

Testimony

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Hello. My name is Charlotte von Salis and I have been sick since August 5, 1990. Most years since my onset have been spent bedridden or housebound. Yet I and the patients you see here are the tip of an iceberg. I have friends who are too ill to watch or listen to this videocast, friends who can't take care of themselves, friends who are in nursing homes, friends who are barely able to pay for food and shelter, friends who live in the desert due to chemical sensitivities or exposure to toxic mold, and friends who have committed suicide.

If they had been properly diagnosed and treated as having a Neuro-Immune Disease (NID) using the Canadian Consensus Criteria (<http://www.cocure.org/ccpcdd.pdf>), perhaps their lives would be different. Perhaps my formerly hardworking friends would not be disabled and in need of income assistance. A recent study indicated up to 68 percent of us are in this state. The cost to the economy? Eighteen to twenty-three billion dollars annually.

Tomorrow you will hear from representatives from the Social Security Administration (SSA) and the Department of Labor (DOL). Both agencies can help. SSA could give this disease the status of a "Listed Impairment" in its "Blue Book" (Disability Evaluation Under Social Security) which would shorten the process to secure Social Security Disability Insurance. DOL has advisors who help those with ERISA plans obtain improperly denied health and retirement benefits (through the Office of Participant Assistance within the Employee Benefits Security Administration). There's no reason these advisors could not be trained to assist with disability plans. DOL (through its Plan Benefit Security Division) also could support plaintiffs whose disability benefits have been denied by filing *amicus* briefs.

But these are band-aids. Income assistance is a necessity only because this Neuro-Immune Disease has been put on the back burner since the CDC investigated an outbreak of Epidemic Neuromyasthenia (aka Myalgic Encephalomyelitis or M.E.) around Lake Tahoe, Nevada in the mid-1980s. "Chronic Fatigue Syndrome" ("CFS"), the name and accompanying definition created by the CDC in 1988, bears no resemblance to the disease those in the outbreak had.

The CDC insists "CFS" is an enigma, yet there is nothing mysterious about M.E. Outbreaks have been documented since 1934. In 1956, Dr. Melvin Ramsay coined

the name and in 1969 the World Health Organization classified it under neurological disorders. Ramsay's description of M.E. in 1986 was built on and expanded by the 2003 Canadian Consensus Criteria. Use this as a blueprint for a new, international research definition. This is sorely needed for selection of proper patient cohorts. And please keep in mind that the CDC does not have exclusive authority to define or name diseases. The American College of Rheumatology, for example, defined Fibromyalgia.

Stop ignoring the evidence of immune dysregulation, neurological dysfunction, and presence of infectious agents accumulated by researchers over many years. Look at the studies by Dr. Elizabeth Dowsett that found enteroviral infection in M.E. in 1975 -- and while you're at it, look at all the M.E. research before 1988. Listen to people like Dr. Martin Lerner who successfully treats M.E. patients with antivirals.

And stop ignoring the most promising research to date, that of a retroviral connection to this disease. This is groundbreaking research. It is unreasonable to ask us to wait three to four years for the results of Dr. Ian Lipkin's XMRV study. Research into this potential infectious etiology should be given the highest priority. But it's not. Applications for research into HGRVs are denied NIH funding, discouraging potential investigators. Why is NIH sending the message that researchers must wait to follow this clue?

Compare the reaction of the US government to AIDS to our disease. Both occurred around the same time. Yet only three years after the first US AIDS case was detected, HIV was identified as the causal agent in 1984 and a test was licensed the following year. Treatment in the form of the drug AZT was approved in 1987.

We deserved the same response. There are approximately one million of us. Twenty-five percent are assumed to be severely ill. Some are unable to move and must be tube-fed. Some die of rare cancers and suicide. There is no quality of life when one is unable to care for oneself. Dr. Mark Loveless told Congress in 1990 that his AIDS patients in their last week of life were less disabled than his "CFS" patients. This has not changed. Dr. Klimas made a similar statement last year.

AIDS is now a manageable chronic disease, yet it still receives huge governmental support. What we need, what we demand, is the same type of response from NIH that AIDS gets. In 1988, the NIH Office of AIDS Research was established directly within the Office of the NIH Director. Due to its multi-systemic nature,

AIDS is coordinated across the various Institutes and Centers. Neuro-Immune Disease (NID), easily affecting 10 million and including ME and CFS, Fibromyalgia, Gulf War Illness, Chronic Lyme Disease, and Autism, is also multi-systemic. An Office of NID Research following the AIDS model could coordinate research, determine IC budgets, and ensure all funding goes to the highest priority research.

Public policy toward this disease must change radically. I am presenting you with a petition signed by over 550 people stating that, collectively, we do not recognize the CFIDS Association as our representative agency (<http://www.change.org/petitions/petition-to-disassociate-from-cfids-association-of-america-as-our-advocacy-representative>). Listen to new voices like ANIDA -- Advocates for Neuro-Immune Disease Awareness (www.anida.co) and the International M.E. Association (www.imeassoc.com). Check out XMRV Global Action (a Facebook group), CFSUntied (www.cfsuntied.com) and MECFSforums Wiki (http://www.mecfsforums.com/wiki/Main_Page) for valuable information.

Stop talking and start acting. There is much work to do. Do it. Do it NOW.