



Jeff Mursau

STATE REPRESENTATIVE • 36TH ASSEMBLY DISTRICT

Assembly Committee on Health
AB313- Establishing a Tick-borne Disease Study Committee
October 16, 2019

Chairman Sanfelippo and Committee Members -

Thank you for the opportunity to testify in support of Assembly Bill 313, which establishes a tick-borne disease study committee.

Specifically, the bill creates a Tick-borne Study Committee that would be comprised of the Secretary of Health Services, the Secretary of Natural Resources, the Commissioner of Insurance, and thirteen members appointed by the Governor. The committee would be charged with studying issues involving awareness, prevention, surveillance, diagnosis, reporting, and treatment of Lyme Disease and other tick-borne diseases and submit a report to the legislature within three years.

Tick-borne illness like Lyme Disease is now considered the fastest growing infectious disease in the US and is the most common tick-related disease seen in WI. As you heard in related testimony, in 2018 Wisconsin had over 3,100 estimated cases of Lyme Disease. The average number of cases has more than doubled over the past 10 years. According to the CDC, Wisconsin is one of the states reporting the highest number of cases and in all reality the actual number of cases is probably a lot higher than what is reported.

In consultation with DHS, we have offered an amendment to the bill that addresses concerns the department raised related to committee make-up and notification about the potential for false negative tests. The senate companion bill (SB 300) as amended was passed last week by the senate on a voice vote.

It's time for Wisconsin to work together on identifying ways we can help address the seriousness of this disease. Establishing this study committee would be great first step.

Once again, thank you for holding a hearing on AB 313 today. I'm happy to answer any questions.

Testimony on 2019 Assembly Bill 313

Senator Robert Cowles

Assembly Committee on Health – October 16, 2019

Thank you, committee members, for allowing me to testify on 2019 Assembly Bill 313 as amended by Assembly Amendment 1. This bill establishes a study committee with experts from state agencies, the medical profession, local government, and more to provide consensus-based recommendations for policy changes on Lyme disease and other tick-borne diseases.

The problem of Lyme disease is growing and shows no signs of slowing. Lyme disease is a bacterial disease transmitted to humans by an infected tick commonly known as the black-legged tick or deer tick. Lyme disease is manageable if caught early, but if left untreated, the infection may spread and produce symptoms that include, but aren't limited to, severe headaches and neck stiffness, pain and swelling in large joints, fatigue, cognitive decline, shooting pains, and heart palpitations.

Lyme disease is the most commonly reported vector-borne illness, which are diseases contracted by humans from insects and usually through a bite, in the United States with an estimated 30,000 Americans diagnosed each year. According to the federal Centers for Disease Control (CDC), in 2014, nearly 96% of the 25,359 Lyme disease cases are reported from only 14 states in the Northeast and Northern Midwest with 2,975 of these cases (11.7%) reported from Wisconsin. Lyme disease is the highest reported tick-borne disease in Wisconsin, with a total of 38,394 cases reported between 1990 and 2015. In 2017, Wisconsin is the 4th-worst state in the nation for incidence of Lyme disease, and rates are only increasing. Lyme disease is most common in the Northern and Western regions of the state, but is contracted in all regions of the state.

While about a dozen other states have taken actions to address the disease in recent sessions, Wisconsin has fallen behind as rates of Lyme disease has doubled in the last decade and experts at the CDC believe the number of cases may be as much as 10 times higher than what is reported through surveillance. This bill is one of five in a series of small, yet important steps to improve our approach and foster continuing discussions to combat Lyme disease in Wisconsin.

Assembly Bill 313 as amended establishes a nineteen-member, Governor-appointed study committee to create a report for the legislature within 36-months on consensus-based recommendations for policy changes on awareness, prevention, surveillance, diagnosis, reporting, and treatment of Lyme disease and other tick-borne diseases. Some of the topics discussed will include: the use of long-term antibiotics by providers; the coverage of long-term antibiotics by insurance providers; an examination of the notification of patients for the potential of false test results, especially early in the diseases progression, and; how to disseminate information to providers on practices to test patients for Lyme disease.



The members of the study committee would represent diverse viewpoints and experiences related to Lyme disease and would include:

- The Secretary of the Department of Health Services or their designee;
- The Secretary of the Department of Natural Resources or their designee;
- The Commissioner of Insurance or their designee;
- Three health care providers with a background in diagnosing and treating Lyme disease, at least one of which shall be from north of Highway 10;
- Two educators with a background in Lyme disease or other vector-borne diseases;
- One representative based in Wisconsin from the private health insurance industry;
- One administrator or employee in the administration of a Wisconsin hospital;
- Three advocates for Lyme disease policy or residents impacted by Lyme disease, at least 1 of which shall be from north of Highway 10;
- One representative of a nonprofit organization focused on outdoor recreation;
- Two representatives from county health departments, at least 1 of which shall be from a county that is at least in part north of Highway 10;
- One representative from a group representing county health departments and boards;
- One technical director or head of a clinical microbiology laboratory, and;
- One pharmacist.

Assembly Amendment 1 was drafted in consultation with the Department of Health Services and will help to further provide professional and personal expertise to this study committee process. The Senate companion to this legislation, Senate Bill 300, was passed on a voice vote as amended by the Senate during last week's floor session on October 8th.

As the other pieces of legislation in the 'Bite Back' package of bill only represent a first step, there may be other changes that can be made to combat Lyme disease. By creating a venue for people with academic, practical and first-hand knowledge to convene, decision-makers in the Legislature, state agencies, and beyond will have consensus-based recommendations to produce the most effective policies to combat Lyme disease.

Testimony in support of Assembly Bills 313 & 317
Assembly Committee on Health
October 16th, 2019

Good afternoon, my name is [redacted] Marshfield Clinic Health System board certified in Clinical Pathology. I currently serve as the Medical Director of the clinical laboratories of the Marshfield Clinic Health System and have worked in academia, for-profit organizations, and currently am working on issues related to accessible and affordable delivery of healthcare laboratory services in our largely rural and northern service area.

Combined - see each testimony for bill #

the physician. I am currently [redacted]. I have [redacted], and [redacted] delivery of [redacted] and northern [redacted]

The subject of this statement is the goals of Assembly Bills 313 & 317 related to creating awareness of the risks associated with tick-borne diseases (TBDs) and addressing priorities for their control and prevention. We have a vested interest in supporting this series of initiatives as I will explain.

MCHS, for the [redacted] risks [redacted] for their [redacted] series of [redacted]

The MCHS serves a largely rural population in central and northern Wisconsin, and the physician and allied healthcare providers at our 55 Marshfield Clinic locations are well aware of the risks associated with TBDs experienced by farmers, farm workers, rural communities, hunters, sportsmen, lakeshore owners and outdoor enthusiasts. Our service area largely overlaps that of the highest incidence of Lyme disease in the state as recognized by the Department of Health Services, with 3,105 cases reported state-wide in 2018, and approximately 1,100 cases alone diagnosed within the MCHS.

Our clinical laboratories use the testing algorithm for Lyme Disease as recommended by the CDC. In addition we have developed molecular diagnostic tests in collaboration with our research scientists at the Marshfield Clinic Research Institute (MCRI) to identify the presence of the other major TBDs including Anaplasmosis, Ehrlichiosis and Babesiosis. These latter infections, while far less common than Lyme Disease, are also a cause for great concern



because of higher risk for acute and possibly life-threatening disease outcomes if not recognized and treated promptly.

In addition to supporting novel diagnostic test development, Research Scientists in the MCRI at MCHS have pursued many published studies in recent years on the genetic characterization of pathogens, immune and physiologic responses to tick-borne diseases, ecologic studies in conjunction with the Department of Natural Resources on tick and TBD distribution, and epidemiologic studies on disease prevalence trends and geographic distribution within our service area. These studies have included practical approaches meant to assess interventions to prevent exposure to ticks through personal protection and land management practices aimed at discouraging tick numbers through alteration of habitat that otherwise supports rodent and deer populations.

Lyme and other TBDs are not a phenomenon common just to the upper Midwest or North America for that matter; indeed very similar ticks and tick-borne pathogens are also common throughout Europe and in other regions of the world. Much can be learned from these colleagues who have been dealing with these same diseases as long or longer than we, and who have been developing diagnostics, therapeutics and control measures for some time. My colleagues and I at MCHS have recently presented a five-year summary of our experience with several of the TBDs at the 2019 European Congress on Clinical Microbiology and Infectious Diseases held in Amsterdam, and became aware of research and management efforts being made by Europeans similar to our own. National and global partnerships between the professions, academia, public health, natural resources and industry are key to creating the necessary cross-disciplinary culture required to address management and control of these diseases. There are many dedicated, knowledgeable and willing partners available once a mechanism is established that can bring focus to the problem and generate reasoned, practical and science-based goals that have a high likelihood of success. We feel that AB 313 offers that opportunity.

Educational efforts to assist healthcare providers and patients alike are clearly key to the success of any control program. In the MCHS we have established on-line practice guidelines for our providers for assessing patients at risk for Lyme and the other TBDs, which diagnostic tests are most appropriate, and recommendations for therapeutic management. Importantly, there are a number of quality resources available through state and national government agencies, private foundations and academic institutions that provide background materials for providers and patients focusing on disease signs and symptoms, and management and prevention topics. It is important, however, to assess the source and credibility of the many resources available on-line that deal with TBD. While many offer accurate and useful background information, others may be



misleading and generate misconceptions that can complicate a serious medical discussion between patient and provider. The MCHS does supply our clinic locations with patient educational materials on these diseases with illustrated brochures demonstrating the tick species of greatest concern, and tips on how to limit exposure to them.

Lastly, I want to alert you to a Lyme Disease medical conference that my colleagues and I at the MCHS and MCRI are planning for next April 30th-May 1st. We have recognized for some years that insufficient focus has been given to these increasingly common and serious infections, and providers and patients continue to have many questions. We will be holding this conference in the Minocqua area, an area well known to have a high incidence of Lyme and the other TBDs. The goal for this initial conference is to increase provider awareness of the risks inherent in Lyme disease, and how to identify and manage these infections in rural and small town practice locations. Recognized state and national leaders knowledgeable in these diseases have accepted invitations to present. While the intent is primarily to aid our medical providers, we would be happy to have select representative(s) of your committee attend. If successful, we envision partnering with other Wisconsin and regional entities to create a periodic recurring conference that would have an expanded focus on broader issues including public health, and the role of government, the professions and industry in working on solutions.

I am personally appreciative of the approaches Representatives Jeff Mursau and Nick Milroy, and Senators Cowles and Miller, and all the sponsors, have taken in these proposed bills that starts a long-needed process whereby science, medicine, public health and natural resources can explore and learn from each other to address the serious nature of these diseases that are so prevalent and a very real threat to the health and welfare of the citizens of this state. The MCHS stands ready to support any forthcoming initiative and be a partner in finding answers to these serious concerns.

Thank you for your time this afternoon.

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Submitted to Assembly Health Committee by Jeanette Wheat, RPh, MBA for Hearing about Lyme Disease Bills 313, 314 & 317 on Wednesday, October 16, 2019

Good Afternoon, My name is Jeanette Wheat. I am a pharmacist with an MBA. I am also a survivor of chronic Lyme disease diagnosed in 1989. The disease disabled me and stole what was left of my career in 1997. I am also a survivor of uterine cancer diagnosed about 5 years ago. Additionally, I am a widow of a man with Lyme disease who passed from cancer 3 years ago.

I currently have one cat diagnosed with Lyme disease and have had at least one other cat with Lyme disease in the past.

Years ago, I used to serve as a leader for a Lyme support group and provided information and support to other support groups around the state of WI as well as individuals seeking information about Lyme and associated diseases- the coinfections.

There are 4 topics about Lyme Disease I want to share with you today.

The first is a 1989 document about Lyme Disease from the WI Dept of Health & Social Services, Division of Health. You should already have this paper.

The second is the controversy surrounding Lyme Disease.

The third is a short version of the story of my life with Lyme Disease and the fourth is my comments on the current Bill(s) under consideration.

1.If you have been trying to learn about Lyme disease and find yourself perplexed or confused, don't feel bad, it is an extremely complex set of diseases and the politics surrounding these illnesses only make it more difficult to understand. The first thing I would like to cite is this 1989 Clinician's Guide produced and distributed throughout WI in 1989 and ask that it become part of the official hearing documents record. One of the most profound statements made in this document is: "Lyme disease has become a "fact of Life" for all citizens of Wisconsin.

The tick vector (*Ixodes damini*) is well established throughout the state." This is found on page two in the second paragraph. And remember this is from 1989! We should no longer be debating this point!

This document also cites *Borrelia burgdorferi* being passed via the placenta during pregnancy. This is another point that should no longer be debated.

2.Whenever things don't make sense, or don't add up, there's a reason. Most commonly, I have found that the reason(s) have to do with power, money and/or ego. With regard to Lyme Disease all of the above are true.

If there are so many people with Lyme Disease, why are there so few physicians treating them?

This is my introduction into the Controversy surrounding Lyme Disease.

It can easily take an hour or two just to go over the reasons why this controversy exists. In lieu of that, I have provided some basic written information about the specific issues with links to webpages that provide greater insight.

Please see these handouts in your packets. All of these topics are central to understanding what goes on with Lyme Disease, but the Controversy of Lyme may be the most important one.

“Why are there so few Doctors Available to care for people with Tick-Borne Infections?”

And

“Supplemental Information about the Controversy of Lyme Disease.”

In order to gain an understanding of the Controversy of Lyme, it is important that you go to at least some of the webpages I listed and read the articles. Most are fairly concise. As an afterthought, I decided it would be easier for you if I attached the first two articles at the end of this testimony. Go to Page 6.

And

“The Bacteria Persists after Antibiotic Treatment”

3. Then to my Lyme story. It goes back to my birth when my mother spiked a 104 degree temperature immediately after my birth. For this she was placed on 10 days of penicillin immediately. Of course, she was not specifically being treated for Lyme Disease, because Lyme Disease had not yet been discovered and was not a known medical entity at that time.

I was not given any antibiotics because I showed no outward symptoms. The immune system of an infant infected in the womb, will not react to bacteria introduced to it while it was in the womb. That is to say, it will not create antibodies to the bacteria.

Growing up I suffered frequent bouts of a sort of tonsillitis type of illness and various and sundry miscellaneous other symptoms. I developed a significant scoliosis, apparently caused by a bone spur misaligning my vertebrae. Some believe the inflammation caused by Lyme Disease can cause bone spurs.

One year, after visiting my grandparents at their little mom & pop resort in central MN, all 3 of my siblings experienced joint pains, with misc. other symptoms, and the younger two were told they had growing pains due to the pain in their knees. The oldest was evaluated for Lupus, but no conclusions were drawn.

My mother was concerned about me because she said I sighed so much- like the "air hunger" seen with Babesia, one of the malaria-like co-infecting organisms. In third grade I recall my hands and fingers often going numb while my hands laid open face down on my desk- a sign of vascular and/or neurological involvement.

I got tired easily. I remember asking my mother if I could be switched to the afternoon kindergarten class so I didn't have to get up so early in the morning. Any of you who have experienced normal kindergartners know that they are generally up at the crack of dawn creating a ruckus and spending a lot of energy. That was not me.

Sometime during my first two years of college, I developed a severe sort of bronchopneumonia. I had frequent severe headaches, light sensitivity, a progressive scoliosis curve and miscellaneous other minor to troublesome symptoms.

My chiropractor asked permission to show my back X-ray during a presentation as an example of a moderately-severe scoliosis in a young person.

It was about 35 degrees at the time.

In my early twenties, I started experiencing compromising cognitive deficits with an inability to remember peoples' names. Even with people I had known for years, I would just go blank when trying to introduce them to others. One time, during a job interview, I could not remember the name of a hospital where I had worked for over a year while attending college. Needless to say, I was not offered that job.

I loved to camp, hike, fish and in general enjoy the outdoors. Eventually, by the time I was about 28 years of age, I had to stop camping completely. By the time my husband and I got our tent set up and gear properly stowed, I was so exhausted it was no longer fun to be camping. There was not enough energy to hunt for fire wood to build a campfire or to fish to catch dinner for supper.

At about that same age, I finally started seeing physicians for my symptoms. The eighth physician I saw finally diagnosed me with Lyme disease, in 1989, at the age of 34, with positive antibody tests. That took about 7 years. Along the way, my chart was labeled with ALS and various psychiatric conditions. At about 29 years of age, one MD told me that I was just getting older and that I should no longer expect to have the energy I had as a teenager. Yes, I said at the age of 29 a doctor actually told me I was just getting older! At the age of 34 one MD wrote that I was a disturbed "middle-aged woman" who just needed to get out more.

Along the way, I gave away my bicycle, my cross-country skis and virtually every other piece of outdoor equipment I owned.

Because I am pharmacist, once I was diagnosed, I started reading and learning all that I could about this disease. I have now been studying this collection of illnesses known as Tick-Borne Diseases for about 30 years. The cognitive deficiencies caused by Lyme prevent me from always being able to cite each specific detail and fact, but I can easily report on the broad overall perspective of the circumstances of Lyme Disease as it has progressed.

After being diagnosed, I managed to work an additional 7-8 years before I became completely disabled. Sometimes, there was an IV pump in the pocket of my lab coat pushing life preserving antibiotics into my veins while I cared for my patients. The most difficult phone call I ever made was to Social Security to request disability papers. I cried uncontrollably throughout that call.

I have been on my death-bed twice with this disease and nursed back to health with intravenous antibiotics and the kind care of my mother. I have been as heavy as 185 pounds and as thin as 106 pounds due to effects of this illness.

I have suffered from depression, extreme fatigue and excruciating pain, requiring what I refer to as elephant pain medicine, 80-some times as potent as oral morphine, but the cognitive dysfunctions are sometimes the most disturbing to me. People used to refer to me as bionic, but since Lyme I am cognitively impaired. I can't do my continuing education with Live or webinar broadcasts. I need text that I can read and re-read to understand. Neuropsychiatric testing also showed deficits in my processing. It is hard to accept the many losses of function Lyme has caused for me.

I am now 64 years old and still disabled by Lyme Disease. Fortunately, little by little, more is known about this disease. I should say collection of diseases, because the Borrelia bacteria infection rarely exists without co-infections. Multiple co-infections have been discovered and mast cell activation syndrome may also play a part for many battling this disease.

I end the story of my struggle here. This disease has gone on far too long for me to be able to convey, in the short time I have at this hearing, all the ways in which it has reduced my quality of life.

4. Lastly, I want to specifically address the Bills, AB313, AB314 & AB317, this body is considering regarding Lyme Disease. First let me say, after struggling with this illness all of my life, I am ever so grateful that finally Lyme disease is being given some thought and action by the Wisconsin legislative bodies.

It is difficult to grasp just how complex Lyme Disease is with regard to the spectrum of symptoms it can cause and the body-wide damage it can inflict. Once one recognizes that the cork-screw shaped bacteria that cause Lyme Disease are not limited to transport throughout the body via the blood stream and that they can and do literally drill through a body's tissues and individual cells from one end of the body to the other, the vast number of symptoms it causes become a bit more comprehensible.

Then there are the known co-infections that now number at about 11* that frequently accompany Lyme Disease making the diagnosis and treatment even more challenging. [*https://www.lymedisease.org/lyme-sci-coinfections/](https://www.lymedisease.org/lyme-sci-coinfections/) "The recognition of tick-borne pathogens that are responsible for human illness is accelerating. Eleven new ones have been discovered since 1960, with over half of those found since 2000."

These facts, alone, make it imperative that individuals, tasked with designing information to educate our citizens, diagnosing and treating this illness, and making recommendations for and/or setting public policy about it, be people who are already deeply involved with and knowledgeable about this disease. Additionally, it is extremely important that these people be free of ulterior motives and conflicts of interest.

I am testifying against AB313.

Appointing people to a committee, such as the one being considered in AB313 based solely upon their current job title will create a committee that will generate subpar outcomes. In my opinion, this is just part of why this committee, as currently envisioned, won't work.

I have submitted additional concerns about this committee in a written document supplied in your packet.

I am testifying in support of AB314 and AB317.

However, I do have recommendations for improving the bills.

I have submitted my thoughts on this in a written document supplied in your packet.

Thank you for allowing me to speak to you today.

Here are the 2 articles about the Controversy of Lyme I said I would attach at the end of my testimony.

1. **Controversy---**

<https://lymediseaseassociation.org/category/about-lyme/controversy/>

There is a controversy surrounding Lyme disease which has prevented many people from being diagnosed with the disease and from being treated appropriately for the disease. The essence of the controversy is persistence of infection versus autoimmunity

One viewpoint espouses that Lyme disease is hard to catch and easy to cure. Its proponents promote short-term antibiotic treatment regimens (a few weeks) that often are not effective for those who have been diagnosed with Lyme disease. The patients sometimes remain symptomatic after that course of treatment. When that happens with other diseases, patients are often given longer courses of antibiotics. However, those holding this viewpoint, including the IDSA (Infectious Diseases Society of America) and insurance companies, have proceeded to take strong actions to prevent Lyme patients from receiving any more antibiotics. Their claim is any remaining symptoms are "autoimmune" in nature, not persistent infection.

The other viewpoint is held by physicians who are treating chronic Lyme patients. They recognize that scientific research shows that even after longer term treatment (more than the few weeks) with antibiotics, some of the Lyme bacteria can survive (persistent infection). They also recognize that although some symptoms can be the result of an autoimmune cascade, that cascade is driven by a small amount of bacteria that remain after treatment. These treating physicians have found that repeated courses of antibiotics and combinations of antibiotics (which attack in different ways) often help patients to become self sufficient and regain functionality in society.

An argument used against long-term treatment is that prolonged antibiotic use develops resistant bacteria. That claim has not been proven. In fact, antibiotic resistance generally develops as a result

of improper usage of the antibiotic—not taking enough, thus the admonition to patients to “take all of your antibiotics that are prescribed, do not stop taking them when you feel better.”

Most treating physicians, patients, advocates and many others feel vested interests control Lyme disease and set the limits for what the disease is, how it can be treated, how it can be tested for, and what science can be published on Lyme disease.

This section presents some of the issues, positions, and players in the controversy.

2. Controversy

<https://lymediseaseassociation.org/wp-content/uploads/2001/04/ConflictReport.pdf>

This is an in-depth report. So, I have just copied the Executive Summary for you here.

“EXECUTIVE SUMMARY For more than a decade, Lyme disease has been the object of debate. On one side are academicians, pharmaceutical companies, and government agencies, who claim the disease is usually mild and virtually always easily cured. On the other side are chronic Lyme disease patients and their doctors, who say that infection may survive the standard four weeks of antibiotic treatment, and that its impact may be debilitating and difficult to treat. This report adds another dimension to the debate by focusing on Lyme disease as a business model. An examination of patents, marketing agreements, and revenue streams reveals the potential for the appearance of conflict of interest for many of the individuals setting Lyme disease policy. These policies, created in part to enable the analysis of data required for product approval, have also served to disenfranchise large numbers of infected patients no longer meeting the official standard for diagnosis with the disease. Untreated by physicians and uncovered by insurance companies, these patients have become increasingly ill. In the pages that follow we will detail the straightforward path of revenue and its relationship to multinational pharmaceutical companies, venture-backed biotechnology firms, government agencies, and academicians. LDA hopes that Congress and other officials will study the information presented in this report as a springboard for their own review. Such review is of the utmost urgency because Lyme disease is the most rapidly spreading vector-borne infection in the United States, prevalent not just in the Northeast, but in California, Wisconsin, Minnesota, and across the continental US. As long as the status quo is allowed to stand, large numbers of people exposed to this rapidly emerging infection will continue to go undiagnosed and untreated for Lyme disease, and will be placed at severe risk for lifelong health problems, including arthritis, neurological impairment, psychiatric illness, cardiac illness, gastrointestinal disease, and more.”

With recommendations for amendments, I am speaking in favor of AB314 & AB317

Submitted to Assembly Health Committee by Jeanette Wheat, RPh, MBA for Hearing about Lyme Disease Bills 314 & 317 on Wednesday, October 16, 2019

Regarding AB314:

I think there should be some provision for who is responsible for confirming the accuracy and completeness and proofing and approving these materials, unless it is thought that 1 individual should bear the complete responsibility for this.

I also believe that it would be appropriate for this individual to prepare a brochure about Lyme Disease and its basic concerns, from prevention to recognizing symptoms..., for the state parks to use when they have not produced other brochures that include Lyme Disease information according to AB317.

Regarding AB317:

I believe there should be a provision that no state park should go longer than 1 year without providing some sort of Lyme Disease informational materials. The epidemiologist cited in AB314 could produce a state-wide Lyme Disease brochure that the state parks could use to distribute when they are not producing their own Lyme Disease informational materials. I also believe there should be a provision that the tick repellent permethrin should be mentioned by name in any materials addressing prevention, as the best currently-known chemical repellent for ticks. (Note: permethrin is a generic name, not a brand name. No brands should be recommended one over another.)

I am testifying against AB313 which establishes a 16-member committee to study Lyme Disease.

Submitted to Assembly Health Committee by Jeanette Wheat, RPh, MBA for Hearing about Lyme Disease Bill 313 on Wednesday, October 16, 2019

Here are some reasons why I am completely against the idea of a 16-member committee to study Lyme disease in Wisconsin.

A 16-member committee is an idea that sounds great on paper, but in practice produces very little of value. First, it attempts to reinvent the wheel. These committees have been done, but they are too big, with too many people and too many egos. What's always wrong with these committees is that they are made up of credentialed people with big titles and no first-hand knowledge of the topic at hand. The individuals appointed have big credentials, but generally very little actual front-line knowledge of the topic they are to study. Additionally, these individuals rarely attend the meetings themselves, sending in designees instead.

Any such committee needs people who work and live in the trenches of Tick-Borne Diseases (TBDs) day in and day out diagnosing, treating, supporting and being the people with Lyme Disease.

In particular the topics of prevention, diagnosis and treatment are not specific to Wisconsin. And again, they have all been studied by committees. There already exist two sets of national guidelines for the diagnosis and treatment of Tick-Borne Disorders, one of which has the support of the Lyme community and people with Tick-Borne illness. In my opinion these areas of study do not vary significantly from state to state, with the exception of where there exist actual different bacterial species, that produce slightly different diseases, requiring slightly different treatment strategies, such as southern tick-associated rash illness (STARI), a variation on the *Borrelia burgdorferi* bacteria, more common in the southern states. These are national concerns and it only serves to produce confusion when states produce their own different, usually underfunded, studies and conclusions.

I have great concern about allowing, much less dictating, placement of insurers on any such committee. They are there because they are called "stake-holders", but what they have at stake is their profits. They would be there only looking out for their profit interests, not the health of the people infected with Tick-Borne Diseases. Look at the handout I provided about the Controversy of Lyme. Go to the website listed under #6 "Massachusetts Blue Cross & Blue Shield denying Lyme treatment claim". Read the text of the news report about how Blue Cross & Blue Shield in MA are ignoring the law requiring treatment of Lyme. Near the end of the text, you will see the Blue Cross & Blue Shield employee's title, which is "Vice President of Clinical Programs and Strategy". The term strategy in the title concerns me a lot.

What is the role of the Commissioner of Insurance in WI, or a representative of a WI insurance company on such a committee? We should not be designing policy built around what insurance companies think. They should not be there to recommend or help set patient diagnosis or treatment policy. Policy regarding patient needs should be designed with healthcare professionals, patients and our departments of health. Insurers need to design their internal policies to work around what patients need as determined by informed healthcare professionals and the patients themselves.

I would consider supporting a Bill that calls for a smaller group, perhaps up to 8 people, that would study more WI specific topics such as awareness by Wisconsinites and surveillance and reporting in WI.

The physicians that would be included on the committee, as amended to require infectious disease specialists, would not necessarily be the best choices. Infectious disease specialists are not routinely specialists in Tick-Borne Disease. Lyme Disease and the associated co-infections are an extremely complex combination of illnesses requiring a specialty all to their own. Some of the best Lyme treating physicians in the country are actually family practitioners who have been in the trenches caring for their patients with Lyme Disease for decades. These are the doctors who understand the illnesses and their diagnosis and treatments as well as how patients respond to them. These are the doctors with the first-hand experiences and knowledge in spite of not having the credentials that other less well-informed MDs may have. Any physicians appointed to any such committee should have practices devoted to caring for patients with Tick-Borne Diseases regardless of their specialty standing. Prior to being considered for appointment to such a committee, these MDs should be members of the International Lyme and Associated Diseases Society and regularly attend conferences on the topic of Tick-Borne Disease as well as share information and questions with other physicians who do the same.

For example; if you had HIV, you would not want just any infectious disease doctor caring for you. You would want one that specialized in caring for patients with HIV. There are now a few infectious disease physicians in this country that are specialists in Tick-Borne Diseases, but there may not be any in the state of WI yet. At least, I am not aware of any. Perhaps Mike Nickels, Wisconsin's current most knowledgeable Lyme Advocate, would know of one.

Additionally, any person named to such a committee should be thoroughly vetted for conflicts of interest and any bias toward the status quo. This alone should deny any seat to any insurance related individual. We need progress, including progressive research, not more of the same failed procedures.

Advocates for Lyme Disease patients serving on such a committee must be willing to be known to the Lyme community, including at least 2 methods of contact, i.e. a phone number and an email address. They must be willing to be, and actively, involved in communications with Lyme patients, support group leaders and local and national Lyme Disease advocacy organizations. It may seem ridiculous to have to put this in writing, but after the debacle with the Infectious Disease Society of America (IDSA) and their guidelines panel, it has become necessary. Their so-called Lyme Advocate(s) refused to even be known by name to the Lyme community, much less to communicate with them or learn of their needs. Clearly, one can not advocate for a person or persons unless one speaks to these persons to understand their needs. The "Advocate" on IDSA's panel was no Advocate at all.

In this Bill 313 there is mention of false negative testing that can occur very early after being infected by the bite of a tick, but there is no mention of the great number of false negative tests that occur in later stages of the disease. Studies have shown that with our current tests and most commonly used testing methods, patients may receive false negative reports nearly 50% of the time, according to reporting on the website of GloballyLymeAlliance.org. This number applies specifically to the ELISA antibody test that is most commonly used as the first test given to rule out Lyme Disease.

Current best practice recommends that when testing a person for Lyme, both the ELISA and the Western Blot antibody tests be drawn and run at the same time. Unfortunately, most non-Lyme literate physicians are unaware of this. When they find a negative result from the ELISA, they inform the person

they do not have Lyme and do no further testing. This allows approximately 50% of the people with Lyme to have their diagnosis missed and delayed. This delay has dire implications for the persons long term health and the likelihood of ever putting the infection into remission. Even when a Western blot test is run after the ELISA it can be falsely negative 20% of the time. Running both together provides the best outcome, but I do not have a % accuracy rate for this to share with you at this time.

Interpretation of these tests is also not black and white and straight forward. One needs to know more than how to read the words on the test report. There are many variations and strains of the Tick-Borne pathogens. Available tests do not account for all of them. The CDC "approved" Western blot specifically leaves out some protein bands that are specific to certain strains of *Borrelia burgdorferi* because they are less common- or at least that's what the CDC has said. So, if you happen to have one of those strains, you will get a negative test purely due to the limitations of the test. This is why reading the test results requires one to have more in-depth knowledge of the bands the tests look for, and to know that a person whose test shows only 4 positive bands, when 5 are required for a positive test, very well may be infected with Lyme. That's also where it is important to understand that at this time, diagnosis is not made by testing. The diagnosis is made clinically based on the person's signs and symptoms with testing only being confirmative if found to be positive. Even the CDC agrees with this.

Because of the number of people receiving false negative ELISA tests for Lyme disease and the lack of information available to them and the physicians ordering the tests, the state of Virginia passed a law requiring information about the tests be given to each person who was tested for Lyme Disease.

<https://lis.virginia.gov/cgi-bin/legp604.exe?131+sum+hb1933>

Each of the 16 member positions listed in AB313 should be justified as to their presence on the committee. Their purpose and what each brings to the table should be identified and spelled out. There should be greater description as to the requirements to fill each position. For example, the Bill calls for two educators knowledgeable about Lyme or another vector-borne disease. What types of educators would be considered here? And why would another vector-borne disease knowledge be applicable?

I should continue on and dissect the rest of the positions on this committee, but I have run out of time and energy to do so. Someone else should take up this task before any such Bill becomes law. I think if proper thought is given to this, it will become clear that a 16 member committee is not necessary or advisable.

As a pharmacist and a person infected with Lyme bacteria and co-infections, diagnosed in 1989, I have been studying TBD's and the politics surrounding them for decades. Although, due to intervening life issues, as I mentioned cancers and the loss of my spouse, I have not been able to keep up with the most current developments as well as I would have liked to over the last, give or take, 6 years. Even so, when I speak of Lyme Disease, I speak with a great deal of authority. So, please take my words to heart. Thank you.



Department of Entomology

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Assembly Committee on Health – Assembly Bills 313, 314, 317
Testimony provided by Susan Paskewitz,
Midwest Center of Excellence for Vector-Borne Disease
October 16, 2019

Chair Sanfelippo & Members of the Assembly Committee on Health,

Thank you for the opportunity to testify today in support of Assembly Bills 313, 314, and 317. My name is Susan Paskewitz and I am the Director of the Midwest Center of Excellence for Vector-Borne Disease at the University of Wisconsin-Madison. The Center was established in 2017 as a five-year program to connect state public health with academic scientists to work to reduce the risk of diseases transmitted by ticks and mosquitoes. I am also the chair of the Department of Entomology in the College of Agricultural and Life Sciences (CALs). During my nearly 30-year career as a professor of medical entomology at UW-Madison, my research, teaching and outreach activities have all focused on mosquitoes and ticks as the most medically important arthropods in Wisconsin.

Lyme disease is an important and growing problem in our state. Wisconsin is one of 14 states that account for 95% of all Lyme disease cases in the nation. While the official Wisconsin case number usually is about 3,000-4,000 cases each year based on reporting, the actual numbers are likely much higher than that, with the Center for Disease Control (CDC) estimating real cases may be ten times higher. The burden of this disease includes a substantial economic cost, including lost days of work and doctor visits and testing, as well as follow-up that may be needed after the initial diagnosis and treatment. In addition, our children are one of the highest risk groups for Lyme disease, probably because of the amount of time kids spend outdoors.

My research on the deer tick, also called the blacklegged tick, starting in the early 1990s, has documented one of the reasons that the problem is worsening: the spread of this particular tick across the state of Wisconsin. In the 1980s and 1990s the ticks were abundant only in the western half of the state and there were many counties where they had never been recorded. However, as of October 2019, there are only three counties left where we haven't been able to find evidence of an established population: Dodge, Kenosha, Winnebago. Thus, deer ticks are likely to be present everywhere in the state where there are forests and patches of woods.

We have also tracked the increasing prevalence of Lyme disease in the ticks and the emergence of new types of tick-borne illnesses. There are now at least seven different types of pathogens that are transmitted by deer ticks, including anaplasmosis, ehrlichiosis, Powassan virus and

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babesiosis. In response to these problems, this year the Center of Excellence launched the first large Tickborne Disease Prevention survey to look at knowledge, attitudes and prevention practices in citizens in Wisconsin, Minnesota, and Michigan. We also are testing control methods like trail mowing in parks and deploying “tick tubes” to gather evidence about what works to reduce the risk of exposure to ticks in the environment. But we know these initiatives are not going to be enough.

The three Assembly Bills (AB 313, AB 314, and AB 317) put forward reasonable steps to try to reduce the impacts of the problem. Assembly Bill 314 provides support for an epidemiologist in the State Department of Health Services while AB 317 calls for an awareness campaign at the Department of Natural Resources: both bills focus on the development and distribution of more educational materials about risks and prevention of tick-borne illnesses. The other bill, Assembly Bill 313, establishing a tick-borne disease study committee, enables a broader conversation about the issues. The study committee will be able to make recommendations for methods that work to reduce human exposure to these ticks and the associated illnesses. Preventing new cases is a core goal that everyone can agree upon.

With this in mind, in my professional opinion, all three bills align with the goal of protecting public health in Wisconsin and that is why I support the proposed legislation.

I would like to thank Senator Cowles and Representative Mursau for introducing this legislation and I thank the Assembly Committee on Health for taking the time to consider these important bills. I would be happy to take questions at this time.

October 16, 2019

The Nature Conservancy Testimony in Favor of Assembly Bill 313, 314 and Assembly Bill 317

Chairman Sanfelippo and Members of the Assembly Committee on Health:

Thank you very much for the opportunity to testify in favor of Assembly Bills 313, 314, and Assembly Bill 317, legislation authored by Rep. Jeff Mursau (R-Crivitz) and Sen. Rob Cowles (R-Green Bay) to fight the spread of Lyme Disease in Wisconsin. My name is Alex Madorsky and I am an External Affairs Associate at The Nature Conservancy in Wisconsin. The Nature Conservancy (TNC) is the world's largest conservation organization working in Wisconsin and around the globe to protect the land and water on which all life depends. Guided by science, we create innovative, on-the-ground solutions to our state's toughest challenges so that nature and people can thrive together. In Wisconsin, the Conservancy has protected more than 233,800 acres of land and water since 1960.

The dramatic increase in diagnosed cases of Lyme Disease in Wisconsin poses an immediate threat to both the lands protected by TNC and its employees. Nationwide, the number one cause of workers' compensation claims among my colleagues at TNC is Lyme Disease. As climate and weather patterns continue to change, we know that ticks and other insects which spread vector-borne diseases will only increase in Wisconsin without a proactive approach to the problem. We also know Wisconsin's outdoor recreation economy is threatened by the spread of Lyme Disease. Fear of Lyme Disease is a leading deterrent to parents and children spending time in the great outdoors who would otherwise be excited to have their children enjoy hunting, fishing, cycling and other activities generally available on TNC lands. TNC's farmer partners are also at risk from the negative impact vector-borne disease can have on the ag workforce in rural Wisconsin.

Assembly Bill 313 creates a task force which will submit a report to the Legislature on Lyme Disease prevention, diagnosis, treatment, and awareness. This task force will be comprised of representatives from non-profit conservation organizations, the Department of Health Services (DHS), the Department of Natural Resources (DNR), the Office of the Commissioner of Insurance (OCI), health care professionals, environmental educators, local public health officials, and Lyme disease patients and advocates. Convening this broad group of relevant stakeholders is a critical first-

step to mitigating the impact of Lyme Disease in Wisconsin and working towards prevention based on the best available medical science. Senate Bill 300, the Senate companion legislation to AB 317, passed the state Senate on a unanimous voice vote on October 8, 2019

Assembly Bill 314 creates a much-needed new position at DHS for a staff advanced epidemiologist. This scientist's mandate will be to raise awareness and create informational materials regarding vector-borne diseases. Current DHS staff receives some funding to study vector-borne diseases, but overtaxed staff do not presently have the resources to adequately combat and educate the public on Lyme Disease. The new dedicated epidemiologist position will greatly increase the state's capacity to address Lyme Disease with a modest increase in resources.

Assembly Bill 317 simply requires state parks which distribute brochures (beyond maps) include pertinent, updated information on Lyme Disease, preventing tick bites, and inspecting oneself and others for ticks after leaving a state park. This bill ensures state park users have accurate information to protect their families from vector-borne diseases, additionally incorporating digital media strategies. Senate Bill 298, the Senate companion legislation to AB 317, passed the state Senate on a unanimous voice vote on October 8, 2019

Assembly Bills 313, 314, and 317 have a broad range of co-sponsors across regional and party lines. These bills bring sound science and public health outreach to the forefront of fighting the growing threat Lyme Disease poses to Wisconsinites eager to recreate in our state's most prized hunting grounds and fishing streams. These bills will also help protect the health of working conservationists and farmers. Thank you again for the opportunity to testify, and I am pleased to answer any questions you may have.

Alex Madorsky

External Affairs Associate, The Nature Conservancy