



## All Party Parliamentary Group on M.E.

**Chair:** Dr Des Turner MP  
**Vice-Chairs:** Andrew Stunell MP  
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**Secretary:** Countess of Mar  
**Treasurer:** David Amess MP

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### **APPG on M.E. Legacy Paper (2005/6-2009/10)**

#### **Introduction**

The All Party Parliamentary Group on M.E. (M.E. as defined by the World Health Organisation) will formally break up for the forthcoming General Election (date to be confirmed.) The Group leaves the following legacy paper to the APPG that will be reconstituted after the election, so that the work that has been carried out over the last four years will be clear and may continue as seamlessly as possible.

The APPG operates a code of practice, circulated November 2006 (see Appendix.)

#### **Background**

##### **1. APPG on ME Inquiry into NHS services**

A Report to the Chief Medical Officer in January 2002 led to the announcement by 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. In 2009, the APPG held an inquiry into NHS services in England. The Inquiry found that *(this point to be completed when the Inquiry report is published)*.

Issues to address *(to be added when the Inquiry report is completed)*:

##### **2. Group on Scientific Research into Myalgic Encephalomyelitis (M.E.) or GSRME**

This Group was chaired by Dr. Ian Gibson and was constituted as a Registered Group which was not on the Approved List. The Group was composed of Parliamentarians who were for the most part members of the APPG on ME, and the formation of this group arose out of the work of the APPG on M.E.

The GRSME report dated November 2006 concluded that the research areas defined by the CMO Report in 2002 had not been addressed. The report's final conclusion was that further research is the single most important area in this field and that the UK should take this opportunity to lead the way in encouraging biomedical research into the potential causes of CFS/M.E.

Many members of the M.E. community did not consider that the report went far enough by simply calling for parity between public money spent on psychological and biomedical research into M.E., as M.E. suffers and carers wanted public research money spent only on biomedical research.

## **Ongoing work / areas of concern**

### **1. Research**

Following the CMO's Report in 2002 the Medical Research Council (MRC) set up a Research Advisory Group in 2003 which was made up of independent scientists and patient representatives, to develop a research strategy.

The advisory group made a number of recommendations, in particular that in the short term the research community should be encouraged to develop high quality research proposals addressing case definition, understanding of the symptoms of CFS/ME, and new approaches to disease management. A 'Highlight Notice' was placed to ensure that research into CFS/ME would receive priority funding. This approach has not succeeded in attracting enough high quality research proposals that have been funded by the MRC, and a new initiative is needed.

In 2008 the MRC set up a new Research Expert Group under the leadership of Prof. Steven Holgate of Southampton University to review current research, identify research opportunities and encourage new research towards understanding the basis of CFS/ME.

#### **Issues to address:**

- a) Review the work of Prof. Holgate's expert group on research
- b) Monitor future allocation of funds for bio-medical research into CFS / ME and the proportion spent on research into paediatric and the most severely affected M.E. patients.
- c) Press for the establishment of at least one specialist M.E. Research Centre to provide a multidisciplinary biomedical research environment to support and provide access to appropriate clinical, educational and support services based on an enhanced understanding of the multisystem organic symptoms suffered by those with M.E. and the disabilities they produce.

### **2. National Institute for Health and Clinical Excellence (NICE) guidelines**

NICE published Guideline on the diagnosis and management of chronic fatigue syndrome/myalgic encephalomyelitis (or encephalopathy) in adults and children, in August 2007.

The Guideline has been criticised by some patient groups as being not fit for purpose and was the subject of a Judicial Review at the High Court in London, February 2009.

This aimed to overturn the Guideline's recommendations for the treatments of Cognitive Behavior Therapy, CBT and Graded Exercise Therapy (GET) as the only effective treatment for CFS/ME, and to open up biomedical treatments precluded by the Guideline. The Judicial Review found in favour of NICE.

The NICE CFS/ME Guideline will be reviewed by NICE from August 2010.

Issues to address:

- a) The Guideline focuses on chronic fatigue and not M.E. as defined by the World Health Organisation. Diagnostic criteria used in the Guideline are too broad. The Canadian Expert Consensus Panel Clinical Case Definition for ME/CFS of 2003 may be a useful starting point
- b) NICE places an over-emphasis on randomised control trial (RCT) evidence over and above evidence from expert clinicians and especially patients.
- c) Some M. E. sufferers and carers points to the interpretation and implementation of the Guideline as having an essentially "psychiatric" approach.
- d) The NICE Guideline should be reviewed in the light of emerging viral research, which should include the possibility of establishing testing and treatment for Xenotropic Murine Leukemia Retrovirus (XMRV), herpes and enteroviruses and other infections which may be found in people with M.E.
- e) The review should revisit NICE's management guidance on ME/CFS, in particular the mounting evidence for the need to broaden the range of appropriate therapies beyond CBT and GET, and to specify that all such therapies should be delivered by specifically ME/CFS trained professionals.

### **3. Welfare benefits and social care**

M.E. sufferers who are too ill to work and their carers, who may also be unable to work as a result of their commitments as a carer, are exceptionally vulnerable within the welfare benefits system. They face a number of very significant problems and hurdles in being able to successfully access, claim and retain their state benefit entitlements including Disability Living Allowance (DLA), Carers Allowance (CA, where applicable), Attendance Allowance (AA) Incapacity Benefit (IB) and more recently, Employment and Support Allowance.

There are serious issues with the Department for Work and Pensions (DWP) and Jobcentre Plus staff. Doctors and assessors in subcontracted medical services and decision makers often do not understand M.E.

Problems involved in benefit-claiming, assessment and decision-making have been illustrated by the high number of awards made at the appeal stage after rejection of the first claim.

Current social care proposals will have a significant impact on people with long-term conditions, in the short term and as they get older. The current economic climate threatens the provision of welfare support to those who need it most.

Issues to address:

- a) The introduction of the new Welfare Reforms and how these affect people with M.E. In particular the impact and effectiveness of Employment and Support Allowance (ESA), Work Focused Interviews and Health Related Assessments.
- b) The need for appropriate support from Government and employers for people with M.E. and other “fluctuating” conditions who want to stay in or return to work.
- c) The impact of National Care Service proposals and the effect of these changes for people with M.E. eg. personal budgets and direct payments of personal allowances such as Disability Living Allowance (DLA) and Attendance Allowance (AA) to Social Services.
- d) Improving knowledge about M.E. within local authority Social Services departments, the Department for Work and Pensions (DWP), Jobcentre Plus, subcontracted medical services.
- e) The need for a fairer set of criteria / guidelines for CFS/M.E. claimants / patients to be issued by DWP and the Department of Health.
- f) Review the current Occupational Health Guideline on CFS/ME used by the Department of Health for its own staff which acts as a benchmark in the health insurance industry.

#### **4. Child Protection Issues**

Some children with M.E. and their families are caught up in unnecessary, damaging and distressing child protection conferences and care proceedings because there is misunderstanding about M.E. amongst teachers, social workers, health workers and other professionals. Guidelines published by the Royal College of Paediatrics and Child Health in 2004 have largely gone unnoticed and have not had any real impact on the situation.

Issues to address:

- a) Consider the needs identified by children and young people’s ME charities for:
  - (i) The Department for Children, Schools and Families to alert Social Services professionals to the frequency of misunderstandings in cases of M.E. There should be an investigation into the cost of pursuing these cases.

(ii) All parents under suspicion of putting their child at risk should be informed of their rights, and given information clarifying child protection procedures and details of organisations which can support them

(iii) Directive to be issued by the Royal College of Paediatrics and Child Health for all paediatricians to refer to the college's guideline when treating children and young people with M.E.

(iv) M.E. to be included in the training of all GPs and paediatricians.

(v) M.E. education for all teaching professionals.

## **5. Mental Health Act and Mental Capacity Bill – the implications for M.E.**

Although the Government made important concessions to protect patients and their families, there have been concerns that the Bill might increase the number of people sectioned for refusing treatment. There was a risk of over-use of community treatment orders and there were concerns about the powers given to clinicians.

Issue to address:

a) Has this proved to be the case and if so, what should be done?

## **6. Occupational Health and NHS Plus guidance**

The APPG played an active role during 2007 in obtaining changes to the NHS Plus guidance on occupational health that is aimed at employees, employers and occupational health staff.

Issue to address:

a) Work related issues, including strategies for returning to work on a flexible or part time basis, and ill health retirement for those who are unable to return to work, continue to cause considerable difficulties for people with ME/CFS.

## **Programme of work**

1. Consider how to take forward issues to be addressed in 1-6 above.
2. Consider future opportunities for adjournment debates (last suggested July 2007; attempt unsuccessful)
3. Consider future opportunities for Early Day Motions (last suggested 2007 but deferred)
4. Possible APPG speakers:
  - Chief Executive of the Medical Research Council (last spoke April 2006)

- Chair of the NHS CFS/M.E. Clinical & Research Network and Collaborative (CCRNC) Conference (last spoke Nov 2005)
  - Secretary of State for Work and Pensions (previously spoke Nov 2006, Oct 2008)
  - Chairman of the National Institute for Health and Clinical Excellence (last represented Feb 2007)
  - Secretary of State for Health Services (last represented by Parliamentary Under Secretary of State for Health Services, January 2008)
  - Baroness Young, Care Quality Commission
  - Inspector of Social Services
5. Encouraging more MPs and members of the House of Lords to join the APPG and take an active part in the proceedings

### **Structural issues**

The new APPG on M.E. may consider the following in order to review the new Group's structure :-

1. Reviewing the Terms of Reference for the APPG on ME.
2. Reviewing the "Code of Practice for the APPG on M.E." (See appendix.)
3. Drawing up a structured and prioritised Work Plan and programme of work, and an annual schedule of meetings each year, to accompany the Work Plan, which the APPG ought to revise and review annually at the APPG's AGM. The Work Plan should be able to be adjusted at each APPG meeting to meet the prevailing needs of the day, and there should be an item on the agenda of APPG meetings entitled "Work Plan" for this purpose.
4. Consider making available a slot on the agenda of its meetings for members of the Public to raise items of concern in accordance with the terms of reference of the APPG on M.E.
5. Should the APPG on ME adopt the specific political objective of seeking parity between M.E. and other neurological and immunological medical conditions such as Multiple Sclerosis and HIV/AIDS?
6. The current Group has committed itself to using the World Health Organisation (WHO) Classification of M.E., for its work. However, it has not committed itself to the use the WHO International Classification of Diseases, ICD Classification Code for M.E. listed in the Neurological Chapter of the WHO ICD – 10 at G93.3, which is the single code the WHO uses for M.E. The new Group may wish to revisit this issue.

**APPENDIX: Code of practice for the APPG on M.E...APPENDIX: Code of practice for the APPG on M.E.**

1. The APPG and the Secretariat (Action for M.E. and the M.E. Association) accepts the WHO Classification of M.E. as a neurological condition and welcomes the recognition by the Department of Health of M.E. as a long term neurological condition.
2. The APPG strives to support the improvement of health, social care, education and employment opportunities for people affected by M.E.
3. The meetings of the APPG are held in public and it is expected that attendees will adhere to the principles of best practice in meetings:

**Attendees will abide by the APPG Governance Procedures and Practices**

This means that the attendees will honour the policies set up by the APPG to govern its own activities, including meeting protocols, committee rules etc. It is anticipated that attendees will follow basic rules of personal courtesy, attendance and being prepared. The APPG and the Secretariat recognise the connection between the behaviour of individuals in meetings and the ability of the APPG to address its business effectively. Attendees will be expected to participate so that APPG business progresses smoothly and efficiently.

- Participants will give apologies ahead of time to the Chair if unable to attend meetings
- The Secretariat will ensure that information is distributed prior to meetings, allowing participants time to read and digest important information ahead of a discussion
- Attendees will honour the authority of the Chair and respect his/her role as the meeting leader. When problems arise with meetings they should be dealt with as procedural issues rather than a personal criticism of the Chair and other officers.
- Participants will engage in debate according to procedures, maintaining a respectful attitude towards the opinions of others whilst making their own point.
- Attendees must express their views clearly when it is their turn to speak and then allow others to express their opinions in turn.
- Attendees must listen respectfully to other meeting participants, to the Chair and to other speakers. They must not attempt to silence minority opinions, nor should they talk over others.
- Attendees must not use their mobile phones in meetings or adopt any other bullying tactics.
- Attendees are invited to offer suggestions to the Secretariat or the Chair on how best to enhance the role and function of the APPG.

These guidelines are produced as a method of efficiency. If an individual attendee does not comply with the code the Chair may institute a warning system. The APPG anticipates that debate should be lively but controlled and every effort will be made to hear a wide range of different opinions and elicit the opinions of those who may be inclined to be silent.