

## CFSAC Testimony

For 30 years now, patients have been complaining of multiple symptoms that while they were vague, most doctors have decided it was benign, temporary, psychosomatic, or depression related. Then some doctors noticed outbreaks of the same symptoms, with some people getting severe form. From the clusters came outbreaks of mantle cell lymphomas.

When the CDC was sent to Incline Village to investigate, they refused to see patients and reported back to the agency that there was no infectious outbreaks. Parallel to this there was an outbreak of HIV, where people died. The outbreak was allowed to become epidemics until funds were released for research and treatments. These days, HIV patients fare much better than ME/CFS patients.

For 30 years, patients have been left in **limbo**. Most doctors still think patients are malingering or have a psychiatric illness. For those that think indeed this is a serious, infectious disease, only very few have become better and able to function in the society and return to a productive life. This is **shameful** for all governments and decision makers. Here are a few stats from the NIH funding for health:

1) NIH funded over 18 billions dollars for habit related diseases, like diabetes, smoking, drinking alcohols or using illicit drugs, 5 billions were allocated for prevention.

While CFS is not related to lifestyle, it got only 5 millions dollar budget (and used pretty badly in my opinion, used to see if CFS came from sexual abuse as a child)

2) NIH allocated 6.33 billions to women's health, including infertility, breast cancer, uterine and female organ cancers and disorder.

We know that ME/CFS affects more women than men, and that a large percentage of these people are greatly disabled. NIH funded only 5 millions (the same 5 millions mentioned above.) Where did the money go, will you ask? Are each of these dollars accounted for? We know that the CDC has a history of using research funds for other purposes or to help different departments.

3) NIH funded 18,3 billions \$ to infectious diseases for 2010. HIV, Hepatitis B and C, Influenza, Emerging Infectious diseases, malaria, Lyme disease, tuberculosis, small pox, etc... Once again, chronic fatigue syndrome got 5 millions. Now could XMRV belong in the "emerging infectious disease" category? Because after all, XMRV is a brand new infectious retrovirus just like AIDS and researchers like Dr Judy Mikovits, Dr Ila Singh and Dr Jose Montoya, amongst all scientists need money to fund research and get some help to the patients that have been ignored for 30 years.

Is this urgent? YES!!!! Patients are tired of waiting and talking suicide. The conditions are difficult. Patients who don't have access to health care, the good specialists have up to 2 years

wait for consultation. Social security disability is difficult to obtain, people lose home and relationship in the meantime.

This is a critical time for CFSAC to get really focus into finding solutions for the lack of attention, lack of funding and the lack of education to the doctors. Here are my recommendations:

- 1) Renew the CFSAC charter as soon as possible and appoint new chairs left empty from the retiring members.
- 2) Lots of work needs to be done to keep the goals and tasks at hand met. I would suggest increasing the CFSAC meeting from twice yearly to 4 times yearly.
- 3) Post the agendas prior to the meetings in a timely fashion.
- 4) Ensure there is a live streaming just as last year for sick patients to watch from their own bed. These are important times and patients from all around the world are interested and watching.
- 5) Ensure that the agenda is posted ahead of time and that the recommendations that were done from the previous meeting shows whether they were done or not and why.
- 6) XMRV is being currently studied, but our scientists need funds in order to do their work properly. I would like to recommend release of funds to the WPI who needs serious grants for research, and incoming clinical trials. Patients see XMRV as a hope to get better. As weird as it may sounds, most of us want to test positive. There is still no FDA approved test for XMRV. Please!
- 7) A very serious inquiry needs to be made about the CDC situation. From the actions they have done in the past, to what needs to be done for ME/CFS patients NOW.

Disclosure: I am a Canadian citizen. Recently I have sent a letter to the minister of health of Canada regarding research money for CFS and XMRV. As you know Canada is the first and only country to ban blood donation from ME/CFS donors. Their rationale was there is no sufficient information at the moment to allow ME/CFS to give blood safely. The health minister also mentioned that they were working closely with the CDC on the XMRV issue, which made me concerned. The CDC has diverted and misused millions of dollars of CFS funds and have lied about it. Research has mainly focused on psychological causes and not bio causes.

CFSAC, the world is looking to you to help. There are millions of people disabled by this terrible disease, primary care providers are helpless or clueless as of what to do. This is not the time to give up. With the concern of repeating myself, funding for CFS has been next to ridicule compared to other comparable or even less serious diseases, with a number of sufferers equal or worse.

My personal experience of ME/CFS: I am 41 years old registered nurse. I contracted EBV 18 months ago after saliva to saliva contact with a cancer patient (patient was spitting when talking to me). Within 4 months I had large ovarian cyst and a necrotic gallbladder, and my health has deteriorated since then. I have been unable to work and spend 22 hours a day in

bed, debilitated by neuro symptoms, orthostatic intolerance issues, chest pain and shortness of breath issues. I was involved in all kinds of activities before this illness including long distance cycling, running, and other ventures. Now I can do none. There are no doctors in town so far that knows ME/CFS well enough to care for me and other than having my gallbladder and ovarian cyst removed, I have received no assessment and no care whatsoever. Like many of my peers, I am in limbo. However I count myself very lucky to receive disability benefits, but will this be cut in the future? My story is one benign one compared to people that have been ill and disabled for DECADES. One thng I know is I miss my life and hope NOT to live like this for the rest of my days.

The last CFSAC meeting in October 2009 gave us all patients some hope. More scientists are getting interested in XMRV and replication studies are expected soon, after 3 negative studies from Europe that made a point to disprove and discount WPI and the Science study. Psychiatry lobby wants to prove this is a psych illness, just like MS, asthma and stomach ulcer in the past. This is time for CFSAC to lend a helping hand to patients and lobby with governments to fund research and get the patients out of their beds.

Thank you, Kati Debelic