

WRITTEN TESTIMONY SUBMITTED TO THE

U.S. HOUSE OF REPRESENTATIVES

APPROPRIATIONS SUBCOMMITTEE ON  
LABOR, HEALTH AND HUMAN SERVICES, EDUCATION AND  
RELATED AGENCIES

HONORABLE DAVID OBEY, CHAIRMAN

BY

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## **Background**

**Chronic fatigue syndrome** (CFS, also known as chronic fatigue and immune dysfunction syndrome or CFIDS) is a complex and debilitating chronic illness characterized by profound exhaustion, widespread pain, problems with information processing, memory and concentration, and other physical symptoms that mimic multiple sclerosis, mononucleosis, flu and lupus. Research published by scientists at the Centers for Disease Control & Prevention (CDC) indicates that at least one million Americans have CFS, but that less than 20% have been diagnosed by a health care professional. A new CDC study has documented an even higher prevalence of CFS in the U.S. and the results of this study are expected to be published in spring 2007. CFS affects four times as many women as men and is most common in adults ages 40-59, but can strike people of any age, race and socioeconomic status. Recovery rates have not been well studied, but early diagnosis and symptom management appear to reduce duration of illness.

Although CFS has been defined and studied for nearly 20 years, there is still no diagnostic test, no cure and no single course of therapy proven effective for even a majority of patients studied. Yet there is exciting promise on the near horizon for diagnostic markers and more effective treatments. Researchers are converging on a more refined understanding of the multiple factors that contribute to the onset and perpetuation of CFS, including genetics, infectious agents and other environmental factors, as well as host response. Multiple abnormalities in the brain and various body systems have been documented and warrant further study. The leadership demonstrated by CDC's application of a systems biology approach to CFS and recent awards made by NIH to support seven new research projects are positive advances, but total federal research funding of \$12 million for FY06 has fallen to the amount spent 10 years ago, in FY97.

In this testimony I will outline signs of progress, as well as needed direction from Congress to ensure that these opportunities are maximized. These requests are backed by the CFIDS Association's established record as a tenacious watchdog over federal dollars directed to and spent by federal agencies for CFS programs. The CFIDS Association is the nation's leading organization working to conquer CFS, representing patients across America and around the globe. A great deal of the progress so far has been achieved through partnership with leaders representing both parties and both houses of Congress. Over the past 15 years, the directive language provided by appropriators has helped demand accountability for the overall direction and specific priorities for federally supported CFS research and education programs. In fact, a February 18, 2007, Associated Press article that ran in more than 625 outlets documents the work that Congress and patient advocates have done together to bolster research on CFS. This story, "Pain meets politics in focus on chronic fatigue," can be viewed at <http://www.msnbc.msn.com/id/17134990>. We hope that the House Labor,

Health and Human Services Appropriations Subcommittee will further this partnership and include the language requests outlined below in its FY08 Report.

### **Secretary for Health**

The Chronic Fatigue Syndrome Coordinating Committee (CFSCC) was chartered in 1996 to provide a forum for researchers, clinicians, advocates and federal health officials to promote better understanding, maximize resources and resolve challenging policy issues. The CFSCC and its successor, the Chronic Fatigue Syndrome Advisory Committee (CFSAC), have enhanced communication, improved collaboration, reduced duplication and strengthened CFS programs supported both by the federal government and private organizations. The recommendations made to the Secretary for Health by the CFSAC have emphasized the need for expanded research and education, as well as increased attention to patient care and training for health care professionals.

**Request:** The CFIDS Association asks Congress to direct the Department of Health and Human Services, Office of the Secretary to prioritize strategies to address the low rate of diagnosis of CFS, lack of defined standards of medical care for CFS patients and the stagnation in research funding by CDC and NIH in spite of progress being demonstrated in the field.

### **Centers for Disease Control and Prevention**

CDC funds for CFS research increased between 1999 and 2005, but have declined again, in spite of important progress and demonstrated productivity. In the wake of a May 1999 report from the Department of Health and Human Services Inspector General that CDC had misrepresented to Congress the amount of money it had spent on CFS by \$12.9 million, CDC restored these funds to its CFS research program between FY00 and FY05. It now boasts the premier CFS program in the nation that blends population-based epidemiology, clinical and laboratory studies. Its scientific work has been complemented by a provider education program and the recent launch of the nation's first public awareness campaign for CFS. An event featuring CDC Director Dr. Julie Gerberding held on November 3, 2006 to officially launch the campaign has so far generated more than 1,500 articles/stories in the press about CFS.

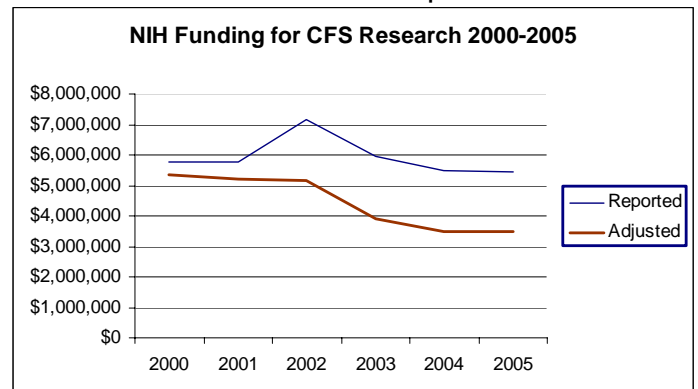
However, now that the "payback" period has ended, funding for CFS research has returned to the FY95 level of \$6 million per year, seriously jeopardizing the progress being made. In addition, CDC is reorganizing all of its programs and the destination of the CFS program is presently undetermined, although two meetings were held recently to make recommendations to the executive leadership about its placement. This uncertainty also puts progress at risk.

**Request:** The CFIDS Association asks Congress to applaud the CDC for launching the first national CFS awareness campaign and the heightened attention being generated by these communications efforts conducted in collaboration with the CFIDS Association of America. In light of CDC's own data supporting the need to educate the public and the medial community, Congress should require CDC to dedicate appropriate resources to this campaign so that precious momentum is not lost. The Association also asks

Congress to commend the CDC's CFS research program for its systems biology approach to CFS and its global leadership. Congress should also recognize that this prominence and progress is jeopardized by the severe funding cuts reported for this program and express concern that funds are dropping even as CDC's own research indicates that the prevalence of CFS may be higher than previously documented, intensifying the need for expanded study and attention. The Association asks that Congress express concern that in FY07, report language provided \$1,000,000 over the budget request to protect the progress being made; however spending for CFS research for FY06 is estimated to reflect a 50% drop compared to the final spending figure for FY05. Congress should insist that CDC restore funding to the FY05 level of \$9 million and provide additional support to continue the effective public awareness campaign. Finally, Congress should indicate that it awaits the report from CDC on how the organizational restructuring will impact the CFS program as well as a report on how CDC will address emerging evidence that human herpesvirus 6A and Epstein-Barr virus may play a role in CFS, perhaps as causative agents.

### National Institutes of Health

Despite the doubling of the NIH's budget in the late 1990s, the agency's CFS research spending has been stagnant, reaching a high of \$7.4 million in FY95 and declining to a reported \$5.5 million in FY05. In its watchdog role, the CFIDS Association carefully analyzed the NIH Budget Office's information from FY00-05 and found that the figures were inflated by nearly 35% through the inclusion of studies that do not pertain to CFS, confirmed by the principal investigators for such studies. A report documenting the necessary adjustments is available from the CFIDS Association and has been presented to the DHHS CFS Advisory Committee and several Congressional appropriators and authorizers.



In July 2005, several NIH institutes joined the Office of Research on Women's Health to announce a Request for Applications for CFS with \$4 million in dedicated funds to support meritorious proposals. Thirty-seven proposals were received and funding for seven new CFS projects was announced on October 30, 2006. However, this funding simply replaces grants that were set to expire and does not expand the total number of awards to support CFS research.

Research centers offer investigators the opportunity to develop collaborative research studies and approaches to patient care spanning multiple disciplines and medical specialties. Presently there are no such centers funded by NIH where CFS patients can participate in research studies and receive care, in spite of recommendations made by the DHHS CFS Advisory Committee and a 2000 State of the Science panel convened by NIH. There is also no intramural NIH research specific to CFS to provide a locus of ongoing investigation and support. While the leadership provided by the Office of Research on Women's Health and its formation of a Trans-NIH

Working Group for CFS have been extremely helpful, more action is needed to reverse the downward funding trend and its dampening effect on progress in CFS science and care.

**Request:** The CFIDS Association asks Congress to express appreciation to the NIH's Office of Research on Women's Health for its leadership on CFS research, particularly the coordination of the Request for Applications that culminated in the October 30, 2006 announcement of 7 new awards for CFS research. Congress should direct NIH to utilize the annual meeting of investigators funded under this initiative to stimulate new research initiatives and build multicenter collaborations that foster success under the Roadmap Initiative. Congress should further direct NIH to develop an intramural CFS research program and to implement the recommendation made by the CFS Advisory Committee 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." Congress should require that within 60 days of passage of the FY08 appropriations bill, that NIH report on how it will move forward on this recommendation and how it will address the erosion of NIH funding for CFS research. It should also remind NIH that it awaits the revised report on funding requested in the FY07 Appropriations Report, regarding the refined coding instructions for appropriate classification of CFS grants and insist that this be a priority for the newly established Office of Portfolio Analysis and Strategic Initiatives (OPASI).

### **Health Resources and Services Administration**

Recent scientific advances have not translated into improved clinical care for CFS patients. In fact, CFS patients frequently cite their most difficult problem is locating informed health care professionals willing to provide the range of services required to care for this multisystem condition. HRSA has supported demonstration grants to develop effective ways to deliver health care to people with other emerging illnesses and complex conditions, although not yet for CFS. The development of centers to define the optimum care of CFS patients, incorporating various medical, rehabilitation and adjunctive services would yield considerable savings through a more strategic approach to case management, offsetting the annual \$9.1 billion cost to our nation's economy resulting from lost productivity due to CFS.

**Request:** The CFIDS Association asks Congress to urge HRSA to announce a demonstration grant program to develop models for CFS clinical care with the goal of improving the diagnosis and management of individuals with CFS. Congress should request a report from HRSA on how the needs of this underserved population will be better met within 60 days of the passage of this bill.

### **Social Security Administration**

CDC researchers have reported that CFS is as disabling as chronic obstructive pulmonary disease, end-stage renal failure and multiple sclerosis, and that approximately 25% of CFS patients are vocationally disabled due to illness. Social Security Ruling 99-2p has improved CFS claims handling and tracking across the U.S., according to SSA officials, CFS patients, and disability attorneys. SSA officials have

indicated an interest in updating the ruling to reflect scientific advances, but no firm plans have been announced. In spite of this ruling that is binding at all stages of the review process, many SSA/DDS employees remain unfamiliar with or misinformed about CFS and the functional limitations it imposes. This leads to unnecessary delays in awarding benefits, as favorable decisions are often made at later stages of the adjudication process, at greater cost to SSA.

**Request:** The CFIDS Association asks Congress to encourage Social Security Administration officials to continue the education of adjudicators at all levels about the functional impact of CFS to ensure that they remain up to date on the appropriate evaluation of disability that results from this condition. Congress should ask that within 60 days of the passage of this bill, SSA deliver a report on these ongoing educational activities as well any plans to update the existing policy ruling on CFS, SSR 99-2p.

### **Department of Education**

CFS affects people of all ages, including children, adolescents and teenagers. It can be particularly difficult for young people because it affects them at a time of crucial intellectual, social and physical development. Many students with CFS experience great difficulty securing appropriate educational accommodations from their local school districts, despite federal educational laws such as the Individuals with Disabilities Education Act and the Rehabilitation Act of 1973 that mandate the free and appropriate education of students with disabilities and illnesses. The Department of Education's Office of Special Education Programs (OSEP) can aid students with CFS to access accommodations from their local educational authorities by informing educators about CFS and the special educational needs often required by students with CFS.

The CFIDS Association of America is very pleased that the Department of Education's National Institute on Disability and Rehabilitation Research (NIDRR) has included CFS in its list of unmet areas of research and has funded some CFS research. Based on recent research publications, there are highly appropriate topics of investigation in CFS that would serve NIDRR's mission, as well as persons with CFS.

**Request:** The CFIDS Association asks Congress to request that the National Institute on Disability and Rehabilitation Research continue to pursue CFS-related research proposals through its investigator-initiated and other grants programs, including sponsoring studies that will illuminate the nature of disability in CFS, particularly the predominant feature of post-exertional relapse, as well as strategies to support the improved function, rehabilitation and appropriate education of CFS patients.

**Thank you for your time and attention to these issues and requests. The magnitude of CFS – its prevalence, economic impact and disabling effects – and the unique opportunities before us warrant expanded federal investment and priority.**