

Good afternoon to everyone who are suffering from ME/CFS, to the committee members and to the CDC.

The Emerald City

On October 8, 2009 major newspapers from the New York Times to the La Times reported that XMRV - a retrovirus and a member of the same family of viruses as the AIDS virus has been found in CFS patients. I feel like I am in the wizard of Oz and the house just landed on the CDC. Now the red ruby slippers are now on Whittemore Peterson Institute. The CDC has been shown up as having been grievously wrong for the past 30 years. Finally, there is real hope, real news, and real science. It is our time even though many lost the best years of their lives, for those who just became ill, I am hopeful. WPI is our Emerald City.

I offer my sincere appreciation to the Whittemore-Peterson Institute, to Annette Whittemore, and especially to Dr. Peterson for spending the time and energy on investigating CFS from a scientific perspective.

The US is facing a serious health crisis that millions of Americans have contracted a disabling AID's like illness. The US is in great risk as this epidemic continues to take the lives of millions. The tragedies and the suffering that befall CFS victims are so immense that it cannot be summarized in few sentences.

Congress must conduct hearings on the travesty of how this illness has been marginalized by the CDC . The damage inflicted on patients who have been told this was a psychological disorder is insurmountable.

While all of this is great news, for those like me who have lost 20 years of their lives, it is a bitter sweet moment. My best years are gone, my 20's and 30's and I cannot get them back. I wanted children and a family, I once had a wonderful career that was cut short because I got EBV/mono and I was told I had the yuppie flu, indicating that it was young professionals who became ill. I had no idea behind closed doors that CDC was telling everyone that CFS was a mental illness. This is outrageous and criminal.

I was going to begin my speech by talking about my own story. But you have heard stories like mine for over 30 years now. How I became ill with EBV. How I was very successful and owned my own computer consulting business only to lose everything because I could no longer work. My symptoms list includes: fevers, night sweats, sleep disorder, pain, chronic infections, cultured aspergilss, mycoplasma, hhv-6a, subclass IgG deficiency, thrush, strep throat, sore throats, headaches, sensitivity to light, and extreme lethargy that is worse after activity. I was told I had Mono or the yuppie flu and that I would be better in six months. I am progressively getting much worse. Sound familiar? I was a beautiful healthy young female who had a wonderful life ahead of me. I was normal in every sense of the word. I had two degrees in Computer Science and Mathematics (cum laude).

In my 20's I was denied by every insurance company because I had a pre existing condition of EBV. So what do the insurance companies know about EBV that the CDC did not?

Patients are unable to get treatments of any kind. Unless they are fortunate to be able to afford ampicillin or see one of the ME/CFS expert doctors, their life is a living hell.

Why waste tax dollars on researching our childhood abuse? If this is what you spend our tax dollars on, and your energy, why bother to be a researcher? Be a priest and give your sermon. Last month all I heard was we have "chronic fatigue". This is not an accurate representation of what we have but only a small component.

Do you laugh at us behind closed doors? Is this a joke to you? It must be for you have done nothing in over 30 years but to call us names. They did it to MS patients once upon a time. It is very harmful to patients who are seriously ill to be called 'mentally ill'. This is what bullies do and those who do it are nothing but shameless cowards.

The CDC is so out of touch with this illness and I wonder if this is on purpose. Why do you ignore science? Why will do you continue to call us CFS? It is like calling people with diabetes, chronic sugar syndrome, or MS, Chronic walking syndrome, or TB – Chronic coughing syndrome?

What exactly is going on at the CDC while there have been years of reports that we are suffering from infections, immune system disorders and neurological illness?

While you are working on your five year plan, I did not hear one thing in regards to treatment or clinical trials. Patients have gone long enough without any treatment of any kind. There are treatments being given by Dr. Peterson, Dr. Chenny, Dr. Levine, Dr. Montoya, Dr. De Meirleir and others. Can the CDC at least begin by making those treatments available to patients as a priority? The second most important thing is clinical trials.

Countries like Japan, Germany, Norway and many others are taking this disease very seriously. Why not look at what Norway and other countries are doing? Norway is doing a clinical trial using drugs that have cured people. Italy is using a drug for Hepatitis off label for CFS with success. Why not invite the scientists into this meeting so they can give you an overview of their treatments that they give to their patients?

Why not see if you get some treatment recommendations from experts and expedite this so we can at least get some kind of treatment.

For your 5 Year Plan:

1. Have a meeting with the best ME/CFS doctors around the country and see what tests and treatments they give.
2. Immediate treatment is necessary.
3. Clinical Trials in to begin immediately not in 5 years.
4. Doctors need to be notified of these treatments immediately. There is a list of CFS doctors you can start with them. This would not be that difficult a task for immediate testing and treatment.
5. Immunoglobulin must be made available for those with subclass IgG deficiency or others who are deathly ill or become too weak or determined by the doctor.
6. Public awareness must be made about ME/CFS and that the name will be changed to include ME or Neuro-immune disease.

7. Must inform hospitals, doctors, colleges, and the media how severely ill people with CFS are. If WPI can do it so can the CDC.
8. Clinical trials like Norway are doing and the drug Italy is using with great success. Make Artunsunate available in the US. Zadaxin is used in Italy for CFS. Reach out to the pharmaceutical companies as I am sure if they know there are 1- 4 million who suffer from this disease they will sponsor clinical trials.
9. CDC must give up this notion that people with ME/CFS are mentally ill.
10. Stop all studies not relevant to treatment.
11. Update your website to include that ME/CFS is a real disease. Not a syndrome.

Millions around the world are sick. There are many who once earned a good living are now living in poverty. How many women who wanted to have children find themselves barren without hopes of ever being whole? How many more will suffer in silence because the CDC does nothing. Break lives, dreams, hopes. Why?

My best friend for nine years always told me that we were a human experiment. I lost her to CFS in 1998. I saw a true story about Tuskegee syphilis experiment. It was a 40 year study where black men were not given penicillin to treat syphilis. They wanted to see how they would suffer and die. They were given vitamins and B shots. To watch men suffer and die from syphilis was heart wrenching knowing there was a cure. To die from any infectious disease is a terrible thing to see. They die a slow tortuous death. As I watched tears rolled down my eyes for I felt a connection to those that endured so much suffering. The question that rises - is this what they are doing to us? I relate to this for I have suffered fevers and night sweats for 20 years now. I have flu like illness. I am progressively getting worse and I am not sure I have two years to wait for treatments. I developed muscle weakness to the point I cannot walk, raise my arms above my head, make a fist, lift a vase and sometimes cannot speak. I became gravely ill this year and desperately need help now.

Are you waiting to see how we will die? Is CFS another experiment?

For over 30 years there have been no clinical studies on us. No treatments other than alternative treatments like vitamin therapy.

How can you let 1-4 million people suffer and die when there are scientists proving that we have an infectious disease, immune and neurological illness? The CDC has continued to deceive Congress and not letting them know how gravely ill people are and it's link to cancer and heart disease.

In conclusion, I can only say, one day the truth will come out. That I believe from my heart. When it does how will you feel knowing you each played a part in this? Could one of you done more? I wonder. Why not be a whistleblower and help millions of people? Why not go to congress and tell them the truth about what has been going on? I would now be worried that time is running out for the CDC and its mistreatment and name calling, and labeling people as mental. The damage is done; history will now look back and ask what the CDC did all these years while millions were sick and many died.

While millions are crippled in bed, most who cannot sleep and have pain that is unrelieved by medicine, many who suffer like no other disease.

Why else would there be such a cover up? To label sick people as mental. Who were perfectly healthy prior to getting ill?

Mrs. Whittmore gave a speech where she read from a government document that those with ME/CFS die 25 years younger than normal. They die from heart disease, suicide and cancer. If the CDC does nothing knowing this is true, you will now begin to see more and more death under your watch. I hope you can live with yourselves knowing these facts while you do nothing to help us.

This is a quote from Dr. Loveless- an infectious disease doctor who said in his testimony to Congress:

"I have treated more than 2,000 AIDS and CFS patients in my career. And the CFS patients are MORE sick and MORE disabled every single day than my AIDS patients are, except for the last two months of life!" – Dr. Marc Loveless  
(infectious disease specialist and head of the CFS and AIDS Clinic at Oregon Health Sciences University, in Congressional Testimony, CFS Awareness Day, May 12, 1995)

To summarize,

- What the CDC has done is a crime against humanity
- ME/CFS, is one of the most serious illnesses of our times
- The CDC has lied to patients, doctors and the country.
- Patients have been mistreated and abused by the CDC.
- CFS is one of the lowest funded illnesses at the US.

The CDC should be held criminally liable for deliberately making a faulty definition and calling people mentally ill when they are gravely ill.

Thank you all for allowing me to testify.

Carol Geraci