

Good afternoon to everyone that is suffering from ME/CFS and to the committee members and to the CDC.

October 8th 2009 came the news that XMRV is a retrovirus, a member of the same family of viruses as the AIDS virus is found in CFS. 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 24 years. Finally, there is real hope, real news, 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.

I offer my sincere appreciation to the Whittemore, Peterson Institute, to Annette Whittemore and Dr. Milovits, the Cleveland Clinic and The National Cancer Institute for spending the time and energy on investigating CFS from a scientific perspective. Also, I would like to thank The NY Times, LA Times, Reuters, US News for reporting this very important news for CFS patients.

Last week Reuters reported that a Study “ isolates virus in chronic fatigue sufferers. Dr. Mikovits said the study offers hope that CFS sufferers might gain relief from a cocktail of drugs designed to fight AIDS, cancer and inflammation.”

Her co-authors (Dr. Milovits from WPI) include scientists from the National Cancer Institute and the Cleveland Clinic.

What I continue to here Dr. Mikovits talk about are clinical studies and treatments that could be used now.

Dr. Schaffner- Vanderbilt University,

“This is going to create an **avalanche** of subsequent studies.”

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, is so immense. Many are close to homelessness because the CDC refuses to investigate the seriousness of CFS. Countries like Japan, Germany and many others are taking this disease very serious. Our press has been unkind to CFS because they follow the lead from the CDC. I now believe this will change but will the CDC now begin to help or hinder? We are all aware of what Dr. Straus and Dr.

Reeves has done over the years. Dr. Straus published a scientific article that found a lifetime history of psychiatric illness among CFS sufferers, which also does not make sense for to have CFS a psychiatric illness must be ruled out. Many believe this is a government cover up.

Now what is the CDC going to do? Hopefully you will not try to sabotage the new findings. I believe science is against you this time. Scientists are going to wonder what you have been doing for over 24 years. Why you called gravely ill people mentally ill. Although I may not be alive in two years to get treatments as I came very close to death this year, I will spend every waking moment I can trying to get Congress to 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 life it is a bitter sweet moment. My best years are gone, my 20's and 30's I cannot get them back. I had a wonderful life ahead of me. 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 the CDC was telling everyone that CFS was a mental illness. This is outrageous.

I was going to begin my speech by talking about my own story. But you have heard stories like mine for over 24 years now. How I became ill with EBV in my 20's. 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 that 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 have two degrees in Computer Science and Mathematics. I was told I had Mono or the yuppie flu and that I would be better in six months. Not only did I not get better, 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.

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 doctors, the CDC and NIH do not?

I began to have severe muscle weakness that I could no longer drive, walk, raise my arms, make a fist or speak correctly. I thought certainly now I would get help. I then realized once you have a diagnosis of CFS doctors do not believe you. None of them were even willing to do a muscle biopsy. I could not raise my legs at all. Do you know what it feels like not to be able to walk and have a doctor not believe you?

Patients are unable to get treatments of any kind. Unless they are fortunate to be able to afford amplitgen or see one of the ME/CFS expert doctors.

I was gravely ill this year almost near death.

I lost my 20's, 30's and now I am about to lose my 40's to this disease.

To continue to do studies in that our child hood we must have been abused, if this is what you spend our tax dollars on why bother? Last month all I heard us being called was "chronic fatigue". This is not an accurate representation of what we have.

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 gravely ill to be called mentally ill. This is what bullies do and bullies are nothing more than 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 are thousands of reports that we are suffering from infections, viral, 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 treatments of any kind. For those ME/CFS expert doctors who are treating patients with antivirals, immunoglobulin's, and many other treatments we need to have doctors informed of these treatments that are available now, so those that are suffering can get help. There are plenty of 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 a priority? The second most important thing is clinical [trials](#). I do not see this in your five year plan and what could be more important than

this. Norway is doing a clinical study that looks very promising. Why are we not doing any clinical studies with those drugs?

Why do patients have to travel across the country and wait a year to see specialists?

How did MS and AIDs get treatments? Clinical trials. Many that were fast tracked. We need treatments now, not in five years. There are plenty of treatments that can help us now.

Why not look at what Norway and other countries are doing? 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?

We need treatments now not 5 years, while clinical trials are needed, patients who have been ill for 10, 15, 20 years need treatments now and there are treatments being given by a few doctors. Why not see if you get some treatments recommendations from experts and expedite this so we can at least get some kind of treatment. Antiviral treatments for viral infections. Antibiotics treatments for bacterial infections. Immune modulators for immune system dysfunction. Immunoglobulin's for immune system problems. Whatever these few doctors are doing why not allow some of these treatments to be done by doctors all over that call themselves CFS doctors but have no idea really how to treat other then the symptoms. Also, the testing, why can we not have other doctors test what Dr. Petersons and others are testing for?

Agenda

1. Have a meeting with the best ME/CFS doctors around the country and WPI to see what tests and treatments they give.
2. Immediate treatment is necessary. Whatever these doctors are using to treat patients make it known to doctors what they are doing.
3. 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.
4. 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.
5. Clinical trials need to begin immediately. Not in 5 years.
6. Public awareness must be made about ME/CFS and that the name will be changed to include ME or Nuro-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.

What has happened to millions of people who have lost their lives to ME is a human travesty. Why do you still continue to use the name CFS when every other country in the world calls CFS ME? ME is a serious disease, so not to use it misleads doctors about the seriousness of CFS. CFS is not taken serious and the CDC already caused serious damage to people by calling very ill patients mental. It is outrageous when someone is very ill that they cannot care for themselves to then call them mentally ill. This is what bullies do, call people name not scientists. We know people who became ill lead healthy lives as it was even called the yuppie flu. Certainly the word yuppie meant to imply young people in careers, hard working young people. To now label them with a mental disorder harms them on many levels. The CDC needs to make a public announcement and apologies for the wrong it has done. The CDC must take responsibility for the lies and misinformation and propaganda it put out. You owe suffers that much.

Millions around the world are sick. Many once earning a good living 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. Broken lives, dreams, hopes. Why?

My best friend for nine years use to tell me that we were a human experiment. I lost her 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 die. They were given vitamins and B shots. Is CFS another experiment? I wonder.

As I watched tears rolled down my eyes for I felt a connection to those that endured so much suffering and I had to then question is this what they are doing to us? Are they waiting to see how we will die? For over 24 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 one that may even be contagious? The CDC has continued to deceive Congress and not letting them know how gravely ill people are and its link to cancer and heart disease.

In closing I can only say one day the truth will come out. That I believe. When it does how will you feel knowing you each played 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 people 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.

I urge everyone with ME/CFS to write to Congress, for the more they understand our story one day maybe they will take the CDC up on charges.

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 in 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 die under your watch. I hope you can live with yourselves knowing those facts while you do nothing to help us.

This is a quote from Dr. Loveless:

"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)

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 their country.

Patients have been mistreated and abused by the CDC.

CFS is the third lowest funded illness 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.

Carol Geraci