

## Informal notes on the issue of funding biomedical research into ME/CFS

Margaret Williams      17<sup>th</sup> July 2006

The problem is firstly that there is still no universally agreed case definition for ME as opposed to the heterogeneous “CFS” into which the psychiatric lobby has subsumed authentic ME, so it’s a chicken and egg situation, yet as recently as January 2005, the ME Association’s medical adviser was of the opinion that there is (quote) “no need” to seek research on the issue of a diagnostic marker for ME. Without such a diagnostic test, how do researchers know what disorder they are studying?

Secondly, there is a lack of good researchers interested in the biomedical model of ME (and without ring-fenced funds, there will not be many such researchers).

Thirdly, researchers get the money necessary for their research only by working *with the establishment view*. It is, for example, known for certain that Wessely's Dean of Psychiatry is very pleased with him for the amount of money Wessely has generated (and that Wessely got a research medal from the Royal College of Physicians for his contribution to the understanding of "CFS/ME").

Fourthly, researchers have to fight each other for research money, and there is a gulf between the biomedical sciences and the mental health brigade: the biomedical sphere is a cut-throat world, so if ME *were* to be accepted as a biomedical disorder, any funding for it would then be competing with funding for cancer, diabetes etc (ie. ME/CFS researchers would be competing against the big boys).

The CMO’s Working Group report came out in January 2002, and despite it paying lip-service to the need to advance the understanding of “CFS/ME”, the MRC itself has today confirmed that from **April 2003 to date**, the MRC has turned down 19 biomedical applications relating to ME/CFS. Those included applications under the headings of pathophysiology, genetics, biomarkers, immunology and neuroimaging.

By contrast, since April 2003 the MRC has funded five applications relating to “CFS/ME”, mostly in the psychiatric / psychosocial domain (Professor Francis Creed; Professor K Bhui; Professor Peter White’s PACE trial; Alison Wearden’s FINE trial, and Richard Morriss’ study of “medically unexplained symptoms”).

Further information about which studies relating to “CFS/ME” the MRC has funded or rejected can be accessed in Hansard for 27<sup>th</sup> March 2006, column 794W, available online: <http://www.publications.parliament.uk/pa/cm200506/cmhansrd/cm060327/text/60327w44.htm>

As far as the MRC is concerned, it likes to fund big trials (which is not the same as funding primary biological research such as that done by Spence or Kerr etc), but without

such primary research projects being funded, there's little hope of getting a big trial looking at biomedical aspects.

The real stumbling block is that it is Government **policy** not to carry out biomedical research into ME/CFS: this is because the Government is taking advice only from the psychiatric lobby themselves. Layard & co are determined that CBT is the answer, and Wessely is on record as stating that ME is simply a “belief” that one has a disorder named ME.

Wessely was on no less than three MRC Boards, which might explain why the MRC itself classified ME/CFS as a mental disorder --- see page 32 of the Report of January 2005 from the MRC Neurosciences and Mental Health Board's Strategy and Portfolio Overview Group, which clearly states: “Mental health in this instance covers CFS/ME” (NMHB Mental Health Scoping Study Report).

Most people who are interested in doing biomedical research into ME do not bother applying to the MRC, as they know their application will be rejected.

Biomedical applications in respect of ME/CFS known to have been rejected include those by Professor Jill Belch (herself a Principal Fellow of the MRC) and Dr Vance Spence of Dundee, as well as Dr Jonathan Kerr of St Georges, London.

A notable comment was made on 10<sup>th</sup> June 2006 by Professor Peter White, who at the fourth Oral Evidence Session of the Gibson Inquiry, said to Vance Spence words to the effect of: “If *we* hadn't got the money from the MRC, do you really think that the MRC would have given it to *you*?”

This would seem to be in keeping with the impression given by Professor Anthony Pinching at the fifth Oral Evidence session held by the Gibson Inquiry on 10<sup>th</sup> July 2006 and carefully noted by some of those present: “My impression was that (Pinching) was talking about serious empire building just to provide CBT and GET; (he said) that what was now needed was to consolidate the current service, ie. to complete the establishment and successful running of the 13 centres (and) to strengthen the current service by increasing patient throughput”.

The point needs to be made that Pinching's implication (whether intended or not) was that without the support of the MRC, researchers would not have the capability to carry out large-scale trials. This would seem to demean the ground-breaking research of people like Spence and Kerr, who are very experienced researchers well able to run large-scale projects involving substantial sums and multi-centre studies, and who have specialised expertise in carefully identified areas that are highly relevant to ME/CFS (for example, muscle function, gene research using advanced gene coding chips, and vascular biology).

Further, some local ME groups have already generated and run small-scale projects in conjunction with local universities, but are in need of central financial support to replicate

their findings (which are important in helping to manage the day-to day problems that are seen in ME/CFS). Some of these studies have involved identifying key features of ME/CFS, for example, in conjunction with the University of Sunderland, the local ME group identified a hypersensitivity to adrenaline in local anaesthesia used in dental practice, which, because of the induced cardiovascular responses, has immediate value and ought to lead to a broader study. Taking care not to use adrenaline makes a big difference to patients' well-being and safety, not to mention to the stress levels of dental practitioners. Other local group findings relate to pain control, for instance, the study of the slow infusion of lignocaine carried out by a consultant rheumatologist, with promising results. Unfortunately, the rheumatologist in question is about to retire and his replacement is refusing to continue with the study. Surely the practical implications to the enhanced well-being of those with ME/CFS of such studies deserve the relatively modest financial support that is needed?

Notably, Professor Pinching informed the Gibson Inquiry that he expects to implement the NICE guidelines next year: since these are not officially known, this lends credence to the widely-held belief that the NICE guidelines will merely re-echo the view already expressed and published in an "Effective Health Care" bulletin, May 2002:7: (4), a publication that was disseminated throughout the NHS and funded by NICE itself, which emphasised that CBT and GET are the treatments of choice for "CFS/ME". There is concern in the ME community that the Government and the MRC set the outcome they wish to achieve. This being so, it would be remarkable if NICE were to produce guidelines that are substantially different from its already documented view of the same issue.

Should the forthcoming NICE guidelines advocate nothing but CBT and GET, this would ignore the significant body of published research and clinical knowledge that ME/CFS is not a mental health (behavioural) disorder and would make a mockery of the Government's purported commitment to improving understanding of what is a serious, multi-system disorder that, unless addressed as a matter of urgency and treated appropriately, will continue to wield a huge potential for bankrupting the NHS.

For those wishing to obtain further information about its funding policies, the MRC is an institution and is therefore subject to the law regarding the Freedom of Information Act, which means that if formal applications are made, the requested information must be produced (this also applies to email correspondence sent to and by the MRC).