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## Some points to put before Professor Sir George Radda, Chief Executive of the MRC, to which answers are required 17<sup>th</sup> July 2002

1. Why was Professor Jill Belch of Dundee not included on the MRC ME/CFS panel? She is a top-rated member of the MRC; she has run an NHS ME clinic; she put her name forward (in fact she was nominated for this panel by Professor Sir Roland Jung, Scottish Chief Scientific Officer); she wanted to be on the panel; she has over 400 publications to her name; she is a major MRC fund-holder, but she was not included. However, the panel includes two people who (far from being "independent" and "fresh minds" as announced by Dr Diana Dunstan of the MRC) are known to favour the psychiatric model of ME/CFS and for promoting cognitive behavioural therapy and for their strong connection to the Linbury Trust, which funds so much of the psychiatric "research". Those two people (Prof Alan McGregor of Kings and Prof Philip Cowen of Oxford) have actually co-authored papers with Simon Wessely (McGrgeor) and Mike Sharpe (Cowen) and Cowen is mentioned in Wessely's book on CFS. It was Sharpe who is known to have recommended to medical insurance companies that claimants with ME/CFS should be subjects of covert video surveillance (and let us not forget that in its "Chronic Fatigue Syndrome Management Plan" the insurance company UNUM proclaims: "DIAGNOSIS: Neurosis with a new banner".

It is simply untrue that these people are "fresh minds" to the matter and the ME community is well aware of this. In his letter of 15<sup>th</sup> July 2002 to Simon Lawrence of the 25% ME Group, Radda himself ducks out of the issue by saying "you cite papers from some years ago" (he cannot deny those papers) but then states that the inclusion of McGregor and Cowen on the panel "is consistent with MRC's intention to select the working group from experts in various fields who do not specialise in CFS/ME". How can he say this, when McGregor is listed in the Linbury publications as being a "*Member of the Linbury Advisory Panel on CFS*" and is closely involved with the psychiatric model. This is disturbing.

- 2. Why does the UK Government listen only to Simon Wessely as their official "expert" on ME/CFS when his beliefs have been so repeatedly discredited in the international literature?
- 3. Why, in contempt of the evidence, did the CMO's report advise that only *basic tests* are necessary and appropriate for those thought to have ME/CFS, when the whole world knows that such tests will be normal in 90% of those with ME/CFS, and why did it specifically advise that no immunological or nuclear medicine investigations

should be done, when those are the very investigations which are delivering hard evidence of an organic pathoaetiology in the USA, Belgium and other countries?

- 4. Given that NICE funds "Effective Health Care" bulletins which are disseminated throughout the NHS (including the recent one on CBT and graded exercise as management for ME/CFS), how can NICE advise the CMO (together with the MRC panel whose membership has been the cause of so much concern) on the direction of future research into ME/CFS when its views on this are already established and can already be seen to be biased in favour of the psychiatric model?
- 5. *Why* is there no neurologist and no neuro-radiologst on the MRC panel, given that ME has been formally classified by the WHO as a neurological disorder since 1969? Is this because Wessely believes ME does not exist except in the minds of sufferers, and that "CFS" is a somatisation disorder?
- 6. Why exactly does Under Secretary of State for Health Mr Lammy say what he does in Hansard about the MRC panel and NICE looking at the "recommendations" of the CMO's Report? That's just going round in the same circle ( as has been happening for the last 15 years ever since Wessely came on the scene)
- 7. Radda is supposed to oversee RESEARCH, so it needs to be pointed out to him just how much credible research on ME/ICD-CFS there **is** (eg. all the international conference reports), but in the UK this research is consistently ignored, trivialised or dismissed by Wessely et al and UK clinicians have been deprived of this information in their own UK journals (which have been full of Wessely's beliefs, seemingly as editorial policy)
- 8. *Why* is no research into the organic pathology taking place in the UK? The MRC always says that the research proposals it receives for ME are not of enough merit to warrant funding (but this is disputed). Is this because of powerful vested interests (eg. Minsiter for Science Lord Sainsbury of Turville and his family's Linbury Trust; Wessely being on the Supervisory Board of PRISMA, which arranges his own CBT package for insurance claimants and is the same package which, via the York Systematic Review (to which Wessely was advisor) underpins the recommendation of the CMO's Report.
  - NB. (i) Wessely did not declare his competing interests (HealthWatch, PRISMA, Linbury Trust) in the CMO's Report
    - (ii) he is also on various relevant MRC Boards
- 9. *Why* did the CMO's Key group persistently ignore so much good evidence which was put before them?

- 10. Where is the *proof* that ME/ICD-CFS is a somatisation disorder which is amenable to CBT? It certainly is not in the York Systematic Review, so *why* is CBT still being pushed as the management of choice?
- 11. What assurances will Radda give that the severely and chronically affected will be considered in future research?