

Testimony

Anonymous

I am an ME/"CFS" patient in my third year of illness. I fell into disability immediately after an acute viral onset of the disease while in the middle of a successful, relatively young, professional career and a fulfilling and active life.

Being single, disabled, and having no other source of financial support, I have spent much of my time fighting to obtain and maintain disability benefits to meet my financial needs for necessities of living, such as rent, food, and basic medical care. It has been a mind-bogglingly difficult and adversarial process, and one that I never imagined I would be going through in my mid-thirties.

With outside assistance, I was approved for Social Security disability last year. I am currently appealing a denial by my long-term disability insurance carrier based on the insurance company's contention (despite having the same objective medical evidence of physical impairment that satisfied Social Security's standards for disability) that my disability is due to some kind of unspecified mental, and not physical, disease (the former is not covered). The burden now falls on me to dispel their accusation that my disease is not a manifestation of mental disease. Because I have the truth on my side, I intend to prevail in my appeal. But the amount of evidence required to prove my disability has forced me to put my health and finances on the line, while the whole point is that I lack the physical capacity to work and earn income, in a situation where (between the insurance company sparing no expense and effort to deny benefits and ERISA law that as a practical matter favors decisions made by ERISA plan administrators) the odds are stacked against me.

Serious disease is an equalizer. It does not discriminate, and once you have one, it doesn't matter that you were smart, hard working, and in great physical shape before you were stricken. I believe the medical and financial situation I find myself in today, however, that all serious diseases are not treated equally in the eyes of the United States federal government or its health agencies.

I cannot just go to a local hospital to get medically accepted tests done for my disability appeal (let alone seek treatment for my disease) because the CDC openly declares that there are none (despite the fact that the Social Security Administration, for example, actually uses certain objective medical tests to make disability determinations for this disease). I have been explicitly or implicitly turned away as a patient by doctors of various specialties that do not want to take me on as a regular patient because they do not “believe in” “CFS” or do not otherwise know how to be of help.

The meager government guidance regarding “CFS” feeds into doctors’ already-existing biases that there is little they can do and that in any event, a disease called “Chronic Fatigue Syndrome” must be psychosomatic or otherwise trivial. This ignorant bias is especially tragic in light of the fact that (a) nothing could be further from the truth, and (b) the “Reeves”/empirical definition that the CDC uses for its “CFS” research purposes have been shown to fold in a multitude of people whose problems are psychosomatic (thus inflating prevalence projections and rendering any so-called research conducted based on the definition useless), while excluding some patients who actually have the disease.

It is baffling that the harmfulness of the Reeves criteria could not be clearer to patients and their caregivers (who once knew their loved ones as everything but depressed, lazy, fat, psychosomatic types), while the CDC defends it. It was especially discouraging to me to see Dr. Elizabeth Unger, the current director of the CDC’s “CFS” research program, talking emphatically about there being a “mind body connection” that is overlooked, presumably in “CFS,” during one of the CFSAC meetings last year. If I had any doubts as to how the CDC views “CFS” today, these recent public statements by Dr. Unger confirmed them, for the worse: that in contrast to more “straightforward” areas like HPV and cervical cancer, “CFS” to this day bears the stigma, and the practical barriers to advances in science that come with it, of being seen as at least partially psychogenic by the CDC’s own director of its “CFS” research program. This is shameful.

- It is also shameful that in 2001, even with studies cleanly demonstrating the nature of the problem by Leonard Jason et al., and after meeting after meeting and conference after conference, no action has been taken by HHS to adopt an accurate, reliable, clinical and research definition for ME/CFS. **An accurate, reliable case**

definition for ME/"CFS" along the lines of the Canadian Consensus criteria should be adopted by the United States.

- It is shameful that despite years of these federal advisory committee meetings, thousands of studies, and the recent association of HGRVs to ME/CFS and concerns about its infectious nature, federal funding for ME/CFS remains at a dismal, almost non-existent level. **Federal research funding should be in the hundreds of millions of dollars, on par with diseases with similar severity, disability rates, and prevalence. Separate funding to implement measures such as CFSAC's recommendations for Centers of Excellence should be established.** While I understand funding decisions are made by Congress, and not by members of this committee, Congress is not going to have the information and convincing arguments it needs to do this without HHS and its health agencies requesting the funding and providing Congress with what it needs to make it happen.
- The fact that the media continues to refer to this disease, and the public continues to perceive this disease, as "controversial" and "mysterious" is shameful. It is the reason ME/CFS patients remain undiagnosed and untreated, marginalized, and the reason it is not a "prestigious" career track for a talented young doctor (with many of the dedicated pioneer doctors for this disease nearing retirement age) or a "prestigious" cause for private donors with the means to provide much-needed research dollars. While research funding into science should take priority, **the government should undertake and make available more rigorous, accurate information that conveys the seriousness of this disease to medical professionals and the general public instead of shrouding the disease in controversy and mystery.** This should not take significant resources if done efficiently. To the extent it is incapable of doing so based on the knowledge base of current government employees, outside experts should be hired for the task.

None of the above requests ask for anything that is not made available by the government to patients with other serious diseases such as HIV, MS, and cancer.

I was barely able to gather my thoughts into a semi-coherent document and am too sick at the moment to make brilliant new suggestions for committee

recommendations. Moreover, it seems from past meetings that the stark realities reflected in personal stories, as well as some excellent, relatively straightforward suggestions for public policy responses or committee recommendations never make it outside this room, and are summarily ignored after each meeting, year after year.

The same appears to hold true for the substance of CFSAC discussions. What accounts for the disconnect between what seems like productive dialogue and exchanges of ideas that occur at the meetings, on one hand, and the lack of action taken on recommendations, on the other? What accounts for the stagnant, shameful level of federal funding available to HHS agencies to advance the medicine for this disease, and to implement the recommendations of the committee? What exactly are the barriers that are keeping this disease and the patients who suffer from acquiring equal access to government funding and talent?

With recent signs of involvement by NIH (i.e., the April 2011 State of Knowledge meeting) and some prominent scientists and institutions finally looking at this disease more closely, however, now is the time to get HHS to act. Please use the considerable expertise, talent and dedication embodied in the membership of CFSAC to do everything you can to not only offer recommendations to the Secretary of Health, but to find innovative ways to get your recommendations implemented.

Thank you.