

Testimony

Lolly McDermott

First I would like to express my appreciation to the Committee for taking the time to come together today and to address these issues. Secondly, I would like to make a request: please do not call this disease “Chronic Fatigue” during this meeting. I understand that it is tedious to say “Chronic Fatigue Syndrome” over and over again, and given the politics behind this disease it is likely that those who originally named it intended for it to be shortened to “Chronic Fatigue”. However, by calling it “Chronic Fatigue” you are contributing to the “confusion” surrounding the disease, and you are also trivializing its symptoms. Please call it “CFS” or “ME/CFS”, as people are watching this governmental meeting around the world, and your words have a great deal of impact. Thank you.

I have requested in the past that CFS be defined correctly. I was diagnosed under Holmes, and then Fukuda, but have been subsequently undiagnosed via the CDC’s Empiric definition. CDC, you have accepted money from Congress for Holmes and Fukuda-defined CFS, yet you have spent it on research using your Empiric-defined patient cohorts. It is unconscionable that you are accepting funds for one disease and then using the money to study something else. You are defrauding the government, and ultimately, the American taxpayers. This goes for your XMRV studies as well: it is unlikely that anyone in your Empiric-defined patient cohorts will ever test positive for XMRV because the symptoms of the infection would exclude them from the Empiric definition. I have been told that the CDC is studying herpes viruses in CFS, but that is also very unlikely since no one with chronic EBV or HHV-6 would qualify for the Empiric definition either. So despite the fact that a substantial number of CFS patients have acute viral onset and chronic herpes virus infections, no one is studying this at the CDC.

FDA, I hope that your representative today is able to remain conscious for the proceedings. It is outrageous that after 20+ years the FDA has still not approved a treatment for a devastating neuroimmune disease that has infected at least a million Americans. Ampligen has been in trials since the 1980s and has benefited a subgroup of CFS patients, and although it is proven to be safe and effective the FDA continues to withhold it from those who desperately need it. Because of your negligence, CFS sufferers have no FDA-approved medical treatments, and patients must resort to paying out-of-pocket for treatments because insurance considers them to be “experimental”. If CFS were as severe as “itchy skin” then this might be forgivable, but since CFS is a devastating neuroimmune disease, your actions, like those of the CDC, are also unconscionable.

We need clinical trials and fast-tracked treatments NOW. We need funding for researchers who are making progress with this disease, in particular the WPI. I will save you millions of dollars right now by telling you that the CDC will never find any kind of biological abnormalities in CFS if they continue using their Empiric definition/cohorts: so why bother throwing money away on their “research”? It is understood that funding is tight these days, so it doesn’t make sense to continue funding the CDC’s CFS research when they’re studying “unwellness” instead of CFS. I propose that the CDC’s funds be reallocated to other agencies and to independent

researchers who correctly define CFS and are making progress with finding answers for this disease.

I also suggest that the FDA review the plethora of current CFS research, and not just the CDC's, so that they can better understand the disease and the symptoms that require treatment. Additionally, the FDA should implement recommendations to ban CFS patients from donating blood: if the blood supply is found to be contaminated then history will not look kindly upon the FDA's refusal to take immediate action to ensure its safety. The Red Cross did the right thing, why can't the FDA act in the best interests of the public?

People are dying from this disease and it is being passed between partners and from parent to child. CFS is progressive, so long-term patients who were functional early in the disease are becoming increasingly sick and debilitated: after 20+ years of this disease and no effective treatment I fall into this category. Government agencies should have addressed CFS in the 1980s before a second generation was infected, but since they neglected to do their jobs it is imperative that government agencies today control the continued spread of the disease and approve treatments immediately. This disease is not going away, and sticking your collective heads in the sand has not been effective thus far. Accepting funds for CFS and then researching "unwellness" hasn't made CFS go away. Refusing to approve treatments for CFS hasn't made CFS go away. This is a public health emergency and it's well beyond time for the politics and the personal agendas to be put aside.

Thank you for your consideration,

Lolly McDermott