

While comment has specifically been sought relating to the CFSAC Charter, I appreciate that some comments pertaining to the administration of the CFSAC and, in particular, how meetings are conducted, may not be appropriate for charter inclusion.

- **Structure.** The charter currently specifies that the Committee shall consist of 11 members, 7 of whom shall be biomedical research scientists with demonstrated expertise in the area, and 4 of whom shall be persons with expertise in health care delivery, private health care services or insurers, or voluntary organizations concerned with the problems of individuals with CFS. The latter category should be broadened to include expertise in Social Security or private disability insurance matters. (Usually there is at least one person, generally a lawyer, serving in that capacity on the Committee.)
- **Frequency and length of meetings.** The charter currently provides that meetings shall be held not more than two times a year and is silent as to their length. I believe that under prior charters meetings were sometimes held four times per year. Given the accelerated rate of developments in CFS research, I suggest that the charter provide for meetings to be held not less than 2 times per year, and not more than 4 times per year, and for not less than 4 days or more than 8 days per year.
- **Accessibility.** The live and archived videocasts of recent meetings have significantly improved effective access to the meeting for the concerned public, and in particular for those disabled by CFS or without resources to attend in person. The charter should embed a requirement for such access. In addition, I suggest the Committee explore the feasibility of further extending access to those without effective computer access (which currently requires broadband computer access, and extended availability of a computer) by providing an option for phone audiocast.
- **Public comment – minimum time.** In practice, a certain amount of time is allocated to public comment. This should be continued, and a minimum allotment of 2 to 3 hours should be reserved for this purpose.
- **Public comment – biomedical scientists and other persons with demonstrated expertise.** One commentator at the October 2010 meeting noted that a number of biomedical scientists who wished to provide testimony were unable to obtain time to do so, and suggested the possibility that a separate time allotment be reserved for such public comment. I think serious consideration should be given to this proposal, perhaps in a modified form that recognizes other persons with specific expertise related to CFS, which might include disability and health insurance. For

example, an hour of time might be preferentially allocated to such testimony, with any unused time reverting to opportunity for questions from the Committee and a waitlist of other public comment. For testimony by this category of persons, it would be appropriate to apply a different “cap” on the length of testimony.

- **Public testimony by the general public.** The opportunity for call-in testimony should be continued. The cap on time allotted for individual testimony should be not less than 5 minutes.
- **Opportunity for Committee discussion and questioning of ex-officio members after public testimony.** The agenda should allow opportunity for the Committee to discuss any issues raised in public testimony, specifically including the opportunity to ask relevant questions of ex-officio members.
- **Advance publication of proposed agenda.** To facilitate focused and effective public participation, a proposed agenda for each meeting should be published at the time of public notice and call for comment. It would be helpful if details (such as topics to be reported on by subcommittees, as opposed to simply the fact of reports) are specified in the proposed agenda.
- **Ability of Committee members to specify agenda items.** Technically, the Designated Federal Officer exclusively sets the agenda for each meeting. I would like to see a structure whereby the Committee itself could also specify agenda items. While this may happen in practice, there appears to be no formal provision for it.

I greatly appreciate the service and dedication of past and current members of the CFSAC. I particularly commend the advances made in broadening accessibility through videocasting of the meetings last year, and would like to commend Executive Secretary Wanda Jones for her role in accomplishing that.