

Congressional Appropriations Directives for Lyme Disease

House Report 105-205 to Accompany H.R.2264 for FY 1998

www.congress.gov/congressional-report/105th-congress/house-report/205/

CDC

Lyme disease continues to be an important emerging infectious disease and is the most common vector borne disease in the United States today. The number of cases of Lyme disease reported to CDC during 1996 was a record high. The Committee is concerned that of the 68,000 reported cases of Lyme disease from 1991 to 1996, 70 percent of those reported cases are in five States. The Committee provides an increase in funding to assist State and local agencies to enhance surveillance, response, prevention and control activities for Lyme disease, and encourages CDC to concentrate on States with the highest reported cases of Lyme disease.

Senate Report 106-166 to Accompany S. 1650 for FY 2000

www.congress.gov/congressional-report/106th-congress/senate-report/166/

Occupational Safety and Health Administration

Committee recognizes the public health threat facing many categories of outdoor workers as a result of occupational exposure to Lyme disease. The Committee encourages the Occupational Safety and Health Administration to develop appropriate mechanisms to help protect these workers from this occupational health risk.

CDC

Lyme disease.--The Committee has been made aware that there are concerns about the CDC surveillance criteria for Lyme disease and urges the agency to consider re-evaluating the current surveillance criteria to more accurately track and evaluate the prevalence of Lyme disease. The Committee has received expressions of concern over the possible mismatched use of surveillance criteria for clinical diagnostic use and urges the CDC to educate the medical and scientific community about this distinction.

Lyme disease.--The Committee urges the agency to give priority to proposals aimed at reducing the deer tick population, which is the prime vector for Lyme Disease. The Committee further recommends that CDC consider proposals that seek to reduce deer ticks through environmental and economically sound means.

NIAID

Lyme disease.--Lyme disease is a complex and debilitating disease that affects many systems of the body and requires long term treatment in some patients. The Committee is concerned about the development of sensitive, specific, and reproducible tests for the diagnosis of Lyme disease. The Committee urges the Institute to make the development of such tests a priority.

House Report 106-370 to Accompany H.R. 3037 for FY 2000

www.congress.gov/congressional-report/106th-congress/house-report/370/

CDC

The Committee is concerned by reports that cases of Lyme disease is under-reported and urges CDC to consider re-evaluating current surveillance criteria used to track cases of

the disease and continue its work to assist States to more accurately evaluate and assess the prevalence and incidence of the disease.

NIAID

Lyme Disease.--Lyme disease is the nation's leading tick-borne illness. It affects many systems of the body and can require expensive, long-term treatment in some patients unless they are diagnosed and treated early. The Committee encourages NIAID, in collaboration with other relevant Institutes, to enhance research in the area of development of sensitive, specific, and reproducible tests for the diagnosis of Lyme disease.

Senate Report 106-293 to Accompany S. 2553 for FY 2001

www.congress.gov/congressional-report/106th-congress/senate-report/293

CDC

Lyme disease.--The Committee is concerned regarding reports regarding the current Lyme disease surveillance case definition. The definition states that "this surveillance case definition was developed for national reporting of Lyme disease, however there is concern that it is not appropriate for clinical diagnosis." The definition is reportedly misused as a standard of care for healthcare reimbursement, product (test) development, medical licensing hearings, and other legal cases. The CDC is encouraged to look into this situation and correct the definition if inaccurate and issue an alert to the public and physicians to correct the definition.

The Committee recommends that the CDC strongly support the re-examination and broadening of the Lyme disease surveillance case definition by the CSTE, with public input into this process. By developing other case definition categories while leaving the current "confirmed case" category intact, the true number of Lyme cases being diagnosed and treated will be counted more accurately, leading to improved public health planning.

The CDC is encouraged to include a broad range of scientific viewpoints in the process of planning and executing its efforts. This includes the incorporation of input from community-based clinicians with extensive experience in treating these patients, voluntary agencies who have advocacy in their mission, and patient advocates in planning committees, meetings, and outreach efforts.

NHLBI (National Heart, Lung, and Blood institute)

Lyme disease.--The Committee urges the Institute to study vascular disease with a specific focus on the unique features associated with Lyme disease.

NINDS (National Institute of Neurological Disorders and Stroke)

Lyme disease.--The Committee urges the Institute to study central nervous system abnormalities associated with Lyme disease. Unfortunately, prognosis of patients with cerebral involvement is not good; even with antibiotic treatment there can be residual disability. The Committee therefore urges that diagnostic techniques including brain imaging and improved treatment protocols be designated as research priorities. The Committee is encouraged by a recent grant for brain imaging in neuroborreliosis patients. The Committee also urges the Institute to study peripheral nervous system abnormalities associated with Lyme disease.

NIAID

Lyme disease.--Rocky Mountain Laboratories (RML) is to be congratulated for their excellent work and the Committee strongly encourages NIH and other DHHS agencies to include these researchers in their activities and meetings. The Committee encourages NIAID to conduct broader outreach to the medical, scientific and voluntary organizations involved in Lyme disease research, treatment, prevention and education in order to better understand the broad range of divergent views about these illnesses as well as understand the plight of the patients affected by tick-borne disorders. This outreach should include the involvement of community-based clinicians with extensive experience in treating patients, volunteer advocacy organizations, and patient advocates in NIH advisory committees, meetings and workshops regarding tick-borne diseases.

NIH

The Committee encourages NIH to take measures to facilitate cooperation among the Lyme disease community and NIH grantee-academic physicians, community-based physicians and the patient community.

NEI (National Eye Institute)

Lyme disease.--The Committee urges the Institute to study the neuro-ophthalmologic abnormalities associated with Lyme disease.

NIH

Lyme disease.--The Committee encourages the NIH to enhance outreach to public and private scientists regarding Lyme disease in order to stimulate research interest in this field.

SSA (Social Security Administration)

The Committee understands that some patients with Lyme disease and other tick-borne disorders have encountered some difficulty when applying for assistance through SSA offices, due to SSA employees' unfamiliarity with these illnesses. SSA is encouraged to work on developing educational materials for SSA employees to facilitate a better understanding of the potential debilitating effects of these disorders. The Committee suggests that SSA collaborate with clinicians who have expertise on the multi-system chronic effects of Lyme, as well as patient and voluntary communities, to accomplish this goal.

House Report 106-645 to Accompany H.R. 4577 for FY 2001

www.congress.gov/congressional-report/106th-congress/house-report/645

CDC

There are concerns that the Lyme disease surveillance case definition, which was developed for national reporting of Lyme disease, is being used inappropriately for clinical diagnosis and as a standard of care. There are also concerns that the surveillance case definition is not accurately capturing the true number of cases being diagnosed. The Committee urges CDC to pursue efforts to address these concerns. In doing so, CDC should include a broad range of scientific viewpoints from the many groups who have expertise in CFS, including community-based clinicians, voluntary agencies, and patient advocates. The Committee understands that the General Accounting Office is studying the Lyme disease program at CDC. It is expected that any problems identified in this study will be addressed as quickly and efficiently as possible.

NIAID

Lyme Disease.--Lyme disease is the nation's leading tick-borne illness. It affects many systems of the body and can require expensive, long-term treatment in some patients unless they are diagnosed and treated early. The Committee encourages NIAID to conduct broader outreach to the medical, scientific, and voluntary organizations involved in Lyme disease research, treatment, prevention, and education in order to better understand the broad range of views about this illness and the plight of the patients affected by the disease.

NIH

Lyme Disease.--The Committee encourages NIH to improve the collaborative efforts of all Institutes involved in Lyme disease research and outreach activities and to identify appropriate NIH advisory committees for Lyme disease representation and appoint qualified persons thereon. The Committee also encourages NIH to include a broad range of scientific viewpoints in the research planning process, including those from community-based clinicians, voluntary agencies, and patient advocates.

HHS

The Committee encourages the Secretary to consider moving the Lyme Disease Coordinating Council to the Office of the Secretary and restructure the Council to include all tick-borne disorders in an effort to assure coordination and communication regarding all tick-borne diseases across all Departmental agencies and with other governmental agencies, the biomedical research community, community-based clinicians, voluntary organizations, and patient advocates.

Senate Report 107-84 to Accompany S. 1536 for FY 2002

www.congress.gov/congressional-report/107th-congress/senate-report/84

CDC

Lyme Disease.--The Committee is deeply concerned about the safety of the Lyme disease vaccine (LymeRix). Over 1,000 adverse event reports were filed with the Food and Drug Administration from December 1998 to October 2000. The Committee encourages CDC to work closely with the FDA to ensure that all adverse event reports are thoroughly and expeditiously investigated to ensure public safety as the vaccine is being distributed. Investigators should pay particular attention to patients' reports of arthritis when evaluating these reports.

The Committee recognizes that the current state of laboratory testing for Lyme disease is very poor. The situation has led many people to be misdiagnosed and delayed proper treatment. The vaccine clinical trial has documented that more than one third (36 percent) of the people with Lyme disease did not test positive on the most sophisticated tests available. The ramifications of this deficit in terms of unnecessary pain, suffering and cost is staggering.

The Committee directs CDC to work closely with the Food and Drug Administration to develop an unequivocal test for Lyme disease. The Committee is distressed in hearing of the widespread misuse of the current Lyme disease surveillance case definition. While the CDC does state that "this surveillance case definition was developed for national reporting of Lyme disease: it is NOT appropriate for clinical diagnosis," the definition is reportedly misused as a standard of care for healthcare reimbursement, product (test) development, medical licensing hearings, and other legal cases. The CDC is encouraged

to aggressively pursue and correct the misuse of this definition. This includes issuing an alert to the public and physicians, as well as actively issuing letters to places misusing this definition.

The Committee recommends that the CDC strongly support the re-examination and broadening of the Lyme disease surveillance case definition by the Council of State and Territorial Epidemiologists. Voluntary and patient groups should have input into this process. Currently there is just one definition ("confirmed case") of seven possible categories. By developing other categories while leaving the current category intact, the true number of cases being diagnosed and treated will be more accurately counted, leading to improved public health planning for finding solutions to the infection.

The CDC is encouraged to include a broad range of scientific viewpoints in the process of planning and executing their efforts. This means including community-based clinicians with extensive experience in treating these patients, voluntary agencies who have advocacy in their mission, and patient advocates in planning committees, meetings, and outreach efforts.

NIH

The Committee recommends that the NIH improve its communication across Institutes in order to better coordinate Lyme disease research and outreach to public and private scientists with the goal of stimulating research interest in this field. The NIH is encouraged to include a broad range of scientific viewpoints in the process of planning and executing these efforts, including community-based clinicians with extensive experience in treating these patients, voluntary agencies who have advocacy in their mission, and patient advocates.

SSA (Social Security Administration)

The Committee understands that some patients with Lyme disease and other tick-borne disorders have encountered some difficulty when applying for assistance through SSA offices, due to SSA employees' unfamiliarity with these illnesses. SSA is encouraged to work on developing educational materials for SSA employees to facilitate a better understanding of the potential debilitating effects of these disorders. The Committee suggests that SSA collaborate with clinicians who have expertise on the multi-system chronic effects of Lyme, as well as patient and voluntary communities, to accomplish this goal.

House Report 107-229 to Accompany H.R. 3061 for FY 2002

www.congress.gov/congressional-report/107th-congress/house-report/229

NHLBI (National Heart, Lung, and Blood institute)

Lyme Disease.--The Committee urges the Institute to study vascular disease with a specific focus on the unique features associated with Lyme disease through all available mechanisms, as appropriate.

NEI (National Eye Institute)

Lyme Disease.--The Committee encourages NEI to study the neuro-ophthalmologic abnormalities associated with Lyme disease through all available mechanisms, as appropriate.

NIH

Lyme Disease.--The Committee encourages NIH to improve its communication across Institutes to better coordinate Lyme disease research and outreach to public and private scientists about Lyme disease with the goal of stimulating research interest and encouraging investigators to bring their research interests to bear in this field. The Committee also encourages NIH to identify appropriate NIH advisory committees for Lyme disease representation and appoint qualified persons thereon and to include a broad range of scientific viewpoints in the research planning process, including those from community-based clinicians, voluntary agencies, and patient advocates. NIH is encouraged to enhance research in Lyme disease and other tick borne disorders through all available mechanisms, as appropriate, including establishment of a pathology lab.

Directives for HHS

The Committee urges the Secretary consider moving the Lyme disease coordinating council, led by National Institute for Allergy and Infectious Diseases (NIAID), to the Office of the Secretary and restructuring the council to include all tick-borne disorders. This tick-borne disorder advisory committee would assure coordination and communication regarding all tick-borne diseases across the Department and with other governmental agencies, the biomedical community, community-based clinicians, voluntary organizations and patients. The Committee would provide advice to the Secretary on matters of program oversight, performance, budget allocations, and priorities for all agencies. The Committee requests that the Secretary be prepared to report on the Department's plans concerning the establishment of a tick-borne disorder advisory committee at the fiscal year 2003 budget hearings for the Department.

Senate Report 107-216 to Accompany S. 2766 for FY 2003

www.congress.gov/congressional-report/107th-congress/senate-report/216

Tick-Borne Disease.--The Committee urges the Secretary to consult with the biomedical community, community-based clinicians, voluntary organizations, patients and appropriate governmental agency officials to ensure coordination and communication regarding tick-borne diseases. These consultations may provide knowledge and support to the Secretary on matters of program oversight, performance, and priority setting for agencies that impact tick borne diseases.

Senate Report 108-81 to Accompany S. 1356 for FY 2004

Line Item for Lyme Disease

\$7,313,000

House Report 108-636 to Accompany H.R. 5006 for FY 2005

www.congress.gov/congressional-report/108th-congress/house-report/636

CDC

Lyme Disease.--The Committee continues to be concerned about the increase in tick-borne illnesses, including Lyme disease and Southern Tick-Associated Rash Illnesses. The Committee urges the Director, in collaboration with other relevant Departmental Operating Divisions, to consider the establishment of a comprehensive, multi-agency, five-year plan that lays out a blueprint for making progress toward effective surveillance, prevention, and control of tick-borne illnesses.

Senate Report 111-66 to Accompany H.R. 3293 for FY 2010

www.congress.gov/congressional-report/111th-congress/senate-report/66

CDC

Lyme Disease.--The Committee encourages the CDC to expand its activities related to developing sensitive and more accurate diagnostic tools and tests for Lyme disease including the timely evaluation of emerging diagnostic methods and improving utilization of diagnostic testing to account for the multiple clinical manifestations of acute and chronic Lyme disease; to expand its epidemiological research activities on tick-borne diseases [TBDs] to include an objective to determine the long-term course of illness for Lyme disease; to improve surveillance and reporting of Lyme and other TBDs in order to produce more accurate data on the prevalence of the Lyme and other TBDs; to evaluate the feasibility of developing a national reporting system on Lyme including laboratory reporting; and to expand prevention of Lyme and TBDs through increased community-based public education and creating a physician education program that includes the full spectrum of scientific research on the diseases.

NIAID

Lyme Disease.--The Committee encourages the NIAID to sponsor a scientific conference on Lyme and other tick-borne diseases that would represent the broad spectrum of scientific views on Lyme disease and include input from individuals with Lyme disease. The Committee also encourages NIH to intensify research that will increase understanding of the full range of Lyme disease processes and the physiology of *Borrelia burgdorferi*, including the mechanisms of persistent infection, and research that may lead to the development of more sensitive and accurate diagnostic tests for Lyme disease capable of distinguishing between active and past infections.

AHRQ

Lyme Disease.--The Committee encourages AHRQ to create a comprehensive clearinghouse of peer-reviewed tick-borne diseases literature that will include literature on persistent infection, appropriately organized for use by the scientific community, treating physicians, and the public.

HHS

Lyme Disease.--The Committee urges the Secretary to improve interagency coordination and communication and minimize overlap regarding efforts to address tick-borne diseases. The Secretary is encouraged to advise relevant Federal agencies on priorities related to Lyme and tick-borne diseases, identify future research needs, and involve CDC, NIH, FDA, and other agencies in the development of a more accurate system of diagnosing and reporting of Lyme disease.

House Report 111-220 to Accompany H.R. 3293 for FY 2010

www.gpo.gov/fdsys/pkg/CRPT-111hrpt220/html/CRPT-111hrpt220.htm

Line Item for Lyme Disease

FY2009 Actual +3,668,000, FY2010 Request +3,668,000, Committee Recommendation 8,938,000

CDC

Lyme Disease.--The Committee encourages CDC to expand its activities related to developing sensitive and more accurate diagnostic tools and tests for Lyme disease, including the evaluation of emerging diagnostic methods and improving utilization of diagnostic testing to account for the multiple clinical manifestations of acute and chronic Lyme disease; to expand its epidemiological research activities on tick-borne diseases to include an objective to determine the long-term course of illness for Lyme disease; to improve surveillance and reporting of Lyme and other tick-borne diseases in order to produce more accurate data on their prevalence; to evaluate the feasibility of developing a national reporting system on Lyme disease, including laboratory reporting; and to expand prevention of Lyme and tick-borne diseases through increased community-based public education and creating a physician education program that includes the full spectrum of scientific research on the diseases.

NIH

Lyme Diseases.--The Committee encourages NIH to intensify research on tick-borne diseases, including research that will increase understanding of the full range of Lyme disease processes and the physiology of *Borrelia burgdorferi*, including the mechanisms of persistent infection. Recognizing NIH's collaborative role with CDC and other agencies in the development of diagnostics, the Committee encourages NIH to support research that may lead to the development of more sensitive and accurate diagnostic tests for Lyme disease capable of distinguishing between active and past infections.

The Committee encourages the Director, in collaboration with the Director of NIAID, to sponsor a scientific conference on Lyme and other tick-borne diseases. The Committee believes that the conference should represent the broad spectrum of scientific views on Lyme disease and should provide a forum for public participation and input from individuals with Lyme.

HHS

Tick-borne Diseases.--The Committee directs the Secretary to review the coordination of efforts across HHS operating divisions with respect to tick-borne diseases to ensure that: a broad spectrum of scientific viewpoints is represented in public health policy decisions, accurate information is disseminated to the public and physicians, and actions are taken by the Department that will foster significant progress in the development and adoption of improved diagnostics for Lyme disease. The Department shall submit a report to the Committees on Appropriations of the House of Representatives and the Senate with the findings from this review not later than September 30, 2010.

Senate Report 111–243 to Accompany S. 3686 for FY 2011

www.congress.gov/congressional-report/111/senate-report/243

CDC

Lyme Disease.—The Committee requests that the CDC report on its implementation of its Lyme disease plan. In particular, the report should include details on grants on diagnostic methods, longterm complications, plans to support community-based Lyme disease prevention and control programs, and the development of Lyme disease education for physicians and communities. The Committee is supportive of innovative advancements and technologies that provide opportunities for improved diagnostics beyond the technologies employed today.

Line Item for Lyme Disease

FY2010 Actual 8,938, FY2011 Request 9,055, Committee Recommendation 10,000

NIH

Lyme Disease.—The Committee is encouraged that the NIH has signaled its intent to hold a scientific conference on Lyme and other tick-borne diseases in coordination with the NIAID. The Committee believes that the conference should represent the broad spectrum of scientific views on Lyme disease as well as individuals with Lyme disease.

AHRQ

Lyme Disease.—The Committee continues to encourage AHRQ to create a comprehensive clearinghouse of peer-reviewed literature on tick-borne diseases. It should include literature on persistent infection organized for use by the scientific community, treating physicians, and the public. In the posting of treatment guidelines for Lyme disease, the Committee supports AHRQ's efforts to reflect the full spectrum of creditable science and diverse clinical viewpoints.

HHS

Lyme Disease.—The Committee encourages the Secretary to better coordinate the Department's Lyme disease activities. A Tickborne Diseases Advisory Committee could achieve this goal by advising relevant Federal agencies on priorities related to Lyme and tick-borne diseases, minimizing overlap in efforts to address such diseases, promoting communication with constituency groups, and ensuring that a broad spectrum of scientific viewpoints is represented in public health policy decisions.

House Report 114-195 to Accompany H.R. 3020 for FY 2016

www.congress.gov/congressional-report/114th-congress/house-report/195

Line Item for Lyme Disease

Committee Recommendation 10,700

CDC

Lyme Disease.--The Committee encourages CDC to consider expanding activities related to developing sensitive and more accurate diagnostic tools and tests for Lyme disease, including evaluating emerging diagnostic methods and improving the utilization of adequate diagnostic testing; expanding its epidemiological research to determine the frequency and nature of the long-term complications of Lyme disease; improving surveillance and reporting of Lyme disease to produce more accurate data on its incidence; and evaluating the development of a national reporting system.