

# ME in Parliament



## ME ENGLAND UPDATE

### Report on the APPG On ME Meeting 25.10.2011 and Parliamentary News

In October I attended the APPG on ME, re-established after the 2010 General Elections, for the first time on behalf of the 25% ME Group. The initial meetings of this new APPG were attended by members of both houses of Parliament and representatives of the MEA and AfME (in the capacity of secretariat) only. Meetings now include representatives of a wider circle of ME/CFS charities. This meeting was chaired by Annette Brooke MP (AB). Others present were the Countess of Mar (MM) (HL), Dr Charles Shepherd (CS) (MEA), Sir Peter Spencer (PS), Tristana Rodriguez (TR) (both AfME), Sue Waddle (SW) (MERUK), Christine Harrison (CH) (BRAME), myself, an (unknown) MP, and three other (unknown) persons.

The main items on the agenda were:

1. Minutes of the 22.6.2011 APPG on ME meeting,
2. Welfare Reform Update,
3. Research Update, and
4. NHS Services Update.

Handouts were circulated on these items.

#### 1. June APPG Meeting on ME

At the June meeting Dr Jane Colby (Tymes Trust) and Mary-Jane Willows (AYME) had spoken about concerns over the number of families of children with ME who are investigated on suspicion of abuse, without reasonable evidence to suggest this was the case. Key issues of concern discussed then were:

- Such investigations are being kept permanently on records;
- problems occur across the UK;
- no such cases have ever been proven;
- the main problem seems to be with Social Services;

It had been decided that a meeting with the Royal College of Paediatrics & Child Health should be arranged.

#### 2. Welfare Reform

The handout of the Welfare Reform Bill update gave a synopsis as follows:

- Means-tested benefits will be amalgamated into the Universal Credit, consisting of a basic personal amount with additional amounts for disability, caring responsibilities, housing costs and children;

- Disability Living Allowance (DLA) for people of working age to be replaced by a Personal Independence Payment (PIP);
- Incapacity Benefit (IB) to be replaced by Employment Support Allowance (ESA) [already underway];
- ESA claimants have to undergo a Work Capability Assessment (WCA), to determine whether they are eligible.

As part of Professor Malcolm Harrington's 2nd year independent review of the ESA Work Capability Assessment (WCA), representatives from the 'Forward-ME' Group and four other organisations - Arthritis Care, MS Society, National AIDS Trust and Parkinson's UK - are continuing to work with Prof Harrington on a group considering problems in how the descriptors relate to people with fluctuating medical conditions.

The report on fluctuating medical conditions and WCA descriptors has been discussed with a DWP Scrutiny Group during the past 3 months and they are close to reaching agreement on a modified version which will go to Professor Harrington very soon.

CH, CS and PS had attended a DWP seminar on 17th Aug where Professor Harrington reported on the current state of his review, in particular implementation by the DWP of his recommendations from the first year review and what still needs to be done. Professor Harrington had invited representatives from a range of charities to comment on specific problems which people currently face with benefit applications and the IB to ESA changeover. Some key points had emerged from the discussion. There appears to be a problem with Atos assessors dealing with cases. These health care professionals are now required to read an 'evidence based protocol' on 'CFS/ME' as part of their induction training and are required to engage in a programme of continuing medical education, including modules on 'CFS/ME'. Feedback to charities shows that patients find it difficult to obtain ESA, but a significant number are successful if they go to appeal.

The Work & Pensions Committee on 26.7.11 had published findings of its Inquiry into the role of Incapacity Benefits reassessment in helping claimants back into employment. The report was critical in many respects; one aspect concerning the fact that the WCA as introduced in 2008 was flawed, which had resulted in the high success rate of appellants.

Those present at the 25<sup>th</sup> October APPG meeting confirmed many of the above problems. MM said she would try to obtain a copy of the 'evidence based protocol' on 'CFS/ME' from the HL library. CS reported on meetings with the DWP; he said they were near to agreeing a final document (on WCA) and Professor Harrington hoped for the end of October for this.

### **3. Research Update**

The Research Briefing included details of the ME Biobank, funding for which has now been secured with contributions from AfME, the MEA, MERUK, and a private donor. Work on setting this up started in August.

Research applications in respect of the £1.5m funding initiative from the MRC are currently being reviewed and a prioritisation meeting is planned for November. CS said that the ME/CFS Expert group was not involved in decisions, which were expected in December.

A recently published Norwegian study using the anti-cancer drug Rituximab on a small number of ME patients had shown promising results; this causes depletion of B lymphocytes. CS stressed that further studies were needed and issued caution because the drug can have serious side effects. [see article on this in Research Update, page 16-17, including reaction from 25% ME Group medical adviser Dr Nigel Speight.]

XMRV research seems to have come to a halt following the publication of results from 9 laboratory US studies which failed to find the virus in blinded samples from patients who had earlier tested positive. Dr Judy Mikovits who led the original XMRV research had left her post as research director at the WPI in Reno, Nevada. CS said that there was now a big question mark over any future research into retroviral disease.

#### **4. NHS Services Update**

The NHS services briefing paper set out concerns from ME patients that the limited NHS services that are currently available will be reduced further, following the closure of the only ME specialist patient unit at Queens Hospital in Romford recently. An AfME survey had shown that the majority of 977 responses wanted specialist ME Services in the NHS to be protected and over 90% wanted an increase in services across the UK. But there are also concerns about the poor quality of treatment in some hospitals and there are great disparities across the country with regard to social care and NHS services, as highlighted in the 2010 APPG Inquiry Report into NHS Service provision for ME/CFS. That report recommended that the DoH takes steps to remedy these shortcomings and ensure that each PCT offers a full range of services, especially to children and the severely affected.

Those present at the meeting commented that GPs admit ME/CFS is a difficult disease to recognize and detect – they realise there is a problem. No other illness is managed so badly. Currently there is little progress with the RCGP and there are problems with the NICE guidelines. CH reported on great difficulties they have in Norfolk in accessing NHS services, and PS said matters were particularly bad in Northern Ireland and Wales. It was suggested that the APPG on ME could encourage parliamentarians to obtain a comprehensive picture of what goes on in the whole country. The chair suggested that a letter should be compiled for MPs, and an appointment with the Minister should be sought.

#### **25% ME Group Input**

Due to a printer failure, papers available from the 25% ME Group could not be presented to the APPG on ME meeting. To highlight the problems which ME/CFS patients now face, the following have subsequently been submitted to the chair and others present at the APPG meeting:

- **Welfare & Disability Benefits** - issues identified & 25% ME Group activity in response;
- **Impact of Spending Cuts on Access to Basic Services** - 25% ME Group briefing paper for elected representatives, produced for ME Awareness Week; covers access to personal care, and access to benefits;

- **Appeal for appropriate care** - from Kay Gilderdale, sent to APPG in response to the NHS services briefing paper (item 4 above);
- **Media Mischief & Misreporting & 25% ME Group responses.**

## Overview of Other Recent Parliamentary Developments

Important updates on recent parliamentary activities are posted on the MEA website, including the following:

- **APPG on ME – summary of the meeting with the Childrens’ Minister:** On the 2nd of November the APPG’s parliamentary members and Tristana Rodriguez of AfME met with Tim Loughton MP, the Childrens’ Minister, and his assistants, who were informed of details on multiple problems which children with ME have in schools, education and with medical support. In addition parents were often falsely accused of Munchausen Syndrome by Proxy and more recently labelled with the term ‘False illness ideation’; allegations which would remain permanently on their medical records, even if parents were exonerated. Details and data had emerged at the June APPG on ME meeting (see item 1. above). The Minister promised to look into the problems, requested more statistical data, and will report back to APPG chair Annette Brooke MP.
- **Welfare & Benefit Reform:** On the 21st of November members of the APPG on ME - MM, AB, Ian Swales - and members of other APPGs involved with Prof. Harrington’s group on fluctuating conditions (see item 2. above) attended a meeting at the House of Commons attended by the DWP and the Chair of the Select Committee on Work and Pensions. Main issues discussed were how proposed changes to the benefit reform - WCA descriptors and change from DLA to PIP for people of working age along with proposed assessment procedures - would affect such people. Also discussed was a proposed time limit on contributory ESA for those in the work-related activity group (WRAG). This means that means testing would begin after a person had received WRAG ESA for a year.

**Work Capability Assessment Review:** Members of Prof. Harrington’s Fluctuating Conditions Group (incl. CS) met before and after the above joint APPG meeting, to finalise a report agreed upon during 6 months’ of discussions with a DWP Scrutiny Group. This report’s conclusions and recommendations on WCA descriptors formed part of Prof. • Harrington’s 2<sup>nd</sup> year review, presented to a DWP meeting on 24th November.

The Minister accepted the latest Harrington recommendations. According to the Ministerial statement, these include introducing checks on benefit decisions to ensure fairness and consistency, and working with disability groups to help develop guidance for Atos healthcare professionals and Decision Makers.

- **Parliamentary Questions, Countess of Mar :** On the 21st of November the Countess of Mar received answers to two questions relevant to ME/CFS in the HL.

The 1<sup>st</sup> question was why the DWP guidelines define CFS/ME as “*an illness that is characterized by physical and mental fatigue and fatigability*” when the WHO classify it as a neurological disease. The Minister for Welfare Reform, Lord Freud, replied that this referred to the symptoms associated with the condition and was not a reference to its aetiology or classification.

Her 2<sup>nd</sup> question was how the government would ensure that children of parents misdiagnosed with fabricated or induced illness, Munchausen Syndrome by proxy, or borderline personality disorder, would not be subject to the recently announced fast-track adoption procedures. Parliamentary Under-Secretary of State for Education, Lord Hill, replied that the government was not introducing new fast-track adoption procedures, but were working with courts and local authorities in efforts to ensure that more looked-after children were placed with prospective adopters more quickly if that was the right plan. The decision that a child in care cannot return safely home must be reached in the light of the best available evidence regarding the capacity of the birth parent(s) to safeguard and promote the child’s welfare, including, where appropriate, medical evidence.

- **‘CFS/ME’ not a mental health disorder, Minister for Welfare Reform tells the Countess of Mar ...**

Also on the 21st of November, the Countess of Mar published an exchange of correspondence she had with Lord Freud, Minister for Welfare Reform, DWP. Lord Freud had sent a letter to her apologising unreservedly for his department’s mishandling of correspondence from Professor Malcolm Hooper, which had requested clarification on that department’s classification of CFS/ME. The Minister confirmed that the DWP does not classify CFS/ME as a mental health disorder.

- .... **“The majority of claimants with CFS/ME do not exhibit such [neurological] signs”** : Lord Freud also discussed the department’s CFS/ME training module and said, regarding why nurses are used to assess people with the illness: *The Government’s contract with Atos Healthcare required that doctors are used to assess claimants with conditions that are likely to have complex central nervous system examination findings. The majority of claimants with CFS/ME do not exhibit such signs and therefore CFS/ME is not on the list of conditions that are required to be assessed by a doctor. However, if a claimant with CFS/ME has neurological signs, they will be passed to a healthcare professional with the requisite expertise.*

*Comment from Helen Brownlie: This is potentially a very important statement:* if you have neurological signs but have been assessed by someone other than a doctor when claiming benefits - either via a face to face assessment or a medical report form completed in your absence - then you may have grounds to challenge any decision so reached. For guidance on neurological signs see the summary ‘Canadian’ guideline. If you require assistance or clarification regarding this please contact me on the advocacy line (details are on p14)

## **Brief details of Forward-ME Group meetings**

**5th May Guest speaker was Arlene Wilkie, CEO of the Neurological Alliance.** The group decided to become a member of the Neurological Alliance; they also invited Ms Wilkie to join the Forward-ME Group, which she agreed to do.

**29th June Guest speaker was Prof Malcolm Hooper**, who started his talk by outlining the 3 “Ts” of criticism of the PACE trial:

- Travesty of Science;
- Tragedy for Patients and Carers;
- Tantamount to Fraud.

A new independent analysis of the raw data was called for. You can view the slides that accompanied Prof Hooper’s talk at the 25% ME Group website: [http://25megroup.org/campaigning\\_me\\_Topics.html#pacetopics](http://25megroup.org/campaigning_me_Topics.html#pacetopics) and then, scroll down till you find this title **PACE - SLIDES FOR HOOOPER PRESENTATION to FORWARD ME.ppt** See also the Petition for the Editor of the Lancet calling for a retraction of the paper with the PACE Trial results:<http://www.ipetitions.com/ppetition/withdrawthepacetrialspaper/>

The group congratulated the Chairman, the Countess of Mar, on receiving the 2011 Outstanding Achievement title in the 8<sup>th</sup> annual Dods Charity Champion Awards.

**26th October Lord Freud, Minister for Welfare reform, addressed the Group.** A copy of the International Consensus Criteria for ME, recently published in the Journal of Internal Medicine,\* were presented to the Minister by the Countess of Mar with a letter following his address. Lord Freud did not comment on these in his later correspondence to the Countess of Mar (see above).

*\*You can read more about this important paper on page 17.*

*More comprehensive details of all the above can be found on the News section of the MEA website and on the Forward-ME Group website. Details of the DWP’s eventual response to Prof Hooper’s protracted correspondence are also available on Co-Cure.*

**Comment:** There appear to have been a number of positive developments on ME/CFS in the UK parliament recently. Dr Shepherd in a recent posting called on all people with ME to urge their MPs to join the APPG on ME, which is very proactive now.

*By Doris Jones 1.12.2011*