Public Comment
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The relationship between ME/CFS advocates and the federal government has never been very good, and there have certainly been many low points like the CDC misappropriation of funds in the 1990's. But in the last two years, we've been on an increasingly slippery slope down to new depths.

- When we asked for a national strategic plan, we were told HHS already had too many plans.
- When we asked for the prioritized outcomes from the NIH State of the Knowledge meeting, we were told this would not be shared with the public.
- When we asked for research funding commensurate with the burden of illness, we were told there are not enough grant applications.
- When we asked for the CFS SEP rosters, we were told this information – public for every other NIH grant review panel – could not be released due to undisclosed security concerns.
- When we said that the CDC multisite study should include 2 day CPET and natural killer cell function as candidate biomarkers, we were told financial and logistical constraints prevented the use of these tests.
- When I requested documents regarding voting member appointments to CFSAC, I was told the Office of Women's Health did not keep such records. Unsurprisingly, a FOIA request revealed just how much documentation is indeed kept.
- This Committee has admitted to one violation of the Federal Advisory Committee Act, and I believe there may be more.

It's not just members of the public who receive this kind of dismissive treatment. It's the voting members of CFSAC, too:

- When you asked at your last meeting for information on the planning of the NIH Evidence-based Methodology Workshop, NIH promised to release that information soon. It hasn't happened.
- When you asked to see a copy of the revised Toolkit before CDC releases it, CDC responded, "We don't do that."
- When you recommended a meeting of ME/CFS experts and stakeholders to arrive at a single consensus definition for clinical and research use . . . well, we all know what happened with that.
- When HHS planned their response to that recommendation – the contract with IOM – they intentionally kept you in the dark for months.

The dismissal, the stiff-arming, and the disrespect have accelerated even since the last meeting of this Committee.

- Claiming budget cutbacks, this meeting is being held by webinar. I have looked and found no other advisory committee in the Assistant Secretary's office that has done so. Only this Committee. Why? Is HHS that concerned about silent protests from patients? Is HHS that unconcerned about the Committee's ability to interact with one another face to face, to have a free communication outside the official public sessions?
- The IOM sole source solicitation was found by advocates, formally announced by CFSAC support staff, withdrawn, then a contract was pursued, finalized and announced again.
- Protests from the scientific, medical and advocacy communities have been ignored so thoroughly for so many weeks that it's as if federal employees have their fingers in their ears and are chanting "la la la la I can't hear you."
- Eight weeks – eight WEEKS – after the IOM contract is signed, the CFSAC support staff issued an FAQ to address the community's questions about the contract. Since I have less than five minutes remaining, I cannot even begin to pick apart the ways in which these proffered answers fail to answer anything at all, but have documented it here: http://www.occupycfs.com/2013/11/18/faqchecking/

You might think that this is enough. You might think that I have no more complaints to lob at the government's feet. But sadly, even the integrity of this Committee has been undermined.

- The membership and expertise of this Committee has become increasingly unbalanced. FACA requires that members of this Committee have sufficient expertise related to ME/CFS, and that a balance of views and areas of experience be represented. Of the eleven voting members, there are eight clinicians and researchers, but only four have a substantial focus on ME/CFS.
- The last three members appointed to the Committee, one of whom resigned after a single meeting, all nominated themselves and all live in the DC area. My FOIA requests have produced no supporting documentation beyond these members' self-nomination letters – no recommendations from patients or advocates, not even references from colleagues or other CFSAC members.
- At the May 2013 meeting, two members of this Committee publicly alleged that Dr. Lee attempted to intimidate them for expressing their points of view, possibly even remove them from this Committee. There was no reaction by the Committee's leadership whatsoever. Therefore, we requested an investigation, and were then ignored for more than four months. When an answer finally came, Dr. Koh dismissed the entire thing as a confidential discussion about FACA rules. He said everyone should conduct themselves in a manner conducive to respectful and candid discussions, while ignoring the elephant in the room: the allegations that the DFO had done precisely the opposite.

These allegations and Dr. Koh's failure to address them have undermined the credibility and integrity of this Committee. I do not see how the public can believe that any of you are voicing your honest opinions and advice when there is a cloud hanging over the DFO and at least two or three of your fellow members.

The Institute for Clinical Research Education at the University of Pittsburgh says, "Effective communication takes place only when the listener clearly understands the message that the speaker intended to send."[1] Many people believe that communication between HHS and the ME/CFS community is about as far from effective as we can get.

That is, unless HHS intends to send the message to the ME/CFS community and to you, CFSAC members, that it does not care what we think, it does not want our input, and it does not intend to do anything beyond or better than what it is already doing. That's what I'm hearing. If HHS intended to send *that* message, then perhaps its communications are perfectly effective after all.

The further we go down the slippery slope of the deteriorating relationship between the government and the ME/CFS community, the faster we slide. Advocates have not sat back, complaining about the government and this Committee without trying to improve things. I've personally participated in multiple efforts to engage with HHS staff, to calmly convey the advocacy point of view, and to suggest ways to improve the engagement and operation of this Committee. With a few minor exceptions, like the renewed acceptance of video testimony, those efforts have failed.

There are three overarching themes to ME/CFS advocacy on federal policy. The first is the demand that our disease be researched to the fullest extent. The second is the demand for clinical care tailored to this complex disease, not stamped with a one-exercise-program-fits-all approach. The third is the demand for transparency and accountability for what our government does.

HHS is failing on all three counts. CFSAC members, you can be part of the solution, or you are a part of that failure. There are no sidelines, here. There is no neutral ground. Not anymore. I fear that things are too far gone for that.

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[1] http://www.icre.pitt.edu/mentoring/effective.html