

CFSAC, MAY 10, 2010 MEETING, TESTIMONY

I am writing to express my strong support for renewal of this Committee's Charter, and to offer recommendations for improvement upon the current Charter.

The world of CFS research and treatment is changing rapidly. New research findings and increased media attention have given CFS patients renewed hope that we may, at long last, see research investment proportional to the burden of this illness on patients, families, and the economy. It is critical that this Committee continue "to provide science-based advice and recommendations to the Secretary of Health and Human Services," as stated in the current Charter. New findings and opportunities must shape policy that improves the lives of patients who continue to suffer from the lack of treatments and lack of healthcare providers who understand this illness. There is no question that we need the CFSAC to continue its work, and the Committee charter should be renewed prior to its expiration on September 5, 2010.

However, I bring to the Committee's attention information from the Federal Advisory Committee Act Database. (<http://fido.gov/facadatabase>, accessed April 21, 2010) The Performance Measures section states that the CFSAC has made a total of 38 recommendations, and further states that only 18% of those recommendations have been implemented. Something is broken here. This Committee exists to advise the Secretary of Health and Human Services and the Assistant Secretary of Health, but only 18% of your recommendations have been implemented. It is not clear to me whether the breakdown is in the Office of the Secretary or in the nature of the Committee's recommendations. Very little information has been made available to the public about responses to the Committee's recommendations. **I urge this Committee to publish a complete list of all its recommendations along with the dates those recommendations were forwarded to the Assistant Secretary, and what response (if any) was received.**

Recommended Changes to the CFSAC Charter

One function of this Committee is the "development and implementation of programs to inform the public, health care professionals, and the biomedical, academic and research communities about chronic fatigue syndrome advances." The description of this Committee in the Federal Advisory Committee Act Database states, "The Committee's recommendations are used to help guide basic, clinical, and population science research related to CFS, assist with development of public and provider awareness campaigns . . . and disseminate information regarding recent scientific findings." (<http://fido.gov/facadatabase>, accessed April 21, 2010) To facilitate and improve the Committee's work in this area, I recommend the following changes to the Charter:

1. A representative from the Agency for Healthcare Research and Quality's (AHRQ) should be appointed as an ex officio member of this Committee. In fact, this recommendation was made by the CFSAC in September 2004, August 2005, and November 2007. The AHRQ works to "Meet the information needs of its customers . . . so that they can make more informed healthcare decisions," and to "Build the evidence base for what works and doesn't work in healthcare and develop the information, tools, and strategies that decisionmakers can use to make good decisions and provide high-quality healthcare based on evidence." (<http://www.ahrq.gov>,

accessed April 21, 2010). The addition of an ex officio representative from the AHRQ to this Committee should facilitate the identification of best practices in CFS treatment, and the dissemination of that information to healthcare providers and patients.

2. A representative from the Office of the Surgeon General should be appointed as an ex officio member of this Committee. In May 2007, this Committee requested that the Surgeon General send a letter to state health departments and other groups regarding CFS. After learning more about the Surgeon General's process for issuing such a letter, this Committee recommended that a concept paper on CFS be produced to facilitate a Surgeon General's workshop (May 2008). Given the slow pace of progress on this recommendation, the appointment of an ex officio representative from the Surgeon General's office should facilitate the Committee's work in this area.

In fulfilling its functions as described in the Committee charter, "It is anticipated that the CFSAC will continue to serve as a conduit for information from the Department to the patient population and vice versa." (<http://fido.gov/facadatabase>, accessed April 21, 2010). In order to facilitate and improve this conduit of information between the Department and the patient population, I recommend the following changes to the Charter:

3. The Charter should require that all Committee meetings be videocast in real time over the web, and that the videocasts be archived on the Committee's website. As the Committee knows, it is beyond the physical and financial means of most patients to attend CFSAC meetings in person. Requiring real-time videocasts in the Charter will guarantee that more patients can observe and participate in the meetings. This will enhance the dissemination of information from the Department, as well as the ability of patients to provide relevant and timely input to the Committee.

4. The Charter should require that physical accommodations be made for patients attending meetings in person. While recent meetings have provided rest areas and other accommodations for patients, this requirement should be stated in the Charter to ensure that future meetings are fully accessible to patients.

5. Given the fast pace of research developments and the increase in information relevant to patients, the Charter should require at least three meetings per year. This change will improve the Committee's ability to monitor developments, address patients' questions and concerns, and communicate information from the Department to patients. I wish to point out that past meetings have been two days in length, but the Committee is only meeting for one day on May 10, 2010. This has shortened the time allotted for public comment to three minutes per person, and will certainly shorten the time available for reports and recommendations.

6. The Charter should specifically identify the Principal Deputy Assistant Secretary for Health, Office of Public Health and Science as the Designated Federal Officer for the Committee. Dr. Wanda Jones has served as the Designated Federal Officer to the Committee, and has made many improvements to the Committee's functioning. Dr. Jones began the practice of meeting videocasts, and moved the October 2009 meeting to a larger space to accommodate the many attendees. Dr. Jones also secured public comment from both Dr. John Coffin and Dr.

Jerry Holmberg on very short notice to address issues related to XMRV and blood safety, respectively. The patient community has applauded these improvements, as well as Dr. Jones' responsiveness and effectiveness. Although the GSA Committee Management Secretariat does not require federal advisory committee charters to identify Designated Federal Officers, the office's guidance on drafting charters recommends that the DFO be included. (Preparing Federal Advisory Committee Charters, GSA Committee Management Secretariat, revised February 2, 2010).

CFS has taken 11 years of my life. I don't think I have much time left. At least help the others.

[Linda R. Oldershaw](#)