

Testimony

Anonymous (2)

Dear CFSAC members.

First I would like to thank all members for their time serving patients. Especially I would like to thank Dr. Nancy Klimas and Dr. Leonard Jason who have fought many, many battles for us, and went out of their ways to do so. Their voice will be missed on the committee.

I have written 3 testimony and this is my 4th one. I have been ill for only 2.5 years, not very long compared to many of my fellow patients who have shared with me their experience. I have felt that my testimonies were all the same thing, and feel like things are not changing. 18 months have elapsed now since the Science paper. The Whittemore-Peterson Institute needs funding. Other research groups need funding, and patients are experimenting with antiretrovirals and other drugs by themselves, most of them out of despair. Of course, they get it prescribed by a doctor. But I feel we are all left in the dark.

The truth is other than just a handful of doctors that see ME/CFS patients on a daily basis, the doctors in the world are unaware, and mis-educated about what ME/CFS is and how it is treated because the wrong information is posted on the CDC website and physicians are not educated properly about the illness. For instance, under treatment, the CDC recommends anti-depressants, therapy, graded exercise therapy, support group, alternative medicine. This is out of my head, but I am very sure this is what it said. This would explain why for the first 20 months of my illness my own doctor have been pushing on anti-depressants. Now, she is just saying nothing. I am left to myself to figure it out, and also to fight my disability insurance who is just taking advantage of the fact that no objective markers of the disease are available and that no doctor is willing to consider my symptoms seriously.

I would like to say that patients with ME/CFS are mostly abused, mistreated, left for dead, ignored and insulted. Yet, we are sick! Patients have known for a long long time that they have a persisting viral illness with multiple chronic viral reactivations, and yet, we are seen as a group of “fatigued” patients. Please, please please. Forget fatigue. We are sick! HIV patients are not fatigued, they are sick!

Funding for this disease has been abysmal. We all know that. Ironic it was that the US government seriously considered a shut down during the State of Knowledge workshop just a month ago. This is the curse that patients with ME/CFS are in. We have been told not to expect much more funding due to the financial situation. Yet, hundreds of other diseases and conditions got an increase in their funding last year. Billions for HIV, hundreds of millions for obesity, smoking cessation and infertility. Agent Orange and bioterrorism gets its fair share. Go see the list on the NIH website.

In the meantime, patients with ME/CFS are sick, too sick and too poor to congregate in Washington DC to scream injustice. All we have is words, and only for a limited time, for our brains will stop working after just a little concentration.

In 2.5 years, I have lost my work, my finances, my friends, my health, my ability to socialize. I have to fight for health care (and I lose), my disability (and I am losing) and keeping my independence (I can barely do my groceries, eat frozen dinners because cooking is too hard.) At 41 I am living out of my retirement fund. This is so wrong!

Not only we have inherited a disabling illness, but we got stigma attached to it, and most doctors find it too complicated to just deal with us. Please, help!!!

Here are my suggestions to the CFSAC committee members for recommendations to the secretary of health.

1. In honor of Dr Leonard Jason leaving this panel, I would like to see the CFSAC committee to recommend only the Canadian Consensus definition to be used. CDC needs to leave the Fukuda criteria behind. Let's compare apples with apples, and leave the fatiguing conditions behind. Please leave the random telephone calls studies behind.
2. Supervise the activities of the CDC CFS program. Patients deserve accountability. We do not need any more psychiatric or behavioral studies. The CDC website needs to be reviewed so patients are not cheated out of health care and disability benefits.
3. Request emergency funding for our disease. Request fast track clinical trials. Clinical trial drugs need to be funded. (Ampligen) and not left to the patients to pay.

4. Encourage researchers to work together. Facilitate publications of papers. Dr Mikovits has difficulty getting peer reviewed and published. Why?
5. Encourage medical students that want to learn from our aging experienced doctor. Could there be a scholarship awarded to one or 2 deserving student?
6. Could there be a legislation passed in order to facilitate what I have discussed so far?

Patients are in a desperate situation and this requires desperate measures. Please help me NOT having to write another CFSAC testimony. Please help us.

Name withheld.