

Public Comment
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My name is Jeannette Burmeister and I'd like to address the IOM contract.

Just to recap briefly, CFSAC recommended at its October 2012 meeting to convene a stakeholders' meeting—in consultation with CFSAC members—with ME/CFS experts, patients and advocates to reach consensus on a case definition. Instead what did we get? A “study” by the Institute of Medicine that includes no patients or advocates nor CFSAC and that will include a number of professionals without any prior experience with ME/CFS. That's \$1 million spent on what basically amounts to a literature review. For the final IOM report, the opinion of the majority of “experts” will be used. Is anybody brave enough to make a bet that the number of non-ME/CFS-experts will outweigh the number of true experts? An when I say true experts, let me clarify that folks who spent millions of dollars on the study of the psycho-social aspects of the disease or on coping mechanisms do not count. Although they will undoubtedly be included in the IOM panel as will likely other folks open to unscientific psychobabble. The IOM “study” is quite obviously not what CFSAC recommended. It is actually the opposite.

In a letter by Secretary Sebelius to our experts, she claims that the IOM study was necessary because “HHS does not generally develop diagnostic criteria for disease conditions.” When I read this, I couldn't decide whether to start laughing hysterically or beating my head against the wall repeatedly. I mean, really? Correct me if I am wrong, but have we not been suffering tremendously for almost 20 years under the Fukuda definition developed and adopted by the CDC? In light of this reality, the letter's assertion is outrageous.

It's true that we've been wanting to get away from the oppressive Fukuda definition. So why the enormous outcry by patients and experts alike about the IOM “study?”

The answer is very simple: Because we have a perfectly good case definition with the 2003 Canadian Consensus Criteria (“CCC”), which have been adopted by virtually all of the U.S. ME experts as well as a good number of international ME experts. The advocacy community stands united behind our experts in this with almost no exceptions. HHS has always said that a definition must originate within the medical community. Well, the CCC did. So, why waste taxpayer dollars on something that is readily available? That's the \$1 million dollar question, especially since the ME experts clearly stated that a definition from the IOM “threatens to move ME/CFS science backward by engaging non-experts in the development of a case definition for a complex disease about which they are not knowledgeable.” The experts decided that the CCC—reflecting about 400 years of clinical and teaching experience, hundreds of peer-reviewed publications and about 50,000 diagnosed or treated ME patients—are more than good enough.

Are the CCC perfect? No, but they are a very sophisticated starting point and a quantum-leap improvement of Fukuda and the experts have already committed to refining it over time. If we allow the IOM contract to proceed, we can expect a disastrous Gulf War Illness-type result.

The IOM, in its most recent report about Gulf War Illness, which it renamed Chronic Multisymptom Illness, recommended antidepressants, cognitive-behavioral therapy and exercise for our vets with a serious physical disease. If the IOM is going to throw our disabled vets under the bus, what hope is there for patients like us who, for decades, have been labeled as lazies and crazies? If the IOM study goes forward, that would be the end of health insurance plans paying for any effective treatments, such as antivirals, IVIG and amino acids. If the IOM “study” goes forward, we will beg to be returned to Fukuda times.

The IOM—as an institution—quite clearly seems to have a conflict of interest, which taints the entire proposed study. It has previously stated opinions relating to ME/CFS, the subject of the planned study. For example, the IOM already decided in its GWI report that there are no biomarkers for ME/CFS, a fact that is to be established in the ME/CFS IOM “study.” It also opined that ME/CFS is “not an organic disease.” There are many other examples in the report. At the same time, the IOM stated in its report that the “Responsibility for the final content of the report rests entirely with the authoring committee and the institution.” This unconditional assumption of responsibility by the IOM creates an obvious bias that cannot be explained away or remedied by conflict-of-interest checks of potential committee members. The institutional conflict of interest of the IOM alone is reason enough to terminate the contract.

I have been asked if I am 100% sure that the IOM outcome will be bad? Well, no, I am not. But I am also not 100% sure that I’d be killed if I stood in the middle of highway 101 for a minute.

I have also been asked what my ultimate goal is in fighting the IOM contract. This is like asking somebody who is trying to stop nuclear war what he or she will do afterwards to end world hunger.

If you want to know whether the IOM “study” can be stopped, look at who is claiming that it can’t. Don’t fall for the propaganda. Of course the IOM study can be abandoned. The expenses the IOM had so far are minor, so most of the committed taxpayer money can be saved. And more importantly, patients can still be saved from the unscientific report the IOM will deliver.

Everybody should ask themselves about the reason for the extreme secrecy in entering into the IOM contract. To this date, the contract has not been available to the public. The nomination process for the committee is completely non-transparent. Three out of the five committee meetings are planned to be closed

meetings. Even Secretary Sebelius's response to the experts' open letter wasn't open.

The even bigger question is the extreme speed at which this study is forced down our throats. After all—in cases other than national-health crises, like a threat to the blood supply—this kind of urgency is highly unusual, if not completely unprecedented.

HHS and IOM, please know this: Patients and experts do not want this study!

Thank you!