

TESTIMONY OCTOBER 29, 2009

It is very painful to have a sick child. It's extremely painful to have a child who has been sick for many, many years. It has been most painful when physicians have told her, "it is all in your head," or "we don't know what to do to help".

It is very painful to have a daughter who, at the height of her career, acknowledged as an expert in her field, invited to speak at conferences all over Europe (which I sometimes attended), voted a favorite teacher by her students, had to leave her position as a tenured professor because she was unable to execute her duties.

It is most painful that, when she sometimes feels a bit better and we all have hope that she is improving, she relapses back to weakness and exhaustion and we go back to feeling dismayed and hopeless.

This pattern has been going on for twenty-three years. Let me describe the differences I see in my daughter so that you can get a sense of the devastating impact of Chronic Fatigue Syndrome.

From the time my daughter was a young girl, she was a ball of energy—always moving, always engaged in some important pursuit. She was athletic, at the top of her class, dedicated to excellence, studious, disciplined and able to think and reason critically. When she became ill, her life, and, as a result, mine and my husband's, changed dramatically. She and her young daughter lived in the University town where she was an associate professor. While fighting a custody battle, being a single parent and working full time, I was aware that she was feeling more and more exhausted. It was extremely painful that after winning the custody battle in court, she had to relinquish custody of her child to her former husband, as she was too ill to take care of her child.

When my daughter received the diagnosis of Chronic Fatigue Syndrome, she drew on her research background immediately. Her extremely high IQ together with her experience doing in depth research about unfamiliar topics served her well. She found doctors who were touted as specialist in CFS. She traveled across the country and to other countries to work with these specialists. All to no avail. However, she did not give up. She began studying the syndrome on her own. This led to her study and subsequent certification as a doctor of naturopathy.

Her perseverance and tenacity also showed up as she explored different modalities to increase the quality of her now compromised life style. She found that yoga helped her feel better during the day. As she practiced yoga, as she tended to do, she became an expert yoga instructor. She hoped to be able to have the energy to teach yoga as it helped her feel so much better. However, after attempting to do so and getting a following quickly, she found that her poor health prevented her from having the consistency necessary to maintain an ongoing class. She now practices yoga regularly for her own well being.

So from being an active person who hiked and biked regularly, visited museums frequently, cooked gourmet meals, wrote and published articles for professional journals, wrote chapters for art history textbooks, taught a full course load at an academically rigorous liberal arts college, and raised a developmentally disabled daughter on her own, she is now an invalid, living an extremely compromised and limited life.

Over the years, I have stayed with her in her home to help out with the bare necessities of life. I am thankful that her partner is a generous and extremely helpful man, quick to take care of many of the chores. She could not have made it on her own as there were days when she could not stand for more than a few minutes let alone go to the grocery store. House chores were out of the question as was any form of exercise other than yoga.

Last year when she had another set back, she came from Ohio to live with me because she was in such a physically weakened condition that she was unable to do even the minimum to care for her self. When she arrived and for several months following, she used my deceased husband's wheel chair as she was unable to stand for more than a few minutes without having to lie down for hours to recuperate. She stayed for six months as I tended to her care –putting my own life on hold as I watched her withered weakness gradually transform into a bit more strength. She found that acupuncture relieved her and helped her feel more comfortable so she went to a practitioner several times a week. Fortunately, I was able to help subsidize the cost of her yoga and acupuncture as none of that was covered by insurance. I am grateful I am able to help but other parents may not be in such a position.

I have been and continue to be distraught. It seems unconscionable to me that we are not putting more research dollars into understanding this syndrome. Somewhere, there must be a researcher who can unlock the secrets of this malady.

Even now, when she is as well as she has ever been with this illness inside her, it breaks my heart to experience the following:

- she needs to rest several times a day,
- she can only make tentative plans as they may need to be broken,
- we cannot go to a museum together here in Washington because she gets too exhausted.
- if she doesn't get to her nap on time she may be negatively affected for two days afterward,
- we can't go out for dinner if there is too long a wait
- if she doesn't eat on time, I can read her weakness on her face.
- she can't stand in line at a check out lane if she doesn't bring along a stool to sit on.

It is unfair and sad that I can run rings around my daughter, energy wise, although there is more than a generation between us and I have a bad back!