



State of New Hampshire

GENERAL COURT

CONCORD

MEMORANDUM

DATE: November 1, 2021

TO: Honorable Chris Sununu, Governor
Honorable Sherman Packard, Speaker of the House
Honorable Chuck Morse, President of the Senate
Honorable Paul C. Smith, House Clerk
Honorable Tammy L. Wright, Senate Clerk
Michael York, State Librarian

FROM: Representative Leah Cushman, Chairman

SUBJECT: Commission to Study Testing for Lyme and Other Tick-Borne Diseases

Pursuant to RSA 141-C:6-a (HB 490, Chapter 9, Laws of 2020), enclosed please find the Final Report of the commission to study the role of clinical diagnosis and the limitations of serological diagnostic tests in determining the presence or absence of Lyme and other tick-borne diseases and available treatment protocols, and appropriate methods for educating physicians and the public about the inconclusive nature of prevailing test methods and available treatment alternatives.

If you have any questions or comments regarding this report, please do not hesitate to contact me.

I would like to thank those members of the commission who were instrumental in this study. I would also like to acknowledge all those who testified before the commission and assisted the commission in our study.

Enclosures

cc: Members of the Commission

FINAL REPORT

RSA141-C:6-a (HB 490, Chapter 9, Laws of 2020)

November 1, 2021

Establishing a commission to study the use and limitations of serological diagnostic tests to determine the presence or absence of Lyme and other tick-borne diseases and the development of appropriate methods to educate physicians and the public with respect to the inconclusive nature of prevailing test methods.

Charge of the commission stated in the legislation

- Consider expert studies and testimony on the role of clinical diagnosis, the limitations of serological diagnostic tests, and the complexities presented by co-infections relating to symptomology, diagnosis, and treatment in determining the presence or absence of Lyme and other tick-borne diseases, including at a minimum testing methods recommended respectively by IDSA, ILADS, the Center for Disease Control and Prevention (CDC), and the Tick-Borne Disease Working Group (TBDWG) established under the 21st Century Cures Act of 2016.
- Consider and make recommendations relative to appropriate methods to educate the medical profession and the public on the inconclusive nature of currently prevailing methods of diagnosing Lyme and other tick-borne diseases.
- Consider the newly proposed recommendations on tick-borne illness by the Centers for Disease Control and Prevention
- Recommend legislation that the commission deems appropriate to address the rising incidence of chronic Lyme and other tick-borne diseases in New Hampshire.

Purpose of the study as stated in the legislation:

- The general court hereby finds that the lack of understanding and agreement on the causes of, and the effectiveness of alternative prevailing tests for, Lyme and other tick-borne diseases, and on the alternatives currently used to treat patients with chronic symptoms after diagnosis of tick-borne diseases, has left patients in a divided world of controversy without adequate access to affordable care. At the same time, the American Medical Association requires that physicians disclose and discuss with patients the risks and benefits of both a proposed treatment and the risks and benefits of available alternative treatments.
- The general court finds that it is in the public interest for the state to encourage development and dissemination of more comprehensive clinician and patient education that highlights diverse symptomology, the expanding geography of infecting ticks, the limitations of current testing procedures and treatment protocols, and the importance of providing patients with accurate information about these testing and treatment limitations and available alternatives. The development of such comprehensive clinician and patient education programs requires the participation of diverse stakeholder groups, including clinicians, research scientists, and patients who represent the spectrum of scientific and medical expertise and perspectives on tick-borne disease.

Findings and Recommendations:

1. Diagnosis of Lyme disease requires clinical judgement taking into account a person's presenting signs and symptoms, risk factors for exposure to ticks that transmit Lyme disease, evaluation for other potential causes for a person's presenting symptoms (including other tick-borne diseases), and diagnostic laboratory testing.

2. While a classical erythema migrans (bull's eye) rash is considered diagnostic for Lyme disease, some patients may never develop a rash, and the Lyme disease rash may not be in the classic bull's eye appearance.

3. Diagnostic testing for Lyme disease relies primarily on detection of antibodies that develop after a person is infected with the bacterium that causes Lyme disease (*Borrelia burgdorferi*).

4. These antibodies take several weeks to develop to the level where they are able to be detected by laboratory tests.

5. Thus testing in the acute setting at presentation with a rash and clinical presentation consistent with early Lyme disease is not necessary.

6. As few as 20-30% of people will have detectable *B. burgdorferi* antibodies shortly after infection using the Standard Two-Tiered Test Methodology which can result in a false negative test. Therefore, diagnosis of Lyme disease within the first few weeks of infection should not rely on a positive laboratory test but rather a clinical diagnosis.

7. At later stages of Lyme disease persons still may not test positive for *B. burgdorferi*, but there was disagreement among Commission members about the accuracy of diagnostic Lyme disease testing after 4-6 weeks of infection.

8. The Commission also recommends increased education and awareness of the risk of other tick-borne diseases present in New Hampshire that should be considered by clinicians evaluating patients with compatible signs and symptoms. These include infections such as Babesia, Anaplasma and Powassan virus.

9. The Commission's website

(<http://www.gencourt.state.nh.us/statstudcomm/details.aspx?id=1515&rbl=1&studyAct=1&statAct=1>) features additional references and presentations on this subject matter, which informed our discussions and creation of this report.

10. The Commission encourages clinicians treating patients presenting with symptoms of or concerns about Lyme disease to listen to them and treat them with respect and dignity.