

## **A 2017 REVIEW OF THE REPORTS “LYME AND OTHER TICK-BORNE DISEASES IN VERMONT: REPORT FOR THE LEGISLATURE”**

### **Executive Summary**

#### **Introduction**

The reports “Lyme and Other Tick-Borne Diseases in Vermont: Report for the Legislature” were submitted to the House Committee on Health Care, and the Senate Committee on Health and Welfare, in December, 2014 and January, 2016. Act 134 (2014) Section 4, required these reports to be submitted for two years. There is no report required for 2017.

The most recent CDC surveillance data lists Vermont as #1 in the U.S. for incidence of confirmed Lyme disease, and Vermont has been designated by the CDC as an “Endemic State”. Both legislative reports note the incidence of Lyme and tick-borne diseases continue to increase, yet the public has not been informed of any plan in place to address the increasing need for effective diagnosis and treatment of Lyme and tick-borne diseases in Vermont. Resources for Vermonters affected by Lyme and tick-borne diseases listed in the legislative reports, and in the VDH Fiscal Year 2017 Budget Presentation, are inoperable, inaccessible, or do not accurately represent surveillance data in Vermont.

#### **Background**

The Vermont Department of Health does not collect data about Lyme disease treatment outcomes in Vermont. While we do have data on incidence of Lyme and other tick-borne diseases, we do not know if Vermonters received effective treatment in our state, if they had timely diagnoses, or how many Vermonters continue to have ongoing complications related to Lyme disease after treatment. According to the CDC, outcomes are better if Lyme disease is diagnosed early and effectively treated, so these are issues that can impact the long-term health of Vermont’s residents. This is especially true of children in Vermont, who are at highest risk for Lyme disease.

#### **Recommendation**

Vermont’s representatives should request an updated report from the Vermont Department of Health regarding Lyme and Tick-borne diseases that addresses the problems of broken or inaccessible resources listed in prior reports, and presents a formal plan concerning the prevention, diagnosis and treatment of Lyme and tick-borne diseases in Vermont. It should be ensured that the VDH is provided with the funding, resources and personnel necessary to educate Vermonters about the prevention of Lyme and tick-borne diseases, and educate health care providers to ensure equitable and effective diagnosis and treatment for all Vermonters.

#### **Conclusion**

These concerns are submitted respectfully. There are many dedicated professionals working at the Vermont Department of Health. Bradley Tompkins, MS, MPH, has made a concerted effort to make himself available to Vermonters affected by Lyme and tick-borne diseases. Other representatives at the Vermont Department of Health have been less available, or have not

responded to requests for information. The VDH report notes funding dedicated to addressing Lyme disease in Vermont is limited. These and other factors, including the rapid rise of incidence in our state, create a valid concern that Lyme and tick-borne diseases in Vermont are not being adequately addressed.

Respectfully submitted on March 16, 2017

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Please read detailed information specific to these concerns, listed on the following pages.

### Summary of Concerns:

- The VDH listed an online resource for health professionals in the legislative report. The website for this resource is offline, and this information has not been accessible since March, 2016.
- The VDH 'Tick Tracker' website is currently inoperable
- Multiple resources referred to in the report are currently inaccessible.
- Six of ten student-created educational videos listed in the legislative reports are currently deleted from the site listed in the report. One of four the remaining videos represents a person concerned about ticks as a mental health patient.
- Despite the Vermont Department of Health's efforts toward educating the public, contradicting statements and misinformation permeates Vermont media reports about Lyme disease. *(See appendix A)*
- A curriculum for elementary school students mentioned in the report is not currently posted on the VDH website, or available through searches online.
- Some resources listed in the report could be confusing to Vermonters and their health providers, as they contain information and statistics not representative of the data seen locally in Vermont, or they present disputable information as irrefutable.
- The VDH website and Google search results have no listings for upcoming presentations about Lyme disease by the Vermont Department of Health.
- The 'Lyme Disease Reporting Form' for providers mentioned in the legislative report is not available on the VDH website or easily accessible by a Google search.
- When doing a Google search on topics in the legislative report such as "Vermont Department of Health Lyme Disease Education", "Vermont Department of Health Lyme Disease Presentation" or "Lyme Disease Reporting Form" *top search results are online copies of the legislative reports.*

Sections titled 'Education and Outreach', and 'Health Care Providers' from the report "Lyme and Other Tick-Borne Diseases in Vermont: Report for the Legislature" submitted to the House Committee on Health Care and the Senate Committee on Health and Welfare in and January, 2016.

Comments are in bold, underneath original text.

### Education and Outreach

Education and Outreach are essential for combatting the spread of Lyme disease. The following outlines the Vermont Department of Health's initiatives and efforts to inform the general public and health care providers about the prevention and detection of Lyme Disease:

#### General Public

1. Public outreach and education remain a key part of VDH's strategy to combat Lyme disease. The VDH website has up-to-date information about Lyme disease, other tickborne diseases, tick ecology and tick bite prevention. Because VDH has limited funds for education and outreach, the website is a cost-effective method for making information available.
  - **The new Vermont Department of Health website contains few resources for Vermonters diagnosed with Lyme and tick-borne diseases, or for those who are experiencing long-term health problems related to Lyme disease.**
  - **It is unclear if the VDH has a current plan for public outreach and education regarding Lyme and tick-borne diseases in Vermont. Such a plan has not been made available through web searches or direct communication with the VDH.**

2. In September 2013, VDH launched the Vermont Tick Tracker website at <http://healthvermont.gov/ticktracker/index.aspx>. This website displays a map of Vermont for people to indicate where and when they find ticks so that others can learn where ticks have been found in Vermont. Most importantly, it provides links back to the VDH website so that people can get more information about ticks and tickborne diseases. In 2014, 249 reports were made to the site. The Tick Tracker website is currently active but the totals for 2015 are not yet available. The Centers for Disease Control and Prevention highly regards and recommends the use of the Tick Tracker for epidemiological purposes.

- **The VDH Tick Tracker website is currently broken. The data map is unavailable for all four years of data. A web professional consulted says this is because the script that operates the data map cannot be loaded onto the site.**

3. In the spring of 2015, VDH sponsored the third annual Lyme disease prevention video contest for high school students. Ten excellent entries were received (<https://www.youtube.com/playlist?list=PLk9-Nj2hBiYrc36wjHyyF-Sb5WDDHqOyT>) and small awards were given out for first, second and third places. The video contest will be repeated in 2016.

**As of March 13, 2017:**

- **Six of ten videos on the youtube site listed in the legislative reports are deleted.**
- **Two of the four remaining videos represented young people who were afraid to go outside because of ticks – one was *represented as a mental health patient*, told by his therapist “tick are easily avoidable” and was ‘cured’ after being given prevention information and a pamphlet.**
- **The site was last updated on July 10, 2015 and has a total of 1,976 views.**

4. A Lyme disease curriculum for elementary school students is posted on the VDH website. The Department is not aware of how broadly this curriculum is accessed and used.

- **A search for “Lyme Disease” under the ‘Resources for Educators’ section on the Vermont Department of Health Website found zero results for a Lyme disease curriculum.**
- **A Google search for “Vermont Department of Health Lyme disease elementary school curriculum” turned up zero results for the curriculum.**

5. VDH staff gave multiple media interviews about Lyme disease and tickborne diseases to television, radio and print journalists throughout the year.

- **Despite these efforts information about Lyme disease in Vermont media is disparate and, at times, false or misleading. (See Appendix A)**

6. VDH continues to look for organizations in Vermont to partner with to educate the public. For the fourth year in row, VDH partnered with Green Up Vermont to educate volunteers and promote tick bite prevention on Green Up Day. VDH will work with Green Up Vermont again in 2016. VDH also provided educational materials to the Vermont Youth Conservation Corps, Green Mountain Club, UVM Master Gardener Program and the Four Winds Nature Institute for dissemination among their members and volunteers. Since 2013, VDH has placed an advertisement and information about Lyme disease in the Vermont Hunting, Fishing and Trapping Laws and Guide

([http://www.vtfishandwildlife.com/UserFiles/Servers/Server\\_73079/File/Hunt/hunting%20guides/2015\\_VERMONT\\_DEER\\_SEASON\\_GUIDE.pdf](http://www.vtfishandwildlife.com/UserFiles/Servers/Server_73079/File/Hunt/hunting%20guides/2015_VERMONT_DEER_SEASON_GUIDE.pdf)) to remind people to take precautions to prevent tick bites when they engage in these recreational activities. The ad will be repeated in the 2016 edition. 8. In August and September, VDH launched a small advertising campaign. VDH paid for underwriting messages about ticks and Lyme disease on Vermont Public Radio. At the same time, ads were placed on Google and Facebook. These efforts increased pageviews to VDH’s Lyme disease web page by over 500% compared to the same time period in 2014. This was a very successful effort, but funds to repeat the campaign are not currently available.

9. In 2015, VDH staff gave 8 presentations about Lyme disease to the general public at venues around the state. Over 400 people attended these events. Presentations are given upon request. In addition, District Office staff provided information about Lyme disease at many health fairs, conferences and meetings around the state.

**While it is excellent that the Vermont Department of Health is giving presentations, information about these presentations is not widely available:**

- In a 3/13/17 google search “Vermont Department of Health Lyme Disease Presentation” the top two results were these reports to the Vermont legislature, and the third result was a 2010 document titled “Update on Lyme Disease in Vermont”.
- There were no listings for upcoming or past presentations about Lyme disease by the Vermont Department of Health.
- It is not clear if any presentations are planned for 2017.

10. VDH maintains an inventory of our “Be Tick Smart” informational booklet and our Tick Identification cards. Over 50,000 booklets and Tick ID cards have been given out since 2010. These materials can be ordered on our website. Printed materials are distributed by District Office staff at health fairs and conferences as well as at a variety of locations in their jurisdictions, including primary care practices, schools and libraries. Materials are also mailed directly to interested parties when requested.

**These booklets include information that does not represent Lyme disease as it is seen in Vermont:**

- The “Be Tick Smart” booklet quotes the CDC, “in most cases, an infected tick must be attached for at least 36 hours in order to transmit Lyme disease.” Ralph Budd, a research professor and doctor who runs the Vermont Center for Immunology and Infectious diseases at the University of Vermont Medical Center, is quoted in The Burlington Free Press on 3/13/17 stating “Ticks take nearly a day to transmit the disease after they latch on.” CDC epidemiologist Kiersten Kugeler was quoted on NPR on 3/6/17 stating “it takes about 24 hours for the tick to infect a person after it starts biting.”
- The EM rash is listed as occurring “in up to 80% of people” though in some years, Vermont Department of Health’s surveillance data showed less than half of children in Vermont with *confirmed* Lyme disease did not present an EM rash, and approximately one in three adults did not have an EM rash.
- The booklet says “Appropriate treatment of Lyme disease with antibiotics almost always results in a full cure.” The CDC estimates 5% of Lyme disease patients treated

in accordance with IDSA guidelines have ongoing symptoms for up to one year and other studies show that incidence to be as high as 20%.

- The “Be Tick Smart” booklet lists no symptoms for Anaplasmosis, Babesiosis or Powassan Virus

#### Health Care Providers:

1. VDH hosted a Continuing Medical Education session on tickborne diseases for health care providers in November at the department’s Immunization and Infectious Disease Conference in Stowe. VDH arranged for an Infectious Disease Specialist from the University of Vermont Medical Center (UVMCC) to deliver the presentation, which is available on the conference website ([http://www.vermontidconference.com/uploads/3/6/0/5/3605970/grace\\_11\\_12\\_15\\_vdh.pdf](http://www.vermontidconference.com/uploads/3/6/0/5/3605970/grace_11_12_15_vdh.pdf)).
  - **The Vermont Department of Health was informed on 4/25/16 that the link above was broken, and the information was not accessible online. They made no changes. This entire website has been offline since March, 2016.**
  - **A request for a copy of the presentation was made to the Vermont Department of Health on 4/29/16 and the VDH representative responded “I don’t have a copy of this presentation.” As a follow-up, the VDH was asked twice if there was another place a health provider could access the presentation. The VDH representative did not respond to either request.**
  - **A VDH representative stated on 3/14/17 that there is no current plan to add a health-care provider section to the Vermont Department of Health section on Lyme and Tickborne diseases.**
2. The Department is planning to sponsor another provider training in the Spring of 2016. This will be the fifth stand-alone Lyme Disease training the department has conducted during the past four years. The proper testing, diagnosis and treatment of Lyme disease was discussed at all of these sessions. The benefits of early treatment and the possible need to retest people if acute tests are negative were also discussed.
  - **An April, 2016 Google search for “Vermont Department of Health Lyme disease training 2016” showed zero results for these training session, or links to VDH training information.**
  - **In April, 2016, the training was not listed on the VDH website section “For Health Professionals.”**

- There is no information or resources from past trainings available on the VDH website.
- In response to a 3/14/17 email asking if any upcoming provider trainings were scheduled in 2017, a VDH representative responded, “If you are referring to the Lyme presentation we are invited to give to providers once a year, that is done by AHEC, not VDH.”

3. VDH maintains a webpage for healthcare providers:

<http://healthvermont.gov/prevent/lyme/provider.aspx>. The webpage includes links to the most current treatment guidelines for tickborne diseases and to the CDC healthcare provider resource page.

- This link no longer exists on the new Vermont Department of Health website. It now links to the general VDH site for Lyme and tick-borne disease.
- A VDH representative stated on 3/14/17 there are no current plans to include a web page designated for health care providers about Lyme disease.
- A search for “Lyme disease” under the ‘For Health Professionals’ subsection turned up zero results until page 8. This single search result linked back to the main VDH page for tick-borne diseases.

4. VDH printed copies of CDC’s quick reference manual for healthcare providers on tickborne diseases. This 30-page manual was provided at the most recent educational sessions.

Similar to the “Be Tick Smart” booklet, this pamphlet includes statements that may be confusing or not applicable to the evidence in Vermont’s surveillance data:

- “The erythema migrans (EM) rash occurs in 70–80% of patients” (*In Vermont the numbers have been lower.*)
- “During the localized (early) stage of illness, Lyme disease may be diagnosed clinically in patients who present with an EM rash.” (*Implying a rash is necessary for clinical diagnosis.*)
- Information about treatment guidelines is limited to the IDSA guidelines, and omit alternate NGC approved guidelines used effectively by some practitioners in Vermont.

5. All healthcare professionals are invited to attend the educational sessions that VDH participates in. It is not clear what role mental health professionals, clinical social workers and clinical mental health counselors would play in the diagnosis of Lyme disease. Therefore, these groups have not yet been targeted.



- **Research has documented people with neurological Lyme disease experience panic attacks, emotional lability, rage, OCD, learning disabilities and other mood and psychiatric symptoms. Lyme disease has also been shown to mimic Alzheimer's and Dementia. Vermonters would benefit from Mental Health and medical professionals being trained to recognize the cognitive and psychiatric signs and symptoms of Lyme disease.**
- **The Vermont Department of Health was notified about the existence of psychiatric and cognitive symptoms of Lyme disease in April 2016, and asked about training for Mental Health professionals in Vermont, but the VDH representatives did not respond.**

6. VDH staff keeps up to date on recommendations regarding best practices for diagnosis and treatment of Lyme and other tickborne diseases. Staff participates in webinars and Vermont Department of Health educational sessions at conferences whenever they are available. Staff is included on public health listservs where ticks and tickborne diseases are sometimes discussed. The VDH website is updated when recommendations are changed.

- **There is no record of the VDH regularly updating their past website with new recommendations.**

7. VDH staff members routinely consult with public health officials in other northeastern states to discuss best practices. VDH continues to encourage providers to report diagnoses of Lyme disease and other tickborne diseases. In 2013, a record number of reports were received, so the surveillance system is working. However, education and outreach about surveillance will continue. An on-line form for reporting is now available. It is hoped that this will encourage more providers to report as well as improve the quality of the information provided.

- **A Google search on 3/14/17 of "Lyme Disease Vermont online reporting form" turned up one relevant result - a 2010 form on 'www.pdfFiller.com'.**
- **Above that search result were links to these Legislative Reports**
- **A 3/14/17 Google search "Vermont Department of Health online Lyme disease reporting form" showed zero links to the form.**
- **A search on the Vermont Department of Health website for "Lyme Disease Reporting Form" showed zero results for the form.**

8. In 2015, VDH took the initiative to bring the CDC Lyme Corps program to Vermont. Lyme Corps is a new initiative designed to train medical, nursing and public health students to become educators about Lyme and other tickborne diseases. These trained educators not only teach the public about these diseases, but they also educate members of their own health care community, thereby helping to inform the next generation of health professionals about these diseases.

9. Seven Vermont students were trained in the spring of 2015 by VDH and CDC staff. Following that, students began reaching out to the public and health community. By October these students

had given 17 presentations, written 15 newsletters, blogs or other articles and engaged in 20 different discussions in online health-related forums. They also posted tick prevention signs around Vermont, distributed educational materials at farmer's markets and libraries and conducted a research project on tick mortality and the effectiveness of running tick-infested clothes through a hot clothes dryer. VDH would like to continue the Lyme Corps program in Vermont, though funding for the program in 2016 is not currently available.

- **Lyme Corps represents a limited view on the diagnosis and treatment of Lyme disease. The program is considered by many to be controversial for its rejection of other peer-reviewed, science based approaches to the diagnosis and treatment of Lyme disease.**

#### Conclusion

Lyme disease will continue to be prevalent in Vermont for the foreseeable future. Other tickborne diseases, such as anaplasmosis, may continue to emerge. VDH will continue to conduct surveillance for these diseases using standardized national case definitions. VDH will continue to provide Vermonters the most up-to-date science-based information available on tickborne diseases.

- **The majority of online resources listed in the 2016 report to the legislature are broken or inaccessible.**
- **Other resources listed in the report may not be up-to-date, or representative of the Vermont Department of Health's surveillance data of the presentation of Lyme disease in Vermont.**
- **It is unclear what the VDH will do to address these problems, and how they plan to promote effective prevention, diagnosis, and treatment of Lyme and tick-borne diseases in Vermont.**
- **With the incidence of Lyme and tick-borne diseases steadily growing, it is important that the Vermont Department of Health is accountable for a working plan to address Lyme and tick-borne diseases in Vermont.**

## Appendix A

### Misinformation about Lyme disease in Vermont media reports 2014-2016

Also available at:

<http://vermontlyme.com/wp-content/uploads/2017/02/misinformation-clarification-chart.pdf>

Misinformation about Lyme disease in Vermont is widespread. An informal analysis of Vermont newspaper, newsletters, and media reports about Lyme disease from 2014-2016 revealed contradicting and inaccurate statements about Lyme disease symptoms, diagnosis, and treatment. Information about other tick-borne infections present in Vermont was also limited or absent. Some examples are listed below:



	VT Media About Lyme Disease	Lyme Disease Summary
<b>'Bullseye' Rash</b>	<ul style="list-style-type: none"> <li>▶ "Only one in three people ever get the tell-tale 'bull's-eye' rash that's associated with an infected tick bite." - VT Sports</li> <li>▶ "It occurs in up to 80% of people." - VT Fish and Wildlife</li> <li>▶ "In Vermont only three of four cases have a rash." - WPTZ</li> <li>▶ "The trademark bullseye rash ... almost always appears that when a person has been bitten by a tick infected with Lyme..." - WCAX</li> <li>▶ "You should find it 70 to 80% of the time." - KIDS VT</li> </ul>	<p>The Vermont Department of Health 2014 Lyme disease surveillance report showed less than half of the children in Vermont with Lyme disease had an EM rash (49.5%). The same report showed an EM rash was present in 66.9% of confirmed adult cases of Lyme disease.</p>
<b>Tick Attachment:</b>	<ul style="list-style-type: none"> <li>▶ "Transmission can be prevented if the tick is removed within about 36 hours." - Newport Dispatch</li> <li>▶ "It takes the deer tick anywhere from 36 to 48 hours to inject the bacteria into the skin. By that point the tick has usually dislodged itself and fallen off the body, thus usually preventing the disease from occurring." - Kids VT</li> <li>▶ "If you do find a tick on you, it should be properly removed as soon as possible as it can take 36 hours for a tick to transmit the bacteria which causes Lyme disease." - NW Medical Center</li> <li>▶ "It turns out that it takes time for a tick to reliably transmit B. burgdorferi to humans - about 36 to 48 hours." - University of VT Medical Center</li> <li>▶ "If the tick is in for less than 36 hours, remove the tick. No further treatment is needed." - Charlotte News</li> </ul>	<p>Studies have shown ticks are able to transmit the bacteria that causes Lyme disease in animal models in as little as 16 hours. According to a 2015 literature review, no minimum attachment time for transmission of infection has ever been established. The Vermont Department of Health advised, if a tick is attached to your skin for less than 36 hours, "just in case, monitor your health closely and be on the alert for symptoms of Lyme disease."</p>
<b>Timing of Lyme Disease Symptoms</b>	<ul style="list-style-type: none"> <li>▶ "Seven to 14 days after the tick bite, but sometimes it takes up to 30 days" - VT Digger</li> <li>▶ "Monitoring your health in the days after a tick bit is crucial." - WPTZ</li> <li>▶ "Lyme symptoms generally appear one to two weeks after a bite" - Kids VT</li> <li>▶ "The initial symptoms of Lyme disease occur within one to three weeks of a tick bite." - Brandon Reporter</li> </ul>	<p>Vermont Department of Health stated "symptoms of disseminated Lyme disease can occur days to months after the initial infection," and "neurological problems can occur weeks or months after a tick bite."</p>
<b>Treatment for Lyme Disease</b>	<ul style="list-style-type: none"> <li>▶ "With antibiotic treatment the infection will cause no further harm." - Brandon Reporter</li> <li>▶ "Relapse and incomplete treatment responses occur with some people developing long-term complications." - Rutland Hospital</li> <li>▶ "The disease is curable and preventable." - MyChamplainValley.com</li> <li>▶ "The problems often get better with antibiotics, but in rare cases they can last the rest of your life." - UVMHealth.org</li> <li>▶ "Late Lyme is a challenge to diagnose and, when found, is treated with prolonged antibiotics." - Charlotte News</li> <li>▶ "Long-term IV antibiotics are not indicated for Lyme disease." - University of VT Medical Center</li> </ul>	<p>Approximately 10-20% of people treated for Lyme disease have continuing symptoms a year after treatment. Some individuals have been disabled by Lyme. The earlier a person is diagnosed with Lyme disease, the more likely standard treatment will work. Most people recover fully from Lyme disease when it is promptly diagnosed and treated.</p>
<b>Diagnosis of Lyme Disease</b>	<ul style="list-style-type: none"> <li>▶ "Early diagnosis of Lyme disease should be made on the basis of symptoms and history of tick bite." - UVM Extension</li> <li>▶ "Only about 30% of people who develop this rash actually recall having a tick bite." - Mt Ascutney Hospital</li> <li>▶ "There is a fairly high rate of false negative results from this [blood] test, so we do not use it as an exclusive diagnostic tool" - Brattleboro Hospital</li> <li>▶ Lyme disease can be confirmed by a blood test." - USDA via GMNF</li> </ul>	<p>According to the CDC Lyme disease is "diagnosed based on symptoms, physical findings and the possibility of exposure to infected ticks." A negative blood test does not mean you do not have Lyme disease. False negatives and false positives do occur.</p>