

Statement On Lyme Legislation H.123
Vermont Lyme Action Committee
March 20, 2014

Summary:

Lyme is the fastest growing vector-borne disease in the U.S. and Vermont has the second highest rate of Lyme infection in the nation.

The IDSA guidelines fail to diagnose and treat the majority of Lyme disease cases.

Alternative evidence-based protocols for Lyme disease, such as those outlined by ILADS, have successfully resolved symptoms for many Lyme sufferers. There is an ethical imperative to treat patients based on existing evidence suggesting long-term treatment with antibiotics may resolve cases of persistent symptoms; research to improve diagnostic accuracy and refine treatment protocols is needed.

An unprecedented history of reprisals against practitioners who choose to use long-term antibiotics as part of evidence-based protocols has created a climate prohibitive of doctors practicing to the best of their ability. Because of this, Lyme Disease in Vermont is critically under-diagnosed and under-treated. Legislation is needed to acknowledge limitations of the IDSA standards and protect a doctors right to employ protocols beyond what is recommended by the IDSA, and to ensure Vermont patients have access to medical options that may help them recover functional lives.

Statement:

Lyme disease in the United States has become the fastest growing vector borne infectious disease and is now estimated to be four times more common than AIDS. The CDC in Oct, 2013 adjusted its estimate of 33,000 new cases to 300,000 new cases per year nationally. Vermont has the second highest rate of Lyme disease in the nation. Despite this epidemic, many Vermonter's are having great difficulty obtaining an accurate diagnosis and access to adequate treatment for both acute and chronic Lyme and other tick borne co-infections and they are traveling long distances to out of state Lyme Specialists. Lyme disease left undiagnosed and promptly and effectively treated, frequently becomes a chronic and debilitating disease. The costs of untreated Lyme disease not only impacts an individual's quality of life and causes undue financial burden from out of pocket medical expense, but impacts families, communities and government from lost wages, loss of productivity, decreased tax revenue and an increasing population dependent on social services and disability payments.

The Infectious Disease Society of America (IDSA) guidelines are not commensurate with available scientific research on the disease and do not adequately address the needs of the Lyme patients in Vermont. IDSA guidelines stipulate a maximum of 30 days of antibiotics as sufficient to treat Lyme Disease. The research supporting these guidelines assumes accurate diagnosis and treatment shortly after exposure to the disease. Treatment is only recommended with a positive Elisa and Western Blot test. Only 50% of those infected with *Borrelia* develop the bulls eye rash, and patients presenting only generic flu-like symptoms common to the early stages of Lyme may not be identified for testing. Other infections, including Tick Borne co-infections, may further obscure the etiology of the disease and this limits the number of infected patients tested (with Elisa). For those who are tested, the Two Tier testing results in an estimated 50% false negatives. Based on IDSA guidelines, Vermont doctors do not diagnose the majority of Lyme disease cases. Left untreated or under treated, infection may persist and result in aggravated systemic illness, often complicated by co-infection, and including physical and cognitive debilitation that often does not resolve after the recommended IDSA short-term course of antibiotics.

In the absence of accurate diagnostic and treatment methods for Lyme disease under the guidelines of the IDSA, Vermont has a moral and strategic obligation to permit Doctors to diagnose and treat patients outside of IDSA

guidelines. International Lyme and Associated Diseases Society (ILADS) guidelines outline evidence-based protocols for clinical diagnosis and treatment of the disease, with a significant success rate for resolving persistent clinical symptoms with long-term treatment with antibiotics. With careful oversight by trained practitioners, risks from long-term antibiotics are mitigated. Diseases such as Tuberculosis, Rheumatic fever, and Acne are treated with long-term antibiotics. 80% of antibiotic use in the US is in the livestock industry. Lyme disease is a debilitating and potentially life-threatening disease, yet in spite of these accepted applications of long-term courses of antibiotics for not only life-saving purposes, but aesthetic and economic purposes, the use of long-term antibiotics in the treatment of Lyme disease is subject of undue controversy.

Because the IDSA guidelines are presented as the single standard, the possibility of medical board disciplinary action, employer and peer reprisal, and excessive insurance audits discourage doctors from diagnosing Lyme disease based on clinical presentation and treating with courses of antibiotics beyond IDSA recommendations. Whether or not medical board action is an actual concern in VT, the history of medical board investigations and sanctions against Lyme specialists in other states is prohibitive for Vermont doctors. The Lyme epidemic will continue to impact the well being and livelihoods of increasing numbers of Vermont citizens unless action is taken to inform Doctors of additional evidence-based options for diagnosis and treatment.

Connecticut, Rhode Island, New Hampshire, Massachusetts, California, Virginia, and Maine have passed legislation acknowledging the validity of non-IDSA options for clinical diagnosis and treatment with long courses of antibiotics. Such legislation does not provide immunity from malpractice, nor does it dictate medical protocol as it serves to protect doctors who exercise their own professional discretion. We Vermonters are asking for doctors and patients to be informed of alternatives to IDSA standards. Legislation should encourage doctors to chose the best options for their practice and patients, and protect them from legal reprisals for following evidence-based protocols not outlined by the IDSA, such as those outlined by ILADS or those that may emerge from other reputable research institutions. Because the disease is so difficult to diagnose and because no single standard of treatment is universally successful, it is unethical to limit patients to a single protocol verified by a limited canon of medical studies. There is a moral imperative to allow doctors to do what they can to help patients recover functional lives. Because of the singular history of persecution of Doctors treating Lyme and the rapidly growing number of infected patients, the need for political action is urgent. We hope that this legislation will help doctors feel more comfortable in treating this terrible disease. We thank you for your thoughtful consideration of this legislation.

**Vermont Lyme Action Committee Requested Amendments to H123
for Senate Committee on Health and Welfare
March 19th, 2014**

The Vermont Lyme Action Committee respectfully submits requests for amendments to the H123 bill. We appreciate the thorough consideration and efforts of the House Committee on Health Care regarding H123. We would like to thank the Senate Committee on Health and Welfare in advance for their consideration of our request for amendments.

1) Include in the Policy Statement: 'Physicians shall inform patients that current laboratory testing for Lyme diseases and co-infections are unreliable and a negative test does not indicate an absence of Lyme and co-infection. Physicians need to also inform patients of the different treatment guideline options: CDC, IDSA, ILADS for patients to make an informed decision. Virginia law for reference: <http://lis.virginia.gov/cgi-bin/legp604.exe?131+ful+HB1933EH1> Include in 'Findings' that current laboratory testing for Lyme and co-infection diseases are unreliable and a negative test does not indicate an absence of Lyme and co-infections, thus the need for a clinical diagnosis, based on patient history and symptoms.

2) The Vermont medical boards issuing this Policy Statement cannot change the intention of the legislator's said policy statement without the approval of the full legislature and that there be no written expiration of H123 bill and it's Sec 3 Policy Statement and to issue a statement that there is no implied sunset provision.

3) H123 Policy Statement to be included on Department of Health website under current policies- Board of Medical Practice: Statutes, Laws and Rules (http://healthvermont.gov/hc/med_board/rules_cases.aspx) and Lyme disease section. Creation of a link to International Lyme and Associated Diseases Society on the Vermont Department of Health Website under treatment of Lyme and tick borne diseases.

4) Change language: In Sec 1, #3, line 13, strike out "a short course"; include in line 15, "diagnosed early and treated effectively." Sec 1, #3, line 16, strike out "as acknowledged by the Centers for Disease Control and Prevention." but only if reference to International Lyme and Associated Diseases Society remains.