

Thank you for this opportunity to tell you about my experience as a person with CFS (PWC).

The people who have taken on the responsibility of protecting the health of all Americans need to know that CFS is a very real, very serious physiological condition.

I became ill in 1986, at the age of 12, and I was diagnosed with CFS in the early 1990's.

I was unable to complete high school because of the illness, but received scholarship offers and awards from several universities nevertheless, based on academic work I was able to complete.

If memory serves, I achieved a 99th percentile (highest possible) ranking on the Armed Services Vocational Aptitude Battery (ASVAB). I love my country, and would have considered serving in the armed services, as previous generations in my family have done, but that opportunity was never available because of my condition.

I obtained the general equivalency degree (GED) in order to attend college. I achieved the highest score in the state of Arizona in 1994.

Now I have been ill for twenty-three (23) years. The psychological toll of living with this illness for so long has left me feeling that even if I make a complete recovery physically, my productive years may have been taken already. Also, the cognitive deficits that are often present with this illness are much more a part of my life today than they were during the first few years of being ill. The accumulated cognitive deficits caused by my long-term living with this illness often leave me unable to study and retain information as I once could.

The fight for recognition, acknowledgment, care and support for this illness over the years has taken so much out of me that I feel I have nothing left to give.

I am among the more severely afflicted: those in the lower 25% of functioning who are considered disabled by CFS.

Is our country willing to let so many lives like mine be left like detritus on a highway--largely ignored--wishing the problem would just go away?

The loss to the nation and the world is incalculable. I have met some of the kindest, most caring, intelligent and resourceful people in the community of CFS sufferers. Even broken by CFS as they are, they contribute greatly to those around them.

Even if the only motivation were simple greed ("enlightened self-interest") it would make sense for this problem to gain significant national attention as a massive drain on our economy.

Even if my opportunity to contribute to the economy may have been lost, there are many others who have not yet been diagnosed, or even fallen ill, who may still have a chance.

I am at a loss to know what will actually get through to the people who have vowed to protect the health of Americans. The toll of suffering experienced by people with CFS (PWC's) is immense, and organizations such as the CFIDS Association of America, of which I am a member, have been making monumental efforts to get this point across for many years.

I appeal to the self-interest of those who would like to see the country remain prosperous and see that each citizen makes the biggest possible contribution to the tax rolls, if nothing else. I really don't care what the motivation is to see PWC's get the help and respect they deserve, as long as something meaningful and truly helpful is done.

I was born in this nation's capital, and I have lived in a number of states from coast to coast. We as Americans developed these institutions (National Institutes of Health, et al) to help alleviate human suffering. Now let's either use them for what they were intended, or admit that they are broken beyond repair and find other avenues to help PWC's.

I am now often too ill to prepare or consume meals, speak on the phone or write with a pen or pencil. My computer allows me to do much more than would otherwise be possible, and I consider it my primary piece of assistive technology. It is only during my better weeks that I might get out of my apartment once or twice. It is not uncommon for me to be housebound for three weeks or a month at a time.

The only time that most people see me is when I am at my best, i.e., when I am well enough to have visitors or go out, so they NEVER get a representative sample of what I go through. This is one of the reasons the toll of CFS remains hidden and misunderstood. Of course, when I am feeling better I am eager to use my energy to accomplish things, spend time with friends and family, and enjoy life. What goes unseen is the price I may pay for simply going to a medical appointment or seeing a movie with a friend. One advocacy effort in which I took part last year left me in more than usually debilitated condition for a month or so, although the event itself took place during just one morning, and required what most people would consider minimal exertion.

Promoting awareness of the condition among the medical community could prevent other people from going through the disheartening maze of seeking a diagnosis and care, often being led toward wrong directions and dead ends, as I have experienced. Doing groundbreaking research on this condition has the potential to discover a cure and methods of prevention which could end tremendous suffering and allow millions to live full, happy lives.

I ask your help to find ways to cure and prevent this devastating condition from which I, and millions of others, suffer.

Thank you.

Patrick B. Holaday

