

April 26, 2010

Dear Dr. Jones and the CFSAC Committee Members:

I'm writing this letter to you at the request of a friend of mine, and fellow sufferer of this terrible disease. I have to be honest with you, because I have to be true to myself. I would not be writing this if I hadn't promised that I would. I am way too ill, and too physically and cognitively impaired to be wasting my precious little energy, struggling to put intelligent sounding words to paper, that always seem to belie the thoughts that are actually running around in my head; all for the benefit of a committee and government that has done absolutely nothing to help the community of CFIDS/ME sufferers except give good lip service when it wasn't stating that we are all hypochondriacs who would be best served by psychiatric counseling. If I sound bitter and angry, it's because I am. I have been sick for decades. I pushed and pushed and pushed my body until I could no longer push it, until my brain had turned to mush, a combination that was deadly to the career of a healthcare CPA, who didn't know what it meant to work a 40 hour week, to have a cognitively impaired brain, and a body in a state of collapse. I haven't been able to work since 1996. I haven't had a PCP since 2003, because I'm too "complicated," which in healthcare jargon means 1) "I don't believe in CFIDS/ME," and 2) "an office visit with you will take longer than the 10 minutes that your insurance or Medicare will pay me for your visit, and I have to make a "living,"" I'm about to lose my husband because he cannot take working full time, grocery shopping, cooking and taking care of me anymore. So yes, I'm angry, I'm jaded, and I don't trust – particularly our government and any entity or agency associated with it. That being said, there is still a part of me that hopes: hopes that maybe this time.....they'll listen, they'll do something besides give good lip service, that maybe with the XMRV connection (and by the way, I'm positive for XMRV), and the world arena watching how the U.S. government will behave – will it step up to the plate or try to bury it like they did at Lake Tahoe back in 1984.....maybe, just maybe, they'll do the right thing by its very ill citizens finally....yes, I would LOVE to have my doubts disproved....and so I write this letter with at least a smidgeon of hope that maybe this time.....

Therefore, I respectfully suggest/request that the CFSAC:

- 1) Renew the charter that expires in September as that way there is already a structure in place from which to work with, but with amendments to the charter, so that the CFSAC might actually be a working and viable committee.
- 2) The committee should meet NO LESS than quarterly, so that it can keep up with, and disseminate information more timely and efficiently.
- 3) That when the committee does meet, it does so for two full days, to allow adequate time to get all of the current research and information out, and to allow time for public input without rushing through it – and all committee members will remain for the duration to be there for questions and answers, instead of catching planes home in the middle of day two proceedings.

- 4) That public comments between each session remain at at LEAST five minutes, as anything less does not allow enough time for comments to be made clearly enough for all to understand, and which also respects the slower brain processing time that affects many, if not most of us, that suffer from this dread disease.
- 5) That replacements for outgoing committee members be filled in a timely fashion, thereby giving the new members the time needed to get up to date with where the committee has been, where it is at present, and hopefully where it is headed. Anything less is disrespectful to both the new members and to the CFIDS/ME community – and is only further evidence that the committee exists for lip service only.
- 6) That the dates of meetings and the agendas be posted in a timely fashion so that the public, i.e. the very sick and barely surviving the daily activities of day to day living, which many of us who are bedbound can't even do for ourselves – have enough time to try to wrap our brains around the issues and respond or comment in enough time to get our testimonies and/or concerns relayed to the committee – which in turn gives the committee time to actually see the public comments/concerns, and to at least think about them before the next meeting commences.
- 7) And to that end, I request that the “status” of the CFSAC’s recommendations be posted in an easily accessible manner, keeping in line with the President’s words, which envision an “open” government instead of the closed door policies of previous administrations, AND that there be follow-up on the research concerning XMRV by the WPI and any other researchers or doctors that testified at the previous meeting, as well as follow-up on all research that has been testified on.... in other words, so that we know what has or hasn't been followed up on, and which balls have been allowed to drop....FULL DISCLOSURE.
- 8) That live streaming internet video of every meeting be done in real time and then posted publicly – but videocast by a respectable videostreaming company that can handle a task of this magnitude, (not like Real Player that lost big chunks of the October meeting in mid-stream), and that for those who don't have broadband internet but can only afford dial-up, if that, there at least be audiocasts for them to listen to as the proceedings go on.
- 9) That doctors be made aware of what's going on in the world of CFIDS/ME research, preferably including this information in their required annual CPE credit work; that the “all in your head” mentality that the U.S. government has perpetuated under the auspices of Bill Reeves for the past thirty years be put to rest, so that we can be taken seriously and receive the medical care that we need; that the input of the doctors and physical therapists who actually work with and treat CFIDS/ME patients on a regular basis, (vs. researchers who may be great in theory but be clueless on a clinical level – the level that affects us), be given extra weight in this dissemination so that no further harm be done to us by the medical community than has already been done to us by the medical community over the years or decades, (for many of us, myself included). In particular, that which comes to mind is the UK's pet theory to treat ME is CBT/GET therapy that Dr. Reeves so willingly embraced, that is in actuality harmful and NOT beneficial to those of us who suffer from true CFIDS/ME. However, we do need physical therapy that is appropriate for bedbound patients to keep them/us from becoming even more deconditioned and disabled with an even lesser quality of life than we already live with.

It should be incumbent upon this committee that it be responsible for the dissemination of such information to all doctors, the vast majority of who still believe that CFIDS/ME is an “all in your head,” “yuppie flu,” “bored or hysterical woman’s” disease. If a subcommittee needs to be appointed for such an action, let that happen, but no more thinly veiled \$4 million dollar “all in your head” type of collaborations such as the one between the CDC and certain CFIDS associations.

- 10) That the makeup of the committee more appropriately reflects that which would serve the patient population best. In particular, I might be okay with the 7 Biomedical researchers as worded in the charter, (except that research and real life clinical practices are worlds apart – I know because I was a healthcare worker before I became a healthcare CPA, and did all of my undergraduate work in a medical university which only produced researchers, doctors and allied healthcare personnel, and have been exposed to both worlds, and all aspects of healthcare life), if the remaining four members were all clinicians. I have concerns about the wording in the charter which uses the word or with respect to the four remaining members. The way that it is worded, those four remaining members could theoretically all be insurers. I think it is a conflict of interest to have any insurer on this committee, as the insurer’s sole purpose in life is to maximize it’s employer’s profits, and it would be in the insurer’s best interests that CFIDS/ME remain an “all in your head” condition, which would allow them to deny us medical treatment and testing. That the wording in this charter that could put four such persons on the committee would most certainly set us back decades instead of move us forward in broadening our knowledge base and providing better and more appropriate healthcare.

The world is watching our country, our government. Canada and New Zealand are instituting policies to protect their blood supply, and Australia is considering doing the same, by forbidding people with a history of ever having the disease from ever donating blood. What will the U.S. do? And how long will it take to decide? You can’t undo the transgressions of the past, but the best amends you can make is by doing what’s right here and now, in the present, and out into the future. And it begins with this committee.

Thank you for your consideration.

Donna Pruitt