

May 20, 2009

To: Chronic Fatigue Syndrome Advisory Committee

To: President Barack Obama

My Testimony:

I am 72 years old, healthy, and a good mother. I want to tell you what our youngest daughter's chronic illness has done to my family.

In May 1994, just after our daughter completed her third year at college, she told us that she was happier than she had ever been in her life. She had a dreamjob for the summer--assisting one of her professors--and a new apartment with housemates she loved, and a new boyfriend.

Then, on June 18, she called us from the emergency room. Suddenly, she said, she was having trouble remaining conscious, trouble sitting up, trouble thinking. She was getting an LV., and told us she would be okay.

But she was never okay after that evening. Fifteen years later, she is in bed about 95% of the time. She can walk a few steps, sit up a little, eat without assistance (from a tray of food that we take to her), and use the computer to complete writing projects--a little at a time. My husband and I provide assistance with simple tasks throughout the day, every day.

Back in 1994, we all thought that our daughter's extreme fatigue and weakness and trouble remaining upright would go away soon. In 1995, when a doctor diagnosed her with CFS, we thought she would recover because she was such a determined person and had a very positive outlook.

We had always been a close family, and at first her three siblings were supportive. They talked to her on the phone, visited, helped with research, tests and doctors' appointments. But as time went on, they couldn't understand why she wasn't getting better. Doctors tried to help, but they didn't know what to do.

Finally her siblings became angry. They are angry at her for being sick and they are angry at my husband and me for taking care of her. Especially me.

They simply do not believe that post-exertional fatigue exists. They don't believe that exercise can make anyone worse. They don't believe that when she pushes herself too far she deteriorates further. They ignore her carefully documented diagnosis of POTS, her abnormal SPECT scan, her Hashimoto's, her positive tests for several pathogens, her primary immune deficiency disease.

They have adopted the attitude of the CDC--that CFS is psychosomatic, and it can be cured with determination, graded exercise and cognitive behavioral therapy. This CDC attitude pervades our society and has reached into my family and almost destroyed it.

One of our sons wrote to our daughter's doctor, "Without drastic changes in her treatment, I suspect [my sister] will remain an invalid until my mother dies or otherwise becomes disabled with age...This doesn't have to be the case. I believe with cognitive behavioral therapy, and disengagement from our mother, our sister could be living a somewhat normal life within months, as could my parents."

At this point our three older children seem to have abandoned their sick sister. My heart is heavy as I watch our formerly close family tom apart by this disease and I worry about what will happen to our daughter when my husband and I die. I am devastated by their belief that my death will cure their sister.

For 15 years I have followed the research decisions made by the CDC and have seen corruption, contempt for patients and a failure to make progress in defining and treating this disease--or set of diseases.

Here's what the CDC can do to help now:

- 1 Get rid of the CDC's vague case definition of CFS. It's pure mush. It is so broad that anyone who didn't get a good night's sleep can be included, and any studies using this definition are tainted. The Canadian Consensus is better.
- 2 Declare a moratorium on funding studies by psychiatrists and psychologists who believe that CFS is psychosomatic. Outlaw the use of biased subjective psychiatric questionnaires that measure mood, but not fatigue. Quit calling those questionnaires "instruments."

- 1 Fund studies that measure fatigue objectively. Start by repeating the Arnold Peckerman cardiac output study.. Then fund the two-day exercise tests developed by the Pacific Fatigue Lab.
- 2 Publish honest studies, including the raw data. Fund outside researchers. Develop subsets. Quit covering up.
- 3 Get rid of the CDC people who are responsible for this sorry mess.
- 4 Tell the world that CFS cannot be cured with CBT or graded exercise therapy. Maybe my children will hear.

Sue Bailey