

Public Comment

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It has been 27 years since the CDC was sent to investigate this illness and yet, here we are with no cure, no treatments, no help whatsoever for a disease that would more aptly be described as Chronic Torture Syndrome, rather than it's given name Chronic Fatigue Syndrome. Naming a severely disabling, life-destroying disease Chronic Fatigue Syndrome.....what a sick little joke that was. However, that IS the name that the CDC decided to give to a typical outbreak of ME Plus. Myalgic Encephalomyelitis, plus the additional evidence of never before documented immune abnormalities collected by Drs. Cheney and Peterson. We must not let that be forgotten. CFS is the name given to a disease entity of ME Plus. IT IS NOT and has never been a social construct, an illness devoid of evidence of severe pathology, or a description of tired people. Chronic Fatigue Syndrome does not and has never had anything to do with fatigue.

The lack of meaningful research on CFS has created an epidemic. The CDC is still claiming that the research program involving their infamous Georgia study (you know, the one where they got their "patients" by random telephone surveys) has, according to them, "greatly increased knowledge about CFS and has helped the health care community develop viable treatments". That is complete hogwash. It has done neither. I suppose that is to be expected from an agency that has spent nearly 30 years trying to frame a severe neuro-immune disease as a psychological defect. They have wasted what little paltry pittance of research dollars allocated towards this heinous disease on garbage studies like the ones that claim that childhood trauma is a risk factor for CFS and that CFS is associated with an increased prevalence of personality disorders, even though psychiatric conditions are an exclusion for CFS. I'd argue that there is evidence that personality disorders seem to be a risk factor for employment at the CDC.

CFS is the term coined in response to a severely debilitating illness with evidence of profound immunological abnormalities. Try working with the evidence instead of inventing psychological drivel, or at the very least, if you are not going to help us, at least stop lying about us.

I developed CFS in 2006. I would never have guessed that what I have would be called Chronic Fatigue Syndrome. Fatigue was the least of my problems. I was experiencing episodes of being unable to move my arms and legs. Days that I was so weak that I had to crawl to the bathroom. Pain so severe that the touch of my clothing was excruciating. Head and neck pain that made it feel as if I had been beaten with a baseball bat. New onset dyslexia. Loss of short-term memory. Frequent syncope. Racing heart rate. Seizures. NKC numbers so low that my doctor first thought it must be a lab error. I lost my career, my friends, and my independence.

On the rare occasions when I was having a "good" day, I sometimes tried to venture out. I knew not to try to go too far, or I'd never make it back. I also knew that I would pay for my time out by an extreme increase in all symptoms by the next day and that I would be bedridden thereafter indefinitely. I would usually use my outings to go drive to the local grocery store just a few miles away. Often when I'd arrive, I would park my car and suddenly realize that I had no memory of how I got there, why I came, or how to find my way back home.

Most days though, were spent in bed, too weak to do anything but lie there in pain. As the days slip away and turn into weeks, then years, you cease to exist to the rest of the world. For the severely ill, chronically bedridden, you eventually come to the realization that you are already dead to the rest of the world. If you want to know why so many CFS patients commit suicide, here it is: There are things far, far worse than death.

We are all aware of the stigma associated with the name Chronic Fatigue Syndrome. The public views us as lazy slugs who won't stop complaining about being tired from normal life stresses. I suppose we can't really expect any other outcome after an almost 3 decades long propaganda campaign by the very people who are supposed to be helping us; who instead continue on with their ceaseless efforts to mislead, deceive, and bury the facts.

Let me make something perfectly clear. The illness known as CFS, based on an outbreak of ME Plus, has never been fully investigated by anyone. Not one researcher has examined all of the evidence that caused the creation of this syndrome. After nearly 30 years NOT A SINGLE ONE. This is a disgrace of epic proportions. A disease that has brought brutal and relentless suffering to now millions of people and yet we have evidence that has been around since the inception of the syndrome that has never been examined.

The reason that I am able to be here today is because I have been fortunate enough to be able to utilize therapeutic strategies based on evidence that has been ignored for over a quarter century. Incline Village survivor Erik Johnson, who served as a prototype for the syndrome, noticed a peculiar phenomenon in regards to biotoxins. He devised a strategy in response to it which enabled him to achieve such an astounding recovery that he is able to climb mountains. Thanks to his work and persistence there are now quite a few CFS patients who have used his techniques to achieve recovery. We are not cured. However, many of us who were severely disabled are now able to live near normal lives. I think that it's about time that researchers start looking into this. It seems to me that discarding evidence for decades on a horrific, life-destroying disease is downright negligent. I want to know why NO doctors and NO researchers are telling patients about this. If it had not been for Erik Johnson, I would either be dead or at home still rotting in my bed. So, to him I would like to say this: with all of my heart and soul, thank you for helping me.And to all of you CFS researchers who claim to be unaware of this particular evidence, I want to say this: You are aware now. What are you going to do about it?