

**Public Comment**  
**Charmian Proskauer**

My name is Charmian Proskauer, and I currently serve as President of the Massachusetts CFIDS/ME & FM Association. However I am testifying as an individual, not as a representative of the Association.

As has been previously pointed out, in October 2012 “CFSAC recommends that you will promptly convene (by 12/31/12 or as soon as possible thereafter) at least one stakeholders’ (Myalgic Encephalomyelitis (ME)/Chronic Fatigue Syndrome (CFS) experts, patients, advocates) workshop in consultation with CFSAC members to reach a consensus for a case definition useful for research, diagnosis and treatment of ME/CFS beginning with the 2003 Canadian Consensus Definition for discussion purposes.”

This recommendation appears to have morphed into two separate initiatives, both begun by a government agency without any consultation or input from this Committee or from the patient community – the Institute of Medicine Diagnostic Criteria for ME/CFS activity and NIH’s Pathways to Prevention, or P2P. I would like to talk about both of these.

First, IOM. Although hundreds, if not several thousands, of ME/CFS patients along with over 50 expert ME/CFS researchers and clinicians, called for the IOM contract to be cancelled, it was not, and the process is going ahead. However, the IOM process has been open to public input from the beginning, and the committee itself has a healthy representation of acknowledged ME/CFS experts, including some who signed the letter urging the contract to be cancelled. These experts, as I understand, have the task of reviewing relevant research and clinical literature, and because of their expertise, they can bring to the committee the judgment to separate the good studies from the bad, and the clinical experience to understand the role of various types of treatments that are applied to this illness. Also the goals that were established in the beginning are still the goals, and they are important ones of recommending a definition of the illness that can be used for making a clinical diagnosis, and developing a plan for education of health care professionals across the board on awareness and diagnosis of the illness. While patients and advocates are still very concerned about what will be in the final report of this committee, at least there is recognized expertise on the committee and public input in the process.

The same cannot be said for P2P. This appears to be a closed process within NIH, which over many years has given little serious attention to this very serious illness. By design, NO members of the panel have any expertise regarding ME/CFS. The literature review has been contracted out to an outside group, again with no expertise in understanding the context of the ME/CFS literature, good and bad. This outside group is then tasked to prepare a summary report, which will be given to the non-experts on the panel for them to use in their deliberations. Furthermore, while the original goals of NIH to “conduct an evidence-based review of the status of ME/CFS research and also convene a dedicated workshop to address the research case definition for ME/CFS” and to create research recommendations made sense, this has since morphed into a different goal which appears to focus on treating “overwhelming fatigue” as a public health problem, and with the treatments of CBT and Graded Exercise Therapy leading the list of treatments! And this BOGUS process, which by its very setup is not likely to come to any

legitimate conclusions about the real disease characterized by Post-Exertional Malaise and Cognitive Dysfunction along with many other physical symptoms, is what will presumably guide NIH in allocating research money (or NOT) for ME/CFS in the foreseeable future!

I therefore urge that the P2P process be suspended, at least until the IOM process has issued its final report and can be taken into account in P2P deliberations, and P2P can address its original goals of creating a research definition for the illness and then addressing research gaps.

Thank you.