

Written Testimony Submitted to the CFSAC (October, 2010 Meeting)

By: Anonymous (5) ME/CFS patient

Thank you for the opportunity to submit testimony for your consideration for this meeting. I have been disabled by ME/CFS for a little over two years. My descent from full health to severe disability occurred swiftly, over a three-week period, following a viral illness that started while on a business trip in 2008.

Before ME/CFS, I thrived on academic and career success. An American-born child of Asian immigrants, I studied hard and performed well in school, obtained an Ivy League education, studied and worked abroad, and was ambitious and successful in my career as a litigator working for a large U.S.-based international law firm. I was blessed with great colleagues who I enjoyed working with and was always surrounded by good friends. I was an avid traveler and had traveled to over 30 countries. I exercised regularly, ate a healthy diet and was in excellent physical shape. I have had no family history of anything remotely resembling ME/CFS. While I would feel normal fatigue (a sensation that I have now almost forgotten) after long stretches of working extreme hours at my job, I would be ready to take on the world after a night or two of catching up on sleep. I thought nothing of flying to the other side of the planet for a weekend to attend a good friend's wedding. I could will myself against the effects of jet lag. Indeed, I seemed to have limitless physical and intellectual energy reserves right up until the days following the severe viral illness that led to ME/CFS, which brought my life to a sudden and indefinite standstill at age 34.

During the past two years, I have witnessed my peers continue their upward career trajectories, have their first children, and buy their first homes, while ME/CFS has reduced me to being little more than a mere spectator of life. My sense of time has completely changed, and my plans for the future are shrouded in uncertainty. The secondary losses and struggles from losing my health and the ability to do the most basic things (working, walking more than a few blocks, being able to sustain more than a few hours of activity) have materialized one by one:

- I have lost my hard-earned career. As I am often forced to explain to well-meaning friends, it was not losing my comfortable six-figure salary or specific job that was hard, but *the indefinite loss of my physical ability* to work in an intellectually rigorous job, and the confidence, financial independence, professional camaraderie, sense of identity and future potential that came with that ability, and more basically, the ability to participate

in “normal” working society in any job, that has made this loss especially difficult.

- I lost my apartment, which I could no longer afford, and was forced to move to cheap housing in a new city, to be near my parents whose help I need to live.
- Former colleagues and all but a handful of longtime friends have gently distanced themselves and are no longer part of my life.
- I have been forced to resort to applying for disability benefits for income to pay for rent, bills, health insurance and medical treatment. The process to obtain and maintain benefits has been difficult, adversarial, and taxing on my health.
- My COBRA health insurance coverage expires at the end of this year, and unless my Social Security claim is approved and I obtain Medicare imminently, I will be without health insurance. I do not yet know if purchasing my own health insurance will be prohibitively expensive given my financial situation.
- A “reverse role reversal” has taken place between my parents and me. Just when my parents had gotten accustomed to their reliable only daughter financially providing for them and looking out for them in their old age (even though at 70, they can run circles around me), I now need their help with living.
- We have quietly accepted the likelihood that I will not be able to have children, if only because I could not take care of a child if my health does not significantly improve within the next few years.

As with the illness itself, some of these profound losses have been private and invisible.

From my perspective as a patient, what distinguishes the situation of ME/CFS patients from many other currently incurable diseases that have similar rates of disability and prevalence is the near absence of options for a patient seeking medical care for the disease (both in terms of doctors and treatments). I cannot simply go to a hospital and ask to be seen by an ME/CFS specialist within the Neurology or Infectious Disease departments to receive treatment, because none exist. As I was effectively told at a prestigious hospital, they “didn’t deal with CFS or fibromyalgia” (notwithstanding the fact that I do not have and never mentioned anything about fibromyalgia). The default advice for ME/CFS patients is still “Cognitive Behavioral Therapy,” which is nothing more than common sense (get good nutrition and sleep, rest a lot, pace yourself, maintain a positive attitude): guidelines which should complement real medical treatments, not serve as a substitute for them.

Indeed, it is remarkable that, in 2010, not a single FDA-approved drug for the treatment of ME/CFS is available to patients 25 years after CDC sent two employees in September 1985

to investigate the Lake Tahoe outbreak of ME/CFS that was reported to the CDC. This dismal situation is a direct result of the CDC keeping the seriousness of this disease in the dark for the past quarter century, during which significant progress could have been made, such as in the case of HIV research and medicine for which hundreds of millions of dollars and top talent were invested and significant progress was made during the same time period.

The CDC's failure to educate the public about the seriousness and possible infectious nature of ME/CFS is also directly to blame for the prevailing view by the public and many doctors that "Chronic Fatigue Syndrome" is little more than a state of being constantly tired. Institutions that the medical profession nationwide (and worldwide) look to for authority on human disease, such as CDC and the Mayo Clinic, are unbelievably still wasting scarce resources on studies based on psychogenic theories for this crippling disease. As recently as July 2010, a CDC team published a study looking for personality disorders in "CFS" patients ("CFS" in quotes because the validity of any study published by the CDC - including the Switzer, et al. negative XMRV study - must be seriously questioned because study subjects are selected using the 2005 empiric case definition of CFS). Mayo Clinic conducted a study on whether a "treatment" that amounts to patients repeatedly telling themselves out loud that they are not really sick was beneficial to "CFS" patients. That a reputable institution like Mayo Clinic would even spend one dollar of its resources on what is obviously a sham treatment is difficult to comprehend. The bias and influence of an institution with the authority of CDC is insidious, and CDC's publication of careless research performed on patients who do not even have the disease still manages to shape public perception of the disease at every level of society: from members of Congress who make budgetary decisions and federal judges who decide individual ERISA disability cases, to doctors, insurance companies, employers, and even well-meaning friends and family. Doesn't someone, somewhere in the government realize that on top of pouring precious federal dollars down the drain, such wasteful "research" causes affirmative harm to very sick, financially strained, human beings suffering from a devastating organic disease? Does this not matter in some kind of absolute moral sense? Can this not be stopped? The removal of Dr. Reeves as head of the program was a commendable first step, but I hope that with the blatant problems surrounding the Switzer, et al. negative XMRV study, it has become obvious to DHHS that the CDC's research of "CFS" is in need of a complete overhaul. As a second bare minimum prerequisite to building a competent research program, **I would like to request the Committee to again recommend that DHHS require that the 2005 CDC empiric criteria no longer be used in ME/CFS research, and to additionally recommend that the United**

States adopt the Canadian Consensus Criteria for use in future ME/CFS research.

Finally, as a patient losing key years of my life to this disease, I am unable to derive any comfort in the knowledge that, while having the misfortune of succumbing to a possibly infectious, disabling disease, a brigade of well-funded, ambitious and talented scientists are racing to find a cure or even effective treatments, because they are not. Even though the recent attention surrounding ME/CFS has been unprecedented, thanks to the publication of the XMRV study in Science last fall, and with the recent publication of the PNAS paper that confirmed a retroviral association with ME/CFS, the focus of the scientific community appears to be on the implications of this newly discovered group of retroviruses in general, and the interest in ME/CFS remains minimal. We have not yet seen any indication that NIH or any other government agency is poised to exponentially increase funding for retroviral and other research in connection with ME/CFS specifically, even after the results of PNAS paper.

I am aware that the difficulties that ME/CFS patients face are ones which members of this Committee and fellow patients are all too familiar with. I have chosen to relate my perspectives as a relatively new patient, however, because the very basic realities of this disease that are obvious to members of CFSAC and patients who have been sick for many years remain unknown outside the very small ME/CFS community, and critically, to date, **that well-informed community does not appear to include the Department of Health and Human Services or the current Secretary of Health.**

Why has the work of this Committee over the years not produced tangible results for ME/CFS patients? Why does DHHS go through the effort of chartering and convening meetings of this Committee (which we as patients are of course very grateful for) if the vast majority of the advice and recommendations that have been made to the Secretary of Health over the years are not met with a response, much less acted upon? I believe these are fair questions, because I would like to believe that if the desperate situation of ME/CFS patients that has been documented in the minutes, patient testimonies and recommendations from these Committee meetings year after year have been communicated to conscientious and responsible government health agency employees and the gatekeepers of federal research funding in a truly effective manner, **funding for ME/CFS would be at the same or similar levels to diseases with similar disability rates and prevalence, i.e., in the \$100 million+ range by now**, not the anemic \$4 or \$5 million we continue to receive each year. Keeping funding at this negligible level especially after recent research developments will be

tantamount to the government declaring that it will continue to willfully ignore the plight of an entire patient population with a conservative estimate of 1 million Americans, whose cost to the economy has been estimated by a recent study to be approximately \$20 billion annually.

I implore Assistant Secretary Koh to be the first in your position to take meaningful action in response to Committee recommendations. **This includes working with the health agencies to exponentially increase funding and the pace of research for ME/CFS,** without which it will be impossible to implement the most urgent Committee recommendations, such as the **recommendation for NIH to fund Centers of Excellence for ME/CFS patients, which I hope the Committee will continue to include in its recommendations.** Funding should be increased to efficiently implement Committee recommendations, not the other way around.

I would like to thank the Committee and the Assistant Secretary for your hard work.