

22 May 2009

My name is **XXX**. I am 48 years old and have had CFIDS and FM for the last 15 years. I have been under the medical supervision of Dr. **YYY** for my entire illness.

I became ill with CFIDS following a virus that both my husband and I got during the summer. He recovered and I became sicker and sicker until I was sleeping 22 hours a day and was in constant pain through out my body, had major cognitive issues (I could not read, write, do basic math, short/medium -term memory gone and still gone, and so on) and severe GI problems (these symptoms continue 15 years later). Pre-illness I was a very hyper active driven Type A personality with two graduate degrees and was working on my doctorate while working as a defense analyst managing 40 senior retired military and 30 technical staff on over 20 different contracts. I also was sleeping four hours a day, exercising from 4 am until 5:30am and taking care of a large home, 10 cats and dogs and a mother-in-law who was living with my husband and I and dying from colon cancer. No one has ever called me lazy, crazy or a faker until I became sick with CFIDS.

Aside from my husband and Dr. **YYY** no one else, including my family, has provided any sort of support to me. My family wants to believe that if I just ate better or got exercise I would be better. I have been demeaned and insulted countless times by doctors and people who do not have CFIDS. I won't go into this situation as you will hear the same theme time and again, but being so damn sick without any energy and then being demeaned by the medical community and the public only makes this disease far more worse. I believe it would have been far kinder to me if I had had a quick and fatal heart attack at age 33 rather than having had to live this type of life for the last 15 years. I really would have preferred death than this long, miserable life. Rather a sad commentary I would say, wouldn't you?

I understand that this is indeed a genetic disease and that my siblings and niece and nephew are targets for getting CFIDS and FM. My father was a general surgeon and also had FM and had to leave general surgery and move into out-patient proctology so that he could sit and not lean over an operating table with burning shoulders, arms, back and legs. So, with this genetic history I am terrified that my other 5 siblings and niece and nephew will also get CFIDS and FM. And this is really why I am writing to you. This illness "game" is over for me. I have not recovered despite enormous amounts of effort and money spent on over 70 physicians, endless tests, and thousands of dollars on medications (that don't work) and vitamins, minerals, and other medical means (e.g., acupuncture, holistic medicine, PT, and even dried Dragon Worms). I have tried and taken everything out there that markets itself as helpful to CFIDS and FM and NOTHING has helped with energy, cognition, or pain. Nothing. It is over for me but it is not over yet for my family members.

HHS MUST push the other organizations like the CDC (worthless and actually

very damaging to the CFIDS community) to find a cure. **CFIDS IS an epidemic with our numbers growing every year.** We do not recover and we essentially are "living dead" people unable to do but the very least amount to survive. Our personal and professional lives are ruined. Our finances are damaged to the point that many CFIDS people have major financial difficulties because they simply can not work - you can't work if you can't walk, stand, sit stay awake and think/remember clearly. I would love to be able to work at Walmarts or clean toilets just to be able to work and feel like I am useful. I don't need to be back on the ladder climbing so that my self-esteem and ego are being bolstered. All I want is to be able to be well enough to work doing anything. But I can't. I sleep. I sleep all night with no critical Delta Wave sleep (no recovery) and then go into "fugues" that are considered "Idiopathic Narcoleptic-Like sleep Disorder" by the sleep study neurologist. Meaning, I pass out cold with warning from one to four hours and am unable to stay awake even with stimulants and am further unable to wake up even when physically lifted up by my husband. These "fugues" are dangerous and have happened to me three times while driving short distances to the doctor and grocery store. I have fallen asleep at the wheel and the car has gone off the road. In those three incidents the rumble strips have jolted me awake enough to regain control of the car and return home to sleep.

This epidemic has gone on far too long. No one in the medical establishment except for the very few outstanding CFIDS doctors and researchers in private practice have done much of anything to help find out what makes us sick and how to cure us. The government has done little to nothing to help us. Many CFIDS people believe that MONEY is at the root of this situation and that the insurance companies and others have gotten to the CDC and made them aware that if CFIDS was validated it would cost the insurance companies enormous amounts of disability money and would essentially ruin their balance sheets. Why else would the medical community ignore us? There is tons of data and studies on CFIDS that show the damage done to our systems. They know for a fact which genes are damaged within us. They can find consistently the same results in our brain SPECTS, our blood and spinal fluids. There is an enormous amount of PROOF that we are very sick people with a horribly shortened life expectancy. We die on average 25 years earlier than normal people. Sadly, to me, dying 25 years earlier than I should is welcomed as I really can not fathom having to continue to live like this another 15 years.

Explain to us why we are ignored and demeaned? Why is there so little funding and research on a disease that really is a true epidemic?? Why?  
Finally, you need to address the **ZZZ** situation in Asheville, North Carolina. WHY is this young man living apart from parents who have taken him to the finest medical facilities in the US? Even Dr. **YYY** has testified that this teen age boy is very sick and must be returned to his parents and provided the medical care he so desperately needs to survive. This boy's case with the Buncombe County DSS is yet another shot at CFIDS and it is probably because of the SSA Disability funds that this young man is receiving. Why else would DSS remove a

child from parents who have spent enormous amounts of money, time, energy on getting him the very best medical care possible and now having to spend over \$25K on legal bills fighting to get him back home and given the medical attention he MUST have to survive. This situation MUST be addressed by your Office of Child Abuse and Neglect (HHS) group. **ZZZ** must be returned to his parents and provided medical care. Those in DSS should be prosecuted for this situation because they removed a young man who was being given the very best, yet because he is getting Social Security money the DSS has grabbed him for the funds and now must cover their actions by claiming the mother is being "overprotective" and preventing him from acting "healthy".

I have rambled in this letter and this is evident to me. I used to be able to write quite well and very clearly. But, my brain doesn't work and writing a letter such as this is quite draining and puts great demands on my limited energy levels. However, you need to hear from as many CFIDs people as possible. There are many millions of CFIDs people unable to sit up at a computer long enough to type a letter and so I felt compelled to give my testimony on what CFIDS has done to people like me. I also am enraged by government organizations such as the CDC for wasting years and years of my life and misusing illegally what tiny funding was provided to them for CFIDs research. Since I do believe that the CDC has proven over the last 20 years that they will NOT take CFIDs seriously and do what must be done to find out what CFIDs is and how it moves (genetically and contagiously probably), then they should be removed from dealing with CFIDs even though we are an epidemic and THAT is part and parcel of their job. They have not done their job. Remove them and place CFIDs research into the hands of another organization. ANY other organization.

We also must have more funding. A great deal more funding than what we have been given over the last two decades. CFIDs people may be dying, but we are not dying off. More and more are getting this disease and the numbers are growing fast. You do have a true silenced epidemic and the government is the one silencing us since we are a very frightening group of sick people. Please do something of value and not the usual government games that have been played and recognized by those of us who have worked for or supported the government. We KNOW what is going on with government organizations such as the Buncombe County DSS and the CDC.

Get us funding for research and treatment. Start to undo the criminal damage done by government organizations. **This is YOUR JOB.**