

April 24, 2010

Dr. Wanda Jones
Department of Health and Human Services
Chronic Fatigue Syndrome Advisory Committee
www.cfsac.hhs.gov

Subject: Requests regarding the Chronic Fatigue Syndrome Advisory Committee (CFSAC).

Dear Ms. Jones.

I request that the CFSAC's charter be renewed, that it once again meet four times per year, and that the meetings be held for two days and not one. Further, I request that an update in the status of the CFSAC's recommendations be posted once or twice per year. In addition, I am requesting that replacements for outgoing members be filled in a timely manner and that agendas be posted in a timely manner as well. Also, please add live televising of the meetings to the charter.

I have watched the televised meetings and am very pleased with your overseeing of this committee. Most of us patients with CFS find it very difficult to attend, and so we appreciate watching the live televising of the event. It seems that in spite of all the efforts on our behalf, the committee may be steadily diminishing in its ability to advance its objectives. With the advent of XMRV, there is a much more pressing need to meet more often than twice a year. And when the committee meets for only one day, the first day is taken up with testimony, which is of course very important. However, there is not enough time left to address the issues which were brought up and which the committee must address. Day two is a critical time for the members to talk, plan and revise. This is an urgent need.

In fall of 2009, as soon as a call went out to nominate replacements for members who are leaving the committee, names of nominees were sent in. We still have not heard who the replacements are. That does not allow enough time for new members to plan and prepare to attend the May meeting. Posting the agenda right before the meetings does not foster preparation either.

Approving the above recommendations and including all of them in the charter would lead to a committee which would be a more potent force for dealing with this devastating illness. Being disabled with CFS has meant that I can not work as a nurse and has caused serious financial consequences since 1994 and for the rest of my life.

Sincerely,

Bonnie G. Mayer R.N.