Obama Health Committee Report - ME/CFS

Obama Biden Transition Project

Health Care Community Discussion Report

December 30, 2008

Mary Schweitzer, Host and Moderator

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We are a small group of friends within a larger long-term online community of citizens who share one attribute: we are all disabled, significantly ill for a very long time, and we share the maddeningly inept diagnosis of "Chronic Fatigue Syndrome" (CFS).

My name is Mary Schweitzer; I am the moderator. I was a tenured professor of history before I was disabled with this disease in 1994. The members of this committee include Karen Campbell, formerly a paralegal; Pat Fero, formerly a special education teacher; PSB, formerly a scientist with Mitre; Carol O., formerly a teacher; Sue C., formerly a sociologist; Steven DuPre, formerly a teacher and athlete; Rik Carlson, a writer; and Meghan Shannon, formerly a nurse specialist. None of us have been able to work in at least 12 years – Pat Fero and Meghan have been sick the longest: 27 years. Our individual stories are appended.

We ask that

1. **The U.S. adopt the Canadian Consensus Document for diagnosing and treating ME/CFS, available online at <http://www.mefmaction.net/Portals/0/docs//ME-Overview.pdf>;**
2. **The U.S. accept the World Health Organization's ICD-10 designation of "CFS" within the chapter on neurology, at G93.3, with M.E.**
3. **NIH and CDC focus on biomedical research instead of psychosocial;**
4. **GAO investigate NIH and CDC for the misapplication of funds; and**
5. **Secretary Daschle take seriously the existing Chronic Fatigue Syndrome Advisory Council to DHHS, along with the 11 recommendations of the CFSAC from 2004 (enclosed)**

Fundamental Inequality in Treatment of ME/CFS at DHHS.

Our primary issue is the **fundamental inequality** in the treatment of patients who have the disease M.E. (Myalgic Encephalomyelitis) and/or have a diagnosis of Chronic Fatigue Syndrome.

We understand the desire to reduce the individual costs of medical care as medical care is extended to all Americans. All of us are convinced that, had we been diagnosed and received treatment earlier (with antivirals or immune boosters, for example), we would never have become permanently disabled. Our disability has cost the nation quite a bit. According to CDC, households with a family member who has "CFS" lose, on average, at least $20,000 a year. Using the DePaul University estimate of **1 million Americans** (the current CDC estimate is 4-7 million), that would mean **the nation loses $20 billion in NNP every year, and at least $6 billion in income tax**

revenues to the federal government, because nothing is being done about ME/CFS. The failure to properly address the problem of "CFS" has been very costly for the nation and the government.[1]

We were asked to examine health care in the United States and how best to reform it. Unfortunately, **it matters little whether you have the best health insurance available or none at all, if you have been rendered an invalid by a condition kept invisible by the actions of NIH and CDC.**

Medical doctors and other medical personnel are members of a larger society and culture in the United States. No matter the extent of professional training, popular beliefs and perceptions will subconsciously influence their behavior. In the absence of information about the depth and severity of our illness, popular norms dominate the attitude that greets us when we walk into a doctor's office or an emergency room.

In a nation where everyone is overworked and hence "a little tired," where the word "chronic" is associated with such terms as "chronic whiner" and "chronic complainer," and the word "syndrome" has become code for "fad of the day," NIH and CDC could not have picked a better way to describe a disease that – quite bluntly – they apparently wish would disappear on its own.

This might have been understandable 25 years ago when a number of cluster outbreaks of the disease occurred in the midst of the AIDS crisis that overwhelmed the medical establishment. Today, however, there are thousands of peer-reviewed research articles into the biological causation of many of the symptoms, and subgroups have been defined through objective testing: biomarkers, SPECT scans, and specific types of stress tests. Almost a decade ago, Anthony Komaroff of Harvard wrote:

> In summary, there is now considerable evidence of an underlying biological process in most patients who meet the CDC [Fukuda] case definition of chronic fatigue syndrome. … [This evidence] is inconsistent with the hypothesis that chronic fatigue syndrome involves symptoms that are only imagined or amplified because of underlying psychiatric distress – symptoms that have no biological basis. It is time to put that hypothesis to rest and to pursue biological clues. … in our quest to find answers for patients suffering from this syndrome.[2]

Yet the NIH and CDC have continued to focus on "psychosocial" research, not biomedical. For that matter, the article presenting the CDC's Fukuda definition clearly

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[1] See Jason LA, Richman JA, Rademaker AW, et al. A community-based study of Chronic Fatigue Syndrome. *Arch Intern Med* 159:2129-2137, Oct. 1999, and Reynolds KJ, Vernon SD, Bouchery E, Reeves WC. The economic impact of chronic fatigue syndrome, *Cost Effectiveness and Resource Allocation* 2:4, 2004.

[2] Komaroff AL. "The Biology of Chronic Fatigue Syndrome." *Am J Med* 108: 169-161, 2000.

indicated that the next task was to identify subgroups, but the CDC continues to lump more vague conditions under the CFS umbrella.[3]

Many CFS patients test positive for reactivated viruses [specifically HHV-6 (Variant A), chronic Epstein-Barr, cytomegalovirus, adenoviruses, and enteroviruses]; some have tested positive for mycoplasma; and some test positive for Lyme as well. For these patients, immune, antiviral, and on occasion antibiotic treatment is necessary. But if doctors do not know about these tests, no one will receive the treatments.[4]

It should be no surprise that, **25 years after the first effort by CDC to study the phenomenon of "CFS," 85 percent of patients today still have no diagnosis (according to CDC)**. Of those who have a diagnosis, even fewer have a doctor who understands it. And because this disease is so poorly understood, many who do have a diagnosis of CFS have no symptoms resembling ours.

It if is popularly believed that a condition is pretty normal, experienced by everyone at some point in time (fatigue), then having an illness defined by that condition is hardly reason for alarm - hardly reason for urgency - and hardly an excuse for not working. More to the point, **it is no reason to spend money** – a position that makes the insurance lobbyists on K-Street happy, and also pleases those within the government who believe that catering to "entitlements" are a main reason for "high" government spending. **Keeping one million patients hidden from view (because of the extent of our disability) has served political purposes that hopefully will change in the Obama presidency.**

The name "chronic fatigue syndrome," however well-intentioned, subliminally accomplishes this mission. No one takes this disease seriously – no one, except those of us who have been saddled with the diagnosis, and our families.

The CDC has become adept at presenting one position on CFS to patient groups, another to physicians, and yet another to Congress. On the one hand, their own literature states that "CFS is a debilitating and complex disorder". Conversely, they have dismissed outright every biomarker that has been discovered with regard to the cluster outbreak patients of the mid-1980s. Their own "CFS Toolkit for Professionals," devotes an entire section to "cognitive behavior therapy" (psychotherapy) and another section to "graded exercise." **The introduction to the CDC Toolkit states, "As yet, there are no diagnostic tests or laboratory markers for CFS, and its pathophysiology is unknown."[5]**

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[3] Fukuda K, Straus SE, Hickie I, et al. Chronic Fatigue Syndrome: a comprehensive approach to its definition and study. *Annals Med* 121:953-959, 1994.

[4] For a recent review of the literature on the relationship between viruses and ME/CFS, see Devanur L.D., Kerr J.R. "Review: Chronic Fatigue Syndrome." *Journal of Clinical Virology* 37 (2006) 3:139-150.

[5] See <http://www.cd c.gov/cfs/pdf/Basic_Overview.pdf

For years I would say that yes, "chronic fatigue" is a common experience, but "chronic fatigue syndrome" is an unfortunate name for a very serious medical condition - and then I would describe how bad things are for me. Simple example: Yes, I'm sure you've gone looking for your reading glasses when actually they were on your head. But I doubt that you ever poured an entire pot of coffee into a silverware drawer, absolutely convinced it was a cup (as I have). You may not be able to pull up the right word for something - but it doesn't happen in every single sentence you try to say. You may feel so tired you don't want to have to move - but have you ever lain in bed, looking at a glass of water on the nightstand, unable to move your arm to get the glass of water and quench your thirst? Your eyes may hurt on occasion because you are tired, but do you regularly need to wear sunglasses indoors because light is so painful? Imagine not being able to read a comic strip because you can't remember the first panel by the time you get to the fourth – and imagine it all accompanied by terrible pain. **The disease CDC named "Chronic Fatigue Syndrome" is very, very different from "chronic fatigue."**

Unfortunately, CDC has recently moved further from the concept of "CFS" as a serious illness with an unfortunate name. They have created a set of questionnaires that - by their own admission - do not distinguish much between "chronic fatigue SYNDROME" and "chronic fatigue." For an example of the troubling nature of this research, see Tables 2 and 5 in Reeves *et al*, "Chronic Fatigue Syndrome – A clinically empirical approach to its definition and study," Biomed Central 2005, which describes the two-day Wichita hospital stay that has served as the basis of all of CDC's research since 2003. In all, **227 *participants* were brought into the hospital, but only *58 were ever diagnosed with CFS, and, according to the article, at most, only 16 of those 58 characterized still suffered from CFS at the time of the hospital stay***. Using the questionnaires and re-sorting the participants, Reeves concluded there were **43 patients with CFS** in that Wichita hospital stay. [You must look at the tables to see the actual numbers; they are difficult to find in the text.] **Compare that with Dr. Reeves' reference to "*227 patients with CFS" in the same two-day Wichita hospital stay* in a conference call to the media and also in a printed press release.** Reeves then published an article claiming that 58 CFS patients in a two-day hospital stay in Wichita showed no signs of Neurally Mediated Hypotension, thereby attempting to refute the Rowe-Calkins study on disautonomia in CFS, published in *JAMA* in 1995. However, **according to the *Biomed Central* article, of the 58 "CFS" patients brought into the hospital, at most only 16 still had CFS at the time of the study. If the *Biomed Central* article is accurate, then both the conference call and the *AJM* articles are incorrect. If the *AJM* article is correct, then the *Biomed Central* article and the press release are incorrect.[6]**

[6] For the April 2006 conference call when Reeves stated there were 227 patients *with CFS* in the two-day Wichita hospital study, see: <http://www.cdc.gov/od/oc/media/transcripts/t060420.htm>. For the written press release from April 2006 that again stated 227 patients with CFS were in that hospital stay, see <http://www.cdc.gov/media/pressrel/r060420.htm>. For the article describing the actual two-day hospital study in Wichita (and Reeves has stated there was only one), see Reeves *et al*, "Chronic Fatigue Syndrome – A clinically empirical approach to its definition and study," *BMC Medicine*

Most troubling, the questionnaires that were supposedly vetted by the 2005 *BMC Medicine* study have formed the basis of Reeves "new" institutional definition, and all of his consequent research at CDC. A match of (at best) 16 out of 48 patients seems hardly sufficiently robust upon which to build the entire research program of CDC regarding a disease that impacts one million patients. Dr. Leonard Jason of DePaul tried the questionnaires on his own data set of patients in Chicago from an earlier demographic study and found that they missed the more seriously ill patients (such as the ones in this group) and instead picked up a lot of patients with mild depression. Private institutions benefited financially from the creation of these questionnaires and their distribution; insurance companies will benefit from their use in disability cases. The entire CDC program in CFS, headed by Dr. Reeves, clearly needs to be investigated by GAO.

The result of this unfortunate name (and the new CDC definition of CFS) extends widely. It is exacerbated by the current climate in medical care that tries to rush every patient through in 5-10 minutes, and penalizes medical practitioners for ordering tests that come out negative.

The Situation for Patients with ME/CFS:

1. People with very serious conditions are misdiagnosed, and a misdiagnosis leads to improper treatment, or no treatment at all. Simple example: a patient with Hepatitis C will be misdiagnosed as having CFS and not receive treatment for hepatitis. Conversely, if a patient has CFS because he/she has an immune defect and viruses, "cognitive behavior therapy" (as recommended by CDC) is not going to be much help, and if a patient has encephalitis or myocarditis, graded exercise (as recommended by CDC) can be dangerous.

2. Even well-intentioned and caring family doctors are baffled by patients with a CFS diagnosis who "refuse to get well" - who do not get better, or even get worse. It makes doctors uncomfortable. A patient with a CFS diagnosis can be reasonably expected to have other things go wrong with their bodies – acute appendicitis, for example - but their family doctor may be "burned out" on having to listen to symptoms that he/she cannot fix. The case of acute appendicitis gets dismissed as "yet another one of those symptoms" for this fuzzy thing called CFS - and the problem may not be resolved until the patient is in the hospital with peritonitis [see the personal story of Pat Fero, attached, for an example of such a misdiagnosis]. At best, there is no treatment offered for CFS; at worst, other conditions are ignored because both doctor and patient become used to ignoring any symptom mentioned by a CFS patient. Patients who

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2005, 3:19 <http://www.biomedcentral.com/1741-7015/3/19>. Finally, for the seminal work in the relationship between dysautonomia and CFS, see I. Bou-Holaigah, P.C. Rowe, J. Kan, H. Calkins. "The relationship between neurally mediated hypotension and the chronic fatigue syndrome," *The Journal of the American Medical Association* 274 (1995), pp. 961-967.

have neither private nor public insurance end up in emergency rooms, where they are treated dismissively if they confess to a diagnosis of "Chronic Fatigue Syndrome."[7]

3. Nobody really believes that somebody with "CFS" can't work. Everyone's tired. Why should one person who claims to be tired get off work when other people who are tired have to remain? Of course, those of us diagnosed with "CFS" are not just "tired" – we have the level of fatigue that is normally associated with congestive heart failure or leukemia. As Dan Peterson noted in the documentary "I Remember Me," his CFS patients are as seriously ill as AIDS patients in the last two months of life. The popular perception that we are "just tired" obviously makes it incredibly difficult to receive either public or private disability. Everyone in the Social Security system, from intake workers to the ALJ level, doubts the disabling nature of this illness. Everyone in the private sector, from personal bosses and colleagues to the Human Resources Department and private insurance companies, is skeptical when you say you can't work. People are human; their prejudices influence their behavior. We know that at least one million Americans currently have this disease. Based upon research by the CDC, which historically has downplayed the severity of this disease, we know that at least half of them cannot work at all at any given point in time. That would mean that ***500,000 Americans (most of whom have no diagnosis) are completely and utterly incapable of paid work because they have "CFS."*** **Few receive SSDI; even fewer receive private long-term disability.** The rest must depend upon family members, and if they have none, their situation is desperate. We all have known of patients who have had to live on the street. How many more are there?

4. If you are denied disability, you are also denied medical care. Admittedly, private insurance and Medicare will not pay for testing and treatment for "CFS." However, there are a number of comorbidities that are recognized by CDC, and (as in the appendicitis example), CFS patients can be expected to have the same general physical problems (such as heart disease and diabetes) and experience the same acute problems (such as a diseased gallbladder or appendix) as the normal population – but if you do not have insurance, it is very difficult to get help.

5. Prejudice against patients "claiming CFS" can infect everyone from family members to neighbors to church groups. During the years that I ran a supportive on-line discussion list (averaging about 500 members at any given point in time), I knew patients who had been cast out by spouses or parents, scolded and disdained by siblings, and even abandoned by their churches.

6. Here we are, a quarter of a century after the set of cluster outbreaks in the 1980s that led to the name "chronic fatigue syndrome" adopted by CDC and NIH, and there simply are no doctors who can treat a patient with the disease. Of the handful who can be considered true experts, who have kept up with thousands of refereed journal articles over the years, I know two who are retiring in 2009. Patients call

[7] Jason LA, Taylor RR, Stepanek Z, Plioplys, S. Attitudes regarding chronic fatigue syndrome: The importance of a name. *J Health Psych* 6:61-71 (2001).

me, email me, implore me to help them find a doctor. I live in the most populated section of the United States - the Northeast Corridor. I don't know what to tell patients. The only doctors I know who have specialized in this disease have retired, left their practice to focus on research, or closed their practices to newcomers because they are so overwhelmed.

7. Changing the name from Myalgic Encephalomyelitis (as it was known in Canada, Australia, and Britain) and Epidemic Neuromyesthenia (as it was known in the United States – or for that matter, "chronic Epstein-Barr Virus," the name NIH first gave to the disease, to "chronic fatigue syndrome," has had international consequences. British psychiatrists picked it up and have successfully convinced British public health (and the "NICE" initiative) that CFS and M.E. are the same thing. But they do not use the same definition for CFS as the U.S. Their definition is entirely psychological, and all they offer for treatment is ten weeks of "cognitive behaviour therapy (CBT)" to convince the patient she isn't really sick, followed by ten weeks of "graded exercise therapy (GET)" to get her back up to speed. They believe the disease should really be called "neurasthenia" – the nervous disease diagnosed back in the 1800s. M.E. was classified as a neurological illness by WHO in the late 1960s, so British psychiatrists have thus far failed in their efforts to reclassify the disease as a neurosis.

Nevertheless, the consequences of applying the name CFS to a psychiatric diagnosis has been horrendous. Patients who once could get treatment can no longer find a caregiver. Schoolchildren, young adults, and even a vocal critic of the NICE guidelines have been "sectioned" – involuntarily committed to psychiatric hospitals. The result has been greater disability (patients who could walk are reduced to needing a wheelchair) and death, including two recent deaths of young people. Young Sophia Mirza, for example, insisted she could not swallow, but was repeatedly sectioned with a diagnosis of anorexia. She eventually died of dehydration. The autopsy showed significant damage to the basal root ganglia – the same finding as in the death of an adult with M.E. who was autopsied after an automobile accident. Any effort to adopt the "NICE" guidelines from Europe should not be attempted without an investigation into the stark criticism of these guidelines by patient groups in Britain. They save money in the short run – but they cause immense suffering. According to patient advocate Margaret Williams, "**The head of the British Department of Health has stated in writing (in 2008) that he knows of *no* evidence suggesting *anyone* has ever returned to work because of CBT [Cognitive Behaviour Therapy] or GET [Graded Exercise Therapy].**" Yet that is all that is offered patients in Britain through the NICE Guidelines – and CDC is beginning to follow suit.

Positive Actions that can be taken by DHHS:

1. There needs to be a sense of urgency. For 25 years patients have suffered from this illness. It is contagious at some point in its course. Consequently, every year there are more sufferers as the disease (or diseases) spreads unabated. At what point do we ask the CDC to stop conducting population studies and begin to educate the public as to biomarkers, objective testing (not questionnaires), and treatment? The NIH has

allocated nothing for the study of CFS in the past two fiscal years. Surely a disease that impacts one million Americans deserves more attention. Finally, despite the insistence of CDC and NIH to the contrary, there have already been deaths from this disease.

2. Change the name. The CDC claims to be waiting for a name chosen by "medical science." Yet the name "CFS" represents an arbitrary name change from the known diagnosis of epidemic neuromyesthenia in the U.S., and Myalgic encephalomyelitis in the old British Empire (and NIH's previous name of "chronic mononucleosis", or "chronic EBV," for the outbreaks of the 1980s). There is no reason to keep this artificial name, which has dramatically failed to accomplish much that is positive. Better alternatives for a name would be:

(a) to adopt the name that has been in continuous use for 50 years internationally, **Myalgic Encephalomyelitis**;

(b) compromise: adopt the designation in the World Health Organization's current International Classification of Diseases - **"ICD-10", in which "CFS" is classified in G93.3, the code created for Myalgic Encephalomyelitis in the late 1960s. Call the disease ME/CFS**, until people get used to the name M.E. or until a new name emerges from research.

(c) acknowledge the complexity of the illness by giving a name that includes the multiple systems impacted by the disease: neurologic, immune, endocrine, cardio. One example is: **neuroendocrineimmune disorders.** One advantage is that the name leaves room to carve out subgroups that would get their own name - "Tahoe Syndrome" (CEBV, HHV-6, low nK function, Rnase-L defect) could be considered one KIND of neuro-immune-endocrine disorder. Another would be that there are probably other disorders that already could be included under this name, such as fibromyalgia, multiple chemical sensitivities, Lyme Disease, and Gulf War Syndrome.

(d) **create an eponym** - as was done with Lou Gehrig's disease (ALS). Name it "Skye's Disease" for the 14-year-old in upstate New York who committed suicide after her peers laughed at her silly-sounding disease (CFS), or "Casey's Disease" for the 23-year-old who died of long-term viral myocarditis, after doctors had ignored his symptoms for years because he and his mother both had a diagnosis of CFS.

The group voted for "Myalgic Encephalomyelitis," with perhaps an interim use of ME/CFS along with the adoption of the Canadian Consensus Document as the standard for treatment. With so many conflicting definitions, the continued use of "CFS" as the name for this cluster of diseases has become counterproductive, resulting in misdiagnosis, failure to treat, and (as in the case of Casey Fero) deaths.

3. Change the definition. The current definition being used by the CDC is a watered down version of the Holmes and Fukuda definitions, both originally designed to apply to "chronic mononucleosis." CDC's current questionnaires diagnose a disorder that is much more about "chronic fatigue" than about the serious disease once called "CFS".

Their "international case definition" effectively drops three of the eight identifying symptoms in the CDC's "Fukuda definition" of 1994, although their literature still insists they are using Fukuda. CDC is drifting towards the British psychiatric definition of CFS.

Adopt the definition from the Canadian Consensus Document for ME/CFS[8] until we learn more about the disease (or diseases). The committee that created this document consisted of clinical practitioners, and about half practice in the United States. All the other definitions created for "chronic fatigue syndrome" were explicitly designed for research. **This is the only definition designed for clinical use, and it offers a means of recognizing the complexity of the condition at the same time it presents options to begin treating it. The pediatric definition created from the Canadian Consensus Document has been adopted as "best practice" by the International Association for CFS/ME.**

4. Change the diagnostic procedure. Make it clear that this is not an easy condition to diagnose, and that the usual 5-10 minute limitation given doctors by insurance companies is simply not adequate. List tests that need to be given to rule out diseases that give similar symptoms: Hepatitis C, congestive heart failure, diabetes, both types of anemia, leukemia, onset of Alzheimers or Parkinson's – these are just some of the illnesses that should be on this list.

Use the Canadian Consensus Document, which was written by clinicians, as a first pass at understanding the complexity and severity of this disease. Make use (as the Consensus Document does) of current published peer-reviewed research into objective biomarkers, testing, and non-psychiatric treatments.

The only options are the CDC's "Toolkit for Professionals," which insists there are no biomedical tests and there are no treatments (except for SSRIs, Cognitive Behavior Therapy, and Graded Exercise Therapy), and the Canadian Consensus Document, which provides information about biomedical tests and about treatments. The choice should be clear, for the CDC approach has been a dismal failure.

5. Inform doctors about the diagnostic testing available now, and require that at least Medicare pay for them. There are immune markers that are found in subgroups of CFS patients and nobody else. There are viruses that we did not know about 25 years ago, but we know about now. For example, HHV-6 encephalitis now has an ICD-9-CM code 049.8, but neither researchers nor clinicians working with CFS patients seem to know this. Why aren't doctors and researchers testing for this virus and using this diagnosis, when there are American patients who, when tested and treated at their own expense, have been shown to have a positive reponse?[9]

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[8] A summary of the Canadian Consensus Document is available in pamphlet form at <http://www.mefmaction.net/Portals/0/docs//ME-Overview.pdf>. It is too long to append here.

[9] See http://www.cdc.gov/nchs/data/icd9/agendamar06.pdf.

6. Fund Centers of Excellence where family doctors can send patients suspected of having ME/CFS. Given the complexity of the illness, and the wealth of information that is emerging internationally, it is impractical to ask family doctors to keep abreast of this disease - as they cannot keep abreast of other complex diseases such as cancers. Centers of Excellence can serve to diagnose patients, to offer treatment plans that are either continued at the Center or by the family doctor, to train *new* young specialists, and to perform research into the causes, nature, and treatments to alleviate the suffering experienced by these patients.

7. Fund external and internal research into biomarkers and treatments ASAP. The Whittemore-Peterson Institute for Neuroimmune Diseases in Reno, Nevada, has only been open two years, but it has already produced more hard research than either CDC or NIH in 25 years. The NIH has allocated little if any funding for the disease in the past few years. Annual funding during the Bush administration has been as low as 0 and claimed to be as high as $12 million, but we can find no evidence of that much money used for research into CFS. CDC's funding is entirely devoted to continually revising a baseline demographic study, and making the diagnostic criteria even more vacuous.

Indeed, the entire story of DHHS's practices with regard to "CFS" (the appearance of research without research, the production of information that contains nothing) can be found in the minutes of the CFSCC and CFSAC.

8. We strongly urge a formal investigation by the GAO into the use of funding by both NIH and CDC with regard to CFS. Several members of this committee have hard evidence into abuse of funding by these two agencies. Patient groups have testified to these abuses at the CFSAC meetings, to no avail. For example, **Pat Fero, president of the Wisconsin CFS/ME Association** (the oldest CFS patient organization in the nation), was given a half hour to speak at the CFSAC in 2006. At that time, she **presented evidence from the CRISP tapes that research presented as "CFS" research was in fact nothing of the sort.** Pat and the WCFSA would be happy to share this extensive research with DHHS. Fero has found that most studies that NIH has funded under the "CFS" umbrella term have nothing to do with CFS at all. The CFSAC's subcommittee on research found that the Congressionally mandated Special Emphasis Panel to allocate funding for CFS research has been largely staffed by researchers who have never worked with CFS (only 17 percent of the members have ever published on the subject). Since the committees operate on consensus, the result has been no funding for CFS research. The funds were diverted to other projects that the committee deemed more important – more important than CFS, one must surmise.

CDC's own research program is at a standstill, yet Dr. William C. Reeves' department at CDC, Emory University, and a consulting firm continue to receive funding. Dr. Reeves styled himself a whistleblower the last time there was a GAO investigation into the misallocation of funding by CDC (the GAO determined in 1999 that indeed the CDC had been misrepresenting its research into CFS), but he is clearly at the center of the current misrepresentation of CDC's CFS program. Just a cursory investigation of the CDC's own website on CFS will expose discrepancies and outright contradictions,

particularly when it comes to the two-day Wichita hospital stay in 2003, and a study that was supposed to be conducted in the Atlanta area since then

According to testimony presented by Amy S. (a former grant administrator for the federal government) to the CFSAC in October, 2008, **"Since 2005, the CDC has spent upwards of $11 million total to begin to study 30 patients and publish three papers…. Of the $11 million allocated to CFS since 2005, several million are sitting in an account somewhere, apparently waiting for the contractor to bill against it."**[10]

9. Revise the information given by the SSA to intake workers and physicians, and reduce the time it takes to receive disability. As objective markers become approved, advise the SSA immediately. In the meantime, the entire Social Security system should act according to court rulings that state clearly that no one should be denied coverage on the basis of the absence of testing, while the CDC insists there are no tests. And no CFS patient should be denied simply because (as one ALJ actually stated), "I simply don't believe in CFS."

At least one million Americans have "CFS." According to CDC, at least one-half cannot work at any given point in time. Are there 500,000 patients on SSDI? No. Not even close. Consequently, there must be tremendous pressure against patients with this disease when they apply for disability through a system they paid into their entire working lives.

End the gratuitous penalty by which young people and stay-at-home mothers are not even entitled to federal disability because "they have not worked enough quarters".

Precisely what is a person who is too sick to work supposed to live on during the time it takes to get SSDI – even if the process goes right? Precisely what are they to live on if the process takes years; if they are denied because SSA does not "agree with" the evidence provided by the patient's doctor? Everyone seems so concerned about those who abuse the system – what about the honest and honorable citizens who are suffering daily because you are, in effect, guilty [of insurance fraud] until proven innocent? Many states used to provide interim funds to keep a disabled person or an invalid alive until federal SSDI came through, but most of these programs disappeared years ago.

When you meet patients who have ME/CFS, you'll find they all badly want to be working. It is awful not to be able to work. The accusation that we are deadbeats, con artists, lazy – the accusations hurt greatly when you are trying your best just to survive. We really would rather be working.

10. Decide whether disability and health insurance companies are going to be regulated locally or federally. If federally [as has been the case since the passage of ERISA], then ***regulate them***. Surely the events of the past year have shown that industries that deal in information need to be regulated. **There is a perverse incentive for disability and health insurance companies to cheat the patient as long as no one checks up on their activities.** The insurance companies even have a name for

[10] See the minutes of the latest CFSAC meeting, October 2008: <http://www.hhs.gov/advcomcfs/meetings/minutes/cfsac20081028min.html>. For minutes from the CFSAC meetings since 2003, see: http://www.hhs.gov/advcomcfs/meetings/index.html. For the charter reauthorizing the CFSAC in 2008, see http://www.hhs.gov/advcomcfs/charter/.

dismissing diseases such as "chronic fatigue syndrome" – they call them "MUS" disorders – "medically unexplained symptoms," which (even if true, which it is not), should not be synonymous with "imaginary." Because of ERISA, a patient whose doctor believes he/she is entitled to private disability is restricted to federal court, and no jury. If the patient wins, all he/she is entitled to is the funds that should originally have been granted by the insurance company. The attorney has to be paid out of that meager amount. Consequently, few attorneys will take an ERISA case. Conversely, if the insurance company cheats and gets caught, all it costs is the funds that should have been given in the first place, plus the time of a lawyer on retainer. Court costs and penalties cannot be awarded unless the court finds "a deliberate pattern of intent to deceive." This would be difficult enough; the practice of requiring a gag order whenever a patient settles out of court makes it even more difficult. The deck is heavily stacked against patients – who, along with their families, have been funding the insurance company all along.[11]

11. We ask that the transition team look at and take seriously the recommendations made by the Chronic Fatigue Syndrome Advisory Committee to DHHS in 2004 (see attachment). The Secretary of DHHS refused to respond to the report for two years. Finally the Secretary sent down a message stating that the committee had nothing to do with the Secretary (despite the supposedly advisory role). Each agency then used this opportunity either to justify their behavior, or to simply state that the suggestions were beyond their mission. We therefore ask DHHS to review these recommendations once more, and to take seriously the existence of this committee.

Furthermore, we request that the incoming Secretary of DHHS either attend future CFSAC meetings, or at least take seriously the committee's advisory mission. Previous minutes can be found at the following website:

<http://www.hhs.gov/advcomcfs/meetings/index.html>

The minutes are incomplete. For years they were heavily edited. The entire collection of minutes and testimony, dating back to the original CFS-ICC - including written testimony - has supposedly been preserved. At least, that is what we have been promised.

[11] For an intriguing new interpretation of ERISA case law, see Yale law professor John H. Langbein's article, "Trust Law as Regulatory Law: The UNUM/Provident Scandal and Judicial Review of Benefit Denials under ERISA." *Northwestern U Law Review* 101: 1315, 2007.

"The Fierce Urgency of Now"

President Obama spoke of "the fierce urgency of now." I cannot imagine anything more urgent than to rescue people who are suffering, and dying, from a disease rendered invisible by the federal government of the United States. The need for care is urgent. The need for research is urgent. Our disease has been allowed to fester untreated in the community for 25 years, causing immeasurable loss to individuals, families, and society at large. On some level this disease is contagious. If nothing else, we need to stop its spread.

Preparing this report has taken us weeks, because we are all quite disabled. An illness that is characterized by massive cognitive dysfunction is difficult for people who used to earn their living with words. Mental activity is as exhausting as physical activity, so we have all needed frequent breaks (in some cases, entire days to rest). One member left her bed at the end of the two weeks to try to edit the completed report (and offered useful suggestions). That will set her back for days. Three members had to drop out of the effort before it was over. But we are speaking for a million Americans – perhaps more importantly, we are speaking for at least 850,000 Americans who have our disease but have no diagnosis. We could not be silent, no matter the personal cost.

As late as the 1960s, patients suffering from Multiple Sclerosis were misdiagnosed as having "hysterical paralysis." A woman with MS would be told to "shape up" - go back to her role as housewife and mother and take care of the kids. If she could not, it was somehow *her* fault.

A similar pattern of cruelty is being inflicted on patients with ME/CFS in the United States, simply because the NIH/CDC approved research has not caught up with the severity of the disease. It is absurd that patients should be penalized because of an assumption that there is nothing left to learn about the human body - but even that sad period in our nation's medical history can be brought to a close. We already know enough about ME/CFS to stop the inhumanity and begin to appropriately deal with patients and their suffering. All that is lacking is the will.

The need to face this disease squarely and honestly is ***urgent***, and it is urgent ***now***.

Thank you for your time. If any of us can be of assistance, please do not hesitate to ask.

Mary Schweitzer; Karen Campbell, Pat Fero, PSB, Sue C., Carol O, Rik Carlson, Steven DuPre, and Meghan Shannon

Enclosed:
Appendix A: 11 recommendations by the CFSAC to the Secretary of DHHS, 2004.
Appendix B. Personal stories of the members of this group.

Recommendations of the Chronic Fatigue Syndrome Advisory Committee To the Secretary of the U.S. Department of Health and Human Services

Primary Recommendations

In the opinion of the CFSAC, the greatest priority for the DHHS is to substantially increase research efforts and funding. Future research efforts must apply an integrative approach because CFS is characterized by dysregulation of a number of highly integrated body systems, particularly the immune and nervous systems. Forming multidisciplinary research teams would provide a platform to conduct well controlled, methodologically sound, longitudinal studies to clarify the pathophysiology of this syndrome, and to develop effective treatment modalities. Serum and tissue banks for future investigations should be established.

1. We would urge the DHHS to direct the NIH to establish five Centers of Excellence within the United States that would effectively utilize state of the art knowledge concerning the diagnosis, clinical management, treatment and clinical research of persons with CFS. These Centers should be modeled after the existing Centers of Excellence program, with funding in the range of $1.5 million per center per year for five years.

2. We would urge the DHHS, through the NIH, expedite the issue of an RFA with sufficient set aside funds to attract senior level researchers to engage in the study of CFS. DHHS should fund extramural grants, reviewed by a special emphasis panel knowledgeable in CFS, through RO1, RO3, R21, and Directors Pioneer Award mechanisms.

3. The DHHS should provide funds to develop an international Network of Collaborators that would allow for multidisciplinary CFS-related research using standardized criteria accepted by the international CFS research community. Such a network would pool a large number of patients from around the world, and would require investigators to develop and employ common protocols.

4. DHHS should provide support and funding for an intramural staffed laboratory committed to CFS research.

Secondary Recommendations

5. The DHHS should promote, encourage and fund research directed toward the diagnosis, epidemiology, and treatment of CFS in children and adolescents.

6. The DHHS, through the CDC and NIH, should continue to sponsor, even accelerate, focused workshops in specific areas of CFS and to invite investigators not currently working on CFS who have been identified as having an interest in the illness.

7. The DHHS should pursue making CFS a topic of training for health care providers, wherever appropriate at regional and national conferences sponsored by the Department.

8. The DHHS should encourage continuing education for Social Security reviewers and adjudicators. The secretary of DHHS should recommend that adjudicators follow the Social Security Policy ruling 99-2P which specifically clarifies policies regarding CFS.

9. The DHHS should increase public education on CFS through a public awareness campaign. Discrimination in health care, education and the workplace should be actively confronted.

10. We would encourage the classification of CFS as a "Nervous System Disease" as worded in the ICD-10 G93.3.

11. The DHHS should consider participation of the Department of Defense, Department of Veteran Affairs, Agency for Healthcare Research and Quality, and the National Institute of Disability and Rehabilitation Research (NIDRR) as ex-officio members of the CFSAC for future deliberations of recommendations.

Respectfully submitted,

David S. Bell, MD, Chairman
Chronic Fatigue Syndrome Advisory Committee
August 23, 2004

December 27, 2008

Pat Fero, MEPD
Executive Director,
Wisconsin ME and CFS Association, Inc
Fero.pat@gmail.com

www.wicfsme.org

Thank you for the opportunity to speak about health care modernization.

Three goals of the Obama Health care modernization plan are to:
- Improve Health care quality and cut costs
- Expand coverage and access; and
- Increase the emphasis on primary care and prevention.

How can health care be improved, with better access and emphasis on primary care, if an illness is subject to bias and bigotry by insurance companies, public health agencies to include the NIH, CDC, state health departments, local medical institutions and community clinics?

This is an urgent message. You need to know the basics before you can make decisions that will help the invisible million people affected by ***this*** illness that disabled me and killed my son.

My son, Casey Fero, died when he was 23 on a significant day in history…July 4 in 2005. Casey had a diagnosis of Chronic Fatigue Syndrome at age 9 and then again at age 15. He died of Viral Myocarditis with fibrosis, that is, scaring of the heart muscle indicating past infections. 3 ½ years later, I am not angry because he died, I am outraged that the illness affecting me and him is disregarded, ridiculed, lacks serious research, is misdiagnosed, over diagnosed in some areas of the county and under diagnosed in other areas of the United States. **NOTHING HAS CHANGED since 1984. Chronic fatigue syndrome is NOT chronic fatigue. Some people with CFS have Myalgic Encephalomyelitis, but in the US, this more accurate term for a subgroup of people with the illness is not recognized.**

When my son became ill, we had Cadillac insurance. *It did not make any difference*. Our illness is red flagged by health and disability companies. The chair of Preventive Medicine at UW Madison Medical School told me that an MD would rather run the other way than see a patient with CFS. How could this be? Nothing surprises me anymore. MD's can simply say…I am not interested and refuse to see us based on the illness. BUT…no need to rely on my word, I suggest that you have an aide call around to a few diagnostic centers, talk about CFS as if a patient and see what turns up.

The Fero Story

Summer 1980 - Spring 1982.
I became ill with a high fever after a summer trip to England. I was teaching high school at risk students in Watertown, Wisconsin. In the fall, I went back to school feeling okay, but with some trailing symptoms that I ignored. Our second child was conceived in the fall of 1981 and during that pregnancy I was ill every single day, but I continued teaching. In March of 1982, I was hospitalized for 2 weeks and Casey was born C-section at 33 weeks. He was tiny, but apparently healthy. I was healthy, too, or so I thought.

Fall 1988. Episodes of exhaustion, weakness, dizziness and cognitive problems are so bad that I cannot function at my job. I went back to school anyway, hoping to maintain, hoping that it would go away. The first day, by 10AM, I was non functional. For the first time, I thought, I can no longer work.

Flashback: Every day I would climb the stairs to my third floor classroom and need to rest on each landing. My leg muscles burned, I was short of breath, and my heart pounded from the exertion. I was neither overweight nor deconditioned. My mental and physical stamina was gone. I was plagued by viral infections. Any energy I had was going to the troubled children of others, and my own two kids got very little, but I kept going. I had worked since I was 16. Why would I think to investigate disability?

Two years prior, I earned my Masters Degree. My thesis on teaching writing using a creative and critical thinking skills curriculum, was in progress and I saw that I was able to teach writing to those considered unteachable. It was exciting. I could not finish the thesis. I had a 3.8 in graduate studies, so the university converted the thesis to credits and added classroom hours so I could finish.

In addition, I was conducting statewide seminars on *Bad Faith*, the destructive belief system of those invisible gifted students who wreak havoc in all school systems. It was exciting and I had fleeting thoughts of working on a PhD, which might give me a more flexible schedule. Silly me. At every seminar, I worried that my thoughts would fly away and I would stand stammering in front of other educators. I could hear the words; just not understand what thoughts came before and what words would come next.

Fall 1990. University of Wisconsin – Pediatric Diagnostic clinic. Casey is 8 years old. He has symptoms of my illness with major sleep problems since age 4. Casey is doing poorly in school. It is not lack of ability or ambition. After all, my little boy could speak in long sentences by age 2. He was a funny, mellow little goofball, cute as could be with big green eyes and long brown hair. He memorized tunes and could sing a perfect scale by age 2 ½, but then came sickness, and near silence, a huge change for my bright little boy.

Dr. Allen asks about symptoms. He asks about family history. Fearful, I tell him about my illness onset, Casey's birth at 33 weeks and my continuing disabling symptoms. I want an explanation and I want some treatment for my son. Silly me.

The doctor does an exam. He is not "impressed" by Casey's symptoms, as they are "unremarkable." The doctor does not believe me when I tell him that the kid's functional ability is diminished and that Casey is sick every week with sore throats, swollen glands, stomachaches and headaches. We leave and I have papers in my hand to return to the doctor. I go down the hall to find a nurse. Past an open door, I hear laughter and, "When I heard her say, " Chronic fatigue syndrome…" more laughter….

I am furious for my boy and for myself. Could I go in to yell at them? My child stands next to me. His needs and his feelings come first. Did he hear? I decide not, and we leave. In the records, the doctor wrote," The child is mimicking his mother's CFS behaviors." I am my son's worst advocate.

Winter 1992. Casey has been to several MDs and no one believes him or me. A few days after one MD visit, Casey said, "She had no right to tell me what to think and how to feel." I told him that all people have a right to think and to feel as they do and to stand up on their own two feet

for what is right. This day Casey is starting a semester at home after a week of severe flu and then a case of chicken pox all over his body, in his mouth, and down his throat. Poor boy. We are alone. MDs ask Casey questions like he has no functioning sense of self and in so, suggest that he has emotional problems. He will if I push him to go to these people.

Spring 1994. I have steady, severe pain, lower right quadrant. I see my MD on Tuesday, go back Wednesday and keep a previously scheduled appt with a specialist on Friday. I almost cancel, but I thought maybe this MD might help me. She asks me why I am hiding the pain. By that evening, I am in surgery. The surgeon thought I had a ruptured appendix, but as it turns out, I had a necrotic fallopian tube. Apparently, my MD thought it was a CFS complaint and all in my head, so he did nothing and I, used to feeling sick, did not go to the ER. I almost died. I changed doctors. I am reminded that people with CFS are misdiagnosed and often lose their ability to know when to go to the doctor.

Fall 1996 - 1999. Casey is in high school. I stopped keeping a daily diary because he thought I was being a drama queen despite school records that he missed 2 – 3 days a week. In 9th grade, the first week, Casey lost 2 textbooks, stopped using a locker because he could not organize fast enough between classes, and carries everything in his backpack. He completes work sometimes 2 or 3 times, but loses it. He refuses to see an MD and the neuropsychologist advised us not to interfere with Casey's decisions. (Apparently this professional thought it was all in our heads, too?) Despite all my attention and information, Casey has developed illness behaviors, that is, he believes he is not sick and it is normal to miss all that school. His sleep disorder is horrendous and he has no treatment. Fall 1999 is a significant time because I am invited to the CDC in Atlanta for a meeting and public apology over 12.9 million dollar misappropriation of funds for CFS research.

Spring 2000. Casey graduates from high school. His grade point is 2.2, indicating his attendance more than anything else. I cry. He made it.

Spring 2004. I attend my first Chronic Fatigue Syndrome Advisory Council (CFSAC) meeting at DHS in Washington, DC. I present on my findings that since 2000, when the GAO made recommendations for the NIH and the CDC, the grant award situation is worse, not better. CFS has received few grants, perhaps one or two a year. I vow to come back with better information from FOIA sources.

June 2005. Casey got his Associate Degree from a Madison technical school and plans to transfer to a 4-year university to major in History. Thing is, this kid just works, works and works because he taught himself to keep going. Summer school started before he called to find out that indeed, he had earned a degree. He is overwhelmed. He made it. I review the first pediatric CFS case definition and e-mail my thoughts back to one of the researchers. I tell him that Casey is happy and if he died tomorrow, I would not be sad because for years he was miserable every day. It is horrible to watch a child suffer, stand by helpless, knowing that the people who could make a difference, do not care.

July 4, 2005. Bruce gets up around 7:30am. He screams for me that Casey is dead. I went to the basement, Bruce calls the Police who call the EMS, but it is far too late. I tell the coroner about Casey's medical history, but she is not impressed. It is not remarkable. She says that CFS would not be taken into consideration. An autopsy and fluid analysis show no toxins, and no apparent gross abnormalities.

September 2005. The forensic pathologist calls. "I was surprised to find a heart muscle loaded with virus. There is fibrosis. The sample shows inflammation." I ask him to find out what virus is involved, but he refuses.

October 2005. Wisconsin Support group leader JoAnn Boyle dies of brain cancer after having CFS for many years. JoAnn also had Breast cancer as well as legionnaires, polymyositis and other diagnosis…. too many to name.

April 2006 I am an invited guest at the CFSAC meeting. I have 30 minutes to present my significant, factual findings that the NIH peer review panel members have no CFS expertise, few CFS specific grants have been awarded and yes, the GAO recommendations are being disregarded.

October 2006. Friend and CFS patient Beth commits suicide. Her illness is out of control. She has given up any hope for better despite the hundreds of self-help books, morning mantras and many, many classes she took on healing. I tell her three days before, that if a limb is missing and the brain feels its pain, the mind cannot bring back that limb. *Phantom limb heal thyself* is the number one therapy for CFS patients. It was decided by her psychologist that summer that electroshock therapy would be helpful. Beth had many in a series of electroshock treatments. There was no cardiology consult despite Beth's open-heart surgery as a child. Her husband had no idea what to do, but Beth did. She saved pills and tossed them down all at once.

Through my work as a founding member of the Wisconsin ME/CFS Association, Inc, the oldest operating organization of its kind in the 50 states (1987), I have learned a good deal about health care, the crisis in chronic illness care, and other ***issues.***

Each year I learn and relearn that we are invisible. My story is common. Most people are house bound and bed bound, feeling horribly ill every minute of every day. Organizing a million strong community of screeching voices is impossible. That takes sustained energy. People with this illness do not have stamina.

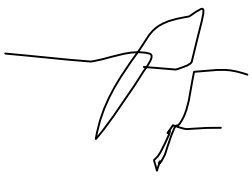
Spring 2008. The pathology lab lost Casey's 7 heart block tissues, but I managed to get the samples of all other major organs sent to the Whittemore Peterson Institute for Neuroimmune Disorders, currently located on the University of Nevada Reno campus. The bio bank was created and dedicated in memory of Casey Ryan Fero.

December 27, 2008. Now as always, I dedicate my energy to the people in this small group, all of whom work on advocacy as best they can. Please know that these people are accomplished and will sound totally capable of working. However, as with this longer than I can edit message, it has taken me at least 8 hours to compose.

THE DEVIL: What is the use of knowing?

DON JUAN: Why, to be able to choose the line of greatest advantage instead of yielding in the direction of the least resistance. Does a ship sail to its destination no better than a log drifts nowhither? The philosopher is Nature's pilot. And there you have our difference: to be in hell is to drift: to be in heaven is to steer.

- George Bernard Shaw (Don Juan in Hell)



Rik Carlson

My name is Rik Carlson.

It was January 1995, and I got the flu. Chills and fever for a couple of days, some chicken soup and dry toast, and I was right back at work. Comtrex was the drug of choice. Slowed me down a little but no big deal, just the price of winter.
Then I got sick again. Back to the chicken soup. It took a little longer, but I recovered enough to function, although I took a few half-days this time. I didn't feel good, but hey, the world wasn't going to slow down because I had a cold. I added Nyquil, and pushed myself. Then I got it again. It came on really fast and slammed into my body. I left work and crawled to bed, only this time no amount of chicken soup would help. When the chills and fever left, the pain and the flu stayed right there. Weird. It was like I had a six hundred pound rock on my chest and I couldn't move. If I got up, I sat at the foot of the bed and stared at the floor. I lost sense of time. I would hit the clicker now and again. Letterman or Kathy Lee, it didn't matter. Simpson trial.

Barbara brought me to the Doctor, and we did tests. Nothing. There were a few discrepancies in my liver, but that was from the virus. Hepatitis. No. Leukemia. No. Mono? not here. We took chest x-rays and I was scared. Nothing. Then he gave me the good news. "I can't find anything wrong, so you don't have to see me for 30 days". Barbara took me home. I was really sick. Being at work became a vague memory. A week later I was back in the doctors office, and I told him, "I'm sick and you're the Doctor." And that was the first time I heard the words. "It seems like some kind of Chronic Fatigue Syndrome. This could take one to three years." Whoa.

That part about years,... well I didn't hear that,.. well I heard it, but I didn't hear it. And Chronic Fatigue Syndrome, isn't that the yuppie flu? Didn't Newsweek call it a bunch of burnt-out stockbrokers? And Rush Limbaugh, a liberal invention? What the heck was going on? Whatever it was I didn't know.

What I did know was that this Doctor had no course of action, and that no matter how sick I was, I had to take the bull by the horns and find my own cure. A daunting task when healthy. Truly formidable now.

It's been thirteen years. I am always flu-like, my brain functioning at a slow crawl. I leave the house sometimes once a day and travel short distances for groceries, banking or th e post office. If I drive more than ten or fifteen miles, I come home toast. I have learned to carve out up to 6 hours each day (not in a row) where I can be somewhat productive. If I break a sweat, I'm bedridden for two days. I always have the flu. Simple tasks require enormous effort and I can't think. My brain is like pea soup. Most normal activities require thinking through sludge. I struggle with simple arithmetic and many times I'm just plain confused.

I've been to a dozen Doctors, had acupuncture twice a week for months, years, and pounded down gallons of Chinese herbs because western medicine comes up blank. I've given myself a hundred injections and had given to me a hundred more. I'm on a program of the best nutritional supplements known to humankind, and monthly receive intravenous therapy. It doesn't go away. It just doesn't go away.

Regarding CFS, CFIDS, M.E., Fibromyalgia, MCS, and Lyme:

There are two categories:

1.) **The disease** (and I'll call it a disease) that leaves us unable to function, care for ourselves, travel, read a grocery list, care for our children, balance a check book,...on and on, ad-nauseum, ... (we all know the long term hideously debilitating symptoms).

2.) The **lack of recognition and understanding from a broad range of the medical community** which is actually worse and far more costly than the disease itself. It is important for you to understand that the dismissal and misdiagnosis of this disease exacerbates the symptoms and sentences it's victims to a lifetime of broken marriages, financial ruin, suffering and despair. I've written chapters on this,

http://www.monkeyswithwings.com/book.html

What needs to be done starts with recognition and credibility. I'm just a lay person, and cannot comfortably carry on the medical conversations beyond personal experience. What has happened in New Jersey and is now being launched in Vermont is the medical scholarship
program to educate medical students. Dr. Friedman's program in New Jersey has found success. Until CFIDS is recognized and taught in medical schools, we'll be ignored.

To quote a Vermont physician who has CFIDS:

> "I am well aware of the ignorance that my colleagues have regarding this illness. When I went through my 7 years of medical training at UVM in `80's, there was nothing even mentioned about CFS, except for a few derogatory remarks about "yuppie flu". No one knew anything about it and fewer cared. Even in the most prominent Medicine (Harrison's) and Family Practice (Rachel) textbooks of the mid `90's, 2000 plus page tomes, there is not even a reference to CFS in the index. Only the pediatrics text(Nelson's) included a 2 page write-up. That means that most MD's practicing now were never formally educated on a devastating illness that affects up to one percent of the population.
>
> In addition to simply lacking the knowledge-base required to care for these patients, an even more sinister result occurs. There is a certain arrogance that develops in even the most conscientious medical school graduate who has just spent 7 years learning about illnesses, often 80 to 100 hours a week, who just doesn't believe that he could have missed studying an illness that was really that important. What results is a doctor who just doesn't believe his patient or thinks his symptoms are the product of an over worked imagination. This causes unnecessary pain and suffering and a poor delivery of health care for these patients. Chronic Fatigue Syndrome patients are already undesirable in the eyes of health care providers. Nobody really wants us. We have lots of complaints about symptoms that don't make sense. We take a lot of valuable time. We require lots of paper work for disability, social security and referral forms. We don't get better. We appear normal yet can't go to work.
>
> I once heard a lecturer talk about the current state of understanding (lack of understanding) of CFS at Fletcher Allen Health Care grand rounds (in Burlington). He finished his talk by saying, "Don't send your patients to me!"

Patients form support groups when conventional medicine fails. There's no where else to turn, but to find others. No one wants to do this and to even imagine a group of CFIDS patients as “activists" is absurd. I have been at the receiving end of an 800 number, have taken hundreds
of calls and over and over again I hear the same thing. "Do you know a good doctor? My doctor doesn't believe this to be real." To the one, these callers are desperate and confused.

In Vermont we have a magnificent medical center and I tracked down the administrative official who represents all of the associated physicians and asked her who I could refer people to. Her response was:

> I have connected with the chairmen of our two primary care services (I apologize for the delay, one of them was on a hiking vacation in the Grand Canyon until yesterday). Neither group employs anyone with a strong clinical or research interest in chronic fatigue syndrome. If there is something else that I can do for you, please do not hesitate to let me know.

Until we become a substantial part of the curriculum of all medical schools, we're just banging our heads against the wall (supporting the hysterical women theory). Our campaign starts one student at a time (how frustrating is that?) We need CFIDS taught in medical schools, we need CFIDS brought to the hospital's in educational training programs and we need the respect and attention deserving of a debilitating long term disease. People with CFIDS in Vermont are
dismissed. Many struggle to find understanding and support within the traditional medical community and repeatedly come up empty. Doctors need to be taught. Recovery programs need to be developed. I hear stories of misdiagnoses and outright ridicule with regularity, events that fracture spirits and destroy families, and it breaks my heart. When we change that, we'll start to understand success.

Rik Carlson
The VT CFIDS Association, Inc.
"Turning the Tides of Modern Medicine is No Small Task."
http://www.vtcfids.org

Carol's Story

My name is Carol, and I have been ill since Jan. 26, 1985 when I contracted a GI virus from a child while substitute teaching. It never went away. We lived in Denver, and I believe the outbreak we had in Denver was the Tahoe Virus coming east. I continued to teach until it became impossible, then saw more doctors than I am comfortable enumerating, none of whom found anything. One doctor sent me to National Jewish Hospital in Denver where a researcher was studying CFS, but he sent me away since my EBV titers were low. It is curious that this same researcher is now at the CDC espousing a psychological origin of ME/CFS. Eventually, this researcher recalled me, found the EBV titers high, and took many vials of my blood for viral studies until we moved to Washington, DC for my husband's business. A major midwest medical center had previously dismissed me, only finding elevated liver enzymes which they termed "an anomaly." We lived in a new house we had made too tight, and thus toxic. I was unable to sleep at night and would itch all night long. My husband said we should video me, since no one would believe it. No one ever explained the itching. I had impossible headaches during which I would lie on the floor and pull on my hair for distraction. Leaving the house helped. I had the malar rash of Lupus, photosensitivity and Hashimoto's thyroiditis, all consistent with collagen vascular disease. I had all of my mercury amalgam fillings replaced sequentially, as recommended by a well-known innovative dentist in Colo. Springs. It made a big difference, but I was still sick.

While on the East coast, I was fortunate to see a well-regarded ME/CFS researcher/clinician in the South. He initiated Kutapressin injections which made a big difference for twelve years until Kutapressin was no longer manufactured. Kutapressin was a totally non toxic broad spectrum antiviral. The replacement has not been helpful. This doctor performed many esoteric tests, all of which proved severe ME/CFS: an elevated antiviral pathway, a compromised immune system, and cognitive deficits. I have done a lot of alternative medicine, most of which has improved my condition.

I also have Chronic Lyme Disease, another politically charged illness, which I contracted as a child. It complicates the treatment of ME/CFS since the treatments cannot be simultaneous because of endangering the liver and kidneys. Lyme treatment has a made a big difference, especially cognitively, since I have neurological Lyme. I had non paralytic polio at age 3 and probably have post-polio syndrome as well.

My husband has been supportive and kind throughout this 24 year journey, and I realize I am very lucky. I have lost friends and family members who cannot understand this disease, but the important people have remained loyal. It has helped me reassess priorities and gain insight. On the other hand, I have not been able to contribute financially or meaningfully to our family or society. I spend many days in bed or in my bathrobe, not by choice. In my older daughter's words, the opportunity cost has been great.

Karen Campbell's Story

I'm Karen M. Campbell. I used to be a litigation paralegal, but when I lost my job due to severe cognitive and neurological symptoms, and no other law firm would hire me when the symptoms manifested during the interview, I re-invented myself as a home-based editor of legal documents (and a few other irons in the fire for the seasonal lulls in that business), a job that I can do lying down (I pass out if I sit up too long) and with as many rest breaks as I need. Ironically, at every point that doctors have accused me of not wanting to work, I have, in fact, been struggling to work at least part-time, and had initially asked the doctor to fix me so I could return to the full-time work that's necessary to pay my bills! I beggar myself to pay for medical insurance, but having insurance does not guarantee appropriate medical care when the doctors don't understand the nature of your condition.

I was 28 when I got the initial virus/105 fever, and worked full-time for 13 years after that (at times doing nothing except working and resting), until I simply couldn't do it any longer. A specialist has now told me that, due to incompetent doctoring at a respected medical group, I deteriorated too far and will never recuperate enough to return to work full-time. Nonetheless, 8+ years after applying for SSDI, I continue to be denied benefits; the judge's interpretation of the specialist's unequivocal statement that I cannot work is that he meant to say that I'm malingering!! The judge refuses to even acknowledge the testimony of his own VocRehab experts, nor the "off the charts" blood test results that prove there is something very very wrong physically. Any witness who testifies that I am physically debilitated is accused of lying; in fact, the only lies are those in the judge's written decision where he invents facts to support the conclusion he wants to reach (e.g., I say I'm not married, he says that I have a husband supporting me).

For several years at the beginning of this relapse, I slept only 2 hours a night, while my doctor refused to give me sleeping pills. (Apparently, he was incapable of differentiating between time spent in bed and time actually spent asleep.) Needless to say, such severe sleep deprivation made my other symptoms worse. Since my own doctors refused to give me appropriate prescriptions, I took matters into my own hands and enrolled in a clinical trial for an experimental sleeping pill. After a few months of sleeping 8 hours a night, I started running a 101 fever; when it didn't go away, I talked to a friend who is a professor of nursing, whose response was "Congratulations, you have a functioning immune system again!" (She pointed out that without adequate sleep, your immune system shuts down.) The fever lasted non-stop about 6 months, burning off the virus that had gotten the upper hand as my immune system got weaker from lack of recuperative sleep.

Although, like some other members of the group, I was very active/athletic, after the virus in 1987 I could no longer keep up my former activity level without serious consequences. After exercising, I am sometimes restricted to bed for 2-3 days; the experts call it "post-exertional malaise". This is not a matter of deconditioning or aging; it's impossible to decondition so fast that one week you can easily walk 20 miles and the next week you can't walk a few blocks without resting. Research has found valid biological reasons for the post-exertional malaise; patients aren't just saying they can't exercise because they're too lazy to get off the couch – even those of us who enjoyed running or dancing find it impossible to continue our favorite activities because of this biological abnormalities.

Nonetheless, when one of my doctors ignorantly insisted that I could exercise my way back to health, I set out to demonstrate he was wrong in hopes that he would finally understand what we were dealing with. For a week, I followed his advice to take a short walk every day, and every day I felt even worse when I returned from the walk. By the seventh day, I couldn't get out of bed without collapsing to the floor. Hardly the result he expected! It took weeks for my health to return to where it was before I followed his erroneous advice.

"PSB"
Living With M.E.

In the next few pages, there is a short summary of my experience with Myalgic Encephalomyelitis. I became ill in 1989, and remain totally disabled now. I have been disabled by M.E. longer than I worked as a productive member of society. I am an astrophysicist, but spent the bulk of my short career working in computer telecommunications. Before moving back to my family home in Alabama, I lived in the Northeastern US, primarily the Washington area. That is where I sought treatment for this new disease when I became ill, and found that there was no treatment that worked. During the years I lingered there trying to find medical help, I became involved with the CFS Coordinating Committee, now called the CFSAC. I gave testimony at several of those meetings. I worked with the NIH to help select the first slate of patient members of the committee, and I was also involved with the meetings at the CDC when the first accounting scandal was made public. Those latter activities are public knowledge and my involvement was small and brought about no positive outcome. That's why my statement here is a personal one about how hard it is to live with this disease.

I was struck down at the age of 40, while working as a consultant for the federal government on communication interoperability issues, in November, 1989. In my case, I had an extreme viral onset that was like a severe case of influenza; it was like Texas flu or Swine flu, both of which I had during the years in which they were pandemic. As usual, there was supreme difficulty in obtaining a diagnosis. My knowledge of this disease was nil at that time. For all I knew, I had Lyme disease, or hepatitis, or any of a very large number of viruses I was tested for. I was finally diagnosed by an infectious diseases specialist who used the CDC 1988 definition of CFS, through a process of elimination. I've come to know a lot about what I now know is Myalgic Encephalomyelitis due to brute force exposure to it.

What is it like to have Myalgic Encephalomyelitis (M.E.)? There are physical, cognitive, and social as well as emotional aspects that have happened in my case; we are all different, for this disease has 'different results after inflicting the same insult' upon us. That is a phrase I learned probably 15 years ago from a fellow activist in the Washington, D.C. area. Here is a little glimpse of how my life crumbled from what was once a promising career at the top of a group of enterprising people who were planning for 'Battlefield 2005 telecommunications,' to what I am now, a broken woman who can barely string sentences together.

I have been totally unable to work since 1991, and have been disabled since that time. I lost my job. My legs literally went out from under me and I had to undergo lengthy physical therapy while using 2 canes to walk, haltingly and for only short distances. I walk much better now, after several courses of therapy, including two at facilities of the Warm Springs Institute in Georgia. There are times when I stand too long, and I begin to black out. I can avoid fainting if I sit down, and I will sometimes sit down in a public place on the floor rather than risk fainting. Other physical problems include the onset of fibromyalgia, and several organ system diseases which may be related to the autonomic nervous system aspect of M.E. Since I don't know if they are cause-and-effect, I don't relate them here, but I have become more-or-less bed bound, with only 2 to four hours of activity per day .

Early in the disease, for some months, I was unable to speak more than a few words. I can usually carry on a conversation now; my self-retraining in what I call word retrieval has been compared to what a stroke victim goes through. Still, I frequently have to close my eyes to remember words though. Reading the printed word became a thing of the past. I can now read a few sentences at a time, but my retention is very poor. I listen to audio books now, and I like to joke that I can listen to the same mystery novel over and over because I don't remember the end. In the past 6 years, I've also developed permanent visual dysfunction too, called palinopsia, which makes it nearly impossible to drive at night, and makes reading from a computer screen much more difficult.

Memory is a very tricky problem now. I have a sort of sliding window of time in the recent past during which I can remember events. It may be 3 days ago up to 6 months ago, or the window may shut down at 3 weeks. I never know if I am going to remember an event, an appointment, or a person. In fact, I have more or less given up on people recognition; unless I see someone daily or maybe weekly, I do not recognize the face. The only reason I know about this sliding memory window is that I have lived with my sister for several years, and she has described it to me. I keep track of appointments and such on my cell phone calendar, without which I would never be able meet any of my obligations. This technology has helped me tremendously in the last few years.

I've written this memory description down and keep it for whenever I need to explain it to people, like doctors. Or, as in for this description of my condition for our input to the policy makers for President-elect Obama.

Maybe it is not obvious, but in becoming this ill and unable to function at any sort of professional level, I lost the friends that I had made throughout the years in my field. I lost track of my friends that I had still kept up with in academia, because I was still living in the same northeastern megalopolis where we had been friends. My extreme inability to travel – energy deficits, the need for frequent stops to sit or lie down, and other problems that are poorly understood by healthy people – also cut me off from many of my dearest friends, including my most 'significant other.' I stopped making new friends, unless they were sick like me and I got to know them through support group meetings, or in attending government committee meetings. Even then, I usually lost track of them (unless I made a photograph – I learned that was an important tool) due to memory problems and lack of functional time during each day.

Social isolation has become probably the most frightening aspect of living with M.E. The physical symptoms can only make you sick or dead. But isolation makes you miserable every hour of your day. It never ends. Of course this is true for all chronic illnesses, but M.E. Is so poorly understood by everyone who does not have it, it's not even possible to get a fair hearing from one's pastor or an organization that is intended to insure against isolation. Socially speaking, I am living in a dead zone.

My own family cannot find their way to an understanding of what has happened to me. I live in my own home, a huge house that I cannot clean, and cannot afford to hire people to clean or to take care of the lawn. So I am always attempting – and always unsuccessfully – to do those chores myself. The result – a feeling of self loathing because I can't do what I should be able to do. After being sick for almost 20 years, I still

try to do what is of course impossible and act like I'm not sick.

That's irrational. So finally, there is the emotional part of this disease. I don't say that I never feel depressed, but I'm not clinically depressed. What I am is just what the book title said: *Sick and Tired of Being Sick and Tired.* Angry that the people I have trusted to find out what is wrong with me and to find out how to treat it, took the money and misused it; they stole my trust. They might as well have stolen my life. Afraid that I will never feel well enough to accomplish any of the things I had set aside in my younger years to do after I climbed my big career mountain. Afraid I will never again enjoy life like I did 21 years ago.

It took me several days to pull these few pages together, from material that I mostly already had written. Along with an "executive summary," I hope it will give some insight into what living with M.E. Is like, and why we who have the disease cannot rest until our few short pleas are met by our elected officials.

Addendum 1: Some things I wrote about CFS/ME in the past

In 1999, I published this information on my web site (since discontinued due to progressive illness) about the first time the CDC misspent funding for CFS research. It was informative then and still is now.

+++ DOLLARS AND SENSE +++ DOLLARS AND SENSE +++ DOLLARS AND SENSE +++

I am working on a way to put these numbers (research funds misspent by CDC) into understandable context. How about this: For every **$0.98** the CDC spent on CFS related research from 1995-1998 inclusive, they stole another **$0.88** from the pot and spent it on other programs, and they stole **$0.41** from that same pot and no one can tell WHERE it was spent.

Another way to state it: For every **$1.00** Congress authorized to be spent on CFS research, CDC spent only **$0.43** on research, stole another **$0.39** and spent it on other programs, and then lost track of the remaining **$0.18** and can't account for that at all. In other words, only **43%** of the authorized funds were actually spent on CFS research.

If I still paid taxes, I'd be hopping mad. As it is, if I could hop, I would be also. I want to see careers in tatters and ruin. I want to see **ACCOUNTABILITY**.

NIH ++ CDC +++ NIAID++NIH ++ CDC +++ NIAID++NIH ++ CDC +++ NIAID

Now I have a question for NIH: How clean are THEIR accounts?

Addendum 2:

This is another snippet of information I put on my web page back in 1998. This is one of the meetings I attended and testified at.

April 1998 Meeting of CFSCC

Before I started my presentation, I displayed a copy of the May, 1998, Reader's Digest which has an article about the American's with Disabilities Act (ADA) in which CFS is lumped with myopia and body odor as 'not a real disability.' After displaying the article, I told the group that more people will see this article than everything that has been produced by this Committee in its entire history. That is the reason I am asking for support from the Committee as follows:

Proposal: CFSCC to reply to media coverage of CFS

*** After 4 years, the CFSCC has yet to produce a single release of corrective information after negative press on CFS**

*** Attacks of CFS and PWCs are never-ending and not improving over time**

*** Who speaks for PWCs?**

Sample of press coverage of CFS: *Washington Post July 1995*
"Chronic Fatigue Rare, HMO Study Concludes"
**** Citing CDC demographic studies, CFS branded as a rare diagnosis not warranting study funding***
**** Major media outlet that provides articles for other newspapers across the country***

Steven DuPre

I would like to first thank you for your willingness to listen to us in the effort to remedy huge deficits in the recognition and treatment of this very serious neuroimmune disease, Myalgic Encephalomyelitis/CFS. The lack of recognition is due to the "fatigue" word, which implies quick recovery, and also the inadequate criteria for the disease, which together militate against early diagnosis and treatment which would serve to decrease the number of people who need to go on disability. In other words, the way things are set up now, getting sick because of a viral assault on the body and being told to try to push through the illness by clinicians and family members instead causes a landslide of serious symptoms that is nearly impossible to overcome as seen by the large-scale studies showing 4-8% recovery rates.

This is true in my own case as a very athletic person in which I mistakenly thought that "fatigue" simply meant pushing through to recovery. When I came down with a disabling virus 15 years ago, I was forced to go part-time in my teaching position and then because of a series of virus attacks was unable to continue the job I loved.

“CFS” is not viewed as a legitimate disease by most physicians and medical institutions, resulting in the universal experience of M.E./CFS patients receiving inattentive and poor medical care once the name “CFS” is spoken or appears in a medical record. Even somewhat aware primary care physicians do not recognize the gravity and truly disabling nature of this disease --not just the myopathy and crushing weakness, but also the post-exertional illness, and all the worsening of pain and other symptoms that are the punishment for that exertion. The medical community still makes the same mistake about M.E./CFS that predecessors made about MS, TB and Parkinson's, illnesses also once thought to be caused by psychological issues.

Steven DuPre (Carmichael, California)
http://www.name-us.org/

Meghan Shannon's Story

I have attended the Chronic Fatigue Syndrome Advisory Committee meetings since Dr. Lee started them and have witnessesed many things I would like to share with you. [The committee was first named the CFS-Interagency Coordinating Committee, then under Clinton the CFS Coordinating Committee, and finally under Bush the CFSAC.]

I am a long standing patient advocate who started the North Coast San Diego CFIDS Support group with 11 other women of various socio-economic groups. I was a Respiratory Therapist in a cluster outbreak of Adeno Virus #2 from 1980-1983 when the infectious disease doctor for the workers at the hospital told me to leave as my immune system was shot.

I saw Dr Allan McCutchen, well known AIDS Specialist, at UC-San Diego.

My blood work mimicked the HTLV-III HIV AIDS patients. The CD4/CD8 ratio is reversed. Post Polio people have the same results.

I was first diagnosed with ARC in 1985 by Dr. McCutchen. Then, in 1988 I suddenly became a "hysterical woman" because you had to be HIV positive for that diagnosis, so I was switched to the diagnosis of "CFS".

In 1998 I was correctly diagnosed with Post Polio. I had Polio virus when I was six, and – yes - I had the experimental vaccines for Polio type I, II and III.

Most symptoms were have been overlooked in this committee in testimony by some at CDC and NIH.

Cardiac problems are *significant*. At least Social Security talked about Johns Hopkins Doctors Hugh Calkins and Peter Rowe, who published a seminal article on the relationship between CFS and neurally mediated hypotension (NMH) in *JAMA* in 1995. **Both Calkins and Rowe have presented multiple times to this meeting starting in 1995.**

Fatigue is a factor in NMH and POTS and can be helped by medicine. Calkins said in the meeting "I am no way saying that these people have only NMH and POTS. Some might be misdiagnosed."

CFS, CFIDS, and NEIDS are names that are misdiagnoses of disease processes that have yet to be discovered in the patients who have been MIS-labeled with these names.

"Myalgic Encephalomyelitis" is the correct term for those who have this. I am classic misdiagnosed. I have Post Polio Syndrome. The late Dr. Judy Morris, who fought for years for disability coverage with a diagnosis of CFS, was finally diagnosed with Multiple Sclerosis before her death.

The names CFS, CFIDS (chronic fatigue and immune dysfunction), and NEIDS (neuro-endocrine-immune dysfunction syndrome) are not real names of a disease. These acronyms are *symptoms* and body systems that 99% of all disease processes have, i.e., Cancer, AIDs, Bells Palsy, MS, Lupus, Arthritis, etc.

In 1994, Dr. Philip R. Lee, Assistant Secretary of DHHS, stated, "CFS was never meant to be the name of a 'new' disease. It was to be a research definition for a surveillance study at CDC and NIH would do testing for what was behind an outbreak of diseases."

EBV and other Herpes Viruses are known to lay latent. Studies in UK and other parts of the world are now looking at the fact that if you test for EBV and some other Herpes viruses (not HHV-6a) that these other Herpes Viruses are what is left behind after some other microbe or environmental insult has done damage to the body.

Listening to discussions about work incentives by government officials makes me wonder if I have accidentally wandered into a UNUM insurance meeting, where the goal is to get people off the support they need as disabled Americans. UNUM is straining Social Security and other agencies in the rest of the world. The only goal seems to be how to get *sick* people back into main stream making money, even if it is nowhere near the job or profession you did before the disease.

Social Security is not really taking that tactic. However, most people I know like myself have been out of the professions we have done long enough that we would need extensive training to get back in.

And that is if we can *learn* the things we did all over again.

Some people can work. But for most of these patients, just because the work is sedentary doesn't mean they can actually *do* it.

I don't think you want me back in the Intensive Care Children's hospital as a Respiratory Therapist after 25 years. Things have changed and I had to leave, as I was unable to be a safe worker for my patients.

Putting people back on the "fast or slow track of going back to work" should not be the Federal Government's job. These people are very kind, but do not know the disease.

To say that if you put us in "sedentary" work then we could work, means they *do not understand* about the severe cognitive problems of our disease. To their credit the presenters at the CFSAC meetings from Social Security seen to understand that was a statement that they should not have said.

CDC should not be allowed to control of this disease. It is not in their mission statement.

The NIH should not, either Just like cancer and AIDS, this should not be a disease that is run by government agencies. There are *lives* at stake here.

Centers of Excellence were brought up under Dr. Donna Dean's watch of CFSCC. Many people, including the private sectors of Womens' Health of Excellence that are connected with universities around the country offered to help.

I have been coming to these meetings for almost two decades. If there has been any change at all, it has been for the worse.

The Obama administration needs to ask GAO to investigate the abuse of funding and science at NIH and CDC where our disease is concerned.

Thank you.

Meghan Shannon

Mary Schweitzer's Story

In the fall of 1994, I lived a charmed life. I was a tenured professor of history at Villanova, a profession I loved and had worked hard to attain. I was happily married with two children. We skied in the winter and went to the beach in the summer, and my husband and I took our children with us to different cities when we went to professional conferences.

On October 24, 1994, everything changed. I was in my office trying to catch up on grading exams. At some point, I blacked out. When I came to, I could not understand a single word in the bluebooks on my lap. I made it home, walked into the kitchen and sat down, with my coat still on. That was where my husband found me, in the dark, two hours later.

My life would never be the same again. I was no longer a normal person who worked out regularly but occasionally got sick. I was something entirely different. I fell into a world that most people fortunately never have to experience - a world of chronic pain, confusion, and the inability to do the most simple of tasks.

It took time to realize that I did not have an acute illness. Everyone, myself included, assumed that with sufficient rest and appropriate medical treatment I would recover from this downturn. I remember thinking that by April, I would probably be well enough to do light research. Instead, I found myself settling into a life that did not change – at least, did not change for the good

Every day was a day survived. To others, I was resting, taking it easy. But not to me. The simplest task took enormous exertion and concentration. My husband and son engineered a lounge chair next to the computer in the family room, so I could go online while still lying flat. But the cognitive effort required to meet with my friends on Internet tired me out as quickly as if it had been physical work. At least on internet you can begin something one day, and finish it on another, and nobody knows. (That is how we all managed to write a report to give to you.)

How could "resting" be this difficult? My prior concept of "rest" always included some kind of activity. During previous bouts of illness, I would lie in bed reading the newspaper or a good book, or perhaps just knitting and watching TV. But now, reading was at first tiring; eventually impossible. Knitting was far too difficult, both mentally and physically. Just getting food during the day was an adventure, because I was so confused all the time.

Months and years went by while I continued to deteriorate. No one except my family saw me at my worst. I began to disappear inside myself when around friends, because I misspoke or misunderstood so much it was hard to have a conversation. And the exertion of being upright, around other people, used up what little energy I had very quickly. While observers might assume I was doing fine (just a little subdued), my family would be watching for signs that we needed to leave and get me back to bed. Outsiders never saw me incoherent at home, lying in a dark room listening to my movies because it was the only way I could bear the pain. I never told them how confused I was. Eventually I used a wheelchair when we went anywhere. At home, I propelled myself around the house by bouncing along furniture and leaning on walls - with the help of my golden retriever, who instinctively stood next to me to help keep me from falling, and stood there patiently when I had to push on her to get up after a fall.

My children took the car keys away after I had a blackout while driving, and came to on top of the stone fence in front of the Hockessin, DE, post office, with no idea of how I got there. The family left me a TastyKake for breakfast, so all I had to do was pour my own coffee - but I often forgot to bring a cup and poured it onto the saucer or the table. Once I poured an entire pot of coffee into the silverware drawer convinced THAT was a cup. When I saw the pretty brown waterfall, I realized my mistake. By then we were all used to this - as long as I had not endangered anybody else or myself, it was okay. But it was not a life.

Before my collapse I was a voracious reader. In addition to my research, I read three newspapers a day plus the *New York Review of Books*. Now I would get confused just trying to read a comic strip, because by the time I had gotten to the fourth panel, I had forgotten the first.

Before I fell ill with CFS, I could never have imagined anything except a stroke that would have prevented my being able to read, to write, to continue to publish - let alone pour a pot of coffee! Who was this new person?

This was what made me disabled. This was my illness. It was not being "tired" or "fatigued." *My brain was broken*.

I was originally diagnosed with "CFS", but I would later discover I fit the definition for M.E. from British MD Melvin Ramsay's textbook on the disease, published in 1988 (See http://www.cfids-me.org/ramsay86.html#chronic).

Myalgic Encephalomyelitis means muscle pain (myalgia) plus encephalitis and meningitis (encephalomyelitis). In our case, the term encephalomyelitis refers to encephalitis, an infection in the brain stem, and severe Central Nervous System dysfunction. CDC has always insisted it cannot use M.E. without evidence of "inflammation" – but I have the symptoms. Proof is impossible without an autopsy, which would clearly preclude any further treatments, and there have been very few autopsies of patients with CFS or M.E.

I could not pass a simple Romberg Test – I fell over the minute I closed my eyes. There was the severe head and neck pain. I had receptive and expressive dysphasia, severe ataxia, dyslexia, dysgraphia, dyscalculia, difficulty making new memories and difficulty recalling formed memories, and loss of spatial perception. If I tried to help out by loading the dishwasher, I would end up crashing one glass against another because I could not judge the proper placement. Someone would have to clean out the glass and vacuum the dishwasher, so I had to quit doing even that. I had no idea where my body was in space – I wasn't dizzy; I used furniture and walls to carefully measure my way around the house. The floor never seemed to be in the right place. In some ways, it was like being terribly drunk – except I had not been able to tolerate alcohol since 1990, when I had a case of Epstein-Barr throughout the fall semester. Finally, I had a very strange gait that was later diagnosed as a dropped foot (actually a post-polio symptom, but patients in England with long-term M.E. have told me some of them have it, too).

I had a good doctor in DC from 1995 to 2000, when she quit her practice. She taught me how to manage my "energy envelope," and she diagnosed and treated a number of comorbidities: fibromyalgia, myofacial pain syndrome, Hashimoto's thyroiditis, and neurally mediated hypotension. However, I tested negative for anything that might explain the disease itself.

Then, in the fall of 1998, I tested positive for an immune defect newly discovered by Temple research Robert Suhadolnik. My body takes normal 80kDa Rnase-L (essential to the body's natural antiviral defenses) and degrades it into 37kDa Rnase-L, plus a rogue protein kinase. I have a low natural killer cell count and function. In addition, I learned that I had reactivated Epstein-Barr, and that I had an active case of HHV-6, Variant A. My blood testing was done by Dr. Dharam Ablashi, the co-discoverer of HHV-6 and its two variants while at the National Cancer Institute. These biomarkers had proved useful in predicting improvement with an experimental drug called Ampligen (a synthetic, double-stranded, asymmetrical RNA).

On February 2, 1999, I began treatment with Ampligen by IV twice a week. The drug cost $60,000 for the first 20 months I was on it; fortunately, our daughter received tuition remission for the college of her choice (USC's film school), so we could use her college fund. Later the cost was reduced to $20,000 per year. But it was well worth it.

The vast number of patients with ME/CFS – including the members of my little group - do not have $20,000 per year to live on. The testing and treatment I have had is completely out of reach for them.

Four weeks after starting Ampligen I walked out of the house without a cane – without difficulty. By May I was driving a car. I read my first book in four years in August, and in September I danced the mother-son dance at my son's wedding. After years of only being able to dream about walking, I walked on a beach on the edge of the waves. I was ecstatic.

After 20 months, I went off Ampligen. I was doing so well that I began negotiations to return to teaching at Villanova. But teaching was not in the cards.

On October 6, 2001, one year after I stopped taking Ampligen, HHV-6 returned. I was at Cal Ripken's last baseball game, and at some point after the 5th inning I suffered a blackout (as I did the first time in 1994). Bob had to take me out of the stadium in a wheelchair. The next morning I forgot that I was an invalid, and I started to hop out of bed. I collapsed to the floor. Dr. Ablashi confirmed the return of HHV-6 (Variant A). It took seven months to get back on Ampligen, during which time I continued to deteriorate.

I finally was approved to begin treatment at the highly respected I. Brodsky practice in hematology-oncology at Hahnemann Hospital in May of 2002. It took longer for me to pull out of the symptoms this time – the dropped foot lasted until the end of 2004. But soon I was walking again, driving again, living again. I did not have the stamina to teach, but I was given a non-paid position as a senior research associate at the McNeil Center for Early American Studies at the University of Pennsylvania. In return, I was supposed to attend seminars given by doctoral and postdoctoral fellows, and asked to work with dissertations when possible. Because I wasn't paid, I didn't have make every seminar. Sometimes I was absent for weeks. The director understood that I could not predict when my strength would fail me. But I was back in history again, and I loved it. I was happy.

Then the unexpected happened. At the end of February, 2008, I received a phone call. Because Dr. Brodsky had died, Hahnemann would have to re-apply for permission from FDA for me to receive Ampligen on a cost-recovery, open-label basis. My doctor at Hahnemann was turned down twice. I learned that there was no place where I could get into a "new" open-label study. Ironically, I still own $1,000 worth of Ampligen, but it is illegal for anybody to give it to me.

I thought I had a year before I would relapse, but as it turned out, I only had seven months. After Labor Day I began running a low-grade fever. I had a sore throat, swollen glands, headaches, pain behind my eyes and in the back of my neck, and I felt just awful. When I saw Dr. Peterson on September 23, he had me stay a week to undergo extensive testing.

Here are some of the results from this past September:

- reactivated Epstein-Barr Virus; evidence of enteroviruses, and a new case of cytomegalovirus (CMV);
- low natural killer cell count and function as well as the 37 kDa RnaseL defect;
- a very poor VO2 MAX score of 16 (where a normal 80-year-old should score 20 and a woman my age should score at least 40) – which explains why stairs were so difficult;
- rediagnosed neurally mediated hypotension
- abnormal findings from a 24-hour Holter Monitor test;
- high thyroid antibodies;
- evidence of protein malabsorption, which Dr. Peterson believes is caused by an enterovirus;
- SPECT scan showing abnormally decreased activity in the left lateral temporal lobe and occipital lobes.

I have an acquired immune defect comparable to AIDS. Yet I do not have AIDs. I do not have HIV, and while I share CMV and HHV-6A with AIDS patients, each side has viruses the other does not. The cancers we are prone to are different, too: we get lymphomas and stem cell cancer. I don't know if they are prone to myocarditis, as we are. My markers fit with those of other patients from the cluster outbreak at Tahoe in the mid-1980s – conversely, there are other clusters whose biomarkers I do not share. But **I have what should be a recognized disease.**

I returned to Reno in early October to begin treatment with Vistide (which Dr. Peterson has found successful for patients with both cytomegalovirus and HHV-6 - at any rate, it is approved for CMV). For days afterwards I was nauseus and weak, like being on chemotherapy. I had to have my blood and urine tested 3 times a week because it can be toxic. After the third dose, two liver markers (SGOT and SGPT) spiked to 400, so we waited a month and tried a lower dose. The next day the liver markers spiked to 500. So no more Vistide.

I took Ampligen for 9 years, except for the 19-month hiatus, and *I never suffered a single adverse side effect*. That doesn't mean my experience will be true for anyone else, but it was for me. Yet I cannot get Ampligen. I was forced to take something more dangerous.

When "fast-tracking" was approved in 1997, patients testified about three illnesses and the drugs that had helped them. One of the three illnesses was CFS, and the drug was Ampligen. Ampligen fits every requirement for fast-tracking, but FDA insists the company hasn't filled the forms out correctly. The company responds that FDA is impossible to work with. The needs of patients - and medical science - are lost in this little dance.

So here I am - we have all the best insurance, and it's even backed up by Medicare. We are not wealthy, but my husband makes a comfortable living as a professor of finance and is intent upon making certain I get as much medical care as I need, even if it means he drives a 14-year-old Maxima with 275,000 miles on it. And I cannot get the one medicine that has helped me. My large extended family backs him up when needed. I am so very lucky that I am not alone.

Physically, I could be worse. I have not yet had the tell-tale blackout signaling the arrival of HHV-6. But I cannot drive because I get too confused. I have trouble breathing if I walk up even the slightest flight of steps. This "living room community meeting" has cost me hours and hours of work (as it did the other participants). The report I am sending you took hours and hours to prepare, as did this personal story (although I have borrowed some from essays I had already written). Intellectual activity is not impossible (yet), but it is as exhausting as walking uphill. The pain is back behind my eyes and in the back of my neck, and my head hurts. Eventually the pain wins and I will have to go lie down in the dark and listen to a movie.

From 1996 until as recently as October 2008, I have testified at every meeting of the Chronic Fatigue Syndrome Coordinating Committee (later renamed an "Advisory" committee) of DHHS. ***Nothing has changed***. For my testimony last spring, I simply handed out my testimony from the fall of 1999, because ***nothing has changed***.

Please take this seriously. Perhaps all that will be necessary is a change in personnel to scientists and doctors who respect our condition and the biomarkers that have already been discovered. Perhaps it will take a full-blown investigation into the misspent funds and outright lies perpetrated by NIH and CDC upon our patient population. Please. This must change.

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