Note on the term "Myalgic Encephalomyelitis"

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Despite the relentless financial, psychosocial and political engineering that seems to underpin the current determination to remove the term "myalgic encephalomyelitis" (ME) from the medical lexicon (where, based on accurate published evidence of the nature of the disorder, it has resided for the last half century), the present proponents of its demise have failed to produce any evidence-base to support their clamour for its removal and its replacement by the less specific term "myalgic encephalopathy".

Such intentional dilution of terminology is puzzling, since it is clearly not the case (as they proclaim in support of their favoured term) that there is no published evidence of inflammation of the central nervous system (CNS) in ME / ICD-CFS --- see for example "Prevalence in the Cerebrospinal Fluid of the Following Infectious Agents in a Cohort of 12 CFS Subjects: Human Herpres Virus-6 and 8, Chlamydia Species, Myco[plasma Species, EBV, CMV and Coxsackievirus" Susan Levine MD. JCFS 2001:9 (1-2):41-51 The abstract states:

"Over the last decade a wide variety of infectious agents has been associated with the chronic fatigue syndrome (CFS) as potential etiologies for this disorder by researchers from all over the world. Many of these agents are neurotrophic and have been linked previously to other diseases involving the central nervous system (CNS). Because patients with CFS manifest a wide range of symptoms involving the CNS as shown by abnormalities on brain MRIs, SPECT scans of the brain and results of tilt-table testing, we sought to determine the prevalence of HHV-6, HHV-8, EBV, CMV, Mycoplasma species, Chlamydia species and Coxsackie virus in the spinal fluid of a group of patients with CFS. We found **evidence** of HHV-8, Chlamydia species, CMV and Coxsackie virus. Attempts were made to correlate the clinical presentations of each of these patients, especially the neurological examinations and the results of objective testing of the CNS, with the particular infectious agent isolated. It was also surprising to obtain such a relatively high yield of infectious agents **on cell free specimens of spinal fluid that had not been centrifuged**".

The use of the important word "evidence" is to be noted.

Given the existence of this evidence, the current attempts to detract from the validity of the WHO international classification of ME (where it has been classified as a neurological disorder since 1969) are scientifically mystifying.

Of relevance to the present furore about the use and meaning of the term "encephalomyelitis", in his article "Neurological complications of vaccinations" (Mealey's Litigation Report, Thimerosal and Vaccinations, April 2003: vol 1, no 10) Professor Charles Poser from the Department of Neurology at Harvard Medical School states unambiguously what "encephalomyelitis" means: "Encephalomyelitis refers to an 'allergic' or immune reaction of the nervous system".

Is that not exactly what is happening in ME / ICD-CFS?

Given the accumulating published international evidence of the immunological dysregulation and CNS abnormalities that have been demonstrated in ME / ICD-CFS, it is necessary to ask why the supposed advocates in the UK of those with ME / ICD-CFS should be so vociferous and so persistent in their refusal to accept the significance of such evidence, amounting even to denial of that evidence.

Professor Poser may have found one possible answer: in the same paper he observes:

"In the last few years a new mantra has emerged to the effect that all published results must meet the test of being 'evidence-based', which means that they must be derived from statistically verified data. Thus calculations of probabilities, also known as educated guesses, will take precedence over clinical, pathological, radiological or experimental data. Close examination of some specific situations will reveal the flaws in this concept".

There are other references to CNS inflammation listed in "What is ME? What is CFS? Information for Clinicians and Lawyers" published in 2001 by Eileen Marshall, Margaret Williams and Malcolm Hooper, an extract of which is produced here:

http://www.meactionuk.org.uk/What_Is_ME_What_Is_CFS.htm#Evidence

Evidence of abnormalities in ME

Despite beliefs and assertions to the contrary, in ME there is evidence of inflammation of the central nervous system (CNS); that is what helps to differentiate ME from other forms of CFS. There are many references in the medical literature to inflammation of the CNS in ME and in ICD-CFS **(37),(38),(39),(40),(41),(42)** but such CNS inflammation is not found in all variants of CFS. It is incorrect to deny the existence of CNS inflammation in ME / ICD-CFS. In some cases of ME, as in multiple sclerosis, there is evidence of oligoclonal bands in the cerebrospinal fluid. **(43),(44).** It is accepted by the most experienced ME clinicians that some degree of encephalitis has occurred both in patients with ME and in those with post-polio syndrome: the areas chiefly affected include the upper spinal motor and sensory nerve roots and the spinal nerve networks traversing the adjacent brain stem (which is always damaged). **(45).** In nearly every patient there are signs of disease of the central nervous system. **(46).** Recent research continues to support neurological involvement. **(47),(48),(49),(50),(51),(52),(53)**

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