

Testimony

John Buettner

Hello,

My name is John Buettner. I am 55 years old and I have been living with the disease known by the names, Chronic Fatigue Syndrome, Myalgic Encephalomyelitis and Chronic Fatigue and Immune Dysfunction Syndrome for more than 25 years. Prior to becoming ill I was very active. I was working full time and overtime as a Senior Technician for GTE Government Systems, going to college nights and weekends working towards my Bachelor's degree in Computer Science, raising 2 children and renovating my first home. With all this going on I was still able to keep myself on the Dean's List at Wentworth Institute of Technology and I received constant accolades from my employer for the my quality of work. I am also a disabled veteran of the Vietnam War.

I remember the exact moment that I was struck with this disease; I was working overtime at GTE and I had just finished troubleshooting a dozen or so printed circuit cards. I had all the cards in a box and as I was walking to the outgoing shelf I was suddenly overwhelmed by an extreme level of fatigue. This isn't the "I'm tired" sort of fatigue, it's the "I've got the worst flu I've ever had" type of fatigue. It's the "I can't remember what you were just saying" type of fatigue.

This level of fatigue didn't leave me for almost 2 years. I've had short periods of feeling fairly well, but just one event can push me back to this level again, and it often does. We refer to these periods as crashes. When I crash I have no idea how long I'll be in this cycle, it can be as short as 2 days or as long as a year or more. There are many triggers for my crashes. Among them are, any type of stress (physical, mental or emotional), a flu shot, having dental work done, taking antibiotics or even eating a big meal.

When I was about a year into this living hell I found myself parked along the power lines in a neighboring town. I had a garden hose on the seat next to me and I was writing my goodbye letter to my wife and children who were 3 and 5 years old at the time. I tried as hard as I could, but I just couldn't force my kids to grow up with only one parent as I had; my mother, an RN, was killed in a auto accident when I was 14 years old. In retrospect, perhaps my children would have been better off if I had gone through with killing myself. As it turned out I wasn't able to be there for them much at all and this disease left me short tempered as it's difficult

to be over stimulated when your brain is having trouble maintaining focus.

In all these years I've learned how to hide my sickness. I'd take drugs that made me physically more awake (Provigil) and I would avoid situations that would require me to multitask as much as I could. The stress involved with a job change always brings on a crash and these generally last quite a while as the stress builds on itself. When working at Bolt, Beranek and Newman in Cambridge, Massachusetts I got into a situation where I had to take on a new position working on a project for the U.S. Air Force. It was a management and technical role and I just couldn't keep all the balls in the air. Because of this I was fired.

In October of 2009 I stupidly got a flu shot at work. I'd been feeling pretty well and everyone else was so I did it too. This was not a good idea; since then not only have I been in a near perpetual crash, but I've developed neuropathy (nerve damage) in my hands and feet. I can only walk about 100 feet or so before my feet feel like they are sunburned and they get progressively worse if I stay on my feet. I also experience a level of incontinence where when I have to urinate, I have to do it immediately or I will have an accident. This symptom has since been alleviated by drugs (Vesicare), but they have affected my eyesight and left me constipated and with a never ending dry mouth. I suppose that's a small price to pay.

This past January (2011) I had no choice but to leave my job. I asked for accommodations so that I could keep working (flexible schedule, occasionally work from home, etc.), but I was denied and told that my only option was to go out on disability. I have exhausted my short term disability (STD) benefits and I have applied for long term disability (LTD) through the insurance (The Hartford) I paid into for 14 years with my employer, EMC Corporation. As of the writing of this letter, I have no means of income, I'm divorced, I have an upside down mortgage that I can't refinance and I'm just wondering when the next shoe will fall.

Please, please, PLEASE... don't let this continue! We need help and we need it now.

Sincerely,

John L. Buettner