

## Testimony

### Anonymous #1

Dear CFSAC panel.

Thank you for your service. I hope that Secretary Sebelius truly listens to your directions and acts. Unfortunately I haven't seen much action since I got ill in the fall of 2008.

Over the past few months, we have witnessed some good scientific debates with exposure to other scientists, and great potential for research breakthrough and funding dollars. Still there is no promises and no grants have been promised, other than a 600 000\$ to research behavior changes. Patients need more than a change of their behavior, in the same way that AIDS patients will not get better by eating less fat and more vegetables.

The CDC promised they would remove offending parts from their website. We have discussed it for the last years. They have not done one change to their website. So my physicians are still being told that I should exercise more, that they should prescribe more anti-depressants and that my natural killer cells should not be tested. It is critical that the CDC gets on with the program, so to speak, and stops studying behaviors and psychology, association with painful periods and more gyne problems. Patients need to know if they have more chance to give birth to children that will have either autism or ME/CFS. Patients need to know if their disease is transmissible sexually or casually.

The CDC needs to apologize to all patients with ME/CFS for the despicable joke they have made of our disease. They need to recognize that they have been wrong since visiting Incline Village and since NOT visiting Lyndonville and take responsibility for stalling research as well as what they didn't do over the last decades, while other diseases like Rheumatoid Arthritis, HIV/AIDS, Cancer, and others benefited greatly from good research and funding.

CFSAC needs to recommend careful research on XMRV and human gamma retroviruses. Some patients are helped with the use of antiretrovirals, which has not been studied formally but prescribed to them compassionately. With the media outlets promoting contamination theory on both sides of the ocean, Dr Mikovits and her group's theory has been torn apart. Research in HIV would have stopped in 1983 but patients were dying so the government was forced into putting money into research. Here we are a very stigmatized group of patients who literally disappeared from society, however somehow it is considered ok to forget us over and over, because we are not dying, and because we are literally subdued- we can't even protest in the streets. It doesn't make it ok to keep on abusing us or make fun of us as a bunch of tired people. It is not ok for the governments of any countries to keep on abusing their patients and denying them a chance at being productive and thriving.

It is in my belief that the clinical trial to confirm the very positive effect of Rituximab needs to happen as soon as possible. With this new data comes many questions. Is ME/CFS an auto-immune illness? Which patients are more likely to respond to Rituximab? Will rheumatologists embrace our illness and give us patients the opportunity to get well like the dozen of Norwegians who benefited from Rituximab? How are the side effects and response rate comparing to Ampligen, which 15 years later is still not approved as an acceptable treatment for ME/CFS by the FDA?

How can CFSAC and Secretary Sebelius facilitate the involvement of rheumatologists with our illness, giving patients the possibility to get treatment near their community? Could this be legislated? The reluctance from the medical community to embrace ME/CFS as an illness is huge. There needs to be an intervention somehow, somewhere. Every single patient with our disease has at least one incident where they feel they were disrespected, not believed, refused treatments and told to exercise and go to a psychiatrist. How many more suicide do we have to witness before our governments start to act? Patients have had hope for two years, and promises for clinical trials and treatments. This has yet to happen. Do we have to wait another two years until Rituximab can be

approved?

Where is the hope when patients cannot see it at their local level and when the CDC cannot be trusted to spread the right message around the world?

Patients from around the world are looking up to you, CFSAC members and US government. The Norwegians have stepped up for their people. What will the USA choose to do?

Anonymous, sick for the last three years; disability insurance in dispute; financially going into a dark, dark hole. Seen by a dozen specialists, 75% of whom lack respect for this disease. 15% more who have no clue as of what to do.