

Testimony

Denise Lopez-Majano

I would like to take this opportunity to welcome Dr. Nancy Lee and Dr. Anne Vincent to this committee.

This committee provides a vital link between those affected by ME/CFS and those who have the power and responsibility to marshal forces, which can change lives.

Before tackling the many problems we still face, we should celebrate some of the successes the CFSAC has created. But time constraints limit me to one example.

In October 2010, Dr. Gudrun Lange's presentation, "Cognitive Function in CFS: a measure of disability?" explained ways of assessing cognitive dysfunction. Corroborating the severity of disability (especially in those with ME/CFS) has always been problematic. Dr. Lange's presentation detailed supporting documentation that should be included in SSDI and SSI applications by those with cognitive dysfunction, as well as in applications for educational accommodations. Our family is among those that have directly benefited from this presentation.

The work of this committee is crucial to everyone affected by ME/CFS.

But, unfortunately, our work has not yet ended. Once again we are here to talk about things that **MUST** be attended to.

1) ALL ME/CFS patients need accurate, appropriate diagnosis by capable physicians, willing to provide appropriate care.

The definition of ME/CFS that is used for diagnosis, research, treatment, and awareness must be uniform and **must emphasize what is UNIQUE to ME/CFS in order to differentiate ME/CFS from other illnesses**. Use of a uniform definition ensures that patients are correctly identified, thereby giving greater validity to diagnosis, research findings and treatment.

I ask committee to lead this work by further encouraging the CDC to frequently, and widely distribute accurate ME/CFS information using a uniform definition that highlights what is UNIQUE to ME/CFS.

2) Widespread publicity of the hallmarks of the illness, **exhaustion after physical or cognitive exertion**, (along with any of the following: changes in ability to perform at school and/or at work; changes in processing speed, working memory in abilities to speak; sensitivity to light, sounds, and smells; orthostatic intolerance; vertigo; headaches; G.I. disturbances; etc.) will improve the accuracy and rapidity of diagnosis.

For far too long, patients have suffered while medical professionals, schools, and many others dismissively say, "this is all in your head".

Included in this ask is that the promised updates to the CDC website include explanations of what has been changed and why. Prompt widespread notification of all updates to the CDC ME/CFS website must also be provided in an ongoing manner.

We **MUST** ensure the development of appropriate social skills in young people with ME/CFS – especially in those who are housebound and horribly isolated because of the severe limitations imposed on them by the disease.

In order to succeed in interpersonal relationships, young people need to have appropriate social skills.

In order to develop those social skills, young people need to interact with others.

People affected by ME/CFS encounter insurmountable obstacles each day in their push to get diagnosed, get treatment, get appropriate services....

These obstacles can be eliminated through the work of this committee.

I ask that the CFSAC work aggressively to remove barriers that prevent patient participation in situations - especially those in educational environments.

Advocates must be empowered to intervene on the patients' behalf.

Studies to identify common barriers for ME/CFS patients must be conducted and those barriers quickly dismantled.

The solutions that work and that strengthen in-person and virtual networking opportunities for those involved, must be identified, implemented and widely publicized.

3) In May of 2011, the CFSAC recommended that HHS organize a workshop to engage experts in disability assessment, with the outcome being documentation of a more efficient and fair disability assessment process that will assist patients and adjudicators alike..

A fellow advocate and I are gathering information from a survey we developed about SSDI and SSI that will provide very useful information for this document. As informed patient advocates and with extensive knowledge about the unique disability issues regarding young people with ME/CFS, we offer our services to work with you to develop and implement this workshop.

Continuation of the hardworking leadership of this committee must be ensured.

The members of this committee have extensive knowledge about ME/CFS and the many concerns of the ME/CFS community. This knowledge has been acquired over many years and many members of this committee have served on the CFSAC for many years. We thank you for doing so.

As the CFSAC roster currently stands, the terms of seven of the eleven members of this committee will expire in 2014. The learning curve for seven new committee members at one time will be daunting and difficult.

I ask therefore, that this committee IMMEDIATELY implement an efficient way to stagger the terms of committee members, thereby ensuring there is no delay in the continuity of the important work of this committee. Additionally, the CFSAC charter must be amended IMMEDIATELY so that a similar situation does not arise in the future.

4) Real-time Livestream (archived promptly afterwards) must be provided for every CFSAC meeting/workshop.

The CFSAC by-laws stipulate it - "To the extent possible, meetings are broadcast over the Internet as real-time streaming video.

However, as we have seen with this meeting, a by-law stipulation is insufficient to ensure real-time participation by those who cannot attend. (My written testimony includes comments from some patients on the benefits of real-time Livestream.)

I ask that the CFSAC charter be amended IMMEDIATELY to include language requiring real-time Livestream to enable participation by everyone who cannot attend in person because they are too sick, and/or are too impoverished because of their illness.

5) Finally, we eagerly await the announcement of the upcoming presentation by CFSAC members, about the impact of ME/CFS on academic careers, at a Department of Education conference in 2012. Again, knowledgeable patient advocates are ready and willing to help you.

I ask that you tell us the details as soon as possible of your participation in this conference. I am willing to help, as are other families affected by early-onset ME/CFS. Let us support you, as you support us.

Thank you
Denise Lopez-Majano

Speak Up About ME – Invisible No More!

Additional important questions that deserve to be accurately answered SOON:

By the way – it seems that over the past ten years, \$18,539, 230 that were designated for ME/CFS research have gone astray. Make sure they are returned (with interest) for their original purpose.

In May 2011 the CDC told us about 2 e-learning initiatives.

What is the status of the "CFS Clinical Diagnosis and Management" and the second is "CFS and Sleep" initiatives?

How many households are there in the US in which more than one person has ME/CFS?

How many people in those households are not blood relatives and have ME/CFS.

Did these people become part of the household before or after they became ill with ME/CFS?

How many ME/CFS caregivers are there in the US?

How many ME/CFS caregivers are there in the US,

who are not able to work at paying jobs,

who do not have health and other benefits because they are not able to work at paying jobs,

who cannot pay into Social Security for themselves because they are not able to work at paying jobs because they are full-time caregivers for people with ME/CFS?

What is the impact on productivity in this country of more than one person in a household having ME/CFS?

What is the impact on productivity in this country of being a full-time caregiver for people with ME/CFS?

What is the impact on productivity in this country of being a full-time caregiver for households with more than one person with ME/CFS?

Patient comments on Livestream –

1. As for livestream, I think it is a huge help to those who can't manage the travel to DC, either physically or financially. It allows us to "be there" virtually. Audio only is no option at all because it is impossible to follow detailed presentations without being able to see the slides. I bet even the members of CFSAC wouldn't be able to do that, and people with ME/CFS are struggling with brain fog - it's enough of a challenge to follow these presentations even WITH the slides - without them, it is impossible.

As for the option of watching videos after the fact, I write a CFS blog with over a hundred readers each day ... , and many people who can not manage to absorb the information on their own rely on me to provide summaries of what went on in the meetings. Any delay means that all those people are kept in the dark.

2. A live streamed videocast with captions has allowed those with ME/CFS to participate in past CFSAC meetings. Watching the meeting live means members of this community can text or email those at the meeting so that timely questions can be asked even by those who cannot be present. It is one of the few ways people with ME/CFS can participate in the meetings as most are too ill and poor to attend in person.

3. I have had numerous e mails from international patients who feel bad, sad, and robbed because the (real-time livestream) meetings were important to them...offering hope that the members...our researchers are on our side. PRE live stream, I had continuous disagreements with people about how the committee members were pawns, uncaring, ornaments. (Real-time livestreaming video allows disabled patients to be part of these meetings despite their disabilities.)

4. Livestreaming the CFSAC meetings is a reasonable accommodation for the disabled CFSAC patient population too ill and too impoverished by their illness to attend. In the past, patients who have attended remotely via live video streaming have participated in Advisory Committee meetings, and made their views known to and through members in physical attendance by tweeting and texting.

Access to an archival version of the meeting's proceedings even one day, much less one week, after the meeting is adjourned denies patients wishing(/needing) to attend remotely the possibility of participation. Access to post-facto archival versions of CFSAC meetings is not a

reasonable accommodation for handicapped accessibility to on-going meetings.

If an archived version of the meeting can be posted one week after a federal advisory committee meeting, or within one week of a federal advisory committee meeting, then live video streaming of what will become the archived feed is more than a reasonable accommodation for having those patients too ill to attend participate in the meeting.

5. How can it cost less to produce the same product a week later? And are all the other government live feeds being cancelled? And do they have the following that this one does? And are their listeners not attending because they are disabled?

Comments made during CFSAC meetings by then Federally Designated Official, Dr. Wanda Jones as well as members of the community about the benefit of the livestreaming of the CFSAC meetings.

"Dr. Jones

Noted improvements to the U.S. Department of Health and Human Services' website, including future integration of historical notes, and significantly improved traffic to the CFSAC, especially for webcasts."

<http://www.hhs.gov/advcomcfs/meetings/minutes/viewattachment.pdf>

"Pat Sonnett (during her public comment time slot said)

Addressed four points about the CFSAC charter:

Called for the charter to include a provision for the video webcasting of CFSAC meetings. If webcasting is not in the charter, it could be removed at any time.

Joan Grobstein (during her public comment time slot said)

The charter should require real time and recorded video casts of CFSAC meetings as a necessary accommodation of ME/CFS patients.

Dr. Jones suggested that the committee also address webcasting in the bylaws so that changes can be made to accommodate technological advancements.

Dr. Jones said that schedules vary among the other 150 advisory committees and include teleconferencing, webinars, and site visits.

Webinar-Based CFSAC Meeting

CFSAC members unanimously approved the following recommendation: CFSAC recommends to the HHS Secretary that she ask Dr. Jones' office to actively explore the feasibility of a webinar-based third CFSAC meeting in 2011 based upon the value of carrying on a meeting in that format.

http://www.hhs.gov/advcomcfs/meetings/minutes/cfsac051010min_pdf.pdf

"Dr. Wanda Jones

- Noted that the web cast of the May 2009 CFSAC meeting attracted more than 100 views on day one, 70 views on day two, and hundreds of downloads.

Dr. Jones then informed meeting attendees of several logistical matters

CFSAC staff is committed to the continuing accessibility of web casts of future meetings. A preliminary count of the previous day's webcast views totaled about 400.