

First I would like to thank the members of the CFSAC for their efforts on behalf of those who suffer from this devastating disease. I would also like to give special recognition and thanks to Wanda Jones, whose organizational skills, professionalism, and sympathy have brought new energy to the CFSAC.

I strongly urge the renewal of the CFSAC charter. This is a period in which it is particularly important that the various branches of the US government involved in research and public health administration coordinate their efforts regarding ME/CFS, especially as regards research into the role of the XMRV retrovirus. It is certainly more efficient that the various branches meet regularly under the auspices of the CFSAC than that they each take their own path, with probable overlaps and gaps. This is also an important time for the Secretary of Health and Human Services to be kept apprised of developments. She wouldn't want to be caught unaware should this prove to be an epidemic larger in scope and impact than HIV/AIDS, which looks distinctly possible.

Another reason for renewing the CFSAC charter is that it encourages transparency and openness. Many patients use the CFSAC meetings to help keep abreast of the state of the research on ME/CFS, and of the government's activities concerning the disease, especially since the meetings started being videocast.

I further suggest that the renewed CFSAC charter mandate quarterly meetings, as had been the practice until a couple of years ago. Research news is coming in with increasing frequency. Should the correlation with XMRV hold up, there will be a need for epidemiological studies and research into means of transmission, which the federal government should coordinate. The CFSAC must be able to move swiftly to react to developments and to keep the Secretary of HHS informed.

I believe that the current CFSAC has worked hard on patients' behalf and has done a good job of making recommendations to HHS. Of course, there is always room for improvement. I would like to see the minutes and testimony of past meeting posted to the CFSAC website in a more timely manner, and for the agenda of upcoming meeting to be posted further in advance. I would also like to see a list of action items with due dates and status. But on the whole, I would say that where the CFSAC has been ineffective it has been because the HHS Secretary has been almost completely unresponsive to the committee (to the extent that the committee often hasn't known whether their recommendations have even been read). Since the CFSAC is only empowered to advise, not act, the fault for their recommendations having not been acted upon must be lie with the department of HHS. It is not the fault of the experts if their advise is ignored.

Another reason I want to see the CFSAC charter renewed is that it is one of the only venues for patients to be heard by the government officials who set policy regarding this disease. I think it is important for the decision makers to have that connection, to be reminded that ME/CFS is not an abstraction, but a disease which is severely impacting the lives of real people.

I am one of those people. Just one of many who has gone from a full and active life of work, volunteer activities, and social activities, to being housebound with profound physical and cognitive difficulties. My life is largely on hold while I wait for answers, wait for a cure or at least a treatment. Please don't cut us off just when we have a reason to hope.

Gay Lyon