

Questions raised over the training role of new body for ME/CFS professionals

The role of the new British Association for CFS/ME (BACME) in the training of doctors and healthcare professionals in ME should be examined by the All Party Parliamentary Group on ME (APPG) when the group reforms – preferably before the next BACME training and education conference due to be held in October 2010.

Who are BACME?

BACME, chaired by consultant paediatrician Dr Esther Crawley, appears to have assumed the functions of what used to be called the CFS/ME Clinical and Research Network and Collaborative (CCRNC) but there is little information available about this change in the public domain.

Who wants the APPG to look at the BACME role?

A total of 26 UK ME support groups and two national ME charities who co-signed a statement on the subject issued by the West Midlands ME Groups Consortium (WMMEG).

Who are WMMEG?

WMMEG comprises local ME groups from Herefordshire, Solihull and South Birmingham, Shropshire, Walsall, Warwickshire and Worcestershire. Between them these West Midlands groups have each had many years experience of running local ME support groups and collectively have spoken to or have had contact with thousands of people with ME. Cumulatively, the six individual groups' representatives have a total over 150 years of

being affected by ME, either suffering personally or caring for someone with ME.

What did WMMEG say to the APPG in March 2010?

WMMEG took the opportunity to place on record their gratitude to the APPG on ME for holding open meetings. This has given pwME and their families the opportunity to put their own questions to speakers and a democratic opportunity to express concerns and raise important issues.

WMMEG continued -

“The APPG are aware of our ongoing concerns with regard to the need for appropriate education and training of those healthcare professionals involved in any ME/CFS services and the particular role of BACME in disseminating training. There remain issues with regard to balance, representation and democratic accountability.”

The group noted that three recommendations (6, 7 & 8) in the APPG Inquiry into NHS Services' Report dealt with the essential role of training for medical students, GPs and supporting health professionals.

The APPG Inquiry report said: “The Group feel that it is inadequate for professionals to treat patients with ME/CFS when they have not been fully trained in the particular characteristic of this disease”.

This most recent WMMEG letter concluded by requesting that “a representative from CCRNC/BACME, is invited to a future APPG on ME meeting in the not too distant future. This would give the APPG on ME an opportunity to hear about the CCRNC/BACME, and people affected by ME an opportunity to voice their questions on the crucial issue of education and training.”

Why is WMMEG concerned?

They think that BACME – which has apparently taken over as the training forum for NHS staff involved in the care of people with ME/CFS – needs to be more publicly accountable, would benefit from wider patient participation and is too much under the influence of the psychiatric lobby.

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Please help improve the climate for professional training in ME/CFS by asking questions on the subject.

If you would like to join the APPG on ME, please email Tristana Rodriguez at Action for ME:

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**Statement issued with the support of
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What are BACME's aims and objectives?

Extracts from BACME's Constitution:

Aim –

BACME is a multidisciplinary organisation which exists to promote and support the delivery of evidenced based treatment for children, young people and adults with CFS/ME throughout the UK.

Objectives –

- 2.2.1 To champion evidence-based approaches to the treatment of CFS/ME, such as those provided in the NICE guidelines

Membership –

Members of the BACME will be represented by an executive committee which will comprise one representative nominated from each CNCC, eight elected individual members, two to four patient/carer members, and one observer/member from each of a maximum of four National UK CFS/ME organisations which support the objectives of the BACME.

What does this mean?

This Constitution makes it clear that BACME is:

- Totally independent and, as far as can be ascertained, is accountable to no-one.
- Responsible for most of the education and training for NHS CFS/ME health professionals.
- Not obliged to report back on anything they do to anyone but themselves.
- Only open to patient representatives who support NICE Clinical Guideline 53 and yet again, the severely affected with ME appear to have no representation whatsoever.

How does this affect patients?

- The majority of NHS professionals in NHS clinics for ME/CFS patients receive their training and

education from BACME influenced conferences and training workshops, therefore patients will only receive evidence-based treatments as described in the NICE Guidelines for CFS/ME. The recent patient led High Court challenge to NICE in 2009 made it clear that over 90% of local ME groups did not support the guidelines, therefore, for BACME to solely promote something that is so deeply unpopular appears to be the antithesis of democracy, and ignores patient opinion.

- The influence of BACME on education and training sometimes leads to inappropriate assumptions about ME in the NHS clinics eg “often maintained by illness beliefs that lead to exercise-avoidance”; “deconditioning”. (*Liverpool CFS Clinic Handout* used by the FINE trial). This can cause further difficulties for patients with ME who often feel their illness is misunderstood by GPs and NHS clinics and that no appropriate advice or treatment is available for them – especially the severely affected patients.
- Leads to major difficulties for people with ME in obtaining benefits and social care.

What would WMMEG like to see?

- The development of a diagnostic test for ME, and some seriously funded and joined up biomedical research into the aetiology and pathogenesis of ME carried out at all LMDTs.
- Appropriate training and education for health professionals which acknowledges the G93.3 classification of ME as a neurological illness.
- ME/CFS health conferences for the training and education of NHS health professionals, aimed at providing a biomedical research agenda and the development of effective treatments that actually enable the patients to be well

enough to go to work, rather than including “Pathways to Work” as a topic.

- BACME to look at other evidence contained in some 4,000 published research papers rather than just focusing on CBT and GET advocated in NICE Guideline.
- Information available for all to see.

Who monitors BACME and the NHS Services for CFS/ME?

Not only is BACME not monitored by the Department of Health, but neither are the NHS services for CFS/ME – although the NHS logo was prominently displayed in the BACME 2007 and 2009 conference documentation). Lord Darzi (Department of Health) confirmed that an assessment (of NHS services for CFS/ME) has not been made. He added that it is the responsibility of strategic health authorities to ensure that services are available, with appropriately trained staff, for people diagnosed with CFS/ME. www.publications.parliament.uk/pa/ld200809/ldhansrd/text/90506w0001.htm#09050675000189

Short summary of events leading up to WMMEG's request to the APPG

- ◆ **2007:** WMMEG first raised their concerns about the psychological bias of the education and training conference held by the CCRNC, at an APPG meeting. No action was taken.
- ◆ **2009 March:** WMMEG sent their “ME/CFS - Education and Training in the NHS” statement to both the APPG and Forward-ME before the second BACME conference in Milton Keynes. No action taken.
- ◆ **2009 July:** Dr Esther Crawley (Chair of BACME) and Dr Hazel O'Dowd attended Forward-ME meeting to give CCRNC presentation and answer questions. www.forward-me.org.uk/8th%20July%202009.htm
- ◆ **2009 August and September:** WMMEG raised the patient representation issue with Esther

Crawley on the grounds that it is 'exclusive'. WMMEG asked for and received a copy of the CCNRC Constitution

- ◆ **2009 October 21:** WMMEG's statement "CCNRC Constitution – transparency, patient representation" read at APPG meeting, challenging once again the legitimacy of the patient representation on the BACME Executive and the fact that the BACME is autonomous and is apparently accountable to no one. http://appgme.org.uk/Downloads/minutes/appgmins2009/Transcript_APPG_21_October_2009.pdf
- ◆ **2009 October 30:** WMMEG wrote to APPG asking some serious questions about BACME. The Countess of Mar (Secretary) replied advising us to take up these issues with the DoH.
- ◆ **2009 December:** WMMEG wrote to DoH who said that they were unable to answer any questions on BACME as this organisation was self-governing and did not come under the remit of the DoH.
- ◆ **2009 December:** Following the publication of the APPG on ME Inquiry into NHS Service Provision for ME/CFS Interim Report – it was noted that there was no mention of BACME and their influence on NHS services. Dr Charles Shepherd of the MEA offered to make the BACME issue a priority item on the agenda for a future APPG meeting.
- ◆ **2010 March:** From the 'APPG on M.E. Legacy Paper': possible APPG on ME Speakers included 'Chair of the NHS CFS/M.E. Clinical & Research Network and Collaborative (CCRNC) Conference: http://appgme.org.uk/Downloads/DRAFT_APPG_legacy_paper_V5_27_11_2009.pdf
- ◆ **2010 March:** WMMEG presented their request to the APPG in Any Other Business. See: www.meassociation.org.uk/images/stories/100309_-_wm_meg_appg_on_me.doc

M.E. issues for the new Government

Dr Charles Shepherd reports on the last meeting of the APPG on ME

The meeting on 10 March was a friendly and harmonious occasion – which finished with a vote of thanks to Dr Des Turner MP (who is retiring from parliament) and all the parliamentarians who have been involved with the current APPG.

After the election, a new APPG on ME will have to be formed – provided there are sufficient parliamentarians willing to do so.

AGENDA

There were two main items on the Agenda – a presentation on disability poverty and a discussion on the final report from the APPG Inquiry into NHS service provision for people with ME/CFS.

VANESSA STANISLAS: TACKLING DISABILITY POVERTY

VS described the work of the Disability Alliance (DA) – an organisation that brings together a wide variety of charities with whom they work collaboratively on issues relating to disability.

A key part of their work had been to prepare for the General Election and the need to highlight to all parties the issue of disability poverty.

To take this forward the DA has prepared a Disability Manifesto titled *Tackling Disability Poverty*. Copies of this publication were circulated to all present and it is also available at the Disability Alliance website.

VS went through some of the key facts and evidence about disability poverty referred to in the manifesto:

- Disabled people are twice as likely to live in poverty as other citizens
- 29% of disabled children live in poverty in the UK.
- A third of disabled adults of working age live in poverty.
- 50% of disabled adults of working age are not in paid work.
- 29% of pensioners in households with one or more disabled adults who were not in receipt of

disability benefits lived in poverty.

- 80% of people with mental health problems and learning difficulties are not in employment.
- Half of all carers subsidise the cost of the disabled person they support because of inadequate disability benefits.

With the UK now experiencing a recession, there is a real risk that the economic downturn will lead to a reduction in action to tackle poverty in those who are sick or disabled.

VS also referred to a number of very practical issues that disabled people have to face, all of which can have a significant effect on their income levels:

- Perverse and complex rules that govern eligibility to DWP benefits – people do not understand the benefit system.
- The resulting low take-up of benefits that people may be entitled to.
- Employer discrimination.

Among recommendations being put forward by the DA to help reduce disability poverty are:

- Measuring disability poverty as a unique form of poverty.
- Excluding disability benefits from 'income assessments', or including the extra costs of living that disabled people experience.
- Measuring disability should be deconstructed by age group.

Following her presentation there were numerous questions and points. These included:

- Fuel poverty and the need to extend the extra heating allowance to sick and disabled people under pension age.

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- Problems relating to the differences between the medical model of disability (ie how illness disables people) and the social model of disability (ie how the world sees and deals with disabled people regarding the provision of services etc).
- Problems with ATOS – the agency that carries out medical examinations and assessments for DWP benefits.
- The Countess of Mar pointed out that a review of the Employment and Support Allowance was taking place and this required representation from the ME/CFS charities
- Tremendous differences in the knowledge and attitude expressed about ME/CFS when cases are brought to tribunal. Des Turner said this was an important part of his workload. He supported these concerns about lack of knowledge regarding both the illness and the actual regulations.
- The political debate over targeting what money there is in the benefit pot at people most in need (ie means-testing more benefits). Or do the problems this could cause mean that there should still be universal benefit provision – regardless of income and capital.
- Sick and disabled children.
- Social Fund - grants have now been replaced by loans. This means that people are reluctant to replace key items that break down.
- Is there enough evidence of discrimination and bad practice in the way the system works to force a judicial review?
- Disability poverty affecting carers.

APPG REPORT ON THEIR INQUIRY INTO NHS SERVICES

The report is now finished. Dr Turner stated that the conclusions and recommendations are exactly the same as in the preliminary report that was circulated at the last meeting in December. The text of the final report

expands on the justification for them.

Copies of the report, along with an appropriate accompanying letter, will now be circulated widely.

Des Turner agreed that a list of PCTs who did and did not reply to the questionnaire should be made available on the APPG website.

Dr Turner circulated a letter he had sent to Mike O'Brien MP, Minister of State, Dept of Health, on the need for biomedical research, along with the minister's reply.

A short discussion followed. Key points included:

- Jill Pigott (Worcestershire ME Support Group) said training of NHS staff was vital and information about a range of ME/CFS conferences and meetings should be made available to NHS staff via BACME and on their website.
- Christine Harrison referred to the continuing problems in Norfolk in trying to re-establish a consultant-led service following the retirement of Dr Terry Mitchell. She pointed out that yet another Working Group had been set up. Local patient representatives had a number of concerns about the report they have received.
- Sir Peter Spencer (Action for ME) referred to the need to try and persuade the Select Committee on Health to get involved.
- Charles Shepherd (ME Association) pointed out that local political initiatives could help here and referred to the situation in Gloucestershire where the NHS Foundation Trust had just been heavily criticised by the county council's health overview and scrutiny committee over lack of consultation on a proposal to cut 200 hospital beds in the area.
- Jane Colby (Tymes Trust) referred to children's services and the need to take note of surveys of what children and young people want – as had been carried out in Essex.
- Ciaran Farrell pointed out that it was very difficult for local people and local groups to make any impact on the decision-

making process at a local level because they often lacked the skills, knowledge and resources to do so.

- Jill Pigott asked if there were any good local multi-disciplinary teams that could be recommended to PCTs interested in setting up an ME/CFS referral service.
- Several people commented on the fact that the lack of direction from central government over local decisions on health issues was not helping people with ME/CFS services they need.

The APPG has also issued a press release. In it, Des Turner is quoted:

“Our report sets out clearly some long standing problems which are simply not being tackled by organisations that should be doing a much better job of supporting the 250,000 people in the UK with ME/CFS. We are particularly concerned by the failure of many Primary Care Trusts to fund any services for ME/CFS patients especially children and the most severely affected. We are also deeply concerned by the poor knowledge that many doctors have about this illness and by the failure of the DWP and its contractor ATOS to understand its adverse impact on many patients' ability to undertake regular work.”

APPG LEGACY PAPER

The final version of the legacy paper was presented and agreed. This is a document that will pass to the next APPG. The paper sets out actions and initiatives that have been taken by the current APPG along with issues that remain to be addressed by the new APPG.

ANY OTHER BUSINESS

Statement from the West Midlands ME Groups Consortium:

With ushers trying to clear the room for the next meeting, there was no time for further discussion. Jill Pigott was allowed to present a written statement requesting that a representative from the CCRNC/BACME attends the next APPG meeting to discuss the nature of education and training for staff involved in providing NHS services.