

Public Comment
CFSAC | December 2014
Claudia Goodell

Since being diagnosed with ME/CFS a decade ago I have aligned myself with other active advocates, have made learning about this disease a priority, and do my best to create awareness within and without the patient community. Having a chronic disease causes one to compartmentalize time – time before diagnosis and time since diagnosis. It doesn't take long for one in this position to become aware that the overall gross mismanagement of this disease has adversely affected the patient population, and when a new advocate talks to a long-time researcher or veteran advocate it quickly becomes evident that this has been happening for a very long time. Despite the many obstacles created by this mismanagement our handful of dedicated researchers and clinicians have made several important discoveries, and identified biomarkers, mostly in small studies due to limited funding. What remains frustrating and damaging are the limitations this mismanagement has placed on these processes. When patients are forced to live within the limitations of THIS disease day after day, month after month, year after year, decade after decade it feels as though progress of THIS disease has moved at an archeological pace.

Since writing the above introduction and main points attached at the end of this document, I learned that the Spring CFSAC recommendations sent to then secretary of health Kathleen Sebelius were seriously and illegally altered in wording and content, and it seems this was done with purpose, and without the knowledge of the majority of CFSAC members or the public.

The details of this violation against the Federal Advisory Committee Act (FACA) are explained in a [blog post by Jennifer Spotila](#), which contrasts the vast differences between the original recommendations voted for during the Spring CFSAC meeting to those actually submitted to the secretary of health. The differences are stark and substantive.

This committee exists to serve patients through their recommendations to the Secretary of Health and Human Services, and is governed by the provisions of the Federal Advisory Committee Act, as amended (5 U.S.C., App.), which sets forth standards for the formation and use of advisory committees. The illegally altered recommendations which were submitted are clearly a violation of this federal act, and responsibility for this falls directly on the Designated Federal Officer and the committee chair.

As a patient who expects to be served by this committee I demand the following:

- 1) That the original CFSAC recommendations voted on by the entire committee at the Spring 2014 meeting be submitted to the current secretary of health as a replacement of those previously and illegally submitted,
- 2) That proof of receipt of this new submission be publicly documented, and
- 3) That the current Secretary of Health acknowledge this violation, as well as the secondary violation which occurred when these illegally altered recommendations were responded to by the Department.
- 4) That those individuals who were involved in or who had knowledge of this violation must be held accountable in a manner commensurate with this illegal activity.

Details can be read here: <http://www.occupycfs.com/2014/11/24/another-cfsac-violation/>

Thank you,

Claudia Goodell
Race to Solve ME/CFS

Claudia Goodell Original Testimony to CFS Advisory Committee written prior to receiving the above information:

It is time for those departments within the U.S. government under which THIS disease falls to listen to the real experts who research and treat THIS disease, and follow their lead in endorsing the most appropriate and dynamic diagnostic criteria and case definition, requiring PEM/PENE as a hallmark symptom, and to then educate the medical community about how to properly diagnose THIS disease.

It is time for the CDC and NIH to stop aligning THIS disease with the symptom idiopathic fatigue, a faulty focus which has allowed THIS disease to become diluted by the inclusion of patients with primary depression, Multiple Sclerosis, cancer, and other yet unidentified diseases, and which has negatively impacted research, funding, diagnoses, treatment, statistics, insurance reimbursement, disability, etc.

It is time for the CDC and NIH to call THIS disease by a name that describes what is evidenced in the many biomarker studies, STOP using the word fatigue and STOP trying to relate THIS disease to any illness with idiopathic fatigue, and STOP assuming that THIS disease is a sub-category of a wastebasket entity of unrelated patients.

It is time for the U.S. government to assign THIS disease to an appropriate medical specialty in order to secure more funding, attract more researchers, to focus the study of treatments, to help identify etiology, properly funnel patients, and successfully engage the medical community.

It is time for the CDC and NIH to end any and all references of THIS disease to somatoform illness, psychological and/or psychiatric or mental illnesses, and the protocols used to treat those entities, which when improperly applied have been shown to be harmful to patients with THIS disease.

It is time for the CDC and NIH to consider the plethora of scientific data that support a neuroimmune basis for THIS disease, which is characterized by post exertional relapse of neuroimmune symptoms.

It is time for the NIH to fund large studies to replicate the findings that brain abnormalities exist in patients with THIS disease.

It is time for this committee's recommendations to not only be heard, but for them to be properly executed in service to the millions of patients who have been mistreated and who have gone

invisible for too long. The high burden and cost of THIS disease in lost productivity alone is staggering, and as a highly educated patient who lost the ability to continue in my profession, participate in my pre-disease volunteerism, and athletic endeavors I remind you that I still want to do all those things that THIS disease has taken from me, and I still hold hope that recovery is possible for me. It is time.

Thank you for your time,

Claudia Goodell

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