

Dear Members of the CFSAC,

My name is Barbara Soliday. My daughter Kristin has been seriously ill with Chronic Fatigue Syndrome since 1998 and I have been active in support and advocacy groups since that time.

I would like to thank you for your service on this committee. Without your dedication, the situation for CFS patients would be much worse than it is now.

The call for public testimony requested our comments on the charter, and I have the following suggestions.

(1) First, please renew the the CFSAC charter. This committee is the channel through which we speak to our government about the terrible suffering of patients like my daughter. Kristin was once a very promising physics major in college but she is now too disabled to do the math required for physics; she is also too disabled to work at any kind of simple job more than a few hours a week. She is a talent lost to our society.

(2) Second, the charter should mandate meetings more frequently than two times a year and also mandate that the meetings last at least two days each. Continuity is essential for any committee to work effectively, and meeting only once or twice a year means that members must devote a lot of time to catching up rather than to moving ahead.

(3) Third, the charter should require that the meeting agenda be posted before the last day that we can send in public comments. How can we possibly speak or write about agenda items when we don't know what they are?

(4) Fourth, the charter should mandate video broadcasts of the meetings, as well as posts of the broadcasts and transcripts later. Most people with CFS are too ill to travel to Washington to meetings. Many are so disabled that they are not able to work and earn enough money to afford such a difficult journey. Lack of attendance in person does not mean lack of interest in the CFSAC; instead, lack of attendance is testimony to the devastation that Chronic Fatigue Syndrome visits upon its victims and their families.

(5) Fifth, the charter should require status reports on previous recommendations. If some recommendations have been farmed out to committees or other agencies, we need to know that. If nothing has been done yet about some recommendations, we need to know that too.

Finally, I would like to comment on an item that I hope will be on the agenda: The XMRV retrovirus. This is both a frightening development and a relief. I urge the government to investigate this situation immediately in hopes that scientists can find treatments for CFS like the treatments that that have been found for HIV-AIDS. If XMRV proves to be the cause of CFS, we may be able to relieve the suffering of hundreds of thousands of people and help them become productive tax-paying citizens

again. My daughter Kristin would like nothing more than to work and pay taxes rather than to continue receiving Medicare at her young age.

Thank you for your attention.