

May, 2009

An Open Letter to: Members of the Chronic Fatigue Syndrome Advisory Committee

I am writing as a father who has witnessed the devastating and debilitating effects of CFS in my daughter's life. Always a self-motivated and high achieving student, our daughter completed a highly challenging undergraduate and graduate program at a top university and secured a professional position in a top international company. She quickly advanced through the ranks and was sought after by competing firms, seemingly on her way to a highly successful career.

But ... it all came crashing down as physical problems began to mount. Just getting out of bed in the morning became a chore, let alone the demands of her job. In short order, her life became more about making it through the day than about making it up the corporate ladder.

My daughter was persistent in trying one doctor after another in an effort to find out what had caused her to enter this downward spiral. Unfortunately, most of the doctors wrote off her symptoms as signs of depression and offered no medical hope. Most people would have just given up at that point, but to her credit, my daughter continued to look for answers. One thing in her favor was that she lives in a metropolitan area; research led her to a practice specializing in CFS. She is also fortunate that she has the resources to pay for medical expenses that are often beyond the coverage of typical health insurance plans.

I am happy to say that under the direction of her doctors our daughter is finally making progress. The prognosis calls for gradual improvement over a period of years; to what extent she will regain her former "self" remains to be seen. I am awed by the perseverance and faith that she has exhibited throughout this trial. She has ups and downs, but overall maintains quite a positive attitude. I am also so very thankful for the love and support that she receives from her husband throughout this whole ordeal.

Most of those afflicted with CFS do not have the resources and/or support that my daughter has. As difficult as it has been, and is, for her, many find themselves in more hopeless straits.

So, on behalf of my daughter and the sons and daughters (and wives and husbands, moms and dads) of families everywhere, I urge you to use your influence to impact the following areas:

- Research – it seems that CFS has only recently been recognized as a medical condition and therefore the knowledge in terms of causes and treatment is quite limited. There are few doctors who are sufficiently acquainted with the disease to diagnose it and suggest treatment. Just as with many other recently recognized conditions like HIV and Hepatitis C, it is critical that more be learned about CFS.
- Promoting Awareness – in addition to the direct effects of the disease, those with CFS also suffer a lack of understanding (and sometimes outright disdain) from friends, family, and coworkers. They are judged as being unmotivated, lazy, or depressed. Employers often do not treat them in the same way that they would someone with a "real" illness. As more knowledge is gained, it will be increasingly important to educate the public.
- Funding – both of the above require capital. You can press national and international health agencies, government agencies, and pharmaceutical companies to dedicate the money needed to accomplish these goals.

Thank you for taking the time to read this letter and for your efforts in this important cause. I hope and pray that your work will pave the way for better treatment and a better future for all afflicted with CFS.