

# Testimony

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## **TURN INVISIBLE ILLNESS TO REALITY AND A SERIOUS MATTER**

First, I would like to thank everyone on the Chronic Fatigue Syndrome Advisory Committee as well as all companies and organizations trying to find the etiology of this syndrome, increasing awareness, better treatment, & patient advocacy.

It has been a long, rough 6 years for me – yes I have M.E./CFIDS. Please note, I think CFIDS is very degrading name and I believe this is why we do not get funding and the respect that we deserve. My last thanks goes to Dr. Susan Levine! I wouldn't be able to be at this meeting without her care/expertise and her passion for treating patients like me. Prior to seeing her, I slept for 6 months straight...saw doctor after doctor for about 2 years and just thought I was dying and no one cared to find the cause of all my symptoms...why was I fainting and falling, etc.,

My greatest fear is not being able to support myself. I lost my thriving career that I worked so hard to accomplish! I was going places...my last two jobs were in upper management in leading pharmaceutical marketing pharmaceutical advertising companies and pharmaceutical companies. Now, I rely on Social Security Disability (which is not a lot but not complaining) and help from my mother and father who are in their late 70s and I feel so guilty for having them to help support me. I feel useless and can't figure out what type of work that I can do especially with my rollercoaster of symptoms. I don't know what each day will be or bring. Lately, my mom has to give me Adderall before she leaves for work than it is up to me to find strength to get more Adderall because I can't get up...I feel like someone is giving me an anesthetic! I have fibromyalgia, IBS, vision problems, FATIGUE, loss of memory and concentration, blackouts – to make it short I have most of all the classic and common symptoms of this syndrome!

**I CANNOT TAKE IT ANYMORE! I WANT MY LIFE BACK! And the only way to do it is to stand up for myself and fight (in a positive and productive manner) for more funding, better research, and centers of excellence! So look out world, I am fighting to get my life back AND GOING TO BE A VICIOUS VOICE TO RECKON WITH FOR PATIENT ADVOCACY!** And, I am hoping other ME/CFIDS patients will join me on my crusade and be more active and not be embarrassed of our syndrome name. This is a debilitating life long illness to date. This makes it even a rougher and tougher syndrome (mentally, emotionally, and physically) ...since most or majority of people with ME/CFIDS will have a life long ordeal unless we get more funding and look for short term and long term ways to manage all of our symptoms of ME/CFIDS.

I did research awhile back and looked up how many people died of ME/CFIDS and all I saw was SUICIDE! I tried to find it again but no luck. People with ME/CFIDS NEED TO MAKE A

LOT of NOISE and take action for better treatment, support and hopefully a cure! We deserve more funding...there has to be a way to take 1 million dollars from the top diseases and add them to our funds! Please note that all illnesses and diseases deserve some type of equal funding.

**Next, I have a list of questions to review and hope that they get addressed in the immediate future:**

1. Why do we get almost the least NIH government funding when we have more prevalence than the West Nile Virus, MS, Lyme disease and the list can go on! ADD gets 66 million dollars (actuals non/ARRA) and/or 15 million (ARRA) in 2010...there is something fishy in the water to me. What do you consider emerging infectious disease...they got 350 million (ARRA) in 2010. Methamphetamine got 73 million (non/ARRA) and 13 million in (ARRA)... this baffles me and we can have more funding. Source:  
<http://report.nih.gov/rcdc/categories/>
2. Why do we get almost the least amount of CDC Funding when we have more prevalence than the disease that I noted above? FYI, the prevalence of ME/CFIDS is most likely a lot more because they are probably stuck in a psychiatric ward or in a sleep clinic!
3. Why does the NIH disregard the CFSAC committee repeated recommendations for Centers of Excellence? I have called CFSAC and email twice to see the proposals and the proposal for the past centers that were closed
4. Why have some past clinical trial protocols have poor design, methodology and statistical considerations! Or tainted? Is this group or someone going to work on these issues so we can focus on getting research done and completed?
5. Why won't leading experts work together (infectious disease doctors, cardiologists, pain management, neurologists) to find the **etiology of this disease so that we can have better treatment options! Until we find the etiology...we can only have treatments to manage our multitude of symptoms...meaning may prescription medications! We are doing research on very toxic drugs on ME/CFIDS patients such as HIV drugs and cancer /RA drugs (rituxan) that makes our immune system weaker and cause long term side effects especially in children! For example, straight from their website:**

RITUXAN has also been associated with serious and life-threatening side effects, including: the return of active hepatitis B virus infection with sudden and serious liver problems including liver failure, and death, other serious infections that can lead to death, heart problems, kidney problems, and stomach and serious bowel problems including blockage and tears in the bowel that can sometimes lead to death.

The most common side effects of RITUXAN seen in patients with non-Hodgkin's lymphoma were infusion reactions, fever, chills, low white blood cells, **infections, body aches, and tiredness.** Before starting treatment with RITUXAN it is important to talk to your doctor about your medical history.

6. We need an action plan with appointed expertise to find the etiology, in the short term why can't we look at better antivirals to treat EBV and HHV6, or better medicines for helping us less feel less fatigue without long-term health risks of cardiovascular disease. Better medications to manage sleep and anxiety!
7. Lastly, if I sat on this committee...I would be pulling my hair out and frustrated...there are so many NO to vital recommendations from this committee and with progress that have Yes...I need further clarification because I believe the CDC is just starting these action items. Action items on Funding...is there enough dollars...is that considered in the CDC Funding report as well as the NIH. If so, it is little funding.

Plus, there are so many doctors that STILL do not know about ME/CFIDS in the US. BELIEVE ME, I SAW THEM ALL in the last 3/4 years! I had a Rheumatologist without any clinical evaluation state to me that I am depressed and stressed because I was over 40, single, and have no children...I walked out of her office. Then I had one sleep clinic fellow tell me that my body needs over 15 hours of sleep. I said ohhh really...I thought it was 8 hours. I ask her about clinical verification. Yes the diary. I asked about next steps to sleep studies and she stated that I did not need one. I laughed and asked to see the medical director of the facility. She said he does not see patients. And I said I would be leaving!

8. If you really want to get the message out, there needs to be a NEW PSA on ME/CFIDS. Maybe it is in the works...I never saw the past ones...I saw a Dr Phil show with Dr. OZ that made me so mad bc they did not fully understand ME/CFIDS. How did the HIV campaign become so successful...who did that campaign..why can't that be done for us! How did the antismoking campaign become so successful...why not do the same for us?
9. Next, please make sure the ICD CODES for managed care ARE APPROPRIATE AND will Provide US THE ULTIMATE CARE WE DESERVE AND also push SOCIAL SECURITY DISABILITY to approve MORE APPROVALS FOR PEOPLE WITH ME/CFIDS!

I have many more questions but I will stop here. I will be back. I wanted to state that I would really enjoy working with this committee. However, my health is taking a toll on me because I am not pacing and not healthy enough yet! 2 to 4 hours!

In closing, many people look at me and say...you are not sick...why are you not working. I state that I am a great actor...I do not let people see my pain and suffering. But, if you want to stick around for several days and help me out...you will see me struggle to stay awake and find words and have black outs, fall, etc. Or I say...We can trade bodies if you like...you can have my illness anytime...ready to switch...No body has said yes yet!

Finally, I do want to reiterate my appreciation for this committee but we still have lots of challenges! And I appreciate all other organizations. I would like to see change more quickly and more awareness and name change to get the attention we deserve. We don't call chicken pox the itching virus or insomnia – Can't Sleep Disease. I am just requesting more immediate action and change before more patients commit suicide or become alcoholics, addicts (but at least there is funding for methadone!) or die from long-term side effects from their medications. Thank you for your time!

**And People with ME/CFIDS Need to Unite & Fight Positively Together for better treatment, research, and funding...Please join Me!**

Thank you for your time.