

“We can rest assured that this serious disability can arise (like polio) from an initially trivial infection which has epidemic and pandemic potential...” (Dr. E.G. Dowsett in “Rose By Any Other Name”. Full article at: <http://www.25megroup.org/Information/Medical/dowsett's/Rose%20by%20any%20other%20Name.htm>)

The U.S. Centers for Disease Control has done its job very well averting and nearly eliminating the epidemic disease Myalgic Encephalomyelitis not through research or discovering modes of transmission and providing education on preventive or curative measures, but through the use of obscurity.

By re-naming the well-defined and recognized disease, M.E., to ‘chronic fatigue syndrome’ and attaching to it so broad a definition that it subsequently included patients with prolonged fatigue of any origin and excluded patients with strictly defined M.E. (a serious neurological disorder with many prominent symptoms besides fatigue, which excludes it from the Fukuda definition), it appears M.E. outbreaks of infectious origin have no longer been isolated since 1990. (After all, how can you isolate outbreaks of fatigue?) I would think researchers would find this interesting, considering there exists documentation of epidemics nearly every year since 1935, and suddenly after 1990 we’ve heard nothing about clusters of M.E. Did a disease with such a well-documented history just suddenly disappear?

See an abridged version of Dr. Gordon Parish's and Dr. Byron Hyde's list of 63 M.E. epidemics at: [http://www.name-us.org/ResearchPages/ResEpidemic.htm#M.E. Epidemics](http://www.name-us.org/ResearchPages/ResEpidemic.htm#M.E._Epidemics). (Summarized from *The Clinical and Scientific Basis of Myalgic Encephalomyelitis / Chronic Fatigue Syndrome*, edited by Byron Hyde, M.D. Chapter 16, entitled, “A Bibliography of M.E./CFS Epidemics,” listing 63 epidemics from 1934 to 1990. <http://www.nightingale.ca/index.php?target=bookoffer>)

Note that the list of outbreaks ends not long after the adoption of “CFS” and its new definition in 1988. If any continuation of this list exists, I have not found it.

Myalgic Encephalomyelitis needs to be recognized in the U.S. as it has been by the World Health Organization since 1969 and most countries worldwide if we are to procure essential funding to study this well-defined, epidemic, disabling, economically disastrous, and eventually fatal disease. Why do some (or most) in the medical community continue to deny that it exists in this country? Are Americans immune to M.E.? Or if they don't deny that it exists, why do they ignore it when patients suffer so severely from it? (What happened to “First do no harm”?)

We desperately need to know what contagion(s) and other factors are at work insidiously within our population, how the disease is spread, and what measures we must take to keep it from spreading. Sadly (or should I say frighteningly for our family and friends), a disproportionately tiny sum of money has gone into searching for the answers to these critical questions. Right now (to the best of my knowledge), M.E. receives \$0 in funding in the U.S., yet it's all too clear that hundreds of thou-

sands of the one million Americans diagnosed and the many more yet-to-be diagnosed with ‘CFS’ have M.E., hidden beneath the pathetically understated guise of ‘chronic fatigue’, with the few well-funded studies being done on fatigued people as defined by Fukuda/Reeves, many of whom may be quite ill with ‘something’ that meets loose CFS definition requirements, but do not meet the stricter Ramsay, Canadian, Nightingale, or new Pediatric definitions for M.E. We need to acknowledge acute onset M.E. as the distinct clinical entity that it is; it has been clearly defined as such for half a century. Most often infectious in origin and quite possibly transmissible, this issue needs to be addressed.

“The prevalence of CFS was higher in genetically unrelated household contacts and in non-resident genetic relatives than in the community, indicating that both household contact and genetic relationship are risk factors for CFS.” (Underhill, R., *Journal of Chronic Fatigue Syndrome*, Volume: 13 Issue: 1, Page Range: 3-13.)

Are we talking about fatigue here, or transmissible disabling chronic disease? (See a full article summary at: <http://www.immunesupport.com/library/showarticle.cfm?ID=7175%22%3eHere%3c/a>. “Unrelated spouses/partners of the CFS patients were eight times more likely than the general population to have CFS.”)

Dr. Byron Hyde and Dr. John Greensmith (among others) posit that M.E. is NOT a sub group of fatiguing illnesses; it is a crippling disease in its own right, with its own history, classification, definitions and research prior to and since CDC enveloping and muddying its definition with CFS definitions. Severely ill patients need researchers to apply the appropriate M.E. definitions (Ramsay, Canadian, Nightingale, Pediatric) of neurological G93.3 to select study subjects if patients are to have any hope of treatment discovery and regaining at least some facets of their lives before it is too late for them. (It is already too late for many. Let us never forget Alison Hunter, Casey Fero, Sophia Mirza and many, many others.) And M.E. needs to be taken seriously and funded through Neurological Disorders and Stroke at NIH, not the Office of Women's Health. (Men and children of both sexes are taken down by M.E., and it is shameful that women's health is not taken seriously. Shameful that Sophia Mirza died in agony after medical abuse and neglect; shameful that Casey Fero was stereotyped with an unimportant ‘women’s illness’ and died suddenly of what can also be classified as a form of medical neglect.)

The CDC and NIH will no doubt continue studying ‘fatiguing illnesses’ as a group and will select study subjects based on fatigue, ruling out other serious illnesses, (such as the serious neurological disease, Myalgic Encephalomyelitis). Because of this, fatigue definitions and labels need to remain separate from strictly defined Myalgic Encephalomyelitis for obvious research purposes: ME is defined by neurological abnormalities; neurological abnormalities are not required and merely optional in CFS definitions. Grouping ME with CFS has resulted in inappropriate treatments as well.

Patients filling the fatiguing illnesses subsets rightly abhor being labelled with 'CFS'. So perhaps with what's known from research under the Fukuda definition these patients and their doctors can choose to re-label CFS as Myalgic Encephalopathy, and continue to have it listed in the current version of the U.S. ICD-9-CM under Symptoms, Signs and Ill-Defined Conditions (780.71) until their diagnoses are further researched and either corrected to Myalgic Encephalomyelitis (323.9) or some other missed diagnosis of major medical illness with profound fatigue as but one of its symptoms (as put forth by Dr. Byron Hyde and the 2007 Nightingale Definition of Myalgic Encephalomyelitis. "M.E. IS A CLEARLY DEFINED DISEASE PROCESS. CFS BY DEFINITION HAS ALWAYS BEEN A SYNDROME." And, "All M.E. patients as well as all chronic illness patients deserve a systematic and total body investigation. No individual should go through life ill, disabled without knowing why he is ill. Simply offering a label, whether M.E. or CFS, without looking at the pathophysiology, is both unacceptable and potentially dangerous both for the patient and the patient's physician." (See <http://www.name-us.org/DefintionsPages/DefHyde.htm> and [http://www.nightingale.ca/documents/Nightingale\\_ME\\_Definition.pdf](http://www.nightingale.ca/documents/Nightingale_ME_Definition.pdf)).

When MEitis and CFS/MEopathy patients are studied separately using their respective definitions, and when new discoveries further define these illnesses, the time to further revise the titles of these diseases will come. But until then, the need to concentrate these patients into their correct distinctions for more valid research is dire. The CDC appears to have chosen to obscure the possibility (probability?) that M.E. is transmissible and pandemic and make it fade into the shadows of fatigue in order to avoid dealing with a complex, difficult disease, we who are hidden by those shadows most of the time are not going away. We continue to be a growing population, a burden to our families and the economy. Those of us getting older will likely die off early from the toll this disease takes on one's body. (See Jason *et al* Mortality Study: <http://www.name-us.org/ResearchPages/ResJason.htm#Mortality>). But there is unfortunately a new generation of PWMEs that cannot escape this disease unless research discovers how it is transmitted and puts a halt to its spread.

Dr. John Greensmith states: "Another of our hypotheses asserts that M.E. is a distinct illness and should not be used interchangeably or synonymously with Chronic Fatigue Syndrome (CFS), that it is of, as yet, unknown physiological cause, with sufferers varying along a continuum of severity. Amongst their symptoms is an experience quantitatively and qualitatively different from mere tiredness or fatigue, which deserves to be named and considered differently from CFS, which is also hampering research progress." ([http://www.mefreeforall.org/What\\_M\\_E\\_is\\_and\\_is\\_NOT.113.0.html](http://www.mefreeforall.org/What_M_E_is_and_is_NOT.113.0.html))

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