

My name is Denise Lopez-Majano. I am the mother of 2 teens with severe ME/CFIDS and orthostatic intolerance. Matthew became ill 2 days after his 12th birthday in 2005 with a very sudden onset of ME/CFIDS which rendered him immediately housebound. He is now 17 years old. Alexander's health deteriorated gradually over the course of about 18 months (beginning at about age 14) until he also became housebound in 2007 at the age of 16. He is now almost 19.

This committee often hears testimony about how debilitating ME/CFIDS is. Dr. Nancy Klimas said in The New York Times, "My H.I.V. patients for the most part are hale and hearty thanks to three decades of intense and excellent research and billions of dollars invested. Many of my C.F.S. patients, on the other hand, are terribly ill and unable to work or participate in the care of their families." (<http://consults.blogs.nytimes.com/2009/10/15/readers-ask-a-virus-linked-to-chronic-fatigue-syndrome/>)

Matthew made the decision to be here with me at the CFSAC meeting last October 29th. It took him more than **three** weeks to get back to where he had been fatigue-wise, and longer in terms of brain fog, before he made that one-day trip. We can all understand his reluctance to put himself through something like again. As of the 26th of April, I do not know if either of my sons will attend the meeting on the 10th of May 2010.

I have nothing earth shattering to tell you about this illness, just more of the same sort of things that have often been heard in testimony here.

Looking at my sons, people cannot tell that they are ill.

And yet:

My sons have been housebound all, or most, of their teen years.

My sons have not learned to drive because they do not think their reaction times are quick enough to be safe drivers. Matthew is concerned also that he might have a syncopal episode (orthostatic intolerance related) while driving, which could be quite a hazard. (He sometimes has syncopal episodes just rolling over in bed, he has them daily while sitting in his chair.)

My sons had to give up competitive swimming, something at which they excelled, because they could not recover from one practice to the next.

My sons have never broken a curfew, because the only places they go are with one or both parents.

For years, my sons have not been able to attend school on a regular basis. Even homeschooling can only happen at those times when they can handle it, because of the drain that cognitive efforts have on their energy.

For years, my sons have been unable to take part in extended conversations, because of the drain on their already scant energy and the overload on their senses.

For years, my sons have not been able to go out with friends, they have never gone on a date.

For years, my sons have tried an array of different medicines for their symptoms, and, sad to say, most resulted in either negative side effects or were of no benefit to them.

For years, my sons have been housebound and incapacitated by this AWFUL syndrome.

(We, refers to my family and everyone personally or professionally affected by this syndrome.)

We **NEED** this Committee.

We need to have its charter renewed.

We need to have this committee meet more than two times a year – preferably four times a year.

We need to know, in a timely fashion, who replacement committee members will be. It has been more than 6 months since names were submitted for consideration to replace outgoing members.

The names of new members ought to be released no more than 30 days after a CFSAC meeting.

We need to know the agenda of the upcoming meeting at least 30 days in advance.

We need to have the live-streaming video (greatly appreciated!!!) of the meetings embedded in the committee charter.

We need follow-through on the committee recommendations.

We need to have the status of the committee recommendations posted and updated in a timely manner.

WE NEED YOUR HELP.

We need to solve ME/CFIDS and give everyone affected by the syndrome, back the lives we each deserve!

Help us get this accomplished **soon**.

Thank you,

Denise Lopez-Majano (and Alexander and Matthew Lopez-Majano)