

CFSAC Testimony Anonymous 3

September 17, 2010

To the Members of the CFSAC:

Please do not use my name when publishing my testimony.

Although I have been ill for 7 years with CFS, I was not diagnosed until May, 2010.

My undiagnosed, chronic illness forced me to withdraw from law school, and also to give up my position as a university lecturer. I had been employed as a professional writer and/or educator for 15 years, until illness made it impossible to continue.

I am no longer able to work or make a financial contribution to my family. I am no longer to do much of what I once did as a matter of course to maintain my home, engage in activities with my family and friends, or take part in my community. I have been disabled by CFS.

Because I am no longer able to work, and our medical bills are very high – I'm not the only person in our family suffering from a chronic illness, and we still have 3 children at home – we were forced to file for bankruptcy in the past month. I have not filed for Social Security Disability as yet, in part because I have heard that claims based on a diagnosis of Chronic Fatigue Syndrome are not taken seriously.

It is obvious to me that CFS has not been taken seriously either by my government, or by the medical profession – the members of whom must largely depend upon the CDC for information about CFS. In spite of research strongly associating several well-categorized cohorts of CFS patients with infection by the new human gamma retrovirus, HGRV, and its variants, we are not seeing renewed commitment to finding a cause and treatments for CFS, by pushing ahead with additional research, funding, and patient clinical trials. The Federal government is not funding the work of the Whittemore-Peterson Institute.

Instead, we are continuing to waste money on CDC research which recruits depressed people to their "CFS" studies, in order to characterize them as mentally ill and personality disordered. This has to stop. It's not science, and it's not helping anyone except those few individuals at the CDC who have based their careers on the theory that CFS is a mental illness, thus setting back research on the actual, infectious cause of CFS for more than two decades.

While we are waiting for medical acknowledgment, let alone a reasonable level of research funding, or actual treatments that would might allow us to live at least a portion of our lives in relative health, others are getting sick. We need to protect the blood supply for the sake of all citizens.

Thank you for considering these issues and responding appropriately – with research funing for biomedical research, with clinical trials, and by protecting the blood supply.

