

van: Ellen Goudsmit
datum: 2005/05/10 di PM 03:15:50 CEST
aan: ME-NET@NIC.SURFNET.NL
onderwerp: Re: London criteria -the Facts

For balance. A formal response to claims by Miss Williams on the 9th May

Consider ALL the evidence and decide for yourself.

My comments are in capital letters for differentiation. I will refer to the London criteria henceforth as the LC. I apologise for any repetition.

Ellen Goudsmit PhD and the "London" criteria

~~~~~  
The facts

Margaret Williams

9th May 2005

Given that the Medical Research Council intends to use the "London" criteria for what is described as 'secondary analysis' in the PACE trials that will use the Oxford 1991 criteria that deliberately include those with psychiatric disorders, it is imperative that the issue of the authenticity of the "London" criteria is publicly addressed.

Miss Ellen Goudsmit PhD has recently posted challenges to information supplied by others:

(i) "As was noted last year, the London criteria have been used in various studies, some of which have been published. The London criteria are as defined and operationalised as the other research criteria from that time. The London criteria were devised for MEAction, now AFME, for use in all studies funded by them. All teams who received a grant, except one, kept to the contract. Amongst those who received a grant were Dr Durval Costa for his study on hypoperfusion (published in the QJM). I urge activists not to undermine (the arguments of authors whom she continues to assert used the 'London' criteria in their research) by giving inaccurate information" ("The London criteria: correction and clarification": Co-Cure, 7th May 2005)

(ii) "The LC ('London' criteria) were devised so researchers could identify the 'real deal' patients and they did! The

abnormalities they found using the LC, e.g. hypoperfusion, reduced muscle power etc were found in ALL the patients who met the criteria. Costa et al was one of the most important studies to date. Too little blood to the brain. Paul et al was good and that too, was on people with ME. Those of us who fought for research on real deal patients back in the early 90s deserve credit. Not denial" (CFS Research, 8th May 2005).

FACT: The "London" criteria have never been published.

**THEY HAVE SINCE BEEN PUBLISHED ON THE INTERNET, AS MANY OF MS. WILLIAMS PAPERS HAVE. IF SHE ACCEPTS THAT HER ARTICLES HAVE BEEN PUBLISHED BY BEING ON THE NET, THEN SHE MUST ACCEPT THAT THE LC HAVE ALSO BEEN PUBLISHED. THEY ARE IN THE PUBLIC DOMAIN, ACCESSIBLE TO EVERYONE. THEY HAVE NOT BEEN PUBLISHED IN A PEER-REVIEWED MEDICAL JOURNAL BUT NEITHER WERE OTHERS E.G, SOME OF THE HOME-MADE DEFINITIONS USED BY THE NIJMEGEN TEAM, AND SHARPE ET AL (THE JRSM IS NOT PEER-REVIEWED). GIVEN THE LC WERE FORMULATED FOR IN-HOUSE USE AS OPPOSED TO GENERAL USE, THERE WAS NO NEED FOR THEM TO BE PUBLISHED IN A JOURNAL AT THAT TIME. THEY COULD NOT HAVE BEEN PUBLISHED EVEN IF WE HAD WANTED TO, GIVEN THE BLANKET BAN ON ANYTHING POSITIVE REGARDING ME IN BRITISH JOURNALS, THE ONLY JOURNALS WHO MIGHT HAVE BEEN INTERESTED. BUT AS A RESULT OF THE ACCURACY OF THE CRITERIA, WE FOUND THAT OTHERS ALSO REQUESTED TO USE THEM. THEY WORKED. AND AS WE KNOW FROM THEIR USE, THE OXFORD AND CDC 1994 HAVE PROBLEMS. THEY LACK SPECIFICITY. WE DON'T HAVE THE EXACT FIGURES,, BUT WE KNOW AND IT IS GENERALLY ACCEPTED, THAT THEY SELECT A MIXED POPULATION. NOT JUST RAMSAY-DEFINED ME.**

They were mentioned in the National Task Force Report as being one of nine different "PROPOSED" definitions and descriptions (see page 88, Appendix B, REPORT from THE NATIONAL TASK FORCE ON CFS/PVFS/ME: 13th September 1994: Westcare,

Bristol --- note that Westcare no longer exists and is part of Action for ME).

**SADLY, THE INFORMATION WAS NOT CHECKED WITH ANYONE WHO KNEW THE FACTS AND WAS WRONG. WE CANNOT BE RESPONSIBLE FOR WHAT THIRD PARTIES CHOOSE TO WRITE IN THEIR PUBLICATIONS. IF MS. WILLIAMS WISHES TO WRITE SOMETHING WITHOUT CHECKING AND GETS IT WRONG, ALL I CAN DO IS CORRECT THE ERRORS AFTER THE EVENT. AS I HAVE CONSISTENTLY DONE. IF PEOPLE CHOOSE NOT TO BELIEVE THIS, AND PREFER TO REPEAT INACCURACIES, THAT IS UP TO THEM. HOWEVER, I THINK THIS IS MISLEADING.**

Merely being mentioned in a Report or published document is entirely different from and does not equate with the criteria having been published and used in research.

**THIS IS TRUE, BUT THEY WERE USED IN RESEARCH. MS. WILLIAMS HAS PREVIOUSLY QUOTED FROM THE WHITING REVIEW, SO SHE HAS A COPY. IN THAT REVIEW, IT LISTS THE CRITERIA AS HAVING BEEN USED IN STUDIES AND GIVES THE REFERENCE OF ONE. WILLIAMS THEREFORE KNEW THAT THE CRITERIA HAD BEEN USED IN RESEARCH AT THAT TIME. AS NOTED BELOW, MS WILLIAMS ACCEPTS THEY WERE USED BY PERRIN IN HIS PUBLISHED STUDY, AND THE ONLY ARGUMENT SHE OFFERS IS THAT HE USED THEM THINKING THAT THEY HAD BEEN PUBLISHED. BUT SHE ACCEPTS HE USED THEM. I WILL DEAL WITH HIS ALLEGED MISCONCEPTIONS BELOW.**

FACT: Before criteria can be USED to select patients for a study, they need to be PUBLISHED in an accessible form in a medical journal (the 1988 Holmes et al criteria were published in Annals of Internal Medicine:1988:108:387-389; the 1991 Oxford criteria were published in the Journal of the Royal Society of Medicine:1991:84:118-121 and the 1994 CDC criteria were published in Annals of Internal Medicine: 1994:121:953-959. The "London" criteria have never been so published or submitted for peer review.

**THIS IS NOT CORRECT. ANYONE CAN USE CRITERIA IN RESEARCH E.G. HO-YEN HAS TENDED TO USE HIS OWN WITHOUT SUBMITTING THEM FOR PEER-REVIEW, BEHAN USED HIS OWN CRITERIA FOR PVFS FOR A TIME, AND I WAS INFORMED BY TWO SCIENTISTS FROM MERGE THAT THEY USE THEIR OWN, UNPUBLISHED CRITERIA FOR ME IN ADDITION TO THE CDC 1994 CRITERIA. CONVERSELY, MANY USE THE PUBLISHED OXFORD AND CDC 1994 CRITERIA, WITH ALL THEIR FLAWS. WHAT MATTERS IS WHETHER CRITERIA WORK WELL IN PRACTICE. THAT IS WHY PEOPLE THINK OF THE LC. IF IN 1994 YOU WANTED TO STUDY ME USING RESEARCH CRITERIA, THEY WERE THE ONLY ONES AROUND, COMPILED BY SCIENTISTS WITH A DEGREE OF EXPERTISE IN THE SUBJECT. AND THEY DID THE JOB.**

**THEY EXIST BECAUSE A CHARITY DID NOT WISH TO SPEND THEIR MEMBERS' MONEY ON RESEARCH INTO CFS\NEURASTHENIA. THEY WANTED THAT MONEY TO GO TO PURE ME.**

**FACT: The London criteria have not been consistently defined -- there are different VERSIONS of them and a definitive version has not been identified.**

**THERE ARE TWO VERSIONS AND I PREFER VERSION 1. PROF. WHITE HAS BOTH. HE CAN CHOOSE. THE LC WERE USED IN STUDIES FUNDED BY ME ACTION, AND THE RESEARCHERS RECEIVED GUIDANCE FROM ONE OF THE PHYSICIANS. USUALLY, THE MEDICAL ADVISOR. THEY WERE ALSO OFFERED A SCREENING QUESTIONNAIRE WHICH ALLOWED THEM TO DEFINE THEIR SAMPLES EVEN MORE ACCURATELY. IT WAS COMPILED BY DR. MACINTYRE. THERE WAS CLEARLY NO CONFUSION IN PRACTICE AS THE CRITERIA WORKED WELL. WE HAD NO REPORTS OF PROBLEMS AND RESEARCHERS WHO WERE ABLE TO COMPARE THEM WITH THOSE USED BY RAMSAY AND OTHERS WERE GENERALLY IMPRESSED. THE SENSITIVITY AND SPECIFICITY WAS HIGH THOUGH DETAILS WERE NOT PUBLISHED. THIS SHOULD BE COMPARED TO THE MANY PROBLEMS REPORTED**

**WITH SOME OF THE MOST OFTEN USWED PUBLISHED RESEARCH  
CRITERIA.**

FACT: The authors of the London criteria are unknown (various differing claims have been made by Ellen Goudsmit about the authorship.)

**THE CRITERIA WERE FOR IN-HOUSE USE WHEN THEY WERE COMPILED  
AND SO THE NAMES  
OF THE AUTHORS WERE NOT IMPORTANT. THE NAMES WERE REQUIRED  
BY WHITING ET  
AL. I GAVE THE NAMES OF THE PEOPLE WHOM I RECALLED HAD BEEN  
INVOLVED AND I  
CONTACTED OTHERS TO CHECK THAT I WAS CORRECT. I HAVE NO  
EVIDENCE FROM ANY  
RELIABLE SOURCE THAT I WAS WRONG.**

FACT: The London criteria have never been officially accepted into common usage, nor have they ever been validated or operationalised (as conceded by Ellen Goudsmit herself on 4th September 2004 where she states "The LC have not been validated").

**AS NOTED, THE CRITERIA WERE AS OPERATIONALSIED AS OTHERS AT  
THE TIME, NONE  
OF THE CRITERIA IN USE HAVE BEEN VALIDATED, AND GIVEN THE  
PURPOSE OF THE  
CRITERIA, THEY WERE NOT AIMED AT GENERAL USAGE. WE LEARNT AS  
WE WENT ALONG,  
THAT THEY DID WHAT THEY WERE SUPPOSED TO. THE CANADIANS HAVE  
NOT DONE THE  
REQUIRED TESTING EITHER, SO ONE CAN'T CLAIM THEY HAVE BEEN  
VALIDATED.**

Ellen Goudsmit makes specific claims about the London criteria:

(i) she claims that the London criteria (LC) have been USED to select patients and she provides various references that purport to support her claim and

(ii) she claims to have been a co-author of the LC but she also claims to have had nothing to do with the authorship of the LC.

These issues are addressed below.

(i) Consideration of the papers that Ellen Goudsmit claims used the "London" criteria in published research:

In an email dated 7th June 2004, Ellen Goudsmit PhD wrote to someone 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".

(Criteria cannot be "operationalised" before they have been defined or published or if the authors have not been ascertained).

**THIS IS INACCURATE. CRITERIA ARE DEFINITIONS, AND THE AUTHORS ARE COMPLETELY IRRELEVANT FOR OPERATIONALISATION. ONE CAN TAKE THE CDC 1994 CRITERIA AND OPERATIONALISE THEM DIFFERENTLY PER STUDY. THE CBT SCHOOL HAVE BEEN DOING THIS FOR YEARS. SOME USE HIGHER SCORES ON MEASURES, OTHER LOWER. THE RESEARCHERS HAVE OPERATIONALISED THE OXFORD CRITERIA FOR PACE. THIS IS THEIR PERSONAL CHOICE. YOU CAN TAKE ANY CRITERIA AND OPERATIONALISE AS YOU WISH. INDEED, YOU CAN REDEFINE ANY CRITERIA, AS LONG AS YOU NOTE WHAT YOU HAVE DONE. NIJMEGEN ARE ADAPT AT THAT AND GET THEIR ARTICLES IN PEER-REVIWED JOURNALS. AS LONG AS ANOTHER CAN REPEAT YOUR STUDY. THERE ARE STUDIES PROMOTED BY MS WILLIAMS WHICH MAKE NO MENTION OF ANY ATTEMPTS TO OPERATIONALISE AND DO NOT HAVE THE INFORMATION TO REPLICATE IN THE PUBLICATION. WE DON'T EVEN KNOW THE AUTHORS. WE CANNOT CHECK. IF OPERATIONALISATION AND VALIDATION ARE IMPORTANT TO HER, AND SHE DOES NOT VALUE STUDIES WHICH USE UNPUBLISHED CRITERIA, THEN SHE HAS TO GO THROUGH HER REFERENCES IN HER ARTICLES AND DO SOME EDITING.**

**I THINK WE SHOULD UNDERSTAND THE COMPLEXITY OF THE ME WORLD AND ACCEPT THAT WE CANNOT ALWAYS WRITE EXACTLY WHAT WE WISH. THE ABOVE DOES NOT IMPLY ANY CRITICISMS OF ANY RESEARCHER. JUST CRITICISM OF COMMENTATORS.**

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.

This is not the case, as can be seen from the papers that Ellen Goudsmit claims USED the "London" criteria (ie. for selection of patients to be studied):

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.

**THE LONDON CRITERIA WERE DEVELOPED FOR ME ACTION, AND COSTA REFERS TO THE CRITERIA AS THOSE FROM ME ACTION. IF WILLIAMS BELIEVES HE USED DIFFERENT CRITERIA, CAN SHE PROVIDE A REFERENCE? A COPY? I HAVE DETAILS OF**

**THE FORM  
HE SIGNED. CAN SHE PROVE HE DID NOT USE WHAT HE AGREED TO USE?**

**IF ONE COMPARES THE LC TO THOSE FROM WEIR, ONE SEES SOME  
NOTABLE  
DIFFERENCES. NO ONE COMPARING THEM WILL BE CONFUSED.**

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. 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, thus it cannot be claimed that the "London" criteria were used for patient selection.

**LORNA PAUL RECEIVED A =A310,000 GRANT FROM ME ACTION AND THE  
CONTRACT  
REQUIRED HER TO USE THE LC. IF SHE DID NOT, SHE BREACHED HER  
CONTRACT AND  
AFME CAN ASK FOR THE RETURN OF THE GRANT. THE CONTRACT DOES  
NOT REQUIRE THE  
CRITERIA TO BE NAMED. SEE ALSO ABOVE. I AM CONFIDENT THAT THIS  
STUDY DID  
NOT INVOLVE PEOPLE WITH CFS\NEURASTHENIA A LA CDC 1994 CRITERIA  
BUT THAT IT  
SELECTED PEOPLE WITH ME.**

Lorna Paul et al 2001  
.....

The effect of exercise on gait and balance in patients with chronic fatigue syndrome. Lorna M Paul et al. Gait and Posture 2001:14: 19-27

Eleven subjects with CFS and eleven control subjects participated in this study. All patients fulfilled the CDC 1994 criteria for CFS. There is no reference to the "London" criteria anywhere in the paper.

**I NEVER CLAIMED THAT THE LC WERE USED IN THIS STUDY. THIS DOES  
NOT  
UNDERMINE MY ARGUMENT.**



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 claims that her own work was based on the "London" criteria and was used in this Systematic Review.

**I NEVER CLAIMED MY OWN WORK FOR MY PHD WAS BASED ON THE LC AND NOTE THE LACK OF A REFERENCE HERE. THE LC ARE REFERRED TO IN THE REVIEW, FULL TEXT AVAILABLE ON CO-CURE. THE REVIEW INCLUDED MY STUDY. I WAS VERY FLATTERED. IT WAS ONLY A PILOT. I DON'T THINK ANY OTHER PILOT STUDIES WERE INCLUDED. I ENDED UP IN A LIST OF THE BEST CONTROLLED TRIALS, AND OBVIOUSLY IT DID NOT MEASURE UP TO THOSE WHICH USED LARGER SAMPLES AND INTENTION-TO-TREAT ANALYSIS WHICH IS SO EN VOGUE. BUT IT WAS STILL IN THERE! AS WAS PERRIN. I DID RESEARCH ON ME, AS DID HE.**

It is submitted that such a claim is misleading because once again, there is no mention of the "London" criteria, but the York Review does reference Ellen Goudsmit's 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.

**MS WILLIAMS IS AGAIN, KNOWINGLY MISLEADING READERS. THE REVIEW DID NOT ASSESS DISSERTATIONS IN FULL. ONLY CONTROLLED TRIALS. AS MS WILLIAMS KNOWS, MY PHD WAS BASED ON MORE THAN ONE STUDY. THE REVIEW DID NOT ASSESS THE TWO OTHERS AS THEY WERE NOT FOCUSED ON MANAGEMENT. AND THIS REVIEW WAS ABOUT MANAGEMENT. I AM PLEASED THAT MS WILLIAMS HAS NOT REPEATED THE ERROR THAT IT RECEIVED THE LOWEST SCORE, AS IT DID NOT.**

On 4th February 2005 Miss Goudsmit publicly posted the following in relation to her thesis: "(The York Review team) only assessed a pilot study which was included in my thesis. The title of my thesis is different". Unless Miss Goudsmit provided misinformation to JAMA which published the York Review

(JAMA 2001;286:11:1360-1368), the reference by Whiting et al of the York Review team to Miss Goudsmit's work was indeed to her thesis. It is submitted that the correct reference and title for something that is within a thesis is the actual title of the thesis (and not the sub-context within the thesis, otherwise how could it be sourced?).

**THE TITLE OF MY THESIS IS AVAILABLE ONLINE AND IN MY LETTER TO JAMA WHICH MS. WILLIAMS WILL HAVE SEEN AS SHE CITED FROM IT ELSEWHERE. THE AUTHORS OF THE REIVEW MISSED OUT A FULL STOP AFTER A FOLLOW-UP STUDY. I DID NOT MISLEAD JAMA. THEY DID NOT REQUIRE ME OR ANY OTHER AUTHOR OF WORK CITED, TO PROOF-READ. I HAD NO CONTACT WITH JAMA ABOUT THIS STUDY BEFORE PUBLICATION, AND DID NOT KNOW IT WOULD BE PUBLISHED THERE. WHITING ET AL FORGOT A FULL STOP. THIS WAS THEIR ERROR AND I CORRECTED IT IN MY SUBSEQUENT LETTER.**

**I THINK TO FOCUS ON TYPOS IS NITPICKING, AS THE BEST OF US DON'T ALWAYS GET IT RIGHT. AND ESPEICALLY IF YOU HAVE ME AND DODGY EYES, AS I HAVE. FOR INSTANCE, I NOTE MS WILLIAMS NEXT SENTENCE. DISCREPANCY ABOUT THE ITS TITLE. I'M NOT GOING TO SPECULATE ABOUT DEEPER MEANINGS. IT'S A TYPO.**

**WHITING INCLUDED A TYPO. I INCLUDE TYPOS. MS WILLIAMS KNOWS THE TITLE OF MY THESIS AS SHE REFERRED TO IT CORRECTLY OFTEN ENOUGH. INCLUDING IN THIS PAPER, SEE BELOW.**

On the subject of Miss Goudsmit's thesis, there would seem to be some discrepancy about the its title, given that on the official doctoral register it is listed as being "The Psychological Aspects and Management of Chronic Fatigue Syndrome", whilst in the JAMA review Whiting et al refer to it as "Learning to Cope with Post-Infectious Fatigue Syndrome: a Follow-up Study in the Psychological Aspects and Management of Chronic Fatigue Syndrome", but in her own CV posted on her website, Miss Goudsmit has changed it to "The psychological aspects and treatment of the chronic fatigue syndrome". She also refers to it by this last title in her "Medical Updates" dated 1st September 1996.

**THE INFORMATION IN THE CV SHOULD BE ACCURATE AND REFERS TO  
MANAGEMENT. IT  
WAS SO THE LAST TIME I CHECKED. TO ERR IS HUMAN. I MAKE THE ODD  
MISTAKE AND  
IF I DO, IT'S NOT DELIBERATE AND I CORRECT IT WHEN I'M ALERTED TO  
IT.  
TREATMENT VERSUS MANAGEMENT. THIS IS SURELY NOT A GRAVE  
ERROR?**

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, 12th 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 BPS DOES NOT KEEP A TRACK OF WHO PUBLISHES WHAT. IT DOES  
NOT HAVE SUCH  
A SERVICE. THEY DO NOT ASK MEMBERS WHAT THEY HAVE PUBLISHED.  
THEY DO NOT  
POSSESS SUCH A DATABASE. PROF. SCHOLEY WOULD HAVE TOLD ANYONE  
WHO ENQUIRED  
THAT HE IS HOPING TO SUBMIT THIS STUDY FOR PUBLICATION. BUT THE  
ISSUE I WAS  
ASKED TO ADDRESS WAS NOT, HAS THAT STUDY BEEN PUBLISHED, BUT  
DID IT USE THE  
LC. IT DID!**

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.

**THEY WERE NAMED AS THE CRITERIA USED TO SELECT PATIENTS.  
ABSTRACTS DO NOT  
GO INTO DETAILS. THEY ARE SUPPOSED TO BE SUMMARIES. IF ONE  
WANTS DETAILS  
ONE CAN CONTACT THE RESEARCHERS.**

Scholey et al also presented another abstract at a BPS  
conference in Belfast held on 8th-11th 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 study has not been published.

**I DID NOT CLAIM IT HAD BEEN BUT THIS INDICATES THAT THE CRITERIA WERE USED IN YET ANOTHER STUDY, WHICH IS HELPFUL. I DID NOT KNOW ABOUT THIS STUDY UNTIL MS. WILLIAMS PROVIDED THE REFERENCE.**

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.

**ALL PATIENTS FULFILLED THE LC. ABSTRACTS ARE PUBLISHED MATERIAL. THEY CAN BE CITED. THE LC REQUIRE THAT OTHER DISORDERS HAVE BEEN RULED OUT. BY DOCTORS. IT'S NOT JUST A LIST OF SYMPTOMS.**

In her post of 8th May 2005 on CFS Research, Miss Goudsmit now concedes that the Scholey work has not been published: "Other researchers who used (the 'London' criteria) were McHale et al and McCue, Scholey et al. The former did not mention them in their paper and the other hope (sic) to submit a paper".

In the same post, Miss Goudsmit now states unambiguously: "Paul et al did not mention them (ie. the 'London' criteria) in their paper".

**THIS IS CORRECT. THE PAPER DOES NOT LIST THEM. I HAVE NEVER CLAIMED THEY DID LIST THEM. THERE IS NO PROBLEM. PAUL ET AL DID NOT TELL ME IN 1999 THAT THEY HAD BROKEN THE CONTRACT TO USE THEM AND HENCE I INCLUDED THE REFERENCE, IN GOOD FAITH, WHEN I DID.**

In that same post of 8th May 2005 on CFS Research, Miss Goudsmit states: "Here are the details of three of the published studies which made use of the London criteria. I hope this ends the misinformation once and for all. Here are the references again:

P McCue, CR Martin, T Buchanan, J Rodgers, AB Scholey  
Psychology, Health & Medicine, 2003, 8, 4, 425-439. An

investigation into the psychometric properties of the Hospital Anxiety and Depression Scale in individuals with chronic fatigue syndrome

Available online

<http://www.tandf.co.uk/journals/online/1354-8506.asp>

Go to Browse the volumes, click on 2003, November. See p. 430.

**ALSO SUMMARISED IN MY UPDATES.**

Perrin, RN, Edwards, J and Hartely, P. An evaluation of the effectiveness of osteopathic treatment on symptoms associated with myalgic encephalomyelitis. A preliminary report. Journal of Medical Engineering & Technology, 1998, 22, 1, 1-13. See p.2.

Listed <http://www.tandf.co.uk/journals/archive/tmet-con.asp> but full text not available (so interested parties will have to order from a library).

**THIS WAS LISTED IN THE WHITING REVIEW.**

Costa, DC., Tannock, C and Brostoff, J. Brainstem perfusion is impaired in chronic fatigue syndrome QJM, Vol 88, Issue 11 767-773.

(Miss Goudsmit did not provide the year of publication).

Summary online at

<http://qjmed.oupjournals.org/cgi/content/abstract/88/11/767>

In the first of the three papers above (P McCue, A Scholey et al in Psychology, Health and Medicine, 2003), the paper itself states: "It is notable that some authors suggest that rates of current depression in CFS generally resemble those of patients with multiple sclerosis or cancer (Goudsmit 1996)" and it gives Miss Goudsmit's dissertation as the reference for this statement (Goudsmit E. (1996). Learning to Cope With Post-Infectious Fatigue Syndrome: A Follow-up Study. In: The Psychological Aspects and Management of Chronic Fatigue Syndrome [dissertation]. Uxbridge, England: Brunel University). No mention is made of the "London" criteria in this reference.

**THE PAPER DOES MENTION THE CRITERIA AS HAVING BEEN USED. AS NOTED BELOW.**

**IT'S ON P. 430 UNDER PROCEDURE. I NOTE THE CORRECT CITATION OF MY STUDY AND**

**THE PHD HERE. AS DISCUSSED BEFORE, I DID NOT USE THE LC IN MY THESIS. I**

**USED THEM IN LATER STUDIES THOUGH.**

Under "Procedure", this paper states: "Participants were recruited in a number of different ways. Advertisements were placed in CFS/ME magazines and newsletters and flyers were posted to public libraries across the North East of England. All participants were requested to go to the study's website, [www.cfsresearch.net](http://www.cfsresearch.net). At the site, participants proceeded to the next page on which the survey instrument was presented. This was comprised of the following questionnaires: a symptom questionnaire (derived from the CDC and London criteria for CFS/ME (and other questionnaires about memory, diet and medication). Having completed the questionnaires, respondents clicked on a button labelled 'Finished' and the information they had submitted was added to our data file".

No reference for or information about the "London" criteria is provided by the authors and it must be noted that patients may have been self-diagnosed and were self-referred, so it is unclear by what methods the authors decided that participants fulfilled the unpublished "London" criteria.

**LIKE THE AUSTRALIAN GUIDELINES WHICH INCLUDE A LIST OF SYMPTOMS TAKEN FROM THE CANADIAN CRITERIA, ONE CAN ASK PATIENTS TO FILL IN A QUESTIONNAIRE, LISTING THE CRITERIA AND ADDITIONAL QUESTIONS RELATING TO CRITERIA, E.G. HAS A DOCTOR RULED OUT OTHER DISORDERS? YOU CAN ASK THE SAME QUESTIONS IN PERSON, OR ASK THEM TO FILL IN A QUESTIONNAIRE IN THE WAITING ROOM (AS I DID AT BARTS) OR ONLINE. THEN YOU CAN ASSES WHETHER YOUR PATIENT MEETS THE CRITERIA. MRS. DORIS JONES USED QUESTIONNAIRES TO INVESTIGATE PATIENTS, AND RECEIVED HER MSC FOR THAT. IS THIS RESEARCH NOT OF INTEREST AND OF VALUE? DR MCCUE WAS NOT TRYING TO FIND THE CAUSE OF ME OR TESTING A DRUG. SHE WAS ASSESSING HOW THE HAD SCALE WORKED IN A DEFINED POPULATION. THIS PAPER IS SYMPATHETIC TO PEOPLE WITH ME.**

In the second of the three papers provided by Miss Goudsmit as having used the "London" criteria (Perrin et al, 1998), under "Procedure" the authors state: "All subjects in the patient group were selected from patients in the clinical practice of one of the authors. Each of them had to satisfy the definition for chronic fatigue syndrome of the Centre (sic) for Disease Control and Prevention (CDC). They also had to satisfy The London Criteria

which were formulated by scientific advisers for the ME Association as well as Action for ME (1, 4) and validated by several groups including the National Task Force on CFS (24, 25)".

The references refer to (1) " 'Epidemic Neuromyasthenia' 1955-1978". Ramsay AM: Postgraduate Medical Journal 1978:54:638: 718-721; (4) "Myalgic encephalomyelitis - a persistent viral infection?" Dowsett et al: Postgraduate Medical Journal 1990:66:526-530; (24) Report from The National Task Force on CFS/PVFS/ME; Westcare, Bristol, September 1994 and (25) "Brainstem perfusion is impaired in chronic fatigue syndrome". Costa, DC, Tannock C and Brostoff J: Quarterly Journal of Medicine 1995:88:11:767-773

Whilst it is true that this paper does indeed state that participants had to satisfy the "London" criteria, the facts are as follows. The lead author has confirmed that he was misled at the time of the study into believing and accepting that the "London" criteria had indeed been published, operationalised and validated. He had no reason to doubt the information he sought and was given by the Medical Adviser to Action for ME, who in turn had been assured by Miss Goudsmit that this was the true situation.

**THE PERSON HE WAS IN CONTACT WITH WAS DR. MACINTYRE, WHO HELPED FORMULATE THE CRITERIA, WHO WORKED WITH DR. COSTA AT THE TIME OF HIS STUDY, AND AT NO TIME NEEDED MY ASSURANCE ABOUT ANYTHING RELATING TO THE CRITERIA. SHE NEVER ASKED ME ABOUT OPERATIONALISATION OR VALIDATION, AND SHE KNEW EXACTLY WHAT HAD BEEN PUBLISHED AND WHERE. I THEREFORE QUESTION THAT THE INFORMATION HERE IS ACCURATE.**

He was dismayed to learn that the "London" criteria had never been published and he cannot be held in any way responsible for having been misled.

**HE WOULD NOT HAVE BEEN MISLED BY ANYONE AT ME ACTION. HE WOULD HAVE HAD ACCURATE INFORMATION FROM ANY OF THE WORKING GROUP.**

Referring to the third of the three papers she provides, it is notable that Miss Goudsmit herself here states about the Costa et al paper that

"Costa did not refer to the London criteria but to the 'ME Action' Criteria. I can't be held responsible for the way he described them in his article. I did not see the proofs so could not correct."

**I WAS REPEATING INFORMATION NOTED EARLIER. THIS IS NOT A PROBLEM.**

Ellen Goudsmit's disparate claims about authorship of the LC:

**THE FOLLOWING INDICATES A LACK OF KNOWLEDGE OF SCIENTIFIC PROCEDURES AND RULES RELATING TO AUTHORSHIP OF SCIENTIFIC ARTICLES ON THE PART OF MS. WILLIAMS. ONE HAS TO FULFIL A NUMBER OF CRITERIA TO BE CITED AS AUTHOR. THEY WERE DEVELOPED TO STOP TEAMS INCLUDING THE NAME OF THE HEAD OF DEPARTMENT AND OTHERS, TO UP THEIR INDIVIDUAL TALLY OF PAPERS. YOU NEED TO BE INVOLVED WITH CONCEPT AND DESIGN, DRAFTING AND REVISING, AND FINAL APPROVAL. YOU HAVE TO MAKE A SUBSTANTIAL CONTRIBUTION. WELL, I TOUGHT OF THE CONCEPT, I WAS INVOLVED WITH THE DRAFTING AND I APPROVED THE FINAL VERSION AND TAKE RESPONSIBILITY FOR WHAT I APPROVED, I.E. VERSION 1. I DID NOT ACTUALLY WRITE A WORD OF THE LC BUT I WAS SUFFICIENTLY INVOLVED TO MERIT INCLUSION AS AUTHOR. IF MS WILLIAMS HAD EVER SUBMITTED A PAPER TO A JOURNAL, SHE WOULD HAVE HAD TO SIGN A FORM AND SHE WOULD HAVE LEARNT ABOUT THE RULES. THE MRC WILL KNOW THE RULES. THEY WON'T HAVE ANY PROBLEMS WITH THIS. NO SCIENTIST WILL.**

As mentioned above, the reason why the matter of the London criteria is important is because the Medical Research Council is about to undertake a major study on "CFS/ME" and intends to use the London criteria for secondary analysis, even though those criteria have never been defined, published, peer-reviewed, operationalised or validated and there is continuing debate involving Miss Goudsmit's role in the authorship.

It is submitted that the following illustrations provide unequivocal evidence concerning her misleading and inaccurate claims about her own involvement with the London criteria:



=B7 "Old lie. [In that it has been stated by others that] I had nothing to do with the London criteria. I not only thought of the idea but was involved in writing and disseminating them" (21st October 2001)

**THIS IS ACCURATE.**

=B7 "The London criteria are research criteria, for use in research, e.g. Costa et al, Scholey et al, Paul et al. I know this as I was one of the co-authors" (9th January 2002)

**ACCURATE**

=B7 "Authors in alphabetical order were Dowsett, Goudsmit, Macintyre, Shepherd. Date was 1993 (I think)" (15th January 2002)

**ACCURATE.**

=B7 "Herewith... my own criteria for ME (son of 'London')" (9th February 2002)

**THIS DOES NOT RELATE TO THE LC BUT MY OWN, LATER ATTEMPT.**

=B7 "London criteria were not Ramsay's. He was deceased by the time they were formulated. By moi and others" (19th May 2002)

**ACCURATE.**

=B7 "There are a number of versions of the London criteria... Ellen (One of the co-authors)" (11th June 2004)

**ACCURATE.**

=B7 "Even on David's site (there are) just my own criteria...I accepted the text from others" (12th June 2004)

**THIS IS ACCURATE. THE FIRST PART RELATES TO MY OWN CRITERIA, THE SECOND TO THE LC. THOSE ARE IMPORTANT.**

=B7 "The London criteria are used to diagnose ME. As I noted before, I did not write any of the text of the LC" (12th June 2004)

**THIS IS ACCURATE.**

=B7 "Most of the text of the London criteria was Betty Dowsett's. I did not write a single word" (4th September 2004)

=B7 "They were initially used by Costa et al. I wasn't involved with later versions" (10th September 2004)

**THIS IS ACCURATE. I DID NOT SEE VERSION 2 AND DO NOT KNOW WHO WROTE THEM. I DO NOT FEEL THEY ARE ACCURATE ENOUGH AND DO NOT RECOMMEND THEM. PROF. WHITE IS AWARE OF THIS. AND IF HE USES VERSION 2, I WILL NOT DEFEND HIM.**

The above quotations from Miss Goudsmit should be compared with what is on her website:

"THE DIAGNOSIS OF ME. The following are my criteria, which I based on the work of pioneers such as Gilliam, Ramsay, Parish, Acheson and Dowsett"  
<http://freespace.virgin.net/david.axford/me-defin.htm>  
- 3k - 1999-08-15

**THESE ARE NOT RELATED TO THE LC AND THEREFORE NOT RELEVANT TO THE CURRENT DISCUSSION. I EMPHASIZE THE USE OF THE WORD '=91MY' IN THE SENTENCE. THERE IS NOTHING WRONG WITH TRYING TO IMPROVE ON EARLIER CRITERIA. ASK THE CDC.**

On 14th September 2004 Miss Goudsmit wrote the following to a university lecturer about the alleged use of the London criteria:

=B7 "Given your status as a University lecturer, I felt it appropriate to offer you good evidence to show that Costa DID use the London criteria. I have his description of the study (and) the contract. It explains why he described them as something else".

**THIS IS ACCURATE. THE EMAIL WAS TO MS. KENNEDY OFFERING THE EVIDENCE THAT SHE ASKED FOR. AS SHE HAS NOTED ON HER WEBSITE, SHE REFUSED THE INFORMATION. HER ADDRESS WAS IN THE PUBLIC DOMAIN SO I COULD HAVE SENT THEM ANYWAY BUT GIVEN THE RESISTENCE, I DID NOT. I THANK MS WILLIAMS FOR CONFIRMING THAT I MADE THIS OFFER AT AN EARLY STAGE OF THE**

**DISCUSSION.**  
**THIS COUNTERS THE SUGGESTION THAT I TRIED TO HIDE**  
**INFORMATION DID NOT HAVE**  
**IT. I'VE COVERED THE DESCRIPTION OF THE CRITERIA ABOVE.**

(The Costa et al 1995 reference that Miss Goudsmit claims used the London criteria makes no mention of them).

On 3rd February 2005 Miss Goudsmit posted the following:

=B7 "I have NEVER made false claims about the London criteria. The BPS does not have information such as whether an (sic) study presented at a conference has been published. It means the person who passed this on was lying. They lied about the information obtained from Prof. Scholey, about what I claimed. I've got a problem and it relates to the rules of my professional organisation".

(Professor Scholey himself has confirmed that, contrary to Miss Goudsmit's claims, his material under discussion has not been published and a search of Medline confirms this).

**AS NOTED BY PROF. SCHOLEY, AND I HAVE AN EMAIL IF PEOPLE WISH TO READ IT, HE HOPES TO SUBMIT THIS STUDY. I DID NOT CLAIM IT HAD BEEN PUBLISHED IN A JOURNAL SO THERE IS NO PROBLEM. I GAVE THE REFERENCE AS A STUDY WHICH HAD USED THE CRITERIA, THAT IS ALL. THE STUDY MAY NEVER BE ON MEDLINE AS MEDLINE ONLY LISTS A LIMITED NUMBER OF PSYCHOLOGY JOURNALS AND THIS IS LIKELY TO BE SUBMITTED TO A PSYCHOLOGY JOURNAL, GIVEN THE SUBJECT. IN THAT CONTEXT, I DO NOT THINK MCCUE'S PAPER IS ON MEDLINE EITHER.**

Another example of Miss Goudsmit's inconsistency in relation to the London criteria is to be found in her letter to the Chief Medical Officer:

=B7 "e.g. wrong reference to the London criteria, cited as 1990 but I didn't think of them until 1993 let alone compile them with colleagues (in 1990)".

**THIS IS NOT AN INCONSISTENCY AS THE PUBLICATION IN QUESTION HAD AN**

**INCORRECT REFERENCE TO SOMETHING PUBLISHED IN 1990 AND I  
CORRECTED IT WHEN  
IT CAME UP. I CANNOT BE HELD RESPONSIBLE FOR THE ACCURACY OF  
INFORMATION I  
WROTE TO ONE PARTY, WHICH WAS COPIED TO A SECOND AND THEN  
COPIED AGAIN TO A  
THIRD.**

*It is submitted that it is only too obvious that Miss Goudsmit has made numerous disparate claims about her involvement with the formulation of the London criteria.*

**THIS IS NOT THE CASE, AS I HOPE THE ABOVE SHOWS.**

*In conclusion, it is submitted that currently, the "London" criteria have no justifiable or validated legitimacy that would in any way provide acceptable criteria for use by the MRC or by any other research bodies for use in identifying patients with ME/ICD-CFS. Not only are they now at least eleven years old, they have been superseded by the more robust and superior Canadian case definition (Myalgic Encephalomyelitis / Chronic Fatigue Syndrome: Working Case Definition, Diagnostic and Treatment Protocols. Bruce M Carruthers et al. JCFS 2003:11: (1): 7-115).*

**THE CANADIAN CRITERIA ARE FOR CLINICAL USE AND NOT FOR  
RESEARCH USE. THEY  
CANNOT SUPERCEDED RESEARCH CRITERIA AS THEY ARE NOT AIMED AT  
THE SAME  
THING. THEY WOULD NEED OPERATIONALISATION AND CLARIFICATION.  
GIVEN PACE HAS  
BEGUN, THERE IS NO TIME FOR THE REQUIRED TWEAKING AND  
PILOTING. IT'S  
COMPLETELY UNREASONABLE TO ARGUE FOR A CHANGE.**

**IF MS. WILLIAMS' LOGIC IS EXTENDED TO MERGE, ALL THEIR RESEARCH  
IS EQUALLY**

**LACKING IN LEGITIMACY, IN REGARD TO ME. PAPERS MENTION THE USE  
OF BROAD  
CRITERIA FOR CFS WHICH SELECT PEOPLE ALMOST INDISTINGUISHABLE  
FROM  
NEURASTHENIA. IT IS BECAUSE WE KNOW THEY USE ADDITIONAL  
CRITERIA,  
UNPUBLISHED, NOT PEER REVIEWED, THAT WE KNOW THEY HAVE  
STUDIED ME. WE TRUST  
THEM AS GOOD SCIENTISTS. DR. DURVAL COSTA WAS A WORLD  
AUTHORITY IN HIS  
FIELD. HE USED THE LONDON CRITERIA. WE THEREFORE KNOW HE DID  
NOT STUDY**

**PEOPLE WITH CFS\NEURASTHENIA AND THAT THERE IS A PROBLEM WITH  
BLOOD FLOW TO  
THE BRAIN STEM IN PEOPLE WITH ME. WHEN THIS WAS REPLICATED IN A  
BROADLY-  
DEFINED SAMPLE, THEY DID NOT FIND THE SAME IMPAIRMENT.**

**I THANK MS WILLIAMS FOR ONCE AGAIN PLACING DETAILS OF STUDIES  
WHICH USED  
THE CRITERIA IN THE PUBLIC DOMAIN. THIS MEANS THAT IT CANNOT BE  
ARGUED THAT  
PEOPLE DID NOT HAVE REFERENCES FOR THEM TO CHECK, E.G PERRIN  
ET AL, MCCUE  
ET AL.**

**MISS WILLIAMS CONTINUES TO CRITICISE ME FOR THINGS I DIDN'T  
WRITE OR SAY OR  
SUGGEST. SHE CLAIMS I WROTE X, THOUGH I DIDN'T, THEN ARGUES THAT  
WHAT SHE  
SAYS I CLAIMED IS INCORRECT. IT MAY SUGGEST TO SOME THAT I AM  
INCONSISTENT  
OR WORSE. I TRUST THAT THE ABOVE SHOWS QUITE CLEARLY THAT I  
HAVE BEEN  
ACCURATE AND THAT ANY MISTAKES WERE NOT PART OF A STRATEGY  
TO DECEIVE OR  
MISLEAD.**

**THE REPETITION OF ERRORS BY MISS WILLIAMS IS OF CONCERN. IN MY  
VIEW, THIS  
DOES NOT CONSTITUTE PERSUASIVE EVIDENCE AGAINST PACE. THE  
DESIGN IS  
SERIOUSLY FLAWED, YET THE ONE POSITIVE, FROM THE PERSPECTIVE OF  
A ME  
PATIENT, IS CRITICISED. I URGE PATIENTS TO INTERPRET THE WRITINGS  
OF MISS  
WILLIAMS IN RELATION TO MY WORK WITH GREAT CAUTION.**

**Ellen Goudsmit PhD. C.Psychol.**

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**PS. The BPS have evaluated previous claims made by Miss Williams relating
to my work on the LC. I will inform people of the outcome when it becomes
available.**