ALL-PARTY PARLIAMENTARY GROUP ON M.E.

Chair: Des Turner MP
Vice Chairs: Andrew Stunell MP
Tony Wright MP
Secretary: Steve McCabe MP
Treasurer: David Amess MP

MINUTES OF THE ALL-PARTY PARLIAMENTARY GROUP ON M.E. HELD ON WEDNESDAY 16th NOVEMBER 2005 IN ROOM Q, PORTCULLIS HOUSE

PRESENT

Des Turner MP (Chair)
Lynne Jones MP
Steve McCabe MP
Andrew Stunell MP
Mark Pritchard MP

Gareth Thomas, Office of John Baron MP
Ian Woodcroft, Office of Tony Wright MP
Christina Naguiat, Office of Stephen Hesford MP

Professor Anthony Pinching, Associate Dean for Cornwall, Peninsula Medical School and Chair of the NHS CFS/ME Steering Investment Group
Chris Clark, Action for ME
Charles Shepherd, The ME Association
Tony Britton, The ME Association

APOLOGIES

Peter Ainsworth MP
David Amess MP
Michael Ancram QC MP
Celia Barlow MP
John Bercow MP
Roger Berry MP
Tom Brake MP
Simon Burn MP
Paul Burstow MP
Sir Menzies Campbell MP
Michael Connarty MP
Jeremy Corbyn MP
Janet Dean MP
Andrew Dismore MP
Jim Dobbin MP
Nadine Dorries MP
David Drew MP
Bill Etherington MP
Lynn Featherstone MP
Edward Garnier QC MP
Linda Gilroy MP
Michael Gove MP
Mike Hancock MP
Evan Harris MP
Lady Sylvia Hermon MP
Jimmy Hood MP
Kelvin Hopkins MP
Gerald Howarth MP
Brian Iddon MP
Eric Illsley MP
Lord Clement Jones
Paul Keetch MP
Fraser Kemp MP
John Leech MP
David Lepper MP
Elfyn Llwyd MP
Peter Luff MP
Ann McKechin MP
Greg Mulholland MP
Eddie O’Hara MP
Lembit Opik MP
Joan Ruddock MP
Bob Russell MP
Clare Short MP
Marsha Singh MP
Gavin Strang MP
Gary Streeter MP
Jo Swinson MP
Richard Taylor MP
John Thurso MP
Mark Todd MP
Ben Wallace MP
Hywell Williams MP
Roger Williams MP
Jenny Willott MP
Peter Wishart MP
Jeremy Wright MP

The meeting started at 1pm.

1. WELCOME

Des Turner introduced the meeting, welcoming those present

2. MINUTES OF THE AGM AND REFORMATION MEETING HELD ON 6th JULY 2005

The Minutes of this meeting were accepted as an accurate record.

3. MATTERS ARISING

There were none.

4. APOLOGIES

As listed.

5. PRESENTATION BY PROFESSOR ANTHONY PINCHING ON 'NHS SERVICE IMPLEMENTATION PROGRAMME FOR M.E. – PROGRESS MADE SO FAR'.

Professor Pinching, Associate Dean for Cornwall at the Peninsula Medical School and Chair of the NHS CFS/ME Service Investment Steering Group, opened by tracing what has happened so far.

He said that one outcome of the Report to the Chief Medical Officer in January 2002 had been the announcement by the Government in May 2003 of an investment of £8.5m over two years in a centrally planned programme to set up new clinical services for people with CFS/ME in England, as development and demonstration pilots. The Steering Group, which he chaired, defined the broad criteria for the new services, oversaw the bidding and allocation process for the funding, and monitors the emerging services.

A total of £2.4m was allocated to the first year, with the remaining £6m to be spent in the following year. The first tranche of services was announced in January 2004, followed by another in August of that year.

The services, which cover all age groups, are mainly provided by local multi-disciplinary teams (LMDTs), of which about 50 were being established. Their development is facilitated and coordinated by regionally-based Clinical Network Coordinating Centres (CNCCs). The 13 CNCCs are led by Clinical Champions, who work together nationally as a "Collaborative" to share ideas and good practice, and to coordinate data collection and training. Some are undertaking projects on self-care and long-term condition care models.

The design and planning of services has been intended as a partnership between the clinicians who provide the services, local patient groups to represent the views of service users, and the primary care trusts (PCTs), who normally commission local NHS services and will take on that role after the two-year start-up programme. The continuing investment of at least £6m a year is expected to be supplemented by additional local funding, through usual planning processes, and other relevant new investment.

Clinical services are based on the principles set out in the Report to the Chief Medical Officer. Services will implement the NICE guidelines after these are announced in early 2007.

The process had drawn in a wide range of clinicians new to the field, with the richness of expertise and experience that this brings. While the programme was based on common themes, local variations have been offered based on local strengths and opportunities. In this way, development and innovation were enhancing existing evidence and experience.

Professor Pinching said that, while the investment was unable to provide complete geographic coverage by local teams in England, further outreach could be obtained by cross-referencing between services.

A major task has been to establish services during the two-year time frame, with the CNCCs collaborating in five two-day training sessions, all rated highly by those attending. These staff will in turn train local front-line colleagues, such as GPs and other clinicians who will be seeing and treating CFS/ME patients in their usual work.

Once established, the core services established by the programme will form a nidus for further growth, development and enhancement of CFS/ME services. In many cases, they will serve as exemplars for similar developments to support patients with other long-term chronic conditions.

There were plenty of challenges to be faced in such a rapid and important development. The initial funding allowed a vital step forward, but cannot in itself meet the whole need. The two-year time frame for getting services operational, mostly from a standing start, was very short – particularly in view of the many other changes and pressures within the NHS.

Many people with CFS/ME had waited far too long to see such developments, and that very waiting had produced its own legacy. There were many patients who have been ill for many years and who have had limited clinical care. Steps had to be taken to ensure the services could cope with early demand as new services get started, by careful prioritisation and communication.

Professor Pinching said careful planning and vigorous implementation had produced encouraging outcomes for patients so far. Some 5,000 patients had been assessed by the new services so far – with about 4,000 of them being referred for specialist follow-up within the new teams. The cost in the first year was about £1,000 per patient.

Commissioners face many pressures on their limited resources. Although the new service funding was set up on the basis of its continuation thereafter, they have understandable concerns about making longer-term commitments. THE CFS/ME Investment Steering Group had demonstrated that the services were an appropriate, cost-effective and exemplary way of caring for and supporting a needy patient group.

Des Turner commented that funds on a much larger scale for the NHS cancer programme had been allocated to the PCTs and it had now become apparent that this funding had disappeared. **Prof Pinching** responded that, while it was clear that many PCTs were having to review their budgets because of the pressure they were under, it was much less likely that the CFS/ME funding would disappear because of the intense scrutiny to which the CFS/ME process was exposed.

Des Turner asked to what lengths Prof Pinching's steering group would be able to monitor the process, in order to establish that local PCTs were ensuring that new NHS clinical services were mainstreamed into their service provision.

Prof Pinching said the life of the CFS/ME investment steering group was limited to another three to four months, but the group was seeking an extension to enable it to write a report to inform the next stage of service development. Clearly, the collaborative of clinical champions will continue and would remain vigilant about what was happening at PCT level.

Charles Shepherd (The ME Association) said experience so far had shown that, in many areas, the new services had commanded the support and respect of patient group. but there were still problems with some. In Oxford, for instance, the local ME group OMEGA had been corresponding with Cherwell Vale Primary Care Trust about their fears that their service might not be funded beyond April 2006.

Professor Pinching said a good service was being delivered in Oxford. Cherwell Vale PCT were involved in establishing their local development plan priorities and a case was being made to show them that they were providing an appropriate, cost-effective and exemplary way of caring for and supporting a needy patient group.

Steve McCabe (MP for Birmingham, Hall Green) said Solihull and South Birmingham ME Support Group had contacted him to express concerns that there was an over-emphasis on fatigue in the new South Birmingham service, with little recognition of the overwhelming physical disabilities suffered by patients with neurological ME. The group was also concerned that the Clinical Network Co-ordinating Centre had used stationery giving the address of the local psychiatric hospital and felt this gave out the wrong message about ME. They did not want only to be offered treatments or therapies that reflected the psychological aspect of ME – they wanted a multi-disciplinary response.

Lynne Jones (MP for Birmingham, Selly Oak) expressed similar concerns. She said her husband had suffered with ME, so she aware of the stigma attached to being treated within a mental health framework. Ms Jones also asked why patients attending the clinics were not sub-grouped and treated according to the various causes and disease processes involved in their illness.

Professor Pinching said he did not accept that the evidence existed to justify treating patients different subgroups of patients differently. It is more appropriate to respond to their unique individual needs, under the broad umbrella term. The various well-established criteria were used mainly as research tools, and had their limitations in the clinical setting.

Andrew Stunell (MP for Hazel Grove), whose wife has ME, said the level of service now provided by the primary care trust in Stockport was no longer as high as in the past, when there was a service funded by the National Lottery. There were concerns about staffing and – with the primary care trust presently £5m in deficit – about future funding.

Professor Pinching said the Lottery-funded service in Stockport had indeed been recognised as a model for provision. The local CNCC/LMDTs were building on that experience in devising models, within Department of Health funding constraints, which capitaised on it and extended it to other areas locally. The DH start-up funding was just that; it was expected to be enhanced by additional funding from PCT budgets through normal commissioning, based on demonstrated need and the quality of service. He was more optimistic than Mr Stunell that levels of expertise among healthcare professionals would continue to be scaled up throughout the area through multi-professional training initiatives and that the local PCT would recognise the continuing value of the present service.

Chris Clark (Action for ME) said independent research commissioned by Action for ME had indicated that the cost to the nation of having such a large pool of people with ME out of work and dependent on benefits was £3.5bn a year. Mr Clark said a fantastic start had been made on the NHS initiative. There were now opportunities to build on the levels of service, and also to obtain research funding.

Dr Shepherd raised a Manchester issue, where one of the patient groups had expressed a vote of no confidence in their local ME/CFS service, saying it was biased towards the psychosocial model of treatment.

Professor Pinching said he was concerned to hear of this. He wanted to see people drawn together so they could work together, and build on the already considerable achievements made so far.

Des Turner thanked Professor Pinching for his presentation and for answering the questions put to him. The APPG would take up the points raised during the discussion with the Secretary of State for Health, and he would write to her.

6. DEPARTMENT FOR WORK AND PENSIONS MEDICAL GUIDELINES – UPDATE

Charles Shepherd said the DWP working group which had drafted an unacceptable new set of medical guidelines for DWP benefit decision-makers on ME/CFS held a very comprehensive meeting on the subject with the ME charities, their medical advisers and other specialist clinicians on 17 October.

As a result, the DWP had agreed to a major revision of the guidelines and would produce a further draft for discussion in the New Year.

Dr Shepherd thanked the APPG for their support in this matter. He had, however, been disappointed to read – following the 17 October meeting – that, in an answer to a PQ from Andrew Pelling MP, the Parliamentary Under Secretary Anne McGuire MP appeared to have no knowledge of the meeting. He would write to her on the subject.

Des Turner said the APPG wished to be kept in touch with developments.

7. SCIENTIFIC RESEARCH INTO ME – UPDATE

Chris Clark (Action for ME) said the Medical Research Council was being pushed hard to fund new research into ME. The latest develpment was that the MRC had apparently agreed to fund an epidemiological study, which grouped ME with other illnesses and psychological conditions.He said that pressure should be put on the MRC to commission a longitudinal study.

8. DATE OF MEXT MEETING

Des Turner said it made sense to devote the next meeting, early in the New Year, to the lack of research into ME and what is required to rectify this situation. Professor Colin Blakemore, chief executive of The MRC, would be invited as the main speaker, on a convenient day.

The meeting closed, later than scheduled, at 2.10pm.