

**Public Comment**  
**CFSAC | December 2014**  
**Jennifer Spotila**

You have asked for testimony on Centers of Excellence and patient registries, yet you gave us less than a week's notice of those interests before the written comment deadline. I'm sure I am not alone in being unable to prepare comments on such short notice.

I also note that your agenda is devoid of any discussion of what has happened to your recommendations this year. Your June recommendations to NIH were both denied. And I must publicly call on you to take note of what happened to your March recommendations.

As detailed in correspondence I have shared with this Committee, and explained on my blog at [occupycfs.com](http://occupycfs.com), your March recommendations on medical education were substantively and materially changed after your vote. Your recommendation that research funding be commensurate with the impact of ME/CFS was deleted. Your remaining recommendations were altered from your original intent.

Circumstantial evidence I have obtained through FOIA suggests that these illegal changes were made by Dr. Gailen Marshall and Dr. Nancy Lee, likely without the knowledge of the rest of the Committee. These invalid recommendations were then sent to the Secretary, and the Department responded to them in September.

When I discovered this violation of the Federal Advisory Committee Act, I contacted Dr. Sue Levine who made efforts to correct the violation. However, after the Department formally responded to the illegal recommendations I wrote directly to the General Counsel of HHS on September 29<sup>th</sup> asking that the original recommendations be restored.

I received no response. But then on or about October 7th, the CFSAC website was changed. The illegal recommendations and the Department's response to them was removed, and a new version of the recommendations that is very close to what appears in the March meeting minutes is now posted. On November 21<sup>st</sup>, an acknowledgement letter from Secretary Burwell was posted to the website, but that letter is dated June 20<sup>th</sup>. I have received no confirmation that the restored and correct recommendations were actually sent to the Secretary in October.

CFSAC members, this was done in your name. Those illegal recommendations appear to have been created without your knowledge, and were sent to the Secretary as a representation of your advice. You cannot remain silent. You cannot allow a few individuals to subvert your advice for reasons unknown. Your hard work and expertise deserve a fair hearing. If the Department is going to continue to reject this Committee's recommendations, at least let it be your actual recommendations. I ask this Committee to speak out on this latest FACA violation. You must do more to ensure compliance with federal law, because it is clear that HHS staff will not. I ask that you establish whether your actual March 2014 recommendations have been sent to Secretary Burwell, and that you be more vigilant on behalf of the people with ME/CFS you are here to serve.