

Testimony - Anonymous 5

Dear Sirs and Mesdames,

Thank you for this opportunity to address members of the CFS Advisory Committee. My comments are directed at the charter and the procedures of the meetings I have observed to date.

The last time the charter needed renewal, members of my support group wrote to our congressional representatives and they responded positively by writing/ signing letters of support. Currently, renewal of the CFSAC charter is essential as progress is being made in a number of different directions, such as use of antiviral/ immunomodulators (rituximab) for treatment, possible unraveling of the mechanisms of post-exertional malaise (via abnormal metabolic/ immune responses to exercise), and potential elucidation of a biomarker for CFS via XMRV. Furthermore, allowing testimony to be phoned or e-mailed in and broadcasting of the meeting live as well as archiving it online for later viewing has permitted thousands of disabled CFS patients in the USA and abroad to participate in the meeting as never before. I hope the federal government recognizes the significance of these events in the 25-year history of CFS and capitalizes on them by renewing the CFSAC charter.

Here are some other concerns I have about CFSAC:

1. Why is renewal required every 2 years? Is this true of all federal advisory committees or only true for some committees? What is the rationale behind this? Requiring renewal every 2 years means that the limited time/ energy of patients/ advocates/ clinicians/ government officials are directed towards this rather than potentially more productive avenues.
2. The CFSAC was established to advise the Secretary of DHHS about CFS and has come up with a list of recommendations each meeting. However, there has never been a direct response from the Secretary to these recommendations, especially the establishment of Centers of Excellence for CFS, which have been suggested the last 5 years. A response from the Secretary's office, whether positive, negative, or neutral with comments, is necessary. Otherwise, the Secretary's office is not fulfilling their role in the CFSAC charter.
3. I was told that the May 2010 CFSAC meeting was shortened to 1-day due to new CFSAC members not yet appointed officially. Due to the meeting being only 1-day, each public testimony slot was shortened to 3 minutes. I hope that this will not set a precedent for future CFSAC meetings as public testimony greatly increased last year, enough to fill up all time slots. Having more time also allows CFSAC to invite more researchers/ clinicians to present their findings/ thoughts to the committee.
4. Consider allowing one or two public testimony spots to be opened to international parties or allowing US testifiers the opportunity to give up their slot to these parties. CFS and the science of CFS do not obey geographic boundaries. International parties can contribute to the US government's knowledge of CFS, in particular cognitive behavioral therapy and graded exercise therapy, which have been implemented on a wide scale in Europe and have caused physical harm/ permanent damage in 29%-79% of participants based on large patient surveys.

5. Allow the public to submit questions to CFSAC members before and during the meeting. CFSAC members can choose some of these questions to answer during or after the meeting. Currently, communication is one-way: we can listen and contribute our viewpoints but no direct questioning is allowed from the public and no direct answers are to be expected from the federal government. CFSAC, DHHS, and the federal government ultimately answer to and are responsible to the American people and should provide a way for two-way communication to occur.

6. Permit CFSAC members to communicate with each other between meetings to make meetings more efficient rather than requiring the majority of discussion to take place during the short and pressured time of the 2-day meetings. In the business world, subcommittees/ working groups often prepare and talk to each other between major meetings.

7. Write into the charter that all future meetings will continue to be broadcasted and archived online to accommodate the needs of disabled CFS sufferers.

Thank you for your time and attention