

What is the purpose of the Chronic Fatigue Syndrome Advisory Committee?
Testimony presented to the CFSAC

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Mary M. Schweitzer, Ph.D.

In the mid-1980s there were a series of cluster outbreaks of disease all over the United States. In an effort to understand this disease better, in an effort to coordinate across disparate federal agencies, Congress created the CFS-ICC, the CFSCC, and today the CFSAC. The purpose of this committee lies *not* in finding tasks to occupy the time of the members, particular the ad hoc members on federal agencies. The purpose is to find answers for a catastrophic, life-altering and deadly disease faced by over one million Americans.

This committee belongs to those patients and their families.

It is owned by the patients, doctors, and researchers who have sought to find the reasons for the series of outbreaks of a mysterious disease in the mid-1980s all over the United States – and the world – a disease that continues to plague those infected with it.

It is owned by the teenager who is trying to understand why she suddenly feels as if she is walking under ten feet of water – and it is owned by the 65-year-old who fell ill in the 1982, but today remains incapable of even going to the store on his own. It is owned by the patient with a feeding tube; it is owned by the families of those who have lost victims of this disease to early heart failure or rare cancers. It is owned by the child who has been removed from his family by protective services, because “chronic fatigue syndrome” cannot possibly be so serious a disease that the child needs a wheelchair.

It is not owned by its name; neither is it owned by the public servants who are supposed to be working for us, citizens, in our time of need.

I was diagnosed with Chronic Fatigue Syndrome 15 years ago. But with the adoption of the new definition implicit in Dr. William Reeves' new questionnaires, I no longer have "CFS". Actually, when I was diagnosed with cytomegalovirus this year, I think I officially no longer had "CFS". Why am I here then?

Again I ask: *who owns this committee?*

Last April and May, Dr. Reeves presented a 5-year plan for CDC that had been developed with a great deal of input from the Department of Psychiatry and Behavioral Sciences at Emory University, and British psychiatrists Simon Wessely, Michael Sharpe, and Trudy Chalder. At the last meeting of the CFSAC, Dr. Reeves spoke glowingly of his good friend Peter White, a specialist in autonomic nervous system dysfunction.

Dr. White is not a specialist in ANS dysfunction. He is yet another British psychiatrist, part of a small group behind a program of "cognitive behavior therapy (CBT)" and "graded exercise therapy (GET)" claimed to cure patients with the illness "chronic fatigue syndrome" – or, as they more often call it, "chronic fatigue."

The main theory behind CBT and GET is that a patient has had some illness in the past (or perhaps even childhood abuse) that has left her stuck in "inappropriate disease behaviors." The patient needs to learn to "relinquish the sick role," along with the crutches that help her maintain it – support groups, sympathetic doctors, even wheelchairs. Once the patient realizes she is not sick after all, she is ready for graded exercise that will return her to both health – and suitable employment.

This is one path down which researchers have gone searching for the elusive condition they named "chronic fatigue syndrome."

It stands in complete opposition to a different path.

I first collapsed with “chronic fatigue syndrome” on October 24, 1994 (although I probably already had it when an outbreak of Epstein-Barr swept Villanova, where I was a professor, in the fall of 1990). In my first year with the disease, I was diagnosed with neurally mediated hypotension and Hashimoto’s thyroiditis. I had significant cognitive and central nervous system dysfunction; I could not pass a simple Romberg test.

In the fall of 1998 Dr. Dharam Ablashi tested me for HHV-6. Dr. Ablashi found I had a bad case of HHV-6, variant A, the type he had found in AIDS patients while a scientist with NCI. At the same time, I was diagnosed with the 37kDa Rnase-L defect.

These two biomarkers had proved good predictors of success with Ampligen, a synthetic double-stranded mis-matched RNA. I began Ampligen (at a cost to my family of roughly \$20,000 cash a year, including testing) on February 4, 1999, and continued to take it until October 2000, when it seemed I had gotten as much as I could from the drug. It was wonderful. Every goal I had set out, and more, was achieved. I could drive a car, walk unassisted on a beach, read a book, and dance with my son at his wedding. This honeymoon only lasted one year off Ampligen. On October 6, 2001 (Cal Ripken’s last baseball game), I blacked out and had to be taken from the stadium in a wheelchair. The next morning I forgot and tried to get up. I crumpled to the ground.

It was seven months before I was able to get Ampligen again, this time at Hahnemann Hospital in Philadelphia. During that time I deteriorated more, needing not only a wheelchair but also sunglasses because of the bright lights. My downhill slide was frightening, and I swore I would not voluntarily go off Ampligen again.

Unfortunately, in January 2008 the head of my practice died. He was the lead investigator in my cost-recovery, open-label study with Ampligen, although I worked

with a different doctor. The study was shut down, and the practice denied twice when they reapplied for the drug. There is no other doctor who dispenses Ampligen within two hours by car or train. Consequently, my family has made the difficult decision that I will have to rent an apartment at one of the few sites where Ampligen is still available, and move there. It will be the first time my husband and I have been separated in 35 years. But we have no other choice; to continue downhill is unthinkable.

That is the disease I have. A very low natural killer cell function, and defective Rnase-L; recurring Epstein-Barr, Human herpesviruses 6 and 7, and cytomegalovirus. Every test I have taken was carefully verified and is based upon publications in peer-reviewed journals, but we have had to pay cash for each one. I share my symptoms, biomarkers, and diseases with many cluster outbreak patients.

For years I took Amtrak from the Wilmington station to Washington, and testified earnestly about the tests I had taken and what we had learned. I testified about NMH/POTS, HHV-6, and the 37kDa Rnase-L defect. I testified about Ampligen.

Each time, I was told there was no evidence of a connection between the tests, the viruses, the drug, the disease. Dr. Stephen Straus rose up to say I probably never had HHV-6 at all, given that only 3 people knew how to diagnose it. When I said Dr. Alashi had done all my testing, he left the room. I was treated in a similar vein when I asked Dr. Reeves if his new definition found little difference between chronic fatigue and chronic fatigue syndrome when it came to cognitive dysfunction and sleep disruption. He refused to answer me, instead turning to face the wall.

This returns us to the original question.

What is the purpose of the CFSAC?

The questionnaires that Dr. Reeves has created to fit the concept of “fatiguing illnesses,” with the help of British psychiatrists and faculty from Emory University’s Department of Psychiatry and Behavioral Sciences?

Or the disease syndrome defined by the immune defects and viruses that I share with patients who were in cluster outbreaks in the 1980s?

Who does the Chronic Fatigue Syndrome Advisory Committee belong to?

Does it belong to government bureaucrats?

Or does it belong to those who were victims of mysterious disease outbreaks in the 1980s (many of whom remain sick to this day), and those who have fallen sick in the intervening 25 years?

I believe it belongs to the citizens. And we have been failed.

Dr. Reeves can continue to study fatigue and fatiguing illnesses to his heart’s content - but not on my time. Not while one million Americans struggle with a devastating illness. Not while young people are confined to bed. Not while some patients survive only on feeding tubes. Not while families face premature deaths.

I have viruses that must be contagious at some point in their origin. I have immune defects shared by others who have the same viruses. We all have similar problems, and they are not going to be helped by talking therapy and exercise before first ridding the patient of the viruses. I know this because when I had treatment with the immune modulator Ampligen, my viruses returned to their dormant state, my immune markers disappeared, and so did the majority of my symptoms. Then I could begin to exercise again, to have a life again. And that should be the goal of this committee.

Who does this committee belong to?