Questions for the MRC

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In her reply dated 16th June 2005 to Mrs Connie Nelson (who had requested clarification concerning at what stage the "London" criteria are to be used within the MRC PACE trial and what evidence supported the use of the "London" criteria for secondary analysis within the trial), Sarah Perkins (Programme Manager, MRC Neurosciences and Mental Health Board) stated: "The main entry criteria for the PACE trial are the Oxford criteria….The exclusion criteria of "proven organic brain disease" will be used to exclude neurological conditions of established anatomical pathology such as Parkinson's disease and multiple sclerosis. **It will not be used to exclude patients with a diagnosis of ME".**

As Ms Perkins is aware, the Oxford criteria expressly exclude participants with organic brain disease, so would she be kind enough to clarify the following:

1. why the MRC is adopting special pleading in relation to ME, when ME is a classified neurological disorder in the ICD and has been so classified since 1969

2. on what scientific evidence-base the MRC is relying to enable it to disregard this international classification that has been approved by the World Health Assembly

3. on what evidence–base the MRC is relying to permit it to disregard recognised research procedure by implementing its own selective modification of the Oxford criteria

4. why it is acceptable to the MRC to disregard the substantive body of scientific evidence of neurological compromise in ME in favour of unsubstantiated beliefs of certain psychiatrists

5. given that these psychiatrists seem to be financially encouraged to demand 100% proof of an organic pathoaetiology for ME before they will "allow" it to be accepted as an "real" organic disorder as distinct from a mental disorder, why the MRC does not equally require a similar standard of proof from these psychiatrists that ME is a mental disorder as they believe, given that these psychiatrists appear to be permitted automatically to reject the convincing evidence of multi-system damage yet have not provided any convincing counter-evidence that refutes such evidence

6. given that in 2003, Members of Parliament so excoriatingly criticised the MRC (see House of Commons Science and Technology Committee: The Work of the Medical Research Council. Third Report of Session 2002-03, 24th

March 2003: HC132), why the MRC is content to continue to support policies and fund projects that are likely to perpetuate such criticism when, for example, gene research is demonstrating that these psychiatrists (whose beliefs about ME the MRC is on record as supporting) have already been shown to be comprehensively wrong about ME

7. in view of the submissions for funding of biomedical aspects of ME that the MRC is known to have rejected on the claimed grounds that they were not of sufficiently rigorous quality, what is the explanation for the seemingly more lax standards required for psychiatric research projects such as the PACE trial (for example, not only the selective modification of the published criteria but also the deliberate inclusion of participants who, from the outset, are known to suffer from fibromyalgia, a separately classified disorder that is not ME).

It cannot be repeated often enough that what Wessely School psychiatrists choose to call "CFS/ME" is not ME/ICD-CFS (a term used because ME is also known in the ICD as "CFS") and should not therefore be described in their studies and results as pertaining to ME/ICD-CFS. To do so is both a failure of their professional responsibilities to patients and a corruption of the scientific process.

Whilst on the subject of apparent discrepancies in matters relating specifically to ME, it is noted that in a Co-Cure post dated 17th June 2005, Vivienne Parry (Administrator of the Great Universal Stores (GUS) Charitable Trust that is currently funding the PRIME project) denies that she has worked with psychiatrist Professor Simon Wessely (who is notorious for his view that ME is a somatoform disorder that is perpetuated by an aberrant belief), stating: "It's been alleged that I have worked with Simon Wessely. I have never even met him" and Ms Parry is also on record on other internet sites as affirming: "I've never actually met him and have certainly not worked with him – a fact the Science Media Centre will confirm to you tomorrow". Is this not curious, given that Simon Wessely sits on the Science Advisory Panel of the Science Media Centre, of which Ms Parry is a member of the Board?

Members of the long-suffering ME community may require their respective Members of Parliament to seek until they obtain believable explanations for such remarkable discrepancies.