

## **CFSAC Charter Recommendations**

### **Submitted by Rebecca Artman**

#### Length and Frequency of Meetings:

During the last four years the CFSAC has gone from holding one day meetings to holding two day meetings. These meetings are held twice a year. For both, committee members frequently complained that there was not enough time to make recommendations and thus in the last hour hasty recommendations were put forward to be word-smithed after the meeting. I believe that having three meetings a year at two and a half days in length. The first and second day could be used for presentations and public comment. The final two hours of the second day for subcommittee meetings (since the meeting usually starts breaking up around 3 pm) and the third day for subcommittee reports, recommendations and robust committee discussion but no public comment or presentations. While conference calls between CFSAC meetings were planned it was frequently difficult to get everyone focused and working on committee business when not in Washington.

#### Location of Meetings

I would like to recommend that once CFSAC meeting be held at the CDC and another at the NIH. These are the two most influential ex-officio members and it would go a long way if the meetings could be held at least once in NIH in Maryland and the CDC in Atlanta.

#### Ex-Officio Membership

Access to care is a vital part of the problem facing the community. I ask that Dr. Jones lead a discussion evaluating if all of the current Ex-Officios need to part of each meeting, and also if there may be other DHHS organizations that might be a good fit on the CFSAC as ex-officio members.

#### The Committee Membership

I would like to recommend that an attorney be a regular part of the committee as there are many legal implications which can and have come in to play during committee discussion about recommendations.

#### Defining the illness

One of the problems with the changing case definition is that CFS is like a tomato, both a fruit and a vegetable. There are so many definitions case definitions that some of the people who

were part of the initial outbreak of CFS in Nevada no longer meet the case definition, which leaves many to wonder what illness they really have. The fact that the CDC has had to declare CFS real and that Regional Health Centers still don't think it is real say a lot about the misnomers of CFS. I would hope that the CDC and NIH would be able participate CME/CEU programs around the country to educate health care providers, in the trenches so to speak, on how to diagnose and treat CFS. That starts with having some tools that can be used for diagnosis, such as those developed by Staci Stevens. And other evaluations that are measurable and objective. The science needs to move forward, and that can be done by private institutions like the WPI and public institutions like Dr. Klimas clinic at UM, but either way we need some evidence based medicine.