

Public Comment
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Note: It took me more than a week and a half, and assistance from my wife and mother, to write this testimony. Reading or writing more than a couple sentences wears me out, making it difficult for me to understand sentences and unable to piece together words. It makes my eyes burn, makes me feel more zoned out, brings on headaches and unrelenting exhaustion. This was a painful labor of love.

To those responsible for health policy on ME/CFS, I need you to listen and fully absorb just how terrible and serious this disease really is.

I never imagined, before becoming sick, that an illness could so completely redefine my life. Instilled with the inspirational ideal of the disabled who rise above their limitations to achieve great heights, I imagined that disabilities were obstacles that could be overcome, at least to some degree. One only had to pull oneself together and rise above the obstacle. It was to my horror, then, to become sick with ME/CFS, an illness that I could not rise above, an illness that wrecks both body and mind, rendering victims living shells of their former physical and intellectual selves and leaving them forever to languish on the margins of an unaware and uncaring society.

No description can do justice to the experience of this illness. To those with only healthy points of reference, ME/CFS can only be described as feeling at *all* times like you have just finished running a marathon, while extremely hung over and severely sick with the flu, after having not slept in at least three days. And even the slightest exertion – brushing teeth, showering, reading the newspaper, washing dishes – amplifies that feeling to even more unbearable levels, to the point where you can only lie on your back, face-up in a dark room to not feel worse. And the longer you are sick, the more ragged and worn out you feel. To state that ME/CFS is comparable to late-stage AIDS, congestive heart failure, and multiple sclerosis does not begin to convey the severity of this illness. The harsh, soul-crushing reality of an incurable illness that strait-jackets the bodies and minds of its victims is lost in translation.

For me, the change from vibrant life to pallid sickness was frighteningly abrupt. I graduated from Connecticut College Phi Beta Kappa and Summa Cum Laude, after winning awards in my final years for outstanding achievement and writing a 275-page honors thesis on the evolution of wartime repression in America. After college, I backpacked across Asia for five months, traveling alone for two and a half months through an unstable part of western China, India, and Southeast Asia. During that trip, I went SCUBA diving in Bali, climbed mountains in Tibet, rode a motorcycle through northern Thailand, found myself targeted by “gem smuggling” scam artists in India, and once rode a train so packed that I was forced to stand for 17 hours of a 25-hour journey. I also met the wonderful woman who has become my wife. A life of joy and promise lay in front of me.

Today, the sense of boundless opportunity is gone, replaced by never-ending sickness that totally dictates the boundaries of my life. Only two years later, I am unable to work, am largely housebound and cannot read or write for more than a few minutes without developing

headaches and becoming confused. I cannot sustain any significant physical or mental exertion without suffering a severe crash. On days when I crash, I am often so sick that I cannot even leave on the TV, as the light and noise aggravate my symptoms. On those days, being too sick to do anything at all, I just lie in bed, lightheaded and zoned out, with my head aching, my eyes burning like fire, my muscles sore and weak, and exhausted to a degree the healthy have never known, yet unable to sleep. My every experience of reality is mediated by pain and incomprehensible fatigue, from the moment of waking till the moment of sleep.

My reality is a daily struggle, not just to overlook the harsh reality of physical suffering that never departs or to come to grips with watching all my peers surpass me, while I grow physically weaker and my mind dulls, but to attempt to find meaning in a life that has been so severely circumscribed at such a young age. Had I only lost an arm or a leg, I could still enjoy my old Sunday ritual of drinking coffee, reading the newspaper, and listening through my stacks of vinyl records, which now gather dust. Had I only lost my hearing or my sight, I could spend my time advocating, or at least find the right words to express my travails. I might even still pursue a career in academia. But, with this illness, those possibilities are off-limits for me. My only hope is that they will not always be so.

You must know that ME/CFS is one of the most severe illnesses in America today. This illness is not the “Yuppie Flu,” as popularly imagined. Nor is it “all in my head,” as our uneducated medical community too often believes. Rather, it is a serious, life-robbing illness that is so torturous and difficult to bear that some choose suicide to escape it. It is beyond travesty, then, that ME/CFS receives such an outrageously small sum of taxpayer funds for research, while other illnesses of similar severity (and often smaller patient populations) receive hundreds of millions and even billions of dollars for research. When this illness is one day solved, it will no doubt be obvious to all, as it is to the doctors, patients, and advocates here today, that those we trusted as stewards of the public health were too busy, too inattentive, too locked into erroneous, outmoded preconceptions to realize how vastly they were failing to meet the trust we put in them.

More than any moment in the past, this moment is the time for change. The Norwegian government has already issued a formal apology for decades of neglect and utter disregard. It is time for our government to follow suit and to embrace this illness with a seriousness and vigor that characterized the fight against HIV/AIDS. For that to happen, public officials responsible for ME/CFS must take seriously the trust implicit in their position, for it is their moral responsibility to break down the doors that we sick patients cannot reach, to give form to the outrage we patients, doctors, and advocates feel by savagely working the message to Secretary Sebelius that this illness cannot be ignored any longer.