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Testimony to CFSAC

September 17, 2010

Sometime prior to 2002 I began having joint pain that started out as just a little annoying but increased as the years passed. I also began to have Charlie horses in my neck around the lymph node areas which were very painful along with obvious swelling in this area. I went to many doctors and dentists regarding this and had a blood test to check my thyroid but never received relief or an answer. In 2002 after my second son was born I had a period of about six months where I had severe muscle fatigue. This progressed to the point that I could no longer get up my stairs, grocery shop or live my life how I had prior to this occurrence. I went to many doctors who ordered many blood tests and finally put me on antidepressants. I took these for a few months but discontinued as I did not like the way they made me feel and did not seem to help with pain or muscle fatigue.

I did begin to feel better after about six months but noticed that I had begun to have shorter relapses of this muscle fatigue that might last several days to several weeks so I began going to the doctor again whenever I would have a relapse. Again...the only "help" I received was an offer of antidepressants. Eventually I relapsed and have never recovered fully. At this time I was in excellent physical condition as I worked out at the gym 5 – 6 days per week and spent several hours in the cycling room per week. I was also very active with my children and their activities. I was forced to stop going to the gym because the pain in my joints had intensified and it took every bit of energy I had with none left over for the kids or house. I continued to deteriorate and went to see a rheumatologist who I saw for about a year. The rheumatologist sent me to a neurologist who also found nothing wrong but did provide me with pain patches and pain medication.

I continued to see the rheumatologist while my condition deteriorated to the point that I was spending most of my day in my chair or in bed. I was no longer able to cook, clean, grocery shop, exercise and had very limited involvement in my children's school and other activities. My symptoms continued to multiply until I was not only having pain in my joints, muscle fatigue and inflamed lymph nodes. My breasts became swollen and painful, muscle twitching, numbness in the left side of my face, left hand and arm, leg and foot; feeling of electrical shocks through feet and legs and hands, cramping causing difficulty in sleep, low grade fevers, chills, flu like symptoms, pain and weakness in the back of my neck so bad that I had to support it with a pillow most of the time. Also, stiffness, body popping, cracking, Rashes, burning skin, blurry vision, dizziness, vomiting, difficulty breathing, pain in chest, migraines, very stiff and painful hands, numbness and lack of blood circulation in tip of some fingers and toes(Reynaud's), feeling of inflammation throughout entire body and a sharp decline in my ability to remember anything. Most concerning was that, often, I would only have pain on one side of my body from a migraine on the left side of my head all the way down to my left foot. Also, I noticed that my pain and inflammation would increase as weather fronts moved in or out. Most recently I am having symptoms of Paraesthesia, as my doctor describes it.

Finally, after trying Lyrica, Celebrex, neurontin, Relpax for migraines, Naproxen and receiving an MRI on my lymph node area, my rheumatologist told me that he did not know what was wrong with me and recommended that I see a doctor in my area that specializes in chronic fatigue syndrome, Fibromyalgia and HIV/AIDS.

In December of 2008 I saw this specialist who was the first to order an MRI to rule out multiple sclerosis and also checked my heart function. She ordered blood test for celiac disease, Lyme, HHV-6, Mycoplasma, Candida, and glutathione/ATP production. I was found to have HHV-6, M. Pneumonia, Chronic Epstein Barr Virus and low glutathione which she felt was consistent with a diagnosis of CFS. I started taking many supplements to support the immune system including Omega 3, vitamin d, cod liver oil, acetyl L carnitine, NAC, vitamin C, calcium, digestive enzymes, D Ribose, Probiotics, P5P, Magnesium, Zinc, 5-MTHF, multi vitamin and selenium.

My doctor prescribed an antibiotic for the mycoplasma, tramadol for pain and glutathione/ATP injections. I became very ill on the antibiotic. The pain became unbearable and I began vomiting. It seemed that all my symptoms were intensified. She took me off the Doxy and prescribed a different antibiotic which I took for several months. I had a very bad herx reaction to this treatment and thought, at times, my body might shut down. Around the sixth week of antibiotics and the glutathione/ATP injections I noticed an increase in energy levels and eventually improved around 80%. However, my labs showed that the ATP and mycoplasma were not improving so I changed antibiotics again. I also started an antiviral for burning skin and fevers, thought to be symptoms of Epstein Barr Virus, this helped tremendously.

A few weeks ago I stopped the Glutathione/ATP injection, and the glycyron plus and started oral ATP. I have been going back down hill ever since.

Nine years after my first symptoms I finally asked for an Igenex Lyme test and was found positive for Lyme through this lab although negative according to the CDC standards.

Today, I continue antibiotic treatment in hopes that this will keep the Lyme under control.

My request for the next CFSAC meeting is as follows:

- Money will be set aside to establish 5 Centers of Excellence throughout the country and especially consider places like the Whittemore Peterson Institute, University of Miami (Dr. Klimas), University of Medicine and Dentistry in New Jersey (Natelson), Stanford (Montoya) and the University of Utah (Bateman).
- Additional funding for new researchers interested in CFS and/or immediate release of funds to speed up research and help patients that have had no support for decades.
- XMRV funding increase to be comparable to that of HIV/AIDS
- Clinical trials-NOW for CFS and XMRV Research
- Recommendations from the CFSAC should be conveyed by Dr. Howard Koh to Secretary Sebelius and must be read and answered rather than no response at all over the 7 years CFSAC has existed.
- The government will begin to work actively with experienced CFS doctors, researchers and patient groups rather than relying on inexperienced staff to find research subjects through telephone calls.

- Studies on long term effects of CFS. The longest studies are less than 5 years yet many have lived with this for 10+ years. There are concerns that CFS might increase the chance of lymphoma.
- Mandatory education for all physicians

Sincerely,

Anonymous