

## The “London” criteria: QED

Margaret Williams 14<sup>th</sup> May 2005

Hopefully this clarification will be the final arbiter of the discrepant assertions made publicly by Miss Ellen Goudsmit PhD about the “London” criteria that the Medical Research Council intends to use in the PACE trials on “CFS/ME”, the results of which will have far-reaching implications for people with myalgic encephalomyelitis (ME). Given the well-documented bias of the psychiatrists involved in the MRC PACE trials, it is of serious concern that they will be using the “London” criteria when those criteria have never been published and are not available as a reference for identification.

1. Miss Goudsmit continues to claim that the “London” criteria were used by Costa et al in their 1995 paper and that it was this paper which operationalised the “London” criteria. (The reference for the Costa et al paper is: “Brainstem perfusion is impaired in chronic fatigue syndrome”. D C Costa, C Tannock and J Brostoff: QJMed 1995:88:767-773).
2. The Costa et al study in question refers at reference 14 to “Criteria for a diagnosis of ME for use in the ME Action funded research. Based on the criteria suggested by WRC Weir in *Post Viral Fatigue Syndromes* by Jenkins and Mowbray, pp 248-9”.
3. The Jenkins and Mowbray book was published by John Wiley & Sons, Chichester in **1991** (“Post-Viral Fatigue Syndrome”. Edited by Rachel Jenkins and James Mowbray. Published by John Wiley & Sons, Chichester, 1991. ISBN: 0 471 92846 1).
4. In her IMEGA post of 8<sup>th</sup> May 2005 Miss Goudsmit is unequivocal: **“Costa did not refer to the London criteria but to the ‘ME Action’ Criteria. The ME Action criteria are the London criteria”**.
5. This accords with a ResAct post in November 2004 by Miss Goudsmit, in which she stated: “Costa did not refer to the criteria as the LC but he did refer to the criteria developed by ME Action **and guess what they are**. People who wish to discredit me are welcome to try but I don’t lie and that makes life a lot easier”.
6. In her [letter to the UK Chief Medical Officer](#), Miss Goudsmit wrote in January 2002 about the Report of the CMO’s Working Group: “Dear Professor Donaldson, I write as a specialist and researcher whose 20 years of knowledge and controlled trial was ignored by the working group. As most of my fellow ME specialists were ignored. Aside from the errors (e.g. wrong reference to the London criteria, cited as 1990 but I did not think of them until 1993 let alone compile them with colleagues.....We can do a lot for these patients. There’s nothing like evidence-based evidence and this is nothing like evidence-based medicine”.

7. From her letter to the CMO, it seems perfectly clear that she did not even think of the “London” criteria until **1993** and indeed, in her formal response about the “London” criteria dated 10<sup>th</sup> May 2005 (posted on IMEGA) about her letter to the CMO, Miss Goudsmit states: “THIS IS NOT AN INCONSISTENCY AS THE PUBLICATION IN QUESTION HAD AN INCORRECT REFERENCE AND I CORRECTED IT” (ie. she corrected the reference to the date of the formulation of the “London” criteria from 1990 to **1993**).
8. The Costa et al reference to the ME Action criteria make it clear that the authors are referring to the criteria suggested by Dr William Weir, and in her formal response dated 10<sup>th</sup> May 2005 on IMEGA Miss Goudsmit states categorically: “IF ONE COMPARES THE LC TO THOSE FROM WEIR, ONE SEES SOME NOTABLE DIFFERENCES. NO-ONE COMPARING THEM WILL BE CONFUSED”, **yet she persistently claims the ‘ME Action criteria’ are the “London” criteria.**
9. To summarise: the Costa et al reference relates to criteria for use by ME Action (now called Action for ME) in a textbook that was published in **1991** but Miss Goudsmit has claimed in writing that she didn’t even think of the “London” criteria until **1993**, so how can Miss Goudsmit now claim, as she does, that the Costa et al reference to the ‘ME Action’ criteria refers to the “London” criteria?
10. They clearly do not: quod erat demonstrandum.

Miss Goudsmit’s many claims that the Costa et al paper used the “London” criteria as operationalised criteria cannot, therefore, be valid and she has apparently misled people about what has become a very important issue in relation to the MRC PACE trials. Without doubt, on the evidence available, she seems to have been involved in a discrepancy, if not a deception.

Quite apart from the MRC issue, there are wider implications: for example, despite Miss Goudsmit’s denial, it is the case that Raymond Perrin has confirmed to two separate people that in his study published in 1998 (this being another paper upon which Miss Goudsmit relies to support her claim that the “London” criteria have been used in published studies) he had *assumed* that the “London” criteria had been published and that it was acceptable for him to use them because he had been advised to use them by Dr Anne Macintyre of Action for ME and by Dr Charles Shepherd of the ME Association, on whose advice he relied. (The reference for the Perrin et al paper is “An evaluation of the effectiveness of osteopathic treatment on symptoms associated with myalgic encephalomyelitis. A preliminary report”. Perrin RN, Edwards J and Hartley P: Journal of Medical Engineering and Technology: 1998:22:1:1-13).

The published study that Perrin had been assured had used the “London” criteria and to which he referred in his own paper was the Costa et al study referenced above, which as has been shown, did **not** use the “London” criteria by a demonstrable time factor of two years.

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**Note from MEActionUK Editor**

It may interest people to know that Ellen's letter to the Chief Medical Officer has since been mysteriously removed from the Axford's Abode website and can no longer be found at...

<http://freespace.virgin.net/david.axford/letter11.htm>

... as you will see by clicking on the link above.