

Rebuttal of misinformation about the “London” criteria

Margaret Williams 19th May 2005

The reason this whole issue of the “London” criteria is so important is **not** to afford unending opportunities for sophism on the part of Miss Goudsmit, but entirely because of the intention of the MRC to use the so-called “London” criteria in the PACE trials. It is for that reason alone that it is imperative to establish the facts beyond doubt and ensure that they are in the public domain. Too many people have suffered too much for too long for them to be once again sold down the river.

In the interests of accuracy and to set in context what Miss Ellen Goudsmit PhD today posted on cfs_research (which she states she has now removed) it is considered necessary to provide the following information.

In one of her two posts, Miss Goudsmit states:

“if you recall, there was a claim by Williams and Jones on various sites that (Perrin) had been ‘misled’ into using these criteria; he’d apparently been told they’d been used by Costa, I believe he felt that previous use validated them, but anyway, then two people informed him that Costa had not used them. And apparently, he was not happy about that. Since his information came from Dr Macintyre and Dr Shepherd i.e. two co-authors who were also familiar with Costa’s study, Williams and Jones were effectively claiming they had misled him. He subsequently wrote to Co-Cure that he did not feel misled by the doctors.....so where are we now? Perrin is happy that Shepherd and Macintyre did not mislead him and he’s not unhappy. I do not feel that Costa mislead (*sic*) me or anyone else at ME Action and so I did not mislead anyone else...”.

In her second post, Miss Goudsmit states:

“Note: Doris M Jones MSc wrote in a message: *Dr Weir in his chapter in the 1991 Jenkins/ Mowbray book refers to the 1988 Holmes et al criteria...* while Margaret Williams said in a former message: *The Jenkins and Mowbray textbook at pp 248-249 sets out Dr Weir’s own modification of the Holmes et al 1988 criteria and makes no mention of any “London” criteria, nor of the authors of the criteria being Miss Goudsmit, Dr Macintyre and Dr Shepherd. From this, it is apparent that the “ME Action” criteria used by Costa, Tannock and Brostoff were based on criteria suggested by Dr Weir...*. Yes, that is perfectly logical! Weir, writing in a book, published in 1991, did not cite criteria formulated in 1993. He, nor anyone else writing in that book, mentioned (*sic*) the authors of criteria which hadn’t been thought of. I am shocked! Admittedly, (Costa) wrote that the ME Action criteria were based on those developed by Weir. I have noted since that he made a mistake. there (*sic*) is no single (*sic*) reference in any publication anywhere (*sic*) in the known universe which has referred to the ME Action criteria for use in research funded by ME Action, as being (*sic*) separate from the London criteria. And they were not based on Weir. I know that as I was part of the group who compiled them. Williams and Jones were not. I wasn’t (*sic*) not expressing an opinion. I was passing on a fact. Williams and Jones were not. I do not know why Costa thought the criteria were based on those by

Weir. I accept his error was a genuine one. (Jones) and Williams are basing their arguments on an error. Arguments based on erroneous information. Is that the best they can do today? No wonder we're in such a mess. Ellen".

On 17th May 2005, Miss Goudsmit wrote: "I noted that Costa's reference was to the criteria from ME Action and that these were known as the London criteria. I accept he did not use the word "London". I accept this might appear ambiguous. Costa would not have passed on inaccurate information to me and the rest of ME Action and Dr Macintyre would not have passed inaccurate information to Dr Perrin. Dr Costa had no reason to mislead anyone about the criteria he was using and he was assisted with selection by Dr Macintyre. She knew exactly what was going on. **When the CMO's report cited that the London criteria were based on a definition by Ramsay and Dowsett 1990, they were right.** But that does not mean they were the same as. (*sic*). I have never suggested that. To the contrary. If activists prefer to repeat erroneous information, that's entirely up to them".

[Despite what she asserted above, it is noted that on 19th May 2005 Miss Goudsmit posted her "Response to Mrs Doris Jones" in which she said: **"(The CMO's) report listed the date of the London criteria as 1990, which was incorrect. I alerted people to this simple error, as has been documented"**].

How does all this accord with the facts? Is all this public acrimony anything other than Miss Goudsmit's determination to be right at any cost (notwithstanding her self-contradictions)? Did Costa et al make a mistake? Knowing two of the authors involved, this seems most unlikely, but if so, for the sake of people like Raymond Perrin who have relied upon what Miss Goudsmit now alleges is a mistake, a correction should be published forthwith by Costa et al and the Journal.

Why, though, if an incorrect reference had been given by Costa et al in 1995, did Miss Goudsmit not request a public correction at any time during the ten years since publication of the study in question?

Even more curious is the apparent failure of any of the alleged co-authors of the ME Action "London" criteria to notice this alleged error when the paper was provided by them as a reference for Mr Perrin in 1998.

As things currently stand, the reference cited by Costa et al clearly refers to "Criteria for a diagnosis of ME for use in the ME Action funded research. Based on the criteria suggested by WRC Weir in Postviral Fatigue Syndrome by Jenkins and Mowbray pp 248-9". In diametric contrast, Miss Goudsmit has many times publicly insisted that (quote) "the ME Action criteria are the London criteria". Both these claims cannot be true.

Regarding the involvement of Raymond Perrin, the facts are as follows:

On 7th September 2004 Mr Perrin was contacted by telephone and asked about his purported use of the "London" criteria in his study that was published in 1998 (ref. "An evaluation of the effectiveness of osteopathic treatment on symptoms associated with Myalgic Encephalomyelitis. A preliminary report". RN Perrin et al: Journal of Medical Engineering and Technology 1998;22:1:1-13).

When asked where the “London” criteria which he had cited were published, he replied that he had used them through Dr Anne Macintyre of Action for ME, and that the charity had a database of members, and that it had been Dr Macintyre who had chosen the names of people to be included in his study from AfME’s list.

When pressed, he said (verbatim quote): “The London criteria are definitely published” and he confirmed that this was indeed his belief from the information he had been given by Drs Anne Macintyre of ME Action and Charles Shepherd of the ME Association. He specifically said that this information came originally from Ellen Goudsmit and that it was she who had informed Anne Macintyre that the “London” criteria had been used in published studies.

Mr Perrin also stated his belief that the “London” criteria had been validated and he referred to The National Task Force Report (Westcare, 1994) to support his belief that the “London” criteria had been validated.

When he was made aware that the Task Force Report simply described the “London” criteria as “proposed” criteria, he expressed surprise, and then said that it was Anne Macintyre, through Ellen Goudsmit, who told him the London criteria had been validated and that the reference for this was Costa, Tannock and Brostoff (QJMed.1995).

Mr Perrin said that he was (quote) “very grateful” to have been made aware of the fact that Costa et al had not cited the “London” criteria in their 1995 QJMed paper because he was intending to quote it in his forthcoming PhD thesis. He finished the conversation by stating that he intended to speak to Anne Macintyre.

On 9th May 2005 Raymond Perrin was contacted again by telephone by the same person to whom he had spoken on 7th September 2004, during which conversation he once more confirmed that he had assumed the “London” criteria had been published and validated because he had been advised to use them by Anne Macintyre and Charles Shepherd, and he had no reason to doubt their advice.

On 10th May 2005 Raymond Perrin was contacted by telephone by a different person about his use of the “London” criteria, and he again confirmed that he did not select his participants from ME Action and that they had been selected for him by Anne Macintyre. He said categorically that he had relied on Charles Shepherd and Anne Macintyre entirely over the matter of the “London” criteria and that he was advised by them to use the “London” criteria in his study.

He once again said that he had not realised the “London” criteria had not been published and that he was concerned about it.

On 15th May 2005 Raymond Perrin posted the following on Co-Cure: “I had no reason to doubt the advice given to me at that time by the medical advisers for Action for ME and the ME Association. As far as I was aware, the criteria used by ME Action were known as ‘the London criteria’ and that Costa et al had used them”.

On 19th May 2005 Raymond Perrin seems to have reconsidered his position and he posted the following statement on Co-Cure: “I wish to place on record right now that I never said to anybody that I believed Anne Macintyre or Charles Shepherd lied to me in any way. I do not believe that I was mislead but some nomenclature or semantics have been confused”.

As far as the various telephone conversations with him are concerned, at no time did any of the three people involved intimate that either Drs Macintyre or Shepherd had “lied” to him and notably, in his post of 19th May 2005, Mr Perrin re-iterates the following: “I was told that the London criteria should be used for the reason I have given in my paper” (his paper states: “The latter criteria are more stringent than the CDC criteria”).

This sorry saga (which to most people is boring beyond measure) will not cease until the existing misinformation --- no matter how voluminous and convoluted -- is replaced by the verifiable facts.