

Summary of Congressional and Appropriation Language, 1992-2026

The primary authorizing legislation for Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) is the proposed [Understanding COVID-19 Subsets and ME/CFS Act \(H.R. 7057\)](#), introduced in the 116th Congress to amend the Public Health Service Act.

**Centers for Disease Control and Prevention**

**Congressional Report Language Accompanying the Labor/HHS Appropriations Bills**

HOUSE	SENATE
<b>Fiscal Year 1992</b>	
<p>The Committee commends the CDC for the progress it has made on CFS, and notes that CFS remains a serious public health concern. Of the amounts provided for chronic and environmental disease, the Committee has included \$2.8 million for activities related to CFS as follows: continuing the surveillance network system in four areas of the United States and expanding to new sites, expanding the surveillance study to include children 8 to 18, conducting exposure histories of patients, providing prompt team reaction to CFS outbreaks which may occur, expanding immunologic, virologic, and toxic studies of CFS, conducting long-term follow-up reviews of CFS patients identified in the surveillance networking program, adding at least three full-time staff for research on retroviruses, conducting a national CFS prevalence survey of CFS in health professionals, and contracting out public information outreach, conference and training services. The Committee suggests that the CDC collaborate with the NIAID to develop recommendations regarding evaluation of the functional health status for individuals with CFS, establish standardized protocols for CFS laboratory tests, and store sera and leukocyte samples from CFS patients for future testing.</p>	<p>(Not available)</p>
<b>Fiscal Year 1993</b>	
<p>Within the funds provided for chronic and environmental disease prevention, the Committee has provided \$3 million for CFS research and activities. The Committee encourages CDC to expand immunological, virological, and toxic studies of CFS. The Committee encourages CDC to expand CFS research activities, including research on the relationship of CFS to pregnancy, a study of CFS patients in remission to</p>	<p>The following amounts reflect increased funding over the fiscal year 1993 budget request: chronic fatigue syndrome, \$239.000...</p>

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<p>monitor the long-term effects of the disease, and the impact of CFS on health professionals. The Committee requests that CDC make available to interested parties preliminary and pending data related to the CFS surveillance system and data from the case-control study that began June 1992 and data related to CDC responses to cluster outbreaks of CFS. As it did in last year's report, the Committee restates its intention that the surveillance system be expanded to 8 to 18 year olds.</p>	
<p><b>Fiscal Year 1994</b></p>	
<p>The Committee has provided increases above the President's request in the areas of diabetes control, CFS, school health education, and epilepsy and expects the CDC to give high priority to these areas.</p>	<p>The Committee notes the need to direct additional resources to chronic fatigue and immune dysfunction syndrome [CFIDS], and has included an increase of \$2,000,000.</p> <p>The Committee requests that CDC complete current surveillance studies and begin community-based prevalence studies which would allow data collection on endemic cases and possible cluster outbreaks. The Committee directs CDC to commence a study on possible transmission of CFS and to provide appropriate education programs. The Committee is encouraged by the possibility of a CDC review of CFS definitions this fall, and encourages concerned participation.</p>
<p><b>Fiscal Year 1995</b></p>	
<p>The Committee has provided increased funding for activities related to chronic fatigue syndrome (CFS). The Committee intends that CDC will allocate these additional funds to community-based prevalence studies which would allow CDC to collect data on endemic cases and possible cluster outbreaks. In addition, the Committee encourages CDC to support studies on possible transmission routes for CFS and to provide educational programs as appropriate.</p>	<p><i>Chronic and environmental disease prevention</i></p> <p>... The programs in this activity include diabetes, developmental disabilities, tobacco use, comprehensive school health, birth defects, fetal alcohol syndrome, spina bifida, chronic fatigue syndrome, prostate cancer, women's health, cancer registries, dental health, skin cancer, and epilepsy.</p> <p>The Committee has provided funding to document the basic epidemiology of Chronic Fatigue and Immune Dysfunction Syndrome [CFIDS]. This funding will allow for community-based prevalence [studies], which would allow CDC to collect data on endemic cases and possible cluster outbreaks. Four studies should be commenced on possible transmission routes for CFIDS and to provide appropriate</p>

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	education programs.
<b>Fiscal Year 1996</b>	
<p><i>Chronic and environmental disease prevention</i></p> <p>The Committee encourages the completion and expansion of current chronic fatigue and immune dysfunction syndrome (CFIDS) surveillance projects at CDC. The Committee suggests that CDC commence a case-control phase of the community-based surveillance study recently completed in San Francisco. CDC is encouraged to conduct appropriate education programs and to commence studies on possible transmission routes for CFIDS, especially among health care workers, family members and maternal transmission to unborn children.</p>	<p>The Committee has provided funding to complete current chronic fatigue and immune dysfunction syndrome (CFIDS) surveillance projects at the CDC. The Committee requests that the CDC consider commencing a case-control phase of the surveillance study recently completed in San Francisco. Furthermore, CDC is strongly encouraged to conduct appropriate education programs and to begin studies on possible transmission routes for CFIDS, especially among health care workers, family members and mothers.</p>
<b>Fiscal Year 1997</b>	
<p>The Committee encourages CDC to enhance its chronic fatigue and immune dysfunction syndrome (CFIDS) surveillance projects to include outreach to populations not formerly recognized as being affected by CFIDS, namely minority populations and children and adolescents. The Committee encourages CDC to consider conducting education programs for health care providers and commencing a series of studies on rates of CFIDS among health care workers, family members of CFIDS patients and pregnant women with CFIDS.</p>	<p>The Committee remains supportive of the CDC's chronic fatigue and immune dysfunction syndrome (CFIDS) surveillance projects. The Committee encourages the CDC to include outreach to minority populations, adolescents, and children. Furthermore, the Committee encourages CDC to consider conducting education programs for health care professionals as well as initiating studies on rates of CFIDS among health care workers, family members of CFIDS patients, and pregnant women.</p> <p><b>Congressional Record</b>, September 30, 1996:</p> <p><b>Mr. Harkin.</b> Would the distinguished senator from Pennsylvania engage in a colloquy to clarify certain congressional intent regarding chronic fatigue and immune dysfunction syndrome, also known as CFIDS?</p> <p><b>Mr. Specter.</b> Yes, I would.</p> <p><b>Mr. Harkin.</b> The first matter pertains to a name change for the illness now referred to as chronic fatigue and immune dysfunction syndrome, (CFIDS), or chronic fatigue syndrome (CFS). There is a consensus in the CFIDS community that the name chronic fatigue and immune dysfunction syndrome does not adequately describe the complex nature of the illness. Is it the committee's intent to agree with language contained in the House Labor, HHS report to the appropriations bill calling upon the Secretary of Health and Human Service to convene a committee for the purpose of examining this issue and to report</p>

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back within 6 months of this bill's enactment with recommendations for a new scientific name or eponym that more appropriately describes the illness?

**Mr. Specter.** Yes, it is the intention of the committee to concur with the House report language concerning a name change.

**Mr. Harkin.** Thank you, Mr. President. The Centers for Disease Control and Prevention recently convened a panel of experts on CFIDS for the purpose of reviewing CDC's current CFIDS program and the direction for future research. The review panel, made up of experts in infectious diseases, internal medicine and epidemiology, met over the course of 2 days and issued a report containing specific recommendations to the Director of the National Center for Infectious Diseases (NCID) and other Center staff. My understanding is that those recommendations have been well received by the NCID staff. Would the committee express its support for the review panel's recommendations, which include: First, establishment of a repository for brain tissue obtained from well-characterized CFIDS patients - upon death - for use in etiology studies; second, proceeding with planned etiology studies utilizing cutting-edge technology, including representational difference analysis (RDA); and third, augmenting existing staff in the Division of Viral and Rickettsial Diseases with an FTE with the demonstrated expertise in neuroendocrinology and neuropsychology to guide case control studies of defects in the HPA axis?

**Mr. Specter.** The recent review by a panel of experts of the Centers for Disease Control's past work and future direction in CFIDS was significant step forward in the Federal response to CFIDS. The committee applauds that initiative and urges the CDC to carry out the recommendations expeditiously.

**Mr. Harkin.** Thank you, Mr. President, for your support of these important CFIDS provisions.

### House-Senate Conference Report:

*Centers for Disease Control and Prevention; Research, and Training*

The conferees are pleased with the recent initiative by CDC to convene a panel of experts on chronic fatigue and immune dysfunction syndrome (CFIDS) for the purpose of examining CDC's current CFIDS program and directions for future research. The conferees urge CDC to consider implementing the review panel's recommendations, particularly in the areas of brain tissue repositories and etiology studies.

**Fiscal Year 1998**

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<p><i>Chronic and environmental disease prevention</i> ¶ The Committee encourages CDC to enhance its chronic fatigue and immune dysfunction syndrome (CFIDS) laboratory studies and surveillance projects, including outreach to populations not previously recognized as being affected by CFIDS, namely minority populations and children and adolescents. The Committee understand that CDC has taken some initial steps to identify adolescents and children with CFIDS and encourages CDC to continue and expand these investigations. The Committee encourages the addition of a neuroendocrinologist to CDC's CFIDS research group to enable expansion of research initiatives to pursue productive findings from NIH and the private sector.</p>	<p><i>Chronic and environmental disease prevention</i> ¶ In many instances, premature death, avoidable illness, and disability are caused by personal behavior, exposure to toxic substances, and/or natural disasters. Prevention of the occurrence and progression of chronic diseases, therefore, is based on reducing or eliminating behavioral risk factors, increasing the prevalence of health promoting practices, detecting disease early to avoid complications, assessing human risks from environmental exposures, and reducing or eliminating exposures to environmental hazards. The focus of the programs in this activity includes diabetes, cardiovascular diseases... chronic fatigue syndrome...</p> <p><i>Chronic fatigue and immune dysfunction syndrome [CFIDS]</i> ¶ The Committee understands that the CDC has taken steps to identify adolescents and children with CFIDS and encourages the CDC to continue, and expand where appropriate, these investigations on populations not formerly recognized as being affected by CFIDS. The Committee has received reports that growth in CDC's CFIDS research program has stalled and promising research is not being published in a timely manner. The Committee requests that the CDC be prepared to report during the fiscal year 1999 budget hearings concerning its allocation of funds to CFIDS, specifically detailing all program and administrative expenses that are charged to these activities.</p>
<p><b>Fiscal Year 1999</b></p>	
<p>The Committee encourages the CDC to enhance its chronic fatigue syndrome (CFS) laboratory studies and surveillance projects including outreach to minorities, children and adolescents. The Committee is concerned about the delay in appointing a neuroendocrinologist to the CFS research group as recommended by the Committee in the fiscal year 1998 report.</p>	<p>The Committee is aware that enhancing laboratory studies, including serial analysis of genomic expression studies, and surveillance projects, would significantly strengthen outreach to populations not formerly recognized as being affected by CFIDS, namely minority populations and children and adolescents. The Committee is also concerned about delays at the CDC in adding a neuroendocrinologist to its CFS research group as encouraged by this Committee, and reiterates its support for this addition to enable expansion of research. The Committee remains concerned about CDC's accounting of CFIDS research funds and</p>

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	<p>expects the agency to provide a clear, accurate and timely accounting of all expenses related to its CFIDS research program for fiscal year 1996 and fiscal year 1997.</p>
<p><b>Fiscal Year 2000</b></p>	
<p>In May of 1999, the Inspector General released her audit of costs charged to the Chronic Fatigue Syndrome (CFS) Program. The Committee was outraged to learn through this audit that, of \$22.7 million charged to the CFS program during fiscal years 1995-1998, \$8.8 million was incurred for non CFS-related activities and the applicability of an additional \$4.1 million of indirect costs could not be determined. As a result of these inappropriate charges, CDC officials provided untrue information to Congress.</p> <p>The Committee regards this as a matter of the gravest concern. The Committee understands that the CDC is undertaking a series of actions to redress this situation, including, but not limited to: restoration to the CFS program of misspent funds; placement of the Division of Viral and Rickettsial Diseases on probationary status; separate apportionment of CFS funds for the Office of Management of the Budget; mandatory training of staff with budget and accounting responsibilities; establishment of an internal review capacity to regularly assess fiscal policies, procedures, practices and controls; and development and implementation of a new system for allocation of CDC-wide indirect program support costs. The Committee supports full implementation of each of these actions and expects to be kept regularly informed of the CDC's progress on these matters, including the status of contracts to develop long-overdue systems to appropriately identify and allocate indirect costs incurred within the Centers, Institutes and Offices and the nature and extent of probationary sanctions ultimately imposed upon the Division of Viral and Rickettsial Diseases. With respect to the restoration of misspent funds, the Committee directs the CDC to include not only the \$8.8 million spent on other activities, but also the \$4.1 million in indirect costs in its four-year restoration plan.</p> <p>Finally, the Committee notes the Director's commitment to reinvigorate CDC's efforts to better understand CFS and its effects on sufferers by establishing a long-term</p>	<p>Chronic fatigue syndrome □ The Committee is exceptionally concerned over the audit and report by the HHS inspector general's office that revealed the agency had not spent funds for chronic fatigue syndrome as intended by Congress. The IG report noted that the agency did not have in place adequate controls to assure compliance with the established financial plan, in particular assigned direct costs. As a result, costs of other activities were assigned to the chronic fatigue syndrome program without appropriate analysis, documentation, or justification. The IG report suggests that as much as half of the \$23,400,000 budgeted for chronic fatigue syndrome between 1995 and 1998 may have been diverted to research on other diseases. The laxity of oversight has resulted in the diversion of a significant portion of appropriated funds Congress intended for chronic fatigue syndrome.</p> <p>The Committee is disappointed that a confluence of factors has resulted in an unfortunate outcome that has strained the reputation of a leading public health agency. Since the agency's creation, the Committee has appropriated billions of dollars to combat and prevent maladies adversely affecting domestic and global health, and depends upon the goodwill and trust of the agency's professionals to attain the goal of better health for all. It is regrettable that certain actions taken has clouded that relationship between Congress and the agency.</p> <p>Because of the tangible consequences of the diversion of funds, namely less money available for CFS activities, the Committee directs the agency to begin to restore the estimated \$12,900,000 in CFS funds diverted to other activities. The additional funds should be spent on the following priority CFS activities: public education programs, efforts to educate primary care providers about the detection, diagnosis and treatment of CFS, surveillance</p>

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<p>research and program agenda with in-depth advice from the research and advocacy community. The Committee has confidence in the Director's ability to make good on this commitment and to work to build the necessary bonds of trust and cooperation between the agency and the public.</p>	<p>projects on children and adolescents with CFS, and an interdisciplinary reassessment of the case definition for CFS. Furthermore, the Committee expects the director of the agency to directly oversee the CFS program budget and the implementation of the above activities until such time as the Committee is satisfied that appropriate reforms have been made to assure that Congressional intent for the program will be followed.</p> <p>The Committee also expects that the current CFS research program will remain in the Division of Viral and Rickettsial Diseases until it is clear to the Committee that a transfer will materially and substantially enhance the accomplishment of the program's key objectives, specifically: the determination of the pathogenesis of CFS; estimation of the incidence and prevalence of CFS in the U.S.; elucidation of the natural history of CFS; identification of risk factors and diagnostic markers; the development of control strategies; and education of the public and health professionals. Prior to any major reorganization involving the CFS program, the Committee expects to receive an explanation outlining full details regarding the transfer or changes to assets and/or personnel. The Committee further urges that the department's CFS coordination committee consider making recommendations regarding future direction and structure of CFS activities at CDC and expects the agency to provide a representative to the committee.</p>
<p><b>House-Senate Conference Report:</b></p> <p><i>Disease Control, Research, and Training</i></p> <p>The conference agreement provides \$371,155,000 for chronic and environmental diseases instead of \$315,511,000 as proposed by the House and \$327,081,000 as proposed by the Senate. In addition the conference agreement provides \$5,000,000 above the request for the environmental health laboratory in the Public Health and Social Services Emergency fund. Included in this amount [is] ... \$503,261 for chronic fatigue syndrome ...</p>	
<p><b>Fiscal Year 2001</b></p>	
<p>The Committee is pleased that CDC is restoring funding to the chronic fatigue syndrome (CFS) research</p>	<p><b><i>Chronic fatigue syndrome</i></b> - The Committee is pleased that CDC intends to restore \$12,900,000 to</p>

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<p>program. The Committee will continue to monitor the CFS research program to ensure that the funds are used in priority areas in CFS research and education. CDC is encouraged to enhance its efforts in CFS to include such areas as prevalence data collection, surveillance activities, identifying risk factors, patient registry, and public education programs.</p>	<p>the CFS research program, in addition to CDC's base CFS funding in fiscal years 2000, 2001, 2002, and 2003. The Committee will continue to monitor CDC's CFS research program to ensure that the funds are used in priority areas in CFS research and education.</p> <p>The Committee strongly encourages CDC to provide the funds and the infrastructure to support its 'reinvigorated' CFS research plan, which includes the estimation of sex-, age-, race/ethnic-, and socioeconomic-specific prevalence of CFS through a national CFS survey; surveillance projects on children and adolescents and minorities with CFS; a national CFS patient registry; development and testing of an empirically derived case definition; studies of etiologic agents, diagnostic markers, natural history, and risk factors using specialized molecular epidemiology techniques and advanced surveillance methodologies; and CFS public education programs with special emphasis on general public service announcements and specialized efforts to educate primary care providers about the detection, diagnosis and treatment of CFS.</p>
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<p><b>House-Senate Conference Report:</b></p> <p><i>Chronic Disease Prevention &amp; Health Promotion</i></p> <p>Chronic fatigue syndrome: \$7,000,000</p>	
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<p><b>Fiscal Year 2002</b></p>	
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<p>The Committee encourages CDC to enhance its chronic fatigue syndrome program to include the study of cancers and linkages with immune-deficiency factors such as multiple myeloma.</p> <p>The Committee is pleased that CDC is restoring funding to the chronic fatigue syndrome (CFS) research program and that these funds are being used in substantive areas of research and education. The Committee commends CDC on its collaborations with</p>	<p>The Committee is pleased that CDC has restored funding for CFS research, and that these funds are being used in substantive areas of research and education. In particular, the Committee would like to commend CDC on its collaborations with prominent CFS clinicians, Emory University researchers, and CFS advocates. The Committee supports efforts to develop and test an empirically derived case definition and initiate a national CFS survey to estimate sex-, age-, race/ethnic-, and socioeconomic-specific prevalence of CFS. The Committee strongly</p>
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<p>prominent CFS clinicians, researchers and advocates and supports efforts to develop and test an empirically derived case definition and initiate a national CFS survey to estimate sex, age, race/ethnic and socioeconomic specific prevalence of CFS. CDC is encouraged to enhance support of its CFS research plan, which includes surveillance projects on children, adolescents and minorities, a national patient registry, studies of etiologic agents, diagnostic markers, identifying risk factors, and public education programs. The Committee recognizes CDC's support of the CFS Coordinating Committee (CFSCC) and urges CDC to continue this support as the CFSCC transitions from a Coordinating Committee to an advisory committee.</p>	<p>encourages CDC to provide the funds and the infrastructure to support other aspects of its "reinvigorated" CFS research plan, which includes surveillance projects on children, adolescents, and minorities with CFS; a national CFS patient registry; studies of etiologic agents, diagnostic markers, natural history, and risk factors using specialized molecular epidemiology techniques and advanced surveillance methodologies; and CFS public education programs with special emphasis on general public service announcements and expanded efforts to educate primary care providers about the detection, diagnosis, and treatment of CFS.</p> <p>The Committee recognizes CDC's support of the DHHS CFS Coordinating Committee (CFSCC) and expect that CDC will continue its support as the CFSCC transitions from a coordinating committee to an advisory committee.</p>
<p><b>Fiscal Year 2003</b></p>	
<p>House-Senate Conference Report:</p> <p>The conferees are pleased that the CDC is restoring funds for chronic fatigue syndrome (CFS) research and that these funds are being used in substantive areas. The conferees encourage CDC to continue the establishment of a national registry.</p>	
<p><b>Fiscal Year 2005</b></p>	
<p><i>Chronic Fatigue Syndrome.</i>--The Committee is pleased that CDC is restoring funds for CFS research and that these funds are being used in substantive areas. The Committee encourages CDC to continue the establishment of a national registry to examine such things as: studies of etiologic agents, diagnostic markers, natural history, and risk factors using specialized molecular epidemiology techniques and advanced surveillance methodologies.</p>	<p>Chronic Fatigue Syndrome.—The Committee commends the CDC for building the leading CFS program in the Nation, supporting crucial population studies, clinical and laboratory research and education. The Committee directs CDC to provide sufficient resources to maintain the high caliber of this program. The Committee is very interested in CDC efforts to document the economic impact of the illness, to identify biomarkers using genomic and proteomics technology and to address health care providers' inability to appropriately diagnose and treat CFS. Further, the Committee encourages CDC to better inform the public about this condition, its severity and magnitude and to use heightened awareness to create a registry of CFS patients to aid research in this field.</p>
<p><b>Fiscal Year 2006</b></p>	

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	<p>With near-completion of the restoration of \$12,900,000 to the Chronic Fatigue Syndrome [CFS] research program in response to a report from the Inspector General dated May 12, 1999, the Committee commends CDC for developing a comprehensive CFS program. The Committee encourages CDC to provide sufficient resources to sustain efforts to identify biomarkers for CFS, educate health care providers about the diagnosis and treatment of CFS, and better inform the public about it to aid early [text ends abruptly]</p>
<p><b>Fiscal Year 2011</b></p>	
	<p>Chronic Fatigue Syndrome.—The Committee urges the CDC to follow recommendations made by the CFS Advisory Committee and the 2008 peer review panel to prioritize laboratory efforts aimed at the identification of diagnostic subtypes and therapeutic biomarkers with increasing efforts in viral etiology. Intervention, including vaccination studies, against pathogens with known associations with CFS should be pursued in collaboration with other agencies and investigators to support genetic, genomic and intervention studies. The Committee continues to support efforts to make data accumulated since 1984 by the CFS research program available to outside researchers to maximize the value of this data.</p>
<p><b>Fiscal Year 2018</b></p>	
	<p>Chronic Fatigue Syndrome.—The Committee applauds CDC’s efforts to collaborate with disease experts in its multi-site study to resolve the case definition issues and urges CDC to complete that effort. The Committee encourages CDC to partner with other HHS agencies, disease experts, and key medical societies to implement a proactive dissemination plan that counters medical misinformation and stigma and addresses other key</p>

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	barriers to clinical care.
<b>Fiscal Year 2019</b>	
<p>Chronic Fatigue Syndrome [ME/CFS].—The Committee encourages CDC to construct a plan that focuses on how it intends to foster interagency and stakeholder collaboration to address the ME/CFS clinical care crisis and to accelerate drug development following the sunset of the Chronic Fatigue Syndrome Advisory Committee.</p>	
<b>Fiscal Year 2020</b>	
<p>Myalgic Encephalomyelitis/Chronic Fatigue Syndrome.—The Committee commends CDC for its recent progress in myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) medical education and in the Multisite Clinical Assessment of ME/CFS (MCAM) study, including the expansion of this study into pediatric research. The Committee is concerned that there is a lack of information about ME/CFS onset and requests an update in the fiscal year 2022 Congressional Justification.</p>	