for clinical development. Furthermore, in the financial year 2006-2007 a 15% reduction in funding for clinical services and all CNCCs was imposed by the DoH, but locally in Norfolk and Suffolk this matter was not raised until October/November 2006 and only in January/February 2007 in the Greater Peterborough/ Cambridgeshire area. Dr Mitchell stressed that the Investment Steering Group did not inform the clinical teams about the reduction in funds. – The situation appears to be the same for 2007-2008 and a significant deficit of around £62,400 is likely to occur, affecting predominantly adult services. Paediatric services in Cambridgeshire are likely to continue, but the adult service in Greater Peterborough is likely to have a 23% budget shortfall, and Waveney most probably a reduction of at least 21%. – This loss of funds has resulted in ‘organisational chaos’. Some patients could not be placed on a waiting list, and most are waiting longer than 13 weeks for an appointment – in one extreme case 38 weeks; patients / carers are fearful of the future without adequate support, he said..

Dr Turner thanked Dr Mitchell for his presentation, which had highlighted a common problem: moneys not ring-fenced by Westminster was likely to be spent on something else. He then invited all present to ask questions in relation to the issues raised by Dr Mitchell. A very lively debate ensued during which divergent views on NHS service provision were aired. Christine and Tanya Harrison as well as Barbara Robinson praised the services provided throughout East Anglia under the leadership of Dr Mitchell; Tanya in particular commented how helpful he had been to her. – Jill Piggott had submitted a statement for the APPG prepared by the West Midlands ME Group Consortium (i.e. Herefordshire ME/CFS/FMS Group, Shropshire + Wrekin ME Support Group, Solihull + South Birmingham ME Support Group, Warwickshire Network for ME and the Worcestershire ME Support Group). This concerned the closure of the West Midlands CNCC due to lack of funding. The statement also criticized the way in which they believed the CNCC Collaborative for ME/CFS was placing too much emphasis on psychological aspects, and finished by criticising the proposed agenda for the NHS Collaborative Conference scheduled for October. – Paul Davis read out some sample letters received from members of his group (RiME), expressing dissatisfaction with the services at the NHS clinics and the (CBT-based) approaches offered, even the services offered in East Anglia were criticized by some of his contacts, but contrary views were expressed by some of the attendants at the meeting. Paul had also written to Dr Turner, explaining the problems his members were experiencing with the CBT clinic in Maidstone; there were also serious problems in Manchester, Winchester, Eastleigh and elsewhere. He also asked Dr Mitchell which criteria were used by his team for patients to gain access to his service and Dr Mitchell replied that a GP referral was needed. – Sir Peter Spencer deplored the failure to prevent the closures of some of the new services and called for urgent political intervention. – Various other points were raised by individuals, e.g. what impact the new NICE guideline would have on NHS clinical services and Tanya replied that PCTs were not legally bound to adhere to these guidelines – they are bound to act in the best interests of patients, but she added that she felt they would nonetheless use the guidelines.

Dr Turner concluded the discussion by suggesting that the new Secretary of State for Health, the

Rt Hon Alan Johnson MP, should be invited to the next APPG meeting, to explain the lack of funding for NHS services, the lack of biomedical research and address concerns over the NICE, DWP and other new guidelines.

John Bercow MP reported on his recent meeting with MEA representatives, during which all current concerns were discussed, i.e. the DWP and NICE guidelines, the NHS Plus occupational health guidance, NHS services and the MRC strategy. He felt the best way to bring these matters to the attention of more MPs would be by way of a 90 minute adjournment debate in the Autumn, but to secure this debate would mean entering a parliamentary ballot and a number of MPs would need to join for this to have a chance of success. The MEA would prepare a media and political briefing paper, which could be used for media and political campaigning, he added.

Issues were then raised by Di Newman regarding the Mental Health Act and Mental Capacity Bill. She was concerned about the amended legislation and possible impact this might have on ME patients; the Bill would increase the number of people who could be sectioned. Criona Wilson stressed again that her daughter Sophia was sectioned and taken to a mental hospital against her will.

Various issues came up during the 'Any other business' part of the agenda, e.g. Dr Shepherd reported that Version 10 of the new DWP medical guidance for DLA benefit applications had been sent to charity representatives previously involved in negotiations. The MEA do not believe these new guidelines will improve an already very unsatisfactory situation, and they have therefore refused to endorse them. This new guidance will be effective as from 20<sup>th</sup> July 2007. Christine Harrison added how disappointed BRAME was that their suggestion to include a disability rating scale had not been accepted in this final version. – Dr Shepherd continued stating that following the presentation by Dr Ira Madan at the May 2007 APPG meeting, she had agreed to meet with one representative each from AfME (Sir Peter Spencer) and the MEA (Neil Riley) on 16.7.07. She was not prepared to meet any more representatives. – Doris Jones stated she wanted it placed on record – on behalf of the 25% ME Group – that they could endorse many of the criticisms of the new NHS clinics raised by Paul Davis, apart from the service provided in Norfolk. She also said serious concerns had been expressed by many patient group representatives about the predominantly psychosocial management representation at the forthcoming AfME/AYME + NHS Collaborative Conference scheduled for October. She finished reading out part of an advert for a research worker at the Institute of Psychiatry, Maudsley NHS Trust, which mentioned 'Anorexia Nervosa and Chronic Fatigue Syndrome' as 'classical psychosomatic disorders'. - Dr Turner said the next meeting should take place on 1<sup>st</sup>, 8<sup>th</sup> or 15<sup>th</sup> November, depending on the availability of the Secretary of State for Health.

**Comments:** The full minutes of this meeting can be accessed on the AfME website. Dr Shepherd gave an overview of the meeting on 15.7.2007, which was posted on Co-Cure. – Doris Jones.