Margaret Williams writes:

<u>More misinformation on ME/CFS?</u>

In his official letter of 11th February 2004 to the Countess of Mar, the Health Minister Lord Warner confirmed that the UK Department of Health now accepts the WHO ICD classification of ME/CFS as a neurological disorder and that ME/CFS does not have dual classification as both a neurological and a psychiatric disorder; specifically he confirmed that the Department of Health accepts that Chronic Fatigue Syndrome equates with ME.

In the recently released second edition of the WHO "Guide to Mental Health in Primary Care" produced by the UK WHO Collaborating Centre based at the Institute of Psychiatry (now re-titled "Guide to Mental and Neurological Health in Primary Care", toward the cost of which the Department of Health has contributed £60,000) it states: "The terms 'Post-viral fatigue syndrome' and '(benign) myalgic encephalomyelitis' (classified under G93.3 'neurological disorders') have been used where there is excessive fatigue following a specific trigger such as a viral disease. **'Fatigue syndrome', both chronic and not, has been classified under 'neurasthenia', F48.0. In practice, there is extensive overlap in symptoms (up to 96%)".**

Not only is there an obvious discrepancy about the classification of " 'Fatigue syndrome', both chronic and not" between what the Health Minister stated in his official letter and what is stated in the "Guide" that his Department has funded, but there is also another serious issue of seemingly deliberate misinformation.

The Institute of Psychiatry was asked for the reference that supported its published claim in the "Guide" that there is up to 96% overlap between ME and neurasthenia. Only one reference was provided, namely "Neurasthenia Revisited. ICD-10 and DSM-III-R Psychiatric Syndromes in Chronic Fatigue Patients and Comparison Subjects". Farmer A., Jones I., Hillier J., Llewellyn M., Borysewicz L. and Smith A. *British Journal of Psychiatry 1995:167:503-506*.

It is noted that the term used in the title is not CFS but "chronic fatigue patients" yet in the text, "chronic fatigue" is referred to as "chronic fatigue syndrome".

The cited paper in fact states "Table 1 shows that 97% *(sic)* CFS subjects and 2% controls fulfilled criteria for neurasthenia (F48) if exclusion criteria were ignored. When the exclusion criteria were applied 40% of CFS subjects (Fukuda et al 1994 consensus-defined CFS) fulfilled criteria for F48 ".

Why would these authors even consider not using the requisite exclusion criteria? Exclusion criteria are very important. If exclusion criteria are ignored, many symptoms and disorders overlap with each other and without using exclusion criteria, the research and conclusions are meaningless.

Were the authors really unaware that those diagnosed with ME/CFS must be excluded from a diagnosis of neurasthenia?

The unequivocal statement in the 2nd edition of the UK "Guide" that there is up to 96% overlap of symptoms between " 'fatigue syndrome', both chronic and not " and neurasthenia is patently untrue. What the cited reference actually says is that 97% of the 1994 CDC-defined "CFS" subjects fulfil criteria for neurasthenia ***only if the exclusion criteria are ignored.*** By contrast, if specific exclusion criteria are used, then only 40% of CFS subjects fulfil the criteria for neurasthenia.

We have been told by Professor Rachel Jenkins at the IOP that the entry in the "Guide" was approved by Professor Tony Pinching (medical adviser to the charity Action for ME) and by Chris Clark (chief executive of Action for ME). Whilst such "research" as Anne Farmer's supports the stance of Wessely School psychiatrists (and Leszek Borysiewicz *(sic)*, together with Simon Wessely, Peter White and Mike Sharpe, was a signatory to the 1991 Oxford "CFS" criteria published in the JRSM: 1991:84:118-121), on what grounds does it qualify as "evidence-based medicine" such as that which Pinching and Chris Clark are content to support in their purported care of ME patients?

What is the justification for including such perverse misrepresentation and manipulation of the facts (taken from a single paper that is now 9 years old) in a new edition of a Guide funded by a UK Government Department, when such a claim seems to be misleading, untrue and therefore unethical?

This is another issue that the Countess of Mar will be raising in a series of forthcoming meetings.

For the avoidance of doubt, she has three important meetings arranged: one with Professor Colin Blakemore (who last September replaced Professor Sir George Radda as Chief Executive of the MRC) and one with David Hinchliffe (Chairman of the House of Commons Select Health Committee), both these meetings being in March 2004, and also a meeting jointly with the Chief Medical Officer (Professor Sir Liam Donaldson) and the Health Minister Lord Warner, which is scheduled for April 2004.

6th March 2004