



DAVID CRAIG

STATE REPRESENTATIVE
CHAIRMAN, ASSEMBLY COMMITTEE ON FINANCIAL INSTITUTIONS

Assembly Committee on Health
Public Hearing, February 3, 2016
Assembly Bill 768 Testimony

Chairman Sanfelippo and Members of the Committee,

Thank you for taking the time to hear testimony on Assembly Bill 768.

Based on my conversations with many of my constituents and other members of the legislature from around the state, there is growing concern with the increasing prevalence of Lyme disease infection in Wisconsin and the lack of clarity in legal treatment options. This legislation ensures that all options are within reach of Wisconsin's medical professionals by providing an avenue for the creation of the best methods of treatment to those suffering from the devastating effects of Lyme disease, persistent or chronic Lyme, and related diseases and complications.

What this bill merely does is instruct the Medical Examination Board (MEB) and the Board of Nursing (BON), which licenses physicians, physician assistants, and advance practice nurses who are certified with prescribing authority, to establish rules of best practices for the diagnosis and treatment of Lyme disease. In particular, addressing the diagnosis and treatment of late stage, persistent, or chronic cases of Lyme disease, or the complications and related diseases that arise from such cases.

While not as prescriptive as legislation passed in Maine, New Hampshire, and Connecticut, which prohibited sanctions against medical professionals for certain actions, this bill would provide a clearer direction to Wisconsin's medical professionals as to what steps can be taken in the treatment of long-term symptoms of Chronic Lyme without risking punitive action.

It is our understanding that this committee will hear concerns from many patients as well as members of the medical community regarding this proposal. Please know this bill is not a line in the sand, but rather the beginning of a broad and much needed conversation to bring this disease to the forefront of issues facing our state. All treatment options must be made clear for Wisconsin residents suffering from the effects of Lyme disease, persistent or chronic Lyme, and the numerous related complications while ensuring more freedom in the patient-physician relationship.

Thank you once again for hearing this bill, and I am happy to answer whatever questions the committee may have.



**Testimony of Rep. Melissa Sargent
Assembly Committee on Health - Public Hearing
Feb. 3, 2016**

Thank you, Mr. Chairman and Committee members, for allowing me to testify before you today on behalf of AB 768.

The prevention and treatment of Lyme disease must be a priority for Wisconsin.

Countless individuals across our state are unable to get the treatment they need to overcome the effects Lyme disease has made on their life.

Recently, I had a very personal encounter with Lyme disease when my son fell ill and I had to watch him lose all energy and suffer while doctors told me it could not be Lyme.

They initially refused to even give him a blood test, suggesting it was likely Lupus.

When he was finally correctly diagnosed, he improved, but I know for many the process is not that simple.

Since I was elected to the Assembly, I have heard from numerous individuals in my district with their personal stories regarding Lyme disease. It has deprived them of their quality of life.

Many have been fighting this disease for years. Nothing has worked for them. They simply want answers and respect.

This bill would require the Medical Examining Board and Board of Nursing to create and update rules for the diagnosis and treatment of Lyme disease.

Rep. Craig and I believe this is a reasonable first step to take.

It is time to help those suffering from Lyme disease to move towards a healthier life. Approximately 95 percent of all cases of Lyme disease occur in the Northeast and the Upper Midwest, and 25 percent of the reported cases are children. That is why we are calling for bi-partisan action on this issue.

I am thankful to Representative Craig for his leadership on this bill.

Neither of us want to put an undue burden on the medical community. Instead, we want to work with them. This legislation aims to honor the needs of patients, and allow our health care providers to come up with 21st century best practices to combat Lyme disease in Wisconsin.



Frank Lasee

WISCONSIN STATE SENATOR
FIRST SENATE DISTRICT



Senator Lasee's Testimony **Assembly Bill 768 — Treatment of Lyme Infection**

Currently, medical boards do not recognize the existence of long-term Lyme Infection despite reams of medical evidence to the contrary. As a result, there are many doctors who understand the devastating effects of long-term Lyme Infection but are unable to treat their patients out a fear of losing their medical license.

There are doctors who are successfully treating patients with this debilitating infection. They are forced to choose whether to meet the desperate needs of their patients or abide by their licensing board's opinion. Some have chosen to help their patients get well despite the risk to their practice. This barrier to care creates a problem for patients seeking treatment and doctors who are willing and able to bring healing, but fear reprisal.

Part of the reason why Long-term Lymes Infection is not recognized more broadly in the medical community is the difficulty and confusion in diagnosis. The infection is hard to detect and may present as many other maladies. However, doctors who are well-trained to spot the specific symptoms and do the proper testing are easily identifying the problem and serving their patients.

You will hear for many people today who have Lymes embedded deep in their system. It is devastating to the body and you will hear their pain and the story of the struggle. We need to unshackle medical professionals so they can treat and heal those suffering with this debilitating ailment. This bill will result in sick people getting well and will allow doctors to fulfill their oath to patients.



Wisconsin Medical Society

Your Doctor. Your Health.

TO: Assembly Committee on Health
Representative Joe Sanfelippo, Chair

FROM: James H. Conway, MD, FAAP – Professor of Pediatrics
University of Wisconsin School of Medicine and Public Health

DATE: February 3, 2016

RE: Opposition to Assembly Bill 768 – Lyme disease and the Medical Examining Board

Chairman Sanfelippo and members of the committee, thank you for the opportunity to testify regarding AB 768 today. I'm pleased to represent the viewpoint of both the Wisconsin Medical Society and the UW School of Medicine and Public Health on this matter. As you know, this bill would require the establishment of rules established by the Medical Examining Board, defining "best practice" in the diagnosis and treatment of Lyme disease.

As a pediatrician and infectious diseases specialist, I have cared for hundreds of patients with Lyme – in both the Northeast and Midwest. I fully understand the stress associated with delayed and missed diagnoses in family members, as well as how challenging it can be to sometimes identify Lyme infections. I fully understand and support the interest of the bill sponsors in trying to improve the recognition and timely treatment of people with Lyme disease.

While the bill proposes the Medical Examining Board as an appropriate venue for establishing these improvements, there may be a better venue: the Wisconsin State Department of Health Services, Division of Communicable Diseases. Improving surveillance and reporting and then using that information to educate both the public and medical communities is part of their established mission. This type of public health activity should remain their responsibility.

More concerning is that the bill includes a provision requiring the MEB to promulgate rules about diagnosis and treatment by the Medical Examining Board. It is important to recognize that every patient is different, and while there are established guidelines for managing most conditions, these need to be personalized for every patient. Having the MEB take responsibility for dictating how medical professionals care for their individual patients seems to be both unnecessary and potentially hazardous.

As science and clinical medicine continue to evolve, there are already well-established guidelines for Lyme diagnosis and treatment that are routinely updated by groups of experts, including the Infectious Diseases Society of America, the American Academy of Pediatrics 'Red Book' Committee, and the Centers for Disease Control. These serve as an invaluable evidence-based guide for providers who care for Lyme patients and are readily available. Importantly, they provide latitude that allows for patient and provider to determine what is best for each individual.

I stand ready to lend my expertise to the sponsors of the bill in order to craft the best piece of legislation possible for the patients in our state. Thank you for your time and I will be happy to take any questions you may have.

February 2, 2016

RE: AB 768

Dear Representatives,

We are excited to hear that Bill AB 768 on Lyme Disease diagnosis and treatment is being brought forward for debate.

I would like to share our recent experience with diagnosing and treating Lyme Disease. For four months my wife has been physically and emotionally ill. Initially, we took blood tests, hormone tests and the CDC ELISA Lyme test. All showed nothing wrong. In the meantime the symptoms continued to worsen. We saw specialist after specialist and nothing worked. Up to that point my wife had visited about a dozen different doctors and a lot of time and money was wasted and she was feeling worse.

At this point we took it upon ourselves, having lost all confidence in the mainstream medical community, to take a Western Blot Lyme Test. Conventional medicine (CDC guidelines) will not allow this test unless the CDC ELISA test is positive, so we eventually found a lab that was able to do this for us. Lo and behold it was positive. We showed these results to our general practitioner and his assessment was the test is negative. His logic was the bars on the read out were not solid enough to read it as positive. From there we took the test results to a practitioner who is familiar with Lyme disease and it took all but 1 minute to review it and confirm the positive result. She is now under treatment and with God's blessing all will go well.

The point of this letter is to highlight to you the woeful lack of understanding about this disease in the mainstream medical community. It is not that they are bad doctors, they just don't understand the insidious nature of this illness and therefore cannot diagnose or treat this properly. Current CDC guidelines fall under Einstein's definition of insanity. Doing the same thing over and over and expecting a different result. If we had not bypassed those guidelines my wife and I would still be searching for answers with yet a dozen or more specialists, more suffering and less resources.

If you truly want to help my suggestion is to not let mainstream practitioners set the guidelines, do not take the CDC guidelines as reasonable. Find the right people who understand this disease to set the guidelines so that others like my wife get the right diagnosis and treatment quickly, without consuming all their resources and give them a fighting chance for getting healthy. Thank you for the opportunity to address this with you.

Sincerely,



Jeff and Dawn Sarandos
W310 S7565 Arbor Drive
Mukwonago, WI 53149
(h) 262-363-8870

Hello,

My name is Susan Allen and I am one battle-weary warrior. I am a veteran of a war I never signed up for, and the victim of a battle between two entities (my government and the medical establishment), that have ethical responsibilities to protect me and ensure my well-being, but have failed miserably to do so.

Five summers ago I was a healthy single mother of three and a high school teacher who had just completed my Master's Degree and ran my first half-marathon. Then I became ill and joined the ranks of the walking wounded. I spent the next four years going from doctor to doctor, from Green Bay to Milwaukee to Chicago to the Mayo Clinic, trying to get answers for what was wrong with my brain. By the time I was accurately diagnosed in 2014 with Neuroborreliosis (Lyme Disease that's infected the brain), I had lost my job, my career, my home, my social network and all economic security. The relief of finally having a diagnosis was short-lived, however, because it didn't take long before I realized the medical and financial maelstrom that accompanies Lyme Disease. It's a sad state of affairs when, as a patient, a diagnosis of cancer would have been preferable, because at least then you could anticipate empathy, support, a plan of action, treatment options, and an understanding of what the possible outcomes might be. At least then there would be physicians who were knowledgeable about the disease and weren't afraid to treat it. At least then insurance would cover it.

Luckily for me, 1,611 days after first falling ill, I finally found a compassionate Lyme-Literate physician that understood my disease, knew how to treat me and wasn't afraid to do so. My physician is a true representation of a hero in my mind, a man of distinguished courage and ability, admired for his brave deeds and noble qualities. He also is a warrior, not only battling for his patients, but fighting back against the state licensing agency trying to prevent him from doing so. He's done this at great personal cost: untold stress, a heart attack, and thousands of dollars in attorney fees. Yet he knows in his heart what is right and continues to provide treatment.

There are thousands of people just like me in our state, and hundreds of thousands like me in our country. There are very few knowledgeable physicians willing to help. Because the government won't acknowledge the existence of chronic Lyme Disease, insurance companies won't provide treatment. This is such a shameful state of affairs, and the silence, apathy and indifference of the government and medical community comes at great human cost. Only those who can financially afford to pay for their own treatment have a chance of recovery.

I applaud the authors and supporters of AB 768. A bill calling for the establishment of rules regarding best practices for the diagnosis and treatment of chronic, persistent Lyme Disease is a step in the right direction. In a state that is endemic for Lyme Disease there are too many physicians that are ignorant about how to accurately diagnose and treat the disease. And those that are Lyme-literate, are understandably hesitant to treat it and risk losing their licenses. Hopefully establishing these guidelines will begin to help remedy this situation.

I only have two concerns as you proceed with this bill. Please make sure that whoever has input into establishing these rules has extensive experience and knowledge in the diagnosis of chronic and persistent Lyme Disease. Since the current blood tests are woefully inaccurate and inadequate, it's a tricky clinical diagnosis. Also, this is a disease that affects every sufferer differently depending on what systems it attacks in their bodies and what co-infections have come along for the ride. There are no two people with exactly the same disease, and thus no one-size-fits-all solution for treatment. I would hope that the rules for treatment that are developed would be broad enough to allow physicians a wide variety of options, and not so narrow that it would restrict them and tie their hands when it comes to treatment options.

Thank you so much for your attention to this important matter!

Susan Allen
920-737-2278
Lydiatha2@gmail.com

CITY OF FRANKLIN, MILWAUKEE COUNTY, WISCONSIN
CERTIFICATION

I, Sandra L. Wesolowski, duly appointed City Clerk of the City of Franklin, Milwaukee County, Wisconsin, do hereby certify that I have compared the annexed copy of Resolution No. 2016-7168 [A Resolution Authorizing Certain Official(s) to Attend and Give Input at the State Capitol Public Hearing Scheduled for February 3, 2016 Related to Assembly Bill 768, an Act to Create Sections 441.16(3)(f) and 448.40(3) of the Wisconsin State Statutes Relating to the Diagnosis and Treatment of Lyme Disease and Requiring the Exercise of a Rule-making Authority] with the original thereof on file and recorded in the City Clerk's Office which was adopted on the 2nd day of February, 2016, and that the same is a true and correct copy of the whole thereof.

In testimony whereof, I have hereunto set my hand and affixed the seal of said City of Franklin, Wisconsin, this 2nd day of February, 2016.



Sandra L. Wesolowski
Sandra L. Wesolowski
City Clerk

RESOLUTION NO. 2016-7168

A RESOLUTION AUTHORIZING CERTAIN OFFICIAL(S) TO ATTEND
AND GIVE INPUT AT THE STATE CAPITOL PUBLIC HEARING SCHEDULED FOR
FEBRUARY 3, 2016 RELATED TO ASSEMBLY BILL 768, AN ACT TO CREATE
SECTIONS 441.16 (3) (f) AND 448.40(3) OF THE WISCONSIN STATE STATUTES
RELATING TO THE DIAGNOSIS AND TREATMENT OF LYME DISEASE AND
REQUIRING THE EXERCISE OF A RULE-MAKING AUTHORITY

WHEREAS, Lyme disease is the most common vector-borne illness in the United States;
and

WHEREAS, according to the Center for Disease Control (CDC) studies suggest that
approximately 300,000 people are infected with Lyme disease each year in the United States;
and

WHEREAS, Wisconsin is among the leading states in the nation in terms of infection
rates and diagnosed cases; and

WHEREAS, untreated Lyme disease can produce a wide range of symptoms, some that
can become debilitating and disabling increasing the risk of serious long-term health
complications; and

WHEREAS, Representative David Craig has introduced legislation in response to the
increasing prevalence of Lyme disease that would instruct boards governing medical
professionals in Wisconsin to establish rules regarding best practices for the diagnosis and
treatment of Lyme disease - in particular late stage, persistent, or chronic cases; and

WHEREAS, under the very best intentions to address the growing concern of Lyme
disease, caution is required as legislation may not ensure freedom in the patient-physician
relationship or guarantee use of the most up to date treatment options resulting in resident's
suffering from the numerous debilitating effects of Lyme disease.

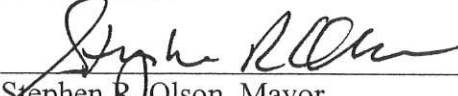
NOW, THEREFORE, BE IT RESOLVED, by the Mayor and Common Council of the
City of Franklin, Wisconsin, that in the public's interest, the seriousness of Lyme disease and the
need for proper testing and treatment is recognized.

BE IT FURTHER RESOLVED, that the Mayor and Common Council of the City of
Franklin authorize a representative of the Common Council to attend and present as needed in
support of increased diagnosis and treatment of Lyme disease based on the most up to date
research to protect the health and safety of its residents.

INTRODUCED by Alderwoman Kristen Wilhelm at a regular meeting of the Common Council of the City of Franklin this 2nd day of February, 2016.

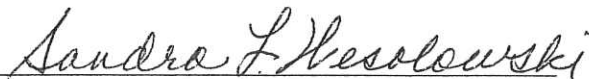
Passed and adopted at the regular meeting of the Common Council of the City of Franklin this 2nd day of February, 2016.

APPROVED:



Stephen R. Olson, Mayor

ATTEST:



Sandra L. Wesolowski, City Clerk

AYES 6 NOES 0 ABSENT 0



Lyme Disease

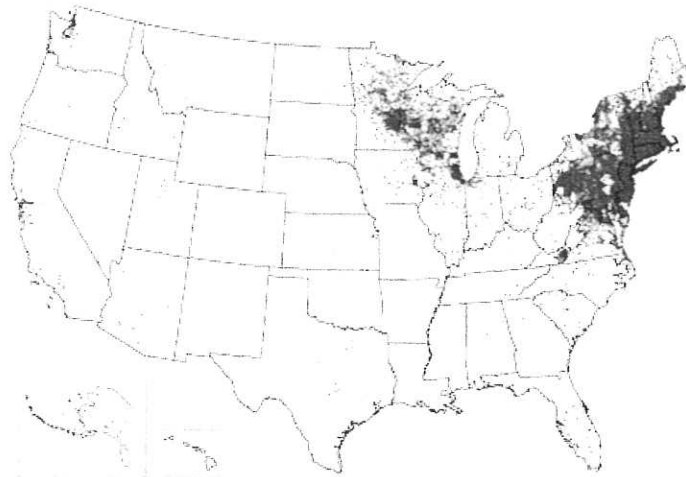
Interactive Lyme Disease Map

Click the links below to see the distribution of Lyme disease cases over 10 years.

Use the navigation to the left to change the year of the map to view

- [Go to Year 2013](#)
- [Go to Year 2012](#)
- [Go to Year 2011](#)
- [Go to Year 2010](#)
- [Go to Year 2009](#)
- [Go to Year 2008](#)
- [Go to Year 2007](#)
- [Go to Year 2006](#)
- [Go to Year 2005](#)
- [Go to Year 2004](#)
- [Go to Year 2003](#)
- [Go to Year 2002](#)
- [Go to Year 2001](#)

Reported Cases of Lyme Disease -- United States, 2013



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

Confirmed cases of Lyme disease by state or locality, 2001-2013

Year	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012	2013
U.S. Total	17,029	23,763	21,273	19,804	23,305	19,931	27,444	28,921	29,959	22,561	24,364	22,014	27,203

Page last reviewed: September 12, 2012
 Page last updated: August 27, 2014
 Content source: [Centers for Disease Control and Prevention](#)
[National Center for Emerging and Zoonotic Infectious Diseases \(NCEZID\)](#)
[Division of Vector-Borne Diseases \(DVBD\)](#)

Hoisington, Joshua

From: Jeff Sarandos <jeff_sarandos@yahoo.com>
Sent: Tuesday, February 02, 2016 8:37 AM
To: Rep.Sanfelippo
Subject: Concerning AB 768

Representative Sanfelippo,

We are excited to hear that Bill AB 768 on Lyme's Disease diagnosis and treatment is being brought forward for debate.

I would like to share our recent experience with diagnosing and treating Lyme's Disease. For four months my wife has been physically and emotionally ill. Initially, we took blood tests, hormone tests and the CDC Lyme test. All showed nothing wrong. In the meantime the symptoms continued to worsen. We saw specialist after specialist and nothing worked. Up to that point my wife had visited about a dozen different doctors and a lot time and money wasted and she was feeling worse.

At this point we took it upon ourselves, having lost all confidence in the mainstream medical community, to take a Western Blot Lyme's Test. Conventional medicine (CDC guidelines) will not allow this test unless the CDC test is positive, so we eventually found a lab that was able to do this for us. Lo and behold it was positive. We showed these results to our general practitioner and his assessment was: the test is negative. His logic was the bars on the read out were not solid enough to read it as positive. From there we took the test results to a practitioner who is familiar with Lyme's disease and it took all but 1 minute to review it and confirm the positive result. She is now under treatment and with God's blessing all will go well.

The point of this letter is to highlight to you the woeful lack of understanding about this disease in the mainstream medical community. It is not that they are bad doctors, they just don't understand the insidious nature of this illness and therefore cannot diagnose or treat this properly. Current CDC guidelines fall under Einstein's definition of insanity. Doing the same thing over and over and expecting a different result. If we had not bypassed those guidelines my wife and I would still searching for answers with yet a dozen or more specialists, more suffering and less resources.

If you truly want to help my suggestion is to not let mainstream practitioners set the guidelines, do not take the CDC guidelines as reasonable. Find the right people who understand this disease to set the guidelines so that others like my wife get the right diagnosis and treatment quickly, without consuming all their resources and give them a fighting chance for getting healthy. Thank you for the opportunity to address this with you.

Sincerely,

Jeff and Dawn Sarandos
W310 S7565 Arbor Drive
Mukwonago, WI 53149
(h) 262-363-8870

Name, age, location, I'm recovering from Chronic Lyme disease, 4 associated co-infections
Husband and I both FA's and I have our own firm
Always been active in community and with my family, and enjoy a physically active and
fulfilling lifestyle.
Simply put, things were very good.
6 years ago, that productive and fulfilling life I was living came to screeching halt.

In early 2010, health began deteriorating.
Several doctors, countless tests, led to lupus diagnosis.
Treated for lupus for year and a half, health continued to decline.
Transferred to new doctor at well-known, highly regarded Milwaukee area hospital, after several
months, told me I DID'NT have lupus.
Asked her to test me for lyme. Told me "I don't see lyme in you. Stop googling so much."

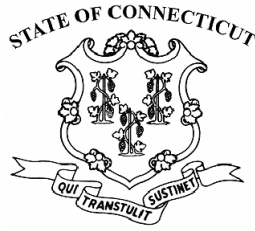
For months after, saw several different specialists, had countless tests, all yielded no results, and
health cont. to deteriorate.
Finally, through my own extensive research and a mutual friend, I was referred to an LLMD,
which stands for lyme literate medical doctor.
Recognized my symptoms immediately, my lyme test was "off the charts" positive.
The past 2 and a half years treatments difficult, no fun at all,
I've gone from not being able to get out of bed without help, to hiking to the top of 10,000 ft Mt.
Washburn in Yellowstone this past September.

I'm here today because every lyme sufferer deserves to have the same successful treatment
opportunities that I had. Unfortunately, most lyme sufferers don't have the opportunity to have
the treatment that would allow them to hike that mountain. You can change that.

This bill is an critical 1st step in allowing Drs to have the confidence and knowledge to diagnose
to treat LD and AC's. If my original Drs would've had this confidence and knowledge, I wouldn't
have had to endure lupus treatment, which greatly damaged my immune system. I wouldn't have
had to endure months of uncomfortable and sometimes painful tests that yielded no results, or the
humiliation of being told to stop googling so much.
These things shouldn't be happening to people but they're happening everyday across Wisconsin.

My story could become the story of anyone in this room and IS the story of people who suffer
from LD and AC's.

You have the opportunity to make it possible for tens of thousands of lyme sufferers to avoid the
pain, humiliation, and loss that I've endured.



Substitute House Bill No. 6200

Public Act No. 09-128

**AN ACT CONCERNING THE USE OF LONG-TERM ANTIBIOTICS
FOR THE TREATMENT OF LYME DISEASE.**

Be it enacted by the Senate and House of Representatives in General Assembly convened:

Section 1. (NEW) (*Effective July 1, 2009*) (a) As used in this section, (1) "long-term antibiotic therapy" means the administration of oral, intramuscular or intravenous antibiotics, singly or in combination, for periods of time in excess of four weeks; and (2) "Lyme disease" means the clinical diagnosis by a physician, licensed in accordance with chapter 370 of the general statutes, of the presence in a patient of signs or symptoms compatible with acute infection with *borrelia burgdorferi*; or with late stage or persistent or chronic infection with *borrelia burgdorferi*, or with complications related to such an infection; or such other strains of *borrelia* that, on and after July 1, 2009, are recognized by the National Centers for Disease Control and Prevention as a cause of Lyme disease. Lyme disease includes an infection that meets the surveillance criteria set forth by the National Centers for Disease Control and Prevention, and other acute and chronic manifestations of such an infection as determined by a physician, licensed in accordance with the provisions of chapter 370 of the general statutes, pursuant to a clinical diagnosis that is based on knowledge obtained through medical history and physical examination alone, or in conjunction with testing that provides

Substitute House Bill No. 6200

supportive data for such clinical diagnosis.

(b) On and after July 1, 2009, a licensed physician may prescribe, administer or dispense long-term antibiotic therapy to a patient for a therapeutic purpose that eliminates such infection or controls a patient's symptoms upon making a clinical diagnosis that such patient has Lyme disease or displays symptoms consistent with a clinical diagnosis of Lyme disease, provided such clinical diagnosis and treatment are documented in the patient's medical record by such licensed physician. Notwithstanding the provisions of sections 20-8a and 20-13e of the general statutes, on and after said date, the Department of Public Health shall not initiate a disciplinary action against a licensed physician and such physician shall not be subject to disciplinary action by the Connecticut Medical Examining Board solely for prescribing, administering or dispensing long-term antibiotic therapy to a patient clinically diagnosed with Lyme disease, provided such clinical diagnosis and treatment has been documented in the patient's medical record by such licensed physician.

(c) Nothing in this section shall prevent the Connecticut Medical Examining Board from taking disciplinary action for other reasons against a licensed physician, pursuant to section 19a-17 of the general statutes, or from entering into a consent order with such physician pursuant to subsection (c) of section 4-177 of the general statutes. Subject to the limitation set forth in subsection (b) of this section, for purposes of this section, the Connecticut Medical Examining Board may take disciplinary action against a licensed physician if there is any violation of the provisions of section 20-13c of the general statutes.

Approved June 18, 2009

Lyme Disease Bill 768 Testimony – 2/3/16

Good Afternoon Committee Members and Chairman,

My name is Kristin Collins. I am a Registered Nurse and have been a Lyme advocate and self-researcher on Lyme Disease and its complexity for 6 years. I am a board member of the Wisconsin Lyme Network a 501 c3 nonprofit organization that was founded in the fall of 2011. I'm not speaking on behalf of the Wisconsin Lyme Network but on my experience as a nurse and advocacy work. I am a Lyme patient with multiple coinfections that has treated for 6 years straight. I have two sons and a husband who have also treated Lyme and multiple coinfections associated with Lyme. Currently my youngest son is still treating. I saw well over 36 practitioners and even as a nurse didn't receive a proper diagnosis. I diagnosed myself and then had to find someone to treat me. Lyme and Associated Disease includes every single symptom of every disease and condition science and medicine knows and I had every single one of them except testicular pain. Although I'm off treatment as of mid-September 2015 I was just diagnosed with a positive Powassan Virus Test just yesterday. Powassan Virus is a emerging discovery in WI and certainly in other states as well.

Today, I would like to focus on the medical side and perhaps clarify information regarding Lyme and Associated Disease vs. my story as we would be hear all day and my families story would cause many open wounds to resurface that I'm trying very much to move past.

I appreciate Rep Craig bringing this to the forefront. However, I agree with Mike Nickel that without amendments this bill will not aide in anything regarding Lyme Disease and its Associated Diseases but cause

more turmoil by having the state medical board (MEB) and Board of Nursing (BON) involved in making diagnostic and treatments protocols. This is not the job of the MEB nor the BON as they don't have the knowledge to be involved in making diagnostic and/or treatments protocols. Currently we do have guidelines in place that were published by the National Guidelines Clearinghouse and were rewritten and adopted in 2014 by the NGC.

So technically there are two standards of care guidelines for Lyme and Associated Diseases. (ILADS and IDSA) I have a copy of the published ILADS protocol per the National Clearinghouse Guidelines that leaves treatment of Lyme and Associated Diseases open ended and provides a guideline only for practitioners and their patients to have open ended treatment based on their response and their symptoms. IDSA has restricted guidelines that allow very limited treatment and restricted treatment that is not working and is causing needless suffering with this Disease entity. They are not individualized and Lyme and Associated Diseases needs to be addressed on a case per case basis by trained practitioners as seen fit, as every case is very different for numerous reasons that include many; multiple strains, genetics, past medical history, etc. It's complicated, these are stealth pathogens. May I request for the record that these ILADS Guidelines be provided to the cosponsors and counsel for their consideration? I would also like to add to the record the most up to date map per the CDC from 2013 that shows how endemic Lyme is in WI. Thank You.

In August of 2013 the CDC made a public health announcement that their reported number of 30,000 Lyme cases annually was grossly underestimated and the numbers were 10 fold higher at 300,000 cases

annually. It is believed this number is much higher and potentially 10 times higher or even greater.

Conventional testing is poor at best and doctors are definitely undereducated on diagnosis and treatment of Lyme and Associated Diseases. Yet Wisconsin is considered to be one of the top 10 most endemic states in the U.S.

The criteria for reporting Lyme Disease in the state of WI is: (I quote)

**“This is a Wisconsin disease surveillance category II disease:
Report to the patient’s local public health department electronically, through the Wisconsin Electronic Disease Surveillance System (WEDSS), by mail or fax using an Acute and iCommunicable Disease case report F-44151 (Word, 166 KB) or by other means within 72 hours upon recognition of a case.”**

This didn’t happen with my family. One of my family member’s cases was reported and we received a call from the health department. So 3 of us were never even reported. I asked the Health Department when they called and we were not listed in their system. So you can see the reporting is grossly underestimated as well.

Lyme disease and its Associated Diseases is considered the “great imitator” and mimics many of the common diseases that conventional medicine diagnosis’s people with daily such as MS, ALS, Alzheimer’s, Parkinson’s Disease, ADD, ADHD, Fibromyalgia, Lupus, Rheumatoid Arthritis, Psychological illnesses like schizophrenia, bipolar disorder, anxiety and depression among others, as well as many autoimmune diseases. These diseases have no scientific testing protocols and are based primarily on symptomology alone. There are a lot of “syndrome like” illnesses out there because medical researchers gather evidence and determine that this subset of symptoms we will call “such and such” syndrome. All testing in medicine is merely a tool to aide in a diagnosis not make a absolute confirmation on many things. Medical testing isn’t a “magic ball” so to speak. Could these diseases be Lyme and/or Co-

Infections or Associated Diseases? How many people are being misdiagnosed every day?

There are many myths surrounding Lyme Disease due to the lack of education among practitioners. One of those myths is that you must have a Bull's eye rash to have Lyme Disease. However, less than 50% of cases develop a bulls eye rash (many may not see them either do to their location on the body as ticks and other vectors like to obtain their blood meal from areas on the body that aren't visible to the eye when looking in the mirror) and yet when patients do have a rash, practitioners don't recognize it and take the "let's wait and see approach" and by then it's disseminated throughout the body and is much more difficult to treat. A bulls eye rash is Lyme Disease, no testing is needed. Rashes also aren't always a "bull's eye" and may be irregularly shaped or look like a mosquito bite or spider bite which we still don't know all the other vectors (biting insects) that have the pathogens in them and what pathogens are still evolving as researchers are uncovering more and more each year.

The CDC even reports that testing is for surveillance purposes only and Lyme is a clinical diagnosis. Then I ask WHY is this Disease not being treated as such at the discretion of a knowledgeable practitioner? Our knowledgeable practitioners are fearful that they will be targeted for their actions of doing just that..... Treating patients how they should be treating patients, under the Hippocratic oath of First Do No Harm. Ignoring positive tests, rashes and multiple complaints of multiple systems of the body with clinical symptomology of a patient in our endemic state of WI and providing "band-aides" that don't work is harming people!

The Infectious Disease Doctor that spoke earlier used the word "home brewed" in association with Igenex Lab and that it was not FDA approved. That's simply not true. This is the best lab to date that we have out there for testing and is CLIA certified. More laboratories are popping up and jumping on board because they see this as a growing and threatening concern for human welfare. His mention of 100% cure for Lyme with 14-21 days of antibiotics...I wouldn't be here speaking with you today if that was the case but likely in my grave. Cure? I don't' know if there is a cure for

Lyme and its Associated Diseases but like cancer I would consider it a remission in such that the load of pathogens is reduced and very individualized as to how long that takes and then the immune system is able to keep it in check at some point with longer term treatment in chronic cases.

Another myth is that the tick needs to be attached for a certain amount of time. Hypothetically speaking, if one was to stick a needle into themselves and push the plunger of a syringe as an example of a tick biting someone and feeding on them to collect their blood meal for survival, would one really believe that you wouldn't get whatever is in the syringe into your body? You might feel a needle like a mosquito but you don't feel a tick bite as they inject an anesthetic like substance so you don't feel it as one of their many survival modalities. So it can take its blood meal and in the nymph stage (which is the size of a period at the end of a sentence) fall off and the individual develops symptoms down the road and has no idea what even hit them. It can be a slow progressive disease that can lie dormant in a person's body for any length of time until perhaps that person has a major life stressor, surgery, pregnancy, accident or even puberty and it explodes!

All ticks and other vectors can spread Lyme and Associated (zoonotic) Diseases not just deer ticks. Various vectors or insects spread the diseases and they are not just from deer but other rodents as well to include mice, voles, raccoons, chipmunks, rabbits, squirrels, farm animals, etc.

Lyme is comparable to syphilis in that it is a spirochetal disease in which the pathogen is shaped like a corkscrew and can invade anywhere in the body it wants to go. It's definitely a multisystemic, stealth like pathogen that is not difficult to get in the great outdoors we enjoy in Wisconsin, nor is it easy to treat once it disseminates in the body within a short amount of time; reported to disseminate in as little as 48 hours and don't forget these ticks transmit more than just Lyme Disease or *Borrelia burgdorferi*.

Lyme is poorly defined. Lyme is *Borrelia Burgdorferi* which is one organism but there are many hundred strains of Lyme and it is more often seen than not that patients carry more than just Lyme, but one and often multiple other coinfections to include pathogens such as Babesia which is similar to Malaria, Rocky Mountain Spotted Fever, Bartonella, Erilichia/Anaplasmosis Tularemia, Q-fever, Powassan virus and others. Some of them just being discovered as continued research emerges. Lyme and Associated Diseases is more than just in the woods, it's in our back yards!

These pathogens are in our blood supply and the screening need for Babesia in our blood supply has recently been discussed as a important one that they are working on. That's scary...the thought of giving a sick patient contaminated blood with something that could potentially kill them or make them much sicker when sick patients already have a immunocompromised system is frightening! What about all these other organisms that are out there? How many patients that have Lyme and Associated Diseases donate blood and don't even know they have it? There is no screening for the numerous zoonotic diseases out there and few limitations as to who can donate blood.

What about transmission? Research has reported that it can be passed in utero from mother to baby at birth. Further research has even discovered that it may be sexually transmitted. Makes sense if it's a spirochete like Syphilis, as it's known that Syphilis is sexually transmitted.

What about it being in breast milk? Further research needs to be done on that topic as there has been no conclusive evidence provided to date on this.

One last myth and one of my favorites is Lyme isn't in Wisconsin. This one I just can't comprehend! When I hear a doctor say this, I know how greatly undereducated they truly are. Lyme Disease and Associated Diseases is everywhere. Lyme disease has no border patrol and vectors such as ticks and other insects can hitch rides on birds and other mammals. Lyme is pandemic and a serious problem that can affect everyone, even our pets. Nobody is excluded from this disease. Vectors such as ticks and others

don't discriminate and will bite anything they can for their survival. Sadly our pets get better treatment for these pathogens than people do.

Other options for consideration moving forward:

1.) Bill that requires all physicians who perform a Lyme Disease test to provide in writing to the patients that a negative test does not mean you don't have Lyme Disease. This would put focus on how poor our testing is (VA and other states adopting, however they are noticing lack of compliance)

2.) Lyme and Associated Disease Task Force including knowledgeable Lyme Practitioners, patients and others to focus on what else can be done as a state to address the numerous issues that need to be addressed.

3.) Practitioner Protection Bill allowing practitioners to treat their patients with Lyme and Associated Disease with long term use of antibiotics that is open ended without being sanctioned for not following IDSA guidelines (see CT 2009 Bill; Public Act No. 09-128)

I would like to thank you all for your time. I would like to request that the state of Wisconsin considers my testimony and includes the research that is out there as there is numerous amounts as well as the testimony of others here today. I hope we have provided enough information to prove that we need change and it's long overdue. Our doctors need to feel safe to help their patients and our patients need help and recognition. We need many more practitioners to feel comfortable learning to treat this illness, as currently those treating are overloaded. We need further awareness regarding risk and prevention as well as curriculum for incoming doctors in their fields. Our children need to be educated as they are a great source to spread information. I feel this would be a great start to have a bill that will support our practitioners and patients, so they can treat and receive treatment for Lyme and Associated Disease, as they feel is fit and is open ended without constraint, would be a great start.

With Science and Medicine always evolving and emerging, in my professional opinion, I feel that patients and their knowledgeable

practitioners in this field need to have the liberty to choose how to treat their illness and not be forced to follow any specific protocol. We are all unique individuals and there is no 'one size fits all approach' in dealing with Lyme and Associated Diseases.

Again, thank you for your consideration.

(Adding to testimony and discussed with Nik Rettinger Staffer of Rep David Craig on 2/5/16 via phone)

Question regarding testing...."would like to know the exact name of the tests or the tests recommended for testing for Lyme and related coinfections"

Two Tiered Laboratory testing per the CDC website:

"CDC currently recommends a two-step process when testing blood for evidence of antibodies against Lyme Disease bacteria. Both steps can be done using the same blood sample."

"The first step uses a testing procedure called the "EIA" (enzyme immunoassay)'(formerly called ELISA that others mentioned in testimony; enzyme-linked immunosorbent assay)' 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 EIA/IFA and the immunoblot are both positive. "

The two steps of Lyme Disease testing are designed to be done together. CDC does not recommend skipping the first test and just doing the Western

blot. Doing so will increase the frequency of false positive results and may lead to misdiagnosis and improper treatment.”

“New tests may be developed as alternatives to one or both steps of the two- step process. Before CDC will recommend new tests, their performance must be demonstrated to be equal to or better than results of the existing procedure, and they must be FDA approved.

Per the International Lyme and Associated Disease Society in regards to testing of Lyme:

“The Centers for Disease Control and Prevention (CDC) surveillance criteria for Lyme Disease were devised to track a narrow band of cases for epidemiologic purposes. **As stated on the CDC website, the surveillance criteria were never intended to be used as diagnostic criteria**, nor were they meant to define the entire scope of Lyme Disease.”

“The ELISA screening test is unreliable. The test misses 35% of culture proven Lyme Disease (only 65% sensitivity) and is unacceptable as the first step of a two-step screening protocol. By definition, a screening test should have at least 95% sensitivity.”

“Of patients with acute culture-proven Lyme Disease, 20-30% remain seronegative on serial Western Blot sampling. Antibody titers also appear to decline over time, thus while the Western Blot may remain positive for months, it may not always be sensitive enough to detect for chronic infection with the Lyme spirochete. For “epidemiological purpose” the CDC eliminated from the Western Blot analysis the reading of the bands 31 and 34. These bands are so specific to *Borrelia Burgdorferi* that they were chosen for vaccine development. Since a vaccine for Lyme Disease is currently unavailable, however, a positive 31 or 34 band is indicative of *Borrelia Burgdorferi* exposure. Yet these bands are not reported in commercial tests.”

“When used as part of a diagnostic evaluation for Lyme Disease, the Western Blot should be performed by a laboratory that reads and reports all of the bands related to *Borrelia Burgdorferi*. Laboratories

that use FDA approved kits (for instance, the mardx marblot) are restricted from reporting all of the bands, as they must abide by the rules of the manufacturer. These rules are set up in accordance with the CDC's surveillance criteria and increase the risk of false-negative results. The commercial kits may be useful for surveillance purposes, but they offer too little information to be useful in patient management.'

“There are 5 subspecies of Borrelia Burgdorferi, over 100 strains in the USA, and 300 hundred strains worldwide. This diversity is thought to contribute to the antigenic variability of the spirochete and its ability to evade the immune system and antibiotic therapy, leading to chronic infection.”

“Testing for Babesia, Anaplasma, Erilichia and Bartonella (other tick-transmitted organisms) should be performed. The presence of co-infection with these organisms points to probable infection with the Lyme spirochetes as well. If these coinfections are left untreated, their continued presence increases morbidity and prevents successful treatment of Lyme Disease.”

“A preponderance of evidence indicates that active ongoing spirochetal infection with or without other tick-borne coinfections is the cause of the persistant symptoms in chronic Lyme Disease.”

There has never been a study demonstrating that 30 days of antibiotic treatment cures chronic Lyme Disease.” However there is a plethora of documentation in the U.S. and European medical literature demonstrating by histology and culture techniques that short courses of antibiotic treatment fail to eradicate the Lyme spirochete. Short treatment courses have resulted in upwards of a 40% relapse rate, especially if treatment is delayed.”

“Most cases of chronic Lyme Disease require prolonged treatment until the patient is symptom free. Relapses occur and retreatment may be required. There are no tests currently available to prove that the organism is eradicated or that the patient with Chronic Lyme is cured.”

Igenex Lab in Palo Alto, CA includes the bands that were removed for the use of the vaccine that failed on the market in the early 90's. Igenex Labs reports on their results both the CDC Western Blot criteria with number of positive bands required for a positive test. As well as, Igenex test adds in the 31 and 34 bands (Borrelia specific) and reports the number of bands needed for a positive Igenex test ; CDC vs Igenex results are both reported for on their lab forms for both IgM and IgG antibodies.

I also discussed with Nik Rettinger that incorporating the ILADS guidelines into the bill may not be the best thing either because what if the guidelines get removed from the National Guidelines Clearinhouse or when they become 'stale' with emerging science and ILADS doesn't have new ones. It takes years to develop new guidelines. I also pointed out the importance of defining Lyme and Associated Co-Infections, as well as, a fear of using testing at all in a substitute bill because it is so poor due to multiple strains, missing specific bands on the Western Blot in conventional testing methods and the fact that the bands are just antibodies which is the immune system response to the DNA of the antigens to Borrelia Burgdorferi and not a test to reveal the organism itself. It's a stealth pathogen!

More labs are looking deeper into testing and change is happening so would prefer to keep things as vague as possible similar to the CN 2009 Doctor Protection Bill. This would eliminate the fear of repercussions to our practitioners for treating their patients as they need to be treated without restraint in using long term antibiotics.