



The History of Lyme Legislation in the United States

As of December 4, 2014

For decades patient advocates have worked with legislators on legislation to increase awareness of Lyme disease, create advisory committees, protect doctors who treat with longer courses of antibiotics, and guarantee insurance coverage. They have had mixed success.

Federal

Every year since 1998, advocates have tried to pass federal bills to create a balanced advisory committee and a federal program to address the growing epidemic. None of the bills even made it out of committee until 2014. It was passed by House of Representatives in September 2014. At this writing, it has not been passed by the Senate.

States

At the state and local level, many communities around the country have passed resolutions declaring Lyme disease awareness week or month. They are the simplest form of legislation and have no hidden downsides.

States that have passed other kinds of Lyme legislation include California, Connecticut, Delaware, Maine, Maryland, Massachusetts, New Hampshire, New Jersey, New York, Ohio, Pennsylvania, Rhode Island, Vermont and Virginia.

Other states have tried but either the bills died in committee or advocates pressured legislators to “kill” them after special interest lobbyists made changes unfavorable to patient interests.

Various states have doctor protection laws, task forces or advisory committees, or laws providing workers’ comp for certain workers who become infected on the job. Several states have conducted hearings and some legislators have hosted Lyme educational forums.

Rhode Island was the first state to pass a law providing mandatory insurance coverage for long-term antibiotic therapy for Lyme disease. Connecticut passed a similar law, although restrictions make coverage harder to get.

Non-legislative solutions

Many more bills have been proposed and have not passed. A dedicated group of New York activists worked for years to pass legislation to reform the Office of Professional Medical Conduct (OPMC), because it prosecutes so many Lyme specialists. Although their bills did not pass, in 2002 they reached an agreement with the OPMC not to prosecute doctors who treat people with chronic Lyme disease with long-term antibiotics. In 2014, New York doctor protection legislation passed both houses. However, as of this writing, the governor had not yet signed it.

Minnesota patients settled for an “agreement” with the medical board when legislators failed to pass doctor protection.

People interested in promoting legislation in their own states can benefit from the experiences—both successes and failures—of activists in other states. Badly executed legislation can cause more harm than good, and the political waters are full of hazards. Please contact LymeDisease.org for referrals before you plunge in.

Chaptered Law

Federal



2008 Public Law No: 110-381 Michelle’s Law amends the Employee Retirement Income Security Act of 1974 (ERISA), the Public Health Service Act, and the Internal Revenue Code to prohibit a group health plan from terminating coverage of a dependent child due to a medically necessary leave of absence from, or any other change in enrollment at, a postsecondary education institution that commences while such child is suffering from a serious illness or injury and that causes such child to lose student status for purposes of coverage under the plan, with certain restrictions and requirements. [Link to Michelle's Law](#)

California



1998 Education Senate Joint Resolution No. 38 requests the State Department of Health Services to begin tracking Lyme disease, to develop, in conjunction with the CDC and community-based support groups, a Lyme disease education program, and to consider the creation of an advisory committee to recommend changes to existing law. The measure also requests the Department of Industrial Relations to begin to review current California Occupational Safety and Health Administration (Cal-OSHA) standards to ensure that

those persons who work in occupations and geographical areas where exposure to the disease is likely are offered the vaccine by their employer.

[Link to CA Senate Joint Resolution No. 38](#)

1999 Advisory Committee SB 1115 added Article 2.5 (commencing with Section 104190) to Chapter 2 of Part 1 of Division 103 of the Health and Safety Code, relating to disease to create a Lyme disease advisory committee and information service. LDo (then Lyme Disease Resource Center) was given a seat at the table.

[Link to CA Senate Bill No. 1115](#)

2002 Worker's Comp AB amended Section 3212.12 of the Labor Code to include Lyme disease as a compensable disability for certain public employees, like policemen and forestry workers. The new law provides workers' compensation to certain state law enforcement and California Conservation Corps personnel, including Lyme disease that develops or manifests itself during a period while the person is in that service.

[Link to CA Assembly Bill No. 2125](#)

2004 Lab Reportable LDo (then CALDA) obtained hearings with the Senate Health Committee and worked with the Department of Health Services to pass legislation streamlining the Department's ability to track emerging infections and making Lyme disease reportable by laboratories starting in January, 2005.

2005 Doctor Protection AB 592 amended Section 2234.1 of the Business & Professions Code to extend the physician protection provision in an alternative medicine bill to physicians who treat persistent Lyme disease, provided they meet certain conditions. The Senate committee amendment specifically recognizes in statute the treatment of "persistent Lyme disease." [Link to CA Assembly Bill No. 592](#)

2008 AJR 30 memorialized the US Congress and the President of the United States to enact the federal bill "Lyme and Tick-borne Disease Prevention, Education, and Research Act of 2007." [Link to CA Assembly Joint Resolution No. 30](#)

Connecticut



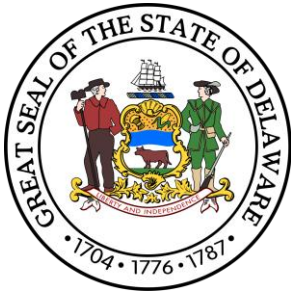
2000 Insurance Sec. 38a-492h. requires insurance companies to provide coverage for Lyme disease treatment including not less than thirty days of intravenous antibiotic therapy, sixty days of oral antibiotic therapy, or both, and shall provide further treatment if recommended by a board certified rheumatologist, infectious disease specialist or neurologist licensed in accordance with chapter 370 or who is licensed in another state or jurisdiction whose requirements for

practicing in such capacity are substantially similar to or higher than those of this state.
[Link to CT Sec. 38a-492h](#)

2009 Doctor Protection Substitute House Bill No. 6200, Public Act No. 09-128, protects licensed physicians from disciplinary action solely for prescribing, administering or dispensing long-term antibiotic therapy to a patient clinically diagnosed with Lyme disease, provided such clinical diagnosis and treatment has been documented in the patient's medical record by such licensed physician.

[Link to CT Substitute House Bill No. 6200, Public Act No. 09-128](#)

Delaware



2004 Task Force SCR 40 created a task force to examine the prevalence of Lyme disease in Delaware and to make recommendations for the prevention of Lyme disease and for educational programs to raise awareness about the long-term effects of misdiagnosis of Lyme disease. Task Force to include two members of the State Lyme Support Group; one member of the International Lyme and Associated Diseases Society, and two physicians who are knowledgeable of, and whose practice includes the treatment of, both early and late stage Lyme disease.

[Link to DE Senate Concurrent Resolution #40](#)

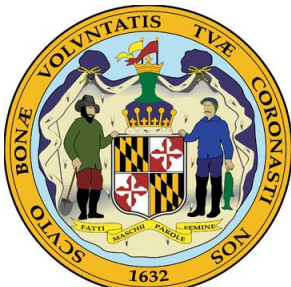
Maine



2013 Education Title 22: Chapter 266-B Requires the Maine CDC to monitor, review and evaluate Lyme disease and other tick-borne illnesses submit an annual report and maintain a publicly accessible website to provide public awareness and education. Requires health care provider to provide the patient with a copy of the results of any Lyme tests ordered.

[Link to ME Title 22, Chapter 266-B](#)

Maryland



2007 Education HB 836 required the Secretary of Health and Mental Hygiene, in collaboration with other State agencies, to establish and promote a public awareness campaign related to the prevention of Lyme disease and other tick-borne illnesses. It expired in 2009.

[Link to MD House Bill 836](#)

Massachusetts



2010 Doctor Protection HB 4683 amended existing law to permit licensed physicians to “prescribe, administer or dispense long-term antibiotic therapy for a therapeutic purpose to eliminate infection or to control a patient’s symptoms” from acute and “late stage, persistent or chronic infection with *Borrelia burgdorferi* [and] complications.” Permits “clinical diagnosis... based on knowledge obtained through medical history and physical examination only, or in conjunction with testing that provides supportive data for such clinical diagnosis.”

[Link to MA General Law Section 67, Chapter 112](#)

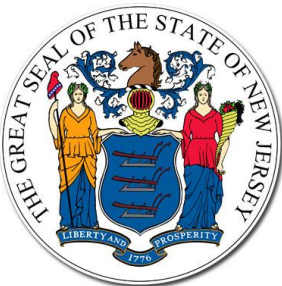
New Hampshire



2011 Doctor Protection HB 295 requires the NH Board of Medicine to post on its website the following statement: “No licensee may be subject to disciplinary action solely for prescribing, administering, or dispensing long-term antibiotic therapy for a patient clinically diagnosed with Lyme disease, if diagnosis and treatment has been documented and monitored in the physician’s medical record for that patient.”

[Link to downloadable NH HB 295](#)

New Jersey



1991 Governor's Advisory Council 26:2P-2 created a 13-member Governor's Lyme Disease Advisory Council to include “10 public members who by virtue of education or experience are knowledgeable about the problems of Lyme disease.”

[Link to NJSA 26:2P-2, PL 1991, c.277](#)

1992 Education in Schools and Teacher Training PL 18A 35-5.1 to 5.3 require the Commissioners of Education and of Health, to develop and distribute a state curriculum for teaching about

prevention of Lyme disease within the public school health curriculum. The guidelines emphasize disease prevention and sensitivity for victims of the disease. Also requires each school district to provide annual training to all teachers who instruct students with Lyme disease.

1997 Commission to Coordinate Pest Management Senate Bill No. 560 authorizes the Board of Chosen Freeholders of a county to designate any county mosquito

commission or other agency or any combination thereof to provide surveillance, education, training and recommendations on integrated pest management for the management of Lyme disease or other tick-borne disease vectors. Exempts tick-borne disease vector management activities from local government budget cap law.
[Link to NJ SB No. 560](#)

New York



2002 Doctor Protection Assembly Resolution 2155 requests "that insurance companies and the Office of Professional Medical Conduct cease and desist from targeting physicians who fall on one side or the other of this controversy, until such time as medical research and the medical community have determined the appropriate parameters for the diagnosis and treatment of tick-borne illnesses."

[Link to NY Assembly Resolution 2155](#)

Ohio



2014 Informed Consent Requires healthcare professionals and dentists to provide patients and obtain their signatures on a written notice saying:

YOUR HEALTH CARE PROVIDER HAS ORDERED A TEST FOR THE PRESENCE OF LYME DISEASE. CURRENT TESTING FOR LYME DISEASE CAN BE PROBLEMATIC AND MAY LEAD TO FALSE RESULTS. IF YOU ARE TESTED FOR LYME DISEASE AND THE RESULTS ARE POSITIVE, THIS DOES NOT NECESSARILY MEAN THAT YOU HAVE CONTRACTED LYME DISEASE. IN THE ALTERNATIVE, IF THE RESULTS ARE

NEGATIVE, THIS DOES NOT NECESSARILY MEAN THAT YOU HAVE NOT CONTRACTED LYME DISEASE.

[Link to OH Revised Code 4730.093](#)

Pennsylvania



2014 Task Force is to educate healthcare professionals and patients about the "broad spectrum of scientific and treatment options regarding all stages of Lyme disease and related tick-borne illnesses." Language includes "informed consent" and patient autonomy. Creates a task force that includes patients and two ILADS members.

[Link to PA Senate Bill 177](#)

Rhode Island



2001 Governor's Commission Executive Order -01-09 created a Governor's Commission on Lyme Disease and Other Tick-Borne Infections to hold hearings and receive testimony from medical, public health and environmental experts, along with members of the public. [Link to RI Executive Order 01-09 2001](#)

2002 Doctor Protection Public Law 159 allows physicians to "prescribe, administer, or dispense antibiotic therapy for therapeutic purpose to a person diagnosed with and having symptoms of Lyme disease if this diagnosis and treatment plan has been documented in the physician's medical record for that patient. No physician is subject to disciplinary action by the board solely for prescribing, administering or dispensing long-term antibiotic therapy for a therapeutic purpose for a patient clinically diagnosed with Lyme disease, if this diagnosis and treatment plan has been documented in the physician's medical record for that patient." [Link to RI Public Law 159](#)

2003 Insurance H 6136 SUBSTITUTE A mandated that every individual or group hospital or medical expense insurance policy or individual or group hospital or medical services plan contract delivered, issued for delivery, or renewed in this state on or after January 1, 2004, shall provide for Lyme disease treatment as provided in chapters 27-18, 27-19, 27-20, and 27-41 of the general laws. Treatment otherwise eligible for benefits pursuant to this section shall not be denied solely because such treatment may be characterized as unproven, experimental, or investigational in nature. Effective for one year. [Link to RI H 6136 Substitute A](#)

2004 Insurance Chapter 04-035 removed the sunset provision from law requiring mandatory insurance. [Link to RI Chapter 04-035](#)

2007 Commission H 5676 as amended created a special legislative commission to study all aspects of Lyme disease in the state and report its findings and recommendations to the General Assembly. This commission was never set up.

Vermont



2014 Doctor Protection Healthcare Bill H123 allows a licensed physician to prescribe, administer or dispense long-term antibiotic therapy for the purpose of eliminating or controlling a patient's Lyme disease or other tick-borne illness and recognizes the guidance for treatment by ILADS. [Link to VT Healthcare Bill H123](#)

Virginia



2013 Education H 1933 requires physicians to provide the following notice related to Lyme disease to each patient for whom a laboratory test for the presence of Lyme disease is ordered:

ACCORDING TO THE CENTERS FOR DISEASE CONTROL AND PREVENTION, AS OF 2011 LYME DISEASE IS THE 6TH FASTEST GROWING DISEASE IN THE UNITED STATES.

YOUR PHYSICIAN HAS ORDERED A LABORATORY TEST FOR THE PRESENCE OF LYME DISEASE FOR YOU. CURRENT LABORATORY TESTING FOR LYME DISEASE CAN BE PROBLEMATIC AND STANDARD LAB TESTS OFTEN RESULT IN FALSE NEGATIVE AND FALSE POSITIVE RESULTS, AND IF DONE TOO EARLY, YOU MAY NOT HAVE PRODUCED ENOUGH ANTIBODIES TO BE CONSIDERED POSITIVE BECAUSE YOUR IMMUNE RESPONSE REQUIRES TIME TO DEVELOP ANTIBODIES. IF YOU ARE TESTED FOR LYME DISEASE, AND THE RESULTS ARE NEGATIVE, THIS DOES NOT NECESSARILY MEAN YOU DO NOT HAVE LYME DISEASE. IF YOU CONTINUE TO EXPERIENCE UNEXPLAINED SYMPTOMS, YOU SHOULD BE RETESTED PERIODICALLY AND YOU SHOULD CONTACT YOUR PHYSICIAN IF YOU HAVE ANY QUESTIONS OR CONCERNS.

[Link to VA H1933](#)

Resources

Article by LDA President Pat Smith and LymeDisease.org Executive Director Lorraine Johnson, JD, MBA: in 3 parts LINK TO <http://lymedisease.org/news/lyme-times/73.html>

A complete history of political activity by patient groups is available in Marcus Cohen's book, *Lyme Disease Update: Science, Policy & Law*, published by the Lyme Disease Association.

To order go to:

LINK [<http://www.lymediseaseassociation.org/Publication.html>]

More info about legislation

LINK <http://www.lymediseaseassociation.org/index.php/govt>