

Public Testimony of Staci Stevens for CFSAC Meeting Oct. 29th

Dear CFSAC:

I would like to express my gratitude to those serving on the CFSAC, now and in the past, who have given of their time and expertise. Despite your good work, there has not been a written response from DHHS to a single recommendation of this committee since 2003. This is unacceptable and must be changed. That said, I give credit to those ex officio members who have acted courageously in moving forward with recommendations from the CSFAC. For those of you who have done so, I thank you.

CFS is a physical disease, and we can identify, characterize, and measure its most distinctive and disabling features. The gold standard in medicine is to identify and employ objective measures to evaluate disease and illness severity. That is what we do at the Pacific Fatigue Laboratory; evaluate multisystem function and impairment in CFS. A medically determinable impairment requires objective evidence. For example, we have developed an objective serial cardiopulmonary exercise test protocol using AMA guidelines that measures functional impairment as well as the metabolic, cardiovascular and pulmonary systems both at rest and during exercise. The protocol elicits and measures both fatigue and post-exertional malaise, considered to be a hallmark symptom of CFS. By contrast, the CDC recommends the use of self-report questionnaires to diagnose and quantify this illness. Questionnaires simply do not provide the evidence required by the Social Security Administration or long term disability carriers to diagnose medical illness or to determine a disability claim. That questionnaires have become the standard of diagnosis for CFS at the CDC shows how little progress they have made in the last 25 years in characterizing this disabling syndrome.

The questionnaire approach to diagnosis in CFS at the CDC has also been criticized by psychiatrist Eleanor Stein, the IACFS Ambassador from Canada. As she was unable to speak today, she asked me to read the following statement,

“I would like to express my strong concern about the harm being done by using the 2005 empiric definition of CFS. This definition recommends diagnosing CFS using 3 self-report questionnaires: 2 of the 3 are non specific and erroneously include people with a wide variety of disorders including primary psychiatric problems. It is obvious to me as a dedicated CFS clinician that I cannot use the Empiric Definition in good faith in my practice; I rely on the Fukuda and the Canadian Consensus definitions for diagnosis and all medical-legal issues. The Empiric Definition has resulted in a dramatically increased prevalence in CFS in the US. Studies by Jason et al have shown that this increased prevalence may be due to the inclusion of persons with depression.

Without a sensitive and *specific* case definition, how can future research hope to uncover the biomedical underpinnings of this disorder for the benefit of those who suffer? It is my hope that the CFSAC will make a public statement that the Empiric Criteria should not be used for either clinical care or research and that until a better definition is created the Fukuda and/or Canadian Consensus Definitions should be used.”

Given the lack of progress at CDC, the CFS Advisory Committee’s number one recommendation from their last meeting was to, “establish new leadership at the CDC for the CFS program.” This recommendation was in concert with those made by the IACFS and CFIDS Association of America. Yet, this unified call for change from the three most respected organizations in the field has gone unheeded. We have objective measures. We have discernable physical characteristics. It is well past time for the CDC to become responsive to the researchers, clinicians and patients who are united in their insistence on objective diagnostic criteria rather than self-report questionnaires to characterize this disabling illness.

Respectfully,

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