

CFSAC oral testimony 2 May 2010

Hello. I'm Dr. Joan Grobstein. Some of you already know me from my testimony in October, 2009, but for those who don't, I've had acute onset Myalgic Encephalomyelitis/Chronic Fatigue Syndrome, or ME/CFS, since 1999. Before my illness, I was a neonatologist at Children's Hospital of Philadelphia.

We have been asked by the Committee to address the issue of the Committee's Charter. I strongly endorse renewing the Committee's Charter with some revisions, which I will discuss. However, I do want to express my disappointment that the Committee does not want to hear testimony on other matters which I consider to be more urgent. I also want to point out the difficulty of saying anything of much use in a sound bite of three minutes.

I suggest the following changes to the Charter:

An additional advisory function should be added: to establish a consistent definition of ME/CFS and evaluate the likely etiology based on that definition. I strongly endorse the use of the Canadian Consensus Definition. The Committee should consider incorporating this definition into its Charter.

Two new ex officio members should be added: a representative from the Surgeon General's office, and a representative from the Agency for Healthcare Research and Quality.

Two new regular members should be added: a patient, and a nonprofessional patient caretaker.

The Committee should restart a schedule of meeting for two days four times a year in order to have time to address the myriad issues facing people with this disease. In my written testimony I have described a regular rotation of topics and addressed the need to organize and follow action plans and recommendations.

The Charter should ensure that all meetings are videocast live via the internet and be archived so that disabled patients can have access to them.

The Charter should require the Committee to produce a report after each meeting with details of requests for information from &/or action by federal agencies as well as recommendations to the Secretary. There should also be a description of the results of previous requests and recommendations. This report should be available on the Committee's website.

I have elaborated on each of these suggestions in my written testimony. Please read it.

In addition, we need increased funding for ME/CFS research, for a collaborative trials network, and for centers of excellence where patients can be studied and treated and

professionals can be trained. The Committee needs to address the issue of the ME/CFS case definition as soon as possible.

Thank you.