

Public Comment
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CFSAC has been asked to considering the value of Centers of Excellence for ME/CFS in this meeting. It is beyond question that these are needed. **I must ask, however, why HHS is asking CFSAC to discuss COE's at the current time.** It has been on the agenda for years, and there are numerous ignored recommendations for COE's. **I believe that this discussion is a red herring, to prevent discussion of the two most urgent matters for those concerned with ME/CFS.**

The first and most crucial Center of Excellence must be the Health and Human Services Department itself. As shown in the recent Freedom of Information Act memo releases, HHS has put bureaucratic CYA over science and patient care. It is incumbent upon this committee to bring this ongoing travesty to the attention of the new secretary of health and human services. **Before any and all other recommendations, this committee must request, in the strongest possible terms, that she initiate a top down change of attitude regarding myalgic encephalomyelitis.** Given the long history of contempt for ME/CFS, it is times for heads – many heads – to roll. Until HHS begins to deal with this devastating disease as a serious, ongoing public health issue, all their supposed research and initiatives will continue to be the fruitless caricature of progress they have always been. **Until HHS can act as a Center of Excellence, it is unbelievable that it would presume to address disease definition, research gaps or research priorities.**

The matter of definition has already been settled. HHS said they wanted a definition which a consensus of experts agreed upon. They got it with the Canadian Consensus Criteria yet HHS immediately began the IOM process to get a definition more to their liking instead. The main argument for the IOM is that it would put its considerable clout behind its findings. That is, in fact, the biggest argument AGAINST the IOM's product, which has no chance of approaching the level of the CCC. If/when it produces yet another status quo definition, it will set back research for decades.

HHS' IOM contract for a redefinition ignores the experts. It is an illogical fantasy to expect experts from other fields to write a better definition in five sessions than disease experts who worked together on a definition over several years. In a vain attempt to be evenhanded, IOM treats all definitions, from the 1991 Oxford to the most current international consensus criteria definition, as equals. This ignores all advances in knowledge in the past two decades, as well as well-known problems such as Oxford overly broad criteria that includes many who don't meet all other definitions' stricter standards. In the rush to apply politically correct evidence based standards, it overlooks the fact that most research is small and non-replicated DUE TO THE LACK OF FUNDS in a drastically underfunded field. It also overlooks that much of the funding has gone to prove psychiatric causation, which has consistently resulted in circular "findings."

The P2P is, if possible, even worse. Even HHS executives can't figure out why it is being done. Even they are being kept in the dark about specifics. What we do know is that people with no experience are going to presume to tell expert clinicians and researchers how to recognize and investigate this disease. The only polite word for that is chutzpah. The level of HHS incompetence is shown in the flyer for P2P, which looks like it was written 30 years ago. HHS

highlighted six "facts" in this flyer and EVERY ONE is wrong, misstated or highly questionable! NONE reflect current research, as shown in the chart below. **If the HHS cannot get these basic facts right, facts that THEY chose, what hope is there that the P2P workshop has any chance of advancing science?**

P2P proposes to look for the gaps in research. Those gaps are obvious and the cause of those gaps is equally obvious: an inappropriate HHS attitude resulting in a massive lack of funding. Addressing the gaps in ME research is as simple as

- 1) Replacing the HHS culture of disdain, with one that acknowledges that ME is a disabling disease that needs significant research,
- 2) Having HHS publically admit that its assumptions that illness was depression or other psychiatric disorders were wrong,
- 3) Having HHS highlight the numerous physical findings in this disease and,
- 4) Having HHS finally provide funding in keeping with the seriousness and prevalence of this illness.

THESE ACTIONS BY HHS ARE THE ONLY THING THAT IS GOING TO ADDRESS RESEARCH GAPS as these gaps are directly caused by HHS' current attitude.

As for COE's, such Centers must understand and reflect the seriousness of this physical illness. COE's would provide invaluable services for primary care physicians, patients, and researchers alike. However, Great Britain currently shows the great harm done by so-called Centers of Excellence that do not understand this illness. In the British National Health Service's determination to force this illness into a psychiatric model, they promote treatment, rigid graded exercise programs, even though exercise can be clearly shown to worsen the illness! Clearly, bad information is even worse than no information. Right now, HHS seems determined to get and use the worst information it can find.

CFSAC must ask the Secretary of Health and Human Services to put an end to these two initiatives and to reform the department without delay.

1984	P2P's published flyer	Current or correct information
Chronic fatigue is the major symptom	Extreme fatigue is the major symptom	Post-exertional malaise is the major symptom
There are numerous minor symptoms (11 in 1988 CDC, 8 in Fukuda)	Complex, multifaceted disorder (a grab bag which will fit all physical and psychiatric theories)	This is a disorder with specific cognitive, neurological, immunological, and autonomic abnormalities
There are no lab tests	There are no lab tests for diagnosing ME/CFS	There are numerous lab tests which show immune, cognitive, and functional abnormalities in ME patients. The Stevens Protocol especially distinguishes patients from non-patients and patients with other

		illnesses. The primary reason it is not considered diagnostic is that HHS, despite numerous requests from CFSAC and experts, has refused to consider it such. What the HHS (CDC, Medicare) doesn't approve, insurance companies can't approve, no matter how strong the evidence.
CFS is not disabling (unspoken subtext: it is just whining women)	ME/CFS can make daily activities... more difficult	ME is a highly disabling disease. A majority of sufferers must make major life changes to cope, about half cannot work, and about 25% are homebound. An unknown percentage remain completely bedbound, unable to do any self-care (including feeding themselves) and unable to tolerate any normal stimulation.
This disease affects white, middle class woman primarily	Women are affected more often than men (given the history behind this illness, the clear implication is that it is highly uncommon in men)	The ratio of woman to men in this disease is similar to many other auto-immune diseases. It affects male and female pre-pubescent children equally.
It is extremely rare	It affects 1 million people	All current estimates are based on poor research definitions. Current prevalence estimates are 17 million worldwide but the truth is no good prevalence study exists.