

November 5, 2005

The Honorable Dianne Feinstein
One Post Street , Suite 2450
San Francisco, CA 94104

Re: Response received from Dr. Julie Gerberding, CDC Director, Department of Health & Human Services

Senator Feinstein:

We very much appreciate your follow-up on the letter that we sent to Dr. Gerberding. We received from you her response to our letter. She did not adequately address the concerns regarding the classification of the neuroimmune disease, Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome (M. E./CFS), as a neurological disease, which the CDC failed to report in their initial findings of the disease, thinking they had found a totally new "syndrome" when actually it was only another outbreak of Myalgic Encephalomyelitis, which had been in the World Health Organization International Classification of Diseases since 1969, long before the CDC came up with their 1988 name, definition and criteria. In other words, Dr. Gerberding does not address the failings of the CDC in the name, definition and criteria, which has caused a lot of suffering by patients and a lack of gold-standard targeted research because the name, definition and criteria are inadequate reference points for the disease. The disease already had a descriptive name, definition and criteria in place that should have been used.

Our other major point was that the 2003 Canadian Consensus Criteria which is an excellent instrument for clinical diagnosis and published by a team of experts in the disease, has been ignored by the CDC. It could be used to correct an unjust situation, and it has been tested and shown superior to the CDC 1994 criteria in the following study by an expert researcher: The recent study by Dr. Leonard Jason ["Comparing the Fukuda et al. Criteria and the Canadian Case Definition for Chronic Fatigue Syndrome," J of Chronic Fatigue Syndrome, Vol. 12 Issue 1, pp. 37-52, 2004] revealed that the Canadian Case Definition is a far superior tool in the clinical setting for diagnostic purposes. This is desperately needed, as many patients are not diagnosed for years or over a decade due to lack of competent clinical criteria, leading to tragic severe progression of the disease.

Jason cogently comments in the study that much of the inability of research studies to reach consistent results is due to the failure to work on research-based subsets under M.E./CFS, as well as the inherent problems of heterogeneity caused by the CDC 1994 Fukuda criteria. Fatigue, as commonly understood, is not the central feature of the illness, but rather it's the relapsing and progression of a number of specific neurological, circulatory, immune, musculoskeletal- weakness like symptoms not contained in the CDC 1994 definition, all of which are described under the Canadian Clinical Working Case Definition for M. E./CFS.

Dr. Gerberding states that she has shared our previous letter with the CFS Research Program at the CDC. We would like a written response from that CFS Research Program or from Dr. Gerberding herself regarding the above-mentioned issues which remain on the table. This disease affects approximately one million Americans and millions more around the world – many of whom eventually die of end-organ failure after years of bedridden or homebound suffering, quite frankly due to neglect from the CDC. We would also like to know to whom we can send a DVD entitled "Engaging with Myalgic Encephalomyelitis," a lecture given by Dr. Malcolm Hooper which details the substantive reasons for the neurological classification in the disease, M. E./CFS (ICD-9 323.9; ICD-10 G93.3). This is a one-hour DVD, which includes explanatory slides.

Sincerely,

Steven Du Pre, Representing Capital Area CFIDS/M.E. Assoc. & Sacramento Valley CFIDS/M.E. Assoc.
Carmichael, CA 95608

Encl: Testimony Re: death of young person with M. E./CFS; letter from Dr. Gerberding & your cover letter

This testimony was given to the CFSAC (The Chronic Fatigue Syndrome Advisory Committee of the U.S. Department of Health and Human Services) on Monday, September 12, 2005.

By Dr. Mary Schweitzer (who suffers from the neuroimmune disease, Myalgic Encephalomyelitis/CFS)

On July 4, 2005, sometime between 2:30 am when his mother kissed him good night, and 6:30 am when his father came downstairs, Casey Fero died in his sleep. His heart simply stopped.

Casey Fero was 23.

Casey was a charming, friendly kid with blue-green eyes. He was first diagnosed with CFS at the age of 9, then again at 15. He was plagued by headaches, cognitive difficulties, muscle weakness, and exhaustion.

In addition to the symptoms of a serious illness, he had to endure doctors who did not “believe” he was “really” sick, and teachers who saw in him only a shirker. By the end of his short life, however, he was happy. He had just completed two years of community college and was looking forward to beginning courses at the University of Wisconsin. He had acquired a summer job. He had many friends, who came to his home for days after he slipped away to mourn the loss together. The family and Wisconsin CFS Association will honor Casey with a blood and tissue bank for CFS/M.E. victims. We will pass the flyer around at the end of this talk.

[The flyer was posted to Co-Cure yesterday, and can be found at http://www.co-cure.org/flyer_WI.pdf.]

In his mother's words, “Casey had bull dog determination. In his mind, he had overcome all illness and if he just worked harder he could do anything.... Interesting, how he died so well, with so much enthusiasm to live.” Most people in this room are acquainted with Casey's mother, Pat Fero, President of the Wisconsin CFS Association; Pat testified before this Committee about a year and a half ago. You may also have met his father, Bruce, and his older sister, Mikol Susan, when the Wisconsin group hosted the October meetings of the American Association for Chronic Fatigue Syndrome.

Pat has had CFS since before Casey was born. She and Bruce sought diagnosis and treatment for Casey, but as he passed into adulthood, he no longer had a doctor of his own. Even at the University of Wisconsin, there were no doctors who “believed in” the disease or, for that matter, really believed Casey was sick. Casey carved his own therapy out of over-the-counter and mail-order supplements such as powdered whey protein and Co-Q-10.

Seeing the supplements, the coroner originally told Pat that this would be their first “steroid” death. Even in death, the first response was that it could not be CFS, because CFS is not a serious disease.

Last Thursday, September 8, Pat received the coroner's report. The University of Wisconsin forensic pathologist found that:

****Casey died of myocarditis that is, his heart was infected with disease. There was inflammation, and the tissue was full of viral infection. Casey also had old fibrosis, indicating that the viral infection was not of a new onset.****

The pathologist was “shocked” at this finding.

Casey Fero died of Chronic Fatigue Syndrome.

Why?

Specialists on NMH said they knew of no cases where someone died from that condition or had there been reason to suspect carditis was involved in NMH.

Using an ultra-sensitive type of electrocardiogram, Dr. A. Martin Lerner of Wayne State Univ. has found evidence that EBV & cytomegaloviruses in CFS patients has caused heart damage. I do not know whether this research has been replicated, but under the circumstances, it takes on a new importance.

There is evidence that HHV-6 can infect the heart. Other possible culprits include Lyme Disease, mycoplasma, and Chlamydia.

In 2003, Arnold Peckerman, Benjamin Natelson and others published their research finding that most CFS patients suffer from cardiac abnormalities [“Abnormal Impedance Cardiography Predicts Symptom Severity in Chronic Fatigue Syndrome,” in *The American Journal of the Medical Sciences* 326:2 (2003): 55-60].

The cause was left to further studies, but Dr. Paul Cheney has suggested viral infection. Clearly this research could lead to an answer to Casey's death, but it has no federal funding.

The harsh reality is that research on CFS, viruses, and cardiac abnormalities is under-funded, ignored, and at times outright dismissed by those charged with informing the public of the dangers of diseases.

However, if you turn to the Myalgic Encephalomyelitis (M.E.) literature in Great Britain, there is evidence of deaths in both adults and teenagers from sudden heart stoppage. Ramsay wrote about such cases, and in correspondence with Dr. Malcolm Hooper I was informed that he, too, was aware of premature deaths from heart failure. Dr. Hooper has long been studying the hypothesis that M.E. is caused by an enterovirus (such as polio and coxsackie). There is no comparable research on enteroviruses in the United States (unless you count the sparse literature on post-polio syndrome). [Ed. Note: As you know, Chia & Chia, *J Clin Pathol* 2007, just published a study reporting the presence of enteroviruses in patients' stomach biopsies. But this only proves that much more investigation is needed in this area.]

Is this the price we have paid because in 1988 we rejected, instead of embracing, the robust research programs and existing literature in the M.E. community?

Had we built on these studies, instead of squandering our time on measures of “fatigue” and a plethora of studies of CFS as a “somaticizing” disorder, where might we be today? For the past twenty years, had we been looking at this as a disease rather than a psychological disorder, would we now know enough to have prevented Casey's death?

And if we hadn't hidden what we already know from the public, would Casey have had a doctor of his own, perhaps even one that would have looked into the condition of his heart?

Pat Fero came down with CFS before her son Casey was born. His entire life was lived under the shadow of this disease a shadow of widespread ignorance.

Why?

The pathologist was shocked to find heart damage.

Why?

What is the virus that the pathologists found? HHV-6? Mycoplasma? An enterovirus? Cytomegalovirus? EBV? Something completely new? Why is there no money for researchers studying these very questions?

We need the public to be told NOW that there is a serious disease out there, and that nearly a million people in the United States have it. They need to be told of the uncertainty about cause, prognosis, and cure. They need to be told what they should be tested for to rule out other diseases. And they need to know that patients die.

Two months after Casey's tragic, untimely death, most primary care physicians know little more about the disease than they did on the day Casey was born. That is criminal.

One year after this committee sent a list of suggestions (as is its task), to the Secretary of the DHHS, there has been no [effective] response. That is also criminal.

What does it take to impart a sense of urgency to this task?

Does it take the tragedy of a young man's senseless death?

Hold Casey's memory high, like a banner. Take him to Congress, to the press, to the appropriate medical specialties. Let this be a turning point.

Casey Fero died too young. Do not let his death be in vain.