

Dear Committee,

I am aware, as you take public comments, that you have heard, or will hear, patient testimonies to the effect of the absolute pain and suffering caused by this illness, ME/CFS. In light of this it is perhaps thoughtless to think this small letter I have written can impact you in any manner if these testimonies have, as I am aware, failed to do so. However I ask the committee to forgive this "illogic" on my part as I have felt that I must do something.

Firstly, it is a fact known to all that the Canadian Consensus Definition 2003 of ME/CFS, published in the now defunct "Journal of Chronic Fatigue Syndrome" comes the closest to describing the actual disorder. This is universally recognized in the patient community and is a fact recognized by all clinicians dealing with a plurality of ME/CFS patients. In light of this accepted fact it is especially surprising that the committee has not recommended this definition, or a slight modification of it, as the research standard in ME/CFS.

As this statement is so uncontroversial and so accepted by the most prominent members of the ME/CFS clinical and research community I merely wish to have the following challenge printed for public record:

---I challenge this committee to produce one clinician, who having had, for any significant length of time, a plurality of ME/CFS patients, regards the other main definition, the Fukuda 1994, as superior to the Canadian Consensus Definition 2003.---

Secondly, the amount of research money spent by NIH in fiscal year 2009 on Chronic Fatigue Syndrome is listed as 5 million dollars, only 4 million dollars ahead of Vulvodynia, and only 301 million dollars behind Multiple Sclerosis. The amount of patients ill with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome is approximately the same or a few times greater than Multiple Sclerosis (1,2) according to the fifteen-year old below references. Chronic Fatigue Syndrome has also been reported to have a higher level of functional disability than Multiple Sclerosis (3).

Lastly, I ask you to remember why you are here. It is well known that Chronic Fatigue Syndrome research is underfunded and it is well known that the Fukuda 1994 definition is quite flawed, yet the committee has done, to my knowledge, nothing to address these issues. To all of the individuals in this committee how has your participation in it in any way advanced the state of research or research funding? How have you, through actions in this committee, in any way contributed to the alleviation of human suffering?

There are people now dead, who, had this committee acted in a more timely and vigorous manner, I can only speculate, may be alive.

There is a huge innovation in the field of ME/CFS and yet the committee apparently did not see fit to invite these researchers to participate.

There are again patient testimonies which would rend the heart of Macbeth himself, and yet the Committee takes no action.

Therefore I suggest to you the following recommendations to the Secretary of HHS:

- That the funding of research into the pathophysiology of Chronic Fatigue Syndrome be immediately increased to at least a level of 30 million dollars. Assuming there to be about 400,000 people sick in the United States with ME/CFS (a very conservative estimate) this is still only about 75 dollars per person which is well below the funding for many other less serious health conditions.
- That the Canadian 2003 Definition be recommended as the new research standard--- or failing this, a new definition which incorporates its crucial components. For example a definition that requires both the Canadian 2003 Definition and Fukuda 1994 Definition to be fulfilled.
- That the Committee recommend a "research blueprint" which includes "step by step" goals, sub-goals, and a time-table for the orderly and prompt fulfillment of these goals. Diagrams analogous to this are commonly used in the business world and I see no reason of competency which would prevent the Committee from doing the same. Crucial goals to be included should be: developing a bio-marker, research in the pathophysiology of the illness over the course of time, differentiating genetic and gene expression markers between patients and controls, and most pressingly research into the relationship between XMRV and the pathophysiology of the illness, among other goals.
- That Secretary of Health and Human Services, be advised to offer funding to the states set up five or more centers of excellence into ME/CFS which encompass both research and clinical care.

There is something inherently deplorable and nauseating in watching people suffer and die while the conditions that make them so are endlessly discussed in expert panels and committees. I should hope all the members of CFSAC feel the same way...

I urge the committee to adopt some form of the above four recommendations; or if it is unwilling to act in the benefit of patients--as was intended-- to be dissolved.

If, as I hope, the committee does intend to make clear and substantial positive recommendations (at this present session) to the HHS Secretary I urge in the future that a "webinar" format be adopted which is more friendly to patients. I also condemn the shortening of the public comment time per individual-- surely in light of the severity of the matter the committee is more than obliged to hear full and accurate testimonies.

- 1.) The prevalence of multiple sclerosis in 3 US communities. Noonan CW, Williamson DM, Henry JP, Indian R, Lynch SG, Neuberger JS, Schiffer R, Trottier J, Wagner L, Marrie RA. *Prev Chronic Dis*. 2010 Jan;7(1):A12. Epub 2010 Jan 15.
- 2.) Chronic fatigue and the chronic fatigue syndrome: prevalence in a Pacific Northwest health care system. Buchwald D, Umali P, Umali J, Kith P, Pearlman T, Komaroff AL. *Ann Intern Med*. 1995 Jul 15;123(2):81-8.
- 3.) Health status in patients with chronic fatigue syndrome and in general population and disease comparison groups. Komaroff AL, Fagioli LR, Doolittle TH, Gandek B, Gleit MA, Guerriero RT, Kornish RJ 2nd, Ware NC, Ware JE Jr., Bates DW. *Am J Med*. 1996 Sep;101(3):281-90.

Signed,

John Duncan.