

**From:** Carol Olsen  
**Sent:** Tuesday, May 19, 2009 11:46 AM  
**To:** OS OPHS CFSAC (HHS/OPHS)  
**Subject:** CFS

To Whom It May Concern:

I am a formerly productive woman who has been ill with ME/CFS, otherwise known as CFS, for 24 years. I had a virus transmitted by a young girl on Jan. 26, 1985 in Denver, Colorado, where an outbreak of a virus was going on. Many friends were sick for a week or so. Two friends immediately sought medical aid and were given Amantadine, and never became more ill. My virus never went away, but changed and became an increasing problem. I could not sleep. I itched all night long, especially in my scalp area.

I would go to sleep studying advanced math for a secondary math certification I was working to complete. Two friends recovered from the flu in 4 months, not doing anything special. I never did. A researcher at National Jewish Hospital rejected me as a CFS patient because my EBV antibodies were insufficiently high. However, any time my daughters became ill, I did whatever was necessary to get Amantadine to them in case there was a genetic component and they were susceptible. This was strictly based on maternal instinct. They are healthy today, and I am not. This same researcher recalled me a year later and the EBV titers were high, so I was then accepted as a research subject. Regretfully, the records were not available for an individual, so I do not have the results, but they were orally said to be high for EBV, all the Herpes virus including HHV-6. He would take 12 vials at a time, every two weeks, and did send us all to the U. of Colo. School of Medicine Chief of Neurology who worked with him and who tested us all. We all had the same cognitive deficits. He also sent us to an MD who prescribed medication for sleep, which never came otherwise.

We have visited more doctors than I am comfortable telling, including those at a large medical facility in the Midwest which sent me away rather unceremoniously, finding nothing but slightly elevated liver enzymes. Two people of greater vision told me I was sick, the doctors just did not understand why and were not doing the right testing.

We moved from Colorado for my husband's profession three years later. I eventually saw a well known CFS researcher in North Carolina and came up extremely irregularly in all of his testing, at that time having an "impressive" alpha interferon level of 2000, being positive for "Dr. Martin's virus", having a poor immune system, shown by an immunologist in Miami, and inadequate VO2 max testing. A porcine liver extract, Kutapressin, said to be a totally non-toxic antiviral, helped greatly for 12 years but was inexplicably removed from the market. This was an established treatment for pernicious anemia prior to B-12 injections. Its replacement has not helped me or many others.

The personal cost, opportunity cost, family cost, sacrifice of my husband, and financial cost has been tremendous. I was once a good student but now can learn very little and only with great difficulty, which is part of true ME/CFS, and came about a year after the initial virus. I would have been employed outside the home if well instead of consuming what resources we have. I had completed graduate work

and was qualified to be a Govt Statistician, which I would have enjoyed. I am also an experienced teacher and truly love teaching. I cannot stand to do that or I faint and am sick for days. This is due to low blood pressure upon standing, common in ME/CFS. I used to love to sing in any group, anywhere, but cannot because of lack of energy and the required standing.

I am so fortunate to have a magnificent husband who has great depth and integrity and has stuck by me. Our daughters are very kind also. Many friends have been lost because I cannot be active with them and inability to comprehend the illness. Others do not understand that one can look normal for two hours after several days of rest and then collapse for a week after an activity, but asthma and epilepsy can also be invisible. The lack of acknowledgment and support has been heartbreaking.

Please understand that this disease is (1) Biological, (2) Infectious, (3) In need of the proper definition, such as the Canadian Consensus Definition, (4) in need of research for cause and treatment. People are languishing in the shadows, unable to fight for themselves. We appreciate your attention to our disease.

Sincerely,

Carol O. Olsen