

## FACTS about the “London” Criteria

**6<sup>th</sup> September 2004**

In view of the fact that Action for ME has announced that the MRC-funded PACE trials on CFS and fibromyalgia are now proposing to use the “London” criteria in addition to the Oxford criteria (and that this is supported by Dr Charles Shepherd of the ME Association), there has been much internet discussion about the “London” criteria.

In order to clarify matters, certain facts may be relevant.

In an email dated 7<sup>th</sup> June 2004, Ellen Goudsmit PhD wrote to Margaret Williams asking her (“for old times sake”) to confirm publicly the following about the “London” criteria:

“that they were first published in the National Task Force report and that they are very similar to Ramsay and Dowsett’s clinical definition ie. they are operationalised criteria for research on ME as defined by Ramsay and Dowsett. Those are the facts. They were, almost word for word, a copy of Dowsett’s work”.

The same email also stated: “They (ie. the “London” criteria) were used in all studies funded by AFME from 1993 to 1997, eg. Costa et al, who discovered hypoperfusion in the brainstem, and Scholey et al, who found cognitive impairment consistent with organic brain disease. Paul et al also used them and found support for Ramsay’s definition, especially the delayed recovery for muscle power”.

From this, it seems that Miss Goudsmit believes that the “London” criteria were *used for patient selection* in the studies she mentioned, and that as a result of using the “London” criteria, significant abnormalities in patients with ME/CFS were elucidated.

Because this seemed to be a misrepresentation of the facts, Margaret Williams was unable to comply with Miss Goudsmit’s request.

### **1. The Sept 1994 National Task Force Report on CFS/PVFS/ME**

This was funded by the charity Westcare (now amalgamated with Action for ME) with a donation of about £10,000 from the Department of Health. On page 88 the Report lists the various terminologies in current usage and underneath lists the nine “case descriptions”, about which it states:

“Definitions and descriptions have been proposed by the following authors or groups:

Benign ME Acheson (1959) (*this was inaccurate, because it was first termed Benign ME in 1956 in a Leading Article in The Lancet (26<sup>th</sup> May 1956:789) which was anonymous but which was later confirmed to be by ED Acheson, who as Sir Donald Acheson became the UK Chief Medical Officer* )

ME Ramsay (1988) (*again, this was inaccurate, because it was November 1981 and was published by the ME Association*)

PVFS Behan & Bakheit (1991)

CFS (CDC) Holmes et al (1988)

CFS (NIAID --- the US National Institutes of Allergy and Infectious Diseases)

Schluedenberg et al (1992)

CFS (Australian) Lloyd et al (1980) (*another inaccuracy -- should have been 1990*)

CFS (Oxford) Sharpe et al (1991)

PIFS (Oxford) Sharpe et al (1991)

ME/PVFS (“London”) International Federation of ME Associations –IFMEA – et al (1993) [Miss Goudsmit founded and signed herself as Director of IFMEA].

On pp 96-98 the National Task Force Report goes into more detail about the “London” criteria.

Thus it is the case that the “London” criteria were described in the National Task Force Report as being a “proposed” case definition.

However, the London criteria have never been officially accepted into common usage, nor have they ever been validated or operationalised (as conceded by Miss Goudsmit in her email dated 4<sup>th</sup> September 2004 where she states “The LC have not been validated”).

To be fair, the “London” criteria are better and more accurate than either the 1988 Holmes et al or the 1994 Fukuda (CDC) criteria.

It was public knowledge at that time (said in the Task Force report to be 1993) that Miss Goudsmit, with the agreement of Dr Charles Shepherd (said to be representing the ME Association) and Dr Anne MacIntyre (said to be representing AfME) decided to refine and reform what Dr Melvin Ramsay (and subsequently Dr Betty Dowsett) had published about ME, which were called the “London” criteria.

## **2. Costa, Tannock & Brostoff (1995)**

(Brainstem perfusion is impaired in chronic fatigue syndrome. DC Costa, C Tannock and J Brostoff. Quarterly Journal of Medicine December 1995;88:767-773)

This paper makes no mention of the “London” criteria. It confirms about the population studied that “All ME/CFS patients were clinically assessed and diagnosed according to standard criteria (Oxford), CDC and ME Action”. The reference in the paper for the ME Action criteria is number 14. That reference states “**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 & Mowbray pp248-9**”. The Jenkins & Mowbray textbook at pp 248-249 sets out Dr Weir’s own modification of the Holmes et al 1988 criteria and is virtually identical to what was later published as the “London” proposed criteria in the Westcare Task Force Report in 1994. Thus the question arises as to how much of the modification to the Ramsay original case description of ME that Miss Goudsmit has

variously claimed as being her own work and then as being taken almost word for word from Dr Betty Dowsett can be ascribed to Dr Dowsett and how much to Dr Weir.

### **3. Lorna Paul et al 1999**

(Demonstration of delayed recovery from fatiguing exercise in chronic fatigue syndrome  
Lorna Paul et al. European Journal of Neurology 1999;6:63-69)

The case definition used in this study was the CDC Fukuda 1994: the authors state “**The patients were all ambulatory, and fulfilled established criteria for chronic fatigue syndrome (Fukuda et al, 1994)**”. There is no reference to the “London” criteria anywhere in the paper itself or in the references.

However, in her own review of the Paul et al paper that she sent out in the IFMEA Updates (then renamed as ME and CFS Capita Selecta Quarterly, March 1999), Miss Goudsmit states “ A fatiguing exercise was therefore carried out on the quadriceps muscle group of 10 patients with CFS (Oxford and CDC criteria '88 and '94 plus others”.

The text does indeed mention the Oxford criteria, but the cited population studied under the “Methods” description refers only to the CDC 1994 Fukuda case definition.

Miss Goudsmit also states in her Capita Selecta Quarterly: “Editor’s Note: The use of various criteria in this study suggest the population had an illness consistent with ME”, but there is no mention in the published text or in the references of “others” in relation to other case definitions of patients used in the study.

### **3. Whiting et al --- the York Systematic Review (2001)**

(Interventions for the Treatment and Management of Chronic Fatigue Syndrome. Penny Whiting et al JAMA 2001;Sept 19: 286:11:1360-1368)

Miss Goudsmit has sometimes claimed that her work based on the London criteria has been used in this Systematic Review. This review purported to assess the effectiveness of all interventions that had been evaluated by the review team (ie. it was limited to what the review team deemed should be included) for use in the treatment or management of CFS in adults and children.

The study looked at “validity assessment” of the 44 studies included in the review and graded them on a scale, with 20 being the top rated outcome: Miss Goudsmit’s dissertation was indeed included; it scored the lowest rating (2 out of a possible 20) of all those included. The authors commented about Miss Goudsmit’s dissertation that “The methodological quality was very poor”.

Once again, there is no mention of the “London” criteria, but it may be that Miss Goudsmit stated something about them in her dissertation itself; it was called “Learning to Cope with Post-infectious Fatigue Syndrome: a Follow-up Study in the Psychological Aspects and Management of Chronic Fatigue Syndrome”: Uxbridge, England, Brunel University, 1996. Note that it deals with the *psychological* aspects and management of CFS, so one would need to ask precise questions about the case definition of the population studied.

#### **4. The Scholey et al presentation (1999)**

(A comparison of the cognitive deficits seen in myalgic encephalomyelitis to Alzheimer's Disease. Pat McCue, Andrew Scholey and Keith Wesnes *Proceedings of the British Psychological Society, 12<sup>th</sup> January 1999* )

This was an abstract that was presented as a poster presentation at a BPS Conference in January 1999. Abstracts are recorded by the BPS but the study itself **has never been published**. This was confirmed by Professor Andrew Scholey himself and also by the British Psychological Society. The study looked at 20 patients (self reported from ME support groups in the North-East of England) and the abstract states that they satisfied the London criteria, although the criteria used were not defined in the abstract.

Scholey et al also presented another abstract at a BPS conference in Belfast held on 8<sup>th</sup>-11<sup>th</sup> April 1999 (Cognitive deficits in Chronic Fatigue Syndrome are reversed by oxygen administration Andrew Scholey, Pat McCue, Ingrid Mackay, Mark Moss and Keith Wesnes). The abstract states that the participants were 16 patients satisfying both the Oxford and the London criteria. Again, this has **not been published**.

With regard to Professor Scholey's work and the significance that can be drawn from it on the basis that the "London" criteria were used, patients were self-reported and it is **unpublished material**.

Thus it is difficult to understand the intention of the co-ordinator (psychiatrist Dr Peter White) of the MRC PACE trials on CFS and fibromyalgia (or the support afforded by both Dr Shepherd of the ME Association and by Chris Clark of AfME) to use the "London" criteria in addition to the Oxford criteria, given that the "London" criteria have so little relevance as a case definition of ME/CFS used in published studies.