

Public Comment

Mary Schweitzer

At the last meeting of CFSAC, I criticized the CDC for not giving a balanced perspective on the bibliography of this disease. Instead, I said, they highlight what *they* have done (often with Emory University) in what I consider a truly embarrassing failure to appreciate what scholarship means.

The response by CDC was that they didn't have to have a balanced bibliography or depiction of the disease because that is not what their website is for. It was just for saying what they were doing, period.

However, recently I heard from two different friends that there are new PSAs on the radio for "CFS". Now, normally I would have been pleased with this. But at the end of the PSA, the listener is referred to ... the CD – to its website and/or the old toolkit for professionals and/or the new brochure, which remain woefully inaccurate.

So it does appear that it is important what CDC places on its website, and in its publications. The prejudices of the personnel at CDC dictate what the public sees and does not see, understands and does not understand, about this disease.

When is that going to change?

I have also criticized the CDC for promoting the combination CBT/GET which is the pet project of a group of psychiatrists in England (most of whom work for insurance companies). I found it most interesting that the only outside resource with a direct link from CDC's website is ... the CFS clinic in the psychiatric department of St. Bartholomew's in London, run by Dr. Peter D. White. Dr. White is not only a psychiatrist, but he is also Chief Medical Officer of two insurance companies – Scottish Provident and Swiss RE. Nowhere has he disclosed that information as a possible conflict of interest when consulting for the CDC. I did tell the CDC about it, but the link remains.

At the same time, there are no links to American researchers or clinicians. None, zero, zip, zilch. Now why would that be?

In fact, there is considerable research by Americans showing that Graded Exercise therapy could be dangerous for patients with M.E. or a CFS diagnosis. Dr. Unger knows this. She knows as much as I do. She chooses to ignore it, and to go with the advice of a British psychiatrist who is an officer at two insurance companies.

CDC has recently improved its website, but only by a minimum. The research is still the CDC/Emory research. If they have branched out to cytokines, that's interesting – but they are not the first researchers to be working on cytokines. Where's the rest of the research? Ignored. Hopefully not because it makes the CDC look more important than they really are.

Why are you hiding patients like me? I have a diagnosis of Myalgic Encephalomyelitis and fit both the Ramsay and WHO definitions, but also the 2011 International Definition (Carruthers et al, *Journal of Internal Medicine*). I have immune defects and am beset by viruses, some of which are in my spinal fluid. There is a large subgroup of patients who are given the “CFS” label who have what I have, and that includes the majority who were in the cluster outbreaks. Why are you hiding us? Why do you say this disease is such a mystery when it is not; that there are no treatments when there are?

Why isn't there an MEAC instead of, or in addition to, the CFSAC?

There are at least one million Americans, of every class and ethnicity, with this disease. There have been cluster outbreaks in the past and there will be cluster outbreaks in the future. How long do you think you can keep this secret?

I had great hopes that Dr. Unger might take this opportunity to change the way CDC did things, but she has not. CDC is just as unresponsive and out of touch as it ever was – either a fool for the insurance companies, or deeply in their pocket.

This disease ruins whole lives. Children get it. Teenagers get it. It ruins families. Yet both CDC and NIH continue to spend less than ONE PERCENT on this disease, per person, than they spend on Multiple Sclerosis.

I have been coming to CFSAC (and CFSCC meetings) since 1996. I can't do it this time. I know that NIH is going to say they don't have enough quality applications for funding. I know that CDC is going to brag about their PSAs, and talk about how they had meetings with constituents (but listened to absolutely NOTHING that was said).

We are forced to listen to it, knowing much of it is inaccurate, and forbidden to respond. Unlike most public meetings, this one does not permit the public an opportunity to question the ex officio members after their presentations. There is no microphone in the aisle. If we hear a mistake, we have to stuff that into the five minutes we are allocated to speak – and if we have already spoken, we are not allowed to say a word.

I can't sit there and listen to it any more.

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