

Dear CFSAC Members:

As a person who has had CFS for over two and a half decades, I would like to make the following recommendations.

The CFSAC is vital to the CFS community. It allows the CFS community to learn from and give input to the committee that is responsible for the coordinating of governmental activities concerning CFS. Given the importance of CFSAC to the patient community, the Committee's charter should be renewed. With research findings now emerging at an accelerated rate, meetings should be held quarterly instead of semi-annually. Since many patients are too ill or financially unable to attend CFSAC meetings, meetings should be video-cast and the video live-streaming of meetings should be made a part of the charter. New members chosen to replace outgoing members should be selected and announced in a timely manner. Agendas for the meetings should be posted well in advance of the meetings. The status of the CFSAC's recommendations and the agency or agencies responsible for the implementation of each recommendation should be posted on the CFSAC website.

As recommended in the past by the CFSAC, the CDC's case definition (the Reeves' Empiric Definition) should be replaced with a more adequate one. It was extremely concerning when the broad Empiric Definition resulted in the estimated number of Americans with CFS jumping from about one million to up to as many as four million. The Empiric Definition included persons whose primary health issue was major depression and has further muddied the CFS waters. Using the Empiric Definition as the basis for CFS research can only result in "fuzzy science." The CDC's highest priority should be the formulation of a sensitive and specific definition for CFS. Given the high level of interest in the CFS case definition among patients, important CDC meetings pertaining to the CFS case definition should be video-cast. Members of the CFSAC and those who work on CFS at the CDC are strongly encouraged to watch Dr. Leonard Jason's video presentation entitled "Defining CFS: Diagnostic Criteria and Case Definitions" at: <http://www.cfids.org/webinar/defining-cfs041410.wmv>

Previously recommended by the CFSAC have been regional centers for CFS treatment and research. Good CFS doctors remain few and far between. Too many sick persons are forced to see doctors with little or no understanding of CFS. The result is poor patient care. The recommended centers, staffed with CFS specialists, would provide patients with much improved care. The centers would also offer rich opportunities for CFS research to advance an understanding of CFS.

Once a tight, consensus definition for CFS is in place at the CDC, medical schools need to include CFS instruction in their curriculum. Dr. Kenneth Friedman explained at the CFSAC meeting in October 2009 that if the CDC were to make CFS a reportable illness, the National Board of Medical Examiners would put CFS questions on the National Boards. Then medical schools would be forced to provide CFS instruction. With approximately one million Americans with CFS, doctors need to be schooled in CFS.

Required reporting of CFS cases to the CDC would not only insure that medical schools include CFS in their curriculum, it would also help legitimize CFS within the community of practicing physicians.

Thank you for allowing public input to the CFSAC, and thank you for your work on the Committee.

Sincerely,  
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