LYME DISEASE IN PENNSYLVANIA

A Report Issued by the Task Force on Lyme Disease

and Related Tick-Borne Diseases

Pursuant to Act 83 of 2014

September 2015

September 2015

Dear Dr. Murphy:

I am writing on behalf of the *Lyme Disease and Related Tick-Borne Disease Task Force*, established through Act 83 of 2014 to address the complicated issues and challenges Pennsylvania faces with Lyme and other tick-borne diseases. The legislation directed the Task Force to provide recommendations to you and the General Assembly. This Task Force report contains a wide range of recommendations, primarily in the areas of education and awareness, prevention, and surveillance.

I commend the Task Force for their dedication and professionalism throughout this process. The Task Force worked diligently and used the significant diversity of perspectives concerning the issues associated with Lyme and tick-borne diseases to its advantage. The Task Force achieved an extraordinary level of collaboration with regard to identifying some of the most appropriate actions for public health officials, medical professionals, and patients.

I am confident this report contains valuable recommendations to improve the current state of activity and understanding of tick-borne diseases, especially Lyme Disease. While the work of the Task Force is now complete, its membership has a strong interest in, and a commitment to, supporting efforts to implement the recommendations.

It has been my distinct privilege to serve as Chairman of the Lyme Disease Task Force. Thank you for your support and interest along the way and for meeting with the Task Force soon after taking office. Your personal interest and involvement has been meaningful to the Task Force.

The entire Task Force looks forward to any opportunity to discuss the recommendations and the various considerations associated with taking action.

Sincerely,

Tomas J. Aguilar

Chairman, Lyme Disease Task Force

We, the undersigned, as members of the Pennsylvania Task Force on Lyme Disease and Related Tick-Borne Diseases, by virtue of our signatures below hereby forward this report pursuant to Act 83 of 2014. The report contains recommendations relative to Education and Awareness, Prevention, and Surveillance that address the growing issue of these diseases. Myriad viewpoints on these components exist and individually we may differ on some. As a body we agree these recommendations provide a starting point to fulfill the intent of Act 83 for a statewide approach to improve and protect the health of the residents of and visitors to the Commonwealth of Pennsylvania.

Tomas J. Aguilar
Chairman, Harrisburg

Gregory P. Bach, D.O.
Physician, Hamburg

Keri-Ann Faley
Patient Representative, Harrisburg

John Goldman, MD
Physician, Harrisburg

Steven Jacobs, MS
Entomologist, University Park

Andrew Kyle
Dept of Environmental Protection, Harrisburg

Meryl Littman, VMD
Veterinarian, Philadelphia

Robert A. Ollar, PhD
Lyme Disease Patient Group, Milford

Harold Smith, MD
Physician, Bloomsburg

Alice Uhrich, RN
School Nurse, Elverson

Robert Aber, MD, MACP
Physician, Hershey

Enzo R. Campagnolo, DVM, MPH, FADD
Acting State Public Health Veterinarian, Jackson Center

Melissa A. Frey
Dept of State, Harrisburg

Jane Huffman, PhD, MPH
DNA Lab Representative, East Stroudsburg

Samantha Koch
Dept. of Education, Harrisburg

Deana Lantz, CRNP
Nurse, Elderton

Sara Nicholas
Dept of Conservation & Natural Resources, Harrisburg

Dana Perella, MPH
Epidemiologist, Philadelphia

Stephen P. Smith
Bureau of Information & Education, Harrisburg

Julia Wagner
Lyme Disease Patient Group, North Wales

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EXECUTIVE SUMMARY

Over the past three decades, thousands of Pennsylvania families have felt the impact of Lyme and other tick-borne diseases (TBDs), with an estimated 50,000–70,000 individuals affected each year. Whether it is a farmer who cannot continue his work because of debilitating joint pain, or a child who misses school because of debilitating fatigue, pain and cognitive dysfunction, TBDs can have a significant effect on the day-to-day lives of Pennsylvanians. Since Lyme disease was first identified in the United States in the 1970's, the disease has spread geographically, and in severity. It has been documented that there has been an increase in tick-borne diseases in Pennsylvania, including early and late forms, as well as an increase in neurological cases.

The patient experience may be characterized by delays in diagnosis, confusion, frustration, limited treatment options, ongoing illness, with, in many cases poor outcomes, disability and a significant financial burden. (Most recently, we have started to record deaths in Pennsylvania from tick-borne diseases.)

Recognizing these facts, the Pennsylvania General Assembly passed – and former Governor Tom Corbett signed – what would become Act 83 of 2014. The Act acknowledged the significant toll TBDs may exact on individuals, families, communities, and the state, noting that TBDs pose a serious threat to the health and quality of life of many residents and visitors of Pennsylvania.

Act 83's purpose was the establishment of a Lyme and Related Tick-Borne Diseases Task Force charged with exploring and identifying recommendations related to Education and Awareness, especially of the long-term effects of misdiagnosis, prevention, and surveillance. The intent of Act 83 is generally to improve Pennsylvania's response to the tick-borne disease burden. Note that the full text of Act 83 is included herein as Appendix A. Its specific intent is found in Section 3.

This report reflects the Task Force's findings in these areas, and includes specific recommendations as well as implementation strategies, case studies, and resource needs. While the report is the result of months of research and collaboration, it is clear to those on the Task Force that this report is merely the beginning of a much-needed dialogue and structured planning process across the State.

The primary recommendations focus on increased and improved surveillance, prevention of tick exposure strategies and tactics as well as Education and Awareness for Health Care Practitioners (HCPs), patients, the general public and other stakeholders

In contemplating each recommendation, the Task Force carefully considered each of the state's key stakeholders, including patients of all ages and their families, vulnerable populations, healthcare providers, domestic animals, researchers, government agencies, policymakers, schools and community organizations, and the general public.

Key Themes:

- Tick-borne disease knowledge and research is evolving rapidly. It will be vital to encourage critical research, to understand the scope and scale of Lyme and other TBDs in Pennsylvania, and to develop options to improve the public health response and community/patient outcomes.
- Different schools of thought exist among all stakeholders regarding Lyme. Ambiguities do exist so it is important to promote a strong and academically rigorous pursuit of better research to help clarify the best options for patients. We are encouraged to keep an open mind, and to continue to explore the nature of these diseases and their health impacts.
- The most critical research gap is the lack of a gold-standard test for Lyme and for other tick-borne infections; a test that can quickly and accurately diagnose the disease, and prove or disprove ongoing persistence.
- Without more research and surveillance, it will be difficult to stay ahead of this rapidly evolving public health problem.
- The cost to Pennsylvania of doing nothing is considerable.

- Without targeted and significant funding, it is unlikely these recommendations can be deployed in an effective and impactful way.
- Collaboration among the commonwealth's diverse stakeholders will help ensure programs and strategies are innovative, effective, and measurable.
- This report contains two recommendations that did not fall neatly within the three major workgroups. These two "Other Recommendations" are critical to the successful implementation of the remaining 14 recommendations.

Too many Pennsylvanians have suffered the consequences of Lyme and TBDs, and without action, thousands more remain at risk. This important public health challenge affects all Pennsylvanians – every county has reported ticks infected with the bacteria associated with Lyme and TBDs. And yet, our children, our elderly, and our immune-compromised are most at risk and most vulnerable to their impact. Our actions now, will significantly impact Pennsylvania youth's risk and future potential.

The Task Force respectfully requests swift action on the enclosed recommendations by all state leaders charged with ensuring the protection and well-being of the commonwealth's residents.

INTRODUCTION & BACKGROUND

ACT 83 & LYME TASK FORCE PURPOSE

Act 83 of 2014 - Pennsylvania
In September 2014, Pennsylvania joined approximately 15 states with current or past legislation establishing task forces, commissions, and/or working groups focused on aligning policy, resources, and programs to support education and awareness, prevention, surveillance, and treatment of tick-borne diseases (TBDs). See Appendix B for these 15 stats' information.

As required by Act 83 of 2014, the Task Force's primary purpose is to make recommendations in the areas of prevention, education and surveillance to the Department of Health (PADOH).

This report reflects the charge set forth in Act 83, and fulfills the Act's requirement that the Task Force issue a report with recommendations to the Secretary of Health within one year of its first meeting. Per Act 83's guidelines, a copy of this report will also be shared with the Public Health and Welfare Committee of the Senate, the Health Committee of the House of Representatives and the Human Services Committee of the House of Representatives.

Task Force Approach & Methodology
The Task Force was established to investigate and make recommendations to the PADOH regarding education and awareness, prevention, and surveillance. The Task Force's 20 members represent individuals from diverse personal and professional backgrounds, as well as geographic locations, including State agency representatives, epidemiologists, entomologists, experts in medical and veterinary research and treatment, registered and school nurses, patients, patient representative groups, and members of the general public.[1]

Upon convening in September 2014, Task Force members were assigned to one of three workgroups:

1. **Prevention**
2. **Education & Awareness**
3. **Surveillance**

These workgroups met on a regular basis and the full Task Force interacted throughout the year to develop problem statements, which defined the issue of TBDs in the commonwealth. After reviewing findings and the problem statements, the Task Force then developed recommendations to address these problem statements.

This final report is a compilation of these findings and recommendations and reflects the productive dialogue between Task Force members, and has been validated to comply with the directives of Act 83, as well as the spirit and intent. With this goal in mind, the findings and recommendations found in this report intentionally reflect a wide range of views found within the medical and research communities that work closely with TBDs.

LYME & OTHER TICK-BORNE DISEASES

Introduction

Lyme disease is the most common vector-borne illness in the United States. The Centers for Disease Control and Prevention (CDC) estimates 329,000[2] cases occur in the United States each year. In recent years, Pennsylvania has led the nation in the number of reported Lyme disease cases, with 7,457 reported in 2014.[3] CDC studies have found that reported cases of Lyme disease underestimate its true incidence by a factor of ten[4], indicating that tens of thousands of residents in the commonwealth may be infected with Lyme disease each year.

High-Risk Populations

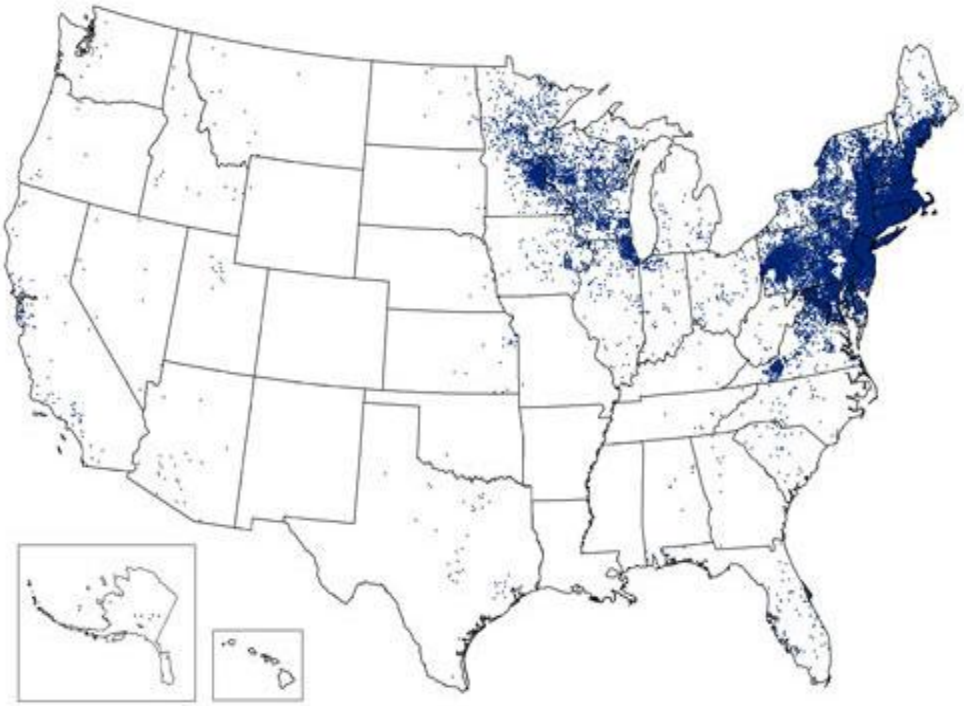
While anyone can be affected by a tick-borne disease, certain populations are more at-risk, including:

- Individuals living in areas with high concentrations of Lyme and other TBDs;
- School-age children (ages 5-14);
- Older adults (ages 45-54);
- Outdoor occupations (construction, landscaping, forestry, land surveying, farming, railroad work, utility line work, park or wildlife management, etc.); and
- Outdoor recreationists (hikers, hunters, fishers, campers, etc.);
- Immunocompromised.

Rates of Tick-Borne Diseases in Pennsylvania

Pennsylvanians and visitors are especially vulnerable given our ranking as the leading state in reported cases of Lyme disease.

Exhibit 1: Reported Lyme Disease Cases (CDC 2013 Data)



1 dot placed randomly within county of residence for each confirmed case

Exhibit 2: U.S. Counties with High Incidence of Lyme

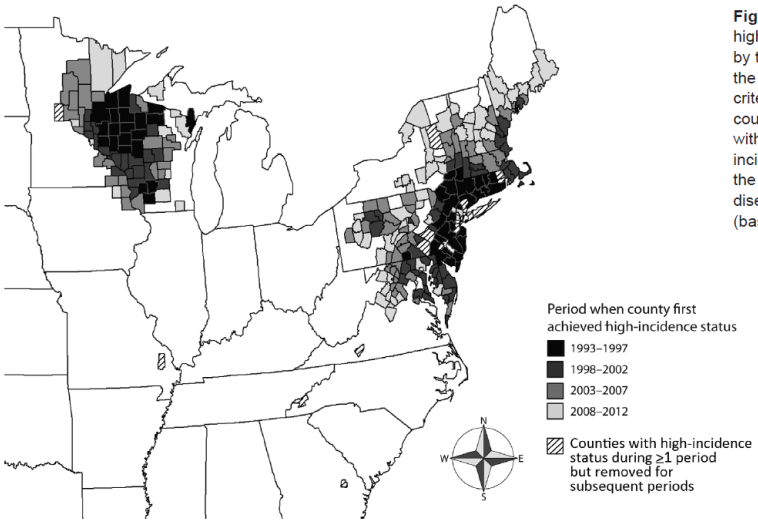
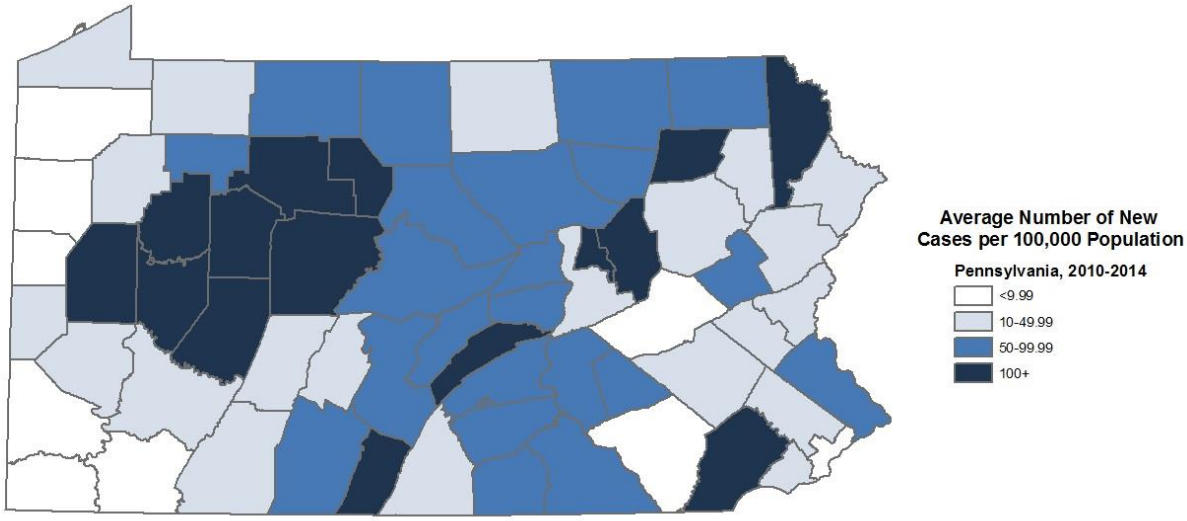


Figure. United States counties with high incidence of Lyme disease by the period when they first met the designated high-incidence criteria, 1993–2012. High-incidence counties were defined as those within a spatial cluster of elevated incidence and those with ≥2 times the number of reported Lyme disease cases as were expected (based on the population at risk).

The evolving landscape and profile of TBDs present significant – and urgent – challenges for public health professionals and policy makers. In April 2015, the Pennsylvania Department of Environmental Protection (DEP) published findings confirming that every county in commonwealth has blacklegged deer ticks that carry *Borrelia burgdorferi*, the bacteria that causes Lyme disease.[5] Further, a recent CDC study has demonstrated the westward progression of Lyme disease across the state with an increasing number of counties being considered high incidence areas in the past two decades.[6] Because of the rapid shifts in the landscape of TBDs as well as the significant stakes for Pennsylvanians, there is an urgent need for research and action (see Exhibit 3).

Exhibit 3: Lyme Disease Five-Year Average Incidence by Pennsylvania County



Significant Impact on the Quality of Life in Pennsylvania

Lyme disease is a complex infection that has several manifestations and can affect different systems within the body including the skin, joints, heart, and nervous system. Lyme disease may carry significant and potentially life-changing burdens, especially if the disease goes undiagnosed or untreated for a prolonged period. Unfortunately, it is common for Lyme disease to go undetected and untreated in absence of the hallmark bull's-eye (erythema

migrans) rash, leading to functional impairments and quality of life impacts, such as damage and infections of the joints, heart, and nervous system.

Many of the symptoms of TBDs are similar to those of other conditions, which further complicates diagnoses at any stage. Like syphilis, which is also caused by spirochete bacteria, some researchers also refer to Lyme disease as "the New Great Imitator." The fever, muscle aches, and fatigue associated with Lyme disease or other TBDS can be mistaken for viral infections, such as influenza or infectious mononucleosis. Joint pain can be mistaken for other types of arthritis, such as juvenile rheumatoid arthritis (JRA), and neurologic signs of Lyme disease can mimic those caused by other conditions, such as multiple sclerosis (MS) and amyotrophic lateral sclerosis (ALS).

As mentioned previously, Lyme disease and other TBDs can have significant consequences for patients, including – in the most severe cases – death. In 2013, a 52 year-old adult in New Jersey died from contracting the Powassan virus and in 2014, a three year-old child in Pennsylvania died from Rocky Mountain spotted fever. Recent research has identified co-infections with Lyme disease and one or more other TBD as a significant concern because of diagnostic challenges as well as the intensity and duration of symptoms.[7]

Economic Costs of Tick-Borne Diseases

Beyond the significant personal impacts these diseases may cause, TBDs also create a significant economic burden in Pennsylvania and the United States. Over $1 billion in annual medical expenses in the United States have been attributed to Lyme disease as well as up to $10,000 per patient annually in lost productivity. Lyme disease patients required 87 percent more visits to the doctor, and 71 percent more visits to the emergency room in comparison with those without Lyme disease. [8]

Applying the above cost estimate to Pennsylvania's 7,400 confirmed/reported Lyme disease cases, the annual estimated cost in lost productivity alone may likely exceed $74 million.

Diverse Perspectives of the Medical Community

The rapid expansion of TBDs in the U.S. and Pennsylvania is further complicated by a lack of consensus among researchers and healthcare practitioners (HCPs) in many critical areas. There are two organizations that have published guidelines for diagnosis and treatment of Lyme and other TBDs: the Infectious Disease Society of America (IDSA), and the International Lyme and Associated Diseases Society (ILADS). The medical community varies in its approach to treating patients with Lyme disease, for example, the adherence to a specific timeframe for antibiotic treatment. Others assess patient response to determine treatment. Pennsylvania's Task Force members considered both perspectives as well as public health considerations in their deliberations. Representation of the diversity of these views was directed by Act 83, which explicitly called for a "broad spectrum of views to be represented and communicated to patients", and is reflected in this report and its core recommendations.

Existing Efforts in Pennsylvania & Areas of Concern

Task Force members identified some progress in Pennsylvania's current efforts related to education and awareness, prevention, and surveillance. For example:

- **Education & Awareness**: National campaigns, curriculum/programming in a few schools, advocacy groups (PA Lyme Resource Network, etc.) focused on community-based work, some school-based and community-based program successes. Tick-borne and other chronic infections research and practice – Drexel University College of Medicine Conference March 2015

- **Prevention**: CDC signage posted in PA State Parks and State Forest Districts in spring 2015, 2015 PADOH community outreach campaign, ongoing community outreach conducted by the Chester County Department of Health and Philadelphia Department of Public Health.

- **Surveillance**: Existing infrastructure for human TBD surveillance by PADOH and tick surveillance by PADEP. Entomology departments at East Stroudsburg University, Indiana University, Shippensburg University, Penn State and other colleges in PA also have the capacity to support tick field surveys.

While promising, many of these efforts are limited in scope and scale, and lack coordination. They depend heavily on limited private funding sources to continue, and require additional research to address unanswered questions about TBDs, such as:

1) What are the biologic processes in humans that cause ongoing symptoms following treatment?
2) How can we advance the development of innovative and more accurate diagnostic testing?
3) Are there additional, more effective treatments and multidisciplinary approaches?

The recommendations within this report resulted from a multidisciplinary, collaborative group and will require significant, ongoing commitment from similarly diverse stakeholders, including healthcare providers (HCPs), scientists, educators, policymakers, state agencies, local community groups, and patients.

Conclusion

The human and economic costs of Lyme and other TBDs demand appropriate action and resources. The Task Force is pleased to present this final report and recommendations for consideration by the Secretary of Health and all Pennsylvanians. The need for action is clear, and this report provides an important "first step" for moving the commonwealth in a healthier direction.

DEFINITIONS & TERMS

To effectively continue and advance a much-needed dialogue regarding Lyme and other TBDs in the Commonwealth of Pennsylvania, establishing a "common language" is critical.[9]

Frequently Used Terms
While Lyme disease is arguably the most commonly occurring and widely-recognized tick-borne disease, it is by no means the only one. As referenced in the definition below, different types of ticks can harbor a variety of microorganisms that can be harmful to humans, including Babesia, Anaplasma, Ehrlichia, Powassan Virus, Rocky Mountain Spotted fever, other Borrelia species, and possibly Bartonella – to name just a few.

To more accurately represent the full spectrum of infectious pathogens affecting Pennsylvanians, this report will use the terms "tick-borne diseases" or "TBDs", unless otherwise specified.

Other common terms used in discussions related to TBDs include "post-treatment Lyme disease syndrome" and "Chronic Lyme Disease". Both are non-clarifying and as such, we have chosen to use "persistent symptoms" to describe long-term impact experienced by some patients who have been diagnosed with Lyme disease.[10]

The following are definitions of terms that are found frequently in this report:[11]

Anaplasmosis is transmitted to humans by tick bites primarily from the blacklegged tick (*Ixodes scapularis*) in the northeastern and upper Midwestern U.S. and the western blacklegged tick (*Ixodes pacificus*) along the Pacific coast.

Antibiotic prophylaxis: Antimicrobial therapy following a known exposure to a bacterial pathogen that is given to prevent the development of disease, e.g. Lyme disease following short-term attachment and removal of a tick.

Babesiosis: Cause by microscopic parasites that infect red blood cells and are spread by certain ticks. In the U.S., tick-borne transmission is most common in particular regions and seasons: it mostly occurs in parts of the Northeast and upper Midwest and usually peaks during the warm months. Although many people who are infected with Babesia do not have symptoms, effective treatment is available for those who do.

Bartonellosis: A disease or infection caused by bacteria of the genus *Bartonella* which primarily cause infection of nonhuman animals and are transmitted via insect vectors (fleas, lice, flies, etc.). The bacteria attack red blood cells and may cause severe anemia and high fever followed by skin eruption. Three species are well documented as human pathogens with as many as 7 others known to be possible human pathogens based on the current evidence. A *Bartonella* infection in humans can manifest with little or no symptoms or as severe as ongoing febrile illness and more rarely, produce serious complications like endocarditis and encephalitis.

***Borrelia burgdorferi*:** The causative agent (spirochete bacterium) in Lyme disease. The organism is transmitted to humans by tick vectors, primarily *Ixodes scapularis* (more commonly known as a deer tick).

Borrelia miyamotoi: A bacterial infection has recently been described as a cause of illness in the U.S. It is transmitted by the blacklegged tick (*Ixodes scapularis*). *B. miyamotoi* causes fever (that can be relapsing), chills, headache, and more rarely rash.

Clinically Diagnosed Lyme Disease Cases: Diagnoses based on medical history, symptoms, physical examination. May or may not be confirmed by lab tests.

Ehrlichiosis is transmitted to humans by the lone star tick (*Ambylomma americanum*), found primarily in the southcentral and eastern U.S.

Epidemiology: Epidemiology is the study of the distribution and determinants of health-related states or events in specified populations, and the application of this study to the control of health problems.[12]

Erythema (chronicum) migrans: A rash due to the bite of a deer tick that spreads into a bull's-eye rash.

Hyperendemic: Exhibiting a high and continued incidence; used chiefly of human diseases.

Infectious Disease Society of America (IDSA): Professional organization that represents physicians, scientists and other health care professionals who specialize in infectious diseases. IDSA's purpose is to improve the health of individuals, communities, and society by promoting excellence in patient care, education, research, public health, and prevention relating to infectious diseases.

International Lyme and Associated Diseases Society (ILADS): A nonprofit, international, multidisciplinary medical society dedicated to the diagnosis and appropriate treatment of Lyme and its associated diseases.

***Ixodes scapularis*:** The blacklegged tick or commonly known as a "deer tick", which can transmit the organisms responsible for anaplasmosis, babesiosis, and Lyme disease. This tick is widely distributed in the Northeastern and upper Midwestern United States. *I. scapularis* larvae and nymphs feed on small mammals and birds, while adults feed on larger mammals. Both can attach to humans.

Lyme disease is transmitted by the blacklegged tick (*Ixodes scapularis*) in the northeastern U.S. and upper Midwestern U.S. and the western blacklegged tick (*Ixodes pacificus*) along the Pacific coast.

Powassan disease is transmitted by the blacklegged tick (*Ixodes scapularis*) and the groundhog tick (*Ixodes cookei*). Cases have been reported primarily from northeastern states and the Great Lakes region.

Q-fever is usually spread when dust contaminated by dried placental material, birth fluids, urine, or feces from infected animals becomes airborne and is inhaled. Tick-borne transmission also has been documented and the bacterium that causes Q-fever has been identified in *Dermacentor* spp. ticks.

Rocky Mountain spotted fever (RMSF) is transmitted by the American dog tick (*Dermacentor variabilis*), Rocky Mountain wood tick (*Dermacentor andersoni*), and the brown dog tick (*Rhipicephalus sangunineus*) in the U.S. The brown dog tick and other tick species are associated with RMSF in Central and South America.

Seroconversion: The change of a serologic test from negative to positive, indicating the development of antibodies in response to infection or immunization.

Serology: Measurement of antibodies, and other immunological properties, in the blood serum.[13]

STARI (Southern tick-associated rash illness) is transmitted via bites from the lone star tick (*Ambylomma americanum*), found in the southeastern and eastern U.S.

Tick-borne rickettsial infections: Anaplasmosis, ehrlichiosis, and Rocky Mountain spotted fever (RMSF) are the most common tick-borne rickettsial infections in PA. These infections are caused by bacteria from the

Rickettsiaceae family and spread by ticks. Each of these tick-borne rickettsial infections has distinct epidemiologic characteristics (type of tick(s) that spreads the bacteria, geographic distribution) and target different types of cells in the body during infection. Despite these differences, these illnesses cause similar symptoms—fever, myalgia, arthralgia, blood abnormalities, and rash (RMSF and ehrlichiosis)

Tularemia is transmitted to humans by the American dog tick (*Dermacentor variabilis*), the Rocky Mountain wood tick (*Dermacentor andersoni*), and the lone star tick (*Amblyomma americanum*). The bacteria that cause tularemia may also be transmitted after bare skin contacts infected animal tissues or contaminated soil or dust particles are inhaled. Tularemia occurs throughout the U.S.

Two-step testing for Lyme antibodies: CDC currently recommends a two-step process when testing blood for evidence of antibodies against the Lyme disease bacteria. Both steps use the same blood sample. The first step uses a testing procedure called "ELISA" (enzyme immunoassay) or, rarely, an "IFA" (indirect immunofluorescence assay). If this first step is negative, no further testing of the specimen is recommended. If the first step is positive or indeterminate (sometimes called "equivocal"), the second step should be performed. The second step uses a test called an immunoblot test, commonly, a "Western blot" test. Results are considered positive only if the ELISA/IFA and the immunoblot are both positive.

CORE RECOMMENDATIONS

1. PREVENTION

The societal burden of TBDs is substantial. The incidence rate of all of the diseases discussed in these recommendations has continued to increase. They have also been expanding in geographic range, and new human tick-borne pathogens continue to be recognized. These trends result in an ever larger number of persons requiring treatment, placing a greater financial impact on the healthcare system and individual patients and ultimately, a greater burden on society.[14]

It is widely agreed that the best way to avoid such outcomes is through prevention actions. Prevention of disease is far preferable to treating the short and long-term consequences once they occur. The increasing burden of TBDs is a clear demonstration that the available prevention measures have been largely ineffective. Whether this is because they simply do not work or because they have been underused or ineffectively applied is far less clear, and clearly better options are needed.

Prevention measures can generally be divided into four categories:

a) Personal protection measures (repellants, clothing, tick checks and other behaviors)
b) Personal tick- and host-targeted strategies (property, landscape, hosts, vaccines, targeted actions)
c) Community-level intervention tick and host-targeted strategies (property, landscape, hosts, vaccines)
d) Pharmacologic preventive measures such as antibiotic prophylaxis or vaccines

1

PREVENTION RECOMMENDATION 1: <u>Protocol and Funding Strategy for Schools in High-Risk Areas</u>

Develop and implement a protocol and funding strategy for schools located in high-risk areas to implement personal protection and property actions (Integrated Tick Management strategies like spraying, various deer management methods, landscape modifications, based on a review of the available evidence on tick reduction approaches) to reduce the risk of tick exposure on school properties and during school activities.

PROS	CONS
• Potential to reduce impact on children quickly • Schools create a setting where protection steps can be ensured (e.g. tick checks after outdoor activities) • Potential to reduce public risk quickly by communicating at the point of risk	• Reliant on compliance with personal protection/passive • Increases school responsibilities and takes time away from activities; may discourage outdoor activities for children

<u>RATIONALE:</u>

Recommended school-based strategies could include:

- Notification to parents regarding risks and protective measures, especially following outdoor activities
- Encourage school staff to remind students and parents of "tick-checks" after outdoor school events
- Implement an awareness campaign for children and parents regarding risks and prevention
- Implement standard protocol within the school for appropriate tick removal and prompt parental notification

Children represent the highest risk group, and schools are an accessible channel to quickly reduce exposures, and catch disease early. Studies have found high tick populations on school grounds, close to playground equipment (Sapi, CT school ground). School property represents a highly utilized public space that could have a significant and rapid impact on prevention awareness.

IMPLEMENTATION CONSIDERATIONS

Who Benefits? How?	• School-aged children by reducing the risk of tick bites and TBD exposure • Dedicated funding for ITM strategies
Implementation Ideas	• Awareness letters to parents giving them information on TBD and the protective measures being implemented at the school • School staff awareness and education • School protocol for the removal of ticks
Resources Needed	• Funding • Health Educator • School nurse • School administrative staff to distribute letters home with students
Suggested Lead Organizations	• PADOH • Pennsylvania Department of Education (PDE)
Suggested Support Organizations	• Department of Conservation and Natural Resources • Community level organizations • Local health systems
Measures/Outcomes	• Measurement of local level diagnosis of TBDs in school aged children

IDEAS IN ACTION: SCHOOL NURSE SURVEY

As part of efforts to understand the impact of Lyme and other TBDs on Pennsylvanians, especially vulnerable school-age children, a voluntary school nurse survey could be developed and distributed by PADOH or relevant associations at the district level. Questions regarding comprehensive prevention programming, risk reduction methods through integrated pest management strategies, and the impact of Lyme and other tick-borne diseases on students' health, productivity, and academic outcomes could be included. This information could be used to support further research as well as investments in school-based health.

2

PREVENTION RECOMMENDATION 2: Park Staff Protocols

Develop and implement a protocol for federal, state and local park staff and properties to include communicating risk awareness (tick presence, tips for personal protection), and taking property actions (Integrated Tick Management strategies like spraying, use of deer management methods, landscape modifications, vehicle spraying, protective clothing and other methods based on a review of the available evidence on tick reduction approaches) to reduce risk to the staff and the public.

PROS	CONS
• Reducing tick populations reduces risk. • Requires action by fewer people	• Some sprays or other means may have risks associated • Programs have to manage spraying at the right time of the year, or keeping deer stations stocked, requiring time and resources

RATIONALE:

At a minimum signage should be posted near high-risk areas to notify the public and staff areas to avoid, and personal protection steps and reminders to be taken. The CDC provides free signage for this purpose.

A critical way to prevent infection is to reduce the likelihood of exposure by reducing tick populations, and by adopting a combination of multiple prevention strategies. The Institute of Medicine formed a working group including schools and public properties, and various other symposiums have been convened to assess and share best practices in reducing tick populations in public properties. The above strategies, especially in combination, were shown to greatly reduce risks to the staff and public.

IDEAS IN ACTION: PREVENTION RESOURCES IN STATE PARKS

In April 2015, PA DCNR began efforts to place tick warning signs in our 120 state parks and 20 state forest districts. These signs were provided free of charge by the CDC.

DCNR field staff, who spend much of their workday outdoors, are particularly vulnerable to tick exposure and tick-borne illnesses, such as Lyme Disease. In fact, DCNR has the second highest rate of workers compensation claims filed among all Commonwealth agencies, driven in large part by tick-related incidents.

The DCNR internal tick/Lyme workgroup is creating a program to take measures that help protect its staff and visitors to state parks and forests from tick exposure. The Agency is providing all staff with tick-removal kits, web-based information on prevention measures, and repellents, which include Off, Deet, Permetherin, and Natrapel, a natural organic repellent. Other measures that are being explored include using lighter colored clothing, chemically treated clothing, and use of repellents inside vehicles.

The ultimate goal of these efforts is to reduce our incidence numbers by providing DCNR employees and park and forest visitors with protection so they can continue to work in and enjoy Pennsylvania's park and forest lands.

IMPLEMENTATION CONSIDERATIONS

Who Benefits? How?	The public including Pennsylvania residents and those visiting the state, especially DCNR staff
Implementation Ideas	Integrated Tick Management strategies, equipment costs and tick presence awareness information
Resources Needed	• Local level funding for awareness materials, Integrated Tick Management and landscape modifications at state and local parks
Suggested Lead Organizations	• DCNR • County Health Departments, District Offices, and other Community level organizations
Suggested Support Organizations	• Community level organizations • Local health systems
Performance/Evaluation Metrics	• Local and state level diagnosis rates • DCNR staff workers' compensation rates • Establish baseline activities among all state agencies related to TBDs • Reduction in disability or other types of medical claims related to TBDs

3

PREVENTION RECOMMENDATION 3: Standard Brochures for Physician Distribution

Develop and implement a standard brochure (based on the Virginia model) that physicians ideally should provide to patients when they are evaluated, either by clinical exam or lab testing, for potential Lyme and related tick-borne infections.

PROS	CONS
• Targeted action when it is most relevant • Supports appropriate communications to carry out the intent of Act 83 • Provides support for HCPs to communicate accurately	• HCPs may replace a discussion with a brochure • Cost of materials • Increasing complexity of HCP job

RATIONALE:

The brochure should clearly communicate that:

- "a negative result cannot rule out Lyme disease, based on current testing (2015) in early Lyme disease. You should talk to your doctor about your exam, results of other testing, and whether another diagnosis is likely based on your doctor's judgment."
- "certain tests for TBDs are based on the body's immune response to the infection, which takes time to develop. If a specimen is collected too early, results may be falsely negative. Use of antibiotics before or at the time of specimen collection may also produce false negative results."
- "science is emerging rapidly in tick-borne diseases. Be aware that there are multiple schools of thought across the medical community regarding diagnosis and treatment of Tick-borne diseases. These are represented by multiple published guidelines available to HCPs through the National Guidelines Clearinghouse and medical professional organizations. These may include American Academy of Neurology (AAN), American College of Rheumatology (ACR), American Academy of Pediatrics (AAP) and American Academy of Family Physicians (AAFP) as well as IDSA and ILADS. Patients should discuss treatment with their healthcare provider's approach."

There is no gold-standard test for Lyme disease today, and patients should be properly informed of the significance of a negative test in absence of another likely explanation for their symptoms as determined by their doctor. It is well agreed upon that testing is inaccurate in early Lyme disease (within 30 days of starting symptoms). The utility of testing in late Lyme disease is even more controversial. Furthermore, health care practitioners today have limited testing options for Lyme disease that are covered by insurance, that is, two-tiered antibody testing based on the CDC criteria for Western Blot interpretation and PCR testing of synovial fluid or cerebrospinal fluid appear to be the only two currently covered by some carriers.

This recommendation has the potential to impact the patient population more quickly than HCP education alone, encourages informed decision making and provides a vehicle to ensure that HCP education is applied in day to day patient interactions.

IMPLEMENTATION CONSIDERATIONS

Who Benefits? How?	Pennsylvania patients and physicians by increasing informed decision making
Implementation Ideas	Meetings with physician offices to introduce the brochure and the benefits of giving the patient information in writing to give them choices in their care
Resources Needed	• Funding for the creation and distribution of brochures
Suggested Lead Organizations	• Task Force, DOH, and health systems
Suggested Support Organizations	• AHA • PAFPF
Performance/Evaluation Metrics	• TBD diagnosis rates, TBD readmissions rates, medical costs of TBD patients, and surveys currently being used to measure patients with long term illness or issues following a TBD diagnosis

4

PREVENTION RECOMMENDATION 4: Strategy for Reducing Transfusion Transmitted Babesiosis

Develop and implement strategy to reduce risk of transfusion transmitted Babesiosis (TTB) resulting from donors with tick-borne infection.

PROS	CONS
• Will ensure that Babesiosis cases are tracked and reported in Pennsylvania to monitor risk and target actions • Heightening the awareness of this serious risk, and begin to engage HCPs in addressing this	• May require that institutions involved in biologic donation, transplants, or transfusions to submit a plan • May require revised protocols relative to Investigational New Drugs (IND)

RATIONALE:

- TTB is the leading infectious cause of mortality (38%) in transfusion recipients as reported to the Food and Drug Administration (FDA).
- The AABB Emerging Infectious Diseases (EID) subgroup of the TTD Committee categorized Babesia as a high priority agent for the development and implementation of an intervention to reduce the incidence of TTB in 2009, and most recently reissued a call for action in July 2014[15].
- Work with CDC to identify Pennsylvania as endemic for Babesiosis (if required: gather reported cases and healthcare institution data, tick and wildlife studies).
- Annually summarize data on TTB collected through surveillance recommendations 1 and 7 and make findings available to the public on the PADOH website.

IMPLEMENTATION CONSIDERATIONS

Who Benefits? How?	• ***Pennsylvania Patients –*** Increased protection from TTB for individuals who are receiving blood transfusions • ***Pennsylvania HCPs*** - Reducing transmission cases that may require extraordinary care
Implementation Ideas	• May require that institutions involved in biologic donation, transplants, or transfusions to submit a plan • May require revised protocols relative to Investigational New Drugs (IND)
Resources Needed	• Blood donor center notifications
Suggested Lead Organizations	• PADOH
Suggested Support Organizations	• Local and regional blood banks
Performance/Evaluation Metrics	• Rates of transfusion transmitted TTB

2. EDUCATION & AWARENESS

This document has laid out specific trends regarding the increasing threat of Lyme and tick-borne diseases, as well as the increasing complexity of these diseases (complicated by multiple tick-borne infections). This clearly points to the need for prevention.

Current state findings regarding physician practices and the patient experience point specifically to the need for education:

* Many common symptoms go unrecognized, even the mostly widely recognized bulls-eye rash[16]
* Physician practices vary significantly in both diagnosis and treatment[17]
* Patients experience significant delays in diagnosis and treatment[18]
* Patient outcomes are less than satisfactory[19]

Studies have found that some tick-borne disease patients experience delays in diagnosis and a portion remain sick for long periods of time. There is a critical need for healthcare education and reform to reduce such delays, and to improve the validity and effectiveness of diagnostic and treatment options available to patients. Thus access to medical care for Lyme disease is improved, and the burden of illness is reduced.

Act 83 states explicitly that these recommendations should ensure that HCPs, insurers, patients, and governmental agencies are educated about the broad spectrum of scientific and treatment options regarding all stages of Lyme disease and related tick-borne illnesses.

Education would bring the healthcare community up to date with rapidly evolving science, the associated risks of exposure, what to do about bites and early stages of disease, and especially how to prevent the progression of disease to later stages with more incapacitating outcomes. The goal is to catch disease earlier, and to provide a better understanding of disease processes and treatment options, to ultimately improve patient outcomes.

Most importantly, education would ensure that patients are properly informed, and positioned to evaluate the risks and benefits of different choices based on their response to treatment, with their HCPs.

Lastly, awareness and education of the general public, insurers, and governmental agencies would address prevention approaches, general awareness, and improve access to early and appropriate treatment, all of which are identified in the intent of Act 83.

This section outlines specific recommendations regarding awareness and education, fundamental to Act 83.

1

EDUCATION & AWARENESS RECOMMENDATION 1: Public Awareness Campaign

Develop and implement comprehensive multimedia public awareness campaign targeting the general public and at-risk population to improve awareness and understanding of TBDs in Pennsylvania, and establish working relationships with partners that represent key stakeholders.

PROS	CONS
• Campaign and related communications will help individuals understand ways to reduce risk of exposure to Lyme disease as well as the importance of early treatment • Partnerships will reduce marketing and information dissemination costs • Existing materials and resources for public awareness (CDC PSAs & Communication Toolkit, "Take a Bite Out of Lyme" campaign, PADOH "Don't Let a Tick Make You Sick" campaign, etc.) • Greater reach and impact on targeted at-risk populations and general public • Expanded communication channels • Create community buy-in around the important issue of TBDs	• Need access to specific skill sets to successfully implement campaign (market research, graphic design, branding, social media, etc.) • Significant planning and ongoing support needed to sustain efforts across state agencies • Takes significant, ongoing effort to build and maintain meaningful relationships with partners

RATIONALE:

Using a schools- and community-based strategy for outreach will increase reach and sustainability of Lyme disease education and awareness efforts. More people who are not aware of Lyme disease will be reached by using messaging, visuals, and media that connect with where people are already going for information (materials in doctor's offices and school nurses' offices, websites with information about Lyme disease, community organizations, social media). Accessibility and appeal of information will help more people understand the risks as well as practical strategies to reduce exposure.

IDEAS IN ACTION: EDUCATION & AWARENESS IN PENNSYLVANIA'S STATE PARKS

As part of its internal Lyme disease work group, DCNR sent out information to all agency staff, which detailed the need to be vigilant in regard to ticks while outdoors. It also provided basic guidelines to help employees identify and properly remove ticks, as well as when to seek treatment. DCNR also acquired "tick awareness" signs from the CDC, which were provided to the agency's park and forest offices where both staff and the general public would be able to see them. Further educational and awareness efforts will be developed and data will be collected to ensure effectiveness.

High-risk groups should be prioritized in outreach campaigns:

- Individuals living in areas with high concentrations of Lyme and other TBDs;
- School-age children (ages 5-14);
- Older adults (ages 45-54);
- Outdoor occupations (construction, landscaping, forestry, land surveying, farming, railroad work, utility line work, park or wildlife management, etc.); and
- Outdoor recreationists (hikers, hunters, fishers, campers, etc.);
- Immunocompromised.

A cross-agency, statewide coalition will create conditions for success. An online clearinghouse will spur the creation of important materials and resources, promote consistency in future communications, and eliminate redundancies in agency efforts. The clearinghouse will also enhance transparency around government efforts to prevent TBDs in Pennsylvania. A cross-sector symposium or tech-based event, such as a data jam or hackathon, will allow for the exchange of ideas, feedback, and information. Finally, funding is critical to the success of all Task Force recommendations and can support vital research, education, surveillance, prevention, and treatment programs.

IDEAS IN ACTION: SCHOOL POSTER CONTEST & AWARENESS CAMPAIGNS

National nonprofit organizations often develop campaigns and contests for students and schools around diverse issues. PDE could assist in connecting these organizations with superintendents and schools across the commonwealth.

To build awareness and increase student engagement around issues related to tick-borne diseases, the Task Force recommends considering partnerships with national organizations focused on these diseases to create voluntary, incentivized, school-based campaigns and contests.

IMPLEMENTATION CONSIDERATIONS

Who Benefits? How?	• ***Schools/LEAs/IUs/General Public*** – Receive more information and resources to share with students and parents, reduce risk and impact of TBDs • ***Healthcare professionals*** - More informed patients, better resources for sharing information and training, etc. • ***Government*** – Reduces direct agency costs by distributing implementation across a broad group of stakeholders • ***Community Partners*** – Raises profile of groups within existing and new audiences; reduces risk of harm for key stakeholders
Implementation Ideas	• May is Lyme Disease Awareness Month – plan activities and community events with partners • Radio/TV spots, social media • Posters distributed and posted in key outdoor areas • Create or enhance partnerships with groups and organizations that have broad reach and those working with at-risk populations (i.e. hunting and outdoor shops, Boy Scouts, school nurses, etc.) • Develop Memo of Understanding or other agreements on a program/project basis to establish roles, responsibilities, and contributions • Gather partner feedback on Task Force recommendations, especially Education & Awareness programs, with a focus on implementation, reach, and sustainability • Poster/video/web competition in schools (voluntary and driven by national/community partners) • School nurse survey assessing prevalence and impact of TBDs. • Research symposium for HCPs, experts, researchers, and other stakeholders • Data Jam/Hackathon – open source data projects with experts, students, policy makers • Pursue CDC grants and NIH National Institute of Allergy and Infectious Diseases (NIAID) grants
Resources Needed	• Staff time (gov't agencies, consultants, partners) • Cost to develop and distribute communication and campaign materials (printing, graphic design, web design, etc.) • Survey development and distribution • Radio/TV spots
Suggested Lead Organizations	• PADOH • PDE • PA DCNR • PA Game Commission • PA Department of Agriculture
Suggested Support Organizations	• Relevant public officials (mayors, parks and recreation departments, state reps, etc.) • Community Groups (Boy Scouts, outdoor clubs, etc.) • Medical associations (IDSA, ILADS, etc.) • Health care organizations • AARP (older Americans)

	• Local Educational Agencies and Intermediate Units (IUs) • Agricultural Organizations • TBDs Support Organizations • Hunting/Outdoor/Garden Businesses and/or Community Groups • Institutions of higher education (can assist in research and evaluation of partnership and campaign outcomes) • Open Data/Coding Organizations
Performance/Evaluation Metrics	• Establish baseline awareness levels among general public/at-risk groups • Increase in awareness among these groups, average monthly visits to online clearinghouse • Participation levels/numbers for events (symposium, data jam/hackathon, etc.) • Increase in awareness among general public and specific at-risk groups • Average monthly visits to online clearinghouse • Aggregate results of survey of licensed healthcare professionals • Aggregate results of school nurse survey (see enclosed) • Meaningful engagement of partners (as measured by number of activities, self-reported data/feedback from participants, and frequency of meetings and interactions between partners) • Number of activities/program elements developed through partnerships

2

EDUCATION & AWARENESS RECOMMENDATION 3: Health Care Provider Prevention Education

Develop and implement an initial and ongoing education program for healthcare providers to include prevention of tick bites, and prevention of disease progression from acute to later stages of infection.

PROS	CONS
• Tailor education and awareness strategies to specific audience (medical community) • Create spaces for sharing resources and up-to-date information that also reflects the diverse views and research regarding TBDs • Mitigate risk of emerging diseases more quickly through improved awareness and knowledge • Incorporate program evaluations to measure effectiveness	• Program administration could incur significant costs (to be determined) • Successful engagement of healthcare professionals in this program requires buy-in from licensing bodies and other medical associations and groups • Significant staff time involved in organizing, monitoring, and evaluating program and its outcomes

RATIONALE:

The content should present the broad spectrum of views (AAN, ACR, AAP, ACEP, IDSA, and ILADS) and where they diverge (prevention, diagnosis, treatment to prevent dissemination, etc.) including the alternative expert interpretations of the evidence, and the recommended options with explicit reference to their assumptions, values and intentions, to inform professionals and public effectively.

The high burden of TBDs in Pennsylvania requires an urgent and ongoing response. HCP education is a specific strategy recommended by the IOM in 2011.[20]

To make effective use of the public's resources, it is essential to ensure education programs achieve the objectives. Up front assessment will ensure that programs are targeted and cost-effective; post-program measurement will demonstrate results and target ongoing programs.

Patient choice is important in considering treatment options with proven safety and effectiveness. Information provided should empower health care providers to weigh the pros and cons of different treatment options, in cases with and without a definitive diagnosis, different patient presentations, and the pediatric aspect of treatment.

Information should be balanced, and should acknowledge discrepancies and misconceptions of transmission, testing and diagnosis of TBDs as well as the need to seek treatment and care immediately.

By providing information through a variety of channels, healthcare professionals can choose the venue that is most appropriate and appealing for them, increasing engagement with the topic. Targeting primary care providers, especially for high-risk areas or populations, will help professionals better understand when to refer to a specialist and who to refer to for ongoing management, if necessary.

Ultimately, all information created with health care professionals in mind should emphasize how to approach weighing risks vs. benefits and providing all patients with choices in care.

IMPLEMENTATION CONSIDERATIONS

Who Benefits? How?	• Medical community benefits from increased access to trends, latest research, and diverse perspectives on TBDs • Patients and the general public benefit from more empowered and informed HCPs who are able to effectively describe options available for prevention, diagnosis, and treatment of TBDs
Implementation Ideas	• Online clearinghouse for healthcare professionals via PADOH website • Annual/biannual symposium that discusses latest trends and promising practices (recordings and presentation slides made available on PADOH website) • Webinars, presentations, emails, and other one-time communications hosted in partnership with HCPs
Resources Needed	• Website/materials development costs • Event-hosting costs • Staff time required for ongoing monitoring and updates
Suggested Lead Organizations	• PA DOH • PA Medical Society • PA County or Municipal Health Departments • PA State Nurses Association or PA State Board of Nursing
Suggested Support Organizations	• Issuing Boards • Licensing Boards
Performance/Evaluation Metrics	• Results of a health practitioner (including school nurses) statewide survey re: scope, treatment, and behavioral norms related to TBDs

3. SURVEILLANCE

A comprehensive and thorough surveillance system for Lyme disease and other tick-borne infections, as with all vector-borne diseases, must incorporate both ecological surveillance (ticks and animal reservoirs/hosts) and disease surveillance (humans and domestic pets), which entails participation by multiple partners (e.g. PADOH, PADEP, universities, healthcare providers, veterinarians, etc.). Information collected through ecological and disease surveillance enables areas and risk groups with high rates of infection to be identified, which can help direct prevention efforts and prioritize how public health resources are distributed. It will also inform members of the medical and healthcare community on the specific types of tick-related infections that are being encountered most frequently in a particular county or geographical region of our commonwealth.

Ecological surveillance provides essential information on the presence of: a) specific tick vectors in specified geographic areas, b) the pathogenic organisms that they carry, and c) animal disease reservoirs and other animal hosts upon which the ticks feed. Ecological surveillance data along with an understanding of factors that impact transmission (e.g., timing of tick attachment for transmission, competency of tick species to transmit infection, host susceptibility to infection, etc.) are necessary to assess the potential for infection with Lyme and other tick-borne diseases throughout the state where Pennsylvanians live, work, and play.

Human disease surveillance for Lyme and other TBDs falls under a core public health activity that aims to provide information to help prevent and control disease, in order to promote the health and well-being of all Pennsylvania residents. Surveillance data along with observational epidemiologic studies can provide a better understanding of the burden and severity of specific tick-borne diseases among Pennsylvania residents. Serologic surveillance of domestic pets provides sentinel information and describes how specific tick-borne infections may impact residents' four-legged family members. Lastly, it is important to note that case classification definitions for disease surveillance purposes are not intended for clinical diagnosis, especially since case identification and investigation for surveillance are most often performed retrospectively after treatment decisions have been made.

1

SURVEILLANCE RECOMMENDATION 1: Disease List Updating and Reporting

(A): Adjust and periodically review the Pennsylvania notifiable disease list. Add Babesiosis and specifically include Powassan virus as an arboviral infection to the state's notifiable disease list and conduct periodic reviews of the list for TBDs.

(B): Report TBDs not included on the Pennsylvania notifiable disease list. Encourage providers to report new and emerging TBDs (i.e., *B. miyamotoi*) not included on the list regardless of whether or not they were acquired in the state using the unusual disease occurrence reporting mandate.

PROS	CONS
• Reviewing the reportable list is a proactive approach to ensure new and emerging TBDs are included in public health disease surveillance • Surveillance data allows for the incidence and burden of illness from tick-borne infections to be measured and helps direct and prioritize prevention and control efforts among Pennsylvania residents	• Resources (staff and supplies) will be needed to disseminate and educate HCPs, as well as other community partners, on updates made to the notifiable disease list • Updating the notifiable disease list requires existing public health law to be amended. Other additions outside tick-borne infections need to be considered since amendments are not made on a rolling basis

RATIONALE:

In recent years, locally-acquired *Babesia microti* infections have been documented among PA residents, along with babesia infections in ticks. Neuro-invasive Powassan virus infections which are rare and can be fatal, have been documented among residents of neighboring states (NY and NJ). Both infections are transmitted by black-legged ticks that are abundant in PA. Lyme disease and tick-borne rickettsial infections (Anaplasmosis, Ehrlichiosis, and Rocky Mountain spotted fever) are already included on the notifiable disease list for surveillance along with tularemia and Q fever which may be transmitted by ticks or zoonotic exposures. Bartonella infections involving the central nervous system regardless of mode of transmission are currently notifiable to the health department under mandates for encephalitis and meningitis reporting in PA.

Documenting new and emerging issues is critical to proactively reducing the impact of TBDs on Pennsylvanians. Periodic examination of TBDs included on the notifiable disease list will allow the public health department to make updates based on current information from the biomedical literature along with human and ecologic surveillance data from Pennsylvania and neighboring states. Emphasis should be placed on new and emerging pathogens that can be transmitted by ticks found in PA, particularly black-legged ticks (B. miyamotoi, E. muris like agent), but also including the more aggressive Lone star tick.

Given these emerging threats, there is an urgent need to develop new and innovative diagnostic technologies that would enable rapid lab based testing systems to identify the specific pathogens or pathogens associated with the tick bite. Such innovative technologies would enable physician to utilize available treatments that are known to effectively target the specific pathogen without the significant delays associated with current serologically based diagnostic methodologies.

IMPLEMENTATION CONSIDERATIONS

Who Benefits? How?	***Pennsylvania residents, healthcare community, and public health officials*** – Gain a better understanding of which TBDs are present in the state and when/where risk of these diseases may be increased
Implementation Ideas	***Develop apps and other e-resources*** that can be updated easily for HCPs and other community partners who report notifiable diseases
Resources Needed	Dedicated staff and supplies (e.g., notifiable disease list posters, etc.) will be needed to disseminate and educate HCPs, as well as other community partners, on updates made to the notifiable disease list
Suggested Lead Organizations	• PADOH • County or Municipal Health Departments
Suggested Support Organizations	• Pennsylvania Bureau of Laboratories • Council for State and Territorial Epidemiologists • Centers for Disease Control and Prevention
Performance/Evaluation Metrics	• Annual literature review conducted to assess TBDs included on the PA notifiable disease list and possible additions to the list

2

SURVEILLANCE RECOMMENDATION 2: Statewide Environmental Survey

Increase the public, medical, and scientific community's awareness of tick populations, and the diseases they carry through a broad and comprehensive statewide environmental survey.

PROS	CONS
• Establishes baseline data for tick distribution, density and infection rates • Increased public awareness • More informed diagnosis by medical professionals • Reduced tick exposures through integrated pest management and avoidance strategies through animals • Robust data sets available for research • Identification of potential exposure hotspots and emerging TBDs	• No existing funding • Significant coordination required to ensure reliable, comprehensive survey

RATIONALE:

Information is not currently available on the distribution and pathogen prevalence of ticks in Pennsylvania. A comprehensive statewide survey will help key stakeholders know more about TBDs and take appropriate actions.

The comprehensive survey should include species distribution, density, phenology, and pathogen prevalence and load. The role of animal hosts and reservoirs on tick distribution and pathogen prevalence should also be assessed, as well as the temporal, spatial and life stage exposure risk, geographic and seasonal hotspots in Pennsylvania. This information will arm the public with more information that will lead to better tick avoidance strategies (see Prevention recommendations regarding protocol and funding strategy for high-risk areas.

IMPLEMENTATION CONSIDERATIONS

Who Benefits? How?	• ***General Public*** **-** Increased knowledge leads to informed decision making regarding tick avoidance strategies • ***Medical Community*** **-** Increased knowledge of tick presence and pathogen level that leads to better patient diagnosis after tick exposure • ***Scientific Community*** **-** Availability of a methodical statewide survey for expanded research
Implementation Ideas	• DEP Vector Management infrastructure is already in place for tick survey and testing of *Borrelia burgdorferi, Babesia microti*, and *Anaplasma phagocytophilum* • Survey and testing methodology coordinated with academia that leads to peer-reviewed research and publication • Multi-agency coordination through the existing Arboviral Workgroup, headed by the PADOH Division of Epidemiology • Existing web-based technology exists for the West Nile virus program. This technology can be adapted for TBDs data collection and sharing
Resources Needed	• Funding needed to support staffing and equipment costs
Suggested Lead Organizations	• Pennsylvania Department of Environmental Protection (DEP)
Suggested Support Organizations	• PADOH • DCNR • PA Game Commission • Pennsylvania Department of Agriculture • Public/Private Universities • Tick-borne Disease Support Organizations
Performance/Evaluation Metrics	• Reduction (as measured against the baseline established through surveys) of human TBDs in Pennsylvania • Number of reports and peer reviewed publications using statewide tick survey data • Public access statistics, such as the number of unique web visits

3

SURVEILLANCE RECOMMENDATION 3: Funding for Research and Information Sharing

Earmark state budgeted appropriations to conduct research and share information for tick distribution, control, infectivity rates, and pathogen load.

PROS	CONS
• County and State Health Departments can focus directly on tick-borne disease • A statewide distribution of tick populations will be documented • HCPs and other key stakeholders could easily access relevant data and research • Funding would advance a critically needed research agenda in Pennsylvania as well as support state institutions of higher education • Multiple organizations will conduct research and publish articles and reports in peer reviewed publications	• No existing funding • County and State Health Departments have limited epidemiological staff available to assist with tick-borne disease issues

RATIONALE:

Currently, there is no dedicated funding to support state agencies or academic institutions that have expertise in place to fulfill field studies and laboratory testing of ticks. The lack of information in regards to the host/vector cycle of TBDs in Pennsylvania contributes to underreporting and underdiagnoses of these diseases.

In addition to the basic gathering of data, a web based site should be funded and designed to provide physicians and the public with the most up-to-date information about tick-borne disease in Pennsylvania. This site should list "Hot Spots" of disease activity so those searching the site can view for more specific information about tick-borne disease in the state. There should be contact information on the site that is specifically for physicians/health care providers as well a link for the general public. A resource guide on the distribution and infectivity of ticks should be provided by county and presented to licensed physicians.

IMPLEMENTATION CONSIDERATIONS

Who Benefits? How?	• ***State, Local and County Health Departments*** **-** Funding will allow staff to provide more pertinent information to physicians, health care facilities and the public • ***State Agencies and Educational Institutions*** **-** Staff can collect ticks, test the ticks and forward the results to PADOH for more informed policies and decision-making • ***Research*** **-** New and innovative research projects will be funded that are related to tick-borne disease prevention
Implementation Ideas	• DEP Vector Management has the infrastructure for tick surveys, tick testing as well as an internal database and public website that can be modified for tick-borne disease use • Designated lead agency can support research opportunities through grants and help coordinate a multi-agency strategy
Resources Needed	• Funding needed to support staffing and equipment costs (especially increasing local and staff capacity to conduct and analyze research) • Where possible, these efforts should leverage existing and advanced technologies[21]
Suggested Lead Organizations	• DEP (tick surveillance) • PA Department of Agriculture (other animal surveillance)
Suggested Support Organizations	• University of Pennsylvania School of Veterinary Medicine (other animals) • Penn State Cooperative Extension (ticks) • Penn State Department of Entomology (ticks) • Indiana University of Pennsylvania (ticks) • East Stroudsburg University (tick/reservoir host testing) • Other Public/Private universities (ticks/other animals) • Research Groups • TBDs Support Organizations
Performance/Evaluation Metrics	• Number of tick-borne disease groups receiving state appropriations • Increased frequency of data published to local and state websites, as compared with a benchmark established prior to beginning funded activities • Increase in published reports or articles on epidemiology of TBDs

4

SURVEILLANCE RECOMMENDATION 4: Funding for Observational Epidemiological Studies
Obtain funding to support observational epidemiologic studies to provide more detailed data on the burden and cost of TBDs among Pennsylvania residents. Observation studies may include: 1) use of prevention practices and risk factors for tick-borne disease; 2) self-reported tick-borne disease illness; and 3) long-term patient outcomes.

PROS	CONS
• More detailed and specific data on TBDs and prevention practices that can be used to direct public health efforts • Provides information to supplement routine disease surveillance data	• No existing funding for universities or PADOH

RATIONALE:
Observational epidemiologic studies are needed to provide more detailed data on the burden and cost of illness among Pennsylvania residents. This information is often difficult to obtain during routine surveillance given the high volume of case reports. Further, observational studies can allow for risk factors and behaviors to be measured among residents regardless of their tick-borne disease history along with providing information to inform tick-borne disease education and prevention activities.

State universities are encouraged to pursue grant funding from federal agencies or private foundations to support this type of research and are encouraged to collaborate with PADOH.

IMPLEMENTATION CONSIDERATIONS

Who Benefits? How?	• ***Pennsylvania Residents, Healthcare Community, and Public Health Officials*** **-** Provides detailed information on tick-borne disease risk factors and illness outcomes including the examination of various treatment approaches • ***State & Federal Policy Makers*** **-** Provides specific evidence on where additional financial resources are needed to improve the health and well-being of Pennsylvania residents
Implementation Ideas	• Explore use of healthcare administrative data/electronic medical record data and if valid, use to supplement surveillance case reporting and conduct long-term outcome studies • Collaborate with academic institutions and seek support for study activities from students who have internship or thesis requirements. • Incorporate TBDs specific questions in PA state supplement for the Behavioral Risk Factor Surveillance System
Resources Needed	• Funding needed to support staffing and equipment costs
Suggested Lead Organizations	• PA institutions of higher education (IHEs) with Masters programs in Public Health or similar programs • PA academic medical institutions • PADOH Bureau of Epidemiology
Suggested Support Organizations	• Healthcare Systems in PA • Local and District Health Departments
Performance/Evaluation Metrics	• Number of observational studies of TBDs underway or completed

5

SURVEILLANCE RECOMMENDATION 5: Diagnostic Testing - Annual Updates

Provide annual updates for, and enhance availability of, a broad array of diagnostic tests for tick-borne disease, as well as encourage the development of innovative and more accurate diagnostic tests.

PROS	CONS
• Annual updates on TBD diagnostics and adoption of valid technologies will help increase the completeness of surveillance data and ensure public health disease surveillance is supported by the best available testing • For-profit biotech companies and laboratories are encouraged to assume a public health approach and incorporate plans to assess innovation, so valid technologies can be made available widely to the public	• FDA approval of innovative technologies requires time and money to accumulate data on the reliability and validity of testing • Given the high volume of Lyme disease in PA, the state public health lab alone cannot support testing for clinical diagnosis and surveillance for the entire state

RATIONALE:

Identify tests with proven performance, reliability, and appropriate clinical indications. These tests should be available through commercial reference laboratories or PADOH's Bureau of Laboratories and/or the CDC to support diagnosis and surveillance. In addition, advocate for the development of innovative, accurate diagnostic tests utilizing advanced technologies which may identify new and emerging TBDs, and support blood supply screening. Ideally, researchers should aim to develop new laboratory tests to support the diagnosis of TBDs that have excellent accuracy (>95% sensitivity and specificity) and only require specimen collection at one time as opposed to multiple specimens at different points in time (i.e., testing of acute and convalescent serum specimens for antibody development).

Widely available diagnostic tests for Lyme disease and tick-borne rickettsial infections rely on the development of pathogen-specific antibodies which takes time. The value of current testing for later disease is viewed differently.

IMPLEMENTATION CONSIDERATIONS

Who Benefits? How?	• ***Pennsylvania Residents -*** Provides a better understanding of the incidence and burden of illness of TBDs in Pennsylvania. • ***HCPs & Public Health Officials -*** Provides access to a comprehensive resource that lists diagnostic tests available to support the diagnosis and surveillance of TBDs
Implementation Ideas	• Encourage participation in tick-borne disease diagnostic development by universities and academic medical institutions in the Commonwealth • The PADOH Bureau of Laboratories, in collaboration with CDC, currently has services available to support the early diagnosis of non-Lyme TBDs (Babesiosis, Powassan, and tick-borne rickettsial infections), and HCPs throughout the state should be made aware of these services (PCR testing, microscopic smear examination-Babesiosis, IgM testing-Powassan]). Federally-funded research to improve Lyme disease diagnostics with the goal of submitting promising technologies to the FDA for approval and wide release is also underway, including the examination of various methods to diagnose early stage Lyme disease, the development of approaches to diagnose Lyme disease and co-infections, and the identification new biomarkers of Lyme disease
Resources Needed	• Staff, equipment, and supplies at the PADOH Bureau of Laboratories • Blood supply screening decisions are based on the availability of approved-assays and cost-benefit analysis of screening in relation to the potential for transfusion-related infection
Suggested Lead Organizations	• PADOH Bureau of Laboratories • PADOH Bureau of Epidemiology • Local and District Health Departments, and other state health departments
Suggested Support Organizations	• Universities and Academic Medical Institutions in PA • Biotech Companies/Commercial Reference Laboratories • CDC • Council for State and Territorial Epidemiologists • American Association of Blood Banks • American Red Cross
Performance/Evaluation Metrics	• Number of TBD tests conducted by the PADOH Bureau of laboratories to support surveillance • Improvement in availability and accuracy • Number of innovative and accurate tests methods. • Completion and publication of annual review indicating new development in testing

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SURVEILLANCE RECOMMENDATION 6: Expand Surveillance Network
Improve healthcare provider and veterinarian participation in tick-borne disease surveillance by disseminating annual advisories on the recognition, diagnosis and reporting of TBDs in PA and by utilizing technology to streamline and enable electronic tick-borne disease case reporting.

PROS	CONS
• Improves the completeness of tick-borne disease data collected through public health surveillance • Improves timeliness of case reporting	• Cost of IT staff and technology to support and implement electronic reporting • Ensuring electronic reporting systems are secure and protect personal information • Cost of health staffing to follow up on reported cases • Cost of testing equipment for veterinary practices

RATIONALE:
Improved reporting ensures case follow-up and counting by PADOH after physician diagnosis and will provide more accurate assessments of the burden of tick-borne disease in PA. To address underreporting, it is important to regularly remind HCPs and other surveillance reporting sources about the recognition, diagnosis/testing, and reporting of suspected tick-borne infections. These advisories also may include information based on the biomedical literature on the pathogenesis of infection, the spectrum of infection from the proportion of asymptomatic infections if applicable to severe disease and complications, updated treatment recommendations, and prevention measures.

Electronic reporting methods for human surveillance have been used to successfully to improve disease completeness and timeliness of reporting in PA from commercial laboratories. Technologic advances (electronic medical record systems, increased use of smart phones) provide an opportunity to make similar improvements to reporting from HCPs and other community-based reporting sources (i.e., school nurses, daycare providers, etc.). Efforts should be made to increase electronic HCP reporting through PANEDSS (state's web-based disease surveillance database) and explore the addition of components to this system to streamline submission of notifiable disease reports.

The current reporting system for human surveillance is overwhelmed by the number of reported Lyme disease cases each year. Investigation follow-up of case reporting needs to be as timely and accurate as possible to ensure appropriate counting of TBDs in Pennsylvania

For domestic pets, web-based data repositories currently exist for sentinel surveillance based on serologic testing for TBDs. Veterinarians throughout the commonwealth should be encouraged to participate in these existing programs, since they serve as an important adjunct to human and ecologic surveillance.

IMPLEMENTATION CONSIDERATIONS

Who Benefits? How?	• ***Pennsylvania residents, healthcare community, and public health officials -*** Provides more accurate data on the incidence of tick-borne disease infections in PA • ***HCPs & Community-Based Partners -*** Various options to report suspected tick-borne infections
Implementation Ideas	• Utilize electronic medical record systems for automated TBD case reporting • Establish a school-based surveillance network for TBDs
Resources Needed	• Cost of IT staff and technology to support and implement electronic reporting • Ensuring electronic reporting systems are secure and protect personal information • Cost of health staffing to follow up on reported cases • Cost of testing equipment for veterinary practices
Suggested Lead Organizations	• PADOH (humans) • PA Department of Agriculture (domestic animals)
Suggested Support Organizations	• Healthcare systems, HCPs, and other community-based partners in the state who report notifiable diseases • Local and District Health Departments • Council for State and Territorial Epidemiologists • CDC • IDEXX SNAP-4Dx and SNAP-4DxPlus test data[22] • Companion Animal Parasite Council[23]
Performance/Evaluation Metrics	• Proportion of tick-borne disease case reports received through electronic methods • Increase in participation rate of HCPs and veterinarians • Results of a health practitioner statewide survey (including school nurses) regarding scope, treatment, and behavioral norms related to TBDs

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SURVEILLANCE RECOMMENDATION 7: Expand and Standardize Data Collection In Case Investigations

Enhance and ensure tick-borne disease surveillance case investigations used by local health department and health district staff to include questions that can identify potential co-infections with other tick-borne pathogens, and help identify potential risk factors for infection.

PROS	CONS
• PANEDSS (surveillance database) infrastructure exists and additional questions can be easily incorporated • Allows tick-borne disease co-infections to be quantified • Ensures that trace back investigations in collaboration with blood banks/donation organizations and CDC are conducted for suspected transfusion/transplant related cases • Attempts to better identify potential risk factors for infections with more detailed investigations	• Difficulty obtaining complete info for Lyme disease given it is a high volume condition and may vary by local jurisdiction • The best source of information varies for the key variables (additional tests-HCP, outdoor exposures-suspected case)

RATIONALE:

Key variables include laboratory testing for other tick-borne pathogens, complete blood count testing results, recent history of transfusions, transplants, or biologic donation, underlying conditions, occupation or school, and outdoor activities during the exposure period. This recommendation aims to improve the quality of data collected during tick-borne disease surveillance and provide a better understanding of where residents are acquiring disease, the incidence of tick-borne disease co-infection, and factors that may increase risk of tick-borne infection among PA residents that should be further explored to aid prevention and control efforts.

IMPLEMENTATION CONSIDERATIONS

Who Benefits? How?	• Pennsylvania residents, healthcare community, and public health officials. Provides more detailed information on the incidence of tick-borne disease co-infections and potential risk factors for infection
Implementation Ideas	• Providers can be encouraged to enter available clinical data elements for their patients when reporting the case electronically through PA-NEDSS
Resources Needed	• The state receives a modest sum in federal funds annually to support Lyme disease surveillance and no federal funding for non-Lyme TBDs
Suggested Lead Organizations	• PADOH • Local and District Health Departments
Suggested Support Organizations	• CDC • American Association of Blood Banks • American Red Cross • Organ Donation Organizations
Performance/Evaluation Metrics	• Proportion of TBDs with extended investigation data captured as part of public health surveillance • Number of Lyme screening tests completed or number requested by patients and/or doctors

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SURVEILLANCE RECOMMENDATION 8: Surveillance Data Website

Use a centralized, publically-accessible website to disseminate summaries of human, other animal, and ecologic tick-borne disease surveillance data at a statewide and county level.

PROS	CONS
• Provides a comprehensive snapshot of tick-borne disease incidence and risk at the state and county level • A link to this website can be easily referenced in health advisories, prevention materials, and other PADOH/DEP documents • Similar web-based infrastructure exists for West Nile Virus surveillance • Collected data sets would be shared on the DOH website • Improve the education and awareness among HCPs and patients	• Data updates will be made annually unlike West Nile Virus given the high volume of Lyme disease reports • Funding for resources and staff from PA DEP and PADOH are needed to collate, analyze, and post data • Surveillance data may be interpreted as diagnostic data

RATIONALE:

The website will centralize available TBD surveillance data and studies from multiple agencies (passive human surveillance, passive domestic animal sero-prevalence surveillance, PADEP tick field surveys, other), along with general and basic information about TBDs. Information regarding diagnostics and treatment will be referred to their HCPs.

IMPLEMENTATION CONSIDERATIONS

Who Benefits? How?	• ***Pennsylvania residents, healthcare community, and public health officials -*** Provides convenient and direct access to available surveillance data on tick-borne disease incidence and risk at the county level
Implementation Ideas	• Multi-agency coordination through the existing Arboviral Workgroup, headed by the PADOH Division of Epidemiology • Existing web-based technology exists for the West Nile virus program. This technology can be adapted for TBDs data collection and sharing
Resources Needed	• Funding for resources and staff from PA DEP and PADOH are needed to collate, analyze, and post data
Suggested Lead Organizations	• PADOH (Humans) • PA DEP (Ticks) • Department of Agriculture (Other animals)
Suggested Support Organizations	• County/Local Health Departments (Humans) • University of Pennsylvania School of Veterinary Medicine (Other animals) • IDEXX SNAP-4Dx and SNAP-4DxPlus test data[24] • Companion Animal Parasite Council • Penn State Cooperative Extension (Ticks) • Penn State Department of Entomology (Ticks) • Indiana University of Pennsylvania (Ticks) • East Stroudsburg University (Ticks) • Other Public/Private Universities (Ticks/Other animals)
Performance/Evaluation Metrics	• Annual updates posted • Number of "hits" on the website

4. OTHER RECOMMENDATIONS

The Task Force recognizes that there are other areas of consideration that either go beyond (or that span) the areas of surveillance, education and awareness, and prevention. As such, this section includes several recommendations that are of an organizational nature as the Commonwealth moves forward on considering the recommendations herein for implementation.

This section includes a recommendation related to estimating the implementation cost of our recommendations as well as establishing some structure for a continued advisory function. Alternatively, an organizational alternative is provided describing a body that would be *both* advisory and that would provide a coalition-oriented partnership approach among public, private, and non-profit stakeholders. This would help to leverage resources for implementing the Task Force recommendations.

1

OTHER RECOMMENDATIONS: Convene an Advisory Body

Convene a task force that reports to the Secretary of Health and operates as an independent advisory group on Lyme disease and other TBDs.

PROS	CONS
• Provides for ongoing program integrity/impact • Provides for balance in perspectives, including patients • Addresses both the short term and longer term needs with respect to Tick-borne diseases in PA	• Requires an extensive commitment of review board members • Requires resources to support the body

RATIONALE:

The task force would continue work from the original Act 83 task force by evaluating the content of all Act 83 programs (including websites, and other communications) against the intent of Act 83, and monitoring the implementation to ensure that the legislative intent is achieved. This task force, along with PADOH, will provide ongoing leadership to address the threat of TBDs in Pennsylvania, especially as new technologies emerge. The review board may be composed of, at a minimum, a balanced representation of stakeholders including patients, HCPs, scientists, relevant government agencies/departments. This body should convene at least bi-annually to review, approve, and update programs (based on ongoing monitoring of research and development), and to handle ongoing changes to the membership (exits and replacements) as required.

The work of the task force will require a multi-year, multi-pronged strategy which requires ongoing attention. The Task Force was originally set up to provide for diversity of thought and balanced participation, to include broad spectrum views, and to ensure patient voice was included in the process. This same diversity should continue to monitor program outcomes, and impact.

This is a situation with significant research gaps, and rapidly evolving knowledge, typical of emerging diseases. In the case of Lyme disease, this is complicated by the lack of a gold-standard diagnostic. Additional TBDs continue to be identified and have not yet been well-studied. In addition, complex, multi-pathogenic disease has not been well studied; yet the few studies that exist have found increased severity of disease. In addition, the threat of these diseases is projected by the IOM and WHO to continue to increase in coming years.[25]

Act 83 was passed recognizing the difficulties of immediate change; therefore ongoing monitoring will be critical.

Therefore, it is essential to build in mechanisms to ensure that the intent of the law is achieved, and also to ensure there is a continued focus on this threat to human and economic health in Pennsylvania.

This task force was set up to provide for balanced participation, including the broad spectrum of views and ensuring patient voice in the process. Since Lyme disease was first identified over 20 years ago, the diverse perspectives regarding its prevention and treatment continue to evolve. In order to bring these perspectives together, Pennsylvania must maintain its focus on this issue and address the issue with a balanced perspective

recognizing the input of clinicians, researchers and patients. The goal should be to strive for the best possible care and outcomes for patients.

Alternative Approach – Lyme and Tick-Borne Disease Partnership Coalition

The Task Force clearly sees the need and opportunity for a continued advisory function particularly as various recommendations contained in this report move to implementation. It is also recognized, however, that there will likely be significant resource challenges associated with advancing the recommendations. As such, the concept of partnership building and resource leveraging will be as or more important than an advisory function only.

To that end the Task Force is offering an alternative approach to an advisory committee with a broader purpose. A Lyme and Tick-Borne Disease Partnership Coalition could carry out *both* an advisory role and also be involved in developing various public, private, and non-profit initiatives aimed at implementing the recommendations of this report as well as possibly other initiatives.

It is still envisioned that the Department of Health would be the appropriate convener for the Partnership Coalition. Further, given DOH's regional structure, it would be possible over time to replicate efforts on a more regional grass roots level.

IMPLEMENTATION CONSIDERATIONS

Who Benefits? How?	• Public
Implementation Ideas	• All core recommendations must be prioritized • A cost of implementation for each core recommendation must be determined • All task force core recommendations should establish a target date for implementation • A panel of experts should be established to identify outside funding sources for Pennsylvania tick-borne disease research
Resources Needed	• Website/materials development costs • Event-hosting costs • Staff time required for ongoing monitoring and updates
Suggested Lead Organizations	• All participating agencies in Act 83
Suggested Support Organizations	• **State and local health departments** • **Community-based organizations**
Performance/Evaluation Metrics	• Ongoing monitoring of achievement, intent and direction • Number of meetings, and minutes • Decrease in patient TBED diagnosis readings

2 OTHER RECOMMENDATIONS: Obtain Independent Implementation Cost Analysis

The Task Force recommends that the independent and bi-cameral Legislative Budget and Finance Committee provide a useful estimate of costs for key recommendations contained in this report and identify any potential sources of public or private grant funding.

RATIONALE AND IMPLEMENTATION CONSIDERATIONS

The Task Force affirms the importance of implementing as many of the report recommendations as possible. It also recognizes that it will require financial and other resources to do so. Many of the recommendations attempt to leverage existing programs, materials and other resources in order to be good stewards. However, the report does include recommendations that would require new funding commitments.

It was generally beyond the Task Force's scope and expertise to develop a reasonable estimate of costs for the recommendations. As such, it is recommended that the state Legislative Budget & Finance Committee (LB&FC) prepare this estimate. Ideally, this cost study would be conducted as soon as possible and preferably be completed before July 1, 2016—the start of the 2016-17 state fiscal year.

It is important to note that the scope of the LB&FC work would not necessarily be to evaluate the Task Force Recommendations, but to provide a useful estimate of costs for key recommendations. However, the Task Force would also welcome any perspectives that the LB&FC might provide regarding constructive implementation considerations.

This recommendation has been discussed in concept with the LB&FC's Executive Director. Without committing himself or the Committee, he did indicate that the staff could conduct this study if authorized by the Committee. More information regarding the LB&FC can be found at http://lbfc.legis.state.pa.us/.

SUMMARY (OR CLOSING)

Lyme disease is the most common vector-borne disease in the United States. The Centers for Disease Control (CDC) estimates that 329,000 cases occur in the United States each year. Pennsylvania has led the nation in the number of reported Lyme cases with 7,457 reported in 2014. CDC studies have found that reported cases underestimate its true incidence by a factor ten, indicating that tens of thousands of residents in the commonwealth may be infected with Lyme disease each year

Tick borne diseases (TBD) also create a significant economic burden in Pennsylvania and the United States. Over $1 billion in annual medical expenses have been attributed to Lyme disease as well as up to $10,000 per patient annually in lost productivity. Lyme patients require 87 percent more visits to the doctor, and 71 percent more visits to the emergency room in comparison to those without Lyme disease.

The rapid expansion of TBDs in the United States is further complicated by a lack of consensus among researchers and healthcare professions in many critical areas. Two organizations have published guidelines for the diagnosis and treatment of Lyme and other TBD's: the Infectious Diseases Society of America (IDSA), and the International Lyme and Associated Diseases Society (ILADS) These organizations vary greatly in their approach to diagnosis and treatment of this disease.

In September 2014, Pennsylvania joined approximately 15 states with current or past legislation establishing task forces, commissions, and/or working groups focused on aligning policy, resources, and programs to support education and awareness, prevention, surveillance, and treatment of tick-borne diseases. The Task Force members included representation from the opposing medical views (IDSA and ILADS), considered both medical perspectives, and the diversity of these views is reflected in the report and its core recommendations.

The task force was subdivided in three main subgroups: Prevention, Education & Awareness, and Surveillance. Their recommendations are as follows:

Prevention:

1) **Develop Protocol and Funding Strategies for High Risk Areas**: Develop and implement a protocol and funding strategy for schools located in high-risk areas to implement personal protection and property actions.

2) **Develop Park Staff Protocols:** Develop and implement a protocol for federal, state, and local properties to include communicating risk awareness, and taking property actions, and other methods to reduce the risk of TBDs to the staff and public.

3) **Develop Standard Brochures for Healthcare Provider Distribution:** Develop and provide a standard brochure that healthcare providers ideally should provide to patients when they are evaluated for tick-borne infection.

4) **Develop a Strategy for Reducing Transfusion Transmitted Tick-Borne Babesiosis**: Develop and implement a strategy to reduce risk of transfusion-transmitted Babesiosis.

Education & Awareness:

1) **Develop a Public Awareness Campaign:** Develop a comprehensive multimedia public awareness campaign targeting in the general public and at-risk population to improve awareness and understanding of TBD in Pennsylvania.

2) **Provide Information for Healthcare Professionals:** Provide information that will give health care professionals options for developing and making recommendations for tick-borne disease, prevention of tick-borne disease, and prevention of disease progression.

Surveillance:

1) **Notifiable Disease List Updating and Reporting:** Adjust and periodically review the Pennsylvania notifiable disease list and specifically include Babesiosis and Powassan virus. Healthcare providers should encourage providers to report new and emerging TBDs not included on the list.

2) **Perform a Statewide Environmental Survey:** Increase the public, medical and scientific community's awareness of tick populations, and the disease s they carry through a broad and comprehensive statewide environmental survey.

3) **Fund Research and Information Sharing:** Earmark state budgeted appropriations to conduct research and share information for tick distribution, control, infectivity rates, and pathogen load.

4) **Fund Observational Epidemiological Studies:** Obtain funding to support observational epidemiologic studies to provide more detailed data on the burden and costs of TBDs among Pennsylvania residents.

5) **Annual Updates on Diagnostic Testing:** Provide annual updates for, and enhance availability of, a broad array of diagnostic test for tick-borne disease, as well as encourage the development of innovative diagnostic tests.

6) **Expand Surveillance Network:** Improve healthcare provider and veterinarian participation in tick-borne disease surveillance by disseminating annual advisories on the recognition, diagnosis, and reporting of TBD's in PA and by utilizing technology to streamline and enable electronic tick-borne disease case reporting.

7) **Expand and Standardize Data Collection During Case Investigations:** Enhance and ensure tick-borne disease surveillance case investigations used by local health department and health district staff in Pennsylvania include questions that can identify potential co-infections with other tick borne pathogens, and help identify potential risk factors for infection.

8) **Develop a Surveillance Data Website:** Use a centralized, publically accessible website to disseminate summaries of human, other animal, and ecologic tick-borne disease surveillance data at a statewide and county level.

Other:

1) **Convene an Advisory Body:** Convene a task force that report to the Secretary of Health and operates an independent advisory group on Lyme disease and other TBDs.

2) **Obtain Independent Implementation Cost Analysis**: Utilize the Legislative Budget and Finance Committee to provide an estimate for implementation of recommendations.

It should be noted that despite the diversity of background and opinion in the members of the Lyme Task Force. There was uniform agreement on the growing threat of Lyme disease in Pennsylvania. The disease is increasing in frequency, is often difficult to diagnose, and requires significant further study. There is strong agreement that there is need for better education, better prevention, better diagnosis, and better treatment of the disease. Despite the many controversies in Lyme disease, there is uniform agreement among members of the committee of the need to implement the above recommendations.

APPENDIX A: ACT 83 OF 2014 FULL TEXT

LYME AND RELATED TICK-BORNE DISEASE SURVEILLANCE, EDUCATION, PREVENTION AND TREATMENT ACT - ENACTMENT

Act of Jun. 29, 2014, P.L. 808, No. 83 Cl. 35

An Act

Establishing a task force on Lyme disease and related maladies; and providing for powers and duties of the task force, the Department of Health, the Department of Conservation and Natural Resources and the Pennsylvania Game Commission to execute surveillance, prevention and education strategies.

The General Assembly of the Commonwealth of Pennsylvania hereby enacts as follows:

Section 1. Short title.

This act shall be known and may be cited as the Lyme and Related Tick-Borne Disease Surveillance, Education, Prevention and Treatment Act.

Section 2. Findings.

The General Assembly finds that:

(1) Lyme disease and other tick-borne diseases are carried primarily by ticks and pose a serious threat to the health and quality of life of many citizens of this commonwealth.

(2) The most common way to acquire Lyme disease is to be bitten by a tick that carries the spirochete.

(3) In 2009 and 2011, this Commonwealth ranked highest in the country in the number of confirmed cases of Lyme disease. From 2002 through 2011, this commonwealth has reported a total of 42,032 confirmed cases of Lyme Disease.

(4) The World Health Organization (WHO) states that Lyme disease will increasingly become a public health threat in the United States.

(5) In August 2013, the Centers for Disease Control and Prevention (CDC) released a report that preliminary estimates indicate approximately 300,000 Americans are diagnosed with Lyme disease each year. This is approximately 10 times higher than the number of cases previously reported to the CDC every year.

(6) Lyme disease is most prevalent in Southeastern Pennsylvania, but it is found and is increasing across this commonwealth.

(7) With proper precautions taken while engaged in outdoor activities, people can greatly reduce their chances of tick pathogen transmission by making sure that frequent tick checks are made and ticks are removed and disposed of promptly and properly.

(8) The early clinical diagnosis and appropriate treatment of these tick-borne disorders and diseases can greatly reduce the risks of continued symptoms which can affect every system and organ of the human body and often every aspect of life.

(9) Left untreated, Lyme disease can cause a number of signs and symptoms which can become quite severe.

Section 3. Legislative intent.

It is the intent of the General Assembly:

(1) To provide the public with information and education to create greater public awareness of the dangers of and measures available to prevent, diagnose and treat Lyme disease and related maladies.

(2) To ensure that:

(i) Health care professionals, insurers, patients and governmental agencies are educated about the broad spectrum of scientific and treatment options regarding all stages of Lyme disease and related tick-borne illnesses.

(ii) Health care professionals provide patients with information about the broad spectrum of scientific and treatment options regarding all stages of Lyme disease and related tick-borne illnesses to enable patients to make an informed choice as part of informed consent and to respect the autonomy of that choice.

(iii) Government agencies in this commonwealth provide information regarding the broad spectrum of scientific and treatment options regarding all stages of Lyme disease and related tick-borne illnesses.

(iv) A system is established for tick surveillance.

Section 4. Definitions.

The following words and phrases when used in this act shall have the meanings given to them in this section unless the context clearly indicates otherwise:

"Department." The Department of Health of the commonwealth.

"Health care professional." A licensed physician, a physician's assistant, a certified registered nurse practitioner or other licensed health care professional.

"Lyme disease." The clinical diagnosis of a patient by a licensed physician, physician's assistant or certified registered nurse practitioner of the presence of signs or symptoms compatible with acute, late-stage, persistent infection with Borrelia burgdorferi or complications related to such infection or with such other strains of Borrelia that are recognized by the Centers for Disease Control and Prevention as a cause of Lyme disease. The term includes infection that meets the surveillance criteria established by the Centers for Disease Control and Prevention and other acute and persistent manifestations of such an infection as determined by a physician.

"Related tick-borne illness." A case of Bartonella, babesiosis/piroplasmosis, anaplasmosis, ehrlichiosis or other tick-transmissible illness. The term does not include Lyme disease.

"Secretary." The Secretary of Health of the commonwealth.

"State officials." The term includes the Secretary of Environmental Protection of the commonwealth.

"Task force." The task force established by this act.

Section 5. Task force.

(a) Establishment.--The department shall establish a task force on Lyme disease and related tick-borne diseases.

(b) Purpose.--The task force shall investigate and make recommendations to the department regarding:

(1) The surveillance and prevention of Lyme disease and related tick-borne illnesses in this commonwealth.

(2) Raising awareness about the long-term effects of the misdiagnosis of Lyme disease.

(3) Development of a program of general public and health care professional information and education regarding Lyme disease which shall include the broad spectrum of scientific and treatment options regarding all stages of Lyme disease and related tick-borne illnesses.

(4) Cooperation with the Pennsylvania Game Commission to disseminate the information required under paragraph (3) to licensees of the commission and the general public.

(5) Cooperation with the Department of Conservation and Natural Resources to disseminate the information required under paragraph (3) to the general public and visitors of State parks and lands.

(6) Cooperation with the Department of Education to:

(i) Disseminate the information required under paragraph (3) to school administrators, faculty and staff, parents, guardians and students.

(ii) Determine what role schools may play in the prevention of Lyme disease, including, but not limited to, integrated pest management strategies, prompt removal and reporting of tick removals to parents, guardians and State officials.

(iii) Update policies to recognize signs or symptoms of Lyme disease and related tick-borne illnesses as health conditions potentially requiring accommodations.

(7) An active tick collection, testing, surveillance and communication program as provided under subsection (f)(2).

(c) Composition.--The task force shall be composed of the following individuals:

(1) The secretary or a designee.
(2) The Secretary of the commonwealth or a designee.
(3) The Secretary of Education or a designee.
(4) The Deputy Secretary for Parks and Forestry in the Department of Conservation and Natural Resources or a designee.
(5) The Director of the Bureau of Information and Education of the Pennsylvania Game Commission or a designee.
(6) Two physicians licensed in this commonwealth who are knowledgeable concerning treatment of Lyme disease and related tick-borne illness and who are members of the International Lyme and Associated Diseases Society.
(7) Two physicians licensed in this commonwealth who are knowledgeable concerning treatment of Lyme disease and related tick-borne illness and who are members of the Infectious Diseases Society of America.
(8) An epidemiologist licensed in this commonwealth who has expertise in spirochetes and related infectious diseases.
(9) Two individuals who represent Lyme disease patient groups and who may be a Lyme disease patient or a family member of a Lyme disease patient.
(10) One individual who is a Lyme disease patient or family member of a Lyme disease patient.
(11) Two registered nurses licensed in this commonwealth, one of whom is a certified registered nurse practitioner and both of whom are knowledgeable concerning Lyme disease and related tick-borne illness.
(12) The Director of Vector Management of the Department of Environmental Protection.
(13) An entomologist with the Department of Entomology of The Pennsylvania State University who has experience in tick identification and tick-borne diseases.
(14) A registered school nurse licensed in this commonwealth who is knowledgeable concerning Lyme disease and related tick-borne illness.
(15) Two veterinarians licensed in this commonwealth, at least one of whom is a veterinary epidemiologist and both of whom are knowledgeable concerning Lyme disease and related tick-borne illness.
(16) A representative from the Northeast DNA Laboratory of East Stroudsburg University who is knowledgeable about vector-borne diseases.

(d) Meetings.--

(1) Within 45 days of the effective date of this section, the secretary shall appoint the members of the task force. The secretary shall appoint a chairman of the task force.
(2) The task force shall convene within 90 days of the effective date of this section and shall meet at least quarterly. The task force may convene meetings via teleconference.
(3) The task force shall issue a report with recommendations to the secretary within one year of its first meeting. The report shall also be transmitted to the Public Health and Welfare Committee of the Senate, the Health Committee of the House of Representatives and the Human Services Committee of the House of Representatives.
(4) Nothing in this act shall be construed to prohibit the task force from making interim reports or taking interim actions.

(e) Compensation and expenses.--The members of the task force shall receive no compensation for their services but shall be allowed their actual and necessary expenses incurred in performance of their duties. Reimbursement shall be provided by the department.

(f) Duties of department.--The department shall:

(1) Develop a program of general public and health care professional information and education regarding Lyme disease which shall include the broad spectrum of scientific and treatment options regarding all stages of Lyme disease and related tick-borne illnesses.

(2) Develop an active tick collection, testing, surveillance and communication program, subject to the availability of funds, in cooperation with the Department of Environmental Protection, to provide a better understanding of, including, but not limited to, the full range of tick-borne diseases, geographic hot spots and levels of infectivity to be used in targeting prevention, information and education efforts. This effort may include the exploration of and recommendations regarding the use of veterinary data on tick-borne disease prevention, specifically dogs and horses and perhaps other animals, as the Centers for Disease Control and Prevention has recommended. The surveillance data shall be communicated to health care professionals via public health alerts and shall be published on the department's publicly accessible Internet website. The department may enter into a contract, memorandum of understanding or other agreement with another governmental or nongovernmental entity to develop an active tick collection, testing, surveillance and communication program.

(3) Cooperate with the Pennsylvania Game Commission to disseminate the information required under paragraph (1) to licensees of the Pennsylvania Game Commission and the general public.

(4) Cooperate with the Department of Conservation and Natural Resources to disseminate the information required under paragraph (1) to the general public and visitors of State parks and lands.

(5) Cooperate with the Department of Education to:

(i) Disseminate the information required under paragraph (1) to school administrators, school nurses, faculty and staff, parents, guardians and students.

(ii) Determine what role schools may play in the prevention of Lyme disease, including, but not limited to, integrated pest management strategies and prompt removal and reporting of tick removals to parents, guardians and State officials.

(iii) Update policies to recognize signs or symptoms of Lyme disease and related tick-borne illnesses as health conditions potentially requiring accommodations.

(6) Cooperate with professional associations of health care professionals to provide the education program for professionals required under paragraph (1).

(7) Cooperate with The Pennsylvania State University, Department of Entomology, cooperative extension program for integrated pest management, to disseminate educational resources about ticks, related diseases and integrated pest management for disease prevention as required under paragraph (1) to health care professionals and the general public.

(8) Identify and apply for public and private grants and funding in order to carry out the provisions of this act.

(9) Within 45 days of the effective date of this section, make available current data on tick surveillance programs in this commonwealth conducted by other entities, including the Northeast DNA Laboratory of East Stroudsburg University and the Department of Entomology of The Pennsylvania State University, until such time as the department publishes the results of the active tick collection, testing, surveillance and communication program as provided for in paragraph (2). The data shall be communicated via public health alerts to health care professionals and made available on the department's publicly accessible Internet website.

Section 6. Effective date.

This act shall take effect immediately.

APPENDIX B: OTHER STATES' LYME AND TICK-BORNE DISEASE LEGISLATION AS OF 2015

# STATE	STATE	YEAR	Bill Policy Regulation	NAME	STATUS	PURPOSE
1	CA	2005	AB592	An act to amend Section 2234.1 of the Business and Professions Code, relating to healing arts.	Law	Added Lyme treating doctors to existing CA law prohibiting discipline for alternative or complimentary treatment.
	CA	2002	AB 2125	An act to add Section 3212.12 to the Labor Code, relating to workers' compensation.	Law	For employees of CA Conservation Corp. and law enforcement agency, covering tick-borne diseases.
2	CT	2009	HB6200	An act concerning the use of Long-term antibiotics for the treatment of Lyme disease. 6-18-09	Law Public Act No. 09-128	Doctor protection for long-term treatment
	CT	1999	Substitute House Bill No. 5694	An Act Requiring Health Insurers to Cover Continued Lyme Disease Treatment.	Law Sec. 38a-492h. Sec. 38a-518h	Lyme treatment - not less than 30 days of IV therapy, 60 days of oral therapy, or both, & rheumatologist or neurologist, infectious disease specialist recommended.
3	DE	2004	Senate Concurrent Resolution 40	Lyme Disease Task Force of Delaware	Concurrent Resolution Adopted	Creation of Lyme disease task force.
	DE	2013	HCR 34	This Concurrent Resolution recognizes the month of July 2013 as Lyme Disease Awareness Month in Delaware.	Concurrent Resolution Adopted	Lyme disease awareness activities encouraged
4	KS	2009	HR 6029	Recognizes May 2009 as Lyme Disease Awareness Month	Resolution Adopted	Lyme disease awareness activities encouraged
	KS	2010	HR6029	A Resolution recognizing May as Lyme Disease Awareness Month	Resolution Adopted	May Lyme awareness
5	MA	2010	H1148	Lyme Disease	Law 6/30/10 Sec 67 Chapt. 112	Doctor right to treat Lyme disease with long-term approach
6	ME	2008	266B	An Act to Implement the Recommendations of the Joint Standing Committee on Ins. and Financial Services Regarding Reporting on Lyme Disease and Other Tick Borne Illnesses	Law	Reports issued
	ME	2013	LD 597 (HP 416)	"An Act To Inform Persons of the Options for the Treatment of	Law. Signed into	Addresses testing, difficulty in treating, Maine website to add

# STATE	STATE	YEAR	Bill Policy Regulation	NAME	STATUS	PURPOSE
				Lyme Disease" Sponsored by Representative Sheryl Briggs. LDA sent in written testimony	law 6/24/13 as Chapter 340	patient support content – Maine Lyme & Lyme Disease Association website to other sites
7	MN	2010	SF1631 HF2597 House Hearing	3-13-10 Med. Board meeting, the BMP agreed to a voluntary moratorium on action related to the treatment of chronic Lyme disease, for a period of no more than 5 years.	Medical Board Policy	Doctors right to treat
	MN	2014	Med Bd Policy	Limited doc protection – right to treat without sanction	11-8-14 MN Med Bd. Policy Renewed	Doc protection and included ILADS Guidelines in agenda material
	MN	1998	Bill	Mandates Lyme insurance coverage.	Law	Allows doctors to determine appropriate Lyme treatment and mandates insurance coverage.
8	NH	2011	HB295	An Act Relative to the Use of Long- Term Antibiotics for the Treatment of Lyme Disease	Law	Doctor right to treat without sanction.
9	NJ	2005	18A:35-5.1.	New Jersey Core Curriculum Content Gr. 6	Law	To insert Lyme disease into the core curriculum content standards.
	NJ	1999	S626	NJ	Law	Requires health insurers to cover Lyme disease treatment costs.
	NJ	1997	S560	Vector Control Bill	Law	Placed tick control under existing Mosquito Control Commission.
	NJ	1995	Bill	Lyme Disease Curriculum Guidelines	Law #18A:35-5.1	Development of curriculum guidelines.
	NJ	1995	Bill	Availability of Guidelines	Law #18A:35-5.2	Make guidelines available to schools
	NJ	1995	Bill	Guidelines for training of teachers instructing infected students	Law #18A:35-5.3	Curriculum guidelines for training of teachers who instruct students with Lyme. Annual in-service mandatory for those teachers.
	NJ	1991	A4223	An act establishing a governor's Lyme disease advisory council	Law PL 1991 Chapter 27	Established governor's Lyme Disease Advisory Council.
10	North East Region	2002	Res. #166	A Resolution of the New England Governor's Conference, Inc. Concerning Lyme Disease & Other Tick-Borne Illnesses	Resolution Adopted & Certified	Encourages state & regional surveillance, prevention initiatives, increase in federal funding for testing & treatment, & encourages regional

# STATE	STATE	YEAR	Bill Policy Regulation	NAME	STATUS	PURPOSE
						cooperation.
11	NY	2014	A7558-B S7854 (Hannon)	Prohibits the investigation of any claim of medical professional misconduct based solely on treatment that is not universally accepted by the medical profession.	Signed into law 12/14	Doctor protection/amended
	NY	2005	OPMC Memo (Office of Professional Medical Conduct)	Investigation of Practitioners Utilizing Treatment Modalities that are not Universally Accepted by the Medical Profession.	OPMC Memo In Force	Doctor protection for long term treatment.
12	PA	2013/ 12014	SB177	Create Task Force (Greenleaf)	Law 2014 Act 83	Task Force
13	RI	2003-04	S2939 H7240	Act Relating to Health & Safety - Lyme Disease and Treatment	Law - Chapter 04- 035	Mandates insurance coverage for long term treatment. (Passed 2003 - 2004 new version passed removing sunset provision) (LDA provided testimony for Senate & Assembly)
	RI	2010	H7418 S2265 substitute A	Beth Bowley Coen Lyme Disease Educational Act	Law - Chapter 087	Lyme disease awareness and prevention resources shall be made available for all public school students in the state. (Click here for LDA testimony)
	RI	2002	H7996A	The Lyme Disease Diagnosis and Treatment Act of 2002	Law #159	Prevents Rhode Island Board from prosecuting physicians for long treatment.
	RI	2001	Executive Order	The Governor's Commission on Lyme Disease and Other Tick- Borne Infections	Executive Order	Created a Lyme commission to study Lyme and co-infections in Rhode Island.
14	WA	2015	SB5448	Long-term treatment of Lyme disease	Law	Medical Quality Assurance Commission to study the effects of long-term antibiotic use on patients with the disease as well the treatment's side effects and efficacy.
15	TX	2009	House Concurrent Resolution 152	Study availability of medical treatments	Law	
	TX	2011	SB 1360	Continuing education requirements for physicians and nurses	Law	CME training for physicians and nurses on tick-borne diseases representing the spectrum of options

# STATE	STATE	YEAR	Bill Policy Regulation	NAME	STATUS	PURPOSE
16	Federal	2015	HR 6, Section 4081	21st Century Cures Act	Law	Boosts funding for biomedical research at the NIH, makes reforms to bring new therapies to market sooner. Establishes an interagency Tick-borne disease Working Group monitoring federal activity on Lyme, recommendations on research and treatment programs, including patients input on research and treatment.

APPENDIX C: OTHER REFERENCES & RESOURCES

There are well over 20,000 peer-reviewed research studies published on Lyme disease alone, not including co-infections. This Task Force did not evaluate these references. Therefore, this Appendix should not be considered a Task Force-approved recommendation. It is merely a random selection of references and a starting point for independent review and research.

References supporting IDSA and ILADS published guidelines for Lyme and TBD may be referred to for a more comprehensive consideration of the broad spectrum of perspectives.

Research is evolving rapidly, as such Task Force members should be leveraged for comprehensive up-to-date research references as well as cited material.

Lyme Disease References	(link to be determined)
Other Tick-Borne Diseases References	(link to be determined)
Other References	(link to be determined)

ENDNOTES

[1] Task Force membership was defined category in Act 83 and named by the Secretary of Health in 2014. Membership of the task force changed as a result of administration changes and state agency staff changes. One Nurse practitioner became unable to participate due to personal concerns and was not replaced.

[2] Nelson CA, Saha S, Kugeler KJ, Delorey MJ, Shankar MB, Hinckley AF, Mead PS. Incidence of clinician-diagnosed Lyme disease, United States, 2005-2010. Emerg Infect Dis. 2015 Sep;21(9):1625-31. http://wwwnc.cdc.gov/eid/article/21/9/15-0417_article

[3] PA Department of Health, http://www.health.pa.gov/Documents/LymeReport2014.xlsx

[4] "CDC provides estimate of Americans diagnosed with Lyme disease each year," Centers for Disease Control and Prevention, August 19, 2013, accessed July 26, 2015, http://www.cdc.gov/media/releases/2013/p0819-lyme-disease.html.

[5] http://www.portal.state.pa.us/portal/server.pt/community/newsroom/14287?id=20732&typeid=1

[6] Kiersten J. Kugeler, et al., "Geographic Distribution and Expansion of Human Lyme Disease, United States," *Emerging Infectious Diseases* 21 (August 2015): 1456, accessed July 26, 2015, doi: http://dx.doi.org/10.3201/eid2108.141878

[7] Co-infection with multiple tick-borne pathogens may make the diagnosis and treatment particularly challenging. Numerous studies demonstrate increased intensity and duration of symptoms. Please see appendix for listing of relevant research.

[8] Emily Adrion, et al., "Health care costs, utilization and patterns of care following Lyme disease," *PLOS One* (February 4, 2015), accessed July 26, 2015, doi: 10.1371/journal.pone.0116767

[9] For a full description of terms used in this report – including definitions for the aforementioned TBDs – please see the "Glossary of Terms" in the Appendix.

[10] Estimates of the percentage of patients diagnosed with Lyme disease who continue to experience symptoms of Lyme disease post-treatment vary significantly. While the CDC estimates approximately 10-20 percent, some studies have found prevalence of persistent symptoms in as many as 63 percent of patients. For more information, please see the references listed in the Appendix. Multiple studies since the 1980s have demonstrated symptom relapse post-treatment (CITE: [The Long-Term Follow-up of Lyme Disease: A Population-Based Retrospective Cohort Study. Authors: Shadick NA; Phillips CB; Sangha O et al. Ann Intern Med 1999 Dec 21;131(12):919-26]).

[11] Note: Definitions from CDC and/or Merriam Webster Dictionary. Please see Appendix B for a comprehensive list and definitions of TBDs found in the U.S.

[12] Source: Last JM, editor. Dictionary of epidemiology. 4th ed. New York: Oxford University Press; 2001. p. 61.

[13] http://www.cdc.gov/vaccines/about/terms/glossary.htm

[14] Critical Needs and Gaps in Understanding Prevention, Amelioration, and Resolution of Lyme and Other Tick-Borne Diseases: The Short-Term and Long-Term Outcomes: Workshop Report (2011) (Institute of Medicine)

[15] http://www.aabb.org/programs/publications/bulletins/Documents/ab14-05.pdf

[16] Dermatology Research and Practice, Volume 2012 (2012), http://dx.doi.org/10.1155/2012/451727, Bull's-Eye and Nontarget Skin Lesions of Lyme Disease: An Internet Survey of Identification of Erythema Migrans, John N. Aucott<http://www.hindawi.com/93717358/>, Lauren A. Crowder<http://www.hindawi.com/87970831/>, Victoria Yedlin<http://www.hindawi.com/19596060/>, and Kathleen B. Kortte<http://www.hindawi.com/86930793/>

[17] Infection. 1996 Mar-Apr;24(2):182-6. Physician preferences in the diagnosis and treatment of Lyme disease in the United States. Ziska MH1, Donta ST, Demarest FC. - J Am Board Fam Pract. 2002 Jul-Aug;15(4):277-84. Lyme disease knowledge, beliefs, and practices of New Hampshire primary care physicians. Magri JM1, Johnson MT, Herring TA, Greenblatt JF.

[18] Johnson, L., Wilcox, S., Mankoff, J. and Stricker, RB (2014) Severity of Chronic Lyme Disease Compared to Other Chronic Conditions: A Quality of Life Survey. PeerJ, DOI 10.7717/peerj.322. (Open access.)

[19] Marques, Adriana, Infect Dis Clin North Am. 2008 Jun; 22(2):341–360, Chronic Lyme Disease: An Appraisal. Aucott, John N; et al, Quality of Life Research, Feb 2013, Vol 22, Issue 1, pp 75-84, Post-treatment Lyme disease syndrome symptomatology and the impact on life functioning: is there something here?

[20] IOM's report specifically recommended a comprehensive program to bring target audiences up-to-date with current knowledge, to level-set the understanding of the state of the science using an evidence-aware approach, to share the evolving and multiple views guiding prevention – of all types. Please see: http://iom.nationalacademies.org/Reports/2011/Critical-Needs-and-Gaps-in-Understanding-Prevention-Amelioration-and-Resolution-of-Lyme-and-Other-Tick-Borne-Diseases.aspx

[21] Leverage other universities technology like URI – tick spotter, and potentially NASAs technology developed to quickly review heat fields to easily locate hot spots??

[22] See "Dogs and Ticks" www.dogsandticks.com/diseases_in_your_area.php

[23] Companion Animal Parasite Council www.capcvet.org/diseases_in_your_area.php

[24] See "Dogs and Ticks" www.dogsandticks.com/diseases_in_your_area.php

[25] "clinical manifestations of simultaneous Lyme disease and Babesiosis tend to be more severe than would be expected if these infections occurred separately", http://cid.oxfordjournals.org/content/33/5/676.long , Clinical Infectious Diseases, Vol 33, Iss 5, pp 676-685, "Coinfecting Deer-Associated Zoonoses; Lyme Disease, Babesiosis, and Ehrlichiosis", 2001, Authors: Charles Thompson, Andrew Spielman, and Peter J. Krause