

Testimony: Janis Bell, October 29, 2009 12:45 pm

I was a distinguished art historian, a Fulbright Scholar who received grants from federal agencies such as the NEA and NEH, who served on a granting board of the NEH, and who received numerous awards from private foundations.

I came down with CFS on May 2, 1987. In addition to the onset of classic physical symptoms of sore throat, low grade fever, dizziness, and muscle weakness, the cognitive effects of the illness were immediate. I developed paraphasia -- pointing like an idiot at forks and bowls because the words for common objects wouldn't come to mind -- and I found it difficult to organize ideas. The only article I ever had rejected for publication was the one I wrote that summer!

The neurocognitive effects of the illness continued over the years, worsening at the end of the first decade. Math had been my top subject in high school, and my math SAT score had been 760 out of 800. As CFS advanced, I found myself unable to do simple arithmetic. I also lost skill in visual recognition -- skills that had made it possible for me to ace art history courses and get my doctorate. When I finally had neurocognitive testing in 2005, at a time when my symptoms had partially abated, I scored down in the 14th percentile for visual recognition and spatial skills. I had once been the Department Chair and could no longer organize a few files in my home.

For a long time I struggled with depression at the tremendous losses I'd suffered -- loss of career, loss of the ability to lead an active life, loss of competence in many tasks. Eventually, working with yoga, meditation, and natural forms of medicine, I was able to make peace with my restricted life and find joy in the simple tasks of living.

My healing journey of 22 years is a modern odyssey. I have travelled to California and New York, Mexico and the Caribbean, exploring protocols of mainstream physicians and protocols of holistic practitioners. Some protocols helped me make substantial progress towards recovery; others caused me to worsen, often creating a ripple effect that continued to shimmer for several years. But when I compare myself to many of the non-working afflicted on the internet forums dedicated to ME and CFS, I know that I am one of the lucky ones. I had the research skills and the brain power to dedicate myself to studying human physiology, homeopathy, herbs, and nutritional supplements. This knowledge has made it possible for me to control my symptoms (and *control* is the operative word) so that I no longer suffer with the ups and downs of passable days and bad days which torment the lives of my friends. I've also had the financial resources to explore acupuncture and other healing modalities.

Because of my relative success, I'm asking the CFS Advisory Committee, to give more attention to nutritional interventions. The pharmaceutical companies have plenty of incentives to develop drugs for CFS, given its estimated prevalence between one to four million Americans. We need YOU to undertake the kind of research that private companies have no incentive to undertake. There is serious and enthusiastic discussion on internet forums about several protocols which have alleviated symptoms in numerous individuals with CFS. Some individuals have improved substantially enough to return to the work force. Others have reduced suffering, doctor's visits, complications, and costs. Here is a brief list:

1. Vitamin B-12. People report success taking only the active forms, adenosylcobalamin and methylcobalamin, while avoiding the inactive forms of cyanocobalamin and hydroxocobalamin. We need more research as to why cerebrospinal fluid shows low B-12 while serum B-12 levels are normal, when MMA is the most accurate way to measure functional need, or whether the new tests of transcobalamin are more accurate.
2. NO/ONOO. People report success taking specific antioxidant supplements designed to scavenge peroxynitrate according to the theory advanced by Dr. Martin Pall. His theory and protocol need further clinical testing.
3. Methylation and reduced glutathione. Dr.s Van Konynenberg and Nathan did a preliminary study of 60 individuals with CFS whose energy improved substantially after less than a year on their protocol of unusual supplements. Instead of using synthetic folic acid, they directly employ substances active in the folate cycle such as 5-methyltetrahydrofolate and folinic acids. They have documented through serum testing the normalization of reduced glutathione, SAME, SAH, adenosine, and various active folates. Some study participants recovered sufficiently to return to the work force.

4. Amino acids therapies, particularly intravenous administration of amino acids, has helped those with low serum and tissue amino acids despite adequate dietary intake.

5. All people with CFS have abnormalities in Krebs's cycle metabolites, most at the aconitase enzyme. Through studies or increased monitoring of organic acid testing -- available through US laboratories such as Genova, Great Plains, and Metametrix -- we might be able to discover patterns revealing how this illness actually decreases the capacity to make adequate ATP. That could lead to interventions that increase energy substantially enough to improve quality of life and return many individuals to the work force.

6. Dr. Sarah Myhill's study of mitochondrial dysfunction and the protocol she uses to reverse it deserves further study in the U.S. as does Dr. Kenneth De Meirleir's discovery of increased H<sub>2</sub>S in persons with ME/CFS.

7. To control costs, we need to stop turning natural nutritional products into drugs just because a pharmaceutical company wants to market it. This has happened in the past year with BH<sub>4</sub> (tetrahydrobiopterin) and a natural, active form of Vitamin B. Restriction of products that have been available for generations is contrary to the principles of a democracy and the free market system on which our country grew to international prominence.

Also, if XMVR turns out to be the cause of CFS, we still need to understand the pathophysiology so that we can intervene in helping long-term sufferers repair and restore their damaged bodies. My friends and I hope the government will be open to studies on non-toxic products that have the potential to support the immune system. We don't want to follow in the footsteps of cancer patients with toxic therapies that often kill the patient before they remove the disease. My friends and I call upon the government to look into the development of

- peptides that disable viral penetration into the cell, such as the one Dr. Candace Pert of Georgetown University discovered for the AIDS virus
- peptides reported by the Thai company Immunitor to extend the life span of individuals with late-stage AIDS
- transfer factors and other markers of healthy immune function that could explain why 3.7% of the healthy population are able to harbor XMVR without becoming symptomatic.

It is also of the utmost importance to revise the case definition of CFS. Those of us with the illness find that the Canadian definition of M.E. is a more accurate description of our symptoms. If XMVR doesn't turn out to be the marker we seek, we need to look at functional markers including organic acids, amino acids, and methylation markers in order to diagnosis new cases before irreparable oxidative damage occurs from overexertion.