

Dear Dr. Jones,

I request that you pre-register me to provide public comment to the CFSAC Committee via telephone at the meeting scheduled for May 10, 2010. I also request that printed copies of my public comments be distributed to the CFSAC members for review in advance of my scheduled time. If the time allotted for public comments has already been filled, I request that my public comments be included in the record and distributed to the Committee members.

**Public Comment Concerning the CFSAC Charter:**

I would first like to thank the CFSAC for your dedication and all the hard work you perform for those of us who live with Chronic Fatigue Syndrome/ME. I have had CFS/ME since 1986, and am all too familiar with the difficulties this illness brings to us, as patients. I also acknowledge the difficulties you face as scientists, researchers and clinicians in attempting to discover treatments and ultimately a cure for those of us who depend upon you so heavily to enable us to live more productive lives.

There are four items I would like to address concerning the CFSAC Charter:

1. Please renew the CFSAC Charter which is currently set to expire on September 5, 2010.
2. Please amend the Charter to direct the Committee to meet four times per year instead of the "not more than two times a year" currently provided for. While the Charter doesn't currently specify how many days the meetings should be held, I request that the Charter call for the meetings to be held over a two-day period. A one-day meeting doesn't allow sufficient time for agenda items to be covered, public testimony to be heard, and sub-committees to meet for discussion. Two-day meetings will allow the Committee to function in a much more efficient manner.
3. Please amend the Charter to include a provision for live videocasting of the meetings. I certainly appreciate that you have provided live videocasting since May 2009, because it gives all of us who are physically unable to attend the meetings the opportunity to participate. I would like to see this provision written into the Charter itself so continuation of the videocasting will be insured for future meetings.

4. Please amend the Charter to provide for status reports at least twice a year on the recommendations presented by the CFSAC to the Secretary of Health. While there is access to the recommendations themselves, there is currently no provision that allows us to know what decisions have been made on the recommendations presented. The status of the recommendations is important for us to know as we pursue advocacy efforts.

Thank you for your time and your consideration of the requested changes to the CFSAC Charter.

Sincerely,

Pat Sonnett