

Courtney Alexander

CFSAC Testimony, October 29, 2009

Chairman, members, my name is Courtney Alexander and you heard my husband Robert's statement a few moments ago.

This is a rare moment in the history of CFS. We have a scientific breakthrough in the discovery of the XMRV retrovirus and its prevalence in CFS. It is a game-changer for CFS and for virology, and every representative from our federal health agencies sitting in this room needs to understand that the playing field has shifted. They found it, now you need to fund it.

Dr. Daniel Peterson, who knows more about our disease than anyone, and the generous Whittemore family have created a place where our country's experts in treating and researching CFS can collaborate with each other to make breakthroughs on the science, indeed a center of excellence.

I am honored to come to you today in the presence of Dr. Peterson and Mrs. Whittemore to reiterate your recommendation to the Secretary of Health (made more than once) that "HHS establish 5 regional clinical care, research, and education centers, centers which will [among other things]... provide effective basic science, translational and clinical research on CFS." The Whittemore Peterson Institute is our Center of Excellence. There can be no argument about that today. So now the Secretary of Health needs to act on this committee's recommendation and fund centers of excellence for CFS. Fund additional research to answer the many critical questions raised by this finding, fund clinical trials on treatments for CFS and XMRV, fund the development of diagnostic tests, fund physician training. I come again, asking the Secretary to provide \$100 million of immediate funding for these critical needs for CFS patients, and I ask that a substantial portion of that be earmarked to the Whittemore Peterson Institute. While we desperately need centers like the Whittemore Peterson Institute in lots of cities, we need to take advantage of what has been created in Reno to quickly get our arms around this devastating new human retrovirus and all its implications for CFS.

In all this excitement, I cannot let stand the appalling comments made by Dr. Reeves from the CDC declaring that they won't be able to replicate the XMRV findings. You can't find what you won't look for. The Director of the CDC should never have let Dr. Reeves comment on such a profound event with reckless abandon of science and CFS patients. A change in leadership of the CDC's program for CFS has been endorsed by virtually everyone in the patient community and by this advisory committee. It is past time the Secretary act on this recommendation also.

I have a simple dream for my family. I dream that my husband can attend our twin sons' baseball and soccer games, and help coach them. To pursue that dream, we now have to move our family back to Reno, Nevada. Despite the presence of the NIH, the FDA and billions of dollars in medical infrastructure in the Washington area, the only place my husband can get Ampligen is in Reno. The only medicine that stabilizes his immune system is only available in Reno. That is a crime. After 10 years of clinical trials, the FDA is still stonewalling, and we can't

wait any longer. To the FDA representative assigned to this committee, I ask you: have you ever had to move your family to get a medicine that has 20 years of safety data, but no approval?

My excitement and hope for understanding and treating CFS is renewed, and I thank the Whittemore Peterson Institute and all of its partners for that. I am grateful for this committee's recommendations from the last meeting in particular, and want to thank the members of this committee for working so hard to bring change for CFS patients. My message to the Secretary of Health is: fund the Whittemore Peterson Institute, fund XMRV research in CFS, and bring responsive leadership on CFS to the CDC and the FDA. My family life depends on it.

Statement of Anita Patton, Reno, Nevada

I also promised to read a statement from Anita Patton, a patient in Reno, Nevada, who can't be here today.

I have struggled, suffered, and been debilitated by Chronic Fatigue Syndrome for 23 years. Before I first became ill, I was a classified top-secret word processor for the Physical Science Laboratory at New Mexico State University. I became ill with the "flu" in 1986, and I had to quit working. I am only 47 years old yet I have significant neurological damage and immune compromised system. At times I can hardly walk, cook dinner, or fight infection. I have lost six teeth and hardly have any left in my mouth to chew, due to bone infections. My gastrointestinal system does not digest food properly.

My request of this committee is to ask two things of you. One, urge the FDA to act on the approval of Ampligen.

XMRV retrovirus has been discovered in the RNase L antiviral pathway. Ampligen helps repair that antiviral pathway and that is what is broken in my body and others with this same illness. I was a patient on the FDA cost-recovery program, meaning I had to pay for it, for 8 years, and I became incredibly well after being on this medicine. It improved my health, my labs, and my life. I did not retain the same level of health after discontinuing the medicine in 2004, and my life has been very difficult being so ill since then.

I am delighted that the scientists and researchers at the Whittemore Peterson Institute have discovered such a medical breakthrough as XMRV and its correlation with the RNase L pathway. I need the FDA to approve this medicine so I can go back on it, and so others like me can get better and return to work.

My second request is to ask you to recommend that the NIH provide funding to the Whittemore Peterson Institute. Without the generous donations provided by the Whittemore family and the perseverance of Dr. Daniel Peterson, we would not have this discovery and the potential to find other treatments to improve my health and that of millions in America. There is much more research to do, and the Whittemore Peterson Institute has shown that it will make the best use of funding to make breakthroughs on our illness. Our federal health agencies now have to step up to the plate. Thank you.