



ALL-PARTY PARLIAMENTARY GROUP ON M.E.

Chair: Tony Wright MP
Vice Chairs: Rev Martin Smyth MP
Secretary: Steve McCabe MP
Treasurer: David Amess MP

**MINUTES OF THE ANNUAL GENERAL MEETING
HELD ON 20th JANUARY 2004 AT THE HOUSE OF COMMONS**

PRESENT

Tony Wright MP (Chair)
Ernie Ross MP
Liz Blackman MP
Tony Cunningham MP
Ivan Henderson MP

APOLOGIES

Harry Barnes MP	Kevin McNamara MP
Hugh Bayley MP	Mr Chris Mullin MP
Anne Begg MP	Peter Pike MP
Henry Bellingham MP	Lord Puttnam
Russell Brown MP	Rt. Hon. Joyce Quin MP
Mrs Angela Browning MP	Syd Rapson MP
Janet Dean MP	Mrs Marion Roe MP
Clive Efford MP	Christine Russell MP
Ian Gibson MP	Robert Smith MP
Lady Silvia Hermon MP	Dennis Turner MP
Andrew Hunter MP	Bill Tynan MP
Nigel Jones MP	Rudi Vis MP
Fraser Kemp MP	Bill Wiggin MP
David Lepper MP	Betty Williams MP
Steve McCabe MP	Mike Wood MP

SPEAKERS

Kathryn Tate, Welfare Benefits Officer, Action for M.E.
Mary-Jane Willows, Chief Executive AYME
Dick Patterson, Chairman Dorset M.E. Support Group
Midge Mitchell, Benefits Adviser Dorset M.E. Support Group
Colette House, Co-ordinator North Herts M.E. Support group
Theresa Coe, InterAction Editor, Action for M.E.

ANNUAL GENERAL MEETING

Tony Wright introduced the meeting, welcoming those present.

He reported that Paul Burstow wished to stand down as a Vice-chair but otherwise all the officers were willing to continue in post, and there being no other nominations the following appointments were made.

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THANKS

Before proceeding to the main business Tony Wright asked that thanks be placed on the record for the administrative role taken by Action for M.E. as Group Secretariat.

1. MINUTES OF THE LAST MEETING

The minutes of the last meeting held on 28th October 2003 were agreed.

2. BUSINESS

Tony Wright introduced the speakers, drawn from a number of different organisations and chosen to highlight “on the ground” experiences of the benefits system. It was acknowledged that the presentations would highlight problem areas rather than claims that were processed sensitively and successfully. Nevertheless as would be shown, the high proportion going successfully to appeal indicated that problems did exist.

Kathryn Tate opened by describing the calls received by Action for M.E.’s (AfME’s) welfare rights line, serving nearly 10,000 members.

The line received 1,200 calls a year, 35% related to Disability Living Allowance (DLA) and 27% Incapacity Benefit (IB).

There was considerable evidence of high proportions of appeals proving successful, indicating problems with earlier stages of the assessment process.

The most common problems with DLA were obtaining medical evidence to support claims, and with Examining Medical Practitioners (EMP’s).

In many cases members had no specialist support or had not seen their GP for a long time. Some of those who had visited their GP’s still encountered a lack of belief in M.E. which affected the support for their claims.

Problems with EMP’s usually related to inadequate notice of visits, rushed visits, and members feeling pressured into signing statements without the opportunity for reflection.

Of particular concern on appeal was the sight of the EMP report, which too often betrayed a general disbelief in M.E. or without evidence suggested the existence of psychological problems.

In support of the experiences recorded by the workers, she drew attention to the Department of Work and Pensions Quarterly Appeal Tribunal statistics from December 2002.

These showed that in 27% of DLA Appeals the EMP's report underestimated the severity of the condition and in 72% of successful appeals, additional evidence (usually medical) had been instrumental.

She recommended that training be undertaken to improve the knowledge and understanding of EMP's and that decision makers request additional evidence prior to the appeal process.

Mary-Jane Willows started by highlighting the impact of M.E. on the 2,000 members of AYME whose ages ranged from 5 to 25. Their problems were exacerbated by their struggle with the benefits system, which she considered emotionally abusive.

She quoted from the Training Notes issued to assessors.

The very first line set the scene by referring to the illness as controversial – as if the validity of the illness remained in doubt. And the overall tone failed to reflect the consensus established by the Chief Medical Officers Working Group on CFS/ME.

She went on to quote other extracts relating to:

it being *"indistinguishable from depressive illness"*, its causation being controversial *"whether it has a physical bias or is purely a psychological disorder"* and stating that *"recovery can be expected within a few weeks or months"*.

These statements were not only wrong, they were also damaging.

She went on to comment on the notes used to train DWP decision makers.

Again the document starts by labelling the illness as controversial.

The notes also give a misleading impression of how far the condition fluctuates from day to day. It also says that there are no physical signs, whereas the truth is that physical signs are always present, but not immediately apparent to the inexperienced.

Causing significant distress is the statement that *"in the severest cases, there is an increased likelihood of a treatable psychological condition"*. She stated that there was absolutely no scientific evidence for this statement.

She then read a series of statements made by young people that highlighted how the misinformation given to those operating the system translated into a harmful impact on individuals.

She called for the claims forms to be amended to reflect the reality of the condition, e.g. not "can you undertake x activity" but "should you" given the likely negative health effect of undertaking it.

In drawing attention to the time and cost of dealing with avoidable appeals she recommended that the training notes and forms be reviewed as a matter of urgency.

Dick Patterson then explained the background leading to the creation of the role of benefits advisor to the NHS Dorset M.E. Clinic. Its establishment had been reported to a previous APPG meeting, and since opening 5 years ago it had treated 700 patients.

Following its establishment the clinic staff had approached the Dorset M.E. Support Group and asked for help. The staff had been seeing numbers of patients with no income, depressed as a result, and in consequence who they could not treat – all because of the operation of the benefits system.

The Group had responded by appointing Midge Mitchell, formerly a Citizens Advice Bureau worker to the role of benefits adviser to the NHS clinic.

He then handed over to Midge Mitchell.

She reported that 44% of those she had worked with had had to go to appeal, with all except one case ultimately proving successful – once again demonstrating the waste and inefficiency of the system.

She referred to research showing M.E. awards were the lowest at the outset, but had the highest success on appeal.

From her experience she drew attention to the lengthy claims form, poor quality of medical evidence and ill-informed decision making.

She supported the statements made in evidence by the previous speakers and **recommended that steps be taken generally to improve the evidence at the outset of claims, but particularly broadening the categories of those supplying medical evidence – to include therapists who worked directly with patients, and thus avoiding a burden on GP's who were often less familiar with the patients capacity.**

Theresa Coe then read extracts from letters and evidence provided by members as part of a series of articles she had commissioned for AfME's members magazine.

She then went on to highlight problems with the new Permitted Work Rules. Her experience was that people with M.E. wanted if possible to return to work, but their recovery was sometimes very slow and over a prolonged period. The new Rules were being reported to be inflexible in the amounts that could be earned and the time period over which they operated.

She quoted the experience of one member who had regained self esteem by being able to undertake very limited work, but who had now had to leave work because of the new Rules.

She recommended that the Permitted Work Rules be reviewed and adapted to make them suitable for M.E.

The final presentation by Colette House drew attention to the impact of the system on individuals. In particular she quoted one EMP who had been quoted as stating that *"if I can't see it down a microscope or on an x-ray screen it doesn't exist"*.

She referred to the inconsistencies contained in the medical report on her own claim and the damage that could be caused by one individual acting on their own prejudices.

She gave support to all the recommendations made by the other speakers.

3. Discussion

Tony Wright thanked the speakers and expressed his concern that progress in the benefits field for ME sufferers had slid back and that the APPG should once again raise this issue with Ministers.

The high level of success made on appeal was again highlighted and Midge Mitchell quoted a legal judgement criticising the use of appeals effectively as part of the adjudication process rather than their intended purpose of hearing appeals.

Tony Cunningham drew attention to the successes achieved generally through the new Permitted Work Rules. This was accepted by the speakers, but they did reiterate that M.E. did not fit neatly with other illnesses and there were negative experiences showing that the Rules could prove counter-productive.

It was also suggested that the presentations were "preaching to the converted" and the real task of the APPG would be to represent the issues to Ministers.

Accordingly it was proposed by Liz Blackman that a meeting be sought with Maria Eagle to discuss the problems highlighted in the presentations.

Tony Wright agreed to invite the Minister to a special meeting of the APPG.

4. Any Other Business

NHS Services

Tony Wright reported the announcement by the Department of Health earlier in the day of the award of funds to establish 12 NHS Regional Clinical Co-ordinating Centres and 28 Local Multidisciplinary teams in England.

This was welcomed.

5. Date of Next Meeting

To be announced following the invitation to the Minister.