

## Testimony

Harriet York

Dear Dr. Lee:

I submit this as my written testimony to the CFSAC for the November 8-9, 2011 meeting. I am not requesting time for oral testimony, but do request that my written testimony be distributed to the committee members.

I would first like to thank all the committee members for their time, dedication and service to the ME/CFS patient community. We are truly grateful for your service.

**At this time, I would like to concentrate on four specific areas of concern.**

1. ICD-10-CM: Please issue another strong recommendation that Chronic Fatigue Syndrome be classified in the ICD-10-CM under diseases of the nervous system at G93.3. I submitted written testimony to the ICD-9-CM Coordination and Maintenance Committee meeting on September 14, 2011, stressing the importance of this classification and indicating that treatment options, insurance reimbursement, and disability claims are directly affected by the proper ICD coding. There is no need to go into further detail here as this committee is already fully aware of the situation and has previously recommended the G93.3 classification.

2. Update CDC Website: Please issue another recommendation that the CDC website be updated to reflect current state of knowledge and expert opinion for ME/CFS management in full partnership with organizations representing ME/CFS clinical and scientific expertise. The current website is having a negative impact on patients in that the insurance companies are using the information contained therein to deny testing

and treatment. See Aetna Clinical Policy Bulletin on Chronic Fatigue Syndrome at

[http://www.aetna.com/cpb/medical/data/300\\_399/0369.html](http://www.aetna.com/cpb/medical/data/300_399/0369.html) which specifically denies coverage based on the CDC recommendations.

3. Live-stream Video of Meetings: While I understand the reasoning, I specifically request that all future CFSAC meetings be made available by live-stream video. Most patients are unable to attend the meetings because of health and financial limitations, but many do “attend” when it is available by live-stream video. Having to call a number to listen to a two-day meeting is very difficult because it would tie up a patient's telephone line for two full days and, if using a cell phone, it would completely drain the battery. We have come to rely upon the live-stream video to identify the person speaking and keep up with the proceedings. It is much more difficult to do this if we can't actually see what's going on.

4. Tissue and Organ Biobank: I request that a repository for ME/CFS tissue and organ samples be established. There are a number of biobanks that have collected samples of ME/CFS patients' blood, but there doesn't currently seem to be any location where patients can donate tissue samples for ME/CFS research. There are many of us who have had this illness for decades and, as part of the general aging process, are making arrangements for burial or cremation upon our demise. I'm sure there are many who would be willing to donate organs or organ tissue to be used for ME/CFS research. I would think that much valuable information could be gained from such research and it would be a shame to pass up the opportunity to collect such valuable data.

Thank you once again for your hard work and your professionalism. If this is the last meeting for Drs. Klimas, Jason and Snell, I extend a special thank you to each of you. Your contributions have been invaluable and you will definitely be missed. May the future bring only good things for each of you.

