

Notes re the evidence of Raymond Perrin PhD to the Gibson Parliamentary Inquiry into ME

Eileen Marshall Margaret Williams 1st July 2006

1. It is common knowledge that the reason Raymond Perrin (an osteopath who has recently obtained his PhD) is involved with the Gibson Parliamentary Inquiry into ME/CFS is that he has “treated” someone known to Lord Turnberg, a member of the Inquiry Committee.
2. Lord Turnberg is known as a staunch supporter of CBT / GET (see Hansard, as well as correspondence signed by him in robust support of the much-criticised 1996 Joint Royal College’s Report on CFS when he was President of the Royal College of Physicians). He is known as a close ally and champion of psychiatrist Simon Wessely. At the third Oral Evidence Session that took place on 7th June 2006, when Dr Jonathan Kerr started his presentation on gene research, Lord Turnberg said openly: “Oh, NO”. Whilst psychiatrist Peter White was permitted to over-run his allocated time, Jonathan Kerr was not permitted to complete his presentation. It was Lord Turnberg who called for Jonathan Kerr to “co-operate” with Trudie Chalder in order to show that CBT can turn genes on and off and that abnormal genes can be normalised by CBT.
3. Although Perrin spoke at the first Oral Evidence Session held on 18th April 2006 (people who attended that session commented that he basically just sold his own wares and that he claimed graded exercise therapy (GET) was helpful when “recovery” had begun), he is scheduled to give a further presentation at the fourth Oral Evidence Session to be held on 10th July 2006.
4. That someone with such limited medical and scientific experience of ME/CFS as Perrin has been afforded two opportunities to state his views when senior NHS clinicians with a professional lifetime’s experience of ME/CFS have been denied the opportunity to present oral evidence to the Committee has caused deep disquiet within the UK ME community. Clinicians who have been excluded from giving evidence include Dr William Weir (an NHS consultant physician who has extensive clinical and research experience of ME and 20 years’ experience of medico-legal work in assisting ME/CFS patients obtain rightful benefits) and Dr Nigel Speight (an NHS consultant paediatrician who specialises in ME/CFS). At the start of the Inquiry, Dr Weir received a letter from Dr Ian Gibson MP asking if he would assist and Dr Weir agreed, supplying his CV; Dr Weir also spoke to the Administrator (then Ian Woodcroft) and expressed his keen desire to submit oral evidence, but has not been called.
5. Perrin’s credentials to be afforded two opportunities to give evidence to the Gibson Parliamentary Inquiry have been the subject of scrutiny, as has his single

published paper on ME/CFS, because his selection criteria for participants in his one published study --- and therefore his alleged results --- give cause for concern.

6. In 1998, before he got his PhD, Perrin published a paper on his experiences of osteopathy in ME/CFS: the reference is **“An evaluation of osteopathic treatment on symptoms associated with myalgic encephalomyelitis. A preliminary report”**. Perrin RN, Edwards J and Hartley P. **Journal of Medical Engineering & Technology, 1998:22:1:1-13.**
7. In this paper, under “Procedure”, Perrin stated: “All the subjects in the patient group were selected from patients in the clinical practice of one of the authors (*ie. Perrin’s own osteopathy practice*). 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 and validated by several groups including the National Task Force on CFS”.
8. The National Task Force on CFS (1994) did not validate the “London Criteria”: it merely listed them as one of nine proposed case definitions. Since the CDC criteria do not exclude those with psychiatric disorder, it was important that people should not be misled by Perrin’s study, as the “London Criteria” have never been officially accepted into common usage, nor have they ever been validated or operationalised, nor have they ever been published (apart from on the internet) or even submitted for peer review; moreover, there are different versions of them, and the authors have never been established.
9. On 7th September 2004, personal contact was therefore made with Raymond Perrin, who confirmed that he believed the “London Criteria” had been published and validated. When informed that this was not the case, he expressed surprise to learn that they had never been published, and said he was grateful for the clarification, as he was then working on his PhD thesis in which his 1998 study featured: he said that in the light of the information he had just been given, he would have to amend his thesis.
10. Perrin confirmed that he had simply relied upon assurances from Action for ME (AfME) that the London Criteria *had* been published. He confirmed that it was through Dr Anne Macintyre (one-time medical adviser to AfME) that he held this belief, and that Dr Macintyre had herself been provided by Miss Ellen Goudsmit PhD with references that Miss Goudsmit claimed were evidence that the London Criteria had been used in published studies.
11. Miss Goudsmit publicly circulated information in which she said: “The London Criteria have been used in various studies, some of which have been published. The London Criteria were devised for MEAction, now AfME, for use in all studies funded by them”. Circuitously, the studies upon which Miss Goudsmit stated she relied for this statement included the paper by Raymond Perrin et al.

12. Another of the studies which Miss Goudmsit claimed had used the “London Criteria” was a 1995 paper by Costa et al: **“Brainstem perfusion is impaired in chronic fatigue syndrome”**: DC Costa, C Tannock and J Brostoff, **Quarterly Journal of Medicine**: 1995;88:767-773. It makes no mention of the “London Criteria”. It states about the population studied: “All ME/CFS patients were clinically assessed and diagnosed according to standard criteria (Oxford), CDC and ME Action”. The reference for ME Action (the previous name of AfME) was 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, pp 248-9”.
13. The Jenkins & Mowbray textbook sets out Dr Weir’s own modification of the Holmes et al 1988 criteria and is virtually identical to what Miss Goudsmit claimed were her own criteria, to which she referred as the “London Criteria”. Despite claiming involvement in the authorship of the “London Criteria” on numerous occasions, she later denied her involvement in their formulation.
14. Other references that Miss Goudsmit claimed had used the “London Criteria” included **“Demonstration of delayed recovery form fatiguing exercise in chronic fatigue syndrome”**: Lorna Paul et al, **European Journal of Neurology**: 1999;6:63-69), which made no reference to the “London Criteria”. When this issue was raised, Miss Goudsmit publicly stated: “Paul et al did not tell me in 1999 that they had broken the contract to use them”.
15. A further example that Miss Goudsmit claimed had used the “London Criteria” were poster presentations to the British Psychological Society on 12th January 1999 and in April 1999 by Andrew Scholey et al. The first looked at 20 patients and the second looked at 16 patients, both cohorts being described as satisfying the London Criteria. The patients were self-reported, and neither study has been published. When questioned about this, Miss Goudsmit subsequently asserted: “Professor Scholey would have told anyone who enquired that he is hoping to submit this study for publication”.
16. On the issue of the “London Criteria” never having been published, Miss Goudsmit stated: “They have been published on the internet. Given that the London Criteria were formulated for in-house use (by ME Action) as opposed to general use, there was no need for them to be published in a journal”.
17. Merely being mentioned in a document, or on the internet, is entirely different from – and does not equate with – the criteria having been published and used for patient selection in legitimate scientific research.
18. Before criteria can be used to select patients for a study, they need to be defined and published in an accessible form in a medical journal. None of the various versions of the “London Criteria” has ever been published in a peer-reviewed journal.

19. Notwithstanding the above, in 2004 AfME announced that the MRC-funded PACE trials on CFS will use the “London Criteria” in addition to the Oxford criteria, and this was supported by Dr Charles Shepherd of the ME Association. Given that, by case definition, the Oxford criteria specifically exclude those with a neurological disorder (and the WHO classifies authentic ME as a neurological disorder), it must be asked what exactly is the case definition upon which the MRC trials are based, and if the necessary rigorous scientific standards are being applied in the case of ME/CFS?
20. In relation to the Gibson Inquiry, as the “London Criteria” have never been defined or published, it is unclear by what methods Perrin decided that his study participants fulfilled the unpublished “London Criteria” and therefore it is unclear of what assistance to the Inquiry Perrin’s evidence can be.
21. Given that the above information has been in the public domain for some time, it surely needs to be questioned why the Gibson Inquiry is hearing evidence twice from Raymond Perrin.
22. As Dr Ian Gibson, Chairman of the Inquiry, is on record as being determined to hear evidence from all sides and as promising that there would be total transparency, there would seem to be a pressing need to question to what extent Perrin’s evidence will advance the understanding of authentic ME to the exclusion of evidence from experienced consultants such as Drs Weir and Speight.