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Memo from Professor Hooper et al to the Gibson Parliamentary Inquiry

8th May 2006

In the light of the recent findings from the US Centres for Disease Control (the principal agency for protecting the health of all Americans, which has invested about $2 million to address the complexity of (ME)CFS and whose findings were published in 14 research papers in the April 2006 issue of Pharmacogenomics), we believe it important to draw to the attention of all members of the Gibson Inquiry the following points:

1. The CDC study was the most detailed and comprehensive clinical study on (ME)CFS to date and it found that there is a clear biological basis for the disorder. Significantly, it found that "CFS" is actually a constellation of five or more conditions with varying genetic and environmental causes (Washington Post, 21st April 2006).

2. Commenting on the CDC studies, Dr Lucinda Bateman from the Fatigue Consultation Clinic in Salt Lake City said: "It is very hard to treat an illness until you understand what it is physiologically" and that the CDC results were "a very important foundation for developing new treatments" (Los Angeles Times, 21st April 2006).

3. In contrast, at a meeting of the All Party Parliamentary Group on ME held on 26th April 2006, the Chief Executive of the Medical Research Council, Professor Colin Blakemore, said (once again) that illnesses can be treated without knowing the causes. Whilst symptomatic treatment without understanding causation may provide some alleviation of some symptoms, only detailed and careful research can provide the knowledge base for the employment and design of comprehensive effective treatment. Surely an illness that extorts such a high personal, social and financial toll demands the highest level of research into its causation?

4. Blakemore also misled the APPG about MRC funding, claiming that a generous 8% of the MRC budget was spent on "CFS/ME". When Jo Dubriel challenged this, Blakemore was compelled to concede that the correct figure was 0.08% (RiME Summary of APPG Meeting 26/04/06). In fact, the MRC "CFS/ME" trials are costing in excess of £4 million but exclude biomedical aspects, being limited to the alleged behavioural and psychosocial dimensions of "CFS/ME".

5. Of particular concern is that when Dr Julian Lewis MP went on record saying that ME patients were being lumped together with people who had psychological problems such as mild "fatigue" (and was supported by the founder of Research into ME, Paul Davis, who pointed out that the MRC trials are using the Oxford criteria, these being criteria that do not select those with ME but instead select a heterogeneous group whose main complaint is chronic "fatigue", yet the MRC trials purport to relate to those with "CFS/ME"), Blakemore openly laughed (RiME Summary of APPG Meeting 26/04/06). He went on record stating that people with "Oxford criteria CFS" would benefit from the MRC trials. Such a view from Blakemore would suggest that as far as ME/CFS is concerned, no matter what calibre of scientific evidence of serious organic pathology is put before the MRC, the MRC intends to ignore it and to pursue its intransigent policy of regarding "CFS/ME" as a behavioural disorder. Given the now irrefutable fact that "CFS" is accepted as consisting of numerous subsets, such disregarding of the evidence by the CEO of the MRC would indicate that there is no prospect of the MRC funding research into the biomedical aetiology and ultimately research into effective treatments for ME/CFS, which is normally the prime target of medical research.

6. Another cause for concern that members of the Gibson Inquiry on ME might wish to consider relates to the NICE Questionnaire that is meant to inform the members of the NICE Guidance Development Group (GDG) on "CFS/ME" who are currently in the process of producing what will be the ultimate policy on the management of such patients. Before the document was circulated, despite persistent requests to provide a more user-friendly Questionnaire (ie. one that was suitable for the needs of the target group), as well as the identification of a significant and inexcusable error, the GDG refused to amend the document before sending it out, with the result that the validity of the Questionnaire must now be in question. Nancy Turnbull, Chief Executive of the National Collaborating Centre for Primary Care (who distributed the Questionnaire on behalf of NICE and others involved) conceded that there was an error in the paper version of the Questionnaire, but confirmed that the error had been corrected in the electronic version. This means that there are now two different versions of the Questionnaire. The error relates to questions 29 – 61 and will inevitably invalidate any data derived from two different sources. The requested extension of time for the returning of the Questionnaire was refused, which had to be received by NICE no later than 5pm on 5th May 2006. This would seem to indicate that NICE is not concerned that its Questionnaire was flawed and will therefore yield meaningless results.

7. The undeniable refusal of Government bodies to address the substantial evidence of organic pathology in ME would seem to be supported by a paper that is currently circulating throughout the ME community. The paper in question eulogises cognitive behavioural therapy for somatoform disorders, in which it includes "CFS". The paper focuses on "amplifying symptoms by adopting the sick role" and refers to "secondary gain" by patients who "scan their body for

symptoms"; it also states that symptoms experienced are "seldom caused by serious somatic disease". It emphasises the message that clinicians must convey to patients: (i) Do not listen to your body's signals (ii) Do not trust your feelings (iii) Do not trust your thoughts. This is the central theme of CBT. (ref: Biological sensitisation and psychological amplification: gateways to subjective health complaints and somatoform disorders. Ingvard Wilhemlsen. Psychoneuroendocrinology (2005):30:990-995). Note that this is the same author with whom in 2002 UK psychiatrist Professor Michael Sharpe collaborated on the "psychobiological" pathway of irritable bowel syndrome (http://www.rikshospitalet.no/view/readforskat.asp?nPubID=799 Medical Research at Gaustad, 2002), a condition now known not to be a psychosocial phenomenon as previously thought, but to be the result of autonomic dysfunction, with objective changes in gut motility and altered gut biochemistry, including molecular changes in serotonergic signalling mechanisms, which can be induced by inflammatory mediators (Gastroenterology 2004:126(7):1657-1664; Aliment Pharmacol Ther. 2006:23:1067-1076; see also IBS overview on http://www.cfids-cab.org/cfs-inform/).

These are all relevant and important points to which we ask the Gibson Inquiry members to pay due heed, since unless they are appropriately addressed, they are likely to have a far-reaching adverse impact on the health and welfare of those with ME.

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