ALL-PARTY PARLIAMENTARY GROUP ON M.E.

Chair: **Tony Wright MP**
Vice Chair: **Rev Martin Smyth MP**
Vice Chair: **Andrew Stunnell MP**
Secretary: **Steve McCabe MP**
Treasurer: **David Amess MP**

MINUTES OF THE ALL- PARTY PARLIAMENTARY GROUP ON M.E. HELD ON MONDAY * AT THE HOUSE OF COMMONS

PRESENT

- Tony Wright MP (Chair)
- Ian Gibson MP
- Ivan Henderson MP
- Andy King MP
- Steve McCabe MP
- Rev Martin Smyth MP
- Andrew Stunnell MP

Apologies for absence were noted from:

David Amess
Harry Barnes
Anne Begg
Liz Blackman
Graham Brady
Tom Brake
Russell Brown
Helen Clark
Tony C Cunningham
Janet Dean
David Drew
Julia Drown
Clive Efford
Howard Flight
Sandra Gidley
Doug Henderson
Lady Silvia Hermon
Jimmy Hood
Joan Humble
Andrew Hunter
Nigel Jones
Mrs E Laing
Chris Mullin
Bill Olner
Colin Pickthall
Lord Puttnam
Joyce Quin
Mrs Marion Roe
Bob Russell
Christine Russell
Rachel Squire
Mark Todd
Bill Tynan
Rudi Vis
Robert Walter
Betty Williams
Mike Wood

SPEAKERS

Chris Clark, Chief Executive Action for M.E.
Mary-Jane Willows, Chief Executive AYME
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* Monday 28 June 2004

ANNUAL GENERAL MEETING

Tony Wright introduced the meeting, welcoming those present.

He offered to hand over the Chair, however there being no other nominee he agreed to serve again, and was thanked by all present for his leadership.

Andrew Stunnell agreed that his name be put forward for the post of vice-chair, and there being no other nominations the following appointments were made.

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1. MINUTES OF THE LAST MEETING

The last meeting held on 14th December 2004 was not quorate, and the notes taken were received by the meeting. The Minutes of the last quorate meeting held on the 28th of June were agreed.

2. Matters Arising

The meeting noted that Tony Wright had written to Maria Eagle to enquire about progress, there having been no response from her to the Charities following the offer of contact made by her at the June meeting.

3. Receipt of Resolution

The meeting received the following Resolution passed by the M.E. Alliance, the umbrella group of the main charities.

"We the members of the M.E. Alliance wish to place on record our sincere appreciation of the work of the All Party Parliamentary Group on M.E.

People with M.E. have never sought "special status" for their condition, but continue to seek the medical care, research programmes and financial and practical support that reflect the severity and impact of the illness.

The existence of the Group has been and is a demonstration to people with M.E. that their needs are understood and recognised by Parliament. We thank the Group for its continued support and its work to ensure that our aims are realised."

4. " Controversies and Challenges" - Presentation by Chris Clark (CC) Chief Executive of Action for M.E.

a) Introduction and Background

CC opened by establishing the credentials of Action for M.E.

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Unlike many who contacted MP's, often via the internet, Action for M.E. was subject to regulation by the Charity Commission, had 9,000 non-voting members and had Trustees, usually drawn from the membership and who themselves were almost all affected by M.E.

Action for M.E. undertook regular surveys of its membership to inform its policies and collect views. Less than 2% thought they were not listened to by the charity. In addition the charity had a Professor of Immunology as its Principal Medical adviser, and its information and website had won awards.

By way of background he reminded the Group that one person in every 250 had M.E. and that ordinary people from all social and ethnic groups and of all ages got the illness, 2/3 of them women. An independent study funded by Action for M.E. had found that M.E. cost the Nation £2.5b a year.

He then went on to review the challenges, and put forward recommendations for future parliamentary activity by the Group.

b) <u>Attitude and awareness</u>

The illness had suffered 50 years of misunderstanding and neglect. However in 2002 CFS/ME Independent Working Group reported to the Chief Medical Officer, the Department of Health response stated:

"….there should be no doubt this is a chronic illness and that health and social care professionals should recognise it as such."

One year on 34% of the charity's members thought attitudes had changed for the better. 35% thought they were the same.

CC went on to quote from respected medical publications showing that sadly some attitudes remained unchanged:

"Barriers to …effective clinical management…are partly due to doctors beliefs, which result in negative stereotyping…." BMJ study of GPs 2004

"Most immunologists…try to avoid building up a practice in the heart-sink areas of CFS and MAS" Career Focus BMJ 2004

He said that the patient organisations are confronted by an illness of enormous severity and impact and affecting hundreds of thousands in the UK – but attract little public sympathy or funding.

The very existence of the APPG is a demonstration to people with M.E. That those in power do understand their needs and are representing them

<u>Discussion and conclusion:</u>

Members of the Group reiterated their support for people with M.E. and undertook to reconstitute the Group after the next election – subject of course to the outcome of the election itself.

c) NHS Services

CC reminded the meeting that historically people with M.E. had often experienced late diagnosis, poor understanding of the illness and its management resulting in harmful treatment regimes, and only a handful of out patient clinics.

For those most severely affected the situation was even worse. The more ill they were, the less care they were likely to receive.

There had however been a number of significant developments:

£8.5m ring fenced funding (in England) to develop new services, subject to bids from PCT's that to be considered, had to demonstrate patient support.

From this funding 13 Regional co-coordinating centres had been established and 50 local multidisciplinary teams were now getting underway, usually with high expectations.

CFS/ME had also been referred to NICE, with Guidelines to be published 2007.

CC commented that Government leadership was to be commended, and the implementation had been excellent.

But this was only the start, not the end. Expectations were very high – possibly too high. There was uncertainty how much the teams can achieve for those most severely affected and whether with some areas funded but others not, there would be inequity of access. There was also a need to continue monitoring progress beyond the ring fenced funding.

Despite these concerns for the future CC said he could hardly find fault with the progress made so far and the commitment shown.

He was also concerned that Scotland and Wales were lagging well behind, though he knew these could not be addressed by the Westminster Group.

Discussion and conclusion:

Mary-Jane Willows confirmed from the perspective of younger people with M.E. that they were delighted by the progress made.

The Group welcomed the developments and the remarkable progress achieved in England, but agreed there was a need to maintain a "watching brief".

d) Support and practical needs

CC reminded the Group that M.E. affects every aspect of peoples lives and contrary to popular myth, most people want to recover what they lost through illness, and only look for benefits as a staging post to recovery.

Most would like to be able to be able to pay taxes again. Yet the illness does not conform to the current rules and the system undermines them and is counter-productive.

The M.E. organisations remain inundated with member complaints.

He reminded the Group of the criticisms made last year of the Benefits Handbook, for example its referral to the Chapter containing references to malingering and hysteria

He referred to the new Incapacity Benefit Rules announced earlier in the day. Whilst no comment could be made on the detail yet, there was genuine fear that government restrictions on Incapacity Benefit could impact on people with M.E.

Regardless of the intent of government, the operation of the present benefits system for people with M.E. had been deeply flawed, and he cited examples of ill-informed comments that portrayed people with M.E. as malingerers. This had impact on the attitudes of those who operated the system, and strident comments made by politicians about malingerers were very unhelpful.

Of enormous concern was that problems with the benefit system are not only causing hardship but are actively preventing people from recovering from the illness.

Help may be needed to stop people with M.E. being "soft targets" in attempts to control DWP budgets. The APPG had shown leadership in the past and continued help is needed

Discussion and conclusion:

The Group reiterated its concern that the current benefits system had not been working effectively for people with M.E., and members undertook to continue to represent the issues to government both with regard to the present system and any future changes.

e) Research

CC opened by reminding the Group of the Medical Research Council (MRC) Strategy published May 2003. Problems identified in the consultation included:

"*Research hasn't yet reached agreement on defining the condition, let alone established its causes, symptoms, prevalence and impact. What research there has been has been short-term, poorly co-coordinated and lacking in patient involvement ….Respondents complained of the low status of research into CFS/ME and an associated shortage of funding and resources."*

And the expert group who wrote the Strategy said:

"*The Group sees a need to attract high quality researchers from basic science and specialised clinical disciplines*

".....recognises the urgent need for research into CFS/ME, and that there are certain groups of patients who may not have been adequately included…"

"Epidemiology has a central role…It is key…"

2 studies (PACE and FINE) had been funded prior to completion of the strategy nearly 2 years ago. But since its completion the MRC actions have been:

- Highlight Notice, prioritising M.E. - but not one study has been funded since publication

* Monday 28 June 2004

- Epidemiology Workshop Sept 2003 – but no studies have yet been funded
- MRC/Linbury Trust Fellowship – rumoured that there were no applicants

In contrast to the lack of progress made by the MRC, even though the charities were all small and financially overstretched:

- Action for M.E. had published “The Cost to the Nation” a study of the economic impact of M.E.
- The PRIME project had been initiated by the voluntary organisations, collecting and representing to researchers the experiences of people with M.E. including the severely affected.
- The CFS Research Foundation had announced a genetics study

CC went on to review the reasons why the research field remained fallow.

Fewer than 1 in 10 of all applications to the MRC achieve funding and the MRC will not fund “second class” studies.

Both those consulted and the MRC Expert Group had identified the need for high quality researchers. CC was concerned that if the MRC waited for them to emerge we could wait a very long time indeed.

In a recent discussion the ME Alliance had considered the lack of research into the causes and treatment of M.E. the single greatest issue in the field.

CC put forward a number of suggested actions

1. Commitment by the MRC and government of the need to take a proactive approach
2. Ring fenced funding to encourage scientists to come forward
3. A programme of commissioned research
4. Action to communicate with and involve scientists

Discussion and conclusion:

The meeting raised a number of questions.

The Rev Martin Smyth asked about chemicals and toxins as a cause. CC replied that the Working Group had identified these as one of the causes, viral infection appeared to be the most common trigger. However the poor epidemiology and lack of research into sub-groups raised more questions than had been answered.

Ivan Henderson asked about the international scene. CC replied that few countries had active programmes. He was aware that the Center for Disease Control in Atlanta had collected a network of researchers from different disciplines.

CC had heard it said that nations should play to their strengths, the UK’s being the NHS and its capacity to collect common common data, often involving primary care. He was hopeful that the new NHS M.E. services would provide an infrastructure on which research could be built.

The Group was concerned to progress research in the field, and it was agreed to make this a focus after the election. It was also agreed to raise the issues with the Health Select Committee and ask for a short Report to be prepared.

f) Understanding Controversies

Context

CC referred to the continuing activity of pressure groups, often internet based, and their criticisms which he wished to address.

In order to understand the controversies it was essential to understand that much of the anger among the complainants was justified and resulted from the ignorance and prejudice encountered by people, and the exclusion from NHS services and research of those most seriously ill.

There was a perceived dominance in research of psychological hypotheses, matched by an offer to those most severely ill of only behavioural or rehabilitative treatments.

The field was blighted by a lack of research evidence for a highly complex illness (or illnesses) – with opinion and dogma filling the evidence gaps.

In addition many of the controversies were fuelled by distorted information on the internet. CC then went on to summarise some of the common controversies and comment.

"CFS and M.E. are different, and psychiatric research has dominated, diluting the illness to encompass people with psychiatric problems - irrelevant to those with M.E."

CC stated that is broad agreement that M.E. is heterogeneous, and there probably are sub-groups. But in its strategy the MRC concluded that there is lack of both a common definition and agreed criteria. Without an epidemiological study, definition of and differentiation between sub-groups is not possible.

Compounding the confusion, in clinical practice, patients may be diagnosed with any of number of labels according to the doctors preference - and their choice usually bears little relation to the debates commonly held within the field.

With regard to research, all studies have been in out patient clinics, and have consequently studied only those mildly or moderately affected. Extrapolating the findings to all may be unsafe. For example whereas Cognitive Behavioural Therapy (CBT) is supported by some research evidence, from Action for M.E.'s members surveys CC doubted whether it had much to offer those most severely affected.

There was a consensus that psychiatric and psychological studies had largely dominated the research agenda. From CC's enquiries this did not result from a plot, but from the lack of strong biological proposals, and the narrow range of scientists in the field. Strong biological proposals from high quality scientists are needed, and this needed to be addressed proactively by government and the MRC.

"Psychiatric" treatments (graded exercise and CBT) are being imposed despite evidence they cause harm. Furthermore the patient representatives (including the APPG) have sold out to the psychiatric model.

In fact graded exercise is better described as a rehabilitation approach, usually practised by physiotherapists.

Cognitive behavioural therapy, usually practised by psychologists, is used in many illnesses, such as cancer, but must not be presented as curative, and is more likely to benefit those who are moderately or mildly affected.

According to numerous member surveys, Pacing is more effective than both but has not been studied, hence Action for M.E.'s support for the PACE study.

With regard to the harmful effects of such approaches, past surveys do show evidence of harm. But recent surveys show a major problem and the probable cause such reports of harm is bad practice [There is a huge difference between being instructed to "go to a gym and work out" and being helped by a therapist who knows and understands the illness and who works in partnership with a patient].

There are grounds for concern when psychological factors have been emphasised and physical markers ignored (though every illness involves interactions between mind and body). Such concerns are shared by all the organisations

With regard to where M.E. belongs in medicine, the World Health Organisation had given M.E & CFS a neurological code, but few neurologists were M.E. specialists.

The M.E. Alliance had agreed a policy on the new NHS services and had put a doctor's expertise and belief as more important than their "ology". Indeed the MRC had recommended an integrated range of research disciplines, and the new NHS services are headed by a wide range of specialties.

CC said that in a highly complex field in which there is little research evidence, controversy is inevitable and there are few certainties. The APPG has to make judgements on whose voice is representative of people with M.E.

But unlike the few self appointed internet campaigners, the leading charities are subject to regulation and have made enormous efforts to systematically collect evidence from their members and represent this in their policies

g) In summary

The existence of the APPG is a source of hope to people with M.E.

A watching brief is needed to ensure that the new NHS Services are the beginning not the end
Direct support is needed to ensure that people get the benefits and assistance to help them recover

Research – much assistance is required. Only through research will the complexities of M.E. be understood and the controversies resolved

Presentation by Mary-Jane Willows (MJW) Chief Executive of the Association of Youth with M.E.

MJW opened by endorsing all that had been said in CC's presentation, and welcoming the commitment given by the APPG to a future programme of work. She then introduced AYME who have a membership aged 4-26 of whom an average of 25% are severely affected. There are an estimated 25,000 young people in the UK and AYME have actively helped over 3,000. It is believed that M.E. has overtaken childhood leukemia as highest cause for long term school absence.

What is Special about AYME is its involvement of Young People. 2 are required by its constitution to be trustees and its services are managed by 6 young people nationally.

AYME manages over 300 national volunteers and its members have been involved in writing the patient leaflet for the Royal College of Paediatrics and Child Health (RCPCH) Guidelines to be launched the next day. One young member will speak at the launch AYME has also been represented on the PRIME research project and has been actively involved in the development of the new NHS services.

Positive Developments in 2005 have included:

- National Service Framework exemplar
- £8.5 million for new services
- RCPCH Guidelines - sent to 10,000 paediatricians

But sadly the system can go wrong, and MJW related the –rare- but devastating experience of one young person subjected to child protection proceedings. Although rare, AYME maintained that one case was one too many.

It is AYME's role to work with and empower families in crisis

They continue to see examples of poor practice in Education and Health and sadly their experience is that a lack of training and education leads to disbelief. What is needed most is:

- Increased awareness and understanding amongst professionals
- Research - specific to Young People and the severely affected
- Continued voice of APPG
- Benefits system still failing - especially concerned in light of today's announcement

AYME's plans for the future include:

- The continued involvement of Young People in the development of new services
- Specialist training for those working with the severely affected
- Development of services in "black hole areas"
- Development of services in Scotland, N. Ireland and Wales

MJW concluded by thanking the APPG on behalf of AYME and all its members - especially Tony Wright MP whose leadership over the years had been a particular source of hope and support.

5. Conclusion

On behalf of the Group Tony Wright thanked Action for M.E. and AYME for their presentations, the secretariat to the Group provided by Action for M.E. and the ME Association – and all members of the Alliance for their representation of their members.

He looked forward to progressing the issues that had been raised both before and after the election – subject of course to the will of the electorate.

5. Date of Next Meeting

To be announced. Probably June 2005.

* Monday 28 June 2004