Public Comment
Kati Debelic

CFSAC testimony Fall 2013

My name is Kati Debelic, I am a registered nurse on disability for the last 5 years. I clearly have myalgic encephalomyelitis.

I have provided testimonies twice yearly for the time I have been sick. I have experienced frustration and neglect in health care, and competent health care is 2 hours away, by plane. I am lucky to be barely able to afford it. I have great reservations that CFSAC can achieve change, and I am very worried about the composition of the committee, pushing away our ME experts and enrolling complimentary medicine practitioners. I get very worried when these people do not know what the main issues are, how sick the patients are, the issues surrounding Fukuda criteria, DSM5 and the psychiatric influence. Moreover, the allegations of threats mentioned at the spring 2013 meeting by committee member Eileen Holderman which have not been addressed publicly provides worrying insight about what is happening behind the scenes.

Patients find themselves telling the same things over and over and quite honestly, we are going in circles. We are facing discrimination in research funding, and this affects all the patients, all around the world.

There are very serious concerns about the IOM contract, that cannot be disregarded. The idea that the flawed UK FINE guidelines will even be considered sends huge warning signals. The fact that the majority of the pannel members will be non ME experts who very likely have not seen hundreds of patients, and not aware of the very critical disease feature that must include post-exertional neuro-immune exhaustion worries all patients.

The IOM has decided that Gulf War illness, which is similar to ME, should be rename chronic mulitsymptom illness should have sent warning signals and despite patients and experts protests, HHS is still going on with the contract.

The stigma of this disease from the patient perspective is unbelievable. Stigma from health care professionals towards patients with ME is even greater. i have great doubts that the IOM group will recognize that they already have a bias towardsthe illness and believe this is purely a psyxhological phenomenon, despite well documented epidemics in the 1980's, overshadowed by the AIDS epidemics.

I am asking you today to be transparent in your dealing with the patients, and respond to allegations of intimidations and discuss the IOM contract just as clearly. Patients deserve answers from this advisory committee.

Thank you.