

**Testimony to the
DHHS Chronic Fatigue Syndrome Advisory Committee
Brian Smith
October 28, 2008**

Good morning, members of the committee, as well as members of the CFS community. My name is Brian Smith, and some of you may remember my testimony before this committee in May of this year. At that time, I detailed how Chronic Fatigue Syndrome has plagued my life for over 13 years, following a severe case of mono at the age of 15, and how it continues to deprive me of any semblance of a normal existence. This committee has heard of the personal toll that CFS has taken on me, as well as other countless sufferers. You have also heard of the financial impact on the American economy and its taxpayers, as well as the reprehensible inaction of the federal government with regard to research, education, and the utter mismanagement of the public health crisis that is CFS. I will not waste your time, or mine for that matter, speaking about these issues that have already been systematically documented. Instead, I will address the economic burden that 4 million Americans must face as individuals, while the federal government -- which we all have ownership of -- fails each and every one of us afflicted with CFS.

As you are all aware, individuals with CFS, at times, are unable to work, or their ability to establish, as well as maintain gainful employment, is severely restricted due to the limitations of living with CFS. In fact, due to the extensive symptom pattern that exists, most, if not all of those afflicted with the disease will, or have, experienced periods where independence is simply not possible. No matter how demoralizing the notion is, I am fully aware that as a young man in America, it is likely not feasible to eventually become, or remain self sufficient due to CFS, and as an adult, I will probably remain the proverbial adult child that still lives with his mother. Although difficult, I have come to terms with this reality, as I am sure many of my peers with CFS have as well -- it is done out of necessity, and undoubtedly, without alternative.

Like many others, over the 13 plus years of living with CFS, I have experienced times of financial solvency; throughout my experience however, I have learned that these periods of financial independence are undoubtedly short-lived, and almost always followed by a period of relapse -- a worsening in the frequency and severity of symptoms, often due to over-extending oneself, just in an effort to meet the standards set by our society, as well as corporate America -- 9:00 to 5:00, five days per week. Many, including myself, have been faced with the reality that in order to pay for rent, utilities, groceries, et cetera, no option exists but to absolutely force our bodies to work, through the overwhelming exhaustion and pain, all at the physical expense of our health. I personally have experienced this cycle a number of times, with the lucid reality, that eventually, over-extending, or "pushing" myself, would most certainly lead to a severe worsening of symptoms, and an eventual state of relapse. But given my situation, I had no alternative.

If I was legally blind, had M.S., or any other number of disabilities, I would have little difficulty acquiring Social Security benefits, as well as other forms of state and federal aid. Even after the landmark ruling of SSR 99-2p nearly ten years ago, individuals with CFS are all too often denied benefits, and discouraged from obtaining their rightful aid, by making the pursuit in itself a battle

of attrition, designed to wear the patient down through numerous denials, forced psychological evaluations, layers of bureaucracy, and years of waiting in limbo. The process in itself is physically, emotionally, and psychologically exhaustive, designed to compel the patient to surrender. And contrary to what the Social Security Administration would have you believe based on their remarks before this committee in May, the process is not becoming easier. It is not becoming faster. It is not becoming more "patient-friendly". Even following the launch of the CDC's Public Awareness Campaign in November 2006, where the CDC stated that they have "documented, as have others, that the level of functional impairment in people who suffer from CFS is comparable to multiple sclerosis, AIDS, end-stage renal failure and chronic obstructive pulmonary disease. The disability is equivalent to that of some well known, very severe medical conditions." As an individual with CFS who is currently attempting to navigate through the Social Security Administration labyrinth, I can tell you first hand that it is indeed a battle of attrition.

I filed for Disability benefits with the SSA in January 2007. If you were present for my testimony in May, I displayed a three inch thick binder that contains much of my medical history over the last 13 years. Unlike many of my peers, my illness history has been meticulously documented, by a number of expert clinicians from literally across the United States, who all agree, that according to SSR 99-2p, I am disabled. Despite meeting, and often times surpassing every threshold set forth in SSR 99-2p, including all of the laboratory findings, I have been denied disability benefits twice, and in April 2008, requested a hearing before an Administrative Law Judge. In Omaha, NE, individuals who requested a hearing for all types of disability claim reviews back in September 2006, are just now beginning to have their cases heard by an ALJ. My attorney estimates that I will not have the opportunity to have my case reviewed by an ALJ for at least another year, but likely two. Not only is this bad government, but it causes a tremendous economic strain on individuals like myself with CFS, as well as others who are also, stuck in limbo.

Often times, if we are fortunate, our families sustain us financially. In the past, my parents have been extremely supportive, and were able and willing to provide for my food, shelter, medical costs, et cetera. More recently, with the recent death of my father, it has become more difficult for my mother to assist me financially. Because I can not work full time, I do not qualify for employee sponsored health care plans. Because I have a pre-existing condition, insurance carriers will not extend coverage to me. Currently, I receive health insurance through a state program entitled Comprehensive Health Insurance Pool, or CHIPS, intended for "high-risk pool candidates." As a 29 year-old, non-smoker, my health insurance premium alone is nearly \$340 monthly, which excludes deductibles, co-pays, et cetera. My monthly costs for health care, including prescription coverage, are over \$900, or nearly \$11,000 annually; remember, these costs are directly related to my medical care, and do not include various indirect costs. If I did not have the support of my mother, I would not have the basic necessities for living. And I am not alone -- I have heard countless stories that mirror mine. Of those individuals who are fortunate enough to get a proper diagnosis, the CFS patient community heavily relies on friends and family for economic assistance. As I stated previously, we would much rather lead "normal" lives, and be contributing members of society -- trust me, based on economics alone, if I were able to consistently maintain employment, and establish a career, I would gladly accept that alternative to the possible pittance that I may eventually receive in the form of Social Security

benefits -- I know my capabilities, and any sort of federal or state aid will come nowhere near what my utility as an employed citizen is financially worth. To put it bluntly, I have no expectations of becoming wealthy through Social Security benefits. Again, I am not doubtful that those who are in similar positions would agree with my sentiments as well, yet the shackles of CFS are often too difficult to break free from.

In 2004, it was estimated that the costs associated with having a family member ill with CFS is approximately \$20,000 per family, per year. Before this committee in May 2008, representatives from the Social Security Administration presented the "Ticket to Work" program, which is a polite way of urging those with CFS who already receive benefits, to "transition" into employment, which according to my understanding, would severely jeopardize the benefits that they were fortunate enough to be "awarded" in the first place. Programs like this are not only fundamentally flawed due to the nature of SSA's Disability design, but honestly, are an insult to individuals like myself who are unable to sustain work, and in my opinion, are yet another waste of taxpayers' money.

I could continue on about many issues facing the CFS patient community, but unfortunately, I am fairly certain that most of the members of this committee are already aware of them. While the CDC's CFS program obviously has major flaws, so too do many other arms of government. Individuals are suffering as a result of CFS; not just physically, but financially as well. I urge you to explore the backlog of SSA Disability cases, the rate of denials pertaining to CFS, as well as the amount of time it takes for an individual to actually receive benefits. Because until that day comes, not only do I wait, but 4 million other Americans with CFS wait with me.

Thank you.

Submitted to the Chronic Fatigue Syndrome Advisory Committee by:

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