

Robert Miller

HHS Chronic Fatigue Syndrome Advisory Committee
10/29/2009

Committee Chair and members, Thank you for hearing my testimony today. I am Robert Miller and I've been ill for over 20 years.

I must begin by thanking those working on the XMRV virus link in CFS with The Whittemore Peterson Institute in Reno, NV.

First, I must thank Dr. Daniel Peterson who has been dedicated to his patients' care since the 1984 outbreak in Tahoe. His continued focus on patient care and research of CFS has been unwavering, while government health agencies scoffed, declaring "The World is Flat" – they're not sick because we can't see what ails them. Dr. Peterson, our Columbus, knew that there was more to the world than what only the eye could see. His patients were very ill and needed treatment. He could have selected an easier patient population, but did not. He sought answers and never stopped looking, dedicating a lifetime to CFS. Few doctors can say that, and many of them are here.

Next, A special Thank you to Annette and Harvey Whittemore who have made The Whittemore Peterson Institute a reality. Their compassion for their daughter who suffers with CFS brought them to the center of the CFS community, for which I am grateful, but saddened. Then there is Dr. Mikovits and her entire team at the Whittemore Peterson Institute for taking the challenge. Finally, thank you to the National Cancer Institute and Dr. Ruscetti, who devoted their time and special skills, and to the Cleveland Clinic for its discovery. This elite group of experts has done something special. They've given us Hope, for answers, treatments and a cure.

I am glad the NIH is beginning to fund the Whittemore Peterson Institute. It is the CFS community's Center for Excellence, as is obvious today. It is no accident this discovery came from expert researchers and clinicians collaborating. But there is an urgent need to expand this research of a new human retrovirus, and to understand XMRV's function in CFS. Dr. Stuart Le Grice, head of the Centers of Excellence in HIV and cancer virology stated;

he is responding to the XMRV discovery like they did in the early days of HIV. I am glad to hear that one of our federal health agencies is taking this discovery seriously.

I have been here before asking you to fund \$100 million in CFS research. Now, based on the XMRV discovery, I don't believe that will be enough, but still funding must come now. More than 1 million people in the U.S. have CFS. How many have XMRV? Have I given it to my wife? My sons? And will you be able to answer these questions before I get cancer?

This all makes sense to me. I've described my family history before. I've lost identical twin sisters, an elder brother, mother and 6 maternal aunts and uncles all to cancer. Did they have XMRV? For those I've lost we'll never know.

My family has participated in clinical trials over the past 49 years furthering cancer research, and I know XMRV research will be funded for cancer. But, I'm here to make sure that our new Secretary of Health and the NIH fund XMRV research as it relates to CFS, because history proves CFS research has been left behind.

For years, this committee has recommended funding regional centers of excellence for CFS. Now is the time to fully fund the Whittemore Peterson Institute and other regional centers devoted to CFS. We should have centers of excellence equal to HIV and Cancer centers. The Secretary needs to act on these recommendations without delay.

Next month, I must return to Reno to restart Ampligen therapy, as I can't get the only medicine that helps my immune system fight this illness here, because the FDA has stalled this application. I participated in two clinical trials of Ampligen 9 years ago and for years I've come here urging the FDA to approve Ampligen. Before Ampligen my T-Cell count was 350, during Ampligen it was over 1000 and I helped care for my sons. I can't help these days. I need Ampligen to function, so we must sell our home, remove our children from their school and their friends and move to the one place devoted to improving my health, Reno. We are not wealthy, so this is a large burden.

How did this small group of researchers in a few short years of collaboration, on limited funds make such a key discovery, while the CDC

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has spent over 20 years and \$\$\$Millions with no results. [, but to say, There are more people sick than we originally thought?]

I am appalled the CDC allowed Dr. Reeves to comment publicly on the critical finding of XMRV without serious thought. I am sickened by his response: Quoted in the N.Y. Times “If we validate it, great. My expectation is that we will not.” Dr. Reeves proves again he does not believe CFS is real or urgent. He doesn’t believe he’ll find anything in his 20 years of patient data? From his view “The world is flat”. When our government funds science, it should fund researchers who hope to discover something new and useful. While we need funding, I don’t believe any more should be wasted on the CDC until they have a leader who believes CFS is urgent and real. Our tax dollars can no longer be used to prove “The world is flat”.

Lastly, I thank the Chairman and members of this committee for your service as your terms end. You have spent precious time validating our illness and fighting with our federal health agencies to make progress for patients. We are honored and we Thank you.