

Testimony

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Hello, I'm Dr. Joan Grobstein. I'm a physician.

I'm going to confine my comments mainly to the function of this Committee: to advise and make recommendations to the Secretary.

However, there are committee procedural issues that require comment. It is imperative that live web-based videocasts of the Committee be continued. Patients are not able to hold a phone for several hours and often cannot concentrate on a pure audio feed. The Committee's charter states, "To the extent possible, meetings are broadcast over the Internet as real-time streaming video". It was very possible to videocast this fall meeting. It should have been videocasted. Failing to videocast is a violation of the Committee's charter. Audio broadcasting is not an adequate accommodation for the disabilities of this patient population.

It is important to make the procedures for public testimony transparent and consistent. The Federal Register notice of this meeting states that "time slots for public comment will be available on a first-come, first-served basis". After the notice procedures seemed to change. Priority was initially given to people who have not testified before. Many patients have acquired considerable expertise over their years of testifying; their experienced voices should be valued and heard.

Turning to the important function of this Committee, these are the recommendations that are critically needed now:

1. Given the success of rituximab for the treatment of severe ME in a small Norwegian study, the NIH should issue an RFA for projects to elucidate the role of B cells in ME. An additional RFA should be issued for projects studying the mechanisms involved in post-exertional malaise, orthostasis, and oxidative stress in ME,

including possible viral or retroviral associations and potential therapeutic options. The rapid government response to XMRV has already been mentioned. We need a similarly rapid response to other important new developments. According to investigations done by Pat Fero and Charlotte von Salis, money that was allocated to ME/CFS research in the past appears to have been used for research that was not related to ME. This money should be traced and re-directed to promising avenues for further ME research.

2. Many citizens have testified about the inadequacies of the CDC website and the real world consequences of those inadequacies. The CDC website must be revised within 60 days.
3. This Committee already recommended rejecting the “empiric” definition of CFS in 2009. It should also reject the further use of the inexact Fukuda criteria and endorse the Revised Canadian Consensus Definition of 2010. The CDC must stop all research using the empiric definition as of tomorrow. Instead, the CDC must immediately begin epidemiologic and longitudinal studies of cohorts defined by the Revised Canadian ME/CFS Case Definition (2010), with special emphasis on cases that occur in geographic or family clusters.
4. A collaborative project between the CDC, HRSA, and AHRQ should be funded to identify and begin to care for the sickest, housebound and bedbound patients who often are not receiving any medical care at all. This is a national disgrace. Programs to deliver appropriate care to these patients should be in place within one year.
5. The ICD-10 coding issue should be solved in a way that prioritizes the practical needs of patients above the needs of researchers and statisticians. I am no expert on coding, but it appears that this is

best done by endorsing option 1, which is the preference of advocacy groups. If researchers or statisticians wanted their results preserved for posterity, they should have insisted on a more appropriate name and definition in the first place.

These five recommendations should be implemented by the spring meeting of this Committee. We need to move forward.

Thank you.