

Incessant Belief?

Eileen Marshall Margaret Williams 19th September 2006

In a recent letter from Heather Finch of the Medical Research Council's Knowledge and Management Group, the MRC repeated its well-worn mantra about "high quality" research: "research excellence will continue to be the primary consideration in funding decisions" (see Co-Cure EDU: 16th September 2006: MRC Doggerel Part I). Of interest is the fact that Ms Finch also stated: "Awards *may* be made according to their scientific quality". "*May*" be made according to their scientific quality? Why not "*are*" made according to scientific quality?

We have previously noted what seems to be a disturbing lack of scientific rigour on the part of the MRC in relation to ME/CFS issues and have noted that high scientific standards seem sadly lacking when it comes to funding research into ME/CFS: see, for example the following:

- (1) **"Some questions about ME/CFS to which credible answers are urgently required"** (22nd March 2004)

<http://www.meactionuk.org.uk/Some Questions - 220304.htm>

This noted that the Oxford criteria (to be used in the MRC 'CFS' PACE trials) have been shown to have no predictive validity and that there has never been international consensus about them: they are used only in Britain, and it is virtually unheard of for studies to use criteria that have been superseded. It noted that vested and competing interests had not been declared and it questioned why such large sums had been granted by the MRC for more trials of management approaches that have already been shown not to work for those with ME/CFS. It noted that the financial interests of the medical insurance industry have been allowed to take precedence over the needs and care of ME/CFS patients

- (2) **"Questions for the MRC"** (18th June 2005)

<http://www.meactionuk.org.uk/Question for the MRC.htm>

This noted that on 16th June 2005, Sarah Perkins, Programme Manager of the MRC's Mental Health Board, stated about the PACE trial: "The main entry criteria are the Oxford criteria: the exclusion criteria will be used to exclude neurological conditions. It will not be used to exclude patients with a diagnosis of ME" and asked seven questions, including (i) why the MRC is using special pleading in relation to ME when ME is classified as a neurological disorder by the WHO (ii) on what scientific evidence the MRC is relying to enable it to disregard this international classification that was approved by the World Health Assembly (iii) given that Wessely School psychiatrists seem to be financially encouraged to demand 100% proof of an organic aetiology before they will 'allow' ME to be accepted as an organic disorder, why the MRC does not equally require a similar standard of proof from these psychiatrists that ME is a mental disorder

- (3) **“Issues re the use of the Oxford criteria for the MRC ‘CFS’ Trials”** (20th June 2004)

http://www.meactionuk.org.uk/SIGNS_in_ME.htm

This lists many of the signs -- as opposed to symptoms -- seen in ME/CFS that the psychiatrists funded by the MRC consistently ignore

- (4) **“ME/CFS and Fibromyalgia: additional considerations for the MRC in relation to the PACE trials”**

http://www.meactionuk.org.uk/Additional_considerations_re_MECFS_and_FM.htm

This provides referenced evidence of the distinctions between ME/CFS and fibromyalgia (the MRC ‘CFS’ trials having made no distinction between the two disorders)

- (5) **“High Standards at the MRC?”** (21st April 2005)

http://www.meactionuk.org.uk/High_Standards_at_the_MRC.htm

This addressed and questioned the MRC’s claim that it insists on a high scientific standard being required for funding

- (6) **“ME Exists: True or False?”** (18th August 2006)

http://www.meactionuk.org.uk/ME_Exists_-_True_or_False.htm

This pointed out that the “Wessely School” psychiatric model of ME/CFS is not evidence-based, nor can it ever be so: it is an hypothesis that cannot be tested, let alone proven, which contrasts with the biomedical model of ME/CFS that is supported by respected literature of solid scientific evidence.

Given its track record, especially the findings in the Report of the House of Commons Science and Technology Select Committee that under the Chairmanship of Dr Ian Gibson MP was excoriatingly critical of the MRC (see The Work of the Medical Research Council: Third Report of Session 2002-2003 / HC132, March 2003), how can the MRC credibly continue to assert that the PACE CFS trial meets the stringent and rigorous criteria that it claims to require?

As ever, the facts speak for themselves: the PACE trial is using criteria formulated by “Wessely School” psychiatrists that have never been adopted internationally and which by definition exclude those with authentic ME/CFS but which include those with psychiatric disorders (the Oxford 1991 criteria); the psychiatrists leading the PACE trial have deliberately diluted the entry criteria in order to enhance recruitment (see the PACE Trial Identifier, which states: “We chose these broad criteria in order to enhance recruitment” and on 19th March 2004 this was expanded by Carolan Davidge from the MRC: “As for the PACE trial, the Oxford criteria are to be used (in the FINE trial) since they are perceived to be broader and more inclusive, and also easier for GPs to screen for”); the same psychiatrists have intentionally amalgamated those with different disorders, with the inevitable consequence that the results will be skewed and therefore

meaningless and, crucially, the MRC trials seem to be paying scant heed to the known dangers of increased oxidative stress for those with severe ME/CFS.

It has just been announced that the combined MRC / AfME “Summit” has been re-convened for November 2006 (see Co-Cure NOT: Research Summit – AfME (UK) 14th September 2006); the announcement states: “As far as we know, this will be the first time that neurologists, immunologists, pain and sleep disorder specialists, epidemiological psychiatrists, pathophysiologists and others will work together to explore innovative ways of tackling ME”.

What an extraordinary claim: why have the MRC and AfME ignored all the international Clinical and Research conferences on ME/CFS since 1988, many of which were reported in AfME’s own magazine?

Have the MRC and AfME forgotten the US NIAID (National Institute of Allergy and Infectious Diseases) Symposium held at the University of Pittsburgh in September 1988; the Rhode Island Symposium in 1988; the Rome Symposium in 1988; the San Francisco conference in April 1989; the British Post-Graduate Medical Federation Conference in London in June 1989; the Los Angeles International Conference in February 1990; the First World Symposium held in 1990 at Cambridge University, UK; the Charlotte Research Conference in November 1990; the Canadian Workshop at the University of British Columbia, Vancouver, in May 1991; the Dublin International Symposium in May 1994 (held under the auspices of The World Federation of Neurology); the First World Congress (also under the auspices of The World Federation of Neurology) in Brussels in 1995; the Second World Congress in Brussels in September 1999; the Bloomington Conference in Minnesota in October 2001, and the International Clinical and Scientific Meetings presented by the Alison Hunter Memorial Foundation in Australia, especially the Third International Meeting in Sydney in December 2001?

Have the MRC and AfME forgotten the biennial International Research and Clinical Conferences hosted by the American Association of CFS (AACFS, now the IACFS / International Association of CFS), including the Albany, New York, conference in October 1992; the Fort Lauderdale, Florida, conference in October 1994; the San Francisco conference in October 1996; the Boston, Massachusetts, conference in October 1998; the Seattle conference in January 2001; the Chantilly, Virginia (Washington D.C.) conference in January – February 2003; the Madison, Wisconsin, conference in October 2004?

Are the MRC and AfME aware of the forthcoming IACFS Professional Research Conference that is to be held at Fort Lauderdale in January 2007? Will they be sending representatives?

Have the MRC and AfME forgotten the Scientific Workshops such as the one co-sponsored by the US National Institutes of Health in June 2003 on neuro-immune mechanisms in (ME)CFS and the two MERGE workshops (including the Royal Society of Edinburgh funded Workshop in 2003 and the MERUK Colloquium in July 2006),

which consisted of presentations by key scientists with a working knowledge of ME/CFS, the aim being to facilitate links between scientists working towards the common goal of understanding the biomedical basis of ME/CFS?

The above lists are by no means comprehensive, so it is absurd for the MRC and AfME to appear to believe that their “Summit” represents the first time that researchers have collaborated “to explore innovative ways of tackling ME”.

How can it be “high quality” science to ignore the evidence that was presented at these international meetings over the last 18 years?

Will the immunologist at the MRC / AfME “Summit” be AfME’s own Medical Adviser, Professor Anthony Pinching, who is responsible for the much-derided CFS Centres that deliver only psychotherapy and who believes that it is unnecessary to study subgroups of “CFS”?

Why are vascular biologists such as Dr Vance Spence and geneticists such as Dr Jonathan Kerr missing from the list of specialists to be invited to the “Summit”, when they are the very people who have provided irrefutable evidence of the organic nature of the disorder?

All this has been pointed out many times before, yet the MRC and the psychiatrists it so favours continue to ignore the evidence.

In “Letter from America” on 31st December 2001 on the BBC World Service, Alistair Cooke -- whilst not referring to ME/CFS -- admirably encapsulated the problems that have for so long beset the ME community, namely that for years the MRC has supported the Wessely School psychosocial model of ME/CFS:

“By shouting the word often enough they hope to turn it into a reality. It’s a case of what the poet William Empson called ‘incessant belief labouring to create its object’ ”.

How true. And how spectacularly unscientific.