

CFSAC Public Meeting May 27th

Lolly McDermott testimony

I had wanted to speak via telephone for this meeting, but have developed laryngitis due to a lingering mycoplasma pneumonia infection. This is what it is like to have CFS: you can never make plans in advance because you don't know how sick you will be, you can't commit to anything, you can't do the things in life that you think are important because your body will not allow you to do so. Chronic Fatigue Syndrome is not the disease that is defined by the CDC: it is not just unwellness and malaise. It is an illness that causes, among many other things, major immune dysfunction. In my case this means that my immune system overreacts to allergens and other mundane threats, while allowing viruses and bacterial infections to go unchallenged. Since I first contracted CFS in 1989 at the age of 20 I have developed severe allergies, asthma, rosacea, endometriosis, chronic Epstein-Barr, chronic HHV-6, chronic Parvovirus B19 and recurrent (usually every 2-3 months, although this current one has been going on for awhile now) mycoplasma pneumonia infections. I was a healthy, happy college student in the Northeast when I unexpectedly became ill with CFS, and it changed my life forever. After about 9 months I recovered enough to resume school and work, but I never regained my health. I often wonder about what I could have accomplished if I had not spent so much time battling this degenerative disease. Yes, it is degenerative, but there have not been any long-term studies so this is not recognized. I have now been sick for over half of my life, and have been disabled for the past 5+ years. I am terrified of what lies ahead for me if no treatment is approved. I have gone from being a productive

member of society to an unwilling invalid, and I am at risk for developing even deadlier diseases like MS and lymphoma.

I believe that 20 years is long enough for anyone to suffer from a disease that is not properly defined, has no treatment, and receives little interest within the scientific community. In fact, I no longer tell people that I have CFS, because the current definition bears no resemblance to my illness. I stopped using the term CFS after a hematologist looked at my blood and told me that I didn't have CFS because "those people have nothing wrong with them, but you do" because I have atypical lymphocytes. Blood abnormalities were also found in CFS patients in Incline Village, Nevada in the 1980s. Like me, many also had EBV and HHV-6, but somehow these viral infections failed to make it into the definition. In fact, I do not think that I would be diagnosed with CFS today because the definition has strayed so far from the actual disease.

Unfortunately, it has now fallen on the patients to inform the medical and scientific community about CFS. I have a quantifiable disease, not some form of post-traumatic stress disorder or psychosomatic illness. Just look at my blood, spinal fluid, and brain scans and you will see that this is an organic illness. I'm tired of being marginalized, of being forced to educate medical practitioners about a disease that they should have learned about in medical school, of being a guinea pig because there is no serious funding behind CFS research. I believe that this can all change, and I am offering my recommendations in the hope that someone there today will value the opinion of a patient with over 20 year's experience with this disease:

1. The CDC must adopt the Canadian CFS definition. It is the most accurate definition in existence, and until they have an accurate definition their research

will go nowhere. It has already been demonstrated that people with major depression are being misdiagnosed with CFS because of the Reeves' definition and included in CDC studies. The CDC is misusing taxpayer money by playing an elaborate game of "bait and switch"-they are taking money for CFS and then studying a completely different illness.

2. The CDC's focus should be on treating those who already have CFS, many of whom have been sick since the 1980s. When they understand the mechanism of the disease, then they will be able to prevent it. It is ridiculous that their focus is on prevention when they don't even have an accurate definition that reflects the actual disease.
3. CFS is an infectious disease. If the CDC had contained it in the mid-80s then it is unlikely that I would have contracted it in '89, thousands of miles away from the epicenter of the initial outbreak. If they had bothered to develop a treatment then my entire adulthood would not have been overshadowed by illness. The CDC must address the viruses involved in CFS, and partner with those who are developing non-toxic antiviral/immune-modulating therapies like Ampligen. They must adopt new technologies like the Virochip to use on their many archived CFS patient blood samples. They must stop ignoring herpes viruses in CFS. If this means a reorganization of the CFS research group at the CDC then so be it. Dr. Reeves should never be able to say that the reason that herpes viruses are not being studied in his department is because a different department studies herpes viruses. Herpes viruses are inherent in CFS: it should be a priority to study them in the CDC's CFS research group.

4. The CDC should be conducting research to study CFS patients long-term.
Contrary to their limited research results, most CFS patient do not recover: we just fall through the cracks. The CDC could easily contact those who provided blood sample in the 1980s to determine their current status.
5. Many of our family members, including our children, eventually become infected, and this is something that the CDC neither acknowledges nor addresses. The same attention that is being paid to the spread of H1N1 influenza must be paid to the spread of CFS.
6. The “ivory tower” mentality at the CDC must end. They must begin collaborating with independent researchers since they have failed to make any significant progress on their own. There is no reason that the CDC cannot share their data, attend important CFS conferences like the recent IACFS/ME meeting in Reno, and partner with the WP Institute and others who have made more progress in less time and with less funding than the CDC has made in 25+ years. The ultimate goals for CFS research at the CDC should be treating, preventing and curing CFS, not putting out meaningless study after meaningless study.
7. The CDC must stop wasting taxpayer money on psychiatric research. It has been well-documented that chronic illness can lead to secondary depression, and that viral infections can cause psychiatric abnormalities. Psychiatric research should not be the primary research conducted for an infectious disease like CFS, and it is distressing that CDC’s Dr. Reeves is being rewarded with professorships and other incentives to ignore the role of EBV and HHV-6. Obviously, psychiatric

research and treatments will not cure a viral illness, nor will they prevent an infectious disease from spreading.

8. An independent audit of the CDC's chronic mismanagement of CFS research and funding must be conducted. If not undertaken by the government then patients will be forced to initiate an inquiry via Congress or take legal action via a class action suit. If the CDC is unable to account for the money that they have received and are unable to make any headway with CFS research then this money needs to be allocated elsewhere. Non-profits like the WP Institute, The HHV-6 Foundation, and The CFIDS Association are making significant progress and would benefit from the funding that the CDC has wasted. New non-profits, like the Enterovirus Foundation, are filling the research void that the CDC has created and would also make good use of the money squandered by the CDC. While I believe that CFS deserves much more federal funding, I do not think that it should be awarded to government agencies unless they are able to prove that they will use it effectively for the benefit of CFS patients.

Thank you for reading my testimony. I hope that you will seriously consider these recommendations. While you will never be able to return all of those years of my life to me, or make up for the pain, loss, and misery that this disease has caused, you can at least ensure that I and others will eventually receive effective treatment for CFS and that others will not have to suffer from this disease in the future.