



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 1.30pm, Thursday 12th July 2007
Committee Room 17, House of Commons**

PRESENT

Dr Des Turner (Chair)
Dr Ian Gibson (Secretary)
David Amess MP (Treasurer)
Celia Barlow MP
John Bercow MP

Koyes Ahmed (Office of Des Turner)

Sir Peter Spencer, Action for M.E.
Heather Walker, Action for M.E.
Neil Riley, ME Association
Dr Charles Shepherd, ME Association
Tony Britton, ME Association
Doris Jones, 25% Group
Tanya Harrison, BRAME
Christine Harrison, BRAME
Barbara Robinson, Suffolk Youth & Parent Support Group, member of EAME
Rosemary Page, Cambridge M.E. Support Group
Richard Crossich, North London ME Network
Hazel Griffiths, North London ME Network
Di Newman, Peterborough ME and CFS Support Group
Paul Davis, RIME
Joy Birdsey, RIME
Bill Kent, ReMEember
Janice Kent, ReMEember
Colin Barton, Sussex and Kent ME/CFS Society
Jill Pigott, Worcestershire ME Support Group
Dr Terry Mitchell, Great Yarmouth and Waveney PCT
Barbara Boyden, Peterborough Team Nurse
Dr Anne Gerken, Norfolk & Suffolk M.E. service
Doug Fraser (?), Hammersmith Group
Brook Hoadley, parent of teenager with M.E.
Annette Barclay, person with M.E.
Christine Russo, person with M.E.
Augustine Ryan, person with M.E.
Criona Wilson, mother of the late Sophia Mirza

1. Welcome

Dr Des Turner thanked everyone for attending and welcomed them to the meeting, particularly the main speaker – Dr Terry Mitchell, the regional NHS clinical champion for M.E./CFS in East Anglia.

2. Apologies

The Secretary of State for Health, Rt Hon Alan Johnson MP, the Parliamentary Under-Secretary of State for Health, Ann Keen MP, Dr Roger Berry MP, Tim Boswell MP, Angela Browning MP, Jim Cousins MP, Andrew Dismore MP, David Drew MP, Mike Hancock MP, Kelvin Hopkins MP, Dr Brian Iddon MP, Eric Illsley MP, Fraser Kemp MP, Eleanor Laing MP, Peter Luff MP, Bill Olnier MP, Sion Simon MP, Clive Page MP, Dr Richard Taylor MP, Mark Todd MP, Rudi Vis MP

Jane Colby, The Young ME Sufferers Trust

3. Minutes of the last meeting:

Subject to the following amendments, the Minutes of the Meeting held on 17 May 2007 were agreed as a correct record:

- i. Page 5: Any Other Business (AOB): NHS-funded services for ME/CFS. Christine Harrison said that rather than just raising the issue of funding for NHS services, she and Barbara Robinson had proposed that the APPG should table a question about the closure of services and call for an urgent meeting with the Minister of Health to address concerns raised in a paper which was circulated.

Dr Turner explained that the Minister had been invited to attend to address these points but as he had just been appointed, it had not proven possible for him to attend on this occasion.

- ii. Omitted under AOB:
Doris Jones said she had raised concerns about M.E. services in the Plymouth area which had not been minuted. She could supply details on request.
- iii. Page 6: AOB: Group for Scientific Research into ME
Tony Britton (APPG Secretariat) said he had inaccurately recorded the names of members attending the last meeting of the GSRME. The list should have read: Dr Ian Gibson MP, The Countess of Mar, Dr Richard Taylor MP and Michael Meacher MP.

The Chair invited anyone wishing further information on any of these points to contact the people who had raised them.

4. Matters arising

There were no other matters arising which could not be dealt with later in the meeting.

5. Annual general meeting

Dr Turner said all the existing officers had agreed to stand for re-election. He reminded visitors that only parliamentarians could vote in the election.

John Bercow proposed the re-election of all existing officers on block. This was seconded by Celia Barlow, and agreed unanimously. The following officers were duly re-elected:

Chair: Des Turner
Vice Chairs: Andrew Stunell and Tony Wright
Secretary: Ian Gibson
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6. NHS services

Main speaker: Dr Terry Mitchell, regional clinical champion for M.E./CFS in East Anglia

- i. Dr Mitchell said he had been asked to speak about the financial problems of specialist NHS services for M.E. and the benefits of taking a biomedical approach to treatment.

He began his presentation by describing how his clinical involvement with M.E./CFS dated back to 1984/5, when he started work as a haematologist at James Paget Hospital. In the beginning he did not have a particular interest in M.E. but he saw patients whose symptoms he could not explain by any other diagnosis and soon a waiting list grew. His workload steadily increased over the years until the ME/CFS service which had developed, which was taking in patients from much of Norfolk and Suffolk, was transferred to Waveney PCT.

Ring fenced funding

In 2003, the Department of Health produced £8.5 million 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 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 – ie. two local multidisciplinary teams (LMDTs); (3) the establishment of Waveney as a clinical network co-ordinating centre (CNCC).

All three bids were successful and received funding. The total amount for 2005-2006 for all three components came to £456,000.

The money was put towards additional therapists, extra medical time being made available, reduction in waiting lists in Norfolk and Suffolk and a new service for Cambridgeshire and Greater Peterborough.

The total population covered (Norfolk + Suffolk + Peterborough + Cambridgeshire) was 2.1 million. In this total were an estimated 8,000 potential M.E./CFS patients.

During 2005-2006 the total workload for the equivalent of almost 7 full time staff was 8717 patient contacts, including 581 new patients. This made Norfolk, Suffolk and Cambridge combined the busiest service in England.

Dr Mitchell described the way in which the service was built up to provide a comprehensive package of care including both diagnosis and on-going management via a therapy team. This is based on a biomedical model with a flexible holistic approach to activity management and appropriate symptomatic management. The service also acknowledges that, as in any chronic illnesses, problems such as depression can also occur.

The service worked closely with local patient groups who formed the East Anglian M.E. Patient Partnership Network.

Overall, the service's own audit procedures and feedback from patients was extremely positive.

At a national level, of the original £8.5 million, only £6.5 million was allocated for clinical development.

Reduced funding

In the financial year 2006-2007 the Department of Health reduced this by 15% to £5.236 million as part of the need to reduce costs across the NHS.

The initial £8.5 million was ring-fenced to the end of March 2006 but was subsequently transferred to an unlabelled financial 'bundle.'

The issue of significant reduction in funding for clinical services and the CNCC was not raised until October/November 2006 in Norfolk and Suffolk, and January/February 2007 for the Greater Peterborough/ Cambridgeshire service.

The situation for 2007-2008 appears to be a continuing and there is a significant deficit of around £62,400. The impact is such that paediatric services will probably continue much as before in Cambridgeshire; the Greater Peterborough adult service will have a likely budget shortfall of 23%; and Waveney is likely to have a reduction in budget of at least 21%.

The loss of funds has resulted in organisational chaos, especially in adult services. Some referrals were not being placed on waiting lists. Waiting lists had been down to 8-10 weeks but most patients were now waiting over 13 weeks and in one extreme case, 38 weeks. Patients

and carers were concerned that the good service they had had, which was highly rated, was under threat. A service level agreement was needed to raise funds in Peterborough.

- ii. Dr Turner thanked Dr Mitchell for his presentation, which highlighted that money not ring-fenced by Westminster would be spent on something else.
- iii. Christine and Tanya Harrison thanked and applauded Dr Mitchell for the outstanding care he had given people with M.E., not least Tanya, who is severely affected, over 16 years, including regular out-of-hours home visits.
- iv. Di Newman added that the Peterborough service could provide a template for developing services elsewhere.
- v. Paul Davis read out a letter from of the Norfolk Group which listed dissatisfaction with CBT-led NHS specialist services amongst local support groups in Norfolk, Manchester and Winchester and Eastleigh, adding that the money would be better spent on biomedical research.
- vi. A number of people responded saying that services had benefited many and provided a foundation on which to build. Christine Harrison and Barbara Robinson said that the views expressed by certain individuals did not reflect the consensus. They described the services provided by Dr Mitchell and his team as 'An oasis in a desert.'
- vii. Dr Mitchell added that patient feedback through the audit process had been positive.
- viii. Dr Ann Gerken pointed out that there was no simple audit system in place across the services, pulling together what has been learned.
- ix. Paul Davis asked Dr Mitchell what criteria were required for people to access his service. Dr Mitchell said: referral from a GP.
- x. The Chair noted that the views of Mr Davis and those quoted in the letter did not seem to reflect those of the majority.
- xi. Sir Peter Spencer said that the failure to expand specialist M.E. services across the whole of England and the failure to prevent closures were inexcusable. The APPG had had a clear warning of the crisis in the paper tabled by Action for M.E. in 2006. Political intervention was urgently needed to protect these services.
- xii. Sir Peter then read out a brief statement at the request of AYME which said AYME was very positive about the CFS/M.E. services and had worked with them in an open and positive way. Although no service could meet every service user's needs, on the whole AYME members reported satisfaction and gratitude for the help and support they

received. AYME wanted to see more services, not less and all fully funded.

- xiii. Annette Barclay asked what impact the new NICE guideline would have on NHS clinical services and to what extent their guidance would be mandatory on clinicians. Colin Barton also voiced concern. Tanya Harrison replied saying PCTs are not legally bound to adhere to NICE as the guidelines are not mandatory and that legally PCTs are bound to act in the best interests of patients. However, she felt that PCTs would use the guidelines.
- xiv. Jill Pigott summarised a statement prepared for the APPG by the West Midlands ME Groups Consortium (Herefordshire ME/CFS/FMS Group; Shropshire and Wrekin ME Support Group; Solihull and South Birmingham ME Support Group; Warwickshire Network for ME; Worcestershire ME Support Group) regarding the closure of the West Midlands CNCC due to lack of funding. The statement went on to criticise the way in which they believe the CNCC Collaborative for M.E./CFS is placing too much emphasis on psychological aspects. It also criticised the proposed agenda for the NHS Collaborative Conference due to take place in October.
- xv. Janice Kent was concerned that the Sussex service was overworked and under-funded and about the length of waiting lists.
- xvi. Joy Birdsey called for consistency across NHS services and was supported by Bill Kent.
- xvii. Dr Turner suggested that the new Secretary of State for Health, the Rt Hon Alan Johnson MP, should be invited to address the APPG about loss of funding for NHS services, lack of biomedical research and concerns about recent guidelines. M.E. needed to be listed as a priority condition so that PCTs would take it seriously.

7. Adjournment debate

- i. John Bercow referred to his recent meeting with the MEA at which all the current concerns relating to DWP medical guidance, NHS Plus occupational health guidance, NICE guidelines, NHS services and MRC research strategy were discussed in some detail.
- ii. John Bercow felt that the best way to bring these matters to wider attention would be through a 90 minute adjournment debate once parliament returns after the summer recess. To obtain a debate would involve entering a parliamentary ballot but if a number of MPs joined in there was a reasonable chance of success.
- iii. This was welcomed by the Chair.

- iv. Sir Peter Spencer strongly supported the idea of an adjournment debate. While he was very grateful to those MPs who had attended the APPG, greater numbers of MPs were needed to achieve the political interest necessary for change. 250,000 people with M.E. were suffering injustice, ignorance and prejudice – probably a million citizens, when their families were included; a significant proportion of the electorate. M.E. cost the nation £6.6 billion every year. The adjournment debate was an opportunity to raise M.E. on the political agenda and provide focus.
- v. Charles Shepherd said that the MEA would prepare a media and political briefing paper, based on the paper prepared for John Bercow, which could be used for media and political campaigning.
- v. Di Newman asked that the Mental Health Bill should also be raised as an issue for concern.
- vi. Christine Harrison asked that the impact on the severely affected of the removal of NHS services should also be highlighted.

Dr Turner suggested that new Ministers responsible for Health should be contacted, such as Ben Bradshaw, Minister of State for Health Services and Ann Keen, Parliamentary Under Secretary for Health Services.

8. Mental Health Act and Mental Capacity Bill

- i. The Mental Health Bill to amend the 1983 Mental Health Act completed its parliamentary stages on 4 July.
- ii. Di Newman raised concerns about the amended legislation and the possible impact for people with M.E.
- iii. Although the Government had made important concessions to protect patients and their families, the Bill would increase the number of people who can section patients. Ms Newman was concerned that people who refused treatment would be sectioned. There was a risk of over-use of community treatment orders and there were concerns about the powers given to clinicians.
- iv. Criona Wilson described how her late daughter Sophia was taken to a mental hospital against her will for two weeks in July 2003.

9. Any other business

- i. Dr Charles Shepherd reported that the tenth and final version of the Department for Work and Pensions guideline on M.E./CFS had been sent to charity representatives involved in the negotiations and would be published officially on 20 July 2007.

Christine Harrison said that BRAME was very disappointed to find that their suggestion for the inclusion of a disability rating scale had not been accepted in the final version.

Dr Turner said that he would invite the new Secretary of State for Work and Pensions, the Rt Hon Peter Hain, to address the APPG at its February meeting.

- ii. The National Institute for Health and Clinical Excellence guideline would be published 22 August 2007.
- iii. As the APPG was now involved in trying to secure an adjournment debate, Dr Shepherd suggested deferring work on a revised Early Day Motion. It was decided that an EDM would remain as a future possibility.
- iv. Dr Ira Madan had agreed to meet two charity representatives, Sir Peter Spencer from Action for M.E. and Neil Riley of the MEA on Monday 16 July. A meeting which included a larger number of patient and charity representatives had been requested but Dr Madan had declined.
- v. Doris Jones expressed concerns about the NHS Collaborative Conference that will take place in October, because of psychosocial management presentations included in the programme and about the wording of an advert for a research worker at the Institute of Psychiatry, Maudsley NHS Trust, which said: "Anorexia nervosa and chronic fatigue syndrome are classical psychosomatic disorders."

10. Date of next meeting

The Chair suggested meeting on 1, 8 or 15 November 2007, depending on the availability of the Secretary of State for Health.