

Written Testimony Submitted to the CFSAC (May 10, 2010)

By: Anonymous ME/CFS patient

The following outlines my reasons for support for the renewal of the CFSAC charter, as well as suggestions for improvements to the charter.

1. The charter for the CFSAC should be renewed. CFSAC is the only federal advisory committee for ME/CFS. As members of the CFSAC are well aware, ME/CFS is a disease with a patient population that continues to be largely neglected by the federal government, as reflected in the near absence of innovative government research programs for ME/CFS; in the tiny scale of federal funding made available for research into ME/CFS that is disproportionately small relative to the threat to public health and relative to almost all other diseases and conditions; in the inadequate education of medical professionals that has resulted in patients being regularly subjected to skepticism and neglect by their doctors, and in the long and difficult process every disabled ME/CFS patient must face to obtain disability benefits for their inability to work due to ME/CFS.

Not renewing the charter for the only federally chartered advisory committee that provides a direct line of communication to DHHS regarding ME/CFS will be tantamount to sending an unequivocal message to the approximately 1 million Americans suffering from ME/CFS that the government simply has no interest or intention in improving the dismal federal response to ME/CFS, now or in the future.

While the record for having CFSAC recommendations implemented by the DHHS and its agencies over the past years leaves much to be desired (one can only guess at the various possible reasons for this), the Committee has served as a valuable venue for productive dialogue by the small number of concerned doctors, researchers and patient advocates devoted to improving the lives and prognosis for ME/CFS patients, as well as a venue for patients to testify to a committee chartered by the federal government, with the hope that their voices will be communicated to DHHS. Accordingly, the CFSAC charter should be renewed.

2. The CFSAC charter should require a more specific scope of activities in order to improve the implementation rate of the Committee's recommendations. The CFSAC charter states that the Purpose of CFSAC is to “provide science-based advice and recommendations to the Secretary of Health and Human Services and to the Assistant Secretary for Health on a broad range of issues and topics pertaining to [ME/CFS].” While the purpose of any federal advisory committee may be to provide “advice and recommendations” to relevant government agencies, the best science-based advice and carefully considered recommendations in the world amount to nothing unless the Committee's recommendations are ultimately acted upon and implemented by the appropriate government agencies. To this end, the CFSAC charter should incorporate a more specific scope of activities (either under the Function section or in a new Scope of Activities section) and require the Committee to present its recommendations to the government in a more formal and comprehensive format (specifically, in a single strategic plan to be periodically updated, as discussed below) and require the Committee to more closely monitor of the federal response to ME/CFS.

As an example, the charter of another federal advisory committee governed by the Federal Advisory Committee Act (the same statute that governs the CFSAC), the Interagency Autism Coordinating Committee (“IACC”), sets out the type of more specific scope of activities and mechanisms that would provide more “teeth” to the Committee's recommendations and which is likely to result in a higher implementation rate by the government of the Committee's recommendations. Specifically, the IACC charter states that that Committee “shall” engage in a very specific list of activities, including the development and annual updating of a single strategic plan for autism research including proposed budgetary requirements, and the submitting of the strategic plan to Congress; the development and annual updating a summary of advances in autism research related to among other issues, the causes, treatment and access to services for autism patients; and the monitoring federal activities with respect to autism and making recommendations to DHHS regarding any appropriate changes to such federal activities. (See IACC charter.) The CFSAC charter should adopt a similarly concrete scope of activities with respect to ME/CFS, such as requiring the development of single, periodically updated strategic plan that encompasses the Committee's advice and recommendations regarding ME/CFS research including proposed budgetary

recommendations that would be submitted to Congress, the development and updating of a summary of advances in all aspects of ME/CFS research, and the requiring more formal monitoring of federal activities with respect to ME/CFS and a mechanism for feedback concerning such federal activities (or lack thereof).

3. The charter should require online video-casting of CFSAC meetings and providing access to the video-casts on the CFSAC website. Many ME/CFS patients are too sick to travel or lack the financial resources to physically attend CFSAC meetings in Washington, D.C. despite their deep interest in the proceedings. Requiring online video-casts such as those organized with success for the last few meetings will greatly increase access to the meetings to ME/CFS patients by permitting them to view the proceedings from a computer at home.

4. The charter should require at least 3 meetings per year. It has been disappointing to learn that in the past, the Committee met as frequently as four times a year, whereas the number of meetings has dwindled to two per year. The fact that ME/CFS research is finally gaining increased attention calls for increasing, and not decreasing, the number of meetings and amount of meeting days devoted to CFSAC proceedings. Twice a year is a long time between meetings, during which valuable momentum on research and other initiatives can be lost. The charter should therefore require the Committee to meet at least 3 times per year.

5. Other requests. I would also like to request that replacements for outgoing committee members be replaced in a timely fashion, and that agendas for upcoming meetings be posted in a timely fashion on the CFSAC website.