

WMMEG (West Midlands ME Groups Consortium)

Herefordshire ME/CFS/FMS Group; Solihull & South Birmingham ME Support Group,
Shropshire ME Group; Walsall & West Midlands ME Link; Warwickshire Network for ME;
and Worcestershire ME Support Group
(website - <http://wmmeg.weebly.com>)

22 January 2011

To: Annette Brook MP, Vice Chair All Party Parliamentary Group on ME
John Leech MP, Secretary All Party Parliamentary Group on ME

cc. Tristana Rodriguez, Action for M.E (APPG on ME Secretariat)
Dr Charles Shepherd, M.E. Association

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 previous related correspondence and the following ME Association's news items:

- ["Parliamentarians should examine role of new NHS training forum for ME/CFS"](#) -
"The role of the new British Association for CFS/ME (BACME) in the training of the next generation of doctors and healthcare professionals in ME should be examined by the All Party Parliamentary Group on ME (APPG) when the group reforms after the General Election."
- MEA ["Brief for Westminster Parliamentarians"](#) giving Questions raised over training role of new body for ME/CFS professionals.

We welcome the wholehearted support of Jane Colby and Tymes Trust. Jane Colby, Executive Director, the Young ME Sufferers Trust (Tymes Trust), recently expressed her thoughts on the 'APPG work for 2011' topic.

"The Trust wishes to make clear its view that should a representative of BACME be invited to a meeting of the APPG (by request of the West Midlands ME Groups Consortium) that meeting of the APPG should, in the interests of balance, be opened to members of the public, who should be able to speak and put questions."

The Trust also wishes to make clear that it expects the APPG to follow through on the presentation made by our Executive Director on Child Protection Issues, which has not yet been acted upon. This issue continues to be of great concern. The presentation in 2008 was given at the request of the APPG. You can read it here:
www.tymestrust.org/pdfs/childprotectionissues.pdf

In the first three weeks of 2011 the Trust has already had another new case of parents referred to social services with a view to removing their teenage girl from their care, because the consultant does not appear to understand that ME can be longlasting and severe. The Trust is also dealing with ongoing cases from 2010. One concerns a teenage boy, one is a 20 year-old whose GP says the illness is 'imaginary' (and who has already been removed from the care of his mother on one occasion) and another two cases concern young people over 18 where the mental capacity act may be employed to remove them from their parents' care. We feel that the APPG should urgently consider the Trust's two recommendations in its presentation, which could help alleviate this damaging trend."

Also, further to the updated WMMEG statement on '**BACME Membership**' of 5 November, forwarded prior to the 9 November APPG on ME meeting, the following provides a reminder of our collective concerns and an updated list of endorsements from other similarly concerned groups.

BACME Membership (Updated - 22.1.11)

Further to the WMMEG statement on *BACME Membership* of 10 October emailed to yourselves, this 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.

Following the consistent concerns expressed by WMMEG and other local and national groups, the British Association for CFS/ME (BACME) has made a rather belated attempt to invite patient groups to join their organisation. WMMEG would like to thank [Invest in ME](#) for their openness in bringing this matter to the attention of the rest of the ME community.

BACME's constitution and the NICE Guidelines

With this move BACME has again demonstrated their lack of real understanding of the views of people with ME & their families. An overwhelming majority of the national and local ME groups do not support the NICE Guidelines for CFS/ME. The BACME Constitution requires its members to support the 'evidence based' treatments defined by NICE. The recent refusals by many of the national and local groups to join the BACME organisation cited difficulties with the BACME Constitution as their reason for not joining.

Training and education of NHS CFS/ME Healthcare professionals

There is also continuing and widespread concern about the transparency and accountability of BACME, and its apparent role in the training and education of NHS CFS/ME healthcare professionals. Many of their conferences and training workshops have lacked balance in their line up of speakers and topics and the 'Draft Program' for the 2010 BACME Conference is still weighted heavily in favour of the psychosocial approach.

To emphasise the importance people with ME place on the need for medical education (we would emphasise *appropriate* medical education), this issue featured very strongly in the recent ME Association poll to vote for 'What should be the top priority for the reformed All Party Parliamentary Group (APPG) on ME?'

There is growing dissatisfaction, particularly amongst grassroots people with ME and their families, with the fact that the BACME organisation appears to have taken it upon itself to influence NHS CFS/ME policy and disseminate its selective view on education and training throughout the whole structure of NHS healthcare for CFS/ME, without having once consulted the wider patient opinion or referring to the biomedical nature of G93.3 neurological ME. A recent letter from the CMO to Invest in ME stated - "The Department's view is that it is important to recognise that CFS/ME is a genuine and disabling neurological illness and health professionals must recognise it as such."

All of this sends a clear message that the BACME organisation is unable to enter into broader dialogue whilst they remain entrenched in their belief that the current evidence based treatments are appropriate for genuine ME patients and what they want! BACME cannot move forward if it remains self absorbed and unwilling to engage in open discussion and debate with the wider audience, who have such a wealth of first hand knowledge and experience.

WMMEG looks to the future

WMMEG call upon BACME to re-write their Constitution to allow transparency and greater inclusiveness, and for BACME to urgently address the issue of the balance, content and appropriateness for ME of their current training and education programme.

If BACME cannot, or will not, reform, then WMMEG advocates the need for the ME community to set up an alternative coordinated education and training programme which:

- acknowledges the G93.3 classification of ME as a neurological illness
- utilises more robust diagnostic criteria for ME (such as the Canadian Clinical Guidelines)
- focuses on ME and not simply chronic fatigue

ADDENDUM

WMMEG commend such ME education and training initiatives as the [liME international conferences](#) on ME and the recent announcement by liME of their determination to set up a biomedical model (to include a biomedical research centre) [NHS clinic for ME](#) . These have the potential to become the basis for the development of an alternative ME education and training programme aimed at NHS healthcare professionals that properly and appropriately, meets the needs and aspirations of pwME and their families.

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Herefordshire ME/CFS/FMS Group

Solihull & South Birmingham ME Support Group

Shropshire ME Group

Walsall & West Midlands ME Link

Warwickshire Network for ME

Worcestershire ME Support Group

Above endorsed by (up till 20 December 2010):

Ashby ME Group

25% ME Group

Beccles & District ME/CFS Support Group

Bispham ME Support Group

Bourne & South Lincs ME Support Group

Bristol ME Support Group

Bury/Bolton ME/CFS Support Group

Cambridge ME Support Group

Chester MESH

Corby ME Self Help Support Group

Eastleigh & Winchester ME Support Group

Guildford & West Surrey ME/CFS

Support Group

Invest in ME

Kent and Sussex Alternative ME Group

Kent ME Network

Kirklees Independent ME Support Group

Leger ME

Liverpool ME Support Group

Manchester ME Society

Mansfield ME Support Group

ME Derbyshire Support Group

ME North Devon Support Group (MEND)

ME Positive East Midlands

ME Support Isle of Man

Mid-Warwickshire ME Group

Northampton ME Support Group

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OMEGA (Oxfordshire ME Group for Action)
Peterborough ME/CFS Self Help Group
Reading Area ME Support Group
Ross-on-Wye M.E. Support Group
Founder of Stockport Group - Jean Holt
Suffolk Youth & South Parent Support
Sunderland and South Tyneside ME/CFS
Support Group
Swindon ME Support Group
The Grace Charity for ME
Wantage & Grove ME/CFS Support Group
York and District ME Support Group

Groups in the London area -
Bexley ME Support Group
East London ME Group
North London ME Network
London ME Central
Richmond and Kingston ME Group
West London Network MESH

Groups in Scotland -
Borders ME Group [BMEG]
Cathcart ME Support Group
Edinburgh M.E. Self-Help Group
Lanarkshire ME Support & Advice
Group
ME East Kilbride (MEEK)
Perth ME Group
ScotME
Wigtownshire FM-ME Support Group
