

Dr. William Reeves presents the biggest obstacle to either controlling or curing CFS. He is both a poor manager as the head of the CDC CFS studies and a completely biased researcher as he unfailingly directs the staff of scientists he leads towards the preconceived conclusion that CFS is exclusively a psychosocial "unwellness".

His most recent attempt to prove his theory precipitated a spending spree of taxpayer dollars that will examine 30 CFS patients and 60 controls and come at a cost of \$149,000 per CFS subject studied.

Because Dr. Reeves refused to accept any previously diagnosed CFS patients as test subjects he paid Abt Associates \$2.6 million rather than "contaminate" his study with real CFS patients. Either he does not believe that we are physically ill and does not acknowledge the expertise of our doctors or he is just stacking the deck in favor of his belief that CFS is psychosomatic and our doctors only encourage our faulty perception of our "unwellness". The CDC has favored the services of Abt Associates since 1988 (according to the Abt website) and were no doubt referred to Abt by one of their many satisfied customers, any of nearly 40 Federal Government Departments, Offices, and Agencies. Abt has clearly been on the fast track for no bid government contracts for many years. I did find it surprising that at the same time Abt was conducting Dr. Reeve's empirical study to determine how to identify and treat PWC, another Abt no bid contract was being done for the Social Security Administration. The SSA commissioned Abt to find out how to motivate disabled SSDI recipients and get them back to work. In March of 2009 the OIG issued a report admonishing SSA due to the Abt contract costs increasing by 340%, a 2-year delay in finishing the project and the use of a no bid contract with the oversight of Abt Associates being performed by Abt Associates. That scenario sounds something like the situation with Dr. Reeves Abt experience.

(The contractor generally adhered to the terms of the contract and delivered the services and final design options that SSA requested under the contract. However, multiple modifications extended the contract period from 2 to 4 years, and obligated costs for the design phase increased to \$10.6 million, or \$8.2 million more than initially expected. In addition, the delay of the BOND design phase led to additional costs under the Four-State Pilot, or \$4.5 million more than initially expected. In terms of contract management, prior SSA management demonstrated inadequate oversight of the contract's planning, scope and expenditures. Finally, we found that the sole-source contract lacked clear separation of duties by allowing the

contractor to evaluate its own performance.)
(<http://www.ssa.gov/oig/ADOBEPDF/audittxt/A-05-08-18041.htm>)

I was very surprised and dismayed when I read a presentation by Dr. Reeves entitled "Unexplained Fatiguing Illnesses and Chronic Fatigue Syndrome in Bibb County (and the rest of Georgia)".
http://www.fatigueregistry.org/sites/fatigueregistry/Gallery/CFS_Reeves_CME%20workshop.pdf

Although the presentation is not dated I can only assume that it is the result of the data collected in Georgia. I live in the Atlanta area and so I must assume that Dr. Reeves is talking to me and about me. I take issue with the conclusions he has drawn and I believe that whatever fatiguing illness he was studying in Bibb County, it is not the fatiguing illness from which I suffer.

Although he does include the 1994 CFS Definition in the presentation, he identifies many of my symptoms as exclusionary. He asks if CFS is real and then proceeds to tell me all reason it is not real, "no diagnostic physical signs, no diagnostic lab markers, or pathophysiology inchoate." He says that after a decade of study and more than 3000 published articles in Medline investigating the etiology or markers of CFS no consistent associations have been identified. He says that CFS patients only perceive that their sleep is of poor quality and I report my sleep behavior more accurately but then he goes on to say that both my alpha and delta sleep are reduced. He says that I am not slow in my decision-making ability but I do have difficulty sustaining my attention. He says I have some trouble with different kinds of memory recognition tasks but my executive function and planning and problem solving abilities are normal. I do not understand this report but that could very well just be my problem. I used to have an IQ of 129 but when the SSA measured my IQ on day 2 of my medical evaluation I scored an 88. I think he is saying that many of my physical symptoms; thyroid, heart, pulmonary, and autoimmune exclude me from a diagnosis of CFS. And although I do not suffer from depression and there are other exclusionary illnesses listed, I do not see depression listed as exclusionary. I do not believe Dr. Reeves is studying my illness and I am a person with 15 years of CFS experience.

Dr. Reeves has repetitively told us that his empirical definition for CFS is only for scientific studies and not for clinical evaluation. Imagine my surprise when I stumbled on to the University of Maryland website and learned the symptoms and exclusionary illnesses of CFS: "In May

2006, the Centers for Disease Control and Prevention (CDC) released a revised definition for Chronic Fatigue Syndrome based on a consensus of many of the leading CFS researchers and doctors (including input from patient group representatives). In the revised definition, chronic fatigue syndrome is considered a subset of chronic fatigue, a broader category defined as unexplained fatigue that lasts for 6 months or longer. Chronic fatigue is considered a subset of prolonged fatigue, which is defined as fatigue that lasts for 1 month or more."

And there was more: "Unexplained chronic fatigue can be classified as CFS if the patient meets the following criteria:

- . Unexplained persistent or relapsing chronic fatigue that is either new or that started at a definite period of time; is not the result of ongoing exertion; is not substantially relieved by rest; and significantly reduces activities such as work, education, and social life.
- . Also, four or more of the following symptoms, which must have continued or recurred during 6 or more consecutive months of illness and must not have started before the fatigue:
 - o Significant impairment in short-term memory or concentration
 - o Sore throat
 - o Tender lymph nodes
 - o Muscle pain
 - o Joint pain without swelling or redness
 - o Headaches of a new type, pattern, or severity
 - o Unrefreshing sleep
- . Malaise that lasts for more than 24 hours after exertion

. **Conditions that Can Rule Out a CFS Diagnosis**

- . Any active medical condition that may explain the presence of chronic fatigue, such as:
 - o Untreated hypothyroidism (underactive thyroid gland)
 - o Sleep apnea and narcolepsy (common sleep disorders)
 - o Side effects of medication
- . An illness (such as cancer, or hepatitis B or C virus infection) that

relapsed or did not completely get better during treatment, that could explain the presence of chronic fatigue.

- . A past or current major depressive disorder, such as:
 - o Bipolar affective disorder
 - o Schizophrenia
 - o Delusional disorder
 - o Dementia
 - o Anorexia nervosa or bulimia nervosa
- . Alcohol or other substance abuse that occurs within 2 years of the onset of chronic fatigue and at any time afterward.
- . Severe obesity, as defined by a body mass index (BMI) equal to or greater than 45. (Note: Body mass index values vary considerably among different age groups and populations. No "normal" or "average" range of values can be suggested. The range of 45 BMI or higher was selected because it falls within the range of severe obesity.)

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 - . People with CFS also can have the following symptoms:
 - . Difficulty thinking, concentrating, remembering, finding the right words, planning, and organizing
 - . Difficulty sleeping
 - . Dizziness or nausea
 - . General malaise or flu-like symptoms
 - . Headaches
 - . Muscle or joint pain in many areas of the body without inflammation
 - . Painful lymph nodes without disease
 - . Fast heartbeat (palpitations) without heart problems
 - . Sore throat
 - . Worsening of symptoms with physical exertion

After ruling out other possible causes, the doctor should consider a diagnosis of CFS if symptoms have lasted for 4 months in adults or 3 months in children. Children should be diagnosed by a pediatrician."

Now I am beginning to understand the symptoms and exclusions of the Reeve's CFS definition. According to his definition my 15-year diagnosis is incorrect. I just wish he would lay it out this clearly on the CDC website.

Dr. Reeves has an agenda and continually misleads and misrepresents his agenda to the CFS patient community. It is time he was removed from any and all association with the CDC and the NIH. He has wasted my life and the lives of million of Americans who suffer from this horror of a disease. It is time for real scientists to take over the study of CFS. There has been more than enough time wasted on psychological studies and CBT and GET. Dr. Peter White should go home to England and stay there. We have no need of his expertise here. The CDC needs to make a fresh start and get back in the business of scientific discovery. Let's leave science to the scientists.