

## Testimony

Marcie Myers

### NOT THE MARCIE WE KNEW

I'll always remember those words, sitting in the SC Disability Hearing room, the response from one of my fellow colleagues to a question: "This is not the Marcie we all knew". For almost 14 years (starting in early 1986) I'd been a Nurse Manager for 2 South Carolina State prison clinics, responsible for close to 1000 inmates, the nursing staff, the physician, the dentist, and anything else that went on. I loved most the direct care and contact with the inmates, most of whom were in dire need of everything I'd taken for granted: healthcare, dental, education, and just attention. In 1994, however, something happened that changed my world forever; I was diagnosed with Chronic Fatigue Syndrome. It was a sudden onset. My daughter was only 8 years old at the time. My family physician, Dr. McRee, God bless him, saved me from the situation I've heard from many others which was that of going from doctor to doctor to doctor only to be told "there's nothing wrong with you" or "it's depression". He ran viral titers and mine were off the charts though none were active. Cytomegaly Virus, Herpes Simplex Virus, Epstein-Barr Virus. My throat hurt, I ran a low-grade fever (still to this day), I had severe headaches, but mostly I was just bone-deep exhausted all the time no matter how much sleep or rest I'd gotten. This fatigue wasn't only in my body. No, my brain also would seemingly just shut down at times, making cognitive and logical thinking impossible and my short-term memory was shorter than I could remember. I went back to Dr. McRee and told him that I didn't like that diagnosis and wanted another one, knowing that CFS had no known reason or treatment. OK, he said, and sent me to 2 Infectious Disease specialists who only confirmed the same diagnosis.

You'd have to have known me back then. Only 38 at the time, I'd spent a lifetime camping, water skiing, hiking, bicycling, gardening, and anything else involving the outdoors. I'd spent each summer during my college years travelling across the US and Canada, setting up my orange and blue K-Mart tent in some forest or desert, making a fire to cook, and then heading out again the next morning to see more of our beautiful American continent. I was and still am by nature the proverbial Type-A person, raised by a Sgt Major MP Dad and German Mom with high standards, taught to have integrity and strive for the best. Close to a straight "A" student no matter when or what. I was fearless, worked hard, played harder, and had no problem standing up for myself as well as for others. Take on city hall? No problem. It was "this Marcie" who was able to continue working for 5 more years until, I guess, age and loss of coping skills finally caught up with me.

In July 1999 at somewhere around 1:30pm I realized that I couldn't answer a most basic question from one of my nurses. I couldn't find the information that my brain had once known for all my years of service with corrections. I left work and never returned to clean out my office. Lucky for me again, I had a well-documented case and letters from the specialists stating that I was not someone that just didn't want to work and in less than 2 years I was receiving a monthly check from SC Police Retirement as well as from Social Security Disability.

On the other hand, however, I was terribly horrifically sick, unable to move any further than from the bed to the couch on any given day. If I did hit a moment of energy, I'd try to do some of all the things that needed doing only to find myself quickly thrown back down. "Crashed". In even worse shape than before for at a minimum of 3 days. One would think that this is as bad as it could get. Until you realize that your husband has closed checking accounts, moved into a

separate bedroom refusing himself to move out, repeatedly taking our daughter under his arm and saying to me "We don't want you any more". We don't want you any more. Erin would stand there silently, not yet 13 years old. What I realized was that he was going to force me to move out no matter what it took. He didn't have the balls to say that he abandoned his sick wife so he went about it by sheer mental abuse and verbal threats until I finally did live while there was but a tiny shred of "me" left. I can't even describe what had happened to my heart and spirit except to say that everything I'd always believed in, everything I'd once held as true, ceased to be. I can't quantify what effect this additional stress had on me. I was completely alone. No support, no love, no one to care for or about me. My Mother, sadly, took on his fabricated image of me and became but another threat, another enemy, another tiger chasing me. I knew I was physically ill and never doubted it. I knew that I'd never allow myself to be in this position, beaten down, left alone, heart and spirit broken, out of "choice"??? And I know that many many of you at home too sick to travel, perhaps too sick to even know of this historic event, you know exactly of what I speak.

Was I depressed? Absolutely! But more than that, I was ANGRY. Angry about what he'd been able to do to me. But, and here I speak directly to our American government, the CDC, the naysayers, the physicians who have allowed this to occur, to our President, Mr. Obama, to the Advisory Committee gathered here, to say that it is YOU who have allowed this travesty to occur. Others will speak of the statistics; how many are ill; how this disease has received NO FUNDING or in reality what amounts to 5 pennies per patient. How people are penniless because their doctor didn't support their Social Security Disability claim. How they have no health insurance to even see a physician in order to even document a claim. How they've been forgotten. How some of our brightest people, most of them female, most of them in their 50's now, have been.... I can't use the word treated because that would imply acknowledgement.... or forgotten because that would mean they were first remembered, or even "dismissed" as that would mean that they were once seen. Angry??? Hell, yes, I am SO angry that I want to show you all my primal scream. Without the pillow.

So, why are you, the Advisory Committee here? Because I tell you now, it'd better not be simply to appease us. No. I demand that you HEAR me. Hang your heads in shame for what you HAVE NOT DONE. For what my life has become while every other stupid cause has gotten funding, lots of it, I submit that not one more second go by without all of you realizing how sick I am, how helpless I am, how hopeless I've become. I thank God and the WPI and Cort and all the other lesser sick individuals who have continued to push the cause and keep the candle burning while NOT ONE of you has seen it or me. I demand that you go visit some of the sickest patients who can't leave their beds. Pray that someone is bringing them food and helping pay their bills and, if they're really lucky, loving them. I want funding TODAY. The recent discovery of the XMRV retrovirus is, ironically, what I have to be thankful for. I'm thankful that I am positive for an HIV-like virus. I wonder if you, the Advisory Committee, can imagine at all what it would be like to wish that you had HIV instead because it's treatable and I'd be well and working and not here stuck in this Purgatory. I hope that it will prove to be the cause and WITH FUNDING that day could be next week. I hope that I will be able to take the triple cocktail that saved the lives of HIV patients. I hope to be well. I hope to be able to work once again, and travel to visit friends and relatives, and have a life filled with purpose. I hope.