

Testimony  
Shelley Stewart Lauer

CFSAC Members:

We are a year out from the meeting with Dr. Peterson's presentation about XMRV. What has changed? How much more research has been funded? What clinical trials have started? What progress has been made in getting a name that isn't demeaning, inaccurate and ridiculous? While some scientists are saying that things are moving quickly, from a patient's perspective it's "same stuff, different day".

When I was going through the disability process over FIFTEEN years ago, the psychologist that Social Security sent me to said that I "had an IQ of 92 and the only thing wrong with her is that she can't handle stress". The level of my medical care and treatment by doctors has not improved by much in all these years. (As I have testified previously, in high school I was a member of National Honor Society, Student Council, Model U.N., Yearbook Staff, award winning photographer at the national level. I am a college graduate and held a professional position at an international company listed in 100 Best Companies To Work For. Then I was given an unnecessary measles shot at age 29 and became dangerously ill for a month, followed two years later by a case of mono from which I never recovered).

Other people with lives devastated by this disease will write in with very intelligent, well written testimony. For the past year and a half, my ability to function has decreased to the point of rarely being able to leave home, cook myself a simple healthy meal, or even have more than one interaction with another person a day. The consequence of any activity, including a shower, is significant.

I am asking, yet again for funding funding funding and more funding. There has to be stimulus money, emergency money, **something**. Someone has to step up, stir the pot, make some noise, and make change happen. Why can't it be the CFSAC?!

We need accurate information distributed to doctors for diagnosis and simply to be believed and treated with respect and treated palliatively if nothing else at this point - while we wait for the science to catch up with what most of us sick people have known for **decades**. This is a real biological disease with numerous facets and complications. This would be information **very different** from the false and misleading propoganda the CDC and Cfids Association of America give out.

I have lost 20 years to this. The cost to my family, my community, my country are mind boggling. I had given up hope and was trying to resign myself to the fact I will never be pain free, active, employed, and have the mental function I had - **and that no one cares**. The

Whittemore Peterson Institute has shown me things can and will happen, and now I need my government to step up and do the same.

Thank you for your time.

Shelley Stewart Lauer