

## Call for Congressional Action for Myalgic Encephalomyelitis/CFS

Myalgic Encephalomyelitis/Chronic Fatigue Syndrome is a disabling neuroimmune disease that affects more Americans than AIDS, breast cancer and lung cancer *combined*; more people than have multiple sclerosis or cystic fibrosis; a disease where patients can be as functionally impaired as those suffering from diabetes, heart failure and kidney disease. **This disease which costs the U.S. more than \$9.1 billion annually in lost productivity has been sorely neglected by government health agencies.**<sup>1</sup>

More than 900,000 Americans of all age, racial, ethnic, and socioeconomic groups suffer for years, decades--and often their entire lives--from this disease.<sup>2</sup> **Its impacts on the economy have been measured and are significant.** Yet after nearly four decades as an internationally recognized and categorized disabling neurological disorder, Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (M.E./CFS) here in the U.S. remains one of the most underfunded, maligned, miscategorized life-altering illnesses of our time.

Why?

- "Chronic Fatigue Syndrome" carries the burden of a flawed case definition<sup>3</sup> as well as an inappropriate, trivializing name, both produced by the CDC. Only in the US among English-speaking countries is the name CFS used to the exclusion of the more accurate scientific name, Myalgic Encephalomyelitis (the US oversight is due to mistaken epidemiology work by the CDC in the 1980s, not recognizing an already existing disease).
- The NIH has misappropriated funds, sent requests for research funding to ad hoc panels with few or no expert members, relegated the disease to the Office of Women's Health although 30% of patients are male, and ignored recommendations by medical committees and the Chronic Fatigue Syndrome Advisory Committee (CFSAC) Recommendations available here: <http://www.cfids-me.org/cfsc/recommend.html>
- Instead of making use of a half-century of research and clinical information available about Myalgic Encephalomyelitis (first identified in 1934 and in the World Health Organization's International Classification of Diseases [ICD] since 1969), the CDC and NIH chose to focus on the non-medical criteria "fatigue", leading to the mistaken impression both within and without the agencies that "CFS" was a psychosomatic or minor illness when ample evidence to the contrary was available.
- The resulting scientific bias against the organic nature of the serious disease (see Expert Testimony below) has been used as an excuse by both agencies to withhold current information from the public and Congress. At the same time, NIH has refused to institute a standing committee or set appropriate levels of funding. Nearly a million Americans have this disease, but in the twenty years since CDC renamed it, neither the general medical community nor the public has learned anything about etiology, transmission, or appropriate treatment protocols even though *researchers* have learned a great deal (with objective findings of clear physical abnormalities), but it's not filtering down to the trenches because the NIH and CDC continue to fund studies that try to promulgate the false premise of psychological problems (Dr. Anthony Komaroff of Harvard Univ. & Dr. Leonard Jason of DePaul Univ., among many others, have refuted that false premise). Both the NIH and CDC have contributed to the continuation of misinformation about outbreaks of the disease by promulgating ignorance.  
**Example:** Recent highly-publicized gene expression research by the CDC conspicuously dodged the major biological underpinnings discovered by many studies here and abroad about this disabling disease. Instead they emphasized how "stress" affects patients, yet again implying a primarily psychological cause. CDC Director Dr. Gerberding's misleading statement: "This is the first credible evidence for a biological basis for CFS" ignores 2000+ prior studies since the mid-1980s demonstrating objective, organic evidence of viral damage, neurological and immunological abnormalities, circulatory abnormalities<sup>4</sup> and other clear physical causes for the symptoms.
- While Congress has increased overall funding to the NIH, NIH allocations for studying "CFS" have declined precipitously. According to CDC, allocations to study "CFS" total less than \$4 per patient. Even more disheartening, investigations have found that some of that money has been spent on researching other diseases with a symptom in common with CFS, rather than specifically on "CFS."

- **As long as NIH and CDC continue to bury what is known about this disease, every man, woman and child in America is at risk of contracting the illness.** Those who do fall ill soon discover the U.S. agencies do not even have the most basic clinical treatment standards available for their doctors. If CDC does not inform the public when a severe outbreak of disease is in process, what purpose does it serve? If NIH refuses to allocate a penny for research on a mysterious disease that has left over half a million Americans jobless, what purpose does it serve?

**WE NEED YOUR HELP. Here are the actions we are asking Congress to take:**

1. By Congressional action, require the NIH to form a standing committee to approve research grants for the neurological disease, Myalgic Encephalomyelitis/Chronic Fatigue Syndrome, ensure that the research is biomedical in nature instead of psychiatric, and also investigate past failure to properly allocate research efforts for this serious neurological disease (proof of failure: <http://www.co-cure.org/PatFero.htm>).
2. Instruct the NIH to place M.E./CFS under Neurological Disorders & Stroke<sup>5</sup>, instead of the Office of Women's Health (30% of all patients are male). Historical precedent: Congressional action in 1950 to place Multiple Sclerosis (formerly called "Hysterics Disease") under the category of Neurological Disorders at the NIH through the efforts of the MS Society. Note that the NIH & CDC ignored evidence of the neurological abnormalities in M.E./CFS when they did their cursory investigation of outbreaks of the disease in Nevada & California in the late 1980s and early 1990s.<sup>6</sup> This provides clear reasons for actions on the part of Congress to correct serious flaws in the handling of Myalgic Encephalomyelitis/CFS outbreaks in the US.
3. Require the CDC and NIH to formally adopt the 2003 Myalgic Encephalomyelitis/Chronic Fatigue Syndrome Clinical Working Case Definition Diagnostic and Treatment Protocols; A Consensus Document (available at: [http://www.mefmaction.net/documents/me\\_overview.pdf](http://www.mefmaction.net/documents/me_overview.pdf)) to replace the present inadequate and inaccurate 1994 Fukuda criteria (proven by Dr. Leonard Jason in the study cited in reference #3). At the same time, implement the internationally accepted name Myalgic Encephalomyelitis/CFS to accurately describe what is currently known about the disease.
4. Require Secretary Leavitt to incorporate the 11 recommendations made by his Chronic Fatigue Syndrome Advisory Committee (CFSAC) in November 2004, recommendations which serve to implement the neurological classification and funding of research. CFSAC is the DHHS-appointed committee comprised of many of the top ME/CFS veteran researchers and clinicians in the U.S. (NOTE: Secretary Leavitt has been urged in writing by several members of Congress to implement these recommendations, yet nothing has been done.)
5. Instruct the CDC to update the information it disseminates to reflect the World Health Organization classification (Myalgic Encephalomyelitis/CFS in the ICD-10 under the neurological classification G93.3) and the above mentioned Congressional orders.

**Why we ask Our Public Servants to Take Action at this time**

For two decades, CDC and NIH have refused to respond to numerous requests by M.E./CFS patients, caregivers, researchers and clinicians, even though most of the requests would involve little or no funding. Ignored by the very agencies that are charged with addressing public health issues such as this, we remain disabled, misunderstood, bereft of sensible treatment and, unable to return to economic productivity, a burden on our families and society as a whole. All Americans would benefit by the simple re-categorization of this disease to the WHO ICD-10 category where it belongs, under neurology, together with the international terms Myalgic Encephalomyelitis and Post-Viral Disease Syndrome. If the NIH and CDC refuse to fund new research into this disease, at least we could benefit from what is already known outside the United States.

More in-depth information is available at your request from <[info@CFSfacts.org](mailto:info@CFSfacts.org)> as well as references supporting the need for immediate action on the above recommendations. Thank you for your consideration and support.

## Expert Testimony

Example #1: According to Anthony Komaroff, Professor of Medicine at Harvard and a renowned world expert on M.E./CFS, there are now more than 2,000 papers which demonstrate unequivocally that M.E./CFS is an organic, and not a psychiatric, disorder.

Example #2: In 1999, Dr. Leonard Jason from DePaul University, Chicago, was outspoken, writing that it is regrettable that the disorder is portrayed in such a narrow way, and that flaws in the case definitions of 'CFS' have led to "inaccurate and biased characterization of ME/CFS which incorrectly favors a psychiatric view of the illness". He correctly pointed out "the erroneous inclusion of people with primary psychiatric conditions in ME/CFS samples will have detrimental consequences for the interpretation of treatment efficacy findings".

As Professor Jason stated in his letter of May 12th, 2005, to the Editor of Psychology Today, ME/CFS is a "devastating chronic disorder," and he questioned why it is assumed that it is only sufferers themselves who believe it to be an organic disorder when many scientists, including himself, support such a view. He further stated that there has been a mass ignoring of "a large body of medical research demonstrating biological abnormalities in individuals with ME/CFS. For years, investigators have noted numerous biomedical abnormalities among ME/CFS patients, including over-activated immune systems, biochemical dysregulation in the 2-5A synthetase / RNASE L pathway, muscle abnormalities, cardiac dysfunction, abnormal EEG profiles, abnormalities in cerebral white matter, decreases in blood flow throughout the brain, and autonomic nervous system dysfunction."

Instead, too many doctors still demonstrate a repeated failure to distinguish between the symptom of "chronic fatigue" resulting from overwork or as a symptom of other medical conditions and the entirely-different disease of ME/CFS (even though the differences have been repeatedly brought to their attention and even though as long ago as 1990, the American Medical Association issued a specific notice emphasizing that 'chronic fatigue' is a symptom that presents with many illnesses, and not at all the same as chronic fatigue syndrome (CFS). This has resulted in suppression of biomedical evidence of ME/CFS. Focusing on the single symptom of 'fatigue' or 'chronic fatigue' in ME/CFS and ignoring the other significant symptoms and signs, especially cardiovascular, neurological and immunological, keeps the focus off the far more debilitating symptoms that these patients suffer from (i.e., Orthostatic Intolerance (OI), cognitive/memory dysfunction, and cardiac insufficiency, etc.)

Example #3: M.E./CFS expert, Dr. Daniel Peterson from Incline Village, Nevada, has gone on record saying that in 1989 he believed that M.E./CFS would be resolved by science; he has since changed his mind and believes that it can only be resolved by politics.

Example #4: Katrina Berne, Ph.D in her book on the disease reported "...The apparently disinterested CDC essentially turned its back on the devastation in Incline Village and elsewhere.

Hillary J. Johnson, author of Osler's Web, commented that the name "Chronic Fatigue Syndrome" was selected by a small group of politically motivated and/or poorly informed scientists and doctors who were vastly more concerned about costs to insurance companies and the Social Security Administration than about public health. Their deliberate intention – based on the correspondence they exchanged over a period of months – was to obfuscate the nature of the disease by placing it in the realm of the psychiatric rather than the organic. The harm they have caused is surely one of the great tragedies of medicine."

Example #5: "I have treated more than 2,000 AIDS and CFS patients in my career. And the CFS patients are MORE sick and MORE disabled every single day than my AIDS patients are, except for the last two months of life!" Dr. Marc Loveless who testified under oath before Congress in 1995.

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<sup>1</sup> Reynolds KJ, Vernon SD, Bouchery E, Reeves WC. The economic impact of chronic fatigue syndrome. Cost Effectiveness and Resource Allocation 2:4, 2004.

2 Jason LA, Richman JA, Rademaker AW, Jordan KM, Plioplys AV, Taylor RR, McCready W, Huang CF, Plioplys S: A Community Based Study of Chronic Fatigue Syndrome Arch Int Med 1999; 159(18):2129-37.

<sup>3</sup> Dr. Leonard Jason, DePaul University expert researcher in this area, has fully demonstrated in a 2004 study (J of Chronic Fatigue Syndrome, Vol. 12, Issue 1) that this 2003 Working Case Definition can identify a clear, definitive cohort of patients with the disease. Also, in 2003, Dr. Jason demonstrated the ineffectiveness of the CDC criteria: "Variability in Diagnostic Criteria for Chronic Fatigue Syndrome may result in substantial differences in patterns of symptoms and disability," Evaluation & the Health Professions, March 2003;26:1:3-22- finding -"Although post-exertional malaise and impairment of memory and concentration are essential for the ME criteria, they are not required for the Fukuda et al (CDC 1994) criteria."

<sup>4</sup> "Abnormal Impedance Cardiography Predicts Symptom Severity in Chronic Fatigue Syndrome." The American Journal of the Medical Sciences. 2003; 326(2):55-60.

Synopsis: While the cause of chronic fatigue syndrome (CFS) remains unknown, researchers have noted circulatory irregularities in many patients. These include autonomic nervous system dysfunction, often manifested as orthostatic intolerance; neuroendocrine abnormalities reduced plasma volume; and low red blood cell mass. In combination, some researchers believe, these factors could create deficiencies in blood flow to organs and muscles — with resultant symptoms, such as post-exertional fatigue, that are hallmarks of CFS

5 Scientific studies on the neurological abnormalities in Myalgic Encephalomyelitis/Chronic Fatigue Syndrome available at this website: <http://www.co-cure.org/neurological.htm> .

6 Osler's Web, by Hillary Johnson and testimony by Dr. Paul Cheney before the FDA Scientific Advisory Committee in 1993 regarding the alarming rate of neurologic & neurocognitive elements of M.E./CFS: <http://www.ncf-net.org/conference/CheneyTestimony.htm>