

Public Comment
Lolly McDermott

Thank you for taking the time to come together today to address these issues. I especially appreciate the presence of practitioners and patient advocates. My testimony today is aimed primarily at the government entities and “advocacy groups” that have incorrectly framed CFS and as a result have prevented research from going forward.

I have had this disease for over 24 years, and have been disabled and mostly housebound for over 8 of those years. This disease is progressive, and the longer I have it the more health problems I develop, despite having a healthy diet, weight, and family history. I am too young to be experiencing heart problems, but after 24+ years of chronic infection with HHV-6, Epstein-Barr, Coxsackie B 1-6, and chronic inflammation, it is not all that surprising. I have had this disease for over half my life now, and there is still no treatment in sight. I am watching in horror and sadness and despair as people from my cohort die from this disease.

I blame the government and advocacy groups for this situation. You have refused to acknowledge that this disease is characterized by acute viral onset, and subsequent chronic neuroimmune dysfunction. By insisting on consensus you have thrown us under a tarp with people who are just tired, depressed, or suffering from “yuppie burn-out”. This makes no sense whatsoever from a medical perspective. What if the same thing had been done for polio: since only a tiny percentage of polio victims develop paralytic polio, then why bother treating them, why not just wait for consensus? Or with AIDS patients: since not all AIDS patients have the same infections, why not just wait for a consensus before treating any of them? This is madness. This is not how you treat desperately ill people, who have very specific, quantifiable biomarkers. You do not continue to make a definition increasingly more vague so that you can include more people under it: you make it very specific, so that you understand what you are treating, so that you can treat it. So why are you people doing what you’re doing?

CDC: you are leading the parade here and your actions reek of incompetence. Surely you should be able to distinguish between “fatigue” and an infectious neuroimmune disease? But you don’t. And you are continuing to defraud the American taxpayer. You were instructed to research CFS, not “Reeves Disease”. However you continue to use a patient cohort for your research that bears no resemblance to the original CFS sufferers. How will any meaningful CFS research ever come out of your program if you are not even studying the patients that you purport to study?

FDA: the least that you could do is to fast track treatments for the chronic infections suffered by CFS patients. For example, why is there no treatment available for Epstein-Barr? The government apparently believes that it threatening enough to deserve a vaccine, so why isn’t a treatment a priority?

CAA & IACFS: by attempting to be inclusive you have alienated the very people you are supposed to be helping. Instead of aiming for consensus you should be screaming for, at the very least, “subgrouping”. It is imperative that you recognize that you no longer represent a disease: you represent a variety of maladies and perhaps that is your goal. However, it is

destructive to those of us with the very well-defined neuroimmune disease, CFS. We have no reason to support you, because you are currently working against us. Your focus on the vaguest of CFS symptoms, pain, fatigue, etc., is what is keeping us in limbo. The latest slap in the face, the Fatigue journal, is unconscionable. Why not call it “Weakness” or “Dizziness” or any of the other non-specific, demeaning-sounding symptoms of the disease? Frankly, fatigue is one of my least concerns: my destroyed immune system and damaged nervous system is much more debilitating and alarming.

We desperately need change, and we need someone in that room today to stand up for those of us who have been sick with this disease for decades; the disease that was named “CFS” in 1988 and is characterized by sudden viral onset, followed by chronic infection/immune dysfunction and neurological abnormalities. I challenge any one of you to call an end to this Kafkaesque nightmare, and to demand that the government entities and our “advocacy groups” recognize what true CFS is, and take steps to find treatments and eventually a cure. This charade has gone on long enough.

Thank you, Lolly McDermott