

Public Comment
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Even before arriving at their first meeting, CFSAC members need to be well versed in the history, politics, breadth of illness, and issues of concern to the community, as well as what has transpired since the committee's current inception in 2003. They also need to be ready to work.

During the December 10th, 2013 meeting Dr. Kaplan said "The Center of Excellence idea I think is extremely important and one that I think we should be recommending..."

It is disconcerting that Dr. Kaplan seemed quite unaware that Centers of Excellence have been mentioned more than 130 times in 10 years of CFSAC meetings. It seems to me that he is not familiar with the past work of the CFSAC. If committee members haven't made the effort to find out what CFSAC *has* discussed, then I wonder if you are sufficiently involved with and knowledgeable about this illness and the issues surrounding it.

Committee members also need to be actively involved in the committee's work. This includes during meetings and in working groups etc.

I understand that not everyone will have input on every point of discussion. However, when committee members are not active participants, it seems those members are chair-warmers or worse yet, just there to pad their resumes.

Most of you don't have this illness. WE however are seriously impacted by it at all times and very few advocates are healthy enough to work on all that needs to be done to improve our situation. So we need an effective CFSAC to help us.

Therefore since this committee is charged with making recommendations to and advising the Secretary of Health and Human Services (HHS), you need to do everything you can to ensure that this committee's work is done efficiently and expeditiously.

In addition, despite assurances from HHS that CFSAC terms would be staggered, five committee vacancies will occur between May and July (2014). Any committee comprised of only 11 voting members, will be unable to work expeditiously if new members need time to learn about the committee, the illness, etc.

I urge the Secretary to ensure that every voting member of the CFSAC is well aware of the committee's work, of issues regarding this illness and of the issues of importance to this community.

I also urge the Secretary to require that the DFO provide appropriate orientation of committee members.

These actions will help ensure that the committee can always work at full-speed to help those affected by this illness.

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