

Testimony

Karen Ficano

My name is Karen Ficano. I am 48 years old. I grew up in Upstate New York. I have a bachelor's in computer science from LeMoyne College in Syracuse, NY. I worked on military radar and sonar contracts for our Marines and Navy, respectively, at General Electric (GE), also in Syracuse from 1986 to 1992. I have a MBA from Cornell University, class of '94. I worked here, in the greater Washington Metro area, for American Management Systems, now a part of CGI, from 1994 through 1999.

On September 23, 1999, I had just finished hosting the first day of my International Conference for my former employer's Network Managers. It was about 5pm when I was suddenly hit with an extraordinary wave of exhaustion and a frightening sick feeling the like of which I had never felt before. CFS had arrived... and my life departed: no more Network Managers conferences; no more Change Management Consulting, my work that I so loved; the ability to sustain friendships and relationships gone; no more hiking in the Shenandoah's or rock climbing at Great Falls just up the Potomac from here; no more dancing, biking, yoga or tai qi; no entertaining; and, most painfully, no more international travel off the beaten path, my greatest passion.

I had been flattened by the symptoms of CFS: brutal, intractable migraines; body-wide pain so intense it felt like my muscles were wrapping themselves into knots around my bones; a previously so-reliable brain that seemed un-wired and filled with sticky wet cotton; and a lack of energy so profound I sometimes felt that breathing was voluntary. I didn't even have the energy to run my personality, to smile. I couldn't be me any longer.

I now live with my 73 year old father who still works full time, downhill skis, and is out at social functions 3-4 times a week. I used to be a relatively fearless, confident person, unflappable according to a former boss. Yet, with CFS, there is this fear I carry around inside me: I never know when my body won't "show up" to function when I need it to or want it to. Not until I moved in with him did I feel a sense of safety and security that I can't really explain.

Per the recommendation of my former specialist, Dr David Bell, I infuse myself with a liter of saline every day under the supervision of my primary care physician. I pay for this treatment almost entirely out of pocket since it is not considered a

recognized treatment or medically necessary under my insurance coverage. This is unfortunate since it increases my average daily functional hours by more than 33%, and generally blunts all of my symptoms enough that if I did not have access to this treatment, I would be devastated to lose that extra 33% of functioning per day and return to the strain of 3 functional hours per day.

This treatment costs me about \$4-5000 per year, out of pocket. I am draining our Social Security coffers by over \$1800 per month in Social Security Benefits. And I am no longer contributing to our economy in any way. I take pride in being a contributor, be it to my family, friends, employer, or country. I would like to return to being a “contributor.”

I know I “look fine,” even “good” or “great” according to my friends. I am grateful that I do not look disabled and have to suffer the stares and discomfort of other people who don’t know how to “be” with me. Please keep in mind how very invisibly debilitated we are.

I am one of the lucky ones: I have CFS of “moderate severity”, a firm diagnosis, physicians who believe me and work hard on my behalf, disability benefits, a large, strong support system, and hope.

Thank you.