

My name is Anonymous and I have had Chronic Fatigue Immune Dysfunction Syndrome for approximately 22 years. I was only 18 years when I became very ill with a severe case of mono, which I believe I caught from a patient in the medical practice where I worked part-time. Three months after my mono diagnosis, I was diagnosed with coccidioidomycosis (AKA: valley fever). My life after that diagnosis would never be the same. For years after I had these infections I was seen in Urgent Care; sometimes monthly. I would often need antibiotic therapy for other frequent infections (URI's, sinus infections, bronchitis, etc.). None of the physicians in Urgent Care could tell me why I was so ill and none of them suggested Chronic Fatigue Syndrome as a possible diagnosis. At least one physician was honest with me... he told me that I needed an HIV test. He also told me that although my immune system was obviously compromised, that I shouldn't be getting so many infections. I agreed with him, but despite seeing numerous physicians, I still didn't have a diagnosis. Approximately 1 1/2 years after my mono diagnosis, I began working per-diem and then full-time. Unfortunately I was too fatigued to attend college again and so I had to drop out completely. Although I worked in the medical field and my co-workers knew that I was ill... I didn't and wouldn't have a diagnosis until many years later. By the time I was diagnosed, I was 36 years old and had postural orthostatic tachycardia syndrome (POTS) and adrenal insufficiency. In addition to that, I also had (for years) a high ANA titer that ranged from 1:320 to 1:640 (speckled pattern). Unfortunately I had to leave my full-time position that I worked so hard to achieve.

Like many other people who have my diagnosis, I am very concerned at the actions that the Center for Disease Control has taken in regards to Chronic Fatigue Syndrome. The name itself of this condition trivializes the seriousness of this "syndrome". There are *still* physicians who do not believe that this illness is even real and this is not only hurting CFS patients, but also costing health insurance companies a lot of money. The CDC simply hasn't done enough and some of the things that they have done have ended up harming people who have this very real illness. Thanks to the new research findings by the Whittemore Peterson Institute, the National Cancer Institute has called together a group of experts to consider its potential effect on public health. Why isn't the CDC doing the same ?

I hope that in the near future, the CDC will listen to us. We are the expert witnesses who know what our life was like before and after we became ill. We know how devastating this illness and we've been sounding the alarm for years. There is something very wrong when an estimated one out of every ten people who have mono are not recovering. The CDC can start making these much needed changes ASAP.... and this includes changing Dr. William Reeves "empirical" definition for CFS.

Sincerely,

Anonymous