

WMMEG Correspondence (October 2010 to February 2011)

**On 5 October 2010 WMMEG emailed Gill Walsh, BACME Chair,
with copy to Sue Pemberton, BACME Secretary**

Subject: British Association for CFS/ME (BACME)

We write as representatives of a consortium of six West Midlands ME Groups (WMMEG), cumulatively with over 150 years of living with, or caring for a family member with M.E.

We continue to have very serious concerns regarding the balance and emphasis of ME/CFS training for NHS healthcare professionals and a key focus of our concerns relates to the British Association for CFS/ME (BACME) - in particular the psychosocial emphasis of its 'education and training' programmes allied to the uncritical promotion of exercise and behavioural interventions.

We have attached a statement from WMMEG (to be forwarded to the All Party Parliamentary Group for M.E. in the near future) which sets out these widespread concerns, particularly with regard to the BACME constitution. Currently this statement has been endorsed by over 40 (forty) patient groups from all over the country.

It is clear from the strength and breadth of support that the overwhelming majority of British groups wish to see a biomedical model for M.E., utilising robust diagnostic criteria, where M.E. is separated from 'fatigue' that in turn unequivocally informs current and future research programmes.

The requirement to (uncritically) adhere to the NICE Guidelines - embedded within the BACME Constitution - along with the general 'direction of travel', appears to be a major reason why a significant number of patient groups have recently declined invitations to apply to join the Executive; it's not clear how many local groups have been invited to join, or upon what basis invitations have been issued. In the interests of open consultation with the ME/CFS community such information should surely be in the public domain?

We understand that BACME are holding their AGM during the forthcoming conference at Milton Keynes, 13 - 14 October and we appreciate that we are outside the 3 week limit (as stated in your Constitution) to go on the full agenda, but could you possibly raise the concerns expressed in our statement and the issue of clarifying how many/which groups were invited in Any Other Business?

On 7 October WMMEG received following response from Gill Walsh

Thank you very much for contacting me and attaching a copy of the letter which will be forwarded to the All Party Parliamentary Group for ME. I have already been in contact with Mr Amess to invite him to the BACME conference next week, but if he is unable to attend, I will be happy to meet with him to discuss our training and BACME in more detail as needed.

BACME is a membership organisation that provides a network for clinicians who work in the CFS/ME services. We deliver care in a similar way to networks such as the cancer network, supporting health professionals working in the field to share good practice. Most of the members of BACME will be employed by a specific NHS trust that will have robust governance systems in place to ensure care is delivered appropriately. BACME has no influence with this process. We will support new development and research, but again, similar to other areas of medicine, this is often undertaken by associated accredited and funded organisations e.g. universities, charitable research organisations, and will have been ratified through the systems defined in the NHS. We are not in a position to fund research or to influence this process.

Similar to other services that are delivered by the NHS, the care that is provided is guided by national guidance and evidence-based approaches. For CFS/ME, this will include the CMO report, the APPG for ME, the Map of Medicine, the NSF for Long Term Conditions as well as the NICE guidelines for CFS/ME. One of BACME's aims is to promote evidence-based approaches for the treatment of CFS/ME, so it is important that this is reflected in our constitution. Health professionals do however need the skills to be able to offer individual CFS/ME management that is appropriate for the severity of symptoms that a person experiences, so the training of health professionals in order to do this is essential.

The conference agenda has changed slightly and there will be a varied number of topics over the 2 days. I enclose a copy of the final agenda which includes a presentation on CFS/ME and XMRV. Many of the CFS/ME services are multidisciplinary teams, and the conference agenda reflects the training needs of different health professional groups as well as specific requests. The final agenda was also dependant on the availability of speakers.

BACME is aware of the need to raise the awareness of CFS/ME within primary care, in particular with GPs and Practice Nurses. This was also highlighted in the APPG report. Patients are still experiencing delays in being diagnosed with CFS/ME, often as a result of a lack of understanding of the clinical presentation and diagnostic process. BACME has close links with the CFS/ME Nurse special interest group who are also looking at the importance of raising awareness of CFS/ME for GPs and nurses.

We are in the process of developing a website for BACME, and I hope that once this is completed, it will provide more transparency and a better understanding of our aims and the work we are involved with. The patient / carer executive members of BACME led the process of defining the National Charitable Organisations who would be eligible to join the BACME executive, and it was agreed that there would be 4 available positions. As a result of this process, we now have a number of groups who have applied for membership on the BACME executive group. I have attached a copy of the application form for the membership of the National Charitable Organisations for your information. We understand that many groups will feel unable to work within the remit of our constitution; however, we still aim to work collaboratively with patient groups to improve the assessment and care of people with this condition.

I hope this provides some additional information about BACME and the conference that will be helpful.

I will raise the concerns that you have listed at the next executive meeting.

Yours sincerely,
Gill Walsh

Gill Walsh
Chair, BACME

On morning of 8 October WMMEG emailed David Amess MP, Chair of APPG on ME:

Subject: British Association for CFS/ME (BACME)

We understand from Ms G Walsh (BACME Chair) that you have been invited to the Conference of the British Association for CFS/ME (BACME) at Milton Keynes on October 13th & 14th.

We do not know whether you will be able to attend or whether you will be meeting with Ms Walsh at a later date, but we would like to forward to you some information which has relevance to this meeting.

We would like to alert you that we will email you these documents, along with an explanatory email, on Monday October 11th so that they reach you in good time.

**On 8 October WMMEG received an email from Joanna Ashworth,
Parliamentary Assistant to David Amess MP**

David Amess MP has asked me to thank you for your kind invitation to the above event, unfortunately due to parliamentary commitments he is unable to attend.

On 11 October WMMEG emailed a response to Gill Walsh, Chair of BACME

Subject: British Association for CFS/ME (BACME)

Many thanks for your reply and for attaching the application form and the revised conference agenda.

We look forward to hearing news following the conference (and AGM) and of course the next Executive meeting. Perhaps it may then be possible to say who the patient group representatives are and how they were selected?

We of course also look forward to seeing the new BACME website.

WMMEG has not heard any further from Gill Walsh

12 October WMMEG emailed David Amess:

Subject: British Association for CFS/ME (BACME) Membership

We write further to our email of 8 October and as representatives of a consortium of six West Midlands ME groups (WMMEG), cumulatively with over 150 years of living with ME, or caring for a family member with M.E.

We have attached a statement from WMMEG which sets out our serious concerns, regarding the balance and emphasis of ME/CFS training for NHS healthcare professionals. A key focus of our concerns relates to the BACME constitution - which seems designed to uncritically promote exercise and behavioural interventions via its education and training programmes.

As you will see the statement has been formally endorsed by 50 (fifty) patient groups from all over the UK - which reflects the genuine concerns of several thousand people with ME and their families. [These endorsements are *still* coming in and we will update you before the next APPG for ME meeting.]

It's clear from the strength and breadth of this support that the overwhelming majority of UK patient groups wish to see a biomedical model for M.E., utilising robust diagnostic criteria, and where M.E. is separated from 'fatigue', that in turn unequivocally informs current and future treatments and research programmes.

As you maybe aware, we have written to Gill Walsh, Chair of BACME, outlining these concerns and advising that we would be bringing this to the attention of the APPG on ME. We have also suggested that it might be appropriate and timely, for BACME to discuss these issues at their AGM this week. Gill has told us that she will raise the concerns we have listed at their next executive meeting and also kindly forwarded us a copy of the application form to join the BACME Executive (attached).

The question posed at the head of the application form is: "*Would you like to get involved in shaping the future of NHS services for people with CFS/ME?*". The answer to this is yes, of course we would like to be involved but we (and many others) *cannot* be, whilst the organisation is exclusive to those who hold different views.

The BACME Constitution clearly states that their objectives are: "*To champion evidence-based approaches to the treatment of CFS/ME such as those provided in the NICE Guidelines*" (2.2.1). The application form requires the applicant to sign up to: "*I confirm that our organisation supports the constitution of BACME and wishes to participate as an Executive Member.*"

This requirement to uncritically adhere to the NICE Guidelines, along with the general 'direction of travel', appears to be a major reason why a number of patient groups have recently either declined invitations to apply to join the Executive, or have been refused membership due to their unwillingness to sign up to the constitution.

Despite the wealth of international biomedical evidence, many of those involved in shaping policy and opinion within the UK remain locked within the confines of the NICE Clinical Guidelines for CFS/ME promoting behavioural therapies rather than opening up the dialogue to include the possibilities of a biomedical model in response to those patients suffering from G93.3 neurological ME. To take such a narrow view of the 'evidence base' - largely derived from non-specific diagnostic criteria - does not reflect the experience of over 90% of ME/CFS sufferers.

We hope that in any future meeting with Gill Walsh (or a representative of the BACME Executive), you will note these widespread concerns from the patient groups and seek answers on our behalf. It would also be appropriate to invite a representative of BACME to attend an APPG meeting in the near future so that we could hear the answers for ourselves. By way of further background, we have also attached a copy of the ME Association's (June 2010) *Brief for Westminster Parliamentarians*, which also addressed this very important issue.

We did not receive a response

On 5 November WMMEG emailed David Amess MP, Chair APPG on ME with copies to Annette Brook MP Vice Chair APPG on ME and John Leech MP Secretary APPG on ME:

Subject: APPG on ME - updated statement from WMMEG

We write further to the WMMEG statement on *BACME Membership* of 10 October emailed to yourselves, the attached updated statement provides the current list of endorsements. It also provides clear evidence that patient groups wish to see education, training and services focus on robustly diagnosed neurological M.E. and not simply chronic fatigue.

We did not receive a response

On 5 November WMMEG emailed Tristana Rodriguez, Action for ME, and Charles Shepherd, ME Association

APPG on ME - statement from WMMEG

With compliments - attached is a copy of document sent by WMMEG to APPG, originally on 10 October and again this afternoon (5 November).

You may wish to include information supplied by this document in ITEM 6 (Provision of NHS Services for ME Patients) which is on the APPG agenda for November 9th. Please note that this document was also sent to Gill Walsh, Chair of The British Association for CFS/ME (BACME) on 5 October

We did not receive a response

On 23 January, 2011 WMMEG emailed Annette Brook MP, Vice Chair APPG on ME and John Leech MP Secretary APPG on ME, with copies to Tristana Rodriguez Action for M.E (APPG on ME Secretariat) and Dr Charles Shepherd, M.E. Association

Subject: APPG on ME - Programme for 2011

With the Programme for APPG work for 2011 being discussed at the forthcoming APPG on ME meeting on 16 February, we would like to draw your attention to our document which is attached to this email.

Also attached are two items linked within the MEA news items described on page one.

We did not receive a response

On 31 January WMMEG emailed Tristana Rodriguez, Action for ME (APPG Secretariat), with copy to Charles Shepherd, ME Association

Subject: Fwd: APPG on ME - Programme for 2011

The WMMEG (West Midlands ME Groups Consortium) would appreciate it if you would forward our email of 23 January to all members of the APPG on ME, together with the three attachments.

Also, we would be grateful if you would confirm the full list of APPG on ME members, so we know which MPs have received our forwarded message. We feel sure there are more than included on this list, so would appreciate your confirmation - <http://www.publications.parliament.uk/pa/cm/cmallparty/register/myalgic-encephalomyelitis-me.htm>

We heard on 4 February that this had not happened

11 February WMMEG reminded Tristana Rodriguez, Action for ME (APPG Secretariat), by email
14 February WMMEG reminded Tristana Rodriguez, Action for ME (APPG Secretariat), by phone
23 February WMMEG reminded Tristana Rodriguez, Action for ME (APPG Secretariat), by email

On 28 February WMMEG received an email from Tristana Rodriguez, Action for ME (APPG Secretariat),

Subject: APPG on ME

Thank you for reminding me to contact you.

I can confirm that the WMMEG's submission was circulated to the office holders of the APPG on M.E. on the morning of 16th February.

To respond to your request for a list of the members of the APPG, the formal list of qualifying members is as published on the parliamentary website. We do keep an informal list of those who have expressed an interest in the APPG so that we can keep them informed of any notices relating directly to the APPG meetings, however we do not feel it would be fair to give this out without their express permission. We have however distributed a message to the mailing list inviting them to opt in if they would like to receive forwards of this kind. In any case, we would advise that the most appropriate course of action in lobbying MPs is to send any correspondence to your constituency MP, who can participate in the APPG in the usual way.

I hope that this information is helpful.

Parliamentary website mentioned in the message above:

<http://www.publications.parliament.uk/pa/cm/cmallparty/register/myalgic-encephalomyelitis-me.htm>
