

## **Public Comment** **Alexander Lopez-Majano**

Greetings to each of you and welcome to the new CFSAC committee members.

1. YEA LIVESTREAM!!!!!! We are glad you listened to us. Watching the CFSAC via LiveStream (web casting/whatever the term) helps people with ME/CFS who are unable to attend the CFSAC, participate in and be part of the CFSAC meetings.

2. Please note - many patients have altered wake/sleep cycles, quite variable health, and are severely disabled, meaning there is no guarantee they can be awake or well enough to give public comment by phone. Participation via DVD or webcam, like the option to participate in the CFSAC via LiveStream, makes the meeting more accessible to patients and enables patients who often live in isolation, to be part of the CFSAC meetings. Providing public comment via DVD or webcam is a very reasonable option, and is one that is **inclusive** for a very disabled population.

3. In October of 2008, the CFSAC made the following recommendation:

“CFSAC recognizes that much can be done to ensure that every child with CFS has the best possible access to support and treatment and asks that the Secretary facilitate a taskforce or working group to establish an ongoing interagency and interdepartmental effort to coordinate school, family, financial, and health care support for children and young adults with CFS.”  
We are still waiting for this taskforce.....

Therefore the CFSAC charter must be strengthened to recognize that CFSAC committee members are THE designated DHHS experts on ME/CFS. Recommendations of the CFSAC, like the one above, must be treated as recommendations made by experts and acted upon accordingly and diligently.

4.. I have read, and I endorse the Joint Letter of Concern.

I endorse the proposal that the “CDC adopt the IACFS/ME primer as its new baseline and collaborate with international ME/CFS experts and patient organizations to refine it where needed and to proactively educate the medical community. “

5. I want it on record though that I have serious concerns about the title of the IACFS/ME's new “subscription-based peer review journal titled: *Fatigue: Biomedicine, Health and Behavior.*”

The title of this new journal does not give warm, fuzzy feelings. Instead, because of its association with the IACFS/ME, it perpetuates the notion that this illness is a result of behavior and that changing behavior will make one well again. **WOULD THAT IT WERE THAT EASY.** If it *were* that easy, more than a million Americans would back to a full life because, believe me – we have tried changing our behavior and we didn't get well! Instead ME/CFS remains imposed on my life (and theirs) without anyone's invitation. I want to be living my life to the fullest, studying, spending time with friends, working, being an independent adult.

6. The points in the Joint Letter of Concern must be enacted to get me there.

The Department of Health and Human Services must undertake a strategic, coordinated, and fully-funded effort to address the critical priorities for adequate ME/CFS research, treatment and provider education.

The ME/CFS strategic plan must be a coordinated and fully funded effort to finally *solve* ME/CFS.

Additionally, the ME/CFS strategic plan must”

1. “Resolve the definition, name and classification confusion
2. Provide a fair share of research funding, focused on biological pathologies, biomarkers and treatment
3. Educate the medical community
4. Accelerate the FDA pipeline for ME/CFS”\*

The ME/CFS strategic plan must result in easily accessible treatments that help patients, caregivers, medical professionals (and everyone else) improve the quality of patients' lives while decreasing disability and sickness.

The ME/CFS strategic plan must start NOW, because, as I said last November at the CFSAC meeting, *I want my life back and so does my brother!*

\*Joint Request from the ME/CFS Community for Action