

My name is Billie Moore, and I am a patient advocate speaking for myself.

Recently Jennie Spotila discovered that the March 11, 2014, CFSAC recommendations to be forwarded to the Secretary of the DHHS were changed from their original wording and falsified. She spoke of this yesterday, and I would like to add more details.

These changes were not minor wordsmithing. Six of the seven recommendations were significantly changed by eliminating any references to the Canadian Consensus Criteria definition as the one to be used as the definition of ME/CFS in HHS projects. The recommendation that was totally eliminated was the one that CFSAC deemed most important – fund all initiatives recommended: (quote) ***CFSAC recommends that the Secretary fund ME/CFS commensurate with the epidemiological prevalence and economic burden that this disease imposes on our American society.*** (endquote)

I repeat: all references to the CCC and funding were removed. Can it be made any clearer what HHS's true commitment is to ME/CFS and the patients? They have none. It is all lip service. The CCC will not be adopted. Funding will not be appropriated.

This falsified set of recommendations was sent to the Secretary of the HHS in April 2014 along with an explanatory letter. They were also posted on the official federal CFSAC website.

These acts were illegal – in violation of the Federal Advisory Committee Act. It was perpetrated by a federal official – the Designated Federal Official of CFSAC, Dr. Nancy Lee, and the volunteer chair of CFSAC at that time, Dr. Gailen Marshall, either on their own or under pressure from higher-level HHS officers. This action showed utter disregard for the CFSAC members who wrote the recommendations in good faith and utmost seriousness. It also showed contempt for the ME/CFS community.

The correct recommendations are now posted on the CFSAC website. However, no corrective letter has been sent to the Secretary, and the (now previous) DFO, Nancy Lee, refuses to share any corrective letter with the public. There also seems to be no timeframe for when that letter will be sent. What new illegality is now in the works?

The obvious question arises from this situation and 10 years of the HHS' adopting almost no CFSAC recommendations – what are we doing supporting CFSAC by attendance at meetings and willingness to sit on CFSAC? Volunteer members are not respected or appreciated if their work can be changed or totally disregarded.

We can continue to pretend that the people in HHS at decision-making levels are listening to CFSAC and patients. Or we can face reality by judging the results of CFSAC's past requests for RFAs for research funding, Centers for Excellence, adopting the CCC as the definition of ME/CFS, updating the CDC's Toolkit, and many other needs to help the patients. These things are just not happening; we are not being listened to.

It is up to each voting and non-voting member of CFSAC and the public to determine at what point we stop trying to help patients through CFSAC when the HHS management is utterly opposed to our ideas. We must stop enabling the HHS to use CFSAC as their pretense for accommodating patient needs. If we don't, we will be in the same spot, making the same sort of recommendations – to no avail - in 2024.