

## CFSAC Written/Public Comment

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(Note: Below is my written comment which contains variations/edits from my public comment because HHS imposed severe time restrictions on speakers during the CFSAC Meeting)

Good morning. My name is Eileen Holderman - I'm an advocate for ME, GWI, and other neuroimmune diseases.

Welcome to the new Committee Members, especially the new Patient Advocate. I wish all of you the very best going forward. Sometimes it's important to look back to see what stands in the way of moving forward.

For the past 4 years, I served as the Patient Advocate on the CFS Advisory Committee; was Chair of 2 Subcommittees; and was a member of the Leadership Committee.

The Leadership Committee helps to set agenda for CFSAC Meetings. About 2 years ago, we managed to get the critical issue of case definition on the agenda.

After, in October, 2012, CFSAC made a recommendation to convene a workshop using only ME/CFS experts (researchers, clinicians, advocates, and patients) to reach a consensus on a research and clinical case definition starting with the Canadian Consensus Criteria (CCC).

Thereafter, in Subcommittee Teleconferences, HHS began to hijack CFSAC's recommendation and impose their will. Committee Members objected to all the changes HHS tried to make to our recommendation. In my Subcommittee for Education, Patient Care and Quality of Life, HHS began tampering with our recommendation which led to conflict. In Jordan Dimitrakoff's Subcommittee for Research, which I attended as a guest, similar contention arose when Committee Members sought information about the NIH's Evidence-based Methodology Workshop (EbMW), now named the Pathway to Prevention (P2P). Many of us asked why another HHS initiative, that in part was to address case definition, was needed - because we just made a recommendation to convene a workshop to address case definition. We expressed concerns about the NIH P2P such as: costs, timelines, the use of non-experts in ME/CFS, no patient input, and no transparency. Soon after, Jordan Dimitrakoff permanently shut down the Research Subcommittee.

Next, 3 CFSAC Members received phone calls from the Designated Federal Official (DFO), who used intimidation tactics and the threat of eviction from the Committee for expressing our views - the very thing we were called upon to do when we took the official pledge to serve.

Then I was removed from the Leadership Committee, which resulted in no patient input into the CFSAC agenda for the past year and a half.

During the May, 2013 CFSAC Meeting, I publicly disclosed that I and 2 fellow Committee Members were threatened. HHS did not take the allegations seriously - but advocates did. Advocates sent a letter to General Counsel, with over 40 signatures from independent advocates and advocacy organizations, asking for an investigation. Months later, Dr. Howard Koh, Assistant Secretary of Health, sent a letter in reply which the ME community viewed as completely dismissive.

While I don't wish to speak about the personal effects of the threats, I want to talk about it as it applies to how HHS continually dismisses and obstructs the good work and authority of CFSAC.

HHS's mission to silence Committee Members is indicative of how they have operated in secret, with an iron will, and with disdain toward the ME community.

Instead of implementing CFSAC's recommendation for a case definition workshop with ME/CFS experts, HHS embarked on an aggressive campaign to redefine ME/CFS and enlisted the aid of NIH, CDC, HRSA, ARHQ, and The Institute of Medicine (IOM).

HHS did this in spite of mass opposition to their 3 initiatives (IOM, P2P, CDC Multi-site Clinical Study) from the ME community such as:

- \* 50 ME/CFS researchers and clinicians signed the Expert's Letter urging HHS to refrain from reaching out to groups such as the IOM to redefine ME/CFS using non-experts, because they reached a consensus on a research and clinical case definition called the Canadian Consensus Criteria (CCC). The experts also urged HHS to adopt the CCC in all Government agencies.
- \* Over 170 advocates wrote a similar letter as the experts to HHS.
- \* Nearly 10,000 patients, caregivers, advocates, and medical professionals signed 2 petitions stating objections to the HHS/IOM Contract and urged HHS to adopt the CCC.
- \* Advocates appealed to Congress with calls and meetings on Capitol Hill.
- \* An advocate-attorney filed a law suit in US District Court against HHS and NIH for non-compliance with a FOIA request pertaining to the IOM Contract. That same attorney filed legal complaints with the Office of the Inspector General for IOM's organizational conflict of interest and related legal issues.
- \* Attorney-advocates filed FOIA requests pertaining to the HHS/IOM Contract.
- \* Advocates participated in radio, TV, and online interviews with the press about HHS's plans to redefine and rename ME/CFS.
- \* Advocates demonstrated in San Francisco and Washington, DC to protest the HHS/IOM Contract.
- \* Advocates from the ME/CFS community collaborated with advocates from the Gulf War Illness (GWI) community because of similar concerns with the VA/IOM reports.
- \* Advocates submitted a position paper, wrote articles, blogs, and opinion posts on Internet forums to protest the HHS/IOM Contract.

HHS has not listened to the 50 ME/CFS expert researchers and clinicians who sent the letter to Secretary Sebelius; nor have they listened to the advocates, patients, caregivers, or stakeholders.

HHS's mission is to control the message - they decide who can speak and who is silenced, who is on the Advisory Committee and who is off the Advisory Committee, what information they will divulge and what information they will hide.

HHS's mission is to redefine ME/CFS with yet another broad, erroneous case definition, which will include countless people who do not have ME/CFS, so they can recommend CBT, GET, and anti-depressants, and so they can bury the scientific, biomedical evidence of ME/CFS. HHS will then not have to fund research into this biomedical disease or fund clinical trials or pay for long term disability and other Government entitlements. Once HHS develops their new definition and name for this disabling, neuroimmune disease, they will embark on their next phase of (mis)educating the medical and scientific communities, the press, and the general public. HHS is acting in bad faith toward the ME community.

Last December, during a CFSAC "webinar," I thanked many people in the ME community, especially my fellow Committee Members, the 50 ME/CFS experts, and the advocates. So, I will end with a special acknowledgement of one advocate, Jeannette Burmeister, whose intelligence, resilience, and courage inspires me and other advocates in our movement to help the 17 million worldwide suffering from ME.

Thank you.